National Committee on Vital and Health Statistics

SPEAKERS

NCVHS Members		
Name	**Organization**	**Role**
Jacki Monson	**Sutter Health**	**Chair**
Sharon Arnold	**DHHS**	**Executive Staff Director**
Rebecca Hines	**NCHS**	**Executive Secretary**
Debra Strickland	Conduent	Member
Denise Chrysler	University of Michigan School of Public Health	Member
Denise E. Love	Individual	Member
Jamie Ferguson	Kaiser Permanente	Member
Margaret A. Skurka	Indiana University Northwest and Principal, MAS, Inc	Member
Melissa M. Goldstein	The George Washington University	Member
Richard W. Landen	Individual	Member
Tammy Banks	Individual	Member
Valerie Watzlaf	University of Pittsburgh	Member
Vickie M. Mays	UCLA	Member
Wu Xu	University of Utah	Member
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Lorraine Doo	CMS	Staff
Natalie Gonzalez	CDC	Staff
Marietta Squire	NCHS	Staff
Nate Kim	ASPE	Staff
Ryan Mintz	ASPE	Staff
Presenters		
Name	**Organization**	**Role**
Elizabeth Pathak	The COVKID Project	President
Seth Spielman	University of Boulder Colorado	Chief Data Strategy and Analytics Officer

David Van Riper	University of Minnesota	Director, Spatial Analysis
Betty Bekemeier	UW School of Public Health	Adjunct Professor
Glen Mays	Colorado School of Public Health	Professor and Chair, Health Systems, Management and Policy
Ninez Ponce	UCLA Fielding School of Public Health	Professor, Health Policy and Management
Reuven Pasternak	Department of Homeland Security	Senior Advisor
Josh Corman	I am the Cavalry	Founder

Call to Order/Roll Call

Rebecca Hines: Welcome again, to the members of the committee, federal staff and HHS colleagues and members of the public. Welcome to day two of the Winter Meeting of the National Committee on Vital and Health Statistics, NCVHS. Glad everyone made it back for day two. My name is Rebecca Hines. I serve as executive secretary and designated federal officer for the committee. We will just go ahead and get starteL

Let's begin with our chair, Jacki Monson.

Jacki Monson: Good morning. Jacki Monson, Sutter Health, chair of NCVHS and no conflicts.

Rebecca Hines: Debra Strickland.

Debra Strickland: Debra Strickland. I am a member of the Standards Subcommittee and the Full Committee, and I have no conflicts.

Rebecca Hines: Denise Chrysler.

Denise Chrysler: Hi, Denise Chrysler. I work for the University of Michigan School of Public Health. I am a member of the Full Committee and a member of the Privacy, Confidentiality, and Security Subcommittee, and I have no conflicts.

Rebecca Hines: Denise Love.

Denise Love: Denise Love, independent consultant. I am a member of the Full Committee and a co-chair on the Standards Subcommittee. No conflicts.

Rebecca Hines: Jamie Ferguson.

Jamie Ferguson: Good morning. Jamie Ferguson. Kaiser Permanente, a member of the Full Committee and member of the Subcommittee on Standards and no conflicts.

Rebecca Hines: Margaret Skurka.

Margaret Skurka: Hi. I am Margaret Skurka. I am a Professor Emerita at Indiana University. I am a member of the Full Committee. I am a member of the Standards Subcommittee, and I also have no conflicts.

Rebecca Hines: Melissa Goldstein.

Melissa Goldstein: Hi, I am Melissa Goldstein. I teach at George Washington University. I am a member of the Full Committee, co-chair of the Subcommittee on Privacy, Confidentiality, and Security, and I have no conflicts.

Rebecca Hines: Rich Landen.

Rich Landen: Good morning. I am Rich Landen, member of the Full Committee, co-chair of the Subcommittee on Standards. I have no conflicts.

Rebecca Hines: Tammy Banks.

Tammy Banks: Good morning. Tammy Banks, independent consultant. Member of the Full Committee, member of the Subcommittee, and a member of Vickie's SOGI Task Force.

Rebecca Hines: Valeria Watzlaf.

Valerie Watzlaf: Good morning. I am Valerie Watzlaf. I am a member of the Full Committee and also member of the Subcommittee on Privacy, Confidentiality and Security. I have no conflicts.

Rebecca Hines: Vickie Mays.

Vickie Mays: Good morning. Vickie Mays. I am at the University of California Los Angeles. I am a member of the Subcommittee on Privacy, Confidentiality and Security. I am also a member of the Full Committee, and I am one of the co-chairs of the new Workgroup on SOGI and Social Determinants of Health. I have no conflicts.

Rebecca Hines: Wu Xu.

Wu Xu: Good morning. I am Wu Xu. I am with University of Utah. I am a member of the Full Committee and also a member of the SOGI Workgroup. I have no conflicts.

Rebecca Hines: Thank you, members. We have a quorum. Everybody is here today. Let's go over to our staff, starting off with Sharon Arnold. Good morning, Sharon.

Sharon Arnold: Good morning. Happy to be here. Thank you.

Rebecca Hines: Thank you, Sharon. Let's see, we have other staff. They are not on so Maya Bernstein is with ASPE. Lorraine Doo, are you here this morning? Lorraine is lead staff to the Subcommittee on Standards. I think she is here. We have Natalie Gonzalez, Nate Kim, Ryan Mintz.

I think with that, we will just take a moment to remind the members of the public that the agenda does include time for public comment at the end of the day today. We have it down for 4:50. It could happen a little earlier. It could shift, depending on how the discussions go. We may be bringing back some things – some topics from yesterday. So just for awareness, be aware if you would like to make an oral comment today to be agenda aware starting around 4:15, 4:30. You can also send your comment by e-mail to the address on the screen there, NCVHSmail@cdc.gov, and we will read it into the record for you.

With that, I think we can go to our chair to review today's agenda. Jacki.

Welcome Remarks/Agenda Review

Jacki Monson: Thanks, Rebecca. We have a very exciting and robust agenda today. We are going to start with a panel on follow-up of COVID, capacity, gaps & quality in collection of race/ethnicity data. We are going to take a break for about an hour and then we are going to move into our new Workgroup discussion, which is committee discussion and follow up on Workgroup o SOGI and SDOH data and measures definitions of collections. We will be talking about the Workgroup charge, priorities and the workplan and key milestones.

We will take another break and then we are going to move into a panel on the impact of cyberattacks and pandemic stress on healthcare. Then we will move back to the Subcommittee on Privacy, Confidentiality and Security to discuss the Letter of Recommendations to Strengthen Cybersecurity in Health Care. We are also hoping to bring back the PHE letter at this time, to potentially get consensus and approval of that letter. Then we will be discussing the 2022 Workplan. We will move into public comment at approximately 4:50, and then we will adjourn for the day.

So that is the agenda, so without further ado of Vickie and Denise, we are ready to go with the panel. Thank you.

Follow-up Panel on COVID-19: Capacity, Gaps and Quality in Collection of Race/Ethnicity Data

Vickie Mays: Okay, the floor is ours. Thank you very much, Madame Chair. It is my pleasure to welcome everyone today. I have to really say a great welcome and debt of thanks and gratitude to the panelist who have agreed to come back again. Particularly since some of them are on the West Coast with me. So I appreciate you getting up early to do this.

As Jacki said, we are revisiting this issue of capacity gaps and quality in the collection of race and ethnicity data. One of the reasons for that is that in our charge of looking at data and responding to the Secretary, we wanted to hear again from our experts to see have things changed, are we in the same place, have we come up with any fixes that may be things to consider for the long haul.

One of the things that we know very clearly, and we have all learned the lesson, is that COVID-19 really exposed a lot of the data gaps in our system. And those systems that we are concerned about are not just the federal system, but state and local systems as well. You will hear from our panelist today that a range of places in which they have had experiences about those gaps.

What they were asked to do is to update us as to what is the issue that they first presented on. Whether or not that issue has in any way changed – gotten worse, gotten better, and in particular, if there are fixes. They have been asked to share those recommendations for changes with us today.

So I am going to get us started. Can I have the next slide, Rebecca? What I want to do is make sure that I introduce my co-moderator and that is Denise Love and introduce the panelists. What is going to happen today is that each of our panelists will be speaking. At the end, I will have some closing comments and then we will have a discussion. Denise is going to help try and keep all of us, including me, to time so that we can have a discussion.

In the discussion the way in which we will proceed is that some of the members that are working on the small ad hoc group will be asking questions of each of the presenters. And then we will open it up to the rest of the committee for questions as well.

Our presenters have wonderful bios in our packages. We will start in the order that we have. We will start with Elizabeth Pathak, followed by Seth Spielman and David Van Riper, Betty Bekemeier, Glen Mays, Ninez Ponce, and then myself.

Without further ado, is Beth with us?

Rebecca Hines: Vickie, what I will do is give them a one-minute warning.

Beth Pathak: Good morning, Everybody.

Vickie Mays: Good morning, my friend. I am glad to have you here.

Beth Pathak: I had to mute myself because of course I started having a terrible coughing fit two minutes before I have to give my talk. Hopefully, we will make it 15 minutes with no coughing.

Greg, I can just share the screen. Right?

Greg Richards: Yes. You should be able to right now.

Beth Pathak: Okay. Last year when I talked to you folks, the title – Vickie asked us to keep the exact same title. The title is Measuring Racial/Ethnic Disparities in COVID-19 in Children and Teens: The Problem of Missing Data. I am going to give you a brief update and unlike last year, I do not have a ton of slides. I decided to let us really pare down just to have a few slides so that we have more time and hopefully time for questions and answers.

I am going to cut to the chase and just tell you right now that we have seen only minimum improvement in this issue. That is the bottom line. We really have not made much progress since last spring.

I just want to acknowledge my collaborators on the COVKID Project, Dr. Janelle Menard, Rebecka Garcia, who is a nurse practitioner who is our clinical expert, Dr. Jason Salemi of the University of South Florida. Some of you may be familiar with Dr. Salemi. He has become one of the COVID new celebrities, especially in Florida, and runs a dashboard, which is really outstanding. We have added a couple of new people in the past few months. We now have a post-doc, Dr. Megan Berry, who is working with us and a doctoral student, Justin Swanson, also at USF. We remain a volunteer effort.

Just a brief reminder on COVID-19 data and kids, and this is just a repeat from last spring. To understand incidence of disease, we need testing and case data. To understand disease severity, we need hospitalization and intensive care admissions data. And to understand disease fatality, we need death certificate data. And to understand racial and ethnic disparities, we need all of these types of data because we need to understand the racial and ethnic dimensions of all the aspects of the disease. It is quite a challenge. As you are already aware, we really lack racial and ethnic data for most of these data points.

I just want to make a note that one of the things that has changed since last spring is that we have updated our Census population denominators. In the COVKID Project, we are using the latest Census 2020 population denominators when we calculate our rates. This is important. It is important that everybody update to those 2020 denominators because there are some states in which population declines. There are some states in which population went up. It is not like on well, the population grew. Every state is a little bit more people. It does not work like that. Some states actually went down from those vintage 2019 to 2020 estimates. That impacts rates and it impacts our comparisons across states.

There are many state dashboards out there that are still using old population denominators. They are using 2018, 2019 they have not updated. And there are national analyses and things that get published where they are not using 2020 population denominators. That is an easy fix, I think, that everybody can do because the data are available. It is just a question of updating what we are doing.

I am going to present just a little bit of information about case data. The main thing that we have done, the COVKID Project, what we do in COVKID is we visit every state dashboard every week. We extract all available COVID-19 case data for kids. Now, we use the word kids because the age range varies by states. We do not have consistent reporting. Some states report 0 to 17. Some, 0 to 19. Those are the two main categories that we got. There are a couple that report 0 to 18. There are three states that report 0 to 20. For Utah, we have a strange age range because of the way that they report data.

In the CDC restricted case file, which is released to researchers, and it is supposed to include all of the cases that CDC gets from the states. We compare our COVKID counts to the CDC counts. You might think if states are reporting data to CDC, it should match. What is on their dashboard should match what they are reporting to CDC. That is absolutely not the case. The data do not match. There are different reasons for that, and the reasons vary by state. We have updated this with data basically through right before Christmas from COVKID and then the CDC, the latest CDC restricted file was released on January 10 of this year, 2022. But cases really go up through December 23. They have a few cases through the 26th, but the counts are incomplete. We cut it off at the 23rd. Our 24th data really counts through the 23rd. These dates really match up pretty well. You can see that the COVKID total is 9.3 million on that date. Now, we are well over 10 million now with the Omicron surge. And the CDC's total is 8.4 million.

Now, a key thing to keep in mind is that the comparison varies state by state. I am not going to get into those details with you, but it is something that we are looking at and analyzing. For some states, we have very good comparison between COVKID and the CDC restricted file. However, there are some states where they are basically just not reporting data to CDC at all by age. This gets confusing.

Take a state like Texas. They report their total case counts to the CDC. But when it is broken down by age, they do not report it. We do not get any kid cases for Texas in that CDC file.

For COVKID, we calculate those estimates using local health department data from Texas to get a good estimate of the number of kids who have had COVID. Right now, it is over a million just in Texas alone.

Sometimes the CDC total is higher than the COVKID total. That happens when the state dashboards only report 0 to 17. But the CDC restrictive file has 0 to 19. Sometimes the CDC restrictive file totals are higher than the COVKID totals. It varies state by state.

But the key thing that we are interested in with race and ethnicity is how is the reporting going. I am going to try to zoom in on this a little bit. This is basically a map of the most recent CDC data and it shows the percent of cases for 0- to 19-year-olds who had missing race and ethnicity.

Now, you can see that these numbers are still pretty high across all states. But I will say that they are improved somewhat from last spring. Right now, the national average is 29.9 percent of cases. In the spring, it was around 40 percent. We have made some incremental progress. That is good news.

But if you look at state by state, you can see that in two of our biggest states in New York, in Texas, the numbers are pretty high. New York is very bad actually. I have a feeling that that reflects a New York City versus New York State split. I would guess that we are getting the race and ethnicity data from the city and we are not getting it from the state. New York State has one of the poorest in my opinion dashboards. They do not report any demographics for the state on their dashboard. It is just kind of incredible, but it is the truth.

Now, Florida looks really good. Only 12.4 percent of kid cases are missing race and ethnicity. But here is the problem with Florida. The entire reporting of child cases to CDC is missing about 35 percent of all cases. In other words, from the dashboard, COVKID, and from the weekly reports that the Florida Department of Health puts out, we know what the total number of cases is. In the CDC restrictive file, it is only about two-thirds of the cases. Those two-thirds have good race and ethnicity reporting but were missing a whole bunch of cases. You can see. There is still quite a ways to go to have uniform, high consistency, high reporting of both the underlying cases, the denominators and the race and ethnicity data for those cases for kids. Bottom line. We have made a little progress. We still have a long way to go on this. A long way.

Now, I want to mention the intensive care data because this is something that I was very enthusiastic about in the spring. I am just going to share my slides from the spring. This is from a registry, a voluntary hospital registry of pediatric intensive care units. They have race and ethnicity data along with very rich clinical data on these kids who were admitted to PICU. At the time of this – this is through March 28. They had data on over 1800 patients. Remember, this is a voluntary registry. This does not capture all of the PICU patients up to that point in time, just a fraction of them. I am personally aware of some of the major children's hospitals, which were not participating in this registry like Children's National in Washington, DC and Boston Children's were not in the registry. This is what we had even without those big hospitals. You can see that the majority of patients were black and Hispanic, non-white. Only 27 percent of these PICU patients were white. The majority were racial and ethnic minorities.

I wanted to give you an update on this. It is not good news. This voluntary registry ceased operations on April 1, basically a few days after I put my presentation together. They decided that they could not afford the resources. They were putting a lot of their nurses, focused on the COVID data. They just decided they were not going to do it anymore. Now, it is still up on the web. You can go and it is data through April 1. It has not been updated since then.

But I really encourage people to look at this registry, the VPS registry because – and I think the link is on this earlier slide. The link is right here. It is really a model. It is really well done and it is really a model for what clinical registry data could and should look like for COVID-19 for kids. It is one of my dreams that

we would have registry – that level of clinical information available for all of our pediatric hospital patients, which is tens of thousands at this point.

Let me now talk very briefly about the death data. The big very good news that has happened with race and ethnicity and death data is that NCHS has put provisional COVID-19 death data on CDC WONDER. This is a huge accomplishment. I know it was a huge amount of work for them to do that and it is a true gift to the research community and to the broader public health community because now researchers can go in and customize their tabulations for what they want to look at with COVID-19. Previously, we were limited to the tabulations that NCVHS chose to put out and they were doing a great job. Every week they were putting out several – maybe a dozen or two dozen files with special particular tabulations. But CDC WONDER just gives us a lot more flexibility.

What this slide shows is the discrepancy and death counts across data sources. When we go into state dashboards, we count 782 cumulative deaths. But remember. Many states are only reporting 0 to 17.

In the CDC restricted file, there are 1500 child and teen cases identified as deaths. In CDC WONDER for 0 to 19, there are 992. Why is this number higher than this number? It has to do with deaths among cases versus having COVID-19 mentioned as a cause of death on the death certificate. We could have a whole long conversation about what is the meaning behind all of that and under ascertainment and missed classification of cause of death. We know that this is an issue. It is something that needs to be explored further.

Just to finish up, I just want to show you – these are the death rates. This is the CDC WONDER data. These are death rates by race and ethnicity. The number on top is the death rate. The number in the box is the number of deaths. These are hatched because NCHS says do not calculate a death rate if you do not have 20 deaths. For NHOPI kids, there has been eight deaths nationally over the two years of the pandemic. It is a small population. We would expect a small number of deaths because the population itself is so small.

American Indian and Alaskan Native. These are non-Hispanic. There are an additional five deaths, which are Hispanic, and they are included here in the Hispanic group.

And then just focusing on the big three that account for 90 percent of the population at risk, non-Hispanic whites, blacks, and Hispanics. These are the death rates and the rate ratios. This is through the end of December.

Now, these disparity ratios have actually come down a bit because the delta wave and the later waves have hit more of the non-Hispanic white population than had happened earlier. Earlier, the rate ratios were higher than this for blacks and Hispanics but still a bit discrepancy for the non-white kids versus the white kids.

Let me just close by encouraging you to visit the COVKID Project. This is our latest dashboard. We will be updating this in another day or two. You can see here – this is the average daily incidence. Here is the delta peak, which seems so high just a few months ago. It has been totally eclipsed by where we are now with Omicron. This is cumulative incidence. We have hospitalization data, death data, vaccination data, and a lot of interesting information.

There is my email address and the COVKID Project website. Thank you very much.

Denise Love: Thank you, Beth. That was fascinating.

We will tee up to the next panelist. Vickie, we will do questions and discussion at the end.

Seth Spielman: David and I sort of did a quick review of our slides in terms of an update. Parts of our presentation have changed to reflect the evolution, in particular, around the 2020 decennial census and parts are the same because other aspects have not changed. We will move pretty quickly, but I think tee up questions and happy to talk later.

David and I are talking about sort of the two primary national sources of denominator data so race/ethnicity data, things that give you population counts. And the two big sources of information for that data are the American Community Survey and the decennial census. The American Community Survey is a sample of housing units. They contact about three and a half million – 3.5 million housing units each year. They get about a 60 percent response rate. That is pre-pandemic. During the pandemic, it has been very difficult to operate the ACS and the planned releases have been delayed. But the important thing about the ACS is that it is a sample of the population as opposed to the decennial census, which in theory counts everyone. And the new thing about the decennial census, the 2020 decennial census, is that some new disclosure control methods have been adopted that sort of changed the nature of the data and David is going to talk about where that is heading.

In terms of the American Community Survey, one of the things – our goal today or in the first half, the goal is really to talk about the quality of the demographic data, in particular, the population counts in the American Community Service.

And the way that we did this the first time around and we will just quickly revisit this now is through plots that look like this. I will just briefly explain how these work. On the Y-axis – let us start on the X. On the X-axis, we have the number of people in a given race/ethnicity group in a census tract. As you go from left to right, the population in a given group gets bigger. In this case, we are looking at the Hispanic, the total Hispanic population. And on the Y-axis, we have the margin of error in the estimate. As you go higher and higher on the Y-axis, the margin of error gets larger and larger.

These colored lines. The red line represents places where the margin of error is equal to the estimate. Any dot that is above the red line means that you have a case where you have a census tract where in this case, the Hispanic population is a thousand people. But it might be plus or minus 1500 people, meaning that you know somewhere between 0 and 2500, Hispanic people live in that census tract.

The yellow line is 50 percent so meaning that the margin of error is 50 percent or more of the estimate. And the green line is 10 percent or more of the estimate. In this case, when we look at the Hispanic population estimates, by census tract in the United States, we see that 15 percent of all census tracts are above the red line, meaning that the margin of error is greater than the estimates. We know it is somewhere between zero and something. Fifty-three percent of all census tracts for the Hispanic population have a margin of error that is 50 percent or more of the estimate. It might be 100 people plus or minus 150. And 99 percent of all census tracts have a margin of error that is greater than 10 percent of the estimate. There is a fair amount of uncertainty in estimates of the Hispanic population.

If we just look at total population, the story is much better. Very few census tracts go above the red line for the total population. Very few go above the yellow line for the total population. And about 35 percent are above that green line, meaning 10 percent or more.

And if we look at all of the different race/ethnicity groups that are – this is not all. If you look at the big five categories, excluding Hispanic because it was on the prior slide – if we look at the African American population, 26 percent of census tracts have a margin of error that is greater than the estimate. About 60 percent. It is 50 percent or more of the estimate. If you look at Native Hawaiians, about 90 percent have a margin of error that is 100 percent or more of the estimate, which makes the data really hard to use. Asian population – it is about 40 percent are above that red line. And American Indian and Alaskan Native – about 80 percent are above that red line. What we see is really substantial levels of uncertainty in the race/ethnicity data from the American Community Survey. That is at the census tract level.

Now, if you look at larger units of geography, all of a sudden, the story gets much better. Here, we are looking at the Hispanic population by county and we can see that very few census tracts sort of are above the red line. About 10 percent are above the yellow line. Most even have a margin of error that is less 10 percent of the estimate. The scale at which you look at things really matters for the quality of the estimates. County works well for certain things. If you want to look at intra-urban variation, county is a way.

Last point is that not only the geographic scale, but the demographic scale at which you look at things matters. Looking at the total population gives you a low margin of error. Looking at the population that is age 65 and up gives you a slightly larger one. If you look at the Hispanic population, it is larger. And if you look at the cross-tabulation of those three things, Hispanic women over age 65, you can see the margins of error go up.

Some quick solutions. We have a couple of different solutions that we put out in the public domain. One is ways to reengineer census geographies. We can think of them as sort of goldilocks geographies. That is ways to automatically or predefine units that are bigger than a census tract, but smaller than a county that give you nicer estimates. And then we also have an approach where we take a bunch of different variables and put them together into a data product. Rather than looking at one variable at a time, you look at a composite of a census tract. We think that gives you a cleaner picture and allows you to differentiate census tracts in a more meaningful way. There are links to all of this in the slides. With that, I will hand it to David.

David Van Riper: I am going to update people on the status of the 2020 decennial data and the products that are coming out from it and give you an update both about the status of the products, some proposed changes that the Bureau is making to the products and some forthcoming demonstration data that may be of interest to the panel and to other people who are on this call.

In terms of the status of the 2020 decennial census data, there are three main products that research scientists, demographers, population scientists tend to use. The PL94-171 redistricting data, which is used for legislative and congressional redistricting within states. It has been released since our last meeting. Those data were released in August of 2021. That was five months after it was originally planned for release in the March/April 2021 time period.

Those data have race and ethnicity counts for persons below and above age 18. We do not get that fine-grained sex or age distributions that many demographers and public health scientists want, but this is the first product that has been released.

The Demographic and Housing Characteristics File, which is formally known as Summary File 1, is tentatively planned for release in mid to late-2022. We do not have a finer grained estimate than that. This is a delay of one year compared to prior decennial censuses.

In the 2010 round, Summary File 1 was released in July and August of 2011. In 2022, we are looking at a delay of at least one year if not longer.

The Detailed Demographic and Housing Characteristics file, which is formally known as SF2. We actually have no current timeline for release. The Bureau has not yet specified when those data are planned to come out. They are typically released six months after Summary File 1. This would put the release of these data into the mid-2023 time periods. That would be one to two years after that it typically comes out.

Why do we have these delays? There are really two main reasons. One, the COVID-19 pandemic wreaked havoc on the Census Bureau's schedule for collecting census responses and doing a non-response follow up. They delayed the end of data collection until October and November of 2020. This pushed back their data processing and quality assurance and quality assessment perspectives so that pushed it out.

The second though is the changes to their disclosure avoidance system. The Bureau has to create their disclosure avoidance parameters for the DHC and the DDHC, and then run them through the system. This requires substantial review and testing. And prior disclosure avoidance techniques were run once on the individual census responses and then all products float out from that single disclosure avoidance technique. Now, they have to refigure their algorithms or reset their parameters for each product.

That leads into my next bullet point. There will be some new demonstration data coming out in the next couple of months from the Census Bureau. This demonstration data product will contain the data tables that are proposed for the DHC release. We are going to get sex by age by race/ethnicity. We are going to get household-type structure, household relationship, and housing tenure. And the Bureau is putting these out in advance of setting the final disclosure avoidance parameters. We are going to be able to compare this demonstration of data, which is based on 2010 responses, with the originally published 2010 data to see how different the sex by age by race/ethnicity counts are and whether or not the discrepancies make them fit for use for a variety of use cases. I would think that the vital statistics of public health researchers on this call will find that of particular interest.

The other thing that has happened since our last meeting is that the Census Bureau has proposed some pretty substantial changes to its data products. I want to highlight three of those here. First, the Bureau has announced that they plan to release some new Census block data tables in the DHC. In particular, they are going to release sex by five-year age bins by race/ethnicity for many more race/ethnicity combinations. We are going to get more sex by five-year age bins by race/ethnicity than we had in prior data products.

But while they are releasing some new data tables, they are taking a few things away. And in particular, they are reducing the geographic details on the subset of tables and they are proposing the elimination of some data tables.

With respect to the reduction in geographic detail. The Bureau proposes to move 69 of its data tables that were previously available at the block or tract level up to the county level. So county will be the smallest geographic unit for which we will get the 69 data tables. And as Seth mentioned in his talk, getting those data at the county level means we are not going to be able to know anything about intra-urban variation. We are only going to get one count for Los Angeles County, which includes 10 million people. We are going to get no detail within LA County. We are also going to get a count for Loving, Texas, which has 64 people in it. That variation, that size variation of the county level is going to make it hard for us to really dig into deep into counties for these tables.

In addition, the current proposal eliminates 169 data tables from Summary File 1 DHC and 67 out of 71 tables are proposed for elimination in the detailed DDHC.

I want to bring your attention to three of those data tables in particular. In prior decennials, the Census Bureau released the counts that were single year of age by sex by race/ethnicity at the Census Track level. That was really helpful because you could get down to those – children 0 to 3 by race/ethnicity and look at potential lead poisoning rates or other things that were particularly targeted towards people of particular age groupings. Those will not be available anymore.

The tradeoff is we are getting more sex by five-year age bins by race/ethnicity combos. That is the tradeoff we are getting here. But for people studying particular age groupings by race/ethnicity, that will go away.

They are also proposing the elimination of Hispanic origin by specific origins. We no longer get the counts of people identifying as Mexican or from Mexico or from Ecuador, where they were born. They are also proposing the elimination of its allocation county table. That tells you something about how many people did not respond with age or sex or race response and that had their data imputed in the final counts. It gives you a sense of the quality of the counts for particular geographic areas. Those are all proposed for elimination.

Great timing. This comes to our conclusion. From the ACS and decennial, I think as Seth talked about and what we know about the small area data from the decennial, we can get good city-level rates and population estimates. Within city or within county, it is a little trickier to understand. Geographic and demographic resolution matter. You are kind of dealing with a tradeoff here, finer grain those groups get, the counts get smaller. The uncertainty around those counts increases, making it harder to know exactly what is going on for those geographic and demographic groups.

It is possible to process the public released data to improve estimates and in particular for ACS data. Seth and his research group have done a great job of looking at how to aggregate geographic units upwards or demographic groups upwards, reduce those levels of uncertainty.

Based on what we know about the 2020 decennial, it is going to be much harder. As of today, the Bureau is not publishing error bounds on its 2020 counts. It is going to make it a lot harder for us to be able to do aggregations to reduce that uncertainty.

I think that is it. Thanks, everyone.

Denise Love: Very good. Thank you so much.

The next panel --

Vickie Mays: I was going say. I think we have Betty next.

Denise Love: Okay. Welcome, Betty. Thank you.

Betty Bekemeier: Thanks, everybody. It is hard to get yourself off mute once you have your slides up. My talk is very different. I am talking about what we are doing at the practice level, at the public health practice level in terms of data if you recall from when I was with you last. I am going to be talking about work we have been doing in terms of focusing on building capacity for and with governmental public health systems, and with the particular focus on assuring that we attend to rural areas.

One example I am going to be talking about again is the SHARE-NW project, which largely serves capacity-building needs and data needs of public health systems in our Region 10, Washington, Oregon, Idaho, and Alaska. I will be referring to this SHARE-NW project today about making health status and social determinants of health data more accessible to rural public health systems in our region.

And then another is from our PHAST team. That stands for Public Health Activities and Services Tracking, for which the PHAST team, we have been working with public health systems to standardize their administrative data, governmental public health administrative data for its use in more equitable and data-driven decision making. I kind of go back and forth between administrative data and health status data. I will be talking about this again.

I talked about this some last time. But in terms of public health status data in our SHARE-NW project, working on health status data, we focused only on rural local health departments. And many of these data gaps and access and use we identified here are true for non-rural agencies too, but they are particularly given in rural areas. They continue today. When I talked with you in April, we had recently interviewed rural public health leaders about data gaps, in particular, during COVID. They talked a lot about being overwhelmed by the data volume during COVID, about being nervous about data trustworthiness, as you can tell by the previous presenters, there was good reason for that. Lack of capacity for assessing and ensuring data quality for communicating with data and lack of data for underserved groups.

And then in terms of public health administrative data, the last time I talked to you, I was distinguishing between public health administrative data versus community data for public health status. Again, both are critical to addressing health equity in our particular problems in rural areas.

I mentioned then that because of administrative data inconsistencies, it has generally been impossible to compare agencies to look at best practices or measure public health impact of their services or resources, and particularly in their application around COVID, et cetera, it has been impossible.

Because no standards have existed for the 2800 local health departments across the US for measuring and prevention activities, their expenditures, et cetera. As lack of comparable data has limited the extent to which policymakers, researchers, public health practice people, can generate the evidence they need and make data-driven decisions around allocating resources, including in response to COVID pandemic. And this really has been exacerbated dramatically in rural areas.

Since I talked to you last, there has been growing attention paid to meeting the needs to estimate the type of and amount of workforce needed to address public health crises. There is a lot of interest. Folks have been crying out for how many people do we need to do this, to do contact tracing, to do epi follow up and surveillance, et cetera. But there has been no way to answer that. We are really working on that now a lot more increasingly since I talked to you last.

Last time I talked, we also – I was talking about – we were helping the – our team has been helping to bridge this gap for public health systems to have data, to have useful access to the data. It is one thing to have data. But when your local public health partner person needing to make decisions around data, you have to have good access to it, meaningful access to it and then have the capacity to understand and leverage the data for community-level decision making.

We have been using this model for ourselves and the circled portion here highlights how important it is to put tools in place for data to be actually available and used by those in practice. Possible channels to make data more accessible and usable are things we have been working on such as centralized web-based data reporting tool, user-centered data visualizations, a dashboard that is really useful to people in practice, particularly in rural areas. Training and education on interpreting data, how to use data, and data visualization. All of these channels need to be attended to for effectively filling these gaps between data public health systems of practice and how to do use it for generating evidence, et cetera.

With some of our current SHARE-NW funding, this funding comes from the Office of Minority Health. We have identified these more immediate solutions we can bring to rural partners and for each of these data gaps. I will not go through them all. But you will note that a lot of the low-hanging fruit here is in the form of capacity building or providing training in data use and understanding what the data mean, et cetera. We have done a lot of work in that area.

This other in the dashboard was finally launched. Our dashboard was finally launched in August. It is entirely focused on what rural users have asked for, the data they have asked for and wanted and given us feedback on. This includes now the development of an infographics tool that they can easily populate and use in communicating with stakeholders.

Here is a screenshot now of the home page of our SHARE-NW dashboard. These topic areas each have a dashboard that was commonly asked for by our rural users and in support of addressing disparities in their communities. They use existing county-level data that we pulled together and linked to these data that they were previously going all over the place and looking here and looking here. They are all linked

together. We linked them together with social determinants of health data. We provide steps for the users in terms of how to make connections between community health status and these underlying determinants.

We did the best we could with county-level data that we could find. But of course, rural data by race and ethnicity were hard to come by. The dashboard – there is a lot to encourage. Also, current users to dig deeper and ask community-level questions about who might not be represented in these data, what factors might be marginalizing specific populations that are represented here and a lot of other questions like that. The data do not always – often do not exist at the race/ethnicity level in rural areas. But we are really also providing tools for people to ask deeper questions and collect more data at a local level, et cetera.

While we have been working hard on development of the user-centered dashboard with linked data sets and information specifically for rural communities, results of some of our more recent interviews with rural public health leaders regarding COVID-related data issues led to our decision to add development of an institutional discrimination dashboard. With these dashboards you see here that we are going to be adding the institutional discrimination dashboard to add to our other health status dashboards, these data will include things like residential segregation, home ownership by race, school segregation, income inequality, jail and prison population data by ethnicity, elections and voting data. These are data where we might expect to see greater disparities during a public health crisis and having broad range of impacts.

We have also recently been hearing more from our rural public health practice partners that they would like to keep track of where the COVID hotspots have been at a local level around their state. They can watch for and respond to future ongoing needs that these populations might have as a result of COVID. We are thinking now about how to help address that. It is a really interesting request.

Another part, as I mentioned, is we also found great gaps in capacity and understanding and communicating with data, the need for related training. We curated existing trainings and have put them in bundles on our website too. But we also found gaps in training that needed to be developed so we did that. We developed three new online training modules. There is a series focused specifically on data for advancing rural health equity. These modules are presented through a narrative problem-based learning format where the learner steps into the role of a public health promotions specialist in a rural health department. We used a rural health department as a model and they helped us with this, et cetera.

And then in terms of agency-level data that local health departments need for more equitably allocating resources and tracking where their resources go, as I mentioned, local health departments have had no standard way of reporting financial information. Although public health funding has been declining for decades, it has recently been in the spotlight because of COVID and how under resourced local health departments are for most emergencies, certainly a pandemic like this.

Over the last five years, our PHAST team, Public Health Activities and Services Tracking Team, has developed and been testing what we call the Uniform Chart of Accounts. We have been doing that with health departments. It is a standard way of reporting public health finance information to show what

exactly is being spent on programs such as communicable disease control, all-hazards preparedness and response, individual services like these. More and more agencies are cross walking their data to the standard system that we have built for this – to bridge this gap between what public health practice needs and wants and how these data can be used.

Since I talked to you last, we have – now, public health agencies are trying to figure out what kind – I have been doing this for a little while now, but what kind of staff and how much they need for responding to health needs in their communities and these emergencies.

In collaboration with these four groups that you see at the bottom of this slide, including our PHAST Uniform Chart of Accounts Team, there at the bottom right, we have all been working together to provide these data needed for what we are calling Staffing Up local health departments.

In Phase 1 of the Staffing Up project that took place about a year ago that led to this initiative to develop a national estimate of FTEs needed to perform what we call foundational public health services in the US that every county, every jurisdiction should have access to.

The conclusion from Phase 1 was that state and local health departments needed an 80 percent increase in their workforce just to provide adequate infrastructure and a minimum foundation of public health services.

Now in Phase 2, we are all about creating a locally usable tool to determine staffing needs at various levels. We are working together on the workforce calculator for public health agencies. It will be resource for the type and number of staff they will need. We are using the main data source for this is this Uniform Chart of Accounts data because financial data are largely reflective of public health staffing. Our team is working to gather more health departments into the Uniform Chart of Accounts and provide those data to feed the calculator.

Some of our larger lessons learned. The data have to be made accessible and designed for the users and for engaging partners. There continues to be a very high need and interest and training and data use when we launched our training series. We had a live portion of it. Overnight, we had 125 people register, way more than we expected for our first pilot. We had to close down registration.

Resources are needed for oversampling and data collection in rural areas and for tracking COVID hotspots into the future. For public health administration data, there continues to be a need for standardization of data. This takes resources and time and coordination and potentially mandates and incentives.

I will go ahead and stop there.

Denise Love: Good work. It is fascinating. I wish we had so much more time. Vickie, is Glen the next one on the roster? Glen, it is all yours.

Glen Mays: Fantastic. Greetings, everybody. Thank you again for the opportunity to join and share some insights from our perspective. I am going to continue along on some of the themes that Dr. Bekemeier raised in her work from a slightly different vantage point. I am looking at what we are seeing in terms of

local public health and community partner access to race and ethnicity data during the COVID response. A vantage point from a national perspective through several, large, national research networks that we lead that involve local public health working with medical and social service partners at the local level.

Just as a reminder, three major research initiatives that give us the lens for studying these issues and how they are playing out in local communities across the country. All of these are research initiatives that are funded by the Robert Wood Johnson Foundation. First is a national longitudinal survey of local, public health delivery systems that we have been manning over time now, for more than 20 years. It originally started with CDC funding and now continues in recent decades with RWJF funding. That allows us to follow about 600 local communities, local public health jurisdictions around the country, a nationally representative by following them by doing surveys every two years to study public health activities, implemented by those agencies and their community partners and the constraints and challenges and opportunities they face in delivering public health services, including looking at issues around data capabilities.

The second is the National Health Security Preparedness Index. This is another initiative started by CDC and now continued by RWJF. This allows us to aggregate data from about 100 different sources to produce annual county-level estimates of public health preparedness and response capabilities.

And the third research lens that we use for this is the Systems for Action, a national research program, another initiative of the Robert Wood Johnson Foundation where we are able to study at a local level initiative that involve helping public health agencies work together with medical and social service providers to address the study and address issues of health equity in their communities. We have now about 36 studies funded through that program all around the country. Almost all of them involve exchange of health and social services data between the sectors, public health, medical care, and social service delivery. The updates – I will be giving you – quickly arrive from looking across these three national research initiatives.

What have we seen since the last time we talked to about access to and use of race and ethnicity data by local, public health and community partners? Very similar to the findings you heard from Dr. Bekemeier and her vantage in terms of public health practice partners.

We have seen some limited improvement particularly in large, urban, public health jurisdictions in those public health agencies gaining access, mostly to state public health surveillance systems that have improved completeness of race and ethnicity data. This is also, I think, consistent with some of the comments you heard from our first speaker as well. Limited improvements in addressing gaps in getting access to racial and ethnic data, primarily through state, public health surveillance systems around COVID. It is the larger, urban, local public health agencies that are reporting better ability to get access to race and ethnicity-specific data, particularly around getting data, race and ethnicity-specific data on cases, hospitalizations, deaths, and to a more limited extent, vaccination rates. Still reporting gaps in terms of incomplete data, unknown race and ethnicity data and all those data sources. But we are hearing reports of improvements, again, particularly for larger, urban jurisdictions.

We are seeing less progress around getting race and ethnicity-specific data around testing, positivity rates, occupational exposures, workforces reporting exposures and outbreaks and then the general area of getting data on unmet social needs related to populations affected by these conditions.

Along with that, a number of other problems that I talked about last spring, we are seeing really no evidence – much evidence of progress on some of these other data access issues that local, public health and community partners on the bottom half of this slide. Still, our partners in research networks are reporting missing and incomplete race and ethnicity data that are being collected through -- locally collected data collection process particularly through case reports and contact tracing activities that are managed through local public health agencies.

Still big problems with missing and incomplete race and ethnicity data from those case reports and contact tracing that are primarily attributable again as Dr. Bekemeier mentioned to limited staffing at the local and public health agency level to be able to do follow up for missing data and to do verification and linkage to try to address incomplete race and ethnicity information on case reports, on outbreak reports, and on contact tracing that are driven through local public health agency data-generating processes.

Similarly, point number two, ongoing problems with limited access to administrative data sources that have important information about populations affected by the COVID-19 pandemic. Very limited local public health agencies reporting being able to access data from all-payer health care claims databases that are available now in more than 30 states. Local public health not getting access to claims data, not getting access to timely state Medicaid data systems, reporting lack of access to statewide hospital discharge data systems that are available in now about 46 of our 50 states and very low very access to statewide social services administrative data systems like SNAP, WIC, unemployment insurance, and others. This is a barrier in access of local public health, being able to access state administrative data systems.

For the small number of agencies that report having access, they are still reporting large problems with incomplete race and ethnicity data in those administrative data sources and limited ability at the state level for cleaning and addressing those incomplete data through data linkage and verification processes. We have seen very little evidence – really no evidence in progress in solving these administrative data access and information issues.

Thirdly, we talked a little bit about emerging opportunities last time with public health access to regional health information exchanges and even more recently, the regional social health information exchanges. We are continuing to see little progress in opening up access to public health agencies and other community partners into those exchanges, which are primarily built around access for large health care providers, hospital systems, and physician practices to have access. Local public health and even state public health continuing to express challenges with gaining access to those systems and race and ethnicity-specific data from those systems to use in COVID response activities.

A few other data points to note. These are data mostly coming from our National Longitudinal Survey Public Health Systems across the country. More than 50 percent of local public health agencies report

no or limited ability to examine issues of racial equity as part of the community health needs assessment processes that public health agencies conduct on a three and five-year cycle.

More than half of public health agencies around the country are reporting not being able to consider issues of racial equity in their community health needs assessment processes. This is a big problem and largely due to that limited access to race and ethnicity data that are not able to incorporate this information meaningfully into the community health assessment processes and then more downstream into their community health improvement plans that are developed and updated on an ongoing basis.

Another notable statistic. Sixty-three percent of the public health jurisdictions in our longitudinal survey report no or limited ability to allocate public health resources based on analyses of racial equity around – health needs through their community health assessment process. They are not able to meaningful incorporate issues of race and racial equity into their assessments and therefore, they are reporting a limited ability to allocate resources based on their assessments with attention to issues of racial equity. Large gaps and the ability to practice evidence-based public health because of these gaps in access to race and ethnicity data.

And obviously, as Betty mentioned and others, rural jurisdictions are a problem. These constraints are much larger, much less likely to report the ability to consider racial equity in their assessment processes and in the resource allocation processes.

Interesting with this last point, we are finding that the public health jurisdictions around the country that report limited ability to do this kind of racial equity assessments and analyses. Those places over 2020 and 2021 have experienced significantly higher death rates from COVID-19, not surprisingly. This is just a correlation analysis that we have done at this stage. We cannot infer causality here. It is the limited access to racial data that is driving the higher mortality rate. But there is a troubling pattern there. The places with experiencing the largest gaps and access to data are places that are having disproportionate burden and health consequences from COVID-19.

Finally, just some thoughts for improving some of these gaps in access. This is going to be very consistent with what you heard from Dr. Bekemeier and others. Number one, if we want to improve access with the local public health data to these data, the ability to act on race and ethnicity-specific data at the local level, we have to expand staffing. Staffing constraints are the largest and most immediate problems here, especially more local public health workers, as Betty mentioned, that 80 percent estimated additional need. But in particular, more public health workers at the local level with specific data science training and skills.

That relates to the second point also mentioned by Dr. Bekemeier, the need for expanded training for local public health workers, particularly in data skills, data collection, data access, and data analysis.

I would note that there are components in the American Rescue Plan that are earmarked for building capabilities at the local public health level. Most of the additional dollars that are allocated to local public heath are non-recurring funds. What we are hearing from public health stakeholders is they are reluctant to invest those new federal dollars in new hires because those dollars are going to disappear.

Investments in training, however, could be a good use of one-time funding. It is not clear to us that the training that is happening is really earmarked for these issues of data access and data use at the local level. That is worth some additional attention.

Third, the need for improved data infrastructure to facilitate local public health access to state and regional data systems that exist. They are there. Local public health is reporting inability to be able to access them. More investments in creating secure data portals that will allow local public health data analysts access into our surveillance systems into administrative data sources and regional health information exchanges. Really important. That could also be good use of existing federal dollars especially nonrecurring dollars into infrastructure that have one-time cost, but potential benefits over a larger time horizon.

And then finally, what locals are telling us is that their states need additional capacity to fulfill local data requests and requests for local analyses. That means the staffing and the trainees are not just as the local level, but they are also at the state level for states who need to have additional capacity for meeting local data needs and data requests that are coming from their communities with a specific eye toward race and ethnicity-specific data.

The last point I will mention is that – I am not going to go into details because I think one of our other panelists here, who has served on this recent Robert Wood Johnson Foundation Commission is going to talk about this. But the foundation a few months ago released results from a national commission that was a panel to make recommendations about how to improve equity-centered public health data infrastructure that goes into more detail about some of these general strategies mentioned here.

Again, my email and contact information are available on this slide. Thanks so much for the discussion.

Denise Love: Thank you very much. You finished under time so kudos.

As our final, I do not have the agenda in front of me. We will hear from Dr. Ponce from UCLA as our last speaker and then we go into Q&A.

Ninez Ponce: I want to thank Dr. Mays for the re-invite for this session, and I wanted to thank all the previous panelists because I have been copiously taking notes and taking screenshots of your slides for all the information that you have provided.

Last time I specifically talked about the vaccine equity issues that were related to COVID-19 via equity issues particularly for two racial ethnic groups, the Asian population and the Native Hawaiian Pacific Islander population.

The agenda and takeaways on the left panel are what I concluded in April of last year and the main message that data disaggregation is related to data equity, and I think taking that logic even further that there is no health equity without data equity.

The specific examples were on two groups, the Filipinx/a/o population and the Native Hawaiian and Pacific Islander population. The way forward, I actually did not have very many recommendations in the way forward because at that time, I was grappling more with this place-based equity algorithms that had

been put forth with the intent of speedily targeting the hotspots and areas of needs where we were seeing outsized tolls on populations. My main point was that some of these place-based equity algorithms might have blind spots and then allocation of resources that are needed then are misplaced. Communities –

The way forward this time – this is a punchline – mindful of time – is that to look at these place-based equity algorithms, what has happened, but also, the data sources, the inputs that go into these algorithms particularly since they do look at the social risk factors – many are sources for social determinants of health measures. The big punchline here is community engagement. I think we have heard a lot about training on the local health department side and engagement with communities. But that is going to be my mind focus.

This is your NCVHS health data framework goals, Dr. Mays. You want help expert support to health ecosystems. Surface the gaps – gaps and data source and methods and then catalyze the development and interactive tools. I think among your panelists today you have heard that there is a lot of progress generally. There is some progress that continues that has to continue. But I believe that there are – we had a discussion today on how to continue this.

On the topic of place-based equity algorithms. There are many developers and there are newer indices. It really is up to the developers on expanding this. I showed this last time. There is a social vulnerability index put out by CDC, the area deprivation index, California Healthy Places Index, which is California specific, and at that time, the preexisting health vulnerability index. And also, at this point, it is California.

The main point here was that only one of these indices, the SVI, actually had an explicit input of minority status and language needs.

Updating a little bit. There is still the SVI, which is widely used across different states and localities. Area Deprivation Index also is still there. But I add from the Graham Center, the Social Deprivation Index, which actually had been around. It is not a new development, but just new here in my slides and also from last time, as Dr. Mays had clarified, that the Preexisting Health Vulnerability Index was a component of a larger index called the Medical Vulnerability Index that has been used, which includes the social barriers that get at minority status and language from the SVI as well as citizenship status particularly in areas like California, which is 25 percent immigrant, is really important in getting at vulnerability.

As I said, only two of these measures explicitly include race/ethnicity and language, R/E/L, and non-citizenship status. I am not a developer of these indices, but we have – in L.A. County, we have started to work with the Southern California Public Health Association that developed the HPI, the Healthy Places Index, in really thinking through how to best understand how these indices might leave out some populations so starting to look at stratification by race/ethnicity, looking at the overlap of what community organizations are seeing, our underserved areas, and what is missed by these indices and threshold levels. I think at the local level, at least, local in Los Angeles area with local health departments and to develop the index developer that we are working pretty actively in making sure

there is a version that will incorporate race/ethnicity language, non-citizen status, as well as other variables such as multi-generational housing.

Another development since April of 2021 was that the California Pan-Ethnic Health Network, which is a community-based organization is a network of community organizations across the state that focus on health and social services advocacy. That they put out a report and I was part of this on using the disability rights movement cry of Nothing About Us Without Us and can area-based social indices effectively advance health equity. Through series of talking to their community members across a state and looking at these various indices, they come up with some suggestions where there is a strong endorsement of directly factoring in race/ethnicity and language and other domains relevant to measuring health disparities in these indices. But also, a cautionary note that even if you do factor in REL that you need to determine this impact on communities, particularly those who are smaller in size like Native Hawaiian and Pacific Islanders, American Indian and Alaskan Natives and subgroups within the larger OMB categories that are heterogeneous. They are displaced or geographically dispersed.

Absolutely do not use it as an end all. You need to pair these indices with other tools and strategies, including authentic targeted community engagement and leading to structural reforms. I was so delighted when Dr. Bekemeier talked about this new domain of institutional discrimination and that these is certainly something that is of import.

And then matching the indices with social determinants of health with specific policy issues. A lot of these indices – the outcome variables that are being modeled may not necessarily be valent to really what you are trying to solve. For example, life expectancy is commonly used by the HPI or looking at different risks. Making sure that these predictive modeling's that you are actually addressing specific policy issues. In one of the indices, they look specifically at COVID-19 deaths, for example.

Then the relevant domains are available at the block level. I think David Van Riper, talking about the accessibility of the Census 2020 data products and absolutely that the denominator issue of using 2020 is important. Again, very important for smaller populations with the Native Hawaiian and Pacific Islander population. Using the older denominator has led to implausible vaccination rates of over 100 percent. Absolutely the denominator is very important.

The data sources. We also did this paper in the Journal of Health Politics, Policy and Law, looking at the federal data sets besides the ones from the Department of Health and Human Services, that disaggregated Native Hawaiian and Pacific Islander from the Asian category. We found that since 1997 with OMB Directive 15 that over 30 percent still failed to provide disaggregated NHPI data. And I think more and more you are seeing this in papers and seeing this in battle cries from advocates, that it is really feeling like this inaction and omission is a form of structural racism or continues to produce structural racist barriers that need to be addressed but are not addressed because of the invisibility of populations in this data and these measures.

I am going to go through – this is the review. We looked at – we expanded on a paper by Panapasa, Crabbe, and Koholokula in 2011. We looked at 29 national data sets in six agencies in addition to HHS, Commerce, Education, Housing and Urban Development, Agriculture, and Justice.

I am going to just really peak through this list of how we collected the data and whether they were – NHPI race was collected where they are reporting and compliant with OMB, and also since we used the previous work by Panapasa et al. that we looked at – is it improving and is it not improving since 2011. That is the last column. We are going to go through this very quickly to make sure that we have time for discussion across all the panelists, because I have some questions for them too.

Just to show the different data sets. Keep going. Agriculture has a development. The Department of Justice – Census of Jails.

This is my attempt to try to summarize all of those results. The right upper quadrant is where there is compliance in collection and compliance in reporting across these data sets. The ones in yellow are the DHHS data sets. Some of these we know off the top of our head. Some alphabet soup, some BRFSS, YRBS, NSDUH. Some of them, I will have to have a cheat sheet to look up if you are interested in it. And then the Census, ACS, CPS, the Survey of Income and Program Participation, the SIPP. You see that there is collection and reporting and then after Dr. Mays' presentation, I feel like there should be a third axis I have to work on, in terms of actually access, like lowering the transaction cost for local health departments and for communities.

We see that there is a lot of compliance. There is collection and reporting seem to be fine. As Dr. Mays said, maybe the SNAP and WIC you could not access as well. But, again, this is what we found in the federal and state. Then there is more where they are collecting data sets, but they are not reporting. This is summarized here. Really, the data sets that I use in NHIS, NHANES, and MEPS are at that point where you do have to go through a secure data access center to get at granular race/ethnicity data. And then these two data sets here. Again, this is a non-exhaustive list of non-compliant reporting.

I think that there is – and we looked, as I said, is it improving. There were definitely improvements where back in 2011 that ten years, more than ten years since 1997, directive that there was still a number of federal data sets that were not separating Native Hawaiians and Pacific Islanders from the Asian group or putting them in some residual category, but it looks like that there were improvements.

My conclusion is that the social indices, which is what I started with in talking about since that is where I left off in April, that they are trying to address health equity and there are absolutely important new tools in the federal, state, and regional policymaking. But they have to address this underlying cause of structural racism, discrimination, and biases. Race/ethnicity is not a perfect proxy for that, but that would be a start.

The limitations though on race/ethnicity, I really think based on just my on-the-ground experience in Los Angeles and California, is that it does necessitate the inclusion of these community center strategies and that is something that we really emphasize, as Dr. Mays has said. I was on the Commission, the Robert Wood Johnson Foundation Commission, to transform public health data. I think that just kept resonating in all the conversations that we had.

The adoption of area-based social indices can supplement. Again, it is a supplement, but should never replace authentic, intentional engagement with the communities that are being affected and impacted

by these decision makings. This has to happen during the planning, the implementation, the evaluation of any public health strategies.

I think the next steps are tools and the data intermediaries' program such as OMH initiatives and Dr. Bekemeier, going to your – you may hear from me very soon about how to make this happen. We did get a grant as well to do this in the Native Hawaiian and Pacific Islander Data Policy Lab at UCLA. And the trainings are absolutely important. We have already completed a community assessment of 30 NHPI organizations. I will not talk about this now. It is very new. And particularly smaller communities. These are our projects.

I do want to end with the main takeaway from our community assessment is a lot of these organizations just do not know where to look and how to ask. Building dashboards and the training and how to do this and reaching out and having that trust, is really important to improve data systems.

I hope you heard everything I said because I have been frozen on the screen for a while.

Denise Love: We heard everything and it was fabulous. I think I hear a lot of pop ups in the brains have a lot of questions. Vickie, I may let you lead off on how we conduct the next section of discussion Q&A.

Vickie Mays: I have a few comments, but given that many of them were covered by my colleagues, I am going to make it very short because Dr. Ponce has to leave at 9. I want to make sure she gets her questions and gets to answer them.

What I wanted to do was just bring to the attention of my colleagues that there is a report. Many of us know Cara James, who used to be the director of the Office of Minority Health at CMS. And their organization put out – she is the CEO right now of Grantmakers in Health. They put out Modernizing Race and Ethnicity Data in Our Federal Health Programs, which focuses specifically on issues that came up in terms of COVID.

For example, I will send you there just so that you can see. For example, they went through much like Dr. Ponce, and looked at places where the data is collected, whether they think it is complete or not and what some of the issues are.

There is a set of recommendations, which were really covered very well by my colleagues. So instead what I want to do is not go there, but just talk about this issue of here is what we have to think about. We follow within the federal government in some data collection and report outs, the Office of Management and Budget. That was done in 1977. HHS also then upgraded their perspective on how to collect and report out the data in 2011.

Part of the inconsistency that exists in the federal system is who uses what to report out where. We have not had an update since 2011. You can see here the differences in the two. And many things have to go through OMB. Here, you can see the differences in terms of OMB in 1997 and HHS in 2011 in terms of ethnicity.

I just want to bring that to our attention. And what you will be able to see is there is a whole set of recommendations, which my colleagues have covered in lots of great ways that I will leave with the committee for us to work on later.

I am going to stop there. I am going to stop sharing there. I am going to open it up because there are members of the group that worked on this that actually have some questions.

But what I am going to do is try and take the co-moderator's prerogative and let Dr. Ponce ask her questions first because she has to leave unfortunately. Can we get you to ask your questions, Ninez?

Ninez Ponce: Thank you. My video is totally frozen, so I am sorry. I am going to turn it off. One question I had for Dr. Mays was there was the access piece. Dr. Mays, you had mentioned something about access through social health information exchanges. Could you elaborate more on that because I frankly have never heard of those? Should we have them? Where are they available? That is what I wanted to ask.

Glen Mays: Fantastic. I think you are referring to Glen Mays. It is so great to have another Dr. Mays on the panel. I rarely get that. Social health information – emerging piece of the data infrastructure we are seeing pop up in communities across the US. But basically, when you think about these, many of them are being built on the platform of health information exchanges. They were created for hospitals and physicians to share electronic clinical information from electronic health records. Increasingly, those regional HIEs are building capacity to incorporate data from social services providers on social needs and social services received health-related social services. We are seeing a growing network of these social health information systems being developed. We are basically opening up regional health information systems to include dataflows from housing providers, from food and nutrition providers, from people providing financial assistance, et cetera.

Those social health information systems are being used to help navigate – help identify people who have unmet social needs and help to navigate them to social service providers and close the loop. They are really promising. But as I mentioned, lots of problems with, again, access to particularly public health access to those regional information systems and then of course lots of problems with incomplete and missing information on race and ethnicity data within those systems.

If you are interested, there are a couple of national networks of these social health information systems. Two of them are sponsored by the Robert Wood Johnson Foundation and my group works closely with them. One is called the DASH network, Data Across Sectors for Health. And the other related network is called the All Un network. I am glad to provide more information as needed.

Ninez Ponce: Thank you. Sorry, Dr. Vickie Mays. But I wanted to ask. I am on the commission, as I said, on the Robert Wood Johnson Commission and they do have dollars, as Dr. Glen Mays had shown on one of his slides. I do think that we felt that the role of good data is still government role and that is where foundations and advocates come in is catalyzing either the coverage or the efficiency and the efficiency of the data systems particularly informing public health decision making. I think something like the social information exchange would be one area. But I just wanted to get a sense from the other panelists on what they think would be ways that an investment, a nongovernment investment in catalyzing and

improving and modernizing public health data or federal data sets like what would their recommendation be.

Vickie Mays: Anyone want to answer from the panel?

Elizabeth Pathak: I will take a stab at that. I think it is a really great topic that we are on right now. In relation to COVID-19, I have been working on this and thinking about it pretty nonstop for the past two years. We did a paper looking at social class disparities and COVID-19 mortality. We found very large disparities which are also racial and ethnic disparities because we live in a system of racialized capitalism where the black and Hispanic and indigenous working class are more disadvantaged than the white working class. We have both of these things operating.

I have really come to understand COVID-19 as a disease of the working class. The working class has been highly disproportionately impacted and that is true across gender and across race. But of course, gender and race and ethnicity are independent risk factors as well.

It also impacts children because children, as you may be aware, are of lower socioeconomic status than adults overall. Children are more likely to be in working class families. And the fact that the majority of the cases and hospitalizations and deaths is we are seeing among minority children is a very strong indirect indicator that these are kids who are coming from working class families.

For me, the main thing that I think is always missing is an explicit class perspective. I think that the concern that I have – of course, I do a lot of work on racial and ethnic disparities. But I think there is always the risk for victim blaming, essentializing, and tying things to individual behavior or health education knowledge and not to the structure of work. This is why I think it is very important to when we use words like class and working class then we can understand why certain groups of people have been at such higher risk than others. It really does come back to the conditions of work and control over the conditions of work. This is an area that I think we can see improvement across the board. And of course, it is a decade's long problem. It is what sets us so far back compared to many other nations that we lack this ability to link in social class data to our health data systems.

With the area indicators, instead of always characterizing small areas by the percent of the people who live there who are black or Hispanic, how about the percent of the people who live there who are blue collar workers or service workers to try to just move away from that racial essentializing that we do so much of in America? I am not obviously talking about the people in this group. When we always put things in those terms and we never marry that with social class information then it can be taken away from us and then used and interpreted in wrong ways. That is my piece on that.

I am going to put in the chat – I am going to put links to our preprints, which I hope you will take a look at. I think they are very useful. Dr. Ponce, we do have disaggregated indigenous Native Hawaiian data in there.

Vickie Mays: Thank you. I am going to let Betty Bekemeier – Dr. Bekemeier also has a hand up here.

Betty Bekemeier: Great. I want to just speak to the issue that I think Dr. Ponce mentioned, the question of foundations, private funding, catalyzing some of this work. But what is the role of the federal

government? An example of that is this work we have been doing with local heath departments around administrative – standardizing some of these administrative data. We really – health departments have been kind of a black box in terms of what is being spent, what is happening in prevention services and delivery and how resources are allocated and where they go and what they can do, et cetera. Glen Mays and I and others have done a lot of work in this area in the past, but it is so limited by the data.

The Robert Wood Johnson Foundation really did catalyze this work we did with the Uniform Chart of Accounts, for example. We developed it with practice partners. Glen Mays has been involved in this to a certain degree too. It is available, ready. We have users using it. But it is so small. It is far too small at this stage. It really needs the federal government to invest in now really ramping this kind of thing up.

To me, it is – there is only so much a foundation can do in terms of catalyzing these kinds of things. But they really are – I would totally agree that these are things that the federal government really needs to get behind and support and then ramp up.

Vickie Mays: Thank you. These are great suggestions. Let me let the committee members in here. Does anyone of the committee members have a question for the panelists?

Denise Love: Seeing no hands. Are there any hands out there that I am missing?

Rebecca Hines: Denise Chrysler and Val Watzlaf.

Denise Chrysler: This question I think, is for Dr. Bekemeier. It also maybe for Dr. Glen Mays. You both talked a lot about local public health workforce and the need for greater expertise in the building of local public health with regard to data collection and data analytics. To what extent does the development of the local public health workforce include attorneys? Being an attorney of course, I am really interested into what extent is law considered an important part to develop so that local public health has experienced public health attorneys who understand, for example, how HIPAA applies or does not apply to local public health who can represent public health in negotiating over data with health systems and that sort of thing?

Betty Bekemeier: I could say the short answer, Denise, is not much and not enough. The very large agencies. They have lawyers. The state health departments have legal folks, et cetera. But we had some years back. It has only been -- public health law programs at the national level, et cetera, have only been around for 20 or 15 years or so. It has been a growing area. And of course, in the last two years, it has been really – this whole area of science, et cetera, has been really devastated. We really need more. Definitely this kind of public health law really needs to be bolstered and relooked at and supported in all areas of practice. Glen, I am sure you have stuff to say about this too.

Glen Mays: I would totally agree. I think – not enough -- I would add that in terms of formal graduate training in public health, there is a recognition of the importance of public health law competencies and they are included in graduate – at the MPH level, training in those competencies, especially training public health professionals and how to work with their colleagues in the legal profession.

One other thing I might add is that public health as a profession has so far been left out of loan repayment programs like the National Health Service Corps that many clinical professionals are able to

tap into. That is another area where there could be a federal role is to incentivize more graduate-level training in public health that would include things like legal competencies, helping with loan repayment at that level.

Valerie Watzlaf: Thank you and thanks so much for your presentations. I know I have been taking many notes. So much of it I think is so concerning and I appreciate the solutions that you also provided.

My question I think more for Elizabeth. I think you had ended your presentation talking about vaccination data as well for children. But I was not sure – are you seeing the same gaps there as you saw with the other data? And if you could talk a little more about that.

Elizabeth Pathak: Sure. I would be happy to. The CDC releases a data set every single day. It is updated daily and it is pulling in data from the states on vaccinations. These are counts of people who fall into different categories of vaccination. They do have data on children, which is great. The age categories are not very fine. We have 65 and older. They put out 18 and older, 12 and older. We subtract to get 18 to 64 and 12 to 17. And now we have 5 to 11 data. There is no race and ethnicity data at all released in the vaccination data. Any race and ethnicity vaccine data that you are seeing coming out of CDC is from smaller samples. It is not national surveillance data.

Now, having said that, like I said, as part of COVKID, I visit the state health department dashboards all the time. There are a few states that do report vaccination data by race and ethnicity. We have not been tracking that directly, which is not because it is not important. It is just really a function of time and funding and all of that.

I suspect that we are going to see the same kinds of challenges that we have seen with access although I have seen some encouraging reports of local health department efforts to really ensure that equity is maintained and distribution of vaccines. I think that the local public health community has really risen to the challenge of that.

At the same time, I think that White House and certain federal decisions to put vaccines in the hands of commercial pharmacies rather than focusing on the government and local public health has created some equity issues.

Let me expand on that a little bit. What happens in the commercial pharmacies even though the vaccines are free to everyone, if you go into CVS or Walgreens, you will be asked for your insurance information.

Now, for people like us with college degrees and getting back to my theme of the working class, for people with education, this is maybe not intimidating. We just say here is my insurance card. Fine. Charge them if you want to. I have insurance. No problem. But for people who do not have insurance and who are being faced with fill out these two pages of forms, show us your insurance card, where is your ID. I have heard numerous stories of people just turning around and walking out. That all of that information gathering, trying to charge insurance is a barrier to vaccine uptakes for working class minority and immigrant populations. I think it is highly variable what is going on at the local level. I think we still have a lot of work to do in terms of equity.

And the other thing. If you look at our dashboard, we are analyzing the data to – this applies to all ages, not just kids. We are analyzing this daily CDC data to account for waning effectiveness. One of the frustrating things that is going on is the CDC's reporting on vaccination is basically cheerleading. And the reality is that we are not in good shape. The majority of the population is not optimally immunized, meaning that many people have not received their booster dose. This is especially true for teenagers. You can go and you will see the maps. There is state data. They are by age. We want the data. If after five months, people have not received a booster then they are no longer in our top category, which is optimally immunized. We still have a tremendous way to go in terms of vaccinating the population.

You would not know that from the way that the statistics – we get a lot of numerator-only reporting. A million doses. Okay. But what is the denominator? What percent of people have actually gotten what they need? This happens from CDC and also state health departments are doing that kind of cheerleading and it is not always giving the most accurate picture, which is not a very positive picture of where we are right now with COVID vaccines.

Wu Xu: First, thanks to all the panelists and the moderator for this great panel. I have a question for Dr. Bekemeier. In your last slides, you have the recommendations. But the last one – you just have mandates. Because we ran out of time you did not talk about that. Could you explain a little bit more detail of what mandates you think we should have?

Betty Bekemeier: Good question. That is more specific to the – what I was thinking about there is our finding in relationship to public health administrative data. We have developed these standard data systems particularly around financial data that seem to work, et cetera. But it takes some initial investment and some initial effort by health departments. Our experience has been that frankly what is really going to make this ubiquitous is if it is mandated. Kind of like other similar data are mandated for health care systems, et cetera. It is kind of a dirty little secret with health departments themselves. They do not like more mandates frankly. It is nothing that we necessarily broadcast or talk about frequently with our public health practice partners themselves.

But clearly, it would get folks over the hump in terms of actually implementing the systems. It is going to take incentives. It is going to take some upfront investment, federal investment. It does not take a lot. We figured out how much it would cost and frankly, it is a one-time investment upfront and then just some of the ongoing maintenance, et cetera. But the effort it takes is not huge. Even that is not huge. But folks need pretty encouragement on a more wide – we have already pulled in the early adopters. The more data you have, the more valuable they are. And to bring in other folks that sort of needs stronger encouragement. That is our sense of what it is going to take.

Vickie Mays: Thank you. Dr. Spielman has to go. I just wanted to see if there were questions for him before has to jump off. Are there any questions that are specific to their presentation? Okay.

Tammy, I cannot tell if your hand is up. Is your question for him or is your question – Denise, is your question –

Denise Love: I think Tammy's and my hands were up before.

Vickie Mays: Yes, but anything specific – okay. Dr. Spielman, I will let you go. David, I am hoping you will stay a little longer. Thank you.

Denise.

Denise Love: Yes. This panel is fabulous and I feel hope that in a hard time that folks like you were working on these intractable problems.

The thing we have heard, and this is for Dr. Glen Mays. We heard yesterday for public health emergencies one of the solutions that might be a lower hanging fruit is better use of existing data even with all its problems and flaws. You mentioned limited access to these Medicaid, APCD, and hospital discharge data sets. They are out there, and my thinking is that should be one of the low hanging fruits that we could solve in a short amount of time. I worked in these databases for long enough to know that sometimes the locals do not know the people who are running the data systems, or the MOUs are too long and too lengthy to develop. But it seems that there is a solution there that we should be able to find. Am I just drinking Kool Aid or something?

Glen Mays: I think you are right on target. These are existing data systems. We do have defined mechanisms for granting access through data use agreements. I think there are issues of lack of knowledge at the local level of how to navigate those mechanisms. And as was mentioned earlier, lack of access to legal expertise. That can be very effective. We do not have nearly as many JD/MPH educated people with legal and public health expertise embedded within the state and local systems to navigate them. I would definitely agree. That is a relatively low hanging fruit way of expanding local access to these data. But we would need significant capacity building, I think, to help broker those data relationships.

Denise Love: The data are there and I think some of that access could be evened out. But I do think as we are talking federal support and brain power from Dr. Ponce and others, we could do maybe a better job of building in indicators that these data could populate that would also feed some demand and smooth out some of these access issues. I am glad that you agree because when you mentioned that, I highlighted that in my notes.

I will turn it over now to Tammy in the interest of time.

Tammy Banks: I will be short. But I did want to commend Elizabeth. I really appreciate your COVKID project data quality report card and that you are identifying the minimum data set and making awareness of the gaps that are out there.

But I recognize that these data sets are only as good as the data that the state health departments get. I come from the health care setting perspective. That is where my comments are coming more than from a researcher. The COVID-19 data request from the state and local government was very burdensome and just as burdensome as the – Dr. Glen Mays, you were talking about all the needs and the improvements. It is the same on that setting side.

I am just wondering, Elizabeth and the other presenters. What do you think of – how do we identify kind of like the Gravity Project where they are looking at the social determinants of health. They are working

through the ONC efforts to get those data in the EMRs and then the other point is how do we put it in the workflow so the collection of some of these data points that are needed becomes more of a routine instead of a burden with an electronic means of exchanging that information so these dashboards can be automatically fed. Because right now, it is extremely manual. And every local department, every state department has different data elements, have different definition of those data elements, requiring manual entry and someone mentioned portals and I just kind of flipped out because the portals are not an answer. COVID-19 was manual update of information that had to be collected from systems that were not in the EMR or PMS. I know we can go on and on about where incentives and others lie.

But my question to Elizabeth is where do you see the primary data source for these gaps and how do we begin to move toward that accurate collection? I will be quiet because I could go on forever on these questions. But just looking more for solutioning and more conjoining of the medical health care community with the public health and the research needs that we know are extreme priority.

Betty Bekemeier: Right. I totally hear you and I think -- I would say that even the situation has even gotten worse recently because I think with the Omicron surge that many state health departments are literally just cracking.

I can tell you that there have been – I have seen more dashboards being down, just not being updated at all. The State of Maryland was subjected to a ransomware attack. Their dashboard was down for two solid weeks. I am still amazed by that. I am still so curious to find out what is the behind-the-scenes story of why it took them two weeks to put their dashboard back online.

We have late updates. There are states where they say we have updated, but it is not accurate because we have a backlog of 20,000 cases that we have not been able to process yet because the volume has just increased so much with Omicron. It is an intractable problem.

The solutions are staff and money. With COVID, the problem starts right at the labs with the testing. When we do not collect race and ethnicity and basic sociodemographic data on the people who are being tested then that is where it all starts. That is where the data systems start is with those tests.

I think Betty really hit the nail on the head that the way that you make things happen is you mandate them. The reason why we have daily reports on COVID hospitalizations from every single hospital in the United States, which is over 5000 hospitals. The reason why we get that is because CMS tells them you have to give us this information or we are not going to give you your Medicare money. CMS has a really big stick that they can use on the hospitals and the hospitals do not like it and it cost them money, but they have to comply. They do comply. Now, I am not saying that that is the ideal model.

There are countries where there is a national data set. It is basically the census. You have names. You have family information. You have educational attainment. You have occupation. That data can be linked to every other data system. Hospital discharge data. Link it to that census data. Vital records. Link it. We lack that in this country for some reason that I really fail to understand. It is political obviously. It is so easy to do things in other countries that it is extremely difficult to do here. And then we make people provide the same information over and over again every time they go to a different place or they are in a different location. They have to provide the same information because there is no behind-the-

scenes linking or connecting of the information that people are providing. I wish I had a great solution. I think everybody is well aware of what our structural limitations are in that regard. It is going to take a lot of concerted effort to break down some of those barriers.

Vickie Mays: We have about five minutes left. Let me just check in with others on the committee to see if there are any questions. If you were not in the small working group if any of you want to ask questions, please raise your hand. If not, I am going to close us out and letting these last couple of comments. I do not see any other hands, Denise, unless I am just missing it.

Denise Love: Dr. Bekemeier, did you get your comment?

Betty Bekemeier: I was just going to reinforce this idea. With our SHARE-NW project, it could be considered a pilot. It was just four states. But it really speaks to this issue of -- the degree to which we have existing data is great. It has some utility. But if it is not accessible and I put "accessible" in quotes because it means spreadsheets, having a bunch of spreadsheets available to people or even a flashy dashboard that does not meet their needs is not accessibility so really linking existing data sets that people need, putting it together in a useful way that meets their needs on the ground is really what – and developing that capacity for utilizing the data is so necessary. That is something we have really found with this project and there is so much more that could be done in terms of scaling it up and implementation science, what gets people to use these data better. How do they make different and different decisions? How do they allocate resources in more equitable ways, et cetera? There is so much more than can be done with that. And, again, it is this low hanging fruit around data that already exists and the data will be better if people are using it as well.

Vickie Mays: Great. Let me just ask a question because I would be remiss for the researcher in me if I did not and it is for David Van Riper. Have you all developed any tools that could make it easier for individuals who work on data to be able to deal with the denominator issue? You have either technical reports, data tools. Because my concern is that as you can see, the best approach to some of this is to bring it down so in terms of having public health workers, in terms of Dr. Ponce talking about her community people, but this is very complicated in terms of doing this work and getting it right. Anything to give us?

David Van Riper: As of now, most of our data products here at IPUMS and Minnesota Population Center are more focused on researchers. That is the typical user community we work with.

We are starting to have conversations with public health scholars here at the U of M about how to create that next layer of data that is more accessible for local health departments and local health professionals, trying to figure out what can we do to make it easier to access our data.

Now, unfortunately, that is hard for us. We have so much data that it is really tricky for us to know how do we engage with the local community groups to know what are the useful data points that they need and separating the core of what is important from the massive volume that we have.

My work with some of our faculty here at the U of M have helped me get a better sense for what those high priority data items are. We are working on a product that will hopefully be a census tract to dataset from 1990, 2000, 2010 and today that lets you measure change over time for local communities for

income, race, age, employment, educational attainment that standardizes all of that data. Something is coming. But we have not quite figured out how to build the systems that meet that varying level of expertise.

Vickie Mays: We will put you together with Dr. Ponce. But I just want to thank the panelists. You have done a great service for us in terms of giving us insight for what our next steps should be. If it was left up to us, we would just keep you all day. But we better do other government business here. I want to thank each of you for your contributions.

I can see my colleagues and their note pads and what have you. I will say I am pretty clear that we are walking away with some very important information to help us to determine what it is that we should say to the secretary to be able to help us. I appreciate the time that you gave to do this. I also appreciate that many of you were very honest about what the problems were. We will take it to heart that we have the responsibility to be reflective of what we heard from you.

I think I will say everybody give you a hand and I will turn this back over to our chair, Jacki Monson.

Jacki Monson: Thank you, Vickie, and thank you to all of the panelists on a very robust discussion.

Let us break now for lunch for those of you that are East Coasters. The rest of us it is breakfast. We will break from 12:15 to 1:15. I will see you all back at 1:15. Thanks, everyone.

(Lunch Break)

Committee Discussion & Follow up on Workgroup to Assess SOGI and SDOH Data and Measures Definitions, Collection and Use

Vickie Mays: Okay. Let us get started for today. First of all, I am very excited as most of the committee about the fact that we have had the privilege of having a group established that is going to assess SOGI and social determinants of health data in terms of looking at measures, definitions, collections, and use.

The goal for today is really to make sure that the Full Committee gets introduced to the workgroup. We want to make sure that you understand the scope of the workgroup charge so that when we charge off to do this, we want to make sure we have in mind the things that were very important to you as well as have in mind that we need to be reasonable about the work that we are doing in order to be able to get it done.

We also want to talk to you today about how we plan to approach the work. Again, the charge is broad. Big is probably a better word and overarching. What we want to do is to be able to have these manageable chunks. We want to set realistic goals, given the timeline request. What you will hear is chunked for us between meetings to be able to get something accomplished.

We also want to work with you today to learn who are the players are both within and outside of HHS. We need to get a sense of what is going on within HHS and its goals. But we also want to know influential organizations such as Robert Wood Johnson Foundation or ASTHO that would allow us to make sure that we bring people to the table with us who can facilitate this work.

And probably the most important thing of all if we can all get excited about the work. But what we really need to do is focus ourselves on those tasks that are best suited for NCVHS and things that we discover – maybe they can be passed on to others. But let us try and stay in our lane because that is when we do really well.

Here we go with what our charge is – our charge. It is to identify considerations and options to define methodologically sound categories for framing sources of these data. What we have thought about is what are the buckets that we want to put this in. When we start to categorize this data, we thought about survey, administrative, clinical, vital records, public health surveillance. We also have to identify what are the domains of SOGI and social determinants of health data that should be collected by data categories and also what we are being asked to do is to think about everybody cannot collect everything in each instance. It is going to require some prioritization among the domains in case there is a burden, a problem with collecting data. Let us be able to comment on what we think is the priority in collecting data in particular buckets.

We also want to look at some of the best practices for how the data should be collected. Again, this is when we begin to talk about specific data elements. We are going to talk about data standards, the order of the questions. We need to include the issues of public trust. Any other kinds of findings regarding either options or alternatives that will allow HHS' ability to improve data equity and equitable evidence-based decision making is important. We are going to make sure that we have comments on that.

Finally, we are going to provide the findings. This is how we work in terms of providing the findings to the Full Committee. We want to look specifically at things like privacy considerations for use and linkage of SOGI and SDOH data in each setting. We are going to talk specifically about privacy considerations for potential us of SOGI and SDOH data such as administrative data, clinical data, public health data, and research purposes.

Who is on this? In terms of our NCVHS members, thank you to all. You can see who we have there. I am very happy in terms of the mixture. We have people that represent the subcommittee so that will be helpful.

We have been also very pleased to be able to get some great staff. As you can see, we have staff from ASPE, CMS, NCHS, and we will see who else will come to the table when needed.

When we have a moment, I will actually ask each of the staff to say hello so that you can see who they are. We have invited them to be with us today.

I am going to turn the presentation over at this point to Jamie Ferguson because what we are going to try and do is to really give you a sense of what we think are issues that fall into either privacy or issues that fall into the Standards Subcommittee. Jamie, can you take it from here?

Jamie Ferguson: I will take a few minutes. Thank you, Vickie. I will call this the overview slide for standards. As you can see, there are different aspects to gender information that really require a use case approach. I will start in the middle of this slide. The recorded sex or gender, sometimes known as the administrative gender frequently comes from vital records.

Then we have right next to that the sex for clinical use. Clinical sex relates to medical procedures or medical observations. The HL7 range of values for this is male, female, specified, or other. This does not yet reflect intersex of transitioning people's state or status. But actually, what we find is that in large group practices, they do standardize the use of SNOMED CT codes for transitioning and intersex people.

Also, related to the sex for clinical use, historically, in this project, there were debates about using the clinical sex field to capture people's genotype and phenotype of sex for clinical use. That is also not currently in there.

Moving over to the left, the gender identity or the GI of SOGI, this is an individual's personal sense of being a man, a woman, a nonbinary, or something else. This can only be ascertained by asking them what that identity is.

You will notice that the SO, the sexual orientation, is not yet on this slide. That is because that is the next major work item for the HL7 Gender Harmony Project. This is from the HL7 standard.

The thing I would like to emphasize here is that ONC requires EHRs to have the ability to collect SOGI in the EHR. But the range of values has not been standardized yet.

I would highlight here also that California requires the collection of SOGI data if known. If known is going to be very important when we go to the next slide. What I wanted to mention here is this is about the data flow. The first sub-bullet there shows data going from the order of EHR to the laboratory information system to public health via electronic lab reporting to public health.

Now, I can tell you that previously earlier in my career, I worked in a clinical laboratory at the Yale Medical School. I was a researcher there. I can tell you that laboratory system data is not patient data. Laboratory data is specimen or sample data for the chemical or biological test only. For example, a sickle cell test actually does not use or relate to race and ethnicity of the patient. It only relates to the test that was ordered, the blood sample that is being tested, the test that is being performed and getting the result back for that sample or specimen whereas the next sub-bullet from the EHR to public health via electronic case reporting. The case report is clinical encounter data. This is where patients are asked questions and where their answers are captured unlike the laboratory system.

Vickie, if I could ask you to go back to the overview slide for a minute. I think that is page 5. Just a couple of my summary of some of the issues here. In terms of data content standardization, the workgroup really should consider the potential for expanding the clinical sex for clinical use and the needs for transgender and intersex people because they would like to be recognized and it is not currently in the value set.

At the same time, the range of values that is currently standardized for gender identity really should be validated. I think we should support standardization of the sexual orientation data values, which are not currently in this project.

Now moving to data collection of these, I think we really are going to need obtain expert testimony on the questions that are used in the clinical encounter setting to get people's data and support standards development and testing as well as conformity assessment for the use of the data that are collected.

And then of course, we would like to move towards federal adoption of the data content and data collection standards.

In terms of the data flow that I mentioned, I think the workgroup is going to have to evaluate the options especially the feasibility of expanding the standardized use of electronic case reporting and make recommendations on that.

Vickie, I will turn it back over to you. That was my summary. Thanks.

Vickie Mays: Great. Thank you. Part of what we were hoping is to try and give you just some insights into what the issues are. We talk about how we are going to work on this. Part of what you are going to see is that we will be talking about how we want to work. The approach that we thought about taking for these buckets and the bucket is for manageability. The bucket, as we saw it, would be taking clinical data, followed by administrative data, followed by surveys, followed by funded research. The reason we are starting with clinical data is because there are many groups that are currently working on their EHRs and they are trying to do their work both in terms of integrating social determinants of health as well as SOGI. Between the two, what we realize is that SOGI is probably going to require the most work.

Even our own subcommittee – our own committee has done work on social determinants of health. There is much more that is out there about the integration of that. There are some EHRs that already have social determinants of health and the people are struggling much more with SOGI.

What we decided is these would be the buckets and in the first one that we are going to take I think has the greatest urgency, which is to work with those individuals who are working on their EHRs because once the train has left to ask someone to redo their EHR I think is a little problematic. That is where we are going to start.

We are going to do this work serially. What we have been asked by Sharon Arnold is to try and by the next meeting, for example, to have something that in June that we are ready to present to the Full Committee for some kind of adoption of recommendations to HHS on how to handle this data. Remember, our whole goal is helping HHS.

We will use a parking lot because as we do this work, the expectation is that there will be things that, for example, in terms of social determinants of health that we will learn when doing SOGI and when doing SOGI, things that will be relevant for vice versa. We want to make sure in terms of our work that it is manageable, that it is reasonable, and that we do not work in a way in which we are so delayed that we are not useful.

As many of you know, HHS is very busy right now working on many of these things. If we are going to be of help, it means really trying to do something soon. As you can see, there is our suggested order that has been discussed in the workgroup. Other examples of SOGI issues for NCVHS --

Rebecca Hines: Vickie, your slides are not showing.

Margaret Skurka: Vickie, while we are waiting, let me say that a lot of – there are lots of good codes for the social determinant health data in ICD-10-CM. You can code homelessness. You can code food

insecurity. You can code all of that kind of stuff. If you want some coding expertise – I know I did not volunteer at the time for the committee. But if you want to run some stuff by me if I can provide any codes or coded data that would be helpful in doing the research, I will be happy to do that.

Vickie Mays: Great. Can I ask you whether or not there are -- thank you. Can we go down and get me to slide 9? Thank you.

The question will be when we open up for discussion, I will ask you about SOGI. This is what I was actually talking about. You have heard it, but that was the slide.

What we want to do is also provide you with some other examples that we think intersect with the work of NCVHS. Denise Chrysler, will you join us in talking about this particular slide?

Denise Chrysler: I am happy to, Vickie. As Vickie said, the potential topics – there are so many and we need to focus and stay with our parameters of our charge and focusing especially on standards and privacy aspects of these topics. Just a few and they can be read expansively or more narrowly on the data systems. The same issue in the prior discussion of race and ethnicity. What is the capacity of systems to collecting the data and the system support collection and exchange and analysis of needed data? And then the collection practices. Jamie talked about best practices and collection of data that are accurate, complete, and – what are the purpose for the collection.

As with the race and ethnicity, it is collection of – a collection that enables comparisons across age groups or geographic areas or data sets. And then Jamie had mentioned how data are captured and patient encounters and surveys and that sort of thing.

And then the purpose. When data are collected for primary purpose, what data are relevant to the intended use and how are data protected so that they are appropriately accessed and used? How are they not protected so they are not used for discriminatory purposes and again privacy issues? And then what are the parameters for secondary uses of the data, uses for which the data was not collected?

Then there are issues again around data quality and integrity. These have been mentioned before. Data completeness, accuracy, timeliness. And then finally – and I will just mention challenges around small cell size that was discussed with the race and ethnicity discussion. And then with social determinants of health, population, race and ethnicity. There are many issues that we will encounter here that are in the other discussions, but also issues about linkage with data for social determinants of health, race, and ethnicity and other data.

That is it, Vickie. Over to you.

Vickie Mays: Thank you, Denise. In particular, you heard many of the issues earlier today in terms of race and ethnicity and some of the population issues. We need to be mindful of that.

But the other question will be in terms of when we get to the social determinants of health is the issue of burden – asking people to do both SOGI and social determinants of health. We need to be mindful of how all this is going to take place. Once we get SOGI done say for example in a clinical setting, we will

then move ourselves to talk about social determinants of health so that what we are giving is a set of recommendations that take into account that both of these things will be done in a clinical setting.

One of the good things that should help us to be able to get ourselves up to speed as well as to help us to be able to frame these issues is that NCVHS has done some work in the past. I think it is going to be important for us to turn to that work so that we are not trying to start from scratch.

Data stewardship, trustworthiness as owners of the data. We have been in this space so data stewardship for quite some time in the Privacy, Confidentiality, and Security Subcommittee. We had a lot of work that was done on that.

We have started to also talk about trust worthiness as owners of data. That has come up and I think that that for us will be a framing because it is one thing to talk about the collection of the data. But if people do not want to give it to you because of their perception of trustworthiness and their concerns about it being protected then we are not going to get anywhere. I can tell as you a person who is in the academic medical center – you can see the number of surveys that are in my medical record asking me to fill out, it is incredible. I choose which ones I will fill out. I think that that is something for us to think about the framing of.

We also had some work on vital statistics. And what we did was talk about that kind of back and forth between the states or the individuals who are collecting it. Locals go up to the state and then the state is sending it to the federal government. And what that relationship is we can say whatever we want to say about what we think should be done. But we need to pay attention to is are there fixes between the federal government and states that we can think about that will help us in terms of timeliness, quality of the data.

The Standard Subcommittee has done work on HL7, as you heard in terms of Jamie is a member of that committee. They have not done SOGI work, as I understand it. But we will be relying on some of their expertise in terms of helping us with the HL7 problem.

And then and I am sure Rebecca remembers this probably very well is the work that we did on the social determinants of health measures and then those got propagated out to community groups and they have even improved on that.

We are going to try and utilize some of what we have had in the past to help us be able to meet the time requirements of getting reasonable products done in reasonable amounts of time.

Here is our rationale in terms of what we are going to do. As I said, the workgroup is going to start with clinical. We are going to start with SOGI. As I said, this really is about the fact that systems are already in place. They are reengineering. Their needs are great in terms of being able to make decisions. And what we want to do is to be able to help them and talk about maybe even a bottom-up approach. Clinical data is the source for other uses also such as public health and research. This is an important place the workgroup decided to start.

Next, we will do administrative data. Again, many of you have used this. But administrative data is really complex. It often has this interdependence between local and state data collection, which then feeds into the federal data sets.

Again, like this hearing on vital statistics, we are going to have to consider a cooperative framing. We have to realize that there are some unfunded mandates. We have to deal with local laws and practices for both privacy and standards. It is not an easy task, but it is one that we have the expertise, I think, to be able to handle it.

Funded research particularly by the federal government is more doable. There are large entities, which tend to fund research. But HHS also has set policies around, for example, how to collect some of the race/ethnicity and social determinants of health that need to be looked at. We have great partners here that have been doing work, the VA, the Office of Minority Health, CDC, NIH.

And, again, one of the things that helps us in terms of the area of health, we are not doing funded research to just do funded research. But if we do not get research in the area of health, it makes it very hard for us to do some of the clinical evidence-based approaches we want to take. It is important to make sure that that is benefiting from recommendations as well.

Finally, the area that I think is furthest along on both SOGI and social determinants of health is really that of survey recommendations. Here is where our colleagues at NCHS have really been leaders. If Jennifer Madans was in the audience, I would call her name out. But we do have other people like Susan Queen at Sutter, who has a very long history in making sure that these issues have been considered.

And also, in partnership with NCHS, we things like the Federation of Statisticians, who have reports that we can look to, CNSTAT, which is a part of the National Academy of Medicine, has been in the forefront of this. We are worried less about surveys. We did not say it is perfect. But if we had to put an order on it, we think the surveys are cruising along quite well.

Here are things that we want to talk about. We want to talk about what is the scope of clinical data and systems that we are going to look at? We – hospitals, labs, health plans, pharma, insurers, health systems, registries. Are we missing anything? Is there are things that we are not thinking about? We would love to hear from the Full Committee on that.

We also want to know – we have the capacity because this is a workgroup. In a workgroup, we are able to bring to the table – what do we call them – experts. What is the term? SME, I think. But anyway, we have the ability to bring experts to the table. Those experts can either be individuals who are sending us information and making sure that we know what they are doing. Those experts can actually participate at the table with us in the workgroup. That is it. Subject matter experts. Thank you, Rebecca. I knew it was SME.

We want to be able to reach out and see who has information that should be considered. We want to reach out and see who has best practices that they think are working well. We, again, will ask you to let us know if there are people that we are missing here.

Then we want to know people. We know organizations. Some of us know people in those organizations. But what we would like to also get from you is if there are experts who are SME individuals in terms of policies and procedures for the clinical SOGI data, we want to get your suggestions.

What I would like to do at this point is to open things up. Before I do that, I want to see if Sharon Arnold, who I am pretty sure is with us – whether Sharon has any comments and if she would talk just a little bit about her perception around our time expectation.

Sharon Arnold: Thank you very much, Vickie and Denise and the rest of the workgroup members. I think this is a really important and exciting area. There is a lot of work going on both within HHS and externally in this area. But I think that my favorite analogy are little kids playing soccer. There is lots of stuff going on. People are kind of clumping together and moving together. But there is not an overarching, I think, structure and theory to how to collect this data and how to ensure privacy protections for this really important data. And given the expertise on NCVHS, I am hoping that the committee can look at the landscape, identify where there are gaps, where the committee has the ability to weigh in and provide guidance.

Since this is happening in real time, I was hoping that recommendations could potentially come out on a flow basis even if it is not a formal report. But I want to see progress. My goal is to have a report or at least initial set of recommendations come out in a letter of the secretary in a year. I know there is a lot of work to do. That is a really short time given the committee only meets three or four times a year. But it is an urgent problem. I think this committee has the expertise that HHS and the community needs to help guide this along.

Vickie Mays: Great. Thanks, Sharon. One of the things we are going to try and do is to have something if no more than kind of a landscape setting for the June meeting. That will help us push ourselves along in terms of clinical SOGI data.

What I am going to do is – Gregg, can I ask you to go backwards in the slides to the slide that is on the charge? Let us start here. Denise Chrysler and I will facilitate a discussion of hearing from individuals as to any questions about the charge, anything that you want to know more about.

Hearing none, that means our charge is very blessed by the Full Committee. You remember that when we come back. We are blessed to go forward. There is an opportunity to comment. But we really want to kick off and go forward after this meeting. If you think of something, please just let us know sooner rather than later. This is the charge that we have from Sharon. We are going to move ahead on it.

Greg, can you go through the slides? I will tell you when to stop. The data workgroup. Can I ask if there are any of the staff that are part of the workgroup that are here if you could say hello and introduce yourself?

Krycia Cowling: Hi. This is Krycia Cowling. I thought I would go first since I am on the list first. I am in the ASPE – Evaluation and Data Policy. I am looking forward to working on this with everyone.

Vickie Mays: Thank you. Meagan, are you here?

Rebecca Hines: She is not.

Vickie Mays: Nate? I think some of us on Privacy –

Rebecca Hines: Nate is on.

Nate Kim: This is Nate. I am also on the same team as Krycia. I am looking forward to working with you all.

Vickie Mays: Great. Is Krycia here?

Rebecca Hines: She is not.

Susan Queen: This is Susan Queen. I am here. I am also in ASPE —-

Vickie Mays: Thank you, Susan. We have known you for a while in terms of your work so thank you.

Is Scott here?

Scott Stare: Hi. This is Scott Stare. I work at the CMS Office of Minority Health and I am also working with Meagan Khau there. I am looking forward to working with the group.

Vickie Mays: Great. Thank you. And of course, Rebecca. Thank you, Rebecca.

We gave you what we thought were some of the NCVHS issues that maybe of concern. Are there any other areas that we should be looking at particularly as we do SOGI that are in standards or privacy that you want to put on our radar. These are the ones that we thought we would start with. Are there any others?

Let me start with the chairs of Standards, the co-chairs, Denise and Rich. You know your agendas. Maybe I could ask the two of you if there are particular issues that you would think we should be taking up.

Denise Love: Do you mean in addition to what is on the slide?

Vickie Mays: Yes. If there are any particular things that you have run across that you think we should be paying attention to, we would love to hear it.

Rich Landen: Nothing like putting us on the spot.

Vickie Mays: You are part of the group.

Denise Love: I will say that the subcommittee has mentioned SOGI and SDOH as did our listening session and the industry input seeking guidance on some of these issues about what is to be collected, what is to be collected by data source. I think a lot of what you presented earlier falls in line with what people want to know. But I do not think the subcommittee has any hard findings to share at this point, but I may be missing something.

Rich Landen: Thinking about it from Standards, Margaret Skurka already mentioned we have some of the codes in ICD-10. If coding issues come up that need to be in the HIPAA code sets, that is something we could probably help with.

I have another thing that I do not see explicitly here, but it may be inside the data system context. Where is the data once collected? Where is that going to reside and from where will it be accessible? Should we think about talking with ONC and including that within an EHR as the primary repository? If so, that would be another standard if we are thinking more of a diffuse or disseminated data system that probably would not be applicable.

Denise Love: Rich, under expansion of HIPAA, are there any implications there as we start thinking of broader transactions and requirements under HIPAA?

Rebecca Hines: Just to remind us that this morning, Elizabeth Pathak brought up the fact that there are certain places where the data are collected and people ask for it over and over again, depending on what the setting is. That gets to your question about the EHR, Rich. Is that what we are shooting for?

Rich Landen: I was not going in that direction that she was talking about this morning. That is more akin to the no more clipboard concept with EHRs and despite EHRs now having the capability, practice on the ground in many places, still requires filling out the same expletive deleted information on an individual piece of paper. The office clerk can scan it into the record each and every time.

With that being said, what would be the role of the EHRs that something ONC should consider for future EHR certification programs?

Rebecca Hines: Jamie's hand is up.

Jamie Ferguson: I think to Rich's question, I think that if we do not already – I thought we did – should have ONC representation on the working group. I thought we did have someone there.

In terms of the SOGI versus SDOH data, as you can see by looking at the different SOGI data elements, most of those come from clinical observations or clinical encounter questions. The EHR is a logical primary source for many if not most of the SOGI data. And that probably is not so true for the SDOH data that typically comes from other community sources. While there may be a place for it in the EHR, I am not sure that that is really the primary source just to your question.

Rich Landen: Jamie, you are absolutely right. I am raising a question. I am not suggesting that it is the solution.

Vickie Mays: Let me ask a question that has to do – Denise kind of broached this a little bit, which has to do with HIPAA. One of the things that you are going to see is that some of the recommendations by other groups and committees are that we amend HIPAA to allow better sharing of data across, not just the health system, but across social services, human services, and the justice system.

The question is are we going too far if we start to consider whether or not this data should be shared differently, whether we should begin to think about amendments to HIPAA.

Rich Landen: Let me take first stab at that, Vickie. The Standards Committee and what I outlined to the Full Committee yesterday is clearly thinking that amending HIPAA to reflect the current state of health information technology and communications capability and privacy and security – we are thinking that some sort of update to the HIPAA framework for the transactions and code sets at least is probable. If we are going to do that, there may be synergies and some compelling reasons to include a more comprehensive approach, including whatever might come out of this workgroup. Again, that is a probability. That is not a guarantee. And certainly we would have to look at it when we are farther down the road and say what is the probability of success for each of these components if they are joined at the hip or if we proceed separately.

Denise Love: Rich, is there a covered entity expansion? Some of these data will be shared with non-covered entities or collected by those so bringing a bigger population or entities into HIPAA requirements might also give us another tool for collecting data elements going forward.

Rich Landen: Certainly that conversation is in both of the subcommittees, PCS and Standards.

Vickie Mays: I think it is something that we should discuss in the workgroup. I think that the issue, which I am about to turn to privacy, I think that the issue of the protection of this data because we are talking about such a vulnerability population is really a big deal.

Can I hear from Privacy? I want to ask a coding question. Is Margaret Skurka – can you tell me about the status of coding relative to SOGI?

Margaret Skurka: I do not think it is being captured. The coding done at the hospital level upon discharge. Those codes do not matter for reimbursement. It is data. It is probably not being collected at the hospital level. An office practice or a physician practice or a clinic – it would be up to them also. The good news is there are codes for everything. The bad news is people that code – the institutions want the codes that impact reimbursement and that they are more interested in that than data.

Vickie Mays: I am hoping you will help us think about that. Denise and Jamie have their hands up.

Denise Love: I think we are in the spirit of brainstorming so if I bring up an idea you do not like, you will be the first to shoot it down. But we heard yesterday from Kate Sapra, CMS, and CMMI and how they are working on the ground with value-based purchasing. They also have some leverage in that they have some funding leverage especially for rurals and small clinics to collect these SDOH and expand the data elements. I just do not want to lose sight that we have CMS out there and other value-based purchasing initiatives that are acting like the small P in population health where they are collecting much more data than they used to.

Jamie Ferguson: -- on coding. The SOGI data are not coded for payment because they generally do not relate to payment. But they are coded in the EHR for clinical and population health purposes and that is where we use the LOINC for the questions and SNOMED for the answers to code those in the EHR. That is where the – as I mentioned before, we want to probably look at the range of values or domain of coding that is used for those purposes and make sure it really captures the full set of information requirements.

Vickie Mays: That sounds great. Can I ask the – is Melissa here? I know she had to teach. Is Melissa Goldstein here?

Rebecca Hines: She is going to be back shortly, but she is out at a class right now. Yes.

Vickie Mays: Okay. I am going to ask our chair because I know our chair knows a lot about privacy. Jacki, are there any particular issues about the SOGI data from the perspective especially because you are in California where we have been pushed here to collect this and have tried to be innovative in California in doing this. Are there any particular privacy, confidentiality, or security issues that we need to be thinking about?

Jacki Monson: I do not see any new ones that you have already noted. Obviously, this data is really sensitive and perhaps we can leverage some of the California practices because I think they are good from a privacy standpoint both from a security – with a security standpoint and how we make sure the data is secure and protect the privacy given the sensitivity of this type of information. I think you are thinking along the right lines. I also know that Melissa is sitting on the workgroup, and I think that is a great – she is a great addition to help you continue to issue spot because I am sure as you go down this road, there is going to be more.

Vickie Mays: Great. Gregg, can you go to the next slide? Are there systems we are not thinking about? Are we happy with these?

Denise Love: I assume, Vickie, embedded in there would be community health centers and other frontline clinics and providers. Is that embedded in there?

Vickie Mays: We kind of thought those were the given. We were trying to do the call outs to make sure that we are not missing any. Maya and then Jamie.

Maya Bernstein: Certainly members first and I will chime if there is something left after that.

Jamie Ferguson: I was just going to add long-term post-acute care facilities. We may want to consider FQHCs. I do not know if there is a separate category, but other kinds of clinics.

Vickie Mays: Denise.

Denise Chrysler: I was thinking all these clinics including public health clinics. I am wondering if primary care covers FQHCs, community health centers, public health clinics, all the various – doctors' offices for primary care and if that would be a category to use.

Vickie Mays: I think that is good. There were assumptions in here. I can tell Rebecca is taking notes.

Rebecca Hines: Sharon just sent a note in the chat. The all-inclusive ambulatory care settings, rural health clinics, FQHCs, public health clinics. It is a catch-all.

Vickie Mays: I think that is good.

Maya, there are no hands up of members.

Maya Bernstein: I was reminded recently at a meeting of the centers that are funded by ACL, our administration for community living, which I do not remember the exact name of. Somebody will tell me. I am looking here for – I cannot put my hand on it right away. Just other types of health organizations that we fund.

I admit that in the run up to the meeting, I did not pay as close attention to the final charges I should have. I will say that when I think about administrative data, I am not thinking about a clinical setting often where there is a division between clinical and administrative. That means the financial side and other sorts of stuff in a hospital.

When I think about administrative data, I am thinking about program data that the department uses to make decisions about people. All of the work of the administration for children and families sort of people who are getting the benefits of social services of various kinds need to give us a lot of information in order to get those benefits and they deserve privacy. I am not sure whether the reach of the workers charged reaches those programs.

You mention, Vickie, earlier about whether we should consider, for example, having to extend to the sharing of information with programs like that. Just thinking about those kinds of things.

When I think about program data, to me that means as opposed to survey research data or data that we use to make decisions as opposed to data that we use to make policy. And other people may have that difference as well. The term administration data is used in both those contexts at HHS so just to be a little bit aware of that.

Vickie Mays: I think that is good. We will clean that up because that is kind of our next bucket that we will go to.

Rich Landen: It has not been mentioned yet. I might suggest home health agencies.

Vickie Mays: Okay. I had not thought of that. That is a good one.

We do not have a lot of time left, as I understand. If we could go to the slide where I ask you about people that have expertise, any experts that you want to make sure that on the SOGI clinical side that we are reaching out to. Next slide. Go back and then people can see what organizations we have gotten. Are there any particular individuals that you think are important for us to reach out to that we are not thinking about?

Rebecca Hines: And conversely, we have too many here to be – there are so many here. What are your top six? What are the most important ones as well in addition to the ones maybe not listed here that should be?

Vickie Mays: Rebecca, I think we can also consider just sending people an email and asking them to send us their latest reports and guidance that they have. I was not thinking we were going to have them all, but we may reach out to them all and just make sure we have the latest.

PARTICIPANT: What about the last speaker. She was more of a concentration about the – population, Asian, and so forth? I think she has an interesting spin on things that we could lose, so to make sure we include that.

Vickie Mays: She runs the California Health Interview Survey. Much of what we know about how to do this comes from that survey. I agree. I can ask Dr. Ponce.

Anybody else?

Denise Love: Bob Phillips' group, AAFP, American Academy of Family Practice/Physicians. I think they had a report out it seems in my mind.

Vickie Mays: I think you are right. We will add them.

Anything else before we have to bring this to a close? I am taking that those hands of Rich and Maya are hanging chads.

Rebecca Hines: Vickie, we have 15 more minutes.

Vickie Mays: I thought I was supposed to be finished at 11:15. I was really ending --

Rich Landen: This time I am not a hanging chad. I see you have State Department of Health, but what about a large urban area? I am thinking specifically New York City Health Department.

Vickie Mays: Okay. I did not think about --

Denise Love: You could probably get that through NACCHO. NACCHO covers some of those too.

Vickie Mays: We are capturing the essence of large and urban – in terms of health, we will figure out the best person.

Valerie Watzlaf: I see AHIMA and I see HIMSS but I think maybe to add AMIA because I think they have done some work and research in the area too.

Vickie Mays: That looks good. Let me ask you if there are any major organizations or groups that you think also should be here. We tried to capture them. We just got another one from Valerie. I will also ask you if you know of within HHS, particular work that we want to make sure that we reach out to.

Before we end, I think unfortunately I rushed this, Rebecca, because I thought I had only the one hour. Before we land, let me ask you about a couple of other things. This is particularly, I think, Margaret, having you speak up on this will be good. Where are the places that we should be looking at in terms of the establishment of the codes and the language? I think that Jamie and I had talked, for example, about Robert McClure's work, the Gender Harmony Project. We definitely will do that. But we may need to understand this a little bit from – oh, okay, the chat is moving quickly with this. NQF, the Joint Commission. Margaret, do you have any others? Add SDO, SNOMED, LOINC. I think we are getting it here in the chat, which is great.

Rebecca Hines: Vickie, do you want to read them out loud so they are on the transcript and I am going to copy them into the notes?

Vickie Mays: Somebody asked – Maya, this is you where you were talking about community-based organizations and the aging and disability network. I think when Jamie said about the long-term care facilities and places like that, we might be able to get into that. But thank you for that.

Maya Bernstein: Did I hear my name? I ran into the other room for a minute.

Vickie Mays: I just said that I read your comment. Rebecca wanted them into the record.

Maya Bernstein: I had a reason for ACL and they reminded me that we should keep in mind these smaller organizations. Here is an opportunity to do that.

Vickie Mays: Yes. The other is Jamie was talking about SDO, HL7, SNOMED, LOINC, and add the individuals Rob McClure, Marjorie Rollins, Jim Case for SNOMED. Who else? And Jeff Swanson from Kaiser Permanente. Also, we want to check to see what NCQA is doing for their measurement in this area. I agree, Denise, with that. I think that is a good one. The Joint Commission, the Federal Committee on Statistical Methodology I think in the surveys is absolutely correct. I think part of what we are thinking about is how you ask in a survey versus how you ask in the clinical encounter may be a little different. But they do have some good work. Valerie, great. WHO for ICD-11. Thank you. This maybe what you are trying to get at, Maya. Tammy got it for you. The National Association for Home Care and Hospice. That is probably one of the groups to make sure that we get to your individuals.

Anything else? This has been very good. We are open to continually to hear from you. Do not be surprised if we continually reach out to you. It is okay that you did not volunteer to be on the workgroup, but you are on the Full Committee so sometimes we will ask you because of your expertise. There may be a question that we will reach out to you to ask about.

What is NCPDP? I do not know what that is.

Wu Xu: National Council for Prescription Drug Programs.

Rebecca Hines: We do a lot with them, Vickie, on the Standards. We have worked quite a bit and often they are at these meetings. I do not see a person from NCPDP on right now, but she often is on so Margaret Weiker. NCPDP is a regular for us to be in touch with.

PARTICIPANT: Then Rebecca, on that same vein, wouldn't you have the other standard setting organizations?

Rebecca Hines: Jamie put them in the chat and I am capturing them. Got it. The usual suspects, as we call them.

Vickie Mays: Rebecca and Sharon, are there any other things that you want to share about next steps of things that I know that you all are going to do? And then I will share our next steps.

Rebecca Hines: I can tell you from our end that we are going to convene the HHS staff to identify HHS activities that would be helpful for you to be aware of. We are going to try to do that in the next ten days or so.

Vickie Mays: What the workgroup is going to do is establish a time that we will meet every couple of weeks. I think one of the first things we are going to do, given you see this big list of things that we have, is that we are going to try and find out in the landscape who has very recent reports that we can rely on.

We know that California and I think Massachusetts have been the states that have been pushing the use of SOGI at a state level. We will also try and get some guidance from them both in terms of like standards issues and privacy issues. Those are our next steps.

Any questions, comments from the group? Okay. Hearing none, Rebecca, I am good. I can turn it back over to Jacki.

Rebecca Hines: Okay. If you have ideas this afternoon, you can put them in the chat or send them to me by email and I will capture them. Thank you, Maya. You just added another pharmacy organization. Jacki, I think we might get a longer break. We have our panel on cybersecurity and the stress on health care at 2:40.

Jacki Monson: Okay. Let us take a little longer break until 2:40. I will see all of you then.

(Break)

Impact of Cyberattacks and Pandemic Stress on Healthcare

Rebecca Hines: Thank you, Stephanie. Members, please turn on your cameras so we know you are back. Denise and Jamie – Denise Chrysler, Wu, Jacki, Vickie, Melissa, Margaret. It is 2:40 and I think everyone is popping back on to Zoom. Jacki.

Jacki Monson: Thanks. Let us go ahead and get started. I want to introduce our speakers. We have two really great speakers today. First is Dr. Reuven Pasternak. He is a physician by trait, both in critical care and anesthesiologist. He spent his training at Johns Hopkins as well as practice medicine. Then went into executive roles and most recently has served for the Department of Homeland Security as well as CISA as an advisor. We are really looking forward to his perspective today.

And then with him is Josh Corman, who is the founder of I am the Cavalry. He is a former senior advisor at CISA. He is also a fellow member of the Health Care Cybersecurity Task Force. Just thrilled to have him and his expertise as well as Reuven.

How this is going to work today is we are going to give them 30 minutes to divide and conquer some slides on the topics that were in your materials and then we will open it up for 30 minutes of committee discussion Q&A. From here, Reuven, I will let you take it over.

Reuven Pasternak: Okay. Thank you. Thank you for having us on. It is a special pleasure also to be sharing a podium with Josh.

Rebecca Hines: Reuven, your screen is not sharing yet.

Reuven Pasternak: Josh and I came on at roughly the same time as part of the COVID taskforce and Josh will be covering that in more detail. He and I have been partners up through this past week. It has truly been one of the pleasures of my career to have a chance to work with him.

What we are going to do over the course of the next half hour or so is I am going to give an introduction in terms of the Cybersecurity Infrastructure Security Agency just to let you know who we are and to lead up into the stresses that health care was facing even prior to the pandemic. At that point, Josh will take over and go into some of the creative work that he led with the taskforce, which has given us new understanding and the importance of cybersecurity.

As many of you probably know, CISA is the youngest federal agency, the fastest-growing federal agency and one that is committed to assessing risk for the entire federal platform and to defend today and secure tomorrow.

As it says here, we are the nation's risk advisor, not just for cybersecurity, but for the full range of infrastructure for health care and the other critical functions of this country.

Within that is the National Risk Management Center, which is where I sit and our role is to analyze strategic risks, lead public/private partnerships, and to collaborate and this is very important, collaborate with the private sector and other stakeholders to better understand future threats and to develop strategies to mitigate those threats.

There are two branches within the NRMC, the Planning and Coordination Division and the Analysis Division, which looks at the analytic functions and is the risk assessment division within the NRMC. That very rapidly takes you from the broad level of homeland security down through CISA down through NRMC.

When we look at the critical infrastructure of this country, there are 16 critical infrastructures that are identified as crucial for the operation of this country. They are not equally large and I would say for many of us, they are not of equal immediate importance health care and public health is one of those 16. Although as you look at these, they all share common issues with regard to exposure to risk and there is a critical amount of interdependence between the two. Obviously, health care cannot work if we do not have water and electricity and other functions happening. Those other functions cannot work if the health care infrastructure breaks down and they lose the health care of their workers and other support personnel as well. These are all interdependent phenomena that CISA has been charged with developing risk assessments for, working in coordination with the SRNAs, the agencies that are principally responsible in those areas, which in our case is health and human services.

To support the 16 functions, there are 55 national critical functions, which are subdivisions of those 16 sectors. Each of these in turn are responsible for discrete activities that are critical for the national function and there are three that are health care related under manage and they are in the area of medical care, which is the traditional aspect of health care, as we think of it. Hospitals, clinics, home health services, management of direct contact for individuals, and there is the population-based care, the public health aspect of the care, which is a broader enterprise, which includes those areas that

touch non-traditional health care, but certainly have the direct impact on the health of our populations and medical records and maintaining access to medical records. Quite a long list of items here in the area of connect, distribute, manage, and supply.

When we look at the framework for the National Critical Function, it is divided into further sub-functions, systems, assets and components. This is a work in progress that we have going now, which is very much an in-depth analysis of the separate national critical functions, how they relate to each other, and the risk that are posed when one breaks down at whatever level to other entities within its own function as well as other functions in the nation or in the region.

When we assess national critical functions in action during COVID-19, one of the major contributions of the task force that Josh led was to identify multiple national critical functions at concurrent times and to look at the impact it had. When we view these, these functions were actually named. You had workforce. You had transportation, the various different phenomenon, supply chains, for example, and the extent to which risk drivers, events that were encountered at the time were driving problems in these national critical functions. These were assessments that were being done as close to real time as possible so to the theme of what we are talking about today, dependent on real-time data as much as it could be achieved and also here, we see the first introduction of the driver scale where it is a low chance of national scale disruption, green through yellow and red, progressive levels of threat to the operation of a national critical function and hence through the performance of the overall health and economic well-being of the nation.

We have a unique challenge of looking at the heath sector. And looking at where we are located now, it is conservatively 18 percent of the gross domestic product. Right away if we are talking about impact on health sector, we are talking about a massive undertaking, trying to gather data and make sense of an analysis of trends within this area.

When something happens in health care, its impact also is usually immediate so that what happens as a disruption in a single day will have its effect in that day. It will be pervasive, and it will be profound. By pervasive, I mean covering an entire region or beyond, depending on how wide the disruption is. And profound in that when you disrupt health care, it has an immediate effect on people in the region. Health is immediately affected. Security is immediately affected. There is little time to try and sit back and assess and gather data in a complicated fashion. You need to know where you are and how extensive the risk that you are facing is at that moment.

In addition to this as I know many people here are familiar, it is a highly fragmented enterprise. There is not an American health care system. There is an America with hundreds of heath care systems. And these health care systems are located by states, regions, by regions, which are multi-state, in some cases, multi-national, covering multiple jurisdictions that often gather the information on the same item in very different fashions.

There is also a high degree of restructure and a high degree of complexity. It is very much a moving target and at the same time that we are trying to get our arms around what is happening in health care today and data sources. New types of delivery and delivery systems are opening up that do things in

their own fashion, generate their own data sets, and add further to the integration challenges on a digital platform and data platform of assessing where we stand.

The last I'll put is there is data reporting overload and that is are we moving to a situation now where there is so much data that is being requested by so many different sources that we are losing the perspective of establishing a data set that is as immediate as possible, comprehensive as possible, and provides an action-oriented and policy-oriented ability to make the best decisions sometimes within a very limited framework. That is something that we have been very conscious of as well and something that we hear a great deal of from colleagues.

I am giving you now the closest to a white board drawing because that is essentially what this was yesterday. We are leading up to the issue of resiliency in health care. Resiliency in health care is a term that we have all heard extensively. We have probably heard very different definitions of it. In this example, if you look at the blue wavy line, the blue wavy line, for example, would be census, number of patients in a hospital, number of patients in a hospital ICU. It varies over time. There could be considerable seasonable variations.

What philosophy do you use in terms of addressing the ability to cope with it? Well, you could staff it so that you never have any doubt about the ability of having the resources you need no matter how much you see in terms of research and perhaps staffing at 105 percent. Or you could staff at 95 percent and say that the circumstances when you exceed your limits are rare and you kind of reach into having everybody do a little bit more pay overtime, bring a few additional people in and somehow tough it through.

And then you can have the phenomenon, as we see here, whereas we have in the case of the pandemic a rapid decrement in the resources and rapid increase and sustained increase in the demand on what we are doing. Up until the pandemic, it was very common to have our resources somewhat strained. We started off with assumptions of 80 percent occupancy of facilities. It was running close to 90. We have thought that we might get 100 percent. It was closer to 90 percent in many areas of possible staffing. We already had in a steady state situation an issue of stress on where we were. If you look at that yellow line at the 95 percent staffing, what we were seeing even before the pandemic was a decrement in staffing especially in bedside clinical personnel, especially among nurses so that the resources available were going down.

What we also saw in the course of the pandemic was that the variability of admissions and the variability of debt ceiling was going up to and beyond the 100 percent level and was sustained so that what you had is what we term a resiliency gap, a persistent gap in the availability of resources to be able to care for a group of patients who had immediate need for care and the resulting frustrations and concerns that go with that.

You can also include in here the problems with supply chain and supplies that were in short supply, medications in short supply, and even inappropriate and inadequate number of beds in the regions to deal with these patients. This was the reality of what we had first in rotating regions for the pandemic, then increasingly nationwide as well.

In a model that was developed for the task force, and you will see Josh presenting this in a different context as well and I want to give credit to Josh and Jeffrey French, and the analytics team of the task force who developed this graphic.

What we have is a situation where we go left to right, describing what we see in a region as facilities start to get stressed. And as a resiliency of one institution starts to fade especially if it is a major institution, other institutions close to it and surrounding it start to have impact as well.

In the model on the left, each institution has some ability to absorb resources, absorb patients, and take care of issues. As you press on, there is increasing stress as you can see by the color-coded system up to a point where you may have across a region an entire cascade that results in the inability to care to meet the needs of a region and no place within that immediate area to go to provide the additional increment of care. We are talking about urgent care, not even elective care. In a regional degradation, which is something that might have been thought to be hypothetical, but actually has occurred during the course of the pandemic where the resources of health care are so overwhelmed because of supply chain issues, staffing issues, facility issues that the only way to provide care for patients is to either go into a crisis standard of care and lower the resources that you normally make available and/or send them to distant locations where perhaps that might be available, but increasingly was less so as the situation became more problematic throughout the United States.

As we go now into what we have faced coming onto the cybersecurity issues about which we will be hearing, is a series of surges and each surge placed us in an increasingly stressed situation. As we had an increase in demand and commodity shortages and workforce shortages, each time we came out from a surge, we came out less strong than we went in. It was not returning to a steady state situation. We had fewer staff. We had fewer stresses on our supply chains, more stresses on what we had and an increase in the baseline load of patients.

As you do this successively, as you see in the diagram that is on the right of this slide, you go from usual patient care to stress contingency of care to crisis standards of care where your ability to maintain what is viewed as a basic standard of care in terms of staffing ratios, in terms of appropriate placement of patients and in terms of provision of a full spectrum of care becomes very compromised so you get to situations such as being unable to provide elective care and some of the elective care being not quite elective care and being able to sustain a standard of care that is necessary for the community.

We have had across this country crisis standards of care declared for regions and in some circumstances statewide because of the inability to across an entire state and sometimes beyond bring forth those resources that are needed to provide for the care for patients who are of immediate need of that care.

As we start getting into need for data and what we measure, one of the things that we had identified that we were missing was the ability to identify entities for regions and put them into a categorization that at least gave some initial indication of where they stood in terms of their ability to meet needs for their populations. This is a disruptive event level system that actually Josh and I had developed based on our separate experiences. Mine in the medical field and Josh in the cybersecurity arena. Interestingly apart for decades and we came together in an afternoon and realized we were totally on the same wavelength in terms of doing this where we had Levels 1 through 5.

I will not go into all of the dots on here obviously. But they represent a progression from a situation in Level 1 where you have normal operations. You have a situation of resiliency. You can absorb more volume or be able to sustain a slight decrease in your staff or other resources and still meet the needs of the community.

It goes down to Level 2, meeting standards of service, but limited ability to absorb more. And then 3 and 4, progressive decrease in resiliency, progressive decrease in the ability to absorb patients until you get to the point especially in 4 where now you have to close some services. You cannot operate at your basic level of operation. You need to divert patients to other locations. You need to divert people who are going to have elective surgery. It may be elective surgery for cancer, cardiac, neurologic, other serious conditions. Community services cannot be sustained. Those resources have to be used. And then Level 5 where a facility is so overwhelmed that it cannot function at all and all of those individuals have to be transferred to other locations. This covers the full range of disruptive events such as resource issues, cyber issues and the color coding on the right, sudden increasing in acute demand, environmental event or infrastructure.

What we have had in the course of the pandemic is not only the issue of infection, not only the issue of increased demand from infectious disease, but in cities like Houston, overwhelmed with COVID patients, sustaining a hurricane, sustaining a power outage and sustaining a cyberattack. This has been a time where we have had a convergence of disrupted events in our health care arena such that we now have and back to this conceptual model, not only hospitals that are coming out because of these events in regions, but coming out because of a convergence of a host of issues that threaten the ability to make and sustain health care, again, not as theory, but as actual fact. Josh will go into more of that information for you.

We have as a consequence of this from the pandemic a rapidly evolving situation where we have had sources of disruption to health care, having a direct effect on the health care system, and at the same time, seeking to establish a methodology to be able to put these into an assignable matrix with discrete levels of interference and also metrics that can be rapidly measured to provide directional input into where these systems are going. I know Josh is going to get into some of this as well. But I want to give this as an introduction to the level of a quick cascade of challenges that we have faced in health care over the last year and a half and then I will ask now that we turn it over to Josh, who can take this further along, give you some of the more dramatic impact on health care. Here is my email address available if anybody wants to contact me afterwards for more information or to discuss. With that, Josh, if you would like to come on the shared screen and I guess we will take questions after that.

Josh Corman: My name is Josh Corman and up until a week and a day ago, I was the chief strategic for the CISA COVID Task Force. I have had the privilege to work with Jacki on the 405(c) congressional task force on health care industry cybersecurity, please let me know. The bad news is my public service has ended for 18 months. The good news is I can speak more freely and with more candor that Jacki is accustomed to.

One of the reasons I was chosen to run the CISA COVID Task Force or design and implement it with a massive multi-disciplinary group of people is that as an altruist, I founded a group called IamtheCavalry.org, a volunteer group of hackers, trying to save lives through security research. Our

tagline is wherever bits and bytes meet flesh and blood. We are deeply concerned about the increasing dependence on digital infrastructure and areas that can affect public safety, human life, and national security. It is through deep collaboration with the US Food and Drug Administration, Department of Transportation, US and foreign governments, to try to bring order from chaos and make sure the dependence we place on the digital infrastructure is dependable and trustworthy. And that has not been the case. In fact, things have gotten pretty bad.

We have done things with models like our Hippocratic Oath for Connected Medical Devices. Let us speak in the language of the people we are trying to influence. This became a blueprint and a roadmap. It merely says that this smart, digital infrastructure should handle failure. How do you avoid failure? Take help avoiding failure without suing the helpers. Capture, study, learn from failure. Contain and isolate or fail safely and respond against future failure. And some of these elements may show up in the letter that this group is working on as minimum viable capabilities to handle hyper connectivity in medicine.

Now, when we first started – this is a river in Ohio called the Cuyahoga River. It caught on fire and stayed on fire. The pollution got so bad and the public consciousness had a tip. I was warned that no one would listen to the cavalry until people died first. While we have had deaths and we knew that we could have deaths, a law professor, Andrew (name) said, Josh, no one is going to listen until the river catches on fire and stays on fire plural times. Apparently, this river caught on fire 22 times across a 70-year period before they built the Rock and Roll Hall of Fame here. But the EPA was founded eventually when people said enough is enough.

We have had fires. We have had a lot of fires and build on and come back to the pandemic. To quote Reuven, we had seams and cracks in health care before the pandemic. The pandemic made it worse. A few weeks before, Jacki and I had our first congressional meeting for the task force. Hollywood Presbyterian Hospital in Los Angeles got hit by accident by the SamSam ransomware and I was deeply concerned that we were going to have a loss of life. They had to divert ambulances to next nearest facility, which in L.A. traffic is not something you want to do when you are bleeding and you need time-sensitive care. But it was not intentional. But after this accidental hit of this piece of ransom, hospitals became the number one target.

Later on we thought well if we just fix medical devices that allowed this thing to be hit, maybe that is enough. But we saw hundred-dollar cameras, internet-based cameras created the Mirai botnet and took out the internet for a day on a Friday right before the US presidential election. This led Congress to say we had a tsunami of technical debt from insecure and indefensible technologies, which eventually led to other things. Our task force built upon this overdependence on indefensible things.

Without going through the whole task force to echo Reuven's point that we had seams and cracks, the headline graphic from our very long report from a consensus was that health care cybersecurity is in critical condition. I was deeply concerned that this was just not a HIPAA thing. I love my privacy. I would like to be alive to enjoy it. We had more incentive and motivation regulation, have a corpse with their privacy intact and to keep patient care available, resilient, and keep patients alive.

Some of the seams and cracks we elevated out of 100 or so with about 85 percent of the 5600 hospitals in the US do not have a single security person on staff. They are not fortunate enough to have someone senior and risk based like Jacki.

Number 2 is they are defending really old equipment that is not supported anymore or not patchable. It is over connected to each other in the outside world as a perverse accident of meaningful use requirements that incentivize premature connectivity.

These vulnerabilities are not just about your privacy. They affected patient care availability. The unavailability of patient care can be not just a single floor or a wing, but an entire facility or even your affiliate networks. And a typical device had over 1000 known exploitable vulnerabilities. And even if only a handful of exploitable, it only takes one to shut down patient care. That was what we were coming into and we had hospitals screaming. But we cannot afford this. Do not make a standard we cannot meet to which initially and flippantly we said if you cannot afford to protect it then you cannot afford to connect it.

The more Stan Lee Marvel universe-ish version – a little softer and kinder was that with great connectivity comes great responsibility. We had this digital divide where we do not want more accountability because we do not have money. But we also want all the benefits. And with that great power comes great responsibility. We really have to find ways to identify and buy down risk to close the gap between where we are and where we need to be.

As we were reeling from that WannaCry affected 40 percent of UK health care delivery as the largest attack to date. As we were trying to talk to the international policy community about the implications of that attack, Notpetya accidentally escaped its blast radius. And while most of the headlines were about the $1.4 billion of damage it did to Merck, it also had severe damage to hospitals and health care delivery in the US, most notably, Nuance software, voice-to-text dictation service was so entangled and intwined with patient care, suitability for surgeries, there were two children depicted in this book that could not get timely surgery because they could not extract the records from Nuance's cloud that was down from a ransom attack.

When we think about patient care and it is not just about patient privacy, we know from a seminal New England Journal of Medicine article that even 4.4-minute longer ambulance ride during a marathon can affect mortality rates 30 days later for heart attacks. 4.4 minutes was enough to measure the difference between life and death for heart attacks. What does that have to do with cybersecurity? Well, what it tells us is degraded in delayed care affects outcomes.

We did what any self-respecting hackers would do and we said if no one is going to listen until someone dies, let us kill people and we started killing people through the CyberMed Summit in ER hacking simulations. We took normal simulations that doctors do all the time for rare conditions. We took actually hacking, combine it with actual physiology, and at least in the initial one, we hacked an insulin pump to empty its full contents, causing the driver of a car to car crash, pass out.

Number two, the very first medical recall in history affected by our group and the FDA was a bedside infusion pump. We gave a three-hour dose of a calcium blocker in 30 seconds causing a heart attack.

And the third one, the most perilous one covered by ABC Nightline, was a subdural pacemaker defibrillator giving an electroshock every minute on the minute and eventually surgery was required to remove that. The doctors had no idea it was coming. We want to give them an experiential thing about this as possible. As we increasingly depend upon connected technology, we may have bits and bytes in flesh and blood.

We started running one to two to three-hour table talk crisis simulations in Arizona, now in San Diego. And we now branched out to OR hacking simulations and changing the blood type for the patient to see how that could be noticed or prevented or if it would complicate things.

And we even prove you do not need to touch a patient at all to lead to loss of life. The golden hour or hours for strokes, we have lifesaving treatments that can bust a clot if you have a clot to causing your stroke. But if it is a rupture, you will bleed out. The very lifesaving things depends upon availability of the imaging in a timely manner. And when patients could not get imaging done and the next proximal alternative care was too far away, we started to see adverse outcomes in simulations. All of this was prior to the pandemic.

And during the pandemic, we also saw telemedicine increasingly dependent upon and outages of the cloud back end rendered multimillion-dollar radiation delivery machines incapable of performing their functional service even though the device itself was probably fine.

As Reuven and I shifted into the pandemic and we saw those seams and cracks shattered by additional strains and constraints and supply chain and staff shortage and space, you might recall the silver milestone when the US hit in February, 500,000 dead Americans to COVID. What my team started looking at is excess deaths on top of the COVID deaths. And at the same time period, we have about 150,000 excess deaths. Excess deaths are determined by the CDC as the difference between expected deaths and actual deaths by cause, by state, by time of year and they are tracked mercilessly. And among those, I was unsurprised to see that delayed and delayed care for things like our favorite heart attack example from the New England Journal of Medicine if -- some of the top contributors were heart, brain, pulmonary, diabetes. These were not older folks with comorbidities. The number one age demographic was age 25 to 44 as the fast-growing age demographic. These are young, critical infrastructure age workers.

If 4.4 minutes can affect mortality for heart attack and 4 hours is the different between life and death for stroke, what do you think 4 weeks did to the State of Vermont for their protracted and pronounced disruption from cyberattack in November and December of last year, a year ago? We studied that. I will show a couple of graphics in a second.

But in parallel before the pandemic, we now also have our first frontpage Wall Street Journal story on the first alleged victim of the cyberattack, a baby in Alabama pre-pandemic. The hospital had degraded and delayed functionality of their equipment. They admitted anyhow without adjusting for diminished technology assist. And ultimately, they are likely to settle out of court just because there were too many admissions and interceptions between staff saying we should not have admitted this patient or the outcome might have been different.

But as you look at this patient care, we forget there are sometimes dozens of computers and connected technologies that help us support that care, but at the center of everything, it should be the patient care itself.

Now, some of that study that we did – we now have the first – in addition to the first acute probable confirmed victim of a loss of life due to cyberattack. We now have statistical proof of loss of life. My team looked at public CDC data. We eventually published this in the Morbidity and Mortality Weekly Report and we also cross referenced with other public data sources from HHS, including adult ICU bed count and utilization.

This is a proxy indicator. It is a trailing indicator. It is an imperfect indicator. But during the pandemic, it is an incredibly strong indicator with peer-reviewed P values.

And what we found was during pre-pandemic conditions, 75 percent bed utilization was optimal. But during the pandemic, it is quite fatal. And the further north you get of 75 percent, the faster the impact accrues with excessive deaths two, four, and six weeks later.

Moving quickly at this pace again, armed with this instrument, we could see that if the country got to 75 percent bed utilization of which many northern states beginning in flu season were well over 100 percent. If you got to 75 percent, you would see 12,000 excess deaths in 2 weeks for a total of about 30,000 across 6 weeks. If you hit 100 percent, you would see 80,000 excess deaths in 2 weeks with additional tranches 4 and 6.

We published this on October 1. I would encourage you to read it. This is where bits and bytes meet flesh and blood. Notice the title: Provide Medical Care, which is our nomenclature for that national critical function Is In Critical Condition, much like our task force report from 2017. And what we really wanted to do was enable the state departments of health, hospital administrators, and others could control the strain on ICU. Net ICU utilization is the key here.

And what was initially published last time this year was a model for a citywide fail over. It began to manifest as a statewide fail over for Idaho or for Texas or for others who had to send plural states away. Again, these top contributors were heart, brain, pulmonary, diabetes. What might have been a diabetes consult may lead to a deferred degraded visit and sub-knee amputation taking this critical infrastructure out of the workplace and occupying beds we do not have.

Again, the fastest growing demographic was age 25 to 44 back in February and March. We re-ran that data. Then we said can this instrument to measure hospital strain tell us anything about cybersecurity. Can cybersecurity make it worse? And we looked at states hit hardest by ransom for five months statistically significant observation period in the same state with the same population during the same pandemic from a five-month slice view, looking at hospital type and hospital size. Hospitals hit by ransomware achieved these fatal excess death ICU strains sooner and stayed there longer, allowing us to have the first statistical proof that bits and bytes can kill. We can strain hospital sufficient to lead to loss of life and adverse outcomes.

These protracted delays take a long time to recover from. It is not just the HIPAA violations. It is not just the cost of the incident response. It is not just the fines. It is not just the ransoms you might pay. It is not

just the $67 million of lost revenue on a public earning statement from one of the victims. But now, it is also degraded delayed patient care, outcomes, and even loss of life.

Now, when we put these together in a conceptual model, that initial cyber compromised in number one initially leads to a diversion of ambulances, the next proximal alternative care. This is an evergreen part of the model that even post-pandemic will tell us how bad it can be if a regional or rural hospital is offline and does not have nearby treatment for heart attacks and strokes.

Ultimately, that leads to increase surging in column 3 for ICU census. And then ultimately, the excess deaths in the time of the pandemic measured two, four, and six weeks later.

As we look at this, we do not want to go back to normal. It was stressed and strained before the pandemic. The pandemic further revealed the CISA pandemic. And part of my hope and solace here is we have lines in the executive order from a year ago. One of my favorite took one of our recommendations from Jacki and I from the need for a software bill of materials or an ingredients list of all the third-party software used and medical technologies. The White House has now pushed this to all federal procurements. And the lines here that could be our North Star of things like in the end, the trust we place in our digital infrastructure should be proportional to how trustworthy and transparent that infrastructure is and to the consequences we will incur if that trust is misplaced.

And what that means is we cannot merely say this is all we can do and all we can afford and use unsupported software that is not patchable or has hard-coded passwords or is directly expose the internet or we are doing the best we can. We really push through that.

And if you do not think the pressure from the White House is material, when it starts to be covered by comedians on HBO and it is a whole segment on how ransomware is affecting hospital care and how most hospitals are ill equipped to deal with it, we are going to lose the institutional trust of the public to know that we are going to be good custodians both of their data, emergency or otherwise, and their lives for timely, available patient care.

We really encourage, and we get to some first principles, and I really like the letters moving from maybe consider these things to these are things we really need to do right now. They cannot be optional. These are table stakes for delivering hyper-connected medicine because best practices from 15 years ago aren't anymore. Good enough security is not and it is being measured in mortal consequences at this point. It is going to take courage because if you believe we are doing the best we can, you will sadly be a self-fulfilling prophecy.

I like to remind us that Semele was trying to warn us for 100 years that we should probably scrub in and be more hygienic when leaving the morgue before delivering a baby or doing a surgery. It took way too long and ultimately dramatically improved mortality rates for post-op.

This stubborn jerk took something like childhood leukemia, which is a near-death sentence, and now it is one of the most survivable conditions in the pursuit and dogged belief that we were not doing our best and there could be more maybe done better invented platelet things and bone marrow samplings and the cocktails now used emblematically as modern cancer treatment at least when the ransoms do not

lock up the medical records for a month, preventing us from knowing those cocktail recipes. But people have to say good enough is not anymore and fight through it.

And as Reuven reminds me, the quality movement also dramatically improves things. This group is on the cusp. We are going to ask the right questions and balance the right equities to get the right information to share the right information so we can manage and buy down risk for timely available health care for such a lifeline bottom of Maslow's hierarchy of needs.

With that, the solution is not going to come from somebody else. My belief and philosophy are that the cavalry is not coming. What are you willing and able to do within the sound of your voice and what can we push for to be better? I said a lot. Thank you for your time. Remember this is not just about records. This is about the availability and timely delivery of patient care for you and those you care for.

Jacki Monson: Thank you, Josh and Reuven. I have lots of questions for you, but I want to open it up to the committee members to see what questions you all have for Josh and Reuven.

Reuven Pasternak: We are certainly happy to take any questions by email that folks do not have time to get to us here and to share.

Jacki Monson: Josh and Reuven, while we wait for the committee members to have questions, if you were in our shoes, what would be the top two things that you would push for, knowing that we currently have a draft security letter in our hands?

Josh Corman: I did not include it in my remarks, but I do recognize that divide for the have and the have nots. And unfortunately – like, take CISA, it has free taxpayer funded services to do cyber hygiene scanning of any one critical infrastructure. Out of the 5600 hospitals in the country for all of the health care and public health sector, we have less than 200 signed up for this free service. Something could be scanning you for free and telling you when you have a known vulnerability. And even if you cannot fix everything, you can at least fix the very smallest of known exploited vulnerabilities we also maintain. And that might be the difference between highly available health care delivery for the rest of the pandemic or being down for a month or more.

I think while there are different aspects of the HIPAA rules and the new discretion from the secretary on HIPAA fines and other things, we have started with an ongoing assumption that we are doing the best we can and we cannot do more. Current status quo is quite dangerous and increasingly so as adversaries are more brazenly attacking.

I would say we should identify with the minimum table stakes are for connectivity. And if people cannot meet that bar, we should assist them in meeting that. Admiring the gap is over. It cannot happen any longer.

And one of the things that CISA has done is we have a CISA.gov/badpractices, which is the most egregious and dangerous practices for intracontrol systems in hospitals. We have a get yourself off search, which is for free, how you might see what adversaries can see, or at least remove the low hanging fruit and shut the front door. This kind of pragmatism should not point at best practices that may be well out of reach for people that are below that poverty line but can get people up above

negligence on things like bad practices or want and exposures or using unsupported end-of-life software and serve as a national critical function.

It is going to be uncomfortable truths. But if we go back to normal, it was not very good to begin with and it is much more imperiled now.

Jacki Monson: Reuven, do you have thoughts on that question?

Reuven Pasternak: I want to add one more thing to something that Josh has already mentioned and when he said we liken this to the quality movement before. And one of the things – when we had that imperative because lives were at stake there as well, is we did not negotiate quality standards. We established what they were based on evidence based on what was needed and said this is what needs to be done to protect patients. And that was a starting point, what is needed to protect patients and do it right and then going from there, establish the models that could guaran tee that that type of care and service was delivered.

As we embark upon this, I know we will hear we cannot do that as Josh has said, but we have to. It will be upon us to develop the clinical and business models that will allow us to get that done and Josh has already explained what some of those are.

Jacki Monson: Thank you.

Rich.

Rich Landen: Thanks. I was intrigued by your remarks and passing about the Office of the National Coordinator and the unintended consequences of moving too far too fast with the connectivity. The question is has CISA had conversations with ONC to talk about mitigation and more importantly, being a little bit more circumspect for future.

Josh Corman: I would say the answer is no, not to my knowledge prior to the hiring of myself and Reuven in the Cares Act. People like to stick to their lanes and very few people have fully embraced the intersectional risk management capabilities of CISA. I think we are pretty far from that trust being sufficient to do that. If you would like to catalyze such a meeting, I would be happy to participate for any of the hats I have worn before. But there is still the sibling rivalry of sorts that suboptimize the outcome for the American people.

And to put 30 more seconds on that statement, meaningful use tying reimbursement to the ability to receive and transmit health records, took devices that were never designed or threat models to be connected to anything and incentivized the rapid connectivity to everything. It is not like it was done to cause harm. It was inadvertent byproduct of that hyper-incentivization.

Rich Landen: Clearly understood and there was intense political pressure to get the connectivity done. Thanks.

Josh Corman: I am teaching at 15.9-year-old to drive and there is an awesome responsibility that comes to driving a car, less so for riding a bike, more for a car. But if I wanted to drive a tractor trailer, I am not

even qualified. I want proportional diligence and proportional risk management for the levels of proportional connectivity and ability to harm.

Jacki Monson: Denise.

Denise Love: This was fascinating and eye opening. I knew the problem, but probably not the scope. I loved how you presented it.

What I am saying is consumers and patients are not aware. Like my mother used to say when we were doing quality measurement requirements, she said, why are you doing this as part of the state government. I thought hospitals did it. I just assumed everyone was measuring quality. The same with computer security. Will this leak into our certification and quality measurement systems to inform the public if the hospital is responding or not because next time if I go for a procedure, I want to ask this question of the hospital. Are they fully secure? I do not even know what to ask.

Josh Corman: There are several leaders in and our I am the Cavalry, CyberMed Summit, folks like Jacki, Reuven, who are trying to get this into the (indiscernible). The future is here already. It is just not evenly distributed. I think we have been very reluctant out of fear of legal exposure to admit that cyber insecurity can lead to loss of life.

It is time to rip that band aid off because this singular opportunity can be wasted. And what people should stop wondering is did I do something wrong or might get it caught and rather let us acknowledge that you are the victim of crimes, often international crimes, that have the ability to affect public safety and human life. And if we have to right size our level of cyber resilience and connectivity to be proportional to the risk landscape. When I started the Cavalry, it was in the wake of my mother dying from hard-to-treat cancer. I understand the promise and the peril of medical advances. It is both. We often adopt things for their immediate and obvious peril. I do not want to slow hyperconnectivity and valuable medical breakthroughs and telemedicine. We need those. What we want to do is make sure they are proportional. We have to understand the cost and the benefit, the risk and the rewards.

And even though there has been bold leadership from Suzanne Schwartz at FDA to do safety communications and recalls for cybersecurity issues, before we saw loss of life, doctors are still reluctant to believe it. We had a recall of 750,000 pacemakers with a three-digit hard-coded password in them. And most physicians said, it is too risky. Do not do it. But they do not yet know how to size or characterize the risk until we show them through cyber simulations like the CyberMed Summit. We have not internalized the true cost. And our best selves will be when we confidently innovate knowing which risks are worth it and which risks are not. There is much more material in another day. But I feel like I have abused your window of opportunity here. We will gladly answer more questions.

Denise Love: Thank you.

Debra Strickland: Thank you very much for your presentation. It was very informative and scary at the same time. It begs to me – we have of course our HIPAA standards that payers and EHRs and folks have to abide by and so forth. Government comes in and they will do an evaluation and say whether you are compliant or not and sometimes people are whistle blowers or whatever and we have ways to sort of enforce enforcement.

To me and, Jacki, this maybe puts a little fire under that letter is I think that every health care organization should have a report card that is online so that we can see what is the relative security of your data in these systems that are going to be plugged into your potential heart or whatever that we could see before we decide to go to this hospital versus that hospital for medical attention.

Reuven Pasternak: Deb, this is Reuven. Thank you for that. I would add one other thing that we need. One of the concerns that Josh and I had when we first started on this journey was that getting information about what is happening at the time it was happening was problematic. If you are hearing that ambulances are being diverted, we are not doing emergency surgery, and then somebody says we are not having disruption to the clinical enterprise, that tells you right away that there is a gap between what is being presented and what is existing. It is even getting into the heart of that matter there and requiring that that data be available in a way so that real-time assessment can be made.

Josh Corman: And policy reform will be data driven. When we started saying could we at least have a 1 to 5 scale of patient care availability, your ability to deliver patient care. Because what we want to know is year over year, how many times to be at Level 2 outage or worse and for how long. Am I affected? To which extent for how long?

At the federal level, we do not have the authorities or infrastructure to ask for that telemetry or to do that yet and it is kind of federated across state level and the Joint Commission and --

Debra Strickland: Shouldn't we though?

Josh Corman: If we are going to manage health with data, we are going to need to know what are the common areas of weakness and how do we do this. In fact, Jacki and I did not just point out problems. One of the best ideas we had in the task force report was a Cash for Clunkers program – of certain really old, really dangerous devices that could be modernized because we do not just want to point out problems. We want to make sure that there is federal assistance to assist with the most egregious exposures. But that is a shared responsibility.

Debra Strickland: Thank you.

Jacki Monson: We have about eight minutes left if there are other questions.

Josh Corman: I did not put it in the slides, but CISA.gov/badpractices currently has three. There will be a fourth one shortly. There are probably going to be less than 10 when we are done. But these are things that are dangerous. They are common and dangerous. And the first one after the Microsoft exchange attacks was that research found that the number one market share on the internet for exchange was the unsupported version. We put a stake in the ground and said the us of unsupported software in service of critical infrastructure and national critical functions is dangerous and materially elevates risk to public safety, economic, and national security. It is especially egregious when remotely advisable the internet.

We talked to a majority of hospitals who are still running on support exchange and have no plans to fix it. It does not matter what best practices we are doing. If you are running an indefensible and supported thing at the gateway into the hospital or an electronic medical system with a hard-coded password or

very large medical equipment from very large medical device makers, who will not let you change the password if you wanted to because it might void the maintenance contract. These common and dangerous practices are probably the first place to start.

Jacki Monson: Denise Love.

Denise Love: I do not want to be too cynical, but as you talk, I think about all the fax machines still in operation across the whole health care system and some of the resistance to moving away from fax. Maybe the fax is more secure at this point, and we should not be pushing people off fax. I do not know. I don't want to be too cynical. But that was a random thought as you were talking.

Josh Corman: The fax machines turn out to be an analog lifesaver for some of these protracted outages that were not anticipated. And even the Navy teaches sailors celestial navigation with fax machines now so that we are not overdependent on dependable things were their electronic warfare in a theater of war. There are belts and suspenders. There are analog fallbacks you do not want to have to need.

But I will tell you one more tiny anecdote. In the first CyberMed Summit we have done in everyone since, every time we do a tabletop crisis simulation, one of the first things the leadership of the hospital says is let us use the paper records. Let us fail over to paper. And every time someone says, sir, we cannot do that or ma'am, we cannot do that, they say why not. We print them out. I tell Congress we do that. And they said we stop training our students on that eight years ago. They have never seen one before.

We have a lot of assumptions about how prepared and resilient we are and a lot of them need modernization and the pandemic really revealed that to us.

Jacki Monson: Tammy.

Tammy Banks: Can you expand a little bit more? You gave a lot of reasons why the small, mid-sized let us say physician practice. I know we were talking about hospital systems, but really it is any patient setting that exchanges data, why they do not have at least one person dedicated to privacy and security, and now with funding. You know talked about some. Can we glean from your knowledge? Is it the message? Is it understanding the urgency? Is it the total inability to dedicate resources?

Reuven Pasternak: Tammy, I will take a stab at that since – and Josh will follow. That was my world before I came in here, adding physician groups, adding hospitals. I will tell you that one of the principal drivers we had of people seeking us out in various relationships was their inability to sustain a sufficient IT platform across the entire spectrum whether for security or the other aspects of communication.

I think part of it is some just do not recognize – we are still there. Some do not appreciate it. The other is some think that you can buy it on the cheap or that they are not going to be at risk because they are too small – very rapidly is a fundamental change in the business model of medicine because of this and other similar factors where small entities simply do not have access on their own to the level of sophistication that is needed to be able to meet this threat because you may have the small entity, but they are facing the same sophisticated threat that the thousand-bed institution is facing as well and they

are more vulnerable because they do not have those defenses. I think it is going to be a change in the business culture as well as the culture of operations.

Josh Corman: You have to first admit you have a problem. And I think no one thought this would ever affect them until it did. I think when they do see it, they see it as overwhelming or they think insurance will cover them and insurance lost a lot of money. They are not in the business of losing money. That is changing fast.

And then when they do go evaluate it, the supply chain they are getting is not very robust or trustworthy. This is a multi-faceted issue. But it starts with things like increased transparency, increased accountability, avoiding the known dangerous known bad practices and holding our suppliers to a higher standard. Some of the worst offenders are some of the biggest brands in medical technologies whether they are medical devices, electronic medical record system providers, biomed services platforms. We take an already weak enterprise, and we make it weaker by the standards we walk past are the ones we endorse. It starts with recognition that we have a problem and then we can make very smart and methodical improvements to make more trustworthy resilient health care delivery.

Jacki Monson: Last question. Denise Chrysler.

Denise Chrysler: With regard to Meaningful Use and the lessons learned from meaningful use and systems being connected that should never have been connected, I am just wondering about all the money that is now going out the door for public health data modernization and interoperability and how long public health has waited for those funds. Is there a similar risk in connectivity?

Josh Corman: Incentives incentivize sometimes reversely. There is always the law of unintended consequences. I do not think the intent of meaningful use was a bad one. It just was incomplete like had we tied it to that you must have a -- we call it a threat model or that you had to meet certain minimum standards as well. I know that the Joint Commission switched more to a point system of aggregate points.

I think the use of incentives is not the thing to – we do not want to throw the baby out with the bath water. We may need to use financial incentives. The question is do you measure twice, cut once, and have you factored in all of the equities and tradeoffs, many of which were balanced yesterday, different ones, the value of sharing data under emergencies versus the privacy-preserving aspects of it over time. These are hard discussions, but to maintain the public trust and do something that is 18 percent of our economy and a vital part of public safety of human life. Those hard equities need to be balanced properly and maybe with hackers at the table.

Reuven Pasternak: Internally as well. You face some hard decisions and it means that sometimes instead of getting that extra robot, you need to be getting something that truly has benefit for the entire organization and make that difficult choice as well. It is a priority.

Denise Love: Can I add one more thing? In public health, Denise, it is not so much the loss of money that I fear, but one bad high-profile breach from an interconnected breach, losing patient data. The way people feel about government and public data right now will just blow up a lot of trust and that is what keeps me up at night.

Josh Corman: Institutional trust is very hard to win back.

Jacki Monson: Josh and Reuven, thank you so much for this conversation and joining us this afternoon. We just really appreciate your perspective.

Now team, we are going to tackle the security letter.

Subcommittee on Privacy, Confidentiality and Security Action: Letter with Recommendations to Strengthen Cybersecurity in Health Care

Rebecca Hines: Maya, are you going to bring that up?

Maya Bernstein: I am.

Rebecca Hines: Everyone, you should have that and Maya is going to bring it up.

Maya Bernstein: Can you see that?

Rebecca Hines: It is the wrong letter, Maya. We need the security letter, and that is the public health emergency data collection letter.

Jacki Monson: While she posts that up, we made the changes that were suggested yesterday so made some very small enhancements. We have not received anymore edits. I kind of want to open it up for any discussion/thoughts based on what we just heard from Josh and Reuven as well as any other thoughts that you had overnight, which I am sure you were all dreaming about the security letter like I was with respect to any enhancements that might need to be made before we discuss potentially approving it.

Any thoughts or comments?

PARTICIPANT: Do you want to focus on what got edited since we discussed it yesterday just to make sure there is no more final comments on what got edited? We do not need to review what is already pretty much there is consensus on.

Maya Bernstein: This is a summary – a couple of things. As I said in my email, I have taken the letter and divided it into two pieces, a short letter to the secretary with a summary here of the recommendations, which I am not sure now are in the right order. They should be in the right order. And then I need the full exposition into an appendix, essentially an attachment, describing all of the recommendations in more detail. Here is the letter and then here is what it looks like in the appendix. I tried to make – I will go back and make sure. But if we look at this version, the detail, I will make it go back and match what we put in the cover letter. The summary part here should match what we did in the other end.

Essentially, I took the first part of the letter and the very last closing notes of the letter and took out some meat in the sandwich and put it as an appendix. Does that make sense – it is attached rather than –

Denise Love: I am having trouble with the wording on that and it is not the specific words. It is just the order of words. It just reads awkwardly to me.

Jacki Monson: Do you have suggestions on how to modify it? This is what we worked on last night. We worked on --

Rebecca Hines: I would move the object so eliminating the choice – or eliminate the choice to not implement a specific specification or alternative from the – just reorder it. It just seems --

Denise Love: It does not read well.

Rebecca Hines: It would be stronger to say eliminating the choice and –

Denise Love: Specification or alternative from the addressable implementation specification and requiring covered entities – thus requiring covered entities.

Rebecca Hines: Move from the addressable implementation specifications to after the choice not to implement. Let us try that. After alternative. So that it means – you can kind of get the meaning.

Denise Love: It just bites differently to me.

Maya Bernstein: Do you want to say avoid or --

Rebecca Hines: No, I think it is good. We are eliminating the choice to not implement a specification or alternative.

Maya Bernstein: It is a double negative, which is why it is difficult.

Rebecca Hines: Right, but it is clearer this way by moving the addressable specifications to the end of the phrase.

Jamie Ferguson: Does it really even need to say the addressable implementation specifications.

Rebecca Hines: I leave that up to the experts.

Jamie Ferguson: Remove the choice not to implement thus requiring covered entities to implement.

Denise Love: It just seems stronger to get right at it.

Rich Landen: I think this choice applies only to those that are categorized as addressable. We need to somehow to keep the addressable language in there.

Jacki Monson: We have addressable though in the paragraph below, which I would suggest we would leave. Do we need it in the recommendation if we specifically mention it in the paragraph below?

Denise Love: But if you wanted it, I would just put it after alternative from the addressable.

Rebecca Hines: Actually, the way she has it now kind of works.

Denise Love: Okay. There are people that know. But it just did not read well.

Rebecca Hines: I do not like the and requiring. That is weak. Eliminating the choice to not implement an addressable – thus requiring.

Rich Landen: Probably thus and then either/or.

Denise Love: Either/or after rule.

Rich Landen: To either implement the specification or to adopt. Your is already in there.

Denise Love: That works better for me.

Jacki Monson: We also added a citation. Yesterday, we had CHIME speak up and share a letter that they had previous submitted. We have also added a footnote, referencing their letter and the specific law that they were talking about.

Maya Bernstein: We did that, but that is further down. There are some other things happening before we got there. I tried to make this paragraph match. It turns out that they are not called standards. They are called, as you know, implementation specifications in the rule. I changed those references.

I added this language about – because we talked about the guidance that OCR provided about – Jacki and I found the 2013 guidance that specifically talked about what addressable means as opposed to required. We cited that. Is that what you meant, Jacki, or do you mean the CHIME letter? I thought you meant the CHIME letter, which comes later.

Jacki Monson: I meant the CHIME letter, but you can keep going on what we added.

Maya Bernstein: I added this reference to the OCR specific guidance from 2013 about what addressable means. I guess Rich pointed us to showing that there are these possibilities and that what we wanted to do was eliminate the third possibility. Does everybody remember that? Either you could address it head on or you could document some alternative or you could document that you are not going to do it all. What we are asking for is to eliminate that third possibility, which after the talk that we had in the last hour – maybe more supported now.

This describes – it allows them to not implement and therefore we are saying that maybe avoid is not the right word here. That they should not be given the option to do that to do nothing – have to do something for these basic cyber hygiene practices.

Any comments on that section? Rich, did you raise your hand?

Rich Landen: I raised my thumb. It looks good. Thank you.

Rebecca Hines: Maya, can we go to the cover page with the summary of the recommendations because we need to – I had suggested this in a previous draft, and it got lost. We need to set it up so that the "shoulds" go away. If you look at the opening salvo to the list on page 2, you can say – it says specifically, NCVHS recommends that HHS, one, strengthen the HIPAA Security Rule by. That way we – there is no

need for the "should" that are embedded in number 2 and number 4. It says specifically above number 1, specifically, NCVHS recommends – up where it says right before the list of number 1, 2, 3, 4. Specifically, NCVHS recommends that HHS – you just need to add HHS after that. Number 1, strengthen the HIPAA Security Rule. Two, in partnership with other appropriate government agencies mandate, not should consider, just mandate.

PARTICIPANT: Shouldn't we lead with mandate?

Rebecca Hines: Yes, I actually agree with that. But let us get the idea down first.

PARTICIPANT: All of them should do that so they are parallel.

Rebecca Hines: I agree.

Maya Bernstein: This is editorial. I can fix it after --

Rebecca Hines: We can fix that stuff, Margaret. We need to get the concept down. Further enhance communication. That is good. And then the fourth one has a should. I do not know if you want to consider evaluating. That is a little weak.

PARTICIPANT: Evaluation of level of compliance.

Rebecca Hines: It would be evaluate to be – evaluate in concert with other appropriate agencies so start off with evaluate. I just wanted to get that out there so that we are very clear on what the actual recommendations are. The rest is window dressing in terms of getting that. But let us just be really clear in the statement of the four recommendations.

PARTICIPANT: It is evaluate in concert with.

Rebecca Hines: If we can start at this high forest level, is everyone good with that framing of the four? If you scroll up, we have the four things. We have: strengthen, mandate, further enhance, and evaluate. Now we have four very clearly stipulated actions recommended for HHS. That is job one. From there, you can --

Denise Love: After the last presentation, enforce, but I do not want to change the letter, but I got really scared.

Rebecca Hines: Right so whether you want to have that conversation today is up to you all.

Debra Strickland: Wouldn't that fit in 4? Could we fit it in 4? Evaluate with other government agencies the level of compliance and enforce the HIPAA Security Rule.

Maya Bernstein: We are enforcing the HIPAA Security Rule now. The concept is can we help -- this is about financial assistance or other kinds of assistance.

Jacki Monson: If we put that anywhere, it would have to be up in the first regulation. But I think the way we have just changed the language is pretty --

Denise Love: Just inspired by Reuven and Josh.

PARTICIPANT: He did put in the chat for us to be bold. Are we being bold enough?

Denise Chrysler: I had my hand up when we were at the other part of the letter down a little bit. Could we down? It was before we went back up to this.

Rebecca Hines: Deb, can we stay with the articulation of these and then get down into the description? I think we need to get consensus on these and then we can get into your level of detail if you do not mind.

Tammy Banks: I just wanted to make sure the A, B, and C that you also change the tense because it is so easy to forget and it is going to be important so provide more, facilitate, leverage, and eliminate on the first one.

Rebecca Hines: 1A, eliminate, B, include. We are good. By eliminating. By including. That is okay on that number 1. I think we are okay, Tammy.

Tammy Banks: I was just going to make it more direct. Eliminate from the addressable implementation specifications the choice.

Maya Bernstein: I understand. But you need to look at what this says here. The – specifically, NCVHS recommends that HHS strengthen, mandate, enhance, and evaluate. These are subtopics. That is why they get a – is that okay, Debra?

Debra Strickland: That is right.

Jacki Monson: Rich, do you have comments on the four recommendations?

Rich Landen: I do. Like Denise Love, the presentation we just went from CISA. That struck me because I have lived in that environment a lot and it is an ever-looming threat.

My thought is if I threw out a suggestion to add a 3D and essentially simple language to encourage covered entities to undergo the CISA. I am not sure if Josh referred to that as a certification or audit or what. We get the exact language from him.

Josh Corman: Yes. CISA offers something called the Cyber Hygiene. It is a free service to anyone in critical infrastructure. And I figured that at least lets you know your exposure. I would think that is the gateway drug, the minimum.

If you wanted to actually have some burden to maintain it, I was also suggesting that specific attention is paid to remediation of what is called KEV or Known Exploited Vulnerabilities list. It is maintained by CISA as well.

Maya Bernstein: We have something like that, Jacki, in another section where we have the minimum requirements.

Josh Corman: I am just going to – right now so you can pluck it wherever you do or do not want it.

And the third thing I said is if it got squeezed together whether it is for here or for later is it may not be a bad idea not just to point to best practices, but to discourage or stigmatize "bad" practices, CISA.gov/badpractices, because that list will evolve based on data overtime.

Maya Bernstein: I think we actually have something like that. If we went to the exposition, we could see where --

Jacki Monson: I think we could footnote probably.

Maya Bernstein: We suggested adding minimum hygiene requirements like have an official, which you mentioned. Elimination of default passwords, which you also talked about in your talk and also user ideas, using multifactor authentication, having backup, installing patches timely, and transparency. Those were the ones we picked out. I do not know if they are among those.

Jacki Monson: Yes. I think the transparency of impact and vulnerability disclosures would be if they went through the scanning exercise and/or they had one of the bad practices noted by CISA, that is where I would add that and I would add them as footnotes.

Josh Corman: It is – like one of the bad practices is hard-coded fixed default password. You might just be more elegant to point at the bad practices list maybe with an example.

Maya Bernstein: Is that not the same as this up here, what we are talking about up here? Hard coded is different than default, I guess.

Josh Corman: I was basically suggesting a friendly amendment that you might have fewer total items if you link them to the growing list of bad practices or you could maybe bolster your current item by saying this similar language appears on CISA.gov/badpractices. I have not digested your letter to the degree you have. I am going to interfere less now.

Maya Bernstein: Before I leave this, could you put a link in the chat or somebody send me an email with that link so that we can get it into the letter as a sight? That would be great.

Where am I going next?

Denise Love: Just go up above 1 just before bad practices thing. I want to see what is above bad passwords. Minimum hygiene requirements. What I was thinking of is under minimum hygiene requirements, would it be better to say avoid bad practices, discuss below, or is it – because passwords are lumped in with bad practices. But a lot of these below are bad practices.

Jacki Monson: I would cite bad practices in here because it just reinforces what we are asking for. Then I will still leave it as cybersecurity hygiene because we are asking for essentially additional requirements that would basically support what we are saying below as far as the various bad practices. I have not looked at CISA's resource to see all of them. It looks like Josh said that one of them is hard-coded

passwords. I think if we cited somewhere within this section and specifically detail that to 3 and 4 to why we are specifically asking for this and then that will probably be sufficient from my perspective.

Denise Love: I do not want to drive Maya crazy. I admire how you guys can take all of our inputs and weave it into a letter. I will let you deal with it.

Jacki Monson: It takes hard work until 3 o'clock in the morning or whatever time she was up to, trying to help.

Maya Bernstein: I am capturing – thank you for the chat because I can copy and paste from there amazingly. I can give us a see also, that kind of thing.

Jacki Monson: We can put that specific one – we scroll down to the vulnerabilities piece. We can add it there. I would put it right there. We can expand this bullet out a little bit more.

Maya Bernstein: The one on critical patches?

Jacki Monson: Yes. We can expand it to say critical patches and known vulnerabilities because essentially what patches are doing is they are addressing the known vulnerabilities.

Maya Bernstein: I will add some of the language – I am going to go back and look at the set here.

Jamie Ferguson: I was just going to suggest putting the known vulnerabilities before reasonable timeframe in that phrase that you just put it. It is patches and addressable vulnerabilities in a reasonable timeframe.

Jacki Monson: That sounds good. That is a good addition.

Maya Bernstein: I do not know where you are talking about.

Jacki Monson: Down where you were with the list of the various cyber hygiene enhancements.

Maya Bernstein: The stem of the introduction of this.

Jacki Monson: Further down where we added vulnerabilities to patching. Jamie, do you want to say what you suggested again to make sure we capture it?

Jamie Ferguson: Yes. I was just saying – that is it. You have it. Installation of critical patches and addressing known vulnerabilities within a reasonable timeframe. Thank you.

Maya Bernstein: I am going to leave this here. It is going to remind me to add some text into the sentence or two in the exposition so that it describes what that is about and then it will cite this website. Okay?

Jacki Monson: The recommendations that we have – do we have consensus on those? If you can give me a thumbs up, that would be helpful and/or put your hand up if you want to say something. It looks like I have thumbs up. Denise, is your thumb up or do you have a comment? Hand and thumb. Perfect.

Maya, let us go through the few other additions that we had and then see if there are any other comments on that. But I think we are good on the recommendations.

Maya Bernstein: I called them justifications rather than explanation in case anyone feels strongly about that.

Given the turnaround of this first one, I tried to turn around some of the language, use the proper term implementation specifications, which is the term used in the Rule. As I was saying, this information about the guidance that we found in 2013 that Rich pointed us to or alluded to that explains what addressable means. I am not sure if this is the right word here. We were saying that covered entities and business associates should not be given an option to avoid the provisions of the rule. That is that third category where you do not have to do anything in the addressable one. Maybe that is okay.

Rebecca Hines: Is the word you really mean ignore?

Jacki Monson: I think we wanted to use a specific term out of the regulation. But I do not know if it was a void. I have to go back and look. Rich, you wouldn't have this handy, would you?

Maya Bernstein: It is right here. It says you may not – they choose to not implement either an addressable implementation specification. It has that double negative.

Jacki Monson: -- failure to comply.

Maya Bernstein: I think it is a mischaracterization of the Rule to say that it allows people to ignore – require people to document why they are not doing it.

Melissa Goldstein: Why don't we say choose not to implement?

Rich Landen: Another possibility is evade.

Maya Bernstein: Do you think people are evading it or they just cannot –

Jacki Monson: No. They are choosing not to implement.

Rebecca Hines: Choose not to implement I think is what you want to say. I think Melissa is right, given the language that is right above.

Melissa Goldstein: It is a lot of negatives except it does follow – it does not characterize their actions in a way like evade or ignore might. It just states exactly what they are doing.

Maya Bernstein: Any further strong feelings about this paragraph?

PARTICIPANT: Can I just ask one question about documented reasonable alternative? Whose opinion is it a reasonable alternative? I am concerned that someone will say this is great. This is perfect. And we are like no. It does not even come close.

Jacki Monson: It would be OCR's discretion to determine that if it is a reasonable alternative.

Maya Bernstein: If something happens that they would open an investigation on you or you had a breach or they did an audit, it is up to them to decide whether what you did was reasonable.

The purple here is what we just added in the previous conversation.

Denise Love: Can you scroll up one more thing? I wanted to nitpick one more thing and then – an entity. This is the last sentence of the paragraph above B. An entity show how they considered. Do you want document there? An entity document how they considered the requirement. How do they show or does it matter legally? Because I would not want a phone call with a bunch of excuses. I want documentation.

Jacki Monson: That is a good suggestion and enhancement.

Maya Bernstein: -- say up here documented, reasonable alternative. That is the proper word, I think.

Any further –

Denise Love: And I am assuming you will have to go back to the body of the letter and paste the exact wording that we have. I will not bother looking at what you have.

Maya Bernstein: I will say as I said in my email, it is not going to be perfect. At the end of the day, there are still citations we have to clean up. We are going to put it on stationery. We will make it the right font, whatever the stupid font used that we are supposed to use. I will make sure that it matches. Rebecca, you can remind me whether the Executive Subcommittee has to bless it before it goes.

Rebecca Hines: No. What you have to vote on today is whether it is materially substantively ready with the amendment to the motion that we will clean up, make these non-substantive cleanups to ensure that the letter has no typos and all of that. That the references/citations are final.

Denise Love: I move we go forward and do that thing you just proposed.

Rebecca Hines: Keep going and see if there are any more comments from the committee on the edits that were made.

Maya Bernstein: Can I just clarify? Did you mean to include here about avoiding bad practices or did you decide to put that along with bad password and so forth?

Jacki Monson: We are going to put it with vulnerabilities. I do not think it needs to be in that secondary place.

Maya Bernstein: It does not need to be here. I think we can get rid of this. What Jacki said in her comment was maybe we will hear something from CISA and that is exactly what happened. Very good. I have added and extended some of the citations for this discussion. This is information we just added. I will clean that up.

I need to know what is the cite that goes along with the transparency and scanning exercise and so forth. Is that in the chat or is that somewhere else?

Jacki Monson: Yes. That should be in the chat.

Maya Bernstein: As soon as this meeting is over, I am going to look at the chat.

Jacki Monson: It is CISA.gov/cyber-hygiene-services. I will add a sentence that makes it look nice. It just refers to the resource.

Recommendation 2. Recommendation 1 is long. It has multi-parts.

Rebecca Hines: And the wording for number 2 is a little different in the main – it will be reworded. This will be in conformance with –

Maya Bernstein: It will happen.

Rebecca Hines: Were there any changes made overnight other than what is in purple?

PARTICIPANT: No.

Rebecca Hines: I am wondering if we should keep hygiene, given today's presentation, which was pretty strong on that terminology. Keep going down.

PARTICIPANT: I agree because I think it now has a major implied –

Rebecca Hines: Keep going down. It was taken out below, Maya.

Maya Bernstein: I was responding to your note. It was taken out in one place. It appeared in multiple places in this document, and this is one of them here that is still there. It was taken out one place here, but you see it is right here.

Rebecca Hines: Leave it up to you.

PARTICIPANT: You cite cybersecurity hygiene. It is either cybersecurity hygiene or it is not. If we are going to keep saying it then keeping saying it; otherwise, let us be consistent one way or the other.

Maya Bernstein: It was done to accommodate you. If you are good with it, we are good.

Josh Corman: I was away from my desk for a second. Since you are touching on this, I almost said this earlier that cyber hygiene is an industry term of art that I think this letter correctly used throughout in the drafts I saw yesterday. But it is also a proper noun for CISA. It could get confusing. I do not know how you would resolve that potentially – other than to maybe specifically call out in quotes like CISA cyber hygiene service when you mean that specific service versus the generic.

Jacki Monson: We can clarify that when we add the footnote. Maya will help you with that.

Josh Corman: It is a very unfortunately named CISA service that I did not know of until I got there and I bet you lots of people remain confused about.

Rebecca Hines: The official name, Josh, is CISA Cyber Hygiene Service?

Josh Corman: I gave a link that – there is actually two services underneath it – link if you want to get the exact terminology.

Rebecca Hines: Maya, today, the zoom chat seems to be copy and paste-able. Thank goodness.

Maya Bernstein: I have been doing that all along.

I do not think I made any changes in this one except to add – to clean up some of the citations. Because it refers to Recommendation 3, I have to reconcile all the internal references when we get it all done.

Number 4, we changed. This is going to match so the should will come out of here.

Rebecca Hines: You can just go to the second page and pull out that down later. I think it is evaluate is where we – exactly.

Maya Bernstein: Okay. That will match.

And then, I had a question here about – I think what the idea here is that the committee is trying to say that it wants to raise the bar for cybersecurity on the ground like in practice and not just the rules and this sentence did not quite match that, I think. It says we raise the minimum level of security requirements, but we really want to raise the level of actual practice and that the requirements were sort of a means to that.

PARTICIPANT: Are the providers challenged by lack of adequate resources to comply or do they not seek them out because they clearly exist because we just had a presentation on that? They clearly exist. They just need to be introduced to them and make sure that they use them.

Jacki Monson: I think it depends on who the practice is, whether they want to spend time or money on it. For example, if you are a solo practitioner, they are going to wager their bet oftentimes because they do not want to spend time outside of seeing patients. But it is not ill intent. It is that they do not actually think they are going to be impacted by a cyberattack and they only call when they are. I think it just depends on who it is, who is leading the organization. It is all risk-based conversations.

PARTICIPANT: I just feel like we are giving them out when we say that they are challenged by the lack of adequate resources. And maybe you are right. Maybe it is the people like Dr. Smith does not have a security dude who knows that this other stuff exists and then to go out and use this free tool. I can see it both ways. But I feel like we are giving them an out there a little bit.

Rich Landen: One of my experiences is working with the small hospitals. There is just no qualified individual within 100 miles of that hospital. What they do is contract for remote services, an occasional once or twice a year fly in. That is the best they can do.

Maya Bernstein: We can add some of these kinds of ideas if that is appropriate and if you guys think that is appropriate.

Jacki Monson: I think that is fine.

Maya Bernstein: Do you have a feeling about any of these words in here, which of these that you like? The level of compliance or adherence or practice.

PARTICIPANT: We are trying to make them compliant. Correct?

Jacki Monson: Yes. Let us use the word compliance even though I do not like that term. I think in this context it makes sense.

PARTICIPANT: It kind of is a little bit more forceful.

Rich Landen: An alternative might be the cybersecurity hygiene.

Maya Bernstein: It is not perfect English at the moment, but this is sort of what this paragraph will look like now.

Denise Love: This is outside of the scope of the letter, but I am going to ask it anyway. Are there models for contracts with vendors and device manufacturers that these hospitals could adopt because I do not see this problem going away until the vendors are forced to build in the proper protections.

Jacki Monson: FDA has a standard bill of the materials that Josh specifically mentioned. We also heard that at the hearing. The problem is the challenge between the device manufacturers and the vendors and the systems. If they build something in today and we are using that technology for another 20 years because it is half a million dollars that standard build the materials is not going to be in the technology for 20 more years because of the purchase point. That is the challenge with this area is just how expensive some of these devices are to replace. Even an infusion pipe is $6,000 to $12,000 for one. Even in a big hospital – you put that in your plans for years to replace them. If today, they put – they use the standard build the materials and security is good, we are not going to see that in life cycle for ten plus years. That is, I think, the challenge, not that they are not coming to the table to some degree and so then it is the push and pull of who pays for that new device.

Denise Love: Right. I would in my imagination, write it into the contract that they would maintain it and update the security patches for X cost. Anyway, that is off track. I am sorry. It is late.

Jacki Monson: We can talk offline about that because that is not how it actually happens, but I am happy to talk to you offline.

Rich Landen: The maintenance contracts are not inexpensive. A lot of organizations forego the full maintenance.

Maya Bernstein: I will say it is one of the strategies if you go look at the guidance that we reference from 2013 from OCR. That is one of about five strategies that they suggest for how to deal with your legacy technologies. Negotiate longer support. That might not be --

Denise Love: It might not be for this letter. I am sorry.

Jacki Monson: Let us keep scrolling, Maya.

Maya Bernstein: This is one thing we found yesterday, Jacki and me. In October 2021 – it is not the 2013 – in 2021, OCR put out a cyber newsletter that specifically talked about legacy systems. That is what I meant. Sorry Denise. That was one of the strategies called out in that October newsletter. That was not even in existence when we had the hearings. Clearly, OCR has been thinking about this. They acknowledge that all organizations would only use IT systems that are fully patched and up to date. I added that if that is okay. It was directly related to the discussion.

And then I modified some of this based on the discussion and the modification to the actual language of the recommendation that you concluded or that you agreed on yesterday and today.

Rebecca Hines: Can we reword HHS should consider and say more like NCVHS – I do not know. I have lost track. There we go.

Jacki Monson: Let us keep scrolling.

Rebecca Hines: Do we want to look at the end of the cover, the main body of the letter to just make sure – can you go to the end of page 3?

Debra Strickland: Can I ask a question, Jacki. Transparency. I am reading this -- number 6 paragraph. I am thinking about what we do for HIPAA transactions and HIPAA violations and stuff and that is out there for us to see like who is in violation of HIPAA Rule or whatever and breaches and stuff like that. I would think that that information similar to what I was talking about with Josh earlier sort of like a report card or a rating where facilities, hospitals should go somewhere where people can have access to what their vulnerability is from a security perspective. It may motivate them in a different way to be like hey wait. This is like marketing. If I do not do this, it is going to be exposed that I do not have great security and I could lose patients.

Jacki Monson: Today, there is a bit site, which does that. They coalesce publicly available information. I think the idea of the scorecard concerns me a bit because in order to actually get to the adequacy of that, you have to share your vulnerabilities and that creates security risks in itself. That is why I worry about going there anymore than generically. I think as an industry just candidly, we are not even close to there.

Debra Strickland: Everybody would be in a D.

Jacki Monson: And they are a lot when you see the publicly available data, assuming that it is accurate. Sometimes it is not. I do not think we are there as an industry when we are not even meeting the basic security controls and that is perhaps something that we can come back and look at later on as what else could be done besides what is there if we get some level of basic cyber hygiene addressed. But I do not think we are there right now as an industry to even make a recommendation like that. I do not know how you balance that with not sharing the – sort of giving the keys to your kingdom to the hackers --

Debra Strickland: True. Maybe it was a bridge too far yet, but maybe we can get there.

Jacki Monson: I hope so.

Debra Strickland: That would be nice. Because I know like even companies like where I work where we have – they do a global assessment, which actually for the individual silos of things, it does not mean anything. But for whatever reason, they give us a rating and then it does affect us. It does pique interest of the executives that they want to change that. Food for thought for later.

Jacki Monson: This is the cover letter that you all are viewing right now. We want to make sure that there is consensus on this.

Rebecca Hines: I suggest that you go to the last attached. You will find detailed justifications for each the committee's recommendations. Let us just make sure everybody is good and then I think we are ready to take the pulse of the committee to approve. But this basically is the – it is the four recommendations and here are your detailed justifications. Everybody read these sentences very carefully because this is what is going to get read.

Maya Bernstein: Do you want to look at the recommendations again?

Rebecca Hines: Let us stay here. Let us get this wrapped up, this part, I think, because this is really the closing salvo. I hate to say it but reading the second to the last paragraph, it almost seems like you need a recommendation that says review the Cybersecurity Task Force and you have not finished the work on that. It seems like that is what you are saying. I do not know if you want to add a recommendation at this late date. But that is really what this – this is like a whole other recommendation. You have the Cybersecurity Task Force that did all this work.

Jacki Monson: Some of the things we are recommending in this report are beyond what the task force report is. The regulatory changes and suggested enhancements. That was not anything that the task force specifically got to.

Rich Landen: I think the task force work can stand on its own. We do not need to take that baggage on ourselves.

Melissa Goldstein: In the first line in the second paragraph, I would take out has been notably higher than in all other industries. I do not know that we have compared it to all other industries or that we have the data to support that statement. Maybe just take it out. It has been super high. Why don't we say that? Super high.

Rich Landen: We got a footnote on that.

Jacki Monson: We do have a source on that.

Rebecca Hines: It is there, Melissa, at the bottom. Cost of a data breach report, IBM.com.

Melissa Goldstein: Have we read it? Do we support it? Do we know that it is accurate? That is quite a statement that is has been higher than all other industries.

Rebecca Hines: Let us check it out. It is IBM after all. Here it is. Data breach.

Jamie Ferguson: You could qualify that statement by saying according to published reports comma.

Denise Love: There is cost in patient life.

Rebecca Hines: That is actually there too. In the last paragraph, it does say that. And even a loss of patient life.

Denise Love: You know these letters, Maya and Rebecca. Sometimes – does it convey the sense of urgency I feel after the last presentation or is it –

Rebecca Hines: I think the last paragraph is pretty strong. I think it could be stronger. The increasing perilous cyber threat landscape has resulted in expensive data breaches, delays, or denials of patient care and even a loss of patient life.

Denise Love: And this is increasing with each – never mind. I am not an expert.

Rebecca Hines: And then you go on. Stress on I would say "the nations" rather than our, stress on the nation's critical infrastructure due to the pandemic further taxes the health care infrastructure. And then instead of therefore, I would say with the ponderance of evidence NCVHS urges. You really need to say like with all of this, what more do you need? The committee or NCVHS urges prompt consideration.

Debra Strickland: That sentence that starts with stress, do we want to say stress on the nation's critical infrastructure due to the pandemic further taxes the health care landscape or something else so we are not saying infrastructure twice in that sentence because we mean it infrastructure by one way and then infrastructure – kind of context. One is critical systems.

Jacki Monson: You could say health care ecosystem.

Debra Strickland: That works for me. I just needed something else instead of that word.

Rebecca Hines: That is good. Thank you. It is easy to lose sight of those things.

Debra Strickland: Maya might have caught that with her final review, I am sure.

Rebecca Hines: I do not know if anyone can improve, therefore, I think to me it is in light of all of the evidence, the committee urges prompt consideration.

Debra Strickland: We plopped this problem on you. Fix it.

Maya Bernstein: -- it is more likely than not –

Jacki Monson: You could just take out therefore and just say we urge –

Rebecca Hines: Take out therefore.

Maya Bernstein: What did you ask for, Jacki?

Jacki Monson: Just take out therefore.

Rebecca Hines: What do you all think about just starting this sentence with the committee urges prompt consideration? Take out therefore, Maya, and just say the committee urges prompt consideration.

Denise Love: Instead of we.

Maya Bernstein: I am waiting for a member to tell me what they want.

Jacki Monson: Why don't we just say NCVHS urges prompt consideration?

Rebecca Hines: There you go. That is a very strong last sentence. To protect the safety and health of all Americans. I actually would reverse it and say health and safety because safety implies possible death.

Debra Strickland: I agree with that.

Maya Bernstein: Does that mean it is more important that it should come first?

Debra Strickland: They are both important, but I think –

Jacki Monson: You are not going to have health if you do not have safety.

Rebecca Hines: That is the privacy expert speaking. Please hit save, Maya. We do not need to have one of those moments.

Jacki Monson: Do we have consensus?

Debra Strickland: Do you want a hand raise or what?

Rebecca Hines: Would you please use the hand raise in your Zoom? And I need to for the record go down and –

Jacki Monson: We need a motion first. Do we not?

Rebecca Hines: Yes, exactly. Thank you.

Debra Strickland: I make a motion to accept this letter with non-substantive changes to be approved by the NCVHS Full Committee.

Jacki Monson: Is there a second?

Valerie Watzlaf: I second it.

Jacki Monson: And all in favor if you could raise your hands, please.

Rebecca Hines: We have one, two, three, four, five, six, seven, eight, nine. We need a tenth. One, two, three, four, five, six, seven, eight. Do I have ten now? Yes. All right. We have ten.

Margaret Skurka, did you want to raise your hand?

Margaret Skurka: Yes. I have it raised.

Rebecca Hines: We actually have 11 yes. We needed 10. The motion to approve the letter is approved.

Maya Bernstein: Jacki, do you want to – if there are any dissensions or abstentions.

Jacki Monson: There are no other members participating.

Rebecca Hines: It is unanimous.

Jacki Monson: Let us take public comment, Rebecca, and then if we can have a brief discussion on the PHE letter since I do not think we will have time to at least get a pulse on that. We are going to defer the workplan to the Executive Subcommittee.

Public Comment

Rebecca Hines: very good. Can we have the public slide up, please?

Greg Richards: Just one moment. In the meantime, the public comment slide will go live in a moment. But you should now be able to submit text – public comment to the Q&A box at the bottom of the screen. If you would like to submit a question via text only, please use it there. If you would like to give a verbal comment, you can raise your hand by selecting the raise your hand button in Zoom if you are on a computer or mobile device. If you are calling in from a cell phone, you can raise your hand on a phone by selecting *9. Once again, if you are on a phone, you can raise your hand to give public comment by hitting *9. Once you are called on, we will ask you to please state your name, title, and organization. If you are on your phone, you can then at this point use *6 to unmute yourself. Once again, that is *9 to raise your hand or *6 to unmute yourself once called on.

Rebecca Hines: I do not see any request for public comment. That are no emails that have come into the mailbox. Let us wait one more moment. Is it just my screen, or is this slide ginormous?

PARTICIPANT: It is fine.

Rebecca Hines: Okay. There is something wrong with my Zoom.

With that, I think we can end public comment. If you want to for whatever reason still would like to make one and did not just now, please send it to the NCVHS mail at CDC.gov mailbox.

Over back to you, Jacki.

Jacki Monson: Thank you. Melissa, do you want to talk about the PHE letter?

Melissa Goldstein: Sure. Denise Love, do you have your hand up or is that just remaining – lingering hand?

Denise Love: A lingering hand.

Melissa Goldstein: Okay. Just checking.

What I am going to do is share my screen. I sent to you at some point this morning revised version. Thank you very much to Maya for seriously heroic efforts all night long and Vickie on the other coast with a lot of edits too. We have been circulating and redrafting during the day as well on top of what we circulated this morning and in between my undergraduate class and my lecture. It may not be perfect right now, but we have a really good draft for you guys.

I will show you and walk you through the major changes, the major differences. We have some comments remaining in the margins. We will make sure that everything is – that we have everybody's comments and then we will recirculate it to you. Think through the comments in the margins, especially do you think we need additional information, how is it. I think it is ready to go as is. But I left some of these questions, many of which are mine. Remember, I am a law professor so I get kind of let us say particular about when I publish things. But that is not what this letter is. These questions are from that mind frame. Look through the changes. I think we have addressed pretty much everything. I think our plan –

Maya Bernstein: Are you sharing your screen because I cannot see it?

Melissa Goldstein: Not yet. I am going to after I finish my speech. I think our plan is to try to convene a brief meeting. We were thinking one to two-hour meeting for the Full Committee sometime before we meet again as a full group. I think that is in June. Right, Rebecca? Is that June? The next Full Committee?

Rebecca Hines: We need to poll. It is June or after July 4.

Melissa Goldstein: Got it. What we are thinking is a brief meeting to look at all of the changes. We can do a lot of that work by email, I think, if you guys have additional comments and then the Executive Committee and then meet for final discussion and vote at some point prior to our next real one- to two-day full meeting. That is the plan.

Jacki, any other summary about what our plan might be?

Jacki Monson: No. I think that accurately captures it.

Melissa Goldstein: I am going to pull up – you will love these new names on this letter. This is the letter for committee review, all comments so far, and then with MG edits. We have been going back and forth all day. We love this document.

I will walk you through it. Can you see the comments in the margins? I do not know that we have any. Yes, there are comments. Can you all see them, the comments in the margins when we get there? I will start at the beginning. There was not really that much commentary on our intro matter, but obviously, we would like for you to view it. You can see the track changes in here. Instead of ensure, we use the word address. We rearranged some of the language, really just improvements. We do still have some

citations to add and to make decisions on. This is the intro material. Again, there is some language changing, additional support.

And then HHS Number 1. Recommendation 1. HHS should – from the past hour, I know we are going to get rid of that language, Rebecca. The HHS should. We can do that. But of note in Recommendation 1, we recommend that HHS collaborate with other parties. That suggestion originally came from Sharon during our last – I believe our Executive Committee meeting. We have noticed over here that Vickie has commented that this seems a little vague, the phrase other parties. We may want to specify in there who the parties are. That is the meaning of that comment there.

In this paragraph, we have added language thanks to Maya and Vickie. Distinguishing between and adding the differences between infectious diseases, other natural disasters. We are talking about both. There are differences and that sort of thing to address what we were talking about yesterday, Rich. Some more language down here. How important it is. Permissions to use data. And remember, this particular recommendation is really focused on public trust and gender and trust, maintaining trust, earning trust.

What we have done here is we have moved up what used to be Recommendation 5 to Recommendation 2. We want to make sure – and Vickie has noted in the comments here and we want to make sure that we adequately address it that we want to in this paragraph when we are talking data governance strategy and data stewardship responsibilities that we talk about secondary uses, returning data after PHE, use of AI should be examined. All of these things. We want to make sure that we are thinking about them. Data governance. We want to make sure that we are citing the HITAC. That is where this is. It is going to be in Footnote 7. I think that was – Denise Love, this was your idea here that we cite that report.

Debra Strickland: I have a question on returning data. I am not familiar with the concept. If someone were to share data, hospital clinic, whatever, would you just destroy it after the point at which you needed it? Why would you return it back to them?

Melissa Goldstein: I am not sure what Vickie meant there. Maya, do you have more ideas? She is not talking about returning it to the people. I think this is also life cycle management that the pandemic itself is over.

Debra Strickland: If you enriched the data, it would be fair for you to say you gave this data, but I have enriched it more. I am going to feed it back to you if you like it. I am not even sure – that is assuming that they want it and that you can enrich it in some way.

Melissa Goldstein: The language is not currently in the letter as far as I understand.

Maya Bernstein: There are two things going on. I think Deb has hit on both of them. One is the disposition of data at the end of your emergency. Make a plan for the whole life cycle of the data upfront. Are you going to keep it, archive it?

Debra Strickland: Get rid of it. Is it appropriate to get rid of it because sometimes we have to keep stuff for ten years? Sometimes – minimum necessary. You should not keep it if you do not need it.

Denise Love: From a surveillance viewpoint, you would not get rid of it.

Melissa Goldstein: How do we protect it? How do we make sure is not misused?

Maya Bernstein: Because it was collected in particular during an emergency and under duress, some people might say that there needs to be a different way of thinking about that data. Obviously, we want to be able to look over time at what happens with COVID and so forth. There are equities to manage there.

I do not want to lose the other point that Debra made, which is that if you have enhanced the data – the committee did a project some years ago, which we referenced yesterday in the toolkit for data stewardship. And one of the things was if you are talking to communities and getting them to give you data and you have learned something from their data and you have manipulated it or added to it or enhanced it, can you give back to that community some information about what you learned based on the base data that they gave you that allowed you to make those insights? I do not want to lose both of those points and I do not know which one Vickie meant. But I think both of them are important to think about.

Melissa Goldstein: We will need to think about that further and what we want to include. I think it is important for people to conceptualize what is going to happen to the data and how we are going to take care of it.

Debra Strickland: A note about getting rid of data appropriately or keeping data or keeping a trail of the data. What is necessary and enrichment of data sharing back?

Melissa Goldstein: And being transparent about what the plan is. I sent you the document, Maya, in email. Can you just write down just somewhere a note to make a note of that? Thank you. Thank you, Debra and Denise. I appreciate it.

Those are the big ones. Recommendation 1, Recommendation 2. We want to make sure we cite earlier work on secondary use language because we do talk about uses of data that go beyond their original purpose. And I know that the committee has done a decent amount of earlier work on that that we should make sure to note. And then the rest of the language here about stewardship practices, what it means, work we have done before.

Recommendation 3. We did not get that many comments on during the meeting itself yesterday. This is, support the development of real-time, interoperable information. We added some language here in response to a comment from Lorraine about interoperability, standards-based, secure. We wanted to fix that language.

Here, public health, vital records, public assistance. We wanted to make sure we added that language here. And then this list remained about the same.

Review the current process for issuance of waivers, Notices of Enforcement Discretion, and guidance. What I put over here in my comment is do we need more detailed citation in this section. I do not think want a tutorial, a legal exposition of what all of these various methods are. It is possible that we want a

little more backup and perhaps some more citations to give people sources. I do not think we want to go into the details of it here because it is too long. That is why I think we need to maybe add some citations to things that the government has already done to explain these various processes. That is what I am thinking currently.

Debra Strickland: And to find out how to do it. Resources to figure out – because if they say I want to do that then this will link to where they can go to figure it out.

Melissa Goldstein: Val had a question earlier. There was a lot of discussion in the hearing itself from panelists about de-identification and thinking about de-identification. We have not addressed it in this letter. But Val suggested that we note in the hearing that there was the discussion and cite the committee's previous letter from 2017.

Debra Strickland: I think we saw above that we said re-identification above in one of those paragraphs.

Melissa Goldstein: Yes, we did that.

Debra Strickland. We do not talk about the de-identifying. We talk about re --

Melissa Goldstein: And use in ways that were not contemplated when we gather the data or when whoever gathered the data. We were thinking secondary uses, re-uses, but we did not really – we have not really address what the people brought up in the hearing about de-identification. But because it was such a big issue of the panelists, we thought we should at least note that it was an issue that the panelists discussed and give a note that we have thought about this before and possibly that many of those recommendations have yet to be acted on.

Jacki Monson: Melissa, just a time check. We are at the top of the hour and I know that a few of our members have some conflicts. Perhaps you could just wrap quickly with where we are and where we need to go and then we can --

Melissa Goldstein: That is where we are. This is Recommendation 5. We could also decide that we wanted to do a cover letter and then appendix of details like we have done in the security letter now. We could make that decision. We want to make sure that the data is in the letters as the most up to date as possible when it is published. We have noted that in the sides.

And then Vickie had another comment about including some sentences from today's information and here which we can do. We could not really do it while it was happening as well. But that will do.

Just basically, we will circulate it. We will make sure that it makes sense when we circulate it and ask for your response via email, comments via email, and then make plans to move forward.

Denise Love: Thank you. Good work.

Jacki Monson: That sounds great. Thanks to everyone, all of our support staff, our lead staff. It truly takes an army of individuals to make this happen over the last two days so just greatly appreciate it. Special thanks to Maya for burning the midnight oil to get these letters as close to the finish line as

possible for us. Very much appreciate it and just want to thank Rebecca and others for all of the behind-the-scenes work. I know many of you are doing many different jobs, multiple hats, and just really appreciate that. Thanks to my fellow committee members. It was a great couple of days. As a chair, you have made it easy on me. I think we have just had really robust discussions, and excited about where we are going and what else we have to get done.

In the meantime, we will follow up to figure out a date where we can talk more about the PHE letter and hopefully get approval, work on securing a date for the next committee meetings, and we are going to defer the workplan to the Executive Subcommittee and then the co-chairs of the subcommittees will follow up with all of the members.

With all of that, thank you very much and have a great rest of your day.

Rebecca Hines: We are adjourned. Thank you, Jacki.

(Whereupon, the meeting was adjourned at 5:05 p.m.)