“This document represents meeting minutes of the CDC/ATSDR Tribal Advisory Committee Meeting and 10th Biannual Tribal Consultation Session and does not necessarily represent Centers for Disease Control and Prevention views or policy. This document is intended for your use only, please do not forward”.
Councilman Chester Antone: Good morning. Can I have all the TAC members up at the table? We're going to go ahead and start. We're running just a little bit late. I'm going to go ahead and go with our agenda. Your binder should have the agenda for Tuesday and we have the opening blessing and I'll go ahead and provide that for us this morning. We can all stand and do prayer. We do that in Indian country all the time, every time we meet.

Opening Blessing

Councilman Chester Antone: Right now I'm going to go ahead and go around the table for introductions. I'll start from over here to the right and we'll come this way to introduce yourself before we get to Dr. Monroe and CAPT Wilkins.

Tim Gilbert: Good morning everybody. My name is Tim Gilbert. I'm from the Portland area. I work for the Confederated Tribes of the Umatilla Indian Reservation. Glad to be here.

Cathy Abramson: Good morning. Cathy Abramson. I am a Council Member from the Sault Ste. Marie Tribe of Chippewa Indians. I'm also the chair of the National Indian Health Board and I am representing the Bemidji area for this committee.

Council Member Leslie Sampson, Sr.: Good morning. I'm Council Member Leslie Sampson. I'm representing the Noorvik Native Community. I'm from the northwest part of Alaska. This is my first TAC meeting and first time in Atlanta.

Vice President Rex Lee Jim: Good morning. I'm Rex Lee Jim, Vice President of Navajo Nation.

(Inaudible speaker)

Chairman Steve Cadue: Steve Cadue, Chairman of Kickapoo Nation.

CDR Bobby Rasulnia: Good morning. Bobby Rasulnia, Acting Deputy Director for the Tribal Support Unit.

CAPT Craig Wilkins: Good morning, Craig Wilkins, Acting Director for the Tribal Support Unit.

Councilman Chester Antone: I'm Chester Antone, currently serving as the chair and I'm from the Tucson area.

Dr. Judith Monroe: Judy Monroe, Centers for Disease Control and Prevention, Office for State, Tribal, Local and Territorial Support.
Chairman Herman Honanie: Good morning everybody. I'm Herman Honanie, Chairman of Hopi Tribe, northeastern Arizona.

Chairman Robert Flying Hawk: Good morning. My name is Robert Flying Hawk, I’m the Chairman of the Yankton Tribe.

Dr. Jay Butler: Good morning. My name is Jay Butler from Anchorage, Alaska. I’m with the Alaskan Native Tribal Health Consortium and I’m the Alaska area authorized representative.

Lisa Pivec: Good morning. My name is Lisa Pivec and I am the authorized representative for the Oklahoma area, Citizen of the Cherokee Nation.

Council Member Patricia “Patty” Quisno: Good morning. I am Patty or Patricia Quisno from the Fort Belknap Indian Community. I’m a council member there and Billings area delegate.

Councilman Chester Antone: Thank you. I’m going to go ahead and turn it over to Judith Monroe.

Dr. Judith Monroe: Thank you, Chairman Antone. First of all, I just want to give a very warm welcome to all of you attending our TAC and our Tribal Consultation. It’s exciting for us here at CDC to have you here. I want to especially welcome our eight new TAC members. I know we just did introductions but I want to call out our eight new members. That’s Principal Chief Michell Hicks with the Eastern Band of Cherokee Indians, Chairman Robert Flying Hawk with the Yankton Sioux Tribe, Chairman Herman Honanie from the Hopi Tribe, Chairman Steve Cadue with the Kickapoo Tribe in Kansas, Secretary Shawna Gavin with Confederated Tribes of the Umatilla Indian Reservation represented by Mr. Tim Gilbert today. I want to also welcome Council Member Patricia Quisno for the Belknap Indian Community and Council Member Leslie Sampson with the Noorvik Native Community and Council Member Andy Joseph, Confederated Tribes of the Colville Reservation who should be calling into the meeting. Do we know, was he able to call in? He was gonna listen in, is that correct? He wasn’t able to join us in person. I do want to give a great thank you to Councilman Chester Antone Tohono O’odham Nation for his leadership on the TAC. Again, we look forward to this particular TAC meeting and look forward to working with you. I also would like to thank the TAC members who are continuing their service with us, President Alicia Reft from the Native Village of Karluk and represented by Dr. Jay Butler today, Lt. Governor Jefferson Keel of the Chickasaw Nation and represented today by Lisa Pivec and Vice President Rex Lee Jim, Navajo Nation. Also with him today is the authorized representative, Ms. Ramona Antone-Nez. Director Cathy Abramson from the Sault Ste. Marie Tribe of the Chippewa Indians, and Councilman Chester Antone with the Tohono O’odham Nation. I would like to thank everyone for continued service, and for those of you that are new with us, thank you for your public service and all that you do for the American Indian/Alaska Native communities. We are very excited to have 13 members on the TAC now and this promises to provide us very valuable insight here at CDC and guidance for our programs and you’ll be hearing over the next couple
of days from many of the leaders here at CDC and you will have a chance to work with them. We look forward to some meaningful discussion and consultation. CDC respects the tribal sovereignty and self determination for tribal governments and we would like to strengthen our relationship and partnership with the tribes. Before I turn it over to Captain Craig Wilkins, Captain Wilkins asked if I might tell a quick story about my own background. So I am a family physician by training and had planned to practice medicine throughout my career. I had a colleague that I worked with in a laboratory that left the laboratory and went to New Mexico to work with one of the tribes in New Mexico. I developed a great interest and hoped to actually practice medicine when I went to medical school with the Indian Health Service. So that was my plan, then I got married during medical school and my husband’s plans changed my plans. But I did have a National Health Service Corp commitment which took me to rural Appalachia and what I learned when I went to this community; the people living in the mountains had a very different culture. I had to learn their values for me to be effective in really treating them, I needed to understand what was important to them, what their fears were, and their great values. So there was one particular individual, his name was Tiny. Now, he was the tallest person in the county but Tiny had never been across the county line. One day he came to see me while very ill and it turned out that he had endocarditis. He had a very severe heart infection and it meant that he had to go two counties over to the large hospital to be able to be cared for. And he didn’t want to go. He was fearful. He’d never left the county line. He feared that if he left the county he would die because people went to the hospital to die. That was his belief. So it took us three days with all the family and all the community to convince him that he should in fact get the care that he needed. He did finally go. He had a very successful surgery and very successful treatment. Returned to the county, of course, telling all of his friends that the hospital wasn’t so bad and that they could cure folks. But I think the most important thing with Tiny is when he returned, he’d always had the best garden in the county and that next summer he was back again providing the best fruits and vegetables that were available in the county and went on to live many years after that. So what I learned in the rural community was the importance of understanding one another, working together, understanding cultural differences and, again, the fears of individuals and their strengths. So I hope with our TAC today that over the next couple of days we enrich one another with understanding culture and for you all to have an understanding of what CDC has to offer and how we might partner together in the most effective way for the best health outcomes. So I’ll turn to Craig Wilkins, Captain Wilkins.

CAPT Craig Wilkins: Good morning, and welcome again. On behalf of Dr. Tom Frieden, our CDC Director, Dr. Judy Monroe, our OSTLTS Director, and on behalf of our Tribal Support Unit within OSTLTS I would like to welcome you here to our annual TAC meeting and our 10th Biannual Tribal Consultation Session. It’s an honor to come before you today and especially welcome our current and new TAC members and to the tribal leaders and tribal elders. I would also like to welcome our Federal Tribal and CDC partners who are in attendance. Also to our CDC /ATSDR leadership, and to our CDC ATSDR staff and colleagues who are here representing your respective programs. The planning of this meeting has occurred over several months and has been planned by you, the Tribal Advisory Committee. And on behalf
of the Tribal Support Unit I would to thank you for your leadership and guidance and efforts to bringing this meeting into fruition. This is your meeting and we thank you for your efforts. I would also like to thank Chairman Antone for his leadership and guidance. I would also like to thank the office of the director, their staff, our OSTLTS staff and other CDC /ATSDR staff for your collective efforts in the planning of this meeting. In particularly our volunteers, our note takers, our tribal escorts and those that are outside doing the registration. But there are three people in this room—actually, I think there’s two right now, on behalf of CDRCDR Rasulnia and myself that I especially would like to recognize at this time who, without their efforts, hard work and dedication, we would not be here this morning: So I would like Molly Sauer, April Taylor, and Miatta Dennis to please stand to be recognized.

(Applause)

CAPT Craig Wilkins cont’d: As most of you know, we are currently in the midst of our 2014 winter Olympics in Sochi and in the spirit of these games I’d like to share a story with you. When I was growing up, some of my favorite sports heroes were Olympic athletes and Olympic champions; in particular, the games of the summer Olympics. These next couple of slides that I’m going to show you are not meant to be exclusive but I wanted to show you a couple of my favorite past Olympic champions that some of you may recognize. This first individual I think most of you know is Jim Thorpe. Jim Thorpe was a member of the second Fox Tribe from Oklahoma who, in the 1912 summer Olympics in Stockholm, Sweden won the biathlon and the decathlon. One of the major things about Jim was the first time he ever entered the decathlon event was at the Olympics in 1912. Second, is Jesse Owens. Jesse Owens, an African American runner who participated in the 1936 Berlin Olympics. He was the first runner and first Olympic athlete to win four gold medals in an Olympic event. Bob Mathias who at the age of 17 had just graduated high school and won the decathlon in the 1948 Olympics held in London, England. Wilma Rudolph who in 1960 participated in the Rome Olympics and won three gold medals. Wilma overcame, as a young child, polio and scarlet fever to become one of the greatest runners ever in the history of the Olympics. I think some of you know this gentleman. One of my heroes, Billy Mills. Billy Mills was the second Native American to win a gold medal. Here he is in the 1964 Olympics in Tokyo, Japan where he won the 10,000 meters. There has been no other American before 1964 or since 1964 that has ever won the 10,000 meters. Shun Fujimoto participated in the 1976 Montreal Olympics and one of the things that impressed me the most about him, he helped Japan win the team gold in the gymnastics on a broke knee. How he could stand during poll vaulting and on a pommel horse and the rings, doctors there could not understand. And finally, Nadia Comaneci. Nadia won the gold medal in the 1976 Olympics also held in Montreal. She was the first gymnast ever to score a perfect ten in gymnastics competition. But probably my favorite Olympic athlete who wasn’t even a champion and actually finished last in his event was John Stephen Akhwari who was a young African runner who participated in 1968 Olympic games in Mexico City in a marathon. Early in the race he was pushed down and fell hard, severely injuring his knee and leg. But he continued to try to run even after his coach told him to stop running, and other competitors told him to stop running. But he continued on.
CAPT Craig Wilkins cont’d: Like John, I think each of us at some point, whether in our personal or professional lives, have fallen but we’ve gotten back up. Some are battered, some are bloody and perhaps with pain hobbling our ever step we have endured with courage in the heart to continue in the race our creator has placed us in. I hope these next two days will allow us to continue to strengthen and to start new meaningful dialog and consultation with you, the Tribal Advisory Committee, and to answer the question John did. We are here not only to start the race but to continue and complete the race in improving Native public health in our American Indian and Alaska Native communities. I would like to close by quoting my favorite Olympic saying out of respect for each of you. Ask not alone for victory but ask for courage, for if you can endure, you not only bring honor to yourself, you bring honor to us all. Thank you.

Councilman Chester Antone: Thank you, Craig. I would like to ask CDR Rasulnia to the microphone and we’re now into our Tribal Advisory Committee business. So if Bobby could go ahead and—or actually I have Bobby Rasulnia and April R. Taylor, but I did ask April if she had gotten everybody at the table as far as roll call is concerned. Have you gotten everybody, April?

April R. Taylor: Councilman Antone, we have everyone except for Principal Chief Hicks. He is on the way. And Council Member Andy Joseph, if you are on the phone, if you would please send us an email and let us know your confirmation. Everyone else is at the table.

Councilman Chester Antone: That’s Andy Joseph and Mr. Hicks?

April R. Taylor: Yes.

Councilman Chester Antone: Okay, thank you. Now I’ll turn it over to CDR. Rasulnia.

CDR Bobby Rasulnia: Good morning everybody. Thank you for being here. We’re looking forward to the next couple of days. What we wanted to begin with is TAC business with Chairman Antone and then discuss the proposed TAC engagement framework. Chairman?

Councilman Chester Antone: I want to begin our discussion today by going over our roles and responsibilities here as members of the TAC. We’re asked that we all make a good faith effort to attend all the meetings. If you can, be sure to send your authorized representative. Also the area reports that the Tribal Support Unit send out, it has been changed from the previous one that was quite a long form. But the objective of those area reports is to give CDC some idea of what’s going on within the tribal nations and they also use that for planning purposes to be able to address policy issues that they may see throughout the Indian country. And thirdly, our dissemination of information to local area tribes and we need to make sure that we give the

---

“This document represents meeting minutes of the CDC/ATSDR Tribal Advisory Committee Meeting and 10th Biannual Tribal Consultation Session and does not necessarily represent Centers for Disease Control and Prevention views or policy. This document is intended for your use only, please do not forward”.

area tribes the information we receive from CDC or anything else they need to know. I know a lot of areas have health boards and I think that would be a good place to do it, so everybody has information. Also we need to be aware of our area health needs as far as public health needs. Anything that has to do with CDC we need to make that known either through our area reports or here at our meeting so we can try to address that somehow. I wanted to say that much to all of us. I think we’ve all been here in these positions long enough to know what we really need to do in order to provide that voice for the tribal nations and being able to consult with the federal government, as governments ourselves also and I think that is the most important thing we need to exercise, so that is our role and responsibility. So from here on, I will give a brief update on our recent Secretary’s Tribal Advisory Committee meeting which occurred last week in Washington, D.C. I’m only going to go over the remarks that were made to the Secretary of Health and Human Services, Kathleen Sebelius. The first priority that we went over with Secretary Sebelius was the consultation item that needs to be upheld to the highest level and that’s what we’re doing here tomorrow, consulting with the CDC and that comes from a long history of the United States recognizing Indian tribes when they first arrived. Even before it was called the United States they realized they had to deal with the populations that were here already and that began the consultation process way back then and it is addressed in the Constitution of the United States. So that becomes really important when raised to the level that we understand, that we are at that level to converse with the federal government on an equal basis, and that’s one of the things that we hold dear but we also—Mr. Bryan Gladys. President had relayed that to the Secretary. The next major issue that we entertained was the contract support cause and I think you all pretty much know how important this is for tribes to be able to get their contract support dollars and we recognize that we should be on the same standing as I’ve heard mention. Some of the defense contractors will get all of their contract support but why aren’t we getting that, and over a period of years it has grown to such an amount that now we’re forced to kind of have to take some out of IHS, you know, Dr. Roubideaux has said that we got an increase—Indian Health Service got an increase. That may be so but it’s actually a ten million decrease because when you pay out contract support cost, you’re tapping into your allocation for direct services. But I think that will work out as we go forward and that’s why we work with the Indian Health Service and figure out ways to minimize impact to the tribes because contract support costs are important. When you look at years from now, 20 or 30 years from now, tribes maybe able to leave IHS with their trust responsibilities and have everything at the tribal level being managed by the tribe, that may be the goal but in the meantime we need to go through the pains of doing that. Also to the discussion we had with exempting IHS from the cost and reduction on the long haul, some tribes had navigator issues. One of the issues is the tribal ID’s and the lack of knowledge about the Indian Health Service from the calling centers. We have limited understanding of the Indian Health Service and language aspect of the navigator centers. The other items that we brought up were the 477 programs that tribes have. Some have it with the states. In fact, in our situation our tribe flows through the state, we don’t have the 477 as on our own. The Indian Health Act, we also have as a priority from last year. The Secretary sent a letter to the governor or the Director of the Child Health.
Vice President Rex Lee Jim: Thank you Mr. Chair, members of the committee. I would recommend that we act on this later on during the day because we haven’t had the chance to read it or consult with those who are representing us. Maybe that’s one of the reasons why nobody is seconding it because it’s the first time we’ve seen it. It’s several pages and….

Councilman Chester Antone: If that’s okay with Ms. Abramson who made the motion, we’ll go ahead and do that and address it at a later time, this afternoon maybe. Is that okay with everyone? Okay, we’ll go ahead and do that and address it at a later time. So at this time, I’m going to continue with two other items we have for our TAC business. Our summer Tribal Advisory Committee meeting which is usually held in Indian country we’re going to need at least maybe three locations. If anybody wants to submit to host, please let the advisory committee know. We do have some issues on that. We need to maybe find out if we’re under the federal government office building still or can we waiver that. Does anybody know? Do you know, Judith? I believe we can ask for a waiver from the Secretary if we wanted to hold our meeting outside of a federal building in Indian country because that was one of the mandates they made, so I think we can go through Stacey Ecoffey at IEA and have her ask to waive that so we can have it in a tribal site. So we just need to clarify that and hopefully we’ll be able to do that. I know we had entertained—once before but it wasn’t working out because of the short notice, I guess. So we welcome any suggestions. Three would be good so we could see which location, what the variables are.

Cathy Abramson: I just recommend when it’s not in the winter. I recommend our place but not in the winter.

Councilman Chester Antone: Okay. Vice President Jim?

Vice President Rex Lee Jim: I think the other restriction with it, I’m not sure whether they left it there, is not to have it at a casino and resort, but if it’s owned by Native, is it allowed?

Councilman Chester Antone: Yeah, I think what restrictions they made at that time was that it had to be a federal building, and I think that we could ask for a tribal site outside of a federal building, then I think that would open up the casino thing because as you recall the transportation services administration did a lot of partying so that’s why they put a restriction on us but, you know, if you agree, we can go ahead and try to ask if any area submits to host and they want to hold it in their casino, we can include that, ask and see if we can get that. Broken Arrow is a good place I think. Never been there, but… Better quit while I’m ahead. Okay, the other—and please just let us know, let myself or April or Craig know if you’re suggesting to host. I’m now going to go into the Tribal Advisory Committee engagement plan and I want to thank Ramona Antone-Nez. She is, I believe, the only one that submitted comments to that and we appreciate that very much. And I just wanted to let you know, especially now with the federal budget as it is, I think it’s going to require us more and more to engage with CDC as well as other agencies that some of us sit on those Tribal Advisory Committees to find out other ways of doing things because an example is I’ll be submitting
testimony and I’ll be talking to what we call the Rocky Mountain Spotted Fever issue in Arizona. One of the things that was suggested early on was if we could engage the military industrial complex as far as kennels are concerned because they can make preparation for housing inmates pretty quickly. So if they can do that, why can’t we try to get them to try to come on to tribal nations to build things of that nature or even to provide services. In Arizona I think we’re toying with that idea. In fact, I think they’re kind of looking at having the Army spay and neuter. So those kind of elaborations is what we really need to look at and this engagement plan becomes very important because then the TAC is engaged in that. It is important, too, because in years past, at least in 2007 when I was first appointed to this committee by the Tohono O’odham Nation, we always had this issue with CDC and probably other federal agencies but from my experience here we’ve always had this issue where we provide testimony. We provide the needs at consultations that the tribes provide information and testimony but we never get a response. It falls into a vacuum of sorts and so that has been one of the main issues we’ve had as the TAC needs to know where our testimony goes. Is it just an exercise that we do? And is that all there is? We do need to get that response from CDC, so that’s where this Tribal Advisory Committee engagement plan comes to the floor because we are here and we need to recognize that we deal with the CDC on a government-to-government level and therefore we need to get in there and work with CDC and see what good we can do. That has been one of the main issues and we do have this engagement plan. Of course, there’s going to be questions coming up. Some of you may have concerns as far as the engagement plan is concerned. It’s a living document and we can play with it, but the important thing to remember is we need to continue that role and our roles as elected officials to be able to do that with CDC, and CDC on their side also needs to recognize this government-to-government relationship and take it seriously because only if both of us tribes and government take it seriously then we can move ahead. Mr. Gilbert?

Tim Gilbert: Thank you Mr. Chair. I’m glad you shared that. I guess I had a question about the process of information you just shared with regards to minutes and testimony, etc. and this is a formal consultation so my question kind of is a little bit about these past minutes but maybe more about how this meeting is being captured both minutes and testimony, I guess. I have a question about the very topic you just spoke to. This appears to be the conversation that the representatives had at that February meeting. I don’t see any motions in here but was there a tribal testimony that accompanied or supplemented the minutes, and maybe more for my own benefit how this meeting is documented, somebody’s probably capturing our dialog here via similar minutes, but are motions not a part of the formal process for the TAC? In other words, when you hand this over to CDC and this is what the tribes want to share, is it the minutes that you’re turning to in terms of guidance or is it the testimony or both, I guess. Thanks.

Councilman Chester Antone: I think both because I know there’s issues that come up in the TAC meeting that are important and have something to do with the tribes and what their issues are but more importantly in consultation where we’re actually submitting testimony and I think that a lot of the issues that when CDC goes back into the minutes and the recordings, then
CAPT Craig Wilkins: Yes, in a few minutes when CDR Rasulnia gives his update on the TAC Engagement Framework, that was one of the things that we noted that CDC as an agency had to have more consistent feedback not only from our minutes but the recommendations that were coming out not only from the senior leadership roundtable discussion but also during formal tribal testimony. So we felt that CDC as an agency needed to have more consistent effective communication that went back out to the Tribal Advisory Committee meetings and capturing all the dialogue that occurred during the consultation.

Councilman Chester Antone: With that, I’m going to turn it over to CDR. Rasulnia on the engagement plan.

CDR Bobby Rasulnia: Thank you Chairman. As Chairman Antone has mentioned, this has been a dialogue in the last seven months about how to formalize the process of capturing the requests coming from the TAC and how CDC can be able to address those in a systematic and timely fashion. So what we’re going to present today is a draft version of a framework we have put together with the 2013 TAC members, and I know those of you that are new haven’t had a chance to really look at this, and we’ll talk about next steps and how you can contribute to the design and framework itself. As Chairman Antone has mentioned, really this came out of the fact of how are we going to implement the CDC ATSDR TAC policy and what are some of the activities that we can begin working on throughout the year and enable some consistent and regular communication with the TAC and CIO offices so we become, at the tribal support unit, a facilitator in addressing some of the issues TAC will bring up during these biannual meetings. The Chairman also mentioned early on in our seven months that we really need to go beyond the two meetings and communicate with the TAC on various issues throughout the year. So I’ll be providing some examples of what the plan looks like. This is, again, in draft format and we welcome all of your input as we move forward in the next month or so. It is a living document which means it does change from time to time depending on the needs that need to be addressed for the TAC members. Some repeat as what Councilman Antone said. And again, really it’s to recognize that this is a government-to-government relationship, implement the TAC and respond to it as requests come forward and the questions come through CDC itself. So the framework as we discussed with the TAC really falls under three large categories. One is the actual policy and consultation, the program support, which we’ll give you some examples, and partnerships which is both internal and external partnerships with our own centers and institutes and offices as well as external partners with national organizations and I will specifically talk to some of the work that we are beginning to do with NIHB tribal public health workgroup which is meeting this Friday at the Emory conference center I believe. And we’ve taken some snippets of activities and objectives out of it. You will find in tab 10 the draft TAC engagement framework and plan, so please refer to that. We will be asking for your comments in the next month or so. Again, when it comes to the policy itself this is designed to implement it through the TAC. Any questions that come through any
presentations that have been requested by the TAC or whether it is through tribal testimonies we do have today five note takers on top of the recording that is being done for the transcription of the notes that are capturing the issues that come up, and today you’ll have two opportunities to hear back what those issues are so we can all be on the same page as to how CDC is going to respond to those within a given timeframe. So one will be at 11:30 where our note takers will be summarizing and giving back those issues that the TAC wants to hear and one will be at 5:00 o’clock again so we are all on the same page. And this implementation of any issues that come up through the meetings or consultations or testimonies, as you can see, has a timeframe on it as to where CDC has to respond back. Now, it may not be directly through the tribal support unit because a lot of these are program-specific questions. Again, we are going to be facilitators of gathering that information asking the CIO’s to respond to it and filter it back to the TAC itself. Some highlights of some of the program support. Again, what we are going to be doing is we need to have a stronger relationship between the TAC and CIO’s. We do know that some of the centers, institutes and offices within CDC already directly work with tribes and national partners, but to have some more coordinated and consolidated way of capturing some of that information through our facilitation back to the TAC so you do know what is happening across CDC at any given point in time. This also will include a quarterly—on top of the minimum monthly calls with the TAC—a quarterly call on any specific issues or new information that CDC is working on with tribes that we’ll be coordinating through the TAC as well. So it’s going to be a full engagement throughout the year beyond the two meetings that we do have. And one of the specific activities here is to take the recommendations, comments and tribal testimonies and either respond to them or begin working with our CIO’s to develop resources for dissemination which I believe is another new concept, and Chairman Antone was very adamant about being able to take that information and making it into a service whether it’s technical assistance, resource delivery, so we are going to be working on operationalizing each of those requests that come through tribal testimony or those requests. The other one as I mentioned earlier, is to really begin strengthening our relationships internally and externally to have some visibility for the TAC within our centers, institutes and offices, and be able to have that dialog outside of this formal meeting structure that we do have. So we’ve already made some rounds with our CIO leadership to begin thinking about how can we engage them in working with specific needs of the TAC. The other one is, again, reaching out to our external partners and the National Indian Health boards has been a great conduit for us. We have a new cooperative agreement with them that is developing a tribal public health workgroup to address some of the Indian Health board issues, and they have just provided us a list of their new membership that is also going to be providing a lot of the technical advice to our members as well as any questions arise. So it’s going to be a great partnership. We are also looking for them as a conduit for resource gathering and dissemination in and out of CDC so we’re really looking forward to the new cooperative agreement and the relationship that we have within NIHB and we are looking to strengthen some of the other relationships but that’s a work in progress at this point. The next steps for this, since there are eight new members is to be able to gather your comments and reviews within a month of our next call, so I’m hoping our next call is going to be in two weeks. I think that’s one of the things the Chairman will be discussing later on. From there, gather
your comments and then take it to our CIO’s because we know that they are going to be—half of the equation here, they are the subject matter experts, they are the programs, and see how we can bridge that gap between the TAC members and our CIO’s especially, and the same thing really goes for working with our partners. So this information is also going to be shared with our partners outside of CDC and see how we can, as a trio, work together to address some of the TAC concerns. We have already started implementation of the 2014 draft engagement plan. The other activity that the TAC has requested in the past is looking at strengthening our relationship and activities with the Indian Health Service. Captain Craig Wilkins and I were in D.C. two weeks ago meeting with the Indian Health Service on what are some of the work that we could do either through the Tribal Epi Centers or through the policy office on examining what are the current activities or MOU’s that we do have with IHS consolidating those and sharing that information with one another, and from there begin developing a game plan on how to bridge clinical services that they provide to the population health based services that CDC provides. So we are already beginning to implement some of the concepts that the TAC has provided in the plan itself. We hope to get a lot of comments from you on the plan and hopefully formalize it within a month after our next meeting. Thank you.

Councilman Chester Antone: Thank you, Bobby. We’re kind of far ahead on the agenda so we’re gonna go on a break in a little bit but I just want to make one final point, that the Tribal Advisory Committee, by its very name, advises CDC on things they may have questions on so I think it is incumbent upon the CDC to ask the Tribal Advisory Committee about any issues they may be seeking advice on from Indian community because if you notice the format, we’re kind of the same way. The TAC meetings from before we have presentations, we have a little business, then we have presentations after. But this go around the Tribal Support Unit did ask what exactly we wanted from these presentations and developed a format to how the presenters are going to make their presentations to us and trying to answer some of the questions in the format that we wanted them to do it in. I think as we move forward, one of the items we may want to address is maybe we might want to have a discussion ask for a particular presentation if we have issues with it and then during that presentation or after we could have a discussion on what we recommend to the CDC. That’s just a thought but we do need to have CDC ask for any issues they may be struggling with as far as the tribal nations are concerned to ask specifically for our input. So with that, I’m going to call for a 15-minute break. It’s 9:45 now so we’ll come back at 10:00.

CAPT Craig Wilkins: Just a reminder for the TAC members, if you want to fill out your lunch order and give that to Miatta Dennis.....(Break)

Councilman Chester Antone: I would also like to mention that we have Jefferson Keel here who just came in, took his seat for Oklahoma area, and Craig Wilkins has an announcement to make and then after that I will turn it over to Bobby who will have some additional comments on the engagement plan, and then from there they will go into their tribal support unit update. So with that I’ll turn it over to Craig.
CAPT Craig Wilkins: Thank you Chairman Antone. Just one final roll call. If you didn’t get a chance to fill out your lunch order…..

Okay, just some clarifications and details on the actual engagement plan. In section ten where you see the draft, the policy and consultation section also discusses renewing the timeline and activities for renewing the actual Tribal Consultation every five years. That includes also the discussions on the charter renewal as well as the issues resolution which is, I believe, some of the concerns that have come up on the TAC before and how to respond to it. So please look at that section carefully when you are reviewing it to make sure that we are addressing your needs as we move along. The section that also is needing some more detail through more discussions with the TAC as well as the CIO’s is the partnerships section which is the very last section of the plan itself. We’re more than happy to put more detail in it. These are just broad strokes. We can divide those out depending on what the TAC feels is necessary, so when you are reviewing this document, please focus on those two areas especially. I’m more than happy to address any questions that you may have.

Councilman Chester Antone: Okay, we’ll go ahead into the Tribal Support Unit update.

CAPT Craig Wilkins: Thank you, Chairman. CDR Rasulnia and I would like to provide a quick update on our Tribal Support unit. We have a small team within the office but a hardworking team that CDR Rasulnia and I have had the pleasure of working with these last 6-7 months that we’ve been on as Acting Directing and Acting Deputy Director details, so it’s been a pleasure to work with them. As Dr. Monroe stated earlier in her opening remarks, CDC/ATSDR has a commitment to our Indian tribes through our special commitment and unique relationship with our tribes and are committed to fulfilling a critical role in promoting the health and safety of our Indian tribes. Before any actions are taken that would significantly affect our Indian tribes, government-to-government consultation is critical to be conducted with our elected Indian tribal leaders or their designated representatives to the extent practical and permitted by law. As CDR Bobby Rasulnia just mentioned about our tribal consultation policy, and Dr. Monroe mentioned that as well, our first tribal consultation policy was signed off in 2005. I had the opportunity to be a part of a workgroup that put the first tribal consultation policy together. As you noted, it was updated last November and signed off and approved by the Tribal Advisory Committee. Basically, the update was—the main revision to ensure compliance with federal law and the current HHS tribal consultation policy. As Chairman Antone mentioned earlier, our TAC charter was also updated basically to ensure the alignment was with our revised policy and then to incorporate some of the TAC member comments that came in that CDC responded to. The charter policy basically again reaffirmed through CDC and ATSDR that we will try to honor the sovereignty of our Indian tribal governments, respect the inherent rights of our Indian tribal self governance, and then continue to work and collaborate on a government-to-government basis. Tribal Advisory Committee, as Chairman Antone mentioned, you as a TAC advise us, the CDC and ATSDR on policy issues and broad strategies that affect native tribes and people. The full core of TAC members is 16 and as Chairman Antone and Dr.
Monroe stated earlier, we just completed our recruitment process where we have now 13 new TAC members. The 16 members are made up of representatives, one delegate and one authorized representative from a federally recognized tribe in each of our 12 IHS areas, and then from our federally recognized tribes at large we have one delegate and one authorized representative from each of the four federally recognized tribes. We have several things within our role within the Tribal Support Unit within OSTLTS. One is we try to serve as a conduit between Indian country and CDC, and one of the things as CDR Bobby Rasulnia stated in his earlier remarks about the engagement plan, how important and critical that is that we serve as kind of what we call that go-between CDC and Indian country. We uphold the tribal consultation policy that was just revised and voted on last November. Our role was to help facilitate and be a part of the Tribal Advisory Committee for our two biannual meetings and our work throughout the year on issues that the Tribal Advisory Committee, you as its body, presents to us. Then our office, we try to provide subject matter expert, technical assistance and policy guidance not only through our office but also through CDC leadership and those CDC/ATSDR staff that are involved in working out in Indian country on public health issues.

And then one critical piece of this is our work in trying to liaison more with the department and some of our federal partners which is key. One of the things that CDR Rasulnia and I, when we came on board in this detail role, we were asked to look at our Tribal Support Unit structure. So in meeting with staff and meeting with OSTLTS we kind of came up with four, what we call buckets of operations that we felt would carry us forward in working out in Indian country being a small Tribal Support Unit. First of all, communication. I cannot stress how important communication is, not only internal to CDC staff and CDC leadership that we work with, but of course external. Communication around policy and communication around reporting. Our technical assistance and partnership support, and our extramural funding. Dr. Frieden will be giving his CDC Directors’ update tomorrow and talk a little bit about funding and budget and then we have our very critical important presentation tomorrow about budget and funding that’s going out to Indian country. Our CIO engagement. That’s one of the things that CDR Rasulnia and I have been involved in, knowing that it was critical that we work with our CIO’s here at the agency on tribal issues. And of course, our partners and stakeholders that we collaborate with and network. And then, of course, our Tribal Advisory Committee recruitment. We just completed I guess I would say our first wave of recruitment. We still have three seats remaining as Chairman Antone mentioned. That process of recruiting for those final three seats will occur after this meeting is over. We have two biannual meetings; our fall/winter meeting, we are here today, and then our summer meeting as Chairman Antone mentioned that we would like for you as a Tribal Advisory Committee to start thinking about so we can start making preparations for hosting the meeting somewhere out in Indian country. I mentioned our charter. Our charter is being revised to align to our revised policy and as Chairman Antone mentioned, looking at it once we fill our remaining three seats on any issues or questions that come up about the charter that we could address those at that time. And then part of this continuing engagement that CDR Rasulnia mentioned that we feel as CDC and we feel as a Tribal Support Unit, needs to have more of it continuous engagement with each of you as well as our Tribal Advisory Committee. And then any management and logistics. Our staff back here, April in particular, is your go-to person with some of these
management and logistics issues. And then management operations. As I mentioned, we’re a small staff. There’s just a few of us. We do not really have a budget per se. Our budget comes under the budget of our overall OSTLTS budget. And one of the things that CDR Rasulnia is going to focus on in his remarks is to talk about data management and how important that is. And then our internal infrastructure. As I mentioned earlier, we revised the CDC tribal consultation policy that was signed off and voted from the TAC last November. We updated our TAC charter. We initiated recruitment for our 11 open TAC seats, and as I mentioned we have three yet remaining that we need to fill. Then we begin work with six awardees under the tribal public health capacity building and quality improvement cooperative agreement which was a new FOA.

CDR Bobby Rasulnia: Great. Out of this slide I want to concentrate on bullet three as well as four and five. One of the things that we notice is a gleaming gap in our work with tribal nations is again partnerships, and our first cooperative agreement that we really have with our partner, with National Indian Health boards, has turned out to be a real complement to some of the activities that TAC has been doing and I believe will be in concert with what they will be asking for from CDC. Caroline, I don’t want to steal your thunder but I’m gonna kind of talk about a little bit of the activities here. I know you were talking with them as well on Thursday. But what we have done is the tribal public health workgroup is going to really be looking at some of the funding issues that CDC has identified for either direct or indirect funding to tribal nations. It is also going to focus on some of the data and surveillance gaps within Indian country whether it is looking at heart disease and stroke, for example, and how to collect data, or YRBSS and BRFSS standardization and the ability to incorporate that within the CDC BRFSS and YRBSS frameworks. They will be doing a presentation for the TAC on Thursday as an example of some of the activities as well as for the workgroup. And the other gleaming gap that we do have here at CDC is at our emergency operation center. There really is very little awareness of where to go access travel information and be able to get a situational awareness on tribes during emergencies. And one of the things that through the cooperative agreement that we are doing through the vulnerable populations desk at the EOC is to put NIHB who really does have the pulse of a lot of the activities around the country with them to be able to identify how to begin devising a plan approach and resources provided to CDC in order to be able to access tribal data and tribal information as events happen. There is an activity through the cooperative agreement that we’re also working on which is the Anthrax Dark Site. So when an anthrax event happens, this site will pop up and what we’re doing through the NIHB cooperative agreement is providing those resources for outreach to be able to both notify as well as gather intelligence within communities about an event such as Anthrax. Now, I’m sure this is the beginning of many types of activities like this for emergency preparedness and response, so these are just several glimpses of work we are beginning to do through out partnerships. There are many more activities such as the public health stories from the field that OSTLTS manages. NIHB will also be coordinating, gathering some of those stories to be published and disseminated through all of the state, local, tribal, territorial health departments as well as through avenues of NIHB to show successes of public health interventions and programs across the nation. And that’s one thing that we really have lacked here at CDC is to
highlight those successes and this will be one avenue out of many such as the “Did You Know” product that OSLTLS puts out, the “Have You Heard”, which I believe Dr. Monroe will be talking about tomorrow. So part of it is to get information out, part of it is to provide CDC with the information that it lacks, and really understanding where tribes are when it comes to issues such as emergency preparedness. So it’s going to be a great partnership, I really do believe, and this is a five-year cooperative agreement which more work through that is going to be coming along. Of course, TAC will be not only notified but asked to provide input on some of this work that is happening as part of our contiguous engagement through the engagement framework that we discussed earlier. So we are working to implement that as fast as possible. The other thing is the consolidation of our data management system. We get a lot of requests from both HHS as well as other entities including within CDC that want to know an X issue about tribes, or it’s a consolidation of funding that is happening through CDC which you will be hearing about tomorrow afternoon through the CDC budget discussion. This data management system is being looked at; it’s a SharePoint system that’s going to be developed. We’re consolidating the number of requests and the timing of the requests so we don’t go out to our CIO’s and ask too many times on what data we need that we need to report either up the chain or within the CIO’s. So right now we’re under the requirements gathering phase of the project identifying variables and timelines and the types of reports that we want to come out of this, either ad hoc reports or standard reports. Within the next two months we will be coming to the TAC to look at the framework itself on the data management plan and see if there’s any gleaming issues we’re missing that could provide input for either any types of reports that are required by you, by HHS and federal opdivs and even within our CIO’s. We will be going to our CIO’s as well to not only test the system but also come up with a protocol of timeline of how we can collect a lot of this information. Most of the time when we send this information out, it’s always an emergency, it’s always due in two weeks’. We’re trying to change that both internally and externally. So it’s a huge project and I hope that we’re able to show this to you in the next two weeks or so. This data management tool is also part of the issues resolution that we discussed earlier so anything that comes out of the tribal testimonies, any technical assistance that is requested either from individual tribes or the TAC or our partners or even within CDC, this will help document and begin looking at patterns of information that are requested from us and be able to predict some of the things where we can be proactive and respond to them. So it’s a huge project but definitely worth it and needed. The other thing that we are also going to be working through the TAC as well as the NIHB workgroup is going to be the redesign of our Tribal Support Unit website within OSTLTS. It took a lot to put the current website together and now we’re taking the next steps of customizing it to both tribes as well as the TAC, to our external partners and then to the CIO’s here within CDC. So we’re in the initial phases of looking at what the structure of this is going to look like and how we’re going to be that conduit, that facilitator of information in and out of CDC. We get requests right now from a tribe or a TAC member that wants information out of some section of CDC, and right now we have to really work, in not so much of an efficient way, of getting that information from the CIO back out to the TAC. So what we want to do is try and provide as much information that is a priority to the TAC as well as to our partners and tribes on this website. Again, this is a pretty big task but we are going to be coming to you for both
the design of it, the beta testing of it and looking for the type of information that you would like to see on this website as well as the usability testing that our communications office will be doing on this website. Big task. May take a few months. Please be patient with us. The design phase is the most important. If we can get the design right this time, what we can do is just built upon it from thereon. Any questions? Thanks.

Councilman Antone: That is our update from the Tribal Support Unit. If there’s any specific questions that you don’t want to ask at this setting, you can always approach Craig and Bobby and ask them what you need to know from them, so feel free to do that. At this time I’m going to move over to the National Center for Environmental Health. Cathy?

Cathy Abramson: I don’t have any questions, just a comment. I just really am excited about how well this is set up and I think it’s going to be really nice and informative. So I look forward to seeing how this all works out. Looks great.

Councilman Antone: Thank you, Cathy and I might add that it was NIHB who requested that there be an office set up for tribal affairs. This is it. Okay, I’m going to turn it over to Annabelle M. Allison, National Center for Environmental Health, Agency for Toxic Substances and Disease Registry, Office of Tribal Affairs update.

Annabelle Allison: Thank you, Chairman. Good morning everyone. My name is Annabelle Allison. I’m a member of the Navajo Nation originally from New Mexico. I’ve been with CDC / ATSDR now for just under six years. It’s gonna be six full years in April of this year. I work for another tribal office here at CDC/ ATSDR and it is for the National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry, or ATSDR for short. ATSDR is involved in hazardous waste issues and helps to prevent or mitigate the harmful effects of exposure to hazardous substances on human health. And so a lot of our focus at NCEH and ATSDR is around environmental health topics and toxic and chemical exposures. Although it is a separate office from OSTLTS we do collaborate very closely with each other. We stay in contact and, again, want to thank you for inviting me to come and speak today. I’m going to talk a little bit about some activities that my office has been engaged in over the past six years and more heavily what’s been happening in the last couple of years. So I’ll talk a little bit about the executive, our mandate and our efforts to really work towards policy implementation of tribal consultation and coordination, and then I’m going to talk a little about an initiative that I began in 2011 called the National Tribal Environmental Health think tank, and of course my office has been facilitating the Working Effectively with Tribal Governments course, and then lastly I’ll follow up with some updates on our epidemiological study known as the Navajo Birth Cohort Study. So as OSTLTS, as the folks here from the Tribal Support Unit have reiterated a lot this morning, we really are trying to ensure that the mandate of consultation coordination with tribal governments is increasing. One of the things that I’ve been doing with my center is to engage with the various divisions and really discuss ways we can encourage coordination and consultation with tribes on concerns they may have regarding hazardous waste sites or public health concerns from chemical or toxic exposures. We also
have been identifying mechanisms where we can invite tribal representatives from across the country to participate in some of our national partnerships and committee that we have going on at the national level as well. We really try as much as possible to utilize the tribal consultation policy as well. In the past I think a lot of discussions had occurred primarily through state and federal government discussions, we are really trying to push more to ensure tribes are at the table for some of those discussions that impact them. And, of course, we also have the HHS tribal consultation policy and annual reporting that we engage in as well. So the National Tribal Think Tank, Environmental Health Think Tank began in 2011 and really the goal with this was for me to develop a strategic plan for my office. At the time I was there, I was three years into the job and one of the things I really noticed was we really needed to build a foundation and to build sustainability, and I needed some input in what the direction of the office we wanted to take. And I felt like if I could do this, I could kind of gage it by talking to my colleagues out there but I wanted to ensure that the input was coming from them and it was a really keen difference because I went in with a certain idea of what I thought the priorities would be and actually came out with entirely different priorities. So this really was a very advantageous effort. So the thing I also wanted to ensure was that we were making the most effective use of my office’s resources by establishing and focusing on key priorities. In the first year with this think tank what I did was recruit 12 tribal professionals from across the country who were either first in public health or environmental issues, or who were new coming into the field. It was a very diverse pool. We had experiences versus new incoming young professionals but we also had very different regions that were represented throughout the United States, and we also had the public health professionals and those who were engaged in the Environmental Protection Agency side that came together. It actually was a very successful engagement. One of the first things that we worked on was to develop a vision and mission for my office. In the mission, the portion, we really discussed to a great deal what we wanted our pillars to be, what we wanted the foundation of the office to be, and policy implementation, communications and outreach, equitable distribution of resources, training, education and workforce development, collaboration and partnership and technical assistance became those pillars. And with policy implementation, of course, the first thing they said they wanted to be clear was to ensure that we coordinate and consult with tribes on issues that affected their lands, their jurisdictions, their people. The second thing that we wanted to do was more communication and outreach. We really wanted to talk and give visibility to some of the issues that tribes were facing. In terms of equitable distribution of resources, one of the things with CDC that many tribal professionals have conveyed is that a lot of the funding, though it is congressionally mandated funding, tends to go to states and local entities and they want to discuss mechanisms for how we could either make it—create a path for direct appropriations or at least engage more closely with the states on some of the priorities that have been established that involved tribes. Training, education and workforce development, this one was really key because there is this emphasis now on really wanting to increase the number of American Indian Alaska Native professionals in public health careers so we’re trying to look at mechanisms that we can engage in order to accomplish this here at CDC. And then collaboration partnerships, reaching out to others whether it be tribal serving organizations, other tribes or other state and local national organizations to really get the word out and to see
if there’s avenues for partnerships. And of course, technical assistance. As I mentioned, ATSDR, a lot of our work is engaging on issues around hazardous substances or chemical and toxic exposures and so we want to ensure that the appropriate technical assistance is there as well. The groundwork for the Office of the Tribal Affairs was also established with the first year of the think tank. They said to the Office of Tribal Affairs, as you do this work, remember these key things: respect the sovereignty and self-governance of tribes; acknowledge trust responsibility; recognize the spiritual and cultural uniqueness of tribes; apply the seven generation teachings; honor the use of traditional knowledge and recognize the relationship between culture and environment and encourage transparency teamwork and collaboration. It’s really been helpful to have these as my guiding principles as I do the work and as I engage with my colleagues internally, and as we work with other national organizations out there. It’s amazing how much education and communications is required to really have an understanding of the importance of why tribes need to be at the table for many discussions. These are just some pictures of our think tank members in action. So we finished year one and the goal, again, for year one was really for my office to establish a strategic plan and at the end of the first year’s efforts, the think tank members really felt like they were getting a lot out of the collaboration we had created, and so they asked us to continue the think tank into year two. So last year one thing we did was increased the membership to 14 members and then we focused on establishing five top priorities that we would then take forward to really focus on in the future. And the things that came out included food safety, resource extraction, infrastructure and system development, climate and health, and clean air. One of my tasks out of year two is really to begin working with the NCEH/ATSDR divisions to address the different priorities that are listed. Yes, sir?

Vice President Jim: I’m just curious as to why water is not up there because in Navajo you have that uranium contamination to water and everything.

Annabelle Allison: That’s a great question. Water was definitely up there. It was probably the 6th one in terms of priorities but when we came together in year two, we did an exercise where we asked the tribal professionals to go out and talk to their colleagues and find out what they would consider some of the top priorities as they did their work. So they brought back these priorities and we probably had at least 25 or 50 different topics, and we had to get that down to the top five and we discuss the different items and had different individuals break out into groups and have discussions, these top five came out. And that’s not to say that we still won’t discuss the other priorities, it’s just these top five are what we’re going to work on over the next immediate year. But water was definitely a close six. Yes, sir?

Vice President Jim: On your category of climate and health, would that include things like droughts?

Annabelle Allison: Yes.
Vice President Jim: Okay, because in Arizona at least we’re being impacted by this long number of years of drought and getting a little concerned with the lack of moisture, and I guess I’m beginning to really believe in this warming of the climate myself. So that’s really concerning because our cultural practices depends largely still on our ability to do dry farming but without the winter and even summer precipitation it’s just getting dryer and dryer so we’re really concerned about that area as well.

Anabelle Allison: Thank you. Yes, climate and health is definitely inclusive of drought and public health so we’re looking at it from the public health perspective definitely. In fact, in 2012 we did host a series of four webinars talking about climate and public health and one of those webinars was specifically geared to American Indian and Alaska Native populations. And for that particular webinar we did have a large turnout. I believe we had something like 180 participants in that and we had several speakers from various tribes and tribal serving organizations who gave the presentations and it was really eye opening in terms of the interest that there were out there but it was also really helpful in terms of the potential for networking that we can do because the participants not only included tribes and tribal serving organizations, it also included federal agencies, academia, national partners, and I think that was a really good opportunity to gain visibility. So other products we hope to get from year two, again, are to consolidate the different five priorities and summarize and develop a plan for how we want to address them. So in year three—we are going to do another year of the think tank—in year three what we’re gonna do is take those five priorities and really get out into the field and start working with different partners and different entities to see if there are ways we can collaborate and see if we can increase the ways that tribes are participating in some of these discussions. Another thing that came out of the think tank is that we were able to get a panel session at the American Public Health Association conference that was held in Boston, Massachusetts in 2013. We had three members of the think tank participate in that panel discussion and we also developed a video to talk about some of the issues tribes were facing and it was a very successful event. We got really good feedback from the participants. The video was really well received. And in terms of getting—again, another example of how we are trying to get more tribes to the table is we do now have two members who serve on a National Tribal Environmental Health partnership council which is hosted by my center. Yes?

Chairman Steve Cadue: This is Steve Cadue, Tribal Chairman of Kickapoo Nation. I’m an At-Large delegate. Had several issues, questions, items. How does your office—I’ll list these things and maybe you can try to answer them if you note them. Climate change, of course, water, drought, the floods, water quality, radon gas, and the issue of fracking that’s a big controversy in drilling into the ground. Can you tell me how your office is dealing with those issues?

Annabelle Allison: We have been working on the various issues on a case-by-case basis. We are definitely getting more interest and inquiries to our agency about fracking, for example. The numbers have increased, and we kind of look at it on a case-by-case basis depending on what they’re asking for and really how it applies to public health and what potential exposures
there might be. I know the Environmental Protection Agency also is really closely engaged in this and we try to collaborate with them as much as possible. If you do have any questions or if you are concerned and would like to inquire more about fracking, we can definitely work with you to try to respond to your concerns.

On the issue of water, that’s a treaty issue.

As a treaty issue, yes.

Water rights is treaty supported. Do you support or work with the Indian Affairs about water rights?

Annabelle Allison: We have not engaged with them, that I’m aware of, on anything in that realm in terms of water rights. We really just look at it from the public health perspective in terms if the water is safe to drink, is the water safe to use? That’s really what we focus on. We don’t get into the legal aspects of it.

Chairman Steve Cadue: Well, you may have heard of the Winner’s Doctrine which I think is a U.S. Supreme Court decision in 1908. It’s a great decision for Indian tribes —and we’re heavily involved in that issue, as many other tribes. But an issue that was not talked about a whole lot nearly a century ago was water quality. Now, of course, it’s paramount. That’s why I think CDC and Indian Health Service should be very supportive and provide assistance, I think, to the mission of water rights in the BIA. That’s more of a comment than a question to you but I hope that you take that under advisement.

Annabelle Allison: Thank you. So as I mentioned in the webinar series that when we did the one specifically for American Indian and Alaska Native populations, unresolved water rights definitely came up as a topic. The other thing that came up was appropriate funding to be able to address concerns from drought. And then I think a third one was access to resources and existing tools that might help tribes to address droughts. So those were some of the things that did come out of this discussion.

Councilman Chester Antone: One of the items back to the issue of radon gas where we’re detecting this emission is with Indian HUD housing and that’s another area of collaboration that I think we need to have you involved with. But I think that’s the charge of this committee and the committee has, since its inception, talked about collaboration between all of the federal agencies having a trust responsibility as you know very well. But the radon gas issue, we fear that when we get into some real intense testing in the next 30 days or so, we may have some real problems. We may have to go back to Indian HUD for assistance on that but, again, I think we’d like to call upon you for support. That’s all I have.

Okay, thank you.
Lt. Governor Jefferson Keel: I have a couple of questions. My name is Jefferson Keel. I’m Lieutenant Governor of the Chickasaw Nation. I represent the Oklahoma City area. I want to just focus on the think tank just a minute. We talk about developing policy and making recommendations on policy. How were those members selected to participate in the think tank? That’s number one. And recognizing it’s a small group, if it’s national in scope then are all areas represented? And then we talk about consultation. Is it consultation—the product then becomes whether or not it’s considered consultation. If not, how does it differ from tribal consultation because we’re talking about developing national policy and it occurs to me and I was just prompted to remind that when we develop policy, everyone should be involved in the process.

Annabelle Allison: Yes. So in terms of the membership, the one thing that we wanted to do was try to make it as diverse as possible. We wanted to get the regions represented as much as possible. We had an existing national initiative known as the National Conversation. In that conversation we had six workgroups and there was a tribal representative on each of those workgroups and we used that as the basis for developing the think tank because we knew that a lot of the topics that were going to come out of the National Conversation were going to fit pretty well with the scope that we were envisioning for the think tank as well. We knew the discussions around environmental health and ways that we could be more effective was really going to help us to move forward. So we used those six think tank members and then we recruited others based on region and based on experience. The other thing that I really wanted to do was get individuals who were funded by Environmental Protection Agency dollars involved as well because we wanted to make that connection between the environment discussion and the public health discussion. So we tried to do that as much as possible, too. And then the other thing that we really wanted to do was include those who were versed, who were experienced, had been in the field for many years and mix that with the individuals who were just coming into the field as well. So really tried to take different things into consideration with the membership. The second thing is—actually I think it was the third thing but the consultation question. Is it consultation? A lot of the tribal think tank members feel that it was consultation, and we really did try to format the meeting so that we were getting as much feedback as we could. We understood that we could not get everybody at the table but we tried to be inclusive—as much as possible we asked the think tank members to reach out to their constituents to gain feedback. They had what we called homework assignments where they had to go out and get feedback and they brought that back as well. I think I might have missed the question.

Lt. Governor Jefferson Keel: Well, my concern is that when you’re talking about being inclusive, there may be areas that have specific focus or priorities that they would want to focus on. Chairman Cadue talked about fracking but there are other regions in the country when you talk about water quality and other things that may be different, for instance, in the northwest when they’re talking about fish resorts and the southwest where there’s very little water where they have real problems with water, not to mention the quality. So I just want to make sure that I understand the purpose of the think tank as well as what the product is going
to be once you finish, and then want to make sure that all areas are represented accordingly. I guess it comes back to my question about consultation. Consultation would then occur if it’s national in scope, then it should be all areas need to be included in that and all tribal leaders need to have the opportunity to consult prior to any decisions being made on expenditure of funds or how we’re going to proceed in the future.

Annabelle Allison: Thank you. Here’s another picture of the think tank members. As I mentioned, what we’re going to do for year three is really try to focus on engaging with external partners and organizations, and I guess the purpose really is—as I mentioned initially, the purpose was to develop a strategic plan for the office and it really is kind of a direction or a scope for my office to focus on because the thing that I realize after being here for several years is that as a one-person office you have to really focus in on certain activities and not run in several different directions because you really can’t, and water quality, fracking, we’ve got a birth cohort study that is happening that brings up the issues of uranium mining and oil and gas extraction. There are various things that come up and the key is really to try to address what you can in a focused way and that’s really what I was attempting to do with the think tank is to hone in on the things that we could do and do effectively. And part of that is recognizing that we need partners, we need to be able to collaborate with others in order to do it effectively and part of that is raising awareness and gaining visibility about some of the issues tribes are facing. So this is a mechanism to be able to do that so we really want to reach out to partners more not only tribal serving organizations but also other national organizations that may not have had tribal issues brought to the table before. So the thing that we’re going to attempt to do this year is really focus on external partners and organizations to continue talking about the different environmental health topics and the priorities and again, offer actionable recommendations that my office can continue to do in order to really bring forth the issues that the tribes are facing. So one of the things that came out of the strategic plan in this logic model representation, this visual representation. So what we’ve done so far is identified short term, intermediate, and long term outcomes and ultimately some of the things that we hope to accomplish as a result of some of the work that we do over the next couple of years. Again, one example of a short-term outcome is to increase knowledge of some of the issues that tribes are facing and getting out there with more agencies. And then some of the long-term work would be systemic change that occurs as a result of some of these discussions. And ultimately we do want sustainable and self-determining tribes and tribal communities. We want access to clean air, clean land, clean water and a holistic view of health and being able to live in healthy conditions. So some of these ideas we’ve put forth are ultimately for that long-term benefit. So switching gears now I also wanted to talk about a training course that my office has been engaged in for the last couple of years. It’s called Working Effectively With Tribal Governments. It’s a course that my office facilitates and offers to fellow CDC and ATSDR colleagues here. I invite two tribal professionals to serve as co-instructors and we go into a little bit of American Indian and Alaska Native history and then we talk about some of the current issues, the public health and environmental issues that tribes are facing today, and some of the unique cultural values that shape American Indian and Alaska Native views of health in the environment. It’s a really good course. It’s a two-day course. It used to be a
Chairman Steve Cadue: CAPT Wilkins, could you go back to that last slide? In the schematic up there it talks about supporting equitable economic development. This is Steve Cadue. Well, that’s a large area that we could spend a whole day on just itself, but Captain Wilkins, when we look at economic development not just here but in the tribal support unit and the mission, is there any one office that’s concerned about this issue of economic development in the—is there something focused about economic development?

CAPT Wilkins: Chairman, I’m not quite sure about economic development. Are you making reference to budget or funding type issues?

Chairman Steve Cadue: Well, we’re here to look for solutions and I think economic development assisting or supporting our health issues is a key, and I think we ought to try to put some more focus about economic development. That’s all I wanted to bring to your attention for now.

Cathy Abramson: Well, when I think of economic development, I think of our fishermen and the importance of keeping our waters healthy so our fish stay alive so that those guys are out there making a living with their fish, and then we have our wild rice, and if our waters aren’t healthy, our wild rice isn’t going to grow. You know, that’s economic development to me because a lot of people sell their rice and their fish. That’s economic development.

There’s three areas that I wanted to bring up. Listening to everybody reminds me of these areas and two are related and that is of dumpsites which have been created in the past by federal agencies which has now created a serious concern and its impact to underground water, drinking water, and local springs and so forth. The other is our one and only landfill on the reservation which was created some 20-30 years ago maybe and I’m not sure at that point what the regulations were, whether creating a landfill versus what the regulations are now and what we need to be able to be in compliance, is a big huge concern to many of us on the reservations of the tribal consult at this point. And then the third one is water, again, with us finding arsenic in our water for the last 15-20 years and it’s just been a really, really slow response by federal agencies and so now where we’re finally getting a little bit of movement in this area to have to work on plans to import water from within the reservation but it’s about a 20-mile solution costing millions and millions of dollars to have to pipe it into 2-3 area myasis which is half of our reservation and nearly practically half of our population. And so with that kind of quality of water it’s very concerning to us and I’m not sure whether there are any other reservations with that kind of situation. So it’s kind of alarming and there’s a real huge dyer need for federal agencies to come in and help us out and look at the situation and see what can be done and hasten the response to correcting the situation. Thank you.
Annabelle Allison: Thank you. The landfill that you mention, is that the current one that is being assessed right now for uranium like previous contamination dumping? Okay. My understanding is that ongoing assessment is happening right now of the landfill and they’re trying to determine any levels of contamination that might be occurring. Thank you.

Cathy Abramson: Finally, on a previous slide you talked about several points and I’ve heard of the seven generations teaching and I’m not very familiar with it. You talk about having respect and knowledge as far as other tribes are concerned and their teaching and I’m kind of curious and maybe you and I can get together later on to get some more information on that. Thank you.

Annabelle Allison: Sure. Just real quick, the general idea behind the seven generation thinking was really like as you do your work, think about the impacts of future generations, you know, understand that our philosophy, the American Indian and Alaska Native philosophy is to look at future generations as we deal with the current issues today. That was really the philosophy from behind that, but we can definitely talk more. Okay, I think I’m running out of time.

Councilman Antone: Thank you. I was curious about that seventh generation philosophy, too, so one time an elder informed me and said a lot of people misunderstood the seventh generation. What he said was, you think three generations back whatever you learned from it and then think three generations into the future, and based on all of that you apply it to this generation, this is the seventh generation, he said. So that’s how it’s—

Annabelle Allison: Yeah, that’s a great way to look at it.

Councilman Antone: Now, the other thing I’m interested in is the think tank we talked about earlier. I’m not sure whether we consider that consultation. I think that needs to be endorsed by tribal leadership to make this tribal consultation and then to send representatives there. The other is when we talk about food, one of your number one pillars under health, food it said. We’re interested also in traditional food and how to re-cultivate not only like corn and squash and those things that we do naturally but sometimes we need to replant traditional food, so I guess that’s out there in the wild because of overpopulation and overuse sometimes they disappear. So we need to find a way to re-cultivate in the natural environment as well and find ways to fund those kinds of activities because they not only function as food to nourish our bodies but also as medicine. They are also connected to our prayers and songs and dances and so it’s a holistic approach. So when we talk about food, we need to look at that as well and not just what we buy in stores or elsewhere. Thank you.

Annabelle Allison: Thank you. So I just wanted to quickly mention that in this fiscal year we are planning to offer two more Working Effectively With Tribal Government training courses; one in April and one in September. It is now offered through our CDC university learning portal. The last thing I wanted to mention is to give a quick update on this birth cohort study
that we are conducting on the Navajo Nation. Back in fiscal year 2010—actually 2010 through 12 we did get a congressional mandate, a congressional appropriation to conduct an epidemiological study on the Navajo Nation for two million per year for the three-year period. And the study is going to follow a cohort of pregnant Navajo women and evaluate the potential associations between uranium exposure during pregnancy and the reproductive outcomes, and the development of the children is going to be followed during the first year of life. So we have just begun the recruitment process of the pregnant Navajo women and so far we’ve analyzed over 80 samples. It is a very comprehensive, very complex engagement process.

We are working with several entities of the Navajo Nation. The University of Mexico was given the award through a cooperative agreement to design and carry out the study and we’ve also had to work very closely with the Navajo Area Indian Health Services to utilize their clinics and also for community outreach as well. We are planning to conduct a best practices training on laboratory sampling, I believe either in March or April of this year. We’ve also hired several—with the monies that were appropriated—several health professionals have been hired to assist with in the field, on the ground activities. It’s been a very extensive collaboration with different entities. A lot of training had to be conducted, a lot of outreach that is still ongoing and numerous attempts to recruit. It’s been a really good process. We’ve learned a lot and we also really have tried to encourage the local entities to really take on a lot of the components of the study as well. That’s all I have in terms of updates.

Councilman Antone: Thank you, Annabelle. I have two, I have Mr. Jim and then Tim Gilbert and I’ll just let you know that we are approaching the lunch break in a couple of minutes.

Vice President Jim: Thank you. Two things. Those two courses you’re talking about, are members of TAC able to attend those or can you do a modified version for this leadership for one day because we also need to learn how to network and collaboration and so on. That’s one. The other is when we talk about best practices, I always say we need to add the word appropriate—best appropriate practices. Thank you.

Annabelle Allison: Absolutely and definitely taking into consideration some of the cultural aspects which have been very unique for the Navajo Nation. Thank you for that. In year three actually one thing I did not mention is we will be taking components of the curriculum for the Working Effectively with Tribal Government(133:38) course and offering it to national organizations. We’ve gotten several requests for that so we’re very happy to hear that and so we can definitely modify something if there’s interest in doing that.

Mr. Tim Gilbert: Hi, Annabelle, thanks for the presentation. The chair is asking me to be quick so I’m going to talk fast. I had two really quick comments. One is related to the funding, the birth cohort study, how is that funded?

Annabelle Allison: That was a congressional appropriation that was given so from 2008 to 2012 Congress had actually given monies to various agencies to conduct assessments and remediation activities of uranium.
Mr. Tim Gilbert: So via CDC?

Annabelle Allison: Yes. So the money came to us at ATSDR and we put it into a cooperative agreement and put it right back out.

Mr. Tim Gilbert: I appreciate that. One of the points I wanted to make was early on in one of your slides one of your pillars was increased resources or equitable distribution resources, and I guess the comment I wanted to make especially with our OSTLTS staff here is that from my perspective if we’re sitting here—I think one of the gentlemen made the comment that this is the 10th tribal consultation. I don’t think that means ten years, it means it’s the 10th, but when we’re sitting here for the 110th consultation, I would like to think that one of the main benchmarks that we took into account and show movement on is that there are more resources coming from the Centers for Disease Control to help tribes whether that’s through cooperative agreements or grants or maybe it’s people like you working with other HHS agencies like NIH to bring more resources to tribes. So I guess as OSTLTS kind of refines their plan, I think that’s in the top three anyway for me that I’d like to know that there are agencies like yourself or departments working with tribes to accomplish that, to get more resources and so I’d like to just throw it out there that it should be a benchmark that we should always be paying attention to. The second one is really quick. I would be remiss if I didn’t mention that the tribal leadership for where I work is also concerned about first foods. It kind of goes back to a comment Mr. Jim made about the importance of traditional foods. We have a real growing interest in first foods and health and finding that right balance. I don’t know how the Centers for Disease Control could help us think of ways to funds those types of efforts. I think there difficulty maybe craft into a usual type of funding agreement but I just wanted to put that out there from our region. So thanks again.

Annabelle Allison: Okay, thank you.

Councilman Chester Antone: Thank you, Annabelle, for your presentation. Right now we’re gonna have Molly give a brief summary of this morning’s session.

Molly Sauer: Okay, good morning. So just as we talked about at the beginning, we’re going to give a quick summary of the morning session right before lunch each day and then the afternoon session at the end of the day to kind of make sure we’ve captured the key points. So we have about five that we’ve grabbed as the top issues from this morning, and of course, there are more in the minutes. As you mentioned, we have five people taking notes right now and we also will have a transcript of the recording that’s being taken as well. So the first issue is on the draft engagement plan, and as a follow-up item just to reiterate, we will be sending out the draft plan to all of the TAC members to make sure we have input from the new members as well as those who’ve already provided input over the last couple of months. Regarding the three vacant seats that still exist on the TAC, we have California, Albuquerque and Phoenix currently open, and after this meeting we will do a second wave of recruitment to
make sure we can get all three of those seats filled. The next meeting of summer 2014 which we anticipate being out in Indian country per discussion. If you have suggestions for a location or dates or if you’re interested in hosting, please let us know. We are looking for three suggestions and we can kind of work out everybody’s schedules to see what works best. You can send those to April or if it’s easier, to tribalsupport@cdc.gov and we will gather them and reach back out to everybody. To reiterate, we touched base on the meeting minutes from the February 2013 meeting and that was just a TAC meeting, we did not have a consultation at that time. So those minutes are in your binders and if you have a chance to review them, we can revisit that later today for a vote. We had an initial motion but have tabled it until later this afternoon. And just to follow up from Annabelle’s presentation there were a couple of items raised about making sure that water, radon, droughts, and economic development are all included in the activities that the think tank is working on. And additionally the request to have a TAC-specific version of the Working Effectively With Tribal Governments training provided so that information is getting shared on both sides of the aisle. So are there any other key issues from anybody?

Director Cathy Abramson:  Yep, somebody said fracking. I know in the Great Lakes that’s a big issue as well as there’s a pipeline that’s old and I can get more information on it but that’s a big issue right now.

Molly Sauer:  Thank you.

Councilman Chester Antone:  I just had one additional comment and that had to do with the think tank and the product not being considered consultation. When we talk about consultation, that means that tribal leadership needs to be involved in that and I didn’t see any tribal leaders in that think tank.

Molly Sauer:  Thank you.

CDR Bobby Rasulnia:  And, Molly, also the comment about budget and being able to see how we can work through more direct funding for tribes which will be addressed tomorrow afternoon with the CDC budget as well, so you can ask more questions at that point in time as well.

Chairman Herman Honanie:  I’m just thinking as I’m listening to everybody and all the topics that are being mentioned and it just occurred to me with this think tank I think it’s a really important initiative and an important effort in talking about the issues that I think every tribe faces out there. And so if the think tank could take it upon itself and think about how it can work with—I know this is a huge task, but the universities throughout the states and wherever. And the reason why I say that simply is because I have a grandson who is just now entering the University and he’s going into public health, and as I was sitting here listening to her, I was just thinking and going through my mind it would be a really, great, great learning and curriculum to make it a part for Indian students that are interested in the area and to combine
that with law and everything else that could really, really be an asset to our tribes respectively. So however that can be able to work I think would be great. I don’t know how you could be able to begin to do that, but just my own idea about things. Thank you.

Councilman Chester Antone: As mentioned by Jefferson Keel that we need to somehow formalize this think tank as part of a consultation because I think the work they do is so important.

Molly Sauer: Thank you.

Also the discussion on traditional foods..?.. follow up.

Councilman Antone: If there are no others, then we can go ahead and break for lunch and 12:30 is the native specimen discussion. Very important, so if we can try to be on time to start that up. And just to offer a suggestion we can always put the product from Annabelle’s presentation as a consultation agenda item.

Councilman Antone:…..and to Delight Satter and Doris Cook. I will turn it over to you.

Delight Satter: Thank you Councilman. My name is Delight Satter and we have a presentation for you today on a really important project. Can you hear me? We’re presenting on a project that is in the early phase. It’s the Native Specimen’s Management Policy for CDC and we are so excited to present to the Tribal Advisory Committee again today. To start off our presentation we thought, because we have so many newer members we should tell a little bit of the history and how we got here. So I’ll give a very brief overview and as anyone in this room who knows me knows I will be available after the meeting if anyone likes to talk story for quite some time. When I first started here a couple of years ago, two women came to me and one was nearing retirement. Judy Delany and her colleague, Carlin Collins, was looking to outreach to the Tribal Advisory Committee. Both of these women had long and stellar careers at CDC and they wanted to provide some technical assistance for Tribal Laboratories, whether that’s a small laboratory in a health clinic with one microscope, or help with how do you write a large contract for outsourcing your laboratory testing. So Carlin presented to the Tribal Advisory Committee in 2012, and it was a great presentation. And then the Tribal Advisory Committee knew she had presented where she comes from and Shambavi will go through where she is now where Carlin was. And the TAC started to talk about native specimens because, of course, that’s an issue across the country and within HHS and other committees. So we began a discussion that, yes, CDC does have native specimens in its collections. And Carlin came back to CDC and reached back to OSTLTS to begin a discussion and a dialogue around the management of these specimens. So I thought I would give a little bit of background as to how come we’re here today. It was because a couple of CDC folks were interested in doing similar work around native communities and through discussion with the TAC, this is where we ended up. Of course, they did follow up on the offer for support for
technical assistance to tribal clinics as well. I just wanted to thank the STAC members who are here. They've heard me present briefly on this project before at the STAC and that's a good connection that we have, and I was really pleased to see that the councilman, Herman Honanie, is here because when I was at the STAC over a year ago presenting, during lunch he said to me, thank you for working on that native specimens and if you ever need anything, just let me know. And that was really wonderful and very helpful to me. It kind of spurred me on and I reported back to the group, do you know that we have support from other members, too, and this is really important work that we're engaging in. So it was really nice and I'm so glad to see that you're on the TAC now. So now we'll enter the formal presentation and I'd like to introduce Dr. Shambavi Subbarao who will correctly pronounce her name for you.

Dr. Shambavi Subbarao: Okay, thank you very much for that introduction. Good afternoon everyone. My name is Shambavi Subbarao and on behalf of the Division of Laboratory Programs Standards and Services I'm honored to be included in this Tribal Advisory Committee meeting this afternoon. The Division of Lab Programs Standards and Services is fully committed to working with the Office of State, Territorial Local and Tribal Support, OSTLTS, in developing a CDC policy for the management of biological specimens collected from Native Americans. I would like to acknowledge Dr. David Holmes who presented to this committee in February of last year. I'd also like to introduce two of my colleagues from my division who are here today and are sitting in the audience. They are going to play a key role in this policy development effort. Dr. Judith Giri who is an expert in specimen management and Stacy Howard who is the Associate Director for Policy in my division. So moving to the next slide, this is an organizational chart of the Office of Public Health Scientific Services (OPHSS). Dr. Chesley Richards is the Director for OPHSS so that's the organization you see in the top blue box. The mission of OPHSS is to lead, promote and facilitate science standards and policies to reduce the burden of disease in the United States and globally. There are two centers in the office. On the left side you see the National Center for Health Statistics and on the right side the Center for Surveillance, Epidemiology and Lab Service, or CSELS. That's the center in which my division is in. Dr. Michael Iademarco is the Director for CSELS. My division is the last blue box at the bottom on the right side. It is one of four divisions in CSELS and I'll talk a little bit more about it in the next slide. The other three divisions are focused on epidemiology and analysis, informatics and workforce respectively. So the mission of the Lab Programs Standards and Services, this is the division, is to improve the quality of lab testing and related practices in the United States and globally and we’ve achieved this through the development and evaluation of innovative training for laboratories by developing technical standards, practice guidelines and reference materials. So a primary area of work that this division focuses on is to provide scientific and technical support to the Center for Medicare and Medicaid Services, CMS, for the clinical laboratory improvement amendments regulation of 1988, also known as CLIA 88. The CLIA 88 regulations include federal standards that are applicable to all U.S. facilities or sites that test human specimens for the diagnosis, prevention or treatment of disease or assessment of health. These sites include hospitals, reference labs, physicians offices, public health labs, a variety of other locations. Anywhere where human samples are handled they come under CLIA 88 federal regulations.
and we provide assistance to CMS on the scientific and technical aspects of implementing those regulations. So a second area of focus for my division is to provide specific cross cutting scientific support services to CDC. One of these is the CDC ATSDR Specimen Inventory and Repository or CASPIR for short. This bio repository is located on a CDC-owned campus northeast of the city, northeast of Atlanta and houses almost six million biological specimens that have been generated from numerous domestic and international studies that CDC has conducted or led. So moving to the next slide. The intent of this slide is just to give you an overview of topics that we will be addressing during this session. First, I will provide some background to put the need for a specific policy for the management of Native American specimens into context. Next, Delight Satter will discuss the proposed approach that we plan to take for developing a policy for Native American specimens. And finally, Dr. Doris Cook who is sitting on my right side will engage all of us in a discussion where we will seek your valuable input.

Chairman Steve Cadue: Steve Cadue of the Kickapoo Nation. I have a couple of questions. About once a month Tribal Government meets with the health clinic director and staff on issues and doing a survey. We don’t get very good cooperation from the State Division of Vital Statistics and we would like to get specific information from the U.S. Census Bureau. It might be a question I would ask Dr. Frieden, too, but do we have a right? What right do we have to Native American data from the Division of Biostatistics or the U.S. Census Bureau?

Shambavi Subbarao: I don’t think I would be able to address that question directly but I can certainly find out from Dr. Richards and see what response we can get or help we can provide from the National Center for Health Statistics which is our sister center. So maybe after the meeting if I can get the specifics of your question I can try to follow up in terms of getting an answer to you.

Delight Satter: As well, the ladies are taking notes and so when a question comes up that might not be directly for this panel, it will go into the system and it will be sorted. Bobby will ensure that it’s sorted to the right center, institute or office, and so we don’t have responsibility for the National Center for Health Statistics or the U.S. Census would be housed, but because you’re present here asking these questions, we can sort it to the right person who can help you with that. And then regarding the Division of Biostatistics and the cooperation, that would be the same group as well as perhaps OSTLTS because it has some partnerships with some of those leaders so perhaps Dr. Monroe would want to—you know, the role of state tribal partnerships and access to information and data that they would want from vital records.

Shambavi Subbarao: Okay, should we continue? So a little bit by way of—

Councilman Chester Antone: Sorry, before you go on I think—Mr. Cadue—that as we speak and as the note takers are taking notes and the recording would take out your question from there and address it more fully. Although they’re saying they can’t address it at the moment, they would have to go back and get some more information, and I guess that’s part of the
response that we want from CDC on those specific questions. So that’s what you’re saying, right? Are you okay with that Mr. Cadue? Are you done?

Okay. Continue.

Shambavi Subbarao: Thank you. So we’re all reminded that the Havasupai case against the Arizona Board of Regions that highlighted the shortcomings of the current legal and ethical framework governing the collection and management of biological materials for research. This also demonstrated the failure to account for assessments of risk and harm that are specific and unique to identifiable population groups and Native American Tribes. At CDC specimens are managed in compliance with specific HHS and CDC policies such as the HHS policy for human subjects research and the CDC specimen policy. However, these policies currently are not specific to Native American specimens. You’re also aware of the Federal Native American Graves Protection and Repatriation Act (NAGPRA) which concerns Native American remains but there is very little information regarding biological specimens. So the purpose of this slide is to put things in context and really highlight the need for us to develop a policy that addresses specifically Native American specimens. The next slide gives you a little more background on CASPIR. As I mentioned earlier, in our division we are responsible for the management of CDC’s biological repository, also known as CDC ATSDR Specimen Inventory Repository or CASPIR for short. Last December, CDC approved its first policy for prospectively managing specimens and sample management at CDC, and the policy does make reference to other applicable guidelines, policies and laws. CDC has specimen collections that were obtained in the course of CDC’s work, utilized to support CDC’s responsibility to protect the health of the public. For example, preserved specimens from CASPIR have been used to study the origins of Hantavirus, HIV AIDS, numerous other diseases as well as setting limits on the levels of lead and gasoline and so on. So it’s impacted a number of different areas. It’s important to note that CDC obtains such specimens from outbreak investigations, routine surveillance that CDC is responsible for, and other public health investigations. The six million specimens in CASPIR are the total number of specimens preserved there, and these include some specifically obtained from Native American populations. The goal is to inventory and preserve the known Native American specimens. The recommended strategy is to focus on developing a policy first to address the governance of these specimens, and in the course of policy development we will address the existing specimens. There are currently only very few existing policies and guidelines that we can refer to in reference to developing a CDC policy for Native American sample management. The first is a tri-council policy statement. The ethical conduct for research involving humans, chapter 9, that is research involving the first nations in Impetus people of Canada. Dr. Doris Cook who is with us today is a world renowned expert in American Indian Alaska Native research ethics and policy, and played a role in developing this document. We’re honored to have Doris Cook here today as part of CDC’s project team providing advice and expert consultation on the development of a policy for Native American specimen and sample management. The second document that I have highlighted on this slide is the Indian Health Service draft guideline for implementing and complying with Indian Health Service policy on specimens. The work in this area by Drs. Bill Freeman, Phil Smith,
and Alan Trachtenberg of the Indian Health Service will be very helpful to us and we look forward to opportunities in the future to engage with our sister agency on this effort. The third document referred to on this slide is the Alaska Area Specimen Bank Policies and Procedures which was co-developed by the Alaska Area Native Health Service or AANHS, the Arctic Investigations Program Indian Health Service CDC. This document was approved by the Indian Health Service and the CDC IRB and the AANHS research and publications committee. So these are the few existing models that we have with us today that will help guide us. We’re also grateful to Dr. Jay Butler and other members of the Arctic Investigations Program CDC Alaska for sharing their experiences and look forward to having a representative from AIP in the workgroup that will develop the CDC policy. I would now like to invite Delight Satter to speak to the next slide which is the approach for policy development.

Delight Satter: Thank you Shambavi. As we have noted earlier, this is a joint effort between the CSELS and OSTLTS. So these are two units within CDC who have a special joint project to develop this policy, and our approach includes the identification and engagement of stakeholders for information gathering and sharing and we can think of a few audiences that we will—well, we already have begun and will continue to turn to for advice. First, of course, is the Tribal Advisory Committee, and we have met on it a few times and we have a great discussion planned for today. We will have an external expert panel and we actually have a cooperative agreement with the Association of American Indian Physicians, AAIP, and this is one of their projects that we partner with them on. They’ll help us with the development and coordination of that body. We also have a CDC internal multidisciplinary working group. This is the group who will actually take the information that we gain from you from the—I call it EEP, the external expert panel and consider those as they develop the policy. Our internal group will include policy experts, ethics experts, legal, scientific experts, those who use specimens and a wide range of stakeholders. It will also include the CDC’s institutional review board, our own IRB, and then we’ll have additional stakeholders. That is our basic plan and we’d like to turn it over to Dr. Cook who could give us some information about our upcoming listening session.

Chairman Steve Cadue: Does the CDC as a federal agency have the final ultimate approval in the United States about this issue of specimen research and collection, or is it a different federal agency?

Shambavi Subbarao: What we are thinking of doing and planning to do is to develop a policy that addresses specimens that CDC, Centers for Disease Control & Prevention, has collected or has in its possession right now from Native American populations. Other agencies might look to our policy when it’s developed as a guiding document but we don’t have jurisdiction over what other agencies might do. So this is for CDC.

Chairman Steve Cadue: When a Native American such as myself utilize Indian Public Health facilities, is that data available to researchers without my approval? Because I’m using a federal agency, have I given something away? My right, I mean my blood, my whole....—
Delight Satter: I did want to respond to the first thing. When you said does the CDC have the authority to develop policy for the nation, we wouldn’t. We have the capacity to develop a policy for CDC and so higher level policy would be developed in another place. So that could be something the STAC would want to raise as a concern to the secretary or even at a different level. This policy would be for our agency. That said, the National Institutes of Health have already expressed that they’re very interested in seeing how our policy formation is developed. Indian Health Service is supportive of us in going in this direction and they are very interested to see what the outcomes of the policy would be and how that could be helpful to other federal agencies. Regarding access to your blood sample or tissue that was taken from you during a medical event, those don’t necessarily show up in our repository at all. We receive things from say an outbreak, medical confirmation that an outbreak was taking place. Sometimes labs are sent to CDC to our laboratories to confirm what was the disease or what was the person exposed to, as well as other ways we receive collections, which Shambavi can describe better than I can.

Chairman Steve Cadue: That slide, CDC internal multidisciplinary working group, you’ve got several different professional people. You’ve got legal. What does that mean? What do the legal people do?

Delight Satter: Whenever we develop a federal policy or management policy inside a federal agency, we include the legal, the Office of General Council. They review the policy to make sure it is correct. As well, within OSTLTS we have a group called the Public Health Law Program. They are not there as legal advisors to the federal agency but they do provide technical assistance to this project and to many other activities. Requests can come in from the public to that group. We had a request from California tribes on what their rights were for hunting and fishing. In our case we asked them to do a review of the legal landscape to see if there were any laws that we didn’t know about that we would want to take into account as we develop an operations policy. So that’s why legal is there. They’re always included in this type of development.

Delight Satter: So could you describe our listening session at the NRN?

Doris Cook: Yes, thank you. (greeting in tribal language). Good afternoon. My name is Doris Cook and I’m very pleased to be here with you this afternoon. I want to speak briefly about the learning session that will be held at the Native Research Network annual health research conference. That’s going to be held this year from June 1 to 5 in Phoenix, Arizona, and this year’s theme is resilience and that opportunity to have a listening session really plays well into the planning for this particular project. One of the major research activities of the Native Research Network which is a proactive multidisciplinary network of indigenous people who promote research, integrity, respect, trust, ethics, cooperation and open communications in the research context. One of their major activities is coordinating the annual research conference. This presents a wonderful opportunity for us, for CDC to begin to engage the indigenous
community and thought leaders from the native community in the policy development process. Now, Delight briefly outlined for us the project strategy which begins with engaging stakeholders, and in this case it is Native Americans, in policy development. Generally the public expects to be involved in the development of public policy. Public consultations serve as a mechanism of public accountability. In the field of environmental health there is a legal right and public expectation for participation in government decision making. Certainly in the context of Native Americans there was also an obligation for consultations and that is through the executive order 13175 that was referenced numerous occasions earlier in this meeting. It requires meaningful consultations and collaboration with tribal officials in the development of federal policies that have tribal implications, and in addition to complying with the federal public policy consultations serve to improve the efficiency of and the transparency of the policy development process. The NRN conference presents an opportunity for CDC to engage native people by first sharing information on the need for policy around the management of native specimens and to continue to gather essential information on traditional values, ethics, and principles that will ground the development of the policy. CDC wants to get it right and start off by listening to what’s important to native people is a first step. Consultations and vetting of the policy with all stakeholders at key points will ensure that the policy developed is useful, usable, and consistent with traditional values and ethics.

Delight Satter: Thank you. Some of the areas that we’ve discussed as the Tribal Advisory Committee in the past include the informed consent process and adequate consent process which Chairman Cadue is basically talking about. When he's in a medical exam, is he consenting to allow his tissue to be used for other studies. And also, of course, this work includes the identification of native specimens in CASPIR, in our collections, and that work has begun. Protecting privacy and confidentiality, we expect to learn a lot about the way native people view that in different tribal settings as well as concerns around research use or the restricted use or is there broad use of specimens and what would tribal communities around research use. The conversations that we’ll have with community really allow us this opportunity, unique opportunity, to talk about the legal and social implications. These are the social and cultural implications, the traditional values and the concerns that only tribal communities can share with us so that we can make the best possible policy for the institution and the management of the specimens. And then finally would be the respectful disposition of the specimens when they’re no longer needed here. The studies may be over. You know, CDC has been here a long time. Some of the collections are from the 40's and so the ultimate goal when there could be no more need for them here for public health purposes would be to identify the tribal community and return those specimens to the tribal community for appropriate ceremonies or whatever that community would choose to do. And that, of course, we would be asking the TAC to help us with the appropriate protocol and traditional protocol for that to happen as well. And with that, that’s the end of our official formal presentation. What we’d like to do now is we’re going to turn it over to Dr. Cook to help us with the discussion with you all and we’ll be listening and very excited to hear the comments and concerns and ideas that you have to share with us. Thank you.
Doris Cook: We have two bullet points that are on the slide and before launching into that discussion I thought it might be useful to speak briefly on the policy development process. If you do an online search on policy development, you can be just overwhelmed with some of the models and diagrammatic depictions of the policy cycle, policy models, and policy stages. What they all have in common are four basic elements. The first is identifying the problem. The second is formulating a policy to resolve the problem. The third is implementing that policy or policy change. And the fourth is evaluating the effect of the policy. The first step in identifying the problem is to define exactly what the problem is. You outline it. It involves not only recognizing that an issue exists but studying the problem and its causes in detail. This stage determines how aware the public is on the issue, decide who will participate in fixing it, and considers what means are available to develop a solution. The answers often help gage which changes are needed to address the problem and the policy agenda, which problems will be addressed. Now, identifying the problem can come from government, from special interest groups, from citizens, etc. The second stage is formulating a policy to resolve the problem. After it’s been identified and studied a new policy needs to be formulated or developed. And this stage typically involves discussions and debates between government officials, interest groups, individual citizens to identify some of the obstacles for policy development to suggest some alternative solutions and to set clear goals and list the steps that will be needed to achieve them. It also involves an information gathering stage, collecting expertise, reviewing existing policies, existing guidelines, programs and research. Once the policy is developed, it then needs to be adopted and that is the implementation stage. It’s that third step in the public policy process and one that can be difficult if those that are in charge of the policy aren’t fully committed. At this stage we want some fairly intensive discussion and debate amongst those establishing the policy to ensure that there is a full understanding of what the issues are and that we eventually get to a yes in the process. Clear communications and coordination are really essential as a dialogue with the public, and those that will be affected by the policy. The final stage is evaluating the effect of the policy change. This step usually involves studying how effective the new policy has been in addressing the original problem and also making some adjustments to the policy, some tweaks here and there and ensuring that those are implemented. Now, through these stages consultation is really quite important; consultation with the public, consultation with government officials; with all the stakeholders, and there are risks associated with not getting consultations right. Those risks of either limited consultations, not undertaking consultations or a poor consultation process are a limited understanding of the problem. For example, CDC goes forward with a policy that does not involve a consultation discussion with indigenous people, with native people, then we’re not convinced that the problem is really being addressed, that the underlying issues have not been addressed. This could lead to poor policy solutions. We could have negative feedback from clients or stakeholders in reaction to the policy, lack of policy coordination, so one area has one policy and perhaps another area has another conflicting policy, and part of that addresses what Delight spoke to earlier about the need for legal opinion, legal review to ensure that there’s consistency in policies that are developed that they are legitimate, and they pass the legal test. Certainly, a potential misdirection of funds. The first bullet speaks to the expectations from Native American communities but before we launch into that discussion I thought it would
be quite beneficial if we discussed what the core values are of the TAC. What core values should guide the development of policy. A value is a guideline or action and core values specify behavior that’s required to successfully accomplish its mission, and these values cannot be compromised. So I’d like to open up the floor to some discussion on the core values of what the TAC has and then we can relate that to community expectations. Just as an example, an example of a core value might be respectful engagement. Does TAC feel that respectful engagement is important, is it a core value of this group? And that would mean respecting each person’s unique attributes, focusing on strengths. Do we value diversity of skills, experiences and perspectives, do we look to the best in every situation.

Councilman Chester Antone: What I would want to know right now is what we’re talking about—the way I understand the conversation as it began is we have specimens here at CDC and so one of our suggestions in a previous meeting was we need to know the tribes that are affected by those specimens because we need to hear from them how they would want to engage with CDC on a return of those specimens to them, and at that time Tohono O'odham Nation has suggested that in conversing with our cultural preservation committee they asked us to look to Native American Graves Protection and Repatriation Act (NAGPRA) but under NAGPRA we would have to find out whether those people that—if our tribal members had any specimens there, we would have to determine whether they are still alive or not. So when we’re talking about these native specimens, my understanding was that we were going to talk about the return of those and the identification of those specimens or the return of those specimens initially. Right now it seems that we’re talking about a return of specimens ultimately, but we’re talking about informed consent which means to me that we are going to do research and what do we need from the tribes in order to do that and that everything else is in between like the core values of how to do that. So now it comes full circle around the return of the original specimens that CDC has to research. I just wanted to lay that groundwork because as I understand it that’s how it began and then how we shifted from the return of specimens to the gathering of specimens.

Doris Cook: Yes, Chairman Antone, I recognize that was the initial concern of the TAC. However, this project is taking a project strategy that includes that but not as the first step. In order to understand respectful treatment of those samples, the ultimate disposition of those samples, we first have to understand what is it that the tribes value. Each tribe, as you know, has different culture, different traditions, somewhat different priority in the set of values. But each one is unique and before we launch on to developing a policy that would cover all of them, we need to understand more about what it is, how we would respectfully treat and therefore manage those samples. As a part of the development of the policy and gathering information toward the management of those samples we will be addressing the issue of disposition because disposition is the end stage, it’s how we manage the samples and how they’re ultimately respectfully treated at the end of it. But the disposition doesn’t come first. It’s getting a better understanding of what it is that tribes value so that we can develop policy that’s consistent with those traditional values and ethics.
Councilman Chester Antone: So presently we don’t have a policy as I understand it since we’re going back into what legal foundations there are or legal decisions that help formulate the CDC’s gathering of data whether it be blood, tissue or blood samples or human tissue.

Dr. Doris Cook: The policy that is currently in place is the health and human services policy that guides the management of all the samples. Now, I believe Dr. Shambavi has indicated that there is an effort to quarantine, to segregate those samples that they know are Native American samples to quarantine them until the policy is developed. Then they will be managed appropriately. But nothing is going on with them now until the policy is developed and implemented.

Councilman Chester Antone: So currently we just have some specimens that we’re discussing right now that are at the north of Atlanta, and so we’re talking about segregating that portion of the specimens and leave them there until we develop a policy not of return of the specimens but of the overall gathering of specimens.

Dr. Doris Cook: Return is a part of the policy.

Councilman Chester Antone: That’s what I’m saying, we’re not talking about returning the specimens until we develop a policy that runs the gamut of the beginning to the end, right?

Dr. Doris Cook: Yes. But nothing will be done with them in the interim until we better understand what a respectful treatment of those samples constitutes.

Delight Satter: Yes, and we had talked over time about identifying the—going through the collections and identifying any that we could, keeping in mind decades ago race and ethnicity might not have been collected, not even gender or some of the things that we do have now. So we do have a very small number of specimens in the collections that we did find that were native. Some are still active and so they are still here because they’re a part of ongoing studies. But this policy would address new collections, newly identified efforts, as well as how do we treat the specimens when they’re here. It could go to Mr. Cadue’s question of who is allowed to use those specimens for other needs or for other research. And then finally, when the samples or the specimens are no longer needed, then what is our policy for their final disposition, the language that’s used in laboratories, or what we’d like to call respectful disposition as Indian Health Service calls it. And as we continue our discussion, we wanted to remind folks that some of our collections aren’t a part of research so there isn’t a consenting process. Not all specimens come from research studies. So we’ll have to have discussions about the values on that. Also, some of the specimens within CASPIR are infectious so it wouldn’t be safe to return some specimens that CDC is protecting the public from and that’s how they ended up here in the first place, but we still want to talk to communities about what their values are and how we can create the best policy that will address all of those concerns. And some of the tribes we don’t know. We know that they were native but we don’t know which tribe.
Councilman Chester Antone: I want to recognize Rex and then Jay and then you… They had their hands up so we’ll go in that order. We’ll have Rex and then Jay Butler and then you. Go ahead Rex.

Vice President Rex Lee Jim: There is a health system on Navajo that has nothing to do with CDC, it has nothing to do with the U.S. policies. It's in place, it’s workable and it’s effective. And it’s a traditional system, probably one of the few systems left where some Navajo’s don’t even go to hospitals or clinics or take pills but they go to the system and some of them live to more than a hundred years old just simply using that system. There are professionals from that area that I think you need to consult and work with. They knew we're going through that external but they weren't up there. We do have traditional laws, fundamental laws that preexisted Europeans coming over that guide how you get rid of certain remains. That system, I think needs to be addressed. When we talk about meaningful consultation and we talk about tribal sovereignty, we’re talking about sovereign practices that existed before all of this existed, and we need to acknowledge that and acknowledge it as a valid health system, it works and that the practitioners are just as professional as anyone with a Ph.D. or medical degree and we need to engage them at that level and respect them at that level. So culture, to validate us, is to simply acknowledge that system exists and there are professionals who exist and need to engage them at the same level as we do with researchers, people with Ph.D.’s and people with medical degrees because their training is just as extensive. So that’s one. When we talk about tribal sovereignty, we need to look into that. The other is we talk about tribal sovereignty in terms of government to government. We also have current systems in place, for example, the Navajo Nation has its own IRB. And some of those policies need to be looked at. Some of the Navajo Nation laws and codes and certain other tribal nations have similar policies and laws in places. We need to also take a look at all of that and see how they interface with what we are attempting to do here. That's important. And then we also have what's called the Medicine Man's Association on Navajo. These are medicine people from different, how do I say, different schools of medicine. We have ceremonies that specifically address mental health, ceremonies that specifically address illnesses that deal with cancers and different stuff like that, internal stuff, just like it's out here. We have systems like that in place. And so these are medicine people who practice this, they come together in association and discuss some of these issues. And the Navajo Nation constantly turns to them, as to how we address these specifics. So those are the types of groups that we need to think about. We have to look at the intellectual property rights, the laws and policies that are in place with indigenous nations as well. A lot of the time it has to deal with collective rights rather than individuals. So collective rights mean sometimes clan rights, extended family rights and then collectively as a whole nation. I think we need to look at that and see where we're at with that. So these are some of the values that you're asking us to look at. The other is in a holistic, comprehensive approach to health, we look at all aspects including the spiritual aspect. And in the specimens that remain that we will still have some tribal nations and some clans within the Navajo Nation believe that some of those are still alive and need to be respected as such. And in some cases, it may require if you're going to return them, certain ceremonies, songs and prayers.
associated with that. Those are the kinds of things that need to be looked at, the whole spiritual aspect. I know in Western medicine, you don't worry about spirituality; it's just a specimen that you collected. But the health of the nation, the health of the community is dependent on how that's taken care of as well, because it's the collective part of the whole process. So I'm just throwing out some ideas out there for now. Thank you.

Councilman Chester Antone: Jay?

Dr. Jay Butler: Thank you, Mr. Chairman. I simply was wishing to respond to Dr. Cook's question and emphasize the value of tribal sovereignty and tribal self-determination. That point has been made by Vice President Jim and much more eloquently than I ever could have put it. Thank you.

Councilman Chester Antone: Mr. Cadue, then after that Cathy, you had your hand up.

Chairman Steve Cadue: Mr. Antone, this issue and discussion, I would like for the TAC committee to explore and in my position, I indeed would like to see Indian medicine men culture people involved in this particular program. I want that entered into the record. Thank you.

Councilman Chester Antone: Cathy?

Director Cathy Abramson: I agree with you. That came across my mind right away when we first started talking about this, Chairman Cadue. But yeah, another thing that expectations in communities I guess would be a definition of specimen would be nice because I think people need to know that. So we need to know what we're talking about. That could range from a number of things, correct?

Shambavi Subbarao: That is correct. For our CDC policy on specimens, we have defined it. I didn't bring it with me. But it includes a variety of biologic samples that I've collected from individuals: blood, plasma, serum, tissue samples. So you're right, we do need to start off with what we have as the definition. I wish I had brought that with me. I don't have it right now. But that's also open for discussion, based upon what we learn. I think we're at the learning stage. We're just trying to gather information and feedback from everyone how best to move forward, but that's a good point.

Director Cathy Abramson: Okay. Thank you.

Councilman Chester Antone: Mr. Gilbert?

Tim Gilbert: Thank you Mr. Chair. I guess I think I understand what you're looking for, what you're trying to accomplish here. I had to review your slide again to make sure I—and I guess I
have to say I think you're on the right track, I think you're trying to do the right thing, have a policy that accounts for American Indian and Alaska Native value systems and how you deal with these specimens. That said, I think you caught us at a disadvantage because there's probably a few of us that understand how exactly any one of those six million specimens you have in your bank ended up there. If I understand it right, so for example, tell me if I'm wrong. If we had an outbreak in Umatilla County, Oregon, for example, something, disease X, and it required some kind of outbreak investigation and CDC was involved, and specimens were collected as part of that outbreak investigation, they might end up in this bank as an example. One example of how they might end up there.

Doris Cook: Yes. That is one example. Not all outbreaks necessarily end up in our bank, but we do have some collections as the result of outbreaks.

Tim Gilbert: So, that's not research really. It's outbreak investigation monitoring. I guess what I'm trying to point out is that understanding how those specimens end up there and how maybe those things that are in your freezers might actually be from American Indian or Alaska Native people would help this group discuss how they ought to be treated. So maybe a little bit more information about the bank would have been useful at some point. But I also, and maybe you've done that at different meetings and I missed it but it seems to me that there's maybe some confusion about this, does this involve Indian Health Service, our tribal sovereignty, etc. Maybe a little clarity about the bank would help. But I also read in here where you may not have to reinvent the wheel here. I know you've listed some Canadian resources as well as the CDC lab up in Anchorage. Or if we have Dr. Hennessy and Dr. Butler here that are more than familiar with the specimen bank up there and I'm sure that there are lessons learned from that journey. But anyway, I just wanted to say that a little more clarity on the bank would have been useful for this discussion. But I actually think you're on the right track. You're trying to honor tribes' values systems in the specimens you might have in your repository and I think that's the right thing to do.

Shambavi Subbarao: If I could respond to that. Yeah, I think that's absolutely right. I think we need to look at what we have. I know that Dr. Giri who is sitting behind us, she started on that. We do know what specimens we have in CASPIR, and so there's some demographic information. I wish that we could have discussed it at this meeting. Perhaps the next time. I don't think this is maybe the second time that this issue has come up at TAC isn't it? It's not that --

Delight Satter: It's pretty fresh.

Fairly recent. And we didn't have all the details at the last one that we have now. And we did our first phase of the legal review. So we gained some new information. So we're at the beginning. Yeah. And it's very helpful to hear how people think the presentation went. You know, like what's missing, because we're in it and so it's helpful to hear we need some
definitions. Clearly, we're using words in different ways and so if we make sure everybody's talking turkey, that'll help.

Councilman Chester Antone: Mr. Honanie, before I recognize you, I have some questions from Councilman Andy Joseph, who is on the line. So I would like to ask those, and then we'll get to Herman and then we'll get back to Mr. Jim. Andy Joseph asks, number one, were the people of sound mind when the specimens were taken? And then second, he asks did the tribal patients speak English.

Shambavi Subbarao: I don't think I could answer that right now. I don't have the data in front of me. But any time, if it's outside of an outbreak or routine surveillance, if it's for a research project, there are very strict guidelines that we have to follow where an informed consent process is adhered to. And whoever is in charge of that, it has to go through CDC's IRB. So I'm quite certain that those issues would have been addressed, but I don't have an exact answer to give you on that specific question.

Delight Satter: What we can do though, Councilman Joseph, is as we get to that place, you know provide that information, and those questions go specifically to a person's right. There are human rights to be included in research, and do they have the capacity to consent to participate in research, and was the researcher following class standards or was the linguistic, first language, was the consenting process done in the language that's understandable to the participant. These are requirements. But I do recall some of the projects that Judith was able to find some of the collections. Some of them are from the 1940s and one is more recent but that's an active project. A more recent one would have followed consenting guidelines. The ones that were from a long time ago, they were studying virus, like in Louisiana I believe, particular viruses. They're just looking for exposure to certain virus and immunological concerns. So it was a long time ago. That kind of information might not have been gathered. It's not sitting with the specimen. Brief note, studies in those days, the record keeping was different. So we wouldn't know the answers to those questions.

Shambavi Subbarao: And for a lot of these answers we would have to go back to the specific programs that conducted these studies. What we do is we provide the repository space if you will, and manage the temperatures and the freezers and so on. But when we start talking about individual collections and projects, we have to go back to the Project Investigator. So that takes a bit of research and investigation to do. I would not have that information right now.

Delight Satter: But it's very important for us to just even hear the questions help us prepare for, it goes to the values. Do people have, are they of sound mind and able to participate in research, if it is a research project. That certainly leads us to thinking about the core values, which of course align with the rules and regulations of research as well.

Councilman Chester Antone: Mr. Honanie, and then Mr. Jim?
Chairman Herman Honanie: My comments are merely that when talking about research and taking specimens, my people have always been very concerned with it. And of course, in the early days because of the lack of knowledge they were pretty receptive to those kind of things until later on. And when you put up in your first slides, to have a supine matter, my immediate concern or question was that court ruling curbed activities with regard to gathering specimens among Indian tribes today? I'm just asking. And then how it impacted actual research in Indian country for that matter. The other thing that Mr. Antone talked about, mentioned the return of these specimens, and I'm only speaking for myself, but I think it was that point, it's one of the things we don't really think about. We may engage and we may accept or approve of specimens or research to be taken and especially in a case of specimens taken, you know, we just kind of take it for granted that the specimens are going to be in good care and everything else. But then, what if there along comes a question and say we want those returned? But the question we don't ask ourselves is how do we handle that return, how do we safely keep them and is it something that we really should, or is it something from our hearts, it's just not within and it goes against our grain of culture and everything else and we should just let it die or whatever. I'm not sure. That's kind of an interesting question that I have to wrestle with and how we would be able to answer that at our local level because I just don't feel and think that we have any of the technical or other kind of means to be able to preserve any kind of return of specimens. That also brings up the point that when you mentioned the NAGPRA Act and the return of artifacts, and what's being done to preserve them and then when they're returned, we have to wrestle with that. We have to hire consultants to assess them, examine them to see what they've been preserved with and if they're usable or not. Then we have to make decisions upon that, from that point on. And so how we keep them at that point is just a matter of utilizing the recommendations of these consultants in terms of how they advise us. So those are really kind of complex issues we have to deal with when it comes to that. But as far as specimens are concerned, that would really be a challenge for me to deal with. And finally, with regard to tribal IRB’s, I don't know how many years it's been since HOPI has tried to develop an IRB and it's a very complex task, it's a very complex matter. And so I guess when you're talking about this kind of effort, I'm just wondering if there's any TA or assistance for respective tribes to get assistance in being able to do that. I know I've seen and I haven't read every page of the Navajo IRB because it's about that thick, but it's a very, very complex matter and complicated matter to deal with and I know that a lot of tribes just don't have the wherewithal to be able to develop something like this instantly. But I think it is important. I just advocate research today from the perspective that if it's going to help our people and so forth, and it really doesn't have to involve specimens, I think for the most part, we can be able to support that. But I think we still need policies and regulations in house to be able to do that and I guess in this case, work with CDC or any other federal agents that's going to conduct these research. So all the way around, we really have to cover ourselves and not just from the point of sovereignty, but in house be able to establish applicable policies and so forth. So I myself, it's going to take a lot of effort and a lot of homework to get to the point where we can safely say we're ready and we'll take on research and we'll be able to call the shots from our perspective. Thank you.
Councilman Chester Antone: I’m going to recognize Mr. Rex Lee Jim, and then after him will be Tim Gilbert.

Vice President Rex Lee Jim: Thank you again, Mr. Chair. In Navajo, they always say [Tribal language]. It means Navajo’s are saying, we’re being over studied. You never tell us what they do with the outcome. So one of the expectations I think is feedback. What do you do with the research, the outcome, how does that inform policies, here, nationally, and how does that help the people from which you have collected data. Is there more money appropriated to prevent more diseases. Were there policies made to make access to health care a lot easier and quicker and more efficiently, effectively and how – what they really want to know is if you take something, how will I benefit from it, how will my community benefit from it? So that kind of feedback is important. Rather than just general national Native American, well this is what's going on, but back to the communities themselves. So that's an outcome that we, that's an expectation we'd like to have. Now, the other is when it comes to the specimens, the return and disposition, maybe we need to have a policy for the old stuff and then another one for the current one to move forward. Thank you.

Councilman Chester Antone: Mr. Gilbert?

Tim Gilbert: Thank you Mr. Chair. I realize I'm using up all my feedback chips here, so I'm going to try to be brief here. I just wanted to reiterate what I said the first go around, which is as part of an advisory role, I really think that your group should sit down with the artic investigations program in Anchorage and review their protocols for specimens, etc. But I guess the longer I sit here, the longer, the more questions I got, but I was curious, we're talking about a policy to deal with the existing specimens, rather than a policy that would deal with incoming new specimens is my first question.

It's both.

All right. I had a third point. Maybe I got hung up on the second point. I might have to come back Mr. Chair.

Councilman Chester Antone: At this point, I need to recognize that Shawna Gavin from the Portland area, general counsel secretary is also on the line. I just needed to let you know that. And she sent along some comments. She says, I agree it's very important to define specimen and the policy that we're working on is that we must address both the informed consent and as Joseph mentioned, ensuring the language barrier issue is properly addressed. Those are two comments from Secretary Gavin. Tim?

Tim Gilbert: Sorry. I just remembered my third point. It's in regard to access to the specimens in the repository. Can you speak maybe briefly about the policy for how those are accessed or not, once they're in the specimen bank?
Shambavi Subbarao: So right now they’re accessed mainly by—the big collections are accessed by researchers, the PIs that want to send it to their collaborators for the studies. So it’s more of an internal access process. There is a new mandate from HHS to make all federally owned collections and policies more publicly available or at least for information sake. So we’re working towards that, but right now the access is more internal for CDC scientists. And one thing Delight wanted me to sort of emphasize or explain a little better, is that a lot of the collections that we hold are not from research projects. These are more from surveillance efforts that CDC conducts for a variety of diseases. Or they are from outbreaks. So I was just looking at the list of specimens collected in the early 1960s, that I think these are linked to Native American samples. For example, incidences of community onset pneumonia. There’s HIV infected men in which the subjects were from Denver, Colorado. Investigation of an outbreak of hepatitis A and B in a community on the border of Utah and Arizona. So these are specimens that I guess came to the knowledge of EIS or epidemiologists at CDC who set up investigations and collect samples and was sent to CDC for confirmation. That’s what these are. So a lot of these, again, I have to emphasize that when we start getting into the discussion through our internal work group, we will need to draw in the people that are PIs, that are project investigators for these studies and really understand what these studies were about, how these were collected. For lack of a better way to say it, we’re sort of managing the repository right now and trying to do due diligence in making sure we have a policy in place that really respects these specimens, taking into account everything that we hear from this group and going forward. So there’s more players than what you see here to help us guide the process.

Tim Gilbert: Mr. Chair, I guess I would just say that, thinking out loud, but I don’t recall details of the Havasupai case, but it seemed like it was an access problem. In other words, there may have been specimens collected for one reason, but accessed for a whole different reason by a different PI to answer a different question. And then there wasn’t the ability to manage that in terms of reporting on that, and how the findings of that secondary analysis was portrayed in the literature. And that’s an area of concern that I would put out there. I don’t know if this group has a fix but if there’s a way that we could understand who is accessing data or specimens that might be from American Indian Alaska Native subjects, however old or however dated those specimens are, and either the research question is, or something to give us a clue about that secondary analysis and so you don’t have a repeat of the Havasupai. The last thing you want is that kind of access and that kind of PR problem of maybe a well intended PI wanting to do some research in his or her area and then misstating things about whatever, in the literature or whatever. I’m just thinking out loud in terms of, is there a gatekeeper. I’m not even sure what to call it, function, that we could at least understand who is trying to access specimens that might be from American Indian and Alaska Native specimens.

Shambavi Subbarao: Well, if it’s an IRB approved protocol, the IRB does not have an annual but periodic reviews of the study. They do look at all of that. The informed consent should be water tight. The Havasupai case was clearly a breach of informed consent. The samples were
given for I think a diabetes study and they were used for other purposes that was never agreed upon. CDC has a human subject protections’ office, they have an IRB, two or three IRBs, I'm not quite sure. But all of this is reviewed and looked at. So again, the internal work group that we're going to have will involve one or more people from the IRB office to specifically inform us and guide us on the process.

Councilman Chester Antone: Okay, go ahead, Delight and I have a few questions before we go to your next question, Doris.

Delight Satter: And what you're describing, what everyone is describing, is exactly what we’re going to explore on site. Coordinating that information and the internal multidisciplinary workgroup helped us learn more about how do you use it, what do you do, what do you know people used to do, and how we are going to get that information together so that all of those positions know their needs. These are actual researchers who are working on public health issues. They need access to the specimens to do some of the studies. How do they need it, how should our policy protect native values and native concerns and still be able to complete the research as well. Then I know, Tim said we should work with AAIP a couple of times, and I forgot to say we already are. So Judith Giri has already spoken with Dr. Hennessy and we are actually meeting tomorrow to further our communications. Thank you.

Councilman Chester Antone: Okay, before we go into the next question, real quickly, the return of specimens and/or human remains is both a celebration and also it has certain things attached to that which falls in the realm of our medicine men. And it is not necessarily bad, but occasionally there are things that need to be fixed up. I want to put that to you because our tribes specifically have these, that’s why we claim human remains that are in the southern Arizona museum and then when we take them, we lay them properly, rebury them properly and that comes with a ceremony, which is usually tended to by our medicine people. And I wanted to relay that to you because all tribes are different, as you well know. The other thing I wanted to let you know in terms of the development of your policy or the policy, or I should say our policy, is that we need to have a trust, particularly the use of others, using for other purposes, that we should be informed of that. I think it's as simple as that, because when we're not, then it raises to a different level. Then we have problems. But if we're aware that these things are going on, then I think we're okay with it, at least some of us. But some of us really need to be informed and I think that informing tribes of your protection that we're holding that trust. I just wanted to leave you with that and then I'm going to turn it over to you, Doris, for the next question that you want feedback on.

Dr. Doris Cook: Yes. Thank you very much. This has been very informative and when we receive the notes, it will be quite useful to get to the next stage. It's been very helpful to hear the listing of those core values that this group has, like respect for tribal sovereignty, trust, information sharing, partnerships, etc. As a next step, I'm wondering how we can best address the expectations for that with the help of the Tribal Advisory Committee.
Councilman Chester Antone: I'll leave it open now for anyone, the membership. Well, I'll take a stab at it. To address the expectations from the tribal communities which are already laid out in some of the responses from the membership, the example I used inform us of how these specimens are going – if there's a change in direction in other words from the collection of specimens from its original purpose, then one of the ways to address our values or the values from the native communities is just to be informed. And that's why I say that for myself, it's really simple to just tell someone hey, this is what we're planning to do. Even though it's not what we originally or we've already finished our original mission but we would like to go into this. And provide the reasons why. The use of these specimens aside from its original purpose, it's going to be used to address this particular onset of this disease which isn't here yet, but we want to know how to deal with it before it gets here. For instance the bird flu. So those questions, I think it's mainly just trust and honesty. And if you incorporate those with the values in this policy, then I think we're on our way. You know, I sit on the health research advisory council for the Department of Health and Human Services. I've always said that it's good that we are the tribe that finally did an IRB for our research code. We haven't formulated the IRB yet but we realize the potential, the benefit of doing research. We look at Alaska's setup over there where they have specimens on hand and if anything breaks out, they're able to use that to determine certain things occurring from there. So that in itself it is something I look forward to. There are certain research activities that I'm interested in but they don't involve blood samples or human specimens, at least not initially. But to test the outcome let's say of traditional foods, if you did research on foods from the desert and you picked what do you call that group? If you pick a group that ate nothing but traditional foods aside from another, the usual group, then you might require blood samples or human tissue in order to analyze how effective that was. You know what I'm saying? So initially it doesn't involve blood or human tissue but somewhere down the road it may, in order to realize what the benefit or the outcome is, whether it benefits us. So I think maybe just putting the honesty part of it, the trust part of it, just informing tribes of what we are doing and what we intend to do aside from the original purpose. I think that goes a long way into carrying those values that you asked about earlier and people here provided you with those values so we just formulate a policy that's based around it. That's what I would lend to this discussion at this time.

Chairman Robert Flying Hawk: Thank you, Mr. Chairman. I haven't said anything up to this point and I think I might have to say something here. But am very thankful for the opportunity to be here and to hear the discussion. And I was just thinking about the words that I've been hearing and respectful and humanity, and thinking about a story I had heard growing up about this place, this land. And then somebody came over, said I'm cold and I'm hungry. So there was a hand that reached out and said here is something to eat and get warm. I see that as humanity in that respect and then the humanity of it all. I believe the community is that unseen and unasked virtue that's there when things like these are done with policy. And for this committee to give an answer, it's nation to nation, I believe, in our Great Plains area. The chairman, the presidents, the leaders of those bands, those tribes are moving towards that and I think across Indian country today and the movement is that as we ask each other, we all are
a nation, we all have our ways of life. But they are basic. And so I have made myself clear as mud I think. But thank you. I just wanted to share those thoughts that I've been having.

Councilman Chester Antone: Mr. Jim?

President Rex Lee Jim: Thank you. We would like to address the second question, the Navajo Nation and then I will allow Ms. Antone-Nez to address that. Thank you.

Ramona Antone-Nez: Good afternoon. There are six points that we would like to share. One is to continue discussion through regular reports back to the TAC. Two is to develop a timeline to meet specific activities. Three is to engage a focus group with traditional medicine people. Four, provide existing policies to the TAC for better understanding of how specimens are now collected and stored. Five, develop a flow chart of feeders into the bank. How are the specimens collected, how are they stored. And I think that would help with knowing what your current policies are now. Number six is to develop a subcommittee or workgroup to help in designing how the policy framework could become. And that would also feed into number one in terms of regular report backs to the TAC. Those are recommendations from Navajo area. Thank you.

President Rex Lee Jim: And just to add one more to that. That is to do a survey of current and existing policies and so on in Indian Country, the nations and what their policies are, their IRBs and use that as a guide.

Councilman Chester Antone: Cathy?

Cathy Abramson: Well, mine was just going to be a quick answer as I'm thinking about how I'm just going to go back home and if somebody would give me a summary of the specimens and just a short summary of what they are, and I want to go give tobacco, not to smoke, to our healers so they can give me advice on what to do. And I will bring it back.

Councilman Chester Antone: Well, if there's no one else, I would just like to ask to conclude your presentation. And if you gotten what you wanted.

Delight Satter: Indeed, I have. Thank you very much. It's been very useful. I'm very pleased with the discussion. I think there was so much information I got on the values and certainly its relationship, the core values relationship to community expectations. I think that you will certainly be very pleased to know that many of these points of recommendation that you have will be included in the work plan as a natural part of policy development. That information gathering of all of the guidelines that are available, what's going on in Indian Country. Also internationally. I mean there have been many developments in countries that have indigenous populations. And we look to them for guidance as well. Many, certainly the items that were raised I think are very easily accommodated and fit in with the overall project strategy which starts off with a sort of a bottom up process, starting with dialogues and discussions with
indigenous communities, with communities, elders, with groups like TAC. One of the things that I'm certainly committed to over the next couple of weeks is to develop a protocol for communications and that would be communications between the internal expert group, the internal working group, the TAC and the body that is yet to be formulated, the expert panel. The regularity of communications, the requirement for reporting, at what point is there a delivery of updates and other reports, and certainly another item that is going to be part of the strategy is also the analysis of particular issues that are special to Indian Country and those that really do need an in-depth analysis. So those are part of the overall strategy as well as the formal consultations and the vetting of the policy that will be developed. We certainly want to insure that CDC gets it right. And that means going back to, back to the well, back to the first folks that we talked to about values and ethics to see if what we heard is indeed what they said. So that would be confirming that those values, which will ground the development of policy, have been appropriately captured. And vetting with other parties. There are other groups that will be affected by the policy and we want to ensure that it's going to be acceptable and workable to them as well. And of course that ultimately means it would stand a much greater degree of acceptance in Indian Country as well as with CDC and those folks who will be implementing that policy. Thank you very much for sharing. I really do feel that I've gotten a lot out of the discussion and look forward to continuing to dialogue with all of the groups and certainly have taken notes about the references to other individuals and other policies in existence. So thank you.

Councilman Chester Antone: Okay. Any additional comments, we are ready to move on.

Delight Satter: Thank you. And we really want to acknowledge, we are very fortunate to have Dr. Cook working with us on this project. And we want to acknowledge Dr. Monroe for providing the resources to allow us to do that, so thank you.

Delight Satter: I also forgot to say something. This happens to me all the time. Mr. Chairman Honanie, two resources for developing IRB exists currently, not that we couldn't talk about others. But Allen Trachtenberg at Indian Health Service has the responsibility for helping tribes develop their own IRB systems. But then also, the Office for the Protection of Research Subjects within OMB at the super level and HHS also has a whole system to help with the development of IRB. And you might not know this, but Bobby actually in his former life, used to work with those folks. And I have too far ago, I can't remember who they are but we can get you connected with that other resource in addition to Indian Health Service. I hate to have those things to come up like that, but that's the way my brain works.

Chairman Steve Cadue: Chairman Antone

This is Steve Cadue, Kickapoo Nation. It's been my good fortune to have practiced tribal sovereign governments for nearly 40 years and I appreciate the sensitivity of this particular discussion. It's probably one the most things that makes us unique in the relationship with the United States of America and what we come here for, consultation with CDC. There is a
uniqueness about Native American people. And we're unique within ourselves also. You don't see one Indian, you see them all. We have a uniqueness and we're very proud of that. And it was recognized by the United States of America at the very beginning of this country. I really hope, Mr. Antone, that this particular discussion gets the proper people that I, and others, have mentioned involved with this committee and this discussion and this program. [Thank you.

Councilman Chester Antone: Thank you for your presentation and the discussion. And we will just go ahead and go on with our agenda. Presently, we'll be entertaining these strengthening tribal public health through accreditation and performance improvement, have that discussion and we'll go turn it over to Liza Corso and Harold Pietz.

Liza Corso: Good afternoon. Thank you for the opportunity to be talking with you today about accreditation. My name is Liza Corso. I'm with OSTLTS with the division of public health performance improvement. Harald Pietz is joining me also with the same division within OSTLTS. We're going to be talking about accreditation today. What I thought would be helpful is if we spend some time quickly reviewing some of the key points about the national accreditation work. I know some of you are somewhat familiar with this and have been engaged in different ways. Others may not know much about the national accreditation program. So we thought it would be very helpful to talk a little bit about the national efforts and what this national voluntary accreditation program looks like. We can also then discuss a little bit about some of the efforts to advance tribal accreditation. And finally, we have some questions to prompt some discussion and we're hoping for some dialogue and questions and answers that both Harold and I can engage with you about. So first of all, the national voluntary accreditation program for public health departments. It's actually run by a 501(c)3 organization named the Public Health Accreditation Board. PHAB is the acronym that's used. Since the very inception of this effort, the work has been co-funded by CDC and the Robert Wood Johnson Foundation which has been a really nice partnership. It's been a nice match between a federal organization and a philanthropic organization co-supporting this effort. But this has very much been an effort driven by the field through practitioner input, through committees, through testing and now overseen by a board of directors that also is very representative of the field. After several years of development and testing, the program formally launched in September 2011 and the website that you see up on the slide here, www.phaboard.org is where you can find all the key information about accreditation. The standards and measures that represent the meat of any accreditation program. Information about the accreditation process and names of the boards of directors and other committee members. Just everything that relates to the accreditation program. At this point, there are quite a few health departments that have applied to accreditation. At the time we actually finalized the presentation, which was in mid-January, the need to put this into clearance, there were 260 health departments in ePHAB. That includes two tribal health departments, 24 states, and the remainder are different local health departments that have applied through different ways, both locally as well as centralized states or multi-jurisdictional applications. At this point right now, 269 health departments in the system. I will say this also includes those that are accredited. So we now have 21 health departments that are accredited, two states and the remainder are locals. The whole purpose

"This document represents meeting minutes of the CDC/ATSDR Tribal Advisory Committee Meeting and 10th Biannual Tribal Consultation Session and does not necessarily represent Centers for Disease Control and Prevention views or policy. This document is intended for your use only, please do not forward".
of the national accreditation effort is not for the sake of a compliance program or accreditation for accreditation's sake. But the real interest in it is to advance the quality and performance of public health departments. And when we say public health departments, this has been a program that has been developed with the eligibility language for state, tribal, local and territorial health departments. And I'm going to talk a little bit about the efforts and engagement of tribal perspectives in this process and how that has led to that piece of that program. As I said, it's really all about advancing the quality and performance of health departments. With that said, as with any other accreditation program that we've seen, hospitals, day care centers, schools, the public really expects accreditation. Many of your organizations may be involved in health care oriented accreditation through AAAHC or CHAP. These are programs that are well recognized in terms of giving a level of accountability or credibility or recognition. That is something that we hope as PHAB becomes more well institutionalized in public health, is something that is really seen as a strong benefit. Obviously, the opportunity to improve the whole public health department and the infrastructure. Thinking of health departments as programs that have different bricks, this is something that really represents the mortar in between those bricks. Something that pulls the health department together. And then all the different services that a health department delivers, seeing that strengthen regardless of the different programs and across all programs. Let me briefly tell you about the different elements of the PHAB accreditation program. As I noted before, all accreditation programs, and many of you may be well aware of this, of course, are based on the existence of standards. What health departments or what any organization being accredited needs to meet to achieve accreditation. And the PHAB accreditation process, those standards and measures exist across a framework of 12 domains. Those domains are based on the 10 essential public health services. Two additional domains have been added to address administrative capacity and management, as well as engagement with the governing entity. And by choosing and by the work groups, again comprised of practitioners from the field, choosing to use the essential services framework as the framework for those domains, they really looked at this as intending to provide a strong foundation for all public health programs. There are three prerequisites that need to be in place before even applying to accreditation. These are actually found within the different standards and measures. But PHAB thought this was a good litmus test to make sure that no one was applying prematurely, because these are fairly hefty documents and do take a real commitment and time. First of all, having a community or state or tribal public health or community health assessment. Obviously, that makes sense because any health department should be working with their community partners to really understand what the prevailing health status of the population is, what the key issues are, and working with their partners to address those issues. And that of course, also where the community health improvement plan comes into place. Using the results of the health assessment, both data and community perceptions to identify priorities and address those and use resources wisely to address the priorities of the community. And finally, of course, a health department strategic plan is the third prerequisite. The PHAB accreditation process is very much like other accreditation processes in that it uses an external validation process, site visitors that are comprised of peer reviewers, state, local, tribal, leader, public health leadership attend the site visit and develop the report. In fact, PHAB is always looking for more site visitors. So if that's something that any
of you are interested in, I know some of you might be doing this already. That is something that it's of keen interest not just to ensure for example there are tribal representatives or tribal site visitors to go visit tribal organizations, but also to visit state health departments and local health departments, because the engagement with tribal populations and with tribal, whether they're in the jurisdiction or adjacent to the jurisdiction and there's collaborative issues that need to be addressed, that brings new perspectives that can be very important to the process. Once accredited, health departments then must be reporting for five years throughout this five year accreditation status. And then that accreditation is good for five years. These are the 12 domains that I just referenced. Again, in accordance with the 10 essential services which have been reworded to better fit what a health department or an organization should be doing. And then those new 11th and 12th domain addressing administrative and management capacity and the engagement with the governing entity. I wanted to very quickly show you a sample standard since I know some of you might be very well familiar with this and others are not. This is what it looks like if you were to take a look at the version 1.0 of the PHAB standards. They also just released version 1.5 which I'll talk about in a moment. But this of course is one that comes from domain two, investigate health problems and environmental public health hazards to protect the community. Within each domain, there are several standards. And then which under each standard, there are measures and required documentation. I want to point out that you see in this one, standard 2.1A. “A” means this is a standard that is relevant for all kinds of applicants, state, tribal, local, and territorial. There are some standards that have a “T” after it. That means that those are ones that are very specific to the tribal organization, or tribal health department that would be applying. That doesn't mean that the domains and standards look extremely different than the state versus tribal organizations, but it does mean that the language and the examples of documentation have been addressed and adapted to better fit the tribal setting, for example, or to best represent what state health departments could be submitting if it's an S, or local if it's an L. So in that sense, PHAB has tried to work with its work groups to develop standards and measures that are both consistent yet flexible to address the different types of applicants. I just mentioned that the one example that you just saw came from version 1.0, which was the first version that has been released to the field. Just a couple of weeks ago, PHAB released its version 1.5. It essentially looks the same. The standards and the domains very much remain the same. However, there are some new areas for emphasis. Health equity, which is something that I know input from tribal organizations was definitely included there as well as in fact all the accreditation improvement processes for development of 1.5. Public health ethics, public health communications, science so a little bit more in regards to communications and updating some of the processes and types of documentation. So for example, if a health department is using social media, the opportunity to prompt for that, it doesn't necessarily require that represent—of course acknowledging that some health departments are not able to do that, or are not seeing that as a good opportunity quite yet. Public health work force and of course public health informatics, a fast moving area that there's a lot of opportunity to see what the trajectory should be from 1.0 to 1.5 and then beyond. So that the standards can represent something that actually continues to push practice forward, but also stays relevant as the practice evolves and updates over time. The majority of the changes from 1.0 to 1.5 however, I don't think were content oriented and I don't think PHAB
would say that either. They really represented editorial changes for clarity and requests from the field for doing this. In fact, PHAB leadership is the first to say that they came out with this new version much earlier than they had anticipated coming out with updated version. So the editorial changes represent wording language changes that are better understood and respond to some of the questions that they’ve heard from applicants or those looking at this, as well as some additional specificity on time frame. So being very clear. This document needs to be something dated within the last three years. Or this document needs to be something that shows a date within the last five years. That does change from measure to measure. PHAB is planning and this is actually part of their CDC work plan with us, to hold a webinar for tribes. And I think they're actually planning this in partnership with the National Indian Health Board to highlight these changes. And so that will help to raise awareness and answer questions and advance dialogue among tribal organizations, looking at the accreditation program, preparing for accreditation and making sure folks are aware of 1.0 and 1.5 as well as where the future might bring. Now let me talk a little bit about CDC's role in accreditation support. As I've mentioned, we have been since the inception of this work, been co-funding the Public Health Accreditation Board. We continue to provide some funding for PHAB. And that goes for some of the operations but also the continuous improvement and evaluation work. Those of you who are familiar with the accreditation program know that applicant fees are required once you apply to accreditation. That actually covers the site visit, the site visitor, travel, the process of monitoring and working with you for five years. So PHAB has done a very nice job of being very specific of what kind of funding goes to what kind of activities. We also support some different national partner organizations and work to develop national resources for technical assistance and training. And I'm going to highlight some of the resources that are available for tribal organizations when we get to some of the latter slides of this presentation. Because we see that technical assistance and training, educational resources, those types of things that reach populations in aggregate are a real opportunity. The National Public Health Improvement Initiative and the Performance Improvement Managers Network, were going to talk about that in a moment, as well as some of the incentives that we're trying to put into place. So NPHII, we have to make an acronym out of everything, don't we. This is the National Public Health Improvement Initiative. And this has been a cooperative agreement that has come out of OSTLTS, the key areas of emphasis for the NPHII cooperative agreement has been to accelerate public health accreditation readiness. It doesn't require accreditation or an application to PHAB but it accelerates the meeting of the standards and looking at those standards as something that represents what strong public health infrastructure could look like and should look like. And it also supports performance management and quality improvement practices. Through this, we've also established a national network of performance improvement managers. One of the elements of NPHII, of the NPHII cooperative agreement was that each grantee should hire or designate a performance improvement manager. And through that, each of those grantees, those PIMs have new connections through what we refer to as the PIM Network. So through a listserv, through monthly seminars, there's been I think a lot of nice peer learning that has occurred. And that includes between all grantees because we've really seen and learned and observed that every type of grantee can learn from every other. This has been supported through the Affordable Care Act, prevention and public health
and more information can be found on this website. There's a quick map of the NPHII awardees, but I'm going to skip right to this one, which specifies the NPHII tribal grantees. And with that, I want to pause here to see if Harald wants to add a little bit more in about any of these slides on NPHII. He's actually the branch chief that oversees where the NPHII program operations rests.

Harald Pietz: Thank you, Liza. Good afternoon. I think you're covering it very well on the points that we're trying to make. We've looked at it in the four years that we've been putting this together, great outreach to the tribes, to the territories, states and many of the locals. I can't stress enough the good work that's been going on, especially in Alaska, between the state of Alaska and ANTHC to really come together. It really embodies a lot of the work that we're trying to do within NPHII. Cherokee Nations certainly a solid grantee, always there, always helping out, always advancing the cause of tribe within NPHII and the proponents that we're trying to make. Not to mitigate any of the other tribes and their activities, but since we have representatives here today, we'll call them out. And certainly Anita at Navajo Nation, many of the work that's going on is really good. We understand that every one of our states, every one of our locals, every one of our grantees is coming from a different point within accreditation and within performance improvements. So our objective is to advance people from where they are. We want to advance them to a state to which they can be a more efficient, more accountable, more effective health department, being able to use their funds as wisely as they can. As Liza pointed out, NPHII was a non-categorical grant or cooperative agreement that was put out and is used for the health department to be able to address those issues that they've found most pressing within their health department to advance that efficiency and that effectiveness concerning a target categorical programs, but also business, administrative issues. And we've seen large headway and great advances across all of the grantees. We look forward to continuing that and we'll be having a lot more discussion at the grantee meeting coming up in April of this year here in Atlanta. And we won't reserve any further time since we're so pressed for questions at the end.

Liza Corso: Thank you, Harald. One of the other ways that CDC has also been supporting and trying to advance accreditation is by making strategic and programmatic connections. Clearly, CDC does a lot to advance program categorical areas across CDC and out in the field. So one of the keen area of interests has been how do all of those programs and services that we're trying to support, how are they reflected in the PHAB standards and vice versa. How can those PHAB standards help to really advance and provide the right foundation for all the programmatic areas that our health departments are undertaking. So that has been a real area of interest. And we've been doing work across CDC, outreach and engagement to really make sure that there's awareness, that project officers that oversee categorical areas are aware of what PHAB accreditation is, so that when their grantee talks about that, that's something that's recognized and valued. But this is something that PHAB has been interested in too. In fact, we have been holding, and by we, I mean the global we. So PHAB in general has often been the one to convene these think tanks or often expert panels to really look at and explore topics that need a little bit more diving into. I mentioned earlier that informatics was an area that was
advanced and updated in the version 1.5. PHAB actually convened a couple of think tanks around public health informatics. Because the question was we really need people from the field and people who are expert, subject matter experts in this area to identify what are the key expectations of public health departments, where's the field going and what might that mean for the PHAB standards. So we're looking at this with lots of different topic areas. We've also looked at this in regards to expectations in regard to different programmatic areas. This is probably not even an exhaustive list. So I did take the liberty of including examples of, because I was sure I've actually forgot some. So this is examples of programmatic areas where we've been making these kinds of connections. Preparedness. There have been think tanks around public health preparedness that PHAB has convened. We've also done significant work with our office of public health preparedness and response to look at how accreditation crosswalks with the PHEP, public health emergency preparedness capabilities. So those expectations of preparedness grantees, how does that crosswalk and mesh with the expectations of health departments as defined by PHAB. One of the things that we've talked about is what we want to look for, we refer to this as the twofers. Where can you be doing things that will meet multiple are of need, because that's, in a time like this when every organization is resource strapped those kinds of questions are really important. Chronic, maternal and child health. The list goes on and on. I've put some asterisks, you can see next to certain bullets up there, preparedness, immunizations, health care associated infections, the guide to community preventative services, a few others. That's where we have actually been working on tangible, concrete crosswalks. To highlight where there are key connections or you could look at PHAB standards in accordance or in relation to these topic areas or recommendations or other specific standards that come out in other areas. The one that came out, we actually just released a couple of months ago, in the fall, late fall. The guide to community preventive services, a crosswalk with the PHAB standards and guide recommendations. So if you're familiar with the guide, you know these are evidence based recommendations. And so this doesn't necessarily mean this is what you should do to meet a standard. But if you need to be doing work in an area to meet a PHAB standard, that crosswalk could help to point you in a direction of some evidence based recommendation and some interventions that come from the guide and vise versa. If you're doing work in certain topic areas in the guide, you can see where that might fit the work that you need to do to identify documentation for your PHAB accreditation activities.

So let's move into talking a little bit about what work has occurred in collaboration with tribes, both in the past and in the present. First of all, I want to acknowledge that some of this work has been CDC supported, but also there's some work I'm going to be talking about that has been RWJ supported, the Robert Wood Johnson Foundation. We work very much in partnership with them on the accreditation activities and we often try to ensure that we are complementing and synergizing our investments. We obviously do not want redundancies, so in some places they've been able to support certain ideas. In other places, we've been able to advance certain efforts. Going back many years before even accreditation was launched and as it was still in development, the Robert Wood Johnson Foundation did do some work to support a very specific process with the National Indian Health Board around exploring tribal public health accreditation. I mentioned that, even though that was quite a few years ago, because I think that still represents the blueprint and the foundation for so much of what has
continued to occur in regards to the collaboration and the input and how tribal accreditation works, how PHAB approaches this. Using that work, they convened, PHAB did convene a tribal think tank, where they spent some focus time looking at very PHAB specific questions that were related to the development of the PHAB accreditation program. And also, they had a PHAB tribal standards work group. So, a work group very much focused on developing the standards that would either say yes, we think the state or local standards are good for tribes, or we want something a little adjusted here. And here's why and here's the language that reflects, or the examples that reflect the documentation that might come from a tribal organization. The tribal think tank and the tribal standards work group actually represent good examples of where CDC funding has been able to support some of that effort in this area. There, of course, was a beta test process in 2010. Navajo, Cherokee and Keweenaw Bay were three tribal beta test sites. We just talked about NPHII and the performance improvement manager network. One initiative I did not mention quite yet is that through NACCHO, in the past, the National Association of County and City Health Officials, we have been able to get them to use their accreditation support initiative to also support tribal work. And that includes organizations like the Yellow Hawk Tribal Health Center and others that have – the purpose of that is a very small amount of funding has gone to all sites, the number of sites that have been funded local or tribal. But with a small amount of funding in a short period of time, often that can make a nice difference and serve as a good catalyst for accelerating work. There's always an ongoing opportunity for tribal participation in PHAB work groups, committees and think tanks. That's actually one of the points for dialogue I want to bring up. How to best make sure these opportunities are realized and how to make sure PHAB gets names of folks they should be inviting, and that tribal participants or tribal representatives are well aware of these opportunities. The work to advance accreditation is not just limited to accreditation. Both CDC and the Robert Wood Johnson Foundation are doing work that extends into the broader performance improvement and quality improvement arena. And so ensuring that there's tribal participation in these broader initiatives is also important. I know that National Indian Health Board is doing tribal public health accreditation advisory board and has convened that. So I wanted to acknowledge that. And of course, there are a variety of resources to support tribal accreditation readiness that have been developed through the years. I especially commend NIHBI and also Red Star Innovation because I think their websites, and I have this on the next slide, they really do a nice job of calling out some of the very specific tribal webinars, as well as the guidebook and roadmap and other documents, tribal community health assessment guide for example, that really helped to provide the resources that organizations need to meet accreditation standards, and to undertake these activities, but also doing it in a way that addresses the approach that a tribal health department may want to take and the culture. The cultural issues that were working with. So the slide that you see up now has a variety of other websites in addition to NIHBI and Red Star that I mentioned. Our own CDC accreditation website page and of course the PHAB page. The last link that I have up here, I just wanted to also mention the Journal of Public Health Management and Practice. The January/February 2014 issue is a special issue on accreditation, it focuses entirely on accreditation. We use some CDC resources to ensure that it was available open access. So anyone can click on this link and see all of the manuscripts within there. It does include a commentary by Joe
Finkbonner and Aleena Hernandez about advancing accreditation among tribal organizations and there are other commentaries and peer reviewed manuscripts that may be of interest as well. So that concludes the more formal part of the presentation. I wanted to finish by sharing a few questions and opportunities that I thought could spark some of the dialog that we could spend the remainder of our time on. And let me just quickly share this and then we can jump in wherever you may have questions or thoughts. How can we advance awareness and interest in PHAB accreditation among tribal health departments? We know that the motivation or the incentives or even awareness for accreditation among tribal organizations may look different than it does among state and local health departments. And so we would love to hear from you what might be the best opportunities to advance awareness and interest. Are there venues or methods that we can better take advantage of, and by doing that, I'm thinking not just the tribal specific settings, like of course there's meetings such as this, there's conference, tribal conferences, such as the NIHB conference. But then, also how do we ensure that there's a strong tribal presence at, and tribal voice and representation among speakers in even more general settings. Settings that include all types of health departments. Harold mentioned earlier in April, we have our public health improvement training and our NPHII grantee meeting, making sure that discussion and dialogue are aware, and the inclusion of tribes is a very important part of that agenda, not just among the participants but having that be something that is very visible to all. And then the last part I wanted to talk about were some of the opportunities and challenges. I mentioned earlier tribal participation in accreditation opportunities. PHAB is always having a need for representation from all kinds of representatives. But this certainly includes the need for tribal representatives in their think tanks. This year, they are planning for a think tank on preparedness, one on health care and public health integration. And one on accreditation and quality improvement. There are others that will be occurring. Another on chronic disease. So how do we make sure that there are some good tribal representation there. We would love to be able to see if the TAC, the Tribal Advisory Committee, could be used to surface ideas, or we could even just let you know when these opportunities are and you can share ideas directly with that if you would prefer to take CDC out of that process. Site visit, as I mentioned there's a perpetual need for a site visitors and especially tribal site visitors. PHAB has a call for site visitors up on their website, so this is a plea to look at that if this interests you, or if you know if this interests any of your staff. We know that support for accreditation is important. We know that financial support is important. We are the first to be interested in more financial support for accreditation. So I am aware that that's probably an idea that you're thinking of and interested in, so we are always looking for those opportunities. But in the meantime, we also want the best ideas so that they're in our back pocket. So if funding becomes, if and when, I'm going to say when, funding becomes available, in the hopes that there is a when, funding becomes available, we have some very viable ideas that will really help to advance tribal accreditation. And then of course, there's an opportunity for continuous improvement and development of all those different kinds of resources and technical assistance and all the different – advancing these concepts among tribal organizations. So with that, I'm going to stop here and see if there are any questions or if this sparks any comments or thoughts that any of you would like to share. Thank you.
Councilman Chester Antone: Jay Butler?

Dr. Jay Butler: Thank you, Mr. Chairman. I wanted to follow up on your comments about the NPHII program. That's really been a marvelous opportunity for at least four of the organizations represented around the table. I can say for us in Alaska, it provided the opportunity to do the community health assessment and what was really unique was the partnership with the state of Alaska, dovetailing with some earlier activities they had which had absolutely zero tribal input to actually be able to come together as equal partners in that process. Unfortunately, we've also received the letter, as did everybody here that support is ending. So we've done the initial assessment and we're in the process of moving towards implementation but it looks like at least support from CDC is no longer present. I'm sure you've given this some thought. I'm wondering if you can give us any insight into where we should go at this point; should we be encouraging people to find other jobs. Thank you.

Harald Pietz: That's a very good question, Dr. Butler. Dr. Monroe and I were just talking about it before this session and were having conversations with Liza, Dr. Thomas and others. We are seriously looking at how to do this. We're refocusing the grantee meeting to really discuss closeout and the opportunities. We envision the opportunity for a no cost extension to be able to take any unspent funds and roll them forward for perhaps another 12 months for that extension to close out the activities. Given the uncertainty of any funding, I don't see any funding coming in FY'14, that is going to support NPHII or an accreditation like an opportunity. It's a very real question and I think every PIM, every PI, everybody that's funded or supported through the NPHII grant has to look at their own individual situation and see what's there, see if there are other opportunities. For those that receive other federal grants from CDC, there is an allowable use of some of that funding if it is one of the new FOAs that's been released in the last year or two, to use some of that money towards accreditation. And certainly those would support that kind of performance improvement aligned with NPHII. We are, everyday, looking at opportunities to see how we can find additional funding and where we can partner with potential funders to be able to support that. It's unfortunate that we're right here in year four making huge strides, everybody is picking up and going out and didn't really see this one coming. Really hoping to get through year five and go out with a big bang. We currently have proposals being drafted for FY'16 and FY'15 to put into the budget to continue these things, but they're uncertain until the budget is actually signed.

Liza Corso: Can I just pick up, explain what, because I realize I did not mention the FOA piece that Harald just alluded to. Since October of 2012, CDC has started using a standardized FOA template and guidance, so that any new FOA, funding opportunity announcement, I'm sorry, funding opportunity announcement that comes out from CDC, which once looked very different from program to program, now has a far more standard look and set of expectations, look and feel to it. Within that standardized template, and within that standardized guidance, there is now language that is since 2012, language that allows in the budget narrative section, language that allows for inclusion of budget items that advance work towards accreditation.
standards and it specifically cites PHAB, the Public Health Accreditation Board accreditation standards, as long as it’s in the spirit and the intent of the FOA. And so this isn't trying to take money away from categorical programs. This is recognizing that so much of what accreditation is about is in alignment and very synergistic with the expectations and the needs of all of the categorical programs. So those new FOAs that you may have been seeing since that time should have that language. What we can do after this point is provide an example of that so that that can go out in a note so you could see an example FOA and see what that looks like, if that's of interest to this group.

Dr. Harald Pietz: If I may, so one of the things we'll be coming back to all the grantees and explicitly reaching out to the tribes, are we are gathering every success story we can get and we are trying very hard to pull all the NPHII successes together so that we don't lose – we mitigate the loss of momentum, that we're going to get with an early kind of shutdown. But we want to make sure that the literature is there, so that when we get another swing at this, we can hit it and we can start, much farther field and I think we've got a good base and we want to get into multiple bases in the next go round. So please, work with your staff back there when we reach out to them and start asking for additional stories, we're just looking for really meaty, I mean Dr. Butler, you get it, right? So what we're trying to get out of this, those are the things we're going to be collecting, putting out and disseminating in every venue that we can, and we encourage to take your own stories and put them out for the population and the whole nation to be able to read those and see the successes from every perspective.

Lisa Pivec: Thank you, Chairman Antone. Lisa Pivec, authorized representative from Oklahoma. I don't have a question, more just comments. I know that the news came as very unpleasant news to all 73, I believe, grantees. But I think that it's important to recognize that tribal grantees are very unique in this sense. While most start and local health departments were using this for quality improvement or solely accreditation we were using it to build infrastructure that does not exist. And CDC of all agencies, should understand that the development of those domains enhances every single program and every bit of funding that CDC puts into Indian Country. Our programs are more effective when we have that infrastructure in place. And I've been the PI for numerous cooperative agreements over the years, and as this came into play, I clearly see how we could have multiplied the successes from past funding opportunities had we had this infrastructure in place. So I'm hoping that this infrastructure continues to be developed and that CDC will pass on the unique message from tribes in how they differ with this funding from local and state health departments. And building this infrastructure, whether we do it internally or we satisfy it through partnerships, it's extremely important for us and for the CDC so that your investments are done in a way that are going to impact Indian people and the people of the communities. Thank you.

Councilman Chester Antone: Mr. Rex Lee Jim.

Vice President Rex Lee Jim: Thank you. Two issues. One is what you're doing in terms of capacity building for long term sustainability of these departments of public health. Two is what
are you doing in terms of allowing travel participation in state accreditation processes under STAC with this tribal state relationships. We’re interested in improving relationship so if some tribes do not have the capacity or desire to have their own public health institutions, how are you helping them with states? In Navajo, we are pursuing our own accreditation, but at the same time, we still would like to have a say in how Arizona, New Mexico and Utah develop theirs.

Liza Corso: Absolutely. Thank you. Those are two very good questions. My understanding of your first question was what are you doing to build the long term sustainability of—I think in essence, the whole concept behind accreditation is that it is something that is intended to build long term sustainability of public health departments in a way not tied to a specific funding program or a cooperative agreement, but by achievement of accreditation and by standards that then their policy makers, elected officials or leaders will expect, brings a level of stability and sustainability even in tough times. We have heard from state and local health officials that during past years when budgets were extremely tight, that they were seeing other fellow leaders for other agencies in the state or local system be exempted from a new round of budget cuts because it would then impact their accreditation status; so the standards that they need to meet. Public health hasn't had that opportunity up until now. And so PHAB accreditation may actually bring a level of protection and stability to what can be expected of state, tribal, local, territorial health departments in a new way. With that said, there's no one place that we're looking for the long term sustainability in regards to building it. It has come from NPHII. We are also looking for it from investments from different categorical areas in regards to this new allowance with our funding opportunity. Many local health departments and state health departments have been doing this work without really acknowledging exactly what kind of cooperative agreement or funding it comes from. So I think it's something that isn't necessarily seen as tied to a specific funding area. For that reason, the incentives that come from CDC, both for preparing for accreditation as well as longer, down the road, once you have accreditation, what does accreditation mean, is it expected? Those are very important. So we've also been looking at incentives. It would be wonderful to hear from you, maybe not now, or in a future meeting, the kinds of incentives that you think would be especially compelling for tribal organizations.

Vice President Rex Lee Jim: I was thinking in terms of the human resource development.

Liza Corso: Yes, workforce.

Vice President Rex lee Jim: So that when the funding runs out, then the people will be there to continue to run…Mm-hmm.

Dr. Harald Pietz: So just to add on to that, there are a couple of things. So certainly NPHII was not the beginning of performance improvement within public health. It's certainly built on the shoulders and giants that were running before us. But we do however, within my branch, provide technical assistance to health departments that are seeking information or technical
assistance around accreditation or any of the prerequisites for community health assessments, health improvement plans and strategic planning. We also work with our partners, and those resources are certainly available and adaptable to particular situations irrespective of the jurisdiction or the locality the individual is coming from. In no small part, with the four years that we have been able to advance NPHII through many of the partners, we hope for those that were directly funded, have learned, have benefited from the TA to understand quality improvement and performance management and may be able to sustain some of that work to offset some of the grants that they may no longer be getting. So we've seen efficiencies and effectiveness in processes that have done a return on investment in different areas and we hope that this ground work that has been laid can be continued and that eventually, NPHII was a five year initiative, we certainly hope for an addition to that and we're still working on those angles but there's hopefully enough penetration that occurred in those four years that people will be able to sustain the workforce improvement and the training around quality improvement that went in. It certainly does not replace the amount of funding that was going out. We had about $10 million go out over four years to the tribes. We'd like to continue that obviously or even expand upon that but we have to plan and all grantees need to be able to plan for sustaining it within their infrastructure because it is unfortunately very surprising but it is one of the few times I've ever seen where it actually said subject to the funding availability, and I've never run into that issue in running a grant program, we actually didn't have that funding that year. So it certainly disappointed all of us. But I looked from the committee here and from all the members outside, whether they're grantees or not, to be able to, what can we do to help you. Our resources are there to be consumed by anybody. They are publicly available. Liza Corso: I want to go back to your second question, Vice President Jim about the state and tribal interaction and the role that tribal organizations, or tribal representatives can play in state health departments that might be looking at accreditation and vice versa. In quite a few areas throughout the PHAB standards, there's a lot of attention to collaboration and interaction between, with partners, between other organizations that might be representing populations that are part of that area or adjacent to. And it's, highly expected in regards to thinking about the documentation that a health department might be looking at and submitting to the public health accreditation board, that they would be looking at the organizations that they're collaborating with. And you just mentioned the Navajo, New Mexico and Arizona. I mean ideally a strong application from New Mexico and Arizona would include some examples of the collaboration with the Navajo Nation. That would certainly be something that they would have to describe as part of describing their state population. The other organizations that provide public health within that organization. PHAB is the accrediting body, so I don't want to get into too much of what they would be looking for as the accrediting body. That's a very different role that we play from CDC. But I think what's in the standards is prompting in the right direction. But this is also why we're really interested in making sure there are very good and diverse perspectives as site visitors. And representation on think tanks and committees is the way to really make sure that the program exists and continues to be improved in the way that best supports and advances the field in the right way.
Councilman Chester Antone: Tim?

Tim Gilbert: Thank you, Mr. Chair. I wanted to throw our vote into the notion of finding that continued funding for the NPHII funding. Obviously, we're in the Portland area, the Yellowhawk Tribal Health Center has been pursuing accreditation for the last couple of years and—it's ironic, last week we presented our community health improvement plan and our strategic plan that was based on our community assessment to our governing board. And I mean it took months. And we wouldn't have been able to get as far as we did without some level of support from the Portland Health Board, which benefited from those resources. So if you could find a way to continue that, we benefited a great deal from that. We'll keep forging on if it's there or not, but just wanted to advocate for that. I guess I also wanted to state that you had a question up there about how we can advance awareness. And I don't know if you've been out to our neck of the woods, or maybe to some of the other grantee sites but what I've experienced when we start to talk about public health accreditation in a community meaning or with our governing board, which is a lay board of members of our community, we're competing with the notion that we're trying to recruit a dentist and we're trying to provide primary care and we're down to two providers and we have such significant disparities in behavioral health and alcohol and drug that you literally are competing with at least half a dozen other things for their attention about why this is important. So I don't know, I don't have an answer for that, but it's been my experience maybe we need to train the people on the ground and on the front line about how to advocate for the benefits of accreditation. But that always seems to be a barrier. How do we get people excited when we have five other things that they think are more important ahead of it in line. The last thing I'd say, for the folks who make decisions about whether something is funded or not, it's also been my experience that it can be eye opening to come out and make a site visit and see what kind of capacity there is. I mean physical capacity and human resource capacity, look at the community, just to get a feel for what the difference is between maybe tribal public health accreditation and what might be state department of public health. I don't want to be a crybaby here, but if the state department of public health accreditation starting point is here, ours is probably somewhere back here, just for where we are and what we do and the whole breadth of services we have to provide. Okay, I'm being a crybaby. But we're just at a different starting point and we had to catch up but we really appreciated the resources that came through that funding. And one last plug. When we also started, we received funds from NACCHO, I want to call it.

Liza Corso: Yes. That's the accreditation support initiative that I mentioned.

Tim Gilbert: Right. And we had to pick some things to work on and one of the things that we chose was our understanding between tribal code and state and federal public health law; a really fascinating area, and just a plug for the CDC, we had folks from CDC, attorneys that really enlightened us on that topic, which can really be complicated. But we've been appreciative of the support all along. So thanks.
Liza Corso: Those are excellent points. Thank you for sharing those comments. Certainly don’t think we could say and echo any more than you’ve said already the support for NPHII and how important that’s been, and I think your comment in fact reinforces the fact that especially with tribal organizations that NPHII support has been felt beyond the direct grantees so much more in the tribal community than for any other grantee, any other type of grantee when you think about the many different Alaska Native Tribal Health Consortium, for example, how many different tribes you’re reaching in Northwest Portland 40-something—

Tim Gilbert: Forty-three.

Liza Corso: Forty-three that are in that area. I do want to mention to you, it’s not CDC but it’s the public health accreditation board, it does speak to ensuring that the organizations you’re working with are well aware of the unique nature and the challenges faced by tribal organizations. PHAB or at Joe Finkbonner is one step ahead of you in that there’s going to be a public health accreditation board of directors meeting this summer in Portland and Joe is already planing to see how he can make use of that so that the board can get some interaction and awareness in regards to that area. So you may hear more about that directly from him. And then you also mentioned the fact that we all need to be—everyone in the field, at CDC, we all need to do a good job about describing the needs for accreditation in a compelling way, and in a way that competes effectively with things that are often seen as much more concrete and tangible. I think that’s a challenge that we face on a daily basis and we will continue to be working on that especially with our communications staff. Thank you.

Councilman Chester Antone: We have two presenters here and we’re kind of running over time so I’ll go ahead and entertain you and then we’ll take a very short break and then we’ll continue.

Lisa Pivec: Mine will be quick, I promise. Just a practical suggestion. I realize that you are not the public health accreditation board but in consulting and providing feedback to them one of the things that I think would help tribes nationally is that if health disparities were better well addressed in the PHAB standards or more articulated as to how you were addressing those as a state or local health department and proving how that you were addressing populations such as American Indian communities. Thanks.

Liza Corso: And I do wonder if the improvements that have been made in version 1.5 addressing health equity really got at some of those health disparities issues. I think they also recognize they didn’t go as far as they could have, there’s a bit of a trajectory there, that’s something that’s going to continue to be pushed and changed over time, and I think the tribal voice in those discussions and those continual updates will be very, very important.

Councilman Chester Antone: Thank you for your presentation and we’ll take a ten minute break and then go right into the other two presentations.

“This document represents meeting minutes of the CDC/ATSDR Tribal Advisory Committee Meeting and 10th Biannual Tribal Consultation Session and does not necessarily represent Centers for Disease Control and Prevention views or policy. This document is intended for your use only, please do not forward”.
Liza Corso: Thank you very much.

Councilman Chester Antone: David Espey, we’re ready to begin the presentation and I’d just like to say that we’re kind of behind schedule now so we do have our five o’clock time to wind down so I’m going to turn it over to Ursula.

Dr. Ursula Bauer: Hi. Good afternoon. Hopefully you can hear me. So my name is Ursula Bauer and I’m the Director at the National Center for Chronic Disease Prevention and Health Promotion here at CDC and I’m delighted to be with you. Thank you for inviting me to provide an update. Since we last spoke, we have had a similar conversation over a number of years. I know that the personnel around the table do change so I’m eager to be with you again today. I thought what might be most helpful for our conversation this afternoon is to talk about our fiscal year 14 budget and how that has changed, particularly with regard to what’s of interest in Indian country. We fared fairly well in fiscal year 14 but our budget was completely turned upside down so there are a lot of changes that we will be undertaking this year and that affects many of our grantees including those in Indian country. So just as a refresher, the chronic disease center includes the agency’s activities around the leading causes of death, heart disease and stroke, cancer, diabetes, the leading actual causes of death, the key risk factors, tobacco use, alcohol use, poor nutrition, physical inactivity, and then oral health, reproductive health. So we focus on those leading actual causes of death and risk factors and one of the approaches we’ve taken to improving health over the last 10 or 15 years has been a community health approach where we invest in cross sectoral programs that really can bring together resources and opportunities and leadership from health, from education, from transportation, the local hospital, the local school, a whole range of sectors within a community and bring resources to bear on a particular problem, and I think you’re most familiar with that approach from our funding through the community transformation grants. And unfortunately, the community transformation grants which was a $146 million program that started in fiscal year 11 is one of the big changes in our budget. That program has been zeroed out by congress so this is the third year of what should have been a five year funding opportunity and that program will end at the end of the current project year. So that’s bad news for a whole number of grantees including seven awardees in Indian country. While we lost those dollars for the community transformation grants, those dollars have reappeared in our budget in our lines for diabetes and our line for heart disease and stroke prevention with the instruction, with the guidance from congress that we deploy those dollars toward primary prevention of diabetes and heart disease and stroke, and that we do that primarily through our state health department grant programs. We have an existing grant program that addresses heart disease and diabetes with state health departments. However, we see those dollars as a real opportunity to really grow and strengthen a coordinated and multifaceted chronic disease prevention program in Indian country that could over time and with some strategic advocacy really blossom into a full fledged chronic disease prevention program. So we are in the initial stages of congealing our thinking about what that kind of grant program might look like and I am fortunate to have the opportunity to talk with you about it this afternoon as well as to have

“This document represents meeting minutes of the CDC/ATSDR Tribal Advisory Committee Meeting and 10th Biannual Tribal Consultation Session and does not necessarily represent Centers for Disease Control and Prevention views or policy. This document is intended for your use only, please do not forward”.
had the opportunity to meet with many of you informally or formally as well as in previous years here with the TAC to get your best thinking about what such a program might look like. I now see an opportunity to begin such a program in the current fiscal year. So that’s one area of discussion that I’d really like to have your input on while we have some time together this afternoon. In terms of the multiple changes to our budget we also will have some additional funding opportunities that you all will be interested in. One is a new community prevention program. You might ask the wisdom eliminating one community program and starting a new program. I can’t really help you with that but that’s the reality that we’re in so we did receive $80 million from congress to begin a new community program with instruction that we pay special attention to local community work and tribes in particular were mentioned as potential grantees so you should look for that funding opportunity announcement coming out later this spring. I want to save time for the discussion that I just teed up so I’ll just give you one last announcement before we move into that, and that is from our tobacco control work. I’m sure that you are very familiar with our Tips From Former Smokers campaign that launched in 2012 and has been running in 13 and now has just launched again in 2014. This has been a very successful program that has helped hundreds of thousands of smoker quit smoking. I had the honor very recently to present the U.S. Surgeon General’s Medallion to Nathan Moose, Oglala Sioux who was a participant in that 2012 campaign. He shared his story with the nation and he passed from his secondhand smoke-related lung disease back in October. Nathan was not a smoker himself but he did work for many years in a smoke-filled casino and suffered lung damage and passed away at the age of 54 last October, and I was able to confer the Surgeon General’s Medallion to his wife, Jean Anne Nespers for his dedicated and exemplary contribution to public health. So with that memory of Nathan, I’d love to hear from you about opportunities and your needs with regard to effective approaches to invest in grant programs in Indian country particularly around primary prevention of diabetes and heart disease and stroke.

Councilman Chester Antone: Questions or comments? Mr. Gilbert?

Tim Gilbert: Thank you, Mr. Chair. Nice to see you Dr. Bauer, Dr. Espey. I wonder if you could, on that last point where you’re trying to get some dialogue, can you maybe—I have a vision in my head about what primary prevention means but is there a CDC definition we should be paying attention to?

Dr. Ursula Bauer: Sure. So in terms of heart disease and stroke and diabetes prevention, we think mainly about diet, physical activity and tobacco use prevention. As I’ve talked with many of you and visited a number of reservations and visited with tribes, I’ve been intrigued by how a number have really been able to organize your chronic disease portfolio around healthy communities and healthy foods. Our traditional foods program in particular I think has been a catalyst for a lot of thinking. How to limit access to unhealthy foods and beverages, create smoke-free environments. So I imagine, although we have discussion before we put pen to paper in terms of the congealing of our thinking we’re looking at how can we deploy across the nation some kind of model that has the opportunity to really grow and flourish. So these might be smaller grants, see grants initially where we could build some success and demonstrate
impact and build the program, receive additional dollars in the future. But we need to focus in on sort of the core behaviors in environments that are causing the diseases. So would like to hear how we could best support tribes in doing that.

Councilman Chester Antone: Cathy?

Director Cathy Abramson: I was going to give some input earlier anyway and you’ll hear me say this over and over again when it comes to diabetes, stroke, and heart disease. Back at home, and I know many different places at a national level and I talk to a lot of tribal leaders and they give the message to as many people as they can that we want to use our own ways of getting back to being healthy again and that would include going out and hunting, fishing, gathering and that’s growing our foods and like we would go fishing, we would be able to take your family out and that’s what we still do; families together with good clean water, and you get exercise by going outside and you’re picking the blueberries and strawberries that have all these whatever it is they have that’s good for you. I don’t know all the names of it but it’s—and then you’re out amongst the—it dawned on me when I went picking medicines for our healers, I went to go look for St. John’s Wart which is for depression and it’s all over the place and you’re looking for this cancer medicine and that’s all there, too. So you’re out in the woods where all of this medicine is and it has to be good for you, you must be getting it all in there and it’s keeping you healthy, you’re gathering your food, you’re getting your exercise and you’re breathing in the medicines that keep you happy and healthy, not depressed, the St. John’s Wart. So those are the types of things that we have to get back to. So those are the types of things that we’ve got to keep teaching our children and our grandchildren. So things like that. Thank you. I do have a question though. The community transformation grants, they’re being zeroed out. When are they going to be done? At the end of 2014?

Dr. Ursula Bauer: So the grants are in their third year. The third year of funding began at the end of September 2013. So there was a full year of funding so that will bring grantees through the end of September 2014.

Director Cathy Abramson: Okay.

Dr. Ursula Bauer: I wonder if I could ask a couple of questions as we think about ways to disseminate awards to tribes. There are a lot of tribes, I’ve heard loudly and clearly, that disseminating dollars through state health departments is not a preferred mode of distribution. But we struggle with our ability to reach many tribes given the number and I’m wondering about different national or regional organizations that might be helpful for distributing awards such as the National Indian Health Board, the Regional Health boards, the Tribal Epi Centers, a number of national American Indian Alaska Native organizations. Are those vehicles that work well or is there a stronger preference for a direct tribal award or does it vary depending on the size and the capacity of the tribe?
Chairman Herman Honanie: Well, I was just going to comment somewhat along the lines of what the young lady talked about, getting back to traditions. I can’t help but recall when I was a young lad maybe when I was 12 or 13 and we had a huge village meeting and there was just some various discussions and I remember my grandfather was there and he spoke quite a bit about the changes, about how life was beginning to change from what they lived, and they also had an idea on how life was going to be. And one of the things he remarked on was there’s going to be a time when we will not be able to control our kids. I had no idea what that meant. I had no idea what that meant until I became a grandfather. And now that vision, philosophy, prophecy is so really true and along the way we’ve endured so many experiences and when we talk about health that’s very key to what he said is that we cannot control ourselves, we have not been able to convince and persuade each other that eating the right foods is the best thing, clinging to traditional practices is what we ought to do and so on. So all the good things we just kind of put to the wayside. But we’d rather engage in a sedentary lifestyle, junk food and foods of that type, and now here we are, we’re kind of going full circle saying, hey, I guess our forefathers or grandfathers were right about what they had to say, we just didn’t listen. We missed the boat ourselves and so here we are struggling and scurrying and trying to do—what can we do to improve our health? Is it too late? What should we do and now what do we do, where are we at? It’s still a struggle, it’s still an uphill battle to try to convince and persuade our young children, our younger people that the traditional viewpoints, traditional practices is a key to good health. So I think that’s where we’re at. We just have to keep moving on, we just have to keep practicing and doing everything we can within the family, within the clan, within the community and across the villages and across the reservation. I think it’s beginning to happen and one of the best things I think that happened, which is I call it a plus out of so many negatives, is the Facebook, social media. I get on Facebook every morning—well, maybe not every morning…four mornings out of five, which is okay, you know, and I post when I’m gonna walk, when I’m gonna jog, and I usually do it at 4:30, 5:00 in the morning. The temperature is this, conditions were this. And I encourage people. I try to do that. I’m the chairman of the tribe and I have a lot of followers or readers and they say, wow, thank you for that. But I’m hoping if we can be able to get everybody out there on the Hopi Reservation, if anything, walking and taking a look at their health and controlling their health and everything else, maybe we’ll get on the road to being a little bit more healthier than we are today. But that has to start someplace and I just say to my people, do it. Then hopefully we’ll get something going. But that’s really what I feel and so I constantly harp on my tribal council leaders and say, go out to the gym or go out in the trails everyday or if not everyday, every other day. We have got to be the ones to set the example and we’ve got to go out to the centers like Head Start, the daycare centers, the elementary schools, and high schools. We’ve got to be the ones to talk to them about what we’ve learned as older adults, as older Hopies and we have a whole lot of knowledge, and that’s what we need to impart on our young people. I guess I was just fortunate enough to be able to realize that and understand that, so it really has a lot of meaning and I take that to heart. A couple of weeks ago my family, my wife, my daughter, my three sons, and my two grandsons, we all ran in the Phoenix Marathon and boom, hit the waves on Hopi Reservation and I got nothing but positive remarks. And I said, it can be done. We just have to put our time to it, we just have to put our learning to it, we have to put our
knowledge to it and really give credit to our elders. We’re losing so many of them, we’re losing so much of that knowledge, we’re losing so much of the ability to do that and some of us are considered young, we have to step up to the plate and we have to be the one to guess maybe re-implement or continue or sustain that practice and knowledge we’ve been given. So that’s why I say it’s very, very important that we continue to educate our people. That’s just one part of it. There are programs right now being put on by the health programs and so forth and I try to support them as much as I can. I try to be out there as many times as I can, but people need to realize and embrace those things that it’s for the good because I look at diabetes for one. We missed the boat on diabetes. What happened? Why are we just so—why are so many people diabetic? Then we have heart disease, then we have stroke, and on and on and on. What has happened to the Indian people? I think we just have to fault ourselves for not being able to keep up with our traditions. I think we owe ourselves a great deal of responsibility to—we must become responsible, we have to assume responsibility and get to where our ancestors came from and what they taught us. We just need to wake up and get on that road. That’s all. Thank you.

Dr. Ursula Bauer: Thank you very much. I wonder if there’s a way that CDC, through our grant program, could help ignite that kind of activity or accelerate the uptake of those behaviors. Is there a role for CDC in providing resources that might accelerate that progress.

Councilman Chester Antone: Mr. Jim and then Cathy.

Vice President Rex Lee Jim: Thank you. The Navajo nation prefers, as much as possible, direct funding. And to us it’s more than funding. It’s a government-to-government relationship; this federal government to the tribes are based on treaties. And those treaties don’t say we’re going to subject you to states or non profit organizations. It’s a direct relationship. So when you give funding to the states and then bring it back, you’re subjecting us to another sovereign jurisdiction. That’s what we don’t appreciate. So it’s best to do direct funding as much as possible. That’s one. The other, and just in conversation, in Navajo they say when our kids become the enemy, and sometimes well educated Navajo homes mean good but they’re conditioned into the western thought that the western way is the only way and the best way. So our own kids are coming back telling us we have traditions and now this thing in the past doesn’t work anymore and we have to move on. And those who also talk about Navajo traditions, sit there and say, oh, that’s coming out of such-and-such anthropologist’s work so they’re leading their culture through anthropological work and then imposing that on themselves and on others. So work used to be done there in terms of—so it really comes back down to traditional people, the ways of life and how do we engage our own young people in those activities.

Vice President Rex Lee Jim: I agree with him, Chairman Honanie. It’s a very simple thing. They are very simple things. I think sometimes we focus too much on money. We think that things happen, that there will be positive results only if we have money. Sometimes I ask myself what can I do that will not cost money? And one of the things that we’ve been doing is
using students. We have what’s called Food Literacy Program, using several Navajo schools, high school students that do research on food stories, family recipes and they analyze it whether it’s a good recipe or not for the nutritional values. And that whole thing mushroomed into the study of food policies on the international to the local level, food economy, food desserts and how it leads to diabetes and obesity and other chronic illnesses, and they write about these and then they present them at different conferences. The latest one they presented at the National Consult Teachers of English. So they end up with having all these professionals, administrators and teachers and then they use social media, talking about Facebook to inform others so that’s something that students, are already there, we don’t pay them to be students, they have English classes, they have access to computers and just need to put a program together. I think CDC could somehow invest at that level because our students are intelligent. If you use their academic skills and knowledge of content areas and focus that to problem solving, how do you address obesity, how do you educate the community about public health and about food and nutrition and exercise and so on, yearly check ups and all these things and use students and their influence on the families, we know a lot of these children are running the families in Indian country, so you might as well tap into them and use them and allow our students to introduce healthy food items to their family and keep journals on what it does. So those are the kinds of activities that we could be doing. The other thing I’d like to do is I would sit with the behavioral health traditional practitioners or spiritual practitioners, preachers, priests, medicine people, NSE people and sit down with them and say here’s the problems we are having, I need your help, you guys have congregations and ceremonial gatherings over weekends and evenings and that’s the best time for you to talk about food, about exercise, put them apart of your prayers. Those are things that don’t cost anything. They are already in existence and we could tap into them and the influence they have. So I’ve been doing a lot of thinking about what are some things that’s already there in existence that I don’t need extra money for, just to sit down and convince them and talk to them. Those are the things that we’ve been doing and we need to do more of that. So the other thing, I think there was a saying that says something like keys to success are very simple steps but we forget those simple steps because they are so simple. Just like walking and running in the morning. That’s what we need to do. So the other thing we’re doing on April 5th is what’s called Talking Things Through. We’re going to have a summit on negotiation, difficult conversations, conflict resolutions and all of that kind of stuff, and one of the main reasons why we’re doing that is we want to re-teach people how to talk things through. When you talk about chronic disease, when your father is diagnosed with terminal cancer, how do you talk about that in the family so that the children do not get depressed and then turn to alcohol and drug abuse and domestic violence. So those are some of the issues we’re dealing with and I think that’s important. CDC would also fund some of those areas, it’s not directly—well, it is directly related but it’s not a disease thing but when you talk about it, you can solve a lot of other issues as well. So those are some of the activities that we’re doing and we’re working with the Harvard Negotiation Project to put some courses together for elementary, junior high, high school and college and then a modified version to be taught at senior citizen centers and non profit organizations, youth organizations and churches and different places so that we really hit every area. And when you talk about education and outreach, I think that would do a lot of
good, especially during those difficult conversations dealing with chronic diseases and how families can respond when it hits them. And I just wanted to share that with you when you talk about asking us where can CDC invest in. I think these are some areas that you can invest in especially with the younger generation because they can do so much. Thank you.

Director Cathy Abramson: Well, there are a number of things that CDC can do with drugs. I don’t believe that going through a state would be helpful. I know it would be, and every one of us in here know it wouldn’t be. We’ve been fighting against that for years and years. It hasn’t helped us any way we tried. So it hasn’t helped us for years so it’s not going to change. We’re here and we’re telling you ways that funding can help us. There is a group of us here that we’ve given you ideas—our traditional ways are out there where I believe helping us to record them, to tell our stories and tell our ancestors’ stories on how we do things or used to do things and I think that’s very valuable for our youth and those to come because I do believe there will come a time in their lives that they will come around and listen and it’s gonna be good for them to have. I know you guys are great runners but I challenge you all to a snowshoe race any day, or maybe a canoe race in the summer time. But there’s many things that we could do with funding that would help our people to get healthier. So to bring that along. But going through the state, No-does not help at all. So thank you.

Councilman Chester Antone: Is there anyone else, Mr. Gilbert?

Tim Gilbert: From the Confederated Tribes of the Umatilla Indian Reservation, we are constantly trying to figure out how to integrate what they call fresh foods and what you’ve heard from other folks around here which are traditional foods into wellness activities. So to your question about what might be good use of these monies or good ideas for primary prevention, etc., we just have struggled with angles from a public health perspective. We think of it one way, the people who are trying to push us to do more foods activities. Our tribal leadership saw it a different way and we haven’t figured out where the two met yet, but we know it’s big and we know it needs more attention. So that’s one thought. The second one I was just going to mention quickly is I was intrigued by what you were sharing with us from Nathan Moose’s story. We last week presented our last year’s report to what’s equivalent of our tribal council and part of that was a report on chronic disease and what we’re doing with that, and for that group, if you would have been speaking to them two years ago. We brought up the idea of second hand smoke in the casino, Umatilla the gaming tribe, and do a little quiz here with you. When we brought it up two years ago and we suggested that it might be a good initiative to think about in the interest of tribal members’ health, anybody who walks into the casino, what would be your thought on why they would push back on that notion?

Dr. Ursula Bauer: Well, the counter argument we always hear is that we’d lose revenue.

Tim Gilbert: That’s interesting. That was number two. The first response surprised me and that was the response we’re a sovereign nation and the state has come to us and said that we need to do this and we’re not doing it because if we do it, we’re gonna choose to do it. And
then this past week when we shared—we have a new board and you can see the kind of the shift in thinking about smoking as a risk factor and its contribution to health. They started to get into that discussion again and they inched more towards it being a viable idea. I guess I’m putting it out there. It really is our number one risk factor for our top two leading causes of death. So we have a smoking casino. We don’t have a smoking policy in our housing for tribal members, just to give you a flavor of what we’re up against. So that would be my second area if I was to choose where we would value some resources on how to move the dot on smoking whether it’s second hand or actual smoking. Thanks.

Dr. Ursula Bauer: Thank you.

Councilman Chester Antone: If there’s no one else, I just want to make a few remarks. Tohono O’odham Nation and we have the Tohono O’odham Nation community action program. Currently, they have two farms where they raise traditional crops and serve it in the Desert Rain Café among other traditional foods. We also have gardening in schools. The project is starting now because we recognize that a lot of the traditional foods have an impact on diabetes. We have 19.9% prevalence rate on the Tohono O’odham Nation. That has not moved for the past two years so we must be doing something right but we don’t know what that is. I think it’s a combination of traditional foods and exercise because the HOP program which is the Health O’odham Program gets into the elder centers. We have a number of them on the reservation and they provide exercise instruction, chair volleyball, chair exercises, but they do it. We also have facilities in about six or seven communities and so that part of it, I think, contributes to that percentage where it’s staying there and we need to know. We’re very good about keeping track of our prevalence rate but we’re not very good at finding out why it stays there, and I think that’s one of the ways in which grants could work because I think if we can bring ours down, then certainly CDC is going to become aware of how it was done, then it transfers over to other tribes. We use the tribal grapevine and things are becoming known pretty quickly. They don’t come in big reports, it’s by word of mouth. So if one tribe succeeds at a certain thing, automatically that word goes out not to CDC but amongst tribes. So I would take a look at that. Unfortunately, or fortunately, I’m not too sure yet, if the IHS data shows 24% now but it’s along with the Tohono O’odham Nation so we have to figure that out. So we’ve been successful I would say at keeping it at that level and we just need to know what combination of efforts contributed to that because then that can be used by other tribal nation’s best practices or appropriate practices as Mr. Jim says. And I just wanted to relay that. I also particularly like the Hopies approach because if you’re an elected official and people know you as such, what you do—if they might emulate that or want to do that, then that also impacts the disease. So I wanted to share that much. I believe that all the people I had were wanting to address this issue, but I also wanted to ask you, are we going into colorectal? Okay, that was part of it so I wanted to make sure when we can go into that.

Dr. Ursula Bauer: Thank you very much.
Dr. David Espey: Thank you very much. My name is David Espey and I’m the Acting Director of the Cancer Division here at CDC and my previous position and my position after this acting position is in the field in Albuquerque working with a team focusing on cancer prevention and some other issues. I would like to make a couple of comments before I launch into my colorectal talk and one is that all of the risk factors that you just talked about in the context of diabetes and heart disease and stroke are the very same leading preventable risk factors for cancer. So by making some progress on those fronts, you would certainly make some important end roads for cancer. Another is to urge the committee to consider and give us feedback about your feelings about the funding mechanisms because that’s a real struggle for us to partner with tribes. How do we overcome some of the administrative hurdles for getting funding out into the field? And then a third, I just found out a very moving testimony about your marathon and your practices in your tribe, and I agree with you I think there’s some modeling there that could be very important and potentially tapped in the context of this discussion. I was very impressed with that. So with that said, I’m going to cover two groupings of activities. One is the Colorectal Cancer Control Program that is supported directly out of CDC here in Atlanta, and then there’s the team I mentioned in Albuquerque with CDC funding coordinates several other colorectal cancer programs in the Southwest, Alaska and Northern Plains so I’d like to break the talk down into those two groupings of activities. But before I do, I thought it would be useful to set the stage a little bit as to why it’s important. I know someone or the committee wanted to hear about this but I think it’s a very timely topic, and the next couple of slides kind of lay out the case why it’s an important issue and this is a graph that shows the incidence, which is a measure based on cases of cancer diagnosed in American Indians, Alaska Natives compared to non Hispanic whites in a group of counties called Chisda Counties which are counties where tribal NIH program provide contract health services and where we believe we get more accurate information. And if you go all the way to the right where it says U.S. under the bottom, those are all regions combined and you can see the blue bar which is the AIAN rate compared to the green bar which is the non Hispanic white, about 20% higher, and this is all regions combined. But the story is really in the bars to the left of that, particularly the far left where you can see the Alaska incidence rate over twice that of the non Hispanic white rate, and important differences also in the northern plains and the southern plains. So the big discrepancies, and then the lowest rates are in the Southwest. And these are a similar graph with the mortality rates which are measured based on deaths from colorectal cancer using the same time period, the same Chisda groupings of counties, and again if you go all the way to the right, you can see about a 25% greater mortality or death rate from colorectal cancer in AIAN compared to non Hispanic white with a similar distribution, Alaska way in the lead. Alaska natives have some of the highest rates of colorectal cancer in the world and similar patterns in the northern plains and southern plains. And then finally in terms of graphs these are two sets of bars that show you the percentage of AIAN and non Hispanic white, they are diagnosed at early stage and late stage. And you can see that early is green and late is orange or brown, and the lower the orange the better and the higher the green the better and you can see pretty clearly just by glancing at this graph that there’s a big difference in the percentage of AIAN that are diagnosed at early and late stages compared to non Hispanic white. So that sort of sets the stage as to why I think it’s an important topic for the committee
and it’s also an important topic for us as a priority for the AIAN community to be talking about and trying to increase our delivery of colorectal cancer screening services. So the first part I’ll talk and give you sort of an overview of the Colorectal Cancer Control Program and then focus in a little bit on the four funded tribal programs, and this is just a graph of the 25 funded states and their four tribal programs; three in Alaska and one in Washington State. And the program is designed to increase colorectal cancer screening in persons over 50 and use to the extent possible the infrastructure that already exits with CDC funded programs like breast and cervical that many of you may be familiar with. The Wise Woman grant that’s in place in many places, and to try to utilize the existing infrastructure to deliver these services more efficiently. So similar to the breast and cervical program, and for those of you who aren’t familiar with it, it’s a program that’s been around for well over 20 years now that was started to provide breast and cervical cancer screening to women who were uninsured or underinsured and low income. And in the early phases of that program AIAN women were a priority for the program. But the breast and cervical program was a model for Colorectal Cancer Control Program but there are some important differences. And the key difference is breast and cervical emphasized early on and has throughout its life directly provided funding services to women so that they get these screening services, with some other promotional components to it but the focus has really been on funding the services. Whereas the colorectal cancer program came about in the era when we were anticipating healthcare reform and anticipating much more robust coverage for preventive services for a much greater proportion of the population so the focus was much more on getting people to have better uptake of those services instead of trying to provide them directly. There is a component of direct services but the focus of the program really is on promoting colorectal cancer screening through policy changes and working with health systems, health providers and public education and partnerships are a key part of that. So that’s sort of an overview of the colorectal cancer program. Now let’s focus a little bit on the tribal programs. There are four. The three in Alaska are the Alaska Native Tribal Health Consortium or ANTHC, Artic Slope Native Association and South Central Foundation, and then in Washington it’s the South Puget Intertribal Planning Agency or SPIPA which is much easier to say. And these programs have really drawn on some of the programmatic experience with other CDC programs like, breast and cervical. And, again, there is a component of providing direct services and as you may be aware, there’s a number of services that are recommended, not only colonoscopy, colonoscopy is the most common one now but also testing stool for blood and flexible sigmoidoscopy are recommended services, and there’s a mix of the types of screening services provided for the direct screening component of all of these programs. ANTHC has always had a very strong colonoscopy program as does Artic Slope which is a much smaller program also provides colonoscopy and mostly by the itinerate endoscope model where persons who are providing the colonoscopy travel from Anchorage to the sites to provide that service, and SPIPA also provides some colonoscopy. Flexible sigmoidoscopy, which is not used nearly as much as the service that is focused on by the South Central Foundation and Alaska, the programs are an unique occurrence in that they both share and manage a colorectal cancer screening clinic jointly. I believe it’s the first time that has occurred in the two organizations with ANTHC focusing on colonoscopy and referral for colonoscopy and South Central of flexible sigmoidoscopy, but orchestrating this through this joint clinic.
And then the Fit test which is sort of a modern version of the stool blood test is being used by SPIPIA and is being introduced in ANTHC. And in terms of promoting screening services the program aims to support services that have had an evidence based and that have been shared with the public health and clinical community through a project called the Guide to Community Preventive Services. So the evidence is vetted for the utility of these services and that includes culturally appropriate patient navigation and provider education, one-on-one education through navigation and other community health training, social media, small media such as brochures in clinical settings, client reminders and the Tobacco Cessation has been a part of the colorectal program from the outset, not just in the tribal programs but throughout the four tribal programs and the 25 state programs. A lot of challenges especially in the Alaska setting with provider shortage, staff turnover, geographic isolation and cost of travel, very expensive to move around those long distances, competing priorities and particularly as programs move and there’s more self governance in Indian country, programs are moving away from RPMS and the programs that are being purchased by different tribal programs are not necessarily talking to one another and creating some problems for referral and coordinating care between programs. A number of lessons have been learned around trying to adapt these interventions that are vetted not necessarily for the tribal or native setting and trying to shoehorn them into a much, much different context, developing and getting culturally appropriate materials out, and then impact is also difficult to measure especially when there’s a mix of screening services, which in the case of colorectal cancer is a minor part of it, and then the broader population-based interventions are difficult to measure impact especially over a short period of time and this project is in its fifth year. So those were the activities that are supported directly out of Atlanta with my colleagues in the division, and this next set of activities covers projects that are coordinated with CDC funding but through the office of Albuquerque. There are three assignees in Albuquerque and one in Phoenix who support colorectal cancer either directly or indirectly in a number of ways and I’ll cover projects that are going on in the Southwest, several in Alaska. We have a long history of collaborating with our Alaskan colleagues. And the northern plains has been a particularly difficult region to get into and it evolves around a lot of the staff turnover issues but also the funding issue that we talked about and Ursula alluded to early on. I organized them just a little bit—most of them are the same. So in the Albuquerque area we have been working for several years with the Albuquerque Area Indian Health Board and the tribal epi center to try to tap the resources and experiences. The connections of the community health representatives (CHR) and the team at the health board, we’ve worked very closely to build colorectal health capacity with CHR’s and a component of this have established a colorectal health taskforce in each of the tribes, implement local health awareness and patient navigation activities, and then share these success strategies with other tribal communities. It’s been a very successful program. The organizers or the CHR’s go through a whole training program to get them up to speed with colorectal cancer, it impacts the screening modalities and they’ve done this with a number of different training tools including videos, anatomic models, visiting a local endoscopic clinic to see what happens when somebody goes to get a colonoscopy or flexible sigmoidoscopy and what they can expect so they’ll know when they talk to the tribal members who are anticipating this, and they in turn will go out into the community and use a number of innovative and
engaging tools like Bingo and some of the same training tools that they learned on to engage the community members and they’ve found this to be a very successful model to raise awareness and buy in by community members. And I think importantly they have found this to be successful in the Southwest and have provided these trainings in a number of other settings and these are just some places and dates where they’ve gone and done one in two-day workshops with those communities to try to raise awareness of the possible role of community health representatives and colorectal cancer screening, and then they’ve also done this at the CHR national conferences a couple of times. They’re developing—the DVD may actually be out, there’s a lot of excitement about producing this DVD that’s going to also be a tool for amplifying the message that the CHR’s are able to do in their communities. In follow up of this CHR activity, in the Southwest one of the concrete ways we would like to see what the CHR’s role is, is a randomized control trial where we’ll actually go to usual care which is generally giving out the stool slides in the clinic and then compare that with mail-out of the collection kits and then mail-out with follow up from the CHR’s to see if the CHR’s can indeed increase uptake because we’re moving into an era where it’s not just having the test available or having coverage, it’s the uptake and the realization that the community member has an important role in getting screened, not just having the screening be available. We’ve supported a number of projects in Alaska along the same lines with the community health AIDS program and Melanie Guava has been a wonderful collaborator on this project, and some of you from Alaska may remember this movie that came out a couple of years ago with the story of a very reluctant tribal member who didn’t want to get screened and didn’t want to hear his family’s messages about getting screened but was finally convinced, and it was a success and I think they even had some events around the release of this piece, and this was also done with funding from the Colorectal Cancer Screening Program for Artic Slope. And then also in Alaska, traditionally the only screening modality that has been recommended or utilized for Alaska natives for years and years has been colonoscopy because of the—I won’t go into the reasons but it was felt, for valid reasons, that the stool test did not work and we were able to do a study in collaboration with a number of partners in Alaska to demonstrate that it actually does perform quite well in the Alaska native setting, but it’s not a test that the provider community or patient community for that matter is used to doing, so we’re working with ANTHC on a demonstration project to introduce it into one or two communities to increase the capacity for screening. And then in the northern plains we’re working with the American Indian Cancer Foundation called Improving Northern Plains American Colorectal Cancer Screening, and the goal here is in a nutshell to go in and do an assessment of what a facility is currently doing in terms of screening and look at their tracking system and reminder systems, measure what the providers feel, know about colorectal cancer screening and then also look at what the referral capacity is or internal capacity for doing colorectal cancer screening, and then the next step of this is to move this into a limited number of the facilities that were assessed and work with to try to improve the performance of those facilities to deliver colorectal cancer screening services. These are GPRA measures. GPRA is a performance measure that is used by some of the tribal programs and used very enthusiastically by the Indian Health Service comparing the three screening services, colorectal, breast and cervical, and you can see there’s been some important progress in colorectal cancer screening, so we are making progress but you’ll
see the top part of that is well under 50% so we’re on a favorable trajectory but there’s a lot of opportunity and need to build on that. With that, I will stop. I’d like to acknowledge Djenaba Joseph and Don Haverkamp who provided most of these slides and Melissa Jim who is with us here who did the analysis for the data slides. So I’ll entertain questions.

Councilman Chester Antone: Thank you. If there are no burning questions, we'll go right to our next presentation. We’re about half an hour into the hour. So are there any questions? Cathy?

Director Cathy Abramson: Is there any way that the community transformation grants, is there any way that they can do something about those that they can—I mean they’ve done such a good job with those. Can they apply for any of those grants coming out?

Dr. Ursula Bauer: This really does represent a broken promise to all of the grantees in the community transformation grant program, and I can’t explain what happened or why it happened but the program is being shut down after the third year of an anticipated five years of funding. We have certainly looked at ways that we could try to continue the program, at least bring it to the end of the five years and we have not succeeded in finding a way, although it’s not any solace to those who will be losing funding after the third year. I did mention two grant opportunities that will be released this year and I’ll mention a third, which is a new, REACH, Racial & Ethnic Approaches to Community Health funding opportunity, and again in the congressional language there’s a call-out to tribes among the eligible grantees. So that doesn’t mean that existing community transformation grant grantees will automatically get one of those awards but given the work that you have done over the last two, and moving into three years, you should be very strongly positioned to be competitive for those grants. And I would certainly urge all of the tribal grantees as well as the entirety of the grantees to really focus on how we can tell the story of what that grant did accomplish in that short period of time and what it could have accomplished had it lived out its full promise.

Councilman Chester Antone: Thank you. And I’ll call on the injury prevention folks. Dr. Ann Dellinger.

Dr. Ann Dellinger: I brought Holly Billie here with me. I think she knows some of you. She runs our Tribal Motor Vehicle Injury Prevention program. So we need our slides. So my request today was to talk about unintentional injury but also to include suicide at least a little bit and so the talk here is focused on unintentional accidents but I also have a little bit of information on suicides and homicides in AIAN communities. So I’m going to show you the picture with data and then Holly is going to talk to you about our program. So all of the information that I’m giving you, you can find on our website. There’s a query system and you can request injury deaths among males in ages 1 to 44, and you can come up with that kind of information. Here I just pulled—actually Holly pulled, this was her slide, unintentional injuries are the leading cause of death among AIAN ages 1 to 44. So we’re making a little bit of a switch. What our young people are dying of in all races and ethnicities are injuries and they’re...
Preventable. Typically, motor vehicle crash injuries are the leading cause. In AIAN populations second is poisoning, third is drowning. So this is five years of data combined looking by race, unintentional injury deaths ages 1 to 44 males and females together. And you'll see that the AIAN community has a higher death rate than others if you go all the way to the end, that's all races combined. So this one is intentional injury deaths so that includes the homicide and the suicide, and this is the same thing but with intentional deaths. You can see that African American Black community has the highest death rates followed by AIAN, and all races combined are at the end at the 16.3. Certainly ask me questions while I'm doing this, send up a flare. So you can also plot the leading causes of death from our website and this is just breaking it down. So that was ages 1 to 44. This is breaking it down, so what's the leading cause of death for 1 to 4 year olds? It's unintentional injuries, and 5 to 9 years old and 10 to 14 and 15 to 24. Actually, in that 15 to 24 years old for AIAN, the first three causes of death are injury, injury and injury; unintentional suicide and homicide. If we go to the next age group, unintentional injury, unintentional injury, and then it drops down to the third leading cause of death but then again, the 25 to 34 years old in that group, the three leading causes of death are all injury. Now, on our website any of these boxes that are colored you can click on it and it gives you this information. So I click on the unintentional injury box and it tells me what kind of unintentional injuries. So more than half are car crashes, second poisoning and then drowning. So if you click on a suicide box, then it gives you this kind of information, the method of suicide. So the suffocation is the hanging and strangulation. And if you click on a homicide box, this is what you get. So about half from firearm. So to give you a little bit of information about something that we call the National Violent Death Reporting System, it started with 16 states. I looked on our website today and there are 18 states that collect information on violent causes of death and these are the states that are giving information. Homicides, suicides, homicide and suicide clusters and this is what they show for violent deaths by race, so you can see that actually among the violent deaths AIAN have the highest death rates. So there's another measure that people use instead of just the deaths or injuries and it's years of potential life lost. I don't know if you've heard that before. People say YPLL like everybody understands it and I'm not sure that we all understand it but it's a way to look at premature death and since injury ends up taking young people, it's a measure that shows that. So say it's potential years of life loss before age 75, so if I die at 54 today, I have 21 years of potential life that we just lost, and we can add up all those deaths and find out basically what's killing our young people. So this is just AIAN, both sexes, all deaths and 23% of the years of potential life lost are to unintentional injury. Just a different way to look at the issue. And this is by race, all races to the end and it shows the unintentional injury death rate is the biggest chunk of years of potential life lost. Okay, so here this is another thing we can do on our website and that's plot death rates by state, and the dark blue have the highest death rates. This is just for AIAN population. The problem with this is that you know that death rates aren't equal across the state, so different populations are going to look a little bit different. So Holly is collaborating on a project that's using mapping GIS, mapping and tribal boundaries and using zip code to see if she can differentiate death rates among different tribal populations in a state. How long will that be going on?
Holly Billie: That will be going on through next year, through 2015.

Dr. Ann Dellinger: Okay. I have one more slide before I turn it over to Holly. So I put this in your notebook. This is the ten leading causes of death by age group just so you would have it in a spot where you could read the print and it wasn’t so small. The last thing I’ll tell you is that this whole little program where we query deaths, injuries, it’s called WHISKERS, and Holly is just finishing a project that has a WHISKERS tutorial for AIAN injury queries which is part of a toolkit that’s almost finished, too. So it’s a motor vehicle injury prevention toolkit with materials that tribes can do. It has posters, brochures, fact sheets and the video. I think that’s it. Holly is going to talk about our program.

Holly Billie: Good afternoon, everyone. I know it’s tough to listen to more information at the end of the day but we appreciate your attention. I’m Holly Billie for those of you who I haven’t met. I am Dine’ from the southern Utah portion of the Navajo Nation, and I work here as an injury prevention specialist and tribal liaison between IHS and CDC, and I haven’t been here too long, it’s almost five years, but I work mostly with tribes and some of the projects we have going on are—the first project I’d like to talk about is the Tribal Motor Vehicle Injury Prevention program. This is a cooperative agreement that looks to reduce injuries and death due to car crashes. And we have asked the tribes to try to reduce alcohol impaired driving, increase child safety seat use and increase safety belt use. This was a cooperative agreement where we asked the tribes to at least pick two of those three strategies to implement in their communities and then to tailor them so that they were appropriate for their communities. You can see that the tribes funded from 2004 to 2009 were San Carlos Apache, Ho-Chunk Nation of Wisconsin, White Mountain Apache, and Tohono O’odham Nation. And we had some really good results from these programs, this initial program that was from 2004 to 2009 and we have a second round of tribes that are funded. We have eight tribes that are funded currently. We are in the last year of funding for this group and that includes Kato Nation, California Rural Indian Health Board, Colorado River Indian Tribes, Hopi Tribe, we have three tribes from South Dakota, Rosebud, Oglala Sioux and Sistema Toyota. We also have Southeast Alaska Regional Health Consortium, and they are in their last year of funding and we have gotten some pretty good results that I’d like to focus on. The things they worked on, the things they included in their communities was working with police departments to increase enforcement because that has been shown to really be effective, and also putting the message out there about buckling up and not drinking and driving. There were several tribes that were able to strengthen or pass new laws that have to do with traffic safety and then there was also child safety seat distribution. And quite a few of the tribes have had pretty good results and there’s some general results up on the screen but I wanted to read a couple of results from some of the tribes that we’ve been able to get most recently that we’re pretty excited about. Oglala Sioux tribe increased their seatbelt use by 25.7%, reduce crashes with either injuries or fatalities by 42%, reduced alcohol impaired crashes by 43%. Hopi tribe increased their seatbelt use by 32%. Colorado River Indian Tribes reduced their crashes with injuries or fatalities by 47%. And Yurok Tribe increased child safety seat use by 21%. So the tribes have worked really hard and they’ve gotten some really fantastic results. We’ve heard today, and we also know from experience, that sometimes it’s hard to measure impact in a community but we know that
if we’re getting folks to buckle up and not drink and drive, that’s going a long way in preventing injuries and fatalities. One of the things that we have planned is to put out for other tribes’ lessons learned and we are collaborating with Indian Health Service and also BIA because they have traffic safety programs. We’re interested in pooling our lessons learned together so that we can get the word out about what has worked with these tribes that were funded through these different federal programs. And we are hoping to put this best practice manual or lessons learned manual out when the TIMVIP is completed, and this should be out in 2015. So that’s what we’re shooting for. Now, the tribes will be sharing their experiences and also their successes in a CDC sponsored webinar and I’d like to announce ahead of time to mark your calendars for June 17th of this year, 2014. CDC will be sponsoring a webinar that starts at 2:00 p.m. Eastern and each of these eight tribes that are being funded now will tell about their programs and about their results. So we hope that you mark your calendars and join us in June. And then in July the tribes will come here and give their presentations in person to CDC Injury Center. So those of you who are in the Atlanta area in July are invited to attend that presentation by these tribes. Another project that we have going on is the CDC and Federal Highway Administration partnership. Dr. Bauer mentioned earlier that they struggle with the ability to reach many tribes. I think that a lot of CIO’s do including the Injury Center, and funding the four tribes was great, funding the eight tribes is better, and in an effort to try and reach more tribes we’re collaborating with the Federal Highway Administration in their Tribal Technical Assistance Program, otherwise known as the TTAP. Some of you may be familiar with the Federal Highway’s TTAP program. They have seven across the country and they cover various regions and if you know anything about federal highways their focus mostly has been on roads and bridges and fixing the roads to make them safer. But they are trying to include the behavioral side of traffic safety which is what CDC focuses on, the seatbelts and DUI prevention and so forth. So we’re partnering with them to provide injury prevention technical assistance to the tribes served by three TTAP centers and you’ll see the three TTAP centers listed. There’s one in California, at the National Indian Justice Center, there’s also the southern TTAP center and there’s the UTTC, the United Tribes Technical College in Bismarck, North Dakota that we’ll also be partnering with. And the idea really is to share with all the tribes in those particular regions what we have learned from the tribes that were funded through TIMVIP and also the tribes that were funded through Indian Health Service. One FTE position will be placed in three TTAP centers and this will be a pilot project for two years, and we’re hoping that this combines what we have learned here at CDC with their behavioral approaches with the Federal Highway experience and they really haven’t established network already in traffic safety. They have an established network much like IHS does. IHS has a lot of people on the ground and CDC doesn’t necessarily have that but we’re able to partner with Federal Highways who has that network that can reach tribes very easily. So these positions will be Modified Safety Circuit Rider and, again, they’ll provide technical assistance and they’ll provide services to tribes in those regions, and they will start out by working with the tribes that are funded by Federal Highways, BIA, CDC and IHS and hopefully expand beyond that. We’re in the process right now of getting an inter agency agreement put together and we’re hoping we can get this started in the spring of this year. So these are the two bigger projects that
we’re working on and I guess that concludes our update from the Injury Center and I guess we can take questions if there are any.

Councilman Chester Antone: Are there any questions for the presenters?

Can you please send us the link to the webinar so we can disseminate it to the TAC, send it to the Tribal Support Unit office at OSTLTS, please?

Sure, we can do that. We can send out an announcement.

I don’t have a question but I wanted to just ask Holly if you know what STOP is on the Tohono O’odham Nation.

Holly Billie: Yep, I’m familiar with that program from the first round of funding. Is that going strong still?

Councilman Chester Antone: I was going to ask you to tell me what that is.

Holly Billie: Oh….It’s a seatbelt program.

Councilman Chester Antone: And when we have major celebrations, we have Police Departments out there making sure people have their seatbelts on. If they don’t have it, they get a ticket. The Tribal Court has a way of trying to reinforce the injury prevention. I just thought I’d throw it out.

Holly Billie: That’s really great news because we always hope for some degree of sustainability. Sometimes it’s tough when funding goes away. You hope that some parts of a program can still move forward and that’s one example of one of the activities that was sustained by the tribe even though there wasn’t additional funding provided. So that’s really good to hear.

Councilman Chester Antone: They also are helping us provide baby seats. Herman?

Chairman Herman Honanie: Thank you. I just want to ask you if our Hopi worker is aware of the TO’s program out there. Would he be knowledgeable of that?

Holly Billie: Greg Sehongva over at Hopi, he would be knowledgeable of the program that occurred over in Tohono O’odham, and if he isn’t, there’s information on our website and certainly we can share that information with him.

Chairman Herman Honanie: Well, you were out there about a month ago on the reservation. We had a chance to talk and meet with Greg and I think it’s a really important program because to this day I will never forget or have not been able to forget an accident, a crash that
occurred in King’s Canyon that took the life of a four-year-old infant, all because the infant wasn’t buckled in a safety seat and the crash took her life, and totally unnecessary. And ever since then when this program came to Hopi, I’ve really tried to do all I could to support, and to this day I do and I did mention to you that I was going to try to see if we could be able to do a mandatory seatbelt law in Hopi. So we’re still working on it. Give us time. Thank you.

Councilman Chester Antone: Thank you very much for that report. At this time we’ll have Molly just give us an update on what we talked about today this afternoon.

Molly Sauer: Good afternoon. We had a lot of discussion in the afternoon so I have a few more items than this morning. We’ll start with native specimens. So there were a lot of issues that came up today as we were talking through the new process that’s going on to develop an agency-wide native specimens management policy. A few highlights from that, and again, there’s a lot more that will be captured in the minutes but just a couple of the key items here. Questions were raised about what rights do tribes have to native-specific data; is the CDC the final authority on specimens management across all of the agencies of the federal government; what kind of ownership exists for the specimens that have been collected and do exist within the specimen bank here; what is the role of the legal entities that have been cited in the process so far; clarification that the discussion now we’re in the preliminary stages, this has not gone out for full consultation yet, so just to clear that up. Wanting to know more details about the specific studies that were conducted to collect the specimens that are currently in the bank here at CDC, specifically regarding informed consent and making sure that the language barriers had been addressed and I think the term was of sound mind while specimens were collected. Another key item was to include traditional medicine practitioners in the discussion as we move forward, and a change that’s been going on of how we’re looking at this process taking it from just a retrospective look at the specimens that already exist in the bank, and moving more into a longer term policy for the agency, so not only what we have but as we move forward and more specimens are collected having this in place for that. So again, there was a lot more that came out but those are some of the highlights. For accreditation we talked about NPHII’s funding coming to an end and looking for a mechanism to continue to support those infrastructure building processes in the tribal awardees and others and specifically the uniqueness of tribal awardees starting to build infrastructure from the ground up rather than just advancing what already exists. We talked about questions about the role of tribes in the state programs that are working on accreditation and similar procedures, and the role of workforce development in that process, and we also discussed needing to incorporate health disparities and health equity into the accreditation standards. For chronic disease a couple of highlights. We discussed that CTG will be coming to an end at the end of this fiscal year and some opportunities for new engagement specifically around heart disease and stroke and diabetes prevention. And the main point that came out of that discussion was the emphasis on trying to get back to traditional foods and traditional activities as a way to address those, and then of course as we’ve been hearing so far through several presentations that funding through states to reach tribes is not the way to go. And again, as several people mentioned, we will be talking more about the budget tomorrow and some of the funding that does exist
direct to tribes and indirect. So hopefully that will help resolve any questions around that. If I missed anything, I know we’re tight on time so please catch me. I will be at the back table and I will type it right into our notes. Thank you.

Councilman Chester Antone: Thank you, Molly. And before we leave, I just want to make an announcement. The CDC ATSDR TAC meet and greet with senior leadership and invited guests, please join us at Bone Fish Grill shortly after our last session today for dinner. We will be walking over to Emory Point across the street. Dinner officially begins at 6:00 p.m. This is an opportunity for our TAC members to meet our CDC ATSDR senior leadership in an informal setting. Also be sure to bring your nametags tomorrow….That concludes our session, and then do a blessing prayer and then we’ll formally end this day’s session….

(Inaudible speaker)

Councilman Chester Antone: Director Cathy Abramson, did you make the motion? And Vice President Jim second it? All those in favor say I. Against? Okay, the minutes are approved. Thank you for reminding me, Vice President Rex Lee Jim. Now we’ll do our prayer.

(Prayer)

END.