

# Transcript

## **HEALTH INFORMATION TECHNOLOGY ADVISORY COMMITTEE (HITAC) PUBLIC HEALTH DATA SYSTEMS TASK FORCE 2022 MEETING**

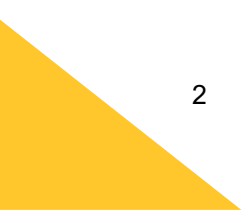
September 28, 2022, 10:30 a.m. – 12:00 p.m. ET

VIRTUAL



# Speakers

Name	Organization	Role
Gillian Haney	Council of State and Territorial Epidemiologists (CSTE)	Co-Chair
Arien Malec	Change Healthcare	Co-Chair
Rachelle Boulton	Utah Department of Health and Human Services	Member
Hans Buitendijk	Oracle Cerner	Member
Heather Cooks-Sinclair	Austin Public Health	Member
Charles Cross	Indian Health Service	Member
Steven Eichner	Texas Department of State Health Services	Member
Joe Gibson	CDC Foundation	Member
Rajesh Godavarthi	MCG Health, part of the Hearst Health network	Member
Erin Holt Coyne	Tennessee Department of Health, Office of Informatics and Analytics	Member
Jim Jirjis	HCA Healthcare	Member
John Kansky	Indiana Health Information Exchange	Member
Bryant Thomas Karras	Washington State Department of Health	Member
Steven Lane	Sutter Health	Member
Jennifer Layden	Centers for Disease Control and Prevention (CDC)	Member
Leslie Lenert	Medical University of South Carolina	Member
Hung S. Luu	Children's Health	Member
Mark Marostica	Conduent Government Health Solutions	Member
Aaron Miri	Baptist Health	Member
Alex Mugge	Centers for Medicare & Medicaid Service	Member
Stephen Murphy	Network for Public Health Law	Member
Eliel Oliveira	Dell Medical School, University of Texas at Austin	Member
Jamie Pina	Association of State and Territorial Health Officials (ASTHO)	Member
Abby Sears	OCHIN	Member
Vivian Singletary	Task Force for Global Health	Member





Name	Organization	Role
Fillipe Southerland	Yardi Systems, Inc.	Member
Sheryl Turney	Carelon Digital Platforms (an Elevance Health company)	Member
Avinash Shanbhag	Office of the National Coordinator for Health Information Technology	Executive Director of the Office of Technology
Dan Jernigan	Centers for Disease Control and Prevention	Deputy Director for Public Health Science and Surveillance
Seth Pazinski	Office of the National Coordinator for Health Information Technology	Acting Designated Federal Officer
Peter Yu	Hartford Healthcare Cancer Institute	Presenter
Stephanie Hill	NAACCR	Presenter
Jeremy Pine	CA Cancer Registry	Presenter
Nigar Salahuddin	NC Central Cancer Registry	Presenter
Chandrika Rao	NC Central Cancer Registry	Presenter





## Call to Order/Roll Call (00:00:07)

### **Seth Pazinski**

All right, well, thank you, everyone. Welcome to the Public Health Data Systems Taskforce. I am Seth Pazinski with the Office of the National Coordinator for Health IT. I want to thank everybody for joining today's taskforce call. We have some guest presenters with us today, so I want to thank them for volunteering their time to participate, along with the members of the taskforce. As a reminder, all taskforce meetings are open to the public, so your feedback is welcome throughout the call, either using the Zoom chat, and at the end of the call, at around 11:50 Eastern Standard Time this morning, we will have the formal public comment period for folks who want to make oral comments. I am going to begin today's call with a roll call of taskforce members, so when I call your name, please indicate your presence. I will start with the cochairs. Gillian Haney?

### **Gillian Haney**

Good morning, present.

### **Seth Pazinski**

Arien Malec?

### **Arien Malec**

Good morning.

### **Seth Pazinski**

Rachelle Boulton?

### **Rachelle Boulton**

Here.

### **Seth Pazinski**

Thank you. Hans Buitendijk?

### **Hans Buitendijk**

Good morning.

### **Seth Pazinski**

Heather Cooks-Sinclair? Erin Holt Coyne?

### **Erin Holt Coyne**

Good morning.

### **Seth Pazinski**

Good morning. Charles Cross? Steve Eichner? Joe Gibson? Raj Godavarthi?

### **Rajesh Godavarthi**

Good morning.



**Seth Pazinski**

Good morning. Jim Jirjis? John Kansky?

**John Kansky**

Good morning.

**Seth Pazinski**

Bryant Thomas Karras?

**Bryant Thomas Karras**

Hello, everybody.

**Seth Pazinski**

Steven Lane?

**Steven Lane**

Good morning.

**Seth Pazinski**

Good morning. Jennifer Layden?

**Jennifer Layden**

Good morning.

**Seth Pazinski**

Les Lenert? Hung Luu?

**Hung S. Luu**

Good morning.

**Seth Pazinski**

Mark Marostica?

**Mark Marostica**

Good morning.

**Seth Pazinski**

I think we have somebody who has their line open, so please mute your line if you are not talking, thanks. Aaron Miri? It would be good to note that Aaron was not anticipating being able to make it today. Alex Mugge? And for folks' awareness, I did get a note from Alex as well that she is actually not joining until later in the call today. Stephen Murphy?

**Stephen Murphy**

Good morning.



**Seth Pazinski**

Eliei Oliveira?

**Eliei Oliveira**

Good morning.

**Seth Pazinski**

Jamie Pina?

**Jamie Pina**

Good morning.

**Seth Pazinski**

Good morning. Abby Sears?

**Abby Sears**

Good morning.

**Seth Pazinski**

Good morning. Vivian Singletary?

**Vivian Singletary**

Good morning.

**Seth Pazinski**

Good morning. Fil Southerland? And Sheryl Turney?

**Sheryl Turney**

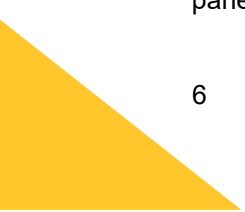
Good morning.

**Seth Pazinski**

Good morning. All right, that completes roll call. Thank you again, everyone, for joining. I am going to turn it back to Arien and Gillian for their opening remarks and go through the agenda.

**(f)(4) Transmission to Cancer Registries (00:03:46)****Arien Malec**

I will do the agenda. Gillian is going to lead us through the taskforce and discussion, and depending on my mental status, I will lead us through the topics worksheet. So, we are pleased today to talk about the F4 criteria, which is transmission to cancer registries. As a cancer survivor myself, it is clearly a topic near and dear to my heart, or my B cells, as the case may be, and so, we have quite an esteemed panel to lead us through the current state of cancer registry public health data systems and the degree to which we have interoperability and data flowing to support those registries. As I said, then, Gillian is going to lead us through a discussion with the panelists, at which time we will transition to discuss the topics worksheet and make some progress, and then, as usual, we will go to public comment. So, with no further ado, Gillian, I will turn it over to you if you want to provide any other setup, and then, otherwise, we will just get into the panel today.



**Gillian Haney**

Thanks, Arien. I am grateful you were able to join us today. This is an area that is outside of my general expertise from infectious disease, but I do know something about public health infrastructure, and I think that cancer is in a place right now for us to provide some meaningful recommendations and really take note of lessons learned through establishing the infectious disease reporting infrastructure write larger. I think there has been a general lack of funding to support cancer data transmission and interoperability, so I am really hoping today that we can learn from our panelists and build on previous experience with infectious diseases and provide some recommendations that will really support data quality. So, with that, I will turn it over to Dr. Peter Yu from Hartford Healthcare. Welcome.

**Peter Yu**

Thank you. If you can pull up my slides, I have a lot of information on the slides. I am going to be moving very quickly through that, but I wanted to have some more detail captured in there so this could be reviewed by this workforce at their leisure. So, if we can have the next slide. What I first want to emphasize is the complexity of cancer data, how it comes from a variety of sources, and the relationship to vendors for capturing cancer data. So, if we could have next on the system animation here. So, just a quick run-through or circle of where cancer data comes from. Certainly, it comes from electronic health records, but our pathology information comes from the laboratory information systems, which is really where the start of cancer diagnosis begins. Next.

Radiation oncology in the United States comes from just two vendors. They are not part of electronic health records, and so, there is a whole different software and data repository for radiation data. Next. Of course, we report to state and federal cancer registries, and we have our own software to facilitate that data transmission. Next. We have a lot of research going on in cancer. There are some 20 new drugs a year approved by the FDA, and so, all that information is in our clinical trials management system. Next. Our imaging data is in a vendor-neutral archive. Next. As we start looking to the future about wearables and the internet of things, that will be yet another rich data source. Next. And, the last data source is genomic data/precision medicine, which current comes from external laboratories. All this data needs to be pulled together. They are all intrinsically, inherently related, but they all tell only a piece of the story of the cancer patient, and in order to pull that together, we need to bring that into a data model. Next.

So, what we are looking at in our healthcare system is how do we adopt data models that organize all this data and then permit data science. So, if we achieve this, then we have data capture and data representation standards, but we still have the issue of data transmission, the challenge of data transmission. So, where does our data go to? Next. So, of course, cancer registries are an important area and the focus of this discussion, both state and federal as well as professional societies' registries for quality improvement. Next.

We also share our data with a variety of academic partners for cancer research and for data science. So, the MIT Sloan School of Management is one of the sources we use for predictive analytics and machine learning. And, the last group I would lump together next is the large group of people who are interested in health economics and outcomes research, whether that is from the payers, industry, or other federal agencies. Next slide. So, in terms of data models, where can we look to data models being developed for the oncology space? There are two emerging data model sources for observational data. One is OHDSI's





OMOP, and the other is the American Society of Clinical Oncology's mCODE, and I will very briefly describe both of those. Next. So, as I am sure you all know, OHDSI's goal is to take data from a variety of sources and to transform that into the common data model, and really, "transformation" is the key word. So, Source 1, 2, and 3 here might be Epic, the electronic health record data, it might be radiation oncology data, but those sources need to be brought together into the common data model. Next.

Recently, OMOP has created what is called an oncology extension. So, OMOP was designed not for the oncology space, but to address that lack. The oncology extension has now been developed and is ready to be deployed. An example of this transmission concept is what OMOP does is it looks at all of the current vocabularies or lexicons that could, in some way, describe cancer diagnosis, and so, you see the CAP electronic checklist for pathology reports and ICD-O-3, and it takes all those existing terminologies, and that maps them to the standard that it anoints, which is the SNOMED CT model in this case. And so, the data elements from these other sources are transformed into the SNOMED model, and it captures a variety of concepts that each of the individual lexicons might capture, but may not have all of those concepts, like histology and grade. Next slide.

The other emerging data model for cancer is coming from ASCO in partnership with MITRE, as well as with the FDA, and the approach here is to look at what types of cancer data are not captured in existing lexicons, such as staging, to really flesh out the full data model, and again, as you can see, to public reporting. Next slide. So, this is a model of all the types of cancer data that are important to capture, and I would highlight the ones in yellow on the right, which are related to cancer treatment, whether that is chemotherapy, immunotherapy, surgery, or radiation, but as we start to look at outcomes and value, we need to capture treatment details, and so, this is some of what mCODE is trying to do. Next slide. ASCO's intent is to develop use cases for this common data model, and one of the ones that are highlighted is cancer registry reporting. Next slide.

So, I want to finish with an example of where a logical place would be to start if one was starting to look at standard data capture as well as data transmission, and that really would be with pathology, since really, that is where cancer diagnosis originates from, the pathology report. And, for the last 10 years, CAP has been developing machine-readable digital synoptic reports for 98 different types of cancer. Each report includes dozens of data elements. The U.S. adoption rate is now 50% for digital capture of pathology reports, and so, we are clearly at a tipping point now where we are poised to begin to use this data out of the electronic checklist for data transmission. Next.

So, while the ECCs, the digital pathology reports from CAP, address the question of standardization of data capture and representation, we still have the issue of data transmission to cancer registries and other areas, and I think this is now being looked at with the 21st Century CURES Act, which has really mandated structured data capture using FHIR, and this, too, has been in development for several years, focusing on transmission of pathology information out of the CAP ECCs using FHIR. This is now close to being ready for piloting, and if I was going to look at an area where ONC might consider expending resources to develop, it would be on pilot areas for SDC transmission to cancer registries. Next slide. This can be read at your leisure. I am going to skip this one. Next slide.

And so, the key takeaways that I hoped I would be able to speak to a little bit are that cancer registry reporting should be considered in the context of a data ecosystem that is being developed and to







understand how that ecosystem is forming and how it can be used to accelerate data modernization of cancer data. Next. Health systems are very reliant on a whole bunch of vendors, and we need to bring those vendors on board if we are going to move this needle. Next. Data liquidity requires data representation and capture as well as transmission standards. Next, Last, the really common data model, which is, I think, where we have to go, and promotion of these common data models and their uptake pilots to support the use is an area that I think ONC can focus on and help us with. And, I think that is the last slide. Yes, it is. Thank you for your time.

### **Gillian Haney**

Thank you so much, Dr. Yu. I am not quite sure who our next presenter is. Ah, Stephanie Hill from the National Association of Cancer Registries. Welcome.

### **Stephanie Hill**

Hi there. Hi, everyone. Thank you. So, I am Stephanie Hill. I am with the North American Association of Central Cancer Registries, or NAACCR. For those who are not familiar, we represent all of the central cancer registries. Those are the primarily state-based cancer registries in the U.S. and, of course, the territories in Canada. We also establish the **[audio cuts out] [00:16:27]** data standards for cancer registry reporting.

These are the data standards that have been used by primarily hospital-based cancer registries for several decades for cancer reporting to the public health agencies, the health departments, and central cancer registries in all the U.S. states and in Canada. These data standards cover everything from details about diagnosis, staging, and treatment. When I say they are collaborative, the data standards are generated by not only NAACCR, but these include the CDC, their National Program of Cancer Registries, the NCI SEER program, the Commission on Cancer within the American College of Surgeons, the AJCC, **[audio cuts out] [00:17:31]**. So, even though they all have their own data, it all comes together under the NAACCR data standards.

So, I just have a couple of slides. So, I am going to talk about we at NAACCR hear in our working with our central registry. I also am the former program manager of operations for the New Jersey State Cancer Registry, where I oversaw all of the incoming data, including the data coming in from ambulatory centers under what was originally called and what we still call Meaningful Use. So, as you can imagine, there is just a great deal of variability among the states in how the reporting is being implemented from ambulatory and outpatient facilities. Hospital-based reporting is the traditional model. It uses certified tumor registrars. They have their own software. It is still primarily manual, but we are working to change that.

But, the reporting **[audio cuts out] [00:18:56]** offices is really still relatively new territory. There is a lot of variability between how each state is implementing it. Most states, unfortunately, even when they are receiving data under Meaningful Use, they have not been able to use it in a meaningful way due to some of the gaps that I will address on my next slide. It has shown to be resource intensive for setting up and maintaining the secure transmission mechanisms. They are provider-by-provider, and it presents a strain on already limited resources in addition to the resources required for processing the data in order to incorporate it over into the primary cancer registry. Again, there is a lot of manual work that is involved, both on the provider side as well as on the central cancer registry side.





And again, it is a lot because we do not have the interoperability between the systems. Reporting requirements at the legal/regulatory level vary by state as well. Most of them are pretty standard as far as what is required to be reported. There are varying degrees of definition on how these things are to be reported. So, for example, if a state law requires physician practices to report using NAACCR data standards, other mechanisms of reporting do not satisfy their reporting requirements under that state law, so it is something to be considered. Luckily, the majority of laws that we have looked at around the states are a little bit more broad, and they do give registries some flexibility for defining what constitutes acceptable reporting.

One of the reasons that some of them do require reporting in a format is because **[audio cuts out]** **[00:20:59]** we get all the necessary pieces of information. As I am sure you all know, cancer is much different from syndromic surveillance reporting and infectious disease. Cancer treatment can go on for months, sometimes even years. Capturing the totality of that patient experience requires more than just a single snapshot at any given point in time. Next slide, please. All right, great. Thank you.

So, one of the gaps that we have experienced is the structure of the data. It is primarily unstructured, free-text data. As we know, that is really difficult to make use of in a meaningful way without advanced AI/natural language processing tools to pull the necessary pieces out of the text. So, the lack of standardization is a real challenge. Missing key information, such as demographics, date, and location of diagnosis are so important because cancer can be a lifelong chronic disease, so it is important for us to know where and when the patient was initially diagnosed with this disease so that we are not duplicating reporting, particularly if that initial disease was diagnosed out of state, meaning it is already being picked up by another registry. The patient now is being treated subsequently for the same diagnosis here in my state. We do not want to be duplicating reporting.

And again, things like patient identifier and Social Security number: I know it is not real popular to be sharing the Social Security number, but it is so important when central cancer registries are receiving all this data from all the data sources, as Dr. Yu showed, that are pooling at the central registry to make sure that we are consolidating appropriately and making sure that we have enough information to match not just the patient, but at the tumor level as well.

### **Gillian Haney**

Stephanie, I just want to be mindful of time.

### **Stephanie Hill**

Okay, thank you, sorry. So then, the transmission mechanism, as I said, setting up and maintaining these other separate transmission mechanisms when we already have mechanisms in place is a bit problematic. The data exchange piece, as Dr. Yu said, making sure that it is part of the larger data ecosystem, and then, the incentives. In the past, what we found was practices would enroll or declare intent, maybe even get some data into the testing phase, but that was the extent of what they were incentivized to do, so it never really went any further than that, so all the work that went into setting them up never actually resulted in data coming in in a consistent way. Next slide, please.

I think these recommendations are really just based off of the gaps I just discussed, ensuring that we transmit data in a structured way that uses existing standards. I think Dr. Yu listed several appropriate





standards on one of his slides. It does not need to be the NAACCR standard. We incorporate data from many different standards as long as it is structured. Using an existing transmission mechanism: The CDC is doing great work with data modernization, and we expect to be using that a lot more for laboratory reporting and reporting from other sources, and making sure that we define what needs to be reported so that we have all the necessary pieces to formulate an entire picture of the cancer diagnosis. And, just an idea that different specialties may have different pieces of information. There is not necessarily one piece that needs to come from everyone. We do not need radiation treatment from a medical oncology practice. I will leave it there. I could go on for hours, but I am happy to at a later time.

**Gillian Haney**

I am sure if you could stick around, people will have questions as well. Thank you.

**Stephanie Hill**

Thank you.

**Gillian Haney**

Jeremy Pine, I believe you are next, from California.

**Jeremy Pine**

Yes, hi, everyone. This is Jeremy Pine. I am the information technology section chief for the chronic disease surveillance and research branch within the California Department of Public Health. Basically, I oversee our initiatives around the California Cancer Registry and the California Neurodegenerative Disease Registry. Next slide. So, I wanted to start the conversation with that there are obviously a lot of individual state registries that are out there. There are county-specific registries and multiple cancer registries throughout North America, multiple programs within public health that are all targeting direct electronic data, which makes this conversation pretty difficult.

When we look at how those programs are targeting electronic data, there is actually very little collaboration amongst these programs, which is also a very difficult conversation. Just as we are talking here, the cancer domain is massive in itself, but I think we need to be working in some ways toward some type of collaboration among public health if we are going to make any progress. Programs and domains working on their own just do not work when you are defining your own electronic exchange specifications and so forth. I think we need to do better on that space of collaboration.

When we talk about these multiple priorities, these reporting entities are being bombarded with requests from public health and elsewhere for electronic exchange. They are asking the questions what is required and what do I have to do, and then, they are only meeting that lowest common denominator of those standards that we are putting out. So, in the cancer registry world, we are not really getting the data that we need. What we are receiving is something of low quality of a time that gets put on the lowest priority to handle because it is very difficult to handle, very difficult to process. We are going to go target the easier data first because we are going to try to meet these numbers around reporting criteria and then trying to push that data through to get things to research and so forth, so it is definitely an issue of getting high-quality data into the registries from these direct electronic sources. Next slide.





So, as far as the current gaps, there is definitely a problem around this availability of high-quality primary data from all reporting sources. I think there is a need to address who can create this type of data. We have the CTR workforce within the cancer registry realm. Oftentimes, the CTR workforce, though, is working in a separate system that is outside of the EHR realm that is specific to cancer reporting only, so there oftentimes is not any integration there, so it definitely needs to be discussed about who can create this data within an EHR system and make things available in order to enable this direct electronic exchange.

I think we need to target around primary core data. This would include patient ID, demographics, and diagnosis. We have had issues with null values in the current specifications, so facilities can transfer values that have nothing in them. I think there needs to be more around the mandates that you need to have specific data within those fields. Again, those null values present data that is not really usable at the cancer registry end, and again, that will get pushed to the side, and we will deal with that if we have time later on because of those issues.

Of course, there are initiatives out there around common data definitions and standards. Things like the USCDI are really important here. The more the cancer registry world and public health reporting in general can standardize around USCDI, the better. That leads into that conversation of a primary data profile. So, can all programs within CDPA use some type of primary data profile and then have program-specific data contained within that? And then, of course, incentives for healthcare entities is also a really big, tough part of the conversation. How do we incentivize these healthcare entities to meet that higher standard and not just target what has to be done and that lowest-common-denominator type of data? Next slide.

And, how do we make things easier. We have already talked a little bit about the program collaboration component. When you look at just my world between cancer registry data and neurological disease data, obviously, those are big conversations. When you look at the infectious disease group within California, the genetic disease group within California, those are also big types of organizations that we do discuss things, but I would not say that we are actually partnering together towards this type of work, so I think a lot more needs to be done there to partner together and kind of create this core, common, unique type of data profiling across programs, even. And then, we need to harmonize on our electronic exchange as well. So, when you look at an infectious disease implementation guide, that can be different from a cancer implementation guide, so I think there definitely needs to be work done around standardizing across public health programs and cancer registries in general for what data we are requesting from the reporting entities. Next slide.

Specific to types of interfaces, again, we need to address that data creation type of issue. From the cancer registry perspective, we definitely know that creating that discrete data is difficult to do, especially to a standard such as the NAACCR standard that we want. Most entities do not have the time or staff resources to be in and creating this type of data that we ultimately want. We do not have public health coding departments, to my knowledge, within any of these reporting entities as well. There is an administrative assistant, there are other types of staff resources that are trying to get this job done to meet the requirements for reporting, but there is not necessarily a public health reporting type of group that does this type of coding for us within these reporting entities. We talked a bit about the primary data profile already, and then that financial support for those implementations. Next slide.





So, the recommendation from my perspective is to address that data creation issue. I have stated that we need to do more work with EHR and EMR vendors to maybe embed workflows within the EHR systems, retrain our workforce that we already have within the cancer registries to be working maybe within that EHR or EMR system, or somehow be storing data to where we can enable these exchanges to happen for this discrete data. We definitely need to work with other public health entities to standardize on these core definitions, work towards this primary type of data profile, which can be consumed efficiently across multiple public health programs, and then, definitely work towards incentivizing these healthcare institutions to meet these higher-level standards. Thank you.

**Gillian Haney**

Okay. Thank you very much, Jeremy. I am just going to push forward right now because we do have one more panelist and we are running a little bit behind time. So, we have Nigar Salahuddin and Chandrika Rao from the North Carolina Central Registry.

**Nigar Salahuddin**

Good morning, everybody. My name is Nigar Salahuddin. I have been working as a coordinator for Meaningful Use since 2014. Just move on to the next slide. I am just going to talk a little bit about the background and our current status with Meaningful Use/Promoting Interoperability onboarding, and what onboarding process we followed, and the challenges that we faced. Next slide, please. So, the Meaningful Use/Promoting Interoperability program was implemented in 2014, and we have been working on it since '10, and we tested and validated cancer cases from eligible providers. Hello?

**Gillian Haney**

We can hear you.

**Nigar Salahuddin**

Okay. So, we tested and validated cancer cases from eligible providers, particularly dermatology clinics, from 2015 onwards, and at 2017, we onboarded 53 providers from 10 physician practice groups, reporting solely through Meaningful Use, and these were all dermatology clinics, and we targeted these physician offices for electronic reporting because the diagnosis and treatment of melanomas can happen entirely in the physician office, and sometimes these patients do not go to any hospitals, etc., so it was a way to capture these melanomas that would otherwise not be reported to us.

And in 2022, the number of providers reporting through Meaningful Use dropped to 40 providers from eight physician offices because the EHR vendor through which this information was coming is no longer certified for the F5 criteria, and we saw a lot of gaps in the data being reported to us. Some of these offices opted to report through an alternate mechanism of electronic reporting because it does not involve vendor support or HL7 CDR format, and they just use our registry's database to report to us. And, the data that comes through Meaningful Use, we have a multi-step process to ingest it into our database. There is lots of validation, editing, linking, and consolidation to get that complete report and to eliminate all the data discrepancies and duplicates and to get that complete record into our database. Next slide, please.

This is our workflow that we have been using. Once the data is exported into the eMaRC database, which is the CDC's registry database that we use, our team developed this workflow to migrate the Meaningful Use data into the registry database. We link the eMaRC file with the latest CRSS extract file using SaaS to





filter for matches and nonmatches. We manually review for nonmatches and remove the nonreportable cases, and also go through a duplication process, and only the files that have not been reported to us are coded, and we have to go through manual coding to make sure that we are not missing any kind of site/laterality/histology information, any of the tumor-specific details like Breslow's depth or their TNM staging category, etc.

And after that, we use SaaS to convert the Excel file where we did all the data editing into a NAACRR record layout, and then make sure that all the data items are there, and then we import it into our registry database. This is just a brief snapshot of the process that we follow. And based on that, we have had 4,308 missed cases in the last seven years, but there is a lot of manual work involved by different members of our team. Next slide, please.

This is just an overview of how the data is transported from the physician office into the registry through our SFTP into our database. Next slide, please. These are the challenges that we faced. It is similar to what was shared by our previous presenters. The main thing was limited uptake from vendors. One of our vendors said that any switch to the 2015 implementation guide would be manual only, requested by the client. Only if the physician office requests that were they going to do it; otherwise, they had no plans of automating the change.

And then, we found many files were misaligned with the 2015 implementation guide, which is Meaningful Use Stage 3. There was a lot of historical data that was missing, and because it was not interoperable with the EHR, cancer reports that were being triggered as part of their workflow did not have useful information, were missing key data items like cancer diagnosis, histology, behavior, and laterality, and therefore, it was not very meaningful when it came to us. And there were coding inconsistencies like histology codes, but incorrectly mapped, etc. So, our recommendations would be similar to what the other presenters had suggested. All the PHAs work in silos, so if there was some sort of collaboration, that would be very helpful, and some sort of an automated triggering device in the electronic health record vendor site to initiate transmission of reportable cancer cases to the public health agencies would be helpful, and if the critical cancer data items, the SSTI values, etc. were getting mapped, that would be helpful when it gets imported into the registries database. So, with that, I conclude.

## **Discussion (00:40:10)**

### **Gillian Haney**

Okay. Thank you very much to all of our presenters here. I certainly am seeing some common themes that are coming through here, as well as some opportunities to make strong recommendations. I know from my experience in Massachusetts, we did have some linkages with our cancer registry partners from infectious disease and utilizing our electronic laboratory reporting feeds, for example, to have data reported through us and then siphon them off, but it was really quite limited due to lack of infrastructural funding, which really plagues public health. So, I will leave it there. Arien, I see you have your hand up.

### **Arien Malec**

I do. So, my transitional from life sciences to healthcare work was applying a clinical trials model to oncology clinical trials, and I learned in that experience that oncology has a rich history of applying advanced informatics, probably the richest and most advanced of all of the medical specialties, which gives oncology some advantages. The disadvantage that oncology has is that it is so unlike general medicine. Particularly,





therapy cycling and therapy treatment protocols are generally unlike medication treatment in other diseases, and then, as you have mentioned, very specific data on tumor staging and pathology.

I was struck, outside of the last presentation, by the lack of reference to the CDA implementation guide, and it sounds like one of the major issues is as we move to modular certification, the incentives to adopt any one particular implementation guide were low, but it also sounds like the CDA implementation guide had some disadvantages in terms of no built-in transport, and then, we did not have appropriate testing of data semantics that were coming through the implementation guide. I wonder whether this notion of using either the OMOP data model, the mCODE data model, or some harmonized OMOP, mCODE, and NAACCR model might be a more useful target.

I also heard mention of use of EICR and query retrieve. I am just also interested in hearing whether the USCDI formatted data that often is not specific to tumor staging or to cycle therapies is useful to be able to capture general information, diagnosis, history, and that kind of thing. That is an open suggestion for the panel to say if you had a magic wand and incentives were appropriate, what structure of interoperability would ideally suit cancer registries? This is to the full panel. I have stumped them. Dr. Yu, maybe you can...

#### **Peter Yu**

You made the point that everyone is so consumed with the problem of getting clean, usable, accurate data that questions of transmission are secondary because if you do not have anything worth sending, why worry about how you are going to send it? So, I think that is what we kept on coming back to, is there is so much manual work in just getting the useful data automated, working with a whole variety of vendors to pull that together, and that is the area to focus on before the data transmission.

I know when I was at Sutter Health, we worked with the California Cancer Registry to test sending C-CDA information from the pathology reports to Eureka, to the state cancer registry, and show that technically, it was possible to do so with speed and accuracy, but we still got stuck because we did not have the data to send over, and that is one thing. I know that Jeremy and the California Cancer Registry have thought about how maybe it is just a minimal data set that should go over, and then, if there is a need for more specific data, a query can be sent back rather than asking everyone to send a massive amount of data and a huge amount of work, and that is another concept that maybe we could touch on.

#### **Gillian Haney**

I think that is a very interesting comment there. I think that is one of the things that the infectious disease community within public health came around for case reporting, is defining that minimal core set of data elements that would be initially reported to public health, and hence, standardizing that across all the infectious diseases.

#### **Arien Malec**

In your mind, would that be more like... Maybe this is naïve, but I am imagining some harmonization of the OMOP research data model with mCODE and NAACCR to make sure that we have captured the required data elements and that we have a data model, not just a structural model. Would that be more in the line of what you are talking about, or something different?

#### **Peter Yu**





Yeah, I think so. So Memorial Sloan Kettering and Dr. Baliacca there in particular has led the OMOP extension for oncology, and Memorial Sloan Kettering has taken OMOP as the base structure and added elements from NAACCR as well as mCODE to create a common data model that they are now mapping their information to. Because of our relationship with Memorial, we have been in discussions about maybe adopting their model. I have a call later this week with them about that. So, I think about that in terms of maybe a pilot to see if there is a common data model that suits the needs of an academic center or an NCR-designated cancer center like Memorial, but also the needs of a large community health network system, and then how that could be used to test data transmission. That might be a project worth looking into.

**Arien Malec**

Thank you so much.

**Gillian Haney**

Ike? Steve?

**Steven Eichner**

Thank you. I think another component of the issue is looking at what fields are actually being populated by physicians within the EHR and how that connects with the data that is actually being exchanged. I am thinking back to the certification criterion that vendors may get their products certified in the laboratory, as it were, but when product is implemented in the field, sometimes additional fields will be created or substituted without recognizing the impact of the creation of these substitute fields on information exchange. So, it comes back around a little bit, perhaps, to looking at where and when we are testing, and we may be testing the lab version, but not the production version, and that is interfering with getting complete, accurate, and timely data. It may be in the EHR, it is just not being populated in the fields that are being exchanged.

**Gillian Haney**

Another common thread. John?

**John Kansky**

Yes. Keeping in mind the scope of the taskforce, I am trying to keep between the lines, but noting prior conversations we have had about trying to meet standards potentially through intermediaries and hearing about all the challenges, Dr. Yu's reaction to Arien's question strikes me that we are at a pretty basic level in terms of just trying to make sure cancer diagnoses are reported, and then getting the right data elements. I may have to ask this question in other circles, but I am curious if any of the panelists are aware of work with health information exchanges to attempt to either A). Capture diagnoses that were not reported, or B). Fill in missing data fields in incomplete reports. Thanks.

**Jeremy Pine**

This is Jeremy. Within California, we have worked with a number of different HIEs throughout the state. I think this goes back to how we are still at that minimal case reporting-type level, still trying to handle that problem of how we generate the minimal case data from the reporting entities and push that out. You can have an HIE that is in between, but still, they are going to have to query against something within an EHR system to also recognize that that data is there and push that data forward, so if you are looking at a pathology lab system, let's say, we have focused a lot on pathology reporting in past years. You have that







pathological diagnosis that you can reference to, but really, in the cancer registry world, we are also looking for that final diagnosis, which oftentimes would come out of the oncology system, these different points that Dr. Yu also pointed to where data originates within that EHR system or that healthcare system, so we are having to look at a number of different places in order to look for where this data should be coming from.

**Gillian Haney**

North Carolina colleagues, do you have any thoughts about using HIEs, or are you aware of any?

**Nigar Salahuddin**

I think only the immunization measures are using HIE, and it is more hospital-related reporting that happens. Since, with cancer, we are targeting only ambulatory clinics and standalone physician offices, we do not get much interest with the HIE.

**John Kansky**

Thank you. My only follow-up comment would be that obviously, it is a challenge that HIE capabilities and depth of data vary, but I would assert that in some states, that would be a worthy conversation for cancer registries, and I am making a note to go talk to ours. Thank you.

**Gillian Haney**

Certainly, for those states that do not have as quite a robust HIE, I would again look to build off some of the infrastructure that infectious disease currently has operational, which is pretty robust. Bryant?

**Bryant Thomas Karras**

First, on the HIE issues, we do have a robust HIE in our state. One of the challenges that we have is that for folks who wanted to opt into using the C-CDA cancer case reporting standard, their vendor had arbitrarily only enabled direct messaging for the reporting infrastructure and did not build in any of the standard HIE connection capabilities for transporting those messages. So, those providers that wanted to could not. It was kind of a frustrating experience. But, the comment I wanted to make was just to emphasize, and maybe I will ask Sandy to follow up, but leapfrogging ahead to what is possible next, MedMorph demonstrated that one could use the EICR infrastructure capability, that core trigger mechanism within electronic medical record systems, to detect cancer diagnoses and transmit them to a cancer registry. We did a demonstration of that concept at HIMSS with a melanoma case. I believe there is a recording of that. So, I think there are some forward-thinking possibilities of what we can do. If what we have currently in the 2015 cert is not working for folks, we can look ahead to what is coming down the pike.

**Gillian Haney**

Thanks, Bryant. I just also want to point out some of the comments about using the ECR infrastructure to support cancer reporting, and certainly, RCKMS, the triggering tool that public health is using, is very scalable. I am just double-checking to see where it is with cancer reporting, and I just got pinged that yes, RCKMS does have cancer reporting authoring capabilities, so I think that is something that we definitely need to explore. Again, I think the challenge will be the triggering to get that longitudinal data, however, but at least if we can get an initial clean report coming out, that might improve things. Chandrika?

**Steven Eichner**





Gillian, I just want to interject really quickly on what you just said, that the back-end FHIR listener being used for ECR is the same listener as what is being used for MedMorph.

**Gillian Haney**

Okay, thank you.

**Chandrika Rao**

I just wanted to point out one thing. Regardless of everything, one of the main challenges that we face is lack of support on the part of the physicians also, because a lack of support and willingness from that physician group to report.

**Gillian Haney**

Is that due to legal requirements around cancer reporting?

**Chandrika Rao**

Because of a lack of incentive and lack of resources on their part also.

**Arien Malec**

Would it be more correct to say that individual oncologists and hematologists, etc., are not unwilling, but the EHRs that they are using do not natively support reporting capabilities?

**Chandrika Rao**

That also, yes. Thank you.

**Gillian Haney**

Thank you. Hung?

**Hung S. Luu**

I want to add to what has been already said. It is very tempting to leap ahead and think about the ideal model, but where we are currently is lack of sufficient infrastructure to capture enough data to generate that, and so, I think the focus initially, and the ECR is definitely very tempting, is to be able to ensure that for people who are trying their best to generate the data and transmit the data, the infrastructure in place is there to easily do that. And so, I think the rest will come, but unless we have a way for people to easily try to transmit data, the best model in the world is not going to do any good because of the fact that the data elements just are not there in the infrastructure to be able to transmit that.

**Gillian Haney**

It seems like there is an opportunity to move both issues forward in parallel. Hans?

**Hans Buitendijk**

Yeah. A comment that I also put in the chat is that I can see that the way that we are thinking about directions of potentially an ECR-like or MedMorph-like approach has a lot of value, but the question I wanted to raise to consider is are we talking about the same EICR standard to convey that data, or as we look at registries, this is one that we are talking about today, cancer, but as we look at registries generally, are we really talking about EICR, or do we talk about registry-specific data sets, and particularly where there are unique





data requirements depending on the registry? So, there is a lot of similarity that we should figure out if we can take advantage of, but the output and what kind of variations that we need to address for which we need additional standards, guidance, or otherwise beyond what we have for EICR.

**Gillian Haney**

Very good point. This may be an area where we want to take a phased approach.

**Arien Malec**

Hans, I want to follow up with that because the EICR model would be beneficial in being standard and across the board if we adopt certification requirements for it, so it would get registries the up-front diagnosis and general health history information. As I think we have been going back and forth on, it would not get the detailed oncology information on tumor staging, tumor path, cycle therapy, etc., and so, this may be a yes-and as opposed to an either/or.

**Hans Buitendijk**

Agreed. I think we then also have to consider, and this is where it needs to evolve, what is in the balance between what you submit at the time of trigger versus what you are going to query for consistently every time for a known set of data, and if that is the most optimum way to do it. So, I think there are many things to be worked out: What is that optimum flow, and what standards do you then need to address across the board? So, it might be an and-and-and.

**Gillian Haney**

Agreed. I hope everybody is noting Sandy Jones's comments in the chat. She is unable to verbalize them, but she is addressing some of the issues that are being raised right now, so we should take note. I think we will pause here and transition, Arien, over to the worksheet, if that makes sense. I understand a lot of progress has been made in terms of commenting and refining recommendations.

**Task Force Topics Worksheet (00:59:42)**

**Arien Malec**

Yeah, none of which is by me since this last week.

**Bryant Thomas Karras**

Gillian, I do want to make sure people do not have a misconception. I do not think that the influx of infrastructure funds is cascading down to cancer registries. Our cancer registry took a \$250,000.00 hit this year in its next five-year block grant, which means we will have two fewer certified tumor registrars.

**Arien Malec**

In fact, probably quite the opposite in the sense that we are taking money for general public health and devoting it for pandemic response issues, which has been a theme. At some point, we are going to need to rebalance. All right, we could take another pass through reportable lab and then go to syndromic surveillance or EICR. I think that makes sense. I am happy to do either. All right, we will see how I do through here. So, I think we have already been through a bunch of this, and I think the sense of the group is that we want to move to the latest LRI guide because it incorporates errata, modifications, and updates off of ELR and fixes a number of the representational data issues associated with ELR.





We want to go back and relook at the very long lab and order recommendation section that the ISP Taskforce created and consider it as a set of mechanisms for more broadly establishing complete, end-to-end transmission chains from order to lab. One thing I am not sure that we have got already on this sheet is the need to ensure that order information that is going to laboratories include a minimum necessary data set that incorporates patient demographic and patient contact information. I see a number of folks who have done adds to the list, so why don't we go through the hands in order, starting with Ike.

### **Steven Eichner**

Thank you. I just want to make sure that we are all still on the same page about the taskforce charter or focus looking at what are the goals of certification and not getting too far afield in spaces that go through a number of items. I saw the line suggesting that ONC work with the FCC on connectivity in disaster situations or looking at what might be within the scope of SANER reporting. I just want to make sure that we have all got a common understanding about what is in scope.

### **Arien Malec**

So, maybe with regard to that, our scope is definitely Parts 1, 2, and 3. Part 1 is relooking at the existing F criteria for EHRs and suggesting any modifications for those F criteria for EHRs, Part 2 is contemplating certification criteria for public health data systems, and Part 3 is considering data flows. So, in the list of things that you mentioned, I would contemplate looking at potential certification for intermediaries as really fitting the definition of Part 3. I think we discussed earlier things like SANER or vital statistics as being areas that are not currently covered by certification and where we might want to consider that ONC work with industry to develop certification or implementation guides, and then, as implementation guides are tested, then contemplate certification. But, the main line here should be on existing F criteria and modifications to existing F criteria, and then, anything that is an incremental expansion off the existing F criteria with a clear focus on EHRs, public health data systems, and the data flows associated with them, which, as I said, could implicate potential intermediaries.

### **Steven Eichner**

I would just like to reemphasize that I think an important piece as we are looking at the data flow piece is not just on process for flow or method of flow, but what are the data quality issues as a persistent issue because if we are not getting good quality data bidirectionally wherever bidirectional exchange is occurring, that is not helpful for anybody and creates a bunch of unnecessary work and perhaps inaccurate decision making. So, if we include that as part of that charter, that component really becomes kind of an essential piece all the way through.

### **Gillian Haney**

Agreed. I think content needs to be front and center.

### **Arien Malec**

I completely endorse that. What we are talking about for standards and implementation guidance is not just standards for the wrappers, but also data quality standards for the data that is intended to be transmitted. Hans, you have your hand up.

### **Hans Buitendijk**





Yes, Arien. I want to highlight one particular part. If you look at the Part 1 and Part 3 comments and **[inaudible] [01:06:20]** those, when we look at lab reporting LRI that is actually about to be published, it is in the pipeline in HL7 in that last stretch, it also includes demographic, ask-at-order-entry, and other data that was seen as critical to public health and the pandemic response, where there is that align-and-optimize opportunity in Part 3. So, I think we have to balance between LRI for many components which is the most current one out there, but there might be some data that, based on timing of when this happens, has opportunity to be optimized in Part 3, and therefore “be removed” from the guide because it can be done elsewhere. So, I think we have to keep that in mind on how we phrase it in the respective Part 1 and Part 3 recommendations.

### **Arien Malec**

I do not contemplate that we would get to specific implementation guide versions in this taskforce. I would contemplate that we would get to general policy mechanisms and general recommendations for updating to the latest, and then, if we think it is important to mention, as you note, that there are areas where there are specifics that are being used in ELR flows that are better served through an EICR-based approach, we certainly can mention that, and that is consistent with the comments that we had in the ISP Taskforce. Erin?

### **Erin Holt Coyne**

Hi. Regarding LRI and this notion of potentially certifying against LRI, if the scope of this group is to make recommendations about certification criteria for public health specifically, while I agree and support the notion of using LRI, I would worry that not certifying the senders and receivers on the same standard would be problematic and could result in further variation, so I do not know if it is in scope, and I guess this is a question to you and Gillian, to whether or not we can also make recommendations specifically for the certification of our laboratory partners as well as our EHR partners regarding LOI and LRI so we are level setting across the board.

### **Arien Malec**

I am inclined to lean on our Part 3 charter, which has us contemplating important data flows as the avenue to look at a potentially broader use of certification. I think this notion of lab in particular as an ecosystem and information flows from order to result through intermediaries that include national labs, local labs, path labs, state and public health labs, and the APHL infrastructure, this is an area where we could focus just on one leg of that reporting and really miss critical bits of the importance to public health as a receiver, so that is kind of where I would line up the conversations. I think we would be out of our lane if we wandered into making specific recommendations for how physicians generally order lab or how lab LIS vendors generally structure their information, but I think if we look at the specific public health data flows, it would be appropriate for us to look at those data flows from order origination to reporting to public health because I think we have seen that be a critical part of data issues that public health has been wrestling with. Is that where you are thinking as well?

### **Erin Holt Coyne**

Yes, thank you.

### **Arien Malec**

Thank you.



**Gillian Haney**

And I concur, and I think that that is also a key component of the North Star architecture as well, and DMI.

**Arien Malec**

Okay. Let's keep going through. I think we have already addressed a bunch of this stuff. Can we maybe go down to the bottom and just make sure there is nothing new that showed up? So, the last bit, I think we are talking about the latest LRI guide. If we go up one and I move all my bits around...yup, I think we are dealing with all the same concepts here. Good, okay. So, let's go to syndromic. All right, so now, we are dealing with stuff that we have yet to deal with. Hans, maybe we can lean on you to represent your fantastic work here.

**Hans Buitendijk**

Just go from the top? That would work.

**Arien Malec**

Yes, please.

**Hans Buitendijk**

Let's see, first one. Is there an opportunity to scroll to the right just a little bit? That sentence is just chopped. I think this stems to a general discussion that we had that this could be used as an example alignment on terminology. It is not only alignment on syntax, but wherever possible, we get alignment on the content where different jurisdictions use different terminology. In this case, patient service would be an example of it. I think what we are trying to achieve is wherever possible, where the concepts are the same, the data sets and value sets are consistent. Commonly, we can do that within jurisdictions and a cross-jurisdiction analysis. That is the main theme behind this.

**Arien Malec**

Hans, would it be appropriate to say that our syndromic surveillance implementation guide should be cross-mapped to the latest version of USCDI?

**Hans Buitendijk**

That would help, certainly. It might not be enough.

**Arien Malec**

Might not be enough, okay. So, what we are recommending, basically, is that we do a revision of the implementation guide for syndromic surveillance, looking at the latest version of USCDI, and then also looking at regional variation and making sure that we harmonize to regional variations, that we have an implementation guide that, as we have been talking about, raises the floor.

**Hans Buitendijk**

Correct.

**Arien Malec**

Cool, thank you.



**Steven Eichner**

Remembering that syndromic surveillance messaging is based on the ADT [inaudible] [01:13:39] as well, so there may need to be a relationship on that core set as well.

**Arien Malec**

That is right. So, the ADT generally can carry a lot of information, and you pick up the information that it wants to carry with the specific implementation guide, but I think you are pointing out that if I have a registration system and it does not spit out the information that is needed for syndromic surveillance, we need to make sure that we incorporate the sending side in the certification process as well as the actual implementation guide. By the way, this is the boring part of our panel. I really want to thank our panelists on the cancer registry side. You are certainly welcome to stay through our laborious work through the spreadsheet, but you are also welcome to take your leave. We really thank you so much for your input and the expertise that you contributed, both directly and, in some cases, through the chat, so no need to stay on if you have other things to do, and we really thank you for your input. All right, go ahead, Hans.

**Hans Buitendijk**

The next one ties also to the general theme of optimizing and aligning across data feeds, but this one is particularly highlighting that there is data that may come in past a discharge that is still relevant, and the comment below that is highlighting that as well. So, here, the recommendation direction is to work between ONC jurisdictions, align where it can be, and complement with case reporting to ensure that the full data set is collected, which means that there might be, at this point in time, better ways to get that data.

**Arien Malec**

Channeling Gillian, syndromic surveillance is anonymized or deidentified and population-based, and EICR is patient-specific and reportable case-based, but to your point, the complete picture of the population may include the initial population-based data derived from syndromic surveillance, and then be augmented by more specific information that is coming in via EICR, ELR, etc.

**Hans Buitendijk**

Agreed, and it introduces the additional challenge of how this data is being shared, moving from identified into deidentified space. Some of the data is already moved into deidentified; how do I make sure that the additional data is associated with the correct patient that is already in deidentified where those flows occur that way? So, it complicates the flow a little bit more on how to do that on what is the best timing, and once that becomes a question there, where is the optimized flow really best suited?

**Gillian Haney**

You channeled me perfectly, Arien. One additional thing is that we use the syndromic surveillance data very differently than we use the ELR/ECR data. It is by definition to look for emerging trends or to be able to have a little bit of visibility about something that may be happening on the ground that may be new. So, very different use of that data set. Thanks.

**Arien Malec**

Thank you.

**Bryant Thomas Karras**



I think there may be some misconceptions about the nature of syndromic... The implementation guide does allow for initial, follow-up, and final updates to that syndromic case, and those are lined up using the same deidentified identifiers, if you will, so that you are updating a record longitudinally. That concept is totally possible with the current implementation guide using customized syndromic surveillance reporting feeds which are not ADTs, though they look like ADTs. So, I think it is a very different animal than case reporting and ends up a very different end product in our agency.

**Arien Malec**

I think the opportunity here is to use the existing potentially updated implementation guide in more settings of care than we currently certify for. All right, Hans, keep going.

**Hans Buitendijk**

I think the next one we effectively have is something we already talked about, so we do not need to cover that.

**Arien Malec**

The next one is our general comment that we want to raise the floor and make sure there is a common floor that all public health can use. Good.

**Hans Buitendijk**

And we are now at 61. I recognize that flows in the end are different, but still opportunities where we have where we are in the identified space and, in particular, where we can take advantage of those flows. So, that is a longer-term overlap of streams where that can be taken advantage of.

**Arien Malec**

Yup, and then, in 64, we are dealing with this notion that we have contemplated that we should be increasing the number of drop points for syndromic surveillance to include urgent care and primary care as well as admit data in the hospital. Good.

**Bryant Thomas Karras**

I really think that 61 is not a good recommendation. Unless I am misreading it, to me, an alignment talks to conversion to a single data stream. That should not be what we recommend. There are different data streams, and I recommend we strike that one from our recommendation.

**Arien Malec**

It works for me. Maybe an alternative framing of this is that right now, we have a set of F criteria, but we do not have a unified map of public health data flows, and since I think we have talked about the overlap between ELR and EICR, it might be worthwhile to create such a map so that in areas where there are overlaps, we identify them, and in areas where there are not, we clearly delineate that. So, it might be worthwhile to contemplate a unified public health data flows map for sender, intermediary, and destination.

**Gillian Haney**

I think the other big thing to note about this syndromic surveillance is the timing of syndromic surveillance. We get syndromic surveillance and are looking at these data several days in advance of when we would get a laboratory report or case report, and I think there are opportunities, perhaps, to use the syndromic







surveillance data to perhaps complete a case report if information may be missing, or there may be opportunities for alignment, but it is really a distinct data flow, and it is really a distinct data use.

**Arien Malec**

It being noisy and early and [inaudible – crosstalk] [01:22:04]

**Gillian Haney**

Yes.

**Arien Malec**

...is by design. Okay, Ike and Hans.

**Steven Eichner**

There are multiple jurisdictional issues involved both in terms of looking at public health data flows and utilization. In places like Washington state, where they may be collecting additional identifying information, syndromic surveillance may make it easier for the mass data. That information is not collected consistently across jurisdictions, and it would not facilitate matching of records, not just between syndromic surveillance and EICR, but across other domains as well. In some cases, there are still silos, and in many cases, legitimate silos between different public health resources.

**Arien Malec**

Thank you. Hans?

**Hans Buitendijk**

Adding, actually, to Ike's comment, which I really appreciate, that optimization of alignment where data flows, particularly when they are still in the identified space, from a data quality, data [inaudible – background noise] [01:23:22] what data is communicated where. Can we take advantage of that? I still believe that there are opportunities to look at that, very much recognizing the different purpose in the end that it is being used for, but just to enhance the flows overall from providers to public health.

**Arien Malec**

Speaking of the public, it is not time for us to transition to public comment.

**Public Comment (01:23:50)**

**Seth Pazinski**

All right, thank you, Arien. Okay, so, we are going to open up the call for any public comment. If you are on Zoom and would like to make a comment, please use the raise hand function, which is located in the Zoom toolbar at the bottom of your screen. If you are on the phone only, press \*9 to raise your hand, and then, once called upon, press \*6 to mute and unmute your line. So, we will give folks a minute to queue up and see if we have any questions. All right, I am not seeing any questions, so we can conclude the public comment period and I will turn it back to Arien and Gillian for any last conversations and to close out the call.

**Next Steps (01:24:48)**



**Arien Malec**

I learned so much about the cancer registry space. I really thank the panel for their valuable input. I think we have a lot to chew on and consider there. We are going to AHIs next week, and correct me, Gillian and Liz, but I think that concludes our tour through the F criteria.

**Gillian Haney**

We have one more. We have surveys after that.

**Arien Malec**

Healthcare surveys, thank you. So, we have AHIs and healthcare surveys, and at that point, we will have concluded our tour through the F criteria. We are also going to contemplate having a public health data systems technology developer panel, really looking at many of the organizations that currently support public health and to get their perspective on the general topic of certification as opposed to the deep-dive topics that we have had, and then we will continue our tour through the input sheet. Generally, we are going to set October as our goal for having a strong set of draft recommendations and consider October 26th and November 2nd and 9th as our opportunity to do detailed tuning toward the final recommendations.

So, John Kansky asks, "What is the deadline to enter our comments in the tracking sheet?" I think we are good through the first part of October of getting in the raw comments, but we need to start converging toward the middle of October to get to draft recommendations in a transmittal letter format by the end of October so that we can deal with more of the fine-scale tuning and wordsmithing and making sure that we captured all of the key points prior to our last meeting on November 10th, and even though we have a meeting on the 9th, for obvious reasons, our FACA coordinators tend to get grumpy if we are dumping large amounts of new information on them the day before the meeting, so we really should be thinking about getting to a good final draft on the 2nd.

**Gillian Haney**

So, with that final comment, I encourage all of you to continue looking at the track sheet and entering your comments so we can revise and move them forward, and I think we are about halfway through all of our meetings, so let's continue to stay healthy and go strong.

**Arien Malec**

We are making good time. Not doing too well on staying healthy, but we are going strong.

**Gillian Haney**

Thank you all.

**Next Steps (01:28:24)**