Continuity after the termination of the grant itself, and that is how we return this work back to your individual registries in ways that actually accomplish the goal and that's to build the concepts within the individual registries. Gonna have whoever is self-appointed for each group come up and chat about the discussion points for your individual workgroups. With each discussion, we'll have a Q&A. With that, who is representing Workgroup One? Come on up. All right.

All right, thanks. (____) and I facilitated, this is a new version of the PowerPoint slides, it doesn't require any confusing battery power I wonder if we can--

I wish I had thought of that.

I don't know if there's a way to just attach it to your phone. The right's holding okay.

I don't know.

We came up with a framework for talking about return on investment for implementing these common data on this registry. We thought a useful way of framing the discussion is to focus on four areas. One is the current state, why are we even doing this in the first place, what are the pain points? Where are we suffering in terms of, if I'm a registry steward, and I've got my participating clinicians, provider organizations, I have the data chain, right, from the clinical information system, from the EHR to the registry, all of the different vendors that are involved with operating the products themselves as well as the people involved in the data chain, doing the mapping translation, the legal work. So what are the concerns with the current state? Because in order to change anything, the desire to change has to be stronger than the resistance to change, otherwise no change. I forgot the original author, somebody created something called a change formula. There's maybe a number of authors that's originally attributed to. So current state, then the business case. A really simple way of thinking about business case is what is the cost to make the change? And then what might the potential benefits be across different dimensions of financial time, resourcing, quality, other kinds of dimensions? And then, what I've been saying all along and earlier today, is if we're gonna study this, we need measures. So how should we measure the current state in a registry? How should we measure the implementation of the data elements as part of a pilot? And then how should we measure the performance across any dimension after? And then, finally, what are some ideas that we have as a breakout group for work that we would do as part of the pilot? Now I get to test my prescription. I don't know if that qualifies as 20-20, but the current state, high cost of manual charge direction. Not a surprise, it's not sustainable for routine clinical care cases, and for cases where the volume is very high. It's also a barrier to adoption of the registry. If the cost of capturing the data is too high, then a provider, organization, or clinician might refuse to participate in the registry. So that hurts your ability to get your representative sample because you need to have good valid data. Some of you have mentioned this, there's many registries because not all participating organizations are capable of electronically providing the data, so you have to offer, in many cases, a manual option as well as an automated option. So the performance of the same clinician or the same case to the same measure, the results are different if it's manually extracted versus automatically extracted, because of the different ways that the data are being mapped and translated, either by the human extractor, extracting for a particular standard, using a data interface that's
enforcing a certain standard with certain types of audits, and then with data automatically extracted, that process is different. It's not really quite inter-rater reliability, but something along those lines. You could have different measure results, which can impact your ability to successfully participate in MIPS or other payment schemes. Then the business case, the cost is the cost of implementing the data elements, stack time, vendor fees, somebody mentioned that particular vendor, will go nameless, with a charge of $30,000, to make this kinda change. It's not that one you're thinking of, but it's another one.

Sounds like...

Yes. How do you handle historical data? If you're changing the data model in the database, what do you do with the old data? Regardless of what you do, there's a cost associated with making those changes. Then the benefits, potential benefits... Perhaps there's the ability to reduce the time required to onboard clinicians or a patient or a site to the registry. For societies, it's a long, laborious process to bring sites into the fold. Perhaps there's opportunities to reduce that. Anyone who's developing a new registry, anyone who's in the early stages of registry development, could start with these data elements to begin with, and then reap the benefits at no cost. Because really it doesn't cost anything more to implement these than it does to implement something else if you're doing it for the first time. And then, what did I say? So the ability of the registry and its participants to easily participate in the data collection that's required for payment models. So, again, whether it's MIPS or the private payers. Then measuring value, some measures we came up with ideas: error rate, again, the time to onboard sites or patients, the percent of capture of pay elements. Let's say you have a case report, you're only capturing this particular element 68% of the time, maybe we can increase that percentage. And then as you trend toward a census, can you increase your sample size? Is your sample size what you want it to be? If not, does making this change make that any easier for you? And then, finally, ideas for potential activities to take place during the pilot. It demo'd the ability of an EHR vendor to capture the data element that you need to populate your case report form. Think of some ways to analyze data three months before implementing the data elements versus three months after, what aspects of the data might be different? Let's see, I can't remember it. Thinking a little bit clinical for a second. Thinking of data elements like the ethnicity or smoking status, before and after implementing these standards, does that give you the ability to improve the quality of your collection of those data elements? Or the data that you have to capture to represent those concepts? And what are some side benefits of having better data? Say, nonsmoking status. Does it improve your ability to make your datasets useful for research? Or some other kinds of things? That's what we came up with, and this is a framework for the next steps, so if you find a study is done and we publish our report, these are some steps or an outline of steps that registries and others could take, and so some of us in this room, including myself, will be looking at how we can support pilots like this in the future. That's ROI. Any questions?

Question.

Okay, go ahead. There's a microphone.

Return on investment here, who's making the investment? The lenders are making the investment? And who's getting the return? Topics like--

In this case, it's the registry steward because this is a registry-focused project. The registry would incur a cost to implement the data elements. Now, of course, some of those costs and benefits might ultimately be shared by the other participants in the chain, but here, we're measuring through the lens of the registry.
Good, thank you for that.

Other questions? (...) I'm gonna ask you to think about it from the ACC perspective. What do you need for an ROI statement? I'm gonna ask you to think about it from the American College of Cardiology's perspective, what would help you in your discussions vis-a-vis the specifics of an ROI statement?

I think the first challenge that we're going to face is if there is an existing registry that is being implemented, the vendors have already implemented it, so the cost is not going to be on the ACC side, yes, but probably for the definition's perspective, we're re-issuing a new data dictionary that all the definitions could be a burden on ACC, but most of the burden is going to be on the vendors. That's for the existing registry. For any new registry or version upgrades that we are doing, the selling point is going to be how readily usable these definitions are, and it is being used by who, when we know who's backing it, that is kind of important, actually that's more important from the vendor's perspective as well. When you're talking about ROI, I tend to do, because I manage the vendors, those questions often come like, "Okay, you are moving towards the standard, "what does it mean?' You are talking about original investment and some of the things that are going to help the hospitals reduce the data collection burden, which means are we talking about implementing it within EHR? All those kinds of questions would arise, like are we talking about direct EHR integration? If that is what we are aiming for, that would be a different kind of argument that we can now place within the ACC. And one of those strategy goals to reduce the burden by integrating it with the EHR as much as possible, as part of workflow.

Great, yeah great comments.

Just fill me in on some details. Present the potential opportunity with the benefit. The vision that I'm working for in my mind is that what we're asking the vendors to do is implement FHIR read and write services. And that changes the argument from saying, "Support my registry" to "Support these underlying functions," because then anybody can write the program that does the extraction or that aids in data entry or something else, and it basically makes it a free market now for people to develop the application. So instead of asking the vendors to support this registry and this registry and this registry, and beyond registries, to support reporting to CMS, to report research forms, to report... What you're asking them to do is create a fundamental function that they create once so that anybody who needs sodiums, or anybody who needs ejection fraction or anybody, they can ask for it. And they don't ask... you don't have to have them implement that every time again for a different purpose. So it can lead to an incredibly more efficient way of developing this kind of information exchange, to support registries, and the work that you do on registries, better fits you in every other way that you want to access and use data.

Right, from the help system point of view, there's some real return.

Let me ask this question, maybe it's impertinent, but say we reach nirvana sometime in the next year or two, where common data elements are all defined, and everybody's agreeing to it, and all the registries, etc. Do we need vendors?

Somebody still has to operate the systems, right?
Would operate what system? The vendors are an intermediary between the hospital and the registry. Will this enable the hospitals to report directly and electronically to the registries without the need of a vendor?

...... might have a comment on that.

Just asking the question.

I know, I'm thinking, yeah.

What--

Yeah, go ahead, sorry...

No, go ahead.

I was gonna say, you know, translation and mapping, if you eliminate that, you're gonna put some people out of business, but the majority of, I think, the data systems, you still need data systems. Now, maybe eventually, the need for separate registries goes away and we're not quite there yet, but I think there's a lot more that these vendors do than simply translation and mapping. They're still data storage, but your point is interesting. If we have a set of interchangeable parts, then we could potentially reduce the number of different data repositories we need in healthcare, which would probably be a benefit.

Except these vendors are really just an intermediary and they don't store data for NCDR.

Some of them, but we do have

Just tell him what your vendors do. They're primarily, they're there to facilitate the transmission of data from the hospital to the registry, and the registry actually stores it elsewhere, but it's not them, they're not...

Not all of them. Because we do have vendors who have CVIS system, that sends data to the registry as well as... I mean, we tried out different models, picturing, that's the good thing about it. What we found out was because the data is sold from different systems, and all of those banks are not in EHR, the model that I see that would work is a local application and transmission to different source. You could use it for your data warehouse, whatever purpose. It's done by vendor, or locally by whoever it is. But done locally, abbreviated, and then transmitted to different registries as possible.

In this same ideal world, the microphone is gonna float automatically to whoever's speaking.

Just raising your hand, nice and light. But I think what it could do is rapidly accelerate the disruption that's needed in the home information technology market. Right now, part of the reason for consolidation of the market is because a single vendor can more easily guarantee communication between multiple systems if they own all the systems in the chain. Part of the reason they need to do that is because of the high cost and effort of mapping and moving data from place to place. The cost of moving data from place to place drops drastically, data quality goes up, and the effort of mapping disappears, it means that you actually could have a competitive market, where the best player for each functionality, current functionality of the EHR, becomes an actual competition. And so people will buy a
data warehouse, and they'll buy an interface, and then they can buy a whole bunch of plugins, instead of having to be forced to choose between one or two different products that are able to semi-do most of those things all at once.

Maybe once standards come in.

Including maybe one that presents a nice user interface for the clinician Great, thank you, ...., any other comments or questions?

Or you can build your own.

All right, ___ and I led the communications group, and I actually did go ahead and put a few slides together here. Just give me the mic. I hope, like all of the other groups, that we had a very robust discussion. Our participants were all representatives of the registries and it turns out that each one of them uses a systems integrator to capture the information, manage the information from EHR systems, so the three EHR systems integrator software solutions that were represented included FigMD, Premier, and Arbor Metrics in our group. I asked a question about how many registries do it this way and kind of a back of the envelope calculation was probably about half of the registries do it this way and half of them manage the registries themselves internally to the individual societies. That's actually something to think about, that I hadn't really quite gotten into my head before, but in terms of communicating the message, and that's to ask folks to rebuild, build, rebuild databases that are consistent in their implementation of the data standards, half of the community that we need to appeal to therefore, are the systems integrators, not the professional societies themselves. If you think about it from that standpoint, pretty quickly, you actually have two different populations or two different groups that need to be appealed to. One is, obviously, the leadership of the society themselves. They are the ones who own the data concepts, they're the ones who use that data for various purposes, performance measurement, quality measurement, etc., etc. If you will, society leadership. The second group that needs to be messaged are the systems integrator vendors themselves. Not just the EHR vendor community, which is what we talked about earlier, that is pushing even more pressure upstream, but the systems integrators will need to be messaged directly. Part of the reason for bringing it forward is that the systems integrators oftentimes are not perhaps well-funded, they have very narrow profit margins, etc. And like any other institution, any other organization, you have to make decisions based upon ROI, based upon the availability of resources, etc. One of the points that was raised is to influence the systems integrator community, there actually is going to need to be a critical mass of you, the registry community, saying that this is something that we are moving towards that we want to accomplish, etc. We talked about what that communications package would include. Think of it from two perspectives again, one is talking to leadership of the societies, of the associations, and the second one is to talk to the IT vendors themselves, especially the systems integrators. We basically danced around this for five, 15, 20 minutes and I'd ask you to also think about this. But the key things are an executive summary, not long, not a white paper. We obviously will have the Pew report available as a reference, but the one page handout, with perhaps four or five bullet points is a powerful tool, especially to executive leaders. It was recognized that there will be times when at least a short presentation needs to be given to others, whether it's your own database developers, whether it's your discussions with the systems integrator, etc. So a PowerPoint set would be helpful, starting probably with this set of slides we put together today. (___) already counted out the ROI statements, from the ROI statement perspective, two different audiences, like we mentioned before. And included in the ROI statement something that's a little harder to do, because it's not actually a positive number, but the cost of not being inoperable somehow needs to be calculated into that. Website, I hope all of you here
recognize that we’ve shown you the website for this particular project multiple times, now that you’ve copied it down, but there is a website where there's gonna be durable materials and other online resources. And then, as far as the package, additional resources need to be at least available for face-to-face meetings, if not face-to-face, then WebEx meetings where one-on-one discussions with each society, one at a time, as opposed to getting the societies together, are warranted. We asked the question, "What should be included "in the package as the drivers, "or the rationale, for doing this?" And I don't think any of this comes as a surprise, but the potential of the enablement of an environment where secondary data use beyond the purpose for which the data was collected obviously is an important driver, with the operability of that data becoming critical. A better, more... increasing the likelihood that you could actually assess longitudinal patient care, especially through patient matching, etc. Benchmarking, several of the registry owners mentioned that the benchmarking that's typically done right now is just your individual practice, the members of your individual practice along with those physicians that one of the key drivers is doing benchmarking outside of your own organization. Going beyond public reporting to all the metrics that associations own that have to do with the fairly narrow focus that both public reporting, as well as other measures like PQRS and now MIPS have, in terms of relevance to an individual practice or an individual discipline, that is that the societies typically have many, many more measures, metrics, performance outcomes, etc. that get measured beyond what the typical MIPS reporting requires. Enabling clinical research. I mentioned before the cost of registry participation in terms of the ROI calculations. We spent a fair amount of time about, not just the personnel that are required to capture the information, but also at the very end of that line, the mapping burden. The folks that own registries spend a lot of time dealing one-on-one with their individual sites just instructing them this is what this particular data element means, this is what this data element X means, etc., etc. Improving data quality. I mentioned before with the longitudinal patient care, but writ large, the ability to accomplish data linkage. And then understanding and managing transitions of care were also identified as drivers. And then the only thing that was actually identified as not being a driver was our federal programs. That at least in 2018, MIPS was not a driver for moving forward on interoperability. So the appeal really needs to be made outside of the programs that the federal government has brought forward. That, in essence, I believe, captures most of the points of discussion. Anything else that needed to be mentioned? Among the discussion points? Comments, questions? All right. So at this point, before we move on to the third report out, I would actually like to...

(____) had to go to a conference call.

---- had to go. We were abusing him a fair amount before Do you have any comments about federal programs? Federal levers trying to leverage what is out there? I actually chatted a fair amount this morning about the CRNs, the Coordinated Research Networks, (____) was here, although he didn't say anything either. I was gonna pick on (____) too, but now it looks like you're the person that's left. How do you envision the federal government, since MIPS has not been effective at moving forward this interoperability, how would you think about the other things that the federal government's doing?

I'm happy to say a few words, but our break-out group addressed this issue in detail, so I don't wanna steal anybody's thunder. Who's gonna do our...

Oh. All right, you know me We identified in our group a number of challenges, and I think we all know the challenges, so I won't be negative about it, but also with government collaboration, the focus I wanted to bring is that the government itself is an obstacle in its effort in its multiple parts and
categorical funding. Oh, (___) is here too though. She can give the AHRQ perspective. The government is part of the problem, it's not just the solution here. Working against government categorical funding is very difficult, because that's where the power is, and that's... agencies at that top level fight for money. There are a number of models where, and one of them, PCORI Trust funds one of them. I think many of you know about that. That incentivizes government agencies to work together around real-world evidence issues. I think that's one. Nothing can replace leadership. Again, not to... Dr. Gottlieb is an incredible leader actually, but Dr. Califf took the out of step with the rest of the government. The head of the FDA doesn't convene the rest of the government, but he did, with FGEN effort. And that was another exercise of bringing private sector and public sector, multiple agencies at the top together to talk about how to coordinate these efforts. I think those are an important perspective we need to continue to chew on, at least for us in the federal government, but also as citizens, to ask our government to work together.

(___), we look forward to your report. Any other comments or questions?

We also have one from NLM, not to erase the spot, but if we're acknowledging all the federal people in the room.

Comment? Okay. All right, let's move on to group three. This is the key technical challenges adoption. (___) and (___), I think you're gonna present.

The first thing that we are doing was to define the data flow from point of care to the registry, and the technological aspects of it. We had a fictional EHR vendor, we called it Epic And so starting from Epic's med reconciliation it takes... med reconciliation is in a "mumps" format, which then has to be transferred into a relational SQL database. That happens at the end of the week, there's one level of technology transfer. Then, from there, we get outputs of Epic drug codes rather than RxNorm codes, so there's another technology transfer. We do that based on MRNs, provider, and date of clinical visit. From the drug codes, we have to convert those to an Rx norm format with a homemade bridge that we made. Even though I made it, I'm sure that it's great, And that provides us with a local list. Now, let's say we're not just going for specific drugs, but we're under drug class. Then we need to identify all of the Rx norm values that make a drug class, and there's another transfer. So before we can even get to the big level, or the extraction level, we have four different ETL protocols just for one data element. So the challenge is, how do we cut those ETLs down? How do we use technology to leverage, to make it so med reconciliation populates the registry? And we identified a few different ways that this problem can be addressed through a few different ideas. Administrative burden. The first thing is, registries have the ability to... Registries are the representative of the clinicians of the society. So all registries, everyone here combined, make up a powerful group of clinicians. And that's enough to leverage and create some sort of unity to stay visible. Now, what do we want? We want something that's both semantic and syntactically interoperable. How can we do that? From this project, we have identified terminologies. One of the specific terminology uses is a new SOLOR, S-O-L-O-R, which is the combination of SNOMED CT, LOINC, and RxNorm. It is identifying interoperable standards between those three. Now that's a possible, where we're going, that's one of our takeouts from our technology. Meaning, is identify to see if SOLOR actually does work as we want it to with all the registries. Whether we can get that information in usable and workable formats. Then finally, we've identified syntactic... It can't just mean the same thing. It has to operate computer-to-computer. And so from that, HL7 and FHIR were additional ways that we were looking to see if that would fit the format. So our take home from this is utilizing SOLOR, does that work to overcome technological hurdles for semantic inoperability? And then using FHIR, does that work to overcome technology, syntactic problems? Are there any questions? Or comments?
So, would you propose that as part of (___’s) framework for testing things?

Yes.

I think we also would recognize that there would be challenges in actually carrying this out and understanding all those individuals or stakeholders that would need to be involved. And also the rules, the framework in which they would operate to achieve this sort of thing. So there's really a need for multi-stakeholder operations, health systems, registries, maybe the vendors participating in developing these solutions, but also a multi-stakeholder governance group that sets the framework for exactly what it is that we're gonna do and quite frankly, coming up with the CDEs and maintaining those over time. And by the way, an editorial comment, I don't think the EHR vendors should be part of the governance group, they are just part of operations.

Yes, so we have clinicians provide the content, the standards on registries organization are the terminology, big governance, ONC, etc, is the rules. The systems leaders administrate it, and the vendors' job is technology. Their job is to get what we tell them we need to work to work.

(__) & (___), and (___), you've been kind of quiet here. Again, appreciate the support the Pew has provided, but what are your perspectives? You guys have been dealing with the HIT area at large for quite a while now. You've been trying to think through what it takes to make change. Part of the reason for the grant itself was to explore the opportunities, identify the holes, identify the gaps, and think through where to take this. Can I impose on you for some comments, impose on you guys?

I'm gonna pass this over to (____)

Thanks for the question. And ( _) & (___), please also chime in. I think this overlaps a lot with what we talked about in workgroup four, so I'll jump ahead to some of that. One of the things we discussed was the real challenges in the past when government has tried to mandate certain things like standards. We all know the challenges of being, Despite those challenges, there’s a real opportunity going forward to encourage standardized common data elements through the US CDI, which was kind of the acronym of the day that everyone used. And the point was made, repeatedly, that the US CDI is really going to be a pool of data elements that vendors and organizations from across the healthcare industry should be pulling from. So that includes both EHR developers and registry stewards. So that everyone’s using the US CDI data element, so that we're really fixing a lot of interoperability problems. And so the best opportunity to generate adoption of the data elements identified for this project is by encouraging ONC to embed them in the US CDI with the level of granularity and standardization that we kind of come up with here. The point was also made that aside from these cross-domain data elements, there are also domain-specific data elements where standardization will certainly be useful. And that is something that should be done in parallel to these common cross-domain data elements, but also the US CDI has an opportunity to get those domain-specific data elements to be incorporated and advanced. There was, from our group, a somewhat near-term opportunity to make progress here on an annual basis when ONC updating the US CDI, which is really still in draft form, still in its infancy, has not been finalized, but as currently envisioned, that's an opportunity that people in this room can take advantage of to encourage adoption.

How about you, (___)?
Just to add on to that, I really appreciate you, (___), in the beginning of the day, when you were talking about the list of data elements that you are proposing, and they stick very closely to what was in the CCDS, and will be a part of the US CDI, certainly, moving forward. And there was also conversation in our work group around the fact that clinicians only want to document the bare minimum. They don't want to spend a lot of time doing all of this extra stuff if it doesn't help them with payment or help them with quality or whatnot. Sticking to a very base set of data elements that are actually going to be federally required that the vendors make available, I think is a really great start for this project. So you're not overwhelming everyone with... these are, out of 40 million ranked data elements, these are 2,000. You're sticking to a very concrete, manageable portion. I think that as we continue along this path, and as you guys continue working to finalize the data elements, making sure that we're keeping in mind the fact that while these data elements are meant to be across domains, we're not trying to boil the ocean. (___), do you have any comment?

Nothing to add on top of what (__) and (___) have already said.

That's probably the perfect segue then to the report out from group four. Who's gonna do that?

Thank you, we've had a very good discussion and it went quite a few directions. I don't have any PowerPoint slides or pieces of paper. But I think there's a couple points to add on to what the discussions that have happened with groups one, two, and three. And the first is that, for me, with the understanding of the limitations that are imposed by the government and which you've talked about, which is, they're really regulatorily bound, statutorily bound, and categorically bound to what they can do. ONC is in a good position to provide some oversight, but they don't have as much freedom in terms of what I see as the uber-strategic planning and high-level thought process. And I didn't hear that we have an answer to that yet. When you look at groups such as HL7 there's a number of groups doing the good stuff, and I'll be interested from your perspective and stand whether it's CIMI or other groups are now coming together in a way that can provide that sort of strategic to tactical guidance that comes through. ONC, FDA, and others can certainly help facilitate this, but there are really limitations to issues there. One of the important things that Rob said before he departed, apparently not knowing the rule of (___) and I that anybody who isn't here, can't vote to not take on more work, it is that he really made, and I think articulated very well, that right now, we currently reward quality reporting and not quality measurements, and so I think one of the takeaways that we have to engrain is we've gotta move to the concept of rewarding quality measurements. And some of the things we talked about in our group is actually, there's an interface that we hear frequently, which is, if you have 10 clinicians, they have 10 different ways they wanna do things, there's 10 different things to do. In our research, one of the things that I thought was interesting in our AHRQ grant is we went to different sites, and they all use different EHRs, and we used a simulated patient, and what we found out is cardiology is practiced the same across all the sites, independent of EHR. So if that is the case, then you can, in fact, establish best practices. And we think, if we thought about this, that specialty societies, you folks, really need to represent the clinicians in terms of what is really important to the clinicians that you could represent forward and then serve at that interface with, as we were talking about the development of the US CDI, it really needs to have some commonality. The other thing Rob talked about, which I thought was important, is really tearing apart CPDA to get down to the common data elements, and I think that's another good concept to take away from this. As we look at this, I wrote down, "US CDI is a great new hope." And I think that's really what we're looking at here. I'll throw it open to Ben, to finish up.
Thanks, (___), and yeah, I already said most of the US CDI discussion. One of the things that ties into what John said, is we should... wanna be able to chop the CPDA into pieces, which will theoretically be more possible once we have an API infrastructure in place, which we hopefully will have in the not-too-distant future, as ONC develops regulations around API, and where our organizations use FHIR, and RDOT profiles for FHIR, that will make it a lot easier to pull the data that you want, so long as everyone’s using the same set of standards for the information, which is why leveraging the US CDI and getting everyone on board with the US CDI, but from the EHR vendor perspective and the registry steward perspective is gonna be really helpful to promote interoperability. That was a big takeaway. Any questions for group four? Any other things that we talked about in group four that any other members wanted to raise?

I have a question. I know FHIR was mentioned a couple of times. FHIR was mentioned couple of times. I have a question. As far as the present implementation of FHIR goes, it supports record at a time extraction, but if I understand it right, it doesn't allow batch extraction.

It does now.

They're working on it.

Oh, okay, it does. Okay.

Well, it's not implemented yet, but they've enhanced the standard to do batch queries and batch population-based queries return.

It is EHR vendors supporting that because the reason why I ask is when we have interaction with Epic, for example, we mentioned multiple times, in terms of performance and scalability, they direct you toward their data mart or maybe latency is not an issue, they generally direct you to Caboodle and their APIs for that purpose. So how practical is a FHIR implementation in terms of batch extract?

It's designed and it's going to ballot. As far as I know, people have done experiments, but I don't know that it's a product yet, that it's deliverable, so it's a future, so I don't think you could use it today, but you should be planning to use it in the future. And it's hard to predict how soon you could buy it at a store near you, but it's been a real emphasis of Don Rucker and ONC to support the population-based FHIR queries, and so it's been a real emphasis for them, so that, if you will, the standard is pretty much there, and then what we're looking for is the actual implementation for vendors so that you can use it in your own institution.

Thank you.

Other questions?

Not a question, but a comment. Just a comment, you mentioned to me in the... What we've been working on, and what occurs to me is that, what we've been doing with HSPC and CIIC are things that we really should correlate very tightly as a complement to US CDI. Because there's no reason for us to do something different or contrary to what's being done there. For those of you who don't know, CIMI is an HL7 work group. CIMI stands for Clinical Information Modeling Initiative. And CIMI is making formal models of the kind that Julia showed in her slides. And so it's a technical modeling activity. And what we realized very early is that we needed what we've talked about here in terms of the governance and
clinical leadership to say what's important to collect, if there are different ways that we can do this, is there one preferred way that we can agree to, and have that driven by clinicians and front-line clinicians. And so CIMI's, if you will, kind of a technical group that's worried about standards of modeling and the style of modeling and CIIC and HSPC are very much concerned with getting clinical input and trying to drive adoption by creating consensus using an open consensus process across specialty organizations, and across government agencies, and patients and other interest groups to decide a preferred way to do things. And there's no reason that that couldn't be thought of as further refinement, if you will, of US CDI. Because US CDI, at least at the level I've seen it so far, wouldn't lead, in and of itself, to true interoperability yet. It's still sort of naming categories of things as opposed to getting to the real explicit details that you need to get to interoperability, and so I think we need to think about, is there a way that we can involve and explain to people that those are complementary activities and we just wanna work together and get it done?

Perfect. Thank you very much, so (___), in answer to your question, I actually have submitted a Pew project as a project for CIIC development and the CIMI augment, so not sure how we're going to do it, but at least it's listed as a project. You saw that the overlap with the US CDI is substantive and substantial; it's probably the pieces that can be developed by CIMI modeling. We've avoided the amorphous ones purposely, but hopefully that will lead us forward. Yeah?

As (___) was talking, I just had another thought. One of the things that we talked about in group three that was mentioned is it may be that the best stakeholders for initial implementation for some of this content may be people who don't have too much skin in the game already. If you're totally invested in one of the specific models I presented, for example, before, there's gonna be relatively high risk and cost in moving to something new, but if there's a use case that's unsupported by the current architecture, that's a real opportunity to bring this stuff to the fold and, as (___) was talking, I have no idea why, but the state innovation model just popped into my head. I think, no one has mentioned those guys yet, so I'm just throwing that out there as another potential use case, because they have something that needs to be vendor-agnostic, that needs to work across multiple settings, and the state can be a powerful stakeholder in terms of partnering.

Great, so let me go ahead and finish up then. The first comment I'll make is this has been a terrific day. I hope everybody shares my personal enthusiasm. I really do think we're on the launching pad to transforming healthcare. I mentioned before and I'll just say it again. This is a journey of a thousand miles. We have to take a few steps. Fortunately, we have a DSR, but fortunately, we have actually multiple oars in the water, and, not that I'm good at metaphors, but I'm obviously mixing them now, but that suffices to say, it really does start with a group, it has to start with a spark, and I think this is the group to actually accomplish that. I showed this slide before, and perhaps now it will mean a little bit more to you. Again, where we started was right in the center is this playbook. What we're focused on is one little tiny portion of the playbook, and that's right in the middle, these general, or core, common data element concepts right here. We mentioned a number of times the need for domain-specific common data elements, but we need the UDI folks to continue to work on the work of device identification, Theresa's been kind to raise the AHRQ banner here, and talk about outcomes. We talked about some of the informatics thereof. The acronyms, CIC for Clinical Information Council, does I mean--Interoperability.
Sorry, Clinical Interoperability Council, where CCRF is housed, the common clinical registry framework that worked in HL7 is housed. That acronym has been mentioned. CIIC, the Clinical Information Interoperability Council, not to be confused with the Clinical Interoperability Council.

Terrible.

We’re working on different names. As (___) just mentioned, CIMI, that sits here. The importance of vendors, the importance of the National Library of Medicine. Thank you for your representation here, in terms of CDE repository, the VSAC repository, and perhaps, more importantly, having somebody to take some degree of overarching responsibility and coralling of all this work, that’s there. We’ve had representation from the Office of the National Coordinator. FDA has been, I think, a great partner in this. Can't wait to consume many of the work products that we’re putting together. Even the National Evaluation System for Health Technology, the thing that, if you will, Rob Califf pushed forward to try to move that forward. We’re meeting here in DC in a few days to talk about how to develop real-world data into real-world evidence, etc. And you can see how other folks on this map here all play a part in trying to make all this happen. So it is fairly complicated, it is fairly convoluted, I think this, hopefully, now makes more sense to you in terms of the diagram. The implications... I put this slide together before the meeting, so I don't know if these implications are right, but where we need to focus, or why we need to focus, I should say, our attention on this, is that data standards really are driven by the use cases. The biggest use case out there for interoperability aside from direct clinical care, that's moving it from one context to another, is the registry. The registry, that's where it is in terms of performance, measure, and quality improvement, outcomes assessment, etc. That's a key use case. The FDA is leveraging the registry community, that's why it's called Coordinated Registry Networks. They're leveraging the registry community. That includes MDepiNET, Medical Device Epidemiology Network. A number of organizations have focused on bringing the registry community together. NQRN, represented by (___) and his colleagues. Also CMSS, Helen Burstin and her group, up in Chicago. The thing that's been missing so far, and what I'd like to change, is that it really hasn’t been clinicians associations, registries that have been pushing the interoperability agenda. So you've heard it from me multiple times today, how we turn that around to make us actually own that. Not to get too heavy into things, so I thought I'd leave you with a couple of more light ideas and concepts here. I've read two books, I'm in the process of reading the second book here. I would highly recommend these to you, to think about how do you change the world. The first one is by Mr. Thayler who is a Nobel Laureate last year in Economics. His field is Behavioral Economics. The title of this is simply Nudge. It talks about improving decisions about health, wealth, and happiness, and he really talks about the need to set up, in order to advance society, in terms of advancing civilization, the need for choice architecture. That is providing framework so that people can do the right thing when they're supposed to. When you sign up as an employee for an organization, one of the things that should be automatic is an investment via 401, 403 or some other type of investment portfolio into your retirement. You should be given the option to choose, but the first choice in that option should be participation in a retirement portfolio and you have to specifically say, "No, I don't want to" in order to, if you will, opt-out from that. Things that he brings up in his book, this concept of unrealistic optimism. And my framing of that for this particular meeting is if interoperability were that easy, we would have done it, if you will, a long time. We’re facing loss aversion. The concept of asking registries or the systems integrator community to change the way they’re doing things, obviously has inertia. It also has this negative thing, that they’ve been doing it this way for 20 years. So we’re gonna lose something if we change the way we do it. Inertia favors stasis. We need to fight that as well. There is a status quo bias. How do we overcome the status quo bias? What we are gonna be producing is an implementation guide that’s an easy button, so you can just hand it to the database developer and say, "Sometime in the next two years, please do this." Hopefully that will hold
sway. And then we need to frame this the right way and that's why we spent these four sessions on how to convince all the leaders, all the people that need to do this, how to sell this concept. That's the first book I would ask you to actually pick up from Amazon or listen to on Audible. It's a great read, if you haven't read it already. The second one is by the inventors of the now-famous psychology experiments with the gorilla. Everybody knows about the gorilla experiment, right? Let me do this. Let me see if I can get to it quickly.

Oh, but you gave away the punchline.

What's that?

You gave it away.

No, no, no, I didn't give it away. You guys should all know already. This is pretty famous. If you haven't seen this, this is pretty cool.

I haven't seen it.

Let's see here. I'm gonna show you this version.

- [Video Narrator] The Monkey Business Illusion. Count how many times the players wearing white pass the ball. The correct answer is 16 passes. Did you spot the gorilla?

Okay, so since you knew that was coming, everybody spotted the gorilla, right? Did you spot the two other things that happened?

- [Video Narrator] For people who haven't seen or heard about a video like this before, about half miss the gorilla. If you knew about the gorilla, you probably saw it. But did you notice the curtain changing color or the player on the black team leaving the game? Let's rewind and watch it again. Here comes the gorilla, and there goes a player, and the curtain is changing from red to gold. When you're looking for a gorilla, you often miss other unexpected events. And that's the monkey business illusion. Learn more about this illusion and the original gorilla experiment at theinvisiblegorilla.com.

Again, just to lighten it up at the end of the day, it has been a long day--

- [Commercial Narrator] I've been exploring the wireless world of Sprint, and I've learned Sprint is building America's mobile 5G network.

Sorry.

- [Commercial Narrator] I've also discovered--

This is the second book I would advise you guys to read. It's called The Invisible Gorilla and it talks about illusions. Illusions of attention, memory, confidence, knowledge, cause, and potential, and there's at least three of these illusions that are applicable to this group. One is the illusion of attention. We've spent a lot of time here talking about what it is that we're trying to accomplish, but unless they continue to pay attention to this, it's gonna go, recede into our background very quickly. Even though you may think, "Oh yeah, I'm ready to go, we're gonna do this," but if I ask you to think about how to make sure
that it maintains a point to your attention. The illusion of confidence. I'd like to say, "Oh, we’re gonna be done in two weeks, "or two months, or two years." I’m not going to say that anymore because the book points that it always takes a lot longer to accomplish things. So I hope that we're all confident that it can happen, but the confidence is something that oftentimes is very quickly passing. It's an illusion, so please, again, pay attention to the work that needs to be done in order to do this. And the illusion of knowledge. I'm not gonna tell you that I actually really understand what is going big, we’re gonna be in this all together. That's part of the reason to get us all together is to try to figure out how to make all this stuff happen. With that, two books to have you read sometime, that's the end of the day. Happy to answer any final questions and/or take comments. Ben, yes?

I just wanted to also thank Jimmy and Becky, and the rest of the DCRI team for all the work they're putting into this research. We have some interesting analysis and I think we're all learning a lot about what registries are collecting. Thank you for that. Also, to (__), who has done a lot of work about working with Duke and working on today's event, and is really taking the lead on a lot of our standards and our interoperability work. And to everyone here today for participating and for providing your insight. I know during the general session and during the workgroup that I participated in I learned a lot and heard some great perspectives.

We will distribute slides. Our emails are up there, Becky.Wilgus and myself @Duke.edu. Everybody who was here will get a copy of the slides plus links to the website where you can figure out what we're doing in terms of progress. Other artifacts will be posted there, etc. With that, any closing comments?

No, I just wanted to thank Anqi and Ben and the Pew Charitable Trust events team and IT support team for all of their efforts to support the meeting and the project. I'd like to thank the project team, Jimmy Tcheng, Seth Blumenthal, Joe Drozda, John Windle, Tom Windle, Julia Skapik, Anne Heath, Mary Williams, and Davera Gabriel for all their help, and last but not least, I'd like to thank all of you for being here and for your contributions and support for the project.

And one last thanks to (____). She really is the person who pulled this off. Thank you very much everyone.