They have two strategies, and they're called push and pull. And so what you really wanna do is, for the most part you wanna pull, because that is the most straightforward and literally it means that they put a connector up against the EHR and the data. I mean, this is a very simplified version, but the data flows into the FIG registry, which is in a cloud, an Amazon Cloud technology.

But some, either contracts that hospitals or physicians have with their EHR vendor, or the EHR technology itself, doesn't allow for that, and in those cases a lot of them push data, which means we give the data elements that we need for it, whether it be quality measures, or disease conditions we're following, or test measures we're looking at, and they push that data to us, and that gets a little bit more complex.

And there's all kinds of protections, obviously, and security around it, otherwise we would never get access.

So we've, over the years, developed a number of custom nephrology measures. We did it back prior to there being any kind of QCDR space back in the PQRS days. Some of them made it into PQRS, some were sort of just hanging out waiting to be used

But we've been struggling with adoption of the registry, struggling to get EHRs on board. So our data format is typically, there's a sort of set data template, data dictionary, that is used by Premier. Usually comes in a flat file format, although we also do take CCDAs.

Gather the data, our eyes on quality improvement initiatives, which the hospitals focus on throughout the state.

Our data model is almost entirely written by ourselves, and then forced upon the vendor to produce that. But it's a complete mess, because it's evolved over 12 or 15 years without any strategic intent

So providing detailed instructions to the vendors is a challenge and that's certainly the work we've seen here. I'm gonna take this away. It's gonna become part of our building or programming instructions, which for me is, I have my what we call our clinical support team with our clinical champions and they write our definitions and decide which direction we're going strategically and then that gets passed to me.
Patching up broken systems is probably the path of least resistance for them to getting internal investment from their funders. That's the bleak vision.

Reference 10 - 0.12% Coverage

I know from, with my own communications that a one-sheet is the way forward.

Reference 11 - 0.53% Coverage

Not that everybody could afford to come here so we had to be fairly selective but doing this, disseminating information by WebEx seems to be actually reasonably effective. Back to the PowerPoint slides, how many is the optimal number? Just thinking about what you would want. So did you see I put the slide back together.

Reference 12 - 0.41% Coverage

An ROI statement clearly is needed from two perspectives. What's in it for each society and then what's in it for the registry vendors so that when you're having a discussion with the vendors they can actually at least have some description of ROI.

Reference 13 - 0.43% Coverage

We have a few people that would be very interested in getting in there and seeing the whole picture, you know why, and the hows, and the history of it, but that's a minority. Most people they're like tell me what I need to know in a nice complete, concise manner.

Reference 14 - 0.40% Coverage

I've sat on the American College of Cardiology's informatics and health IT task force now for the better part of a decade plus and we've largely sat on the sidelines because we've dabbled in trying to build data elements into data standards.

Reference 15 - 0.61% Coverage

I see you some of the drivers for the companies they all work with like the registries they work for or the physicians over there because when I talk about interoperability, the things that come to my mind are uses of the data beyond what it's collected for, but not a lot of people understand that and it's hard to translate that message into something that's meaningful.

Reference 16 - 0.29% Coverage

One of the things that attracted our people and I don't think we're actually fully really there yet is getting more of a complete picture of patient care, a longitudinal picture.

Reference 17 - 0.70% Coverage

But one thing we just started exploring is this whole area of clinical research and participation in research studies even at a private practice level and taking the data that they're providing us and providing that to groups that do research trials so they can more easily identify principal investigators and people to participate in clinical research and I think that's a huge thing, and it also would help with the cost.
Reducing the burden of manual obstruction is key.

Big data is such this, such a sexy subject or perhaps but a few years ago because we can. And then throw big data and do magic at it. People are still doing that with their data and actually I mean I was going to talk about data linking to other data sources as being a key piece of. But the way that's being done right now is through this sort of black box data science that is pretty effective in our case at the University of Michigan, and we can link data from anesthesiology registry to our general surgery registry to our, we have a Michigan value collaborative that takes claims data out of numerous payers and we can link across those with pretty amazing success using this black box science that I have no idea how we're doing it.

Is interoperability going to help and that? Of course, but it might be a struggle to persuade stakeholders that this is the way to do it if our data scientists are already showing that you can do some data science magic.

Our Blue Cross Blue Shield funding model is about quality improvement. We don't have resident cost and value but nonetheless we have this very rich data that is used for research purposes mostly internal

I think the idea was that people that are participating in it collect data in a similar way and so their data, they send queries, the PCORnet Coordinating Center sends queries out to see who wants to participate in various research studies and then those people get a query that's written a certain way using standard, you know, their model and then they run it against their data.

It's still more expensive than $295. How much do you find that the federal initiatives for the assessment of quality like PQRS, we mentioned, PQRS, now MIPS et cetera, et cetera, how well or poorly does that align with the registry mission? Do you try to, is it a subset? Do you try to align, do you try to ignore it, what would you say? Would that ultimately be a driver for...?

Yeah we had the same thing in cardiology. Cardiology core measures, even me who used it, it was such a joke that for many of us were like, really?

So, you know, we have maintained, several dozen different measures that when you participate in any one of the registries you get these multi-page reports that have got all the measures and no one pays any attention.
I mean I, well not social media. There's a critical mass that general surgeons have not reached. Move over to bariatric surgeons and social media is a very important channel. But in general surgery for whatever reason not the case.

Reference 27 - 0.76% Coverage

One of our key ways of communication is face-to-face meetings, is getting everybody in a conference room, presenter, three or four times a year and so to have somebody from your project come and talk to us, talk to our representative of 70 hospitals, knowing that this would happen means we could even get IT decision-makers to come to that meeting too and they wouldn't typically be there. Typically our surgical champions, data abstracters, and quality people.

Reference 28 - 0.54% Coverage

I mean I know we spent a lot of time talking about burdens. So paper burdens, reporting burdens, you know, just the time burdens of all the documentation and then if you're adding on an extra layer where you have to add all these other things and have to double enter it that what would be the swivel chair of the two systems?

Reference 29 - 0.73% Coverage

The mapping burden actually is huge for society registries because we spend hours on the phone, the practice, the vendor, you know, going through, you know, what's unique about their EHR or how they've modified it and how we have to get that data into a good form to be in the registry. So I think if we could streamline some of that, just the medication piece that he was talking about. We spend hours on that. I think that would be great.

Reference 30 - 0.56% Coverage

There's a group at the University of Michigan that's working on knowledge objects to plug in to chart to make some of this more automated, but it's still very early. Sort of still a research paper as opposed to actually something that's being actively used, but I think that's the way we would probably end up going. Epic plug-ins basically.

Reference 31 - 0.99% Coverage

One question that came to my mind was how much time do you think somewhere along the lines of changing data or losing has to get the quality of the data that's reported back to you or that's reported to you through the EHR systems? It seems like if there's transmission that goes on between the EHR and the registry that there's meaning loss there or that there's an opportunity for human error or another kind of error. How much correction of those kinds of things happen and could any of that correction time cost, et cetera be reduced if there was some more interoperability between the two systems?

Reference 32 - 0.25% Coverage

I think that's the whole point I was talking about. We call it mapping, but it's just getting the data in shape to feed whatever you're going to use it for

Reference 33 - 0.15% Coverage

So I do think that this whole interoperability would reduce the hours spent doing that work.
We have a lot of registries, the burden of data collection is getting larger and larger.

Define some of those standards in a way that would increase interoperability in probably a dramatic way within the industry.

I think the problem is created in large, in part, not just the lack of regulatory focus on this, but the categorical needs of government, of various government agencies.

We did pre surveys from vendors and then various stakeholder groups like the standards organizations, the healthcare organizations, subspecialty societies related to cardiovascular medicine. All of them saw the same problem and honestly everybody was trying to come to a solution.

But part of that is also a recognition that we are across governments, we are totally compartmentalized.

That is not a horrible criticism of the bureaucracy, somebody else can do that. It's the nature of the statutory authority. I mean, it happens that way, it evolves that way. You end up again, with things like this.

If there were common data elements in that domain including the pathway to achieve a diagnosis of catheter-related, bloodstream infection, then physicians, for example, who are seeing a patient with fever and rigors, but don't draw cultures, but do pull the catheter, but don't culture the catheter tip, but do treat them with antibiotics give every evidence that they believed that there was a catheter-related infection without appropriate due diligence to discover and report it. Should CMS be paying for that service?

They can't identify quality versus non-quality and they can't relate it to outcomes accurately.

I will tell you it is my absolute personal opinion that we do not have quality measurement as an industry at all in this country. What we have is quality reporting.
The performance within that program is primarily one that rewards participation rather than outcomes.

Sometimes you will get some internal things where you will get people who will push for certain things because from a workflow perspective it works. But in a large healthcare organization or a hospital organization, bean counters let that go so far, I mean, let's just be honest here.

True, so if you were able then to offer participating institutions indemnification or whatever word would be appropriate from penalty, by virtue of participation, then you've got a economic lever for that.

Because currently, we're incentivizing provision of low quality data. And low quality practice, right?

UDI, unique device identified for devices. FDA worked with ONC, they got it as a required element for a certified EHR. Unfortunately, that doesn't mean it has to be collected.

But the uptake is in the dollars right. I mean, when you look at the end of the day the reason that hospitals participate in the Meaningful Use hospital program, now that a lot of CMS,

Incentives also works inside government. I really like the PCORI Trust Fund out of ASPE which is a program that has, its money that came from from PCORI, but where the money came from is less important than how ASPE coordinated across government and gave money only if proposals came jointly from multiple agencies to build real world evidence systems. That incentivized programs to bring people together.

Which is the difference between quality measurements and quality reporting. Is there a way to build out quality measurement as a rewardable outcome?

"Hey, you're doing a great job measuring the data." And then make it a secondary use of the data, rather than the primary use. Is that feasible?
Whether those are electronic or whether those are chart abstracted. Those hundred people really only understand one particular way of looking at quality metrics. They have a particular challenge, and it's not just theirs, but they get paid a certain price. They have a particular challenge for looking at improvement.

Reference 20 - 0.60% Coverage

On the one hand, I have absolutely heard physician and physician organizations scream that none of these quality measures accurately assess true quality and they would like measures that are relevant to their practice. On the other hand, the moment that you try to get rid of a top-down measure on which everybody scores over 95%, well you're killing their children.

Reference 21 - 0.45% Coverage

There are different ways the government could be involved. We could give financial incentives to registries of professional societies and we could provide standards by which they should follow. There's all sorts of levers, the way the government could promote that activity.

Reference 22 - 0.28% Coverage

There are path codes using pathways. We've built, and are building a whole payment model around pathways. The idea being that pathways they do give you a lot less variation.

Reference 23 - 0.65% Coverage

Give people the rules, or give them concept and a pathway to build the rules? They've decided to hand out the rules for data elements that they've selected. But I think, there's a real case to be made for pushing some prototypes through at different conceptual levels, to provide a pathway to lower the barriers for others to follow suit. Once you've got a format to fill in, people can do that.

Reference 24 - 0.32% Coverage

There's one prototype that's pretty close, SHIELD. Laboratory data has been digitalized for over 30 years. However, it's still not at the point that it's really, truly, semantically interoperable.

Reference 25 - 0.74% Coverage

They're putting together federal agencies, multiple private settings, multiple big payers, and labs around having LOINC, Livid, UDI, OMA all the different standards that are associated with lab, communicating and coordinating. It's also connected with the next layer up with I understand is part of SHIELD too. That's an activity that's very close to being successful at the most basic level about having true semantic interoperability across the nation.

Reference 26 - 0.19% Coverage

The clinicians need to define what's important and, I agree, it has to be done at the level of domain specificity.

Reference 27 - 0.42% Coverage

The fundamental thing, we use a simulated patient who goes in and does this, and you see a lot of variation. But, fundamentally, cardiology's practiced the same across the country and independent of the EHR. Which means, best practices can be established.
And yes, there is a burden, initially, towards building that standardization into the workflow. I think, if you go to Duke, and I've actually been a simulated patient going through a STEMI at Duke. Interesting, slight digression. I was asked five times in the ER about was I sexually abused because, apparently, as a 68 year old male coming through with chest pain that's the place to gather that information. At Parkview Health, I was asked three different times if I'd been outside the country in 21 days because, apparently, Ebola was still a thing in Fort Wayne, Indiana in 2018 because they hadn't taken it off the list.

Given a level of agreement, do we have agreement here, where, despite the challenges with government running the show on some of the standard information that the USCDI, which is is a sense, still presents an opportunity that we should be leveraging to potentially encourage ONC to adopt the common data elements, both ones that are cross specialty and then, eventually, domain-specific.

I think, we need to look at some messier issues about interoperability, like patient engagement and the ability of the patient to move their data around at will without special effort. That's a little bit of a hurdle to mount.

I just want to add, I was in an interoperability forum two weeks ago, and that's one of the issues that was talked about was the differentiation between interoperability standardization adoption. Where if you have five different standards, somebody's gonna say well, we wanna make this interoperable, well, you're gonna come up with another standard and then you're in the same quagmire that you are before. It's just, standard upon standard.

The entire point of ripping the CCDA apart into individual data elements is to foster an interoperable exchange.

There were a couple, the engine that drives this train. At the end of the day that is true of any of the uptake and adoption. Everything you have seen, the only reason we are sitting around this table and having this involved of a conversation is because there were pretty big incentive dollars that were attached to this and now there are, for organizations, pretty large percentages that can be tied to some of the Medicare things. I would think, especially, in this registry sphere about what those, if this, going way back to the beginning, what are those pathways of programs to incentivize? Because that gets to the provider uptake and that's what drives it.

So I'm not a vendor but I work with one. So based on being on the provider's side, working at a University Hospital we're in a situation where we have to provide data to all the different registries along with all the
other research efforts, along with everybody else who wants data. And so at both institutions I recently
have been part of, as Jimmy mentioned we had a crew down at the bottom and that's all they did was
churn out data extracted from EHR to all the different registries and we kept adding new people and
adding more people and it just got to the point where it's really difficult to keep up with all of the data
requests. And everybody wants to know a lot of the same data but in all their own unique format and
methods and that sort of thing so it's a challenge on the provider side regardless of the EHR or not. But
everybody, even if you could get data out of the system in a standard way, everybody has their own flavor
of the same thing and how they want it. And so that's the challenge from the provider point of view as far
as providing data to the registry.

Reference 2 - 0.52% Coverage

I'll just speak from the oncology perspective to vendor related comments, I mean certainly in oncology
probably the most important clinical concepts that describe the cancer patient's journey are simply not in
the structured fields that are built into, you know, even the specialty specific EHRs like staging and
biomarkers and progression and those kind of concepts.

Reference 3 - 0.17% Coverage

We're kicking off a common data element project, you know, to say, and again this is probably our fourth
attempt at this

Reference 4 - 0.44% Coverage

If we can identify a parsimonious set of data elements, again, exactly what we're talking about here, that
are specific for oncology we can go to the vendor community and say, this is as neutral vendor, this is a
neutral party, special society, and represents the oncology community, right, so that's our hope.

Reference 5 - 0.28% Coverage

The 21st Century Cures Act requires ONC, although they have not taken any action on this yet, to create
a program and mechanism to support specialty clinical care through the certification program.

Reference 6 - 0.18% Coverage

The problem I have with that is that is, that puts the entire burden on the clinician to enter all the fields in
that form,

Reference 7 - 0.29% Coverage

For us to feed the entire list of elements that should be incorporated into EHR may not come all at once.
Because many of our registries are procedure focused and to just give them that information up front.

Reference 8 - 0.47% Coverage

Yeah I think that's why a lever like the ONC mechanism is so important, because it's a function that
requires a common definition or use case across different systems and so if you push your content
through that mechanism not only as I said earlier you'd get some guarantee that there's some basement
level of testing at least,

Reference 9 - 0.23% Coverage
But we need, for our purposes, system agnostic sets and you need to conform to at least being able to spit those out even if that's not part of your interface.

Reference 10 - 0.60% Coverage

So that's up to them but when you look at the content of the registry forms, things that have no reason to be individually defined, like race and ethnicity in individual registries, imagine the level of effort decrease if all the registries collectively stopped doing anything to maintain or code all of that content. Content that's not even in the clinical domain, really. That's a huge benefit and a huge lift to everyone.

Reference 11 - 0.40% Coverage

So to have, we can't get any more medications unless we customize the form completely, even from an electronics standpoint. So to make it into your standard of drug, dosage, type, it would completely change things for the better but would also mean we'd have to redo a lot of our work

Reference 12 - 0.28% Coverage

And right now basically what you're getting when you go in there is administrative data solely. You're getting information about the patient's coverage and about activities that were billed for.

Reference 13 - 0.30% Coverage

The information on the administrative side is standardized because they've had decades longer to standardize it because, you know, it was on paper forms and all they've done is make the paper forms electronic.

Reference 14 - 0.04% Coverage

Version control is essential

Reference 15 - 0.35% Coverage

Because different systems use different coding and if Epic is implemented in five different places you could be coding it differently based on what standard you have. You're picking CPT and other things you could see the variability in the coding.

Reference 16 - 0.49% Coverage

So there have been instances where you can use multiple code systems for the same purpose. And what we discovered is that two supposedly equivalent ways of coding something are not in fact equivalent. The examples are myriad and then CMS Electronics have quality measures where they're allowing you to use IC-9, IC-10 and SNOMED at the same time.

Reference 17 - 0.68% Coverage

I welcome that because I was part of a standard, in fact I've been recommended to multiple code sets but initially we had a stake in the ground. So I'll take another example for procedures. The recommendation is, this is the standard terminology that you should use, you should use SNOMED. We got a lot of bellyaching from people who don't use SNOMED and organizations like the AMA who said, we'd love to be a part of that because a lot of people haven't made the transition.
So the theory would be that putting a stake in the ground right now might not be practical from the standpoint of a lot of people.

created a terminology server that is a combination, it's a non-redundant, non-overlapping subset of SNOMED, LOINC, and RxNorm, and other coding systems so it's meant to be the subset of things that people are really using and it's, you know, if there are truly duplicate, exactly duplicate concepts in those terminologies then there really only ends up being one concept in SOLOR and it's mapped to the SNOMED, the LOINC code and the other code and that's the terminology that we're using within SIMI because the other thing about SOLOR is that we can get, we can create concepts that we need at SOLOR more quickly than we can get to the official SNOMED mechanism. And so we're working very closely so that all of the terminology we've created at SOLOR.

that if we're gonna identify, make a recommendation about resources, you know, on the informatics end, you've identified here a resource from the terminology side in SOLOR and, you know, I think that's a big, I think that's a pretty good identifier because we get into this whole thing about supposedly synonymous codes that aren't really synonymous.

The burden I see here that's going to be shifted might be that I'm just really expecting SOLOR to cut the coding, the burden is going to be shifted to the EHR who is transmitting data to us. If it is the other way around, if it is to facilitate data transfer between the histories or research or other purposes, secondary use, then the registry has to do the transformation and say, okay, I'm ready with so much trouble but I would control it with the SOLOR concept ID within the system.

So another way to think about this, I hate beating a dead horse too much but if we identify that we're going to collectively as registries use a data standard and let's say it's, race. And we're gonna use the USCDI, We're gonna use that, but we all agree that that's really crappy, right, we all agree that that's not the way that it should be.

I think one thing that should be recognized is there's not just one definition for everything in the universe in clinical care, right? There will be multiple terms for some things that fit different kinds of use cases. And there will be nested things, a lot of nested things.

And I think smoking status would be a great example for what we just talked about, knowing whether or not someone currently smokes a lot, a little bit, or they did, is useful information. Knowing how many their lifetime history is is also very useful information. Those things are related to one another but they're not the same thing. And for some purposes you need to know one and for other purposes you need to know the other.
We have our vendor who keeps the data. We have ourselves which are kind of the clinical trueness of what the data points are. We have the EHR, so Epic or whoever, and then we have the organization.

I requested simply affects data quality, 'cause when you look at, 'cause a lot of healthcare systems have Epic, but they also have a data warehouse. Are they getting the data from Epic or are they getting it from the data warehouse? If they're getting it from the data warehouse that information has been translated and changed from the original.

So, and then also when in Epic there may be two different tables where the data is stored. One that also functions transformation for purposes of payment which might be cleanest data and which you're getting, so you're normally not getting the original data. data quality to know exactly how the data is defined and where you're getting it from.

Well I think the reason I say that is because on part of the definition, when we talk about data quality, the definition is more than just what is the name of the data element. But where is the context of that data element.

Hypertension doesn't have a number. Hypertension has a relationship and that definition is made by either specialty societies or the doctor at hand.

Because those operational things are the way that we can get accurate comparisons institution to institution as long as we all have that conceptual definition and then it's a homework example for us to figure out how we find it in our system then you're gonna get different answers from every institution because they implement that definition different.

We're talking about definitions of the data elements, computable definitions at the data element level. We're not defining diabetes anymore. And then we can with diabetes it becomes an inference that we get from our data.

So the data elements are sort of the start of a learning health system and the start of knowledge because if you, so, looking at simplistically what we want to be able to do, what we want to do is create an infrastructure that says when this thing happens in the real world this is the way you create an accurate explicit representation of that electronically.
The unified SOLOR. There's an ID that is so if there's the same thing, so there's the SNOMED and LOINC code that are similar, there's a SOLOR code. If there's an RxNorm and LOINC code, there's a SOLOR code. If there's just a LOINC code it's just a LOINC code. And so forth and so forth. I don't know how well it works the other way around. So if you provide a LOINC code whether it

Reference 34 - 1.63% Coverage

There were clinicians, there were vendors, there were governance, standards and terminology, and then also health systems administration. So administrators and standards of terminology groups, governance, FDA, NLM, NIH, sort of. So actually let me just kind of back up and frame this a little more broadly. This is a very important point you brought up in terms of technical challenges. To the operational challenges and the governance challenges, you've identified operational, bringing people together that have the technical capabilities of making identified changes and implementing the common data elements. Governance means you've got to bring together the people to say that's okay, you know, this is what we're gonna do and this is what we're not gonna do, and that have set the framework, right? Data governance is always something that people just, you know, talk about, you know, it's one of those things that's an ideal but not a value. Everybody says, gee, we should have data governance. But nobody really does it well. An ideal is, we should do it, a value is actually, we're doing it. But we need governance over this process.

Reference 35 - 0.55% Coverage

Think the whole concept though is that everything, all data will be tracked from the registries, come from that, the initial clinician entry of the data. So it's not that, like I look at all those translations you did and it makes me nauseous. And I can't imagine, I mean, but that's where, at the core root of this it has to be that it's that enter once and use many times, right?

Reference 1 - 0.05% Coverage

Prevention and Treatment. Yes, thank you. The prevention comes first.

Reference 2 - 0.09% Coverage

We wanted to be able to create an implementation guide for the data elements that are recommended, so that we can advance interoperability.

Reference 3 - 0.08% Coverage

It's easily possible for two systems that have implemented the exact same quote “standards” and not be interoperable at all

Reference 4 - 0.06% Coverage

The government is not the only person who has created large-scale common data element efforts.

Reference 5 - 0.26% Coverage

Anyone who's done a one-to-one mapping knows that the number one thing you should avoid setting yourself up for is having to do a lot of one-to-one mapping because you never stop having to maintain
them, right? Terminologies get updated, practice changes, et cetera, so you basically, for life, are locked into an activity which you hate and which adds only the value of giving you one point of interoperability.

Reference 6 - 0.53% Coverage

This started out as a goal to create interoperability at exchange points of static data for transitions of care and it was updated at the 2015 addition certification rule. I'm gonna show what's in that layer, in part, because CMS has recently announced that they do intend to enforce their requirement that systems are using this version of certification, so those people should have this level of interoperability starting in January 1st, 2019. The USCDI took the common clinical dataset and turned it into sort of a living, breathing thing where there's annual update process and there is a sort of a half force group of experts for it to go to work with the community around how to maintain and extend so content appears. I looked at the ONC interoperability form recently and there was a fairly robust discussion on this topic.

Reference 7 - 0.30% Coverage

So USCDI describes interoperability at the data class level. That kind of makes sense, I think, from their perspective because staying on each individual data element would mean taking on some fraction of 40 million, obviously, a lot of those things are duplicates, but, so they have to take the data class level because that also tends to be the approach that was taken in the common clinical dataset, but in reality, it's actually a combination of data elements.

Reference 8 - 0.44% Coverage

Absolutely, and there are items, I believe, within all of these and I don't know how death's cause is structure specifically, but you can see, yep, sort of from a clinical perspective, I think it makes sense for us to think about groups of some contents and classes and groups of other things as specific data elements, but you always have to remember, can a machine understand the difference between members of a class just with the site or at the class level? And, I think the answer's probably no. FHIR. So, FHIR is all the rage and FHIR is excellent for its purpose, facts, healthcare and interoperability resources. This is the data element resource. But, FHIR is not a content standard.

Reference 9 - 0.21% Coverage

FHIR is one of those and it takes the open-inclusionary process of anyone can purchase state and building content and providing feedback on content, but again, it's not a physical representation, so you need to decide to implement it specifically in the standard at an O-4 kind of system level before you have the ability to use it.

Reference 10 - 0.14% Coverage

I'm gonna start by doing a scan and defining what your scope is, bringing together your stakeholders, thinking about what your standards and workflow requirements are and then you'll want to look around the world,

Reference 11 - 0.04% Coverage

You want to do the process where you identify overlap misalignment.

Reference 12 - 0.42% Coverage

So, a person who's not a clinician right now can't come in and build some amazing cool app in five minutes like they can build a video game because they don't know what content is and how to define it
and they have no guarantee that a system will be able to track that information, right? If we can create the building blocks for a developer to come in and start doing this, then people who have never been able to access the health IT sphere, can suddenly come in with their technical knowledge and build the stuff that we really want to see. And so, this is sort of the vision. Seamless semantic interoperability thanks to common data elements.

Reference 13 - 0.32% Coverage

So, ultimately, it comes down to the clinician and the patient are sitting in the room and the doctor has to record the information. So, I see that you have a data element for sitting. I mean, are you going to require the doctor to put in that the patient is sitting or do you just assume it is? Then, do you get a missing data problem? How do we, or even the right arm? How do we come up with a practical set of data elements that can really be collected accurately at the point of care?

Reference 14 - 0.10% Coverage

In our situation, one of the big motivating things is that if clinicians understand why you're collecting the data, then they don't mind the burden so much.

Reference 15 - 0.05% Coverage

But, if it just looks like recreational data collection, then people get angry.

Reference 16 - 0.54% Coverage

That's the patient, so the tests, and the test goes off every five minutes, and the test records the blood pressures, and that goes into the system, then the system can know, this is an orthostatic blood pressure, here are the time intervals and here are the three measurements and the patient was sitting with the test in these positions, we can support users with clinical decision support for data entry and not just for did you comply with an evidence based guideline? And we have to do that because that's why people are so angry, right? That's why I get very frustrated when I have to enter the same information that I know is in the system. Why should I tell you that I'm not giving aspirin if the patient has nine platelets? You just told me the patient has nine platelets. This is insanity if you're a clinician. It's obvious to you.

Reference 17 - 0.18% Coverage

I've designed systems for collection of tissue for research and one of the things that I learned is you have a data model. This is all the important things. Maybe you don't always collect them, maybe you do. That helps. But, the way in which you collect them has to follow the workflow.

Reference 18 - 0.62% Coverage

…Have mental models of how this stuff works. It's sort of just ingrained in my head. If the community together comes and spits their mental models out into this and then we build machine-readable things from that, then over time we develop a collective mental model of how information exists and is structured and relates to one another. I think it's very valuable in improving the quality of data that we're getting. Right now, when I look at the EHR, I see a field and it's usually defined by a single word and I have no idea what's gonna happen to that information or what it should include and what it shouldn't include, et cetera. If we include in the model definitions of terms, then that information can be populated by the machine, so that if you want to hover over the field, for example, you can see what's this data used for, what's the data mean, what does it include, what does it not include? If you want to see that. Have I been talking too long?
So, part of the genesis of the project here has been what I would call, falls into the category of ‘nature abhors a vacuum’.

So, my concern is that we have lots of people building clinical data models and CD sets and so, Stan has mentioned many times over the years that that creates a condition for many silos of non-interoperable interoperabilities and at the end of the road, you diffuse the capacity for interoperability instead of condensing it.

If ONC can establish a pathway to certification of the domain specific data element sets and clinical models, that would be marvelous because at least there's a pathway to getting those into EHRs and other IT products.

One way to think about this is that we're actually done with the grant because nothing meets the 50% criteria. However, I'm not gonna, I'm not gonna let everybody off the hook that easy, including our team here. So, and you'll see what we're going to propose as a result of all this work.

Sometimes we put it into the registry through a mapping process, so those data elements are specific in the registry. That's what I meant by it's not EHR based, it's EHR extraction.

Just at the level of content, I think in a data dictionary, ideally, if the registry data model uses semantic standards, which I think is what we're talking about now as opposed to transport or other layers of abstraction. Then, ideally, that data dictionary would reference original sources.

It's the difference in the data element name, so what they called it. Race, structure, definition. You record race and then race here for the third row. It's just the different options. So, I was looking for exact concordances. If they have the same data element name and the same permissible value I said they were a direct match. If not, then I said they were different.

Yeah, my team on insurance claims data, you're not gonna even have the opportunity to know a patient refused.

Part of the exercise today is to convince you guys that this actually needs to be done and to encourage you to go back to your leadership and say, "Okay, these are the resources "that's gonna be required to do it."
What we wanted to do was create something that we could hand off to registry owners to say, "Give this to your database developers "to implement."

You're actually anticipating the key homework assignment, which is we're going to represent the information here straight up. What we find in the existing ontologies, the representations, et cetera, et cetera. Return these to you and say, what would you, do you agree or what would you do differently?

...Think part of the value of bringing together straightforward groups like this is the opportunity to educate and to create and apply best practices.

There is a bit of a golden goose here for professional societies who built these registries and a bit of a, if you will, cash cow for those registries, but that approach is short to be here because there are gonna need to be better, more efficient ways to capture the information and that's part of what we're driving towards here.

The other thing I wanted to point out is the context, temporal context, our registries capture that information. Most of the time it's metadata driven, and also the workflow context in the data has been documented.

Some vendors have multiple places where you could find medications and there's lack of consistency internally within their system, let alone in communicating that without set systems. I would say that's a real problem and is a key finding that we need to communicate to vendors.

So, I did a lot of mappings to pull medications for ECQM and found, depending on the vendor, you would think that our accounts would automatically be connected to a medication and they could have been in the order field, but then in any other field, there would be no RxNorm. So, to be able to pull the medications was such a challenge. Medications is very, very complex and you wouldn't think that because it's very straightforward, right? The medication and the RXNorm, but the way that they're structured in EHRs, they're so complex.

There's not 100% mapping, even between those two critical data sources, let alone vendor specific drug codes that they might have put in their system before they even knew what RxNorm was.
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.

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.

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.

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.

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.

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 USCDI, it really needs to have some commonality.

Reference 9 - 0.96% Coverage
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.