

**HIT Policy Committee
Quality Measures Workgroup
Transcript
April 22, 2013**

Presentation

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thank you. Good afternoon everybody. This is MacKenzie Robertson in the Office of the National Coordinator for Health IT. This is a meeting of the HIT Policy Committee's Quality Measures Workgroup. This is a public call and there is time for public comment built into the agenda, and the call is also being recorded, so please make sure you identify yourself when speaking. I'll now take the roll call. Helen Burstin?

Helen Burstin, MD, MPH – National Quality Forum

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Helen. Terry Cullen? Chris Boone? Tripp Bradd?

Tripp Bradd, MD, FAAFP – Skyline Family Practice, VA

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Tripp. Russ Branzell?

Russell P. Branzell, FCHIME, FACHE, FHIMSS, CHCIO – Poudre Valley Medical Group – CEO

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Russ. Cheryl Damberg?

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Cheryl. Timothy Ferris? Letha Fisher? David Kendrick? Charles Kennedy? Karen Kmetik? Saul Kravitz?

**Saul Kravitz, MD – MITRE Corporation – Principal Health IT Engineer, Center for Transforming
Health**

Yeah.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Saul. Norma Lang?

**Norma Lang, PhD, RN, FAAN, FRCN – University of Wisconsin College of Nursing – Professor,
Health Care Quality and Informatics**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Norma. David Lansky? Mark Overhage? Eva Powell?

Eva Powell, MSW – National Partnership for Women & Families – Director

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Eva. Sarah Scholle?

**Sarah Scholle, DrPH, MPH – National Committee for Quality Assurance – Vice President, Research
& Analysis**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Sarah. Cary Sennett? Jesse Singer? Paul Tang? Kalahan Taylor-Clark? Aldo Tinoco? Jim Walker? Paul Wallace? Mark Weiner?

Mark G. Weiner, MD – University of Pennsylvania Perelman School of Medicine

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Mark. Olivier Bodenreider?

Olivier Bodenreider, MD, PhD – National Library of Medicine

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks. Niall Brennan? Ahmed Calvo?

**Ahmed Calvo, MD, MPH – Health Resources and Services Administration – Senior Medical Officer,
Office of Health IT and Quality**

Here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Ahmed. Carolyn Clancy? Westley Clark? Kate Goodrich? Dan Green? Peter Lee?

**Daniel Green, MD – Centers for Medicare & Medicaid Services – Medical Officer, Clinical
Standards & Quality**

Dan Green is here.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Great. Thanks Dan. Marsha Lillie-Blanton? Michael Rapp? Steven Solomon? Tony Trenkle? Jon White?

P. Jonathan White, MD – Agency for Healthcare Research & Quality (AHRQ)

Yo.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Jon. And any ONC staff members on the line, if you could identify yourself please.

Jesse C. James, MD, MBA – Office of the National Coordinator

Jesse James from ONC is on.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Jesse.

Michelle Consolazio Nelson – Office of the National Coordinator

Michelle Consolazio Nelson.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Thanks Michelle.

Kevin Larsen, MD – Office of the National Coordinator

And Kevin is on, too.

**MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act
Program Lead**

Great. Thanks. Okay with that, I will turn it to you Helen.

Helen Burstin, MD, MPH – National Quality Forum

Great. Thanks everybody and thanks for joining us today. So we're going to go through several things today. We're going to talk briefly, once again, about the issue of the principles for quality measurement, and we'll talk about a process we're going to go through, Jesse will describe, to kind of wrap this up. And then we're going to really spend the majority of the time working through again something we started last time around, how we are considering quality measure development as it relates to data registries and we'll walk through those slides. So, I guess first and foremost, I'll turn it back over to you, Jesse, to talk about the process for updating the principles.

Jesse C. James, MD, MBA – Office of the National Coordinator

Absolutely. Thanks Helen. The attachment that you should have up is the guiding principles of eCQM development that's dated 2013, April 19th, version 6. And I received a few edits to the document. I'll walk you through the edits and then we can open for comments. Our plan is to accept comments, have another round of review and then we'd like to post the document to possibly a blog post on HealthIT.gov to allow broader comments on the document, once the Quality Measures Workgroup itself has passed it on to the Health IT Policy Committee.

So, diving right in, we went over this in the last meeting, so we should all be familiar with each of the principles listed. So the first edit I made was really a question on principle number 2, to eliminate defects. We were considering a change in language to minimizing defects or some language that would be less negative and describe the same goal. For number 3, and there was a change of wording, and both Helen and David made similar points about we currently say we'd like to balance scientific reliability and validity with face validity on the clinician end. But in reality, it might be more powerful and clearer to just mention validity and reliability and to not parse between face validity or practitioner validity. The next point, testing extensively or having a description of testing and the importance of incorporating the QRDA into EHR programs.

For building valuable measures, I did not make any changes to that point. For updating frequently, we left that unchanged. The final edit was to the principle on democratizing development. Terry Cullen, in the previous call, described a need from the measure developer and by the vendor community to have consistent toolkit that was useful, because that had a number of requirements that she described or implied, having the ability to curate value sets, edit value sets, create logic, verify codes, test – apply test cases to logic. And I'm not sure in this document whether we should go into the detail of describing those requirements, but it might make sense to just say at a high level to say that there should be some integrated toolkit for measure developers that allows testing and editing of both logic and value sets. And finally, the last point – I'm sorry, go ahead.

Theresa Cullen, MD, MS – Director, Health Informatics – Veterans Health Administration

This is Terry, sorry. I just joined and I would agree with what you just said.

Jesse C. James, MD, MBA – Office of the National Coordinator

Oh thanks Terry.

Kevin Larsen, MD – Office of the National Coordinator

Jesse, this is Kevin Larsen. Maybe one question is the goal to have this toolkit for measure developers or is the goal to have this for a wider audience beyond who have historically been developers?

Jesse C. James, MD, MBA – Office of the National Coordinator

I think the broad goal for the document, and what the Health IT Policy Committee and this group has described is a broader definition of what a measure developer is. And really to the aim of democratize development and to keeping meaningful use meaningful, we really – we have to engage the groups that are already making measures and putting measures to work and practice in this national development process. If there was a tool that accomplished that goal, that would be success, I think, in the group's eye. So is that something that the group thinks we should call out more clearly, that we want a tool that's broadly useful and that extends the population of measure developers?

Helen Burstin, MD, MPH – National Quality Forum

This is Helen, I'm happy to start it. I think in general we should, as long as we put out this sort of reusable rockets of data people could use or information people could use, I think anybody should be able to develop and standardize measures. But I'm not sure we initially need to call it out in this, perhaps as it says here, to keep meaningful use relevant to our providers and patients, perhaps and to allow any end-user to develop measures, or something as simple as that. A set of reusable, valid tools will be available to help with development. Does that sort of work for you Kevin?

Kevin Larsen, MD – Office of the National Coordinator

Yeah, measure developer just has a specific meaning that I think this group is talking about something different.

Helen Burstin, MD, MPH – National Quality Forum

Yup. No question. The category is called democratized development; it's clear that's the intent.

W

I think that sounds good.

Helen Burstin, MD, MPH – National Quality Forum

Okay. Other specific comments on these?

Eva Powell, MSW – National Partnership for Women & Families – Director

This is Eva. I just had a quick question. I apologize, I think I had to drop off the previous call and so I'm sorry if this was discussed then, but, is there – I feel like there should be a way to address in these principles this notion of feasibility and how closely tied it is to technology. Because what makes so many of the measures that we don't have but desperately need, infeasible is the fact that the technology, at least to this point, has not supported that and current technologies may not support that, or may not be using...may not be used for purposes of certain measures, because the measures don't yet exist. And so I feel like this is very one-sided on the measure development piece, which is – it's really important to have that focus, but I don't feel that there's really a – the balancing factor, the complimentary factor rather, of is the technology being developed to make these kind of measures feasible. Otherwise, the measures themselves are not going to be developed. Does that make sense?

Helen Burstin, MD, MPH – National Quality Forum

Yeah, that's actually a pretty major focus of the work we did on eMeasures feasibility with ONC and CMS, was this idea of having both a set of measures now, as well as having more of a sort of a launching pad for those future case, measures that we really want, but which the technology needs to follow. Yeah.

Kevin Larsen, MD – Office of the National Coordinator

So Eva, this is Kevin Larsen. Just so I'm clear, are you talking about electronic health record vendor technology or are you talking about technology for people to create measures.

Eva Powell, MSW – National Partnership for Women & Families – Director

I'm talking about the former, yes.

Kevin Larsen, MD – Office of the National Coordinator

Okay, that's what I thought. I just wanted to be sure.

Eva Powell, MSW – Director – National Partnership for Women & Families

Yeah.

Russell P. Branzell, FCHIME, FACHE, FHIMSS, CHCIO – Poudre Valley Medical Group – CEO

And this is Russ. I'll give a little different spin, but to compliment that, the technology itself, the software may exist and what's not available is clear, standardized data definitions and field formats. The actual technology exists, but what we don't have is a very clear, standardized approach for data and data management on top of those technical platforms, therefore people are still putting data in lots of different places, in lots of different formats, and then somehow we're supposed to aggregate these to create quality measures. And so there seems to be three pretty fundamental pieces here; one, the core technology, the other, the standards for data definitions and then third, the actual quality measures. And maybe even in the first two we're not hitting the mark completely.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

This is Cheryl Damberg; I would concur with that. A comment that I'm going to make when we get to the registry discussion, and Jesse and Kevin, I'll send you some materials offline between this meeting and next is, this issue around a standard for data storage and retrieval is really critical.

Theresa Cullen, MD, MS – Director, Health Informatics – Veterans Health Administration

And this is Terry. I would also echo that. And I think it's really, it goes back to this whole concept of what's the capability that you need to have and I like that three-tier model. I don't know how to put that in here, but...

Kevin Larsen, MD – Office of the National Coordinator

This is Kevin Larsen. Just also a point of clarification here, at any point that we would want to ask our partner committees on the standards group to think about topics like this, we can queue them up and send them over to people that are more technical and would give us some input if we have specific questions.

Jesse C. James, MD, MBA – Office of the National Coordinator

This is Jesse. To Russ' point, it brings to light findings from our Vendor Tiger Team, which said something similar in that the quality measures in existence are not really leveraging the technology that is in place. And that there's some work to be done on the development end, perhaps, either to push harder, not just to push harder on development of the technology, but also to push harder on development of the measures that fit the technologic capabilities that are in place.

Sarah Scholle, DrPH, MPH – National Committee for Quality Assurance – Vice President, Research & Analysis

Hi, this is Sarah Scholle and I apologize, I got disconnected. But I wanted to raise a couple of points about these principles. First, that this issue of getting standardized value sets and implementing those, I think it's really important that we think about this as a constant feedback loop, and our experience in specifying and re-specifying and re-specifying – measures is that as we do this work, we're constantly updating our approach to it. And that as we bring new – look to outsiders or to this democratized development process, that we think about how do we really understand the new capabilities that we need in the QDM and the data sets and how will those decisions be made and how will that information be fed back to update the existing specifications for measures. It's not a one-time thing; it's really constantly improving and learning in this work. So, the second thing is – and what we've realized even here, at NCQA, where we do a lot of this work, there's just a couple of people on our staff who are really experts in how to do this. And we're – the rest of us are constantly going to them to say, well how would this happen? And, that expertise it's in not too many people right now and we need to figure out how to learn and how to learn from the new opportunities and new experience. So that constant updating workflow, feedback loop is important.

The second thing is really about the tension between measure opportunities in a single site and measures that we might want for a national program. As we've been working – you know I work on the Center of Excellence, where we're working with a lot of academic sites and looking at new measure opportunities. What organizations might do in one place feels very good for that organization from a quality improvement perspective, but when we try to take that measure and put it in a national framework where we're applying a national lens on the evidence, and trying to think about how we might replicate that work nationally, we...in other places and promote something as a national measure, we find that those things might...that idea of what you can do in one setting and what we need in...for a national measure that can be reported consistently at multiple sites. Sometimes those things are at odds and so I think that we're talking about a very broad funnel to get to a smaller number of activities.

Then the third thing I would say, in addition to – standards and the quality measures, it's really that workflow. And understanding how workflow is, has to be adapted to use and measure these new activities is critical. And that kind of gets into our frame of, we want things to be tested extensively before release, because actually, it's by implementing that we realize the flaws and the workflow that's needed and the development, testing, implementation back to revision and testing and implementation. So, there's not...one of the main challenges we find is that the work – the capabilities exist, the fields exist, the workflow is implemented in a not very consistent way that makes testing difficult to accomplish. So I just wanted to highlight some of those things – some of those issues – we can provide some comments in writing on these principles but I think we might want to keep some of those things in line.

Helen Burstin, MD, MPH – National Quality Forum

That's really helpful Sarah. Thank you. Other comments, broad comments on the principles? All right. Well it sounds like one of the things we thought would be useful is, Jesse will get this documented in a place that we can all kind of go at it, perhaps just get one round of editing from everybody, or comments from everybody and see if we can try to wrap this up quickly. How soon do you think that'll happen, Jesse, get this document up?

Jesse C. James, MD, MBA – Office of the National Coordinator

I could – so, I think posting it to Google docs might make it easy for anyone to edit it and also for multiple folks to edit it at a time, if there are no objections to that, we can have that out as soon as today or tomorrow.

Helen Burstin, MD, MPH – National Quality Forum

Great. And would a week turnaround timework for folks? Okay. So, we'll plan on trying to have this all wrapped up within a week. And then as Jesse mentioned earlier, we'd love to also get this out into the broader public space and get input beyond the workgroup as well, since it does have, I think, some important implications for the broader community. All right. So, on to the next agenda item which is back to the discussion we started on our last call about data registries. Jesse's got, has sent around the materials for this meeting which – for this discussion, which includes the slides we – he went through last round, but with a set of key questions for the group to kind of work through, that were brought up on the last call. So Jesse, do you want to ...?

Jesse C. James, MD, MBA – Office of the National Coordinator

Yeah, absolutely. If we can pull up the slides, this is for the attachment titled Qualified Clinical Data Registries. And the second slide describes again the legislation behind the registries and there's no need to go through that again, but essentially, it said that providers that use qualified clinical data registries can be considered participating in lieu of other programs. Those other quality programs are PQRS and the Meaningful Use Program. So the next slide, this describes the RFI. So CMS posted an RFI earlier this year and has received comment back. Some of the questions focused on what types of entities should be considered registries, the type of data they should be able to capture and how, the types of measures the providers should report on. The next slide is CMS' RFI and that includes some additional questions we discussed at last call.

We also discussed last call, the next slide is the DITT tasks, so the Data Intermediary Tiger Team will dive deeply, given the report out from this team, on privacy, security, data quality, the business governance of entities and standards for alignment. So finally, in the previous call we decided that registries should be defined broadly, that we should...our goal should be to enhance and maintain interoperability that both interoperability required on the EHR side or the Health IT side to send to the registries and for registries to receive from them, there's an important role for management of data. And that there should be – there's a potential for a role of innovation in the areas of eMeasurement. So in the following slide, the requirements for the QCDRs, we split up some of the actions that a registry might take.

So the Data Intermediary Tiger Team previously noted that a registry perhaps would be – what a registry should do and the task – those tasks that a registry should do would be able to accept data and, for the EHR Incentive Program, those data should conform to the standards of the 2014 Standards for Certification Criteria. David Lansky made the point on the previous call that perhaps patient-reported outcomes type data should be a requirement or should be supported or encouraged through the program. That they should be able to analyze data and we should be ensured of the validity and integrity of that data. They should be able to export data in a manner that is consistent with the 2014 Criteria, and that would be QRDA categories 1&3 and that they should have some level of review or auditing for privacy and security compliance.

So, finally, some points to discuss on this call, and some questions. We discussed that EHRs need to have the ability to automatically export relevant data to registries. But what might that look like in the short-term when the measures, if they're innovative measures from registries, they won't be consistent with the previous 2014 or Meaningful Use 2 measures. These could be new measures and the ability to export new clinical data, or new clinical data elements, would not be a criteria that we certify to. Finally, they should be able to accept the clinical data as previously described, this is probably a shorter list than expecting the EHRs to be able to transmit all the data elements that a new registry might come up with their measures. There should be some role around data quality and integration and we could discuss that further. The final two roles are the design of the measures and their ability to perform analytics.

So, Paul Tang has mentioned his interest and concern on being sure that the registries use measures that are of high quality and that are outcomes-focused. So, that could – we could go deeper on whether the group feels that outcomes measures only should be allowed or should we allow some process measures in the meantime. Interoperability, to be sure that the measures that registries create are consistent with the 2014 measures, they would need to use similar data sets, value sets and logic; however, constraining them to value sets and logic that are in place might also limit innovation. And then if there are measures that are of high quality to the group, then features of them – describing features of them would be important going forth. Finally, there's a role for reporting data and the results of the measures and two questions to consider are, should there be public reporting of all the measures that the quality clinical data registries capture data on. So, should they be required to report generally to the public on physician or provider performance. And if that is the case, should providers be afforded an opportunity to view all results prior to public reporting of them.

And in the final slide, additional questions. What other roles might be required for certification? What other roles are required for the data registries? And what level of verification might be required for each? So, we use certification now, might it be reasonable in the early years of the program only to attest, or should we be asterisked as requiring auditing for some parts or some attributes such as data quality or for privacy and security.

Helen Burstin, MD, MPH – National Quality Forum

Thanks Jesse. So lots of good food for thought there. Let's open the discussion. Any comments on what Jesse's presented around registries and how it might relate to eQMs.

Russell P. Branzell, FCHIME, FACHE, FHIMSS, CHCIO – Poudre Valley Medical Group – CEO

Hey Jesse, this is Russ again. I guess the question is, and maybe I misunderstood your statement, that this next round of quality measures would not be included in the certified EHR requirements?

Jesse C. James, MD, MBA – Office of the National Coordinator

Well what the potential is, is this hasn't entirely been defined. So we can make recommendations in either direction...implications of the recommendations that'll be important. So, the status of the program is that in 2014, the Qualified Clinical Data Registries can be used for providers to report for Meaningful Use 2 measures.

M

PQRS is what's clear and Meaningful Use 2 is up in the air.

Russell P. Branzell, FCHIME, FACHE, FHIMSS, CHCIO – Poudre Valley Medical Group – CEO

I think where possible, it will aid us in having certified EHR technology that is a foundation for us to build and submit and be able to manage these measures, regardless of where they come from. What we will hear is from, I think, is people will try to do this, the vendors will say, it wasn't a requirement of certification, therefore you've got to buy my new module to do this and we will have an uproar from the industry.

Kevin Larsen, MD – Office of the National Coordinator

So this is Kevin Larsen. A little bit of clarification. Many vendors are already certified for Meaningful Use 2 to submit data, much in the same way a registry would be. And so, for the Meaningful Use 2 Program, many registries are certified, because they provide this reporting function, calculation and reporting, for sites. The difference we're talking about here is that under PQRS, the goal is for historical registries like the surgical registry, which hasn't been a meaningful use submitting registry, for a site to be part, be using the surgical registry, they could get credit for PQRS. And right now that surgical registry isn't certified and we're kind of talking through what those issues are. At least for our understanding right now is that to get credit for meaningful use, the EHR HITECH Incentive Program, you need to use certified technology for reporting, under the current ...

Russell P. Branzell, FCHIME, FACHE, FHIMSS, CHCIO – Poudre Valley Medical Group – CEO

Then I think we're probably saying the same thing, that the more we can get those as part of a certified platform, even those like the surgical registry, then I think the better off we are from an industry perspective.

Kevin Larsen, MD – Office of the National Coordinator

Yeah, the – so to Jesse's point about how the measures in those registries right now aren't very amenable to certification, because the whole history of how the measurement and benchmarking has happened to data has been outside the context of certified EHR technology. And so, that's the sort of question on the table, is what's the...what are people's ideas and thoughts about how we migrate those two goals, certified technology and the large, long, experience of the registries in doing things that have a sort of different goal and a different frame.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

This is Cheryl. I agree that I think historically they've had a very different goal than what we're trying to use them for. But, I guess one of my concerns would be, if the context is the PQRS and the like physician value-based payment modifiers that that are going to be used to report performance measures, I think somehow or other there's – that space is kind of rife for things going wrong if each individual registry or the people sending data to the registries are writing programs separately. And so somehow or other I think you have to bring them under some set of standards for data storage and retrieval. So, I'll stop there.

Mark G. Weiner, MD – University of Pennsylvania Perelman School of Medicine

This is Mark Weiner. A lot of times data that goes into a registry is sort of integrated from across different data sources, of which the EHR is only but one. And a lot of times, the registry is very specifically designed to cover a specific disease area that the EHR only cursorily covers. And I know, particularly in rheumatology and cardiology, there's actually a lot of rich detail in the registry that's not in the EHR and it may be in some ancillary electronic system, but I know people work very hard to make the data in the registry very rigorous and very true. And also, there's the combined research value of the registry as well as the clinical value.

Sarah Scholle, DrPH, MPH – National Committee for Quality Assurance – Vice President, Research & Analysis

This is Sarah Scholle again. And just want to emphasize what people have said here about this positive opportunities of using the registry, you know, that it's gonna be useful in specialties, particularly where there are fewer measures. It might get us to some outcomes, patient safety, this ability to look at measures that draw from different data sources. All of that is exciting and a great opportunity, but, just want to reiterate and build on the comments that I think Cheryl was making and others have made about the need for standardized measurement so that this – and the use of the terminologies and the data sets that we have for other eMeasures.

And just a caution about thinking about how these registries are set up, because a number of them are procedure-oriented. So, it's identifying people based on something, some service that they had and what it doesn't get you to is a true population-based focus of people who might have been eligible for that, but did not get this service. And so you're not really getting at appropriateness or efficiency issues, and overuse issues, you're really getting at some technical issues – a technical quality for people who got a particular service and we know that sometimes if we just look in that group, we're going to find people who do well, but may not have needed the service. I just want to raise that caution about when we want to use ... registries.

(Indiscernible)

Mark G. Weiner, MD – University of Pennsylvania Perelman School of Medicine

I agree with that, and so I had in mind a certain angioplasty registries, the ACC has their PCI, the percutaneous intervention registry, that obviously is only geared towards people who have actually had a percutaneous intervention. But what I really like about that registry is, it gives very objective measures of disease severity that are very difficult to obtain out of EHRs. And then a second one, which I think gets more to the point of capturing a broader population is rheumatoid arthritis. And I challenge anyone here to look for disease severity of rheumatoid arthritis just based on what you can find in an EHR. But within a specific rheumatoid arthritis registry, you're going to be able to capture the number of joints involved and which joint's involved and the progression of joint involvement over time in ways that like trying to say hard, you cannot get out of EHRs are you really lean on registries for that information. And that kind of information can really separate people who really need...management from people who have just a touch of rheumatoid arthritis.

(Indiscernible)

W

But wouldn't you be able to get that infor – just a question. Wouldn't you be able to get that information out of an EHR if people were including that in their workflow and their documentation?

Mark G. Weiner, MD – University of Pennsylvania Perelman School of Medicine

They should, but often times the EHRs are too generic to capture very, very disease-specific information and I know, these sub subspecialists really look to the registry, not to the EHR for capturing cohorts for research or for finding who the problem patients are. I think that's how they're actually being used within provider facilities, and I think it would suit us to behave similarly, and maybe even talk to some of the designers and users of these registries.

Helen Burstin, MD, MPH – National Quality Forum

Right.

Jesse C. James, MD, MBA – Office of the National Coordinator

This is an important tension to discuss. So to the earlier point of this being a program for PQRS, but also a program that in the RFI that CMS released, it also defined a role for this for the clinical data registries in meaningful use as well. Some discussions have been around whether the program, in terms of the Meaningful Use Program, whether the measures should be limited to EHR-captured data or whether it might make sense to use some of the richer, more granular, more sub subspecialty specific related data for quality measurement and for innovative measures.

Kevin Larsen, MD – Office of the National Coordinator

This is Kevin Larsen. Just to put a concrete example on this. Where I came from we used the NSQIP registry, which is the surgical registry, and we had a nurse who at 90 days, called every surgical patient to see if they were still alive and how they were doing. That wasn't information in our EHR that was information only available in the NSQIP registry.

Helen Burstin, MD, MPH – National Quality Forum

Right, and just to build on this, this is Helen. It seems like there's a couple of really important questions here for us. I think one of the first is, and I agree with Sarah, while these registries can't be all things to all of us around quality, they're powerful tools in terms of getting at outcomes and particularly patient-reported outcomes with the kind of information that otherwise we have a really hard time getting. Maybe that's one way to think about framing it is, what would be most useful in terms of what could be captured, to drive quality outcomes. I think the second and related piece of that though is, since it is for meaningful use, is there actually a consideration of ultimately having some sort of glide-path that helps us understand which of the data elements that currently only live in registries, but are really critical to those outcome measures, are ones we need to ultimately build-in to standardized data elements that can be found in EHRs, so that there's not this sort of sense of a work-around.

I guess thirdly I'd be curious about the requirements that Jesse put up front, specifically around the idea of the auto-export of data to registries and the acceptance of clinical data from registries. And that might be sort of a starter point of at least indicating there's some engagement of the registries back to the clinical system, rather than being completely isolated. And ultimately, is there a core set of data that we want to think about of what's in an EHR that should automatically be something that gets exported to registries that might be incredibly useful to get at some issues like disparities or targeting of improvement or issues along those lines.

Theresa Cullen, MD, MS – Director, Health Informatics – Veterans Health Administration

Helen, this is Terry. I think that those are really important comments and while I understand that the current state of the industry is that things like the 90-day follow up call only live in registries, one can argue that at the point of care, that may actually be really important information for me to know ...

Helen Burstin, MD, MPH – National Quality Forum

Right.

Theresa Cullen, MD, MS – Director, Health Informatics – Veterans Health Administration

... about the patient that I'm providing care for. So I think it's important that we look at the whole continuum of the health care delivery model and figure out, does it make sense in the long term to actually have data sky loads, which is what one could argue are registries that don't communicate back to the EHR and/or back to any patient-facing mechanism for the patient to share them. So, I think this really large issue looms before us, how do we support registries that currently exist and are being used, the surgical quality registry is a great example Kevin. But yet from a glide path perspective, develop specific ways that encourage the coordination of that data with other data sets or electronic health records that live outside of the registry.

Helen Burstin, MD, MPH – National Quality Forum

Yeah. That's a critical issue for us.

Norma Lang, PhD, RN, FAAN, FRCN – Professor of Health Care Quality and Informatics – University of Wisconsin

This is Norma Lang. Would you ever think of a measure that would be required to be taken at 90 days, especially as we go into integrated systems?

Helen Burstin, MD, MPH – National Quality Forum

Yeah, I mean and actually Norma, this is Helen, some of the NHSN measures, for example, from CDC go out really quite far around surgical site infection. In fact, if somebody has an implant, they go out 180 days.

Norma Lang, PhD, RN, FAAN, FRCN – Professor of Health Care Quality and Informatics – University of Wisconsin

I think that's another way of looking at it then.

Helen Burstin, MD, MPH – National Quality Forum

Yup. Yup.

Jesse C. James, MD, MBA – Office of the National Coordinator

So is there consensus around, I'm sorry – you can go ahead.

Russell P. Branzell, FCHIME, FACHE, FHIMSS, CHCIO – CEO, Poudre Valley Medical Group

I'll make this quick. This is Russ again. I think the other thing to understand is this ecosystem of systems within an organization, and in many cases, these registries are already getting interface feeds from the EMR, it's just not bi-directional. It seems like we have a unique opportunity to close that gap, as many have said in different ways, to actually create this as an information flow between them, so it's available at all the appropriate places of care and management.

Kevin Larsen, MD – Office of the National Coordinator

And Russ, this is Kevin Larsen. I totally agree, but also we haven't standardized how that information flow goes. We could make this more plug-and-play ideally, I think, if we come up with some ways to leverage the current standardized transport.

Helen Burstin, MD, MPH – National Quality Forum

Absolutely.

Russell P. Branzell, FCHIME, FACHE, FHIMSS, CHCIO – Poudre Valley Medical Group – CEO

I would agree completely. So we need to do that.

Jesse C. James, MD, MBA – Office of the National Coordinator

Russ, you made exactly the point I had hoped you would make. So, it sounds like there is a consensus around – there's a longer-term goal and a shorter-term goal. And the longer-term goal that's more important is that registries are brought into the fold and that they're able to capture the types of data that EHRs should be able to capture in the places that they aren't currently capturing them. And then what this group might do, and what may be an important output of the group, is not necessarily what this program looks like in 2014 or perhaps 2015, but it's more aspirational on what the 2016 or 2017 type goals are for the clinical data registries. And one important goal would be this bi-directional flow of information, that if clinical data registry has a measure that counts as an eMeasures that there is the capability within EHR to pass information between the two.

Helen Burstin, MD, MPH – National Quality Forum

And some of – this is Helen again. Some of it also may be as we think about measures going down to the data element level, I think the key issue, as well as thinking about how data elements exist in registries and begin doing some of that mapping. I've had some discussions with some of the leading folks in registries like Frank Opelca from NSQIP and David Sheehan from STS and there's a great deal of interest in actually sitting down and beginning to understand how the mapping of the data elements begins to show where there are significant opportunities for where bringing those data's together would just offer all of us better data without creating those silos that Terry talked about.

Kevin Larsen, MD – Office of the National Coordinator

And this is Kevin Larsen. I'll put one other question on the table for the group. There is another data standard this group could consider, QRDA2, which splits the difference between QRDA1 and QRDA3. It's like sending a spreadsheet. So if you think of QRDA1 as detailed data about one patient at a time and QRDA3 as a numerator and denominator, think of QRDA2 as sending a spreadsheet back and forth. And that has been balloted, it is currently not part of certification, but it's the sort of thing that I think this group would be, especially in this sort of swapping back and forth between registries, something for the group to contemplate.

Helen Burstin, MD, MPH – National Quality Forum

Good idea. Any other thoughts from the group?

Norma Lang, PhD, RN, FAAN, FRCN – Professor of Health Care Quality and Informatics – University of Wisconsin

A question from Norma.

Helen Burstin, MD, MPH – National Quality Forum

Yes.

Norma Lang, PhD, RN, FAAN, FRCN – Professor of Health Care Quality and Informatics – University of Wisconsin

We've spoken so much about registries, can somebody help me understand how we will eventually deal with these huge data warehouses that many integrated organizations are developing? Do we have to ship data out to a different kind of registry or will those data warehouses eventually be, or data clinical repositories within an integrated system be sources?

Jesse C. James, MD, MBA – Office of the National Coordinator

We've used the term registry, because that's the term that was used in the legislation, and in the RFI. But there's been some change in the use of the term, in some places the term entity is used instead, as not to bias our understanding of what a registry is now to what the capabilities of this type of entity would be in the future. So you could imagine that a clinical data warehouse with a quality cube for ad hoc queries, might be able to make measures and develop measures and report on those measures in a way that's similar to the requirements of the program. So, it's probably better to say entity than just registry. When we say registry, we're thinking more broadly than the current state of registries.

Norma Lang, PhD, RN, FAAN, FRCN – Professor of Health Care Quality and Informatics – University of Wisconsin

Thank you.

Jesse C. James, MD, MBA – Office of the National Coordinator

I'm curious, Terry or someone who's dealt with this a lot, what are your thoughts? That's a great question.

Russell P. Branzell, FCHIME, FACHE, FHIMSS, CHCIO – CEO, Poudre Valley Medical Group

This is Russ. Up until recently, obviously I was with an organization that had a very large data warehouse running on top of our EMR and other systems that are there. I think the advantage you have with organizations that have done that is there actually is a single point of consolidated data that you can mine feed from and actually accept. In organizations that have that stuff all spread out through different EMRs without a real repository, actually it hinders, to some degree, the data sharing and specifically the data quality aggregation. And so, those that have those I think are going to have a better chance of being able to populate that data, and an easier place to accept data from a registry if we get the bi-directional work.

Theresa Cullen, MD, MS – Director, Health Informatics – Veterans Health Administration

Yeah, this is Terry. I would agree with that. I mean, the advantage...having a large data warehouse with people that are just doing analysis and business intelligence is you can try out cubes and then you can see if something's going to work or not work. The disadvantage is that that analysis occurs at the warehouse level and may or may not get back to the provider that needs it to change outcome. So, I'm really supportive of it. And actually, the pure DAQ spreadsheet, I like that analogy Kevin, that spreadsheet going back and forth. It's kind of, I don't want to say primitive, but it's pretty – it looks like a nascent clinical data warehouse, right there, your spreadsheet.

Norma Lang, PhD, RN, FAAN, FRCN – Professor of Health Care Quality and Informatics – University of Wisconsin

Could we, this is Norma again. Could we at least start to say some words that would go in that direction? I mean, even if we're headed for those future years. Because many people are building those clinical repositories or integrated systems and big data warehouses, and I think to know that there's some vision out there for what this could do might be good.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

This is Cheryl. Can I just ask for some clarification? So, when I hear the words warehouse, I think of something different than what I've been thinking a registry is, and maybe there's some overlap or synergy there, but it seems like they're potentially two different beasts. Do I have that right?

Kevin Larsen, MD – Office of the National Coordinator

So this is Kevin Larsen. I'll give it a stab. We worked hard to think this through where I came from. So if a clinical data warehouse is all the data that you could get or have or compile in one place, a registry tends to be a focused subset of the data that you use for typically a specific patient population and activities often around quality improvement and case management. So, the registry tends to be a subset of other data, but often it's augmented at an organization with data that you don't get in any other way.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

Right, but that type of registry is conceivably different than say some of these national registries, right?

Kevin Larsen, MD – Office of the National Coordinator

Well...so they benchmark. So what happens is, those national registries, at least most of them, but again, there's not consistency across them, most of them have a local instance and then a national instance. So the local instance is your local population that you're benchmarking against – or the local population that you're managing and the national instance is typically your benchmark population.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

Right. So I swear I'm getting a little confused, or at least where my experience comes into play is, at least looking inside say the ACC or the STS registry, and even like the orthopedic registry that's being built in California. If you've got different providers who are querying their systems in lots of different ways, sort of hopefully applying the same set of specifications. And this was the issue that I was raising a minute ago, that that area's sort of rife for errors. And so I guess somewhere in this conversation, I would like to see represented that to the extent that we want to go down this path, that there's some type of standardization for how the data are stored and retrieved, otherwise I think you're going to have the wild west in terms of the data that's submitted.

Helen Burstin, MD, MPH – National Quality Forum

Yes, that's a good point Cheryl. This is Helen. I also just think we really just need, and this was one of the questions Jesse teed up for us, I think one thing we might want to do with this group is actually with more of an IT lens, come up with some definitions of what is a clinical data registry? When is it a subset or not a subset of a warehouse? When is a warehouse something different? And again, my experience from having been running quality in a large teaching hospital, I mean our registry lived completely external to our EHR, but we were able to sort of marry the data and it was very useful. But, it certainly didn't have any standards for how we did those queries by any means.

Kevin Larsen, MD – Office of the National Coordinator

This is Kevin Larsen. The third sort of function I often hear people talk about when they talk about registry is, outpatient case management systems a la patient-centered medical homes. So they – if you talk to the community clinics who've done these community clinic collaboratives for a long time, they'll refer to their registry and they're referring to sort of a case management like set of functions that they use to manage their population.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

Right. And I think in some respects, those have been set up to do more what I'm going to call performance measurement, where some of these national registries, they're producing measures but they aren't sort of the typical ones that are in the quality measurement mix. And it doesn't mean we don't want to go after those, but I just think it requires a little bit of thinking about what it means to capture all that information and what it's really telling you.

Helen Burstin, MD, MPH – National Quality Forum

Since they're being positioned now, Cheryl to be in the quality measurement space...

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

Right.

Helen Burstin, MD, MPH – National Quality Forum

I think it's the right time for that thinking.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

Absolutely. Absolutely.

Helen Burstin, MD, MPH – National Quality Forum

This is it.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

I think there's a huge opportunity here...

Helen Burstin, MD, MPH – National Quality Forum

I agree.

Cheryl Damberg, MPH, PhD – RAND Corporation – Senior Policy Researcher

So like I look at the ACC space and I'm thinking, okay, they've been assessing the appropriateness of surgery, and that is the holy grail, and if we can somehow or other bring that into the mix, that will be terrific, related to potential overuse or underuse of services.

Helen Burstin, MD, MPH – National Quality Forum

So just looking at the time, it's almost 5 of. Jesse, is it, I'm just curious, Kevin and Jesse, you're thoughts about how we might want to proceed. Is it worth trying to get perhaps a workgroup of people who sort of want to dive deep on some of these registry issues and report back?

Jesse C. James, MD, MBA – Office of the National Coordinator

Yeah. Well, that's exactly the plan. The Data Intermediary Tiger Team has started deep – well, they started work on this, they started describing some of the issues going forward, and they start meeting again in May, early May. So, a hand-off from this group will be a list of questions and issues, a description of our goals on interoperability, that we previously described and a broad definition of a registry, but additional questions to distinguish the difference between a registry and a warehouse. So what I'll do is take our outputs from this call, write up the notes, send them out to the group, let the group edit them and then that will be a straw man for the Data Intermediary Tiger Team calls to come. That group is going to split into two separate groups, so anyone from this group that would like to continue to contribute to the work on this over the next two months will be able to do so. There will be a report back from the Data Intermediary Tiger Team in June-ish and the goal will be a report to the Health IT Policy Committee in the July timeframe. And if there, if it's in time for some rulemaking on CMS' side, there might be time for some comment to CMS' rules on the subject.

Helen Burstin, MD, MPH – National Quality Forum

Yeah. We should clarify as well as their finalizing their RFI and their rule, whether they've actually got some definitions so we're not reinventing the wheel as well.

Jesse C. James, MD, MBA – Office of the National Coordinator

Yes one – so we – CMS has received comments back and sent some to us, so in a follow up call, we'll describe some of the comments that deal with the same questions that we've been discussing.

Helen Burstin, MD, MPH – National Quality Forum

Great.

Kevin Larsen, MD – Office of the National Coordinator

This is Kevin Larsen. Any particular things this group wants to charge the Data Intermediary Tiger Team that we haven't talked about yet?

Ahmed Calvo, MD, MPH – Health Resources and Services Administration – Senior Medical Officer, Office of Health IT and Quality

Yeah, this is Ahmed. I'm – I want to again open up our thoughts a little bit. It seems to me that we keep referring to data repository and making an assumption that it's owned by one organization. You could think of an EHR, say Kaiser's EHR with multiple different locations, but it's still one company or one corporation. Theoretically neither the data repository nor the registry concept require that it be one

organization that owns it or one location that it sits in, right? You could theoretically have multiple EHRs that could load up to a data repository for the purposes of analysis of something, like say a particular chronic disease condition or prevention, or something like that. And the same thing is true for a registry if you think it through.

So I want to make sure that we don't make a leap of logic that it has to be a single organization. The data could actually sit in multiple different places, i.e. multiple EHRs, multiple even different types of organizations, it doesn't even have to be a healthcare setting, it could be a public health department, etcetera. So if we think about that in a broader sense, then a data registry has to be a much more broader conceptual level than just the question of where the data sits itself. It brings us back to that other discussion last time, which I popped in with, namely the notion of an algorithm. And we have to sort of think about that as a data registry algorithm conceptually could be a query function to multiple different locations where the data fields might actually fit, meaning totally different types of organizations, not just separate corporations. And the fact that it would be updated by that hospital or that facility, but still be able to be standardized to meet the field, so that the query could work.

Anyway, so the point of this is I think we've been talking about this almost from a hardware point of view and not necessarily also the software conceptually. So I want to again re-emphasize this notion of an algorithm analysis, so that we don't lock ourselves into only the hardware, sort of, where the data repository sits, etcetera.

Kevin Larsen, MD – Office of the National Coordinator

Ahmed, this is Kevin.

Ahmed Calvo, MD, MPH – Health Resources and Services Administration – Senior Medical Officer, Office of Health IT and Quality

I hope that's helpful.

Kevin Larsen, MD – Office of the National Coordinator

Yeah well, Ahmed, this is Kevin. Is there a sort of charge in there to the Data Intermediary Tiger Team, some specific question like please consider query-based analysis for registry reporting or, how can we make sure we get a good answer from the Data Intermediary Tiger Team, focused around this issue?

Ahmed Calvo, MD, MPH – Health Resources and Services Administration – Senior Medical Officer, Office of Health IT and Quality

I'll have to think about the right phrasing of the question, and I'm happy to help with – I guess I'll volunteer to help over the next couple of months to kind of make sure we get the right phrasing there. I just want to make sure we don't fail to think about that very, very, very carefully, because we want the information to be really useful to us and to the HIT Policy Committee, as opposed to people just sort of going, oh well, that's too abstract and I don't know it'll help.

Helen Burstin, MD, MPH – National Quality Forum

Great. Thanks Ahmed.

Kevin Larsen, MD – Office of the National Coordinator

No, that's a good point. And thanks Dr. Calvo. I think we're, MacKenzie, ready to open up to public comment.

Public Comment

MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead

Operator, can you please open the lines for public comment?

Rebecca Armendariz – Altarum Institute

If you would like to make a public comment and you are listening via your computer speakers, please dial 1-877-705-2976 and press *1. Or if you are listening via your telephone, you may press *1 at this time to be entered into the queue. We have no comment at this time.

Helen Burstin, MD, MPH – National Quality Forum

Great. Thank you much. So, our next steps here Jesse, we'll ...

Jesse C. James, MD, MBA – Office of the National Coordinator

So, look for an update to the guiding principles on Google docs Google drive and look for an update to our questions out to the Data Intermediary Tiger Team and important attributes of the clinical data registries. That should be out this week. Thanks all.

Helen Burstin, MD, MPH – National Quality Forum

Great. Thanks everybody.

MacKenzie Robertson – Office of the National Coordinator – Federal Advisory Committee Act Program Lead

Thanks everyone.