NATIONAL QUALITY FORUM

Moderator: Meredith Gerland
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11:00 am ET

Meredith Gerland: My name is Meredith Gerland. And I'd like to welcome you all today to our fifth committee web meeting for Improving Diagnostic Quality and Safety/Reducing Diagnostic Error: Measurement Considerations.

Before we begin, I'd like to share a few housekeeping items with the group. The call is being recorded and we will post the recording on the committee's SharePoint page after today's web meeting. All of your lines are open, so please do mute your lines when you're not speaking and please refrain from placing the call on hold.

We know many of you are following along with the slides on the web platform. So if you are on the web platform and have also dialed in through your phone to be able to contribute to the conversation, please go ahead and mute your computer speakers to avoid getting any feedback.

I'd like to take a moment to briefly review the agenda for our web meeting today. After our introduction, we'll go over a brief overview of the use case approach to remind everyone the purpose of the use cases. We'll then dive into a discussion on Use Case 3 and Use Case 4 before having an opportunity for public comment at the end of the call. We'll conclude today's web meeting with a brief discussion of the next steps for the committee.

I'd also like to introduce our NQF project team who's on the line today. This is Meredith Gerland speaking, the Director of the project. We also have Deidra Smith, our Project Manager, Carolee Lantigua, our Project Analyst and Jesse Pines, our Consultant. I'd also like to welcome Udobi Onyeuku as a new Project Analyst from NQF joining the team.

I'll now turn it over to Carolee Lantigua to perform a committee roll call.

Carolee Lantigua: Thank you, Meredith. Why don't we start with our co-chairs, David Andrews?

David Andrews: Here.

Carolee Lantigua: David Newman-Toker?

David Newman-Toker: Present.

Carolee Lantigua: Flavio Casoy? Karen Cosby?

Karen Cosby: Present.

Carolee Lantigua: Sonali Desai?

Sonali Desai: Present.

Carolee Lantigua: Jane Dickerson? Andreea Dohatcu? Mark Graber?

Mark Graber: I'm here.

Carolee Lantigua: Helen Haskell?

Helen Haskell: Here.

Carolee Lantigua: Cindy Hou? John James?

John James: Here.

Carolee Lantigua: Joseph Kunisch?

Joseph Kunisch: Present.

Carolee Lantigua: Prashant Mahajan?

(Prashant): Yes, I'm here.

Carolee Lantigua: Kathy McDonald? Lavinia Middleton?

Lavinia Middleton: I'm present.

Carolee Lantigua: Craig Norquist? Shyam Prabhakaran? Ricardo Quinonez? Roberta Reed?

Roberta Reed: Here, I'm here.

Carolee Lantigua: Hardeep Singh?

Hardeep Singh: Yes, I'm here.

Carolee Lantigua: Colleen Skau?

Colleen Skau: Present.

Carolee Lantigua: Michael Woodruff?

(Julie Wright): Hi, this is (Julie Wright). I'm here in place of Dr. Woodruff today.

Carolee Lantigua: Welcome Julie. And Ronald Wyatt? Is there anyone that I missed or who joined while I was doing the call?

Andreea Dohatcu Andreea Dohatcu, I just joined. Thank you.

Carolee Lantigua: Welcome, Andreea. We also want to recognize and see if our federal liaisons are on the call today. Andrea Benin?

Andrea Benin: Yes. I'm on for a while, yes.

Carolee Lantigua: David Hunt?

David Hunt: Yes, I'm here. Thanks.

Carolee Lantigua: And Marsha Smith?

Marsha Smith: Yes, I'm here.

Carolee Lantigua: Okay. Well, thank you everyone for joining us. And now I'll turn it over to Meredith who will guide us through an overview of the use case approach.

Meredith Gerland: Thank you, Carolee and thank you for everyone for joining us on today's web meeting. Before we begin our discussion on use cases 3 and 4, we wanted to reiterate I think the purpose of the use cases. The use cases will really be used to describe a specific diagnostic error and identify the causal factors and diagnostic challenges that may be contributing to it. The use cases will share solutions to overcome the error. The use cases are intended to apply to various system, settings, stakeholders and populations.

As you'll see in the discussion questions included in the agenda and the slides today, we'll have a robust discussion to help identify actionable solutions that apply to different stakeholders.

Use cases will also identify measurement approaches and concepts to assess the degree to which the identified solutions are being implemented and are facilitating a reduction in diagnostics error.

The solutions within the use cases will be both global and granular. To help identify the more granular solutions, we will discuss a series of possible case exemplars that illustrate the error in practice.

As you'll see in the discussion guide that was shared in advance of the web meeting, we'll move through the conversation today by first describing the clinical context that contributes to the type of error. We'll then share possible case exemplars that help demonstrate the error in practice before diving into a deeper discussion on diagnostic challenges, causal factors, solutions and quality measurement approaches.

The goal today is to begin the discussions on use cases 3 and 4. And then we'll continue to build on these discussions in our next web meeting. We'll aim to focus the discussion today on those challenges, solutions and measurement opportunities for each use case.

As a reminder, our previous two web meetings, Web Meeting 3 and Web Meeting 4 were focused on discussing the first two use cases. We synthesize those discussions from our past web meetings to incorporate the committee's feedback and have developed the draft use cases for cognitive error missed subtleties and system error communication failure.

The discussion guide and materials you've seen in the web meeting so far as well as the conversations and dialogue we've had on the web meetings are what have informed those draft use cases. We're now transitioning to begin our discussions on use cases 3 and 4.

During our last web meeting in January, we had a brief discussion with strong committee support for moving forward with the topics of cognitive error information overload and cognitive error dismissed patient as the topic for use cases 3 and 4. Today our two committee co-chairs will guide us through a discussion for each of the use cases.

I'd now like to turn it over to our Co-Chair David Newman-Toker to begin the discussion on Use Case 3. David?

David Newman-Toker: Great, thank you. So, Use Case 3 is the - this notion of information overload the idea that in complex or critically ill patients where it's clear that the patient is sick, but there're so many things going wrong that it's hard to find the story amidst all of the signal indicating that the patient is ill in so many ways.

There is increasing complexity in both the content of clinical care and the delivery of that care. It's a faster paced environment, patients are sicker, people move in and out of the hospital faster, it requires a higher level of illness to be in a setting like an intensive care unit or even in a hospital because care has been - for less sick patient is being pushed further and further out into the field. And in many of these patients, the sheer volume of information, how it's presented to clinicians can sometimes itself lead to errors.

Ultimately, this boils down to being about excessive cognitive load, intrinsic and extraneous loads. And there are a lot of props that we've put in place to try to help people that they actually in some places make things worse through alarm or alert fatigue as well.

The first section of this is really talking about case exemplars. Here are a few potential case exemplars that we've prepared as drafts, one about a burn victim intubated in the ICU needs fluid repletion and after a blood job and low grade fever, cultures, so on and so forth thinking about sepsis which is would be sort of the obvious cause in a situation like this, but other causes of hypotension were investigated, the patient dies of a massive pulmonary embolus.

Second case where a post-operative heart valve repair patient has some subtle laboratory abnormalities are evolving and near a delay in identifying the sepsis amidst all the other things that are going well with the patient leads to additional problems stay, surgery, repeat surgeries, so on and so forth.

And the third in which the - we took an outpatient case, somebody with multiple comorbidities, multiple medications, seeing multiple doctors, getting multiple tests in which things aren’t kind of assembled properly and somebody misses a test results in that context and there’s a delay in diagnosis.

In cases like this, obviously, there are specific diagnostic challenges that are posed and how do these - and we have to ask questions around what are the common causes of information overload.

And I guess I’ll pause there just ask our NQF colleagues, what’s our timing for this case until - what time approximately?

Meredith Gerland: Thanks, David. We’ve about until 12:30 for the full discussion on Use Case 3 and then we’ll transition the Use Case 4.

David Newman-Toker: Okay. Maybe let’s just take a minute with the committee before we get into the causal factors, questions and just talk a bit about the case exemplars whether what’s listed there seem like reasonable choices, whether there are other types of cases or issues that you think need to be raised in the context of discussing this issue of information overload.

John James: This is John James, can you hear me?

David Newman-Toker: Yes.

John James: Okay. Anyway, I guess I think you (unintelligible) counted in the roll call. Anyway, I’m seeing quite a bit of traffic in the medical literature about looking after physicians that are aging and ensuring that their cognitive abilities are up to the cognitive load or the overload they may have in their practices. Is that something that should be mentioned here? I’m only looking in as an outsider. I don’t know if that’s a big problem or just one that makes it into the medical journals.

David Newman-Toker: Yes, it's a fascinating issue. Do others have any comments? I have some thoughts if others - let's first hear from other people first.

David Hunt: Hi, this is David Hunt. I don't know if it should be necessarily an age specific decline that we're looking for, because, you know, I think we've all seen individuals who perform exceedingly well, well into their 80s and some of us are going rapidly downhill in their 40s. So I'm not sure if it needs to be an age specific decline.

David Newman-Toker: So, as a neurologist, I'll sort of throw in here. Everybody's cognitive capacity starts declining from age 25 on. And if you just look at elemental skills, everybody loses cognitive function over the course of the years, you know, things like memory and digit spans, so on and so forth, wherever the baseline was, it starts to dwindle overtime.

When people have looked at this at least to my knowledge in the literature, what they've found is that older physicians compensate for these deficiencies with essentially wisdom, so they lose some elemental cognitive abilities, but their experience and knowledge, they use sort of other tricks and clues to be able to kind of keep pace and they generally do assuming they don't develop some sort of neurological decline.

Probably the bigger loss from the (unintelligible) in general is from the past recency of the information that they have. As they get older, they're further and further removed from their training and the CME process doesn't kind of keep up with them.

But I do think the idea of pointing out that the cognitive load notion is there is a balance, right, there is cognitive capacity and then there is the load placed on it and if the load outstrips the cognitive capacity regardless of what the reason is whether that's a decline in the cognition or an increase in the load that would lead to this scenario. So I think it's a good suggestion.

Others have any additional comments on that? I know it's always sort of a sticky issue for physicians in general of any age, but especially as people get older.

David Andrews: This is David Andrews. So just like I mentioned, it is not just capacity of mode, but there is also a kind of personal inclination if you will, there is a lot of literature on so called cognitive complexity and cognitive simplicity and the more simplistic cognition is those who will quickly latch on to a specific answer and not rapidly relinquish it in absence of the load. So it's another benefits puzzle, but it's more an individual difference than an age related issue.

David Newman-Toker: Other comments on that issue?

Hardeep Singh: So this Hardeep.

Jesse Pines: Sorry, go ahead.

Hardeep Singh: No, please go ahead.

Jesse Pines: Yes. This is Jesse Pines here. I think another consideration is the volume that an individual clinician works. I mean I think that there is some evidence that, you know, clinicians that work less clinically, you know, may have, you know, higher risk of medical errors, you know, and that can be sort of compounded with age. So I think that's another consideration.

Hardeep Singh: So this is Hardeep. So I think again, we'll probably have to sort of focus the cases a bit to be more prototypes of things people can relate to and sort of the more complex and challenging we make them for, you know, the regular audience to understand, the harder it is going to be to get the message through.

So I think we need to sort of pick one that illustrates best of, you know, if you're focusing on information overload, we're not going to be able to get rid of all the cognitive tasks that we're doing or we're not going to get rid of some of the cognitive complexities that come with age, we're not going to be able to get rid of all the multitasking that we do. But we can make our systems better so we can present information that is - you know, it doesn't overload the people who, you know, are using them.

So I think the third case probably is a lot better in terms of, you know, direct message with information overload, something concrete that could, you know, get better. And I don't know how much we're focusing on the EHR and the other two cases and I can't remember. But it's something concrete that, you know, people can understand, people can relate to and say, we can fix this problem by making, you know, trends better or making the EHR better, I mean, we've shown in our work that people miss abnormal test results because of too many notifications in the EHR. And it's something that we can be doing something about.

So I would say, you know, we need to sort of be careful of what cases we end up picking based on all this discussion.

David Newman-Toker: So Hardeep, just to follow up on that. As you look at the cases that are listed there, do you see those as fitting the mold that you just described?

Hardeep Singh: No, I don’t see one at all fitting that mold. I don’t - I mean that’s like normal medicine. I mean choosing between different things to do.

The second one gets to the point about, you know, yes, we can do a better trend analysis and display information better so we can, you know, increase situational awareness of the clinician who is taking care of the patient. And the concept of situational awareness is important. It’s been sort of vetted study in the aviation, human factors work. I mean the goal will be how can we increase the situational awareness of the provider and decrease information overload.

And the third one is also gets to that when it talks about large volume of results, not organized and lack of cogent, narrative summaries. I think that one gets the point across better as well. I would probably not pick the first one for sure and we can discuss two and three.

Helen Haskell: This is Helen.

David Newman-Toker: Go ahead Helen.

Helen Haskell: No, I was just going to say these cases really resonated with me as a patient. I have heard all of these scenarios from patients who’ve suffered serious medical harm. And often the solution - and I think what (unintelligible) Hardeep is saying is that they’re not solutions to all this and that it’s sort of business as usual. But often the solution is greater family input. And I think that’s something we need to think about. I like these cases, I feel excellent. So that’s just my input on the patient perspective.

Hardeep Singh: Yes. And Helen, I want to clarify. It’s not that the case number one, there is something kind of wrong with other case is bad. For the communicating information overload as the reason to focus on, case one doesn't come across as communicating, not to me at least.

Karen Cosby: This is Karen. I understand where Hardeep is coming from. I'd like to counter an argument in favor of one. I think that one typifies the common problem I see where we chase - we rely too much on chasing symptoms and signs rather than doing some sort of routine surveillance and active surveillance were things we know are likely to go wrong.

And I think that it's particularly in ICU and very acute care settings where things are complex, it could be a case that would be used to argue for team based processes and problem and a management approach that has a very organized systematic method of actively surveying for the kinds of diagnosis we know that are likely going to kill someone rather than wait reactively for some evidence to suspect them.

And I think there is a lot of good that could come from that case. It doesn't exactly fall in the category of information management. That's the second two cases do. But I think there is something very relevant about it and I wouldn't want to abandon that too easily.

Hardeep Singh: Well, I mean, you could put it under the team based cognition, you know, how to improve team based cognition. I mean that's why it maybe fits better, you know, can - your point well taken. It's just not - to me, it's not just a information overload problem for one.

David Newman-Toker: Well, I think Hardeep what we're hearing from some of the others is that information overload doesn't necessarily just mean through the EHR.

In other words, I think what Karen's getting at and correct me if I'm wrong is that it's a little bit around this idea of, you know, what's the most commonly missed fracture, you know, the second one, the - this notion of being systematic, having protocols in place, the same way we have protocols for treating somebody who's had a cardiac arrest where there is a systematic and, you know, that's sort of the ultimate and systematic structured protocols.

In theory, things like hypotension in an ICU patient are things where there should be a protocol rather than relying on kind of the initial context to go kind of for the common things or common - you know, how the patient must be septic without kind of ticking off the list, whether that's checklist or whether it's something in EHR or not.

Hardeep Singh: So how is this differ from any other case of like diagnostic data due to - I don't know some kind of knowledge of a cognitive bias or overconfidence or whatever else?

David Newman-Toker: Yes. So I mean I think that's an interesting question at least for me, I'll answer that and I'd like to hear from others. The challenge that faces a patient who comes in for instance to a clinic or an emergency department with a relatively mono symptomatic presentation and who doesn't look sick, somebody with a headache or chest pain or whatever and they don't have disturbed vitals and whatnot is that you're trying to figure out is this patient sick, sick enough that they need to be admitted to the hospital or triage to a higher level of care or get some sort of emergent treatment.

When you have a sick ICU patient, you already know they're sick and you're trying to kind of keep your fingers in the dam and there is a lot more going on. You're not chasing to see if there is an illness causing their one symptom, you're chasing everything and there are a lot of things going on at the same time.

Do we have others on the call who have, you know, other ICU or ED experiences to lay in on this issue or anyone who would like to weigh in?

Jesse Pines: So this is Jesse. I would agree with that. You know, sometimes we are in a situation in the emergency department where there is, you know, a information overload kind of situation where it's a very complex patient with - that we've never seen before with some new complex presentation.

So, you know, that can happen in the emergency department. But really the design of this case was around, you know, what you just said where, you know, there are a lot of moving parts and you just, you know, didn't think that, you know, you sort of permuted, you know, a signal for something else and didn't think broadly enough, you know, because of this information overload. So that was this line behind this.

(Prashant):So, this is Prashant. So I'm not necessarily convinced that this whole aspect of information overload is always pertinent in all of these cases, right? Because like when we are working in the ER or when we are working in the ICU, you are expected to get a lot of information especially like this sort of a patient, right? And then your system is primed to receive that information and act upon it.

To me, if you look at case one, now this to me seems to be like, you know, you are - you have mentally closed on one diagnosis and hung on to it and you are not willing to think of other causes. I mean and that could be due to many things. Part of it could be just too much information, part of it could be that the whole team is not even thinking about this or part of it could be just an atypical presentation.

So I'm not necessarily convinced that you can isolate information overload as an modifiable and often as an, you know, individual factor which has contributed substantially to the diagnostic error. And it's very hard to parse it out given a burned victim who is intubated who is probably on, you know, vasopressors and multiple others such medication, yes.

David Newman-Toker: Other comments?

Joseph Kunisch: Hi, this is Joe. Just kind of a quick comment as you move into the question to diagnostic challenges, because when I was reading these scenarios and looking at the challenges, I don't know the scenarios capture all of those challenges, maybe the first two bullets. But things like the alarm, fatigue interruptions, process, complexity, physical fatigue and mental fatigue, how to tease those out in each of these scenarios, how do they play into that?

So maybe a scenario that's more related to those like ED physicians that have, you know, four patients that they have to see, you know, one of them is very complex, maybe, you know, a trauma patient that just came in and they've got to see three other patients that are, you know, level two or three emergency severity index, something that, you know, also brings those into play.

David Newman-Toker: Okay, thank you. Now that we're…

Kathy McDonald: This is Kathy. I think it's also - I mean its back to the sort of signal versus noise challenge in clinical practice. And I just want to reinforce what Helen said that, you know, we're having a discussion that typically will migrate towards the one individual clinician, you know, thinking about what they could do differently or what, you know, kind of the context is in terms of why the situation is - it's harder to get the signal from the noise.

So I mean I think that thinking about this overload issue is important. And I think thinking about the, you know, types of contributors to that signal to noise challenge is important. I'm thinking about countermeasures is important too. You know, but we should not do a case because it's hard to come up with countermeasures or it's hard to tease out which countermeasure is under what circumstances and that's what it gets down to some countermeasures will be appropriate and some of these types of overloading contexts and some will not and that's the challenge. But if we can have these kinds of - this is a good set of cases as far as (unintelligible).

Jesse Pines: Yes, this is Jesse again. Just to comment and, you know, the design of these different case scenarios is not to say that the information overload is the only causal factor, because we have those listed here. It's just a group of cases where there is a lot of information and there are multiple contributing causes, so I just wanted to clarify that.

(Prashant):So Jesse, can I ask a quick question then? Do we as a group are required to define what is information overload, because, you know, the earlier point you mentioned, right, clinicians at different stages in their careers are experienced or volume of shifts or work that they do, they may have a different or a shifting information load threshold, right?

Jesse Pines: Right. So different clinicians certainly are going to have thresholds at which they reach our cognitive load and I think that that may (unintelligible) that in, but (unintelligible) a lot of moving parts simultaneously (unintelligible) signal gets a (unintelligible) that's really what we're trying to capture (unintelligible) case, the (unintelligible) where there is not a lot of a signal spread, you know, there is a tiny (unintelligible).

Helen Haskell: You are really cutting out. I don't know if you can do anything about the audio.

David Newman-Toker: Is it Helen? Are you able to hear me okay? Is it just Jesse? Because I was having the same problem, Jesse cutting in and out, but I just want to clarify that…

((Crosstalk))

Jesse Pines: Okay. So let me move my…

((Crosstalk))

David Newman-Toker: Okay. While Jesse gets his audio worked out, I think what he was saying was just that, you know, articulating this notion that the signal is very high. And so even a moderate signal if something going wrong like somebody being hypotensive which would immediately be a massive red flag in a clinic setting is sort of par for the course in an ICU. And so it's sort of demands a different set of approaches.

I think the key question here that really Karen raised and Kathy has, you know, sort of piled on a little bit around this idea that the kind of countermeasures you use might actually be something different.

So if you have this kind of a complex care for a patient, it might be oriented around teamwork as just as much as it's oriented around making changes to the EHR and data visualization to decrease some of that cognitive load whereas you probably wouldn't be able to do the same and saying in an outpatient clinic where you're in a one-on-one with a patient, you know, evaluating their headaches or whatever their, you know, cough, you can't bring a team of six people into the room to help you figure that out. But in an ICU setting, you already have six people that are around and everybody's eyes and ears are there. So perhaps that's part of the contextual difference that's important to draw out as well.

Okay, other comments? We'll take that into consideration around the whole cases themselves and see if we can work in some of these other causal factors, maybe into some of the cases make them even more distracting and difficult. But to sort of emphasize the information complexity, are there other things that people feel like needs to be articulated that are not articulated in this list of diagnostic challenges or causal factors?

Andrea Benin: Sorry, this is - it's Andrea, sorry. The one other thing you might consider about revising the cases, the third one I think might be better to choose the final diagnosis that's something other than Lyme disease. I think given some of the drama around various Lyme disease things, but I think it's a little distracting, but that's what the final diagnosis is. You know, it could be leukemia, you know, some whatever, something else, I'm not sure what you consider those diagnoses, but I would just suggest something else that the discussion isn't distracted into that arena.

David Newman-Toker: Okay, sure.

Karen Cosby: This is Karen…

John James: This is John. One thing that's I'm not sure about at all is how often obtaining a medical record is important to the care and diagnosis of the patient. For example, I look at the first scenario and I say did they have the EHR on this patient? Maybe he had coagulation problems somebody see beforehand and if we'd had the medical record, we would have known that tended to be one of his problems. Is that common or is it rare that one cannot get the medical record that's very much needed?

David Hunt: I suspect it's highly dependent on your clinical practice setting. But if people want to comment on the issue of how common getting medical records is important and difficult, I suspect it's much harder, for instance, in an emergency department if somebody is not within the system then in other contexts probably less so with referrals and specialty care or whatever where it's almost mandatory that all the records be sent over to begin with.

John James: And it kind of goes to the idea of interoperability and I don't know how well that's working. I have a suspicion it's not working all that well based on some things obviously. But there again, I have no first-hand knowledge.

Jesse Pines: Yes, this is Jesse. A comment on that that is a huge issue, you know, in particular where you've got people who are seen in multiple emergency departments that where the records don't connect with one another. You know, some of that has been helped with information exchanges, you know, with Epic has care everywhere in communities. So, you know, you can sort of get everything assuming the patient has consented to that. So that is a big issue in the emergency department.

I think sort of less so in the ICU setting where really it's this information overload related to the physiology - the active physiology that's going on to the patient. They were trying to really describe in this case here where there're, you know, so many things going on that, you know, something that in a retrospect, you know, yes, you should have thought of that. But because there was so much going on, you didn't think about pulmonary embolism.

David Newman-Toker: And Karen, you had a comment that you were holding on to?

Karen Cosby: Well, I'm toying with the idea of - to me there is a difference between information overload and cognitive load. A cognitive load is sometimes partly incomplete information or uncertainty. And I think it's a similar problem, but you can't call it obviously overload of information. It's just not sufficient or a high degree of uncertainty. And that certainly factors in this, but I don't know if you would include it here, but I just put it out, because I think that's a big part of the cognitive load in a lot of clinical practice.

David Newman-Toker: So that high levels of uncertainty would be part of the causal factors increasing the cognitive load, did I understand that right?

Karen Cosby: You know, if you have incomplete pictures, a lot of missing information or it creates so much more cognitive load to try and discriminate between what you know, what you don't know and what that means. And to me the greatest burden of the cognitive load I would deal with would be more - not too much information, but just information that doesn't add up well where it's difficult to synthesize.

David Newman-Toker: Yes, okay.

Karen Cosby: And I think the question I would bring that out is we build these cases right somewhat, because we think we know what strategies and solutions we want to suggest. And that problem perhaps result with more with AI machine learning, some sort of surveillance going on that would help guide people.

Jesse Pines: And then (unintelligible) I think a good segue too. David, we could move on with the challenges and I'll go back to maybe comment and then look to add on.

David Newman-Toker: Yes, for sure. So any final comments on the causal factor issue? Other things people want to suggest maybe we consider on the list?

Okay, let's spend some time talking about solutions. There are a number of solutions that have already been raised teamwork to distribute the cognitive load, artificial intelligence for data patterns, improve the HR visualizations protocolizing the high stakes pathways. Are there other things that people would like to put on the list of potential solutions that are not listed? And are there things that people think are particularly promising in this kind of a case scenario or context?

Colleen Skau: This is Colleen. I was just going to say, you know, given the recent interoperability rules put out by HHS from ONC and CMS, I think, you know, that - some of that is intended to get at exactly these kind of issues. And, you know, we do have improved the usability of EHRs on this list. But I wonder if it would be worth adding a little bit more weight to the idea of interoperability and increasing patient access to their own medical records to reduce some of the burden on doctors, you know, that clearly is a priority of the health system right now? And I think it fits nicely into solving some of these challenges. I don't exactly know what their concrete solution is, but it's kind of another aspect to consider.

Hardeep Singh: And could you just - just to clarify Colleen, just one second, I just want to clarify with Colleen so that I make sure I understand what we're saying. So you mean for instance, around the third case, where there is sort of a foundationally sort of an interoperability challenge, because there is a lot of crossover to different providers and everybody is ordering tests in different spaces that kind of thing?

Colleen Skau: Yes, exactly. I know we talked briefly earlier about, you know, interoperability among EHRs as well, but I think it's probably most naturally in the third case where a patient having access to his or her own data and would reduce some of the burden of multiple providers and everyone keeping track of who is seeing this patient, when, for what, et cetera, et cetera.

David Newman-Toker: Great, thank you. It was…

Roberta Reed: This is Bobby Reed. I'm the - I guess the patient person that's on the committee here. And I have a comment too regarding the medical records and access to them, because it's something personally that I am experiencing right now. And some of the things that I would like uncover during my investigation to find out to actually get copies and access to my records because of the very fact that was just mentioned about multiple providers and the fact that all systems do not talk to one another.

Some of the things that I've discovered or one important thing that I think will be crucial to maybe tying this together is that on our (unintelligible) that you can actually link to your - I guess insure your health provider to the hospital system or whatever it might be so that when you go to the different providers, whether they're inside your healthcare system or outside the system that you can click one button on the app and it brings up all those records which are centralized.

Currently, my health system is still trying to navigate the obstacles of making this work apparently, reviews with the iPhone which is what I have. There're certain hierarchy levels of things that they have to jump through in order to make the systems talk to one another. And it is one of the hard pointing items that they're working on in terms of technology and moving forward.

So I think that that might be one of the positive (experience) to the number three thing that you have on here that it might help. And I just wanted to add that comment.

David Newman-Toker: Thank you very much. I appreciate that insight. And maybe you can share with the NQF staff offline the specifics around the app so that we can do a little bit of looking behind the scenes and figure out what - whether others are doing something similar to the health system that you're working with.

There were at least two people who had something to say. I think one of them was Helen and maybe Joe or John or someone, I'm not sure exactly who the other person was. Helen, do you - did you have a comment that you wanted to voice?

Helen Haskell: I just wanted to reinforce the idea that protocol so that people don't overlook things, I think that is well placed in the number one position. And also when you're talking about access to medical records, it is really helpful to have access on an inpatient basis to see so the family can see things that are overlooked. I know that, you know, some of the IQ dashboards that were developed under the Moore Foundation Grant were really good on this as well, so just to…

David Newman-Toker: So really, Helen, taking this patient engagement idea beyond what would seem to be the sort of prototypical setting of an outpatient clinic where, you know, results are dribbling in overtime and the doctors have sort of got 100 patients and they've forgotten about one or two of them, but the patient has a focused interest in their own healthcare. But here you're saying, even in the ICU where all hands are on deck, it may be a good idea to have patients monitoring their own care, their families monitoring their own care in such a way that they can help serve us an additional safety net?

Helen Haskell: I think it's even more important in the hospital and even more in the ICU, because there is such an information overload that people can overlook things whereas the family member, you know, who is watching symptoms change and seeing it real time and longitudinally can really come to (unintelligible).

David Newman-Toker: Got it. Okay, thank you. There was another comment that somebody had started to speak up.

John James: Yes, this is John. I want to reiterate what Colleen and Helen said, I also want to add the idea of shared decision making which was one of the themes in one of the papers we had and I don't remember which one of the scenarios it was, but that's very important to get. By doing shared decision making, you begin to fold the patient into the whole process in a better and assertive way so that when they get a chance to look at their medical records, they have a better idea of what's going on and so the idea of shared decision making I think should be reflected somewhere in the solutions here.

David Newman-Toker: Okay, thank you.

Andrea Benin: This is Andrea. I might add in. I think it fits in here the idea of having access to online textbooks or online journals, textbooks in particular in a way that they help you organize information. I think not everybody has access to that.

And I think that I would - it's a little bit different, but related and I suspect there're some folks on the phone who know even more about this than I do.

But those tools that generate differential - list of differential diagnoses and sort of the rigor with which one considers a full differential at different times and the ability to access either a tool like that or some other mechanism that helps you to generate a differential so that you have something that you can check through and not be blinded by, okay, I have a lot of information that's suggesting whatever sepsis.

David Newman-Toker: And just to clarify Andrea, you were talking about these tools, whether it's the online textbooks or the diagnostic reminder systems facing the clinicians as opposed to facing the patient?

Andrea Benin: That is correct.

David Newman-Toker: Okay. Are there other thoughts or comments before we…

Mark Graber: Yes. David, this is Mark. I wonder if there is some value in discussing the concept of high risk situations in terms of diagnostic error. And all three cases today would fall into that category. But it seems to me that there might be some value in designating high risk situations because it would change kind of how you approach them and what solutions you would bring to bear or maybe you would prioritize the research projects that will be funded to study them. But certainly information overload creates a high risk situation.

And if you're in an ICU where the consequences are extremely high of making a mistake that adds to the high riskiness of what's going on. And in those kinds of situations, I think, you know, you'd be more likely to invoke mandatory things like getting the team involved or, you know, whatever else you would come up with that you wouldn't invoke in low risk situations where the consequences are less and the decision making environment is much easier.

David Newman-Toker: Thank you, Mark. Let me just ask a clarifying question. So do you - so for instance, if the ICU is a high risk situation and let's say we exempt patients who are just sort of routine post-op patients, but, you know, patients who are in the ICU for medical reasons of one sort or another. Are you envisioning that that's a high enough bar already that where essentially we should fundamentally alter the architecture of the way we provide care there and change the nature of kind of teamwork and double checking to add additional layers of safety nets? Or are you thinking even within a context like the ICU for specific kinds of scenarios like someone's blood pressure is crashing or something like that…

Mark Graber: No, I think you - yes, you would - you know, you spend more time on those patients, you bring more resources to bear, you'd invoke more precautions to prevent a diagnostic error. So I think it is worthwhile to think about it in that terms of prioritizing the decision making that has to be done.

David Newman-Toker: Okay, thank you. Any final comments before we move on?

Joseph Kunisch: This is Joe.

David Newman-Toker: Go ahead Joe.

Joseph Kunisch: Yes, this one, I might add something to increase access to specialists by telemedicine. I'm looking at these kind of thinking at the rural providers and hospitals that, you know, may have difficulty implementing some of these, but that's one that can definitely help us increasing that access.

David Newman-Toker: Certainly. We've seen a lot of that with things like a tele work for, you know, neurologic care and critical care settings or things like that where not everybody's got access to somebody on site if they need a little extra help. And so, thank you, yes.

Okay. Let's move to the question of quality measurement. As we think about these sorts of things, here are some, you know, constructs around measure concepts, obviously EHR related measurement to some of the things that Hardeep has suggested for the overall way one should rate an EHRs on its usability or its data visualization and other related tools, issues about total productivity as measures of cognitive load or outcome oriented things like time to detection of clinical events like sepsis or otherwise? Are there other concepts that people think should be on this list? And are there any of these that are particularly jumping out at people as particularly helpful in this kind of use case?

Lavinia Middleton: Hi, it's Lavinia Middleton. I think looking at advocacy risk root cause analyses per provider or per team is another outcome quality measure that I would recommend.

David Newman-Toker: Okay, great, thank you.

Andrea Benin: This is Andrea. It would seem like there might be some things on the previous list that then this will be like presence of would be the metrics like protocols for, you know, AMI, so a measurement will be like does that exist or whatever the - or is it correct or how often is at use. I think some of those are up against the previous list.

David Newman-Toker: Got it.

Colleen Skau: This is Colleen. Just - I'm not sure if this is sort of captured in the surveys by clinicians on the EHR usability. But something regarding alarm fatigue, but kind of broader than just alarm fatigue. I know this is something that we come up against when we're thinking about quality measures to measure how well pathologists communicate with ordering clinicians that, you know, anytime we want to put something in place that encourages pathologists to communicate with ordering clinicians, we have to be really careful of, you know, exactly alarm fatigue. So I don't know if that's kind of captured in EHR usability if there is a broader way to say like just too much notification, something like that.

David Newman-Toker: Okay. So broaden the notion of over notification. But it's not just the beeping from the device next to you or the alert on the EHR, it's also people calling you and paging you to tell you about test results or communicate with you effectively. The overall load is - goes even beyond what you're dealing with in the technology per se.

Colleen Skau: Exactly.

David Newman-Toker: Okay, other comments?

Kathy McDonald: There're some measures related to - this is Kathy, there're some measures related to teamwork that might be appropriate here on different levels of teamwork. So there is a measure called relational coordination that gets at the level of ability of a team that needs to be identified as, you know, working towards a task like diagnosis in particular situations that team has the ability to have a shared understanding of what they're doing and have timely enough communication, problem solving enough communication and seeing higher levels of that and conditions of uncertainty and interdependence would be a reasonable proxy for saying that the overload situation is being addressed well by the teamwork and having lower levels of that would mean you'd have a poor capacity to do so.

David Newman-Toker: Got it.

Helen Haskell: And I would also…

David Newman-Toker: Thank you.

Helen Haskell: Sorry. This is Helen…

David Newman-Toker: Go ahead Helen.

Helen Haskell: …I don't mean to be a broken record, but I would also add patient survey if there is, you know, lack of communication and coordination and lack of inclusion of patient input. The patients and families certainly are careful of seeing that and identifying it.

Roberta Reed: Hi, this is Bobby Reed. So I have something to add here as well. I noticed that some of our clients while leaving the doctor's offices that I've seen recently that (unintelligible) the notes it says for after visit summary report or there was, you know, what was discussed on with my appointment is not on there, you know, wasn't on there.

So when I brought this to the attention of the healthcare system that I have, they informed me that their systems, they - even though they do have like sort of an open notes format for their revisions to see in between one another, it is supposedly open to patients as well to see that in order to not be seeing that information on my reports. The physicians that I've been seeing have to physically go in and deactivate that button that prevents - that would prevent me from seeing those notes.

So for that reason like when leaving the ER or updates are given in the - if they're in intensive care or daily update, I feel that that information in the doctor's notes to keep the patient better informed in on this same page should be visible to them by way of that electronic measures - the measurement that's already there. And that too would help prevent maybe errors or diagnosis - errors and diagnosis or delays from happening because if the information is inaccurate from what the caregiver or the patient has actually seen, it would call back to their attention and give them yet another opportunity to express that to the people that are caring for them.

David Newman-Toker: So Bobby just to clarify - just to clarify, are you thinking of this more of as a solution as that involves more patient engagement by showing the summary report for more of a measure or both?

Roberta Reed: Both really, because, you know, when you're in a critical care situation in an intensive care, it is overwhelming. You know, I've been there with my son with his kidney disease and, you know, crisis situations and it's too much to take in and to remember everything at one time. And even though you might take somebody with you to an appointment or have somebody there when the doctors are talking to you and hope that they take down the notes or absorb that information, things are (knit). If it was written down or if it was at least stayed available in the way of, you know, maybe a daily report or summary of some form of what the doctors were actually saying and thinking that would just create or promote more of a team effort involving the patients, caregivers and so forth in the care and resolution to their treatment.

David Newman-Toker: Okay, thank you. Maybe time for one more…

Helen Haskell: You can think of quality measures there as, you know, being able to see more signs of really authentic, you know, useful patient partnership versus less signs. I mean there could be some quality measures around that in the diagnostic space.

David Newman-Toker: Got it, okay. And there is maybe time for one more comment if anybody has a quick one.

Joseph Kunisch: Hi, this is Joe. I got a quick one. I would just add in using EHR log data to measure usability, there is quite a bit of literature out there and work being done around that to measure usability and the burden on physicians.

David Newman-Toker: Great. Thank you. That's super. Okay. I'm going to turn it over to my Co-Chair, David Andrews.

David Andrews: Hi. There we go. We're going to begin to look now at what we perhaps slightly inflammatorily described this to dismiss patient. The whole issue of the patient being somehow regarded as the solution solved without pursuing to an adequate solution to the problem. So I had thought that I could advance the slides, but I can't. There we go.

Okay. So here is the kind of context and I'll sort of skim through these a bit. You know, patients with uncommon conditions where there is a presentation as if it may be a more common condition often leads to a problem or a delay in a diagnosis. So there is a tendency to assume the common - you know, the horses rather than zebras when in fact it's a zebra back there.

Patients often - and this is a common thing I hear many complaints from patients about this being dismissed as having no real problems or being - having hypochondriasis or as they quaintly say all in their heads rather than drilling down to try and identify a more fundamental source of the problem.

There may be a delay in the condition that rare or in the length or the condition is unknown. This is a problem often with primary care physicians who may encounter an unknown condition or rare one and for whatever reason, not make an immediate referral to a specialist who may be more likely to be familiar with the problem. And I personally had that experience with condition of mine.

Nonspecific symptoms that, you know, promote the diagnostic odyssey where symptoms may cross specialty lines. It's not unusual with certain kinds of rare disease for it to be unclear what specialty is appropriate for exploring or examining the problem until you can begin to hone in on the specific source and identifying accurate diagnosis.

You know, patients often report that they feel they haven't been heard by clinicians. This is probably related to the time demand issue, but it's also a problem where patients feel that they haven't been able to adequately express what their experiences with their problems, their history and the symptoms in a way that they're adequately interested into the whole diagnostic process. And, you know, they have to keep that bias as well. You know, the clinician is not hearing, listening or just giving up and throwing up their hands.

I have several friends and relatives in here lots of stories of patients who, at the end of the day, ever, having seen a lot of clinicians basically say, well, they have no idea what's wrong with me and so here I am stuck with this problem that's getting steadily worse over time.

So to put this in a slightly larger framework, I think there's been a lot of discussion so far about the whole issue of having the patient as a part of the diagnostic team or the family is also for caregivers as a part of the diagnostic team.

And I think what we're more we're looking at in this, this case four is the whole issue of how do we effectively include the patient and family or caregivers as part of the diagnostic team in a way that can contribute to more timely and accurate diagnosis.

Okay. So we have these case exemplars, and you probably looked at these but I'll sort of go through these reasonably quickly and see what your reaction is. So pediatric patient with abdominal pain caused by gluten intolerance the pain is attributed to reflux including intolerance was not investigated by multiple family practice clinicians and ultimately the mother self refers to a specialist in order to make the diagnosis of the failure to make the diagnosis and often the situation where a family member or the patient is the one who recognizes the need for referral to a specialist.

Second case a patient with multiple sclerosis is misdiagnosed as having Fibromyalgia which resulted in certain dismissal of the patient. Often the case at least in the past perhaps not as much now with fibromyalgia complaints and chronic fatigue complaints and some other things where it's often attributed to the psychological state of the patient.

Patient is finally taken seriously when a condition becomes concerned with possibility of a stroke into an MRI and the diagnosis is correctly identified as AMS patient with (unintelligible) migraine chronic unrelenting dizziness triggered by head eye or world load motion presents with intermittent severe dizziness, a patient may have negative test results, but the correct diagnosis is discovered by a neurologist who trials migraine medications.

So these are these are three case exemplars that in various ways try to identify the failure to adequately include the patient in the process or perhaps more pointedly dismiss the patient as no longer worthy of further analysis and diagnosis , so reactions suggestions for others, other cases.

(Prashant):So I can give you one case which is very common in the pediatric ER setting and that goes by the EDM, you know, all that eases is not asthma. And patients who keep on coming with recurrent episodes of wheezing are labeled as asthma because the first chart or the second chart record, it states that the patient has asthma and then that diagnosis is perpetuated. But it could have like a vascular ring as an anatomical malformation that causes which I believe that could be an interesting case and it’s a fairly frequent occurrence also.

David: Great. Okay. Other suggestions or reactions?

Woman: I think these are good, David. I'm wondering if there is an occasion to have an inpatient case added to it. The others were - the last case - set of cases was primarily inpatient, but this does also. Well, maybe not - I mean, maybe - there's the idea of being dismissed, but people can be dismissed in the short-term, as well, (unintelligible)...

David: Right. Yes. With an inpatient presumably there's a - there's an existing diagnosis for why they're there, but there may be a dismissal of other issues or even of that issue along the way. Any specific examples you or anybody else have of a good inpatient possibility?

Woman: Well, (unintelligible) on fire case. That’s a pretty good one. I forget the girl's name. But a young woman who had some - David, help me out. I'm sure you know the case I'm referring to. She was (unintelligible)…

Woman: (Unintelligible) about brain on fire. Yes.

David: Yes.

Woman: Yes. That - and was rapidly dismissed as having psychiatric illness when somebody caught it and treat it.

David: Okay. Yes, that's a good example.

John James: Yes. This is John. I just helped a young mother who was a very good friend of my daughter. Navigate a children's hospital with a very ill six-year-old daughter. Five admissions between Christmas and early February, and five discharges.

And they missed - a rare diagnosis. But they kept sending her home with not very much information and she'll get better. And what struck me about this case is, first of all, they were very late to call in the team. And secondly, they weren't giving her advice on when to worry again.

In other words, how long do you wait for your six-year-old daughter to get better before you call. And after about the third admission, this young mother got very assertive and ultimately she got the right diagnosis for her daughter who is slowly recovering.

But it's - I've advised her to call for a root cause analysis on all of this. She's tried to dialogue with some of the doctors involved and they're stonewalling her basically. So I think in some cases, the patient - the way to integrate what they're thinking would be through the ability to call for a root cause analysis and maybe independently of the organization where the patient has been seen.

It's a bit of a heavy hammer. (Unintelligible)...

Man: Yes. What was the example again? I missed the example there. Could you just spell the clinical - what the clinical example.

John James: Well, the final diagnosis was acute disseminated encephalomyelitis and that's pretty (unintelligible)...

Man: ADEM, okay. Yes.

John James: And - but the little girl was being dismissed first and then treated for infection to the spinal cord and so on...

Man: Yes.

John James: ... without any (bacteria) being cultured from the cerebral spinal fluid. And that struck me as a little odd. But anyway, finally, they got a team and they got a neurologist and he figured it out. But going back to the infection doctor, he was like, "It's not my fault."

So anyway, five admissions, that's pretty scary, a six-year-old girl (unintelligible)...

Man: Thank you.

Man: The ability to cause for - call for a root cause analysis probably falls into our possible solutions category along the way. But it's a - there certainly a lot of those kinds of examples that are - in some cases rather frightening where people - patients have been dismissed.

The other thing that couple comments would suggest is that the knowledge that the patients have is often or family members have and their assertiveness becomes a critical part in arriving a good example. I certainly hear this from lots of people that I talked to that ultimately they were able to get a diagnosis only because they took matters into their own hands and became very assertive in the presence of a system that wasn't - that was planning to dismiss them.

So other thoughts on the case (exemplars) or other examples?

Woman: Yes. I would think when we're talking about an ER - (John's) point is well taken and I could give other examples as well, but ER (unintelligible) is also - might be helpful (inaudible).

David: Okay. (Unintelligible)...

Man: What do people think...

David: Go ahead.

Man: ... what do people think about the idea of calling for root cause analysis, the patient or the patient's advocate? Is that something that there's going to be a lot of discomfort over?

David: As a patient, that's not my area. So some of you physicians have a reaction to that?

Mark Graber: This is (Mark). It's a great idea, but health care organizations generally don't know how to do a good job with root cause analysis of diagnostic error. The tools that they have in place don't take into account human factor elements and cognitive elements, which are often problematic.

Joseph Kunisch: Yes. This is Joe. Just a quick comment that it's - for us, it has serious safety event at some level needs to occur and they all get the RCA done on them. So if a patient did bring this up and request it, we more likely would do it. But I think some of these that just aren't brought into a serious safety event are overlooked.

Man: So I'll just say that we had a whole conversation about this just the other day at (Hopkins) and the (Armstrong Institute). And we're trying to construct ways to make it more liquid for patients to be able to do that. We have some pathways. We essentially have a team of people who deal with patient safety related complaints and we're trying to plug that back into the root cause analysis and risk management process.

I actually think Mark's concern, notwithstanding, every place needs to get better at doing RCA analyses. So that's part of the charge is to do better with diagnostic RCAs. But I like the idea of the patient being able to initiate that and articulate it. We're doing a lot of stuff to try to get patients to be the source of information, to tell us when we've made diagnostic errors because otherwise we don't find out.

Roberta Reed: I have something that - this is (Bobby) Reed again, perhaps you - where I get a lot of my information and where I communicate more so today than ever before is through my patient portal. And even before my appointments, when I go, I get these pre appointment information needed and there's often surveys and so forth in there because their - the doctors get in advance and they can look at it even before they see me.

If you're seeking to get this type of information, why not put something out as a follow up after the appointment or during your hospital stay maybe daily, like a survey, how are we doing or have you missed something, that kind of thing like through the patient portal. I know in a lot of cases too at least in some of the hospitals we have here, they even provide like iPads to those patients while they're in the hospital that they can access such information, more of an open format.

So that might be a good resource for you to use or tap or ask if available to use in that type of setting that would be beneficial in getting the information out there and see if there are any conflicts or wrong information so to speak in there.

Man: It's a great idea. (Kelly Gleason) here is doing just that.

Man: (Unintelligible) we're all at some level chomping it a bit to get onto the solution. So let me just sort of pause a second and see other suggestions for case exemplars, in particular an example perhaps of what Helen suggested of an (ER) case where the patient has been dismissed?

Woman: I have a pediatric example. And I've seen it about four times now with children - the discouragement of head CT scans in children, children who present with serious neurological symptoms have repeatedly and consistently turned away until something really terrible happened. So I've had a couple of cases of brain abscesses and they're treated as migraines and just treat it and the parents take them back and that's not seen as a signal and then, I think, two deaths that I know of from that.

And I've had other cases because …

David: Yes. In sitting in quality meetings in the hospital, I've often heard people talk about the frequent fliers in a dismissive sort of way, the people that show up in Emergency Department with great regularity about something rather where they're sort of dismissed as being there for reasons that has nothing to do with the real illness.

And in some cases, they ultimately have a real illness that has been dismissed. I don't have a good specific example of that, but I think it's a real issue.

Woman: Well, and particularly (unintelligible) patients with documented mental health issues...

Man: Right.

Woman: So they (go) up with sometimes almost anything advanced cancer and it can be sort of written off as part of their original diagnosis.

Man: Yes. Great.

Woman: (Unintelligible)...

Man: Yes. I want to echo that I've seen a number of serious misdiagnoses of, especially neurological illnesses in patients with underlying - they've got well-controlled major depression or whatever. It has nothing to do with the story. But once there's a mental health diagnosis, then that's a huge red herring that a lot of stuff gets dumped into that bucket as, oh, it must be whatever the underlying mental illness is. I think that's a major risk factor in situations like this.

Man: Okay.

Man: Can I (unintelligible) one issue of balancing measures, because since we are going to use the (QI) type of an approach, we need to look at it on the

(ADEM) side, right? And I'll just tell you from my personal experience, because we right now are developing a headache algorithm in children. But we are involving the community pediatricians, the ER physicians, the neurologists, the imaging folks, and also the payers, right?

And there are various nuances to this incentive of patients with recurring headaches who come - a few of them who end up having catastrophe diagnosis. So I think it means - I think we should have some there, the whole issue about what the balancing measures should be and how do we use this rather than looking at the case as an anecdote, but look at the case, how it fits into the system.

So for instance, if the patient were to come to the primary care visit again and again, then could that be a flag or to the ER again and again, could that be a flag so that the system now extend for appropriate and timely reference, rather than using the anecdote for imaging or anything that probably has a downside too.

Helen Haskell: I think that's really important (unintelligible) I'm sorry.

David: Go ahead, Helen.

Helen Haskell: No. I just - I see that a lot. For example, you have the measure not to perform CT head scans in children. But there's no balancing measure saying how many terrible incidents they may have been in children around conditions relating to the head CTs. I've seen the same thing in other areas. So I think the balancing measures is something we need to really be careful about.

Because I've seen in all of these cases, for example, the ones that David is presenting as well, the protocols become the obstacle. People can't get past the protocol. They can't see the (zebra). They're not willing to look for the (zebra).

David: Okay.

Man: Right, (unintelligible)...

David: They're great comments but I think we need to - in the interest of time, we need to - we sort of fudged over a bit into some of the others.

Man: We did.

David: But let's just take a quick look at the causal factors before we begin to move on to look at some of the solutions. So in the causal factors, we've listed the relatively rare conditions, which obviously is the (zebra) problem, if you will. Nonspecific nature symptoms, the involvement of multiple clinicians along - across settings and the lack of somebody who synthesize the information from multiple sources.

I guess I would add to that, the whole issue of the relative - I don't want to be too heavy-handed here, but the relative tendency to undervalue the knowledge and contribution of the patients to the diagnostic process.

David: And this is David, I think you also have...

David: Go ahead.

David: This is David. I think you also have to add implicit bias to this list in its multiple forms, whether that's based on gender, based on race, based on something like mental illness, I think that's an important piece of the puzzle here that puts people at much greater risk.

David: Yes. Right. Other suggestions for...

Woman: Good suggestion, yes.

David: ... yes, go ahead.

Woman: No, I was just saying that's a good one. I'm glad you got that one on there, David.

Woman: I would add what I was just saying over here (unintelligible) protocol failure to sort of individual patient cares in point of seeing exceptions.

David: And are there other...

(Colleen): This is (Colleen). I was wondering if it would be worth calling out more explicitly something about failure to explain, I guess, what has been done if a patient is seeing multiple clinicians and having multiple tests and having - even if they're having things ruled out, I feel like frequently there is a failure to explain what has been tested for, what has been ruled out or not ruled out so that a patient can end up starting over again because he or she is not aware or previous tests rule this out.

If they don't understand the test results and no one takes the time to explain those to them, they could have the same test over and over by multiple clinicians in multiple settings. The kind of an aspect of the multiple clinicians, but I wonder if the failure to explain should be called out more explicitly.

David: Yes. I think that's a good thing to say explicitly. It's sort of a sub part of my larger concern for not - appropriately and fully engaging the patient as a part of the diagnostic process. Others?

Okay. Let's move on to the solutions. So we got some solution suggestions here. (AI) early referral for genetic counseling, which presumably would pick up some of the rare diseases of that sort, early referral for specialist caring and for the diagnostic testing protocols that include consultation as in, for example, three visits for the same symptoms and no expectation, no explanation, move on to a referral for consultation with a team or specialist.

Clinical - clinician education on effective bias. This is related to (David's) suggestion about the various populations that are - may be treated differently, a homeless person or racial or sexual orientation groups that may not be adequately responded to.

Clinician education on patient centric diagnostic decision making and patient engagement and diagnosis. So, several of those are things that we refer to in some of the earlier discussion but reactions or additional suggestions?

Helen Haskell: I think these are good, David. (Unintelligible) I would like a little more (unintelligible)...

David: You seem to be breaking up a little, Helen, I'm not (unintelligible)...

Helen Haskell: ... oh, I said it would be nice to have a little emphasis on personalizing medicine and access to the medical records as a subset of some of these. But I think this is a really good list.

David: Yes. The earlier comment about explaining of test results and what's been excluded and included to the patient is a bit of an elaboration on the patient engagement issue at the bottom there.

Helen Haskell: Yes. That’s it.

David: Did we hit everything?

Helen Haskell: Well, I keep thinking that, so you got protocols for inducing consultations. I think one of the things that people don't always seem to understand about protocols is that they're not meant to be to be universal and there are exceptions. And so many caregivers, providers don't seem to realize that.

So I get things like these brain injuries being ignored or needed C sections, people not doctors not being called in for consultation. There's a lot of just blindly following something that's meant to be only for the majority and that - it would be really nice to have something in there that would counter that, not just about seeing measured, but also some kind of education.

David: Yes. Also, when the patients are all individuals and protocols are great, but as we all know there are always things that don't work in a given protocol or outside the frame of it. And in the end of the day, the individual has to be considered as an individual and not just a stereotypic presentation.

So how we identify that issue of treating every patient as an individual and not getting sort of sucked in by a preamp really closer that protocol may lead you toward is a good issue.

Helen Haskell: Yes. I think the issue is whether the protocols that people take as sort of closing down inquiries as opposed to protocols like the ones (David Nemacova) was proposing in the ICU that would open up inquiry checklist...

David: Right.

Helen Haskell: ... should have (unintelligible)...

David: Yes. Good. Others?

(Unintelligible) for some of these, the implementation is certainly a major issue though. It's not as though patient engagement has been talked about in all aspects of health care for many years, but I think if you talk to a range of sample patients, you'd find that there's still a lot of concern about the inadequacy of engagement, particularly with the non-assertive patients.

So that whole issue of how the solution becomes operationalized is certainly a continuing issue. So other comments before we go into...

Man: Yes, I wonder...

David: ... go ahead.

Man: I asked about your comment a second, is there efforts - concerted efforts to try to find a way to measure shared decision making in a context of diagnosis or even in general? I mean, I think that's hard to do. Smart clinicians should be thinking about how to do that, it seems to me.

David: I would agree, it's hard to do. But can we hang on to that issue, how to measure it and see if we got any final comments about the solution list and then we can go on to the measurement.

Hardeep Singh: David, I could add - this Hardeep. So maybe one of the things we could consider is institutions doing more to learn from what sort of patients are saying in terms of either complaints or experience surveys and using that as a data pool and harvest that data to figure out what they can do better in terms of either a shared decision making and (sizing) for instance has a program where they actually have a refund program where if you're sort of not satisfied with your care for some reason, some of it could be related to diagnostic care.

They actually refund a whole or part of your - the money that you spent. So I think institutions could do better in harvesting their own data for looking patterns.

David: Your comments, Hardeep, remind me of something that I was thinking of in earlier discussion about the root cause analysis with a patient trigger for such a thing. But it seems to me that there's a - there's something between go home and have a nice life and root cause analysis that we're at sort of a postdoc review of cases that don't reach the level of the root cause analysis that could be triggered by patient concerns and maybe (unintelligible) process does that kind of thing.

But it would seem to me that's the kind of solution where there's a trigger that doesn't necessarily result in a whole root cause analysis, but at least the kind of a postdoc review of the process and the conclusions.

Hardeep Singh: Yes, that's exactly right. I mean, it's mostly not the level that it would make everything into a root cause analysis, because then we'll be so overwhelmed with doing these, because patients - several patients have several concerns. But there's ways to sort of look for the pattern exactly the way you described and make it useful for the institution.

Mark Graber: This is (Mark). There is - just to extend that, there would be great value in having some way to harvest the lessons learn from those root cause analysis. Right now, I mean, even if you do it there may be some local learning, but there's no way to generalize it.

So the kind of project where like (Gordie Schiff) is trying to collect cases and collect learnings from those and put the lessons into textbooks of medicine or some way to generalize the knowledge I think would be very valuable.

David: Right.

(Kathy): I think there's also an opportunity - this is (Kathy), there's also an opportunity from a solution perspective to think about ways to create more interaction between the clinical team and the patient and family members in a preventive fashion, so if - using the patient family advisory councils around this issue, bringing folks together to have health systems say what they can - figure out what they can do proactively to have the interaction about what might be going very poorly and what might be going really well and understanding that together, coming together and understanding that together.

David: Yes. It might be - I haven't mentioned this patient family advisory councils much in these discussions, but it might be an interesting use of some of those groups often relatively underused or might editorially (unintelligible)...

(Kathy): Yes. And when they're used well it's helpful.

David: Right. And that some of the kinds of aggregating of the concern and organizing both for patient and physician review might be a useful thing for some of those groups to be engaged in. Okay, let's - in the interest of time again move on to the measurement issues.

So the issue of quality measurement, again, this is with regard to the dismissal of patients or the delays that are produced by the various kinds of things we've talked about. We have just three major concepts listed here. Time diagnosis of rare conditions, patient surveys of their diagnostic odyssey and then total cost of the diagnostic odyssey.

Those are broad umbrella to be sure. Certainly, the second one is a big umbrella. But, again, additional possibilities or reactions to some of those.

Helen Haskell: This is Helen. I have a couple of comments. One is I would add another broad umbrella which is balancing the sort of a - the landscape for balancing measures and gaps in balancing measures. And I'm wondering currently diagnosis career conditions, that would probably be something that encompass - or could be encompass many years and many providers, how would you capture that? Same thing for total cost, how would you capture it?

David: Helen, I'll allow for other people's comments. My personal sense of that is mostly true specializations.

Helen Haskell: Yes.

David: Yes.

Helen Haskell: Okay. No, that's great.

David: But other thoughts on how those might be captured?

David: Yes. This is David. Actually, a lot of insurance companies have all of the data to be able to ask those questions. So to the extent that people don't frequently crossover insurance provider claims pools, an individual insurer may have 10 years worth of data and it's much easier to look back from a rare disease, somebody has (ripples) disease or some other thing that takes a long time to diagnose in an average of 10 years or more.

It's more likely that you'll be able to get that out of some insurance claims data to sort of look back and go how many of these visits were linked, because they were abdominal or GI symptoms. They went back for 10 years so it's often recurrent visits for similar type stuff.

So there are ways that you could imagine doing it. And I'm not saying it would be easy, but in some sense because rare - relatively rare conditions are, by definition rare. It's a little bit easier to sort of pick through that and try to figure it out. I think the bigger challenge has to do what (Prashant) was sort of talking about before and again, I know it's sort of a sensitive topic, this issue of balancing measures.

But I do think that at some level, diagnosis happens prospectively. So there's sort of retrospective scope look that says - well, it took 10 years to diagnose (ripples) disease. That shouldn't have happened. We also have to have some mechanism for kind of ascertaining what is happening in real world practice.

I do think some data mining approaches that (Gotham Raul) and others have suggested around diagnostic has may be opportunities for learning there.

Mark Graber: This is (Mark). There's also process measures that could be considered. For example, does there exist the - a team that comes into play when patient remains undiagnosed after X number of visits, the second opinion come into play.

David: Right. That's basically operationalizing some of the earlier solutions, comments to actually turn those into measurements. Other thoughts.

Hardeep Singh: Yes. (Mark's) comment made me think - this is Hardeep again, I'm wondering, this is where we could even specifically pick out, so there's a lot of data that people who do some of these second opinion collect. Some of that could be available to people who want to use them.

So crowdsourcing for instance as crowd meant where we've been able to get data. They used to be best doctors, I think they call it something else. Now, they are able to share data on some of these people who undergo this diagnostic journeys. And I think there are ways - I think David said that earlier to where something about either the cost or the time or how much investigations they went through could be calculated in some way.

David: (Unintelligible) I'm going to thrown a - perhaps the (settling) issue. I mean, when we think of measurement, we typically think of some variant of more relatively objective data measurement.

And in the case of probably things that certainly Helen deals with and I've dealt with - in my case myself, but a lot of other patients, the individual stories of the odyssey are somehow very compelling, but there are stories there, there are anecdotes and there's a certain amount of aggregation of anecdotes that that could happen in ways that would be, I think, helpful for a lot of this, although it's a complex process to do that because of their narrative anecdotes.

But I think though we ought to keep in mind the possibility of more subjective measures in their possible aggregation as ways of getting some insight into the process.

(Prashant): This is (Prashant). One other way to look at measures, I'm not suggesting one, but one other way would be to see what measures we would like to have ideally and what measures we can actually have and give it out to public to get, right?

So just as an example, the cost is a very appealing measure, but it's going to be extremely hard because of how you define cost, right? So that could see like a (unique) measure where we could say that certain systems changes have to be implemented or identified to measure that. But other could be patient with recurrent visits for - over a period of time and that could be a measure for these complex illnesses for (unintelligible).

So my point being that a measure that we can give to the public that they can potentially get for (unintelligible) and a measure that we or a set of measures that we think are needed, but currently not achievable.

Man: Thanks. Could I just add to that? I think (Prashant's) concept here sort of recurrent visits around complex illnesses, I actually think that you could roll that back, not just as a measure, roll that back into the solution space.

So for instance, there may be some particular diagnoses that are kind of notoriously bad. We happen to see this with vestibular migraine a lot where people just bounce around from place to place to place and this is not actually as rare an illness as everybody thinks it is. It's just hard to - people don't know to think about it and don't have a grasp on it, because then everybody sort of thought about it.

I think being able to feed that loop back in and say, okay, look, our problems are celiac disease and vestibular migraine and whatever the other sort of really common - commonly missed rare disorders, if you will, are maybe a way to kind of help improve the process of care for patients with complaints that are potentially linkable to those illnesses.

Woman: (Unintelligible)...

David: So - go ahead.

Helen Haskell: ... measure specifically related to those illnesses sort of (unintelligible)...

Man: I'm sorry, I didn't follow the question, Helen.

Helen Haskell: Well, I'm sorry, it's (unintelligible) but I'm looking at global measures and I'm wondering if there's a benefit to have a measures that are specifically linked to an ultimate diagnosis, if there is an ultimate diagnosis that looks back over the course of that - those patient's diagnostic (unintelligible)...

Man: Yes. I think look back to measures from these uncommon diseases are going to be critical, because look forward measures for really rare diseases are going to be tough to - it's going to be tough to get enough signal Really kind of know what's going on. You're going to have to do a little bit more of this retrospective look and picking through to find patterns in the process that may help ultimately shorten the time of the journey to get to some of these particular diagnoses that are known to be problematic.

The average time to a cluster headache diagnosis is three years or something. I mean, things that we know are sort of known problems.

Helen Haskell: So is there a way - and I'm sorry (unintelligible) let me ask one more question and I'll be quiet. But is there a way, for example, so many of these disruptive diagnostic - diagnose illnesses have large support groups on the internet and I'm wondering if there's a way to somehow lose that information with measurement? And I know it's sometimes it can be sort of (unintelligible) but it seems to me that it's a huge pool of resources there. I'm just wondering if there's a way to connect with it.

Hardeep Singh: So Helen, this is Hardeep. I'm just sort of thinking along - I think this is also an area where maybe not just support groups, but some of the platforms that I was trying to allude to earlier could help - we ask - we got a lot of the data about crowd (unintelligible) from asking sort of patient to use that. And we had sort of questions on, did your medical expenses get better? Did your productivity in school or work get better? And so on and so forth. I think I believe may have said, the - did you see more or less doctor visits before or after.

So I think there are sort of ways to get some of this data and I think the communities you're referring to could actually be a useful source of data if we were to collect that similar to the platform concept that I was describing earlier.

David: There are a lot of the patient disease specific organizations (unintelligible)...

Man: Yes.

David: ... but also things like smart patients and patients like me that have a lot of data they've collected as well. It could be useful. We're kind of getting close to time, Meredith, (unintelligible) time, so I turn it back to you at this point.

Meredith Gerland: Sure, David. That sounds great. And thank you so much for all of the committee members for that robust discussion about both use case three and use case four on the NQF and we'll work together with the co-chairs and (in advance) of our next meeting to help synthesize the conversation we just had and make sure we capture all of the feedback and inputs you all shared.

And then we'll do a deeper dive and some opportunities to refine these two use cases a little bit further during our next use case. So right now before we proceed, I wanted to allow the opportunity for public comment. Is there anyone on the line who's not part of the committee who'd like to provide feedback or input?

Okay, hearing none, we'll move on to the next steps and I'll turn it over to my colleague, Carolee.

Carolee Lantigua: Thank you, Meredith. So this slide provides the final (unintelligible) and indexes for the upcoming web meetings. You should have hopefully receive all of the outlook education for these. If you have not, please email us letting us know and we'll make sure to send those to you. (Unintelligible) meeting will be taking place on May 19th and as Meredith said, we'd be continuing to refine use cases three and four.

As always, if you have any additional feedback, questions or concerns, please don't hesitate to reach out via email at (diagnostic@qualityforum.org) or by phone. AND for any information or for the details, you can check out the project page online as well as the community support page.

And with that, I'll pause and see if there's any parting questions.

Meredith Gerland: Okay, thank you. Well, if any questions come up or if any committee members have additional ideas or input for the two use cases, please don't hesitate to reach out to the NQF team. We welcome your feedback over email. If you think of something after the web meeting, that would be important to include as we begin developing these two use cases.

So with that, I think we'll adjourn. Thank you very much for your time and I hope everyone great afternoon. Thank you.

Man: Thank you.

Man: Thank you, everybody.

Man: Thanks, everyone.

Man: Thank you. Bye-bye.

Woman: Thank you.

Woman: Bye.

Man: Bye-bye.

END