Person-Centered Planning and Practice Committee Web Meeting 6

Moderator: Kim Patterson
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1: 00 pm ET

Kate Buchanan: Hello everyone. Happy Monday.

Group: Hello.

Kate Buchanan: And we'll - this is (unintelligible), we'll begin in just a couple minutes. Thank you. It's Monday. And, some people may not realize that they're not on mute. So, some people are having private conversations that we can hear. So, we would appreciate people who are - if you're not currently talking, please be on mute. Happy New Year.

Hello, this is the National Quality Forum. We will be beginning in just a couple minutes. Thank you for much for your patience and thank you for joining us. Okay. Before we begin, just a friendly reminder to - this is NQF Staff - to please mute your phones if you are not currently talking. On our end we've had to mute a couple lines. So, to unmute yourself, you hit Star 7. If you have any difficulty with that, please chat us in the chatbot. But I just wanted to let you know that you may have been muted just because we were getting a lot of background noise, especially for our participants who participate using headsets. Unfortunately, sometimes we would often get a lot of background noise so we co have to mute.

But to unmute yourself, hit Star 7. And if you have any trouble, please just chat in the chatbot in the lower left-hand side and staff will manually unmute you. But, with that, I am actually going to turn it over to Sam.

Sam Stolpe Hell, and welcome everyone. This is Sam Stolpe with NQF. I'm delighted to have us all convening for this, our Sixth Web Meeting for the Person Centered Planning and Practice Committee. I'm very happy to be here to everybody and very much appreciate your participation on our Webinar today. Also, I wanted to extend a welcome to Gretchen and Cheryl, our two Co-Chairs. I just want to double check that you're both on the line. Cheryl and Gretchen, are you there?

(Cheryl): Cheryl is here.

(Gretchen): Yes, and this is Gretchen, hi.

(Sam): Very good. Thank you both for joining us. And, as always, thank you for your leadership and guidance on this committee. So, just a couple of things I wanted to say is that we have a fairly focused meeting ahead of us, so we really just have one large objective that we're trying to get at related to (measures) and framework. So, we're going to take our time and talk very stepwise in our fashion in talking about Healthcare Quality Measurements so that we can get to our larger objective. So, with that, I'll just hand it directly over to our Co-Chairs to welcome the group. Cheryl and Gretchen.

(Cheryl): Great, thank you. This is Cheryl and, you know, looking back, this has reflected a huge amount of work of all of you on the call. Thank you for not only your participation on the calls, but the engagement in between. Gretchen and I do review all the comments. We talk about them with Staff.

One comment that I have heard now a couple of times, and it's probably something worthwhile to just lay out for this group - is we want to make sure that we are hearing from all voices that Person Centered Care Planning is - should be inclusive of all individuals. Those with physical disabilities and intellectual disabilities, serious mental illness. Also, older adults with functional and cognitive disabilities.

So, as we think about our comments, each of us may represent a very specific constituent group. But I want to make sure that we are - and Gretchen and I may periodically call out to make sure that we're getting the voices from all. And I'm going to turn over to Gretchen so I don't do all the talking.

(Gretchen): Thank you Cheryl. Well, you did a good job of outlining our priorities and thank you for that. I, again, want to thank everyone just for remaining committed to a process and an outcome that keeps us all focused on the persons being served. I think that's what brought us all here and we all want to continue to develop something that keeps that at the forefront. So, thank you all for the time that you all have devoted to making that happen.

Kate Buchanan Great, thank you so much. Before we dive into work, I want to go through some of our housekeeping. So, as many of you know, Google Chrome is the preferred browser for (unintelligible) (link). We do ask if not speaking to please mute your line by Star 6. Unmuting your lines is Star 7. And, as I said earlier, if you have any problems please just chat in the chatbot and we'll be sure to assist you.

Here we have the Project Team. Sam Stolpe, myself, Kate Buchanan, colleague, (Yvonne Kollavanda), and actually, our colleague Jordan has been

able to - has moved onto another opportunity. So, he will not be joining us moving forward. But we wish him all of the best in his new role.

I want to do a quick roll call. So, now that we have Gretchen and Cheryl, do we have (Brenda)?

(Brenda): I'm here.

Kate Buchanan: Thank you. Pearl?

Pearl: I'm here. I'm here, this is Pearl.

Kate Buchanan: Great. Do we have Sally Burton-Hoyle?

Sally Burton-Hoyle: Yes, I'm here.

Kate Buchanan: Excellent. (Amber) (Unintelligible).

(Amber): I'm here.

Kate Buchanan: Great. And I believe (Bruce) said he was unable to attend. And I saw that (Devon Cross)'s here. Thank you for joining us (Devon).

(Devon): Yes, hi everyone.

Kate Buchanan: Do we have (Amber Decker) on the line? (Gail Sanders)?

(Gail) Yes, I'm here.

Kate Buchanan: Great. And, we're getting some feedback. So, one second. I think that we were able to address it. Okay. Thank you very much. So, we have - is (Susan) (Seegan) here?

(Susan): Yes, I'm here.

Kate Buchanan: Thank you Susan. (Sarah Link)?

(Sarah): I'm here. I'm here. Yes, I'm here thank you.

Kate Buchanan: Thank you Sarah. (Joseph) (Nefett)?

(Joseph): I'm here.

Kate Buchanan: Wonderful. Denise (Meyer)? And I saw Denise, she was (as I know) on - I see that she is…

Melissa Nelson: Melissa Nelson is here.

Kate Buchanan: Okay, thank you Melissa. And Denise, I see that you are on. I'm unable to hear you though. So, if you wouldn't mind just chatting us in the box. And I did hear - and I do have (Susan Seegan) on. So, thank you. And Melissa Nelson. Do we have Pat (Nobe)?

(Pat Nobe): Yes, I'm here.

Kate Buchanan: Wonderful. And I believe Kate (Nordi) is unable to attend. Do we have Ann (O'Hare)? (Leo Linda Parlin)? Richard Petty?

(Richard Petty): I'm here.

Kate Buchanan: Great, thank you Richard. (Mia Pfeiffer)?

(Mia Pfeiffer): Yes, I'm here.

Kate Buchanan: Thank you Mia. (Michael Small)?

(Michael Small): I'm here.

Kate Buchanan: Thank you for joining us Michael. Do, we have (Dory Tempia)?

(Dory Tempia): Here.

Kate Buchanan: Great. Thanks Dory. (Janice Tandora)? Maggie Winston?

Maggie Winston: Hi, I'm here.

Kate Buchanan: Thank you, Maggie. Do we have Daniel (Fritter)? Matt McCullough? Pam Montana? (Penny Shaw)?

(Penny Shaw): Yes, I'm on the line.

Kate Buchanan: Thank you so much Penny. So, quickly go over our meeting objectives for today. (Unintelligible) is a very targeted meeting. We are going to introduce the concepts for Quality Measure, Measure Applications, and Measurement Framework. We are then going to have committee members and liaisons work with staff to help draft the measurement framework.

So, with that, I actually going to turn it back over to Sam and give you a Quality Measure Overview.

Sam Stolpe: Very good. Thank you, Kate. Okay everybody. So, for those of you who are very well (unintelligible) in Health Care Quality Measurements, this overview that I'm going to do will very much be kind of review (vein) for you. I don't think that you'll learn a tremendous amount, but it may help you to start thinking about how we could appropriately approach the framework in a way that would be meaningful and actionable. If we could go to the next Slide please.

The first place that I wanted to start is at the very beginning. What are we talking about when we say Health Care Quality Measurement? And what is a measure? Well, within healthcare, including long-term (unintelligible) reports - Performance Measures are tools that we use to quantify the quality, or the cost of care that's provided to persons and their families within that setting. I mean I think about Healthcare Quality Measures, is they allow us to gage that care quality. And help us to understand whether improvement activities are being effective when they're deployed as part of that environment and if we're getting to better care - better outcomes through efforts in quality improvement.

So, that'll lead us to the next question is why do we bother to measure to begin with? Of course, the idea around Healthcare Quality Measurement and Performance Measurement in general, is to improve the quality of healthcare, including healthcare (unintelligible) settings and (unintelligible). And ultimately to improve the health and well-being for those who are served inside of those settings.

So, perhaps the largest challenge associated with healthcare quality measurement, is giving that good data. Finding good quality data to inform measures, is really representative of a (unintelligible) a good challenge in

healthcare. We have listed on this Slide several sources that are commonly used inside of healthcare quality measurement. For example, paper and electronic medical records. Other electronic data such as pharmacy or laboratory data, electronic assessment data, for example MDS or (Oasis) data which are used inside of long-term care settings. There's also administrative claims. Clinical data registries, or individual reports that a person may give to an instrument such as a survey.

These (don't) represent data sources and some of them are part of everyday routine care, such as billing data, or administrative claims. Other's can be a little bit more cumbersome to get, such as the individual report. So, if we're administering a survey to somebody, that means that's going to take time on the part of the person, as well as on the part of the person who's administering the survey. So, there's real burden associated with quality measurement and we need to take into account when we're thinking about which measures are appropriate.

And this leads to the next question which is who do we apply healthcare quality measures to? Typically, what we think about is providers of healthcare. And in the context of healthcare quality measurement, provider takes on somewhat of a broad sense. So, that could include home and community-based services providers. It could be individual clinicians or a group of clinicians. It could also be a hospital. It could be a skilled nursing facility or another nursing facility. It could include home health agencies and hospices.

Or it can be something as large as an entire health plan that covers a fairly broad population. And speaking of populations, that's another category that we can use for measurements. We can break down by a geopolitical area for example. A county or a state level analysis to try to improve quality within a

region. Or we can break down populations through the subpopulations and individuals that we categorize either by disability or age, race, ethnicity, et cetera.

Now this is where we get to the application portion of this. So, what do we do once we actually start measuring and how does that lead to improvement? Well, what we have depicted on this Slide are three levels of accountability - or excuse me - three levels of applications of healthcare quality measures. The first, which is sort of the, has the lowest level of unintended consequences, is internal quality improvement. So, a facility for example, could use healthcare quality measures to try to get them to be better year over year on a given healthcare quality (metric).

Could also be used for benchmarking just compared to between other entities to see how you tend to do, or how you're trending in comparison with other entities. Now perhaps the most important application in the way that we're thinking about healthcare quality measurement, largely as a health system, is around how measures are used for accountability.

And here we have the bullets, again, listed in increasing order of consequence. So, the first being certification of accreditation. Then defining provider networks or public reporting. And then lastly for payment. And I wanted to just particularly emphasize how critical it is that healthcare quality measures be robust and scientific. Especially when they're being applied towards payment (levers), because of the very intense consequences associated with having healthcare measures used for this particular accountability application.

I wanted to give an example of a measure that I think would be fairly intuitive to everybody on the committee. And this one is - there's certified by NQF Endorsed Measure and it has an NQF number to indicate where it (comes

down). So, NQF 2967 is the (CAP) Home and Community Based Services Measure, which undoubtedly, everybody, or nearly everybody on the call, has probably heard of. Or, many of you may have experienced it directly.

So, this measure, has a numerator and a denominator, exclusions. It has a population and it has a variety of (things) that are specified that allow us to do comparisons on the HCBS (CAP) Survey, between providers of Home and Community Based Services.

So, the description of the measure is that it's a Cross Disability Survey to elicit feedback from Adult Medicaid Beneficiaries, receiving Home and Community Based Services (above) the quality of the long-term services and supports they receive in the community and delivered to them under the auspices of a State Medicaid HCBS Program.

So, the numerator is the percentage of respondents that give the most positive response to survey questions. Target population is populations at risk, adult Medicaid beneficiaries receiving HCBS. And the exclusions are individuals who are less than 18 years of age and individuals who have not received HCBS services for at least three months. So, you can see why those exclusions might be important.

Now, when we're going to talk about measures today, when we're - as we're thinking about a framework around Person Centered Planning, I want you to keep in mind that there's a whole range of measurement development. It's an iterative process where we take a measure from an idea or a concept and then build out specifications throughout measures and then eventually get the measure testing.

Now, I'll reemphasize this point (unintelligible) later, but as we're thinking about the framework, what we're hoping the committee will stay focused on is what needs to be measured and, not necessarily feel like you need to solve every problem associated with measuring that thing. It's more just identifying which areas are important to measure inside of, Person Centered Planning, and who the accountable entities should be related to that idea that we want to measure. And, to the extent that we're able to get into some specifics that's great, but again, we don't need to solve every problem associated with measurement when we're building a measured framework.

Okay, so that's a brief overview of what healthcare quality measures are and how they're applied. I want to just speak briefly about what we have done as staff to start identifying measures that could potentially fit inside of the Person Centered Planning Measure framework. So, if you will recall, several months ago, back in the Summer, the NQF Staff conducted an Environmental Scan - can we go to the next Slide please?

So, this was a scan of existing Person Centered Quality or Efficiency Measures that were intended to inform several objectives and projects. First, of course, the framework that we're going to discuss today. A Research Agenda for Person Centered Planning, identification of Gaps and Quality. And also, identification of Priorities to Advance or Address Measurement Gap.

What we found from that is that there were not a lot of healthcare quality measures out there. I'll show you some of the results here in a moment. We didn't identify a lot of measure concepts or performance measures, specific to Person Centered Planning.

But just to get a distinction in front of you about measure concepts and performance measures - a measure concept is an idea for a performance measure. It's just a description of an existing or potential tool or instrument that includes a description of the measure, including a planned target and population.

A fully developed performance measure, on the other hand, consists of a metric that has very detailed specifications and may have undergone some scientific testing. You take data from several healthcare entities who've been measured and then you compare that data and look for a reliability and validity in the testing result.

So, this Environmental Scan that we as a staff conducted, we used 15 search terms and we searched through three measured databases, as well as (Pugmat) and (Google Scholar) to try to identify both fully developed healthcare quality measures, as well as measured concepts related to Person Centered Planning. So, we looked at NQF Quality Positioning System which houses NQF Endorse Measure (stats).

We also looked at CMS's measured inventory tool. And we also looked at a set of - excuse me a set of registries called Qualified Clinical Data Registries that are used for reporting healthcare metrics to CMS. The results of the scan were that we identified well north of 600 total measures of 366, which we deemed the (unintelligible) and this Slide depicts the category of the measures that we found and kind of gives an outline of which databases we found in there.

So, the measured scan results were that we didn't find any direct measures of Person Centered Planning. Of the 366 total measures that we identified, we found 206 of them to be what we would consider relevant. And by relevant -

can we go to the next Slide please - we mean that they fell inside of certain categories. That they were either related to patient or a person and experience - lots of them use the term patients inside of healthcare quality. So, forgive us if we're not being sensitive to using person appropriately in this instance. But also, frequency, complexity of care, care transitions, communications, and shared decision making, were all measured categories that we thought would be pertinent to how we're approaching Person Centered Planning. And measure ideas that we could potentially migrate over to those ideas around the Person Centered Planning Quality Measure Framework.

We did find a number of gaps in healthcare quality measures. Especially around beneficiary experience, communications, shared decision making, and consumer directed care for all those (IDD), geriatrics, chronic care, and mental and behavioral health. So, there're quite a few gaps in healthcare quality measurements, especially as it pertains to Person Centered Planning.

Okay, so one thing I did want to talk about - and we don't have a well-developed Slide for this - is where NQF fits inside of this process for Healthcare Quality Measures and Quality Measure Development. And so, NQF, as many of you are aware - we endorse healthcare quality measures. So, we really come in at the end of a measure development lifecycle.

So, when a measure has been fully developed and specified and has had some measured testing, then it's brought to a body of peers that are convened in a - as a multi-stakeholder group to evaluate the strength of those healthcare quality measures. Their importance to measure. Their scientific acceptability, namely their reliability and validity. The usability of those measures and their use. As well as the feasibility for implementing those measures.

NQF also, inside of our maintenance of our measured portfolios, is trying to reduce the total number of duplicative measures that exist in the marketplace. And, so we also have a related and computed criteria that we use to evaluate what's called Best in Class Performance Measures, where, if there are two measures that we consider to be competing with each other, the committees on the NQF will determine which of those, between the two of them, is the best one to use.

So, we're very much involved in the science of healthcare quality measurement and we're also (interested) in making sure that the right measures get to the marketplace and (unintelligible).

So, I'm talking a lot about healthcare quality measurements here and I (would like) to answer any questions that we might have. So, I've seen a couple arise in the chat. If you want to go ahead and vocalize those for the group, I'm happy to answer any questions.

Amber Decker: This is Amber Decker. I wanted to just touch base on Slide 7 where the - we don't really define what we mean by improvement activities. So, that was one question that I had. You know, if you already answered it.

Sam Stolpe: So, the question is, what are improvement activities?

Amber Decker: Yes. So, Slide 7, originally had the term Improvement Activities. I'm pretty sure it was on Slide 7 originally and maybe it's changed. I would have to go in and see. But maybe that is on a different Slide. So, actually it's Slide - it wasn't numbered - but what is a measure is the question?

So, on the Slides that we received, it is right after Quality Measure Overview, which would be…

((Crosstalk))

Sam Stolpe: Yes, so it would be like Slide 9.

Amber Decker: Yes, sorry. So, Slide 9. I just wanted to…

((Crosstalk))

Sam Stolpe: So, the Improvement Activities are generally structures, processes, intervention, or services that could be deployed by a healthcare entity to try to improve on the measure of (picture). So, let's say for example, we had a measure - and this is - you'll forgive me, this is my friend and mentor's favorite example - diabetic foot exams. If a patient with diabetes is generally expected to receive regular foot exams, and if we had to measure to just determine whether or not over the period of one year, that person received that exam is a fairly simple measures to take a look at.

Now if we're thinking about how to actually improve that, that would be what we would consider an improvement activity. And there's a lot of things that a provider could do to improve on that measure. And that could be something as simple as having a standing order put in place that that exam occurs. Or that they put reminders inside of the chart. Or they hire an extra nurse whose specific tasks is to do that one thing.

So, there're lots of way that you could do it. But we just want to - what we had checked, of course, is to see those improvement activities going into place and it's nice if we can compare them one with another to see which ones work better under some given set of circumstances.

Amber Decker: Okay. Thank you. That helps a lot. This is Amber Decker again. The next question I posed was, some other reasons from Slide 10 that we measure other than what was listed as the primary goal? And the reason I think that it's important to bring up is because I think that we should also consider maintenance versus just improving health and well-being. Because while improving health and well-being is great, I think that there is also a real reality to just maintaining one's health and well-being as well. And so, I just wanted to kind of add that maintenance is also important, other than just improvement.

And so, I thought that that would be another reason to consider why we measure, as well. But - just because sometimes people's health can't - their situation can't be improved because of the disability that they're dealing with. But their access to care and treatment and services can be maintained versus improved sometimes. So, I think that that's important in considering a measurement to some extent. I'm not sure if anyone else agrees or not, but…

Sam Stolpe: I think that's a terrific point actually Amber. And it's certainly one that we consider a healthcare quality measurement as well. Absolutely. Are there any other questions?

(Cindy Hilar): This is (Cindy Hilar). I agree with Amber. We do need that in because when you have somebody with a physical disability, some of those physical disabilities do tend to have a lot of degeneration to them.

Gretchen: And this is Gretchen. And I think that, you know, that we measure improvement also, of course, has to keep in mind the perspective of the person. So, what is it that they want for their lives? And is that improving and the measures would need to focus on that? So, these are ways to incorporate that into the work that we're doing today too.

(Pat Nobe): Yes, this is (Pat Nobe). I agree with that. I think, whether improvement or maintenance is the goal is in the eye of the beholder - the person we're trying to support with the plan. I had a couple other questions while I'm on if that's okay?

I'm concerned that the way the frame - I think the framework aligns with what we've just accomplished in the last meeting. But I'm concerned that it's still very process oriented and not outcome driven in terms of the quality of life of the person, for whom Person Centered Planning is, you know, geared for. And I know that in the HCBS Measure Initiative - the (MAPs) Process that was a few years ago, there are pretty substantial work around measure concepts and a sort of timeline in how well-developed some of those are for things that are, sort of, short term, ready to go. Things that are (baking), so to speak, and in intermediate phase and those that are sort of what we need to aim for.

And there's a whole section on Person Centered Planning and Coordination and another one on Choice and Control. And another concept - another domain for system, you know, improvement. And so, I'm wondering if anything that we are going to undertake here is going to jump off of what that effort accomplished?

Sam Stolpe: Okay, Pat. Thanks for your question. Yes, absolutely. What - as you mentioned, generally speaking, it's highly desirable to get to outcomes. That's what the, sort of, the goal of healthcare quality measurements is. We don't want to just be doing processes for the sake of doing processes. But especially if we can get there directly through healthcare quality measurement. That is generally considered preferred over process (measures).

And what we are hoping to accomplish when we jump into our section on developing the framework, is certainly leveraging in the understanding of everyone on the committee for what should be measured in Healthcare Quality Measurements pertaining to Person Centered Planning and flushing out the domains themselves.

The examples that we have in front of us today - which we'll get to in a moment, are not intended to be prescriptive. They're just examples that we're putting out there and we're very much going to be taking the feedback of the committee to make these domains more robust in our conversation today.

(Pat Nobe): Okay. And can I ask a quick follow up?

Sam Stolpe: Yes, you bet.

(Pat Nobe): So, are the QPS measures that are listed as a source for where you guys started - are those only endorsed measures? Because I know one of the challenges with the previous work on the ACS measures is that many of those measures - I think maybe most of them - are not endorsed by NQF. So, is that going to be a limitation going forward, I guess is the question

Sam Stolpe: Well the quality positioning system that we used in our Environmental Scan was just to identify a starting point for our discussion, for measures that exist. Which - there aren't any measure concepts inside of our Quality Positioning System. It's only measures that have gone through the NQF Endorsements Process.

(Pate Nobe): Okay.

(Amber Decker): So, this is Amber - sorry…

((Crosstalk))

Sam Stolpe: …we would have flagged them in QPS if they were just a measure concept. Go ahead - sorry, go ahead Amber.

(Amber Decker): This is (Amber Decker). I just had a quick comment and you can read what I wrote in the chatbot, but I think that electronic assessment data is very limited. And especially the ones that were mentioned, because they're both electronic assessment that are targeted uniform instruments that are geared towards assessing nursing home residents and/or adult home care patients. And it leaves, really a host of other populations out.

And I think that it's a problem that data, for measures, does not come directly from individual families or community based organizations, social service sectors, human service sectors. And I do think that there is a lot to be said of trying to see if there's any, you know, measures from those - directly from those players that I listed.

Sam Stolpe: Amber, that's a terrific point. And what we're really hoping to capture in this very admittedly generalized overview of what Healthcare Quality Measurement is and what it's intended to be for and what it's intended to accomplish - is that there's a very big difference in the burden based on those data sources. So, while it may be really desirable to get a person directly reported data, that's actually tremendously challenging to do.

But it is very, very desirable. So, that's where the…

(Amber Decker): Right - but I think - I think that the problem is that we're limiting it to healthcare providers and not including community based organizations and

social service sectors that are dealing with some of these populations as well, that also gather information through their intake process, et cetera. And so, you know, Slide number 12 it says providers of healthcare. And so, I think that there is room there for other providers besides healthcare providers when it comes to measuring, you know, outcomes of LTSS and Person Centered Planning.

When we say HCBS providers, that's very broad and so I think that that can be a little bit more specific personally.

Sam Stolpe: Yes, sure. Well this is just an overview. That is exactly the sort of thinking that we're hoping will be part of our approach as we're thinking about how to measure and inside of the Person Centered Planning Framework that we're going to be moving towards.

Amber Decker Yes, I mean, I'm just bringing it up because of things like, you know, (district) for example, you know. That includes some portion of community-based organizations providing services and access and persons under planning. And so, I think we might want to be a little bit more inclusive of community-based organizations as it stands to some extent. So, thank you.

(Richard Petty: This is (Richard Petty). I have a question for clarification. And how much - how frequently are we going to expect to use the provision of another service as a measure - as an outcome measure? And so, I think, most of us would know that in most cases we would expect that examining the feet of someone who's a diabetic would probably lead to better outcomes for that individual.

And do we consider something like that to be well enough established to use that as a measure and are there other - how often do you think we'll be doing things like that?

Sam Stolpe: Hi, Richard. Thanks for your question. This is Sam. We can use something like that which we would deem a process measure, right? Having your foot examined is not an outcome. Keeping your foot is an outcome.

(Richard Petty): Absolutely.

Sam Stolpe: But as it pertains to Person Centered Planning, we could do a - let me give you an example okay, of a process measure related to Person Centered Planning. Did the individual receiving home and community-based services for - just as an example - actually have a planned meeting once in a calendar year? I'm not saying that's a good measure or a bad measure, but that's just an example of process measure that we could use towards Person Centered Planning.

Now to get back to Amber's point on how desirable it is to get this person specific information, we could also have an outcome measure around goal attainment, for example. To what extent did the person who had the plan feel that they were making progress or maintaining progress towards the goals that they had articulated six months' previously. We would consider that to be an outcome measure and one that's more desirable, but also more burdensome to get at.

So, when we're constructing the measurement framework, which I think we're probably getting closer to jumping into, actually - if we don't have other questions. But I'll welcome other questions as well.

We're going to be trying to think of as many measures as we can. And what could be measured and, maybe to some extent, how - or what should be measured inside a person's (PET) Centered Planning and the (source)

(unintelligible)) that we would think would be accountable to those things. Be they processes, or structures, or outcomes that we would expect to occur from the Person Centered Planning.

(Richard Petty): Okay, well that's very good. Thank you, just sort of defining in a broad way what's in the box - what's out of the box. So, thank you so much.

(Sally): This is Sally. I guess I just kind of wanted to clarify some things because I'm trying to make sense of this. Each person's plan is what's important to them. I get that. So, I'm trying to think, in this scenario of the foot, where the foot and the issues with the foot is a barrier is if the person, like wants to go out dancing once a week. Okay, so please tell me that we're also thinking beyond healthcare in this? Because if we're not, that's a little frightening to me.

Sam Stolpe: Yes, and perhaps it wasn't the best example. Because it probably wouldn't be a measure for Person Centered Planning per se. That's more of a just a product…

((Crosstalk))

(Sally): I mean it could be if the person's outcome was something that required their foot to be, you know, feeling good. So, I'm not saying it's not - but I just kind of wanted to make sure that - how we're thinking about things. Because it would be a problem. If I wanted to dance and my foot had a wound on it that wasn't healing or whatever - just like - is that how we're - is that what we're talking about here?

Sam Stolpe: I think in this instance for that particular measure, we would be getting a bit too nuance or a little bit too granular for what would be actually broadly applicable, inside of a facilitation or a care provision setting, specific to

Person Centered Planning. So, we're talking about the desirable outcomes of Person Centered Planning, we probably wouldn't be able to factor in things like diabetic foot exam.

But we could be talking about things that we've discussed quite extensively thus far. Like, what are the desirable components of a plan? What are the desirable aspects of a facilitator? Or their characteristics? Or competencies? And then at a Systems Level, like, what sort of accountability should be put into play at a Systems Level? Either related to the structures that they have or related to the, sort of, processes structures or outcomes that we think they should be responsible for (unintelligible).

(Amber Decker): This is (Amber Decker). I had a quick question. NQF 2967 - this measure on Slide 14 - is that something that we can look up?

Sam Stolpe: Yes, you bet. That's to…

((Crosstalk))

(Amber Decker): The actual survey?

Sam Stolpe: Yes, yes. That's a real measure. The (CAP) Home and Community Based Services Measure. And the survey's available online, posted on the (AHRQ) Website.

(Amber Decker): Okay, thank you.

(Richard Petty): Just to go back to Sally's question. It's certainly well within the realm of possibility that someone would create an (unintelligible) of living well in the community and may have specific measures themselves that would involve

integration into the community and connection and it might be that the physician that they might have chosen having good health and they might have chosen participating in community activities and, you know, heaven sakes, if one of those is dancing they need health to do that, could be a measure of that also.

(Sally): Right.

Sam Stolpe: Yes, absolutely. I agree with that. But if we're talking about the overall goal. We would probably have to frame a measure that addresses that more broadly then getting into, sort of, what I would call, subsidiary measures that could inform a larger measure around whether or not a person was able to reach their goals. And since those would be broad and varied, it probably, at least with this specific example, would be very challenging to have a measure as specific as the diabetic foot exam measure that I offered as an example, as a measure specific to appropriate Person Centered Planning.

(Richard Petty): As a process measure, yes.

Sam Stolpe: Yes. Okay. Any other questions related to the overview of Healthcare Quality Measures before we jump into the Person Centered Planning Framework Approach?

(Penny): This is (Penny) can you hear me?

Sam Stolpe: Yes, (Penny) go ahead.

(Penny): I'm wondering, an outcome I'd like to see as part of the (social process), is whether we can establish that each individual - and I use the word patient very liberally because they could be residents or whatever of a facility - actually

knows their rights around (persons) (in charge) to speak up, to self-determination and how it can be (implemented) (unintelligible). Like I had to use my federal nursing regulation about two weeks ago and stunned someone. A new Director of Clinical Operations came to my facility. Never talked to me. Told my unit manager that I would have to show her every week that I could belt and un-belt - open and close my belt on my power chair. When I've been doing this for ten years because it was potentially a restraint.

I emailed her and gave her the federal regulation that was self-determination. She violated my rights. I never heard a word back. Now the point is, most people don't stand up to these people who come along from nowhere and think they can change your chair plan or try to do something that you don't have to do.

But this is what I expect, is how are we going to establish that people can become empowered like me. What kind of measure to we have for empowerment of people who have the rights?

Sam Stolpe: Okay, thanks Penny.

(Cheryl): I just want to say, this is Cheryl. That was awesome. Good job. And you're right. There're few people that have the knowledge that you do, but that was an impressive story.

(Penny): It was impressive. It shut her up in one minute.

(Cheryl): Yep.

Sam Stolpe: All right. Thank you, guys. Well let's go ahead and jump into our Person Centered Planning Framework Approach. So, our goal for the remainder of

our time together as a committee today is to really build out this framework together. So, let's just describe what that is.

Okay, a Measure Framework is a way of structuring measures within a conceptual model of the system. Now that's just a bunch of big fancy words. But what we're actually saying is, if we have a measurement area, like Person Centered Planning, and we want to describe all of those measures - well how can we categorize them in a way that makes sense at least to the systematic organization of those measures? So, that when we're thinking about how to apply them, they're naturally (grouped) together.

And the ideas around measures that may be similar or measuring comparable things, are grouped into the same setting or the same subdomains or domains, if you will. So, this includes measures to influence desirable structures, processes and outcomes. And the idea here, is to focus on the strategies, the goals, and the objectives that lead to good improvement or, as was pointed out, in some instances, improvement might not be the goal, it might be maintenance. But are leading to desirable things.

And some examples of this might be like a Pain Management Care Quality Healthcare Quality Measurement Framework. How would we characterize appropriate pain management? What sort of domains would we MAP that to? Or another example, to be a Physical Trauma Care Quality Measurement Framework. Like, what sorts of things should we be thinking about as far as categorizing measures that relate to physical trauma.

Now those are actual frameworks that NQF has worked on with comparable stakeholder groups in the past, with pain management experts, or with clinicians and care providers, or patients that have experienced trauma care. And how to think about measurements within those particular domains?

Next Slide. Those kind of framework domains for Person Centered Planning - we as staff, thought it made sense to come up with three domains related to Person Centered Planning. Now the first relates to the plan itself. What are the desirable things for the plan to be done right?

The next domain that we thought of, was related to the Person Centered Planning Facilitator. This includes a Person Centered Planning Process Measures as an example. Or it can be an Accountability Measure related to the plan itself. Or it can be something as simple as a Check the Box Measure around whether or not that person has received some sort of training as an example.

And then lastly, the System Level Measures. Like, what kind of measures do we think would be appropriate at, like a population health level. If an entity that's being measured is responsible, that ensuring beneficiaries within some certain region received a type of care - what sort of accountability do we think they should have? And how would we measure it? Okay, next Slide please.

So, here's just some ideas to help us think about Person Centered Plan Measures that the staff wanted you to have for some consideration. It isn't meant to be exhaustive, but just to help generate some ideas around Person Centered Plan Measures.

So, one measure - and this is one that I just discussed in response to (Richard Petty's) question, which is - is there a plan in place? That's a really simple Check the Box Measure that we could include inside of this domain. You know, like the documentation of the plan. Was the plan updated? Or did the plan assessment occur during important care transition, such as moving from an acute setting back to the community setting as an example?

We can also measure the content of the plan. What is it - is it expected to be inside of that plan? You could have - again, this would be a process measure where we're looking to ensure that certain things are reflected inside of the plan. We would say that it was (inappropriate) plan if it did not have that (unintelligible).

Another area that we identified was related to, what are called, patient reported outcomes. In this context - it's probably better to call them Person Reported Outcomes - Based Performance Measures that - I hope you'll forgive that particular term of art that gets used inside of healthcare quality measurements. So, a Patient Reported Outcomes Performance Measure could relate to something like (goal attainment) which in (NCQA), who - if you're not aware - is the measure developer that's built the (HEDIS) Measures. NCQA has a Goal Attainment Measure that they're currently testing that might be appropriate for LTSS Studies as well.

One that - I thought this group would be interested in - but, again, it's just an example of a Patient Reported Outcome Measure - is Cantril's Ladder. And this is a simple survey consisting of two questions. The first related to current life satisfaction. And then the second question related to how you see your satisfaction at some point in the future? Will you be able to reach your goals? Do you think you'll be able to continue to be satisfied? Or do you feel yourself as dissatisfied now and continuing to be dissatisfied in the future? It's kind of an interesting look at both current satisfaction and overall hopefulness for the future.

And then lastly, I wanted to point out another way that we could use patient reported outcomes is the Person's Assessment of the Planning Experience. Did they perceive that they had a leadership role? Did they feel empowered in

the process? Did they perceive that they were able to make informed decisions based on what the facilitator helped them with? Did it focus on their strengths? Did it address their goals and preferences and things that were important to the person according to their point of view? And were the correct people in the room?

So, these are all things that we could ask the person after they've developed their plan to help them to identify the things that they liked or did not like about the Person Centered Planning Process. Okay, so this is just a handful of examples of things we could put in there. Let's go to the next Slide.

So, the next domain that we had in mind is related to the facilitator and things we couldn't measure about them. We kept the examples to this fairly limited and we'll, again, what we'll be doing is revisiting each of these domains and asking for what you think should go into these particular areas and if there's anything new.

So, instead of the Person Centered Planning Facilitator Measures, we identified a couple of like process and structure related measures that could potentially (roll with) this. For example, were (Maintenance Services) made available to the person receiving the planning? Was there Screening Performed for Preferred Spoken Language? Or Hearing Tools and Communication Tools made available to the Person?

We could also do Competency Measurement, which aligns with our previous work that we as a committee worked on. Looking at the sorts of things that we would expect facilitators to - either to know, or to be competent in before they conduct a Person Centered Planning Session.

For example, did they complete training? Did they have knowledge of key Person Centered Planning Principles? And it's also possible to do Direct Measurement of certain knowledge and skill sets, such as Cultural Competency, Resource Knowledge, or Knowledge of Policy Regulations as directly impact persons who are having their planning facilitated?

Okay, next Slide. Our last domain of interest was around the System Level Measures. We thought of a couple of areas that would (natively) house the potential measurement (unintelligible). And those can be structural measures such as training programs in place, appropriate numbers of staff (perhaps), like some ratios or something of staff to total number of beneficiary populations served.

We can also look at Process Measures such as (completeness rate) measure that I mentioned. The staff training completeness (rates). We can also look at Outcome Measures. Again, revising like the Person Reported Outcome Measures around satisfaction with the overall experience of planning. Their quality of life or measures to that effect.

And next one. I think I'll bring this to our discussion portion. So, I'll hand it over to (Cheryl) and (Gretchen) for this next bit. And what we're looking to do - just to summarize - is to think of the Healthcare Measures that would directly impact Person Centered Planning that would lead to improvements in Person Centered Planning and help persons that are developing their plans to live better, fuller lives as a result of these measures going into place.

We're going to try to come up with appropriate categories for those. Most of the three domains that were identified by staff and any subdomains that you thing would natively fall underneath the domains that we've identified? Okay,

so with that being said, I'll hand it over to (Cheryl) and (Gretchen) to lead us through this next part.

(Gretchen): Great.

(Cheryl): Thank you Sam, we appreciate that.

(Gretchen): So, I think we were going to get started with the Person Centered Plan Measures. So, we wanted to go back to that Slide - 26 I think. There we go, thank you. So, I'd love to hear - Amber has made some comments in the chatbot, which I think are great to think about including accessibility of and to a plan, planning tools, and the right to a plan. So, we definitely can think about including those.

Who else has some suggestions for either eliminating any of these that you think are not appropriate for Person Centered Plan Measures, but you know, I think this is really a brainstorming session, as Sam had said - what other measures would be helpful in this Person Centered Plan Domain?

Denise: This is Denise.

(Gretchen): Hi, Denise, go ahead.

Denise: Several things have kind of popped into my mind. Goals - you know, there might be one goal or several. What are some of the barriers that need to be identified, whether they be Systematic, or family barriers? Are we talking - we also should perhaps look at not only the transition from the institution to the community, but we may face some people who at some point in time are - just because of the nature of say their physical disabilities - they may have to

transition the other way - from the community into an institution and what can go there.

And then, I was thinking about -- Okay, we need to have an initial date on the document plan and then maybe like plan review goals every, you know, like week, month, six months - review the whole plan at least yearly, three years, depending upon the person's goals and how long it may take to accomplish them?

(Gretchen): Great. So, you're saying you want to be sure that we are - that the plans be updated on a frequent basis and considering that those parameters might be - great. Thank you. Who else has some components they would like to add to this domain or to discuss under Person Centered Plan Measures?

(Amber Decker): This is (Amber Decker). I just wanted to, again, kind of reiterate what was just said in terms of time? You know, when I think about the (IET) Process, there is a time in which a plan must be produced or provided, or a meeting must be had. And so, you know, just - I know that this is not the same thing, but you know, do we - wouldn't a good measure be was the plan produced within the timeframe allowed or required? Because it could take one - it could be one day, it could be three years. Like what are we talking about when it comes to time? And I think that is a really good point that was brought up earlier, in terms of thinking about time and what do we think is a reasonable timeframe to produce a Person Centered Service Plan or Person Centered Plan?

Because one of the biggest complaints that I hear from families and individuals that are in receipt of LTSS is the waiting and how long - time, time, time is always a factor here. So, I think we're kind of missing that. And I don't know how to get it on here or in here, but I think it's important.

(Mia): Hi, this is (Mia). Just to add to what (Amber) was suggesting. I was thinking the same thing and the measure that I was thinking about were related to, like, timely comprehensive assessment and update of the plan. Timely sharing and review of the plan. I think, at this point, it's really important that we have something in there that speaks to the timeliness or the development, the ongoing review, and the communication and evaluation of the plan.

But in addition, I - you know, I think we might be capturing this in the section around the Person's Assessment of Planning. But I think emphasizing choice and ability to drive the development execution and a review of the plan is critical. So, making sure we have some measures that really tie into the role of the individual and the expectation that the plan is based upon the individual's choice and determining factors is really critical in evaluating the outcome.

And again, I'm not sure if we captured it in that last bullet around Person's Assessment of Planning Experience. But, of course, there may be an opportunity to expand on that to make it clearer, the evaluation of the individual's engagement or the development and execution and review of the plan is critical.

(Gretchen): Thank you, Mia.

(Devon Cross): Hi, this is (Devon Cross).

(Gretchen): Hi, (Devon).

(Devon Cross): Yes, just a couple to add and I think (it would be) (one would be) (unintelligible) ensuring that the person invites who they wish to the (place)

(unintelligible) and implementation of that. And then with regard to content of the plan, a few things I would offer, you know, if this were done with, you know, perhaps auditing (a sample of plan or something like that), ensuring that plans operate in the (persons own) words when in fact the person has written the plan in their own words.

So, reviewing plans to see that (goal) (sort of cookie cutter) and the same from person-to-person, but rather that the goals are actually tailored to - you know, that they contain a diversity of goals. And then incorporating in the plan strategies that promote dignity of risk, dignity of choice, evidence that those conversations have taken place.

(Gretchen): Thank you. And I want to - before we move on - I want to just take a minute to remind everybody that if you can not repeat the same thing that a previous speaker has said, that helps us just get the most brainstorming done and come up with the most measures possible. Once it's been noted we're adding it to the list and can go onto move to some other things.

I want to recognize (Susan) because she has her hand up.

(Susan): Hi, I just want to comment on that last statement and I understand the importance of us writing goals in a fashion that's (number wants). But we have to also look at the logistical - or the time that's involved. Because when we write a measure, then anyone who writes the plan is held accountable for that, which is a wonderful thing, but how do we audit that? If each goal - if each part of the plan is written in their words, exact words, how does a person audit that without physically having to sit and read each and every word on that plan as we go through.

And then how do we gather data from that? There has to be some type of parameters. Something in there that allows this information to be gathered.

(Gretchen): Right. And so those are definitely some good points that we'll have to think about as we consider measures. So, thank you for brining that up. But at this point, we want to just identify as many measures as we can relating to Person Centered Planning in this domain. So, if others have things please speak up.

You know, one thing that I wanted to address is about the preplanning, you know, if there is a way to get that information to individuals so they can begin to think about (though) - I'm going to need - a planning meeting. I'm going to need to be able to talk about goals. And the rights I have includes inviting who I want to come to the meeting. So, some kind of preplanning process that allows that person (served) to be as prepared for a meeting as possible.

What other ideas does the group have about Person Centered Plan Measures for this domain?

((Crosstalk))

(Gretchen: I heard Melissa?

(Pat): Go ahead. This is (Pat), but go ahead and I'll go next.

(Melissa): Okay, this is (Melissa Nelson). I'm hearing an echoing. Is anyone else?

(Gretchen): Yes, I am too. Melissa are you on your phone and on the computer?

(Melissa): I didn't think so. We'll let someone else go first and I'll figure it out.

(Gretchen): Okay. Who was the other person that was going to speak?

(Pat): Hi, it's Pat.

(Gretchen): Hi, Pat.

(Pat): So, I'm thinking a measure that is kind of a look-back. So, asking the person what was the last year like? You know, just to kind of review what was accomplished or how they felt they fell in to (unintelligible). And then what do you want to change? Or what have we learned about supporting you better towards the next year.

(Gretchen): Okay, great. That's a great idea to have a conversation about look-back.

(Amber Decker): Hello, this is (Amber Decker). I have my hand raised (for you to call on me).

(Gretchen): Hi, (Amber). Go ahead.

(Amber Decker): I just want to emphasize the importance of access to the plan. Because a lot of the - and the tools in order to access the plan. So, for example, if a plan is provided digitally, and the individual doesn't have to tools to access it, then, you know, determining whether the individual had access to the plan agreed to it would be really important. And so, you know, I think that that should be a question for individuals that are in receipt of Person Centered Planning, either as a service or as a plan. Because I'm still not clear on whether we have decided if Person Centered Planning is a service or not.

But nonetheless, I do think that just asking if the individual had access to the Person Centered Plan dated, whatever, the date is - you know. That would be a fantastic measure because I think a lot of the time there is evidence that

speaks to this as well through audits, that individuals simply did not get a copy or did not get access to their plan. So, I think that's important to consider.

(Gretchen): Right. The access to the plan is an important measure here in this domain. Thank you. Who else would like to add something to the plan measures?

(Pearl): Hi, this is Pearl.

(Gretchen): Hi, Pearl.

(Pearl): So, I see that updating the plan is there, but I would suggest there be a delineation and I think it was mentioned earlier, but not - I don't know in detail - but a delineation between like the routine update of the plan, which could be annually or every six months or however the plan specifies. But delineation between that and then updating according to a change in the person's needs, which could be at any time during the plan. So, I think there should be a delineation between those measures.

(Gretchen): Absolutely. Considering a fixed timepoint though for (unintelligible) changes in the person's (goal), that's great. Thank you.

(Melissa Nelson): This is Melissa Nelson. I'm just checking to see if I solved my echoing problem.

(Gretchen): Yes, Melissa. I can hear you only once. So, go ahead.

(Melissa Nelson): Okay, all right. Now I feel like I can go ahead. I, this morning was just reviewing some of the public comments that had come out about the draft report that was issued late last year. And one of the things that struck me was

that there were a number of people who voiced some concerns about our making this too bureaucratic and turning it into just another tool. And a fear that we could be sort of missing the bigger Person Centered Picture of each person has a story. Has a life. Needs to be heard.

So, I'm wondering if there'd be a way that we could actually measure and maybe you're capturing it under your Patient Reported Outcome Piece. But some - even a possible survey that says like a person could say was I treated with respect? Did people listen to me? Did people, you know, take my point-of-view in and use it as the foundation of building this plan, might be ways to get to the true Person Centered Piece in a little less bureaucratic or healthcare focused manner.

(Gretchen): Okay, thank you. Gail, you have your hand up next. Can you go ahead please?

(Gail): I'll try. Just kind of jumping off, what needs to happen I think before anybody puts pen to paper - which we find to be a rich process when we support people to develop Person Centered Plans (of the Planning Process) is really concentrating on People's (who have some interesting capacities), not their deficits. And so, sometime before, you know, we begin - or when we're talking about it - before even jumping off a path idea - we really kind of try and make an exhaustive asset inventory and it helps guide the discussions so we make sure that we are really sticking to what's good about that person and what they're interested in going forward, not their deficits.

(Gretchen): Thank you, Gail. Sally, you're up next.

(Sally): Yes. I guess I'm going to go back to what a specific measure of the Person Centered Planning Process should be and that is having a preplan. If you don't

have a preplan with the individual, you're taking all power away from them. Topics, the participants, all those things are going to be out of their hands and if they do not have the advocacy skills to stop (unintelligible) they're going to end up with more of what they don't want.

So, the preplan is something that I have made sure happens. Because, the worst plans I've every facilitated, have been when I've listened to the case manager who says, oh we know her really well. We don't need one. And then, so I think we need to stop and think every single person, we need to check with them before and say who do you want to have there? What do you want your focus of the meeting to be? What do you want to talk about? So, I can't be strong enough about that?

(Gretchen): Thank you, Sally. I appreciate that. Anyone else have comments they want to add to the Person Centered Plan Measure before we move onto the next domain?

(Penny): This is (Penny). I'd like to say something.

(Gretchen): Thank you, Penny, go ahead.

(Penny): The fact is - hang on - (I'm - my cell phone) I'd better move my phone so you can hear me. One thing I think is wrong with the whole idea of (unintelligible) - once you have one - I went to a team meeting - I'm on (unintelligible) 18 years now. I went to a meeting once and there were like six or eight people there besides and it was very intimidating. I think that fact that you outnumber the person is (unintelligible) to be a problem and that shouldn't be done with a team like that.

I think you have to think about the balance of power just by bodies - body count.

(Gretchen): Thank you. That's an important thing to consider, not to outnumber the person. I appreciate you bringing that up.

(Amber Decker): This is (Amber Decker). I have my hand raised when you're ready.

(Gretchen): Okay, go ahead, Amber.

(Amber Decker): I just wanted to say that I think the Person Centered Plan Measure Slide 26 is missing a Person With Decision Making Authority to provide access to services. So, while it says the perception of leadership goal empowerment is the concept, I think at lots of planning meetings that are supposed to be Person Centered that I've been to, there are individuals who say well I don't know if that can be done. I'm not sure if that's something we can provide.

So, I think having people there that can provide, you know, access - or at least tell the individual yes or no, that they have decision making authority to say yes or not to whatever the person is requesting, is very important and might be missing from our measure - measurement (set) if there was someone there.

Also, due process rights - were they provided? Were due process rights provided to the person, family, or guardian. I mean, that's very basic - a very basic, simple way to measure some degree of Person Centered Planning.

Woman 1: (Unintelligible).

(Amber Decker): Thank you.

(Penny): This is (Penny). I'd like to make a comment again. One of the reasons I'm not too popular in my nursing facility is we might have an Assistant Director in our nursing home is (new) and I say well listen I don't want you to feel bad but I will have - there's no services you can provide for me, I said, because you don't have the authority to implement my requests. Therefore, I always go to the (second) (unintelligible). I do have a number of people, like the social workers and I have no need for social workers.

And there's a whole bunch of people like that. You can't believe the looks in their eye when I say, I just won't be taking any of my problems to you. I only go to the people who can actually solve them. I hope you don't mind? I'm just thinking and you're not the only person I've said this to. That's essential to my well-being is just to avoid the bureaucracies from the bottom up.

(Amber Decker): And I think - this is Amber - I think that this is something we have missed in terms of this whole process, whether or not the facility - is the facilitator have the authority to say yes to what the person is asking for? Who has the authority to say yes? Because a lot of the times, the issue is we had a meeting and everything is on paper, but the person was asking for X and no one there had any idea if X could be achieved. And, you know, or done?

I've sat through lots of meetings where tier managers said, I have no idea what nonmedical transportation means. You know, and meanwhile that's something that they're claiming they provide as a service.

(Penny): Can I make a couple more points on a personal - (unintelligible) medical appointment - there was an ambulance company that I had been going with for about 15 years and I always make my own appointments. When the driver came, the receptionist said the nurses could no longer sign. I'll have to get back to it.

So, I of course contacted the Director of Medicaid who I know, who - I'm going to fast-forward to the solution. It turns out at a morning meeting some nurse raised the question about whether I was eligible for Medicaid non-emergency medical transportation. Which I - which is a national program. Because some of them in the meeting said well, she goes out with the local public transfer for other things, why would she qualify for this.

Well it turns out - whether you can believe it or not - in the morning meeting was the Director of Nursing, the Administrator, the Physician - nobody but me in the whole frigging building knew what the policy was. So, they couldn't stand up for me. So, I had to go get to the Director of Medicaid who I knew, I'd worked with on some issue - and (unintelligible) to contact the building and tell them, how can a building with 140 residents who go out for medical appointments not know (not health policy - on non-emergency medical visits.

These are the things that astound me is how ignorant - excuse my language - the - and these are people who are working there 10-15 years. These are not newbies in these jobs. These are not even basic things that I know. It astounds me, how little - how (can we react) to educate them about basic things like that? Of course, I'm (unintelligible) you've been perjuring yourself for 10 years signing these forms and all of a sudden, you're not going to sign? And how much fraud - that was Medicaid fraud. But they're the ones that have been signing. All nurses, right? I mean, I really cannot believe what goes on.

The ignorance is beyond belief. I do this all the time. It's a full-time job.

((Crosstalk))

(Gretchen): Right, right. And so, you know, another thing you would add is was the person present for their updated plan? You know, because I'm sure there're lots of plans that are Person Centered that are updated without the person even invited or present. Or just activities and decisions that are made without the person's knowledge or input.

(Penny): But the only thing you need to know is that different parts of the plan come under different specialties within the facility. So, that's complicated. It may be nursing to make the decision. Like I wanted to - I have a backup power chair - also I want my power chair charged in my room because (it was being taken down the hall and they wouldn't charge you many years ago).

They told me that was illegal. I contacted the state fire department, the state building department and it was perfectly legal. Other nursing homes were doing it. So, each of the buildings, they don't know basic things that go on. So, the thing is that could be (a private care plan) need, but nobody in the building would know the answer to it.

So, one thing - the people with chair plan needs, wouldn't have the expertise for all the kinds of requests you'd have because they're varied. It's important to know that.

((Crosstalk))

(Gretchen): …that's such a great point that you're bringing up Penny. We absolutely - it leads right into our next domain. So, I'm going to use that as a way to transition our conversation to the next domain. Which is the PCP Facilitator Measures. And what I hear you saying is that it's so important for the people facilitating to have the knowledge about the services and to have the right people in the room who can either - are willing to advocate to get what they

need, even if they don't know what's happening in the room. But to be able to get the person who could…

((Crosstalk))

(Penny): Willing to do the research and find out the answer. Make a commitment in the meeting. I don't know the answer to that to be honest, but I'll find out whether that's something we can do or if there's any legal issues or any - you know, repayment issues, or whatever any (unintelligible), what the (unintelligible) might be.

(Gretchen): So, those are great things to add to the Facilitator Measure. What other ideas do you, Penny, or others have to add to the Person Centered Planning Facilitator Measures. And if we can go ahead and move to that Slide in the presentation that would be helpful.

(Penny): Well, humility is one of them. I am very intimidated in my building. It's very intimidating and (unintelligible) but what can I say. I'm very knowledgeable. But the thing is, how can people who've been the Staff Development Coordinator - the Staff Development Coordinator (jumped) (unintelligible) within the last two weeks with me. HIPPA is like an open faucet.

If you go - can you imagine - if you go to your provider and you waive the HIPPA Rights, we can ask you any questions we want. I said, (Scott), how long have you been a nurse. Of course not, it's limited, you chose what you want. I mean, they say things to me that are astounding. They don't even understand HIPPA. They don't understand non-emergency transportation. This is the last three or four weeks of my life (in the facility). All this stuff has come up recently. I know I'm stunned. Just coincidentally, that (unintelligible) just come out in compensation.

I mean how could they not know basics like that. So, HIPPA is not open faucet (unintelligible) have forms sometimes where (unintelligible) read that.

(Gretchen): There's a global consent HIPPA if you are in some type of case management or care management. Sometimes they have something called Global Consent. Which you might have signed in the past at some point.

(Penny): Well I didn't, but I'm just saying - he didn't say you had a choice to sign it or not. (I'm just saying) (unintelligible). It's very bizarre. Some things they say to me recently just stun me. They're so naïve.

(Gretchen): Penny, thank you for sharing you experiences. It's so helpful to us to really get that lived experience. So, we appreciate you sharing that.

(Penny): Uh-huh. No problem.

(Denise): This is (Denise).

(Gretchen): Go ahead, Denise.

(Denise): The very things Penny has just mentioned, knowledge of HIPPA, knowledge of non-emergency medical transportation - those should be two areas that we have under Facilitator Training.

(Penny): I'll be happy to provide you with a list that I think in addition to those. I won't bore people right now.

(Gretchen): That'd be great Penny, yes. So, okay, definitely under Facilitator Training, we need to add those things. What else should we measure under the Facilitator Domain to be able to validate or not, the quality of the Person Centered Plan?

(Penny): I think humility is important, especially with people who are alert like me. But, like I said, that they're willing to learn from the resident. I did send people that piece I wrote about that - from the Mass General Hospital about the User Expert. I mean, I could go to the Mass General Hospital and probably one or two in the country and get a physician who doesn't know me. And they don't want to listen, but I know more about my medical care, because I have a rare disease that I know better than anybody knows. Anybody who doesn't know me.

And yet these doctors - even at the Mass General, they look at you like - well we're in charge here. We're sending you to the emergency room. I said uh-uh - no you're not because it's not an emergency. You have to stand up to them. It's just astounding that they don't understand that people with disabilities - long-term disabled like myself - know what we're talking about. Know what the symptoms are. I mean, so, a certain humility - a certain ability to respect people who know their medical conditions, for example. That's the (unintelligible) of it. And how can you not trust people who have the illness when you don't even know that person.

And there are patient's at Mass General - I know all the specialists - I got all the information from the specialists. It's not like I'm living in a time warp or something and I made it all up myself. I mean this is Massachusetts General Hospital. And I can say right now, I'm the representative for all surgical (mobilities) at Mass General and their Website is very exciting. I share my (unintelligible).

(Gretchen): (Unintelligible) congratulations.

(Penny): Yes, so. I'm (their accessible)…

((Crosstalk))

(Penny): I mean, they got everyone to listen. They have to know that, they got to listen - they need to learn from their clients or their patients. (Unintelligible) to learn.

(Gretchen): Thank you Penny. I think humility and (risk factor) important measures. Dory, I see that you have your hand raised? You want to go ahead.

(Dory): Yes, I think they also have to have a knowledge of disabilities and health conditions. I think sometimes what enters the picture is personal bias, instead of factual knowledge and information. Be familiar with individuals - well them themselves - and their interests (and all). But then also have some familiarity with health conditions, disabilities that people have that you're working with. Except I think, I can see from myself, and other people's personal experiences, folks didn't even know anything about the types of disabilities and what was coming out in conversation were people's personal belief, instead of actual understanding.

(Gretchen): Thank you, Dory, yes. It's really understanding the…

((Crosstalk))

(Penny): At the Mass General - sorry - at Mass General we do have a Disability Program Manager. So, you know, if they're smart enough to go to that person she could assist them. And that's part of a settlement we - it was a settlement.

They were sued by (unintelligible) living. So, that's part of the settlement that they would have a person that would be the go-between for people with disabilities.

And, by the way, the Mass General Hospital has 90-thousand self-identified people with disabilities asking for accommodations. That's a big number, so.

((Crosstalk))

(Penny): …self-identified that, yep. But they have someone to manage that. So, it's good if there are resources like that to share that in our list of things people should know about in the community. Who are the resource people for people with disabilities who can help them out and advise them?

(Gretchen): Yes. Thank you. (Pat), I see that you have your hand raised.

(Pat): Yes, just to echo what (Dory) and (Penny) have said about humility and listening and being curious about the person and (patients) and receptive. And I think we also need to keep in mind for, you know, many people, there are significant patient barriers and inability to control their meeting or lead their meeting. So, we have to figure out how to work in partnership with them to get a plan that will support them.

And that takes time and it takes patience and being open to, you know, new and different ways of (being) with people.

(Gretchen): Thank you. (Devon), I see that you made a comment about would it make sense to draw from the extensive list of staff competency to develop PCP Facilitator Measure. Do you have any in particular that you thought would be good to highlight?

(Devon): I don't and I say that with caution because that list is so long and so much of the (feedback) was that the list was so long. But it just occurred to me listening to this discussion that we've had similar discussions when we were generating that list. So, I wondered if it might make sense to kind of go through that list and kind of pull out the pieces that are essential?

(Gretchen): Okay, thank you. Who else has some ideas that we can add to Facilitator Measures to measure the quality of facilitation?

(Devon): This is (Devon) again. I just have one reflection that might be a good time - this might be a good time - and this in in regard to the method of collecting the data. So, maybe this is a different part of the discussion. But I just want to note that having some sort of - you know, if people's experience with the Facilitator or people's perception of the Planning Experience, if that kind of data are gathered by the Person Centered Planning Facilitator, that's probably not a good idea in terms of getting, sort of, accurate information.

(Gretchen): All right. Thank you for pointing out. Yes, that's helpful.

(Amber Decker): This is (Amber Decker). I have my hand raised. I don't know if anyone else has their hand raised.

(Gretchen: Go ahead, Amber.

(Amber Decker): I just wanted to say that, you know, we never really defined a Facilitator. And I think it would be safer to say Facilitator Entity or you know - when we talk about things like case managers and care managers and facilitators - it's really confusing. So, maybe it would be better to say entity, that's facilitating. Because I think that a lot of the time, that that person is representing more

than just what they're doing there. They're representing an agency or an entity of some sort.

So, how are we defining - how are we going to measure something that we have not defined really, at this point, I'd like to know?

(Pearl): Hi, this is (Pearl). I want to say I agree completely with that comment. And then also acknowledge that there may be multiple people that are responsible for facilitating some, or part of the Person Centered Planning Process. And so, how is that looked at, when, like, there may be pieces that are broken up or provided to different folks that are involved?

(Gretchen): Sure, some multiple facilitators collect data facilitator represents are important things to keep in mind. Thank you all. I see that (Allen) has also mentioned that tracking what happens after a plan is in place is also essential. And (Alan), can you talk more about that and clarify what you think should be measured afterwards? Like referrals or what did you have in mind?

(Kate): This is (Kate) and (Allen) (unintelligible) really (wasn't) a full contributor. But I think it would be best if we waited until the Public Comment Gretchen for (Alan Lords) to provide his thoughts.

(Gretchen): Oh, sorry. Okay. Thank you. I have a hard time keeping up with the comments and who's a member and who's from the public. So, thank you for that. Anybody else from the committee have an addition to how we measure facilitator quality?

(Amber Decker): This is (Amber Decker) my hand raised.

(Gretchen): Go ahead, Amber.

(Amber Decker): But if anyone else wants to say something first I - okay, I just - I wanted to add that I'm asking a question and I don't know who can answer it and no one's answered it. So, have we defined what a Facilitator is? And can we agree that a Facilitator is usually a representative of some entity, like a CEO, or a health plan, or an agency or some sort? I mean, I'd like to kind of get to the root of this question and somebody to answer it. Maybe it can't be answered right now, but if anyone can answer it, it would be good?

(Gretchen): I don't know if we can answer that ahead of time or if it's important to answer that ahead of time. As long as, when we actually sit down to do the planning, the Facilitator is acknowledged and recorded. So, it could be a friend. It could be somebody who knows the person very well, who's going to facilitate the plan. The agency folks, whoever needs to provide services would be accountable is there.

But I've been in situations where the "Facilitator" - air quotes Facilitator is not an agency person or anybody being paid, but somebody that the individual knows well and can (die)…

((Crosstalk))

(Amber Decker): Okay, so then can we define - can we say that? Can we say a Facilitator is not limited - I mean, can we just define what a Facilitator is in order to ensure that it isn't confusing so that - I mean - and we'd simply just say, in order to measure something, how do we measure it without defining what it is? So, this is the problem that's I'm having here is that Facilitator is a person - unless we're talking about Facilitation. Like what are we talking about?

(Gretchen): Okay, I think that's not a question that can be answered right here, but I'm definitely taking note that your comment is that we need to clearly define Facilitator as we go through the process. That it would be helpful to define what is the Facilitator as we also define how to measure facilitation quality. So, thank you for bringing that out.

(Amber Decker): Right. Thank - yes, it doesn't have to be limited to - sorry, it doesn't have to be limited to - and they can say, including, but not limited to, a family member, the person themselves. I don't know. I just think it's important to differentiate here. Sorry Sam.

Sam Stolpe: No worries. I just wanted to point out that this isn't one of those things we actually don't necessarily need to solve for. Because once the measures become well-defined - and inside of the specifications, it'll say who the measured entity is and will define Facilitator as part of the specifications.

So, we can say that it's very important for a Facilitator to be well defined and just an example - if you wish, but again, because measurement is so nuance, the expectation for the committee is not that you come up with a fully specified measure or solve every problem related to how to measure something.

But identify something challenging like this - like, that it is challenging to define exactly what a Facilitator is, will be an important part of what we capture in this portion of the discussion.

(Amber Decker): Well I just figure it would be better - this is (Amber Decker) - to say a Person Centered Planning Facilitation Measurer instead, if we're going to like not define a Facilitator as a singular person. Thank you.

(Gretchen): Okay. One more call or comment on the Facilitator Measure…

((Crosstalk))

(Gretchen): …in the HCBS settings you'll that describes Person Centered Planning they refer to the Person's Representative as someone who would facilitate the Person Centered Planning Process. So, I don't know that we - come up with a term Facilitator, but that's not referenced in the Regulations. So, I think figuring out how to allow for a designation of that person when you go into a plan and then assessing how well that person accomplishes the planning, is going to be a decision made in time. You know, at the time the Person Centered Planning is taking place.

And that's something you need to set out ahead of time - I don't know, I think it does require some thought. But I think part of the problem we got into is we created this laundry list of qualifications for a Facilitator and it's unrealistic. And it's not going to apply to every person that goes to Person Centered Planning. It really is - is the person that's going to help with the plan - do they understand the person? Do they know the person? Are they willing to listen to the person? Learn from the person and gather resources that the person needs to have a good life?

And I don't think it's possible to set out those requirements ahead of time and make people be accountable to them. I think that's the challenge.

Kate: Okay, thank you. I think we're going to end the Facilitator Measures on that last comment. I appreciate you bringing that kind of to close with that comment, that was very helpful for us. Now I'm going to turn it over to Cheryl who's going to facilitate the next section.

(Cheryl): Excellent. And I just want to let people know, not only will we go through these three domains, but we'll also end this part of the discussion with what other domains. If there's other things that you just feel strongly that are missing.

So, we've talked about the elements of the plan. We've talked about the facilitation and this recent discussion of what is a Facilitator? Who is it? How is it measured? What are the characteristics? And now we want to look at the System Level Measures. And I think this comes out of the context that you can have an ideal construct for a plan and a great facilitator. But if the System of care and services that the individual finds himself is not receptive to acting upon or acknowledging the plan, is that individual any better off for having one?

So, let's think about when we talk about System Level - I mean, yes it could be Healthcare Systems. It could be other systems of services and care. It could be a network of community base. It's really in that environment in which the individual is experiencing their life.

So, I'm going to open up now to the measures we have Structural Measures (in force) but are there Training Programs in Place? CMS has lots of Structural Measures for nursing homes and I think those of you who know that well can attest maybe to those parts, the most powerful vehicle. Number of Staff. Is that an important measure? But when I say staff or whom, under what setting? The kinds of process measures, I know that we prefer Outcome Measures, but very (often) in the Measurement Development Areas, process measures help us understand what's getting done and what isn't done.

So, are there Process Measures that you feel are relevant? And then, ultimately, what are the Outcomes Measures? And it's not the Outcome for

the System. I think it's the Outcome for the individual. The person. What does this mean to them? To their lives? So, let me pause and see if anybody has comments that they would like to start with?

(Linda): This is (Linda). One of my concerns is - I'm sure, not just me - but I'm trying to figure out how to put accountability into this process? Accountability in terms of, you know, barriers (unintelligible) or even closing the loop. Closing the loop on services or issues that needed follow-up. And with some, I guess, cloudiness in some of the different roles, it's kind of hard to know, who's going to be accountable? Who's going to be responsible?

And how do you track - how do we track that? And how do we make sure those loops are closed? And if there's not going to be one specific responsible person that's named or delegated to - then how (is it we have)?

(Cheryl): And I think accountability is a very important piece in that as a framework domain could (unintelligible) and come through a number of issues that you touched on. Excellent point. And several people have talked about number of staff. If it's staff to individual ratios that clarification of numbers of staff would need to be more defined.

(Maggie Winston): Hi, this is (Maggie Winston). I have a comment about staff also. And I just feel like it would be a more appropriate measure to denote number of trained staff. Or, you know, the quality of staff, just because we know that quality is better than quantity. And so, maybe something about the training of staff.

(Cheryl): Yes, so, I'm hearing and I totally agree. The training and quality - so having a designated person who does not have training skills or competencies is not terribly helpful. I think the other point that was raised - if you have one

trained staff, but there's (a close to) 10-thousand members in a health plan - I'm exaggerating here - but obviously that's not very helpful.

So, some sort of number to people (per) ratio is what I'm hearing in comments and also the capacity and competency of the staff that are identified (unintelligible).

((Crosstalk))

(Penny): Can I say something? This is (Penny) can you hear me?

((Crosstalk))

(Penny): You can hear me? I'm on the Executive Committee of a group in Massachusetts called the (Visionary Policy Consortium). We are the only group in the whole world that does the (following). We have the Ombudsman Contract with Medicaid (unintelligible). We are the Ombudsman. We run the Ombudsman Program. Everyone on Medicaid, whether you're disabled or not - whether you - except for people living in institutions. It's quite unique and we're it's extraordinary actually.

We have a multi-million-dollar contract and almost everyone who works for us is disabled themselves. It's quite an extraordinary endeavor, which I'm looking forward to (this information about). But the important point here is that we need Independent Ombud people. Out side of the vendor service, the healthcare provider, and things like that - we are a useful group who represents people on Medicaid in Massachusetts which (unintelligible). So, we need Ombudsman, is what I'm talking about here.

(Cheryl): Yes, and I think the point thing - I know that in prior settings talking about case management, the concept of conflict free case management. But really the essence that you are getting at is that, to be at a system level of meeting the individuals, Person Centered Care Planning goals, there has to be a neutral process that can (preface) it. Otherwise it can very quickly can become self-serving to the entity. Yes.

(Penny): That's what people do. They come to us and we're the Ombudsman and we look at everything and we try to mediate basically. It's like a mediation (unintelligible). Ombudsman work is complex.

(Cheryl): Yes. And it's also acknowledged on comments, that we need a due process measure as part of a - either a process measure or as part of the structural measures. But that there needs to be a mechanism where there's - I don't want to say adjudication. That sounds very judicial. But there is a process of how do individuals need to get a fair hearing and an open discussion about options and possibility?

I may not be using the right words here, but I think we're all speaking about the same thing. What is the due process?

(Penny): And one group of people we've not mentioned I think, are the (unintelligible) look at the (unintelligible) colleagues (in the community) is the Vendors. A friend of mine is a (unintelligible), but she's also an (event). And she has to have her blood drawn everyday and all kinds of other things. If these vendors do not do their job, which is a service provider, but even vendors for equipment like - she has to change her own trach. She has to change her own IV lines. She can do all this herself.

But if they don't deliver her supplies, she has to go to the hospital to go get supplies, because she could die without it. So, the thing is, we haven't mentioned vendors - like supply vendors - and how expensive they are to Person Centeredness. Because people have unique needs and if they don't deliver the supplies that she needs, it really, really, really makes a mess of things.

(Cheryl): Yes. Yes. And we'll have to think about how to work that in. But to the…

((Crosstalk))

(Penny): No, as I say, that's a kind of service of the community. I'm just saying it's not all - sometimes they're just businesses that are not doing their job but they're providing essential supplies.

(Cheryl): Right. Are all the essential services available and reliable? And of quality that can actually support the individual Person Centered Planning Roles.

(Penny): So, I think medical supplies (should) be a lot more important to people in the community, because I can get my own (liabilities).

(Cheryl): Yes, yes. That's a very good point. And that, in fact, is often a differentiator of whether or not people no longer are able to live in the community is the access of medical supplies. Durable medical equipment, et cetera. Very good point.

(Penny): Well, she can self-advocate. So, people who live in the community have to self-advocate to get them. It's when people get to the point where they can't manage their own care anymore. I think that's where they end up in these situations. But as long as she can manage her own care. But she knows what

to do in (unintelligible). She knows. Those are how she gets them. (Unintelligible). I mean, it's crazy, but - I mean the point is to live in the community you have to have some self-(unintelligible) skills or have someone who can do it for you.

(Cheryl): Or someone who can do it for you is what we have.

(Penny): That's right. Like a family member or, you know, someone. Yes.

(Cheryl): Anything else under System Level. I know, that I think we covered really the bulk of the real meat of the things we want to see accomplished under the measures and under the qualifications and characteristics. But I think we've touched on some important additional System Level Measures. And so, if there's any others. I see a couple of hands raised. Let me - this is a little bit…

((Crosstalk))

(Connor): This is (Connor).

(Cheryl): Oh, (Connor) let's start with you.

(Connor): So, a couple comments. First, I just want to make the point that I don't train at the System Level. We are looking at individual outcomes. Individual outcomes should be looked at when we're considering the individual level, which we talked about, you know, a while ago. At the System Level, we're needing to think about how well does the system support a Person Centered Planning Process for everybody who is engaged in the system?

So, it's - I think it necessarily involves the feedback (loop) which gets to some of the stuff (Penny) was talking about, you know, with accountability and the

Ombudsman, due process. Is there a way that the system gets information about things that are going - that maybe are not going well and do they have a corrective loop?

So, they learn from what went wrong and they correct it and there's responsiveness to the people who are receiving services and providing services. So, is there an effective feedback loop? Does the system have a capacity and a mechanism for learning how well they are doing? I think that's really important in terms of Systems Capacity.

(Cheryl): It's almost like an equivalent of a population health measure. I can, as a clinician assess individuals' diabetic status, but if I have an effective System of Care, I will want to have some Measurement that looks at the entire population of individuals with diabetes. So, in the same way, I think you're talking about - it's important to have individual accountability for the Person Centered Care Plan. But we also need to have a System Level Accountability that looks at all the individuals within that systems service network. Is that what you're saying?

(Connor): Right. Yes.

(Cheryl): Okay.

(Connor): And something Systems need to have - we need to see if there's some way we can assess their openness to innovation. Do they change, if things are becoming static or it's not effective? Does the system have the capacity to adapt and change with newer, better, more impressive things?

(Amber Decker): This is (Amber Decker). I don't know if anyone else has their hand raised.

(Cheryl): No, go ahead.

(Amber Decker): I think that Outcome Measures, while they're important, I also think that if we can somehow include barriers and personal factors and needs and choice in - or if choice is available somehow in there - because it shouldn't always be about improving or you know, like, you can measure just capturing someone's needs and barriers were included, you know, to some extent.

I think that that's something that should be measured. Even though it's not like a positive - it shows that there was consideration of it. And that their voice was heard. And it's a good way to measure if a plan is Person Centered, right?

So, I don't know, I just feel like a lot of the times barriers are conveyed by individuals, but they're not captured. And so, just being able to have a place to do so on a plan, I think would be important in a way to measure some sort of System Level.

(Cheryl): Good point. Anybody else who hasn't had a chance to speak? Do you have - I want to make sure that we get all voices and I know some of you are writing and not as comfortable talking out loud, but I want to give some space for everybody to have their words heard, as well as read.

(Denise): (Cheryl), this is (Denise). This has been a good meeting and conversation. I'll look forward to the notes. I've got to run to another meeting. Thank you.

(Cheryl): Okay, thank you Denise. And I see a few others that need to be heading off as well. Because we're at the top of the hour and there's conflict. Anybody else want to come up with something at the System Level. I think that we - too

bad we can't do red lines as we go along, because these were all very good ideas and comments as we've moved. Anything else on System Levels?

(Dolly): Hi, this is (Dolly). And I want to say, on a System Level, knowing that this is an - like in Michigan, it's for all population, Person Centered Planning is. So, as such, it's all going to be individualized. But still the focus needs to be on Outcomes which are going to get that person in the community as they define the community.

And so, I think that some of the little things - and they're not little - they're not little - nothing's little, but they are process oriented as was, you know, explained to be earlier. If somebody needs healthcare, then that's obviously a part of it. But still the focus needs to be on the outcome of the person being a part of the community in the way that they define community.

So, I don't want us to get bogged down in the, you know, - because we want everybody in the community. We don't want people in places where they don't want to be. In a nursing home, or in any sort of facility. So, I guess I want to say that. And I also want to say to stay away from any - because I have to field comments, but whenever I get together with people from my state is that, why are you guys so (medically) oriented. And so, to stay away from that - that any orientations towards a medical model.

We need to call people, people and not patients and I think we all need to be on our toes to make sure because that is so insulting to so many individuals.

(Cheryl): Oh, absolutely. But I think this is a group - and that's a good reminder at the System Levelness. Because there is - we all know, that there is an arrogance on the medical side that they sort of own the whole process. And really what we're talking about is the person - the individual. Not defined as the patient. I

don't go to my dentist to tell me where I should live. I don't know that I would go to my doctor to tell me other things.

But we also are acknowledging that there is a fluid partnership within Systems of Care that can optimally, if done well, enable the individual. Not from a medical context, but from a life context. So, very good point.

(Dolly): Thank you.

(Cheryl): Anything else on System-ness. I also want to - as we're kind of wrapping up on Systems, we do want to go to the public comment. But if there's nothing more that jumps out on a System Level, what else is missing? Is there any other general domain? So, we've got the Measure Process. We have the Facilitator and the Characteristics. We have the System within, which that process is being acknowledged and executed with the individual at the center.

What else is missing in a domain as we talk about this process?

(Melissa Nelson): This is (Melissa Nelson). I'm not so sure if it's a domain or not, but I'm thinking when we had talked about some ways of measuring are easier than others, but hearing directly from the person is so critically important - I'm thinking it would be important to have some sort of a survey or something, where the person really gets to give the feedback on was I respected? Did I get the opportunity to lead the meeting? Are my ideas valued? To get to some of those larger point issues. Thank you.

(Cheryl): Very good point. Thank you. Anyone else? Well this has really been - for all the areas, plus the additional comments on domains - I think has been phenomenally rich. And you guys have done a superb job. One of the things that Gretchen and I had talked about is that we would get too lost into

measurements specs, which we're really not in a position to do. And you guys have been phenomenal in looking at it from a framework. What are the concepts? What are the perspectives that we're trying to capture with measurement?

Realizing that some are easier to measure than others. And that there will be probably considerable back-and-forth on the measurement specifications and the testing. But we, I think have given a rich, vocabulary and encyclopedia, if you will, of the concepts of areas to measure.

I think it's a good time now and I don't know if, Sam, we want to turn it back to you. But I think it is a good time to start talking with the public.

Kate Buchanan: Thank you so much (Cheryl). This is Kate Buchanan. So, this is an opportunity for members of the public to comment. I want to provide a couple of, kind of, overview comments. We receive many - much, much public participation on these calls. So, there are many, many wonderful feedback items we got via the chat function.

We haven't been able to respond to all of them. But we do share them. So, everything that is written to chat is downloaded and is not only shared with staff, it is shared with the committee members and the liaisons. It is posted on the Project Page.

So, all of the resources, people have been sending links. People have been sending questions, resources - all of that is used and shared. So, I just wanted to preface that. So, if people who had written something in the chatbot didn't want to then say it aloud, we do want you to know that this information has been kept and the resources have been kept.

Another thing we wanted to say is that some of you may have been put on mute because we heard some ambient noise coming from your line. So, in order to unmute yourself, it's Star 7. So, if you would like to make a public comment, you are able to do so either through the phone or through the chatbot.

What we're going to do is, I'm actually not going to go back and read the public comments we've received so far, since we've received 50 to 60. So, moving forward, I'll read public comments that we get in the chatbot, but I did also want to give anyone the opportunity to, if they have comments, to say them aloud.

So, I'll take a breath here and ask if there is anyone who would like to comment via the phone?

Judy (Styke): Hello.

Kate Buchanan: Yes.

Judy (Styke): Hi, my name is Judy (Styke). I'm calling from Wisconsin and this has really been a very interesting discussion to listen to. And as I'm listening, I'm kind of thinking, you know, overall, ultimately some consideration for what the final product is, is how can the whole thing be kept simple. In terms of the audience for this - the Outcomes of this Project and whether or not it's going to be feasible for (stat) audience to actually be able to collect data, to compute the measures.

And so, kind of keeping that in mind, with regard to not making it too complex or too minute, because when you look across states, the System has various ways of being able to collect data and we want to keep it flat enough

so that there could be greater ease for collection of data from state-to-state. So, I was looking back at the Interim Report and looking at the title itself, as Person (Unintelligible) Project, that consists of the definition and then you do talk about System Characteristics.

And I'm kind of thinking about what the discussion was about System Level Measures and what the domain should be. And so, I just offered the suggestion of the idea that there be a definition of Person Centered Planning and then that the group itself would prioritize what they see to be the ideal characteristics for a Person Centered Planning System.

And that is when speaking about System, rather than the System in terms of the Healthcare System or the Social Service System, but that - we're talking here about a Person Centered Planning System. And what should that look like. What would be an ideal Person Considered and Planning System?

And then within the context of that, think about the Structural Measures, Process Measures, and Outcome Measures that relate back to the discussions that were held related to what should be part of a Person Centered Plan? What should be from an Incompetency of Facilitation? I think of those, for example, having structural measures in the domain of what should a Person Centered Plan include? And then also structural measures related to what facilitation should include. Process Measures for Person Centered Planning Facilitation.

Outcome Measures for Person Centered Planning of facilitation. And kind of simplify it a little bit that way and then the overall gist of it is that as we look at those measures, those all feedback into what a Person Centered Planning System would look like. And I use the word System kind of loosely here, because we don't necessarily think of Person Centered Planning as a System.

But in terms of this project, that's kind of the overarching objective to achieve is what is Person Centered Planning? What should it look like? And how can we then measure it? And by measuring it we break it down into the couple of domains, a Person Centered Planning and Facilitation.

And then within those domains, with all the different discussions that have occurred about what should be the plan or what Facilitation should look like, then I would suggest that the group consider prioritizing what is most important about planning and what is most important about Facilitation.

Because there's a lot of layers that want to go down into. But when you're thinking broadly and what could be applicable for whoever the audience is for this project, whether that be the federal level, the state level or regional level, it needs to be broad enough so that it's going to meaningful for that audience.

So, the other pieces are two - I mentioned a bit earlier, is the capacity to collect the data. It's challenging sometimes to find the right resources to be able to collect the data. So, it may be easier to keep it higher level than to get too far into the trenches with what we want to know.

And technically, in a good plan, the - irrespective of this piece, the person themselves, as well as the care team that's working with them, the support team that's working with them, should ideally also be evaluating between themselves, about how is it working for that person.

And so, I just think if it's too different levels, one is a broader one national focus, versus a smaller, more individual focus, and I guess I'm seeing this project as more of a national focus as opposed to individual. So, that's it. Thank you.

Kate Buchanan Thank you. Thank you. Anybody else on public comments?

((Crosstalk))

Kate Buchanan: Oh, go ahead.

(Allen Rosen): No problem. This is (Allen Rosen). And I was offering additional comments on my submit to the chatbot. But one of the things that may help in putting this in context is what may come out of the committee's report may also be a roadmap, in that not necessarily everything has to be accomplished or set up initially, because it may be too overwhelming or may get too bogged down. And in some of these ideals, if we consider advanced directives as an example, not only assessing the entities and parties that track it, understand it, and use it - but then over time, how is that information recorded? How is it then disseminated?

So, going to the Person Centered Planning and Practices, once you have a plan, what happens afterwards? Is it disseminated to, not just the clinicians involved or the settings, but important recognition for social determinants of health, has the individual for that particular plan reviewed it, agreed, or their legal representative?

And has it been shared with other community networks and systems approved by that person or their representative because just having a plan while the process can be very beneficial, it'll be important to understand who uses it? When, and any outcomes that get measured afterwards, will also need to be correlated when that plan was created or those wishes were all relevant entities aware of it and able to access it.

I just wanted to add that. I'm also more than willing to answer any questions on prior comments. Thanks for the efforts of everyone involved.

Kate Buchanan: Thank you. So, yes, two very good points. One is that we need to think of this as a roadmap and not have better (unintelligible) good and so overwhelmed with the details that it can't get accomplished. But there also needs to be an awareness of the overall impact. Is, this is actually doing what we were hoping it would accomplish. And so, all of those are remarkable considerations.

Anything else from public comments? And as Gretchen has pointed out, if you've already heard your comments, you can just echo it on the chatbot, but we don't need to necessarily restate them. But if there are ideas or thoughts that have not yet been mentioned, that you think are important for the group to hear, please share.

But do know, that the comments in chat do not just get lost. They are captured as well and the become part of the documentation of this discussion. Gretchen, I can turn back to you too, so that I'm not dominating this conversation.

(Gretchen): Well I think, I'm so excited about the progress that was made today, I feel like the diversity of opinions and experience that has contributed, so that's just really going to make us end up with a much better Out-Product. So, I thank you all again for your participation today.

Kate Buchanan: Great. Well I will (unintelligible) our colleague (Yvonne) for our next step.

(Yvonne): Thank you very much Kate. Well thank you everybody for (this is for discussion). We'll be sure to reflect your feedback in the development of the

paper. I just wanted to go through the Project Timeline. So, our next meeting is going to be on February 3rd. We'll be posting reading materials as soon as they become available on the project page. So, we're going to probably do all of to subscribe to the Project Alert if you have not yet done so.

And during this meeting, we will aim to finalize the draft measurement framework prior to public commenting. So, we're going to gather committee input on the PCP Research Agenda as well. So, we'll take into consideration what was shared today and make sure that we update the Draft Measurement Framework and then we will also seek committee input on the PCP Research Agenda.

Our next meeting after that, will be the 8th, our final Web Meeting. Which will be to review the Public comments received on the comprehensive draft of those points. I just want to go to the next Slide to mention when those dates will be. We will have a 30-day public commenting, that will run from April 8th to May 28th - May 8th. sorry about that. May 8, 2020. And in this final report we will include the portions that we had in the interim draft report, as well as what we are discussing after in (this year) which is Framework for PCP Measurement Development, the Research Agenda, as well as the Environmental Scan.

Next, as usual, our contacts - feel free to email us any other resources or comments that you may have. We have our email address projected there on the screen. We have our telephone number. The Project Page where you can access Project Materials. The SharePoint is supposed to be for the committee where we post resources that ae being important to them and the last link is that of the Project Alert Subscription.

I'll hand it over to my colleague to close this out.

Sam Stolpe: All right. Thanks very much. It just remains for us at NQF to say thank you so much for your participation today. We've really made some headway on breaking out of this Measurement Framework. We'll finalize some thoughts and input and we'll - the next time we'll be (unintelligible) will eventually be in the final publication as we put that out for draft. You'll have a chance once again to weigh in on it and add any additional thoughts or reactions that you have.

So, once again, on behalf of the staff, myself, Sam Stolpe, and Casey (Cannon) and (Yvonne Kollavanda), thank you so much for joining us today. Any closing remarks from our Co-Chairs?

(Cheryl): No, I think we're doing well and again thank you.

(Gretchen): I agree. This is Gretchen. Thank you all and we look forward to our next call.

Sam Stolpe: Very good. Happy New Year everybody. We'll talk again soon. Bye now.

(Cheryl): Bye-bye.

(Gretchen): Bye.

END