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Moderator: Marisa Scala Foley
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Coordinator: Welcome and thank you for standing by. Audio participants are in a listen-only mode for the duration of today's conference until the question and answer session. During the question and answer session to ask a question press star 1. State your name clearly when prompted. Today's conference is being recorded. If you have any objections you may disconnect at this time.

Now I would like to turn the meeting over to Ms. Marisa Scala Foley. Thank you, you may begin.

Marisa Scala Foley: Good morning everyone. Thank you all for being here today. My name is Marisa Scala Foley. I work in the Center for Disability and Aging Policy, the Administration for Community Living.

And we want to thank you all those of you who are in the room as well as those of you who are joining us virtually for being here today to be part of our meeting, putting the person at the center, integrating plans for long term services and support and healthcare delivery through health information technology. We thank you all for joining us today for what we believe is going to be a very exciting conversation.

A conversation that originated actually when our administrator from ACL Kathy Greenlee met with Dr. Karen DeSalvo the National Coordinator for Health Information Technology to talk about where they needed go in terms of integrating healthcare and long term services and support information through long term services - and long term services and support through health information technology.

So with the person themselves owning that record and really being the person who is driving their care or their services. So we thank you for joining us today. I'm going to give you a real brief overview of the day and then we'll have some housekeeping announcements and then we will move into opening remarks. So a couple of - just in terms of the day we will begin with opening remarks from Kathy Greenlee and from Karen DeSalvo.

Then we'll move into - our first couple of sessions are really designed to make sure that we have grounding in what we mean when we talk about person-centered planning which is an extremely important concept when it comes to the integration of services with a person whose needs and preferences is really driving all of that.

We will hear from Mary Lou Bourne who will provide that overview of person-centered planning. And then we will hear from John Moore who will talk about his own plan and what that means to him in - (and to add to listed price). We will then go from John Moore's presentation into first of our three panel presentations.

The first panel presentation Care Planning Technology and Integration, Bright Thoughts and a View From on the Ground. We'll do exactly what it says in terms of talking about where innovation is happening when it comes to

person-centered planning and the integration of healthcare and long term services and support information. Then we will take a break for lunch. After lunch we will come back. We will have two additional panels.

The first panel will talk about what are the - what the key issues and challenges are with regard to bringing all of this information together with the person at the center. And then we will have a panel that will talk about a policy reverse that can help to advance this work. And finally we will conclude the day by - with - we will have some concluding remarks and invite you all to help us think about action steps to move this agenda forward.

So that's a really quick overview of our day. But let me - I should mention if at any point those of you who are in the room or who are joining us virtually have trouble hearing please do notify us so that we can - okay - that we can try to troubleshoot it and make things work. So let me go through some of the housekeeping announcements for everyone.

First of all there are two sets of restrooms on this floor. There is one immediately on your left just past the registration desk outside the doors. The restrooms - there is another set of restrooms that is past the elevators on your left - or past the elevators. It'll be to your left. And there's a large restroom sign there.

Those are approached with automatic doors. If you are not an HHS employee and you need to leave the eighth floor we ask you to let us know so that because we will need to escort you back up on the elevators particularly if you leave the building.

And we'll talk more about that when we get to our lunch. There will be opportunities for questions and comments throughout the day particularly

after the three panel sessions that I mentioned earlier. When the time comes for those of you who are in the room or on the phone we will give you instructions as to how to queue up.

For those of you who are joining us on the web you can submit your questions anytime through the Chat function and go to webinar and we invite you to do that. We'll be tracking those and synthesizing them and we will answer those through the microphone when we take breaks for questions and public comments.

This meeting as you may have heard (Arlene) the operator mention this meeting is being recorded and transcribed. It will be publicly available the transcript and all materials will be available on the Web site, the ONC Web site after the event. That will be at http://www.healthit.gov/person-centered-care.

Again that's http://www.healthit.gov/person-centered-care. We also invite you to submit written comments or questions after the workshop. You can submit those to our dedicated email address which is personcenteredhealthit@hhs.gov. We will also put that information on the screen. We will have it up there at different times throughout the course of the day.

So with that I would like to start our opening remarks. I understand we were having some sound issues on the phone. We are - for those of you who are on the phone we are working to resolve those right now and we will try to make this experience as easy as possible for you to hear.

So we're working on adjusting the sound, know that we are working on that right now and we will continue to do so. But please do keep us posted it's - if there continue to be any issues. Okay.

With that I would like to introduce Kathy Greenlee who is the Administrator of the Administration for Community Living who will start things off with our opening remarks.

Kathy Greenlee: Good morning everyone. Good to see you all. I used to introduce myself as Kathy from Kansas for a long time. So I'm a happy baseball fan. Just wanted you all to know that. I'm glad you're here. Thank you for those of you who are on the phone.

Thank you Karen. As Marisa said this all started with a conversation with Karen. Karen began here at HHS ONC earlier this year and we would see each other in meetings. And it went something like this. We should meet. Like yes we should meet.

So this went on for several weeks. Meanwhile my staff started Karen to listen to what you were saying, and to pay attention to what you were doing out on the road in your to your approach to people and patients. So we knew by the time you and I had our first meeting that you were a friend in ACL and that was very clear in our first meeting. So we have plans that okay she's was a friend already, what are we going to ask her?

So it was very simple and obvious. And I went in and said can we do okay at it? What's one of the best kind of the ideas to move this work forward. And we talked about the need to kind of integrate the work and how could we introduce the people we know to each other.

So we had this meeting back in April and she and I showed up here this morning. And in the meantime our staff had done an incredible job of putting this all together. And it's just so- a wonderful example of the type of teamwork we have here at HHS.

So I really do want to get that out to Karen and her staff at ONC and our staff at ACL. You saw Marisa at the door. Many, many members of our team put this together including (Caroline), the other people kind of running the chats this morning with IT helping us put this together.

We also know that it's essential to have support from federal partners to (unintelligible), TMS, the Veterans Administration neither of which changed its acronym recently but it's the Institute of Support Research for People with Disabilities coming over from the Department of Ed. to ACL to make that an essential partner today.

And you won't see when this morning that we've included John Moore who's a consumer because we think it's very important to be grounded in consumer experience as we do this work.

What Karen and I talked about when we had our meeting what's really a reflection of where we are which is what we're hoping to tackle today. There has been a significant move forward in the entire mission of the ONC in the development of health records focused primarily I think at least on hospitals and doctors.

Meanwhile in our world long term supports and services we know that community organizations provide critical supports to people. And those people really need to be put in. They have - there hasn't been the same

investment in community-based services that there has in the clinical/medical settings.

And we really need to talk about how to bridge across community settings, health information systems, long term supports and services while keeping the person at the center and their family.

You will hear us talk today in a different way about language what we usually refer to at ACL as person-centeredness, person-centered plan. That's our general approach to the world having come from an area of long term supports and services. It's also reflected in the Affordable Care Act especially Section 2402 when we're really talking about the new person-centered planning.

So good morning as we start to really focus there at the beginning as a way to ground us all and introduce us all to at least our concept of what person-centered planning is and how fundamental it is to everything that falls from there in terms of helping support the individual in a holistic manner. And it really includes what our goals and hopes and visions of the person? What do they want? What do they in their lives whether they're formal or informal.

And it's a slightly different approach or maybe a fundamentally different approach than having healthcare professionals decide what we should do for someone but instead what we should do to support someone based on what their goals are. And it really involves a team of organizations, a team of individuals to support true person-centered planning, that's very fundamental.

So what you will hear this morning after Karen and I have both had a chance to say good morning is Mary Lou Bourne talk about person-centered planning, give us all some specific training on that, talk about the need to transform our

healthcare system in regard to access, quality healthcare outcomes and how we make this all work with regard to healthcare delivery, HealthIT.

And Karen and I talked about this in our very first meeting. How do the records that we provide, how does this system that we're developing become the ownership of the consumer? How is this really grounded in their life and their experience? That's what we hope to achieve today a grounding, an introduction. So I would like to thank all of you who are joining us on the panel throughout the day. I'll be here most of the day.

We've really attempted to bring different people together and I hope you will see that we're talking in very parallel tracks. They're not necessarily converging. And I think that's what we're trying to do today is we're all talking along the same lines. How can we talk together in terms of where this whole goal is taking us?

Please don't let language get in your way today. We know that part of the world we intersect in long term supports and services, the healthcare side is that we do come from different fields, different professions, different orientations. There are people who always talk about patients, there's us who always talk about persons.

And really those are not areas or signals that they're a signal of an intersection between two different worlds and this is a positive and that we need to find a way to have these conversations together, to translate across the field to come out with a good holistic approach and how we can be seamless across the fields of community-based services, long term supports and services and healthcare.

So that's what we're hoping to achieve today. It's a fundamental mission that we have at ACL to continue to have conversations and dialogue, to hope to maximize in every way we can the independents and help people with disabilities and older adults and their families. So this is a good alignment of the stars.

And I again want to thank everybody who's participated in getting us here, everyone who will be here today and I think that even though it's taken hours of work to get to this morning we arrived from where we started and that's in fact what we knew from the beginning that Karen was our friend and ally so I look forward to doing this work with her. Thank you. Come on up.

Karen DeSalvo: Well now people like Kathy are what makes my job so wonderful. And I just want to thank you for being so warm and welcoming and also capable of experience and thoughtful about the work that we have to do together.

She told the story very well so I won't repeat it because it's all true and it was a really perfect timing actually and the perfect moment that we were beginning to think about how ONC could increasingly play a critical role in the work that we are doing here at HHS.

Which is to see that everyone in the country has a chance at the kind of health that will bring them the quality of life and vitality that will allow them to do what they love to do every day with the people that they love in the places that they love in the ways that they love.

This is what drives us, gets us to come here and stay late and to try to broaden our (hand) as much as possible and our thinking so that we're considering how to improve care but also improve health. And one thing I do know is that if

we're going to improve the health of this country we've got to do an awful lot more conjunctive through the healthcare system.

And we have to do that well beyond the providers who require the Meaningful Use Program who have been able to adopt and ditch time for the care experience. And that's going to require some thinking at the partnership well outside of the great partnerships we've already had at ONC and within the government and externally.

And so as I stepped in the door of the ten year mark of ONC's life and I looked at the team and said this is great. We've done amazing work and we're helping to advance better care and better health for the country. So let's take a minute to think about where we need to go in the next decade, how we can best serve our primary customer which is every individual out there.

And that sounds like an easy conversation but as you can imagine in a very tactical world that we've been living in off of the HITECH apps so I'm going to translate some of this in a minute.

We will really focus on a set of providers who require the Meaningful Use Program or part of our grant program and ensuring their success because we felt a responsibility around from almost $30 billion that had been entrusted to us to see if we could advance, that the participation of healthcare experience in improvement of health and care in the community.

We'll stop for a minute for those of you who are not from our world. So I don't want you to get stuck on language and make sure I explain who ONC is, the Office of the National Coordinator for Health Information Technology and explain to you a little bit about what I mean when I say that we've been

focused on HITECH and why that's necessary but not sufficient and where we want to go next.

So the Office of the National Coordinator was created actually a decade ago by President Bush. It was very important to be created by people who were from the world of public health so they understood that there was a care continuum and a health continuum beyond healthcare, that they were thinking about the work that we needed to do to coordinate the federal government HealthIT policy.

They were also understanding that we needed to work with state and with the private sector to really drive change in such a way that information would become available when where it mattered most to inform, engage, empower individuals and consumers and providers in the healthcare continuum.

And now regarding many others beyond who are in the innovation stage or scientific phase or the safety phase who want to use that information to the betterment of people in the country.

In 2009 ONC was put into law essentially in the HITECH Act which is part of the Stimulus Act and that provided for a program that is called Meaningful Use beloved by all of the country which it asks for acts of providers who are eligible, providers of professionals do certain things with certified electronic health records and for that would be rewarded financially or over time be penalized if they did not function in that way.

We are in what we call the second stage of that program. The first stage was successful and what you should know about your country is that we now have about 97% of Medicare discharges in our country happening as the healthcare environment that's (dish tied). So there's a (dishful) imprinter record, there's

data that's being collected and in some cases aggregated about that healthcare experience for the person.

And that's where the 90% of the hospitals have the doctor's electronic healthcare group and more than 3/4 of (sedition). As one very old black person on our quality committee said yesterday that (break) the glass was half full but it's a little glass.

And if you step back and you realize that that is just eligible providers and professionals you miss some of the most in my opinion important parts of the care continuum and it's not just long term forms of acute care or the kind of institutional care that comes to mind is healthcare.

It's not even just behavioral health. But there's another world beyond which impacts people's health. And I'm preaching to the choir I think for this group but I want to make sure that you all understand that we know at ONC that our work is only just beginning.

And that what we have to do is broaden our view of what contributes to health, make certain that whatever policy and technology framework that we're developing for our country going forward that it is able to handle, protect, include, support, advance help beyond healthcare.

Help that includes social determinants, help that includes community-based support, help that allows people the kind of dignity and opportunity to age and place, day and place that they all deserve. This is no small task.

It has been our work for the last two months to take that breath, look out on the horizon, see what else is there, see what's happening in the community to

help shape our priorities for the federal government. We do that through the federal HealthIT strategic planning process.

The good news is that in the last six months of that work we never once had any pushback from leadership across the federal government, from NASA to (FPC) to (BADRD) and the HHS family, the health informant healthcare and that the HealthIT infrastructure that we need to get there is going to be much more than electronic health records.

And that we all have to sort out what policy and other levers we have to put forward that go beyond the Meaningful Use Program or any simple grant program. I want to say in addition to strategic priorities and thinking through what that pathology and policy framework would be we worked discreetly on some projects.

And I just want to give a nod to Kelly Cronin who's here today who you will hear from. Kelly is a champion for reminding all of us that there is a care continuum well beyond the Meaningful Use Program. And she scours the world every day, she and her team to find ways that we can advance the collection sharing the use of appropriate health information.

That has been (dish tied) so that we're not just stuck sitting on the Meaningful Use but thinking much more broadly. She was doing that well before I walked in the door. And that work is really going to have to ramp up because we can't leave stuff behind. We work on certifications programs so when we're ready and we have a (dishful) of our electronic health records they'll be products that can plug and play.

And we're working on developing electronic care support mechanisms that really are more person-centered and not institutionally-centered which is

really where one and - the biggest - all those are stretches as you might imagine for people who are living in (unintelligible) and trying to do the right thing every day.

But I think the bigger stretch for us and the bigger question that I want you all to help us understand is in a perfect world I won't put a timeline on it if we had really person-centered care what is the kind of person-centered health information technology infrastructure that that would require?

Right now most of our data is institutionally-based so we're free from (recalling) electronic health records that are owned by institutions. And those data is under the control of the consumer. It's not wrapped around them in that way.

It's sort of a longitudinal view of our health in ways you might wish and hope and the way you have for your financial data for example. And so as we're thinking about the future we want to make sure that our work in technology mirrors this sort of work in person-centeredness so that we don't cause extra burden for people and families and caregivers and others that they might understand the full picture of the people for whom they're caring.

And that kind of policy and technology framework is the biggest work I think we have ahead. And the policy work which I think we'll talk a little bit more about today is where I really need some help to lay in. Now I'll be very specific and I'll talk about governance and then I'll stop. The governance piece of this data - and what do I mean by that?

I mean if you're going to - if we're going to continue to (dish talk) the care and health experience of people in our country there will be enormous amounts of data collected that will need to be shared, aggregated and used.

But that data requires a trust framework. It requires us to understand as a country who should have access to it, what should we use it for, what happens to bad actors when they misuse the data in some ways for discrimination or other purposes.

And right now as we're thinking through our responsibilities as a national coordinator to support and assist better health for the country I want to make sure that we don't miss this important issue about data not just being fun to collect or fun to use but that there's a real responsibility in that.

And that the governance of that data going forward for this country is it's important for us to think about, it's important for us to design well because we have to make sure the right people are at the table making their decisions about that data and not just the traditional actors who have been in the HealthIT services but the broader family that we want to include and you all are part of that.

So I thank you so much for making time today. This is going to really help us understand what we need to be doing on behalf of this community and others like you.

We want to partner, we want this to be the beginning of a conversation, we want you to know as I said to Kathy that day you are more than welcome in the work that we do you are critical to the work that we do because this country's not going to move forward unless we really understand that health is much more than getting people to the doctor. Thank you all very much.

Marisa Scala Foley: All right, thank you to both Kathy and Karen for kicking us off. It was really a wonderful way of providing a foundation for what you're going to

hear today and the work that we're going to do together today here in the room.

And now I'd like to invite Kathy up to introduce our first speaker, Mary Lou Bourne.

Kathy Greenlee: And let me say there are many of us in the room and I know on the phone who've done this work for decades. And we'd just like to know where you've been all our lives because this is really music to our ears and we're very excited about your approach in this partnership. So thank you.

Let me introduce our next speaker and tell you a little bit about her. Since 1997 Mary Lou Bourne's career has focused on supporting human service systems interested in redesigning their organizational structures and aligning their work culture to become person centered organizations.

She has over 29 years of experience in human service systems including mental health services, Veteran support, early intervention, substance abuse, aging and developmental disability service delivery.

As a former Executive Director for a service provider agency Mary Lou has developed a strong interest in supporting executive teams from government and private organizations to successfully implement transformational change.

From her early experience on Pennsylvania's Statewide Representative for Young Leaders on the President's Committee on DDs. Through recent work with transforming the infrastructure in several statewide systems her work has focused on change.

She has consulted and trained in more than 22 states in the U.S. Her current practice includes large scale systemic change and the development of methods to support a learning culture within government funded human service systems.

She's a mentor/trainer for the learning community for persons in her practice and has supported the development of persons in her practices across the U.S. and in the U.K. I'm almost done.

Mary Lou is a partner in Support Development Associates and has been appointed the Malcolm Baldrige National Program Examiner four times, serves as faculty to the National Leadership Institute on Developmental Disabilities. She currently lives here.

So we're glad to have you here. We're looking forward to what you have to teach us because we are all about system change. So welcome.

Mary Lou Bourne: Thank you. Thanks Kathy. So I'm going to hit my little timer here and make sure I try to do a decent job staying on time. Thank you very much. It's a little embarrassing to hear all those things. Thank you very much though Kathy.

And I just have to reiterate so thrilled to hear Karen DeSalvo. Never thought I would hear somebody say these three things in an opening remark at the federal level, the people we love matter the most, data is fun and person-centeredness matters.

That does - talk about making your heart sing. Really incredible to put those three things together. There's lots of people in the world who think those three things don't fit together. And we really believe they do.

So we are just going to jump kind of right into person-centered planning. And some of the foundation I'm hoping that I can provide for you is a little bit of a framework for the rest of your thoughts not only today but as you go forward with the design and development that people are facing.

One of the things that I had considered doing was helping people understand the misconceptions when I was trying to put together how do you get this across in a relatively short period of time.

Sometimes using the misconception really works. I decided not to do that mainly because I think as I will tell stories to you as we go forward you'll really start to understand that some of the misconceptions of person-centered planning which I can summarize really quickly. It takes too long. And it's only dream-oriented. And it's not grounded in reality.

That's what we hear very frequently about person-centered planning. And we've been really trying to help people understand none of that needs to be true. It's how you design and how you create the boundaries and the standards for it.

So this is one way that we frequently describe it. And that is to really understand the unique characteristics of that person so that they have control in their life. We can almost end there but we also recognize that it's a crucial piece that people contribute to and are valued by their communities.

And so how do we make sure that the services in long term support make that happen and don't interfere? What we see very frequently is long term systems interfere with people actually being able to be valued and create value for the community. So we'll talk a little bit more about that.

And then it's relationships that really matter. I hear very frequently physical disabilities and people start talking about physical healthcare as if it is something that is completely separated and how is it different from long term support.

And what I try to help people understand is long term services and support, it's my life. It's day to day. It's in and out of the shower in the morning. It's the end of the day. It's the friends I see in between.

It's not something that happens occasionally when I need to visit the physician, when I need to visit nurses, when I have something that needs to be done to me. This is my life. This - most of us don't want to frame our life by what's wrong with us.

And I'll give you a little more insight into that in a minute. We also - and this was what I heard Karen mention person-centeredness. Jamie had to hold onto me so I didn't start jumping up and down in joy.

We really try to help people get that in order to do effective person-centered planning you have to start with person-centered thinking. And what does that actually mean? We do a lot of - we spend a lot of time helping think that through.

And then at the bottom of this it's really going to lead to a person-centered system. So developing a person-centered plan is going to help people have a good piece of paper or in this world, in this room a good electronic file.

But what we're really interested in is how can an electronic file help people have a good life and the good life that they're looking for? So good planning

has to result in implementation. That takes thinking and a system that's behind it.

You're going to hear a lot more about this from our friends from Ohio when they talk to you about the system that they've developed that they realized had to be - the whole system needed to be person-centered.

From the time a family picks up the phone and says we really think we need to talk to somebody or we need some help all the way through a contract in place and you're delivering services and you're monitoring them now. How does a system be person-centered at its core?

So this - core values again love (and critical) core values that are part of the Office of the National Coordinator really looking at or we're talking about do people have control of their life? Do we recognize people for what they have accomplished and can potentially accomplish? Are we looking at the talents that we're committed to focusing on the talents and the abilities that people have to offer?

Or are we focused primarily on what's wrong with somebody? What needs to be fixed? What we have to address? Another core value is that the person is the expert in their own life instead of a whole army of professionals that surround them and convince that family or that individual that they are the experts?

And so switching the power that happens in a meeting so that people really are recognized as the experts in their own lives is a key piece of creating a person-centered system. Your language really does matter.

And let me just - we had a little discussion about whether or not I would be introduced this way but let me just share with you how we would introduce me to you if I was really engaged in most long term care systems.

And that would be Kathy would have said to you this morning this is Mary Lou Bourne. She is a 50 something year old Caucasian woman who is slightly overweight, has a history of presbyopia and ovarian cancer.

She's got a mild obsessive compulsive disorder, intermittent explosive disorder neither of which have been formally diagnosed by her psychiatrist, needs support at work, occasionally she gets off task and is my husband said chronically behind in her work.

So that's how we introduce people who then also say are the most vulnerable and expect that they're going to be able to overcome that. So we don't say this is Mary Lou Bourne. She's been involved in (unintelligible). She has started four companies.

She's really into gardening. Loves to hear about the Civil War. She'll talk to you forever about it if you're an expert in that. She really cares about her family and is focused on taking care of other people.

Totally different introduction. And so what you expect is completely lead by how you're introduced to somebody. And when we talk about HealthIT systems one of the first things that we say and I really help people and again you're going to hear about this from Ohio sequence matters. What you say first really matters and how you say it.

How you introduce people really has a lot to do with what the system that expects their job is and how they'll interact with people. This is that piece.

This is exactly what I just said. Creating an effective electronic record is really not helpful if it doesn't help the person have the life that they want to lead.

So we start with two very simple concepts and we try to help people really understand that they are distinct and integrated at the same time. What's important to an individual? What's important to any of us?

If I ask most of you in this room right now to raise your hand about what's most important to you about 90% of you would say another person, a relationship with somebody whether it's friends, neighbors, family, somebody, a significant other.

The other 5 to 10% is split between working out and exercising spirituality. Status and control. Having a valued role. Being treated like an adult. Being treated like the person who like if I'm 80 years old and I have accomplished tremendous things in my life and I'm now totally dependent on others.

I still want the status. I still want to be treated like an adult. If I'm somebody who has used substances and abused alcohol or drugs for a period of time I don't want you to define me that way.

I still want to have status. I want to be treated like a person who has value and has an opportunity to contribute. Those are the two most important. And from there rituals and routine, both culture and personal. Rhythm, pace of life, are you go, go, go, go, go? Or are you yes I'm going to mosey into things? Give me a chance. Are you in charge of your own schedule?

Things to look forward to. It's really missing for a lot of people in long term support. All of us really - we can put up with a lot of other stuff when we have

something to look forward to. There's a whole lot of people that long term support are engaged with that have very, very little to look forward to.

Promises are broken quite often. So how do we - these are the things that we identify as what's important to - what's important for. Things that other people see as necessary in our life. Now this doesn't mean that I don't pay attention to it. It just means that I don't necessarily want to have to do it.

I'll put up with it. Taxes. Anybody in the room say love April 15, you know? I just love paying my taxes. None of us do. But we all put up with it and we all know it's important for us either not to go to jail or so that we can have interesting discussions at the cocktail party.

But it's important for you to follow the rules of society. To be an effective citizen. And these are things that society requires of us. One of the examples I use is in the United States it's really important for us, society's health, is it written - I don't think it's written down anywhere in Congress but it might be at this point actually in the Federal Register.

You need to not smell that. Societal expectations. You need to not smell that. Anybody here that rides public transportation will attest to how you feel when somebody comes on. But some folks don't pay attention to that.

They understand it's important for them or maybe they don't really understand it's important for them. And they're going to need support in that area. But it doesn't mean that we use that to take over their entire life.

And that's where the long term system really - where we have to help people understand do we have to assess absolutely everything about a person's life?

Or is it just one small area? So important four, the things that get assessed, prevention of illness, treatment of illness, medical condition, wellness.

Safety. How a person defines their own safety really matters. So someone who lives in the city, has lived in the city all their life they're very comfortable with that. Someone who lives in the country no way they're going to feel safe in the city perhaps.

But we have to be able to define it according to that individual, what that individual is willing to take a risk on and not. The whole risk management and how IT addresses risk, identifies risk and then clearly describes how this is going to be addressed with the people who love this person the most.

So this an important piece. Health and safety dictating lifestyle means we only pay attention to important four. We feel that important four is what needs to be brought forth into - and all of our systems of documentation, all of our system of electronic health records focuses on what's wrong and how we can fix it, how we can make sure you stay healthy.

When we're in a situation like this important two doesn't necessarily - isn't being paid attention to then you have people who are very unhappy. You have people who are then typically labeled as combative, non-compliant. And we wonder why.

And it's because we're approaching things as if all that matters is that diagnosis and whether or not you're complying with and following through with the recommendations that were made by professionals in your life.

Tell you a quick story about a young man - not a young man, a man named (Sam) who lives in I guess it would be actually considered the bayou in

Louisiana. (Sam) was somebody who hospitality really matters to him. It's really important to him to help people feel comfortable and taken care of especially when they come to visit him in his house.

(Sam) has two daughters. Both of them live pretty far away from him. Both of them love him very much and just was a matter of economics and they can't live close by. (Sam) is also somebody who was a builder all of his life, very proud of his carpentry skills. Took care of his daughters quite well through that and then himself.

(Sam) is now pushing 80 and who is a Vietnam veteran. He is actually going through end of life care. And (Sam)'s daughter (Tanya) got a call one day from the folks who were providing daily IV medication and some daily support in his home.

And they were very concerned and wanted her permission over the phone to provide other medications because as they said (Sam) was combative. And he was being aggressive and she actually said he tells some pretty off color jokes. Are you sure it's not just his bad jokes?

They said no, no, no he's really fighting us. So (Tanya) asked a few more questions and long story short it turns out (Sam) has spent his entire days waking up and there are two things that he always does.

One is check on the birds outside and make sure that the hummingbird feeders are full. And so that is very much a part of his life. The other thing is if you come to his house he wants you to have some type of a drink.

He's going to offer you lemonade, ice tea, something more than that. Doesn't necessarily matter if it's noon or not at (Sam)'s house if he's offering you tea.

And he wants you to accept. And so a simple thing what's important to him that people give him a chance to be hospitable.

And that he knows the hummingbirds are taken care of. And what he was trying to get across to them was I need you to take care of the hummingbirds. Can you check and see? And would you have a drink of lemonade or a tea or maybe a Budweiser with me?

So people - as soon as they addressed that and as soon as (Tanya) was successful in helping them to understand that needed to be written down, things got better for (Sam). Until there was a different staff person with him. And that information never got passed on.

So those are not the kinds of things we typically write down. They're not the kinds of things that we typically share with each other. And in that situation they were dictating that what they were recommending was not only further medication but they really felt that he needed to be moved to a nursing home so he could be restrained.

So that he wouldn't continue to pull out - he was just refusing to allow them to do his IV until he knew everything else was taken care of. So in that situation they were really recommending further much more intensive and much more life limiting support only because they weren't paying attention to the things that really mattered to him.

All choice and no responsibility is the reputation of person-centered planning. People often say it's their choice. Here we have to do - are you saying we have to do anything the person wants? I'll never forget one of my first experiences many, many years ago now was around people saying look, you know, if this guy wants to live in a house on the Rhine don't we have to plan for that?

It's like not with Medicaid dollars you don't. I'm not sure about you but I'm pretty sure I'm not going to be planning that paper. So - but it's the dream, you know, it's the whole idea of we have to do whatever somebody wants.

And so person-centered planning means we can't even talk about health and safety. That would be neglect. There's a great quote and I might be paraphrasing it just a little tiny bit from (John O'Brien) that is abandoning people to choice is a form of neglect. So this is the reputation. This is what people tend to think about person-centered planning. And it's what we say completely unacceptable. We can't do that.

There's a gentleman in - well it's not too far from here actually who - he's rather hard to understand. He needs total physical support from other people. And he really - it's very important to him that he's in charge of his own schedule and that he makes decisions again that he be treated like an adult.

Same situation. Staff on the weekend knew what was up. Staff during the week didn't know. This one little crucial piece when he was in the shower. And they knew that they were to listen to him and do what he said.

And as they were trying to put the seatbelt on him in the shower chair he began saying no, no, no, no, no. They assumed that meant didn't want the seatbelt on and of course he slipped, he fell off the shower chair, broke a hip.

Not okay. Absolutely not okay. When they talked to the weekend staff they said oh when he says that it just means he wants you to put a towel underneath the seatbelt because it scratches, it's itchy and, you know, in an area where none of us really want to be scratchy or itchy.

So people really didn't understand that this idea of all choice not okay. What we're shooting for and what your records really need to be thinking about is finding that balance. We need to do both hands.

We need to pay attention to what's important to the individual. What's the context of their life? What drives them to do the things that they do? And then how can we support and provide support for healthcare, other types of services in the background.

How can we fit it into the context of that individual's life? What you decide to write down, what you ask gets written down. What you require in that documentation system has a whole lot to do with it.

I've spent a lot of time with direct care staff. And they will tell us and we always ask them what's the most important part of your job? Paperwork. How do you know that? My supervisor asks me about it all the time.

So when you really talk to them and say but what really matters in your work? They'll say well absolutely the relationship I have with my friend John who you're going to meet in a few minutes, you know, the relationship I have with my supervisor. Really cares about the paperwork.

So when we're talking about electronic records we really need to think about what we're asking people to write down or record however they're recording it and how important that is.

And how much that influences their understanding of what their job is. So that's what this slide is saying to you, you know, the idea that it's either/or. We're really hung up on it's either someone is happy or they're healthy and safe.

We have to help people get past that and understand - every one of us in this room, our life is both hands. We are happy. We are satisfied. We're content mostly because we're in control. And we manage our health. We manage our safety. We manage how we make contributions to our community, ourselves.

For people who need support we can't get them started right from the beginning six steps backwards. And how we present information and what we talk about causes people to be that much further behind.

So as a system we really have to understand some of it is the infrastructure that we've created that's making this happen. Just a quick word on choice because this is a really big part of this discussion. It's several levels.

So when people have - everybody needs to have choices. But choice never happens without boundaries. All of us live within boundaries whether it's the rules - again the rules imposed by society, our own values, our personal values about what is and isn't okay.

Sometimes, you know, the ripple effect, where I choose to live. I used to live in central Pennsylvania three and a half hours away. My husband worked about six blocks from the White House. He has for the last 12 years.

So some of our decisions about where I live and what work I do had an impact on my relationships and how we saw each other and how much time he had to see our children. We all have boundaries. We can't have it all basically is what this is saying.

Finances and time. Time that's available sets limits on our choices. We have to make sure though that one middle sentence says options have to be from among things people find desirable.

It's a really simple way to explain it to you. So if you're saying that choice means pick, pick between a few. If someone is vegetarian - I actually heard somebody in the room today say they were looking for a vegetarian restaurant just as we walked in this morning.

So someone who's vegetarian or vegan if I take them into a butcher shop and say pick anything you want is that the choice for them? So why isn't it a choice? Because it doesn't even start to be something that they would find desirable.

And long term care systems tend to do that a little bit. So would you like this type of home or that type of home? Well no, no, no we'd really like to stay at home, at our own home. We'd like to figure this out.

Would you like this place to spend your day or that place to spend your day? Well I was really thinking more a job like a day treatment right now. We think you need day treatment for these reasons.

And so options need to be among - so we need to start - our very first question, the first time we talk to families on the phone what's a good day like for your mom? What's a bad day like for your mom? What kind of support would you like?

What are you hoping the future will look like? What can we do to support you in the way life has been and you want it to continue to be instead of I've got these four waiting lists, which one would you like to be on?

So really helping people understand that options. And then that last piece. Boundaries frequently exist due to the inefficiency of the system. We create a lot of boundaries for people based on - I have ten minutes to talk to you.

I have to find out all these things and so I'm really moving to important four because I only have ten minutes to talk to you. So I have to get - I know all that other stuff, yes, yes, yes, that matters. But I need to get to the important four.

Operating hours, available staff, policies and confusion. So I was in a place just very recently where the policy is family visitation is - and this is a group home - family visitation is between 4:00 and 6:00 Monday through Friday and a couple hours on Saturday.

Are you kidding me? It's the only time? And so we have inadvertently inserted ourselves between people and their families and said well-meaning it's okay, it's okay, it's okay, we'll take care of things.

So person-centeredness means we really have to stay focused on what matters the most to - oftentimes relationships with people we love. And we have to make sure that - understand the system. I mean I get the system is what it is and it has limits. But we have to really check ourselves and see when are those limits of the system really interfering with assuring what's important to somebody's health.

So some of the key elements. This is really a big piece of it, the power struggle. The power - I shouldn't even say struggle. I will take that back. The power differential that exists in a planning meeting.

For professionals we really have to pay attention to that. We really have to understand that there are many, many, many people that one of the things that's important to them is listening to authority and you're an authority figure.

So if you've got three professionals sitting in a room with a parent and her 18 year old daughter or with a 50 year old daughter and her 75 year old mom and they're trying to figure out what life can be like.

And all of you as professionals, all of us as professionals are saying you have to do this and we have to do that. And it's all about health, safety and required rules. We have the obligation to make sure that we make the power switch.

That we say we're really interested in knowing how you want life to be. It really matters to us to first hear what should your life be like and what are the things you're looking for? And then we'll help you figure out how that can happen.

So that's one of the very first pieces for me is that we have the obligation to understand the power difference in there and understanding that people and their loved ones are the experts in their lives.

These are all of the others - we have to describe - we have to start with abilities and strengths. We have to understand that risk is an opportunity to learn. Risk is an opportunity to learn. Risk is not necessarily something to be completely mitigated and avoided and taken care of at all costs.

We have to understand that people learn from taking negotiated risks. So we have to start talking about what's - and I can just - from my own experience really quick story. I was - a word that I always forget - neutropenic for a while in the middle of chemotherapy.

It happened to be right before Christmas. And the doctor called me, you know, you really need to be careful. Levels are really, really low, no fresh vegetables, no seafood, no shellfish, none of blah, blah, blah. Don't be around people. Stay away from crowds. It's December 23 are you kidding? I'm the youngest of eight.

I have 47 people in my family that all get together on the 26th of December every year. I'm not skipping it. It's just like I can't - I got to tell you, you can't do that. You can't go there. You got to wear a mask. I'm not wearing a mask. So what did I do?

I negotiated that risk myself. Talked to my family who are also kind of jumping up and down and saying you got to listen to the doctor. But what we did was we showed up, I didn't wear a mask and I said no hugs, can't really shake your hand, can't kiss, no, no, no, you got - I can't really get close to you and I had a wonderful time and I didn't get sick.

So negotiating risk is a negotiation. Let's talk this through. What can I do? What are my options? Telling people you must do this because I have to cover my butt because I have to make sure that I've addressed the liability if I don't? I get that.

But there also has to be an open - one of the core values in this - in the ONC around electronic HealthIT system was about bringing patients in as a shared partner in the decision making. Will that put that? It really means taking the time to find out what's important too and how can we negotiate through the risky stuff.

Choice requires there be desirable goals need to focus on what the person sees, the outcome needs to be what this person wants in their life. So what does this all mean for HealthIT?

I don't have on here - it was really difficult to try to figure out let me just boil this down as much as I can. Sequence really matters. So probably the first thing on here should say sequence matters. The information that gets presented really matters. The order in which you talk about it has a lot to do with the end result.

I won't go into a whole lot of the details about that but if you haven't read it there's a great book called Nudge about behavioral economics that makes that point much, much better than I could ever make it. But sequence really matters.

We have to honor the abilities and capabilities of people and not just stay focused on what they can't do. Context of the person's life needs to drive the option. People need to think about integrating person-centered practice in intake and referral. Working with a group actually in Charlotte, North Carolina that's the - all of their work is around helping veterans return home after military life. Kathy, that means my time is up.

So two quick - one quick story. After military life when they return home their focus - they are starting to really pay attention to what the capabilities or the abilities of these young soldiers, sailors, airmen and women. One of the things they really talk about though is the referral needs to be not here's John. He was an S1 and he was in infantry support with whatever, he did trucks and he did blah, blah, blah, all this stuff.

It needs to start with understanding that the referral needs to be here's a young man who has these skills and these abilities and these are the things. He's never had to open a bank account. He's never had to sign his own lease and he's never had to choose who his doctor was going to be. So he needs somebody to help talk to - help talk him through all those major life decisions.

It's a very different way of talking about and making referrals rather than all the things that are wrong. I think that those were really the primary - there are several other stories that I could tell you but I think that's probably good enough to - I hope that helps you frame some of the rest of your discussion and there is more information if you're interested in knowing anything more about how we've done this.

We do have a Web site that - most of this stuff on our Web site is free and can be downloaded and we broadly want you to utilize so there's lots of information there. And thank you very much for inviting me.

So the next person you're going to hear from and John would you like to come on up and - my good friend John Moore. John and I have trained together for I think it's going on about 14 years now. It was shortly after 2000. And John is I have to tell you is someone who has taught me a tremendous amount about being clear and keeping my promises.

And also helping people to - helping people to really understand that listening isn't really just something to do if you have time but making sure that we really clearly understand what it is that matters the most to somebody can make a tremendous difference in the way systems deliver support in places where people live. And in - well I'm not going to steal all your thunder John.

So John's a staunch self-advocate who lives in Altoona, Pennsylvania about three hours north of here. They actually considered bringing - taking a canoe yesterday instead of driving. Might have been a little better off if they had. And I'd also like to introduce Jamie Henry. Jamie is a Program Director in that area of Pennsylvania for Developmental Disability Services and also a person-centered, thinking mentor/trainer.

Jamie Henry: Can we start? Say hello?

John Moore: Hello.

Jamie Henry: So if it's all right with you, John, Mary Lou and I are going to ask - well we're just going to have a conversation and I'm going to make sure that everybody understands what you're saying. Is that okay?

John Moore: All right.

Jamie Henry: So we're going to start briefly - I know you - we had a discussion when we started that you didn't really want to talk about (feelings) right a lot. And that it was just you weren't being listened to there.

John Moore: (Exactly).

Jamie Henry: So, you okay? Should we move on? So after (feelings growth) you got to do - you got to move somewhere, correct? Where did you go? Need another second?

John Moore: (Coleridge).

Jamie Henry: (Coleridge) and that was - you want to take a second and I'll talk for a minute and you can get yourself together? All right, sorry. So that was in the '80s and '90s and you lived in what they called a non-ambulatory community living arrangement. And you went to a pre-vocational program, right? And you still go there part time?

John Moore: (Unintelligible).

Jamie Henry: Yes, part time.

Mary Lou Bourne:Is there anything about (Coleridge) that you wanted to talk about?

Jamie Henry: So what would you like to tell us about where you lived at (Coleridge)?

John Moore: (Unintelligible).

Jamie Henry: So that was - everybody was getting in your room and...

John Moore: (Unintelligible).

Jamie Henry: ...and took your stuff.

John Moore: (Unintelligible).

Jamie Henry: So we're just going to pass - we're just going to do this to the left. So some of the stuff that - you said that you didn't like people were getting in your stuff. You didn't get to pick who you lived with. And what was the one thing that you were always waiting for? All right, we'll...

John Moore: (Unintelligible).

Jamie Henry: We'll just - I'll give you a second to get...

Mary Lou Bourne: So let me just intervene for a minute and John if it's okay with you if I can share with people I've never seen this happen in 14 years. So clearly this is pretty strong and very important thing in John's life. He was pretty excited to be here.

But when - and we talked about needing to talk about the past. I think what we're going to do you can see the slides and you can see what his goals are at that time and I think what we'll do is just pay attention to what's going in slides on right now. Will that be all right?

One of the things you can see at the bottom John had never said he lives in an non-ambulatory community living arrangements with people who selected for him. He always consistently from the day I met him said he wanted to have his own place and his friends and really wanted to have his girlfriend.

So this is a little better part of the story and let's see John 2003 I believe was - maybe the year 2002 actually the first time that people really committed to a person-centered experience for John and he rather shocked people when the first thing he said was I want my own place. Would you like to say anything about that?

Jamie Henry: Your first apartment.

John Moore: (Unintelligible).

Jamie Henry: It was a one bedroom apartment, one person, just you.

Mary Lou Bourne: Anything you remember about your neighbors or anything you want to tell me about your neighbor at that time, the people who live down the hall from you?

John Moore: (Unintelligible).

Mary Lou Bourne: So and you're pretty good friends, some of them. And so we moved I mean part of what we want to help you see is that some of it is gradual. The quitting, things would work. It's going to change very rapidly however John moved into his apartment. It's not actually the building is in right now. It was the first place that he moved to.

And they still had 24 hour supervision written into his plan. He still had to have his own private home, his own private apartment that he finally licensed because the requirements are if you need 24 hour supervision the help has to be licensed, the apartment has a building license. He continued to have fire drills in the middle of the night when nobody else did. He tried to explain that to people.

John Moore: (Unintelligible).

Jamie Henry: It was loud and you couldn't hear anything and you were telling me this morning - when did you go to bed?

John Moore: (Unintelligible).

Jamie Henry: He went to bed in his shoes so he could evacuate on time.

Mary Lou Bourne: So you attuned to the evacuation plan and knew he needed able to get out pretty quickly and John preferred to - well maybe not such anymore but kind

of pushed himself backwards and he would sleep with his shoes or heavy leathered slippers on.

Pretty important is his safety is very important to him. And he was much more comforted in knowing that he could get out fast. So we all had to get up ourselves, myself included in thinking that was something he didn't need to do but for him it was really for his comfort. So anything else about that particular part? Okay, so like today when talking about life decisions.

John Moore: (Unintelligible).

Mary Lou Bourne: And how often do you do that?

Jamie Henry: Want me to tell them what you were saying?

John Moore: Yes.

Jamie Henry: He works at the county courthouse. He also works in our office doing document destruction. He also does a variety of trainings with people.

John Moore: Mary Lou.

Jamie Henry: With Mary Lou a lot, sometimes with me and recently on your own, correct?

John Moore: Yes, (unintelligible).

Jamie Henry: He's been doing trainings on his own with the Self Advocacy Alliance, recently been to some state centers and down to Philly and today in Washington DC...

Mary Lou Bourne: And so can you tell people about the structure? Did John move to his apartment at the top right building, the top right corner of the picture there. He now has less than six hours a day and that's split across the week.

John has a lot to do with deciding what hours and when. He has a lot more control over his schedule, what time he gets up, when he goes, the things he does. And the part that he would particularly - and I tell you I'm very disappointed that I couldn't figure out how to make this happen. Do you want to tell people what this is?

John Moore: (Unintelligible).

Jamie Henry: You drove Cheryl.

Mary Lou Bourne: So apparently it's the best thing that's ever happened in your life. So John we really tried to figure out how we could get pictures of this. He wanted you to see and it's really forthcoming to see because not only does he have this year - I wish my husband did this John I got to tell you.

These are last year's pictures on here too and really and you can see kind of the - I mean John likes to have this slide you can pull it out of your bag and show people so if you're wondering why we would like to keep them because he looks like either a truck driver or janitor.

So he can pull it out of his bag whenever he was to show people. And if you meet John later today he is really going to want you to see the pictures and it's up here actually. So do you want to hold this or do you want me to hold it?

John Moore: Hold it.

Mary Lou Bourne: So one of the things we'd like you to kind of notice that at one point in 2003 even when we were doing a much better job the goal for self-mobility and to access and limitations and fire drill.

The page before this I'm not going to go back to as it was around (wayfaring) and John would hold a napkin for so many seconds at a time and productivity was increased by 10% or something. And at that point one of the things you shared with me this morning what you really like about your job - can you tell people here what you like most about your job?

John Moore: (Unintelligible).

Mary Lou Bourne: And you like what you accomplished so you liked showing the paper on what you accomplished. And what did that get you?

John Moore: Money.

Mary Lou Bourne: What do you do with the money?

John Moore: (Unintelligible).

Jamie Henry: He says he saves his money so that he can go away.

Mary Lou Bourne: And I think (Cheryl) might like you to spend a little bit more on her sometimes.

John Moore: (Unintelligible).

Mary Lou Bourne: So he likes to spend it when he and (Cheryl) go out which is pretty much one night a week, maybe more than that.

John Moore: (Unintelligible).

Mary Lou Bourne: What's going to happen tomorrow night?

John Moore: (Unintelligible).

Jamie Henry: There's going to be a Halloween bash so he's going to take (Cheryl) to so her phobia is a picture on a keychain.

Mary Lou Bourne: So part of what we wanted to do to help and to show you the goals were really focused on what the professionals thought needed to be fixed in John's life. And now our comps that are actually in his plan and I can show you this plan.

Jamie Henry: We do.

Mary Lou Bourne: We have a copy of this to take with you that Jamie will show up with probably and I apologize apparently don't have enough for everybody. So - but it's exactly what you're looking at on the slides right now so when you download the file if you print in full size you'll have this exact handout.

So what you'll see and what started to really change things was a point in time when we started in the middle section asking what do people like and admire about John.

They say he is devoted to his family. He's daring and gutsy, is a happy person. This is what all people around John told us, right. Any of those that you agree with the most, self-confident, helpful, devoted to his work, friendly and caring, courageous. Which one do you think you agree with the most?

Jamie Henry: We haven't got to that part yet.

John Moore: (Unintelligible).

Jamie Henry: Your picture. You like that it shows who you are.

Mary Lou Bourne: You like having your picture on the plan so that people understand who he is. And actually when he walked in Marisa said hello John and Marisa said can we just he said how do you know? She said I saw your picture on your plan and he went ah, all right.

John Moore: (Unintelligible).

Mary Lou Bourne: So this was a one page profile. It's what we used to help people understand. You'll notice the scale and size is important to what we like and admire but then on the left side what's important for John and what you need to know to do. He's going to let you know when to call - when he wants to call to reach his family but he needs you to dial for him.

Accessibility and adaptations we needed so he can do as much for himself as possible. He really wants to do as much as he can with them. It's important that he looks good. He wants to look his best but you need to wait until John asks you for assistance. He does not want to be treated like a child. Sometimes people have a hard time understanding what John is saying.

He is really patient and he will repeat it as long as you're being respectful. Help him to use the stove and microwave. He really does not want to get burned and that's an issue really matters to him a lot so he really works out with people around how does that happen.

So professionals tend to think we even have to address issues of safety like that. I don't think it will work for you. Electronic health records wise, this is actually John's IFP. All of his staff can see it. Everybody who interacts with him that has access to that system, this is the system can actually see it and this is the first and how it starts out.

So it's very first queue individual preferences, what do people like and admire about John, what do you need to know to do so those other people as I just read to you. And then it goes on to say the very first two sections are what are his desires and activities that John would like to be involved in and what's most important to John.

So it sets the tone from the very beginning about what is the context of John's life, how does he want to live his life and then it goes on and talks about safety, health, physical health and other things that help support needs to be provided. Anything else you want to say to people?

John Moore: (Unintelligible).

Jamie Henry: That he does do his own training of people, that people need to be quiet and listen to him.

John Moore: (Unintelligible).

Jamie Henry: Just the large picture at the beginning kind of upsetting so even though we practiced but apologies.

Mary Lou Bourne: And really helping John it was really intrinsic when we asked him if he wanted to do this he wanted to know how many people are going to be here

and he was really interested in knowing who's going to help. So I was willing to make the trip in the car that felt like a canoe yesterday to come down and turn around and go back today but we really appreciate that you're willing to come today John.

John Moore: (Unintelligible).

Mary Lou Bourne: Okay, we will. We're going to be out.

John Moore: (Unintelligible).

Mary Lou Bourne: I will, I will. So John - my old man introduced John and I to each other and he knows - he was talking about my husband (Beau) and they were good friends back then, knew each other well. And he knew that (Beau) here and wants to know if we were talking about whether or not we can maybe have - grab lunch with him today.

John Moore: (Unintelligible).

Mary Lou Bourne: Oh, okay. My husband ran a sheltered workshop and the short version of this story is...

John Moore: (Unintelligible).

Jamie Henry: John was saying the people know but were get this work out of here. There was simulated work that was not been sorting and he kept getting...

John Moore: (Unintelligible).

Jamie Henry: ...and was dirty.

Mary Lou Bourne: And what John remembers is they had a very clear time to field all the rivets and all the dirty work up in big tins and put lids on them and my husband jumped up and got on top of the lids and said no more unpaid work and they stopped having any unpaid work in that workshop.

That was 20 years ago and so all of the work that was being done then was only paper. So okay John our times up so thank you very much and I am going to hand the microphone over now to Sharon Lewis I believe.

Sharon Lewis: Thank you John for coming and sharing your story with us. I'm going to ask our first group of panelists to come on up. I know that we have a little bit of a different set up today. We don't have a table in the front. Folks are going to sit here and want to use the podium and they see. I'm Sharon Lewis, I'm with the Administration for Community Living and I'll introduce our panelists here in a second.

Our first panel today is really pulling together those who are doing some of this work on the ground and who are thinking about how do we begin to bridge the components within this conversation that you started today, right?

The Administration for Community Living I think a lot of our work these days is about bridging. Sometimes were talking about bridging in regards to disability, sometimes were talking about bridging between long term caring and support and our clinical healthcare system.

And I think in this case we are talking about this notion of how do we take vision time information, electronic information, information that is important to and for people in our clinical settings and our home settings?

We were talking this morning a little bit about our successes and moving forward in that aspect of our healthcare system and begin to hold the conversation that John just talked about into that so that we don't have the stories about (unintelligible) getting in the way of the ability to access any medications.

And I know that this is hard sometimes to connect the dots but we have got people who are thinking about this and moving forward and the conversation over the course of the day is critically important. I have one story I have to tell, last week I was lucky to be in Colorado and I was thinking about technology and technology access for individuals with cognitive disabilities.

And in being there I was fortunate to be introduced to some folks in the U.K. who are working on some of these issues as well and they are working on systems and demonstrated to me. And the system itself is important and the technology is important but what the technology has done in certain circumstances is really important.

So the story that was shared with me and was unfolded was in using technology to bring person-centered thinking into our system and change our business practices how does this play out for one person without a family is that there is a young man who is nonverbal, requires a fair amount of support in terms of his personal care needs as well as interjections with the health and education system.

And one of his needs is that he wears orthopedic braces on his legs that had to be put on every day and had to be managed carefully because if they are not it results in sores that then result in hospitalizations for him rather rapidly.

And he had gone through a cycle over the course of several years where he would leave his home environment, go to school or to be out in the community and they were having problems with the (greater good) and they were constantly creating sores and he had a (state) of hospitalizations over the course of a very short period of time.

The family made a video two minutes after their questions on time, a two minute video. It was narrated by his siblings. They talked about how to put braces on appropriately, why it was important and how it needs to be managed throughout the day. Two minutes. In two years or so I think that was about more than two years - two years?

In two years since the video went up on the person-centered planning electronic record there has not been one incident of a sore or hospitalization. Now this is information that was written into records, was in health records, it was, you know, it was not - it was within the information.

So it was never sequenced properly, it was never prioritized properly and it wasn't communicated in a way that multiple teens across the community and across the different environments where the person was being supported like with human services and health professionals and educational professionals could access the information and understand it and act on it. That's the opportunity in this conversation.

The opportunity we have is we are informing the process that our systems across the country are going to take in how we bring in this notion of the person at the center is the person owning the record, the person driving the information into the conversation, it can help us with our goals of better care, higher quality and ensuring that we are not creating additional health risks for individuals because we don't use technology to maximize those opportunities.

So that's what some of these folks are thinking about and what you're going to hear about from throughout the day. I'm going to start with just really quick introductions and if I gloss over something that's important to y'all please add it when you come up here and I apologize because some of the team members because I have the primary speakers and if anyone else, you know, you'll have to introduce yourself.

First we are going to hear from John Martin who is the Director at the Ohio Department of Developmental Disabilities where he has been - served as Director since 2007. He - John, he's work in the field of disability for many years in a variety of capacities including as a provider, executive director of a large diverse provider organization working as a direct care worker, a special education teacher and the president of a software company.

He is the parent of three children including one with a significant disability. Then we will hear from Joanne Lynn who is Director of the Center for Elder Care and Advanced Illness, at the Altarum Institute. Joanne is engaged in work that is implementing and measuring care plans, developing methods for counties and cities to monitor and manage for elder care, coaching having these cities and developing support for caregivers.

Sharon Lewis: She's also been doing this work for a very long time in primarily around comprehensive support for elder care in a variety of (different) communities and she will tell you a little bit more about some of the really interesting work they're doing with (elder care). Rick Bahr is with Innovative Services Incorporated. Innovative Services is dedicated to supporting people in living the life of their choice and being active citizens in the community.

Rick has been - Rick was a founding member of the organization and has been with them since 2004 and has over 20 years of experience working in the field again ranging from director, staff to quality assurance and operating provider (SB). And then finally we are going to hear from David O'Hara who is with the Westchester Institute for the University - for - that's not right. For the university...

((Crosstalk))

Sharon Lewis: That's not right. For the University of Development - human development. That's not right. Where he is an associate professor at the School of Health Science and Practice. He is also - this is where our cross fertilization is very interesting and fortuitive. One of the new ONC Health Information Technology services as well as working within the university center environment which is the supported entity at ACL.

Dr. O'Hara is currently working on the ways that smart technology and accessible software applications can transform healthcare experiences for - and outcomes for people with disabilities by promoting self-direction and independence and (boldness) and health more respectively.

So without further ado I'm going to go ahead and ask John to come on up and (this is our first speaker). Thank you.

John Martin: Thanks Sharon. And just to say it's a real honor to be here. We are on a journey in Ohio and we have not reached the end of it yet and we're kind of humbled and proud to be able to present part of the product that we've developed and how it's being used in Ohio.

I'm going to do a kind of a real brief introduction to it after which Debbie Albert who is the person who works on the ground, it's her job to interface between folks in the field, families, guardians, et cetera with our IT folks who sometimes speak of it as a different language. And so Debbie's going to do that and in the last 30 seconds I just wanted (Brian) to say a few words about the technology platform that this operates on in 30 seconds.

Okay, so an overview the development of this product in a lot of ways mirrors how person-centered planning works which was - it was to involve the entire team of folks on the ground including individuals who receive services, families, guardians, providers, folks in the county force, et cetera that they all worked together to help us develop this product.

And because you always need a moral ideological compass we brought in Mary Lou Bourne to play that role for us as this product was developed. And so our challenge was could we develop an information technology platform that would create fidelity to the person-centered planning process?

Could we build it? And we received a lot of criticism early on when we had this idea because people said an online service plan is an oxymoron with person-centered planning. Every plan is so different that you should not be trying to do that and what we have found out however is as we started to roll this out that if you aren't doing person-centered planning the system doesn't work and you can't use it.

So it's really helping us strive to practice which is something that we wanted to do. And so by using it here are some of the things today increasing individual guardian input and control, making the plant organic rather than static so just to we kind of blew off - it's hard to do screenshots as you probably can't see them.

But we wanted to show you what the front screen was like following up on Mary Lou and the example of John is that this is the first thing that you see and this is controlled by the person. So this is what the person wants to be the first contact with them to be. So it is developed by the individual with the support of their team.

And you can see it gives a nice overview about who (Joshua) is. You can see he is interested in sports, football, wrestling, likes to watch them on TV, movies, video games, going out to eat, et cetera.

The power of this is that if you're a new staff person coming on as a support person who's going to be helping John right away you know what his interests are and it gives you something to start the conversation with and then start building that relationship that is so important.

And so if you don't know what's important to the person and you don't know what they like to do you're not going to build the kind of relationship that's going to become necessary to appropriately be able to support them. Also the best way to communicate.

You'll notice important people in my life and when we flip back to this increasing participation of the individuals in their life by the people that they choose that these are the folk that this (Josh) indicates are important to him. We can then give access. He controls who in this group has access to his plan.

And so you'll know those are important but for example if Grandma K is a med lover and even though is an important person he doesn't want Grandma K to have really anything to do with him or going on in this life he doesn't have to give her access to his plan.

So again it's part of that power and control that rests with the individual. Increasing transparency, this is connected with all of our cost-related sorts of things and one of the interesting things as we've integrated this with our other modules you'll note that we have 13 different applications that connect to this plan.

And one of them is our cost instrument. And so as we have had some families get involved with this and starting to realize how much services are being spent on their son or daughter.

We have had them challenge us about being good stewards and looking at better ways of using support because now for the first time they have a sense to see what we're spending money on and starting to see how these connect to outcomes. And then just kind of the standardization of our processes

And last thing to say before I kick it to Debbie to talk about how some of the modules actually work security was a huge issue when you start giving lots of folks access and figuring out what do they have access to that one of the things that slowed down our implementation of this was developing a security platform that both gives access to and restricts access to all or various parts of this program.

So an incredibly important part of the work as well as training. Current status we have about 2600 folks who have started to answer into the system as of today in the 17 county region and they're use of it really varies as we're starting to bring that system up.

And we're learning how important training is both in person-centered thinking as well as in the technology as we're bringing it up and it's more in people

quickly want to get on it. They just want to learn the technology. And we have to slow them down and say no you need to really understand person-centered planning before you do that.

So quickly then jumping in you'll note there's some icons on the top that you can click on and I'm going to turn it to Debbie. Hopefully I didn't use all of your time.

Debbie Albert: Okay, so as we focus on this page up here so we have the portal that the case managers there's a little more dynamic but we also have the individual or a provider portal which is what you're seeing up here. And then their access when they get notifications or they say - let's say because this is something that you use it's so that they get feedback and everybody can kind of talk to each other online.

So as a plan an outcome is updated then the person and the provider will get a notification. And that would turn red up at the top, they would know something needs to be looked at. They can go in and look at it and then provide feedback or just like know that it looks okay and then we can provide feedback status.

We wanted to kind of go through the components with you and again this isn't how it would look in the system but we wanted to pull it up so everybody could see it. So person-centered planning component discovery, the case manager would put in the results of discovery.

So that's what's important to - what's important for and the risk and that kind of folds into planning, the outcomes that are identified for the person. The planning the query there's important consideration for the person so out of

outcomes we kind of identify what support the person's going to need in order to help this outcome come through.

The action plan actually lives outside of the plan. We still consider it part of the planning processes but the provider and the individual's family can make changes to the action plan without having to bring back the whole team and get signatures and everything.

And that was purposeful. We had heard that having it inside the plan really ties the provider's hands. So we wanted to move it outside of it so that they could get their work done. The resource management part of it has both local dollars, Medicaid and community resources.

We wanted a total budget for the person in the plan. So we first look at any kind of community resources that are identified for the person so if there is a class in the community that can be taken we look at that first before we go to look for Medicaid dollars.

But all we do is show it in different ways. And then the agreement that occurs also is done within these portals notifications. So once the plan is ready for it both the provider the guardian, the individual would get notifications that it's ready to be looked at for agreement and they could do that right online.

So we don't have to print out plans, send them unless the individual or the providers don't have portal access. The other kind of supporting elements as far as the notifications, the alerts - the notifications are more about that you just need to go take a look at something. Alerts are more of the things that need your immediate attention.

A learning log because it is this online community - there is a space where people can put in new information that they learn. So if a provider takes somebody to a walk-in appointment. They can go into the learning log and put the new information that they learned during that doctor's appointment.

So let's say a new medication gets prescribed for the person. They can put that in the learning log and then the case manager can see it there and if there is a medication order the provider could scan and upload a document there and the case manager can get and do another medication assessment for the person.

So it's all in real time. Documents, there are folders that are preset within the system where the SSA - oh I'm sorry - the SSA are our case managers - the case managers can either if the individual has a document that they don't want shared with the rest of the community.

So let's say they got a psychological report and they're willing to have it used for whatever assessment is being done but they don't want it shared with the rest of the community they can put it in the confidential but it's something that they do want shared like an employment report they can put it in non-confidential and that goes out with everybody else.

I did not do very well on that. So sorry. There's a lot to share on this system. Outcome let me say very briefly every point on here was purposeful. We really wanted to make sure that we had a desired outcome as the person wanted it not as a professional or a team member thought the person should have it.

So we try to keep the outcome as the person describes it. And so that in order to really guess how they were going to accomplish it, how we balance support and to forward is in here so as long as this person's entered principals.

And then lastly what progress will look like. And that's going to be different for every person involved in planning. And we want to keep it that way. So we'll let - the official health field we have it up there described for you but if anybody has any questions I'll go over this with you.

Then if you want to have (Brian) illustrate more about technology.

(Brian): Ten seconds.

Debbie Albert: That's all right.

(Brian): I have a ten second overview of the technology. We use - our platform is built in Microsoft Dynamic 2013. And we did that because we're a Microsoft-centered shop and that we can - it was a faster build, took us about eight months to get it up and running.

And because it gives us security, it gives us alerts and notifications, it gives us a lot of those things that just come out of the box that we did not have to build ourselves and then with some configurations and - we could utilize SharePoint for document management and that sort of thing. So we've got some documents back there that we'll be passing out. It kind of tells you everything about it so it works it through there.

Joanne Lynn: Hi, I'm Joanne Lynn. I'm here on behalf of your future. How many people here expect to grow old? How many expect to count on your two years or more on healthcare disability while old?

You know, this is a large crowd so there's quite a few hands down. How many have already taken care of somebody older who took care of someone for

more than a year? How many expect to in your lifetime? So it's going to be a universal experience. We all are either caregivers, have been caregivers, will be caregivers or we'll need caregivers.

So the experience of a lifespan has developed a new phase. That new phase is the period in which we'll need help and one is declining in old age and that is a phase of life which almost didn't exist when Medicare passed in 1965.

So we're people who grew that old. They were not thought to be appropriate targets for medical care well for that matter for almost anything else other than shelter and emotional family support. And they were tiny in numbers.

Now most of us who made it through their childhood and young adulthood they haven't managed to be hit by a car or shot in the war we'll make it into old age. And our average will have more than two and a half years in self-care disability.

People entering that part of their lives have a bizarre sense that people have sat down and thought about how it is we're going to provide for them in that piece of time. It is a thorough illusion. No one has sat down and thought it out.

It is a hodge podge of all sorts of creative endeavors and what you get is a real lack. And if you ask ten people about the experience they had as their mother or father got older sick and frail you will have two or three really wonderful stories and all of them will end with weren't we lucky.

I'm here on behalf of getting rid of I need to be lucky to have a decent shot at a fair end of life. The other seven or eight will have terrible stories and they will assume that's the norm. Why is that the norm? That's the problem.

Here's an article from the paper the New York Times from a couple of weeks ago. This poor gentleman when through a year of absolute hell in the most well financed Medicaid and community support system in the country.

He spent over million dollars of Medicare and Medicaid benefits and never got what he wanted. Never got what mattered to him. He was home for a very short time in his last year of life. A million dollars and never got what he wanted.

That's the problem. We've come to believe that there are these six elements that must come together. They sort of work as a Rube Goldberg apparatus. Nothing works unless all of the pieces are there.

So the first is you have to see this part of life. Where are the stories of this as part of life? What do we know of Ronald Reagan dying of dementia? Nothing. He went away. We know nothing of Barry Goldwater dying of dementia. We learned nothing of almost anyone dying is a part of life. The few movies that are out there are bizarrely sensationalized.

I want to see the first sitcom on evening television and I mean sitcom in which, you know, you could go and kind of bring the Golden Girls back. I want Maude cracking jokes about the fact sitting in a wheel chair and faking death.

We don't talk about this part of life. So we don't have any stories. We don't see this part of life. We don't develop our data this way. We do not have measures that measure the wellbeing of this part of life.

So first you have to see it. Second you need longitudinal care plan. The most missing part of good medical care is and actual care plan. The doctor thinks

it's a care plan to say see your doctor in two weeks and here's your list of medications.

They have no idea that you have two steps up to your house and can no longer take them. Have no idea you left the house in utter disarray when the EMTs picked you up and you're going to go back in with your kitchen smelling awful.

None of those sorts of thing matter because no one is thinking comprehensibly. We need more efficient medical care that is tailored for elders. It is different to be 90 than it is to be 60. It is different in terms of what we should be measuring as outcome.

We have not had any metric whether it's (cover me) perhaps partial sections or partial options. That's our biggest issue? Everything else is bizarrely mismatched. We're still having to have a hematoma in A1C under 7 for a person who's 90 years old for who it is contraindicated, for who it is actually dangerous.

And yet that's the metric we have up there because we don't have enough developed metrics for this part of life. I was keeping metrics how much is my healthcare system likely to spend down in an imprudent way?

I want to see if in Washington D.C. that's getting better or worse over ten years. I want to know what my lifetime is of (pressure ulcers) are if I grow old and die in Washington D.C. I want to incorporate health, social and supportive services.

We have a remarkable misallocation. In this country we stand out way out of sorts on this. First thing is - this thing is we need some degree of local management. We have no place at which these things come together.

And finally we've raised so much on Medicare we can get through the next 10 or 15 years building the care system we want simply by harvesting the waste and low valued care that is rife in Medicare.

So this is one of my favorite slides - this is (Mary Garver)'s presentation of a care plan. The reason we don't have care plans is because life is complicated. It is difficult to build a care plan. You can't do it in three minutes with a discharge planner at the end of a hospitalization. It takes some time.

All of these pieces are important and they all interrelate. It's not unheard of to build a good care plan. You'll see some good examples from here and from later talks. It's just not valued. We do not require care plans in Meaningful Use.

We don't even require a slot for a care plan in Meaningful Use. The only nod to a real care plan, a longitudinal care plan that you get in purpose Meaningful Use is an advanced care plan, yes or no not what does it say. But just do you have one or not. That's more dangerous than not knowing whether you've fallen or not if you don't know it's content. So we have been just systematically terrified of actually dealing with care plans.

One of our big problems we have broken all of our social support in one room and all of our medical support in another. Both are dysfunctional on their own but they're even more dysfunctional in that there's no way in which they come together.

Every other country has a place at which you can argue whether the next investment needs to be in housing or an MRI machine. We have no place in which we even have a shared literature.

If I accidentally call a person here a patient half of you will immediately tar and feather me as being part of the enemy here. If on the other hand I say you're a client I get tarred and feathered by the other half.

We need a way to integrate even our language, our literature, our finances. The fact that we don't have that means we keep moving on two tracks and they do not adequate support a very large and growing part of the population.

You will have 14 million frail elders in the next 30 years. We need a plan for this population. So when we're talking about how IT can help here are some of the things I think will really work.

First off we need to have an understanding of each individual situation. There is an enormous boost to this. Have all of you seen the Impact bill like it's an act now not just a bill such that you can act.

Impact will change the world for several others. Impact requires that all of the parties to take care of people after hospitalization is the organizational parties such as home care, skilled nursing facility, elders with high risks all have to use the same metric and they all must do comprehensive studies.

Remarkable. When I first worked at CNN I picked up the testimony from 1982 on uniform assessment instrument. It's taken what 32 years but we are finally getting around to a uniform assessment instrument.

Once that is the common place element in all of these different parties we're going to begin to know what two ADLs mean. It won't be measured in any of 15 ways. It will be measured one way. It's like standardizing a thermometer.

We'll finally be able to start following people across settings with a common language. Pretty neat. But now we need to get it into the records. So we'll get it into records so we can actually follow how people are doing.

We need an adequate partner application of the widely course. This is has been bizarre that it's missing. We have all this stuff about records but it's all history. I mean history that's from importance, it's even from your tree.

But what matters to people is their futures. We know we can tell stories about their past but what matters is what's happening tomorrow, what's happening in a month. We used to do the rounds, you know, with the trainees in hospitals and say what's this person life is going to be like in a two months.

And it drove me crazy that the trainees would say glad that's not my job. It is your job. But now we can actually answer. How long is it going to be before every grandchild turns to the doc and says well what's been the outcome of the last 100 people similar to our grandmother when they had a stroke two years ago?

How many of them died, how many of them are living in a nursing home, what's their functional status, from how much does it cost to how many dollars. And expect an answer. Right now we don't have any prognostic information worth having for this population.

We don't have things about actual survival span but there are only about the midpoint in the survival (might that be a little more curved). We have

essentially nothing about functional span where support needs and that's what the family needs to know.

So we need some big data applications on that. Failover and fame and goals and priorities just like my partners here have been talking about this idea of is what matters to the person. The person who has, you know, five daughters that live within two blocks. They have all kinds of personal support.

Doesn't have a shareable priority with regards to going into a nursing home. Other people do. Somebody has a dependent handicapped adult child and wants very much to save money to make sure that person can live out their life in reasonable style.

So there's others with no other dependents. These things matter in your goals. I've had people who had goals that are not (costable) being on low affairs. I've had people who have goals of trying to make sure that their spouse was not impoverished with their illness.

You need to know those things. We don't even have a slot for goals in most records. And that's what matters. So we need to do that and we need to figure out how to make them not just regard the expirational or earlier arrival - dementia moving on the rise.

It has to be something within the range of what can be reasonably provided in work for them. And that takes some negotiation. It takes some give and take. Limitations in the services available we need ways to electronically match up people with the services that are available. And to make note of the ones that aren't.

So that we can track what it is that people need and also maximally use the capacity that the communities generated. We have to be able to converge upon a plan that takes some iteration. It's a hard thing to converge upon a plan when people have to give up things. They've had to give up safety. They've had to give up resources. They've had to give up their aspirations for staying in their home.

It is hard to lose (everything). It is not an easy thing. And yet all of us will have to go through that. It's one great virtue of getting to grow old is that you will have many more years to enjoy life. On the other hand it is very uncommon to arrive that likely you'll still be fully capable and even if you are you will have no reserve. Your kidneys will be down to a quarter and your heart will be at its maximum production.

You will have poor hearing. You will have limited vision. And these are just the physiologic picture. You're fixed elements. So the plans really take some empathy, it really takes some negotiation. It takes some iterative work. And the person who insists now I'm going home, I know that I'm safe and I'm taking my risks and I'm going home anyway.

And then three days later is back in the ER. It takes some empathy, some non-judgmental negotiation. Okay, so what do we do next? This didn't work out so well so what do we do next? We need to make it available that is the care plan and dynamic and efficient.

I've had people who generated 30 page care plans and sent them off to the emergency room. Then they're shocked that it's not going to be used. We need to really work on the presentation layer. You know, what is it that the Meals on Wheels needs to see? What is it that the specialist doctor needs to see?

What is it that the ER needs to see? We need a presentation layer that's efficient.

Then you'll be able to get to punch in and get to deeper layers but you need a presentation layer that quickly orients the person to what's going on in this person's life. What matters to them? What are the major treatments?

We need to have feedback on the care plan performance. There is almost no feedback on care plan performance. So no one knows that they've developed a screwed up care plan. No one realizes just how bad it is when you're counseling patients.

How can it be possible for the person downstream to be able to say to the doctor in the hospital you gave me thoroughly wrong medical advice about what my future would look like and you need to give people more realistic advice?

How often do I hear in the hospitals, the hospital was saying now you need to understand we just don't know how much recovery your mother will have from her stroke? You know, dog gone it we mostly do. We know a lot about the range. Why are we telling people that?

Because it's hard, because it's painful, because it's better when we for somebody else downstream who knows things better to tell them. We need feedback loops that are self-correcting. We need feedback loops that tell people that they're seven people (armed) wrongly.

And then we need to aggregate the care plan. This is a really remarkable enterprise. There are 5000 roughly elders in Washington D.C. today. Probably

about 1500 of them are living in facilities and the rest are probably living at home.

If I had their care plan at the present moment I could geo-map and calibrate all the services needed. I could look for the area people had to make compromises because the services weren't available. I look for the most proficient way for providing those services.

You developed a remarkable management tool once you aggregate care plans in a way that's useful to a potential manager. And of course one of our contentions is there needed to be a mobile manager system who has access to friendly sources, can shift things around and can report to their public about how it is that they're doing.

This is an area that we can fix. Global warming, the challenges in Iraq and Iran and Syria those may be really, really tough things. This is one that is predictable. Every one of us is invested in it.

We're already are spending the resources and we're spending it in a such wrongheaded way that we are right now guaranteed that everyone in this room who plans to grow old is going to be at risk of having to be lucky.

We could instead build the care system of the future right now. We have the resources. We know enough to do it. What's missing is the anger and the will. So get angry and wish your will.

Rick Bahr: All right, I'm Rick Bahr with Innovative Services and I'm honored to be here today to get a chance to share our story and the services that we provide in our care system. I thought I would start by acknowledging this is kind of our starting point.

This has been the product called Our Meter. My mentor is certainly a close friend of mine, (Allan Ray), who continues to preach to the organization the expectation of be passionate about what you do.

If you want to know what to improve speak to those doing the work or those receiving the services and lastly when it comes to making a decision never compromise our simple values of doing the right thing. So what now has become the bulk of our operations is supporting people without the concept of walls.

But based upon what their desires and wishes are in a format that's identified as G&D living arrangements where we have combined the responsibilities of caregivers along with technology to provide new options for community living.

But initially when we began exploring in technology I went back to a statement of what I thought we would find out and the first is that we could come up with a mass of data that we would be able to analyze with some sophisticated algorithms to predict future behavior.

Well I'm certain that that's what we thought. What we came to discover by applying our basic principles is we're able to discover new opportunities to change our existing care value to provide person-centered services at lesser cost.

So rather than being and identifying of ourselves as a group home provider it was our focus and support offered to people and cannibalizing ourselves and providing ways to support people in homes of their choice and places they wanted to live and rent and put the person as a center of our own plan.

And what our program now look like are supporting people in community maps where we identified own homes through the conversation of identifying what's most important to the person and that we have a shared goal amongst every person we're supporting is that they live a life of their choice.

Their place they want to live and that we're part of the ongoing connection to the community for them to be active citizens. We provide support when needed but have staff available 24 hours a day.

So rather than having people waiting for a caregiver to come by we work around people's schedules and we're able to find funding partners to initiate this program where they would pay for outcomes versus (unintelligible) which allowed us to provide as much support as was needed but to price the outcome of a person to live in their own home and to be serviced successfully at the point in time they required it.

We also look to support the impaired person in action that they need rather than go back to the broader picture like how do we ensure a person's success in a place of their own setting and city.

We want to continuously find ways to bring in natural support rather than paid caregivers. We view success as when we're able to decrease rates that we originally negotiated because they are more attached to their community resources.

We had to retrain our caregivers to think differently and to see their role in a different light is that their job wasn't to provide transportation but to teach a person how to access community transportation.

And to find ways to reconnect them or to transfer relationship to a family member and bring them in as part of the regular support provided versus just a person who was visiting to make sure they were active and that there was that regular engagement with their communities and were seen as a valuable contributor to that community.

So we took the approach the service of support typically provided in licensed settings and applied it across communities where staff are aware of the choices being made through the use of technology.

And people have life interactive virtual environments to where they can communicate their satisfaction of their services directly to their care managers, to our staff, to our leadership teams, to their families.

So that there's real kind of information exchange occurring for a person to be self-directing and changing in support rather than waiting for some schedule meeting between the funder, ourselves as the provider and their families to all attempts.

So it's that combination of in-home monitoring technology and ongoing real time information exchange and communicating in a digital format that allows us to implement this sort of a program.

The result and this is from an independent study conducted by In Control, Wisconsin that came into look at that how our program had achieved different outcomes as well as opened up more opportunities for people who are not traditionally viewed as being able to live in a place of their own choice.

But would need to live in a licensed study what they showed by the data that was collected by the funder was that certainly their overall cost of care

dropped as an organization in developing a relationship and choosing the finally outcome with providers.

And most importantly the red line indicates increased satisfaction with a person's life by the members that this managed care organization is providing services to. The direct outcome based upon our service model within this care area is annual savings in 2012 of $1.6 million saved for the 128 people participating in comparison to the alternative model of care that would have been or was their choice.

I think it's funny when our initial speaker said our own person said are planning them is not much of a choice if you're not offered the real thing that you want.

But any of their service offers that were available certainly chose an ongoing dramatic savings as well as in that last year looks like the margins made up actually changed or lessened. It really looks like there's a higher opportunity in their assessment process that are receiving community living support.

So those combinations when environments are created that use technology in ways to implement service rather than just collect people's medical records. It's an important thing to consider in the ongoing evolution of where health information technology looks at. My daughter and I were talking last night. Four kids. So sometimes it's nice to get away even in a hotel room. So they're from a year to eight so they ask a lot of interesting questions.

And my seven year old daughter who is really gift that we didn't think we would ever meet her she was a very complicated pregnancy has - we thought that if we did it would only be maybe six months worth of time - very complicated medical heart condition.

And so right then she asks a question well daddy do I have a person-centered plan? And I thought well yes, I think we all do. We all get interested in our own lives but I said what we're trying to understand is how do we start collecting the right information in the right way.

So that when we cross that process threshold and begin to need a chair from our system how do they know who we really are besides from where blood transfer has been and the medications we take in and what happens in the doctor's office what about you as a person and not just your medical records.

And I think that's where identifying and providing solutions that allow people to self-direct and capture the information and looking at it through our own eyes versus having to look at - I think viewing people differently because of the services they be needing.

I think I go back to the basic principle that we continue to have to meet within our leadership is if you want to know the right things to do ask the people who saving the support and services of those directly providing it and you'll find the very best answer. So I might actually because (burly) so...

((Crosstalk))

Rick Bahr: It is a pure honor to be here and be able to share the story and the process created and I applaud the efforts being made to recognize how there's some really unique opportunities that can be created. That we continue to go down this path and offer different types of care that before people never knew was possible.

David O'Hara: So Sharon said I'm in the very unusual position in this group of being a representative of an Administration on Community Living because we're one of the university center's for excellence in development of the education, research and service.

And I'm also a newly chosen qualified health and protection technology fellow for the Office of the National Coordinator on Health Information Technology and I'm going to be showing you today is some of the technology we've been working on that specifically address the health issues of people with cognitive disabilities in ways that do put them at the center of service planning and how they experience services.

And I going to try and keep my remarks short so I can show you some of the technologies that we've been developing. Part of our role as the university center is that for the last 40 years we've been a comprehensive healthcare resource for people with intellectual disabilities.

And we currently serve about 7000 people a year through that bubble of caring includes both primary care and specialty care, behavioral and mental health services as well as dental services. So we've got a very comprehensive look at people.

The last several years we've also been very involved in taking advantage of the incentives that have existed in the Affordable Care Act for the meaningful use of electronic health records as well as then moving ourselves towards being certified as a patient-centered medical home in which you have to be able to demonstrated through surveyed responses from people that you're caring for that you were in fact met certain standards of care.

And I'm going to be addressing those kinds of things as I talk today. Fundamentally we've known since 2002 from the Special Olympics data that we have significantly health disparities for people with cognitive disabilities.

The most recent data scrub is from 2002 and it talks about the prevalence of Type 2 diabetes among people with cognitive limitations versus the general population and it's six times as high.

(Unintelligible) even though our life expectancy has been increasing in general people with intellectual disabilities die much sooner than the general population so that's a pretty bleak issue.

And an issue of medicine in the U.K. and the U.S. has told us that one of the biggest cost drivers - avoidable cost drivers in the way you provide healthcare in the U.S. is that so few people actually are fully competent when it comes following care plans over time. Those are all things that we're trying to address through our technologies. Well we're missing - there were some things on there - I'm sorry.

Where our model came from a CDC funded project the Rehabilitation Engineering and Research Center at the University of Montana about 15 years ago in which they looked at a group of people in Montana that had long term physical health issues and they were at a higher risk of developing secondary health problems.

What they did was they created a ten week workshop model in which people would come together without some with problem in talk about what do I want to achieve in my life. Over the course of these sessions they were setting personal goals for themselves. What is important for me to achieve with my life?

And then they would start to work on with the thought what do I need to do to achieve those goals and eventually at about the third or fourth session they'd start to look at specific health issues that might be a barrier to them achieving personal goals and look at ways that they could mitigate those health issues over time so that they no longer are a barrier to helping them achieve those life goals.

We brought that fine practice into the digital age on behalf of people with cognitive disabilities by taking advantage of smart technologies and creating something called my health, my choice, my responsibility.

And essentially what we've done is online app you can get if you want to go to the app store for Apple. It's now an app in which you can look at different areas of your life and think them through in terms of what can I do to optimize my health.

So what do I want to achieve as my personal plan and unduly hampered by whatever health issue I have. So that's one goal of it. The other is that this is also a tool that we want to use. Under Meaningful Use criteria this next year we have to start to make our patient/physician portal available to as many of the people that we serve as possible.

So what we've taken on as a task and what I'll be talking about in the HIT Fellows program is we want to make our patient portals fully accessible to people with cognitive disabilities.

We can provide tools for the access of that patient portal then enables them to create self-directed healthcare plans. And this is the process that we would see. We would have a whole menu of choices depending that we could

customize to their health status and then we will populate those with information and content that was relevant to them.

Behind each of those icons what we have and this is currently in place we have the ability to provide video patient education materials around what it takes to manage a specific healthcare task.

One of the ones that we focused on and done trials on before and chose it looks very well is oral health. Typically the people that come into our center do not seem to have put a toothbrush into their mouth over the course of the last six months.

And so we've developed a strategy using smart technology to put education through the listen and learn module on why it's important to maintain good oral health, a little Q&A on did they get the messages and then you can have a good docking oral health on the bottom.

Images that would talk them into specific materials designed to prompt and approach them on the aspect of their healthcare status. So this is what a little video clip would look like if in fact we're using smart technologies to pursue this health goal.

The beauty of smart technologies is that they contain built in prompting features so you can tell them to turn themselves on a given time. You can display an icon or you can actually have them go straight into a piece of material. In this instance they display an icon and it brings up a two minute tooth cleaning sequence that they have been trained to follow using the primary modules that are in this living well curriculum.

Where - given the two example that we had earlier today that Sharon talked about along with the young man in the U.K. system that needed to have braces positioned carefully otherwise he developed sores and was hospitalized.

We've heard about the person who had a fall and broke a hip. What you can do with these using this technology you don't need fancy technology to populate this health information portal.

You can use these at home that are in here and the ability to record audio to go with images and dump the material into this template that you've already created so that you have a completely unique profile of the person plus a unique profile for their particular living situation and a way to modify it to maintain good health.

But the other key thing that I think you brought up at the end of your presentation is how do we know that all of this is actually working in ways that satisfy the person themselves. Are they getting the care they want in ways that they wanted and are they happy with the providers of that care?

In the U.S. system if we want to become a patient-certified medical home we have to show that we can provide data on the experiences of the patients in our care. The existing survey is a paper and pencil survey. It's sent out once a year.

And it is not easy for people with cognitive disabilities to fill out. So we've created an alternative survey with technology which is read to the person and gives them transferring capability to answer the questions.

Working with the U.K. partner that Sharon mentioned earlier the Rix Centre for People with Learning Disabilities at the University of East London we

were asked if we could help work with the U.K. international health service to create an equivalent model for patient experience with the National Health Service in England.

And that came about because of that health data that I showed you earlier in the slide. They had various reports of unavoidable death and predicated deaths and wanting to do something to allow people with learning disabilities to say what they thought about their own healthcare. And our - just because it's so good to see these things I'm going to plug them in and show you this experiment just for a moment.

Marisa Scala Foley: For those of you joining us via the phone or the web we're getting a live demo of one of the tools that David is talking about. You may not be able to see this but we will try to get you a link afterwards so that those of you are participating virtually can see this as well.

David O'Hara: So what you have here is the way we adapted the CAHPS survey for use in the U.S. system. And the consent will be read to people and then you would be able to go through the survey. But I just want to take - in certain interest of time I want to take you to...

((Video))

Woman: Welcome to My Health, My Say. You saw your own psychology. We want to ask you some questions about your...When you are ready to begin press the start button. We want to ask you about your visit. I'm going to ask you some questions using the iPad.....Each question and see the words on the screen.

Answer the question then press next to see the next question. Press next to begin the question. First question, are you a man or a woman? Next question, which picture shows your ethnic background?

David O'Hara: In the U.S. system we have to enter this question using the text of the slide because of offensive definitions. Can you hear the slide?

((Crosstalk))

((Video))

Woman: Next question, tell us your age.

David O'Hara: Over 60. Over 60.

((Video))

Man: Over 60.

Woman: Next question, who do you think is....?

((End Video))

David O'Hara: So what you're seeing there some features that have been built into the U.K. model will take an experience survey that begins to really tailor it to the unique experience of that individual by giving them pictures of that particular health provider that they might have dealt with that particular day so they can see who they are being asked to express their opinions on.

Plus the ability to do free form responses if you have the ability to speak and describe what you want to say. And you go through and you complete it and it takes about three or four minutes. This software is the application package that can be populated with any content anyone here would like to put into this kind of specific focus.

The other thing that you being to see with this one versus the other one is the use of icons and imagery and animation to create a more interactive environment. We see that this kind of a survey capability should be intrinsic to any of the innovation chains that we want to do with person-centered planning.

From no matter where it starts that you really are building in the big bubble that allows you to get the right responses from the people participating on this online experience along with changes that might be needed and we can do that. Actually my task this next year with the HIT Fellows is to try to get this made in health information technologies so wish me well.

Marisa Scala Foley: All right, I want to thank all of our presenters for a wonderful look at where innovation - the kind of innovation that are happening around the country and where they're happening. You've given us a lot to think about.

So what we'd like to do now for the next 20 minutes - I can't see the clock from here - is to open up - open this up for questions as well to our panel as well as for comments so a few housekeeping announcements with relation to that.

First of all for those of you who are here in the room you can either if you have questions or would like to make comments you can either line up at the

microphone stands that you see at the front of the room or signal us and we will run back microphones to you.

We also for those of you participating virtually we invite - we have gotten some of your questions through chat which is how we'll start while people are queuing up. And we also invite you to continue to submit your questions through the Chat function and go to webinar.

With that we'd like to ask - we also know there are some folks who are on the phone and who may not necessarily on the web so we would like if Operator you could let people know how they go about queuing up on the phone for questions.

Coordinator: Thank you. We will begin the question and answer session. If you'd like to ask a question please press star 1. Please ensure your phone is unmuted and clearly record your name when prompted. To withdraw your question please press star 2. One moment please to see if we have any questions.

Marisa Scala Foley: Okay, thank you. And just general guidelines for everyone in order to ensure that we have enough time to - as much as possible to answer as many questions and field as many comments as we can we are going to limit your time to speak to three minutes.

When making your comments we do - and are really keeping time on that - so when you're making a comment we ask that you please state your name and your organization. If your comments do exceed three minutes I will need you to stop speaking but I will try to give you a 30 second warning before that happens so that you can try to wrap up.

And we will - and so with that we have a couple of question from the web and then we'll move to questions in the room and then on the phones. So John, first question for you and your team I'll hand the microphone over to you was can you tell us a little bit about which service providers are using the system?

John Martin: We use this program in our waiver programs and so the service providers would be the individuals who work for a particular provider who are working directly with the individual whose plan is in the program. Does that make sense?

Marisa Scala Foley: Let me give an example, which delivers what types of waivers or types of programs?

John Martin: Oh, okay. So our types of waivers are 1915, 1915C waivers. We call it the individual options waiver. It is a comprehensive waiver in our system. The kinds of providers would be - most would be using would be the direct service support person so it would be the person in the example of (Josh) it would be the person who would be coming into his house.

And you might have seen one of his outcomes was that he wanted more time alone. The reason he couldn't have more time alone is he needed help doing his medication. And so one of the things that staff are working with him on is to become independent in doing his medications.
So it would be that staff person who is coming in working with (Josh) helping to teach him to take his medication on his own so that down the road he wouldn't need a staff person coming into to do it and he could be alone.

Marisa Scala Foley: Thank you. I think we'd like to take our first question in the room.

Francis Norwood: Thank you. My name is Francis Norwood. I'm with the Center for Medicare and Medicaid Services, and specifically in the Innovation Center in Baltimore. I'm very interested - before I jumped into government I was working for 15 years in research within the disability community.

So it's very exciting for me to hear that person-centered planning is making the jump and potentially being a concept that can be spread to all kinds of different populations whether it's for the elderly, dementia or (unintelligible).

So I'm very, very happy to hear what you had to say and I'm interested to know as somebody who's within CMS what would you like to see government do - or CMS do to help spread person-centered planning to more populations?

Marisa Scala Foley: Is that directed to anyone in particular or anyone...

Francis Norwood: Anybody on the panel.

Joanne Lynn: I would like to start.

Marisa Scala Foley: Joanne would like to start it.

Joanne Lynn: We desperately need developmental as a metric and we need the openness to the innovation that would allow them to be fully implemented. And right now it is very hard to engineer the metrics at all, pretty much requires an interview.

And you will find that people individually in the room and the innovation really needs to allow some community to step forward just like you were doing in Ohio where some communities need to be able to step forward - to be enabled to step forward in teach us how to really make the engine work and

we think innovations at that level urgently needed at least in healthcare of
elder care.

Man: I think certainly to have language request our current tools availability to tool
is to also encourage as the new codes or methods that are more definition is
written that it's focused on values rather than specific situations.

That it becomes the value and the intent versus something that had to be very
restricted. That translates being very restrictive on the local level for a
provider and what they could be funding.

David O'Hara: Have they done with this - they say you need to look at the design of your
interface and applications and words and make sure they are addressing the
accessibility issues of people with developmental and (ventral) disabilities.
And we've shown some today some of the tools that are out there that should
be built in some of your future funding projects.

Marisa Scala Foley: We're going to try and take a question from the phone and then we'll come
back to the room. Operator, do we have any questions through the audio line?

Coordinator: Yes, we do have a question from Abigail Morgan. Your line is open.

Abigail Morgan: Thank you. And thank you to all the panelists for the models and the options
that you've present as a blueprint for scaling person-centered planning. I'm
calling from Direction Home in Akron-Canton and the area agency on aging
in Ohio.

And I see a tremendous opportunity within states participating in the financial
alignment demonstrations for Medicare and Medicaid beneficiaries. States and

health plans are bringing the coordination of Medicare benefits with Medicaid long term services in support.

In partnerships with community-based organizations such as area Agencies on Aging in Ohio as you can imagine we continue to learn from each other in terms of the lingo that's needed to kind of cross the boundaries between health plans, medical providers and long term services and support providers and I really see an opportunity for using person-centered planning as the vehicle for that.

In Ohio there are about five plans working with Triple As across the state and with long term services and support providers to meet the needs of beneficiaries and there's an opportunity to scale or to build a plan that is scalable across these health plans that are also operating in other states.

So there's an opportunity to really take these blueprints and the options presented here and use these demonstrations that are going on in some states as kind of the, you know, mini-microcosm for sending out person-centered planning options across many different boundaries.

I just wanted to put that out there, you know, in response to CMSs comment about what can CMS or government entities do to support this process. There's a lot of opportunities within demonstrations to do this.

Marisa Scala Foley: Okay. Thank you, Abigail. I just want to - I understand it's a little difficult to hear in the back in terms of questions or comments so I'm going to try and repeat the ones that come in from the phone so that everyone in the room can have benefit - I'm going to try to encapsulate your comments.

And so Abigail works with a Triple A that is in Ohio which is participating in the duel financial alignment initiative and she talk about the potential for integrating person-centered planning into demonstration such as the duel financial alignment initiative.

And that even that those demos are happening in number of different states that there's real potential there in terms of being able to scale some of these applications across states. So hopefully I have encapsulated your comments correctly and with that I think we'll turn to a question here in the room.

(Gerald Roberts): Hello, my name is Dr. (Gerald Roberts) and I'm here actually in three roles. One, my - oh I can't be trusted, I'm dropping as I'm talking. My primary role here is I am working for a company called (Trimetrica).

It's a quality measure developer who recently obtained the funding for the grant - the contract to develop quality measures for the program Who Takes Care of the Elderly. I believe that including quality measures around HealthIT would be very important.

My second role and I'll ask you a question about that - my second role is I'm the youngest brother of a developmentally disabled sister who is in her late 50s and is starting to become less and less capable of taking care of her own care.

And in my third role I'm a registered nurse of 25 years who actually started my career as a nurse caring for individuals who were actually dying in hospice care. I had the privilege of working at a church-owned hospice one of the first hospices in the U.S.

From the quality measures perspective though my question is how could we design - what quality measure could we design that would affect health information technologies at the point of care in a way that long term care could use it broadly?

Considering that there are thousands of long term care centers throughout the United States in home care settings, assisted living, long term living in the center settings and among those thousands are equally hundreds of electronic health records that are being used in thousands of different ways.

What types of metrics would be effective to develop that would improve the care for these individuals but from the perspective of a registered nurse not increase significantly work at all? The amount of work that has to be done when I've got - when I worked in long term care 17 to 20 patients to care for.

((Crosstalk))

Marisa Scala Foley: (Valerie), you talk about this a lot. I'm sure you have questions yourself but it seems that even the most elementary of things are critically missing things as far as they're very straightforward things. Do you know what this person's functional status has been?

If not it's a big black mark. I have often proposed that the CMS failed to pay or pays only half for the second DRG within six months for a person who had no care plans in the interim and was discharged without a care plan. I think we'd have a care plan let's say this is Thursday by next Monday for everybody being discharged if there was such a plan. Think of a 1% penalty.

We haven't paid attention to this at all so getting under way is going to be fairly easy but it seems that as long as it really matter for things like does the

care plan actually support your goals and is the care going to be unreasonably prudent about use of personal resources with using everybody's money who contributed to the pot in an effort, you know, you put on these clothes and we haven't even started to put our clothes on much less really measure

But the IT stuff, you know, just basically isn't there, you know. And of course when we can put this stuff in the Cloud the care issue was programed for the Cloud and except for the Pact TRD has never been used. Why did CMS pay $2 million to get the care givers in the program in the Cloud and never hardly anybody actually uses it? You know, let's get out there and using it.

((Crosstalk))

Man: Yes, this would not get into technical kind of quality metrics but I think until we do a better job of connecting the services and support information with that electronic medical record so that the practitioners - if you look at the field of services and supports we have a fairly significant turnover of our direct service staff and it is those folks who are talking somebody in to see the neurologist or to, you know, to see the primary physician.

And because we often don't have good continuity of those support records and what the individual's experiencing, what the staff are experiencing and kind of a history of that that oftentimes that physician is kind of operating in the dark so to speak because we don't have those two pieces of our system linked.

And if we had them better linked I think we would see improvement and get some quality metrics particularly in our system where we see a lot of negative pharmacology, you know, focused on just treating this symptom versus that symptom.

But not really good coordinated care that is bringing in the knowledge from the people who are working with that individual every day. So just a real encouragement for support of connecting those two together and I think it'll allow us then to develop better quality metrics as we go forward.

Marisa Scala Foley: Okay, thank you. I just wanted to make sure. It was a little difficult for me to see up here. Here is there anyone who needs a mic? Who is here in the room who needs a mic brought to them for a comment or a question? If there is please do signal us so that we can make sure to get that to you.

We'll take this next question here in the room and then we probably only have time for maybe one other question from the phone lines and then we're going to need to take a break.

(Choqui Chong):   Hello everyone. My name is (Choqui Chong). I'm from the company called (unintelligible). And also the same (unintelligible) of Maryland. I don't have a question but I do have some comment from the (unintelligible) about just where we are in this field with the person-centered we have long term technologies here and of course the long term care services and the support.

It has been my personal experience as I have been working with SID and the Poplar House and my education and I care about in the cost effective years but when I came into this field about the long term care services and the support I found a mirror like. There are a lot of challenges.

One of the major challenges that came from the social survey is part of the whole system. The good news is as the ones that actually we do have solutions self-help. The problem is today we define that person-centered, the care plan and both of which have information hasn't audited about it but the electronic long term past service and support.

And so under the leadership of ONC and the pre-measures of health problems the CMS is a partner for over five years and we asked them about our progress. So the (unintelligible) on the technology was the problem. The big problem is one is for the senior healthcare solution we already brought that into two stage.

In one stage today they support more than 5000 of your services so the patients and our patients selected their long term service they want. So that challenges but as long as you can really, really define those elementary rules is he heart again so the solution is to involve all efforts implementing.

So what I think is this, you know, one is to leverage the (unintelligible) solution including the new technology. But you don't have one technology of expectation current delivery for that EVVE, electronic verification of vital events.

So why do we have so many different sorry - (unintelligible) this is a hope so you have to verify. At that moment that patient had to be billed for that service and that provider had a certificate for that survey. Not only the plan did Provider A save and when that service is provided.

Marisa Scala Foley: You have about 20 seconds and then we need to interrupt.

(Choqui Chong): Okay. The other one is about the patient who can chart their information. So one part basically was made for us at ONC and on some occasions they can chart out the work they have and you have like the option like to share. So patients select which doctor, which housekeeper and then...

Marisa Scala Foley: We're going to need you to end.

(Choqui Chong):   Okay. We will type that, re-type that right in front of patient and sit them down and say okay you like this? So as doctor I am aware we are looking for a fine alternative to support the patient in partnership.

Marisa Scala Foley: Thank you. Thank you. All right, I think we have time for one last question from the phone so that we make sure our virtual participants can participate as well. Operator, do we have any additional questions from the phone?

Coordinator: I see no further questions and as a reminder if you do have a question please press star 1 and record your name.

Marisa Scala Foley: Okay then we'll take one last question from the room.

Barbara Gage: Okay, thanks. This is Barbara Gage from the Substitute Care Center for Research and I was just wanting to follow up on the fabulous presentation today. There is a lot going on.

I think we'll be hearing from (Stan Lessano) this afternoon about some of the initiatives currently under way to develop quality metrics for the LTSS population working with the states to identify those factors that are critical for changeability and cost effective systems. So there's a lot going on I can tell you that.

Marisa Scala Foley: All right, thank you so much. I want to take this opportunity to first of all to thank our morning participants, our morning presenters both this panel as well as John and Mary Lou for getting us off to really a wonderful start to the day.

We are now going to take a break for lunch. For those of you who are here in the room the Humphrey Cafe is just down the hall past the registration desk to your right. We do encourage - because we have a limited amount of time we are going to ask everyone - we're going to start at 12:40.

We're going to reconvene at 12:40 so we do ask as this is not a very long lunch break. We do encourage you to stay in the building. If you do leave the building we will need to escort you this morning. If you're not an HHS employee we will need to escort you back up so we ask that you're back in the building and downstairs by 12:30 so that we can make sure to get you back up here and back in your seat.

For those of you on the phone and on the web we thank you so much for joining us this morning virtually and we will be back on line at 12:40. Thank you again everyone and we look forward to seeing you back in about 45 minutes.

Liz Palena Hall: Hello welcome back everyone. My name is Liz Palena Hall and I am the Long Term and Post-Acute Care Coordinator at ONC and we are so excited that you are here this afternoon. We have a terrific panel lined up for you. And so before I get into introducing our next panel I'm going to go through a few housekeeping comments.

So first I just want to remind everybody in the room and on the phone that we will have a transcript available following the meeting as well as all the materials are already posted on the Web site and that is available at http://www.healthit.gov/person-centered-care.

We also recognize that everybody was able to ask their questions at the end of the last panel and so we encourage you. Your comments are certainly valuable

to us and so we encourage to submit those comments after the workshop to personcenteredhealthit@hhs.gov That mailbox will be available and open until October 31.

As well as the folks in Ohio, the Amanda Project also have a handout for you I think outside of the room. Those handouts are at there for pick up. And for the folks online we will be posting that after the meeting.

I also want to let you folks know that at the 3:30 panel we will be inviting organizations to comment about action steps that they might want to take to advance this topic about how we can begin integrating and advance the integration of volunteers for work information and health information. So that will be for the 3:30 panel's meeting so we encourage you to start thinking about those comments now.

And so then I want to start now by kicking off our next panel and introducing Dominick Frosch. Dominick is a Fellow in the Patient Care Program at the Gordon & Betty Moore Foundation. He oversees the Foundation's activities related to patient and family engagement in healthcare.

Before joining the Foundation Dominick served as Associate Investigator at the Palo Alto Medical Foundation Research Institute. And is Associate Professor of Medicine at the University of California at Los Angeles. For over a decade he has conducted research on developing and implementing interventions to increase patient participation in clinical decision-making.

And with that I'll pass it off to Dominick.

Dominick Frosch: Thank you very much and good afternoon everyone. It's an honor to be here with you today. So really to talk about some of the key challenges that we've faced in putting the person at the center - can you hear me better now?

Group: Yes.

Dominick Frosch: I'm sorry about that. What we're really going to talk about now this afternoon is some of the key challenges we face in putting the person at the center in making plans for long term supports and services.

And so I come from the Gordon & Betty Moore Foundation in Palo Alto and we launched a patient care program about two years ago and I need to state here given that we've got a broader focus in our discussion today than we do in our program at the Foundation where we're really focused specifically on the healthcare delivery system.

But our vision for what we want to achieve I think is very consistent also with what we're talking about today here which is about bringing humanity back into healthcare and ensuring that when we eliminate preventable harm we also realize that when persons receive care that isn't consistent with their roles and preferences that is also preventable harm.

I wanted to spend a few moments on framing up our discussion this afternoon. We recognize at the Moore Foundation that health information technology plays a key role in advancing patient and family engagement, engaging persons in helping understand what their goals and preferences are and ensuring that they can actually meet those.

But we also recognize that there're a number of questions we need to figure out about how we can best leverage health information technology and for that

purpose we convened together with NCQA a task force last year to develop a strategy for how we can best leverage health information technology. And there's a lot of hype about this but there are also a lot of complex issues that remain.

The key findings and recommendations from our account were that one, we need a comprehensive statement of joint principles for the advance and design of these technologies that really help us leverage the tools to achieve the triple aim.

We need to develop and implement an evaluation framework so that we can actually understand where it works, why we need to invest our dollars and organizations but also I think we need to identify data strategy so that we can bring all of the elements together and I think we're already hearing today that that is a key issue.

And we need to demonstrate innovative uses of HealthIT so that we can have cases that we can take on the road and thereby spur more action in this direction. But let me focus just briefly on this key issue advancing unified data strategy. What we really need is to make the data available and actionable and for that what we need is interoperability and integration and there're some huge challenges there.

And I'll tell you just a very personal story which is I am a Type 1 diabetic and I wear a continuous glucose monitoring device but when I take this back to my doctor's office she tells me to bring some printouts because there's no way for us to integrate this into the electronic medical records.

And that's just an illustration of the magnitude of the problem that we face in solving this issue. But the other thing we should recognize in all of this is

technology alone is not the solution. Technology is a tool that can make things easier but new technologies also require new actions and new behaviors and sometimes the technologies will have unintended consequences but these will be distant unforeseen.

We need to recognize that we just as much in developing the technology and making the integration and for operability to happen we need to pay attention to how people use the technology so that we can really optimize its impact on what we're trying to do.

So with that thought let me now introduce our panel of the day. We're going to get a terrific set of presentations to really flesh out many more of the details on some of these challenges that we face.

And so first will be Mark Savage. Mark is the Director of Health Information Technology, Policy and Program at the National Partnership for Women & Families. At the Partnership Mark oversees the HIT strategy and work to advance electronic health information access and exchange as the necessary back bone to the delivery forum, personal engagement, quality measurement and population health.

Next we will have June Simmons. June is the President and CEO of Partners in Care Foundation which she launched in 1997. The Partners serve as a catalyst for shaping innovation in healthcare by partnering with organizations, families and community leaders in the work of changing healthcare systems in the community and lives.

And next we will have Andrey Ostrovsky who is the co-founder and CEO of Care at Hand. He's a social entrepreneur and a practicing physician who leads Care at Hand's executive management and strategic vision.

And then finally we will hear from Terry O'Malley who is a physician at Mass General Hospital who is an internist in geriatric nutrition with an active nursing home practice at Mass General Hospital.

He's also the co-principal investigator and evaluation liaison on the ONC-funded project focused on improving Massachusetts' post-acute care transfers. He's also a member of the National Quality Forum on Care Coordination Steering Committee, the Care Coordination Measure Endorsement Maintenance Project and serves on the Board of Directors for Long Term Quality Alliance.

So with that let me have Mark as our first speaker and we look forward to enjoying the discussion this afternoon. Thank you.

Mark Savage: Thanks Dominick. Do I have any slides in here?

((Crosstalk))

Mark Savage: I'll mention that. So it has been wonderful for me to hear the presentations this morning on bringing a fantastic speaker perspective to my presentation this afternoon but it was wonderful to hear some of the details of work on the ground doing exactly what people have been trying to lift up and build into the policy at the federal level.

Marisa Scala Foley: (Unintelligible) in one second.

Mark Savage: You want me to just keep talking?

Marisa Scala Foley: Yes.

Mark Savage: Okay. So we often start first by asking ourselves at the National Partnership who are the people that we are caring about? Who are the people who are active in our - who are the people that we are trying to do this with? Not you, not (Flora).

Who are the people we are trying to do this with? And so we sometimes do something that looks like a demographic profile. And I took a look at some of the literatures and not so good literature on the long term services and supports population. This may be well known to all of you but I think it's a good role setting. So most live in community settings, residential settings. They're not just the elderly. In fact, over half are non-elderly. They are diverse by race and ethnicity.

In residential hospitals, 15% are African American, 10% Latino, 3% Asian, 2% Native American. And we know from the national partnership's health disparities work that health conditions and needs can differ quite a bit across those disparity barriers (unintelligible) information. We know that there are different kinds of disability. 89% have a mobility impairment. 55% have a cognitive impairment. We know that in these residential hospitals, 25% are living alone and 92% are receiving unpaid (unintelligible).

There's also according to the side literature, there's new (unintelligible) situations where sons and daughters are taking care of their parents. Parents are taking care of their children, and there - 22.9% of friends are the ones providing the unpaid care, so this is - because we're thinking about it, this is an illustration that one side of the plan is not going to (unintelligible), and that we need to have flexible adult in care planning tools in place to adapt to their respective situations.

So it's just an illustration of some of the statistics that I gave you from the literature, so if you'll go to the next slide please, here's what the national partnership and the - our coalition and consumer partnership for key health, which includes a number of leading charity organizations who are trying to do what we do and it's the federal policy. Some of our work has been trying to leverage the efforts of the health office and the national coordinator and the centers for Medicare and Medicaid services to build the - increase the adoption of meaningful use of electronic health records.

Care (unintelligible) the HR incentive program, this is an opportunity to build in policy requirements that are going toward electronic health records cost (unintelligible). Stages one and two are already in place, and we're now currently working on stage three, and what you have in front of you are some proposals that we have been trying to build into this third stage. The idea is that if we can get these deals built into electronic health records being used by all Medicare and Medicaid professionals across the United States, and they in turn are using it not just for their Medicare and Medicaid populations, so for all of their patients.

We've actually created a system, a national system, that will reach far more people than are being reached right now. (Unintelligible), so the important recommendations here, and I'm almost embarrassed to say took us all the way to stage three and (unintelligible) included, but to get the record into the EHR of the patient's goals, we heard a lot of that this morning, about (unintelligible) patients goals.

So we're actually getting - this is a proposal for appeal for these occupations and goals. There is a deal proposed for the designated caregivers, and we're not just talking about the provider levels. The - this would include people - the patient has designated persons that - and patient instructions. Now as you

heard this morning, these are tremendously important to people who are using long-term services and supports.

And what I would - what I want to take from this though is not just what's up there on the slide, what I was going to say - because so much of what you heard this morning went beyond just a few things that are right there. Long-term services and supports entails so much more in health. Go to the next slide. So I want to share a brief summary of the signature initiative, the national partnership and the consumer partnership for health (unintelligible) to develop care plans 2.0, which are health and care defining principles (unintelligible) environment to go beyond the care setting.

And my colleague (Erin Makai) was - has been leading this - the national partnership, and she's actually gotten copies of care plans to find out if you want to get those. A couple of points here, this is - we consulted with the - all of the members, the 15 organizations with benefits in our partnership for health, state, national, local levels, including the caregiver organizations now, and what is the importance to them for taking - or how can care (unintelligible), they're not just the care client but health clients.

This is the trajectory we're supposed to be on because you - to achieve the triple lane, and this is the definition that they came up with: multi-dimensional, person-centered, health and care planning process. It's not the technology itself, but it uses the tools and the dynamics, electronics (unintelligible) to connect all the individuals and persons involved, so you've heard about community resources. You've heard about family caregivers. This is the possibility of connecting that.

Paid caregivers and non-paid caregivers as appropriate, and the person would be at the center. It could provide actionable (unintelligible) is important

because as you heard this morning, most people would like to have a (unintelligible) in order to achieve the (unintelligible). A couple of illustrations, so and I mean, just to lift up what you've already heard this morning, this is ordered around the patient's goals, the person's goals.

That for some people might mean not in terms of what number their blood pressure is at, but rather they might think, I would really like to be able to walk two to three miles a day, and if you tell me that that's my goal or if I tell you that's my goal and I organize my health are around that and actually achieve reduction of my blood pressure, then I walk into the doctor's office and the doctor tells me to reduce my blood pressure by X percent, I may never accomplish that.

So this is specifically (unintelligible) designed around the patient's goals. It's also designed to connect to different community and social services. So we know for example that some people will have transportation needs. There are resources for transportation in community. Some people may have need to consult a nutritional person. That's available too. So you can build all of this - all these things - this is (unintelligible). We don't have any of this in stage 3.

But that's the reason we're trying to lift this up as a matter of policy. The last thing (unintelligible) is that in this vision that the consumer partnership coalition has lifted up, these are not just resources to be made available to the person as the percent of care. The notion is that when we think about caregivers as well, caregivers may have - especially if you have older parents taking care of children, caregivers can have some needs too.

We need to make allowances and - for that and to meet their needs in order for them to be able to meet the tasks they're trying to do as caregivers, so that is part of the vision as well. So I'll close with a sneak peak at a survey that the

national partnership has recently fielded. And this is actually (unintelligible) in 2011 and covers 2012, but earlier this year we did it for the second time, parents polled, (unintelligible) for us.

And we took care to pick people who actually had some experience, so they had a doctor, and they knew what kind of record system the doctor used. They knew if the doctor was using an electronic health record or if the doctor was using a paper record system. We had about 1000 respondents with EHR systems, a little over 800 paper record systems. We did (unintelligible) samples for the Latino, African American, and Asian communities in order to make sure that we built in that diversity.

It's so important, and we added some hot topics because we've been looking at care-giving and care-applying in front of the HIT policy committee, and so we actually asked the respondents what their views were on some of these topics that are becoming fore in policy discussions. Go to the last slide, please. So we - one of the things that we asked, we asked quite a few questions, (unintelligible). We asked them about the impact of online access to their medical and health information, which is (unintelligible) being built in at stage 2. And so that should be available.

And it will be continued in stage 3, but we asked specifically about the impact on key domains, knowledge of health, the ability to communicate, the quality of care. So - and we then differentiated that by how often they accessed their own information. And the key takeaway here, that when people started accessing their information more frequently online, there is actually a much bigger impact on things like (unintelligible) their quality of care, as they see it.

And as they become more engaged in (unintelligible), more involved, and they have more access to their information, (unintelligible) there's a

tremendous impact on the result. And for today's purposes, the last column, what (unintelligible) what was the impact on their ability to share medical and health information with their family or their other caregivers?

And once again, when they have online access and when they are able to use this more frequently, it's useful to them, they have a much more significant impact on their - well, their existing care (unintelligible). So with that I'll close and thank you very much for your response.

(Judith Wren): Hi, I'm (Judith Wren) for Partners in Care Foundation, and it's a community based organization and a change agent in southern California, so I want to chat about this transformational moment we're in, where we're trying to create a platform that really supports the sharing of information, greater dialogue about there are different kinds of care and care plans, and (unintelligible).

(Unintelligible), so what we're really looking at is dramatically changing the environment across reform, is this social services, community based services (unintelligible) opportunity to actually reach far more people who are in much greater need as does medicine, but to do so together. And that means two very important (unintelligible) learning each other, two different cultures, two different languages, two different (unintelligible) of power and capital.

So social services coming in has a new source of strength because of who (unintelligible), knowledge, skill, we bring in because we can't help build a speaker system for the voice of the patient and the family. So we kind of represent a new specialty. I'd say, well, in this specialty you have trouble coming in and getting recognized, but because we are potential to some of the new outcomes that are really (unintelligible) there's a lot of agreement that we need better outcomes.

We need right care, right place, right time, we want to reduce inappropriate use of the ER, and avoidable use of the hospital and nursing homes, so you know, my peeps, that's us, we're skilled at partnering with patients and families to get those outcomes. So these are opportunities really to enhance health and try to prevent avoidable crises and suffering by catching chronic conditions earlier, by managing transitions from hospitaling and from nursing homes to home or managing - avoiding transitions from home to those other settings, avoiding admission altogether.

Next slide, (unintelligible), so we're trying to integrate two such very different worlds, and that's an even bigger world, so we're kind of the new kid in town I think as CBOs that have to establish our credibility, show our expertise and (unintelligible) amazing reality of what the - what really happens when we say health happens at home, and (unintelligible) is a highly pressured, structured world that is (unintelligible) of the data's going to be critical to helping really put that in place.

And yes, to use information technology in the homeland community getting settled, it's (unintelligible) not that well advanced, and that's you know, health plans and hospitals pretty strong, but as we heard meaningful use has strength that doesn't involve that all - those other sources are used to finding (unintelligible). It's always looking or reading.

So I think you know, on both sides of medicine I think we based our invitation on huge culture change, huge general partnership of, of course, change on both sides, on the CBO side really standing up and having the skills for a true shared practice, having the ability to create new infrastructures, a partnered foundation, ACLs and working hard, national (unintelligible) business

documents, new kinds of infrastructures, and the ability to scale up to much larger populations.

So that's clearly critical for that. And then the whole world of HIPAA, privacy information, all the security issues, even cyber-insurance, which helps community based organizations that have to have in the past tremendous changes on both sides. And then there's really not a strong set of competing information technology and resources. They're emerging. I guess we're (unintelligible), but they're not many and they're not fully grown and (unintelligible) this broad array of fiscal services that are home community based organizations (unintelligible).

And are they wholly interoperable, flexible, comprehensive to the scope of service and care, affordable? We could ask almost everybody here to develop a go to market that's community based organizations (unintelligible). Still, for the community based organizations, information technology is the potential. Our organization started doing care transitions a year ago May. Around that time we were serving about 800 people in long term supports and services and a range of other people since that time.

With short term interventions, we served 8000 people. So the need to coordinate, manage, the need to build, communicate, internal care internally and partner with health services and to see that that scaling is essential to have tools. So information technology is not necessarily strongly represented in those organizational structures, so we (unintelligible) and we didn't need a help desk - we still need a help desk, but we need a strategic help desk for IT.

(Unintelligible) with a strong IT number, so lots more expertise and lots more capital investment. So as the foundations are stepping up after that, we've got a lot of training and culture change and CBO just ask in medicine the

introduction of IT in medicine was a huge change, is a huge change so to the community. So but we won't do it as part of the critical ways to communicate without all those preferences, all those choices, who I am, and I guess most of these don't include what do I want and where do I need it, because (unintelligible) organized strength and how to identify myself so I may be a piece (unintelligible).

We have problems in care point, but that's just transformational, what we heard this morning. But all these critical pieces because what's meant to happen, an understanding of someone in a hospital bed or a nursing home bed or in the doctor's office, but we like to think of the CBOs as the eyes and ears of the system, especially for people who are complex and frail or facing disabling conditions, to create a host of specific issues to be managed.

And that information needs to be part of what (unintelligible) takes into account, and we can't just keep doing two, there is a benefit from knowing who the person is and partnering with them and this vision. So these kinds of really basic issues, especially medications as one of the bridges where between the two worlds there's a commonality, because by going into the (unintelligible) found that we really are able to bring information that (unintelligible) can't live without medically.

And so it's been kind of a common ground if you will that we can find, because physicians are very (unintelligible) even to think about function, about a lot of people's ability to really move around in their environment or to access food or other just basic (unintelligible) are a good example. It's about 50% really of community living and health put on Medicare have significant medications issues because (unintelligible) but right now we don't know what the full schedule is, but right now we have multiple specialists.

And they all do things with individuals and care is still not fully coordinated. It's moving that way, that will help, but we may have found what the home edge program, which ACL and (unintelligible) is still a tremendous impediment problem of people especially (unintelligible) 52% of readmissions that are medical are coming from medications, and the huge surprise is in the home.

So (unintelligible) there's great leadership among the agent services network and they've been using the home evidence based software and found that as they looked into people's homes, 70% of people have medication related issues that the physician needs to know about. At least 25% were probably what we call therapeutic duplications. You go to someone and because your knee hurts, you get a pain med.

You go to someone because you're not sleeping, you get a something, and then you go to someone because you're having anxiety reactions, you get similar medications from different specialists. And suddenly (unintelligible) yourself, and geriatricians often are having to identify (unintelligible) combinations of meds. But that also falls under confinement, so on a community-based organization, (unintelligible) do gather meds, but they have to only when they're included in IT.

And even public health, but we always shares the information. We have a fully integrated record. These (unintelligible) stories about fall risks, about medication issues, come to bear. We did a pilot with a very fine medical group looking at patients coming out of the hospital and seeing what is the story about home and community based services, but that wasn't (unintelligible) the non-medical person could go to the home and not be distracted by medical tasks and actually pay attention to and listen to and observe the person in the environment and details.

And using of course (unintelligible) screening criteria, see who is at risk of readmission, of those patients, and this is a very good medical practice, managed care is coordinated if they can be. 66% had reportable medications issues the doctor needed to know about. That's after (unintelligible) to screen out the false positives, so dramatically powerful partnerships between elder persons, because they know the effect of other medical care, but obviously also in an environment - 77% falls risk.

The doctor would never know why this lady who kept falling, that the problem was that sharing her kitchen had (unintelligible). It just didn't work out well, so these are very important pieces of knowledge that community-based organization, a wide range, meals on wheels, the (unintelligible) program, care coordination, the transitions programs that they can gather, but how you get them to measure them, so you need a way in (unintelligible).

And I think we all know you know, multiple (unintelligible) mandated, many organizations have only a few major funders and typically many of them have been government funders, and so they have their required reporting, and so (unintelligible) are not necessarily what we really need, and those don't integrate those very often, part of you know, analytic family and quality improvement, track and learn for those since they won't accommodate.

And we have to you know, now we need to scale it right away. We have to scale over 8000 patients. Fortunately there was an IT. It was a lot more than we're used to paying, but it did the job and we were grateful. There's some skill (unintelligible) standard certification and ability guidelines to (unintelligible) for our main focus in the community and you know, you really want to get it right if you're going to invest in this kind of program.

You might need a central data warehouse and search multiple programs to be able to manage those different kinds of services and the many kinds of payers you tend to have. That's why it's complex, and those programs, they need to have interactivability (sic) as we have heard, as well as all the security, and then they need to support a range of functions in the agency, workload managing productivity, analytics, quality improvement, and then going and posting those payments and yet be portable and yet be secure devices.

We don't want any more to go into the home and work on paper and come back and enter the data. We want real time drive, and yes, we need full security on phones (unintelligible) subject more to protected information. We're finding out all these issues about cell phones, (unintelligible) what kind of encrypting we can do and all these things, so - and uploading the data into a system. We're working with Blue Shield now on our exchange commissions.

They're the sponsor and they want us to record it and we won't have the data. How are we going to get the data to all of these programs? And so I think it's a fantastically (unintelligible) opportunity to move our work fully forward and leverage that as a tremendous opportunity between medicine and social services together represented, but it's a major investment and a major and exciting time for invention and innovation in patient care. Thank you.

Man: Thank you very much, really an honor to follow (Judith). (Judith) and people like (Judith) have inspired my career literally, so thank you all for having me here. (Unintelligible) a physician, but I'm a pediatrician, and so my (unintelligible) is not from my pediatric (unintelligible) necessarily. I apologize if I'm a little bit (unintelligible) more so in my capacity as a CEO of a software company, and I won't really talk about my company per se, but rather the themes that I'm observing from the digital health communications base and how they pertain to the work that I think we're all trying to do here.

Next slide, so this slide is just trying to emphasis what in (unintelligible) the digital community sees in terms of (unintelligible). They see that reimbursement used to pay the hospitals as you went through it, and now reimbursement is starting to change a little bit towards more valuated care (unintelligible). Having said that, what a lot of my colleagues in digital health states are trying to create business models around delivering value as opposed to volume.

We're finding that hospitals will say something like it's a technology company. I say, hey, we're going to reduce your readmissions. Oh, okay, okay, cool. Well, I'm going to get hit with 100 (unintelligible) $18 account for my readmissions, and you all are a - not just technology but a service model that would be cheaper than $118 per readmission. And then the technology side will say you know, if I could identify the (unintelligible) patients that are actually going to be readmitted, and I can guarantee that they won't be readmitted, maybe we'd be onto something in the (unintelligible).

But if you look at the reality of the situation, creating business models in technology, or even service delivery around that $118 mark, then current standards of (unintelligible) transitions are anywhere from $400 to $1000 to $1700 per consumer per year to interactively keep someone out of the hospital, so the affordable care act has created an entire ecosystem of digital health innovation.

Most of the actual business models are really slow driven around fee for service. So it's one thing for us to continue the lines. Next slide please. But what's interesting though, is this space we're working in now, which is a space of long term support (unintelligible) consumers, this space for service tends to be higher cost for service than your average 56-year-old fee for

service (unintelligible) patient who may but probably not (unintelligible) the day after the (unintelligible).

This is the space that involves the eligible patients, the space that involves (unintelligible), perhaps medicating long-term care or patients who are reversed in that measure. And the opportunity here is interesting because now we have potentially very high cost consumers or patients and a real impetus to keep them from unnecessarily utilizing acute care resources, and so then the question becomes how can technology support, those very (unintelligible), those offering support services to eliminate the communication barriers between this and the barriers to effective care coordination?

And that's what some of the themes that (Judith) alluded to, how can we have a great, comprehensive system that serves all of the needs of the (unintelligible) providers? I would argue that there is no such thing as one comprehensive system, one technology that can serve all of this need (unintelligible), but I think it's going to - environmental (unintelligible) is more of – not that Apple has anything to do with it -- but an app store approach, where you can have general health innovations that can vary.

They can be varied (unintelligible) problems and then the aggregate of those apps or platforms together sharing data in a way that they can solve the whole slew of (LTSF) patients and providing their services. So this is a slide that's an example of when we help (unintelligible) areas on aging, and this area in which you (unintelligible), they try to have dialogue with hospitals and hospital CIOs, and hospital CIOs who work with EMRs (unintelligible).

But then they also speak to payers, and payers want something a little different and their policies on long-term care space when (unintelligible) different uses of that data. So a ten-year payer is something like who are the

(unintelligible) patients? Okay, so the (unintelligible). A triple A might want to know, well we deliver or we help to administer and coordinate meals on wheels services or transportation services or food delivery, lots and lots of geographically dependent help in long-term support and services.

So they might want to know which neighborhoods with the highest admission rates do you support active transportation? And other home care providers would say; they might want to know, and a particular patient needed to be seen by a nurse today, four or five community health workers that's half the cost of a nurse. Acute – the immediate post-acute care until (unintelligible), they are also now (unintelligible) for readmission, and so they want to know which day of the week should I be discharging the patient to avoid them bouncing back.

And the hospitals - now the age-old question; do they buy or bill a (unintelligible) program? Do they repurpose their own stock and try to get it out to the community, or are they giving back in communities, which may or may not have the data to show that they actually are a positive effect? So these are all of the requests of how data can be used that are being put upon digital health innovators.

And so the challenge we have and opportunity that we have is if we can create internal abilities database, and if we can create a common language for technologies to communicate without inhibiting those technologies from doing what they do best, which is figuring out what this customer needs, that is the holy grail of interoperability. Today what we've seen when it comes to interoperability are a lot of our ability (unintelligible), we have (unintelligible).

And a physician I've gone through (unintelligible) EMRs, and you know, not to be too blunt, but (unintelligible) all of them are truly building a system that allows my companions to go and build so that they don't get in trouble and they can (unintelligible) at the hospital, but me as the direct (unintelligible) so as the actual, you know, boots on the ground, ERs rarely actually help in the delivery of the care.

How can we avoid that type of mentality in that (unintelligible) or IT care in the digital health and innovation (unintelligible)? What I'm going to do is not waiting for standards to evolve, so I'm heavily involved in the (unintelligible) from you know, a federal level, but my, you know, real job is I am not waiting for standards to be bought. I want to help - you know, you shaped it a little bit, but we're asking our customers what do they need, and frankly we're helping to teach them how to ask their customers what do they need with the data, so that we can create a (unintelligible) network for care to say, well, I'm only going to reimburse you for the top 18%, most six valued patients.

Or the AAA ones, you know, which areas, which (unintelligible) can we not get abandoned to because it's just not (unintelligible) people, so they redoubled their efforts in packaged transportation. In the modern (unintelligible) risk guidelines, (unintelligible) but we absolutely can't forget (unintelligible), and I'll show you some of this in depth, the challenges that most of the evidence is around (unintelligible) patient risk based on ICD9 codes or client data.

But there's a black hole, there's a blind spot in between acute care utilization - the services that (Judith) provides in her organization, they need track patients on a daily basis. Why not use those trackings to reciprocate? And so on and so on and so on, so we're not waiting for standards to evolve into a whole new ecosystem. We're not waiting for standards to evolve, but they will smell and

hear, and if there's over ventilation, they might not be interested and they might go to the other interesting places where they can make money.

And so I think - I'm not (unintelligible) $5 billion of investment that went into funding digital health this year, and (unintelligible) last year (unintelligible), investors don't know what (unintelligible). They know aging because it's a data (unintelligible) kit. They don't know what it means to be functioning top line or (unintelligible) like have all sorts of accumulative terms, including (unintelligible), and you know, investors are (unintelligible).

(Unintelligible) people, okay? (Unintelligible) - anyway, here's some data to show that (unintelligible) so community based organizations using multiple technology can significantly drop their readmissions by about 40%. They can save approximately $2.54 for every one dollar spent, and they can substantially (unintelligible) for Medicare or for tools or for Medicaid. So that's great.

Okay, HRQ publishes data - on the right we have the publishers, the (unintelligible) but this can't be heard showing any red - sorry, any blue to the left of the green line is basically saying there are more true positives than there are false positives based on our risk tool, and what the risk tool is, is using a community worker, a (unintelligible) person, to make some observations and using those observations for patients that are (unintelligible) hospitalization rates.

What we now forget with a pretty good level of statistical significance, 30 day hospitalization rates using a $10 community worker, not actively (unintelligible), so this is any AAA out there in the country has this value to be able to create hospitalization rates. Now having advocated for having (unintelligible), other (unintelligible) practices have me concerned that it's a

great template, but there is so much (unintelligible) in each microsystem that AAAs are - that deploying evidence-based practices likely may not - it may not always - not only will it not potentially lead to the desired result, it may have adverse effects.

We don't know because many times in deploying our practice, we don't have 18 years of measurements about what I just described continuous measurement outcomes is quality improvement, so again we built into our technology and what I think the standards practice should support is how do we support interoperability standards that work in parallel with rapid cycle testing, rapid cycle quality measures, rapid cycle quality improvements?

This way the evidence-based practice that guides us to really effective work, especially in the community, it can be adapted in real time to the local nuances of the organization, the local nuances of the people that are being served - and - but I think - and finally, you know, I (unintelligible) if I don't close the deal and direct revenue, it doesn't (unintelligible) great value. But now - but in this conversation the fact that OMC and ABL are together talking in one place, it's actually creating an opportunity for money to be made for you know, not to be crude, but rich white guys who will then fund innovation that helps support the consumers in our working community.

There is now starting to be alignment there, so you have more people from Google and Twitter like my co-founded to not go, you know, join Apple, okay, or go back (unintelligible), or rather come into a great big unknown and actually have a financial driver to say we're going to save lives, we're going to prove aging or (unintelligible). Okay, by the way, there's an opportunity for scale because there's an up financial (unintelligible) behind it all. So that was my deal, and thank you very much.

Man: Thank you, (Unintelligible), so it's a tough act to follow. I'm going to keep this fairly simple. I'm just going to go over four challenges. I've been asked to talk from the perspective of a provider and a payer. Well, I'm not a payer, because I don't do anything from the payment side, but I am a geriatrician and I take care of folks like this all the time. So I care. I care. Okay, so these four challenges as I see them, they're really all actually intersecting.

But they are in many ways separate and they have their own issues surrounding them. And I think the first one, agreeing on what's important, that we've heard a lot today, and what's important to the individual, okay? Persons, not patients, the individual, so there's a third group (unintelligible). So it's what are the priorities and what really drives what's most important to them? So that's one issue that we have.

Second is how with all the services we're providing folks, how do we know that what we're providing is actually addressing what matters most to the individual? That's a question we have (unintelligible) we have to come back to yet, we'll touch on. No answers but lots of questions, and then finally in order to get this to really work and I think (Andre) alluded to that as did (Judith), but that we really need to have a common vocabulary between health care and support services, because they are two entirely different universes that are just a close touch but never really merge.

And now we're forcing them to really merge, but what they lack, among other things, is a common vocabulary. Is that right? They don't know how to talk to each other. They don't know what's important to them, important to the other folks, (unintelligible). And then finally even if they could talk to each other and had a shared vocabulary, and that vocabulary had to be directed at meetings directed with the individual.

How are they going to exchange information? Are they all going to be in one package? Probably not. (Unintelligible) a few hundred trillion dollars out there? (Unintelligible), but we're not going to build a single IT platform on which everyone is going to be a partner, not going to happen. We're going to have to figure out a different strategy for exchanging interoperable standardized information, so the next slide please.

So this is sort of what matters most to the patient, what matters most to the individual, (unintelligible) what matters most. And it's not preferences in my mind, but really this is priority. What do you rank as the most important thing for you? And it can be across a whole bunch of domains. The domains we use in the longitudinal coordination of care, (unintelligible) workers just based on a domain management model created by (Hillary Stevens), (Stevens) management model.

And it really has four big buckets, and buckets were med search, quality service, standard health care issues, the issues around cognition, behavior, mood, spirituality, stretches a little bit, you know, the idea that this has impact on behavior. Third and most important (unintelligible) of geriatrition, everything provides a function, so functional status is what is this that you can do? What do you need to do?

And finally the fourth big bucket and functionally makes sense in the setting of the environment that that function has to occur in, the combination of environment and function, so to help this going on, what's out there? How's the transportation, phone support, you name it? This is sort of the catch all, but if you were to ask someone, what's most important to me, they might pick an item in each of these buckets, in only one bucket, who knows?

The point is that we were trying to be as all inclusive as we could. I mean, whatever concern or priority an individual has, it could be represented in the model for the longitudinal coordination of care. And we then took this, some of these four concerns as we call them, and we set up a master list designed to catch interventions to these concerns, and the other (unintelligible) and then finally assigning who on the care team (unintelligible) those patients, families, home supports, or the health care team.

But look at design to it, (unintelligible). This is sort of a model of how do you know what's most important to the patient, and we sort of drove it back to the issue of identifying the priority. And the priority really comes with the importance (unintelligible). The second piece, next slide, so how do you know that the priorities and the services you've provided are somehow aligned? And we use the term concordant.

How concordant are the priorities identified by the individual and their family and their caregiver as much as the individual itself, constructs around the individual? How do those separate the line with the priorities of the care team, whoever they are? And how do you know that what the care team is working on is what the individual and their family and caregivers want to work on? Well it turns out that within the - you know, this is a different domain (unintelligible) they have ACL set the international standards, but through created a knowledge map with they call this and then a knowledge model.

Within that knowledge map or transferring health care information there are concepts around patient priorities, (unintelligible) priorities, key members, goals, interventions, and finally there is a hospitalizational (sic) concept (unintelligible) that allows us to link all of those concepts, because there's no denying that the impossible amount is possible by being done within this new construct of their information.

We actually link priorities to the patient and the team and the caregiver. You can do that on the basis of exchangeable standardized information, so within the concepts of the interoperable health exchange based on the standard electronic exchange of criteria required, we can now measure concordance. It's never been done, but it's there. It could be done, if we wish to do it. And it really gets to the - my final point on this slide.

And that's if you're thinking about an outcome measure and we're talking about the metrics, and this is my attempt at a patient-centered outcome measure, and it's really that my priorities were addressed in a manner acceptable to me to create an outcome I value. If you think about it, if you could ask - if you were to ask Mass General (unintelligible), how many times have you indicated in your record the patient's priorities? I know the answer to that. Zero.

And if you had said, how many times have the priorities of the care team and the patient been aligned, I know the answer to that, too. We have no patients, right? We can't prove that. But if we hadn't published the fact that only 10% of our discharged patients had priorities listed and they were actually concordant with care - or the care team was concordant with that? And we probably (unintelligible) CMS Web site.

(Unintelligible) doesn't sound good today, but anyway, maybe they've changed it. Next one, so moving on, how do we talk to each other? How do these two entirely different systems, different cultures, different hang-ups, the one thing that really unites them is the fact that they're skeptical around staying individual, but they're doing different things. They only touch by the individual. They don't have a common way of talking to each other.

So I think one of our next big challenges - fortunately this is being addressed - is how do we create a common standard, a common vocabulary that allows us to measure function in a home that's operated A, surgically, but report it in a way that is consistent with how hospitals report function, how a care team reports function? So how do we get on the same line, which I think the line which is going to have to be the consolidated (Cidual), but they're doing different things. They only touch by the individual. They don't have a common way of talking to each other.

So I think one of our next big challenges - fortunately this is being addressed - is how do we create a common standard, a common vocabulary that allows us to measure function in a home that's operated A, surgically, but report it in a way that is consistent with how hospitals report function, how a care team reports function? So how do we get on the same line, which I think the line which is going to have to be the consolidated CBA, HL7.

That's the one meaningful use that is required (unintelligible), will be the one that probably makes sense for ALS to have to acquire and internally develop, because somebody a lot bigger than you has already put it in place, and you might as well go with the flow. But I think that what we - the challenge is going to be that there are probably several concepts that are very familiar to health ESS. They're (unintelligible), the no representation at all, no one - the data itself and the value of (unintelligible).

There's a lot of work that's going to come just to build this vocabulary, but it's doable, and the task ramp, and the (unintelligible), and the new work that's being set up by (Unintelligible) and (Owen C), on the (unintelligible), which is a (unintelligible) commercial, so everyone (unintelligible). And then there's two elements that are already in value with us, connect, and the final slide, (unintelligible).

So even if we had this common vocabulary aimed around (unintelligible), how do we get it to each other? How do we exchange it? How do we just function with different IT systems that are out there, all of which by the way, share one common factor. They're all designed to maximumly (sic) build the services to your eligible people. They are not designed to deal with managed care, to coordinate care, to exchange critical information.

So we need to create a - not just a parallel system, but take a good step out of the system we have, the valuable information that we need to exchange, and put this in a medium that we can exchange readily. We've got a (unintelligible), I don't - HL7 is as far as I get, consolidated CBAs, but you know, we need to - we need the highways, so some of that may be in the electronic health information exchanges that are non-universal.

(Unintelligible), so you know, maybe there's another cloud-based solution you know, HIB or a like solution. So we have the trust. We have standards for exchanging information by consolidated CBO and HL7. We've got the current (unintelligible) a lot of the data elements for a new CEA update that came out last year, has those concepts for function and (unintelligible), issues that are really important to both sides of the - all the (unintelligible) health care design.

And then finally what's new in the last year are easy ways to get on and off the pilot, and you don't need to spend a billion dollars. You can get on the highways, with Internet based Web page tools that are very (unintelligible), and you're $100 (unintelligible), so the barriers to being on and off highways to exchange standardized information are really (unintelligible). What we need, (unintelligible) we need more (unintelligible).

We need people that really work on how are we going to exchange this (unintelligible). So what are the big challenges that we need to get to the - better equipped matters to individuals, which is their priorities. We've got to be able to measure that our services meet those priorities. We've got to find a vocabulary where we can talk to other with, and finally we've got to be able to exchange the data (unintelligible).

Woman: Okay, so (unintelligible). So now we're going to open it up for Q&A, so as far as folks in the room, if you want to make a comment, please go up to the mike. I have a few housekeeping reminders. I will first of all also ask the operators to start queueing up the line for questions on the phone. I want to remind everybody that when making a public comment, please state your name and organization, and remember that you have three minutes to comment. I will give you a thirty second warning, but (unintelligible) we'll have to ask you to wrap up your comments. And so we'll start here in the room and then move to the phones.

(Carol Roberts): Hi, I'm (Carol Roberts) again. I'm from Econometric Incorporated. I wanted to make a comment to the last speaker and (unintelligible) I've been a nurse for 25 years. I worked in MediSearch, I worked in hospice and I worked in home care, and every patient I ever cared for has a processment of his, of her capabilities, and that assessment of what his or her needs would be at the time.

So unless things have changed a great amount with nursing and I don't think they have because I taught nursing for a decade after that, I think if you go to the electronic health record, you will find in the nurse's notes, maybe not in the standardized field because there hasn't been enough thought put into standardized fields, but good nurses are documenting excellent care, and part of excellent care is defining what are the needs at home and how can we do that gap assessment and fill that gap, because we - so we're taken care of. And

we want to do that in a way that we don't get to see that wonderful patient again. We see them in the next 30 days, like (unintelligible) efforts.

Woman: Thank you. Now I'll go to the phone. Operator, do we have any questions? Do we have any questions from the chat?

((Crosstalk))

Woman: This is a question from (unintelligible). In (unintelligible) included in the poll and if not, why? And (unintelligible).

Man: So to the extent that they - that our committee is and it all happens, or the heart of the - overall decide what they were, included, and you know what happened with maybe the data about how (unintelligible) they were, but they were not over-sampled. The other samples were however to reach out to our populations and make sure that they were because of their residential status (unintelligible) they are tenacious. They were over-sampled, so we have statistically (unintelligible). Short answer, Native Americans were included and (unintelligible).

(Terry Daniels): And this is (Terry Daniels). If I could respond to the gentleman, so (unintelligible), it's actually the nursing model of permeating the model that came out as longitudinal coordination of care workers so trials, interventions, and goals for an extended amount of time. But one of the issues and one of our big challenges is that a lot of the observations that nurses make are not required that any documents be sent to anywhere else.

So you have just another example of sort of (unintelligible) and finalization of the data, even though that information would be incredibly valuable to all the other providers, and similarly if you have a nurse case manager, the

observation about the assessment (unintelligible) because they share I think - nursing and LPA probably share a more common (unintelligible) than the other types of (unintelligible), so just wanted to comment on that.

Woman: Okay, that's great. (Joanne)?

(Joanne):   Hi, (Joanne) (unintelligible). A couple quick questions, (unintelligible) meaningful use history and where people could weigh in and try to improve things and make sure that these things get through. (Andre), I wonder if you can comment a bit on the very different financial stakes when you're dealing with Medicare or ACLs?

Woman: (Unintelligible) I think there's a real shift here going on to understand not just in the medical community level, but at a provider level, not just getting community based care, it's not the best home care, you see, well that nursing home, so what they say they're thinking, central (unintelligible). What we need to do in terms of our electronic connections to covering that shift.

(Andre):   So in answer to your questions, a lot of our good giants make recommendations of all of the various committees, DHS policies and committees, and (unintelligible) recommendations transmit to (unintelligible). We are told my (unintelligible) that there will be public domains and draft forms issued this winter, so specifically noted that that's going to be good.

We don't know where in the winter, whether it'll be at the end of this year or sometime in - sometime early next year. At that point the public will be invited to comment. The national partnerships will be preparing analysis and we'll be making direct comments.

Man: Thanks for that question. You bring up a great point. I think from my customers' perspective, it's an (unintelligible) a lot of newly developed areas because there's a lot more margin in their pockets that they can realize, and just all of our numbers if you look at (unintelligible) or carries right now, especially if we don't get our tools back, you're looking at anywhere on the lower side of say, $1800 per (unintelligible) of (unintelligible) $3000 per room per month.

It may be - not to get into the 85% (unintelligible) nuances, but right now the margins that they achieve on that are if they're doing really well, there are 3 to 6% margin. If you look at the inexpensive nature of home and community based services, assuming they can deliver on reducing acute care utilizations, they can drive up margin volume 1, 2, 3 percentage points. I mean, you're - instead of having a nurse and doctor led delivery model, you can have someone that is a $29,000 a year or $40,000 a year primary provider or providing primary intervention and as needed intervene with the nurse or the doctor or the social worker.

Then you can have payers that are consolidated over their financial savings, not to mention that withholds for volume metric is not a dual pilot plan. It's a pure Medicare (unintelligible). You'll be starting - I mean, even though the margin on the stop point start reading, you're talking about a (unintelligible) so if - when it comes down to it, when I advise my customers at AAA that they - this is something they should probably tell the payer, and then they go and tell the payer well we'll (unintelligible) a two month pilot.

If we hit the pilot threshold you pay us a percentage of your revenue, and then the payer, and then as long as they go into a pilot saying here's the measure we're going to use at the end of two months to go into the larger KD pilot, deals get signed. AAAs are signing deals, (unintelligible) there's like 25 of

them in the country that are really, really doctors that benefit from ACL membership and Hartford Foundation membership.

There is no early return. Everyone else is back to back, so it's rarely (unintelligible) and back to the task. I think interoperability has the potential to actually create more of an early return used to get into the game, went by agreeability and a method accepting what we have and lots of different organizations gathering information. At the moment it's just so - it's a mess, the system, but even if it does - the medical system doesn't measure the outcome, (unintelligible) waivers that saves money for Medicare.

But it is demonstrated, so I think it's very, very crucial that the quality improvement and the results measurements be integrated with Blue Shield. Now their exchange patients, they're testing a new benefit, just what I see (unintelligible) with PTTPs, most success and they'll benefit from Medicare. Blue Shield's doing random controlled trials, so there are folks starting to look at the hard changes in service use and patient satisfaction, patient preference based on these interventions.

And early adopters are always going to be early, and then if we get an update and assure them consistency and quality I think that you know, today we can take and then we transform lives since we can really say all these things. But (unintelligible) trying to be (unintelligible) these people are hidden from us in the community and then the community has to deliver in a consistent way and then the integrated communications structures and their refining and shared care delivery has to be put together.

Man: (Unintelligible) so it's - as far as metrics go, I think in my mind the basic metric - you know mentioned metrics, I think it's so important to start with you can actually do - get out there and stay very simple, and so probably one

of the things that might help the data bank adjust would be testing anyone spending an individual - or requesting services from one vendor to another based on value, it has to be individual. What does the individual prioritize?

So if you just sent me a list of priorities and you're sending a patient to my nursing home or hospital, (unintelligible), that would be the start of a chain, because I would clarify that. I'd add to it, and send it off to the next person. So I think exchange priorities, (unintelligible) with that one simple step I think we can build a whole bunch of metrics on top that.

Woman: Okay, I've been made aware that the operator may not have made an announcement to the folks on the phone, so I want to give folks on the phone the opportunity to provide comment if there's anybody that wants to make a comment, operator?

Coordinator: Yes, if you have a question, please press star one. State your name and your affiliation. We have a question from (Miss Abigail Morgan). (Miss Morgan), please state your organization. Thank you. Your line is open, (Miss Morgan).

(Abigail Morgan): Hi, yes, this is (Abby Morgan) from direction home area agency on aging and I'm from Canton, and I apologize. I'm having a little trouble hearing so if this was already addressed my question is to (June) around best practices, of addressing IT and security concerns with payers. What we really see a need for is kind of what is a single or streamlined strategy for working with health plans or working with our payers to have access to the data that we're entering into their proprietary platform at any given time across different payers.

We see a need to build the level of sophistication for analyzing the data for the people that we're working with in the community for planning and targeting services, and also improving our performance, but we can't get access to data

in a useable fashion because there are these IT concerns or HIPAA concerns, and we just need to know how to talk to plans about these questions.

Woman: (Unintelligible) for funding, I know (unintelligible) and (unintelligible) will be building some tool kits for home and community based organizations from a learning prototype building under the Hartford in partnership with the administration on community living, that at our agency we have to go to a health law firm and get records of a top tier security consulting firm and engage them and have the full agency on it, learn all the rules and all the ways that we're - because one of the surprising things that the community finds are no smaller than health fines or breaches, but a way much smaller pocketbook.

So the risk, the moral risk is high but so is the business risk high. But then I think it's that the plans and the physician, whoever's the payer, that guy will impose through a contracting process whatever their requirements are, so Blue Shield does that with cyber insurance. We don't have cyber insurance. It's a good idea, I guess. So now, do all the agencies just kind of have to have one, or can a network be built with a shared infrastructure that creates a new community based integrated delivery system that's easier to work with so that these costs are not duplicated over and over and over?

So I think it's very important to share the learning, and we have been (unintelligible) and meals on wheels and Hartford and ACL and lots of groups coming together to build tools and share the learning and then building integrated delivery systems that don't duplicate the costs. I don't know if that answers your question.

(Abigail Morgan): It does, thank you. You - there is such a need for a coordinated strategy in this space. I feel like we've all made so much progress in developing our contracts

and developing the partnerships needed and this is kind of the next step that we see that we need to develop across our region but also across our state.

(Kelly Cronin):   It is. Okay, so it is break time, so I want to thank everybody who has made a comment or a question, also to our fabulous panel. I also wanted to provide a reminder that if folks wanted to leave 8:40, we'll need an escort to come back up, so find one of us to help you with that, and we will have a ten-minute break, so we'll see you back here in about ten minutes.

To the panel that will be discussing (unintelligible) programs and (unintelligible) advanced person-centered planning. And I'm (Kelly Cronin), director of care transformation, LLC, and I'm just going to get started now with just some comments and then introduce our panelists. First of all let's just thank the last panel for an amazing set of presentations and the dialogue after was really terrific.

And I think it really keyed up a lot of the issues that we're probably going to touch on across the three presentations and then the panel, and hope to give you a better sense of what state and federal governments are trying to do to advance person-centered planning, and really take this opportunity (unintelligible) a delivery system (unintelligible), be thinking about the individual's needs and priorities and values and really what matters to them to figure out what is the shared care plan and integrate that with the service plan and long term service and support.

So really think holistically about where we can go and I think well, there were some really interesting observations in the last panel that were still really were operating, and I think for a service environment, there is a real commitment not only with the department of health and human services to advance value-

based care and (unintelligible), but it's rapidly impossible across (unintelligible).

I think commercial payers are also being as rapidly as possible to various forms of accountable care and value-driven payment. So we are a shifting environment, and there's an increasing amount of financial incentives, critical targets, and I think you know, as we touched on it's really a moral imperative to get this right, because frequently as you know we're getting (unintelligible) for shipping increased (unintelligible) over the next 78 (unintelligible).

And large over time, frail elderly, but just any aging population, that's really going to be in need. And these meetings to this person-centered approach and the integration of these services to make sure that there is - there's been a - they're living life the way that they want to. So just wanted to touch on a couple of things that we've been hearing about and honestly we've been talking quite a bit about care plans and tri-care plans.

However, there's not a lot of context of you know, what might be part of sort of future stages or the HR status program and how that involves their certification we have, and there's been a lot of work as far as standards development which you'll hear about on the panels, which is exciting and being implemented now in different communities across the country, but we also have a hearing on the practical realities of where we are today, both in our accountable care work group at our health (unintelligible) and our health IT fellows.

We're going to hear how they're challenged by existing EHR vendors that maybe have a care plan module and they think it will document a person-centered goal, but they are not dynamic. They're not allowed to be entered as far as the point of service team to have this individualized, personalized view

of that plan, and they can't really all maintain it, you know, because (unintelligible) are really going to be (unintelligible) virtual.

People (unintelligible) devices are going to have to contribute to maintaining that plan, creating and maintaining it, and right now we really don't have all of the dramatic option - (unintelligible) option of endless range of care. The schools aren't - and (unintelligible) schools aren't really set to allow for the interdisciplinary character obtained to do what we've been talking about all day. That said, you know, we know there's current innovation - we've been hearing about the innovation.

There are some care management software platforms we've also been hearing about, especially in the context of medical health problems that allow the case manager to make sure that long-term services and support is being integrated and contributing to the care plan itself and (unintelligible) at a community level and that the key health providers, primary care providers, also have this data and are contributing to it.

So I think there's a lot that we still need to understand like where does this person-centered care plan get created and when? Is it in their file? Is it community level? Is it case - you know, is it a health column? Is it you know, is it part of what maybe a future community governance model that (Joanne) was talking about (unintelligible) earlier? So I think it's an exciting time.

There's clearly a lot going on for us (unintelligible) to advance this conduct and really do this through a few different models and get our communications out there and about, also testing of new care models after scaling in a couple cases, doing that through state-led reform. States are very interested and the LCSS and really shifting away from institutional care, getting into community

and home-based care and making sure patients are highly independent with the least expense possible.

And so I think there's going to be a lot in here about this, but it is still early days. There's a lot left to figure out. So as we move to the last part of our meeting today, we will try to sort of tie together some of the themes. So why don't I go ahead and introduce our panelists and we'll go ahead and get started with the presentations? We have (Jean Boyd) with us from Minnesota. She's been directing aging and adult services in Minnesota Department of Human Services.

She's also the executive director for the Minnesota Board on Aging and she's been very (unintelligible) with the elderly waiver and alternative care programs and senior linkage (unintelligible) and Minnesota health information and many other exciting programs, and I think just to give you a preview of her slides, a lot of interesting insights to share with us from a lot of different initiatives that are going on in Minnesota looking at our reforms.

We also have Dr. (Max Fress) who we're welcoming to HSS in a way, so he's somewhat new to our community, but we're delighted to have him onboard. He's in the center for Medicare and Medicaid innovation and is peer advisor to the director. He is a board certified general internist and previously a clinician at (unintelligible) college. And his research is focused on care coordination, and if any of you are interested, he wrote a terrific article on (unintelligible) and (unintelligible) care coordination (unintelligible) together write typically with sort of distributed virtual team of professionals working to coordinate assigned care.

(Les Claycalls) is a colleague of mine and (unintelligible) LP path coordinator and a nurse by training with a dramatic background in NDA, terrific member

of (unintelligible) coordinator on policy and areas of related (unintelligible) and has done a lot to better the certification specifically the last couple years, and then Dr. (Cuchinda), the executive director from South Aberdeen from the VA is here, just joined as well and has an interesting experience to share from the VA, particularly as they're paying for their efforts to incorporate social determinants into electronic health records and into (unintelligible).

And then finally (John Toshiga) (unintelligible) is the director of the national institute on visibility and kind of looking at rehab research. He's spent the last 15 years using data research to drive policy change. He came from a line of health in Minnesota where he served as director of policy, public policy and innovation, has a tremendous background related to (unintelligible) today, and (unintelligible) around Manchester College. So I will go ahead and turn it over to our first presenter, Dr. (Fress), and - I'm sorry, no, (Jean), (Jean), yes, sorry.

(Jean Boyd):   Thank you. (Unintelligible) I'm going to talk about what Minnesota has done in this area by (unintelligible) have used, policy we presented to be getting familiar, and specifically we are looking at currently at making integrated personal alternatives available to like right now, our (unintelligible) and concentration is to withdraw a case maker with just two eligible, but ultimately and through the practice we would identify to everyone that we touch, including those under the older Americans act and the individuals who are pre-eligible.

In our vision, we are doing this across all populations that we touch with a (unintelligible) waiver, and who might be truly eligible, so we not only talk to the elderly, but maybe those with physical disabilities, persons who have (unintelligible) disabilities, and also across all funding sources. And the state has had the opportunity to learn support in the race. Several major policy areas

have to support each other, including areas like care transitions, person centered planning, (unintelligible), electronic health records, family caregiver support, aging and disability resource center, just to name a few.

So what really draws us though was the idea that we had a medical system that somehow believed that 15 minutes with a doctor a quarter or half an hour with a doctor a quarter was quality health care, when they were spending the rest of their hours, the rest of their time in the home and in the community, and that is really about what quality of life was about. And so this started as our goal, (unintelligible) looking at electronic health records and looking at integration of (unintelligible).

And so our vision starts with better outcomes and quality of life, and helping more members of the community that are transitions for people and their caregivers moving through health care support and long-term care services and supports. We believe very firmly in early intervention with meaningful and usable information so that consumers and caregivers can make important decisions all the way.

And then when we look at - I didn't bring new policies into what we do as a state, we're also looking at sustainability of long-term care services and supports funding and health care funding, our belief is that if we can deliver more efficiently and more technically, that will also really be what sensitive care (unintelligible) and also (unintelligible) markets, so we're going to talk a little bit about the - some of the building blocks and start with Minnesota service strategies.

And these kinds of things, this is what's in my background. This is what's in our DNA. And first thing is that we have a fairly highly developed integrated health care philosophy within the state. We have integrated public health care

prior to the go back - quite a few years, and (unintelligible) supports the primary health care. Medicaid managed long-term care services and support I know has gotten a lot of talk here recently.

We have been looking at that, working with that through our health plans for a number of years. We also want to know the strengths, gaps, desired outcomes for people from a person-centered planning process, and in doing that we have developed a comprehensive assessment of a person-centered plan we call good choices, and we're also just did some person-centered planning, thinking, training, and this has been fairly early on and still in the process of for us with the person-centered thinking was a - is a culture change.

It's not a method. It's a culture change. It's the first thing you have to do is get it into all your people who are touching people they serve, even if they aren't going to put anything into a health record necessarily, and then we also believe in giving good quality information on community service choices, and an advocate health (unintelligible) to answer the question. And so we have several areas in which we could (unintelligible) that.

In kind of a way, we were working with e-health, also, and so we started a savings how is your home initiative that required that the health care home needs to know all about care plans and this is through the department of health. We also worked with dissemination of the administrative high tech brands along with sort of help our TIO in this coordinated (unintelligible) use for hospitals and clinics.

Our state e-health law requires that by 2015 that the exchange of waiver service information home care has to be present in our electronic health records and that goes back quite a ways. And so I'm very positive, really concentrate on the personal health record and to talk a little bit about next

steps, and just a first start (unintelligible), individuals (unintelligible). There's no reason that we should be keeping them somewhere not having them use it.

It's a part of their person-centered planning. It's really a building block in terms of saying it comes first, but they are linked together. I think that due to the quality of life in developing home and supporting caregivers with systems and cash (unintelligible) for us to help the state. So through our (unintelligible) to our work with stakeholders, we know there are something they really need help with.

An the state really needs to have people thinking about this nationally. The first thing is that we have to develop services and supports data sets between the exchange forms, and it has to become (unintelligible), and that's what told me that we can necessarily do a vote. We need to have some input in how to display it for understanding by participants and sort of how to best use it, because to give people 200 points of information is not very helpful.

You need to give them 10 points of information and then they really, really have time to reason it out. We know that we want our data set to include assessment, clinical care plans and service plans. We know that for sure, and then for us, of course we have several health information exchanges. We need some decisions made around the health information exchange infrastructure. And so again, those are things I know that our previous speakers gave good examples, and scrutinizing some inside challenges that resulted in (unintelligible) and in effect this (unintelligible).

(Max Fress):   Thank you, (Jean), that was very interesting. Thanks, everyone for sticking around, the (unintelligible) for inviting me here. I'm thrilled to be here. As (Kelly) mentioned I'm actually pretty new to the federal government, and have been at CMS for about two months, but I think that my background in

primary care physician and office researcher has given me some insight into the issues that have been discussed today.

And thanks, (Kelly), for the slides on the article. It's no exaggeration today that coordination of care is my passion. The way - you know, the way certain of my patients, coordinating their care was a top priority along with diagnosis and everything else that we traditionally think of as physicians doing. I (unintelligible) with my research focusing on studying and improving how clinicians communicate with each other.

And that was (unintelligible) in my journal, so it's that experience and insight that I'm trying - that I brought to PMMI and actions, fortunately there are some folks at the innovation center who are arguable subject matter experts in this. We have somebody on e-health from ACL, with the PMMI, and some other folks. I didn't want to search the room who was next (unintelligible) patient centered planning, so expect they're a real benefit to have that expertise in the underlying.

So I want to just spend a few minutes giving you an overview of what the innovation center is and what we do. So we were created from the affordable care act, and our purpose is to pass the innovative payment and service delivery model to reduce program expenditures while preserving or enhancing the quality of care furnished to individuals under such titles. So I'm not sure if you can see this from the back, but I want to give you an overview of the types of programs that we're running payment service (unintelligible) at the innovation center.

And some of these may be more familiar to you than others, but I want to just run through the broad categories. So the first and perhaps the most well-known are accountable care organizations, and we have several different -

under the ACO programs by including the (unintelligible) ACO model, then shared savings, and then comprehensive (unintelligible) care initiative.

Then we have the center models for testing under the broad category of primary care transformation. That includes the comprehensive primary care initiative, which is a healthy (unintelligible) initiative to transform primary care. Several of us also - several models in the primary care transformation category. Next is bundled payments for care improvement. It's a program in which acute or acute and post-acute care services are bundled.

And then just to hit a couple others, again at a high level, we have quality improvement programs like the partnership for patients, health care innovation awards, state innovation models which actually fall into (unintelligible) over here and we're going to spend a few more minutes talking about, and then (unintelligible) focused on the Medicaid (unintelligible) and Medicare and dual eligible (unintelligible). Next slide.

Okay, at this point we have innovation really literally occurring throughout the country. There is - as you actually go to the innovation (unintelligible) studies and kind of zoom in and see which models are actively in which parts of the country. Next slide, so again I just wanted to drill down a little bit into two of the models that I mentioned earlier. The first is the accountable care organization, and just wanted to go over the goals for those who may not be familiar with ACOs.

So the goal of the ACO set of programs is to improve the safety and quality of patient care while lowering the cost, promote shared accountability across providers, increase coordination of care in best infrastructure resigned care services, achieve quality of better care at lower cost, and just to know that

Medicaid and prior care is (unintelligible) launching both ACOs and other forms of alternative contracts.

Next slide, so the sustaining of aging models really is a fascinating program. Just the innovation model partners with states to develop broad-based state health care innovation plans and the round one of the innovation model included state implementation stage, and then came the nine or pre-testing stage, and the goal really of the plan was to test and support new patient service delivery models that they were all utilizing as tools and policy levels.

It's never their level state, particularly the AHA, a broad group of stakeholders in future iterations and coordinating all those strategies there as providers into a plan for health system improvement. So you know, I'm going to add this looking forward at the innovation center, we've got a few - a number of things that we're focused on, including continued limitation of models, moderating and evaluating how to get results, evaluation of the current model and (unintelligible) models.

Continuing to integrate innovation across the method, not just with any (unintelligible) and then to analyze our portfolio pretty much, new models to round out the portfolio. So thank you again for having me here and your support to (unintelligible).

Woman: Hello, again. I am (Unintelligible) in Washington territory to (unintelligible), and we've heard a lot today about (unintelligible) and you know, across care settings and also you know, coordinating care among the people that provide care to the person, whether it's at home or in other - a designated care setting. So that brings me to (unintelligible) interoperability business, and I really just want to talk to you about how this (unintelligible) what we've been discussing today.

You know, it's not just about mainstream providers. It's about all the stakeholders across the (unintelligible) and we have integration (unintelligible). And so as (unintelligible) increase, better quality and lower costs and population healthy, and it supports health. And it's not bringing people health care information, but all the things that we talked about today. You know, it's supportive information into the picture so that we're - have a whole different view of that person.

And it's about building incrementally from the current technology that we already have built within the (unintelligible), it's a huge investment and it's in health IT and how can we leverage that to expand upon (unintelligible) for the state? And we think about how to invest in as soon as possible, so what are those key bits of information that need to be available to the income across the - I think we'll move across settings and when you're thinking about coordinating care.

A lot of times when we're talking about care coordination, that's an ounce of (unintelligible) passed between different providers, but it's really about what is - what's the data that's most valued, valuable, and that needs to be sustained (unintelligible)? And creating opportunities for information, so we talked about various models and how - and we be supportive of that information.

Empowering and engaging individuals so providing not just the care, but engaging individuals in their plan, and so the next two are talking about the milestones, so we have divisions. It's really broken down into time increments, and so in the first three years, it's really - the focus is around settings and savings, (unintelligible) health information. In the next six years, it's about expanding those sources of information and the users that are able to access information.

And continuing to improve upon quality and lowering costs. Increasing automating (unintelligible) and (unintelligible), and then quietly (unintelligible) to really build upon our evidence base so that we're able to afford that process in much clearer cycle. And so some of the five building blocks that we've already fond outlined for this vision is really around of course establishing the four steps of technology standards and functions.

Having the sort of indication which can support adoption and the automation of health IT, having privacy and (unintelligible) attached to all information, having supportive business and clinical, cultural, and regulatory environments, and full engagement from clients. So one of the key features and it's the talking about leveraging (unintelligible) infrastructure, and yet as we talked about earlier, my friend (Molly) was - there was a (unintelligible) eligibility framework, and this is an approach that (unintelligible) standard highly trained together community of persons (unintelligible) fill roles their own ability challenges.

Previous initiatives really looked at (unintelligible) interoperability on account of medically (unintelligible) characters, so part of this initiative was updates to consigned PDA standards, with these two for transitions of care and care planning. And so we're excited for that, but starting in November, there will be a new initiative focused on a longer sort of support, and it will build upon this entire initiative.

And this is found in support of - in collaboration with CMS and the attachment program, which will be discussed in a little bit more in detail by (unintelligible) our next panel. But we - for this initiative to be successful we really need patients from a broad community of stakeholders. So I'm going to call up my colleague (unintelligible) who is in the audience today. Raise your

hand, (Unintelligible). She will be the coordinator of this initiative, so if you're interested in participating either email or just chat with her today, and she'll be meeting with you (unintelligible).

And finally I want to talk a little bit about certification. So one of the other areas that (unintelligible) evolved in certification, and we are currently examining areas where we can expand certification for interoperability, and for the first step, have them looking at (unintelligible) care and (unintelligible), but they will be also looking at other areas. And so (unintelligible) really supports communication across care settings, and it supports key business of (unintelligible) and right now areas of transitions of care and (unintelligible) help to improve the state and use of information.

And so the modularity aspect of it is one issue (unintelligible) ability of providers to adopt criteria that gives people their functional needs, so I will stop with saying again, we encourage you to engage in our future work, and thank you very much.

Woman: Thank you. Thanks, and (unintelligible) represent (unintelligible) and actually I'm wearing the hat of my division (unintelligible) program (unintelligible) where this has been (unintelligible). It's housed by - I'm very excited to be partners with (Warren), and (unintelligible) but I feel that we are helping people and we are happy to be here with you (unintelligible) and I'm here to (unintelligible) a project that we envision of course on finding Medicaid and we finally are working a couple of states in the beginning of this year.

(Unintelligible) demonstrate concurrently innovative services (unintelligible) and participate in state Medicaid and (unintelligible) time for the grand tour also encouraged to apply for this (unintelligible) testing of a standard or standards for (unintelligible) sectors and also to make a comment that ties into

(unintelligible) actually to demonstrate the personal health records (unintelligible) for populations that are affected.

And I would think it's tied into the third component because if you were to choose a (unintelligible) you would - you have to participate in the (unintelligible). Identifying standards for (unintelligible) as I mentioned grantees will work hand in hand with our partners called the international (unintelligible) in identifying evaluating, harmonizing new electronic sounders for (unintelligible).

(Unintelligible) is not only open to the grantees that are awarded (unintelligible) funds. There are also all sorts of stakeholders - we - I encourage everybody (unintelligible) work with my other people, so hoping that you will (unintelligible) interview as well to them and take with, and then (unintelligible) and we have only identified (unintelligible) standards with providers and beneficiaries.

(Unintelligible) I think it's very ambitious component of (unintelligible) and I'm sure we would be able to (unintelligible) because (unintelligible) current health records putting the patient in control of their care as (Jean) mentioned and asking them to push it forward or use it. It would be a stepping stone forward I say, a user, a teacher, but not have the user (unintelligible) again that innovation a way of advancing and modeling your personal health records.

They provide (unintelligible) making (unintelligible) and health information, and there's a way to manage health care stats and health care services. It's particular that (unintelligible) for available health for services, for providers, (unintelligible). I mentioned the grantees, we had nine applicants, and

(unintelligible) and (unintelligible). A patient (unintelligible) around chart here and all applied for all components.

I broke down together and they all have (unintelligible) because they are participating in PHR and (unintelligible) PHR (unintelligible) looking to identify (unintelligible) the standard for (unintelligible). The competitors are meeting today, and each has a huge opportunity, a learning experience only for (unintelligible), but also for states and all sorts of stakeholders. We have a diverse (unintelligible).

We have huge opportunity for learning in the community based type of community based (unintelligible) services and support. Part of the competition I believe we'll have a complete (unintelligible) care survey and you know, all kinds of (unintelligible) targeting aging populations. We will know for sure then that health information technology involves (unintelligible). I think so (unintelligible) personal health records (unintelligible) defining the standards that are going to be appropriate and (unintelligible).

Our technical lead is (Unintelligible) and our director of the community (unintelligible), we have our own information there. It is basically charted for any questions. Also you can find on the Web site information about this grant, and thank you very much for having me and thank you all for the great work that you're doing.

(Alisha):   Okay, I guess I'm slotted between you and the (unintelligible), so hopefully (unintelligible). My name is (Alisha) (Unintelligible) background and we just wanted to (unintelligible), and you know that they do (unintelligible) to contribute to this discussion (unintelligible) how they can help us be aware of IT standards and all that, so (unintelligible). (Unintelligible) thank you so much or your service.

(Unintelligible) so that's my teach board, and you see up (unintelligible). Next slide, but anyways, I do absolutely from the bottom of my heart. I use to teach my (unintelligible) there'll be no meeting (unintelligible) as well. I'm going to give you the weaker rendition of the year when I talked to (Unintelligible) earlier she said (unintelligible) and let everybody (unintelligible) and then I will miss the health MVPs, which is my thing, roll correctly but (unintelligible).

So in terms of you know, (unintelligible) and then (unintelligible). This is just the (unintelligible). As you all know, the safety (unintelligible), do you know who the first is? Oh come on, (unintelligible), thank you so much. So this is (unintelligible) again, (unintelligible) administration (unintelligible) and not just secondary application, which you may not get right now, but all of the dignitaries and (unintelligible).

Next slide, this is for your homework later on, but the intention I'm putting in here is for you to (unintelligible) again (unintelligible). They don't realize (unintelligible) what they call them, the way everything (unintelligible) including (unintelligible). We have 116 medical centers, so when you compare that to a medical center, you're not really doing that justice because (unintelligible). We operate (unintelligible) community based (unintelligible).

And the (unintelligible) changing rate on the graph, you see that the only generation that can (unintelligible) are aging, and that is pretty much average (unintelligible) and then population of (unintelligible) and PMH, but here I want to take the time for you from the (unintelligible) down. We are talking about policy and how these things impact, and we connect a lot of dots. I'm coming here from the health (unintelligible), but really (unintelligible) another IT effort (unintelligible) to health.

(Unintelligible) so I'm talking about (unintelligible) quality and equity, and the strategy we're using to reach two words in, but (unintelligible) to draw for you is the incorporation of (unintelligible) health, you know, that kind of health regs and personalized health plan, and who better to do it than the VA? We have to back the electronic health care system (unintelligible), and we have been (unintelligible) some of the things that (unintelligible) earlier are people not reaching records.

We have integrated health care teams (unintelligible) see what the primary care doctor mentions (unintelligible) we're talking about every member of that team (unintelligible) and I can have a patient who (unintelligible) and we can report this to their (unintelligible) and he will not be (unintelligible) and things like that. So I feel like those are strengths and (unintelligible) will be to be able to be support for the innovation, to take a piece on (unintelligible).

So I'll move on, and here, just one more point (unintelligible) piece (unintelligible) for old people, and you know if you help every (unintelligible) who needs help (unintelligible) my notes on the population we are discussing here (unintelligible) kind of brought up next (unintelligible) physical populations (unintelligible) challenge you, the one you care most about (unintelligible) maybe, but then (unintelligible) things that we also count on the clinician to be (unintelligible).

I think this here, now this is some of the discussion that we've had in terms of operating with how do we incorporate these items into a (unintelligible), and now here we talk about and we're talking about (unintelligible), some people (unintelligible), and basically they define it as social behavior that impacts your health, including also if the individual is a population that (unintelligible) and how you (unintelligible) impacts your health. And (unintelligible)

electronic health record, we have all that rich health record, and sometimes social history is very (unintelligible) and may not necessarily (unintelligible).

And so when we talk about integrating (unintelligible), we - it's not that we don't already collect it. It's how do we modify that environment so that it comes up (unintelligible) very easily (unintelligible) and so doing incorporates it into a lot of that (unintelligible) have a collaborating on health records and how we have made (unintelligible) to share with you, and I'll do that on the (unintelligible).

Challenge, again, the innovations remain (unintelligible), that's what I already have mentioned, and the creation part of it, you're usually creating (unintelligible) or an issue at hand and we mentioned earlier about the (unintelligible), looking at the wide picture of incorporating that and see the key areas where they work particularly within the health care system and primary care (unintelligible).

I think the next slide shows challenges - oh, sorry, these are - this roadmap, right, is described day to day as (unintelligible) and the working (unintelligible) and they were talking earlier about (unintelligible) information. I got all that from this map, and if you had (unintelligible) documents and critical (unintelligible), they were challenges, and I think that's - okay, (unintelligible) should be (unintelligible) physical health records.

And data is not necessary to (unintelligible) as well so that (unintelligible) to another, and then (unintelligible) in a way that makes sense, and by so doing (unintelligible) health, and (unintelligible). I think that's all I have to say and thank you.

Man: She thought she was going to close the action. (Unintelligible), really exciting. We have had a great discussion. The main takeaway message everyone should have has to come to (unintelligible) need to focus on (unintelligible). As a research agency that policies and programs are much easier to create and implement if you have a solid foundation of research and development, findings. It was exciting to hear this morning (unintelligible) the evaluation of his program (unintelligible).

$150 million in savings, that's great, (unintelligible) program which (unintelligible) CDC (unintelligible) many, many years before that (unintelligible) fantastic approach (unintelligible). I think we need to connect with these different initiatives, folks who are doing this good work, hard work and experienced people (unintelligible) better because of the care that's out there.

My agency, the (unintelligible) institute is located in (unintelligible) location recently (unintelligible) by the 4th being moved to our new home, and (unintelligible) health and human services saw that legislation passed just a couple of months ago. We submitted that to the department of education, it's been around 35 years, and please use our research database (unintelligible). We are at (unintelligible), 35 years (unintelligible) number of projects open period versus every claim.

Also significant part of our budget is devoted to rehabilitation (unintelligible) and technology. We are seeing tremendous growth in the number of proposals that we are getting related to the technology, largely around mobile, patients, and portable tablet devices for all (unintelligible). I'm excited to see. Again, we need to do some work as an agency in assisting the connection piece and in getting together the things that we're seeing (unintelligible) our new

projects to share with you all and others who are interested in both (unintelligible) and this (unintelligible) the health information act.

I got a little specific prize. I wasn't sure (unintelligible) about a year ago funded a significant grantee (unintelligible) developing electronic support systems to maximize the (unintelligible) for adults with disabilities, (unintelligible) cognitive (unintelligible) as well as (unintelligible) or sensory conditions. The Michigan team is using technology already familiar to these kids, and (unintelligible) cases, it's mobile technology to implement innovative types of supports, (unintelligible) motivation about these health related areas, project for individuals (unintelligible) issues (unintelligible).

Also let me (unintelligible) from the University of Pittsburgh related to the mobile health tools and support (unintelligible) and optimized health and invented (unintelligible) and disabilities. They're incorporating (unintelligible) as well. It's peer support to hold onto that and yet we can rework details about that later, (unintelligible) earlier with, then at the university search (unintelligible) and (unintelligible) can improve health and related outcomes for people with disabilities.

The second point which really (unintelligible), just to say that we are (unintelligible) University of California San Francisco that's managed (unintelligible) that ACL going forward and to speak to one additional (unintelligible) material as well, additional (unintelligible) community based so we are excited about that. Accessibility (unintelligible) initiatives, that is multi-dimensional. It is complicated.

It is technically complicated, it is disability complicated, but (unintelligible) necessarily. There's also a chance to listen to (unintelligible) this morning to talk about this concept of important to and important for and finding that

balance and then once you see what thing matter, how we would talk to people, not just people who are in (unintelligible) suppliers, to try and draw information out (unintelligible) that the words we are using. Is there anyone in the room (unintelligible)?

Man: (Unintelligible) health policy (unintelligible), they're spending a fortune (unintelligible) like this and this resolution in particular, how to talk to people, what words to use, what sequence to ask the questions again, it's all about being person-centered and user friendly and drawing the information from them in meaningful ways to optimize health benefits for all of the outcomes.

We mentioned the connectivity already, so I think just in closing I will say that our failure to do this has consequences, has real consequences. I feel that it's a very personal need (unintelligible) and those consequences are felt by providers and by payers, policy makers, and by (unintelligible). So I'm excited for me in this assignment, (unintelligible) great work. I can see the level of energy through all of you all.

Again, please go to our Web site mira.com, and like (Unintelligible) said, the work that we've done in the last two decades can only contribute to that connectivity piece (unintelligible) and the scalability of that (unintelligible) to achieve different outcomes. Thank you.

Woman: Thank you to all the panelists for those (unintelligible) presentations. So operator, could you open up the phone lines and remind people how to ask questions and invite anybody in the room who has comments, observations, questions, please come up to the mike or let us know and we should get a mike back to you. (Unintelligible) is there anybody on the phone, or in the chat?

Coordinator: Once again if you have a question please press star one, state your name and affiliation, but at present there are no questions in the queue.

(Terry O'Malley): Hi, (Terry O'Malley), Partners Health Care in Boston. This is for (Liz). So (Liz), you implied that there is a list or a starter set of data elements (unintelligible) look at for inclusion in this shared data set. Did I hear you correctly?

(Liz): I was - I think what I said was - I meant is that with the LDS (unintelligible), so that's part of what we'll be doing to start the new initiative and the environmental stance so we will have a concert period, to key up some of the great work that's been done by the states and by the providers.

(Terry O'Malley): Okay, and sort of corollary to that, within the discussion that was going on around (unintelligible) stage 3, is - there will be an opportunity, do you think, to - that we can push some of the data in earlier?

(Liz): I think the timing for this particular initiative because it's starting in November is such that it will be - I think the timing for stage 3 is probably a little bit off set to something, you know, after we're trying to break into all of it that we're doing.

(Terry O'Malley): Thank you.

Woman: Yes, I can speak to that a little bit, (unintelligible) you know, we're looking at EHR clinics for a number of (unintelligible) just one of many, many, many policy levers that HHS and the federal government and state government has. So when thinking about a lot of the Medicaid clients for long-term service and support (unintelligible) found the incentives, the wait time and 15 waivers, all sorts of funding that (unintelligible) provide state funded efforts.

And we really want it comprehensively and how we've reinforced interoperability and exchange which includes shared longitudinal patient centered plan, so I mean, we're going to hold both of these levers that will be more articulated than (unintelligible) than that.

Man: Okay, I'm just encountering some people (unintelligible) as well, also the position, we had it - projects already looking at this and key projects for example (unintelligible) project and my care plan sharing between (unintelligible) you're saying and health care providers covering asthma, so there are a number of these kinds of models of community or community health integration of (unintelligible) in place, but like the team asked me to share a little bit about the (unintelligible) for (unintelligible) as I hoped to know that.

(Unintelligible) program, and one of the components of that, so we actually - we got additional transformation painted so that if we want to (unintelligible) and one of the requirements was a patient-centered plan, and that patient-centered plan has had a number of (unintelligible) audited around, including 24/7 access by providers who (unintelligible) from those patients. And other patients, and the patient advisory group helped us create what that would look like.

Because the data had such a high EHR adoption, many of us were thinking (unintelligible) precepts at any time, these (unintelligible) community members and hearing that difficulty (unintelligible) organization, including the (unintelligible) with our model of care plan it looked like health workers and how we could serve multiple needs simultaneously (unintelligible) that information be used for (unintelligible).

It was not an easy process (unintelligible) because the day when you probably put together (unintelligible) the group, they have a very different point than what we were trying to accomplish, albeit some organizations are getting paid for their care plans, because they were very focused on care plans to meet their regulatory requirements, and then their regulatory requirements for their care plan were different from some other sector or other (unintelligible) that data, (unintelligible) about what action should (unintelligible).

Now that low-cut (unintelligible) confirming what the patient needed, and that became a firm component of the care plan, and we would simultaneously collect and make ultimate access to everything else that had different views for different purpose, so if you had something related between, or something for your particular side of care, that was there available to all of us, to be prioritized where other theories of care that didn't quite match their priorities sort of continued much more dynamic item than like a single piece of paper.

But the information is too much content for one piece of paper so technology really helps so that each user has a right (unintelligible). So I think we have a lot of (unintelligible) collectively and (unintelligible).

Woman: Thanks, (Unintelligible).

Woman: I'm (Unintelligible) from the National Association of State Developmental Disability Directors today, 51 directors who operate for the different states. We wanted to make (unintelligible) I'll just say this is a great day, it's great to see so many players across such a wide sector talking about combination IT and person centered practices. A couple things I wanted to say, one is that as we talk about this and think about this and I appreciated the comments about investors unaware that (unintelligible) long-term care.

One good thing takes a lot of shape and I said my advice for long-term care to my mom, I mean for (unintelligible), and the nature of that long-term care is different than the nature of long-term care at the end of life. And so because of that, it's much more medicalized with a need for much more related to a threatening health condition, whereas people (unintelligible) end of life simply need support to keep going.

And so that should inform what we expect to get out of IT and how we expect to use IT. The second is just a comment, I felt compelled to share about the power of IT and the limitations of IT to be first and centered. I represented a (unintelligible) the interaction occurring between human beings, and so it means every caregiver looks you in the eye and says this is what you have to say and takes time with you and prioritizes what you have to say.

And so the best IT application in the world can't make that happen, and so operators of programs have to set usually for more in the training and the guidance and the mentoring of the deliverers of the care so that it will be first and center and we're generating data that's very much needed. But a higher presentation is a reflection of that, based on that two-year redesigning of their practices from the first point they say hello to somebody all the way through, and then build an IT platform to support those person-centered behaviors, practices.

And so that technology and that fit will be very powerful to create the pathways for people in the future, but if we are made, what we do now places the anchor (unintelligible), so just a thought, and the last thing I wanted to say is that let's not forget that there are (unintelligible) domain systems, state governance sponsored systems, that are very robust and very (unintelligible), and have a tremendous amount of interoperability.

And sometimes I think we forget that Ohio's one that's so good because they have a system where they allow already operationalizing a person's best practices, but (unintelligible) a large section of those applications are getting a lot of data, most (unintelligible) are starving for personnel, so they don't get to promote what they do, but (unintelligible) work there.

Woman: Thank you, great comment. Others said it's interesting that health care in communication is also showing that if you (unintelligible) care process redesign, and a lot of other entities have shown this too, right? The change in their practices is not just putting the IT in place. It's only a tool in place, and the data is only data. It's how you use it and how you make it as you prove you're the way you do what you do.

((Crosstalk))

Woman: Sorry, yes, questions on the phones?

Coordinator: At this time there are no questions in the queue. However, a reminder, if you have a question please press star one and state your name and your affiliation.

Woman: Great.

(Sandy): I'm (Sandy). I'm from the foundation of care foundation. (Unintelligible) is kind of ironic, because I would like to argue a little bit for standards and standardization, because you know, right now in the (unintelligible), we think that purity of choice, and I've been watching our state, California, bicker for over 20 years about what could (unintelligible) in a universal (unintelligible), and I know that nursing homes, they have EMEA.

Not everybody likes it, but it's a standard and it was required because they had all their money from the government, and so you know, you can build around some of those standard elements for person-centeredness, but unless we have an agreement about what to put in the record, it's just going to go around and around and around for 20 more years, in my personal opinion.

And my second little thing is that we have a medication (unintelligible) system that we use and we send postal workers and community health workers into the home, and we ask consumers to do the same thing, which is to write down all of their medications, and then start to find out if they could be causing adverse effects. Well in my pocket I have the ability to add the pharm code, except none of the bottles - I have one bottle that has three - no, two bar codes and one 2R code, none of them readable, because every pharmacy, every dispenser has a different standard.

So I would argue for you know, if you want person-centered, (unintelligible) data collection using with the tool would be a lot better (unintelligible), and if you could possibly standardize some little piece of that barcode so that we all know what's the name of the medication, and when are you supposed to take it, and then we can compare things easier, you know, that we had. Thank you.

Woman: I'm going to reinforce the point that was made earlier around standards, (unintelligible) to reinforce the option of those, but we - in the consolidated clinical data our impression that (Liz) referred to, there is now ability to have that managed and data elements for caravan, and that was (unintelligible) process that really had a diverse group of stakeholders thinking through what should all pieces of the care plan be.

So that now would be (unintelligible) regarding some of that, so that's not (unintelligible) a lot more from the (unintelligible) work group and think

amore about (unintelligible) and how this is all been evolved because as documents, you know, they have standards that we're starting to now may not be what we need in five or ten years, you know, and any result of recognized charting, we're dealing with a web of relationships across, you know, an individual family, their (unintelligible) working with them and all the kind of care they're given.

And all those relationships need to be taken into account and if we're really going to get to sort of a user-centered line and evolve, you know, the schools that are going to support and give their time, we need to take all that into account. So we're still early days, but the standard that we have been (unintelligible) forever, we have something that (unintelligible) organization and is now being implemented as a starting point.

Woman: Any more questions or comments? Okay, great, so I guess we can finally transition to the last part of our agenda, which we were going to try to reflect on you know, what we've all heard today, and seek your thoughts and input, so (Sharon Lewis) from APL is going to join me. We were going to try to report back to you I think what we heard today, at the starting point, and sort of the key themes and maybe insights that we've drawn from all the great presentations and across (unintelligible).

And we really would like to hear from you all, both the virtual audience and folks in the room, about what you think needs to get done, either actions that you want to take on within your organizations, or actions you think someone needs to take on so that we can come out of this meeting today with a better understanding of what's next. Do you...?

(Sharon Lewis):   Sure, so first of all thank you, everyone, especially all of you who have come in on a really hard (unintelligible) day in our lives to talk and think and hear a

variety of different notions, and so you know, I am grateful for the fact that we've come into something (unintelligible) and virtually as well. I think this last conversation has been very interesting and actually (unintelligible) as well (unintelligible) in terms of things that I heard him speaking about at the end of the day here.

We have a lot that we can take a lesson from in the world that we're in together this morning. You know, we've got - I mentioned that we feel like there's a lot of bridging that needs to be done, and whether you want to thank about it in terms of interoperability from a technology perspective, or living together from kind of a cultural piece that has yet to be addressed in order to do this work in the way that I've heard everybody across the entire day wants to see this happen, where it is respectful of the individual, whether we want to talk about the person who has - the consumer, or the care beneficiary, the older adult person with the disability, the recipient of services, I've heard a commonality that everyone sees the import of doing that with a virtual partner.

However, there are a lot of different ideas about what that means, and I think that we have to as the (unintelligible) on hold as we tell them (unintelligible) and we look at the models that states are implementing and we figure out the bridging and we're looking at the standards, that complication about culture cannot get lost. There is a distinction between initiatives and at risk of disagreeing with my boss from this morning, there is a distinction between the notion of a first encounter, and the patient encounter.

There's a fundamental cultural distinction there that we have to figure out first. I am a (unintelligible) for a very small potential (unintelligible). I know her personally, and when we think about person-centered care, it is important that you care about and you help me throughout the day today to acknowledge

the distinction and find ways to build those bridges, and the information that is relayed to me as the patient is important.

But it is not more important than the information relayed between me and the person, when it comes to - when the support means it upholds efforts that we're trying to get to, and then will the technology - because like, in flowing that cultural conversation. So one other thing that I think I heard today that I'm hoping we can use in our work going forward is just noticing - this notion of acknowledging the distinction in both the (unintelligible) in terms of the economic levers and who has the opportunity to (unintelligible) conversation forward in a variety of contexts, both in terms of where they're in contact in private investment.

And you know, and again that need to understand the perspective of the individual, and how are we going to navigate that, and how as we talk about just saying (unintelligible), how do we make sure that prior to the conversation (unintelligible), that if me as an organization to our (unintelligible) innovators and our system are equal players at the table, with the state Medicaid (unintelligible), or with care and HHS.

And how are we going to navigate that (unintelligible) power investment imbalances we have in our system in order to achieve our goals? So you know, I love them and I think all of you love them and I see your response and how can we do that and how do we do that in the air that's (unintelligible) with us and it came to the forefront, and encouraged that (unintelligible). So I don't want to take any more time.

I want to give this - (unintelligible) I think we want to make sure that you know, this is the beginning of the conversation. ACL (unintelligible) are very excited about the opportunities to engage with our (unintelligible) across HHS

and working with our partners and states to make sure that again, that role of that quality and using the (unintelligible) or technology (unintelligible) to improve quality of care and support with our partners (unintelligible).

Woman: Yes, I would just reiterate what you all were thinking about the cultural challenges, because they are really significant, and we've actually before the meeting and for many months have been thinking about just in the clinical sphere, you know, the way that nurses are trained and practice versus physicians and therapists, and sort of the interdisciplinary care team has a very different approach for maybe awareness around what is care planning or what is person-planned planning.

And I think now that we have all these sort of the push to find good care and the common care incentives and transforming the system into something that really is person-centered really creates this need to not only get the political side around what everybody's role in developing and making a plan, but also now we're looking at closely where the community-based perspective (unintelligible) really for partners.

And so have all the answers there. And I think we recognize there has to be much more of a dialogue to get to agreements between those (unintelligible), and how we enable this kind of collaborative planning process and then the standards and tools will go behind that, but it's not - it's the culture's a priority and agreement or the health pattern first, and then we can make sure that the technology of standard can enable everybody at once to have capped in, but I think you know, it's what's great about having all this reform now is that it stays in (unintelligible) are recognizing (unintelligible).

So there's more of a target. We should enjoy this opportunity, and I was really also drawn that even though there's different terminologies from different

sides of - different perspectives, everybody can agree on personal ventures, I think. Everybody can read on the contact living shared across everybody that's involved in someone's care or well-being or support, and the competent actions, having, you know, an action plan or having specific actions being documented and maintained is important, and also just knowing what somebody's priorities are, not their health priorities or what's important about their care, but as individuals, what's really important to them from their bodies when you know, their personal experience.

And that goes right back to the cultural side of this, right? We're not all physicians are taught to approach the patient like, oh, you know, how important is it to you to go take your grandchild tonight or you're starting this conversation like what matters, and it's - it goes back to how everybody's trained and how you know, they approach their work. So these are all bigger challenges, but important to consider.

And I guess the other thing to note in terms of opportunity, there's a lot of conversations about measurement today, which was really interesting, and (Terry O'Malley) brought up this concept of importance, and we can think about having more importance about what the patient really cares about, and then what is the outcome, and do they match? So if the care team is driving to an outcome that is really what the patient is asking for and what their priorities are for the person, then that's accountability.

That could start driving some of the change we're talking about, so basically look at opportunities for new measurement and ways to sort of drive some of these fundamental changes in the way people already practice. And I think you know, there's also, when we think about spreading and scaling this, we know that we need to you know, further develop standards involve these platforms, think less - think about changing the way we would file those

fragmentations that we know exist, so on the (unintelligible) and the category side.

But I think when we think about spreading or scaling, we need to think about strategies that build in standards that we all agree on as sort of the (unintelligible) community to get to the connectivity again our ability that we're going to need, so whether that's through all the funding from the state or it goes to the federal contracting, you just need to think more exclusively about how do we do that spread and scale that we can reduce the fragmentation.

But I think there's a lot of lessons learned in what's happening in parts of the country which was just talked about today that we all need to take into account all of these spread and scales, so how you work out the role of this access with this interdisciplinary team, how you figure out how to do a customized presentation on some of these integrated plans that's not a HIPAA violation for non-covered entity because you don't have a treating relationship necessarily.

So there's a lot of lessons learned that I think we're going to have to harvest and capture as we think about spreading and scaling, so there's so many rich things said today, but the only other thing - we don't have time, but I thought was such a great concept was health factors at home, (unintelligible) mentioned that, and you know, I hear what you're saying. You live the rest of your life as a person, not a patient.

Most of us do not want to end up in institutional care as we age. I think a lot of us, like everybody thinks that - in my family, everybody I talk to has said no, I prefer to be at home. You know, that's (unintelligible) much different and system and approach (unintelligible), so I think we just - it really helps

around us when we think about where do we all experience our lives, and it's not in the health care system for the most part.

So I think we can turn now to opening it up to everybody here today, the folks on the phone, and (unintelligible). You could share your thoughts on what you think needs to happen. What are the actions that either you know, within the organizations you represent or what do you think any of us here today should be doing? Oh, great. Okay, so one definite that we need online schools for PCB, that will be much more person-centered - okay, yes, person-centered planning, that would be wonderful.

Yes, because part of person lead is what's linked to interoperability, so I think it's - maybe this in part leads back to the standards and making sure that tools that are being developed are following standards that other people can recognize so that they can get access and consume a person-centered plan. Great.

Man: (Unintelligible), I would love to see two things, one is a taxonomy of priorities, because I think that (unintelligible) and I would love it if someone has one. How do we you know, talk among ourselves about what individuals say and what - so that would be a nice project to work out, and then once we got that, we could require people to exchange a list of priorities they've arrived at potentially with individual persons, (unintelligible). So I would love to see those two things.

Woman: So you've bridged the role of (unintelligible) to (unintelligible) in our kind of development work, and can think of a collection and also we really understand the patient as a person and all these different tiers you're talking about, and so to get structured data is eventually what you're talking about, if we had a

taxonomy that could eventually be computable that would allow for exchanges (unintelligible)?

Man: Yes, that would be wonderful.

Woman: Yes.

Man: (Unintelligible), this is actually directed to you, that since back in the late '90s, (Jim Cemino) put together a (unintelligible) of what ought to be an electronic health record. That was a very valuable document, very valuable journal article, that really start - kick started some of the process that got into EHRs. It might be time to look at that in the context of what you're asking and say here's what we ought to have.

                Here's what we'd love to have, basically looking at a logic model of (unintelligible), so where we are, what our future state should be and what our ideal state could be, and historically look back at (Cemino)'s (unintelligible) and see, you know, what have we achieved so far where we need to go to get to where you're talking about too.

Woman: Okay, thank you. Yes, is there any suggestions or ideas from the phone?

Coordinator: Yes, we do have some questions in queue. Our first question comes from (Bob Anderson). Your line is now open.

(Bob Anderson): Yes, hi, this is (Bob Anderson) at Offline, Massachusetts. Through the course of the day we've heard a lot about this federal and state perspective on the role of CBO, community based providers. Haven't heard much about the private payer, commercial payer perspective. I'm wondering if maybe Dr. (O'Malley) or Dr. (Estroski) could role play a commercial payer. If so, two questions, one

is does the commercial payer see an opportunity with community based providers in improving outcomes, and if so, what are the predominant payment models? Thank you.

Woman: Does anyone want to take that on?

((Crosstalk))

Woman: Yes, do you want to talk about it in the context of your relationship with the private payers?

Woman: Well you know, California's kind of crazy, so you know, maybe - but anyway, making the point (unintelligible) is going kind of - it is sort of like waiting forever then the goal comes up on track, since I've been here without a new contract, we've gotten one to do the eligibility determinations for federal health centers that's required by the state now by RNs, and with the violation, also do the in-home evaluation and purview and they said no, and then about a week later they said we want it, and we want the center first.

And then today we got, oh no, we need it much sooner. We only have 1000 people, you know? We had a meeting with the medical group that's a progress kind of community, and they're getting their duals, but also they have their Medicare Advantage special needs just in the plan and it pays then they have their Medicare Advantage in general, and they wanted to start in two months. They wanted to pilot in 100 and then they wanted to see 3000 Medicare Advantage I think with 1000 dual.

I mean, that's - others will sign a contract, you know, that if the uptake of referrals is very, very small, but I mean, something we have many contracts, I - it's not like we're the only one, but I don't know, we're all busy doing it, so

we haven't been chatting, but it's you know, it's Blue Shield, and then Anthem, there's Southern California President, was interested in the work and has set up a Webinar for the CEOs of this great western state, Anthem CEOs coming up, a two-hour Webinar, on what are these services, what do they represent, and UCLA's taking us private contracting (unintelligible) PCCP results.

So they're having to add (unintelligible) - so the (unintelligible) taking, and of course we want to do it all ourselves, we're going to stop other (unintelligible), you know, (unintelligible) but it's an impressive level of activity and it shows a contagion that's been kind of fun. We have two medical groups, we've got a mixed bag of health plans. Some are dual, some are you know, (unintelligible) PCP.

So it's - I'd say that there's a market there, and it appears to me now for funds, with the track record we've got client lists, with a good track record, good results, so now we don't blow it, when we don't blow it. When we shine, and continue to show those results, it seems to me that this took, but it's all managed care, it's all managed, so I think like - I think it's all managed care.

Yes, because there's the (unintelligible) competition, and that's a (unintelligible) expanding. They're adding new functions and opportunities and pieces of work, so I think (unintelligible) you know, filled with potential. (Unintelligible).

Woman: Yes, we have two (unintelligible), one's paying additional funding in the community organizations, integrated health IT plans, and another is a (unintelligible) health policy the data on the cost of (unintelligible) coordination (unintelligible), data, cannot engage providers and health system vending (unintelligible).

And so what you're saying is, especially if community care organizations all (unintelligible), and you were saying before, it becomes the service or the specialty service provider (unintelligible) value and will more likely be on the contract.

Woman: But if it matched the DR reduction it's reducing admissions and readmissions and as for the dual it's the nursing home, but also for ACOs, (unintelligible) nursing home. We just got contacted by an ACO, right? We were recently contacted by a board member who had just joined an ACO. We haven't worked with them, and then they were intrigued with this. I'm not sure they'll want to pay, but they're very worried about use of ER, but mostly hospital under 21 day fully covered nursing home stay.

So they're taking a whole new look at how they practice and questions that physicians should ask before they make these kind of snap decisions about where there's enough and how people flow, so this is interesting just to listen to what drives their thinking and what - we learned a new term, (DOFR), the delegation of financial responsibility, so we have a physician coaching.

We just have to ask what's their DOFR, or what they pay for is where they can save money and say if they deliver what they pay for, see where you can demonstrate your value in something sort of a low-hanging fruit opportunity for them to see this - the clinical business case that the (unintelligible).

Woman: And also the (unintelligible) survey (unintelligible) the patient is last year (unintelligible) and it's producing (unintelligible) top priority.

Woman: Yes, it's very interesting.

Woman: Yes, it is.

((Crosstalk))

(Joanna):   This is (Joanna) from (unintelligible). We're gone I think for a really big
                (unintelligible) and we're saving (unintelligible) but right now there's so
                much low value care and so much (unintelligible) her doctor said well she
                didn't pay for the 21 days in the nursing home. I said my jaw was on the floor
                like, wait, this chart reflects that - you know?

                (Unintelligible) and there's a tremendous opportunity and many are seeing it
                to take huge (unintelligible) out of Medicare payments, not for (unintelligible)
                community, we'll reinvest it in other services, but (unintelligible), you know?
                Sure you need private gain in order to internalize good behavior, but there's a
                point at which the community ought to bear the concern of (unintelligible).

Woman: Yes, and it's (unintelligible) - I think there's a lot of interest now in state and
                (unintelligible) law and in the innovation center there's also some things that
                developed and we're really conscious of how that appears in the community,
                and my team works at community-wide orientation and accountable care,
                where CBOs would have a large (unintelligible) there would be that
                community governance that you were talking to (unintelligible) how these
                things are getting distribute and how you really think about continuity across
                the full spectrum.

Man: Maybe just to build a comment that (Nancy) made, and that would be one of
                the things in talking to my fellow state directors and kind of our experience in
                Ohio, you know, becoming the CMS global and the fact that person-centered
                planning is called out in there and one of the things I think a lot of us heard

from folks that we work with is oh, that's nothing new. We've been doing that for 20 years.

And one of the things that we were seeing, I think, it was a disappointing revelation to me learning as our staff were out looking at things that a substantial number of folks in our field really weren't practicing person-centered planning, and that is a common theme that I'm hearing from a lot of other state directors, is that people say they're doing it, but they're not really doing it, and so the real danger in developing long-term service and support IT systems is that we don't want to be putting concrete around stuff that really isn't person-centered planning.

And I think that's a concern and some of us have seen some instruments like that, and I - from what little I've seen from having a mother in the long-term services and supports system for the elderly, I don't see a lot of good person-centered planning going on in that arena from the very limited view that I've seen, so you know, thinking about as we go forward how we continue to emphasize the training and the you know, other parts of this, if you really want to make folks' life better and we really want to enhance the control that they have over their lives, you know, I just think we've got a lot of digging to do, yet, so...

Woman: Thank you very much. And on the phone, are there any other questions or comments?

Coordinator: Yes, we do have one other question in the queue, and this question comes from (Steve Kay).

(Steve Kay):   Hi, this is (Steve Kay) from the community living policy center at the university of California San Francisco. This is all very interesting stuff, and

here's what I'm wondering about. We usually talk about care coordination in general and person-centered planning in particular in the context of particular populations with high need such as people with multiple chronic conditions, people with intellectual developmental disabilities, people who use long-term services and support.

So is our efforts to move this into an electronic forum meant to be a specialized service for particular people or will they be for everyone, because I feel somehow that if it's a specialized service for particular people, then it won't be as effective as if everybody is using you know, if everybody's medical record has the same sorts of stuff in it. I wonder what (Kelly) and (Sharon) and others might think about that.

Woman: (Unintelligible). I'll (unintelligible). I mean, I do think that there's a high need population presents sort of a short term liability to the (unintelligible), because of their need and quite frankly because of the costs involved, so as I start, and I think there's some you know, evolving of the policy to look into (unintelligible) scheduled around care management and new bill of service that refers to components of the care plan that (unintelligible) that we talked about today, that you know, can (unintelligible) population (unintelligible), and the population served by them we all need to serve, and at least stable.

I guess if there's - if you think about accountable care as (unintelligible) not only about payment, it is a much broader contract, and ultimately I think all of us, whether we're healthy or sick, we'd like to know that anybody who's taking care of us would have a plan and that would be based on what we - what matters to us. I mean, I was lucky enough to be healthy. I was in the hospital when it was time to have kids, but you know, that was ten years (unintelligible).

But I'd certainly like it if you know, if my kids got sick or like my husband. So I can (unintelligible) with my family when they're sick (unintelligible), yes, their needs are not met. So my guess is that we are going to let (unintelligible) stand, but because there's a policy and then there's clinical priorities for these high need populations, we might be starting there, but we - (unintelligible) but we probably need to design for the broader application and think about how it's going to unroll over time.

Woman: Here's what I would add is, I think there are two ways to think about this. I think as (Kelly) indicated, we're all interested in moving the system forward so that they are person-centered, and that all of us would hope to receive first class care, and that there would be information that is available to our care providers in the health facility that reflects our personal priority values.

That being said, because of the economic and policy levers that are related to individuals who have optional (unintelligible) that require long term services and support that that's a limited population and there are constant (unintelligible), when the reality of it is two persons that are (unintelligible), there's a constant limitation.

And I just wanted to run and I guess get to the point where I have some concerns for our nation that we would be able to get to cost perspective and then around a person-centered plan for every single recipient of health care in our system that then would not (unintelligible) the opportunity in terms of the resources - the resource intensity that is that (unintelligible) to a person-centered setting well and right and informed with the complexity of needs that any of us could potentially end up having.

But you know, just to think about it in the context of a (unintelligible) population, it's hard to see the cost in that - from that perspective, so that (unintelligible).

Woman: Hi, (Bob). (Unintelligible). Hi, so I just have been here all day and thought you were in the building. When I started working in the field, we used to talk about the concept of diversions and discharge, and we don't talk about diversion anymore. It's just not language that we continue to lift, but the result of these questions, after the point in which this becomes standard for everyone, that's what I think true prevention looks like, that there's a cost driver focused on people with multiple functional needs now.

And we should attend to that first, but true diversion and true prevention is to know that I'm diagnosed with cancer tomorrow, where's my family, what supports do I have, and what will I need? And I think it will be good for us frankly as (unintelligible) people when we think about what diversion and prevention really are, although that's not been always tried in conversation. There's a construct here that we have to get at immediately. But to me, the question is (unintelligible) prevention and how it really helps people for their whole lives, not only (unintelligible).

Woman: I just wanted to add that (unintelligible) the personalized health plans briefly are actually downloaded in some of our (unintelligible) institutions with the home health approach, and it's not (unintelligible). It's basically state health center, so it's going across the board, and it's being tried including training for clinicians. I'm not in charge of that program but I thought it was also (unintelligible) that transformation that was really bad because I (unintelligible) occupation.

So they are - the way that he is currently doing it is across all occupations and without you know, going into detail but that broken (unintelligible) will be the (unintelligible) occupation. So again, we are I hate to say in control, but we're not under the same gun as far as the results and the projects that (unintelligible) change to try it this way. But I think we're looking at it from the angle of being a good (unintelligible) across the board.

And then just to reference what you talked about earlier, (unintelligible) and nation, it's - I think it's also (unintelligible) health care and so it began in the long run, anybody having it actually benefits all because you would have had (unintelligible) and you would have established what you wanted to (unintelligible).

(Erin O'Connor): (Erin O'Connor) for the national partnership for (unintelligible) and families. First off just thank you so much (unintelligible) and ABL and the others, such a wonderful inspiring meeting. It's been a great day. I wanted to throw in a comment about something that you said, (Kelly), about the importance of measure development, and as you think that the big area that you want to focus, one of the themes that we catch in returning to all day was the importance of asking people to identify what their priorities, needs, and values are, shifting from you know, what's the matter with you to asking what matters to you.

And I think it's very important to our certain metric care, and I think that we are starting down that road that (Mark) mentioned in terms of being able to capture patient goals and electronic health records, and that's great, very important. But we also need to be making sure that that data is being used. I'm very intrigued by Dr. (O'Malley)'s outcome measure.

All my family (unintelligible) accessible to me to achieve the outcome that (unintelligible). I think we're going to be - we need to - in order to ensure that data is used, we're going to have to break away from measure whether or not you know, Dr. (O'Malley) said care is being delivered in a manner that (unintelligible) preferences that we can only hopefully incorporate the requirement into the program of accountable care organizations and other, you know, make me think that innovation center and other (unintelligible) that we're doing.

So just wanted to remind (unintelligible) measures (unintelligible) that's very important. And I think it's (unintelligible) because as we talked about people who are older are often much more qualitative, that (unintelligible) clinical goal and that presents us a serious I'm not a quality measure expert, but as I understand it, that makes quality measurement and the development of measures much more difficult. So it's probably going to take a long time, so it's (unintelligible).

((Crosstalk))

Woman: Well, and actually one of us mentioned whether - I mentioned if the (unintelligible) to address part of that conversation is that a (unintelligible) and HRQ are working. We just know where the new task force with (unintelligible) to begin the process and talk about measures related to quality and community living and what does that mean in particular focused on LPN stats and what individuals want to prioritize in terms of (unintelligible).

And so we're excited about that. It's a two-year process in terms of getting started around looking at literature and engaging with (unintelligible) in developing priorities and building (unintelligible) areas where they are all

alone and we are way behind when you talk about (unintelligible) relative to the evidence based the trial metrics of the clinical side, and (unintelligible).

Woman: (Unintelligible) are intact. They're protecting test based care survey (unintelligible) and we envision being (unintelligible) we working hard with contractors to really make this happening, and (unintelligible) targeting Medicaid populations. Also (unintelligible), so I think (unintelligible) opportunities but also quality at this opportunity to (unintelligible).

Woman: I think we are over - I'm getting the (unintelligible) here. Well, again, I just want to say thank you from ACL and all the additional staff who worked so hard to put this together. Thank you very much for being here today. We look forward to continuing the conversation and (Kelly), do you want to say anything, any wrapping up here?

(Kelly):   No, thank you so much for everything. I think we learned a lot and we have a lot to improve on (unintelligible).

END