

**The CMS Innovation Center's Approach to Person-Centered Care: Commitment to Patient  
Partnership Across the Model Lifecycle  
March 31, 2023**

>>**Purva Rawal, CMS:** Good afternoon. Everyone and welcome to our listening session on the CMS Innovation Center's Approach to person-centered care commitment to patient partnership across the model life cycle. My name is Purva Rawal, and I'm the Chief Strategy Officer of the Innovation Center. I'm joined by Kate Davidson, the Director of our Learning and Diffusion Group, as well as our colleagues and leaders from the Innovation Center, who are excited to be with everyone today to share updates on our beneficiary engagement efforts. Next slide, please.

Before we get started I have a few administrative items to address. First, the session is being recorded. After the session concludes, the reporting and slides will be available on the CMS Innovation Center website under the Strategic Direction page. The link to that page will be shared now in the chat. Second, closed captioning is available for this event by clicking the CC button that you see at the bottom of the screen. And third, I want to point out that we have a Q&A function available to us during this meeting, and I encourage you all to use it. Due to the size of the event, we may not be able to respond to everyone's questions, but we will be monitoring the Q&As closely to inform our work. In addition, we use questions that are posed during the listening session to periodically update the Innovation Center's frequently asked questions, so please take a look at those if you have questions about our programs, models, or events. And last, if there is any press on this call, please submit questions through the CMS Media inquiries, portal. That link is being shared now. Next slide, please.

For our agenda this afternoon, we will first recap the Innovation Center Strategic Refresh to frame today's discussion. Kate Davidson will then provide updates on our patient and caregiver strategy. We will then facilitate a panel discussion with representatives for patient and caregiver focused organizations on priorities regarding some key areas of interest, primary and specialty care coordination, serious illness, and maternal health. We'll introduce them a little bit, but a big thanks to all of them for joining us today in sharing their thoughts and insights. We will close with a few summary remarks and other ways you can engage with the Innovation Center moving forward. Next slide, please.

With that, I'm excited to officially start our discussion today, particularly on the heels of the 13<sup>th</sup> anniversary of the Affordable Care Act being signed into law. I'll start with an overview of our Innovation Center Strategic Refresh, which guides all of our work, including our beneficiary engagement work. Next slide, please.

The Innovation Center Strategy Refresh consists of five strategic objectives, that you see here, that guide the implementation of our vision. The first objective is to drive accountable care by increasing the number of beneficiaries in a care relationship with accountability for quality and total cost of care. The second objective is to advance health equity by embedding equity in every aspect of our models, and increasing the focus and underserved populations. The third objective is to support care innovations to enable integrated, person-centered care. This objective connects to knowledge sharing, peer-to-peer learning collaboration, and will include closing care gaps and delivering whole person care. The fourth objective is to improve access by addressing affordability through strategies that address health care prices, affordability, and reduction of waste. The fifth and final objective is to partner to achieve system transformation by aligning priorities and policies across CMS and engaging with payers, purchasers, states, and especially beneficiaries. This requires us to work across CMS and

the broader federal government, and with external organizations and interested parties, some of them, many of them, are joining us here today.

And for those of you that may not be aware, in November of 2022, so just four months ago, we released a one-year report on the implementation of our strategy. The report provides updates on our implementation. It outlines our accomplishments across each of the five strategic objectives, I just described. The report also articulates areas of focus for the coming year, some of which we're going to discuss today, and it includes metrics for how we're going to measure our progress against each of these objectives. So, we're excited about our achievements, but even more so about the work ahead of us, especially with our beneficiary partners. Next slide, please.

For today's discussion, we're going to focus on our commitment to partnership with people and families. To build a more person-centered health system, we have to understand the needs and experiences of beneficiaries, patients, their caregivers, and families. The goal of such partnerships is to better understand the beneficiary perspectives so that we can incorporate that across the lifecycle of our models, from the very beginning of when we are developing them to when we are implementing them, and then all the way through to evaluation to see what is and isn't working. Incorporating beneficiary perspectives into our work will also guide and help the Innovation Center continually refine its models and other innovations so that people are at the center of our work. Next slide, please. Now we're going to cover the Innovation Center's patients and caregiver's strategy. Next slide.

The Innovation Center is working to place patients and caregivers at the center of our models. This means you focus on improving the quality of care that people receive the experience of care for both patients and their caregivers, and most importantly, health outcomes. To accomplish this, last September we announced our strategy to help us to understand patient and caregiver perspectives through engagement opportunities that promote rich patient and caregiver feedback to us, on our work and our future directions. We announced our strategy to help us act on the experience information that we receive from patients and caregivers to communicate how we are acting on the feedback that we receive, and to ensure that we're able to continue to harness that feedback over time and sustain engagement.

So, this year we're focusing on achieving our aims in a few key areas. We want to be inclusive and capture a range of perspectives that reflect the health care ecosystem. We're going to be promoting a partnership approach for understanding patient experience, to solicit real world feedback, and support ongoing and continual improvement. And we're focused on being transparent about how that feedback we receive gets translated into our programs and models. Next slide, please.

The Center is pursuing additional opportunities to incorporate patient considerations at each phase of development and release. It's critical to ensure that patient and caregiver perspectives are captured and addressed at the outset of model development. So, we want to be thinking of quality measures that address patient experience and priorities. When I think about how a model might impact the priorities that patients and families themselves have identified, especially affordability, access to care, and access to equitable care. During recruitment, when we're bringing providers into our models, we want to be thoughtful about what kind of information patients want to know about an Innovation Center model test and how we can communicate what that model might mean for improving their care or the experience of care. And as providers and organizations are applying to join one of our models, we're focused on recruiting and making it possible for more safety net providers and those caring for underserved populations to participate in our work. And throughout the duration of our model. So,

during implementation of a model, we want to understand how patients and caregivers are actually experiencing changes in the delivery of their care in their health, outcomes, and quality of life. And last, we can consider how scaling up a model, or features of models that are successful, affect patients, and then ensure that the benefits that patients have gained are built into new programs, even after a model ends. Next slide, please.

Part of our commitment to transparency and strengthen regular communication is to send clear signals about where the Innovation Center is heading. This timeline lays out three areas of activity, our engagement and learning activities, examples of model types of the Innovation Center has launched and will be developing over the coming years to advance person-centered care, and last, cross-model issues or building blocks that are critical to developing and implementing a more streamlined and harmonized portfolio of models that drives health system transformation with patients and families at the center.

Next, I'm happy to hand it over to Kate Davidson, who leads our beneficiary engagement efforts across the center. She's going to dive into one of the key ways for promoting patient partnership through journey mapping strategy. Next slide, please.

>>**Kate Davidson, CMS:** Thank you so much Purva, and thank you to everyone for joining us today. It's my pleasure to share with you the work that we are doing at the Innovation Center to better understand patient and caregiver experiences using journey mapping as a tool and a strategy. Next slide, please.

Improving patient and caregiver experiences in the health care system is a key priority for the Innovation Center. This means we need to understand how patients and caregivers' experience care in our model, and that we design models that address their highest priorities, concerns, and needs. We're using patient journey mapping as one strategy to systematically explore gaps between what patients and caregivers are currently experiencing in their course of care with what they wish were happening within their care, and to better identify and the real-world pain points, the solutions by way of design features, and new and existing payment models. Additionally, it will enable us to foster two-way communication with patients, caregivers, and their representatives; gather real-world feedback throughout the model life cycle and ultimately build better measures with patient data. Next slide, please.

We can apply journey mapping strategies across the model lifecycle from new model ideation to implementation and all the way through to evaluation. In the very first stages of model development, we can improve our understanding of patient and caregivers' social and health care needs to inform how we select model care design elements, benefit enhancement and quality measures. During recruitment and application, we can use our findings to educate stakeholders, including potential participants, about the intended impact on patients and caregivers that we anticipated during our design of the care delivery, and of the payment models. Journey mapping can also inform our approach to model participant recruitment to better reflect patient and caregiver needs and build partnerships with key patient organizations to strengthen their involvement in the model early on. After the model is implemented, working with our model participants, we'll use journey mapping to solicit real-time feedback from patients and caregivers attributed to our models to understand their experience and identify opportunities for quality improvement, and support model participants with showing best practices in improving patient care. Journey mapping can also be used to inform qualitative data collection throughout our model evaluation. Next slide, please.

We piloted the use of patient journey mapping to inform our strategy and model development for patients and our caregivers who are experiencing the impact of serious illness. We use information gathered from interviews, listening sessions, and other research to better understand challenges that patients with serious illness and their caregivers experience along the continuum of care to identify key areas to inform our model design features, particularly related to patient and caregiver support, health equity, and education. If we can move to the next slide, please, then we can discuss these in more depth.

We hear consistent themes from patients with serious illness and their caregivers and advocates, about key areas related to access, care coordination, and patient partnership. Related to access, we are hearing that the Innovation Center should consider things like monitoring our models for unintended consequences, such as decreased access to care, breaking down barriers for receiving care, or being denied eligibility based on non-curative treatment. Creating clear, consistent definitions for concepts and services related to serious illness, increasing access to services, to reduce caregiver burden like respite care and other supportive resources.

Related to care coordination, the Innovation Center can require a single point of contact for patients and caregivers to relieve the burden of coordinating fragmented care. Enhance education to improve provider skills for culturally appropriate and effective discussions with patients and their caregivers about care options and end of life care. Related to patient partnerships we can improve communication with patients, caregivers, and beneficiary representatives about the processes for model development. Engage them in the design of programs, solicit input from patients, caregivers, and representatives, from historically marginalized and under-representative populations as well as their providers. Include patients and caregivers and their advocates in the governance of model participant organizations.

As you can see, we are already implementing many of the recommendations about engaging patients, caregivers, and beneficiary representatives in our model design and implementation work. With that I'd like to hand it back over to Purva to move us into our panel discussion. Next slide, please.

**>>Rawal, Purva, CMS:** Thanks, Kate. I'd like to welcome our guest speakers for today's discussion. Next slide, please.

We're pleased to invite representatives from a range of organizations and experiences to participate in today's panel and provide their perspectives on patient-centered care. Our speakers include: Edith Clifton, Board Member and Chair of the SEMATAC Steering Committee with the Coalition to Transform Advanced Care; Aza Nedhari, Co-Founder and Executive Director of Mamatoto Village; Erin Mackay, Managing Director for Health Justice of National Partnership for Women & Families; Libby Hoy, Founder, and CEO of Patient and Family-Centered Care Partners, and Dennis Heaphy, Health Justice Advocate and Researcher at the Disability Policy Consortium. Once again, we're grateful for your time and willingness to join us today and are excited to hear your input. Next slide, please.

We hope to focus today's conversation on three areas that the Innovation Center would like to learn more about from the patient and caregivers. Kate spoke just now about serious illness, which we just walked through. We're also focusing on patient needs and goals across primary and specialty care and maternal health. So, in relation to these areas, we'd like to ask our panel to provide their perspectives on several broader questions you see here.

Number one: What are patient and caregivers' priorities around access, coordination, care experience, partnership, and communication? Number two: What recommendations do you have for building engagement and partnership at the patient and at the community level, and what are the best ways to identify and engage the trusted partners and organizations at the community level? And last, what kind of CMS supports would accelerate your work. First, I'm going to turn it back to Kate, so we can hear from you. Next slide, please.

>> **Kate Davidson, CMS:** Yes, thanks, Purva. So, before we hand it over to the panel. We wanted to hear from the audience, and we've posted a question here as well as a poll. We'd like to know from you all: What are the top two priorities that you would like to be addressed by the Innovation Center? And the responses, or response options are: A) Equitable access to care and support services; B) Overall coordination of care by a primary care provider or team member; C) Better two-way communication between providers and patients or caregivers; D) Better coordination and communication between primary care providers and specialists; E) More collaborative care planning and decision-making with patients and caregivers or F) if you have another priority, please feel free to write that answer into the Q&A chat function. The poll should be launched now.

So, let's give folks a second to finish answering and then we'll see the result of the poll. Okay, so the results of the poll are in, and it looks like, you know, we've got, in terms of the top two priority areas: A) equitable access to care and support services, as well as more collaborative planning and decision making with patients and caregivers. So those things that really it seems like all of these areas are of high priority for folks.

So definitely looking forward to digging into some of the answers. The more specific answers are coming into the Q&A function, but this is really helpful feedback. So, thank you all for that.

Okay, so with that, I'm going to kick us off with the questions to our panelists. And I'm going to kick us off with Edith. Edith, it would be really great to hear from you, given your experience as a caregiver for someone with serious illness, as well as a community organizer. What do you see as the most critical care coordination needs for both patients with serious illness as well as their caregivers? And what recommendations would you share for building partnerships at the community level?

Edith, do we have you? There you are. And Edith, I think you might still be muted, or double muted. It looks like we might be having some technical difficulties. Purva, what do you think about reordering and we can come back to Edith? Oh, no, I see her, yup, she is lit up now, so Edith, over to you. I don't know if you want me to repeat the question, would that be helpful?

>>**Edith Clifton, Coalition to Transform Advanced Care:** Please, yes.

>> **Kate Davidson, CMS:** Happy to do that. So, we wanted to hear from you, given your experience as a caregiver for someone with serious illness, and also a community organizer, what do you see as the most critical care coordination needs for both patients with serious illness and their caregivers? And what recommendations would you share for building partnership at the community level?

>>**Edith Clifton, Coalition to Transform Advanced Care:** My answer to that question is that communication is key. The patient must feel that they have an important role in their illness, treatment, the options being presented, and that they must be heard in accordance with their feelings, their values, etc. Often, when I would take my patient to the clinic, and if I would wheel her into a

reception even, the communication would commence with me rather than with her. She was sitting right there. Patients do not lose their intellect, or their personality. Patients must feel that they are part of everything that's going on around them. And I think that's more and more happening, but it hasn't been the case in many, many instances. And another problem that we may have faced, that others may not, is that we are minority community, and that there is this sense of mistrust between minorities and the medical community over a period of time.

The good thing was, that I represent a faith-based institution. That's why the job, and often the patient would express to the pastor or to somebody else in the congregation things that they should have been saying or addressing to the doctor, clinician, or whomever it was that they were to be talking to. So, our job was to urge them to be more involved.

My patient was very much involved. She insisted on seeing all of her charts, all of her test results, and to the best of her ability, trying to understand what was going on. And it helped her to be involved, and she urged others to do so too. "Don't be a passive patient, be involved." I don't know if this answers any of the question that you're asking. But I found that to be the most important thing with her. Shirley was diagnosed in 2008, and she lived for 14 years. But she was aggressive, and she insisted upon being involved in every aspect of her treatment. And she urged her fellow patients to do the same, and it seemed to help.

>> **Kate Davidson, CMS:** Edith, one of the things that you said that I thought was really, really poignant was that when you would take your patients to the doctor that they would, that the doctor would be speaking to you as the caregiver, and not directly to the patient themselves. And I wonder what if you could tell us a little bit about what we could learn from that? And how we could better support and enable some of that direct dialogue with the patients, and what you did as a caregiver to try to empower the patient that you were, that you were providing care for?

>>**Edith Clifton, Coalition to Transform Advanced Care:** It may be a matter of training that the doctors and other clinicians be trained to address the patient directly. Do not assume that they don't understand what's going on, or what's being spoke to them, but just the opposite. This is a person, they have feelings, intellect whatever. And just make that assumption walking into the room or coming into the treatment, whatever it is. I don't know if that's a matter of training or just experience, but that's what I observed.

>> **Kate Davidson, CMS:** Thank you so much for sharing that with us.

>> **Purva Rawal, CMS:** Great, thank you. Thanks Edith, and before we go to Aza, I just wanted to say, you know, I think your experience Edith, and some of the stories that you just told us really, at the Innovation Center help us think about how we do our work. You know, we're testing new payment and care delivery models. But our goal is to use those models to unlock that kind of, you know, the supportive and collaborative relationship between patients and providers. So, thank you for sharing that.

Next, I'm going to turn to our second panelist. Aza, could you talk about your work with Mamatoto Village, you know, not only as its founding Executive Director, but also as a Certified Professional Midwife and Family Counselor? We'd love to hear more about your work, and how Mamatoto Village is advancing maternal health equity through patient and community engagement.

>>**Aza Nedhari, Mamatoto Village:** Thank you for that question, and thank you for having me here today. So, Mamatoto Village is a DC-based organization. Our mission is to serve black women through the creation of career pathways and perinatal health through our workforce development program and providing accessible perinatal support services, through home visiting which equips families with the necessary tools to make the most informed decisions in their maternity care, their families, and their lives.

So, for the past 10 years, we're actually celebrating our 10-year anniversary all year long. But Mamatoto has been advancing maternal health through a framework of reproductive and birth justice that really focuses on three key areas, two of which I mentioned in our mission, which are perinatal home visiting, workforce development, and then advocacy and policy.

Our Mother's Rising Program, which is our perinatal home visiting program, is home-grown and bridges the gaps for communities, both in the District and PG County existing on the margins which for us is black women and birthing people. In that program, we are delivering care in a team-based approach to really offer a protective factor against burnout. And we pay equitable wages that exceed both the DMV and the national average compensation for community health workers and home visitors. To date in that program we serve 2,500 over 2,500 birthing people and women with a 100% of our clients being Medicaid eligible. We've maintained a 0% maternal mortality rate and a 93% breastfeeding initiation rate. 81% of our clients deliver full term and 84% of our participants go through the entire program, and that's about serving about 450 people per year in this innovative, promising practice. This program is also partially funded through our contracts with Medicaid Managed Care, which for us, historically has been a source of stability in being able to deliver these services. At the beginning of the program it was our main source of funding that allowed us to deliver care in the way that we do it.

Secondly, is our workforce development track. So, we deliver about 200 hours of education for our perinatal community health worker training. It's a training that we have been delivering since 2013. And one of the most unique aspects of this training is that it focuses on the specialty of perinatal health, and infusing that with the community health worker model and grounding that in both reproductive and birth justice. We've trained about 200 black women and people have used it as a stepping stone into leadership and economically sustainable careers. Our trainees are directors, they are midwives in all tracks of midwifery, they're IBLCs. One of our trainees actually is starting her Residency at Howard University. We have therapists, social workers, running the gamut. And so, this approach to training and workforce development really elucidates the necessity to invest in community created and culturally resonant models of education and training and care that really go beyond just representation in a space. But this deeper awareness of operationalizing adjusted, centered approach to perinatal care, and really offering a framework for decolonizing the way in which we're currently both training people, who we train, and diversifying the health care workforce with members who are representative of the community.

Lastly, is our approach to policy. And so, we know that policy advocacy initiatives within community really require a reckoning with the legacy of medical racism, and its symbiosis with the manifestations of multiple intersections of injustice. And so, for Mamatoto, we believe that we are a conduit that resources and amplifies the voices of black women and their families to be witness, to be funded, to be elevated as subject matter experts as based on their own lived experience at the intersections of multiple oppressed identities. That they are also change agents who identify and evaluate the implementation of justice in our community solutions. And so, we take that approach both in policy and advocacy and thinking about whose voices are amplified. We believe that everybody deserves to

be at the table. We also believe that any person who has been a victim or survivor of racism deserves to have their voices heard and their stories amplified. And so, that is the approach that we take, and we try to be a translator in policy, understanding that often times the policy is happening in the silo, and that the people who are impacted by that policy are not often at the table. And so, we want to make sure that as policies are being created both at the local, the state, and the federal level, that the community understands the direct implication of that on their lived experience in their life.

One of the things that makes Mamatoto unique is both our intention, our orientation, and our delivery of our mission. No organization, no institution, can deliver its work or do its work without people power, without vision, strategy, and innovation. And so, I have an amazing staff, you know, I feel really lucky and grateful. But 100% of our staff are reflexive of the community of service. Our staff truly are invested in this aspect of collective liberation, and our unique skill sets, whether it's in public health or law, organizational development, midwifery, organizing, mothering, right. We all come together and merge to support this common goal, which is to radically shift systems to support optimal wellness for black women, birthing people, families, and communities.

The second thing that makes us unique is that two-pronged approach that we take to service delivery and workforce training that's operationalized through an economic justice framework in our prioritized community. So, we do intentionally train, hire, and cultivate pathways towards leadership in the community that we serve in and about 20% of our current home visiting staff were former clients, and several of those individuals have now moved up into other leadership roles within the organization. Yeah, that's it.

>> **Purva Rawal, CMS:** Can I just ask a quick follow up? I know, that's a fantastic overview of the work that you all do, but what makes it possible? And there's a lot of moving pieces that you and your team, clearly, you know, are putting together. Can I ask you just what kind of feedback do you get? You know. How do you hear from your patients? How do you, within, at Mamatoto Village get their feedback?

>>**Aza Nedhari, Mamatoto Village:** So, we hear feedback from multiple different, I would say, points of feedback. Some of that is through surveys. We are constantly in a process of communication with our clients, and so some of that is one to one with their perinatal community health worker. Our clients are actually not shy to give feedback. Much of how our program has iterated and evolved over the years has been based on the feedback that has come from our clients. We also ask them both at the beginning of their engagement with us, "What are they expecting from us, and what are they hoping to achieve while they're in the program?" And then at the end, once they have received the services, we ask them again in that discharge planning, survey about their experience with the organization, about whether or not they achieve the goals that they wanted to achieve, whether or not the organization met their needs. And then we also invite our clients to participate in focus groups that we're doing. We take a qualitative approach to that. When we do focus groups, we're listening, we're hearing from them, and we then incorporate that into making quality improvements within the program. We also do the same thing with our staff. We take the same approach, both through survey through one-to-one communication with myself or with other members of the team as well as through group sessions, where we open it up for innovation, for a workshopping, as a way to continually improve, but also as a way to ensure that everybody's voice is included in that process of improvement in a development of the organization in our programming.

>>**Purva Rawal, CMS:** Thank you so much. I think it was really powerful how you were able to talk about the vision that you have in Mamatoto Village, how you pull that through the services and the supports that you provide to the people that you work with, how you pull that through to workforce development, and then you use all of that to inform policy and change, and then improvements again, at like the patient and family level. So, thank you, Aza.

>>**Aza Nedhari, Mamatoto Village:** Yes, thank you.

>>**Purva Rawal, CMS:** Erin, we just heard from Aza about what we can learn, and their experience at Mamatoto Village at the community level. From where you sit at the National Vantage Point, what kinds of maternal health needs should the Innovation Center prioritize as we consider work and models in the space? And in particular, are there any highlights you might share from the partnerships recent report, Raising the Bar for Maternal Health Equity and Excellence?

>>**Erin Mackay, National Partnership for Women & Families:** Thank you, Purva. We appreciate the invitation, and the Innovation Center's focus on maternal health and are excited to share recommendations from that recent report. I think I'd like to highlight three maternal health needs.

The first of, being treated with dignity and respect, which I think both Edith and Aza have already spoken to, social needs and mental health needs, because the mental health of mothers in the United States is in crisis. So, with regard to dignity and respect, whether it was from community and consumer focus groups that we held as part of the Raising the Bar Project or our National Listening to Mother's Surveys. Childbearing families experience a lack of dignity and respect in navigating the health care system in paying for, excuse me, paying for care and receiving treatment. People tell us they are highly attuned to verbal and non-verbal cues. They feel signaled disrespect from providers and administrative staff that might be their health concerns not being listened to, or taken seriously. Perhaps not being addressed directly or included as part of the conversation, as Edith has mentioned, and people being considered and valued and believed as the experts in their own health experiences.

There are a range of reasons that people feel, have felt, judged or discriminated against, whether it's being enrolled in Medicaid, having a low income, being African American, or being Spanish-speaking. And we really are encouraging providers and payers and the entire ecosystem to actively work to elicit and listen to, and respond to the experiences of birthing patients and their families as a first step towards establishing a culture of dignity.

With regard to social and mental health needs, you know, given what we know about how different socioeconomic factors affect maternal and infant health, we have a great series of moms and babies' bulletins that that look at ten different socio-economic factors and the outsize impact those have, particularly on black and indigenous and people of color communities. We know we're not going to be able to achieve maternal health equity and excellence until we go beyond the focus on physical health to fully incorporate mental health and social needs. And so, we recommend screening for mental and social needs periodically during pregnancy and in the post-partum period, developing and modifying care plans, and addressing identified needs.

I think there's a lot of recent focus on social needs screening which is great. When we have looked into and asked how people feel about sharing information about their vital needs with their health care providers, two themes have emerged over and over again. If you're going to ask people about their

needs, do so with respect and compassion. And, ask with the intention and the ability to help people then meet the needs that have been identified in that screener or that conversation.

So, thinking about the important work that the Innovation Center can do, you know, we would love to see the Innovation Center prioritize person reported outcomes of experience of care. We know there's really exciting and important work to adapt the CAHPS survey to maternity care. But also, outcomes and experiences related to respectful care and mistreatment, stratified by race and ethnicity and other demographic dimensions, disability status, sexual orientation, and gender identity. We think performance measures specified for this timeframe, clinical area, and the population for social need, screening depression and anxiety screening, and follow up as indicated, is really important. And then to be baking into the design and implementation of new models of care delivery and payment, enhanced capacity to advance health equity.

So, whether that is partnering with perinatal and other community-based groups like Mamatoto Village and other social service agencies, to really learn from their expertise and incorporating them in governance and advisory roles and, and I think probably most importantly supporting these groups and community experts with financial, so financial compensation and other in-kind services. Providing culturally congruent and linguistically appropriate care is a critical aspect of being able to advance health equity. You know, one strategy is to include community health workers on care teams, especially those workers that are embedded in community settings, have an intimate knowledge of community socioeconomic resources and supports, and even share a socio-cultural affinity with their clients. And I think, I believe, as Kate mentioned, just the importance of providing a champion for childbearing families. A navigator, a coordinator, a community health worker who can really connect them to the services that they need and advocate them, for them throughout the process.

>> **Kate Davidson, CMS:** Thank you so much Erin for so much to unpack there. What I really appreciated was all the themes that were connected to what we heard from Aza that's happening at the community level and the advocacy work that you guys are doing at the national level. It's really nice to hear that.

One quick follow up question, if you don't mind. I'm just wondering if you have any recommendations for us at the Innovation Center on the piece that you talked about around dignity and respect. And I think this actually links back to also this kind links back to Edith and some of her remarks as well, about her experience as a caregiver, and patients experiences as when they go in to see their doctors. I'm just wondering, or their providers, I'm just wondering if you could give us any thoughts about what the Innovation Center could do specifically to enable, improve the dignity and respect that the patients are experiencing at the point of care.

>>**Erin Mackay, National Partnership for Women & Families:** Sure, I think there are measures of dignity and respect that are underway by leaders like the National Birth Equity Collaborative, so helping in in any way that you can to foster and encourage the development and eventual use of those measures would be wonderful.

I think, you know Edith mentioned, training, I think that's critical, I think implicit bias training, you know, being able to enhance providers ability to provide culturally-centered and appropriate care. Aza also mentioned reckoning, excuse me, dealing with the history of medical racism, and Edith talked about sort of that, the sense of mistrust with communities of color. So, making, you know, in terms of training and education, helping providers at all levels of institutions. Those that I think provide clinical

care and maybe interact with patients on an administrative level, helping people understand this history and learn tools and strategies to provide higher quality, more equitable, culturally centered care.

>> **Kate Davidson, CMS:** Thank you so much Erin, it was really helpful and very concrete. So, we will definitely be following up on all of that.

So, I'm going to move us on to Libby Hoy. Libby, I want to ask you a question about patients and caregivers. You know, one of the sticking points that patients and caregivers encounter, that we hear a lot about, is how they are navigating a fragmented system with their primary care and specialty care providers, who are often disconnected from one another. So, we're wondering how patients and families, how we can help, and patients and families can help design processes and support to enhance primary care, primary and special care coordination. Do you have any thoughts on that?

>>**Libby Hoy, Patient & Family Centered Care Partners:** I do, and I just want to first of all thank you all for the invitation to be here today and really commend your team on the efforts to have this listening session. I think it sets a wonderful example of how we can bring patient family engagement very far upstream to really be thoughtful about the people who are experiencing disparities, and the crises that we see in the health care. So, to really hear from people and communities, I think, is really important.

To get back to your question about navigating a somewhat fragmented system, I think one of the first things, maybe that the models could consider is providing access to patients and families of their health data. Not just their medical record, but all of their health data, their care plans, their health goals, and clinic notes as well. And the reason for that is, while the efforts around interoperability, I can never say that word, but you know what I'm trying to get to, with all of those efforts alongside, really recognizing that the one common thread between specialty and primary care is the patient and the family caregiver. And as an example of that, we hear from our patient family advisors in our network who experience kidney transplants. They get a care coordinator for the kidney transplant team. They get a care coordinator for their cardiac issues. They get a care coordinator.

And so myself, as a person with lived experience and caring for my kids. At one point we had seven care coordinators because we have the insurance care coordinator in each different discipline. Ultimately, we are responsible to be the final care coordinator. And so how, but it's really hard to do that when we don't have all the information. And so, providing patients and families a path towards getting their information in a more timely manner, and really having that transparency so that we can be empowered in that role of care coordinator.

I also think that that plays really definitively into patient safety, and I'll just share a quick anecdote from my own experience. I had an ultrasound in 2016 of some lump in my neck, and as it turned out, I had stage four salivary gland cancer. To this day, I'm still waiting for my primary care to let me know that that was malignant. And so that's the kind of coordination that and transparency and timeliness that that patients and families need to their own care information.

I think another thing that the models can do, and it speaks to what's been said before about dignity and respect, and that is, increase the capacity of clinicians and office staff to believe, and hospital staff, to believe the patients and family caregiver experience with their own condition. I can't tell you how many times in the patient safety world, particularly in communities of color around sepsis and sickle cell disease. How many times patients and family caregivers were speaking up and saying something's

going wrong, something's weird. I can't say what it is, but something is different. Something is different. And not having the capacity within the health system for anyone to respond. So, I think that's a staff, you know, training potentially, yes, but it's also a systems problem, because even when we have nurses with the most well-meaning hear what they're saying, but they don't have anywhere to take that information or change course because of it. I think that is really an important aspect these models can start to say, what do we do when we hear that, when that letter gets pushed? What then? And so, I think that's a really important place.

I also think that it would be helpful and useful to decouple the terms patient family engagement, and patient experience. And both are so necessary in our health system, and both are definitely related. But we really see patient experience as an outcome measure, and we see patient family engagement as an active strategy to improve outcomes. So, that's whether, as either Edith's friend was very involved in her care, that source of engagement can improve my outcomes, can improve my family's outcomes.

But it also applies when we're talking about building models. When we're talking about evaluating those, and we heard some of that from Aza, you know, going back to her community and saying, is this working? That continuous feed. And so, in that way we really move patient family engagement from feedback to feed. It's a continuous feed that will improve outcomes for myself, but also for our health systems. And most importantly, it gives opportunity to engage those voices that have been under represented in developing these programs.

I would also say that to that point of engaging patient family caregivers and community members in health care operations at every level. This is a great example of that, and what you've put together in terms of really wanting to engage the perspective of people with lived experience. As you're developing these models, it's a perfect example, and I applaud you for making these efforts. This is a continuous improvement process. We are all still learning how to do this. I've been a patient family advisor since the nineties, when we were super excited to comment on the color of the paint on the wall. And now, I'm here on a CMS call. I mean that's crazy progress, but we have so much further to go.

So, thinking about patient family engagement in hospital operations, in model design, in clinic staffing patterns, all of that. It's not just bringing in the patient perspective, listening to it and then moving away and seeing how our work happens. It's really baking it in. We like to refer to it as the Funfetti approach to patient family engagement; baking in the patient and family perspective across all activities of health care, from the policymakers in Washington to the clinicians in the outpatient clinic and all the way through. And you'll also notice that Funfetti, if you've enjoyed a Funfetti cake, you know that there's all different color sprinkles, and there's all different color flavors. That's a key ingredient to really optimizing what patient family engagement as an active strategy can be.

And then, finally, I would encourage you to think about how to build on the PFE metrics that were developed in partnership for patients. Let's move beyond the traditional PFAC. Let's move into really creative innovative systems like, as Aza mentioned with how she connects with her community. Let's build more doors, so that there are opportunities for everyone to be influencing and informing how we develop our health care systems. To do that, I think we have to add infrastructure, and I think that's one of the things the models can do. They can add what pieces of infrastructure need to be in place to really engage the patient family perspective in program, design, implementation, and evaluation.

Infrastructure, what am I talking about? I'm talking about building it into that org chart. I'm talking about building it into the budgets. We know that compensation is a barrier to inclusion. And so how are we compensating people with lived experience to participate in these activities in such a way that creates more doors for more people? Again thinking, growing on the PFAC structure, but thinking about how else do we solicit those critical insights that people have.

I think, also we have to think about preparation and really looking at patient families as partners. I'll, give you a great example, prepping for this very listening session that I'm on today, we had a prep session. We talked about key messages, not in a way that was telling me what to say, but in a way to say, here's the context of our meeting. This is what we're trying to get across. Do you have thoughts on that? And here I am giving my thoughts on that. We have to do that at every level, and that's part of the infrastructure that has to get built into models, so that we're not just pulling somebody in and say, tell us your story, but we're really eliciting those insights of that person's experience.

So, I think that, providing the necessary context and support to people that particularly people who have been underrepresented, and may need additional support to participate. And then, encourage primary and specialty care to do the same as you are all doing in this listening session by engaging people with lived experience in the health system. It's, let's help our health system to learn how to listen with for the benefit of all, so that we can design programs that really, truly meet the needs of all Americans. Thank you.

>> **Kate Davidson, CMS:** No, Libby, thank you. Every single time I hear you talk about your experiences, and also giving us, you know perspective on how you think that we can make some meaningful change at the system level, I learn something new. And I walk away thinking that just makes really good sense, and so really appreciate all that you share. I mean, seven care coordinators. That really made me think about how much progress we need to make around primary care and specialty care integration. And even the elements that you talked about regarding data. It all really resonates. And so, thank you so much for sharing all of those insights.

I'm going to keep us moving, so that we can hear from Dennis. And so, Dennis, I was hoping that you could share with us some of the issues that are related to health equity that are facing people with disabilities and their impact on access to care. How should the health system engage with people with disabilities and their caregivers around needs and goals for improving access to care?

>>**Dennis Heaphy, Disability Policy Consortium:** Thank you very much. Do I need to myself on the video?

>> **Kate Davidson, CMS:** That would be great. We would love to see you.

>>**Dennis Heaphy, Disability Policy Consortium:** I don't know, okay, give me one second.

>> **Kate Davidson, CMS:** There you are.

>>**Dennis Heaphy, Disability Policy Consortium:** Thank you very much. And my thoughts come after all these people because so much of what was said is the things that I would, that I have to say as well.

I do want to jump up where Libby just said about our health system and one of the problems, we don't have a health system, we've got a fractured health, set of systems, and that system is based on where

we live, by a race, by our abilities, or incomes. It's really is fractured, fragmented, and so we would one thing that CMS could do is how were figure out how we create a more unified health care delivery system that serves the needs for all people.

Although one second, I apologize. Something just came up but I'll be back in one second.

>> **Purva, Rawal, CMS:** While we're waiting for Dennis, Kate, I am happy to offer just a couple of kind of remarks just from the themes that we've been hearing, and then hopefully Dennis can rejoin us. But you know we're hearing words like you know, themes like how important access to care is both primary and specialty care, access to information. I think Libby really tells the power of giving information to patients and families, and the need for continual communication, collaboration, and improvement.

And that got me thinking about some of the tools that we have at the Innovation Center to support these kinds of care experiences as we test different innovations. So, you know, like Aza talks about, community health workers and patient navigators, you know, driving access to information for patients and providers. And our models about the patients have information about their own care. And then this whole idea of an infrastructure support, and we are providing infrastructure support, making sure that it is enabling the delivery of this kind of care and care experience.

So, I'll stop there. Dennis looks like you're unmuted, so we'll turn it back to you.

>>**Dennis Heaphy, Disability Policy Consortium:** I am so sorry, but my dog needed to go to the vet. They came in just a second to take him out and that's just people need doctors.

But as I was saying, it's the health care delivery system is, it is really a fractured set of systems and people with disabilities as Lisa Lezzoni, recent article published in Health Affairs talked about the various barriers people with disabilities face in gaining health care access to health systems, and just even to health care settings themselves. And how a lot of providers, healthcare providers don't even want to work with people with disabilities, or have implicit or explicit bias against folks with disabilities. Viewing people with disabilities as poor health outcomes, is not, and not as full as that, and not as full people. And that there's often lack of just physical access to a care provider's office, so people can't get the services they need. And all these, all these barriers that we've disabled are exacerbated depending on the person's you know, race or language, because of racism and linguistic and I've spoken with who don't have English as their primary language.

I think it's important too, I think about disability to, is people like myself, we don't view ourselves as patients that we need to contextualize when a person's a patient, and when they're actually an individual living in the community. I'm a sequelae quadriplegic. I've got other medical complications that have nothing to do with the disability, but ongoing chronic illnesses. But when I'm in the community and I'm working, and I'm living in my life, I'm not a patient. I'm a person who needs services, home and community-based services, supports and things like that that enable me to live a full life in the community. So, in this context, I'm not a patient.

When I need the assistance of a of a medical provider, and that in that in that space I'm a patient. But when there's this umbrella terms probably use the of the word patient when identifying anyone who utilizes CMS services or services that are covered under the hub scheduling system. Then we're really narrowing the scope of what our understanding is, of what it means for person to be a whole

individual. And I think this is particularly important for folks who require long term services and support to live in the community. Those are supports like durable medical equipment or personal care attendant services to help folks get in out of bed. The assistance with this activity to daily living, that when those, when those supports are viewed through a medical lens, it very much reduced to what is needed for the person to get from point A to Point B, within a narrow understanding of health as opposed to what is needed by that individual to support their ability to live in the community, and to have, you know, consumer choice and control over where they live, who they engage with and the types of services that they receive in general.

Of we folks I'm actually a dual eligible, and we see systems changing all the time, and not having much voice and how those systems are changing, and who's in control of those changes. There's a general mistrust among the other folks with disabilities of managed care, especially among folks with behavioral health diagnosis, whether it be whether it be substance use disorder, or about the health, mental health diagnosis. And that's because so much there's so much emphasis on driving down costs rather than looking at and bending the cost curve, and there's lack of recognition of substitutes or mental health as being recovery, a journey it's not an end in itself. There's no there's no place for money savings. But someone like myself who has really complex needs that the focusing on as the money savings as a goal. This not is not going to improve my access to the services I need to live in the community, to reduce our risk of hospitalization. And I'm a strong proponent of reducing hospitalizations, reducing emergency department visits as appropriate, but there are population and times when that's actually antithetical to what the person needs. I think particularly children with complex health care needs. There are times when they when they need to go to the hospital, and they need the services that are there and yet we're looking at them as cost, as a cost centers rather than as full human beings who actually require these services.

And so, I think, if I look at this, think about the provider relationship it's about trust. It's about ensuring that the provider is not only somebody you can trust and have a relationship with, but they're also a decision maker. Something that that really, that negatively impacts the provider and individual's relationship is utilization management practices and the lack of transparency around decision making. That they really get in the way because we can do journey mapping and look at what service someone needs, and have the best care plan in the world, but the care plan does not have any meaning, if the care plan actually cannot be used and implemented to provide and do what they need. And in terms of the care planning itself, is we need to make sure that the person themselves are driving the care plan, and when it's appropriate that the person is doing that, you know, with the with the family member or a guardian. And so, we need to just take a holistic look at all these, all these sorts of things.

I think that something that I think it's also important to discuss and we talk about it quite a bit, is - are people satisfied with the services they receive, or are we using satisfaction as determination of whether or not a program is doing well or not? And yet satisfaction, people will be satisfied with services, because they really don't know what sort of services they have right to receive. So, someone who had received, with, receives the access to medical transportation to some of their doctor's visits, maybe is satisfied with their health plan because they're getting those visits. But then, if they find out that they actually have a right to get non-medical transportation, but they weren't aware of that right to get non-medical transportation that might actually shift their understanding whether or not they're satisfied with their care plan or the care they're the receiving. So, I think when we're looking at quality. We need to do a better job of defining what the quality measures we're using, and how we engage folks, and actually defining what the meaningful measures are of quality.

I think in terms of care coordination, care coordination is so critical, but it should be conflict free care coordination. When the health insurer is involved in that care coordination there can be real distrust to the care coordinators. Is that care coordinator acting in the individual's best interest or in the health insurers best interest? I think it could actually advocate if an if it is going to advocate for the person, if they were denied a service, or they actually going to just let that that denial stand. And so it's a very complex, very complex system, and we're high utilizers of that system but I think it's just important to start with trust, relationship, and having a locus of control within the care team that's rooted in a person-ended care plan, designed by that individual with their care team that not only looks at what their medical needs are, but looks at what the social determinant of health needs and all other of their other needs at home, and community services, etc., so I'll stop there. But thanks.

>>**Rawal, Purva (CMS/CMMI)**: That does. Thank you. I think we could spend all day hearing from you, the way that you connected these huge concepts. We talk about the quality, cost, bending the cost curve, care coordination, and the way you tie them all together, so that we need to find a way to make them meaningful to each individual person that is moving through the health care system.

So, thank you for those thoughts. I know that you are generating a lot of questions and a lot of enthusiasm in the Q&A as well. And I know we're a couple of minutes on over, but it looks like folks are hanging on, because this has been such a great discussion. I think I'll just close by saying that one of the things that I think is clear to us today, that real time feedback and two-way communication is really key to enabling, and I think, unlocking the improvements that people want to see in our health system and in their experiences. And you know, today's webinar is one small part of that effort from the vantage point of the Innovation Center. But we are open to our panelist's ideas and our audiences' ideas about the best and most innovative ways to get that real time feedback. So again, we are then able to engage in a process of kind of continual improvement.

So, I just want to thank everyone on this call for joining today's listening session, especially our panelists, for their time and thoughtful comments. This is a really productive conversation. We look forward to future dialogue. The Innovation Center is going to be synthesizing today's conversation so that we can distill some of the key insights and feedback that we received today to inform our work. Just like to ask you all to participate in the survey for today's event by clicking the link in the chat window really helps us think about planning for future events, and what we can do differently and better. And, also please just take note of the following actions to continue engagement. You can learn more. Please sign up to receive regular email updates from us. You can visit our website and our model specific pages where we're making more information available that's more accessible to those following our work, and then follow us at CMS innovates on Twitter. But thank you all. I hope you all have a great weekend, and thanks for joining us.