

Centers for Medicare & Medicaid Services

Organ Transplantation Affinity Group (OTAG) Webinar

Wednesday, January 31, 2024 2:00pm Eastern Time (US and Canada)

WEBINAR RECORDING:

- [Link to Webinar Recording](#)
- **Recording Passcode:** vB^u?D0b

TRANSCRIPT:

[captioner standing by]

We're just waiting for a few people still joining us and want to give everybody an opportunity to get in and then we'll get started. Numbers are still climbing. It might be slowing down a bit. We are also recording this. Good afternoon and thank you so much for joining us today. I am Jean Moody-Williams, the Deputy Director for the Center for Clinical Standards and Quality. I am joined by my colleague Dr. Suma Nair, and we're excited to co-present today as we reaffirm that HHS remains committed to advancing equity in organ donation and transplantation, so everyone has a fair and just opportunity to obtain optimal health. And often it's depending on being able to get the organs you need when necessary. I need to do a few housekeeping items before we dive in. This Webinar today is being recorded. And it will be posted on the CMS National Stakeholder Call Webpage, and you'll see the link there. We'll also drop that in the Q&A section. All participants will be muted throughout the call.

And closed captioning is available via the link in the closed captioning window at the bottom of the screen. You should be able to see that right at the bottom. The Q&A section is open.

So, we invite you to put your questions but also your answers.

For Q&A Please put your answers to some of the questions that were sent out ahead of time. The chat function is closed. Members of the press may be on the call today. However, all press and media questions should be submitted using the CMS media inquiry form, which may be found at our newsroom, and we'll also drop that in the chat for you as well. So, we can move on to the next slide. And we really just want to start by especially thanking you all for your dedication to the transplant system as we are all really working together on shared goals and you're going to hear a lot of information from us today. But most importantly, we want to hear from you today and moving forward. So, this is the first but not the last opportunity for this joint session or OTAG, or the organ transplantation affinity group work we will be having. And ever since we published the Blog, entitled organ transplantation affinity group: strengthening accountability, equity, and performance, we received a number of responses acknowledging the effort and wanting to contribute to the development of the action plan.

And to that end our goal really is to receive any input that will foster collaboration, improvement and accountability across the spectrum and that includes the voices of donor recipients and caregivers, living donors, donor families, primary care physicians, dialysis facilities, transplant centers and many others and I name all of those just to talk about the fact that this is a system-wide effort and it really takes all of us. So, I'll turn to my colleague for a few introductory remarks, and we'll jump right in.

>> Great. Thank you so much Jean. Hello, I'm Suma, the Associate Administrator for the Health Systems Bureau here at HRSA. The Health Systems Bureau oversees a portfolio of public health and health systems programs including supporting the national transplant programs both solid organ and blood cell transplantation. We oversee the Organ transplantation network, support organ donation and public outreach and education on organ donation. And I will echo Jean's sentiments about our shared commitment to improving the equity and performance of the organ procurement and transplantation system to better meet the needs of patients and families. I'm really pleased to be sharing this virtual stage with my CMS colleagues as we describe our collaborative efforts to support all of you who are working so hard to ensure that everyone who needs a transplant can receive one in a timely manner. With that back over to you Jean to get us kicked off.

>> Thank you. You see here our session objectives here.

We really want to provide an overview of the OTAG, the formation, framework, address questions we received just about OTAG. Then we want to describe our collaborative efforts between HRSA and CMS and throughout HHS. And then get feedback as we mentioned in a few of the key areas and that's how we have designed today's session. Next slide please. The agenda we plan to wrap up around 2:45 and cover the areas that we talked about in the objectives and next slide. I'm going to kind of speed through some of this. We know that tackling the challenges of the transplant ecosystem is larger than the work of what CMS regulates and to that point we formed an agency-wide and interagency wide collaborative group known as the OTAG and to ensure really a strategic and comprehensive approach to overall system improvement. And on the next slide I know I really don't have to state the concerns that the OTAG is addressing for most on this call, but I want to offer just a few highlights because I know we sent a broad invitation to a broad audience and invited new participants to the call because we know that they are important. So, every ten minutes another person is added to the national transplant waiting list and as of October 23rd more than 103,000 individuals, that's men, women, children remained on the national transplant waiting list. 17 people die each day waiting for an organ transplantation and approximately 36 million adults suffer from chronic kidney disease and as of 2020 more than 800,000 suffer from end stage kidney disease. These are two of the most common conditions that can be treated with a kidney transplant. Next slide. Now, data from the OPTN database show that in 2023, 23.2% of black people on the waiting list received an organ transplant while 50.3% of white people received an organ transplant. So, 23.2%, 50.3%.

Wait list data from the database show that 39.5% of patients on the waiting list are white while 27.6% are black. So overall 60.5% of patients on the waiting list are from an ethnic minority group. I can go on listing disparities, but I believe the case has been made through publications and testimonials that we don't have to spend a lot of time saying we need to work in this area. What we need to spend our time on is what are we going to do about it. On the next slide recognizing there is a need to ensure coordination among the agencies and to achieve system improvement. The secretary established an effort to improve donation procurement and transplant and I can remember asking, the secretary, what is the secretary's desire here. And he said really two things. The system improved and I want equitable organ transplant.

That sounds like that boils the ocean. But when you think about it, I think that's what we all want. Led by the Center for Medicare and Medicaid services, this collaborative seeks to drive an improvement in those areas for donations, clinical outcomes, system improvement, quality measurement, transparency, and

regulatory oversight. So, we often get the questions well who exactly is on this OTAG. And there are more than 30 staff at CMS and HRSA.

We meet at least monthly for routine interagency collaborations. But in addition, I mean that's the formal meeting, but in between that we have many meetings for planning purposes, to talk about emergent issues and concerns and really to do the work of establishing many of our processes and goals. And we report up to the agency administrator, I mean administrators because it's for both and to the secretary through his counselors. Next slide. One thing I'll mention is all the members -- because we also get this, all the members are federal employees. But while the group is composed of federal employees, we have and we will continue to seek input from interested parties such as those on the slide. As we talk about this whole government approach, we also get the question: well, who does what and how is the work divided? We have separate and complimentary roles in the oversight of the system.

The differing roles impact the nature of the oversight process for each agency and how we interact on our oversight activities, for example, HRSA's division of transplantation oversees the Organ Procurement and Transplantation Network for the statutory framework including the National Organ Transplant Act or NOTA and they oversee the regulatory framework including the OPTN Final rule.

And the OPTN contract requirements. They also have responsibility for the Scientific Registry of Transplant Recipients known to most as the SRTR, the living donor reimbursement program and the public awareness program. All those wonderful PSAs and the like generally are going to be coming from HRSA. CMS provides oversight of many of the facets of the transplantation eco system for organ procurement organizations, transplant programs and providers and suppliers that are participating and paid for through the Medicare and Medicaid program. That includes establishing quality and safety requirements. Those are generally known as conditions or requirements of participation, oversight through survey and enforcement of those requirements and quality measures and improvement and of course payment policy. I saved that for last but that is a very important function that we hold here at CMS. In addition to HRSA and CMS, however the Center for Disease Control and Prevention has an important role in issues related to transplant diseases and transmission. The Food and Drug Administration related to the regulation of transplant productions and transplant related research provided by the National Institute of Health. I can go on. They do a lot of the quality improvement initiatives.

It is all of HHS that has a role ensuring the system is improved.

I also mentioned we have begun to align many efforts to improve the organ transplantation system. So, I talk about kind of how each of the agency's function and their role and the things that we do that may appear as our separate activities. So, you may wonder: What are you doing as a group to ensure that we have joint activities and that remains coordinated? And the first thing, because we do policy development in each of our agencies, we want to ensure that we are aligning that. We're collaborating, we're talking together and communicating about what our agency is doing, what HRSA is doing and how do they intersect and more importantly that they don't conflict. And so, we do work on that. We also are looking at the data across the organ transplantation system to improve the performance and easier way to develop a core set of national organ transplantation system. It really is working together and we are evaluating that. Looking at the gaps in the data. And doing information to determine where we go from there. And most importantly we want to strengthen accountability to patients and families and the public by advancing equitable access and collecting data for example on transparency of wait list practices. We can both work on together. Stakeholder complaints. Many times, interested party will send a complaint and

CMS will get something or HRSA will get something. How do we coordinate that? How do we make sure we're both pulling all forces together to resolve any problems? We spent quite a few months working on that. And doing process improvement maps there. And then of course promoting patient safety engagement. So, we'll continue to work and refine these processes. I just want to give a couple slides on how we developed the action plan that we have. And then we'll go into a little more detail of the action plan so we can get your feedback there. How did we come up with this action plan? Well, first we did a landscape assessment and looked at the points and we, you know, we know that we didn't have to do a lot to know what the problems were because there's already been a lot of work done in this area.

And quickly, you know, we said we don't want to spend all our time trying to diagnose what the problems are because I think the public and the families, they want us to take action on these issues. We did the landscape assessment, looked at the points and there were numerous areas that we could start to work on. I'm going to prioritize that because we know when you try to do too much, nothing gets done. So, what are those areas that we can really make an impact? We developed the action plan and here we are today with our interested parties and asking for your input on the plan. Next slide.

One of the things was to do a journey map and we did this many times when we want to tackle a problem because being in quality improvement you start to throw solutions when you don't really know what the issues are that you are solving. So, through all the work we did in our landscape assessment, and we also did journey maps. So, we could see each step what some of the issues are. I'm not going to read through this for the sake of time. But I will say if you just look at a few, there are certain things that stand out.

Lack of data. No transparency in particular areas. Not knowing --

[Indiscernible/Audio Issue]

Standardized wait lists criteria. Financial areas. And then using medical context used on organs and all of these things no matter where you look along the journey these issues came up. So, it became readily apparent where we needed to focus efforts. So, with that I'm going to turn to Suma to give more information on where we land with the action plan.

>> Great. Thanks, Jean. Okay.

Great. So that was helpful overview and kind of the background and context that led us to the development of the goals, our aims, and the action plan. So, I'll take a few minutes now to walk us through and orient us to the action plan itself. First, a highlight level based upon all of the insights and information that Jean just walked through, we have two primary aims. We really want to support system equity and system performance. And in order to do that the organ transplant affinity group established the five goals you see on the slide here. One to reduce variation of pre-transplant and referral practices, to increase availability and use organs, increase accountability for organ procurement and matching, to promote equitable access to transplant and finally very importantly empower patients, families, and caregivers to actively engage in the transplant journey. Let's go to the next slide and click down to the next level so we can look at the goals and some of the strategies we're going to employ to make progress on our aims and goals. So, this is a high-level orientation. You see the two aims of improving system performance and equity and the five goals associated with those two aims and then you see the strategies that we have there on the right most side of the slide. We'll click into the next slide and take a peek at our goals around system performance improvement. So here you see in order to kind of really achieve that aim of improving system

performance we think a focus on reducing variation of pre-transplant and referral practices, increasing accountability for procurement and matching are important goals. And so initially our considerations are on these key strategies. Improving the transparency of pre-wait list and referral practices, establishing criteria for standardization and transparency of wait list practices. Removing barriers to the use of donated organs including both living donations and medically complex organs. Ensuring that organs acquisition payment policies promote equity and support procurement. Identifying performance incentives to drive accountability for systems change and supporting the U.S.

Organ transplant system operations including really imbedding that continuous quality improvement, mind-set, and effort across all the parts of the system. By way of example let's take one of the strategies and drill down a little bit of some of the efforts already under way. So, let's take the strategy around identifying quality metrics and performance incentive priorities. So here are some of the things that we have done in that space of quality and performance measurement. Last year we had a consensus conference on performance metrics and get from families, donor recipients the feedback and folks on the transplant wait list what was important to them in terms of system performance metrics. And so that was really helpful. There are some reports documenting the key insights and findings from that and that information will support one of the areas in terms of us thinking about a national set of performance metrics. In addition, I think you all are familiar with the technical assistance and quality improvement and learning efforts in dashboard that really focus some of that effort on reducing discard rates and CMS has focused on thinking about their regulatory levers to propose and finalize some wait list measures. Also, in the area on HRSA's side around our work with the OPTN thinking about metrics and how we support system improvement by making sure we collect the right data, that we streamline all the data that we collect, make sure it's the most important and actionable data and then working together to drive improvement on that data. Another area I'll point out for example is the strategy around removing barriers to incentivizing the use of medically complex organs and looking at CMS's regulatory levers to see how they can support, you know, and address procurement of medically complex organs and use of those appropriately. Also, I think that on the HRSA side includes a look at OPTN policies and practices to look at increasing procurement of medically complex organs and supporting utilization, increased utilization of donated organs and there's work under way in those areas as well. So that's just a couple of examples that kind of draw the connection between our aims and goals and some of the strategies we have been putting in practice. With that let's look at our second aim. We can jump to the next slide and focus on equity as Jean said at the top of our call, this is a key priority for us. And here to really advance equity in the transplant system we want to focus on equitable access to transplants, empowering patients, families and caregivers to engage in the transplant journey and the strategies are ensuring that OPTN policy making processes and policies really drive equity in organ donation and transplantation, ensuring that transparency of referral and wait list practices for patients, families and caregivers as Jean mentioned as we have done our engagement, this is an area where there's a lot of opportunity to make sure as we have in other parts of health care that patients, families and caregivers are fully informed throughout the process and supported in robust shared decision making around their care. And then the third strategy is enhancing patient, family and caregiver education and engagement to really support shared decision making in their journey here. So an example around how we're focusing on promoting equitable care, CMS's levers are often their regulations around ensuring competent and patient centered care and similar on the HRSA side we have been working closely with the OPTN to support adoption of race neutral allocation policies, looking at equity as a part of our modernization efforts just to name a couple of the ways we're looking at improving and advancing equity in the system.

We also have been working with the OPTN and the community at large exploring joint data collection efforts in partnership with our colleagues at CMS on the HRSA side to see how we get data to better understand the variation and really see how we can improve referral evaluation and wait list processes to get us closer to equity in each of those areas. So that gives you a quick orientation to the action plan itself. I think as Jean mentioned it is a living action plan as we have more strategies here from you all we may be adding to it. There's obviously a series of activities that have to go along with advancing each strategy and making progress on the goals and aims ultimately.

We look forward to continuous dialogue with you all on each of these areas and soon kind of giving you a heads-up we'll turn it over to you to give us feedback but before we do that, because this work has been under way for a period of time, we should highlight some recent accomplishments. Glad to see Jean back on and let's just to our next slide. All right. I guess maybe we should go in time sequence. So I'll start at the bottom of the slide and talk about back in March of 2023 HRSA launched the OPTN modernization effort, really our effort to respond to the significant feedback we got from the community around opportunities to do things differently and really support system performance and equity and so on HRSA's side we wanted to make sure given the complexity of the system and all of the people in it are we bringing the right expertise, do we have a system that is developing organ allocation policy and overseeing compliance with that that is really reflective of the community that we're serving.

Really independent using the best practices governance and has the best expertise necessary in all the critical functions from operations to technology to data analytics et cetera. So, all those parts together really what we laid out in March talk about our efforts to improve some of the core functionality and operations to support the OPTN in their essential role of organ allocation policy and ensuring compliance with policy and supporting the improvement and operations of the organ transplant system. Jean.

>> Thank you. Can you hear me?

>> Yep. You were coming through just fine.

>> You heard me just fine?

Okay. I just wanted to -- I was getting note that people were having difficulty hearing. I wanted to make sure.

[Audio is echoing]

Oops. All right. We had in December of 2020, I think everyone knows that we released the regulation that really looks at the conditions for coverage for organ procurement organization. And within that regulation it did have how we use data to determine certification of organ procurement organizations moving forward. On April 28th of '23 we released -- we reinforced that strategy and released very important data on public performance. We are now planning to again release data in 2024.

This will be a very important year I think that everyone will realize and we continue to work with that data and we look forward to releasing that and I know that many on this call look forward to seeing that.

>> Great. And then in September of 2023 we had the passage of the securing the U.S. OPTN act and that act really supports our efforts around modernization for OPTN modernization. It really expanded our authority to use a variety of award mechanisms to get in the best support to support the OPTN. It removes preparations cap to make sure we're resourced appropriately to make sure we have the right support for

the system moving forward and make sure that we can get the best-in-class experts to help us through all the complex roles and responsibilities and functions that the OPTN serves on behalf of the entire organ procurement and transplantation system. Very excited that law was passed and, you know, before I turn it over to Jean to end with the January, I will say I know that folks are eagerly awaiting the release of some of our next set of work based upon the listening and engagement we have done with the community and so look forward to sharing that information with the community very soon and shortly.

>> Great. I would really like to call your attention to a memo that was sent out on January 18th of 2024 just about a couple weeks ago. We released a memo clarifying the definition of donor and organ procurement organization, conditions for coverage. This addresses the use of islet cell research that are included, it's a memo that many may be familiar with but we can drop that link as well into the chat. The cell transplantation act of 2004 amended the section of the public health services act to require that pancreatic procured vital organ reorganization and use for islet cell transplantation research shall be counted for purposes of certification or recertification. To avoid any potential confusion, we're clarifying that in the definition of donor the reference to pancreatic research specifically refers to research for islet cell transplantation and that is consistent with the statutory requirement. So very important clarification there.

And I think the whole point of us going through these accomplishments is to say that work continues to occur as we continue to refine these goals and strategies and your input today will help us as we move to the next level. Thank you. Next slide.

>> All right. I think that brings us into our listening mode to kind of hear from you all. So, as we have gone through, we're excited about the work done to get us up to this place to have an action plan, to be able to present this to the community at large and start to get some of your feedback on the strategies and activities that could support some of the areas that you think are priority areas amongst the ones we have laid out. We will now transition over to Ashley to help us get through -- I see in the Q&A chat some feedback and comments and so look forward to receiving those and I think Ashley if you'll tee us up with the questions, we put out to the community to focus our discussion, that would be great.

>> Sure. Will do. Good afternoon, everyone. Happy to kind of drive us through the Q&A. I do want to say thank you in advance to some of you who submitted some of your responses beforehand. If you don't get an opportunity to submit today, maybe you need more time to think about it, we have an OTAG e-mail box on the screen. So, you're more than welcome to submit your comments after today. And we will still review them and as always it helps us to make informed decisions. Just to jump into the questions that we pose today, so we have two questions that were a part of your registration. The first is so the national goals presented to you today of course are not, they are not an exhaustive list of all of CMS and HRSA's work but it is in fact -- they are in fact the immediate priorities that OTAG has identified to address some of the system challenges. So, from your perspective do you think those national goals identified today do they address transplantation system challenges accurately and if not, are there any gaps in the goals proposed? So that's question one. And so, I'll read question two but feel free to drop in your questions for question one. So, the second question of course we always appreciate that there are different perspectives depending on where you are and where you serve in the system and thinking about the goals and the aims presented today, what types of activities would you consider as the highest priority to help us achieve the goals that we presented today? So, we'll pause for a second and take a look at the Q&A.

>> While people are putting in their responses, I see a couple questions that have come through about who sits on the OTAG, the individuals. We won't give out the individual names there, I will say that from CMS we have representatives from our clinical standards group, our quality measurement, and innovations group, our -- I call it our quality improvement group. And as well as our survey and operations group, our state operations group and our quality, safety, and oversight group. I've almost named every group in CCSQ as well as our Center for Medicare. We have our payment policy group. And in our Medicaid, we have a group from our Center for Medicaid Services. Suma, do you want to say who sits on the group?

>> And it's a short list on the HRSA side. All our programs are concentrated within the Health systems Bureau and the Division of Transplantation. At any given point you have a large showing of RT members focused and engaged on this effort. I will say Jean as you mentioned we have colleagues -- we have engaged colleagues from NIH, CDC, and colleagues from the VA to join.

So, we're really taking not only a department-wide consideration but even more broadly as appropriate so we can get all of the important kind of federal partners together. So, in the chat if you felt like we have missed an important federal partner, you can share that with us, and we'll be happy to reach out and consider on that part.

And then I see a similar thread, Jean, around patient representation or other -- you know, how can someone be a part of the OTAG. I think as Jean highlighted the focus is it's a federal working group. But through venues like this and other venues that we have for your engagement, that's really how we can ensure we're getting all of the diversity of perspectives from the organ transplant community engaged.

Right. So, this is the federal working group working together to ensure we have alignment and coordination on policy making, data, all of these efforts that we have laid out here. And all of that also goes through the regular processes that we have for all of our regulations, all of our policies, et cetera. I think those are really the opportunity in addition to providing feedback and engagement on the OTAG activities directly in venues like this and other ones that we will have. Spoiler alert. We will have a session at the CMS Quality Conference on OTAG and invite people to join us there.

But also, through all the channels that we regularly solicit public comment, feedback on our activities.

>> I thought of one other partner that's not a part of HHS but that we have reached out to and that's the Veterans Administration and so we hope to continue to work with them as well. I see in the chat it says sharing for your consideration that we should look at leveraging United States core data set or USCDs and I think that's extremely important source of data and really as we move forward with all of that that working with? is important. Thank you for putting that into the Q&A.

>> Yeah. Absolutely agree on that point. I think, you know, as Jean and I both mentioned, around the data harmonization and standardization and making sure we have the right data in the least burdensome way and high-quality data to really fuel the improvement and decision-making in the system leveraging technology and standards is essential to that.

So, thank you for that comment.

>> I'm looking through the questions. Ashley, do you see other things that we should be pointing out here?

I see one regarding donation rate lagging behind transplantation so even with the reduction in waste --

[Indiscernible/Audio Issue]

Cannot meet the need of the actual effort to improve donation for --

[Indiscernible/ audio issue]

Can that be added as a goal.

Thank you for that and we will look at that -- this has come up during our discussions for sure and as we begin to look to specificity of how we achieve these goals, we appreciate that comment. And I will also say that our efforts are not the only efforts under way. There are other efforts that we are connected to that will improve this whole donation --

[Indiscernible/audio issue]

>> Also, just another comment here, I'm scrolling through, there is a -- in the Q&A box from the American Society of Nephrology, University of Pennsylvania, just stating the appreciation for the efforts to establish criteria for standardization and transparency for pre-transplant and referral and just wondering if CMS and HRSA are considering a complimentary mechanism to incentivize standardization for screening.

>> Good suggestion. Go ahead Jean.

[No audio]

>> Jean, we're losing your audio.

[Audio going in and out]

>> Jean, what was the last thing? Sorry. We lost your audio on that.

[Audio echoing]

>> I think we lost you completely, Jean.

>> Okay. Let's see. Ashley, what other questions are you seeing that we should tackle? I see a thread around the importance of thinking about pediatric populations and I think as you may be aware, there is on the OPTN side a focus on pediatric populations in the development of organ allocation policy and the various metrics and the like and so that will continue.

Obviously a very important population. I'm sure that similar efforts obviously across CMS and the development of any policies there and as we develop some of this work, really, I think that's why we feel it's so important to benefit from the diversity of perspectives from the community in the feedback.

So, we want to make sure as we put out these potential policy changes, add new data collections, incentives, different models that we do have a key consideration, especially from an equity perspective across all of our subpopulations. Definitely very important consideration and invite full engagement from those very focused on the pediatric community to engage with us.

>> Thank you, Suma. Just a comment here. Thank you for this comment that you are glad to see the use of deceased donor organs as a goal as our organ rates have sky rocketed. The fact that we did not use over 8,500 kidneys last year that were donated and recovered is disappointing and so I applaud the strategies included around removing barriers and identifying performance measures and incentives accordingly. So

just wanted to say that. There's also some kudos here, OPTN modernization efforts, congrats to the HRSA team on that which has been incredibly valuable and important and of course, I know Suma mentioned this before, but just to reiterate that there is more to come. I believe there's questions here about the timeline and next steps on OPTN structural reform. Be on the lookout. More to come from the HRSA team on that. And we thank you for your comment.

>> Ashley, I see a number of comments related to COPs and accountability and how we're holding facilities accountable, and I will say I think it is in the agenda that we are continually working on our regulations and particularly right now in the organ procurement organization space which I see a number of comments about that. And as those regulations come into play, particularly as we said from the 2020 regulation and others that we have, we do have a system of accountability. We do -- not only for organ procurement organizations but for transplant centers and other hospitals.

There's the donor hospital question as well which follows under our general conditions of participation. We have survey and oversight where we find deficiencies. We have the ability to ask for corrective action plans. And other enforcements that becomes available to us. The ultimate enforcement is Medicare and Medicaid payment which of course is valuable, but it is an action that can be taken.

>> Thanks, Jean. I see a question. Go ahead.

>> No. Go ahead. You saw one that we should answer?

>> Yeah. I saw another one for us to tackle. It's for the both of us. A question about how we're working together on the pre-wait listing data effort to ensure this data is used for quality improvement to really help us understand and support access and equity. And so -- I think it's a really great question because it gets to the overarching intent and kind of premise around OTAG. We have different authorities and different levers that we have but taken together the complimentary accountabilities, regulations, authorities that we have, the different stakeholders really work together seamlessly to improve the system and so let's use that example as kind of pre-wait listing data.

Honestly thinking about that, something that we have heard from the community is that there are variability and disparities, but we don't know the level of information or the variation across, right. So as with most things in quality improvement, health care, data is really important to that. And so, we identify a data gap that we wanted to fill and so that was based upon joint work between HRSA and CMS to really figure out how what are the data elements important and helpful in collaboration with the community. We're going to work it through kind of the OPTN process that helps us delineate what data we need to better understand and improve system performance. So that's really how we'll work together there.

Working through the OPTN and the data collection efforts there.

And then we have been working together I think -- once we have that data, you know, and we are sure that it is high quality data, people understand how to collect it, how to submit it, that we look at it and work with the community to make sense of it and look for opportunities to improve and what are some of the key insights, what are the bright spots, what are the opportunities for improvement.

Where do we need to dig deeper and how do we use our various authorities and venues to understand that data, where do we work with researchers and others to figure out how we really improve. I think it's fair to say often with data it's really important to collect it.

It's important to look at it, assess the opportunities for improvement and before you can assess opportunities, it's really to understand the data and that's often-best-done hand in hand with the community and then the best interventions or strategies for improvement often born from innovators in the community who have done really well. So I think if that gives you a sense of our trajectory is to work together to get the right data, support collection and then really think about how we support improved quality and how we use that if it's appropriate for improving the system or as kind of a benchmark that we then figure out how together between our authorities and levers in HRSA and CMS that we work to make sure that that data informs the system and supports system performance as we move forward. Hopefully that's helpful as an example and of how we're working together to advance our two aims of improving system performance and equity.

>> Absolutely. And I think as I was looking through and you were talking there are several questions about how we're going to measure something and so as you have ideas of measurement, we welcome those, and you can send those in. We are working on looking to see to make sure that we coordinate and align in that area, but we also welcome ideas.

There's also quite a bit about supporting caregivers and the support system that are available to those who are living donors and those that are recipients of organs as well. So, as we noted, that is a very important part of the action plan, and we appreciate you highlighting that, and we will continue to look at how we might support families in this effort.

And a question on how families might be engaged since they're not federal partners and so we plan to have more activities such as this and we particularly want to make sure that we are hearing those voices. So, if some group or people that you think need to be invited to that, make sure we are made aware of that, and we will continue to hold these kinds of listening sessions.

>> While you're bringing up the next question, I'll add to one I saw around payment models and innovation and how that intersects with the work you're doing on the OPTN modernization side. Just to give more color there, you know, we talked about working together, CMS and HRSA on kind of federal policy making, regulations, even though our work with the OPTN and there are efforts to really like we put, like we highlighted, look at different payment models, innovation models. Often those to support some of that you want to make sure you have the right data, make sure you're looking at the incentives or barriers produced by policy or models. We're really taking a wholistic look across what are the incentives and barriers that exist in the system today, what is the data we have, what's the data we're missing and if we really want to work towards increasing organ procurement, donation, procurement, and transplantation what are the levers that HRSA and CMS have and how are those strengthened by us working together. For example, if we want to have some models, those models are best informed and evaluated by data we don't have today and where do we collect that data to support those efforts. There are efforts already, there's appreciation in the community for the increasing rate of organ non-utilization and efforts taken up by the community to really think about across all the parts of the organ transplant system where are the places that we can increase efficiency. That's an area that the OPTN is working, and they have a task force to tackle that issue now and having listened to some of their discussions and deliberations they're looking at all parts and identifying where there may be barriers and those are opportunities we must look at as well to how do we support that. Right. And to really understand what the barriers are and how do we work to support some of the incentives to get to our aim of better performance and better equity.

>> Thanks, Suma. I know we're getting to time, but I see guidance to the organ procurement regulation. With that I will say that we are as noted we are preparing a proposed rule, and we want to put that out which will provide more information and also provide the opportunity for comment. So please continue to look for that as we will be proposing the next steps of implementation. Thank you.

>> Great. Thanks for that reminder of the time. As you all continue to enter your thoughts, questions, feedback, I see some people pointing us to good models to consider. Welcome that as well. Please add into the chat pod. I will just remind us as Jean said, this is the first and not the last. We have a commitment to an ongoing dialogue with all of you on the efforts of the OTAG, a commitment to keep you updated on our actions and progress that we're making towards our goals and so clearly the next opportunity is at the April CMS quality conference to engage in person around that. But also, as you see on the slide, please feel free to send feedback to OTAG@CMS.HHS.gov. We have that venue for receiving feedback and questions, comments, the like on our work together in the organ transplant and affinity group.

We so appreciate your time and attention today. If you had a colleague who you think this session will be of interest and they missed it, please share it with them. That mailbox is a continued open place for us to receive that feedback and we look forward to future sessions that we can continue to get this kind of feedback from you all and our moving forward on to the aims and goals that we have laid out as well as the activities.

So, thank you for your time and Ashley, I'll let you have the last word or Jean if there's anything else we should remind folks of.

>> No. I think you summed it up.

The Q&A section is rich with information, and we'll keep that transcript I assure you and we'll be reading through that, and you gave us plenty to discuss in our OTAG meeting.

Ashley.

>> Thank you, Jean thanks to, you Suma for driving this session today. Thank you everyone for joining. As mentioned, we will post the recording for today and the transcript on the national stakeholder call page. It does take a couple days just to have everything compliant, but we expect to have this posted for you early next week. So, we thank you for your time today. And we look forward to engaging with you all soon. Have a great day.