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Office of eHealth Innovation

Meeting Name: Consent Management Working Group**Call In:**

Zoom Link: <https://us02web.zoom.us/j/84144212711>

(Panelists, please use your individual links sent to your email)

Meeting Materials:

- [Washington SUD Consent Script](#)
- DRAFT SHIE Consent Wireframes
- [Consent Workgroup Recording](#)

Meeting Date: 10/18/24**Meeting Time:** 10:00-11:00am

Agenda Topic	Time
Welcoming Remarks & Introductions Cory Hussain Attendees: Allie McGee, Stephanie Pugliese, Bianca Melancon, Lyn Snow, Dalia Ritvo, Jane Wilson, Justin Man, Mary Beth Haugen, Matt Arment, Codie Leighton, Tracy McDonald, Roberta Lopez, Karen Haneke, Melissa Gillespie, Amin Kamranfar, Kathryn Lofy, Alexis Harper, Cory Hussain	2-3 mins
Updates: Consent for SHIE (Workgroup members, please see your emails for draft wireframes) Cory Hussain Allie McGee: All right, I'll hand it over to Cory. Cory, if you want to give that quick update about what we're doing with the Colorado Social Health Information Exchange (CoSHIE), then we can jump into the main agenda. Cory Hussain: So, as far as our consent process is concerned, we've been looking at the three layers of data exchange: social health, health information, and behavioral health. We decided that the initial use case will focus primarily on social health, specifically housing and the involvement of Homeless Management Information System (HMIS). We wanted to simplify the process for now because one of the challenges we're seeing is pushback on how we'll collect, store, and manage consents. Some organizations, like HMIS, also want their own organizational consent, and we don't want to override that. Kathryn suggested we start with just social health information, as it's the easiest to consent to. We'll need to consult legal counsel to determine if verbal consent will work for this, especially for case coordinators. So, we've decided to narrow the scope to	5 mins



social health information for the first use case.

The idea is that once people are comfortable with exchanging social health information, understand it, and see the system's value, we can then consider expanding it to other referrals, such as health-associated referrals like DMEs or behavioral health referrals for substance use. But starting with those areas right now would be complicated, so we've excluded health information and behavioral health information from this phase of the consent process.

For now, we're focusing on social health needs like food insecurity, housing, and transportation. Even within that, we'll likely begin with housing. There was also feedback, particularly from Federally Qualified Health Centers (FQHCs), about collecting sensitive social health information, such as domestic violence. But we're not addressing those areas—we won't be exchanging information related to domestic abuse or highly vulnerable populations at this point. That's where we've landed for now.

Allie McGee: To set the stage; this is the perspective of a care coordinator using our portal for someone whose consent has expired.

When you go through the portal, you can see that the "share social health information" button isn't selected. You can also see that all their consents have expired. If the coordinator checks the box, the person can consent to share their information. We're still working to determine if verbal confirmation can legally serve as consent, but we're in the process of clarifying that.

Once the consent is updated, the coordinator can go ahead and proceed. Our idea is that if someone changes their consent later, like unchecking the box, they'd see which organizations currently have access to their information and be able to deselect specific ones.

This is a rough draft, and it is very much a work in progress. It's not final and subject to change, but we wanted to quickly share this with you to show where we're at in the process.

Review of Washington State's Example Script

Cory Hussain:

Yeah, and then the other question is about the signature requirement. We need to have a legal way to include it if it's necessary. For our first use cases, which we're thinking of starting with FQHCs and the care coordinators there, how do we incorporate the signature portion if it's required?

This will serve as more of a template. There are organizations that still want their own consent processes as part of their workflow. We're not going to replace that, and we're not going to force them to say this covers everything. We can have both processes moving forward.

Organizations can still store their own consent on their own servers or systems, and they can use this for other healthcare or community-based organizations receiving referrals. Those organizations will be able to see, "Oh, this patient has consented to

5 mins



social health information exchange,” and then provide services without needing another consent.

For example, community-based organizations like Meals on Wheels or Project Angel Heart can function using that consent. We’ve narrowed the scope to focus on social health information exchange only, not on health information like diabetes, hypertension, or behavioral health.

Now we need to consider how to roll this out when it goes live and how to get everyone on board. One of the key things we’re hearing from care coordinators is that they need support or a script to explain this to patients. Allie found a provider script from the Washington State Healthcare Authority, which is more nuanced because it involves substance use disorder (SUD) information. It’s more detailed, as it deals with SUD specifically, but we’re thinking of using their framework—not the content—to create our own script for our state. This would be part of the consent toolkit.

We’re thinking of keeping this short, so it’s not pages and pages of information because that’s going to be difficult for people to go through. Maybe a one-pager or a double-sided one-pager at most—so, a maximum of two pages.

Cory Hussain:

Another thing we’re hearing is the need for the script to explain what happens if the patient doesn’t consent. We need to make it clear that this doesn’t mean their social health information won’t be shared at all. I would still have to make a referral, but the process could take longer. For instance, I might need to call the organization directly or fax them the details, and that could delay things.

Instead of instantly sharing the information with multiple organizations, I may have to reach out to three or four individually to find the right fit for their needs. So, without consent, the process becomes more manual and time-consuming.

Discussion: Feedback on Training Script

Allie McGee:

Like Cory was saying, one of the things I’d like you all to think about—and that I started thinking about yesterday—is what if there’s someone who is mistrustful of their care coordinator or the healthcare system in general? How would you, I guess, not necessarily calm them down, but how would you create an environment where they feel comfortable enough to even have this conversation?

For example, I might not be a fan of having a brand-new doctor if I’ve had the same one for five years. How might you make me feel more comfortable talking about this private information and agreeing to consent?

Melissa, I’m going to pick on you for a second because I’ve heard you have experience working with patients. Have you ever had to help someone who was more mistrustful of the system and get them to participate?

Melissa Gillespie:

So my experience was when I worked at a case management agency. Most of it

40 mins



involved getting people to sign releases of information related to working with providers or the agency I was part of. In those cases, it was pretty much necessary for them to consent in order to receive services or for case managers to coordinate everything.

I didn't personally encounter many situations where people were particularly mistrustful, but I know those situations do happen. There were definitely cases where people were more concerned or wanted to be very intentional about how their information was shared. In those situations, we would explain that we were asking for them to share their information so we could support them in coordinating services.

Most people were willing to sign once they understood the purpose. Sorry if that's not super helpful for that specific challenge, but that was my experience.

Cory Hussain:

So, Melissa, having been on the front lines, we're going to put you on the spot here. The first thing is, there's very little time they have with patients. We want to make sure this process is really concise, right? The second thing is the consent form wireframe we showed. We want to make it as easy and simple as possible, right? Verbal consent is something we're considering, especially since a lot of care coordination happens over the phone.

Melissa Gillespie:

From my experience as a care coordinator—before I moved more behind the scenes—I was often going into people's homes to do assessments. We were usually signing papers in person, and I could explain what each document meant right there.

But during the pandemic, case management shifted to more phone and video calls. So, we relied more on verbal consent, or the case managers would explain the need for signatures and send the forms afterward. That presented a challenge, as getting people to sign after the fact wasn't always straightforward. Depending on the case manager, they may not have had a system where the individual could see the documents directly during a virtual meeting.

I'm not sure if that might be a scenario that could come up related to consent and care coordination, especially if it's virtual. It's something to keep in mind—if verbal consent isn't sufficient and you actually need a signature, it could become a challenge.

Cory Hussain:

Mary Beth, you had a comment?

Mary Beth Haugen:

We do a lot of education for front-end staff, like patient registration teams at hospitals or clinics. We have a course called *Gathering Information from the Unwilling*. Allie or Cory, if you'd like to review the course and see if there's anything helpful, I'm happy to give you access.

Cory Hussain:

That would be great. We've also developed a script for asking about race and ethnicity, and it's similar to what we're discussing here. It includes responses for when a patient asks, "Why are you asking me this information?"



Mary Beth Haugen:

I'm happy to share that, and if there's anything in it we can use, we can integrate it into this process.

Cory Hussain:

I really appreciate that Melissa is bringing up the use case scenarios—whether in front of the patient or away from the client, whether it's over the phone or video. We also need to recognize that people with health-related social needs often have limited access to technology. Kathy, this might resonate with you—many of them use their phones as their primary device, like a computer.

So, maybe we could have an option to send a Short Message Service (SMS) with a link if a signature is needed. It could pull up a simple form where they see the health information and have the ability to sign and upload it right from their phone. That would really make the care coordinators' work a lot easier, especially if they're not physically with the patient or client. A mobile device workflow would be really useful.

Allie McGee:

I keep thinking about the verbal consent or verbal confirmation piece, because I can't recall a situation where I've had to just verbally consent to sharing something. I'm not sure if that's even legal, especially since we're not dealing with health or medical-related data right now. So, I'm wondering about that... Go ahead, Melissa.

Melissa Gillespie:

I can't really speak to its legal aspects. I know verbal consent was allowed during the pandemic, likely due to the unique circumstances and the fact that in-person interactions weren't possible. So, it was more of an exception for that time.

I believe the preference has always been to get an actual signature, and my understanding was that once things returned to normal, the plan was to move away from verbal consent. But I'm not sure if that's changed since then. So, I don't know how helpful that is.

Allie McGee:

So, it sounds like it may have been a temporary measure.

Melissa Gillespie:

Yeah, that's what it seemed like to me.

Cory Hussain:

And I'm not sure that will hold now, right, Melissa? Since the pandemic is over, legal might come back and say we need to return to traditional consent practices. Karen might already know the answer to that.

Karen Haneke:

Once again, I'll caveat this by saying I'm not a lawyer either, but I wanted to add another nuance to this. If we're looking at a system like the Homeless Management Information System (HMIS), which we're planning to share data with, individuals are entered into the HMIS system by a client navigator who sits with them and gets written consent on a form.



Now, I know with CoSHIE, we don't want to require organizations to modify their forms. But I'm wondering—since they're already sitting with the person and obtaining a signature—could that signature also authorize them to sign on behalf of the individual while they're in that session? I'm not sure, but it's something to consider.

Cory Hussain:

No, because technically, they're not a proxy, right? Legally, a proxy is someone designated to sign on behalf of an individual who can't sign for themselves. There's usually a document stating that the person is disabled or unable to communicate, and a healthcare proxy is appointed.

A care coordinator isn't considered a healthcare proxy, so it would still require the provider's signature. However, if we can get HMIS on board—since they already handle their own organizational consent—they could potentially do both their consent and the CoSHIE consent at the same time.

Karen Haneke:

Right.

Cory Hussain:

So, they could simply say, "Hey, while you're doing your own consent, go ahead and have the patient sign this one as well."

Allie McGee:

Right. I actually want to pass my turn to Codie Layton—I saw his hand raised for a while.

Codie Layton:

Thanks so much. This kind of ties into Karen's point. My question is, if a care coordinator is sitting next to the person and collecting consent, could they be considered a witness, like in a court scenario? For example, if there's a dispute down the line and someone says, "I never consented," could the person who collected the verbal consent be called in as a witness during a legal dispute? I'm getting into some tricky legal territory here, but it's something to think about, especially when considering verbal consent from a legal standpoint. It could definitely work if we put the right pieces in place.

Allie McGee:

That's a great point, and now I'm wondering if we'd need some kind of additional safeguard. This could get messy quickly.

Codie Layton:

Yeah, I agree, it could work, but in my experience working with legal teams, there are usually two types of consent: one where you agree to terms and policies by checking a box, which acts as an electronic signature, and the other where you sign a document, like with DocuSign.

Allie McGee:

So, it sounds like we'd need to add another layer of consent for care coordinators, especially if they're getting verbal consent. But I want to pass this to Jane since she has



her hand up.

Jane Wilson:

Thank you. I might be introducing a bit of a wrinkle here. Cory mentioned that a decision was made to go with the less complicated piece first, which makes sense. The question now is, what kind of consent, or what form of consent, do we need to collect social health information? I understand that part.

But I want to point out that somewhere in this plan for the Colorado Social Health Information Exchange (CoSHIE), we're planning to combine social health information with payer information—specifically whether the person is enrolled in Medicaid or not. Once we couple social information with the fact that the individual is a client of Health Care Policy and Financing (HCPF), we'll likely need to be looking for Health Insurance Portability and Accountability Act (HIPAA) consent. At that point, we're dealing with protected health information (PHI), and I just wanted to add that consideration.

Cory Hussain:

I think verbal consent is a landmine. Even at our facility, if we saw a verbal consent, we'd ask, "Who gave the verbal consent? Who were the witnesses that recorded it?" We need something from the patient, and it becomes a trust issue. Melissa, did you have something to add?

Melissa Gillespie:

Yes, I definitely agree with that, Cory. I think we're better off if we can get an actual signature. I just wanted to add another layer from my experience. I worked with individuals with intellectual and developmental disabilities, and there are additional considerations around guardianship that we need to be aware of. Some individuals are their own guardians but may be unwilling to sign or may not fully understand the situation. Others may have guardianship issues that haven't been fully figured out yet, or they might have difficulty signing due to physical limitations. In some of these cases, verbal consent might be provided instead of a handwritten signature or mark to indicate the individual's consent. We've done things like this before, but it's something to keep in mind, especially around accessibility for individuals with developmental disabilities. It's a challenge, and we need to be aware of that.

Cory Hussain:

I'll pass it over to Karen, but just to note, we do this now. For any medical procedure, we need patient consent, and it has to be signed. If the patient can't sign, we usually document the guardian's name and relationship, or if the patient is a minor, which we haven't even discussed yet—because children will also be referred in this process. We need a signed consent, and if the patient doesn't have the ability to sign, like if they don't have arms, for example, we need to explore alternative methods. The justification for why verbal consent was necessary must also be included, along with who obtained it, when it was obtained, and the reason it was used. Karen?

Karen Haneke:

Yes, I think we all agree that we don't need to go back to using a lot of paper consent forms. What we might want to do is take this back to our technical team for some brainstorming. Maybe the care coordinator could click a button to create an account for the user, where the user could immediately go through multi-factor authentication and give their consent. If we could do that seamlessly, I think electronic consents would



work well.

Codie Layton:

I love that idea, Karen. Do you think the person would have access to something like a portal? For example, would a text message be sent to their phone for multi-factor authentication, and then they'd enter it into the portal? What's your best idea for how that might work?

Karen Haneke:

Codie, I think it would be something like that, but I'd prefer to have our team explore it further. Most people have a cell phone, so ideally, there would be a ping sent to their phone. We haven't talked about doing this for individual users yet, but it's something we might need to reconsider as we work through the consent process.

Kathy Lofy:

That is on the roadmap. The first step is for the CoSHIE system to be able to ingest a consent message in the event that we're integrated with another data system. The second step is to generate a link to a consent form that someone can fill out, so that data can be transmitted, or we can integrate with the backend of that tool and bring the data into CoSHIE.

The third step is considering whether a care coordinator could consent a patient through the portal or if an individual could log into the portal themselves to change their consent whenever they want. So, there are three stages of work that we'll be progressing through, and the link to the form is one of them.

Cory Hussain:

I think the ability to sign the form is going to be important right from the start. So, there are two things that need to be addressed. First, we need to enable the ability to sign the form, which we'll have to work through from a technical standpoint, both at the care coordinator level and at the client level if they want to sign it.

Second, if someone isn't able to sign the form—because that's a real scenario—we'll need a process for that. Some people do have accessibility issues. As Melissa explained earlier, we already have processes in place for situations like this. If a patient can't sign, we record the reason, and either a proxy—like a caregiver, next of kin, or someone with legal authority—signs on their behalf, or verbal consent is obtained when the patient is physically unable to sign, such as in cases where they can't move their arms or have a developmental disability.

Allie McGee:

Actually, on that note, I saw an interesting point from Justin in the chat. I'm not sure if this is feasible, but he mentioned that while there would be technical costs, there are ways to record verbal consent using audio fingerprinting that holds up in court. It would be straightforward to add a recording button to allow for verbal consent, but it might not be a comfortable user experience for the person. So, that's something to keep in mind.

Roberta also mentioned that if consent is required, we'd want auditing capabilities to confirm later that it was indeed the client or guardian who consented and signed. This could involve multi-factor identification and other methods that are compliant with the Americans with Disabilities Act (ADA). So, we need to think about accessibility as we



move forward.

Cory Hussain:

At Denver Health, about 3% to 4% of consents are actually signed by guardians or verbal consent is obtained because the patient isn't able to sign.

Allie McGee:

Okay. So, like when you go to a doctor's office and sign the privacy policy or whatever it is, there's that extra line for a witness or a guardian. I always thought that was for minors, like when I was 12, my mom had to sign it for me. But once I'm an adult, is that line for a caretaker or someone who would sign if I were really sick? Is that what it's for?

Cory Hussain:

Yes. When it says "guardian" or "caretaker," sometimes it will say "guardian/caretaker." For medical procedures, because they're considered high risk, a witness is required.

Allie McGee:

And we wouldn't be doing anything like that with CoSHIE, especially not if we're just dealing with referrals.

Cory Hussain:

No, but I would recommend that if a care coordinator knows the guardian is signing, they document the guardian's name or initials and the date, so there's a record. Legal will likely ask, "Who witnessed this?" and it's good to have that information available.

Codie Layton:

Witnesses can get complicated, though. They might move away, pass away, or simply not want to participate. A lot of things could happen.

Cory Hussain:

True, but it's still better than having no witness at all. We face the same issue—our witnesses, like a nurse, might leave. But at least there's a record in the system showing that someone witnessed it at that time, and you can make an argument for that if needed.

Justin Man:

Hey folks. I can't remember who mentioned letting the technical teams take a stab at this, but I agree—this is a technically solvable problem. While the person who said this is a bit of a landmine isn't wrong, that's mostly true from a discussion standpoint.

This is absolutely a solvable technical issue. So, if you're interested in having options to choose from, just set your tech teams on it. I can already think of three or four ways to handle this from a technical perspective.

Cory Hussain:

Yeah, but we also want to make sure legal is okay with those options.

Justin Man:

There will definitely be legal challenges, and legal will likely choose the option they're most comfortable with. But to save everyone time and headache, set the tech teams on it. They'll come back with options. Lots of people have done things like this before—I've



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worked on similar projects myself.

I'd be happy to go away and come back with some options for voice signatures, including guardian consent, witness processes, and the user experience.

Cory Hussain:

Justin, it works really well in many industries, but in healthcare, people are often set in their ways.

Justin Man:

I totally hear you on that. But it's a lot easier to have a productive discussion when you have concrete options in front of you. Once you have those options, you can ask, "What's technically possible, and what's wrong with it?" Then we can work on solving those problems. Does that make sense? I feel like we're having this conversation without concrete anchors, and those could really help move things forward quickly.

I know there are great technical people at the Office of eHealth Innovation (OeHI), Health Care Policy and Financing (HCPF), and the Behavioral Health Administration (BHA) who can help with this. Many of us have dealt with similar challenges before.

Cory Hussain:

We have a timeline—February 2025 is when we need to have something ready. What would you suggest, because we can't have this open-ended forever? We need options for testing.

Justin Man:

If you really wanted, I could spin up a prototype for you in a week. If you just need options to discuss, that can happen quickly. If you're looking for a final solution, that'll take a little longer, but definitely not until February.

That said, I don't want to overpromise on behalf of OeHI or commit to their timeline.

Cory Hussain:

No, because the reason is we want to get this process in front of a clinic that does a lot of referrals. We've been talking about Stride as a (FQHC) that handles many referrals. One of the things we've noticed is that when we develop something and take it out into the community, it either falls apart or works beautifully. We won't know how this process plays out until we put it in front of the people on the ground.

That's why I'm glad we're having this discussion, reducing the scope, and talking about the verbal consent process for people who can't provide consent, as well as the in-person consent process. In conjunction with that, I'd like to form a smaller working group to develop some language based on what Washington has done, as well as other resources, to create an explanation of what CoSHIE is.

As Melissa and Marybeth mentioned, if a patient asks, "Why are you asking for this information?" or says, "I don't trust you with this information," how should we respond? These are the types of scenarios we need to consider. I think we need to reach out to case coordinators in institutions right now to find out what clients are saying when they're doing referrals to community-based organizations for provisional services. For example, when a coordinator says, "I'm going to fax this information to X, Y, and Z,"



what language are they using that creates buy-in with clients?

It would be useful to collect feedback on the pushback they're receiving and how they're addressing it. We could gather insights from case coordinators and case managers across different institutions and then perform thematic analysis on the responses to identify effective approaches. This process will help us develop the script rather than trying to create it from scratch. Does that approach make sense?

Allie McGee:

Yeah, I see what you're saying. By pulling from what's already working, we're not reinventing the wheel. The care coordinators already know how to communicate with patients, so it makes sense to adjust what's already being used.

Cory Hussain:

Exactly. Now, we need to create a process for reaching out to case coordinators and organizing these focus groups. Do we send out invitations and hold Zoom calls with 15 or 20 people to discuss this? I've done this for other studies, and you can even use tools like ChatGPT to help with thematic analysis—it can literally analyze the responses for you.

Allie McGee:

Lyn, go ahead—I saw you had your hand raised.

Lyn Snow:

I was wondering if anyone is working with patient navigators who are trained through PCN at Anschutz. They deal a lot with social determinants of health in their work and have likely done extensive work in this area. Is anyone familiar with the organization I'm talking about? I can make a connection. This is a specialty they've been working in for years, and I thought we could tap into their expertise and knowledge.

Allie McGee:

I think that it would be a good idea to connect with anyone we can. Actually, I wanted to ask Kathy—I saw a comment in the chat about the timeline for collecting information, particularly from case and care coordinators. I know we need a working product by February, and we've been in talks with All Health to see if they could be a use case for us to test this on.

I'm assuming we could also gather some care coordinator feedback from them, but my question for you, Kathy, is about the timeline. Do we need the feedback from care coordinators before testing with All Health, or could we consider gathering feedback as part of the testing phase with them?

Kathy Lofy:

I'm not sure if the question relates to how care coordinators communicate consent to patients or if it's about the overall timeline for testing.

Allie McGee:

Megan, I'm not sure if I can let you explain further, but do you mean specifically the information on how case coordinators are talking to patients about consent?

Megan (Guest):



Yes, that was about collecting information on how case coordinators are currently communicating about consent with their patients and when we'd want to gather that information.

Allie McGee:

Okay, so it sounds like if we use All Health as an example, we could ask them how they currently collect consent and how they talk to patients about it. Does that sound right?

Kathy Lofy:

Yes, I think the sooner we do that, the better.

Allie McGee:

Agreed, as soon as we can.

Cory Hussain:

You know how you did those listening sessions where you reached out to the community and people came to you? It might be helpful to reach out to some of the FQHCs, like Stride, Denver Health, or Intermountain, and ask if they could provide the names of Patient Care Navigators (PCNs) we could email. Then we could send a mass email and invite them to a listening session. We could ask them questions like, "How do you talk to patients about consenting to share their social health information?" and let the discussion flow from there.

What you'll see is that themes will emerge from how different people share their processes.

Allie McGee:

I wonder—Karen or maybe Stephanie mentioned before that some folks were interested in consent and listening sessions. I wonder if they'd be willing to attend an open forum or listening session. I'll take that back to Stephanie, and we can discuss it further.

It sounds like we have our next steps—getting in touch with care coordinators and addressing the legal aspects. Kathy, I know you don't have exact details, but we have a meeting with Colorado Access. How soon do you think we could move forward with testing this out if they agree to work with us?

Kathy Lofy:

It's all moving along, but a lot of the work would be on All Health's side if they agree to participate. They may need to adjust their system to capture consent electronically, and we don't know how they currently capture it. We'd need to develop a process, including a script, and provide training so they could pilot obtaining consent and transmitting that information to us. Ideally, we'd have materials ready before they start testing, and then they could give feedback throughout the process, such as what worked, what didn't, and what took too long.

We need a solid process to test.

Cory Hussain:

Are we also going to engage with the folks HMIS about their consent process?

Kathy Lofy:



We could ask. Right now, their data is being shared under organizational consent, but I think they're refining their process to ensure individuals know their data is being shared with CoSHIE. We'd need to discuss how they capture consent in their system.

Cory Hussain:

And mapping it to the CoSHIE consent, basically?

Kathy Lofy:

Yes. If they're capturing it in some way, we could map it to our consent. They might have a field that indicates a release of information has been signed based on what the data folks have told us.

Cory Hussain:

Okay. So they wouldn't need to follow the full process—they could do a pass-through from their own organizational consent to the CoSHIE consent, essentially.

Kathy Lofy:

What do you mean by that?

Cory Hussain:

So, they collect their own organizational consent using their own form, right? That consent is retained with them, but they're not going to upload that directly to CoSHIE, correct?

Kathy Lofy:

They told us they have one field where each patient consents to a release of information. Karen, you might know more, but I believe they're tweaking their script to include that the information will also be released to CoSHIE. Then they'll pass on a variable indicating whether a release of information has been signed. If it hasn't, the data won't be sent to us.

Cory Hussain:

Karen, you were going to add something?

Karen Haneke:

Yes, it's in line with what Kathy is saying. In this case, we're relying on organizational consent that's obtained in person. For context, HMIS already shares information with a number of organizations, and they have a form for that. They also refer individuals to a website listing all the organizations they share data with, and CoSHIE will be added to that list.

We could ask them to be a partner, but we don't want to complicate the process we've already established. We need to think carefully about how we engage them here.

Cory Hussain:

Right, but how do those organizations currently know that consent has been collected?

Karen Haneke:

As Kathy mentioned, there's a field within the HMIS system that indicates consent has been obtained. We've also discussed the revocation process, because individuals can revoke consent. In that case, HMIS sends us regular data feeds, and if someone



revokes consent, their data will no longer be included in those feeds. Their information won't be in our system if they revoke consent at the HMIS or Continuum of Care (COC) level.

Cory Hussain:

One of the things we talked about yesterday is how consents are currently obtained—patients provide consent at the level of the organization where they're receiving services. The organization then sends the data to the Health Information Exchange (HIE) or, in this case, CoSHIE, but they retain the consent at their own organization for sending the data. Is that correct?

Karen Haneke:

Yes, the COCs retain their own consent. Kathy can provide more details on the fields, but there are one or maybe a few fields that indicate consent has been obtained, and that's how it's captured digitally.

Cory Hussain:

Correct. What we're trying to avoid is requiring patients to re-consent every time they visit a new organization. That would defeat the purpose of having a universal consent process, right?

Karen Haneke:

Part of the challenge right now, Cory, is that we're still early in the process, so we're dealing with these one-off scenarios. We're trying to envision a consent process that will eventually be larger and give individuals more control. But currently, the amount of information in the CoSHIE system is limited, and you're right—it's mostly handled at the point of care. This is an incremental first step as we work toward a future where there's more data in CoSHIE, allowing for more individual outreach and control.

Cory Hussain:

Exactly. The goal is to have a universal consent that allows multiple entities to share data without requiring patients to re-consent at each organization, again and again.

In the meantime, as part of phase one, we can use the consent template we've already created. Organizations can continue to collect their own organizational consent and retain it, but if they want to use our template with the scripting and fields we've developed, that would be an option. It's not mandatory—it's just a suggestion.

Karen Haneke:

That's true for now, but eventually, there will be situations where we'll need individual consent, especially when we start sharing behavioral health or health information. At that point, we'll need to roll this out more systematically.

Conclusions and Next Steps

2-3 mins

Cory Hussain:

Right, because I don't think anyone is currently collecting that type of consent other than through the Health Information Exchange, which already has a process in place.



So, as this is my last meeting with everyone, I want to take a moment to express my appreciation. This has been a great group to work with. Moving forward, we have two key tasks: first, figuring out the verbal consent process, including what fields are needed and the technical aspects of that.

Second, we need to bring care coordinators together in an open forum or focus group to gather their feedback on the language they use. Mary Beth has also been great about providing training materials for handling difficult conversations, which can serve as a primer for developing the script—what to say and how to respond to patient concerns.

This toolkit is not mandatory, but I can tell you that many organizations will find it incredibly valuable. When we developed a similar script with input from patients, we asked them what challenges they faced when asked about race, ethnicity, and language and what triggered them. Listening to their feedback helped us develop a script that addressed those barriers and concerns. I believe we can use the same approach with our case managers, care coordinators, and patient care navigators to develop this.

So, I'll leave it to Allie to set up that focus group and send out invites.

Allie McGee:

Yes, leave it all to me. We'll get it done.

Cory Hussain:

So, that's the technical development of how to capture verbal consent. I believe Justin mentioned a few ways we could approach it.

Allie McGee:

Yes, I think Justin sent me a message with some additional ideas on how we could do that. But before we wrap up, I just want to say a huge thank you to you, Cory, for leading this work group. You've done an amazing job, and we've made so much progress, much faster than we would have without your help. We really appreciate everything you've done, and we hope you stay in touch.

Everyone, thank you so much for joining. And just a quick note—starting next month, we'll begin having conversations about House Bill 2417 and the consent repository. So, please keep that on your radar.

Other than that, thank you all so much, and we'll get back to the drawing board with this. Have a great Friday, everyone!

<u>Follow Up:</u>	<u>Complete By:</u>	<u>Responsible:</u>
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