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Meeting Name: Consent Management Workgroup

Call In: Zoom Link: <https://us02web.zoom.us/j/84144212711>
(Panelists, please use your individual links sent to your email)

Meeting Materials:

- [House Bill 24-1217 Sharing of Patient Data](#)

Meeting Date: 12/20/24**Meeting Time:** 10:00am-11:00am

Agenda Topic	Time
Welcoming Remarks & Introductions Allie McGee and Tiffany Sailer Attendees: Allie McGee, Tiffany Sailer, Stephanie Pugliese, Bianca Melancon, Erin Crites, Truman Esmond, Janel Wilson, Megan Cliff, Tracy McDonald, Karen Haneke, Lyn Snow	5-7 mins
Overview of House Bill Allie McGee and Tiffany Sailer Allie McGee: So for today, I wanted to tell you guys if you have not already heard about a recent bill that OeHI was graciously written into earlier this year, and that's House Bill 24-1217. It's the Sharing of Patient Data Bill. So a little bit about that bill, there are two parts to the bill. One part is for BHA, and one part is for OeHI. BHA's role is that they are to create a friends and family consent form. For OeHI, we are to conduct a feasibility study to see what it would look like to create a digital repository for the State of Colorado. All of this work that we're going to do to create this study is going to be culminated into a report that we plan on submitting to the Joint Technology Committee, the Senate and House Health and Human Services Committee, and will be posted as well to our public website. I want to reiterate that we're not creating a solution. We are basically having the opportunity to have the state to be interested in our work. They saw what we've been doing for the last couple of years and thought 'okay, you guys seem like the experts we're interested in building up something in Colorado. What should we do? You guys have been working on this for a while. We want your feedback and your input.' So I want everyone to keep that in mind when we're talking about this. It is not final. It is not said and done. We are trying to make sure that the State keeps Colorado in mind when	15 mins



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they're working on this and that's where we get to come in, have say and give recommendations.

So for this particular bill. The biggest objective is obviously to empower individuals, because that's what we all work for when it comes to consent. The way I see consent is, I'm allowing you to share my information, and I just want to make sure that it's protected, and that I have the right to revoke that sharing when I want to. The second piece that I'm very, very hopeful for is that this is going to help enhance data exchange across the state. So part of the ask in the bill is that we want something that providers, state agencies, community organizations, and all different types of organizations across Colorado can use to store any consent forms that they come up with, or that we recommend that they use in this repository. I think of it almost as those grain silos that you see on the Interstate. That's what I would like it to be for Colorado. I would like it to be something that people can use and feel comfortable, and knowing that their consent is stored there, and that they can easily say 'Hey, you know I've signed this paper once and now WIC or SNAP can connect with CoSHIE and be able to see that I've recently signed up for these benefits'. Now we see that Allie's got food and now we can worry less about her following our prescription regimen or worry less that she's starving at home. I definitely encourage you guys to think about how this could enhance State exchange across the State.

Another point is that it's meant to also enhance care, coordination. So a huge sponsor of this bill was actually representative and advocate for those with disabilities and those who experience serious mental illnesses. So what we're wanting to do is make it easier for not just those individuals, but all individuals, to have care coordinated more seamlessly for them not having to constantly repeat their story.

The final big piece of this that I know is important to everyone in this group is if we're going to give recommendations to build something like this? How can we make sure that it is safe? The biggest thing I've heard over the last couple of months is 'How are you guys protecting our data?', 'How are you going to keep anything that you build safe?'. That's where we get to come in and learn how can we do that. What are the best recommendations for protecting something that we keep in a very large repository?

Lastly, the biggest key considerations for this bill is we want to explore what it looks like to address consent in an emergency. When we say emergency, think about how, if you've ever been to the emergency room. It's a very stressful, intense situation. You are going to a strange doctor, you can't get a hold of your current doctor. How can the person who's seeing you in the emergency room know who can be contacted and what role does that play in the outcome of a patient's care.

And then, lastly, making sure that whatever the State decides to build, whatever they go with complies with current federal regulations, and that's involving HIPAA or 3CFR. Part 2. Any privacy laws, any current laws that we need to make sure we keep in mind. We want to make sure that when we're building out these recommendations, those are at the forefront.



So I'll take just a minute for you guys to digest that and ask any questions or give your feedback.

Erin Crites:

At the point also of global crisis team intervention or EMS intervention, What that might look like for our folks who are in a behavioral health crisis, not necessarily a medical crisis or in a medical crisis and ending up in the emergency department.

Allie McGee:

That's actually a really good question. So the way that I interpreted this was, it is having to do with a behavioral health crisis because the Behavioral Health Administration so written into this bill, so I intend to work very closely with them.

Jane Wilson:

Will the repository also hold medical records data?

Allie McGee:

The way I understood it, it would be holding consents, but I can see it going in the direction of how it can facilitate better data exchange. And I think we want to explore that more deeply once we do start this research because I don't think it will be very helpful to sort consents. But if it's supposed to be helpful for moving, or at least like making it easier for people to coordinate care and making it easier for people to coordinate data, it should at least be able to support the facilitation of data exchange.

Stephanie Pugliese:

I don't think that we want to store medical records in this. I feel like that's a whole nother security risk. But yeah, we would want to lean more on the EHRs, HIEs and other infrastructure.

Tiffany Sailer:

So one thing I just wanted to mention is, you know, when you look at these national frameworks, such as TEFCA and E-health exchange and carry quality, a lot of us take the approach that patients are opted in by default to those exchanges. Here at Denver Health, we add that consent in our consent to treat form. So if a patient shows up for any sort of medical or behavioral health need, they sign that consent to treat form, basically stating that they're agreeing that their information will be on this framework and network, and we'll be able to be queried under the rules of that framework. So we have, like an opt out approach. I guess patients are opted in by default and opted out if they choose to be. So. That's one thing that I think we definitely need to let the State know from a healthcare organization perspective is that a lot of this is already happening, at least between organizations that we're already having this consent on file and already opting people into this information exchange. I'm guessing that when they're thinking of this they're thinking more of like the HIE than one of these frameworks.

Allie McGee:

I want to delve a little bit deeper into our research as we currently have a lot of different



EHRs in Colorado. And obviously we have the HIE. So we want to understand how this can work with those to help improve processes that are already there.

Justin Man:

I'm really excited about the scope of this consent repository. I'm curious how that will interact with identity like, how do we match the consent for Justin, man with the consent? For with the record for Justin M. The second tier of that is, what are the obligations for someone like the BHA to implement which master patient index to make sure that we are compliant with the consent and what are the integrations and requirements for opting into this central consent system.

Allie McGee:

That's something that I want to keep in mind, too. I'm writing down all of these questions to ask these things. I guess that is also another meeting I want to have with BHA. How are they going to identify each person because I know that they're working on their own form too.

Roberta Lopez:

Consents typically are specific to a particular provider for a particular set of data. I'm not sure how useful that would be to have a consent, for, let's say, an assisted living center that's providing medical care in a database for then, emergency medical care. There would be a disconnect there, and that patient would likely have to sign another consent when they're at the hospital. Has there been consideration about how that's going to work?

Allie McGee:

This meeting right now is really just to give you guys like the high level, here's what we're getting ready to do. Your question actually is going to be a consideration. So when we start working with this research firm, those are the kinds of questions that I want, because in my head, and I'm not an expert by any means, but in my head, if I'm a patient facility, it'd be nice to know that I already have a data exchange agreement.

Workgroup's Role and Input Session

Tiffany Sailler and Allie McGee

Allie McGee:

We are an extremely unique state. Colorado has a lot of different challenges and a lot of things that make us very uniquely positioned. I don't know all of those different challenges, but this workgroup has a lot of different expertise and perspectives. So what I want to move forward thinking about is, how do we ensure that whatever recommendations we give, we keep in mind Colorado. We have things that make it harder or easier to work here. So I want to keep that in mind when we're thinking about what are the opportunities that this repository can create.

And then, next, the biggest thing for me in this repository is to make sure that everybody can use it. We do have a lot of diverse populations here, especially folks

20 mins



who deal with disabilities. My goal is always something that can be beneficial for everyone in Colorado. Again, I don't represent every single type of person in Colorado, and that's where I'm hoping that the workgroup can fill in. Who else might we need to include, to make sure that we are giving broad recommendations that include as many folks as possible. Is there anything that we're missing? Are there any groups that you feel might need to be added into this?

Another big thing for this group is providing insight. In my opinion, you guys are kind of like, you're sort of like my superheroes. You guys are like, in my opinion, experts in what you do. So I rely heavily on that perspective that you bring, and I want the research firm that we work with to rely heavily on you guys as well. Part of what we're going to do is have an ongoing report document every month that research firm is going to tackle a different subject. And every month I want the work group to give them feedback, and don't take it easy on them, either, like actually say 'hey? Did you think about this?', 'Did you think about that?', 'You're not considering this perspective.' This is not just an OeHI project.

Does anybody else have any opportunities that you think this could really help with, or any maybe challenges we haven't thought of yet in this meeting?

Erin Crites:

[recommended involving some justice involved organizations for clients receiving care in a custodial setting]

Lyn Snow:

[recommended provider input such as more direct care providers- behavioral health, doctors, etc.]

Allie McGee:

How would this affect more rural organizations? Because I know not. Everybody is like a big Denver health or university health. So this would look different for them. And I want to keep that in mind, too.

Does anybody have any recommendations for how this could be a helpful opportunity for solving a problem or making jobs easier? Like, if you guys did want to see a repository. How would you think it might benefit Colorado, and how it might benefit maybe even your jobs?

Tiffany Sailer:

This type of consent, like there are some nuances when it comes to behavioral health. I think the jail point was really good, but just basic consent to be able to find data for a patient that shows up at another site, especially in the case of an emergency. We don't really run into problems like 'Oh, well, we can't pull this data, because we don't have consent from the patient' because, again, that's not really how consent works. So I think that that's the struggle that I'm personally having with coming up with like 'Hey, this is gonna help something' because this doesn't seem to be really a big problem for us (Denver Health).



Allie McGee:

That's a fair response. Could it help in any way facilitate any data exchange? Because I see this as a lot of different organizations in Colorado are very siloed. Is it possible to talk with those different organizations and see if something like this might be beneficial for them. It might not just be something for patients to take advantage of. It could just be something that individuals could take advantage of. Maybe it makes it easier for different State agencies to share information between each other if they have something standard to copy. But again, that's on us to decide that we've been given a pretty broad scope with this, too. So I think we could give in those recommendations.

Here's something else you guys maybe think about if you're wanting us to pursue this, because currently, here's how things are set up in Colorado, we do, or we don't necessarily think this might be helpful, and if we want it to be more helpful, maybe you should have it lean more towards this, so it is valuable to to know like, Hey, it's not necessarily a problem. But if you want to help, maybe think of it like this. So that's a good opportunity.

Tiffany Sailer:

I think your example for, like State agency to State agency would be a good one, because they're not getting any sort of consent when the patient enrolls, you know, in that effort, like array for an example. Do we have anybody from one of the RAEs?

Allie McGee:

I don't believe we do on this call.

Tiffany Sailer:

That's all right. When a patient is enrolled in Medicaid, they're assigned to a RAE, does that RAE get any sort of consent to share their data, say, HCPF, or with another organization? If they don't, and the RAEs have to go out and get that themselves, I could see how this would be beneficial for them.

Karen Haneke:

As we start to frame how digital consent could be used, there is that other legislature ask not of us to create that Friends and Family sharing, and I'm just wondering if that is also a piece in wanting to do this, or if they're entirely unrelated.

Allie McGee:

They are related from my understanding. The thought actually came up first for the BHA to make the Friends and Family Form, and then there started becoming conversations around where they would store that, because there's already lots of forms as it is, and that's how OeHI became involved. So there is a connection. I intend to bring their lead into some of these calls as well, because she's leading the charge on that particular form.

Timeline and Next Steps

Allie McGee and Tiffany Sailer

10 mins



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<p>Allie McGee: So I want to give you guys kind of a brief overview of what our next steps are right now we are looking at different firms to engage with for research. These are going to be the folks who put this report together. This will be who we want the work group to work with to give that feedback and let them get comments and recommendations. We plan on getting this started in January of 2025, and have them present to our work group in February. The first ask I have of them is to give us a scan of what other consent repository efforts have been engaged around the nation. I know we're not the first to try to do something like this. I wonder what other States have done around consent in general. So their task will be to look into that over the next couple of months and give us a presentation of what they find in February, and in that presentation they will be giving Colorado specific findings as well. Once that happens, I'm wanting this work group to give feedback on that presentation.</p>	
<p>Public Comment Tiffany Sailler and Allie McGee</p>	5 mins
<p>Conclusion Tiffany Sailer and Allie McGee</p>	2-3 mins

<p>Follow Up: Contact individuals and orgs who could provide insight to see if they are interested</p>	<p>Complete By: 12/30/24</p>	<p>Responsible: Bianca Melancon</p>
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