OeHI
Office of eHealth Innovation

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: N/A

Meeting Date: 3/21/25	**Meeting Time**: 10:00am-11:00am

Agenda Topic	**Time**
Welcoming Remarks & Introductions *Bianca Melancon*	5 mins
Introduction to Mission Analytics *Bianca Melancon* **Bianca Melancon:** Mission Analytics will be doing a high level focus on the states that we've chosen to research to help inform our research for the Consent Repository project. For those of you who were here a few months ago, whenever we found out that we'd be working on this project, we did a very brief introduction. So today, Mission Analytics will walk us through those states, the kind of questions we're wanting to ask those states. Following that, we would like feedback from you all on if there are any questions that we're missing. We'll also spend some time understanding any priorities or concerns that you want to ensure we focus on in this study. **Overview of Multi-State Review and Study Approach** *Ed Kako and Breck Frye (Mission Analytics)* **Breck Frye:** Thanks, Bianca. That's a helpful introduction to our team. So we are going to go over	15 mins

OeHI
Office of eHealth Innovation

the overview of our multi-state review and the approach that we're going to take to that. The State of Colorado has chosen some States to review and take a look at. So we want to share those with you all and give you a little bit of the why behind why those states are particularly selected. We'll talk a little bit about some of the general questions. We're going to talk about what from those different states we're looking for, and then we'd love to have the majority of the rest of the time devoted to you all, hearing your questions, your comments, your thoughts, your concerns. After the call, at some point in the next few days Bianca or Allie will be sharing a stakeholder survey with you as well, so that we can collect a little bit of additional information from you. So we're really looking forward to getting to know the team. You're going to see our faces at your work group meetings through the rest of this year. We're excited to be working with you, and we're looking forward to presenting the different things that we are working on in this consent repository research. I will hand it over to Ed to run through our deck. **Ed Kako:** Thank you, Breck. Our presentation today has a few goals with regard to the multi-state review that we want to review with you all. One is to identify similarities and differences between Colorado's past approaches and those of the states that OeHI has identified for additional research. The second is to identify best practices from those states that could apply to the project we're working on now, including strategies for securing buy-in from key stakeholders. The 3rd goal of the multi-state review is to identify lessons learned from the experiences of other states, including any pitfalls or challenges to avoid along the way to a consolidated consent repository. Our approach is to start by reviewing current Colorado options or those that have been considered in the past and systems that are currently operating in various parts of Colorado. We also plan to examine, as I've said, other States methodologies, their infrastructure and their regulatory frameworks. We'll review relevant documentation, like statutes and regulations and identify key informants in each of the states that OeHI has identified for analysis. OeHI has identified four different states. Those are Rhode Island, Connecticut,	

Michigan, and Alaska, and we'll talk a bit about why those states have been selected. So, why Rhode Island? Rhode Island is one of the few States with a centralized, patient, controlled health information exchange, with structured consent storage. It has transitioned from an opt-in system to an opt-out consent model, and that has increased provider participation in the HIE (health information exchange). Rhode Island also has a strong technical and legal framework for consent storage.

Why Connecticut? Connecticut has established legal mandates requiring all licensed providers to connect to the state's HIE, and that requirement has ensured wide adoption of the HIE. And has made it easier for providers to access patient consent information. Connecticut also has a strong governance policy related to consent, storage and revocation.

Why Michigan? Michigan has an advanced electronic consent management system or an ECMS for behavioral health in particular, that complies with 42 CFR part 2, along with a system for general health data sharing. The state's ECMS is a structured statewide consent repository that tracks, stores, and enforces consent choices. Michigan also has a strong technical architecture for retrieving stored consents across different kinds of providers.

Finally, why Alaska? Alaska has a state HIE with a structured consent management framework that allows patients to opt-out while still maintaining secure consent records. It is one of the few models in the country where consents are centrally stored and queried before providers access data. Alaska also has a strong governance model for tracking and updating consent choices and patient rights as well as data sharing regulations in remote and rural settings.

So next, we'd like to review with you all the questions that we plan to ask of these states, both in the document review process, and in the key informant interviews that we plan to conduct. Some examples (these are not exhaustive) of the questions we plan to ask in our analysis are, “What are your biggest challenges in implementing the consent model?” or “What were your biggest challenges?”. “How do you handle cases

where the consent preferences of patients conflict with legal requirements or raise challenges during emergencies?", "How does the system handle sensitive health information like in particular behavioral health data or genetic information?", And "What steps have you taken to make the consent process user friendly and accessible for patients with diverse needs and backgrounds?". Again, this is not an exhaustive list, but these are some of the core questions that we plan to address both in our document. Review our review of statutes, regulations, other documents, as well as in the protocol that we'll develop for interviewing key informants in those four states.	
Workgroup Feedback and Discussion ● Suggest additional questions to ask states ● Share concerns, or priorities you'd like considered *Ed Kako and Breck Frye (Mission Analytics) , Bianca Melancon* **Ed Kako:** So now we'd like to open it up to all of you to ask questions about the process, to recommend additional questions that we might want for our interviews with these four states. Or if you have questions about the States that we have identified. **Jane Wilson:** Would any of the four states that you were looking at have an established commercial HIE in their state or were they all states where there was an absence? **Ed Kako:** We don't know that yet, and that's one of the things that we'll be looking at when we compare the four states. **Jane Wilson:** When we get an answer to that, I'm thinking if they are like Colorado, where we do have an established commercial HIE, how would you get that buy-in you need from providers to say we want you to switch and drop being involved with this current HIE and switch to a state owned and managed HIE. Also, what about the expense for the state? Why are we wanting to switch it away from the commercial? Those are just some of my thoughts.	35 mins

OeHI
Office of eHealth Innovation

Ed Kako: Yeah, thank you. We'll make note of that and incorporate that into our analysis. **Justin Man:** Great to see this work happening. If it is helpful, the BHA recently did some related primary research around HIEs' interoperability. In particular, we spoke to Liv King over in Rhode Island about their central system. So if we can make our research available to you or contacts over those states, please feel free to reach out. Bianca has our contact information. I'm happy to set up some time to share what we already have learned. It wasn't directly related to consent, but we do have some some names and some findings that may help accelerate or add some other dimensions to your research. **Ed Kako:** Thanks, Justin. That's great to hear, and we would love to set up a time to chat with you all and and learn more about what you learned, and use the what you've done, rather than repeat anything that you've done. **Breck Frye:** Jane, I don't know if you saw in the chat that Evelyn from EMI did note that Michigan does operate in a state with other health information exchanges, so we will get some good information from them along those lines. Anyone else have comments or thoughts? I'm happy to pull back some different slides if it's helpful for you to have something to look at about a particular state, or some general questions that we're looking at. **Bianca Melancon:** While we give folks a little bit of time to think, Jane, I did have a question for you in response to your question. Did you have any ideas in mind about buy-in for Coloradans? Of course this is just a study, but were there things that you had in mind, or were you mostly just highlighting the fact that it would be a good idea for us to do research on that? **Jane Wilson:** Just asking us to take that into consideration. I think they said Alaska was one where they mandated that providers use the state HIE, so if we're going to make that argument, I think we kind of have to anticipate people saying "Why not contexture?"	

"What's wrong with it?" **Bianca Melancon:** Absolutely. That's a really good point. And as Ed said, we'll definitely make sure that that's a part of the conversation. **Cody Leighton:** To go at that point of how to get the buy in, it's like trying to sell. What is the value of consent? Why should somebody sign up for it? Once we kind of figure out what this value is, then you can figure out what the buy-in is. Hopefully, through research and these meetings, we can kind of figure out what value provided to the state would be, and then we can sell as the buy in to these companies. **Ed Kako:** Yeah, that's a really good point. Understanding the value that these other states have identified and how they have persuaded providers and users to adopt that particular model. There is a certainly a marketing component in all of this that we will pay attention to as we're talking to these states. **Bianca Melancon:** Just to open up the discussion again, our goal with this meeting today is that we really want to make sure that with this study, we're not missing anything. Of course with a study, there's a lot that we don't know right now, because we're doing a study. So, sometimes it's difficult to foresee challenges. With this group we have a lot of different expertise. And so we want to lean on you all to see if there are any concerns that you might have or anything that you feel like we're not accounting for in this process, based on the information that we've given you, any additional information that we need to collect anything like that. So any input on that would be really helpful. **Justin Man:** On the accessibility and user friendliness, I'm just curious if you're taking into consideration translation and localization, and how other states have gone about that because that can be a fairly gnarly technical challenge as well as cost and political consideration. **Ed Kako:** Yeah, that's a great point, Justin. Most of the states have lots of languages that they have to localize for, so we will add that to the list of questions that we pose.	

Codie Leighton:

Have you guys considered partner integrations for this consent repository like possibly partnering with, myColorado, for example, because they have a digital wallet. If you're able to create a partnership with them, essentially, you could store your consent within that wallet within that Colorado ID.

Bianca Melancon:

Yeah, that's a great point. So if you all are familiar with the CoSHIE, the Colorado Social Health Information Exchange, we are working with myColorado in that space. For the consent repository, I think long term that's definitely something that would be good to consider, since this is just a study, and we don't necessarily have funding beyond the study right now. That's something we're considering, so thank you for that comment. I totally agree that that would be a really good partnership, but luckily, we have developed somewhat of a partnership with them just with another consent project.

Any other ideas of partnerships or people that we should get involved in this work. We feel really good working with these four states, but if there are other organizations. Internally with the state or externally, I think that would also be helpful.

I see in the chat there is a question. “Just wondering what the scope of data is in the various states that folks are consenting to share. Does it include social determinants of health data in any or all of the states?”

Ed Kako:

Yeah, that's a really good question, John, and something that we've been talking about internally is how these systems would integrate in Colorado with the CoSHIE. And then by extension, what have other states done to connect or not connect their consent repository system to their SDOH systems if they have them.

Roberta Lopez:

I'd like to know in your list of questions, with regard to stakeholder sessions and the process for stakeholder engagement, who were the stakeholders in the various states? So not to answer that now, but that might be something that would be beneficial for Colorado to learn that.

Ed Kako:

Yeah, definitely, we'll be asking the key informants in particular who the stakeholders

were and looking at where available. Colorado is, in our experience, pretty unusual in how transparent it is about its stakeholder processes. Other states are not quite as transparent, so we anticipate having to kind of go through the key informants that we speak to to kind of get at the stakeholder process. **Allie McGee:** This is a question for the group. So one of the states we picked was Alaska, because, like Colorado, Alaska also has a lot of rural areas. And I was thinking, what are some things we should keep in mind for those areas that aren't as robust as Denver health, or the University of Colorado, where they don't have all of these same sort of funds and access to technology. What are some things we can ask like Alaska? **Justin Man:** With anything rural, I'm always curious about how other states have addressed digital connectivity issues in lower technology penetration areas, and what is the elegant fallback so that we aren't reliant on a purely digital consent model? **Ed Kako:** That's a really good point, Justin, and something that we are also thinking about in relation to another piece of this work which is looking at consent for vulnerable populations and in emergency situations. So if you have an emergency such as a wildfire which interrupts connectivity even in the metro area, what is, to use your phrase, the elegant fallback? **Allie McGee:** Along those lines, I think about general emergencies as well as mental health emergencies because that's a big part of some of the language in this bill, too. How can this help in those sorts of situations which are very different from what a broken leg in the emergency room might be. **Justin Man:** On that note, for both individuals experiencing homelessness as well as individuals experiencing severe mental health challenges, trust and stability are big things, and I don't know if other states have found an elegant solution to do that, but for individuals who don't have fixed addresses or don't necessarily have fixed access to a singular device, who might be using libraries for connectivity, and public or shared devices, how might we ensure that they have a usable, meaningful experience or an alternative	

pathway that might have a delegated case manager or family member who can help with those processes? **Bianca Melancon:** Yeah, thank you for that, Justin. I also see, Jane, that you have something else for us to consider. So Jane said that she'd like to understand if other states are collecting medical records, only health related social needs, payer records (health insurance). I think those are are great questions and things that we can make sure that we're asking about. Justin talking just made me think about our initial conversation, about this consent repository. In that meeting, the question was, is there anyone that we're not accounting for? Now that we're actually executing this study, I want to ensure that we are aligning with Governor Polis' mission of creating a 'Colorado for All'. Is there anyone or any population that we are not considering or have not alluded to a lot? **Breck Frye:** That just brought something to mind for me, based on other Colorado projects we've worked on. I know that you and Ali are working on connecting us with some rural contacts and rural organizations. We haven't discussed or considered our tribal organizations or tribal contacts, so that might be a population that we haven't fully included in our scope of thought. **Bianca Melancon:** Yeah, that's a really good thought. And off the top of my head I do have some tribal connections that I think would be useful for this. So yeah, thank you for that. **Jane Wilson:** I guess it goes without saying, but since we're talking about electronic consent and participation in electronic systems. Of course, there is a population in our state (hopefully always getting smaller) of people who don't have access to internet-based activity. So we might have an alternate plan for them. **John Green:** Yeah, this may have already been accounted for. kind of under the emergency room. Umbrella. But I'm thinking about the IDD (intellectually and developmentally disabled) population or anybody who's in a situation where they're not able to provide consent themselves. Maybe they have a caretaker, and just wondering if the consent models	

account for somebody else providing consent on behalf of the actual client or or patient?

Ed Kako:

Yeah, that's a great question, John, and something that we will definitely be looking at in our analysis is ‘what happens in those cases where, for whatever reason, the individual is not in a position to grant consent? What happens when someone else is in a position to do that? And what counts as someone who is legally in a position to grant consent on behalf of someone else?’

Allie McGee:

Actually, that has a lot to do with the backstory for this bill as well. I know, for Representative Amabile, she's most certainly coming from the point of a caretaker who has to potentially grant consent. Having been given permission to take care of someone else's affairs like that is a huge part of this bill. So I do want to make sure that we focus on that very deeply, because that's quite literally why we got here. I know that there is so much that goes into this with behavioral health. There's emergency situations where, even if someone has preemptively granted the consent, if in that situation they say “No, I don't want you to do this anymore.”, you have to abide by that too. So that is something very important to factor into this as well.

Oh, and I see that Evelyn said “What about reproductive health and gender affirming care?” And these are the sensitive data types, too. That is something to bring up.

Evelyn Gallego:

I'm in Maryland. So I think you all know Maryland has just passed a bill to block sharing of reproductive health data across borders for cross sharing. So I think also, as you think through of a consent repository, who has access to that outside of Colorado, and whether you have to determine that no one's going to access this type of sensitive data in particular, that it may have repercussions, because you have bordering states that have very restrictive reproductive health laws.

Allie McGee:

That's very true, and given the climate we're dealing with, I'd really like to try to focus on something that just works within the State of Colorado. I want to make sure that Coloradans know that they have protection, that they have control over their own data.

OeHI

Office of eHealth Innovation

I would not even want to approach sharing necessarily across the borders unless someone has explicitly given me permission to do that. I want to make sure the people in Colorado feel safe first in Colorado. But I do agree about that. That's a good point about reproductive health and gender from here, because I know that more rulings are coming out about hiding that sort of information, or just not being so willing to share it, so I want to most certainly keep that in mind. **Evelyn Gallego:** Yeah. And it's more around, as you mentioned, trust right? You want to be able to build trust across all populations. But I do agree with that incremental find. And as we go through and again, we can help inform. What are those priority, data, elements, or components that you want to protect and show that increment across the state before you go to other sensitive data? So is it just overall primary care, or moving on to a sensitive data type? But I agree, that's something that could be discussed after.	
Public Comment and Closing *Bianca Melancon and Allie McGee* No public comment. **Bianca Melancon:** As always, Allie and I are available to answer any questions that you all may have, or if anything pops up outside of the meeting. I also want to take some time to thank Mission Analytics for being here today. Also, EMI for being here today. And Ed, leading the conversation. This was really helpful. Thank you so much to the work group. You all are always so helpful, providing your expertise and sharing the input that you have. We will be reviewing everything that was discussed today. Allie and I meet with Mission Analytics weekly so we'll be talking about these things and giving updates along the way about the different states that we meet with. One other thing we want to note is that you will be receiving a survey. We would greatly appreciate it if you could fill that out. It's a stakeholder survey to gather information on your expectations for these work group meetings and your interest. We want to ensure	5 mins

OeHI
Office of eHealth Innovation

that everyone here is getting value out of these meetings. So thank you all in advance for filling that out. If you have any questions along the way, feel free to reach out to us.	

Follow Up: Bianca Melancon to follow up with Justin Man about HIE interoperability contacts and findings	**Complete By:** March 28, 2025	**Responsible:** Bianca Melancon