OeHI
Office of eHealth Innovation

Meeting Name: Consent Management Working Group
Attendees: Cory Hussain, Jackie Sievers, Stephanie Pugliese, Abigail Tucker,Tom Ventura, Jane Wilson, Erin Crites,Tracy McDonald, Karen Haneke, Mary Beth Haugen, Alexis Harper, Allie McGee
Meeting Materials: - Meeting Agenda

Meeting Date: 7/19/24	**Meeting Time**: 10:00-11:00 am

Agenda Topic	Time
Welcoming Remarks and Icebreaker **Cory Hussain**	2-3 mins
QHN: Community Resource Network Security and Data Sharing Scenarios **Jackie Sievers:** The Community Resource Network, or CRN, is our social determinants of health tool. It is both a closed-loop referral system and a case management system for organizations that need those functionalities. Today, I'll dive into some specific data sharing scenarios and who can see what within the platform. - Let's start with some definitions to help you understand the terms and acronyms I'll be using. 'Network partners' are organizations that have contracted with us and have at least one user in our CRN platform. These partners can receive and manage electronic referrals actively within the platform. We also have 'associate partners'—these are organizations that have agreed to accept referrals via email or fax from CRN but do not log in and interact within the system; it's a one-way referral pattern. - The 'client' refers to the person seeking services or the patient, and the 'user' is a platform user working for a network partner, typically navigators or case managers, though we don't restrict users to these roles. Now, I'll explain our model of consent and security. It's a layered process, which I'm sure, will not surprise you. We have contractual frameworks, ROI and consenting processes, security roles, and data content permissions. These are probably domains you have discussed in this group already, and we felt a multi-pronged approach was necessary. - CRN went live four years ago this month, in July 2020, and we had been working on this model since 2018. To give you some context, as the Health Information Exchange HIE, we already had a contractual framework for our HIE customers, which we replicated for CRN with some additions to include non-HIPAA covered entities. Our contractual framework binds all parties to HIPAA and other regulations, ensuring even our non-covered entities adhere to these protocols. - We have strict security measures to ensure people only see what they should. We've designated domains and user roles with permissions. Content permissions tag data so it is stored and viewed appropriately. One of the things we decided early on was to define our overall concepts and values to guide our	25 mins

conversations. As you know, there is no universal guidance in this space, so we needed clear principles.

- CRN is an opt-in platform. Clients must give permission to be part of CRN, have their information in it, and allow any data exchange about them. We wanted to be flexible and HIPAA compliant, ensuring all network partners and users understand their responsibilities. Contracted entities are responsible for the activities of their users within our platform, with many provisions in our policies to support this.
- It was crucial for us that clients have choice and control over who sees their information. We examined different models across Colorado and decided on a two-year consent expiration, aligned with Colorado's behavioral health consent guidelines. We formed a work group of lawyers from various domains, compliance officers, and stakeholders from medical, behavioral health, and social sectors. We only moved forward once this group reached consensus, which took considerable time.
- Now, let's look at who can be a network partner and the rules around domain access. CRN policies specify that covered entities providing healthcare or behavioral health services can participate, as well as organizations offering services to clients in need at no cost or reduced cost. This broad definition allows for diverse participants, such as a taxi company providing Medicaid rides, but excludes entities like insurance brokers, which would engage in direct marketing.
- Impermissible use of CRN includes data subject to VAWA or 42 CFR Part 2, and law enforcement activities unless related to care coordination. We have steering committees to vet requests from law enforcement entities, ensuring their participation aligns with care coordination. Every click within CRN is recorded, and we can audit by user or client. We send auditing reports to the primary contact of each contracted organization.
- Users must adhere to agreements upon login, attesting to appropriate use of CRN for care coordination. If misuse occurs, or if users are inactive for a period, we can deactivate their access. Our client consent and authorization process is informed, requiring training for network partners. Clients can choose from three consent options: limited sharing, network-wide sharing, or customized sharing. Consent is not required for service, ensuring clients can refuse data sharing while still receiving services.
- Network-wide consent allows any team member to access and share information, while team-based consent requires approval from existing team members. Client-based consent requires the client to approve each data sharing request via text or email. We support traditional paper consent and digital methods like text and email, though many partners have reverted to paper.
- I'll now demonstrate the CRN platform. Here, I'm logged in as 'Jackie Training,' a case manager for a community-based organization. I'll show how to find a person and gain consent within the system. Searching by last name and date of birth, I attest that I'm providing care coordination, which is audited. If the person is found, I can view their profile and see activity summaries, but without consent, much information is restricted.
- When I provide consent, the client's information is pulled in, and they can choose their sharing preferences. Options include network-wide, team-based, and client-based consent, with choices for text, email, or print confirmation. Once consent is given and the signed form uploaded, more information unlocks,

such as care team member additions and detailed timelines. ● In summary, we combined organizational contracts, user agreements, policies, technology features, client consent, and user permissions into our comprehensive layered approach. This framework supports secure, informed, and flexible data sharing within CRN.	
Discussion and Questions **Cory Hussain:** Could you go back to the consenting form and show the different options? Specifically, when you were doing a new consent, you had the full option and then below that, you could piecemeal it. Could you show that portion again? **Jackie Siever:** Sure. So, here's the consent form. You can see the options for full sharing, and below that, the team member approval option. This allows clients to specify that only team members can see their data. However, clients can't specify to share only social or only health data. The data shared is based on the domain of the users. **Cory Hussain:**So, clients have to get approval every time they want to access or need data shared? **Jackie Sievers:** Correct. The client can set it so that any time an agency wants to access their data, it needs to be approved by the client or a team member. This way, the client maintains control over their data sharing. **Jane Wilson:** Along the lines of Cory's question, when you ask a new patient if they would like to disclose their medical information, social information, or behavioral health information, is that all happening in a single document? **Jackie Sievers:** Yes. The consent process is designed to ask if the client wants to share information within CRN. We then explain what types of information might be included, such as medical, social, and behavioral health data. **Jane Wilson:** So, CRN is structured so that CRN decides what information can be shared based on the consent given. However, a network partner might only be enrolled in the physical health domain and not have access to social information? **Jackie Sievers:** Yes, social is the most basic domain. Organizations can then add health or behavioral health as needed based on their services. **Alexis Harper:** Does CRN have accessibility options for screen readers or if someone's first language is not English? **Jackie Sievers:** Yes, CRN includes an accessibility module. The consent forms can be converted to Spanish, and we are working on adding more languages. There is also an icon for accessibility options, including screen readers. **Jane Wilson:** So, screen readers and other assistive technologies work with the system?	20 mins

Jackie Sievers: Yes, they do.To summarize, the client can request to remove consent for an agency at any time, which affects all users at that agency. This happens in real-time, and all data sharing stops immediately. Additionally, no data is pulled from the HIE until consent is in place. This ensures that client data remains protected until the client agrees to share it.Overall, our consent model incorporates organizational contracts, user agreements, policies, technology features, and client consent. This layered approach ensures that data sharing is secure, informed, and flexible.

Cory Hussain: Thank you, Jackie.That was a great presentation. When we talk about CoSHIE, we want the domains to be consentable so people can consent separately for behavioral, social, and healthcare data. This level of information sharing at the agency level is crucial. Does anyone have questions about how QHN has implemented this with CRN?

Karen Haneke: Yes, I have two questions for you, Jackie. This is great, by the way. Thank you so much, it's very informative. You mentioned in the beginning that this is a HIPAA-compliant system. However, there are data sources in there, like free services that may not be HIPAA entities, for example, the taxi or ride services. I'm just curious, we can have folks sign HIPAA forms, but how does that work on the backend with that data sharing, knowing that service would not comply with HIPAA?

Jackie Sievers: We bind them to a BAA contractually.

Karen Haneke: Okay, and then you put specific HIPAA-related stipulations within that?

Jackie Sievers: Yes, exactly.

Karen Haneke: The other question is about the revocation of consent. If an individual wants to take away their consent, is there a portal or a way they can log in to do that in real-time, or do they need to be in person with their care coordinator?

Jackie Sievers: Currently, they have to do it through a user. It could be anyone on their care team. It doesn't necessarily have to be in person; it could be via email, a phone call, or an in-person conversation. It is on the roadmap to get a portal, it's just not there yet.

Karen Haneke: Thank you.

Cory Hussain: I see Abigail has a question, and then Janie.

Abigail Tucker: Thanks, Cory. Jackie, that made sense, especially with Karen's follow-up question around HIPAA compliance. I apologize if I missed this, but the 42 CFR compliance, how does that work, especially with the extra stipulations of that above and beyond HIPAA?

Jackie Sievers: We can't handle 42 CFR data with this consent model yet. So, when we work with an entity, like we have one network partner who does have a 42 CFR service, our agreement is that they won't enter any data subject to 42 CFR within CRN.

Abigail Tucker: Got it. The follow-up consideration I would offer is that if I think about most behavioral health organizations that are supplying both services, since most

electronic health records don't offer a way to bifurcate that data, it means many organizations might opt out because it would require manual and administrative effort to separate mental health data from substance use data. It's just something to consider. And I apologize, but I will have to step off early today. I'll be eager to review any notes or minutes and see if there's anything I can do to follow up. **Jackie Sievers:** Great, thank you. In general, CRN is not the clinical repository; the HIE is. I've experienced what you're describing with medical records. Our partner that handles 42 CFR data also gets an additional release on their side in addition to the CRN authorization to conduct referrals and care coordination activities. They don't bring any SUD information into the CRN platform, but they might still make referrals and such. **Cory Hussain:** Abigail, just to answer your question real quick, you could put in metadata associated with what information is coming in to mark that as SUD data with SMART and FHIR resources so that it's not transported into the HIE. **Alexis Harper:** Thank you. So, Erin and I have been working on a project to help with information exchange between jails. For the most part, it's security information, but there are health alerts. We found that descriptions in the health alerts sometimes have detailed information that would be helpful, but they are in free text fields. We can't exchange these because we don't know what kind of information might be included that could violate HIPAA or 42 CFR Part 2. How does CRN control the exchange of notes or other free text fields that might contain sensitive information? **Jackie Sievers:** In the health and behavioral health alerts, we're currently excluding the free text fields for that exact reason. It's challenging to know what might be included in those fields. We're exploring ways to handle this, but for now, the alerts we allow are very high-level, and we've identified specific fields to include. **Cory Hussain:**Yes, and I agree with that because one of the things we want to ensure is data standardization. We want to make sure an apple means an apple everywhere, and no one's calling it a peach somewhere else. It's crucial to avoid exchanging data that has no meaning or is ambiguous. Jane, I will pass it to you, and then I'd like to open this up to our individuals who were upgraded to our panelists for public comments. **Jane Wilson:** Thank you. I think I have a pretty quick question. Do you anticipate expanding to include payer or insurance information at any time? **Jackie Sievers:** Yes, we would love to. Currently, payer information is part of the demographics, but it's not auto-populated. Users would have to enter that information manually. We hope to enhance this feature in the future.	
Public Comment **Cory Hussain:** I'd like to open this up to our public comment section now. If anyone has any comments or would like to ask a question, please feel free. **Kelly McGann**:I always love seeing a CRN demo, and I should know this already, but I'm curious if you can expand on what information can be pulled over from the HIE.	5 mins

Jackie Sievers: Currently, we pull over some demographic information upon client creation, such as address, phone number, and basic info. Once consent is given, we pull over any SDOH assessments and ADTs. We do a look-back for assessments, but for ADTs, we start at the point of consent and move forward. We also have a health page and a behavioral health page, but the latter isn't populated yet. We wanted to start in a controlled way and then expand. **Kelly McGann:** Awesome, thank you for that. In Arizona with Community Cares, the duplication of data entry is a significant issue. Reducing this is critical for users. **Arthur Davidson:** Hi, great to see all my old friends and some new ones. Jackie, QHN has always been in the lead and done great stuff. Kudos to you.I want to get back to the question. Cory asked about SMART on FHIR. How is QHN looking at FHIR and its role in CRN development? **Jackie Sievers:** Nine Patch, our CRN vendor, is diving deep into FHIR. They're leading the effort to bring it into CRN. I can get a more detailed answer from them if needed. **Arthur Davidson:** I thought there was a desire to stratify the data more finely. You've done great stuff, but clients will likely ask for this at some point. How is the organization planning for this? Is this a three-to-five-year goal? **Jackie Sievers:** Yes, absolutely. Particularly for Nine Patch and CRN, we are looking at a three-year timeline. The team is already working on Consent 2.0, aiming to achieve more detailed data stratification in multiple phases. **Arthur Davidson:** Great, thank you. **Cory Hussain:** I don't see any other questions. Jackie, thank you so much for presenting CRN and the conduit QHN has developed. This is great work. We are learning from our network partners and the state of Colorado. This is an amazing system. We envision a social health information exchange working with granular data, collecting health-related social needs data, and codifying it into Z codes or LOIN codes for interoperability.	
Conclusions and Next Steps **Cory Hussain & Allie McGee** **Allie McGee:** Thank you so much, Cory. I'm surprised we're a little bit early today. Usually, we're right on time with this call. Jackie, thank you so much for coming. This was phenomenal and very timely, considering what we've been discussing earlier this week. Seeing how someone else has been handling consent and thinking through some of the challenges we've been facing is incredibly helpful. Thank you, everyone, for attending. I do want to mention that we have some exciting developments coming down the pipeline in the next few months, so please stay tuned for that. Other than that, I don't have anything else to add. Cory, do you have any final words? **Cory Hussain:** No, I just want to say to everyone, keep on gardening and watering your	2-3 mins

plants. It's going to be hot. Thank you all for coming. This has been great. This is a really wonderful group of people, with a lot of talent from many different places. It’s amazing to see. Thank you so much. **Jackie Sievers:** And thank you for having us. It's been a pleasure to present to such an engaged and knowledgeable group. **Erin Crites:** Bye everyone. Have a great weekend. Thanks again. **Cory Hussain:** Take care, everyone. Have a wonderful day.	