

## **Health Information Technology Oversight Council (HITOC) Strategic Plan Update Consumer Listening Session:**

### **Anonymized Comments**

Tuesday, March 10th, 2020; Portland, Oregon and via phone/webinar  
1:00pm – 4:00pm

This transcript has been anonymized for comments by all non-Oregon Health Authority (OHA) participants.

Responses from OHA Office of Health Information Technology (OHIT) Staff Susan Otter, Director of Health IT, OHA (SO) and Karen Hale, Oregon Provider Directory Program Manager, OHIT (KH) are identified.

HITOC members in attendance/participating: Bill Bard and Amy Fellows

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### Agenda

- Welcome and introductions
- Overview of the Strategic Plan
- Your experience, thoughts for the future and input
- How to stay involved

*See meeting materials posted on the HITOC website ([https://www.oregon.gov/oha/HPA/OHIT-HITOC/SP%202021%20Meeting%20Documents/Consumer\\_LS\\_Slides.pdf](https://www.oregon.gov/oha/HPA/OHIT-HITOC/SP%202021%20Meeting%20Documents/Consumer_LS_Slides.pdf)) for presentation slides.*

Participant: While going through this process, I just read that the feds have approved a bill as of Monday, where patients will be able to see patient records on cell phones. How's that going to reflect with this work you're doing?

Susan Otter (SO): Thank you for that question – yes, that's right. There are new federal rules that require software companies to make data downloadable into an app of patients' choice. The idea is that right now, patients can log into portals from specific providers, but patients may want all records in one place like a health record bank or app that helps with a disease or condition. HITOC will look at the implications of rolling out those rules, studying what the timeline is for those rules to be implemented, when do the systems have to be able to handle the new expectations, what are the concerns that providers, consumers, or patients have about this new world. The rules aren't in the slide deck, but we'd love to hear from you on that today. It's extremely relevant to HITOC's work in the next five years.

Participant: What are the app companies doing with the data would be the question I have. Are they going to sell it?

SO: That's the big question that was raised when these rules were put into draft. When you download an app onto your mobile phone, you agree to the terms of that company and they may include terms where they can sell or share your data and you, as the patient/consumer, may or may not read all the terms and conditions. We haven't gotten a look to see if they have addressed that in a meaningful way in the rules. We want to hear from folks in Oregon.

Participant: I met some people from startups where people would retain their data and choose how to share it and then they would get paid for it. There is something called "Patient Story" for example. How does blockchain fit into this?

SO: There are a lot of changes, technology is constantly evolving. Does that help with your questions?

Participant: You said WA and OR? Are you following what Reliance is doing, when they're in other states as well besides WA and OR?

SO: We are following along with what Reliance is doing. Is there a particular part you were wondering about regarding EDie?

Participant: Reliance is in Arizona, as well as Nevada along with Northern California. will you be following the same concepts?

SO: What we're hearing from providers is that patients have data in other states, (if they move to another state or come from other states, and particularly those on the border, are getting care in other states), even if they are Oregon residents. So, the federal rules around sharing health information under HIPAA apply nationally. We don't have any Oregon specific rules that would be different from federal rules. In terms of being able to share under HIPAA, that's why EDie can share between WA and OR because we're sharing with providers, payers, CCOs and health plans and emergency departments that are treating or paying for that patient's care. It's all managed under HIPAA. It's the same with Reliance, having a footprint or coordinating with anyone in Arizona, Northern California, and Nevada. I'm not sure if I'm answering your question but I think cross-state sharing is important and is necessary and helpful, and there are provisions in HIPAA that make sure that only providers or health plans that are treating or paying for that patient have access to their data.

Participant: EDie is in Oregon and part of Washington?

SO: EDie is the Emergency Department information exchange. The company that developed EDie is in many other states; they have some footprint in Northern California, Idaho, they're in Alaska and several other states as their business is growing.

### Goal 1

Participant: It's not my personal experience, but I'm on a lot of committees. Something people forget is the behavioral health part of the care team in jails. A lot of people end up in jails. You guys don't talk about that, I hope it becomes part of the conversation. As far as I know, in Multnomah county, I don't know how it is now, but they can't afford EDie or Epic. I'm worried because I've seen people from hospitals taken to jail. I'm always worried the jail won't know about the medications, things like that, so making sure that information is shared all the way around.

Participant: I think the Youth Authority is on OCHIN Epic, the Juvenile Justice is on EDie, Multnomah county is on EDie. I hope the Oregon Health Authority brings that to the care team because of people cycling in and out of jails.

Karen Hale (KH): Make sure we include the jails, that's a good one.

Participant: One ongoing issue with the hospital is the issue of medication reconciliation. Are you familiar with that issue?

SO: I am somewhat familiar, do you want to talk about your experience?

Participant: It's confusing as a patient. For example, going into hospital, explaining my medications, because they don't have the right list or its outdated. Even if I try and update it something seems to go wrong and when they discharge, it's not correct. And because of having old medications and dosages on the printout, with no indication of what's old and what's current, it looks like someone is supposed to take 3 doses. So, there's too much, or too little, or you might be allergic now. So, the discharge summary printout is incorrect, it could cause life or death, it doesn't update. I really wish they would fix it. It needs attention. Another thing, making psychotherapy notes available to anybody on the team. Some people, like counselors who prepare notes, who may not prepare them consistently so some might have no information, some might have too much. I think there needs to be a standard, and some protection on that, especially for the release of information. I thought there was supposed to be some protection for that, but it doesn't sound like the system is protecting that. For example, survivors of domestic violence and sharing that info to broadly, mean it could get into the wrong hands which can cause life or death safety issues for people. I hope there's some consideration around that. Some hospitals enable breaking the glass when an extra layer of security is needed. There will be a digital trail in the access logs.

SO: Thank you.

Participant: This came up two years ago, especially with the health notes, how long do you have that going on for? Is it viewable by everybody, I'm worried about how people see us? An example for me, when I was seen at a behavioral health center the first time, my doctor actually lied about my behavior. My family saw that, and my partner saw that. Usually, doctors don't lie but that doctor lied and now it's in the record forever and I have no control over that.

Participant: I hear that a lot. There's no way for patients to contest things, or get things omitted. For example, my daughter was misdiagnosed at age five and correctly diagnosed at 10 – do I want her to be diagnosis with Oppositional Defiant disorder for the rest of her life? No. But that's still on a lot of records. That got sent to DDS as she got approved for services, this whole bundle of labels meant she was autistic because the U.S. is 20 years behind understanding girls. They misdiagnosed her, I don't want her viewed through an ODD lens for the rest of her life, she's a black child, it could be dangerous as well.

Participant: If doctors were consistent with the diagnosis, they make it a different diagnosis at every ED we go to. And that's not your fault, but it's on the record.

Participant: She got diagnosed at age five for throwing a stethoscope. Because we were talking about her ODD and the PCP wanted us to get more support and there was a parenting group across town, so that's why she gave a label to get us more support, even though it wasn't really accurate. I just don't believe in the label at all.

Participant: People want to choose their labels. Can people say this is the label I choose to work with or have on my record? Some folks want that.

Participant: Opportunity to annotate the record if you find an error. First of all, the person needs the right to access and review, and if they find something is inconsistent, they should be able to enter an annotation. That feature should be built into the systems created so the consumer perspective shows. Maybe the consumer wants to enter a document that counters what was said or done or shows the

error. At least you can annotate if you can't change the original but can show what should be allowed to be included in the record.

KH: What does sharing of information across the care team looking like for you? Have you had experience with information being shared and how well that actually goes? If you are a patient being referred to a specialist or maybe the referral is between behavioral health and physical health. Have you had experience with how well that information is shared?

Participant: I still have to do ROIs for my information.

Participant: I had a pleasant surprise. I had a worker's comp issue, had me outside of network, if the situation continues, going to get an MRI back with my network. Provider was trying to find MRI results in whatever system; they couldn't find the old results, but she dug deeper, and they ended up finding them, so it was like, good! Somehow, things talked to each other in the way we wanted them to. So that's a positive story without giving any specifics. Ultimately, MRIs outside of their system made its way into the system upon my request.

Participant: I'm in a place where I've been paying for my daughter's private insurance. She's been approved for OHP and the same insurance will be the CCO she's assigned to. She has a lot of medical trauma and getting her to a doctor is really hard, but the person who does her meds is a developmental pediatric specialist and that's the only provider she's seen for the last two years. I now have to figure out how to get my daughter into a PCP, to refer her to the doctor she is already seeing, who is doing her medication management and get a new prior authorization. Do they really want to pay for her to go to a PCP, to refer her to the doctor she is already seeing? I'm going to call the insurance and see if we can find a way to work around that since they already have prior authorization. I worked on the PCPCH project; I see the importance of having a PCP but having a child who is really difficult to get anywhere is a barrier. I don't care if she has a PCP as long as we can keep seeing the developmental pediatrician. I continue to pay \$300 a month for her private insurance until I can figure how to get her into a PCP, so she has no gaps in meds. It's a headache and expensive.

KH: And it's a lot of coordinating for you.

Participant: Yes, a lot of coordinating,

Participant: I just want to encourage OpenNotes again. It would solve a lot of problems. At [behavioral health organization], we built in enough electric places to have the big screens in there, but they aren't using it yet. If you have OpenNotes, you're not going to have the same problems, more transparency.

KH: What was it about OpenNotes that allowed you to...

Participant: We don't have it yet. Please keep promoting OpenNotes, keep that in mind. It would solve those Behavioral Health note problems. If you're at this meeting already agreeing at that meeting what will be written, then you won't have to go back and change things.

Participant: I worked on OpenNotes for five years. We were so excited [behavioral health organization] was open to using it.

Participant: The building is ready for it, the mentality isn't. With technology, you have to think about that too, how to set up rooms, the future changes.

Participant: I was on a community board some years ago, they were talking about preventing people from overdosing on meds. Electronic records where doctors or hospitals would know right away so they wouldn't prescribe overdoses to them. Is that same context with your team?

SO: Yea, one thing at the state level is PDMP which is in Public Health which is a registry of controlled substance prescriptions and being able to login to the web systems and look up patients. The work we've done with Reliance and EDie and others is that you can push a button in the system you're in – if you're looking at the patient record for Susan Otter, you can push a button and it will retrieve the PDMP record for Susan Otter in the system you're in. It is only for prescribers who have registered with the PDMP at Public Health. It allows for ease of access. It takes the guesswork out of needing to login to the system. That's some work that's been happening at the state level that's had some great impact.

KH: Rounding out this particular goal and getting your feedback, over the next 5 years, what do you want HITOC to be looking at? What are your recommendations for HITOC?

Participant: Again, this is futuristic, but I was at a tech conference a year and a half ago where they have chips in the psych drugs and can tell whether people are taking them or not. They've actually made that with one of the popular psych drugs. I, as a person with mental health, am worried about that. They do, AOT, assisted outpatient treatment – it's not assisted, it's more like they make you do it. If these pills are now controlled by electronic means, what does that mean for the state of Oregon? How they keep records; are people going to have the right to not take medication? This could possibly come up in 5 years because it's already in California. In thinking about that, what are the rights of people? How do you get that data?

SO: I'd heard of chips in the bottle, but never that.

Participant: I met the guy that made it. He's so excited. This is happening.

SO: Before we forget, someone on chat had a question about EDie and sharing info across the state, the same concept you used for online banking or thinking about access to your online record.

Participant (chat): EDie – could it be like online banking rules? Your information is pretty secure, it would be good to have something like that for health records, then the fear of people getting into health records would be not there.

Participant: What about across state agencies? Just having come through the DDS nightmare. DDS would email me, it has to go through DDS, they need the records, then they send it to OHP. They would send me documents in adobe that I couldn't open because the county's adobe is so old. It really feels like, and other parents agree, they're purposely slowing down the process, maybe for budgeting purposes. Then they'd mail it to me, I'd scan it and send it right back. If they just had at all current infrastructure that was at all current in the county systems that need to communicate with the state systems it would be more streamlined, then people would get support sooner. It's another place where the medical and social services overlap.

SO: Absolutely.

Participant: Again, I have mixed feelings, even though I do this work I don't trust any of these systems. I want to control who gets the information and when.

SO: Can you say more about what you want?

Participant: I gave the example of old labels and the diagnosis of my daughter, and people seeing her through an inaccurate lens because of our outdated system. I don't necessarily want that to be the first lens that the next person working with her sees her through, especially when it's about behavior.

SO: Thank you.

KH: So, when those records are shared there is some level of intervention by the patient or the person who is managing that to flag something or put a comment in there so it's not so automated that you're dealing with another massive thing.

Participant: In hospitals, making sure all care team people are educated on how to use electronic records, use them well, use them to the best for all of us. I don't think all employees know how to use them yet.

Participant: In the next 5 years I'd like to see that your system is connected with the health departments across the state, and also with nursing homes. So, if someone is in a nursing home, they can pull the health records on the system and see what medications a person can and can't take, so they wouldn't have overdosed.

SO: Yes, great.

KH: When you say health departments, what kind of information are you looking for?

Participant: For example, if someone goes into a health department in Medford, and they have a personal thing being taken care of, the health department has no idea how to get records to see if they're allergic to something or some type of medicine. They need to be able to pull it up and say "oh this person is allergic; we can't give this to them we need to do something else".

Participant: In 5 years, for behavioral health people, if we knew which hospitals had beds open, so we wouldn't go and wait for hours or days. We would know we can look on an app and see this hospital has this amount of beds open or not. And also, for children. How long would they have to wait? I've personally called around hospitals this winter, and they wouldn't give me the information. It'd be cool to have that within 5 years.

Participant: As far as information sharing between schools and health care providers, I do have a 9-year-old granddaughter on the autism spectrum disorder, but they didn't have a teacher to back it up. Healthcare providers kept telling my daughter she needs to be spanked. My daughter tried to explain that I do correct her, I have all these other kids and you don't see what's going on and I do. If there was an information exchange between the school and healthcare provider, you could put that information together.

Participant: With IEPs you need an educational and medical evaluation. A lot of parents have to fight to do both.

Participant: Exactly, then they would already have that in there.

Participant: That's like an OHA ODE, I don't know

SO: Thoughts about goal one?

Participant: No, I've been listening and taking notes.

Participant: It's helpful to hear the stories, it helps us understand from a practical standpoint, and we are listening.

SO: Thank you, I agree. Any thoughts on goal one before we move to goal two?

Participant: I would like to make a recommendation, as far as information being exchanged from one place to another, putting in 64-bit protection, instead of a 32-bit, that might protect the records of people.

SO: You mean the technical 64-bit vs 32-bit? Is that what you're talking about.

Participant: Yes, it would make it harder for hackers to get into records. The higher the bit, it's harder to hack in.

SO: Anything else on goal one before we move on?

Participant: When you're in hospitals, not everyone has access to computers or telephones. I know you can't control that, but thinking about access to records, how could we get access. At some hospitals they do have terminals you can get to, but how to get equity to access when we're in those places.

## Goal 2

Participant: I'm thinking about this from the perspective of a service utilizer – it'd be interesting, I know some clinics are doing this, keeping data on their therapists, for example. If a therapist has a lot of "no shows", that could be because of the therapist. Let's look at it that way, look at the quality. Is there a way to look at it through the lens of service users to help better quality?

Participant: With the data, there's a lot of different definitions for transitioning youth, it could be 12-25, 16-25, 14-24, it helps to have some way to organize it by age, then you can do better comparisons. I also think some of the data – they don't look at population growth factors. Sometimes the metadata is as important as the data.

Participant: Thinking about human rights, I wanted to do my own project on civil commitment, they didn't keep the data in the counties on civil commitment. I tried to talk to the top IT person for the state. Let's keep those kinds of data facts, especially for human rights. We want to show why is one county having so many civil commitments than another. They just didn't keep the data.

KH: Other feedback?

Participant: I know what it means on the CCO side, but what does it mean from the state's side to incentivize improved health outcomes?

SO: Today we would say Value Based Payment in that spot, we're trying to incentivize providers to focus on improving health outcomes, in how they treat and manage patient populations. When we say incentivize, we're talking about funding. When a CCO has a contract with a PCP clinic, they can receive incentives if they meet targets around breast cancer screenings or if they can reduce the number of patients readmitted to the hospital in 30 days. As CCOs and other health plans set those quality incentives or targets, those are some of the ways we think about incentivizing those metrics.

Participant: Is it the State or the CCOs sending the metrics for the clinics?

SO: Typically, the CCOs setting them but the state holds the CCOs accountable, and the CCOs work with the clinics to achieve those outcomes. CCOs may have additional metrics or data they want to put in dashboards or matrices for their clinics. We certainly have expectations of CCOs, and they roll those expectations down to the clinics.

Participant: When CCOs set metrics, do they match what the metrics you have for them?

SO: They often count on the clinics to help them meet the metrics that we set. An example might be for depression screening and follow up. They work with providers to figure out how they will change workflow and with the information and assistance they need and how they chart it when they've done a screening around depression and how the needs to look in the EHR, so they get credit for it. They will often pass down some of that funding from us to the providers that help them meet the metrics. We hear from providers that there is difficulty managing all the metrics. The provider may have a commercial health plan or federal metrics that are different than CCO metrics. There are too many metrics that are similar but not the same. A participant talked about metrics around age – we call it 18-64, but it can be very burdensome to providers to meet all of those metrics.

Participant: I'm wondering, as hopefully there's more Community Health Workers and Traditional Health Workers use, what their role will be in data collection depending on whether they're working for CCOs or clinics or other community organizations, how they're doing, so we can see if the use of Traditional Health Workers improves health outcomes as they're employed in a number of ways. Is any of that streamlined? A lot of times they might not have access to the health records as they might not be clinical.

Participant: I like the idea of keeping data on how Community Health Workers and Traditional Health Workers actually help. I don't think that's a thing we do in Oregon.

Participant: There's self-determination for consideration. Some metrics are driven by consumers and people who receive peer support and Community Health Worker supports.

SO: If they aren't working with someone who is effective for them, they have the self-determination to choose to work with someone else. Is that what you mean?



Participant: A little bit different. Allowing the individual to define for themselves their values, quality of life, satisfaction. For them, how do they know if it's working or not? There was a research project with Dartmouth in which they let the individuals choose what they wanted to track about themselves and discovered that loneliness was among the top choices as one of the most important things they wanted to move the marker on. That's not universal, but it's an example of self-determined choice as far as what to measure. You were saying clinical and administrative data, whether or not that falls under clinical measures, I couldn't be sure. There have been multiple research projects that help bring insight to the selection of metrics in that area and there has been research happening for 15+ years. At the time, we were looking at instruments and data for family support and health.

Participant: Behavioral health again, you have these apps for people to control their moods, how do you keep the data, how do you work with it? I like what was brought up about you can self-determine that, sometimes in those apps, you can do that as well.

SO: Any more thoughts around what HITOC needs to be thinking about for data and system improvement in the next five years?

Participant: Make it easy for the public to access. The justice reinvestment form has that really easy dashboard to use. Could you make that? For example, we could do better by getting it that day, instead of having to contact the state to have someone track it down for us.

Participant: Data collection itself should be trauma-informed and thought put into how that looks. What is the individual's option to choose or not choose access, any level of public investment, who does the data belong to, who can access it and benefit from it or opt-out, etc.

Participant: I'll be more concerned with what happens in November if people have concerns as to what is collected.

SO: About things like immigration status?

Participant: I just heard that in China, they have a website listing people who have COVID-19. I know we wouldn't do that, but I am just thinking about it.

Participant: Because then people would be targeted.

SO: Anything else on goal two?

Participant: I would like to suggest, either the state or CCO, put out a metric or gather info electronically whether a person has had shots for polio and stuff like that and tetanus.

SO: We do have the public health immunization registry that's available for providers to look at – are you thinking about a person's immunization record?

Participant: Yea, if someone goes to the hospital and had already gotten shots, it gives the CCO an idea of how many shots they've had in so many years. That way the state's not scrambling figuring how many or who has shots if Polio or something like that comes back.

SO: I know we have a lot in the registry about children, but we didn't start collecting adult immunizations as early in the registry. You might have immunizations from other states or something like that. But I hear your point about being prepared for public health needs.

Participant: Governor's Behavioral Health Advisory Council- an executive order for Governor's Behavioral Health Advisory Council to be created that's providing input for the Governor's recommended budget for 2021-2023. There is simultaneous work at OHA about its internal agency request budget. High urgency recommendations had to do with a universal assessment that would cover SDOH. One of the high recommendations. I was recently at a medical appointment and the paperwork for a new patient included SDOH, they had a colored sheet of paper, front and back, with all kinds of questions like things you see on the SNAP applications. Do you have any food insecurity, housing insecurity, what's your transportation situation like? These are different parts of SDOH. There is a proposal to incorporate a universal assessment for behavioral health providers.

### Goal 3

SO: What is your experience in terms of accessing your own care information?

Participant: With Reliance I've been trying to get them to have a portal so it would be easy access for patients and clients. They haven't done that yet. It was in the works when I brought it up, but they haven't done it yet through Reliance. I've been trying to push that so people in southern OR can have easy access to their records when going to the doctor and hospitals and such.

Participant: I think some of the things we're doing in Southern OR. For example, we have Asante link through Epic. Things are wonky in that the systems don't integrate. Things are starting to get better. Lab work is starting to cross over. Some providers have started using different authentication features you can use with a Google account or some other username-password combination – that one gets trickier. If I don't use Google to log in the password doesn't work.

SO: Do you have concerns about using the Google account? I know for some folks that is easy since they don't have to remember it, but some might have concerns.

Participant: For a while, I did have concerns. I wanted to keep things separate, but I finally threw my hands up because I couldn't get in the other way. The primary clinic my daughter and I go – the login is really wonky. For myself, as the parent of the minor child everything has to be separate and I can't integrate our accounts. That's where it gets really challenging, so I gave up and started logging in with Google credentials. Which I didn't really want to do, but it's like the systems force your hand.

SO: Any other folks have experience accessing your own patient info or using technology to engage with providers?

Participant: I don't have experience with it, but I have three different families – how do I integrate accounts so I can look at all of my children's portals?

SO: I will just tell you, my understanding is some portals work better than others when linking accounts by proxy. When your children become teenagers, you don't have the same ability to see their records because of individual rights to privacy. We just heard that the accounts weren't linking well. Some link better than others.

Participant: Something else I noticed – any time a provider, whether it's a hospital on Epic, or another provider, when there is an update in the technology, there is a huge change in medication lists. It looks like the med list is long, but they get duplicated.

Participant: Or meds don't always get discontinued. From an OpenNotes movement perspective, the quarterly consortium was disbanded, there are still some that haven't flipped the switch but aren't telling anyone. I'm not sure if that has improved for some of the systems. But if no one knows, it's not very helpful.

Participant: What can Google access? From the state's perspective – what can they access?

SO: I don't know. They shouldn't be able to access anything you don't permit them to access.

Participant: I don't use Google. I know Google developers. One county is on Google. With those departments being on Google, what can it access? I don't know.

Participant: Their records aren't on Google. Their records are in Epic.

Participant: Yeah but if you're doing emails about people....

Participant: With HIPAA, they shouldn't be putting patient identifiers on Google. I know shouldn't among other things are two different cases.

KH: The HITECH act put penalties for HIPAA violations to put force behind the policy on that. As has been said, there should be no sharing of patient info outside of the EHR.

Participant: You should be messaging within the EHR or using other secure messaging.

SO: Other thoughts on goal three?

Participant: There are two hospitals down here and they have portals patients can go into and I can go in and see what tests I got done. I can see what tests I had five years ago. I can see emails as to when my next appointment. If the state could, put a website on computers as well.

SO: Talk more about your recommendation. What does that mean for the state to put up a website?

Participant: Patients should be able to go on the state website through a portal with a password and have access to it through the state of Oregon and see what the records have been on the private meds they have been taking. Maybe someone has dementia and doesn't know what meds they have been taking or what doctor they have been seeing over the last five to ten years. It reminds them about looking at their records to see what they had at the time as they may not have them on paper.

SO: I see, thank you. Any other thoughts on goal three? What should HITOC be thinking about in the next five years as we're looking at this area?

Participant: Nothing about me without me.

SO: Ooooooh say that slower.

Participant: Nothing about me without me. Making sure there is transparency for the patient as much as possible. It will require a culture shift. I've been trying to convince doctors to share their notes. Providers are trained to think that the notes belong to them and not the patients. There needs to be medical school training to make that shift. They are trained to use language such as: "patient denies" "patient complains of", "the patient is non-compliant". These are all negative terms. There are different ways to communicate the same thing. I don't know if that is HITOC specific, but there will have to be a culture shift to obtain that kind of transparency.

SO: Great, thank you.

Participant: We had a national leader who brought this up at a national conference, that the data belongs to the patient period. There is somewhat of a shift underway. Thankfully there is some leadership at that level, but how does it get to our providers?

SO: I'm glad you brought that up. That's part of the federal rules that just came out. Patients having their choice in apps and being able to pull their data from one app and put it into the other. That's part of the same federal effort.

Participant: I have a concern that when the data leaves the provider to a patient, they have the disclaimer that they aren't responsible for what happens to the data. It seemed like there was more protection of the data before one formally accesses their data to be released remotely. Is there any accountability for the security of information, if the disclaimer is that the info will be released to the client in near real-time? It's a two-way street. You can't expect providers to be held responsible if something happens as a result of app coding being insecure. If something happens once, it leaves them, but they should be protective of the data they do have. There have been instances where they've created training documents and they insert real names and social security numbers. It happened here in Oregon. There have even been data breaches here at the state and with other providers. What will happen with that aspect of responsibility and security or do they instantly get a free pass because it's been released to the patient and we have no control over it?

SO: Thank you. Anything else on goal three?

Participant: You brought up vocabulary – some people don't like the word patient because it's 'power down'. I collected 10 other terms that I would like to be used that don't have a power differential.

SO: That would be great, thank you

Participant: Like the word client?

Participant: No, the term "client" is a power-down term. Something more neutral like "service user" and not someone.

#### Emerging area – SDOH

Participant: Workforce does not reflect the population. If you are a person of color or someone with neurodiversity it is easy to either not feel safe being your full self or to get gas lit. Even as a mom of

someone – my daughter barely leaves the house partly because of her autism or anxiety or because of racism. She can't leave the house without someone commenting on her hair. I shared this with a provider that is white and conversely a different one who understands generational trauma. One left me feeling supported and heard and the other did not. We need more people in the workforce, especially in behavioral health, but across the board, who are representative of the populations. Do we have data on the current workforce, by role, in different communities? I know the Health Policy Board talks about the workforce, but I haven't delved in to know what data they have on that.

Participant: I know in one county, when I was volunteering in quality management, we were asking agencies to report. But It's self-reported so it's not always reliable, including languages and linguistic abilities.

Participant: Providers are just asking questions about some things and if they don't understand historical trauma and if there is no basic level of training, it seems like it's not a good idea. Ask the questions, but providers won't get everything they're asking for and it won't be helpful if they don't have the necessary training and education.

Participant: What someone brought up, having people choose what determinants they are being labeled as. I know that's harder, but do we have a choice in our label?

Participant: I need clarification about transportation? Does that mean transportation like busses or is that EMT services?

SO: When we talk about transportation it could be any of those. It could be that people need general transportation, school, community, getting to a job. It could be more of an issue in rural areas but is an issue in urban areas as well. Folks need transportation to Dr. appointments, that is a service folks need to access, so we're talking about both.

Participant: Would you be requiring, as a state, once they are referred to EMT, are you going to be requiring them to keep data for that?

SO: That's a good question. The idea, when we're talking about transportation, for a person who needs help getting to a doctor, they need non-emergency transportation associated with being on the OHP plan. But they also might need help getting to a job or the grocery store, they can be referred to social services and get the transportation they need. We aren't saying non-emergency transportation is going to be transporting clients to work, we want to make sure that health care providers can help patients with transportation outside of healthcare-related needs.

KH: Are you asking about patient access to EMT services and listings of that or having access to what is available or whether it's covered?

Participant: That would be a good idea but I'm also referring to when doctors have to fill out info about their clients having food insecurity, transportation, and housing, I'm wondering if doctors have to get that data or if EMT services will have to keep data to report to the state for this type of situation.

SO: I'm not a great resource for this. I don't have a lot of info about non-urgent medical transportation, but that is part of what's covered when we think about what is required to help people get to their medical appointments.

Participant: So EMT service companies, under CCOs, it sounds like there is uncertainty as to whether EMTs will be keeping records that will be sent to the state for how many clients have to be picked up.

SO: I know they send records – I just don't know more than that. To get paid they have to send info about the clients they transported.

Participant: Will doctors be required to give information on transportation on both food insecurity as well as housing?

SO: Good question, what do you think we should be doing?

Participant: If the doctor is required to do that, the doctors that help the CHP (community health improvement plan) process with the state improvement plan with their strategies along with your strategies.

SO: So, if we had more data on your needs it could help with the planning for the state health improvement plan and community health improvement plan?

Participant: Yes.

SO: I think there could be real value in that and finding out where there are social needs within a community, where there are needs that aren't being met, where we might need to invest differently in social services and where there might be capacity issues with those social services.

Participant: I can say any type of disability – I do know in the coming years, the population of people with all types of disabilities will be increasing enormously. The state needs to prepare for increasing numbers of folks with disabilities.

Participant: I heard someone say to prepare for a tidal wave that is coming. I'm speaking to kids with autism. I know three young adults, because the U.S. is 20 years behind in treating women and girls, who have been diagnosed with bipolar and they are just now being diagnosed in their early 20s as autistic. Only now, are they getting linked up with disability services?

Participant: I've noticed, in long term care, seeing more people with Traumatic Brain Injuries

Participant: I believe there was a study of Traumatic Brain Injuries in the homeless population.

Participant: I think some things OHA will need to take into consideration while moving the CCOs through 2.0, is the way SDOH data is captured. As a healthcare community, we are making some strides, but we are not there at all to truly be capturing a patient's full story with the data that needs to be collected. Just with race, ethnicity, and disability status you cannot get a full picture of what is going on in the patient's home. Something very concerning, because this piece is being so heavily looked at the state level and it will get moving quickly, the providers know they have to do it, but with very little guidance in how to do it, how to do it correctly and telling the story correctly. Unless we get a hold of this thing, whether it's education but really it will be an early grassroots conversation with providers, and they'll all want to do it in different ways because they all work in different systems. We need to find some common ground because even with the Plus D data at the CCO level, that data didn't even tell us what

we needed to manage patients. I think we were making some strides, but we haven't gotten there just yet.

SO: Any other thoughts on the role of technology or data and what we need to think of over the next five years?

Participant: There's a universal assessment, I mentioned two topics ago.

SO: Yep.

Participant: There is something that hasn't been mentioned and should be – neurologists should be included in this. They are surgeons and doctors that operate that help our paraplegics and quadriplegics.

SO: Neurologists need to capture social needs and help with those needs and connecting folks with social services, is that what you're saying?

Participant: Definitely. When you're on the front lines and you don't know if you're a paraplegic or a quadriplegic, they should know automatically what the needs are when they come out of the hospitals.

Participant: I'm not sure how you do this from a data perspective but understanding intersectionality and what that means and how that impacts access to services. How are people counted? Are they double counted? My daughter is black, identifies as LGBTQ, disabled, Jewish, historical trauma – which bucket is she put in and how do providers see her full picture and what that means, or would she only be counted once. I don't know how that works with intersectionality and data. And multiple race data.

Participant: I keep coming back to – if there needs to be an update, change, or correction, there really needs to be a way to do that.

SO: If there is an error in the record?

Participant: Yes.

SO: Anything else on SDOH and Health Equity? Okay, let's move on to what we missed?

Participant: Psychiatry and telehealth and quality. It would be nice if the tech division of the state of Oregon said hey, if you're going to have telehealth in hospitals, you must be able to see the face of the doctor, you must be able to see the doctor; doctors need to be looking at the camera so it's more personable. Let's have the technical requirements necessary. I've had the worst experiences in hospitalizations and telehealth. Another thing they do is have other people with the doctor at the same time. You're losing confidentiality when there are one or two other random staff there. Let's make it human as possible. If you have to do this, make sure it's working and have the requirements.

SO: Anything else on your mind that we didn't get to? (No responses.) Thank you for the input – if something comes to you after the meeting please send us written comment through April 30th.