Governance of the Community Information Exchange Networks

Assessment Report

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Oregon Consensus Assessment
Governance of the Community Information Exchange Networks

Assessment Team
Sofia Castellanos, Project Associate, Oregon Consensus, Portland State University
Bobby Cochran, Senior Project Manager, Oregon Consensus, Portland State University

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About Oregon Consensus
Oregon Consensus was established by state statute[1] as the State of Oregon's program for public policy conflict resolution and collaborative governance. The program provides mediation and other collaborative services to public bodies and other interested parties who are seeking new approaches to challenging public issues. Oregon Consensus conducts assessments and, where appropriate, designs and facilitates impartial and transparent collaborative processes that foster equitable participation and durable agreements. The program is housed in the National Policy Consensus Center in the Mark O. Hatfield School of Government at Portland State University.

Contact
Sofia Castellanos, Project Associate
Oregon Consensus, Portland State University
506 SW Mill Street, Suite 720, Portland, Oregon 97207
acastel2@pdx.edu, www.oregonconsensus.org

[1] Mediation and other alternative dispute resolution services for public bodies, ORS 36.179, Accessed at https://oregon.public.law/statutes/ors_36.179.

Contents

1. Executive Summary

Oregon Consensus was asked by the Oregon Health Authority and other partners to assess the potential for collaboration to build statewide Community Information Exchange (CIE) governance. A 2022 CIE Workgroup defined CIE as,

"CIE is a network of collaborative partners using a multidirectional technology platform to connect people to the services and support they need. Partners may include human and social service, healthcare, and other organizations. Technology functions must include closed loop referrals, a shared resource directory, and informed consent." (CIE Workgroup, 2022, p.5)"

The Workgroup went on to recommend a governance approach (CIE Workgroup, 2022, p17) that is:

- Led by a neutral third-party or public/private partnership and should promote alignment across systems and sectors;
- Representative of the individuals, communities, and organizations participating in and impacted by CIE efforts. Their priorities should drive discussions and decisions around CIE; and
- Engaging Community Based Organizations (CBOs) and communities in decision-making processes is crucial to the success of CIE and to advancing health equity.

Oregon Consensus interviewed 45 community-based service providers, healthcare, state agency and other people interested in CIE across Oregon (20 people via one-on-one interviews, 25 people via focus group, and referred to as participants throughout this report). Oregon Consensus prepared an assessment report to document the themes that came up, and Oregon Consensus' process recommendations for building statewide CIE governance. This is an executive summary of that full assessment report.

Interest in collaborating to build community-driven governance of CIE

There is interest in collaborating to improve how CIE is governed in Oregon, but productive collaboration requires clarity on the scope of "what is being governed." Oregon Consensus recommends that decisions on A) the scope of what is being governed and B) whether to proceed with collaboration be made collectively by representatives from CBOs, healthcare, and state and local agencies. For instance, a one-day or half-day workshop could help define the scope and determine whether to move forward.

If the process is community-driven, there will likely be greater interest in a decentralized approach where service providers and healthcare networks share information, coordinate efforts, and strengthen relationships outside of a centralized platform. This approach would involve both formal and informal collaboration among partners, tailored to different geographies, service types, or demographic needs. In contrast, if the focus shifts toward improving technology effectiveness, interest may center on developing a hub to manage service directories, data standards, and privacy protections. Both pathways—decentralization and centralization—were of interest to participants. Some believed these topics could be addressed in a single conversation, while others felt that each required distinct processes and participation to achieve meaningful outcomes.

Interest in collaborating to share information

There remains strong interest in the promise of CIE to have better access to information, smoothing the ability for service providers to provide the best care coordination and access to health and social care for low-income Oregonians and their caregivers. That sharing of information on service location and availability is happening via convenings of Community Health Workers, associations of service providers

in similar geographic regions or service types, and the relationships that form between individual service providers. It is happening via technology platforms like 211, Unite Us, and findhelp too.

Key issues to consider when building statewide CIE governance

Oregon Consensus interviews and the CIE workgroup identified several potential "focal issues" that statewide CIE governance could focus on. In addition to the Workgroup's coordination and convening priorities (CIE Workgroup, 2022, p22), data types (p28), and coordinating roles (p150), participants also identified these potential priorities:

- Resources: adequate staffing for tech-based platform navigation and service delivery
- Data Privacy: address and clarify HIPAA and FERPA compliance[2]
- Data access and sharing: improve patient/client information access, and mechanisms for sharing
- Data quality/accuracy: ensure up to date service eligibility and screening, service availability and location information and requirements
- Creating a centralized, hub-based organization to oversee technology platforms and referral systems
- Supporting informal networks of CIE partners (e.g., by geography, service type, and/or demographic served) to improve cross-organization collaboration and coordination outside of functions provided by technology

If one of the goals for statewide CIE governance is to be community-driven, then CBOs likely need to play a central role in deciding to convene a process to build statewide CIE governance. This could be done via a one or half-day workshop, but likely needs to be a conversation that includes decisions around:

- A neutral convenor and facilitator for the process to build statewide governance;
- Roles, responsibilities, and decision-making processes in building statewide governance; and
- The best ways to structure a process that strengthens both A) the coordination networks between CBOs via decentralized conversation, and B) the hubs, data standards, and central information needed for successful use of technology.

CBOs are overloaded. Smaller, culturally-specific and rural-based CBOs will have limited capacity to participate in building statewide governance. Compensation for time might help some for that, but there just aren't enough hours in the day. Any process to design governance will likely need some kind of "core group" that may include more "hub-type" organizations such as nonprofit convenors of a type of service organization, Coordinated Care Organizations (CCOs), and larger CBOs, and then a process to meet smaller CBOs where they are already gathering to get their input and hear their voices (e.g., regional gatherings of community health workers).

Remaining questions and information gaps

After all the interviews and focus groups, Oregon Consensus identified some questions that could help partners interested in CIE decide if, and how, to move forward with statewide CIE governance. Some of those questions include:

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[2] The CIE Workgroup identified types of data where privacy and security was important (p31):

- Identifying: Name, address, contact information, etc.
- Demographic: Age, income, household size, REALD, SOGI*, etc.
- Health: Dietary restrictions due to health conditions, etc.
- Behavioral health: For delivering community services or referring to behavioral health organizations, etc.
- Sensitive: HIV/STI** services, legal services, situations of intimate partner violence, etc." p31

- What are the priorities, especially from CBOs, for statewide community-driven CIE governance?
    - And if those priorities include both A) supporting informal networks that communicate via meetings, phone, and email to stay connected and exchange client and community information, and B) centralizing a hub-based organization model for data and information management; and
    - If use of a specific technology is not a priority is that acceptable for OHA? for healthcare? for other partners?
- How would the group designing governance operate? How would priorities be set, how would decisions get made and by whom? Who would determine what sectors are represented and by how many seats?
- Who should convene the process to build statewide governance? Neutral convening may or may not be the same as leadership in the process. Which voices can "drive" leadership of the process to design statewide governance?

Areas of potential agreement to build from

Nearly all participants recognized the power differentials between healthcare systems and direct service providers (including larger nonprofits, health clinics, and CBO social service providers). And most participants felt that power differential was not a barrier to collaboration so long as:

- There were clear directives from the state agencies and healthcare system leaders that CBO priorities would drive statewide governance discussions; and
- Participants building statewide governance recognized those power differentials, and worked to center the needs of low-income Oregonians and their caregivers.
- The governance structure accounted for these power differentials (e.g. # of seats, other ways this has been done?)

Most participants still recognize the need for holistic care, easy access to centralized information, and improved coordination across service providers–even if a number of participants did not feel technology could fully meet those needs.

Areas of potential disagreement that could be barriers to collaboration

Most of the areas of disagreement Oregon Consensus heard stemmed from different priorities on where to focus attention. Many of the CBOs interviewed were focused on informal networks of coordination that may or may not be mediated by technology. Those networks would be decentralized, so they could be responsive to differences by geography, service type, or demographic served. Many of the people interviewed that are sitting in roles as "hubs" where they are working with multiple service providers, and across healthcare and social service systems, spoke more to prioritizing data standards, privacy and security, and centralized information. There was no agreement that a focus on improving technology (with a shared resource directory, informed consent, screening, closed loop referrals, and reporting) should be the primary focus of collaboration. Some participants wanted to focus on the inter-organizational collaboration that cannot or should not be mediated by technology.

In sum, this assessment shows there's real interest in building a collaborative, community-driven governance model for CIE in Oregon, but it won't be without its challenges. The successful governance of a community-driven CIE will require balancing decentralized informal networks with the use of centralized hub-based organization and technology platforms, along with making sure smaller CBOs have a voice despite capacity limitations. Moving forward, clarity on governance scope, shared decision-making, and strong leadership will be essential. CIE governance must align with community priorities,

the focus needs to stay on what really matters—coordinating services effectively while keeping the human touch that makes a difference for the communities being served.

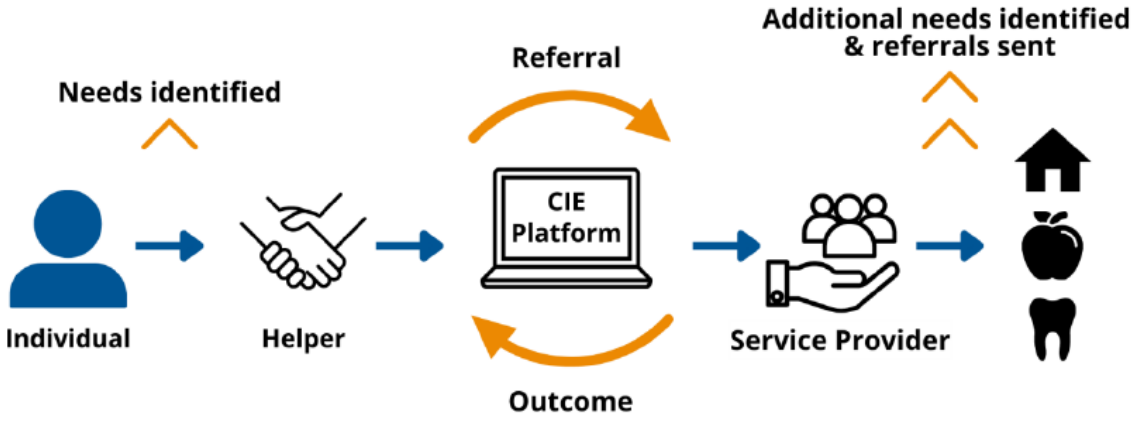
2. Introduction and Background Information

Oregon Consensus was asked by the Oregon Health Authority (OHA) and other partners to A) assess the opportunities and challenges around a process to build community-driven, statewide governance for Community Information Exchange (CIE), and B) recommend if and how a collaborative process to build that CIE governance could happen in a community-driven, statewide, and vendor neutral way. The House Bill 4150 (2022) Final Report: Supporting Statewide Community Information Exchange, brought together recommendations on how to support, accelerate, and improve statewide CIE efforts from the Health Information Technology Oversight Council (HITOC), their CIE Workgroup, and input from CBOs. It was submitted to the legislature in January 2023.

Table 2.1. CIE definition and vision

CIE Definition (CIE Workgroup, 2022, p.5) "CIE is a network of collaborative partners using a multidirectional technology platform to connect people to the services and support they need. Partners may include human and social service, healthcare, and other organizations. Technology functions must include closed loop referrals, a shared resource directory, and informed consent." **Community Information Exchange Vision (CIE Workgroup, 2022, p.13)** "All people living in Oregon and their communities have access to community information exchange that creates seamless, trusted, person-centered connections and coordination to meet people's needs, support community capacity, and eliminate silos to achieve health equity."

Figure 2.1. CIE concept diagram (CIE Workgroup, 2022, p.7)



A lot of CIE conversations occurred in 2022 as part of the CIE Workgroup (HB 4150). This assessment work built on two of the cross-cutting priorities of the Workgroup (CIE Workgroup, 2022, p20):

1. "CBOs[3] were identified as a priority partner for the success of CIE. CBOs must be supported in these efforts and at the table in decision-making.
2. Inclusive and neutral statewide governance is needed and is the critical next step for statewide CIE."

This assessment does not offer specific recommendations about what statewide governance should look like. It is focused on assessing the feasibility of collaboration and interested parties in shaping those recommendations through a community-led and/or community-driven process. The questions asked during the assessment (see Appendix B) were co-developed between Oregon Consensus, OHA, and feedback from a small sample of CIE partners. Oregon Consensus asks questions during an assessment, but participants often talk about whatever feels most important to them. This assessment report is a reflection of what participants wanted to share about CIE as it is Oregon Consensus' recommendations for a process moving forward.

Table 2.2. Defining community-led and community-driven process for this report

Community-led process: the community, or its representatives, holds the leadership role in governance and is primarily responsible for the decision-making and strategic direction of the CIE effort. **Community-driven process:** where the community, or its representatives heavily influences or drives decisions, but may not have the direct authority to make decisions. **Shared decision-making:** and there are many "in between" models of decision-making where decision-making authority can be shared between community, healthcare, state government, and other interested parties.

The assessment was conducted through a combination of focus groups and interviews facilitated by Oregon Consensus. All one-on-one sessions were confidential, both focus group and interview results have been anonymized, and the findings are compiled into this report to be shared with participants and other interested parties.

This report aims to inform decisions on whether and how to pursue a collaborative effort to design a statewide governance framework for CIE. Section 3 does lift up themes heard from 45 participants during the assessment. Section 4 includes Oregon Consensus' process recommendations.

This assessment is built from the insights of a diverse range of partners, including community-based service providers, healthcare providers, health plans, counties, community leaders, Tribes, funders, and other interested parties who are invested in integrated health and social service provision. Key topics explored included:

- What does community-led or community-driven decision-making look like?

[3] For the context of this paper community-based organizations (CBOs) are defined similarly to the CIE Workgroup report. CBOs are, "generally non-profit organizations working to support social needs and advance health equity across Oregon particularly in communities of color, Tribal communities, disability communities, immigrant and refugee communities, undocumented communities, migrant and seasonal farmworkers, LGBTQIA2S+ communities, faith communities, older adults, houseless communities, and others. This definition is not meant to be limiting." p22

- What specific issues or needs are being governed, and what is bringing groups together for decision-making?
- What capacities do CBOs need, desire, and currently possess to participate effectively in governance?
- What would successful governance look like in terms of benefits and risks, particularly when implementing collaborative decision-making processes?
- What are the potential barriers to achieving effective governance?
- What people, information, and resources are available to support a collaborative process?

There are a number of related, ongoing efforts in Oregon to improve coordination between service providers in Oregon supporting people who need help with access to services and resources like food, housing, transportation, childcare, and other health and human services. OHA was recently awarded a federal 1115 Medicaid Waiver that provides additional funding and flexibility for addressing some of the Health-Related Social Needs (HRSN) for Oregon Health Plan Members. Statewide, more than 1 in 3 people in Oregon (about 1.4 million people) receive their healthcare from Oregon Health Plan, so the recent 1115 Waiver represents significant, new support. The 1115 Waiver requirements include requiring the Oregon Health Plan, Open Card care coordinators, coordinated care organizations, and HRSN service providers to communicate using closed loop referrals which can be achieved using CIEs like Connect Oregon (powered by Unite Us), or findhelp.

Other states (e.g., WA, MI, CO) are also exploring statewide CIE. There are similar core elements in CIEs developing across the country (see Table 2.3).

Table 2.3. Core elements of CIE

Core elements of CIE (CIE workgroup, 2022, p8)

- Shared resource directory: Users can search for available local resources, including services provided in a person's preferred language, in one centralized place.
- Informed consent: Individuals needing help provide permission for their information to be shared after understanding what they are agreeing to share.
- Screening: Questionnaires help users identify a person's needs.
- Closed loop referrals: Referring organizations can see when a person is connected to services from receiving organizations. This is a distinguishing feature of CIE.
- Reporting: Users can analyze data and produce reports.

3. Key Themes from Assessment Interviews and Focus Groups

Many of the concerns and hopes expressed during the CIE Workgroup process (HB 4150 CIE Workgroup, 2022)[4] reemerged during our interviews and focus groups. However, the context for these conversations have evolved, specifically influenced by:

- A decrease in available service funding as federal COVID-19 response funds reduce;
- Several years of experience using the Unite Us and findhelp platforms; and
- An increase in the number of certified Community Health Workers (CHW) coordinating and navigating care within healthcare and social service settings.

[4] Accessed at https://www.oregon.gov/oha/hpa/ohit-hitoc/pages/cieworkgroup.aspx.

The themes below capture participants' real-world experiences and illustrate the practical realities of navigating the network of CIE partners. These themes reflect the challenges, issues, and potential opportunities for collaborative governance of CIE identified during the interviews and focus groups. Participants spoke about what successful community-driven CIE governance could look like, capacities needed to engage CBOs, potential barriers to collaboration, and what happens if collaboration does not work.

The definition of CIE may be clear to some, but throughout development of this assessment, from creating interview questions and guiding conversations, it was evident that many participants still find the concept, purpose, and vision of CIE unclear (see Table 2.1 above). The themes highlight areas where participants think early CIE implementation is struggling to meet the needs of community-based organizations, healthcare providers, and other interested parties.

One of the main themes our conversations focused on was the various modes, norms, and mechanisms for communication, interaction, and coordination between service providers (larger nonprofits and smaller community-based organizations), healthcare providers (large health systems, CCOs, and clinics), state agencies, and other partners. These interactions can happen through technology platforms, communities of practice, and regular meetings where service providers and healthcare professionals connect, or through traditional methods like phone calls, faxes, e-mails and established relationships used before the implementation of any form of CIE.

Across all the conversations, there was a strong call for improved communication and engagement practices to support effective collaboration, better use of the technology platforms, and understanding of the requirements and processes of others participating in them in order to help individuals navigate their way to better care. This need is particularly important for low-income populations (e.g., Medicaid-eligible people), culturally specific communities, and their care providers (e.g., families). The themes most frequently mentioned by participants, highlighting opportunities to improve and address gaps in CIE governance, are described more below.

3.1. What does community-led or community-driven decision-making look like?

Defining roles, responsibilities, and decision-making processes are a crucial starting point for effective, community-driven CIE collaboration. The 2022 CIE Workgroup identified the need for governance that was community-led. For the purposes of this report, in a community-led initiative: the community, or its representatives, holds the leadership role in governance and is primarily responsible for the decision-making and direction of the effort. In the Oregon Consensus interviews, we also heard about community-driven governance: where the community, or its representatives heavily influences or drives decisions, but may not have the direct authority to make decisions. For this report, wherever interviews were vague about their preference for community-led or community-driven decision-making, Oregon Consensus used the term "community-driven".

Participants suggested it was important to collectively define in more detail, and refresh, a shared understanding of the specific challenges the CIE is meant to address and to clarify who, exactly, will benefit from collaborative efforts. A number of participants stressed that alignment on the problem definition and the focal populations that will be served was important. They articulated that different problem definitions might change the focus of a collaborative effort.

Establishing clear governance boundaries for decision-making processes is a significant challenge for CIE. Participants in the interviews frequently expressed confusion between CIE, the Connect Oregon network, and the Unite Us platform. There is often no clear distinction between these entities, leading many participants to focus only on the technology platform rather than the broader CIE framework. This confusion highlights the need to clearly define the roles, responsibilities, and decision-making processes for each.

CIE started with technology-based platforms before defining the purpose: a tool without a clear vision. The technology arrived first, yet the purpose and vision of CIE remained unclear. This created a disconnect—people found themselves using a platform without a shared understanding of its role, responsibilities, and workflows within the broader system of care. Without a clear mission, the platform becomes just another piece of technology, disconnected from its potential impact. Even though some participants felt defining and aligning around a shared vision has been done, and done several times already, the interviews reflected remaining lack of clarity around the exact and operational definition, purpose, and vision of CIE itself.

Many participants reported a decline in referral volumes on the Unite Us platform, with some opting out due to uncertainty about whether referrals will be successfully fulfilled. This uncertainty has led to a lack of confidence in the referral functions of CIE, discouraging use and diminishing its effectiveness. Several participants compared the rollout of the Health Information Exchange (HIE) to the current development of CIE. They pointed out that HIE focused on creating a shared set of information that could be accessed across multiple platforms, rather than focusing on the service referral functions. Those same participants emphasized the need for CIE to focus on centrally accessible and up-to-date client information, service needs, and available services, which could improve coordination and service delivery across the network.

3.2. What specific issues or needs are being governed, and what is bringing groups together for decision-making?

With a clear scope in mind, most participants expressed a strong desire to be involved in the creation of a more community-driven governance model for CIE. Many participants felt that the current structure is too focused on vendors, which often takes attention away from broader governance needs. Participants expressed that while technology is a crucial tool for managing referrals and sharing information, it cannot address the deeper issues related to the organization and capacity of community-based organizations (CBOs) or the availability of services to meet demand.

The CIE Workgroup report noted the questions around “what would be governed” (p21), and our assessment found many participants had similar questions but unclear answers to those questions.

Some visions of success (hopes and dreams or the promise of CIE) for a community-driven CIE governance model include:

- Creating a space for a community-driven governance structure, in which participants support informal CIE networks (organized by geography, service type, and/or demographic served) collaborating, sharing resources, and communicating service availability to accomplish a common goal; but also a centralized hub-based approach that organizes or facilitates the coordination and connection of a large group of organizations that better serve the CIE purpose of connecting people to the services and support they need

- With clear communication channels and a shared understanding of roles and responsibilities, service providers can coordinate more effectively. This will lead to smoother referrals, reduced duplication of efforts
- A governance model reflects and respects the diverse cultural needs of the communities it serves. Service delivery is tailored to meet these needs
- A governance model functions as a central hub, with its governing body or board, from local to statewide, facilitating connections between organizations. This to ensure that services are delivered as requested and that collaboration between partners is smooth and efficient
- A model promotes collaboration while ensuring compliance with FERPA and HIPAA regulations by establishing clear data-sharing protocols and safeguarding personal information.

3.3. What capacities do CBOs need, desire, and currently possess to participate effectively in governance?

CBOs face significant challenges that limit their capacity to participate effectively in CIE and other collaborative efforts. CBO participants spoke often to the dual pressures of increased service demand (driven by housing costs, mental health, and substance use) and decreased funding (especially loss of COVID-19 funding). These combined challenges heavily impact how CBOs prioritize their involvement in collaborative initiatives.

Many CBO participants, especially smaller culturally specific CBOs, were concerned about how to manage the surge in referrals CIE could bring while ensuring that each person gets the care they need. This issue was raised as an unresolved concern, and is consistent with the CIE Workgroup report, which said, "Implementing CIE in an under-resourced health and social care system will be difficult if the broader need for more services and resources is not also addressed." (2022, p17). Many participants pointed to stable, ongoing investment in culturally-specific service capacities.

That said, the CBOs we interviewed wanted to participate in statewide CIE governance and recognized that participation might vary. Some CBOs had interest and capacity to be part of a core team designing governance, other CBOs wanted to be consulted so their needs were being met even if they didn't have capacity to participate for so many hours.

3.4. What would successful governance look like in terms of benefits and risks, particularly when implementing collaborative decision-making processes?

Most participants were hopeful that successful CIE governance could continue to improve service coordination (both between CBOs and between CBOs and healthcare providers) and care for low-income people and their caregivers.

Technology is still limited and a source of frustrations. According to several participants, the platform, currently, feels more like a barrier than a bridge. There are recurring questions about data standards such as accessibility, usability, as well as interoperability and integration with existing systems like EPIC and Activate Care, and the ability to report information to state agencies effectively. Data standards for keeping up-to-date service information (e.g., opening times, eligibility requirements) are still lacking.

The goal of securely sharing and accessing information across systems is still desired, but out of reach. Participants shared some examples of functions they expected, but are not operational in a way that fully meets their needs:

- Like Health Information Exchange, appropriately access and securely share a person's vital (e.g., name, contact information, screening information) information electronically
- Securely sending and receiving information electronically (coordinated care)

- Finding and/or requesting information on a walk-in patient from other providers (unplanned care)
- Enabling patients to aggregate and control the use of their information among providers
- Single intake forms and application programming interfaces (APIs) to access that intake information as a person moves houses and across services (like PointClickCare[5])

Successful governance would fill some of the gaps in coordination. Some of the gaps in coordination named by participants included:

- Coordinating services, identifying and understanding the information and processes gaps through local forums
- A need to improve coordination within the Community Information Exchange (CIE) by focusing on key goals/objectives such as avoiding readmissions, reducing errors, improving service quality, and minimizing duplication of efforts
- Communication barriers, often linked to worries about Health Insurance Portability and Accountability Act (HIPAA) and/or Family Educational Rights and Privacy Act (FERPA) compliance
- Synchronizing service eligibility requirements
- A need to increase the number of navigators who can help guide clients through complex service systems
- Keeping service information up-to-date and consistent to maintain trust and ensure that people can access services when they need them: "keeping doors open"
- Defining access permissions for raw and processed data within a CIE technology platform

When participants were asked which kinds of actions might improve some of these coordinating challenges, they sometimes struggled to name clear strategies, but did speak to some of the following themes:

- Participants spoke to strengthen communication mechanisms to improve collaboration and decision-making. Creating a space for open and ongoing dialogue between CIE partners was identified as an important need. There are some communication channels, and hubs where service providers gather to coordinate, but participants suggested these could be improved. It's about more than just exchanging information—it's about fostering transparency, building trust, and making decisions together. When there are clear paths for communication, it's easier to align expectations and bridge the gaps between community-based organizations, healthcare providers, and the vendor.

- There is this tension between vendor-driven processes and community leadership. Many participants expressed frustration over CIE being perceived as driven by the vendor rather than by the communities the vendor is meant to serve. When asked to envision a community-driven alternative to the same participants, participants struggled to define what that would look like in practice. It might be as simple as who convenes and facilitates conversations between the vendors and CBOs. There was a clear desire for a shift, but the path forward or the model to be adopted remains uncertain.

- Participants shared the imbalance between administrative work and direct service delivery as a significant issue. A common question was whether the time spent managing the CIE technology

[5] FULL CITATION. Accessed at https://pointclickcare.com/resource/payers-software/videos/care-oregon-care-improved-outcomes/.

platform and handling administrative tasks actually is balanced with the time spent actually providing care. Both CBOs and healthcare organizations expressed concerns about being stretched too thin, with limited capacity to fully engage in the CIE system. Many are overwhelmed by reporting requirements that do not align with their current capabilities. Some participants pointed to an explicit goal of reducing the ratio of admin FTE per frontline service provider needed.

3.5. What are the potential barriers to achieving effective governance?

Cultural and power differences between healthcare and service providers exist, but participants do not see them as barriers to collaboration

While power imbalances between healthcare providers and culturally-specific CBOs exist, many participants felt these issues could be managed with clear guidance from healthcare leadership and the State of Oregon (e.g., the Governor's office, legislature, and/or state agencies). They noted that these imbalances, though present, are not the main obstacles to effective collaboration.

Inclusion of more languages and culturally appropriate processes remains a concern, particularly for smaller CBOs serving specific language communities. Many participants highlighted that current systems fall short in meeting the diverse linguistic and cultural needs of these populations. Several participants from culturally-specific CBOs mentioned they rely on basic tools like Google searches rather than more formal technology platforms for coordinating services.

Many participants referred to "governance" as the workflow and navigation associated with the tech-based platform rather than decision-making processes, norms/procedures, or other governance structures. For them, governance encompassed the day-to-day use and management of the tech-based platform, including how data is entered, accessed, and shared; how referrals are made and tracked; and how users across different organizations communicate and coordinate using the technology. However, several participants viewed governance more broadly, beyond technology, as encompassing decision-making processes, data standards, and workforce development that shape the collaborative environment. For these participants, effective governance involved establishing shared standards and supporting a workforce prepared to manage both technological and relational aspects of CIE. The experiences shared during our interviews and focus groups described a system that, while well-intentioned, faces significant foundational challenges. The CIE Workgroup acknowledged that CIE was more than just effective use of technology, "While a technology platform is one aspect of CIE, to be effective the needs of partners and the realities of the health and social care systems must be recognized and addressed." (2022, p18).

Challenges with a current technology platform and how it is used

Participants highlighted several specific challenges with a current closed-loop referral platform (that also included a shared resource directory, informed consent, screening, and reporting). Some of the challenges and issues with this tech-based platform included (some of these are technology-related, and some are service coordination-related):

- Declines in outgoing referrals being "picked up", which has led to a decline in participants "sending" referrals;
- Inconsistent availability of services as community-based providers come and go;
- Some of the initial configurations did not include the kinds of services providers were providing, and customization was slow to occur;
- Lack of time for frontline and navigation staff to use the platform;
- Insufficient training and lack of technical understanding to use the platform; and

- Perceived worries about HIPAA and/or FERPA compliance, especially between behavioral health providers and social service providers.
- Unable to integrate with other systems/platforms used by healthcare and community providers to deliver services.

Potential actions for improving the functionality of the Unite Us platform
Several participants provided recommendations to improve the Unite Us platform to better support their service delivery. Oregon Consensus was not able to interview CBO users of findhelp or other technology platforms to get similar feedback. These recommendations may not directly relate to governance, but were raised more than once during conversations, so they are reflected here. Recommendations from participants included:

- Provide functionality for clients to directly use the platform (e.g., let client self-select services of interest and use the platform from home);
- Enhance the platform's ability to provide information in other languages, particularly for services in rural and marginalized areas;
- Improve the accuracy of service eligibility and availability so referrals are more likely to be "picked up" smoothly;
- Smooth the ability to remove duplicate records;
- Improve access to a client/patient's vital information (e.g., name, contact, screening for needs and service preferences), to remove duplicate data entry and re-telling of traumatic stories;
- Improve accuracy of client/patient contact information as people move cell numbers and across services; and
- Work through data privacy policy and practice improvements, so frontline service providers run into fewer real and perceived HIPAA and/or FERPA barriers (e.g., improve ability to text message clients).

4. Process considerations for how to build a community-driven CIE governance model

Successful collaboration to build community-driven, statewide, vendor-neutral governance for Community Information Exchange has to hold the tension of a desire for improvements to the technology platforms currently in use for CIE, and the recognition that community-driven CIE is an effort broader than technology where solutions need to be durable and long-term.

In their responses, many participants spoke to the promise of CIE governance being as much about organizing people/organizations as they are about sharing information and data. The technology, while an important tool, cannot by itself solve the deeper issues of coordination and capacity. There is a need for a shared purpose, improved interoperability, and more support for the people and organizations at the heart of this system.

The convenors and participants in a structured collaborative process may need to take a phased process approach, for example by:

- Establishing/designing the collaborative process and defining a common scope of work to focus on;
- Using both a governance process convenor with some subject matter expertise and a neutral facilitator;
- Reaffirming a statewide vision and goals for CIE;

- Identifying near-term or immediate actions that add value to service providers and healthcare organizations; and
- Continuing to address broader-systemic changes that are needed to better support and serve low-income Oregonians, and their caregivers.

Table 4.0. Assessing equitable collaborative processes

Questions Oregon Consensus asks itself to ensure an equitable collaborative process
Oregon Consensus recognizes that collaboration can sometimes disadvantage less vocal and less politically experienced participants. It is important to be aware of disparities in access to social and economic resources and differences in participants' abilities to influence decisions that are important. To create an equitable collaborative process Oregon Consensus, consider the following questions to make process recommendations: ● Who will be affected by the decisions resulting from this process? What does meaningful involvement in a collaborative process from these communities and individuals look like? ● How do impacted communities and individuals define meaningful involvement? ● How can Oregon Consensus best communicate with these communities and community members/representatives? ● Is a collaborative process appropriate for this situation? When would it not be appropriate?

Based on Oregon Consensus' interpretation of feedback from over 45 participants (20 contacted via one-on-one interviews and 25 via focus groups), Oregon Consensus offers the following recommendations for a collaborative effort to design a more community-driven governance approach to Community Information Exchange.

4.1. Convene a workshop (or other similar conversation format) to decide whether to proceed with collaboration

Most participants expressed hope that collaboration would be valuable and showed a willingness to participate, but that willingness to collaborate was conditioned on a clear focus for collaboration and a shared understanding of what CIE should be. The themes we heard from participants reveal many layers of complexity, from challenges in using the tech-based platforms to the limited capacity of CBOs to fully engage with it. As a result, collaborative negotiations and agreements may be difficult. Important initial steps for a collaborative process include relationship and trust-building, developing a shared understanding of information, and negotiating goals, scope, and process. These elements will support a collaborative workgroup in identifying near- and long-term actions that contribute to developing a governance model for CIE, built by and for the network it aims to serve.

Existing governance structures may need to evolve in the context of a statewide CIE. There may be elements of governance structures already in place (e.g., between CCOs and social service networks; between Unite Us and users; between networks of service providers), but these need to be looked at outside of their current context to see what might be useful, or need adjustment, in a statewide CIE context. During our interviews, it was often difficult to get clear recommendations on that statewide context. Being clear on who makes decisions and how these decisions impact important aspects of CIE, will help shape how to talk about:

- Resource allocation;
- Community involvement; and
- Data standards: accessibility, interoperability, usability, as well as data security and privacy.

Oregon Consensus recommends that something like a one-day workshop could help "test" key questions around shared CIE vision, elements that need to be governed, and whether to proceed with collaboration. Interviews revealed enough differences in opinions on the scope of collaboration and what should be governed, and a shared desire to be meaningfully involved in key CIE decisions, that the decision whether to proceed with collaboration should not rest with one organization. Basically, the decision to convene, design governance, and implement CIE governance each need to look like some version of community-driven decision-making. There are also enough similarities and commitment that a focused conversation could help interested parties decide whether and how to proceed. Some of the questions a workshop could ask, and answer, are presented in Table 4.1.

Table 4.1. Potential convening workshop questions and options from participants

Questions	Options offered by participants
What, if anything, has changed about the vision and commitment to statewide CIE?	- Clarify shifts in goals or priorities based on recent experiences - Reaffirm or revise the statewide vision for CIE governance - Have any of the governance principles from the CIE Workgroup changed (p33): Inclusive, neutral, priorities of individuals and communities drive decisions, representative across social service, health, and government with equal CBO to non-CBO representation, multitiered with an overarching governance group with subgroups on specific topic areas and statewide and regional/local subgroups.
Should Oregon convene a statewide process to design CIE governance?	- All participants said the risk of "no action" was greater than deciding to move forward with some version of statewide CIE governance
Who should convene a collaborative workgroup/table?	- A convenor with subject matter expertise, respect in the community, but no vested interest (e.g., a retired CBO, state, or technology leader) + a facilitator responsible for ensuring shared power and a third-party process - Not OHA, healthcare, or technology vendor - A hub-oriented nonprofit (e.g., 211) - A well-connected community health worker
What are the governance priorities (in near and medium term) for the collaborative workgroup/table?	<u>From Oregon Consensus interviews</u> - Standards: setting agreed upon standards for interoperability, data sharing by vendors who are in the network and how data can and cannot be used. Resources: increasing funding for adequately staffing CBOs to handle the tech-based platform navigation and service delivery. - Data Privacy: address and clarify HIPAA and FERPA compliance[6]

[6] The CIE Workgroup identified types of data where privacy and security were important (p31):

- Identifying: Name, address, contact information, etc.
- Demographic: Age, income, household size, REALD, SOGI*, etc.

	- Data access and sharing: improve patient/client information access, and mechanisms for sharing - Data quality/accuracy: ensure up to date service eligibility and screening, service availability and location information and requirements - Creating a centralized hub to oversee technology platforms and referral systems - Supporting informal networks of coordination organized by geography, service type, or demographic served <u>Coordination and convening priorities from CIE Workgroup (p22)</u> - Alignment of efforts - Governance - A referral coordination center - Best practice sharing - Research and evaluation. <u>Additional data types from CIE Workgroup (p28)</u> - Services searched for and search area - Demographic data (e.g., race, ethnicity, language or disability (REALD)/sexual orientation or gender identity (SOGI) - Referrals made and whether referrals resulted in services being provided or not - Social care record <u>Additional coordinating roles from CBO interview report included in CIE Workgroup report (p150)</u> - Coordinating the activities of partners - Technical assistance and training - Statewide policy and legislation - Education resources - Aggregating statewide data for using in creating policies - Setting up for financial incentives or payment models
How should a governance design collaboration be structured?	- A “coordinating” group of people who are “network” weavers connecting to other hubs of interested parties - Conversations at the tables CBOs, especially culturally-specific CBOs, are already convening - A mechanism for clear leadership from the state (e.g., OHA, Governor’s office, etc.)

• Health: Dietary restrictions due to health conditions, etc.
• Behavioral health: For delivering community services or referring to behavioral health organizations, etc.
• Sensitive: HIV/STI** services, legal services, situations of intimate partner violence, etc." p31

4.2. While it's possible to conduct a statewide, third-party process, strong leadership is still needed

Some recommendations for bringing a collaborative group together that is statewide and impartial to any particular interests include:

- Start by using an impartial process manager and facilitator. Participants recommended a third-party facilitator could help build the trust and relationships needed to start a collaboration.
- The role of the facilitator is to guide the process and manage the conversations. The complexity of content and relationships for statewide CIE points also to the need for a convenor who understands CIE, but is also trusted by interested parties and can help the collaborative group overcome barriers or choose their direction. Subject matter experts can also help a collaborative group with additional information (e.g., generating and analyzing options).
- There are already regional tables convened where service providers coordinate. Build from those spaces by joining existing meetings, and start early building the capacity for local convening and facilitation.

But the third-party facilitation will be the easy part. There is not a clear, consistent direction that is shared by all parties for what Oregon's statewide network of partners in CIE should do, what they should look like, or how they should be governed. That direction will take some leadership that a third-party facilitator can nurture, but cannot provide. Leadership needs to include state government, a critical mass of nonprofit service providers, and a critical mass of healthcare representatives.

It is not uncommon that collaboration around a first set of topics leads to collaboration around future topics, which means who is in leadership roles can evolve.

4.3. Develop a charter for how the collaborative workgroup will operate and make decisions

If a collaborative workgroup is established to lead changes in CIE governance, we recommend creating collaboratively a charter document. This charter should outline the group's operational structure, including decision-making processes, agenda-setting, participant expectations, communication methods within the group and with external interested parties, and procedures for resolving disagreements. This will help ensure transparency, accountability, and effective collaboration as the group works to implement needed changes in CIE governance. As mentioned earlier, each key decision on a pathway to community-driven, statewide CIE governance will likely have to be a mini model of that final governance structure (i.e., even a group charter should be built with a community-driven, statewide approach that is effective, but also efficient with people's time).

4.4. Develop a collaborative process map to follow

A process map is a tool that can help a collaborative move through the stages of process design and organization, deliberation and decision-making, and implementation and adaptation (see Figure 4.4 for an example process map). A complete process map would include timelines and when key information might be available or when decisions might get made. This helps participants with limited capacity plan and make space to participate over time.

Figure 4.4.A. Example collaborative process map

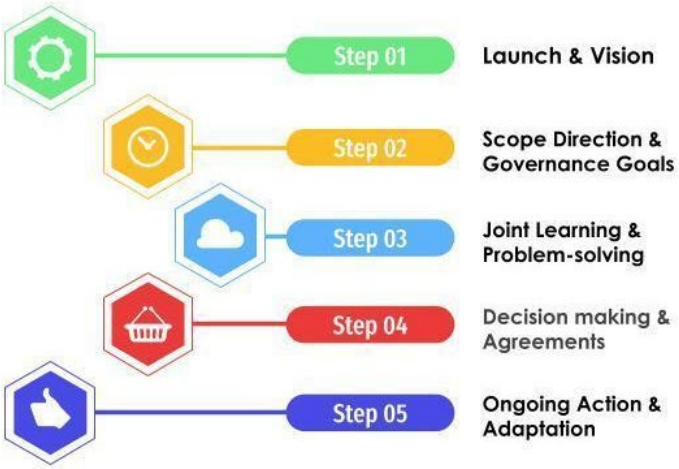
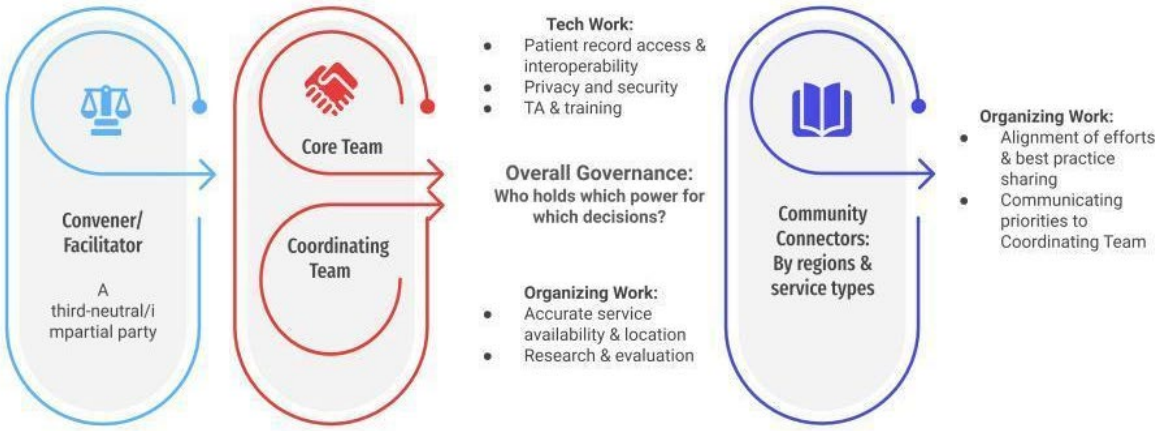


Figure 4.4.B. Example process structure (with a convener, core team of hub organizations, and community connectors helping weave a network)



4.5. Ensure inclusive and equitable participation in the collaborative process

Participants expressed concerns that many smaller, culturally and linguistically specific CBOs have not been included in decision-making processes related to the CIE framework. Some participants also expressed that there is a need to represent the perspectives of the end-users—the community members these organizations serve. To address this, it is likely important to convene not only facilitators but also a core planning team to guide the process and ensure diverse representation in the collaborative effort. The core planning team could be responsible for identifying and inviting the appropriate organizations to participate at the collaborative table, ensuring that all voices are heard and valued.

Participants regularly commented that the people being interviewed did not represent everyone who needed to be involved in a collaborative process. There may be some need for a core, representative group to invite people to the process, set agendas, and work with a third-party facilitator to manage the process.

The planning core team could also be made up of the different kinds of voices represented at the collaborative (e.g., culturally-specific CBOs, nonprofits that are hubs for service providers, healthcare leaders, and state agencies). Beyond any kind of core, or coordinating, team, there needs to be a way to engage the diverse networks that organize by geographic region and/or type of services being provided. A process should:

- Clarify what it means to be an active participant in the collaborative, and what are alternative ways of participating (e.g., one-on-one or formal government-to-government consultation with a Tribe, participation in topic-specific work groups);
- Make it as easy to participate as possible (e.g., locating conversations to meetings where people are gathering, designing meeting agendas on one set of topics so people can attend the meetings relevant to them, or making stipends available for time and travel costs);
- Be efficient with time and allow adequate time for thorough discussion; and
- Establish how the group will communicate regularly with other interested people who want to track the collaborative effort (e.g., the legislature, other service and healthcare providers, or the members of organizations who are participating in the collaborative process).

CBOs expressed the need for funding to cover their time for participation, but funding will not be a substitute for the intense time constraints CBOs face. Oregon Consensus invited 145 people for interviews and focus groups, and reached 45, missing many of the rural, Native-serving, and CBOs serving other than Spanish or English-speaking communities. Many participants recommended engaging with the tables where these CBOs already gather to gain their views on CIE governance.

4.6. Some governance priorities may be in conflict, that's OK, so long as those tensions are recognized and incorporated into the sequence of governance design conversations

Community-driven efforts that prioritize the needs of communities not often engaged in decision-making often require more informal and/or decentralized processes that meet community leaders where they are. Similarly, conversations focused on systems change and transformation need to recognize many of the fundamental harms created by generations of inequity and the root causes of poverty. Conversations around data standards, centralized information, and adapting to a more uniform workflow require some leadership and conversation to settle on the "one answer".

In training for a marathon, runners need both days of working out and days of rest. Runners can't do both on the same day, and too much running leads to injury and too much rest doesn't create the fitness needed for a marathon. The concept of Polarity Thinking[7] let groups hold a paradox like this.

Any collaborative to build CIE governance may need to embrace Polarity Thinking if the collaborative wants to:

- Center the diversity of community voices and modes of interacting & strive toward uniform workflows; and
- Center system changes & define data standards and processes for central information.

Polarity Thinking, also called dilemmas, tensions or paradoxes, are differences between two alternatives that cannot be ignored without serious negative consequence. They are a pair of interdependent alternatives/elements, topics or poles that are ongoing and unsolvable. When the benefits of both alternatives are experienced at the same time, people and organizations thrive. When one side is focused on to the exclusion of the other, people and organizations underperform.

7 https://universityinnovation.org/wiki/Resource:Polarity_Mapping#:~:text=Polarity%20Mapping%2C%20also%20known%20as,organizational%20paradoxes%20that%20may%20arise.

In Oregon Consensus' interviews and focus, participants did frame the tension between governance of A) shared "workflows" which implied more informal and human-to-human collaboration, and B) shared "technology" and "data standards" which implied technology-mediated collaboration as polarities. Both are good, neither can be ignored, and they are difficult to do at the same time.

5. Conclusion

Most of the participants expressed a strong desire to collaborate on statewide CIE to improve and smooth out access to services for Oregon residents who most need the help (e.g., Medicaid-eligible people, and the caregivers who support them).

Oregon Consensus agrees on the need for collaboration long-term given the acuity of the need for services and coordinated care, and the complexity in the systems that provide healthcare and social services. Oregon Consensus agrees that most participants are interested in collaboration. However, Oregon Consensus feels the readiness for collaboration is conditioned on:

- Getting clarity on the scope of CIE governance collaboration, so participants understand why they are collaborating and if they should invest limited capacity in building CIE governance together; and
- Finding some way for a critical mass of CBOs, healthcare, and state agencies to collectively decide to move forward to design CIE governance via a collaborative, community-driven, statewide process.

Oregon Consensus has presented this assessment with over 45 participants from interviews and focus groups, and will leave it to that group to decide if and how to move forward with collaboration.

Appendix A: Assessment participant list

The list below includes only the entities or individuals interviewed (via one on one and focus group interviews) as part of the Oregon Consensus assessment. It does not imply that those named will necessarily be invitees or participants in any future collaborative efforts. Additionally, several entities or individuals with relevant expertise and interests in improving the governance of the Community Information Exchange (CIE) network were not interviewed due to time and budget constraints. Their involvement and input should be considered in any future steps.

211 info
Community and Social Health; Kaiser Permanente
Early Learning Hub - Family Resources & Education Center
Northwest Senior and Disability Services
Oregon Department of Human Services (ODHS)
Oregon Health Leadership Council (OHLC)
Oregon Spinal Cord Injury Network
Project Access Now
Unite Us
Oregon Health Authority
Oregon Health Authority
Oregon Health Authority
Oregon Health Authority
Hood River County Health Department
Reliance eHealth Collaborative
Findhelp
Comagine Health
Bridges for Health
Children's Health Alliance
Oregon Department of Human Services (ODHS)
Oregon Health Equity Alliance (OHEA)
Community Services Network
Nonprofit Association of Oregon
Early Learning Hub, Linn-Benton Community College
Virginia Garcia Memorial Health
Children's Health Alliance
Children's Health Alliance
Head Start of Lane County
Rogue Community Health
Food For Lane County
Advantage Dental from Dentaquest
Mid-Columbia Community Action Council
Mid-Columbia Community Action Council
New Horizon Program
Willamette Education Service District
Boys and Girls Club of Marion and Polk Counties
CareOregon
Children's Health Alliance
Familias en Accion

Oregon Association of Area Agencies on Aging and Disabilities
Greater Oregon Behavioral Health, Inc (GOBHI)
Oregon Wellness Network
Oregon Latino Health Coalition
NorthWest Senior and Disability Services

Appendix B: Interview questions

Background Information
We work for the Oregon Consensus Program (we're the state's policy collaboration and conflict resolution service). And we have been asked to assess collaborative opportunities around a statewide approach to Community Information Exchange (CIE is a network of collaborative partners using technology for the exchange of information to connect people to the services and supports they need. The main functions of CIE are closed loop referrals, a shared resource directory, and consent by the person needing services. There's also data reporting. We know a lot of CIE conversations occurred in 2022 as part of the CIE Workgroup (HB 4150), and we're not going to repeat that work, but we may check to see if some of the findings still hold true for you.

We're excited to chat with you today. Feel free to steer our conversation in any direction you're comfortable with. Just so you know, everything we talk about will be kept confidential; and any quotes would be anonymized meaning we will not include your name with what you say. And after we've talked to everyone, we'll put together a report summarizing what we've learned and share it with all the participants. Can't wait to hear your thoughts and insights!

To provide a brief background: *Oregon's healthcare and social service providers, community-based organizations, and other partners are using technology-based approach/platforms, community information exchanges, or CIE, to better address social needs and access resources, like housing, food, and other services. It's about making it easier for health and social care providers to identify and connect people to social needs services that really matter for people's health.*

One way of thinking about improving how care is coordinated, including both health and social services, is by using a CIE like Connect Oregon (also known as Unite Us) and findhelp (for those in southern Klamath county say "also known as Healthy Klamath Connect"). CIEs are basically networks where various partners use technology to share information, find appropriate resources, make service referrals, and hear back on the outcome of those referrals, aiming to connect people with the services and support they really need.

Any CIE, just like using any technology, requires decisions (e.g., on how to protect privacy, how to exchange money, or how to ensure someone receiving referrals actually receives the services in a way responsive to their culture and needs). The way those decisions are made is what we're calling "governance" for today's conversation.

CIE efforts have been growing across Oregon for the past several years, and today we're hoping to hear about collaborative decision-making, coordination, or governance of this work…
So, to begin our conversation:

Issues, Scope, and Vision for Success

1. Tell me a little bit about your role and how are you connected in this world of social needs referrals among healthcare, social service providers, and other partners?
    - What aspects of the history and past relationship and communication among healthcare and social service providers matter to you before we discuss its current state and future?

- Did you participate in or have awareness of a CIE vendor being selected in your area, how it was rolled out/implemented, and any community rules made about its use?
    - Follow up: If you participated or were aware, what did you like about it and what didn't you like?
    - If not, what would you have wanted to know or how would you have liked to participate?

In 2022, community organizations prioritized the roles they would like a statewide CIE coordinating entity play (see Appendix Handout if needed). These next questions aren't as much about "using" CIE, but about "governing or making decisions" about how a CIE works.

2. For governing CIE, what decision-making processes need to be clarified now?
   Some examples of governance:
    - Ensuring community-based organizations have a voice in decision-making as CIE grows.
    - Supporting linguistic and cultural needs in use of CIE.
    - Ensuring systems and practices keeping information private to build trust.
    - Maintaining commitment from funders and service providers for solid partnerships.
    - Streamlining contracting around how to use CIE.
    - Promoting consistent use of technology for better referral coordination and information sharing.
    - Improving access to services that support all aspects of well-being, not just medical needs.

3. How could adopting a more collaborative approach to governing, not just using, CIE statewide benefit your organization and the communities you serve? Why?
    - Would you be interested in playing a role in CIE decision-making processes or governance of CIE? Why or why not?
    - How important is it for you to focus on CIE governance given your other work priorities?

4. What are the three to five major challenges you foresee in creating the ideal governance you described? Why?

People and Relationships

5. Collaborative governance does mean sharing power in decision-making. Where do you see the best opportunities to share decision-making power?
    - Are there decisions where you feel funders (health care) need to have the final say after input from community partners? If so, what are they?
    - What barriers do you see to collaboration across sectors like health care, government, social services, community-based providers, and other partners? How can these be addressed?

6. OK, we've discussed governance needs and the related strengths and challenges, but do you think a "collaborative process" is essential to address these issues?
    - If yes, who needs to be at the table to resolve this issue (CBOs, CCOs), health care, behavioral health, county government, policymakers, public, private, Tribes, civic partners)?

- What kinds of resources would these groups need to be most effective as participants?
- How do you meaningfully engage these groups in the process?
- Imagine the first 6-12 months of a collaborative group–what could they focus on that would be most immediately helpful?

Process, Resources, and Additional Information

7. Have you come across any successful collaborative decision-making approaches we could draw lessons from? Are there examples where efforts fell short and could be improved?

8. What are the potential risks if collaborative governance of CIE doesn't take place? What are the benefits—or drawbacks—of a collaborative decision-making process for CIE efforts, and why?
    - Reality check here… Do people really have the capacity to collaborate on statewide governance? Is this valuable enough that capacity needs to be supported somehow? If there is strong interest, what would we need to do to set up collaboration for success (e.g., information, focused scope, funding for participation)?

Closing

Who else do you think we should speak with? We're interested in connecting with individuals or organizations committed to advancing social justice, diversity, and equity. Is there anything else you'd like to mention that we haven't covered? Do you have any questions for us?

Appendix C (CIE Workgroup report charts, 2022)

The following charts are from the House Bill 4150 (2022) Final Report: Supporting Statewide Community Information Exchange, and were generated by conversations with community organizations on statewide coordination of CIE and challenges using CIE.

Figure C.1. CIE coordinating roles (p150)

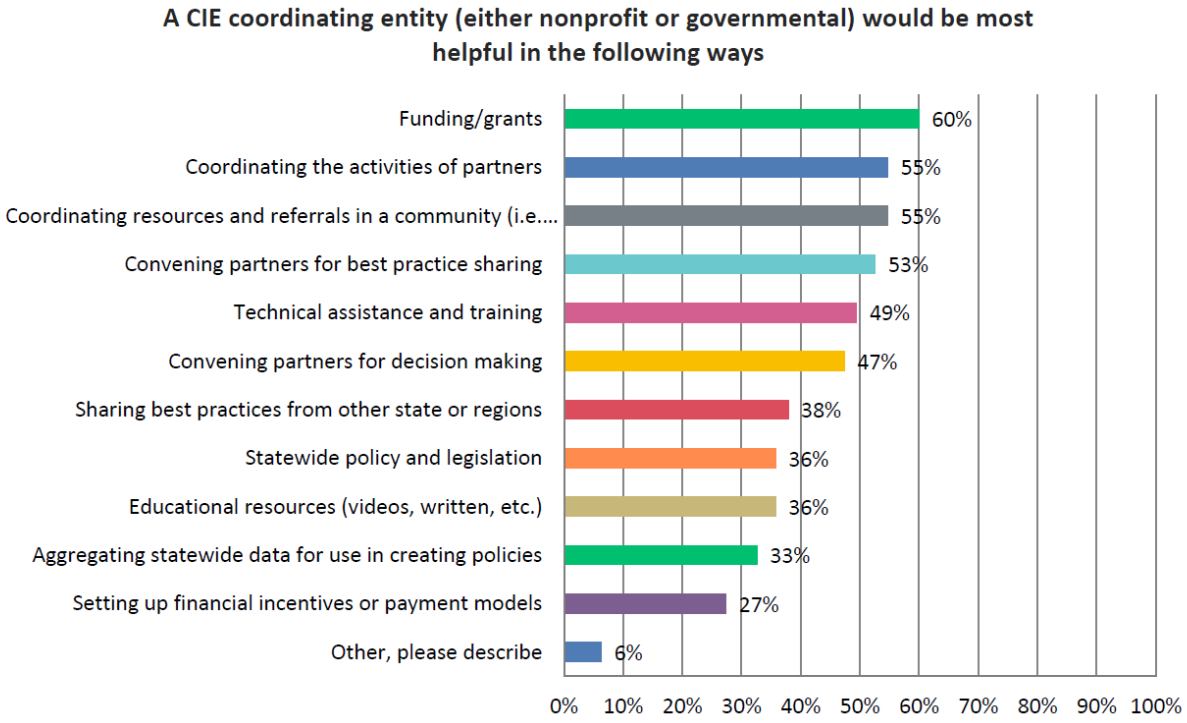
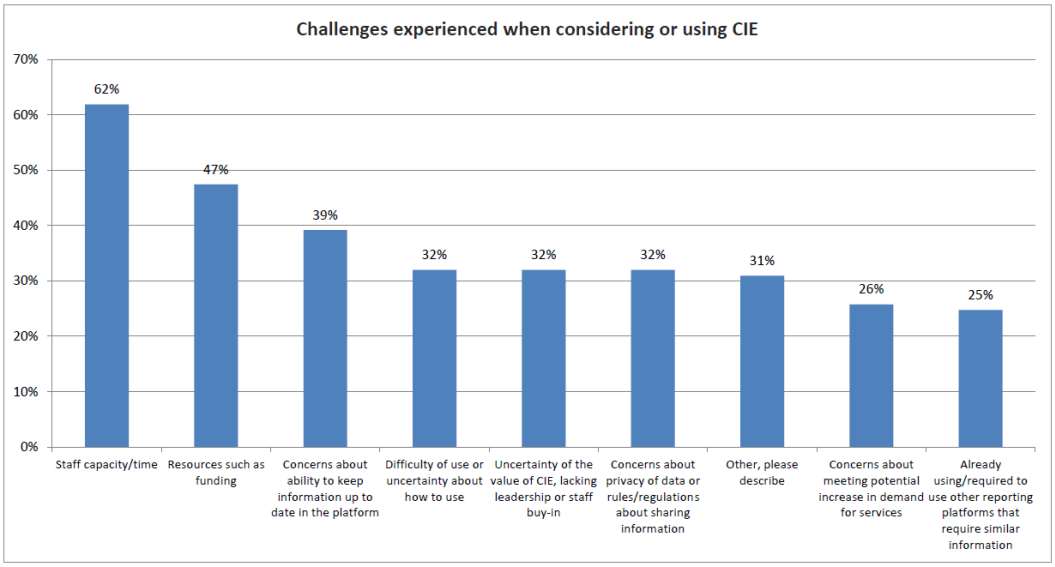


Figure C.2. Challenges for CBOs using CIE in 2022 (p126)



Answers with less than 10% of responses include: Language access (e.g., platform or resources are not available in my primary language), 9%; Leadership or staff discomfort with using technology, 9%; Lack technology needed (e.g., computers, reliable internet), 5%.