

House Bill 4150 Final Report:

Supporting Statewide Community Information Exchange

Health Information Technology Oversight Council

January 30, 2023



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Accessibility and Questions

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¹ See [Appendix A: CIE Workgroup Members](#)

Executive Summary

To fulfill the requirements of House Bill (HB) 4150 (2022) the Health Information Technology Oversight Council (HITOC) chartered a Community Information Exchange (CIE) Workgroup, sought input from community-based organizations (CBOs) on CIE, and provided recommendations on strategies to build on current CIE networks to accelerate, support, and improve secure, statewide CIE. CBOs are critical to the success of CIE and it is important to elevate their input. The September 2022 draft report to the legislature, and this January 2023 final report reflect the work of the CIE Workgroup, CBO perspectives, and HITOC comment. **To ensure CIE efforts reach the ultimate goal of supporting health equity, this report details actionable steps to support health equity throughout each recommendation.**

Value of CIE in supporting health equity and efficiency

To further health equity and the long-term vision of systemic change, it is critical to better coordinate health care and social services to connect people to the services and supports they need.

When organizations use CIE, people get efficiently connected to resources they need, like food, housing, or transportation; to tell their story fewer times, reducing re-traumatization; and a person-centered approach to meeting their needs.

Organizations benefit from CIE by improving care coordination across a variety of health and social service partners by sharing available resources, sending referrals, and “closing the loop” on referrals through a web-based tool.

Decision-makers, such as communities, organizations, health care, and policy makers can use data on existing community resources to understand needs, identify gaps, and **plan for future social services and supports**.

CIE efforts are underway to help tackle these issues. However, these potential benefits require substantial investment as well as widespread and consistent CIE use for success.

CIE Definition

A network of collaborative partners using a multidirectional technology platform to connect people to the services and supports 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.

Recommendations to the legislature

Overarching priorities: The CIE Workgroup, CBO input, and HITOC aligned on several priorities:

1. **CIE requires investment in systems change, as well as building trust and relationships:** Sustainable investment is essential to achieve the intended value of CIE.
2. **Support for CBOs is paramount:** CBOs are a priority partner for the success of CIE. CBOs must be supported in these efforts and at the table in decision making.
3. **Equity, accessibility, and person-centered:** Ensuring health equity across CIE efforts necessitates prioritizing culturally and linguistically specific organizations. CIE needs to be

person-centered and directed, and adequately address literacy, language, and digital access needs.

4. **Governance and alignment:** Inclusive and neutral statewide governance is needed.
5. **Privacy and accountability:** Privacy and security of data must be prioritized.

Community perspectives: CBOs are critical to the success of CIE and were actively engaged to inform this report. The following recommendations are summarized from surveys and interviews with **99** CBOs:

1. Offer **robust funding** to support CBO use of CIE
2. Promote **equity**, accessibility, and accountability
3. Advance **privacy**, data protections
4. Provide **technical assistance**, training, and education
5. Create a **statewide coordinating entity** to promote alignment across organizations, sectors, and systems
6. Prioritize **relationships**, communication, and engagement
7. **Align CIE efforts** with other systems level efforts that are crucial to ensuring health equity

CIE Workgroup recommendations: HITOC supports five recommendations from the CIE Workgroup, is neutral on one*, and notes the significant alignment with the CBO community recommendations. **The CIE Workgroup recommends that legislation support:**

1. **CBO participation in CIE:** Support should include ongoing sustainable funding and grants, technical assistance, coordination and convening, and education.
2. **Additional partners to participate in CIE:** Additional partners will need the same supports as CBOs and could include behavioral, oral, and physical health organizations, local public health or county social services, safety net clinics, and others.
3. **Oregon Health Authority (OHA) and Oregon Department of Human Services (ODHS) roles in statewide CIE efforts:** These should include OHA and ODHS program use of CIE where appropriate, supporting neutral statewide governance, leveraging policy and contractual levers, supporting CBOs' and additional partners' participation in CIE, and supporting and participating in coordination.
4. **A statewide CIE data program:** This should include data governance, aggregation of data, datasets, technical assistance, dashboards and reports, and evaluation. The program should be guided by principles that center equity, transparency, neutrality, accessibility, accountability, security, and community/individual data ownership and decision-making.
5. **Considerations for privacy and security:** This should be guided by principles that center community/individual decision-making around their information, adherence to applicable privacy and security laws and national standards, equity, transparency, and inclusivity.
6. ***Governance of statewide CIE:** This must be inclusive and neutral, with the priorities of individuals and communities driving decisions. Governance should include representation across sectors and have a multitiered structure.

Next steps: The recommendations were strongly aligned to move statewide CIE efforts forward in support of health equity and improved service coordination. The critical next steps to accomplish this are **financial investment** for participants, particularly CBOs, and **statewide governance**.

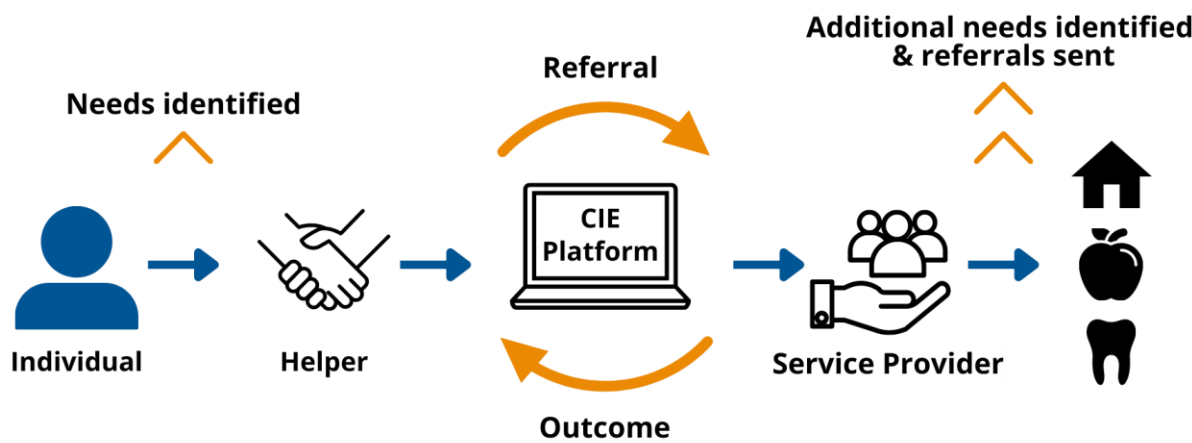
Background and Methodology

House Bill (HB) 4150 (2022)² directs the Health Information Technology Oversight Council (HITOC)³ to convene one or more groups to explore strategies to build on current CIE networks to accelerate, support, and improve secure, statewide community information exchange (CIE) and provide recommendations to the legislature in a draft report⁴ by September 15, 2022, and a final report by January 31, 2023. To fulfill these requirements, the Oregon Health Authority (OHA) engaged a health equity consultant to conduct interviews and a survey with community-based organizations (CBOs), and HITOC chartered a CIE Workgroup⁵ and a Health Information Exchange (HIE) Workgroup.⁶ Recommendations and considerations are detailed in the sections below.⁷

What is community information exchange?

The CIE Workgroup defined CIE as a network of collaborative partners using a multidirectional technology platform to connect people to the services and supports 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.



Simply put, a person seeking help is referred to services they need through the CIE platform, which documents information about their needs as well as their consent to share their information. The organization helping them can search for appropriate resources in the CIE and send a referral to another organization. This receiving organization indicates if they were able to provide the services, so the referring organization sees what happened with the referral, a process known as “closing the loop”.

² HB 4150: <https://olis.oregonlegislature.gov/liz/2022R1/Downloads/MeasureDocument/HB4150/Enrolled>

³ HITOC: <https://www.oregon.gov/oha/HPA/OHIT-HITOC/Pages/index.aspx>

⁴ House Bill 4150 Draft Report: Supporting Statewide Community Information Exchange: <https://www.oregon.gov/oha/HPA/OHIT-HITOC/Documents/HB4150DraftReport.SupportingStatewideCIE.pdf>

⁵ CIE Workgroup: <https://www.oregon.gov/oha/HPA/OHIT-HITOC/Pages/CIEworkgroup.aspx>

⁶ HIE Workgroup: <https://www.oregon.gov/oha/HPA/OHIT-HITOC/Pages/HIEworkgroup.aspx>

⁷ See sections: [Summary of Recommendations to the Legislature](#) and [Recommendations to the Legislature by Topic](#)

The tools provided in CIEs allow for efficient and person-centered care, those include:

- **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.

CIE enables a broad variety of service providers to connect easily and quickly to organizations across the health and social service spectrum. This increased connection between all types of organizations supports addressing health inequities and improving the overall well-being of individuals. When widely adopted in communities, CIE helps eliminate many of the barriers between people and the services designed to support them.⁸

Example CIE Scenario

In the aftermath of a wildfire people become displaced, fleeing or losing their homes. Many needs arise, such as housing, food, clothing, and medical care. With consent, a caseworker can coordinate by using CIE to search and refer a person to multiple services, and then track which needs were met and if additional referrals are needed.

Oregon CIE Landscape: December 2022

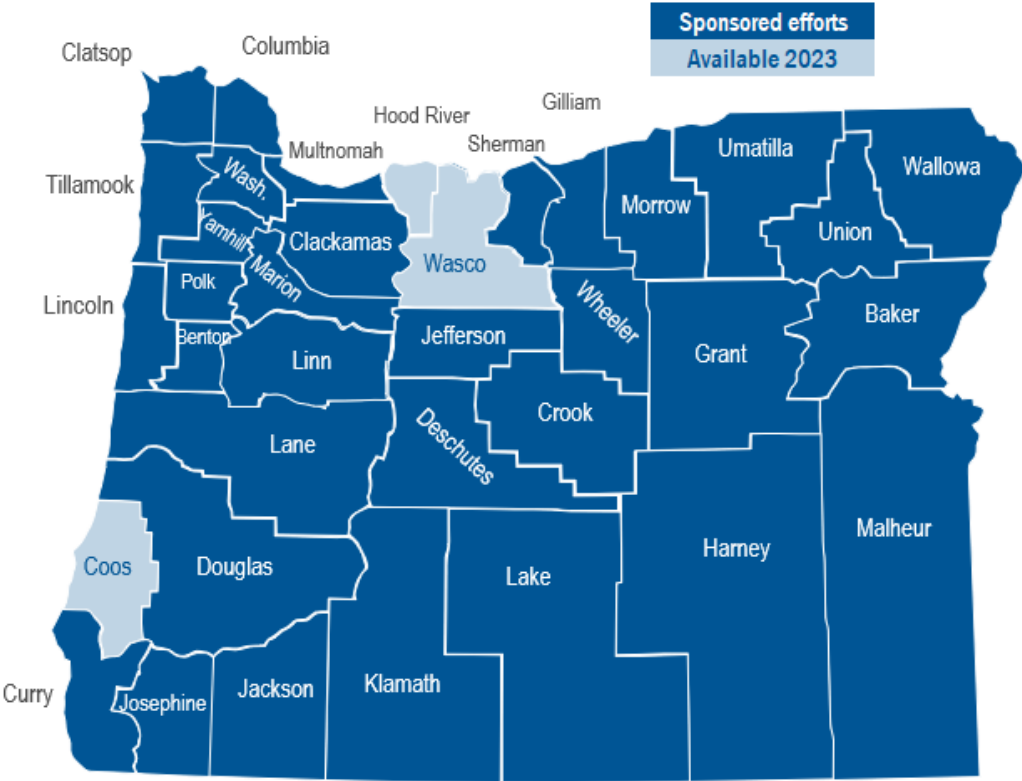
CIE efforts are developing across Oregon, largely sponsored by Medicaid coordinated care organizations (CCOs), health systems, and health plans. CIE networks have taken root in some communities and are expanding across the state. Community partners, including CBOs, clinics, local public health departments (LPHAs), and others participate in these efforts throughout the state. At this time, while OHA and ODHS are not using CIE, ODHS' Office of Resilience and Emergency Management is in the process of evaluating how CIE could fit into department operations. There are two main CIE efforts in Oregon — Connect Oregon (powered by Unite Us) and findhelp (formerly Aunt Bertha, known locally as Healthy Klamath Connect). The recommendations in this report are intended to build on existing CIE networks, identify gaps, and develop state-level strategies.

See the next page availability of sponsored CIE efforts in Oregon as of December 2022.

⁸ For more information see OHA CIE Overview Website: <https://www.oregon.gov/oha/HPA/OHIT/Pages/CIE-Overview.aspx>

Oregon CIE Maps: Status of sponsored efforts as of December 2022

Connect Oregon (powered by Unite Us)



findhelp (formerly Aunt Bertha)



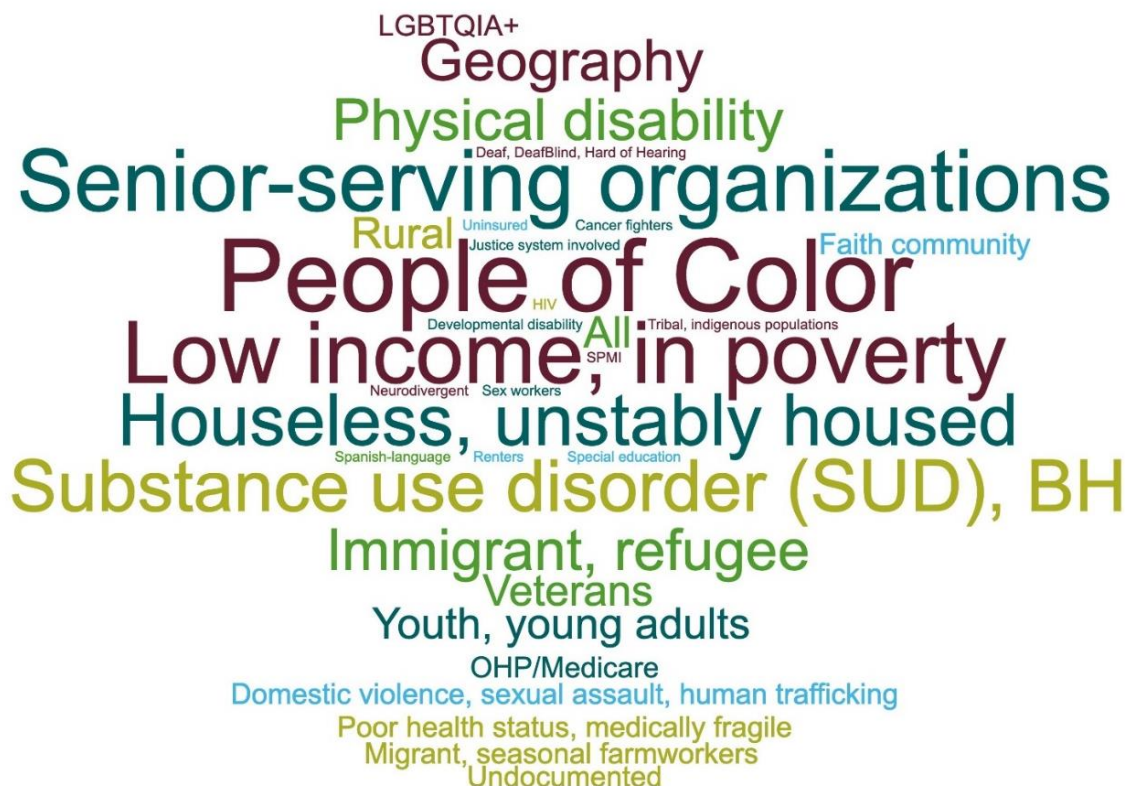
Community perspectives: CBO engagement methodology

CBOs provide many needed services and supports to communities throughout Oregon and thus are critical to the success of CIE. Their knowledge of how best to address people's needs is vital to supporting the overall health and well-being of those living in Oregon.

In addition to CBO membership on the CIE Workgroup, OHA, HITOC, and the CIE Workgroup determined that further CBO perspectives and experiences were paramount to informing the recommendations in this report.

Health equity consultants from the Collective Health Strategies team, on behalf of OHA, engaged 99 CBOs statewide between May and July 2022 through in-depth interviews and an online survey. The aims were to understand CBO views and experiences with CIE and solicit input to inform the CIE Workgroup and HITOC's discussions, and the legislative recommendations. Twenty interviews and 97 survey responses were collected and analyzed to inform the HB 4150 legislative reports and the CIE Workgroup's legislative recommendations. Respondents represented a broad set of CBO sizes, populations served, experience with CIE, and covered organizations in every county in Oregon.⁹

The graphic below represents populations served by CBOs as described by survey respondents (font size indicates proportion of CBOs serving a specific population):



⁹ See section: [Community perspectives: Summary of CBO recommendations](#). See [Appendix I: CIE: Community Engagement Findings and Recommendations](#) for full report, which includes a description of the survey respondents and interviewees.

HITOC

To ensure that health system transformation efforts are supported by health information technology (IT), the Oregon legislature created HITOC. HITOC brings together partners across Oregon for centralized policy work, strategic planning, oversight of health IT efforts and landscape/policy assessment so health IT efforts are more coordinated. HITOC is currently comprised of 16 members appointed by the Oregon Health Policy Board.¹⁰ HITOC members represent a broad range of organizations that are impacted by the Oregon Health IT Program, including consumer/patient advocates, providers, hospitals, health plans, CCOs, Tribes, oral health providers, behavioral health providers, and CBOs. HITOC members represent organizations that use a wide array of health IT tools and systems and HITOC strives to represent the diversity of people living in Oregon. Technology vendors are not eligible to serve on HITOC.

HITOC recognizes the value of both CIE and HIE for addressing social determinants of health, coordinating care across a variety of clinical and non-clinical partners, and streamlining access to health and non-clinical services (e.g., social services and supports). Improved care coordination and data sharing is also a core underpinning of value-based payment models, which are central to Oregon's health system transformation and health care cost containment efforts.

HB 4150 directs HITOC to convene one or more groups to provide recommendations on strategies to accelerate, support, and improve statewide CIE in Oregon and evaluate whether legislative or policy changes are needed to drive statewide participation in CIE. Although HB 4150 focuses on CIE, the subsection referring to legislative recommendations includes both CIE and HIE.¹¹ HITOC chartered a CIE Workgroup and an HIE Workgroup to meet the requirements in HB 4150 as well as to develop strategies for the HITOC's updated Oregon Strategic Plan for Health IT. The HIE Workgroup began meeting monthly in May 2022 and continues developing concepts. At this time, HITOC does not have any HIE recommendations for the legislature to consider and therefore this report focuses on CIE recommendations.

HITOC's charter for the CIE Workgroup noted that today CIE efforts are developing across Oregon to address these issues.¹² Given the rapid development there is considerable risk of confusion, duplication, inefficiencies, and reinforcement of systemic inequities. HITOC charged

HIE Definition

Health Information Exchange (HIE) refers to the electronic transfer of health-related information between two or more distinct health IT systems. Discussions of HIE typically include the concept of interoperability, which is the ability for a distinct health IT system to communicate and exchange data meaningfully to other systems without significant human intervention.

¹⁰ See [Appendix B: HITOC Members](#)

¹¹ HB 4150, Section 1 (3) (h): <https://olis.oregonlegislature.gov/liz/2022R1/Downloads/MeasureDocument/HB4150/Enrolled>

¹² For more information see CIE Issue Brief: <https://www.oregon.gov/oha/HPA/OHIT-HITOC/Documents/HITOC-CIEIssueBrief.pdf>

the CIE Workgroup to explore strategic direction related to CIE, mitigate risks, and identify opportunities that may arise quickly for statewide coordination.

HITOC reviewed and commented on the CIE Workgroup's recommendations and considerations at its August and December 2022 meetings, and HITOC's feedback is included in the overall and specific recommendations sections in this report.

CIE Workgroup

The CIE Workgroup was tasked by HITOC under HB 4150 with providing recommendations on strategies to accelerate, support, and improve statewide CIE in Oregon. HITOC also prioritized engaging CBOs in addition to those on the CIE Workgroup to further inform the process and provide input to HITOC and the CIE Workgroup's discussions and recommendations. These efforts advance OHA's goal of eliminating health inequities by 2030 and creating a more equitable, culturally, and linguistically responsive health care system.

HITOC's charter for the CIE Workgroup¹³ notes the opportunity to build off existing CIE efforts across the state and emphasized the need to develop state-level strategies. HB 4150 and HITOC tasked the CIE Workgroup with identifying the following:

- A shared strategic vision and common goals, leading with health equity
- Whether legislative or policy changes are needed to support the CIE goals, and in turn how learnings from CIE can support policy changes
- How community voices can be centered
- How to overcome barriers to participation in CIE, particularly for CBOs serving culturally and linguistically specific populations
- Whether statewide governance is needed and explore statewide strategies
- How to apply data equity principles to CIE related to access, analysis, and interpretation of aggregated data
- In what ways OHA and Oregon Department of Human Services (ODHS) may play a role in CIE

CIE Workgroup operations

The CIE Workgroup was comprised of 16 members and two HITOC liaisons representing diverse professional experiences as well as lived and cross-cultural experience. It included representation from all regions of Oregon and across Oregon's diverse health care, social services, and community landscape.¹⁴ Members shared lived experiences identifying as Black, Latinx, person of color, and LGBTQIA2S+. Some members also shared experiences such as being raised in poverty and using public assistance programs. Members' experience included

¹³ CIE Workgroup Charter: <https://www.oregon.gov/oha/HPA/OHIT-HITOC/Documents/HITOC-CIEWorkgroupCharter.pdf>

¹⁴ See [Appendix A: CIE Workgroup Members](#)

working with populations experiencing inequities as well as experience using different CIE technology platforms, and some members do not currently use CIE.

Operating as an advisory group rather than a decision-making body, this group was not tasked with the details of CIE implementation, creating technical solutions, identifying funding streams, nor identifying a vendor. The CIE Workgroup and OHA are vendor neutral.

The CIE Workgroup met monthly March through November 2022 to discuss CIE strategies and develop recommendations and considerations for this legislative report. Workgroup meetings included virtual whiteboard exercises, breakout small group discussions, full group discussions, polling, and receipt of public comment.¹⁵ Work outside of meetings included email communication, reading materials, and Workgroup member surveys. Six concept papers¹⁶ were developed as a result of these exercises and discussions and were delivered to HITOC in August and December 2022 to inform the draft and final reports to the legislature. The Workgroup has completed the work required under HB 4150 and the Workgroup charter and has concluded their meetings.

Vision, Equity, and Value

Vision for CIE

The CIE Workgroup developed this vision for statewide CIE:

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 siloes to achieve health equity**.

How CIE supports health equity

A critical component of achieving health equity is addressing people's basic needs such as sufficient food and safe housing. Food and housing insecurity are examples of social factors that can contribute to poor health outcomes. OHA seeks to eliminate health inequities by 2030 and to create a more equitable culturally and linguistically responsive health care system, including through the Oregon 2022-2027 1115 Medicaid Demonstration waiver.¹⁷

Research has shown that what improves health is largely what happens outside of a medical setting. The typical separation of the health care system from the social services system has created barriers to accessing care, information, services, and resources. It also makes it difficult to coordinate based on a person's needs. These barriers contribute to poor health outcomes and exacerbate health inequities.

¹⁵ CIE Workgroup Public Comment March-November 2022: https://www.oregon.gov/oha/HPA/OHIT-HITOC/CIE%20WG%20Meeting%20Docs/20221115_CIEWG_PublicComment_MarNov2022.pdf

¹⁶ See [Appendix C through H for Full CIE Workgroup Recommendations](#)

¹⁷ For more on Oregon's 1115 Medicaid Waiver: <https://www.oregon.gov/oha/hsd/medicaid-policy/pages/waiver-renewal.aspx>

OHA and the Oregon Health Policy Board's Health Equity Definition

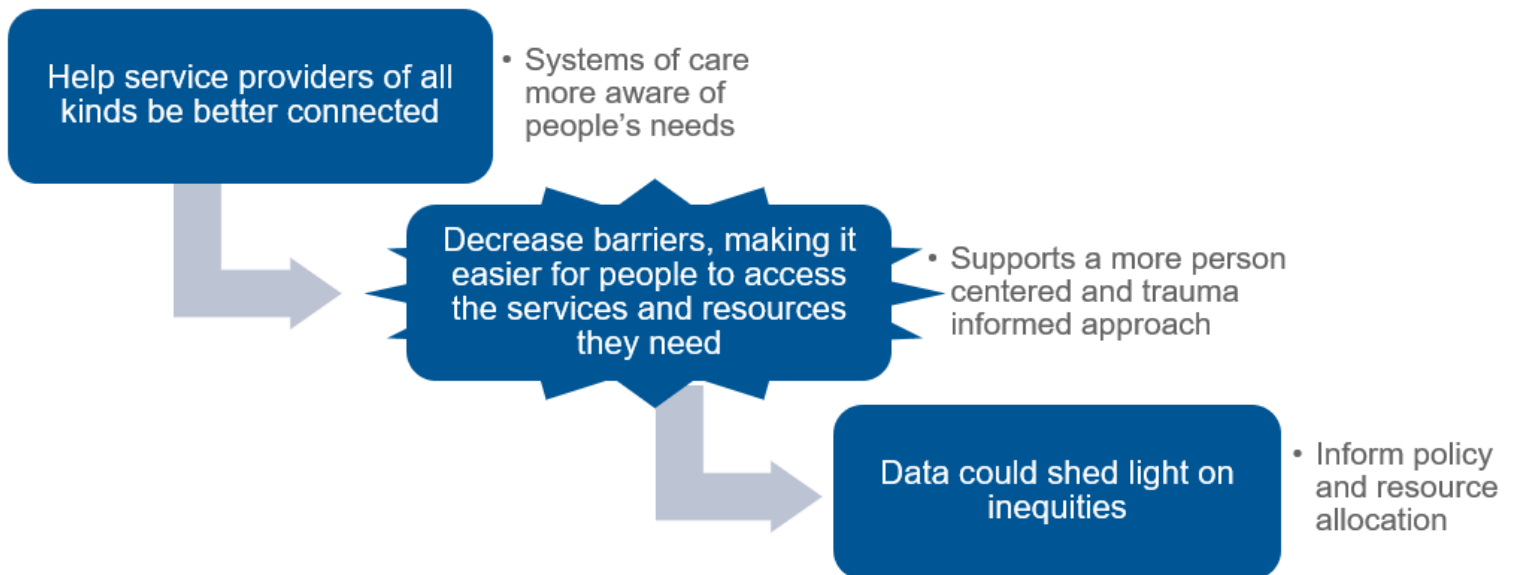
Oregon will have established a health system that creates health equity when all people can reach their full health potential and well-being and are not disadvantaged by their race, ethnicity, language, disability, age, gender, gender identity, sexual orientation, social class, intersections among these communities or identities, or other socially determined circumstances.

Achieving health equity requires the ongoing collaboration of all regions and sectors of the state, including tribal governments to address:

- The equitable distribution or redistribution of resources and power; and
- Recognizing, reconciling and rectifying historical and contemporary injustices.

Statewide CIE networks are foundational elements to building a more equitable system in Oregon. Connecting health care and social services sectors across Oregon supports meaningful efforts to address social determinants of health (SDOH) in communities impacted by historical and contemporary structural disparities. When people's needs are met, such as housing, food, and transportation, health outcomes improve. CIE enables healthcare and social service organizations to coordinate more efficiently to address these needs and can help address health equity at multiple levels in Oregon. CIE networks have taken root in some communities and are expanding across the state to address these issues.

The CIE Workgroup identified the following ways CIE supports health equity:



Value of CIE

Most CBOs interviewed or surveyed for this report agreed that having easier access to resources and information is a huge benefit of CIE. This is especially important for those in more isolated or underserved areas. It gives CBOs the ability to connect within and beyond their local area, forge stronger connections, and access resources in other parts of the state,

including building pathways to culturally and linguistically specific CBOs. Connecting people to services and the health and social care system would promote health equity.

Additional benefits of CIE include the following:

When organizations use CIE, people get...

- Efficiently connected to resources they need, like food, housing, or transportation
- Services in their preferred language and that meet their cultural needs, which improves their overall health and well-being
- To tell their story fewer times, reducing re-traumatization
- A person-centered approach to meeting their needs

Organizations benefit from CIE by...

- Simplifying how they connect people with social services and supports that meet their needs
- Improving patient care and health, increasing provider satisfaction, and leveraging data to focus on patient outcomes and reduce costs
- Improving care coordination across a variety of health and social service partners by sharing available resources, sending referrals, and “closing the loop” on referrals through a web-based tool

Decision-makers, such as communities, organizations, health care, and policy makers can use CIE data on existing community resources to...

- Understand needs, identify gaps, and plan for future social services and supports
- Advocate for and drive policy change and investment in future social services and supports

Community-based organizations, peer-run organizations like ours, we are, you know, feet on the ground organizations, we're grassroots, and I think this tool to be able to reach out, because we're always underfunded, we're always understaffed, you know, and this cuts down on hours and hours and hours of time that we would be on the phone, we have to do one referral, we can send it out, we can make notes, we can talk back and forth with other people, we only have one consent form, you know, all these things have made it a lot easier for us to operate, made it to where we can spend more time with our feet on the ground. – Interviewee

I know the CCOs have their flexible funds that they're required to use, maybe having the information that comes from the CIE kind of analysis of what's working, what's not working, and have that inform how they use their flex funds and how they invest those funds. – Interviewee

Summary of Recommendations to the Legislature

Overarching priorities and principles for CIE

To ensure CIE efforts reach the ultimate goal of supporting health equity, this report details actionable steps to support health equity throughout each recommendation. In addition, these recommendations seek to build on and improve current CIE networks. The CIE

Workgroup, CBO community engagement input, and HITOC aligned around several priorities that were cross-cutting:

1. CIE requires investment in systems change, as well as building trust and

relationships. Sustainable investment is essential to achieve the intended value of CIE. These efforts are an investment, over time, in systems change and connecting siloes.

- Many CBOs recognize that building strong relationships, with other CIE users and people served alike, will be key to successful statewide CIE.
- Address historical mistrust of government and healthcare systems through listening, understanding concerns, and providing clear and accurate communications from trusted voices.

No matter how complicated or sophisticated or fancy that system is, the platform is, it's always going to depend on relationships.
– Interviewee

2. Support for CBOs is paramount: CBOs are the priority partner for the success of CIE. CBOs must be supported in these efforts and leaders in decision making. In particular:

- CBOs need robust funding, training, technical assistance, and education to initiate and use CIE. Support should acknowledge and address the significant staff and technological capacity needed to engage in CIE efforts.

If you wanted to really open the doors, and really have it be a successful system, we would need a much more increased capacity, which would just be staff costs, and all the other things associated with that, including infrastructure money. – Interviewee

3. CIE should promote equity and accessibility, and be person-centered

- Many CBO respondents believe CIE could promote equity by getting more services to more people most impacted by health inequities. CIE needs to be person-centered and directed, and adequately address literacy, language, and digital access needs.
- Ensuring CIE efforts support health equity necessitates:
 - Prioritizing culturally and linguistically specific organizations in funding, technical assistance, and other supports
 - Equitable access to CIE technology
 - Leading with community, individuals impacted, and CBOs in decision making through neutral inclusive governance
 - Development of a data equity framework

I think it would make it more seamless for the community and let them know that even though we as an organization can't serve them, we have the tools and the partners in the community to make sure that they're served in the capacity that they need.
– Interviewee

4. Inclusive and neutral statewide governance is the next step and must be responsive to CBO and community needs.

- A neutral third-party or public/private partnership should lead governance and promote alignment across systems and sectors.
- Governance should be representative of the individuals, communities, and organizations participating in and impacted by CIE efforts. Their priorities should drive discussions and decisions around CIE.
- Engaging CBOs and communities in decision-making processes is crucial to the success of CIE and to advancing health equity.

My understanding is that CIE...has been driven by major stakeholders in the health sector...and not been fully informed by the other half of the users, which is community-based organizations or people or organizations that are being referred those clients. – Interviewee

5. Privacy and security of data must be prioritized; as must transparency and accountability about data.

- Decisions around data collection, storage, sharing, and use should be led by individuals and communities whose information will be shared in CIE. This transparency and accountability are also essential to building trust.
- Analysis of interviews and survey responses showed that the more CBOs are engaged with CIE, the fewer data privacy concerns they have. However, for the success of CIE it is important that privacy and data concerns of CBOs and individuals are addressed, particularly around access to sensitive information.

Next steps

The critical next steps to accelerate, support, and improve statewide CIE are **financial investment** to support participants, particularly CBOs, then OHA/ODHS, as well as additional partners, and **statewide governance**.

Potential risks and other considerations

The CBO community engagement, CIE Workgroup, and HITOC identified potential risks to be mitigated and other considerations, including:

There's still a lot of reservation among CBOs...with the CIE when there isn't funding that comes with it. But because it's, we see it as increasing demand without increasing supply. – Interviewee

- CIE is a large investment in systems change that will take time and sufficient funding to see the intended value. Widespread and consistent use is needed for success.
- There are not enough services and resources to meet people's needs currently. The social services system is fragmented and historically underfunded. Although CIE may help bridge this fragmentation, CBOs and the CIE

Workgroup recommend increasing overall services and resources alongside CIE to mitigate this risk. 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.

- CBOs are the priority partner for CIE but are already beyond capacity. Avoid placing additional burdens on them or provide appropriate support to offset demands on staff capacity and support potentially increased referrals.
- It is important to consider technology needs and opportunities to streamline existing software and tools where possible to avoid duplicative reporting and reduce staff burden.
- OHA and ODHS are critical participants and partners but need sufficient time and resources for analysis and preparation. However, there are also concerns about bureaucratic processes slowing down the progress of CIE.
- 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.

CBOs across the state, we're just yeah, we're all worn really thin. And so asking us to do anything else is like, Oh, no. So whatever support y'all can provide, would be a leading selling point.
– Interviewee

Community perspectives: Summary of CBO recommendations

The following summary is a result of the in-depth interviews and survey conducted with CBOs to better understand their views and experiences with CIE and solicit input into recommendations.

Findings:

Most respondents were supportive of the overall vision of CIE and its potential to improve health equity, and could clearly see the benefits of connecting more people to services through CIE. Yet respondents also had concerns about successful implementation of robust, statewide CIE. The greatest concerns were:

- Staff capacity/time
- The need for widespread, consistent use
- Having to use multiple data systems that don't integrate
- Language/digital access
- Attending to an increased volume of referrals (which could overwhelm the capacity of the current social services system).

I think the CIE needs to be more than just culturally and linguistically responsive but it also needs to be responsive to each community it is working within. That means being a part of the community, listening to the community. We have not seen that [from CIE]. It feels like something that is being pushed on organizations without capacity, interest or some who have specific requests that are not being met. – Survey respondent

CBOs that were more engaged with CIE were more enthusiastic about CIE and had fewer concerns. Those not using or familiar with CIE had less understanding of CIE but were optimistic about its potential to coordinate services for individuals they serve. Many CBOs

recognize that building strong relationships, with other CIE users and clients alike, will be key to a successful statewide CIE effort.

Recommendations: The following recommendations emerged from the CBO community engagement:

1. **Offer robust funding to support CBO use of CIE:** To address CBO concerns, promote health equity, and ensure successful CIE implementation, CBOs should be offered robust funding to initiate and use CIE.
2. **Promote equity, accessibility, and accountability:** There is widespread agreement that culturally and linguistically specific organizations are an important part of a robust CIE network and investments should prioritize these CBOs in a manner that does not increase burden. Also, language access, literacy, and digital access need to be prioritized to ensure health equity.

There's also making sure that like, the information that we provide is accessible for our community, some of our community members have reading levels that aren't beyond like, fifth grade.

– Interviewee
3. **Advance privacy, data protections:** Investigate data use protections and address concerns about privacy of data collection and use by clearly communicating about data privacy features in specific CIE technology, data justice principles, and consumer protections.
4. **Provide technical assistance, training, and education:** CBOs should also be offered technical assistance, training, and education that is ongoing, easy to access, and responsive to their needs.
5. **Create a statewide coordinating entity to promote alignment across organizations, sectors, and systems:** CBOs support the creation of a neutral, third-party, statewide coordinating entity that is community-led to promote alignment across organizations, sectors, and systems.
6. **Prioritize relationships, communication, and engagement:** Relationship building and communication among partners across the system will lead to greater engagement and increased use of CIE overall.
7. **Align CIE efforts with other system level efforts that are crucial to ensuring health equity:** CBOs think implementing CIE in an under-resourced health and social care system will be difficult if the broader need for more services is not also addressed. They felt that CIE efforts should avoid or remove duplication with existing databases or systems and note that behavioral health providers should be included in statewide CIE.

Specific themes from the CBO community engagement are included with each recommendation topic later in this report. ***The full report of survey and interview responses is also available in the Appendix.***¹⁸

¹⁸ See [Appendix I: CIE: Community Engagement Findings and Recommendations](#)

Summary of CIE Workgroup recommendations

The CIE Workgroup recommends that legislation support:

1. CBO participation in CIE

- Support should include ongoing sustainable funding and grants, technical assistance, coordination and convening, and education.

2. Additional partners to participate in CIE

- Support should include sustainable funding, grants, and offsetting costs; technical assistance; coordination and convening; and education.

3. OHA and ODHS roles in statewide CIE efforts

- These should include OHA and ODHS program use of CIE where appropriate, supporting neutral statewide governance, leveraging policy and contractual levers, supporting CBOs' and additional partners' participation in CIE, and supporting and participating in coordination.

4. A statewide CIE data program

- This should include data governance, aggregation of data, datasets, technical assistance, dashboards and reports, and evaluation. The program should be guided by principles that center transparency, access to understandable data, neutral oversight, a data equity framework, accountability, security, and community/individual data ownership and decision-making.

5. Privacy and security

- This should be guided by principles that center community and individual decision-making around use of their information, adherence to applicable privacy and security laws and national standards, always considering what information will support improvements in equity and services, transparency, and inclusive neutral governance to support privacy and security. Considerations are needed in supporting consent, individual access to CIE, and what types of information should be included.

6. Statewide governance

- This should be inclusive, neutral, and driven by the priorities of individuals and communities. It should include representation across social service, health, and government sectors with equal CBO to non-CBO representation and should have a multitiered structure.

Across all concept areas, the Workgroup elevated several priorities that were cross-cutting:

1. CBOs 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.

3. Financial investment for participants is also vital, as sustainable investment is essential to achieve the intended value of CIE. These efforts are an investment, over time, in systems change and connecting siloes.
4. The key goal is to improve lives and build trust through systems change.

Each concept area is further described below and includes associated input from HITOC and the CBO community engagement. ***See the Appendix for the full CIE Workgroup recommendations and considerations.***¹⁹

Summary of HITOC comments

HITOC supports five CIE Workgroup legislative recommendations and is neutral on one area. HITOC also reviewed the CBO community engagement findings and recommendations and notes the significant alignment between the CBO community engagement recommendations and the Workgroup. HITOC offered specific support for the following overarching areas:

- **Support for CBOs:** HITOC highlighted the significant amount of CBO input into this process and supports the Workgroup's recommendation that CBOs need robust sustainable support for successful statewide CIE. Participating in CIE takes significant resources for these groups, many of which already face resource constraints.
- **Equity:** HITOC highlighted the need to prioritize culturally and linguistically diverse organizations, and center those impacted in the development of CIE and the need for many different partners to participate in CIE for it to be successful.
- **Digital divide and historic underinvestment:** HITOC also emphasized the need to avoid exacerbating the digital divide that contributes to the fragmentation between health care and social services systems. They urged the legislature to invest in organizations who have not previously benefitted from federal investments in healthcare technology (to transition to electronic health records), specifically those outside of traditional physical healthcare, such as CBOs, behavioral health, and oral health.
- **Technical and standards alignment:** HITOC emphasized the importance of aligning with national privacy and security laws and standards, streamlining technology, and aligning data standards where possible to avoid duplication and reduce staff burden.
- **Empowering individuals and communities:** HITOC appreciated the emphasis on individuals and communities driving priorities and decisions throughout the Workgroup's recommendations.

Remaining questions

- **Governance:** HITOC had remaining questions regarding the implementation of governance that were out of scope for the CIE Workgroup and could not be further explored at this time. These included what power governance would have and what would be governed. HITOC also recognizes the strength governance may have and

¹⁹ See [Appendix C through H CIE Workgroup Full Recommendations](#)

potential impact on current CIE efforts. Therefore, while HITOC supports the majority of elements in the governance recommendations, they remain neutral overall.

Specific themes from HITOC's input are included with each CIE concept in the next section. The full summary of HITOC's comments is also available.²⁰

Recommendations to the Legislature by Topic

When widely adopted in communities, CIE helps eliminate many of the barriers between people and the services designed to support them. CIE enables a broad variety of service providers to connect easily and quickly, which is essential to supporting Oregon in addressing health inequities and the overall well-being of individuals.

1. Support for community-based organizations (CBOs) to participate in CIE

CIE Workgroup recommendations: CBO focus

The CIE Workgroup recommends that legislation support CBO participation in CIE. The Workgroup's top priorities within this area are:

1. **Ongoing sustainable funding and grants:** Priority recommended areas for funding and grants are staff capacity, incentivizing CIE use, supporting organizational infrastructure, and increasing overall services. CBO funding support should prioritize CBOs that support culturally and linguistically specific populations.
2. **Technical assistance:** Priority recommended technical assistance areas are privacy and data integration, workflow, data support for funding, and user training.
3. **Coordination and convening:** Priorities for coordination and convening are alignment of efforts, governance, a referral coordination center, best practice sharing, and research and evaluation.
4. **Education:** The Workgroup identified five priority education topics for CBO CIE use: billing/budgets, use of CIE data, consent processes, privacy compliance, and trauma informed practices. Three additional audiences for which education may be beneficial and support CBOs' participation in CIE

What are CBOs?

For the context of this paper community-based organizations (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.

²⁰ Summary of HITOC comments on Legislative Recommendations: <https://www.oregon.gov/oha/HPA/OHIT-HITOC/Documents/HITOCCommentsonHB4150LegislativeRecommendations.pdf>

were also identified (i.e., public, community leaders, and consumers/clients).

Overarching Principles

The overarching principles to be considered in implementing these recommended solutions are:

- The needs of communities and CBOs should drive discussions and decisions around CIE; listening to CBOs and communities is crucial to the success of CIE and to advancing health equity.
- Recognize the capacity of CBOs; any increase in expectations or burden should be offset by increased funding and other supports.

See Appendix for full CIE Workgroup recommendations to support CBOs.²¹

Community perspectives: CBO focus

The priorities recommended by CBOs through the community engagement process strongly align with the recommendations made by the CIE Workgroup.

- These include the need to support CBOs in adopting and using CIE by supporting staff capacity, offering funding, training, and technical assistance as well as the creation of a referral coordination center.
- In alignment with Workgroup principles around equity, CBOs also noted the importance of decision-making centering communities and populations that experience current or historical inequities and the need for relationship building.
- They also highlighted promoting equity and accessibility in CIE systems and the need to address access and resource challenges faced by communities in rural Oregon to ensure CIE use.

In our nonprofit, we'd say like, there's no such thing as like, too much communication. And in that same regard, I would say that there's no such thing as like too much support. I would say, you can't go wrong with having multiple different ways to provide support. – Interviewee

HITOC support: CBO focus

HITOC supports the recommendations of the CIE Workgroup that legislation support CBOs to participate in CIE. Members noted that CBOs are the critical partners in CIE efforts and their needs and voices must drive decisions for CIE efforts to be successful.

- HITOC emphasized the need to acknowledge and address the significant staff and technological capacity needed to engage in CIE efforts as many CBOs already use multiple systems.
- Funding needs to be robust; it is important to ensure there is a realistic budget for each stage and that funding is effectively delivered to the CBOs.

²¹ See [Appendix C: Full CIE Workgroup Recommendations: Support for CBOs to Participate in CIE](#)

- HITOC also identified the importance of supporting best practices which aligns with the CIE Workgroup recommendations on technical assistance and best practice sharing to support CBOs.

Further considerations identified by HITOC: CBO focus

HITOC noted the strong alignment between the Workgroup recommendations and the CBO input through the CIE: Community Engagement Findings and Recommendations. Analysis of areas of alignment or points of difference are incorporated into this report.

2. Support for additional partners to participate in CIE

CIE Workgroup recommendations: Additional partners focus

The CIE Workgroup recommends that legislation support additional partners in CIE. The Workgroup's top priorities within this area are:

1. **Sustainable funding, grants, and offsetting costs:** Priority recommended areas for funding, grants, and offsetting costs are staff capacity, incentivizing CIE use, supporting organizational infrastructure, increasing overall services, and leveraging Medicaid funding.
2. **Technical assistance:** Priority recommended technical assistance areas are privacy, workflow, data support for funding, data integration, and user training.
3. **Coordination and convening:** Priorities for coordination and convening are best practice sharing, governance and alignment of efforts, and research and evaluation.
4. **Referral coordination center:** The Workgroup recommends a referral coordination center to help address issues that may arise in service navigation.
5. **Education:** The Workgroup recommends education to support additional partners that is tailored to organizational needs, focused on CIE platforms, supports using CIE for data collection and payments, and involves diversity, equity, and inclusion training. In addition to education for additional partners, the Workgroup members recommend a range of supportive education for other parties involved in CIE.

Who are additional partners?

For the context of this paper additional partners include:

- Behavioral health organizations
- Oral health organizations
- Physical health organizations
- Safety net clinics (e.g., federally qualified health centers (FQHCs), rural health centers, free clinics)
- Coordinated care organizations (CCOs)
- City or county government (e.g., local public health or county social services)
- And others (e.g., early childhood, school-based social supports)

In the context of the above recommendations, the CIE Workgroup recommends prioritization of the types of additional partners across all areas of support, in particular that culturally and linguistically specific organizations be prioritized. Overall, the Workgroup recommends

considering organizational size and capacity, communities and populations served and their needs, and the types of services provided by the organizations. In addition, behavioral health, safety net clinics, city or county governments and CCOs are higher priority partners (though they noted CCOs are not high priority for funding).

See Appendix for full CIE Workgroup recommendations to support additional partners.²²

Community perspectives: Additional partners focus

CBO recommendations about use of CIE by additional partners paralleled the Workgroup recommendations with regard to support for staff capacity, funding, and the need to improve existing services to ensure effective use of CIE. The need for a referral coordination center was also called out. CBOs emphasized the need for CIE to support and connect with behavioral health providers.

HITOC support: Additional partners focus

HITOC supports the recommendations of the CIE Workgroup that legislation support additional partners to participate in CIE.

- HITOC agreed that, while CBOs are the primary partner for CIE work, additional partners' participation in CIE is important to accomplish the goal of connecting across sectors and to prevent fragmentation between systems.
- HITOC recognized that physical health entities have historically received federal funding to support health IT implementation, which was very successful in moving hospitals and primary care clinics to standards-based electronic health records. Funding could prioritize additional partners who did not benefit from those federal initiatives to support infrastructure growth.
- Additional partners highlighted during the discussion included local public health and county social services, behavioral health, oral health, and correctional systems among others.
- Members also called out the benefit of a referral coordination center.
- HITOC noted that there should be a focus on accessibility of CIE and information about CIE for culturally and linguistically specific populations, including those that come to the United States from other countries. Additional focus populations mentioned by members included persons with developmental disabilities, older adults, children and youth in foster care, and persons who may not have familiarity with or understand new and developing technology.

Further considerations identified by HITOC: Additional partners focus

HITOC highlighted a few areas for further investigation and consideration, including:

- Prioritization of First Nations communities and organizations and the needs of rural and small organizations.

²² See [Appendix D: Full CIE Workgroup Recommendations: Support for Additional Partners to Participate in CIE](#)

- As efforts develop, it will be important to consider the complex roles that some counties play in health and human services programs (e.g., Area Agencies on Aging and Community Action Programs) to reduce concerns around duplicative work.

3. OHA and ODHS roles in CIE

CIE Workgroup recommendations: OHA and ODHS focus

The CIE Workgroup recommends that legislation support OHA and ODHS roles in statewide CIE efforts. The Workgroup's priorities for the roles of OHA and ODHS are:

1. **OHA and ODHS use of CIE:** The priority recommendation in this area is that OHA and ODHS actively participate in CIE and their programs use CIE where appropriate. Assessment and planning are important first steps that require appropriate time and resources.
2. **Ensure neutral statewide governance:** The Workgroup recommends vendor-neutral governance across statewide CIE efforts that is inclusive of those impacted by and participating in CIE efforts. Workgroup members are about equally divided between recommending that OHA and ODHS lead governance efforts or that their appropriate roles are to participate in and support governance, and potentially identify a neutral third-party convener.
3. **Leveraging policy and contractual levers:** Recommended roles in this area are that OHA and ODHS incentivize use of CIE as part of contracts or grants, strengthen policies around care coordination and social determinants of health to encourage use of CIE, and utilize data to further inform policy decisions. It is important to note that with CBOs, the Workgroup explicitly recommends against requiring use of CIE as a condition for receiving contracts or grants, but does recommend incentives or other ways to encourage CIE use.
4. **Support of CBOs and additional partners:** Priority recommendations to support CBOs and additional partners focus on leveraging funding opportunities, providing sustainable funding, and supporting technical assistance, interoperability, and advocacy for connections with existing systems.
5. **Participation and support in coordination:** Priority roles in convening and coordination include assuring a focus on health equity, facilitating communication, helping CBOs participate in convenings, and participating in learning and collaboration opportunities.

Overarching Principles

Implementation of these recommendations should take several overarching principles into account.

- There is a power differential between OHA and ODHS and their non-state partners. The agencies should leverage this influence in a measured way that does not dominate non-OHA and -ODHS entities but works to bring different partners together.

- Sustainability of CIE is needed; this requires both funding and support of efforts and resources at all levels.
- It is critical that access to use of CIE within Oregon is equitable. OHA and ODHS are stewards of the public good and should work for all in Oregon, not only those who currently have access and sufficient resources to engage. CIE can bring many benefits to bear, but to achieve the vision of referrals and accessible information sharing across multiple systems to benefit people, OHA and ODHS should play an integral role in ensuring equity in design and implementation.
- If/when appropriate, OHA and ODHS can act as neutral parties, bringing together a variety of different partners with varying perspectives and priorities.

These principles should be considered during review of the full recommendations on OHA and ODHS roles in CIE.

See Appendix for full CIE Workgroup recommendations on OHA/ODHS roles in CIE.²³

Community perspectives: OHA and ODHS focus

CBO recommendations on the appropriate roles for OHA and ODHS in CIE aligned with the recommendations made by the CIE Workgroup.

- CBOs see a need for neutral statewide governance and suggest that OHA/ODHS could play key roles in coordination and facilitation of CIE, inclusive of funding and oversight.
- Additionally, CBOs see many roles for a statewide convening entity including providing oversight and convening partners for decision-making, funding and grants, and technical assistance and training. More roles include coordinating the activities of partners and monitoring and evaluation to make improvements in CIE and the overall social and health systems in response to findings.
- CBOs suggested that programs run by OHA/ODHS should use CIE themselves but noted that a statewide coordinating body should be a neutral, non-government entity.

I like the idea of a statewide process so that we can be communicating across county lines, because I know that our services blur across county lines, and so, you know, if we can all be hopping on and using the same thing, that would be amazing.
– Interviewee

HITOC support: OHA and ODHS focus

HITOC supports the recommendations of the CIE Workgroup that legislation support OHA and ODHS roles in CIE. HITOC agreed that involvement of OHA and ODHS is important in these efforts.

- HITOC emphasized the importance of inclusive governance. It is critical to establish trusted relationships among the groups involved and have accountability.
 - Governance should be facilitated by a neutral entity at the community and regional levels as well as statewide to ensure people have equal access and influence.

²³ See [Appendix E: Full CIE Workgroup Recommendations: OHA and ODHS Roles in CIE](#)

- Governance should include people served by CIEs so that development of CIE is person-directed.
- HITOC also indicated that governance should allow space for health care and CBOs to meet separately and together, and to allow for alignment across health care implementations so CBOs are not overburdened.
- HITOC stated active use by OHA and ODHS programs is key, where appropriate, as having closed loop referrals between CBOs, additional partners, and OHA and ODHS will be important.
- However, the agencies' adoption will be complex due to the numerous program areas and technology systems. Some members expressed concerns that OHA and ODHS programs may not have capacity to adopt and use CIE.
- HITOC commented that OHA and ODHS should create a glide path over time around any policy or contractual levers for CBOs or additional partners.
- HITOC elevated and agreed with the potential risks to be mitigated identified by the CIE Workgroup.

Further considerations identified by HITOC: OHA and ODHS focus

HITOC called out that further investigation is needed regarding streamlining of agency systems.

4. Statewide CIE data program

CIE Workgroup recommendations: Data program focus

A statewide CIE data program is an integral part of CIE efforts; success of the program depends on overall systems change and the use of CIE being successful. It is necessary to bring together data across efforts and regions to not only accelerate, support, and improve statewide CIE efforts, but to support whole person health and well-being outcomes for persons and communities in Oregon.

The CIE Workgroup recommends that legislation support a statewide CIE data program. The following outlines the value and potential benefits and risks of a statewide CIE data program and the recommended principles, parts, and roles for OHA and ODHS in a statewide CIE data program:

1. **Value of a CIE data program:** The CIE Workgroup would like to elevate the significant value of a statewide CIE data program for understanding social needs and resource gaps, measuring outcomes, informing future policy

What could be considered CIE data?

For the context of this paper, examples discussed as CIE data include:

- Types of services available and their locations
- Services searched for and search area
- Screening and assessments
- 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

and investment decisions, supporting efficiency, and improving processes.

2. **Potential benefits and risks:** The CIE Workgroup highlights potential benefits and risks to a statewide CIE data program, such as the potential to increase or decrease trust. Additional potential benefits include identifying needs and inequities, empowering interested parties for decision making, and making data available. Potential risks include data quality issues, privacy and security risks, and reinforcing inequities.
3. **Principles:** The Workgroup recommends several principles to guide a statewide CIE data program. The principles center transparency, access to understandable data, neutral oversight, a data equity framework, accountability, security, and community/individual data ownership and decision-making.
4. **Parts:** Recommended parts of a statewide CIE data program are data governance, aggregation of data, datasets to support access and transparency, technical assistance to support community analysis and data use, dashboards and reports, and evaluation to identify gaps, strengths, and opportunities for improvement in Oregon's social care system and the CIE system itself.
5. **OHA and ODHS roles:** The CIE Workgroup recommends that OHA and ODHS play a role in funding and supporting a neutral organization to lead a statewide CIE data program. The Workgroup also outlined potential benefits and risks to OHA and ODHS having roles in a statewide CIE data program.

See Appendix for full CIE Workgroup recommendations for a statewide CIE data program.²⁴

Community perspectives: Data program focus

Recommendations from CBOs relating to a statewide CIE data program aligned with priorities and principles around privacy, data security, ownership, and accessibility identified by the CIE Workgroup. Like the CIE Workgroup, CBOs highlighted the importance of advancing equity through data use and analysis and echoed the need to center the perspectives of populations experiencing inequities in considerations and decision making about a statewide CIE data program. CBOs also recommended oversight with CBO and community representation to ensure issues of data justice²⁵, decolonization, and privacy are adequately addressed, aligning with the Workgroup's recommendations for data governance and a data equity framework.

Our network is so young, we're not having these conversations [about data equity], but I think that's something to put on the horizon to make sure that we're really looking at and being thoughtful about like, what data we collect, how we're using it, engaging the community and making sure that's okay. That, you know, all the stakeholders agree with the appropriateness of what we collect and how we use it will be important.
— Interviewee

²⁴ See [Appendix F: Full CIE Workgroup Recommendations: Statewide CIE Data Program](#)

²⁵ Data justice is an approach that redresses ways of collecting and disseminating data that have invisibilized and harmed historically marginalized communities.: <https://www.coalitioncommunitiescolor.org/-why-research-data-justice#:~:text=Data%20justice%20is%20an%20approach,and%20harmed%20historically%20marginalized%20communities>.

HITOC support: Data program focus

HITOC supports the recommendations of the CIE Workgroup that legislation support a statewide CIE data program.

- HITOC affirmed the importance of several principles recommended by the CIE Workgroup including that a data equity framework grounded in data justice should be developed and applied to a statewide CIE data program, and that populations whose data are collected through CIE should be central to decision making about data use. HITOC highlighted the need for an intersectional approach to applying a data equity framework, inclusive of race, behavioral health experiences, and disability status. Data governance is necessary to carry out these principles.
- HITOC also agreed that any data collection should not cause additional burdens for CBOs, or that expectations are accompanied by appropriate support, which could include financial, technical, or data interpretation assistance.
- Members said there should be alignment of data standards and emphasized that a statewide data program should adhere to federal and industry data standards to reduce duplicative reporting and mitigate staff burden.
- HITOC also affirmed that it is important for OHA and ODHS to participate in a statewide CIE data program, although some members questioned whether OHA/ODHS were well suited to lead or run the program.

Further considerations identified by HITOC: Data program focus

HITOC agreed with the CIE Workgroup that the scope of a statewide CIE data program needs further investigation, such as what data would be included and how long data would be held. Additionally, further consideration is needed on how individuals and communities would have ownership over their data.

5. Privacy and security of statewide CIE

CIE Workgroup considerations: Privacy and security focus

The CIE Workgroup recommends several privacy and security guiding principles as well as considerations for statewide CIE.

The following outlines **privacy and security principles** to guide statewide CIE in Oregon:

1. **Communities and individuals must guide decisions around collection, storage, sharing, and use of their information:** The CIE Workgroup elevates the need to empower individuals and communities whose information will be shared in CIE to play a central role in guiding decisions about how that information is handled.

Privacy generally refers to an individual's ability to keep certain personal information free from unauthorized access and the ability to access and share the information themselves.

Security is the way organizations control access and protect this information, including safeguarding it from accidental or intentional disclosure.*

2. **CIE systems must adhere to applicable privacy and security laws and should follow national standards:** The CIE Workgroup recommends that statewide CIE efforts adhere to existing and future privacy and security laws as well as to established standards at the national level rather than focus on developing new stand-alone approaches.
3. **Information that will improve services, care, and equity should be collected and shared in CIE:** The Workgroup prioritizes information that will improve service provision, care, and equity, both for the individual being served and the overall health and social care systems. It will be important to be thoughtful about what information to collect to maximize privacy, have sufficient information to provide services easily, and avoid asking individuals repeatedly for the same information.
4. **Transparency on how information will be stored, shared, and used is essential to building trust:** The Workgroup asserts that transparency about what will happen with information individuals provide is critical to ensuring trust. Clear and understandable information on how information will be protected and shared is necessary to achieve this.
5. **Inclusive neutral governance is needed and would include governance of information privacy and security:** The CIE Workgroup recommends including oversight of information privacy and security in the CIE governance process. Members elevate the need for additional working groups with this focus.

The CIE Workgroup also discussed several key areas and puts forth the following initial considerations:

- **Types of information in CIE:** In addition to the social needs and services information that must be included for the primary purpose of CIE, the CIE Workgroup feels there is value in collecting and exchanging identifying, demographic, physical health, behavioral health, and sensitive information in CIE, with appropriate safeguards in place.
- **Informed consent:** Informed consent is essential to building trust and maintaining transparency. Members provide considerations on the clarity, frequency, and content of the consent process as important factors to consider in planning for informed consent.
- **Individual access:** Most CIE Workgroup members agreed that individual access should be part of CIE, meaning that individuals could access their own information in CIE, or search for resources and self-refer.

Types of CIE information discussed for the context of this paper included examples such as:

- **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.

See Appendix for full CIE Workgroup privacy and security considerations.²⁶

Community perspectives: Privacy and security focus

CBO recommendations for privacy and security aligned with the Workgroup's recommendations. These areas of alignment include the need for clarity and transparency in how data is used and shared, and that CIE information must not be used for profit. Also, the need to ensure information in CIE is protected, particularly when it is sensitive and/or gathered from individuals who experience inequities because of their identity or circumstances. CBOs emphasized a need for training on privacy and security compliance, as well as communication with individuals about privacy, data justice, and individual ownership of their data. CBOs shared concerns about privacy and lacked a clear understanding of how information is protected in CIE, but some CBOs that use CIE were comfortable with the ways privacy is handled.²⁷

HITOC support: Privacy and security focus

HITOC supports the CIE Workgroup's privacy and security guiding principles and considerations for statewide CIE. Moreover, HITOC stated that all five principles align well with HITOC's health IT strategies for Oregon.

- In particular, HITOC strongly supported leveraging national standards and policies, rather than developing anything state specific.
- HITOC strongly supported the emphasis on empowering communities and individuals in decision-making about their information and transparency in information sharing and use.
- Members also strongly supported the guidance that the information collected and shared should be used to improve services and equity.
- Members supported the idea of collecting consent the first time a referral is made, but not each time a referral is made, unless necessary for safeguarding privacy, as repeated documentation could get in the way of caring for a person.
- Members appreciated the considerations for individual access to CIE, and felt it supported accountability.
- Lastly, HITOC emphasized the importance of financially supporting CBOs in adhering to privacy and security standards.

Further considerations identified by HITOC: Privacy and security focus

HITOC agreed with the CIE Workgroup that further consideration is needed on the types of information in CIE, particularly, what CBOs would need to collect. They also noted sovereign Tribal nations may have laws governing information use and sharing that differ from state or federal laws; those will need to be accounted for and considered. HITOC highlighted a few areas for further investigation and consideration such as how to ensure that CIE information is not sold or used for profit. Also, it is important to look at whether and how individuals can add

²⁶ See [Appendix G: Full CIE Workgroup Considerations for Privacy and Security of Statewide CIE](#)

²⁷ See p.103 of [Appendix I: CIE: Community Engagement Findings and Recommendations](#)

or change what information is included in CIE as inaccurate or out of date information can cause unintentional harm.

6. Governance of statewide CIE

CIE Workgroup recommendations: Governance focus

The CIE Workgroup recommends that legislation support inclusive neutral governance of statewide CIE efforts.

Governance is the process of bringing groups together for decision-making, direction setting, evaluating progress, and/or norm setting.

1. **Inclusive**: Governance must be representative of the communities, individuals, and organizations participating in and impacted by CIE efforts. Thoughtful planning, facilitation, and understandable materials are necessary to support inclusivity.
2. **Neutral**: Governance should be led by a third party or through a public/private partnership.
3. **Priorities of individuals and communities drive decisions**: Governance should involve ongoing direct engagement with community members and/or CBOs that represent them to ensure that their perspectives and input drive decisions about statewide CIE in Oregon.
4. **Groups to include**: Governance should include representation across the social service, health, and government sectors with equal CBO to non-CBO representation.
5. **Multitiered structure**: There should be an overarching governance group as well as subgroups focused on specific topic areas. Governance should also have statewide and regional/local groups.

The CIE Workgroup views statewide governance as the critical next step to support, accelerate, and improve statewide CIE efforts.

See Appendix for full CIE Workgroup recommendations for governance of statewide CIE.²⁸

Community perspectives: Governance focus

CBO recommendations for governance aligned with those made by the CIE Workgroup. CBOs see a need for neutral statewide governance that should be led by a third party or public/private partnership.

- CBOs supported recommendations for community-led governance with diverse representation that is responsive to the needs of community and clients.

I think it would be less chaotic or less unorganized if we have someone in charge, ... Yes, but for that it has to be a central organization that understands the complexity of Oregon. And the different regions. I think it cannot be just a government, it has to be private or nonprofit and government together as a partner. – Interviewee

²⁸ See [Appendix H: Full CIE Workgroup Recommendations for Governance of Statewide CIE](#)

- CBOs see many roles for a statewide convening entity including providing oversight and convening partners for decision-making, which aligned with the Workgroup's recommendations.

HITOC comments: Governance focus

HITOC is neutral on the recommendations of the CIE Workgroup that legislation support statewide governance of CIE efforts. HITOC was supportive of the recommendations for inclusivity, neutrality, broad representation, and the multitiered structure, and agreed that governance is the next step in statewide CIE efforts. However, members had remaining concerns about implementation that were outside of the Workgroup's scope. Therefore, while HITOC supports the majority of elements in the governance recommendations, they remain neutral overall.

Areas of support:

- HITOC strongly supported the Workgroup's recommendations for inclusive governance that is representative of the individuals, communities and organizations participating in and impacted by CIE.
- HITOC also strongly supported the Workgroup's recommendation that governance be driven by the priorities of individuals and communities impacted.
- HITOC emphasized the importance of neutrality, that governance is not solely done by state agencies or by private organizations.
- Members agreed with the recommendations for subgroups, as well as the call outs for representation by technology experts and rural communities.
- Some members agreed with the Workgroup that statewide governance is the critical next step.

Areas of concern:

- While HITOC was supportive of the Workgroup's conceptual vision around governance, members did not feel comfortable fully endorsing the recommendations without a better understanding of what power governance has, who it reports to, where it sits, and specifically what CIE efforts are governed.
- HITOC was cautious regarding the strength of a recommendation for wide-ranging governance at the state level and recognized the sway a governance process could have for CIE efforts.
- Members recognized the power that a group with this breadth and depth of partners would have.
- Members were also concerned that governance could slow down the progress of current efforts. This could especially impact CCOs given their current CIE investments and future obligations. However, HITOC noted the need to balance forward movement on CIE with thoughtful decision-making to avoid exacerbating inequities.

Further considerations identified by HITOC: Governance focus

In order to move forward with governance, HITOC stated it must be clear what effort or efforts are being governed. Members highlighted that it is important to be inclusive and continue to incorporate language about “raising all boats” to reach HITOC’s goals of health equity and health system transformation supported by health IT. The purpose of governance should be to accelerate CIE, making it more likely to achieve those goals.

Conclusion

To further health equity and the long-term vision of systemic change, it is critical to better coordinate health care and social services to connect people to the services and supports they need. The recommendations and considerations across all three groups, CBOs, the CIE Workgroup, and HITOC, were strongly aligned in support of building on and improving current CIE efforts in support of these goals and moving forward statewide CIE. Each of these groups contributed important information to guide CIE efforts. Many CBOs, from a variety of organization sizes, geographic locations, and populations served, took the time to share their perspectives on opportunities and barriers for CIE. It is important to elevate their voices and take action to support them in CIE efforts.

To accelerate, support, and improve statewide CIE efforts, it is clear that steps should be taken to coordinate across the state, support CBOs, and utilize data to improve outcomes. Financial investment for participants and statewide governance are priorities for moving this work forward in Oregon.

Appendix A: CIE Workgroup Members

Name	Organization	Title
1. Ryan Ames	Washington County – Research Analytics Informatics & Data	Research & Evaluation Analyst
Has worked on initiatives that coordinated social services and made data more accessible to families and communities. Has used person-centered, culturally responsive, and community oriented data and technology design. Helped establish family-lead interviews, responsive information sharing, and technology-oriented solutions for public health surveillance and program evaluation. Initiatives sought deeper understanding of the inequitable contexts from which they operated, and developed goals to address equitable access of services and health resources.		
2. Jenna Cohan	Oregon Coalition Against Domestic and Sexual Violence	Sexual & Domestic Violence Program Coordinator
Program coordinator at the Oregon Coalition Against Domestic & Sexual Violence, an organization that supports community-based and Tribal advocacy agencies in Oregon to make sure survivors of sexual and DV have access to confidential advocacy services. Leads work at intersections of survivorship, health, and advocacy. Has participated in a healthcare policy workgroup that has spoken with a CIE. Would like to bring advocates' (and therefore survivors') voices forward. Prior experience includes direct work with survivors, where much work was with people from historically marginalized communities, and systems advocacy with communities to build better responses and collaborations around violence. Experience includes working with incarcerated youth, monolingual Spanish speakers, Native folks, and people experiencing homelessness.		
3. Zoi Coppiano	Community Action	Manager of Coordinated Systems
Zoi is From Ecuador, has nine years in social services including experience as an eligibility worker for ODHS self-sufficiency programs and working at a DV Resource center. Over the past seven years at Community Action in Washington County has coordinated entry for homeless individuals and families to Housing Programs and Stability, and now oversees three coordinated entry programs that include making connections with partners and referrals to various programs to help the community thrive like: OHP, home visiting programs, WIC, rent, utility assistance and more. Wants to provide input about navigating the many systems of care and the barriers encountered, especially to disadvantaged communities.		

Name	Organization	Title
4. Tanya DeHart	NorthWest Senior and Disability Services	Executive Director
Tanya has worked at NorthWest Senior and Disability Services (NWSDS) in a variety of positions for the last 26 years and is currently the Executive Director. NWSDS serves older adults and individuals 18 and over with physical disabilities in Marion, Polk, Yamhill, Clatsop, and Tillamook Counties. They have 300 FTE staff, serving over 30,000 consumers a day in a wide range of programs funded by Medicaid, Older Americans Act, and various other contracts and grants. Additionally, Tanya has served on the Governor’s Commission on Senior Services for three years and was recently elected Vice-Chair of Oregon Association of Area Agencies on Aging and Disabilities (O4AD).		
5. Susan Fisher-Maki	AllCare Health	Director, Community Benefit Initiatives
Almost a decade of experience in systems development, significant experience managing CIE implementation, community buy-in, and working on health equity and SDOH. Coordinates internally with care coordination, customer care, IT, and provider services teams, also at community tables focused on SDOH. Outlined several clear opportunities for the Workgroup to address racial and health equity, understands opportunities across efforts (e.g., 1115 waiver, REALD, etc.), long term vision, and also that ensuring CIE is human centered, trauma informed, and culturally and linguistically responsive is a priority.		
6. Dan Herman	211info	Chief Executive Officer
Dan has been CEO at the private nonprofit 211info for the past eight years, overseeing the organization that provides connections to health and human service resources across the entire state of Oregon. 211info is an important operational catalyst for Kaiser Permanente’s Coordination Center demonstration, functioning as the Connect Oregon central hub of community resources. Dan has a background in originating and implementing SDoH work at 211info and interacts with similar work being done by other 211s and nationwide organizations, such as United Way Worldwide and Alliance of Information Referral Systems. Dan’s goals for health and social care integration include achieving the Triple Aim; reducing friction in a fragmented system; using data to inform strategies; and having both data and human feedback loops for continuous improvement. Dan holds an MBA from University of San Diego and BS from Arizona State University.		
7. Anne King	Oregon Rural Practice-based Research Network	Associate Director
Anne King, MBA is the Associate Director of the Oregon Rural Practice-based Research Network (ORPRN), a research and quality improvement organization housed at Oregon Health & Science University. She leads ORPRN’s health systems innovation line of business which includes Medicaid innovation, primary care quality improvement, and value-based payment models. Since 2016, Anne has served as Project Director for the Accountable Health Communities (AHC), a CMS-funded research study which implements social needs screening and navigation to community resources for Medicaid and Medicare members. Through AHC she led an effort to link a screening data system to a community resource database, and an electronic health record. She also championed a partnership with a CIE to enable closed loop referrals. Anne co-facilitated the recent OHA Social Determinants of Health Screening Workgroup.		

Name	Organization	Title
8. Barbara Martin	Central City Concern	Medical Director of Health Informatics, Physician Assistant
Barbara is a Physician Assistant (PA) with 17 years of experience at Central City Concern, an FQHC and healthcare for the homeless site, doing primary care as well as being part of an integrated team including behavioral health. She also oversaw operations of the primary care services for 9 years. In addition to still seeing patients for both primary care and substance use, she is now in a clinical informatics role. Her organization works to provide better access to translation, culturally relevant care, and adapting screenings to address health disparities. She sees the potential of CIE and technology in supporting efforts and highlights that CBOs will need resources to do so.		
9. Kat Mastrangelo	Volunteers in Medicine, Clinic of the Cascades	Executive Director
Served for the last 13 years as the Director of a free clinic for low income people who are not able to get insurance. Patients are 90% Spanish speaking, immigrants with trauma, and little to no access to the usual safety net resources. Experience in key metrics for health inequities and is currently serving on the Public Health Advisory Board-Scoring and Metrics subcommittee. Also, serves on the Board of Directors and on the Roadmap To Health Equity task force for the National Association of Free and Charitable Clinics.		
10. Megan McAninch-Jones	Providence Health & Services	Executive Director, Community Partnerships
Has worked in SDOH for almost a decade. Administers community health needs assessment and community benefit programming for hospital system. Wants to reduce number of times clients must share their experiences and is passionate about using data to provide best care across the continuum. Also a demographer, evaluator, and mixed methods researcher. Has worked to improve qualitative and community engagement practices to ensure prioritization of people and communities underrepresented in quantitative data. Has worked work in other countries with displaced and refugee communities, as well as in the U.S. with people in recovery, experiencing homelessness, and SNAP and WIC recipients through the community health assessment and improvement process.		
11. Princess Osita-Oleribe	Cascade Health Alliance	Health Equity Manager
Professional focus is centered around community development, justice, equity, diversity, and inclusion of and for people at the fringes of the society. Has fought for gender equality against historical cultural inhibitions and power imbalances. In current role as Health Equity Manager, oversees the Health Equity Plan, SDOHE trainings and implementation of interventions, and the operations of the Health Equity Councils and the subcommittee. Also coordinates the Community Advisory Council and represents the organization in many coalitions, committees and leadership groups of local partners that provide services and supports that address the SDOH. Coordinates with the local programs listed on the CIE used in the region. Served as the Executive Director of the Centre for Family Health Initiative in Nigeria overseeing the planning, implementation, and evaluation of several social and health development projects.		

Name	Organization	Title
12. Anirudh Padmala	Multnomah County Community Health Center	Chief Information Officer
Anirudh serves as the Information Officer at the largest FQHC in Oregon, where they are in the process of expanding their ability to understand data utilizing the factors of SDOH and build operations, services accounting for SDOH. Through participation in CIE, he sees opportunities to develop best practices to model de-segregated data, communicate usage of data, best practices, and data warehouse capabilities, and processes to empower communities. Has lived experiences navigating the systems that are not set up to access care and information in a meaningful way.		
13. Catherine Potter	Kaiser Permanente	Senior Manager, Community and Social Health
Has managed the community engagement efforts of Kaiser Permanente's CIE rollout for the past 2.5 years, working directly with healthcare and social service partners. Has significant experience and learnings to bring on CIE implementation and community engagement. Prior experience includes working directly with FQHCs and other safety net providers as Safety Net Partnerships Manager, including piloting the electronic medical records integration of a CIE platform. Previously spent 16 years managing community health worker programs with Providence, El Programa Hispano, and Community Action Org of WA County. Speaks Spanish and has extensive experience working with Latinx immigrant community and undocumented people.		
14. Michael von Arx	Umpqua Health	Chief Administrative Officer
Current role is at a rural CCO that also operates a full service clinic providing primary, urgent, and behavioral health care. Partners closely with their Health Equity Officer in identifying solutions and programs to promote their Health Equity Program, including identifying technology opportunities (e.g. REALD, CIEs) to address SDOH and health equity, and work in establishing contractual relationship with community organizations. Participates in the local CIE and worked with community around identifying needs. Former in-home intensive child and family therapist for OHP members.		
15. Tiana Wilkinson	PacificSource	Director of Community Health Strategy
Tiana Wilkinson (she/her) is the Director of Community Health Strategy at PacificSource and is responsible for directing the SDOHE strategy as well as PacificSource Community Solutions' Health Equity Plan and team. Previously she served as PacificSource's SDOHE Program Manager, where she organized 24 health equity listening sessions with community stakeholders and managed the CIE rollout for PacificSource's four CCO regions, working closely with the technology vendor, community partners, and providers. She has also helped to onboard PacificSource's Care Management and Flex Service teams to the CIE platform and developed success metrics, including an emphasis in tracking and addressing health inequities. Tiana also has a background in community health, homeless services, and HIV prevention. Tiana is also a member of the LGBTQ+ community and has assisted many workplaces and clinics to develop LGBTQ+ inclusive practices.		

Name	Organization	Title
16. Mary Ann Wren	Advantage Dental from DentaQuest	Director of Integration and Community Programs
Oversees dental community care program, which provides dental services in non-traditional settings. Through this they learn of additional needs community members have and see CIE as a way to help bridge this gap. Much of their work is to reduce barriers to oral health care and help individuals connect with the additional resources they need.		
17. David Dorr Vice-Chair & HITOC Liaison	Oregon Health and Science University	Chief Research Information Officer
OHSU's Chief Research Information Officer and an internal medicine doctor. Focuses on improving capabilities and innovations to manage data, information, and knowledge in research and in translating it to health care. Has significant strategic and policy experience, particularly in the design, evaluation, and implementation of health IT intended to improve the health and well-being of populations impacted by systemic inequities. Interested in what clinical information systems need to support quality and collaborative care. Has worked on longitudinal care management systems, which are holistic, patient-centered plans that help keep better track of patients' needs and goals, help them manage their conditions better, and make them feel like a valued member of the team.		
18. Carly Hood-Ronick Chair & HITOC Liaison	Project Access NOW	Executive Director
Carly Hood-Ronick is the Executive Director at Project Access NOW, a non-profit partnering with health systems, community clinics, and social service entities to improve access to care, services, and resources for the un/underinsured. Over the past decade, she has worked at the intersection of policy and public health in multiple states and developing countries to support community driven priorities, promote upstream investments, and publish best practices in financing social system efforts. Carly has participated on several state-level and national boards and committees, including past Co-Chair of the Oregon Health Policy Board's Health Equity Committee, Health Information Technology Oversight Committee, and supporting Medicaid metric and measurement development with regard to upstream investments. Carly's prior experience includes leading strategy and implementation of social health and Medicaid engagement efforts alongside community health centers across Oregon, as a Director at the Oregon Primary Care Association.		

Appendix B: HITOC Members²⁹

Erick Doolen, Chair

Chief Operating Officer and Executive Vice
President
PacificSource

Amy Henninger, MD, Vice Chair

Primary Care Medical Director
Multnomah County Health Department

Bill Bard

Retired
Consumer

Maili Boynay

Vice President of Information Systems
Applications
Legacy Health

Manu Chaudhry, MS DDS

President
Capitol Dental Care

Romney Cortes

Director of Clinical Applications
Central City Concern

David Dorr, MD

Chief Research Information Officer
Oregon Health & Science University

Amy Fellows

Executive Director
We Can Do Better

Valerie Fong, MSN, RN

Executive Director of Regional Informatics and
Chief Nursing Informatics Officer
Providence St. Joseph Health

Carly Hood-Ronick, MPA, MPH

Executive Director
Project Access NOW

Kellen Joseph

Information System Manager/Clinical App
Coordinator
Yellowhawk Tribal Health Center

Ann Kasper

Mental Health Senior Digital Peer Outreach
Specialist
Community Counseling Solutions

Kristina Martin

Chief Information Officer
Curry Health

Abdisalan Muse, MS

Data and Reporting Manager
Multnomah County Health Department

Dave Perkins

Chief Information Officer
Yakima Valley Farm Workers Clinic

Mark Hetz, Ex Officio

Executive Director
HIT Commons

²⁹ HITOC member biographies: https://www.oregon.gov/oha/HPA/OHIT-HITOC/Documents/HITOC_RosterBios.pdf

Appendix C: Full CIE Workgroup Recommendations: Support for CBOs to Participate in CIE

Recommendations: Support for Community-based Organizations to Participate in CIE



Introduction and Purpose

The [Community Information Exchange \(CIE\) Workgroup](#) has been tasked by the [Health Information Technology Oversight Council](#) (HITOC) under [House Bill 4150](#) (2022) with providing recommendations on strategies to accelerate, support, and improve statewide CIE in Oregon.

The CIE Workgroup met in April and May 2022 to discuss strategies on how to best support community-based organizations (CBOs) to participate in CIE. This concept paper is a result of the discussions and was given to HITOC in August to inform their draft report to the legislature in September and final report in January 2023 as required under HB 4150.

To supplement this information, a health equity consultant conducted CBO interviews and a survey on CIE in May and June 2022 to further inform the recommendations. The report on the [findings of the CBO interviews and survey](#) was given to HITOC in August as well to inform their draft report to the legislature in September. In August the CIE Workgroup reviewed the CBO interviews and survey report and updated this concept paper as a result.

What are CBOs?

For the context of this paper community-based organizations (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.

Problem

CBOs are *the* key partners in successful CIE. As the entities providing services and supports to address people's needs, which research shows largely drives health outcomes, it is imperative that CBO resources are part of any CIE network. Only with broad CBO participation in communities can CIE help improve health and well-being through completed closed loop referrals and service provision; without CBO participation this cannot be accomplished. CIE participation takes significant time, money, and human resources for CBOs. They must manage the adoption of technology, new workflows, and the increase in service demand due to receiving more referrals. Many CBOs that provide vital services operate under limited budgets and staffing structures that are already stretched to capacity. In addition, while healthcare organizations have received more funding and face more requirements around advancing technology, improvements and funding for CBOs have not moved as quickly, leaving a disparity in technological capabilities and financial resources between CIE partners.

August 2022

Recommendations: Support for Community-based Organizations to Participate in CIE



Sustained support for CBO participation in CIE is critical for the success of statewide CIE in addressing health inequities.

Summary of Recommendations

When widely adopted in communities, CIE helps eliminate many of the barriers between people and the services designed to support them. CIE enables a broad variety of service providers to connect easily and quickly, which is essential to supporting Oregon in addressing health inequities and the overall well-being of individuals.

The CIE Workgroup recommends that legislation support CBO participation in CIE. Support should include ongoing sustainable funding and grants, technical assistance, coordination and convening, and education. The Workgroup's top priorities within these areas are:

1. **Ongoing sustainable funding and grants:** Priority recommended areas for funding and grants are staff capacity, incentivizing CIE use, supporting organizational infrastructure, and increasing overall services.
2. **Technical assistance:** Priority recommended technical assistance (TA) areas are privacy and data integration, workflow, data support for funding, and user training.
3. **Coordination and convening:** Priorities for coordination and convening are alignment of efforts, governance, a referral coordination center, best practice sharing, and research and evaluation.
4. **Education:** The Workgroup identified five priority education topics for CBO CIE use: billing/budgets, use of CIE data, consent processes, privacy compliance, and trauma informed practices. Three additional audiences for which education may be beneficial and support CBOs' participation in CIE were also identified.

Community-based organizations, peer-run organizations like ours, we are, you know, feet on the ground organizations, we're grassroots, and I think this tool to be able to reach out, because we're always underfunded, we're always understaffed, you know, and this cuts down on hours and hours and hours of time that we would be on the phone, we have to do one referral, we can send it out, we can make notes, we can talk back and forth with other people, we only have one consent form, you know, all these things have made it a lot easier for us to operate, made it to where we can spend more time with our feet on the ground. – Interviewee

Overarching Principles

The overarching principles to be considered in implementing these recommended solutions are:

Recommendations: Support for Community-based Organizations to Participate in CIE



- The needs of communities and CBOs should drive discussions and decisions around CIE; listening to CBOs and communities is crucial to the success of CIE and to advancing health equity.
- Recognize the capacity of CBOs; any increase in expectations or burden should be offset by increased funding and other supports.

Recommendations

The following recommendations and details are written in ranked order according to the priorities set by the CIE Workgroup.

1. Ongoing sustainable funding and grants

Principles: The Workgroup recommends that several key principles guide funding/grants to CBOs to support their participation in CIE.

- Support for CBO participation in CIE must include ongoing sustainable funding and grants as the success of CIE is inextricably linked to CBO sustainability.
- Minimize associated reporting to focus funding on dedicated CBO resources to address referrals. Any anticipated increases in reporting and referrals should be offset by accompanying increased funding support.
- Recognize CBOs may not be able to respond to all referrals; research reasons behind this and investigate how to further support them.

Adopting CIE is an investment in a changing health and social support ecosystem that runs the risk of not achieving the benefits if it is not sustainable. To reach the anticipated value of CIE (i.e., meeting social needs and moving toward health equity), investments in overall CBO capacity must be sustainable. CIE network participation and technology use will impact CBOs at multiple levels. A core aim of the technology is to facilitate easier referrals, which may increase the number of requests a CBO receives. This will result in greater stress on the system, and document and reveal unmet needs, necessitating the presence of additional funding and grants for CBOs, both around CIE and around service provision and operations.

If you wanted to really open the doors, and really have it be a successful system, we would need a much more increased capacity, which would just be staff costs, and all the other things associated with that, including infrastructure money.
– Interviewee

To support CBO participation in CIE, the Workgroup recommends that sustainable funding and grants focus on the following areas.

1. **Support staff capacity:** A critical priority will be CBOs' need for increased staff capacity to engage in a CIE network, including both use of a CIE platform as an

Recommendations: Support for Community-based Organizations to Participate in CIE



alternate method for working with partners, and to address the likelihood of increased referrals for services (see 4 below). They may also need additional staff support due to training time dedicated to CIE.

2. **Incentivize use:** A second priority for support is to incentivize adopting and using CIE.

For example:

- Tie utilization of CIE to dedicated funding and to meeting certain criteria (e.g., # of referrals or value-based payment model social care contracts)
- Pay for engagement
- Pay to pilot a CIE and provide onboarding support

CIE is an important tool, but it is also important to consider how that tool is adopted, used and shared within the community. We risk alienating smaller clinics or CBOs if we force them to onboard to a system that we cannot incentivize them to use either with staff time or supports. – Survey respondent

3. **Support organizational infrastructure:**

Sustainable funding or grants could support organizational infrastructure and data capture/use. As part of CIE implementation, CBOs may need:

- To update information technology (IT) equipment
- To integrate with existing IT systems CBOs already use (e.g., APIs or application programming interfaces, enabling automated connections between existing systems to reduce data entry burdens)
- Assistance utilizing and analyzing CIE data
- Operations support

4. **Increase overall services and resources:** While the technological infrastructure to support ease of referrals is critical, so are the underlying resources to address the need. For CIE to be successful, it is also a priority that CBOs are appropriately resourced to increase services. CIE can demonstrate resource availability in regions or which types of resources may be lacking, however, for CBOs to join, it is important to anticipate there will be an overall increase in demand for services.

There's still a lot of reservation among CBOs...with the CIE when there isn't funding that comes with it. But because it's, we see it as increasing demand without increasing supply. – Interviewee

Prioritize certain types of CBOs: As CBO funding support is designed, it must be available to a broad range of organizations that provide vital support to communities throughout the state. Within the breadth of organizations, key types must be prioritized including CBOs that support culturally and linguistically specific populations. Over time social needs may change, and CIE data can track and reveal these gaps. Initially the Workgroup believes CBOs that focus on housing and food accessibility and availability should be prioritized. Ultimately, the focus of prioritization should be to reduce inequities.

August 2022

Recommendations: Support for Community-based Organizations to Participate in CIE



2. Technical assistance

Principles: The Workgroup recommends that several principles guide technical assistance (TA) to CBOs to support their participation in CIE.

- Ensure that key people from impacted communities receive training in how CIE works.
- A commitment to continual TA and training rather than a one-time opportunity.
- Tailoring training for each CBO, if desired, to explore how they want to engage in or use the network.

TA and training can cover a wide variety of areas and can support CBOs in managing complex change while also helping them leverage CIE to support existing strategic initiatives. While all areas are important in providing support for CBOs, some TA options are a higher priority.

- 1. Privacy and data integration:** TA support and training in rules and regulation compliance, especially around HIPAA, FERPA, and 42 CFR Part 2¹, and information as to how different systems can achieve interoperability or integration around data is also needed. This will support CBO work overall, and connections between social service providers and other types of partners, while increasing knowledge around key information sharing rules and regulations.
- 2. Workflow:** CBOs need TA to support changes and adjustments to existing organizational processes and workflows as CIE is adopted and utilized within the organization. This ensures that users understand what the technology does and does not do, how it fits with current processes, and how processes may be improved.
- 3. Data support for funding:** This TA will support and train CBOs to build reports and analyze data within CIE to show service delivery, gaps in needed services, and other items that support continued and enhanced funding for staff and services, particularly for reporting to grantors.
- 4. Training:** Many CBOs are in the nascent stage of CIE implementation so support for trainings should include new and advanced use, software, super users, and training of trainers to help ensure that CIE is used to its greatest capacity to support the aims of CBOs. Helping CBOs have full awareness of CIE capabilities will enhance the user experience while maintaining appropriate expectations.

In our nonprofit, we'd say like, there's no such thing as like, too much communication. And in that same regard, I would say that there's no such thing as like too much support. I would say, you can't go wrong with having multiple different ways to provide support.
– Interviewee

¹ HIPAA-Health Insurance Portability and Accountability Act; FERPA-Family Educational Rights and Privacy Act; 42 CFR Part 2-Confidentiality of Substance use Disorder Patient Records



3. Coordination and convening

Principles: The Workgroup recommends that the following principles be kept in mind when considering coordination and convening to support CBOs.

- A key principle is that CBOs must be substantively included in governance at all levels.
- Also, coordination needs to happen across social service, health, and government systems including with policymakers. This will help streamline social service information gathering and referrals as well as promote rules, policy, and legislation that facilitates the provision of sufficient and appropriate services to those that need them.

Coordination is necessary to ensure that CIE is usable across social service and healthcare organizations, useful across sectors, and leveraged by policymakers. Various efforts, investments, and organizations will need to align for successful statewide CIE. Also, the different players need to convene to best coordinate. Convening would consist of two separate but aligned efforts: best practice sharing and governance.

- 1. Governance:** For successful governance, it is critical to establish trusted partnerships where all sectors are represented and there is equal distribution of power.² CIE necessitates CBOs be equal partners in statewide and local decisions, and that community drives governance needs. Governance must enable CBOs to engage locally as well as participate at the broader statewide level. Governing of CIE needs to include equal CBO to non-CBO representation for uptake and buy-in. CBOs should drive expectations, network standards, and membership in their area.

My understanding is that CIE...has been driven by major stakeholders in the health sector...and not been fully informed by the other half of the users, which is community-based organizations or people or organizations that are being referred those clients.
– Interviewee

- 2. Referral coordination center:** In addition, a referral coordination center that accepts calls and referrals and helps traffic them to the appropriate CBO, or other network partner, would help alleviate some burden from CBOs.
- 3. Best practice sharing:** Best practice sharing on CIE use would support CBOs to learn from each other, and other types of organizations across sectors. This would take place through local, regional, and state level convenings.
 - Peer-to-peer meetings and discussions would allow CBOs within the same service area or serving similar populations to support each other, building each other's knowledge and skills with an understanding of the specific needs of their organizations and communities.

² From Office of National Coordinator for Health IT (ONC) [SDOH Learning Forum](#)



- Cross-sector convenings and meetings would expand conversations and highlight different use cases that may spark innovation and new ways of thinking about using CIE to facilitate coordination across the different sectors or services.
 - Statewide convenings and meetings would enhance new and existing networks and connections across Oregon, allowing organizations serving similar populations in different areas of the state to discuss needs and best practices.
- 4. Research and evaluation:** Coordination is needed for research and evaluation of CIE to demonstrate the value, determine what gaps remain, support policy advocacy, and examine what additional investments are necessary for the continuation and sustainability of successful CIE. Evaluation is also needed to make improvements to technical systems, workflows, training, education, and governance. The resources for adequate evaluation need to be included in any developed support.

4. Education

Principles: In considering CIE education that supports CBO participation in CIE, a key principle is to listen to CBO staff and the community regarding how education should look for them. Also, support for training and education should be available in various forms (e.g., virtual, in-person, pre-recorded).

- 1. Various topics for CBOs:** Education in the following areas is necessary to support the implementation of CIE technology and processes. Priority areas are:
- Billing/budgets
 - Use of CIE data
 - Consent processes
 - Privacy compliance
 - Trauma informed practices
- CBOs across the state, we're just yeah, we're all worn really thin. And so asking us to do anything else is like, Oh, no. So whatever support y'all can provide, would be a leading selling point.*

– Interviewee

The following types of educational support would be beneficial to CBOs as well as additional partners in participating in CIE across Oregon. Education to others in the landscape beyond CBOs will support their own participation in CIE and thus support statewide CIE.

- 2. Promotion and public awareness:** Education needs to move forward with promotion and public awareness as well. It is important to publicize participation in CIE and inform the community about CIE through methods such as highlighting stories of success, benefits to communities, new functionality, grants, and opportunities to support utilization.
- 3. Community leaders:** Education and awareness would also help build CIE advocacy by community leaders. This advocacy is necessary for continued engagement with and enhancement of CIE as it matures and develops within the state. This could be supported by education and training for community leaders.

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4. **Consumer/client:** Consumer/client education is needed around CIE as well. This could take the form of handouts, talking points for staff at CBOs, and/or community videos to support education on the tool itself and how and why information is shared. Familiarizing people with CIE could increase the likelihood of engagement in services when they receive outreach from a CBO as the result of a referral.

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August 2022

Appendix D: Full CIE Workgroup Recommendations: Support for Additional Partners to Participate in CIE

Recommendations: Support for Additional Partners to Participate in CIE



Introduction and Purpose

The [Community Information Exchange \(CIE\) Workgroup](#) has been tasked by the [Health Information Technology Oversight Council](#) (HITOC) under [House Bill 4150](#) (2022) with providing recommendations on strategies to accelerate, support, and improve statewide CIE in Oregon.

The CIE Workgroup first discussed how to best support community-based organizations (CBOs), given they are key partners in the success of CIE. The Workgroup met in May 2022 to discuss strategies on how to best support additional partners outside of community-based organizations (CBOs) to participate in CIE (see [Recommendations: Support for CBOs to Participate in CIE](#)). Following the meeting, Workgroup members provided additional input via a post meeting survey. This concept paper is a result of that discussion and survey and will be given to HITOC in August to inform their draft report to the legislature in September and final report in January 2023 as required under HB 4150.

Problem

To successfully support whole person care, a wide variety of organizations must coordinate. CBOs play an integral role in this, and the Workgroup prioritizes CBO support, however additional partners are also necessary for creating a strong integrated social care system. A CIE network can support this coordination and the technology can be a tool for additional partners to send or receive referrals. However, these additional partners may face barriers similar to CBOs and also need support to participate in CIE. CIE participation takes time, financial investment, and human resources for any organization; they must manage the adoption of technology and new workflows. These additional partners may have varying levels of capacity to adapt to these changes. Support for additional partners to participate in CIE is needed to accelerate, support, and improve successful statewide CIE.

Who are additional partners?

For the context of this paper additional partners include:

- Behavioral health organizations
- Oral health organizations
- Physical health organizations
- Safety net clinics (e.g., federally qualified health centers (FQHCs), rural health centers, free clinics)
- Coordinated care organizations (CCOs)
- City or county government (e.g., local public health or county social services)
- And others (e.g., early childhood, school-based social supports)

Summary of Recommendations

When widely adopted across different types of organizations, CIE helps eliminate many of the barriers between people and the services designed to support them. CIE enables a broad

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variety of service providers to connect easily and quickly, which is essential to supporting Oregon in addressing health inequities and the overall well-being of individuals.

The CIE Workgroup recommends that legislation support additional partners in CIE.

Support should include sustainable funding, grants, and offsetting costs; technical assistance; coordination and convening; and education. The Workgroup's top priorities within these areas are:

1. **Sustainable funding, grants, and offsetting costs:** Priority recommended areas for funding, grants, and offsetting costs are staff capacity, incentivizing CIE use, supporting organizational infrastructure, increasing overall services, and leveraging Medicaid funding.
2. **Technical assistance:** Priority recommended technical assistance (TA) areas are privacy, workflow, data support for funding, data integration, and user training.
3. **Coordination and convening:** Priorities for coordination and convening are best practice sharing, governance and alignment of efforts, and research and evaluation.
4. **Referral coordination center:** The Workgroup recommends a referral coordination center to help address issues that may arise in service navigation.
5. **Education:** The Workgroup recommends education to support additional partners that is tailored to organizational needs, focused on CIE platforms, supports using CIE for data collection and payments, and involves diversity, equity, and inclusion training. In addition to education for additional partners, the Workgroup members recommend a range of supportive education for other parties involved in CIE.

In the context of the above recommendations, the CIE Workgroup recommends prioritization of the types of additional partners across all areas of support. Overall, the Workgroup recommends considering organizational size and capacity, communities and populations served and their needs, and the types of services provided by the organizations.

Recommendations

The following recommendations and details are written in ranked order according to the priorities set by the CIE Workgroup.

Prioritization of additional partners

The CIE Workgroup recommends that:

1. Culturally and linguistically specific organizations be prioritized, and support should be tailored to their needs.

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2. Organizational size and capacity be considered as a factor in providing support for additional partners. Often small organizations lack resources, but medium and large organizations may as well. In considering size and capacity, prioritize organizations that need more support.

Holding size and capacity the same, the CIE Workgroup recommends the following prioritization for supporting additional partners across all areas of support:

1. Behavioral health organizations
2. Safety net clinics (e.g., FQHCs)
3. City or county government (e.g., local public health or county social services) and CCOs (tied)
4. Physical health organizations
5. Oral health organizations

The Workgroup considered a subset of additional partners for the purposes of this concept paper and did not prioritize all types of organizations. Note that the above ranking is across all types of support recommended below. The Workgroup had more nuanced thoughts on additional partners' funding support needs, which is explained in the first section.

1. Sustainable funding, grants, and offsetting costs

CIE is an investment in a changing health and social support ecosystem that runs the risk of not achieving the benefits if it is not sustainable. Participating as a collaborative partner in a CIE network impacts organizations at multiple levels, and many types of partner organizations are needed for successful CIE.

To support additional partner participation in CIE, the Workgroup recommends sustainable funding, grants, and offsetting costs focus on the following areas.

1. **Support staff capacity:** A critical priority for any partner organization adopting CIE will be supporting staff capacity. Specifically, hiring new or retaining current staff to increase overall service provision, provide training time, manage the CIE platform, and meet CIE referrals. Additional capacity is needed for adopting and long-term engagement in a CIE network.
2. **Incentivize use:** A second priority to focus funding support is to incentivize adoption and use of CIE. For example, organizations could receive incentives for closing the loop or documenting the outcome of a referral. Incentives will urge partner organizations to prioritize implementation of CIE and could reduce organizational burden thereby supporting sustained CIE use. Another strategy to incentivize use of CIE is to incorporate payments for services into CIE.

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- 3. Support organizational infrastructure:** Sustainable funding or grants could support organizational infrastructure for additional partners. As part of CIE implementation, organizations may need to update information technology (IT) equipment and/or integrate with existing IT systems. Some organizations may already use existing referral systems.
- 4. Increase overall services and resources:** While the technological infrastructure to support ease of referrals is critical, so are the underlying resources to address the need. For CIE to be successful, it is also a priority that additional partners are appropriately resourced to provide services.
- 5. Leverage Medicaid funding:** Federal Medicaid funding could also be leveraged to offset costs for additional partners. This, coupled with incentives, would be useful as funding is required to establish and maintain systems. One member noted this is necessary for sustained CIE use.

CIE Workgroup members had nuanced recommendations on what types of additional partner organizations to prioritize for sustainable funding, grants, and offsetting costs. Behavioral health organizations and safety net clinics need funding support the most. A majority said oral health organizations need this type of support as well. The group was split on this need for physical health and city/county government. Funding support was perceived as a lower priority for CCOs and large health systems.

2. Technical assistance

Technical assistance (TA) and training can cover a wide variety of areas and can support additional partners in adopting and leveraging CIE. Effective TA may have the added benefits of supporting resource-constrained or culturally specific organizations to focus more of their time on the communities they serve and may support organizations to expand their current programs. The Workgroup believes some TA topic areas are a high priority for additional partners, though all topics should be available to partners in order to meet unique organizational needs for adopting and using CIE.

- 1. Privacy:** TA and training on privacy will be a vital component of CIE participation for additional partners. Many organizations need support in understanding and complying with privacy rules and regulations. This TA should include a security and privacy assessment for readiness and strategies for mitigation of risks to ensure data integrity. TA on client privacy and consent will also be an important topic for organizations and individuals. This may encourage organizations who are hesitant to engage with CIE due to privacy concerns.
- 2. Workflow:** Additional partners may need specific TA around workflow to effectively incorporate CIE use into their existing processes. TA should involve workflow mapping

Recommendations: Support for Additional Partners to Participate in CIE



to align with the needs of organizations of all sizes, and to determine the best CIE workflow fit for an organization.

3. **Data integration:** TA for additional partners should also include skill building on interoperability, integration, and information exchange. Integration or interoperability with systems already in use may support more organizational buy-in.
4. **Data support for funding:** TA on how best to use data to support funding and reporting efforts can demonstrate the value in CIE and enable additional partners to better identify community needs, demands, and service gaps. This can be used to plan service provision by leveraging CIE data.
5. **Training:** There are a range of CIE training needs for additional partners. Training should be simple and easy to navigate and consist of both general and tailored training options. High quality accessible trainings may have particular importance for reducing burden for small organizations or those with staff capacity challenges that could impact CIE uptake.

3. Coordination and convening

The CIE Workgroup recommends coordination to support alignment across various efforts and organization types. This is needed to ensure that CIE is usable and useful across sectors and leveraged by policymakers. In order to coordinate, the different players need to convene for best practice sharing and governance. Research and evaluation should also be coordinated.

1. **Best practice sharing:** Best practice sharing would be useful for sharing information and lessons learned across organizations and may be especially beneficial for new partners to CIE who can learn from the experiences of similar organizations. One member shared the idea of a cohort model to group organizations based on factors such as readiness, implementation stage, or expertise. This could also be combined with IT support or education.
2. **Governance:** Governance must ensure all voices will be heard and curtail power imbalance and exclusionary practices. It is needed to make decisions and set standards. Governance is critical to success and consistency for the experience of people being served. It will support organizational engagement through clear agreements and policies, and a space to resolve issues.
3. **Research and evaluation:** There are several areas that can be supported by research and evaluation, which can demonstrate the value of CIE use and social determinants of health (SDOH) screening. Research and evaluation can also support the need to address gaps in services. Evaluations should be leveraged for quality improvement as well as ensuring CIE meets established goals. It can also support additional partners' CIE use by building confidence in the technology and eliciting feedback. Lastly, it can support establishing a value proposition for additional partners to join CIE.

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4. Referral coordination center

A referral coordination center would support successful statewide CIE as well. Given the diversity of organizations and populations that may need to be served by a CIE network, a referral coordination center would help address issues that arise in finding the needed services. A referral coordination center that accepts calls and referrals would help connect people to the appropriate partner. This would especially support organizations with limited capacity as they could screen people and route them to the referral coordination center if they cannot connect them with the correct services.

5. Education

Workgroup members recommend that education be available for additional partners and that it should:

- Be tailored to organizational needs

- Involve diversity, equity, and inclusion training (e.g., unconscious bias or cultural responsiveness trainings)

- Support use of CIE for data collection and payments

- Focus on use of CIE platforms

In addition to education for additional partners, the Workgroup members recommend a range of supportive education for other parties involved in CIE. Notably, they recommend that education involve the creation of client-facing materials to support the use of consistent messaging about CIE, thereby reducing burden on partners to develop materials independently and promoting client/consumer confidence. They also recommend providing education to community leaders to support CIE engagement and as an avenue for professional development. In addition, direct promotion can be used to support public awareness via mainstream and social media to support community access to information about CIE.

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Appendix E: Full CIE Workgroup Recommendations: OHA and ODHS Roles in CIE

Recommendations: OHA and ODHS Roles in CIE



Introduction and Purpose

The [Community Information Exchange \(CIE\) Workgroup](#) has been tasked by the [Health Information Technology Oversight Council](#) (HITOC) under [House Bill 4150](#) (2022) with providing recommendations on strategies to accelerate, support, and improve statewide CIE in Oregon.

The CIE Workgroup met in May 2022 to discuss potential roles for the Oregon Health Authority (OHA) and the Oregon Department of Human Services (ODHS) that would accelerate, support, and improve statewide CIE. This concept paper is a result of that discussion and will be given to HITOC in August to inform their draft report to the legislature in September and final report in January 2023 as required under HB 4150.

Recommendations represent the comments from Workgroup members on OHA/ODHS role(s) and do not necessarily represent the perspectives of OHA/ODHS.

OHA and ODHS Missions and Responsibilities

OHA's and ODHS' responsibilities to people in Oregon include equitable support for holistic health and well-being through funding and programs for social services and health care. The pursuit of equity in support and provision of services is an integral part of the work of these state agencies.

The mission of OHA is ensuring all people and communities can achieve optimum physical, mental, and social well-being through partnerships, prevention, and access to quality, affordable health care. OHA established a 10-year strategic goal to eliminate health inequities in Oregon by 2030.

The mission of ODHS is to help Oregonians in their own communities achieve well-being and independence through opportunities that protect, empower, respect choice and preserve dignity.

Tribal consultation: If OHA or ODHS move forward with CIE activities that impact the nine Federally Recognized Tribes of Oregon or the Urban Indian Health Program, they will follow applicable agency Tribal consultation policies.

OHA Health Equity Definition:

Oregon will have established a health system that creates health equity when all people can reach their full health potential and well-being and are not disadvantaged by their race, ethnicity, language, disability, age, gender, gender identity, sexual orientation, social class, intersections among these communities or identities, or other socially determined circumstances.

Achieving health equity requires the ongoing collaboration of all regions and sectors of the state, including tribal governments to address:

- The equitable distribution or redistribution of resources and power; and
- Recognizing, reconciling and rectifying historical and contemporary injustices.

ODHS Vision for Equity:

Every individual in Oregon has dignity, respect, and full measure of human rights. On October 19, 2020, ODHS adopted The Equity North Star to operationalize this vision.

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Note: While the Workgroup's scope includes OHA and ODHS agencies, the Workgroup recognizes the significant benefit of future engagement by additional state agencies, particularly Oregon Housing and Community Services, the Oregon Department of Education, the Department of Emergency Management, and the Higher Education Coordination Commission. Recent events, including the COVID-19 pandemic, wildfires, and extreme heat events, have exemplified the need for cross-agency use of technology to share information across many partners to ensure no one falls through the cracks.

Problem

OHA and ODHS play critical roles in the provision of social supports, services, and health care. Both agencies play key roles in service delivery, providing critical resources and social services, and referring people to resources in their community. These agencies also work at an organizational and policy level to coordinate and provide guidance to partner organizations and contractors who provide these supports, including health care and social services.

OHA and ODHS are major providers of social services and health care and the ultimate goal of both agencies is for people to achieve their optimum health and wellbeing. Lack of participation by OHA and ODHS in CIE efforts would leave large gaps in the network and risk creating a network that does not reflect the full spectrum of available social services and supports in Oregon.

Summary of Recommendations

When widely adopted across the state, CIE helps eliminate many of the barriers between people and the services designed to support them. OHA and ODHS could play multiple roles to accelerate, support, and improve statewide CIE efforts to support whole person health and well-being outcomes for persons and communities in Oregon.

The CIE Workgroup recommends that legislation support OHA and ODHS roles in statewide CIE efforts. This should include OHA and ODHS program use of CIE, supporting neutral statewide governance, leveraging policy and contractual levers, supporting community-based organizations' (CBOs) and additional partners' participation in CIE, and supporting and participating in coordination. Within these areas, the Workgroup's priorities for the roles of OHA and ODHS are:

1. **OHA and ODHS use of CIE:** The priority recommendation in this area is that OHA and ODHS actively participate in CIE and their programs use CIE where appropriate. Assessment and planning are important first steps that require appropriate time and resources.
2. **Ensure neutral statewide governance:** The Workgroup recommends vendor-neutral governance across statewide CIE efforts that is inclusive of those impacted by and

Recommendations: OHA and ODHS Roles in CIE



participating in CIE efforts. Workgroup members are about equally divided between recommending that OHA and ODHS lead governance efforts or that their appropriate roles are to participate in and support governance, and potentially identify a neutral third-party convener.

3. **Leveraging policy and contractual levers:** Recommended roles in this area are that OHA and ODHS incentivize use of CIE as part of contracts or grants, strengthen policies around care coordination and social determinants of health (SDOH) to encourage use of CIE, and utilize data to further inform policy decisions. It is important to note that with CBOs, the Workgroup explicitly recommends against requiring use of CIE as a condition for receiving contracts or grants, but does recommend incentives or other ways to encourage CIE use.
4. **Support of CBOs and additional partners:** Priority recommendations to support CBOs and additional partners focus on leveraging funding opportunities, providing sustainable funding, and supporting technical assistance, interoperability, and advocacy for connections with existing systems.
5. **Participation and support in coordination:** Priority roles in convening and coordination include assuring a focus on health equity, facilitating communication, helping CBOs participate in convenings, and participating in learning and collaboration opportunities.

Overarching Principles

Implementation of these recommendations should take several overarching principles into account.

- There is a power differential between OHA and ODHS and their non-state partners. The agencies should leverage this influence in a measured way that does not dominate non-OHA and -ODHS entities but works to bring different partners together.
- Sustainability of CIE is needed; this requires both funding and support of efforts and resources at all levels.
- It is critical that access to use of CIE within Oregon is equitable. OHA and ODHS are stewards of the public good and should work for all in Oregon, not only those who currently have access and sufficient resources to engage. CIE can bring many benefits to bear, but to achieve the vision of referrals and accessible information sharing across multiple systems to benefit people, OHA and ODHS should play an integral role in ensuring equity in design and implementation.
- If/when appropriate, OHA and ODHS can act as neutral parties, bringing together a variety of different partners with varying perspectives and priorities.

Recommendations: OHA and ODHS Roles in CIE



These principles should be considered during review of the below recommendations on OHA and ODHS roles in CIE.

Recommendations

1. OHA and ODHS use of CIE

Principle: In using CIE, OHA and ODHS should be held to the same network expectations, and use CIE in the same way, as other participating partners.

OHA and ODHS role: The Workgroup recommends that OHA and ODHS programs use CIE. Active participation by OHA and ODHS in CIE was highlighted as a critical factor for the success of statewide CIE.

Assessment and planning are important first steps.

- The Workgroup recognizes OHA and ODHS are large, complex state agencies with multiple programs that have a wide variety of partners, workflows, and technology systems. This would require engaging partners and significant assessment and planning to determine where and how CIE use is appropriate. The Workgroup recommends that sufficient time and resources be allocated to these efforts.

Active participation should include adoption of CIE by OHA and ODHS programs where appropriate. This should include:

- OHA and ODHS programs send and receive referrals through CIE where appropriate.
- Ensuring OHA and ODHS case managers and staff are trained and able to use CIE to send and/or receive referrals with CBOs and other partners, to better coordinate care and service provision.
- Development and dissemination of best practices around closed-loop referrals within OHA and ODHS programs and between these programs and external organizations.
- Deliberate communication between OHA and ODHS and CBOs to build relationships that support closed loop referrals.
- Engagement with communities and persons receiving services about what OHA and ODHS program participation means for them.

Potential benefits: There are multiple potential benefits to OHA and ODHS use of CIE. Bringing OHA and ODHS into CIE efforts could streamline processes, increase connectivity, and reduce the steps required to connect people with OHA and ODHS services, thereby improving navigation to the appropriate services. Moreover, the accessibility of appropriate information and increased connectivity between external organizations and OHA and ODHS can also enhance the speed of referrals and meeting needs. Overall, collaboration and multi-directional referrals between CBOs and other community resources, state services, and healthcare, help ensure patient and family health and social needs are met.

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OHA and ODHS participation in CIE can also create shared and increased knowledge of what services are available in the landscape. With resources from OHA and ODHS as well as non-state resources included in the system the referral base would be increased for those in need. CIE can also facilitate the ability of providers and CBOs to refer individuals to OHA and ODHS programs that participate as well as track a referral's progress to ensure it has been fulfilled. Likewise, OHA and ODHS can refer to CBOs and other partners and track those referrals as well. By reducing the burden of manual referrals, minimizing delays for contacting and following up, and streamlining data collection and storage, CIE can also help OHA and ODHS staff focus more of their time on service delivery.

OHA and ODHS participation in CIE also widen program and client participation and moves the whole health and social care system closer to closed-looped referrals and monitoring if needs are met.

Overall, with OHA and ODHS participation in CIE, the health and social services system can become more holistic, treating the individual as a whole person, and better supporting a no-wrong-door approach, where someone can be connected to the help they need no matter where they first engage. Finally, as stewards of public good, OHA and ODHS participation and involvement provides greater support for equitable access and supports reducing health disparities within systems of care.

Potential risks: There are some potential drawbacks or risks as OHA and ODHS participation is considered.

- OHA and ODHS and their staff, similar to some CBOs and additional partners, may face barriers to learning new systems. For example, they may have recently switched to a new system, their caseload is high, etc.
- Any new technology or workflow requires extra time and energy to implement and learn; expecting this effort to be done without additional support would reduce the likelihood of success and reduce any of the benefits in the above section.
- Use of a new technology could result in duplication of work or additional workload for OHA and ODHS staff and partners which may increase response times for provision of services.
- Use of CIE by OHA and ODHS programs would also have a direct impact on partner organizations; partners would need to be included in an assessment process to determine when and where CIE use is appropriate.
- While sustainability of funding, participation, and support is critical, it can be challenging to maintain in a dynamic environment with multiple priorities.
- OHA and ODHS involvement could potentially increase bureaucracy and process burden, and a CIE procurement process could be lengthy.
- OHA and ODHS CIE participation could duplicate other efforts to streamline application processes to OHA and ODHS programs.

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- Without due diligence and sufficient funding to ensure barriers are mitigated, there may be unintended negative outcomes for clients
- Using a technology system could distract from the client focus during service provision by OHA and ODHS staff.
- Clients may not wish to sign a release of information to have OHA and ODHS enter information into a CIE, and/or clients may not wish to have their information entered into CIE if OHA or ODHS may have access to the data.
- Safeguards would be needed to protect sensitive information held by ODHS and OHA to only share what a person has authorized.
- Careful consideration regarding state and federal requirements for programs should occur prior to recommending inclusion in CIE, as it may not be appropriate for all OHA and ODHS programs or partners.

These are factors to consider for risk mitigation, but not factors that should halt the recommendations from moving forward.

2. OHA and ODHS to ensure neutral statewide governance

Principle: For successful governance, it is critical to establish trusted partnerships where all sectors are represented and there is equal distribution of power.¹ CIE necessitates CBOs be equal partners in statewide and local decisions, and that community drives governance needs.

OHA and ODHS role: Overall, there was consensus that governance is needed across statewide CIE efforts, and the Workgroup recommends vendor-neutral governance that is inclusive of those impacted by and participating in CIE efforts. In this context, governance is the process of bringing groups together for decision-making, direction setting, evaluating progress, and/or norm setting.

The Workgroup did not come to consensus between recommending that OHA and ODHS lead governance efforts or that their appropriate roles are to participate in and support governance led by a neutral third party. Suggestions included that a representative group or alternatively OHA and ODHS identify a neutral third-party convener. Various suggestions on ways OHA and ODHS could support and participate are:

- Provide a collaborative space facilitated by neutral entities. This would provide for the viewpoints of all to be brought to the table and avoid a focus on vendor or existing system concerns.
- Engage in a public/private partnership or contract out for support of governance efforts. This could include staff and policy support for governance efforts, or potentially the

¹ From Office of National Coordinator for Health IT (ONC) [SDOH Learning Forum: https://www.healthit.gov/news/events/oncs-social-determinants-health-information-exchange-learning-forum](https://www.healthit.gov/news/events/oncs-social-determinants-health-information-exchange-learning-forum)
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creation of an oversight council. (Note: There was some but not significant support for an OHA and ODHS-led oversight council.)

- OHA and ODHS could support the process for developing a long-term governance structure which is inclusive of all interested parties.
- OHA and ODHS could also support the outreach and promotion of the governance group to ensure information is equitably distributed statewide to gain the widest representation possible.
- OHA and ODHS participation in governance is critical for success, but it is important that OHA and ODHS not overwhelm the governance.
- OHA and ODHS could support the leadership and collaboration between CBOs and other partners while providing necessary resource supports for these statewide governance activities.

Potential benefits: There are a myriad of potential benefits with OHA and ODHS participation in and support of statewide governance.

- OHA and ODHS support can provide a space where those participating and impacted can come together and shape CIE efforts. This will help avoid an overemphasis on vendor opinions and voices.
- OHA and ODHS can support the development, implementation, and maintenance of statewide data standards.
- OHA and ODHS's duties to uphold public good and equitable access to services helps to ensure that services and resources are accessible to all, including all languages, cultures, regions and other needs within Oregon.
- OHA and ODHS participation can also help to set norms, guidance, and direction at the statewide level instead of solely at the regional level, facilitating coordination across Oregon. The involvement of OHA and ODHS would help to keep health equity centered within CIE efforts.

Potential risks: There are some potential risks to OHA and ODHS participation in statewide governance.

- There may be a reluctance to comply with standards or guidance from OHA and ODHS as they may not be seen as close enough to the “market” to be relevant for decision-making.
- The agencies may also be seen as too removed from communities, leading to a concern that rule making and norm setting influenced by OHA and ODHS is not culturally relevant or responsive and dynamic enough to meet community needs.
- Partners may not feel empowered if they are seen as having to answer to OHA and ODHS within CIE governance structures. It is important that OHA and ODHS empower CBOs and partners to participate in governance. OHA and ODHS could also be seen as

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working within the confines of bureaucracy, slowing down processes and stifling creativity. Bureaucracy and too many requirements may make decision-making slow and ineffective. Professional, thoughtful, skilled facilitation could help ameliorate this risk.

3. OHA and ODHS to leverage policy and contractual levers to support CIE adoption and use

Principles:

- OHA and ODHS policies should be derived from CBO and community-identified needs and feedback.
- One approach will not fit all entities or clients. It is important to bear this in mind when considering incentives and/or requirements.

OHA and ODHS role: The CIE Workgroup recommends that OHA and ODHS leverage policy and contractual levers to incentivize use of CIE as part of contracts or grants, strengthen policies around care coordination and social determinants of health (SDOH) to encourage use of CIE, and utilize data to further inform policy decisions.

OHA and ODHS have several levers available to support CIE adoption and use that should be utilized, including:

- The Workgroup recommends that OHA and ODHS incentivize and encourage CIE as part of existing or new contracts and grants with CBOs and partners.
 - The Workgroup feels that in some cases requiring use of CIE with non-CBO partners may be appropriate within contracts or grants.
 - With CBO partners, the Workgroup explicitly recommends against requiring use of CIE as a condition for receiving contracts or grants, but does recommend incentives or other ways to encourage CIE use.
- Examples of where CIE may be included in contracts or grants are:
 - Contracts or grants could incentivize initiatives that involve connecting people with social services to utilize CIE infrastructure (e.g., COVID-19 CBO grantees, home visiting programs, rent assistance, utility bill paying assistance).
 - Value-based payment arrangements could include incentives to encourage CIE use.
- Policies around whole person care, care coordination, and SDOH may indirectly encourage CIE use. Policies could be developed or strengthened around use of CIE for SDOH screening, navigation, and care coordination.

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- For example, if the 2022-2027 Medicaid 1115 Waiver application² is approved, OHA could leverage CCO contracts to support CIE utilization.
- The CCO Incentive Measures (e.g., social needs screening and referral measure³, as well as the system-level social-emotional health metric⁴) indirectly support CIE use currently and could be strengthened.
- OHA and ODHS should also use data from CIE, such as around service utilization or gaps in available services, to further inform policy decisions and needed programs. This point will be explored further in [Recommendations: Statewide CIE Data Program](#).

Potential benefits: State policies can serve as a guide toward whole person care becoming the norm, centering equity, and addressing the components of the SDOH. Policies could streamline statewide CIE utilization and encourage partnerships between all types of care including behavioral and oral health as well as survivor of domestic violence programs.

OHA and ODHS have levers available through legislation, contracts, grants, and other program requirements to scale up CIE adoption and use statewide. It would be beneficial to support adoption through both incentives and requirements to support efforts. OHA and ODHS policy and contractual levers can influence an increase in CIE adoption for healthcare providers and state-funded CBO partners.

Leveraging CIE data by OHA and ODHS for further policy development and decision-making can be a critical component of the evolution of CIE statewide.

Potential risks: There are some potential drawbacks and risks to consider for the recommendation around policy and contractual levers.

- Contractual requirements that incentivize or require CIE could increase the reporting burden. This could impact both new organizations and those already effectively using CIE. It will be important to ensure reporting can happen through CIE for the full benefit and to avoid this burden.
- One set of policies or requirements will not fit every organization or situation. Collaboration and cooperation will be necessary to ensure that new requirements support equity and do not exacerbate or continue inequities. Also, if contracts or incentives are tied to CIE use, regions with lower CIE adoption may have less access to that funding.
- The Workgroup would like to caution the legislature against any “unfunded requirements” in considering these recommendations around policy and contractual levers. It is important to ensure adequate funding and resources to carry out any

² [OHA 2022-2027 Medicaid 1115 Demonstration Application](#)

³ [OHA Social Determinants of Health: Social Needs Screening and Referral Measure](#)

⁴ [OHA social-emotional health metric webpage](#)

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requirements are provided, and that there is coordination with recipient organizations to ensure that requirements are reasonable.

4. OHA and ODHS support for CBOs and additional partners

OHA and ODHS role: CIE Workgroup members agreed that OHA and ODHS playing direct roles in support of CBOs and additional partners is necessary to accelerate, support, and improve statewide CIE. Recommendations focus on leveraging funding opportunities, providing sustainable funding, as well as supporting technical assistance (TA), interoperability, and advocacy for connections with existing systems to the extent possible. Specifically, recommended roles for OHA and ODHS in this area are:

- Leverage funding opportunities that would not otherwise be available: OHA is in a position to leverage funding opportunities, particularly federal funding (i.e., Medicaid funding) for certain activities, that would otherwise not be available for CBOs and other non-state organizations.
- Provide sustainable funding for participation and support TA around CIE: This is key for human and social service organizations, CBOs, and healthcare partners to adopt and utilize CIE for core functions. Additionally, strategic funds around boosting participation and engagement could promote participation in CIE for those who may not need ongoing support.
- OHA and ODHS can also support technical integration/interoperability between CIE and existing systems that CBOs and other organizations use. This would include efforts by OHA/ODHS to encourage other systems (e.g., housing systems like HMIS) to coordinate and align efforts around CIE adoption and implementation.
- OHA and ODHS can help CBOs and partners identify where gaps may exist in resource availability. Funding can also focus on areas that will improve overall stability for communities receiving support.
- Support for CBOs and additional partners is explored further in [Recommendations: Support for CBOs to Participate in CIE](#) and [Recommendations: Support for Additional Partners to Participate in CIE](#).

Potential benefits: OHA and ODHS support of CBOs and additional partners in CIE efforts provides beneficial leadership, a sense of legitimacy, and increases confidence in CIE efforts. This involvement exemplifies public sector interest and priority. It is also beneficial because OHA and ODHS have policy levers and funding priorities that other entities do not have and these capabilities can encourage the growth of CIE throughout Oregon.

Another benefit is that through CIE, OHA and ODHS can simplify processes for CBOs and additional partners both to report data and to refer to state services. OHA and ODHS can also encourage adoption, promote consistent processes, and support integration of systems across

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multiple organizations within the state. This can ultimately lead to a greater proportion of people in Oregon receiving support around their social service needs.

Potential risks: There are a few potential risks to consider while determining next steps for OHA and ODHS support of CBOs and additional partners.

- Financial sustainability can be a challenge and if funding ended abruptly that could affect the reputation and credibility of CIE, OHA, and ODHS.
- Organizations may not consider the funding worth the burden if there are onerous reporting requirements.
- Multiple technology systems could increase the burden on organizations and could duplicate data entry. Many Workgroup members think interoperable systems could prevent this and some feel one statewide CIE system could mitigate this risk.
- OHA and ODHS involvement could potentially incur resistance from communities or CBOs if the approach is considered top down or lacking community involvement, particularly if programming or funding does not prioritize Tribal programs and/or programs that serve communities that have been left out of previous programs or efforts.

This paper focuses on OHA and ODHS roles in supporting CBOs and additional partners. For additional considerations regarding CBO and additional partner participation in CIE, see [Recommendations: Support for CBOs to Participate in CIE](#) and [Recommendations: Support for Additional Partners to Participate in CIE](#).

5. OHA and ODHS participation and support in coordination

OHA and ODHS role: The Workgroup recommends that OHA and ODHS support and participate in coordination around statewide CIE efforts. This would include bringing people together for best practice and knowledge sharing, education, and/or coordination of efforts.

Workgroup members recommend that OHA and ODHS fill some important gaps in current convening and coordination, keep health equity a priority, help CBOs, align efforts, and potentially be a neutral entity to lift voices involved in and impacted by CIE efforts. Learning collaboratives would build sustainable knowledge and support throughout the state. OHA and ODHS could support and participate in convening and coordination in the following ways:

- Health equity is an important focus for OHA and ODHS participation and support in convening and coordination.
 - OHA and ODHS can support culturally specific partners to access assistance and ensure their needs are considered in CIE efforts.
 - OHA and ODHS can provide financial support to CBOs for participation in convening and coordination. Smaller organizations often do not have sufficient

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resources to allow staff to participate in convening and coordination as doing so reduces staff available for providing services.

- Funding continues to be of critical importance for OHA and ODHS roles. OHA and ODHS could be contributors of funding for convening and coordination efforts.
- OHA and ODHS can also facilitate communication, learning, and sharing to ensure CIE partners are up to date on resources, and services provided are timely and culturally relevant.
- OHA and ODHS could also help build awareness by sharing information around metrics and outcomes to improve service provision overall.
- OHA and ODHS can also participate in learning and coordination opportunities, such as:
 - Internal OHA and ODHS staff learning collaboratives or participation in staff learning collaboratives with CBOs and partner organizations
 - Information sharing and bringing learnings from other states
 - Leading and supporting collaboratives or communities of practices that support best practice sharing
 - Using contacts and resources to source input on topics and find suitable speakers to address the needs of collaboratives
- OHA and ODHS can be a neutral entity bringing people together to shape and align efforts.
- In addition, OHA and ODHS can further extend the use of CIE by coordinating between OHA and ODHS agencies and local public health to encourage adoption of CIE platforms to connect people with services (e.g., WIC).

Potential benefits: The benefits of OHA and ODHS participation and support in coordination and convening of groups around CIE include:

- Ensuring the voices of all are heard, not just large systems and established vendors and organizations within the CIE space
- The ability to provide funding for smaller and less well-resourced groups to participate
- Expression of a global perspective to resolve issues and address common concerns statewide
- Providing infrastructure to promote statewide CIE success.

OHA and ODHS participation in convening and coordination can also bring necessary leadership and funding; increase the visibility and legitimacy of CIE efforts for those that are not as familiar with the technology; and support the creation or increase in capacity for learning and coordination through learning collaboratives and other opportunities for all organizations.

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Ultimately, OHA and ODHS may have greater ability to convene and coordinate across efforts to increase capacity, programming, and statewide adoption than if CBOs and local partnerships had to complete this on their own.

Potential risks: OHA and ODHS participation in convening and coordination may have some drawbacks and risks. Some organizations and participants may feel that OHA and ODHS involvement means a top-down rather than a collaborative approach to CIE. As efforts are already underway, there may be a preference for OHA and ODHS to join existing coordination efforts or some may not see a role for OHA and ODHS in convening and coordination. To mitigate this, OHA and ODHS should join existing conversations and support or create space for conversations that are not being convened. It will also be important to find a balance between statewide efforts that would benefit from standardization and the unique local efforts that already exist.

OHA and ODHS may not be well-suited to convene partners at very local levels as they may miss key local partners and should instead focus on convening and coordinating with counties and across the state. If OHA and ODHS do not engage in the appropriate ways, (e.g., by maintaining sensitivity to local needs) their needs could engulf CBO needs. OHA and ODHS involvement may also encourage local partners to increase reliance on OHA and ODHS to communicate and/or deliver care as part of the coordinated approach, leading to a less adaptable and responsive network.

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Appendix F: Full CIE Workgroup Recommendations: Statewide CIE Data Program

Recommendations: Statewide CIE Data Program



Introduction and Purpose

The [Community Information Exchange \(CIE\) Workgroup](#) has been tasked by the [Health Information Technology Oversight Council](#) (HITOC) under [House Bill 4150](#) (2022) with providing recommendations on strategies to accelerate, support, and improve statewide CIE in Oregon.

The CIE Workgroup met in June 2022 to discuss a statewide CIE data program that would support, accelerate, and improve statewide CIE. This concept paper is a result of that discussion and was given to HITOC in August to inform their draft report to the legislature in September. The CIE Workgroup met again in October 2022 for a follow-up discussion focused on the principle of a data equity framework. The Workgroup's additions were shared with HITOC in December and incorporated into these revised recommendations to inform HITOC's final report to the legislature in January 2023 as required under HB 4150.

Problem

Currently, siloed systems and data present barriers to fully understanding the resources, gaps, and needs of people across Oregon. There are various efforts to share social needs data, some using CIE and some not, but Oregon lacks a way to bring together statewide data on people's social needs. Visibility into and understanding of these data are needed to build an equitable health and social care system and eliminate health inequities. A statewide CIE data program is a way to bring together data from various CIE efforts on social service needs, resources, and referrals, and provide access to analysis and reporting for decision making and systems level change. It will be difficult to realize the full value of the collaboration between CIE partners or the technology supporting those connections without a coordinated, statewide effort supported by transparent data on the state landscape and what people's true needs are. That visibility can help move systems from individual-level to structural solutions.

Summary of Recommendations

When widely adopted across the state, CIE helps eliminate many of the barriers between people and the services designed to support them. A statewide CIE data program is an integral part of these efforts; success of the program depends on overall systems change and the use of CIE being successful. It is necessary to bring together data across efforts and regions to not only accelerate, support, and improve statewide CIE efforts, but to support whole person health and well-being outcomes for persons and communities in Oregon.

The CIE Workgroup recommends that legislation support a statewide CIE data program. The following outlines the value and potential benefits and risks of a statewide CIE data program and the recommended principles, parts, and roles for OHA and ODHS in a statewide CIE data program:

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1. **Value of a CIE data program:** The CIE Workgroup would like to elevate the significant value of a statewide CIE data program for understanding social needs and resource gaps, measuring outcomes, informing future policy and investment decisions, supporting efficiency, and improving processes.
2. **Potential benefits and risks:** The CIE Workgroup highlights potential benefits and risks to a statewide CIE data program, such as the potential to increase or decrease trust. Additional potential benefits include identifying needs and inequities, empowering interested parties for decision making, and making data available. Potential risks include data quality issues, privacy and security risks, and reinforcing inequities.
3. **Principles:** The Workgroup recommends several principles to guide a statewide CIE data program. The principles center transparency, neutrality, accessibility, equity, accountability, security, and community/individual data ownership and decision-making.
4. **Parts:** Recommended parts of a statewide CIE data program are data governance, aggregation of data, datasets, technical assistance (TA) to support community analysis and data use, dashboards and reports, and evaluation.
5. **OHA and ODHS roles:** The CIE Workgroup recommends that OHA and ODHS play a role in funding and supporting a neutral organization to lead a statewide CIE data program. The Workgroup also outlined potential benefits and risks to OHA and ODHS having roles in a statewide CIE data program.

What could be considered CIE data?

For the context of this paper, examples discussed as CIE data include:

- Types of services available and their locations
- Services searched for and search area
- Screening and assessments
- Demographic data (e.g., REALD/SOGI)
- Referrals made and whether referrals resulted in services being provided or not
- Social care record

Recommendations

The following begins with the rationale for the recommended statewide CIE data program, outlining the value and potential benefits and risks the Workgroup would like to highlight (sections 1-2). The second part (sections 3-5) is the Workgroup's recommendations on guiding principles, program parts, and OHA and ODHS roles in a statewide CIE data program. The recommendations are not presented in a ranked order.

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1. Value of a statewide CIE data program

The CIE Workgroup would like to elevate the significant value and many applications for CIE data and recommends a statewide CIE data program to realize the following opportunities:

1) Understanding needs and resource gaps

A CIE data program would provide an opportunity to define and understand social needs across Oregon as well as within populations and communities. Data on available services and resources, referrals and requests, what needs are able to be met, and what is left unfulfilled can provide an understanding of existing resource gaps. The data could also document inequities through analysis of regional needs and demographic information. A statewide CIE data program could help paint a picture of funding needs for specific service types, regions, populations, and organizations. This could be used to increase access to services and lead to system change.

2) Outcomes measurement

There is also the potential for measuring overall outcomes of people accessing or attempting to access services and resources throughout the state. Data could be used to shed light on whether people are equitably receiving the services they need. With follow-up, the success of services provided or of CIE could be measured. It could also show long-term changes or connections across other types of outcomes. For example, becoming housed may connect to lowering food insecurity, which in turn may connect to lower diabetes risk. This information could also be visualized by overlaying resource maps with outcomes maps. In the long term, CIE data can contribute to improving research on the models and approaches to meeting needs at various levels (e.g., the social-ecological model¹).

3) Future policy and investment decisions

A CIE data program could leverage data to guide policy and investment decisions in services and programs. Improving the depth of knowledge of people's needs and outcomes across the state could shape policy and target services based on social determinants of health (SDOH) or other relevant data. Understanding could be gained about changes over time as community conditions shift as well as analyzing how investment in certain sectors or services changes the availability, demand, or access to services. This improved understanding could have implications for future local, regional, or state allocation of funds and legislative efforts.

4) Efficiency

A statewide CIE data program could support efficiencies in the social care system. The data provide opportunities to track time to receiving services, identify and understand

¹ [CDC Social-ecological model explanation](#)

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incomplete referrals, and overall identify system barriers to getting people the care they need. These data could also be used to build better cross-entity connections to improve the effectiveness and efficiency of services. Organizations could know at an aggregate level to what partners they refer most frequently, or what needs their clients have that they do not have connections to and can take steps to build those connections.

5) Process improvement

A statewide CIE data program could also track process measures, such as CIE utilization, which could be used for process improvement.

6) Coordinated care organization (CCO) metrics

CIE data could support upstream CCO quality measures, such as the systems-level social-emotional health metric² and the social needs screening and referral measure³. For example, a statewide CIE data program could support asset mapping through understanding and mapping services available throughout the state or by region, or potentially analyzing relationships between organizations based on referrals.

2. Potential benefits and risks of a statewide CIE data program

The CIE Workgroup recognizes a number of potential benefits as well as risks to be mitigated if a statewide CIE data program were to be implemented.

Potential benefits

1. Identifying needs and inequities

A large benefit of a statewide CIE data program is the potential to identify needs and inequities across Oregon. The ability to bring together and look at statewide data on resources, needs, and referrals will provide a clear picture of Oregon's diverse communities' needs as well as a better understanding of the whole state's population. A statewide CIE data program would provide the ability to track trends in social needs closer to real time. It could provide a snapshot of community resources as well as historical trends. If the types and location of services are not sufficient to meet the needs in an area, this could be shown, and potentially highlight inequities (e.g., in rural areas or certain neighborhoods). A data program could also provide an inventory of services, particularly specialty services.

2. Empowering for decision making

Another potential benefit of a statewide CIE data program is that it will provide information to empower individuals, communities, service providers, policy makers, and others for

² [OHA social-emotional health metric webpage](#)

³ Final specifications for 2023 SDOH social needs screening and referral measure will be posted on the [CCO Quality Incentive Metrics webpage](#)

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decision-making. Data, dashboards, and reports would be tools to advocate for systems change.

3. Increase trust

A statewide CIE data program could increase trust in CIE itself, systems of care, government, health care organizations, etc. This could occur through the transparency and accountability of acknowledging and acting on data, as well as improved and more agile responses to needs.

4. Data availability

A statewide CIE data program would increase the availability of data so that it can be leveraged by those who would not typically have access to it. This directly relates to the benefits mentioned above of identifying inequities and empowering people for decision making. Additionally, it is difficult to manage what is not measured. These data need to be available to understand how to improve the social care system to address social needs and impact SDOH upstream.

5. Support cross-regional partnerships

A statewide CIE data program could also support partnerships across regions as partners connect, collaborate, and build relationships.

Potential risks

1. Data quality issues

In a statewide CIE data program, there could be risks to data quality, as with any data program. If CIE is not widely adopted, data would not be comprehensive. Low utilization of CIE would lead to incomplete data, which would lessen the utility of a data program. Data could be inaccurate or incomplete, which would not reflect the reality of community needs. Communities who face current and historical inequities should be engaged to identify and address areas where there are issues with data quality. The data equity framework recommended in Section 3 (page 8) will have implications for how these data are analyzed and represented. Without care and thoughtful planning, data on sensitive services may be underrepresented. Also, people may diminish the data captured by paraprofessionals, those outside the clinical system, traditional health workers, etc., not valuing it as strongly as clinical data are viewed.

2. Risks of CIE/data implementation

It is important to avoid the risk of prioritizing funding the referral system technology rather than the services themselves. Additionally, there could be duplication of efforts, staffing concerns, and increased referrals to already taxed systems. There is a risk that CIEs would not be used consistently in all parts of the state or that there would be too many similar types of measurement that do not directly overlap (e.g., similar sets of screening questions

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that don't explicitly match). Lastly, there is a risk that multiple CIE platforms could make statewide data collection challenging and potentially disadvantage regions not using the same platform.

3. Privacy and security

Privacy and security of the information would need to be considered in a statewide CIE data program. All data must be balanced with risks to privacy and security. Particularly, the confidentiality of sensitive information would need to be considered. Also, legal protections must be adhered to, such as HIPAA⁴.

4. Inequity

There remains a risk that even with a statewide CIE data program, access to data could remain inequitable. It is paramount to consider at every step how to avoid reinforcing inequities in a statewide data program. Also, there is a risk that positive measures would not be included in the CIE data set and result in a focus on gaps and needs rather than highlighting the capacities that already exist in communities.

5. Reinforce distrust and stigma

If requests are frequently ignored or denied, or the data are not acted on to improve access to needed services or respond to community needs this could create distrust. Long standing systemic inequities have also created distrust among some populations and communities who may not want information linked to state agencies or in a technology system in this way. Lastly, although statewide data would be used at an aggregate level, some may be concerned about the stigma of the potential visibility of the services they are seeking.

6. Sufficient funding

A risk to the statewide CIE data program is insufficient funding to operate. Without adequate funding, there is a risk to data quality and the ability to use data to gain the intended value. If adequately and sustainably funded, there are great potential benefits to a statewide CIE data program.

3. Recommended principles of a statewide CIE data program

The CIE Workgroup recommends the following principles to guide the development and utilization of a statewide CIE data program. These principles center transparency, neutrality, accessibility, equity, and security in the development of a data program that can serve the needs of people and organizations across Oregon.

⁴ HIPAA-Health Insurance Portability and Accountability Act
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1) Build trust through transparency

Transparency should be a central principle of a statewide CIE data program and is essential for building trust. Achieving trust through transparency requires foundational relationship building with communities, ensuring individuals' rights to their own data, neutral ownership of aggregated data, and openness about how data will be stored and used.

2) Easy access to understandable data

Another important principle is that a statewide CIE data program provide easy access to understandable data. Data from the program should be in easy-to-access formats and available analyses should be easy to understand. Technical assistance (TA) should be widely available to support communities and organizations in using the data, including interpretation and visualization. The data program should establish mechanisms to ensure access to the data across all organizations, even those not enrolled in CIE, is available free of charge. Data should be accessible regardless of CIE vendor used or other private entities involved. To support access, data reports could be regularly posted online and additional opportunities to innovatively disseminate data to all communities should be explored further. Continuous evaluation of the program for data quality, utility, and equity will also be necessary to support meaningful data access.

3) Communities and individuals guide decisions around data sharing, visibility, and ownership

Decisions around data ownership and use should be led by the people receiving services and communities. This will require equitable representation of CBOs in planning for a statewide CIE data program and for individuals to decide if and when their information is shared. Additionally, historically underrepresented communities need to be overrepresented at the table in decision making. Embedding this principle in the decision-making process is essential for supporting trust and sustainability of a statewide CIE data program.

4) Neutral statewide convening for data use principles and oversight

Workgroup members recommend neutral statewide convening around data use principles and data oversight. A statewide oversight council composed of consumer/client and organization level interested parties representing the diversity of identity, culture, language, disability, and geography of people in Oregon would be responsible for the oversight. The oversight would include data coordination across CIE efforts, ensuring adherence to established data use principles and standards, and updating such principles and standards as needed.

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5) Develop and apply a data equity framework

The Workgroup recommends the development and application of a data equity framework to guide the statewide CIE data program. A data equity framework would ensure that the needs of and impacts on people whose information are part of the statewide CIE program remain at the center of approaches to data collection, storage, treatment, use, interpretation, and sharing. This framework should be anti-racist and designed to center the perspectives and needs of the communities most impacted by systems of oppression in order to support all people in Oregon in reaching their full health potential free from disadvantage based on their identities, community membership, or other socially determined circumstances.

The data equity framework should aim to prevent intentional or unintentional harm from the data program. This should involve identifying the influence of power dynamics on the data program, including funding relationships, examining how these dynamics impact which data are collected, how they are analyzed, and who benefits from the data. Additionally, qualitative data must be incorporated into the data program; they provide insight into people's lived experiences and must be valued.

To be effective, development of the data equity framework should include further review of data equity frameworks used in other communities or other settings and incorporate additional best practices that are relevant for Oregon. Oregon's CIE data equity framework will need to allow for the time needed for the statewide data program to demonstrate impact.

Ultimately, the end result of the CIE data program should be to look upstream and help address the root causes of inequities. The data equity framework should be designed with this end goal in mind.

6) Accountability through commitment and participation

Those participating in statewide CIE are essentially contributing data and therefore need to be accountable to each other for the success of a statewide CIE data program. This necessitates commitment and participation as fully as is appropriate for their role or organization. Firstly, this would involve outreach, education, and listening in order to come to consensus on standards that meet the needs of a multitude of participating organizations. Next, this would involve adhering to standards to support data quality, such as placing referrals and documenting the outcome in CIE, whether a need was able to be met or not, to close the loop.

- **Further explore if a principle around scope is needed**

Workgroup members questioned whether there is a potential need to explore the scope of a statewide CIE data program. Determining what types of data may be aggregated under a

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statewide CIE data program may be needed. For example, defining what types of services fall under CIE data.

4. Recommended parts of a statewide CIE data program

The CIE Workgroup recommends the following parts make up a statewide CIE data program:

1) Data governance

Data governance would entail the development, implementation, and oversight of standards for data collection, quality, and management, as well as principles for data use. It would also include privacy and security policies to ensure the data are protected. As mentioned above, the Workgroup recommends neutral convening for data governance. Data governance is an integral part of a statewide CIE data program to ensure that data are reliable and trustworthy, standards are followed, data are coordinated, and that interested parties have a voice in data decisions.

2) Aggregation of data

Aggregation of data is a recommended core function of a statewide CIE data program. This aggregation, bringing together data from various systems, is necessary to understand the needs and resource gaps statewide, and ultimately gain the potential value of CIE. The data could be centralized in one place and could integrate with existing systems, including systems service organizations are already required to use. A centralized database should allow for efficient connection and data extraction and data fields should be aligned with state of Oregon requirements, such as race, ethnicity, language, and disability (REALD) and sexual orientation and gender identity (SOGI) standards. Access and permissions to the aggregated data must be appropriate to each CIE user's role.

In addition to a statewide view, aggregated data would provide the ability to segment and view different levels of data where appropriate, allowing communities to view and use community-level referral and outcomes data to drive decisions about existing and future service needs in their own communities. The aggregation of data allows for the following parts of the statewide CIE data program to occur.

3) Datasets

To support transparency and access to the aggregated data, de-identified datasets should be made available as part of a statewide CIE data program. Making high-quality and appropriately vetted de-identified data available to the public aligns with the CIE workgroup recommendation of building trust through transparency. The availability of these datasets for research is also an important mechanism for building trust in CIE among people in Oregon by facilitating regular reporting and use of datasets by researchers engaging in evaluation.

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4) Tools and technical assistance (TA) to support community analysis and data use

Workgroup members also recommend that the statewide data program offer tools and TA to support community members and organizations in understanding where the data comes from, the potential uses, and the reports. Tools and TA would also support communities and organizations to analyze and apply the data. Specifically, TA could help organizations easily access and use information about their own services, referrals, and outcomes to best inform programmatic decisions. Tools could also be in the form of guidance.

5) Dashboards and reports

Additional components of a statewide CIE data program are publicly available data dashboards and reports to make analyzed data available to the public and decision-makers, including community members and legislators. These could include dashboards that display needs, gaps, and supply of services; quality metrics; maps; and infographics to visualize data elements. This could also include public reporting on how data are being made available and how data are being used. These are all essential to the accountability and transparency of the program.

6) Evaluation

Evaluation is another needed part of a statewide CIE data program. Evaluation utilizing the data of a statewide CIE data program will help identify gaps, strengths, and opportunities for improvement in Oregon's social care system and the CIE system itself. A CIE network would need to be dynamic and responsive to these changes. Meaningful metrics and objectives will need to be set and evaluated to demonstrate progress in improving referrals via the use of a CIE statewide data program. Evidence generated by such evaluation can provide lessons learned and best practices which can be shared across regions and communities in the state. CIE Workgroup members note the importance of developing relationships and contracting with researchers who can maintain neutrality while evaluating data and systems within the statewide CIE data program.

5. Recommended OHA and ODHS roles in a statewide data program

OHA and ODHS Role: The CIE Workgroup recommends a number of roles for OHA and ODHS in a statewide CIE data program:

- OHA and ODHS play a role in funding and supporting a neutral organization to lead a statewide CIE data program: This organization would have experience in community outreach, listening skills, data gathering and cleaning, and making meaning of qualitative and quantitative data. Funding from OHA and ODHS could support the data program technology for aggregating, analyzing, and disseminating data, as well as support of some staffing at the neutral coordination organization. The Workgroup recommends that OHA and ODHS be funders, data contributors, data users, and

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participants in governance. However, OHA and ODHS would be fully responsible for data governance of state-managed data.

- OHA and ODHS participate in CIE and data program: CIE adoption and use by OHA and ODHS⁵ is an important part of a statewide CIE data program so that services and resources provided by the agencies are part of the aggregated data, providing a full picture of services and needs across the state. OHA and

See [Recommendations: OHA and ODHS Roles in CIE](#) for details of Workgroup recommendations on OHA and ODHS use of CIE. The following will focus on OHA and ODHS participation in a data program.

ODHS could use aggregated data on the people they serve to better understand how various services impact outcomes. This will enable state agencies to make evidence-informed programmatic decisions and to invest strategically in programs and services that best support positive outcomes for people in Oregon. The agencies should leverage data to coordinate on improving outcomes of the people they serve. Overall, OHA and ODHS participation in the statewide data program will result in a more robust data resource.

- OHA and ODHS provide training and other support: This could be related to data collection workflows and data use, including regional support staff to facilitate data coordination. OHA and ODHS could also provide informatics and information technology (IT) staff to build out and manage data in CIE as well as to support CIE partners.
- A minority of Workgroup members recommend OHA and ODHS fully run data governance, standards, and regulation of CIE data as part of a statewide CIE data program.

Potential benefits: The potential benefits of OHA and ODHS supporting a statewide CIE data program include:

- Reports, dashboards, and some aggregated data would be available to the public
- Data consistency through standards creation and enforcement
- Added credibility to the services and platform(s)
- Data from different sources could be accessed and combined
- Systemwide CIE data could be used to enhance available programs or create new ones
- Enhanced capacity of some partners and CBOs to contribute and utilize CIE data
- Knowledge from health IT leadership could advance the data system and ensure it is useful and usable

⁵ While the CIE Workgroup's scope is specific to these two state agencies, they recognize the benefits of future participation in CIE by additional state agencies using lessons learned from their participation.

Recommendations: Statewide CIE Data Program



- OHA and ODHS programs utilizing CIE would add to the quality of data
- Cost savings, for example integration with CCO metrics could reduce resources required of CCOs

Potential risks: There are potential risks both to OHA and ODHS participation in a statewide CIE data program and substantial risks to the agencies *not* playing a role. These include the following:

- Risk of *not playing a role*: The failure of OHA and ODHS to participate in and support the data system could lead to a poorly maintained and incomprehensible system. Lack of support and data contribution would be a risk to the success of CIE efforts and a statewide CIE data program.
- Bureaucracy: There is a risk that the bureaucracy of OHA and ODHS involvement could be slow and cumbersome. Getting through the multi-layered systems and policies of the agencies prior to adoption could slow down efforts.
 - Shifts in leadership could affect the level of commitment to participation.
 - This would also put demands on OHA and ODHS staff time and administrative burden. There is a risk if there is not sufficient funding and staff capacity to support this large undertaking.
 - As mentioned previously, OHA and ODHS participation could cause a lack of trust and alienate potential clients.
- Data management burden: There is a risk that managing data quality and data reporting creates burden. This could increase demand on staff time and administrative burden for organizations participating in CIE and a data program.

You can get this document in other languages, large print, braille, or a format you prefer. Contact Hope Peskin-Shepherd at Hope.Peskin-Shepherd@dhsosha.state.or.us.

Appendix G: Full CIE Workgroup Considerations for Privacy and Security of Statewide CIE

Considerations for Privacy and Security of Statewide CIE



Purpose

The [Community Information Exchange \(CIE\) Workgroup](#) has been tasked by the [Health Information Technology Oversight Council](#) (HITOC) under [House Bill 4150](#) (2022) with exploring strategies to accelerate, support, and improve statewide CIE in Oregon.

The CIE Workgroup met in September 2022 to discuss privacy and security of statewide CIE. The discussion generated guiding principles and initial privacy and security considerations for CIE in Oregon. This concept paper is a result of those discussions and will be reviewed by HITOC in December to inform their HB 4150 final report to the legislature in January 2023.

Context

When widely adopted across the state, CIE can help eliminate many of the barriers between people and the services designed to support them. It enables a broad variety of service providers to connect easily and quickly to organizations across the health and social service spectrum. Organizations can search a shared resource directory for appropriate services, send timely referrals, and receive feedback on whether the services were provided, a process known as “closing the loop”. CIE can save consent, demographic, and other types of information to help coordinate services. The information from CIE can also be leveraged to improve the health and social care systems and support equity in service delivery. Ensuring privacy and security of this information is a critical consideration for CIE efforts in Oregon, as well as important for building trust with individuals and communities.

Privacy generally refers to an individual’s ability to keep certain personal information free from unauthorized access and the ability to access and share the information themselves.

Security is the way organizations control access and protect this information, including safeguarding it from accidental or intentional disclosure.*

Since CIE encompasses a wide variety of social service, health, and additional partners who need to collect and exchange different types of information to coordinate care, multiple laws (e.g., HIPAA, FERPA, 42 CFR Part 2, and FTC regulations¹) and standards may apply to how information is handled in CIE. This information may include identifying, demographic, physical health, behavioral health, or other sensitive information, in addition to the social needs and services information necessary for CIE. CIE partners may encounter types of information new to them and requirements they are unfamiliar with. Moreover, individuals may have expectations about how their information is handled that differ from the legal requirements for its use. These standards, expectations, and legal requirements for different types of information and organizations create a complex environment for CIE partners and individuals

¹ HIPAA-Health Insurance Portability and Accountability Act; FERPA-Family Educational Rights and Privacy Act; 42 CFR Part 2-Confidentiality of Substance use Disorder Patient Records; FTC-Federal Trade Commission

*<https://www.healthit.gov/playbook/privacy-and-security/>

Considerations for Privacy and Security of Statewide CIE



being served. This complexity will need to be considered as CIE efforts continue and laws and standards evolve.

Summary of privacy and security principles and considerations

The CIE Workgroup recommends several privacy and security guiding principles as well as considerations for statewide CIE.

The following outlines **privacy and security principles** to guide statewide CIE in Oregon:

- 1. Communities and individuals must guide decisions around collection, storage, sharing, and use of their information:** The CIE Workgroup elevates the need to empower individuals and communities whose information will be shared in CIE to play a central role in guiding decisions about how that information is handled.
- 2. CIE systems must adhere to applicable privacy and security laws and should follow national standards:** The CIE Workgroup recommends that statewide CIE efforts adhere to existing and future privacy and security laws as well as to established standards at the national level rather than focus on developing new stand-alone approaches.
- 3. Information that will improve services, care, and equity should be collected and shared in CIE:** The Workgroup prioritizes information that will improve service provision, care, and equity, both for the individual being served and the overall health and social care systems. It will be important to be thoughtful about what information to collect to maximize privacy, have sufficient information to provide services easily, and avoid asking individuals repeatedly for the same information.
- 4. Transparency on how information will be stored, shared, and used is essential to building trust:** The Workgroup asserts that transparency about what will happen with information individuals provide is critical to ensuring trust. Clear and understandable information on how information will be protected and shared is necessary to achieve this.
- 5. Inclusive neutral governance is needed and would include governance of information privacy and security:** The CIE Workgroup recommends including oversight of information privacy and security in the CIE governance process. Members elevate the need for additional working groups with this focus.

The CIE Workgroup also discussed several key areas and puts forth the following initial **considerations**:

- Types of information in CIE:** In addition to the social needs and services information that must be included for the primary purpose of CIE, the CIE Workgroup feels there is value in collecting and exchanging identifying, demographic, physical health, behavioral health, and sensitive information in CIE, with appropriate safeguards in place.

Considerations for Privacy and Security of Statewide CIE



- **Informed consent:** Informed consent is essential to building trust and maintaining transparency. Members provide considerations on the clarity, frequency, and content of the consent process as important factors to consider in planning for informed consent.
- **Individual access:** Most CIE Workgroup members agreed that individual access should be part of CIE, meaning that individuals could access their own information in CIE, or search for resources and self-refer.

Guiding principles for privacy and security

The CIE Workgroup recommends the following principles to guide decisions about privacy and security in CIE efforts. For example, the principles would be applied to decisions about implementation of CIE technology; privacy and security related governance; types of information; processes for collecting, sharing, and analyzing the information; interactions with individuals being served; and/or agreements between CIE partner organizations. These principles center individuals and communities, their needs and decision-making power, and the safeguarding of personal information that can be shared through CIE.

1) **Communities and individuals must guide decisions around collection, storage, sharing, and use of their information**

People and communities that will have their information in CIE must guide decisions about how that information is handled. It is important to share the appropriate amount of information so as not to burden a person with re-telling their story or completing repetitive forms, while at the same time protecting and securely exchanging that information, to ensure individuals have access to the services they need. Individuals should also be able to guide decisions around what information is essential to their care and have information corrected when it is wrong. The Workgroup recommends further exploration of allowing individuals to restrict what information they want shared via CIE without disrupting service provision.

It will be important for communities and individuals to guide how information is used to identify disparities and opportunities for interventions to address them. Workgroup members emphasize that protecting individual privacy is not in conflict with allowing for aggregation of information in CIE to better understand service gaps and opportunities for policy change.

2) **CIE systems must adhere to applicable privacy and security laws and should follow national standards**

Adherence to established laws, such as HIPAA, FERPA, 42 CFR Part 2, and FTC regulations² and aligning CIE systems with national and industry standards are Workgroup

² HIPAA-Health Insurance Portability and Accountability Act; FERPA-Family Educational Rights and Privacy Act; 42 CFR Part 2-Confidentiality of Substance use Disorder Patient Records; FTC-Federal Trade Commission October 2022

Considerations for Privacy and Security of Statewide CIE



priorities. Monitoring and adapting as laws and standards change will be necessary. Members emphasize relying on these standards rather than redesigning existing regulations and practices, as developing state-specific requirements could be difficult to implement for example. Workgroup members also highlight that many organizations, particularly smaller ones, need support to understand and follow privacy and security laws and standards.

3) Information that will improve services, care, and equity should be collected and shared in CIE

When considering what information to include in CIE, decision makers should prioritize information that will improve service provision, care, and equity, both for the individual being served and the overall health and social care system. It will be important to be thoughtful about what information to collect in order to maximize privacy, but still have sufficient information to provide services easily. The Workgroup suggests basing data collection and sharing decisions on necessity and basing data storage decisions on whether there is an ongoing need for the information.

Members also highlight a need to balance privacy protections with client experience to avoid asking individuals repeatedly for the same information. Further consideration should be given to connecting CIE with other data sources to support the collection of minimal information and critical equity goals, while also maintaining privacy.

4) Transparency on how information will be stored, shared, and used is essential to building trust

For individuals and communities to trust CIE, it is critical to be transparent about what will happen with the information they provide. One opportunity to achieve this is through a clear, understandable informed consent process. During this, individuals will need clarity about how their information will be stored and shared and what their options are, including the option to opt out of participating in CIE and still receive referrals or services. Staff at organizations using CIE need training on how to have trauma-informed conversations about information sharing, as well as training on privacy and confidentiality laws. Another opportunity to provide transparency is through education with communities, organizations, and individuals around CIE efforts and how it works when implemented. Relationships between organizations and with individuals being served will still be important to building trust.

Informed consent in this context means individuals provide permission for their information to be included or shared within CIE, with an understanding of what will happen with their information in CIE and possible risks and benefits.

See p. 7 for considerations to achieve informed consent.

Considerations for Privacy and Security of Statewide CIE



5) Inclusive neutral governance is needed and should include governance of information privacy and security

The CIE Workgroup recommends that inclusive neutral governance include oversight of information privacy and security, likely through a specific group or subcommittee that includes privacy and security experts. Members emphasize this would likely entail an organized process and in-depth procedures to ensure the different types of data collection and methods of information sharing can be accomplished while protecting privacy and security. Members also highlight the need to allow enough time for governance processes to accommodate the complexity of privacy and security issues for CIE in Oregon, and the importance of centering community, CBOs, and individuals impacted in governance decision-making.

Considerations for privacy and security

CIE should support seamless exchange of information between organizations that provide health and social service supports while maintaining privacy and security. The CIE Workgroup highlights the need to balance privacy with timely access to critical information to ensure that people receive the help they need where and when they need it. This is crucial during times of public crisis such as wildfires and pandemics as well as during circumstances requiring urgency for individuals.

The CIE Workgroup puts forth initial considerations and recommends additional exploration of the privacy and security topics below:

1) Types of information in CIE

The CIE Workgroup discussed types of information that may be collected and exchanged in CIE and considered potential benefits and risks. Social needs information and social services must be included as they are the main purpose of CIE. Additional information may be necessary or helpful for providing services. Types of information considered included identifying, demographic, health, behavioral health, and sensitive information.

- **Identifying:** The majority of Workgroup members feel identifying information needs to be part of CIE and is necessary to provide services. There

Types of CIE information discussed for the context of this paper included examples such as:

- **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.

* Race, ethnicity, language, and disability (REALD); Sexual orientation and gender identity

** Human immunodeficiency virus/sexually transmitted infection

Considerations for Privacy and Security of Statewide CIE



may be situations where people need the ability to indicate specifically how to contact them, such as an intimate partner violence situation, and this should be considered.

- Demographic: CIE Workgroup members also see significant value in collecting demographic information, and most members feel this information should be part of CIE. Some potential benefits include identifying linguistic or culturally specific services to refer to and leveraging data to ensure equitable access to services. However, the options in technology systems do not always capture people in the way they would like to be represented. Also, people may be concerned that sharing that information would make them less likely to receive services or change how they are treated. Some individuals may only want certain people to see demographic information, such as sexual orientation or gender identity. These potential risks or safeguards should be considered as CIE efforts develop.
- Health and behavioral health: Most Workgroup members also felt that physical health and behavioral health information should be collected and exchanged as part of CIE. Although the Workgroup did not explore this topic in detail, they identified situations where a CIE referral could be more valuable with specific health or behavioral health information. One potential benefit of including these types of information is the improvement in physical and behavioral health outcomes as a result of receiving social services. However, there are implications due to privacy requirements when including this information in CIE. These areas will need to be thoughtfully considered during further exploration.
- Sensitive information: The Workgroup recognizes there may be circumstances where availability of certain information to coordinate services could overly compromise privacy, such as in situations of intimate partner violence or HIV/STI services. In circumstances such as these or similar, privacy takes precedence and CIE should have safeguards in place to handle such information appropriately and protect the individual. However, this should also be balanced against ease of information collection and exchange to minimize barriers for people being served. Regulatory requirements for protections of certain information should also be accounted for as CIE efforts are developed and implemented.

Overall, people accessing social services are asked for their information repeatedly, and in multiple settings. CIE is an opportunity to reduce the frequency that people are asked for the same information, potentially reducing trauma for the individual and stigma around receiving services. Additionally, Workgroup members emphasized that to make CIE valuable, there needs to be enough information provided with a referral to appropriately serve the person and not slow down the provision of services. In general, the more information a social service provider has about a person, the better they can deliver for the

Considerations for Privacy and Security of Statewide CIE



individual overall. Workgroup members suggest that further exploration is needed on how to handle various types of information in CIE.

2) Informed consent

Informed consent is a critical aspect of CIE efforts and is essential to building trust and maintaining transparency in what will happen with information. The CIE Workgroup highlights clarity, frequency, and content as important factors to consider in planning for the process of informed consent by people served with CIE.

- Clarity: Members emphasized the importance of ensuring that people understand what they are consenting to. Consent information needs to be accessible, readily understandable, and clear. To support these needs, service providers and clinicians should be trained on how to provide consent information clearly. Consent information should be available in a wide variety of languages, in plain language, and through multiple formats including remote/telephone options. The consent process should also include clear information on how to revoke consent to CIE and that individuals can opt out of CIE, but still receive referrals to services. These steps can ensure that people being served are able to make well-informed decisions about whether to consent to CIE.
- Frequency: Members also considered whether consent to participate in CIE should be obtained a single time, before every referral, or somewhere in between. Most members felt that consent should be obtained once, or potentially more than once in certain situations, but not each time there is a referral. They mentioned the importance of balance between the need to obtain consent and the need for expedient referrals. Requiring repeated consent may conflict with the goal of using CIE to reduce barriers to care, as repeated consent could be a burden, especially for someone in crisis who needs help quickly. Rather, a conversation with the individual regarding each referral, even if a consent form is not required each time, may support a person-centered approach. Members suggested that reducing barriers to providing and revoking consent will be important and should allow for both in-person and remote options. The Workgroup indicated that further exploration is needed in this area.
- Content: Determining what details should be included in the informed consent process will also require further discussion and decision-making, but Workgroup members suggest that any informed consent process lay out the options, potential outcomes, and benefits and risks of consenting. It should be clear in the consent process who will have access to the information shared and how protections function to ensure only the appropriate CIE users see certain information. The Workgroup highlighted that additional discussion is needed to explore safeguards to address safety concerns, for instance in the context of intimate partner violence, and how

Considerations for Privacy and Security of Statewide CIE



such safeguards should be clearly communicated during the consent process. Members also felt that a universal template or form may be helpful.

3) Individual access

Most CIE Workgroup members agreed that individual access should be part of CIE, meaning that individuals could access their own information in CIE or search for resources and self-refer. This can support transparency as people could see or potentially update their information. Additionally, people could learn about services they may not have known existed, get information, potentially fill out a form in advance, etc. Additional consideration is needed by others on this area.

The Workgroup asserts that CIE systems and processes should ensure that technical components and workflows are built to provide the appropriate information to support both privacy and service delivery. Moreover, organizations need to prioritize privacy and security and staff must be trained to have comprehensive conversations with individuals seeking services about privacy and informed consent in CIE. Access to relevant information to provide quality coordinated services while ensuring privacy are priorities to the Workgroup. As CIE efforts continue, decisions should account for these needs.

Next Steps

The CIE Workgroup provides these guiding principles and initial considerations around privacy and security and recommends that an additional group or groups, including subject matter experts and communities and individuals impacted, continue to explore these questions. In other regions, groups have met regularly for a year or more to explore the nuances around the implementation of CIE. CIE efforts will need to adapt with the landscape and new learnings, and plan as funding and/or technology opportunities arise. The CIE Workgroup recommends allowing time for this process.

The impact of social determinants of health and the importance of connecting to services across health and social services is well established. However, laws and standards related to social service referrals through CIE are still developing, including for privacy and security, leaving many questions to be considered in the future.

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October 2022

Appendix H: Full CIE Workgroup Recommendations for Governance of Statewide CIE

Recommendations for Governance of Statewide CIE



Purpose

The [Community Information Exchange \(CIE\) Workgroup](#) has been tasked by the [Health Information Technology Oversight Council](#) (HITOC) under [House Bill 4150](#) (2022) with exploring strategies to accelerate, support, and improve statewide CIE in Oregon.

The CIE Workgroup touched on governance of statewide CIE in previous meetings and met in October 2022 for a focused governance discussion. This concept paper brings together these discussions and prior Workgroup recommendations into a single set of recommendations for governance. This was reviewed by HITOC in December to inform their HB 4150 final report to the legislature in January 2023.

Problem

CIE efforts are developing rapidly across Oregon to help eliminate many of the barriers between people and the services designed to support them by enabling organizations across the health and social service spectrum to connect more efficiently. Currently, Oregon lacks a way for individuals and organizations to come together statewide and make decisions to coordinate and align across CIE efforts. Also, community-based organizations (CBOs), who are the key partners in successful CIE, need to be sufficiently involved in decision-making around CIE efforts. CBOs must have a voice in ongoing decisions to ensure that CIE efforts work for them and for there to be buy-in.

Governance is the process of bringing groups together for decision-making, direction setting, evaluating progress, and/or norm setting.

Summary of recommendations for governance of statewide CIE

The CIE Workgroup recommends that legislation support inclusive neutral governance of statewide CIE efforts.

- 1. Inclusive:** Governance must be representative of the communities, individuals, and organizations participating in and impacted by CIE efforts. Thoughtful planning, facilitation, and understandable materials are necessary to support inclusivity.
- 2. Neutral:** Governance should be led by a third party or through a public/private partnership.
- 3. Priorities of individuals and communities drive decisions:** Governance should involve ongoing direct engagement with community members and/or CBOs that represent them to ensure that their perspectives and input drive decisions about statewide CIE in Oregon.
- 4. Groups to include:** Governance should include representation across the social service, health, and government sectors with equal CBO to non-CBO representation.

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- 5. Multitiered structure:** There should be an overarching governance group as well as subgroups focused on specific topic areas. Governance should also have statewide and regional/local groups.

The CIE Workgroup views statewide governance as the critical next step to support, accelerate, and improve statewide CIE efforts.

Recommendations for governance of CIE

Governance of statewide CIE efforts is integral to ensuring the aims of CIE efforts, connecting individuals to needed services and furthering health equity, are realized. It is necessary to coordinate decision-making, align efforts, and ensure equitable decision-making across CIE partners. An effective governance process will not only accelerate, support, and improve statewide CIE efforts, but ensure that CIE will support whole person health and well-being outcomes for people and communities in Oregon.

The CIE Workgroup recommends that legislation support inclusive neutral governance of statewide CIE efforts. The Workgroup also has specific recommendations for community-led decision-making, groups and partners that should be represented in governance, and the need for multitiered governance that occurs at state, regional, and/or local levels.

1) Inclusive governance

The CIE Workgroup recommends governance that is inclusive of a comprehensive range of perspectives and experiences. Governance should be representative of the individuals, communities, and organizations participating in and impacted by CIE efforts. Thoughtful planning, facilitation, and consistent follow-up are necessary to ensure participating individuals and organizations feel their time is well spent and their input is valued.

Participant stipends are also needed to support inclusivity. Prioritizing inclusivity in these ways can mitigate barriers some groups may face in committing staff and time in order to participate in governance. Attention is also needed to the development of accessible and understandable materials. Maintaining transparency in decision-making is important for inclusive governance and building trust. Supporting governance with necessary resources, such as staffing, to support this inclusivity, develop and maintain trust among CIE partners, and maintain equitable distribution of power across participants will be critical.

2) Neutral governance

The CIE Workgroup recommends neutral governance led by a third party or through a public/private partnership. To accomplish this, the third party or private entity leading or partnering on governance should not stand to benefit or lose from CIE governance decisions. The third party or public/private partnership must have the capacity necessary for outreach and recruitment of representative members, facilitation of accessible meetings, and development of understandable materials to achieve the inclusivity described above. If

Recommendations for Governance of Statewide CIE



a partnership, the public entity would be the Oregon Health Authority (OHA) and/or the Oregon Department of Human Services (ODHS), but not led by the state agencies. Statewide governance should not be led by a vendor of CIE technology.

3) **Priorities of individuals and communities drive decisions**

The Workgroup recommends that the needs of individuals, communities, and CBOs participating in and impacted by CIE efforts drive discussions and decisions around CIE. Governance should involve ongoing direct engagement with community members and/or CBOs that represent them to ensure their perspectives and input drive decisions about statewide CIE in Oregon. The governance structure and process itself may need to adapt to remain responsive to the changing needs and priorities of communities. Participation could include membership on a governance group or engagement through community forums (e.g., regional health equity coalitions (RHECs)), surveys or interviews, or providing input through other means. Flexibility for various types of engagement helps meet people where they are, with the time they are able to commit, thus supporting the inclusivity described above. Prioritizing the needs of CBOs and communities is crucial to the success of CIE and to advancing health equity.

4) **Groups to include in statewide governance**

Governance should include representation across the social service, health, and government sectors.

- **There should be equal CBO to non-CBO representation in governance.** CBOs must be strongly represented and substantively included in governance at all levels. CBOs need financial compensation for their time and participation.
- **Governance must also include additional partners**, such as representatives from behavioral health, oral health, and physical health organizations, safety net clinics (e.g., federally qualified health centers, rural health centers, free clinics), coordinated care organizations, city or county government (e.g., local public health or county social services), and others (e.g., early childhood, school-based social supports).
- **OHA and ODHS should also participate in governance of statewide CIE.** This participation is critical as OHA and ODHS should play an integral role in ensuring CIE efforts support equity, as stewards of the public good. The agencies also have significant roles in delivery of services and supports that individuals could seek through CIE. Involvement of these state agencies may also be seen to signal that efforts are concrete; organizations want to know the state is engaged. However, it is important to have awareness of avoiding a power imbalance and to build trust with communities who have concerns about working with government agencies. Additional state agencies may need to participate as efforts develop.

Recommendations for Governance of Statewide CIE



- **It is important to have people with different perspectives.** Governance should include culturally and linguistically specific organizations, rural and frontier communities, tribal organizations, and representation from different service sectors, such as food, housing, and transportation. Technology experts who can represent the capabilities and solutions possible for CIE should also be included in the governance process.

5) Multitiered governance structure

The Workgroup recommends a multitiered governance structure, meaning there should be an overarching group as well as subcommittees or workgroups focused on specific topic areas. For example, data governance and privacy and security are areas that need a focused subgroup or groups.

The Workgroup recommends governance at the statewide level, as well as at the regional or local levels. Local or regional groups will be critical for maintaining community voice and local involvement, while statewide governance is needed for alignment of efforts. Current and local efforts should inform the statewide governance.

The CIE Workgroup touched on governance of statewide CIE in its previous concept papers. For more details on CIE governance see Workgroup Recommendations on:

[OHA and ODHS roles in statewide CIE](#)

As well as:

[Support for CBOs](#)

[Statewide CIE Data Program](#)

[Support for Additional Partners](#)

[Considerations for Privacy and Security](#)

Next Steps

The CIE Workgroup views statewide governance as the critical next step to support, accelerate, and improve statewide CIE efforts. The Workgroup felt strongly that it is time to move to action and that a statewide decision-making governance structure is the right action to take. Carrying out the Workgroup's recommendations to realize the vision of statewide CIE that eliminates siloes and supports health equity will require many well-considered decisions. The Workgroup recognizes that existing CIE efforts are underway that include effort-specific governance and sees an opportunity to build on this for governance at a statewide level. The Workgroup feels statewide governance that is inclusive, neutral, and centers CBOs must be a priority for CIE efforts in Oregon.

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November 2022

Appendix I: Community Information Exchange: Community Engagement Findings and Recommendations

Community Information Exchange: Community Engagement Findings and Recommendations

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July 29, 2022



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EXECUTIVE SUMMARY

Background

The Oregon Health Authority's (OHA) Office of Health Information Technology (OHIT) is interested in the growing community information exchange (CIE) efforts across the state. In 2022, the [Health Information Technology Oversight Council \(HITOC\)](#) was directed by the state legislature through House Bill 4150 to gather information from community-based organizations (CBOs) to inform recommendations to accelerate, support, and improve statewide CIE efforts that serve the needs of communities. Between May - July 2022, the Collective Health Strategies (CHS) team, on behalf of OHA, engaged 99 CBOs statewide through in-depth interviews and an online survey to understand views and experiences with CIE, and solicit input into recommendations to inform the CIE Workgroup and HITOC's process, discussion, and recommendations, including legislative recommendations. Through this, twenty interviews and 97 survey responses were collected and analyzed to inform the statewide CIE Workgroup's legislative recommendations. Findings and recommendations from the community engagement are detailed in this report.

What is CIE?

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.

Key findings from CBO surveys and interviews

See full report [Findings section](#) for more detail.

Most respondents are supportive of the overall vision of CIE and its potential to improve health equity, yet struggle to envision successful implementation of a robust, statewide CIE network

- Many respondents pointed to the importance of connecting - or strengthening connections across - services, organizations, and resources with clients as a key reason they found CIE important or useful.
- Other clearly stated benefits include increasing staff capacity and efficiency, improving coordination and collaboration across organizations, easier access to services and information, accessibility in rural areas, and opportunities for CBOs to connect with culturally and linguistically specific organizations that would better serve client needs.
- Those who use CIE generally understand and believe in the benefits, yet many worry that if the system is not widely used enough it will not achieve these benefits fully.

- Many interviewees expressed concern about implementing CIE in a “broken” social services system, yet they still feel that it’s an important part of the solution.
- General attitudes about CIE are positive, with concerns focusing on staff capacity/time; the need for widespread, consistent use; having to use multiple data systems that don’t integrate; language/digital access and attending to an increased volume of referrals.

Greater understanding brings greater engagement with CIE and support for use

- The CBOs that worked with OHA and county health departments to use CIE for COVID-19 wraparound work had a positive experience and saw value in the system. Organizations in nearby areas also saw this success and saw it as a reason to participate.
- Perspectives of CBO interviewees were diverse, ranging from strong support to skepticism of CIE. Organizations currently using CIE are generally aware of the benefits and bought into the vision. Organizations not using or familiar with CIE generally expressed a lack of understanding what CIE is and what it can do, however many were optimistic about the opportunity CIE provides to connect and coordinate services for their clients.
- Many people leading their organizations to use CIE are enthusiastic supporters or champions who believe in the CIE Workgroup’s mission.
- CBOs that are currently using a CIE are comfortable with how privacy concerns are handled, despite privacy being a big concern for CBOs that are not yet actively using CIE.

Strong relationships are key to a strong CIE network

- Relationships are key, and while many believe that CIE can help make connections easier and strengthen relationships, it will not replace the time-intensive need to form and cultivate relationships with community members and fellow CBOs/service providers to successfully deliver services.
- Those who strongly believe in the value of CIE - often those already using CIE - generally understand that pairing relationships with CIE technology has the potential to bolster existing relationships and forge new ones.
- Many CBOs, in particular culturally and linguistically specific organizations that serve communities of color, emphasized that trust is essential for clients to engage with services, especially where there is historical mistrust of systems that needs to be repaired.
- There is also an expressed need to ensure adequate resources for continued relationship building as an important part of implementation so that CIE doesn’t “depersonalize” services.

Staff capacity to implement CIE is the greatest concern for CBOs

- Many CBOs shared that with funding for staff time and adequate training they could start using CIE at their CBO.
- Existing CBO staff are stretched thin, and many organizations are struggling to find and retain staff.
- Patchwork grant funding makes broad infrastructure investments like CIE even more challenging for CBOs, as staff time is tightly tied to funding for specific programs or initiatives.
- Some CBOs are already at service capacity, making them nervous about receiving too many referrals and not being able to fulfill them.

Recommendations

Recommendations are listed in order of priority based on information gathered through CBO interviews and surveys.

1. Offer robust funding to support CBO use of CIE

- General financial support needed for adoption/use of CIE (in particular for startup costs) is between \$25,000 - 1 full-time employee (FTE) (amount for 1 FTE varies by organization).
- Funding is needed broadly to increase staff and organizational capacity to use CIE, connect systems, and maintain or grow service offerings. Specific CBO needs include funding for CIE system set up, staff time, resource navigation, and training. Relationship building will require dedicated time to successfully grow the CIE network, so adequate funding should be built into budgets.
- Pilot grants are a mechanism that CBOs have found to be successful in the past. Providing 1-2 year pilot grants for implementation would allow CBOs to support systems development, testing, evaluation, and improvements on CIE use, but more importantly to create a network/cohort of CBOs implementing CIE together.
- Financial incentives (e.g., payment per referral) built into CBO contracts may help accelerate adoption of CIE, yet incentives should be crafted in a way that minimizes impacts on equity.
- Consider funding to support integration or connection with other data systems to considerably lessen the administrative burden on staff.
- There is widespread agreement that culturally and linguistically specific organizations are an important part of a robust CIE network, yet are more likely to experience capacity issues due to chronic underinvestment. Prioritize these CBOs for investments and administer grant funds in a manner that does not increase burden (e.g., use fiscal intermediaries or minimize prescriptive funding requirements).

2. Promote equity, accessibility, and accountability

- Ensure the most important foundational components that will promote equity are in place: language access (in multiple languages for both staff and clients), literacy (including compliance with existing laws like the Americans with Disabilities Act), and technology access.
- Challenges specific to rural communities like gaps in broadband access, funds/transportation to travel to trainings and lack of access to virtual services need to be addressed to ensure rural communities are not excluded from participating in CIE.
- Ensure that CIE platforms have the technological capabilities to identify culturally and linguistically specific organizations and make their services accessible. Work with CBOs to ensure that referrals can be made in a culturally and linguistically responsive manner and to organizations that can meet those needs.
- Be responsive to the needs of the community and clients through good governance, person-centered values, and accountability.
- Address historical mistrust of government and health care systems through listening and understanding concerns, and providing clear and accurate communications from trusted voices.

3. Advance privacy, data protections

- Investigate data use protections and address concerns about privacy of data collection and use by clearly communicating about data privacy features in specific CIE technology, data justice principles, and consumer protections. Ensure ongoing oversight of protections, perhaps through an oversight committee that utilizes the expertise of CBOs currently collecting protected information in this area.
- Ensure legal backing for protections for sensitive information (i.e., to ensure immigration status is not inappropriately shared). Create a Bill of Rights for CIE users to ensure no one is profiting from the use of the community's data.

4. Provide technical assistance, training, and education

- CBOs desire a single, clear place to access resources and support.
- Provide ongoing technical assistance (possibly through office hours) to ensure CBO staff are able to use CIE and resolve issues quickly and efficiently. Ensure support staff are easy to reach, responsive to questions, and knowledgeable about the local community.
- CBO staff desired training from other CBOs, technology vendors or state agencies on CIE use and best practices generally, but also suggested training would be helpful on cultural humility, implicit bias, communicating about privacy with clients, resource navigation, and data management.

- Consider funding CBOs to provide training, education, and capacity building to those in their community.

5. Create a statewide coordinating entity to promote alignment across organizations, sectors, and systems

- A statewide CIE coordinating entity should be a neutral, third-party convener (i.e., not state government) and community-led through diverse representation, including CBOs that serve culturally and linguistically specific populations, serve all geographic regions, are of varying staff sizes, and have varying experiences with CIE. OHA and/or other state agencies should coordinate and support the entity.
- The roles of the entity should be:
 - Lead the collaborative creation of statewide goals and priorities, and monitor progress
 - Coordinate and convene partners, including a statewide community of practice
 - Communicate about CIE-related opportunities
 - Provide oversight and governance, with CBOs providing leadership in these areas
 - Collect, monitor, evaluate, and report on statewide trends, especially with regard to equity, functionality, and success. Make improvements in response to findings.
 - Administer or oversee funding and pilot project grants
 - Support ongoing training for CBO staff
 - Advocate for increase in social services and behavioral health funding alongside CIE implementation
 - Plan ahead for increase in system needs related to emerging threats (e.g., natural disasters, wildfires)
 - Outreach and recruitment to encourage participation in CIE to quickly get as many organizations using CIE as possible (so that organizations do not lose interest and the system has greater functionality as a whole), but do not force participation
 - Consider a hub-and-spoke model (which has been successful in other states), with someone embedded in each community as the main point of contact and trusted local voice for CIE in each region.
 - Utilize data gathered through the system to make improvements in CIE and in the overall social and health systems

6. Prioritize relationships, communication, and engagement

- Prioritize fostering relationships, trust, and engagement across CIE partners/users by communicating with CBOs frequently.

- Center trusted community leaders in communications.
- Use recommendations in “[Advice to OHA, healthcare and vendors for CIE outreach](#)” section of this paper to craft key communications and messages.
- Conduct outreach to educate the CBO community on the benefits of CIE and clarify the relationship to other existing systems (e.g., 211 or other resource navigation systems).

7. Align CIE efforts with other systems level efforts that are crucial to ensuring health equity

- Target behavioral health providers for inclusion in a statewide CIE network.
- Take a statewide or regional approach to technological improvements to avoid or remove duplication with existing databases or systems.
- Beyond CIE, contextual factors like chronic lack of social services availability statewide, and the strength of a CBO’s reimbursement capabilities will impact their ability to implement robust CIE systems. Statewide partners supporting CBOs should make efforts to align with other statewide opportunities to support CBO capacity building and social service availability.

BACKGROUND AND CONTEXT

Oregon Health Authority (OHA) Office of Health Information Technology (OHIT) is interested in the growing community information exchange (CIE) efforts across the state. In 2022, the [Health Information Technology Oversight Council \(HITOC\)](#) was directed by the state legislature through House Bill 4150 to gather information from community-based organizations (CBOs) to inform recommendations to accelerate, support, and improve statewide CIE efforts that serve the needs of communities. To this end, from May - July 2022, the Collective Health Strategies (CHS) team, on behalf of OHA, engaged CBOs statewide to understand views and experiences with CIE, and solicit input into recommendations to inform the CIE Workgroup and HITOC's process, discussion, and recommendations, including legislative recommendations.

What is CIE?

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.

Project goals

Through in-depth community engagement, CHS endeavored to identify common challenges, barriers, and opportunities for support for CBOs to participate in CIE. Findings are intended to inform the development of legislative recommendations to advance strategies to support statewide CIE in a way that works for people and organizations in Oregon. The goals of this project were to:

- Conduct a survey, in-depth interviews, and engage CBO partners to identify challenges and barriers to CIE utilization, as well as strategies that would help in adoption and participation in CIE. Eligible participants included individuals, CBOs (including those who serve culturally and linguistically specific populations), and other interested parties.
- Analyze results from data collection efforts, summarize key themes, and report on findings.
- Inform HITOC and the CIE Workgroup (a subcommittee of HITOC) on process, discussion, and recommendations, including legislative recommendations.

Background on CIE in Oregon

As part of House Bill 4150 (2022), HITOC chartered a CIE Workgroup to make recommendations to accelerate, support, and improve statewide CIE. The Workgroup identified a vision that all people living in Oregon and their communities have access to CIE that creates seamless, trusted, person-centered connections and coordination to meet people's needs, support community capacity, and eliminate silos to achieve health equity.

Regardless of the vendor, free tools are available to CBOs across the state. CIEs are available statewide, and in Oregon concentrated efforts are sponsored by Medicaid coordinated care organizations (CCOs) and health plans that are then extended to community partners for use. The two main CIEs in Oregon are Connect Oregon (powered by Unite Us) and findhelp (formerly Aunt Bertha).

Strong CBO participation and partnerships are crucial for the success of statewide CIE. CIE can contribute to Oregon's vision for addressing social needs and promoting health equity. CIEs help advance health equity by reducing many of the barriers between people and the services designed to support them by helping connect people to a comprehensive range of available services. This connection is integral to addressing health inequities and the overall well-being of individuals. CIE strategies must incorporate the voices of communities, especially those organizations that are on the forefront of providing services to communities who face health inequities.

METHODOLOGY

The CHS team, in partnership with OHA OHIT, developed a plan to identify common challenges, barriers, and opportunities for support related to CIE adoption and use among CBOs in Oregon. Through a combination of surveys and interviews, the CHS team explored:

- Current CBO awareness, use, and experiences with CIE
- Barriers, challenges, and perceived benefits to adoption or use of CIE
- The role of CIE in promoting health equity
- Recommendations on a variety of supports needed to bolster current use of CIE or expand CIE adoption, including ideas related to governance and the role of OHA and Oregon Department of Human Services (ODHS)

Two key frameworks informed the approach to both questions and analysis: the awareness, desire, knowledge, ability, and reinforcement (ADKAR) change-management methodology and the technology acceptance model (TAM).

ADKAR provides an approach that supports an understanding of current views and attitudes about CIE as well as what might be needed to support individual and organizational use of the technology.

TAM is a theory to model the acceptance and use of a technology. The theory is characterized by a validated questionnaire that covers perceived usefulness and perceived ease of use. Question wording was adapted to fit Oregon's CIE use case. To ensure a focus on advancing

health equity, questions were added to understand CBO's perceptions about how CIE might support or hinder progress toward health equity.

CHS used a mixed-methods approach to ensure representation from a large, diverse group of organizations, and that a mix of quantitative and qualitative data is collected and synthesized. Information was gathered through two primary methods:

- 20 in-depth interviews with key stakeholders from 19 CBOs and one county government office
- A brief quantitative and qualitative survey distributed to a range of CBOs statewide through existing networks and trusted community contacts

Interview and survey question development

Interview and survey questions were developed in tandem to elicit insights across key project goals utilizing existing frameworks mentioned above to ensure a broad understanding of challenges and opportunities. The interview questions were organized into broad themes that were identified through CHS' review of project background materials, including CIE Workgroup surveys and ideas, [CIE Issue Brief](#), and the legislation that initiated this project. The themes identified include: current use of CIE systems, reflections on current CIE systems in use, perceived functions and benefits, barriers, solutions, needs, equity, roles of various entities, and governance. Interviewers also asked whether the interviewee would be interested in providing feedback at a future date on the CIE Workgroup's proposed legislative concepts. As mentioned above, the interview questions were designed around the ADKAR model, which acknowledges that CBO interviewees are at all levels of engagement with CIE efforts, from basic awareness of CIE to frequent use. TAM questions were included in the survey to gather quantitative insights into the acceptance of CIE.

Interview questions and script are included in [Appendix I](#). Survey questions and introductory text are included in [Appendix II](#).

Interview planning and recruitment

CHS developed a list of key contacts to identify potential interview participants and then solicited names of CBOs and staff representing organizations that were both using and not using or unfamiliar with CIE. Those key contacts included:

- OHA staff:
 - Programs managing networks of CBO grantees (i.e., the OHA Community Partner Outreach Program, or CPOP, and the OHA Public Health Community Engagement Program)
 - Outreach at Tribal Monthly Meeting

- Outreach to Area Agencies on Aging (AAA)
- CIE Workgroup members and chairs, including coordinated care organization (CCO) representatives and CBO representatives
- Unite Us, a CIE vendor in Oregon branded as Connect Oregon
- Findhelp, a CIE vendor in Oregon
- Cascade Health Alliance, the CCO utilizing findhelp CIE, in Klamath county
- Oregon 211info
- Regional Health Equity Coalition (RHEC) representatives
- Oregon Community Health Workers Association (ORCHWA)
- Project Access NOW (PANOW)

Based on this outreach, a list of over 60 CBOs was compiled that included CBOs with various levels of engagement with CIE, organization size, priority population, and geographic area served. The team strived for a balance of breadth and depth - looking to reach CBOs of varying staff sizes that were both using and not using CIE already and that served specific cultural or linguistic populations across the state.

Specifically, prioritization was based upon: 1) CBOs that represent culturally and linguistically diverse communities, 2) CBOs that represent a range of geographic regions, and 3) CBOs that represent a range of different levels of engagement with CIE (i.e., using successfully, using with issues, considering but not currently using, and not yet using/unfamiliar).

Connections to key interviewee contacts were made via email, either through direct contact introduction, or through referencing a recommendation. CHS offered accommodations to minimize CBO barriers to participation, including the opportunity to complete the interview virtually on the phone or through a video platform (e.g., Teams or Zoom). Real-time language interpretation through the video platform was available as needed. Evening and weekend interview times were also available to accommodate different scheduling needs. All interview participants were offered a \$50 store value card for one hour of their time.

Twenty one-hour interviews were conducted via Zoom video conference between May 24, 2022 and July 19, 2022. Interviews were recorded and transcribed by Otter.ai for analysis.

Survey planning and dissemination

In addition to targeted interviews, CHS developed a comprehensive survey tool and broadly distributed it between June 10 - June 30, 2022 utilizing SurveyMonkey Pro. The survey was translated into Spanish by Language Link, an external translation provider, to ensure Spanish-speaking CBO staff could respond in their preferred language. Instructions on accessing other

accommodations accompanied the survey dissemination. To incentivize responses, survey respondents were entered into a drawing to receive one of ten \$50 store value cards.

The survey was widely distributed through existing CBO networks to increase participation and rely on trusted partners to deliver the survey request. These networks included:

- CCOs and CCO Community Advisory Councils
- CIE Workgroup member networks
- HITOC members
- OHA CPOP and Public Health community engagement teams
- Outreach at Tribal Monthly Meeting
- Area Agencies on Aging (AAA)
- Traditional Health Workers (through the Oregon Community Health Workers Association or ORCHWA)
- Regional Health Equity Coalitions
- ODHS Self Sufficiency program network
- Oregon Health Leadership Council
- Oregon 211info
- Oregon Unhoused Network (through Oregon Housing and Community Services)
- OHA COVID-19 funding grantee network
- Healthier Together Oregon network
- Findhelp
- Unite Us

Survey questions were customized to match participants' level of engagement with CIE. The survey took an average of 14.5 minutes to complete, with 82% of those who started the survey completing all questions. In total, 97 complete responses were received.

Interview and survey response summary statistics

Responses were received from a wide range of CBOs statewide. Organization names are not shared in this report to protect the confidentiality of respondents and interviewees.

Survey response summary statistics

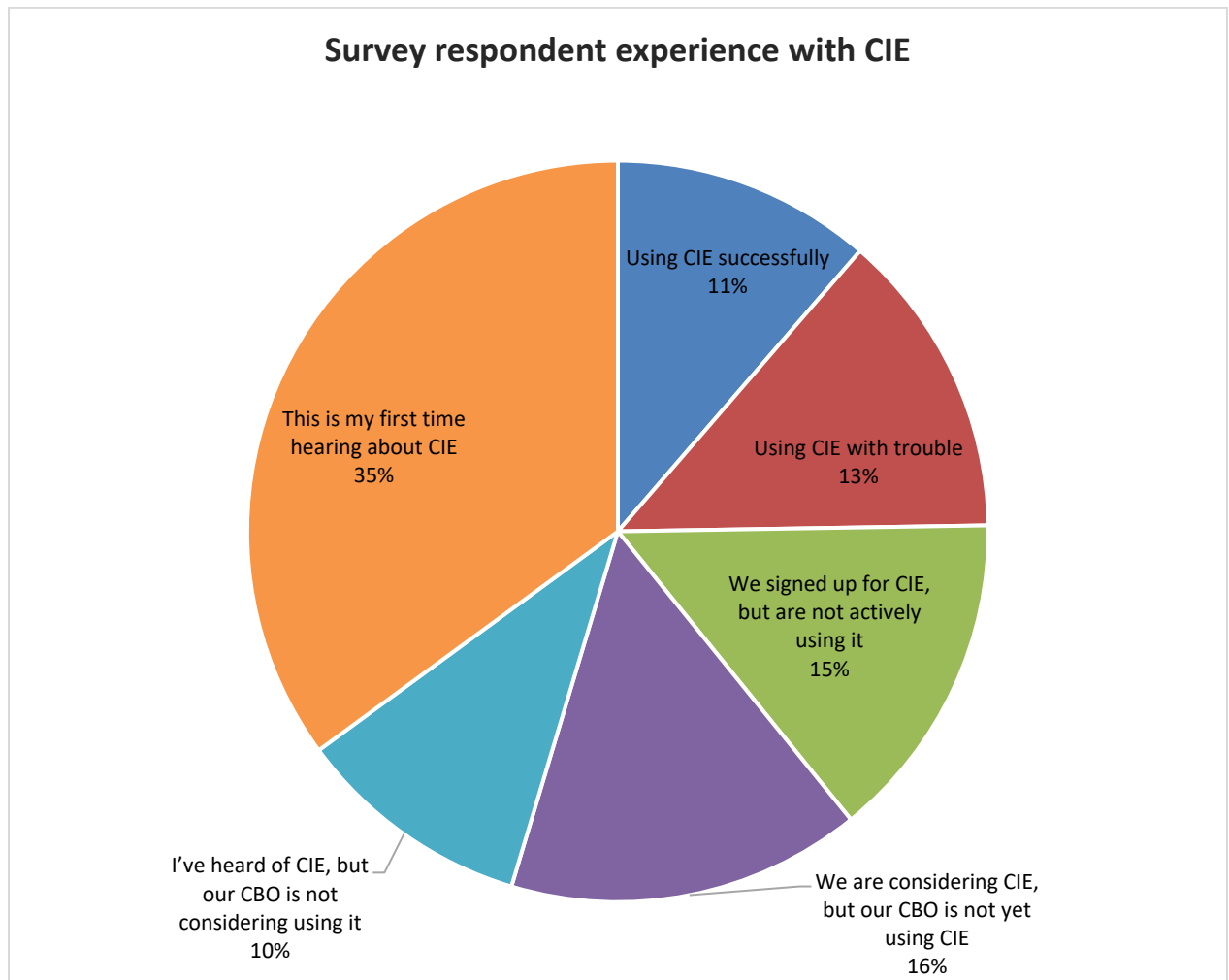
Organizational characteristics and individual demographics for the 97 survey respondents include:

- CBOs with staff sizes ranging from 0 - 1800
- Top three most frequent CBO staff roles responding were: Director, Executive Director, or CEO; Manager or Program manager; Community Health Worker
- CBOs serving all counties, including six CBOs that serve clients statewide

The graphic below represents populations served by CBOs as described by respondents (font size indicates frequency with which an organization serves a specific population):

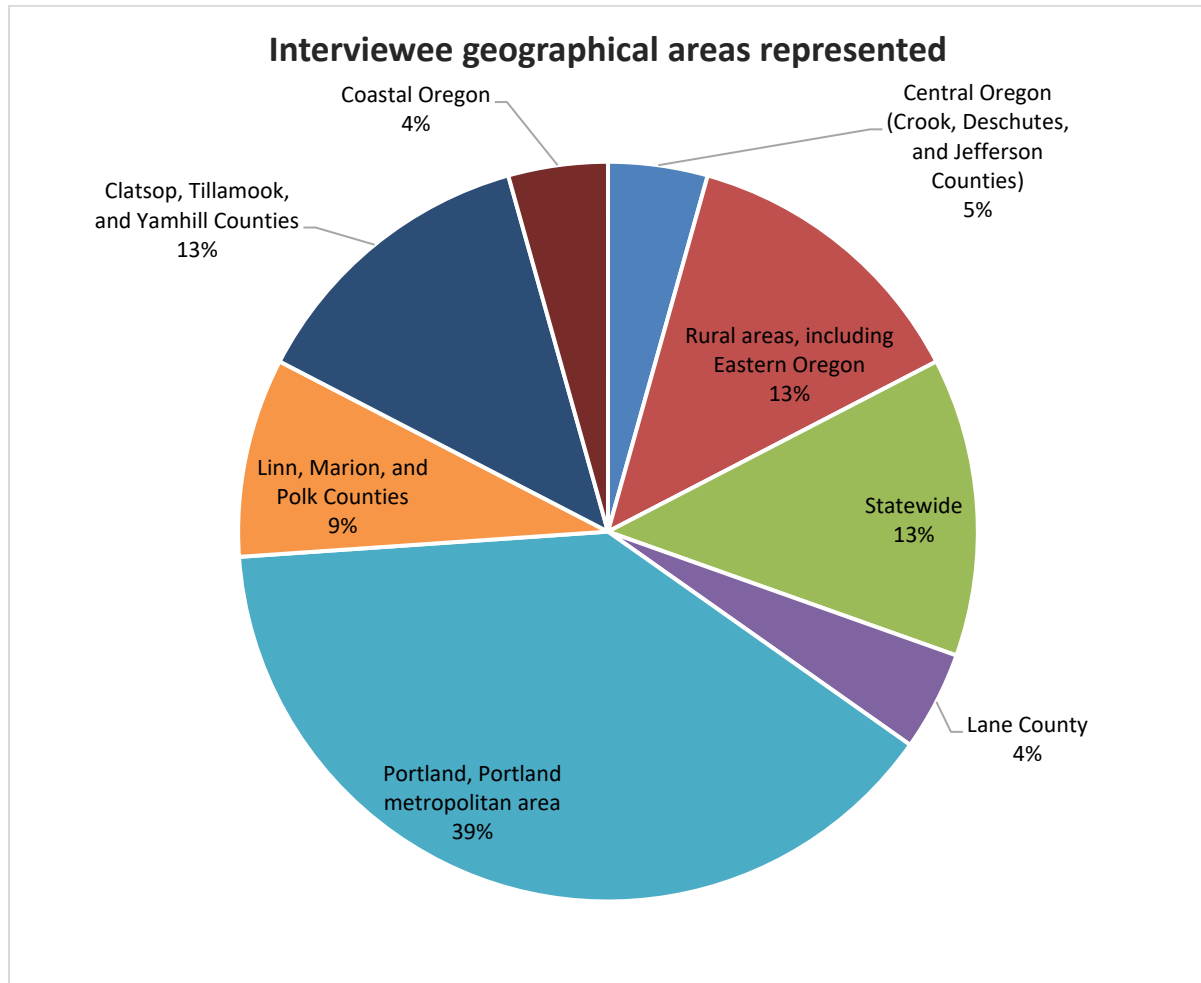


Survey respondents represented a variety of experiences with CIE at the time of the survey:



Interview response summary statistics

Interviewees included representatives from CBOs serving the following geographic areas:



Interviewees included representatives from CBOs serving the following priority populations:

- Anyone within a given geographical area
- Underserved, underrepresented populations
- People struggling with housing or houselessness
- Mental and behavioral health, including SUD, addiction, and trauma
- Multicultural support, including English as a Second Language and cultural preservation
- Underserved youth, including those recovering from substance use disorders
- Latino community
- Black/African American
- Individuals who are experiencing food insecurity
- Spinal cord injury survivors
- Health, healthcare, and health related services
- People experiencing poverty

Interviewees included representatives currently using CIE and not currently using CIE (includes those who were: unaware of CIE prior to the interview; aware, but not sure yet of value; aware, not interested; planning to join, just have not registered yet):



9 interviewees use CIE; 11 do not

Interview and survey analysis

Interview and survey data were analyzed separately.

Interviews were coded across key themes identified at the outset of the project and from the interviews themselves, including:

- Barriers, challenges, and reluctance to use CIE
- Perceived benefits and functions of CIE
- Ideas for addressing barriers and creating a robust system
- Reflections on the OHA CIE Workgroup vision and CIE systems
- Funding and incentives
- CIE and health equity
- Ideas for the role of a statewide convening entity
- Advice to OHA, health care, and vendors for CIE outreach

Survey responses were further stratified by CBO size based on staff size (small (30 or fewer FTE), medium (31 - 200 FTE), large (201 or more FTE)), population served (for populations with sufficient representation in responses, including older adults, people of color, and rural geography), and current use or awareness of CIE (using, not using). Responses within each stratification were compared with each other and the mean across key questions, including:

- Current awareness or use of CIE
- Priority level
- Estimated cost to use or implement CIE at their organization
- Top challenges indicated from a list of options
- Top support requests indicated from a list of options
- Top roles for a statewide governing entity

Findings were remarkably similar across interviews and surveys, with quantitative survey data bolstering the findings from qualitative interviews. Given the similarities in findings, analysis of interviews and surveys used the same coding framework and were combined to illustrate the insights gathered throughout the entire engagement process.

Data limitations

It is important to note that the voluntary nature of both the survey and interviews, along with the hand-selection of interviewees solicited by the project team (including CHS and OHA) produces some limitations on the general applicability of these findings. Some organizations were unable to participate in interviews due to staff capacity. Those who have more extreme - positive or negative - thoughts on CIE may have been more likely to participate. These factors may result in a selection bias. The number of responses to both the survey and interviews is limited and not intended to be a representative sample of the range of CBOs working in fields where CIE may be relevant. While undoubtedly relevant, these findings may not represent all CBO views on CIE in Oregon.

FINDINGS

The surveys and interviews resulted in significant, highly valuable data that detailed a range of experiences, including challenges or concerns, benefits or opportunities, and suggestions for CIE support and improvements.

Throughout this report, findings from surveys and interviews are interwoven. Analysis of both interviews and surveys were remarkably similar, pointing to general agreement across key themes. In interviews, responses differed most prominently by use/awareness of CIE - those who were not using CIE were more concerned about certain key aspects of CIE (privacy and capacity) than those who are using CIE, however the sentiments themselves were aligned with those who are using CIE. When stratifying survey responses by CBO size, population served, and current use/awareness of CIE, responses to key questions were also very similar. Findings relevant to certain subsets of those either surveyed or interviewed are indicated within the line.

Findings that are most important for achieving health equity are marked with an asterisk (*).

1. Awareness of CIE

Interviewees learned about CIE in a variety of ways including:

- Kaiser Permanente grant funding opportunity
- Project Access NOW
- Connect Oregon (Unite Us) regional meetings and events
- CCO meetings and events - GOBHI, Health Share of Oregon, Cascade Health Alliance

- OHA COVID-19 grant program
- Healthy Klamath and Cascade Health Alliance announcement at community meeting
- Clinical healthcare partners
- San Diego 211 conference
- National work with human service providers

2. Perceived benefits and functions of CIE

In general, attitudes about CIE were positive across survey and interview respondents. CBO staff see the realized and potential value in using CIE to increase connections among healthcare, social services, and communities.

There really are two things about the CIE that are very attractive to us. One is the ability to build a customer profile. And then retain the history associated with that individual. Right now we do that in a very, quite honestly clunky, semi manual fashion that we know we are quickly outgrowing so having that ability to build that database, the customer information is really attractive to us. The second component about a CIE that we really like is our ability to connect with and source other nonprofits to help address more broadly the needs of the client.

- Interviewee

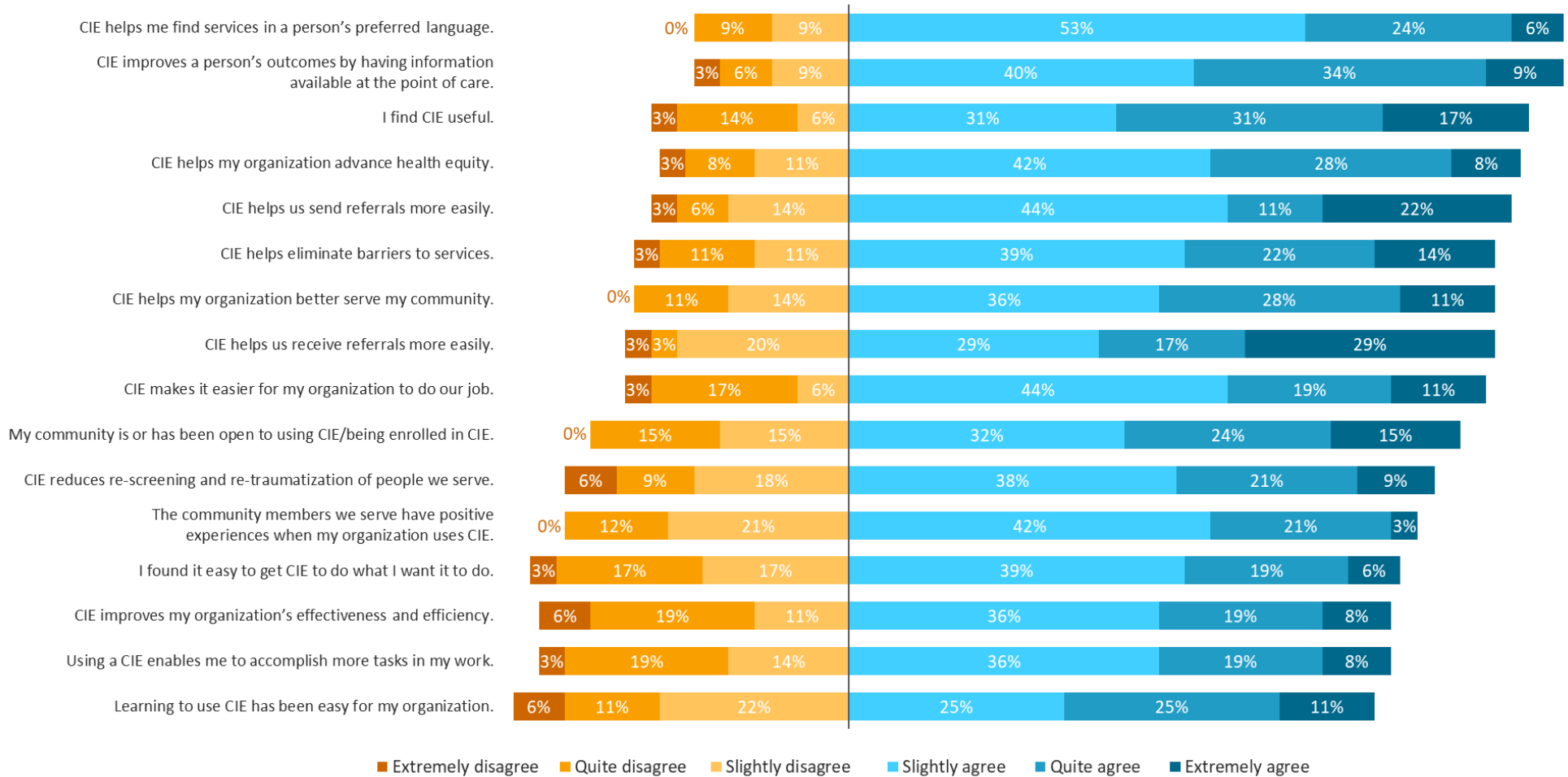
Survey respondents using CIE overwhelmingly agreed that:

- CIE helps me find services in a person's preferred language. (83% agree)*
- CIE improves a person's outcomes by having information available at the point of care. (83%)
- I find CIE useful. (79%)

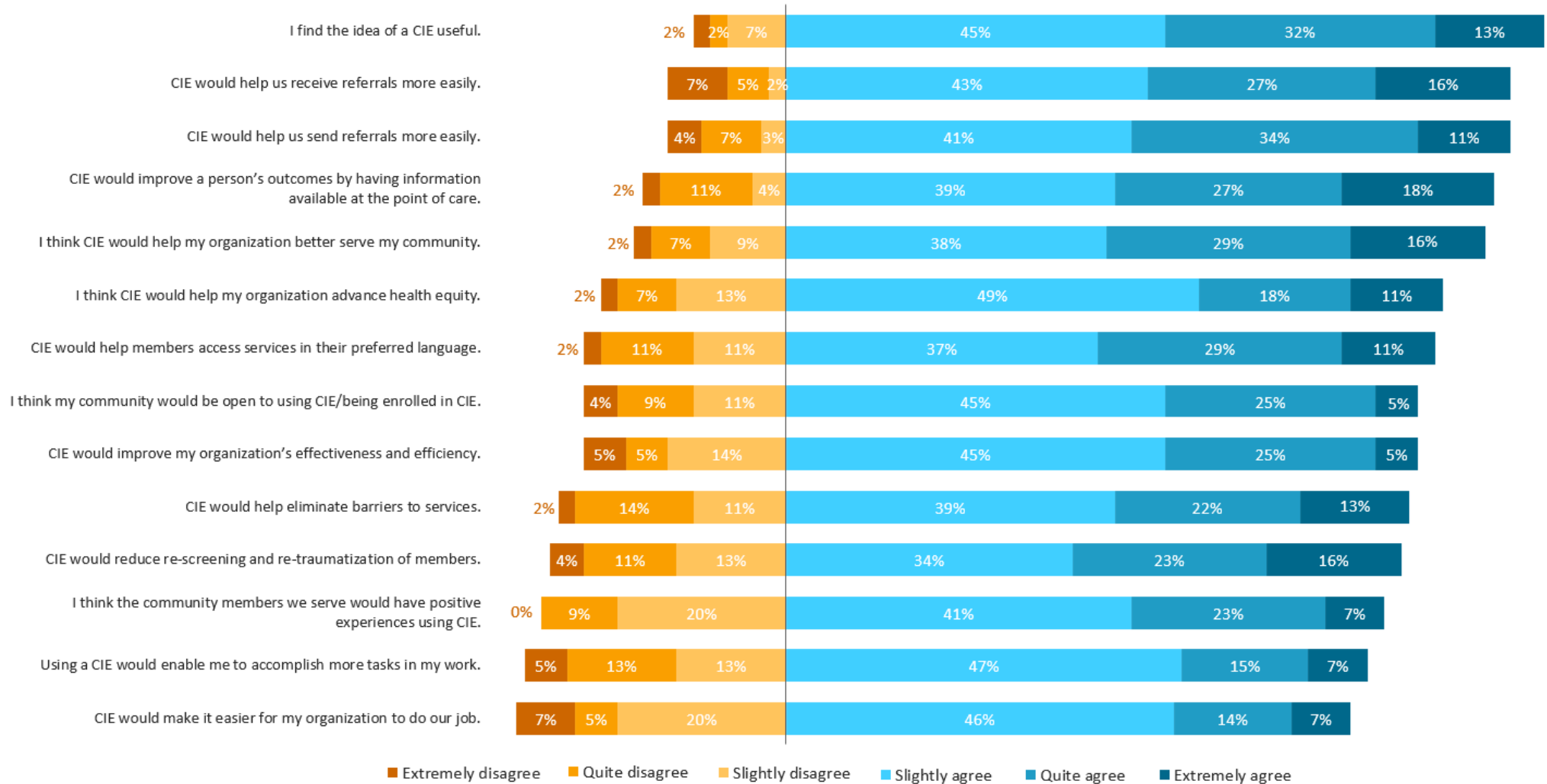
Survey respondents not currently using CIE overwhelmingly agreed that:

- I find the idea of a CIE useful. (90% agree)
- CIE would help us receive referrals more easily. / CIE would help us send referrals more easily. (86%)
- CIE would improve a person's outcomes by having information available at the point of care. (84%)

Perceived usefulness, ease of use and ability to support equity for those who are using CIE



Perceived usefulness, ease of use and ability to support equity for those who are not using or are unaware of CIE



2.1 Easier access to resources and information

- Most CBOs agree that having easier access to resources and information is a huge benefit of CIE. Especially for those in more isolated or underserved areas. It gives them the ability to connect beyond their local area to access resources in other parts of the state, including through increased referrals to virtual social and health care opportunities. Connecting people to services and the health and social care system would promote health equity.*

I think with more partners hopping on and learning and having it be such an easy way to make that referral, it just helps educate and connect people to the programs, and then hopefully, reduce stigma. We keep hearing stigma in accessing food assistance is one of the biggest barriers. - Interviewee

- CBOs are especially interested in finding, connecting to and funding behavioral health services to fill the great need of clients, including community mental health services.*
- There is interest in connecting health care to social service agencies, even among those who voiced concern about connecting between social service providers due to the lack of supply of existing social services and potential for increased CBO workload.
- People see the potential to prevent further negative health impacts through more tightly connected medical and community-based care, ensuring clients receive wraparound support they need in a timely manner.

[CIE] builds a bridge between inpatient care and community-based care. In cases [redacted] where health is dramatically shifted, and there's a possibility of a lot of complications. The greater that bridge is, the greater the communication, the greater the collaboration and continuity of care is, the more likely that person is to have kind of an upward health trajectory. - Interviewee

- Many are excited about the ability to help meet clients' needs by using CIE to find and create pathways to other CBOs for services they might not offer, in particular CBOs that serve culturally and linguistically specific populations.*

I think it would make it more seamless for the community and let them know that even though we as an organization can't serve them, we have the tools and the partners in the community to make sure that they're served in the capacity that they need. - Interviewee

A lot of our focus has been currently with COVID-19. But in dealing with families and providing wraparound support for those services, a lot of other needs have come to light with securing housing, for example, has been one of them, food, and also job security. So being able to connect these clients with these other resources has really been a challenge because sometimes we're not completely prepared. So we have to look around or ask around to see if the services are being provided by any partner organizations. - Interviewee

- CIE helps CBOs promote their services and programs and raise awareness of their partners' services. Many CBOs have existing relationships with culturally and linguistically specific organizations. CIE could help support and strengthen these relationships, improving the ability of CBOs to identify the "best fit" organization for their clients, especially those with culturally and linguistically specific needs.*
- There is interest in the ability of clients to easily self-refer, with CBOs able to follow up instantly in multiple ways depending on the individual's preferences. CBOs using the self-referral capabilities of CIE have found it successful. However, many clients are mistrustful and others prefer to use the phone to access services.*
- Mobile intake capabilities would be enhanced or possible with CIE.

Having like the self-referral button, and the ability to communicate by email, [text] and phone allows us to follow up with folks more, it feels like there's less shame in filling out the form. And following up in a way where you don't have to actually talk to someone, you know, it minimizes some of that, like trauma of having to make that crappy call when you're in crisis. - Interviewee

2.2 If implemented thoughtfully, CIE could promote health equity

Overall, interviewees feel that CIE will increase equity because it allows more information about services to get to more people, and it could possibly allow groups of CBOs to see issues way in advance and avoid a crisis down the line.*

2.3 CIE could improve staff capacity and efficiency through more streamlined communications and documentation, simplify workflows, and reduce burden of phone calls and searching for other services, especially with closed-loop referrals

Community-based organizations peer-run organizations like ours, we are you know, feet on the ground organizations, we're grassroots, and I think this tool to be able to reach out, because we're always underfunded, we're always understaffed, you know, and this cuts down on hours and hours and hours of

time that we would be on the phone, we have to do one referral, we can send it out, we can make notes, we can talk back and forth with other people, we only have one consent form, you know, all these things have made it a lot easier for us to operate, made it to where we can spend more time with our feet on the ground. - Interviewee

That closed loop referral process would probably provide a little bit more efficiency and a better way to track especially across systems, because it's easy to track that within a health system, but across health systems, or contract. So I could really see the benefit there. - Interviewee

2.4 CIE would promote collaboration and coordination between organizations

It would create a larger message for the community, right, that even though we serve separate communities that we stand together and the services and the goals that we're trying to provide. - Interviewee

That's what I liked about this ... everyone's welcome at the table, which is awesome. So it's not like an exclusive group where only your medical and behavioral health and people can, can you know, reside. So it's a place for everyone. - Interviewee

So when we go in there, we can see that, hey, you know, they've already been to Catholic Community Services, and they're helping them with, you know, 123, all these things. And we're like, Okay, well, that's great. So we don't need to try to help them with those things. So you're already getting help, so we're not duplicating our efforts, or, or people will come in and be like, Oh, well, they didn't call me and you must not have done the referral like, Well, according to the notes, they tried calling you for that, and have not been able to get a hold of you. - Interviewee

2.5 CIE worked well for COVID-19 wraparound services work

- Those that used CIE for county-level COVID-19 wraparound services said that their experience was positive because it helped them organize and coordinate efforts. Organizations also had a script so communication about what was happening was very clear, the services were concrete and well-defined, and reimbursement/payment for services was addressed.

2.6 CIE helps multiple agencies “see the whole person” by getting a view of all the services they need holistically

- This is especially important for serving whole families.

But really all we're doing is sharing, and it's with a release, you know, with informed consent, we're just sharing that this is the client, and these are the entities that they're touching, and contact information for that, for that case manager or whoever. So we can see if they're being served. - Interviewee

2.7 Avoiding rescreening and retraumatization

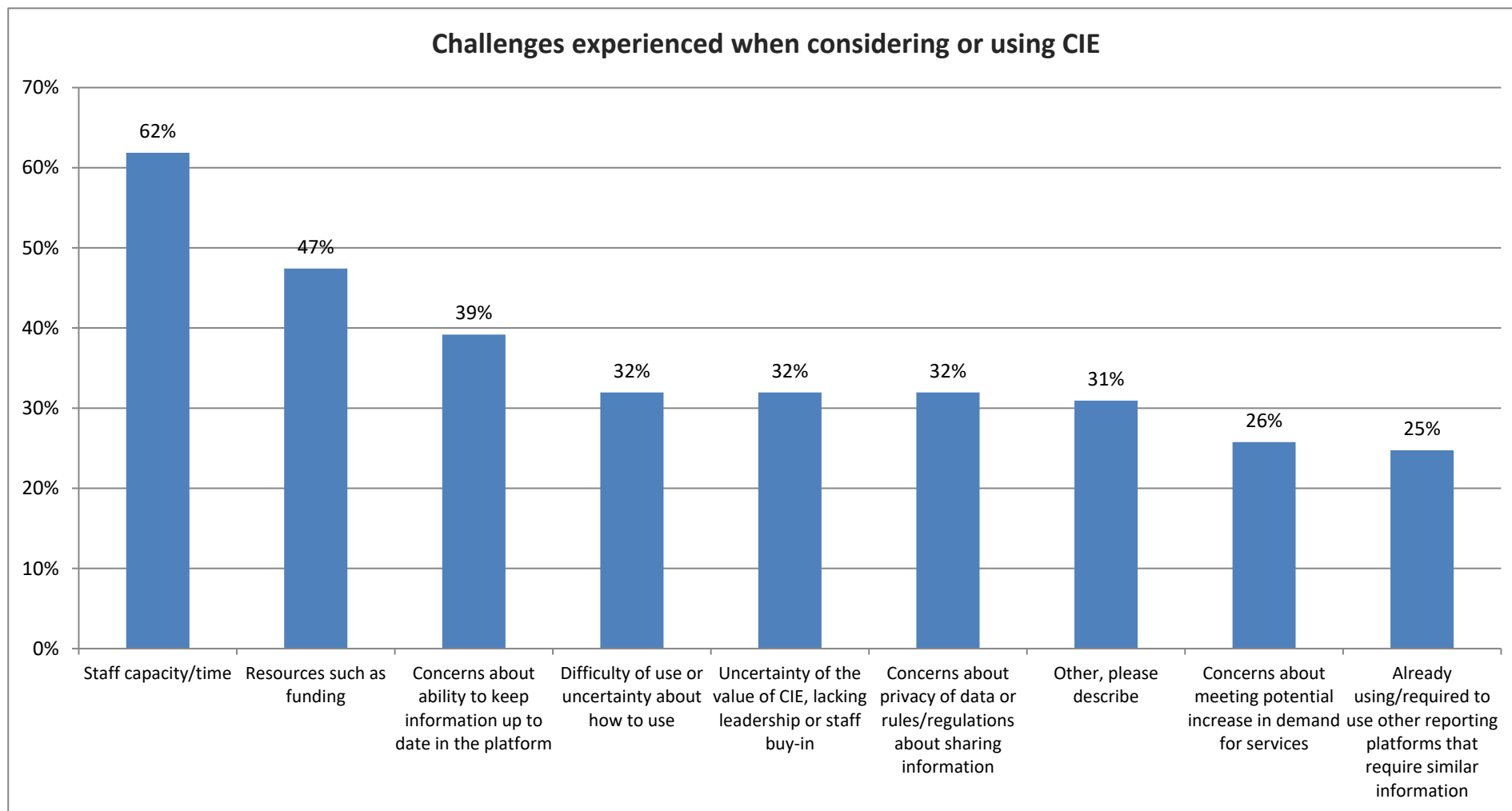
- Many social service organizations are already gathering data, such as entry assessments, for required reporting and end up collecting the same information over and over. Some CBOs agreed that avoiding rescreening and retraumatization could be a benefit of CIE, but overall this was not something CBOs brought up in interviews unprompted. Despite the perceived benefits of CIE, interviewees could not envision that other duplicative screening requirements for federal or other funding sources would be reduced or eliminated with CIE use because many times these programs require different questions.

2.8 For CBOs that bill Medicaid, there could be a financial benefit if CIE helps create sustainable reimbursement systems which would allow CBOs to increase the volume of services provided (e.g., they can get more clients into behavioral health services)

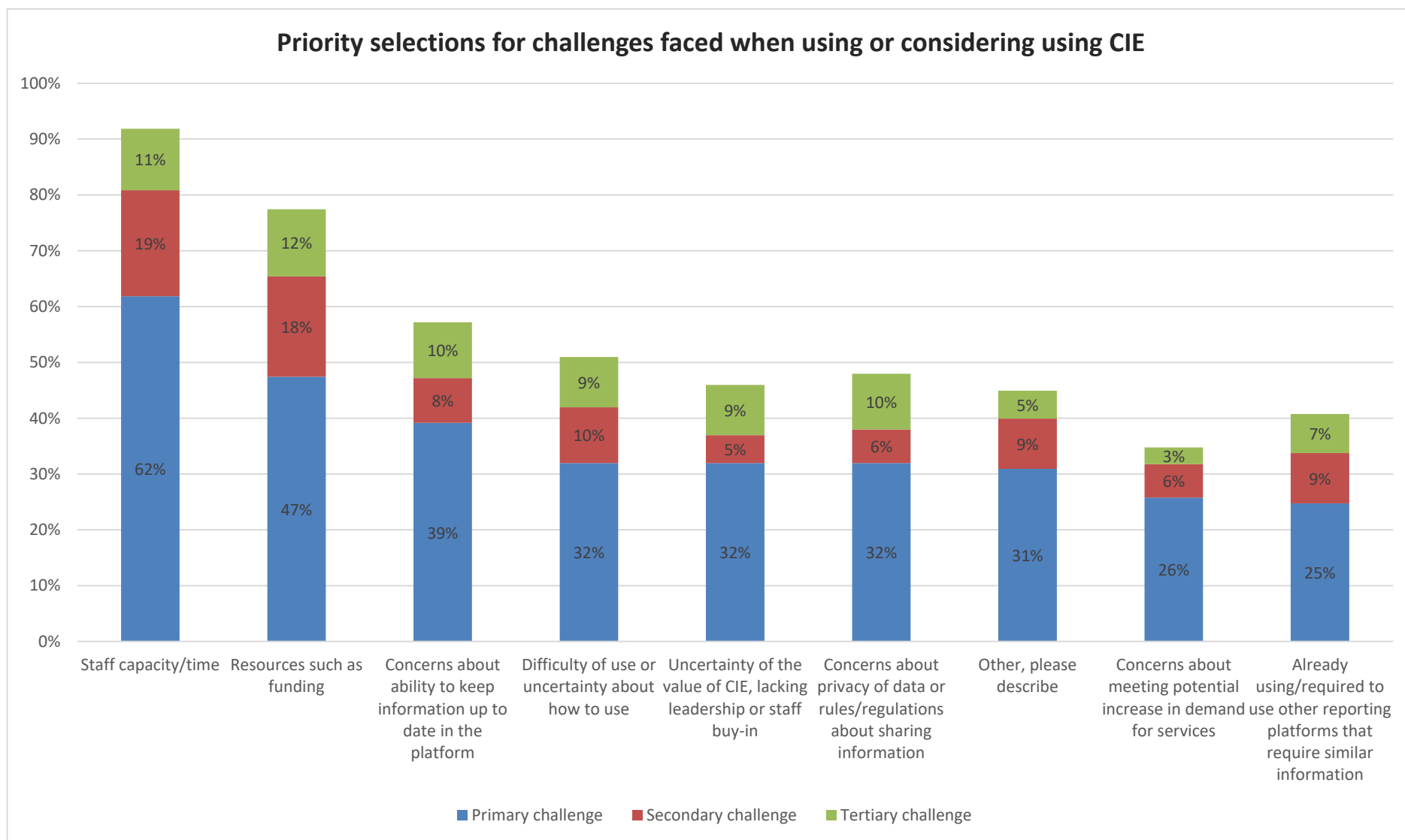
- This provides financial stability, sustainability, and lends credibility to the organization.
- Even for those that do not currently bill Medicaid for services, using CIE was a strategy to gain credibility and collect data to demonstrate their impact in the hopes of becoming a covered service.

3. Challenges, barriers, and concerns

While respondents recognize the importance and ability for CIE to have a positive impact on their clients, partners, and community, the challenge is in how to conduct effective, efficient, and equitable implementation of CIE. Interviewees shared that the most significant challenge CBOs are currently facing and are most concerned about is staff time and capacity, with 62% of survey respondents also indicating this as a concern. Many of the other most commonly selected challenges are closely connected to staff capacity, including resources such as funding (47%), and concerns about ability to keep information up to date in the platform (39%). These findings held true in interviews, where nearly all interviewees indicated a concern about staff time and capacity, including funding for staff time.



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%.



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3.1 Concerns about staff capacity

- CBOs are concerned about staff capacity to initiate and maintain CIE, including additional work of more intensive referral navigation or case management, increased need for client follow up, updating and maintaining the system periodically, and more data entry needs. Smaller, culturally and linguistically specific organizations often have very limited capacity to begin with.*
- There is a shared concern about joining a system that would increase referrals when staff (and services they provide) are already at capacity, in both the social and health care systems.
- Many felt that a dedicated staff person would be needed to monitor the system.

Our experience is that without a dedicated staff member with time to constantly update our listing in any CIE, it is not worthwhile. And similarly, CIEs are only as good as the data (and time) that are put into them by other entities. Currently most CBOs we partner with don't have FTE they can dedicate for this purpose.

- Survey respondent

- Some worried that staff time required upfront to build relationships with clients and get buy-in for connecting them to services would be significant. Resource navigation staff already spend a lot of time trying to track people down when referrals are made without significant clients' engagement and readiness upfront.
- Organizations may be unstable post-COVID since they have been navigating a lot of change. That needs to settle before starting new programs.
- Interviewees seem to be split in their opinions about the digital literacy capabilities of staff, with some sharing that their resource navigation staff that would use CIE lack sufficient digital literacy, and others sharing that their staff (especially those out in the community) would be comfortable with a digital platform.*
- Beyond initial startup, funding, and time to train staff on an ongoing basis is a challenge.
- Even if CBOs had the ability to support CIE-related positions, there was a short-term concern about hiring staff. Current workforce shortages could make it difficult to find staff. Many CBOs have current open positions and recruiting in rural areas is especially difficult. Additionally, much current CBO grant funding is restricted to specific projects or conditions, so could not support CIE.

3.2 Privacy concerns

- CBOs and clients alike are concerned about privacy and confidentiality of data in CIE. People from groups experiencing inequities, in particular communities of color, LGBTQ, undocumented, sexual and domestic violence survivors, and minors, are wary about

sharing their information because of safety and legal concerns, and historic mistrust of government data collection efforts. (Although many CBOs are currently collecting and storing confidential information, interviewees were not asked about how those current systems function).*

- Despite concerns, those currently on the network acknowledged privacy concerns, but were generally satisfied with HIPAA compliance and indicated that their clients often already needed to provide the information that would be collected on CIE.
- There is a general distrust of the health care system in certain communities, especially with people that have been historically mistreated or left out.*
- CBOs have concerns about data collection, ownership, and equity. CBOs posed questions about who owns the data and how it is or will be used.*

What's the central energy or driver for this platform? And if they're trying to, I don't know, develop metrics that make them look good in order to sell it to other organizations, or states or whatever, that's gonna really complicate what we're trying to do, what the state is trying to develop. - Interviewee

- Some groups would need assurance that things like immigration status would not be shared with the government.*
- There are also specific privacy concerns related to federal or organizational requirements or limitations for personal data collection. Closed loop referrals may not even be a possibility for some, including organizations that serve those experiencing domestic violence.*
- Some CBOs do not want liability for holding personal information.

3.3 Concerns about duplication of existing systems

- Many CBOs are using CIE alongside other systems due to requirements from other grants and programs (e.g., from county, federal sources). Additionally, some organizations already use other data tracking systems created within their CBO. If this adds another intake assessment or becomes a requirement for CBOs, it will add to staff capacity burden and concerns.

We've got, you know, case notes in one system, we've got medical stuff in this other system, we've got rental history in this system, and they're not communicating with one another. So if someone were to look at this person, they only see this one side of them, as opposed to seeing kind of a full 360 view of where they're at. - Interviewee

We work with community health workers at a bunch of different clinics and behavioral health organizations. They all use different electronic health record systems. So we can't just like get a report from them and say, this is what we did, we have provide our own online data collection system, which means that they're already double documenting work, in order for it to get the payment that we provide. - Interviewee

- Other data reporting, management, and storage systems used include 211; Efforts to Outcomes (ETO); Homeless Management Information System; Portland Public Schools; Aging and Disability Resource Connection; Compass; Link to Feed; Activate Care; Eastern Oregon Community Resource Network; EPIC
- Some expressed a worry about CIE being duplicative of 211, currently the most comprehensive database and resource navigation service in the state.
- Whole resource navigation organizations do similar functions to what CIE does without a referral technology. So there is concern, especially among CBOs that primarily conduct case management, that CIE is duplicative of entire organizations.
- Even in the absence of other technology systems, organizations have robust internal referral systems and workflows built already.
- There is concern that referrals put into the system without time invested with clients or partners to understand the problem will be poorer quality referrals - ones that increase volume of referrals but are not likely to get buy-in from clients.

I don't know that words can express the problem of being on the receiving end of other CBOs having free reign to just send referrals without any investment, any personal relationship or investment to the situation. - Interviewee

3.4 CIE efforts are relatively new and current use is limited, it will only be effective if most organizations are actively using it

- Many CBOs using CIE have received very few referrals through the platform. Referrals are still frequently received in traditional ways, including through fax, email, and phone call. These are often in addition to occasional CIE referrals.

It's as meaningful as the users make it by feeding information into it and using it. - Interviewee

- Not having enough CBOs on board in an area reduces the impact of the system. Some CBOs noted they are ready to use CIE, but since others in their area are not on the system it has not been used or has limited value.

- Acceptance of CIE by clients will most likely happen by word of mouth in communities.
- There is concern about CIEs being able to record a full range of services and service providers, especially in rural areas where services are often provided by neighbors or small churches that will not join the network.
- Technology is a barrier for some.

People are going to go the traditional way, how we've always made referrals, we fax them, or we call our favorite connection person, you know, that kind of stuff. And he can't take emails and he only takes faxes. - Interviewee

3.5 Demand for services is already high, and there is concern that CIE will increase that demand

- CBOs wonder what the added value is of signing up for a system that will not increase the availability of services. More funding is needed for services alongside CIE efforts, otherwise CBOs will not adopt it because they won't be able to find and/or provide the services they need.
- CBOs already bear the burden of trying to provide services that cannot meet the demand. They may not be interested in more referrals from other CBOs or health care partners without an increase in availability of services.

There's still a lot of reservation among CBOs. And among the AAAs, about, you know, how much we want to be involved with the CIE when there isn't funding that comes with it. But because it's, we see it as increasing demand without increasing supply. - Interviewee

I'm concerned CIEs are building a bridge to nowhere and creating undue burden without compensation to social service organizations, for the benefit of health care systems who reap the reward. - Survey respondent

- Some culturally and linguistically specific organizations worry that increasing referrals will put pressure on them to serve clients outside of their priority groups or mission. On the other hand, other CBOs are also frustrated that presently there is no central database of culturally and linguistically specific social or health care organizations to refer to.*

[There is] always the concern of, if I'm working with a client and I know the client [has] language barriers or culturally specific needs - [whether] I'm sending my

client or my participant to an organization that I don't know if it's going to have the same awareness. - Interviewee

3.6 People will need help navigating the social services system, even with robust CIE

- Health and social service systems are complex. Many believe better-funded navigation services are essential to improving the system, and even well-functioning CIE won't replace this need. Complex decision making about which service might be best for a client will still be needed.
- Navigation services and case management are relationships-based, and at best empower clients to navigate complex systems on their own, so it may not be feasible or desirable to replace or lessen this with CIE.

People in the most vulnerable (groups) need navigation help to navigate the system. So even a technology platform probably by itself isn't going to do that. - Interviewee

3.7 Local relationships are the core of a well-functioning referral system

- Trusted relationships are crucial to a local, well-functioning referral system. These include CBO to CBO, CBO to client, and CBO to health care system. Some were concerned about the influence of CIE on these relationships, indicating it might distance those serving the client from each other and the client alike.

It's taking away personal and it's taking away the educational component. Yeah, it's like, magically, this referral is made for someone and they're not any part of it. So they still don't know how to get their needs met. - Interviewee

No matter how complicated or sophisticated or fancy that system is, the platform is, it's always going to depend on relationships. - Interviewee

- CBOs expressed concern that CIE would “depersonalize” or “dehumanize” the process of working with clients.*

How are we building profiles on people and then are we like, just kind of McDonald-izing services in a way so that we're not really paying attention to the person because we've built this, like, we've farmed this data to build a profile on what they need. And we're just kind of looking at that as what, how we're going to help the person versus kind of talking to them. - Interviewee

Anytime you try to describe a client and what they need, using a drop-down menu or something like, you just immediately lose a case and you start creating boxes. So I think that that's how I see that system, the system could just dehumanize a person. - Interviewee

The main issue for these CIE is that they don't take into account community health workers' principles that are based on face and heart connection at all levels especially during referrals. This digitization of referrals misses completely these values. I will concede that for us CBOs staff, this is a convenient system, but I would like something that can satisfy both community members who have low literacy and the CBOs staff. - Survey respondent

3.8 Some CBOs struggle to see the added value of the system for staff and organizations

- This is especially true for organizations that don't yet have exposure to CIE.

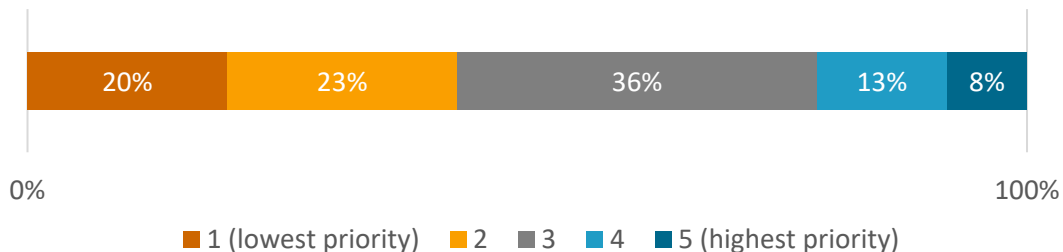
I guess I'm not entirely sure how CIE could be helpful in that, because I'm not super knowledgeable on everything that CIE could do. - Interviewee

- Some feel that CIE isn't a huge need. People are already sending referrals - usually via phone or email - without trouble.
- Technology may not be the top priority for organizations, especially in rural areas.

I think that in organizations, even big ones doing a lot of work out here, I think we see a lot of that technology isn't always their biggest priority. - Interviewee

- The priority level of CIE varies widely across organizations. Among those viewing CIE as their organization's lowest priority, there were an elevated number of organizations serving older adults. Those currently using CIE were the most likely to rank CIE as their organization's highest priority.

How would you rate CIE as a priority for your organization?



3.9 Concerns about equitable accessibility of CIE

- Using a CIE can be cumbersome - there are many steps to getting programs and services to use a CIE.
- CBOs worry about how accessible CIE is for clients and staff alike, especially regarding digital/technology access, internet access, and language access. In one example, a CBO with a Spanish-speaking staff member had to hire a translator for their staff to be able to use a specific CIE.*

3.10 Concerns about the current state of implementation and use of CIE in the state, and generally about state-led or initiated technology systems

- Both from those using and not using CIE, there was some concern about how CIE has been rolled out in Oregon. CBOs are concerned about large health insurers and systems advancing CIE efforts without consultation or input from CBOs.

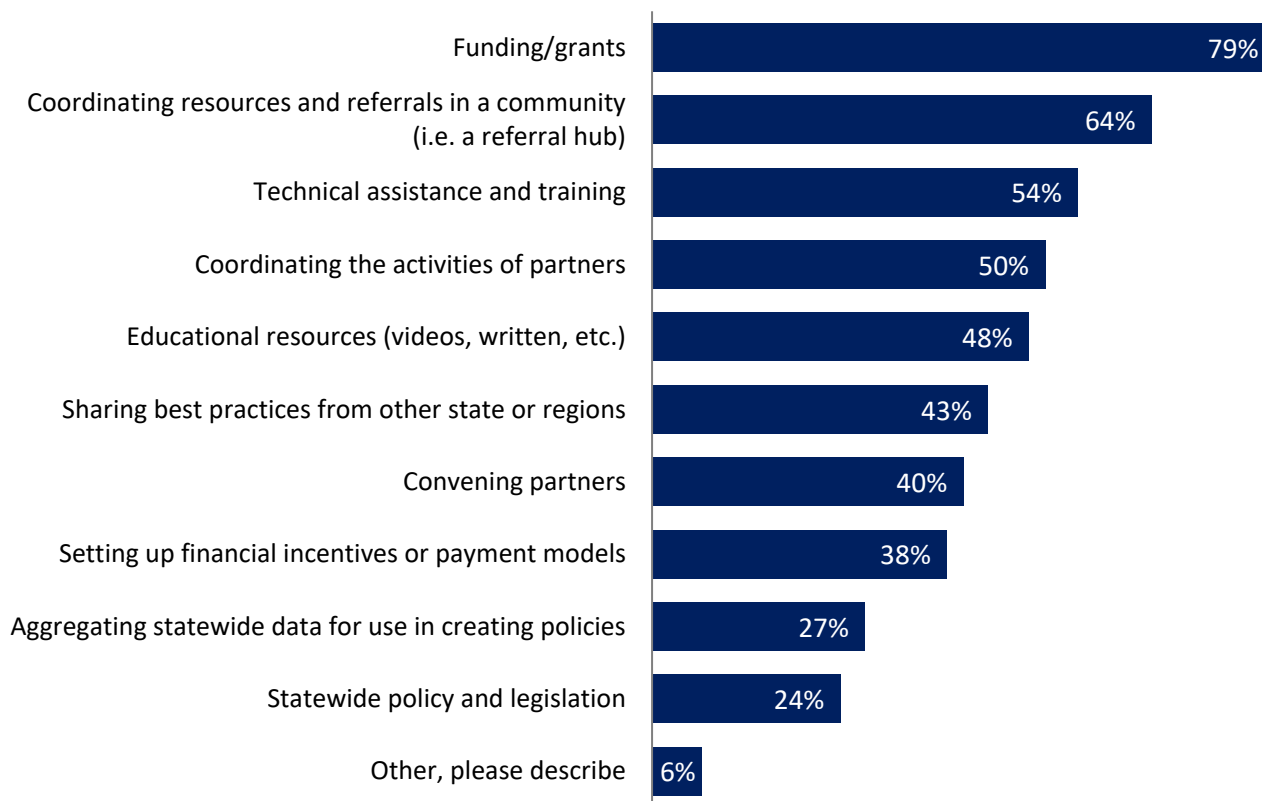
Currently the majority represented are health systems, CCOs, and [local public health agencies]. Not a lot of CBO voices or perspectives which means not a lot of CBOs are connected to the CIE. - Survey respondent

- Some shared that previous experience with other state-led technology systems implementation has not gone well. Examples shared included the ONE system interfering with existing data systems.

We've had to take on a lot of new technology systems from the state already. And it hasn't always done all that well. In fact, recently it hasn't done very well at all. So I think a good example is ONE, you know, the rollout of ONE has ended up being really significant on employees, and their ability to serve clients, and as constant barriers for clients to actually access services. - Interviewee
I think there's definitely a challenge in hesitance too, because systems kind of come and go at the state level. - Interviewee

4. Interviewee and survey respondent ideas for addressing barriers and creating a robust system

In order to participate in CIE, what types of support would be most helpful?



4.1 Invest in CBOs to increase organizational and staff capacity to implement CIE

- CBOs will require funding to get started with CIE, for staff time, technology, training, and other needs. CBOs are increasingly being asked by health care to work with health plan members, so they will need investment in infrastructure to be successful. Unrestricted funds are most useful for implementing CIE.

If you wanted to really open the doors, and really have it be a successful system, we would need a much more increased capacity, which would just be staff costs, and all the other things associated with that, including infrastructure money.

- Interviewee

- Dedicated staff are needed to lead CIE work within CBOs. Many CBOs say that they will require at least one internal staff person to take the lead and train other staff, monitor

referrals, troubleshoot technology, learn the system, participate in advisory boards, workgroups, or coalitions, and work with vendors and other external partners.

- Many CBOs suggested a 1-2 year “pilot” program approach where CBOs would be given grants with few limitations to adopt and use CIE. Some CBOs have had success with this type of model (including Kaiser CIE grantees). It will be essential to continue to provide support for CIE use among those who choose to continue post-pilot.
- Almost all interviewees mentioned the need for startup cost support, while less shared the need for significant ongoing funding to maintain CIE once implemented with the exception of support for ongoing training.
- Additional funding is needed at the system and organizational level to build a “data bridge” that would connect CIE with other systems being used (e.g., HMIS).
 - Integration is already possible with some platforms, but the integration cost is prohibitive for many CBOs (e.g., Activate Care).

4.2 Increase in demand created by CIE should be coupled with increase in funding for services

- CBOs consistently stated that the value of CIE will be diminished if it is not coupled with an effort to address the greater need - not enough social services available to meet the needs.

If there's true acknowledgement of the importance of social determinants of health, then they need to start to pay for those social determinants of health, they need to start paying for those services. - Interviewee

4.3 Training and technical assistance

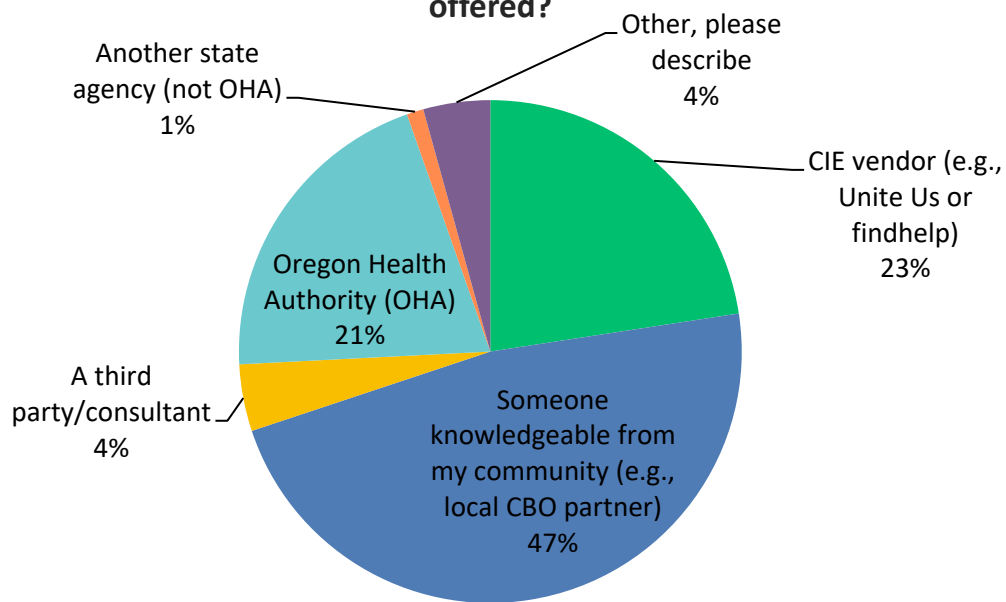
Respondents provided ideas about how CIE training and technical assistance could best support them:

- IT technical assistance and support
- Office hours
- Training
 - Group training in-person is ideal, but virtual or recorded sessions (like on-demand tutorials) would also be helpful
 - Training from vendors or other CBOs would be most useful
 - Training should be ongoing
 - Preferred training topics include: how to use the system, communicating about CIE, addressing and communicating about privacy concerns, troubleshooting technology issues, cultural competency training for all CIE users, basic resource navigation skills, and data management

- Training can be tailored to specific groups of users, like community health workers
- Create a community of practice for CIE organizations to meet periodically to share challenges and successes
- Build on current networking events or meetings to engage users (i.e., some community health workers already gather to share resources and ideas and some counties host meetings for social service partners)

In our nonprofit, we'd say like, there's no such thing as like, too much communication. And in that same regard, I would say that there's no such thing as like too much support. I would say, you can't go wrong with having multiple different ways to provide support. - Interviewee

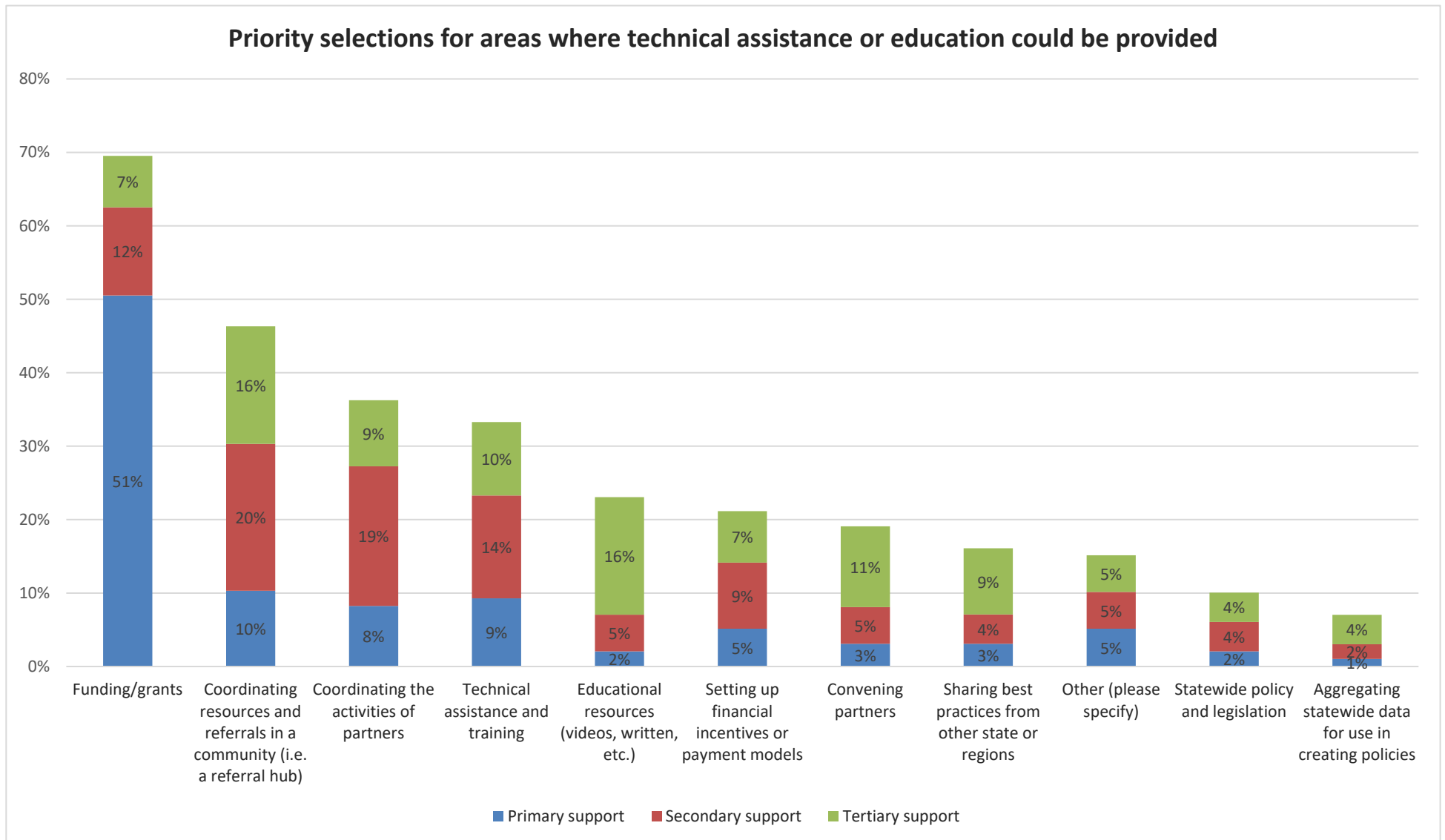
Who would you most like to receive technical assistance from if offered?



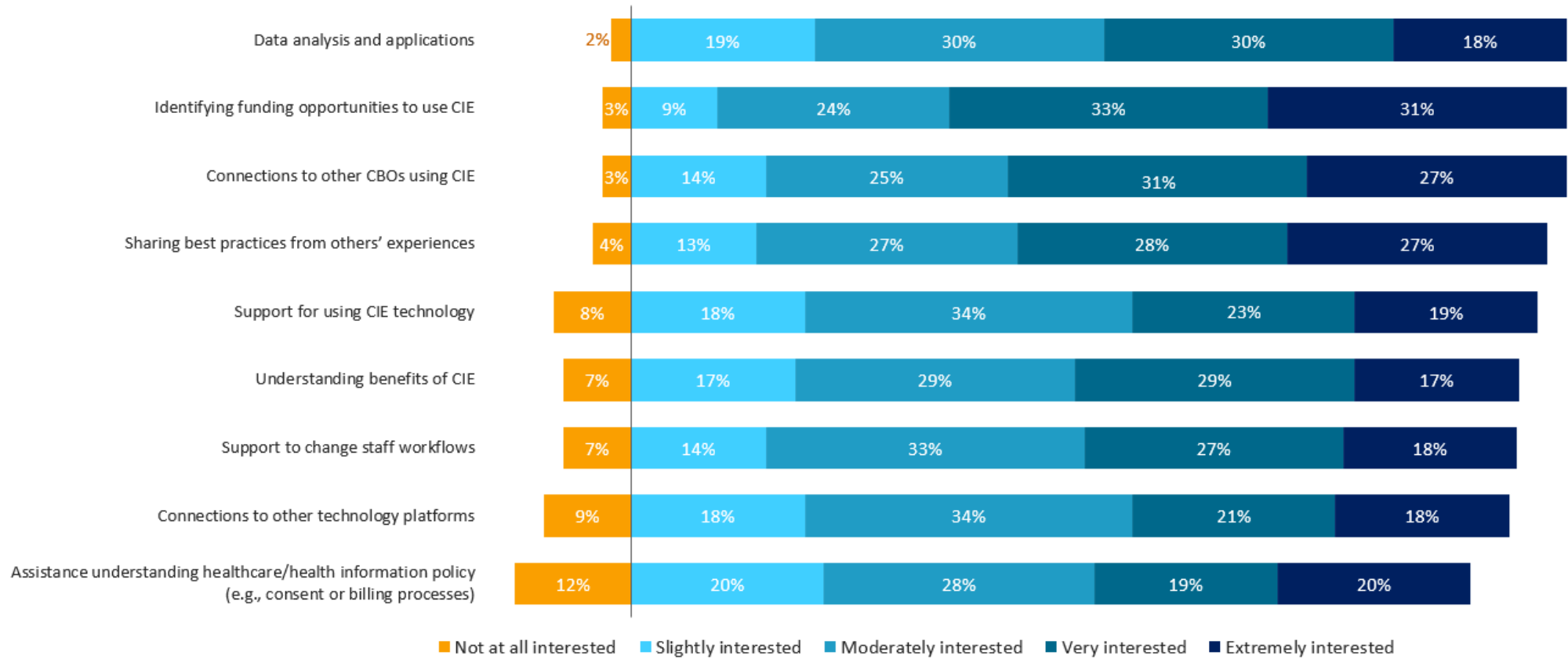
Other responses: ODHS; CIE vendor and local knowledge expert partnership

- Overall, survey respondents were enthusiastic about interest in technical assistance or education across a wide variety of supports

When provided a range of options for support, survey respondents across both those who are using CIE and not using CIE, the top supports requested were (#1) funding/grants and (#2) coordinating resources and referrals in a community (i.e., a referral hub).



Level of interest in areas where technical assistance or educational opportunities could be provided



4.4 Very clear, frequent communication with clients and broader communities is needed to build relationships and maintain trust

- CBOs could use support from OHA or other statewide entities on developing clear and consistent messaging.
- Communications to clients should highlight the added value of the system to CBOs, address historic mistrust and privacy concerns, and share clear information about why you are calling, where you are from, what you are providing, and what to expect.*
- CIE efforts can build trust by communicating through trusted voices already embedded within the community.*
- The county public health COVID-19 wraparound support “pilot” could be used as a model for how to set up networks that promote frequent and clear communications among CBOs and with OHA.
- Outreach needs to be focused on the communities that are least likely to access CIE, with more time spent to reach them and share the value of participating. Otherwise CIE won’t be equitable because it will just reach those that are already connected to services.*

4.5 Privacy concerns should be addressed

- Clearly communicate and educate CBOs on HIPAA compliance and other privacy and security measures.*
- Build in a process for getting permission from clients to use/store their information.*
- Provide clear, transparent communication in understandable ways about how collected information is used and shared.*
- Ensure protections for sensitive information with legal backing (i.e., ensure immigration status wouldn’t be shared with the government).*
- Consider use of a coding system to deidentify information.
- Ensure Bill of Rights to ensure technology platform is not profiting off of community’s data.*
- Consider convening a data justice and oversight committee composed of community and CBO leaders to ensure issues of data justice, decolonization, and privacy are adequately addressed.*

4.6 Language access and health/digital literacy should be addressed

- Almost all CBOs shared the need for access in multiple languages. Spanish is essential at a minimum, yet some communities (e.g., immigrant and refugee communities) will require access to many more languages.*
- Some indigenous people do not have a written language, so videos would be helpful.*

- Interviewees using a CIE stated that delays in getting the language functionality working are having an impact on users.*
- Language access is important for both clients and for CBO staff.*

We have a lot of staff that are monolingual in Spanish only. So if we could maybe give them access to the system, we have a lot of community organizers that only speak Spanish, so we're not able to assign them with the system if it's only in English. But if it was in Spanish, we might be able to pass over some of that work to them. - Interviewee

- CIE information should address literacy access needs as well. Many clients have low literacy which is a barrier to accessing services.*

There's also making sure that like, the information that we provide is accessible for our community, some of our community members have reading levels that aren't beyond like, fifth grade. - Interviewee

- Rural communities face issues with technology access and abilities. CIE may exacerbate technology inequities for rural communities if these issues are not addressed.*

4.7 Systems should be created to help reduce duplication with collecting information for multiple data entry platforms

- Creating uniform or standard questions across social services and health care organizations would be ideal.
- In the meantime, provide something that would help easily integrate/transfer CIE data with existing systems (e.g., a csv file that could be pulled easily).

4.8 Users need to be “guaranteed” success with the system, or they will stop using it (i.e., early reassurance that referrals made are picked up, a robust network of CBOs regularly using the system from the beginning)

- Many indicated that the success of the network relied significantly on the uptake among CBOs and healthcare providers in their area.
- Incentivizing use alongside an equity-focused roll-out plan that is sensitive to the challenges CBOs are facing today will be essential to foster trust and longevity of CIE.

4.9 Desired functions of CIE

- Easy to navigate user interface where clients can easily see where they can access services (even if clients are not directly accessing it right now, CBOs would like to show the interface to clients)
- Easy, automatic connection/integration with other systems
- CIE tracks organizational capacity, so users know when another organization has capacity to accept new referrals (in real time)
- Ability to easily identify and access culturally and linguistically specific organizations and medical providers (e.g., many people prefer to receive services from a fellow community member or someone with a shared identity)*
- A decision tree is built into CIE that allows the referring agency to be more thoughtful and intentional when adding referrals to a CIE. For example, maybe a CBO connects a person directly if it is easy enough, versus putting a referral into the system.
- CIE has the ability to filter by local/regional/statewide resources, and a mapping feature is available
- Needs to be mobile friendly
- Needs to have a good search engine
- Provides CBO phone number for those who prefer calling
- Improved or easier access to service insights and reporting for CBOs to compile data

4.10 Building relationships and trust with communities must be factored into building a CIE system

- CIE implementation should be coupled with investments in relationship and trust building among CBOs on a system, perhaps regionally.*

Ensuring that we are working in a way that uplifts people feeling safe and comfortable. So just maybe being, you know, like, cognizant that it might be something that may require more time than what may be originally anticipated.

- Interviewee

And if there was funding for some kind of universal Oregon-wide thing, I think investing in relationship building between the refer-er and refer-ee is really valuable, like face to face, coffee, or whatever, saying like: this is this is the organization and these are the things that we do and this how it works best, like that is really helpful. Making it a living network versus just electronic.

- Interviewee

- Ensure CBOs are able to understand others' services, values, mission, and population served.*
- Create opportunities for organizations to share about their work, including educating others on the culturally and linguistically specific needs of their community, to spread awareness.*

I think one of the first things I would like to see is representation because that's the only way we are gonna make our culture, our voice known in different you know, in different parts of policy making legislation. - Interviewee

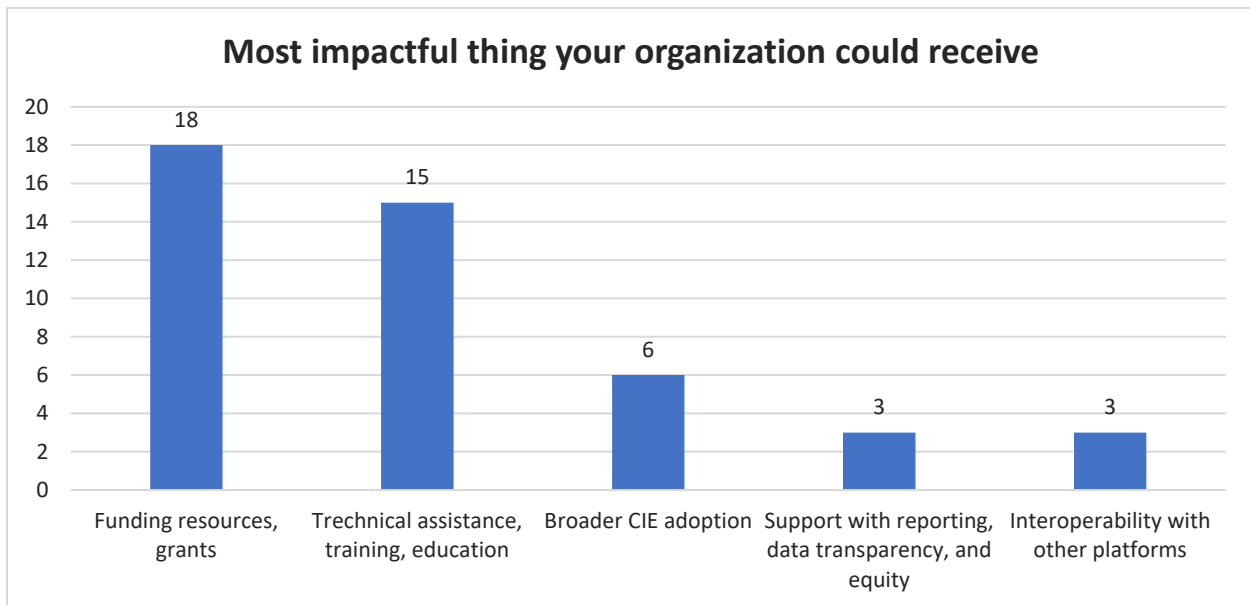
4.11 Address data equity needs and concerns

- CBOs and statewide groups should use data collected on the platform to improve the overall system, yet it should be done in a way that respects community needs and concerns.*

Kaiser required us to attend their conference last fall, and it was about data equity. Our network is so young, we're not having these conversations, but I think that's something to put on the horizon to make sure that we're really looking at and being thoughtful about like, what data we collect, how we're using it, engaging the community and making sure that's okay. That, you know, all the stakeholders agree with the appropriateness of what we collect and how we use it will be important. - Interviewee

If there's some intention around how to roll it out how to do kind of iterative. Really, actually really rapid process improvements. And use the data to do that, and get some of those resources back to the community, and really be intentional and thinking about what's the workflow analysis impacting what's happening in the community, I think it could be really beneficial. - Interviewee

Survey respondents indicated the most impactful areas for support:



5. Reflections on broader statewide CIE goals

5.1 CIE may not be enough on its own to fulfill the vision of the Workgroup or promote equity, yet it could be an important part of the solution

- CIE has the potential to improve how communities collaborate to address intersecting challenges.
- Most interviewees support the vision of the CIE Workgroup, but are unsure if CIE will be successful in getting us all the way there for many reasons:
 - Current technologies used may not be the right tool
 - CIE is functioning in an imperfect system
 - Larger systemic issues like the housing crisis, cost of living, and the minimum wage are playing into this
 - The behavioral health system must be better coordinated first

I don't think that any existing system can provide that. Because they're all thinking that they can do it all, but they can't do it all, you know, that's the first thing they have to realize is, you know, whether it's Unite Us or Aunt Bertha, it has limitations. And, you know, maybe they should be realistic about what they can do, versus trying to be the end all for everything. - Interviewee

- Some of the other important pieces of a system that will lead to health equity include:
 - Investing in relationships
 - Persistent outreach to priority communities or those experiencing inequities
 - Systems change in US healthcare

5.2 Interviewees agreed about the complexity of navigating complex social and health care systems, but disagreed about whether CIE would improve or worsen the issue

- Resource navigation in general is solving a problem navigating many overlapping, complex, and confusing health care and social service systems. The problem is that clients cannot navigate those systems easily. Some interviewees felt that CIE will not solve that problem and could potentially make it worse if clients are further removed from understanding the existing health and social service systems when CIE is implemented (because organizations may spend less time educating clients through intensive case management).
- Other interviewees felt differently, that the connections created through CIE would strengthen relationships between CBOs and clients, and CBOs with other CBOs. In general, CIEs need to be able to address that issue - making the various existing health and social care systems easier to navigate, not harder.

5.3 Multiple referral systems need to be coordinated and connected

- Multiple referral systems should be connected, maybe with a centralized repository. CBOs are stretched thin and checking multiple places for referrals is challenging. Systems must talk to each other.

5.4 Further implementation of CIE statewide should include community and CBO voice

- CIE has been informed and driven by health care to date, not the local community or CBOs.*

My understanding is that CIE....has been driven by major stakeholders in the health sector, Kaiser CEOs, health systems, and not been fully informed by the other half of the users, which is community-based organizations or people or organizations that are being referred those clients. - Interviewee

I think the CIE needs to be more than just culturally and linguistically responsive but it also needs to be responsive to each community it is working within. That means being a part of the community, listening to the community. We have not seen that [from CIE]. It feels like something that is being pushed on organizations without capacity, interest or some who have specific requests that are not being met. The perception is that [the CIE] is in over their head with unmet promises from a boots on the ground perspective. - Survey respondent

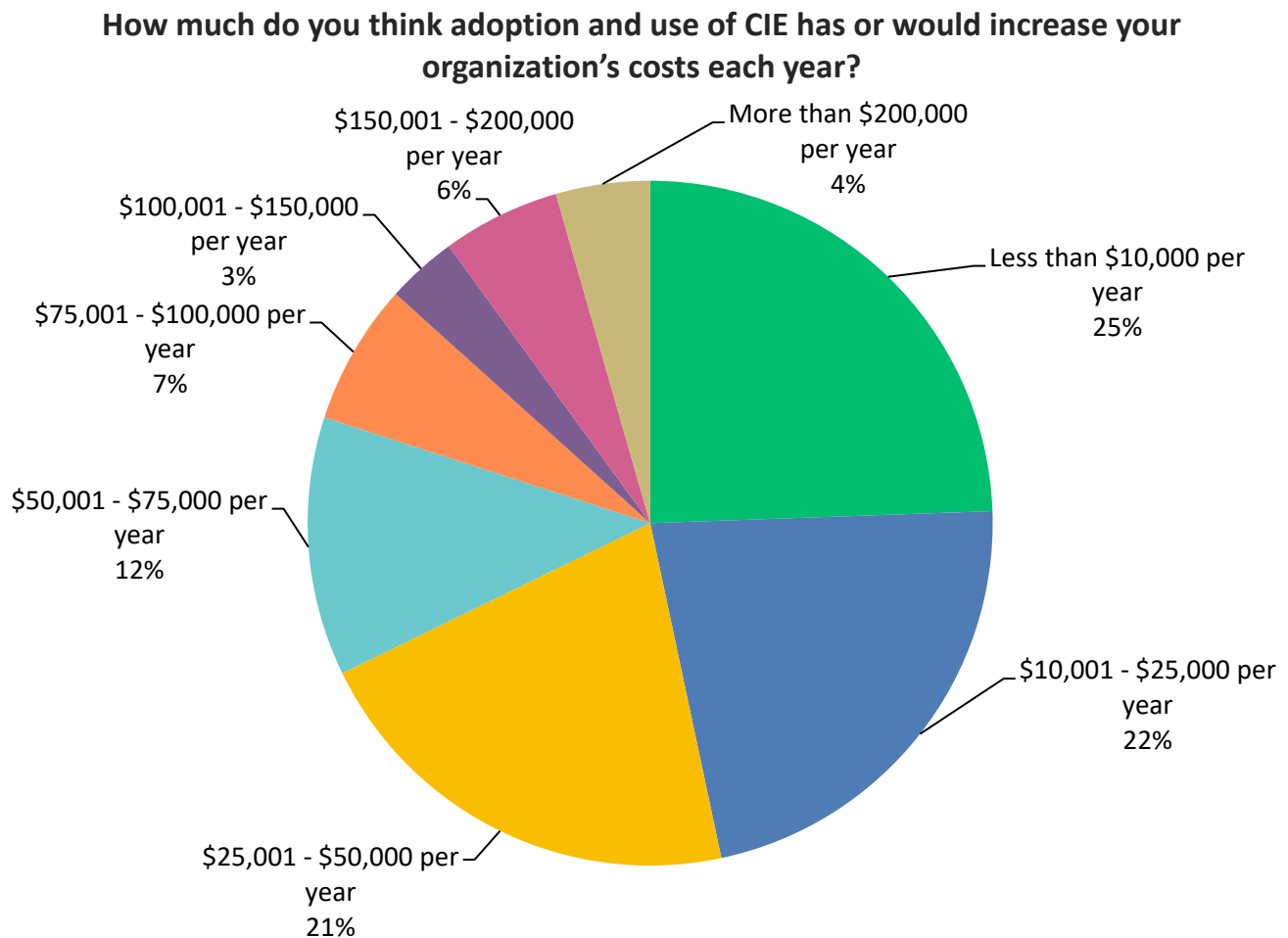
5.5 Historical underinvestment of CBOs needs to be addressed if health care and other partners want to rely on CBOs to implement CIE at the community level

- Staff and organizational capacity and function is limited in part due to historical underinvestment in CBOs, especially those providing social services.*
- Some shared the concern that while attention in the healthcare and public health community is shifting to focus on the social determinants of health (SDOH), funding for CBOs that address SDOH has not caught up to this shift.*

6. Funding and incentives

6.1 Funding is needed to support the implementation of CIE

- CBOs surveyed reported how much they think adoption and use of CIE has or would increase their organization's costs each year:



- To understand differences across varying CBOs, responses were stratified across key groups:

Organization size:	Annual cost							
	Less than \$10,000	\$10,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	\$75,001 - \$100,000	\$100,001 - \$150,000	\$150,001 - \$200,000	More than \$200,000
Small (0 - 30 FTE), n=67	30%	24%	16%	15%	5%	5%	3%	2%
Medium (31 - 200 FTE), n=23	13%	22%	26%	13%	13%	0%	13%	0%
Large (201+ FTE), n=7	17%	0%	50%	0%	0%	0%	0%	33%
Overall	24%	22%	21%	12%	7%	3%	6%	4%

Green or red = more than 10% away from overall response. Green +10% or more, Red -10% or more, bold is concentration of responses.

Population served:	Annual cost							
	Less than \$10,000	\$10,001 - \$25,000	\$25,001 - \$50,000	\$50,001 - \$75,000	\$75,001 - \$100,000	\$100,001 - \$150,000	\$150,001 - \$200,000	More than \$200,000
Older adults, n=9	18%	18%	18%	0%	9%	9%	18%	9%
People of Color, n=17	18%	18%	18%	29%	0%	6%	12%	
Rural, n=6	40%	0%	40%	0%	0%	0%	0%	20%
Overall	24%	22%	21%	12%	7%	3%	6%	4%

Green or red = more than 10% away from overall response. Green +10% or more, Red -10% or more, bold is concentration of responses.

- The less restrictions on funding the better. Specifically, unrestricted grant funds would be most helpful.

I know the CCOs have their flexible funds that they're required to use, maybe having the information that comes from the CIE kind of analysis of what's working, what's not working, and have that inform how they use their flex funds and how they invest those funds. - Interviewee

- Funding is needed for:
 - Staff - CIE could be a full-time job for some and is often spread across multiple staff. There is a need for one person within a CBO to take the lead in a referral coordination role.

- General administrative burden
- Technology systems
- Startup costs
- Stipends/support to attend trainings
- Pilot projects
- Services
- Workflows
- Staff training
- Participation in statewide or other coordinating entities
- Building relationships and trust, and increasing buy-in (between CBOs, communities, and health care)
- The Kaiser grant funding for CIE implementation through their Community Clinic Integration (CCI) Grant Initiative was \$30,000 per year for 2 years. Many interviewees said this was sufficient as a starting point but was not enough for a full-time staff person to maintain and use the system which would be ideal.

6.2 CBOs had mixed perspectives on financial incentives for increasing the use of CIE

- Many CBOs currently using CIE thought incentives could be a good way to recruit organizations to the platform and ensure use among individual staff members. This is essential given the perspective that CIE will only achieve the vision if use is widespread.

Again, unless all CBOs and agencies using a CIE have time to keep their information current, accurate, and reflective of capacity, no CIE will be successful because once a tool is determined to be ineffective, people stop using it.
- Survey respondent

- Generally, interviewees not currently using CIE had a negative view of financial incentives. Within the behavioral health community, there may also be restrictions against incentive use, which could be perceived as steering clients towards/away from certain services.

If the incentives are to use CIE I'm not sure that's the right incentive. I think the incentive needs to be to serve people and to improve wellbeing in the community. And CIE is a tool toward that. - Interviewee

It feels kind of icky to me. It feels like a financial incentive to do less personal, less relational work. - Interviewee

- Some felt that incentives were messy and not ideal, but if necessary, a tiered approach to incentives works better than a per-referral incentive.
- There are potential downsides and unintended consequences of incentives that should be addressed. For example, for organizations that provide long term care, closed-loop referrals are not a good indicator for success due to lengthy timeline of care and completion of care.

CIE is an important tool, but it is also important to consider how that tool is adopted, used and shared within the community. We risk alienating smaller clinics or CBOs if we force them to onboard to a system that we cannot incentivize them to use either with staff time or supports. Ultimately this may mean we miss clients who would otherwise have their data captured by this system and risk retraumatization by having them to explain their story over and over to each agency. - Survey respondent

6.3 Reimbursement for services needs to be built into the system to promote long term sustainability for CBOs

- Interviewees desired reimbursement for services or a system where payment follows the referral.
- CBOs cannot support this long term through relying on grants to fund services, so they will eventually need to transition to a sustainable reimbursement model.

7. Ideas for the role of a statewide convening entity

- Most CBOs embraced the idea of a statewide coordinating entity for CIE. Among survey responses, 65% of respondents extremely or quite agreed that a statewide entity to coordinate and convene partners (either nonprofit or governmental) would help facilitate the adoption and use of CIE.

I think it would be less chaotic or less unorganized if we have someone in charge, yes. Because we can, like I said, synchronize our information. Because every organization is different and is using different platforms. We're gonna have one that is going to serve us well. Yes, but for that it has to be a central organization that understands the complexity of Oregon. And the different regions. I think it cannot be just a government, it has to be private or nonprofit and government together as a partner. - Interviewee

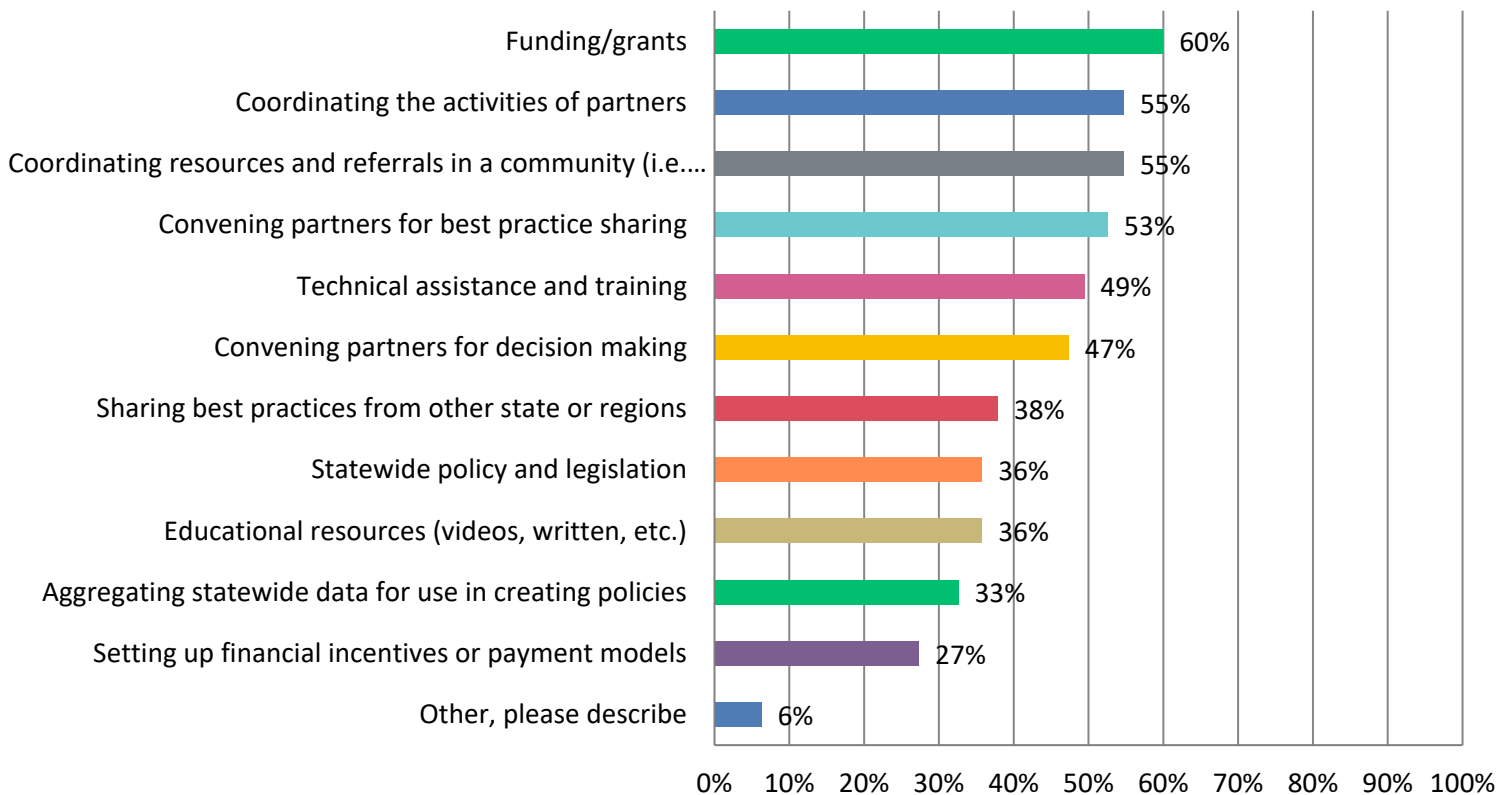
- Some CBOs said that a third-party organization would be preferred over OHA for this role, in particular to promote continuity in staffing and ensure it is community-led.

- CBOs shared ideas about the possible role that a statewide coordinating entity could play to support alignment across organizations, sectors, and systems. Ideas from CBOs are included in the [Recommendations section](#) below.

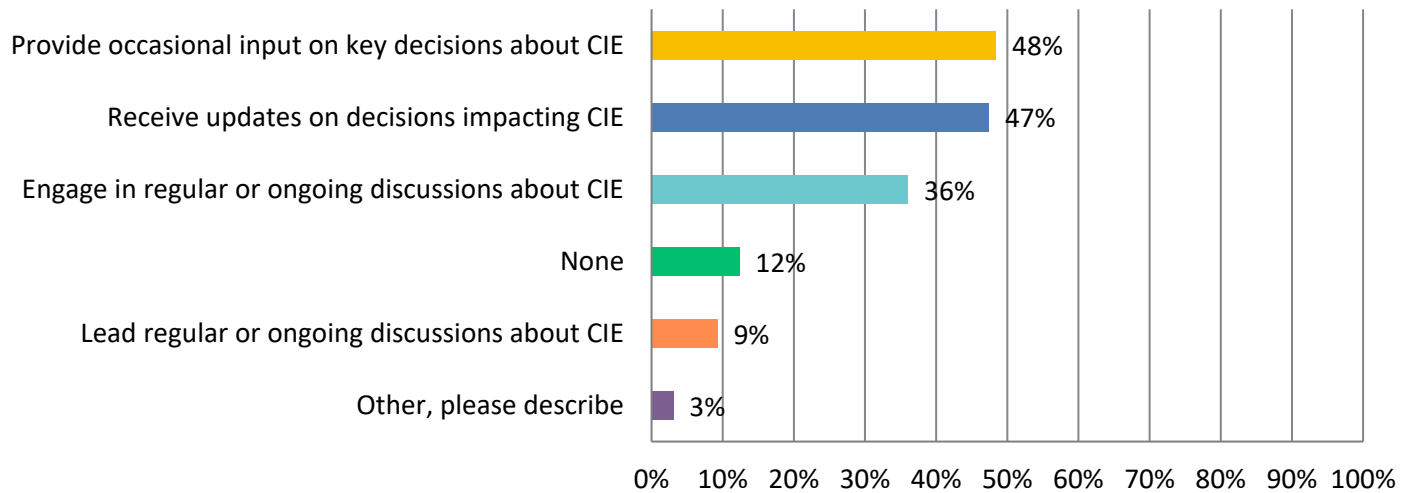
I like the idea of a statewide process so that we can be communicating across county lines, because I know that our services blur across county lines, and so, you know, if we can all be hopping on and using the same thing, that would be amazing. - Interviewee

- Additionally, CBOs mentioned that OHA could play a key role in coordination and facilitation, advocating for more funding and resources for CIE and services, and coordinating statewide access to those resources. They could also provide oversight to make sure the system is working and evolves with needs, and track and monitor data over time.
- Survey respondents shared top priorities for the role of a coordinating entity as well as their desired input into decision-making around CIE:

A CIE coordinating entity (either nonprofit or governmental) would be most helpful in the following ways



What role, if any, would you or your organization like to play in decision-making about CIE? Select all that apply.



8. Advice to OHA, health care and vendors for CIE outreach

- First, ask questions and understand what people are already doing, and where their hesitation and mistrust stems from. Then, demonstrate the value add of CIE for them.
- Demonstrate the benefits of CIE:
 - Highlight the benefits compared to the burden on staff capacity
 - Emphasize the benefits of having access to more resources than are currently available
 - Highlight the support and resources that will be provided to get the system up and running
 - Share who else is using the system and how prevalent CIE use is

CBOs across the state, we're just yeah, we're all worn really thin. And so asking us to do anything else is like, Oh, no. So whatever support y'all can provide, would be a leading selling point. - Interviewee

- Be accountable and knowledgeable about historical context of government working with communities*
- Engage outreach staff from the community*
- Describe expected workload impact clearly and concisely
- Be sensitive to challenges with capacity/time and demands CBO staff are experiencing
- Promote transparency around data collection and use

- Describe expected or achieved outcomes
- Consider potential negative impacts of CIE use and identify ways to mitigate

RECOMMENDATIONS

Recommendations stem directly from respondents' stated needs as well as from thorough analysis of survey responses and interview transcripts. They are designed to strategically address multiple challenges and affect multiple positive outcomes. For example, addressing privacy concerns could also promote health equity.

Recommendations are also designed to address the broader goals discussed earlier in this paper - promoting the CIE Workgroup's vision, OHA's strategic goal to eliminate health inequities in Oregon by 2030, and the intent of HB 4150 to "accelerate, support and improve secure, statewide community information exchanges that would allow the seamless coordination of health care and social services across all delivery systems, prioritizing health equity, confidentiality and the security of information".

Recommendations are generally presented in order of priority, with strategies that address the most commonly reported barriers to CIE shared first.

1. Offer robust funding to support CBO use of CIE

- General financial support needed for adoption/use of CIE (in particular for startup costs) is between \$25,000 - 1 FTE (amount for 1 FTE varies by organization).
- Funding is needed broadly to increase staff and organizational capacity to use CIE, connect systems, and maintain or grow service offerings. Specific CBO needs include funding for CIE system set up, staff time, resource navigation and training. Relationship building will require dedicated time to successfully grow the statewide CIE network, so adequate funding should be built into budgets.
- Pilot grants are a mechanism that CBOs have found successful in the past. Providing 1-2 year pilot grants for implementation would allow CBOs to support systems development, testing, evaluation, and improvements on CIE use, but more importantly to create a network/cohort of CBOs implementing CIE together.
- Financial incentives (e.g., payment per referral) built into CBO contracts may help accelerate adoption of CIE, yet incentives should be crafted in a way that minimizes impacts on equity.
- Consider funding to support integration or connection with other data systems to considerably lessen the administrative burden on staff.
- There is widespread agreement that culturally and linguistically specific organizations are an important part of a robust CIE network, yet they are more likely to experience

capacity issues due to chronic underinvestment. Prioritize these CBOs for investments and administer grant funds in a manner that does not increase burden (e.g., use fiscal intermediaries or minimize prescriptive funding requirements).

2. Promote equity, accessibility, and accountability

- Ensure the most important foundational components that will promote equity are in place: language access (in multiple languages for both staff and clients), literacy (including compliance with existing laws like the Americans with Disabilities Act), and technology access.
- Challenges specific to rural communities like gaps in broadband access, funds/transportation to attend trainings and lack of access to virtual services need to be addressed to ensure rural communities are not excluded from participating in CIE.
- Ensure that CIE platforms have the technological capabilities to identify culturally and linguistically specific organizations and make their services accessible. Work with CBOs to ensure that referrals can be made in a culturally and linguistically responsive manner and to the appropriate organizations.
- Be responsive to the needs of the community and clients through good governance, person-centered values, and accountability.
- Address historical mistrust of government and health care systems through listening and understanding concerns, and providing clear and accurate communications from trusted voices.

3. Advance privacy, data protections

- Investigate data use protections and address concerns about privacy of data collection and use by clearly communicating about data privacy features in specific CIE technology, data justice principles, and consumer protections. Ensure ongoing oversight of protections, perhaps through an oversight committee that utilizes the expertise of CBOs currently collecting protected information in this area.
- Ensure legal backing for protections for sensitive information (i.e., to ensure immigration status is not inappropriately shared). Create a Bill of Rights for CIE users to ensure no one is profiting from the use of the community's data.

4. Provide technical assistance, training, and education

- CBOs desire a single, clear place to access resources and support.
- Provide ongoing technical assistance (possibly through office hours) to ensure CBO staff are able to use CIE and resolve issues quickly and efficiently. Ensure support staff are easy to reach, responsive to questions, and knowledgeable about the local community.

- CBO staff desired training from other CBOs, technology vendors, or state agencies on CIE use and best practices generally, but also suggested training would be helpful on cultural humility, implicit bias, communicating about privacy with clients, resource navigation, and data management.
- Consider funding CBOs to provide training, education, and capacity building to those in their community.

5. Create a statewide coordinating entity to promote alignment across organizations, sectors, and systems

- The statewide entity should be a neutral, third-party convenor (i.e., not state government) and community-led through diverse representation, including CBOs that serve culturally and linguistically specific populations, serve all geographic regions, are of varying staff sizes, and have varying experiences with CIE. OHA and/or other state agencies should coordinate and support the entity.
- The roles of the entity should be to:
 - Lead the collaborative creation of statewide goals and priorities, and monitor progress
 - Coordinate and convene partners, including a statewide community of practice
 - Communicate about CIE-related opportunities
 - Provide oversight and governance, with CBOs providing leadership in these areas
 - Collect, monitor, evaluate, and report on statewide trends, especially with regard to equity, functionality, and success. Make improvements in response to findings.
 - Administer or oversee funding and pilot project grants
 - Support ongoing training for CBO staff
 - Advocate for increase in social services and behavioral health funding alongside CIE implementation
 - Plan ahead for increases in system needs related to emerging threats (e.g., natural disasters, wildfires)
 - Outreach and recruitment to encourage participation in CIE to quickly get as many organizations using CIE as possible (so that organizations do not lose interest), but do not force participation
 - Consider a hub-and-spoke model (which has been successful in other states), with someone embedded in each community as the main point of contact and trusted local voice for CIE in each region
 - Utilize data gathered through the system to make improvements in CIE and in the overall social and health systems

6. Prioritize relationships, communication, and engagement

- Prioritize fostering relationships, trust, and engagement across CIE partners/users by communicating with CBOs frequently.
- Center trusted community leaders in communications.
- Use recommendations in “[Advice to OHA, healthcare and vendors for CIE outreach](#)” section of this paper to craft key communications and messages.
- Conduct outreach to educate the CBO community on the benefits of CIE and clarify the relationship to other existing systems (e.g., 211 or other resource navigation systems).

7. Align CIE efforts with other systems level efforts crucial to ensuring health equity

- Target behavioral health providers for inclusion in statewide CIE.
- Take a statewide or regional approach to technological improvements to avoid or remove duplication with existing databases or systems.
- Beyond CIE, contextual factors like chronic lack of social services availability statewide, and the strength of a CBOs reimbursement capabilities will impact CBO ability to implement robust CIE systems. Statewide partners supporting CBOs in their efforts should make efforts to align with other statewide opportunities to support CBO capacity building and social service availability.

CONCLUSION

This community engagement effort painted a vivid picture of the awareness, challenges, and needs of CBOs statewide related to statewide CIE. Findings related to perceived benefits, key barriers or concerns, and CBO ideas on how to address these provided a frame from which to approach findings and develop actionable recommendations.

This report is intended to help inform CIE workgroup legislative recommendations under HB 4150. We strongly recommend sharing key findings or insight on what steps will be taken to use or address the findings. Many interviewees were interested in reviewing and potentially providing additional input on Workgroup recommendations once they are developed. This is an important first step to ensure CBO needs and priorities are reflected in a community-centered, trusted CIE network in Oregon. We recommend developing a pared down summary version of this report, including any specific action items that stem from the findings that would be suitable for public dissemination, or at a minimum, suitable for CBO partners.

Overall, this effort confirmed that CIE is an important part of statewide efforts to improve systems and services to achieve health equity, and there are practical, actionable ways that the implementation process can be strategic and thoughtful to achieve that goal.

Considerations for implementation of recommendations

The findings from this community engagement effort offer an important view into the many overlapping and interconnected challenges and opportunities for CIE in Oregon.

Recommendations cover a broad range of organizational, policy, and systems level interventions that, when paired together, have the potential to drastically improve connections and coordination within the broad social service system and beyond.

Regardless of the approach to implementation of recommendations, it is necessary to think through implications and be sensitive to the time and capacity of CBOs. Across the state, CBOs are facing staff shortages and high turnover. In the assessment, some indicated the need for a carefully planned roll out that is sensitive to the stress on the social service system experienced during COVID and the ongoing capacity limitations due to historic disinvestment in the system.

A proven way to ensure recommendations are implemented in effective, sustainable ways, is to incorporate diverse partner perspectives into the decision-making and planning process. Any recommendations planned for implementation should be vetted by partners from CBOs to ensure concerns about capacity are mitigated. Best practices for community engagement call for inclusion of network members in leadership and decision-making.

Interview script (in English) and survey questions (in English and Spanish) are available in the full report document.⁴⁴

⁴⁴ CIE: Community Engagement Findings and Recommendations:
https://www.oregon.gov/oha/HPA/OHIT-HITOC/Documents/CIE_Community_Engagement_Findings_and_Recommendations.pdf



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