

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.



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

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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.

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- **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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