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:

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?**
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> 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.

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 model[1]).

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 incomplete referrals, and overall identify system barriers to getting people the care they

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

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 metric[2] and the social needs screening and referral measure[3]. 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

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[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

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

3. <u>Increase trust</u>

   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. <u>Data availability</u>

   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. <u>Support cross-regional partnerships</u>

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

Potential risks

1. <u>Data quality issues</u>

   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. <u>Risks of CIE/data implementation</u>

   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

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 HIPAA[4].

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.

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[4] HIPAA-Health Insurance Portability and Accountability Act

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.

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

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.

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:

- <u>OHA and ODHS play a role in funding and supporting a neutral organization to lead a statewide CIE data program</u>: 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

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 ODHS[5] 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

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[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.

Oregon Health Authority

- 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.

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