Leveraging CIE for Public Health Needs and Response

March 2022

Karis Grounds, MPH
Vice President of Health and Community Impact
211/CIE San Diego

Beth Johnson, MPH
Senior Consultant, Strategic Initiatives
211/CIE San Diego

Sheena Nahm McKinlay, PhD
Vice President, Research & Development
Health Leads
Acknowledgements

This paper was produced as part of *Leveraging Community Information Exchanges for Equitable and Inclusive Data*, a project supported by the Robert Wood Johnson Foundation (RWJF).

We give special thanks go to our partners at Health Leads for their thoughtful collaboration and insight, especially our co-author, Dr. Sheena Nahm McKinlay. We also extend our appreciation to the many partners and contributors whose thought leadership and ideas helped guide and strengthen the concepts presented throughout.

We appreciate the time and feedback our CIE National Members have contributed, and for asking critical questions to inspire and challenge this work. We honor and appreciate the important work they do every day to improve the health and well-being of communities.

The information generated through this activity has informed RWJF’s public health data infrastructure portfolio.
Social determinants of health (SDoH) are the conditions where we live, learn, work, and play that affect everyday health and well-being. Public health practitioners and advocates have long understood that health happens wherever people are, and as people move throughout their daily lives, their experiences span across multiple sectors including health, social, and human services. Like many sectors that operate within systems that have perpetuated or exacerbated racial inequities, public health is reckoning with ways to better gather and interpret data to actively address structural barriers to health. Historically, public health systems have not been held accountable for the harm disproportionately shouldered by racial/ethnic minorities and other under-resourced populations. In keeping with its goal of prevention and protecting the health of people and communities, public health should employ community-driven strategies to develop a data infrastructure that supports cross-sector information sharing and is truly responsive to community needs.

How can public health recognize the harmful processes that have contributed to a service delivery infrastructure that reinforces systemic racism, exacerbates local resource distribution issues, and promotes public narratives that misrepresent populations who rely on public services and benefits?

How can public health deepen investment in communities, local infrastructure, and practices that advance racial health equity?

One promising and emerging model is the Community Information Exchange (CIE). The CIE provides a unique approach to community-designed, driven, and led data systems that simultaneously support care coordination across sectors while also gathering data that can inform population health management strategies that are accountable to the communities most impacted by the rollout of new programs and policies. Members of a CIE nurture trust through a community-governed body and core components and processes intended to rebuild trust with the community, with the aim of building an anti-racist system that is working towards health equity.

A CIE can effectively support public health data systems by providing a CIE data infrastructure that enables real-time and comprehensive data collection.
Current State of Public Health

Centering Racism as a Public Health Issue

According to the Centers for Disease Control and Prevention (CDC), communities of color in the United States experience higher rates of chronic health conditions and diseases including diabetes, hypertension, obesity, asthma, and heart disease. Root cause analysis of each of these health conditions reveals racial inequities historically built into a wide range of systems from health and social services to education, housing, and built environment. Additionally, research has shown that medical care accounts for less than a quarter of modifiable factors that contribute to population health outcomes. Although underserved populations should benefit from more public health services, current public health systems lack the infrastructure needed to effectively coordinate services. In order to advance health equity, public health practitioners, advocates, and researchers alike must take a whole ecosystem approach to systems redesign and center racism as the core issue.

Missing Real-Time Data

Public health's reliance on lagging data sets from surveys and government data sets has fostered a system that is not truly responsive to the emerging needs of communities. As a result, public health is often inhibited from identifying current population health challenges as well as opportunities for timely response that would support the thriving of groups who could benefit most from public health intervention.
Public health would benefit from having systems in place that can collect and use real-time data, thereby enabling accurate, data-driven decision-making about current population health challenges and gaps between needs and resources.

**Lack of Inclusive and Aligned Data Sets**

As public health leaders continue to work furiously to manage the impact of COVID-19 across the U.S., it is more evident that disaggregation by race and ethnicity is necessary to accurately understand how disease impacts communities. It is only with accurate assessment and understanding that we can develop and implement better strategies for response. When available and reported, data clearly demonstrates COVID-19 disproportionately impacts Black and Latinx communities.\(^4\),\(^5\),\(^6\) Additionally, the lack of inclusive data sets, such as the ineffective collecting and reporting of data for American Indians and Alaska Natives, means that historically under-resourced communities continue to receive fewer resources due to poor data collection and reporting standards.\(^7\)

Data disaggregation is an important step in public reporting and accountability to accurately understand how health outcomes differ by race and ethnicity; but data cannot be effectively disaggregated and reported if it does not exist in ways that represent all populations. For example, traditional data sets, including those held by public health departments, are collected without considering outside events, which can lead to gaps in demographic information. Questions that classify groups in ways that do not resonate can lead to lower response rates or less meaningful answers. An environment where the use of collected data is perceived as more of a threat to respondents than a tool for self-determination also likely leads to hesitancy to participate in data collection efforts and any subsequent undercounting of populations. Gaps in data standards that bridge across sectors can also limit alignment in efforts to collect, analyze, and regularly report on health outcomes at the population level by race and ethnicity.

Real-time data from systems like a CIE can fill in major gaps from miscounts or undercounts in place-based demographic data, such as census data. Population statistics gleaned from census data influence local community funding. Additional challenges created by the current pandemic will undoubtedly have impact on the validity and accuracy of census findings. This is where real-time CIE data can make a significant difference.\(^8\)
An Equity-Oriented Approach to Data Modernization

At its core, data modernization is defined by movement from legacy databases to modern ones that can rise to the challenges of complex data structures, increasing volume of data and the need for greater data velocity to inform strategies and practices for better population health management. However, improved capability to analyze large volumes of data in real time alone is not a straightforward solution. Modern databases can support goals that are not always aligned with the very individuals, families, and communities consenting to provide said data. Reexamining how data is interpreted and leveraged for trends and who benefits from any subsequent solutions is critical to developing an equity-oriented approach to data modernization efforts. Public health practitioners, advocates, and researchers can serve as significant translators and push to align data modernization efforts with a commitment to advancing racial equity. Opportunities for new ways of achieving equity-driven data are highlighted through new models, including the CIE Data Equity Framework (Figure 1), which was developed to highlight the impact of data system design and drivers, as a model for the future.

System types partially adapted from the National Institute for Children's Health Quality. https://www.nichq.org/insight/savior-designed-equity-empowered-systems
Opportunity to Leverage CIE Infrastructure

CIE as a Public Health Data Source

CIEs are one approach to integrating data across a multitude of agencies—from city and county entities to community-based organizations to health plans and hospitals—to respond to public health needs in real time. Data integration reduces silos in everyday practices like screening, case management, and care coordination across providers. The system can support trauma-informed care, reducing the number of times that a person must retell their history and current needs as they navigate the resource ecosystem. Without trust from our communities and those sharing the data, equitable data modernization is not possible.

At the same time, data integration also presents understandable concerns about data privacy and how data is used, especially in communities that have observed the misuse of their data to spread damaging and inaccurate narratives. Therefore, in a CIE shared language and technologies that support data integration are aligned with other critical CIE components, including a network of partners that work together on a governance structure that is community-centered and led.

A CIE is a community-led ecosystem comprised of multidisciplinary network partners who use a shared language, resource database, and integrated technology platforms to deliver enhanced community care planning. A CIE enables communities to shift from a reactive approach to addressing social needs, to an approach that is more proactive, holistic and person-centered. At the very core of a CIE is the community it serves, and with the community as its compass, a CIE works towards achieving antiracism and health equity.
Supporting Better Population Health Management to Address Racial Inequities

Figure 2 shows CDC's vision for the future state of public health data. Figure 3 demonstrates the opportunity to realize this vision with an innovative and equity-oriented Community Information Exchange model.

The New World of Public Health Data

Figure 2

The Opportunity to Leverage CIE Infrastructure for Public Health Data

Figure 3

The Reality
- Reacting
- Counting
- Storing Separately
- Moving Slowly
- Using Resources Inefficiently

The Opportunity
- Predicting
- Understanding
- Sharing Effectively
- Moving Fast
- Connecting Resources

The CIE Opportunity
- Predicting Needs
- Leveraging for Action
- Sharing Efficiently & Effectively
- Responding Rapidly
- Coordinating Connection to Resources

Original design concept by Centers for Disease Control and Prevention: https://www.cdc.gov/surveillance/pdfs/New-World-of-Public-Health-Data.pdf
Predicting Needs

In the CIE, shared data across agencies, sectors, and systems provides the opportunity for analysts to forecast community needs including upstream barriers that prevent individuals from connecting to the resources they need and desire. Prediction is also possible for individuals or families, where CIE can risk identifiers or likely eligibility can populate within the CIE to identify acute problems and intervene.

Leveraging for Action

The role of the CIE is to use the information directly from community members to inform decisions in real time and ignite action. This goes beyond garnering trust from participants to consent to sharing their data. In the CIE, the data informs actions that benefit the community.

Sharing Efficiently & Effectively

CIEs are technology-agnostic and their core infrastructure focuses on interoperability, allowing for information sharing and bidirectional exchange across health and non-health systems of care regardless of the technology platform partners use to best support their industry's functional requirements. In this way, the CIE model meets community providers where they are and aims to be supportive rather than disruptive to their operations, fostering more engagement and utilization among partners at the outset. While CIEs do not require a particular data source or platform, they do offer the opportunity for all partners to align around shared values related to equitable development and application of technology.

Responding Rapidly

CIEs provide the opportunity to share and analyze data in real time, informing timely decision-making and response to community needs during times of crisis, as well as informing day-to-day operations that benefit from more accurate data than are often available through older and more limited datasets. In addition, CIE data can produce a visualization of population-level patterns of needs according to client demographic and geography over time. For example, public health analysts could explore patterns of food insecurity during specific periods of time over the course of the COVID-19 pandemic rather than relying on the Behavioral Risk Factor Surveillance System (BRFSS) data which can take up to a year for researchers to obtain for analysis.

Coordinating Connection to Resources

CIEs align existing services that provide resources and care coordination, thus streamlining the navigation and receipt of services and resources for individuals. CIEs also provide data for participating organizations and institutions to collaborate, positioning them to respond collectively to new policies and protocols, funding opportunities, or emerging crises. At the macro level, data can be analyzed to highlight and map community assets to inform and improve strategic planning and investment across the resource ecosystem.
Figure 4 illustrates how micro/mezzo/macro value propositions can intertwine to inform strategies in population health management and deliver impact in timely and relevant ways.

**Micro to Macro Value**

*Figure 4*

<table>
<thead>
<tr>
<th>Micro Impact Examples</th>
<th>Mezzo Impact Examples</th>
<th>Macro Impact Examples</th>
</tr>
</thead>
</table>
| • Families don't have to retell their stories or trauma over and over again  
• Agencies can reach out directly, instead of adding additional work on the person to follow-up with the agencies for support  
• Care gets coordinated within the individual having to remember who they are working with | • Breaking down of siloed data systems  
• Ability to search patients/members to see historical use of social services and closed loop referrals  
• Shared screening or prioritization of resources and care team members receive alerts to be proactive or responsive | • Collective aggregate community data that is provided by community members  
• Wholistic data is collected, understanding connection between health and social |
| Example Cohorts:  
*Homeless*  
*Older Adult* | Example Issue Brief:  
*Using CIE To Respond To Real-Time Community Needs During COVID-19* | Example Policy Brief:  
*Housing Instability in San Diego County* |
Interest in developing effective and efficient strategies that improve health outcomes for groups affected by health inequities has increased in the public health arena. An active continuum of care is among the most important, practical implications of a collaborative population health approach. The increased interest has resulted in investment in the development of comprehensive metrics and dashboards that support targeted interventions as well as the development of predictive analytics as a tool that can bolster targeted prevention efforts for individuals experiencing inter-related risk factors.

How can CIE infrastructure be leveraged for Population Health Management?

211/CIE San Diego stewards the CIE for San Diego and Imperial Counties, managing a growing network of over 100 partners from health, human, and social services sectors. With funding from the Agency for Healthcare Research and Quality (AHRQ), and in collaboration with the University of California, San Francisco’s Social Interventions Research & Evaluation Network (UCSF SIREN), 211/CIE San Diego created two dashboards to support population health management: (1) a case management dashboard to support sorting and filtering of individuals based on specific data points, like “homeless” and “income,” for more effective interventions; and (2) an aggregate community dashboard to provide CIE Network Partners with comprehensive data sets to compare regions, social needs and other relevant data to improve and advocate for its local system of care.
The dashboard enables CIE San Diego partners to collectively explore and better predict resource and service needs by neighborhood and demographic. Real-time data collected from community members supports long-term planning that benefits the community and holds end users accountable. All partners in the network have unique data use agreements that detail how data has been contributed, as well as which data is accessible to them. More importantly, policies are in place to ensure that individuals can opt in or out of having their data shared. This process ensures both streamlined and transparent data sharing. CIE San Diego partners meet regularly to review population-level data and needs that are arising among certain groups or in certain neighborhoods. In this way, the partner network is armed with the information needed to fuel a resilient system that is tailored to meet emerging needs in a timely manner. Lastly, CIE San Diego's system provides up-to-date information on services and resources for the individuals that need to utilize them. This feature was especially important during the COVID-19 pandemic as information about available housing, vaccinations, employment, and financial support was constantly changing.

National implementation of coordinated systems of care and prevention could eliminate redundancies in screening and data collection, improve efficiency, and reduce costs through more proactive resource connection. More upstream efforts to address utilities and other essential needs have been shown to be predictive factors to adverse events, such as homelessness, as well as preventing or addressing health concerns early on before they become urgent. Investing in upstream efforts could potentially save lives and improve the health and well-being of individuals, families, and communities. Additionally, an interoperable system would contribute data that would provide more comprehensive insight into historically overlooked populations and geographic locations that struggle to receive critical services and resources.

At a macro level, CIEs are a unique population health management infrastructure, enabling access to ethical and equitable comprehensive data sets that can be used to support targeted interventions, track community outcomes, and drive advocacy for better systems of care.
Examples of Short-Term and Long-Term Impact

Below are some examples of the impacts of implementing a cohesive and coordinated service delivery system across the country:

Short-term impacts of CIEs could include:

- Significant increase in the number of people connected to community-based organizations and services across the country
- Reduced utilization of EMS
- Reduced interaction with the criminal justice system
- Decrease in prevalence of individuals in “crisis” (the most immediate measure in a spectrum that ranges from crisis to thriving, with data available across multiple SDoH domains such as housing and employment)
- Increase in the utilization of available services, resources, and benefits like SNAP and subsequent reduction of hospitalization and Medicaid costs
- Streamlined operations at the community level
- Enhanced collaboration and coordination among community-based organizations, as well as increased number of network providers across all sectors
- Increase in the amount of demographic, SDoH, and service delivery data

Long-term impacts of CIEs could include:

- Improved quality of life and well-being
- Reduced risk factors ultimately leading to a decrease in number of adverse childhood outcomes
- Reduced number of at-risk homeless or homeless clients and families and prevention of chronic displacement, with potential cost savings to health systems
- Reduced number of clients entering the criminal justice system by ensuring clients have better access to preventive services such as mental and behavioral health care for combat related stress
- Increase in protective factors, family stability, and building resiliency
- Enrolling in prevention programs (or programs in general)
- Improved health outcomes and clinical markers
- Reduction in racial and health disparities
Recommendations for the Future

While some cities and counties are already benefitting from some of the short- and long-term impacts of a CIE, additional steps are needed to fully realize the potential of this model for more equitable public health systems redesign. Going forward, here are three important steps public health can take to support this framework:

1. **Support local initiatives to align new data integration efforts with existing networks that exchange data and have established community governance.**
   One example of this can be found in the recent resolution passed by the Board of Supervisors in San Diego County, which called for health plans to participate in the local CIE in order to receive a Letter of Support as part of the procurement process for Medi-Cal providers.

2. **Invest in the analysis of longitudinal shared data records available within CIEs to deepen understanding of macro level impact on health equity.**
   This includes examination of indicators such as the comparison of populations receiving services with those requesting services and levels of access to resources, as well as utilization and successful connections disaggregated by race, ethnicity, age, gender, and other critical demographic variables.

3. **Value and support local, community capacity and shared governance.**
   Similar to existing county-established public health programs, information should be stewarded by and for the community. This requires supporting the existing local infrastructure and community-based organizations. For local initiatives to be successful, publicly and financially supporting convenors or network lead entities is essential, including participating community-based organizations and BIPOC organizations.
References


