

# CIE Phase II Draft Final Report

**Our mission is to advance health equity, reduce health disparities, and improve overall well-being of people in Maine, through coordinated information-sharing, standards, resources, and technology.**

## Executive Summary

In 2020, a broad group of stakeholders in Maine began a journey to develop a community information exchange (CIE) that would lead to better health for the people of Maine. Four years and a global pandemic later, this initiative has produced the Maine Community Information Exchange (ME CIE), a network connecting healthcare providers and community-based organizations' efforts to advance health equity, reduce health disparities, and improve overall well-being of people in Maine through information-sharing, standards, resources, and technology.

Phase I of the initiative sought to determine how a CIE could fit within Maine's existing healthcare and social service systems. The Maine CIE team began with a definition used by 2-1-1 San Diego, a CIE operating in California since 2011:

*A CIE is an ecosystem comprised of multidisciplinary network partners that use a shared language, a resource database, and an integrated technology platform to deliver enhanced community care planning. Care planning tools enable partners to integrate data from multiple sources and make bi-directional referrals to create a shared longitudinal record. By focusing on these core components, a CIE enables communities to shift away from a reactive approach to providing care toward proactive, holistic, person-centered care.*

CIEs exist across multiple states: while each share some or all these elements, factors such as funding sources, state-level government support, the presence of technical vendors, and existing relationships between medical providers and community organizations drive variation in implementation.

The power of a CIE arises from the recognition and incorporation of the social risk factors that impact individual and families' well-being. One of the five goals of the U.S. Department of Health and Human Services Healthy People 2030 campaign spotlights social determinants of health (SDOH): "the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks." Along with access to healthcare, wellness relies on education access and quality, economic stability, neighborhood and lived environment, and social and community connections.

All sectors supporting health and wellness within Maine benefit from a CIE, from patients to providers to payors. Quality of patient care improves as healthcare professionals become aware of individual and families' social risks and the impacts of those factors on care plans. Relationships between medical and social service providers grow through collaborating on strategies to address social risk factors. Community-based organizations (CBOs) gain access to information and technologies to manage the demand for their services more effectively. Greater information on health and wellness status and services strengthens healthcare systems, public health programs, and healthcare funders' capabilities to design and implement population-level planning and evaluation.

With the Phase I vision of how a CIE can improve health and wellness in Maine, the group began to identify the elements needed for a Maine CIE to be successful. Representatives from healthcare providers, community-based organizations, state government representatives, the state-identified health information exchange, and advocates organized a steering committee to steward the initiative. The work was funded by the Maine Health Access Foundation (MeHAF). Workgroups formed to better define the components of a CIE: Legal and Policy to identify existing regulations, rules, and ethical standards; Governance to determine processes and structures

that included community and provider voices in decisions; and Data and Technology to outline the systems and tools that could facilitate improved coordination and information sharing. Community Information Sessions, held in May and October, introduced community members and providers to the CIE concept and gained input regarding objectives, needs, and existing resources.

During Phase II, engagement from major health systems, innovative community projects, and health information technology experts grew and understanding around health information tools and existing community collaborations expanded. These developments prompted a refocusing from technology solutions to the coordination, alignment, growth, and support of the existing and burgeoning initiatives arising across Maine through the formal creation of a CIE ecosystem that is supported by consumers and providers.

Potential pieces of a CIE ecosystem already exist. 211 Maine, MaineHealth, and findhelp are piloting a shared provider and service directory, which can better ensure accurate and up-to-date information, while decreasing administrative burden on CBOs and healthcare providers. Maine's statewide health information exchange (HIE), HealthInfoNet, and York County Community Action Corporation (YCCAC), which includes a federally-qualified community health center, are exploring the feasibility of a shared health record that integrates information from medical services, community supports, and social determinants of health. Community Caring Collaborative has launched an online platform, The Connection Initiative (TCI), that connects Washington County community members to needed resources across the region. The Centers for Medicare & Medicaid Services have signaled their increased focus on social determinants of health and health equity, proposing new hospital quality measures and payment codes. The Maine Shared Community Health Needs Assessment (CHNA), Maine CDC's Behavioral Risk Factor Surveillance System, and local community health and social need assessments are collecting the information to assess social risk factors. The HIE operated by HealthInfoNet to manage data captured in electronic medical records offers lessons on collecting, standardizing, and analyzing health-related information that can be applied to a statewide CIE.

However, there is no formal space to share information, align best practices, and solve collective problems through a set of accepted governing principles. A successful CIE Phase III will establish the foundation for communication, coordination, and collaboration that extends existing initiatives and partnerships and generates new opportunities. Phase II produced core resources to guide CIE development in Maine: a survey of regulations and ethical considerations regarding the collections and sharing of personal and health information; a governing structure built around an independent nonprofit entity, board, and brand that could leverage the existing structural and operational capacity of a partners and, as needed, sub-contractors; the creation of a Community Advisory Committee consisting of advocacy group representatives, consumers with lived experience, and representatives from underserved populations and a group of network providers actively engaged in the conversation; and a shared health record model that demonstrates the data elements and pathways undergirding communication and coordination between medical and social service providers.

The journey begun by that group of stakeholders in 2020 has led to the formation of a non-profit entity, ME CIE, in October 2023. Phase III is beginning, but slowly as we identify and secure additional resources to support this work.

## **Introduction**

In recent years, there has been a nationwide movement to use data to promote individual wellbeing as a foundation for a more holistic approach to community health. In 2020, a broad group of stakeholders in Maine began a journey to develop a community information exchange (CIE) that would lead to better health for the people of Maine through improved information quality, closed-loop referrals, and timely coordination and provision of services that respond to health-related social needs. Phase I of the Maine CIE Project was finalized in May 2022 and Phase II was initiated. A Steering Committee was formed to lead Phase II. They created three workgroups focused on key requirements for CIE development under the headings of governance, legal and

policy, and data and technology. This report outlines the work undertaken in Phase II by these groups to further the development of a Maine CIE. Phase II work concluded in December 2023.

## What is a CIE?

During Phase I of the CIE Project, the Maine CIE team consulted with 2-1-1 San Diego; a CIE established in California in 2011. 2-1-1 San Diego defines a CIE as follows:

**“A CIE is an ecosystem comprised of multidisciplinary network partners that use a shared language, a resource database, and an integrated technology platform to deliver enhanced community care planning. Care planning tools enable partners to integrate data from multiple sources and make bi-directional referrals to create a shared longitudinal record. By focusing on these core components, a CIE enables communities to shift away from a reactive approach to providing care toward proactive, holistic, person-centered care.”**



**Figure One Source: San Diego 2-1-1**

CIEs have been established in multiple states, and each have some or all elements described in the foregoing characterization. Development of CIEs vary based on funding sources, state-level government support, the extent to which third-party vendors are present, and other factors. Start-up funding and long-term sustainability are fundamental challenges in establishing and maintaining a functional CIE.

## Problems to Solve

The U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion’s Healthy People 2030 has five overarching goals specifically related to social determinants of health (SDOH): “Create social, physical, and economic environments that promote attaining the full potential for health and well-being for all.” Social determinants — like structural racism or systemic bias — can affect health literacy and contribute to health disparities. Taking steps to address these factors is key to achieving health equity. [Social Determinants of Health - Healthy People 2030 | health.gov.](https://www.health.gov/social-determinants-of-health)

Additionally, there are barriers to individuals seeking care and resources:

- Some individuals receive duplicative care coordination and support while others receive none.
- Many people are asked to provide their personal identifying and health information to different organizations multiple times before they receive the help they need. Not only is this inconvenient, but it can also exacerbate negative feelings related to trauma and can be a barrier to seeking care for those being asked to repeatedly share sensitive information.
- Individuals may not know what resources could be available to them and how to access those resources.
- Individuals may develop serious, long term health issues that could have been prevented with timely interventions and/or preventative care.

- Some resources are offered in a manner that makes them inaccessible or ineffective: for example, referrals made to providers who do not offer services in the client's area or are not taking new clients.
- People who would like to self-report their current needs and receive connections to services in real-time are not able to do so.

For communities and health care teams, barriers include:

- Many community organizations and healthcare systems do not have a systemic approach to identify and address gaps in needed services for their clients/patients in an efficient and coordinated way.
- Care team members may not be familiar with all the resources that could potentially be available to their clients/patients.
- Care team members are unfamiliar with who else is on a client's care team, short-circuiting effective communication and coordination of support.
- Many community organizations and healthcare systems do not have an analytical view of subpopulations they serve. These data would illuminate where needs exist and identify effective interventions for specific populations.
- Individuals seek care in suboptimal settings: for example, using emergency departments for primary care or behavioral health care.
- Community based organizations may not have data to demonstrate the value of the services they provide.

The impact for funders and insurers related to these barriers include:

- Funders and insurers pay for high-cost healthcare services that could have been prevented with timely access to less costly outpatient or community services.
- Funders of services do not have adequate population data about resource utilization and need, which can be used to inform future investments to optimize services across Maine.

Federal and state governments are also impacted by these barriers:

- Government entities may not have the data to identify gaps in services to qualifying individuals.
- Health and social service planning may not have adequate information about service gaps and underserved populations.
- Medicare and Medicaid costs of care may be higher than necessary because of lack of timely intervention/preventive care and services.
- Vulnerable populations may be underserved by not getting referrals to appropriate resources.

## **Social Determinants of Health in Maine**

The Maine CDC's publication, *The Way Health Should Be, Social Determinants of Health in Maine 2019* defines social determinants of health (SDOH) as including factors such as poverty, unemployment, poor education, inadequate housing, exposure to violence and discrimination, lack of transportation and unhealthy and unsafe physical environment. [SDOH-Report-11-15-2019.pdf \(maine.gov\)](#).

Maine's geography and demographics create challenges for its residents in accessing health care and social services. The following statistics, from the Maine CDC's 2019 report, outline some of the SDOH challenges facing Maine residents:

- One in ten Maine people live in poverty
  - Almost one in ten people over 65 live in poverty, with women 2 times more likely to be poor

- Among female-headed households with no husband present, 29% live in poverty<sup>1</sup>
- The percentage of Black Mainers experiencing poverty is three times higher than white Mainers (42.9% vs. 12.7%)
- More than one in three Native Americans live in poverty
- The poverty rates in Maine's rural counties are higher than in the more populated southern counties (Aroostook, Piscataquis, Somerset, and Washington counties have about 13% of families living in poverty vs. 8% of Cumberland County and 6% of York County families)
- One in three homeowners in Maine spend 30% or more of their household income on their housing; almost half of renters spend 30% or more of their household income on rent and utilities
- One in six Maine households struggles with food insecurity. Food insecurity may stem from issues with cost, distance, and transportation to food vendors. Rural places have fewer transportation options and Mainers living in rural areas travel greater distances to grocery stores, pharmacies, and medical care. Those particularly likely to be food insecure:
  - One in five Maine children are food insecure
  - One in six Maine seniors are at risk of going hungry
  - More than a third of Maine's food insecure population does not qualify for public assistance.
- About 17% of Mainers are 65 years of age or older; in some of Maine's more rural counties, about 25% of the population is over age 65.
- Specific groups of Mainers are more likely than others to lack needed healthcare, including those:
  - With lower incomes
  - Without full-time employment
  - Living in rural areas
  - LGBTQ+ adults
  - Persons of color
- Many transgender adults (28%) in Maine report experiencing housing discrimination such as being evicted or denied a home or apartment because they are transgender

The implications of these factors can have a profound impact on Mainers' health and well-being:

- Mainers making less than \$25,000 per year are more likely to have asthma and to have been diagnosed with heart disease, diabetes, or cancer
- Across the lifespan, food insecurity is shown to increase the risk of poor health outcomes:
  - For children: a greater risk of asthma, poor general health, depression, poor oral health, suicide ideation, and increased risk of hospitalization
  - For adults under age 65: a greater risk of mental health issues, diabetes, hypertension, high cholesterol, poor overall health, poor sleep, and poor oral health
  - For adults over age 65: a greater risk of depression, poor health, and limitations on activities of daily life.

Additional information regarding SDOH, and social risks of Maine residents can be found in The Maine Shared Community Health Needs Assessment (CHNA). The 2022 CHNA report included information from those who may experience systemic disadvantages and therefore experience a greater rate of health disparities: Black or African Americans; people who are Deaf and Hard of Hearing; people with a mental health diagnosis; people with a disability; people who define themselves or identify as lesbian, gay, bisexual, transgender, queer and/or questioning (LGBTQ+); people with low income; older adults; people experiencing homelessness; and youth. In addition, 1,000 oral surveys were conducted in collaboration with 10 ethnic-based community organizations'

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<sup>1</sup> Note: the term "no husband present" is taken verbatim from the CDC report *The Way Health Should Be, Social Determinants of Health in Maine 2019*. It is not the word choice of the authors of the CIE Phase 2 report

community health workers to better reach Maine’s immigrant population.) [State Report .12.2022revision.pdf \(maine.gov\)](#)

The 2022 CHNA report includes the following information:

- Social determinants of health were a top priority identified across 15 counties and seven community sponsored events. Poverty was the most mentioned health indicator of social determinants of health.
- Substance and alcohol use was identified as a top priority among all counties across the state.
- Drug overdose deaths were identified by the majority of participants (79%) as a top health indicator of concern.
- Participants identified poverty, unemployment, limited transportation, and education as ongoing challenges or needs that impact individuals who are Black or African American.
- Communication access was a top issue for the Deaf and Hard of Hearing community. Participants identified interpretation/miscommunication, provider competency and Deaf awareness, mistrust/disrespect, and patient education and support as ongoing challenges or needs that impact the Deaf and Hard of Hearing community.
- The majority (58%) of participants identified the availability of mental health care providers as a top health indicator. Over half (52%) identified the use of the emergency department for mental health issues.
- Participants identified housing, transportation, and the limited number of providers as ongoing challenges or needs that impact the homeless and formerly homeless community.
- For immigrants, barriers related to language accessibility and cultural sensitivity, including cultural awareness, community norms, isolation, and stigma, made up 58% of the responses when combined.
- LGBTQ+ event participants were divided in naming their top health priority between Mental Health and SDOH. Participants identified a lack of access to providers specializing in LGBTQ+ issues, transportation, and housing in rural areas as ongoing challenges or needs that impact the LGBTQ+ community.
- Older adults identified access to care as their number one priority health area of concern, with the lack of health care services and providers, long waitlists, and transportation issues as ongoing challenges that impact Maine’s older adults.
- Community members identified a lack of social connections, food insecurity, and a lack of affordable housing as ongoing challenges that impact Maine’s older adults.

## **Benefits of a CIE**

**A CIE improves care for individuals** by ensuring that health care providers understand the full range of drivers impacting a person’s health. Providers who are aware of a patient’s social factors are fundamentally better positioned to provide comprehensive clinical care. For example, a patient experiencing homelessness without access to a refrigerator should not be prescribed medication that requires refrigeration. It is important to be considerate of the patients’ identity – including but not limited to their race, age, gender, sex, sexual orientation, and ability when approaching whole-person care. A connected system identifies individuals and families who may benefit from whole-person care coordination and assistance to prevent and/ or address crises. Coordination saves time and allows care coordinators to focus on helping those with more complex needs. In addition, better access to information and data empowers patients and providers to find and access community-based services.

**A CIE strengthens relationships** among providers of all types of services, which positions Maine to fully participate in state and federal value-based payment programs, as well as other programs that require whole-person care.

**A CIE eases the burden on community-based service organizations (CBO)** by reducing the number of times CBOs and other partners submit and update information about services. In addition, CBOs are often small, under-resourced, and unable to build sophisticated and efficient systems to track individual service referral and utilization. A connected system can give these organizations access to information and infrastructure they otherwise would not have.

**A CIE enables population-level planning and evaluation** by informing communities and decision-makers about available social and community resources and any gaps in services. Data can also be used to track demand for services and make the case for increased investments. This informs decision-makers on how to allocate resources and measure the performance of programs and interventions. It also gives community-based service providers information about how to improve their services

**A CIE will complement Maine's robust State-designated health information exchange (HIE)** operated by HealthInfoNet (HIN), a nonprofit organization formally established in 2006 with financial support from the Maine Health Access Foundation and Maine's largest health systems. HIN was designated Maine's statewide Health Information Exchange (HIE), responsible for increasing connectivity and enabling patient-centric information flow to improve the quality and efficiency of care. This statewide HIE is designed to link an individual's health information from unaffiliated healthcare sites to create a single electronic health record, allowing authorized providers across the state to better support and coordinate the care of individuals. Maine is very fortunate and ahead of many states in its ability to share health information among healthcare providers because of the ongoing work and innovation of HealthInfoNet.

There is recognition, however, that the overall wellbeing of individuals is strongly influenced by factors other than healthcare. Research shows that the social determinants of health (SDOH) can be more important than healthcare or lifestyle choices in influencing health. Numerous studies suggest that SDOH account for between 30 – 50% of health outcomes. Estimates show that the contribution of sectors outside health to population health outcomes exceeds the contribution for the health sector. Addressing SDOH appropriately is fundamental for improving health and reducing longstanding inequities in health, which require action by all sectors and civil society. [Social determinants of health \(who.int\)](https://www.who.int/social-determinants-of-health)

**A CIE will enable connectivity** for many of Maine's CBOs that do not have a technology platform that allows them to connect and communicate directly with healthcare systems or primary care providers. A Maine CIE would create a bridge of communication and collaboration that would connect health care and community-based organizations to create a community care plan with care goals and accessible resources for individuals and families in need. The rural landscape of Maine also further supports the need for consensual sharing of clinical and social information through a Maine CIE to help increase access to care and improved health and quality of life outcomes for rural Maine people.

## **Elements of a CIE**

There are four main elements of a CIE:

- 1) **Resource Directory** – while resources can and should be available and maintained at the local level, CIE infrastructure leverages local directories to improve and expand existing statewide resource databases. The goal is to reduce duplication and make resource inventories accurate and complete, so users can trust the information in the directory. Statewide connections among directories also reduce the burden on CBOs, which will be able to submit and update their information to one place, rather than try to keep up with multiple directories. Reducing duplication also increases efficiencies and will ultimately result in cost savings.

- 2) Closed Loop Referral System – it can be extremely frustrating for both consumers and providers when referrals are made and there is no process for ensuring that a) the referral has been received and b) action has been taken on it. A closed loop referral system would allow healthcare providers, CBOs and others making referrals to determine whether the service was received and if it met the needs of the individuals. This system would also allow partners within the CIE to proactively contact referred individuals. It is important that the system has appropriate security measures and role-based access to store and manage personally identifiable information related to assessments and referrals. The system must provide for secure messaging and communication among providers and protect the privacy of an individual’s information within the CIE.
- 3) Shared Health Record - it is important to have a way to record health and social service information that will allow providers to determine a comprehensive understanding of an individual’s health and well-being at any time. The shared health record is a technology platform that facilitates the integration of individual data from multiple CIE partners’ data systems to populate a single, person-centric longitudinal record of a person’s demographics and history of interactions with participating health, human, and social services. This technology platform also allows CIE partners to make and accept or decline bi-directional closed loop referrals. Together, the components of the CIE enable partners to communicate with each other and contribute case notes and other information to create a single, unified shared care plan. Tools within the technology support proactive community care planning by enabling partners to share individual demographic and program enrollment information and send alerts and notification of significant events.
- 4) Data Analytics – creating the capacity for interoperability between healthcare and social service providers’ data management systems creates a more complete view of population health data. This connectivity supports cross-system care coordination as well as population health or community-level assessment and planning. A master patient/client index allows individuals to be identified and their individual data included in their record across systems.

### **Finding a Way Forward – Advancing a Maine CIE**

In Phase I, the Maine CIE Workgroup came together to start building the foundational cornerstones for a CIE in Maine. Phase II focused on the recommended next steps identified in Phase I, as follows:

1. **Strengthen Stewardship:** A Steering Committee was formed with membership from healthcare providers, community-based organizations, state government representatives, the state-identified health information exchange, and consultants. The Maine Council on Aging provided administrative support for this Phase and engaged project coordinators to assist with the Phase II work.
2. **Engage Community Voices:** The importance of engaging members of Maine communities in building a CIE cannot be overemphasized. A Community Information Session was held in May 2023 to provide a forum for community members to learn about the CIE concept in general, and more specifically, the work being accomplished by the CIE Steering Committee and Workgroups. A stakeholders meeting, including original stakeholders involved in the initial planning process, along with the invitees to the Community Information Session will be held at the end of Phase II to report the accomplishments and to identify the objectives for the next phase of CIE development.
3. **Maine CIE Development Workgroups:** Three workgroups were formed to address key areas of CIE planning, with members chosen from the original stakeholder group. The workgroups were:



- a. **Data/Technology** – this workgroup focused on the technology infrastructure needed to support the various CIE components, with the shared health record its priority for Phase II.
- b. **Legal/Policy** – this workgroup focused on identifying federal and state regulations that address legal considerations for data sharing, security and risk, patient consent models, ethical considerations, pending regulations, and legal agreements/contracts needed for the CIE.
- c. **Governance/Capital and Operational Costs** – this workgroup identified the requirements for two advisory committees that will help inform ongoing CIE planning (Community Advisory Committee and the Network Provider Advisory Committee), addressed governance structures for the CIE, and made recommendations for a ‘governance roadmap’ for the CIE.

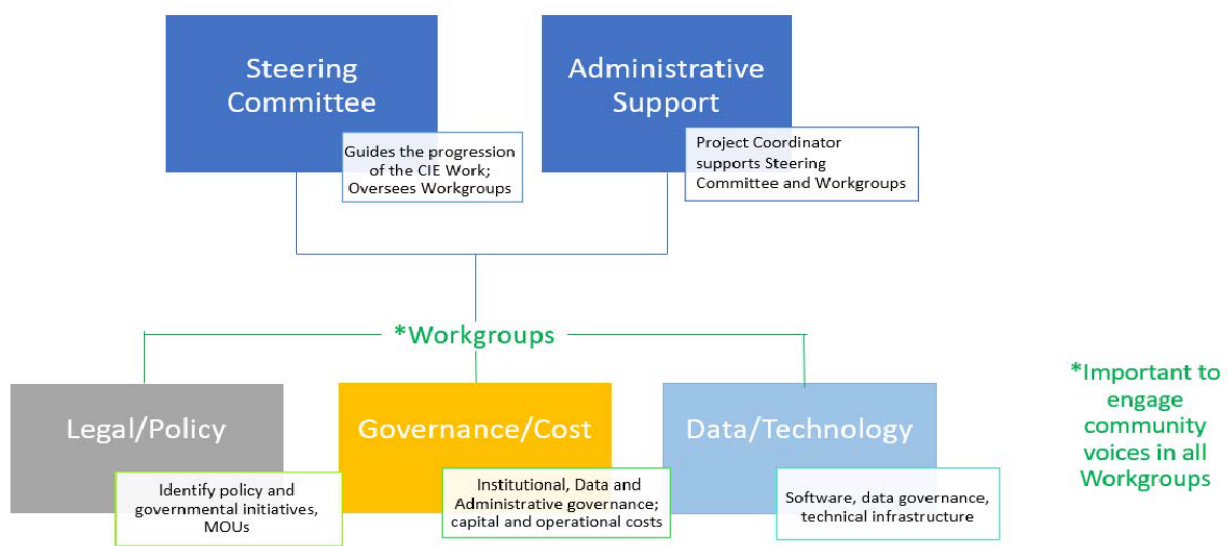
**4. Build Upon the Use Case – the Data & Technology Workgroup also developed a use case created in Phase 1 to help illustrate how a CIE could assist in addressing the needs of community members.**

Roles and responsibilities were identified for Steering Committee and Workgroup members, and charters for each of the Workgroups and for the two Advisory Committees were also developed. Regular meetings were held for the Steering Committee and Workgroups, with minutes documenting the discussions and accomplishments. A summary of the work accomplished by each Workgroup was developed and reviewed by the Steering Committee. In September 2023, a decision was made to merge the workgroups with the Steering Committee to allow for integrated work to finalize the deliverables for Phase II and plan for Phase III.

### Governance Structure for Phase II

The governance structure for Phase II that had been established in Phase I was implemented, as the diagram below demonstrates:

### Maine CIE Phase II Work Governance/Organizational Structure



### **Figure Three Source: Phase I CIE Report**

- Roles and responsibilities were identified for Steering Committee and Workgroup members. See Appendix A.
- Charters for each of the Workgroups and for the two Advisory Committees were also developed. See Appendix E.
- Regular meetings were held for the Steering Committee and Workgroups, with minutes documenting the discussions and accomplishments.
- Summary reports of the work accomplished by each Workgroup was developed and reviewed by the Steering Committee. See Appendix G.
- In September 2023, a decision was made to merge the workgroups with the Steering Committee to allow for integrated work to finalize the deliverables for Phase II and plan for Phase III.

### **Key Outcomes of Phase II**

Statewide CIE advancement will require a long-term commitment, including coordination across many agencies and funders and the development of an overarching CIE Roadmap. On a shorter-term basis, certain modules can be implemented sooner than others, particularly those that have fewer interdependencies and barriers (e.g., privacy and security constraints). The CIE Steering Committee determined that it would support incremental implementation in terms of scope and scale while maintaining a focus on long-term interoperability standards.

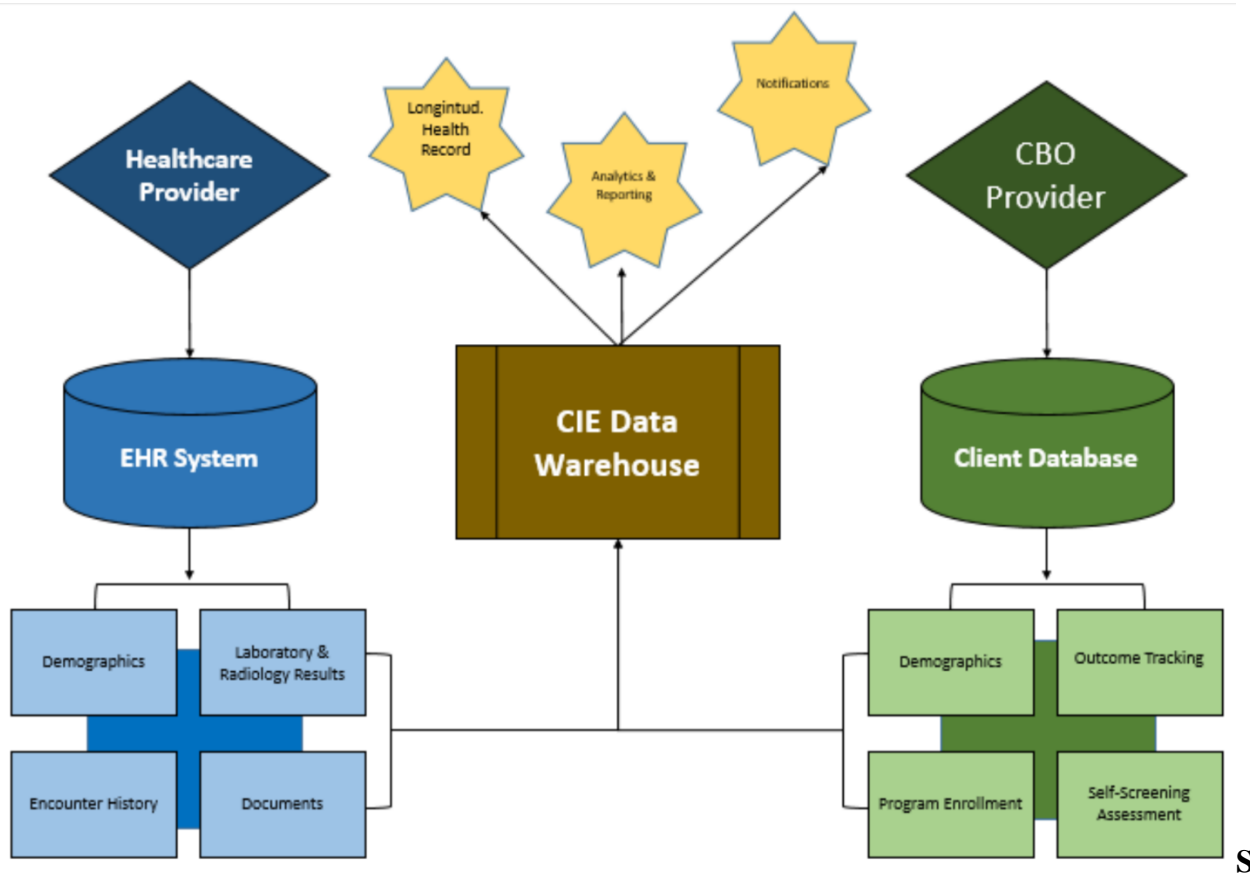
Summary reports of the three Workgroups are included in Appendix G. Below are some of the highlights of each of the Workgroups.

### **Data and Technology Workgroup**

*Shared Health Record* – the Data and Technology Workgroup recommended, and the Steering Committee approved a focus on the shared health record. The reasons for prioritizing this element of the CIE are as follows:

- There are already referral and information vendors in the marketplace, CBOs are feeling pressure to participate in these various platforms and if the closed loop referral was prioritized, the CIE could be perceived as just another referral management platform.
- Some CBOs have not been interested in referral management platforms as this participation requires additional time and costs to them.
- Many CBOs are struggling to address referral volumes and might not support any efforts to increase referrals without additional resources.
- A shared health record could provide a critical pathway for building a data feed that could support additional support and funding for the work being done by CBOs
- While the shared health record was the initial priority, it would help support a closed loop referral process in the future.
- The return on investment for a shared health record could be higher than that for a closed loop referral process.

Below is a graphic that illustrates the elements of a shared health record.



**Figure Four Source: Chad MacLeod**

The Data and Technology Workgroup developed a Business Requirements document that outlines the various elements required to build a shared health record. See Appendix G3 for full report.

### Legal and Policy Workgroup

The Legal and Policy Workgroup completed a comprehensive review of federal and state regulations that relate to privacy of personally identifiable information (PII) and protected health information (PHI) and how these regulations would impact the operations of the CIE. See Appendix G2 for full report.

- While the Health Insurance Portability and Accountability Act (HIPAA) has extensive requirements for the use and disclosure of PHI by entities covered by the HIPAA regulations, the CIE would include non-covered entities as well as PII that does not fall under the HIPAA regulations. The Legal and Policy Workgroup reviewed the implications of non-HIPAA participants and PII data to determine the implications for the CIE.
- The Legal and Policy Workgroup also identified ethical issues and concerns that, apart from federal and state regulations, could inform the requirements of CIE participating organizations.
- The Legal and Policy Workgroup reviewed state and federal pending regulations that could impact the CIE moving forward. There is strong support at the state and federal levels for increased protection of PII.
- Components of the legal agreements/contracts between the CIE and its participating members were identified and examples of each type of agreement/contract were provided in the Comprehensive Legal and Policy Report.

## **Governance Workgroup**

A main focus of the Governance Workgroup was developing the two Advisory Committees, with a prioritization of the Community Advisory Committee. The Workgroup reviewed organizational engagement elements from seven different community organizations, including San Diego 211. The Governance Workgroup emphasized the need to include those groups that have, historically, been under-represented, for example, those who are homeless, those with disabilities, new Mainers, members of the LGBTQ+ community and older adults. They also identified the need for geographical diversity, ensuring that the needs/wants of rural communities are represented. See Appendix G1 for full report.

Charters for both the Community and Network Provider Advisory Committees were presented to the Steering Committee, along with draft Roles and Responsibilities documents for each committee. See Appendix F.

The Governance Workgroup presented potential Advisory Committee members to the Steering Committee. The Community Advisory Committee recommendations for membership were targeted for three groups: advocacy group representatives, consumers with lived experience, and representatives from underserved populations. The Network Provider Committee membership would include representatives from healthcare, CBOs, and others, such as professional associations.

The Governance Workgroup identified three possible governance structure models for the CIE and presented these to the Steering Committee:

Model 1 “Owner-Operator” Create a vertically integrated CIE Nonprofit, establish the needed structures, process, and practices under a single entity, hire and manage staff

Model 2 “Outsource” Turn over governance and operational functions to an existing nonprofit entity (or consortium) with shared values and the appropriate structures, process, and practices ready to govern and operate the CIE

Model 3 “Hybrid” Establish good governance, contract for operational excellence. Create a new CIE Nonprofit entity, board, and brand. Leverage existing structural and operational capacity of a core backbone partner (and sub-contractors as needed).

The Steering Committee felt that the Hybrid model was the most advantageous for the Maine CIE governance structure.

A Community Information Session was held in May 2023. A diverse group of community members participated and several of the participants were invited to join the Steering Committee to strengthen the consumer voice in future strategy and planning for the CIE.

## **Next Steps**

A Strategic Planning Meeting was held on September 5, 2023, including all of the Steering Committee members, plus the new members from the Workgroups and individuals from the Consumer Information Session who had expressed interest in participating in the CIE.

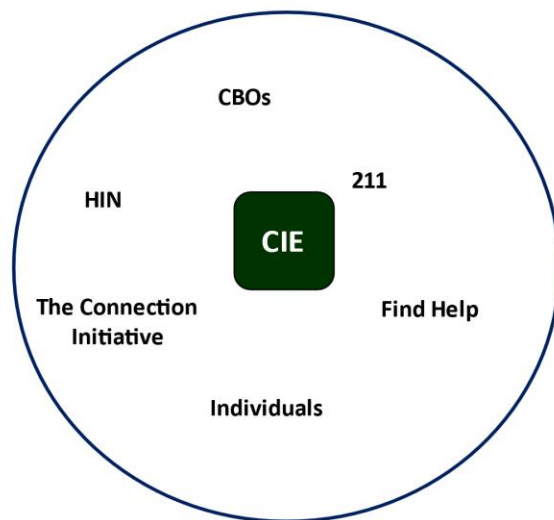
There is recognition that there are vendors already working within the State of Maine that are developing and providing elements of a CIE. However, these efforts lack coordination, shared standards, and technology integration. The Steering Committee therefore identified the need to establish a network governance function that would serve to:

- 1) Create shared standards for data sharing and information exchange;

- 2) Leverage resources and investment to accelerate the adoption and integration of enabling technologies;
- 3) Establish shared goals and benchmarks for implementing a CIE in Maine;
- 4) Advocate for public policies which ensure all people in Maine benefit from emerging CIE resources;  
and
- 5) Ensure individual privacy protections and for all information shared in the CIE.

The shared vision:

The Maine CIE is a *network* that constitutes the information and services *ecosystem* that responds to the health-related social needs of individuals and communities. The network includes organizations that manage and coordinate information exchange, organizations that provide services, and individual and organizational users of information and services. Following is a graphic depicting the CIE as a network (ecosystem):



**The gist of the graphic above: The CIE is a legal entity that convenes and advocates for a network of organizations providing information management and coordination of services that respond to health related social needs, along with the individuals and organizations that utilize their services. The entities shown in the above graphic are examples only of possible network participants.**

Maine CIE will be a Maine nonprofit organization that convenes and promotes collaboration for mutual benefit among network members. Participation in the CIE network will be open to all who abide by its governing principles and standards of operations, including best practices, as assured through Memoranda of Understanding (MOU) or Memoranda of Agreement (MOA). The Maine CIE will provide support for pilots like the ones below and others through advocacy, shared funding opportunities and guidance as requested to ensure that the voice of the consumer is represented.

### Pilot Projects

*Shared health record* - A pilot project has been developed with HealthInfoNet (HIN) and the York County Community Action Corporation (YCCAC). YCCAC is uniquely organized to address the health and social service needs of the community it serves. YCCAC has recently completed consolidation of its various databases and is partnering with HIN to begin a feasibility study of the steps it would need to integrate its data into the HIN platform. This pilot will help to identify the necessary steps and requirements for this data integration. Because other Community Action Programs within Maine are using the same data platform as

YCCAC, this pilot will be replicable and will have significant implications for the development of a statewide shared health record, one of the key components of the CIE.

*Resource Directory* - 211 Maine has developed formal relationships through MOUs with MaineHealth and findhelp. The objectives are to ensure resource databases are as accurate as possible and to decrease the burden for CBOs and health providers for entering their information in multiple locations. They are working on resource data sharing, a bidirectional updating process, and 211 Maine platform functionality testing. The target audience is CBOs. MaineHealth and findhelp have been partnering to develop a ‘no wrong door’ process for obtaining information about resources. Northern Light, MaineHealth, findhelp, 211 Maine and Intermed are contributors. The goal is to have a user-friendly way of connecting and make it easier for CBOs. The hope is to expand this to other health systems and other platforms. MaineHealth is in the process of developing CBO Social Care Mapping that will allow users to identify resources by hovering over a data point on a map of Maine. This will eventually help identify gaps in resources.

## **CIE Governance**

The CIE Steering Committee has filed Articles of Incorporation with the Maine Secretary of State to become a nonprofit corporation. The three incorporators, Jess Maurer, Betsy Sawyer Manter and Meaghan Arzberger, will serve as the governing board until such time as the new corporation is able to hold its first annual meeting. This will include the ability of the incorporators to approve bylaws. A draft set of bylaws has been developed.

Once the corporation has been formalized, the incorporators will identify members of a Board of Directors. The Board will have a minimum of five and a maximum of fifteen members. The Board will elect officers and establish working committees.

The CIE Board of Directors will be developing a set of principles for participation in the CIE to ensure that the CIE remains consumer-centric, that the voice of the consumer is included, and that the needs/wants of underserved populations are considered. Of key importance is identifying the barriers for participation in the CIE for CBOs that are not “Medicaid/Medicare covered entities.” It is essential that support of CBO participation is prioritized and supported.

## **Future Work**

*Identifying potential CIE Partners* – a subgroup of the Board should review other potential vendors already working in Maine to determine if they would consider participating in the CIE. The essential elements of a CIE have been identified. Potential vendors will be vetted to determine which of these elements they could provide.

*Identifying funding sources* – Funding sources will be needed to sustain the CIE. Funding may include grants, support from healthcare systems, support from third party payers, or support from the federal or state governments. Crucial to this is determination of the costs associated with the ongoing financial needs of the CIE. Funding for the next phase of the CIE must include staffing to support the work of the Board of Directors and grant writing, at a minimum.

*Advocacy* - the CIE will play a crucial role in advocating for consumers and CBOs. The CIE will develop two Advisory Committees:

- Community Advisory Committee – this group should include members representing advocacy groups, consumers with lived experience and representatives of underserved populations.

- Network Provider Advisory Committee – this group will include representatives from healthcare organizations and CBOs. The special concerns of CBOs will be important to elicit from Advisory Committee members.

CIE network participation and technology use will impact CBOs at multiple levels. A CIE is meant to facilitate easier referrals, and, as such, may increase the number of referral requests a CBO receives. To address the stress on individual CBOs, the CIE will need to assist in identifying and documenting unmet needs and advocate for funding to help support CBOs as their referral volume increases. Specific types of support may include:

- Support increased staffing capacity to address increased referrals for services.
- Incentivize adopting and using the CIE
- CIE can help demonstrate where resource availability may be lacking.
- CBOs may need support to improve internal infrastructures with IT equipment, integrating existing CBO IT systems, assistance in utilizing and analyzing CIE data, and operations support.

The CIE will also play a role in advocating for support at the state-level. Long term sustainability may require legislation to support the CIE. The CIE Board/Committee members will need to educate legislators regarding the CIE, the need for a CIE in Maine and the costs associated with ongoing CIE operations.

## **Conclusion**

A Maine CIE offers the opportunity to enhance the health and well-being of all Mainers through efficient and effective transfer of information among health and social service care providers; improved access to a comprehensive, accurate directory of resources; a closed loop referral system, and data analytics that would help identify gaps in services. The development of a fully operational CIE will be an ongoing, iterative process that will require support from diverse stakeholders. To date, the Maine CIE work has been conducted through grants from the Maine Health Access Foundation and has been undertaken by a dedicated set of volunteers, supported by project coordinators. Phase III of the CIE must include funding for support staff, grant writing and support for CBOs.

## **APPENDIX A**

### **Members of the Maine CIE Phase II Steering Committee and Workgroups**

The following list includes those members of the Steering Committee and Workgroups who participated throughout the Phase II Project.

#### **Steering Committee**

Doug Michael, Northern Light Health, Co-chair  
Meaghan Arzberger, York County Community Action Corporation, Co-chair  
Jess Maurer, Maine Council on Aging  
Charles Dwyer, Maine Health Access Foundation  
Chad MacLeod, HealthInfoNet  
Betsy Sawyer-Manter, Seniors Plus  
Lisa Letourneau, M.D., Maine DHHS  
Nikki Williams, Maine 211  
Ellen Freedman, MaineHealth  
Heather Pelletier, Maine DHHS Office of MaineCare Services  
Michael Pancook, Maine DHHS Office of MaineCare Services

#### **Governance Workgroup**

Betsy Sawyer-Manter, Seniors Plus, Co-chair  
Jess Maurer, Maine Council on Aging, Co-chair  
Doug Michael, Northern Light Health  
Jen Battis, Disability Rights Maine

#### **Legal and Policy Workgroup**

Heather Pelletier, Maine DHHS Office of MaineCare Services, Co-chair  
Virginia Dill, Maine DHHS Office of Behavioral Health Services, Co-chair  
Charles Dwyer, Maine Health Access Foundation  
Charley Martin-Berry, Community Caring Collaborative  
Noah Nesin, M.D., Penobscot Community Health Center

#### **Data and Technology Workgroup**

Chad MacLeod, HealthInfoNet, Chair  
Meaghan Arzberger, York County Community Action Corporation  
Nikki Williams, Maine 211  
Christine Maglione, Seniors Plus  
Laura Vinal, Good Shepherd Food Bank  
Gerry Queally, Spectrum Plus  
Michael Pancook, Consultant  
Tabitha Caso, Eastern Area Agency on Aging  
Justin Bylina, MaineHealth  
James Moorehead, Maine DHHS, Office of Aging and Disability Services  
Michelle Davis, Northern Light Health



## **Program Coordinators**

Sarah Taylor, Safer Healthcare LLC  
Jeffrey Brown, Safer Healthcare LLC

**APPENDIX B**  
**Community Information Session Participants**  
**May 2023**

Pat Kimball – Elder Abuse Institute of Maine

Karen Parker – Mid Coast Hunger Prevention Program

Donna Kelley – Waldo Community Action Program

Ted Rooney – Health and Work Outcomes

Kelly Sirimoglu – Piscataquis Regional Food Center

Peggy Newton – Tri-County Mental Health Services

Kim Humphrey -Community Connect Maine

Micaela Cassily - MaineTransNet

Gia Drew – Equality Maine

Deqa Dhalac – Maine House of Representatives

**APPENDIX C**  
**MAINE COMMUNITY INFORMATION EXCHANGE (CIE), PHASE II**  
**STAKEHOLDER PRESENTATION**

**AGENDA**

**November 6, 2023, 12:00 – 2:00 Zoom Call**

**Doug Michael, Northern Light Health, Steering Committee Co-chair**

Introduction and Brief Description of a CIE

**Charles Dwyer, Maine Health Access Foundation**

Importance of CIE – Problems to be Solved

*Social Determinants of Health and Social Risks*  
*Current Barriers*

Phase I Brief Recap

**Jess Maurer, Maine Council on Aging** Phase II Governance Workgroup & Steering Committee

*Phase II Accomplishments*  
*Plans for Phase III*

**Michael Pancook, Maine DHHS, Office of MaineCare Services** Legal and Policy Workgroup

*Phase II Accomplishments*  
*Plans for Phase III*

**Chad MacLeod, HealthInfoNet** Data and Technology Workgroup

*Phase II Accomplishments*  
*Plans for Phase III*

**Charley Martin-Berry, Community Caring Collaborative** The Connection Initiative, Community Caring Collaborative

*Description, Challenges, How a CIE Could Support this Effort*

**Meaghan Arzberger, York County Community Action Corporation (YCCAC)**

Pilot Project YCCAC and HealthInfoNet

**Nikki Williams, 211 Maine**

Pilot Project 211 Maine, MaineHealth, and findhelp

**Jess Maurer, Maine Council on Aging**

Conclusion

**Q&A**

## APPENDIX D

### Roles and Responsibilities Document

#### Steering Committee Roles and Responsibilities

##### Maine Community Information Exchange (CIE) Phase II Steering Committee Roles and Responsibilities

This document sets out the roles, responsibilities, and expectations for the Maine CIE Steering Committee (SC) for Phase II of the Maine CIE Project (Project).

#### **1) Background**

In 2020, a series of discussions were convened with a broad group of stakeholders to learn about CIEs – tools and approaches used in other states to share person-level information and make referrals between healthcare and social services providers. These discussions led to the creation of a working group of volunteers from the stakeholders to create a shared vision and begin laying the foundations of a Maine CIE. The goal of a CIE, as developed by this group, is to better health and well-being through improved information, referral, and coordination. To accomplish this goal, the group agreed that functionality of a CIE should generally include:

- A shared, longitudinal health record that spans clinical and community settings
- The ability to collect health related social needs (HRSN) information (a common language and understanding of the HRSN), as well as social risks information and the ability to compile and share this information individually (with permission) and in the aggregate.
- A resource directory that is maintained with up-to-date information. The ability to meaningfully refer individuals seeking assistance to providers of health and social services using an interactive platform that allows for real-time and asynchronous communication, to determine if the referral was accepted and if the services were delivered based on information provided by the provider and/or the seeker of assistance. Equally important is the ability to understand why the referral was not accepted, or the services were not delivered, or not delivered satisfactorily.
- The ability to analyze results and take action to improve care coordination for patients, make the best use of resources within health and social services organizations, address unmet need in communities and increase health equity throughout the state.

The Maine Council on Aging (MCOA) has agreed to act as a neutral convener and to oversee Project. The Maine Health Access Foundation (MeHAF) is the sponsor for the Project.

#### **2) Project**

With the support from Project Coordinators, Sarah Taylor and Jeff Brown, Safer Healthcare, LLC, the work of the Project will be completed by a Steering Committee (SC) made up of volunteers who were participants of the initial workgroup. The membership will be balanced between governmental, community based social services, healthcare providers, and consumers/community leaders. This will be the decision-making body. The SC, along with the Project Coordinators, will support the work of three workgroups: 1) Governance, 2) Policy & Legal, 3) Data & Technology. Each of these workgroups will develop a plan to address each of the technical component areas needed for a functional CIE. The SC will be responsible for reviewing and advising regarding capital and operational costs associated with a CIE.

#### **3) Role and Responsibilities**

##### **Generally**

The purpose of the SC will be to oversee the three workgroups and to ensure that the voices of consumers and network providers are incorporated into CIE plans through the establishment of a Community Advisory Panel and Network Provider Panel.

##### **Specifically**

In line with this oversight role, the SC responsibilities also include:

- *Management*
  - Overseeing development of the Project strategy in alignment with the defined Maine CIE vision
  - Monitoring of the Project performance, outcomes, and impact
  - Reviewing the Project governance structure and the practices/progress of each of the workgroups

- Reviewing Project performance against diversity, equity and inclusion commitments and goals
- *Programming and Outreach*
  - Supporting and serving as a sounding board for the Project Coordinators, workgroups, and advisory committees
  - Serving as an advocate, ambassador, spokesperson, and connector for the Project in the community
  - Facilitating introductions to potential workgroup members, advisory committee members and stakeholders
  - Reviewing branding and outreach strategies
- *Personnel*
  - Evaluating Project Coordinators' performance in concert with MCOA
  - Recruiting, selecting, and integrating new SC members
  - Recruiting, selecting, and integrating new workgroup and advisory committee members
  - If needed, assisting in terminating workgroup or advisory committee members

The SC does not have fiduciary duties related to participating this Project. The SC does not serve as a representative or agent of MCOA, MeHAF, or any other party.

#### **4) Expectations of Individual Members**

The SC members are expected to actively contribute their leadership, time, and talents to help the Project achieve its goals. Each individual SC member will:

- Learn about the Project strategy
- Assist in developing of a project management plan
- Participate in at least one workgroup or advisory committee
- Demonstrate core values and competence as members of the SC
- Serve as the eyes and ears on-the-ground in key geographic areas and among key stakeholders and will keep SC and other Project participants apprised of developments in the field and emerging opportunities or challenges
- Prepare for and participate in SC meetings, including reviewing agendas, background materials and draft minutes
- Attend, be prepared to report progress on work, and contribute at all SC meetings
- Undertake and follow up on action items assigned from SC meetings or other Project member requests
- Communicate proactively during and in between scheduled SC meetings
- Update parent organizations on Project II progress and share Project documents within parent organizations, as appropriate
- Provide timely feedback and comments as requested on submittals and deliverables
- Send updates to Project Coordinators for meetings you are unable to attend
- Represent the Project vision, values, and work to the community
- Leverage their own personal networks to further the Project goals
- Foster an inclusive environment and community

#### **Conflicts of Interest**

SC members are expected to use good judgment and to avoid situations that create an actual, potential, or perceived conflict with the purposes and activities of Project.

I have read and agree to the Steering Committee Roles and Responsibilities outlined in this document:

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

# Workgroup Roles and Responsibilities

## Maine Community Information Exchange (CIE) Phase II Workgroup Roles and Responsibilities

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This document sets out the roles, responsibilities, and expectations for the Maine CIE Steering Committee (SC) for Phase II of the Maine CIE Project (Project).

### **5) Background**

In 2020, a series of discussions were convened with a broad group of stakeholders to learn about CIEs – tools and approaches used in other states to share person-level information and make referrals between healthcare and social services providers. These discussions led to the creation of a working group of volunteers from the stakeholders to create a shared vision and begin laying the foundations of a Maine CIE. The goal of a CIE, as developed by this group, is to better health and well-being through improved information, referral, and coordination. To accomplish this goal, the group agreed that functionality of a CIE should generally include:

- A shared, longitudinal health record that spans clinical and community settings
- The ability to collect health related social needs (HRSN) information (a common language and understanding of the HRSN), as well as social risks information and the ability to compile and share this information individually (with permission) and in the aggregate.
- A resource directory that is maintained with up-to-date information. The ability to meaningfully refer individuals seeking assistance to providers of health and social services using an interactive platform that allows for real-time and asynchronous communication, to determine if the referral was accepted and if the services were delivered based on information provided by the provider and/or the seeker of assistance. Equally important is the ability to understand why the referral was not accepted, or the services were not delivered, or not delivered satisfactorily.
- The ability to analyze results and take action to improve care coordination for patients, make the best use of resources within health and social services organizations, address unmet need in communities and increase health equity throughout the state.

The Maine Council on Aging (MCOA) has agreed to act as a neutral convener and to oversee Project. The Maine Health Access Foundation (MeHAF) is the sponsor for the Project.

### **6) Project**

With the support from Project Coordinators, Sarah Taylor and Jeff Brown, Safer Healthcare, LLC, the work of the Project will be completed by a Steering Committee (SC) made up of volunteers who were participants of the initial workgroup. The membership will be balanced between governmental, community based social services, healthcare providers, and consumers/community leaders. This will be the decision-making body. The SC, along with the Project Coordinators, will support the work of three workgroups: 1) Governance, 2) Policy & Legal, 3) Data & Technology (“Workgroups”). Each of these Workgroups will develop a plan to address each of the technical component areas needed for a functional CIE. The SC will be responsible for reviewing and advising regarding capital and operational costs associated with a CIE.

### **7) Role and Responsibilities**

#### **Generally**

The purpose of the Workgroups is to ensure that the CIE Phase II Project makes substantial progress and to ensure that the voices of consumers and network providers are incorporated into CIE plans.

#### **Specifically**

In line with this role, the Workgroup responsibilities also include:

- Finalizing Workgroup Charters and presenting these to the Steering Committee (“SC”) for review and approval
- Developing plans to meet the goals and objectives of the Workgroup Charter
- Communicating with the Project Coordinators and SC regarding progress towards meeting Charter goals/deliverables
- Communicating with the Project Coordinators and the SC regarding barriers to accomplishing Charter goals/deliverable in a timely manner
- Defining next phase priorities and estimating budget & resource needs to operationalize next phase deliverables.

### **8) Expectations of Individual Members**

The Workgroups members are expected to actively contribute their expertise, time, and talents to help the Project achieve its goals. Each individual SC member will:

- Learn about the Project strategy
- Assist in developing and refining the Workgroup charter
- Assist in developing a work plan for the Workgroup based on the Workgroup charter
- Serve as the eyes and ears on-the-ground in key geographic areas and among key stakeholders and will keep SC and other Project participants apprised of developments in the field and emerging opportunities or challenges
- Prepare for and participate in Workgroup meetings, including reviewing agendas, background materials and draft minutes
- Attend, be prepared to report progress on work, and contribute at all Workgroup meetings
- Undertake and follow up on action items assigned from Workgroup meetings or other Project member requests
- Communicate proactively during and in between scheduled Workgroup meetings
- Update parent organizations on Project II progress and share Project documents within parent organizations, as appropriate
- Provide timely feedback and comments as requested on submittals and deliverables
- Send updates to Project Coordinators for meetings you are unable to attend
- Represent the Project vision, values, and work to the community
- Leverage their own personal networks to further the Project goals
- Engage in the Workgroup in good faith
- Foster an inclusive environment and community

### Conflicts of Interest

Workgroup members are expected to use good judgment and to avoid situations that create an actual, potential, or perceived conflict with the purposes and activities of Project.

I have read and agree to the Workgroup Roles and Responsibilities outlined in this document:

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## APPENDIX E

### Workgroup Charters

#### Governance Workgroup Charter

General	
<b>Project Name:</b>	Community Information Exchange (CIE) Phase II <b>Governance Workgroup</b>
<b>Project Sponsor:</b>	MCOA/MeHAF
<b>Workgroup Co-Chairs:</b>	Betsy Sawyer-Manter, Doug Michaels, Jess Maurer
<b>Phase II Time Frame</b>	August 2022 – April 30, 2023
<b>Date Charter Approved</b>	October 6, 2022
CIE Steering Committee	Rev – 11/15/22

#### GOAL

The **Governance Workgroup** will develop a plan to illustrate and articulate the governance requirements for a functional CIE, including recommendations for the phased (timing) implementation of key CIE governance elements.

#### SHARED VALUES

- *A CIE's governance should be designed to build and carefully preserve trust, with inclusive methods for participation of key stakeholders (service providers, help-seekers, and the collective interests of the CIE Network community)*
- *The CIE Network should be locally owned and managed collaboratively by the community; not by one organization, platform, or group.*
- *A neutral community-based governance structure will sustain an inclusive, transparent, intentionally equitable and sustainable network.*
- *The strongest governance structures are simple, effective, adaptable, and accountable to the common shared goals of the network.*

#### DELIVERABLES

1. **Governance Model** – defining desired (future state) governance structures, interdependencies, authority, and functional responsibilities
  - a. **Community Advisory Committee**
  - b. **Network Provider Advisory Committee**



2. **Governance Road Map** – proposed timing and sequence for developing and operationalizing key governance elements
3. **Budget Considerations** – estimated resource requirements to launch and maintain governance elements
4. **Next Steps** – defining Phase III Governance priorities (2023/2024)

## SCOPE & DEFINITIONS

Nesting governance elements include:

### 1. **Network (Institutional) Governance**

Includes defining the governing structures, policy purview and authority of the CIE Network.

Considerations include:

- How will the CIE Network Community be represented?
- How will leadership be instituted, evaluated, and removed?
- How will priorities be set and adjusted?
- How will policymaking take place?
- How will conflicts be addressed and resolved?

### 2. **Administrative Governance**

Administrative governance flows from Network Governance, and includes the operational structure(s), purview and authority of agency(s) engaged by the CIE with delegated authority to carry out the day-to-day operations of the CIE Network.

Considerations include:

- How are policies designed, implemented, monitored, and enforced?
- How will the Network community's interests and concerns be addressed?
- How are operational standards established?
- How will clients' rights be protected?

### 3. **Data Governance \***

Addresses the standards by which the CIE Network (and its Administrative Agents) will steward and manage the availability, usability, integrity, and security of the data exchanged. Data governance flows from administrative governance.

Considerations include:

- Technical and operational standards required, and how they will be validated?
- Data Lifecycle; how is data collected, used over time and when it should be destroyed?
- License; who has rights to access which kinds of data, and for how long?
- Data Protection; How will data be protected, what happens if data is breached?

### 4. **Community Governance**

Community data governance is the process of establishing and ensuring the freedoms, constraints, and incentives that determine how two or more parties agree to conduct the ingress, storage, protections, use and egress of data, tools, methods, and knowledge amongst themselves and others.

- CIEs need to design mechanisms for monitoring the uses of aggregated data, assessing the impacts of that use, and making and enforcing rules that preserve the communities' related interests.
- Community data governance must go far beyond the 'secure data systems plus informed consent' model. What data should be collected in the first place, according to whose interests and under what oversight?

*\*Data Governance intersects with the Data/Technology and the Legal/Policy Workgroups*

### **Project Scope**

#### **Assumptions:**

- ❖ Phased implementation will ensure the Governance model does not get ahead of the CIE Network functions to be governed. This will keep the Governance focused on near term functions, be more efficient and adaptable.

#### **Constraints:**

- ❖ Phase II needs to be completed by April 30, 2023.

#### **Out of Scope:** [What will be excluded from this project?]

- ❖ Detailed modeling of governance elements not implemented or planned in the next 12 months
- ❖ Draft Bylaws, Articles of Incorporation, Application for tax exempt status

### **High-Level Project Risks**

There are significant asymmetries in resources between healthcare systems, community-based organizations, and community members. Proposed governance elements and processes will need to ensure all stakeholder voices are represented and have appropriate agency, authority and accountabilities.

Individuals' data is often entwined with that of family members, caregivers, and others in their community: one person's consent to share information about their own self status might affect others in the household without providing any methods by which those others can themselves consent.

### **Stakeholders & Affected Business Areas**

Individuals seeking care/services; healthcare providers; social service providers, communities

### **Core Team Members**

Seeking team members with aptitude and experience with multi-sectored Network governance models.

## **Legal and Policy Workgroup Charter**

General	
<b>Project Name:</b>	Community Information Exchange (CIE) Phase II <b>Legal &amp; Public Policy Workgroup</b>
<b>Project Sponsor:</b>	MCOA/MeHAF
<b>Workgroup Co-Chairs:</b>	TBD
<b>Phase II Time Frame</b>	August 2022 – April 30, 2023
<b>Date Charter Approved</b>  <input checked="" type="checkbox"/> CIE Steering Committee <input type="checkbox"/> Project Sponsors	October 20, 2022

## GOALS

The **Legal & Public Policy Workgroup** will complete the following activities to inform the deliverables:

- Include consumer and provider feedback in the identification of legal and policy best practices and the ‘user friendly’ mechanisms for consent processes.
- Research and elicit legal guidance from subject matter experts to identify and design effective consent procedures and architectures defined by the correct and accurate interpretation of regulations impacting protected health information (PHI) and/or personally identifiable information (PII) exchange.
- Research and elicit legal guidance from subject matter experts to identify and mitigate the regulatory and policy gaps regarding protected health information (PHI) and/or personally identifiable information (PII) exchange that occur across the patchwork of state and federal public health programs.
- Identify the administrative, legal, and policy complexities required for the full CIE model:
  - where CIE network partnership and data sharing agreements will be required in the information exchange process.
  - when standardized consumer/patient consent will be required in compliance with both state and federal regulation in the CIE consent model.
  - required state and federally compliant standard privacy (confidentiality) and security measures.
- Work closely with the Data and Technology Workgroup to ensure that the legal and regulatory compliant electronic consent technological interface and processes are well defined and implemented to effectively protect PHI and/or PII while supporting the functionality and value of the CIE.
- Identify ethical and data security concerns in the CIE processes and functions to propose legal, policy, and functionality solutions that fully address these concerns.
- Ensure that example consent language is clearly written, honors individual autonomy without coercive language that implies that service access is dependent upon CIE consent with the inclusion of revocation language.
- Identify administrative, legal, policy, and resource complexities and barriers to full implementation and adoption of the CIE model.

## General

- Address the legal and public policy considerations and requirements for a functional CIE, including recommendations for the phased (timing) implementation of key CIE legal and policy functions.
- Project the funding and subject matter expert resources required to develop and implement the CIE.
- Identifying the legal and public policy resources needed to support, develop and implement the CIE.

*\*Security and privacy technical requirements and monitoring intersects with the Data/Technology Workgroup*

*\*\*HIPAA – Health Insurance Portability and Accountability Act*

*PHI – Protected Health Information*

*PII – Personally Identifiable Information*

## SHARED VALUES

- *Maine CIE is a collaborative network inclusive of trusted public and private sector partners*
- *The Maine CIE will require public policy innovation and support at both state and federal level*
- *Respecting the privacy and agency of individuals; individuals choose to share their information or not*
- *Maine CIE should facilitate the responsible flow of Information; data sharing choice is specific and clear; for what purpose and with whom*
- *Clients/patients own their own information; the CIE facilitates accountable sharing of information*

## DELIVERABLES

**The Legal and Policy Workgroup’s findings as developed in the execution of the stated goals will be reported in the following deliverables:**

- Legal & Public Policy Plan** – outlining the planning process, recommendations, opportunities, challenges, and next steps to address the legal and public policy requirements of a Maine CIE model as defined by the Steering Committee and Workgroups to include, but not be limited to:
- a. A section that defines and summarizes the state and federal rules and regulations that impact the development and implementation of a Maine CIE.
  - b. A section that identifies the administrative, legal, policy, and resource complexities and possible barriers to full implementation and adoption of a Maine CIE model.
  - c. Legal and policy recommendations on role-based data access permissions to ensure each end user and partner organization has the right level of access to and use of data; permissions managed on a need-to-know basis.
  - d. Recommendations to address patient data (substance use disorder (SUD), Sexual Orientation and Gender Identity SOGI, mental health, and HIV/AIDS that require unique or more restrictive privacy and security legal and security rules and processes.
  - e. Ethical, privacy, and security legal and policy challenges identified with recommendations for best practices and risk mitigation.
  - f. Consumer-focused recommendations for policies and procedures regarding the participation agreement, informed consent agreement, information release, and other transactional legal forms to support both best practice and consumer feedback. This report should include examples of consent and participant agreements currently used in data sharing healthcare exchanges that are clearly written, honor individual autonomy without coercive language that implies that service access is dependent upon CIE consent with the inclusion of revocation language.

## General

- g. A survey of state and federal governmental and community programs that may impact the development of the CIE both positively and negatively with recommendations for next steps to enhance synergistic opportunities and mitigate risks.

**Timeline & Road Map** – proposed timing and sequence for developing and operationalizing key legal and public policy elements and identified timeline overlaps with both the Governance and Data and Technology Work groups’ plans.

**Resource Considerations** – identify the resource requirements to launch and maintain legal & policy functions in a Maine CIE.

**Next Steps** – defining Phase III legal and public policy priorities (2023/2024)

- a) Identified Maine statute challenges and make recommendations for changes
- b) Outstanding formal legal analysis of the Legal and Policy Workgroup’s deliverable reports for recommendations for Phase III.
- c) A list of documents and processes that will require legal and operative final review and approval for CIE implementation

**Model CIE Legal Agreements** – examples of model data sharing agreements, patient consent models

## Project Scope

### Assumptions:

- ❖ Compliance with state and federal regulations regarding privacy and data sharing

### Constraints:

- ❖ Phase II needs to be completed by April 30, 2023.

### Out of Scope: [What will be excluded from this project?]

- ❖ Detailed modeling of legal and policy considerations not implemented or planned in the next year
- ❖ Formal legal review of the Legal and Policy Workgroup’s deliverables and operational recommendations for the model that overlap with the other workgroups’ deliverables.
- ❖ Processes defined for how data breaches would be identified and reported in compliance with HIPAA.

## High-Level Project Risks

While data standards for healthcare providers are established through HIPAA (privacy and security of PHI), data standards are scarce within and across social services sectors.

Ensuring clients are presented with appropriate language and context to inform their consent decisions. If a multi-page ‘Terms of Service’ presents too much information or in language that the client does not understand, how will the CIE strike the appropriate balance between transparency and user-friendliness?

<b>Stakeholders &amp; Affected Business Areas</b>
Healthcare providers, social services providers, clients of providers and communities.
<b>Core Team Members</b>
Sarah Taylor, Megan Hannan, Charles Dwyer, Jeff Brown, Virginia Dill, Lisa Harvey McPherson, Aaron Carpenter, Charley Martin-Berry, Heather Pelletier

## DATA AND TECHNOLOGY CHARTER

General	
<b>Project Name:</b>	Community Information Exchange (CIE) Phase II – Data & Technology Workgroup
<b>Project Sponsor:</b>	MCOA/MeHAF
<b>Workgroup Chair:</b> <b>Workgroup Co-Chair:</b>	Chad MacLeod, HealthInfoNet
<b>Approved:</b>	October 20, 2022

Business Case Statement
<p>It is estimated that medical care accounts for only 20 percent of the modifiable contributors to healthy outcomes for a population. Social and economic factors, such as income, housing, and healthy food, also play a significant role in a “whole person” approach to health care and are often referred to as Social Determinants of Health (SDOH). These factors can drive as much as 80 percent of health outcomes. Healthcare systems and organizations across the state of Maine recognize the impact of SDOH on overall health, and they are looking for proactive pathways to screen people for social health risks and needs, connect them with the necessary social supports, and track cross-sector referrals and outcomes.</p> <p>The goal of a Maine CIE, as determined in Phase I of the Maine CIE project, is to better the health and wellbeing of Maine residents through improved information sharing, referral, and care coordination. To accomplish this goal, the group agrees the functionality of the CIE should include the ability to:</p> <ul style="list-style-type: none"> <li>• Collect health-related social risks information using a shared language</li> <li>• Compile and share this information individually (with permission) and in aggregate</li> <li>• Meaningfully refer individuals seeking assistance to providers of healthcare and social services using an interactive resource directory platform that allows for real-time and asynchronous closed-loop communication</li> <li>• Analyze results and take action to improve care coordination for patients</li> <li>• Make the best use of resources within healthcare and social services organizations</li> <li>• Address unmet need in communities and increase health equity throughout the state</li> </ul>

Technical Components	
<i>The following components are considered in scope for the Maine CIE project, though their dependencies, prioritization, and release will be determined by the workgroup.</i>	
Infrastructure & Environment Configuration	Creation of infrastructure to support secure and authorized role-based access to both the backend and frontend CIE system and its related services. Infrastructure should support the configuration of Development, Test, Production, and Demonstration environments with varying amounts of identifiable and de-identifiable person health information to meet privacy standards while also enabling proper software development life cycle (SDLC) processes. This also includes detailing the necessary support staff to ensure that all infrastructure and environments are running and operating as intended at any given time.
Interoperable Data Exchange Standards	Establishment of the necessary interoperability protocols and data standards across healthcare and social services sectors to ensure high-value, high-quality integration capabilities to/from the CIE system and its participants’ internal applications as well as compliance with federal/state/local program requirements and expectations.

<b>Technical Components</b>  <i>The following components are considered in scope for the Maine CIE project, though their dependencies, prioritization, and release will be determined by the workgroup.</i>	
Data Integration Services	Development of a data integration enterprise solution that can accept, route, map, translate, and cleanse incoming data sets from healthcare and social services organizations according to custom configurations to assure high-quality data outputs. Data sets may include clinical event-based information from healthcare providers and services/supports information from community-based organizations.
Person Consent Management	Construction and management of technical systems to support persons' decisions to participate in the CIE system, which may include various consent choices to opt-in or opt-out of specific CIE services on either a global or encounter-by-encounter basis.
Person Identity Management System	Implementation of a service that allows the CIE system to track individuals – and their various health-related information – across disparate and diverse data sources and over time using probabilistic and deterministic matching measures to ensure that records are as comprehensive, consolidated, and up to date as possible.
Terminology Management	Compliance with cross-industry vocabulary standards that allows the CIE system and its services to translate local coding norms into industry-standard values (e.g., ICD, CPT, HCPCS, LOINC, SNOMED, AIRS, etc.) and flagging value sets of interest to block or sequester to ensure the delivery of consistent, easily understood, and highly secure data sets.
Universal Social Risk Assessment Tools	Delivery of universal social risk screening tools (e.g., NACHC PRAPARE, CMS AHC-HRSN) commonly employed by healthcare and social services providers during intake procedures to surface social risk factors and to determine social needs. These tools would be made available to providers who may not have the same technology available within their internal organizations so that they can benefit from such risk-assessment measures.
Resource Directory Management	Development and maintenance of a resource directory management system that clearly articulates information about healthcare and social services resources available to people in need to support service discovery and accessibility.
Closed-Loop Referral System	Availability of a mechanism that allows providers working with people for various care needs to make referrals to outside organizations. Closing-the-loop requires bi-directional information sharing and communication among providers to ensure that persons obtain the services and support that they are intended to receive.
Longitudinal Health Record	Creation of a person-centric health record that compiles the history of all information received from CIE data-sharing participants and organizes it within a single, intuitive view that persons' care team members can access on a role-based basis to gain insights on how best to provide care and support.
Notifications	Delivery of real-time alerts of time-sensitive events (e.g., emergency department visits, new program enrollment, etc.) that make it possible for care managers and other providers following an individual's healthcare and social services activities to intervene early and establish the right care plan for follow-on action.
Analytics & Reporting	Formation of various use-case driven analytic and reporting capabilities, spanning descriptive, utilization, predicted risk, and quality measurements available at both person and population levels, to help better target care for persons and/or populations with certain risk factors, needs, or gaps in care.
Downloads & Exports	Functionality to download and/or export available information from within the CIE system to inform offline study and review.



## Technical Components

*The following components are considered in scope for the Maine CIE project, though their dependencies, prioritization, and release will be determined by the workgroup.*

Help Desk Support	Management of user accounts for individuals who have access to the CIE system and maintaining technical and operational support functions to users in the event of system failure, downtime, or other such issues requiring troubleshooting.
Auditing Functions	Automated and manual review functions of audit logs and privacy reports that ensure users are leveraging the CIE system and its services in compliance with the intended and authorized data use cases and governance policies.
Training & Education	Development of procedures and protocols intended to assist organizations in (a) determining their CIE-participation eligibility, (b) implementing patient consent within their internal workflows, and (c) continuing to use the CIE system and its services within the bounds of the intended and authorized data use cases and governance policies. This includes the creation of various educational resources to assist participating organizations, as well as staff resources to assist with questions as they arise.
User Interface Design and Workflow	Establishment of overarching style, design, and workflow principles to be incorporated within the frontend CIE system and its services to facilitate streamlined and simple usage, as well as incorporation within internal organizational standards (e.g., branding, white labeling).
Consumer Application	Creation of a web-based portal that allows the consumer (i.e., person, patient, client) with information included within the various features/functions of the CIE system to view a curated health record of activities initiated by their healthcare and community-based provider team (e.g., referrals, risks, assessments, etc.) as well as to engage with certain self-service features/functions of the CIE system to input data on their own (e.g., self-refer, self-assess, etc.).

Goal Statement	
1.	A healthy information ecosystem must be built upon “open access” infrastructure, using standardized protocols, so that any compliant platform can perform critical functions through interoperability with other connected platforms – and that these activities should be governed by local communities to ensure responsiveness to beneficiary needs (a critical driver of health and racial equity).
2.	A CIE should facilitate interactions beyond service transactions to encompass information about networks of people and ongoing case management.
3.	Consent should be freely given, reversible, informed, enthusiastic and specific.
4.	Communities should have meaningful control over how aggregate data is used to construct population-level representations and processes, such as structuring algorithms that might be used to allocate resources and make other kinds of critical decisions about <i>who</i> should have access to <i>what</i> under <i>which</i> circumstances.
5.	CIEs need to compensate for the ethical immaturity of consent frameworks through the investment in the development of governing processes in which stakeholders (service providers and users) are structurally empowered to co-design, monitor, audit, evaluate, and sanction the various methods of consent solicitation and preservation through the lifecycle of various projects conducted through the CIE.
6.	A CIE should ensure that the systems and activities associated with the coordination of social care are equitably developed and implemented according to expressed interests and active participation of stakeholders in a local community.
7.	Given that health equity is a function of collective well-being, CIEs need to design mechanisms for monitoring the use of aggregated data, assessing the impacts of that use, and making and enforcing rules that preserve the communities’ related interests.

## Project Scope

### **Deliverables:** What will be the result of the project?

- Prioritization of various CIE components into a phased/modular development and release approach, and the understanding of the interconnectedness/dependencies of the many components.
- Business (and technical, whenever possible) requirement drafts for each of the priority technical components of the CIE system.
- Clear recommendations for specific vendors/partners required to fulfill the priority technical components of the CIE system, including the execution of letters of intents with each vendor/partner that are contingent on procuring the necessary funding to proceed.
- Project plan drafts for each of the priority technical components of the CIE system, highlighting necessary staff, resources, and time to complete the effort (and which could be used for budgeting purposes).
- Budgets to support the priority technical components of the CIE system, which explicitly can be traced back to funding opportunities identified through the Steering Committee.

### **Assumptions:** Build upon what already exists whenever possible and appropriate.

- The Steering Committee trusts the Workgroup to work toward the scope defined in this charter and allow the Workgroup to work as a self-motivated group to come to key decisions and milestones, while also supporting the Workgroup by assisting with decision making, resolving barriers as they arise, and encouraging progress and collaboration.
- The Workgroup members consist of the necessary stakeholders that can define technical requirements for the technical components of the CIE system.
- The Workgroup is committed to routine and frequent meetings to complete its desired deliverables in a timely manner.
- The Workgroup can define a decision-making and consensus process among its members such that progress is not stalled by disagreement or hesitancy among a minority of members.
- The other CIE workgroups have shared visions for the project scope, including the ability to help resolve overlapping matters and dependencies, and are equally devoted to achieving productive deliverables that clearly articulate detailed next steps toward system implementation.

### **Constraints:** **Timeframe** for Phase II ends 4/30/23.

### **Out of Scope:** [What will be excluded from this project?]

TBD upon further discussion of charter with Steering Committee and Workgroup members.

### High-Level Project Risks

The challenge of ethical management of consent for data sharing – especially through systems that integrate across institution and technological boundaries – is particularly difficult. There is near universal agreement that clients should have control over what information is shared with whom and in what context, but there is no broad understanding of the tradeoffs and tensions that make it difficult or even impossible to fully uphold such a principle.

There are real and near-term prospective costs for social service providers to adapt their processes to engage in a CIE (even if the software being offered to them is free).

There is likely to be an imbalance in incentive structures (as well as power) between healthcare providers and social services providers in the CIE's development, and among larger and smaller social service providers.

Data sharing agreements frequently do not address the use of metadata, anonymized aggregated data, and algorithmic processes that may be applied in unanticipated ways, sometimes with harmful effects.

### Stakeholders & Affected Business Areas

Healthcare providers, social service providers, clients, communities

### Core Team Members

Chad MacLeod

Laura Vinal

Meaghan Arzberger

Nikki Williams

Michael Pancook

Gerry Queally

Christine Maglione

Tabitha Caso

Michelle Davis

Justin Bylina

James Moorehead

## DRAFT Discussion Questions

*The following discussion questions are the outcome of various conversations regarding the technical components of the CIE system and by no means constitute a comprehensive or all-encompassing guide. Rather, this table should be used as a “living document” to continue to add questions to over time as the Workgroup meets.*

Infrastructure & Environment Configuration	<i>TBD</i>
Interoperable Data Exchange Standards	<ul style="list-style-type: none"><li>• How might the CIE (and its associated partners) establish compliance with interoperability protocols through procurement policies – such that, for instance, adoption of an open standard is required as a condition of executing a contract?</li><li>• In a shared system, to what extent should healthcare protocols be imposed upon social service sectors and to what extent should data exchange about social service clients reflect the needs and conventions of social services?<ul style="list-style-type: none"><li>○ Does the CIE need to adhere to and/or support the various federal regulations on healthcare systems to adopt FHIR-based API standards and general data standards/stewardship (e.g., ONC USCDI).</li></ul></li><li>• What will be the “common denominator” for allowing healthcare and social services providers to connect to the CIE as a data-sharing participant? In other words, what is the mechanism by which the CIE will accept person information (e.g., flat files via SFTP, interface feeds from electronic health record (EHR) systems, etc.)?</li><li>• What are the technical specifications involved in sharing personal information with the CIE? Will providers interested in sharing data be required to send information in a discrete data format (rather than in a blob structure) to enable the most useful application of the information across the CIE’s services?</li><li>• What sort of privacy and security considerations and protocols need to be made within the CIE technology stack to protect patients’ protected health information (PHI) and other non-PHI sensitive health information?</li><li>• What local, statewide, and/or national data systems does the CIE want to be able to integrate with for more expansive feature/functionality use cases?<ul style="list-style-type: none"><li>○ In what conditions would the CIE accept and/or share data with other systems?</li></ul></li><li>• Will the CIE allow providers to perform single-sign-on to the CIE from each of critical internal electronic applications?</li><li>• How can communities navigate the risks and potential benefits of centralized, decentralized, or federated approaches to data exchange?</li></ul>
Data Integration Services	<ul style="list-style-type: none"><li>• Ensure that information collected from CBOs is standardized either before the CIE’s receipt, or during the processing through the CIE’s data integration engine; also related to the terminology management service functions.</li></ul>
Person Consent Management	<ul style="list-style-type: none"><li>• Are there already existing person consent management infrastructures that might be available for use by a CIE, such as through a regional HIE’s Person Identity Management system?</li></ul>

## DRAFT Discussion Questions

*The following discussion questions are the outcome of various conversations regarding the technical components of the CIE system and by no means constitute a comprehensive or all-encompassing guide. Rather, this table should be used as a “living document” to continue to add questions to over time as the Workgroup meets.*

	<ul style="list-style-type: none"><li>• What additional consent and governance considerations are required by the creation of a person-specific longitudinal health record?</li><li>• What additional consent and governance considerations are required by the creation of a closed-loop referral system?</li><li>• What kinds of activities should require users to actively agree to ‘opt in’ and what kinds of activities should merely offer an option to ‘opt out’? Should these decisions be associated with distinct levels of permissiveness and sensitivity of the resulting data exchange and use?</li><li>• How can users retain specific control over what kinds of data they do or do not agree to share, with whom, and for what purpose?</li><li>• How will the CIE ensure that users are presented with an appropriate amount of context to inform their decisions?</li><li>• How will the CIE ensure that consent is sustained over time and revocable as necessary?</li><li>• Should clients be able to change their data sharing relationship with their providers and associated institutions over time, or is consent/governance more of a global decision?</li><li>• How will the CIE address the entanglement between one person’s data and data about other individuals in primary, secondary and tertiary relationship with them?</li><li>• How will consent to share be ethically managed among a connected cohort of individuals, families, caregivers, and communities?</li><li>• How will the CIE solicit and sustain the consent of its community for data about the community to be extracted, used, and governed – especially for policy making and resource allocation?</li></ul>
Person Identity Management System	<ul style="list-style-type: none"><li>• Are there already existing identity-matching infrastructures that might be available for use by a CIE, such as a regional HIE’s Person Identity Management system?</li><li>• How can CIEs evaluate identity matching frameworks across care management systems with a minimally viable set of fields and processes (name, DOB, etc.)?</li><li>• How will the CIE monitor for, address and redress instances of false negatives (failure to match an individual’s existing records, resulting in duplicates) and false positives (incorrectly matched individuals)?</li><li>• Which priority local, statewide, and/or national data systems does the CIE want to be able to integrate with through the creation of a shared person identifier?</li></ul>
Terminology Management	<ul style="list-style-type: none"><li>• Are there already existing terminology standards for social risks and needs, diagnoses, interventions, and goals that can tell a comprehensive story about a person’s condition?</li></ul>

## DRAFT Discussion Questions

*The following discussion questions are the outcome of various conversations regarding the technical components of the CIE system and by no means constitute a comprehensive or all-encompassing guide. Rather, this table should be used as a “living document” to continue to add questions to over time as the Workgroup meets.*

	<ul style="list-style-type: none"><li>• How will a CIE foster semantic interoperability (via shared taxonomies and vocabularies) for data about types of people and situations stored in its systems?</li><li>• How will the CIE use existing standardized taxonomies (e.g., LOINC, SNOMED, ICD-10, etc.), and how will these terminologies be locally adapted to reflect the needs and culture of the community?</li><li>• To what extent will the CIE’s strategy depend upon processes of translation, alignment, and clarification across a diverse landscape of service provision?</li><li>• How will a CIE establish methods by which stakeholders – primarily service providers and service users – can participate in these processes of vocabulary definition and alignment?</li><li>• How will stakeholders be able to challenge and improve the formulation and application of terminology about themselves?</li><li>• What are the “minimally viable” protocols and processes that will enable exchange of data about patients across platforms and sectors?</li><li>• What are some of the use cases that the CIE’s features and functionality may want to leverage local and/or industry standard vocabularies?</li></ul>
Universal Social Risk Assessment Tools	<i>TBD</i>
Resource Directory Management	<ul style="list-style-type: none"><li>• Who should be responsible for ensuring the accuracy of resource data in the CIE, and how can these efforts be sustained?</li><li>• What role should service providers, and funders of services, play in resource data management?</li><li>• How will data stewardship be delegated and sustained?</li><li>• How can multiple, subjective vocabularies (such as service taxonomies) be aligned around shared resource data?</li></ul>
Closed-Loop Referral System	<ul style="list-style-type: none"><li>• What is the workflow by which healthcare and social services providers would want to create a referral through the CIE, and would this process include the ability to close the referral?</li><li>• What does the workflow look like for providers that are in the CIE network versus those that are not?</li><li>• How does the referral system interact with and rely on the resource directory?</li><li>• How will the CIE facilitate access to information about resources that ‘don’t fit’ within the conceptual box of ‘closed-loop referrals’?</li><li>• To what extent do various stakeholder groups ‘want to have’ as opposed to ‘need to have’ loops closed?</li></ul>

### **DRAFT Discussion Questions**

*The following discussion questions are the outcome of various conversations regarding the technical components of the CIE system and by no means constitute a comprehensive or all-encompassing guide. Rather, this table should be used as a “living document” to continue to add questions to over time as the Workgroup meets.*

	<ul style="list-style-type: none"><li>• What kinds of activities other than ‘warm referral’ and ‘loop closing’ might improve social equity and health outcomes in a community if facilitated through cross-platform data exchange?</li><li>• What role-based permissions come into play for CIE providers who want to view certain information about their client’s referral history?</li><li>• Is the referral information tracked through the CIE translated into a series of data entries into a broader database that can be mined and analyzed?</li></ul>
Longitudinal Health Record	<ul style="list-style-type: none"><li>• What kind of information should be contained in a person’s longitudinal health record?</li><li>• How would this information be received from participating CIE healthcare and social services providers?</li><li>• Who would be able to access a person’s longitudinal health records – and when and in what circumstances would this access be acceptable?</li><li>• What types of user roles should be developed in the CIE system to support “minimal viable” viewing of persons’ longitudinal health records?</li></ul>
Analytics & Reporting	<i>TBD</i>
Downloads & Exports	<i>TBD</i>
Help Desk Support	<i>TBD</i>
Auditing Functions	<i>TBD</i>
Training & Education	<i>TBD</i>
User Interface Design and Workflow	<i>TBD</i>

## **APPENDIX F**

### **Advisory Group Charters**

#### **Community Advisory Committee Charter**



General	
<b>Project Name:</b>	Community Information Exchange (CIE) Phase II <b>Community Advisory Committee</b>
<b>Project Sponsor:</b>	MCOA/MeHAF
<b>Workgroup Co-Chairs:</b>	TBD
<b>Phase II Time Frame</b>	September 2022 – April 30, 2023
<b>Date Charter Approved</b> CIE Steering Committee	

<p>• <b><u>Background</u></b></p> <p>In 2020, a series of discussions were convened with a broad group of stakeholders to learn about CIEs – tools and approaches used in other states to share person-level information and make referrals between healthcare and social services providers. These discussions led to the creation of a working group of volunteers from the stakeholders to create a shared vision and begin laying the foundations of a Maine CIE. The goal of a CIE, as developed by this group, is to better health and well-being through improved information, referral, and coordination. To accomplish this goal, the group agreed that functionality of a CIE should generally include:</p> <ul style="list-style-type: none"> <li>• A shared, longitudinal health record that spans clinical and community settings</li> <li>• The ability to collect health related social needs (HRSN) information (a common language and understanding of the HRSN), as well as social risks information and the ability to compile and share this information individually (with permission) and in the aggregate.</li> <li>• A resource directory that is maintained with up-to-date information. The ability to meaningfully refer individuals seeking assistance to providers of health and social services using an interactive platform that allows for real-time and asynchronous communication, to determine if the referral was accepted and if the services were delivered based on information provided by the provider and/or the seeker of assistance. Equally important is the ability to understand why the referral was not accepted, or the services were not delivered, or not delivered satisfactorily.</li> <li>• The ability to analyze results and take action to improve care coordination for patients, make the best use of resources within health and social services organizations, address unmet need in communities and increase health equity throughout the state.</li> </ul> <p>The Maine Council on Aging (MCOA) has agreed to act as a neutral convener and to oversee Project. The Maine Health Access Foundation (MeHaf) is the sponsor for the Project.</p> <p>• <b><u>Project</u></b></p> <p>With the support from Project Coordinators, Sarah Taylor and Jeff Brown, Safer Healthcare, LLC, the work of the Project will be completed by a Steering Committee (SC) made up of volunteers who were participants of the initial workgroup. The membership will be balanced between governmental, community based social services, healthcare providers, and consumers/community leaders. This will be the decision-making body. The SC, along with the Project Coordinators, will support the work of three workgroups: 1) Governance, 2) Policy &amp; Legal, 3) Data &amp; Technology (“Workgroups”). Each of these Workgroups will develop a plan to address each of the technical component areas needed for a</p>

functional CIE. The SC will be responsible for reviewing and advising regarding capital and operational costs associated with a CIE.

To ensure that network providers and consumers are integrated into the plans for the CIE, two advisory committees will be formed: the Community Advisory Committee and the Network Provider Advisory Committee.

## **GOAL**

The **Community Advisory Committee** will help ensure that the voice of the consumer is integrated into the development and planning of the Maine CIE.

## **SHARED VALUES**

- *Maine CIE should facilitate the responsible flow of Information; data sharing choice is specific and clear; for what purpose and with whom*
- *The Community Advisory Committee represents consumers as key stakeholders of the Maine CIE.*
- *The Community Advisory Committee will develop questions, based on input from consumers, that will be shared with the CIE workgroups and the CIE Steering Committee.*
- *The Community Advisory Committee will use its best efforts to highlight consumer questions and concerns related to the Maine CIE.*
- *Clients/patients own their own information; the CIE facilitates accountable sharing of information*

## **SCOPE & DEFINITIONS**

The following represents some of the issues/questions that the Community Advisory Committee will consider when providing feedback for each of the CIE Workgroups

**Governance Workgroup** – the Governance Workgroup will define the governing structures, policy preview and authority of the CIE Network.

Considerations include:

- What data should be collected in the first place, according to whose interests and under what oversight?
- How are the CIE policies designed, implemented, monitored and enforced?
- How will the community's interests and concerns be addressed?
- How will clients' rights be protected?
- How will the community be represented?
- How will policymaking take place?
- How will conflicts be addressed and resolved?
- How is data collected, used over time and when it should be destroyed?
- Who has rights to access which kinds of data, and for how long?
- How will data be protected, what happens if data is breached?
- What data should be collected in the first place, according to whose interests and under what oversight?
- How will aggregated data be used and how will the communities' related interests be incorporated in this decision?

**Legal & Policy Workgroup** – The Legal & Policy Workgroup will help define elements of consent documents that allow the sharing of consumers based on the consumer's wishes; review legal and regulatory compliance related to the sharing of personal information, including health information; and track federal and state regulations that may impact the Maine CIE.

Considerations include:

- How will consumer rights to privacy regarding the sharing and use of their personal information be protected?
- When and how will consumers have the opportunity to limit use of their personal information?
- How will consent documents be communicated to consumers? Will there be alternative means of communicating the content of consent documents for consumers who may have reading comprehension challenges or for whom English is not their primary language?
- How will the CIE ensure that providers (health care and community based organizations) are adequately informing their patients/consumers of their privacy rights?
- What legislative action may be necessary to help support Maine's CIE?
- How will the CIE ensure that all consumers are treated with dignity and respect?

**Data & Technology Workgroup** – the Data & Technology Workgroup will be responsible for technology and technical components of the CIE, such as infrastructure & environment configuration; interoperability; person consent management; person identity management; resource directory management; closed-loop referral system; longitudinal health record; data analytics and reporting.

Considerations include:

- What kinds of activities should require users to actively agree to 'opt in' and what kinds of activities should merely offer an option to 'opt out'? Should these decisions be associated with different levels of permissiveness and sensitivity of the resulting data exchange and use?
- How can users retain specific control over what kinds of data they do or do not agree to share, with whom, and for what purpose?
- How will the CIE ensure that users are presented with an appropriate amount of context to inform their decisions?
- How will the CIE ensure that consent is sustained over time and revocable as necessary?
- Should clients be able to change their data sharing relationship with their providers and associated institutions over time, or is consent/governance more of a global decision?
- How will the CIE address the entanglement between one person's data and data about other individuals in primary, secondary and tertiary relationship with them?
- How will consent to share be ethically managed among a connected cohort of individuals, families, caregivers and communities?
- How will the CIE solicit and sustain the consent of its community for data about the community to be extracted, used and governed – especially for policy making and resource allocation?
- How will the CIE monitor for, address and redress instances of false negatives (failure to match an individual's existing records, resulting in duplicates) and false positives (incorrectly matched individuals)?
- What kind of information should be contained in a person's longitudinal health record?
- How would this information be received from participating CIE healthcare and social services providers?
- Who would be able to access persons' longitudinal health records – and when and in what circumstances would this access be acceptable?

<b>Project Scope</b>
<p><b>Assumptions:</b></p> <p>The Steering Committee trusts the Community Advisory Committee to assist the three CIE workgroups in addressing key considerations of consumers in developing the Maine CIE.</p> <ul style="list-style-type: none"> <li>• The Community Advisory Committee members consist of the necessary stakeholders that are capable of representing themselves and other consumers in helping the CIE workgroups understand the needs/wants of consumers related to CIE activities.</li> <li>• The Community Advisory Committee is committed to routine and frequent meetings to complete its desired deliverables in a timely manner.</li> <li>• The Community Advisory Committee is able to define a decision-making and consensus process among its members such that progress is not stalled by disagreement or hesitancy among a minority of members.</li> <li>• Compliance with state and federal regulations regarding privacy and data sharing</li> </ul> <p><b>Constraints:</b></p> <ul style="list-style-type: none"> <li>❖Phase II needs to be completed by April 30, 2023.</li> </ul> <p><b>Out of Scope:</b> [What will be excluded from this project?]</p> <ul style="list-style-type: none"> <li>❖Detailed modeling of governance elements not implemented or planned in the next 12 months</li> <li>❖Draft Bylaws, Articles of Incorporation, Application for tax exempt status</li> </ul>

<b>High-Level Project Risks</b>
<p>Healthcare systems, community-based organizations, and community members have different resources for accessing and utilizing technology and data systems. The CIE will need to ensure all stakeholder voices are represented and have appropriate input.</p> <p>Individuals’ data is often entwined with that of family members, caregivers, and others in their community: one person’s consent to share information about their own self status might affect others in the household without providing any methods by which those others can themselves consent.</p> <p>The challenge of ethical management of consent for data sharing – especially through systems that integrate across institution and technological boundaries – is particularly difficult. There is near universal agreement that clients should have control over what information is shared with whom and in what context, but there is no broad understanding of the tradeoffs and tensions that make it difficult or even impossible to fully uphold such a principle.</p> <p>There are real and near-term prospective costs for social service providers to adapt their processes in order to engage in a CIE (even if the software being offered to them is free).</p> <p>There is likely to be an imbalance in incentive structures (as well as power) between healthcare providers and social services providers in the CIE’s development, and perhaps also among larger and smaller social service providers.</p> <p>Data sharing agreements frequently do not address the use of metadata, anonymized aggregated data, and algorithmic processes that may be applied in unanticipated ways, sometimes with harmful effects.</p> <p>While data standards for healthcare providers are established through HIPAA (privacy and security of PHI), data standards are scarce within and across social services sectors.</p> <p>Ensuring clients are presented with appropriate language and context to inform their consent decisions. If a multi-page ‘Terms of Service’ presents too much information or in language that the client does not understand, how will the CIE strike the appropriate balance between transparency and user-friendliness?</p>
<b>Stakeholders &amp; Affected Business Areas</b>
Individuals seeking care/services; healthcare providers; social service providers, communities
<b>Core Team Members</b>
Seeking team members with interest in representing consumers in this Advisory Committee.

## Network Provider Advisory Group Charter

<b>Project Name:</b>	Community Information Exchange (CIE) Phase II <b>Network Provider Advisory Committee</b>
<b>Project Sponsor:</b>	MCOA/MeHAF
<b>Workgroup Co-Chairs:</b>	TBD
<b>Phase II Time Frame</b>	September 2022 – April 30, 2023
<b>Date Charter Approved</b> CIE Steering Committee	
<b>Assumptions:</b> <ul style="list-style-type: none"> <li>• The Steering Committee trusts the Community Advisory Committee to assist the three CIE Workgroups in addressing key considerations of consumers in developing the Maine CIE.</li> <li>• The Community Advisory Committee members consist of the necessary stakeholders who are capable of representing themselves and other consumers in helping the CIE Workgroups understand the needs/wants of consumers related to CIE activities.</li> <li>• The Community Advisory Committee is committed to routine and frequent meetings.</li> <li>• The Community Advisory Committee is able to define a decision-making and consensus process among its members such that progress is not stalled by disagreement or hesitancy among a minority of members.</li> </ul> <b>Limitations:</b> <p>The Community Advisory Committee will provide recommendations and feedback to the CIE Steering Committee and the CIE Steering Committee will have the final decision-making authority.</p> <p>Phase II will be completed by April 30, 2023. Further phases will be dependent upon funding and available resources.</p>	

<b>High-Level CIE Project Risks</b>
<p>Healthcare systems, community-based organizations, and community members have different resources for accessing and utilizing technology and data systems. The CIE will need to ensure all stakeholder voices are represented and have appropriate input.</p> <p>Individuals' data is often entwined with that of family members, caregivers, and others in their community: one person's consent to share information about their own self status might affect others in the household without providing any methods by which those others can themselves consent.</p> <p>The challenge of ethical management of consent for data sharing – especially through systems that integrate across institution and technological boundaries – is particularly difficult. There is near universal agreement that clients should have control over what information is shared with whom and in what context, but there is no broad understanding of the tradeoffs and tensions that make it difficult or even impossible to fully uphold such a principle.</p> <p>There are real and near-term prospective costs for social service providers to adapt their processes in order to engage in a CIE (even if the software being offered to them is free).</p> <p>There is likely to be an imbalance in incentive structures (as well as power) between healthcare providers and social services providers in the CIE's development, and perhaps also among larger and smaller social service providers.</p> <p>Data sharing agreements frequently do not address the use of metadata, anonymized aggregated data, and algorithmic processes that may be applied in unanticipated ways, sometimes with harmful effects.</p> <p>While data standards for healthcare providers are established through HIPAA (privacy and security of PHI), data standards are scarce within and across social services sectors.</p> <p>Ensuring clients are presented with appropriate language and context to inform their consent decisions. If a multi-page 'Terms of Service' presents too much information or in language that the client does not understand, how will the CIE strike the appropriate balance between transparency and user-friendliness?</p>
<b>Stakeholders &amp; Affected Business Areas</b>
Individuals seeking care/services; healthcare providers; social service providers, communities
<b>Core Team Members</b>
To be determined.

## APPENDIX G (1)

# Maine CIE Governance Workgroup Summary

## Background

Between 2020 and 2022, a group of stakeholders held a series of meetings to explore the concept of a Community Information Exchange (CIE) and whether a CIE would benefit the citizens of Maine. The work of this group was outlined in the document, *Maine Community Information Exchange: Current Status and Next Steps*. A shared vision for a Maine CIE was defined in this Phase I as “better health and well-being through information, referrals, and coordination. This Maine CIE vision would shift away from a reactive Better health and Well-being through information, referrals, and coordination. This Maine CIE vision would shift away from a reactive approach to a proactive approach to provide person-centered care.”

In May 2022, Phase II of the Maine CIE Project was launched. As part of Phase II, three workgroups were developed.

## Getting Started

Governance Workgroup membership included representatives from Northern Light Health, Disability Rights Maine, Maine Council on Aging, Seniors Plus, Greater Portland Health and Neptune Consulting. The Governance Workgroup’s goal was to develop a plan to illustrate and articulate the governance requirements for a functional CIE, including recommendations for the phased (timing) implementation of key CIE governance elements.

This group developed a charter that included the following Shared Values:

- *A CIE’s governance should be designed to build and carefully preserve trust, with inclusive methods for participation of key stakeholders (service providers, help-seekers, and the collective interests of the CIE Network community)*
- *The CIE Network should be locally owned and managed collaboratively by the community; not by one organization, platform, or group.*
- *A neutral community-based governance structure will sustain an inclusive, transparent, intentionally equitable and sustainable network.*
- *The strongest governance structures are simple, effective, adaptable, and accountable to the common shared goals of the network.*

The Governance Workgroup Charter outlined four main deliverables:

5. Governance Model – defining desired (future state) governance structures, interdependencies, authority, and functional responsibilities
  - c. Community Advisory Committee
  - d. Network Provider Advisory Committee
6. Governance Road Map – proposed timing and sequence for developing and operationalizing key governance elements



7. Budget Considerations – estimated resource requirements to launch and maintain governance elements
8. Next Steps – defining Phase III Governance priorities (2023/2024)

## **Governance Model**

### Advisory Committees

A main focus of the Governance Workgroup was developing the two Advisory Committees, with a prioritization of the Community Advisory Committee. The Workgroup reviewed organizational engagement elements from seven different community organizations, including San Diego 211. The Workgroup emphasized the need to include those groups that have, historically, been under-represented, for example, those who are homeless, those with disabilities, new Mainers, members of the LGBTQ+ community and older adults. They also identified the need for geographical diversity, ensuring that the needs/wants of rural communities are represented. Recommendations to the Steering Committee regarding the Advisory Committees are as follows:

- The Steering Committee would develop some initial operating principles for the Advisory Committees but allow the Advisory Committees to further develop their own operating principles.
- There should eventually be representation from the Advisory Committees on each of the Workgroups and the Steering Committee. This will help develop leadership and will keep the CIE community-focused and community-driven.
- A member or members of the Steering Committee and the three Workgroups will help convene the Advisory Committees, but the Advisory Committees will choose a chair and there will be a transition of power and authority to the Advisory Committees.
- Community Advisory Committee membership should include representatives from diverse racial and ethnic backgrounds
- Advisory Committee membership should include individuals and organization living and working in 'remote rural' and island communities as part of its geographic diversity
- Advisory Committee membership should include people with lived experience as well as advocates or those who serve people with lived experience
- The Advisory Committees will become informed of and educated about the CIE and how it functions.
- The Advisory Committees will be encouraged to ask questions of the Workgroups and Steering Committee.
- In the early-stage planning, Advisory Committees would meet at least quarterly, with ad hoc meetings scheduled, as necessary. The Advisory Committees would eventually determine the frequency of meetings once the Committees are established
- Term limits for Advisory Committee members would be identified once the Advisory Committees are established
- There would be up to fifteen members for each Advisory Committee
- Membership – Governance Workgroup will make recommendations for initial membership of the Advisory Committees to the Steering Committee, who will ultimately determine the Advisory Committee membership. This will be the same process for replacement of

Advisory Committee members initially. Once the Advisory Committee is established, they will make recommendations to the SC about replacement of members.

Draft Charters for both the Community and Network Provider Advisory Committees were presented to the Steering Committee, along with draft Roles and Responsibilities documents for each committee.

The Governance Workgroup presented potential Advisory Committee members to the Steering Committee. The Community Advisory Committee recommendations for membership were targeted for three groups: advocacy group representatives, consumers with lived experience and representatives from underserved populations. The Network Provider Committee membership would include representatives from healthcare, community-based organizations, and others, such as professional associations.

Although the Governance Workgroup had recommended having initial meetings for both Advisory Committees early in 2023, the Steering Committee finally determined to conduct information sessions for community members and later for network provider members. The rationale was that it would not make sense to convene advisory committees for only a brief period of time and funding for Phase III has not been identified. The Community Information Session was held on May 22, with representatives from Piscataquis Regional Food Center, Equality Maine, Waldo CAP, Community Connect Maine, Mid Coast Hunger Prevention Program, Cross Cultural Community Services, Elder Abuse Institute of Maine, Maine Access Immigration Network, Maine Transnet, and a consumer.

The agenda for the Information Session included a description of a CIE, what it is and what it does; the history of the Maine CIE Project; the status of the Maine CIE Project to date (including a description of the longitudinal health record); the next phase of the CIE; and an open question and answer section. A post-presentation survey was conducted with the following results:

- 100% either agreed or strongly agreed that they understand the purpose and goals of the Maine CIE
- 92% either agreed or strongly agreed that they see the value of the CIE for themselves or other community members
- 100% either agreed or strongly agreed that including community members in planning and oversight of the CIE is important
- 93% either agreed or strongly agreed that their questions were answered.
- 4 participants expressed interest in being more involved with the Maine CIE Project.

All those who had been invited to the Community Information Session received an audio recording of the session and those who were unable to participate were offered an opportunity to complete the post-presentation survey.

The Governance Workgroup is recommending to the Steering Committee that the Network Provider Information Session be held in September. The summary of the work done through June 2023 will be completed, and there may be more information about Phase III at that time. A draft agenda and a list of recommended invitees has been presented to the Steering Committee.

### Governance Structure Phase III

A presentation of three governance structure models was presented to the Steering Committee by the Governance Workgroup:

Model 1 “Owner-Operator” Create a vertically integrated CIE Nonprofit, establish the needed structures, process, and practices under a single entity, hire and manage staff

Model 2 “Outsource” Turn over governance and operational functions to an existing Nonprofit entity (or consortium) with shared values and the appropriate structures, process, and practices ready to govern and operate the CIE

Model 3 “Hybrid” Establish good governance, contract for operational excellence. Create a new CIE nonprofit entity, board, and brand. Leverage existing structural and operational capacity of a core backbone partner (and sub-contractors as needed)

The Steering Committee felt that the Hybrid model was the most advantageous for the Maine CIE governance structure. A more detailed governance structure, including a Steering Committee, Workgroups and Advisory Committees will be determined once a core backbone partner has been identified.

### Organization Partnership Options

A meeting was held on June 8 with members of the CIE Steering Committee and representatives from HealthInfoNet (HIN), Shawn Alfreds and Chad MacLeod. HIN presented information about the formation of HIN; which included participation of Health systems, payers, State representatives and MeHaf came together to form the HIE. They raised \$6M in funding for the implementation phase. It was determined that there should be an independent entity to oversee and operate the HIE, and HIN fills this role. This allows for neutrality and inclusiveness of the community. HIN is the state-authorized health information exchange for Maine.

Other information about HIN operations was also shared.

- The HIN Board of Directors is very engaged. The concept of a CIE aligns with the HIN mission and vision. The HIN Health Data Equity Plan link was shared ( [Health Equity - HealthInfoNet](#)).
- HIN is looking to bring on CBOs who could be participating partners in HIN. Currently HIN works with CBOs that are covered entities and compliant with HIPAA.
- HIN could help facilitate closed loop referrals and a directory of services through its structure.
- End-user services include a clinical portal that can be used by clinicians, a help desk, and an auditing function.
- HIN offers notification of the provision of services in real-time, alerting providers of time-sensitive information.

- The Analytics and Reporting Platform can be used to track organizational performance, identify population risks, and track 30-day readmission risks.
- The HIN consent process has both opt-in and opt-out options. HIN is managing the consent options and the consent is between the individual and HIN. However, the participating providers are required to educate patients about the consent options at least once in their interactions with patients. The opt-in model is global and allows for the use and disclosure of all information within HIE. Patient can opt-out of this or revoke the opt-in at any time. There are also opt-out choices for sensitive information – behavioral health and HIV/AIDS.
- HIN has an engagement team and an education team who help in bringing on providers and helping them

CIE specific discussion: how can HIN and CIE align their respective efforts? It was suggested by HIN that it might be helpful to engage in a Use Case for a pilot project that is actionable and measurable. This could help address nuances related to the CIE.

It was agreed that further discussion of the possibility of a CIE/HIN alignment was needed.

**Governance Road Map** – proposed timing and sequence for developing and operationalizing key governance elements.

The CIE Steering Committee will be meeting in early September 2023 to discuss next steps for the CIE, including Phase III. Governance decision points to be made include:

- Formation of a legal entity for the CIE to formally identify the Maine CIE as a legal entity, to facilitate discussions with possible partners, to engage in contract negotiations, to apply for grants.
  - For profit LLC versus Nonprofit corporation
  - Maine requirements for corporations
    - Members
    - Identify registered agent
    - Articles of Incorporation
    - Bylaws
- Determine governance structure for the CIE
  - Steering Committee – review membership and identify potential new SC members
  - Workgroups – determine whether to have workgroups or to have subcommittees of the SC
  - Advisory Committees
    - Initiate Community and Network Provider Advisory Committees
    - Include Advisory Committee representatives on SC and subgroups
- Identify possible entities to become the backbone organization for the CIE and how to engage with these entities.

**Budget Considerations** – estimated resource requirements to launch and maintain governance elements.

Operating expenses and potential revenue sources will be driven, in large part, upon the governance structure and backbone organization. A pro forma template was developed and shared with the Governance Workgroup.

## **Financial Sustainability**

### Operating costs:

- **Convening costs** – costs to support the work of the Steering Committee and Workgroups. To date, this support has been provided by consultants. Consideration should be given to employing staff to support the CIE. This will be dependent upon the governance structure of the CIE and potential backbone organization support. Staffing costs will include labor costs, benefits, workers' compensation insurance, and other related expenditures. Additionally, staff would need to be provided with appropriate equipment, including computers, phones, supplies and workspace. To the extent that staffing and related resources can be provided by a backbone organization, this would be beneficial to the CIE. Additional convening expenses may include stipends for Community Advisory Committee members.
- **Legal counsel** – legal counsel will be required to develop contracts and agreements. Initial legal consultation will be necessary to develop contracts with potential partners. Further review of the work of the Legal and Policy Workgroup related to compliance with federal and State regulations, development of the various types of contracts/agreements between the CIE and its participating providers, and consents processes will all require legal review and oversight.
- **Costs to incorporate** – if the CIE follows the Hybrid model governance structure, formation of a limited liability corporation will be required. If the CIE wishes to gain not-for-profit status, additional costs will be associated with start-up and ongoing fees related to the 501(c)(3) status.
- **Technology costs** – it is difficult to estimate the costs of technology until a vendor for the longitudinal health record has been identified. It is anticipated that this vendor will have additional costs associated with the CIE that will have to be funded.
- **As the CIE matures**, it will be important to have a presence on social media. The CIE will need to develop and maintain a website. Website design costs should be included in budget considerations as well as website management.
- **Other potential expenses** would include costs associated with meetings/conferences (the CIE Summit), and other materials for training/education.

### Sources of Funding

Funding for the CIE is one of the most critical issues that will need to be addressed prior to Phase III. Funding sources to be considered include:

One time or limited time funding – grants. Grants may be available for planning purposes or specific initiatives and do not need to be repaid. Many grants require that the receiving grantee be a not-for-profit organization. Until such time as the CIE becomes a not-for-profit entity it will have to find a not-for-profit organization to file grant applications and be the holder of the grant funds.

Revenue generated for services rendered – this could include participation fees for CIE participating providers, membership fees, or contracts for developing data/reports. One important consideration with regard to fees is the potential barrier to smaller CBOs who may not have the resources to pay for membership or participation fees.

Public appropriations – this would include funds appropriated by State government and allocated according to the impact on health and healthcare costs. This would likely require legislative support but could also be funded through some federal dollars through a MaineCare waiver.

Investments by health systems and/or third-party payors – initial start-up costs could be funded through investments by larger health systems and/or third-party payors if a compelling demonstration could be developed to show how the CIE would impact the costs of healthcare.

### **Next Steps – Defining Phase III Governance Priorities**

Phase II tasks yet to be completed – addressing key governance elements for the following:

- Network/Institutional Governance - defining the governing structures, policy purview and authority of the CIE Network.
- Administrative Governance - includes the operational structure(s), purview and authority of agency(s) engaged by the CIE with delegated authority to carry out the day-to-day operations of the CIE Network.
- Data Governance – intersects with Data & Technology and Legal & Policy Workgroups and addresses the standards by which the CIE Network (and its Administrative Agents) will steward and manage the availability, usability, integrity, and security of the data exchanged. Data governance flows from administrative governance.

Draft Governance priorities for Phase III – this will include sharing these with the other Workgroups and Steering Committee before finalizing them. Considerations include:

- Finalizing governance model for the CIE – form legal CIE entity required to enter into contracts/agreements and to seek funding
- Define governance structure for Phase III – Steering Committee, Workgroups, and Advisory Committees – this will depend, in part, on a backbone organization and whether that entity already has appropriate governance structures that will support the CIE
- Combining the Legal and Policy Workgroup with the Governance Workgroup to align the legal, policy and governance work
- Develop the principles and requirements for CIE partnership
- Determining desired relationship with HealthInfoNet and finalize alignment
- Identifying potential partners and working with the Steering Committee to engage these potential partners in discussions related to providing functional aspects of CIE operations

- Identifying possible legislative supporters for the CIE and drafting legislation to have formal State support of the CIE and possible funding
- Refine the budget and resource requirements
- Explore and secure funding options
- Engage in Use Case pilot project

## **APPENDIX G (2)**

### **Legal and Policy Workgroup**

#### **Executive Summary**

##### **Background**

Between 2020 and 2022, a group of stakeholders held a series of meetings to explore the concept of a Community Information Exchange (CIE) and whether a CIE would benefit the citizens of Maine. The work of this group was outlined in the document, *Maine Community Information Exchange: Current Status and Next Steps*. A shared vision for a Maine CIE was defined in this Phase I as “better health and well-being through information, referrals, and coordination. This Maine CIE vision would shift away from a reactive Better health and Well-being through information, referrals, and coordination. This Maine CIE vision would shift away from a reactive approach to a proactive approach to provide person-centered care.”

In May 2022, Phase II of the Maine CIE Project was launched. As part of Phase II, three workgroups were developed. The Legal and Policy Workgroup was charged with:

- Helping to identify any government action or policy initiatives that are enacted or needed that are relevant to the Maine CIE efforts.
- Reviewing legal considerations for data sharing, security and risk, and patient consent models.
- Ensuring that the patient’s voice is included in defining the Maine CIE’s patient consent model.

##### **Getting Started**

The Legal and Policy Workgroup membership included representatives from MaineHealth, Northern Light, HealthInfoNet, Disability Rights Maine, Community Caring Cooperative, the Office of MaineCare Services, and the Maine DHHS Office of Behavioral Health. This group developed a charter that included the following Shared Values:

- Maine CIE is a collaborative network inclusive of trusted public and private sector partners
- Maine CIE will require public policy innovation and support at both state and federal levels
- Respecting the privacy and agency of individuals; individuals choose to share their information or not
- Maine CIE should facilitate the responsible flow of information; data sharing choice is specific and clear; for what purpose and with whom

- Clients/patients own their own information; the CIE facilitates accountable sharing of information

The Legal and Policy Workgroup Charter outlined five main deliverables:

1. Legal & Public Policy Plan - outlining the planning process, recommendations, opportunities, challenges, and next steps to address the legal and public policy requirements of a Maine CIE model as defined by the Steering Committee and Workgroups.
2. Timeline & Road Map – proposed timing and sequence for developing and operationalizing key legal and public policy elements and identified timeline overlaps with both the Governance and Data and Technology Workgroup’s plans.
3. Resource Considerations – identify the resource requirements to launch and maintain legal & policy functions in a Maine CIE.
4. Next Steps – defining Phase III legal and public policy priorities (2023/2024)
  - Identified Maine statute challenges and make recommendations for changes.
  - Outstanding formal legal analysis of the Legal and Policy Workgroup’s deliverable reports for recommendations for Phase III.
  - A list of documents and processes that will require legal and operative final review and approval for CIE implementation.
5. Model CIE Legal Agreements – examples of model data sharing agreements, patient consent models.

The Legal and Policy Workgroup used several resources in conducting its work. The San Diego 211 CIE Toolkit ([Toolkit - CIE San Diego](#)) was invaluable. Another resource referenced was [Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration](#) created by Actionable Intelligence for Social Policy (AISP) ([Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration – Actionable Intelligence for Social Policy \(upenn.edu\)](#)). This document helped form the Workgroup’s thinking about how to address legal considerations in establishing the cross-sector data integration necessary for a CIE. AISP outlined the following assumptions:

- There are risks and benefits to sharing and integrating data that must be carefully considered
- The legality of data integration depends on the specifics of data access and use
- Not only must data integration be legal, but it must also be ethical and a good idea
- Ethical use is context specific and requires strong data governance and legal frameworks

AISP also poses four questions for determining how data integration will occur:

- Is it legal?
- Is it ethical?
- Is it a good idea?
- Who decides?

The Legal and Policy Workgroup (Workgroup) has based its work on answering these questions.



## **Is It Legal?**

### **Legal & Policy Impacts on the Implementation of a Full CIE**

Values identified in the Legal and Policy Workgroup Charter relate to respecting the privacy of individuals, the ability for individuals to choose when and with whom to share their personal information, and the CIE's responsibility to facilitate a responsible and accountable flow of information. The first step in ensuring that the CIE supports these values is to review the legal considerations:

- What legal authority is in place to use these data?
- Are there federal or state statutes that prevent or constrain this data access or use?
- What are the particular state and federal law requirements enabling data sharing?

### **Legal Review**

The Workgroup's first tasks included identifying and reviewing federal regulations and Maine statutes related to privacy and confidentiality of personal information.

The Workgroup reviewed the following Federal regulations:

- Health Insurance Portability and Accountability Act (HIPAA)– requires 'covered entities' to protect the privacy and confidentiality of patients' protected health information (PHI) and stipulates security measures that must be taken to prevent PHI from being unlawfully obtained.
- Health Information Technology for Economic and Clinical Health Act (HITECH) - the HITECH Act strengthened the HIPAA Privacy and Security Rules, required Business Associates to comply with the HIPAA Security Rule, and introduced the Breach Notification Rule
- CARES Act – proposed rulemaking to bring requirements for Part 2 (Substance Use Disorder treatment) in line with the HIPAA requirements for other PHI.
- CURES Act - is designed to give patients and their healthcare providers secure access to health information.
- Family Education Rights and Privacy Act (FERPA) protects the privacy of student education records and gives parents certain rights with respect to their children's education records.
- Homeless Management Information System (HMIS) is a local information technology system used to collect client-level data and data on the provision of housing and services to homeless individuals and families and persons at risk of homelessness
- Supplemental Nutrition Assistance Program (SNAP) The SNAP Policy Database provides a central data source for information on State policy options in the SNAP.

- Violence Against Women Act (VAWA) requires all grantees and subgrantees receiving VAWA funding from the Department of Justice, Office on Violence Against Women, to protect the confidentiality and privacy of persons to whom those grantees and subgrantees are providing services

- Sections of the Social Security Act Other federal regulations reviewed included, Title IV Grants to States for Federal Aid to Needy Families with Children and to Child Welfare Services; Title IV B Child and Family Services; Title IV E Federal Payments for Foster Care, Prevention and Permanency; Title XVI Supplemental Security Income for the Aged, Blind and Disabled; and Title XX Block Grants for Social Services and Elder Justice.

The Workgroup reviewed the following Maine statutes:

- MRSA Title 34-B Confidentiality of information – Behavioral Health - All orders of commitment, medical and administrative records, applications and reports, and facts contained in them pertaining to any client shall be kept confidential and may not be disclosed by any person. A client or client’s legal guardian may give informed written consent to the disclosure of information.

- MRSA Title 22 Confidentiality General Medical Information An individual's health care information is confidential and may not be disclosed other than to the individual by the health care practitioner or facility. A patient may authorize disclosure of their information and may revoke the authorization at any time.

- MRSA Title 10 Notice of Risk to Personal Data An information broker that maintains computerized data that includes personal information who becomes aware of a breach of security of its system is required to conduct prompt investigation to determine the likelihood that personal information has been or will be misused and to give notice of the breach

### **Analysis of the Impact of Regulations and Statutes on Managing Specially Protected Data in a CIE**

The Workgroup identified regulations and statutes that stipulate special protections for data/information use and disclosure that are relevant to CIE operations. These specially protected types of data/information are recognized as potentially stigmatizing to individuals experiencing these conditions and must be treated with care. Recognizing that the CIE is not a provider of care for these specially protected areas, the CIE should include language in its business associates’ agreement and/or participation agreements that require participating providers to comply with the regulations and statutes related to specially protected information. Specially protected information includes behavioral health information, substance use disorder information, HIV/AIDS testing, domestic violence, education records, homelessness, and sexual orientation/gender identity (SOGI).

### **In Process, State and Federal Regulatory Changes**

The privacy and confidentiality of personal information continues to receive considerable attention at both the Federal and the State level. The Workgroup reviewed work being done

across the country related to states' initiatives to protect the privacy and confidentiality of information. Additionally, the Workgroup reviewed the following federal and state initiatives that may have an impact on the CIE: LD 1902, An Act to Protect Personal Health Data; LD 1792 – Resolve, Establish Rural Health Services Task Force; **HIPAA Privacy Rule and Reproductive Health Care; Section 3221 of the CARES Act; HITECH RFI (Recognized Security Practices and Civil Money Penalties and Settlement Sharing); Notice of Public Rulemaking for HIPAA Privacy Rule and Care Coordination; and the American Data Privacy and Protection Act.**

**It will be important for the CIE to keep up to date with federal and state initiatives related to protecting data and information. While the proposed federal and state data protection initiatives that were reviewed may not pass in their current forms, given the attention that is being given nationally to protecting personal data/information, it is likely that more federal regulations and state statutes related to privacy and confidentiality of personal information will be forthcoming.**

### **Is it Ethical?**

As defined in the CIE Project Phase I, the Maine CIE vision would shift away from a reactive approach to a proactive approach to provide person-centered care. Additionally, the Legal and Policy Workgroup Charter's values include ensuring that Clients/patients own their own information; the CIE facilitates accountable sharing of information. In order to address these values, the Workgroup identified four key areas of concern: privacy, equity, transparency, and consumer-centered principles. Information regarding these areas of concern was gathered through review of the American Medical Association statement of Rights, the National Association of Social Workers Code of Ethics, and feedback from focus groups conducted by the Community Caring Collaborative in Washington County. Further considerations for the CIE related to the identified concerns are contained in the body of this report.

### **Privacy**

Privacy concerns identified in large part relate to information that is sensitive to the individual. Some of these sensitive types of information are protected with existing laws and regulations, addressed separately in the report, while other types of information may not be specifically governed by existing regulations, but are, nonetheless, of a sensitive nature, for example, history of justice involvement, person-specific attributes/conditions that involve embarrassment/shame for an individual, pain management treatment, sexual functioning, information that would trigger mandatory reporting; interaction with the welfare system; or work-related injuries.

Other areas of concern related to clients' lack the capacity to provide informed consent, and the importance of seeking permission from an appropriate third party, reluctance of the part of patients/clients to share information with a provider.

### **Equity**

There were a number of concerns related to equity, diversity, and inclusion. Equitable access to resources will require that consumers be presented with information in a way that is

understandable to everyone. This includes taking into account the diversity of literacy levels, cultures, and experience with or access to technology. English language learners and people with certain disabilities that may require special consideration. Failure to take into account the skills, abilities and unique circumstances of individuals who may use the CIE could result in barriers to its access and efficacy.

## **Transparency Concerns**

Transparency within the CIE functions is essential to building the trust necessary for individuals to feel comfortable with their providers, access of patients/clients to their own information, and the importance of using clear and understandable language when providers are talking with patients/clients.

## **Consumer Centric Principles**

Key issues related to consumer centric principles included the importance of a response to each referral that is made, equal treatment of all patients/clients, imbalance of advocacy leading to lack of awareness of resources, and failure to communicate with patients/clients.

## **Is it a Good Idea?**

AISP posits the following questions to

- What action can be taken as a result of this data use?
- What can reasonably be changed or improved based upon this analysis?
- Is this a priority among marginalized populations and/or individuals included in the data system?

These questions were addressed in Phase I of the Maine CIE Project and have continued to be discussed in Phase II. From the Legal and Policy Workgroup perspective, the information shared in the CIE for determining and making referrals to address the health and social needs of individuals is essential. The Data and Technology Workgroup has shared the data elements suggested for use in the CIE, and the Legal and Policy Workgroup has reviewed these data elements. Particular consideration of those data elements that include sensitive information and how best to protect this information from inadvertent sharing will require review of the technical safeguards that can be hard-wired into the CIE as well as policies, procedures and legal agreements that outline the responsibilities of network providers in educating patients/clients about consents.

This report points out the considerations for implementation of the CIE from a legal and ethical perspective. The Workgroup believes that the formation of the CIE will be an iterative process, and continued review of the CIE and its policies/procedures will be important. The inclusion of the voice of the consumer in oversight of the CIE, as well as ongoing discussions with network providers will be essential to the continuous process improvement approach to the CIE.

## **Who Gets to Decide?**

**Legal questions** – The Legal and Policy Workgroup has reviewed federal regulations and state statutes that we believe are the underpinning of the legal aspects of the CIE. However, as laypeople, we acknowledge the need for a formal legal review of this work. In particular, it will be important to have legal reviews of the various agreements and contracts that the CIE will have with participating providers, the Privacy Notice requirements, and consents to ensure that the CIE is in legal compliance with both federal and State requirements.

**Ethical questions** – The ethical considerations posed in this report will need to be considered by the Governance Workgroup, which will need to make recommendations to the CIE Steering Committee related to the four ethical areas reviewed: equity/diversity and inclusion, privacy, transparency, and consumer-centric principles. This will help drive the CIE policies, procedures and practices and will help inform content for legal agreements and contracts.

**Is it a good idea?** – The CIE Steering Committee will be responsible for determining if the CIE is prioritizing the needs of consumers, including underserved and marginalized populations; healthcare and CBO providers; and other stakeholders, such as local and state government agencies, third party payors, or other groups that may wish to use aggregated data and reports available from the CIE. The latter is of particular importance as there can be unintended negative consequences if aggregated data is used to disenfranchise segments of the communities served by the CIE. Some significant discussion is warranted by the Steering Committee related to the sharing of aggregated data and reports. Input from the Consumer Advisory Committee will be very important in this discussion.

### **Legal and Policy Next Steps for Phase III**

**Critical First Step-** Taking initial action on phase three steps requires that the CIE project either become a legal entity or shift the work to an existing legal entity.

**Formal Legal Analysis** - As noted above, formal analysis by legal counsel is a critical step in Phase III of the CIE Project and legal review will need to be an ongoing requirement of the CIE as federal and State regulations change, particularly as they relate to the privacy and confidentiality of personal information.

**Strategic Development of CIE Contracts and Agreements** – In the Appendices of this report, the Workgroup has included information about the types of contracts/agreements that will be necessary for the CIE. An outline of the elements of these contracts/agreements, as well as samples of the contracts/agreements are included in the Appendices. These include privacy notices, authorization for uses and disclosures of information, business associate agreements, CIE participation agreements, and quality service organization agreements.

**Strategic Partnerships** - A key precept of the CIE is that it does not duplicate efforts that are currently in place within the State. The Workgroup reviewed commercial, State and community initiatives in process: HealthInfoNet (HIN), Treatment Connections, findhelp, Healthy Living for ME, 211 Maine, and HMIS. This was not an exhaustive review and there will likely be more initiatives or platforms that could impact the work of the CIE. The Governance Workgroup and

the CIE Steering Committee will need to determine if any or all of these initiatives has a role to play in fulfilling the functions of the CIE.

**Financial and Resource Cost Projections** – the most significant expenditure from the Legal and Policy Workgroup perspective will be related to obtaining formal legal counsel. As noted above, this will be necessary in determining how the CIE works with strategic partners and there will need to be a review of all contracts and agreements used by the CIE. Ongoing legal support will be a requirement of the CIE.

**Legislative Support** – as with other states, the support of the Maine legislature may be important to the sustainability of the CIE. Phase III work should include identification and education of legislators who would sponsor legislation that could help support CIE funding. The Legal and Policy Workgroup suggests it merges with the Governance Workgroup to best address public policy issues and then develop a subgroup to focus on legislative advocacy and education to obtain support and authorization for this CIE project.

**Timing and Sequence** – the timing and sequencing of next steps depends on a number of factors. Governance structure, including the identification of a backbone organization, will have significant impact on timing and sequencings of Phase III work. If the backbone organization already has internal legal counsel that is able to provide legal review and ongoing oversight, this would address a main Legal and Policy requirement. If, conversely, the governance model moving forward includes a separate CIE corporation, legal consultation costs will need to be included in the Phase III budget.

## **I. Legal and Policy Impacts on the Implementation of a Full CIE**

### **A. Federal Rules and Regulations**

#### **1. Health Insurance Portability and Accountability Act (HIPAA)**

While there are a number of federal regulations relating to the privacy and confidentiality of data and information, the most comprehensive is the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and its various amendments. HIPAA pertains to ‘covered entities’, defined as: (1) A health plan. (2) A health care clearinghouse. (3) A health care provider who transmits any health information in electronic form in connection with a transaction covered by this subchapter. The HIPAA Privacy Rule protects all *"individually identifiable health information"* held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral. The Privacy Rule calls this information *"protected health information (PHI)"*. The HIPAA Privacy Rule allows use of PHI, without a patient’s specific consent or authorization, for purposes of treatment, payment, or healthcare operations, with the exception of information related to the diagnosis/treatment of substance use disorders, covered under 42 CFR Part 2. The Maine CIE must comply with HIPAA requirements with regard to PHI.

The HIPAA Security Rule addresses the requirements for safeguarding PHI. As a BA of a covered entity, the CIE must comply with all of the Security Rule requirements, including policies and procedures.

2. The Health Information Technology for Economic and Clinical Health Act (HITECH)

The primary purpose of the HITECH Act is to improve the quality, safety, and efficiency of healthcare by expanding the adoption of health information technology to facilitate (among other things) Health Information Exchanges. In order to enable the increased adoption of electronic health and medical records and keep the data maintained in these devices secure, the HITECH Act strengthened the HIPAA Privacy and Security Rules, required Business Associates to comply with the HIPAA Security Rule, and introduced the Breach Notification Rule – with increased financial penalties for those who failed to comply.

As the CIE will be a business associate of its covered entity partners, the CIE will need to comply with all HITECH requirements

3. Coronavirus Aid, Relief, and Economic Security (CARES) Act\*\*

The CARES Act was passed by Congress on March 27, 2020, to ensure that every American has access to the care they need during the COVID-19 pandemic and to address the economic fallout from the SARS-CoV-2 and COVID-19. The CARES Act improved 42 CFR Part 2 regulations by expanding the ability of healthcare providers to share the records of individuals with SUD but also tightening the requirements in the event of a breach of confidentiality.

On November 28, 2022, the U.S. Department of Health & Human Services, through the Office for Civil Rights (OCR) in coordination with the Substance Abuse and Mental Health Services Administration (SAMHSA), issued a Notice of Proposed Rulemaking (NPRM) to revise the Confidentiality of Substance Use Disorder Patient Records regulations. The NPRM proposes to bring requirements for Part 2 (Substance Use Disorder treatment) in line with the HIPAA requirements for other PHI. It would allow use of a single prior consent by the patient for future uses for treatment, payment, and operations; it would allow redisclosure of Part 2 records; it provides patients with the right to an accounting of disclosure and to request restrictions of disclosures; and it modifies confidentiality notice requirements to align with the HIPAA Notice of Privacy Practices.

Passing of these rules would essentially allow the CIE to handle the use and disclosure of SUD information in the same manner that it handles other PHI.

However, until the rules change, the CIE must comply with CFR Part 2 requirements related to SUD information.

4. An Act to accelerate the discovery, development, and delivery of 21st century cures, and for other purposes (CURES Act)

The 21st Century Cures Act is a federal law that aims to improve the speed and efficiency of medical product development and delivery. It also includes provisions that promote the sharing of health information between patients and healthcare providers. Cures Act Overview (harvard.edu) One such provision is the **information blocking rule**, which requires healthcare providers to give patients immediate access to their health information, free of charge. Information Blocking is defined as a practice by a healthcare provider, health information network, health information exchange or developer of certified health IT that interferes with access, exchange, or use of EHI. Under the CURES Act information blocking is prohibited, and if a patient requests their health information, healthcare providers are required to provide it. Federal Register :: Certificates of Confidentiality; Draft Guidance for Sponsors, Sponsor-Investigators, Researchers, Industry, and Food and Drug Administration Staff; Availability

The Cures Act also requires vendors and users to enable the development of computer and smartphone applications that give patients full and portable access to their health care information. To increase the interoperability across EHR platforms, the final rules of the Act specifically require that patients have access to their personal EHR notes without delay.

In addition, the Cures Act requires that eight categories of clinical notes created in an electronic health record (EHR) must be immediately available to patients through a secure online portal. These categories include consultation notes, discharge summary notes, history and physicals, imaging narratives, lab report narratives, pathology report narratives, procedures notes and progress notes.

The CIE will need to ensure that any limitations on access to information do not constitute information blocking and must ensure that patients have access to the eight categories of clinical notes through a secure online portal.

5. The Family Education Rights and Privacy Act (FERPA)\*\*

FERPA is a Federal law that protects the privacy of student education records and gives parents certain rights with respect to their children's education records, including the right to inspect and review them. Under FERPA, a parent generally must provide signed and dated written consent before a school discloses personally identifiable information (PII) from the student's education records. Personally identifiable information (PII) includes not only direct identifiers like name, Social Security number, etc., but also indirect identifiers such as the student's date and place of birth and the mother's maiden name, and any other



information linked to a specific student that would allow a reasonable person in the school community to identify the student with reasonable certainty. Health records that directly relate to students and are maintained by a health care provider, such as a third-party contractor, acting for a FERPA-covered elementary or secondary school, would qualify as education records subject to FERPA regardless of whether the health care provider is employed by the school. Conversely, student health records that are maintained by a health care provider that provides services directly to students and that is not acting for a FERPA-covered educational agency or institution do not constitute FERPA-protected education records. For example, the records created and maintained by a public health nurse who provides immunizations to students on a FERPA-covered elementary or secondary school's grounds, but who is not acting for the school, would not qualify as "education records" under FERPA.

#### 6. Homeless Management Information System (HMIS)\*\*

HMIS is a local information technology system used to collect client-level data and data on the provision of housing and services to homeless individuals and families and persons at risk of homelessness. HMIS: Homeless Management Information System - HUD Exchange Information may be entered into an HMIS without consent but may not be shared/disclosed without a client's consent. If an HMIS automatically shares information with other HMIS participating projects, client consent is required prior to entering information into the HMIS. The privacy and security standards, as described in the 2004 Data and Technical Standards Notice, seek to protect the confidentiality of personal information while allowing for reasonable, responsible, and limited uses and disclosures of data.

#### 7. Supplemental Nutritional Assistance Program (SNAP)

The federal SNAP program, which provides food assistance to low-income households, allows State programs to maintain longitudinal databases that include the following information, if available, on beneficiary households and their members:

- demographic characteristics;
- income and financial resources used to determine program and benefit eligibility;
- employment status;
- household circumstances, such as deductible expenses; and
- the amount of the monthly allotment received under the supplemental nutrition assistance program.

In addition, the database may include information from other State data sources regarding earnings and employment data from the State department of labor, health insurance program data, or data from participation in other programs administered by the State.

While the national longitudinal database does not include personally identifiable information (including social security number, home address, or contact information), State databases may house this information and be bound by data-sharing requirements to support federal or state law enforcement efforts.

HMIS requirements do not establish additional data-sharing limitation beyond those existing under other laws and does not override any limitations existing under other laws, therefore, there are no legal implications for the Maine CIE.

8. Violence Against Women Act (VAWA)\*\*

The VAWA Confidentiality Provision refers to 34 U.S.C. 12291(b)(2), a provision of the Violence Against Women Act (VAWA) that requires all grantees and subgrantees receiving VAWA funding from the Department of Justice, Office on Violence Against Women, to protect the confidentiality and privacy of persons to whom those grantees and subgrantees are providing services. The VAWA Confidentiality Provision is designed to ensure the safety of adult, youth, and child victims of domestic violence, dating violence, sexual assault, and stalking. Grantees and subgrantees “covered” by the VAWA Confidentiality Provision may not disclose, reveal, or release personally identifying information or individual information collected in connection with services requested, utilized, or denied through grantees’ and subgrantees’ programs, regardless of whether the information has been encoded, encrypted, hashed, or otherwise protected. Personally identifying information” means information about an individual that may directly or indirectly identify that individual. In the case of a victim of domestic violence, dating violence, sexual assault, or stalking, it also means information that would disclose the location of that individual. Personally identifying information includes information such as an individual’s name, address, other contact information, and social security number, but it also can include information such as an individual’s race, birth date, or number of children if, in the particular circumstances, that information would identify the individual. Personally identifying information also may include information that is encoded, encrypted, hashed, or otherwise protected.

9. Other Federal Regulations

Other federal regulations reviewed included, Title IV Grants to States for Federal Aid to Needy Families with Children and to Child Welfare Services; Title IV B Child and Family Services; Title IV E Federal Payments for Foster Care, Prevention and Permanency; Title XVI Supplemental Security Income for the Aged, Blind and Disabled; and Title XX Block Grants for Social Services and Elder Justice.

## **B. State Statutes**

1. MRSA Title 34-B, §1207 Confidentiality of information – Behavioral Health\*\*

All orders of commitment, medical and administrative records, applications and reports, and facts contained in them pertaining to any client shall be kept confidential and may not be disclosed by any person. A client or client's legal guardian may give informed written consent to the disclosure of information. Disclosure of client information (except psychotherapy notes) to a state-designated health information exchange (HIE) is allowed if the HIE provides clients with the option of opting in to allow disclosure of the client's healthcare information to a healthcare provider/facility for the purposes of treatment, payment, or healthcare operations. The HIE must also provide a general opt-out provision to clients at all times.

2. Title 22 MRSA §1711-C. Confidentiality of health care information

An individual's health care information is confidential and may not be disclosed other than to the individual by the health care practitioner or facility. A patient may authorize disclosure of their information and may revoke the authorization at any time. A health care provider/facility may disclose patient, without authorization, to another healthcare provider/facility patient information for diagnosis, treatment or care of the patient or to complete the responsibilities of a health care provider/facility that provided diagnosis, treatment or care of individuals. The disclosure without authorization of health care information to a state-designated HIE is allowed providing that a general opt-out provision is available at all times and that patients may choose to opt in to allow the HIE to disclose that individual's health care information.

3. Title 10 MRSA §1346 Notice of Risk to Personal Data

An information broker that maintains computerized data that includes personal information who becomes aware of a breach of security of its system shall conduct a good faith, reasonable, and prompt investigation to determine the likelihood that personal information has been or will be misused. The information broker must give notice of the breach to a resident of the State whose information has been or is reasonably believed to have been acquired by an unauthorized person.

4. Title 5 MRSA §19203 HIV/AIDS Testing \*\*

In accordance with Title 5 MRSA §19203 no person may disclose the results of an HIV test except as outlined in the statute, without obtaining informed consent. In order to comply with this statute's requirements, patients should be allowed the opportunity to 'opt in' or 'opt out' of releasing HIV test results. If the patient has opted out, HIV test results should not be shared unless the patient gives express authorization for the release of the HIV test results.

\*\* For CIE Implications for these Regulations, see Section I C. Analysis of the Impact of Regulations and Statutes on Managing Specially Protected Data in a CIE

## **C. Analysis of the Impact of Regulations and Statutes on Managing Specially Protected Data in a CIE**

### **1. Behavioral Health Data**

#### **A. Mental Health Records**

Generally speaking, behavioral health information (all orders of commitment, medical and administrative records, applications and reports, and facts contained in them, pertaining to any client) must be kept confidential and may not be disclosed by any person in accordance with MRS Title 34-B, Behavioral and Developmental Services § 1207 Title 34-B, §1207: Confidentiality of information (maine.gov). A client, a client's legal guardian, if any, or, if the client is a minor, the client's parent or legal guardian may give informed written consent to the disclosure of information.

The Statute does allow disclosure of any information, except psychotherapy notes as defined in 45 Code of Federal Regulations, Section 164.501(2010) eCFR :: 45 CFR 164.501 -- Definitions., concerning a client to a state-designated statewide health information exchange (HIE) that provides and maintains an individual protection mechanism by which a client may choose to opt in to allow the state-designated statewide health information exchange to disclose that client's health care information covered under this section to a health care practitioner or health care facility for purposes of treatment, payment and health care operations, as those terms are defined in 45 Code of Federal Regulations, Section 164.501 eCFR :: 45 CFR 164.501 -- Definitions. A state-designated statewide HIE may disclose a client's health care information covered under this section even if the client has not chosen to opt in to allow the state-designated statewide health information exchange to disclose the individual's health care information when, in a health care provider's judgment, disclosure is necessary to: (1) Avert a serious threat to the health or safety of others, if the conditions, as applicable, described in 45 Code of Federal Regulations, Section 164.512(j)(2010) eCFR :: 45 CFR 164.512 -- Uses and disclosures for which an authorization or opportunity to agree or object is not required. are met; or (2) Prevent or respond to imminent and serious harm to the client and disclosure is to a provider for diagnosis or treatment.

#### **Implications for CIE**

*While there are a variety of exceptions to this confidentiality requirement, as outlined in the Statute, for purposes of a CIE, behavioral health information should not be disclosed without the permission of the patient/client or the patient's/client's legal guardian. An authorization to disclose information could take the form of an 'opt in' option when a patient's/client's protected health information is first entered into the CIE. There would need to be an opportunity for the patient/client to opt out of having their behavioral health information shared at any time in the future.*

#### **B. Substance Use Disorder Health Records**

Title 42, United States Code, Section 290dd-2(g) Records provides protection for substance use disorder patient records which would identify a patient as having or having had a substance use disorder either directly, by reference to publicly available information, or through verification of such identification by another person; or containing drug abuse information obtained by a federally assisted drug or alcohol abuse program; or as part of an ongoing treatment of a substance use disorder, making a diagnosis for that treatment, or making a referral for that treatment . These regulations are intended to ensure that a patient receiving treatment for a substance use disorder in a part 2 program (a federally assisted program as defined in CFR 42 eCFR :: 42 CFR 2.12 -- Applicability, and program as defined in this section) is not made more vulnerable by reason of the availability of their patient record than an individual with a substance use disorder who does not seek treatment.

Substance abuse disorder treatment programs most often make disclosures after a patient has signed a consent form that meets the requirements of 42 CFR Part 2. A patient may access their own records, including the opportunity to inspect and copy these records.

Patients/clients may provide authorization to share the information related to the care and treatment of their substance use disorder. Consents must be in writing and must include: the name of the individual/entity permitted to make the disclosure; how much information and what kind of information is to be disclosed; the name of the name of the individual/entity to which the disclosure is to be made; the purpose of the disclosure, limited to that information necessary to carry out the stated purpose; a statement that the consent may be revoked at any time (except to the extent that information has been shared by a previous consent); the date/event/condition upon which the consent will expire if not previously revoked; the signature of the patient/client/guardian and the date of the consent.

If the recipient entity facilitates the exchange of health information or is a research institution, a written consent must include the name of the entity and the name of entity participants; or a general designation of entity participants or class of participants that must be limited to a participant who has a treating provider relationship with the patient. When using a general designation, a statement must be included on the consent form that the patient (or other individual authorized to sign in lieu of the patient), confirms their understanding that, upon their request they must be provided a list of entities to which their information has been disclosed pursuant to the general designation.

Each disclosure made with the patient's written consent must include written statements that indicate that further disclosure of this information is prohibited unless the patient has given written consent for this further disclosure. A general authorization for the release of medical or other information is NOT sufficient for this purpose.

A patient may consent to a disclosure of their records for payment or health care operations activities. If a patient consents to a disclosure of their records for payment or health care operations activities, the entity who receives such records under the terms of

the written consent may further disclose those records as may be necessary for its contractors, subcontractors, or legal representatives to carry out payment and/or health care operations on behalf of such lawful holder. Examples of permissible payment or health care operations activities under this section include but are not limited to: billing, claims management, collections activities, obtaining payment under a contract for reinsurance, claims filing, and/or related health care data processing; clinical professional support services (e.g., quality assessment and improvement initiatives; utilization review and management services); patient safety activities; activities pertaining to training of students and healthcare professionals; and assessment of practitioner competencies. A complete list can be found in the regulations.

Entities that wish to further disclose patient identifying information must have in place a written contract with the contractor that requires the contractor to comply with provisions of Part 2 upon receipt of the patient identifying information. In making any such disclosures, the entity must furnish such recipients with the notice required under eCFR :: 42 CFR 2.32 -- Prohibition on re-disclosure.; require such recipients to implement appropriate safeguards to prevent unauthorized uses and disclosures; and require such recipients to report any unauthorized uses, disclosures, or breaches of patient identifying information to the lawful holder. The lawful holder may only disclose information to the contractor or subcontractor that is necessary for the contractor or subcontractor to perform its duties under the contract. Contracts may not permit a contractor or to re-disclose information to a third party unless that third party is its contract agent, helping them provide services described in the contract, and only as long as the agent only further discloses the information back to the contractor or lawful holder from which the information originated.

A part 2 program may disclose patient records to a central registry or to any withdrawal management or maintenance treatment program not more than 200 miles away for the purpose of preventing the multiple enrollment of a patient only if: the disclosure is made when the patient is accepted for treatment, the type/dosage of a drug is changed, or the treatment is interrupted, resumed, or terminated. This disclosure must be made with the patient's written consent. A withdrawal management or maintenance treatment program which has received a disclosure under this section and has determined that the patient is already enrolled may communicate as necessary with the program making the disclosure to verify that no error has been made and to prevent or eliminate any multiple enrollments.

*Implications for the CIE (Practical considerations for the CIE from SAMSHA Disclosure of Substance Use Disorder Patient Records (samhsa.gov)):*

*Query-based exchange* - Query-based exchange enables health care providers to search clinical data sources and discover information about a patient. Query-based exchange typically involves an intermediary - often known as a health information exchange (HIE), but this could also be a CIE. The HIE/CIE either maintains a centralized data repository

that includes data from connected systems or facilitates requests from one system to search another system.

*A Part 2 program would either need to obtain patient consent before disclosing Part 2 patient-identifying information to the HIE/CIE or execute a Qualified Service Organization Agreement (QSOA) with the HIE/CIE.*

*Written QSOA with an HIE/CIE:* A qualified service organization (QSO) is an entity that: provides services to a Part 2 Program (such as data processing, bill collecting, dosage preparation, laboratory analyses, legal, accounting, population health management, medical staffing, or other professional services) and has entered into a written agreement with a Part 2 Program under which the QSO. The QSOA: (1) acknowledges that in receiving, storing, processing, or otherwise dealing with any patient records from the Part 2 Program, it is fully bound by 42 CFR Part 2; and (2) If necessary, will resist in judicial proceedings any efforts to obtain access to patient identifying information related to substance use disorder diagnosis, treatment, or referral for treatment except as permitted by 42 CFR Part 2. Because the HIE/CIE is considered a QSO, Part 2 programs would not need patient consent to disclose patient information to the HIE/CIE. However, providers participating in the HIE/CIE would need the patient's consent to view SUD patient records. The HIE/CIE would be restricted from re-disclosing patient identifying information to participating providers without the patient's consent.

If a Part 2 program and the HIE/CIE did not sign a QSOA, the Part 2 provider could have their patients fill out a consent form to disclose their SUD treatment records to other health care providers through the HIE/CIE. Health care providers listed on the patient's consent form could access the HIE/CIE to view the patient's records. The consent form would need to include the name of the HIE/CIE, as well as (1) the name of a specific individual/entity participating in the HIE, or (2) a general designation of individuals/entities that have a treating provider relationship with the patient. The consent form would also have to fulfill all other requirements as specified by Part 2.

If a patient used a general designation, the consent form would also have to include a notice stating that the patient understands that upon written request, they must be provided with a list of entities to which their information has been disclosed within the past two years. The HIE/CIE would be responsible for responding to the request within 30 days. For each disclosure, the HIE/CIE would have to include the name(s) of the entities to which the disclosure was made, the date of the disclosure, and a brief description of the patient-identifying information that was disclosed.

### C. **CARES Act**

The CARES Act Federal Register :: Confidentiality of Substance Use Disorder Patient Records will significantly impact the regulations governing the confidentiality of substance use disorder treatment records. On November 28, 2022, the U.S. Department of Health & Human Services, through the Office for Civil Rights (OCR) in coordination

with the Substance Abuse and Mental Health Services Administration (SAMHSA), issued a Notice of Proposed Rulemaking (NPRM) to revise the Confidentiality of Substance Use Disorder Patient Records regulations.

The NPRM proposes to:

- Permit Part 2 programs to use and disclose Part 2 records based on a single prior consent signed by the patient for all future uses and disclosures for treatment, payment, and health care operations.
- Permit the redisclosure of Part 2 records as permitted by the HIPAA Privacy Rule by recipients that are Part 2 programs, HIPAA covered entities, and business associates, with certain exceptions.
- Expand prohibitions on the use and disclosure of Part 2 records in civil, criminal, administrative, or legislative proceedings conducted by a federal, state, or local authority against a patient, absent a court order or the consent of the patient.
- Create two patient rights under Part 2 that align with individual rights under the HIPAA Privacy Rule:
  - Right to an accounting of disclosures
  - Right to request restrictions on disclosures for treatment, payment, and health care operations.
- Modify the Part 2 confidentiality notice requirements (“Patient Notice”) to align with the HIPAA Notice of Privacy Practices.
- Modify the HIPAA Notice of Privacy Practices requirements for covered entities who receive or maintain Part 2 records to include a provision limiting redisclosure of Part 2 records for legal proceedings according to the Part 2 standards.
- Permit investigative agencies to apply for a court order to use or disclose Part 2 records after they unknowingly receive Part 2 records in the course of investigating or prosecuting a Part 2 program, when certain preconditions are met.

*Implications for CIE- While the Department is undertaking this rulemaking, the current Part 2 regulations remain in effect.*

## **2. HIV/AIDS Testing**

In accordance with MRS §19203 [title5sec19203.pdf \(maine.gov\)](#), no person may disclose the results of an HIV test except as follows: to the subject of the test; to a healthcare provider designated by the subject of the test in writing; to a person to whom the test subject has authorized disclosure in writing; to a healthcare provider who deals with human body parts donated for a purpose may, without obtaining informed consent, perform an HIV test in order to assure medical acceptability of the gift; by a research facility if the HIV testing of body fluids or tissues is performed in a manner by which the identity of the test subject is not known or may not be retrieved by the researcher; to anonymous testing sites; to employees or, or other persons designated by the Department of Corrections and DHHS to the extent that those individuals are responsible for the treatment or care of subjects of the test; as part of a medical record when release or



disclosure of that record is authorized; by court order when an authorized person receives test results following an accidental disclosure; to a victim-witness advocate authorized to receive the test results of a person convicted of a sexual crime, who shall disclose to a victim; to a HIE designated by the State that provides and maintains an individual protection mechanism by which the individual may choose to opt in to allow that the HIE disclose that individual's healthcare information to a healthcare provider for purposes of treatment, payment, or healthcare operations.

An HIE may disclose an individual's HIV test results even if the individual has chosen not to opt in to allow the HIE to disclose the individual's HIV information when in a healthcare provider's judgement disclosure is necessary to avert a serious threat to the health or safety of others or to prevent or respond to imminent or serious harm to the individual and disclosure is to a provider for diagnosis or treatment.

*Implications for CIE: patients should be allowed the opportunity to 'opt in' or 'opt out' of releasing HIV test results. If the patient has opted out, HIV test results should not be shared unless the patient gives express authorization for the release of the HIV test results.*

### **3. Domestic Violence**

The VAWA Confidentiality Provision refers to 34 U.S.C. 12291(b)(2) , 34 U.S. Code § 12291 - Definitions and grant provisions | U.S. Code | US Law | LII / Legal Information Institute (cornell.edu), a provision of the Violence Against Women Act (VAWA) that requires all grantees and subgrantees receiving VAWA funding from the Department of Justice, Office on Violence Against Women, to protect the confidentiality and privacy of persons to whom those grantees and subgrantees are providing services. The VAWA Confidentiality Provision is designed to ensure the safety of adult, youth, and child victims of domestic violence, dating violence, sexual assault, and stalking.

All grantees and subgrantees providing services to victims and receiving VAWA funding from the Office on Violence Against Women are covered by the VAWA Confidentiality Provision and must adhere to the requirements of that Provision; that is, they may not disclose, reveal, or release personally identifying information or individual information collected in connection with services requested, utilized, or denied through grantees' and subgrantees' programs, regardless of whether the information has been encoded, encrypted, hashed, or otherwise protected. The VAWA Confidentiality Provision applies to all operations of the victim service provider or victim services division/component, even if the OVW funding is only for a small part of those operations.

"Personally identifying information" means information about an individual that may directly or indirectly identify that individual. In the case of a victim of domestic violence, dating violence, sexual assault, or stalking, it also means information that would disclose the location of that individual.

By statute, a grantee or subgrantee may share personally identifying information in three specific circumstances: when the victim provides written, informed, and reasonably time-limited consent to the release of information; when a statute compels that the information be released; or when a court compels that the information be released. If a statute or court compels the release of information, the grantee or subgrantee releasing the information must make reasonable attempts to provide notice of the release to affected victims and take steps necessary to protect the privacy and safety of persons affected by the release.

Providers that do not receive VAWA funding are not covered by the VAWA Confidentiality Provision. The Office of Violence Against Women encourages such partners to voluntarily “opt-in” to the requirements of the VAWA Confidentiality Provision; opting in is a best practice for keeping victims safe.

Releases must be written, informed, reasonably time limited, and signed by the victim or, if appropriate, a parent or guardian. Grantees and subgrantees may not use a blanket release and must specify the scope and limited circumstances of any disclosure. At a minimum, grantees and subgrantees must: discuss with the victim why the information might be shared, who would have access to the information, and what information could be shared under the release; reach agreement with the victim about what information would be shared and with whom; and record the agreement about the scope of the release. The release must specify the duration for which the information may be shared. Releases should be for a “reasonable” time period. The reasonableness of the time period will depend on the specific situation.

*Implications for CIE: grantees and subgrantees of entities receiving VAWA funding. The CIE cannot be responsible for determining which organizations receive VAWA funding. The Business Associate Agreement, a Data Use Agreement, or a CIE Participation Agreement should address the requirements of entities receiving VAWA funding to comply with the regulations relating to confidentiality of information regarding victims of domestic violence and should specify that any information related to victims of domestic violence provide an authorization to release information to the CIE before such information is shared with the CIE.*

#### **4. Education Records**

The Federal Educational Rights and Privacy Act (FERPA) 20 U.S.C. § 1232g; 34 CFR Part 99 eCFR :: 34 CFR Part 99 -- Family Educational Rights and Privacy is a Federal law that protects the privacy of student education records and gives parents certain rights with respect to their children’s education records, including the right to inspect and review them. Under FERPA, a parent generally must provide signed and dated written consent before a school discloses personally identifiable information (PII) from the student’s education records. FERPA directly applies to all educational agencies and institutions that receive funds under any program administered by the Secretary of

Education ("Department"). FERPA affords parents certain rights with respect to their children's education records at schools and local educational agencies (LEAs) to which FERPA applies. These rights include the right to have access to their children's education records, the right to seek to have the records amended, and the right to provide consent for the disclosure of PII from education records, unless an exception to consent applies.

Under FERPA, an "education record" is one that directly relates to a student and is maintained by the school or an entity acting on a school's behalf. Education records include student health information, such as nurses' exam notes in the student's file, immunization and physical exam records, health screening results, and records related to special education or student health plans. FERPA generally forbids schools from disclosing personally identifiable information (PII) contained in students' education records without written consent from a parent or guardian. However, the law does provide some exceptions that allow school personnel to share certain PII without parental consent,

"Personally identifiable information" provides that PII includes not only direct identifiers like name, Social Security number, etc., but also indirect identifiers such as the student's date and place of birth and the mother's maiden name. It also includes "other information that, alone or in combination, is linked or linkable to a specific student that would allow a reasonable person in the school community to identify the student with reasonable certainty.

"Directory information" means information in an education record of a student that would not generally be considered harmful or an invasion of privacy if disclosed (student's name; address; telephone listing; electronic mail address; photograph; date and place of birth; major field of study; grade level; dates of attendance; participation in officially recognized activities and sports; weight and height of members of athletic teams; degrees, honors and awards received; and the most recent educational agency or institution attended). A school may disclose directory information without consent if it has given public notice to parents of students in attendance and eligible students in attendance of the types of information it has designated as directory information, the parent or eligible student's right to opt out of the disclosure of such information, and the period of time within which a parent or eligible student has to notify the school that he or she does not want any or all of those types of information designated as directory information.

A parent or eligible student must provide a signed and dated written consent before a school discloses PII from the student's education records ( eCFR :: 34 CFR 99.30 -- Under what conditions is prior consent required to disclose information?), unless an exception to the general consent rule, as set forth in eCFR :: 34 CFR 99.31 -- Under what conditions is prior consent not required to disclose information? of the regulations, applies.

Schools do not need to obtain written consent or to inform parents or eligible students when releasing properly de-identified information.

Schools would not be considered Covered Entities under HIPAA unless they are providing healthcare services. In a few limited circumstances, an educational agency or institution subject to FERPA can also be subject to HIPAA. For instance, a school that provides health care to students in the normal course of business, such as through its health clinic, is also a “health care provider” under HIPAA. If a school that is a “health care provider” transmits any PHI electronically in connection with a transaction for which HHS has adopted a transaction standard, it is then a covered entity under HIPAA. As a covered entity, the school’s health care transactions must comply with the HIPAA Transactions and Code Sets Rule (or Transactions Rule). However, many schools that meet the definition of a HIPAA covered entity do not have to comply with the requirements of the HIPAA Rules because the school’s only health records are considered “education records” or “treatment records” under FERPA. *See* 45 CFR § 160.103 eCFR :: 45 CFR 160.103 -- Definitions. (definition of “protected health information”). The HIPAA Privacy Rule specifically excludes from its coverage those records that are protected by FERPA by excluding such records from the definition of “protected health information.

Under FERPA, “treatment records” are excluded from the definition of “education records.” Treatment records are: records on a student who is eighteen years of age or older, or is attending an institution of postsecondary education, which are made or maintained by a physician, psychiatrist, psychologist, or other recognized professional or paraprofessional acting in his professional capacity, or assisting in that capacity, and which are made, maintained, or used only in connection with the provision of treatment to the student, and are not available to anyone other than persons providing such treatment, except that such records can be personally reviewed by a physician or other appropriate professional of the student’s choice. For example, treatment records may include a student’s health or medical records that a college’s psychologist maintains solely in connection with providing treatment to the student. An educational agency or institution may only disclose an eligible student’s treatment records to individuals who are providing treatment to the student (including health care professionals who are not part of, nor acting on behalf of, the educational agency or institution (e.g., third-party health care providers)), and a physician or other appropriate professional of the student’s choice. For all other disclosures of an eligible student’s treatment records, an educational agency or institution must obtain the student’s prior written consent or satisfy one of the exceptions to FERPA’s general written consent requirement, as the records would no longer qualify as “treatment records” (and thereby be excluded from the definition of “education records”) and, instead, become subject to all other FERPA requirements

While public school nurses are generally subject to FERPA, the health care providers with whom they want to share data must adhere to the HIPAA privacy rule. HIPAA allows health care providers to disclose protected health information (PHI) without

parental consent or authorization for treatment purposes. Likewise, a school nurse may (under FERPA) communicate with a student's outside health care provider to clarify that provider's treatment orders. To facilitate ongoing communication with students' outside medical care providers, school nurses should consider obtaining a parental release that allows free exchange of information relating to the student's care plan and progress.

Educational entities and those with whom they wish to share information should put agreements in place that guide data disclosure, use, and maintenance by everyone that will have access to the student data. Agreements among the parties should be specific, compliant with applicable federal and state laws, and should support the purpose of the data sharing arrangement. Determining why data is being shared with these specific partners can help determine which type of agreement is most appropriate. Depending on the circumstances, a Data Sharing Agreement (DSA) or MOU may be appropriate.

FERPA does not allow for redisclosure of a student's personally identifiable information to another party without the written permission of the parents, guardians, or student (when applicable).

*Implications for CIE: The Business Associate Agreement, a Data Use Agreement, or a CIE Participation Agreement should address the FERPA requirements of entities regarding redisclosure of personally identifiable information of students.*

## **5. Homelessness**

A Homeless Management Information System (HMIS) HMIS: Homeless Management Information System - HUD Exchange is the information system designated by a local Continuum of Care (CoC) to comply with the requirements of CoC Program interim rule 24 CFR 578 eCFR :: 24 CFR Part 578 -- Continuum of Care Program. It is a locally implemented data system used to record and analyze client, service, and housing data for individuals and families who are homeless or at risk of homelessness. At this time, there is no requirement that client consent be obtained to enter client information into HMIS. There is only a requirement that client consent be obtained to share information entered into HMIS with one or more other HMIS participating providers. This means that it may not be necessary to obtain written consent from every client to simply enter the data into your HMIS. However, if the HMIS is configured in such a manner that information entered into HMIS is automatically shared with other HMIS participating projects, then client consent is necessary.

HMIS privacy standards apply to any homeless assistance organization that records, uses or processes protected personal information (PPI) for an HMIS. A provider that meets this definition is referred to as a covered homeless organization (CHO). All PPI maintained by a CHO is subject to these standards. Any CHO that is covered under the HIPAA is not required to comply with the privacy or security standards in this Notice if the CHO determines that a substantial portion of its PPI about homeless clients or

homeless individuals is protected health information as defined in the HIPAA rules. Exempting HIPAA covered entities from the HMIS privacy and security rules avoids all possible conflicts between the two sets of rules.

A CHO may use or disclose PPI from an HMIS under the following circumstances: (1) To provide or coordinate services to an individual; (2) for functions related to payment or reimbursement for services; (3) to carry out administrative functions, including but not limited to legal, audit, personnel, oversight and management functions; or (4) for creating deidentified PPI. There are additional uses and disclosures of personal information that are permitted. Under the HMIS privacy standard, these additional uses and disclosures are permissive and not mandatory (except for first party access to information and any required disclosures for oversight of compliance with HMIS privacy and security standards). A CHO may use or disclose PPI when required by law to the extent that the use or disclosure complies with and is limited to the requirements of the law. Uses and disclosures to avert a serious threat to health or safety.

A CHO may, consistent with applicable law and standards of ethical conduct, use or disclose PPI if: (1) The CHO, in good faith, believes the use or disclosure is necessary to prevent or lessen a serious and imminent threat to the health or safety of an individual or the public; and (2) the use or disclosure is made to a person reasonably able to prevent or lessen the threat, including the target of the threat. Uses and disclosures about victims of abuse, neglect, or domestic violence.

A CHO must comply with all baseline privacy protections and with all additional privacy protections included in its privacy notice. A CHO may maintain a common data storage medium with another organization (including but not limited to another CHO) that includes the sharing of PPI. When PPI is shared between organizations, responsibilities for privacy and security may reasonably be allocated between the organizations.

*Implications for CIE: The CIE and HMIS may want to utilize a Multiparty Authorization Agreement to Use and Disclose Information (Authorization) which would allow the respective databases to provide referral services to social service agencies for individuals with healthcare, housing, food, transportation, financial and other needs.*

The Authorization would allow HMIS and CIE participating agencies to collect information from an individual and their care team to assess the individual's needs and put them in touch with social services agencies that provide services that can address the individual's needs to coordinate referrals and services. The Authorization would permit a CIE participating agency to re-disclose health information to another CIE participating agency.

The Authorization would be signed by the individual and would include a right to decline or revoke the authorization, the timeframe covered by the authorization, the right to renew the authorization, the right to refuse to sign the authorization, the right to a copy of the individual's information that will be shared with referral sources and the right to a

copy of the authorization. The Authorization should also include or have a link to a listing of the CIE participating agencies that might access the individual's information.

## **6. Sexual Orientation and Gender Identity**

The Office of Civil Rights is responsible for enforcing Section 1557 of the Affordable Care Act (Section 1557) Section 1557 of the Patient Protection and Affordable Care Act | HHS.gov, which prohibits discrimination against individuals on the basis of race, color, national origin, sex, age, and disability in covered health programs or activities.

Section 1557 protects the right of individuals to access the health programs and activities of recipients of federal financial assistance without facing discrimination on the basis of sex, which includes discrimination on the basis of gender identity.

While there is significant evidence of the value in collecting SOGI information, there is also a recognition that some individuals may not want to have their SOGI information shared with others. On March 2, 2022, the Office of Civil Rights published the following: “HHS Notice and Guidance on Gender Affirming Care, Civil Rights, and Patient Privacy”. (HHS Notice and Guidance on Gender Affirming Care, Civil Rights, and Patient Privacy) The following statement is taken directly from this publication: “OCR enforces the HIPAA Privacy, Security and Breach Notification Rules, which establish requirements with respect to the use, disclosure, and protection of protected health information (PHI) by covered entities and business associates; provide health information privacy and security protections; and establish rights for individuals with respect to their PHI.

OCR reminds covered entities (health plans, health care providers, health care clearinghouses) and business associates that the HIPAA Privacy Rule permits, but does not require, covered entities and business associates to disclose PHI about an individual, without the individual's authorization, when such disclosure is required by another law and the disclosure complies with the requirements of the other law. This “required by law” exception to the authorization requirement is limited to “a mandate contained in law that compels an entity to make a use or disclosure of PHI and that is enforceable in relevant requirements of such law. Disclosures of PHI that do not meet the “required by law definition” or exceed what is required by such law do not qualify as permissible disclosures under this exception.

**HIPAA prohibits disclosure of gender affirming care that is PHI without an individuals' consent except in limited circumstances.”**

*Implications for CIE: Based on the OCR publication noted above, the CIE should protect the privacy and confidentiality of individuals by requiring patient authorization before disclosing gender affirming care.*

## APPENDIX G (3)

### Maine CIE Data and Technology Workgroup Summary

#### Background

Between 2020 and 2022, a group of stakeholders held a series of meetings to explore the concept of a Community Information Exchange (CIE) and whether a CIE would benefit the citizens of Maine. The work of this group was outlined in the document, *Maine Community Information Exchange: Current Status and Next Steps*. A shared vision for a Maine CIE was defined in this Phase I as “better health and well-being through information, referrals, and coordination. This Maine CIE vision would shift away from a reactive Better health and Well-being through information, referrals, and coordination. This Maine CIE vision would shift away from a reactive approach to a proactive approach to provide person-centered care”.

In May 2022, Phase II of the Maine CIE Project was launched. As part of Phase II, three workgroups were developed.

#### Getting Started

The Data and Technology Workgroup (Workgroup) membership included representatives from HealthInfoNet (HIN), Good Shepard Food Bank, York County Community Action Corporation, Northern Light Health, Maine DHHS Office of Aging and Disability Services, MaineHealth, Eastern Area Agency on Aging, 211 Maine, Spectrum Generations, and Seniors Plus.

To accomplish the goal of the Maine CIE as defined in Phase I, the Workgroup agreed that the functionality of the CIE should include the ability to:

- Collect health-related social risks information from clinical providers using a shared language
- Collect social services information from social services/community-based providers used a shared language
- Compile and share this information individually (with permission) and in aggregate using a shared health record design
- Meaningfully refer individuals seeking assistance to providers of healthcare and social services using an interactive resource directory platform that allows for real-time and asynchronous closed-loop communication
- Analyze results and take action to improve care coordination for patients
- Make the best use of resources within healthcare and social services organizations
- Address unmet need in communities and increase health equity throughout the state

The Workgroup’s goals included:



- A healthy information ecosystem must be built upon “open access” infrastructure, using standardized protocols, so that any compliant platform can perform critical functions through interoperation with other connected platforms – and that these activities should be governed by local communities to ensure responsiveness to beneficiary needs (a critical driver of health and racial equity).
- A CIE should facilitate interactions beyond service transactions to encompass information about networks of people and ongoing case management.
- A CIE should facilitate interactions beyond service transactions to encompass information about networks of people and ongoing case management.
- Communities should have meaningful control over how aggregate data is used to construct population-level representations and processes, such as structuring algorithms that might be used to allocate resources and make other kinds of critical decisions about *who* should have access to *what* under *which* circumstances
- CIEs need to compensate for the ethical immaturity of consent frameworks through the investment in the development of governing processes in which stakeholders (service providers and users) are structurally empowered to co-design, monitor, audit, evaluate, and sanction the various methods of consent solicitation and preservation through the lifecycle of various projects conducted through the CIE.
- A CIE should ensure that the systems and activities associated with the coordination of social care are equitably developed and implemented according to expressed interests and active participation of stakeholders in a local community.
- Given that health equity is a function of collective well-being, CIEs need to design mechanisms for monitoring the use of aggregated data, assessing the impacts of that use, and making and enforcing rules that preserve the communities’ related interests

The Workgroup identified five main deliverables:

- Prioritization of various CIE components into a phased/modular development and release approach, and the understanding of the interconnectedness/dependencies of the many components.
- Business (and technical, whenever possible) requirement drafts for each of the priority technical components of the CIE system.
- Clear recommendations for specific vendors/partners required to fulfill the priority technical components of the CIE system, including the execution of letters of intents with each vendor/partner that are contingent on procuring the necessary funding to proceed.
- Project plan drafts for each of the priority technical components of the CIE system, highlighting necessary staff, resources, and time to complete the effort (and which could be used for budgeting purposes).
- Budgets to support the priority technical components of the CIE system, which explicitly can be traced back to funding opportunities identified through the Steering Committee.

## CIE Components

The Workgroup began by addressing the two options for addressing the technical components of the Workgroup's Charter: Option 1) Closed loop referral management and Option 2) Longitudinal Health Record – getting data from a variety of sources and integrating it for patients/consumers.

Workgroup members unanimously supported moving forward with Option 2, the shared health record. Some of the reasons for this decision included the following:

- Option 1 - Referral management is already well represented in the market. It is a bit of a crowded space for information and referrals.
- There is a lot of pressure for providers to participate in the various information and referral management platforms.
- CBOs have not been interested in referral management platforms like Find Help as this participation requires additional time and costs for them.
- Focusing on a closed loop referral system may be giving the wrong message to providers – the CIE may be perceived as just another referral management platform.
- There are national movements (CMS and ACL) that are going in the direction of building community-based networks. Option two would be a critical pathway for building the data feed first.
- Most CBOs are not short of clients – Option 1 – closed loop referrals – might be seen as just adding to the referral volume they already have.
- The closed loop referral option could be added later.
- ROI may be higher for Option 2.
- Option two may provide added value for CBOs by building a case for increased support for CBOs.

The Workgroup's recommendation to focus on the longitudinal health record was presented to the CIE Steering Committee and the other two workgroups at a Combined Meeting held in December 2022 and received the go-ahead from the Combined Meeting attendees to move forward with the longitudinal health record.

A longitudinal health record is a person-centric health record that compiles the history of all information received from CIE data-sharing participants and organizes it within a single, intuitive view that persons' care team members can access on a role-based basis to gain insights on how to best provide care and support.

### **Business Requirements Document**

A Business Requirements Document was developed that included a purpose statements, focus areas, key definitions, technical components diagrams, longitudinal health record examples, priority domains, use case statements and discussion questions.

*Core Service Components:* The technical components that are considered the critical function of the initial release on which the requirements for all other technical components are defined. These include data integration services and a longitudinal health record.

*Optional Service Components:* The technical components that complement the core service components, but which are not required for the initial release and include notifications (Delivery of real-time alerts of time-sensitive events) and analytics/reporting.

*Infrastructure Components:* The underlying, backend technical components that together develop the critical functions of the initial release.

- Infrastructure & Environment Configuration
- Interoperable Data Exchange Standards
- Person Consent Management
- Person Identity Management System
- *Terminology Management*
- *Downloads and Exports*

*Support Services Components:* The various self-service and/or staffed support functions that are necessary to operationalize the technical components once deployed: help desk support, auditing functions and education/training.

*User Interface Components:* The user interface and workflow requirements governing the user experience of the technical components.

*Access Components:* The specific user roles governing the design, accessibility, and permissions associated with the construction of a frontend system: provide application and consumer application.

The Business Requirements Document also identified components that are outside the scope of this phase of the CIE project, including: Universal Social Risk Assessment Tools, a Resource Directory and Closed Loop Referrals. These will be prioritized in the future and included in a broader platform.

The Business Requirements Document included a review of key social risk domains prioritized for inclusion within the CIE system based on survey results from Phase I planning efforts:

- Food Security: Individuals' access to food and/or the necessary tools to prepare meals and/or competence of how to prepare meals successfully.
- Transportation Access: Individuals' abilities to get to and from work, access healthy food options, visit healthcare providers, and generally travel to and from appointments and other locations critical to daily living
- Homelessness: Individuals who are lacking housing, including the use of shelters, transitional housing, and other day-to-day paid options (e.g., motels, hotels, etc.), or who are living with others temporarily or on the street
- Housing Insecurity: Individuals who are at risk of losing their homes due to the inability to consistently afford payments
- Housing Inadequacy: Individuals who are living in housing of poor quality and/or condition

For each of these domains, the Business Requirements Document outlined data collection methods, data storage methods, relevant data elements, data-informed actions and partner organizations.

Use Case Statements – the Business Requirements Document outlined use case statements for each of the prioritized technical components involved in the initial release of the Maine CIE system to network partners as a way of articulating the business requirements of the platform from which the technical specifications will be derived.

The Business Requirements Document also included a section for Discussion Questions.

The Business Requirements Document was shared with all of the Workgroups and the Steering Committee members who were asked to review it and to add their comments/questions. Some of the comments related to renaming the longitudinal health record to make it more explanatory, the scope of the first phase and whether it was limited to older adults, and whether the CIE would help smaller CBOs with terminology standardization. There was also discussion at the Workgroup meeting regarding HIPAA and CBOs that are not covered entities as defined by HIPAA related to accessing protected health information (PHI). Individuals can authorize the release of PHI through a consent process. There was discussion about how a CIE could make this consent process more effective. It was agreed that further review and identification of the different types of CIE participants and whether or not they are HIPAA covered entities. CIE Participation Agreements will need to clearly articulate access to information and recipient organization will need to have some mechanism for ensuring that only minimally necessary information is accessed.

### **Data Elements Review**

The Workgroup members outlined priority data elements to include in participant's shared data sets. Data Elements included: record location, data component, data element, definition, participant source, whether the data should be behind a privacy shield, the medical provider, CBOs compliant with HIPAA, and CBOs not compliant with HIPAA. They also identified potential participant organizations that could share data sets to inform the longitudinal health record: contributor, participant type, participant name, record access, record contribution, permission, and notes.

### **Shared Client Record Mockup**

The Workgroup created a visual mockup of how the various data elements that had been identified could potentially be organized within an electronic shared health record user interface. Data elements are compiled into a medical record and a social record. Medical record data elements include care plans, consultations, discharge/history/physical notes, hospital/ED/PCP visit notes, immunizations, radiology/microbiology, summary documents, operative/diagnostic/procedure notes, vital sign information and CCDAs. Social record data elements include referral eligibility applications, referral forms and referral actions.

The Data Elements and Shared Client Record Mockup documents were shared with the Governance and Legal & Policy Workgroups. The Legal & Policy Workgroup provided feedback regarding types of organizations that might participate in providing information to or access information from the CIE. The Legal & Policy Workgroup did an extensive review of Federal and State regulations regarding privacy and confidentiality of protected information. Their recommendations can be found in the Legal & Policy Workgroup report.

### **Recommendations for specific vendors/partners required to fulfill the priority technical components of the CIE system**

The Data and Technology Workgroup has worked to date in the direction of defining the necessary underpinning technologies and data set specifications necessary to support a CIE-sponsored cross-sector shared health record system. The idea being that the CIE would serve as an entity to connect disparate partners that could work together to develop the shared health record system and provide the requirements/guidance necessary to those partners in order to fulfill a CIE-specific design. This was the path established in the Workgroup's charter and agreed to by the CIE Steering Committee.

In recent discussions with HIN, the CIE Steering Committee confirmed that HIN is the right partner for the longitudinal health record. However, it is unclear whether the CIE would simply be responsible for identifying partners in the State that are actively developing a shared health record system (i.e., HIN) and allowing those partners to continue in their development and maintenance of that system. As maintenance and development continues, the CIE would collaborate with the identified partners to provide feedback/suggestions to the system design based on market needs/stakeholder interests, but ultimately would not have technical/legal/governance oversight of the system. Additionally, the CIE would serve in an advocacy and marketing role to promote the use of the identified partners' system(s) to its stakeholders/audience to demonstrate success on its mission and vision statements.

These approaches differ significantly. Whereas the first approach is declaring the CIE as an entity with oversight responsibilities, the second approach is declaring the CIE as a convenor and advocate.

The second approach may be more sustainable for given the current structure of the CIE as well as the fact that the Maine landscape is going to constantly be ahead of the CIE in terms of implementing systems and encouraging health equity and access through them. It would therefore be the CIE's role to connect the dots that already exist – and foster ways in which they could be bolstered to support CIE-specific use cases. The CIE serving in this capacity would be incredibly useful.

### **Project Plan Drafts (for each of the priority technical components – staff, resources, time to complete)**

Until decisions have been made regarding partners for the CIE, it is impossible to draft project plans in any detail. Therefore, this deliverable will need to be completed after the CIE Steering Committee has made some decisions regarding how to proceed with potential partners.

**Budgets to support the priority technical components of the CIE (can be traced back to funding opportunities identified through the Steering Committee)**

As noted above, the CIE Steering Committee's decisions will impact resources necessary to support the priority technical components of the CIE.

## APPENDIX H

### Data and Technology Workgroup Business Requirements Document

<b>Maine Community Information Exchange (CIE)</b> <b>Data and Technology Workgroup</b> <b>Business Requirements Document</b>
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#### Purpose Statement

Develop of a longitudinal health record that compiles critical information from diverse cross-sector services that individuals are accessing throughout the state of Maine in support of their health, wellness, and wellbeing.

#### Focus Areas

The initial release of the Maine CIE's longitudinal health record will be built in alignment with use cases that specifically target improving the quality, safety, and delivery of services to Maine's older adult residents as they pertain to food security, transportation access, and housing quality and stability.

This focus is subject to change based on future funding opportunities.

#### Key Definitions

The following section includes definitions for key technical components involved in the development of the Maine CIE's longitudinal health record.

*Core Service Components: The technical components that are considered the critical function of the initial release on which the requirements for all other technical components are defined.*

Component	Description
Data Integration Services	Development of a data integration enterprise solution that can accept, route, map, translate, and cleanse incoming data sets from healthcare and social services organizations according to custom configurations to assure high-quality data outputs. Data sets may include clinical event-based

Component	Description
	information from healthcare providers and services/supports information from community-based organizations.
Longitudinal Health Record	Creation of a person-centric health record that compiles the history of all information received from CIE data-sharing participants and organizes it within a single, intuitive view that persons' care team members can access on a role-based basis to gain insights on how best to provide care and support.

*Optional Service Components: The technical components that complement the core service components, but which are not required for the initial release.*

Component	Description
Notifications	Delivery of real-time alerts of time-sensitive events (e.g., emergency department visits, new program enrollment, etc.) that make it possible for care managers and other providers following an individual's healthcare and social services activities to intervene early and establish the right care plan for follow-on action.
Analytics & Reporting	Formation of various use-case driven analytic and reporting capabilities, spanning descriptive, utilization, predicted risk, and quality measurements available at both person and population levels, to help better target care for persons and/or populations with certain risk factors, needs, or gaps in care.

*Infrastructure Components: The underlying, backend technical components that together develop the critical functions of the initial release.*

Component	Description
Infrastructure & Environment Configuration	Creation of infrastructure to support secure and authorized role-based access to both the backend and frontend CIE system and its related services. Infrastructure should support the configuration of Development, Test, Production, and Demonstration environments with varying amounts of identifiable and de-identifiable person health information to meet privacy standards while also enabling proper software development life cycle (SDLC) processes. This also includes detailing the necessary support staff to ensure that all infrastructure and environments are running and operating as intended at any given time.
Interoperable Data Exchange Standards	Establishment of the necessary interoperability protocols and data standards across healthcare and social services sectors to ensure high-value, high-quality integration capabilities to/from the CIE system and its participants' internal applications as well as compliance with federal/state/local program requirements and expectations.
Person Consent Management	Construction and management of technical systems to support persons' decisions to participate in the CIE system, which may include various consent choices to opt-in or opt-out of specific CIE services on either a global or encounter-by-encounter basis.
Person Identity Management System	Implementation of a service that allows the CIE system to track individuals – and their various health-related information – across disparate and diverse data sources and over time using probabilistic and deterministic matching measures to ensure that records are as comprehensive, consolidated, and up to date as possible.



Component	Description
Terminology Management	Compliance with cross-industry vocabulary standards that allows the CIE system and its services to translate local coding norms into industry-standard values (e.g., ICD, CPT, HCPCS, LOINC, SNOMED, AIRS, etc.) and flagging value sets of interest to block or sequester to ensure the delivery of consistent, easily understood, and highly secure data sets.
Downloads & Exports	Functionality to download and/or export available information from within the CIE system to inform offline study and review.

*Support Services Components: The various self-service and/or staffed support functions that are necessary to operationalize the technical components once deployed.*

Component	Description
Help Desk Support	Management of user accounts for individuals who have access to the CIE system and maintaining technical and operational support functions to users in the event of system failure, downtime, or other such issues requiring troubleshooting.
Auditing Functions	Automated and manual review functions of audit logs and privacy reports that ensure users are leveraging the CIE system and its services in compliance with the intended and authorized data use cases and governance policies.
Training & Education	Development of procedures and protocols intended to assist organizations in (a) determining their CIE-participation eligibility, (b) implementing patient consent within their internal workflows, and (c) continuing to use the CIE system and its services within the bounds of the intended and authorized data use cases and governance policies. This includes the creation of various educational resources to assist participating organizations, as well as staff resources to assist with questions as they arise.

*User Interface Components: The user interface and workflow requirements governing the user experience of the technical components.*

Component	Description
User Interface Design and Workflow	Establishment of overarching style, design, and workflow principles to be incorporated within the frontend CIE system and its services to facilitate streamlined and simple usage, as well as incorporation within internal organizational standards (e.g., branding, white labeling).

*Access Components: The specific user roles governing the design, accessibility, and permissions associated with the construction of a front-end system.*

Component	Description
Provider Application	Creation of a web-based portal that allows providers (i.e., healthcare providers, community-based providers) to view a curated health record of activities for individuals they serve initiated by those individuals' healthcare and community-based provider team (e.g., referrals, risks, assessments, etc.) as well as to engage with certain value-add service features/functions of the CIE system (e.g., downloads/exports, notifications, analytics/reporting, etc.).

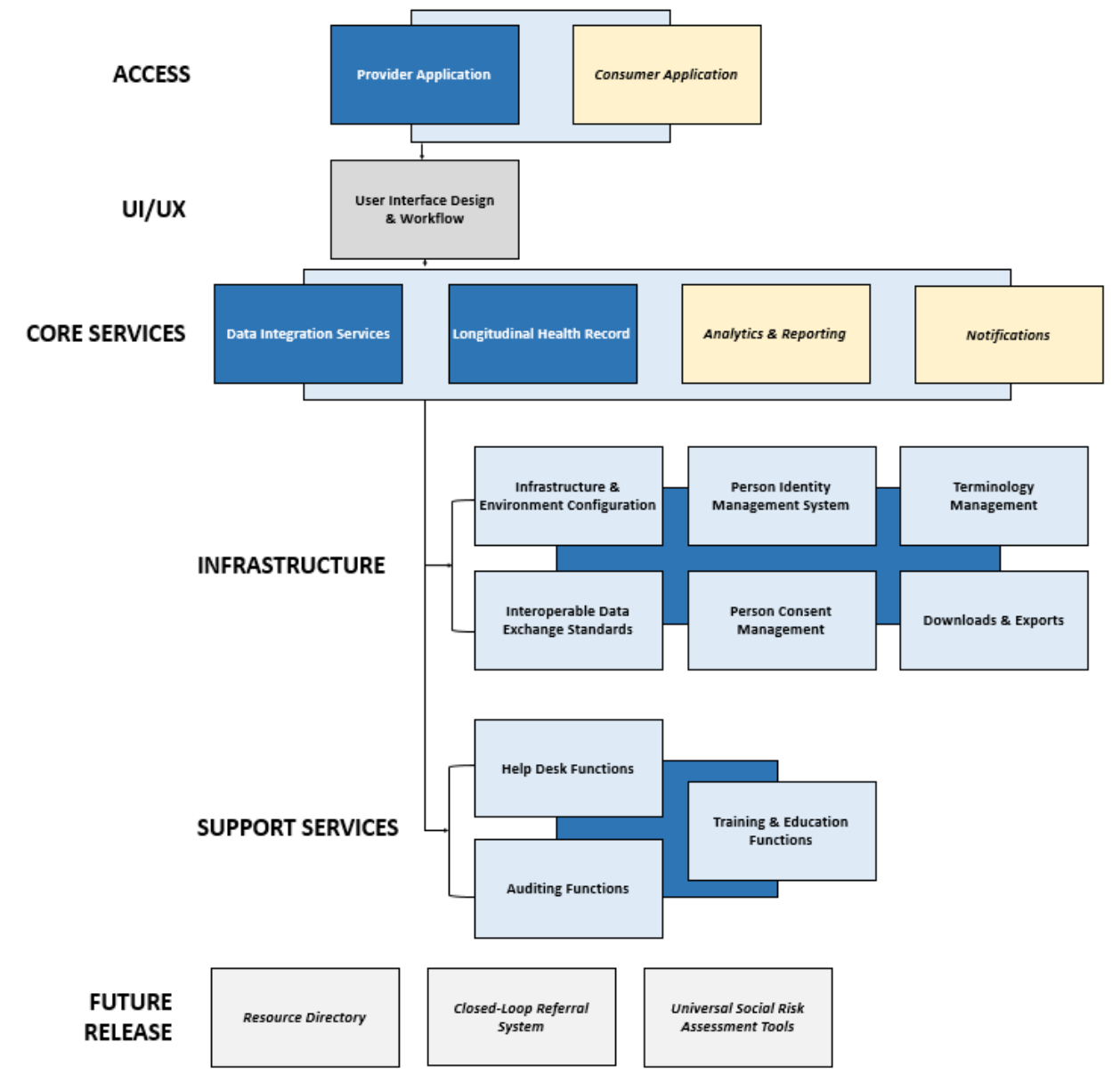
<b>Component</b>	<b>Description</b>
Consumer Application	Creation of a web-based portal that allows the consumer (i.e., person, patient, client) to view a curated health record of activities initiated by their healthcare and community-based provider team (e.g., referrals, risks, assessments, etc.) as well as to engage with certain self-service features/functions of the CIE system to input data on their own (e.g., self-refer, self-assess, etc.).

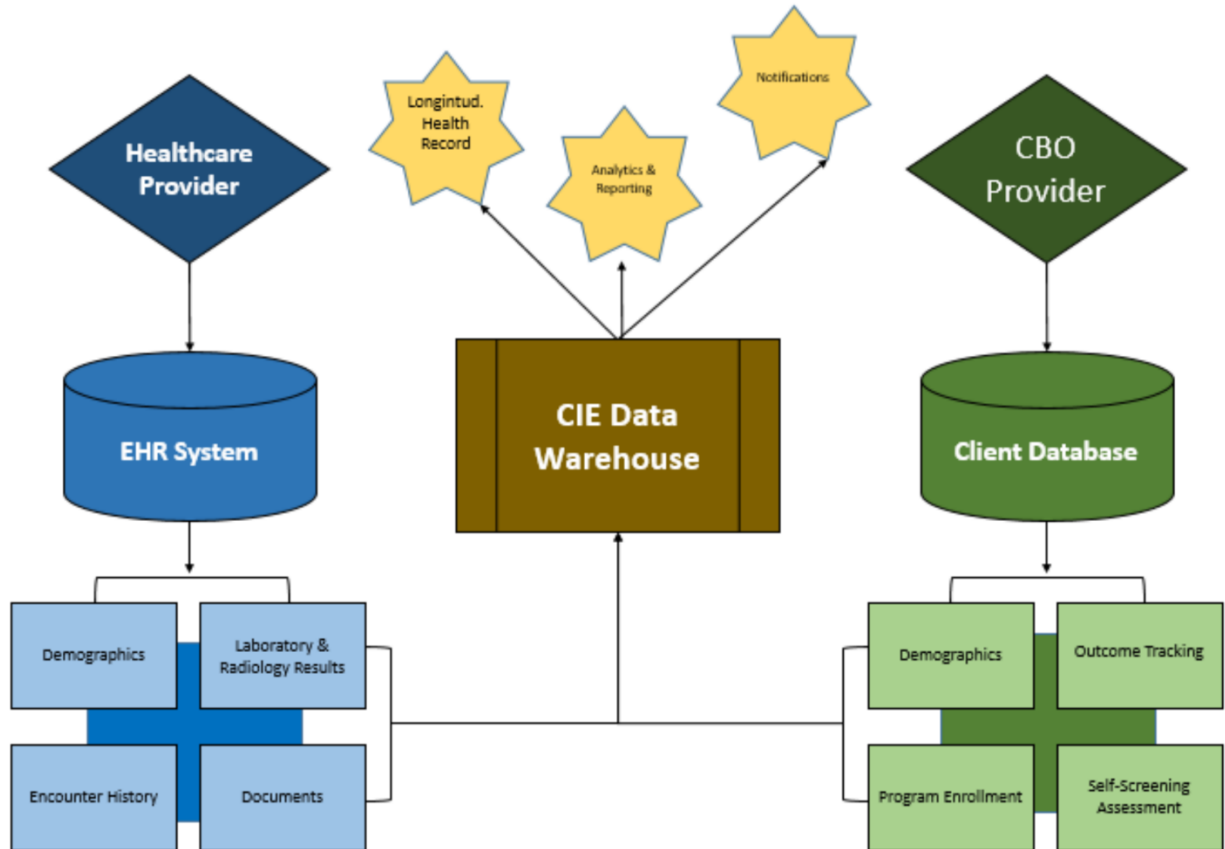
*Out of Scope Components: The technical components that are not considered the critical function of the initial release and which will be re-prioritized in the future for inclusion within the broader platform.*

<b>Component</b>	<b>Description</b>
Universal Social Risk Assessment Tools	Delivery of universal social risk screening tools (e.g., NACHC PRAPARE, CMS AHC-HRSN) commonly employed by healthcare and social services providers during intake procedures to surface social risk factors and to determine social needs. These tools would be made available to providers who may not have the same technology available within their internal organizations so that they can benefit from such risk-assessment measures.
Resource Directory Management	Development and maintenance of a resource directory management system that clearly articulates information about healthcare and social services resources available to people in need to support service discovery and accessibility.
Closed-Loop Referral System	Availability of a mechanism that allows providers working with people for various care needs to make referrals to outside organizations. Closing-the-loop requires bi-directional information sharing and communication among providers to ensure that persons obtain the services and support that they are intended to receive.

## Technical Components Diagrams

The following diagrams illustrate the high-level design of key technical components involved in the development of the Maine CIE's longitudinal health record.





## Longitudinal Health Record Examples

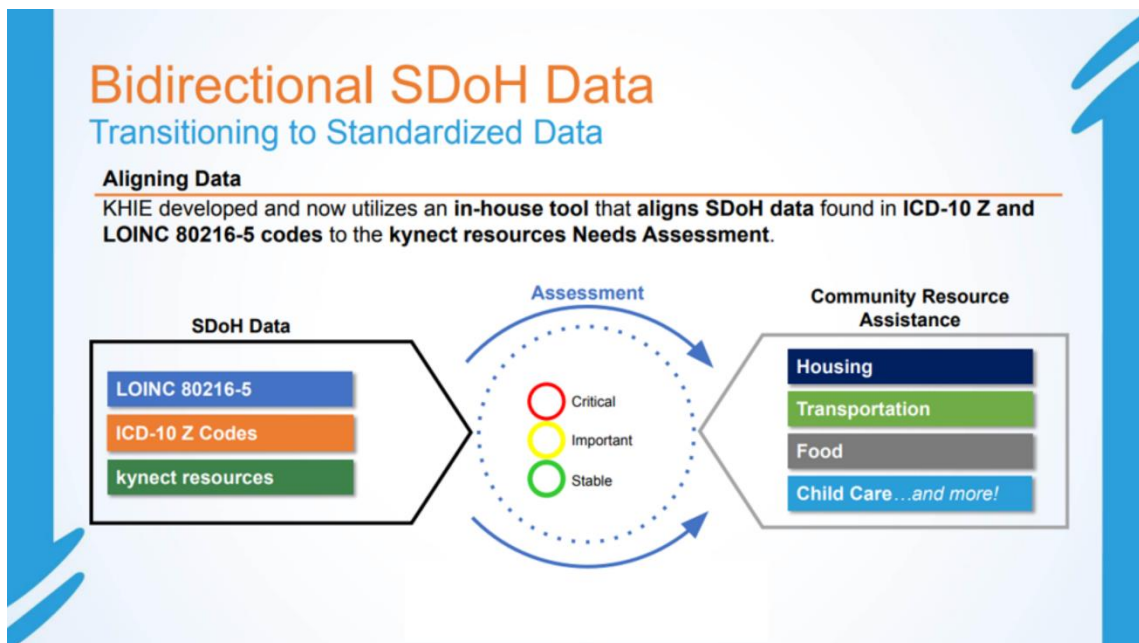
The following section shares a few examples of longitudinal health records developed by other CIE stewards throughout the country as a way of demonstrating the concept of the Maine CIE's vision.

### *San Diego 211 “Shared Client Record”*

The screenshot displays the 'Shared Client Record' interface for a client named SADIE TEST23. The interface is divided into several sections:

- Client Details:** Account Name (SADIE TEST23), Age (28), Email (andrew.barnhart@...), Social Security Number (123456789), Monthly Income Amount (2,500.00), Phone ((770) 402-5192), Percent Of FPL (144.37%), Military Service Status (Data not captured), Birthdate (1/17/1990), Gender Identity (Man), Health Insurance Type (Military (TRICARE)), Employment Status (Data not captured), Highest Level Of School Completed (Data not captured), Last Assessment (9/14/2018 4:00 PM), and Account Owner (211-Nav Test [Access]).
- Domain Nutrition:** A form for the Nutrition domain with fields for Prescreen Completed (Not likely eligible because: Not Applicable), Declined Prescreening (checkbox), Language (Data not captured), Including yourself, how many people live in your household that you purchase and prepare meals with regularly? (3), What is your household's gross income in the last 30 days? (2,500), and Does your household have any more than \$100 in resources? (Data not captured).
- Domains:** A list of domains on the right side of the interface, each with a status and last assessment date:
  - Nutrition (Thriving): Last Assessment: 9/14/2018 4:00 PM, Actions: 11, Referrals: 12
  - Transportation (Critical): Last Assessment: 9/13/2018 11:37 AM, Actions: 3, Referrals: 2
  - Primary Care (Vulnerable): Last Assessment: 9/12/2018 4:18 PM, Actions: 1, Referrals: 0
  - Housing (Thriving): Last Assessment: 8/14/2018 3:05 PM, Actions: 13, Referrals: 9
  - Utility (Thriving): Last Assessment: 9/5/2017 9:22 AM, Actions: 5, Referrals: 5
  - Social/Community Connection (Critical): Last Assessment: 8/17/2018 12:15 PM, Actions: 4, Referrals: 7
  - Health Management (Thriving): Last Assessment: 8/16/2018 3:28 PM, Actions: 5, Referrals: 3

### *Kentucky Health Information Exchange “Integrated Health Platform”*



### Enhanced functionality in ePartnerViewer

**Patient-specific  
SDoH data  
aligned with  
kynect  
resources  
domains**

## Priority Domains

The following section provides additional information about each of the key social risk domains prioritized for inclusion within the CIE system based on survey results from Phase I planning efforts.

### *Food Security*

**Definition:** Individuals' access to food and/or the necessary tools to prepare meals and/or competence of how to prepare meals successfully.

The following information was collected during the Maine CIE Phase I planning convening series:

Category	Healthcare Organizations	Community-Based Organizations
Data Collection Methods	Primarily assess person-level risk via social risk screening tools conducted during intake processes.  Common tools include <b>Hunger Vital Signs, PRAPARE, custom EMR assessments</b> , other unspecified SDOH tools.	Primarily assess person-level risk via individual <b>requests received and referrals received</b> from healthcare organizations, insurers, other CBOs.  May also collect population-level data via <b>Feeding America, USFDA, health systems' EMR-specific reports</b> .
Data Storage Methods	Primarily store person-level screening response(s) data in internal EMRs and/or social/community data platforms (e.g., findhelp, empowOR); some using Excel-based processes.	Mixed methods to store person-level risk/need information, including Link2Feed, Well Sky, iCarol, empowOR, and other internal systems, as well as Excel-based or other similar manual processes.
Relevant Data Elements	<p><u>Population-level metrics:</u> Screening rates (adults, children); at-risk/in-need counts/rates.</p> <p><u>Person-level data elements:</u> Demographics, screening response(s), risk score, insurer, primary healthcare provider, chronic conditions.</p>	
Data-Informed Actions	<p>Partner with/refer to local food pantries and GSFB, give access to Patient Assistance Line and other resource materials, provide emergency food boxes/bags, collaborate with SNAP/WIC services.</p> <p>Additionally, organizations will track at-risk/in-need persons over time, continuously assess community utilization/need against service availability, make program/partner decisions, inform internal quality improvement activities, build advocacy efforts.</p>	<p>Distribute food, provide program funding/support, partner with/refer to local food pantries, GSFB, and AAAs (Meals on Wheels), enable access to Cooking Matters classes and other nutrition education/counseling, collaborate with SNAP/WIC services.</p> <p>Additionally, organizations will track at-risk/in-need persons over time, continuously assess community utilization/need against service availability, make program/partner decisions, inform internal quality improvement activities, build advocacy efforts.</p>

Category	Healthcare Organizations	Community-Based Organizations
Partner Organizations	Both healthcare organizations and CBOs commonly share both population- and person-level data with the following entities: Internal organizational departments, State programs (e.g., WIC, SNAP, OMS), Good Shepherd Food Bank, United Way, Area Agencies on Aging, funders, general public/consumers.	

### *Transportation Access*

**Definition:** Individuals' abilities to get to and from work, access healthy food options, visit healthcare providers, and generally travel to and from appointments and other locations critical to daily living.<sup>1</sup>

The following information was collected during the Maine CIE Phase I planning convening series:

Category	Healthcare Organizations	Community-Based Organizations
Data Collection Methods	Primarily assess person-level risk via social risk screening tools conducted during intake processes.  Common tools include PRAPARE, CMS Accountable Health Communities, custom EMR assessments, and other unspecified SDOH tools.  Some organizations have non-scripted conversations with patients to assess risk.	Primarily assess person-level risk via individual requests received.
Data Storage Methods	Primarily store person-level screening response(s) data in internal EMRs and/or social/community data platforms (e.g., findhelp, empowOR) and other domain-specific services (e.g., Mobilitat).	Mixed methods to store person-level risk/need information, including Well Sky, iCarol, and other internal systems.
Relevant Data Elements	<u>Population-level metrics:</u> Number of individuals receiving services. <u>Person-level data elements:</u> Demographics, screening response(s), services received. Many of the assessments/tools used do not attribute the use of related services to person-level needs or challenges	
Data-Informed Actions	As a result of identifying in-need populations and/or persons, the following actions are commonly performed by both healthcare organizations and CBOs: provide public transportation/taxi vouchers (e.g., Lynx Transportation, UberHealth) and gas cards, refer to volunteer-based transportation services (e.g., Friends In Action), make referrals to Community Action Program (CAP) agencies and AAAs and other local municipal programs and services	
Partner Organizations	Both healthcare organizations and CBOs commonly share both population- and person-level data with the following entities: Internal organizational departments, Greater Portland Council of Governments (GPCOG), United Way, State programs (e.g., OADS), general public/consumers  However, the majority of organizations do not share their transportation data externally. Furthermore, if they do, it is not in a consistent way each time; it is more on a per individual basis.	



## Housing Stability & Quality

### Definition:

- *Homelessness* – Individuals who are lacking housing, including the use of shelters, transitional housing, and other day-to-day paid options (e.g., motels, hotels, etc.), or who are living with others temporarily or on the street.<sup>1</sup>
- *Housing Insecurity* – Individuals who are at risk of losing their homes due to the inability to consistently afford payments.<sup>1</sup>
- *Housing Inadequacy* – Individuals who are living in housing of poor quality and/or condition.<sup>1</sup>

The following information was collected during the Maine CIE Phase I planning convening series:

Category	Healthcare Organizations	Community-Based Organizations
Data Collection Methods	Primarily assess person-level risk via social risk screening tools conducted during intake processes.  Common tools include PRAPARE, CMS Accountable Health Communities, custom EMR assessments, other unspecified SDOH tools and eligibility checks.  Some organizations have non-scripted conversations with patients to assess risk.	Primarily assess person-level risk via individual requests received
Data Storage Methods	Primarily store person-level screening response(s) data in internal EMRs.	<u>CBOs</u> : Mixed methods to store person-level risk/need information, including Well Sky, iCarol, and other internal systems.
Relevant Data Elements	<p><u>Population-level metrics</u>: Number of individuals requesting services and where they receive services.</p> <p><u>Person-level data elements</u>: Demographics, screening response(s) (i.e., housing insecurity risk, utility status), household information, rental information, income, housing safety issues.</p>	
Data-Informed Actions	Partner with organizations (e.g., CAP agencies, Community Health and Counseling Services, local municipalities) that can assist with rental payments and provide homebuyer educational resources, foreclosure prevention information, home repair services, utility assistance, and supportive housing units and residential services for women (and their children) in recovery; refer to local housing authorities (e.g., Community Housing of Maine), transitional housing developments (e.g., Hope House), and	Provide individuals with information and referrals to statewide and local programs upon conducting eligibility/enrollment checks; inform programmatic decision-making as well as community needs assessments.

Category	Healthcare Organizations	Community-Based Organizations
	shelters (e.g., York County Shelter Programs).	
Partner Organizations	Both healthcare organizations and CBOs have limited data sharing capabilities outside of their organizations; though both may share both population- and person-level data with the following entities: MaineHousing, United Way, and State of Maine programs (e.g., OADS)	

## Use Case Statements

The following section provides use case statements for each of the prioritized technical components involved in the initial release of the Maine CIE system to network partners as a way of articulating the business requirements of the platform from which the technical specifications will be derived. Note that “Consumers” are not yet a defined stakeholder as part of these use case statements, as the consumer-facing application is not considered a priority technical component as part of the CIE’s first release.

*Core Service Components: The technical components that are considered the critical function of the initial release on which the requirements for all other technical components are defined.*

Component	Healthcare Provider	Community Based Provider	CIE Administrator
Data Integration Services	<ul style="list-style-type: none"> <li>● I want to share discrete HL7 messages (and/or blob-formatted documents, if necessary) from my organization’s EHR system that contains social risk factor information (screeners, diagnoses, interventions, and/or goals) about my patients so that it can be shared with those patients’ cross-sector providers.</li> <li>● I want to share discrete HL7 messages (and/or blob-formatted documents, if necessary) from my organization’s EHR system that contains relevant clinical information about my patients so that it can be fully integrated with their social health risks and needs.</li> </ul>	<ul style="list-style-type: none"> <li>● I want to share information about the programs, services, and referrals received by my clients in whatever form my organization stores the data so that it can be shared with those clients’ cross-sector providers.</li> </ul>	<ul style="list-style-type: none"> <li>● I want to be able to receive other miscellaneous federal/state/local data sources (e.g., Medicaid eligibility/claims, medication information, USCDA, Feeding America, etc.) to supplement network partners’ data sets to help inform care delivery.</li> </ul>
Longitudinal Health Record	<ul style="list-style-type: none"> <li>● I want to be able to look up a particular person in the CIE platform and find a record of all of their relevant health-related encounters and services received from diverse network partners to help inform the best possible care delivery.</li> <li>● I want my organization – and specific subsets of users at my organization – to have varying levels of access to the necessary information about persons’ cross-sector health-related encounters and services so that it prevents information over-sharing and over-use.</li> </ul>		<ul style="list-style-type: none"> <li>●</li> </ul>

Component	Healthcare Provider	Community Based Provider	CIE Administrator
	<ul style="list-style-type: none"> <li>● I want the longitudinal health record to be available to my organization at the point of care so that it makes for the most effective and efficient care delivery.</li> <li>● As a CBO, I want to see services and referrals provided by other CBOs.</li> <li>● As a CBO, I want to see clinical information trends/patterns at an aggregate, population-health level as it relates to social service needs.</li> </ul>		

*Optional Service Components: The technical components that complement the core service components but which are not required for the initial release.*

Component	Healthcare Provider	Community Based Provider	CIE Administrator
Notifications	<ul style="list-style-type: none"> <li>● I want to be able to receive real-time alerts on critical health-related and social health-related activities that are triggered by new data received by cross-sector providers on the individuals that I serve so that I can inform appropriate next steps in their care delivery.</li> </ul>		<ul style="list-style-type: none"> <li>●</li> </ul>
Analytics & Reporting	<ul style="list-style-type: none"> <li>● I want to be able to receive descriptive analytics on the types and amounts of cross-sector services received by the individuals that I serve so that I can get a sense of cross-sector utilization.</li> <li>● I want to be able to receive standard quality performance measurement aligning with federal/state/local program requirements and expectations so that I do not need to invest in internal resources to develop the same metrics for my organization.</li> <li>● I want to be able to receive predictive risk measurement on the patients that I serve to help inform future care delivery actions.</li> </ul>		<ul style="list-style-type: none"> <li>●</li> </ul>

*Infrastructure Components: The underlying, backend technical components that together develop the critical functions of the initial release.*

Component	Healthcare Provider	Community Based Provider	CIE Administrator
Infrastructure & Environment Configuration	<ul style="list-style-type: none"> <li>● I want the infrastructure and environment configured to support the CIE platform as secure as possible so that my organization – and the individuals that we serve – feel safe and confident in sharing the information beyond the confines of my organization.</li> </ul>		<ul style="list-style-type: none"> <li>● I want access to a backend data warehouse that includes a data model storing an integrated cross-sector data set so that I can mine the data for clients to find new insights beyond the</li> </ul>

Component	Healthcare Provider	Community Based Provider	CIE Administrator
	<ul style="list-style-type: none"> <li>● I want the CIE infrastructure and environment to prevent bi-directional access to my organization's internal data system so that my organization's internal workflows are not disturbed.</li> <li>● I want a Demonstration environment with de-identified data sets so that I can demonstrate the environment and/or use the environment for training purposes with new end users at my organization without having to expose PHI/PII.</li> </ul>		<p>restrictions enforced by the front-end user interface.</p> <ul style="list-style-type: none"> <li>● I want the CIE to have backend and frontend versions of a Development environment for creating new features/functionality, a Test environment for performing quality assurance on new features/functionality before deploying to Production, and a Production environment that maintains the current configuration of the system as it is available to end users.</li> <li>● I want a support staff of database architects, software engineers, data analysts, customer support analysts, and project managers available at any time in the event that the CIE infrastructure and/or environment experiences a downtime or bug so that network partners and their end users feel supported and in-the-know when technical issues arise.</li> <li>● I want a Demonstration environment with de-identified data sets so that I can demonstrate the environment to new network partners and/or to train new end users without having to expose PHI/PII.</li> </ul>
Interoperable Data Exchange Standards	<ul style="list-style-type: none"> <li>●</li> </ul>	<ul style="list-style-type: none"> <li>● I want to assure that the information that I have available within my internal organization to share with cross-sector providers can be shared</li> </ul>	<ul style="list-style-type: none"> <li>● I want to leverage the most contemporary interoperability standards (e.g., FHIR-based APIs) so that the platform is capable of meeting</li> </ul>

Component	Healthcare Provider	Community Based Provider	CIE Administrator
		with and stored within the CIE platform regardless of its source format so that my organization doesn't have to endure any additional administrative burden to participate in the network.	ever-evolving data-sharing use cases defined by federal, state, and/or local program requirements and expectations.
Person Consent Management	<ul style="list-style-type: none"> <li>● I want to ensure that the individuals whose data is stored within the CIE platform have the right to share or not share their information with cross-sector providers so that their privacy and security concerns are respected.</li> <li>● I want to ensure that individuals have options in terms of what data they choose or choose not to share with the CIE so that it is not a one-size-fits-all solution.</li> <li>● I want to allow individuals to change their decisions to share or not to share information with the CIE at any given time so that they can feel comfortable participating when they do or do not want to participate.</li> <li>● I want individuals to have the option of allowing referrals across service providers resulting in contacts by those service providers.</li> </ul>		<ul style="list-style-type: none"> <li>● I want the CIE infrastructure to provide comfort and confidence in its ability to effectively and ethically manage individuals' consent choices over time so that network partners can clearly articulate the safety protocols to their organization and patients/clients.</li> <li>● I want to give the option to individuals whose information is stored within the CIE system to be able to request audit reports detailing every user who has accessed their health records so that they can feel comfortable and confident that their information is being used properly to support care decision-making.</li> </ul>
Person Identity Management System	<ul style="list-style-type: none"> <li>● I want to be able to look up a particular individual in the CIE system and only need to select one (or as few as possible) entry point to access all of that individual's health-related information so that I don't have to piece together different data points to identify the person's full story.</li> </ul>		<ul style="list-style-type: none"> <li>● I want to be able to collect enough demographic information on individuals whose data is shared with the CIE so that I can create a single health record for that individual that encompasses their encounters and services received across organizations and time.</li> <li>● I want to ensure that staff are available to make manual patient matches when</li> </ul>

Component	Healthcare Provider	Community Based Provider	CIE Administrator
			automated processes do not suffice in order to ensure the highest possible match rates for patient safety and quality purposes.
Terminology Management	<ul style="list-style-type: none"> <li>● I want to be able to send either local or standard terminology describing key health-related activities and have the CIE system standardize the information into a shared language so that cross-sector providers can easily understand and interpret the information without having to understand the many source systems.</li> <li>● I want to be able to constantly import new local codes into the CIE system to resolve unmapped or unknown lookups before their insertion into the data repository.</li> </ul>		<ul style="list-style-type: none"> <li>● I want to be able to establish uniformity of local coding norms to enable meaningful data analysis, performance measurement, and standardized reporting.</li> <li>● I want to ensure data privacy and security by flagging configurable value sets to block or sequester so that sensitive information is prevented from processing further downstream.</li> <li>● I want to leverage the most contemporary terminology management standards, such as The Gravity Project and/or the United States Core Data for Interoperability standards.</li> </ul>
Downloads & Exports	<ul style="list-style-type: none"> <li>● I want to be able to download all selected content stored in an individual's longitudinal health record to a standardized PDF format so that I can review the information offline.</li> <li>● I want to be able to export all selected content stored in an individual's longitudinal health record and electronically transfer it back into my organization's internal data warehouse.</li> </ul>		<ul style="list-style-type: none"> <li>●</li> </ul>

*Support Services Components: The various self-service and/or staffed support functions that are necessary to operationalize the technical components once deployed.*

Component	Healthcare Provider	Community Based Provider	CIE Administrator
Help Desk Support	<ul style="list-style-type: none"> <li>• I want self-service functionality that allows me to give new users at my organization role-based access to the CIE system so that I can easily expand my organization's access to the system when needed.</li> <li>• I want the CIE to provide staffed help desk support functions in the event that I do not have the staff internally do leverage self-service functions as well as to provide assistance when technical troubleshooting/issues arise.</li> </ul>		•
Auditing Functions	<ul style="list-style-type: none"> <li>• I want self-service functionality that allows me to view which users have viewed which individuals' longitudinal health records – and the specific content viewed within those records – so that my organization is constantly able to confirm that users are appropriately accessing records.</li> </ul>		•
Training & Education	<ul style="list-style-type: none"> <li>• I want self-service education and training opportunities that allow me to learn the business and technical nuances of the CIE system so that I don't have to spend time in a formal training to do so.</li> <li>• I want the CIE to provide staffed education and training support functions in the event that I do not have the capability of leveraging the self-service functions as well as to receive ad hoc assistance when needed.</li> <li>• I want a de-identified demonstration environment to be able to train new end users at my organization without needing to display PHI/PII.</li> </ul>		•

*User Interface Components: The user interface and workflow requirements governing the user experience of the technical components.*

Component	Healthcare Provider	Community Based Provider	CIE Administrator
User Interface Design and Workflow	<ul style="list-style-type: none"> <li>• I want to be able to log in to one frontend system that is intuitive and user friendly, and which allows me to access all of the desired cross-sector information on the individuals who I serve.</li> </ul>		•

*Access Components: The specific user roles governing the design, accessibility, and permissions associated with the construction of a frontend system.*

Component	Healthcare Provider	Community Based Provider	CIE Administrator
Provider Application	<ul style="list-style-type: none"> <li>• I want to be able to receive role-based access to a frontend system that gives</li> </ul>	•	•



Component	Healthcare Provider	Community Based Provider	CIE Administrator
	my organization access to information on my patients' cross-sector services.		
Consumer Application	<ul style="list-style-type: none"> <li></li> </ul>	<ul style="list-style-type: none"> <li>● I want to be able to receive role-based access to a frontend system that gives my organization access to information on my clients' cross-sector services.</li> </ul>	<ul style="list-style-type: none"> <li></li> </ul>

## Discussion Questions

The following section captures various questions pertaining to each of the prioritized technical components involved in the initial release of the Maine CIE system to network partners that the Data and Technology Workgroup will resolve within this document to help inform technical specifications.

*Core Service Components: The technical components that are considered the critical function of the initial release on which the requirements for all other technical components are defined.*

Component	Description
Data Integration Services	<ul style="list-style-type: none"><li>• Do we want to ensure that information collected from CBOs is standardized before the CIE's receipt or during the processing through the CIE's data integration engine? (Related to the terminology management service functions.)</li><li>• Add new questions here.</li></ul>
Longitudinal Health Record	<ul style="list-style-type: none"><li>• What kind of information should be contained in a person's longitudinal health record?</li><li>• How would this information be received from participating CIE healthcare and social services providers?</li><li>• Who would be able to access a person's longitudinal health records – and when and in what circumstances would this access be acceptable?</li><li>• What types of user roles should be developed in the CIE system to support "minimal viable" viewing of persons' longitudinal health records?</li><li>• Add new questions here.</li></ul>

*Optional Service Components: The technical components that complement the core service components but which are not required for the initial release.*

Component	Description
Notifications	<ul style="list-style-type: none"><li>• Would/should users be able to set notifications based on certain criteria and if so, which criteria?</li><li>• Add new questions here.</li></ul>
Analytics & Reporting	<ul style="list-style-type: none"><li>• Do we have a system that allows for building custom reports and who would have access to this?</li><li>• Add new questions here.</li></ul>

*Infrastructure Components: The underlying, backend technical components that together develop the critical functions of the initial release.*

Component	Description
Infrastructure & Environment Configuration	<ul style="list-style-type: none"><li>• Add new questions here.</li></ul>
Interoperable Data Exchange Standards	<ul style="list-style-type: none"><li>• How might the CIE (and its associated partners) establish compliance with interoperability protocols through procurement policies – such that, for instance, adoption of an open standard is required as a condition of executing a contract?</li><li>• In a shared system, to what extent should healthcare protocols be imposed upon social service sectors and to what extent should data exchange about social service clients reflect the needs and conventions of social services?</li></ul>

Component	Description
	<ul style="list-style-type: none"> <li>○ Does the CIE need to adhere to and/or support the various federal regulations on healthcare systems to adopt FHIR-based API standards and general data standards/stewardship (e.g., ONC USCDI)?</li> <li>● What will be the “common denominator” for allowing healthcare and social services providers to connect to the CIE as a data-sharing participant? In other words, what is the mechanism by which the CIE will accept person information (e.g., flat files via SFTP, interface feeds from electronic health record (EHR) systems, etc.)?</li> <li>● What are the technical specifications involved in sharing personal information with the CIE? Will providers interested in sharing data be required to send information in a discrete data format (rather than in a blob structure) to enable the most useful application of the information across the CIE’s services?</li> <li>● What sort of privacy and security considerations and protocols need to be made within the CIE technology stack to protect patients’ protected health information (PHI) and other non-PHI sensitive health information?</li> <li>● What local, statewide, and/or national data systems does the CIE want to be able to integrate with for more expansive feature/functionality use cases? <ul style="list-style-type: none"> <li>○ In what conditions would the CIE accept and/or share data with other systems?</li> </ul> </li> <li>● Will the CIE allow providers to perform single-sign-on to the CIE from each of critical internal electronic applications?</li> <li>● How can communities navigate the risks and potential benefits of centralized, decentralized, or federated approaches to data exchange?</li> <li>● <b>Add new questions here.</b></li> </ul>
Person Consent Management	<ul style="list-style-type: none"> <li>● Are there already existing person consent management infrastructures that might be available for use by a CIE, such as through a regional HIE’s Person Identity Management system?</li> <li>● What additional consent and governance considerations are required by the creation of a person-specific longitudinal health record?</li> <li>● What additional consent and governance considerations are required by the creation of a closed-loop referral system?</li> <li>● What kinds of activities should require users to actively agree to ‘opt in’ and what kinds of activities should merely offer an option to ‘opt out’? Should these decisions be associated with distinct levels of permissiveness and sensitivity of the resulting data exchange and use?</li> <li>● How can users retain specific control over what kinds of data they do or do not agree to share, with whom, and for what purpose?</li> <li>● How will the CIE ensure that users are presented with an appropriate amount of context to inform their decisions?</li> <li>● How will the CIE ensure that consent is sustained over time and revocable as necessary?</li> </ul>

Component	Description
	<ul style="list-style-type: none"> <li>● Should clients be able to change their data sharing relationship with their providers and associated institutions over time, or is consent/governance more of a global decision?</li> <li>● How will the CIE address the entanglement between one person's data and data about other individuals in primary, secondary and tertiary relationship with them?</li> <li>● How will consent to share be ethically managed among a connected cohort of individuals, families, caregivers, and communities?</li> <li>● How will the CIE solicit and sustain the consent of its community for data about the community to be extracted, used, and governed – especially for policy making and resource allocation?</li> <li>● <b>Add new questions here.</b></li> </ul>
Person Identity Management System	<ul style="list-style-type: none"> <li>● Are there already existing identity-matching infrastructures that might be available for use by a CIE, such as a regional HIE's Person Identity Management system?</li> <li>● How can CIEs evaluate identity matching frameworks across care management systems with a minimally viable set of fields and processes (name, DOB, etc.)?</li> <li>● How will the CIE monitor for, address and redress instances of false negatives (failure to match an individual's existing records, resulting in duplicates) and false positives (incorrectly matched individuals)?</li> <li>● Which priority local, statewide, and/or national data systems does the CIE want to be able to integrate with through the creation of a shared person identifier?</li> <li>● <b>Add new questions here.</b></li> </ul>
Terminology Management	<ul style="list-style-type: none"> <li>● Are there already existing terminology standards for social risks and needs, diagnoses, interventions, and goals that can tell a comprehensive story about a person's condition?</li> <li>● How will a CIE foster semantic interoperability (via shared taxonomies and vocabularies) for data about types of people and situations stored in its systems?</li> <li>● How will the CIE use existing standardized taxonomies (e.g., LOINC, SNOMED, ICD-10, etc.), and how will these terminologies be locally adapted to reflect the needs and culture of the community?</li> <li>● To what extent will the CIE's strategy depend upon processes of translation, alignment, and clarification across a diverse landscape of service provision?</li> <li>● How will a CIE establish methods by which stakeholders – primarily service providers and service users – can participate in these processes of vocabulary definition and alignment?</li> <li>● How will stakeholders be able to challenge and improve the formulation and application of terminology about themselves?</li> <li>● What are the “minimally viable” protocols and processes that will enable exchange of data about patients across platforms and sectors?</li> <li>● What are some of the use cases that the CIE's features and functionality may want to leverage local and/or industry standard vocabularies?</li> </ul>

Component	Description
	<ul style="list-style-type: none"> <li>● Add new questions here.</li> </ul>
Downloads & Exports	<ul style="list-style-type: none"> <li>● Add new questions here.</li> </ul>

*Support Services Components: The various self-service and/or staffed support functions that are necessary to operationalize the technical components once deployed.*

Component	Description
Help Desk Support	<ul style="list-style-type: none"> <li>● Add new questions here.</li> </ul>
Auditing Functions	<ul style="list-style-type: none"> <li>● Add new questions here.</li> </ul>
Training & Education	<ul style="list-style-type: none"> <li>● Add new questions here.</li> </ul>

*User Interface Components: The user interface and workflow requirements governing the user experience of the technical components.*

Component	Description
User Interface Design and Workflow	<ul style="list-style-type: none"> <li>● Add new questions here.</li> </ul>

*Access Components: The specific user roles governing the design, accessibility, and permissions associated with the construction of a frontend system.*

Component	Description
Provider Application	<ul style="list-style-type: none"> <li>● Add new questions here.</li> </ul>
Consumer Application	<ul style="list-style-type: none"> <li>● Add new questions here.</li> </ul>

## **APPENDIX I**

### **Resources Used in the Maine CIE Phase II Project**

The Maine CIE Phase II Steering Committee and Workgroups used a variety of resources to inform their work.

**San Diego 211 CIE Toolkit** The CIE<sup>®</sup> Toolkit is designed to assist communities interested in learning how to harness the value of cross-sector collaboration and data sharing to develop a Community Information Exchange (CIE) that enables a network of health, human, and social service providers to deliver coordinated, person-centered care to address social determinants of health to improve population health. [Toolkit - CIE San Diego](#)

**San Diego 211 The Community Profiles** were produced as part of our project, *Leveraging Community Information Exchanges for Equitable and Inclusive Data*, with support from the Robert Wood Johnson Foundation (RWJF). Engaging community members who are most impacted by services is one of the most critical elements to the successful design and implementation of a CIE. As such, these Community Profiles were developed to explore strategies and provide examples of how community members can be involved in the development and maintenance of community data systems, like CIEs. The project team conducted stakeholder interviews with seven (7) communities that are currently in planning and early implementation stages for their CIEs. [Community-Profiles-FINAL.pdf \(ciesandiego.org\)](#)

**A Toolkit for Centering Racial Equity Through Data Integration** This body of work seeks to encourage shifts of awareness and practice, by centering racial equity and community voice within the context of data integration and use. Our vision is one of ethical data use with a racial equity lens, that supports power sharing and building across agencies and community members. Actionable Intelligence for Social Policy. University of Pennsylvania. . [A Toolkit for Centering Racial Equity Throughout Data Integration – Actionable Intelligence for Social Policy \(upenn.edu\)](#)

**Social Determinants of Health Information Exchange Toolkit FOUNDATIONAL ELEMENTS FOR COMMUNITIES** February 2023 (ONC) The *Social Determinants of Health Information Exchange Toolkit* (Toolkit) can support communities working toward achieving health equity through SDOH information exchange and the use of interoperable, standardized data to represent SDOH. [Social Determinants of Health Information Exchange Toolkit 2023\\_508.pdf \(healthit.gov\)](#)

**Best Practices for Community Health Information Exchange** Center for Community Health Leadership With *Best Practices for Community Health Information Exchange*, the Center for Community Health Leadership has created a guide for the establishment of community-based data exchange. By following the blueprint laid out in these pages, communities can establish a solid foundation for achieving a sustainable HIE capable of providing demonstrable returns and accommodating the diverse needs of multiple stakeholders. [CCHL BPG.pdf \(ahrq.gov\)](#)

**SHIE White Paper** This white paper was created in collaboration with the Colorado Health Institute, the Colorado Office of eHealth Innovation (OeHI), the eHealth Commission, and the OeHI Care Coordination Community Engagement Task Force in support of the Colorado Health Information Technology (IT) Roadmap. In 2018, a group of governmental, health care, public health, philanthropic, and community-based partners published the first white paper on social health information exchange (S-HIE), emphasizing the importance of planning for a statewide infrastructure and recommending ways for these sectors to work together. Two years later, this updated white paper reiterates the need for core components for S-HIE infrastructure and highlights key considerations for moving statewide S-HIE collaborative efforts forward. [SHIE White Paper \(1\).pdf \(colorado.gov\)](#)

**Colorado Health Information Governance Guidebook** PDF September 2021 Version 1.3.pdf The Colorado Office of eHealth Innovation (OeHI) and eHealth Commission developed this Guidebook with support from Colorado Health Institute to advance Colorado's Health IT Roadmap Information Governance Initiative. This Guidebook aims to inform and align information sharing and information governance efforts underway across Colorado. [Information Governance Guidebook PDF September 2021 Version 1.3.pdf \(colorado.gov\)](#)

**Interests, dualities of interest and conflicts of interest** Conflicts of interest (COI), need to be identified and managed appropriately. It is important to define the concept of a COI carefully and to clarify strategies available to address and resolve such conflicts. It is emphasized however, that the absence of COIs does not imply that residual decisions relating to the play of interests are not complex and difficult. Accordingly, although COIs are important, it is essential not to exaggerate their role or to use them to obscure the importance of the interest-laden decisions that are made routinely. <https://www.racp.edu.au/fellows/ethical-guidelines/interests-dualities-of-interest-and-conflicts-of-interest>

**Backbone Starter Guide, A Summary of Major Resources about the Backbone from FSG and the Collective Impact Forum** The *Backbone Starter Guide* summarizes the collective impact approach and highlights the major ideas and learnings that have been previously published by FSG and the Collective Impact Forum. Backbone support is critical infrastructure for successful collective impact efforts. Without a dedicated backbone performing core functions to support the cross-sector collaboration of diverse partners, collective impact will not succeed. Thus, careful consideration is necessary when designing and structuring the backbone, selecting backbone staff, and allocating the backbone's capacity across six core functions during each phase of a collective impact effort. Sustained funding for the backbone is also important to provide continuity, stability, and support needed for the effort's members and partners to achieve a shared goal. [Backbone Starter Guide: A Summary of Major Resources about the Backbone - Collective Impact Forum](#)

**Data Sharing and Law Deep Dive on Consent** During a Deep Dive workshop at the 2018 All In: Data for Community Health National Meeting, attorneys from the Network for Public Health Law explored when consent may or may not be the key to sharing data and how policies and regulations governing health care,

education, and behavioral health data like HIPAA, FERPA, and 42 CFR Part 2 impact consent. The Colorado Regional Health Information Organization (CORHIO) shared insights from the Colorado Advanced Interoperability Initiative deploying a SAMHSA-sponsored, open-source Consent2Share consent management platform. This workshop proceedings report shares some of the key themes that engaged participants. [Data-Sharing-and-the-Law-Deep-Dive-on-Consent.pdf \(squarespace.com\)](#)

### **Modernizing Consent to Advance Health and Equity**

#### **A NATIONAL SURVEY OF KEY TECHNOLOGIES, LEGAL ISSUES AND PROMISING**

**PRACTICES** (Stewards of Change Institute) - review consent-related initiatives not just in the world of healthcare, but also in other domains that significantly impact health and well-being. Those include but are not limited to education, justice and human/social services. The content in this report comes primarily from health care-related domains, because those are where issues related to consent currently receive the most attention and 1 where, generally speaking, the most progress on modernizing consent processes is being made. That said, our “target audience” is not solely healthcare institutions and systems. [1-7-22-SHORT-with-TOC-.pdf \(stewardsofchange.org\)](#)

### **Tackling Data Dilemmas in Social Care Coordination Pursuing Open and Equitable Infrastructure Across a Fragmented Health and Social Service Landscape**

This project was supported by Data Across Sectors for Health (DASH), a national program of the Robert Wood Johnson Foundation led by the Illinois Public Health Institute in partnership with the Michigan Public Health Institute. Throughout the past decade, a flurry of software companies, data systems, funding programs and other initiatives have engaged in efforts to “address SDOH” — i.e. improve patients’ social circumstances and overall wellbeing — by improving the coordination of health and social care. This paper explores common challenges that hinder such efforts, focusing specifically on how data are — or are not, or could be, or shouldn’t be — shared among organizations across diverse institutional contexts. [social-care-data-whitepaper-october-2021.pdf \(umsl.edu\)](#)

### **Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration Actual Intelligence for Social Policy, Expert Panel Report**

Actionable Intelligence for Social Policy. University of R. Created to support the essential and challenging work of exchanging, linking, and using data across government agencies. [Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration – Actionable Intelligence for Social Policy \(upenn.edu\)](#)

#### **Culhane**

### **The HIPAA Privacy Rule and Electronic Health Information Exchange in a Networked Environment**

This guidance is composed of a series of fact sheets that clarify how the HIPAA Privacy Rule applies to and can be used to help structure the privacy policies behind, electronic health information exchange in a networked environment. [introduction.pdf \(hhs.gov\)](#)



**CMS Proposes Rule to Expand Access to Health Information and Improve the Prior Authorization Process** Press Release The Centers for Medicare & Medicaid Services (CMS) issued a proposed rule that would improve patient and provider access to health information and streamline processes related to prior authorization for medical items and services. CMS proposes to modernize the health care system by requiring certain payers to implement an electronic prior authorization process, shorten the time frames for certain payers to respond to prior authorization requests, and establish policies to make the prior authorization process more efficient and transparent.

<https://www.cms.gov/newsroom/press-releases/cms-proposes-rule-expand-access-health-information-and-improve-prior-authorization-process>

**Advancing Interoperability and Improving Prior Authorization Processes** Proposed Rule CMS-0057-P: Fact Sheet The Centers for Medicare & Medicaid Services (CMS) is continuing to advance our interoperability goals and tackle process challenges related to prior authorization to increase efficiencies in healthcare <https://www.cms.gov/newsroom/fact-sheets/advancing-interoperability-and-improving-prior-authorization-processes-proposed-rule-cms-0057-p-fact>

**Policies and Technology for Interoperability and Burden Reduction with a link to the proposed rule:**

The CMS regulations include policies, which require or encourage payers to implement Application Programming Interfaces (APIs) to improve the electronic exchange of health care data – sharing information with patients or exchanging information between a payer and provider or between two payers. APIs can connect to mobile apps or to a provider electronic health record (EHR) or practice management system to enable a more seamless method of exchanging information. The regulations also include policies which may reduce burdens of the prior authorization process by increasing automation and encouraging improvements in policies and procedures to streamline decision making and communications.

<https://www.cms.gov/regulations-and-guidance/guidance/interoperability/index>

**Understanding HIE CIE Alignment by Mark Elson | Aug 3, 2022 Intrepid/Ascent, [Understanding HIE and CIE Alignment - Intrepid Ascent](#)** this article contrasts Community Information Exchange (CIE) with Health Information Exchange (HIE) to cast into relief important differences, highlight core similarities, and explore the alignment of HIE and CIE services. A primary goal here is to assist health care colleagues who are familiar with HIE to grasp more concretely the opportunities and challenges of CIE and what they mean for our field. I conclude with considerations for HIOs that wish to expand to offer CIE services and, on the other side of the coin, offer recommendations for CIEs that seek to leverage the value of health information exchange in their communities.

**The Maine Shared Community Health Needs Assessment** (Maine Shared CHNA) is a collaboration between Central Maine Healthcare (CMHC), Maine Center for Disease Control and Prevention (Maine CDC), MaineGeneral Health (MGH), MaineHealth (MH), and Northern Light Health (NLH). The vision of the Maine Shared CHNA is to turn health data into action so that Maine will become the healthiest state in the U.S. The mission of the Maine Shared CHNA is to: • Create Shared CHNA Reports, • Engage and activate communities, and • Support data-driven health improvements for Maine people. This is the fourth Maine Shared CHNA and the third conducted on a triennial basis. [Maine Shared CHNA Final Reports](#)

**Leveraging Integrated Networks in Communities to Address Social Needs Act** A lack of coordination and longstanding programmatic siloes between social service organizations and health care organizations make it difficult for states to promote coordinated service delivery and manage public health emergencies. The health care and social services sectors are not generally connected in a sustainable, standardized way, which limits data sharing, shared accountability, and service coordination. The bipartisan, bicameral *Leveraging Integrated Networks in Communities (LINC) to Address Social Needs Act* (S. 509/H.R. 6072) will serve as a catalyst to enable states, through public-private partnerships, to leverage local expertise and technology to overcome longstanding challenges in helping to connect people to food, housing, child development, job training, and transportation supports and services. [LINC to Address Social Needs Act](#)

**Leveraging Integrated Networks in Communities To Address Social Needs Act of 2021** This bill requires the Department of Health and Human Services to award states competitive grants for technology networks that coordinate the provision of health care and social services (e.g., nutritional assistance, housing, and transportation). States must use the grants to support statewide or regional public-private partnerships in establishing or enhancing such networks. The bill outlines requirements concerning the governance structure of the networks, privacy and security, and related matters. <https://www.congress.gov/bill/117th-congress/house-bill/6072/all-info>

**Leveraging Integrated Networks in Communities to Address Social Needs Act of 2021 or the LINC to Address Social Needs Act of 2021** This bill requires the Department of Health and Human Services (HHS) to award grants to better integrate health care and social services using technology platforms and related infrastructure. To receive a grant, a state or territory must enter into a partnership with nonprofits and similar organizations or tribal nations. These public-private partnerships must foster the use of technology platforms by providers and payors of health care and social services to improve cross-sector coordination. This includes developing funding models to make the platforms financially self-sufficient. HHS must consult with stakeholders to develop data standards and guidelines for these grants, and the Government Accountability Office must evaluate the impact of the grants. <https://www.congress.gov/bill/117th-congress/senate-bill/509>

**No Going Back - Integrated Care Takes Hold in Western NH** This inexpensive patient questionnaire is taking hold in Western NH as a new ‘vital sign’ to be gathered at primary care and behavioral health appointments, as simply and routinely as height, weight, and blood pressure are gathered. Region 1 Integrated Delivery Network is one of 7 IDNs that support the NH Medicaid 1115 Waiver. Region 1 IDN has completed a 5-year demonstration program to integrate primary care, behavioral health care, and community supports. [No Going Back Integrated Care Takes Hold in We.pdf \(wsimg.com\)](#)

**The Impact of Community Health Information Exchange Usage on Time to Reutilization of Hospital Services** Increased utilization of community HIEs by primary care physicians on behalf of their recently discharged patients may dramatically increase the time until inpatient or ED reuse. [Community Health Information Exchange Reduces Likelihood of Re-Hospitalisations and Emergency Visits - HealthManagement.org](#)

**Adopting a Community Resource and Referral Platform: Considerations for Texas Medicaid Stakeholders** (Center for Healthcare Strategies and Episcopal Health Foundation) This paper was prepared by Shao-Chee Sim, PhD, Vice President for Research, Innovation and Evaluation, Episcopal Health Foundation; Anne Smithey, MPH, Program Officer, Anna Spencer, MPH, Senior Program Officer, and Diana Crumley, JD, MPAff, Senior Program Officer, Center for Health Care Strategies. To develop this brief, the Center for Health Care Strategies interviewed 11 Medicaid stakeholders in Texas, including Medicaid MCOs, HHSC staff overseeing the 211 system, provider organizations, and community resource

and referral platform staff. The goal of these interviews was to better understand how member needs are being addressed, how community resource and referral platforms are being used to support identified needs, and how cross-sector partnerships are forming in this context. [Adopting a Community Resource and Referral Platform: Considerations for Texas Medicaid Stakeholders - Center for Health Care Strategies \(chcs.org\)](#)

### **How Do Community Resource Referral Platforms Work for Social Service Organizations?**

**Lessons Learned in Trenton, New Jersey Webinar** - A collaboration between Trenton Health Team and the Social Interventions Research and Evaluation Network at the University of California, San Francisco March 1, 2023, Creating a Technology-Powered Social Service Network in Trenton, New Jersey [How do community resource referral platforms work for social service organizations? | SIREN \(ucsf.edu\)](#)

Thompson Hine **2023 U.S. State Data Protection Laws A Summary of Opt-Out Rights and Preference Signal Requirements** In 2023, new data protection laws and regulations will enter into force in California, Colorado, Connecticut, Utah, and Virginia. These new legal requirements will address a broad range of data protection rights and obligations, including how individuals can opt out from having their personal data used for targeted advertising or sold to third parties. As set forth in the table below, each state has created a unique framework for how covered businesses must allow consumers to exercise these rights via the use of opt-out “links” posted on their websites and/or through the implementation of website technology adapting to a device’s privacy configurations. [2023-U.S.-State-Data-Protection-Laws\\_A-Summary-of-Opt-Out-Rights-and-Preference-Signal-Requirements Thompson-Hine.pdf \(thompsonhine.com\)](#)

**US State Privacy Legislation Tracker Comprehensive Consumer Privacy Bills** (iapp) State-level momentum for comprehensive privacy bills is at an all-time high. The IAPP Westin Research Center actively tracks the proposed and enacted comprehensive privacy bills from across the U.S. to help our members stay informed of the changing state privacy landscape. This information is compiled into a [map](#), a [detailed chart](#) identifying key provisions in the legislation, and [links](#) to enacted state comprehensive privacy laws. [US State Privacy Legislation Tracker \(iapp.org\)](#)