Centers for Disease Control and Prevention's National Center for Chronic Disease Prevention and Health Promotion:

# Social Determinants of Health Data Exchange for Chronic Disease Prevention Initiative

Public Health Use Case Package | Version 1.2 | August 10, 2022







DISCLAIMER: This Use Case document was developed solely for informational and decisional purposes in the identification of three public health use cases for documenting and sharing social determinants of health data. This document is not policy binding, does not recommend policy directions, nor provide policy guidance.

# **Revision History**

Date	Version Number	Author	Description
July 13, 2022	1.0	Centers for Disease Control and Prevention's (CDC) Social Determinants of Health (SDOH) Public Health Use Case Workgroup for Chronic Disease Prevention	End-to-End version for workgroup members to Review.
July 27, 2022	1.1	CDC SDOH Public Health Use Case Workgroup for Chronic Disease Prevention	Incorporated End-to-End review comments submitted by workgroup members. Published for Use Case Consensus Voting.
August 10, 2022	1.2	CDC SDOH Public Health Use Case Workgroup for Chronic Disease Prevention	Incorporated Consensus Vote comments submitted by workgroup Committed Members. Published as a final deliverable.

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# 1.0 Preface and Introduction

## **1.0 Preface and Introduction**

The CDC's National Center for Chronic Disease Prevention and Health Promotion's (NCCDPHP or "Center") mission is to help people and communities prevent chronic diseases and promote health and wellness for all. Chronic diseases are defined broadly as conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both.<sup>1</sup> Presently, six in ten Americans live with at least one chronic disease such as <u>heart disease and stroke</u>, <u>cancer</u>, and <u>diabetes</u>, among others. These, and other chronic diseases, are the leading causes of death and disability in America as well as a leading driver of <u>health care costs</u>.<sup>2</sup>

The Center promotes chronic disease prevention efforts in four key areas<sup>3</sup>:

- **Epidemiology and Surveillance**. Epidemiology and surveillance entail gathering information from multiple data sources, including behavioral risk factor surveys, birth and death certificates, registries of cancer cases and deaths, and health care systems. This also involves using health information technology to improve efficiency and timeliness of public health surveillance (e.g., to speed reporting to state cancer registries).
- **Environmental Approaches**. Environmental approaches include initiatives such as fluoridating community water systems and increasing access to healthy foods and beverages (e.g., full-service groceries and farmers' markets, healthier menu items in restaurants).
- Health Care System Interventions. Health care system interventions encompass improving access to health care for populations with little or no access. This includes interventions such as cancer screenings for people without health insurance and management of high blood pressure through team-based care, the use of community health workers, patient and digital navigators, and other allied professionals delivering high-quality care.
- Community Programs Linked to Clinical Services. Community programs linked to clinical services involve increasing the use of effective community-delivered interventions such as chronic disease self-management programs including the National Diabetes Prevention Program, through clinician referrals and health insurance coverage. It can also include linking public health services to health care systems, such as tobacco quitlines.

#### **NCCDPHP's Social Determinants of Health Priorities**

The Center has long recognized the importance of addressing Social Determinants of Health (SDOH) as they are the primary drivers of health outcomes, especially for vulnerable persons and populations.<sup>4 5</sup> Differences in SDOH contribute to the stark and persistent chronic disease disparities in the United States among racial, ethnic, and socioeconomic groups. As part of the CDC's commitment to achieving health equity, the Center has developed a framework for addressing SDOH.

<sup>&</sup>lt;sup>1</sup> <u>https://www.cdc.gov/chronicdisease/about/index.htm.</u>

<sup>&</sup>lt;sup>2</sup> https://www.cdc.gov/chronicdisease/programs-impact/pop/index.htm.

<sup>&</sup>lt;sup>3</sup> https://www.cdc.gov/chronicdisease/center/nccdphp/how.htm.

<sup>&</sup>lt;sup>4</sup> <u>www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-5-key-</u> guestion-and-answers/.

<sup>&</sup>lt;sup>5</sup> De Lew N, Sommers BD. Addressing Social Determinants of Health in Federal Programs. JAMA Health Forum. 2022;3(3):e221064. doi:10.1001/jamahealthforum.2022.1064.

The five priority SDOH domains the Center is addressing are:

- **Built Environment**. The built environment is human-made surroundings that influence overall community health and individual behaviors that drive health.
- **Community-Clinical Linkages**. Community-clinical linkages are connections made among health care systems and services, public health agencies, and community-based organizations to improve population health.
- **Food and Nutrition Security**. Food and nutrition security exists when all people, at all times, have physical, social, and economic access to food that is safe and consumed in sufficient quantity and quality to meet their dietary needs and food preferences. This SDOH domain also requires an environment of adequate sanitation, health services, and care, allowing for a healthy and active life.
- **Social Connectedness**. Social connectedness is the degree to which individuals or groups of individuals have and perceive their desired number, quality, and diversity of relationships that create a sense of belonging and being cared for, valued, and supported.
- **Tobacco-Free Policy**. Tobacco-free policies are population-based, preventive measures to reduce tobacco use and tobacco-related morbidity and mortality.

As NCCDPHP carries out its mission, it supports state, local, tribal, and territorial public health jurisdictions to collect and analyze data on chronic diseases and leading health indicators through various surveillance systems and data collection efforts. This information helps public health professionals and partners understand how chronic diseases affect people and places across the United States and how well public health interventions work.<sup>6</sup>

NCCDPHP's commitment to addressing SDOH also extends to the Center's engagement in national SDOH efforts, including the <u>Gravity Project</u>. While many recognize the importance of collecting data related to SDOH, data is often collected in different formats, using different semantic or vocabulary standards. This creates additional data sharing challenges and burdens for patients, families, communities, providers, public health agencies, and other partners in addressing SDOH and achieving health and well-being for all. Addressing SDOH helps advance health equity, where "every person has the opportunity to attain his or her full health potential, and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances."<sup>7</sup>

## **Gravity Project**

Launched as a multi-stakeholder public collaborative in May 2019, the Gravity Project develops, tests, and validates standardized SDOH data for use in patient care, care coordination between health and human services sectors, population health management, public health, value-based payment, and clinical research. The Gravity Project has convened over 2,000 participants from across the health and human services ecosystem. This includes:

- clinical provider groups,
- patients, patient advocacy organizations and caregivers,
- community-based organizations,

<sup>&</sup>lt;sup>6</sup> <u>https://www.cdc.gov/chronicdisease/center/nccdphp/how.htm.</u>

<sup>&</sup>lt;sup>7</sup> <u>https://www.cdc.gov/chronicdisease/healthequity/index.htm</u>.

- standards development organizations,
- federal and state government,
- payers, and
- technology vendors.

To date, the Gravity Project has focused on developing data and exchange standards that represent patient-level SDOH data documented across four clinical activities: screening, assessment/diagnosis, goal setting, and treatment/interventions.<sup>8</sup> The Gravity Project's conceptual framework has primarily explored SDOH data standards and representation from a clinical care perspective. An individual may be seen in a clinical or community-based setting where an entity administers a screening questionnaire. Then, the framework maps how to incorporate that information into care processes. However, the Gravity Project, NCCDPHP, and many of its participants across the ecosystem believe this data can be reused upstream to support public health. To identify how best to reuse SDOH data for public health purposes, the CDC utilized the Gravity framework and collaborative consensus-building process to develop a set of use cases to galvanize public health professionals.

<sup>&</sup>lt;sup>8</sup> <u>https://www.healthit.gov/sites/default/files/facas/2021-04-08\_Gravity\_Project\_Presentation.pdf.</u>

# 2.0 Initiative Overview

## 2.0 Initiative Overview

The CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) Office of Informatics and Information Resources Management (OIIRM), in partnership with EMI Advisors LLC, launched the Social Determinants of Health (SDOH) Data Exchange for Chronic Disease Prevention Initiative to inform and drive SDOH data sharing and interoperability within public health agencies supporting prevention and control of chronic disease and health disparities. The initiative builds on the social risk domains defined under the Gravity Project, a national public collaborative focused on the development and use of consensus based standardized SDOH data.

This initiative aligns with the U.S. Department of Health and Human Services (HHS) strategic approach to address SDOH<sup>9</sup> by leading coordinated activities to better integrate health and human services to advance public health through cross-sector partnership and community engagement.

## 2.1 Public Health Business Needs Statement

CDC recognizes that conditions in which we are born, grow, live, learn, work, play, worship, and age-known as SDOH,<sup>10</sup> have a profound impact on health. Research indicates that as much as 80% to 90% of a person's health is determined by health-related behaviors, socioeconomic, and physical environment factors that typically are outside of medical care.<sup>11</sup> Individuals managing chronic medical conditions find it increasingly difficult to prioritize care through preventive measures such as eating well, being physically active, avoiding tobacco, and getting regular screenings if needing to manage social risks such as housing insecurity or financial instability. Equally challenging is the ability for partners such as public health agencies, providers, and policymakers to access, and thereby act on, data about an individual's or community's social determinants. These partners often work in siloed sectors, resulting in disconnected technical systems with incomplete, unstructured, and outdated data. This makes it more difficult to proactively address the health and well-being of individuals and communities, such as supporting immediate needs for interventions and services. These silos can adversely influence community priorities and capacity for addressing community gaps in care and services. The need for more robust, standardized, interoperable, and timely SDOH-related data to support 2030 Healthy People objectives, the Ten Essential Public Health Services, and current, and future public health emergencies will take a concerted effort across all partners.

Reference: Business Case is available at https://confluence.hl7.org/display/GRAV/Documents.

<sup>&</sup>lt;sup>9</sup> <u>https://aspe.hhs.gov/sites/default/files/documents/aabf48cbd391be21e5186eeae728ccd7/SDOH-Action-Plan-At-a-Glance.pdf</u>.

<sup>&</sup>lt;sup>10</sup> <u>https://www.cdc.gov/chronicdisease/programs-impact/sdoh.htm</u>.

<sup>&</sup>lt;sup>11</sup> Magnan, S. 2017. Social Determinants of Health 101 for Health Care: Five Plus Five. NAM Perspectives. Discussion Paper, National Academy of Medicine, Washington, DC. https://doi.org/10.31478/201710c.

# 3.0 Use Case Scope and Approach

## 3.0 Use Case Scope and Approach

## 3.1 Background

The CDC's NCCDPHP and EMI convened an open, cross-sector <u>SDOH Public Health Use</u> <u>Case Workgroup for Chronic Disease Prevention</u> to engage with public and private sector partners to advance SDOH data exchange for chronic disease prevention and health promotion. This Workgroup followed the Gravity Project framework, a national public collaborative developing structured data standards to help reduce current barriers for documenting and exchanging social risk and protective factors within the healthcare enterprise and other sectors.

The integration of health care, public health, and social services would provide significant gains in combating upstream SDOH, the macro factors that comprise social-structural influences on health and health systems, government policies, and the social, physical, economic, and environmental factors that determine health. SDOH have a direct impact on the health of individuals and populations; they also help structure lifestyle choices and behaviors, which interact to produce health or disease. At the same time, SDOH are shaped by public policy and thus, in theory, are modifiable. To this extent, the public health approach is focused on population-level interventions, disease prevention, and health metrics that address SDOH through leadership and expertise. In practice, this often involves removing barriers to services and increasing access to successful interventions.

## 3.2 Objectives

Using a consensus-based approach, CDC's SDOH Public Health Use Case Workgroup:

- 1. Convened and collaborated with industry experts including federal, state, and local multisector partners, and developed a SDOH public health business case; and
- Designed three high-priority public health-focused use cases for chronic disease prevention and health promotion that extend on those developed for <u>clinical care</u> by the Gravity Project.

Public health in the context of this SDOH initiative is defined as "the science of protecting and improving the health of people and their communities. This work is achieved by promoting healthy lifestyles, researching disease and injury prevention, and detecting, preventing, and responding to infectious diseases"<sup>12</sup> and chronic disease prevention and health promotion.

## 3.3 Out of Scope

This initiative will not focus on defining SDOH or Race, Ethnicity, Sex, Primary Language, Disability, Sexual Orientation and Gender Identity (SOGI) data elements or data exchange standards, nor will it create use cases that do not directly support the public health data activities listed in the Scope Statement. This initiative will not provide incentives for implementation of the use cases or develop data-sharing agreements and policies that promote public health and health care provider data exchange.

## 3.4 Partners

Partners engaged in the initiative include the following but are not limited to:

<sup>&</sup>lt;sup>12</sup> CDC Foundation: Public Health Connects Us All. Retrieved from <u>https://www.cdcfoundation.org/what-public-health</u>.

- Gravity Project Members and other Health Level Seven (HL7) Fast Healthcare Interoperability Resources (FHIR) Accelerator Members (Helios, CARIN, DaVinci, CodeX, Vulcan)
- State, Tribal, local, and territorial (STLT) public health agencies
- Tribal Entities
- Human Services Organizations
- Other governmental federal/state/local agencies
- Providers, Provider Associations, and Provider Settings (workplaces)
  - o Clinical and non-clinical staff within clinical settings
  - Community-based including Home and Community-Based Services (HCBS)
  - o Long-term and post-acute care
  - o Medical homes
  - Accountable Care Organizations (ACO)
  - o Health systems
  - o Hospitals
- Payers and Sponsors
  - o Federal
  - o State
  - Commercial
  - Employers
  - Non-profit foundations
- Patient, Consumer, and Beneficiary advocates (beneficiary representative and/or delegate, caregiver, family member, and other advocates).
- Government Agencies
  - Centers for Disease Control (CDC)
  - Centers for Medicare & Medicaid Services (CMS)
  - Health Resources and Services Administration (HRSA)
  - HHS Administration of Community Living (ACL)
  - HHS Agency for Healthcare Research and Quality (AHRQ)
  - HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE)
  - HHS Office of the National Coordinator for Health Information Technology (ONC)
  - National Institutes of Health (NIH): Office of Minority Health and Health Disparities
  - Social Security Administration (SSA)
  - State Medicaid offices, state health and public health departments, and state and regional health information exchange (HIE) and community information exchange (CIE)<sup>™</sup> organizations
  - HHS Indian Health Service (IHS)
  - Veterans' Health Administration (VHA)
- Vendors
  - Clinical IT Systems including electronic health records (EHR) systems, care management systems, care coordination systems or population health platforms
  - Patient/consumer tools including patient health record (PHR) portals, mobile health systems, and apps
  - Health information exchange (HIE) systems, community information exchange (CIE) ™ systems, and system integration platforms
  - Community-based IT systems including HCBS, Long-Term Services & Supports (LTSS) information systems, and community-referral platforms

- Screening tool developers
- Quality measure developers
- Data analytics developers and technologies
- Digital health technologies
- Device manufacturers
- o Data warehouse/data mart
- Standards-Related Organizations
  - Standards development organizations
  - Vocabulary/terminology organizations
- Health Information, Privacy, and Security Professionals and Advocacy Organizations

### 3.5 Use Case Approach

The Use Case package will be reviewed and finalized following nationally recognized standard development principles of openness and due process. The Workgroup activities and deliverables are:

- An <u>SDOH Public Health Business Case</u> articulating a clear business need and value proposition for investing and engaging in the project. The business case incorporates the business needs statement, goals, identified benefits, significant assumptions and constraints, issues/risks, return on investment, and schedule.
- One Public Health Story representing the personas and users engaging with a service, technology, or setting over a period of time to accomplish a specific goal. The Public Health Story will serve to illustrate an example of a real-world application of the use cases.
- A set of three SDOH Public Health Use Cases describing key conditions and business rules to enable the data collection, aggregation, and use of SDOH data to support essential public health services. The Use Case package consists of three primary components: personas, a story, and three use cases.

#### 3.5.1 Personas

Personas are commonly used in user-centered design to describe a fictional character who would represent a real user type that might use a site, brand, or product in a similar way. Personas describe the fictional character in terms of their behaviors, skills, preferences, and needs.

The workgroup developed personas to represent various user types. They focused on the following key areas:

- Name and Role
- Age
- Family Status
- Education
- Employer
- Preferences: What does this persona enjoy? What are their interests?
- Challenges: What are the persona's primary challenges and obstacles?
- Goals: What are their short-term and long-term goals?

The Public Health Story (described in the next section) includes the personas listed below. Details are available in Appendix A: Personas.

- Kevin (Care Coordinator)
- Jessica (Case Manager)
- Claudia (Public Health Analyst)
- Victor (Public Health Program Director)
- Makayla (Project Officer)

Workgroup members submitted additional personas candidates for future work considerations, available in Appendix C.

### 3.5.2 Story

The story describes the various personas engaging with a service, technology, or setting over a period of time to accomplish a specific goal. It summarizes the interactions among personas and specifies what information is captured, shared, and exchanged from a contextual perspective. Stories serve to illustrate examples of real-world applications of technical solutions. Although stories may not fully represent every real-world scenario in every instance, they are presented in a manner that will support and illustrate the Use Cases defined in this document. The story is used to identify a series of value-add transactions among the personas in the story and the technical systems they use to access and share electronic information. The Public Health Story for this initiative is described in Section 4.0.

### 3.5.3 Use Cases

Use Cases are technical narratives of the interactions between the personas and the systems they use. They are described using the following elements:

- Actors and Roles: Actors may be a person, entity, or system. An Actor describes the role within a specific transaction in a series of steps in a use case. Roles indicate the relationship between the sender and receiver of the data exchange through a specific transaction.
- Assumptions: Items expected to be true or to be in place such as a policy, process, or procedure for the execution of a specific transaction.
- **Pre-conditions:** Refers to the initial state of the system before an action or transaction occurs. These describe what must be in place from a systems perspective to support interoperable data sharing for a specific transaction.
- **Transaction:** The data exchange between two systems.
- **Message Content:** The content or substance of what is exchanged within a specific transaction.
- Post-conditions: Refers to the state of the system that will result after the execution of a processed transaction.
- Alternate Flow: Describes a scenario other than the basic flow that results in a user completing his or her goal.

Use case elements are typically illustrated using an actor-transaction diagram. The Public Health use cases and respective actor-transaction diagrams are presented in Section 7.0.

# 4.0 Public Health Story

## **4.0 Public Health Story**

The following is a detailed story that provides context around the interactions between and among actors and systems for the purpose of illustrating the Use Cases defined in this document. Some of the scenarios herein may not fully align with every role or experience in a real-world situation.

- Claudia's county Department of Health established a Public and Environmental Health Advisory Board, a citizen group to advise the Department of Health and County Board of Supervisors on community concerns and emerging public health issues.<sup>13</sup>
- During a recent meeting, Kevin, a care coordinator at one of the county's Federally Qualified Health Centers (FQHC), indicated that his FQHC is seeing a rise in levels of food insecurity among its patient population. He is worried about his patients, especially those with, or at risk for, diabetes. Jessica, a case manager from Lakeview Social Service Non-profit Organization (CBO), is also seeing a similar rise in levels of food insecurity and other social needs among her community members.
- Claudia's county Department of Health will be kicking off a community health needs assessment (CHNA) soon. As part of the CHNA, the county will conduct key informant interviews with clinical and community providers, community leaders, and advocates and hold focus groups with county residents.
- The CHNA will help identify and prioritize community needs and issues through systematic and comprehensive data collection and analysis. In preparation for the assessment, Claudia's team will identify various data sources that can help them assess the county's needs, along with the qualitative data they will obtain through interviews.
- According to the Public and Environmental Health Advisory Board's feedback regarding social needs and food insecurity, Claudia believes her team could leverage individual level social risk screening data from FQHCs and clinical and community providers. She is aware of the national initiative, the Gravity Project, that is developing data standards to capture and exchange social risk and social needs information.
- Claudia calls Jessica, Kevin, and other clinical and community providers, to establish an understanding of screening tools and SDOH-related data collection in her local community. She finds that some organizations use electronic social risk screening tools and conduct e-referrals.
- Claudia learns the regional health information exchange (HIE), which receives and exchanges identifiable data from most of the county's clinical providers,<sup>14</sup> has recently started collecting standardized SDOH-related data across some clinical and social services providers.
- Given the county's data landscape and limited resources at her county Department of Health, Claudia's team believes it worthwhile to receive SDOH-related data from clinical and community organizations via the regional HIE to support the CHNA.
- After further research and review, Claudia's county Department of Health develops an initial partnership with the regional HIE and signs a data use agreement (DUA) that permits the county to use HIE data for the CHNA. The DUA specifies that the data will be encrypted.

<sup>&</sup>lt;sup>13</sup> https://cchealth.org/public-health/pdf/community\_engagement\_in\_ph.pdf.

<sup>&</sup>lt;sup>14</sup> Clinical providers can also include providers affiliated with Department of Defense, Veterans Health Administration, and Indian Health Services.

- Claudia's county Department of Health receives the data from the HIE and assesses it for completeness and quality.<sup>15</sup> This assessment includes understanding the type of available SDOH-related data and the reason for missing data (e.g., data is incomplete, missing patients' screening assessments, bias in data collection, and/or providers not conducting screening assessments).
- One of the first concerns Claudia's team assesses is the burden<sup>16</sup> of food insecurity among people with, or at risk for, diabetes in their county. This information is paired with data on types of interventions, social services, programs, and/or resources already implemented for individuals within the zip code(s) served.
- Meanwhile, Victor, who works at the state's Department of Health, is assessing the state and CDC-funded diabetes programs. The results of his assessment will be included in the state's continuation application for their cooperative agreement supported by CDC's Division of Diabetes Translation (DDT). DDT funding supports programs and activities to prevent or delay the onset of type 2 diabetes and improve health outcomes for people with diabetes. These activities may include support for addressing individuals' social needs.
- Victor understands the state can use CDC's DDT funding to provide grants to a broad and diverse range of organizations that support the delivery of evidence-based programs to prevent and manage type 2 diabetes.
- Additionally, the state's Medicaid Program is participating in a Delivery System Reform Incentive Payment (DSRIP) program and other all-payer value-based care initiatives that encourage or mandate the documentation of SDOH-related health assessment/diagnoses using nationally recognized standards ICD-10-CM Z codes.<sup>17</sup>
- Given the recent COVID-19 pandemic and its economic ramifications, Victor wants to address food insecurity levels in areas of the state where the burden of diabetes is highest. He also wants to determine if organizations in his state are offering CDCrecognized <u>lifestyle change programs (LCPs)</u> or <u>diabetes self-management and</u> <u>education (DSMES)</u> programs in these areas.
- To begin his assessment, Victor wants data that includes a) the number of people who have, or are at risk for, diabetes by zip code and b) how many people are food insecure by zip code.
- Victor learns a regional HIE can provide limited but timely data on the burden of diabetes and food insecurity by zip code for certain geographic regions in the state.
- Victor acknowledges that it is important to understand both the resources and needs in a geographic area to determine what gaps and overlaps exist.
- Similar to the county Department of Health, Victor's state Department of Health develops an initial partnership with the HIE and signs a DUA that permits the state to use the data.
- The HIE data, along with data from other clinical and community providers, supplemented with existing Medicaid claims data (Z codes) gives Victor a more robust and comprehensive view of what is occurring across the state. He overlays this aggregated data (data from multiple sources) with the state's DDT-funded program data by zip code to identify which areas in the state to prioritize.

<sup>&</sup>lt;sup>15</sup> Additionally, it is imperative to acknowledge that state, tribal, local, and territorial (STLT) health departments can share data and information back to community members, providers, and other stakeholders that would benefit from analyses of individual level SDOH-related data. <sup>16</sup> In the context of this story, burden is defined as:

https://link.springer.com/referenceworkentry/10.1007/978-1-4020-5614-7\_297.

<sup>&</sup>lt;sup>17</sup> https://www.cms.gov/files/document/zcodes-infographic.pdf.

- Victor is aware that this method does not give him complete data on all persons in the state. However, he appreciates the data as the most robust, standardized, interoperable, and timely SDOH-related data he can leverage to help understand the burden of diabetes and food insecurity to support resource allocation effectively.
- Victor wants to understand the type of SDOH-related data sent from the clinical providers, community providers, HIE, and the state Medicaid Agency. He also wants to understand why data may be incomplete. This data analysis helps Victor identify missing population groups and possible data collection bias due to incomplete data.
- Victor learns that not all screening assessments are coded using nationally recognized standards. He works with the clinical providers, community providers, and the HIE to learn which screening questions and responses have not been mapped to these code sets. With this knowledge, Victor engages stakeholders to develop a plan to address the gaps.
- Victor disseminates his analysis of SDOH-related data to others in the state (e.g., HIE, county departments of health, providers, payers, CBOs, and other state leaders) to help inform stakeholders to make data-driven decisions, develop and implement programs and allocate resources.
- Makayla is a CDC DDT Project Officer for Victor's state. They often touch base to discuss the DDT-funded programs and share promising practices they see in the field.
- Victor informed Makayla of the SDOH-related data analysis findings, which leveraged clinical, social, community, and claims data to better understand food insecurity among people with, or at risk for, diabetes in his state.
- As the Project Officer, Makayla wants to ensure that all awardees leverage data to better assess and monitor their programs based on CDC cooperative agreement requirements.
- DDT is encouraging its awardees to implement food insecurity strategies to track and report the number of individuals with diabetes by demographic factors (e.g., race and ethnicity). These individuals have been identified with food insecurity as a social risk factor and the awardees will set target outcomes to reduce household or individual food insecurity.
- CDC is committed to achieving health equity and has developed an SDOH framework to describe the center's vision and approach to addressing the fundamental causes of health disparities in <u>five priority social determinants of health</u>: Built Environment, Nutrition Security, Community Clinical Linkages, Tobacco Free Policy, and Social Connectedness.
- CDC has specified outcomes, measures, and associated data sources for each of the five priority SDOH areas. This will be intended for use in routine grantee data reporting to monitor progress and demonstrate the impact of programmatic investments.
- Makayla and her team provide technical assistance and support to her awardees to assess SDOH activities that support diabetes prevention and management strategies. Awardees report on performance measures related to the SDOH strategies and report on individual and community level social risks associated with health outcomes.
- Once her team receives awardees' progress or evaluation reports, DDT analyzes the data to assess progress toward their targets.
- The data from multiple awardees are aggregated to assess population trends and identify innovative practices. Makayla and her team will disseminate the summary data and any analytic results (e.g., reports, dashboards, benchmarks) to all program awardees, national and public health partners, DDT, and other federal leadership to help inform data-driven decisions.

# **5.0** Story Assumptions

## **5.0 Story Assumptions**

Assumptions outline what needs to be in place to meet or realize the requirements of the story. The assumptions listed below are ones that are applicable to all parts of the story. Assumptions that are specific to each use case are defined in the use case table in Section 7.0. Please find the assumptions that are applicable to all parts of the story below:

- Patients' information will be shared and accessed in compliance with appropriate federal and state privacy, security, and consent laws and regulations.
- All entities have signed appropriate governance and data use agreements to enable the sharing of data whether identified or de-identified.
- Clinical and community-based settings routinely collect SDOH-related information on the individuals they serve, have quality assurance and feedback processes to assure data collection is occurring and data is being used.
- Information Sources and Information Recipients will work together to identify mutually agreed upon technical standards to support data exchange.
- SDOH-related screening, assessment, diagnosis, goals, and interventions collected in clinical and community-based providers IT systems are coded using nationally recognized terminologies defined under the U.S. Core for Data Interoperability (USCDI), USCDI+ and the Gravity Project. Examples of the type of screening tools mapped to national standards include but are not limited to the Protocol for Responding to and Assessing Patients' Assess, Risks, and Experiences (PRAPARE), Hunger Vital Sign, Accountable Health Communities (AHC) Health-Related Social Needs (HRSN) Screening Tool, and many others. The Gravity Project-defined coded concepts are agnostic to the screening tools and data capture systems used in the field.
- The data provided from clinical and community-based settings as well as Medicaid does not provide complete data on all persons in a specified area on a regular basis.



## 6.0 Actors

Actors are participants in the information exchange requirements of the story. Each actor has a role (e.g., document, send, receive, aggregate, and publish) and performs a set of activities to support the transactions of the story. Actors include:

- **Human Actors:** A human actor is associated with one or more use cases. They call on the system to deliver one of its services. For example: a Patient Persona.
- **Business Actors:** Defined as the entity that performs business processes or functions. Examples include health system, primary care physician (PCP) practice, etc.
- **System Actors:** Entities of the real world that interact with the system through the use case.

For the purposes of this story, the workgroup leveraged existing definitions of system actors from the <u>Making EHR Data More Available for Research and Public Health (MedMorph)</u><sup>18</sup> Initiative. Please find definitions of system actors below:

- **Data Repository:** A system receiving the data from the clinical care system. A Data Repository is used to represent systems such as cancer registries, National Healthcare Survey data stores, surveillance systems, and electronic vital records systems. Data Repositories are actively managed and are used to receive data, store data, and perform analyses as appropriate. These data repositories could be operated or accessed by Public Health Authority (or their designated organizations) or research organizations, with appropriate authorities and policies.
- Electronic Health Record (EHR): A system used in patient care delivery that captures and stores data about patients and makes the information available instantly and securely to authorized users. While an EHR does contain the medical and treatment histories of patients, an EHR system is built to go beyond standard clinical data collected in a provider's provision of care location and can be inclusive of a broader view of a patient's care. EHRs are a vital part of health IT and can:
  - Contain a patient's medical history, diagnoses, medications, treatment plans, immunization dates, allergies, radiology images, and laboratory and test results
  - Allow access to evidence-based tools that providers can use to make decisions about a patient's care
  - Automate and streamline provider workflow
- Trusted Intermediary: A system (e.g., Health Information Exchange, Community Information Exchange<sup>™</sup>, Community Based Referral Platform, APHL (Association of Public Health Laboratories) Informatics Messaging Services (AIMS)<sup>19</sup>) at an organization that serves as a conduit to exchange data between provider organizations and an endpoint. It performs the intermediary functions (e.g., apply business logic and inform the Reportability Response) using appropriate authorities and policies

<sup>&</sup>lt;sup>18</sup> <u>http://build.fhir.org/ig/HL7/fhir-medmorph/usecases.html</u>.

<sup>&</sup>lt;sup>19</sup> <u>https://www.aphl.org/programs/informatics/pages/aims\_platform.aspx</u>

# 7.0 Use Cases

## 7.0 Use Cases

The use cases focus on the functionality and interoperability required to allow an end-user to send and exchange coded SDOH-related data. These use cases are high-level descriptions of the most value-add interactions between the various actors identified within the story. In order to be consistent with the Gravity Project's Terminology Workstream communications and messaging, the descriptions of the use cases will utilize the term "social care data" in lieu of "SDOH-related data".

The three use cases are as follows:

- 1. Community Health Needs Assessment Leveraging Individual Level Social Care Data;
- 2. Assessment of STLT Health Department Diabetes Programs; and
- 3. Monitoring Federal Program Successes for Individual, Program, and Population Health Advancement.

Figure 1: Complex Transaction Diagram of Individual Level Social Care Data To Support Multiple Public Health Uses Cases



Reference: CDC Social Determinants of Health at <u>https://www.cdc.gov/socialdeterminants/about.html</u>.

## 7.1 Community Health Needs Assessment Leveraging Individual Level Social Care Data

Transactions:

- 1. Send social care encounter data in standard format
- 2. Send individual level social care data in standard format

#### Table 1: Use Case 1 Actors

Human Actor	Business Actor	System Actor	Technical Role
Care Coordinator	Federally Qualified Health Center (FQHC)	Electronic Health Record (EHR)	Information Source/Data Sender
Case Manager	Social Service Non- profit Organization (CBO)	Case Management Technology System	Information Source/Data Sender
Director	Regional Health Information Exchange (HIE)	Trusted Intermediary	Information Recipient /Data Aggregator/Data Sender
Public Health Analyst	County Department of Health	Data Repository	Information Recipient

#### Table 2: Use Case 1 Transaction 1

Use Case	
Assumptions	<ul> <li>Some FQHCs and other clinical providers capture screening, assessment/diagnosis, and interventions information in their EHR related to social care.</li> <li>Some CBOs capture screening, assessment, and interventions information in their Case Management Technology System related to social care.</li> <li>Most FQHCs and clinical providers in the county are sending clinical data and if available, social care data, to the Regional HIE.</li> <li>FQHCs and CBOs have participation agreements with the Regional HIE that allow them to send and receive encrypted identifiable data.</li> <li>The Regional HIE collects both structured and unstructured social care data.</li> <li>The Regional HIE will only share standardized social care data with the County Department of Health.</li> <li>The medical diagnosis data being shared with the County Department of Health will be related to diabetes.</li> <li>The County Department of Health will assess data sources and gaps in data collection and adjust for data collection bias as needed.</li> </ul>
Preconditions	<ul> <li>The Information Sources' (FQHC and CBO) systems have the ability to capture and share standardized individual level social care data with other systems. This information is automatically prepopulated with available patient demographic information, date, and appropriate unique identifiers.</li> <li>The clinical Information Source (FQHC and CBO) system is able to generate standardized diagnosis codes and send that information to the Trusted Intermediary (Regional HIE).</li> <li>The Trusted Intermediary (Regional HIE) can accept both standardized medical information and social care data.</li> </ul>
Transaction #1	Send social care encounter data in standard format. Information Sources (FQHC and CBO) pushes social care data to a Trusted Intermediary (Regional HIE).
Message Content	Encrypted identifiable individual level social care coded data gathered at the encounter level could include screening questions and responses, diagnoses, goals, and interventions.

Use Case	
Post Conditions	Trusted Intermediary (Regional HIE) accepts encrypted data.
Alternate Flow	Since each community may have different data assets capturing and aggregating information related to social risks, needs, and interventions, there are alternate flows to consider. This can include, but is not limited to, data captured from health payers, community information exchanges, community-based resource platform technology vendors, care coordination platform vendors, and other providers' IT systems. Some of these system actors may play dual roles of information sources and trusted intermediaries.

#### Figure 2: Use Case 1 Transaction 1 Diagram



#### Table 3: Use Case 1 Transaction 2

Use Case	
Assumptions	<ul> <li>The Regional HIE collects both structured and unstructured social care data.</li> <li>The Regional HIE will only share standardized social care data with the County Department of Health.</li> <li>The County Department of Health has a participation agreement with the Regional HIE that allows them to receive encrypted data for a community health needs assessment.</li> <li>The County Department of Health is able to process and use this encrypted individual level social care data.</li> </ul>
Preconditions	<ul> <li>The Trusted Intermediary (Regional HIE) can accept and send individual level social care data.</li> <li>The Information Recipient (County Department of Health) has a data repository that can accept standardized individual level social care data from a Trusted Intermediary (Regional HIE).</li> </ul>
Transaction #2	Send individual level social care data in standard format. Trusted Intermediary (Regional HIE) pushes individual level social care data to the Information Recipient (Regional HIE and County Department of Health).
Message content	Encrypted coded social care data identified for supporting the County Department of Health's community health needs assessment. This will include but is not limited to data on screening, assessment/diagnosis, and interventions. *Please see Appendix E for Available Document and FHIR Resource Standards for Message Content under Gravity Project Use Case Package.
Post Conditions	Information Recipient (Regional HIE and County Department of Health) accepts, analyzes, and acts on encrypted data.
Alternate Flow	Since each community may have different data assets capturing and aggregating information related to social risk factors, needs, and interventions, there are alternate flows to consider. These can include, but are not limited to, data captured from health payers, community information exchanges, community-based resource platform technology vendors, care coordination platform vendors, and other providers' IT systems. Some of these system actors could play dual roles of information sources and/or data intermediaries.





## 7.2 Assessment of STLT Health Department Diabetes Programs

Table 4: Use Case 2 Actors

Human Actor	Business Actor	System Actor	Technical Role
Care Coordinator	Health System	Electronic Health Record (EHR)	Information Source/Data Aggregator/Data Sender
Case Manager	Social Service Non- profit Organization (CBO)	Case Management Technology System	Information Source/Data Sender
Data Analyst	State Medicaid Agency	Data Repository	Information Source/Data Aggregator/Data Sender
Director	Regional Health Information Exchange (HIE)	Trusted Intermediary	Information Recipient/Data Aggregator/Data Sender
Public Health Program Director	State Department of Health	Data Repository	Data Aggregator/ Information Recipient

#### Table 5: Use Case 2

Use Case	
Assumptions	<ul> <li>The Regional HIE contains standardized social care data that is collected from clinical and community providers in the region.</li> </ul>
	<ul> <li>The State Department of Health will work with clinical providers, community providers, and the Regional HIE to evaluate and address gaps in social care data capture.</li> </ul>
	• The State Department of Health has the appropriate participation agreement with the Regional HIE that allows them to receive encrypted individual level social care data to identify areas with a high burden of diabetes and risk for diabetes, and areas with a high amount of food insecurity.
	<ul> <li>The State Department of Health is able to process and use encrypted individual level social care data.</li> </ul>
	<ul> <li>Medicaid has a Memorandum of Understanding (MOU) and other applicable data sharing agreements with the State Department of Health to share Z codes.</li> </ul>

Use Case	
Preconditions	<ul> <li>The Trusted Intermediary (Regional HIE) can both accept and send standardized medical information as well as social care data.</li> <li>Some Information Sources (Health System, CBO, and State Medicaid Agency) can send both standardized medical information and social care data to the Information Recipient (State Department of Health).</li> <li>The State Medicaid Agency's data repository can send Z codes to the Information Recipient (State Department of Health).</li> <li>The State Medicaid Agency's data repository can send Z codes to the Information Recipient (State Department of Health) data repository.</li> <li>The Information Recipient (State Department of Health) data repository has the capability to accept standardized individual level social care data from external sources including Trusted Intermediaries (Regional HIE), clinical and community providers, as well as the State Medicaid Agency.</li> <li>The Information Recipients (Regional HIE and State Department of Health) will have appropriate methodologies to identify and remedy duplicate records.</li> <li>The Information Recipient (State Department of Health) has the necessary analytic capabilities to better understand food insecurity in areas where there are high rates of individuals at risk for, or diagnosed with diabetes (e.g., GIS, mapping tools, and other methods of analyses).</li> </ul>
Transaction	Send individual level social care data in standard format. Information Sources (Health System, CBO, and State Medicaid Agency) and Trusted Intermediary (Regional HIE) push individual level social care data to the Information Recipient (State Department of Health).
Message content	Encrypted coded social care data identified for supporting the state's assessment of funded programs. This will include but is not limited to data on screening questions and responses, interventions, and diagnoses.
Post Conditions	Information Recipient (State Department of Health) accepts, analyzes, and acts on encrypted data.

Use Case	
Alternate Flows	Since each state may have different data assets capturing and aggregating information related to social risk factors, needs, and interventions, there are alternate flows to consider. These can include, but are not limited to, data captured from health payers, community information exchanges, community-based resource platform technology vendors, care coordination platform vendors, and other providers' IT systems. Some of these system actors could play dual roles of information sources and/or data intermediaries.

#### Figure 4: Use Case 2 Transaction Diagram



## 7.3 Monitoring Federal Program Successes for Individual, Program, and Population Health Advancement

### Table 6: Use Case 3 Actors

Human Actor	Business Actor	System/Technical Actor	Technical Role
Public Health Program Director	Program Awardee: State, Tribal, Local and Territorial (STLT) Health Department	Data Repository	Information Source/Data Aggregator/Data Sender
Senior Director	Program Awardee: National Association	Data Repository	Information Source/Data Aggregator/Data Sender
Project Officer	CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) Division of Diabetes Translation	Data Repository	Data Aggregator/Infor mation Recipient

#### Table 7: Use Case 3 Elements

Use Case	
Assumptions	<ul> <li>CDC's Division of Diabetes Translation (DDT) awards funding to state and local health departments, national organizations, tribes and tribal-serving organizations, US territories and freely associated states in the Caribbean and the Pacific.</li> </ul>
	<ul> <li>Program Awardees can be funded under different funding opportunities which include scaling and sustaining the National Diabetes Prevention Program (DPP), supporting programs and activities to help prevent or delay the onset of diabetes and improve health outcomes for individuals diagnosed with diabetes, as well as support prevention activities related to diabetes, obesity, heart disease and stroke.</li> </ul>
	<ul> <li>CDC will leverage individual level social care data from program awardees related to recommended SDOH performance measures to inform overall program efforts and help improve program practices.</li> </ul>
	<ul> <li>All Program Awardees capture individual level social care screening, assessment/diagnosis, goals, and interventions data coded to nationally recognized terminologies defined under the U.S. Core for Data Interoperability (USCDI),<sup>20</sup> the Gravity Project,<sup>21</sup> and USCDI+.<sup>22</sup></li> </ul>
	<ul> <li>Program Awardees that distribute funding to other organizations will aggregate individual level social care data in alignment with program reporting requirements.</li> </ul>

 <sup>&</sup>lt;sup>20</sup> SDOH data classes included in USCDI are developed and submitted by the Gravity Project.
 <sup>21</sup> <u>https://confluence.hl7.org/display/GRAV/Social+Risk+Data+Elements+And+Status</u>.
 <sup>22</sup> <u>https://www.healthit.gov/topic/interoperability/uscdi-plus</u>.

Use Case		
Preconditions	<ul> <li>The Information Source (Program Awardees) has a data repository that can capture, aggregate and send individual level social care data for program monitoring and evaluation purposes.</li> <li>The Information Recipient (CDC) has a data repository that can accept standardized individual level social care data from its program awardees.</li> <li>Both Information Sources (Program Awardees) and Information Recipient (CDC) will share data in a secure manner using appropriate methodologies that support identity management, identity resolution including deduplication, and record linkages.</li> <li>Information Recipient (CDC) has the necessary analytic capabilities to better understand food insecurity in areas where there are high rates of individuals at risk for, or diagnosed with diabetes (e.g., GIS, mapping tools, and other methods of analyses).</li> </ul>	
Transaction	Send individual level social care data in standard format. Information Sources (Program Awardees) push social care data to the Information Recipient (CDC).	
Message content	Encrypted individual level social care data identified for CDC tracking and monitoring of funded programs towards program goals and objectives. This will include but is not limited to data on screening questions and responses, interventions, and diagnoses.	
Post Conditions	Information Recipient (CDC) accepts, analyzes, and acts on encrypted data.	
Alternate Flows	Since each program awardee may also be working with affiliate sites that are capturing and aggregating information related to social risk factors, needs, and interventions, there are alternate flows to consider. These can include, but are not limited to, data captured directly from health payers, community information exchanges, community-based resource platform technology vendors, care coordination platform vendors, and other providers' IT systems. Some of these system actors could play dual roles of information sources and/or data intermediaries.	

#### Figure 5: Use Case 3 Transaction Diagram



# 8.0 Issues, Risks, and Obstacles

## 8.0 Issues, Risks, and Obstacles

Key risks, issues, and obstacles for consideration in the use and implementation of this document include but are not limited to the following:

- Lack of and misaligned incentives across the ecosystem for collecting and using social risk data to inform public health practices.
- Limited experience in clinical and community workflows for documenting and addressing social risk factors.
- Lack of standardized or evidence-based workflows for administration of social risk screening questions.
- Unintended consequences of social risk screening in clinical settings to include medicalizing interventions.
- Issues of trust between diverse partner groups, specifically for smaller entities that are often in competition for funding and other resources while working toward similar aims.
- Failure to get adequate representation from the public health community.
- Failure to reach alignment with other CDC activities, including national public health and SDOH initiatives.

## References

- 1. The Gravity Project Use Case Package.
- 2. Social Determinants of Health Public Health Business Case.
- 3. HL7 FHIR Making EHR Data More Available for Research and Public Health (MedMorph) Implementation Guide.

## **Appendix A: Story Personas**

**Table 8: Case Manager Persona** 



Jessica

Role: Case Manager | Age: 33

#### Highest Education Level Master of Social Work

Family Status Married and living with spouse

#### Employment

Lakeview Social Service Non-profit Organization (CBO) located near Sunville Community Health Center (FQHC)

#### **Preferences**

She loves engaging with members of the community she serves and working with local community leaders and like-minded organizations.

#### **Challenges**

Her organization has seen an influx of referrals during COVID-19 and is struggling with the capacity to serve those in need. As her organization establishes more partnerships, staff must log into multiple systems that are not integrated with their case management platform, escalating the administrative burden.

#### Goals

She strives to be an advocate for people in need and help them access services to improve their overall health and well-being. She wants to work towards an easier way to receive and respond to referrals from various organizations, allowing her to spend more time with her clients.

#### **Table 9: Care Coordinator Persona**



Kevin

Role: Care Coordinator | Age: 48

#### Highest Education Level Bachelor of Social Work

#### **Family Status**

Single Parent of 2 children ages 13 and 16

#### Employment

Sunville Community Health Center, a Federally Qualified Health Center (FQHC) located in Forest County

#### Preferences

He enjoys engaging with his patients directly to identify and address health and social needs.

#### Challenges

He cannot maintain increasing care coordination needs due to limited resources for rising patient numbers with food insecurity and other economic hardships escalated by or resulting from the COVID-19 pandemic. He struggles with locating health and social support services for his patients because the resource lists are outdated. He finds it hard to be efficient and effective in his work as he collects and documents patients' SDOH needs in the FQHC's EHR system.

#### Goals

He wants to identify patients' SDOH needs, resources, programs, and/or services to address their health and wellbeing. He works toward referring patients to needed health and/or social services and tracks these referrals to monitor their outcomes.

#### **Table 10: Public Health Analyst Person**



## Claudia

Role: Public Health Analyst | Age: 29

## Highest Education Level

Master of Science in Data Analytics

#### **Family Status**

Not married, without children

### Employment

Forest County Department of Health

#### Preferences

She loves analyzing data, identifying trends, and engaging with community stakeholders to understand community needs, strengths, available resources, gaps in services, and strategizing to find solutions.

#### Challenges

The lack of consistent and timely data related to social services, programs, or resources in the community makes it harder for Claudia to evaluate community needs and deploy evidence-based interventions.

#### Goals

She aims to conduct a community health needs assessment to identify the health and social support gaps of individuals and communities, specifically surrounding diabetes care, as she has witnessed the impact of diabetes and other chronic conditions on family members.

#### **Table 11: Public Health Program Director Persona**



Victor

**Role:** Public Health Program Director | Age: 55

#### Highest Education Level Master of Public Health

Family Status Married with one child in college

#### Employment

State Department of Health's Diabetes Program Director. Forest County is located in his state.

#### Preferences

He enjoys building partnerships with stakeholders across the health ecosystem and learning about innovative solutions to challenging problems. He does not want to let "perfect" be the enemy of good.

#### Challenges

His department is short-staffed, and leadership has been focused on the pandemic response. The data he reviews is limited in helping him identify what community resources are available or are required to address his population's growing social needs.

#### Goals

He wants to help advance and deploy the needed interventions, social services, programs, and/or resources to address SDOH needs and health disparities, especially for those at risk for, or managing, diabetes.

#### **Table 12: Project Officer Persona**



# Makayla

Role: Project Officer | Age: 38

#### Highest Education Level

Master of Science in Public Administration

#### **Family Status**

Married with a 3-year-old child

#### Employment

CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) Division of Diabetes Translation

#### Preferences

She loves to work with grant awardees on implementing public health programs across the US. She recognizes the importance of establishing performance and outcomes measures to achieve goals.

#### Challenges

Given the diversity of her awardees, it is challenging for Makayla to make recommendations about available social services, programs, and resources at the community level. CDC does not have granular-level data across all SDOH domains to help guide program decisions and identify the needed resources to support her awardees.

#### Goals

She wants to help all her awardees be successful, disseminate best practices, facilitate meaningful peer-topeer connections, and help reduce health disparities among those at risk for, or diagnosed with, diabetes.

## Appendix B: Feedback Received from Centers for Disease Control and Prevention's SDOH Public Health Use Case Workgroup

 Table 13: Feedback Received Summary

Theme	Response
Personas and Story Feedback	
Add additional personas (i.e., CBO staff, patient, staff at food insecurity program, health care academician).	EMI added Jessica, a case manager at a Social Service Non-profit Organization (CBO). Workgroup members submitted additional personas for future design and development, see appendix C.
Add specificity and clarity to challenges and goals for several personas, especially Kevin's persona.	EMI revised all personas based on comments received.
Concerns regarding applicability of story to Tribal Nations.	CDC addressed concerns during workgroup calls. Meeting materials and recordings are available <u>here</u> .
The story does not represent the current state. The electronic collection, documentation and interagency sharing of SDOH data is not widespread, therefore there is limited data.	This is not the current state. This initiative will help drive additional adoption to get to the desired future state. The story assumes some level of SDOH data collection and data sharing is occurring.
Questions related to the use of the Health Information Exchange (HIE) as a Trusted Intermediary, including whether there is sufficient SDOH data, the extent to which the HIE (or trusted intermediary) has the capability to accept and share the data in a standardized manner.	EMI acknowledged that it is important for public health professionals to consider what data assets exist in their community that could be leveraged. The story assumes that providers and the HIE have the capability to send and receive some standardized SDOH data.
Questions related to the data's representativeness of population if leveraged from both HIE and Medicaid.	EMI revised the story to more explicitly state that Claudia knows the SDOH data obtained may be limited and is not representative of all persons.

Theme	Response
Clarify if the SDOH data being shared is de- identified.	EMI revised the story to indicate that data being shared is encrypted. EMI added an assumption which indicated that data is being shared under appropriate consent policies, in addition to applicable privacy and security regulations and laws. In order for the use cases to have broad applicability, we did not specify whether data is de-identified or identified.
Data on interventions is not being captured by EHRs or HIEs in sufficient manner.	The ability for EHRs to track and "link" interventions to support care coordination is a known challenge. US Core is currently being updated. Please consider providing public comment to federal partners on certification requirements.
Suggest having the state use CDC's cooperative agreements funds to encourage greater automation of data and improve exchange of real time data between clinical and community providers.	EMI included this as a recommendation in the final recommendations report to CDC NCCDPHP.
Suggest modifying focus to decrease food insecurity in areas where diabetes prevalence is high.	EMI revised the story to include the modified focus.
Appropriateness of term "prevalence" in context of story.	EMI removed the word prevalence and utilized "estimated burden" where applicable.
Broaden the story to include people at risk for diabetes.	EMI revised and included people at-risk for diabetes in the story.
Include a bidirectional data flow into the use cases and transaction diagrams.	EMI enhanced the story to public health by sharing the results of the data analyses back to their stakeholders. EMI also included a separate diagram in the use case package to illustrate that summary data and analytic results (e.g., reports, dashboards, benchmarks) will be disseminated and shared with program awardees, states, and other partners.

Theme	Response
Use Case 1 Feedback	
A Community Health Needs Assessment (CHNA) may have biases based on gaps in data collection and could end up reducing the inclusion of specific groups. This could be addressed through an assumption indicating that the County Department of Health will assess and adjust for data collection bias.	EMI added this assumption to the Use Case.
Type of data being shared: Unless there is a treatment purpose, SDOH data being shared for a CHNA likely needs to be de- identified. This could be addressed through constraining the use case to de-identified, aggregated data.	While it is likely that data needed for the CHNA would be aggregated, de-identified data, EMI chose to avoid specifying identifiability to best support broad applicability. Additionally, Use Case 1 assumptions state that all local, state and federal privacy, security and consent laws and regulations will be adhered to.
Clarify specifically what medical and SDOH data are being shared, e.g., diagnoses.	EMI added an assumption that medical diagnosis data shared will be related to Diabetes and SDOH risks. It is anticipated that specific data elements will be identified through the future development of an implementation guide (IG).
Use Case 2 Feedback	·
Add an assumption to appropriately adjust for the amount of missing SDOH data.	EMI added an assumption that the state and county department of health will work with clinica providers, community providers, and the HIE to evaluate and identify the amount of missing SDOH data. This includes both: 1) Empty fields within a patient's SDOH screen, as well as, 2) Patients not getting screened. This information will be analyzed and included in the reporting of the data.
Suggestion to add a Community Health Worker.	EMI recommended workgroup members to submit a Persona for Community Health Worker via Persona worksheet.

Theme	Response
Suggestion to clarify that a standardized SDOH screening tool be adopted by all clinical and community providers that are part of the HIE.	The Gravity Project is agnostic to the screening tools (e.g., PRAPARE, AHC Screener, Health Leads) and data capture systems (e.g., electronic health record platforms, community-referral platforms, care coordination systems) used in the field to collect, exchange, and aggregate SDOH data. The current assumption states that the clinical and community providers can send the SDOH data in a standardized format using the Gravity code sets.
Clarify that food insecurity is not just about having sufficient food but also about the quality.	Please see the Gravity Project value sets for level of food insecurity. Link: <u>https://vsac.nlm.nih.gov/</u> For example, there is a diagnosis code "Nutrition impaired due to limited access to healthful foods (SNOMED CT: 445281000124101)".
Concern that not all screening tools support Gravity project standards. Some screening tools include individually developed questions and responses that are text- based, making it difficult to send all SDOH data to the HIE.	This is a known issue in the field. EMI modified the assumption to indicate that a number of the common screening tools questions, responses, and interventions have been mapped to codes developed through the Gravity Project. The various actors will work together to assess which questions are not mapped, understand why, and work with stakeholders to develop a plan to address this issue.
Concerns about the lack of widespread use of Z codes, the need to have Z codes more uniformly used for documentation, and the need for other health care providers (who do the screening) to apply the codes.	EMI added a recommendation in the final recommendations report to CDC NCCDPHP that will address the need to promote the widespread use of Z codes across the care ecosystem.
Use Case 3 Feedback	
Expand the precondition in Use Case 2 and 3 to include a broader set of analytic tools, not just mapping tools.	EMI reworded the precondition to clarify that the Information Recipient (State Department of Health) has the necessary analytic capabilities to better understand food insecurity in areas where there are high rates of individuals at risk for, or diagnosed with, diabetes (e.g., GIS, mapping tools, and other methods of analyses).

Theme	Response
Clarify how private vendors collecting and sharing SDOH data fit into the use cases.	EMI clarified in the use case package that the term "Trusted Intermediary" refers to any data aggregator (private, non-profit or public) that is collecting, aggregating, and sharing data on behalf of its participants.
Add an assumption that the Information Sources and Recipients will have appropriate methodologies to identify and remedy duplicate records.	EMI added a precondition that indicates: "Both Information Sources and Information Recipients will share data in a secure manner using appropriate methodologies that support identity management, identity resolution including deduplication, and record linkages."
Address the assumption that "all program awardees capture SDOH diagnosis, goals, and interventions data using nationally recognized terminologies defined under the Gravity Project." Program awardees are dependent on receiving data from their health and social service providers.	This assumption is not the current state. This initiative, which is focused on capturing SDOH diagnosis, goals, and intervention data using nationally recognized terminologies defined under the Gravity Project, will help drive additional adoption to get to the desired future state.
Consider PPRL being identified as an alternative flow versus a necessary step to support CDC obtaining individual-level data. Determine who will apply PPRL to the data prior to sharing it with CDC.	EMI added a precondition that indicates: "Both Information Sources and Information Recipients will share data in a secure manner using appropriate methodologies that support identity management, identity resolution including deduplication, and record linkages."
Recommend that CDC's DDT funding to STLT and national organizations include public access to virtual and remote services (e.g., WIFI and reimbursement of virtual health services across the spectrum of care to support digital health equity).	EMI included this as a recommendation in the final report to CDC NCCDPHP.
Recommend that CDC add SDOH data collection and performance measures for Electronic Case Reporting (eCR) and contact tracing from STLT.	EMI included this as a recommendation in the final report to CDC NCCDPHP.

Theme	Response	
Update the assumption to include that data is shared using a zero-trusted security model.	EMI recognized the importance of assuring strong security measures are in place when sharing data but we have chosen to avoid naming specific approaches. An assumption is included that indicates "Patients' information will be shared and accessed in compliance with appropriate federal and state privacy, security and consent laws and regulations."	
Expand actors to non-CDC DDT awardees in the transaction diagram, not limiting data sent to CDC from just program awardees.	EMI and CDC discussed adding non-CDC DDT awardees. DDT needs OMB clearance to receive data voluntarily. The team brainstormed adding Lifestyle Change Programs and Diabetes Self- Management and Education Programs however data collected may not be similar. EMI included recommendations to the final report to consider supportive or enabling policies and regulatory levers that would enhance CDC's ability to collect SDOH related data from non-CDC DDT awardees.	
Use Case Package Feedback		
Expand story assumption to consider technical standards workflow be used as the data exchange standardized format.	EMI added an assumption to the story that indicates that "Information Sources and Information Recipients will work together to identify mutually agreed upon technical standards to support data exchange."	

Theme	Response
<ul> <li>Request for more specificity throughout the story on what data is being sent from the HIE to the County Department of Health, for example:</li> <li>Is it line level, fully aggregated or partially aggregated by certain demographic parameters (race, age, gender).</li> <li>Is it only on patients that had an SDOH screening vs every individual.</li> <li>How will diabetes and at risk for diabetes diagnosis data be shared from the HIE, and if in CCDs, then does the County Department of Health have to abstract that information which is a large task.</li> </ul>	While it is likely that data needed for the CHNA would be aggregated, de-identified data, EMI chose to avoid specifying the data specifications sent to the Regional HIE to allow for flexibility. In the context of this story, use cases and transactions, the term "aggregated" refers to multiple lines of individual level data.
Request to define the term "burden" as it related to "areas of highest burden of diabetes."	Based on the workgroup feedback, the term burden was preferred as opposed to prevalence. In the context of the story and use cases, the term burden is used as a concept and can be defined as: The burden of disease generally describes the total, cumulative consequences of a defined disease or a range of harmful diseases with respect to disabilities in a community. These consequences include health, social aspects, and costs to society. The gap between an ideal situation, where everyone lives free of disease and disability, and the cumulated current health status, is defined as the burden of disease. The definition will be included as a footnote in the use case package.

Theme	Response
Request to relate CDC's five priority SDOH to the appropriate categories from the Gravity Project.	It is important to clarify that CDC's 5 priority SDOH areas to address health equity are purposefully broad in nature. While there are many areas of overlap and alignment with the Gravity Project SDOH Domain Areas (for example with food insecurity, housing instability, and social connectedness), there is not a complete 1:1 alignment. Additionally, different organizations and initiatives define SDOH domain areas inconsistently. Given this is a known issue in the field, EMI will address the need for better alignment and consistency across all organizations in the final recommendations report. EMI has also included a table in Appendix D to show the current Gravity Project SDOH Domains. Reference: <u>Alderwick HA, Gottlieb LM.</u> <u>Meanings and Misunderstandings: A Social</u> <u>Determinants of Health Lexicon for Health Care</u> <u>Systems.</u>
Request to add a general assumption that states that "Patient information on SDOH is collected in a systematic manner for those visiting clinical or community-based settings."	EMI added the following story assumption: "Clinical and community-based settings routinely collect SDOH information on the individuals they serve, have quality assurance and feedback processes to assure data collection is occurring and data is being used."
Request to clarify that data repositories exist at health care institutions and not just at public health authorities.	EMI aligned with the existing definitions of system actors from the MedMorph project. The definition states the data repositories could be operated by public health authorities or research organizations but it does not exclude them from being operated by others.
Request to include APHL's AIMS platform as an example of a Trusted Intermediary in the definition.	EMI added the AIMS platform as an example of a Trusted Intermediary; the definition aligns with MedMorph.

Theme	Response
Under Use Case 1: Concerns related to difficulty of adjusting for bias based on gaps in data collection.	Previous workgroup feedback indicated that a CHNA may have biases based on gaps in data collection and could end up reducing the inclusion of specific groups. To address this issue, EMI included an assumption and an activity in the story.
Under Use Case 1: Request to clarify that the data being sent from FQHCs and CBOs to the HIE is identifiable and to include in assumptions that there is a BAA in place between FQHCs and HIE as well as the CBOs and HIE.	EMI included that the data being shared from the FQHCs and CBOs to the HIE is identifiable since this typically happens in current state and this is specified through Gravity Project use cases.
Clarify what is meant by the term aggregated in the story and Use Cases 1-3.	EMI proposed to clarified this in context of this story and these use cases, the definition of "aggregated" most often refers to multiple lines of individual data.
	Based on the workgroup feedback from July 27, 2022, EMI changed the term "aggregated" to "individual level" and as a result utilized the term "social care data" instead of "SDOH data" to be in alignment with current messaging by Gravity Project Terminology Workstream.
Under Use Case 2 transaction diagram: Clarify in the diagram that the data from the Health System goes into the HIE.	The transaction diagram shows the data sources sending data to the State Department of Health. Since the HIE is regional, it does not contain data for all health systems and providers in the state. In this use case, the State Department of Health receives some provider data from the Regional HIE, some directly from providers, and some from Medicaid.

## **Appendix C: Additional Personas Candidates Received**

Table 14: FQHC Director Persona

Persona Name	Otto	
Role	FQHC Director	
Age	43	
Highest Education Level	Master of Health Administration	
Family Status	Single	
Employment	FQHC	
Preferences	Has a commitment to help people. Wants to position his organization for P4P and demonstrate the value of FQHC coordinated/continuous care. Embraces the patient-centered care model.	
Challenges	Staffing is always short, there are too few bodies for the existing work. Reimbursement levels challenge his ability to implement all of the strategies identified to help improve the health of his patient population. Staff fight new processes and feel they are already overworked.	
Goals	Can't wait to implement SDOH data collection with standardized tools. Is trying to fund a software upgrade that will allow standardized generation and transfer. To provide a 'play book' that staff can use to match services to SDOH needs.	

### Table 15: FQHC Clinical Staff Persona

Persona Name	Julie	
Role	FQHC Clinical Staff	
Age	38	
Highest Education Level	Bachelor of Science in Nursing	
Family Status	Married with 2 small children	
Employment	FQHC	

Persona Name	Julie		
Preferences	Loves working with patients but is tired most days from dealing with family issues, especially small children and daycare. Is burned out from trying to help those who continue to circle back to the clinic due to non-compliance and inability to manage their disease.		
Challenges	Sees all the need but little resources. Knows most of the SDOH needs the patients have but has no mechanism to help them or refer them. Considers much of what is available to be difficult to access. Has little or no time for people who are not willing to participate in their care. No time to get more information from patients.		
Goals	Wants to get people the care they need without having to spend extra time finding service sources that are accepting patients. Want to help those with a commitment to help self.		

## Table 16: Patient Persona

Persona Name	Terry
Role	Patient
Age	74
Highest Education Level	High School
Family Status	Widowed
Employment	None
Preferences	Is eligible for Medicare but pays for care herself as she does not want government intervention in her life. Is distrustful of organizations. Lives alone and spends most days watching television. Has no immediate family in the area. Has diabetes and Coronary Artery Disease (CAD), eats very poorly and cannot clean or maintain home.
Challenges	Difficult to collect data from Terry. She will not provide any extra information, nor does she want her data shared with others. Methods for connecting her to services, such as referrals, are difficult to complete due to her concerns with letting others into her home or providing information. Family is far away and does not want to be involved.
Goals	To find services that will help with chores, home maintenance and are sensitive to Terry's concerns.

#### Table 17: Business Owner Persona

Persona Name	Theo		
Role	Business Owner: Durable Medical Equipment (DME)		
Age	57		
Highest Education Level	Associates in Art		
Family Status	Married, no children		
Employment	DME Provider		
Preferences	Spends most days at work with staff that have been employed for many years at this location. Still enjoys working directly with clients to provide them with the best DME solutions. Has had a stagnant income for the last 5 years due to mounting expenses and regulations.		
Challenges	Has a difficult time predicting what will be needed within his store, inventory and overhead are expensive, focusing on needs would be helpful to reduce both. Beginning to think about retirement and how to transition his business to someone/thing else.		
Goals	To minimize inventory while being able to meet the immediate needs of individuals. Planning for areas of growth in the near term. Determining payment sources and how to balance properly to allow for adequate staff salary raises and store upgrades.		

#### Table 18: Public Health Informatician

Persona Name	Maria		
Role	Public Health Informatician		
Age	42		
Highest Education Level	Masters in Informatics		
Family Status	Married with two young children in school		
Employment	Federal/State Department of Health		
Preferences	Likes to bridge the gap between stakeholder requirements and technical work, to ensure that projects are carried to successful completion from inception.		
Challenges	Informatics staff are not available during all stages of project implementation. Oftentimes, areas of importance like technical standards, available implementation guides, and best-suited tools get overlooked in the need for project completion.		
Goals	To ensure that SDOH elements are included and addressed from data collection to analyses and that these data elements follow national standards. To provide the often-required translation between technical staff and management/users.		

## **Appendix D: Gravity Project Social Risk Data Elements**

The Gravity Project seeks to identify coded data elements and associated value sets to represent social determinants of health (SDOH) data documented across the following four clinical activities: screening, diagnosis, goals, and interventions. It focuses on identifying, developing, and validating 1) the data elements needed to document SDOH data across all four clinical activities, and 2) national standards to support the electronic capture and exchange SDOH data across a variety of systems and settings of care and social services. The following formal submissions have been made to coding stewards in order to address the social risk data concept gaps identified during the domain work. Codes that are accepted by the respective standards developing organizations will be published in upcoming releases.

Learn more about Gravity Published Social Risk Data Elements at <a href="https://confluence.hl7.org/display/GRAV/Social+Risk+Data+Elements+And+Status">https://confluence.hl7.org/display/GRAV/Social+Risk+Data+Elements+And+Status</a>

### **Gravity Published Social Risk Data Elements**

Published Gravity Project social risk data elements are curated within <u>Value Set Authority</u> <u>Center</u> (VSAC) value sets. Gravity Project VSAC value sets are updated after the completion of each social risk domain, and with major terminology release dates (SNOMED: March and September, ICD: October, LOINC: February and August). You will need to create a free account to access the value sets. The value sets can be identified by searching for "The Gravity Project" steward.

#### Gravity Project SDOH Domains as of July 2022:

- 1. Food Insecurity
- 2. Housing Instability
- 3. Homelessness
- 4. Inadequate Housing
- 5. Transportation Insecurity
- 6. Financial Insecurity
- 7. Material Hardship
- 8. Employment Status
- 9. Education Attainment
- 10. Veteran Status
- 11. Stress
- 12. Social Connection
- 13. Intimate Partner Violence (IPV)
- 14. Elder Abuse
- 15. Health Literacy
- 16. Medical Cost Burden
- 17. Health Insurance Coverage Status

## Appendix E: Available Document and FHIR Resource Standards for Message Content under Gravity Project Use Case Package

A core principle of the Gravity Project is the reuse of existing standards to represent and exchange electronic information. Table 19 lists the message content needs identified in the Use Cases developed by the Gravity Project. Column 2 describes the coded information the Gravity Project is working toward. Columns 3 and 4 identify relevant HL7® Clinical Document Architecture (CDA) Templates and HL7® Fast Health Interoperability Resources (FHIR) available to format the coded information. Although the Gravity Project is not specifying which templates and profiles implementers must use to share SDOH information, it is helpful for these potential data structures to be considered as the code sets for SDOH information are developed.

#### Table 19: Applicable Message Content Standards

Message Content	Coded Information	CDA Document Options	FHIR Resources Options
Prepopulated SDOH Screening Questionnaire (with coded questions and answer fields where available).	Assessment questions with potential answers	<ul> <li>Transport:</li> <li><u>DIRECT Message</u></li> <li><u>ITI Transactions</u></li> <li>FHIR API using <u>DocumentReference</u> (<u>US Core</u>)</li> <li>SDOH Content (Figure 6):</li> <li>C-CDA Document (See <u>Companion Guide</u> <u>Release 3</u>)</li> <li><u>US Realm Header</u></li> <li><u>Assessment Scale</u> <u>observation</u></li> <li><u>Social History</u> <u>Observation</u></li> <li><u>Problem Observation</u></li> </ul>	<ul> <li>SDOH FHIR API:</li> <li>Questionnaire</li> <li>Screening Response Observation (derived from QuestionaireResponse)</li> <li>Observation assessment</li> <li>US Core DocumentReference</li> <li>FHIR ClinicalDocument Profile</li> <li>C-CDA on FHIR</li> </ul>

Message Content	Coded Information	CDA Document Options	FHIR Resources Options
Populated digital SDOH questionnaire with patient's answers (includes the patient identifier (MRN) and the unique request ID and any other patient demographic information supplied by the patient).	Assessment questions with patient's answers	Transport: • <u>DIRECT Message</u> • <u>ITI Transactions</u> • FHIR API using <u>DocumentReference</u> <u>(US Core)</u> SDOH Content: C-CDA Document (See <u>Companion Guide</u> <u>Release 3</u> ) • <u>US Realm Header</u> • <u>Assessment Scale</u> <u>observation</u> • <u>Social History</u> <u>Observation</u> • <u>Problem Observation</u>	<ul> <li>SDOH FHIR API:</li> <li>Questionnaire</li> <li>Screening Response Observation (derived from QuestionaireResponse)</li> <li>Observation assessment</li> <li>US Core DocumentReference</li> <li>FHIR ClinicalDocument</li> <li>Profile</li> <li>C-CDA on FHIR</li> </ul>
Relevant information needed for the Order Filler to start the ordered activity.	Initiated Task Referred/Order ed Activity Background on Assessments given Assessed Needs/Risks	Transport: • <u>DIRECT Message</u> • <u>ITI Transactions</u> • FHIR API using <u>DocumentReference</u> ( <u>US Core</u> ) C-CDA SDOH Content: C-CDA Document • <u>US Realm Header</u> • <u>Referral Note</u> • <u>Assessment Scale</u> <u>observation</u> • <u>Planned Procedure</u> • <u>Intervention Act</u> • <u>Assessment</u> <u>Scale observation</u> • <u>Planned</u> <u>Procedure</u> • <u>Procedure Activity</u>	<ul> <li>FHIR API:</li> <li>Task for Referral Management</li> <li>Task for Patient</li> <li>ServiceRequest</li> <li>FHIR ClinicalDocument</li> <li>Profile</li> <li>C-CDA on FHIR</li> <li>Referral Note</li> </ul>

Message Content	Coded Information	CDA Document Options	FHIR Resources Options
Information about the initial request that was completed and information about the activity that was performed to complete the request (completed interventions). Includes the ID of the original service request and the ID of the ordered activity in the system where completion of the activity is documented.	Progressing/C ompleted Task Completed Activity (with associated order/referral information) Other relevant progress notes or consultation notes	Transport:• DIRECT Message• ITI Transactions• FHIR API using DocumentReference (US Core)C-CDA SDOH Content: C-CDA Document• US Realm Header• US Realm Header• Consultation Note• Progress Note• Assessment Scale observation• Planned Procedure• Procedure Activity• Intervention Act observation• Planned Procedure• Observation • Planned observation• Observation • Planned • Planned • Observation• Observation • Planned • Planned • Procedure• Observation • Planned • Planned • Procedure• Observation • Planned • Planned • Procedure• Observation • Planned • Procedure • Procedure• Observation • Planned • Procedure • Procedure• Observation • Planned • Procedure• Observation • Procedure• Observation • Procedure• Observation • Procedure• Observation• Observation • Procedure• Observation • Procedure	SDOH FHIR API: • Task for Referral Management • Task for Patient • Procedure • ServiceRequest • Observation assessment • US Core Encounter • HealthcareService FHIR ClinicalDocument Profile C-CDA on FHIR • Consultation Note • Progress Note
Aggregated coded data identified for a particular purpose (quality measure, stratification, risk adjustment).	Computed Quality Measure score for a population and a given measure definition	Transport: • <u>DIRECT Message</u> • <u>ITI Transactions</u> • FHIR API using <u>DocumentReference</u> ( <u>US Core</u> ) <u>QRDA Cat III Report</u> • Header Constraints • QRDA Category III Measure • Promoting Interoperability Measure • Improvement Activity	<ul> <li>FHIR API:</li> <li>MeasureReport</li> <li>US Public Health Profile Library</li> </ul>

Message Content	Coded Information	CDA Document Options	FHIR Resources Options
SDOH data documented within a clinical encounter for a specific period.	Patient level data needed for assessing a quality measure with a given measure definition Encounter data which can be harvested as needed Patient summary data which can be harvested as needed Screening information gathered Assessed needs/diagnos es Goals Planned interventions Completed interventions Outcome Observations (progress toward goals)	C-CDA SDOH Content: C-CDA Document US Realm Header Encounter Summary Document(s)(e.g. H&P, Progress Note, etc.) Patient Summary Document (e.g., CCD) Assessment Scale observation Planned Procedure Procedure Activity Intervention Act Assessment Scale observation Planned Procedure Procedure Activity	<ul> <li>FHIR API:</li> <li><u>MeasureReport</u></li> <li><u>C-CDA on FHIR</u> <ul> <li>Encounter Summary (e.g. <u>H&amp;P</u>, <u>Referral Note</u>, etc.)</li> <li>Patient Summary (e.g., <u>CCD</u>)</li> </ul> </li> </ul>

**Table 20: Applicable Population Search Parameters** 





#### Figure 6: C-CDA SDOH Content: SDOH Assessment and Planning Process

Source: Companion Guide to HL7 Consolidated CDA