

Maryland Community-Based Organization Data Sharing Implementation Guidance

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This and other CODI resources are available at <https://mitre.github.io/codi/>.

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1 Introduction

Community-based organizations (CBOs) play an essential role in maintaining and improving health by providing critical programs and services outside of a healthcare setting to people who have unmet food, housing, and other social needs. Unfortunately, most social care data are siloed at CBOs and are not easily accessed by other CBOs, health information exchanges, healthcare providers, or payers. CRISP recognizes the value of social care provided across Maryland and, as part of the [Community and Clinical Data Initiative \(CODI\) project](#), has built the infrastructure required to connect social care data from the community with clinical data from healthcare providers.

The purpose of this document is to provide guidance to Maryland CBOs who are interested in sharing social care data with CRISP. This document also provides information for healthcare providers in Maryland already participating in CRISP who want to encourage CBOs to share social care data with CRISP or want to explore what social care data may contain to support their workflows.

2 What is Social Care Data?

For the purposes of this document: **social care** is a term that describes a variety of services provided by organizations to help people maintain their independence and improve their quality of life, such as evidence-based classes, meals, and rides; **social care data** are the data about the organizations that provide programs, the programs offered, and the people enrolling in or receiving programs. Social care data also include **screening and assessment** data which identify individual needs and which programming is best fit to address each identified need.

Program is a broad term that can encompass single or recurring individual or group classes provided virtually or in person; one time or recurring services such as care coordination, home-delivered meals, or assisted transportation; home health services or supports; and public benefits such as supplemental nutrition assistance program, waivers to support health benefits, or housing assistance. CRISP places no restrictions on how an organization defines a program as long as the data meet the minimum requirements for use.

Social care data must be:

- Collected and documented at the individual level (not aggregate counts),
- Inclusive of enough individual identifiers to match individuals with clinical data (at minimum first and last name, address, sex, and date of birth),
- Stored in an electronic system as structured data (not as unstructured notes),
- Exportable in a structured format (e.g., a .csv file but not a PDF), and
- Allowed to be shared (based on organizational policy and individual consent).

CRISP appreciates that every organization is unique and uses a carefully curated workflow to deliver programs in the best way for that organization. CRISP has developed a technical specification that details one way that social care data can be formatted and structured (**Appendix A**); however, CRISP can receive data in a variety of ways and can help connect, coach, and provide technical assistance as appropriate to help guide organizations through this process.

3 Why Share Social Care Data?

Connecting social care data from CBOs with clinical data from healthcare providers is intended to:

- **Support Care Coordination:** CRISP processes and stores screening and assessment results, program enrollments, and program delivery information to share with care teams and providers, CBOs, and other partners according to data use agreements.
- **Facilitate Evaluation:** CRISP provides CBOs with aggregate reporting tools¹ to measure clinical outcomes among individuals who have enrolled or participated in social care programs.
- **Support Partnerships:** Sharing social care data can support partnerships between CBOs and healthcare providers who are increasingly collaborating to detect social needs, identify programs to meet those needs, and ensure those programs reach the right individuals in a timely fashion.
- **Enable Reporting to Communicate Impact:** By sharing social care data with CRISP, CBOs can gain the ability to assess clinical outcomes among individuals participating in their programs. Understanding who is receiving services as well as how those services affect clinical outcomes help CBOs better understand and showcase the vital work that they are doing in their community.

While this document is focused on how to get started sharing social care data, the content may also be useful to modernize or expand existing social care data sharing. **Appendix B** provides tips for data collection and storage that can benefit data sharing efforts like this. Additionally, the social care data pipeline may be used for sharing data about other types of programming or services such as falls prevention classes, depression interventions, diabetes self-management classes, or care transition services.

4 Who Can Share Social Care Data with CRISP?

Any organization (e.g., CBO, public health department, local or state government, or other organization) providing social care to individuals residing in Maryland can share data with CRISP by becoming a CRISP participant and notifying CRISP that they want to initiate social care data sharing. For organizations not already participating in CRISP, please review the “Getting Started with CRISP” information at crisphealth.org.

5 What Else Should My Organization Consider?

Beginning to share social care data with CRISP could **require 6-12 months to complete**, sometimes more. Regular engagement between your organization and CRISP is required throughout that time. CRISP recommends that implementers identify an organizational lead and requires a technical resource who can complete the data extraction activities described below. This is a **free service** – no funding is required to pay CRISP to support your organization’s social care data sharing; however, since it requires a sustained effort, organizations should verify support from their leadership before they initiate a social care data sharing project. Grants

¹ Reports will present counts of individuals and will suppress small numbers (less than 11) to protect individual privacy. Aggregate estimates are considered deidentified so that reports can be shared.

or funding to support staff time to complete the implementation steps below can accelerate progress.

Implementers should also know that:

- Data sharing can be stopped or paused at any time.
- Not every individual who has received a social service will have matching clinical data. When a match is not found, CRISP does not have the clinical data to measure outcomes for that individual. This could impact how useful the evaluation tools will be to your organization. Implementers can work with CRISP during planning to understand match rates.
- CRISP has defined several outcome measures (e.g., diabetes control and hypertension prevalence) but recognizes that these outcome measures may not be applicable or valuable to all organizations.
- Changes in your organization's programs, workflow, information systems, or documentation practices could require more work to maintain data sharing.
- Your organization's data will only be visible to authorized individuals and is accessible in reporting tools only by authorized users from your organization.
- Organizations will only have access to their aggregated reports.

With all of these points in mind, only your organization can decide if this data sharing project is valuable enough to undertake. CRISP understands that each organization collects and stores social care data in different information systems and formats and that each organization has differing abilities and resources to extract and share data with CRISP. CRISP can receive data in a variety of ways and can guide your organization through this process. Figure 1 provides an overview of the implementation process for CBOs to share social care data with CRISP. CRISP recognizes that social care organizations have considerable demands of their time and resources and is committed to meeting CBOs where they are.

6 How Does My Organization Get Started?

We encourage your organization to reach out to CRISP to let them know that your organization is interested in sharing social care data. This document is intended to provide general guidance about data sharing and should not be used to make decisions before talking with CRISP. An initial discussion is the best way to help you understand the specific next steps that your organization needs to take.

To get started:

- Contact CRISP at support@crisphealth.org to set up a meeting to discuss sharing social care data.
- If your organization is not already a CRISP participant, review the "Getting Started with CRISP" information and steps at crisphealth.org.
- Identify which social care data and programs your organization may want to share by completing the social care data sharing planning and implementation checklist (**Appendix C**).

THE IMPLEMENTATION PROCESS

CBOs meet with CRISP to learn about a partnership and sign the CRISP participation agreement.



JOIN CRISP

01

CBOs work with CRISP to determine data format and extract data from source systems based on data sharing plan



EXTRACT DATA

03

CRISP processes social care data, links individuals in social care to patients in clinical data, and stores data for use.



CONNECT DATA

05



PLAN

02



CBOs select which social care programs to share data from, which source systems data will be pulled from, and who and what time period will be shared

CBOs send social care data files to CRISP – first a test file and then the full extract

SHARE DATA

04



CBOs login to secure portal and run reports to visualize demographic data & outcomes for each program.

06

Figure 1. The implementation process for CBOs to share social care data with CRISP

Appendix A Social Care Data Description

Social care data—data about who has social needs and what services or programs they receive—is crucial to ensuring that every identified need is met with the appropriate resources or intervention. The following describes data elements associated with social care data categories: the Organization and its Programs, the Person receiving services, Program Enrollment, and Program Delivery provided to the Person receiving services.

Organization

These are the entities providing social care services. Key data about an organization includes:

- Organization Information
- Organization Name
- Organization Address: street, city, state
- Organization Description
- Identifying Code known to CRISP

Program

These are the services, benefits, and classes in which the Organization's clients/customers participate. Programs can be services or items provided to the participating Person. Key data about a program include:

- Program Name
- Program Description
- Program Duration and Frequency
- Identifying Program Code known to CRISP
- Contact Information for person responsible at the organization:
 - Contact name
 - Email address
 - Phone number

Person

This represents the individual who enrolls in and/or receives the Program from an Organization. CRISP would use this data to identify unique patients and associate the social care data with other clinical data. Key data about a person includes:

- Person's Name: first, middle, family names
- Person's Date of Birth
- Address: street address, city, state, zip, county
- Contact Information: phone, email, etc.
- A Unique Identifier for that person that the Organization uses (when available)
- Sex
- Race and Ethnicity

Program Enrollment

For Persons participating in a Program, enrollment information can include dates of Program enrollment and participation as well as status. Ideally, dates would reflect when the Person enrolled in the program. Program enrollment data may not always be available as some organizations do not formally enroll people in their programs. In this case, the program enrollment may be considered optional when Program delivery data is available. Key data about enrollment includes:

- Program Name or Uniquely Identifying Program Code known to CRISP—to identify the specific program
- Program Enrollment Date: start date
- Program Disenrollment Date: end date
- Program Enrollment Status
- Program Disposition Reason

Program Delivery

This represents the actual goods and service delivered to the Person as part of a program. Key data about program delivery includes:

- Program Name or Identifying Program Code known to CRISP—to identify the specific program
- Program Delivery Date: date the goods or services were delivered
- Item Information: what goods or services were provided?
- Quantity and Units (when necessary): number of deliveries/quantity in each delivery
- Delivery Category: when an organization or sector categorizes its delivery items

CRISP is able to receive the above data in a variety of formats. CBOs can share the data that they want in a format that is convenient for them and their systems. Please contact CRISP directly for the most current data model specifications as they are continually updated based on interactions with community-based service providers.

In addition to the social care data above, CRISP receives data from screening and assessments for a variety of medical and non-medical topics such as screening to identify social needs (Figure A-1). This data is received through a different set of data services and includes Social Service Questionnaires and corresponding Answer Responses from the Person being screened. Please contact CRISP directly to discuss sharing screening and assessment data.

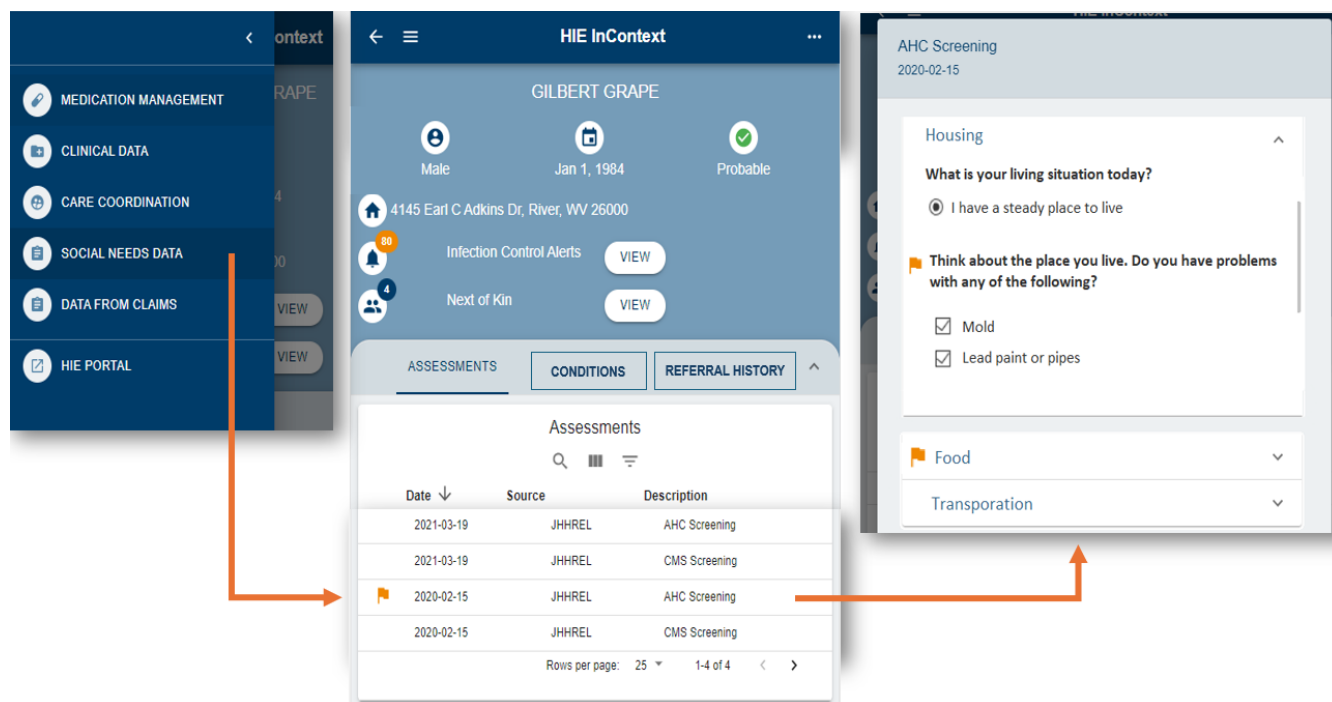


Figure A-1. Schematic of CRISP Social Needs Data Sharing Process

Appendix B Best Practices in Collecting and Storing Data for Reuse

The fact sheet shown below is available at <https://mitre.github.io/codi/docs/>.

Best Practices for Community-Based Organizations in Collecting and Storing Data



Community-based organizations (CBOs) often use multiple information systems to document the clients they serve and the services that they provide. While the primary purpose of these systems is to support service delivery, data from these systems are increasingly useful for many other purposes, such as reporting impact of services. This means that the data in an information system needs to be collected and stored in a way that allows it to be linked to other data sources, as appropriate, to inform decision making and enable more impactful reporting.

For organizations collecting person-level information electronically, this document provides recommendations for data collection and storage, as well as best practices for staff who are manually entering data into information systems. When best practices are not followed, the ability for data to be linked to other data sources, and subsequently the ability of the CBO to gain deeper understanding of the benefit of their services, will be limited. The following best practices are foundational and are not intended to be comprehensive. If a CBO has not implemented one of the best practices below, a plan to address the gap should be created.

1. **Collect Individual Identifiers:** Identifiers are necessary to link an individual's data across multiple sources; data without identifiers cannot be linked. At a minimum, organizations should collect first and last name, date of birth, phone number, and address. Collecting additional identifiers, such as middle name, secondary phone number, and email, will further improve linkage. If linking data between partner organizations, the organizations should communicate matching requirements and protocols.
2. **Train Staff:** Staff who collect or enter identifiers into an information system may perform these tasks differently, leading to variation in resulting data. For example, some staff may record date of birth as 'Feb 2' which is less complete than 02/02/1969. Training staff who collect and enter data according to a standard protocol can improve data quality.
3. **Store Identifiers in Distinct and Structured Fields:** When configuring an information system, the fields that hold identifiers should be structured, unique fields that use appropriate formats. For example, use separate fields for first name and last name rather than one field for name and collect date of birth in a date format rather than in characters.
4. **Use Predefined Values:** For fields like race, ethnicity, or sex, allow staff to select from predefined values (e.g. M and F for sex) rather than letting staff type in an unstructured free text field. Using predefined fields ensures that those values will be entered consistently and avoid multiple values that could have the same meaning such as Male, M, Boy, Man.
5. **Minimize Missing Identifiers:** Missing data is common and missing identifiers in particular can make linkage challenging or of lower quality. One way to minimize missing identifiers is to make this information required so that the information system will not save the record without data in those fields. The minimal set of identifiers required to link data should be required, with additional identifiers as optional; this approach balances data quality with data entry workflows.
6. **Maintain a Single Master Record and Identifier:** For organizations using multiple systems, establishing one master record that maintains the most complete and current identifiers for that person means that identifiers will not vary or conflict between systems. Most information systems assign a unique identifier (ID) to each person, and whenever possible, that ID should be reused across systems. Deconflicting IDs for the same person between systems can be laborious, complicated, and make determining the unique number of people served difficult.

Appendix C Social Care Data Sharing Planning and Implementation Checklist

The questions below address the key information that CRISP needs to begin a social care data sharing project. To get started, CBOs can complete this checklist and provide responses to CRISP at support@crisphealth.org. These questions should be answered for each program that the CBO is interested in sharing data with CRISP.

Program Questions

1. What is the name of the program?
2. Does the program record data electronically?
☐ Yes ☐ No ☐ Unsure
3. Are documentation practices for this program standardized? (e.g., Is everyone recording data in the same way?)
☐ Yes ☐ No ☐ Unsure

Questions about Program Data

4. Does the program record individual-level data?
☐ Yes ☐ No ☐ Unsure
5. Which of the following data is available for the program? (select all that apply)
☐ Screening data about each individual's social needs
☐ Assessment data specific to each identified social need
☐ Program enrollment data
6. How is program delivery tracked? (select all that apply)
☐ Roster of served individuals (e.g., list of people who received a meal on a specific day)
☐ Aggregate counts of delivery (e.g., 5 meals delivered last week)
☐ Individual delivery transactions (e.g., list of each meal delivery)
☐ Other (please specify):

7. Please indicate which identifiers your organization collects about the persons receiving this program. For each identifier collected, please specify the available format. Structured data have a defined format (e.g., date format, value list) while unstructured data do not (e.g., free text field).

Identifier (check if collected)	Format (if applicable)
<input type="checkbox"/> Name (first and last)	<input type="checkbox"/> Structured <input type="checkbox"/> Unstructured <input type="checkbox"/> Unsure
<input type="checkbox"/> Date of birth	<input type="checkbox"/> Structured <input type="checkbox"/> Unstructured <input type="checkbox"/> Unsure
<input type="checkbox"/> Phone number	<input type="checkbox"/> Structured <input type="checkbox"/> Unstructured <input type="checkbox"/> Unsure
<input type="checkbox"/> Email	<input type="checkbox"/> Structured <input type="checkbox"/> Unstructured <input type="checkbox"/> Unsure
<input type="checkbox"/> Address	<input type="checkbox"/> Structured <input type="checkbox"/> Unstructured <input type="checkbox"/> Unsure
<input type="checkbox"/> Sex	<input type="checkbox"/> Structured <input type="checkbox"/> Unstructured <input type="checkbox"/> Unsure
<input type="checkbox"/> Race and ethnicity	<input type="checkbox"/> Structured <input type="checkbox"/> Unstructured <input type="checkbox"/> Unsure
<input type="checkbox"/> Other identifier (e.g., medical record number, social security number, insurance member number) Please specify:	<input type="checkbox"/> Structured <input type="checkbox"/> Unstructured <input type="checkbox"/> Unsure

8. Does this program or your organization have a common ID that is used across systems?

☐ Yes ☐ No ☐ Unsure

9. How often are these identifiers missing (% missingness estimate)?

10. Are data quality checks run on these data?

☐ Yes ☐ No ☐ Unsure

Information Systems and Capabilities Questions

11. What is the name of the information system or systems used to record this data?

12. How long has this system been used?

13. Have there been changes to documentation or recording during that time?

☐ Yes ☐ No ☐ Unsure

14. Is this system integrated with any other information systems your organization uses?

☐ Yes ☐ No ☐ Unsure

15. Does this system allow data extraction?

☐ Through a reporting tool?

☐ Customizable data extracts?

16. Is your organization supported by staff or contract information technology professionals?

☐ Yes ☐ No ☐ Unsure