

Clinical & Community Data Initiative (CODI) - North Carolina



Why do we need CODI?



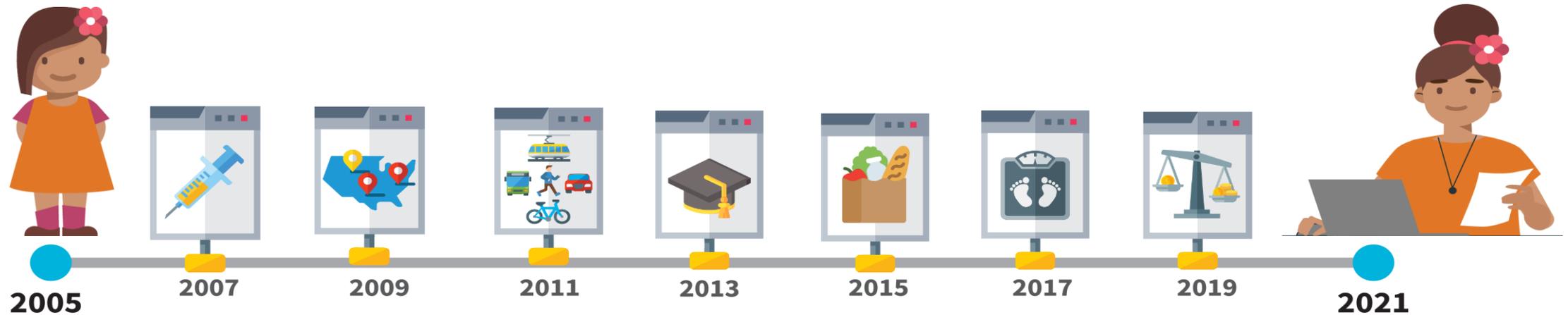
- Important information about our health can be found in places **throughout the community – not just at a doctor’s office.**
- This **information** may include participation in physical activity programs, use of community support services such as a food bank, education, clinical data, social determinants of health (SDOH), and so much more.
- Putting the pieces of this information puzzle together can help us better **understand the full picture of the diverse factors that affect our health.**

Why do we need CODI?



- CODI brings together local **people** (local individuals, organizations, collaboration), **processes** (data assessments, sharing, and governance) and **technology** (linking data, organizing data components, technology programs) in order to create a **local framework or infrastructure** to support evidence-based efforts that are driven by data to achieve improved outcomes and health equity

What does CODI do?



CODI aims to **build an infrastructure or framework** in the NC Triangle region that can be used to link an individual's data throughout the community into a **single record** that can be used to **help us answer questions** related to health, community programs, local policies, and other topics of interest to local collaborators.



How are CODI data used?



Researchers: Enables comparative effectiveness studies

Community Partners: Provides data on health improvements associated with interventions



Policy Makers: Increases understanding of community chronic disease prevalence

Clinical Partners: Increases awareness of community-based program for patient referral

Who is involved?

CODI@NC will include multiple collaborators from clinical and community-based organizations. The project is sponsored by the US Centers for Disease Control and Prevention (CDC).

The Project Management Team

Centers for Disease Control and Prevention

The MITRE Corporation

Public Health Informatics Institute

National Association for Community Health Centers

Potential Partners in North Carolina Triangle Region

Duke University

University of North Carolina Chapel Hill

Lincoln Community Health Center

Piedmont Health

Parks & Recreation – Durham, Chapel Hill, Raleigh

YMCA of the Triangle

Girls on the Run of the Triangle

Special Supplemental Nutrition Program for Women, Infants and Children

Local Health Departments – Wake & Durham County





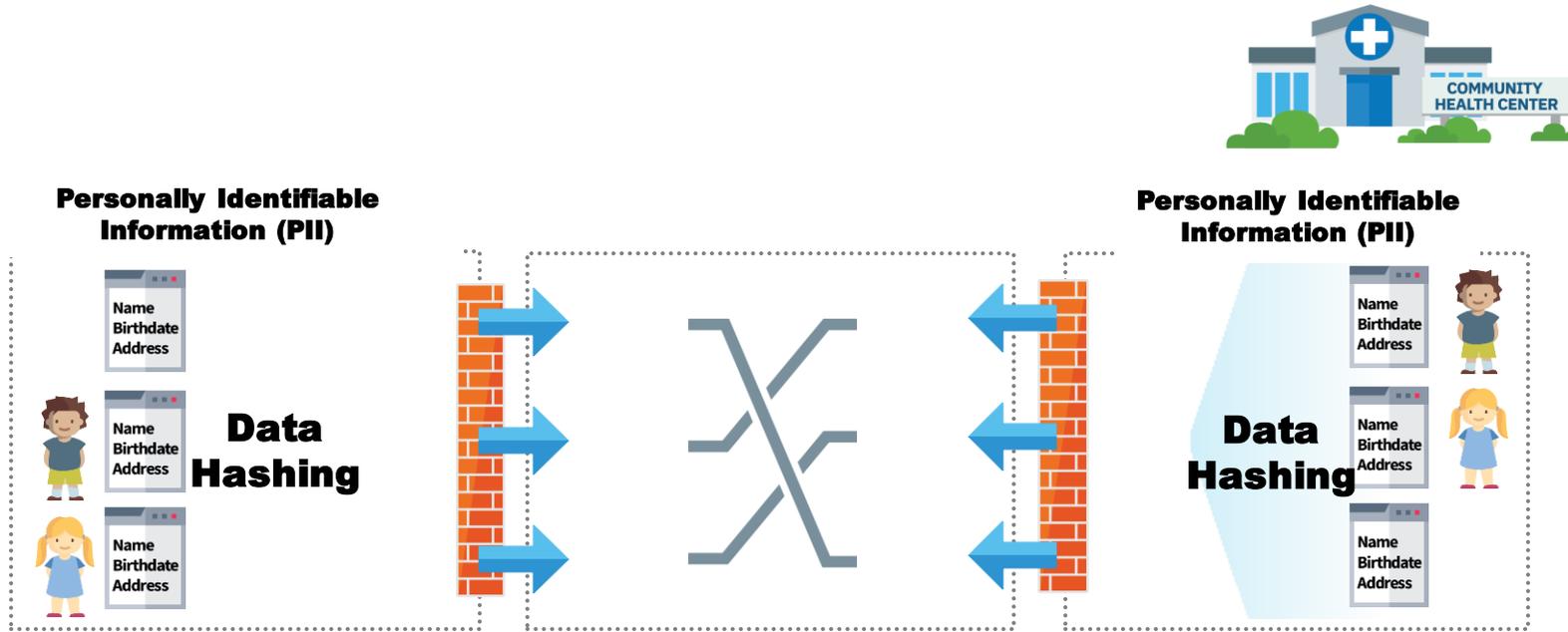
What are the potential benefits of participating in CODI?

- Understand health inequities
- Identify evidence-based practices
- Attract funding
- Enhance evaluation and continuous improvement
- Demonstrate leadership
- Cultivate partnerships



Ensuring Data Privacy and Protection

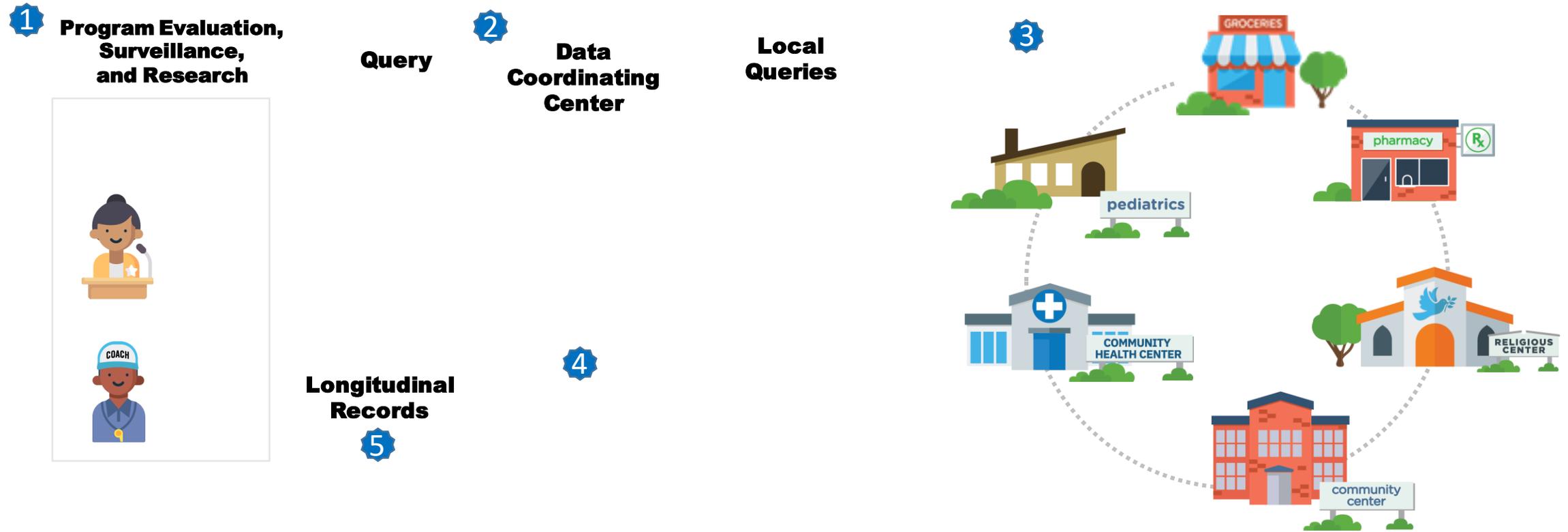
How does CODI work?



In order to ensure that an individual's identity is protected, the CODI project uses a process called **Privacy Preserving Record Linkage (PPRL)**. PPRL creates “garbled” identifiers for individuals that are used to link their data across the community into a single, longitudinal record.



How does CODI work?



CODI functions as a **Distributed Data Network**. This means that each organization's data **stays secure behind their secure firewall**. When someone asks a question about this data, 1) a query or inquiry is sent to each participating organization, 2) a subset of the relevant, de-identified data is pulled from each database, and 3) finally assembled into a single record.

What steps does CODI take to protect & ensure privacy of your data?

- CODI creates a technology and partnership network that allows **partners to maintain control over their own data**
- The queries are designed to **extract on the minimum required data**, without PII
- The **Privacy Preserving Record Linkage process** is designed to use “garbled” identifiers to link data that protect individual identities
- Before data is shared, CODI implementing partners will establish governance or a process of creating data sharing rules, in order to build trust and reconcile regulations, policies, and norms needed for data exchange. For CODI, governance includes policies, processes, and agreements to assure Data Owners that **data sharing is ethical, transparent, and compliant with appropriate laws and regulations**

Will your organization's participants need to provide consent about the use of their data in CODI?

This depends on your organization's current policies. Below are some approaches our partners in the CODI Denver pilot exercised:

- One of the organizations felt that it was part of their treatment/payment/operations and there was no need to provide a disclaimer
- One organization sent a letter to participants to let them know that they would be sharing deidentified information, and offer them the opportunity to opt out; but none of the participants chose to
- One of our current partner organizations currently has a disclaimer in their registration language that indicates that deidentified information may be used, and many organizations have similar language; you may already have such language in your registration materials

Expectations for Partner Participation



What are we asking partners to do?

Attend meetings and provide input on strategy, governance, and the questions you want answered with the data

Engagement

Use the CODI tools to map your data to create the linked dataset w/ other organizations

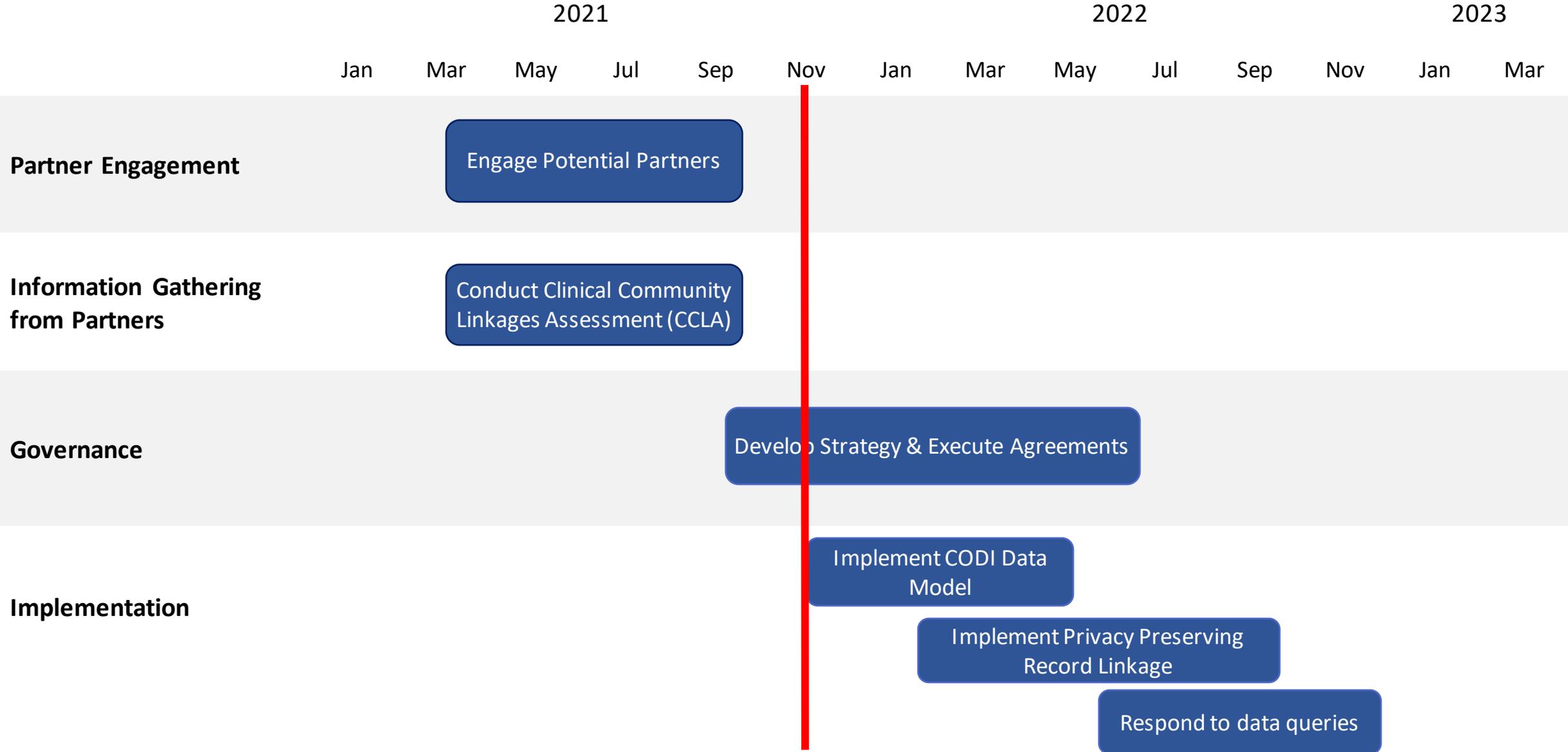
Technical Implementation

Are there resources available to support your participation in CODI?

YES!

The following slides provide more information on estimated hours for CODI participation to help start the contracting process for financial support.

Timeline



CODI Denver Partner Experience

"We were initially intrigued when we were approached to participate in CODI, but we didn't quite know where it would lead. Since we joined the project, we've received some preliminary **insights from our data**. We've **strengthened connections** to clinical partners in our state. And the CODI team has made participating with the **technology turnkey, supporting and guiding us throughout the process**. We look forward to continuing to participate as the project continues to evolve here in Colorado."

Lisa Johnson, Executive Director
Girls on the Run of the Rockies



Thank you!



Please email CODI@cdc.gov with questions.

Additional Slides

What CODI Is & Isn't

What CODI is	What CODI is NOT
A sustainable data infrastructure that leverages your current electronic information	Not a data reporting project
Technical support for data exchange and access to de-identified longitudinal health data	Not an onerous data collection process
An opportunity to collaborate with local and national experts on strategies for community-clinical data linkages	Not a one-off task to test an application
	Not a grant program