

“I Want to Say ‘Yes,’ But...” —  
*A Webinar for Lawyers Advising Data-Sharing Efforts*

Presented November 30, 2022

## Group Facilitators



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## About the Network for Public Health Law

We provide visionary leadership in the use of law to promote, protect and improve health and advance health equity.

We work with local, tribal, state and federal public health officials and practitioners, as well as attorneys, policymakers, advocates and community organizations.

We provide information, resources, consultation and training, as well as opportunities to connect. We are supported by the Robert Wood Johnson Foundation.

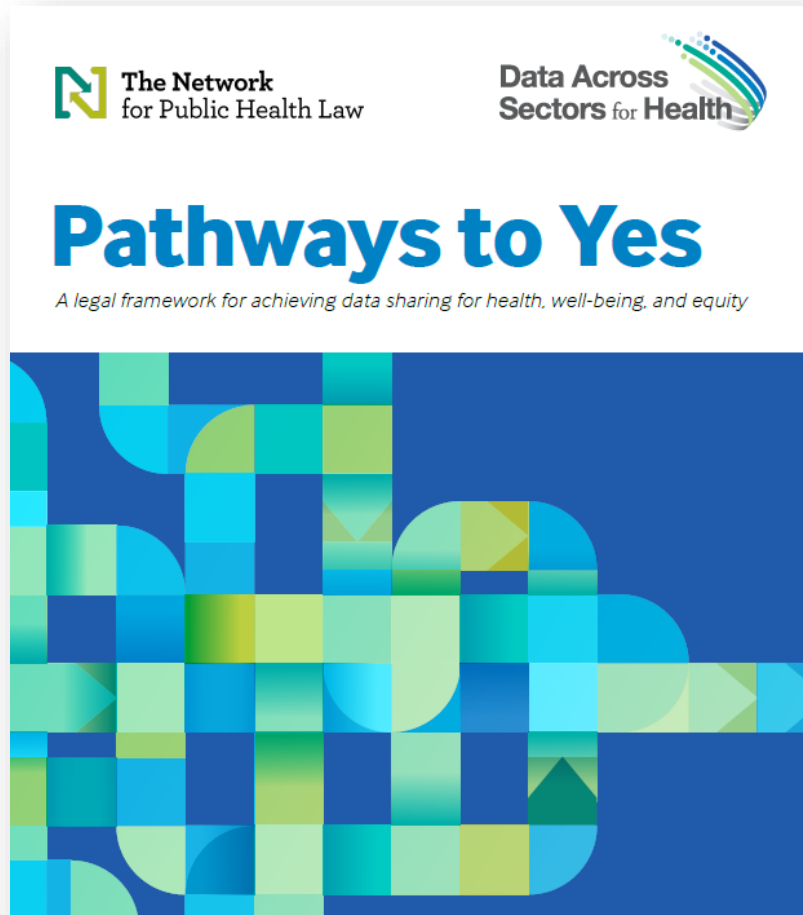


## About Data Across Sectors for Health (DASH)

DASH, led by the Illinois Public Health Institute, in partnership with the Michigan Public Health Institute, and with support from the Robert Wood Johnson Foundation, supports alignment among healthcare, public health, and other sectors to systematically compile, share, and use data to understand factors that influence health and develop more effective interventions and policies. DASH and its partners in All In: Data for Community Health are creating a body of knowledge to advance this emerging field by identifying and sharing opportunities, barriers, lessons learned, promising practices, and indicators of progress for sharing data and information across and beyond traditional health sectors.



## About *Pathways to Yes*



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Road map for successful data sharing to promote health, well-being, and equity

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Not intended to be legal advice

Please make sure to always consult your attorney regarding the specifics of your proposed data-sharing project

[Networkforphl.org/pathwaystoyes](https://networkforphl.org/pathwaystoyes)

## Learning Objectives

Through this presentation you will:

1. Obtain strategies for effectively collaborating with data-sharing project proponents
2. Learn how to create/use a data flow map
3. Explore approaches for working within the law when the law doesn't necessarily work for you

# The Problem

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A user-friendly guide to data sharing doesn't exist.

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Hoping to share data, people often get deep into their project before hitting the data-sharing culture of “no”.

## Polling Question #1

What prompted you to come to this webinar?

Go to [Mentimeter.com](https://www.mentimeter.com)  
Use Code 7837 3524



## Data Sharing Culture Clash

Health departments/advocates work to improve individuals' and communities' health outcomes

- County PHD wants data from County jail on inmates who have SUD history to do pre- and post-release prevention work
- School district and local FQHC want to share data (attendance records, medical records, treatment plans) to reduce absenteeism due to medical issues

Lawyers are charged with reducing risk

- HIPAA, 42 CFR Part 2, FERPA, state laws on privacy, mental health records, minors' health records, etc.

## Data Sharing Culture Clash

Health departments/advocates work to improve individuals' and communities' health outcomes, supported by the lawyers who advise them

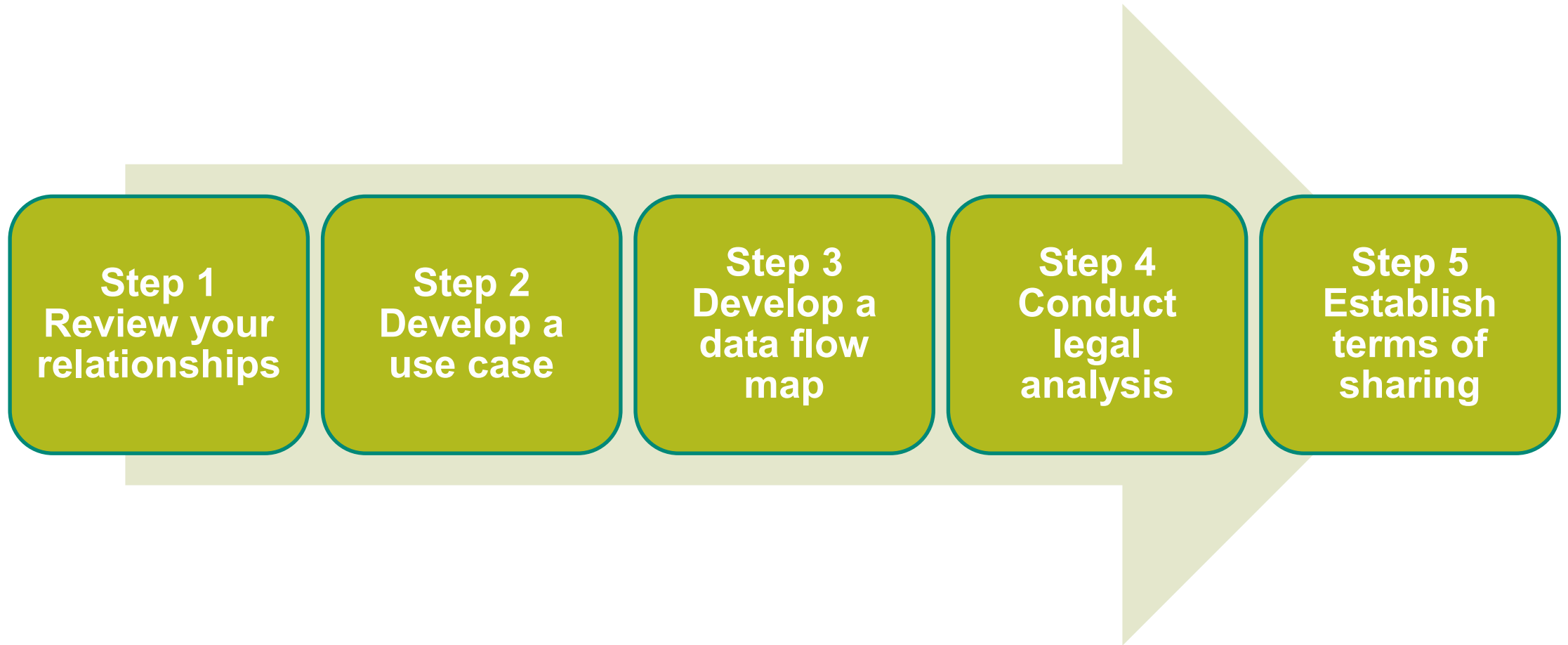
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## Pathways to Yes Framework



## Case Study: Fall Prevention

Every year, older adults in the project city suffer over 4,000 serious falls that require a visit to the emergency department or an inpatient hospitalization. These falls frequently lead to death, disability, or loss of independence. This project is aimed at reducing the number of falls in the project city that require inpatient hospitalization or emergency department care by one-third over three years.

The purpose and use of the data will be to identify problem locations that contribute to a disproportionately high number of falls, to investigate the reasons for falls, and to immediately use the information to advise community partners on where to locate interventions.





## Case Study: Fall Prevention (*con't*)

The state health information exchange (HIE) serving the project city is the data source. The HIE serves as the hub of the project by collecting identifiable hospital emergency department data based on ICD11 codes. The HIE curates, summarizes, and visualizes the data in a dashboard and makes that available to the local health department.

### Core Data Elements

- Date of fall
- Location of fall
- ED admission date
- Age of patient
- Patient health outcome



# Step 1: Review Your Relationships

## Step 1: Review Relationships

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1. Review relationships with partners
2. Identify data to be shared
3. Explore relationships with internal partners, including attorneys
4. Identify project champion
5. Understand role of attorney

## Role of Attorney

Attorney's role begins at project inception

Present attorney with project goals and desired outcomes

Demonstrate how you intend to achieve those goals through data

Attorney should feel ownership in the project

# Step 2: Develop a Use Case



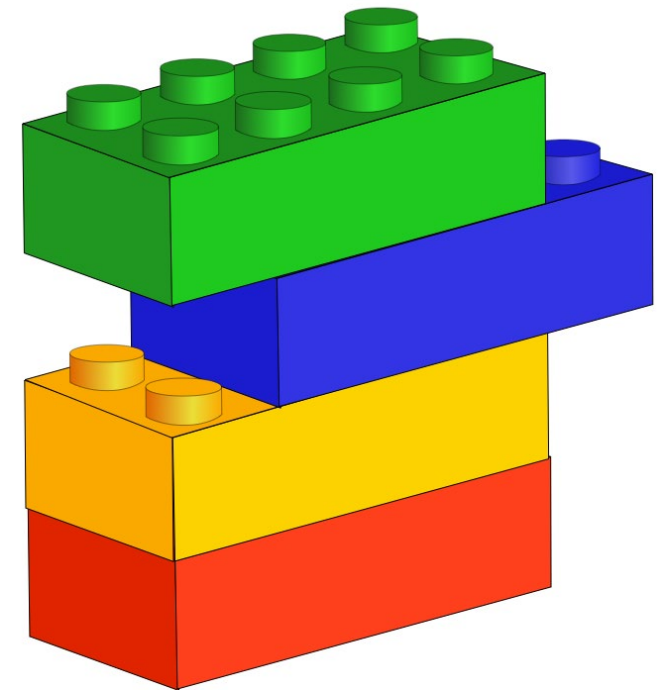
## Step 2: Develop a Use Case

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1. Understand a “use case”
2. Articulate your use case
3. Identify its essential elements

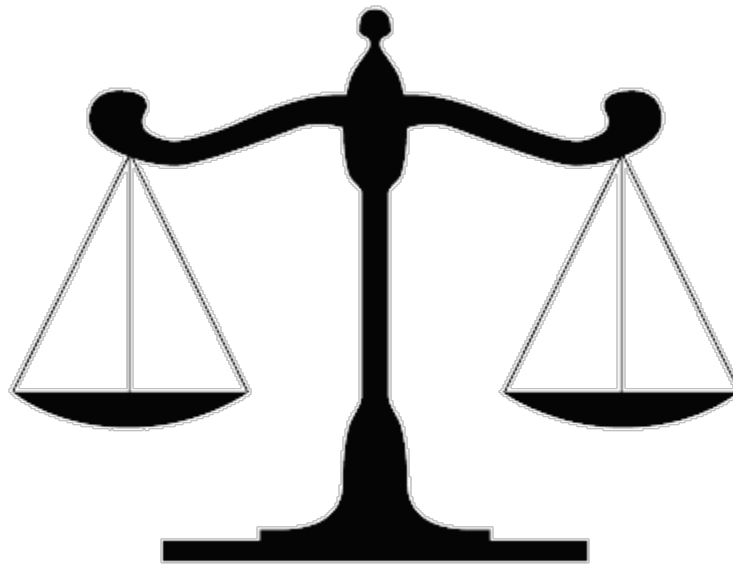
## 7 Building Blocks of a Use Case

1. What's your objective?
2. What do you want to do with your partners together?
3. What info do you need to share/access/use?
4. Where will the data come from?
5. What will you need?
6. How will the data be transmitted and stored?
7. Who are your partners (revisit)?



## Privacy Rights and Consent

Health information privacy laws are designed to balance



personal privacy interest

*with*

public good/need for information

# Application to Case Study: Fall Prevention

## Step 1: Review Relationships

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This project is notable for its large number of stakeholders and partners, including:

- Local health department
- State HIE
- City housing authority
- Local schools of public health
- Nursing
- Pharmacy and medicine
- Several local health systems
- Meals on Wheels
- Religious organizations
- Several other organizations interfacing with the elderly population in the project city.

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Collaboration chose the state HIE as central data hub for data sharing

- Already has rules on privacy, security, and breach notification
- Complies with all state and federal privacy and security laws
- Has capacity to collect, curate, analyze, and visualize the hospital emergency department data

# Application to Case Study: Fall Prevention

## Step 2: Develop a Use Case

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**Partners:** *Cooper County Public Health Department, Memorial Hospital (ER Department), Council on Elder Services, Cornerstone Home Health Services.*

**Data Sources:** *hospital admission and ER data for visits with ICD11 codes W00, W01, W05-W10, W17-W19 for the past 3 years to be transmitted via State HIE.*

**Data elements:** *patient first name, patient last name, patient DOB, treating hospital, date of ER visit or hospital admission, ICD11 code, date of fall, location of fall, [etc.].*

**Legal issues:** *Due to protected nature of medical data, analysis needed for applicability of HIPAA and state privacy law and what legal agreements need to be in place for the proposed data sharing to occur.*

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# Step 3: Create a Data Flow Map

## Step 3: Create a Data Flow Map

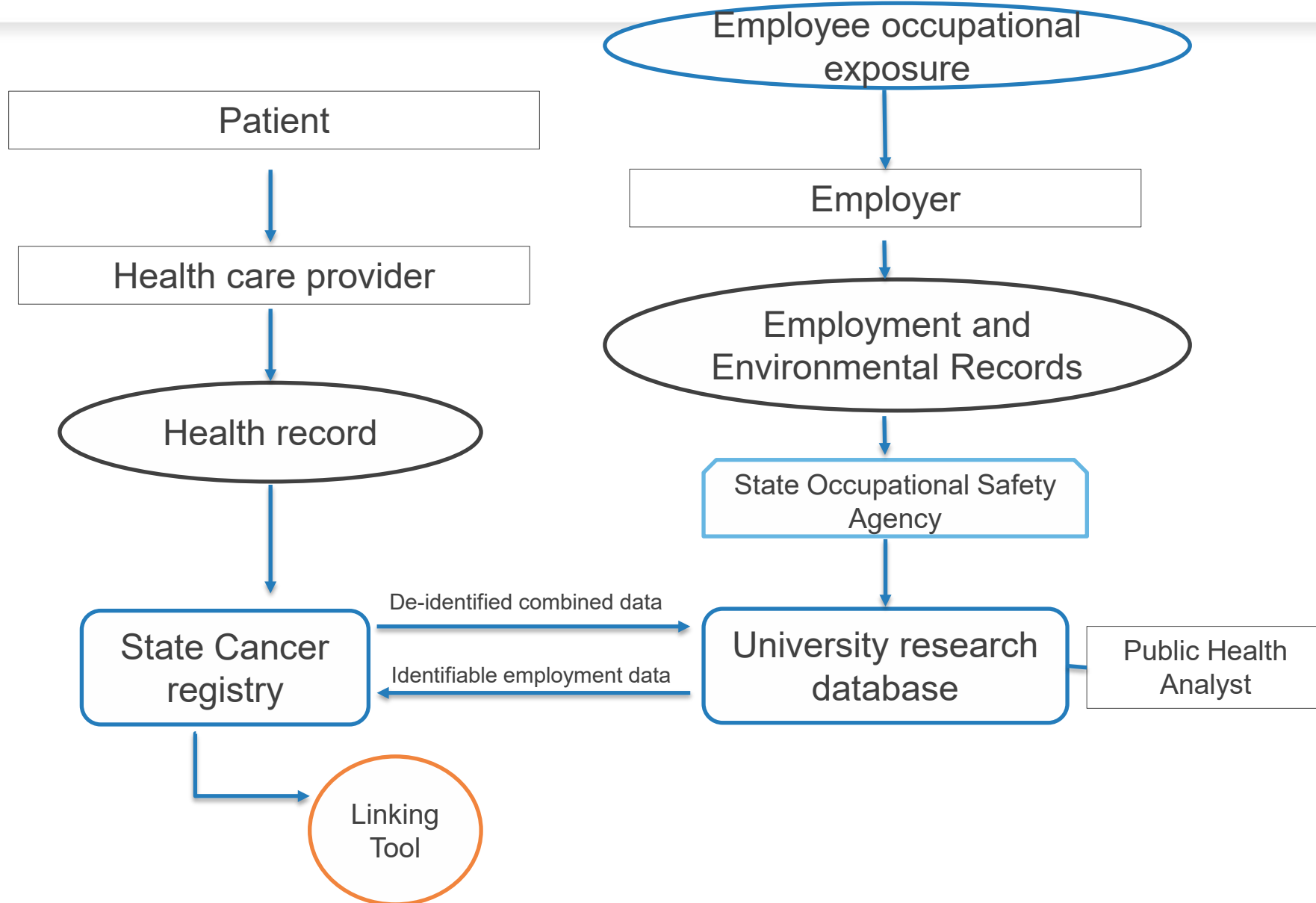
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1. Devising data flow map
2. Identifying data flows
3. Pinpointing data transfer points

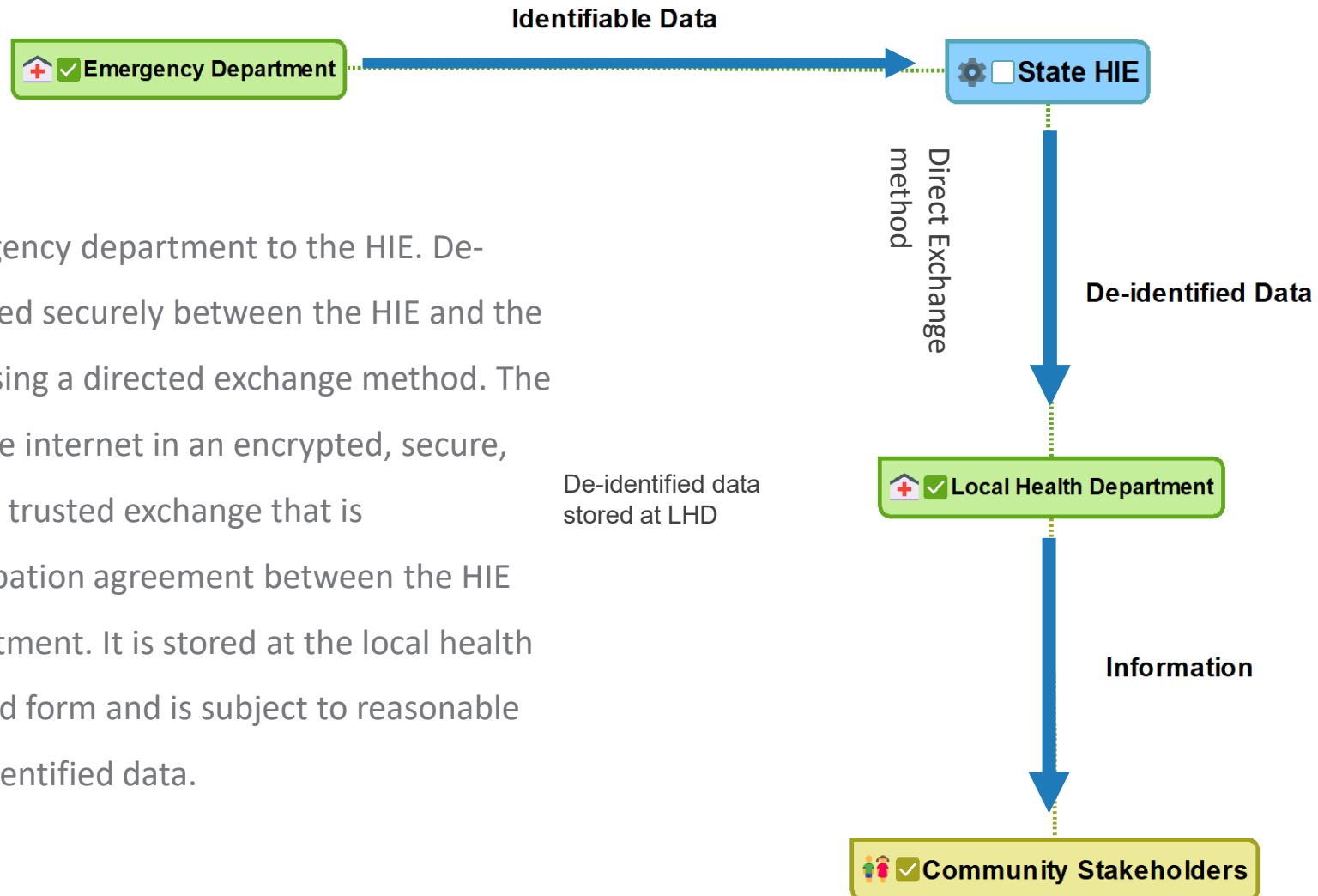
## Data Flow Map

1. Identify every point where people and systems interact
  2. Helpful for legal analysis
  3. Identify every point where data is transmitted
  4. Important to make data flow map as complete as possible
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# Data Flow Map Example



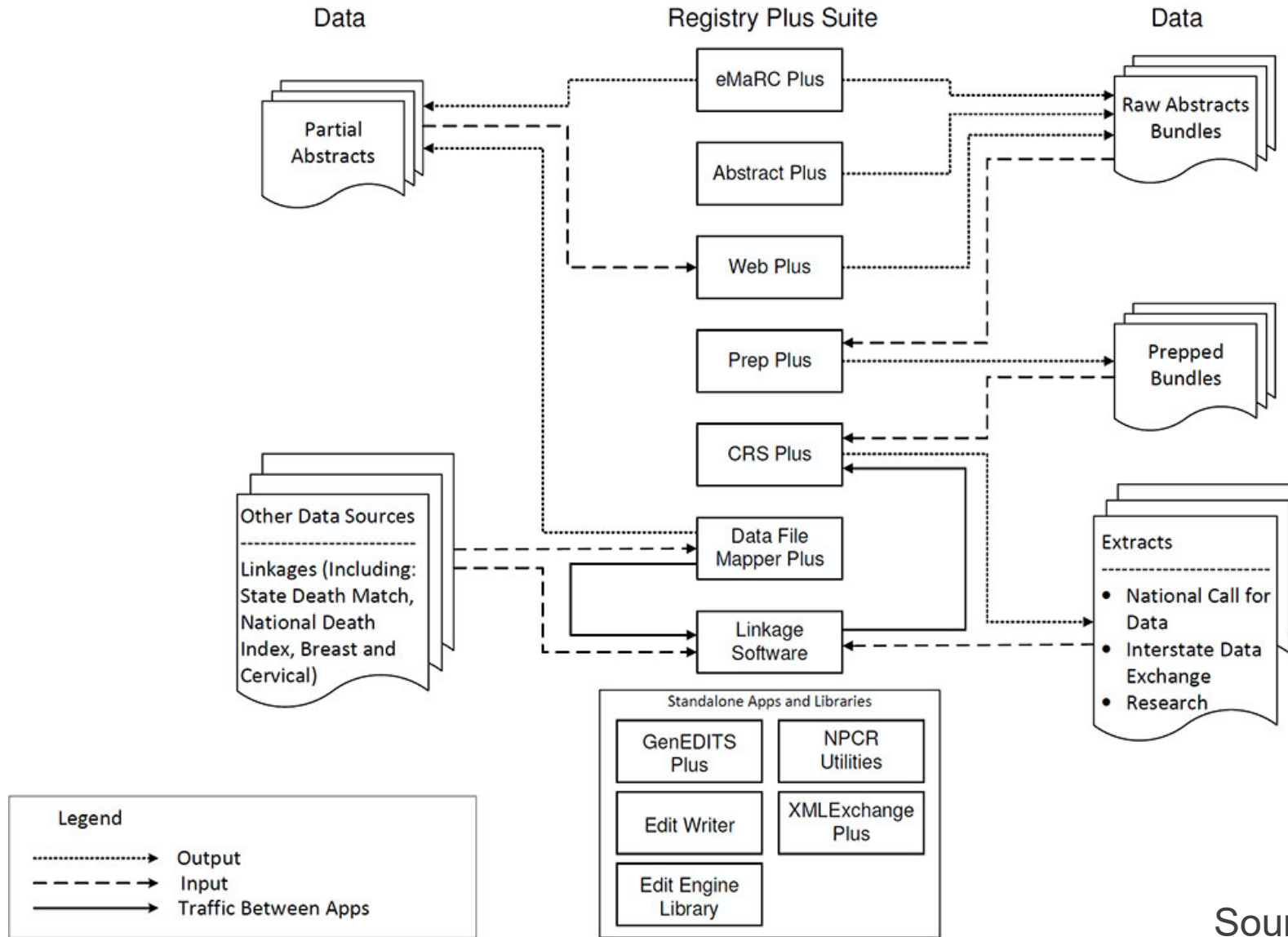
# Fall Prevention: Data Flow Map



Data flows from the emergency department to the HIE. De-identified data is transmitted securely between the HIE and the local health department using a directed exchange method. The information is sent over the internet in an encrypted, secure, and reliable way through a trusted exchange that is documented in the participation agreement between the HIE and the local health department. It is stored at the local health department in de-identified form and is subject to reasonable security standards for deidentified data.



# Data Flow Map Example

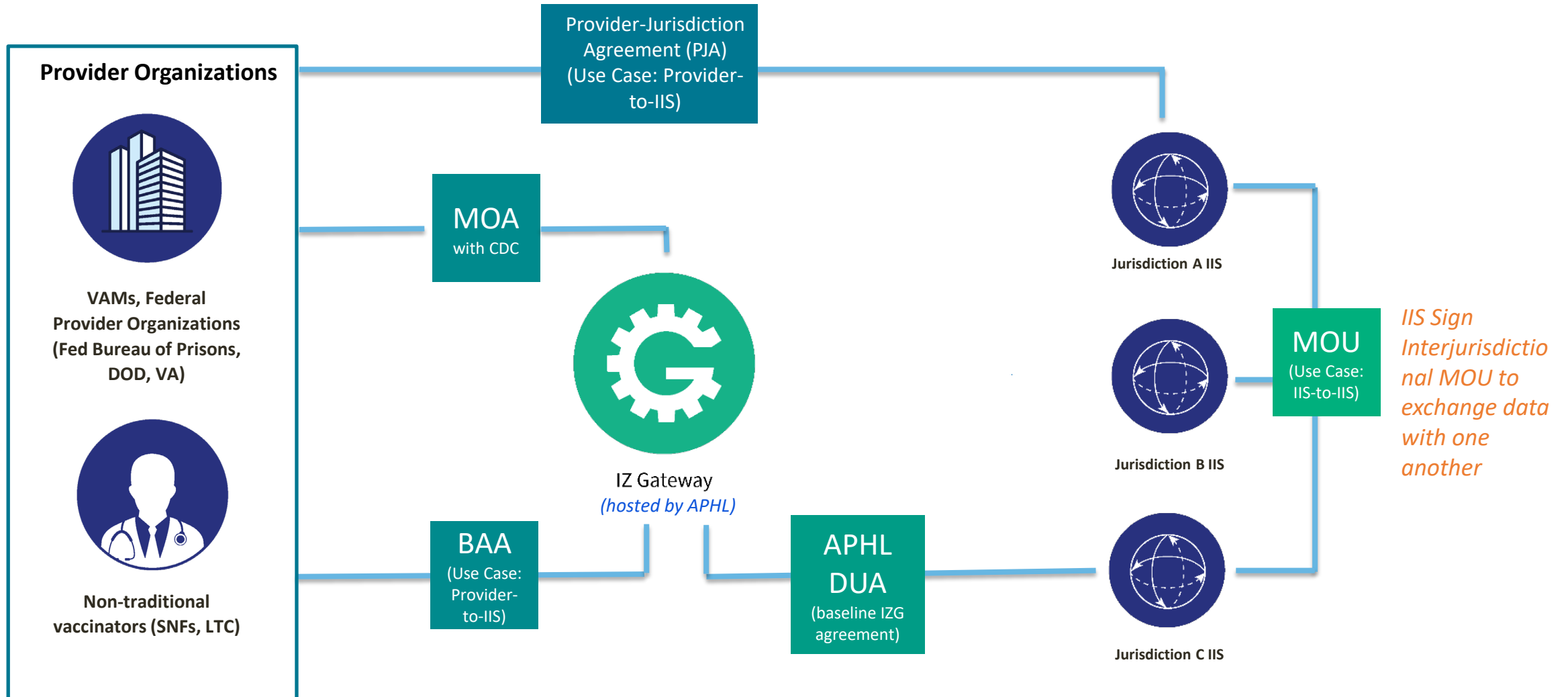


## Polling Question #2

What barriers to creating an accurate data flow map have you encountered most often?

1. Lack of familiarity with data flow maps
2. Poorly defined roles and responsibilities
3. Incomplete information available
4. Obscure processes
5. Getting overwhelmed with details

# IZ Gateway Trust Framework



# Step 4: Conduct Legal Analysis

## Step 4: Conduct Legal Analysis

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1. Consulting attorney
2. Identifying relevant laws
3. Applying laws to proposed sharing
4. Strategizing to navigate barriers

## Identifying the Laws: Considerations

Federal, state and local laws

Preemption

Most restrictive applies

General v. Specific

Involve your attorney



# Applying the Law

## Finding a Pathway to Yes When the Law Doesn't Work for You

1. Find similar data
  2. Obtain consent
  3. Use de-identified information
  4. Restructure your relationships
  5. Redefine your overall approach
  6. Modify your organization's structure
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## Common Types of Data Laws

| Health Information      | Identity Theft Protection         |
|-------------------------|-----------------------------------|
| Public Health Reporting | Patient Rights                    |
| Medical Records         | Professional Licensing            |
| Data Practices          | Facility Certification            |
| Privacy                 | Insurance Law                     |
| Security                | Consumer Protection               |
| Breach Notification     | Health Information Exchange       |
| Sunshine Law            | Social Security Number Protection |

# Case Study: Fall Prevention

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## Identifying laws

### HIPAA

- De-identification standards

### State laws

- General privacy protections

- Medical records privacy

## Rule out other laws

## *Case Study: Fall Prevention*

This project is aimed at reducing the number of falls.

The purpose and use of the data will be to identify problem locations that contribute to a disproportionately high number of falls, to investigate the reasons for falls, and to immediately use the information to advise community partners on where to locate interventions.

# Step 5: Agreements for Data Sharing

## Polling Question #3

What do you find to be the most challenging aspect of drafting a data sharing agreement?

Go to [mentimeter.com](https://www.mentimeter.com)  
Use code 7837 3524



## Step 5: Agreements for Sharing

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1. Establishing and documenting agreements for sharing data
2. Understanding Data Sharing Agreements, Data Use Agreements, Memorandum Of Understanding
3. Identifying elements of legally enforceable DSA/DUA

## Agreement Types

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### **Data sharing agreement (DSA)-**

document that outlines the terms, scope, and details of an agreement, including each party's requirements and responsibilities, to share data among two or more parties while protecting privacy, confidentiality, and other data rights. ***Legally enforceable***

### **Data sharing memorandum of understanding (MOU) –**

document that outlines the terms, scope, and details of an agreement, including each party's requirements and responsibilities, to share data among two or more parties while protecting privacy, confidentiality, and other data rights. ***Not legally enforceable***

## Functions of an agreement to share data:

- Describe the relationships between parties
- Define the project's purpose and goals and how data sharing supports same
- Clearly state the legal authority for data sharing
- Outline the terms agreed upon by the parties
- Identify data elements to be shared
- Provide monitoring and accountability methods for compliance

## Other terms or considerations

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- Minimum security requirements for all participants (possibly detailed as an attachment).
- Any legal prerequisites, conditions, and limitations should be included in the agreement for compliance purposes.
- Where multiple agreements in place, each agreement should be compliant with all the others.
- DSAs should also comply with institutional data-sharing policies and any other legally binding agreements.
- If a governmental agency is a party, state the authority of the signatory.
- If an individual's consent is needed to share their data, identify the party responsible for obtaining the consent.

## Case Study: Fall Prevention

### Cooper County Public Health Department and Memorial Hospital Data Sharing Agreement *(some elements)*

**Parties:** Cooper County Public Health Department, Memorial Hospital, State HIE

**Purpose:** To use hospital data to identify problem locations that contribute to a disproportionately high number of falls of older adults, ... to reduce number of falls by one-third over 3 years.

**Definitions:** ...

**Data to be provided:** all entries of Memorial Hospital ER visits or hospital admissions with an ICD11 code of W00, W01, W05-W10, W17-W19 for the period of January 1, 2019, to December 31, 2021. State HIE shall prepare a report of same and transmit to Cooper County Public Health Department via a system meeting FHIR standards.

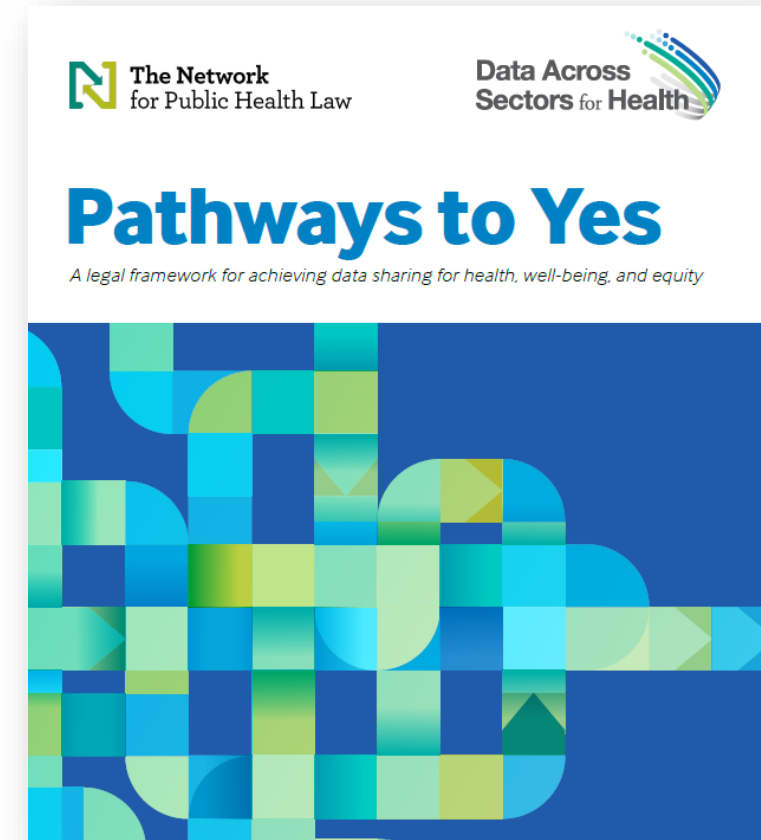
**Privacy and security requirements:** This Agreement adopts and incorporates by reference the privacy and security requirements in the State HIE Participation Agreement to which all parties are or must be a signatory prior to execution of this Agreement. All data transmissions shall meet FHIR standards.

**Period of Agreement:** This Agreement shall terminate on December 31, 2023, unless the Parties have negotiated an extension prior to that date.



## Pathways to Yes Framework Recap

- Step 1 Review your relationships
- Step 2 Develop a use case
- Step 3 Develop a data use map
- Step 4 Conduct legal analysis
- Step 5 Establish terms of sharing



[www.networkforphl.org/pathwaystoyes](http://www.networkforphl.org/pathwaystoyes)

# Questions & Answers

## Some Network's Resources for Data Sharing

1. [Pathways to Yes: A legal framework for achieving data sharing for health, well-being, and equity](#) (document, 2022)
2. [Pathways to Yes webinar for non-attorneys](#) (slides and webinar recording, 2022)
3. [COVID-19: Data Sharing for Public Health Surveillance, Investigation and Intervention](#) (webinar recording, 2021)
4. [Reproductive Health and Data in a Post-Roe World](#) (upcoming webinar, Dec 7, 2023)
5. [Checklist of Information Needed to Address Proposed Data Collection, Access and Sharing](#) (guidance document, 2019)
6. [Data Governance Strategies for States and Tribal Nations](#) (fact sheet, 2020)
7. [Tackling Tough Public Health Problems through Cross-Sector Data Collaborations](#) (webinar, 2019)
8. [The \(Largely\) Unknown HIPAA Privacy Rule Provision that Speeds Access to Social Services](#) (blog, 2021)

# Thank You for Joining Us

*Please take a moment to offer feedback in the evaluation to guide our future webinars.*