



Getting from the Data Sharing Land of No onto Pathways to Yes:

Navigating Data Sharing Projects for Non-Attorneys

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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.

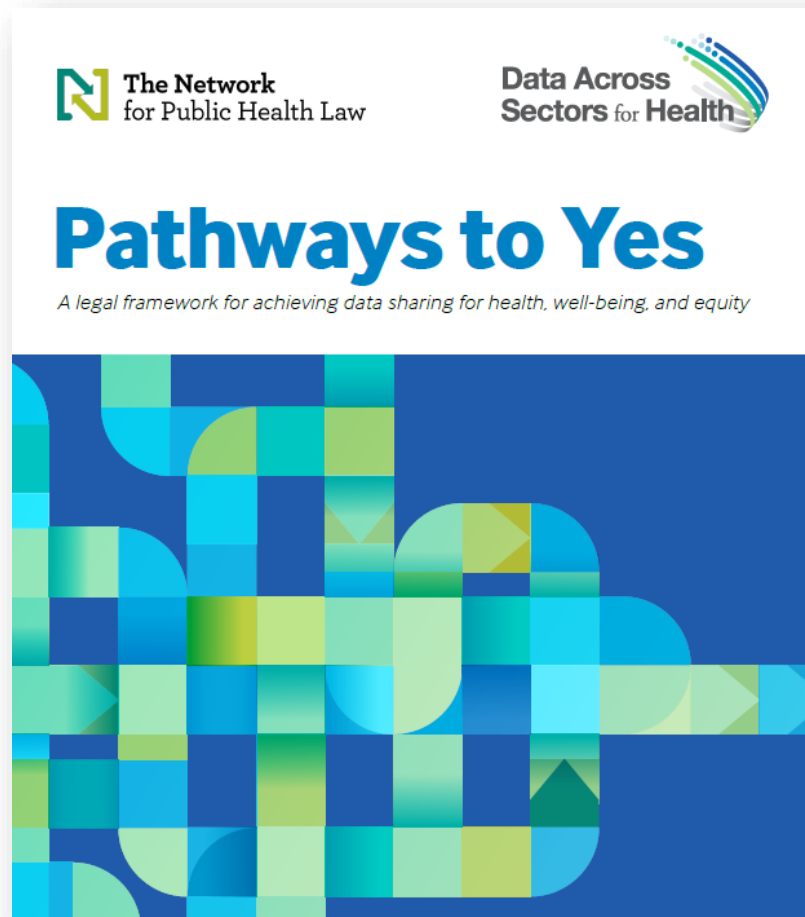
We provide information, resources, consultation and training, as well as opportunities to connect. We are supported by the Robert Wood Johnson Foundation.



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*



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

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

Polling Question #1

Are you, or will you soon be, working on a data sharing project?

1. I'm not working on a data sharing project and don't have plans to
2. I am currently working on a data sharing project
3. I will be working on a data sharing project in the future

Defining the Problem

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

People don't have a user-friendly guide to data sharing.

Confirming the Problem: Affinity Group Feedback

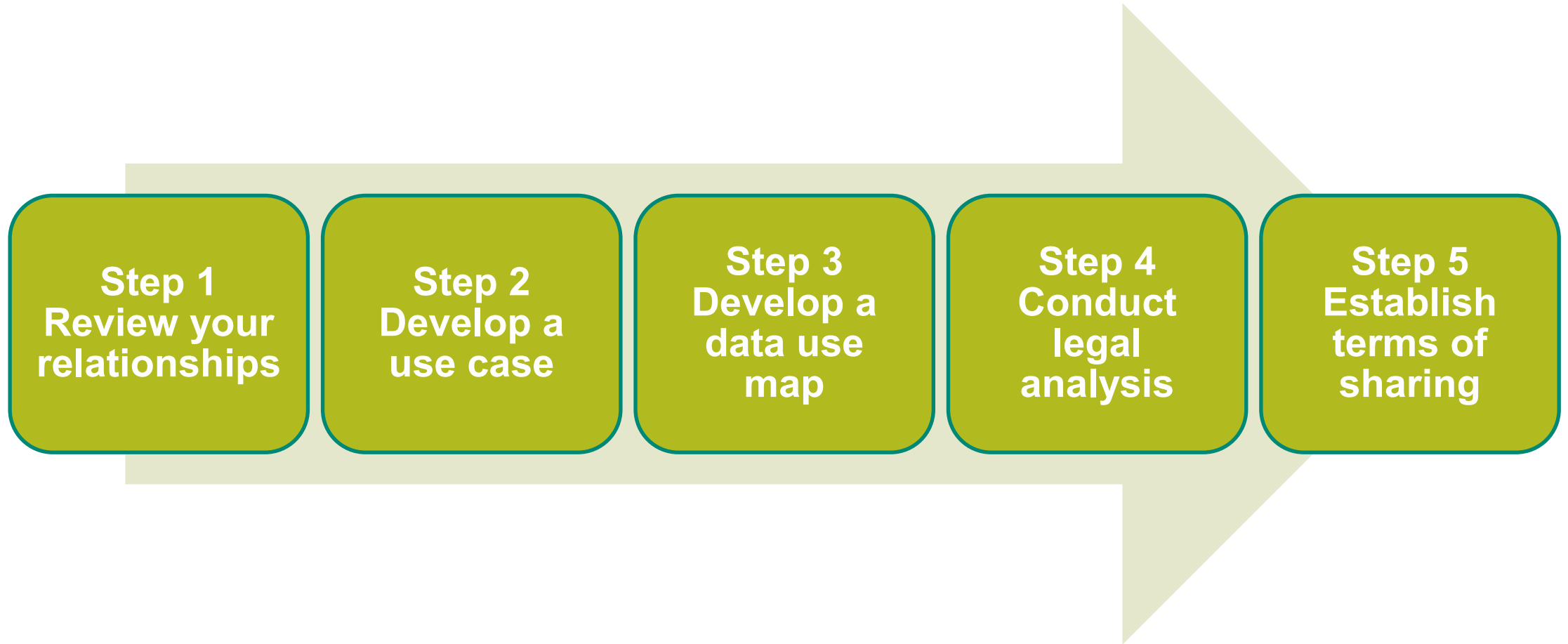
Words Used to Describe Interactions with Attorneys on Data Sharing Projects

Difficult, ambiguous, necessary nuisance, expensive, conflicting answers, mixed experience, **“no is easier,”** conservative in approach, challenging, protective, passionate, vital and valuable, brilliant

Affinity Group Main Barriers to Developing a Data Flow Map

Obscure processes, lack of transparency, **incomplete information about who needs data, how and when,** getting partners to share details, getting overwhelmed trying to capture too much detail, input from IT, **getting right people to the table**

Pathways to Yes Framework



Polling Question #2

Of the five Steps in the Pathways to Yes, which is most challenging for you?

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

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

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

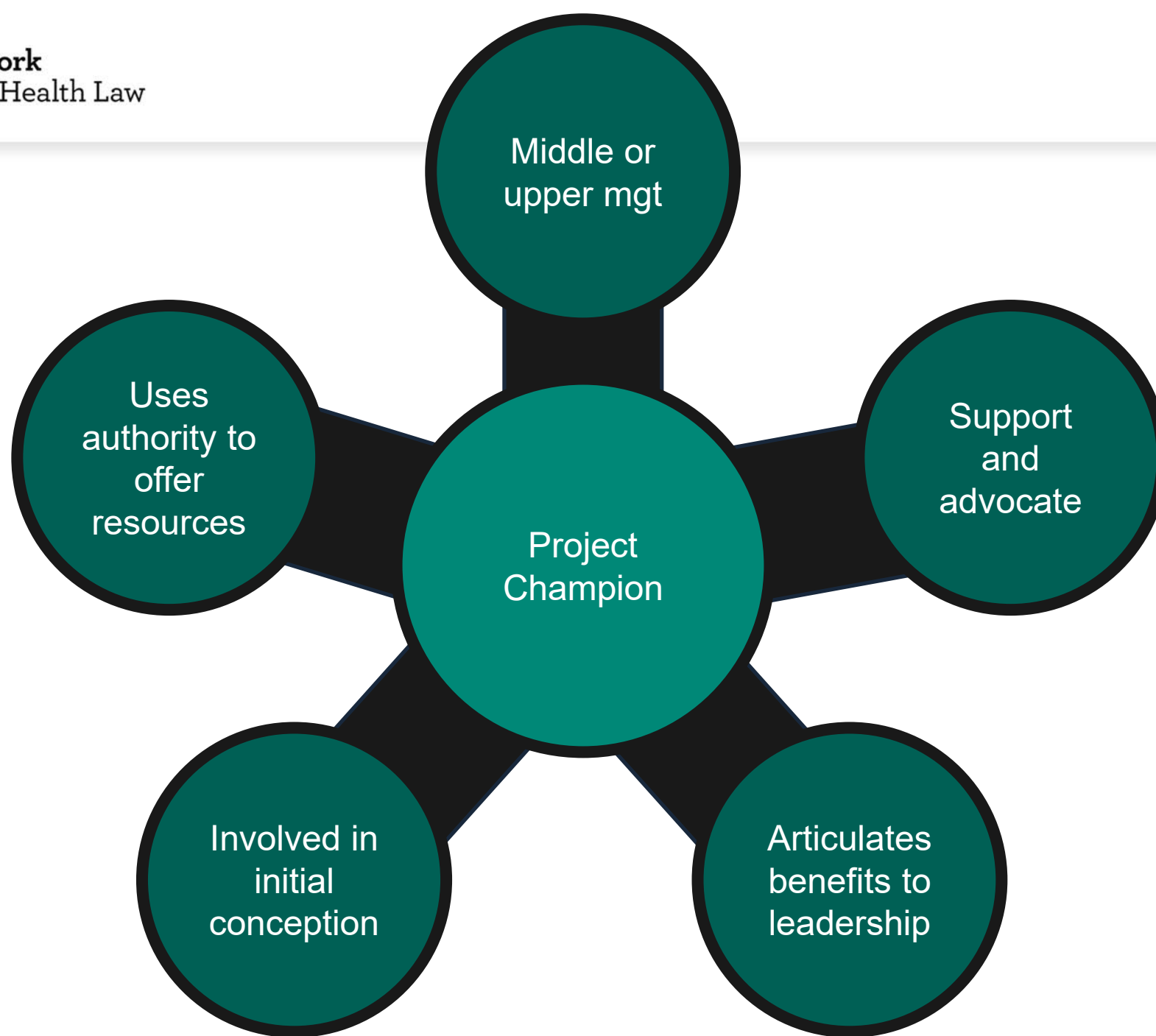
- Date of fall
- Location of fall
- ED admission date
- Age of patient
- Patient health outcome



Step 1: Review Your Relationships

Step 1: Review Relationships

1. Review relationships with partners
2. Identify data to be shared
3. Explore relationships with internal partners
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

Case Study: Fall Prevention

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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Case Study: Fall Prevention

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
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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

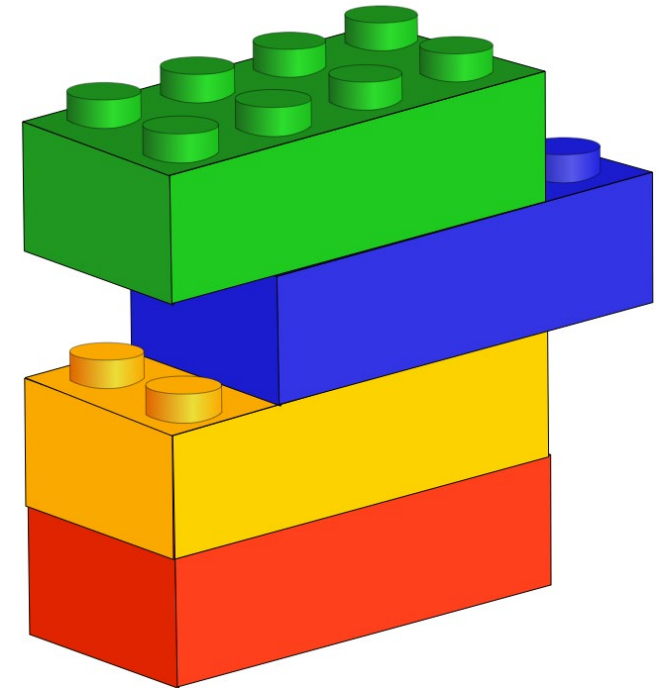
What is a use case? How is it useful?

A use case is the written guide for your project.

- Help identify/resolve important project elements: Who? What data? How used?
- Simplify the project development process
- Contain all necessary information to communicate value of project
- Help develop a legal analysis of proposed data-sharing activity to identify and resolve any legal issues

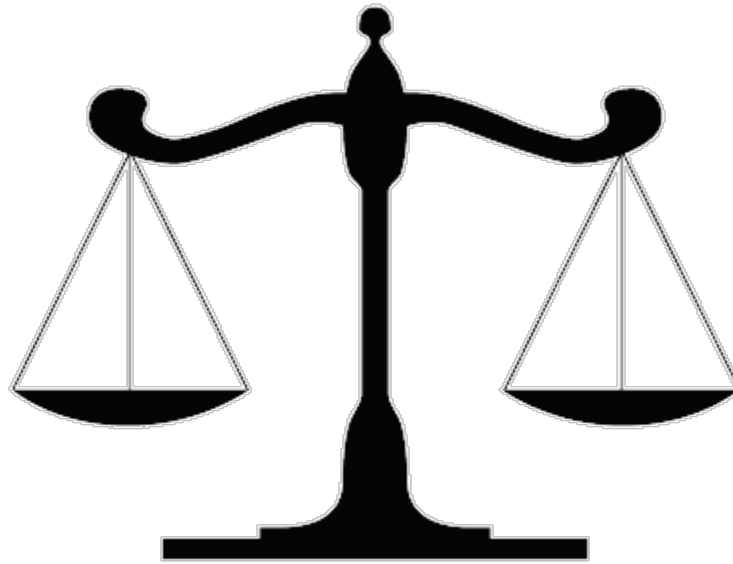
7 Building Blocks of a Use Case

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

COOPER COUNTY FALL PREVENTION PROJECT USE CASE

Problem: *Older adults' falls often lead to death, disability, and loss of independence. In addition to the people directly impacted, medical resources and limited home-health services are being stretched thin by what could be avoidable falls.*

Purpose/goal: *To identify problem locations that contribute to a disproportionately high number of falls of older adults, to investigate the reasons for falls, and to immediately use the information to advise community partners on where to locate interventions to reduce number of falls by 1/3 over 3 years.*

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.*

Polling Question #3

What types of individuals' data do you want to share or do you currently share? [check all that apply]

1. Behavioral health data
2. Health data (non-behavioral health)
3. Social service (non-government) program data
4. Governmental agency program data
5. Other

Step 3: Create a Data Flow Map

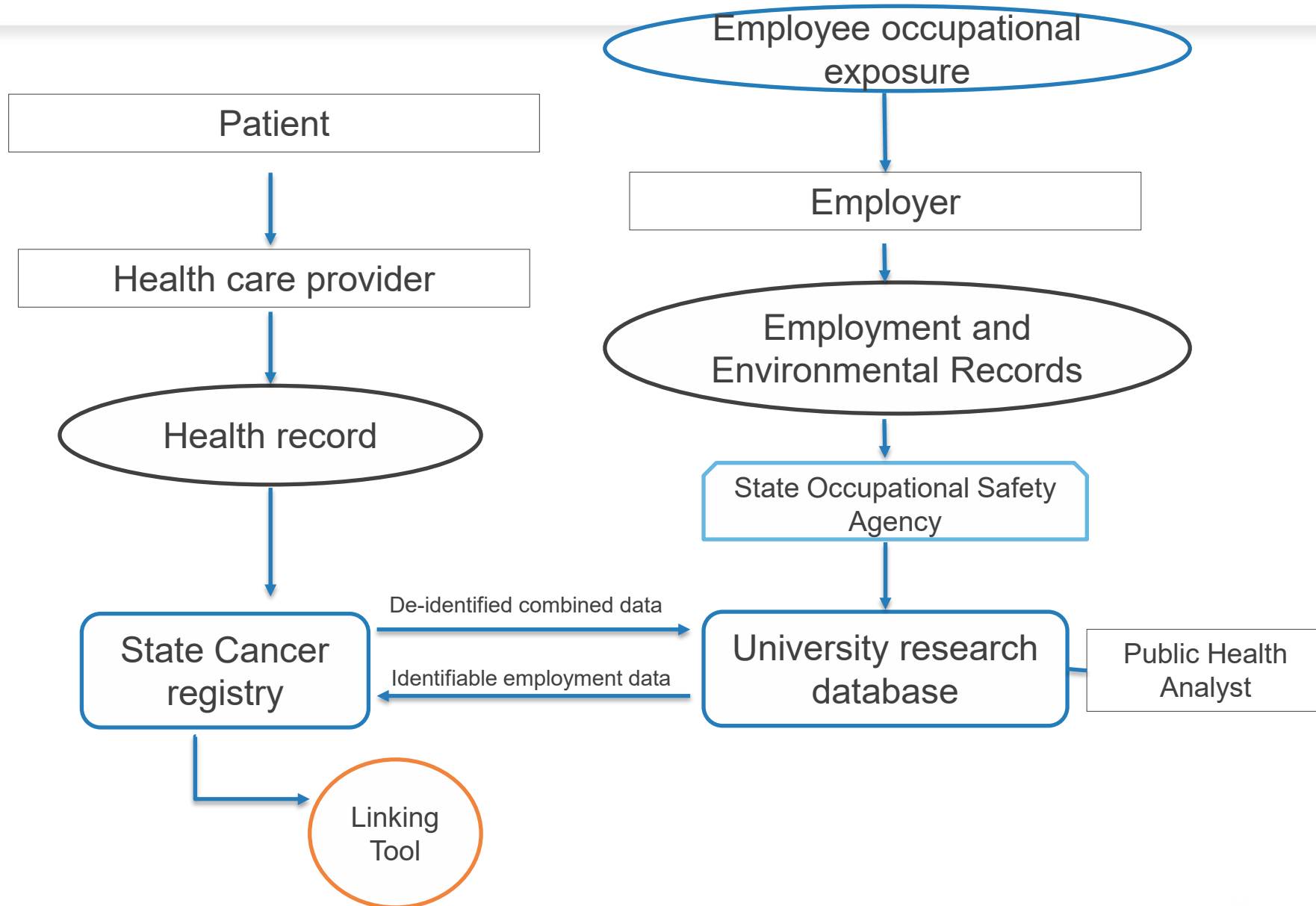
Step 3: Create a Data Flow Map

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

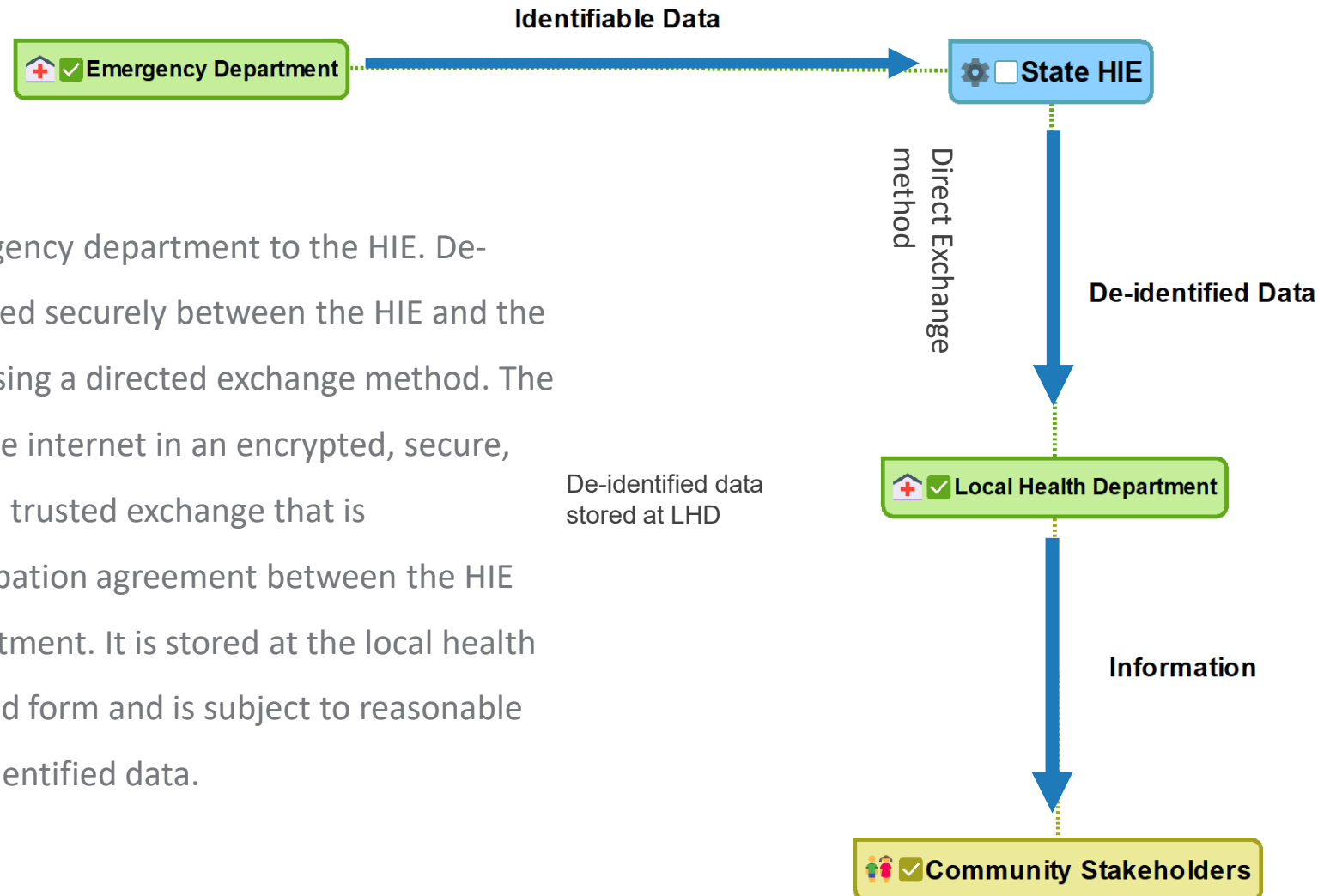
Data Flow Map

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

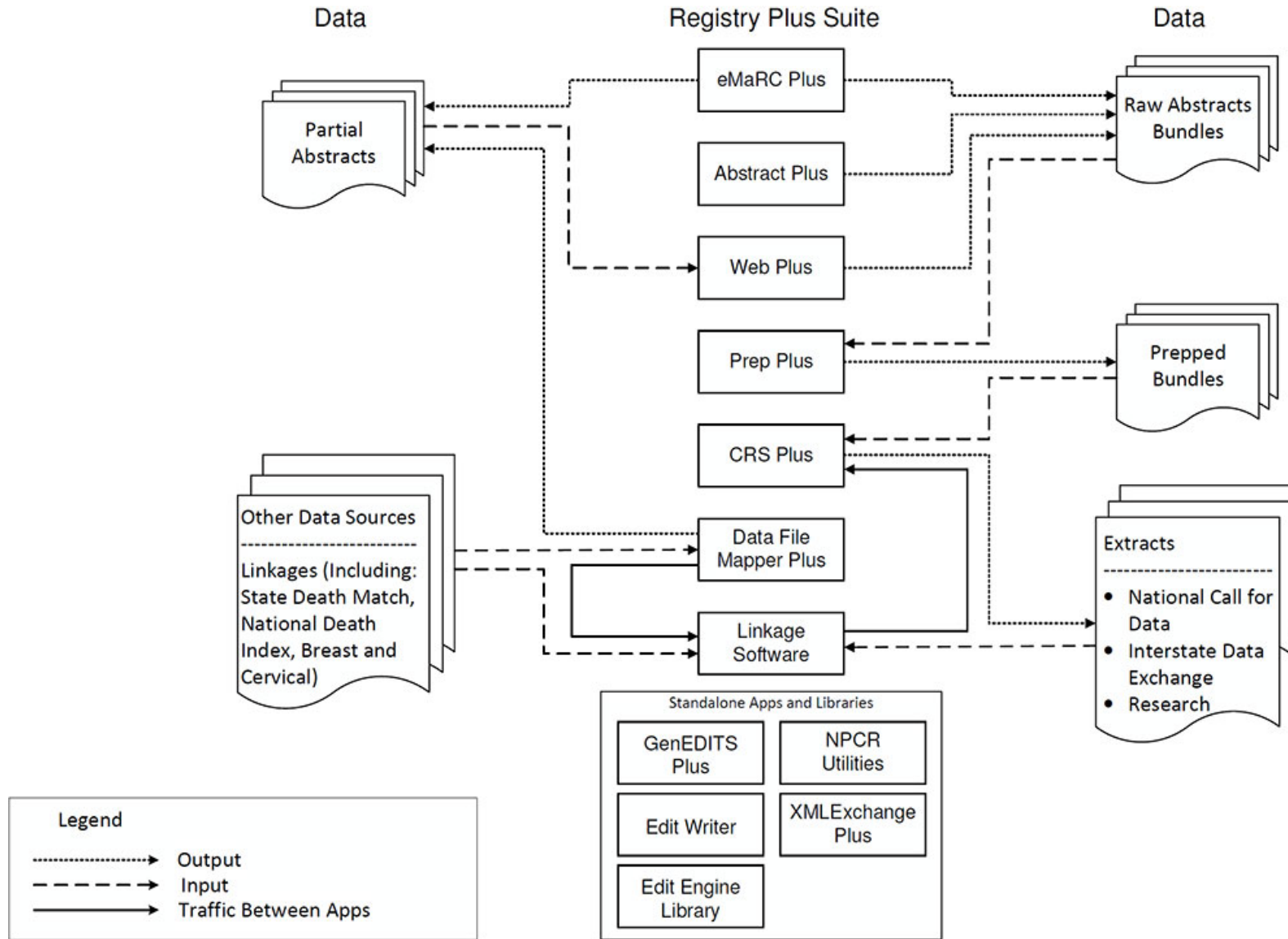


Fall Prevention: Data Flow Map



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 #4

Think about a data flow map for your data-sharing effort. Where in the data mapping process have you had successes? [check all that apply]

1. Establishing the interfaces/connectivity needed to share the data
2. Identifying a data lake or clearinghouse or storage location
3. Obtaining individuals' authorization/consent to share their data, if needed
4. Ensuring all data sharing partners have sufficient data security systems
5. Data governance policies
6. Other

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
-

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

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

Step 5: Agreements for Sharing

1. Establishing and documenting agreements for sharing data
2. Understanding DSAs, DUAs, MOUs
3. Identifying elements of legally enforceable DSA/DUA

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

Agreement Types

1. Data Sharing Agreement (DSA) or Data Use Agreement (DUA)
2. Memorandum of Understanding (MOU)
3. Others

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 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.

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

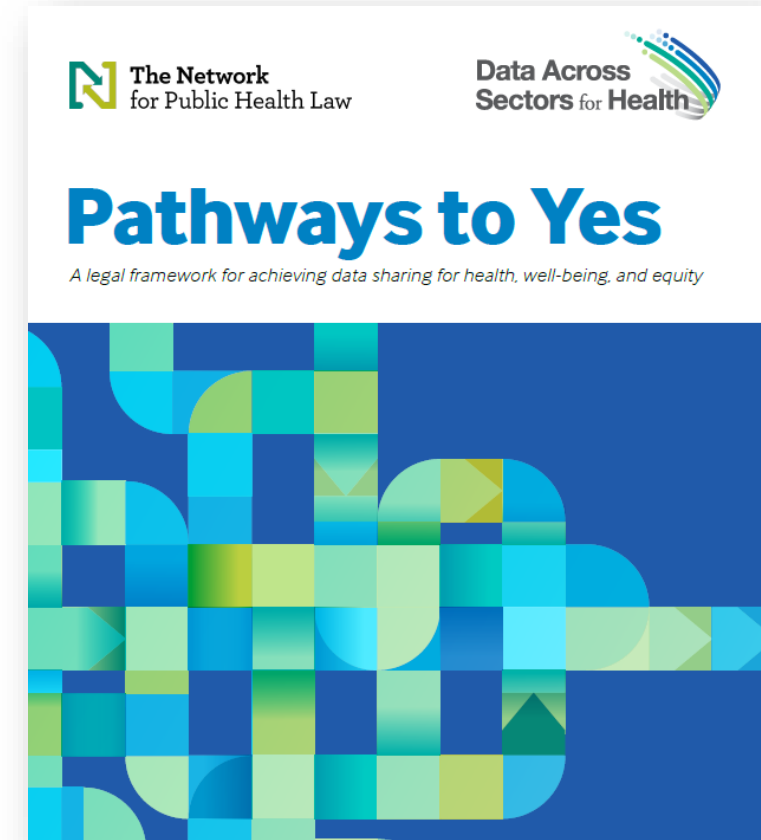
Step 1 Review your relationships

Step 2 Develop a use case

Step 3 Develop a data use map

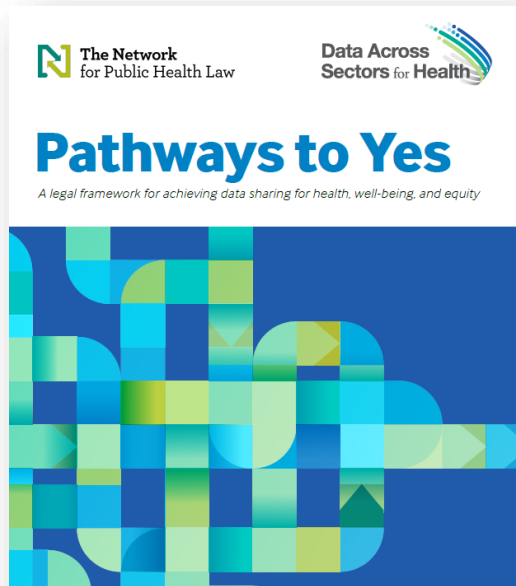
Step 4 Conduct legal analysis

Step 5 Establish terms of sharing



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Pathways to Yes Webinars



Upcoming Webinar

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

November 30, 2022 | 1:00-2:30 pm EST

www.networkforphl.org/webinarfordatasharinglawyers

Questions & Answers

Thank You for Joining Us