

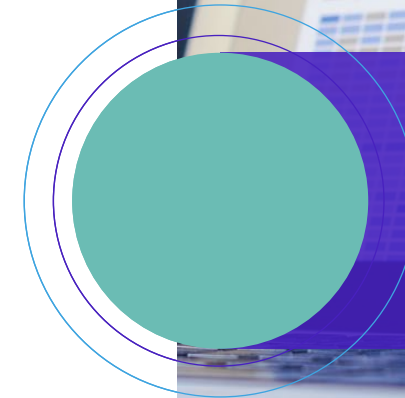


Getting Started:

Legal Frameworks for Data Sharing and Legal Analytics 101

Deja Kemp, JD
Director of Legal Policy
Actionable Intelligence for Social Policy

Laia Tiderman
Associate Director
Data Integration Support Center



TELL US IN THE CHAT:
What reasons have
you heard for why
data cannot be
shared?



Agenda

- Introductions and Overview of AISP & DISC
- Legal Frameworks
- Site Examples
- Q&A

What We Do

- **Convene** and advocate on behalf of communities that are sharing and using cross-sector data for good
- **Connect** to innovations, best practices, and research and funding opportunities that support ethical data sharing
- **Consult** with data sharing collaborations to build the human and technical capacity to share data and improve lives

Why We Do It

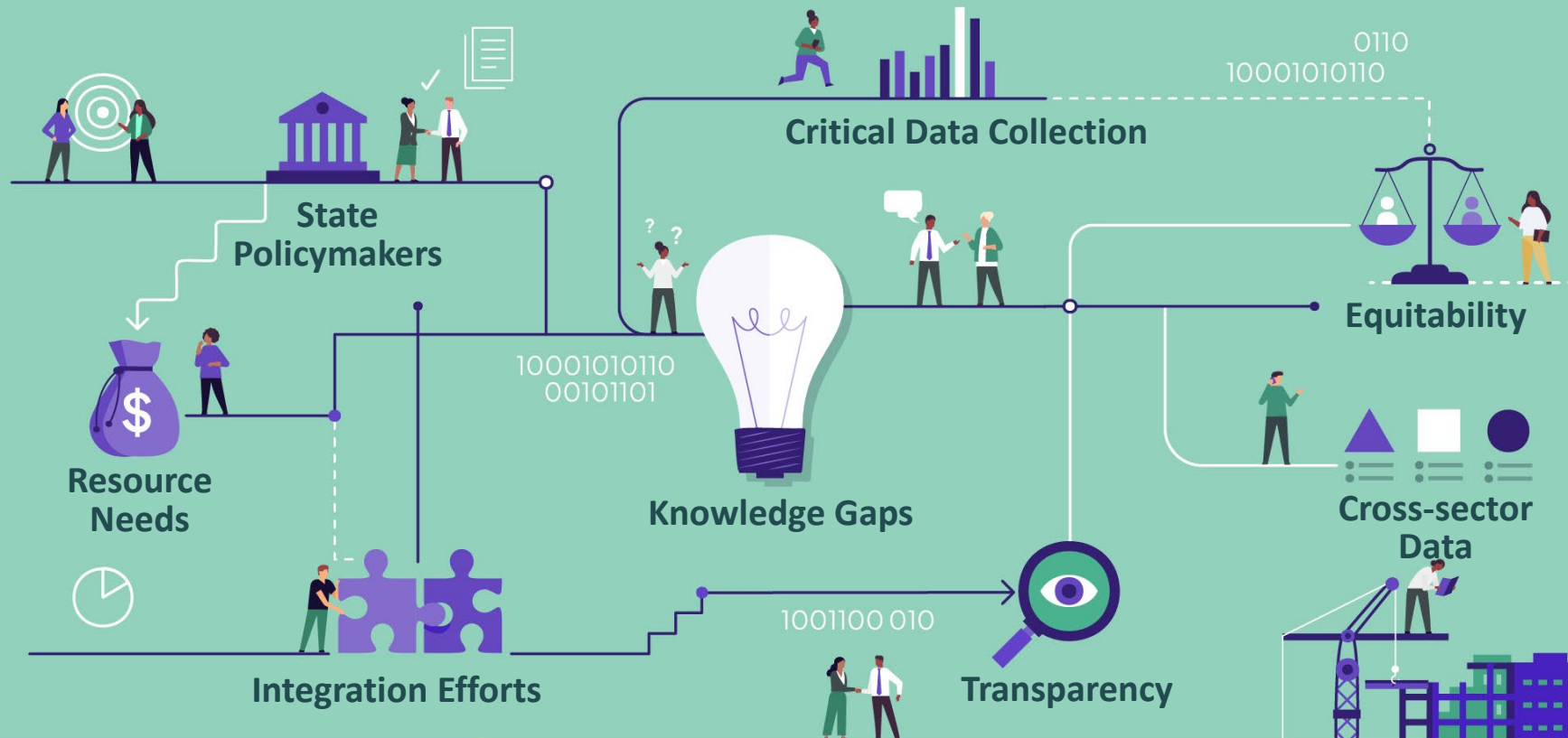
When communities bring together cross-sector data safely and responsibly, policy-makers, practitioners, and schools are better equipped to:

- Understand the complex needs of individuals and families
- Allocate resources where they're needed most to improve services
- Measure long-term and two-generation impacts of policies and programs
- Engage in transparent, shared decision-making about how data should (and should not) be used

www.aisp.upenn.edu



The Data Integration Support Center (DISC) at WestEd provides expert integrated data system planning and user-centered design, policy, privacy, and legal assistance for public agencies nationwide.



Our roles



We are:

Data evangelists

Connectors, community builders, thought partners, cheerleaders, and data sharing therapists

Focused on ethical data use for policy change



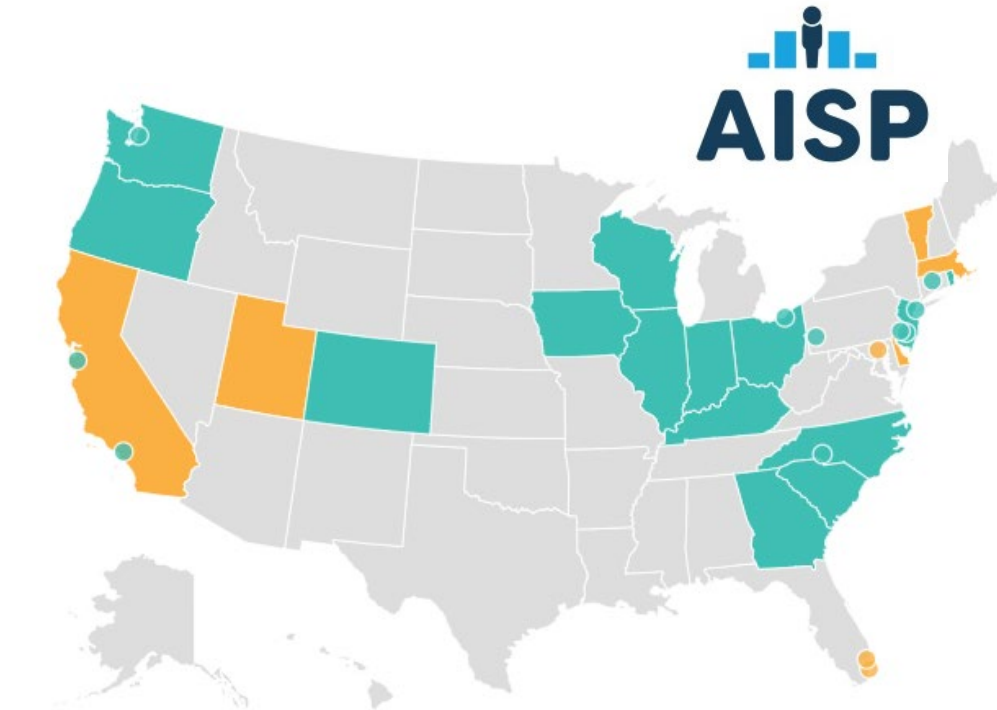
We are not:

Data holders or intermediaries

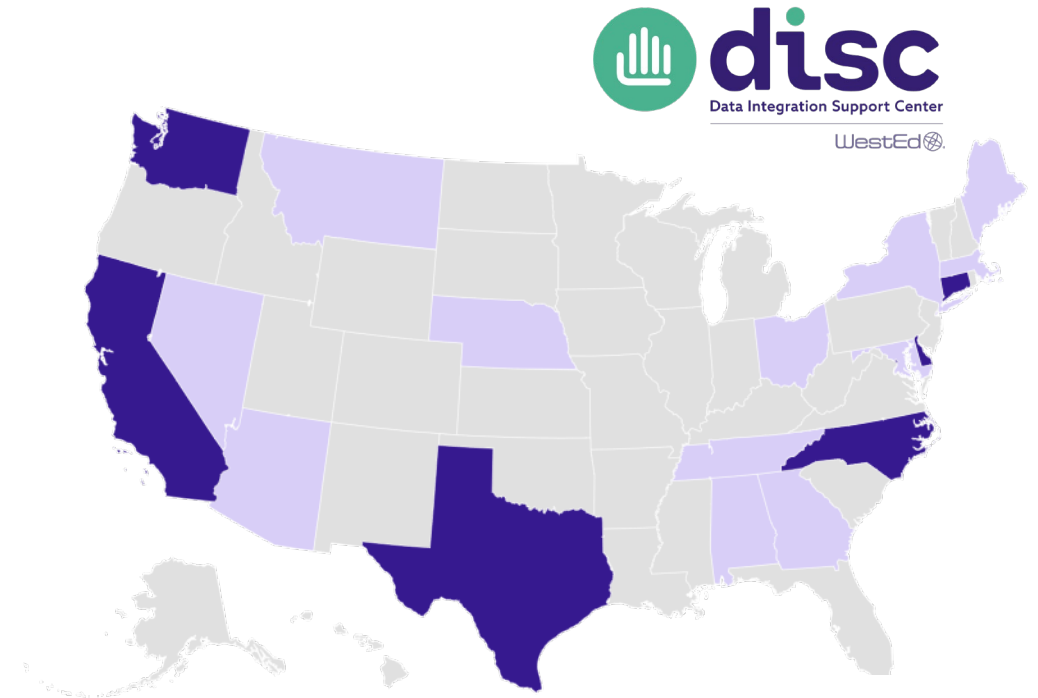
A vendor or vendor recommender

Focused on academic research

Our Networks



● Network Sites ● Developing Sites



● Intensive TA support ● Moderate TA support

What we do

AISP

IDS Peer Network

Guidance & Standards

Training & Consulting

Advocacy & Communications

Multi-site Research

DISC

Planning & User-Centered Design

Legislative Analysis

External Legal Support

Privacy

System Security

Our approach

The left side of the slide has a teal background. At the bottom, there is a white decorative arc that is part of a larger circle.

Data sharing is as relational
as it is technical.

A large, grey, downward-pointing arrow connects the top box to the bottom box.

We don't just need to integrate
data;
we need to integrate people.

ESSENTIAL QUESTIONS



What legal instruments are used to facilitate routine data sharing and integration?



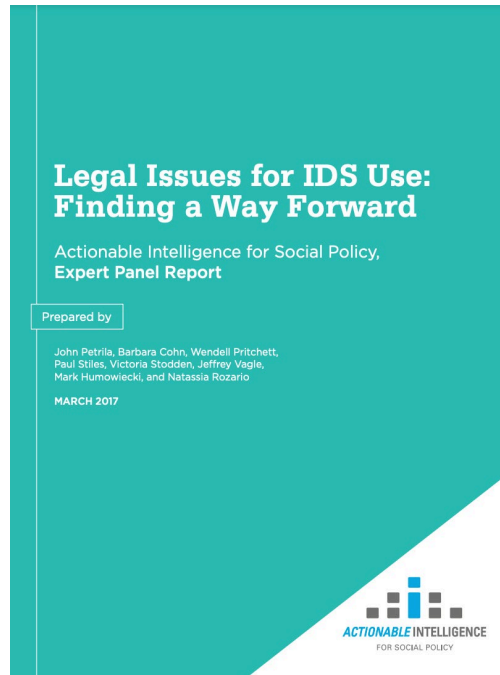
What are some commonly perceived legal barriers to data sharing and integration?



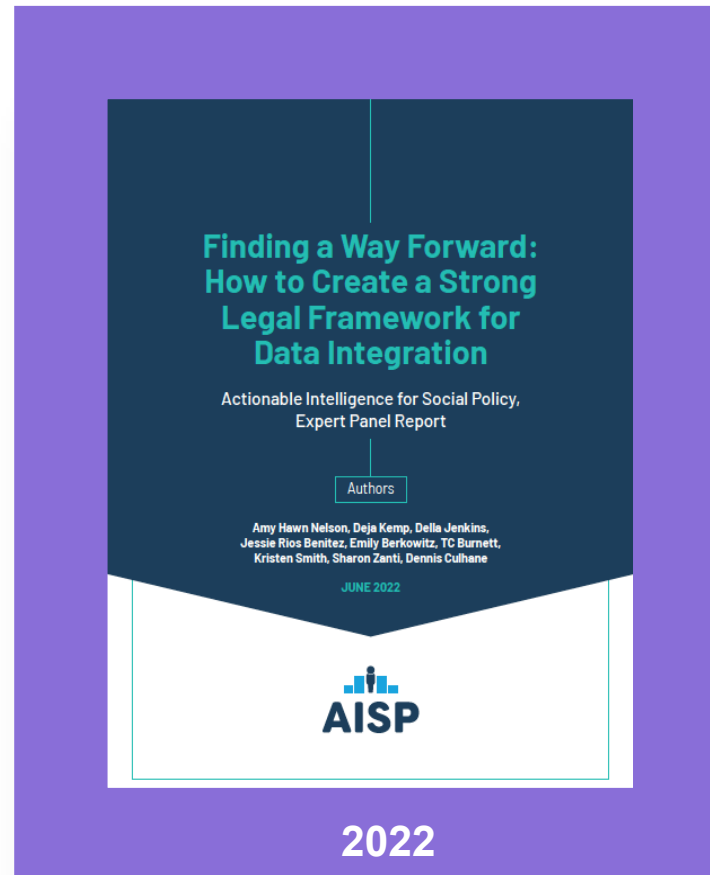
What are some current positive practices in the U.S. of data sharing and integration, with a focus on robust legal frameworks, data governance and routine data access and use?

Legal Frameworks

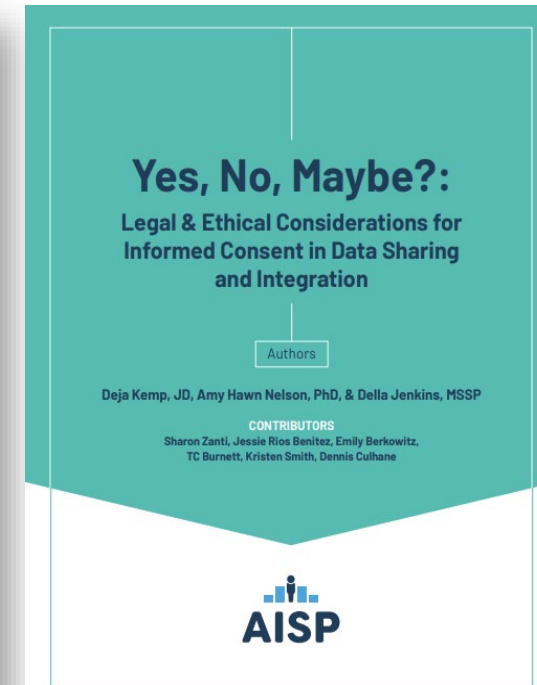
Legal Publications



2017

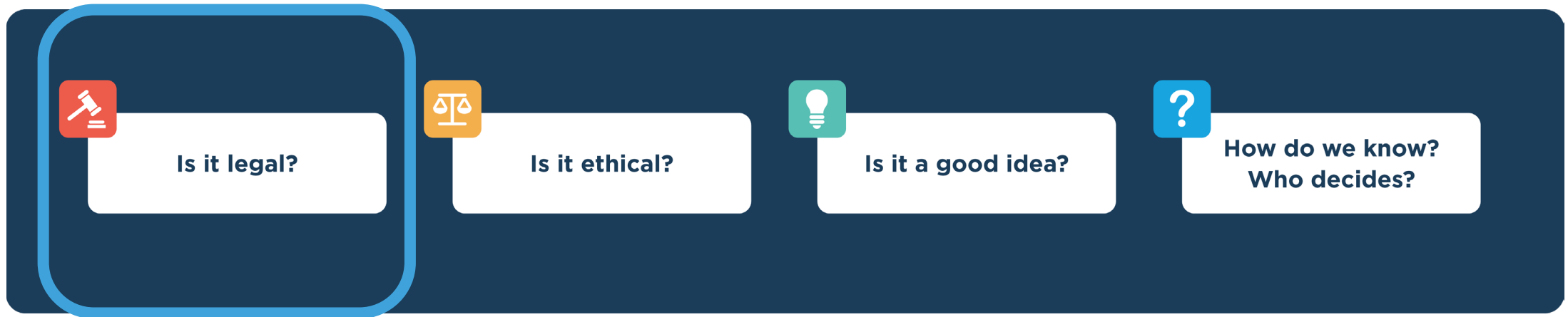


2022



2023

Why: The Four Questions



Where to begin?

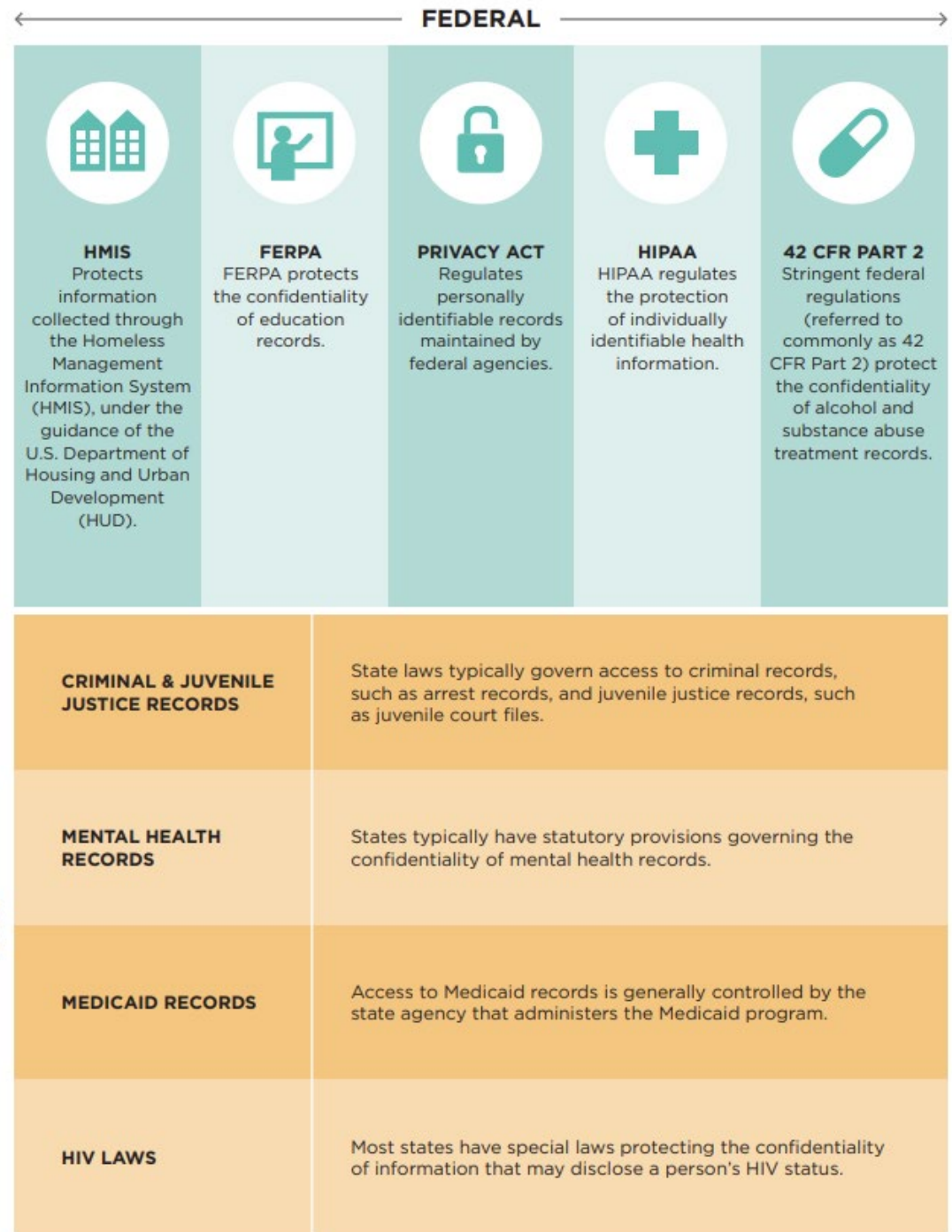
Legal Authority



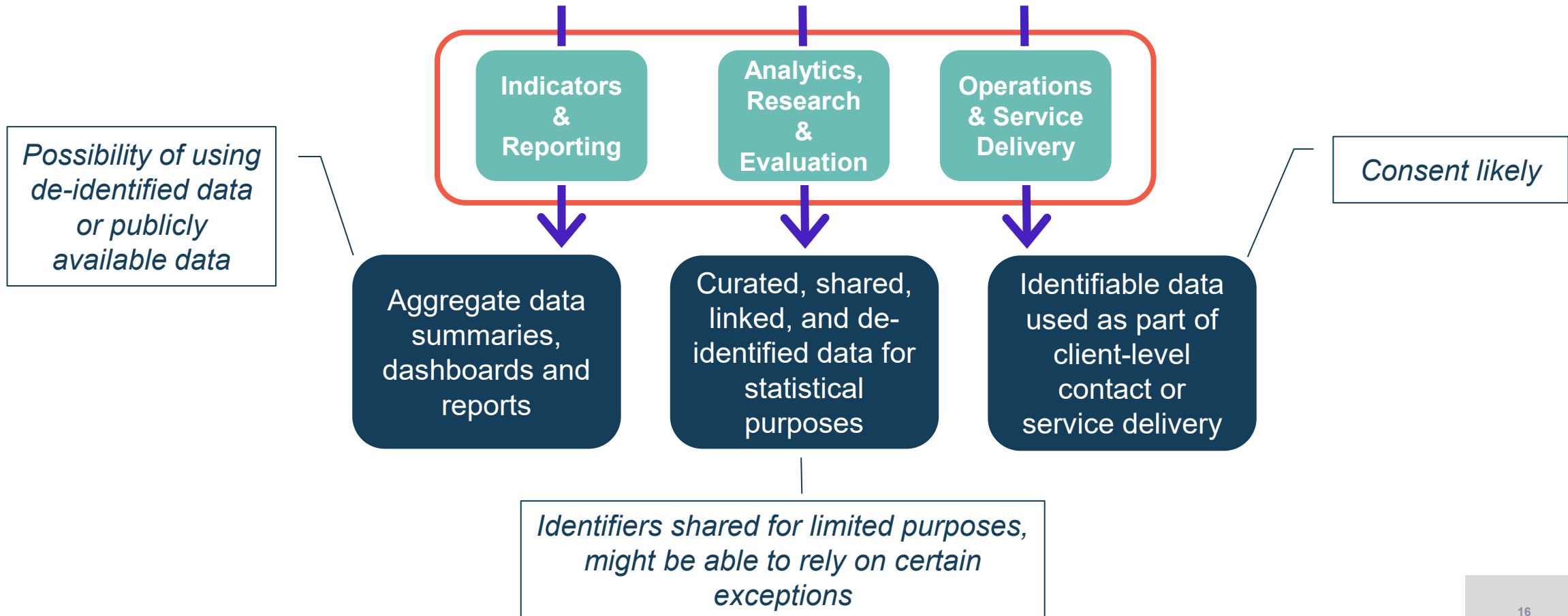
Data Classification

Open Data	Data that can be shared openly, either at the aggregate or individual level, based on state and federal law.
Restricted Data	Data that can be shared, but only under specific circumstances with appropriate safeguards in place.
Unavailable Data	Data that cannot or should not be shared, because of legal restriction or another reason (e.g., data quality concerns).

State & Federal Laws



Purpose will inform legality of use



Guiding Principles for Legal Agreements



A complex legal landscape governs data integration, especially regarding sensitive information.



Law is a real and perceived barrier to integrating meaningful data.



It is possible to navigate law to facilitate data integration.



When law is not clear, written agreements should be used to provide clarity.

Role of legal agreements in data integration:

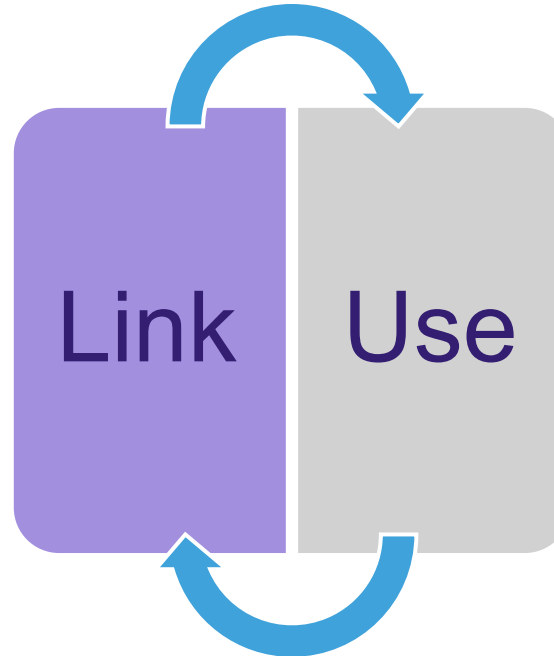
- **Identify and codify purpose**
- **Identify and codify relevant laws**
- **Clarify appropriate use and access**
- **Clarify where law is not clear**

Considerations for Legal Agreements

- **Time**
- **Adaptability**
- **Administrative burden**

Data Integration Purpose in IDS

1. Bring administrative data together to describe a population



2. Identify policies and programs that are most impactful in preparing residents to thrive

Foundational Legal Agreements

LEGAL AGREEMENT	PURPOSE	PROCESS	SIGNATORY
<p>Memorandum of Understanding MOU</p> <p><i>Overarching process document signed on by all data partners</i></p>	<p>The MOU documents the purpose and governance process. The MOU will be signed by all data partners as they enter the collaboration. The MOU references the DSA, DUL, and relevant policies, and procedures for data access and use.</p>	<p>Drafted in partnership with legal counsel from all participating data partners</p>	<p>Lead agency/ies + all data partners</p>
<p>Data Sharing Agreement DSA</p> <p><i>Agency-specific to how data will be used for integration</i></p>	<p>The DSA includes the specific terms and conditions that govern how data are transferred, stored, and managed when shared and integrated. The DSA references the MOU and the DUL. This document is specific to data held by a data partner.</p>	<p>Template is drafted in partnership with legal counsel from all participating data partners. Completed according to specific data assets of the data partner. Reviewed and updated annually, or as agreed upon.</p>	<p>Lead agency/ies + data partner</p>
<p>Data Use License DUL</p> <p><i>Data use-specific once data has been integrated</i></p>	<p>The DUL outlines the role and responsibilities of the data recipient. The DUL is often executed after the Data Request Form is approved. The Request Form and/or DUL should include: purpose, data fields, anonymization procedures, dissemination plan, and timeline of project completion. A DUL must be executed prior to data access.</p>	<p>Template is drafted in partnership with legal counsel from all participating data partners. Once data request is approved, a DUL is executed.</p>	<p>Lead agency/ies + data recipient</p>

Tiered Agreement

Data Use License (DUL)

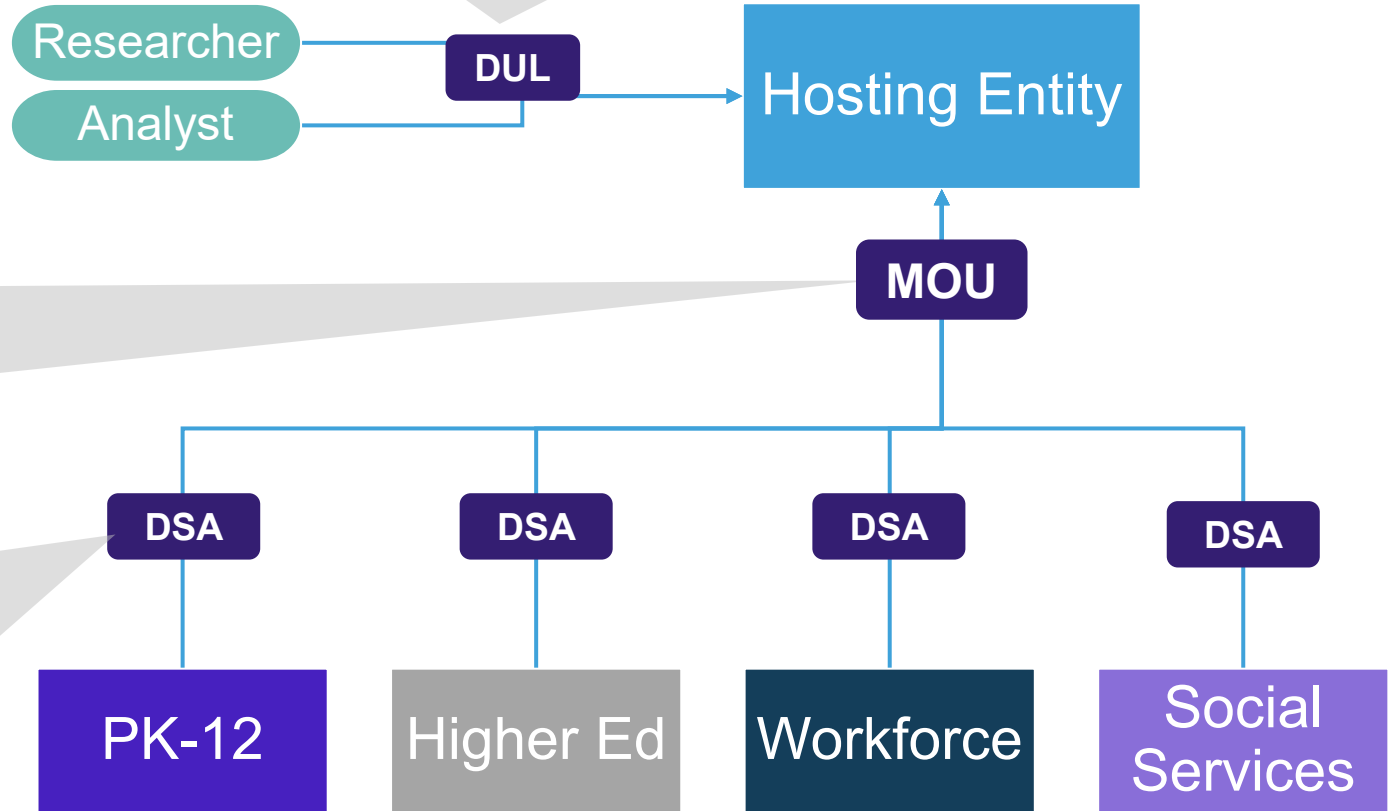
- Between Hosting Entity and Data Recipient
- Roles and responsibilities of the data recipient, often executed after a Data Request is approved.

Memorandum of Understanding (MOU)

- Between Hosting Entity and Data Partners
- establishes the specific context in which the host may access and use the data in the IDS
- MOU references the DSA, DUL, and relevant policies, and procedures for data access and use

Data Sharing Agreement (DSA)

- Between Hosting Entity and Data Partners
- includes the specific terms and conditions that govern how data are transferred, stored, and managed when shared and integrated
- DSA references the MOU and the DUL



Pros & Cons of Tiered Legal Agreements



PROS

- Purpose is inclusive of the data integration effort
- Flexible and adaptable
- Standardized
- Transparent and understandable to non-legal staff
- Ease of administration

CONS

- Longer initial development time
- More complex to understand and socialize

A Practical Example



Lease = Legal Authority

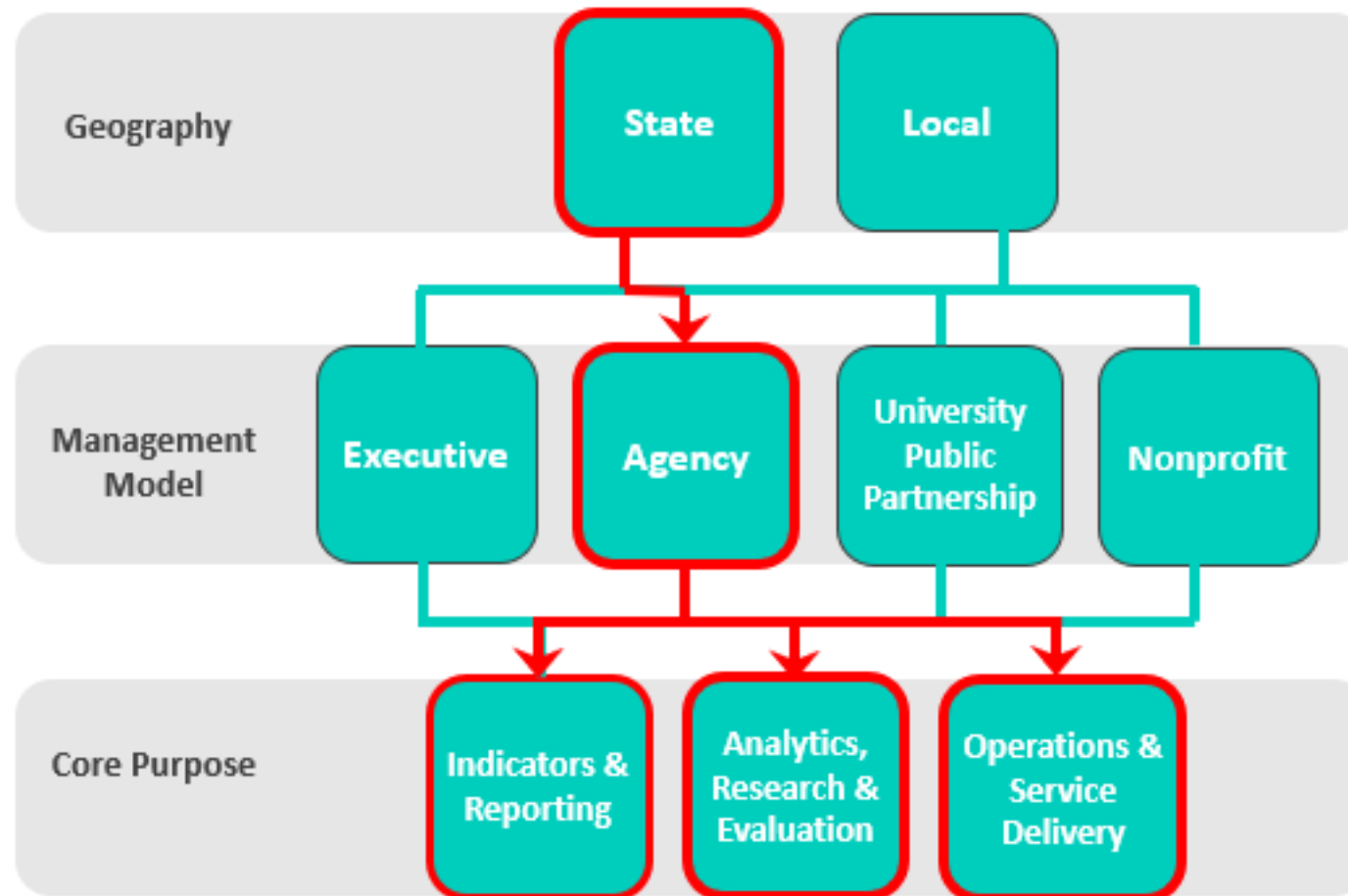
MOU = Roommate Agreement

DSA = Individual Agreement re assets

DUL = Details the use

Site Examples

North Carolina Department of Health & Human Services



Legal Framework History



2019

- ✓ Staffing of Data Office
- ✓ Data Strategy Development



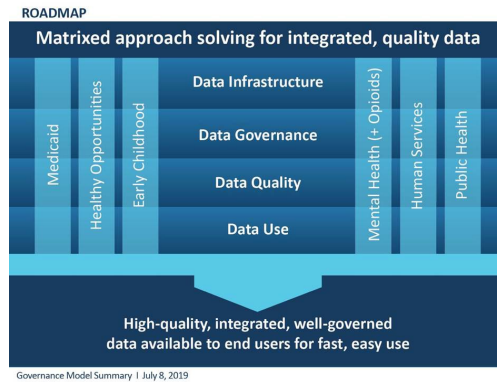
2020

- ✓ Data Landscape
- ✓ ID key steps to improve data access and use



2021

- ✓ Data Sharing Guidebook
- ✓ Data Request Forms
- ✓ Legal Framework



Hoping you have seen this document?

January 2020



North Carolina Department of Health and Human Services
Data Landscape Overview

Goals of this document:

- Describe perspectives of DHHS staff and contractors in regards to data infrastructure, data governance, data quality, and data use across the DHHS enterprise.
- Identify strengths, weaknesses, opportunities, and threats in regards to infrastructure, governance, quality, and data use to support data strategy development by the DHHS Data Team.

Data Collection Activities:

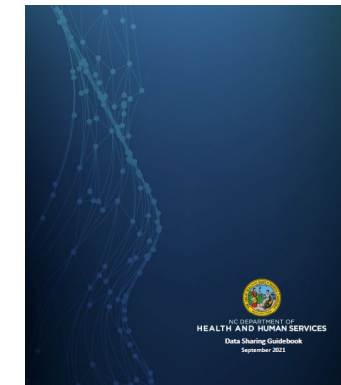
This Data Landscape Overview has been developed through engagement with NC Department of Health and Human Services staff and contractors via in-person meetings, document review, a survey of data sharing agreements (led by division director and legal counsel), weekly calls with DHHS Data Team, and structured interviews, both in-person and by phone, with 44 individuals from September 2019 to January 2020.

Analytic Approach:

Notes from structured interviews were reviewed multiple times and thematically coded. A theme was not included in this overview document unless mentioned 3+ times by respondents and/or corroborated by another data source (document, meeting, email, etc.).

Amy Hawn Nelson, PhD
Actionable Intelligence for Social Policy, University of Pennsylvania
ahnelson@upenn.edu, 704-616-0796
Funded by NC Department of Health and Human Services

NC DHHS Data Landscape Overview January 2020 4



Legal Framework History



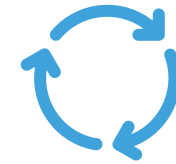
November 2021

- Executed Intradepartmental Memorandum of Understanding (IMOU)



January – June 2022

- Draft Division and Office Specific Data Sharing Agreements
- Begin Executing DSAs



July 2022 – Present

- Continuous process improvement
- Demonstrated use cases across all of DHHS
- Executing Remaining DSAs

The Framework – Foundational Legal Agreements

NCDHHS' FOUNDATIONAL LEGAL AGREEMENTS

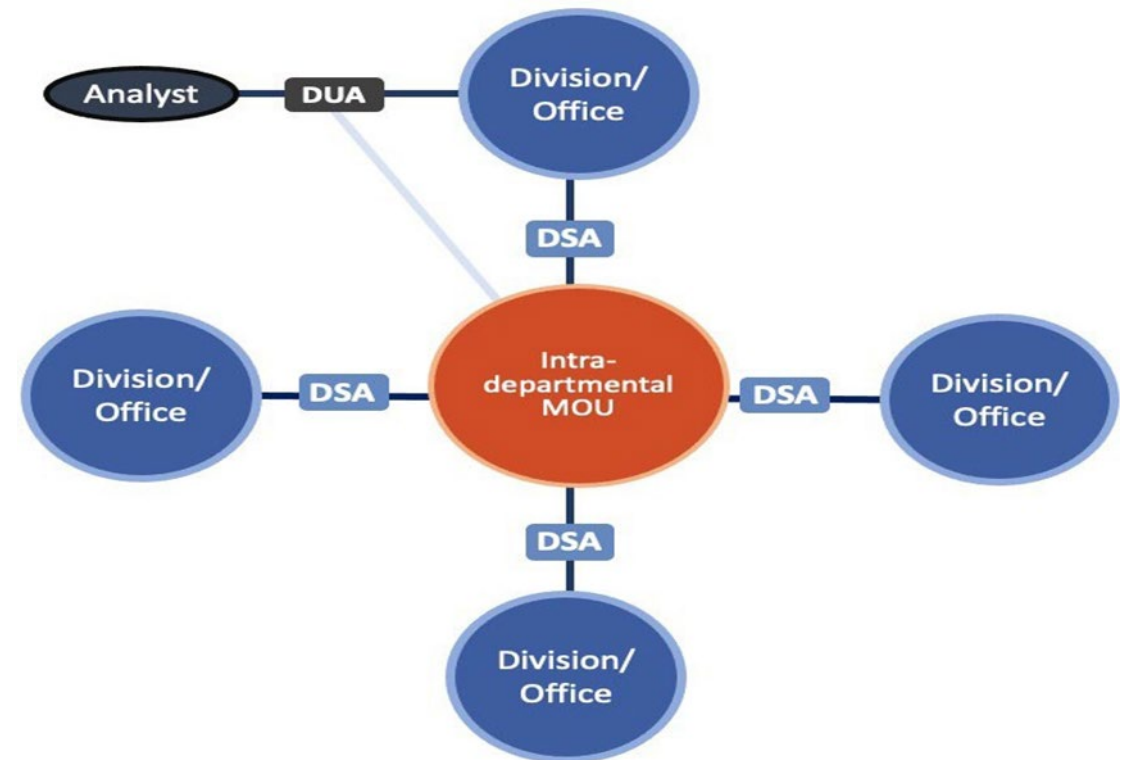
LEGAL DOCUMENT	PURPOSE	PROCESS	SIGNATORY
Intradepartmental MOU <i>Overarching process and guiding principles document signed by all Divisions / Offices</i>	<ul style="list-style-type: none"> Documents the purpose and governance process. Is signed by all data partners as they enter the collaboration. Sets the stage where collaborators understand and agree on the basic premise that data use must be legally compliant, responsible, and only to the extent required. References the data sharing agreements, data use agreements, policies, and procedures for data access and use (e.g., NCDHHS Data Sharing Guidebook). 	<p>Drafted by Data Office, reviewed by legal counsel, signed by Executive Leadership and updated through the NCDHHS Data Governance Council as needed.</p>	<p>All Division and Office Directors and Secretary's Office are parties to 1 agreement</p>
Data Sharing Agreement <i>Division / Office Specific</i>	<ul style="list-style-type: none"> The DSA includes the specific terms and conditions that govern how division- and office-specific data are transferred, stored, and managed when shared and integrated across the Department. The DSA references and reinforces the IMOU and the DUA. It is specific to Division and Office held data and incorporates language around use of data for administrative purposes, which if legally permissible is by default approved unless the data owner decides otherwise. 	<p>Drafted by Data Office and Division/Office specific legal counsel. Reviewed and updated annually, or as agreed upon.</p>	<p>1 DSA per Division/Office</p> <p>Signed by Division and Office Director, the Data Office, and Information Technology Division</p>
Data Use Agreement <i>Data Request Specific</i>	<p>Legal counsel determines if a DUA is needed for a specific request. The DUA outlines the role and responsibilities of the data recipient. If applicable, this document is attached to the Data Request Form, which includes relevant fields, depending on the request, including: purpose, data fields, anonymization procedures, dissemination plan, and timeline of project completion. A DUA must be executed prior to data access.</p>	<p>Data request is identified by type and reviewed appropriately based upon the type of request. Legal counsel determines if a DUA is applicable. If yes and request is approved, a DUA is executed.</p>	<p>DUAs are used as needed for use cases not covered by DSAs.</p> <p>Signed by Data Recipient and Data Owners (if applicable)</p>



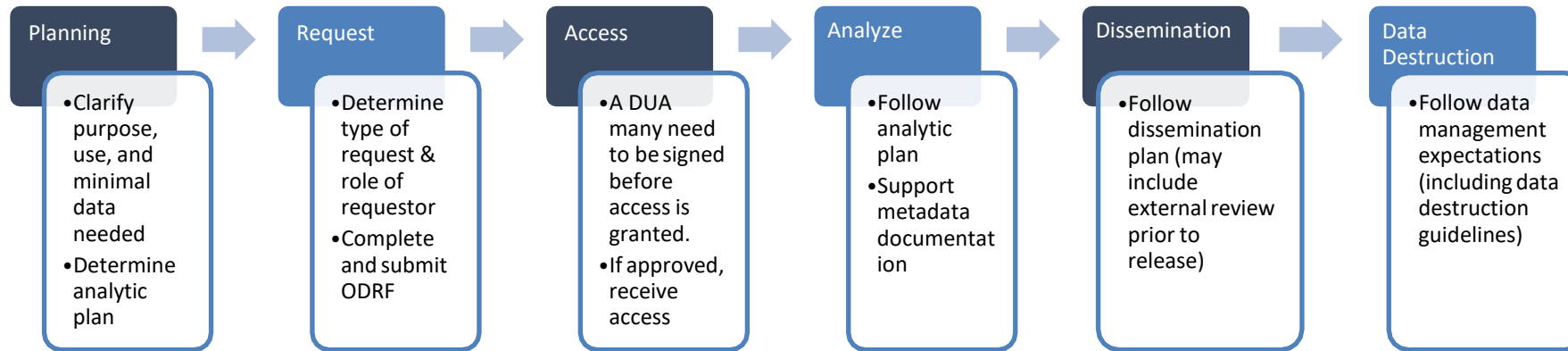
NCDHHS' Foundational Legal Agreements



Illustration of the intradepartmental legal agreements used to govern data access and use across NCDHHS Divisions and Offices and Programs.

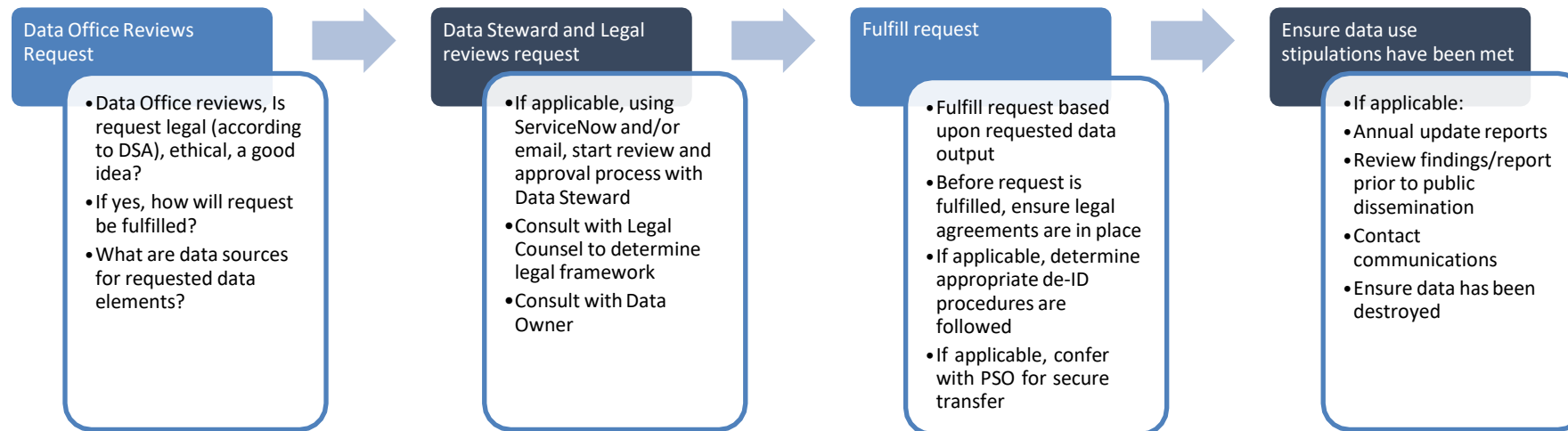


Data Request Process for Data Requestors

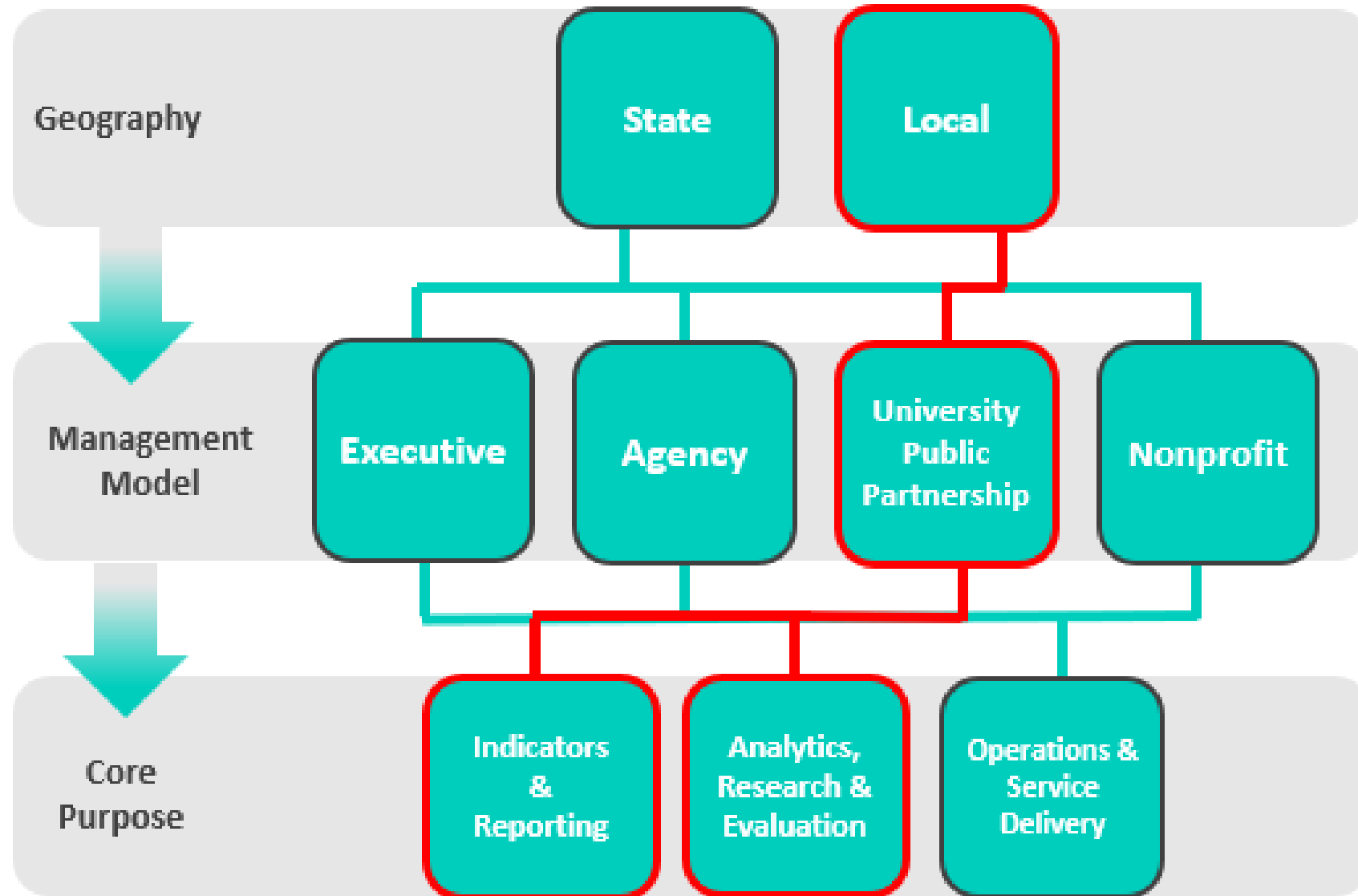


Data Request Process For Request Recipients

(including Data Steward, Data Owner or Designee, & Data Custodian)



Charlotte Regional Data Trust





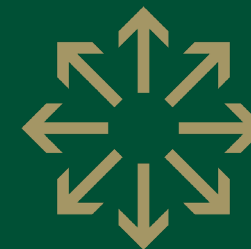
Charlotte Regional
Data Trust



Community
Research Services



Regional Policy &
Issue Analysis



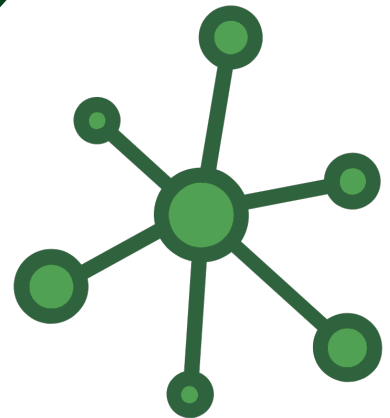
Research Outreach &
Engagement

The Charlotte Regional Data Trust

We seek solutions to the complex social, economic, and environmental challenges facing our communities. We engage expertise across a diverse set of disciplines and life experiences to curate data, conduct actionable research, and provide relevant policy analysis to inform better decisions that benefit all of us. **We support knowing for doing.**

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Governance Documents

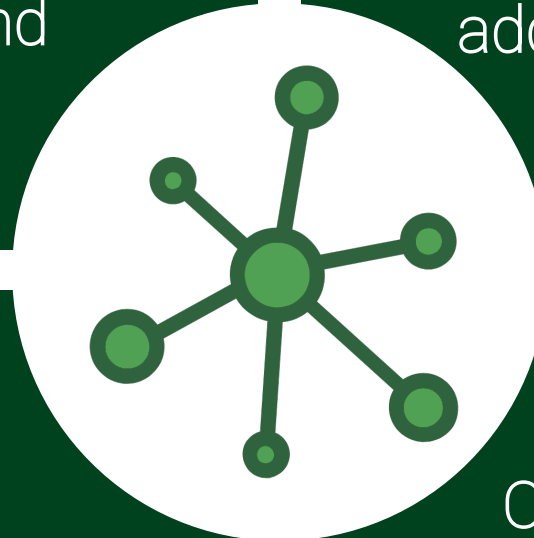


Enterprise Memorandum of Understanding (EMOU)

Documents the shared ISC mission, purpose, and governance process and establishes buy-in to a shared community asset.

Data Sharing Agreement

Describes the terms of data sharing with each data partner and may include additional negotiated language specific to the partnership and organization.



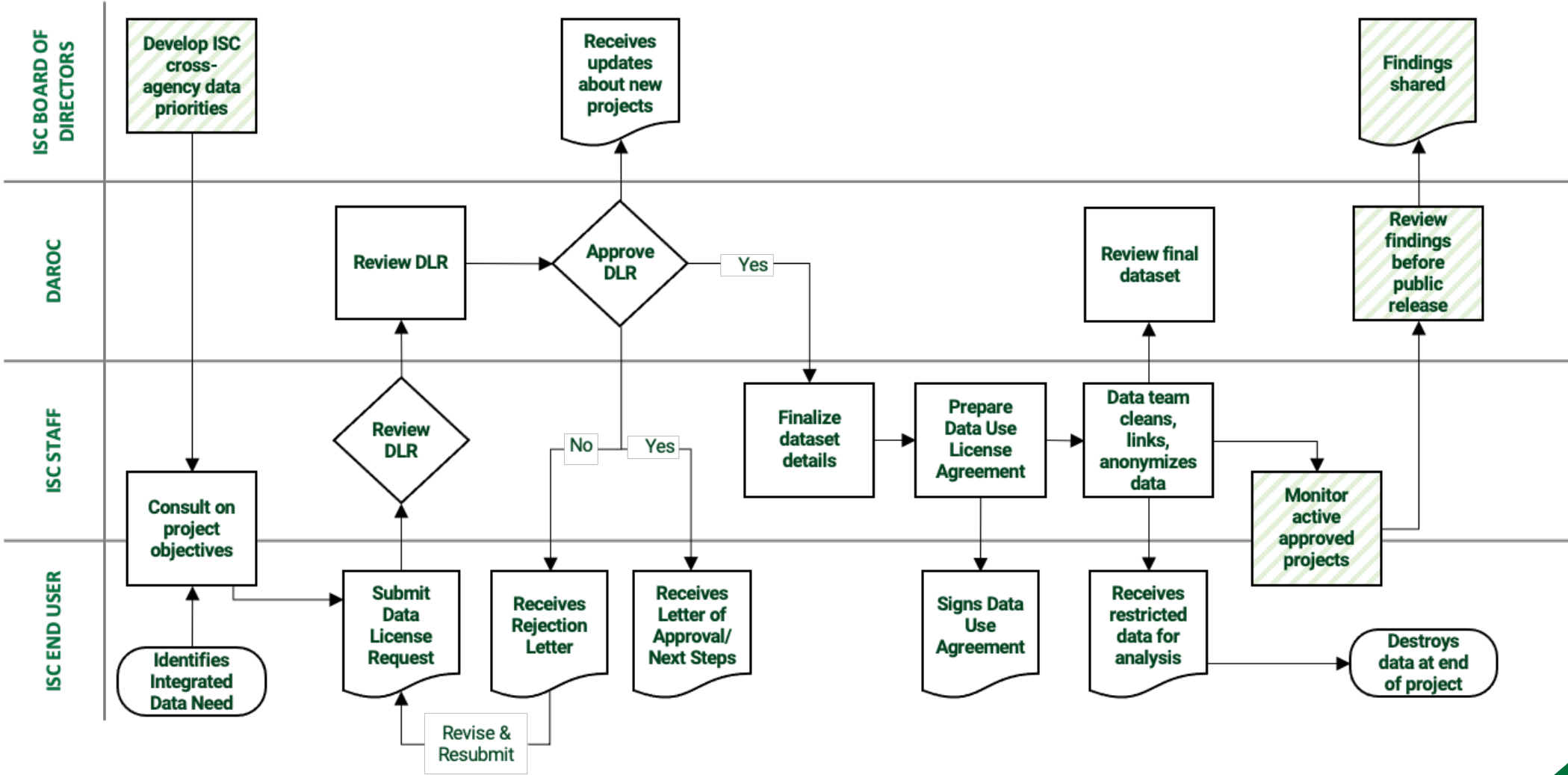
Security Policy

Describes ISC security and privacy agreements and procedures, including the incorporation of the latest data security advancements (use of cloud technology, for example).

Data Use License

Outlines the legal terms of data use by approved end users.

Charlotte Regional Data Trust **Data Use Process**



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 L. Thomas 9/10/19 (with thanks to LINC & Whitney Leboeuf)

Questions?

Closing Reflections

TELL US IN THE CHAT:
What is one thing you are
taking away from this training
today?



Thank you.

Deja Kemp, JD

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Laia Tiderman

DISC Associate Director
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A Project of
WestEd 



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