

# Plenary 3

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Evolving legal frameworks for data integration

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Director of Legal Policy



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# Agenda

- *Finding A Way Forward*
- Community Oriented Data Governance
- Crafting Consent to Build Trust
- Co-creating Enterprise Data Governance and Legal Framework
- Panel, Q&A Discussion

## Legal Issues for IDS Use: Finding a Way Forward

Actionable Intelligence for Social Policy,  
Expert Panel Report

Prepared by

John Petrillo, Barbara Cohn, Wendell Pritchett,  
Paul Stiles, Victoria Stodden, Jeffrey Vagle,  
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MARCH 2017



2017

## Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration

Actionable Intelligence for Social Policy,  
Expert Panel Report

Authors

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2022



# Quality Framework for IDS

Governance	Data governance is the people, policies, and procedures that support how data are used and protected.
Legal	Whether data can be shared legally depends on why you want to share, what type of information will be shared, who you want to share with, and how you will share the data. Legal agreements should reflect the purpose for sharing, document the legal authority to serve that purpose, and ensure that data sharing complies with all federal and state statutes.
Technical	Technical components are created to support analytics and insights that can help further improvements in policies, practice, and outcomes.
Capacity	Data sharing capacity refers to the staff, relationships, and resources that enable an effort to operate governance, establish legal authority, build technical infrastructure, and above all else, demonstrate impact.
Impact	All components of quality—governance, legal agreements, technical tools, and staff capacity—exist to drive impact.

See more at [aisp.upenn.edu](https://aisp.upenn.edu)

## Why: The Four Questions



Is it legal?



Is it ethical?



Is it a good idea?



How do we know?  
Who decides?

# 1. Is this legal?

## Authority and Access



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



# Practice:

## Defining Access and Use to Determine Legality

### Practice: Defining Access and Use to Determine Legality

Ready to get started? Use the following prompts and examples as a guide to clearly define your data access and use, which then allows you to determine legality.

<b>WHY do you want to share and integrate data?</b> For example, to: <ul style="list-style-type: none"><li>• Track indicators at the population level</li><li>• Identify a target population</li><li>• Describe cross-enrollment patterns</li><li>• Identify geographic areas of greatest impact</li><li>• Evaluate program outcomes</li><li>• Improve services at the point of intervention</li><li>• Conduct mandated reporting</li></ul>	<b>WHO do you want to share it with, and who conducts the integration?</b> For example: <ul style="list-style-type: none"><li>• Executive leadership</li><li>• Agency serving the same client</li><li>• Probation officers</li><li>• A community treatment provider</li><li>• A hospital emergency department</li><li>• A university-based researcher</li><li>• An agency-based analyst</li></ul>
<b>WHAT type of data do you want to share and integrate? Is it open, restricted, or unavailable?</b> For example: <ul style="list-style-type: none"><li>• Information that does not identify individuals</li><li>• Information that does identify individuals</li><li>• Information that might identify a person</li><li>• Health information</li><li>• Educational records</li><li>• Housing status</li><li>• Demographics</li></ul>	<b>HOW will you share the data?</b> For example, provide: <ul style="list-style-type: none"><li>• Aggregate counts at the block group level</li><li>• Credentialed access to source data</li><li>• Access to public-facing dashboard</li><li>• View-only access to data underlying a dashboard</li><li>• Edit access to data underlying a dashboard</li><li>• Row-level data with identifiers</li><li>• Row-level data without identifiers</li></ul>

Why do you want to share and integrate data?

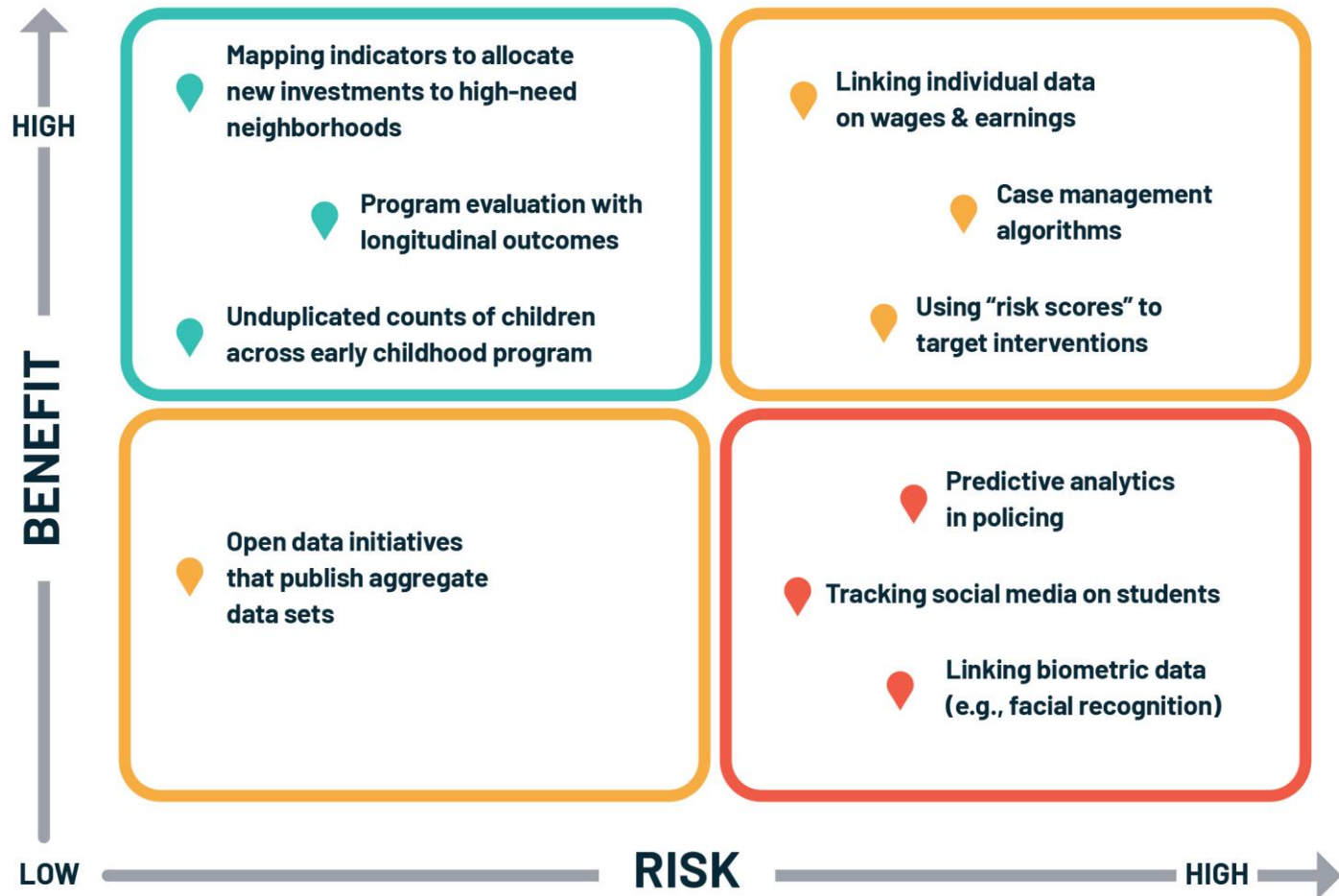
Who do you want to share it with, and who conducts the integration?

What type of data do you want to share and integrate? (Is it open, restricted, or unavailable?)

How will you share the data?

## 2. Is this ethical?

### Social License. Risk v. Benefit



### 3. Is this a good idea?

#### Data availability, Resources, Action

- Are available data of sufficient quality to answer the question at hand?
- What action can be taken as a result of this analysis?
- How will programs/policies/lives be improved by this use of integrated data?
- What can reasonably be changed or improved based upon the findings? What cannot be changed?
- Has this question already been answered?
- Will the resources needed to conduct this integration yield more benefit than using these same resources for programmatic or direct funding?
- Who is conducting this integration and analysis? Do they have sufficient understanding of the program/policy/population that is being studied?
- Who is “asking” the question? Is this topic of interest to the broader community? Do community members, including those “in” the data, know about and support this work?

## 4. How do we know? Who decides?

### Data governance

Data governance: The people, policies, and procedures that support how data are managed, used, and protected.

Strong and inclusive data governance for cross-sector data sharing and integration should be:

- Purpose-, value-, and principle-driven
- Strategically located
- Collaborative
- Iterative
- Transparent

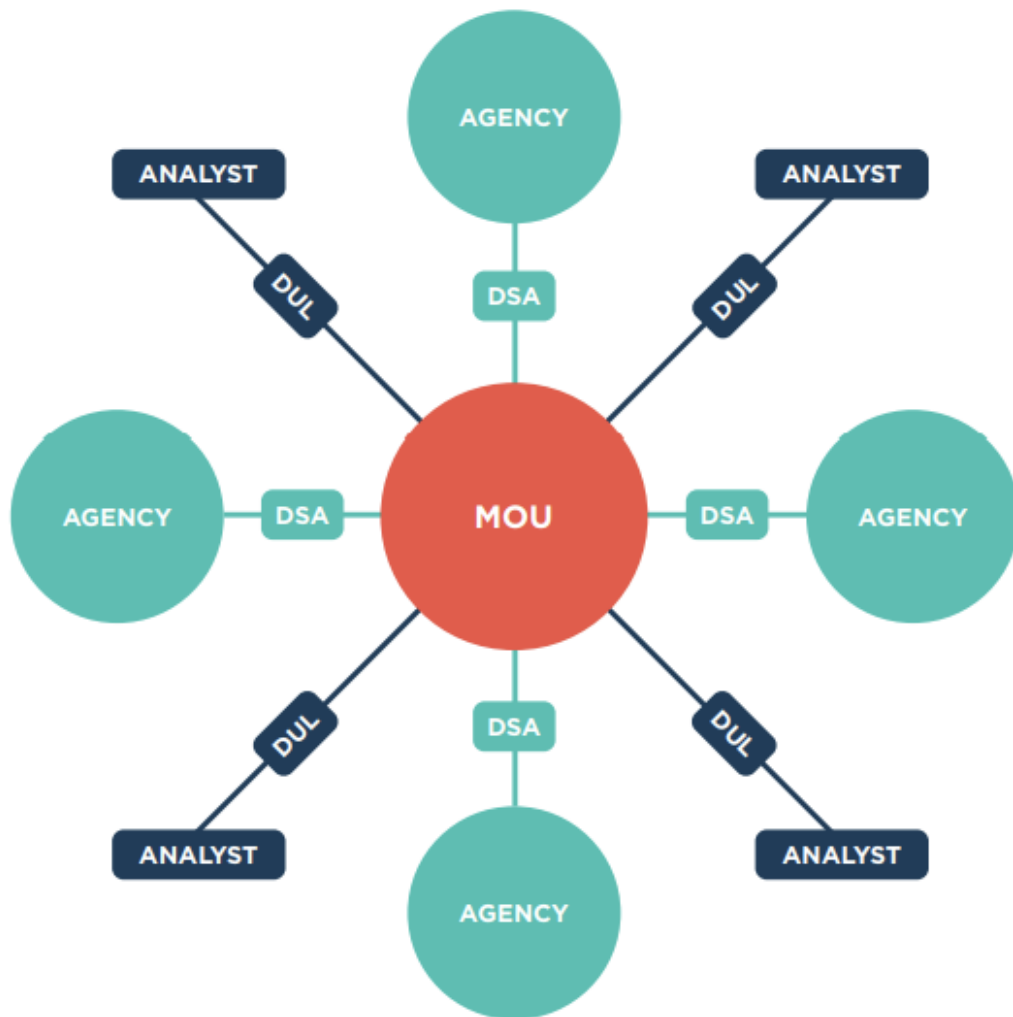
## *The Role of Data Owners, Data Stewards, and Data Custodians*

	Role in data sharing and integration process	Role within agency
<b>Data Owner</b>	Accountable for the quality and security of the data and holds decision-making authority over access and use.	Typically agency leadership that has signatory authority
<b>Data Steward</b>	Responsible for the governance of data, including transfer, alteration, storage, retention, disposition, classification, etc. Includes supporting established processes and policies for access and use, documenting limitations and bias, and maintaining metadata.	Typically subject matter experts and data analysts that regularly work with specific data
<b>Data Custodian</b>	Responsible for the technology used to store, transport, and dispose of data, and for activities and safeguards required to maintain confidentiality, integrity, and availability. Communicates with Steward and Owner regarding any data management issues that pose a risk to data security and/or access.	Typically information technology staff or team

# How: The Legal Agreements

## FOUNDATIONAL LEGAL AGREEMENTS

LEGAL AGREEMENT	PURPOSE	PROCESS	SIGNATORY
<b>Memorandum of Understanding MOU</b>  <i>Overarching process document signed on by all data partners</i>	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.	Drafted in partnership with legal counsel from all participating data partners	Lead agency/ies + alldata partners
<b>Data Sharing Agreement DSA</b>  <i>Agency-specific to how data will be used for integration</i>	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.	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.	Lead agency/ies + data partner
<b>Data Use License DUL</b>  <i>Data use-specific once data has been integrated</i>	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.	Template is drafted in partnership with legal counsel from all participating data partners.  Once data request is approved, a DUL is executed.	Lead agency/ies + data recipient



We suggest agreements that are:

Tiered

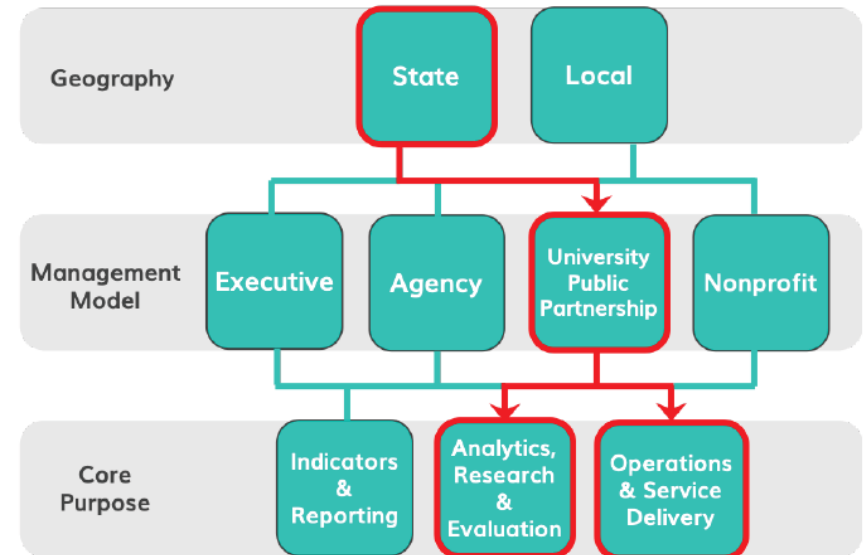
Standardized but flexible

Transparent and Comprehensible

## How: Site examples

The Linked Information Network of Colorado (LINC) is a collaborative partnership between the Colorado Governor's Office and the Colorado Evaluation Action Lab at The University of Denver. Their capacity for data integration helps strategically target services and benefits to vulnerable populations and identify opportunities to improve services, delivery, and opportunity.

### Linked Information Network of Colorado (LINC) University Public Partnership, State



► [Learn more about LINC here.](#)

**Lead Agencies:** Governor's Office and University of Denver

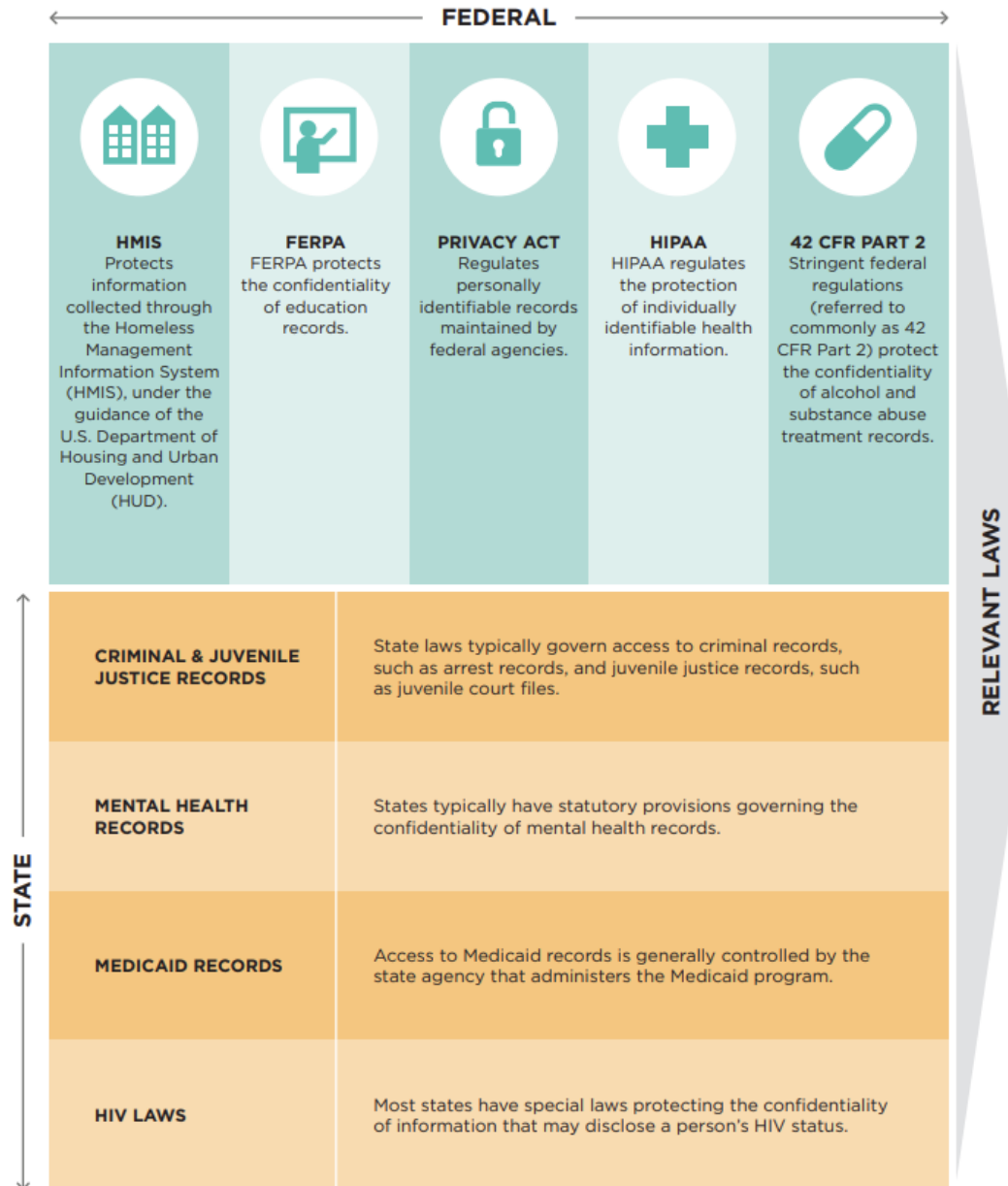
**Data Partners:** Birth and Death Records (CDPHE), Child Welfare (CDHS), Early Intervention (CDHS), Childcare subsidies (CDHS), EC Workforce Data (CDHS), Postsecondary Education (CDHE), Juvenile Justice Services (CDHS), Juvenile Courts (Judicial), Adult Court (Judicial), Denver Police Department (DPD), W-2 Employment and Wages (CLDE), Workforce Training Programs (CDLE), SNAP (CDHS), WIC (CDPHE), Denver Metro Homeless Initiative (HMIS), Denver Public Schools (DPS), see [LINC Data Partners](#)

**Legal Authority:** Contracts (e.g., [EMOU](#), [DSA](#), [DUL](#))

**Funding:** State, federal, philanthropic partners, fee for service



# State & Federal Laws



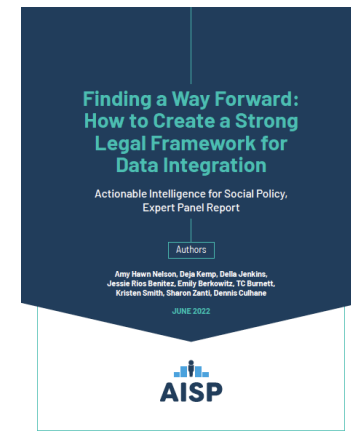
# Tribal data sovereignty

- Tribal Data Sovereignty = inherent right of a nation to govern the **ownership**, **collection**, and **use** of its own data
- Tribes have the authority to administer the collection, use and ownership of their own data
- Tribes can enter into data sharing agreements with States
- Tribes are subject to plenary power of the United States

# Overview of appendices

- Appendix A- Federal Law and Policy
- Appendix B—Selected State & Tribal Laws, Policies and Rules
- Appendix C—Sample Executive Orders and Authorizing Legislation Facilitating Data Integration
- Appendices D-J—Sample Legal Agreements & Checklists

FIND IT ALL HOT OFF THE PRESS HERE:  
<https://bit.ly/3bhQuqt>



# Questions?

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Check out our publications & quality framework: [www.aisp.upenn.edu](http://www.aisp.upenn.edu)

Subscribe to our newsletter: <https://bit.ly/signupAISPnewsletter>

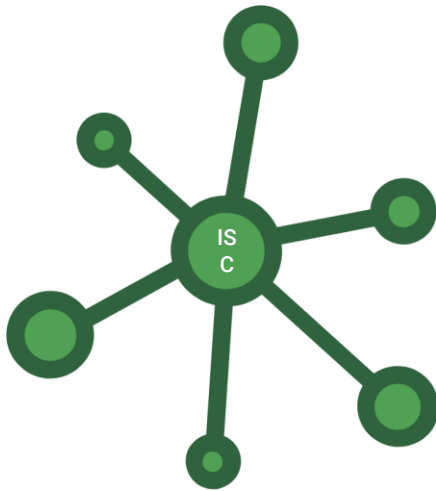


# Sydney Idzikowski

Associate Director, Institute for Social Capital

Community Oriented Data Governance





# Institute for Social Capital

Legal Framework

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Institute for  
Social Capital



Community  
Indicators



Survey &  
Research  
Services



Regional  
Policy

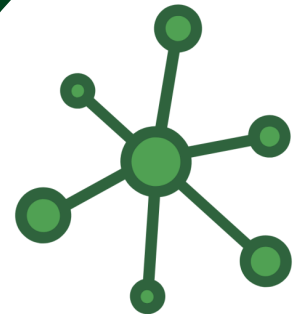


Outreach

## ISC is a part of the **UNC Charlotte Urban Institute**

An applied research and community outreach center **seeking solutions** to the social, economic and environmental challenges facing our communities since 1969. As a part of the UNC Charlotte Urban Institute, ISC has additional research and support capacity.

# 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**

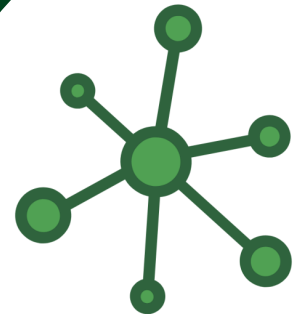
Describes ISC security and privacy agreements and procedures, including the incorporation of the latest data security advancements (use of cloud technology, for example).

## **Data Use License**

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



**The legal  
documents exist,  
now what?**



## The **Messaging**



Shared resource  
for shared  
problem-solving



Established  
and secure



Sustained and  
structured  
oversight



Value-add for  
partners

## **We take a relational approach to data sharing**

and our governance documents reflect that.

## Data Partner Onboarding

**Relationship  
building and  
information  
sharing**

**Review,  
negotiation, &  
execution of  
governance  
documents**

**Coordinate data  
deposit with  
“data person”**

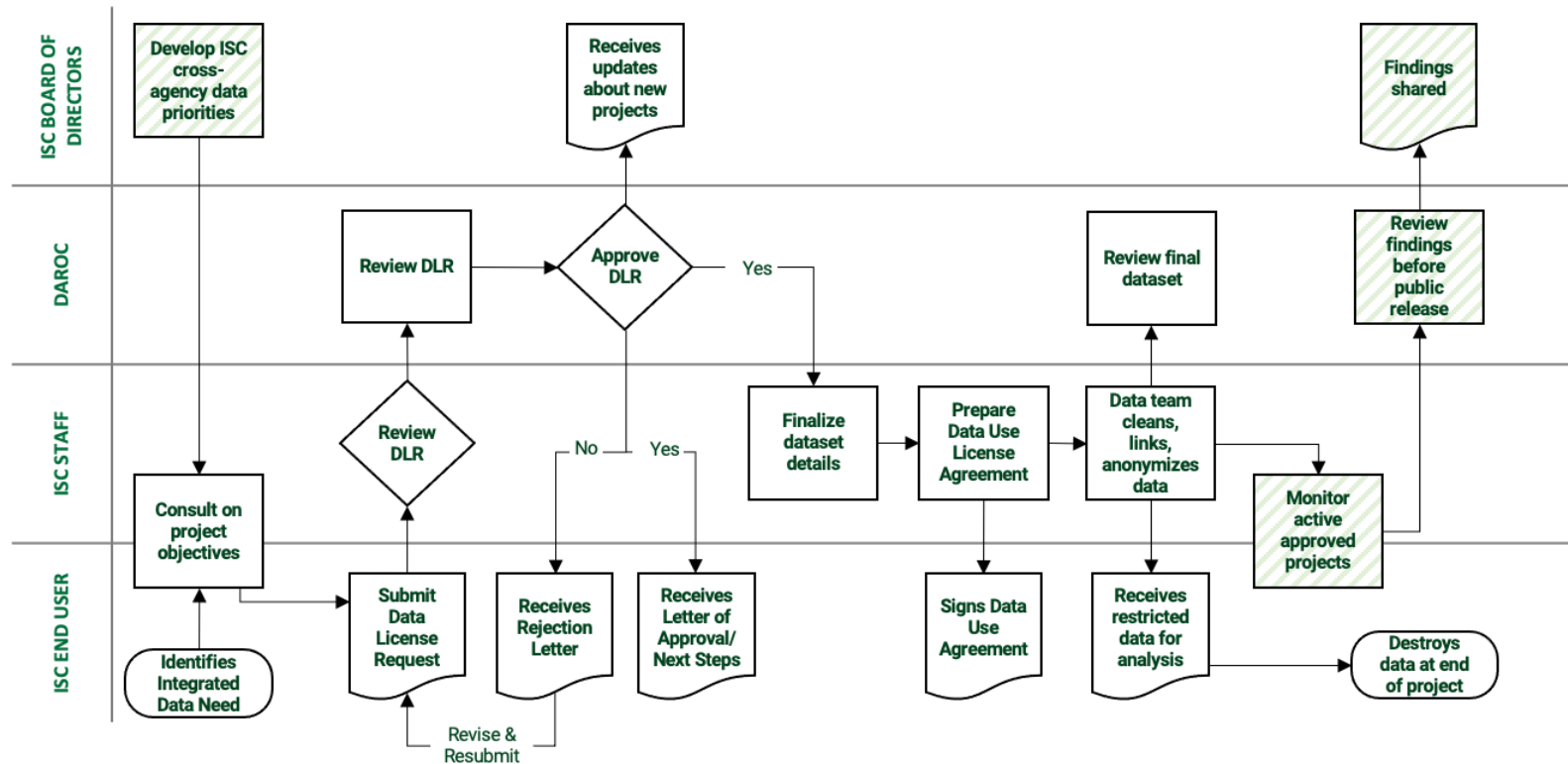
**Data onboarding  
process**

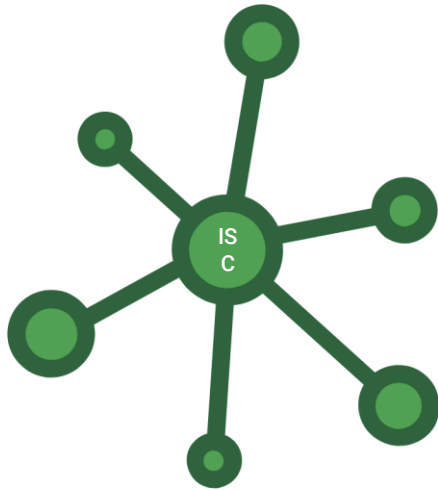
**DAROC  
onboarding**

## Data sharing involves multiple people.

We engage with executives, people close to the data, and others for successful data sharing, oversight, and use.

# ISC Data Use Process





# Thank you!

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Richard Gold  
Attorney & Consultant

Crafting Consent to Build Trust  
*(no slides)*



Penn  
Social Policy & Practice  
UNIVERSITY of PENNSYLVANIA

# Paul Hogle

Associate General Counsel, NCDHHS

Co-creating Enterprise Data Governance and  
Legal Framework





**There are 16 Divisions and Offices.  
This is what we are doing to make  
data sharing less painful.**

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Paul Hogle, Associate General Counsel and Chief  
Records Office, NCDHHS

Amy Hawn Nelson, NCDHHS Data Office and  
Actionable Intelligence for Social Policy (AISP)



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**HEALTH AND  
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# 2019

- ⑩ Staffing of Data Office
- ⑩ Data Strategy Development

# 2020

- ⑩ Data Landscape
- ⑩ ID key steps to improve data access and use

# 2021

- ⑩ Data Sharing Guidebook
- ⑩ Data Request Forms
- ⑩ Legal Framework

## ROADMAP

Matrixed approach solving for integrated, quality data



Governance Model Summary | July 8, 2019

*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:

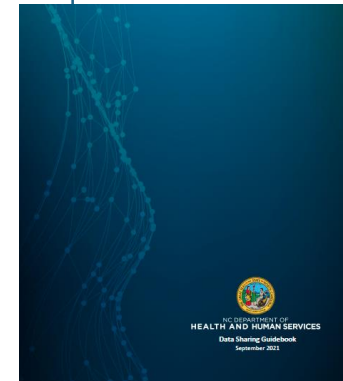
This Data Landscape Overview has been developed through engagement with NC Department of Health and Human Services staff and contractors via in-person meetings, document review, a survey of data sharing agreements (led by division director and legal counsel), weekly calls with DHHS Data Team, and structured 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



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# NCDHHS Data Sharing Guidebook

We have developed a Data Sharing Guidebook, that includes:

- Department priorities for data access & use
- Overview of department roles that support data sharing and use to better understand purposes and best practices
- NCDHHS high value data asset inventory
- NCDHHS data request process for 9 common pathways, with operational requests being the most common
- General data classification guidance (open, restricted, unavailable)
- A legal framework for internal and external sharing and integration, including an overview of relevant federal and state statute and rules

**Access NCDHHS Data Sharing Guidebook Here:**

<https://www.ncdhhs.gov/about/administrative-offices/data-office/data-sharing-guidebook>



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We now have  
metadata, processes,  
forms, roles, and  
improved data flow

## NCDHHS Data Sharing Guidebook

Why a Guidebook for Data Sharing?

Data Access and Use Across NCDHHS

How to use this guidebook

Data Use Priorities

Requesting Data Access and Use

Requesting Data from a NCDHHS Division or Office

Purpose of Request Determines the Data Request Pathway

Data Being Requested

Requested Data Output

Data Request Processes

Know your role

Data Owner (or Designee)

Data Steward

Data Custodian

How Your Role Supports Data Access and Use

NCDHHS Data Asset Inventory

Legal Considerations

Legal Framework

Federal Laws Regarding Data Sharing

Relevant State Rules & Regulations

Considerations for Permitting Data Access and Use

Prioritization of Data Requests

Data De-identification

Data Transfer

Data Access and Use FAQs

Terms



### North Carolina Department of Health and Human Services NCDHHS Operational Data Request Form

This request is related to ongoing work of NCDHHS that supports business intelligence with a NCDHHS division or office, department and/or strategic partner (under current agreement with NCDHHS), including local offices.

Submit this form and any questions by email to [dataoffice@dhhs.nc.gov](mailto:dataoffice@dhhs.nc.gov)

Internal Use, Request #:

1. Does this data request align with NCDHHS priorities and support business intelligence of NCDHHS?

☐ Yes ☐ No ☐ Unsure

2. What is the main purpose of this operational data request?

☐ Reporting ☐ Quality Improvement ☐ Evaluation  
☐ Legal Implications ☐ Health Care Operations, Payment, and Treatment  
☐ Other: (please specify)

Please describe the purpose of this request and how data will be used to support operations of NCDHHS:

3. Why does this request involve the NCDHHS Data Office?

☐ I am requesting data from 1 Division/Office, and there is not a Division/Office specific process  
☐ I am requesting integrated data from across NCDHHS Divisions/Offices.  
☐ I am requesting identifiable records for the purpose of integrating data from NCDHHS with another data source.  
☐ I'm not sure. I would need to discuss my data request with someone.  
☐ Other: (please specify)

4. Requestor's Contact Information

Name of Requestor:

Title / Role:

NCDHHS Division / Office, or Institution / Agency

If request is a part of contract with NCDHHS, and you are not NCDHHS staff, please check here. ☐

If yes, what is the term of your contract? (MM/DD/YY to MM/DD/YY)

Phone number:

Email:

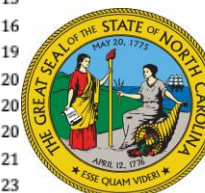
I have read and agree to the NCDHHS Terms and Conditions of Data Use

Yes ☐

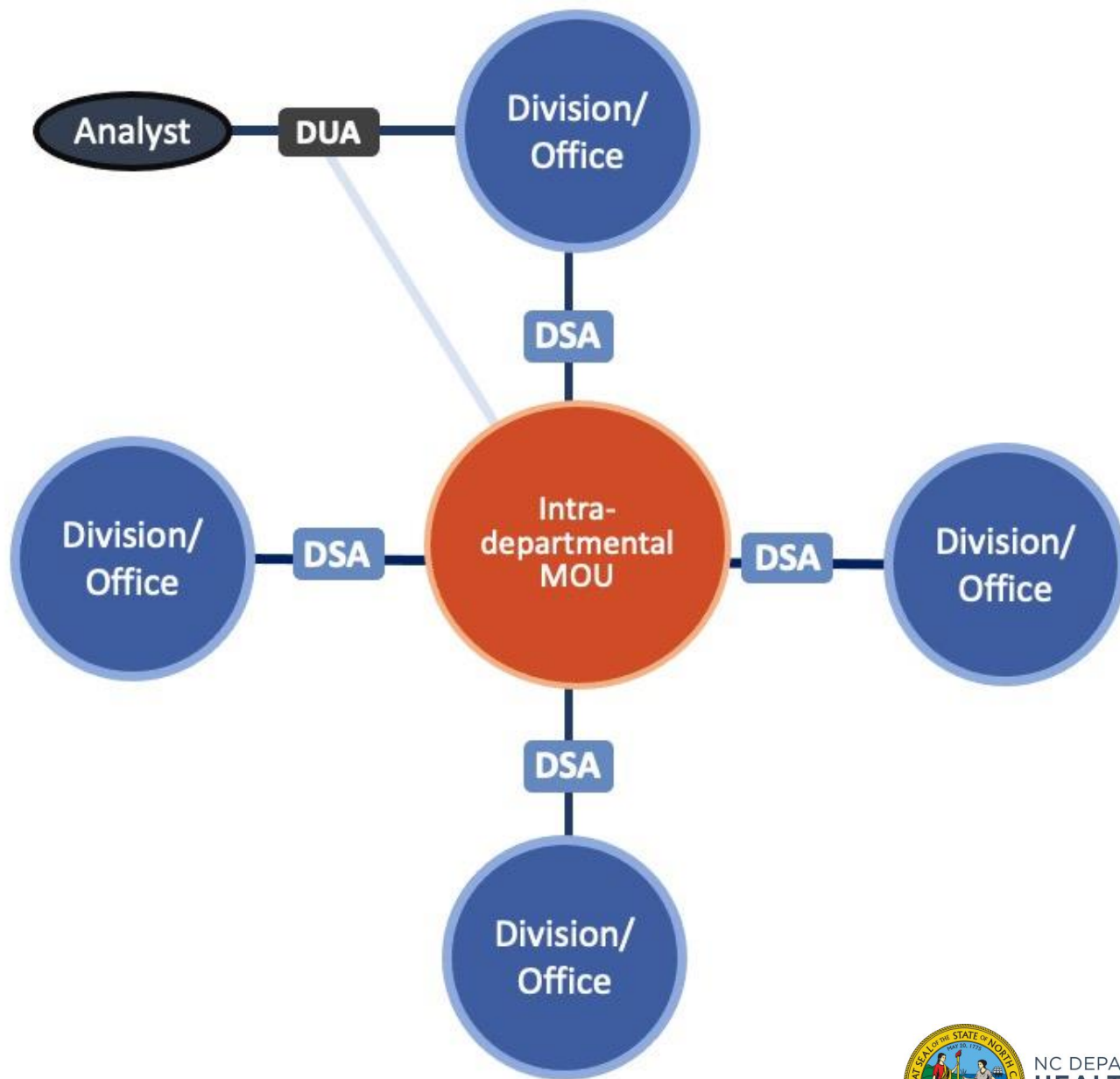
5. Description of the Requested Data

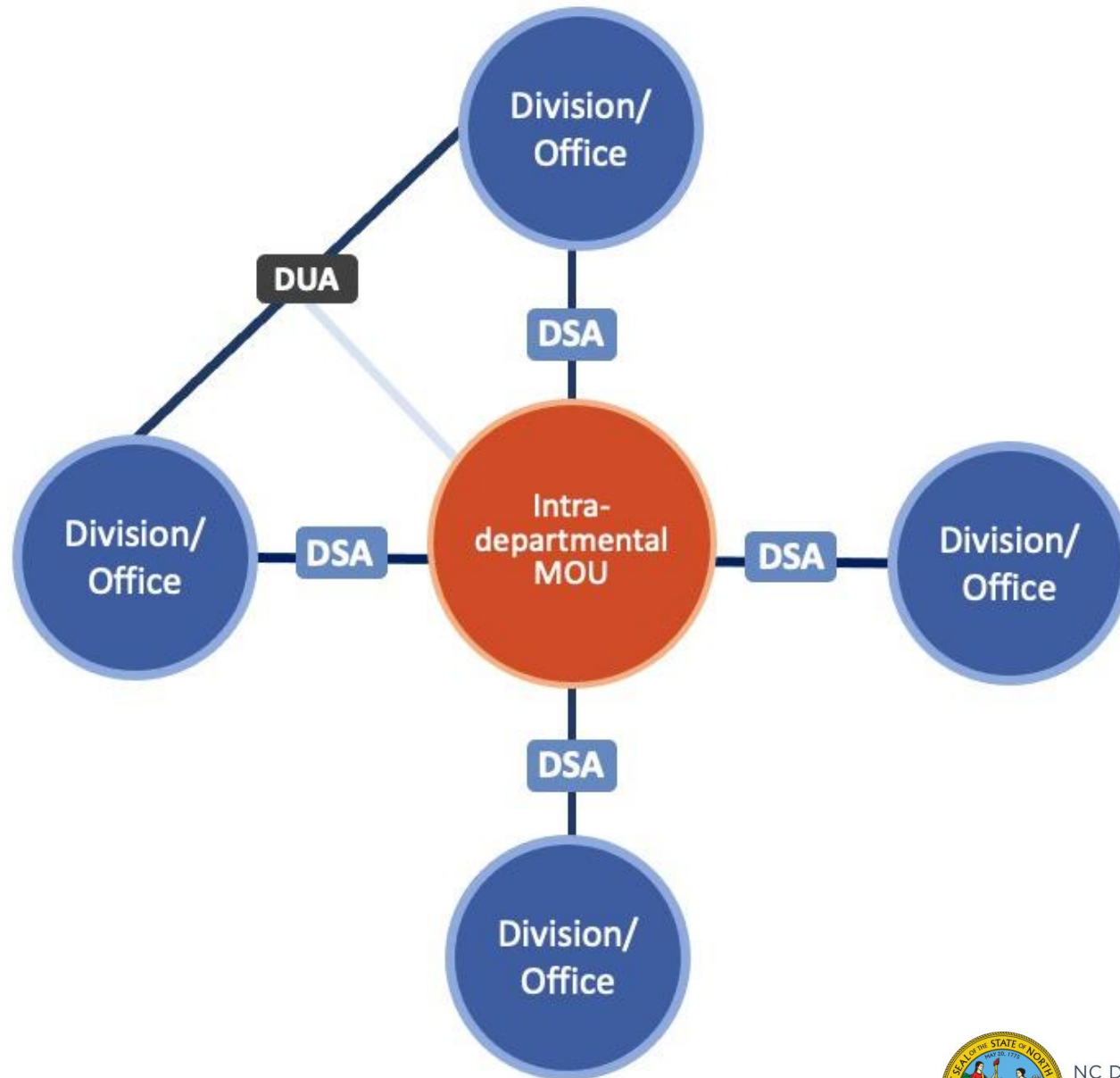
How often does the Recipient want to receive data?

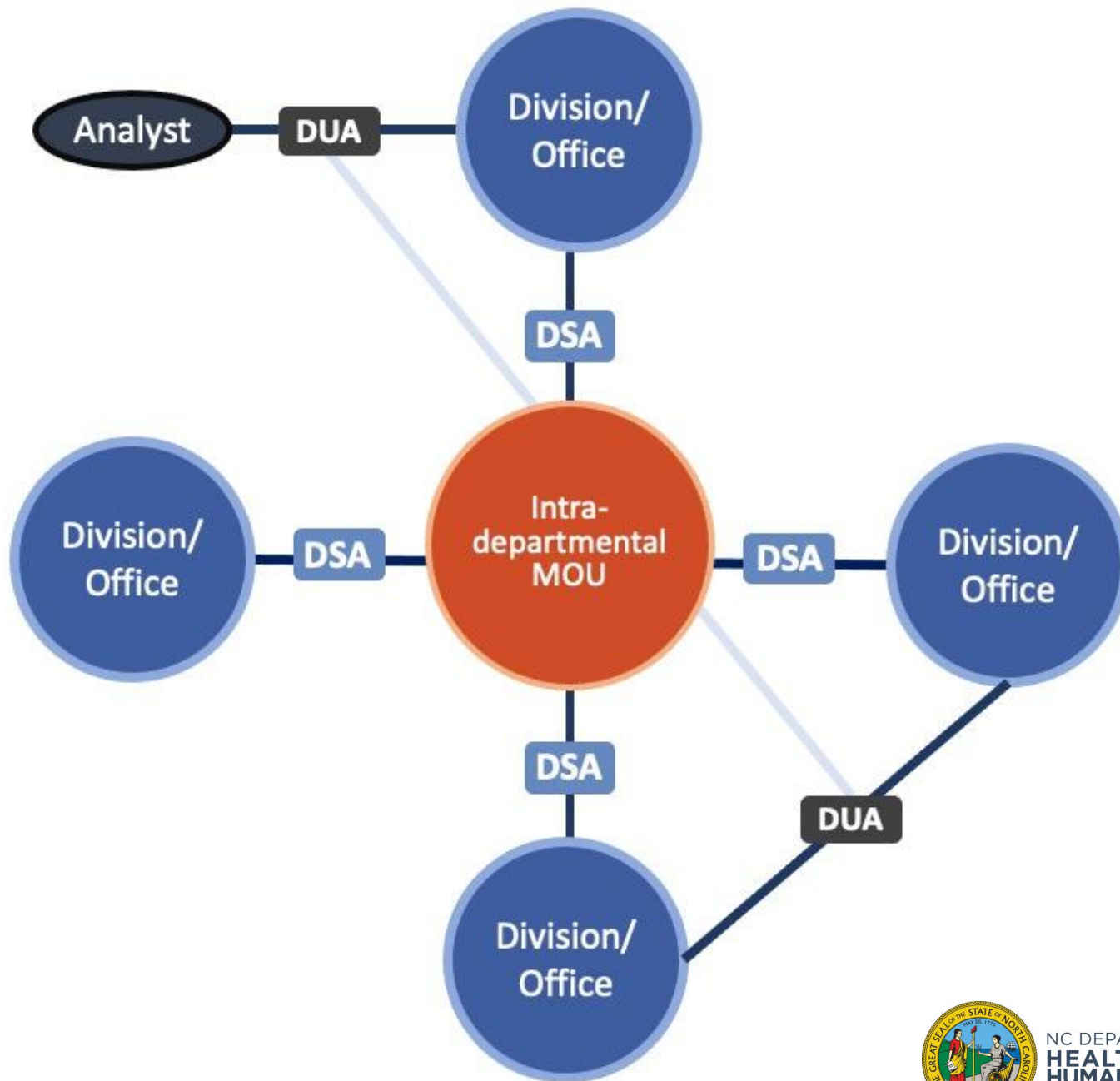
☐ This will be a one-time provision of data  
☐ Daily ☐ Weekly ☐ Monthly ☐ Quarterly ☐ Annual  
☐ Other



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# FOUNDATIONAL LEGAL AGREEMENTS

LEGAL DOCUMENT	PURPOSE	PROCESS	SIGNATORY
<b>Intradepartmental MOU</b>  <i>Overarching process document signed on by all Divisions / Offices</i>	<p>The IMOU documents the purpose and governance process. The IMOU will be signed by all data partners as they enter the collaboration. The IMOU references the data sharing agreement, data use agreements, policies, and procedures for data access and use, e.g. NCDHHS Data Sharing Guidebook.</p>	<p>Drafted by Data Office + reviewed by legal counsel, signed, and updated through the NCDHHS Data Governance Council as needed.</p>	<p>All Division and Office Directors and Secretary's Office</p>
<b>Data Sharing Agreement</b>  <i>Division / Office Specific</i>	<p>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 the IMOU and the DUA. This document is specific to division and office held data.</p>	<p>Drafted by Data Office + Division/Office specific legal counsel. Reviewed and updated annually, or as agreed upon.</p>	<p>Each Division and Office Director + Data Office + ITD</p>
<b>Data Use Agreement</b>  <i>Data Request Specific</i>	<p>Legal counsel determines if DUA is needed for 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 entitled by type and reviewed appropriately based upon the type of request. Legal counsel determines if DUA is applicable. If request is approved, a Data Use Agreement is executed.</p>	<p>Data recipient + Data owners (if applicable)</p>

# Key Points:

- Ethical data use—including data use that centers racial equity—is only possible with strong data governance.
- Framework is flexible (because legality of data access and use depends on a lot of things)
- Legal Counsel are guiding the use of the framework, **at all times**. This doesn't take it "out of legal," it just puts a clear process around when legal weighs in, and takes some work off their plate
- Data Owners have full control over the use of their data
- NCDHHS Data Office serves as a Shepherd or Midwife (whatever metaphor works for you). Not as a decision maker. We are process and support

# Questions?

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North Carolina Department of Health & Human Services

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(member of NCDHHS Data Office since 2019)

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Deja Kemp

Director of Legal Policy

*Moderator*



# Panelist Q&A

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# Closing Reflections

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# Thank You

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