NCDHHS

Data Sharing Guidebook

Pathways, legal framework, and considerations for requesting, granting, and governing data access and use across the Department.

North Carolina Department of Health and Human Services

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NC DEPARTMENT OF HEALTH AND HUMAN SERVICES

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This Guidebook has been created by NCDHHS employees in collaboration with Actionable Intelligence for Social Policy (AISP) to establish clear(er) processes for data sharing and integration, both across NCDHHS (intradepartmental) and with external partners, including other State departments (interdepartmental). This is a guidebook for requestors (those who request data) and for data owners (those who have permission to share data). This document is not a policy manual, but if we adhere to the pathways described here, we will be better able to use data as a strategic asset across our department as a whole, while complying with relevant local, state, and federal law and regulations.

Data improves as it is used, and North Carolina residents benefit from improved data quality and data flow for strategic use. This guidebook will get us started, and it will continually improve with your help as it is updated annually. Most importantly, this document is not meant to be read cover to cover, but used as needed based upon your role. **Guidebook Quick Start Guide. Data Sharing Guidebook Terms.**

Data Access and Use Across NCDHHS

In collaboration with our partners, the North Carolina Department of Health and Human Services provides essential services to improve the health, safety, and well-being of all North Carolinians. Much of this work involves managing the delivery of services to North Carolina's most vulnerable populations, including children, seniors, people with disabilities, and low-income individuals and families. NCDHHS touches the lives of millions, and our goals reflect the wide range of programs we administer and populations we serve.[1]

Any request for data access and use should be aligned with our goals that drive our mission to provide essential services to improve the health, safety, and well-being of all North Carolinians.

NCDHHS Goals as of 2024 are to:

1. Advance health by increasing opportunity and improving outcomes for people who face greater health and situational challenges within NCDHHS and across the state.
2. Promote child and family well-being by making it easier for children and families to access the health care, programs, and supports they need to thrive.
3. Support behavioral health and resilience by prioritizing investments in coordinated systems of care that make services easy to access when and where they are needed and reduce the stigma around accessing these services.
4. Build a strong and inclusive workforce that supports early learning, health, and wellness across North Carolina. This includes investigating opportunities to further build workforce pipelines, forge career pathways, and promote inclusive employment strategies that will support a workforce that is ready for our next challenge and is reflective of our communities.
5. Achieve operational excellence by enabling efficient, effective, and innovative processes and services.

[1]See NCDHHS Strategic Plan, 2024-2026

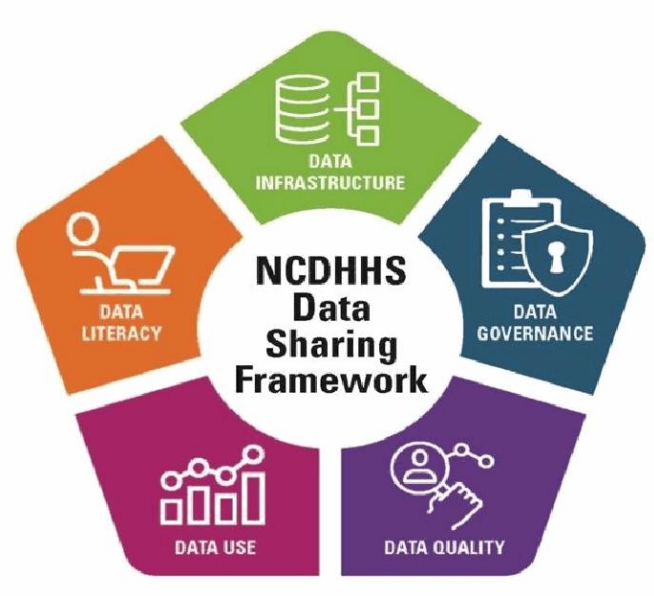
Divisions and Offices within NCDHHS may have their own strategic goals and priorities as well.

Why a Guidebook for Data Sharing?

The North Carolina Department of Health and Human Services regularly shares data across Divisions and Offices, as well as with other local, state, and federal level government agencies and research partners. Both sharing and integrating data are common practices to support operational goals. The purpose of this Guidebook is to:

- • Establish clear pathways for data sharing and integration, for requestors and data owners
- • Establish a common legal framework for data sharing and integration across NCDHHS
- • Support data use that leads to improved data quality, insights, and improvements
- • Clarify processes to reduce burden on staff requesting and granting access to data, increase efficiencies, and ensure privacy and security safeguards

Data sharing and integration are essential to data use. An effective NCDHHS data strategy must support data integration so that business users and leadership can answer questions and meet needs that rely on information from multiple data sources.[2] Data sharing is the practice of providing access to information that is not owned or otherwise accessible to the requestor. Data integration involves record linkage, which refers to the joining or merging of data based on common data fields. These data fields may include personal identifiers (e.g. name, birth date) or a "unique ID" that is used to link or join records. While data integration may involve more perceived and actual risk, and therefore requires more oversight, it is essential for understanding multi-service involvement.



[2] **See** [NCDHHS Data Strategy, 2019]

Unless requested as part of a public records request pathway, audit pathway, or legal request pathway, each instance of data sharing and integration needs to be driven by the need for staff or partners of NCDHHS to answer a question using data as a strategic asset. Access and use are dependent upon need. For example, an evaluator conducting a Community Health Assessment may use population-level aggregate statistics that are open or publicly available, while a University-based researcher may use row-level data that is restricted or confidential, requiring the use of a Data Sharing Agreement. The following table describes some common examples of each type of request.

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

Requestor for Data Access and Use	Data sharing and integration needed to…	Questions to Guide Data Request Pathways
Epidemiologist with local Health Department	…Evaluate the health outcomes related to a local policy that has been implemented	Operational
Epidemiologist within NCDHHS DPH	…Better understand effects of county-based restrictions on rates of infection	Operational
Community Collaborative	…Better understand population-level outcomes for NC residents	If a strategic partner,* this would be operational. If not, this could be a public record request.
Community advocate	…Better understand the lived experiences of NC residents	If a strategic partner,* this would be operational. If not, this could be a public record request.
Department of Justice and DHHS Attorney	…address a legal matter	Legal purposes
Consulting vendor	…Complete the terms of their service agreement to conduct work on behalf of NCDHHS	Operational
Legislative Staffer	…Better understand current problem for draft legislation	Legislative request
Program evaluator	…Evaluate the effectiveness of a program	If a strategic partner,* this would be operational. If not, this could be a public record request.

Requestor for Data Access and Use	Data sharing and integration needed to…	Questions to Guide Data Request Pathways
Director of a large regional non-profit	…Better understand the backgrounds, experiences, and future outcomes of service recipients	If a strategic partner,* this would be operational. If not, this could be a public record request.
Business unit leadership	…Better understand cross-enrollment between programs	Operational
Internal audit for Office of Internal Auditor	…Conduct an audit	Audit purposes
State audit for Office of State Auditor	…Conduct an audit	Audit purposes
University-based researcher	…Better understand whether certain characteristics or experiences are predictive of later outcomes	Research
Deputy Director of another state department	…Better understand policy levers to improve outcomes with a population by incorporating outcome data from NCDHHS for predictive models	Operational
Media outlet	…inform the public of an emerging public health issue	Public records request
Staffer at the Governor's **Office**	…Draft a strategy to target new investments in X for the residents who are most in need of support	As a strategic partner,* this would be operational.

Pathways for Requesting Data Access and Use

There are multiple pathways to request data, depending on the purpose. See **Appendix A for Questions to guide data request pathways.**

Requesting Data from a NCDHHS Division or Office

1. If you are requesting data from one NCDHHS Division or Office, identify the specific Division or Office that holds the data.

2. Determine if the data you are requesting are already publicly available. To do so, see Data Dashboards, Action Plans/White Papers, publicly available data links within each Division and Office, and NCDHHS Open Data Assets.

If the data are not publicly available,

1. Determine if there is an established Division/Office specific request process, and follow that process (see Divisions / Offices starting on pg. 6)
2. If you are unsure of the Division/Office, or you are requesting data from multiple Divisions or Offices, contact dataoffice@dhhs.nc.gov.

Division of Aging and Adult Services

The Division of Aging and Adult Services (DAAS) is responsible for planning, administering, coordinating, and evaluating activities and programs for older adults.

Publicly available data: Division of Aging and Adult data report

Data request process: Requests can be made to the Division Director by email

Division of Child and Family Well-Being

The Division of Child and Family Well-Being works to meet the health, social and educational needs of children, youth, and families in North Carolina. The division includes complementary nutrition, prevention, and physical and behavioral health programs to improve the health and well-being of children and families.

Early Intervention Section:

Publicly available data: Division of Child and Family Well-Being Publicly available data report and research

Data request process: Data requests should be made via email to the Early Intervention Section Part C Data Manager or to the Deputy Director of Early Intervention. Contact information can be found at: DCFW Data Requests Email Directory

Community Nutrition Section: Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)

Publicly available data: WIC Publicly available data program resources

Data request process: Requests can be made to the Assistant Director, Division of Child and Family Well-Being, Community Nutrition Services Section by email.

Child and Adult Care Food Program (CACFP):

Publicly available data: Child and Adult Care Food Program Publicly available data

Data request process: Requests can be made to the Assistant Director, Division of Child and Family Well-Being, Community Nutrition Services Section by email.

Whole Child Health Section:

Publicly available data: n/a as of Q2 2024

Data request process: Requests can be made to the Assistant Director, Division of Child and Family Well-Being, Whole Child Health Section by email.

Child Behavioral Health:

Publicly available data: Child Behavioral Health publicly available data dashboard

Data request process: Requests can be made to the Assistant Director, Division of Child and Family Well-Being, Child Behavioral Health Section by email.

School, Adolescent, and Child Health

Publicly available data: SCH Annual Report
NCSCH Annual Report
Public Health Families pediatric data report
Public Health Families school data report

Data request process: Pursuant to data guide for DPH process except for Care Impact. For Care Impact, data is requested by Opioid Action Team of CMARC program which pulls from Virtual Health/Care Impact.

Genetics & Newborn Screening:

Publicly available data: n/a as of Q2 2024

Data request process: Pursuant to DPH data request process

Child & Family Wellness:

Publicly available data: n/a as of Q2 2024

Data request process: Requests can be made to the Child & Family Wellness Section by email.

Food and Nutrition Services (Food Stamps):

Publicly available data: Food and Nutrition - Social Services program statistics reports
University of North Carolina School of Social Work

Data request process: Requests can be made to the Assistant Director, Division of Child and Family Well-Being, Food and Nutrition Services Section by email.

Division of Child Development and Early Education

The Division of Child Development and Early Education (DCDEE) implements quality standards for childcare and increases access to families and their children across North Carolina.

Publicly available data: DCDEE Data Dashboard for NC Early Care and Learning NCChildcare County child care snapshot statistical report

Data request process: DCDEE Data Request Form Contact, DCDEE.Data@dhhs.nc.gov

Division of Disability Determination Services

Disability Determination Services (DDS) is a North Carolina government agency that is largely funded by the federal government's Social Security Administration. The DDS provides services to NC citizens through determination of entitlement decisions on Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and NC Medicaid Disability Insurance claims.

Publicly available data: n/a as of Q2 2024

Data request process: Requests can be made to the Division Director by email.

Documents and information generated at DDS are property of the Social Security Administration (SSA) and subject to Federal Privacy Rules and SSA regulations. Requests for documents and information can be requested through a Freedom of Information Act (FOIA) request.

Division of Health Benefits (NC Medicaid)

The Division of Health Benefits (DHB) (NC Medicaid) helps low-income parents, children, seniors, and people with disabilities receive physical and behavioral care and services to improve their health and well-being.

Publicly available data: Medicaid publicly available data reports

Data request process: Submission of detailed data requests (i.e., claims or member-level information) through the DHB Privacy Officer, summary data requests through the Business Information and Analytics Office,at Medicaid.Data.Requests@dhhs.nc.gov ,with notification to the DHB Privacy Officer.

Division of Health Service Regulation

The Division of Health Service Regulation (DHSR) licenses and inspects health care facilities, emergency medical service providers, in-home care providers, and entities handling radioactive materials. DHSR is also responsible for inspecting county jails. And DHSR administers the Certificate of Need laws in accordance with State law and the State Medical Facilities Plan.

Publicly available data: DHRS publicly available data index

Data request process: Data requests may be initially directed to the appropriate section chief. Certain information is confidential (e.g., complaints made to the Complaint Intake Section) and requests for additional information related to inspections of CMS certified facilities must be submitted to CMS via a FOIA request.

Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

The Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MHDDSAS) provides quality support to achieve self-determination for individuals with intellectual and/or developmental disabilities and quality services to promote treatment and recovery for individuals with mental illness and substance use disorders.

Publicly available data: MHDDSAS Annual Statistical Reports

Data request process: For Controlled Substances Reporting System: MHDDSAS controlled substances data request For all other requests, email DMHquality@dhhs.nc.gov

Office of Economic Opportunity

The Office of Economic Opportunity (OEO) helps low-income individuals and families achieve self-sufficiency by working to improve the social and economic well-being of individuals, families, and communities across North Carolina.

Publicly available data: n/a as of Q2 2024

Data request process: Requests can be made to the Office Director by email

Office of Health Equity

The Office of Health Equity promotes and advocates for the elimination of health disparities among all racial and ethnic minorities and other underserved populations in North Carolina.

Publicly available data: Health Equity data and statistics statistics

Data request process: Requests can be made to the Office Director by email

The Office of Procurement, Grants and Contracts (OPCG)

The Office of Procurement, Grants and Contracts (OPCG) is responsible for managing and overseeing the procurement of goods and services, administration of grants, and execution of contracts to support the mission and operations of the organization.

Data request process: Request can be made via this form:OPCG data request form

Office of Rural Health

The Office of Rural Health (ORH) assists rural and underserved communities by providing supports to improve health care access, quality, and cost-effectiveness for all North Carolinians.

Publicly available data: ORH analytics and innovations program publicly available data

Data request process: Requests can be made to the Office Director by email

Division of Public Health

The Division of Public Health (DPH)'s mission is to lead an integrated and equitable public health system that protects and improves the public health's health and environment. DPH promotes disease prevention, health services, and health promotion programs that protect communities from untoward outcomes, such as communicable diseases, epidemics, and contaminated food and water, and the impact of chronic and oral diseases.

Publicly available data: DPH - publicly available data SCHS DPH - publicly available data EPI - DPH oee figures
NCDETECT dashboard

Data request process: SCHS DPH - Data FAQs NC public health - Data Request Policy OCME - data request NCDETECT - data request information For all other data requests, contact, for all other data requests, please

contact, Shelby Taylor, DPH Office of Regulatory and Legal Affairs and copy, Virginia Niehaus, DPH Director of Regulatory and Legal Affairs (shelby.taylor@dhhs.nc.gov, cc: virginia.niehaus@dhhs.nc.gov).

Division of Services for the Blind

The Division of Services for the Blind provides services to people who are blind or visually impaired to help them reach their goals of independence and employment.

Publicly available data: Division of Services for the Blind - publicly available report

Data request process: Requests can be made to the Division Director by email

Division of Services for the Deaf and Hard of Hearing

The Division of Services for the Deaf and the Hard of Hearing provides people who are deaf or hard of hearing with the information, skills, and tools needed to achieve effective communication as well as access to resources in their community for independence and full participation in society.

Publicly available data: n/a as of Q2 2024

Data request process: Requests can be made to the Division Director by email

Division of Social Services

The Division of Social Services (DSS) provides guidance and technical assistance to agencies that provide direct services that address issues of poverty, family violence and exploitation. DSS promotes self-reliance and self-sufficiency and works to prevent abuse, neglect, dependency and exploitation of vulnerable individuals, children and their families. DSS works to accomplish this through Family Centered Principles of Partnership.

Publicly available data: DSS publicly available data - statistics and reviews

Data request process: External Requests, DSS data request contact form Internal Requests, Economic & Family Services Data Requests (Food and Nutrition Services, Energy Assistance, Work First Cash Assistance, and Program Integrity), contact, DSS.EFSDataRequests@dhhs.nc.gov Child Welfare Data Requests, contact, CWSDataRequests@dhhs.nc.gov

Division of State Operated Healthcare Facilities

The Division of State Operated Healthcare Facilities oversees and manages 14 state operated healthcare facilities that treat adults and children with mental illness, developmental disabilities, substance use disorders, and neuro-medical needs.

Publicly available data: Division of State Operated Healthcare Facilities data reports

Data request process: Request can be made to the Division Director by email

Vocational Rehabilitation Services

The Division of Vocational Rehabilitation Services provides counseling, training, education, transportation, job placement, assistive technology, and other support services to people with disabilities.

Publicly available data: n/a as of Q2 2024

Data request process: Vocational Rehabilitation Service - Data Request information

Purpose of Request Determines the Data Request Pathway

The following are the types of requests made in order to access and use NCDHHS data. The process of requesting data, including the appropriate pathway, depends on the type of request. If there are any questions, contact dataoffice@dhhs.nc.gov.

Operational Data Requests—for NCDHHS administrative and business purposes

Requests related to ongoing work of NCDHHS and supports business intelligence with a Division, Office, strategic partner (under a current agreement with NCDHHS), including local offices. The majority of requests made by NCDHHS staff fall under operational requests. ***TIP: Check the Division and Office specific Data Sharing Agreement (DSA) to see whether your request is already approved and what conditions apply.***

Data request process: If requesting data from a specific Division or Office, follow process outlined in previous section. Otherwise, contact dataoffice@dhhs.nc.gov. See **Operational Data Request Form**.

Legal considerations: Access will likely fall under the Intradepartmental Memorandum of Understanding (MOU) and established Division and Office specific Data Sharing Agreements (DSA). A Datia Use Agreement (DUA) may be necessary depending on the source, purpose, and data output.

Operational Data Request Flow

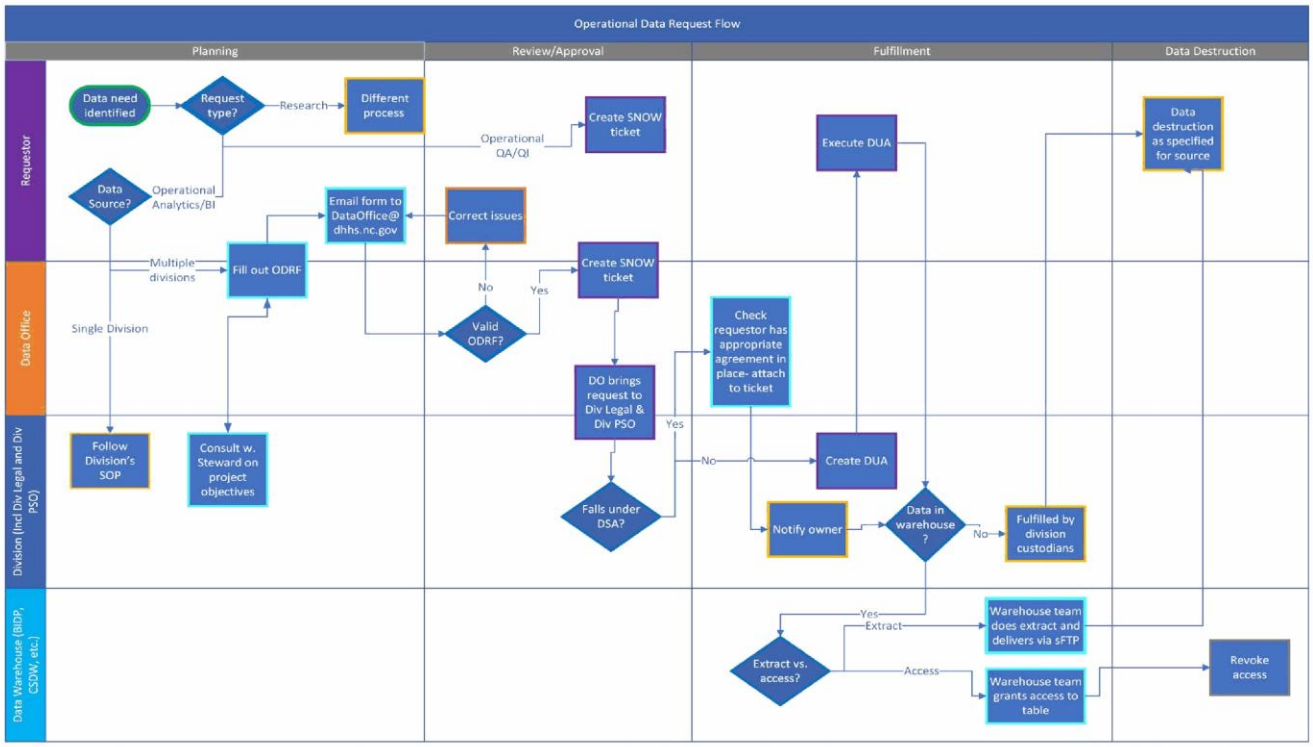
Operational Data Request Flow — step by step

Linear reading of the swimlane flowchart below. Decision points are written as paired conditional steps rather than branching arrows. PSO means the Division Privacy and Security Office.

Step	Phase	Responsible	Action or decision	Where it goes next
1	Planning	Requestor	Data need identified.	Step 2
2	Planning	Requestor	Decision — what type of request is this?	Research: step 3. Operational QA/QI: step 4. Operational Analytics or BI: step 5.
3	Planning	Requestor	Research request. A different process applies; this flow does not continue.	Ends here
4	Planning	Requestor	Operational QA/QI request. Create a ServiceNow (SNOW) ticket.	Step 9

Step	Phase	Responsible	Action or decision	Where it goes next
5	Planning	Requestor	Decision — what is the data source?	Single Division: step 6. Multiple Divisions: step 7.
6	Planning	Division (incl. Division Legal and Division PSO)	Follow that Division's standard operating procedure.	Ends here
7	Planning	Division (incl. Division Legal and Division PSO)	Consult with the Data Steward on project objectives.	Step 8
8	Planning	Data Office	Fill out the Operational Data Request Form (ODRF), then email the form to DataOffice@dhhs.nc.gov.	Step 9
9	Review and approval	Data Office	Decision — is the ODRF valid and complete?	No: step 10. Yes: step 11.
10	Review and approval	Requestor	Correct the issues identified and resubmit the form by email.	Return to step 9
11	Review and approval	Data Office	Create a ServiceNow (SNOW) ticket.	Step 12
12	Review and approval	Data Office	Bring the request to Division Legal and the Division Privacy and Security Office.	Step 13
13	Review and approval	Division (incl. Division Legal and Division PSO)	Decision — does the request fall under an existing Data Sharing Agreement?	Yes: step 14. No: step 15.
14	Fulfillment	Data Office	Check that the requestor has the appropriate agreement in place and attach it to the ticket.	Step 17
15	Fulfillment	Division (incl. Division Legal and Division PSO)	Create a Data Use Agreement.	Step 16
16	Fulfillment	Requestor	Execute the Data Use Agreement.	Step 17
17	Fulfillment	Division (incl. Division Legal and Division PSO)	Notify the Data Owner.	Step 18

Step	Phase	Responsible	Action or decision	Where it goes next
18	Fulfillment	Division (incl. Division Legal and Division PSO)	Decision — do the data live in the warehouse?	No: step 19. Yes: step 20.
19	Fulfillment	Division (incl. Division Legal and Division PSO)	Request is fulfilled by Division custodians.	Step 22
20	Fulfillment	Data Warehouse (BIDP, CSDW etc.)	Decision — extract or access?	Extract: step 21. Access: step 23.
21	Fulfillment	Data Warehouse (BIDP, CSDW etc.)	Warehouse team performs the extract and delivers it by sFTP.	Step 22
22	Data destruction	Requestor	Destroy the data as specified for the source.	Ends here
23	Fulfillment	Data Warehouse (BIDP, CSDW etc.)	Warehouse team grants access to the table.	Step 24
24	Data destruction	Data Warehouse (BIDP, CSDW etc.)	Revoke access.	Ends here



The original diagram, shown for reference. The table above is the authoritative version.

Research Data Requests

Request that will be used for "a systematic investigation designed to contribute to generalizable knowledge."[3] Institutional Review Board (IRB) review and approval may be required.

Data request process: All research requests should originate in the Data Office, except those involving Divisions/Offices with research review processes, specifically DPH, DHB, and DMH. Contact dataoffice@dhhs.nc.gov. See **Research Data Request Form.**

Legal considerations: A Data Use Agreement may be necessary depending on the source, purpose, and data output. Key exceptions exist for IRB-exempt research and non-human subjects research.

Audit Purposes

Request for audit purposes, including the NCDHHS Office of Internal Audit (OIA), the NC Office of the State Auditor (OSA), NC Office of State Budget and Management (OSBM) and federal agencies.

Data request process: If NCDHHS Office of the Internal Auditor (OIA), see relevant Legal considerations below. If request is for audit purposes, but not OIA, the requestor should contact the applicable Division Director, Data Owner, and/or designee for approval, as well as the NCDHHS Privacy and Security Office and OIA.

Legal considerations: For OIA, right of data access for audit purposes is granted by NCGS § 143B- 216.50 and the OIA Charter. OIA shall have access to any records, data, or other information of the Department the Internal Auditor believes necessary to carry out the Internal Auditor's duties

Public Records Request

In NC, anyone can make a request for public records, for any reason. NCGS §132-6 states that a requester does not have to provide their identity or purpose for the request and public data must be provided as promptly as possible, which means a reasonable amount of time under the circumstances. If public data is already accessible online and a person can print or download it, then you can simply point the person there—you are not required to produce data in any other way. You do not have to create a computer database that doesn't already exist. By law, NCDHHS is required to produce data as it exists at the time of the request, but it is not required to create data (though it may choose to). If the public records request involves any analysis (e.g. any data manipulation beyond a data system query of existing data points held within NCDHHS servers), then responding with generated data is permissible but is not required.

If the request is: 1) not from an entity who already has an agreement in place (aka Operational Data Requests from DHHS partners); 2) not routine or easily processed internally; or 3) invokes the public records law, it can be routed to the public records team (legal counsel who determine whether this is a public records request) within the Office of Communications. Note: media are not research institutions. All media requests should be routed to the public records office so the Office of Communications has an opportunity to respond. Specifically, any

[3] See 45 CFR 46, the "Common Rule."

requests made on behalf of a nonprofit or community-based organization without a current agreement with NCDHHS, a media source, or a commercial entity (that is not an operational request) are public records requests.

Data request process: Contact public.records@dhhs.nc.gov

Legal considerations: No agreement is necessary.

Legislative Request

Request from or on behalf of a legislative member, committee, or Division.

Data request process: Contact DHHSlegislativeaffairs@dhhs.nc.gov.

Legal considerations: A DUA may be necessary depending on the source, purpose, and data output.

Legal Request

Request related to a subpoena, court order, discovery, litigation, investigation, and/or as instructed by a NCDHHS attorney or the NC Department of Justice.

Data request process: Contact the relevant **Legal Counsel.**

Legal considerations: A DUA, authorization, or legal protective order may be necessary depending on the source, purpose, data output, and recipients.

Interdepartmental data sharing request related to ECIDS and ELDS

If a request involves integrated data related to children ages 0 – 5, contact the Early Childhood Integrated Data System (ECIDS). If a request involves the integration of early childhood data, student data, and workforce data, contact the Education Longitudinal Data System (ELDS), through the Government Data Analytics Center (GDAC).

Think Through the Data You Are Requesting

Once you have determined what type of data request you are making and the appropriate pathway, it is important to think about the specific data you are requesting and follow the appropriate process.

What data are you requesting?

Questions? Contact dataoffice@dhhs.nc.gov

A. I know what data I plan on requesting, the level of aggregation is permissible based upon my role and use, and I have an existing contact within a NCDHHS Division or Office.

   See Division / Office list specific process above and contact directly.

B. I know what data I plan on requesting (and/or need to review data dictionary), the level of aggregation is permissible based upon my role and use, and I need a contact at a specific NCDHHS Division or Office. See Division / Office list specific process above and request directly.

C. I am requesting integrated data from across NCDHHS Divisions or Offices or I am requesting identifiable records for the purpose of integrating data from NCDHHS with another data source. Contact dataoffice@dhhs.nc.gov.

D. I'm not sure. I would need to discuss my data request with someone. Contact dataoffice@dhhs.nc.gov.

Requested Data Output

The type of data output may depend upon both the use case and the role of the requestor. A data use agreement may be necessary for any of the following request types, including aggregate data, for example, if small numbers are not suppressed.

What is your requested data output?

Questions? Contact dataoffice@dhhs.nc.gov

1. Aggregate

A. Aggregated data by specified subgroup / population / geography from a single Division/Office

B. Aggregated data by specificized subgroup / population /geography from multiple divisions/offices

C. Linked and aggregated data by specified subgroup / population / geography from multiple Divisions/Offices

2. Row level

A. Row level data that has been de-identified

B. Row level data with identifiers

C. Underlying source data that has not been curated or manipulated (e.g. for data management or audit purposes)

3. Integrated Row level

A. Row level data without identifiers, linked with another data source owned by NCDHHS linked within NCDHHS data infrastructure

B. Row level data with identifiers to link with another data source owned by NCDHHS linked within NCDHHS data infrastructure

C. Row level data with identifiers to link with another data source owned by NCDHHS linked outside of NCDHHS data infrastructure

D. Row level data with identifiers to link with another data source not owned by NCDHHS, linked within DHHS data infrastructure

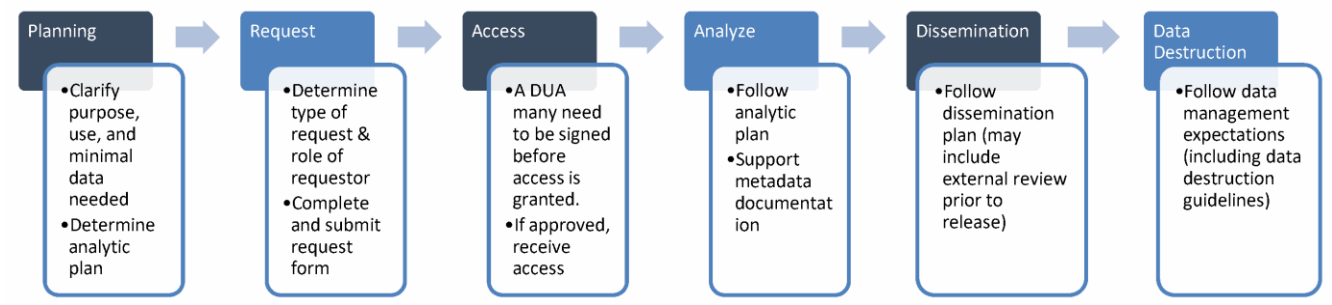
E. Row level data with identifiers to link with another data source not owned by NCDHHS, linked outside of NCDHHS data infrastructure

Data Request Processes

Data Request Process for Requestors (Data Recipient)

Data Request Process for Requestors (Data Recipient) — stage by stage

Stage	What the requestor does
1. Planning	Clarify purpose, use, and minimal data needed. Determine the analytic plan.
2. Request	Determine the type of request and the role of the requestor. Complete and submit the request form.
3. Access	A DUA may need to be signed before access is granted. If approved, receive access.
4. Analyze	Follow the analytic plan. Support metadata documentation.
5. Dissemination	Follow the dissemination plan, which may include external review prior to release.
6. Data destruction	Follow data management expectations, including data destruction guidelines.



The original diagram, shown for reference. The table above is the authoritative version.

Data Request Process for Receiving and Processing a Request

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

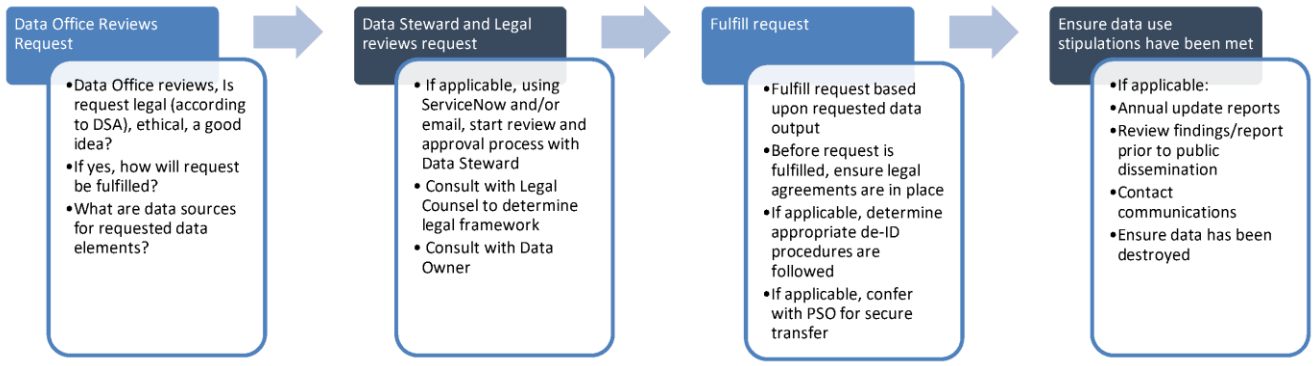
** If request sent to Data Owner or Designee, request is reviewed in accordance with Division/Office specific process.*

TIP: Use the NCDHHS Data Request Reviewer Worksheet to begin your review.

Data Request Process for Receiving and Processing a Request — stage by stage

Applies to the Data Steward, the Data Owner or Designee, and the Data Custodian.

Stage	What the reviewer does
1. Data Office reviews request	Data Office reviews: is the request legal (according to the DSA), ethical, and a good idea? If yes, how will the request be fulfilled? What are the data sources for the requested data elements?
2. Data Steward and Legal review request	If applicable, using ServiceNow and/or email, start the review and approval process with the Data Steward. Consult with Legal Counsel to determine the legal framework. Consult with the Data Owner.
3. Fulfill request	Fulfill the request based upon the requested data output. Before the request is fulfilled, ensure legal agreements are in place. If applicable, determine that appropriate de-identification procedures are followed. If applicable, confer with the Privacy and Security Office for secure transfer.
4. Ensure data use stipulations have been met	If applicable: annual update reports; review findings or report prior to public dissemination; contact communications; ensure data has been destroyed.



The original diagram, shown for reference. The table above is the authoritative version.

NCDHHS Employees, Know your role

There are many roles that support data sharing and use, and each role has a part to play in successful data sharing and data use that supports the work of NCDHHS. See the **NCDHHS High Value Data Asset Inventory** **to think through the roles of specific data assets. What role(s) are you in?**

Data Owner (or Designee), the data decision maker

Accountable for the quality and security of the data. If you are a data owner, you generally have signatory authority for access and use of these data for permissible purposes and are responsible for provisions of Data

Sharing Agreements. You may identify a Designee to make decisions regarding access and use for specific datasets on your behalf. This distinction should be formalized within the **NCDHHS High Value Data Asset Inventory**.

> **Data are owned by DHHS if they meet any of the following criteria:**
>
> - The data are created specifically by or for DHHS
> - The data are collected specifically for use by DHHS
> - DHHS is given ownership through statutory or regulatory requirement(s)
> - DHHS is given specific ownership through a written agreement

Examples: Leadership of Department, Division, or Office

Data Steward, the data expert

Responsible for the governance of data (including: support data request processes, assessing data requests, transfer, alteration, storage, retention, disposition, classification, etc.). This includes supporting the ethical access and use of data, including documenting limitations and bias within data. Support established processes and policies for access and use, including metadata, which is essential for strategic use. Collaborate with Data Owner to ensure strategic use. Collaborate with Data Custodian to ensure data availability. When applicable, responsible for cell suppression methodology and other statistical, data-based safeguards. Often the subject matter expert that works with data regularly for business purposes.

Examples: Analyst, Epidemiologist, Data Lead, Data Manager, Data Governance Specialist

Data Custodian, the data handler

Oversee the safe transport, storage, and disposition of data, including infrastructure, activities and safeguards required to maintain the confidentiality, integrity, and availability of the data. Collaborate with the Data Stewards to ensure data availability. Communicate with Data Owner and Data Steward regarding any data management issues that pose a risk to data security and/or access.

Role: Information Technology Staff

How You Support Data Access and Use

Based on your role, there are clear ways that you can support data sharing, access, and use across the Department. All of these following roles, with the exception of data requestor, are filled by NCDHHS employees.

As a data owner, you should

- Establish clear delineation of roles across your Division/Office, including data owner or designee (for certain data sets) and data stewards within the **NCDHHS High Value Data Asset Inventory**, to be reviewed annually
- Ensure that data stewards and data custodians are sufficiently resourced
- Maintain staff training and management that supports strong communication practices to ensure data access and use are legal, ethical, and a good idea.

Tip: Encourage use of the **NCDHHS Data Request Reviewer Worksheet** to think through these questions.

- Commit to transparency and continuous improvement
- Participate in data governance processes or designate a proxy

As a data steward, you should

- Support Data Governance activities, such as review of data requests

Tip: Use the **NCDHHS Data Request Reviewer Worksheet** to think through these questions.

- Establish and regularly update metadata
- Update the **NCDHHS Data Asset Inventory Form** annually
- Acknowledge and document limitations and bias within data
- Develop and share data-specific expertise
- Clearly communicate limitations and strengths of the data with requestors
- Actively participate in data governance and request processes

As a data custodian, you should

- Adherence to data management best practices and policies and processes set forth in the DHHS Security Manual and the DIT Statewide Information Security Polices, to ensure security and privacy
- Support structuring data for optimal access and use
- Work with Data Owner and Data Steward to ensure that anonymization requirements are met prior to data transfer

As legal counsel,

- Monitor changes in law (federal and state) that impact data access and use, and advise individuals in other roles of these changes in a timely manner
- Support implementation of changes in law through policy and agreement updates
- Support drafting of template agreements and review of Data Sharing Agreements

- Support Privacy and Security Office in security incident or breach response
- Support Division Contracts Offices/OPCG in procurement processes
- Review data requests to determine whether federal, state, and local law and regulation permit the disclosure of the data for the proposed use case

As a Privacy and Security Office (PSO) or PSO Official, you should

- Provide security policy and advisory service for data access and use
- Review contracts, Data Use Agreements (DUA), Non-Disclosure Agreements (NDA), Business Associate Agreements (BAA), Standard Operating Procedures (SOP)
- Review for Mental Health and Controlled Substance related data and associated regulatory requirements
- Review data classification based on data requested and state and DHHS policy
- Review security artifacts of data destination or intermediaries (e.g., Privacy Threshold Assessments (PTA), Vendor Readiness Assessment Reports (VRAR), SOC2)
- Review for security and privacy enforcement for the storage and transfer of data based on data classifications
- Lead privacy and security breach or incident response

As NCDHHS Data Office staff, you should

- Maintain the **NCDHHS High Value Data Asset Inventory**, including owners, stewards, and custodians
- Regularly refine data request processes
- Shepherd data requests, both internal and external
- Support data quality improvements
- Support data stewards in documenting limitations and bias within data
- Act as process experts, not necessarily content experts

As a reviewer of data requests, you should

- Support NCDHHS Data Use Priorities
- Support strong review practices to ensure data access and use are legal, ethical, and a good idea. Tip: Use the **NCDHHS Data Request Review Worksheet** to think through these questions.
- Support refinements and improvements to the data request process

As a data requestor, you should

- Support NCDHHS Data Use Priorities

- Request minimum data needed for inquiry
- Adhere to **NCDHHS Terms and Conditions of Data Use**
- Adhere to terms of your Data Use Agreement, if applicable
- Support data request process and data quality improvements

NCDHHS Data Asset Inventory

Access the **NCDHHS High Value Data Asset Inventory** here. This is an inventory that is updated annually by Divisions and Offices and includes information about high value data assets across NCDHHS.

Each Division and Office should identify "high value data," i.e., any data that:

- Is critical to the operations of NCDHHS
- Serves the strategic goals of NCDHHS
- Can improve public knowledge of NCDHHS and its operations
- Is frequently requested
- Responds to a need and demand as identified by the Department through public consultation
- Is used to satisfy any legislative or other reporting requirements

The **NCDHHS Data Asset Inventory Form** includes the following fields

Data Repository where asset is contained

PII data (Y/N)

Application/dataset description

PHI data (Y/N)

Division/Office

Protected data (Y/N)

Function/Utilization

Data Steward

Dataset Structure

Data Custodian

Major Entities in Dataset

Data Owner or Designee

In addition to updating the Data Asset Inventory annually, Divisions and Offices are asked to fill out a summary report of Division/Office specific data requests that have been fulfilled during the calendar year. This summary reporting form will be sent to Divisions/Offices by November 1 of each year and returned by February 1 the following year. If the Division/Office has a standard report, then the existing document can be submitted. It the responsibility of the Data Owner to determine how this summary report will be completed. The purpose of this summary report is to better understand how data are accessed and used across the Department as a whole, while not interrupting Division and Office specific requests.

To update the **NCDHHS High Value Data Asset Inventory** or submit the **Annual Data Request Summary Report**, **email** dataoffice@dhhs.nc.gov.

Legal Considerations

When data are requested, it is important to first consider whether data are classified as open, restricted, or unavailable. See the **NCDHHS High Value Data Asset Inventory** as a starting point.

Go to **NCDHHS Open Data Assets** to view data that are currently available online. If data are classified as "open," then a legal agreement is not needed, and extracts of these data can be provided as long as data are aggregated appropriately (see De-Identification). NCDIT Data Classification and Handling Policy **may also be helpful in thinking through data classification for sharing purposes.**

Data Classification

Classification	Description	Example data types
Public	Available and intended for public access.	Information on publicly accessible websites; routine correspondence; employee compensation; press releases (final); job postings.
Internal	Typically used within the agency and not for public sharing. Most documents are classified as Internal within the organization, and most employees would have access.	Employee work schedules and assignments; administrative records; internal newsletters; drafts of documents not yet published, such as press releases, draft communication and draft policies.
Confidential	Often limited to a small audience on a need-to-know basis.	Business unit plans; security features; sensitive public security information; draft versions of an agency's annual or quarterly reports; forecasting assumptions.
Restricted	Represents the highest level of sensitivity and presents the highest risk if disclosed. Access to this information is restricted to a limited audience.	Personally identifiable information; PCI data security standards; PHI and HIPAA; criminal justice information; state and federal tax information.

When thinking about the legality of data sharing, access, and use, there is typically not a plain answer on whether something is "legal" or permissible according to federal or state law or regulation. In summary, it all depends. The majority of human service data can be legally accessed when done so in a permissible way. For example, a requestor may not be able to access identifiable row level data, but it may be permissible to receive similar information as aggregate data at the state or county level.

So, does the law let me disclose? It depends.

Why do you want to access or share the data?

- To identify a target population?
- To evaluate program outcomes?
- To conduct/perform research?

What type of data do you want to access or share?

- Data that does not identify individuals?
- Data that does identify individuals?
- Data that might identify individuals?

Who wants to access?

Who do you want to share it with?

- NCDHHS staff for operational purposes?
- University-based researcher?
- Local health department?

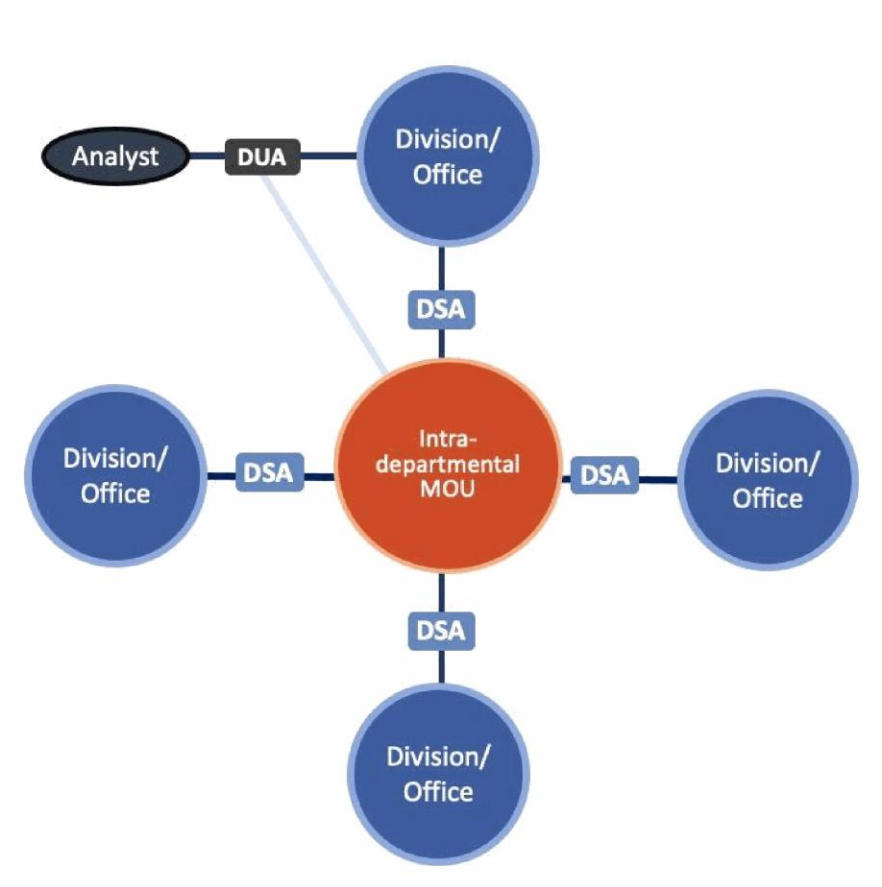
North Carolina General Statutes and rules and NCDHHS and Division/Office policies inform how data may be shared and used. **Legal Counsel** and the **Privacy and Security Office** **should be involved in determinations about which data can be shared, for which purposes and with whom, and which agreements are required. Involving Legal Counsel and the Privacy and Security Office early in the data request review process benefits everyone.**

Legal Framework

There are several legal agreements that are frequently used across NCDHHS to support data access and use. It is important to note that legal agreements will be stored by signatories, with duplicate copies provided to relevant Privacy and Security Office (PSO/ISO) contacts upon execution. These include:

- Business Associate Agreement (BAA): Outlines each party's responsibilities of safeguarding protected health information (PHI). Note, this is only applicable to data covered by HIPAA where a 3rd party is involved and is conducting services or performing a function on behalf of the covered entity as a business associate. (See Privacy Manual, Sec VIII, Administrative Policies, Business Associates.) Applicable only to HIPAA-covered data. Consult PSO if you are unsure whether HIPAA applies.
    - Signatories: NCDHHS and Business Associate
- Confidential Disclosure Agreements: Outlines permissible disclosures of confidential data and information between a third-party and NCDHHS, typically initiated by the third party.
    - Signatories: NCDHHS + individual/company under contract for goods or services
- Data Use Agreement: Contract that outlines permissible data use and disclosure for specific purposes.
    - Signatories: NCDHHS Data Owner(s) + data recipient
    - Signatories: Depends on use. E.g., NCDHHS (Division/Office administering program) + Individual; Researcher requesting identifiable NCDHHS data + Individual
    - Signatories: The individual or legally authorized individual who is authorizing the release of the individual's own HIPAA-covered information
- Informed Consent Form: Involves providing an individual with sufficient information to determine if they consent to an action. This could be a number of reasons, such as inclusion within a research study or involvement in a program that will share data for specific purposes.
- HIPAA Authorization Form: Form specific to access and use of HIPAA data. Form must satisfy the requirements of 45 CFR 164.508 to be valid.

The following intradepartmental legal agreements are used to govern data access and use across NCDHHS Divisions and Offices and Programs. Note that the **DUA** **is signed by all Data Owners involved in the request, as stipulated by the** IMOU. (This framework does not include DUAs with one Division or Office, as the process is described on pg. 6).



FOUNDATIONAL LEGAL AGREEMENTS			
LEGAL DOCUMENT	**PURPOSE**	**PROCESS**	**SIGNATORY**
Intradepartmental MOU *Overarching process and guiding principles document signed by all Divisions / Offices*	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 agreements, data use agreements, policies, and procedures for data access and use (e.g., NCDHHS Data Sharing Guidebook).	Drafted by Data Office, reviewed by legal counsel, signed by Executive Leadship and updated through the NCDHHS Data Governance Council as needed.	All Division and Office Directors and Secretary's Office are parties to 1 agreement

FOUNDATIONAL LEGAL AGREEMENTS			
LEGAL DOCUMENT	**PURPOSE**	**PROCESS**	**SIGNATORY**
Data Sharing Agreement *Division / Office Specific*	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. This document is specific to Division and Office held data.	Drafted by Data Office and Division/Office specific legal counsel. Reviewed and updated annually, or as agreed upon.	1 DSA per Division/Office Signed by Division and Office Director, the Data Office, and Information Technology Division
Data Use Agreement *Data Request Specific*	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.	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.	DUAs are used as needed for use cases not covered by DSAs. Signed by Data Recipient and Data Owners (if applicable)

Think Through the Impact of Federal Laws on Data Sharing

Health Insurance Portability and Accountability Act (HIPAA): is a federal law with specific requirements to maintain the privacy and security of "protected health information." HIPAA applies to any data from a Covered Health Care Provider, Health Care Clearing House, or Health Information that is created, transmitted, stored or received.

This can include demographic information collected, including:

- Health data created by a health care provider, health plan, employer, or health care clearinghouse;
- Data that identifies the individual;
- Data relating to the past, present, or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present, or future payment for the provision of health care to an individual.

When thinking about data sharing across NCDHHS, it is important to remember that we are a hybrid entity under HIPAA, meaning that not all Divisions and Offices, or even Programs in the same Division or

Office are covered entities. This means that not all data owned by NCDHHS is subject to the requirements established under HIPAA. See this guidance for more information.

NCDHHS Covered Entities	NCDHHS Non-Covered Entities	NCDHHS Hybrid Entities
Division of Health Benefits (NC Medicaid)	Division of Child Development and Early Education	Division of Public Health, includes Healthcare Provider, Health Plan, and Clearinghouse components and Internal Business Associate
Office of Rural Health and Community Care	Office of Property and Construction	Division of Aging and Adult Services, Internal Business Associate (nothing is listed on the document under this section)
Division of State Operated Healthcare Facilities	Division of Services for the Deaf and the Hard of Hearing	Division of Vocational Rehabilitation Services, Internal Business Associate
Information Technology Division	Disability Determination Services	Division of Social Services, Internal Business Associate
Office of the Controller	Division of Health Service Regulation	Division of Child and Family Well-Being
Division of Mental Health, Developmental Disabilities and Substance Abuse	Office of Human Resources	Division of Vocational Rehabilitation Services

NCDHHS Covered Entities	NCDHHS Non-Covered Entities	NCDHHS Hybrid Entities
Office of Communications	Office of Minority Health and Health Disparities	Division of Aging and Adult Services
Office of the Internal Audit	Health Service Regulation	
Office of the General Counsel	Budget and Analysis	
Office of Government Affairs	Office of Procurement, Contracts, and Grants	
Office of the Secretary	Services for the Deaf and the Hard of Hearing	
Office of Privacy and Security	Services for the Blind	
NCFAST	Office of Economic Opportunity	

Federal Educational Rights and Privacy Act (FERPA): sets out requirements for the protection of students' education records, and provides parents and eligible students (a student who reaches the age of 18 years or attends a school beyond the high school level) certain rights with respect to the student's education records, including the right to maintain the confidentiality of the education information. This law applies to an educational agency or institution to which funds have been made

available under any federally-administered Department of Education program if: (1) the educational

institution provides educational services or instruction, or both, to students; or (2) the educational

agency is authorized to direct and control public elementary or secondary, or post-secondary educational students. Within NCDHHS, this includes several Divisions that hold data that are protected under FERPA, including DCDEE and DSOHF.

Relevant State Rules & Regulations

See **NCDHHS Data Statutes and Rules** for some of the restrictions and allowances of data sharing access and use that might apply to the data.

The NCDHHS Data Statutes and Rules is not a substitute for making a determination on the legality of any specific data sharing. It is important to consult with Legal Counsel to determine what data sharing, access, and use is permissible, in addition to any associated penalties for misuse.

Considerations for Permitting Data Access and Use

As a Data Owner or Data Steward, your role requires you to carefully consider requests for data access and use. It is important to consider **Appendix B, NCDHHS Terms and Conditions of Data Access and Use**, which are the

conditions that requestors of NCDHHS data agree to. Broadly speaking, we are aiming to support data access and use that is legal, ethical, and a "good idea." The following questions can help guide your decision making, as well as using the **NCDHHS Data Request Reviewer Worksheet**.

1. Do these data already exist in a public facing format? Should these data be public facing?
2. Has anyone else made a similar request in the past?
3. Is fulfilling this request legally permissible? (Consult with legal to think through considerations)
4. Is this ethical use of data? Have the intended and unintended consequences of this data access and use been carefully considered by a variety of stakeholders?
5. What are the risks to privacy and security? (Consult with PSO/ISO to think through considerations). Do the benefits of the data use outweigh the risks?
6. Is this request a good idea? Can action be taken as a result of this data access and use that improves the lives of NC residents?
7. How much effort would it take to fulfill this request?
8. How do equity and bias need to be considered in this request? For more information, see: A Toolkit for Centering Racial Equity Throughout Data Integration
9. How will information about the data end product need to be communicated to internal and external stakeholder groups? Does the Communications Office need to be involved?

***Tip: Use the* NCDHHS Data Request Reviewer Worksheet** when reviewing a data request.

Prioritization of Data Requests

The prioritization of requests is an ongoing process and will ultimately be decided by the NCDHHS Data Office, Divisions, and Offices based upon the urgency of the request, data availability, and staff capacity. Requests will be categorized as high, medium, or low priority.

All requests from the Office of the Secretary, the Governor's Office, and Legislative Requests will be high priority. Any request that is not aligned with NCDHHS Goals will be considered low priority.

Data De-identification

As discussed previously, whether a data request can be fulfilled may depend upon the level of de-identification of the requested data set. The data output is an important consideration when reviewing and fulfilling a request. HIPAA and FERPA have different standards around de-identification, and not all data held by NCDHHS is governed by HIPAA and/or FERPA. The general rule and best practice is where there are different de-identification standards, NCDHHS should implement the standards that are most protective. Check with the Data Steward and Division Legal Counsel regarding appropriate deidentification standards for a particular data set.

De-identification Standards under HIPAA

De-identified data set

For a data set to be considered de-identified under the HIPAA Safe Harbor Standard, the data set must meet the requirements set forth under 45 CFR §164.514(b). Specifically, a data set is de-identified when the following identifiers of the individual or the individual's relatives, employers, or household members are removed from the data set:

1. Names
2. All geographic subdivisions smaller than a state, including: street address, city, county, precinct, ZIP code, and their equivalent geocodes, except for the initial three digits of the ZIP code if, according to the current publicly available data from the Bureau of the Census:
    a. The geographic unit formed by combining all ZIP codes with the same three initial digits contains more than 20,000 people; and
    b. The initial three digits of a ZIP code for all such geographic units containing 20,000 or fewer people is changed to 000
3. All elements of dates (except year) for dates that are directly related to an individual, including birth date, admission date, discharge date, death date, and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older
4. Telephone numbers
5. Fax numbers
6. Email addresses
7. Social security numbers
8. Medical record numbers
9. Health plan beneficiary numbers
10. Account numbers
11. Certificate/license numbers
12. Vehicle identifiers and series numbers, including license plate numbers
13. Device identifiers and serial numbers
14. Web Universal Resource Locators (URLs)
15. Internet Protocol (IP) address numbers
16. Biometric identifiers, including finger and voice prints

17. Full face photographic images and any comparable images
18. Any other unique identifying number, characteristic, or code

If a data set contains any of the 18 identifiers described above then the data set is not de-identified and may be considered a limited data set or an identified data set.

Limited data set

A limited data set ("LDS") is defined at 45 CFR §164.514(e) and must exclude most, but not all, of the 18 identifiers that must be excluded in a de-identified data set.

A limited data set cannot include the following information pertaining to an individual or the individual's relatives, employers, or household members:

1. Names
2. Street addresses
3. Telephone numbers
4. Fax numbers
5. Email addresses
6. Social security numbers
7. Medical record numbers
8. Health plan beneficiary numbers
9. Account numbers
10. Certificate and license numbers
11. Vehicle identifiers and serial numbers
12. Device identifiers and serial numbers
13. Web Universal Resource Locators (URLs)
14. Internet Protocol (IP) addresses
15. Biometric identifiers (i.e. finger and voice prints
16. Full face photographic image

A limited data set can include the following information: some geographic information (such as town/city, state, county, and zip code – but not street addresses), dates (such as birth date, date of death, admission date, discharge date), and age (as described in years, months, days, or hours).

Identified data set

An identified data set includes information beyond what is permitted to be included in either a limited data set or a de-identified data set. For example, any data set that includes names, telephone numbers, or street addresses would be considered an identified data set. There are also specific de-identification parameters for specific data sources (and these guidelines would be included with the Division-/Office-specific Data Sharing Agreement).

For example, for release of data specific to communicable diseases,

- All unstratified data are released at the state and county levels.
- If data are stratified (e.g., state by age or county by age), data are suppressed for any cell for which the cell denominator (i.e., population denominator) is less than 500, and for additional cells as needed to prevent discovery of the suppressed cells by subtracting from row or column totals.
- For suppressed data that is downloadable, if number is <5, they are grouped in a suppressed column.
- An "other" category grouping small populations together is sometimes used in a table to help avoid suppression.
- Higher denominators for suppression may be necessary if other publicly available information, such as press reports, may increase the likelihood of identification, or if other conditions that would increase the likelihood or stigma of identification are present.
- If both numerator and denominator are small, rates may be unstable. In this case, NCDHHS often includes a footnote stating: "Please use caution when interpreting numbers less than 5, and rates and trends based on these numbers."
- Discussion with experts with local knowledge also help determine the importance of changes in rates based on small case numbers.

De-identification Standards under FERPA

FERPA's accompanying regulations do not expressly specify any required method for de-identification, but rather requires that for any de-identification method, NCDHHS makes a "reasonable determination that a student's identity is not personally identifiable, whether through single or multiple releases, and taking into account other reasonably available information."[4] The Department of Education's Privacy Technical Assistance Center (PTAC) has created guidance offering up some examples of de-identification techniques that an institution can elect to use to de-identify PII:[5]

- Blurring: This technique reduces the precision of disclosed data to minimize the certainty of individual identification.

[4]34 CFR § 99.31(b)(1).

[5]For more information on these techniques, please refer to Privacy Technical Assistance Center. (2013, May). *Data De-identification: An Overview of Basic Terms.* US Department of Education.

- Perturbation: This de-identification method involves making small changes to data to prevent individual identification from unique or rare population groups.
- Suppression: This method involves removing data (e.g., from a cell or a row in a table) to prevent the identification of individuals in small groups or those with unique characteristics

Again, there is no singular way to de-identify, but PTAC emphasizes that, "de-identification is considered successful when there is no reasonable basis to believe that the remaining information in the records can be used to identify an individual."[6]

Data Transfer

The method for transferring data will depend upon whether data are unrestricted (open, publicly available) or restricted (confidential). Data that are publicly available do not require a secure method for data transfer. If data are restricted, only secured and approved data transfer methods should be used, and data transfer should be in alignment with the Data Use Agreement.

DHHS Data (file) Sharing Mechanisms with Internal and External Requestors

Prior to sharing, ensure the recipient is authorized to receive these data and the data is being sent to the authorized recipient.

Technical Approach	File Size Limits	Security Considerations	Other Considerations
Email (@dhhs.nc.gov)	150Mb	Publicly available data only	One-off requests not preferred. Store appropriately.
Encrypted email (@dhhs.nc.gov)	150Mb	Ensure that restricted or confidential data are encrypted as per NCDHHS policy. File should also be password protected.	One-off requests not preferred. Store appropriately once transferred.
Google Drive	5Tb	Only the use of state-owned and approved Google tenant is allowed for sharing data with specific authorized partners.	e.g., to share video files with partners. Mainly between DHHS and Universities
Microsoft Office 365 OneDrive	100Gb, total up to 1Tb per user	Internal only	

[6] Ibid. at 3.

Technical Approach	File Size Limits	Security Considerations	Other Considerations
Microsoft Teams	15Gb per file	Internal only	Ensure that all members of the "Team" are authorized to access
Internal SharePoint	100Gb	Internal only (must have NCID and DHHS email)	Ensure that all files are categorized and filed appropriately to prevent accidental disclosure via access permissions.
SFTP	Multiple SFTP services are being used; depending on the service, different limits may apply	Ensure that restricted, or confidential data are encrypted as per NCDHHS policy	Usually sent as CSV files
External drive	None, but total will depend on drive size	Ensure that confidential data are encrypted as per NCDHHS policy	e.g., courier of USB drive (if using courier, add tracking receipt)

*Note that this table does not include automated exchange mechanisms

Data Storage

Data should be transferred using the appropriate method on the previous page, and then stored within the appropriate approach. The method for storing data will depend upon whether data are unrestricted (open, publicly available) or restricted (confidential). Data that are publicly available do not require a secure method for data storage. If data are restricted, only secured and approved data storage methods should be used, and data storage should be in alignment with the Data Use Agreement, as applicable. It is important to rely upon proper data classification and the advice of the appropriate Data Custodian (e.g. ITD / DIT staff) to determine the appropriate data storage solution for a given data set.

DHHS Data (file) Storage Mechanisms

Technical Approach	File Size Limits	Security Considerations	Other Considerations
Google Drive	5Tb	Only the use of state-owned Google tenant is allowed for sharing data with specific authorized partners.	

Technical Approach	File Size Limits	Security Considerations	Other Considerations
Microsoft Office 365 OneDrive	100Gb, total up to 1Tb per user	Allowable for restricted data.	
Internal SharePoint	100Gb	Internal only (must have NCID and DHHS email). Allowable for restricted data.	Ensure that all files are categorized and filed appropriately to prevent accidental disclosure via access permissions.
Secure /U/ Drive	Varies	Internal only (must have NCID and DHHS email). Allowable for restricted data.	Preferred approach
DHHS owned Database (example, BIDP, CSDW, etc.)		With support from the Data Custodian, data can be loaded into appropriate database after secure transfer.	Preferred approach
Discuss storage options with the appropriate Data Custodian (e.g. ITD / DIT staff) to ensure that best practices are being followed.			

See: DIT Memo regarding Secure Cloud Storage, File Sharing and Collaboration (2017); DIT Memo regarding Secure Cloud Storage, File Sharing and Collaboration – Phase 2 (2018); DIT Data Classification and Handling Policy (2026)

Data Access and Use FAQs

Q: I'm DHHS staff, and I'm submitting an operational request for data from my Division and another Division. Do I need a Data Use Agreement?

A: Probably not, but you will need to defer to Legal Counsel, as this will be dependent upon your request. If this is an Operational Data Request, your request may be allowable without a specific Data Use Agreement if it is within the terms of the NCDHHS Intradepartmental MOU and the Division and Office Data Sharing Agreements.

Q: What is "business intelligence"?

A: Operational and Business Intelligence Activities: Data Integration and/or exploratory analysis of one or more sets of data so that Data Owners and DHHS leadership can better answer policy and business questions or meet DHHS' programmatic or business needs.

Q: I'm under contract with NCDHHS (but I'm not a state employee) and need to access data to fulfill my scope of work. What do I do?

A: You are a "strategic partner." You will need to submit an Operational Data Request Form to the Division / Office or dataoffice@dhhs.nc.gov.

Q: What is a "strategic partner?"

A: "A strategic partner" is an individual / agency / organization / company / local office / or other entity that is under current agreement with NCDHHS, and conducting ongoing work of NCDHHS that supports operational and business intelligence. As a "strategic partner," you will need to submit an **Operational Data Request Form** to the Division / Office or dataoffice@dhhs.nc.gov.

Q: I'm submitting a Research Data Request Form, but I only want to use de-identified data. Do I need to submit an IRB application or provide proof of an IRB approval or exemption?

A: Yes. The Revised Common Rule is the set of federal regulations that governs research involving human subjects. The regulations recognize eight categories of research that are exempt from review by an IRB. Though your research may be exempt, you are required to submit to IRB for review to determine exemption status.

Q: I'm conducting a research study using death records. Do I need IRB approval?

A: Death records do not involve living subjects, and therefore are not considered Human Subjects Research. But, review is still required. It may be necessary to complete the "Request for Non-Human Subjects Research Determination" form. Some privacy laws apply to decedents, so some sensitive data may still have separate protections and may require a Data Use Agreement.

Q: I'm conducting research about things that are not human beings (e.g., built environment, neighborhood amenities, pollution and weather, etc.). Do I need IRB approval?

A: No, since this research does not involve living subjects, IRB review is not needed, though determination of non-human subjects research may be necessary.

Q: I'm a NCDHHS Data Custodian or Data Steward, and I received a data request from a journalist. What is the process that they need to go through if they want data?

A: This is a Public Records request under NC state law. Or, a Freedom of Information Act (FOIA) request under federal law. Forward to public.records@dhhs.nc.gov, and the request will be assessed by attorneys to determine next steps.

Q: I'm a NCDHHS Data Custodian and have received a subpoena, Order, and/or similar request from an attorney, court, tribunal or the Department of Justice.

A: Submit request to Legal Counsel.

Q: I'm a NCDHHS Data Steward and received a data request from an individual or organization that is not a strategic partner of DHHS (no agreement currently in place), and they are requesting data in relation to a project with public health significance (not research). What am I able to release?

A: Direct requestor to NCDHHS public facing dashboards and open data assets (listed by Division here). This may also be a public records request. See **Appendix A, Questions to Guide Data Request Pathways**.

Terms

The following terms are commonly used and defined here. You can access a more comprehensive list of terms here. Additional terms can be found within the N.C. DIT Statewide Glossary of Information Technology Terms.

Aggregation: Combining data about individuals while protecting individual privacy by using groups of individuals or whole populations rather than isolating one individual at a time.

Breach: An incident wherein information is taken from a system without the knowledge or authorization of the system's owner. This could be inadvertent, accidental, or malicious. A data breach can occur within a small company or a large organization, and it may involve sensitive, proprietary, or confidential information, such as credit card or bank details, personal health information (PHI), personally identifiable information (PII), trade secrets of corporations or intellectual property. Also called Cyber Breach or Data Breach. Source: N.C. DIT

Business Intelligence: Data Integration and/or exploratory analysis of one or more sets of data so that Data Owners and DHHS leadership can better answer policy and business questions or meet DHHS' programmatic or business needs.

Data dictionary: A centralized repository of information about data (e.g., meaning, origin, usage, format, relationship to other data elements). A file that defines the organization of a database. Source: N.C. DIT

Data governance: The people, processes, and technology required for data quality, integrity, availability, usability, and security throughout its lifecycle. Can also be referred to as a set of processes that ensures that data assets are formally managed throughout the enterprise.

Data minimization: The idea that one should only collect or share the personal data that is necessary to achieve a specific goal.

Data management: An overarching term that describes the process used to plan, specify, enable, create, acquire, maintain, use, retrieve, control, and purge data. Data management is a maturing discipline and exists in a broader context of technology adoption, use, community, and collaboration. Data management concepts and supporting technology have evolved quickly with the advent of big data and continues to evolve. Source: Adapted from the DAMA-DMBOK2 Framework

Data stewardship: Data stewardship includes the processes involved with acquiring, storing, using data, as well as the data's security and quality. While data stewardship is the overarching principle, data governance includes the processes of how these principles are carried out.

Metadata: Metadata describes a number of characteristics or attributes of data; that is, "data that describes data." For any particular data set, the metadata may describe how the data are represented, ranges of acceptable values, its label, and its relationship to other data. Metadata also may provide other relevant information, such as the responsible steward, associated laws and regulations, and the access management policy. The metadata for structured data objects describes the structure, data elements, interrelationships, and other characteristics of information, including its creation, disposition, access and handling controls, formats, content, and context, as well as related audit trails.

Personal Information or Personally Identifiable Information (PII): Under state law, personal information is a person's first name or first initial and last name in combination with other identifying information (see N.C.G.S. 75-61(10)).

Protected Health Information (PHI): PHI is defined in federal law (45 CFR 160.103) and pertains to information that contains the following types of data:

- Individually identifiable health information
- Transmitted or maintained in any form or medium by a Covered Entity or its Business Associate
- Health information including demographic information;
- Relates to an individual's physical or mental health or the provisions of or payment of health care
- Identifies the individual

Source: N.C. DIT

Strategic Partner: "A strategic partner" is an individual / agency / organization / company / local office / or other entity that is under current agreement with NCDHHS, and conducting ongoing work of NCDHHS that supports operational and business intelligence. "Strategic partners" can submit an **Operational Data Request Form** to the Division / Office or dataoffice@dhhs.nc.gov.

Appendix

Appendix A: Questions to Guide Data Request Pathways

If you have a data request, use these questions to guide the process.

1. Does the request support work in alignment with **strategic priorities of NCDHHS**?

If yes or no, proceed to Q2. Note that requests may be prioritized based upon alignment with priorities.

2. Is this an operational request—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?

Is this request for data from a specific Division/Office? If yes, contact that Division/Office directly. Does this request involve data from multiple Divisions/Office? If yes, please contact dataoffice@dhhs.nc.gov. And see the **Operational Data Request Form**.

If no, proceed to Q3.

3. Is this request for research purposes?[7]

If yes, are you DPH staff? You may need to submit an application to **DPH IRB**.

If yes, are you working in collaboration with NCDHHS staff or a consultant of NCDHHS for research purposes? If yes, Institutional Review Board review and approval may be required. Contact dataoffice@dhhs.nc.gov

If no, proceed to Q4.

4. Is this request for audit purposes, including the NCDHHS Office of the Internal Auditor (OIA), the NC Office of the State Auditor (OSA), or NC Office of State Budget and Management?

For OIA, right of data access for audit purposes is reinforced by NCGS § 143B-216.50 and the OIA Charter. OIA shall have access to any records, data, or other information of the Department the Internal Auditor believes necessary to carry out the Internal Auditor's duties.

If yes, but not OIA, contact the applicable Division Director, Data Owner, and/or Designee for approval, as well as the NCDHHS Privacy and Security Office and OIA, before fulfilling the data request.

If no, proceed to Q5.

5. Is this a Public Records Request for Data Access and Use?

- **Y / N** Is this request for a nonprofit or community-based organization without a current agreement with NCDHHS?
- **Y / N** Is this request from a media source?
- **Y / N** Is this request from a commercial entity that is not operational (See Q1)?

If yes to any of the above questions, then this is a Public Records Request.

- **Y / N** Does the Public Records Request involve any analysis? (e.g. any data manipulation beyond a data system query of existing record that is held within NCDHHS servers)

If yes, data access is permissible but not required. NCDHHS is required to produce data as it exists at the time of the request but is not required to create data.

[7]There are many definitions of research. For example, research is defined by federal regulations as "a systematic investigation, including development, testing, and evaluation, designed to develop or contribute to generalizable knowledge" (See, Common Rule). Generally, the term "research" refers to the testing of a hypothesis. Research generally does not include operational activities (e.g., public health surveillance) and studies for internal management purposes such as program evaluation, quality assurance, quality improvement, fiscal or program audits, marketing studies, or contracted-for services. Research generally does not include journalism or political polls. However, some of these activities may include or constitute research in circumstances where there is a clear intent to contribute to generalizable knowledge.

If this is a Public Records Request, contact public.records@dhhs.nc.gov

If no, proceed to Q6.

6. Is this a legislative request?

- **Y / N** Is this request from or on behalf of a legislative member, committee, or Division (e.g. the Fiscal Research Division)?

If yes, contact DHHSlegislativeaffairs@dhhs.nc.gov

If no, proceed to Q7.

7. Is this a request related to legal affairs?

- **Y / N** Is this request related to a subpoena, court order, discovery, litigation, investigation?
- **Y / N** Are you making a request on behalf of the NC Department of Justice?
- **Y / N** Are you making this request on behalf of a legal team?

If yes, contact the relevant Legal Counsel

If no, proceed to Q8.

8. Does this request involve interdepartmental data sharing (beyond NCDHHS) related to children and youth?

- **Y / N** Is this request related to children age birth-5? If yes, contact ECIDS, ECIDS data requests for researchers
- **Y / N** Is this request related to the integration of Early Childhood Data, Student Data, and Workforce Data? If yes, contact ELDS, through GDAC, NC Government Data Analytics Center

9. I have a data request that supports NC DHSS use data as a strategic asset, but I am unsure what type of request it would be considered. Who should I contact? Contact dataoffice@dhhs.nc.gov

Appendix B. NCDHHS Terms and Conditions of Data Access and Use

Benefit to the community and the common good

Use of NCDHHS data should provide reasonable potential to benefit the community and the common good. Reasonable benefit to the community and the common good includes any questions that, when answered, provides direction for improving processes and/or outcomes for human service delivery, funding priorities, or policy development. The common good also includes the benefit of developing new knowledge and efforts leading to the development of evidence-based practice.

Requestor Credentials

NCDHHS employees have signed the **NCDHHS Data Use Confidentiality Agreement, and understand that ensuring the security and confidentiality of information about the people we serve is of critical importance to NCDHHS.**

Credentials for all requestors who are not NCDHHS employees or credentialed contractors must be evidenced by appropriate documentation (i.e., current professional role, CV or resume). As appropriate, NCDHHS Data Office will review credentials to determine whether the requestor has the appropriate credentials to access data, prior to approval.

Beyond NCDHHS employees and contractors, Data Use Agreements can only be granted to an appropriate agent from one of the following institutions: a governmental institution, an institution of higher education; an organization funding or providing services and programs related to NC government agencies; or a direct service provider that provides services to North Carolina residents.

IRB Approval

Research requests may require review and approval by an Institutional Review Board with jurisdiction to review the proposed project. If you are DPH staff engaged in research activities, you may be required to submit an application to DPH IRB.

Privacy and Confidentiality

Data released to the requestor must be kept secure and cannot be shared with unauthorized users. Data Senders and Data Recipients must comply with all DUA provisions.

Data Recipient responsibilities before disseminating results

Data Recipients for Operational Purposes related to COVID-19 or Substance Use Disorder, and/or otherwise designated within the DUA, are required to share externally disseminated findings (any release external to NCDHHS) to the Data Office at least 5 working days prior to dissemination. The Data Office will communicate with the Communications Office prior to release.

Unless otherwise stipulated within the DUA, Data Recipients for Research Purposes are required to share findings to the Data Office at least 30 days prior to any public release. Data Office staff will confirm in writing that key findings have been reviewed prior to release.

Appendix C. NCDHHS Confidentiality Agreement

Ensuring the confidentiality of all health reports, records, and files containing patient names and other individually identifying or sensitive information is of critical importance to the North Carolina Department of Health and Human Services (NCDHHS). Breaches of confidentiality can undermine public trust in NCDHHS and thereby obstruct efforts to improve the health, safety, and well-being of North Carolinians.

The NCDHHS Data Office and the Information Technology Division (ITD) shall designate individual staff members ("designated staff members") who will be permitted to view, access, and/or use data belonging to other NCDHHS Divisions or offices (the "Owner") consistent with the terms of the Data Sharing Agreement (DSA) entered into by the Owner, the NCDHHS Data Office, and ITD and the Interdepartmental Memorandum of Understanding (IMOU) ("the Purpose"). Before a designated staff member may be given access to the Owner's data, the designated staff member shall sign the Confidentiality Agreement included within the NCDHHS PSO Acceptable Use for DHHS Resources and/or the form below. Copies of signed Confidentiality Agreements shall

be kept on file by the Employee Supervisor, NCDHHS Data Office, and/or ITD and shall be furnished to the Owner upon request.

The data to which the designated staff member will have access may include information that is confidential under State and federal law and regulations, including but not limited to the protections set forth in 45 C.F.R. parts 160 and 164, subparts A and E, ("the Privacy Rule"), 45 C.F.R. Parts 160, 162 and 164, subparts A and C ("the Security Rule"), the applicable provisions of the Health Information Technology for Economic and Clinical Health Act (HITECH), and N.C.G.S. §§ 75-65 and 75-66.

Confidentiality Agreement Acknowledgement:

- I understand that I may have access to Owner's data that is confidential under State or federal law. I will maintain the confidentiality of Owner's data in accordance with this
- agreement and applicable State and federal law as well as the requirements set forth in the NCDHHS Privacy and Security Policies and Manuals[8] and the NC Statewide Information Security Manual.[9] I understand that unauthorized access or disclosure may be a violation of State and/or federal law.
- I will limit my access and use of the Owner's data to that which is minimally necessary to accomplish the Purpose set forth in this agreement.
- I will keep any account credentials granted by the Owner private. I will not share my account credentials with other users or any unauthorized individual. I will neither request nor use another person's account credentials, other credentials, or other unauthorized means to access Owner's data.
- I will provide Owner with notice no later than twenty-four (24) hours from the termination of this agreement, my departure from employment with NCDHHS, or my assignment to different duties within NCDHHS that do not require access to Owner's data.
- I will provide Owner with notice of any violations of this confidentiality agreement, including suspected and confirmed privacy/security incidents or privacy/security breaches involving unauthorized access, use, disclosure, modification, or destruction of Owner's data, including a breach of any account credentials. Notice shall be provided within twenty-four (24) hours after the incident is first discovered.
- I understand that my failure to abide by the terms set forth in this Confidentiality Agreement may result in consequences that include, but are not limited to, the immediate termination of my access and/or the termination of the NCDHHS Data Office or ITD's access to the Owner's data.

By signing below, I affirm that I have read this Confidentiality Agreement and agree to be bound by the terms therein.

Print Name: _____

[8]Located at NCDHHS Privacy and Security Policies and Manuals

[9]Located at NC Statewide Information Security Policies

Signature: _____

Date: _____

Division / Office: _____

Supervisor: _____

Appendix D: NCDHHS Artificial Intelligence (AI) Governance Charter and AI Strategy – Brief Summary

The North Carolina Department of Health and Human Services (NCDHHS) is advancing a structured and responsible approach to Artificial Intelligence (AI) adoption through an AI Governance Charter and enterprise AI Strategy. These efforts are intended to support innovation while protecting privacy, strengthening public trust, and ensuring alignment with departmental and State priorities.

NCDHHS AI Governance Charter – Purpose and Approach

The AI Governance Charter establishes the foundational governance model for evaluating, approving, monitoring, and overseeing AI use across NCDHHS. The charter is designed to ensure AI technologies are implemented in a manner that is:

- **Human-centered and mission-aligned with improving health and human services outcomes.**
- **Ethical and accountable, with clear ownership, oversight responsibilities, and decision authority.**
- **Secure and privacy-preserving, protecting sensitive and regulated data assets.**
- **Transparent and explainable, enabling appropriate documentation of AI-supported decisions.**
- **Risk-based and compliant, incorporating legal, security, procurement, and operational review processes.**
- **Integrated with enterprise data governance, leveraging existing data stewardship and data-sharing practices.**

The governance structure supports enterprise visibility into AI initiatives and establishes mechanisms for intake, review, monitoring, and continuous improvement of AI-enabled capabilities.

NCDHHS AI Strategy – Strategic Direction

The NCDHHS AI Strategy provides a roadmap for the responsible adoption of AI to enhance operational effectiveness and improve service delivery outcomes. The strategy aligns with the department's broader goals of operational excellence and data-driven decision-making.

Key strategic focus areas include:

1. Responsible AI Adoption – Enable innovation while maintaining governance, compliance, and public trust.
2. Data and Technology Readiness – Strengthen data quality, interoperability, infrastructure, and lifecycle management to support AI use.
3. Workforce Enablement – Build AI literacy and equip employees with training, guidance, and approved usage practices.
4. Risk and Compliance Management – Incorporate privacy, cybersecurity, procurement, and regulatory controls into AI deployment.
5. Operational Value and Outcomes – Prioritize AI use cases that improve efficiency, decision support, customer experience, and measurable public value.

For purposes of the Data Sharing Guidebook, AI governance should be considered an extension of NCDHHS's existing enterprise data governance and data-sharing framework, ensuring that AI use remains compliant, secure, transparent, and aligned with agency mission objectives.

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