

NC DEPARTMENT OF
HEALTH AND HUMAN SERVICES

Data Sharing Guidebook
May 2022

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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:

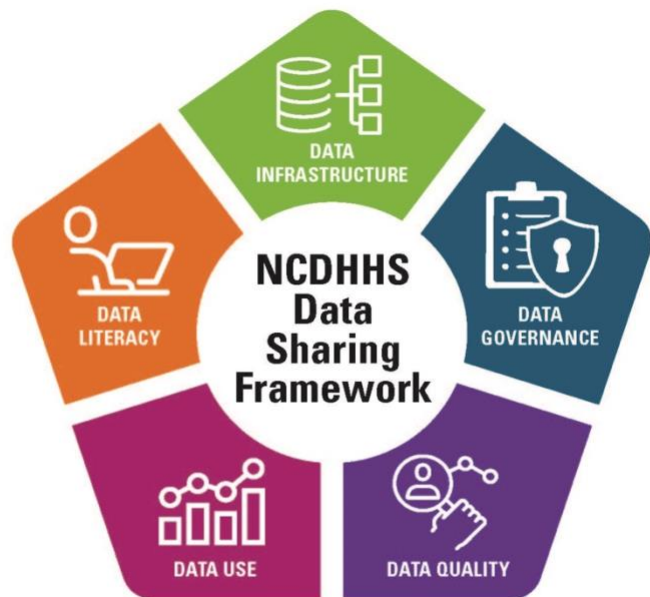
- Establish clear pathways for data sharing and integration, for requestors and data owners
- Establish a common legal framework for data sharing and integration across NCDHHS
- Support data use that leads to improved data quality, insights, and improvements
- Clarify processes to reduce burden on staff 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.¹

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 risk, and therefore requires more oversight, it is essential for understanding multi-service involvement.

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.



¹ See [NCDHHS Data Strategy, 2019](#)

Requestor for Data Access and Use	Data sharing and integration needed to...
Epidemiologist with local Health Department	...Evaluate the health outcomes related to a local policy that has been implemented
Epidemiologist within NCDHHS DPH	...Better understand effects of county-based restrictions on rates of infection
Community Collaborative	...Better understand population-level outcomes for NC residents
Community advocate	...Better understand the lived experiences of NC residents
Program evaluator	...Evaluate the effectiveness of a program
Director of a large regional non-profit	...Better understand the backgrounds, experiences, and future outcomes of service recipients
University-based researcher	...Better understand whether certain characteristics or experiences are predictive of later outcomes
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
Staffer at the Governor's Policy Office	...Draft a strategy to target new investments in X for the residents who are most in need of support

Data Access and Use Across NCDHHS

How to Use This Guidebook

This Guidebook has been created by NCDHHS staff 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 be continually improved with your help. Most importantly, **this document is not meant to be read cover to cover, but used as needed based upon your role.**

Data Use Priorities

The Department of Health and Human Services works to advance the health, safety, and well-being of all North Carolinians in collaboration with a wide array of partners and stakeholders. 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.²

Any request or permission for data access and use should be aligned with NCDHHS goals.

NCDHHS Goals as of 2021 are to:

- 1) Advance health equity by reducing disparities in opportunity and outcomes for historically marginalized populations within DHHS and across the state.
- 2) Help North Carolinians control the spread of COVID-19, recover stronger, and be prepared for future public health crises with an emphasis on initiatives serving those communities most impacted.
- 3) Build an innovative, coordinated, and wholeperson — physical, mental and social health — centered system that addresses both medical and non-medical drivers of health.
- 4) Turn the tide on North Carolina's opioid and substance use crisis.
- 5) Improve child and family well-being so all children have the opportunity to develop to their full potential and thrive.
- 6) Support individuals with disabilities and older adults in leading safe, healthy and fulfilling lives.
- 7) Achieve operational excellence by living our values – belonging, joy, people-focused, proactive communication, stewardship, teamwork, and transparency.

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

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 below and [NCDHHS Open Data Assets](#).

If the data are not publicly available,

- 1) Determine if there is a Division specific request process (below), and follow that process.
- 1) If you are unsure of the Division/Office, or requesting data from multiple Divisions or Offices, please contact dataoffice@dhhs.nc.gov.

² See [NCDHHS Strategic Plan, 2021-2023](#)

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: <https://www.ncdhhs.gov/Divisions/daas/data-reports>

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

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. Sections include: Early Intervention, Community Nutrition,

Early Intervention Section:

Publicly available data: n/a as of Q2 2022

Data request process: Data requests should be made via email to the Early Intervention Section Part C Data Manager or to the Part C Director. Contact information can be found at: <https://beearly.nc.gov/index.php/contact/central-office>

Community Nutrition Section:

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

Publicly available data: <https://www.nutritionnc.com/nutrsurv.htm>

Data request process: Request 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: <https://www.nutritionnc.com/snp/resource.htm>

Data request process: Request 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 2022

Data request process: Request 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: n/a as of Q2 2022

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

School Health

Publicly available data: <https://publichealth.nc.gov/wch/doc/stats/18-19-SN-AnnualReport-Brochure-011420-FINAL-WEB.pdf>

<https://publichealth.nc.gov/wch/doc/aboutus/NCSHC-AnnualReport-FY2013-2018-WEB.pdf>

<https://publichealth.nc.gov/wch/families/pediatrichealth.htm>

<https://publichealth.nc.gov/wch/families/schoolhealth.htm>

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 2022

Data request process: Pursuant to DPH data request process

Child & Family Wellness

Publicly available data: n/a as of Q2 2022

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

Food Nutrition Services/SNAP:

Publicly available data: <https://www.ncdhhs.gov/divisions/social-services/program-statistics-and-reviews/fns-caseload-statistics-reports>
<https://ssw.unc.edu/ma/>

Data request process: DSS web, and request can be made to Food Nutrition Services Section by email.

Child Development and Early Education

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

Publicly available data: <https://ncchildcare.ncdhhs.gov/County/Child-Care-Snapshot/Child-Care-Statistical-Report>

Data request process: https://northchealth.az1.qualtrics.com/jfe/form/SV_9BUtBqXVZvYL6yp
Contact, Justine.Rogoff@dhhs.nc.gov

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 2022

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

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: <https://medicaid.ncdhhs.gov/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.

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: <https://info.ncdhhs.gov/dhsr/index.html>

Data request process: Data request 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.

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: https://www.ncdhhs.gov/Divisions/mhddsas/reports/annual_statistical_reports

Data request process: For Controlled Substances Reporting System:
<https://www.ncdhhs.gov/Divisions/mhddsas/ncdcu/csrs/deidentification-documents>
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 2022

Data request process: Request 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: <https://schs.dph.ncdhhs.gov/data/minority.cfm>
<http://nc.maps.arcgis.com/apps/MapSeries/index.html?appid=def612b7025b44eaa1e0d7af43f4702b>

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

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: <https://www.ncdhhs.gov/Divisions/office-rural-health/office-rural-health-programs/analytics-and-innovations-program/health>

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

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: <https://schs.dph.ncdhhs.gov/>
<https://epi.dph.ncdhhs.gov/oeefigures.html>
<https://ncdetect.org/dashboard/>

Data request process: <https://schs.dph.ncdhhs.gov/data/faqs.htm>
<https://ivp.ncpublichealth.com/DataSurveillance/DataRequestPolicy.htm>
<https://www.ocme.dhhs.nc.gov/docrequest.asp>
<https://ncdetect.org/data-requests-for-applied-public-health-research/>
For all other data requests, please contact, Kirsten Leloudis, Policy and Legal Specialist, NC DPH Office of Regulatory and Legal Affairs, Kirsten.leloudis@dhhs.nc.gov

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: <https://www.ncdhhs.gov/divisions/services-blind/reports-and-publications>

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

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 2022

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

Social Services

The Division of Social Services (DSS) provides direct services that address issues of poverty, family violence, and exploitation. The Division aims to prevent abuse, neglect, and exploitation of vulnerable citizens, and promote self-reliance and self-sufficiency for individuals and families.

Publicly available data: <https://www.ncdhhs.gov/Divisions/social-services/program-statistics-and-reviews>

Data request process: External Requests, <https://www.ncdhhs.gov/Divisions/dss/social-services-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, CWSDDataRequests@dhhs.nc.gov

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: <https://www.ncdhhs.gov/documents/facility-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 2021

Data request process: <https://www.ncdhhs.gov/divisions/vocational-rehabilitation-services/vocational-rehabilitation-information-request>

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. The majority of requests made by NCDHHS staff will be operational requests. If there are any questions, please contact dataoffice@dhhs.nc.gov.

Operational Request

Request 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.

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 Data Use Agreement (DUA) may be necessary depending on the source, purpose, and data output.

Extract of Dashboard

Request for extract of dashboard data that are publicly available (have been shared previously) and not downloadable online. E.g., daily numbers over time

Data request process: Email dashboard specific data contact (listed on dashboard) or dataoffice@dhhs.nc.gov if not listed. See [Data Dashboard Request Form](#).

Legal considerations: No agreement is necessary if data underlying the dashboard are considered public record.

Research Purposes

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. Please 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.

³ See 45 CFR 46, the “[Common Rule](#).”

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. The requestor does not have to provide a statement of purpose for the request. There are no restrictions placed on the use of records, and there is no time limit for a response. NCGS §132-6 states that a custodian of public records shall make the records available "at reasonable times and under reasonable supervision by any person, and shall, as promptly as possible, furnish copies thereof upon payment of any fees as may be prescribed by law."

Specifically, any 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.

If the public records request involves any analysis (e.g. any data manipulation beyond a data system query of existing record held within NCDHHS servers), then data access may be permissible but not required. 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.

Data request process: Please 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: Please 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 on behalf of the NC Department of Justice, and/or on behalf of a legal team.

Data request process: Please 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 children and youth

If a request involves integrated data related to children ages 0 – 5, please contact the [Early Childhood Integrated Data System \(ECIDS\)](#).

If a request involves the integration of early childhood data, student data, and workforce data, please contact the Education Longitudinal Data System (ELDS), through the [Government Data Analytics Center \(GDAC\)](#).

Data Being Requested

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 counts by specified subgroup / population / geography from a single Division/Office
- B. **Linked and** aggregated data by specified subgroup / population / geography from multiple Divisions/Offices

2. Row level

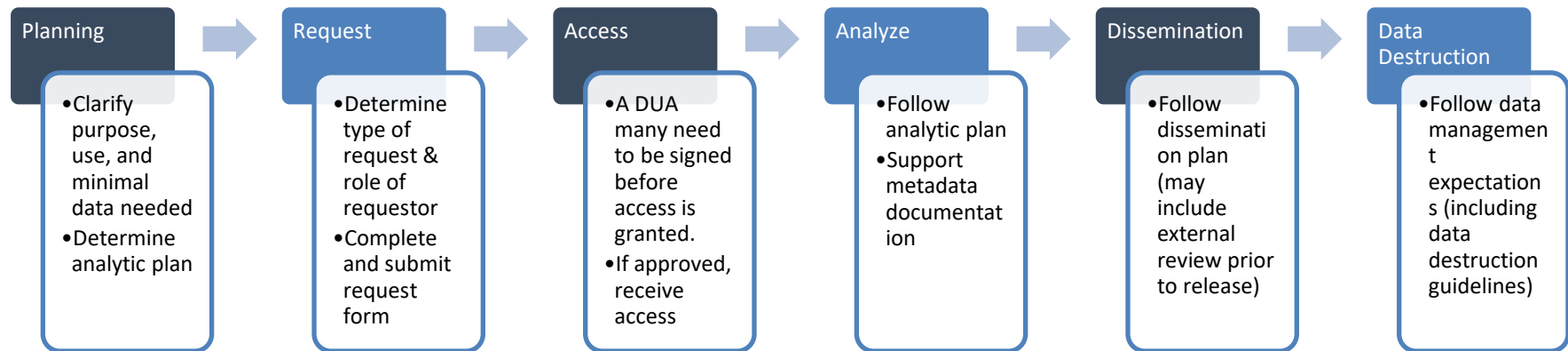
- A. Row level data that has been de-identified
- B. Row level data with identifiers
- C. Underlying source data that has not been curated or manipulated (e.g. for data management or audit purposes)

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

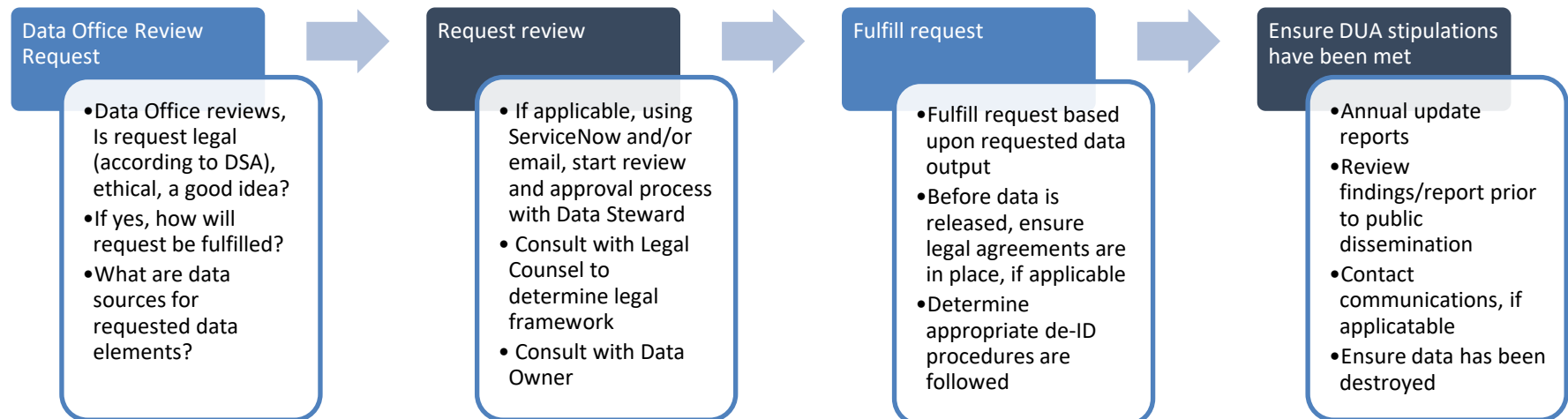
Data Request Processes

Data Request Process for Requestors



Data 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*



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. What role(s) are you in?

Data Owner (or Designee)

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 Data Asset Inventory.

Role: Department, Division, Office Leadership

Data are defined to be 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

Data Steward

Responsible for the governance of data (including: transfer, alteration, storage, retention, disposition, classification, etc.). This includes 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.

Role: Analyst, Epidemiologist

Data Custodian

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 Your Role Supports Data Access and Use

Based on your role, there are clear ways that you can support data sharing, access, and use across the Department.

As a data owner,

- Establish clear delineation of roles across your Division/Office, including data owner or designee (for certain data sets) and data stewards within the [NCDHHS Data Asset Inventory](#), to be reviewed annually
- Ensure that data stewards and data custodians are sufficiently resourced
- Staff training and management that supports strong communication practices to ensure ethical data access and use
- Commit to transparency and continuous improvement
- Participate in data governance processes or designate a proxy

As a data steward,

- 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,

- Adherence to data management best practices and policies and processes set forth in the [DHHS Security Manual](#) and the [DIT Statewide Information Security Policies](#), 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
- 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 Division or PSO Official,

- 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,

- Maintain list of high value data assets, 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 data requestor,

- Support [NCDHHS Data Use Priorities](#)
- Request minimum data needed for inquiry
- Adhere to [NCDHHS Terms and Conditions of Data Use](#) (see Appendix B)
- 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 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 by the public
- 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	Protected data (Y/N)
Division/Office	PHI 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. At a minimum, this report should include requestor name, institution, date of request, date of receipt of data, and description of data provided to requestor. The purpose of this summary report is to better understand how data is accessed and used across the Department as a whole, while not interrupting Division and Office specific requests.

To update the inventory or submit the year end 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 [NCDHHS 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.

Open (Public, or low risk)	Restricted (Confidential, medium or high risk)	Unavailable (highly restricted, high risk)
Can be shared without Data Sharing Agreement	May require Data Sharing Agreement(s)	
Data that can be shared openly, either at the aggregate or individual level, based on state and federal law. These data often exist in open data portals or in data reports.	Data that can be shared, but only under specific circumstances with appropriate safeguards in place.	Data that cannot or should not be shared, either because of state or federal law, lack of digital format (paper copies only), or due to data quality or other concerns.

Data Classification Categories for Purposes of Sharing

Open Data, can be shared without an agreement (low risk data)	Data can be shared with agreement and approval through governance (medium and high risk data)
Technology and/or data structure limits ability to share data	Not shareable (highly restricted, high risk data)

When thinking about the legality of data sharing, access, and use, there is typically not a clear 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 are able to be accessed and used, if 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.

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.

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

Why do you want to share the data?

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

What type of data do you want to share?

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

Who do you want to share it with?

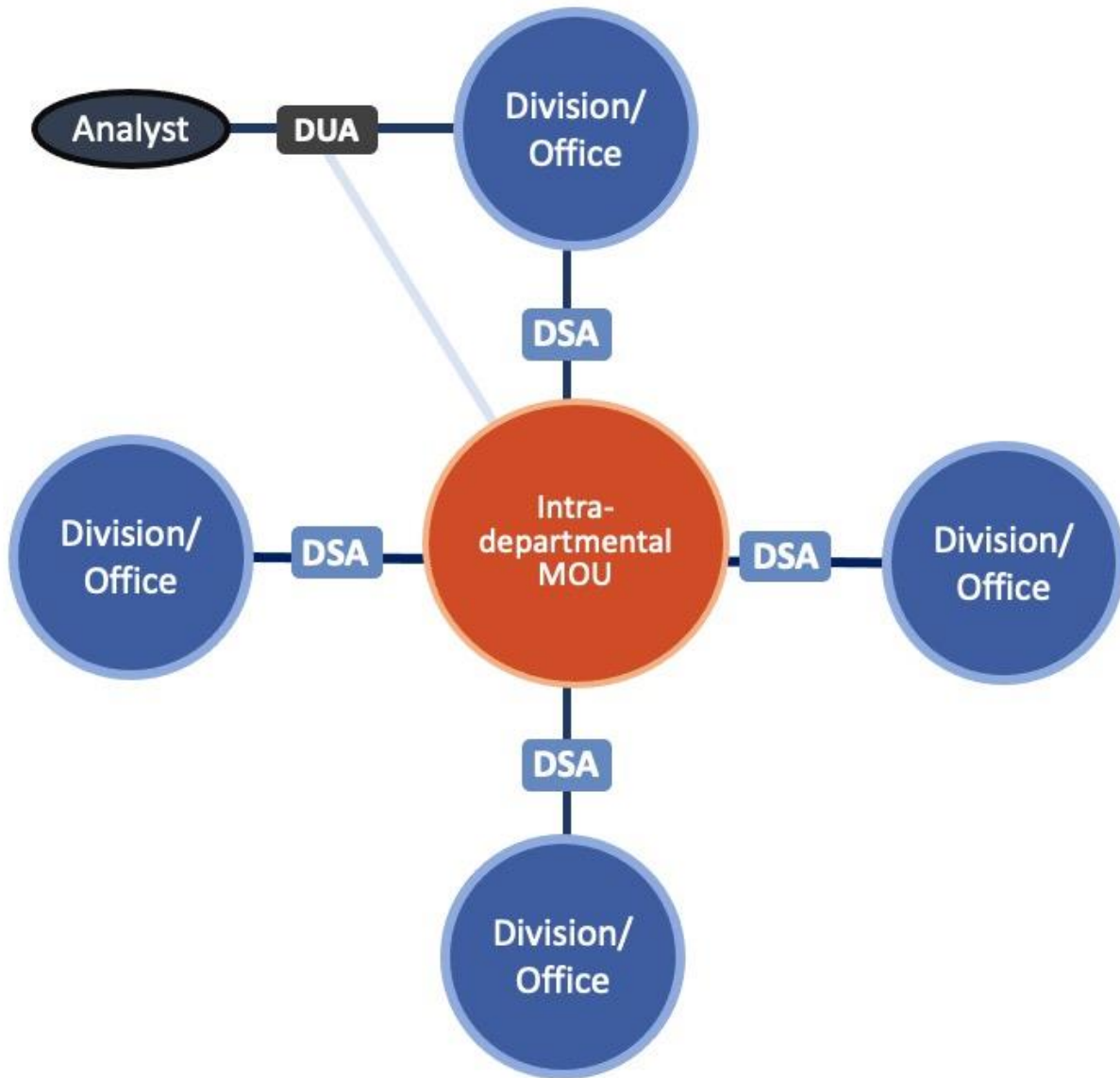
- NCDHHS staff for operational purposes?
- University-based researcher?
- Local health department?

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:** 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.](#))
 - Signatories: NCDHHS and Business Associate
- **Non-Disclosure Agreement:** Outlines permissible disclosures of confidential data and information between a third-party and NCDHHS, typically for operational purposes.
 - Signatories: NCDHHS + individual/company under contract for services
- **Data Use Agreement:** Contract that outlines permissible data use and disclosure for specific purposes.
 - Signatories: NCDHHS Data Owner(s) + data recipient
- **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.
 - Signatories: Use dependent. E.g., NCDHHS (Division/Office administering program) + Individual; Researcher requesting identifiable NCDHHS data + Individual
- **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.
 - Signatories: The individual who is authorizing the release of the individual's own HIPAA-covered information

The following intradepartmental legal agreements will be used to govern data access and use **across** NCDHHS Divisions and Offices, with the goal of executing agreements and finalizing DUA template by Winter 2021. **Please 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 <i>Overarching process document signed on by all Divisions / Offices</i>	<p>The IMOU documents the purpose and governance process. The IMOU will be signed by all data partners as they enter the collaboration. The IMOU references the data sharing agreement, data use agreements, policies, and procedures for data access and use, e.g. NCDHHS Data Sharing Guidebook.</p>	<p>Drafted by Data Office + reviewed by legal counsel, signed, and updated through the NCDHHS Data Governance Council as needed.</p>	<p>All Division and Office Directors and Secretary's Office</p>
Data Sharing Agreement <i>Division / Office Specific</i>	<p>The DSA includes the specific terms and conditions that govern how division and office specific data are transferred, stored, and managed when shared and integrated across the Department. The DSA references the IMOU and the DUA. This document is specific to division and office held data.</p>	<p>Drafted by Data Office + Division/Office specific legal counsel. Reviewed and updated annually, or as agreed upon.</p>	<p>Each Division and Office Director + Data Office + ITD</p>
Data Use Agreement <i>Data Request Specific</i>	<p>Legal counsel determines if DUA is needed for specific request. The DUA outlines the role and responsibilities of the data recipient. If applicable, this document is attached to the Data Request Form, which includes relevant fields, depending on the request, including: purpose, data fields, anonymization procedures, dissemination plan, and timeline of project completion. A DUA must be executed prior to data access.</p>	<p>Data request is identified by type and reviewed appropriately based upon the type of request. Legal counsel determines if DUA is applicable. If request is approved, a Data Use Agreement is executed.</p>	<p>Data recipient + Data owners (if applicable)</p>

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 are covered entities. This means that not all data owned by NCDHHS is subject to the requirements established under HIPAA.

NCDHHS Covered Entities	NCDHHS Non-Covered Entities	NCDHHS Hybrid Entities
Division of Health Benefits	Division of Services for the Blind	Division of Public Health, includes Healthcare Provider, Health Plan, and Clearinghouse components and Internal Business Associate
Office of Rural Health and Community Care	Division of Child Development and Early Education	Division of Aging and Adult Services, Internal Business Associate
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	NC Council on Developmental Disabilities	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 Budget and Analysis	
Office of Communications	Office of Human Resources	
Office of the Internal Audit	Office of Procurement, Contracts, and Grants	
Office of the General Counsel	Office of Property and Construction	
Office of Government Affairs	Disability Determination Services	
Office of the Secretary		
Privacy and Security Office		
NCFAST		

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 specific restrictions and allowances of data sharing access and use.

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 and Data Steward, when considering a request for data access and use, it is important to consider [Appendix B, NCDHHS Terms and Conditions of Data Access and Use](#), and the following:

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. 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 racial equity and racial bias need to be considered in this request?
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?

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. Although not all data held by NCDHHS is covered by HIPAA, HIPAA standards are often used as a best practice. Data not covered by HIPAA may be de-identified in another way. Under HIPAA there are three types of data sets: de-identified, limited, and identified. All are potentially permissible, depending upon the request.

Please check with the Data Steward and Division Legal Counsel regarding appropriate deidentification standards for a particular data set.

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

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.

Data Transfer

The method for transferring data will depend upon whether data are **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 secure 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 that recipient is authorized to receive these data

Technical Approach	File Size Limits	Security Considerations	Other Considerations
Email (@dhhs.nc.gov)	150Mb	Open, or publicly available data only	One-off requests, not preferred. Please store appropriately.
Encrypted email (@dhhs.nc.gov)	150Mb (may be less based on encryption server like ZixMail)	Ensure that restricted or confidential data are encrypted as per NCDHHS policy. File should also be password protected.	One-off requests, not preferred. Please store appropriately once transferred.
Google Drive	5Tb	Only the use of state owned 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	
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 https://files.nc.gov/ncdit/documents/Statewide_Policies/SCIO_Media_Protection.pdf	e.g., courier of USB drive (if using courier, please add tracking receipt)

*Please 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 **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 secure 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 the advice of the appropriate Data Custodian (e.g. ITD / DIT staff) to determine appropriate data storage.

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.	
Microsoft Office 365 OneDrive	100Gb, total up to 1Tb per user	Not 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 Data Custodian, data can be loaded into appropriate database after secure transfer.	Preferred approach

Please discuss storage options with the appropriate Data Custodian (e.g. ITD / DIT staff) to ensure that best practices are being followed.

See: <https://files.nc.gov/dit/documents/files/Secure-Cloud-Storage-Policy.pdf>;
https://files.nc.gov/dit/documents/files/Secure%20Cloud%20Storage%20and%20File%20Sharing_Phase%20II.pdf; and <https://it.nc.gov/media/1545/open>

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. Your request may be allowable without a specific Data Use Agreement within the terms of the NCDHHS Intradepartmental MOU and the Division and Office Data Sharing Agreements.

Q: I'm under contract with NCDHHS and need access to data to fulfill my scope of work. What do I do?

A: You will need to submit an [Operational Data Request Form](#) to dataoffice@dhhs.nc.gov.

Q: I'm submitting a [Research Data Request Form](#), but I only want to use de-identified administrative data. Do I need to submit an IRB application?

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 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. Please forward to public.records@dhhs.nc.gov.

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](#)). Requestors can request access to historical data from a public dashboard by submitting a [Data Dashboard Request Form](#) to dataoffice@dhhs.nc.gov.

Q: I want to access historical data from a public facing dashboard. What do I do?

A: Submit a [Data Dashboard Request Form](#) to dataoffice@dhhs.nc.gov.

Terms

The following terms are commonly used and defined 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*

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*

Appendix

Appendix A: Questions to Guide Data Request Pathways

If you have a data request, please 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, please 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?⁴**

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. Please contact dataoffice@dhhs.nc.gov

If no, proceed to Q4.

4. **Is this request for extracts of dashboard data that are publicly available and not downloadable online (e.g., at <https://covid19.ncdhhs.gov/dashboard/about-data>)?**

If yes, please contact dataoffice@dhhs.nc.gov and see [Data Dashboard Request Form](#).

If no, proceed to Q5.

5. **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, please 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 Q6.

⁴ 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.

6. 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.

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

If no, proceed to Q7.

7. 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, please contact DHHSlegislativeaffairs@dhhs.nc.gov

If no, proceed to Q8.

8. 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, please contact the relevant Legal Counsel

If no, proceed to Q9.

9. 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, please contact ECIDS, <https://www.ecids.nc.gov/ecids/ecids/researchers/datarequests>

Y N Is this request related to the integration of Early Childhood Data, Student Data, and Workforce Data? If yes, please contact ELDS, through GDAC, <https://it.nc.gov/services/data-analytics/nc-government-data-analytics-center>

10. 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?

Please 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 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 is not to be shared with unauthorized users. 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 hinder 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 Manuals⁵ and the NC Statewide Information Security Manual.⁶ 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

⁵ Located at <https://policies.ncdhhs.gov/departmental/policies-manuals/section-viii-privacy-and-security/manuals>

⁶ Located at <https://it.nc.gov/statewide-information-security-policies>

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: _____

Signature: _____

Date: _____

**Division /
Office:** _____

Supervisor: _____