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| North Carolina Department of Health and Human Services |

# NCDHHS Research[[1]](#footnote-1) Data Request Form

NCDHHS strives to provide accurate and timely data to enable legal, ethical (including fair data practices), actionable, and beneficial data use. Not all research requests will be approved. Some research requests may be rejected, postponed, or take longer than expected in accordance with the Department’s core responsibilities, priorities, and resource limitations.

**Submit this form and any questions by email to dataoffice@dhhs.nc.gov**

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| **Internal Use. Request #:**  |

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| **1. Does this research request align with NCDHHS priorities?**  |
| [ ]  Yes  | [ ]  No  | [ ]  Unsure  |

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| **2. Has this study been approved by an Institutional Review Board? [[2]](#footnote-2)**  |
| [ ]  Yes, an IRB approved this study and a copy of the application, materials, and determination letter is attached.  |
| [ ]  No, an IRB has not approved this study, but I have submitted an application (attached).  |
| [ ]  Other, (please specify): Click or tap here to enter text. |

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| **3. Requestor’s Contact Information** |
| Name of Requestor:  | Click or tap here to enter text. |
| Title / Role:  | Click or tap here to enter text. |
| Institution:  | Click or tap here to enter text. |
| Phone number:  | Click or tap here to enter text.  | Email: Click or tap here to enter text.  |
| I have read and agree to the [NCDHHS Terms and Conditions of Data Use](https://www.ncdhhs.gov/appendix-bncdhhs-terms-and-conditions-data-access-and-usepdf/open).  |  Yes [ ]  |
| My CV or resume is attached to this request |  Yes [ ]  |
| I understand that a Data Use Agreement will need to be executed prior to receipt of requested data. I understand that the DUA must be signed by an individual at my institution with signatory authority.  |  Yes [ ]  |
|  I understand that a fee may be charged for fulfilling this research data request. If applicable, I will be provided with a fee estimate prior to the fulfillment of request. |  Yes [ ]  |

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| **4. Description of the Requested Data** |

How often does the Recipient want to receive the data?

 [ ]  This will be a one-time provision of data

 [ ]  Daily [ ]  Weekly [ ]  Monthly [ ]  Quarterly [ ]  Annual

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| [ ]  Other  |  |

What is the date by which you would like to receive the requested data? (e.g. by 6/15/24)

By date: Click or tap to enter a date.

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| **Please list the data elements that are being requested in the table below.**  |
| **Time period** | **Data element** | **Description/Notes** | ***Data Source (INTERNAL)*** |
| *E.g., from 3/1/2020 to 10/1/2020* | *E.g., total COVID-19 test results*  | *E.g., Total count of COVID-19 test results (negative, positive, undetermined)*  |  |
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(please add rows as needed)

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| **5. What is the requested data format?**  |
| [ ]  | CSV  | [ ]  | Excel | [ ]  | Access to Dashboard |
| [ ]  | I’m not sure. I would need to discuss my data request with someone.  | [ ]  | Other: (please specify) Click or tap here to enter text. |

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| **6. What is your requested data output?** Please note that informed consent or waiver is required for release of identifiable data. |
| a. **Aggregate, *Data Use Agreement may still be required*** |
| [ ]  | Aggregated data by specified subgroup / population / geography from a single division/office |
| [ ]  | Aggregated data by specified subgroup / population / geography from multiple divisions/offices |
| [ ]  | **Linked and** aggregated data by specified subgroup / population / geography from multiple divisions/offices |
| b. **Row level, *Data Use Agreement may still be required, even if anonymized or pseudonymized*** |
| [ ]  | Row level data that has been de-identified |
| [ ]  | Row level data with identifiers  |
| c. **Integrated Row level, *Data Use Agreement may still be required, even if anonymized or pseudonymized*** |
| [ ]  | Row level data **without** identifiers linked with another data source **owned** by NCDHHS **linked within** NCDHHS data infrastructure  |
| [ ]  | Row level data with identifiers, linked with another data source **owned** by NCDHHS **linked within** NCDHHS data infrastructure |
| [ ]  | Row level data with identifiers to link with another data source **owned by** NCDHHS **linked outside** of NCDHHS data infrastructure  |
| [ ]  | Row level data with identifiers to link with another data source **not owned** by NCDHHS, **linked within** NCDHHS data infrastructure |
| [ ]   | Row level data with identifiers to link with another data source **not owned** by NCDHHS, **linked outside** of NCDHHS data infrastructure |

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| **7. If you have requested identifiable data,** |
| [ ]  | I have obtained written informed consent and if applicable, HIPAA authorization, from every person whose data is included in the requested data set. I am able to provide NCDHHS with copies of informed consents and HIPAA authorizations upon request.  |
| [ ]  | An IRB has approved a waiver of HIPAA authorization for this request in accordance with 45 CFR § 164.512, attached.  |
| [ ]  | An IRB has approved a waiver of informed consent for this project, attached.  |
| **8. What is the purpose of this request? What are you trying to understand better? What generalizable body of knowledge are you contributing to? How will this benefit the residents of NC?**  |

Click or tap here to enter text.

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| **9. Please describe the security characteristics of the location where the NCDHHS data will be stored** (e.g. physical and technical safeguards, encryption applied to transmissions as well as files at rest, etc.). |

Click or tap here to enter text.

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| **10. How will you address issues of data equity and bias within this research?**  |

Click or tap here to enter text.

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| **11. How will you ensure that privacy risks of re-disclosure or re-identification are mitigated?**  |

Click or tap here to enter text.

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| **12. How will the findings from this research be used and disseminated?** |

Click or tap here to enter text.

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| **Data Recipient Agreement** |

I have reviewed and agree to the [NCDHHS Terms and Conditions of Data Use](https://www.ncdhhs.gov/appendix-bncdhhs-terms-and-conditions-data-access-and-usepdf/open). I agree to regularly communicate with NCDHHS Data Office Staff and promptly respond to any questions or concerns. I agree to only use data as described in this request. I agree to report promptly to Data Office Staff all problems or any incident with possible adverse events involving NCDHHS data.

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|  Click or tap here to enter text. |  Click or tap to enter a date.  |

Signature of Data Recipient (electronic signature is permissible) Signature Date

\* *Note that a signed Data Use Agreement may also be executed prior to the release of any data pursuant to this request.*

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| **Complete below to begin the process of developing a Data Use Agreement** |

1. What is the desired DUA effective date? Click or tap to enter a date.

 2. Is there a funding, publishing, or other deadline related to the desired effective date? If yes, please explain:

 3. Names of principal research and co-investigators, as well as anyone else who will have access to the data:

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|  Name:  |  |  Role:  |  |
|  Institution:  |   |  Email:  |   |
|  Name:  |   |  Role:  |   |
|  Institution:  |   |  Email:  |   |
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|  Institution:  |   |  Email:  |  |
|  Name:  |   |  Role:  |  |
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*Add additional names as necessary.*

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|  4. Expected project completion date: | Click or tap to enter a date.  |

5. Name and title of the authorized signatory official who will sign the DUA:

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| *Name* |
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| *Title* |
| *Email & Mailing Address* |

1. 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](https://www.ecfr.gov/cgi-bin/text-idx?tpl=/ecfrbrowse/Title45/45cfr46_main_02.tpl)). 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. [↑](#footnote-ref-1)
2. If you are DPH staff engaged in research activities, then you may need to submit an application to DPH IRB. [↑](#footnote-ref-2)