

The Linked Information Network of Colorado

Data Use License

1. Preamble

This Data Use License (“DUL”) is entered as of _____ (the “Effective Date”) by _____ (“LINC Data Recipient”).

This DUL addresses the conditions under which the Colorado Governor’s Office of Information Technology (“OIT”) will disclose, and the LINC Data Recipient may use, the Anonymized Data for LINC Projects specified in this DUL and/or any derivative file(s) (collectively, the “LINC Project Data”). The terms of this DUL are consistent with those in the LINC Enterprise Memorandum of Understanding (EMOU) and can be changed only by a written and signed amendment to this DUL or by terminating this DUL and entering a new DUL, after approval by the LINC Review Committee.

Definitions

- a. Anonymized Data: Integrated data that do not include Personal Identifiers. The specific set of Personal Identifiers that must be removed from Anonymized Data are established by each LINC Data Provider in a separate legal agreement with OIT. LINC will use the most restrictive definition of Anonymized Data among all LINC Data Providers contributing data to the LINC Project in this DUL.
- b. Authorized Personnel: The members of the LINC Data Recipient team who have been listed in this DUL as having approved access to the LINC Project data and agree to abide by the terms of this DUL.
- c. LINC Data Provider: An organization that has direct responsibility for a source of data contributed to the approved LINC Project. This may be an Office or Division of a larger organization, in other cases it may be the organization itself.
- d. LINC Data Recipient: The individual or organization that made the approved LINC request for data analysis, research, or evaluation purposes. The LINC Data Recipient will be an employee from a LINC Party or an external researcher.
- e. LINC Director: The individual who is responsible for facilitating LINC committees, developing and managing partnerships with Party organizations, overseeing LINC staff, consulting with data requestors, monitoring LINC Projects, and managing the inventory of documents associated with LINC operations and LINC Projects.
- f. LINC Project: A project approved by the LINC Review Committee that is analytic, research or evaluative in nature. A LINC Project requires data from two or more Data Providers and must be achievable by LINC Data Recipients with Anonymized Data.
- g. LINC Project Data: Anonymized Data for use by the LINC Data Recipient. These data are only to be used for the approved purposes outlined in the approved LINC Request Form.

- h. LINC Request Form: The document that is reviewed by the LINC Review Committee for approval, revision or rejection decisions. The approved LINC Request Form is attached to this DUL as Exhibit 1.
- i. LINC Review Committee: The committee composed of representatives from each LINC Data Provider with program or policy expertise and data expertise. At least one of these representatives must have decision-making authority over the use of their data.
- j. Personal Identifiers: Any information about an individual that can directly or indirectly distinguish or trace an individual's identity, associate or link an individual to private information, distinguish one person from another, or be used to re-identify individuals.

Financial Understanding

The LINC Data Recipient agrees to pay a fee of _____ to be invoiced upon secure transfer of the LINC Project Data. Payment is expected to be executed within 30 days of receipt of invoice.

2. Permitted LINC Project: Approved Use and Data Elements

This DUL pertains to the LINC Project _____ This LINC Project was approved by the LINC Review Committee on _____ and the approved LINC Request Form is attached and incorporated into this DUL as Exhibit 1. The approved LINC Request Form details the permitted use of the LINC Project Data as well as the approved data elements to be included in the LINC Project Data.

The LINC Data Recipient shall not use the LINC Project Data for any purpose independent of, separate from or not directly connected to the purpose(s) specifically approved by the LINC Review Committee. The LINC Data Recipient shall only receive Anonymized Data and will not be permitted to receive any Personal Identifiers.

3. Data Ownership and Accuracy

LINC Data Recipient acknowledges that LINC Data Recipient has no ownership rights with respect to the LINC Project Data, and that the LINC Data Recipient may only receive and use the LINC Project Data for the purposes approved by the LINC Review Committee.

The LINC Project Data is current as of the date and time compiled and can change. The LINC Data Providers do not ensure 100% accuracy of all records and fields. Some data fields may contain incorrect or incomplete data. OIT and LINC Data Providers cannot commit resources to explain or validate complex matching and cross-referencing programs. LINC Data Recipient accepts the quality of the data they receive. Questions related to LINC Project Data completeness (i.e., approved data elements in the attached Exhibit 1 were received) or matching accuracy shall be sent to the LINC Director within sixty (60) days of receipt. Data that has been manipulated or reprocessed by the LINC Data Recipient is the responsibility of the LINC Data Recipient. OIT cannot commit resources to assist LINC Data Recipient with converting data to another format or answering questions about data that has been converted to another

format. Additional issues with the LINC Project Data shall be noted in the Regular Project Report(s) (described in Section 9 below).

4. Data Transfer

LINC Project Data will be transferred to the LINC Data Recipient through a Secure File Transfer Protocol (SFTP) provided or approved by OIT. The LINC Data Recipient will be provided secure access to the SFTP and will be allowed to download the LINC Project Data file(s) for a limited period of time after which access to the SFTP will be removed.

5. Safeguarding Data

Security Controls. The LINC Data Recipient shall implement and maintain the data security controls specified in the LINC Request Form (attached as Exhibit 1) that has been approved by the LINC Review Committee.

Re-Disclosure of Data. LINC Data Recipient shall not use the LINC Project Data for any purpose beyond that specified in Exhibit 1, attached hereto. Furthermore, LINC Data Recipient shall not use the LINC Project Data in an attempt to track individuals, link to an individual's data from other data sources, determine real or likely identities, gain information about an individual or contact any individual (or next-of-kin) who is the subject of the LINC Project. Re-disclosure of data shall result in the immediate suspension of the LINC Project and possible termination of the LINC Project by the LINC Review Committee. Furthermore, individuals engaging in re-disclosure of data will not be approved Authorized Personnel on future LINC Projects.

Cell Suppression Policy. The LINC Data Recipient agrees that any use of LINC Project Data in the creation of any dissemination materials (manuscript, table, chart, study, report, presentation, etc.) concerning the specified purpose must adhere to the cell size suppression policy as follows. This policy stipulates that no cell (e.g., grouping of individuals, patients, clients) with less than _____ observations may be displayed. This is the most stringent cell size allowable among the LINC Data Providers for the LINC Project specified in the approved LINC data request in Exhibit 1. Also, no use of percentages or other mathematical formulas may be used if they result in a cell displaying less than _____ observations. Individual level records may not be published in any form, electronic or printed. Reports and analytics must use complementary cell suppression techniques to ensure that cells with fewer than _____ observations cannot be identified by manipulating Data in adjacent rows, columns or other manipulations of any combination of dissemination materials generated through this LINC Project. Examples of such data elements include, but are not limited to, geography, age groupings, sex, or birth or death dates.

6. LINC Project Authorized Personnel

Any person or entity that processes or receives the LINC Project Data and its agents must be obligated, by contract, to adhere to the terms of this DUL and agree to follow the data security

controls approved in the attached Exhibit 1, prior to being granted access to LINC Project Data. The following named individuals, and only these individuals, will have access to the LINC Project Data. The LINC Data Recipient will submit a LINC Project Change Request to the LINC Director when an individual leaves the project. The LINC Data Recipient will obtain written approval from the LINC Director for additions to this list prior to granting access to LINC Project Data.

Name	Role	Organization

7. Accountability: Unauthorized Access, Use, or Disclosure

LINC Data Recipient shall take all steps necessary to identify any use or disclosure of LINC Project Data not authorized by this DUL. The LINC Data Recipient will report any unauthorized access, use or disclosure of the Data to OIT via the LINC Director within two business days from learning or should have learned of the unauthorized access, use, or disclosure. In the event that OIT determines or has a reasonable belief that the LINC Data Recipient has made or may have made use or disclosure of the LINC Project Data that is not authorized by this DUL, OIT may, at its sole discretion, require the LINC Data Recipient to perform one or more of the following, or such other actions as OIT, in its sole discretion, deems appropriate:

- a. promptly investigate and report to OIT the LINC Data Recipient's determinations regarding any alleged or actual unauthorized access, use, or disclosure;
- b. promptly resolve any issues or problems identified by the investigation;
- c. submit a formal response to an allegation of unauthorized access, use, or disclosure;
- d. submit a corrective action plan with steps designed to prevent any future unauthorized access, use, or disclosures; and
- e. return all LINC Project Data or destroy LINC Project Data it has received under this DUL.

The LINC Data Recipient understands that as a result of OIT's determination or reasonable belief that unauthorized access, use, or disclosures have taken place, OIT may refuse to release further LINC Project Data to the LINC Data Recipient for a period of time to be determined by OIT, in its sole discretion.

8. LINC Project Reporting Requirements

Regular Project Reports. LINC Data Recipients must submit Regular Project Reports to the LINC Review Committee, annually or at the midterm point of the project cycle, whichever comes first. The report shall be a standard form automatically distributed by the LINC Director or support staff and shall require:

- a. IRB approval documentation
- b. Summary of progress to date
 - How project is informing policy or practice
 - Description of anticipated and unanticipated findings
 - Description of challenges encountered and how they are being resolved
- c. Dissemination materials and key findings to date
- d. Project funding source (if applicable)

Change Requests. LINC Data Recipients will initiate, when necessary, a LINC Project change request. Minor requests (e.g., change in key personnel, a first-time extension of up to six months) will be reviewed by the LINC Director. Major requests (e.g., additional research questions; change in organization using data) will be reviewed by the LINC Review Committee.

Key Findings and Interpretations Release Request. LINC Data Recipients are required to share LINC Project findings to the LINC Review Committee prior to any public release. LINC Data Recipients shall submit key findings and interpretations in a standard format provided by the LINC Director or support staff. LINC Review Committee members shall confirm in writing, via a standard form provided by the LINC Director, that key findings have been reviewed and are ready for release. The LINC Review Committee members can request review of specific dissemination materials (e.g., presentations, publications).

LINC Acknowledgement. All publicly-released materials resulting from the LINC Project referenced in this DUL shall include the following acknowledgement: "This work would not be possible without anonymized data provided by the Linked Information Network of Colorado (LINC) in the Colorado Governor's Office of Information Technology. The findings do not necessarily reflect the opinions of the Colorado Governor's Office of Information Technology or the organizations contributing data."

Final Publication(s). The LINC Data Recipient shall provide the LINC Director with an electronic copy of all published work resulting from the LINC Project associated with this DUL within 30 days of publication.

9. Data Retention and Destruction

The LINC Data Recipient agrees to destroy all LINC Project Data by the approved LINC Project end date, in accordance with the “Guidance to Render Unsecured Protected Health Information Unusable, Unreadable, or Indecipherable to Unauthorized Individuals,” as established by the U.S. Department of Health and Human Services (HHS). The LINC Data Recipient may request an extension of the Data Retention Period by submitting a written request that includes justification to the LINC Review Committee via the LINC Director. This extension request must be submitted 30 days prior to the LINC Project end date.

When retention of the LINC Project Data is no longer justified, the LINC Data Recipient agrees to destroy the Data and send a completed “Certification of Project Completion & Destruction of Data” form (Attachment 1 to this Agreement) to OIT via the LINC Director by the approved LINC Project end date. The LINC Data Recipient agrees not to retain any LINC Project Data, or any parts thereof, or any derivative files that can be used in concert with other information after the aforementioned file(s) and LINC Project Data are destroyed unless the LINC Review Committee grants written authorization. The LINC Data Recipient acknowledges that such date for retention of LINC Project Data is not contingent upon action by OIT.

10. Term and Termination

By signing this DUL, the LINC Data Recipient agrees to abide by all provisions set out in this DUL. This DUL will become effective upon the last date of execution by OIT and the LINC Data Recipient to this DUL. Unless terminated sooner pursuant to Sections 6 and 8 above, this DUL will remain effective in its entirety until the completed “Certification of Project Completion & Destruction or Retention of Data” has been received by the OIT.

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11. Signature

The effective date of the DUL shall be _____, 20 _____. The DUL will remain in effect until _____, 20 _____.

IN WITNESS WHEREOF, the Party hereto have caused this Agreement to be executed by their duly authorized representative.

[NAME]

_____ Dated: _____

[TITLE]

[ORGANIZATION]

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Attachment 1:

Linked Information Network of Colorado (LINC)**Certification of Project Completion and Data Destruction**

The LINC Data Use License (DUL) signed by _____ (“Data Recipient”) on _____ date for LINC Project # _____ allowed for the receipt of anonymized LINC Project data during the project period. The Principal Investigator (PI) and/or Co-Principal Investigator (Co-PI) identified in the LINC DUL is required to destroy all data provided for the approved LINC Project by the end date of the project specified in the LINC DUL. In the DUL, the LINC Data Recipient agreed not to retain any LINC Project Data, or any parts thereof, or any derivative files that can be used in concert with other information after the aforementioned file(s) and LINC Project Data.

By signing below, the PI or Co-PI assures that all data elements loaned to the authorized personnel listed in the DUL for LINC Project #19-01 have been destroyed in accordance with the “Guidance to Render Unsecured Protected Health Information Unusable, Unreadable, or Indecipherable to Unauthorized Individuals,” as established by the U.S. Department of Health and Human Services (HHS). The details of data destruction are as follows:

1. Data destruction date:
2. Data destruction personnel:
3. Data destruction method:

Signature: _____ Date: _____

LINC Project # _____

PI/Co-PI Name: _____

Organization: _____

Phone Number: _____ . Email address: _____

Address: _____

Please send the signed and completed form to:
Whitney LeBoeuf, Acting LINC Director (whitney@coloradolab.org)