This document is the property of CyncHealth. It is to be used for the intent of developing and implementing projects as a partner in the Collaborative.
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Section I. Introduction

Background on the Collaborative

Vision: To transform the health of our population.

Mission: To facilitate cross-sector collaborations of diverse stakeholders optimizing health care delivery through teams that study and propose solutions to improve population health.

Values:

- **Collaboration is our core** – Addressing complex problems and societal issues requires collaboration across sectors and industries. No one can do it alone, and we engage our collaborators to tackle challenges and develop solutions related to population health.
- **Diverse perspectives solve complex problems** – Complex problems have many potential solutions, and we value diverse expertise to generate questions and solutions that drive us toward clarity and enhancements.
- **Data drives decisions** – Data exists in many forms and from many sources in today’s healthcare landscape. Addressing current challenges requires turning disparate data into actionable information. We design and implement projects using data from comprehensive and reliable data sources that inform our decisions in population health.
- **Learning and teaching focused** – The current and future workforce needs assistance with managing the multiple complexities of health data to improve cost, quality and experience of patients and providers. We support collaborations that promote learning and teaching across sectors both for teams and individuals to transform health care education and delivery.

Tagline: Cultivating collaborative, informed, and innovative solutions for health

Aims of Projects

The aims of projects are to align with the strategic vision of the organization. The intent is to support a threefold approach:

- Develop an informed workforce with an understanding of data science and population health.
- Engage in projects that improve population health.
- Support innovation to improve health care delivery for our partners.

Intent of Manual
The intent of this manual is to provide guidance for individuals submitting a project proposal to the Nebraska Healthcare Collaborative (NHC), powered by CyncHealth. Proposals must align with organizational values and include the rigor associated with excellence expected for dissemination either through presentations or publications. Additionally, project requests must align with the data available within CyncHealth and congruent with the goals of our partners. Proposals will be peer reviewed and must adhere to data governance protocols along with federal, state, and institutional guidelines. Not all proposals submitted will be accepted due to proposal volume, quality of proposal, value alignment of proposal, and other potential rationales. Questions on aspects of these statements should be directed to collaborative@cynchealth.org.

Section II: Project Requirements

Project Categories

The Nebraska Healthcare Collaborative supports projects that fit into the following categories:

Research – A research project seeks to answer a defined question(s) with rigor and methods established through best practices in scientific inquiry. Research projects with CyncHealth typically use aggregate, limited data sets from CyncHealth’s population health utilities, including the health information exchange (HIE), prescription drug monitoring program (PDMP) and social determinants of health (SDOH) platform.

Example: Using data from the HIE to explore low back pain diagnoses and imaging diagnostic codes to determine if imaging was necessary.

For more information on how to conduct a research project with health care data, consult the following resource:

- Patient-Centered Outcomes Research Institute - Research Fundamentals: Preparing You to Successfully Contribute to Research

Quality improvement - A quality improvement (QI) project focuses on an organization’s current performance in a specific area using an attribution or eligibility file. QI projects intend to lead to improved health care delivery or positive impact on the health of patients or populations in that organization.

QI projects follow a process improvement lifecycle (e.g., Plan Do Study Act (PDSA)). Data may include personally identifiable information (PII) and include HIE, SDOH and/or prescription medication elements as approvable by data governance.

Example: A hospital wants to determine if a new medication reconciliation process at discharge is effective at reducing readmissions for its hospitalized patients.
For more information on how to conduct a QI project, consult the following resources:

- How to get started in quality improvement
- Institute for Healthcare Improvement Quality Improvement Essentials Toolkit

Program evaluation – Program evaluation is a process to demonstrate the outcomes and effectiveness of a program. The format and approach of program evaluation varies based on the type of program. Data elements may include a hybrid of internally sourced and tracked data as well as data obtained from the HIE.

Example: A local county Area office on Aging wants to track the utilization, falls within 6 months, and cost savings of a fall prevention program for older adults in its catchment area.

For more information on how to conduct a program evaluation project, consult the following resources:

- Introduction to Program Evaluation for Public Health Programs: A Self Study Guide
- J-PAL Evaluation Toolkit

Types of Datasets

CyncHealth has a variety of options for data when considering data requests as a health data utility.

- Health information exchange (HIE) – electronic health record data from data sharing organizations in Iowa and Nebraska
- Prescription drug monitoring program (PDMP) – dispensed medications from pharmacies in Nebraska
- Community data exchange – social determinants of health data using a closed loop referral system located in seven states: Kansas, Iowa, Minnesota, Missouri, Nebraska, North Dakota, and South Dakota.

When engaging in a project, the type of data requested is an important consideration and will be weighted in the review of projects. In addition, the type of data approved will be influenced by the reported project design.

Projects approved typically use de-identified or limited data sets.

- Deidentified data set - a data set which has identifying information removed and is often considered low risk by data governance and an institutional review board (IRB). Identifiers removed from this data set include any information that is specific to a person’s identity including name, age, gender, racial/ethnic identity, etc.
• **Limited data set** - a data set that is stripped of certain direct identifiers specified in the HIPAA Privacy Rule. A limited data set may be disclosed to an outside party without a patient’s authorization only if the purpose of the disclosure is for research, public health, or health care operations purposes and the person or entity receiving the information signs a data use agreement (DUA) with the covered entity or its business associate.

Limited data sets may include only the following identifiers:
- Dates, such as admission, discharge, service, and date of birth (DOB)
- City, state, and zip code (not street address)
- Age
- Any other unique code or identifier that is not listed as a direct identifier.

A limited data set is private health information (PHI) that excludes the following direct identifiers of the individual (or the individual's relatives, employers, or household members):
- Names
- Address information, other than city, state, and zip code
- Telephone numbers
- Fax numbers
- E-mail addresses
- Social Security numbers
- Medical record numbers
- Health plan beneficiary numbers
- Account numbers
- Certificate/license numbers
- Vehicle identifiers and serial numbers, including license plate numbers
- Device identifiers and serial numbers
- Web Universal Resource Locators (URLs)
- Internet Protocol (IP) addresses
- Biometric identifiers, including fingerprints and voiceprints
- Full-face photographs and any comparable images

A limited data set is still protected health information (PHI) under HIPAA. It is not de-identified data, as that term is defined under HIPAA, and thus, must be safeguarded and protected as required under the Privacy Rule. As part of the project proposal, the types of data sets for the project are required to determine next steps in data governance. For more about the HIPAA Privacy Rule, visit [here](#).

**Project Eligibility**

All project proposals must align with the values and mission of CyncHealth. The individual or team submitting a project must be:
- A CyncHealth participating organization
• An employee and/or student of a community-based organization, academic institution and/or health system whose mission aligns with the mission of CyncHealth

Most proposed projects will be retrospective in nature, and de-identified samples are encouraged when possible and appropriate. All projects must satisfy state and federal statute, meet data governance guidelines and be compliant with other relevant CyncHealth policies. Projects involving certain data may require additional review and approval based on data privacy and security standards.

Prior to project approval, a member of the CyncHealth Support Team will conduct a scoping session based on submitted documents and prepare an estimate of labor for data extraction and preparation. Data requests or assistance that exceed the initial estimate and reasonable follow-up and consultation may result in additional fees. Due to data governance guidelines for PII/PHI, data analyses should be performed based on the research question and/or project purpose and only include members of the project team identified in the Data Use Agreement (DUA) and IRB protocols.

All projects must be reviewed and approved by the CyncHealth data governance process. Projects must obtain and report to CyncHealth IRB approval prior to project implementation. CyncHealth does not host its own IRB and recommends use of the requester’s IRB. If the requestor does not have access to an IRB, CyncHealth can assist in this process. All participants in projects must demonstrate successful completion of HIPAA training prior to project approval. Participants may be asked to sign a conflict-of-interest form or other necessary business requirements dependent on the project type.

Projects that fail to follow all policies and data governance will be terminated immediately. Questions about project appropriateness can be vetted by contacting CyncHealth at collaborative@cynchealth.org. The NHC team is here to provide support and ensure project success.

Project Cost

NHC does not charge for health information data from any of the platforms. However, data extraction and statistical analyses has cost commensurate with the request. The NHC offers an hourly rate for services and will work with each requester to establish a cost estimate and explore funding options.

Section III: Project Process

a. Step 1: Collaborative Project Request Form

Prior to submitting a full proposal, the team must submit an initial Collaborative Project Request Form for review by the NHC to determine the project’s viability. The Collaborative Project Request Form is available on the website. The Collaborative
Project Request Form is a brief overview of the proposal including the following components:

1. Applicant Information including contact information and organizational information
2. Project Title
3. Proposed Project Overview
   a. Brief description of needs for data and intent of the project
4. Match with Mission
   a. Brief description of how the proposed project supports the NHC mission
5. Data and Timeline
   a. Identify if the request is a de-identified or limited data set
   b. Timeline for expectation of receipt of data

You are strongly encouraged to contact the Collaborative to discuss questions about fit or scope prior to submitting a Collaborative Project Request Form. Once a Collaborative Project Request Form is submitted, a team member will review and determine the following: 1. Match with mission, 2. Project viability, 3. Project appropriateness, 4. Reasonable timeline, and 5. Project category. If upon review, questions arise, staff of the NHC may reach out for further clarification on the project request.

b. Step 2: NHC Data Request Form

Once NHC has identified the project as viable, the next step is to complete a Data Request Form in one of the three project categories: Research, Program Evaluation or Quality Improvement. Section III outlines the requirements for a Data Request Form.

Section IV: Data Request Form

If a project has been approved, a Data Request Form in one of the three project categories: Research, Program Evaluation or Quality Improvement will be emailed to the requestor. Quality and thoroughness are expected in all Data Requests to ensure scoping and appropriate data governance. When complete the form, submitters should consider the following guiding questions to ensure a comprehensive data request.

1. Project Plan: This section should be supported with literature and evidence to support the project. Consider the following questions throughout this section to develop a quality proposal:
   • Does the project summary establish a clear understanding for the intended project?
   • Are refereed journals and primary sources appropriately used?
• Are the references relevant to the topic areas of CyncHealth (i.e., health information exchange, population health)?
• Are there sufficient credible sources?
• Are the findings of the sources appropriately analyzed and appraised?
• Is relevant information carefully selected from the various sources?
• Is relevant information critically integrated into major topics?
  a. What is the plan for data use and analyses?
    • Is your analysis plan outlined and commensurate with the sample size and data elements requested?
  b. If research, what is the hypothesis or the research question?
    • Are the research questions based on findings gleaned from the project background?
    • Are the research questions linked to the study purpose?
    • Are the research questions answerable with CyncHealth data and partnership?
    • Are variables or constructs clearly identified in the research questions?
    • Are the hypotheses clearly stated and linked to the research questions?
  c. What data elements are requested (e.g., aggregate data, Personal Health Information (PHI)/ Personally Identifiable Information (PII), de-identified data)?
  d. What is the sample size needed and inclusion or exclusion criteria (e.g., power analysis)?
    • Standardized data elements
    • Who are the targeted participants?
    • What is the desired sample size?
    • How was the sample size determined?
    • What are demographic characteristics of the sample?
    • What are the inclusion and exclusion criteria?
    • If applicable, identify any ICD-10 and/or CPT codes.
    • See the Data Request Form for other data standards that might be needed
  e. When do you need the data and how frequently do you need data refreshed (e.g., one-time, or ongoing)?
  f. Describe funding source(s) for this project (e.g., source, amount, duration)?
g. Who will access this data in any form (e.g., name, titles, role, level of access)?

2. Project Value: This section focuses on how the project supports and enhances population health aligning with the mission of the Collaborative, CyncHealth, or DHHS
   a. How does the project facilitate better experiences and/or health outcomes for Nebraskans?
   b. How does the project align with the business needs of Nebraska Department of Health and Human Services (DHHS), CyncHealth or the participating organizations? (e.g., For Medicaid data requests, describe direct benefits to the Medicaid program.)

3. Compliance and Risks: This section focuses on procedures to ensure project compliance, protect health information, and mitigate project risk. When writing this section, consider the following questions:
   a. Are the steps for the execution of data collection clearly and succinctly described?
   b. Are there any ethical issues regarding the steps of data use? If so, how will these be addressed?
   c. Are procedures in place to ensure confidentiality of data?
   d. How will any risks associated with data use be addressed?
   e. How will you protect any limited data sets provided to you by CyncHealth?
   f. How is the request compliant with HIPAA and other state and federal policies and regulations (e.g., combining with other datasets, completed HIPAA and/or CITI training (attach certificates))? If not, how will you remediate any concerns?
   g. If requesting PII/PHI, can this project be completed with de-identified information? Why or why not? What measures are planned to ensure privacy and confidentiality?
   h. Is consent required from the data owner to access this data? If yes, describe how you will obtain consent. If no consent is required, provide a rationale.
i. How long will the data be stored and how will it be destroyed after the specified retention period? (e.g., Will any data be retained for re-use in the future?)

j. What potential risks may be present for this request and what safeguards have been implemented to address these risks?

k. Have you received IRB approval? If not, do you plan to? (Attach a copy of the approval.)

l. What precedent exists for sharing similar data within Nebraska or other states? (e.g., literature review, state statutes, federal regulations)

4. Technical Feasibility: This section focuses on the technical support for the project.
   a. What is the proposed data flow to fulfill the request? (e.g., Who will receive the data and how will it be transferred?)
   b. What technology/software is needed for the project? (e.g., Will any web-based applications or interfaces be used? What type and level of data encryption will be used?)
   c. What other technology considerations are needed to manage risks?

Section V. Project Review and Data Governance Process

A. NHC Data Request Form

A NHC Data Request Form is submitted via a weblink and must follow the guidelines outlined in this Manual. The NHC Data Request Form will be reviewed by the Collaborative team members for project rigor, methodology and fit. If deemed to have any concerns, the submitter will be notified promptly and asked to clarify the request. The project will be reviewed for mission alignment/fit, quality, applicability, cost, timeline, and workload by the NHC staff. If questions arise, the submitter(s) may be asked to meet with the Collaborative team to discuss and further review the project. If no revisions are needed, the proposal will be reviewed following NHC’s data governance processes.
The review will lead to three outcomes:

1. **Endorsement** – The proposal meets all requirements, is well written and aligns with NHC mission. Once endorsed, the NHC Data Request Form will be sent for project scoping and cost estimation.

2. **Endorsement pending revision** – The project fits NHC mission but needs modification and/or editing prior to moving forward. The proposal will be returned with suggested modifications and a timeline for re-submission. The proposal must be resubmitted with a redline and clean copy version and include a cover letter identifying changes made or include rationale for reasons not to include suggested changes. Once resubmitted, the proposal will be re-reviewed. If revisions are appropriate, the project will receive endorsement and the NHC Data Request Form will be sent for project scoping and cost estimation. If revisions are not appropriate, the proposal may be allowed further edits or may be rejected per the purview of the reviewers.

3. **Rejection** – Projects may be rejected for the following reasons. A rationale for rejection will be provided for each proposal submitted.
   a. Project does not align with organizational mission and/or priorities.
   b. Project does not meet formatting requirements and/or is of poor quality.
   c. Project does not benefit from or align to the data that CyncHealth can provide.
   d. Project is outside data governance guidelines established by CyncHealth.

**(b) Institutional Review Board Process**

Projects are not allowed to begin, and data will not be shared with teams until CyncHealth is provided with formal organization IRB approval. Upon IRB approval, and completion of all required project documentation and governance processes, the project can proceed in partnership with CyncHealth.

**Section VI: Project Implementation**

**(c) Project Implementation Workflow**

Investigators must be mindful that careful data management is essential and fundamental for reliable and valid results. While implementing data use and analysis, the project must comply with proposal guidelines approved through data governance and IRB guidelines focused on maintaining participant confidentiality; protecting any collected records and/or data; and securing approval of any change from the original IRB approved proposal/protocol.

B. Data Governance
Once a project has been endorsed, it goes through the CyncHealth data governance process. For data requests related to data from the health information exchange and/or social determinants of health, the data governance process is managed by CyncHealth. For data requests from the prescription drug monitoring program, the data request must be presented, reviewed, and approved by the Health Information Technology (HIT) Board. The NHC will work to ensure a data request is presented to the HIT Board for review.

C. Data Use Agreement

Once a project is approved, the submitter will be sent a Data Use Agreement (DUA) which outlines project data guidelines and must be signed by an authorized representative. The DUA outlines the submitter’s responsibilities with the data once received.

For all projects, CyncHealth maintains data rights. During a project, all team members are responsible to ensure proper data protection and storage procedures as outlined in the approved DUA. Failure to comply with any of these guidelines will lead to project termination and other appropriate consequences.

For research integrity, it is the responsibility of the project team to review the IRB policies of your institution. Also, it is your responsibility to protect participants’ rights and confidentiality. More importantly, it is your responsibility to follow the ethical research standards that are presented and discussed in the Collaborative Institutional Training Initiative (CITI) training courses in protection of human research subjects.

D. Data Delivery

After receipt of the DUA and any other required documents, a CyncHealth analyst will collaborate with the proposal team for data extraction and delivery through an approved and secured mechanism. Additional requests for data that exceed the initial estimate and reasonable follow-up, or consultation may result in fees. The data analysis should be performed based on the research question and/or project purpose and include only members of the project team disclosed to CyncHealth in the DUA.

E. Project Dissemination

CyncHealth encourages authors to disseminate results of projects with proper attribution and acknowledgement. CyncHealth will provide logos and support to disseminate projects successfully. Publication guidelines will be outlined in the DUA.

Additionally, all publication materials must be reviewed and approved by CyncHealth to ensure appropriate use of data and attribution prior to submission for publication. If CyncHealth team members are not included as co-authors on the project, the following acknowledgement is required:
E. Determining Authorship

The following are guidelines for authorship of an approved project. Authorship should be discussed with the entire research team including those involved at CyncHealth. The decision of authorship needs to be reviewed starting at the selection of the topic and throughout the entire project sequence. The authorship hierarchy depends on the level of contribution for the following:

(a) the conception and design, acquisition of data, or analysis and interpretation of data
(b) writing and revising the paper
(c) final approval of the final draft of the paper

Additionally:

(a) Each author takes personal and public responsibility and credit for the work
(b) Each author can present, discuss, interpret, and defend the work, analysis, and conclusions

Completing ONLY one of the following DOES NOT justify authorship:

(a) identifying the title of project
(b) acquisition of funding
(c) collection of data
(d) general supervision of the research group
(e) providing consultation for statistical analysis or editing
(f) contributing to/completing isolated portions of the project/paper

Author order should be determined prior to the beginning of a manuscript and discussed collectively among the team. If heavily involved, CyncHealth staff are encouraged to act as co-authors.

Most professions agree that:
(a) the first author is principal contributor (not necessarily the principal investigator)
(b) subsequent authors listed in order of decreasing contribution.

Preventing authorship problems:
(a) identify and assign study tasks that are key for authorship, and those warranting only acknowledgement
(b) link authorship to quality and completion of work not to an individual’s role or title
(c) renegotiate authorship and author order when new tasks emerge, responsibilities alter, or people enter or leave the collaborative group.
In addition, International Committee of Medical Journal Editors has guidelines that define the role of authors and contributors (http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html).
Glossary

Data governance - the process of oversight of the use of data focused on privacy and appropriate ethical use of data

Data science – “the application of quantitative and qualitative methods to solve relevant problems and predict outcomes” (Waller & Fawcett, 2013)

Data use agreement (DUA) - a specific type of agreement that is required under the HIPAA Privacy Rule and must be entered into before any use or disclosure of a Limited Data Set from a health care record to an outside institution or party for one of the three purposes: (1) research, (2) public health, or (3) health care operations purposes.

De-identified data set – According to HIPAA, de-identified “information does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual is not individually identifiable health information” (Health and Human Services, 2012)

Electronic health record (EHR) – digitized patient record

Health information exchange (HIE) - a source of vital health information often fed from electronic health records (HealthIT.gov, 2019)

Interoperability – “ability of different information systems, devices and applications (‘systems’) to access, exchange, integrate and cooperatively use data in a coordinated manner, within and across organizational, regional and national boundaries, to provide timely and seamless portability of information and optimize the health of individuals and populations globally” (HIMSS, 2020)

Limited data set – A data set that is stripped of certain direct identifiers specified in the HIPAA Privacy Rule. A Limited Data Set may be disclosed to an outside party without a patient’s authorization only if the purpose of the disclosure is for research, public health, or health care operations purposes and the person or entity receiving the information signs a data use agreement (DUA) with the covered entity or its business associate. A Limited Data Set is still Protected Health Information (PHI) under HIPAA. It is not De-Identified Data, as that term is defined under HIPAA, and thus, must be safeguarded and protected as required under the Privacy Rule.

Population health – the health outcomes of a group of individuals, including the distribution of such outcomes within the group (Kindig & Stoddard, 2003)

Prescription drug monitoring program (PDMP) - electronic database that tracks prescriptions (CDC, 2017)

Program evaluation - a process to demonstrate the outcomes and effectiveness of a program
Protected health information (PHI) – any identifiable health information

Quality improvement (QI) – a project that focuses on an organization’s current performance in a specific area using an attribution or eligibility profile and intended to lead to improved health care delivery or positive impact on the health of patients or populations in that organization

Research - seeks to answer a defined question with rigor and methods established through best practices in scientific inquiry

APPENDIX A

If necessary for the institutional review board (IRB), here is a template Letter of Agreement to partner with CyncHealth.

Letter of Agreement

_______________________
DATE

Dear Members of the IRB:

We are familiar with [NAME OF PI]'s research project entitled [XXXXX]. I understand [Agency or Organization’s name]'s involvement to be [specific and detailed description of the ROLE OF THE AGENCY or ORGANIZATION]. (List all data collection activities and groups.)

We understand that this research will be carried out following sound ethical principles and analytical strategies, that participant involvement in this research study is strictly voluntary, and that confidentiality of participants' research data is ensured, as described in the protocol.

Therefore, as a representative of [Agency or Organization], I agree that [NAME OF PI]'s research project may be conducted in partnership with our agency/organization.

Sincerely,

_____________________________
Signature

_____________________________
Typed Name
Title
APPENDIX B

Collaborative Project Request Form

The form is digitally linked on the [NHC website](http://example.com). A copy of what the form requests is located here to provide a preview.

<table>
<thead>
<tr>
<th>First Name:</th>
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<tbody>
<tr>
<td>Last Name:</td>
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<td>Credentials:</td>
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<td>Title:</td>
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<td>Phone:</td>
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<tr>
<td>Organization Name:</td>
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<tr>
<td>Organization Address:</td>
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<tr>
<td>Project Title:</td>
</tr>
<tr>
<td>Proposed Project Overview - Brief description of needs for data and intent of the project</td>
</tr>
<tr>
<td>Match with Mission - Brief description of how the proposed project supports the NHC mission</td>
</tr>
<tr>
<td>Data - Identify if the request is a de-identified or limited data set</td>
</tr>
<tr>
<td>Timeline - Timeline for expectation of receipt of data</td>
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</tbody>
</table>
Data Request Form – Research – Below is the Data Request Form for research projects. After the Collaborative Project Request Form is reviewed and a project is determined as research, a copy of a digital form will be emailed to the submitter.

CyncHealth
Nebraska Collaborative Project Data Request Form – Research Project

Thank you for your interest in submitting a data request to the Nebraska Healthcare Collaborative, powered by CyncHealth. To ensure your data request is reviewed, please fill out this form thoroughly and completely. All fields are required to have a response. Should questions arise during completion of this form, please refer to the website and manual or contact CyncHealth at collaborative@cynchealth.org. After this form is properly completed and submitted, we will be in touch with the next steps in the process.

Requestor Information

<table>
<thead>
<tr>
<th>Request Date:</th>
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<tbody>
<tr>
<td>Organization:</td>
<td></td>
</tr>
<tr>
<td>Name, Title, and Credentials:</td>
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</tr>
<tr>
<td>Contact Information (email, phone #):</td>
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</tbody>
</table>

Project Team: List all members of the team who will have access to the data.

<table>
<thead>
<tr>
<th>Team Member Name</th>
<th>Credentials and Titles</th>
<th>Email</th>
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<tbody>
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Project Information

1. Project Title
2. Provide a detailed overview of the project’s intent and desired project outcomes. The overview should be supported with evidence-based literature and provide a clear rationale for why the project is needed. Citations from peer-reviewed literature are expected.

3. Identify the proposed hypothesis or research question. If the request is not a research project, put Not Applicable and provide a rationale.

4. Clearly identify the objectives for the project.

5. Describe how the project aligns with the mission of the Nebraska Healthcare Collaborative, powered by CyncHealth.

Project Approach & Methods

6. Provide a detailed summary of the project’s methodology and analyses.

7. Identify the requested sample size along with clear inclusion/exclusion criteria.

8. Identify the project timeline and how frequently data will be needed throughout the project. Specifically identify if this is a one-time request or a multiple-time request. If multiple data requests are needed, identify how many and the proposed timeline for these requests.

9. Describe any potential risks that may be present for this request and the safeguards that have been implemented to address these risks. Include how the project will follow HIPAA and other regulatory guidelines (i.e., has your institution completed the CMS Security Assessment and Authorization process?).
10. Do you have approval from an Institutional Review Board (IRB) for this project? If yes, please attach a copy. If no, please provide evidence as to why IRB approval is not necessary.

Project Sustainability

11. Describe the funding source(s) for this project (e.g., source, amount, and duration). If you do not have funding, provide this information as well as how much funding you think you will need to complete the project. All projects are scoped for data completeness and cost prior to implementation.

12. Explain your dissemination plans as well as how you plan to acknowledge CyncHealth as a project partner (e.g., publications, presentations, and sharing with other organizations).

Data Request

13. In which of the following categories does the request fall under?
   a. De-identified data set (no identifiers such as age, gender, and race/ethnicity requested)
   b. Limited data set (some or minimal identifiers requested)

14. Identify, in detail, the elements of your data request. If you are not requesting data for a specific category, please write Not Applicable.

<table>
<thead>
<tr>
<th>Data Sets</th>
<th>Detailed Description of the Request</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item</td>
<td></td>
</tr>
<tr>
<td>Coding Standard (i.e., ‘SNOMED CT’ or ‘ICD-10-CM’):</td>
<td></td>
</tr>
<tr>
<td>Diagnosis Codes (list of SNOMED CT or ICD-10-CM codes):</td>
<td></td>
</tr>
<tr>
<td>Encounter Type (i.e., Inpatient/ER visits/Readmission, etc.):</td>
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</table>
### Time Period

<table>
<thead>
<tr>
<th>Problems/Co-morbidities (list of SNOMED CT or ICD-10-CM codes):</th>
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<tbody>
<tr>
<td>Labs (list of LOINC codes):</td>
</tr>
<tr>
<td>Lab Result Values:</td>
</tr>
<tr>
<td>Procedures (list of SNOMED CT or CPT or HCPCS or ICD-10-CM codes):</td>
</tr>
<tr>
<td>Medications (RxNorm):</td>
</tr>
<tr>
<td>Vitals (Units for Measure for Diastolic Blood Pressure; Systolic Blood Pressure; Body Height and Weight):</td>
</tr>
<tr>
<td>Immunizations (list of CVX, NDC codes):</td>
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</tbody>
</table>

### Unique Identifier Data Sets

<table>
<thead>
<tr>
<th>Item</th>
<th>Detailed Description of the Request</th>
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<tbody>
<tr>
<td>Geographic location</td>
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<tr>
<td>Age range</td>
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<td>Gender</td>
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<tr>
<td>Race/ethnicity</td>
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</tbody>
</table>

15. Detail how the project will facilitate better experiences and/or health outcomes for Nebraskans.

16. Provide a detailed response on how the project aligns with the business needs of the Nebraska Department of Health and Human Services (DHHS), CyncHealth, or the participating organizations (i.e., for Medicaid data requests, describe direct benefits to the Medicaid program).
17. Identify how long the data will be stored and how will it be destroyed after the specified retention period (i.e., will any data be retained for re-use in the future?).

18. Describe in detail the proposed data flow required to fulfill the request (i.e., who will receive the data, and how will it be transferred?).

19. Identify in detail any technology/software needs for the project (i.e., will any web-based applications or interfaces be used? What type and level of data encryption will be used?).

Thank you for completing this Request Form. All complete requests will be reviewed, and you may be contacted for clarity or questions surrounding your request. In addition, CyncHealth reserves the right to reject requests for any reason. If the request proceeds, it will be scoped for data completeness and cost. After being scoped, this information will be sent back to you to determine if the project is ready to proceed.

Thank you for your patience in this process. A member of the CyncHealth Nebraska Healthcare Collaborative Team will be in touch with more details regarding your request.
APPENDIX D

Data Request Form – Quality Improvement – Below is the Data Request Form for quality improvement projects. After the Collaborative Project Request Form is reviewed and a project is determined as quality improvement, a copy of a digital form will be emailed to the submitter.

CyncHealth
Nebraska Collaborative Project Data Request Form – Quality Improvement Project

Thank you for your interest in submitting a data request to the Nebraska Healthcare Collaborative, powered by CyncHealth. To ensure your data request is reviewed, please fill out this form thoroughly and completely. All fields are required to have a response. Should questions arise during completion of this form, please refer to the website and manual or contact CyncHealth at collaborative@cynchealth.org. After this form is properly completed and submitted, we will be in touch with the next steps in the process.

Requestor Information

<table>
<thead>
<tr>
<th>Request Date:</th>
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<tbody>
<tr>
<td>Organization:</td>
</tr>
<tr>
<td>Name, Title, and Credentials:</td>
</tr>
<tr>
<td>Contact Information (email, phone #):</td>
</tr>
</tbody>
</table>

Project Team: List all members of the team who will have access to the data.

<table>
<thead>
<tr>
<th>Team Member Name</th>
<th>Credentials and Titles</th>
<th>Email</th>
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Project Information

1. Project Title
Project Overview

2. Provide a detailed overview of the project’s intent and desired project outcomes. The overview should be supported with evidence-based literature and provide a clear rationale for why the project is needed. Citations from peer-reviewed literature are expected.

3. For the quality improvement project, identify the problem statement which has led you to want to understand this problem. Consider: Why are you doing this project? What is the problem you are addressing? Who is affected? When is it a problem? Why does it matter? How does it affect the patient?

4. Clearly identify the objectives for the project.

5. Describe how the project aligns with the mission of the Nebraska Healthcare Collaborative, powered by CyncHealth.

Project Aims

6. Provide a detailed summary of what you hope to accomplish with the project and how the data will support this effort.

7. Identify the project timeline and how frequently data will be needed throughout the project. Specifically identify if this is a one-time request or a multiple-time request. If multiple data requests are needed, identify how many and the proposed timeline for these requests.

8. Describe any potential risks that may be present for this request and the safeguards that have been implemented to address these risks. Include how the project will follow HIPAA and other regulatory guidelines (i.e., has your institution completed the CMS Security Assessment and Authorization process?).
Project Sustainability

9. Describe the funding source(s) for this project (e.g., source, amount, and duration). If you do not have funding, provide this information as well as how much funding you think you will need to complete the project. All projects are scoped for data completeness and cost prior to implementation.

10. Explain your dissemination plans as well as how you plan to acknowledge CyncHealth as a project partner (e.g., publications, presentations, and sharing with other organizations).

Data Request

11. In which of the following categories does the request fall under?
   a. De-identified data set (no identifiers such as age, gender, and race/ethnicity requested)
   b. Limited data set (some or minimal identifiers requested)

12. Identify, in detail, the elements of your data request. If you are not requesting data for a specific category, please write Not Applicable.

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13. Detail how the project will facilitate better experiences and/or health outcomes for Nebraskans.

14. Provide a detailed response on how the project aligns with the business needs of the Nebraska Department of Health and Human Services (DHHS), CyncHealth, or the participating organizations (i.e., for Medicaid data requests, describe direct benefits to the Medicaid program).

**Technical Feasibility**

15. Identify how long the data will be stored and how it will be destroyed after the specified retention period (i.e., will any data be retained for re-use in the future?).

16. Describe in detail the proposed data flow required to fulfill the request (i.e., who will receive the data, and how will it be transferred?).

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Thank you for completing this Request Form. All complete requests will be reviewed, and you may be contacted for clarity or questions surrounding your request. In addition, CyncHealth reserves the right to reject requests for any reason. If the request proceeds, it will be scoped for data completeness and cost. After being scoped, this information will be sent back to you to determine if the project is ready to proceed.

Thank you for your patience in this process. A member of the CyncHealth Nebraska Healthcare Collaborative Team will be in touch with more details regarding your request.
APPENDIX E

Data Request Form – Program Evaluation – Below is the Data Request Form for program evaluation projects. After the Collaborative Project Request Form is reviewed and a project is determined as program evaluation, a copy of a digital form will be emailed to the submitter.

CyncHealth
Nebraska Collaborative Project Data Request Form – Program Evaluation Project

Thank you for your interest in submitting a data request to the Nebraska Healthcare Collaborative, powered by CyncHealth. To ensure your data request is reviewed, please fill out this form thoroughly and completely. All fields are required to have a response. Should questions arise during completion of this form, please refer to the website and manual or contact CyncHealth at collaborative@cynchealth.org. After this form is properly completed and submitted, we will be in touch with the next steps in the process.

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Project Information

1. Project Title
Project Overview

2. Provide a detailed overview of the project’s intent and desired project outcomes. The overview should be supported with evidence-based literature and provide a clear rationale for why the project is needed. Citations from peer-reviewed literature are expected.

3. For the program evaluation project, identify the aspect of the program you want to evaluate. Consider which aspect(s) of your program you are evaluating: Is it program outcome? Is it program process? How will this data support you to demonstrate the impact of your program?

4. Clearly identify the objectives for the project.

5. Describe how the project aligns with the mission of the Nebraska Healthcare Collaborative, powered by CyncHealth.

Project Aims

6. Provide a detailed summary of what you hope to accomplish with the project and how the data will support this effort.

7. Identify the project timeline and how frequently data will be needed throughout the project. Specifically identify if this is a one-time request or a multiple-time request. If multiple data requests are needed, identify how many and the proposed timeline for these requests.

8. Describe any potential risks that may be present for this request and the safeguards that have been implemented to address these risks. Include how the project will follow HIPAA and other regulatory guidelines (i.e., has your institution completed the CMS Security Assessment and Authorization process?).
Project Sustainability

9. Describe the funding source(s) for this project (e.g., source, amount, and duration). If you do not have funding, provide this information as well as how much funding you think you will need to complete the project. All projects are scoped for data completeness and cost prior to implementation.

10. Explain your dissemination plans as well as how you plan to acknowledge CyncHealth as a project partner (e.g., publications, presentations, and sharing with other organizations).

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14. Provide a detailed response on how the project aligns with the business needs of the Nebraska Department of Health and Human Services (DHHS), CyncHealth, or the participating organizations (i.e., for Medicaid data requests, describe direct benefits to the Medicaid program).

### Technical Feasibility

15. Identify how long the data will be stored and how it will be destroyed after the specified retention period (i.e., will any data be retained for re-use in the future?).

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Thank you for your patience in this process. A member of the CyncHealth Nebraska Healthcare Collaborative Team will be in touch with more details regarding your request.
**APPENDIX F**

All projects will be used following the below rubric to analyze the project viability.

**Nebraska Healthcare Collaborative Data Request Form Review Rubric**

**Title of Project:** ________________________________________________________________

**Reviewer Name:** ________________________________________________________________

**Date of Review:** ________________________________________________________________

<table>
<thead>
<tr>
<th>Proposal Review Checklist</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
<th>Comments</th>
</tr>
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<tbody>
<tr>
<td><strong>Applicant Information</strong></td>
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</tr>
<tr>
<td>1. Identifiers included: organization; name, title, credentials; contact information</td>
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<tr>
<td>2. Title is reflective of the project planned</td>
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<tr>
<td><strong>Project Overview</strong></td>
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<tr>
<td>3. Project overview gives clear summary of project</td>
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<tr>
<td>4. Project overview includes citations from reliable sources</td>
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<tr>
<td>5. Importance and relevance of project is clear</td>
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<tr>
<td>6. Research question is clear and executable</td>
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<td>7. Research question aligns with project background</td>
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<td>8. Research question aligns with study purpose</td>
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<td>9. Research question is possible with CyncHealth</td>
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<td>10. Hypothesis is well written and clear</td>
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<tr>
<td>11. Hypothesis links to research question</td>
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<tr>
<td>12. Project objectives are clear and relevant</td>
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<tr>
<td>13. Project aligns with the mission of the Nebraska Healthcare Collaborative</td>
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<td><strong>Approach/Methods</strong></td>
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<td>14. Project methods and analyses are appropriate for proposed project</td>
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<tr>
<td>15. Project design has clear rationale included</td>
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<tr>
<td>16. The specific number of participants to be included in the study is identified along with rationale for sample size</td>
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<td>17. Demographic criteria for sample are explicit and clear</td>
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<tr>
<td>18. Both the inclusion and exclusion criteria are identified</td>
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<tr>
<td>19. Project timeline is clear</td>
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<tr>
<td>20. Individuals accessing data are clearly identified</td>
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<tr>
<td>21. Any possible risk or discomfort that may be experienced as a result of participation is described</td>
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</tbody>
</table>

**Project Sustainability**

| 22. Funding sources included and described |
| 23. Dissemination plans included and described |

I recommend this project be

| Endorsed (i.e., ready to move to Data Request Form) |
| Endorsed pending revisions (Please provide a rationale for edits) |
| Rejected (Please provide a rationale for rejection) |

Provide any additional comments or thoughts below you want the project submitters to know.
APPENDIX G
Project Memo

Once a project is reviewed via the rubric, the NHC will send out the memo below to let submitters know the next steps.

Memorandum

Nebraska Healthcare Collaborative

To: Submitter
From: Reviewer
CC: Team members on proposal
Date: Re: Nebraska Healthcare Collaborative Proposal Review Feedback

Thank you for submitting your project for review. The purpose of this review is to determine that the proposal

1. uses procedures consistent with sound research and or project design,
2. uses procedures which minimize risk to participants, and
3. advances the scientific knowledge in areas consistent with the vision of the NHC

The NHC has reviewed your research proposal as required prior to IRB submission. The Proposal Review checklist used to review your proposal is attached. Please read carefully. The outcome of the review was:

_____ Endorsed. Your project is approved to move to the next phase. You will be sent the Data Request Form and your project will be scoped by an analyst for any applicable cost estimates.

_____ Endorsed pending revisions. Please review the required revisions needed to move to the next phase. Return a redline copy and clean copy and include a cover letter outlining changes made within four weeks of receiving this notice. Once revisions are received, the proposal will be re-reviewed and a recommendation for next steps will be made.

_____ Rejection. Your proposal has been rejected for the following reasons:
APPENDIX F

Overview of Project Phases

Please note, CyncHealth has an obligation to ensure responsible stewardship of health information. This process from project ideation to implementation takes times. Please note some of these committees only meet monthly or quarterly. Contact the Collaborative for more details on the timeline.
Reference List


