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PROJECT REPORT

FINAL

Longitudinal Maternal & Infant Health Information for Research FHIR Implementation Guide: Maternal Mental Health Use Case

Pilot Implementation and Lessons Learned Report

Prepared for
The Office of the Assistant Secretary for Planning and Evaluation (ASPE)
at the U.S. Department of Health and Human Services

by
NORC at the University of Chicago

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Office Of The Assistant Secretary For Planning And Evaluation

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Table of Contents

Executive Summary ..... **iv**

1. Introduction **1**

1.1 Objectives and Structure of the Report 1

2. Development of the Research IG Maternal Mental Health Use Case **1**

3. Pilot Implementation of the MMH Use Case **4**

3.1 Pilot Site Selection and Overview 4

3.2 Piloting the MMH Use Case 6

4. Lessons Learned from the Pilot **9**

5. Discussion **11**

5.1 Broader Implications 11

5.2 Recommendations for Future Work 12

Appendix A. Maternal Mental Health Use Case Value Sets **15**

Appendix B. Form to Assess HIE Capacity to Participate in the Pilot **16**

Appendix C. Candidate HIE Characteristics for Inclusion/Exclusion Based on HIE Form Responses **18**

Appendix D. Data Elements Extracted in Pilot **19**

References **21**

Executive Summary

Funded by the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF), the Longitudinal Maternal & Child Health Information for Research Fast Healthcare Interoperability Resources® (FHIR) Implementation Guide (Research IG) enables researchers to aggregate and analyze electronic clinical data related to maternal health using standards-based approaches for two use cases: maternal mortality and hypertension. The Office of the Assistant Secretary for Planning and Evaluation commissioned NORC at the University of Chicago (NORC) to develop a maternal mental health (MMH) use case for the Research IG. The MMH use case provides a standard approach to access and use real-world data for research on mothers experiencing mental health conditions during pregnancy and/or postpartum as well as the outcomes of their infants. The updated Research IG MMH use case was piloted with a health information exchange (HIE) to test the validity of the technical specifications and implementation in a real-world setting. This report describes the pilot implementation, lessons learned, and recommendations for further work.

Development of the Research IG Maternal Mental Health Use Case

The MMH use case covers four high-priority MMH conditions—depression, anxiety, bipolar disorder, and psychosis—and was informed by a review of clinical guidelines and input from subject-matter experts. The use case was added to the Research IG in three stages.

Stage 1: The NORC team reviewed the original Research IG use cases and other relevant FHIR IGs to identify relevant models, structures, and content. The team determined there was no straightforward way to use FHIR to define criteria and extract a cohort dataset. To address this, the team used the workaround applied in the Research IG original use cases, which relies on the Health Level 7 Clinical Quality Framework and FHIR Quality Measure IG using Clinical Quality Language (CQL). Also, the FHIR IGs in the U.S. Realm do not include a specification for linking the records of mothers and their infants; therefore, capacity to conduct record linkages was included as a pilot site selection criterion.

Stage 2: The team compiled value sets (i.e., collections of standardized clinical codes) for the MMH use case, guided by U.S. Core standards and standard terminologies. Existing relevant value sets were identified, compiled, and de-duplicated, resulting in 30 value sets for the MMH use case.

Stage 3: The team drafted the MMH use case using the approach outlined in the FHIR Quality Measure IG to define and extract data on a cohort of patients meeting the MMH use case inclusion criteria. Full testing of the MMH use case would require a CQL engine and synthetic dataset. Since this was not possible, the code was reviewed for technical accuracy but not formally executed in a test environment.

Pilot Site Selection and Implementation

The pilot site was selected through a multistage process, beginning with 11 candidate HIEs, to assess the HIEs' data availability, FHIR experience, ability to share a limited dataset for research, capacity to link mother and infant records, and data governance processes. CyncHealth, Nebraska's state-designated HIE, was chosen as the pilot site.

NORC worked with CyncHealth to iteratively review the MMH use case content to translate it for CyncHealth's environment. CyncHealth did not have a CQL engine (i.e., software programs that implement CQL logic) to directly execute the MMH use case, so the Research IG served as a specification

rather than an executable extraction tool. CyncHealth employed use case cohort definitions, data element specifications, and value sets to develop Structured Query Language code to extract data. CyncHealth applied a proprietary deterministic approach to link mother and infant records. The final data were shared as flat CSV files.

Lessons Learned

The pilot process yielded several lessons learned.

- First, the HIEs engaged in the pilot site selection process had differing policies and processes for accessing data for research, including mental and behavioral health data. Understanding an HIE's ability to share data for research, the types of data that can be shared within the research project timeframe, and the legal and governance requirements are critical when selecting an implementation site partner and planning the timeline logistics.
- Second, real-world data availability and formatting may differ from what is specified in the Research IG, including data completeness, quality, and alignment with the latest FHIR and terminology standards. This requires careful mapping of HIE data to the Research IG to identify gaps.
- Third, HIEs reported not having the CQL engines needed to directly execute the MMH use case, necessitating a hybrid approach where the specifications guided the HIE in developing and implementing its own queries. Additional challenges were related to implementing mother-infant record linkages and data format and privacy.
- Finally, pilot implementation required a collaborative, iterative approach to bridge the gap between standards-based specifications and real-world data. Throughout, CyncHealth highlighted the utility of the Research IG specifications.

Future Directions

The pilot yielded key insights that can inform future efforts to refine the Research IG, address implementation challenges, and expand its application across research and health data environments.

- *Data Governance*: Develop a standardized HIE checklist to assess implementation readiness (e.g., data governance, availability, technical capabilities, timelines) to expedite site selection and reduce implementation delays.
- *Data Availability and Format*: Explore opportunities for data standardization, such as the use of common data models and analytic techniques, and how to integrate these approaches with FHIR-based specifications to enhance usability for research.
- *Leveraging the FHIR Quality Measure IG:* Prioritize development and validation of standardized mother-infant record linkage methods and support for FHIR/CQL capabilities; and extend the Research IG to better support cohort extraction, research-ready output formats, and de-identification workflows.
- *Implementation Processes:* Maintain and enhance the Research IG over time; expand the MMH use case to better capture the full spectrum of MMH conditions; and test implementation across other HIEs.

Conclusion

This pilot demonstrated both the potential of using a FHIR IG to extract data for research and the limitations of current standards and tools to enable this in practice. Lessons from this pilot suggest areas for future work that could support a more standards-based, computable approach to extracting data for research. Addressing existing challenges and testing the Research IG in additional contexts will advance the ability to conduct comparative clinical effectiveness research on maternal and infant outcomes.

1. Introduction

Funded by the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF), the *Longitudinal Maternal & Child Health Information for Research Fast Healthcare Interoperability Resources® (FHIR) Implementation Guide*[1] (Research IG) enables researchers to aggregate and analyze electronic clinical data related to maternal health. The Research IG represents a standards-based approach to data extraction that can be applied across institutions. By providing specifications on standardized clinical data elements and value sets, the Research IG enables a consistent approach to data extraction and aggregation for multi-site research studies.

The original Research IG (v1.0.0, released December 8, 2022) covered two cohorts: 1) women who die within 365 days of a pregnancy, regardless of cause of death or pregnancy outcome; and 2) women diagnosed with gestational hypertension and/or postpartum hypertension within six weeks of delivery.

Maternal mental health (MMH) conditions are leading contributors to maternal morbidity and mortality in the United States[2]—identified as the underlying cause in over 25% of pregnancy-related deaths[3]—yet remain underdiagnosed and undertreated.[4] Existing MMH research is constrained by a lack of accessible, comprehensive, standardized, and interoperable data.[5] The Office of the Assistant Secretary for Planning and Evaluation (ASPE) commissioned NORC at the University of Chicago (NORC) to add a MMH use case to the Research IG to extract data for women experiencing depression, anxiety, bipolar disorder, and/or psychosis during pregnancy or postpartum. The updated Research IG will provide a standard approach to access and use real-world data related to MMH to conduct patient-centered outcomes research (PCOR) and comparative clinical effectiveness research (CER). The results of such research can be used to improve MMH treatments, care delivery, and policy decisions, ultimately strengthening the care and outcomes of mothers with mental health conditions and their infants.

The updated Research IG MMH use case was piloted with a health information exchange (HIE) to test the validity of the technical specifications and implementation in a real-world setting.

1.1 Objectives and Structure of the Report

This report describes the pilot implementation of the updated Research IG MMH use case, lessons learned, and recommendations for future work based on the pilot experience. The remainder of the report:

- Summarizes the development of the MMH use case.
- Provides an overview of the pilot site selection and implementation process.
- Summarizes lessons learned from the pilot implementation.
- Discusses implications of this project and offers recommendations for future efforts.

2. Development of the Research IG Maternal Mental Health Use Case

For this project, a new use case was added to the Research IG focused on four high-priority MMH conditions—depression, anxiety, bipolar disorder, and psychosis—which were chosen based on clinical significance, prevalence, and relevance to maternal and infant outcomes. Development of the use case began with identifying the target cohort, which is described in **Exhibit 1**. The cohort definition was

informed by a review of clinical guidelines and engagement with subject-matter experts and served as the basis for developing the Research IG MMH use case specifications, as described below.

Exhibit 1. MMH Use Case Cohort Definition

Definition

Female patients who experienced a delivery event and had evidence of depression, anxiety, bipolar disorder, and/or psychosis, regardless of delivery outcome. These conditions are defined as meeting at least one of the following criteria during any time of their pregnancy through up to 12 months postpartum:
• A diagnosis of depression, anxiety, bipolar disorder, and/or psychosis based on the International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM) codes.
• Prescription or active medication for treatment (e.g., selective serotonin reuptake inhibitors [SSRIs], serotonin-norepinephrine reuptake inhibitors [SNRIs], tricyclic antidepressants, mood stabilizers).
• Screening scores documented in the patient record that indicate presence of a condition:
  ○ Score of 10 or greater on the Edinburgh Postnatal Depression Scale (EPDS).
  ○ A score of 10 or greater and/or a non-zero response on the last question (self-harm question in red) on the Patient Health Questionnaire (PHQ)-9.
  ○ Score of 8 or greater on the General Anxiety Disorder (GAD-7).
  ○ Score of 3 or greater on the GAD-2.
  ○ Score of 20 or greater on the Perinatal Anxiety Screening Scale (PASS).
  ○ Score of 7 or greater on the Mood Disorder Questionnaire (MDQ).

Review of Existing FHIR IGs

To determine how to structure the MMH use case and identify relevant models and content, the NORC team reviewed the existing use cases in the Research IG as well as other relevant FHIR IGs.

The NORC team first reviewed the two original use cases in the Research IG—for maternal mortality and pregnancy-related hypertension—to understand their structure and content. For these cohorts, the Research IG pulls data using the approaches outlined in the Health Level 7 International® (HL7) Clinical Quality Framework (CQF)[6] and FHIR Quality Measure IG,[7] which define and extract data for quality measure calculations. In the Research IG, this approach is used to define a "cohort measure" and identify individuals who meet the cohort criteria. The logical criteria and data selection expressions are written in Clinical Quality Language (CQL) and packaged in various FHIR R4 resources, including Library and Measure resources. Code sets are represented as FHIR ValueSet resources.

The NORC team also reviewed other FHIR IGs on similar topics to identify any applicable models or content. The most closely aligned FHIR IG was the Making Electronic Data More Available for Research and Public Health (MedMorph) IG.[8] However, the MedMorph approach is more suitable for extracting data from a FHIR server (such as one associated with an electronic health record) one patient at a time for inclusion in a prospective research registry. It is not optimal for extracting a large dataset as a one-time or periodic event for retrospective research, as required for the MMH use case. While the MedMorph IG has beneficial features related to privacy and data exchange, it was not an appropriate choice for this project.

The FHIR Bulk Data Access IG[9] was also reviewed. While the Bulk Data IG specifies a mechanism for accessing specific datasets from a FHIR server, it does not contain specifications for dataset criteria (i.e., cannot define logic for cohort selection). Therefore, it also did not align with this project's needs.

Based on the review of the Research IG and other FHIR IGs, two main gaps were identified in current FHIR standards that had implications for development of the MMH use case. First, there is no straightforward way to define criteria for, and then extract a dataset for, a research cohort using FHIR. Most FHIR IGs are designed for clinical data exchange for individual patients. In contrast, the Research IG requires population-level cohort identification and multi-patient data extraction. For the original use cases, the Research IG developed a workaround to this gap by employing the HL7 CQF and FHIR Quality Measure IG, which typically are used for calculating quality measures (e.g., numerator and denominator) and applying them instead to define a cohort and extract a research dataset. Given this assessment, the NORC team applied the same approach for the MMH use case. It is worth noting that use of the FHIR Quality Measure IG for research dataset creation has not been widely implemented in practice and therefore remains relatively untested in real-world settings.

Second, FHIR IGs in the U.S. Realm do not include a specification for mother-infant record linkages. The narrative text of the original Research IG described a conceptual approach to linking mother-infant records. However, the Research IG did not provide technical specifications or CQL expressions for record linkage. The NORC team investigated this issue further and determined that there is no specification or implementation guidance in FHIR to link maternal and infant records. This issue would need to be resolved in FHIR before it could be implemented in the Research IG. In addition, CQL engines, which are software programs that execute CQL logic, currently do not support record linkage across patients. These limitations prevented implementation of a standards-based approach to mother-infant linkage within the scope of this project. For the MMH use case, the NORC team developed proposed CQL logic for mother-infant linkage but noted in comments that it is currently nonfunctional. The logic could potentially be operationalized in the future if FHIR implementation guidance and CQL engines are enhanced to support extraction of data from linked patient records.

Developing Value Sets

The NORC team compiled value sets (i.e., collections of standardized clinical codes) for the MMH use case, including for identifying eligible mothers as well as data elements to support research on relevant maternal and infant outcomes. These elements covered diagnoses, pre- and postpartum care utilization, mental health treatments, pregnancy outcomes, and infant outcomes.

Value set development was guided by US Core standards[10] and standard terminologies such as SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms), LOINC (Logical Observation Identifiers Names and Codes), and ICD-10. Where possible, existing value sets were used, rather than developing new ones. Value sets were identified via the National Library of Medicine Value Set Authority Center (VSAC), which is a value set repository. The NORC team searched VSAC to identify value sets containing the data elements required for the MMH use case. Often, more than one value set represented similar concepts (e.g., psychotherapy). When this occurred, the NORC team selected the value sets that were actively maintained and reflected the most recent standards. Once relevant value sets were identified, they were compiled and reconciled to remove duplicative content, resulting in 30 final value sets for the MMH use case (**Appendix A**).

Drafting the MMH Use Case Specifications

The NORC team drafted the CQL-based logic used to define patient eligibility criteria and specify the data elements to be extracted, leveraging the FHIR Quality Measure IG. Where possible, CQL

expressions from the existing Research IG use cases were reused, such as for identifying pregnancy and delivery, with updates made to logic, syntax, and other elements to align with current FHIR tooling. As noted previously, proposed CQL logic for the maternal-infant record linkage was included but documented as nonfunctional given current limitations in FHIR and CQL engines.

Quality Assurance Process

The code was developed using a CQL plugin that included built-in features to detect syntax errors, which were corrected as needed. The plugin also included a CQL execution framework for testing purposes. A sample patient dataset was used to test code validity through the execution framework. Finally, the HL7 IG Publisher, which was used to generate the updated IG, validates the files and identifies any errors. These errors were corrected prior to final publication. As noted previously, however, it was not possible to test the mother-infant record linkage specifications.

Additionally, although the use case was designed to be executable within a FHIR-based environment, the team was unable to test the Research IG using a CQL server and a synthetic dataset. As a result, the code was reviewed for technical accuracy but was not formally executed in a test environment.

3. Pilot Implementation of the MMH Use Case

This section describes the pilot site selection and MMH use case implementation process.

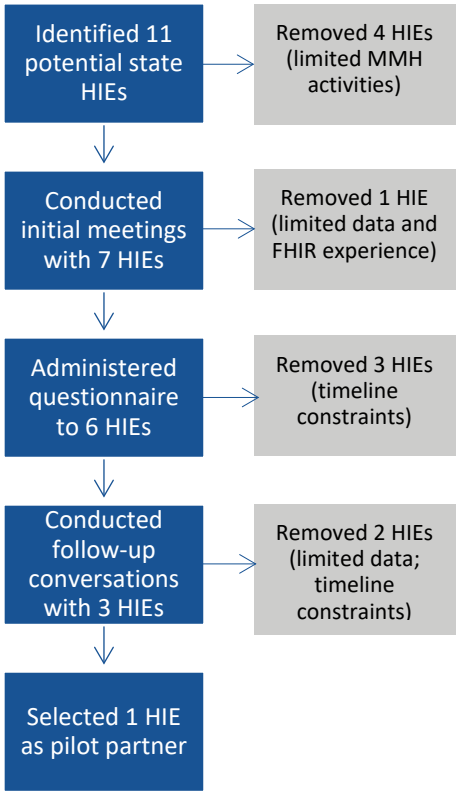
3.1 Pilot Site Selection and Overview

The NORC team went through an iterative process over four months (October 2025-January 2026) to select an HIE partner to pilot the Research IG MMH use case (**Exhibit 2**). First, through a rapid review of online documentation, the NORC team identified 11 state HIEs with demonstrated interest in advancing maternal and/or behavioral/mental health through HIE activities. The NORC team selected seven HIEs for outreach based on their work related to MMH and/or experience with FHIR. (**Exhibit 3**).

Initial discussions were held with the seven HIEs to understand their 1) governance processes for making data available for research, including defining conditions for safe and appropriate use of the data as well as consent procedures; 2) types and format of data available; 3) technical infrastructure and capacity to implement the Research IG and produce research datasets; and 4) experience with FHIR. One HIE was removed from consideration at this stage due to limited behavioral health data availability and experience with FHIR.

The remaining six HIEs were asked to complete a brief form to collect additional information on their technical capacity to

Exhibit 2. HIE Selection Process



implement the Research IG, data element structure and availability, and governance processes. Through this form, the NORC team learned that no HIEs had the capacity to use a CQL engine to execute the computable artifacts in the MMH use case. See **Appendix B** for the form and **Appendix C** for high-level characteristics of the six HIE candidates that informed the selection process.

Finally, based on questionnaire responses, the NORC team conducted follow-up discussions with three HIEs and consulted ASPE to identify the final HIE partner. These discussions confirmed 1) organizational interest in participating in the pilot; 2) ability to provide requested data as a limited dataset, including behavioral health data that may be restricted under federal regulation 42 CFR Part 2;[1] 3) data governance and compliance policies and processes; and 4) feasibility of completing the pilot within the project timeline. During these discussions, the NORC team learned that one HIE had more limited availability of key data elements (e.g., medications, MMH screening, pregnancy outcomes), while another ultimately withdrew from consideration due to timeline conflicts.

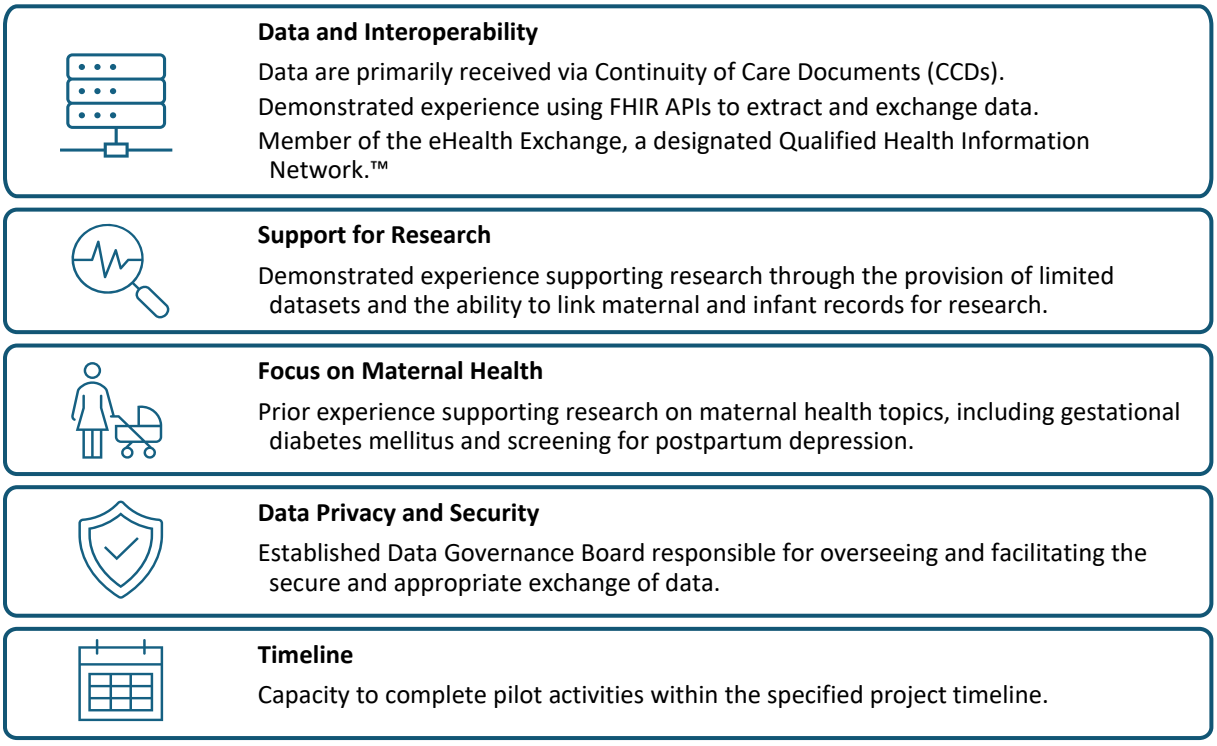
Exhibit 3. Candidate HIEs Prioritized for Initial Outreach

HIE and State	Reason for Inclusion
Connxus Texas regional HIE	▪ Maternal health experience: Partners with Texas Health State Authority to improve care coordination and reduce maternal mortality ▪ FHIR and research experience: Contributed data to the Sentinel Common Data Model's project mapping data to facilitate population health research[11]
Contexture Arizona statewide HIE	▪ Maternal health experience: Plans to implement maternal and child health smart alerts ▪ FHIR experience: Plans to expand FHIR-based application programming interfaces (APIs) to search for participant-specified data elements
CyncHealth Nebraska statewide HIE	▪ Maternal health experience: Implemented programs focused on improving maternal care, including identifying postpartum women and connecting them with follow-up care ▪ Behavioral health experience: Participated in a project on behavioral health integration among HIEs[12] ▪ FHIR: Uses FHIR for clinical data exchange
HCP OneHealthPort Washington statewide HIE	▪ FHIR and research experience: Launched an initiative to securely connect health, social, and research data using FHIR, SMART Health Cards/Links, individual access services, and quality measures[13]
HealtheConnection New York regional HIE	▪ FHIR, research, and maternal health experience: Served as the pilot site for the original Research IG
MyHealth Access Network Oklahoma statewide HIE	▪ FHIR and behavioral health experience: Tested and implemented the Gravity Project standards for social determinants of health data using FHIR
PelEx Louisiana HIE for Medicaid population	▪ MMH experience: Focus area on improving the exchange of behavioral health data for mothers with substance use disorder

[1] A limited dataset is protected health information that excludes direct identifiers of the individual and/or of relatives, employers, or household members of the individual. Unlike a de-identified dataset, limited datasets may retain certain HIPAA-defined identifiers such as dates of service and geographic information (e.g., city, state, ZIP code).

Overview of CyncHealth. CyncHealth, Nebraska's state-designated HIE, was selected as the partner to implement the MMH use case pilot. CyncHealth has provided HIE services since 2008 and is governed through a public-private partnership model. Healthcare providers and health plans across the state are mandated to share health data with CyncHealth, and the network included 265 healthcare facility participants, five payer participants, and 21 public health department participants as of March 2026. CyncHealth has several characteristics and past experiences that positioned it for pilot participation (**Exhibit 4**). Importantly, CyncHealth has supported research on several topics related to maternal health, including gestational diabetes mellitus and screening for postpartum depression. For example, CyncHealth was awarded U.S. Department of Health Human Services funding to support efforts to improve postpartum care for mothers with high-risk conditions enrolled in Medicaid and the Children's Health Insurance Program.[14] Through this program, care teams received notifications for postpartum patients to prompt additional care, including screenings, proactive communication with the primary care team, or additional lab tests.

Exhibit 4. Why CyncHealth: Key Characteristics for HIE Partner Selection



3.2 Piloting the MMH Use Case

The purpose of the pilot was to assess the feasibility of operationalizing the MMH use case within a real-world HIE environment and extracting data that could support a proof-of-concept CER study. The study was conducted to assess the utility of the extracted data and was not intended for public dissemination. The pilot was conducted through three main phases: 1) securing the necessary data governance approvals and agreements, 2) preparing for data extraction by translating the MMH use case specifications to the CyncHealth environment, and 3) implementing the extraction process and generating the CER study dataset. These steps are described in greater detail below.

1. Establishing Data Governance

As the pilot was initiated, the NORC team worked with CyncHealth to establish the appropriate data governance processes to ensure data were securely exchanged and stored in accordance with NORC and CyncHealth policies and relevant laws and regulations. The project was approved by the CyncHealth Data Governance Committee and a Data Use Agreement (DUA) was established between CyncHealth and NORC. The DUA enabled the exchange of a limited dataset containing the subset of Research IG data elements required for the proof-of-concept CER study.

Accessing prescription medication data required additional approvals. CyncHealth administers Nebraska's Prescription Drug Monitoring Program (PDMP) in collaboration with the Nebraska Department of Health and Human Services. Nebraska's PDMP is a standalone medication query platform that stores data on all prescriptions dispensed, as established through Neb. Rev. Stat. § 71-2454.[15] Requests for PDMP data are subject to a separate governance process that includes approval from the state's Health Information Technology Board. During the pilot, the Board's meeting schedule was delayed, preventing the NORC team from obtaining the necessary approvals within the project timeline. As a result, prescription medication data were unavailable for inclusion in the pilot dataset.

2. Preparing to Implement the Research IG

The NORC team and CyncHealth held weekly meetings to iteratively review the MMH use case, determine how to translate it for CyncHealth's environment, and specify how the data would be formatted and transmitted to the NORC team for analysis. Beginning in the pilot site selection phase, the NORC team and CyncHealth held detailed discussions regarding the use case data elements and the subset of data needed to conduct the proof-of-concept CER study (**Appendix D**). CyncHealth assessed data completeness and feasibility, flagging challenges such as incomplete mental health screening scores.

During initial conversations with CyncHealth, the HIE shared that it did not have a CQL engine to automate the process of implementing the MMH use case. As a result, the NORC team and CyncHealth agreed that the MMH use case specifications, including the cohort logic, value sets, and data element definitions, would serve as a guide for data extraction. CyncHealth translated these specifications into Structured Query Language (SQL)-based queries within its local environment. Additionally, it was agreed that CyncHealth would deliver a research-ready flat CSV file (rather than a FHIR-formatted output) to streamline the analytic process.[2] The NORC team provided table shells and data element lists to support this process.

CyncHealth provided test data extracts, including mock data, based on the data elements requested in the DUA. These elements represented a subset of those specified in the Research IG and were selected to support the proof-of-concept CER study. The NORC team reviewed these extractions to understand the structure of the final dataset and requested clarifications as needed. The teams discussed limitations during established weekly meetings related to mental health screening data, PDMP approval processes, and differences between encounter-level and patient-level data. As new information emerged regarding

[2] The Research IG exports data in FHIR format. Transformation of the data to a format such as a flat CSV can facilitate use of data for research analysis.

data availability and feasibility, the NORC team refined the requested data elements and updated the DUA accordingly.

As noted previously, the NORC team was unable to obtain prescription medication data within the project timeline because of the additional approvals required to access PDMP data. The original proof-of-concept CER study was designed to compare outcomes among mothers receiving pharmacotherapy and psychotherapy treatments for MMH conditions, making access to medication data a key study requirement. During weekly meetings and follow-up discussions by email, the NORC team and CyncHealth explored alternative options for CER questions that did not rely on access to medication data. This included exploring the availability and quality of psychotherapy data for the cohort, ultimately leading to the development of revised research questions that compared outcomes associated with psychotherapy treatments rather than comparing pharmacotherapy and psychotherapy treatments.

3. Implementing the Research IG and Extracting the Data

Building on this preparatory work, CyncHealth implemented the specifications and extracted the data specified in the DUA for the proof-of-concept CER study. CyncHealth used a hybrid approach to implement the MMH use case, leveraging the use case as a specification to guide cohort identification and extraction while translating its logic into CynHealth's local analytics environment. The implementation process began with a detailed review of the MMH use case cohort definition, value sets, and data element specifications. CyncHealth reported that the value sets were particularly useful for identifying relevant data elements and assessing how those concepts were represented within the HIE database. The specific data elements included in the extract were guided primarily by the study-specific requirements outlined in the DUA, with the value sets included in the MMH use case serving as a broader reference for relevant concepts and structure. CyncHealth translated the cohort logic and value set specifications into SQL-based queries that could be executed within its data environment.

CyncHealth evaluated the availability and representation of relevant codes within the HIE database by conducting exploratory data analyses, including assessing the frequency and location of codes contained in the value sets. This process enabled CyncHealth to map the MMH use case specifications to locally available data and identify any gaps between the use case requirements and the data available within the HIE.

CyncHealth extracted data using structured SQL-based workflows and assembled a comprehensive dataset consisting of several linkable files with patient-level data. CyncHealth also applied its internal approach to linking mother and infant records: a deterministic matching algorithm that matches records based on information such as last name, date of delivery and birth, address, and insurance ID. CyncHealth produced a series of flat CSV files containing the data, with mothers and infants linkable by identifiers, and shared these with the NORC team via a secure file transfer platform. This structure met the team's research needs by providing analysis-ready data rather than preserving the native FHIR resource format. All data were de-identified before transfer, and the NORC team received nine de-identified data files from CyncHealth. The files included both patient-level, wide-format datasets with one row per patient (i.e., demographics, care utilization, labor and delivery records, mental health treatment and service use, pre-pregnancy psychotherapy visits) and long-format datasets containing multiple rows per patient or pregnancy (i.e., mental health diagnoses, screening results, medical conditions, and infant records). Records were linkable across files using a unique patient identifier and

delivery date, and dates were standardized across datasets. The NORC team merged files using patient ID and delivery date.

Overall, CyncHealth's implementation demonstrated how the MMH use case can be operationalized in real-world HIE environments by using standards-based cohort definitions and value sets to guide local data extraction and mapping activities. Although the computable artifacts were not directly executed, the MMH use case provided a useful framework for identifying the cohort and relevant data elements and structuring the extraction process.

4. Lessons Learned from the Pilot

This section describes lessons learned from pilot site selection and implementation with CyncHealth (**Exhibit 5**). Lessons were identified in four main categories: data governance, data availability and format, leveraging the FHIR Quality Measure IG, and implementation processes.

Exhibit 5. Summary of Lessons Learned from the Pilot

Pilot Lessons Learned
• HIE policies for sharing data for research differ, and behavioral and mental health data often have distinct data governance requirements. • Real-world data will likely differ from what is specified in the MMH use case, with issues such as data completeness and standardization requiring careful mapping of what is available locally to the use case specifications. • HIEs reported that they did not have CQL engines that would be needed to execute the computable artifacts in the MMH use case, which necessitated a hybrid approach in which the specifications served as guidance to the pilot site HIE to develop and implement its own SQL queries. • Current FHIR implementation guidance and CQL engines do not allow for linking mother and infant records, requiring alternative approaches. • The FHIR Quality Measure IG has limitations in terms of supporting data formats and privacy requirements desirable for CER. • Successful implementation of the MMH use case relied on close collaboration with the HIE to translate and apply the use case in the HIE's unique environment.

Data Governance

HIEs have differing policies and processes for accessing data for research. Research is not the primary purpose for which HIE data are collected, and HIEs engaged during the pilot selection process varied in their experience supporting research activities. Some had established policies, governance structures, and processes for reviewing and approving research data requests, while others had more limited experience making data available for research. As demonstrated during the pilot, understanding an HIE's ability to support research, the types of data that can be shared, and the data governance and approval requirements are critical in selecting an appropriate HIE partner, assessing feasibility, and developing realistic implementation timelines.

Additional governance approvals may be needed to access mental and behavioral health data. PDMPs are centralized programs that electronically track prescriptions of controlled substances.[16] In Nebraska, all dispensed prescription drugs, not just controlled substances, are reported through the state's

PDMP.[17] These data are governed separately from the rest of the HIE's data, and access requires approval from both CyncHealth's Data Governance Committee and the state Health Information Technology Board. During the pilot, delays in the Board's meeting schedule prevented the NORC team from obtaining the necessary approvals within the project timeline, resulting in the exclusion of prescription medication data from the data extract. Researchers aiming to access medication data using the Research IG should carefully assess all applicable governance and approval requirements early in the implementation process to ensure sufficient time to obtain approvals and access data.

Data Availability and Format

HIEs engaged during the pilot selection reported varied availability of behavioral and mental health data for research. Some HIEs did not collect any behavioral or mental health data, while others, like CyncHealth, had considerable data available, including data related to screening, diagnoses, and pharmaceutical and non-pharmaceutical treatments. However, data availability did not necessarily translate into data accessibility for research. HIEs' ability to share these data varied based on state regulations, organizational policies, consent requirements, and other data governance considerations.

Among HIEs with behavioral and mental health data, data availability and format may differ from the Research IG specifications. The MMH use case specifies a set of data elements for a cohort using current terminology and FHIR standards. However, real-world data systems vary in the types of data they contain, data completeness and quality, and data standardization. For example, the MMH use case includes a value set defining different types of psychotherapy based on SNOMED CT, ICD-10-PCS (Procedure Coding System), and Current Procedural Terminology (CPT) codes, but CyncHealth only had data on the relevant CPT codes. Therefore, not all data elements defined in the use case were available. Working closely with CyncHealth to map the MMH use case specifications to the available data was critical for identifying where the data aligned and where gaps existed.

Mental health data may not be consistently available in structured formats, making them more difficult to access and use for research. Many healthcare facilities report mental health screening data (e.g., from instruments like the PHQ-9 and GAD-7) to HIEs as PDFs. In these cases, the HIE may have a record that a screening was completed but not capture the underlying numerical score in a structured database field. As a result, key information used to identify patients, characterize symptom severity, or assess outcomes may not be readily available for analysis. Accessing these data may require either time-consuming manual review of PDF records or automated processes using techniques such as natural language processing (NLP). Because the Research IG is designed to query standards-based, structured data sources, these approaches fall outside its scope. Additional efforts by HIEs and researchers may be needed to access and integrate these data for research purposes.

Leveraging the FHIR Quality Measure IG

HIEs engaged during the pilot section process reported that they did not have necessary CQL engines to directly implement the specifications outlined in the Research IG. The HIEs engaged in the pilot selection process lacked CQL engines to enable automatic execution of the computable artifacts in the MMH use case. As a result, for the pilot, CyncHealth implemented the MMH use case by using the Research IG specifications as a guide rather than directly executing the logic. In particular, the MMH cohort definition, value sets, and data element specifications informed development of SQL-based

queries within CyncHealth's local environment. The table shells and data element list shared by the NORC team served as guides for structuring the extraction processes.

The FHIR Quality Measure IG has limitations in terms of supporting data formats and privacy requirements desirable for CER. For example, CER researchers typically prefer flat files, while the extract from the FHIRQ Quality Measure IG is typically a FHIR Bundle resource. It should be noted that there are efforts to map FHIR resources to the CER-friendly Observational Medical Outcomes Partnership common data model. Additionally, FHIR was designed primarily for clinical data exchange, not research, which is reflected in how data are retrieved: There are no built-in anonymization or de-identification capabilities. Patient identifiers are included in retrieved FHIR resources and must be removed before data can be shared as a limited or de-identified dataset. Further efforts may be needed to define FHIR-based approaches that better support research-oriented data extraction.

Implementation Processes

Implementing the MMH use case required a collaborative, iterative approach. The pilot required weekly working meetings with CyncHealth to review the specifications, work through data governance, and test and refine the data extraction process. The NORC team responded and addressed issues that emerged while working with real-world HIE data that were neither collected nor formatted with research in mind. This included working with CyncHealth to map the MMH use case specifications to locally available data, identify data gaps, and adapt data requests and research plans based on data availability and feasibility. Additionally, the NORC team worked through several iterations of how the final data would be formatted in a series of CSV files linkable by patient identifiers. Throughout the process, CyncHealth indicated that the MMH use case value sets and specifications were useful for identifying relevant data elements and guiding the extraction process. At the same time, CyncHealth noted that additional plain language implementation guidance could help future implementers more efficiently understand the intent of the Research IG and apply its specifications within their local environments.

5. Discussion

The pilot implementation of the MMH use case provided an important opportunity to assess not only the feasibility of using the updated Research IG for MMH research, but also its broader applicability for supporting research using interoperable clinical data. This section examines the implications of the pilot findings, considers how the lessons learned can inform future refinement and implementation of the Research IG, and explores what would be required to scale this approach across settings with varying levels of technical and organizational maturity.

5.1 Broader Implications

The pilot demonstrated both opportunities and limitations in using the updated Research IG to support extraction of clinical data for CER. The pilot showed that a FHIR-based IG can be extended beyond traditional clinical data exchange to support MMH population-level, longitudinal research use cases, including CER. By leveraging existing FHIR standards, the Research IG provides a structured approach to defining research cohorts and extracting relevant clinical data. Although the computable artifacts were not directly executed, the pilot demonstrated that the MMH use case specifications, particularly the cohort definition and value sets, can serve as a valuable framework for identifying and extracting

relevant data from real-world systems. This represents an important step toward enabling standardized, interoperable approaches to MMH CER using routinely collected clinical data.

However, the pilot also highlighted limitations within the FHIR ecosystem. Specifically, the lack of standardized mechanisms to support maternal–infant record linkage underscores systemic gaps in existing standards and tools, and the ability to directly execute CQL-based cohort logic remains limited in real-world HIE environments. These gaps suggest a need for investment in tooling, testing infrastructure, and further development of standards and implementation guidance. As a result, the current standards only partially address the needs of research use cases and require site-specific workarounds, such as translating CQL logic into other query languages or relying on alternative data extraction methods. The pilot demonstrated the value of hybrid approaches as an interim solution as FHIR tooling continues to mature.

The pilot also highlighted the importance of data availability and governance in enabling research using HIE data. HIEs with well-established behavioral health data governance processes, clear approval pathways, and experience sharing data for research are best positioned to support similar use cases. In contrast, variability in access to data (e.g., due to regulatory constraints or consent requirements) may limit the feasibility of implementing similar approaches across sites. Furthermore, key data elements, such as mental health screening results, are not always available in structured, standardized formats, which can limit their usability for research and potentially affect cohort identification and outcome measurement. Additionally, the resource-based structure of FHIR data does not always align with the tabular, analysis-ready formats required for CER, requiring additional efforts to prepare data for research.

5.2 Recommendations for Future Work

The pilot provided several insights that can inform future development and implementation of the Research IG.

Data Governance

Develop a standardized HIE checklist to assess data governance and availability. To streamline site selection and minimize delays, future efforts could develop a standardized toolkit to assess HIEs' data governance and data availability for participation in research leveraging the Research IG. This could include structured templates and checklists informed by the lessons learned from this pilot to evaluate key factors such as data sharing policies, governance processes, approval requirements, availability of key data elements, and expected timeliness for data access. Using such a toolkit early in the planning process could help identify implementation risks, improve site selection, promote consistency across projects, and streamline assessment of feasibility.

Data Availability and Format

Explore opportunities for data standardization. The findings indicate that common data models and analytic techniques may be necessary to fully support the use of FHIR-based IGs for MMH CER in the near term. For example, techniques such as NLP can help extract information from unstructured data sources (e.g., maternal health screening scores stored in PDFs or clinical notes). Integrating these approaches with FHIR-based specifications could enhance usability for research. Additionally, variation in coding practices across HIEs (e.g., reliance on ICD codes or CPT codes versus SNOMED CT codes)

highlights the need for standardized crosswalks and guidance to support mapping between Research IG specifications and locally available data.

Leveraging the FHIR Quality Measure IG

Enable mother-infant record linkage. A critical gap identified through the pilot is the lack of standardized, testable approaches to linking mother and infant records due to FHIR and CQL limitations. One key purpose of the Research IG is to extract data on cohorts of both mothers and their infants to enable research on how maternal diagnoses and treatments impact maternal and infant outcomes. However, limitations in currents standards and implementation guidance prevent using FHIR to extract linked mother-infant records. Addressing this gap will be essential for enabling longitudinal and dyadic analyses of maternal and infant outcomes. Future efforts should prioritize the development and validation of reproducible linkage methodologies, along with corresponding updates to standards and supporting tooling. This could include developing standardized approaches for representing and operationalizing mother-infant linkages within FHIR and enabling execution of those linkages within CQL-based workflows.

Develop research-oriented tooling to support use cases within the Research IG. Future efforts should focus on enhancing the Research IG and associated tooling to better support research applications and address the limitations of the Clinical Quality Measure-focused approach. These efforts can include defining standardized approaches for specifying research-ready output formats. Additionally, implementation guidance should incorporate clear, reproducible approaches for creating limited and de-identified datasets from data extracted using the Research IG.

Implementation Processes

Maintain and enhance the Research IG. Continued maintenance, governance, and engagement with the standards development community will be necessary to ensure the Research IG's continued relevance and usability. This includes updating the Research IG to align with evolving FHIR and terminology standards, incorporating feedback from pilot implementations, and adding more use cases. Community support, implementation resources, and ongoing refinement can help reduce implementation burden and promote broader adoption.

Expand the MMH use case to include additional diagnoses. While this initial pilot focused on four MMH conditions, there is an opportunity to expand the scope of the MMH use case to better capture the full spectrum of MMH conditions experienced during pregnancy and postpartum. Additional conditions such as substance use disorders, trauma-related conditions, and other mood and behavioral disorders may impact maternal and infant outcomes. Expanding the MMH use case to include a broader range of diagnoses would enhance its comprehensiveness and utility.

Test implementation across other HIEs. Another key next step is to expand the pilot to additional HIEs that vary by geography, patient population, data availability, and technical maturity. Testing the Research IG across settings will help assess generalizability, identify common versus site-specific challenges, and refine implementation guidance. The pilot also demonstrated the need for practical implementation resources to support adoption, including plain-language descriptions of use case content, user guides, example workflows, and navigation aids to help implementers understand how different Research IG components should be used. These resources can reduce implementation burden

and help HIEs and other stakeholders interpret and apply the Research IG more effectively in their local environments.

6. Conclusion

This pilot demonstrates that the Research IG holds meaningful promise for enabling standardized, interoperable approaches to extracting clinical data for MMH research, including CER. The findings also make clear that current standards, tools, and data infrastructure are not yet fully equipped to support automated implementation of the use case. Bridging the gap between conceptual specifications and fully computable, reproducible implementation will require coordinated efforts to enhance standards development, technical tooling, and technical assistance to support implementation. At the same time, the pilot demonstrated that the MMH use case specifications, particularly the cohort definition and value sets, can provide a useful framework for identifying and extracting relevant data, even in environments that cannot directly execute the computable artifacts. This work provides a foundation for advancing the use of the Research IG to extract real-world clinical data to support CER that could improve maternal and infant health outcomes.

Appendix A. Maternal Mental Health Use Case Value Sets

The MMH use case includes 30 value sets covering the following topics:

1. Antenatal visits *(Object Identified [OID]: 2.16.840.1.113762.1.4.1196.4873)*
2. Antipsychotics and mood stabilizers *(OID: 2.16.840.1.113762.1.4.1196.3347)*
3. Anxiety *(OID: 2.16.840.1.113762.1.4.1196.1933)*
4. Anxiolytics *(OID: 2.16.840.1.113762.1.4.1196.4809)*
5. Bipolar disorder *(OID: 2.16.840.1.113762.1.4.1196.3301)*
6. Bipolar disorder medications *(OID: 2.16.840.1.113762.1.4.1196.4810)*
7. Cesarean section *(OID: 2.16.840.1.113762.1.4.1196.4837)*
8. Congenital defects *(OID: 2.16.840.1.113762.1.4.1196.4840)*
9. Depression medications *(OID: 2.16.840.1.113762.1.4.1196.350)*
10. Depression *(OID: 2.16.840.1.113762.1.4.1196.2251)*
11. Developmental delays *(OID: 2.16.840.1.113762.1.4.1196.4834)*
12. Eclampsia *(OID: 2.16.840.1.113762.1.4.1196.4821)*
13. Gestational age at delivery *(OID: 2.16.840.1.113762.1.4.1196.4855)*
14. Gestational diabetes *(OID: 2.16.840.1.113762.1.4.1196.4817)*
15. Hypertension during pregnancy *(OID: 2.16.840.1.113762.1.4.1196.4843)*
16. Labor and delivery complications *(OID: 2.16.840.1.113762.1.4.1196.4868)*
17. Neonatal Intensive Care Unit (NICU) *(OID: 2.16.840.1.113762.1.4.1196.4856)*
18. Postpartum hypertension *(OID: 2.16.840.1.113762.1.4.1196.4865)*
19. Postpartum visits *(OID: 2.16.840.1.113762.1.4.1196.4854)*
20. Preeclampsia *(OID: 2.16.840.1.113762.1.4.1196.3403)*
21. Pregnancy loss – miscarriage or ectopic pregnancy *(OID: 2.16.840.1.113762.1.4.1196.4825)*
22. Psychiatry *(OID: 2.16.840.1.113762.1.4.1196.4871)*
23. Psychosis *(OID: 2.16.840.1.113762.1.4.1196.3340)*
24. Psychotherapy *(OID: 2.16.840.1.113762.1.4.1196.4847)*
25. Serum levels for mood stabilizers *(OID: 2.16.840.1.113762.1.4.1196.4861)*
26. Stillbirth *(OID: 2.16.840.1.113762.1.4.1196.4828)*
27. Suicidal ideation *(OID: 2.16.840.1.113762.1.4.1196.4265)*
28. Suicide attempt *(OID: 2.16.840.1.113762.1.4.1196.4814)*
29. Vaginal delivery *(OID: 2.16.840.1.113762.1.4.1196.4851)*
30. Well-baby visits *(OID: 2.16.840.1.113762.1.4.1196.4862)*

Appendix B. Form to Assess HIE Capacity to Participate in the Pilot

Maternal Mental Health Data Project HIE Background Form

Background

NORC at the University of Chicago has been contracted by the U.S. Office of the Assistant Secretary for Planning and Evaluation (ASPE) to improve data infrastructure for conducting perinatal and postpartum mental health research using data from electronic health records (EHRs) and health information exchanges (HIEs). Specifically, NORC will:

- Extend the **Longitudinal Maternal & Infant Health Information for Research** Fast Healthcare Interoperability Resources (FHIR®) Implementation Guide to include a new use case that supports the extraction of data on maternal mental health for use in research.
- Collaborate with an HIE to conduct a one-time data extract using the maternal mental health specifications in the updated Implementation Guide.

The data extract will pull HIE data related to four maternal mental health conditions—anxiety, depression, bipolar disorder, and psychosis—in the pre-natal, perinatal, and post-partum periods. It will also include data on pregnancy outcomes. The project will utilize existing HIE data; it will not require any new data collection. The data will be used to conduct a comparative effectiveness research study examining the relationship between maternal mental health and pregnancy outcomes.

Available Data Elements

1. From which of the following facility types does the HIE receive data? (select all that apply)
    a. Hospital inpatient
    b. Hospital ER
    c. Hospital outpatient
    d. Primary care
    e. Pediatric care
    f. Specialists (e.g., OBGYN)
    g. Urgent care
    h. Behavioral health providers
    i. FQHCs
2. Does the HIE receive Continuity of Care Documents (CCDs)?
3. Which of the following data elements are currently available in the HIE related to maternal behavioral/mental health? (select all that apply)
    a. Medications (e.g., antipsychotics, antidepressants, anxiolytics)
    b. Diagnoses (e.g., postpartum depression, anxiety, psychosis, bipolar disorder)
    c. Procedures (e.g., psychotherapy, psychiatric referral)
    d. Healthcare utilization (e.g., hospitalizations, ED visits)
    e. Maternal Mental Health Screenings (e.g., PHQ9, GAD7, EPDS)
4. Does the HIE have prior experience linking mother and infant records?

Data Exchange Capabilities

5. Does the HIE have prior experience using FHIR APIs to extract data?
6. Does the HIE use FHIR R4 APIs?
7. Do the FHIR R4 APIs support US Core?
8. Can the HIE support bulk data extraction?
9. The FHIR Implementation Guide uses the FHIR Clinical Quality Framework for Research, specifically relying on the Framework's measure model to define populations of interest and aggregate data (read more here). Does the HIE have the ability to run a FHIR Quality Measure (specifically, a cohort-type measure)?

Data Governance

10. Does the HIE need to obtain patient consent to share maternal mental health data?
11. Is the HIE prohibited from sharing maternal mental health data due to 42 CFR Part 2 requirements?
12. Can the HIE share a limited dataset?
13. Does the HIE have prior experience sharing limited datasets for secondary research purposes?

Timeline

14. Is the HIE available to work on this pilot project in the first quarter of next year (January-March 2026)?
15. Are there any other considerations you would like to share with us that are relevant to the proposed project?

Appendix C. Candidate HIE Characteristics for Inclusion/Exclusion Based on HIE Form Responses

HIE Name (State)	Available to Participate within Project Timeline	Sources of HIE Data (e.g., hospital inpatient, primary care, etc.)	Types of Requested Data Available (e.g., medication, diagnosis, etc.)	Prior Mother-Infant Record Linkage Experience	Uses FHIR	Processes for Making Data Available for Research
Contexture (AZ)	No	All	Most	Yes	Limited	Yes
Connxus (TX)	Yes	Most	Some	Yes	Yes	Yes
CyncHealth (NE)	Yes	All	All	Yes	Yes	Yes
HealtheConnections (NY)	Initially yes, but later became unavailable	All	Most	Yes	Yes	Yes
MyHealth Access Network (OK)	Did not complete form (alerted NORC team via email they were unavailable during the project timeline)	Did not complete form	Did not complete form	Did not complete form	Did not complete form	Did not complete form
OneHealthPort (WA)	No	Some	Most	No	Limited	Yes

Appendix D. Data Elements Extracted in Pilot

Category	Data Elements
Maternal Characteristics	• Age • Race • Ethnicity • Level of education • Language • Medicaid Coverage Status
Mental Health Diagnosis	• Depression • Anxiety • Bipolar Disorder • Psychosis
Other Maternal Diagnoses	• Diagnosis of High Blood Pressure During Pregnancy • Diagnosis of Gestational Diabetes • Diagnosis of Preeclampsia During Pregnancy • Diagnosis of Preeclampsia Postpartum • Diagnosis of Suicide Ideation • Diagnosis of Suicide Attempt • Diagnosis of Labor and Delivery Complication
Prenatal Care	• Gestational Weeks at First Prenatal Visit • Number of Prenatal Visits • Maternal Weight at Initial Prenatal Visit • Maternal Weight at Final Prenatal Visit
Delivery and Pregnancy Outcomes	• Date of Labor and Delivery • Cesarean Section (Y/N) • Vaginal Delivery (Y/N) • Still Birth • Pregnancy Loss (Miscarriage or Ectopic Pregnancy)
Postpartum Care	• Date of First Postpartum Visit • Diagnosis of High Blood Pressure Postpartum
Mental Health Screening	• Initial PHQ-9 Score • Latest PHQ-9 Score • Initial EPDS Score • Latest EPDS Score • Initial GAD-7 Score • Latest GAD-7 Score • Initial GAD-2 Score • Latest GAD-2 Score • Initial Perinatal Anxiety Screening Scale • Latest Perinatal Anxiety Screening Scale • Initial Mood Disorder Questionnaire • Latest Mood Disorder Questionnaire

Category	Data Elements
Medications	• Medication Prescriptions • Date of Initial Prescriptions • Date of Medication Refills • Serum Levels for Mood Stabilizers
Psychiatry/ Psychotherapy	• Date of Psychotherapy Referral • Date of Initiating Psychotherapy • Number of Psychotherapy Appointments • Type of Therapy Received
Hospital Utilization	• Number of Emergency Department Visits • Number of Psychiatric Hospitalizations
Infant Outcomes	• Gestational Age at Delivery • Infant Weight at Birth • Diagnosis of Congenital Defect • Diagnosis of Developmental Delay • Neonatal Intensive Care Unit Admission • Date of Initial Well-Baby Visit • Infant Death Within One Year

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