MaternalHealthLink

# Agenda

## Project Overview

## Standards Overview

## Tooling and MaternalHealthLink (MHL)

- Piloting MHL
- Data Visualization
- Future Recommendations

# Project Overview

## Background

The U.S. lacks consistent ways to collect and share data needed to analyze how a pregnant woman's longitudinal medical history and socioeconomic and demographic characteristics affect outcomes for both the mother and infant.

## Purpose

Develop a standardized approach to link electronic data on maternal and infant health for use in studying the effect of medical conditions and/or interventions on pregnant, postpartum, or lactating women and their infants.

**Produce a final HL7® published standard and distribute to research and public health partners. Pilot the standard using open-source tooling.**

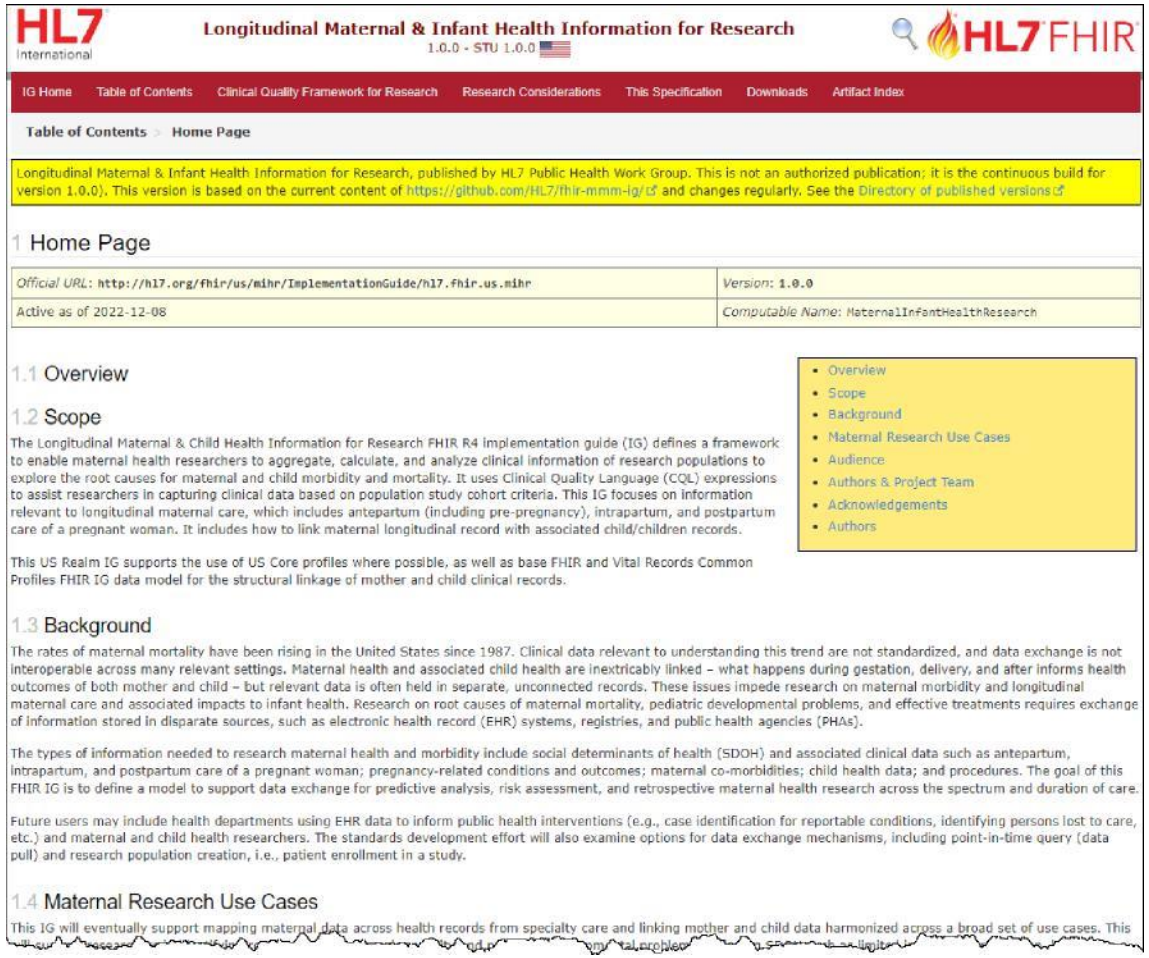
# Standards Overview

## Longitudinal Maternal & Infant Health Information for Research FHIR IG

## Clinical Reasoning Module framework

## Two Use Cases

- Hypertensive disorders of pregnancy
- Pregnancy associated maternal deaths



HL7 International

Longitudinal Maternal & Infant Health Information for Research
1.0.0 - STU 1.0.0

HL7 FHIR

IG Home | Table of Contents | Clinical Quality Framework for Research | Research Considerations | This Specification | Downloads | Artifact Index

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Longitudinal Maternal & Infant Health Information for Research, published by HL7 Public Health Work Group. This is not an authorized publication; it is the continuous build for version 1.0.0). This version is based on the current content of https://github.com/HL7/fhir-mmm-ig/ and changes regularly. See the Directory of published versions

1 Home Page

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|---|---|
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- Overview
- Scope
- Background
- Maternal Research Use Cases
- Audience
- Authors & Project Team
- Acknowledgements
- Authors

1.1 Overview

1.2 Scope

The Longitudinal Maternal & Child Health Information for Research FHIR R4 Implementation guide (IG) defines a framework to enable maternal health researchers to aggregate, calculate, and analyze clinical information of research populations to explore the root causes for maternal and child morbidity and mortality. It uses Clinical Quality Language (CQL) expressions to assist researchers in capturing clinical data based on population study cohort criteria. This IG focuses on information relevant to longitudinal maternal care, which includes antepartum (including pre-pregnancy), intrapartum, and postpartum care of a pregnant woman. It includes how to link maternal longitudinal record with associated child/children records.

This US Realm IG supports the use of US Core profiles where possible, as well as base FHIR and Vital Records Common Profiles FHIR IG data model for the structural linkage of mother and child clinical records.

1.3 Background

The rates of maternal mortality have been rising in the United States since 1987. Clinical data relevant to understanding this trend are not standardized, and data exchange is not interoperable across many relevant settings. Maternal health and associated child health are inextricably linked – what happens during gestation, delivery, and after informs health outcomes of both mother and child – but relevant data is often held in separate, unconnected records. These issues impede research on maternal morbidity and longitudinal maternal care and associated impacts to infant health. Research on root causes of maternal mortality, pediatric developmental problems, and effective treatments requires exchange of information stored in disparate sources, such as electronic health record (EHR) systems, registries, and public health agencies (PHAs).

The types of information needed to research maternal health and morbidity include social determinants of health (SDOH) and associated clinical data such as antepartum, intrapartum, and postpartum care of a pregnant woman; pregnancy-related conditions and outcomes; maternal co-morbidities; child health data; and procedures. The goal of this FHIR IG is to define a model to support data exchange for predictive analysis, risk assessment, and retrospective maternal health research across the spectrum and duration of care.

Future users may include health departments using EHR data to inform public health interventions (e.g., case identification for reportable conditions, identifying persons lost to care, etc.) and maternal and child health researchers. The standards development effort will also examine options for data exchange mechanisms, including point-in-time query (data pull) and research population creation, i.e., patient enrollment in a study.

1.4 Maternal Research Use Cases

This IG will eventually support mapping maternal data across health records from specialty care and linking mother and child data harmonized across a broad set of use cases. This

# Standards Overview and Health Level Seven (HL7®)

| TIMELINE | HL7 ACTIVITY/PROCESS |
|---|---|
| 2021—May, Sep<br>2022—Jan, May, Sep | **Socialize** the Implementation Guide (IG) at HL7 Working Group Meetings (WGM)<br>• Project Proposal<br>• Project Scope Statement (PSS) – HL7's Public Health WG (sponsor) |
| **Phases:**<br>Connectathon(s)-ready<br>IG Ballot-ready IG<br>Publication-ready IG | **IG Development (iterative)**<br>• Requirements gathering, data analysis, environmental scan<br>• Stakeholder engagement, Technical Expert Panel, HL7 Guidance<br>• Feedback from FHIR Connectathons, ballot comments, non-ballot comments |
| 2022—Jan, Sep | **Tested**<br>• At 2 FHIR Connectathons gathering feedback to inform the IG |
| Feb—May 2022 | **Ballot**<br>• Notice of Intent to Ballot (NIB)<br>• Prepare ballot-ready IG<br>• 1-month Open ballot-comment period |
| May 2022 (began) | **Ballot reconciliation & IG Updates**<br>• Review, triaged comments<br>• Disposition, seek approval<br>• Update IG based on approved comments |
| January 2023 (began) | **Publication**<br>• Seek HL7 approvals |

# Tooling—MaternalHealthLink (MHL)

## Significant milestone—to publish the first Longitudinal Maternal & Infant Health Information for Research IG

- An IG is only as good as its adoption rate. Identifying tools and strategies to increase widespread adoption is key to making progress
- To ease adoption and the implementation burden, Lantana piloted automation and standards tooling using MaternalHealthLink for research data acquisition.
- An open-source, measure-based application, MaternalHealthLink provides data access and flexibility to accommodate researchers' needs over time.

# What is MHL?

MaternalHealthLink was customized from NHSNLink, an open-source FHIR application for public health reporting developed under contract with CDC's National Healthcare Safety Network (NHSN).

NHSNLink's architecture connects securely to electronic health record (EHR) systems via a standard, open application programming interface (API).

The application extracts data, evaluates data using pre-defined measures, generates measure and patient-level reports, and submits data directly to NHSN.

# What is MHL?

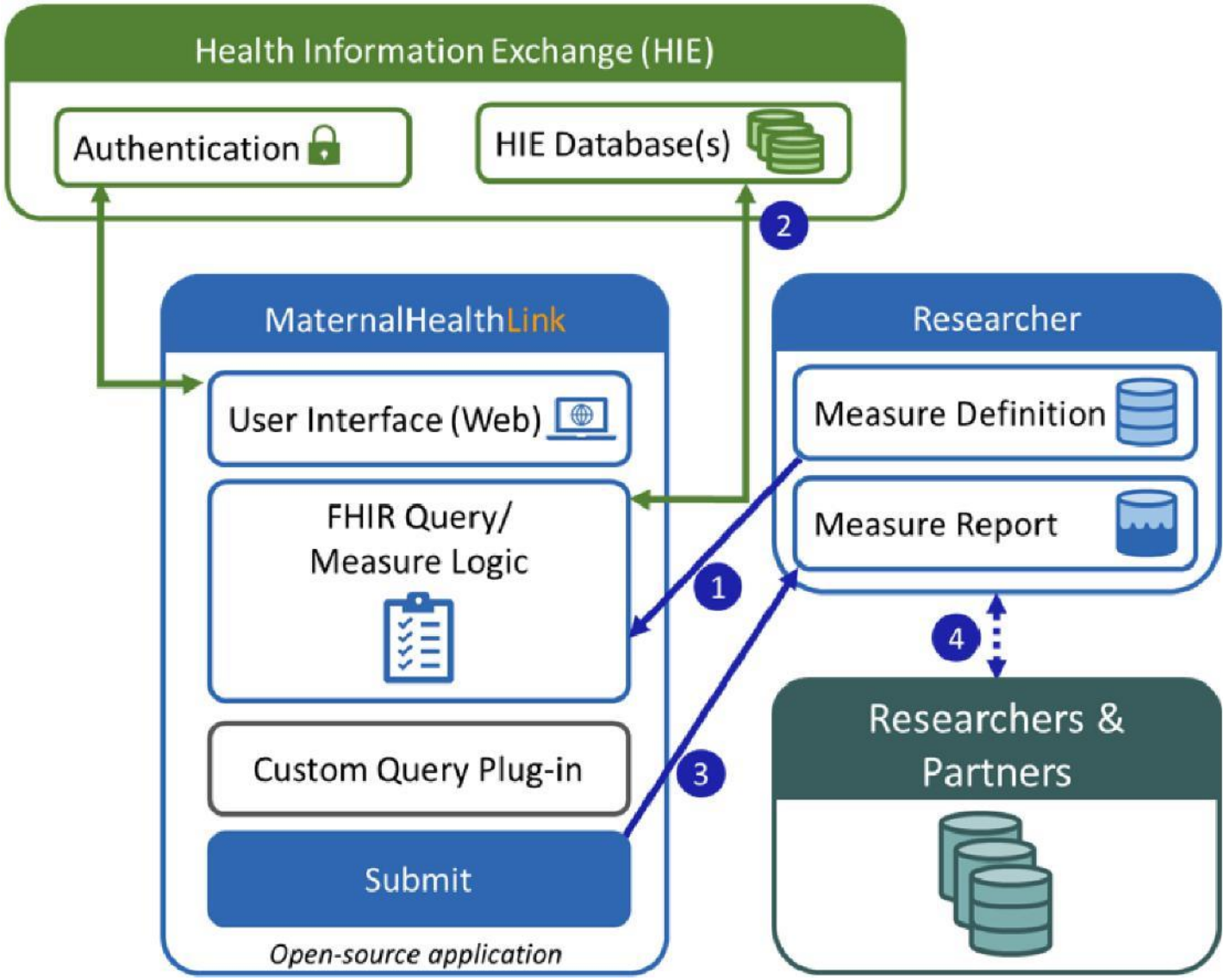
## Lantana

- Customized NHSNLink for MaternalHealthLink
- Proposed piloting it with a health information exchange (HIE) to automate data collection
- Developed measures to support data collection for cohort populations

## Measures ("Research Questions")

1. Death within 365 days of the end of a pregnancy
2. Pregnant person with diagnosed hypertensive disorder of pregnancy

# Piloting MaternalHealthLink



## Pilot Tasks Included

- Defining criteria for ideal pilot site
- Identifying and recruiting a pilot site – **HealtheConnections selected (NY HIE)**
- Finalizing business and legal agreements with pilot site administrators
- Leading technical implementation planning and training sessions
- Performing initial data collection to assess data quality and completeness prior to subsequent pilot data collection
- Providing technical support through pilot launch and testing
- Making data available in a visualization environment (i.e., Microsoft® Power BI)
- Drafting a final pilot report that summarizes lessons learned and recommendations for next steps

## Development Work Included

- Authentication setup ("successful handshake between HeC and MHL")
- Updating user interface to accommodate researchers
- Automating child queries for mothers determined to be in-cohort
- Setting up FHIR sandbox environment in HeC
- Developing simple Microsoft PowerBI visualization to easily see resultant data

# Pilot Success

| | |
|---|---|
| Obtain | Obtained a pilot participation agreement from an HIE or similar health data aggregator |
| Integrate | Integrated the MaternalHealthLink application with the pilot site |
| Collect | Calculated the two new measures and collected aggregate deidentified data for the linked mother/child target population |
| Visualize | Produced a simple Microsoft® Power BI visualization of the reported data |
| Report | Delivered a final report with recommendations for scaling MaternalHealthLink |

# Future Recommendations

# Future Recommendations

## Conduct second expanded pilot with real research study

- Test for incorporation of additional data sources
- Increase direct engagement by researchers
- Test scalability of solution with greater volume of data from multiple sources
- Increase understanding of data quality and analytics needs of researchers

## Enhance MHL security and authentication options

## Scale MHL capabilities for identity management

## Account for appropriate resources to support expected data persistence

## Develop maternal health research tool kit

# Closing