



EOHHS Ecosystem

November 17, 2022

4:00-5:15 pm

RHODE
ISLAND

The Rhode Island EOHHS Data Ecosystem

Agenda

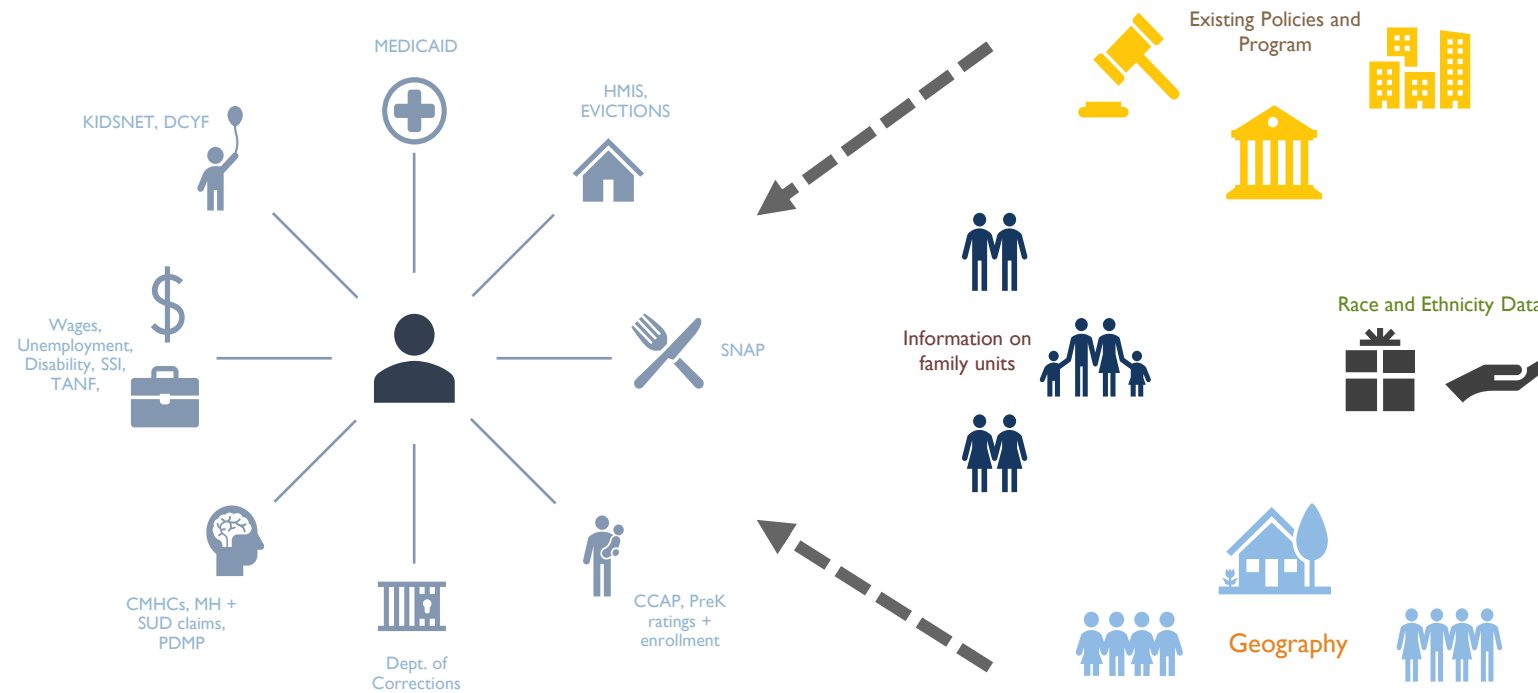
- What is the RI EOHHS Data Ecosystem?
- Data Governance Framework
- Future Vision
- Questions

THE RI EOHHS Data Ecosystem

- Established in 2017, the Rhode Island Data EOHHS Ecosystem is an integrated data system that links data at the person and family level across state agencies to drive holistic improvements in human well-being.
- It allows the state of Rhode Island to ask and answer complex questions spanning state agencies. Through carefully governed, permissioned access to de-identified data, we empower state leaders and community voices with the information they need to best serve the people of Rhode Island.
- Key Ecosystem projects include:
 1. Developing effective analytic files that are targeted to specific business needs and can be efficiently exchanged within and across agencies,
 2. Creating interagency analytic teams to identify over-arching cross-agency programs that meet organizational priorities,
 3. Establishing inter-agency performance analytics that serves the oversight and monitoring functions of all agencies with an equity lens.

THE EI EOHHS Ecosystem Continued

The RI Data Ecosystem pulls together data from many different sources to provide a more complete, interconnected picture of the well-being of individuals, families and communities in Rhode Island



Once linked across data sources, all Ecosystem data are de-identified

What Data are Included in the Ecosystem?

Agency	Fully Integrated Data Sets (At the Person-Level)
Medicaid	Medical and pharmacy claims; enrollment
Medicaid	Early intervention (EI) evaluation and encounters data
DCYF	Case management (RICHST)
DHS	TANF, SNAP, CCAP, SSI, & SSDI program eligibility (BRIDGES)
DLT	Wages, employer, and industry records
DLT	Temporary Disability Insurance (TDI) claims
DLT	Temporary Caregiver Insurance (TCI) claims
DLT	Unemployment Insurance (UI) and Pandemic Unemployment Assistance (PUA) claims
DLT	Workers Comp data
DLT	Real Pathways, Real Skills, and Real Jobs program data
DOH	Child screening, immunization, outreach program referrals (KIDSNET)
DOH	Birth and death records (VITALS)
DOH	Race and ethnicity data (VITALS)
DOH	COVID testing, cases, and vaccination data
RICEH	HMIS housing insecurity and homelessness data
(APCD)	Medical and pharmacy claims; enrollment *APCD data is <u>not</u> linkable to other Ecosystem datasets
Agency	Newly Integrated Datasets
RIDOC	Incarceration, trial, and probation data
Unite Us	Social determinants of health and referrals data
Agency	Limited Use Datasets *Data is stored separately and can only be used for specific pre-approved projects
DHS	Long-term Services & Supports (LTSS) application and billing data
DOH	Prescription Drug Monitoring Program (PDMP) data
RIDE	Education data

The Value of Integrating Data

Provide better understanding of the **whole person** and their various service touchpoints

Fill in data gaps across datasets – especially related to social determinants of health

Enable **comprehensive** performance analytics and program evaluations across state agencies

Data Governance

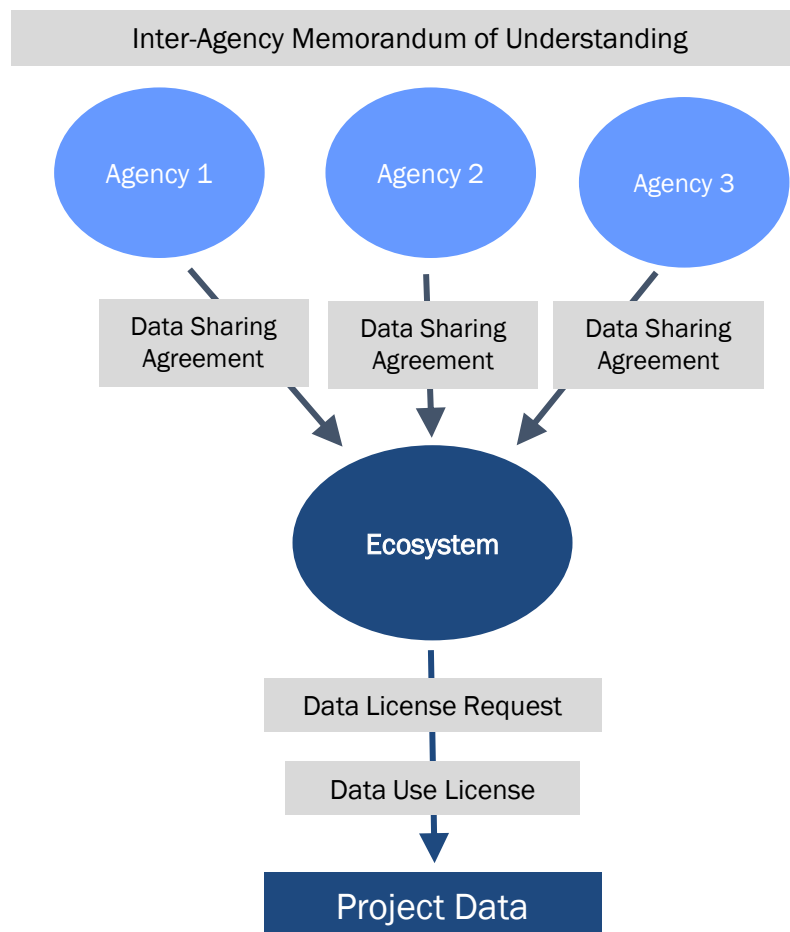
Data Governance – Legal Documents

The **Inter-Agency Memorandum of Understanding** documents the vision, mission, and governance process of the EOHHS Ecosystem.

The **Data Sharing Agreement** is a two-party agreement signed by each of the data providers and EOHHS that allows data to flow into the Ecosystem.

The **Data License Request** is the “application” for data. It is completed by the data requester in coordination with the Ecosystem team and executed by all data stewards whose data are being requested. It includes the data requester's credentials, project purpose, project methodology, a statement of benefit, and how the project will center equity. This document includes all data tables and data elements requested for a project.

The **Data Use License** is a multi-party agreement signed by the data recipient and EOHHS once a Data License Request has been approved by all data stewards. Importantly, it only allows for anonymized data to be released to data recipients. Recipients are required to safeguard the data (security controls, re-disclosure restrictions, and cell suppression policy) and are accountable for unauthorized access, use, or disclosure.



Data Governance - Roles

Executive Board Directors of agencies or organizations that submit data and other significant stakeholders (IT, Gov's office)

Meets quarterly | Sets priorities for Ecosystem | Directors are data owners and sign DSAs + I-MOUs | Legal chiefs advise directors but do not sign documents

Data Stewards 1 person per data set who has the expertise and authority to review and approve data use
Meet monthly | Sign project approvals and materials before publication | Advised by agency and community SMEs as needed

Project Advisors State and community subject matter experts who guide projects from inception through dissemination

Meet as needed | Influence and advise but do not veto / approve

Ecosystem Team Staff; propose, support, and complete projects; maintain operations and the data asset; frame decisions for Board + Stewards

Advise and guide Board + Stewards | Implement direction of Board + Stewards

Recent Projects



Central Demographics Table

Large amount of missing or “Other” race and/or ethnicity data within most data sources

We see *changes* in self-reported race and ethnicity within the same data source, over time

- Example: the same person has identified as one race/ethnicity at first, and then a different race/ethnicity later, within Medicaid data

We see *changes* in self-reported race and ethnicity across data sources

- Example: the same person has identified as one race/ethnicity in the Medicaid data but a different race/ethnicity in the COVID vaccine data

Different source systems collect data differently

- Example: Some systems consider race and ethnicity separate concepts while others combine them
- Example: Some systems allow the selection of multiple races while others force a single selection

No single source system represents the entire population

Central Demographics Table Development

Community Stake holders and Data Stewards Convened to Arrive at the Final Decision:

- Identify all data sources that have race and ethnicity data
- Do not standardize race and ethnicity categories – keep R&E data as detailed as possible, in the way it comes in (as opposed to converting to standard OMB or Census categories)
- Conflicts within same data source – use most recently provided data
- Conflicts across data sources:
 1. Prioritize self-reported data sources, those updated most frequently, and those offering most allowable values and multi-selection for R&E
 2. Prioritize most recently provided data at the record-level
 3. Consider data use frequency and quality

Conflicts Across Data Sources Analysis

Priority Order	Self-report	Recency	Data Use, Quality	Standard fields	Multi select
COVID Vaccines	<ul style="list-style-type: none"> Self-scheduled: Yes Pharmacy / Provider: likely Children: Vitals / Birth Cert as reported by parent or PCP 	<ul style="list-style-type: none"> Self-scheduled: At time of Vaccine Pharmacy / Provider: Various Children: Birth or various if from provider 	Used Often	Census + Multiple Races, Unknown	
COVID Cases	X	At time of case	Used Often	Census + Multiple Races, Declined, Unknown	
COVID Tests	Yes, for self-scheduled	At time of test	Self-scheduled: Used often	Census + Multiple Races, Declined, Unknown Detailed nationality collected – not yet in the Ecosystem	
RIQI / CurrentCare	Various	Patient registration; ad hoc thereafter	Used Often	Census + Multiracial, No Data Available, Patient Refused, UNK	
HMIS	X	At intake	Used Often	Census	√
DCYF	X	At intake	Used Often	Census, with ability to multi-select on detailed nationality (limited responses)	
Medicaid	X	At recertification	Minimal Use	Census with detailed nationality selection, but limited responses	
Bridges	X	At recertification	Minimal Use	Census with detailed nationality selection, but limited responses	
Vitals (Births)	X	At birth	Used Often	Detailed nationality-based selections that can be rolled up to Census categories	√

What We Learned and Where we Landed

Central Demographics Table Includes:

- A record for each unique set of Race/Ethnicity values from each source system
- Eco_ID for longitudinal tracking and linking across data sets.
- Source System for each record (e.g. “HMIS” or “Medicaid”)
- Date of collection or observation
- Source Priority indicating relative priority assigned to this data source
- A “Recommended_Race” flag to indicate that this record is the one recommended to represent this person’s race
- A “Recommended_Ethnicity” flag to indicate that this record is the one recommended to represent this person’s ethnicity
- Race Fields: “African American”, “Asian” (also comprises Pacific Islander), “American Indian”, “White”, “Race Declined to Answer”, “Race Other”, “Race Unknown”, “Race Multiple”, “Race Description”
- Ethnicity Fields: “Hispanic”, “Hispanic Declined to Answer”, “Ethnicity Description”

What We Learned and Where we Landed

Condensed the Central Demographics Table to a “Best Race/Ethnicity Table” to simplify reporting

- Each Eco_ID has one record in this table
- Includes only the best available race and ethnicity data
- Also includes a field combining race and ethnicity (Priority is given first to "Hispanic", then to "Multiracial" over the person's specific races.)

Take Aways

Important Take-Aways from the Process

- Get Started. Do not let Perfection be the Enemy of Better
- Data, especially regarding Race and Ethnicity, are messy
- Design a model that best represents the available data, with all their limitations
- Acknowledge and document the limitations
- Ensure the known limitations are expressed in all data visualizations
- Respect people's self expression
- Advocate for improved data collection up the data supply chain
- This is marathon, not a sprint. But get running

The Future Vision

Ecosystem Goals for the Coming Year

Integration of Covid QI data from RIDOH, Court data, and DLT data

Creating an amendment to our IMOU for the agencies under EOHHS to be able to **share** data more quickly and easily

Consolidation and streamlining of all EOHHS **data request/review/approval processes**

Focus on Ecosystem as the **trusted database of choice** for RI EOHHS state agencies

- Prioritizing high value data questions and projects that **support our internal organizations**
- Establishing dashboards (both internal and external facing) that showcase **interagency collaboration**
- Continuing to build our **demographic data** by combining multiple sources of data

Questions?

**RHODE
ISLAND**