EOHHS Data Ecosystem

Central Demographic Table Discussion

HIT Steering Committee

December 16, 2021

EOHHS Data Ecosystem

People are not slices of data.
We are whole human beings,
raised in families,
rooted in communities,
bearing our history.

The Data Ecosystem honors this complexity by connecting information from across our state so we can **serve Rhode Islanders with respect, relevance, and understanding**. It 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**.

GOVERNANCE MATTERS
DIFFERENT LAYERS OF AUTHORITY, EXPERTISE, AND RESPONSIBILITY

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

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

Data Stewards: One person per data set who has the expertise and authority to review + approve data use

Meet monthly | Sign project approvals and materials before publication | Advised by agency and community SMEs as needed

Project advisors: State + community subject matter experts who guide projects from inception through dissemination

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

Ecosystem Team: Staff; propose, nurture, and in some cases complete projects; maintain operations and the data asset; frame decisions for Board + Stewards

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

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ECOSYSTEM DATA SOURCES

Some of our data sources include:

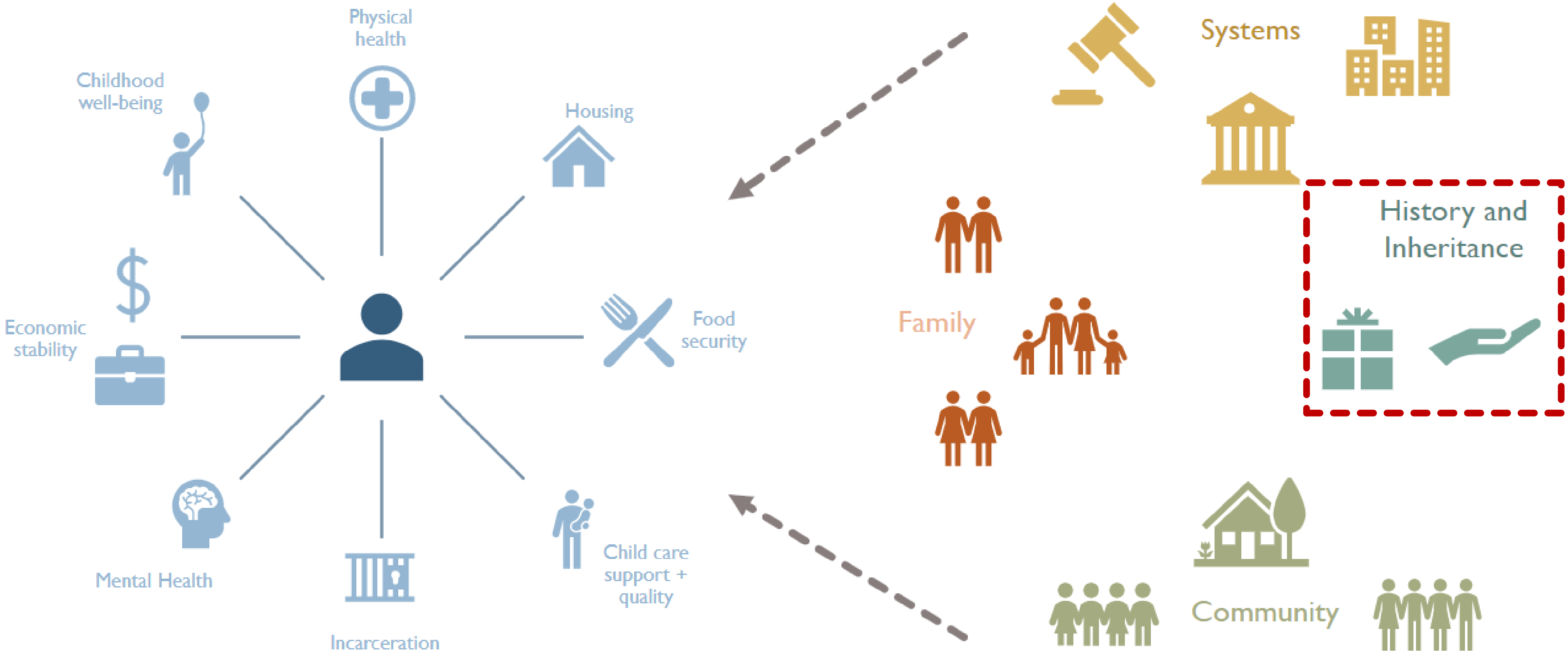
- RI Medicaid claims, encounters, and enrollment
- Dept. of Human Services programs including: TANF, SNAP, CCAP, and SSI
- Wages, income insurance, and job training from the Department of Labor and Training
- Child screening, immunization, and outreach program referral from the RI Dept. of Health
- Birth and death records
- Housing insecurity and homelessness data
- COVID testing, case, and vaccine information
- Developmental disabilities case management data from the RI Dept. of Behavioral Healthcare, Developmental Disabilities, and Hospitals
- Rhode Island Courts data

We are always working to intake data from additional sources. They currently include:

- Department of Corrections data
- Unite Us data on social service referrals and SDoH

Well-being is a web of personal, family, system, and generational influences.

But we are too quiet on racial disparities, not because we don't care – because we lack reliable data.



Physical health

Childhood well-being

Housing

Economic stability

Food security

Mental Health

Incarceration

Child care support + quality

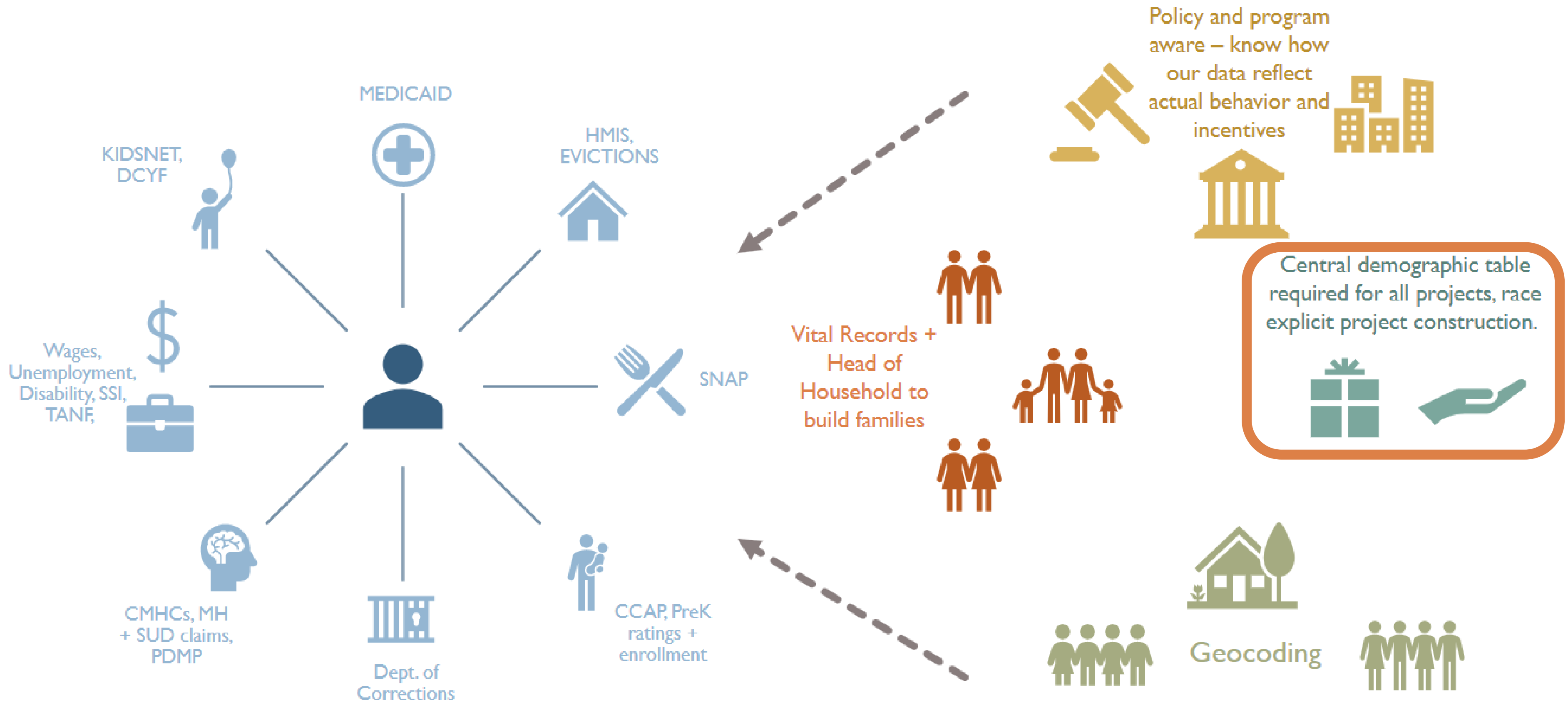
Systems

Family

History and Inheritance

Community

Ecosystem architecture and process honor the dimensions of complexity and connectedness.



MEDICAID

HMIS, EVICTIONS

SNAP

CCAP, PreK ratings + enrollment

Dept. of Corrections

CMHCs, MH + SUD claims, PDMP

Wages, Unemployment, Disability, SSI, TANF,

KIDSNET, DCYF

Policy and program aware – know how our data reflect actual behavior and incentives

Vital Records + Head of Household to build families

Central demographic table required for all projects, race explicit project construction.

Geocoding

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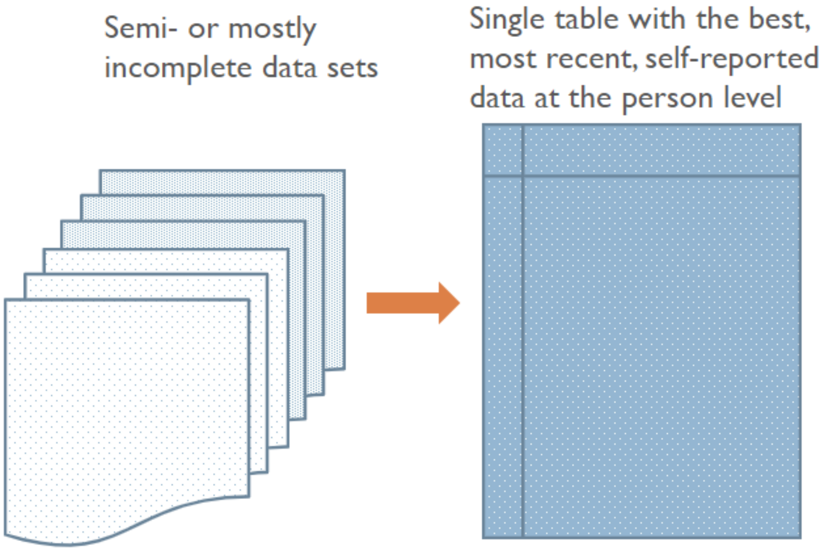
CENTRAL DEMOGRAPHIC TABLE VISION



- **Intention**: Ensure that every project can highlight the full, accurate picture of disparities and gaps in equity
- Ensure that the process of integrating these data respects **privacy, autonomy, and consent** of those represented in the data
- Develop a clear, functional, and respectful **governance structure** to ensure that use of this table conforms to Ecosystem standards

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Central Demographic Table Scope

Not in scope right now

- **Demographic data beyond race and ethnicity**. We plan to repeat this process for language, disability, SOGI, and immigration status, among other categories in the future
- **Data flowing back and integrating with source systems**. It could be a future feature – but is not the focus of our work right now

ADVISORY GROUP MEETINGS TO DATE

Week of	Meeting #, Audience	Topics
July 26th	Meeting 1 | State team	Standard categories | Conflicts within data source
August 31st	Meeting 2 | State team	Conflicts among sources: Characteristics of data sets
September 1th	Meeting 0 | Comm. Leaders	Community Advocates – Intro and Context Meeting
September 13th	Meeting 1 | Comm. Leaders	Standard categories | Conflicts within data source
September 20th	Meeting 2 | Comm. Leaders	Conflicts among sources: Characteristics of data sets
September 27th	Meeting 3 | Combined	Review Recommendations and prioritize data sets
October 4th	Meeting 4 | State team	Governance of central table

Summary of "best practice" recommendations so far

To the extent possible, race and ethnicity data collection should

- Be self-reported
- Be updated at least on an annual basis
- Combine race and ethnicity (the Census makes the case for this **here**, strongly supported by the community leaders)
- Collect details on nationality
- Offer "decline to respond" as an option
- Offer multi-selection

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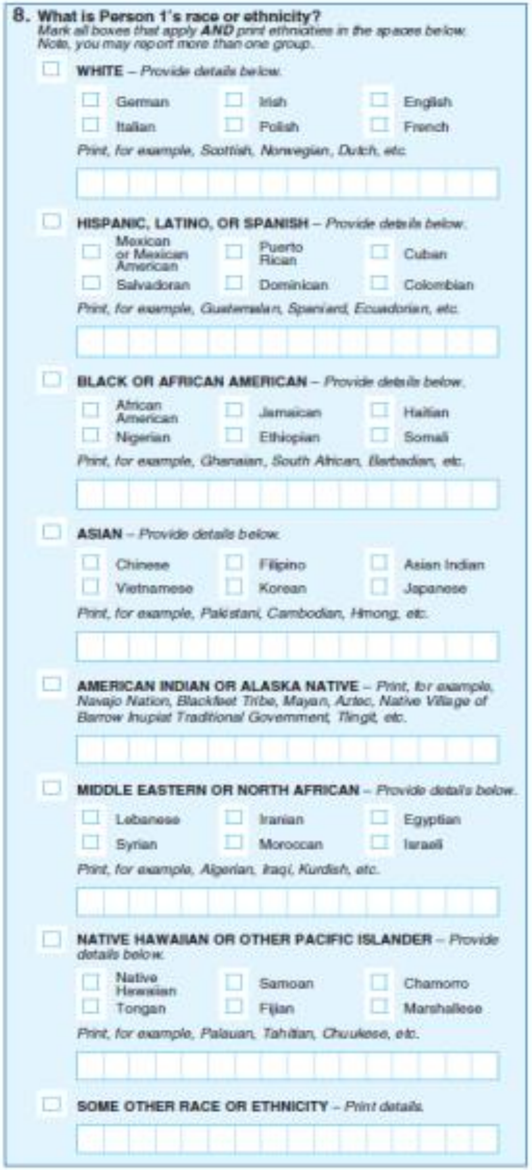
Detailed recommendations so far

1. Main categories:
   - **Census categories** as the recommended high-level categories for comparisons.
     - Community recommend using *nationality and tribal affiliation* where available and sufficiently populated as the default categorization, rolling up to census categories only as needed.
     - If multiple data sets report nationality, we will default to the highest priority data set (right now, this is Vitals Births)
   - **Combine race and ethnicity** per Census Bureau recommendations
     - Most Ecosystem data sets have separate race and ethnicity fields that we may opt to combine after collection. The exception is COVID Cases + Tests, which combines the race and ethnicity question.

2. Conflict within a single data source: choose **most recent affirmative record**
   - Community wrestled with this: sometimes a blank / no response *is an affirmative response*. But because we can't assume intent, and there are not often options for "decline to answer", the group agreed to use the most recent non-blank response.

Combined race/ethnicity question designed via Census Bureau research



8. What is Person 1's race or ethnicity?
Mark all boxes that apply ***AND*** *print ethnicities in the spaces below. Note, you may report more than one group.*

☐ **WHITE** – *Provide details below.*
☐ German ☐ Irish ☐ English
☐ Italian ☐ Polish ☐ French
Print, for example, Scottish, Norwegian, Dutch, etc.

☐ **HISPANIC, LATINO, OR SPANISH** – *Provide details below.*
☐ Mexican or Mexican American ☐ Puerto Rican ☐ Cuban
☐ Salvadoran ☐ Dominican ☐ Colombian
Print, for example, Guatemalan, Spaniard, Ecuadorian, etc.

☐ **BLACK OR AFRICAN AMERICAN** – *Provide details below.*
☐ African American ☐ Jamaican ☐ Haitian
☐ Nigerian ☐ Ethiopian ☐ Somali
Print, for example, Ghanaian, South African, Barbadian, etc.

☐ **ASIAN** – *Provide details below.*
☐ Chinese ☐ Filipino ☐ Asian Indian
☐ Vietnamese ☐ Korean ☐ Japanese
Print, for example, Pakistani, Cambodian, Hmong, etc.

☐ **AMERICAN INDIAN OR ALASKA NATIVE** – *Print, for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Tlingit, etc.*

☐ **MIDDLE EASTERN OR NORTH AFRICAN** – *Provide details below.*
☐ Lebanese ☐ Iranian ☐ Egyptian
☐ Syrian ☐ Moroccan ☐ Israeli
Print, for example, Algerian, Iraqi, Kurdish, etc.

☐ **NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER** – *Provide details below.*
☐ Native Hawaiian ☐ Samoan ☐ Chamorro
☐ Tongan ☐ Fijian ☐ Marshallese
Print, for example, Palauan, Tahitian, Chuukese, etc.

☐ **SOME OTHER RACE OR ETHNICITY** – *Print details.*

Detailed recommendations so far

3. Priority data set **characteristics** : (1) self-reported, (2) recent, (3) frequent use of demographic data, (4) nationality data available [recommendation from community], (5) multi-select available

4. Community teams affirmed data set **priority order** (next slide)

5. Affirmed need for best practices for **data collection**, with HIT Steering Committee as a key audience

Priority Order of Ecosystem Data Sets

Priority Order	Self-report	Recency	Data Use, Quality	Standard fields	Multi select
COVID Vaccines	• Self-scheduled: Yes • Pharmacy / Provider: likely • Children: Vitals / Birth Cert as reported by parent or PCP	• Self-scheduled: At time of Vaccine • Pharmacy / Provider: Various • Children: Birth or various if from provider	Used Often	Census + Multiple Races, Unknown	X
COVID Cases	X	At time of case	Used Often	Census + Multiple Races, Declined, Unknown	X
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	X
RIQI / CurrentCare	Various	Patient registration; ad hoc thereafter	Used Often	Census + Multiracial, No Data Available, Patient Refused, UNK	X
HMIS	X	At intake	Used Often	Census	
DCYF	X	At intake	Used Often	Census, with ability to multi-select on detailed nationality (limited responses)	X
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	X
KIDSNET	• Rhode Island births: as reported by mother on birth cert • Other: Reported by PCP, unclear self-report	• Rhode Island births: at birth • Other: Various	Used Often	Vitals Births	X

NEXT STEPS

- Broader community engagement via structures established through the CDC COVID racial and ethnic health disparities grant and in coordination with EOHHS' Director of Race Equity and Community Engagement.
- Finalize governance of the central demographic table with EOHHS legal. Likely an I-MOU/DSA supplement versus obtaining sign-off from all Data Stewards on all projects.

DISCUSSION

- Given that many organizations are working on this shared issue, **how can we best work together**?
- Are there any best practices that seem **achievable**? What have you been doing that is effective in improving data collection?
- What are the **challenges and barriers** to operationalizing some of these best practices?
- What **training and resources** would be most impactful for improving data collection at the source?
- What could the **role of the HIT Steering Committee** be?

APPENDIX

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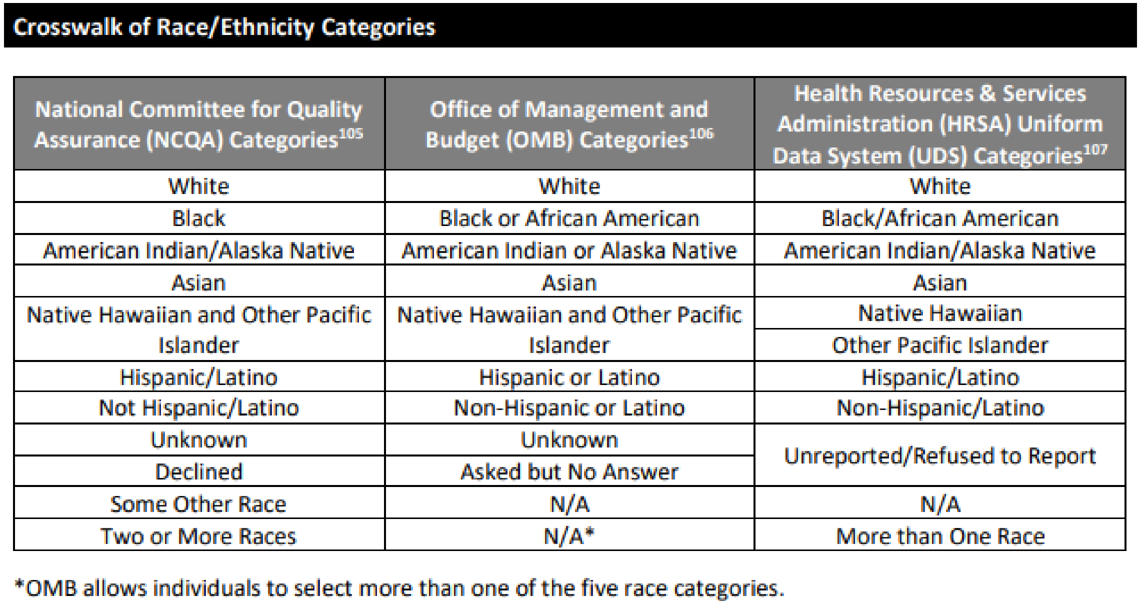
FOR REFERENCE: CROSSWALK OF REPORTING CATEGORIES

Different national authorities require different reporting categories.

Crosswalk of Race/Ethnicity Reporting Categories



Crosswalk of Race/Ethnicity Categories

National Committee for Quality Assurance (NCQA) Categories[105]	Office of Management and Budget (OMB) Categories[106]	Health Resources & Services Administration (HRSA) Uniform Data System (UDS) Categories[107]
White	White	White
Black	Black or African American	Black/African American
American Indian/Alaska Native	American Indian or Alaska Native	American Indian/Alaska Native
Asian	Asian	Asian
Native Hawaiian and Other Pacific Islander	Native Hawaiian and Other Pacific Islander	Native Hawaiian
		Other Pacific Islander
Hispanic/Latino	Hispanic or Latino	Hispanic/Latino
Not Hispanic/Latino	Non-Hispanic or Latino	Non-Hispanic/Latino
Unknown	Unknown	Unreported/Refused to Report
Declined	Asked but No Answer	
Some Other Race	N/A	N/A
Two or More Races	N/A*	More than One Race

*OMB allows individuals to select more than one of the five race categories.

Standard rolled Up Race and Ethnicity Fields based on Census (OMB 1997 guidelines) and Center for National Healthcare Statistics

https://www.cdc.gov/nchs/nhis/rhoi/rhoi_glossary.htm

Race
American Indian or Alaska Native
Asian
Black or African American
Native Hawaiian and Other Pacific Islander
Other
White
(Blank)
Ethnicity
Hispanic or Latino
Non-Hispanic or Latino
Unknown

Hispanic or Latino – A person of Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino."

Race – The revised race standards identify five categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. These represent the minimum categories for data on race and ethnicity for Federal statistics, program administrative reporting, and civil rights compliance reporting. The minimum categories are defined as follows:

- **American Indian or Alaska Native** – A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.
- **Asian** – A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- **Black or African American** – A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."
- **Native Hawaiian or Other Pacific Islander** – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- **White** – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

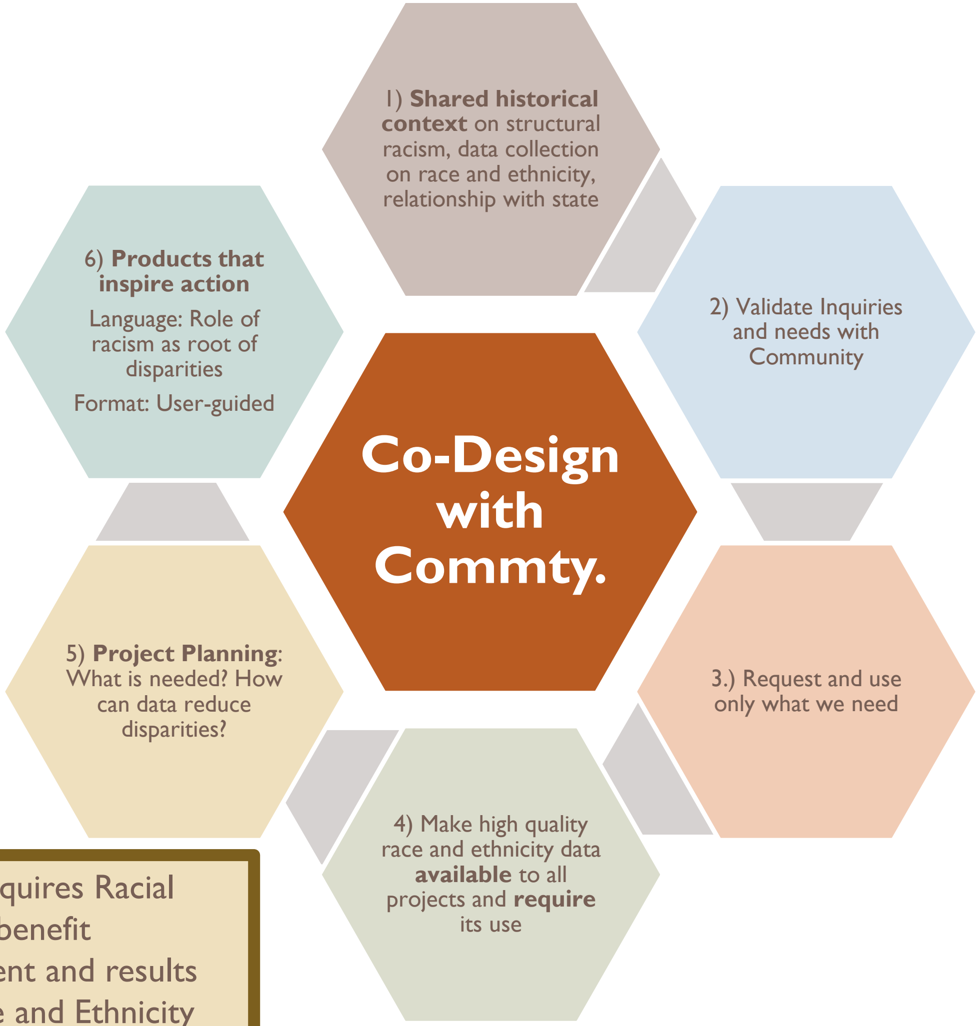
We recommend adding: Multiple Races, Declined, and Unknown

COVID CASES AND TESTS: COMBINED RACE + ETHNICITY

0.Hispanic or Latino (any race)
1.American Indian or Alaska Native (non-Hispanic or ethnicity unknown or declined)
2.Asian (non-Hispanic or ethnicity unknown or declined)
3.Black or African American (non-Hispanic or ethnicity unknown or declined)
5.White (non-Hispanic or ethnicity unknown or declined)
6.Other race (non-Hispanic or ethnicity unknown or declined)
7.Multiple races (non-Hispanic or ethnicity unknown or declined)
8.Declined race (non-Hispanic or ethnicity unknown or declined)
9.Unknown or pending further information

What does 'Centering Racial Justice in Integrated Data' mean to us?

Racism is a public health crisis. How can our data and language promote equity in actions, decisions, and understanding?



Co-Design with Commty.

1) **Shared historical context** on structural racism, data collection on race and ethnicity, relationship with state

2) Validate Inquiries and needs with Community

3.) Request and use only what we need

4) Make high quality race and ethnicity data **available** to all projects and **require** its use

5) **Project Planning**: What is needed? How can data reduce disparities?

6) **Products that inspire action**

Language: Role of racism as root of disparities

Format: User-guided

DLR requires Racial Justice benefit statement and results by Race and Ethnicity

Central Demographic Table that leverages the best self-reported and most complete R/E data

STATEMENT ON CENTERING RACIAL JUSTICE IN INTEGRATED DATA

Centering Racial Justice in Integrated Data Work

The Data Ecosystem recognizes that racism is a public health crisis, and a social determinant of health. All Data Ecosystem work will center in racial justice, have a race-explicit orientation, and promote racial equity.

Race Explicit means speaking about race or racism without vagueness, implication, or ambiguity. Centering efforts in race equity means that we seek to understand how institutional, societal, and interpersonal racism has differently, and negatively, affected the health, well-being, and economic opportunity outcomes for those who experience racism.

A race-explicit framework and a race equity lens includes:

- *Study planning that starts with a shared understanding of the role racism plays in the outcome(s)*
- *Study planning includes a representative group of stakeholders who experience racism and want to guide the analytic questions, data use, interpretation, and impact from start to finish.*
- *Study intent explicitly seeks to support, not punish or further harm, populations who currently do or who have historically experienced racism.*
- *All analyses show results by race, ethnicity and other key demographics (age, gender, SOGI, location) where possible – and identify means for completing data where not possible.*
- *Acknowledge the role the state government or non-state actors may have perpetuated these harms and seek healing, community-led, anti-racists paths forward as part of the study's findings and recommendations.*

For a reference framework, please refer to resources including Actionable Intelligence for Social Policy's Toolkit for Centering Racial Equity Throughout Data Integration and University of New Mexico's Community Based Participatory Research.

INVITED COMMUNITY LEADERS

Organization	Name
ARISE	Chanda
Bristol Health Equity Zone	Emily Spence
Cape Verdean American Community Development of RI	Elmer Pina
Center for Prisoner Health and Human Rights	Heather Gaydos
Center for Southeast Asians	Channavy Chhay
Cranston Health Equities Zone	Kayla Arrington
East Bay Community Action Plan	Rita Capotosto
Federation of Aboriginal Nations of the Americas (FANA)	Ray "Two Hawks" Watson
Latino Policy Institute	Marcela Betancur
Lifespan Community Health Institute	Carrie Bridges Feliz
Local Initiatives Supporting Corporation	Robin Hall
ONE NB / Olneyville HEZ	Dominique Resendes
ONE NB / Olneyville HEZ	Jennifer Hawkins

Organization	Name
Progreso Latino	Mario Bueno
United Way	Larry Warner
RI Coalition Against Domestic Violence	Cynthia Roberts
RI Indian Council	Darrell Waldron
RIPTA, NAACP	Jim Vincent
South County Community Action Agency	Susan Orban
Thundermist Health Center	Tamara Burman
TriCounty Community Action Agency	Kristen Edward
Rhode Island Foundation	Angie Ankoma
West Elmwood Housing Development Corporation	Jessica Thigpen
West Warwick Health Equity Zone	Susan Jacobsen
Women's Resource Center	Jessica Walsh