

**Care Transformation Collaborative of Rhode Island (CTC-RI) Demographic Data Collection Pilot  
Environment Scan: 1A.5 Baseline RI Demographic Data Collection Performance Assessment  
Report**

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## *Background*

The Rhode Island Department of Health (RIDOH) has been granted the Center for Disease Control and Prevention (CDC) National Initiative to Address COVID-19 Health Disparities among Populations at High-Risk and Underserved, including Racial and Ethnic Minority Populations and Rural Communities Award. As part of this grant, CDC has identified improving health outcomes with priority given to increasing and improving demographic data collection and reporting. Important activities associated with this strategy include:

- Building on plans for collecting and reporting timely, complete, representative, and relevant data (1);
- Educating providers, community partners and programs on the importance of data and how to collect it;
- Disseminating health equity-related data and related materials tailored to be culturally and linguistically responsive;
- Providing resources for collecting, analyzing, reporting, and disseminating health equity-related data and for data infrastructure and workforce.

Improving demographic data collection is a foundational activity for promoting health equity and addressing COVID-19 health disparities. COVID-19 has disproportionately affected populations who are medically underserved including community members who are Black, Indigenous, and People of Color (BIPOC) and people living in rural communities. The intent of improved demographic data collection is to assist providers who work with priority populations (including BIPOC communities, groups that are more effectively served in a language other than English, veterans, people who are unhoused or housing insecure, the LGBTQ+ community, people living with disability or in rural communities) apply this information to understand and improve gaps in care.

Two decades have passed since the 2002 publication of the Institute of Medicine (IOM) report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, which defined race as a “sociocultural” concept wherein groups of people sharing certain physical characteristics are treated differently” and which defined ethnicity as “shared culture and way of life.” The most pressing finding of the report was that “Racial and ethnic disparities in health care exist even when insurance status, income, age, and severity of conditions are comparable.” (2). Unfortunately, the Agency for Healthcare Research and Quality reported that in 2020, Black, Hispanic, and American Indian and Alaskan Native populations continue to experience significant disparities in healthcare quality (3). In 2021, the CDC reported that the rate of maternal mortality for non-Hispanic Black women was 2.6 times higher than for non-Hispanic white women. (4) Similarly, the importance of complete and accurate collection of demographic data has been equally well documented (5). Yet, the availability of demographics, including race, ethnicity, and language (REL) data has remained a challenge, even as the country responded to the COVID-19 pandemic. According to a Kaiser Family Foundation analysis of COVID-19 cases through April 2022, states varied considerably in the percent of COVID cases reported with unknown race, from 9% in Utah to 100% in North Dakota, with eight states reporting unknown race on greater than 50% of their cases. Rhode Island, matching the national mean, reported 36% of their COVID cases with race unknown (6).

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While state-wide, disease specific data on health disparities have been reported, to date, we are unaware of a systemic review of the completeness and quality of demographic data available in health systems across Rhode Island. This information is critical to multiple audiences in the state, including EOHHS, the Department of Health, as well as the Care Transformation Collaborative, as they develop interventions to reduce health disparities in the state. Additionally, key stakeholders in the healthcare industry, including payers and providers may find this information useful in establishing programs to improve the availability of complete and accurate demographic data. The focus of this report is on race, ethnicity, and language data, though additional information is provided about sexual orientation and gender identity (SOGI) where provided.

### *Approach*

The goal of this report was to conduct a landscape review to understand the current state of demographic data collection in the Rhode Island healthcare ecosystem, with a focus on completeness and quality of race, ethnicity and language data collected in primary care practices. EOHHS and the CTC Demographic Data Collection Pilot Project Planning Committee identified potential data sources for inclusion in this report. Data was obtained from the state's two primary data aggregators, the Quality Reporting System (IMAT Solutions) and the Health Information Exchange (Rhode Island Quality Institute), along with data from the Health Resources and Services Administration (HRSA), which requires that Federally Qualified Health Centers collect and report on demographic data through their Uniform Data System (UDS) (7,8). Additionally, EOHHS reached out to systems of care and commercial payers with a request to submit demographic data performance reports be sent to CTC. At the time of writing, Lifespan had submitted demographic data performance data which is included in this report. Finally, the data was evaluated for comparison with the 2020 US Census data (9) where applicable.

### *Key Findings*

#### **UDS**

Federally Qualified Health Centers (FQHC) and look-alike programs funded by the Health Resources and Services Administration (HRSA) are nonprofit organizations that provide or coordinate healthcare for underserved communities, including preventive healthcare, dental services, mental health, and substance use care, regardless of the ability of the individual to pay. FQHCs are required to provide data annually in a predetermined format to Uniform Data System (UDS), which HRSA uses to assess the quality of services rendered by the FQHCs as well as to promote quality improvement activities. The data collected reflects patient characteristics, services rendered, health outcomes, along with other health center operational and financial data. In Rhode Island, health centers pull these data from their varying electronic health records (EHRs), which include NextGen, eClinicalWorks, and others. All are required to use the Health and Human Services race and ethnicity standards, which in 2021, the reporting year available online at the time of writing, was limited to the 5 category Office of Management and Budget (OMB) race categories and the 2 category ethnicity categories. Health Centers offer patients the option to select more than one race and to decline to provide race and ethnicity data. Both the OMB standards

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and the HHS standards are currently in process review and change (10,11), and health centers are in the process of modifying their systems to accommodate more granular data collection.

Raw data obtained from data.HRSA.gov for calendar year 2021 for FQHCs in Rhode Island is included in this report as Appendix I, which provides the data aggregated for the entire state, and Appendix II, which provides practice level data for the five years ending in 2021. Rhode Island’s FQHCs reported providing services to 189,496 patients in 2021, or approximately 17% of Rhode Island’s population. Data available on data.HRSA.gov provided more detail on racial breakdowns than included in this section of our report, which is focused on data completeness. No information is available about the quality or accuracy of the data in the EHR used to populate the UDS reports. UDS reports combine declined to respond and unknown categories.

Table 1, below, provides a summary of data availability for key demographic data collected by Rhode Island’s FQHCs in 2021 (race, ethnicity, preferred language, gender identity, and sexual orientation). It reflects significant gaps in completeness of data, with the best data capture performance surprisingly being seen for collection of ethnicity data with that data being input 94% of time. Complete race and ethnicity data is available 77% of the time, followed by complete gender identity data being present 76% of the time and sexual orientation being completed 48% of the time. The only data presented regarding language is the row labeled “best served in a language other than English” which presumes all patients have answered this question in some manner, which may in fact be an erroneous assumption.

Table 1 reflects the status of demographic data collection for the FQHCs in the state as a whole, there is considerable variability among health centers in the completeness of collection of race, ethnicity, and language data. Information at the practice level on SOGI data was not available for this report. While the statewide rate of unknown race and ethnicity data is 23%, the range among Rhode Island’s FQHCs is 8% to 31%. And, while it appears that ethnicity data collection is more complete across the state, with 6% missing, the minimum missing percentage among health centers was 3% and the maximum missing percentage was 15%. Finally, while we do not know with certainty that the data collection is complete on preferred language, we do know that the range of patients who are best served in a language other than English ranges from 1% to 48% among the FQHCs in RI.

<b>Completeness of 2021 UDS Data for Rhode Island Health Centers</b>	<b>N</b>	<b>%</b>
<b>Total Patients</b>	189,496	
<b>Total Known Race and Ethnicity</b>	145,916	77%
<b>Total Known Ethnicity</b>	178,309	94%
<b>Total Best Served in a Language Other Than English</b>	42,101	22%
<b>Total Known Gender Identity</b>	143,771	76%
<b>Total Known Sexual Orientation</b>	91,755	48%

Table 1. Summarized Data on Completeness of Demographic Data as Reported to HRSA by RI’s FQHCs.

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**Health Information Exchange: Rhode Island Quality Institute**

Rhode Island Quality Institute (RIQI) is the state designated Health Information Exchange (HIE) and manages CurrentCare, a database consisting of information for over 537,000 enrolled patients (representing approximately 50% of the population of Rhode Island), from 48 data sharing partners, including hospitals, laboratories, provider practices, pharmacies, and imaging centers (12). Data is captured at the time of care and transmitted from care delivery organizations to CurrentCare using standardized formats. Health Level Seven (HL7) Admit, Discharge, Transfer (ADT) data includes information about the patient (including demographics), their visit, and insurance. Patient information is updated in the database when new encounters are submitted. Continuity of Care Documents (CCDs) provide a summary of clinical encounters.

RIQI provided a Data Quality Scorecard from October 2022 (See Appendix III), which is updated quarterly for the state, as well as a one-time report for this project on patient demographics from CurrentCare in May 2023 (See Appendix IV). The scorecard identifies both the completeness and the percent of records that comply with specified data standards, CDC standards for race and ethnicity and HL7 standards for language and SOGI data.

Table 2 summarizes the RIQI Data Quality Report from October 2022, which exposes significant missing data for race, ethnicity, and language, consistent with the data completeness of other sources such as UDS. Sex assigned at birth was available 100% of the time, but it is unclear if that data includes gender identity. None of the organizations supplying data to CurrentCare are providing data on sexual orientation. RIQI also reported on the normalization of data received to OMB standard data categories. Race, ethnicity, and gender data were normalized at a rate of greater than 97%, while language data was normalized less than 1% of the time.

<b>Completeness of Q3 2022 Data from RIQI Data Quality Scorecard</b>		<b>%</b>
<b>Total Completed Race</b>		83%
<b>Total Completed Ethnicity</b>		72%
<b>Total Completed Language</b>		69%
<b>Total Completed Sex assigned at birth</b>		100%
<b>Total Completed Sexual Orientation</b>		0%

Table 2. Summarized Data on Completeness of Demographic Data as Reported in the RIQI Data Quality Scorecard, October 2022

**Quality Reporting System: IMAT Solutions**

IMAT Solutions is a health data services company, providing data aggregation, quality analytics and reporting services as Rhode Island’s Quality Reporting System (QRS) vendor for Accountable Entities participating in contracts with Rhode Island’s EOHHS. IMAT collects patient data and clinical

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information from approximately 75 practice locations in Rhode Island, primarily via CCDs submitted when clinical encounters are closed. They also receive HL7 lab messages from one laboratory and monthly flat files, (simple row and column text files which can be created without special software) from two practices. IMAT Solutions manages clinical encounter data (excluding HL7 laboratory results data) for over 538,000 patients (representing approximately 50% of the population of Rhode Island).

IMAT Solutions provided a custom, one-time, report for this project, providing de-duplicated patient counts for each practice for race, ethnicity, language, sex, gender identity, and sexual orientation. Practices provided these data in both standard and non-standardized (invalid) data formats, and both were included in the report. IMAT works with practices, usually during implementation, to normalize their demographic data, but since most data updates occur at the time of an encounter via CCDs, data for patients seen in the past is not updated. For the purposes of this report, individual practice level data will not be identified, and therefore a copy of the raw report will not be included in the report as an appendix.

Table 3 provides a summary of state-wide availability and quality of demographic data in the IMAT Solutions QRS. Because not all practices submitting data to IMAT provide the same data in the same formats, the denominators for each demographic data element presented are not consistent across all elements; the total patients column reflects the number of patients for whom we have valid data for each data element. Race data is present and valid in records for approximately 85% of the patients, sex data is present in nearly 100% of the records, and sexual orientation is missing for most patients. Only two practices provided data on gender identity. Ethnicity and language data were present in more IMAT records than those in the RIQI dataset. Like the UDS dataset, the variability between practices represented in the IMAT QRS was significant for data on race, with a range of known/complete data being from 1% to 100%, with a median of 90% complete/valid data. Similarly, ethnicity data completeness/validity ranged from 0 to 100%, with a median of 89%.

<b>Completeness and Quality of June 2023 from IMAT Solutions QRS System</b>					
<b>Data Element</b>	<b>Total Patients</b>	<b>Known Data</b>	<b>% Known</b>	<b>Unknown Data</b>	<b>Non-standardized (Invalid) Data</b>
<b>Race</b>	538,712	460,607	85.50%	62,619	15,486
<b>Ethnicity</b>	427,600	355,768	83.20%	61,287	10,545
<b>Language</b>	427,795	411,943	96.29%	785	15,067
<b>Sex</b>	544,451	544,298	99.97%	115	38
<b>Gender Identity</b>	32,508	32,448	99.81%	0	60
<b>Sexual Orientation</b>	1,257	100	7.96%	0	1,157

Table 3. Summarized Data on Completeness and Quality of Demographic Data as Reported by IMAT Solutions from the QRS system in June 2023.

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## Lifespan

Lifespan collects demographic data across multiple hospital facilities, laboratories and clinic sites using their Epic EHR. Using the Epic data tool, called the Slicer/Dicer, they provided a report for this project to EOHHS of deduplicated patient demographic data across all their locations across all time, including data pulled from records that were created prior to the go-live of their EHR in 2015. Thus, the data set contains information on over 2.5 million patients. This data has been informative to Lifespan leadership, who are highly prioritizing equity and belonging, because the data demonstrates a historical lack of focus on complete and accurate demographic data collection. This large dataset is missing information on race for 26% of patients, ethnicity for 41% of patients, language for 35% of patients, and gender identity and sexual orientation data, which have only begun to be collected recently, are missing for 97% and 99% respectively. Because the data reflects patient demographics over many years, it does not present a like comparison to other data sets in this report and much of the data is incomplete, only the available race data is included in this report, as part of the comparison to the US Census data.

## Comparison of Available Data Sources to US Census Data

While the datasets available for this report have important differences, including patient cohorts and data collection and reporting methods, it is worth considering the demographic representativeness of each source. To that end each of the data sets provided for this project, the known/valid information on race and ethnicity was compared to the most current for Rhode Island from the 2020 US Census. For ease of presentation, Table 4 provides a comparison across all data sets. We see that the UDS dataset representing the health centers patients reflects a more diverse population, than the state as a whole, with a larger percentage of patients who are Black or African American (13.6%) than the state (5.7%), as well as a larger percentage of patients who identify as Hispanic or Latinx (24%) as compared to the state (16.6%). Both the RIQI and IMAT datasets appear to have a larger percentage of White patients represented (76.1% and 75.6% respectively) than the state (71.3%), and those datasets reflect fewer patients who identify as one or more races (12.4% and 13.3% respectively) than the state (18.7%).

Race	US Census		UDS 2021				RIQI				IMAT				Lifespan		
	N	%	N	% Known	UDS Known % - Census %	% Total	N	% Known	RIQI Known % - Census %	% Total	N	% Known	IMAT Known % - Census %	% Total	N	% Known	Lifespan Known % - Census %
American Indian / Alaska Native	7,385	0.7%	1,166	0.8%	0.1%	0.6%	2484	0.6%	-0.1%	0.5%	2,471	0.5%	-0.1%	0.5%	1,485	0.1%	-0.6%
Asian	38,961	3.6%	5,412	3.7%	0.2%	2.9%	8827	2.0%	-1.6%	1.6%	10,072	2.2%	-1.4%	1.9%	25,361	1.3%	-2.2%
Black or African American	62,168	5.7%	19,906	13.6%	8.0%	10.5%	33890	7.6%	1.9%	6.3%	35,928	7.8%	2.1%	6.7%	151,967	7.8%	2.2%
Native Hawaiian or Other Pacific Islander	536	0.0%	1,822	1.2%	1.2%	1.0%	1655	0.4%	0.3%	0.3%	3,409	0.7%	0.7%	0.6%	10,268	0.5%	0.5%
White	782,920	71.3%	104,675	71.7%	0.4%	55.2%	339434	76.1%	4.8%	63.2%	348,313	75.6%	4.3%	64.7%	1,524,193	78.7%	7.4%
Other Race or More than one race	205,409	18.7%	12,935	8.9%	-9.9%	6.8%	55445	12.4%	-6.3%	10.3%	60,350	13.1%	-5.6%	11.2%	223,315	11.5%	-7.2%
Declined to Answer			43,580	N/A		23.0%	4071	0.9%		0.8%	64	0.0%	0.0%	0.0%			
Unknown			(Combined with declined to answer)	N/A			893	N/A		0.2%	62,619			11.6%			
Missing			N/A	N/A			90535	N/A		16.9%	N/A						
Invalid Codes			N/A	N/A							15,486			2.9%			
<b>Total</b>	<b>1,097,379</b>	<b>100.0%</b>	<b>189,496</b>	<b>100.0%</b>		<b>100.0%</b>	<b>537234</b>	<b>100.0%</b>		<b>100.0%</b>	<b>538,712</b>			<b>100.0%</b>	<b>1,936,589</b>	<b>100.0%</b>	
<b>Ethnicity</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>% Known</b>		<b>% Total</b>	<b>N</b>	<b>% Known</b>		<b>% Total</b>	<b>N</b>	<b>% Known</b>		<b>% Total</b>	<b>N</b>	<b>% Known</b>	
Hispanic / Latino	182,101	16.6%	72,420	40.6%	24.0%	38.2%	71,822	15.9%	-0.7%	13.4%	94,587	26.6%	10.0%	22.1%	237,114	15.4%	-1.1%
Not Hispanic / Latino	915,278	83.4%	105,889	59.4%	-24.0%	55.9%	379,247	84.1%	0.7%	70.6%	260,889	73.3%	-10.1%	61.0%	1,297,892	84.6%	1.1%
Other											292	0.1%	0.1%	0.1%			
Unknown or Declined to Answer			11,187	N/A		5.9%	86,165	N/A		16.0%	61,287			14.3%			
Invalid Codes											10,545			2.5%			
<b>Total</b>	<b>1,097,379</b>	<b>100.0%</b>	<b>189,496</b>	<b>100.0%</b>		<b>100.0%</b>	<b>537,234</b>	<b>100.0%</b>		<b>100.0%</b>	<b>427,600</b>	<b>100.0%</b>		<b>100.0%</b>	<b>1,535,006</b>	<b>100.0%</b>	

Table 4. Comparison of Available Data Sources to US Census Data

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## Comparison of Unknown Data in Available Data Sources

Again, the datasets available for this report reflect different patient cohorts and data collection and reporting methods, however, it remains of interest to examine the completeness of demographic data collection for each source. Table 5 below shows a side-by-side comparison of data reported as unknown for each data source for each of the data elements examined in this report: race, ethnicity, language, gender/gender identity, and sexual orientation. This comparison clearly demonstrates that each of these sources reports a large percentage of unknown data for multiple key demographic data elements, however, important differences between the datasets must be acknowledged. While the patients included in the data may be overlapping, this comparison does not provide a comparison of the same cohort of patients across data sets. Additionally, because the datasets include information from different practice sites, the quality of the data itself has not been evaluated, and we are aware that there are differences among practices in key processes which impact these data, including data collection, EHR configuration and input, data export and validation, and reporting parameters. The key takeaway remains, however, and that is the large percentage of unknown data on critical demographic data, regardless of the data sources, cohorts included, or processes associated with data management and reporting.

Percent Data Reported Unknown by Source						
	Race	Ethnicity	Language	Sex	Gender Identity	Sexual Orientation
<b>UDS</b>	23%	6%	N/A	N/A	24%	52%
<b>RIQI</b>	17%	28%	31%	0%	N/A	100%
<b>QRS</b>	15%	17%	4%	0%	N/A	92%
<b>Lifespan</b>	26%	41%	35%	N/A	97	99%

Table 5. Percent data reported unknown by data source.

## Conclusions

This report reflects a qualitative review of readily available data sets to develop a broad view of demographic data capture, transmission, and reporting in Rhode Island. The data sources have important differences in data capture and reporting, as well as patient cohorts included. The UDS dataset reflects patients served at 8 Federally Qualified Community Health Centers serving approximately 190,00 patients in 2021. These practices provide services to communities at risk and are required by HRSA to collect more comprehensive demographic data and to report these results from their various medical records systems. Data provided by RIQI was aggregated over the course of nearly a decade for over 500,000 Rhode Islanders who voluntarily opted into the state HIE; this data includes information from hospitals, labs, and provider practices, and is updated when a clinical encounter occurs. Similarly, IMAT Solutions has been aggregating data for over 500,00 patients from over 75 provider locations for the past four years and the data is updated when encounters occur; however, IMAT data is primarily from primary care practices, and because the data is used for quality improvement (operations under HIPAA), it does not employ direct patient opt-in, again influencing the



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cohort comparability. Lifespan's data is longitudinal for all patients in their electronic medical record since inception, well before EHR standardization occurred.

While a sample of convenience, the data presented here captures approximately 50% of the state's population and is likely adequate to draw the conclusion that across multiple data sources, there are gaps in availability of demographic data, which if corrected could be used in efforts to better understand and intervene to reduce known health disparities in the state.

Given the impact of health disparities as underscored by the COVID-19 pandemic, the foundational activity of accurately and completely collecting data on race, ethnicity, language, gender identity and sexual orientation should be a priority for those delivering and paying for healthcare in Rhode Island. The ability to understand and intervene to reduce health disparities is dependent on the ability to stratify and analyze patient treatment and outcomes for subpopulations, which in turn is wholly dependent on accurate, complete demographic data.

Based on the entirety of the CTC Demographic Data Collection Pilot Landscape review and not limited to this report on baseline data, considerations for future efforts to improve completeness and accuracy of demographic data collection in Rhode Island include the following:

1. The state could consider incentives to provider organizations to improve the completeness and accuracy of demographic data collection, including:
  - a. Establishing a threshold for missing demographic data
  - b. Routinely reporting on quality metrics broken out by demographic data elements (e.g., race, ethnicity, etc.)
  - c. Providing financial support for needed EHR modifications to support standardized demographic data collection
  - d. Exploring a pilot project to leverage a shared data set with validated demographic data to reduce incomplete and inaccurate demographic data.
2. A research study could be undertaken to assess the accuracy of the data in various datasets included in this report.
3. Practices should consider engaging in activities to:
  - a. Improve processes for data collection and routine validation of demographic data;
  - b. Make necessary EHR configuration modifications to support data collection consistent with new standards for demographic data elements;
  - c. Clean and normalize historical data, with reasonable time cutoffs
  - d. Routinely monitor the completeness and accuracy of demographic data in their systems

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**Appendix I  
Table 3B: Demographic Characteristics - Rhode Island Data  
Raw Data as Collected from data.HRSA.gov (7)**

**Patients By Race and Hispanic or Latino/a Ethnicity**

Line	Patients by Race	Hispanic or Latino/a (a)	Non-Hispanic or Latino/a (b)	Unreported/Refused to Report Ethnicity (c)		Total (d) (Sum Columns a+b+c)		
		Number (a)	Number (b)	Number (c)	% of Total Patients <sup>±</sup>	Number (d)	% of Total Patients <sup>±</sup>	% of Known Race <sup>±</sup>
1.	Asian	142	5,270			5,412	2.86%	3.71%
2a.	Native Hawaiian	64	43			107	0.06%	0.07%
2b.	Other Pacific Islander	1,088	627			1,715	0.91%	1.18%
2.	<b>Total Native Hawaiian/Other Pacific Islander (Sum Lines 2a + 2b)</b>	<b>1,152</b>	<b>670</b>			<b>1,822</b>	<b>0.96%</b>	<b>1.25%</b>
3.	Black/African American	3,625	16,281			19,906	10.50%	13.64%
4.	American Indian/Alaska Native	274	892			1,166	0.62%	0.80%
5.	White	30,424	74,251			104,675	55.24%	71.74%
6.	More than one race	9,109	3,826			12,935	6.83%	8.86%
6a.	<b>Total Known (Sum Lines 1+2+3+4+5+6)</b>	<b>44,726</b>	<b>101,190</b>			<b>145,916</b>		
7.	Unreported / Refused to report race	27,694	4,699	11,187	5.90%	43,580	23.00%	

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Line	Patients by Race	Hispanic or Latino/a (a)	Non-Hispanic or Latino/a (b)	Unreported/Refused to Report Ethnicity (c)		Total (d) (Sum Columns a+b+c)		
		Number (a)	Number (b)	Number (c)	% of Total Patients *	Number (d)	% of Total Patients *	% of Known Race *
8.	<b>Total Patients</b> (Sum of Lines 1 + 2 + 3 to 7)	72,420	105,889	11,187		189,496	100.00%	
<b>Total Known Ethnicity (Sum line 8, columns A+B)</b>		178,309						
		<b>% of Hispanic or Latino/a of Total Known Ethnicity *</b> (a)	<b>% of Non-Hispanic or Latino/a of Total Known Ethnicity *</b> (b)					
9.	<b>Total Patients</b>	40.61%	59.39%					
Line	Patients Best Served in a Language Other than English	Number (a)	% of Known					
12.	Patients Best Served in a Language Other than English	42,101	22.22%					
Line	Patients by Sexual Orientation	Number (a)	% of Known					
13.	Lesbian or Gay	2,040	2.22%					
14.	Heterosexual (or straight)	86,331	94.09%					
15.	Bisexual	2,464	2.69%					
16.	Something else	920	1.00%					
		Number (a)	% of Total					

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Line	Patients by Sexual Orientation	Number (a)	% of Known
17.	Don't know	5,758	3.04%
18.	Chose not to disclose	14,897	7.86%
18a.	Unknown	77,086	40.68%
<b>19.</b>	<b>Total Patients (Sum of Lines 13 to 18a)</b>	<b>189,496</b>	<b>100.00%</b>

Line	Patients by Gender Identity	Number (a)	% of Known
20.	Male	57,784	40.40%
21.	Female	84,518	59.10%
22.	Transgender Man/Transgender Male/Transgender Masculine	420	0.29%
23.	Transgender Woman/Transgender Female/Transgender Feminine	294	0.21%
		Number (a)	% of Total
24.	Other	755	0.40%
25.	Chose not to disclose	5,606	2.96%
25a.	Unknown	40,119	21.17%
<b>26.</b>	<b>Total Patients (Sum of Lines 20 to 25a)</b>	<b>189,496</b>	<b>100.00%</b>

**Footnotes**

'-' Data cannot be calculated or has been suppressed for confidentiality purposes.

Cells that are shaded blue represent data that was not reported or null values. [OBJ]

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**Appendix II  
Health Center Program Uniform Data System (UDS) Data Overview  
Selected Data by Practice by Year, as collected from data.HRSA.gov (8)**

**Blackstone Valley Community Health Care Inc. Pawtucket, Rhode Island**

<b>Age and Race / Ethnicity</b>	<b>2017</b>	<b>2018</b>	<b>2019</b>	<b>2020</b>	<b>2021</b>
<b>Total Patients</b>	<b>18,107</b>	<b>18,732</b>	<b>21,333</b>	<b>19,016</b>	<b>20,170</b>
Total Patients with Known Race <i>AND</i> Ethnicity (Denominator)	14,298	13,554	14,909	13,217	13,975
Percent	79%	72%	70%	70%	69%
Total Hispanic/Latino & Non-Hispanic Latino Patients (Denominator for Hispanic/Latino Ethnicity) << <i>KNOWN ETHNICITY</i> >>	17,171	17,867	20,458	18,139	19,102
Percent	95%	95%	96%	95%	95%
Number of Patients Best Served in a Language Other than English	5,241	5,979	7,100	6,116	6,465
Percent	29%	32%	33%	32%	32%

**Comprehensive Community Action, Inc. Cranston, RI**

<b>Age and Race / Ethnicity</b>	<b>2017</b>	<b>2018</b>	<b>2019</b>	<b>2020</b>	<b>2021</b>
<b>Total Patients</b>	<b>15,805</b>	<b>15,548</b>	<b>16,152</b>	<b>16,002</b>	<b>17,581</b>
Total Patients with Known Race <i>AND</i> Ethnicity (Denominator)	13,105	13,104	14,236	13,598	13,905
Percent	83%	84%	88%	85%	79%
Total Hispanic/Latino & Non-Hispanic Latino Patients (Denominator for Hispanic/Latino Ethnicity) << <i>KNOWN ETHNICITY</i> >>	15,341	15,141	15,719	14,889	15,945
Percent	97%	97%	97%	93%	91%
Number of Patients Best Served in a Language Other than English	802	982	1,367	1,394	1,445
Percent	5%	6%	8%	9%	8%

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**East Bay Community Action Program, Newport, Rhode Island**

Age and Race / Ethnicity	2017	2018	2019	2020	2021
<b>Total Patients</b>	<b>11,003</b>	<b>10,543</b>	<b>10,598</b>	<b>9,766</b>	<b>9,961</b>
Total Patients with Known Race AND Ethnicity (Denominator)	9,495	9,491	9,490	8,587	8,818
Percent	86%	90%	90%	88%	89%
Total Hispanic/Latino & Non-Hispanic Latino Patients (Denominator for Hispanic/Latino Ethnicity) <<KNOWN ETHNICITY>>	10,043	9,967	9,989	9,059	9,377
Percent	91%	95%	94%	93%	94%
Number of Patients Best Served in a Language Other than English	648	681	786	678	795
Percent	6%	6%	7%	7%	8%

**Northwest Community Health Center, Pascoag, Rhode Island**

Age and Race / Ethnicity	2017	2018	2019	2020	2021
<b>Total Patients</b>	<b>16,154</b>	<b>16,640</b>	<b>16,561</b>	<b>15,470</b>	<b>16,407</b>
Total Patients with Known Race AND Ethnicity (Denominator)	14,515	14,654	14,165	12,783	13,458
Percent	90%	88%	86%	83%	82%
Total Hispanic/Latino & Non-Hispanic Latino Patients (Denominator for Hispanic/Latino Ethnicity) <<KNOWN ETHNICITY>>	15,198	15,347	14,683	13,467	13,891
Percent	94%	92%	89%	87%	85%
Number of Patients Best Served in a Language Other than English	186	182	165	166	193
Percent	1%	1%	1%	1%	1%

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**The Providence Community Health Centers, Providence, Rhode Island**

<b>Age and Race / Ethnicity</b>	<b>2017</b>	<b>2018</b>	<b>2019</b>	<b>2020</b>	<b>2021</b>
<b>Total Patients</b>	<b>51,163</b>	<b>53,971</b>	<b>60,606</b>	<b>56,805</b>	<b>58,798</b>
Total Patients with Known Race AND Ethnicity (Denominator)	33,325	34,587	39,144	40,787	42,488
Percent	65%	64%	65%	72%	72%
Total Hispanic/Latino & Non-Hispanic Latino Patients (Denominator for Hispanic/Latino Ethnicity) <<KNOWN ETHNICITY>>	45,530	48,022	54,039	54,712	56,322
Percent	89%	89%	89%	96%	96%
Number of Patients Best Served in a Language Other than English	24,893	26,666	29,502	27,269	28,111
Percent	49%	49%	49%	48%	48%

**Thundermist Health Center, Woonsocket, RI**

<b>Age and Race / Ethnicity</b>	<b>2017</b>	<b>2018</b>	<b>2019</b>	<b>2020</b>	<b>2021</b>
<b>Total Patients</b>	<b>45,044</b>	<b>48,586</b>	<b>51,405</b>	<b>48,786</b>	<b>52,208</b>
Total Patients with Known Race AND Ethnicity (Denominator)	36,112	38,487	40,702	37,715	41,070
Percent	80%	79%	79%	77%	79%
Total Hispanic/Latino & Non-Hispanic Latino Patients (Denominator for Hispanic/Latino Ethnicity) <<KNOWN ETHNICITY>>	43,896	47,000	49,577	46,225	49,829
Percent	97%	97%	96%	95%	95%
Number of Patients Best Served in a Language Other than English	4,578	5,139	5,402	4,604	4,518
Percent	10%	11%	11%	9%	9%



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**Tri-Town Economic Opportunity Committee, Johnston, RI**

Age and Race / Ethnicity	2017	2018	2019	2020	2021
<b>Total Patients</b>	<b>7,092</b>	<b>7,296</b>	<b>8,101</b>	<b>6,957</b>	<b>7,207</b>
Total Patients with Known Race <i>AND</i> Ethnicity (Denominator)	6,123	6,243	6,474	5,492	5,581
Percent	86%	86%	80%	79%	77%
Total Hispanic/Latino & Non-Hispanic Latino Patients (Denominator for Hispanic/Latino Ethnicity) <<KNOWN ETHNICITY>>	6,957	7,149	7,975	6,852	6,992
Percent	98%	98%	98%	98%	97%
Number of Patients Best Served in a Language Other than English	324	420	489	463	472
Percent	5%	6%	6%	7%	7%

**Wood River Health Services, Inc., Hope Valley, RI**

Age and Race / Ethnicity	2017	2018	2019	2020	2021
<b>Total Patients</b>	<b>6,840</b>	<b>6,717</b>	<b>6,716</b>	<b>6,499</b>	<b>7,164</b>
Total Patients with Known Race <i>AND</i> Ethnicity (Denominator)	6,513	6,297	6,305	6,097	6,621
Percent	95%	94%	94%	94%	92%
Total Hispanic/Latino & Non-Hispanic Latino Patients (Denominator for Hispanic/Latino Ethnicity) <<KNOWN ETHNICITY>>	6,725	6,516	6,500	6,289	6,851
Percent	98%	97%	97%	97%	96%
Number of Patients Best Served in a Language Other than English	130	126	94	86	102
Percent	2%	2%	1%	1%	1%

# Care Transformation Collaborative of Rhode Island (CTC-RI) Demographic Data Collection Pilot Environment Scan: 1A.5 Baseline RI Demographic Data Collection Performance Assessment Report

## Appendix III RIQI Data Quality Scorecard October 2022 Presented to the EOHHS HIT Steering Committee in January 2023

### Data Quality Scorecard

Below are screenshots as of October 2022 for the RIQI data quality scorecard, now in production:

#### DATA QUALITY SCORECARD

MEASURE	Problem (SNOMED-CT)	Medication (RXNorm - Dev)	Medication (RXNorm - Prod)	Discharge Dispo. (CMS)	Race (CDC)	Ethnicity (CDC)	Gender (HL7)	Primary Language (HL7)	Sexual Orientation (HL7)
% Complete	99.67%	90.16%	90.16%	60.74%	83.48%	72.06%	100.00%	68.76%	0.00%
% Standardized	75.86%	93.46%	23.43%	95.99%	97.19%	99.93%	100.00%	0.15%	0.00%

  

MEASURE	Problem (SNOMED-CT)	Medication (RXNorm - Dev)	Medication (RXNorm - Prod)	Discharge Dispo. (CMS)	Race (CDC)	Ethnicity (CDC)	Gender (HL7)	Primary Language (HL7)	Sexual Orientation (HL7)
Total Data Fields	13,681,848	88,783,942	88,783,942	5,276,917	2,072,849	2,072,849	2,072,849	2,072,849	2,072,849
Populated Fields	13,636,608	80,050,117	80,050,117	3,205,159	1,730,327	1,493,742	2,072,849	1,425,247	0
Null or N/A	45,240	8,733,825	8,733,825	2,071,758	342,522	579,107	0	647,602	2,072,849
Standardized	10,344,973	74,815,202	18,758,518	3,076,638	1,681,620	1,492,688	2,072,849	2,076	0
Unable to Map	3,291,635	5,234,915	61,291,599	128,521	48,707	1,054	0	1,423,171	0

#### DATA QUALITY HISTORICAL TREND

##### % Standardized: Historical Trends by Field

FIELD	QUARTER	Q4 2021	Q1 2022	Q2 2022	Q3 2022
Discharge Dispo. (CMS)		95.66%	95.77%	95.88%	95.99%
Ethnicity (CDC)		95.22%	99.93%	99.93%	99.93%
Gender (HL7)		100.00%	100.00%	100.00%	100.00%
Medication (RXNorm - Dev)		93.65%	93.58%	94.48%	93.46%
Medication (RXNorm - Prod)		22.12%	22.55%	23.18%	23.43%
Primary Language (HL7)		.15%	.15%	.15%	.15%
Problem (SNOMED-CT)		75.63%	75.51%	75.80%	75.86%
Race (CDC)		96.62%	97.67%	97.29%	97.19%
Sexual Orientation (HL7)		.00%	.00%	.00%	.00%



