Care Transformation Collaborative of Rhode Island (CTC-RI) Demographic Data Collection Pilot 1A.7 Baseline Practice Needs Assessment Summary Report

Contents

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.
- 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 disproportionally 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.

The fourth component of the RIDOH contract with the Care Transformation Collaborative of RI (CTC-RI) is a baseline practice needs assessment regarding the complete and accurate collection of demographic data to inform the learning series to be developed and delivered by CTC-RI to practices selected to participate in the Demographic Data Collection Pilot – Baseline Practice Needs Assessment and Train the Trainer Webinar Series. Four distinct questionnaires were designed to address overarching practice needs (including considerations about patients, staffing, training, data use and supporting technology), patienfindingsiences, and staff experience, as well as a “walk-around” tool for practices to document the collection and use of demographic data, from the perspective of all stakeholders in the process and share those finding with their internal teams.

Approach

The Practice Needs Assessment was developed based on the Environmental Scan Best Practices Summary Report completed for this project in June 2023. Practices selected to participate in the CTC-RI Demographic Data Collection Pilot, (the Pilot) and their identified Trainers were asked to complete a Practice Needs Assessment, comprised of four components:

1) Practice Needs Assessment Tool, which collected information about:
    a. Practice structure.
    b. Current demographic data collected.
    c. Patient engagement.
    d. Data collection policies, staff engagement, and accountabilities
    e. Data standards in use, collection processes and use of technology
    f. Ratings of practice performance on demographics data collection
    g. Recommended topics for inclusion in the learning series.
2) Staff Engagement Survey, which collected information about
    a. Description of staff completing the survey
    b. Staff experiences with demographic data collection
3) Patient Survey, which collected information about
    a. Description of patients completing the survey
    b. Patient experiences with demographic data collection
4) Walk Around Tool to document the collection and use of demographic data, from the perspective of all stakeholders in the process and share those findings with their internal teams.

Data for the practice needs assessment was collected electronically via SurveyMonkey online software tool. The recommendation was that the Practice Trainers work with Practice Managers to complete the tool with support from others in the practice as needed. Data collection began in August 2023. Practices were asked to complete the survey by September 15, 2023, and were given an extension to September 22, 2023.

Practice Trainers were asked to coordinate collection of data for the Patient Engagement and Staff engagement surveys. Staff and Patient surveys were completed electronically or on paper and later input into SurveyMonkey by staff at the practice. Patients were to have received services at the practice in the past 12 months. Sampling was not centrally controlled by CTC-RI and may be considered samples of convenience. To protect the confidentiality of staff and patients, no data is presented which is individually identifiable or re-identifiable. Any potentially identifying data point, such as age, race, or ethnicity with less than 5 respondents was aggregated where possible or masked with a tilde (~) if non-quantified results could be beneficial (e.g., patient languages spoken with small denominators).

Data was exported from SurveyMonkey and analyzed using IBM’s SPSS Statistical Analysis software. Frequencies were tabulated for each categorical variable and are included in Appendices II - IV. Data was sorted in descending order of frequency. Percentages are presented as whole numbers; as such, the sum of the percentages may appear to be greater than 100%. Missing values (answers left blank) were included in the analysis to ensure learning from what questions people chose not to answer. Cross tabulation analyses with Chi Square statistics were conducted on selected categorical variables to identify differences between practice level performance on patient and staff engagement surveys. Free text fields will be made available to CTC-RI and the practices, in a de-identified manner so that additional information may be gleaned from them.

Data for the walk around tool was collected via observation by practice staff. Data was coded and summarized for key concepts by a Providence College intern.

Key Findings

Practice Needs Assessment Tool

Fifteen (15) practices are included in this pilot project and care for a wide variety of patients in both private practices and a federally qualified health center. Pediatrics, family medicine, and internal medicine are well represented, with 20% of the practices providing care using the internal medicine and family medicine models, and 33% of the practices serving pediatrics patients. Staffing models are quite variable among the practices, with a range of less than 1 full-time equivalent (FTE) primary care provider to 10 FTE providers. The mean number of primary care providers among this cohort is 2.8, and the mean number of supporting clinical staff are 0.6 FTE behavioral health specialists, 0.9 FTE nurses, 0.7 FTE social support specialists, and 0.6 FTE pharmacists. Similarly supporting teams range from 0 to 25 Medical Assistants and 0 to 17 non-clinical administrative staff. The majority (73%) of practices are using Epic as their electronic health record (EHR), and all use certified health records.

All practices are currently collecting demographic data, however the data elements collected are not obtained across all sites. While 100% report collecting the language a patient prefers and 93% collect data on race, there is a decline in the collection for other information from patients, reaching a low of 5% collecting data on military service for a patient’s family member. (See Table 1)

Does the Practice Collect the Following Demographic Data Elements:	Percent
Language	100
Race	93
Ethnicity	87
Sexual Orientation	67
Other Social Determinants of Health	67
Gender Identity	60
Housing Status	60
Disability Status	33
Pronouns	27
Income	27
Military Service for Patient	20
Military Service for Patient’s Family	5

Table 1. Percent of practices collecting specific demographic data elements among CTC-RI Demographic Data Webinar Learning Series Participating Practices.

These data are collected in large part by registration staff (67%), verbally (93%) or by paper intake form (67%), during the check-in process (87%). Most of the practices collect the data at both new patient registrations (93%) and annual physical or wellness exams (53%).

Patients are permitted to self-report their demographic data at 40% of the practices participating in the Pilot, and at 27% of the practices, patients are allowed to use multiple selections to reflect their identity accurately and completely. Among the practices in this Pilot, 73% have processes to support patients who choose not to respond to demographic questions; 67% support patients who are unable to read/write in English; and 80% ensure patient privacy during data collection. However, the majority (73%) indicated that they do not educate their patients on demographic data collection and have not surveyed their patients about demographic data collection or about experiences with health disparities.

While 87% of practices indicated that they provide their staff with training on the process of accurate and complete demographic data collection, only 40% reported having written policies to support the process. Practices were split regarding the critical support for staff to ensure complete and accurate demographic data collection. Fifty-three (53) percent of the practices queried felt that staff had enough time to complete the work and 47% provided education to staff about the importance of demographic data collection. Beyond basic training on process and the importance of data collection and adequate time, fewer practices engaged staff by providing training on health disparities (27%) or scripting to support data collection (27%) or by surveying the staff to understand their comfort with data collection (33%) or with the staff's personal experiences with health disparities (7%).

The majority (60%) of the practices indicated that they have taken steps to improve demographic data, routinely measure the completeness and accuracy of demographic data (53%) and engage in quality improvement efforts based on identified disparities (53%). Yet less than half (47%) report having established clear accountability for complete and accurate demographic data collection, 27% stratify quality measures based on demographic data, and 20% have established accountability for reducing health inequities.

Sixty (60) percent of the practices in the pilot are employing the Office of Management and Budget (OMB) 1997 standards for the collection of race and ethnicity data; 27% of those completing the survey did not know the standard in use; the Federally Qualified Health Center in the cohort is using the Health Resources Services Administration Uniform Data Set standard, and one practice (7%) is using a modified OMB approach, allowing patients to decline or select more than one race. Only one practice (7%) is collecting data on a more granular level based on their local community needs.

A large majority of practices (73%) reported that demographic data fields are mandatory in their EHRs and that their EHR is configured to support race and ethnicity mapping and the elimination of free text. And 87% indicated that their EHR systems can differentiate between declined to answer and unknown responses. Less than half (40%) have used other technologies (e.g., portal or kiosk) to capture demographic data.

Respondents were asked to rate their perceptions about how their practice was doing around demographic data collection as it pertained to various processes important to complete and accurate data collection. See Table 2 below. A minority (13-20%) indicated that their practice was doing well or very well on any of the identified processes: leadership and accountability, patient engagement, staff training and engagement, IT support, and reporting and quality improvement. Sixty (60) percent of the practices indicated that leadership and accountability and IT support were adequate or going well or very well, and 53% reported the same about reporting and quality improvement activities. Sixty (60) percent reported that their practice was doing poorly or needed improvement in the categories of patient and staff engagement.

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Rating of Processes Necessary for Successful Demographic Data Collection (Percent)	Very Poorly	Needs Improvement	Adequately	Well	Very Well
Leadership Support and Accountability	0	40	47	7	7
Patient Engagement	7	53	27	0	13
Staff Training and Engagement	0	60	20	7	13
IT Support	0	40	40	20	0
Reporting and QI	7	40	40	0	13

Table 2. Percent of practices reporting each overall rating of how the respondent believes their practice is doing around demographic data collection for each of process area.

Practices were asked about the topics that should be offered in the learning series. See Table 3. The strongest interest was for best practices for engaging patients about demographic data, with 80% seeking learning about asking patients for race/ethnicity data, 73% for asking about sexual orientation and gender identity, and 60% seeking methods and tools to collect this data, including scripts, frequently asked questions, etc. The second largest grouping of interest was around technology and data, with 67% seeking training on working with IT vendors, and 53% of expressed interest in both using data to understand and address disparities and using alternative technologies (e.g., kiosks, tablets) to collect demographic data. Sixty (60) percent also indicated that the topic of workflows to improve data capture should be offered.

What topics should be offered in this learning series?	Percent
Best practice for asking patients for race, ethnicity and language information and responding to their questions/reaction	80
Best practice for asking patients about sexual orientation and gender identity.	73
Working with IT and vendors to improve data capture and reporting	67
Methods and Tools such as scripts, role playing, frequently asked questions documents, front desk standard sample	60
Best practices in workflow to improve the completeness and accuracy of data collection	60
Using data to understand and address disparities in the healthcare delivery and outcomes	53
Using technology to collect demographic data (patient portal, kiosk, tablet)	53
Collaborating with local community groups to engage and understand specific sub-populations served by your practice	47
Cultural competency, systemic racism, implicit bias, and implications for health equity	47
Changing federal and state data standards for collection of race and ethnicity data	27
Establishing a process such as a patient advisory committee to improve health equity in your practice	20

Table 3. Percent of practices reporting interest in various topics for inclusion in the learning series.

Staff Engagement Survey

Staff Engagement Surveys were completed by 89 individuals across the 15 pilot practices. The respondents hold a variety of clinical and administrative roles (19) in their respective practices. Forty-two (42) percent of those surveyed work in reception, 25% are medical assistants, and 7% are primary care providers. Many staff responding to the survey were female (84%), 63% reported being white and 28% reported being Hispanic or Latino. This stands in contrast to the patient population, which more closely mirrors the state population; however, because demographic data on the staff for all practices involved is not available, it is not possible to determine if the survey sample provides a representative sample of the staff at each practice. Like the patient population a majority of staff (63%) reported not having experienced discrimination, but a higher percentage of staff (12%) responded affirmatively to that question (vs. 7% for patients).

Staff were asked to rate their comfort in asking patients about various data types (see Table 5) and about their confidence in the quality of the data captured for each data type (see Table 6). Staff reflected the highest degree of comfort in collecting and confidence in quality around language, race, and ethnicity. Sixty-one (61) percent were comfortable or very comfortable asking about language, 45% about ethnicity, and 43% about race. While still the highest rated among the data elements, confidence in the quality of the data was lower than comfort in collecting these elements, with 54% being confident or very confident in the quality of language data, 50% in race data, and 48% in ethnic background data. Interestingly, the trend flipped regarding comfort and confidence around sexual orientation and gender identity (SOGI) data. There we see staff reporting being comfortable or very comfortable ranging from 26% to 33% but confidence in the data is higher, with a range of 38% to 46%. The lowest comfort and lowest confidence (not at all confident and not confident combined) were for use of pronouns, with 29% reporting discomfort and 17% reporting lack of confidence.

Demographic Data Type	Very Uncomfortable	Uncomfortable	Neutral	Comfortable	Very Comfortable	Left Blank
Race	9	8	27	20	23	14
Ethnic background	8	7	26	23	23	15
Language you prefer to use to talk about your health	7	1	18	28	33	14
Gender assigned at birth	14	10	30	15	18	14
Gender Identity	12	15	34	17	9	14
Use of pronouns	15	14	33	16	10	14
Sexual Orientation	14	14	33	14	12	15
Other Issues impacting your health including housing, income, safety at home, etc.	10	12	25	20	19	14

Table 4. Percent of staff reporting comfort with asking patients for the following data types.

Demographic Data Type	Not Confident at All	Not Confident	Neutral	Confident	Very Confident	Left Blank
Race	2	6	29	32	18	14
Ethnic background	2	5	32	32	17	14
Language you prefer to use to talk about your health	1	1	29	30	24	15
Gender assigned at birth	2	7	32	27	19	14
Gender Identity	2	12	33	23	17	14
Use of pronouns	7	10	32	20	18	14
Sexual Orientation	5	8	34	20	20	14

Table 5. Percent of staff reporting confidence in the quality of the following data types.

Regarding time needed to ensure accurate and complete data collection, staff were split with 49% indicating that they had the time needed. The majority indicated that they had received training on the following: systemic racism, sexual orientation and gender identity, implicit bias, and healthcare disparities (62%), the best way to collect complete and accurate demographic data from patients (63%), and the best way to document demographic data in your practice's EHR (69%). Fifty-three (53) percent reflected that they had access to needed policies and scripts to collect demographic data. Challenges in data collection reported included patient willingness/ability to share data (34%), staff's own comfort in asking sensitive questions (11%), technology issues related to data capture (6%), and other issues including time, language barriers, and privacy concerns.

A large majority (82%) of the staff reported that their practice has been sensitive and respectful when asking patients about demographics and only 7% felt that there were additional things that the practice could do to help them to be more confident and comfortable in collecting and recording patient demographics. Those who felt more could be done requested more training, improved confidentiality, and the use of paper questionnaires for patients.

Staff engagement survey responses were consistent across the 15 practices in this pilot, with no statistical differences on Chi Square analyses of categorical variables being seen on the majority of questions. (See Appendix VI) The exception was that the staff at the federally qualified health center was less confident than expected about the quality of data on sex assigned at birth, gender identity, and pronouns relative to other practices ($p < 0.05$).

Patient Engagement Survey

Pilot participants collected survey data from 1190 patients across the 15 practices. The survey was translated into Spanish and Portuguese and was made available to the participating practices to ensure widespread participation among their patient populations. With the practice mix in the pilot including internal medicine, family medicine and pediatrics, the age of the patients was spread across the age spectrum, with 38% of the patients 18 and under, 40% between the ages of 19 and 64, and 18% who were 65 or older. Fifty-six percent of respondents completed the survey for themselves, while 41% completed it for patient under their care, either a parent or guardian (39%) or caregiver for an adult (2%). Given the topic of the survey, patients generally appeared willing to answer questions about their demographic data, with data left blank or patients actively selecting ‘I preferred not to say’ at a rate combined of 2 to 10 percent of the time. Age, gender, and language were not reported for 3-4% of patients, and race and ethnicity were not reported for 8% and 10% respectively. Most patients were female (55%), 41% were male, and 2% reflected their gender as transgender, non-binary, or other. The vast majority (94%) reported English as their primary language, while 1% reporting Spanish and 1% reporting other languages (9 languages). Eighty-one (81) percent of the patients reported their race as White, and 77% indicated that they were not of Hispanic or Latino ethnicity. While practices were asked to survey a representative sample of their patient population, we do not have population level demographics for the practices to validate if in fact the surveys reflect a representative sample of the patients at each practice.

Patient comfort with being asked about various demographic data elements was assessed for both data collection being conducted by practice staff (see Table 6) and by providers (see Table 7). For this part of the survey, 21% of patients left their answer blank. Many patients felt comfortable or very comfortable providing data on race, ethnicity, language, gender, gender identity, sexual orientation, and other social determinants of health data with office staff (range 61-68%) as well as with providers (64 – 70%). Fewer than 10% were very uncomfortable or uncomfortable sharing these data with either party. Many patients recognize the value of demographic data collection to improve their own care (64%) and to address health disparities (53%). While most (66%) reported that they had not been subject to discrimination in healthcare, 7% had experienced it, and 7% were unsure, and 20% of respondents left this question blank. Most patients (74%) reflected that they felt treated with respect when being asked about demographics in their practice.

Demographic Data Type	Very Uncomfortable	Uncomfortable	Neutral	Comfortable	Very Comfortable	Left Blank
Race	6	1	10	17	46	21
Ethnic background	5	1	10	17	47	21
Language you prefer to use to talk about your health	5	1	6	17	51	21
Gender assigned at birth	6	1	5	15	52	21
Gender Identity	7	1	6	15	50	21
Use of pronouns	7	2	9	14	47	21
Sexual Orientation	7	2	8	15	47	21
Other Issues impacting your health including housing, income, safety at home, etc.	6	2	9	19	44	21

Table 6. Percent of patients reporting comfort with providing the following data types to the office staff at their doctor's office

Demographic Data Type	Very Uncomfortable	Uncomfortable	Neutral	Comfortable	Very Comfortable	Left Blank
Race	5	1	7	16	52	21
Ethnic background	5	1	7	15	51	21
Language you prefer to use to talk about your health	5	0	5	16	54	21
Gender assigned at birth	6	0	5	15	53	21
Gender Identity	6	1	6	14	52	21
Use of pronouns	7	1	8	14	50	21
Sexual Orientation	6	1	8	14	51	21

Other Issues impacting your health including housing, income, safety at home, etc.	5	1	8	17	48	21

Table 7. Percent of patients reporting comfort with providing the following data types to their doctor.

When asked about the importance of communication about the rationale, use and protection of their demographic data, 45% indicated that it was important or very important to be informed about why the data was being collected and 55% reported feeling it was important or very important to be told how the data would be used and protected.

Finally, patients were asked their preferences about how their demographic data is collected and by whom. Consistent with earlier questions in the survey about comfort with data collection, patients indicated a preference in sharing data with clinical staff (primary care provider 68%, nurse 40%, medical assistant 38%) over administrative staff /reception (30%). Patient's preferences about how to share the data are not highly consistent with current approaches in these practices. As noted above, demographics are most frequently collected by registration staff verbally or by paper intake form during the check-in process. While paper forms are the patients' first preference (45%), followed by verbally in the exam room (37%), their last preference is verbally at reception (16%), the most common approach used by the practices in the pilot.

Patient survey responses reflect statistically significant differences between practices on a number of data elements (See Appendix V). Patient populations differ across practices on age, race, and ethnicity ($p < 0.001$) as well as on patient comfort in sharing their demographic information with staff or providers ($p < 0.05$) for various demographic elements (race, ethnicity, gender, gender identity, sexual orientation, pronouns, and other demographic data) and on their personal experiences with discrimination which impacted their healthcare. Patients' experiences with discrimination were significantly related to comfort in sharing demographics with staff or providers. ($p < 0.001$) for all the above demographic data points.

While the overwhelming majority of patients across all practices indicated that the practice was sensitive and respectful when asking about demographic data, six of the fifteen practices (40%) in the pilot did see statistically significant Chi Square statistics when a cross tabulation was performed on patient experience with discrimination by office sensitivity, with patients experiencing discrimination being less likely than expected to report the office as being sensitive.

Walk Around Tool

The walk around tool was designed to provide practices with insights about their demographic data collection processes at a more granular level, with perspectives of patients, staff, and providers in mind. See Appendix VII. The process documentation questions aligned in many ways with the practice needs assessment, as did some of the responses.

Similarities were found regarding the types of data collected, with a large majority collecting race, ethnicity, and language and fewer collecting SOGI data. (See Charts 1 and 2). Likewise, most practices (12 of 15) reported that they ensure privacy during data collection in the Practice Needs Assessment and the majority (10 of 15) observed that data was collected in a manner to support patient privacy.

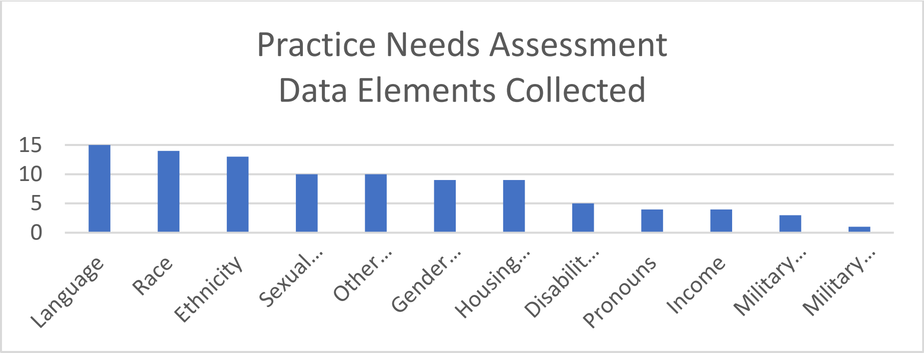

Chart 1. Practice Needs Assessment: Frequency among 15 practices reporting collection of various demographic data elements.

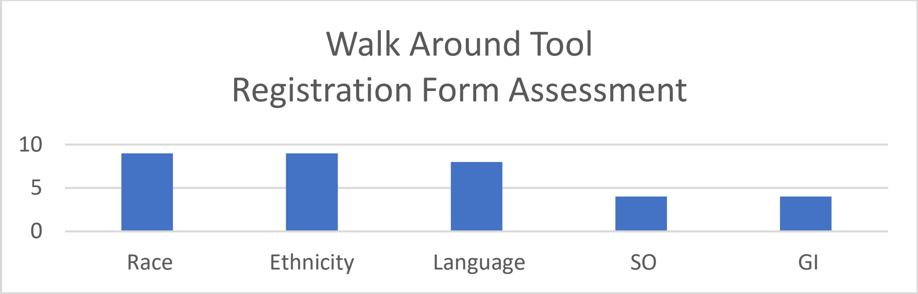

Chart 2. Walk Around Tool: Frequency of various demographic data elements from available registration forms among 15 participating practices.

During direct observation in the practice, nearly all reported that the noted demographic data elements were recorded in the EHR (93%) and most reported that it was captured in a consistent manner (80%), while the majority (73%) of those completing the practice needs assessment indicated that demographic fields were mandatory in their EHR and that their EHR was configured to eliminate free text and supported race/ethnicity mapping for greater consistency. Interestingly, 67% of those completing the walk around tool reported that patients could update their demographic data on the patient portal, while only 40% of those completing the practice needs assessment indicated that their practice was using the portal to capture demographics.

Finally, the overarching lessons and plans derived based on the walk around tool yielded similar needs relative to the practice needs assessment: staff education, improved collection of SOGI data, and reconsideration of workflow.

Conclusions

While the practices completing the practice needs assessment are taking steps to improve the complete and accurate collection of demographic data as well as in the use of that data to improve health outcomes, they appear to be early in process. While it might be expected that 100% percent of practices are routinely collecting race and ethnicity data, that is not the case, and less than 70% are collecting SOGI data. Most have training for their staff on the process for data input into their health record, however, less than half reported having written policies about demographic data collection, providing training on disparities, or providing scripting to ease the process of data collection for staff. Those completing the practice needs assessment reflected that their practice was doing adequately, well or very well with leadership and IT support but not doing well on engaging patients or staff to improve demographic data collection. This need is reflected in the most frequently identified request for the webinar series topics: best practices and scripting for engaging patients on collection of demographics, including SOGI data. Additionally, practices are seeking support for how to best use technology to efficiently capture these data and the best ways to use the data for quality improvement.

In contrast to the information reported in the practice needs assessment, the staff surveys reflect the sense of the majority that they have in fact received training on systemic racism, sexual orientation and gender identity, implicit bias, and healthcare disparities and that they have access to needed polices to do their job effectively. They report being comfortable asking about language, race, and ethnicity and less comfortable asking SOGI questions. Similarly, staff are more confident in the quality of the race, ethnicity, and language data than in the SOGI data in their practice.

Patients who responded to the survey who identified as non-white were more likely to experience discrimination. Those who had experienced discrimination were more uncomfortable providing demographic data to staff or providers and were less likely to see the staff at the practice as sensitive. This speaks to the ongoing need to continuously educate staff on patient experience and to engage patients more earnestly to learn how to best address their needs.

Supports needed for improvement identified in the walk around tool were consistent with needs identified by patients, staff and practice managers who completed the practice needs assessment, and inform the topics that should be considered for inclusion in the webinar series include:

a. Ongoing training on cultural sensitivity and discrimination.
b. Developing scripts and training for staff on the best practices for collection of race, ethnicity, language and SOGI data.
c. Documenting policies and procedures (workflow) on demographic data collection.
d. Considering the best technology and processes for demographic data collection to ensure confidential, accurate and complete data.
e. Using demographic data to understand the practice population and take action to improve outcomes and reduce disparities.
f. Developing patient engagement strategies such as routine surveys or a patient advisory council.

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Appendix I

CARE TRANSFORMATION COLLABORATIVE OF RHODE ISLAND (CTC-RI) PCMH KIDS DEMOGRAPHIC DATA COLLECTION PROJECT

Demographic Data Collection Practice Needs Assessment

The Rhode Island Department of Health (RIDOH) received funding from the Center for Disease Control and Prevention to improve health outcomes with priority given to increasing and improving demographic data collection and reporting. Care Transformation Collaborative of Rhode Island (CTC-RI) in partnership with RIDOH is seeking to better understand practices' needs with regards to demographic data collection as well as practices' interest in an upcoming Demographic Data Collection Webinar Learning Series. The practice selected for the "Train the Trainer" program is asked to review this survey within your practice, solicit feedback from your team and complete this online survey by September 15, 2023. Thank you for your participation. Understanding your current work and needs is an important step in identifying how we can work together to improve quality.

A. General Practice Information (Suggested to be filled out by the Practice Manager)
   1. Practice name (<free text box>)
   2. Health System name (<free text box>)
   3. Organization Affiliation/Company (<free text box>)
   4. Physical address of practice (<free text box>)
   5. Website of practice (<free text box>)
   6. Electronic Health Record (EHR) used (Drop-down menu: Epic, Athena, Amazing Charts, e-Clinical Works, NextGen, Greenway, Cerner, Meditech, Other – free text)
   7. Is the version of your EHR being used by your practice certified?
   8. Which of the following best describes the practice? (Choose all that apply; Drop-down menu)
      a. Federally Qualified Health Center
      b. Primary Care
      c. Internal Medicine
      d. Family Medicine
      e. Pediatric Medicine
      f. Geriatric Medicine
      g. Practice includes onsite Behavioral Health
      h. Other (<free text box>)
   9. Who is helping to fill out this survey? Please check all that apply.
      a. Clinician (MD, DO, NP, PA, RN, MSW, PhD, RPh)
      b. Medical Assistant
      c. Practice Manager
      d. Front Desk Staff
      e. Community Health Worker
      f. IT Staff
      g. Other (free text box)
   10. Provider Information: (Suggested to be filled out by the Practice Manager)

    a. How many FTE primary care providers (MD, DO, NP, PA) practice at this Practice? (<free text box>)
    b. How many FTE behavioral health specialists practice at this Practice? (<free text box>)
    c. How many FTE non-clinical patient-facing administrative staff work at this Practice? (<free text box>)
    d. How many FTE pharmacists practice at this practice?

B. <u>Current practices in demographic data collection and use</u>: (Suggested to be filled out with feedback from the Practice Manager, Clinical and Support staff)

1. Does your practice currently collect demographic information from patients?
    a. Yes
    b. No
    c. Unknown
2. What fields are currently being captured? (Select all that apply)
    a. Race
    b. Ethnicity
    c. Language
    d. Gender Identity
    e. Preferred Pronouns
    f. Sexual Orientation
    g. Military Service for Patient
    h. Military Service for Patient's family
    i. Disability Status
    j. Income
    k. Housing Status
    l. Other Social Determinants of Health
3. Who (or how) in your practice collects demographic data? (Select all that apply)
    a. Registration staff
    b. Medical Assistants
    c. Nurses
    d. Clinicians
    e. Technical Solution, such as the patient portal
    f. Other, please specify
4. When is demographic data collected or updated? (Select all that apply)
    a. New patient registration
    b. Annual physical/wellness exam
    c. Every visit
    d. Other, please specify
5. At what point in the new patient visit cycle is demographic data collected? (Select all that apply)
    a. During scheduling
    b. During check-in

   c. During rooming
   d. During a visit
   e. During check-out
   f. Other, please specify
6. At what point in the existing patient visit cycle is demographic data updated? (Select all that apply)
   a. During scheduling
   b. During check-in
   c. During rooming
   d. During a visit
   e. During check-out
   f. Other, please specify
7. What modes are used to collect the data? (Select all that apply)
   a. Online registration form
   b. Paper intake form
   c. Verbally
   d. Kiosk
   e. Texting system
   f. Patient portal
   g. Other, please specify
8. Do patients self-report their demographic data?
   a. Yes
   b. Sometimes
   c. No
   d. We do not have the capability.
   e. Unknown
9. Are patients allowed to reflect their identity using multiple selections if one category does not capture their identity?
   a. Yes
   b. No
   c. Unknown
10. Do the processes and systems in your practice support patients who decline to respond if they are not comfortable sharing demographic data?
    a. Yes
       i. If yes, please explain how that is recorded in your EHR.
    b. No
    c. Unknown
11. Does your practice have a process in place to address data collection for patients who are unable to read/write in English or their preferred language?
    a. Yes
    b. No

   c. Unknown

12. Does your practice have a way to ensure patient privacy when collecting demographic data?
    a. Yes
        i. If so, how?
        ii. If yes, please explain how patient privacy is protected (e.g., physical space, paper form, etc.)
    b. No
    c. Unknown
13. Does your practice provide patients education about the importance of complete, accurate and ethical collection, use, and protection of their demographic data?
    a. Yes
        i. If so, what materials have you used?
        ii. If so, how did you collect the data?
    b. No
    c. Unknown
14. Has your practice surveyed your patients about their experiences around demographic data collection?
    a. Yes
        i. If so, what survey instrument did you use?
    b. No
    c. Unknown
15. Has your practice surveyed your patients about their experiences around healthcare disparities?
    a. Yes
        i. If so, what survey instrument did you use?
    b. No
    c. Unknown
16. Does your practice have written policies about demographic data collection?
    a. Yes
    b. No
    c. Unknown
17. Are staff at your practice trained on the internal processes for accurate and complete data collection?
    a. Yes
    b. No
    c. Unknown
18. Do the staff at your practice have the time needed to collect accurate and complete demographic data?
    a. Yes
    b. No
    c. Unknown

19. Does your practice provide staff education about the importance of complete, accurate and ethical collection, use, and protection of patient demographic data?
    a. Yes
        i. If so, at what frequency?
        ii. If so, with what mode (online, in-person, other)
    b. No
    c. Unknown
20. Does your practice provide staff education on health disparities and cultural competency related to the social issues around demographic data collection?
    a. Yes
    b. No
    c. Unknown
21. Has your practice provided staff with a script to ensure that the language that is used in requesting demographic data is culturally appropriate, and sensitive to both REL and SOGI questions and categories, creating the best experience for the patient?
    a. Yes
    b. No
    c. Unknown
22. Has your practice surveyed your staff about their experiences and barriers around demographic data?
    a. Yes
    b. No
    c. Unknown
23. Has your practice surveyed your staff about their experiences and barriers around healthcare disparities?
    a. Yes
    b. No
    c. Unknown
    d.
24. Has your practice established clear accountability for complete and accurate data collection?
    a. Yes
        i. If yes, please specify job title of the person accountable.
    b. No
    c. Unknown
25. Does your practice regularly measure the completeness and accuracy of demographic data?
    a. Yes
        i. If yes, please specify the frequency.
    b. No
    c. Unknown
26. Do you know the level of completeness and accuracy of demographic data in your practice?
    a. Yes

    b. No

27. Is your practice working with the Quality Reporting System (QRS) hosted by IMAT Solutions?
    a. Yes
    b. No
    c. Unknown
28. Has your practice taken steps to improve the completeness and accuracy of demographic data (e.g., independent project or working with the QRS to validate your data)?
    a. Yes
        i. If yes, please specify
    b. No
    c. Unknown
29. Has your practice established clear accountability to reduce health inequities?
    a. Yes
        i. If yes, please specify job title of the person accountable.
    b. No
    c. Unknown
30. Does your practice regularly stratify quality measures based on demographic data?
    a. Yes
    b. No
    c. Unknown
31. Does your practice engage in quality improvement projects based on any identified disparities in health outcomes?
    a. Yes
    b. No
    c. Unknown
32. What standards are used in your practice to collect race and ethnicity data? (Provide standards table as attachment)
    a. 1997 OMB
    b. Proposed OMB
    c. OMB with ability to decline or choose more than one race (CMS Medicare, State, NCQA)
    d. HRSA/UDS
    e. UDS+
    f. Other, please specify
33. Does your practice collect data at a more granular level based on local community population needs, with proactive mapping to aggregated standards (OMB)?
    a. Yes
    b. No
    c. Unknown
34. Are demographic data mandatory fields in your EHR?
    a. Yes
    b. No

   c. Unknown

35. Does your EHR prompt staff to update demographic data at a predefined frequency?
    a. Yes
    b. No
    c. Unknown
36. Is your EHR configured to support race / ethnicity mapping and eliminate free text data input?
    a. Yes
    b. No
    c. Unknown
37. Does your EHR have options to differentiate “declined to respond” vs. “unknown” responses?
    a. Yes
    b. No
    c. Unknown
38. Has your practice used other technology to capture demographic data from patients, for example pre-registration on a portal, kiosk, or texting system?
    a. Yes
    b. No
    c. Unknown
39. Overall, *please rate how you believe your practice is doing* around demographic data collection for each of the following areas:

	Very Poorly	**Needs Improvement**	**Adequately**	**Well**	**Very Well**
Leadership Support and Accountability					
Patient Engagement (getting input on experiences and processes)					
Staff Training and Engagement					
IT Support					
Reporting and Quality Improvement					

C. <u>Best Practice Sharing, Assistance and Resources</u>

1. Is your practice prepared to participate in an upcoming Demographic Data Collection Train the Trainer Webinar Learning Series – over the course of 6 months, 1 topic per month? (Anticipated to start in October 2023)
    a. Yes
    b. No

2. What topics should be offered in this Learning Series? (Select all that apply)
    a. Changing federal and state data standards for collection of race and ethnicity data
    b. Collaborating with local community groups to engage and understand specific sub-populations served by your practice
    c. Best practice for asking patients about sexual orientation and gender identity.
    d. Best practice for asking patients for race, ethnicity and language information and responding to their questions/reactions.
    e. Methods and Tools such as scripts, role playing, frequently asked question documents, front desk standard sample demographic data collection form
    f. Cultural competency, systemic racism, implicit bias, and implications for health equity
    g. Establishing a process such as a patient advisory committee to improve health equity in your practice
    h. Best practices in workflow to improve the completeness and accuracy of data collection
    i. Using data to understand and address disparities in the healthcare delivery and outcomes
    j. Working with IT and vendors to improve data capture and reporting
    k. Using technology to collect demographic data (patient portal, kiosk, tablet)
    l. Other (please specify – free response)
3. Are there tools or resources that would be useful to your practice to support the complete, accurate and respectful collection of patient demographic data? (Free response)
4. Would you be willing to share your best practices in demographic data collection and use to reduce healthcare disparities? If so, please share in the response box below.
    a. Yes (please explain – free response)
    b. No
5. Does the practice have any recommendations for community solutions to improve demographic data collection and use to reduce healthcare disparities? (Free response)

Thank you for your time in completing this important survey!

Staff Engagement
Survey for Staff Who Collect Demographic Data

As a result of health outcomes being unequal for various groups, our organization is committed to improving the way we collect and use demographic data. We want to better understand how you feel asking patients about their race, ethnicity, language preference, sexual orientation, and gender identity. Your information will be summarized for management so they can develop programs to help you and our patients. Your answers NOT be shared in any way that can individually identify you to your boss or your team.

6. What is your role in the practice?
   - a Reception
   - b Medical Assistant
   - c Physician
   - d Nurse
   - e Other?
2. Gender (Choose one)
   - a. Male
   - b. Female
   - c. Transgender
   - d. Non-Binary
   - e. Other
   - f. Prefer not to say.
3. Race
   - a. American Indian / Alaska Native
   - b. Asian
   - c. Black / African American
   - d. Native Hawaiian / Other Pacific Islander
   - e. White
   - f. Other Race or More Than One Race
   - g. Unknown
   - h. Prefer not to say.
4. Ethnicity
   - a. Hispanic or Latinx
   - b. Not Hispanic or Latinx
   - c. Other Ethnicity or More Than One Ethnicity
   - d. Unknown
   - e. Prefer not to say.

5. How comfortable do you feel collecting the following demographic information from patients?

	Very Uncomfortable	**Uncomfortable**	**Neutral**	**Comfortable**	**Very Comfortable**
Race					
Ethnic background					
Language you prefer to use to talk about your health					
Gender at birth					
Gender Identity					
Use of pronouns					
Sexual Orientation					
Other Issues impacting your health including housing, income, safety at home, etc.					

6. How confident are you in the quality of the following demographic information in your practice's EHR?

	Very Uncomfortable	**Uncomfortable**	**Neutral**	**Comfortable**	**Very Comfortable**
Race					
Ethnic background					
Language you prefer to use to talk about your health					
Gender at birth					
Gender Identity					

Use of pronouns					
Sexual Orientation					

7. Do you feel you have the needed time to ensure the complete and accurately assure the collection of patient demographic data?
    a. Yes
    b. No
    c. Unsure
8. Have you received training about: (Yes, No, Unsure for each question below)
    a. Systemic racism, sexual orientation and gender identity, implicit bias, and healthcare disparities?
    b. The best way to collect complete and accurate demographic data from patients?
    c. The best way to document demographic data in your practice's EHR?
    d. How does your practice use demographic data to reduce health disparities?
9. Do you have access to policies and scripts to help you accurately, completely, and respectfully collect demographic data from patients?
    a. Yes
    b. No
    c. Unsure
10. Have you encountered the following challenge when collecting demographic data? For each response (Yes – please provide details, No, Unsure)
    a. Related to patient ability or willingness to share the information?
    b. Related to your comfort asking about the data?
    c. Related to the medical record systems or other technology used to capture the data?
    d. Other?
11. What strategies do you use to ensure that patients understand the purpose of collecting demographic information? Free text response
12. Have you ever experienced discrimination which impacted the healthcare you received?
    a. Yes
    b. No
    c. Unsure
13. Do you feel this office has been sensitive and respectful when asking patients about demographic data?
    a. Yes
    b. No
    c. Unsure
14. Are there things this practice could do that would make you more comfortable and confident in collecting and recording complete and accurate demographic data?
    a. Yes, please provide details

   b. No
   c. Unsure

15. Do you have any ideas, comments, or suggestions for improving our collection of demographic information? (Free response)

Thank you for your time in completing this important survey!

Patient Engagement

Survey for Patients Regarding Demographic Data Collection

Survey Monkey Link:

Patient Survey – Patients who have had a visit in the past 12 months

Our practice wants to better understand how patients feel about being asked questions about themselves - including your race, ethnicity, language, sexual orientation, and gender identity. Your responses are completely confidential. Your information will NOT be shared with your doctor or staff collecting this survey data. (The State of RI and Department of Health will see a summary of this information (not individual data) because they are working to improve health outcomes after seeing unequal outcomes for various groups during COVID-19.) Please complete the survey for yourself or a patient for whom you are a caregiver. This survey will take about 10 minutes. Thank you.

Primary Care Provider's Name/ or Medical Practice Name: (<include free text box>)
Town where the medical practice is: (<include free text box>)

Patient Information:

1. Who are you filling out this survey for? (Choose one)
    a. For myself
    b. For an adult patient for whom I am a caregiver
    c. For a patient aged 18 or under
2. Gender of patient (Choose one)
    a. Male
    b. Female
    c. Transgender
    d. Non-Binary
    e. Other
    f. Prefer not to say
3. Primary language of patient
    a. English
    b. Spanish
    c. Portuguese
    d. French
    e. Haitian
    f. Chinese
    g. Other (<include free text box>)
    h. Prefer not to say.
4. Age of patient (Drop-down menu)
    a. 0-4
    b. 5-13
    c. 14-18
    d. 19-24
    e. 25-34

    f. 35-44
    g. 45-54
    h. 55-64
    i. 65-74
    j. 75-84
    k. 85-94
    l. 95 and older
    m. Prefer not to say.
5. Race
    a. American Indian / Alaska Native
    b. Asian
    c. Black / African American
    d. Native Hawaiian / Other Pacific Islander
    e. White
    f. Other Race or More Than One Race
    g. Unknown
    h. Prefer not to say.
6. Ethnicity
    a. Hispanic or Latinx
    b. Not Hispanic or Latinx
    c. Other Ethnicity or More Than One Ethnicity
    d. Unknown
    e. Prefer not to say.

<u>Insurance Information</u>:

7. What type of health insurance do you/the patient have? (Choose all that apply) (Drop-down menu)
    a. Commercial insurance (Aetna, Blue Cross Blue Shield, Cigna, Neighborhood Health Plan, UnitedHealthcare, Other)
    b. Medicare
    c. Medicaid (State of RI Insurance/RIte Care, including Tufts Health Plan, Neighborhood Health Plan of Rhode Island, and UnitedHealthcare Community Plan)
    d. No health insurance
    e. Other (<include free text box>)

Demographic Data Collection

1. **How comfortable are you providing information to your doctor's office staff** about each of the following (demographic data): (Drop down 5-point Likert scale of Very Uncomfortable to Very Comfortable for each data element)

	Very Uncomfortable	**Uncomfortable**	**Neutral**	**Comfortable**	**Very Comfortable**
Race					
Ethnic background					
Language you prefer to use to talk about your health					
Gender at birth					
Gender Identity					
Use of pronouns					
Sexual Orientation					
Other Issues impacting your health including housing, income, safety at home, etc.					

2. **How comfortable are you providing information to your doctor** about each of the following (demographic data): (Drop down 5-point Likert scale of Very Uncomfortable to Very Comfortable for each data element)

	Very Uncomfortable	**Uncomfortable**	**Neutral**	**Comfortable**	**Very Comfortable**
Race					
Ethnic background					
Language you prefer to use to talk about your health					

Gender at birth					
Gender Identity					
Use of pronouns					
Sexual Orientation					
Other Issues impacting your health including housing, income, safety at home, etc.					

3. Do you think it is important for your healthcare provider to understand these aspects about you as a person and about your life experience to provide the best care for you?
    a. Yes
    b. No
    c. Unsure
4. How important is it to you that your healthcare provider explains to you why they are collecting demographic data as well as how they will use and protect your information?
    a. Not at all Important
    b. Not important
    c. Neutral
    d. Important
    e. Very Important
5. How important is it to you that your healthcare provider explains to you how they will use and protect your demographic information?
    a. Not at all Important
    b. Not important
    c. Neutral
    d. Important
    e. Very Important
6. Do you think that collecting demographic data could help healthcare providers understand and address unequal healthcare among different groups of people?
    a. Yes
    b. No
    c. Unsure
7. Have you ever experienced discrimination which impacted the healthcare you received?
    a. Yes
    b. No

    c. Unsure

8. Do you feel this office has been sensitive and respectful to you when asking about your demographic data?
    a. Yes
    b. No
    c. Unsure
9. Are there things this practice could do that would make you more comfortable and confident in sharing your demographic data?
    a. Yes, please provide details
    b. No
    c. Unsure
10. Who do you feel most comfortable asking you these questions (select all that apply):
    a. Reception
    b. Medical Assistant
    c. Physician
    d. Nurse
    e. Other?
11. How do you prefer for this information to be collected (select all that apply)?
    a. Verbally at reception
    b. Verbally during the visit
    c. Paper form
    d. Kiosk or tablet
    e. Medical portal?

Thank you for your time in completing this important survey!

Appendix II

Practice Needs Assessment Results

Descriptive Data about the Practice

Type of Practice	Frequency	Percent
Federally Qualified Health Center	1	7
Primary Care	3	20
Internal Medicine	3	20
Family Medicine	3	20
Pediatrics	5	33

Staffing (Number of FTEs)	Minimum	Maximum	Mean
Primary Care Providers (MD, DO, NP, PA)	0.7	10	2.8
Behavioral Health Specialists	0	8	0.6
Non-Clinical Patient Facing Administrative Staff	0	17	3.4
Nurses (RN, LPN)	0	6	.9
Medical Assistants	0	25	3.9
Social Support Specialists (CHW, Case Managers)	0	6	.7
Pharmacists	0	6	.6

Electronic Health Record in Use*	Frequency	Percent
Epic	11	73
Amazing Charts	2	13
NextGen	1	7
Greenway	1	7

*100 Percent of EHRs are certified

Data Collection

100% of Practices Collect Demographic Data

Does the Practice Collect the Following Demographic Data Elements:	Frequency of Positive Responses	Percent
Race	14	93
Ethnicity	13	87

Language	15	100
Gender Identity	9	60
Pronouns	4	27
Sexual Orientation	10	67
Military Service for Patient	3	20
Military Service for Patient's Family	1	5
Disability Status	5	33
Income	4	27
Housing Status	9	60
Other Social Determinants of Health	10	67

Does the Following Staff at the Practice Collect Demographic Data	**Frequency of Positive Responses**	**Percent**
Registration Staff	10	67
Medical Assistants	3	20
Front Desk	2	13
Patient Services Representatives	1	7
Clinicians	*1*	7

Is demographic data collected or updated at the following times:	**Frequency of Positive Responses**	**Percent**
New Patient Registration	14	93
Annual Physical or Wellness Exam	8	53
Every Visit	5	33
When prompted for applicable changes	3	20
Randomly	*1*	7

Is demographic data collected during the following parts of a NEW PATIENT VISIT	**Frequency of Positive Responses**	**Percent**
Check-in	13	87
Scheduling	6	40
Clinical Encounter	5	33
Rooming	3	20
Other (during initial encounter at a facility or lab)	1	7
Check-out	*0*	0

Is demographic data collected or updated during the following parts of an ESTABLISHED PATIENT VISIT	Frequency of Positive Responses	Percent
Check-in	13	87
Clinical Encounter	6	40
Scheduling	2	13
Rooming	1	7
Check-out	*0*	0

What modes of data collection are used to obtain demographic data from patients	Frequency of Positive Responses	Percent
Verbally	14	93
Paper Intake Form	10	67
Patient Portal	6	40
On-line Registration Form	2	13
Kiosk, Texting, Other	0	0

Patient Engagement Regarding Data Collection

Do patients self-report their demographic data	Frequency	Percent
Yes	6	40
Sometimes	4	27
No	2	13
Unknown	2	13
Do not have the capacity	1	7

Are patients allowed to use multiple selections to capture their identify	Frequency	Percent
Yes	4	27
No	7	47
Unknown	4	27

Does the practice have a process to support patients who choose not to respond to demographic data collection questions	Frequency	Percent
Yes	11	73
No	2	13
Unknown	2	13

If yes, how does the practice record data in the EHR if the patient chooses not to provide the information	Frequency
Declined	4
Refused	3
Prefer not to Answer	3
Declined, not ascertained, and refused options available	1

Does the practice have a process to support patients who are unable to read/write in English to complete demographic data collection questions	Frequency	Percent
Yes	10	67
No	4	27
Unknown	1	7

Does the practice have a way to ensure patient privacy during demographic data collection	Frequency	Percent
Yes	12	80
No	2	13
Unknown	1	7

If yes, how does your practice ensure privacy	Frequency
Physical Space or Dividers	9
Use a Paper Form	3
Ask in the Exam Room	2

Does the practice provide education to patients about the importance of demographic data collection	Frequency	Percent
No	11	73
Yes	2	13
Unknown	2	13

Has the practice surveyed patients about their experience with demographic data collection	Frequency	Percent
No	11	73
Yes	2	13
Unknown	2	13

Has the practice surveyed patients about their experience with healthcare disparities	Frequency	Percent
No	11	73
Yes	3	20
Unknown	1	7

Data Collection Policies and Staff Engagement

Does the practice have written policies about Demographic data collection?	Frequency	Percent
No	8	53
Yes	6	40
Unknown	1	7

Are the practice staff trained on processes for accurate and complete data collection?	Frequency	Percent
Yes	13	87
Yes	2	13

Do the staff have the time needed to collect accurate and complete demographic data?	Frequency	Percent
Yes	8	53
No	4	27
Unknown	3	20

Are the practice staff trained on the importance of complete, accurate and ethical use and protection of patient demographic data?	Frequency	Percent
Yes	7	47
No	7	47
Unknown	1	7

Does the practice educate staff on health disparities and cultural competency related to demographic data collection?	Frequency	Percent
No	8	53
Yes	4	27
Unknown	3	20

Has the practice provided staff with a script to ensure language used to request demographic data is appropriate and sensitive	Frequency	Percent
No	10	67
Yes	4	27
Unknown	1	7

Has the practice surveyed staff about their personal experiences with demographic data collection?	Frequency	Percent
No	10	67
Yes	5	33

Has the practice surveyed staff about their personal experiences with healthcare disparities?	Frequency	Percent
No	14	93
Yes	1	7

Has the practice established clear accountability for accurate and complete data collection?	Frequency	Percent

Yes	7	47
No	6	40
Unknown	2	13

Has the practice established clear accountability for accurate and complete data collection?	Frequency	Percent
Yes	7	47
No	6	40
Unknown	2	13

If yes, who has accountability for accurate and complete data collection?	Frequency
Office or Practice Manager	3
Clinician	2
VP Operations	1
Front Desk Staff	1

Does the practice regularly measure the completeness and accuracy of demographic data?	Frequency	Percent
Yes	8	53
No	7	47

Do you know the level of completeness and accuracy of demographic data in your practice?	Frequency	Percent
No	8	53
Yes	7	47

Has your practice taken steps to improve the completeness and accuracy of demographic data?	Frequency	Percent
Yes	9	60
No	5	33
Unknown	1	7

Has the practice established clear accountability to reduce health inequities?	Frequency	Percent

No	9	60
Yes	3	20
Unknown	3	20

Does the practice stratify quality measures based on demographic data?	**Frequency**	**Percent**
No	11	73
Yes	4	27

Does the practice engage in QI based on identified disparities?	**Frequency**	**Percent**
Yes	8	53
No	7	47

Data Standards and Collection Processes

What standards are used to collect race /ethnicity data?	**Frequency**	**Percent**
1997 OMB	9	60
Unknown	4	27
HRSA/UDS	1	7
OMB with ability to decline or choose more than one race	1	7

Does the practice collect data at a more granular level based on local community and population needs, with proactive mapping to OMB standards	**Frequency**	**Percent**
No	13	87
Yes	1	7
Unknown	1	7

Are demographic data fields mandatory in your EHR?	**Frequency**	**Percent**
Yes	11	73
No	3	20
Unknown	1	7

Is your EHR configured to support race /ethnicity mapping and eliminate free text ?	Frequency	Percent
Yes	11	73
No	4	27

Does your EHR have options to differentiate “declined” vs. “unknown” responses?	Frequency	Percent
Yes	13	87
Unknown	2	13

Has the practice used other technologies to capture demographic data (e.g., portal, kiosk)?	Frequency	Percent
No	8	53
Yes	6	40
Unknown	1	7

Rating of Processes Necessary for Successful Demographic Data Collection (Percent)	Very Poorly	Needs Improvement	Adequately	Well	Very Well
Leadership Support and Accountability	0	40	47	7	7
Patient Engagement	7	53	27	0	13
Staff Training and Engagement	0	60	20	7	13
IT Support	0	40	40	20	0
Reporting and QI	7	40	40	0	13

Topics for Inclusion in the Learning Series

What topics should be offered in this learning series?	Frequency	Percent
Best practice for asking patients for race, ethnicity and language information and responding to their questions/reaction	12	80
Best practice for asking patients about sexual orientation and gender identity.	11	73
Working with IT and vendors to improve data capture and reporting	10	67
Methods and Tools such as scripts, role playing, frequently asked questions documents, front desk standard sample	9	60
Best practices in workflow to improve the completeness and accuracy of data collection	9	60
Using data to understand and address disparities in the healthcare delivery and outcomes	8	53
Using technology to collect demographic data (patient portal, kiosk, tablet)	8	53
Collaborating with local community groups to engage and understand specific sub-populations served by your practice	7	47
Cultural competency, systemic racism, implicit bias, and implications for health equity	7	47
Changing federal and state data standards for collection of race and ethnicity data	4	27
Establishing a process such as a patient advisory committee to improve health equity in your practice	3	20

Appendix III

Staff Survey Results

Descriptive Data about Staff

What is your role in the practice?	Frequency	Percent
Reception	37	42
Medical Assistant	22	25
Primary Care Provider	6	7
Left Blank	5	6
Practice Manager	~	~
pharmacist	~	~
Nurse	~	~
Admin / IT	~	~
Clerical	~	~
facility screener specialist	~	~
Front office, medical assistant, referral coordinator	~	~
Intake Screener	~	~
LICSW	~	~
MH Therapist	~	~
Office Manager	~	~
Office Staff	~	~
Registration	~	~
site manager	~	~
Supervisor	~	~
Triage Clinician for Behavioral health	~	~

Gender	Frequency	Percent
Female	75	84
Male	8	9
Left Blank	5	6
Prefer not to say	1	1

Race	Frequency	Percent
White	56	63
Other Race or More Than One Race	14	16
Black / African American	6	7
Prefer Not to Say	5	6
Left Blank	5	6
American Indian / Alaska Native	~	~
Asian	~	~
Unknown	~	~

Ethnicity	Frequency	Percent
Not Hispanic or Latino	52	58
Hispanic or Latino	25	28
Left Blank	5	6
Prefer Not to Say	4	5
Other Ethnicity or More than One Ethnicity	~	~
Unknown	~	~

Staff Experience

Percent of staff reporting comfort with collecting the following data types to the office staff at their doctor's office	Very Uncomfortable	Uncomfortable	Neutral	Comfortable	Very Comfortable	Left Blank
Race	9	8	27	20	23	14
Ethnic background	8	7	26	23	23	15
Language you prefer to use to talk about your health	7	1	18	28	33	14
Gender assigned at birth	14	10	30	15	18	14
Gender Identity	12	15	34	17	9	14
Use of pronouns	15	14	33	16	10	14
Sexual Orientation	14	14	33	14	12	15
Other Issues impacting your health including housing, income, safety at home, etc.	10	12	25	20	19	14

Percent of staff reporting confidence in the quality of the following data types to the office staff at their doctor's office	Not Confident at All	Not Confident	Neutral	Confident	Very Confident	Left Blank
Race	2	6	29	32	18	14
Ethnic background	2	5	32	32	17	14
Language you prefer to use to talk about your health	1	1	29	30	24	15
Gender assigned at birth	2	7	32	27	19	14
Gender Identity	2	12	33	23	17	14
Use of pronouns	7	10	32	20	18	14
Sexual Orientation	5	8	34	20	20	14

Do you feel you have the needed time to ensure the complete and accurate collection of patient demographic data?	Frequency	Percent
Yes	44	49
No	20	23
Unsure	13	15
Left Blank	12	14

Percent of staff reporting having received training of the following	Yes	No	Unsure	Left Blank
Systemic racism, sexual orientation and gender identity, implicit bias, and healthcare disparities?	62	20	5	14
The best way to collect complete and accurate demographic data from patients?	63	17	7	14
The best way to document demographic data in your practice's EHR?	69	11	7	14

Do you have access to policies and scripts to help you accurately, completely, and respectfully collect demographic data from patients?	Frequency	Percent
Yes	53	60
Unsure	15	17
Left Blank	12	14
No	9	10

Have you encountered challenges related to patient ability or willingness to share their demographic information?	Frequency	Percent
No	38	43
Yes	30	34
Left Blank	12	14
Unsure	9	10

Have you encountered challenges related to your comfort asking patients about demographic information?	Frequency	Percent
No	54	61
Unsure	13	15
Left Blank	12	14
Yes (please provide details)	10	11

Have you encountered challenges related to the medical record systems or other technology used to capture patient demographic data?	Frequency	Percent
No	62	70
Left Blank	12	14
Unsure	10	11
Yes	5	6

Are there any other challenges you have encountered related to collecting patient demographic data?	Frequency	Percent
No	70	79
Left Blank	12	14
Yes (time, language, privacy, pt. homeless, pt refusal)	7	8

Have you ever experienced discrimination which impacted the healthcare you received?	Frequency	Percent
No	56	63
Left Blank	12	14
Yes	11	12
Unsure	10	11

Do you feel this office has been sensitive and respectful when asking patients about demographic data?	Frequency	Percent
Yes	73	82
Left Blank	12	13.5
No	4	4.5

Are there things this practice could do that would make you more comfortable and confident in collecting and recording complete and accurate demographic data?	Frequency	Percent
Unsure	38	42.7
No	33	37.1
Left Blank	12	13.5
Yes (training, confidentiality, paper questionnaire)	6	6.7

Appendix IV

Patient Survey Results

Descriptive Data about the Patient

Who are you filling out this survey for?	Frequency	Percent
For myself	667	56
For my child or a child for whom I am a guardian	461	39
For an adult patient for whom I am a caregiver	18	2
Left Blank	44	4

Patient Gender	Frequency	Percent
Female	655	55%
Male	486	41%
Left Blank	18	2%
Prefer not to say	13	1%
Transgender	9	1%
Non-binary/Other	9	1%

Patient Age	Frequency	Percent
18 or under	455	38%
19-64	689	40%
65-74	152	13%
75+	58	5%
Prefer not to say	2	0%
Left Blank	44	4%

Patient Language	Frequency	Percent
English	1113	94%
Left Blank	44	4%
Spanish	14	1%
Prefer not to say	5	0%
Portuguese	~	0%
Haitian	~	0%
Russian	~	0%
Chinese	~	0%
Arabic	~	0%
Catalan	~	0%
Creole	~	0%
Filipino	~	0%
Pushto	~	0%

Patient Race	Frequency	Percent
White	969	81
Other Race or More Than One Race	61	5
Prefer Not to Say	46	4
Left Blank	44	4
Black / African American	39	3
Asian	20	2
Unknown	5	0
American Indian / Alaska Native	~	0
Middle Eastern or North African	~	0

Patient Ethnicity	Frequency	Percent
Not Hispanic or Latino	913	77
Hispanic or Latino	90	8
Prefer Not to Say	65	6
Other Ethnicity or More than One Ethnicity	58	5
Left Blank	44	4
Unknown	20	2

Patient Insurance	Frequency	Percent
Commercial	684	57%
Medicaid	180	15%
Medicare	149	13%
Left Blank	139	12%
Other	27	2%
No Insurance	11	1%

Patient Experience

Percent of patients reporting comfort with providing the following data types to the office staff at their doctor's office	Very Uncomfortable	Uncomfortable	Neutral	Comfortable	Very Comfortable	Left Blank
Race	6	1	10	17	46	21
Ethnic background	5	1	10	17	47	21
Language you prefer to use to talk about your health	5	1	6	17	51	21
Gender assigned at birth	6	1	5	15	52	21
Gender Identity	7	1	6	15	50	21
Use of pronouns	7	2	9	14	47	21
Sexual Orientation	7	2	8	15	47	21
Other Issues impacting your health including housing, income, safety at home, etc.	6	2	9	19	44	21

Percent of patients reporting comfort with providing the following data types to their doctor	Very Uncomfortable	Uncomfortable	Neutral	Comfortable	Very Comfortable	Left Blank
Race	5	1	7	16	52	21
Ethnic background	5	1	7	15	51	21
Language you prefer to use to talk about your health	5	0	5	16	54	21
Gender assigned at birth	6	0	5	15	53	21
Gender Identity	6	1	6	14	52	21
Use of pronouns	7	1	8	14	50	21
Sexual Orientation	6	1	8	14	51	21
Other Issues impacting your health including housing, income, safety at home, etc.	5	1	8	17	48	21

Do you think it is important for your healthcare provider to understand these aspects about you as a person and about your life experience to provide the best care for you?	Frequency	Percent
Yes	760	64
Left Blank	243	20
Unsure	101	9
No	86	7

How important is it to the patient that the provider explains the following:	Not at all Important	Not Important	Neutral	Important	Very Important	Left Blank
Why they are collecting the information	6.00	5	25	27	18	20
How they will use and protect the information	4.00	3	18	26	29	20

Do you think that collecting demographic information could help healthcare providers understand and address unequal healthcare among different groups of people?	Frequency	Percent
Yes	635	53
Left Blank	243	20
Unsure	228	19
No	84	7

Have you ever experienced discrimination which impacted the healthcare you received?	Frequency	Percent
No	781	66
Left Blank	243	20
Yes	88	7
Unsure	78	7

Do you feel this office has been sensitive and respectful to you when asking about your demographic information?	Frequency	Percent
Yes	879	74
Left Blank	243	20
Unsure	53	5
No	15	1

Who do you feel most comfortable asking you questions about demographic information	Frequency	Percent
Primary Care Provider	812	68%
Nurse	473	40%
Medical Assistant	452	38%
Reception	352	30%
Other (free text included anyone and no one)	50	4%

How do you prefer your demographic data be collected	Frequency	Percent
Paper Form	540	45%
Verbally during the visit, in the exam room	443	37%
Medical Portal	381	32%
Kiosk or tablet	332	28%
Verbally at reception	186	16%

Appendix V

Walk-Around Tool Summarization

Question 1: Begin by making an appointment with the primary care practice as a patient. Did the person helping you make the appointment ask you for any demographic information? (race, ethnicity, language preference, sexual orientation, and gender identity)?

	Asked During Scheduling	**Ask only NP during Scheduling**	**Ask, confirm or collect at Check-In or on NP Registration Form**	**Ask during visit**	**Was Not Asked**	**Did not complete**	**Notes**
Practice 1			1				
Practice 2						1	
Practice 3	1						ONLY REL
Practice 4					1		Only ask for Name, Address DOB
Practice 5		1					
Practice 6	1						
Practice 7						1	
Practice 8						1	
Practice 9		1					
Practice 10						1	
Practice 11			1				Gender Only
Practice 12					1		
Practice 13		1					Existing patients confirmed at check in
Practice 14					1		
Practice 15					1		
Total	**2**	**3**	**2**	**0**	**4**	**4**	

Question 2: During your visit, ask to fill out a patient registration form. Observe whether the form includes questions about demographic information such as race, ethnicity, language, and sexual orientation.

	Form Contains Race	Form Contains Ethnicity	Form Contains Language	Form Contains SO	Form Contains GI	Form Does Not Ask for REL/SOGI	No Registration Form Available	Notes
Practice 1	1	1	1	1	1			
Practice 2	1	1	1	1	1			
Practice 3	1	1	1					
Practice 4	1	1	1					SOGI asked in exam room
Practice 5	1	1	1	1	1			Collected at NP Intake and updated annually for existing patients
Practice 6						1		
Practice 7	1	1	1					
Practice 8						1		
Practice 9	1	1						
Practice 10	1	1	1					SOGI asked in exam room for patients 13+
Practice 11						1		Form only asks for Gender
Practice 12							1	
Practice 13							1	
Practice 14	1	1	1	1	1			
Practice 15						1		REL are collected verbally at check in. EMR has a hard stop

Total	**9**	**9**	**8**	**4**	**4**	**4**	**2**	

Question 3: If the registration form does not include questions about demographic information, ask the front desk staff if the practice collects this information. Take note of their response.

	Practice Collects Demo Data	**Practice Does Not Collect Demo Data**	**Practice Has a Reg Form**	**Reg Form does not include REL/SOGI**	**Notes**
Practice 1			1		
Practice 2			1		
Practice 3			1		
Practice 4			1		Providers collect SOGI in exam room
Practice 5			1		
Practice 6	1		1	1	Collected during appt scheduling on the phone
Practice 7			1		Doctor asks for info in exam room but documents in note, not in Demo section
Practice 8			1	1	
Practice 9			1		
Practice 10			1		
Practice 11	1		1	1	Provider asks demographics in exam room
Practice 12		1			These were the only two practices that
Practice 13	1				indicated they did not have a reg form.
Practice 14			1		
Practice 15	1		1	1	REL collected during check in; EMR has hard stop
Total	**4**	**1**	**13**	**4**	

Question 4: Take note if patients are able to provide their demographic information comfortably in the physical space (privacy barriers, on paper, private room).				
	Yes	**No**	**Ambiguous**	**Notes**
Practice 1	1			Paper or Exam Room
Practice 2	1			Parents report to front desk they are not comfortable when provider asks SOGI question
Practice 3	1			
Practice 4			1	Response indicates paper is used by waiting room is not private for confirming info verbally
Practice 5	1			Barriers and paper forms are used
Practice 6	1			Practice only allows one patient at a time in waiting room
Practice 7			1	Waiting room can be crowded; exam room is private
Practice 8			1	Sometimes provided on paper; sometimes in exam room; verbal confirm is not private
Practice 9			1	Information is sometimes confirmed by reception; sometimes in exam room
Practice 10	1			
Practice 11	1			Patient asked by PCP in exam room
Practice 12	1			Privacy barriers
Practice 13		1		Asked verbally in open space next to another check in window
Practice 14	1			On Paper
Practice 15	1			Usually only 1 patient at a time in waiting room
Total	**10**	**1**	**4**	

Question 5: Ask to see a copy of the practice's electronic health record (EHR) or paper charts. Look for demographic information on the patient's profile or chart.

	EMR Includes Demo Info	**EMR Does Not Include Demo Info**	**Did not answer question**
Practice 1	1		
Practice 2	1		
Practice 3	1		
Practice 4	1		
Practice 5	1		
Practice 6	1		
Practice 7	1		
Practice 8	1		
Practice 9	1		
Practice 10	1		
Practice 11	1		
Practice 12			1
Practice 13	1		
Practice 14	1		
Practice 15	1		
Total	**14**	**0**	**1**

Question 6: Review a sample of patient charts to determine whether demographic information is consistently collected and recorded.

	Consistent	**Somewhat Consistent**	**Not Consistent**	**Not Collecting**	**Did Not Answer**	**Notes**
Practice 1	1					EPIC Hard stops
Practice 2	1					
Practice 3	1					
Practice 4	1					
Practice 5	1					Reviewed routinely for completeness for UDS
Practice 6					1	Stated charts were reviewed but did not provide detail
Practice 7		1				Review indicates 80%
Practice 8	1					Just started collecting consistently
Practice 9	1					Recently started confirming info verbally
Practice 10	1					
Practice 11	1					
Practice 12				1		No
Practice 13	1					
Practice 14	1					
Practice 15	1					Collect info during PE due to having the most time with patient
Total	**12**	**1**	**0**	**1**		

Question 7: Observe the interactions between the provider and the patient during the visit. Note whether the provider asks about demographic information and how they document it in the patient's chart.

	Provider Asks	Provider Does Not Ask	Documents in Chart	Not able to observe	Did Not Answer Question	Notes
Practice 1	1			1		Provider reported they ask patient; no info about documenting
Practice 2				1		
Practice 3	1					
Practice 4				1		
Practice 5	1					Providers will ask based on need during visit; no info about documenting
Practice 6		1				Patients are aske verbally when they call to make an appt
Practice 7		1				May ask about SOGI if relevant to visit; Can see REL on form
Practice 8	1		1	1		Provider described process the process of asking and documenting in a chart.
Practice 9					1	
Practice 10	1			1		Provider uses scribe to ask for information and document in EMR
Practice 11				1		
Practice 12	1					Gender, Sex, Pronouns, Ethnicity, Address
Practice 13		1				
Practice 14				1		
Practice 15					1	
Total	**6**	**3**	**1**	**7**	**2**	

Question 8: Ask the provider or clinical staff about the importance of collecting demographic information and how they use it to inform patient care.

	Staff Understands	PCP Does Not Use Demo Data	Did Not Answer	Notes
Practice 1	1			Helps with visit; makes patient more comfortable; makes patient feel valued and heard
Practice 2	1			Staff would like to know or learn the right way to educate patients
Practice 3	1			
Practice 4	1			helps you understand the patient and their background. They use it to inform themselves about a patient's history and understand what factors may contribute to a patient's overall health. Referenced understanding patient's family's financials, and understanding what they can afford, if a patient needs a certain medication. They also said understanding demographics helps a provider treat the whole patient.
Practice 5	1			Certain demographic questions can be relevant to the clinical staff to address specific healthcare needs and health disparities and improve health care delivery
Practice 6		1		
Practice 7			1	
Practice 8		1		Provider does not understand purpose - treats all patients the same
Practice 9			1	
Practice 10	1			PCP understands/staff does not
Practice 11	1			to best provide point of care testing and complete routine preventative care specifically pertaining to race.
Practice 12	1			Used for reporting and to determine resources/services appropriate to their race/ethnicity/beliefs
Practice 13	1			important to tailor care to patient's individual needs
Practice 14	1			Helps determine what kind of care is given to specific patient
Practice 15			1	
Total	**10**	**2**	**3**	

Question 9: If the practice has a patient portal, log in and review the patient registration form to see whether demographic information can be updated online.

	Can Update in PP	**Cannot Update in PP**	**N/A**	**Unknown**	**Did Not Answer**	**Notes**
Practice 1	1					MyChart
Practice 2	1					Can be updated online
Practice 3			1			
Practice 4		1				My Chart Only update on reg form
Practice 5	1					My Chart
Practice 6	1					My Chart
Practice 7				1		Practice Manager looking into using PP to update demographics
Practice 8	1					My Chart
Practice 9					1	
Practice 10	1					Address & Phone #
Practice 11	1					My Chart
Practice 12	1					
Practice 13	1					
Practice 14	1					
Practice 15					1	
Total	**10**	**1**	**1**	**1**	**2**	

Question 10: After your visit, review the practice's website and patient materials to see whether they address the importance of collecting demographic information and how it is used to improve patient care.

	Website / Materials Address Importance	Website / Materials DO NOT Address Importance	NA/No Website	Not Answered	Notes
Practice 1		1			Website has antidiscrimination message
Practice 2		1			
Practice 3			1		
Practice 4		1			Website has demo form that patients can download and complete and other helpful info about patient care and pediatrics
Practice 5		1			
Practice 6		1			
Practice 7			1		No website
Practice 8			1		No website - Provider does not understand importance of collecting data
Practice 9				1	
Practice 10		1			
Practice 11		1			
Practice 12			1		
Practice 13			1		
Practice 14			1		
Practice 15				1	
Total	**0**	**7**	**6**	**2**	

Question 11: Compile your observations and share them with the practice leadership, along with any recommendations for improvement.

	Plan Outlined	No Plan Outlined	Not Answered	Focus
Practice 1	1			Process to improve completeness & SOGI
Practice 2	1			Staff training on why and how to speak to/educate patients
Practice 3		1		
Practice 4	1			Improving SOGI data and patient privacy
Practice 5	1			Work with leadership to discuss opportunities for improvement
Practice 6		1		
Practice 7			1	
Practice 8			1	
Practice 9			1	
Practice 10	1			Staff education on importance of data collection
Practice 11	1			Workflow improvement/data collection tool
Practice 12	1			Implement Workflow
Practice 13			1	
Practice 14			1	
Practice 15			1	
Total	**7**	**2**	**6**	