CARE TRANSFORMATION COLLABORATIVE RHODE ISLAND

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ADVANCING INTEGRATED HEALTHCARE

Demographic Data Collection Pilot Opportunity

HIT Steering – January 18th, 2024

Agenda

Item	Presenter
Introductions & Presentation Overview	***Yolanda Bowes***
Environmental Scan: Best Practice Literature Review & Key Informant Interviews	***Kerri Costa***
Baseline RI Demographic Data Performance Report	***Elaine Fontaine***
Environmental Scan: Current & Anticipated Standards	***Kerri Costa***
Baseline Needs Assessment Summary Report	***Elaine Fontaine***
Webinar Series, Technical Enhancement Funds, Quality Improvement	***Yolanda Bowes***

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Environmental Scan – Best Practice Literature Review & Key Informant Interviews

Kerri Costa

OVERARCHING FINDINGS: CRITICAL TOPICS FOR THE CTC WEBINAR SERIES

1. Systemic Racism, health inequities, SOGI, and implicit bias
2. Cultural sensitivity and awareness of the populations served in the community.
3. Scripting to support staff and patient's increase comfort and confidence in asking for and providing sensitive demographic information.
4. Workflow considerations to support complete, accurate, confidential, and respectful collection of demographic data, including recognition of challenges for patients posed by language, literacy, and ability.
5. Changing national and local standards for collection of race, ethnicity, and language, as well as consideration for granular data collection that can be aggregated to required national reporting standards.
6. Electronic Health Record modifications to support granular data collection and re-aggregation to national standards.
7. Use of demographic data for quality improvement activities to reduce health disparities.

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Baseline RI Demographic Data Performance Report

Elaine Fontaine

BASELINE RI DEMOGRAPHIC DATA COLLECTION PERFORMANCE

KEY FINDINGS

Percent Data Reported Unknown by Source

	Race	Ethnicity	Language	Gender	Sexual Orientation
UDS	23%	6%	N/A	76%	52%
RIQI	17%	28%	69%	100%	100%
QRS	15%	17%	96%	100%	92%
Lifespan	26%	41%	35%	97%	99%

While data sources have important differences in patient cohorts and processes associated with data collection, input, transmission, and validation, all data sources reflect a large percent of unknown data on important demographic data elements.

CONSIDERATIONS (based on entirety of landscape review)

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

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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Environmental Scan: Current & Anticipated Standards

Kerri Costa

Key Findings

Common Demographic Data Elements Collected

- Race, Ethnicity, Language, Gender Assigned at Birth, Gender Identity and Sexual Orientation with a primary focus on Race and Ethnicity

Key Findings Summary

- All organizations that research was completed on are following the OMB 1997 standards at a minimum
- Recommendation to follow the HHS standards – used at Health Centers
- Recommendation to incorporate granular data collection based on practices community / patient population
- All must roll up to the OMB standards for reporting

Recommendations and Suggested Next Steps

1. Practice Engagement with Local Community Leaders to Understand Patient Population
2. Review EHR Reporting Capabilities & Create Reporting Mechanisms that Provide Roll-Up of Granular Data into OMB Standards
    - May Require Clear Mapping between data to OMB Standards
    - May Require External Technical Assistance
3. Update CCD Configurations to Include Race, Preferred Language, Sex/Gender and Ethnicity
4. Update Patient Surveys to include Updated Expanded Options
5. More Engagement with EHR re: enhancements/ Upgrades
6. Continue to Allow Patients the Right to Decline to Answer both R/E and Ability to Choose More than One Option
7. Review 4 Main Areas of Demographic Data Collection and Reporting to Identify and Address Gaps
8. Educate Staff on Why Demographic Data is Collected and How to Assist Patients
9. Review Resources and Time Allotted per Patient during Existing Data Collection and Reporting Workflow
10. Educate Staff on Patient Population and Difference in Medical Needs

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Demographic Data Practice Needs Assessment Summary Report

Elaine Fontaine

Demographic Data Collection Practice Needs Assessment

Components

1. Practice Needs Assessment Tool
2. Staff Engagement Survey
3. Patient Survey
4. Walk Around Tool

Approach

1. Practice Needs Assessment Tool Completed by Practices Managers, included information about:
    - Practice structure;
    - Current demographic data collected;
    - Patient engagement;
    - Data collection policies, staff engagement, and accountabilities
    - Data standards in use, collection processes and use of technology
    - Ratings of practice performance on demographics data collection
    - Recommended topics for inclusion in the learning series.
2. Staff Engagement Survey, which collected information about
    - Description of staff completing the survey
    - Staff experiences with demographic data collection
3. Patient Survey, which collected information about
    - Description of patients completing the survey
    - 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 finding with their internal teams.

Demographic Data Collection Practice Needs Assessment

Approach

Data Collection

- Managed by practices
- Input into SurveyMonkey

Data Analysis and Aggregation

- Surveys Assessed Using SPSS Statistical Software
- Walk Around Tool Coded and Aggregated

Demographic Data Collection Practice Needs Assessment

Key Findings: Practice Needs Assessment Tool

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.

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

Demographic Data Collection Practice Needs Assessment

Key Findings: Staff Survey

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

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

Staff Comments

- “Maybe collect some data prior to appointment in case patient does not feel comfortable.”
- “Private, sensitive information that they may not want to share with the receptionist in lobby”.
- “Some elderly find the questions insulting”
- “Help them understand why the information is important to gather the information to serve the communities we serve and how to better serve the population”.
- “[Patients]Refuse to complete gender identity. Refusal of providing any information regarding sexual orientation, gender, identity, pronouns. Some only want to discuss in private.”
- “It is uncomfortable to ask in front of everyone.”
- “Don’t collect. Don’t see it as necessary”.
- “Not everyone is comfortable sharing personal things.”

Demographic Data Collection Practice Needs Assessment

Key Findings: Patient Survey

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	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

Demographic Data Collection Practice Needs Assessment

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Key Findings: Patient and Staff Comfort Side by Side

	Patients		Staff	
Demographic Data Type	**Comfortable**	**Very Comfortable**	**Comfortable**	**Very Comfortable**
Race	17	46	20	23
Ethnic background	17	47	23	23
Language you prefer to use to talk about your health	17	51	28	33
Gender assigned at birth	15	52	15	18
Gender Identity	15	50	17	9
Use of pronouns	14	47	16	10
Sexual Orientation	15	47	14	12
Other Issues impacting your health including housing, income, safety at home, etc.	19	44	20	19

Demographic Data Collection Practice Needs Assessment

Patient Comments

- “To provide the best care, medical providers need to be perceived as trustworthy. Having this info should be as important as “do you have an allergy...”
- “There is zero privacy with personal information when checking in with the receptionist.”
- “Keep your politics out of my medical care.”
- “I don’t like it when they ask for pronoun info, sex at birth. Someone who that applies to should disclose that and not ask every patient.”
- “Unsure why any of the current demographic questions would be of concern to US citizens”.
- “I dislike questions on what ethnic group. I am many different ethnicities and prefer to be an American.”

Here's What Patients Had to Say

Demographic Data Collection Practice Needs Assessment

Patient Comments - Continued

- "Make it optional and don't need yearly. I am a 60-year-old, and I won't be changing my gender and all the other stuff that has been the same for 60 years. Collect if relevant".
- "I am very comfortable with being asked questions about gender and gender identity and think that is important for these aspects of ourselves to be respected and discussed openly".
- "I always wonder why the information is necessary and how it will affect my care."
- "I prefer it to be more private, but I absolutely understand the importance of demographic data so am willing to share the info."
- "Sometimes the staff seem uncomfortable asking personal questions which I can imagine for some people could cause them not to reveal the truth because they get the sense that the asker either doesn't really know how to handle what they could be said, which isn't their fault. They are not trained mental health workers".

Here's What Patients Had to Say

Key Findings: Walk Around Tool

Tool was designed to provide more granular level of information to practice improvement teams. Interestingly, quality improvement leaders noted some inconsistency between information reported in the practice assessment tool and the walk around tool. For example, 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. The disconnect between policy and implementation and staff understanding was interesting to the practices.

Demographic Data Collection Practice Needs Assessment

Prioritized Needs Identified Across Surveys

- Best practice for asking patients about sexual orientation and gender identity.
- Methods and Tools such as scripts, role playing, frequently asked questions documents, front desk standard sample
- Best practices in workflow to improve the completeness and accuracy of data collection
- Cultural competency, systemic racism, implicit bias, and implications for health equity

Demographic Data Collection Practice Needs Assessment

Recommendations

Topics that should be considered for inclusion in the webinar series include:

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

Demographic Data Collection Environmental Scan Reports

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Full Environmental Scan Reports Are Available on the CTC-RI website:

https://ctc-ri.org/other-programs/demographic-data

- ➢ Environmental Scan Best Practice Summary Report
- ➢ Key Informant Interview Table
- ➢ Environmental Scan RI Demographic Data Performance Assessment Report
- ➢ Environmental Scan Current and Anticipated Standards Report
- ➢ Best Practice Needs Assessment Summary Report

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Demographic Data Participant Activities

Yolanda Bowes

Participating Practices

- Concilio Pediatrics
- East Bay Community Action Program
- The Center for Primary & Specialty Care
- The Miriam Hospital Medical Clinic
- University Internal Medicine

RIPCPC Practices

- Atlantic Pediatrics
- Children First Pediatrics
- East Bay Pediatrics
- Family Doctors Group, PC
- Jamiel Ambrad, MD
- Olga Tverskaya, MD
- Richard Ohnmacht, MD
- Smithfield Pediatrics
- Snow Family Medicine
- Your Health

Webinar Series

DATE	TOPIC	PRESENTER
October 10th, 2023	Why Demographic Data is Important	Christin Zollicoffer (Lifespan)
November 14th, 2023	Demographic Data Standards	Jennifer Etue & Natasha Viveiros (PCHC)
December 12th, 2023	SOGIE	Quinten Foster (EBCAP)
January 10th, 2024	Patient Perspective	Farah Kader (Westchester County Dept of Health) & Lusia Cardenas (New York Academy of Medicine)
February 29th, 2024	Best Practices Improving Demographic Data Collection and Reporting	Marsha McGehee & Damaris Constantinople (Cornell Scott) & Darcey Cobb-Lomax (Yale Center for Health Equity)
March 13th, 2024	Participant Sharing	All Participating Practices

Newly Added Initiatives

Technical Enhancement Funding

- Application Period – **January 8 – February 2, 2024**
- Practices eligible to apply for up to **$920 per practice**
- Technical Enhancements to Support Improvements Identified in Practice Baseline Needs Assessment

Quality Improvement Initiative

- Funded by United Healthcare and Rhode Island Foundation
- Application Period 2/8 - 3/2/24; Program Period April through December
- Open to Existing Practices and New Practices
- Improve Demographic Data Completeness & One Practice Selected Measure

Thank You

Demographic Data Project Team

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