Demographic Data Collection Pilot
Key Informant Interview Table

Organization	Interviewee(s)	Date of Interview	Webinar Series Potential Speakers/ Tools	People			Process			Technology		Reporting / Analysis	
				Patient Experience	Staff Experience	Training Needs	Walk Around Tools	Workflows	Policies	Tools In Use	System Changes Needed	Metrics & Outcomes	Lessons Learned
Health Begins	Sadena Thervarajan, Director Taleen Yepremian, Program Mgr. Vince Panucci, HE Project Coord. Rishi Machanda	4/10/2023	A demonstration of the ReaL Data Accelerator 12 Week Program is an option if CTC plans to utiize their program, or a portion of.	N/A	Support with ReaL data collection with live learning sessions, live modules, faculty in racial, ethnic data	Education on rules and regulations and understanding of how and why it matters to strategic priorities, gives deeper understanding of inequities	N/A	REaL data collection training program implements new workflows around data collection	N/A	ReaL Data Accelerator Program (12 weeks); Assessment completed to assess the orgs opportunities, idenfity strengths, weakness and opportunities	Completed during data collection program, if applicable	Reporting on inequities	Practices are not reporting and planning based on REaL data
John Snow Incoporated / Health Information Technology Evaluation, and Quality Center (HITEQ)	Jillian Maccini, JSI Research & Traning	4/17/2023	"How to Love your Data" Training on UDS+ data requirements, The use of Phreesia for patients to use to answer the demographic data questions	Mistrust; pushback due to volume of questions; Published researched say patients seem to be ok with answering questions;	Not working on data collection, due to staff turnover; No assessments completed FQHCs do not want it; Some practices want to have face to face conversation with care team (some data); Patients not always truthful	Training on data collection to meet UDS+ requirements; 5 Part series "How to Love your Data" – tells story with data, equity and data governance; Training that incorporates technology, education and addressing on an ongoing basis	None	Need workflows on capturing adequate data	None discussed	Use UDS data annually to share with practices or question data submitted; Email mailing list – monthly; Tweaked electonic system to include social determinants of health (trying to determine best place for this to be filled out); Phreesia used to collect data; Health center survey (but difficult); Patient portal used to capture some	3rd party sale of data when using Phreesia; Updates to include all demo data they want to collect	Data shared with practices mnonthly and annually; Report on completeness metrics	Need job descriptions that include data collection task; Measuring data completeness doesn't include accuracy
NCQA	Jeni Soucie, Mgr Product Mgt. Elizabeth Ryder, Assistand Dir., Product Dev. Rachel Harrington, PhD, Sr. Research Scientist, HE	4/28/2023	Health Education Trust Disparities Toolkit (HRET), PCMH / HE standards (portion with collection of R/E data)	Self reporting is gold standard; Confused about receiving a letter to opt out, where are they getting my data? – sensativity sharing data'	Challenging for data collection; struggle with patients and technology literacy and language barriers.	Understanding that disparities exist and how they persist, recording and reporting data, need collection from health plans in the same way; Improvement needed with imputation methods for addressing missing and conflicting data (technical methods, processes for implementation; Staff must be trained so no assumptions are	None	Use cases for collecting, docuenting, using and sharing race/ethnicity data, create a guide for using interoperability standards to support the collection, documenting, use and sharing	None discussed	Health Equity Accreditation (standards), Health Education Trust Disparities Toolkit (HRET) for practices seeking best practices in R/E data collection	System changes required to capture the data requirements for the Health Equity accreditation standards.	Data standards in place for management of this USCDI, Core Interoperability and common rubric granularity – CDC REC	How to aggregate categories for people reporting more than one race and/or ethnicity, missing or incomplete data, medicaid data overrides the health plans; need to clarify a point of collection and providing a mechanism for updating it – how do you know the member selected their own value
Open Door Health	Yelena Malyuta, Dir. Of Evaluation Amy Nunn, MD Exec. Dir (did not attend)	5/17/2023	Registration, Questionnairre, LGBTQ Language and Gender Resources that the practice shared with us. Refer to Appendices VIII – XI in report	Responsive and respected and feel validataed that their "options" are included on the questionnaire; Literacy is an issue	Work with communities, education on demographic info and how to address questions sensatively; training is completed on some podcasts, journal articles and more info via conversations –no formal training	Possibly formal training where a comfortable space is created so that questions can be asked for staff / trainees	Community Needs assessment; Patient demographic survey	Process for capturing community demo appts, has registration form	None discussed	Clinic came up with their own system because the STI EMR are confining and can't ask the questons in the way the org wants. Uses kiosk for STI program that includes questionnaire (risk behavior and demo	Used their own system rather than changes in their EMR.	Qualitative data – present baseline and options to Commuity Action & Advisory Board (CAB) and get feedback;	Need to be inclusive of all ethnicities when implementing surveys, need to be sensative to aging population

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Coastal Medical	Jeffrey Cumplido, MD, Assoc, Medical Dir. Debra Reakes, Dir. Of Quality Mike Almonte, Manager of Quality	5/10/2023	Training on LGBTQ Language, Formation of a board or panel that includes community members that represent the entire community	Patients did not like kiosk and stopped using during covid due to infection control; Some afraid to answer questions because they do not know where the info will be used. Some spanish speaking patients truly don't understand what is being asked of them. Resistent to say that they don't understand	Staff expectation to collect info via intake forms and manully enter into the chart, Some staff don't have time, communication barriers.So many tasks to complete during check in process, so not everything is captured effectively and thoroughly.	Manual data entry errors. NCQA HE Training; Staff needs education on why they are asking the questions	None	Front Desk Staff collects demo info via internal forms and updated at annual visits	N/A	NCQA PCMH	Will be working NCQA HE accreditation - system may need changes, will be moving from eClinicalWorks to Epic EMR	Receives reports on all 14 demographic fields from PCMH standards	Need to clatify process for collecting and stratifying outcomes data. Need to close gaps with groups. Miscategoriziation errors (Ie. Patient speaks spanish but is listed as english speaking). No focus on demo surveys – no baseline needs survey. Need to take literacy into consideration, hearing impaired
Brown – Stella Yi	Stella Yi, MPH, PhD	4/4/2023	Expansion upon the OMB standards within a practices EMR to reflect granular R/E data	Patients do not have accurate choices to select their true race and ethnicity. Feel they are being discriminated	Must rebuild trust with patients. Patients do not feel their true race/ethnicity is being captured/noted	Training on capturing accurate demo data from patients. If data infrastructure is modified, training is required	N/A	New workflows should be put into place to reflelct accurate data capture for race and ethnciity	OMB used as stardard but updates should be made for more accurate data collection	EMRs	Data infrastructure changes must be made to iclnude racial/ethnic minority groups who are limited english proficient.	Must include community input for appropriate translations, framing and context.	Must change the processes, workflows, systems to accurately capture all minority groups
Lifespan	Christin Zollicoffer, VP and Chief Belonging and Equity Officer Richard Gillerman, MD, VP Chief Medical Informationn Officer (CMIO)	6/15/2023	Christin and the Manager at the Women's Medicine Collaborative could share their experience with their demographic data collection. Survey staff members before and after training and program rollout to see if some gaps	No patient experience surveys were completed. Management wants to patients to be educated on why it is important to collect the data, they want the process easy ,streamlined, and appealing.	One site was trained (Women's Medicine Collaborative) on demographic data collection. A survey was conducted with Lifespan staff - not all staff responded but it gave them a sense that the staff was uncomfortable asking the demographic questions.	All sites within the organization need to be trained on why they questions are being asked, the definitions of each category and how to support patients with answering the questions.	N/A	Workflows need to be developed and rolled out to all lifespan organizations	No policies are being used on demographic data collection	Epic EMR and forms that patients fill out at time of visit	System changes may need to be made once a full analysis is done and the training plan has been developed	They have a report that was shared with the stated re: completion of fields by patients but it is not being analyzed or used to address disparities	Staff needed more education on the definitions of gender identity, etc. They realized that the staff had discomfort asking the questions.
Providence Community Health Center (PCHC)	Jennifer Etue, Integrated BH Manager Natasha Viveiros, Dir. Of Site Operations & Special Projects	6/7/2023	Jennifer / Natasha as speakers to share their experience with the development of their training program and the importance of training staff to ask the demographic questions and feel comfortable doing so. Can also utilize patient placard (Appendix IV on report)	Patients are treated with respect from the moment they walk into the practice. Patients are receptive and appreciative of private area and time staff spends with them on the questions. Only self reporting is promoted.	Staff was surveyed and education and gaps were addressed through training. Pre and Post training assessments were completed. Staff more comfortable asking questions and answering pt questions re: demo data.	Training program was developed to provide education to staff on why asking the questions are important, how to ask the questions so they are comfortable doing so, etc.	N/A	Created workflows for staff on how to obtain and enter demo info.	None	EMR Patient Placard (dry erase) around literacy/ health literacy,	New EMR soon – will need to implement new workflows	Used Exception Report from IT to see which sites and FD staff needed assistance with capturing and entering demo data (REaL and SOGI)	Staff was encouraged to promote engaging patients when there were blank responses. Wish they worked on the project sooner.
FQHCs	Interviews Completed by Amy Zimmerman	N/A		Some patients upset with gender identity questions. Patients completing most fields in many cases, ethnicity was left blank. Some patient pushback when completing the information.	Quality Director / Staff responsible for collecting demographic data. Data is updated annually. Staff not comfortable with pushing the issue with patients to complete entire form and ethnicity field.	Training needed when working with patients to ensure all demo fields are completed, especially ethnicity (usually left blank). Training needed on accuracy for inputting data into patients charts. Training needed at sites implementing Phreesia – as new workflows will be needed	None	Phressia to be implemented at sites. New workflows will be implemented	None discussed	All FQHCs are using UDS requirements	Added fields are needed to capture demo info.	One FQHC has a QI team that is reviewing info for completeness	N/A