Care Transformation Collaborative of Rhode Island (CTC-RI) Demographic Data Collection Pilot Environment Scan: Best Practice Summary Report

Contents

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Background

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

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

Improving demographic data collection is a foundational activity for promoting health equity and addressing COVID-19 health disparities. COVID-19 has 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.

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

This report will address the current and recommended best practices for demographic data collection. It will also discuss the importance of quality reporting to improve data collection and the outcomes of addressing disparities to promote health equity. The best practices learned through the literature review and the key informant interviews will be shared with CTC for the creation of their webinar training series for practices participating in the demographic data collection pilot project.

Approach

The goal of this report was to conduct a landscape review to gather the best practices on demographic data collection in primary care for the purpose of developing improvement efforts, including a webinar series. There are three main components to this review: 1) a literature review of the past 5 years related to best practices on the collection of demographic data; 2) key informant interviews with high performing practices and with organizations engaged in demographic data collection improvement efforts; and 3) Lessons learned and recommendations for resources, tools and potential speakers to be included in the webinar training series for practices.

The project team conducted a targeted literature search using google scholar and PubMed to identify peer reviewed literature on best practices in demographic data collection, with particular attention to race, ethnicity, and language (REL) data. Literature that addressed sexual orientation and gender identify (SOGI) as well as social determinants of health (SDOH) was also considered. Additional google searches yielded invaluable playbooks and implementation guides produced by organizations focused on quality improvement, such as the Agency for Healthcare Research and Quality (7), the California Improvement Network (8) and the American Hospital Association (9). The literature search was limited to reports published since 2018, but references from earlier dates were included as deemed relevant. The project team developed a matrix with key concepts from each source to identify consistent themes across publications.

The key informant interviews were designed to elicit best practice information from clinical practices and from organizations supporting quality improvement and were conducted with organizations both inside and outside of Rhode Island. The literature review identified potential key informants outside the state, and EOHHS and the CTC Demographic Data Collection Pilot Planning Committee identified additional individuals and organizations that were thought to be leaders in improving the collection of complete and accurate demographic data. Key Informant Interview guides for practices and for quality improvement organizations are included as Appendix I.

Key Findings

Literature Review

Patient Experience

A recent Deloitte Health Equity Institute survey of 3,000 adults found that 81% of respondents were comfortable with sharing REL data with their providers, and approximately 7% of patients were patently uncomfortable/unwilling to share such data. However, the same was not true for ethnicity information, and comfort was highly variable based on the recipient the information and the specific subpopulation being queried. For example, 79% of individuals were comfortable sharing REL data with their health plan, while 75% were comfortable sharing with a governmental agency; and people who identified as Black were more willing to share REL data, while those who identified as being of African descent were less comfortable. Among those uncomfortable sharing REL data, the following reasons were identified: fear of judgement or discrimination, lack of clarity about the need for and use of the data, privacy concerns, fears about clinical misdiagnosis, and/or increased costs or denial of coverage. (10)

Unfortunately, patient concerns are warranted. In a 2019 cross-sectional survey of US adults, 21% experienced discrimination in the healthcare system, with REL discrimination being cited by 72% of those reporting discrimination. (11) Additionally, the available choices for REL data collection may not accurately reflected the patient's self-perception of race or ethnicity, and this is often seen among patients who self-reported their race as "other" and their ethnicity as "Hispanic or Latino". (12,13) Patient comfort may be increased when data collection is conducted by clinical rather than clerical staff and clear explanation is provided regarding the need for the data to ensure care delivery is equitable. (14) These findings are remarkably consistent with research conducted fifteen years earlier. (15)

Staff Experience

Primary care teams experience a number of non-technical barriers to the complete and accurate collection of demographic data, including: lack of time, feeling uncomfortable asking about REL, fear of offending patients or about the legality of asking questions about REL, knowledge deficits regarding the importance of demographic data collect, belief that the practice does not have any disparities in care, fear about being accused of discrimination if disparities are identified with the data collected. (16, 17)

Training Needs

To address socio-cultural barriers to accurate and complete REL data collection, training should include the following components (18,19):

- Definitions of race and ethnicity
- Awareness of unconscious bias
- Cultural competency, with particular focus on issues germane to the local community
- Purpose for, legality of, and regulatory requirements for REL data collection
- Methodology for data collection: the who, what, when, and where of data collection
- Examples of disparity dashboards
- Confidence building exercises for the collection of sensitive information.
- Technical aspects of consistent data collection and input into the system of record (EHR)
- Scripts to support the request for information.
- Frequently Asked Questions Support Documents (for staff and patients)

Training should be delivered via multiple communication channels (e.g., written, classroom, self-directed learning), and should be updated based on implementation experience. Additionally, training should be required on a regular basis.

Accountability

As is true for all meaningful organizational change, support from senior leadership is foundational to ensure success. (16, 20) Adequate resourcing and accountability for the desired outcomes of the change must be clear at the outset. For example, including improvement metrics associated with a reduction in the percent of REL data in the unknown category could be part of performance evaluations for staff at multiple levels of the organization. (21) Certainly, when the metric is included in the performance review of senior staff, it will receive the attention needed to drive improvement.

Workflows

Overarchingly, key components of a REL data improvement project include leadership support, improvements in REL data collection, staff training, patient engagement, and measurement/monitoring. (20)

How should REL Data be collected and by whom: While patients reflect that they prefer to be asked sensitive questions about REL by clinical staff (14), most organizations include the collection of such data by the registration staff, either on paper at time of visits or electronically via online tools such as the patient portal, a kiosk, or a tablet in the waiting room.

In 2018, the State of Connecticut SIM project sponsored a review of and report on "the importance of collecting granular race and ethnicity data to inform population health strategies that reduce health disparities." (22) Below are findings related to this effort:

- The gold standard for REL data is self-reporting
- REL data fields should be mandatory in the EHR.
- Patients must be allowed to select more than one race or ethnic group

The literature is not consistent regarding the added value of allowing individuals to choose to select "Other" with a write-in as their race, as the data generally needs to be re-aggregated into the 5 OMB categories. The complexity of both data collection and data management should be weighed relative to the value of having more granular data available in a given community. In a 2022 Statistical Policy Directive issued by the White House state, 'Unless required by statute, data collection efforts by Federal agencies should not include a "Some Other Race" (SOR) response category.' (23)

When should REL data be collected: There is consensus that REL should be collected during registration at the individual's first encounter with a clinical system. There is also agreement that the data should be validated (actively verified with the patient of the information in the system) and updated with some defined periodicity, but that frequency appears to be based on the population being served. Some references suggest validation at each encounter, while others suggest annually. Regardless, the validation of the data remains important because errors are common in EHR systems, and individuals may experience a change in their REL identity over time. (24, 25)

Policies

An extensive literature search did not yield any sample policies on demographic data collection. A sample policy was generated by Chat-GPT on 5/8/23, with minor edits for clarity provided by Elaine Fontaine. (26) See Appendix II.

Data Standards

Data standards will be addressed in full in the project deliverable 1.A.4. However, consensus in the reviewed literature reflects the need to collect disaggregated race and ethnicity data with proactive clarity about the reaggregation into national OMB categories as needed. (27, 28, 29) For example, people of Eastern European ancestry have poorer health outcomes than those of Western European descent, but both groups would be categorized as White using the OMB race categories. Differences exist in health disparities and concerns about sharing demographics between people born in the US of African American descent vs those born in Africa, and the diaspora among people of Spanish speaking and South American descent is significant. (30) Thus, understanding the relevant subpopulations in the local community is essential.

Systems Changes Needed

The Office of the National Coordinator has stipulated requirements for certified electronic health record (EHR) vendors related to the collection of demographics data, including REL data. Specifically, 'The software must be able to aggregate each one of a patient's race(s) and each one of a patient's ethnicity(ies) and record the race(s) and ethnicity(ies) according to the § 170.207(f)(1) The Office of Management and Budget (OMB) Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity.' (31) Modifications to the existing data standards (United States Core Data for Interoperability, USCDI) for REL are expected to be updated upon the finalization of the Notice of Proposed Rule Making published in the Federal Register in April of 2023, with the goals of aligning the EHR certification standards with the upcoming standards set out by OMB. (32, 33)

While ONC standards determine what vendors must include in the EHR, individual practices made decisions about local configuration. That includes decisions about allowing free-text or drop-down menus for various demographic data element collection as well as the granular data collected which is later aggregated to the OMB standards.

Successful data quality improvement efforts have focused on limiting or eliminating free-text as well as prioritizing subpopulations in the local community to be mapped and aggregated to the OMB standards. (18) Additionally, consideration for the patient's right to decline to respond should be addressed in system configuration, differentiating that response from that data which was unknown or not collected.

Metrics and Outcomes

The two most critical metrics associated with the quality of demographic data collection are completeness and accuracy. As noted previously, during the COVID-19 pandemic, Rhode Island reported out cases with unknown race/ethnicity in 36% of cases. Given that less than 10 percent of patients are actively reluctant to share their REL data with their provider, as a state, we have a significant opportunity for improvement.

To date, an analysis in Rhode Island has not been conducted to estimate the accuracy of the data in our health systems relative to the gold-standard of self-report. However, several studies looking at data in EHRs vs self-report reflect significant discrepancies. (34, 35)

Overarching Lessons Learned

1. Leadership support is essential for organizational improvement.
2. Respect for the individual and their lived experience is foundational to reducing disparities.
    a. Patients should self-report their demographic data and be allowed to decline to respond; however, accurate recording of their decision to decline should be recorded as an option in mandatory fields.
    b. Patients should be allowed to reflect their identity using multiple selections if one category does not capture their identity.
    c. Patients require education about the importance, use and protection of their data.
3. Staff require training to understand the importance of demographic data collection and on the tools used to collect it accurately and consistently.
    a. Data should be updated on a periodic basis.
    b. Staff should be trained to understand both the social issues around demographic data collection as well as the internal processes for accurate and complete data collection.
4. Demographic data should be collected at a granular level based on local community population needs, with proactive mapping to aggregated standards (OMB).
5. The EHR should be configured to support the REL mapping and eliminate free text data input.
6. As part of leadership support, it is essential to establish clear accountability for success as defined by complete and accurate data collection.
7. The goal of demographic data collection in the health setting is to reduce health inequities, which can only occur if we have the needed data to understand them in the first place.

Key Informant Interviews

As part of this pilot project, Key Informant Interviews were completed to gain insight into best practices for Demographic data collection. The interviews were conducted with Rhode Island based provider organizations as well as out-of-state quality improvement support organizations to get a well-rounded perspective. The project planning committee agreed upon the interviews with the organizations listed below. Some were added by Elaine Fontaine after conducting the literature review. The appropriate participants at each organization were left up to the key contact that we reached out to, as they know the best source of information for demographic data collection, training, education, etc.

1. **Provider Organizations**
    a. **Open Door Health**, an initiative of the Rhode Island Public Health Institute
        i. Amy Nunn, Executive Director
        ii. Yelena Malyuta, Director of Evaluation
    b. Coastal Medical
        i. Jeffrey Cumplido, MD, Physician and Associate Medical Director
        ii. Debra Reakes, Director of Quality
    c. Providence Community Health Center
        i. Jennifer Etu, Integrated Behavioral Health Manager
        ii. Natasha Viveiros, Director of Site Operations & Special Projects
    d. NYU School of Medicine
        i. Stella Yi, MPH, PhD, Department of Population Health Section for Health Equity

   e. **Lifespan**
      i. Christin Zollicoffer, Vice President Chief Belonging and Equity Officer
      ii. Richard Gillerman, MD, Vice President Chief Medical Information Officer (CMIO)

2. **Quality Improvement Support Organizations**
   a. **Health Begins**
      i. Sadena Thervarajan, JD, Managing Director
      ii. Taleen Yepremian, MHA, Training Program Manager
      iii. Vince Panucci, MPH, Health Equity Project Coordinator
      iv. Rishi Machanda, MD, MPH, CEO
   b. **John Snow Incorporated** / Health Information Technology, Evaluation, and Quality (HITEQ) Center
      i. Jillian Maccini, MBA, PCMH CCE, Project Director, JSI Research & Training
   c. **National Committee for Quality Assurance (NCQA)**
      i. Jeni Soucie, Manager, Product Management
      ii. Elizabeth Ryder, Assistant Director, Product Development
      iii. Rachel Harrington, PhD, Senior Research Scientist, Health Equity

Below are the essential findings after all the interviews were conducted over a three-month period. Refer to Appendix I to view the *Key Informant Interview Facilitator Interview Question Guide and* Appendix III to view the *Key Informant Interview Table*.

Patient Experience

It is important to each organization, whether a practice or quality improvement organization, that the patient's experience is a high priority. Some organizations have patients complete a pre-visit demographic data survey or a survey upon patient check in at the front desk. Patients feel that a private conversation or private area where they can respond is more comfortable than answering the questions with the front desk staff while standing at the front desk. Coastal Medical initially had patients answering questions via kiosk but due to COVID-19 and the concern for infection control, they stopped offering that option. Some patients push back due to the volume of questions, but most patients seem to be accepting of answering the questions. Demographic questions about race, ethnicity, and language were deemed less sensitive relative to sexual orientation and gender identity questions. None of the organizations we interviewed separated out the collection of these data elements between the administrative and clinical staff, as some organizations suggested in the best practices toolkits reviewed.

All organizations want their patients to feel respected, confident, seen, and heard. Based on best practices, the patient's experience includes education on why they are being asked the demographic questions to avoid their misconceptions of feeling discriminated against, that their care will be denied, or they are just a number rather than a person to the practice. The goal of each organization is to provide whole patient care while being sensitive and respectful to all patients. However, patient experience surveys about demographic data collection and committees chartered to review policies and practices broadly and address demographic data collection specifically have not been instituted in the practices interviewed. Dr. Stella Yi encouraged the receipt of community feedback and that patients should be asked questions that are relevant to the community. Questions and selection of fields related to demographic data collection should be geared toward the patient population.

Staff Experience

All interviewees reflected that they have staff members who are uncomfortable asking patients the REL and SOGI questions and require some type of training on the importance of the data to quality of care, the best way to ask the questions and address questions or concerns raised by patients. When staff members were educated on the importance of the data being collected, they were more likely to address the REL questions. With the proper training, they became more comfortable and confident with the entire demographic data collection process. Organizations should be aware of their patient population and provide the questions in a language that the patient prefers as well as ensure that they understand how to use the technology, if applicable. The common theme among the organizations was the concern for the staff experience with addressing demographic data collection as a whole. The staff needs to understand the biases and racism and how to properly and comfortably ask the patients for the information and address their questions appropriately.
For example, Lifespan conducted a staff survey regarding the collection of demographic data collection and were asked the frequency that they collect the information. The concerning responses were that they were not comfortable asking the questions, there were communication barriers with the patients, they did not see the importance of collecting the information, and that responded didn't feel that they had time.

Training Needs

Patients require education on why they are being asked the questions and why they need to be truthful and accurate when doing so; this includes all applicable rules and regulations.

Staff require training in how to educate, the best way to communicate and support the patient when answering questions. They must be trained in how to explain things in a sensitive and respectful way to the patient so that they feel confident and comfortable. The staff needs to be prepared with how to approach the patient when there is missing or conflicting demographic data. Staff should not make assumptions and answer the questions for the patient and should be trained in ensuring that the patient is entering their own responses as fully and accurately as possible.

Training for the staff should include the use of any tools used to obtain information (i.e., Kiosk, tablet, survey) as well as the EHR and which fields to enter the data into at time of registration/ check in. Training must be completed for all new hires and on an ongoing basis. IT staff members should work with the EHR vendor if they need instruction on how to edit fields or customize the existing fields in the medical record, to be able to capture all demographic data. In addition, the front desk will need to be trained on the location of the new fields and workflows to work with the patients on obtaining the information.

Walk Around Tools

None of the organizations that were interviewed conducted a walk around survey or utilized walk around tools to assess the demographic data collection process and the perceptions of the patients and the staff during said data collection. The only tool that was used to gage the patient experience was OpenDoor Health that included community members, that were also patients to ensure that their registration forms and questionnaire met the sensitivity needs of their primarily LGBTQ community.

Workflows

Workflows should be implemented when collecting REL and SOGI data and should be included in the data collection training program. Workflows should include patient education, confirming that the patient understands what they are answering and why, capturing as much data as possible, confirming that all data is accurate, and standards that support the collection. Workflows vary between organizations dependent on the resources and technology used to capture demographic data. There were some recommendations to capture ethnicity prior to race but also taking into consideration the patients preferred language so that any resources shared with them can easily be comprehended. Depending on the practice and their existing workflows, there are a variety of ways to collect the demographic data. Some practices capture it at the front desk, while others felt it was sensitive information and should not be asked at the front desk and should be done in a private area, or with the use of a kiosk or tool such as Phreesia. This is all based upon practice preference, existing workflows and if the practice has enough resources for options other than the front desk.

Policies

None of the practices interviewed had or provided policies on demographic data collection. They were either in the beginning stages, such as Coastal Medical or they had begun collecting demographic data but did not have any policies as it was something that they just began asking and did not formalize it.

There is a need for this to be addressed at each practice when workflows are put into place. The policies will help to prioritize the initiative and assign individuals roles so that they are held accountable.

Technology

Tools in Use

- Organization Electronic Health Record Systems (EHRs) – a variety utilized with different configurations and choices to collect race and ethnicity data. All systems used are CEHRT and have the capability to collect and report the data within the minimum OMB standard.
- Standardization tools that utilize technology:
    - National Committee for Quality Assurance (NCQA) Patient Centered Medical Home and Health Equity Accreditation programs.
    - OMB Race and Ethnicity Standards
    - UDS standards
- Tools for patients to enter demographic data.
    - Free standing Kiosks
    - Phreesia
    - Patient Portals
    - Patient Placard, provided in multiple languages (refer to Appendix IV)

Systems Changes Needed

To promote best practices with data collection, many system changes are needed within the health care system itself and with the technologies used. Dr. Stella Yi discussed systemic racism and how accurate race and ethnicity data is not being captured. Patients require more options when choosing their race and ethnicity – which requires a disaggregation of data based on the current OMB and UDS standards that are being used in healthcare organizations. In addition to the expansion of choices required, almost all EHR systems used by healthcare organizations require modifications to capture existing standards. Some practices are not able to make the technology updates to include all existing standard options currently and are therefore not able to capture the information. It is recommended to capture more granular data and be able to map the data and roll it up to the category so that it can be included in reports.

Metrics and Outcomes

Most practices interviewed were having difficulty capturing race and ethnicity from patients and therefore were not even looking into reporting functionality to view and act on the health disparities and inequities within their patient populations.

After working with staff to improve the completeness and accuracy of demographic data collection, organizations need to begin reporting on this data to provide whole patient care to those patients within their population that need it. There were a few practices that were doing some reporting for data completeness of the demographic data collection but not truly reporting on outcomes and how to address them.

Health Begins was doing some quality improvement work with practices that have committed to making improvements. Because each practice is at a different stage of data collection and reporting, any quality improvement initiatives should be customized to the practice needs and current status. Providence Community Health Center conducted a staff survey and used it to address gaps through a training program. They completed pre and post assessments to ensure that the staff was more comfortable asking patients for their information as well as answering patient questions. They also utilized their IT staff to create an exception report to see which of their sites and Front Desk staff needed assistance with capturing and entering REL and SOGI data. The report allowed them to pinpoint the sites and areas of improvement. John Snow used UDS data annually to share with their practices. It allowed them to question the data that was submitted. They modified their electronic system to include social determinants of health; they initially had difficulty determining the best place to include them.

Data must be shared with the organization's quality management team regularly; monthly is recommended. Reports should be created on the completeness of metrics and the metrics themselves. The metrics must be determined by each organization. A team should be assembled that includes quality improvement, leadership within the organization and individuals from the community. Community input is encouraged for translations, framing, context, etc. Lifespan and OpenDoor health recommended utilizing the local community for input with all patient resources. OpenDoor Health presented their data to their Community Action & Advisory Board (CAB) regularly to get feedback on the best way to approach making improvements. Coastal Medical used their NCQA PCMH program data and reported on 14 demographic data fields for data completeness.

Lessons Learned

Many organizations shared lessons learned throughout their initial and ongoing process to collect demographic data from patients. Overarching lessons learned are listed below:

- Support from leadership and supervisory positions is essential to ensure the collection and improvement of demographic data.
- Practices need to consider reporting requirements when planning workflows for collecting new demographic data elements or improving the collection and accuracy of existing data.

- Organizations should have job descriptions that include the data collection task and performance should be routinely assessed by measuring data completeness.
- There should be a mechanism to aggregate categories for those reporting more than one race and/or ethnicity.
- Staff should work with patients to ensure that the patient is self-reporting AND reporting as much demographic data as possible.
- Staff should educate patients on the importance of this data collection, including the use of written materials that are appropriate to reading level and language of choice for the patient population.
- Practices should provide patients with definitions of REL and SOGI data fields so that they may accurately choose the category which reflects their self-identification.
- Practices should have a policy which reflects the regular updating of demographic data (e.g., annually) since patient self-reported identity may change over time.
- Practices should use demographic data to stratify outcomes data to better understand and intervene to reduce health disparities.
- Practices should consider collecting granular data on race and ethnicity to ensure that subpopulations at risk are accurately identified (e.g., Eastern European Causations experience health disparities relative to those of western European descent)
- Practices should configure their EHR to limit or eliminate where possible free text entry, instead using structured data to avoid poor quality, inconsistent data.
- Practices should put in place quality control standards for the completeness and accuracy of demographic data collection.
- The practice should have a plan in place to support patients with various abilities, e.g., hearing impaired, aged, etc.

Conclusions

On a national level, health disparities have been understood for decades, with negative impact for both the individual patients and for society as a whole. However, the complete and accurate collection of demographic data, which is foundational to understanding and addressing disparities, has remained a low priority for primary care practices. The COVID-19 pandemic brought these issues to the fore.

The objective of this report was to identify best practices in demographic data collection in primary care to support improvement activities across the state of Rhode Island. Our review of peer-reviewed journal articles, and toolkits published by federal agencies and various quality improvement organizations, alongside our key informant interviews yielded very consistent findings regarding best practices. Below are the essential components necessary to ensure complete and accurate collection of demographic data in support of activities designed to reduce healthcare disparities:

1. Senior leadership support and clear accountability is foundational to improvement efforts.
2. Respect for the individual patient is essential and best reflected by providing them with:
    a. Information needed to help them best understand the rationale for collection of sensitive demographic data collection.
    b. Information provided in a way that they can understand, whether it be related to language, literacy, or ability.

    c. A means to accurately reflect their self-identification, be it related to race, ethnicity, language or SOGI data, including the right to make more than one selection or to decline to respond.
3. Administrative staff require:
    a. Training on discrimination and bias
    b. Training and tools (e.g., scripts) to collect demographic data in a way that demonstrates respect for the individual/patient.
    c. Training on and documentation of workflows for accurate and complete data collection, including the frequency of data updates.
    d. Clear policies, expectations, and metrics regarding the quality of their efforts to collect said data.
4. Management and Quality staff require:
    a. IT support to ensure clean capture of data based on defined data standards that have taken future reporting needs into account.
    b. Clear metrics on completeness and accuracy of data collection, produced timely to allow for feedback to staff who collect the data.
    c. Routine review of quality metrics with subpopulations identified to identify and address any health disparities identified.

It may be worth considering bringing such reports to the board level or incorporating performance improvement incentives either for management or for the organization via pay-for-performance contracts to further incentivize the desired outcome, a reduction in healthcare disparities.

Critical components of best practices that should be considered in the development of the CTC webinar series include training on the following topics:

1. Systemic Racism, health inequities, SOGI, and implicit bias
2. Cultural sensitivity and awareness of the populations served in the community.
3. Scripting to improve staff and patient 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.

Supporting materials are included in Appendices IV - XI

- Sample demographic data collection questionnaire (placard from PCHC) (Appendix IV)
- Sample patient survey (Appendix V)

- Sample staff survey (Appendix VI)
- Sample “walk around” tool (Appendix VII)
- Sample Registration Form (Appendix VIII)
- Sample Patient Questionnaire (Appendix IX)
- LGBTQ Language Presentation (Appendix (X)
- Gender Resources (Appendix (XI)

Based on the feedback from the Key Informant Interviews, the recommendations for speakers / topics / Tools are as follows:

- Health Begins demonstration of the REL Data Accelerator 12 Week Program or utilization of this program for those practices that have been working on demographic data collection for some time.
- Review John Snow’s “How to Love Your Data” on UDS+ data requirements
- Use of the American Hospital Association’s Health Education Trust Disparities Toolkit (HRET) recommended by NCQA. Link: https://www.aha.org/hretdisparities/toolkit
- Education and Use of NCQA’s PCMH and/or Health Equity Accreditation programs
- Use of the LGBTQ+ Language presentation and Gender resource document used by OpenDoor Health to educate staff on the population and how best address them (both included in Appendices)
- OpenDoor Health and Coastal Medical’s recommendation to form a panel that includes community members that represent the entire patient population
- Discussion on the possible expansion of the minimum OMB standards to include granular REL data that represents the practice’s patient population – recommendation by Dr. Stella Yi
- Christin Zollicoffer and the Women’s Medicine Collaborative could share their experience with their demographic data collection. Also, their recommendation to provide a staff survey pre and post data collection rollout.
- Jennifer Etu and Natasha Viveiros at PCHC could speak about their experience with the development of their training program and the importance of training staff to ask the demographic questions. Use of their patient placard

Acknowledgements

The Care Transformation Collaborative, the State of Rhode Island Executive Office of Health and Human Services, and the Rhode Island Department of Health wish to express deep appreciation for the generous participation and collaboration of many partners who shared time and expertise in providing input for this report, including: Coastal Medical, Health Begins, John Snow, Inc, Lifespan, NCQA, NYU, Open Door Health, Providence Community Health Center, and the Rhode Island Health Center Association.

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Appendix I

Key Informant Interview Guide

1. Please describe your project and how you began working on demographic data collection improvement? Who were your partners?
2. What best practice research did you do?
3. How did you measure baseline performance and success?
4. Did you train practices on improving data collection? How did you decide what to include in training?
5. Did you have to support the practices with EMR changes?
6. Did you develop any of the following:
    a. Walk Around Survey?
    b. Patient Experience Survey?
    c. Survey baseline needs for the practices?
    d. Survey of policies and procedures regarding demographic data collection and reporting? Measure accuracy of data?
7. Were there any lessons learned that you could share?
8. What standards for demographic data collection were used?
9. Was there anything specific to REAL or SOGI data that created unique challenges?
10. What other questions should we have asked you about your project, but we didn't?
11. Are there any materials you can share with us regarding any of the above?

Appendix II

Sample Demographic Data Collection Policy

Composed by ChatGPT on 5/8/23, with edits by Elaine Fontaine

Purpose: The purpose of this policy is to ensure that demographic information is collected from patients in a respectful, sensitive, and consistent manner to support the delivery of high-quality patient care and the identification of healthcare disparities.

Scope: This policy applies to all healthcare providers and staff involved in the collection, documentation, and use of demographic information in patient care.

Procedures:
1. Patients will be asked about their preferred language for reading and speaking with clinical teams.
2. Healthcare providers and staff will educate patients and provide written material regarding the importance of collection of demographic data to ensure equitable care to all. (e.g., Why We Ask Posters) in a language of the patient's preference.
3. Patients will be asked to provide their demographic information during the initial registration process and ***XX*** (consider annual) interval.
4. Demographic information collected may include, but is not limited to, race, ethnicity, language, sexual orientation, gender identity, and preferred name/pronouns.
5. Healthcare providers and staff will make it clear that the patient may decline to respond to sensitive questions but will provide an explanation of the importance of the collection of these data to reduce health disparities to attempt to facilitate an accurate, complete response.
6. Healthcare providers and staff will be trained on the collection, documentation, and use of demographic information in patient care, including the use of standardized questions and culturally appropriate communication techniques.
7. Demographic information will be collected and documented in a secure and confidential manner in the patient's electronic health record (EHR) or paper chart.
8. Patients will have the right to access and review their demographic information and request updates or corrections as necessary.
9. Demographic information will be used to support the delivery of high-quality patient care and the identification of healthcare disparities. It may also be used for research and population health management purposes, with appropriate patient consent and data security measures in place.
10. Demographic information will be protected from unauthorized disclosure, consistent with applicable laws and regulations governing patient privacy and data security.

Responsibilities:
1. Healthcare providers and staff are responsible for following this policy and ensuring that demographic information is collected, documented, and used in a respectful, sensitive, and consistent manner.
2. Practice leadership is responsible for providing training and resources to support the implementation of this policy and monitoring compliance with the policy

Appendix III
Key Informant Interview Table

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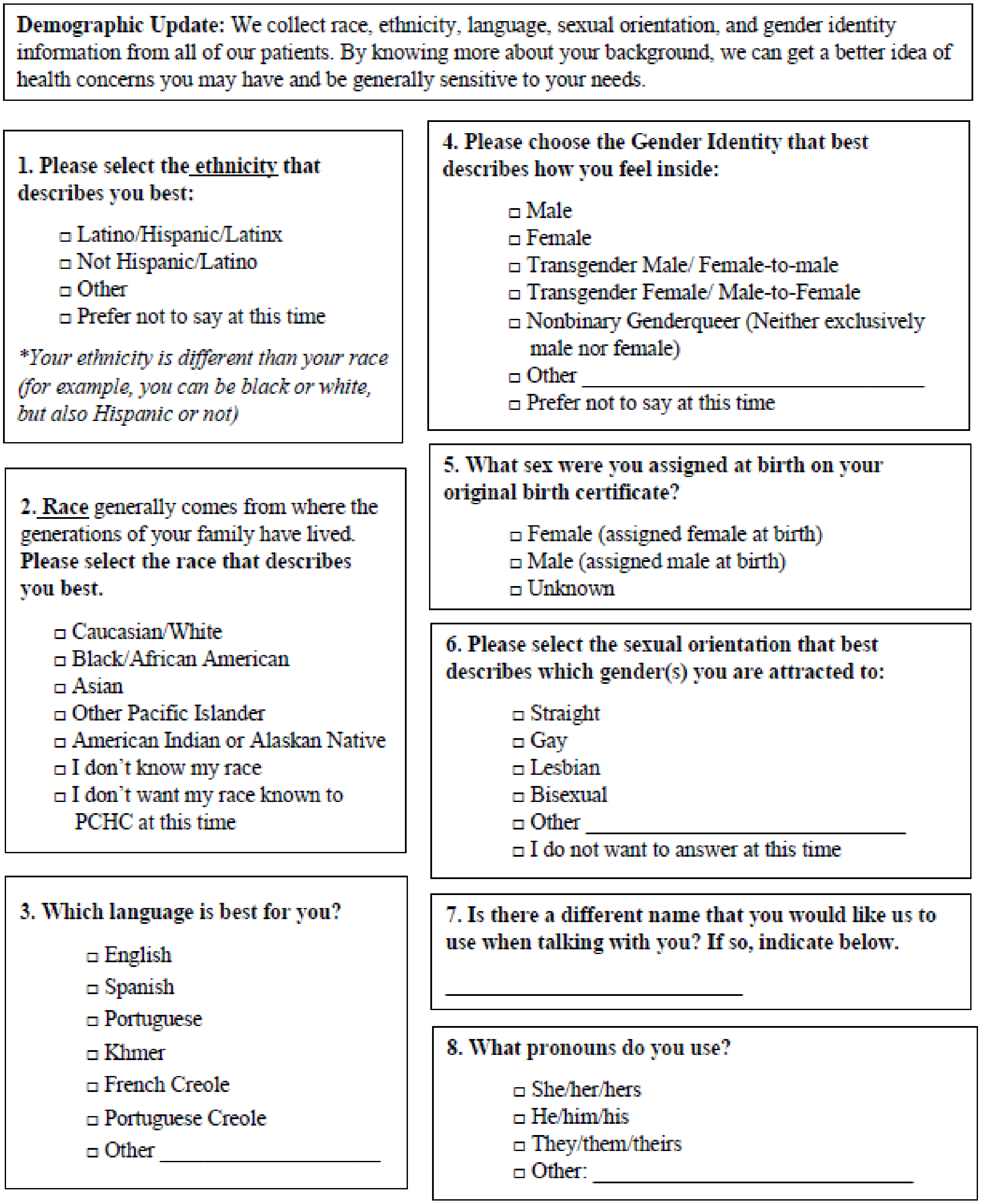
Appendix IV
PCHC Patient Demographic Data Collection Placard



Demographic Update: We collect race, ethnicity, language, sexual orientation, and gender identity information from all of our patients. By knowing more about your background, we can get a better idea of health concerns you may have and be generally sensitive to your needs.

1. Please select the ethnicity that describes you best:

☐ Latino/Hispanic/Latinx
☐ Not Hispanic/Latino
☐ Other
☐ Prefer not to say at this time

**Your ethnicity is different than your race (for example, you can be black or white, but also Hispanic or not)*

2. Race generally comes from where the generations of your family have lived. **Please select the race that describes you best.**

☐ Caucasian/White
☐ Black/African American
☐ Asian
☐ Other Pacific Islander
☐ American Indian or Alaskan Native
☐ I don't know my race
☐ I don't want my race known to PCHC at this time

3. Which language is best for you?

☐ English
☐ Spanish
☐ Portuguese
☐ Khmer
☐ French Creole
☐ Portuguese Creole
☐ Other ____________________

4. Please choose the Gender Identity that best describes how you feel inside:

☐ Male
☐ Female
☐ Transgender Male/ Female-to-male
☐ Transgender Female/ Male-to-Female
☐ Nonbinary Genderqueer (Neither exclusively male nor female)
☐ Other ______________________________
☐ Prefer not to say at this time

5. What sex were you assigned at birth on your original birth certificate?

☐ Female (assigned female at birth)
☐ Male (assigned male at birth)
☐ Unknown

6. Please select the sexual orientation that best describes which gender(s) you are attracted to:

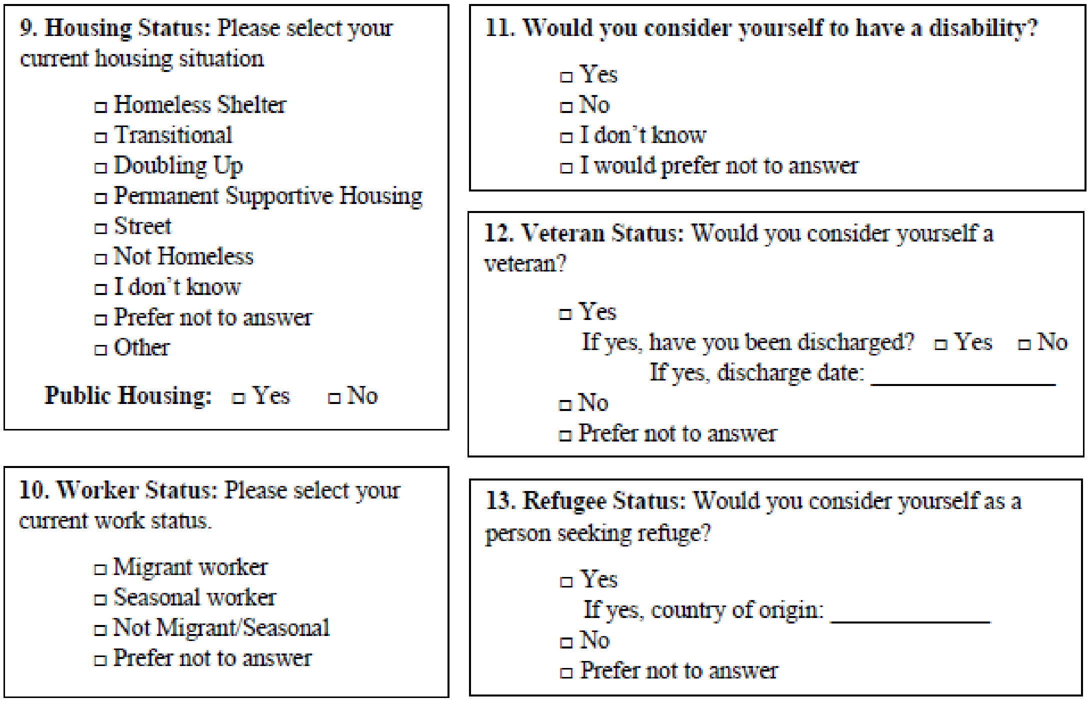
☐ Straight
☐ Gay
☐ Lesbian
☐ Bisexual
☐ Other ____________________________
☐ I do not want to answer at this time

7. Is there a different name that you would like us to use when talking with you? If so, indicate below.

____

8. What pronouns do you use?

☐ She/her/hers
☐ He/him/his
☐ They/them/theirs
☐ Other: ____________________________



9. Housing Status: Please select your current housing situation

- ☐ Homeless Shelter
- ☐ Transitional
- ☐ Doubling Up
- ☐ Permanent Supportive Housing
- ☐ Street
- ☐ Not Homeless
- ☐ I don't know
- ☐ Prefer not to answer
- ☐ Other

Public Housing: ☐ Yes ☐ No

10. Worker Status: Please select your current work status.

- ☐ Migrant worker
- ☐ Seasonal worker
- ☐ Not Migrant/Seasonal
- ☐ Prefer not to answer

11. Would you consider yourself to have a disability?

- ☐ Yes
- ☐ No
- ☐ I don't know
- ☐ I would prefer not to answer

12. Veteran Status: Would you consider yourself a veteran?

- ☐ Yes
  - If yes, have you been discharged? ☐ Yes ☐ No
    - If yes, discharge date: ______________
- ☐ No
- ☐ Prefer not to answer

13. Refugee Status: Would you consider yourself as a person seeking refuge?

- ☐ Yes
  - If yes, country of origin: ____________
- ☐ No
- ☐ Prefer not to answer

Appendix V

Sample Patient Survey

Composed by ChatGPT and edited by Elaine Fontaine

1. How comfortable are you providing information to your doctor's office staff about each of the following (demographic data):
    a. Your race
    b. Your ethnic background
    c. The language you prefer to use to talk about your health.
    d. Your gender identity
    e. Your sexual orientation
    f. Other issues impacting your health, such as housing, income, safety, etc.?
2. How comfortable are you providing information to your doctor directly about each of the following (demographic data):
    a. Your race
    b. Your ethnic background
    c. The language you prefer to use to talk about your health.
    d. Your gender identity
    e. Your sexual orientation
    f. Other issues impacting your health, such as housing, income, safety, 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?
4. Do you think that healthcare providers should tell patients why they are collecting demographic data as well as how they will use and protect your information?
5. Do you think that collecting demographic data could help healthcare providers understand and address unequal healthcare among different groups of people?
6. Have you ever experienced discrimination which impacted the healthcare you received?
7. Do you feel this office has been sensitive and respectful to you when asking about your demographic data?
8. Are there things this practice could do that would make you more comfortable and confident in sharing your demographic data?

Appendix VI
Sample Staff Survey
Composed by ChatGPT and edited by Elaine Fontaine

1. How comfortable and confident do you feel in collecting the following demographic information from patients?
    a. Race
    b. Ethnic background
    c. Language preferred
    d. Gender identity
    e. Sexual orientation
    f. Other issues impacting patient health, such as housing, income, safety, etc.?
2. Do you feel have the needed time to completely and accurately collection patient demographic data?
3. Have your received training about:
    a. Systemic racism, 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 your practice uses demographic data to reduce health disparities?
4. Do you have access to policies and scripts to help you accurately, completely, and respectfully collect demographic data from patients?
5. What challenges have you encountered when collecting demographic data?
    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?
6. What strategies do you use to ensure that patients understand the purpose of collecting demographic information?
7. Have you ever experienced discrimination which impacted the healthcare you received?
8. Do you feel this office has been sensitive and respectful when asking patients about demographic data?
9. Are there things this practice could do to ensure complete and accurate collection and recording of patient demographic data?

Appendix VII

Sample Walk Around Tool

Composed by ChatGPT and edited by Elaine Fontaine

1. Begin by making an appointment with the primary care practice as a patient.
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.
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.
4. 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.
5. Review a sample of patient charts to determine whether demographic information is consistently collected and recorded.
6. 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.
7. Ask the provider or clinical staff about the importance of collecting demographic information and how they use it to inform patient care.
8. If the practice has a patient portal, log in and review the patient registration form to see whether demographic information can be updated online.
9. 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.
10. Compile your observations and share them with the practice leadership, along with any recommendations for improvement.

Appendix VIII
Sample Registration Form

Shared by OpenDoor Health

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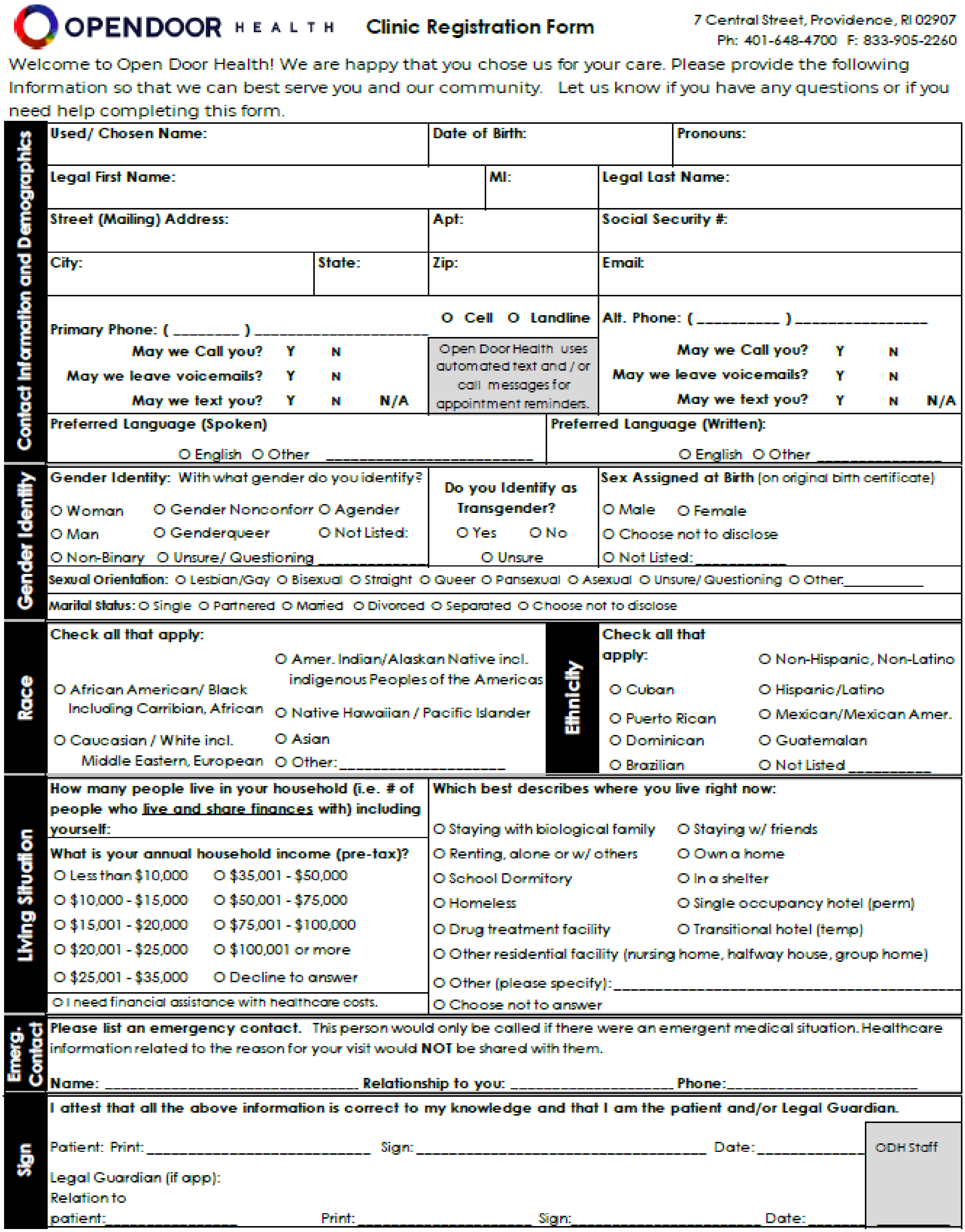

OPENDOOR HEALTH **Clinic Registration Form**

7 Central Street, Providence, RI 02907
Ph: 401-648-4700 F: 833-905-2260

Welcome to Open Door Health! We are happy that you chose us for your care. Please provide the following Information so that we can best serve you and our community. Let us know if you have any questions or if you need help completing this form.

Contact Information and Demographics

Used/ Chosen Name:	**Date of Birth:**	**Pronouns:**

Legal First Name:	**MI:**	**Legal Last Name:**

Street (Mailing) Address:	**Apt:**	**Social Security #:**

City:	**State:**	**Zip:**	**Email:**

Primary Phone: (________) ______________________ ○ **Cell** ○ **Landline**
May we Call you? **Y** **N**
May we leave voicemails? **Y** **N**
May we text you? **Y** **N** **N/A**

Open Door Health uses automated text and / or call messages for appointment reminders.

Alt. Phone: (__________) ________________
May we Call you? **Y** **N**
May we leave voicemails? **Y** **N**
May we text you? **Y** **N** **N/A**

Preferred Language (Spoken) ○ English ○ Other ________________________

Preferred Language (Written): ○ English ○ Other ______________

Gender Identity

Gender Identity: With what gender do you identify?
○ Woman ○ Gender Nonconforr ○ Agender
○ Man ○ Genderqueer ○ Not Listed:
○ Non-Binary ○ Unsure/ Questioning ____________

Do you Identify as Transgender?
○ Yes ○ No
○ Unsure

Sex Assigned at Birth (on original birth certificate)
○ Male ○ Female
○ Choose not to disclose
○ Not Listed: ___________

Sexual Orientation: ○ Lesbian/Gay ○ Bisexual ○ Straight ○ Queer ○ Pansexual ○ Asexual ○ Unsure/ Questioning ○ Other: ___________

Marital Status: ○ Single ○ Partnered ○ Married ○ Divorced ○ Separated ○ Choose not to disclose

Race

Check all that apply:
○ African American/ Black Including Carribian, African
○ Caucasian / White incl. Middle Eastern, European
○ Amer. Indian/Alaskan Native incl. indigenous Peoples of the Americas
○ Native Hawaiian / Pacific Islander
○ Asian
○ Other: ___________________

Ethnicity

Check all that apply:
○ Cuban
○ Puerto Rican
○ Dominican
○ Brazilian
○ Non-Hispanic, Non-Latino
○ Hispanic/Latino
○ Mexican/Mexican Amer.
○ Guatemalan
○ Not Listed ___________

Living Situation

How many people live in your household (i.e. # of people who live and share finances with) including yourself:

What is your annual household income (pre-tax)?
○ Less than $10,000
○ $10,000 - $15,000
○ $15,001 - $20,000
○ $20,001 - $25,000
○ $25,001 - $35,000
○ $35,001 - $50,000
○ $50,001 - $75,000
○ $75,001 - $100,000
○ $100,001 or more
○ Decline to answer

○ I need financial assistance with healthcare costs.

Which best describes where you live right now:
○ Staying with biological family
○ Renting, alone or w/ others
○ School Dormitory
○ Homeless
○ Drug treatment facility
○ Staying w/ friends
○ Own a home
○ In a shelter
○ Single occupancy hotel (perm)
○ Transitional hotel (temp)
○ Other residential facility (nursing home, halfway house, group home)
○ Other (please specify): ______________________________________
○ Choose not to answer

Emerg. Contact

Please list an emergency contact. This person would only be called if there were an emergent medical situation. Healthcare information related to the reason for your visit would **NOT** be shared with them.

Name: ____________________________ **Relationship to you:** __________________ **Phone:** ______________________

Sign

I attest that all the above information is correct to my knowledge and that I am the patient and/or Legal Guardian.

Patient: Print: __________________________ Sign: _________________________________ Date: ____________

Legal Guardian (if app):
Relation to patient: ______________ Print: ____________________ Sign: ______________________ Date: _______

ODH Staff
____

Appendix IX

Sample Patient Questionnaire
Shared by OpenDoor Health

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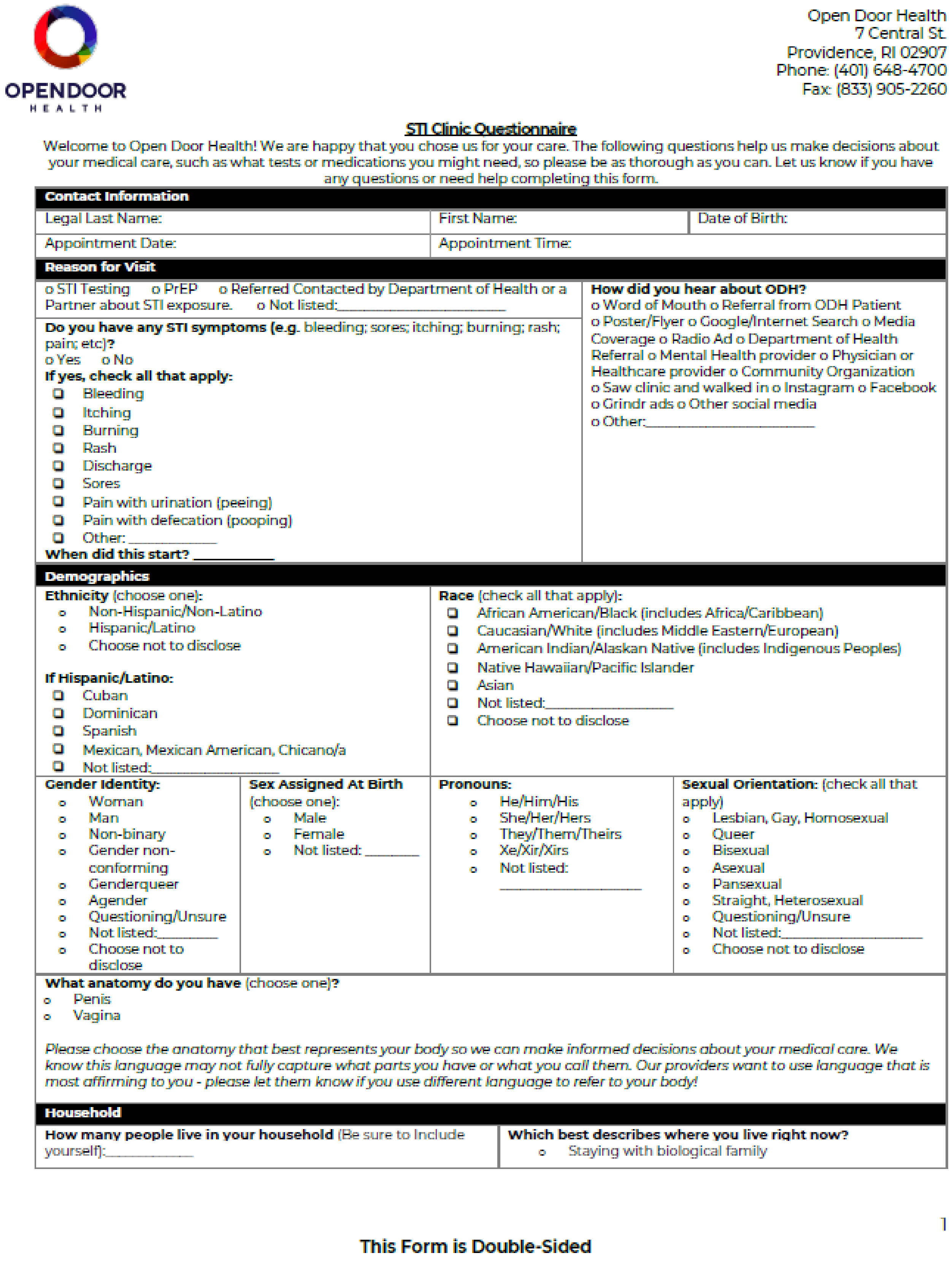


OPENDOOR
HEALTH

Open Door Health
7 Central St.
Providence, RI 02907
Phone: (401) 648-4700
Fax: (833) 905-2260

STI Clinic Questionnaire

Welcome to Open Door Health! We are happy that you chose us for your care. The following questions help us make decisions about your medical care, such as what tests or medications you might need, so please be as thorough as you can. Let us know if you have any questions or need help completing this form.

Contact Information

Legal Last Name:	First Name:	Date of Birth:
Appointment Date:	Appointment Time:	

Reason for Visit

○ STI Testing ○ PrEP ○ Referred Contacted by Department of Health or a Partner about STI exposure. ○ Not listed:______________________

Do you have any STI symptoms (e.g. bleeding; sores; itching; burning; rash; pain; etc)?
○ Yes ○ No

If yes, check all that apply:
- ☐ Bleeding
- ☐ Itching
- ☐ Burning
- ☐ Rash
- ☐ Discharge
- ☐ Sores
- ☐ Pain with urination (peeing)
- ☐ Pain with defecation (pooping)
- ☐ Other: ____________

When did this start? ___________

How did you hear about ODH?
○ Word of Mouth ○ Referral from ODH Patient ○ Poster/Flyer ○ Google/Internet Search ○ Media Coverage ○ Radio Ad ○ Department of Health Referral ○ Mental Health provider ○ Physician or Healthcare provider ○ Community Organization ○ Saw clinic and walked in ○ Instagram ○ Facebook ○ Grindr ads ○ Other social media
○ Other:_______________________

Demographics

Ethnicity (choose one):
- ○ Non-Hispanic/Non-Latino
- ○ Hispanic/Latino
- ○ Choose not to disclose

If Hispanic/Latino:
- ☐ Cuban
- ☐ Dominican
- ☐ Spanish
- ☐ Mexican, Mexican American, Chicano/a
- ☐ Not listed:_________________

Race (check all that apply):
- ☐ African American/Black (includes Africa/Caribbean)
- ☐ Caucasian/White (includes Middle Eastern/European)
- ☐ American Indian/Alaskan Native (includes Indigenous Peoples)
- ☐ Native Hawaiian/Pacific Islander
- ☐ Asian
- ☐ Not listed:_________________
- ☐ Choose not to disclose

Gender Identity:
- ○ Woman
- ○ Man
- ○ Non-binary
- ○ Gender non-conforming
- ○ Genderqueer
- ○ Agender
- ○ Questioning/Unsure
- ○ Not listed:_________
- ○ Choose not to disclose

Sex Assigned At Birth (choose one):
- ○ Male
- ○ Female
- ○ Not listed: ________

Pronouns:
- ○ He/Him/His
- ○ She/Her/Hers
- ○ They/Them/Theirs
- ○ Xe/Xir/Xirs
- ○ Not listed: ____________________

Sexual Orientation: (check all that apply)
- ○ Lesbian, Gay, Homosexual
- ○ Queer
- ○ Bisexual
- ○ Asexual
- ○ Pansexual
- ○ Straight, Heterosexual
- ○ Questioning/Unsure
- ○ Not listed:___________________
- ○ Choose not to disclose

What anatomy do you have (choose one)?
- ○ Penis
- ○ Vagina

Please choose the anatomy that best represents your body so we can make informed decisions about your medical care. We know this language may not fully capture what parts you have or what you call them. Our providers want to use language that is most affirming to you - please let them know if you use different language to refer to your body!

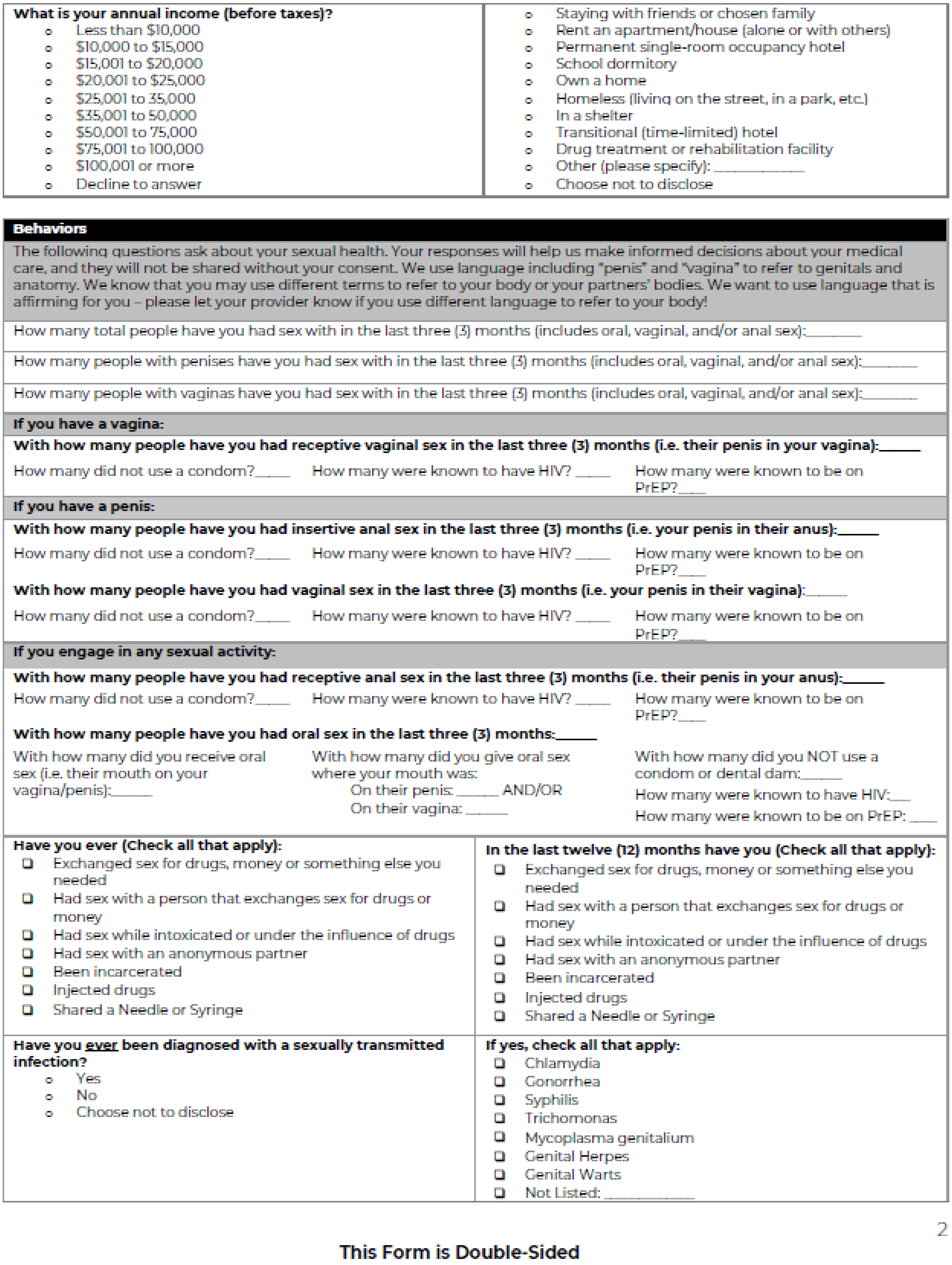
Household

How many people live in your household (Be sure to Include yourself):____________

Which best describes where you live right now?
- ○ Staying with biological family

1

This Form is Double-Sided



What is your annual income (before taxes)?
- ○ Less than $10,000
- ○ $10,000 to $15,000
- ○ $15,001 to $20,000
- ○ $20,001 to $25,000
- ○ $25,001 to 35,000
- ○ $35,001 to 50,000
- ○ $50,001 to 75,000
- ○ $75,001 to 100,000
- ○ $100,001 or more
- ○ Decline to answer

- ○ Staying with friends or chosen family
- ○ Rent an apartment/house (alone or with others)
- ○ Permanent single-room occupancy hotel
- ○ School dormitory
- ○ Own a home
- ○ Homeless (living on the street, in a park, etc.)
- ○ In a shelter
- ○ Transitional (time-limited) hotel
- ○ Drug treatment or rehabilitation facility
- ○ Other (please specify): ____________
- ○ Choose not to disclose

Behaviors

The following questions ask about your sexual health. Your responses will help us make informed decisions about your medical care, and they will not be shared without your consent. We use language including "penis" and "vagina" to refer to genitals and anatomy. We know that you may use different terms to refer to your body or your partners' bodies. We want to use language that is affirming for you – please let your provider know if you use different language to refer to your body!

How many total people have you had sex with in the last three (3) months (includes oral, vaginal, and/or anal sex):_______

How many people with penises have you had sex with in the last three (3) months (includes oral, vaginal, and/or anal sex):_______

How many people with vaginas have you had sex with in the last three (3) months (includes oral, vaginal, and/or anal sex):_______

If you have a vagina:

With how many people have you had receptive vaginal sex in the last three (3) months (i.e. their penis in your vagina):_____

How many did not use a condom?_____ How many were known to have HIV? _____ How many were known to be on PrEP?____

If you have a penis:

With how many people have you had insertive anal sex in the last three (3) months (i.e. your penis in their anus):_____

How many did not use a condom?_____ How many were known to have HIV? _____ How many were known to be on PrEP?____

With how many people have you had vaginal sex in the last three (3) months (i.e. your penis in their vagina):_____

How many did not use a condom?_____ How many were known to have HIV? _____ How many were known to be on PrEP?____

If you engage in any sexual activity:

With how many people have you had receptive anal sex in the last three (3) months (i.e. their penis in your anus):_____

How many did not use a condom?_____ How many were known to have HIV? _____ How many were known to be on PrEP?____

With how many people have you had oral sex in the last three (3) months:_____

With how many did you receive oral sex (i.e. their mouth on your vagina/penis):_____

With how many did you give oral sex where your mouth was:
On their penis: _____ AND/OR
On their vagina: _____

With how many did you NOT use a condom or dental dam:_____
How many were known to have HIV:___
How many were known to be on PrEP: ____

Have you ever (Check all that apply):
- ☐ Exchanged sex for drugs, money or something else you needed
- ☐ Had sex with a person that exchanges sex for drugs or money
- ☐ Had sex while intoxicated or under the influence of drugs
- ☐ Had sex with an anonymous partner
- ☐ Been incarcerated
- ☐ Injected drugs
- ☐ Shared a Needle or Syringe

In the last twelve (12) months have you (Check all that apply):
- ☐ Exchanged sex for drugs, money or something else you needed
- ☐ Had sex with a person that exchanges sex for drugs or money
- ☐ Had sex while intoxicated or under the influence of drugs
- ☐ Had sex with an anonymous partner
- ☐ Been incarcerated
- ☐ Injected drugs
- ☐ Shared a Needle or Syringe

Have you *ever* been diagnosed with a sexually transmitted infection?
- ○ Yes
- ○ No
- ○ Choose not to disclose

If yes, check all that apply:
- ☐ Chlamydia
- ☐ Gonorrhea
- ☐ Syphilis
- ☐ Trichomonas
- ☐ Mycoplasma genitalium
- ☐ Genital Herpes
- ☐ Genital Warts
- ☐ Not Listed: ___________

2

This Form is Double-Sided

Appendix X

LGBTQ Language - Presentation

Shared by OpenDoor Health, created by Equitas Health – Institute for LGBTQ Equity

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Refer to LGBTQ Language PowerPoint presentation

Appendix XII
Gender Resources

Shared by OpenDoor Health

Readings

Intersex People Deserve Proper Healthcare — So We Created a Hospital Policy Guide
Them - September 14, 2018

What It's Like to Medically Transition as a Nonbinary Person
Them - August 1, 2018

Meet the Doctors Revolutionizing Healthcare for Trans Teens
Them - July 16, 2019

7 Trans and Nonbinary People on Why We Need More Trans-Inclusive Therapists
Them - November 18, 2019

The XX and XY Lie: Our Social Construction of a Sex and Gender Binary
Medium

Not Born in the Wrong Body
Everyday Feminism - July 26, 2015

On Neopronouns
Medium - March 15, 2018

Why the LGBTQ+ Community Must Fight for Disability Rights
Them - May 14, 2018

Reconnecting Disability and Asexuality
Autistic Hoya, - This article originally appeared in Disability Intersections on 29 January 2014

Gendervague: At the Intersection of Autistic and Trans Experiences
Autistic Hoya - 22 June 2016

What It Means to Identify as Agender
Vera Papisova - January 20, 2016

Trans Student Educational Resources
https://transstudent.org/

US Transgender Survey, Executive summary
https://transequality.org/sites/default/files/docs/usts/USTS-Executive-Summary-Dec17.pdf

Queer Sex Ed Podcast

Cannot recommend this resource highly enough. The hosts are two transgender sexual health educators, one of whom has a background working in healthcare. They have episodes on a wide variety of topics, but the ones below are my (Alfie's) recommendations to listen to first as I think they are most relevant to the work of ODH. Episodes can be accessed on Apple Podcasts, Spotify, and queersexed.org

History of Transgender Medicine: Episode 49

Jay and Sara share some of the deep and complicated history of transgender medicine to discuss how physical differences become a medical diagnosis. Also discussed: the "medical model" of trans identities, and the process of medical pathologizing

Modern Transgender Medicine: Episode 51

Jay and Sara continue their discussion of trans medicine by focusing on current barriers to care caused by our medical model of trans identity. Also discussed: transmedicalism, solidarity work, and what non-binary transition can look like.

Biological Sex and Expanding the Trans Medical Model: Episode 53

This week Jay and Sara dig down into "biological sex" and break down why it's a problem, how it's more complicated than you probably know, and new ways to discuss bodies without binary sex. Also discussed: research impacts of using biological sex, expanding the trans medical model, and how we project gender and sexuality onto animals.

Body Changes on Hormones: Episode 59

This week, Jay and Sara spend some time talking about the general changes people can expect when starting testosterone or estrogen, progesterone, and spironolactone as hormone replacement therapy (HRT). Also discussed: muffing, exploring new sensations, and a response to Buck Angel's recent fearmongering about the risks of taking testosterone.

Sexually Transmitted Infections and Getting Tested: Episode 20

This may be a lot of known information, but it's a great resource for hearing current language regarding STIs and getting tested used by trans people. Especially recommend listening from 1:34:00 onward as it talks very specifically about the experience of getting STI screenings for trans people and gives ideas of ways to improve the experience.

Reproductive Justice and Family Building: Episode 21

Jay and Sara discuss the broad spectrum of reproductive justice work as well as contraception, abortion, adoption, foster care, and ART (assisted reproductive technologies) from a trans-focused and queer-focused perspective.

The History of Queer Criminalization: Episode 30

Sara and Jay cover a brief overview of ways that colonialist states have used police, incarceration, and state violence to criminalize and punish queer and trans people.

Modern Queer and Kink Criminalization in the US: Episode 31

Sara and Jay finish their discussion from last week with how modern laws, policies, and structures continue to fuel queer criminalization today. Also discussed: ICE and immigration enforcement, BDSM criminalization case law, HIV laws, SESTA/FOSTA, mass incarceration, and more. Thanks for sticking with us through a pair of difficult and important episodes.

Heteronormativity and the Nature vs Nurture Debate: Episode 34

Sara and Jay dive deep into heteronormativity, including how the assumption that everyone is straight shapes our world and what we can do to fight back against it. Also discussed: searching for a trans gene, assimilation, and how the nature vs nurture debate harms us all.

Sexuality Research and Academia: Episode 29

Sara and Jay sit down with Chris Barcelos, a researcher studying queer sexuality, teenage pregnancy, and health messaging. We discuss many different things including whether to double down on a moderate message in times of crisis or transform, messaging around teen pregnancy, how sex health is racist, the untold history of sexual health education in the USA, and much more.