Patient Advocate Foundation

PATIENT INSIGHT INSTITUTE



Exploring Patient Perspectives: Cognitive Testing of Demographic Data Collection and Identity Preferences in Healthcare

Executive Summary

Health equity efforts must be data-driven to be successful. Despite significant investments by providers, health plans, and governmental agencies, the demographic data currently collected is often insufficient and inadequate.

Accurate demographic information helps healthcare professionals provide optimal care, gain insight into the needs of diverse patient populations, and design services and programs that better serve the health needs of different communities, ensuring the high-quality care. However, the detailed demographic data that are necessary for monitoring are not routinely collected from patients in a uniform manner. Creating demographic data standards that are aligned across the health care ecosystem will enable information to be collected once and reused across trusted partners.

We took a mixed methods approach to understand if revised questions on personal identity and demographics were understandable by patients, if they aligned with how they identify, and how comfortable they would feel answering questions on personal identity. In addition, we also wanted to understand how practices collect and utilize patient demographics, as well as understand how skilled and comfortable they are asking patients questions about personal identity.

Most of the survey respondents felt that collecting demographic data was useful to informing patient-centered care. The use of introductory scripts, specifically to clarify 'what, why and how' this information will be used at both the individual and populations level, provides a platform for communication and trust between the patient and the provider. When an organization has staff skilled in collecting this information and comfortable conversing with patients' identities, it fosters trust in how this information can and will be used, not only to benefit individual patients but also to improve outcomes at the population and system levels.

Evidence highlights the significant role of demographic variables, such as race, pronouns and spoken language, in shaping the quality of care experienced by patients. Incorporating demographic data collection as a routine part of the intake or triage process, using simple and concise language to explain the domains and response options, offers an opportunity to normalize and standardize this aspect of a patient's healthcare experience. When used effectively, demographic data can help health programs and health systems address historical inequities and provide high-quality, individualized, and culturally competent health care.

Introduction

Patient demographic data has been collected in the United States for several years and is essential for identifying inequities in health outcomes. Patient demographic data includes all non-clinical data collected about a patient.[1] As part of the patient registration process, providers routinely ask questions about demographics, such as race, ethnicity, preferred pronouns, sexual orientation, gender identity, and disability status. By sharing this information, patients help healthcare professionals better understand the communities they serve and ensure that all patients receive equitable care. Having accurate demographic information helps healthcare professionals know how to best care for their patients and provides insight into the needs of diverse patient populations to create services and programs to better serve the health needs of different communities, ensuring the best quality care.



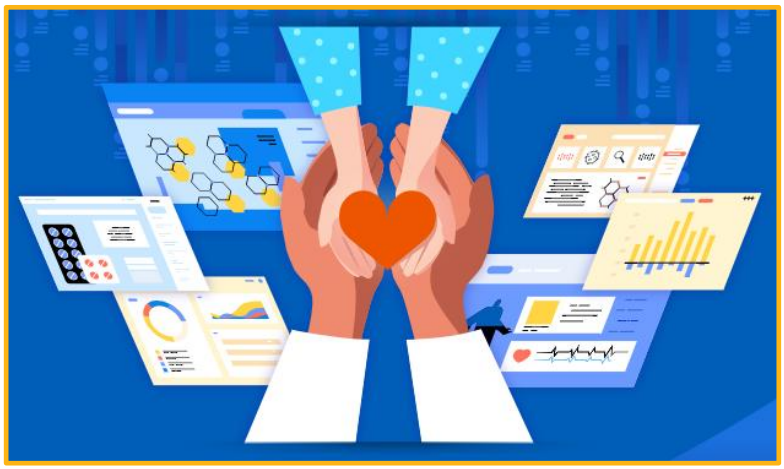
Background

Existing demographic data standards often lead to inaccurate or incomplete data. Often, demographic data that is collected is often misspelled, numbers are reversed, or just overall not captured.[1] On top of this, the lack of alignment and standardization of demographic data standards across markets, states, and health care stakeholder groups makes it difficult to aggregate, analyze, and enable direct comparisons across the health care ecosystem. Creating interoperable demographic data standards that are aligned across the health care ecosystem will enable information to be collected once and used many times across trusted partners. This will ease the burden on all stakeholders while enhancing stakeholders' ability to identify and address disparities, improve quality of care, and advance health equity.

Insufficient understanding of data collection goals, staff discomfort with collecting demographic information, and patient reservations are all frequently cited as system level and individual-level barriers to sustainable demographic data collection and use. Evidence points to the significant role of collecting demographic variables in shaping the quality of care experienced by patients.[2] With equity now universally recognized as a pillar of quality, providing excellent care cannot be achieved without integrating an equity component.[3]

Patient Perspectives

Patients describe feelings of bias and prejudice in clinical encounters that are often reflective of shared and assumed demographic characteristics. However, little is known about patient perspectives around the collection and utilization of demographic information. When demographic information is used to guide doctors in making the best decisions for patients' health and in offering new treatments, patients are more receptive to sharing this type of information.



Provider Expectations

Individuals collecting demographic data play a significant role in determining the success of the initiative. It is critical that health care providers and staff understand that demographic data collection is an essential building block for ensuring equitable and quality care. Staff discomfort is frequently cited as a major barrier to demographic data collection, typically stemming from uncertainty about how to ask demographic questions and address any patient concerns.

Utilization of Demographic Data

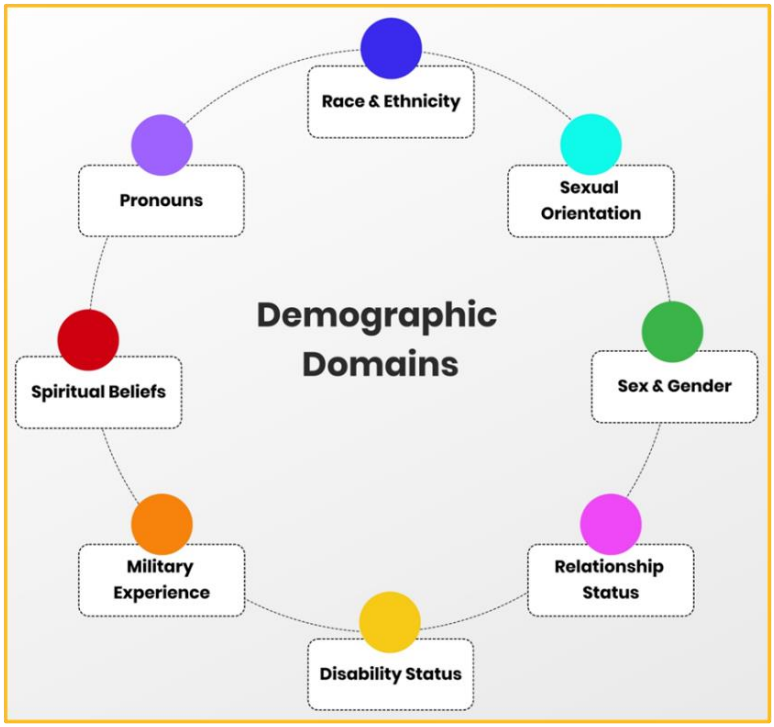
Two frequently asked questions that arise when organizations plan for data collection are "why are you collecting the data?" and "how are you going to use the data?". Having clear goals for data collection can provide those answers and function as a highly effective engagement tool.

Goals for collecting data can include three levels of use:

- ***Health system use*:** Support population health and system planning. Looking at results across geographic areas may illuminate gaps in service specific to local regions or smaller areas (which may not be a challenge across the broader region), identify new connections between patient population characteristics and service utilization, and measure disparities in service outcomes across equity-seeking groups.
- ***Organizational-level use*:** Socio-demographic data, when aggregated to provider level, may flag unrecognized and emerging needs or populations that may require additional or customized support in their care delivery. This supports quality improvement initiatives and organizational planning and changes to target health inequities that are identified.
- ***Individual-level use*:** Improving care for patients/clients and families at the point-of-care. Asking the socio-demographic questions allows the provider to quickly flag patient characteristics that may impact care delivery and planning.

Methods

Beginning in January 2024, AHIP brought together a diverse set of over 130 stakeholders including health plans, federal agencies, provider associations, consumer groups, patients, standards development organizations, and more. Through a series of five national virtual focus groups, participants considered straw man questions and response choices for demographic domains including race, ethnicity, language preference, sexual orientation, sex, gender, relationship status, pronouns, military experience, disability status, and spiritual beliefs. Participants were invited and encouraged to leverage their unique expertise and experience to offer feedback and suggestions for revisions.



The results of this work developed the final set of survey questions and response choices for each domain. Patient Advocate Foundation (PAF) conducted cognitive testing of the recommendations to ensure respondents understand the questions being asked, believe the answers offered provide an opportunity to appropriately identify themselves, and are comfortable answering the questions as written. The second phase of the project included qualitative and quantitative assessment of the demographic domains, and the results of those activities are provided in the report.

Patient Survey

A survey tool was developed by PAF with input from our partners at AHIP and was based on a subset of the demographic domains identified through previous work. Each domain consists of 2 universal questions asking about clarity and needs of the provided introductory, and then followed by a free text open response for patients to provide in their own word(s) how they identify with the demographic domain (open text vs. response options provided will be analyzed in a separate research brief). After responding to the demographic choices provided, respondents are then asked if the provided choices match their chosen identity followed by a free text open response area to share any missing choice options.

We recruited English speaking individuals from our Patient Insight Network aged 19 years and older with a valid email address to take part in a cross-sectional national survey launched in August

2024 over a 3-week period. Over 600 participants finished the survey, yielding a completion rate of 79%. Frequencies are reported for categorical variables.

Focus Groups

Research questions were developed to address key project objectives before conducting the focus groups. A discussion guide was developed by PAF based on the survey results with additional review and feedback from our partners at AHIP. Each session covered conversations around which demographic domains are medically necessary, how granular this data should be, feedback on introductory language and the frequency of updating that data. We also explored how to capture gender fluidity and the perception of the use of the term "disability".

Focus group participants (n = 30) were recruited from a subset of the survey cohort and 90-minute sessions were held on three separate days in September 2024. Thematic analysis of the transcripts was conducted by a single individual (MSD) in NVivo.

Provider Survey

A companion survey was sent to clinical providers who assisted PAF patients over an 18-month period (January 2023 – June 2024). This survey asked questions about the collection and utilization of demographic data at their organization. Secondly, we asked about communication skills and comfort with acquiring and using demographic data. The final set of questions shared the introductory language for race and ethnicity, sexual orientation and gender identity, and spiritual beliefs. Provider respondents were then asked about language clarity for staff as well as patients served by their practice. Over 80 responses were collected, and frequencies are reported for categorical variables.

Survey Incentives

Survey respondents were entered into a random drawing for three $150 Amazon gifts and focus group members were provided with a $75 Amazon gift card for their participation. Access to survey tools and focus group guide can be made by contacting the team at the Patient Insight Institute.

Results

Patient Survey (N = 617)

Cohort Demographics

Due to the unique design of this survey tool, demographics were collected for each domain in a cascading format. Overall, the survey cohort was 65% white, 68% heterosexual, 65% female, 35% married, 64% disabled, and 6% reported prior military service (**Appendix A**). Additional details for

each of the demographic domains are provided later in this report. A comparison between free text responses and provided choices will be analyzed in a separate data brief.

Language Clarity

Many peoples' identities are informed by their race, culture, ethnicity, gender, or religion. When it comes to receiving medical care, many patients will make decisions based on their identity in some or all these categories.

Each section of the survey included introductory language describing one of the eight demographic domains (**Appendix B**). Respondents were then asked whether or not they felt the provided description was clear. As we can see from the figure below, there was consensus from most of the respondents (97-98% 'yes') that the provided language was clear in describing the type of demographic information being requested (**Fig. 1**).

Figure 1: Language Clarity

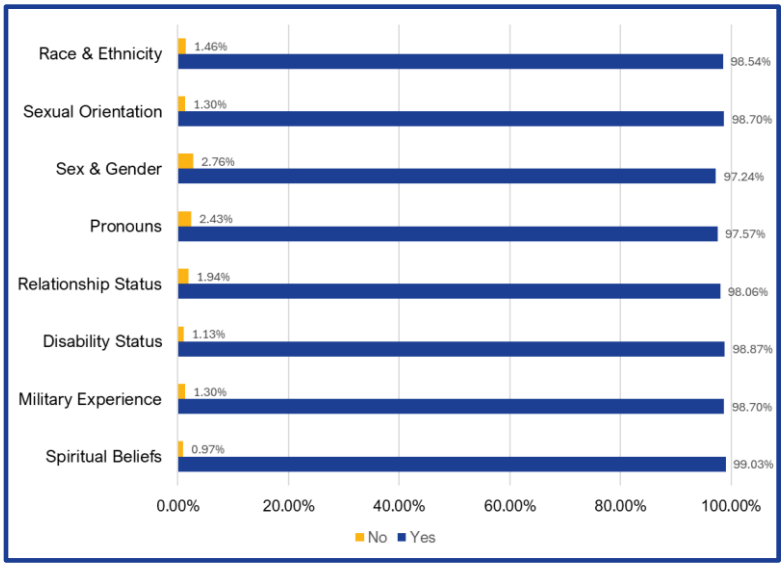
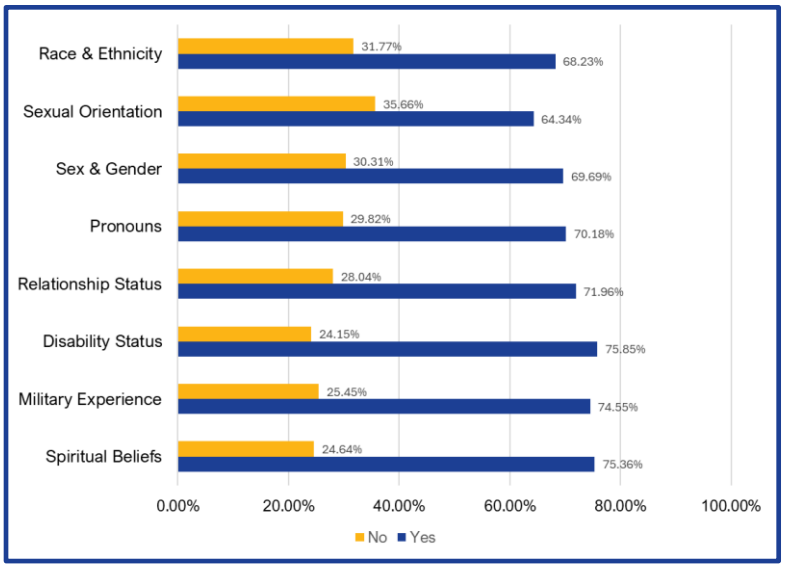


Figure 2: Domain Definition



Domain Definition

The second question then asked respondents to indicate whether or not they felt the provided script was necessary to define the demographic domain. We saw more variation in responses to this question with two-thirds to three-quarters of respondents (64 – 75%) indicating that this language was needed to assist in correctly answering demographic questions (**Fig. 2**).

Identity Choice Match

After responding to the specific domain questions, we then asked if respondents felt that the provided questions choices provided responses that they felt correctly reflected their identity (**Fig. 3**). Two thirds of respondents felt a strong connection to the responses provided for Sex and

Gender, Pronouns and Relationship status (63-65% 'Completely'). Sexual orientation also performed well with only 10% reporting 'Slightly' or 'Does not'. The poorest performing category was Race and Ethnicity, which was surprising as this domain had not only main demographic categories, but also a secondary question which allowed identification at a nationality level.

Figure 3: Self-Reported Choice Match

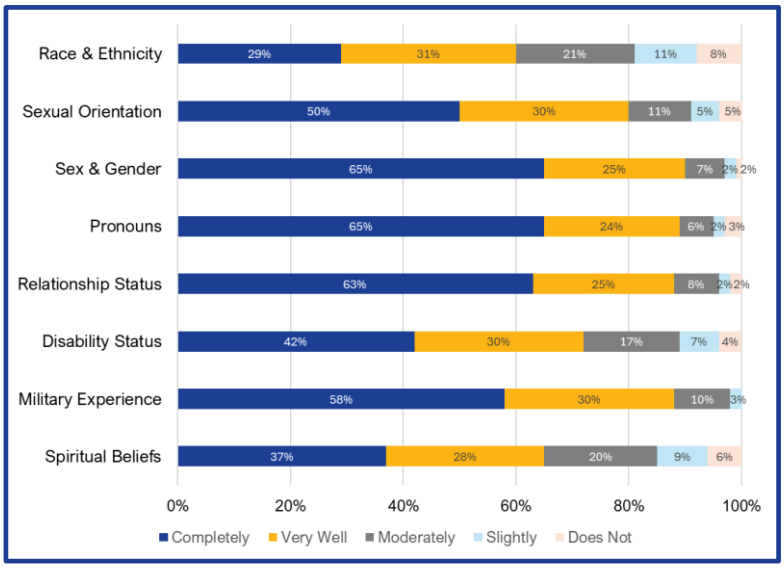
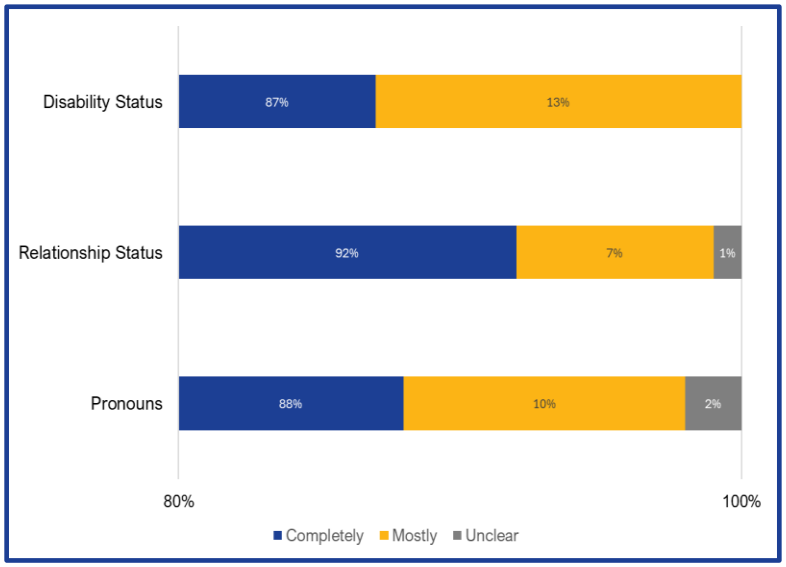


Figure 4: Response Definition Clarity



Choice Definitions

For three of the domains (Pronouns, Relationship Status, Disability Status) we provided not only response options, but definitions with those options (**Appendix C**). Overall (87-92%) respondents found the choice definitions to be clear and understandable (**Fig. 4**).

Domain 1: Race & Ethnicity

Race and ethnicity are socially constructed categories that have tangible effects on the lives of individuals who are defined by how one perceives oneself and how one is perceived by others.[4] Measuring differences in access and use of services, satisfaction with and quality of care, and health outcomes can help to better understand the underlying causes of disparities and how to address them.

Respondents were initially provided with 7 main categories (Asian or Asian American; Black, African, or African American; Hispanic or Latino/a/e; Middle Eastern or North African; Native American, Alaska Native, or Indian; Native Hawaiian or Pacific Islander; White or European) to select their race and/or ethnicity (**Fig. 5**). They had the ability to select multiple identities or to respond that they 'did not know' or opted to not provide that information (**Appendix A**).

Based on their primary selections, participants were then provided with a second set of questions that allowed them to select their background from an expanded list of nationalities (multiple responses allowed).

Figure 5: Race and Ethnicity

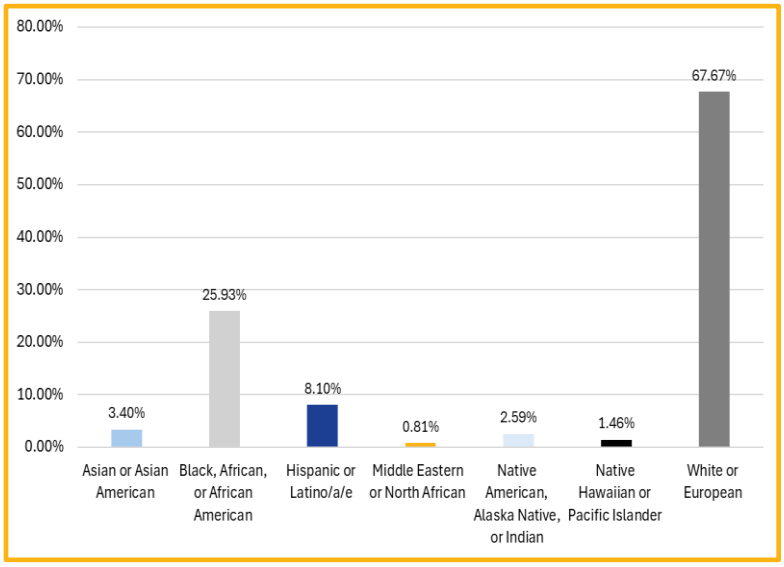
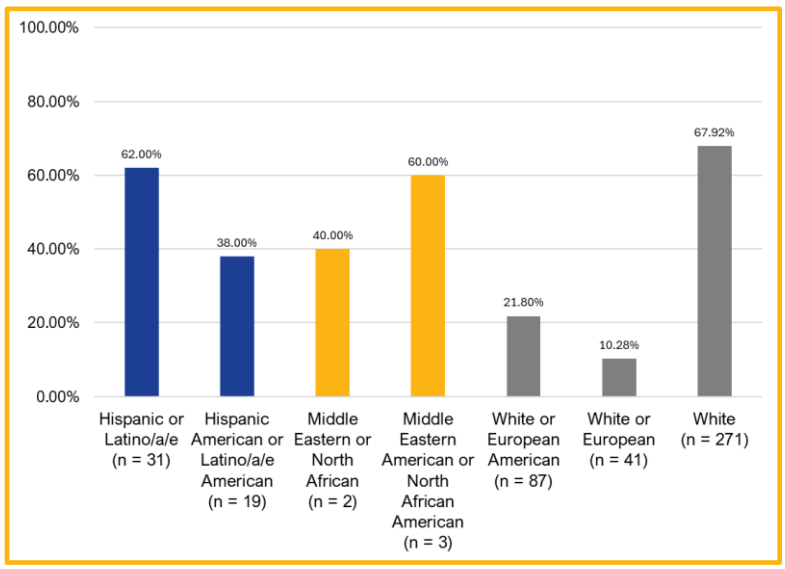


Figure 6: Race & Ethnicity Term Preference



For many of the response options our sample size was low (<5%), however White or European (n = 399) and Black, African, or African American (n = 160) had a large enough response rate to report out their background selections. In our project sample, White respondents most often selected English (51%), Irish (35%), and German (34%). Seventeen percent reported that their background was not listed. Black participants strongly identified with the option African American (89%) and 11% reported that their background was not listed.

We also wanted to evaluate high level response options to see which ones resonated with our respondents. We asked these questions for three categories (**Fig. 6**).

Domain 2: Sexual Orientation

Health disparities that affect LGBTQ+ people will only be addressed if the health system collects data on sexual orientation and gender identity. The healthcare needs of the LGBTQ+ community should be considered to provide the best care and avoid inequalities of care.

Two thirds (68%) of our respondents selected heterosexual (**Fig. 7**) as their identity and only a small percentage opted out or did not know (<4%). Gay/lesbian (18%) was the second largest response group and 'Queer' was the option most often cited as missing in the response options (**Appendix A**).

Figure 7: Sexual Orientation

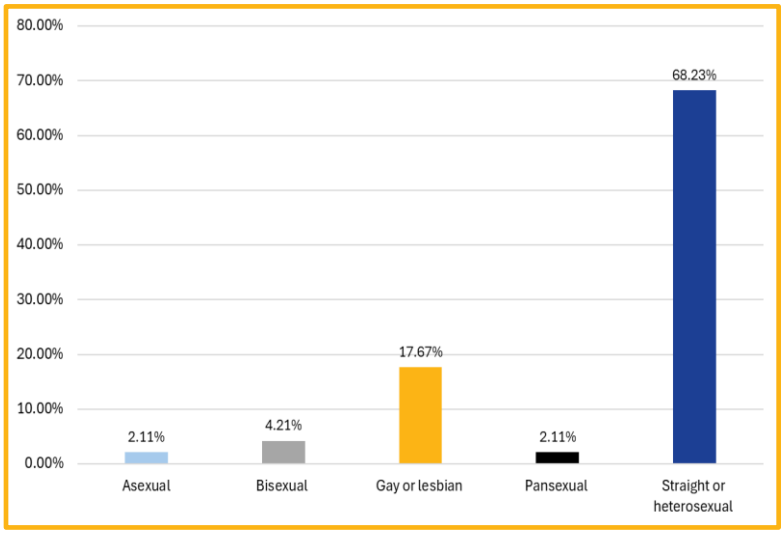
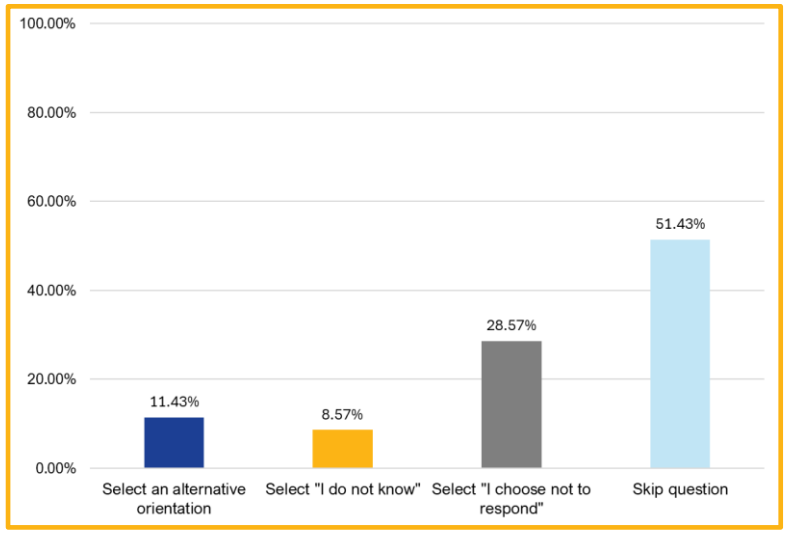


Figure 8: Sexual Orientation Response Alternatives



In addition, we asked respondents about their comfort in disclosing their sexual orientation in a healthcare setting. 11% (n = 70) stated that they were uncomfortable sharing this type of information. We then asked those respondents how they might go about answering that question (**Fig. 8**). Most (80%) would opt to skip the question entirely or select not to respond.

Domain 3: Sex & Gender

Gender norms, roles and relations, and gender inequality and inequity may affect a patient's healthcare experience. Gender interacts with but is different from sex. The two terms are distinct and should not be used interchangeably. It can be helpful to think of sex as a biological characteristic and gender as a social construct. Sex refers to a set of biological attributes in humans and animals. Sex is mainly associated with physical and physiological features including chromosomes, gene expression, hormone level and function, and reproductive and sexual anatomy.[5]

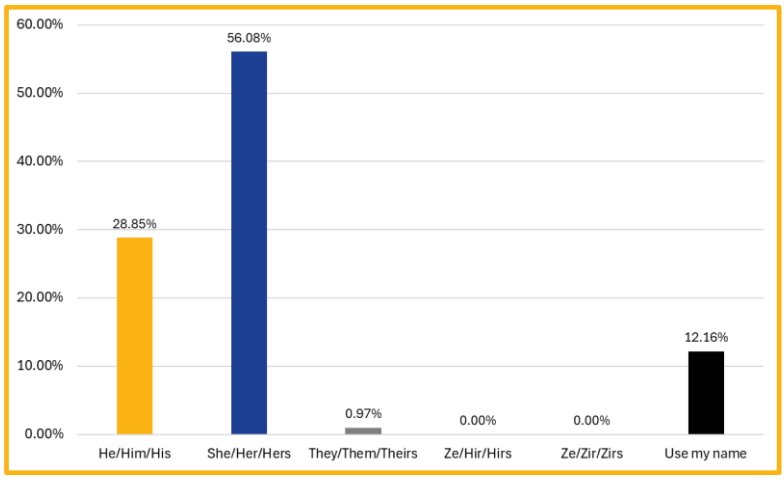
Most of the respondents in our survey (99%) selected female or male as the sex they were assigned at birth. Comparable results were seen when asked to identify their gender (**Appendix A**).

Domain 4: Pronouns

Pronouns are a fundamental aspect of our identities. Understanding and correctly using a patient's pronouns promotes trust, demonstrates respect, and contributes to a more inclusive and supportive healthcare environment. When healthcare providers consistently use the correct pronouns, they acknowledge and validate their patients' identities.[6]

Pronoun identification had more variability than the sex and gender identification (**Fig. 9**). Male pronouns (he/him/his) were selected by 29% of respondents and female pronouns (she/her/hers) by 56%. Being called by their name (12%) was also a choice that resonated with respondents (**Appendix A**).

Figure 9: Preferred Pronouns



Domain 5: Relationship Status

Living arrangements and marital status can have a significant effect on a person's health and mortality.[7]

Most respondents reported that that they were single (35%), married (34%), or divorced (12%) (**Appendix A**). This domain was expanded to include four new response options (dating (4%); committed relationship with 1 person (10%); committed relationship with more than 1 person (1%); registered domestic partnership (1%).

Domain 6: Disability Status

People with disabilities often are more susceptible to preventable health problems that decrease their overall health and quality of life. A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities.[8] It can also be a status used by the social security administration to determine government benefits. We approached asking this question in two separate ways. Respondents answered a question listing specific tasks they might have difficulty doing (multi-select), and then a second question if they identified as disabled (single select).

Approximately one third (31%) indicated that they did not have any physical or mental challenges. For those who had difficulty (n = 426), common responses included 'walking or climbing stairs' (60%), 'concentrating, remembering or making decisions' (39%), and 'other difficulties through the day' (33%). Additional responses can be seen in **Appendix C**.

Sixty-four percent (n = 392) identified themselves as disabled (**Appendix A**), which is lower than those reporting a specific difficulty (**Table 1**).

Table 1: Disability vs. Accommodation

	Disability	No Disability
Hearing	16.33%	8.24%
Seeing	20.41%	5.29%
Concentrating/Remembering/Making Decisions	36.48%	8.24%
Walking/Climbing Stairs	57.91%	8.24%
Dressing/Bathing	17.09%	0.00%
Cooking	19.90%	0.00%
Feeding	3.83%	0.00%
Using the Toilet	5.87%	0.00%
Doing Errands	28.83%	0.00%
Communicating	7.91%	0.00%
Understanding	5.36%	0.59%
Other Difficulties	32.40%	4.12%
	392	**170**

Additional questions about disability were asked during the focus groups and will be shared later in this report.

Domain 7: Military Experience

Military service members and veterans may face lots of different health issues and may also face different health risks than civilians.[9] Military personnel and veterans may also face unique risks and challenges to their mental health.

Only a small subset of our respondents (n = 40) reported serving in the United States Armed Forces, Reserves, or National Guard. Responses to this question can be found in **Appendix A**.

Domain 8: Spiritual Beliefs

Diverse religious and spiritual beliefs can impact patient experiences and influence their decisions regarding treatment. Individuals may address medical issues in diverse ways depending on their religion's teachings and traditions.[10] Honoring religion in healthcare yields a variety of benefits for patients. When patients feel respected by their nurses and doctors, they can develop a foundation of trust and feel more comfortable.

Over half (52%; n = 318) of respondents reported Christianity as their spiritual belief; 36% identified as Protestant (Anglican, Baptist, Calvinist/Reformed, Episcopalian, Lutheran, Methodist, Nondenominational, Pentecostal, Presbyterian, or Seventh-day Adventist); and 16% as Catholic. The next two most reported categories were 'spiritual but not religious (12%) and agnostic (8%). Additional responses can be seen in **Appendix A**.

As reported above, we separated Christianity into two separate categories, Catholic and Protestant, but wanted to know how Christian patients wanted to report their identify if presented with different options. Almost half (47%) indicated that just using the term Christian was sufficient, followed by a quarter (26%) stating that they would like to have the ability to write in their specific Christian denomination (**Fig. 10**).

Figure 10: Alternative Christian Response Options

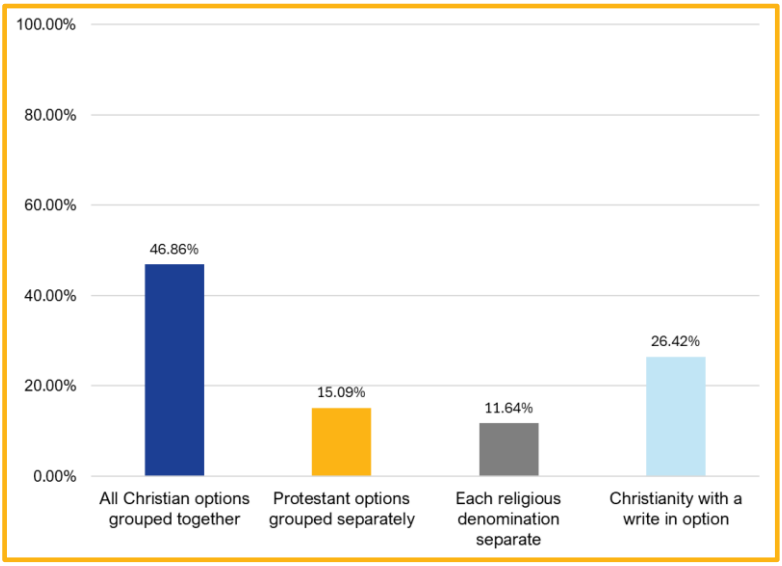
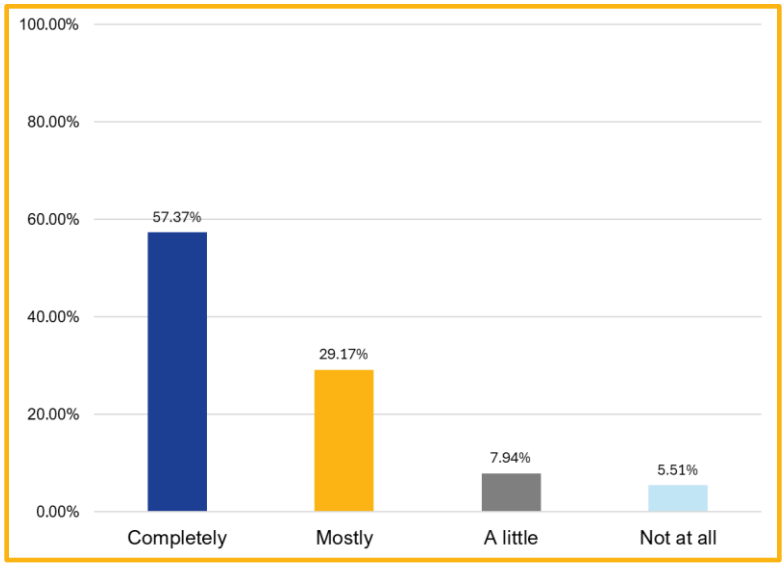


Figure 11: Introductory Script Comfortability



Healthcare script

Not only was it important to understand patient perspectives on the specific domains and responses to demographic questions, but we also needed to understand how to approach patients in collecting this information (written/verbal). Scripts help to create a predictable experience and guide for the collection of demographic information.

We shared a sample script (**Appendix D**) with respondents and then asked them if this wording would make them feel comfortable about answering demographic questions in a healthcare setting. Eighty-seven percent of respondents indicated that the script we shared gave them comfort in being approached and answering these types of questions (**Fig. 11**).

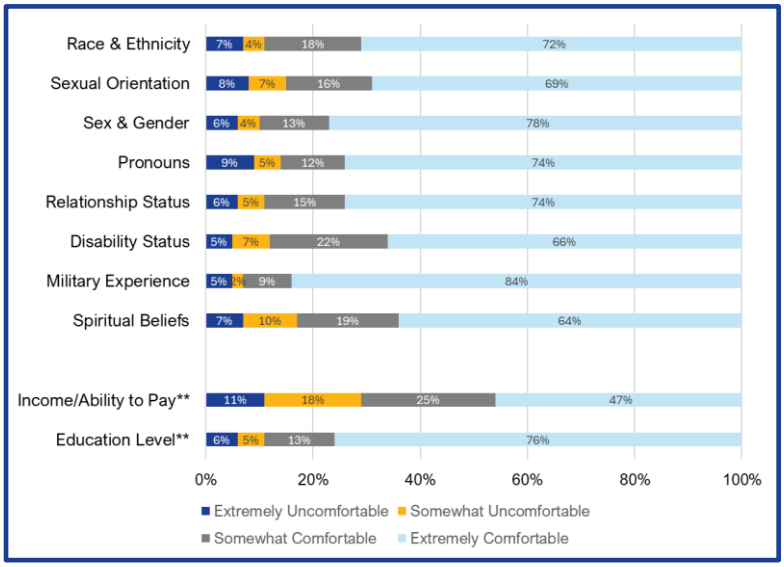
Topic Area Comfort Level

Self-identification is complex, as it relates to how we see ourselves, the histories of our families and our communities, how others see us and affix labels to us that we do and do not agree with, and how we relate to others. Many patients intuitively understood how the data could be helpful for their health care providers. Few patients in our study reported any discomfort with the question

domains (<10%) and high comfort levels within a primary care setting where patients had ongoing, trusting relationships (**Fig. 12**).

In addition to the demographic domain areas covered in this project, we also asked about two additional areas – education and income/ability to pay. Sharing education levels did not cause discomfort among our respondent cohort (6%) and income remains an uncomfortable topic for patients to disclose as there is a fear of this impacting the type of care offered.

Figure 12: Comfort Answering Domain Questions



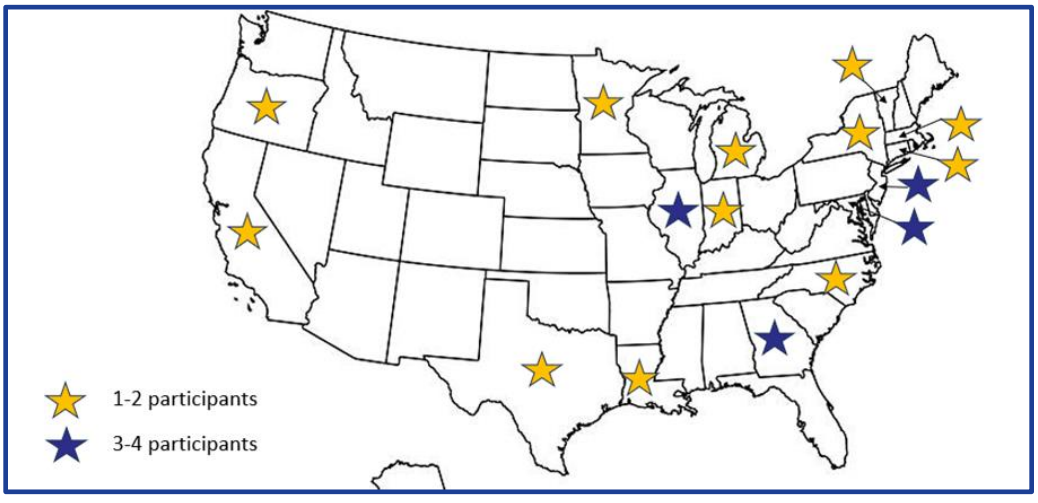
Focus Groups (N = 30)

Demographics

Focus group participants were generally reflective of the larger survey cohort. They represented 16 states and all regions (**Fig. 13**). To ensure that diverse patient voices were represented in these conversations, we did oversample our non-white and non-heterosexual respondents. Complete focus group demographics can be seen in **Appendix E**.

Many patients appreciated being able to select from a variety of specific response options, but this also posed a difficulty for patients who could not easily find an option that reflected their identity. In addition, focus group conversations centered on two larger themes around provider awareness when collecting or asking about demographic data as well as suggestions for best practices when asking about sensitive information. Participants also brought up suggestions for how to address identity fluidity and awareness around disability as a status vs. an identity.

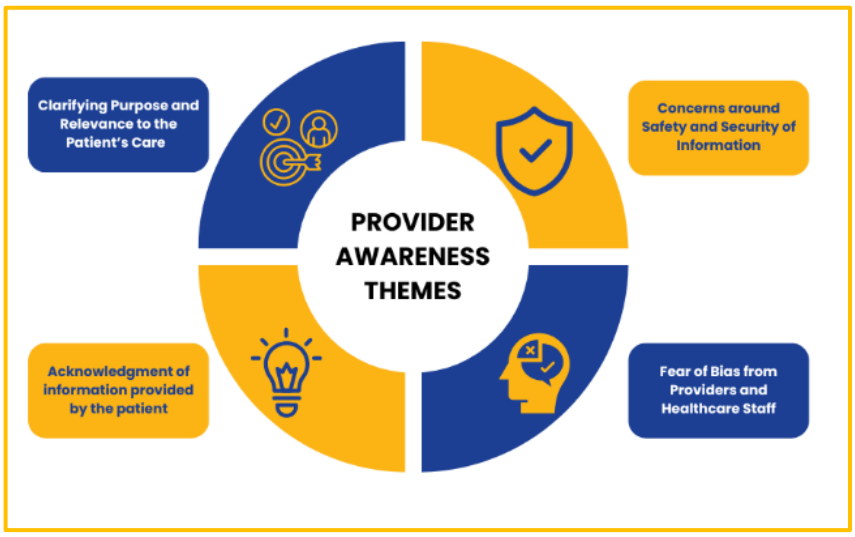
Figure 13: Focus Group Participant Locations



Provider Awareness

Physicians' ability to effectively and compassionately communicate information is key to a successful patient–physician relationship. When it comes to the collection and use of demographic information, we probed focus group participants to help identify what was important to them when it comes to these types of conversations. Four distinct themes were identified (**Fig. 14**).

Figure 14: What Providers Should Know



Participants reported that the questions were easy to understand and that the introductory language was clear, but that all of the scripts were missing a clear purpose for why that demographic information was being collected.

> *"So, like, it's not that I object to any of these questions being asked or answering them, but I do. I certainly wonder about the relevance before a provider comes into the exam room, or whatever with me. Why do they want to know? The importance of knowing my race and or ethnicity, which is such a kind of fluid, confused category."*

Concern was also expressed about the fact that often this information is collected and kept in their electronic health record, but then never reviewed and/or used by the provider during their visit.

Providers should acknowledge that this information is being reviewed so the process feels meaningful, but that collecting this information should not interfere with the quality-of-care patients will receive. Safety concerns about stored information and who has the ability to view and share it was minimal; however, explicit consent should be obtained if the provider/clinic plans to share this information with external partners (e.g., insurance company, research dataset).

"I was a victim of my confidentiality, being breached actually more than one occasion due to me. . .living in a small community. You have to just be very mindful of what information is being shared. . .For example, I'll go into the dentist. And they were asking me questions about like my sexuality. My background and sex. And I'm like, oh. what does this have to do with my dental treatment? . . .But I'm very mindful about how I handle certain things, because at the end of the day I'm the only one that's gonna protect myself."

Participants also expressed concerns around certain demographics being used to "put them in a box", as this could create preconceived bias when determining their treatment options or other facets of their care.

"I feel like. If I answer these questions, would I be treated differently; you know, or would I get the same treatment as everyone else?"

Suggested Provider Best Practices

We also identified four distinct themes regarding participant conversations around best practices for providers when collecting demographic information (**Fig. 15**).

Figure 15: Best Practices for Collecting Data



Several of the focus group respondents felt that they were familiar with demographic domains and that introductory language (for themselves) was not needed; however, when asked about the necessity for general patient populations, they expressed that this language would be helpful as it would ensure that the questions would be understood and interpreted correctly. This was especially important for patients who may not speak English as a first language or whose culture may not readily identify with some of the collected domains.

"In my culture there is no gender, so my parents will say he she but like I have a daughter, and my mom will say he and I'm like Wait, you mean she, because there is no gender [in my culture], I mean, we say, girl boy, but there is no gender difference. It's all the same. And my parents, I know they would appreciate more information because English is their second language. So, I like that, too. That there's more [introductory language]. It may be redundant for people like me who grew up here. And but for others I think that'd be helpful."

When it came to the relevance of the collected demographic data most participants felt that these domains would stand the test of time and continue to be important to their care. When asked about the frequency of collecting this information, most felt that an annual review of the information made sense – many of the categories would remain static over time, but others could potentially change. Fluid or changing identities (e.g., gender, pronouns, religion) could be best served with open text responses – the term "other" did not resonate as an option (even when paired with open text).

"Gender identity and sexual identity are complicated things, and they're not. They're not always cut and dry like if somebody's bisexual. They may not have had a relationship with somebody of the same sex for the past, for who knows how long, or they may have not had the relationship with somebody of the opposite sex for a really long time. That's still their identity. just because they're in a heterosexual relationship right now doesn't make them a heterosexual. On the other hand. if they're indicating bisexual on this checkbox. then potentially the doctor is looking down diagnostic avenues that are irrelevant."

Finally, we probed focus group participants about the concept of disability as an identity and how to best collect this information. Many participants expressed that they did not identify as a "person with a disability" or as "disabled" even if they were legally categorized as such. Participants preferred being asked about disability in a manner similar to employment status, focusing on how a specific condition or aspect of their "ability" affects their daily life, and what accommodation a provider may need to provide. Specifically asking about accommodation instead of disability should be a part of best practices.

"But if you look at me, I don't look disabled. I don't present disabled in any way, shape or form. but it's really really important for healthcare providers and their entire team starting with reception to know that I am disabled and that I need accommodation, and I need to be respected. And I've been disrespected in medical settings."

Provider Survey (N = 82)

Organization Type

Respondents were provided with 5 options to identify their organization type. Most (68%) identified as specialty clinics, primary care clinics (21%), hospital (5%), or pharmacy (1%). Four respondents (5%) chose "other" and identified themselves as a cancer center (n = 2), community health organization, or left the open text blank.

Organizational Role

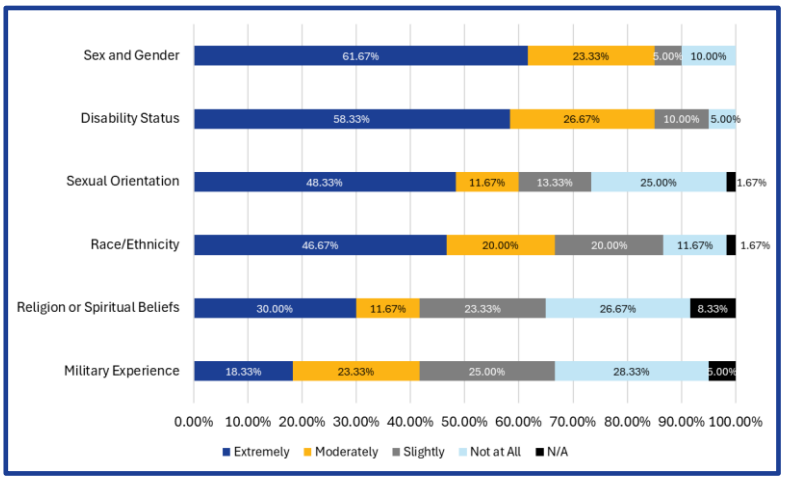
There are a variety of medical and non-medical staff that interact with patients during healthcare visits, and many of these may be responsible for collecting demographic and other health related information. One quarter (26%) identified their roles as nurse/medical assistant, 16% had an office/clinic manager/administrative role, and 13% were social workers (**Appendix F**).

Demographic Data Collection

Sixty respondents (73%) reported that they were currently involved in the collection or use of patient demographic data. This information is collected in multiple formats (multi-select), and most reported collecting this information in the clinic setting through verbal, written, and/or electronic portals (**Appendix G**).

When asked about the usefulness of this information to patient care, most respondents felt that sex and gender (62%), disability status (58%), sexual orientation (48%), and race/ethnicity (47%) were critical to know (**Fig. 16**).

Figure 16: Domain Data Usefulness to Care



Patients' ability to understand why demographic data is being collected is key to their willingness to share. To better understand the ability of providers to communicate the rationale for collecting this information, we asked respondents to share will us how skilled their organization's staff was with collecting and describing the demographic domains. Overall, respondents felt that their organizations were extremely or moderately skilled at communicating and collecting this information (**Fig. 17**).

Figure 17: Communication and Data Collection Skill

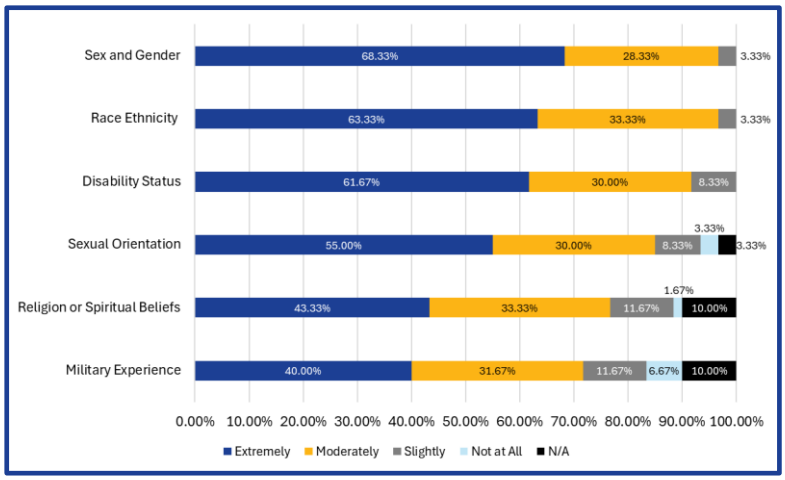
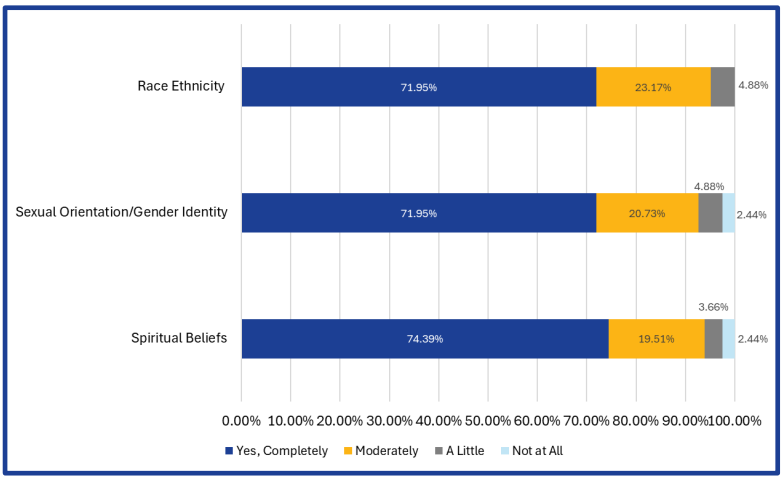


Figure 18: Comfort Level



In addition to whether or not an organization is skilled at communicating and collecting demographic data, staff comfort with directly asking patients about providing what may be sensitive information is also important to know. Respondents reported that they were more comfortable with asking patients about this information than they were skilled at collecting it. All categories were reported as being extremely comfortable (60-72%) except religion or spiritualty (**Fig. 18**).

For those who responded that they were 'slightly' or 'not at all' comfortable with any of the domains, we gave them the opportunity to share with us what would make them more comfortable. Suggestions included education/training, informing patients in advance that this information will be verified at each visit for chart accuracy, understanding how this information will be used to improve patient care and how to incorporate this information gathering into the triage process.

Language Clarity

The closing section of the survey mirrored the patient survey where we asked about language clarity for the introductory scripts for the demographic domains (**Appendix B**). We were especially interested in getting respondents (n = 82) feedback about race and ethnicity, sexual orientation, and gender identity, as well as spiritual beliefs. Instead of asking them to simply respond 'yes or no', we used a 4-point Likert scale (**Fig. 19**).

Figure 19: Language Clarity

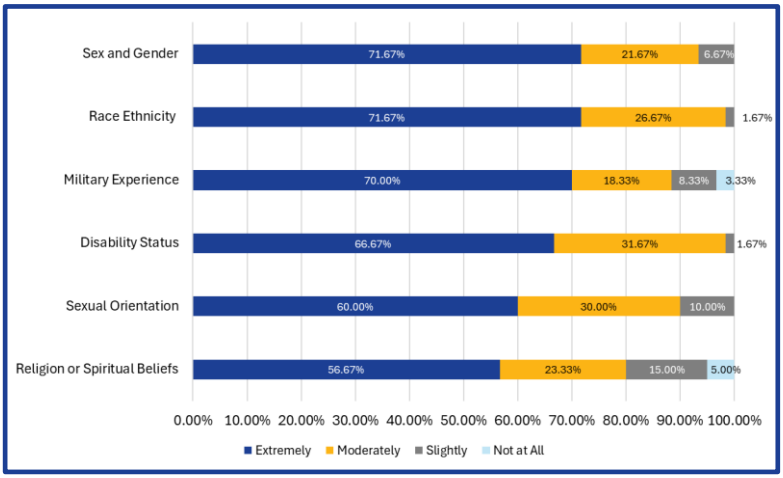
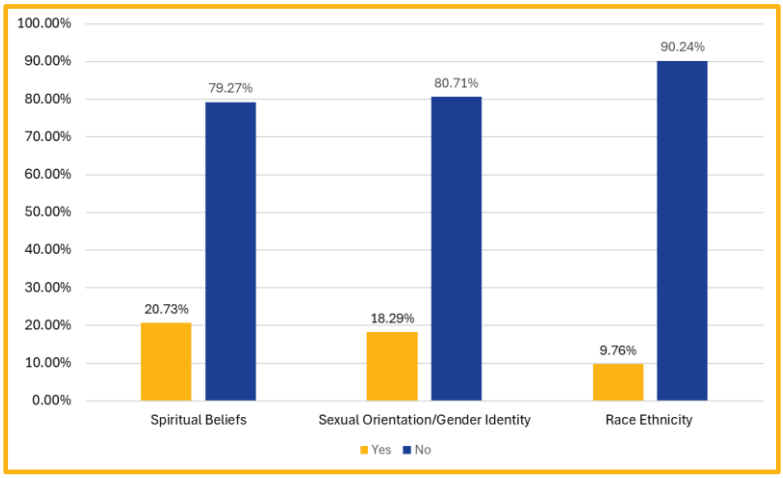


Figure 20: Additional Clarification



In addition to whether or not they found the script language clear, we also asked respondents to share whether or not they thought organization staff would need to provide clarification, additional information, or repeat the script for patients. Respondents overwhelmingly felt that they would not need to provide additional information with at least 70% responding no for each of the shared demographic domains (**Fig. 20**).

Reasons for the need for additional clarity across these three domains included having the ability to share information in different ways/formats, different age groups having separate experiences with some of these domains (e.g. older adults may not have the same exposure to sexual orientation responses), confusion around the meaning of response items, and education on how to address patient questions about the different demographic domains when they arise.

Discussion

Health equity efforts must be data-driven to be successful. Despite significant investments by providers, health plans, and governmental agencies, the demographic data collected today is often insufficient and inadequate. Missing, incomplete, or overly broad demographic data can impact an individual's care and their experience of that care. To provide culturally appropriate

and competent care, it is important that demographic questionnaires provide more inclusive response options.

Data collection by such large programs is not without risks, particularly in a world where vast and seemingly unrelated pieces of individual data are commercially traded. Without transparency and clarity in how demographic information will be used, data collection can generate skepticism or mistrust in systems that are meant to improve health care quality and prevent historical discrimination. These missteps or misuses render demographic data more harmful than helpful and work against the purpose of improving health care access and outcomes across all populations.

Patient Perspective

In general, patients were receptive and supportive in the disclosure and collection of their demographic data. The use of introductory scripts, specifically to clarify the 'what, why, and how' this information will be used at both the individual and populations level, provides a platform for communication and trust between the patient and the provider. We presented 8 demographic domains to respondents and gave them the ability to not only identify themselves first in free text, but then collected feedback on their perspective of collecting information in broad commonly used categories as well as more granular options when appropriate.

When provided with some of these more specific or granular options it was interesting to note that respondents often defaulted to an option that they were more familiar with (e.g., "White" instead of "White or European'). For some of the domains, respondents noted that they would prefer to have a more flexible or fluid response option (sexual orientation) as ridged or static response options did adequately reflect how this identity can change over time.

Focus group conversations explored several topics, but specifically targeted the concept of disability and how it should be captured in regard to providing patients with equitable healthcare experiences. Although respondents identified as 'a person with a disability', the preference was for this information to captured as the specific condition (e.g. hearing, sight, mobility) which would then alert a provider to ensure that the appropriate accommodation would be provided.

Provider Perspective

Monitoring inequalities in healthcare is increasingly being recognized as a key first step in providing equitable access to quality care. However, the detailed demographic data that are necessary for monitoring are currently not routinely collected from patients in a uniform manner. Most of the survey respondents felt that collecting demographic data was useful to informing patient-centered care.

Effective patient-provider communication is also a critical aspect of the delivery of high-quality patient care. When an organization has staff who have the skills to collect this information and feel comfortable conversing with patients about their identity it builds trust in how this information can and will be used for the greater good at not only the individual level but at the larger population and system levels. By establishing demographic data collection as a routine part of the intake or triage experience and using simple, clear, and concise language to describe the domains and response choices, we have the opportunity to normalize and standardize this part of a patient's healthcare experience.

Strengths

There are several strengths to this project. First, the domain development was done by our partner AHIP, and then PAF independently created the cognitive testing survey which helps to mitigate any leading questions or bias in the responses. We also took a mixed methods approach, allowing us to probe beyond the patient survey questions to help fill any gaps in the collected information. Additionally, we created a companion provider survey to better understand their perspectives on the collection, understanding and use of demographic data.

Limitations

There are limitations to the results shared in this report. While the respondents to our survey are representative of the patients served by Patient Advocate Foundation[11], they are not necessarily representative of the larger cohort of chronically ill patients in the United States. Our project was also limited to participants who speak English as a primary language and therefore some of the domains (e.g., race, religion) were limited in the depth and breadth of responses. In addition, most patients who served in some capacity in the military would receive healthcare services at military hospital facilities or through the Veterans Administration (VA), so those response rates were low as well.

We also had a low response rate to the provider survey, and we were limited to providers who had previously engaged with PAF, which limits the generalizability of the data we collected.

Recommendations

Based on input from patients, healthcare organizations collecting demographic data should make sure to identify and share the following:

- **Why the organization collecting demographic data**
  The consensus is that when patients understand the importance of sharing their demographic data they are significantly more likely to share that information. Share your

goals for demographic data collection, such as outlining how the data can be used to plan services and provide actionable recommendations for staff (e.g., identify need for interpreter).

- **Who has access to the patient's demographic data**
  A significant piece of consent and comfort with sharing the data is knowing who will have access to it both internally (e.g., 'your healthcare team') and externally (e.g., 'research') and how you're protecting it. Identifying how data can be used at the individual level to appropriately customize their care experience and that at a population level this data can help to identify trends and gaps in services.
- **Do patients have to respond to all questions**
  We highly recommend that patients have the option of 'prefer not to answer' to any or all of the questions and that their care will not be affected if they do not answer the questions. This respects their right not to participate and makes staff more comfortable about asking.

Demographic data should be collected in an environment where patients and clinic staff feel respected and safe. Moreover, developing the skills that would enable providers to use clear and simple language for these types of conversations and sharing why the information is essential to their care experience.

Conclusion

Demographic data is essential for healthcare institutions to understand the communities that they serve. It enables us to identify and study health programs and monitor trends in population health and can illuminate differences in outcomes, access, enrollment, patient experience, and utilization in programs like Medicaid, CHIP, Medicare, and the Health Insurance Marketplaces. These differences can point to problematic health disparities or bring to light the specific health needs of various populations. However, it is important to collect and store demographic data in a secure manner and to give patients access to their data and the right to have it corrected.

When used effectively, demographic data can help health programs and health systems address historical inequities and provide high-quality, individualized, culturally competent health care.

References

1. The office of the National Coordinator for Health Information Technology. What's the big deal about patient demographic data? Playbook. Accessed December 16, 2024. https://www.healthit.gov/playbook/registrar/chapter-1
2. Centers for Medicare & Medicaid Services. CMS Framework for Health Equity | CMS. Minority Health. December 3, 2024. Accessed December 16, 2024. https://www.cms.gov/priorities/health-equity/minority-health/equity-programs/framework
3. Ensuring Equity Remains a Pillar of Health Care Quality | HMS Postgraduate Education. December 21, 2023. Accessed December 16, 2024. https://postgraduateeducation.hms.harvard.edu/trends-medicine/ensuring-equity-remains-pillar-health-care-quality
4. National Academies of Sciences E, Division H and M, Practice B on PH and PH, et al. The State of Health Disparities in the United States. In: *Communities in Action: Pathways to Health Equity*. National Academies Press (US); 2017. Accessed August 7, 2024. https://www.ncbi.nlm.nih.gov/books/NBK425844/
5. Gender and health. Accessed December 9, 2024. https://www.who.int/news-room/questions-and-answers/item/gender-and-health
6. The Importance of Pronoun Use in Healthcare Settings | Quality Interactions. Accessed December 9, 2024. https://www.qualityinteractions.com/blog/the-importance-of-pronoun-use-in-healthcare-settings
7. Robards J, Evandrou M, Falkingham J, Vlachantoni A. Marital status, health and mortality. *Maturitas*. 2012;73(4):295-299. doi:10.1016/j.maturitas.2012.08.007
8. CDC. Disability and Health Information for Healthcare Providers | CDC. Centers for Disease Control and Prevention. September 15, 2020. Accessed December 16, 2024. https://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html
9. MedlinePlus. Veterans and Military Health. National Library of Medicine. April 16, 2024. Accessed December 16, 2024. https://medlineplus.gov/veteransandmilitaryhealth.html
10. AdventHealth University. Religion and Healthcare: The Importance of Cultural Sensitivity. Blog. December 29, 2020. Accessed December 16, 2024. https://www.ahu.edu/blog/religion-and-healthcare-the-importance-of-cultural-sensitivity
11. Patient Advocate Foundation. 2023 Annual Impact Report. Patient Advocate Foundation. May 2024. Accessed December 16, 2024. https://www.patientadvocate.org/download-view/2023-annual-impact-report/

Appendix A: Patient Survey Demographics

	n	%
Race & Ethnicity		
Asian or Asian American	21	3.40%
Black African American, or African American	160	25.93%
Hispanic or Latino/a/e	50	8.10%
Middle Eastern or North African	5	0.81%
Native American, Alaska Native, or Indian	16	2.59%
Native Hawaiian or Pacific Islander	9	1.46%
White or European	399	64.67%
I don't know	4	0.65%
I choose not to respond at this time	12	1.94%
Sexual Orientation		
Asexual	13	2.11%
Bisexual	26	4.21%
Gay or Lesbian	109	17.67%
Pansexual	13	2.11%
Straight	421	68.23%
Please specify [open text]	14	2.27%
I don't know	4	0.65%
I choose not to respond at this time	17	2.76%
Sex		
Female/Woman	404	65.48%
Intersex	0	0.00%
Male/Man	205	33.23%
I don't know	6	0.97%
I choose not to respond at this time	2	0.32%
Gender		
Female/Woman	395	64.02%
Gender Fluid	3	0.49%
Male/Man	202	32.74%
Non-Binary	3	0.49%
Transgender Female/Trans Woman	0	0.00%
Transgender Male/Trans Man	2	0.32%
Two Spirit	3	0.49%
Please specify [open text]	2	0.32%
I don't know	1	0.16%
I choose not to respond at this time	6	0.97%

	n	%
Pronouns		
He/Him/His	178	28.85%
She/Her/Hers	346	56.08%
They/Them/Theirs	6	0.97%
Ze/Hir/Hirs	0	0.00%
Ze/Zir/Zirs	0	0.00%
Please specify [open text]	10	1.62%
Use my name	75	12.16%
I don't know	1	0.16%
I choose not to respond at this time	9	1.46%
Relationship Status		
Dating	22	3.57%
Divorced	76	12.32%
In a committed relationship with one person	60	9.72%
In a committed relationship with more than one person	5	0.81%
In a registered domestic partnership	9	1.46%
Married	210	34.04%
Separated	14	2.27%
Single	213	34.52%
Widowed	42	6.81%
Please specify [open text]	12	1.94%
I don't know	2	0.32%
I choose not to respond at this time	13	2.11%
Disability Status		
Person with a disability	392	63.53%
Person without a disability	170	27.55%
I don't know	28	4.54%
I choose not to respond at this time	27	4.38%
Military Experience		
September 2001 or later (Post 9/11)	13	32.50%
August 1990 through August 2001 (including the Persian Gulf War)	12	30.00%
June 1975 through July 1990	12	30.00%
August 1964 through May 1975 (including the Vietnam War)	7	17.50%
February 1955 through July 1964	3	7.50%
June 1950 through January 1955 (including the Korean War)	0	0.00%
January 1947 through May 1950	0	0.00%
December 1941 through December 1946 (including World War II)	0	0.00%
November 1941 or earlier	0	0.00%

	n	%
Spiritual Beliefs		
Agnostic	51	8.27%
Ancestral, indigenous, or tribal beliefs	2	0.32%
Atheist	35	5.67%
Baha'I	0	0.00%
Buddhism	5	0.81%
Christianity: Catholic	97	15.72%
Christianity: Protestant	221	35.82%
Church of Scientology	0	0.00%
Hinduism	1	0.16%
Islam, Nation of Islam (Muslim)	4	0.65%
Jehovah's Witnesses	3	0.49%
Judaism (Jewish)	14	2.27%
Mormon (Church of Jesus Christ of Latterday Saints/LDS)	4	0.65%
Orthodox Christian	12	1.94%
Orthodox Judaism	2	0.32%
Pagan or nature-based beliefs	5	0.81%
Philosophical beliefs	3	0.49%
Rastafarianism	0	0.00%
Sikh	1	0.16%
Spiritual but not religious	72	11.67%
Taoism	0	0.00%
Unitarian Universalist	4	0.65%
Zoroastrianism	0	0.00%
Please specify [open text]	44	7.13%
I don't know	7	1.13%
I choose not to respond at this time	30	4.86%

Appendix B: Introductory Language Scripts

Domain	Script
Race & Ethnicity	*The following questions will ask you to identify your race and/or ethnicity. Race is one way our society groups people together. Categories of race have been made up over time. These categories are often based on things we can see, like a person's skin color, but do not indicate real biological differences. Ethnicity is based on how we identify with other people when we share certain experiences or backgrounds with them. This may include things like language, history, religion, or culture.*
Sexual Orientation	*The following questions will ask you to describe your sexual orientation. Sexual orientation means which gender you have an emotional, romantic or sexual attraction to. We recognize that these are personal questions and responses may change over time.*
Sex & Gender	*Sex means the sex you were assigned at birth by a doctor or midwife, based on external body parts. Gender is one's own sense of self and their gender, whether that is man, woman, neither or both. Your gender may differ from your sex assigned at birth. We recognize that these are personal questions and responses may change over time.*
Pronouns	*Pronouns are how you identify yourself apart from your name and how someone refers to you in conversation. To make sure we are communicating with you respectfully, the following question may be asked in a healthcare setting about the pronouns you use. We recognize that this is a personal question, and responses may change over time.*
Relationship Status	*To make sure we have the information we need to identify potential health insurance eligibility and are considering lifestyle factors that can impact your health, the following question will ask you to identify your relationship status. This can include legal agreements with another person (marriage or a registered partnership) or relationships that are not legally recognized (in a committed relationship or dating). We recognize that this is a personal question, and responses may change over time.*
Disability Status	*The following question will ask if you have difficulty doing certain things or completing certain tasks because of a physical or mental health condition that greatly limits your daily activities.*

Military Experience	The following questions will ask you about your experience, or an immediate family member's experience, serving in the armed forces of the United States. The armed forces of the United States include the Army, Navy, Marine Corps, Air Force, Coast Guard, and Space Force. There is also an optional question on your experience in the armed forces of another country other than the United States. This information would be collected by healthcare providers to identify potential eligibility for U.S. Veteran benefits and referrals, and to ensure you are receiving the treatment and services you need and want.
Spiritual Beliefs	To make sure we are providing you with care that is appropriate and accommodating to your lifestyle and values, the following questions will ask you about any beliefs we should know about before we provide care. These beliefs can include religious, health, cultural or any others you feel are important to your care experience.

Appendix C: Choice Definitions

	Response Option	Definition
Pronouns	He, him, his	someone who might identify as a male
	She, her, hers	someone who might identify as a female
	They, them, theirs	non-binary, for someone who does not identify as either male or female, can be used in singular form
	Ze, hir, hirs	non-binary, often used by people who do not identify as either male nor female
	Ze, zir, zirs	non-binary, often used by people who do not identify as either male nor female
Relationship Status	Dating	in a non-committed relationship with one person or more than one person
	Monogamous Relationship	in a committed relationship with one person but not married
	Polyamorous Relationship	in a committed relationship with more than one person
	Registered Domestic Partnership	legal relationship between two people who live together and share a life together but who are not married and are not blood relatives

	Choice/Choice description	n = 426	%
Disability Status	Hearing	85	19.95%
	Seeing (even when wearing glasses)	96	22.53%
	Concentrating, remembering, or making decisions	168	39.43%
	Walking or climbing stairs	256	60.09%
	Dressing or bathing	69	16.19%
	Cooking for oneself	80	18.77%
	Feeding oneself	17	3.99%
	Using the toilet	23	5.39%
	Doing errands alone such as shopping or visiting a doctor's office	117	27.46%
	Communicating or being understood using your usual language	31	7.27%
	Understanding when someone speaks to you in your usual language	23	5.39%
	Other difficulties when doing activities throughout your day (please describe)	140	32.86%

Appendix D: Healthcare Provider Script

"We understand that many things in life can affect your health. We are always looking to better understand our members' needs to improve the services we can offer. Would you be willing to help us learn more about you? It should only take 5 – 10 minutes. Some of the questions are personal and you don't have to answer them if you don't want to. We protect everything that you share just like how we protect your health information. Only members of the care team and other support service staff will have access to this information. This information will be used to help inform care and services that we provide you, whether now or in the future. It will also help us make sure you're getting the care you want and need. Your decision to answer or to refuse to answer will NOT impact your ability to receive care."

If administered in-person or orally over the phone:

"Do you have any questions before we get started?"

If administered on paper form:

Please let us know if you have any questions or concerns by contacting <insert name/number/email>

Appendix E: Focus Group Demographics

	n	%
Race & Ethnicity		
Asian or Asian American	3	10.00%
Black African American, or African American	9	30.00%
Hispanic or Latino/a/e	3	10.00%
Middle Eastern or North African	1	3.33%
Native American, Alaska Native, or Indian	1	3.33%
Native Hawaiian or Pacific Islander	0	0.00%
White or European	15	50.00%
Sexual Orientation		
Asexual	2	6.67%
Bisexual	1	3.33%
Gay or Lesbian	6	20.00%
Pansexual	2	6.67%
Straight	18	60.00%
Other	1	3.33%
Gender		
Female/Woman	20	66.67%
Gender Fluid	2	6.67%
Male/Man	8	26.67%
Non-Binary	0	0%
Transgender Female/Trans Woman	0	0%
Transgender Male/Trans Man	0	0%
Two Spirit	0	0%
Please specify [open text]	0	0%
Disability Status		
Person with a disability	22	73.33%
Person without a disability	6	20.00%
Choose Not to Response/I don't know	2	6.67%
Pronouns		
He/Him/His	6	20.00%
She/Her/Hers	15	50.00%
They/Them/Theirs	1	3.33%
Ze/Hir/Hirs	0	0%
Ze/Zir/Zirs	0	0%
Please specify [open text]	2	6.67%
Use my name	6	20.00%
I don't know	0	0%
I choose not to respond at this time	0	0%

	n	%
Relationship Status		
Dating	1	3.33%
Divorced	2	6.67%
In a committed relationship with one person	4	13.33%
In a committed relationship with more than one person	3	10.00%
In a registered domestic partnership	0	0%
Married	7	23.33%
Separated	1	3.33%
Single	10	33.33%
Widowed	2	6.67%
Please specify [open text]	3	10.00%
I don't know	0	0%
I choose not to respond at this time	0	0%
Military Experience		
September 2001 or later (Post 9/11)	3	10.00%
August 1990 through August 2001 (including the Persian Gulf War)	1	3.33%
June 1975 through July 1990	0	0%
August 1964 through May 1975 (including the Vietnam War)	0	0%
February 1955 through July 1964	0	0%
June 1950 through January 1955 (including the Korean War)	0	0%
January 1947 through May 1950	0	0%
December 1941 through December 1946 (including World War II)	0	0%
November 1941 or earlier	0	0%

Appendix F: Provider Roles

	n	%
Doctor	4	4.88%
Financial Navigator, Counselor, or other Billing/Coding role	8	9.76%
Nurse or Medical Assistant	21	25.61%
Nurse Case Manager, Practitioner or Physician Assistant	9	10.98%
Patient Care Coordinator/Navigator/Liaison	7	8.54%
Pharmacist	1	1.22%
Pharmacy Technician, Pharmacy Billing Specialist, or other Pharmacy role	1	1.22%
Office/Clinic Manager or another Administrative role	13	15.85%
Social Worker	11	13.41%
Patient Advocate or Coordinator	7	8.54%

Appendix G: Data Collection Methods

	n	%
Online via personal device before/after visit	28	46.67%
In-clinic digitally (tablets, etc.)	20	33.33%
In-clinic verbally (staff asks patient)	44	73.33%
In-clinic written forms (paper)	45	75.00%
Other	1	1.67%