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North American Genetic Counselors' Approach to Collecting and Using Ancestry in Clinical Practice

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North American genetic counselors' approach to collecting and using ancestry in clinical practice

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Abstract

Current guidelines from the National Society of Genetic Counselors (NSGC) recommend that patients' ancestry be obtained when taking a family history. However, no study has explored how consistently genetic counselors obtain or utilize this information. The goals of this study included assessing how genetic counselors collect their patients' ancestry, what factors influence this decision, and how they view the utility of this information. Genetic counselors working in a direct patient care setting in the US or Canada were recruited to participate in an anonymous survey via an NSGC email blast. Most participants ($n = 115$) obtain information about their patients' ancestry (96.5%), with the most common methods being directly asking the patient (91%) and utilizing intake forms (43.2%). Of participants who ask about ancestry directly, 50.5% *always* ask about the presence of Ashkenazi Jewish ancestry and 70.3% *always* ask about additional ancestries, suggesting that for most genetic counselors' collection of ancestry is standard practice. However, the clinical utility of ancestry information is highly variable, with the impact on genetic testing choice being particularly low. A slight majority of participants support a reevaluation of current ancestry guidelines (51.3%), with many participants suggesting that the varying utility of ancestry in different clinical indications/specialties should be incorporated into guidelines. Despite being standard practice for most genetic counselors, no unified approach or standard for how ancestral information should be used in genetic counseling practice was identified.

KEYWORDS
ancestry, cultural competence, diversity, genetic counseling, practice guidelines, utility

1 | INTRODUCTION

Race, ethnicity, and ancestry are the most common diversity measures used in a medical setting. Race reflects a purely social identity dependent on physical differences that are considered distinct by a cultural group. Ethnicity is a cultural identity which can be based on a variety of shared qualities, such as language, ancestry, and beliefs. Ancestry is a genetic concept which describes the origin of an individual's line of descent or country of origin. While used interchangeably in some contexts, each term serves to define a different aspect of human diversity.

Ancestry has been traditionally assessed by genetic counselors based on the varying frequencies of certain genetic conditions between ancestral groups. For example, individuals of Ashkenazi Jewish

or French-Canadian ancestry are more likely to be carriers of Tay Sachs disease, while individuals of Southeast Asian or African ancestry are more likely to be carriers of Alpha-Thalassemia (Petersen et al., 1983; Piel & Weatherall 2014; Sillon et al., 2020). Until 2021, both the American College of Obstetricians and Gynecologists (ACOG) and the American College of Medical Genetics (ACMG) recommendations supported ancestry-based carrier screening, with screening for only two conditions, cystic fibrosis and spinal muscular atrophy, being recommended universally (Gross et al., 2008; Prior, 2008; Rink et al., 2017; Watson et al., 2004). Additionally, in a cancer genetic counseling setting, identifying individuals of Ashkenazi Jewish ancestry is important considering the higher frequency of Hereditary Breast and Ovarian Cancer in this population. Those with Ashkenazi Jewish ancestry are at a 1 in 40 risk of carrying a *BRCA1* or *BRCA2* pathogenic variant, in comparison with a 1 in 300 risk for the general population (Foulkes, 2008). Based on this understanding, a patient's ancestry may impact both genetic/genomic testing choice and risk assessment in a genetic counseling context.

Despite the previously described impact ancestry has on genetic testing choice, there are documented limitations to the use of carrier screening based on self-reported ancestry, and some studies have recommended the use of pan-ethnic carrier screening panels (Kaseniit et al., 2020; Shraga et al., 2017). In 2021, ACMG updated their guidelines to recommend against ethnicity or ancestry-based carrier screening in order to provide more equitable screening for patients of all racial and ethnic groups (Gregg et al., 2021). However, with this recent change in guidelines, and the present discordance between ACOG and ACMG guidelines, it remains unclear how clinical practice will change in response. Genetic counselors use both guidelines in making their clinical practice decisions, thus these conflicting guidelines leave uncertainty in how carrier screening should be implemented.

In addition, ancestry-related limitations exist for individuals of non-European ancestry undergoing genetic testing. When performing multi-gene hereditary cancer testing for individuals who are of Hispanic, African, Asian, or Pacific Islander ancestry, there is a higher rate of variant of unknown significance (VUS) results (Caswell-Jin et al., 2018; Ndugga-Kabuye & Issaka, 2019). When discussing testing limitations with patients of non-European ancestry, it is important to establish the possibility of a VUS result based on this known disparity. Some genetic testing, such as carrier screening, also has lower sensitivity for individuals of non-European ancestry. In this case, individuals of non-European ancestry with negative screening have a higher residual risk than individuals of European ancestry, for which the screening has a higher sensitivity ("Sema4 Residual Risks by Self-Reported Ethnicity," n.d.). For these reasons, it is important for a genetic counselor to have knowledge about a patient's ancestry in order to identify relevant testing limitations and discuss these when a patient is considering large panel testing or carrier screening.

Although having accurate ancestral information is often useful for genetic counselors, self-reported ancestry is known to be inaccurate and unreliable. Self-reported information when collected via different methods, such as written on a requisition form or obtained verbally in a genetic counseling session, has been shown to result in discrepancies (Shraga et al., 2017). Patients appear to answer this question differently depending on the method of information collection. Beyond differences based on collection methods, it is understood that self-reported ancestry does not always accurately capture true genetic ancestry (Kaseniit et al., 2020; Shraga et al., 2017). This may be one underlying factor that influences how genetic counselors consider the utility of ancestral information in their clinical practice. Given the discussed benefits and limitations of using self-reported ancestry in clinical practice, continued research is needed to determine the impact these factors have on clinical decision-making in genetic counseling.

Guidelines from the National Society of Genetic Counselors (NSGC), initially published in 2008, regarding pedigree nomenclature recommend that ancestry should be included, as it is considered relevant for risk assessment (Bennett et al., 2008). In 2022, an updated guideline on pedigree nomenclature was published, stating that ancestry should be collected when clinically relevant, although no description of clinical relevance was included (Bennett et al., 2022). Of note, this revision was published after completion of the current study. The NSGC guideline for clinical documentation recommends including ethnicity in the family history summary, particularly if it is relevant to risk assessment and/or genetic testing interpretation (Hunt Brendish et al., 2021). In addition, organizations such as the National Comprehensive Cancer Network (NCCN) similarly consider ancestry to be an important part of taking a family history, and their guidelines take into consideration the presence of Ashkenazi Jewish ancestry ("NCCN Genetic/Familial High-Risk Guidelines for Breast, Ovarian, and Pancreatic," 2020). Since NCCN guidelines are often used to determine insurance coverage, a patient's ancestry may impact whether their genetic testing is covered by insurance. Of note, there are discrepancies in the diversity measure that these guidelines recommend using,

What is known about this topic

The relationship between genetics, race, and ancestry is complex. Previous studies have shown that genetic professionals have an inconsistent understanding of this relationship, but little is known about how genetic counselors approach this in their clinical practice.

What this paper adds to the topic

This study demonstrates that although an assessment of patients' ancestry is standard practice for genetic counselors, there is a high level of variability in the way this information is assessed and utilized. As support for a reevaluation of ancestry guidelines is high, this is an opportunity for the genetic counseling profession to reconsider whether ancestry collection should remain a part of standard clinical practice across the profession.

as some recommend "ethnicity" and others recommend "ancestry." This may result in confusion regarding what measure should be used in clinical genetics practice.

The genetic counseling profession is primarily composed of white women, with 89% of respondents to the NSGC 2022 Professional Status Survey identifying as White ("NSGC Professional Status Survey," 2022). With 89% of genetic counselors being white, there exists a high rate of racial discordance between genetic counselors and the patients they care for. Unlike other medical professionals for which racial discordance is observed, genetic counselors directly discuss ancestry with their patients during their visit. Therefore, it is especially important to understand how ancestry is currently being addressed in sessions. While we understand that visual racial discordance has been shown to have negative effects on patient experiences, it is not understood how verbally discussing that discordance in the form of ancestral information may further impact patient experiences.

In addition to the potential inaccuracies of ancestral information and the impact of racial discordance, concepts regarding cultural competency are pertinent to the discussion. Based on the high level of cultural diversity present within the U.S. population, cultural competency education has been integrated into many healthcare profession training programs in order to improve care and patient experiences. Studies have found that these cultural competency training programs are effective in improving patient satisfaction among minority groups (Govere & Govere, 2016). Cultural competency training has been integrated into the genetic counseling profession and is required to be included in genetic counseling training programs (Accreditation Council for Genetic Counseling, 2019). The focus of this training, as defined by the Accreditation Council for Genetic Counseling (ACGC), is on recognizing and responding to cultural differences in genetic counseling practice. It remains unclear whether discussions on the use of ancestry in clinical practice would be included in this training. The question remains whether cultural competency training, integrated into further education or training programs, has any impact on how genetic counselors communicate with their patients and how they view concepts of race and ancestry in relation to genetic counseling.

As our understanding of how genetics relates to health has developed, the question of how genetics relates to race and ancestry has become more complicated. In both genetic research and clinical practice, there have been debates about the significance of race, ethnicity, and ancestry in this field, and how they should be used. Particularly in the clinical setting, it is critical to consider how race impacts health through social mechanisms which are independent of genetic factors. An understanding of race has developed which considers the construct to have a social component as well as an association with genetic ancestry (Borrell et al., 2021; Oni-Orisan et al., 2021). Our understanding of how genetic professionals view the use of these constructs in their clinical practice is still developing, though one study identified that in a clinical setting the use of race as a proxy for ancestry is more accepted than in a research setting (Nelson et al., 2018). Another recent study identified that genetics professionals have an inconsistent understanding of the constructs of race, ethnicity, and ancestry, as well as how they should be used in clinical practice (Popejoy et al., 2020). These findings suggest the need for standardization of race, ethnicity, and ancestry data collection. The current study builds on this knowledge base, working to understand the current use of ancestral information in genetic counseling practice.

1.1 | Study purpose

The goals of this study included determining how genetic counselors are obtaining information about their patients' ancestry, understanding how consistently this information is obtained, and identifying what factors influence genetic counselors' decision to ask about ancestry. In addition, we aimed to determine how genetic counselors view the utility of ancestral information in their clinical practice and to assess their support for a reevaluation of ancestry guidelines.

2 | METHODS

2.1 | Participants

Two emails were distributed to members of the National Society of Genetic Counselors inviting them to participate in an anonymous, voluntary online survey. The second email was sent 2 weeks after the initial notice, and the survey was open to participants for a total of 5 weeks from October 2020 to November 2020. Genetic counselors who work in direct patient care were eligible to participate in the study. The study was approved as exempt by the Case Western Reserve University Institutional Review Board.

2.2 | Instrumentation

The survey was conducted through REDCap software and consisted of five sections. The survey was piloted by three genetic counselors prior to distribution to confirm the clarity of survey questions and appropriate skip logic. Section 1 addressed demographic questions such as participant age, gender, race, ethnicity, length of practice in the field of genetic counseling, specialty, and diversity of patient population. Section 2 addressed how participants obtain information about their patients' ancestry, including what information sources are used, the frequency with which they ask about patients' ancestry (never, rarely, sometimes, often, always), the language participants use when asking about patients' ancestry, and factors which influence participants' decision to ask or not ask about ancestry. Section 3 addressed how participants view the utility of ancestral information and contained a total of eight questions. Four of the questions in this section assessed participants' agreement with statements

pertaining to the importance of ancestral information for genetic/genomic testing choice, genetic/genomic testing limitations, risk assessment, and variant interpretation. Agreement level was indicated using a 5-point Likert scale from strongly disagree (1) to strongly agree (5). The other four questions in this section asked participants to report the frequency with which ancestral information impacts their genetic/genomic testing choice, the genetic/genomic testing limitations discussed with the patient, risk assessment, and variant interpretation. Additionally, section 4 addressed participants' level of cultural competency training, which was assessed via a series of three yes/no questions. This section also assessed whether participants desired additional cultural competency training, whether they received cultural competency training which impacted how they assess ancestry, and their perceived sufficiency of cultural competency training which was received from their genetic counseling training program. Lastly, section 5 addressed participants' opinions on whether current guidelines regarding ancestral information should be re-evaluated, including participant's thoughts on what specifically should be addressed or discussed when considering a reevaluation of guidelines. Participants were provided with definitions of the terms race, ethnicity, and ancestry while taking the survey. The survey is available for review as a supplemental file S1.

2.3 | Data analysis

Descriptive statistics were calculated for responses to all survey questions. Relationships between survey constructs were calculated using linear regression, *t*-test, and ANOVA analyses. For ANOVA analyses comparing between genetic counseling specialties (prenatal, cancer, and general), participants who reported practicing in more than one specialty were removed from the analysis ($n = 13$). Results with $p < 0.05$ were considered statistically significant. Responses to three questions regarding cultural competency training were combined to make a total cultural competency training level for each participant. Participants received one point each if they received cultural competency training in their graduate program, if they received training in continuing education programs and if any of their training addressed working with patients of different racial backgrounds. Total scores ranged from 0–3, with an average score of 2.5. Responses to open-ended questions were reviewed by the research team and coded for common themes. A subset of open-ended responses which were representative of identified themes is available for review as a supplemental file S2.

3 | RESULTS

3.1 | Demographics

A total of 122 surveys were submitted, of which 115 were complete. The seven incomplete responses were removed from analysis. Participants were predominantly white women between 21–30 years of age. Most participants had less than 5 years of experience practicing as a genetic counselor. Demographic information is provided in Table 1.

TABLE 1 Demographic information of study participants

Characteristic	Descriptor	*n (%)*
Gender ($n = 114$)	Male	2 (1.8%)
	Female	111 (97.4%)
	Non-binary	1 (0.9%)
Race and Ethnicity ($n = 115$)[a]	East/Southeast Asian	6 (5.2%)
	South Asian	4 (3.5%)
	Middle Eastern/North African/West African	2 (1.7%)
	Black/African American	1 (0.9%)
	White	103 (89.6%)
	Hispanic/Latinx	3 (2.6%)
	Ashkenazi Jewish	1 (0.9%)
Practice Length ($n = 115$)	<1 year	27 (23.5)
	1–4 years	50 (43.5%)
	5–9 years	15 (13%)
	10–14 years	9 (7.8%)
	15–20 years	5 (4.3%)
	21–25 years	4 (3.5%)
	25+ years	5 (4.3%)
Age ($n = 115$)	21–30 years	70 (60.9%)
	31–40 years	30 (26.1%)
	41–50 years	10 (8.7%)
	51–60 years	2 (1.7%)
	>60 years	3 (2.6%)
Specialty[b] ($n = 115$)	Prenatal/Preconception	32 (27.8%)
	Cancer	51 (44.3%)
	General[c]	47 (40.9%)
% of patients with at least 50% non-European ancestry ($n = 113$)	0%–20%	29 (25.7%)
	21%–40%	42 (37.2%)
	41%–60%	24 (21.2%)
	61%–80%	11 (9.7%)
	81%–100%	7 (6.2%)

[a]Participants selected all options that fit their racial/ethnicity identity.
[b]Participants selected all specialties that they practice in.
[c]Including subspecialties such as neurology, cardiology, and ophthalmology.

3.2 | Current practices related to collecting ancestry and other diversity measures

A majority of participants, 96.5%, reported that they obtain information about their patients' ancestry ($N = 115$), with only four participants reporting that they do not obtain any information about

their patients' ancestry. Most participants who obtained information about their patients' ancestry (N = 111) asked their patients directly (91%), with other sources of information including intake forms (43.2%) and from other clinical team members (8.1%). Of these participants (N = 111), 53.2% *only* obtain this information by asking directly, while 32.4% obtained ancestral information by asking directly *and* from intake forms. In addition, of the 101 participants who ask directly about their patients' ancestry, most (50.5%) always asked about Ashkenazi Jewish ancestry, and an even larger majority (70.3%) always asked about the presence of other ancestries beyond Ashkenazi Jewish ancestry (Table 2). However, only 16.2% of participants (N = 111) reported that they have guidelines or standardized questions which are used by their office or practice to help obtain this information.

Most participants (75.2%, N = 101) reported using the same language when asking their white and non-white patients about their ancestry, while 24.8% of participants changed the language they used when discussing this question with non-white patients. Table S1 provides a summary of what language participants used when asking about ancestry. Only 45.5% (N = 101) of participants reported that the manner in which they ask about ancestry is sensitive/appropriate for patients of a racial minority, with 31.7% reporting that the way they ask is *somewhat* sensitive/appropriate and 21.8% of participants being unsure.

Participant-free response comments suggested a lack of consensus on what diversity measure should be used in clinical practice, as both ancestry and ethnicity were discussed frequently. Although the use of ethnicity was not specifically addressed in this survey one participant noted that "it [cultural competency training] has changed the wording I have used in asking this question, including expanding it more to ethnicity rather than just ancestry," while another participant described, "I think, years ago, I used to say 'ethnicity or ethnic background' before I [understood] that ethnicity is more of a social construct." There appears to be a lack of consensus on the understanding of these terms and how they influence clinical practice. Some participants appear to be aware of the inconsistent understanding of these constructs: one recommended that additional training should focus on "the differences between race, ethnicity, and ancestry."

3.3 | Factors which influence genetic counselors' approach to assessing ancestry

Participants also considered eight factors which may influence their choice to ask about their patients' ancestry. These eight factors were: considering ancestry as part of taking a complete family history, ancestral information being needed for clinical decision making, recommendation of current guidelines, concern for the inaccuracy of self-reported ancestry, viewing ancestry as an inadequate measure of genetic variation, concern for patient stress or anxiety, concern for lost rapport, and viewing patients' ancestry as not important for their care. A multiple linear regression was performed to determine how these eight factors explained how often participants obtain ancestry. These eight factors explained 31% of the variance in the dependent variable, how often participants obtained ancestry. Three factors drove the model and significantly predicted how often genetic counselors ask about ancestry. These three factors were: considering ancestry as part of taking a complete family history, viewing patients' ancestry as not important for their care, and viewing ancestry as an inadequate measure of genetic variation ($F(3, 97) = 29.5$, $p < 0.001$). Many participants reported in open responses to this question that institutional precedent or clinical group expectations influence their decision to ask about ancestry. One participant described, "I only ask because it is required by my institution. If I did not have to ask about ancestry, I would likely only ask about Ashkenazi Jewish ancestry." Another factor which influences this decision is the need to input ancestral information on test requisition forms when ordering genetic testing for patients. A participant discussed this along with a consideration that this information may expand the presence of minority populations in research:

> "The laboratories I use ask about this information on their TRFs - it impacts for example if a risk score is calculated. In addition, my hope is that including this information can help expand research that includes minority populations."

A majority of participants (83.1%) reported that their patient's racial identity had no impact on whether they ask about ancestry. However, 5.9% of participants reported that they are *more* likely to

TABLE 2 The frequency with which genetic counselors collect patient ancestry (N = 101)

	Frequency	*n* (%)
How often do you ask patients about the presence of Ashkenazi Jewish ancestry?	Never	1 (1%)
	Rarely	7 (6.9%)
	Sometimes	18 (17.8%)
	Often	24 (23.8%)
	Always	51 (50.5%)
How often do you ask patients about their ancestry (beyond asking about Ashkenazi Jewish ancestry)?	Never	0 (0%)
	Rarely	2 (2%)
	Sometimes	9 (8.9%)
	Often	19 (18.8%)
	Always	71 (70.3%)

ask a patient's ancestry if they are a racial minority, while 5% of participants reported that they are *less* likely to ask in this situation. Most participants (74.2%) reported that racial discordance does not influence the way they ask their patients about ancestry, with 15.8% of participants reporting that racial discordance influences or somewhat influences the way they ask about ancestry. A simple regression showed that participants with a higher percentage of patients with non-European ancestry were more likely to report that racial discordance impacts how they ask about ancestry ($R^2 = 0.043$, $F(1, 113) = 3.98$, $p = 0.049$).

Although most participants report that race does not influence how frequently they ask about ancestry or what language they use, some participants described why their approach varies, particularly when working with Black patients:

> "Especially with my African American patients, I may be more hesitant to use the phrase 'which countries are your ancestors from' as there is a loss of this knowledge in many cases due to slavery. I may ask 'what do you consider your ancestry or ethnicity' instead."

This is consistent with our finding that 24.8% of participants reported changing the way they ask about ancestry for their non-white patients. As can be seen in Supplemental Figure 1, there is less consensus on how to address ancestry with non-white patients.

Some participants described discomfort or concern for damaged rapport when addressing ancestry with non-white patients:

> "For those with African American descent, I find it difficult sometimes to ask what their ancestry is; sometimes they don't know it, and I also don't want to state the obvious or not be culturally insensitive [*sic*] about it by saying, 'You identify as African American, correct?'"

Genetic counselors appear to be aware of the need to be sensitive when addressing ancestry in sessions, but are not confident that patients perceive this discussion as such:

> "I may think that I am being sensitive as I ask the same questions regardless of their racial background, but patient may perceive it as insensitive. I tend to think more when I ask patients of different racial backgrounds about their ancestry."

Only 32.2% of participants reported that they have received cultural competency training which has impacted or changed the way they ask their patients' ancestry. Not surprisingly, participants who had a higher cultural competency training level were more likely to report that they received cultural competency training which influenced how they ask about ancestry ($R^2 = 0.066$, $F(1, 113) = 7.99$, $p = 0.006$). However, no statistically significant association was identified between participants' level of cultural competency training and their belief that their method of assessing ancestry is appropriate/sensitive for their patients of racial minorities. Additionally, no association was identified between participants' cultural competency training level and how frequently they reported obtaining ancestral information from their patients. A majority of participants, 76.5%, reported that they desire additional cultural competency training.

No statistical significance was found based on clinical specialty (prenatal, cancer, or general) regarding how often genetic counselors ask about ancestry (beyond Ashkenazi Jewish). A one-way ANOVA revealed that there was a statistically significant difference in how often genetic counselors in different clinical specialties ask about Ashkenazi Jewish ancestry ($F(2, 91) = 29.03$, $p < 0.001$). Tukey's HSD test for multiple comparisons found that the cancer counselors ask about Ashkenazi Jewish ancestry significantly more often than prenatal counselors ($p = 0.012$), and prenatal counselors ask significantly more often than general counselors ($p = 0.004$). This is consistent with free response statements in which cancer genetic counselors described that Ashkenazi Jewish ancestry has the largest impact on counseling, and that identification of other ancestries has relatively minimal impact: "In my practice (cancer), I don't see a reason to ask beyond Ashkenazi Jewish."

3.4 | Current view on the utility of ancestral information

A summary of how participants viewed the *importance* of ancestral information for genetic/genomic test selection, genetic/genomic testing limitations, risk assessment, and variant interpretation as well as how that information impacts clinical decision-making is available in Table 3. A repeated measures ANOVA was performed to compare the *importance* of ancestry across these aspects of clinical practice ($F(3, 114) = 33.162$, $p < 0.001$). Participants reported the highest level of agreement regarding the importance of ancestral information in understanding genetic/genomic testing limitations, while they reported a significantly lower level of agreement in the other three areas, being risk assessment, variant interpretation, and genetic testing choice ($p = 0.004$, $p < 0.001$, $p < 0.001$, respectively). There was no statistical difference between the level of agreement regarding the importance of ancestral information for risk assessment and variant interpretation, though these had a significantly higher level of agreement than was reported regarding the importance of ancestral information for genetic/genomic test selection ($p < 0.001$ and $p < 0.001$, respectively). A summary of how frequently participants report ancestral information to *impact* genetic/genomic test selection, genetic/genomic testing limitations, risk assessment, and variant interpretation is available in Table 3. A repeated measures ANOVA was performed to compare the *impact* of ancestry across these aspects of clinical practice ($F(3, 114) = 9.15$, $p = <0.001$). Participants reported that ancestral information impacts testing choice significantly less often than it impacts testing limitations ($p = 0.005$) or risk assessment ($p < 0.001$). In addition,

TABLE 3 Genetic counselors' view regarding the utility of ancestral information in clinical practice ($N = 115$)

Importance of knowing ancestry	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
It is important to know a patient's ancestry when selecting genetic/genomic testing.	6 (5.2%)	33 (28.7%)	30 (26.1%)	41 (35.7%)	5 (4.3%)
It is important to know a patient's ancestry when considering *genetic/genomic testing limitations*.	1 (0.9%)	7 (6.1%)	11 (9.6%)	71 (62.6%)	24 (20.9%)
It is important to know a patient's ancestry when performing a *risk assessment*.	1 (0.9%)	8 (7%)	32 (27.8%)	60 (52.2%)	14 (12.2%)
It is important to know a patient's ancestry for *variant interpretation*.	2 (1.7%)	10 (8.7%)	36 (31.3%)	55 (47.8%)	12 (10.4%)
Impact of ancestry on counseling	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
How often does a patient's ancestry directly impact the *genetic/genomic testing* you offer the patient?	15 (13%)	49 (42.6%)	40 (34.8%)	9 (7.8%)	2 (1.7%)
How often does a patient's ancestry directly impact the *genetic/genomic testing limitations* you discuss with the patient?	6 (5.2%)	35 (30.4%)	57 (49.6%)	15 (13%)	2 (1.7%)
How often does a patient's ancestry directly impact your *risk assessment?*	5 (4.3%)	32 (27.8%)	52 (45.2%)	23 (20%)	3 (2.6%)
How often does a patient's ancestry directly impact your *variant interpretation?*	12 (10.4%)	36 (31.3%)	51 (44.3%)	16 (13.9%)	0 (0%)

ancestral information impacts risk assessment more often than it impacts variant interpretation ($p = 0.022$).

A one-way ANOVA revealed that there was a statistically significant difference in level of agreement regarding the importance of ancestry in variant interpretation based on clinical specialty ($F(2, 99) = 5.12$, $p = 0.008$). Prenatal counselors report a lower level of agreement regarding the importance of ancestry in variant interpretation than cancer ($p = 0.035$) and general ($p = 0.007$) counselors. There were no significant differences based on clinical specialty regarding the reported importance of ancestry for genetic testing choice, genetic testing limitations, risk assessment. A one-way ANOVA revealed that there was a statistically significant difference in level of agreement regarding the impact of ancestry on genetic testing choice based on clinical specialty ($F(2, 99) = 7.07$, $p = 0.001$). Prenatal counselors report that ancestry has a higher impact on genetic testing choice than cancer ($p = 0.007$) and general ($p = 0.002$) counselors. There were no significant differences based on clinical specialty regarding the reported impact ancestry has on genetic testing limitations, risk assessment, and variant interpretation. These data can be view in Figure 1.

Study participants also highlighted the utility of diversity measures in research settings, where this information will be critical in reducing ancestry-based testing limitations:

> "I will be honest that when I hear GCs discuss this it is often white GCs who are uncomfortable with the topic as they address non-white patients. I don't think it should be about our profession's discomfort with its whiteness. We should be able to get over whatever feeds that discomfort. As a Latina GC my ethnicity is integral to who I am and my family's story to ignore and not acknowledge it is to ignore my family's immigrant story, their triumphs and challenges. Additionally, we can't ignore the fact that variant rates are higher for racial/ethnic minority groups, that some tests are not optimized for non-white patients or may not even be available (i.e. PRS scores in cancer). I am proud that our clinics are diverse and I want my patients represented in clinical research so that we can get better at addressing certain aspects of our testing and assessments that are limited for non-white patients."

The utility of diversity measures in genetic counseling practice is more nuanced than the direct impact it has on counseling and testing for each individual patient.

3.5 | Current view on a reevaluation of ancestry guidelines/practices

Just over half of participants (51.3%) supported a reevaluation of current practices and policies regarding obtaining ancestral

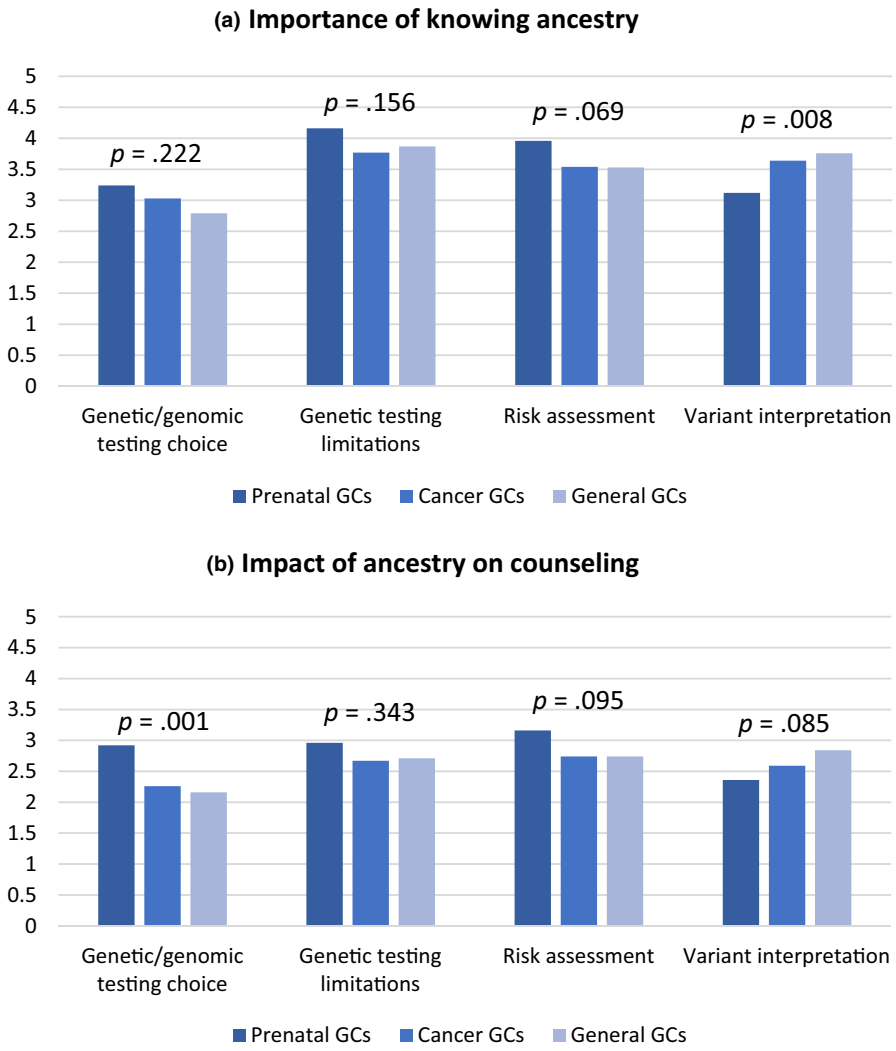

FIGURE 1 Impact of clinical specialty on genetic counselors' view regarding the utility of ancestral information. Bars represent the averaged response to each question for prenatal GCs ($n = 25$), cancer GCs ($n = 39$), and general GCs ($n = 38$). Chart a displays responses regarding the *importance* of ancestral information. These responses were on a 5-point scale with a higher number corresponding with a higher level of agreement. Chart b displays responses regarding the *impact* of ancestral information on counseling. These responses were on a 5-point scale with a higher number indicating a greater frequency in which ancestry impacts their decision. *p* values displayed above the bars represent the result of a one-way ANOVA comparing the response to each question across all three groups

information ($N = 115$). Participants who ask about patients' ancestry less often were more likely to support a reevaluation ($t(103) = -3.91$, $p < 0.001$). Participants who reported a lower level of agreement regarding the importance of ancestral information in genetic/genomic testing choice ($t(113) = -5.59$, $p < 0.001$), risk assessment ($t(113) = -5.08$, $p < 0.001$), and variant interpretation ($t(113) = -2.29$, $p = 0.024$) were more likely to support a reevaluation, while there was not a significant difference based on the important of genetic/genomic testing limitations. Similarly, participants who reported that ancestral information impacts their genetic/genomic testing choice ($t(113) = -3.354$, $p < 0.001$), risk assessment ($t(113) = -4.78$, $p < 0.001$), and variant interpretation ($t(113) = -2.321$, $p = 0.022$) less often were more likely to support a reevaluation, while there was not a significant difference based on the impact on genetic/genomic testing limitations. Moreover, there was no significant difference between genetic counselors in different specialties regarding their support for a reevaluation of guidelines.

Multiple independent t-tests were performed to determine how multiple factors explained genetic counselors' support for a reevaluation of ancestry guidelines. Participants who supported a reevaluation were less likely to consider ancestry to be part of taking a complete family history ($t(99) = -3.78$, $p < 0.001$) and more likely to consider a patient's ancestry as not important for their care ($t(103) = 6.36$, $p < 0.001$), have concern for lost rapport when asking about ancestry ($t(103) = 2.37$, $p = 0.02$), have concern for patient stress/anxiety when asking about ancestry ($t(103) = 4.11$, $p < 0.001$), view ancestry as an inadequate measure of genetic variation between populations ($t(103) = 5.31$, $p < 0.001$) and have concern for the inaccuracy of self-reported ancestry ($t(103) = 4.46$, $p < 0.001$). These data can be viewed in Figure 2.

This study's data shows that a significant number of genetic counselors desire a reevaluation of guidelines regarding the use of ancestral information in clinical practice. Genetic counselors desire additional information and guidance regarding how and when this information should be obtained, as well as how it should be used in their practice. This desire was clear in participant-free responses, including:

> "The reasons why we are asking about ancestry to have a better breakdown of when it is helpful versus not. We ask our students to think about why they ask a question during an intake with a patient to make

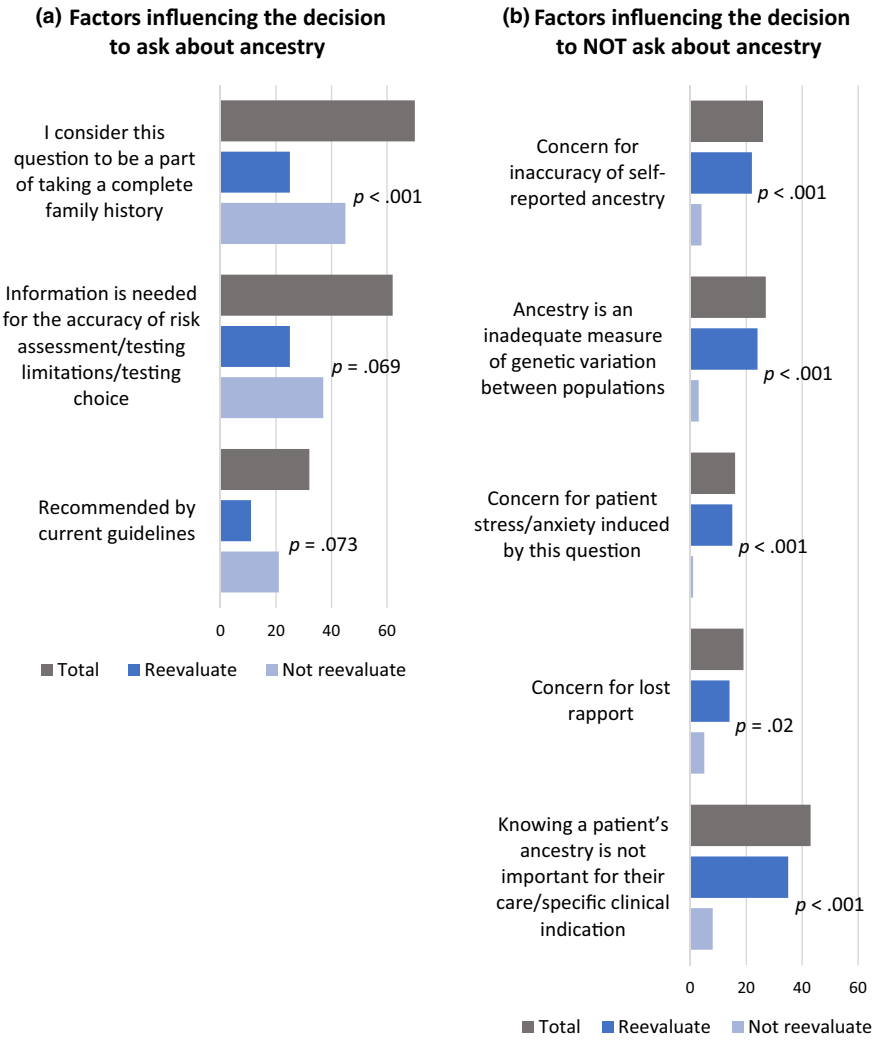

FIGURE 2 Factors influencing genetic counselors' decision to ask about ancestry and the impact these factors had on desire for a reevaluation. Bars represent the number of respondents who indicated who indicated that this factor influences their decision to ask or not ask about ancestry. Gray bars represent the total number of respondents influenced by the factor (both those in support of reevaluation and not), with dark blue bars being the number of respondents who supported a reevaluation influenced by the factor, and the light blue bars being the number of respondents who did not support a reevaluation influenced by the factor. *p* values represent differences between the group in support of a reevaluation and the group not in support of a reevaluation in how they responded to these two questions. The factors included in (a) and (b) were asked in two separate questions. (a) $N = 101$ (b) $N = 105$

> sure they know how to use the information and to make sure the information is useful. I'm not sure we can hold the ancestry questions to that standard universally at this point."

Participants in this study also noted desire to understand the patient perspective on this topic when describing additional training which may be beneficial in this area: "How useful does the patient perceive these questions? How would they like to be asked?"

Participants also recognized the lack of clarity between race, ethnicity, and ancestry in the context of genetic counseling practice, and recognized this as a way that guidelines can be modified in order to improve the use of these concepts in our practice:

> "Clear distinguishing between race, ethnicity, and ancestry. Guidance on how to interpret the use of race/ethnicity/ancestry in genetics similar to what ASHG [American Society of Human Genetics] has done in their position statements."

In 2018, ASHG issued a statement rejecting the correlation between genetics and race by describing how studies of genetic variation cannot draw distinct lines between racial groups. This statement suggested that constructs such as genetic ancestry are more accurate ways to describe an individual's origins than race (The American Society of Human Genetics, 2018).

4 | DISCUSSION

4.1 | Use of race, ethnicity, and ancestry in genetic counseling practice

Previous studies have shown that genetic professionals have an inconsistent understanding of race, ethnicity, and ancestry (Popejoy et al., 2020). The approach to using these constructs in clinical practice is similarly discrepant. Participant-free responses commonly discussed both ethnicity and ancestry. There appears to be a lack of consensus on the type of diversity information that genetic counselors should utilize, which further complicates the approach to using this information to make clinical decisions.

Despite these inconsistencies, 70.3% of participants who obtain ancestry information directly from their patients *always* ask this question. This reflects that for a large percentage of genetic

counselors, obtaining information about their patients' ancestry is standard practice. Knowing that this is standard practice for many genetic counselors underscores the need for a standardization of ancestral information collection and use in clinical genetics, as suggested by Popejoy et al. (2020).

In addition to understanding how genetic counselors view race, ethnicity, and ancestry in their clinical practice, this study provides insight into how genetic counselors view the interaction and relationship between these constructs. Ancestry can be considered privileged information, as many Black Americans have lost details about their heritage due to the long history of slavery in the United States. This reflects a case in which genetic counselors need to approach ancestry collection with additional sensitivity. Many participants described using the terms "race" or "ethnicity" with their Black patients possibly because these constructs are more easily self-reported than ancestry for this population. Previous studies have suggested that race is used as a proxy for ancestry when ancestry is not available in a clinical setting (Nelson et al., 2018). Though race is an imperfect measure of genetic variation and involves more social components, the use of race as a proxy for ancestry may be most appropriate in these situations where ancestral information has been systematically erased.

Clearly, genetic counselors are attempting to address diversity measures in sensitive and appropriate ways with their patients; however, many are uncertain whether this is being achieved successfully. This underscores the need to consider how diverse patient populations interpret and respond to these questions.

The field of genetics carries explicit connections to racist ideologies. In light of this history and ongoing racial health disparities, it is critical to determine how to use race, ethnicity, and ancestry within our field in an equitable and ethical way. Guidelines for how race, ethnicity, and ancestry should be used in a research setting recommend against the use of race as a proxy for ancestry and recommend against the use of continental ancestry, such as Asian or African ancestry (Brothers, Bennett, & Cho, 2021). Although self-reported race and ethnicity are recommended, Brothers suggested that ancestry should be determined via ancestry informative genetic markers rather than self-report (Brothers, Cho, & Hercher, 2021). This discussion focuses around the use of these constructs in genetic research; however, it leaves questions for how we move forward on the clinical side, as genetic ancestry is not typically calculated in this setting. These recommendations raise further questions regarding the utility of self-reported ancestry in clinical practice.

4.2 | The utility of ancestral information in genetic counseling practice

Relatively few participants reported that ancestry has a high impact on their clinical decision-making. Only 9.6% of participants report that a patient's ancestry often or always influences the genetic/genomic testing choice, while 55.7% report that it never or rarely impacts this decision. This relationship is true for all other assessed areas of clinical utility with fewer participants describing the impact as often or always than never or rarely: 14.7% versus 35.7% for testing limitations, 22.6% versus 32.1% for risk assessment, and 13.9% versus 41.7% for variant interpretation. However, the most common response regarding the impact of ancestry on testing limitations, risk assessment, and variant interpretation was "sometimes." These data demonstrate that there is high variability regarding the utility of ancestral information in genetic counseling practice, with the impact of ancestry on genetic/genomic testing choice being the most notably low.

Of the four contexts assessing the utility of ancestral information, genetic/genomic testing choice was the clear outlier. There was a lack of consensus on whether ancestry is important for testing choice, with 40% of participants agreeing or strongly agreeing and 33.9% of participants disagreeing or strongly disagreeing. However, 55.7% of participants reported that ancestry never or rarely impacts genetic/genomic testing choice. This may be reflective of the fact that there are often not alternative testing choices available for patients of non-European ancestry, despite the current limitations regarding the utility of genetic testing for these populations. With the expanded availability of multigene panel testing options, single-site testing for founder variants is less frequently performed. Although ancestral information remains relevant for other areas of genetic counseling, its utility has decreased in the context of genetic/genomic testing choice.

In addition, this study identified that ancestral information has varying utility between genetic counseling specialties. Ancestral information appears to have the highest level of clinical utility in a prenatal genetic counseling setting. Although prenatal genetic counselors reported that ancestry impacts their genetic/genomic testing choice more often, they also reported that ancestry has a lower importance for variant interpretation. Many of these differences in utility are likely reflective of the fact that prenatal genetic counselors are more frequently ordering ancestry-based carrier screening, as current guidelines recommend this practice (ACMG, ACOG). Although ACMG has recently revised their carrier screening guideline to include the recommendation against ancestry-based carrier screening, this was published after the completion of the current study. In addition, prenatal genetic counselors may interact with variants of uncertain significance (VUS) less often than genetic counselors in other specialties, as VUS are not reported on carrier screening results.

In a cancer genetic counseling setting, participants reported that ancestries outside of Ashkenazi Jewish ancestry have minimal impact on clinical recommendations and counseling. Consistent with this, cancer genetic counselors reported asking about Ashkenazi Jewish ancestry more often than genetic counselors in other settings. The impact Ashkenazi Jewish ancestry has on cancer genetic counseling is likely related to the founder variants in this population and insurance coverage criteria for cancer genetic testing. If genetic counselors identify that asking about the presence of specific ancestries is more beneficial than asking generally, guidelines could be modified to reflect this. A small number of genetic counselors in this study report already practicing in this manner (Table S1).

Specialty-specific recommendations could be beneficial given these findings which reflect differences in the use of ancestry in both cancer and prenatal genetic counseling.

Despite the inaccuracies that can arise from the use of self-reported ancestry or ethnicity when assuming those correlate with genetic variation (Kaseniit et al., 2020; Shraga et al., 2017), acknowledging diversity in our patient populations can be beneficial for other reasons. One particular concern which was raised in this study was whether not collecting ancestry universally will make it challenging to track the increasing ancestral diversity of genetic databases. Recognizing and documenting the diversity of our patients may help track and identify improvements in current genetic testing limitations. Ancestry and ethnicity measures have use outside of current clinical utility, thus the genetic counseling profession must work to recognize those uses and determine how they influence our path forward.

4.3 | Practice implications – A need for further guidance

These results underscore a need for further training and education around the use of diversity measures in genetic counseling. Current cultural competency training programs within genetic counseling appear to be insufficient, as less than one-third of participants described having such training impact their approach to assessing ancestry and over three-fourths of participants desire more training. The use of diversity measures may not be directly discussed in all cultural competency programs; however, the need for additional training in this area is clear. Many participants discussed concern about a universal standard of ancestry collection despite the fact that this information is not impacting clinical decision-making in all instances. However, if genetic counseling standard practice evolves to exclude ancestry for certain indications, we must consider how this would impact efforts to decrease ancestry-based genetic testing limitations and diversify the populations included in genetic research. In order to quantify these changes, ancestry has to be collected in a standardized and detailed manner. Not obtaining information about patients' ancestry in any capacity could be explicitly harmful to these efforts. Increased standardization for how ancestry and/or ethnicity is collected may benefit genetics professionals working in both clinical and research genetics settings.

The current NSGC pedigree guideline does not provide guidance on how ancestry should be collected or used. Additionally, no guidelines provide standardized information about how other constructs such as ethnicity or race should be used in genetic counseling practice. Moreover, there is a growing body of literature showing that genetic professionals have an inconsistent understanding of these constructs, which should warrant additional professional guidance (Nelson et al., 2018; Popejoy et al., 2020). It is critical that the genetic counseling profession clarify the use of these constructs in our practice. More detailed guidelines would help standardize how genetic counselors collect and use ancestry in their clinical practice.

Given the common misconceptions regarding the relationship between genetics and race, it is important for organizations such as NSGC to make a clear stance on these issues. Increased standardization and education around the use of diversity measures in clinical genetics is necessary, and professional organizations play a critical role in implementing these changes.

4.4 | Study limitations

Participation in this survey was voluntary, thus response bias may be present. Participants may have chosen to take part in the study because they have a higher interest in issues of race, ethnicity and ancestry, or because they have a strong opinion about how genetic counselors should be using this information in their practice. Only 115 genetic counselors participated in this study, so it is challenging to know whether the views and opinions of this group are representative of the profession as a whole. There was an overrepresentation of genetic counselors with <1–4 years of experience who participated in this survey, compared to the 2020 PSS. Thus, results may be biased towards the opinions of less experienced genetic counselors and may be less representative of the opinions of more experienced genetic counselors. Prenatal genetic counselors represented the smallest group in our study, thus there may be additional differences between clinical specialties regarding the use of ancestry that could not be identified due to the small sample size. In addition, there is a risk of social desirability bias when discussing the topics of race, ethnicity, and ancestry. Participants' responses may be skewed towards the more socially acceptable responses to survey questions, as they may have been hesitant to acknowledge that factors such as a patient's race and racial discordance influence their approach to assessing ancestry. Most study participants identify as white, with relatively few participants reporting other identities. However, this demographic makeup is consistent with that seen in the population of NSGC members.

4.5 | Research recommendations

Though study results provided insight into how genetic counselors use ancestral information in their practice, it did not assess the perspective of racial minority populations on this topic. Further research could determine how minority patient populations prefer to be asked about their ancestry and how they perceive the use of this information in their clinical care. This would allow us to identify areas of discordance between genetic counselor practice and minority population preference, which could be addressed to improve patient experience and care. Less than half (44.5%) of participants believe that the way they ask about ancestry is sensitive and appropriate for patients of racial minorities, with 31.7% of participants responding that they are somewhat sensitive and appropriate and 21.8% being unsure. This shows an area in which genetic counselors

can make a significant improvement with the help of continued research. Understanding the patient perspective on this topic could also help inform guideline modifications and provide genetic counselors with another perspective which may inform how they approach this question in their practice.

In addition, further research could provide additional information about the utility of ancestral information for common referral indications, and provide more detailed information about how useful this information is at different clinical decision-making points. Study data helped identify differences between genetic counseling specialties regarding the utility of ancestral information in clinical practice; however, a more detailed analysis would be beneficial when considering guideline modifications. Genetic counselors would benefit from additional guidance about whether ancestry is relevant for certain indications, specialty practices, or at certain clinical decision-making points. In order to develop more specific and clinically actionable guidelines and recommendations, we must develop a more robust understanding of current practices.

The need to expand the utility of genetic testing for patients of non-European ancestry is a pressing issue in the field of genetics. Some genetic counselors feel that sharing ancestral information when ordering testing for patients may benefit this issue. However, information about how genetic testing laboratories use ancestry and ethnicity is unknown, and there is significant variation in what language laboratories use when collecting this information. A more detailed understanding of how laboratories utilize this information and how it may or may not benefit efforts to expand the utility of genetic testing for patients of non-European ancestry would be beneficial. This information could help guide genetic counselors in their practice and assist them in understanding what types of diversity measures are beneficial for laboratories to have.

5 | CONCLUSIONS

Although collecting ancestry is standard practice for a large percentage of genetic counselors, it is clear that this information is not always impacting clinical practice. This presents an opportunity for genetic counselors to think critically about how they use ancestry in their clinical practice. It is important that genetic counseling practice is evidence-based and is not merely an artifact of historical standards within the profession. There are clearly various approaches and opinions genetic counselors hold regarding the use of ancestral information in their practice, but moving towards a more unified practice would be beneficial. Crucially, the genetic counseling field needs to integrate more focused and comprehensive education around the collection and use of diversity measures into our training. Efforts to increase the diversity of the genetic counseling profession will also benefit this issue, as the voices of diverse genetic counselors are critical in determining how our field should use diversity measures. As our field works towards improving care for our diverse patient populations, we must determine how to recognize diversity in appropriate, sensitive, and useful ways.

AUTHOR CONTRIBUTIONS

Alexandra Hubbel: Conceptualization; data curation; formal analysis; investigation; methodology; resources; visualization; writing – original draft. **Elizabeth Hogan:** Conceptualization; methodology; writing – review and editing. **Anne Matthews:** Methodology; writing – review and editing. **Aaron Goldenberg:** Methodology; writing – review and editing. All of the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST

Alexandra Hubbel, Elizabeth Hogan, Anne Matthews, and Aaron Goldenberg declare that they have no conflict of interest.

DATA AVAIALBILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

HUMAN STUDIES AND INFORMED CONSENT

This study was reviewed and granted an exemption by the Case Western Reserve University Institutional Review Board. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Implied informed consent was obtained for individuals who voluntarily completed the online survey and submitted their responses.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors for this article.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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