

DISAGGREGATING RACE AND ETHNICITY DATA: FINDINGS FROM COMMUNITY FOCUS GROUPS



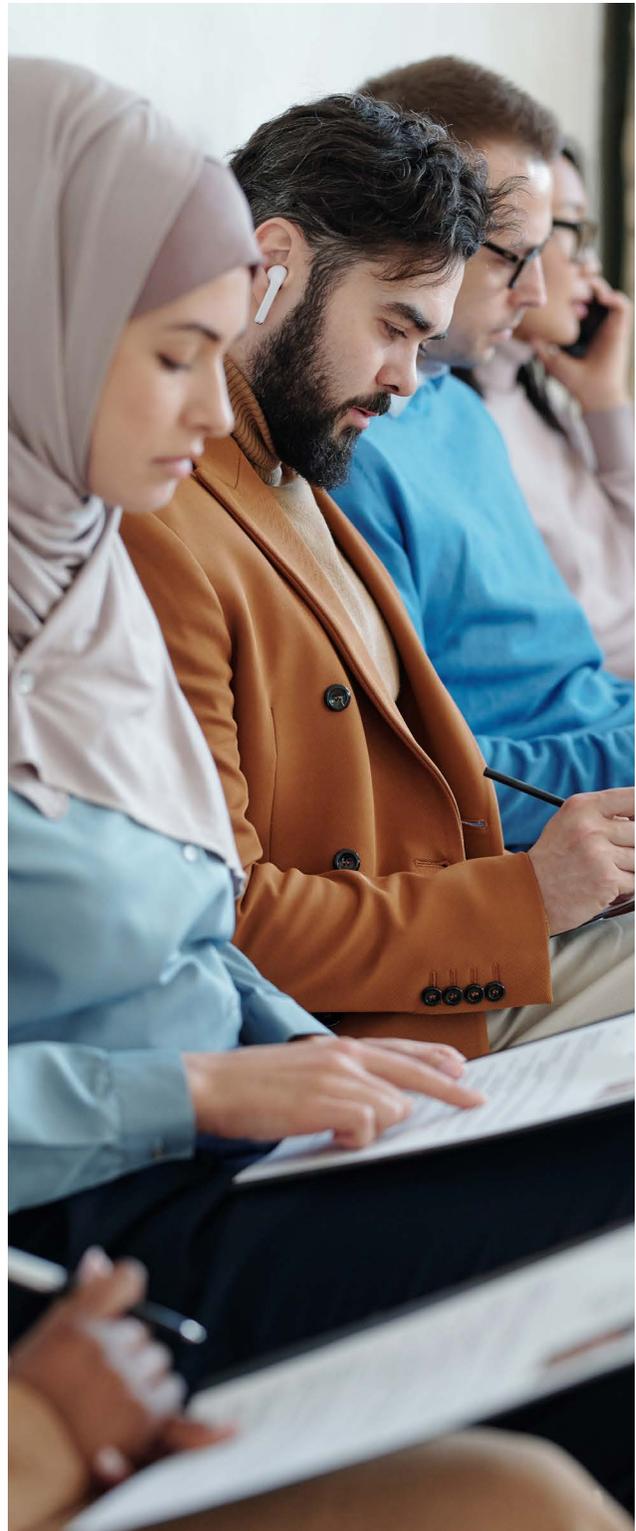
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INTRODUCTION

Categorizing race and ethnicity data has been an ongoing endeavor of many political, academic, health, and social institutions in the United States. This information is used for a range of purposes including describing populations, understanding community needs, and designating resources. The ways in which racial and ethnic identities are grouped for these purposes has changed over time. With respect to their most recent form under the U.S. Office of Management and Budget (OMB) standard categories, concerns have been raised over the need to disaggregate these broad categories for a more comprehensive accounting of racial and ethnic identities within the United States.

The Center for the Study of Asian American Health (CSAAH) at New York University (NYU) is working to develop tools and systems to prospectively and retrospectively disaggregate race and ethnicity data collected, with a particular focus on use by public health practitioners and health professionals. In order to support these efforts, the Center for Evaluation and Applied Research (CEAR) at The New York Academy of Medicine (NYAM) convened a series of focus groups with diverse community members to gain perspectives on race and ethnic identity, preferences for reporting race and ethnicity, beliefs, and other factors that underlie these perspectives and preferences, and recommendations regarding communications on race and ethnicity. The aim of this study was to provide community input to inform the development of tools and approaches to disaggregating race and ethnicity data in New York State.

METHODS

CEAR convened thirteen focus groups and one key informant interview with individuals who self-identify as belonging to one of the racial and ethnic groups listed in the table to the right. Participants were asked how they think about their race and ethnic identities within each broad category, how they identify themselves in different contexts—including healthcare—and how they choose to identify when asked to fill out a survey or questionnaire. Participants were also asked to provide feedback on a set of questions that update the current OMB standard race and ethnicity questions in order to disaggregate groups that combine diverse subgroups (for example, the Asian category includes large populations from across East, Southeast, Central, and South Asia, with disparate communities with different languages, cultures, and ethnic identities). Participants were additionally asked to provide recommendations about how health information should be communicated to individuals who belong to their race or ethnic group.

Eligibility criteria included age 18 years or older, New York State residency,¹ ability to communicate in English, and ability to participate remotely using Zoom. Participants were largely recruited through the internet platform craigslist and community-based organizations serving individuals whose identities fit particular target populations². An additional community-based

Race/ethnic category	Number of focus groups
Asian	2
African American/Black	2
Latine	2
Middle Eastern/North African (MENA)	2
Multiracial/Multiethnic	2
Native Hawaiian/Pacific Islander (NH/PI)	1
White	2
TOTAL	13
Race/Ethnic category	Number of key informant interviews
American Indian/Alaska Native (AI/AN)	1

organization (CBO) was engaged to help recruit older adults so as to ensure diversity by age. All potential focus group participants were asked to complete a screening questionnaire, which asked them to self-select into the appropriate focus group race and ethnicity category (e.g., African American, Latine, White, etc.).

¹ One exception was the Native Hawaiian/Pacific Islander focus group. The research team encountered challenges recruiting participants in New York and ultimately decided to open eligibility to individuals living outside New York State, working with colleagues at the National Association of Pasifika Organizations (NAOPO).

² The study team experienced difficulty recruiting participants for a Native Hawaiian/Pacific Islander group and American Indian/Alaska Native group. Ultimately, a key informant interview was conducted with two staff at a New York City based indigenous organization instead of a focus group, and a Native Hawaiian/Pacific Islander group was conducted with individuals living outside of New York State, some of whom worked at organizations focused on providing services to Native Hawaiian and Pacific Islander communities.

The study team used these data to invite participants to the groups.

Focus groups were conducted in English by facilitators who were of the same race and ethnicity as the participants in the group³ and were trained in focus group facilitation using a topic guide developed by NYAM in collaboration with the NYU research team. Two facilitators conducted each group. Focus groups lasted two hours and were recorded using the Zoom record feature. Audio recordings of the groups were professionally transcribed. Participants received an information sheet about the research prior to their participation and a \$50 electronic gift card as an incentive.

Transcripts were maintained and coded by NYAM researchers using NVivo, a qualitative data analysis software. The coding scheme reflected the study objectives and included pre-identified topics, as well as topics deriving from the data themselves. Thematic analysis of the data was conducted by multiple members of the study team who met regularly throughout the analytic process.

The research protocol and study documents were approved by the NYAM Institutional Review Board. All study documents (i.e., screening questionnaire, information sheet, and focus group topic guide) can be found in the appendix of this report.



³ Because of delays in recruitment and resulting scheduling challenges, the Native Hawaiian facilitators were unable to facilitate the Native Hawaiian/Pacific Islander group. As a result, the group was facilitated by two researchers at NYAM whose identities are White and Latine. This fact was disclosed to the group at the beginning of the session.

FINDINGS

Description of the sample

Table 1 shows the demographic characteristics of the eighty-one individuals who participated in the focus groups. Approximately one third (30%) were between the ages of 25 and 34 years; close to half (51%) resided in New York City; and approximately two-thirds (67%) identified as women.

Information about how participants identified their race and ethnicity using (1) OMB standard questions and (2) updated questions that disaggregate groups is included in the appendix.

Table 1. Focus group demographic characteristics		N=81	
	n	%	
Age			
18-24	10	12%	
25-34	24	30%	
35-44	13	16%	
45-54	13	16%	
55-64	10	12%	
65-84	11	14%	
Residence			
New York City	41	51%	
New York State other than New York City	31	38%	
Outside of New York State	9	11%	
Gender			
Woman	54	67%	
Man	25	31%	
Transgender man	1	1%	
Transgender woman	1	1%	

Factors that influence how people identify themselves in daily life

Participants across focus groups⁴ indicated that the context in which they are asked to describe their race and ethnicity can impact how they identify themselves. For many, conversations with individuals outside of their own race or ethnic groups leads to use of broad categories such as, “African American” or “Asian.” Within groups, however, participants are more likely to provide specific details about their ethnicity or country of origin. Participants said they are also likely to provide more detail if asked, though most situations require only a more general descriptor. Several participants across groups felt that providing more general information was often “easier” or “simpler” than going into detail.

“If I’m surrounded by Asians, other Asian people, and they ask that question, I think they usually want to know what country I’m from. So, I usually would say Korean American.”

—Focus group 7, Asian

“When I’m speaking to someone of the same race and ethnicity, I try to diversify and tell you details of my origin; where I come from, if I’m from the Caribbean, if I’m from Africa, what country I was from African, where my roots are from, where my dad was from, and how I got to the United States.”

—Focus group 2, Black

“It’s depending on the context. Let’s say I’m being introduced to someone and they say, “Where are you from?” Then I say, okay, “I’m from the Dominican Republic.” But if somebody said, “How do you define yourself?” Okay, “I’m Latino.” Or, “Are you Latino, European, where you from?” “I’m Latino.” I don’t go into details unless they ask me for more specific information.”

—Focus group 5, Latine

⁴Reference to focus groups in this report includes findings from the one key informant interview that was conducted.

"I identify as American, and then West Indian following that—from the Caribbean. So, I know that's a very broad category that has a lot of mixes and some people don't really understand it...I kinda just stick to more of the, "I'm American," just to keep it simpler... Some people, they then follow up with, "Okay, so then where are your parents from?" And then, I just respond back with, "Oh, they're from South America, from this country."

—Focus group 10, Multiracial/Multiethnic

In some groups, participants also spoke about the value of using the word "American" within the description of their race or ethnic identity (e.g., African American). For those who were born in the U.S., or born to a parent from the U.S., adding this modifier felt like a way to more accurately or specifically label themselves.

"I always joke because I always say technically I'm a true African American because my mother's American, Black, and my father's Nigerian, African. It really depends on the situation, but I just like to acknowledge both."

—Focus group 2, Black

"I, too, was also born and raised in the States and sometimes – it doesn't really matter. Sometimes I say I'm Filipino or Filipino American if they want to be more specific."

—Focus group 6, Asian

Participants across groups additionally described ways in which, regardless of their own preferences, their identity is sometimes defined for them by others.

"Since my mom's side's more Caucasian and my dad's Mexican, I just say I'm half Mexican because I'm pretty much White-passing and I'm raised in America and westernized. I'm kind of estranged from the Mexican side of my family. I'm kind of, like, don't really fit in with them and I'm, like, the weird American around them. But over here people kinda look at me as exotic. Like, "Oh, you're Hispanic.""

—Focus group 9, Multiracial/Multiethnic

"Generally, I feel like I have a hyphenated experience in terms of my nationality, where I always feel like I have to say South Asian American or Pakistani American, because it's how I'm perceived. No matter how American I am, the fact that I was born here, people will always perceive me—not everyone—but I will always feel a little bit an "other.""

—Focus group 9, Multiracial/Multiethnic

"Growing up, I was very confused about that, because when I saw my teammates, they were from such and such country, but then we were talking about race, they were Black or they're more Indian or they're Chinese. And it's like, who am I? Because when I said White, the American kids said you're not White."

—Focus group 5, Latine



Special considerations within racial and ethnic groups

Key themes within specific racial and ethnic groups are described below.

African American/Black

Many participants used both Black and African American to describe themselves. As described above, some participants in the African American and Black groups perceived “African American” to be an accurate descriptor when individuals were both from the United States and knew that their family originated in Africa. The use of African American was less consistent for individuals who did not have immediate African ancestry.

"I have relatives in that but for me, I was born here in New York. And I was brought up again in Manhattan area, New York. And what I will always like to refer to myself is Black American, or African American."

—Focus group 1, Black

"I would always say Black American to grasp my southern roots because I noticed as time went on, a lot of people have a nationality. Black Americans, we don't have a nationality, we don't know who we are... everyone has a nationality except for us. We're here, and unless you know exactly where you come from way back when, you're American but you're colored so you have to say something, you know what I mean, to distinguish yourself from the White people."

—Focus group 2, Black

White

Discussion among participants in the White-identified groups centered largely on being asked to describe themselves on surveys and forms rather than in conversation with others. Generally, participants said they identify as “White” or “Caucasian” depending on which option is available. Several participants expressed discomfort identifying themselves according to their race.

"I usually just stick with White. It's not really brought up a lot. I don't really bring—it's not really brought up a lot. I mean, obviously on job applications or actually just about any kind of application, it's on. But yes, I just keep it simple."

—Focus group 3, White

"And almost invariably it's in a written request. So, if the written request asks if I'm White, I'll just check White. If it asks if I'm Caucasian, I'll check Caucasian. And increasingly I've seen a remark that says, "Are you European American?" I go, "Yeah, that's me too." But I don't find myself in situations where somebody says, "What is your race?" And it may be obvious, and that's why nobody asks. I'm very pale."

—Focus group 4, White

"White to me is a problem because of this – it's not really new, I guess, but you hear more and more about White supremacy, and sometimes I feel like okay, well, I shouldn't say I'm White because it associated very much, more and more, to White supremacy. And so that is why for me, that's another reason why I prefer Caucasian. I don't particularly like the word White. But that's me."

—Focus group 3, White

Latine

Within the Latine-identified groups participants often included their country of origin in their race and ethnic identity, describing themselves as “Dominican American,” “Puerto Rican,” “Mexican American or Chicana,” among others.

"I was born here in the United States in New York, but I describe myself as Dominican American. My parents were born in the Dominican Republic. My sister was born there. Even though I was born here, I still feel that bond and that pull from the Dominican race. And I try to participate in anything Dominican."

—Focus group 8, Latine

"I identify as Mexican American... or Chicana. So, I was born in New York. My parents were both born in Mexico. And I try to be as close, as much as I can, to my Mexican heritage. So, Chicana basically is that, right? Chicana is someone who was American born with Mexican parents."

—Focus group 8, Latine

Many said they experienced discomfort trying to fit themselves into the broader racial categories common in the U.S.

"I don't see myself White or Black or Indian or whatever, okay. Don't see that as something that has to be defined. If they ask me specifically what race are you? I'm defined and White and my parents – but, to me, it doesn't have much relevance in defining my identity... I try to avoid the topic because, for example, for some Latinas or Dominicans, I am too White. For the Americans, I am too dark... So, I try not to go into that because it's tricky territory..., my mom is blonde and green eyes, but for Americans, she's Latina."

—Focus group 5, Latine

"I don't identify as any race. Right? As a Hispanic Latina, I feel like we have a mixture of everything. So, I don't identify as White, I don't identify as Black, I don't identify as Pacific Islander. So, I kind of just put other, and I kind of put in there Hispanic and Latina."

—Focus group 8, Latine



Asian

Participants in the two Asian-identified groups emphasized the impact of context on how they identify. In both groups participants indicated that the broad category “Asian” was appropriate in some contexts but not others. For example, participants often choose “Asian” on surveys and forms, as they find it to be the most appropriate option. However, in social situations, identifying themselves as Asian may seem too broad or confusing given the complexity of identity within the broader category.

"It all depends on the situation. If I'm like a survey thing, you get only a couple of options like White, Black, Hispanic, and Asian. So, I only pick Asian. I don't really have any option to do more detail. But if people ask me, I would probably point out I was Taiwanese."

—Focus group 7, Asian

"For me, it depends on whether I'm checking off boxes or if someone's asking me verbally versus in writing. So, usually in writing I'll see Asian, so I'll check off the box Asian. But in person, I'll identify as South Asian, because people get confused when I say Asian. Because when people think of Asian, they generally think of Southeast Asian or East Asian. They don't generally think about South Asian or Middle Eastern, so people get confused. So, I specific South Asian. And then ethnicity, I say Pakistani."

—Focus group 6, Asian

Middle Eastern/North African (MENA)

When describing how they identify, many in the Middle Eastern and North African group referred to their country of origin or ethnic group but acknowledged that the response they give when asked depends on the context. They highlighted the fact that on questionnaires and forms they are expected to check “White,” but this is not how they identify in conversation with other people. Like respondents in other focus groups, they said they are more likely to provide details about their identity to individuals who are Middle Eastern or North African, and to be more general with individuals who are not.

"I also have a hard time to identify myself because in the U.S. check box, I'm gonna be White, which I feel like it is not that much fair because I'm not White, so this is the first problem. I wanna say except - yeah, it's a big deal, but yeah, if someone would just ask me more questions, I would clarify them about Whiteness."

—Focus group 11, MENA

"I think it depends on the situation and people who are trying to ask this question. So, if it's during, let's say, a survey or if it's anonymous, the options would include White, but if you are talking to someone specific, I feel that sometimes you have to say Middle Eastern because that's what they would identify me with, rather than myself identifying myself with, and if you're talking to someone from the Middle East, you might mention the country specifically."

—Focus group 11, MENA

"I would say I tend to specify ethnicity if I'm talking to someone else who's Middle Eastern but otherwise not really. Just doesn't come up."

—Focus group 12, MENA

Multiracial/Multiethnic

Individuals in the multiracial and multiethnic groups identified in many different ways. Several described the interest other people express in their identity and how strangers sometimes make incorrect or incomplete assumptions based on how they look. In these cases, participants said they must decide whether to clarify or provide more detail. Participants in the multiethnic and multiracial groups also described how they struggle to fit themselves into the predominant race and ethnic categories.

"Generally, most people don't believe I'm half Latino, they just think I'm 100% White. So, I don't know, I just really don't wanna get into it. So, it's kinda more so just people not believing the Latino aspect. If they see my mom, they'll be like, "You're not lying.""

—Focus group 10, Multiracial/Multiethnic

"When filling out forms, I would fill out Hispanic. But speaking casually, I don't have to tell somebody that I'm Black. They can see that. But if it comes up, I let them know I'm half Hispanic as well. But on forms that would be the only time that I really pinpoint that, yeah, I'm Hispanic. Otherwise, it's something that I'll let come up if it does."

—Focus group 9, Multiracial/Multiethnic

"My mother is White, from upstate New York. My father is Black from a tobacco farm in the south. I am sort of, not totally ambiguous, nobody has mistook me from White. But people my whole life have asked me like, "What are you?" Which is the rudest way to form a question. And then, people are always a little disappointed that it's so basic. So, if you ask me, I would say biracial. But most forms don't give you that option. And so, then I pick off African American usually."

—Focus group 10, Multiracial/Multiethnic

Native Hawaiian/Pacific Islander (NH/PI)

Participants in the Native Hawaiian and Pacific Islander group generally identified themselves according to the specific island in the Pacific they are from and the cultural traditions in which they were raised. Although Native Hawaiian and Pacific Islanders are often grouped together, participants described a meaningful difference between someone from Hawaii versus another island given Hawaii's American statehood.

"I define myself as a Tongan Pacific Islander. But now that you're asking the question, when I think about it, I think about my upbringing. My upbringing: Both my parents were very traditional. They're both Tongan, and our home was very traditional Tongan. We had a very traditional Tongan upbringing, even though I left Tonga at the age of five and moved to Hawaii, stayed there for a couple years, left there in '65 and moved to the Bay Area. And I basically grew up in the Bay Area, but my upbringing was very Tongan. So, I think that has a lot to do with how I identify myself."

—Focus group 13, NH/PI

"Native Hawaiian and Pacific Islander are always put together, but there's a lot – Just because we're from the islands, it doesn't really make us very similar. Native Hawaiians, Hawaii has been part of the U.S. All other Pacific Islanders are not a part of the U.S. We have Guam and all this stuff, but still, they're not like Hawaii where they can vote. American Samoa and the Chamorros, even though those islands had been overtaken by the United States, they still are not able to vote. So, they don't have the same rights and duties or same rights that Native Hawaiians do. So, I'm one that would go down to separating the two, Native Hawaiians and then Pacific Islanders."

—Focus group 13, NH/PI

They additionally described the difficulty others have identifying their race based on looks and a few shared experiences of being mis-identified on official documentation like birth certificates and driver's licenses.

"My birth certificate – I was born in the Philippines. My birth certificate said Mongolian... and it wasn't until I was, I want to say fifth grade, sixth grade, we finally got it changed to Guamanian."

—Focus group 13, NH/PI

American Indian/Alaska Native (AI/AN)

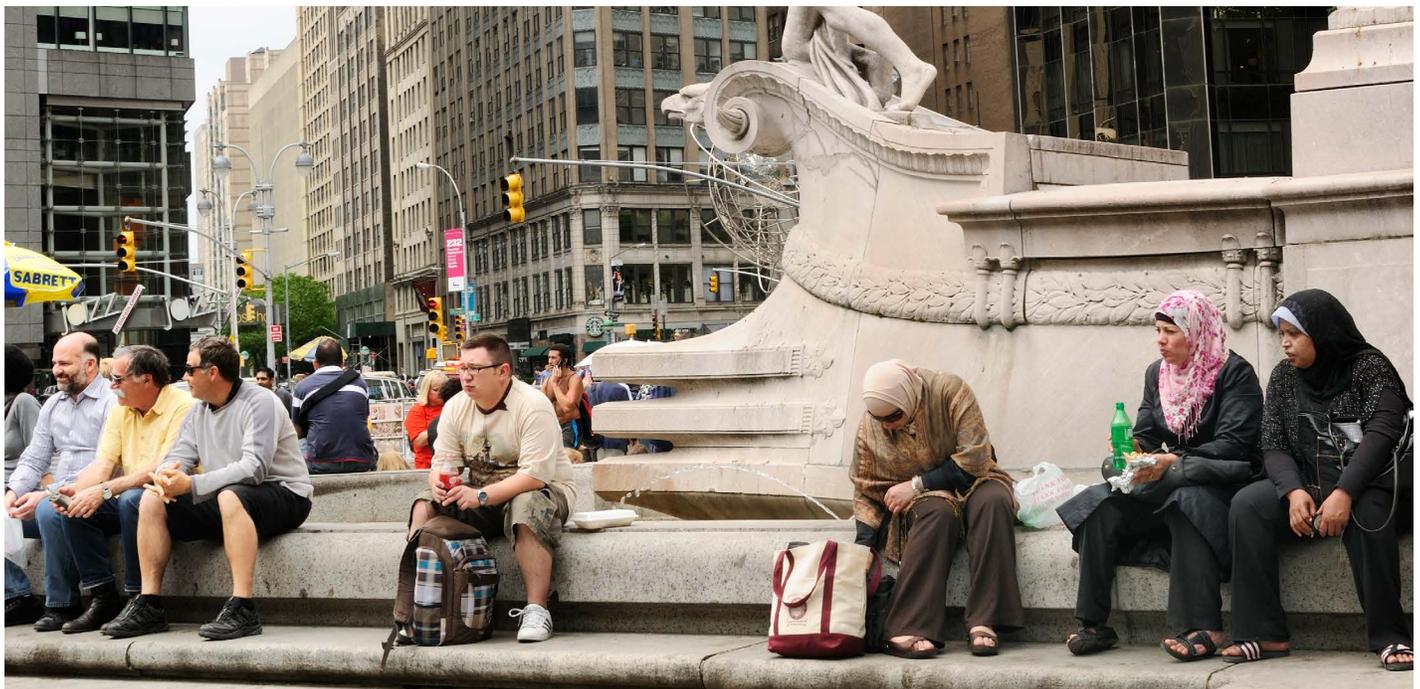
The two participants in the key informant interview indicated that tribal membership, family culture, phenotype, and origin (within or outside the U.S.) are factors that play a role in how they identify themselves to others.

"I identify as Afro-Indigenous. I identify that way because my mother is Native American and White. And my father is African American. And I identify as Afro-Indigenous more specifically, because I was raised as a native woman. I come from the Wisconsin area. I come from the Menominee/Oneida Reservations. And my cultural beliefs, the way that I was raised is really ground by indigeneity. And so, to honor my father and mother I've chosen to identify as Afro-Indigenous."

—AI/AN key informant interview

"It's kind of hard to just say indigenous on its own. So, [another participant's name] is able to follow up with Menominee. And I'm able to follow up with the Carib people of Venezuela and Trinidad and Tobago, because you could really say that in whatever land you are on. So, I'm learning how to speak about it differently for people who have very little context about who we are."

—AI/AN key informant interview



Data use: Asking about race and ethnicity in health and non-health related settings

Health and healthcare context

Across focus groups, participants generally felt it was appropriate and important to provide race and ethnicity information about themselves in a health-related context. When asked how they believe this information is used, participants provided a variety of answers, including:

- to understand a person's health status, lifestyle, and/or disease risk in order to determine effective and appropriate treatment;
- to understand who is being served by the healthcare institution;
- to identify individual and community challenges, concerns, and needs in order to better address them;
- for research purposes; and
- as a data point that can be used to confirm patient identity.

"I know there are trends within Asian populations for certain diseases and conditions. I think it's important to be part of that dataset so that it can strengthen the research that's done out there... because I'm Asian, it disposes me – it makes me more... more pre-disposed, I guess, to certain diseases."

—Focus group 7, Asian

"I think it's being used for statistical purposes. Just being able to gather information about the demographics in the area and what the needs and concerns are."

—Focus group 10, Multiracial/Multiethnic

"I wouldn't be surprised if they didn't at least ask to have my race. Because they're gonna go operate on you, and they want some identifying characteristics. And what's a very short characteristic to say? Oh, he's male. Okay, he's older. He's White. And you know, and it's the right leg not the left leg."

—Focus group 4, White

As noted above, information about a patient's race and ethnicity was considered relevant in the context of healthcare, because participants felt it may enhance a provider's ability to screen for disease and treat illness given that certain diseases and risk factors are associated with specific racial and ethnic groups (e.g., African Americans and sickle cell anemia). Participants felt it was important to be as detailed as possible when reporting race and ethnicity in this context to increase the likelihood that this information can help tailor and improve care. Participants noted the importance of confidentiality when collecting such information, though were generally unconcerned about who within the healthcare setting asks (e.g., nurse vs. doctor).

"If I'm at a doctor's clinic or in a hospital, I'm really comfortable with expressing my identity, because this is actually gonna help them treat me. Because certain ethnicities have tendencies to develop diabetes, hypertension, or so on. So, expressing your ethnicity or nationality might even get you a better treatment."

—Focus group 11, MENA

"There are genetic diseases that are more – that people of some regions of the earth are more prone to get, and if you're sick, you want to give them all the information you possibly can. If you don't help them, they can't help you, so you have to give them everything they ask for."

—Focus group 3, White



"If it's medical forms then I'll check Asian and then put other to know I'm South Asian or Pakistani only because in my head I usually think, "Well, certain ethnic groups or certain groups of folks have certain risk factors." South Asian folks, we have risk factors that East Asian folks don't have and vice versa. So, I am disappointed when I see Asians lumped in this one check box because of that, especially in medical forms. Because I would hope that the medical community would do better and I'm sure there's probably conversations happening about that."

—Focus group 6, Asian

"You can even tell your information to a doctor. You know he's not going to go spread it around to everybody he knows. He knows there's that confidentiality in there, so there is some level of privacy and security there. So, you're less concerned."

—Focus group 8, Latine

Participants also recognized that gathering this information—whether by a hospital, another health-related institution, or the government—is valuable for understanding health trends within specific racial and ethnic populations.

"With this COVID nightmare, everybody was classified. Well, when you went and got sick and went to the doctor, the news was that this Hispanic part of the City had more higher percentage of cases than this different ethnic part of the City, and they were actually categorizing areas of the City as being hot spots. So, that's how they used the information. They could target what areas needed more awareness, needed more vaccines, education about it, and that sort of thing."

—Focus group 3, White

"I feel totally comfortable, because I feel this is how they get data on what Hispanics are subjected to or can have high blood pressure or whatever. So, I don't mind it."

—Focus group 8, Latine

In the Native Hawaiian/Pacific Islander group and American Indian/Alaska Native key informant interview, participants noted that limited health data are collected about their communities. Consequently, they valued the opportunity to provide race and ethnicity information in healthcare settings and hoped the data would be used to inform the development and implementation of services provided to their communities. They also felt this information could help community organizations and organizers better advocate for resources.

"I think it's a good thing whenever [healthcare settings] are collecting data, are including Native American, Alaska Native, or Indigenous Peoples because of the data misrepresentation that we do experience and the lack of data that does exist for Indigenous Peoples. So, I think it's a great thing... Hopefully it motivates them to create more culturally tailored health services and think about the way that they're communicating to Indigenous Peoples."

—AI/AN key informant interview

"I need to look at the data like, "Okay. This is how many have gout. This is how many have diabetes or high blood sugar, high blood pressure." And then I could use that information to get back to the faith-based organizations or the CBOs that I advocate for and say, "This is what the data is showing us." And then we attack, one by one, the issues based on what the data shows from the healthcare systems."

—Focus group 13, NH/PI

Despite an overall interest in sharing their race and ethnicity in a health-related context, some participants did feel uncomfortable—or could understand why others may feel uncomfortable—being asked by hospitals and by departments of health for this information. These participants shared concerns about racism and stereotyping and expressed uncertainty about the underlying purpose for the questions and how the information would be used.

"I wouldn't be comfortable. I wouldn't [provide] that information to the Department of Health, just personally... I just have trust issues with state and local government, and I just don't want them to know that information... I guess just not trusting them in how they would use that information."

—Focus group 10, Multiracial/Multiethnic

"I can imagine that as a person who would be on the bad end of that stick, that could make me uncomfortable, because I would then maybe expect to receive worse care if I identified as something rather than as something else."

—Focus group 11, MENA

"Medical racism is real. Right? They have beliefs that African Americans, particularly African American women who are pregnant, have higher thresholds and tolerance for pain, which is why they didn't want to prescribe you drugs when you really need them. They have a tendency not to listen to what you are saying. And that you have to fight to survive a hospital visit. Right? It doesn't matter how you self-identify yourself unless in that lineage, you're checking "White." So, maybe the answer is just to check "White." And I say that tongue in cheek."

—Focus group 1, Black

Non-health related contexts

Across focus groups, participants reported that their comfort level answering race and ethnicity varies according to setting. Most commonly, participants said they disliked providing their race and ethnicity on job applications, as they were concerned about employer discrimination.

"I'm very much comfortable giving out my details about my ethnicity in [healthcare] as compared to doing so on a job application. I feel when it comes to filling out a job application, your ethnicity kind of plays a role in putting your chances in whether you're gonna get a job or not."

—Focus group 2, Black

"Where it makes me feel a little bit uncomfortable is for employment if they're asking your race or ethnicity. You're not going to hire me for my race or ethnicity. You're going to hire me for my resume, for what my experience is, so don't look at my name, don't look at my last name, don't ask me if I'm a veteran, don't ask me if I'm Hispanic or Latino because that should not matter to you. My experience, my ability to do my work, is what should matter to you only."

—Focus group 8, Latine

Concerns about discrimination in job applications were particularly salient among participants in the Black-identifying focus groups. A few of these participants reported not disclosing their race and ethnicity or selecting "White" (either instead of or in addition to Black or African American) in job applications to increase the likelihood that they would be considered for employment.

"If it's a job application, that's why I said sometimes I will click "White" or "Two races," because I feel like when you put "Black" or "African American," they're just gonna automatically put you to the "no" pile."

—Focus group 2, Black

"I usually tend to identify as African American, but most of the time I just put "do not choose to identify," because I don't want to be identified by what color I am. I'd rather just put my name down on a paper and just get the job offer that or whatever the case might be."

—Focus group 1, Black

Answering race and ethnicity questions on forms and surveys

Overall, participants described a variety of factors that influence how they respond to race and ethnicity questions in forms and surveys. These factors include: the response categories that are listed, ability to select multiple categories, the type and purpose of the questionnaire, whether they perceive that their race and ethnicity is relevant to the main focus of the questionnaire, and how they are feeling that day.

"When I check boxes, if it allows me to be multiple things, I select "White" and "Indigenous"... but because my people come from South America as well, I also pick "Hispanic." But there are some instances on some boxes where I can't be anything. I can't be Hispanic and Black, and I can't be Hispanic and White at the same time. So, there are some instances where I don't exist."

—AI/AN key informant interview

"Say I'm applying for funding for tuition or something, I might put "Asian." Or any government papers, I might put "Asian." But if I think it's something pointless for commercial purposes, I'm most likely to put "Prefer not to answer." It just depends on my mood that day really."

—Focus group 6, Asian

"I feel unhappy about having to identify myself. So, sometimes I check everything. And sometimes I check nothing. Or sometimes I just write "human," just for the way of conversation."

—Focus group 1, Black

Participants acknowledged that categories typically offered in race and ethnicity questions are broad, grouping many different subgroups together.

"Most forms online... they really just say "African American," there's never really any other option. You're African American, or you're Hispanic or not Hispanic, or you're White, or you're Asian. There's never really a drill down in the level of diaspora that people come from, right, on any form, really. And if there was a form, it's usually a study."

—Focus group 1, Black

"So, usually in most of the forms, it's "Asian." And then, it's a big category... They don't give a lot of categories."

—Focus group 7, Asian

"I cringe when I see those boxes, because it strikes a chord with those that are missing. The Pacific Islander box is often there, but then the subcategories leave out so many of us, so many others of us."

—Focus group 13, NH/PI

Additionally, participants questioned why the "Hispanic/Latino" category is often separated into its own question and expressed a preference for having "Hispanic/Latino" listed alongside the other groups (e.g., White, Black, Asian).

"I don't really get why that's everywhere, that, "Are you Hispanic or Latino?" How is that so different from being Black, Middle Eastern, or Asian? I've never quite understood that. I don't think that it is."

—Focus group 1, Black

"There is no Hispanic or Latino option. But then they have the – as an after question, but are you of Hispanic race or origin? So, if they could put that as the second question, why can't they put [Hispanic or Latino] with White, Black, Asian?"

—Focus group 8, Latine

Some participants in the Middle Eastern and North African identifying focus groups – as well as other individuals who identified in part as Middle Eastern but participated in other focus groups – reported disliking that "Middle Eastern" is usually missing from the list of race and ethnicity categories.

"I feel completely overshadowed, being of Middle Eastern origin and non-Muslim in those forms... If we've reached the point where we can identify as non-binary on a form for gender, okay, maybe it's just a matter of time before we can get there and say, "I do not identify with any of the races listed.""

—Focus group 10, Multiracial/Multiethnic

"I'm not White. I'm Middle Eastern, but they don't have this choice there... They just have the basic ones which is "Hispanic," "African American," and "White," and I end up like choosing "White" by force."

—Focus group 12, MENA

Similarly, some participants in the Multiracial/Multiethnic focus groups stated that "Multiracial/Multiethnic" is not frequently an option in the race and ethnicity questions they see, which makes it challenging for individuals who are of multiple races and ethnicities to answer these questions.

"If you ask me, I would say biracial. But most forms don't give you that option."

—Focus group 10, Multiracial/Multiethnic

"On a lot of forms, it's annoying that it doesn't have biracial or multiracial options. But it'll say Hispanic, not Black. So, it forces me to choose between Hispanic or Black... A lot of the options, "African American" or it might say "Black," and then the other options are "White" and "Hispanic" with "not Black" in parenthesis. So, I have to choose from "Hispanic" or "Hispanic" with "not Black" in parenthesis."

—Focus group 9, Multiracial/Multiethnic

When asked what they do when presented with race and ethnicity categories that don't match their identity, participants reported taking a wide range of approaches – and often answering differently depending on the context, including: selecting "Other" and writing in a response; selecting the option that is closest to how other people or institutions perceive them and would identify them; selecting the option that is closest to how they self-identify; writing "Not applicable;" or skipping the question(s) altogether.

"Most of the time I leave it blank, either that or I write it in, one of the two."

—Focus group 13, NH/PI

"It would seem to make sense to me to just pick the closest one to you, even though it's not accurate... In terms of [picking the one that's closest], I'm looking at just race. Because sometimes, you can't see culture. Even though, culture is important in

identifying someone, you sometimes can't see culture... But I would say with those limitations, it's generally how people see you racially, that is taken into consideration here."

—Focus group 10, Multiracial/Multiethnic

"It really depends on the circumstance. But if it is mandatory and there is no "Other" then I'll put "White" just because that's what the Census Bureau says to do."

—Focus group 12, MENA

"Well, sometimes I put "African American," sometimes I would put "Other." Sometimes I would put like "All of the above..." I think sometimes it's a choice where you could put "I refuse to answer" or something like that... So, I've put that couple of times."

—Focus group 1, Black

Across focus groups, participants reported that clear explanations about why race and ethnicity information is being collected and how it will be used would be helpful. Some explained that providing information like this could result in people being more willing to disclose their race and ethnicity.

"Is it asking too much for, when we're filling out these forms, for these facilities to tell us why they're asking for this information? What's being done with it? Would they tell us?"

—Focus group 6, Asian

"If you're coming to me, and you want to know something about my particulars, I'm gonna need to know what that reason is and where you're gonna go with it. Because even since the pandemic, I cannot even count on these two hands how many surveys we have participated in just trying to find out what's going on in our community or across the nation or whatever."

—Focus group 13, NH/PI

"I think that if you're telling us why you need that information, we're going to be a little bit more understanding as to why you need it and why we should provide it to you. So, convince me, pretty much, why you need my info."

—Focus group 8, Latine

Example set preferences, concerns, and recommendations

The findings below represent feedback from study participants on the two sets of race and ethnicity questions presented to focus group participants for discussion. They are:

Set 1: OMB Standard Question

Question 1: Are you of Hispanic, Latino or Spanish origin?

- Yes
- No
- Prefer not to answer

Question 2: What is your race? Select one or more.

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Some other race, please specify: _____
- Prefer not to answer

Set 2: Updated Race and Ethnicity Question

Question 1: What is your race or ethnic origin (check all that apply)?

- White
- Hispanic, Latino, or Spanish origin
- Black
- Middle Eastern or North African
- Native Hawaiian or Pacific Islander
- Asian
- American Indian, Native, First Nations, Indigenous Peoples of the Americas, or Alaska Native
- Some other Race or Origin: _____
- Don't know
- Prefer not to answer

Follow up questions for each race and ethnicity listed in set 2 question 1:

Question 2: Since “American Indian, Native, First Nations, Indigenous Peoples of the Americas, or Alaska Native” was selected, which group best represents your origin or ancestry (check all that apply)?

- Blackfeet
- Cherokee
- Choctaw
- Iroquois or Haudenosaunee
- Sioux
- Central American Indian (For example, Mayan-K'iche', Mam, Yucatan, Garifunas, among others)
- Mexican American Indian (For example, Mixteco, Nahua, Otomi, Tlapaneco, among others)
- Southern American Indian (For example, Quechua, Kichwa, Shuar, Aymara, among others)
- Other: _____
- Don't know
- Prefer not to answer

Question 2: Since “Asian” was selected, which group best represents your origin or ancestry (check all that apply)?

- Asian Indian
- Chinese
- Filipino
- Guyanese
- Japanese
- Korean
- Nepali
- Taiwanese
- Thai
- Vietnamese
- Other: _____
- Don't know
- Prefer not to answer

Question 2: Since “Black” was selected, which group best represents your origin or ancestry?

- | | |
|---|---|
| <input type="checkbox"/> African American | <input type="checkbox"/> Nigerian |
| <input type="checkbox"/> Barbadian | <input type="checkbox"/> Somali |
| <input type="checkbox"/> Ethiopian | <input type="checkbox"/> Trinidadian and Tobagonian |
| <input type="checkbox"/> Ghanaian | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Guyanese | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Haitian | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Jamaican | |

Question 2: Since “Hispanic, Latino, or Spanish Origin” was selected, which group best represents your origin or ancestry (check all that apply)?

- | | |
|-------------------------------------|---|
| <input type="checkbox"/> Colombian | <input type="checkbox"/> Peruvian |
| <input type="checkbox"/> Cuban | <input type="checkbox"/> Puerto Rican |
| <input type="checkbox"/> Dominican | <input type="checkbox"/> Salvadoran |
| <input type="checkbox"/> Ecuadorian | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Honduran | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Mexican | <input type="checkbox"/> Prefer not to answer |

Question 2: Since “Middle Eastern or North African” was selected, which group best represents your origin or ancestry (check all that apply)?

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> Algerian | <input type="checkbox"/> Syrian |
| <input type="checkbox"/> Armenia | <input type="checkbox"/> Turkish |
| <input type="checkbox"/> Egyptian | <input type="checkbox"/> Yemeni |
| <input type="checkbox"/> Iranian | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Lebanese | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Moroccan | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Palestinian | |

Question 2: Since “Native Hawaiian or Pacific Islander” was selected, which group best represents your origin or ancestry (check all that apply)?

- | | |
|--|---|
| <input type="checkbox"/> Chamorro | <input type="checkbox"/> Tongan |
| <input type="checkbox"/> Fijian | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Marshallese | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Native Hawaiian | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Samoan | |

Question 2: Since “White” was selected, which group best represents your origin or ancestry (check all that apply)?

- | | |
|------------------------------------|---|
| <input type="checkbox"/> English | <input type="checkbox"/> Polish |
| <input type="checkbox"/> French | <input type="checkbox"/> Russian |
| <input type="checkbox"/> German | <input type="checkbox"/> Ukrainian |
| <input type="checkbox"/> Greek | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Hungarian | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Irish | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Italian | |

Set 1 (OMB Standard Questions)

A minority of participants preferred Set 1, because it was perceived as simpler and more direct than Set 2. Some said they liked this set because they did not want to provide more detailed information about themselves on a questionnaire, as would be required by Set 2.

"I don't like set two, because I think it's too specific. If I say I'm Black or if I'm African American. So, what's the need of me saying that I'm a Ghanaian, I'm a Nigerian, or a Somali, so I think it wastes a lot of time. So, I prefer the first set."

—Focus group 2, Black

"I think there was no point asking for the specific countries. So, if you're selecting Black then it's Black. So, there was no point getting to know what country are you from so, I would just go with the first one."

—Focus group 1, Black

"If I'm filling [out] the form or I'm answering these questions, I don't really want to explain what ethnicity or what race [I am]. I just want to go straight to Black American or African American. That's fine. What else would you like to know?...This is where I'm from. My mom's from in South Africa. My dad's from America. "It's a very, very long conversation - one which I don't really wish to have."

—Focus group 9, Multiracial/Multiethnic

"I like the first set because it's more simple."

—Focus group 4, White

Set 2 (Updated Race and Ethnicity Questions)

Most participants preferred the updated Set 2 questions, as they perceived them to be more accurate and inclusive than Set 1. Overall, they felt the expanded response options demonstrated an increased awareness of—and interest in—how people self-identify their race and ethnicity. They also felt it provided an opportunity for individuals to share more detail about themselves, resulting in feelings of greater representation.

"I like that Set 2 is more in detail. It's more expansive. I think it allows the person answering the question to feel more seen."

—AI/AN Key informant interview

"I would go with Set 2, personally, because it seems more inclusive."

—Focus group 10, Multiracial/Multiethnic

"If I saw these two, I would think the second one they care more about your answer and the first one they don't care. So, the first one I'd probably be more inclined to select "prefer not to answer," because they don't really care about specifics."

—Focus group 6, Asian

"I would prefer Set 2 because naturally I love showing off my origin. So, I want to tell people I'm a black man, I am an African and I'm a Nigerian by origin."

—Focus group 1, Black

"So, in Set 2, when Question 1 just kind of lays everything out, I think that, to me, seems more intuitive. And if I choose Asian, and I see the list of other Asian groups there, I would be actually more likely to write in other and Singaporean because I'm like, "Wow, we're all getting represented, and I want to be represented too."

—Focus group 7, Asian

Participants across groups also appreciated that Set 2 offers Hispanic/Latino as an option within the race and ethnicity question, rather than separating it.

"This one, Set 1, I don't like too much because it's like why are you asking if I'm Hispanic or Latino. What is - why is that the first question you're asking right away. It feels kind of offensive to me."

—Focus group 8, Latine

"I'll always have a question why do they ask the Hispanic or Latino first?... I don't know why like this would be separated from the other question. Like they can just ask, "What is your race?" And add the Hispanic or Latino in the same one."

—Focus group 11, MENA

Set 2: Concerns about the updated questions

Despite this strong preference for Set 2 over Set 1, participants described several concerns with Set 2. One set of concerns focused on the list of countries and ethnicities included in the Set 2 follow-up question. It was unclear why some countries/ethnicities were listed while others were not.

"Yet it doesn't include all of the Middle Easterners. For example, it doesn't include Persians, like Afghanistan, Tajikistan, or other countries in the Middle East...We have so many people from Afghanistan living here, they should be acknowledged."

—Focus group 11, MENA

"What comes up for me in question two is only seeing a select number of tribal nations within the question could trigger people in feeling a sense of erasure not knowing that maybe these options come from looking at data that signifies the most prevalent Tribal Nations. And so maybe that should be stated so people aren't feeling that maybe their tribe's sovereignty doesn't matter or having to feel excluded by having to write in their other tribe."

—AI/AN Key informant interview

"The list of countries do seem a little random to me. I can't tell if it's based on population, size – it's definitely not based on population size if it's excluding Pakistan. So, it just seems strange to me that these were the countries represented here."

—Focus group 7, Asian

"But that's my point. Why should they select 'Other' when there's a big group of people just like Ethiopians, Guyanese, Haitians, Jamaicans, Nigerians, so forth so on. If you're gonna do this, let's do it correctly all the way. This is what I'm saying...because Brazil is the second largest place where Africans were sent to."

—Focus group 2, Black

"And then, for Question 2 in Set 2, it seems like the choices are very specific, but they don't really encompass all of Asian countries. Where is Pakistan? Where is Malaysia? And for all of them to be typed into 'Other', I don't know if that's expected or proposed. But it just seems strange that there are some very select countries there but not all of them. So, I'm a little thrown off by Set 2, to be honest."

—Focus group 7, Asian

An additional criticism of Set 2 was that it held underlying assumptions about where people of different races might come from. For example, individuals who identify as Black (or anything other than White) would not see European countries in the follow-up options.

"It's a little bit problematic to me that you have the certain White groupings and the Black groupings. Because maybe I'm not White, but I'm from Ireland, that's where I was born. So, just sort of assume that you're a certain race from a certain country, I think, makes some assumptions that aren't always true... And the same with African countries. You don't have to be Black to be from an African country"

—Focus group 10, Multiracial/Multiethnic

Finally, a few participants in the Multiracial/Multiethnic focus group questioned whether the additional detail gathered in the updated question would ultimately be used by those collecting the information or whether it is solely for the purpose of making people feel included.

"So, I felt better with more of the choices, but I'm like, 'That doesn't really make a difference, I feel like they're just gonna boil it down into the same categories.'"

—Focus group 10, Multiracial/Multiethnic

"The rephrasing of the questions in set two seems more to make the people answering more comfortable, is this really gonna change the way they categorize the data? Are they just gonna go back to the standard categories in set one, when they're reporting the data? This feels like maybe it makes people more comfortable if they see more choices but doesn't really change anything about how they collect this information."

—Focus group 10, Multiracial/Multiethnic

Set 2: Participant recommendations

Participants had four main recommendations to improve the Set 2 questions. The first recommendation, noted in the Black and White focus groups, was to alphabetize the response options rather than show “White” as the first option.

"I've noticed lately that like 80 percent of the time, White is at the top of the list when you have to check what race you are, and it's made me very, very uncomfortable lately, because it's sort of like racist, you know what I mean? Like the White is at the top of the list."

—Focus group 3, White

"In question one, on set two, it says, 'What is your race or ethnic origin? Check all that apply?' Maybe it should be alphabetical... People of color are more than two-thirds of the planet from a global perspective. So, I don't really understand why in any questionnaire, that it's just not alphabetical. Because that is fair, right? If I'm looking at it from a point of fear, when White is first you're telling me who's most important, and I am more inclined to answer prefer not to answer."

—Focus group 1, Black

The second recommendation was to minimize the number of answer options for a given question. Long lists were largely considered to be overwhelming, and participants thought that breaking them down into more manageable groups would be helpful. Some suggested categorizing subgroups by region before providing a list of specific countries.

"This is overwhelming. When I work in community, a lot of times, all these words would just turn them off. And so, yes, I don't know. For me, I love the detail. But at the same time, all this kind of stresses me out, just to be honest."

—Focus group 13, NH/PI

"If you're going to start naming countries, you have to literally name every country, right? So, I think to make a solution, maybe just put East Asian and then put slash Chinese, Korean, Japanese – and then, go to Southeast Asia and then Lao, Thailand, Malaysia, Singapore. And then, definitely South Asian because India, Bangladesh, Pakistan – I don't know if you want to combine all of that... maybe just taking it region by region."

—Focus group 6, Asian

"You can group certain countries under a title, so you can, for example, say the Gulf area, and then, if you would put the Gulf area, you would have the set of all of the countries in that specific place, and then you would pick your nationality from there. So, maybe that could be made for even the Persian area, and then you can pick whether you're Pakistani, whether you're from Afghanistan, from Iran. So, in that way, more people would feel that they are being included."

—Focus group 11, MENA

Third, participants in several groups indicated that providing additional background information would be helpful, including a definition of race and ethnicity and the rationale for why certain groups are included in the answer categories over others.

"If you want to dictate the terms of the definition because you want a certain kind of set of answers, in terms of data, then yes, a glossary, kind of, 'Here's what we mean by this,' is helpful."

—Focus group 10, Multiracial/Multiethnic

Lastly, participants felt use of the word “Other” was exclusionary and recommended replacing it with language such as, “My race or ethnicity is not listed” or, “If your race/ethnicity is not listed, please write it in below.” A few participants additionally suggested including a “write in” option.

"And if it's to make people feel comfortable and feel like they're being treated in a certain way, then, once again, I would just say that that word 'Other' needs to go."

—Focus group 10, Multiracial/Multiethnic

"Because ["Other"] is not an identifier. It's about the list. It's not about you. So, I'm not an "Other." I am something that is not listed and doesn't put the otherness on me as much."

—AI/AN Key informant interview

"I also like it when they don't put "Other" but "If not listed." When you say it's not listed, then you write it in, because then we're not a second thought. It might have been just not enough room kind of thing. It gives a little bit more – "Other" just seems like – I'm so tired of "Other." But if not listed, write it in."

—Focus group 13, NH/PI

Additional recommendations made by participants included:

- Add "Jewish" as a response option to Set 2 Question 2.
- Include the 6 different Tribal nations as the follow-up options if someone selects American Indian or Alaska Native.
- If the researcher chooses to add some of the island names in Micronesia, all island names should be added (e.g., Marshallese, Pohnpei, Chuukese).
- Change the singular "Pacific Islander" to the plural "Pacific Islanders" to allow for the plurality of the other islands.
- Include thoughtful language (i.e., "Unsure" or "Do not know") for individuals who may not know their ancestry due to family lineages being cut off for a variety of reasons (e.g., slavery, adoption).

Health and healthcare communication recommendations

Participants were asked to provide recommendations for communicating health information to people who share their race and ethnic background. The most common recommendations across groups were largely consistent with existing best practices, and often included recommendations for healthcare communication more generally. For example, participants felt it was important that people from their community be treated with respect in a healthcare setting and that staff be adequately trained to provide culturally competent care.

"To me, it's respect. Respect is huge in our community. And if we don't feel like you're respecting us and you're not understanding to what our needs are and what our worries are, then we're going to – as a Hispanic or Latino, we have that history of not trusting medical providers due to what has happened in the past. Right? So, if you're respectful, you're approaching someone respectful, you're understanding, you're caring, then that's how you're going to get individuals' attention and they're going to be more interested in continuing their healthcare with you. Or following up."

—Focus group 8, Latine

"I think for approaching the community perspective is that there is generational mistrust from our folks to colonizers or people in power, and just recognizing those power dynamics and that you need to break down those power dynamics from your institution with our people in order for us to rebuild that trust. And it's not gonna happen overnight."

—Focus group 13, NH/PI

Participants also asserted that health services and education should not rely on stereotypes or assumptions about race and ethnic groups.

"When you go to a doctor for your hair, or doing a laser or something, they would say that Middle Eastern hair is so thick, it is like this, it is always curly. I don't mind it, but it depends on the context. Some nurses or doctors, they make some jokes about this, which, at the end of the day, makes someone uncomfortable, so I would reduce any sort of stereotyped speech from my convo. This is my takeaway."

—Focus group 11, MENA

"Not making assumptions. Right? Because I know the majority of Hispanic and Latinos, yes, we eat rice and beans. Right? We put a lot of Sazón on stuff. So, that's why we're a little bit more predisposed to have hypertension, more predisposed to have diabetes due to our diet, but not everyone has the same diet. So, making no assumptions, being respectful, not going with those stigmas."

—Focus group 8, Latine

"I presume that assuming that – that may be completely off, but “Oh, very sugary diet” would probably be a trope, and if you connect it with the diabetes and all that, so maybe there’s... It just seems very judgmental."

—Focus group 11, MENA

"Training of staff and just cultural humility... but I will bring up about being indigenous and stuff. And people are like, “Oh, and alcoholism.” I’m like, “How did that reach here? You don’t know anything, and that is the thing that you’ve heard?” So, that seems to be very deep-seated... And I think that can really color how services are provided for indigenous people because of those stereotypes. Or those data points that are true, but there’s no understanding about the whys, the trauma, and that sort of stuff."

—AI/AN Key informant interview

Participants additionally felt that it was important to provide healthcare and health information in simple terms and in people’s preferred language.

"And obviously, for me, huge is language access... We’re able to provide information in their native language... [And] third grade level literacy, right? Because if you’re giving someone a whole document... and they pull out this whole paper that is filled with words. We’re not going to read it. We’re not going to read it. Keep it simple. Keep it to the point. But make sure that they’re being educated."

—Focus group 8, Latine

"Your parents or your grandparents, if you’re lucky to have them with you, they’re gonna have language barrier in the healthcare facility. So, what happens to these people? How are they helped? We need to see what happens. That I want to see. How many are they, and what happens to them, and what is being done to improve?"

—Focus group 13, NH/PI

"[There should be] an intermediary to those who don’t understand or who don’t have fluent communications so there should be an interpreter or an intermediary... however communication or however information should be passed [on] for easy access."

—Focus group 12, MENA

Finally, a few participants in an African American and Black focus group did not believe health communication should be tailored specifically for them.

"Like treat us normal. I just couldn’t see, again, why you would think there’s a different way for you to communicate with me as opposed to anybody else. We’re human, too."

—Focus group 1, Black

"We’re all human beings. So, trying to treat some people separately, like giving a distinct kind of treatment to them, to me looks like segregation, where you’re trying to segregate them or something like that. The same way you would treat a White man should be the same way you would treat me. Treat human beings with respect, treat them with dignity, treat them with love, treat them with whatever you’re gonna do for a White man, do it for me, that’s life."

—Focus group 1, Black

"I think medical professionals should remember to take a better family history, rather than emphasize race as being an indicator of certain health issues. Because again, it more depends on family history, genetics, and then a person’s diet and the general care of themselves over the years."

—Focus group 1, Black

CONCLUSIONS

The findings described in this report outline important perspectives from community members on race and ethnicity, including how people prefer to identify, factors underlying those preferences, and how they respond when asked to provide this information on a survey or form. Participants also gave valuable feedback on the ways in which updated race and ethnicity questions can be improved and provided recommendations for healthcare and health-related communications.

Participants described themselves in many different ways both across and within the race and ethnic groups that were the focus of this study. Opinions regarding how questions about race and ethnicity should be asked also varied. As a result, it is difficult to assume that any one version of these questions would be completely satisfactory to all people. However, several key findings should be considered as updated race and ethnicity questions are being developed:

- Questions should be simple and answer categories should not be so numerous that they overwhelm respondents. In addition, they should not appear arbitrary (e.g., including only particular countries or tribal groups without explanation).
- Race and ethnicity should be combined into one question (i.e., Latine identity should not be the focus of a separate question).
- Given the complexity and intersections between race, ethnicity, and national origin, individuals should be able to provide some level of detail in their responses; they should be able to choose more than one answer category and have the option to provide additional detail about their identity as needed.

- Providing respondents with specific information about why race and ethnicity information is collected and how it will be used may support efforts to collect more robust and accurate data. Reporting findings back to community members may also support improved data collection.
- Collecting race and ethnicity information in a health-related context was largely viewed positively, not least of all because participants felt it might improve the quality of care they receive. As a result, individuals may be eager to answer detailed race and ethnicity questions in this context. Participants also generally supported the use of data collected by healthcare and health-related institutions to better understand and serve specific communities.

Several limitations to this study exist. Although the study team recruited a large number of participants through craigslist and by partnering with CBOs, some individuals who agreed to participate in the focus groups later declined or failed to show up the day of the group. These recruitment challenges resulted in fewer participants in some groups than anticipated. Additionally, difficulty recruiting for focus groups with Native Hawaiian/Pacific Islander and American Indian/Alaska Native groups meant that recruitment and data collection for individuals who belong to these groups varied from the original study design. Despite these challenges, we are confident that findings represent important perspectives from across all the race and ethnic groups of focus in this work and that general consistency regarding key findings affirms the value of study results.

Thank you to our partners at ARC Seniors, the National Association of Pasifika Organizations, Salted Logic, and the Urban Indigenous Collective for their partnership and support in this work.

APPENDIX I – STUDY DOCUMENTS

Race and Ethnicity Data Disaggregation Focus Group Screening Questionnaire

Hello! We are looking for people to participate in focus groups about the way that race and ethnicity data are collected on surveys and in healthcare forms, and how the answer options usually given can be improved. Please take this short survey (less than 5 minutes) to let us know you'd like to participate. Individuals who participate in a focus group will receive a \$50 gift card to Amazon or Target in appreciation of their time.

Focus groups will take place on Zoom and last for approximately two hours. Not everyone who fills out a screening questionnaire will be invited to participate. If you are selected to participate, someone from our team will reach out to you with more information. Staff from The New York Academy of Medicine and New York University will conduct the focus group and the results will be used to make recommendations to New York State regarding how best to update the race and ethnicity questions used for official data collection purposes.

Would you like to continue?

- Yes
- No (takes participant to end of survey)

If you would like to participate, please answer the questions below. Your answers will be kept confidential and will only be used to help us identify participants for these focus groups. We cannot invite everyone who completes this survey to attend.

1. What is your age?

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85+
- Prefer not to answer

2. What is your zip code? _____

3. What is your gender?

- Woman
- Man
- Transgender man
- Transgender woman
- Genderqueer/ Gender nonconforming
- Self-describe: _____
- Prefer not to answer

The next few questions ask about your race and ethnic identity in different ways.

4. Are you of Hispanic, Latino or Spanish origin?

- Yes
- No
- Prefer not to answer

5. What is your race? Select one or more.

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Some other race, please specify: _____
- Prefer not to answer

6. What is your race or ethnic origin (check all that apply)?

White:

Branching: If selected, "Which group best represents your origin or ancestry?"

- | | |
|------------------------------------|---|
| <input type="checkbox"/> English | <input type="checkbox"/> Polish |
| <input type="checkbox"/> French | <input type="checkbox"/> Russian |
| <input type="checkbox"/> German | <input type="checkbox"/> Ukrainian |
| <input type="checkbox"/> Greek | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Hungarian | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Irish | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Italian | |

Hispanic, Latino, or Spanish origin:

Branching: If selected, "Which group best represents your origin or ancestry?"

- | | |
|-------------------------------------|---|
| <input type="checkbox"/> Colombian | <input type="checkbox"/> Peruvian |
| <input type="checkbox"/> Cuban | <input type="checkbox"/> Puerto Rican |
| <input type="checkbox"/> Dominican | <input type="checkbox"/> Salvadoran |
| <input type="checkbox"/> Ecuadorian | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Honduran | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Mexican | <input type="checkbox"/> Prefer not to answer |

Black:

Branching: If selected, "Which group best represents your origin or ancestry?"

- | | |
|---|---|
| <input type="checkbox"/> African American | <input type="checkbox"/> Nigerian |
| <input type="checkbox"/> Barbadian | <input type="checkbox"/> Somali |
| <input type="checkbox"/> Ethiopian | <input type="checkbox"/> Trinidadian and Tobagonian |
| <input type="checkbox"/> Ghanaian | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Guyanese | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Haitian | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Jamaican | |

Middle Eastern or North African:

Branching: If selected, "Which group best represents your origin or ancestry?"

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> Algerian | <input type="checkbox"/> Syrian |
| <input type="checkbox"/> Armenian | <input type="checkbox"/> Turkish |
| <input type="checkbox"/> Egyptian | <input type="checkbox"/> Yemeni |
| <input type="checkbox"/> Iranian | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Lebanese | <input type="checkbox"/> Don't Know |
| <input type="checkbox"/> Moroccan | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Palestinian | |

Native Hawaiian or Pacific Islander:

Branching: If selected, "Which group best represents your origin or ancestry?"

- | | |
|--|---|
| <input type="checkbox"/> Chamorro | <input type="checkbox"/> Tongan |
| <input type="checkbox"/> Fijian | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Marshallese | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Native Hawaiian | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Somoan | |

Asian:

Branching: If selected, "Which group best represents your origin or ancestry?"

- | | |
|---------------------------------------|---|
| <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Taiwanese |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> Thai |
| <input type="checkbox"/> Filipino | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Guyanese | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Japanese | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Korean | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Nepali | |

American Indian, Native, First Nations, Indigenous Peoples of the Americas, or Alaska Native?

Branching: If selected, "Which group best represents your origin or ancestry?"

- Blackfeet
- Cherokee
- Choctaw
- Iroquois or Haudenosaunee
- Sioux
- Central American Indian (For example, Mayan- K'iche', Mam, Yucatan, Garifunas, among others)
- Mexican American Indian (For example, Mixteco, Nahua, Otomi, Tlapaneco, among others)
- Southern American Indian (For example, Quechua, Kichwa, Shuar, Aymara, among others)
- Other _____
- Don't know
- Prefer not to answer

7. **Participants in these focus groups will be grouped together with others who have a similar racial and ethnic identity. Please check the answer below that best represents the group you should participate in.**

- American Indian/Alaska Native
- Asian
- Black
- Latinx/e
- Middle Eastern/North African
- Multiracial/Multiethnic
- Native Hawaiian/Pacific Islander
- White

8. **Do you have access to a reliable internet connection and Zoom (video and audio) capabilities?**

- Yes
- No

9. **How did you hear about this meeting?**

Thank you for taking the time to complete this questionnaire. If you do not receive an email or phone call from us by [DATE TBD], that means we cannot invite you to participate in a focus group.

Please type your contact information below.

Name: _____

Email address: _____

Phone number: _____

Thank you for completing this questionnaire and for your interest in a focus group! We will be in touch with you if you are selected to participate.

RACE AND ETHNICITY COMMUNITY FOCUS GROUPS

Participant Information Sheet

Summary: You are being asked to participate in a focus group discussion. The purpose of the discussion is to better understand how you identify your race and ethnicity and how you think ways of categorizing race and ethnicity can be improved. Results will be used to improve the way race and ethnicity data are collected in New York State. The focus group is being conducted as a collaboration between New York University and The New York Academy of Medicine.

Focus group process: The focus group will last approximately two hours. You will be asked to talk about how you identify your race and ethnicity, what you think about the race and ethnicity categories usually given on formal questionnaires and health forms, your opinion about new ways of categorizing race and ethnicity, and any recommendations you have about how this information can be gathered better. At the end of the group, you will receive a \$50 gift certificate to show our appreciation for your time.

The focus group will be audio taped. The recording will be sent to a professional company so they can type notes of what was discussed and translate them into English. We do this so we have an accurate record of what was said. The recording will be deleted once we finish writing our reports.

Participation is voluntary: You can decide to join this group or not. If you decide to participate, you may still skip particular questions.

Risks and benefits of participation: Taking part in this focus group may not benefit you personally, but we may learn new things that will help improve how race and ethnicity data are collected and used to improve health and wellbeing in New York. Although the questions are not personal, you might feel uncomfortable when discussing race and ethnicity. You do not have to answer questions that make you uncomfortable.

Information is kept private: Any information you provide will remain confidential. We will not ask for your name or include anything that could be used to identify you on any study documents. We ask all participants to keep the information they hear in the group private, but we cannot ensure that another group member won't repeat what he or she hears. If you are worried that something you say might be repeated later, you do not need to say it.

Questions? The group leader will answer any question you may have about the focus group. If you feel that you have been harmed or have additional questions later, please contact:

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Consent Statement

I have read this form or it has been read to me. I have had a chance to ask questions about this focus group and my questions have been answered. I agree to be part of this study. I will receive a copy of this form.

Data Disaggregation Community Focus Groups

Topic Guide

Thank you for participating in this focus group. My name is [name] and I will be facilitating this discussion on behalf of The New York Academy of Medicine and New York University. Today, I'd like to speak with you about your race and ethnicity and what you think when you are asked to identify yourself in this way.

Before we start the discussion, I want to acknowledge that the way information about race and ethnicity is generally collected, and specifically the categories that are usually used—including the ones we used to select you for this focus group today—do not fully represent the range of racial and ethnic identities that people have. Through this conversation and others like it, we are hoping to change that. We also want to acknowledge that we understand race and ethnicity are just some of many other identities that may be important to people, like gender identity or disability status, though we won't be able to talk about them today. Thank you for your willingness to participate.

Finally, I want to remind you that everything you say will be kept confidential and will be reported in summary form only. I also want to mention some guidelines for discussion. We need for everyone to participate, but we won't have time for each of you to respond to every question. Information shared during this focus group should be treated as confidential by everyone present today. Also, we expect people to disagree, and that is fine as long as we are all respectful. We ask that everyone keep their cameras on during the group; we are trying to have this resemble an in-person group as much as possible. We will be recording the discussion and sending the audio recording to a professional transcription company, so we have a complete record of what everyone said. Finally, the facilitators will lead the discussion to make sure that all topics are covered, and everyone has an equal opportunity to speak.

Do you have any questions for me before we start?

Great. To begin, I'd like to ask you a few general questions about your identity.

1. In general, when asked, how do you describe your race and ethnicity to others?

- a. Can you explain what you say and why?

2. Do you distinguish between your race and ethnicity in your identity? Can you tell me about why you do or don't?

- a. Is one more important than the other?
- b. How important is your nationality to your identity?

3. Does how you describe yourself change depending on who you're speaking to?

- a. Is it different when you're speaking to someone who has the same or similar race or ethnicity versus someone of a different race or ethnicity? Can you explain?
- b. Are there different words or language you use to describe yourself at different times, or depending on who you're speaking to?
Can you explain?

4. Have you ever been confused for a member of another race or ethnicity? How did you feel or what did you say when this happened?

Next, I have some questions about how you feel when you're asked to identify your race and ethnicity in different contexts.

- 5. How easy or hard is it for you to choose a response to closed-ended questions about your race and ethnicity—for example, when a form has a set of check boxes for you to pick from. Can you tell us more about that?**
 - a. What are some things you consider when you're answering?
- 6. What do you do if you see race and ethnicity options listed and none of them match your identity (if needed: e.g., check a box that doesn't fully represent you, write in your answer, skip the question altogether)?**
 - a. How do you feel about making that choice? Can you explain?
- 7. When you give your race or ethnicity on a questionnaire or form, what do you think the people who see the information might assume about you?**
 - a. Are any of those assumptions helpful? Why is that?
 - b. Are there any assumptions that might be harmful? Can you explain?
- 8. In general, how comfortable are you being asked to give your race and ethnicity on a questionnaire or form? Why?**
 - a. Are there some settings—or contexts—that make you more uncomfortable than others when you're asked about race and ethnicity on a questionnaire? Can you explain?
 - b. Does it matter to you who is asking?
 - c. Does it matter to you why you think they're asking?

Now I'd like to talk to you about sharing your race and ethnicity in a healthcare setting.

- 9. How comfortable are you being asked to identify your race and ethnicity in a healthcare setting, like at your doctor's office, urgent care center or hospital?**
 - a. Does it make a difference to you who is asking the question in this context? As in, do you care whether it's a nurse, a doctor, a health tech, or if it's being asked on a form you fill out?
 - b. How comfortable are you being asked in a healthcare setting compared to other places where you might be asked, like on a school application or applying for services?
- 10. When you are asked to give your race and ethnicity in a healthcare setting, why do you think you are being asked?**
 - a. How do you think this information is being used—or should be used?
 - b. Is there any reason you think it is good to be asked about your race and ethnicity in a healthcare setting?
 - c. Is there any reason you think it is a bad thing?

As you may know, information collected about peoples' race and ethnicity is often used to help describe the health and health related characteristics of specific communities, and to compare the health of groups to one another – as in, “this group has a higher rate of diabetes than another group.” Collecting this information can also be used to connect people to services that meet their specific needs or to make political decisions about how to distribute resources and community services.

- 11. Considering the different ways this information may be used, is there anything you would change about how your race or ethnicity is identified on questionnaires or intake forms related to health and healthcare?**
- Can you explain?

Now I'd like to show you two sets of questions and answer categories for race and ethnicity questions and get your feedback.

[Show OMB standard categories and new categories – OMB labeled Set 1 and Set 2]

- 12. What do you think about these two sets of questions?**
- What do you like about them? What don't you like?
- 13. Which of these sets of questions and response categories do you like better, is it set number one or set number two? Can you tell us why?**
- 14. Which answer category would you choose for yourself in the question set you like best? Why?**
- How well would you say it fits your identity? Why is that?
 - Is there anything that would make it fit better?
- 15. Is there anything you don't you like about the answer categories in either set of questions presented here?**
- Do any of the answer options seem inaccurate or offensive in any way? Can you tell me why?
- 16. What do you think about how race and ethnicity are combined into one question in the second set of questions?**
- In your opinion, does that make sense or not? Can you explain?
- 17. How do you think the answer options in the second set of questions can be improved?**

Now I have some final questions.

- 18. Are there any ways you think that information about health (for example, information about disease or about healthy behaviors) should be customized for people who share your race or ethnicity? For example, is there particular wording or language to use or avoid? Can you explain?**
- From your perspective, is there anything else people who communicate about health – like doctors, nurses, the department of health—should know about how best to communicate with people who share your race or ethnicity?
- 19. Is there anything that hasn't come up today that you think is important for us to know? Is there anything I forgot to ask?**

Thank you!

APPENDIX II – PARTICIPANT RACE AND ETHNICITY TABLES

Table 2. OMB Standard Race/Ethnicity Questions

N=81		
	n	%
Hispanic, Latine, or Spanish origin		
No	68	84%
Yes	12	15%
Prefer not to answer	1	1%
Race^a		
Black or African American	33	41%
White	29	36%
Asian	13	16%
Native Hawaiian or Other Pacific Islander	11	14%
American Indian or Alaska Native	4	5%
Other race ^b	11	14%
Middle Eastern	2	
Arab	1	
Asian American Negro	1	
Central Asian/Middle Eastern, etc	1	
Hungarian/South American	1	
Mixed	1	
Mulatto	1	
Multiracial	1	
Persian	1	
Turkish	1	
Prefer not to answer	1	1%

^a multiple responses permitted

^b sub-categories are text responses that participants submitted when selecting 'Other race'

Table 3. Updated Race/Ethnicity Question

N=81		
	n	%
Race or Ethnic Origin^a		
Black^b	28	35%
African American	18	64%
Nigerian	6	21%
Jamaican	5	18%
Barbadian	3	11%
Ethiopian	3	11%
Trinidadian and Tobagonian	3	11%
Ghanaian	2	7%
Guyanese	2	7%
Haitian	2	7%
Somali	1	4%
Other ^c	4	14%
Kenyan	1	
Panama	1	
South African	1	
St. Vincent, West Indies	1	
White^d	23	28%
English	6	26%
French	6	26%
Irish	6	26%
Polish	6	26%
German	4	17%
Italian	3	13%
Russian	2	9%
Ukrainian	2	9%
Greek	1	4%

Table 3. Updated Race/Ethnicity Question, continued

Other ^c	5	22%
Arabic	1	
Middle Eastern	1	
Portuguese	1	
Scottish	1	
Spaniard	1	
Asian^e	16	20%
Chinese	4	25%
Filipino	4	25%
Asian Indian	3	19%
Korean	2	13%
Guyanese	1	6%
Japanese	1	6%
Taiwanese	1	6%
Vietnamese	1	6%
Other ^c	2	13%
Pakistani	1	
Singaporean	1	
Prefer not to answer	1	
Hispanic, Latino, or Spanish origin^f	13	16%
Puerto Rican	3	23%
Peruvian	2	15%
Mexican	2	15%
Cuban	1	8%
Dominican	1	8%
Salvadoran	1	8%
Other ^c	4	31%
Argentinian	1	
Guatemalan	1	
Panama	1	
Spaniard	1	

Middle Eastern or North African^g	10	12%
Lebanese	5	50%
Egyptian	3	30%
Syrian	3	30%
Iranian	2	20%
Moroccan	2	20%
Armenian	1	10%
Palestinian	1	10%
Other ^c	3	30%
Assyrian	1	
Kurdish	1	
Sudanese	1	
Native Hawaiian or Pacific Islander^h	10	12%
Native Hawaiian	3	30%
Samoan	3	30%
Chamorro	2	20%
Tongan	2	20%
Don't Know	1	10%
American Indian, Native, First Nations, Indigenous Peoples of the Americas, or Alaska Nativeⁱ	3	4%
Cherokee	2	67%
Blackfeet	1	33%
Other^c	5	6%
Central Asian, Aboriginal, Middle Eastern	1	
Mulatto	1	
Multi	1	
Missing	2	
Missing	1	1%

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