PERSPECTIVES ON PRECISION HEALTH AMONG RACIAL/ETHNIC MINORITY COMMUNITIES AND THE PHYSICIANS THAT SERVE THEM

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Background: In order for precision health to address health disparities, engagement of diverse racial/ethnic minority communities and the physicians that serve them is critical.

Methods: A community-based participatory research approach with mixed methods was employed to gain a deeper understanding of precision health research and practice among American Indian, African American, Latino, Chinese, and Vietnamese groups and physicians that serve these communities. A survey assessed demographics and opinions of precision health, genetic testing, and precision health research. Focus groups (n=12) with each racial/ethnic minority group and physicians further explored attitudes about these topics.

Results: One hundred community members (American Indian [n=17], African American [n=13], Chinese [n=17], Latino [n=27], and Vietnamese [n=26]) and 14 physicians completed the survey and participated in the focus groups. Familiarity with precision health was low among community members and high among physicians. Most groups were enthusiastic about the approach, especially if it considered influences on health in addition to genes (eg, environmental, behavioral, social factors). Significant concerns were expressed by African American and American Indian participants about precision health practice and research based on past abuses in biomedical research. In addition, physician and community members shared concerns such as security and confidentiality of genetic information, cost and affordability of genetic tests and precision medicine, discrimination and disparities, distrust of medical and research and pharmaceutical institutions, language barriers, and physician's specialty.

Conclusions: Engagement of racial/ethnic minority communities and the providers who serve them is important for advancing a precision health approach to addressing health disparities. *Ethn Dis.* 2020;30(Suppl 1):137-148; doi:10.18865/ed.30.S1.137

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INTRODUCTION

Health disparities related to race/ethnicity and socioeconomic status are a vexing problem in the United States and, if left unaddressed, will continue to widen, negatively impacting individuals, families, and society.[1-6] Addressing health disparities and promoting health equity requires attention to root causes across the lifecourse, particularly those associated with social disadvantage and historical and contemporary injustices.[7,8] Precision health is a new paradigm for health promotion, disease prevention, and treatment that takes into account heterogeneity in genes, environment, lifestyle, and social factors across groups for optimal maintenance of health and wellness across the lifecourse.[9-11] Precision health advances have already led to improved treatment and health outcomes for cancers such as breast, lung, and colorectal.[12] A precision health orientation to health disparities and health equity has great potential for reshaping population health as it takes into account the complex interplay between important root causes (eg, behavioral, environmental and social factors) and lifecourse influences (eg, genetic, epigenetic).[11,13,14] Despite the

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potential, precision health may widen disparities if underrepresented groups are not included in the research and do not have access to precision health and health care approaches that develop from this research.

Racial/ethnic minorities are underrepresented in precision health research[15,16] and have not been meaningfully engaged in developing this research agenda to date.[17] To address this gap, a deeper understanding of attitudes and beliefs toward precision health among racial/ethnic minority and low-income communities and the physicians who serve them is urgently needed. The goal of this study was to examine views from these groups about precision health and precision health research to inform strategies for conducting precision health research that will address health disparities.

> *The goal of this study was to examine views from these [minority] groups about precision health and precision health research to inform strategies for conducting precision health research that will address health disparities.*

METHODS

This study used a community-based participatory research (CBPR) approach[18] employing mixed methods to gain an in-depth understanding of awareness, attitudes, and concerns regarding precision health and precision health research among racial/ethnic minority communities and the providers who serve them. In partnership with community leaders and community-based organizations, we conducted focus groups with five different race/ethnicity groups: American Indian, African American, Latino, Chinese, and Vietnamese and with physicians who serve these diverse groups. We also administered a survey to assess demographics and awareness and attitudes toward precision health and genetics specifically. In accordance with CBPR principles, the community partners were integrally involved in all phases of the research from conceptualization to analysis and dissemination. This study was approved by the Stanford Institutional Review Board.

Participants and Setting

Using flyers, phone calls or in-person outreach, community partners recruited up to 30 healthy adults (>18 years of age) in each of the racial/ethnic groups and physicians. The study was conducted in community-based settings that were convenient for each racial/ethnic community and physicians in the San Francisco Bay Area.

Data Collection

A total of 12 focus group discussions were conducted: two with each racial/ethnic group and two with physicians. The focus groups with African American, American Indian and physicians were conducted in English. For Vietnamese, Chinese and Latinos, one of the focus groups was conducted in the native language and one in English. Informed consent was obtained from all participants. All participants received a $40 gift card.

All participants filled out a brief survey. The survey for community members assessed demographics, knowledge of precision health (eg, "Are you familiar with the terms "precision medicine" or "precision health"?) and genetics (eg, "Are you familiar with any of the terms "genetics," "genetic testing," or "genome"?), and attitudes toward precision health, genetic testing, and precision health research. Questions assessing attitudes asked the degree to which participants agreed with statements such as "The use of personal genetic information in health care is beneficial to patients." The survey for physicians assessed demographics, self-efficacy with precision health, and perception of their patients' knowledge and attitudes toward precision health.

Trained community partners and researchers facilitated focus group discussions. Facilitators were matched on race/ethnicity and/or language for each focus group. The focus group guide covered awareness and attitudes toward precision health and genetic testing, the potential of precision health to address health disparities, and views of precision health research. Focus group discussions were recorded and transcribed verbatim.

Analysis

Survey data were analyzed using STATA 15 to calculate means and percentages stratified by racial/ethnic group; survey data from providers were analyzed separately. The qualitative data analysis occurred in two phases. In the first phase, an experienced qualitative researcher (CN) read through all transcripts and developed a codebook with definitions using the topics in the focus group guide. Emergent codes were added on an ongoing basis. The codebook and definitions were refined through study team meetings with researchers and community partners. Then three qualitative researchers coded the 12 transcripts individually according to the codebook and reviewed each other's work. Discrepancies were resolved via consensus meetings. Coding was performed in Dedoose (Version 7.0.23). The goal of the second phase of the analysis was to identify cross-cutting themes and subthemes and to compare findings across racial/ethnic groups in a systematic and iterative manner following Braun and Clarke's guide

Table 1. Demographic characteristics of community member participants in focus groups by racial/ethnic group

Characteristic	Overall		American Indian		African American		Chinese		Latino		Vietnamese	
	N=100		n=17		n=13		n=17		n=27		n=26	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Sex												
Female	69	(69.7)	13	(76.5)	5	(41.7)	12	(70.6)	20	(74.1)	19	(73.1)
Male	30	(30.3)	4	(23.5)	7	(58.3)	5	(29.4)	7	(25.9)	7	(26.9)
Age category												
18-49 yrs	55	(57.3)	6	(40)	7	(58.3)	16	(94.1)	13	(50)	13	(50)
≥50 yrs	41	(42.7)	9	(60)	5	(41.7)	1	(5.9)	13	(50	13	(50)
Employment status												
Employed	43	(44.3)	10	(58.8)	7	(58.3)	4	(25)	11	(42.3)	11	(42.1)
Not employed	54	(55.7)	7	(41.2)	5	(41.7)	12	(75)	15	(57.7)	15	(57.7)
Education level												
High school or less	34	(36.2)	2	(11.8)	1	(9.1)	4	(25)	13	(52)	14	(56)
Some college or more	60	(63.8)	15	(88.2)	10	(90.9)	12	(75)	12	(48)	11	(44)
Marital status												
Single never married	30	(30)	5	(29.4)	5	(38.5)	7	(41.2)	6	(22.2)	7	(26.9)
Single ever married (widowed/separated/divorced)	13	(13)	3	(17.7)	2	(15.4)	0	(0.0)	8	(29.6)	0	(0.0)
Married/having partner	57	(57)	9	(52.9)	6	(46.1)	10	(58.8)	13	(48.2)	19	(73.1)
Has children												
Yes	54	(54.6)	13	(76.5)	7	(53.9)	3	(17.7)	17	(63)	14	(56)
US born												
Yes	41	(41.8)	17	(100)	13	(100)	4	(23.5)	1	(4.0)	6	(23.1)
No	57	(58.2)	0	(0.0)	0	(0.0)	13	(76.5)	24	(96)	20	(76.9)
Years lived in US[a]												
< 10 years	17	(11.5)	N/A	N/A	N/A	N/A	8	(47.1)	5	(20.9)	4	(15.4)
≥ 10 years	80	(88.5)	N/A	N/A	N/A	N/A	9	(52.9)	22	(79.1)	22	(84.6)
Native English speaker/fluent												
Yes	68	(68.7)	17	(100)	13	(100)	12	(70.6)	12	(46.2)	14	(53.8)
No	31	(31.3)	0	(0.0)		(0.0)	5	(29.4)	14	(53.8)	12	(46.2)
Has health insurance												
Yes	88	(88.9)	13	(76.5)	13	(100)	16	(91.1)	21	(77.8)	25	(100)
No	11	(11.1)	4	(23.5)	0	(.0)	1	(8.9)	6	(22.2)	0	(.0)
Household income level[b]												
Low	67	73.6	11	64.7	10	76.9	11	78.6	18	75	17	73.9
Middle	22	24.2	5	29.4	3	23.1	3	21.4	6	25	5	21.7
High	2	2.2	1	5.9	0	.0	0	.0	0	0.0	1	4.4

a. Not applicable for African American and American Indian participants who lived all their life in the United States.
b. Low: <$35,000, Middle: $35,000- $100,000 and High: >$100,000.

for thematic analysis.[19] Some survey results and the cross-cutting themes are presented in this manuscript.

RESULTS

Demographics

One hundred community members who self-reported their race/ethnicity as American Indian (n=17), African American (n=13), Chinese (n=17), Latino (n=27), and Vietnamese (n=26), completed the survey and participated in the focus group discussions (Table 1). Most participants were female (70%) and over half were between 18 and 49 years old (57%). A total of 14 physicians participated, nine females and five males, with an average age of 51 (SD ±13.07) and an average number of years practicing medicine of 16 (SD ±10.3) (Table 2). The physicians represented various specialties including primary care, gynecology, oncology, psychiatry, neurology, and podiatry. The majority were practicing in a safety net setting (57%).

Table 2. Physicians' demographic characteristics

Characteristics	Physicians N=14	
Sex, n (%)		
Female	9	(64.3)
Male	5	(35.7)
Age, mean (SD)	51	(13.07)
Race/ethnicity, n (%)		
African American	5	(35.7)
Latino	2	(14.4)
Asian[a]	5	(35.7)
Non-Hispanic White/Caucasian	1	(7.1)
Medical Specialty, n (%)		
Primary care (family/internal medicine)	5	(35.9)
Obstetrics & gynecology	3	(21.4)
Oncology	2	(14.3)
Other[b]	4	(14.2)
Number of years practicing, mean (SD)	15.5	(10.3)
Racial/ethnic groups of patients serving the most, n (%)[c]		
Asians	12	(85.7)
Latino/Hispanic	9	(64.3)
African American	4	(28.6)
White/Caucasian	2	(14.3)
Other[d]	2	(14.2)
Type of setting practicing in, n (%)[e]		
Public/county health system	8	(57.1)
Private office	5	(35.7)
Academic medical center	3	(21.4)
Retired	1	(7.1)

a. Out of which: 3 Chinese (21.5%), 1 Korean (7.1%), 1 Vietnamese (7.1%), 1 south Asian (7.1%).
b. Other including: psychiatry, Neurology, Pediatric and Podiatric.
c. Not mutually exclusive: Multiple selection.
d. Other including Native American or not a specific racial group.
e. Not mutually exclusive: Multiple selection.

Themes

Five cross-cutting themes were identified: 1) familiarity and attitudes toward precision health; 2) familiarity and attitudes toward genetic testing; 3) familiarity and attitudes toward precision medicine research; 4) concerns, sources of distrust and challenges; and 5) cultural norms and beliefs.

Theme 1: Familiarity and Attitudes toward Precision Health

The majority of participants (80%) reported that they were not familiar with the terms "precision health" or "precision medicine" (Table 3). However, participants posited that precision health is used to screen, prevent and treat certain diseases, including genetic conditions (Table 4: Quote 1.1.1 & 1.1.2). Following a discussion of the definition of precision health, the idea that it would be based on genetic, environmental, and lifestyle characteristics was appealing to almost all participants. At least some participants in each of the five racial/ethnic groups stressed the importance of addressing environmental, social, and lifestyle factors for health promotion in their communities (Table 4: Quote 1.1.3 & 1.1.4). Almost all physicians were knowledgeable about precision health and described it as a type of patient-centered care that provides personalized disease prevention and treatment. The two physicians less familiar with precision health reported they had not been involved in its clinical implementation (Table 4: Quote 1.1.5 & 1.1.6).

All Latino, Chinese, Vietnamese and some African American participants expressed a positive attitude toward precision health, commenting positively on it as a new direction to prevent, detect, and treat certain diseases as well as an opportunity to increase quality of care (Table 4: Quotes 1.2.1 to 1.2.4). However, the majority of American Indian and some African American participants had a negative attitude toward precision health because of historically based distrust (Table 4: Quotes 1.3.2 & 1.3.3). One American Indian participant equated precision health to "continued genocide" (Table 4: Quote 1.3.1). Physicians were generally supportive of precision health, although a few did mention concerns related to its novelty, its use among specific patient populations (Table 4: Quote 1.3.4 & 1.3.5), and its potential to widen health disparities.

Theme 2: Familiarity and Attitudes toward Genetic Testing

The majority of African American (83%) and around half of all the other racial/ethnic groups (American Indian: 53%, Chinese: 53%, Vietnamese: 46% and Latino: 46%) reported that they were familiar with terms such as genetics, genome, or genetic testing on the survey (Table 3). In focus groups, some Chinese participants explained that their limited knowledge resulted from a lack of exposure in China (Table 5, Quote 2.1.1). The majority of Chinese (77%), Latino (84%), and Vietnamese (84%) participants agreed that genetic testing is beneficial to patients in health care as compared with half of African American (54%) and American Indian (53%) participants (Table 3). In focus groups, participants in all groups mentioned that genetic testing is an important technique for the

Table 3. Knowledge and attitudes toward precision medicine and genetic testing: participants' survey

Knowledge and Attitudes	Overall, N=100		American Indian, n=17		African American, n=13		Chinese, n=17		Latino, n=27		Vietnamese, n=26	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Familiar with precision health												
Yes	19	(19.8)	3	(17.6)	3	(25)	1	(6.3)	6	(24.0)	6	(23.1)
No	77	(80.2)	14	(82.4)	9	(75)	15	(93.7)	19	(76.0)	20	(76.9)
Willing to participate in precision health research												
Agree	52	(53.1)	1	(5.9)	5	(38.5)	11	(64.7)	18	(69.2)	17	(68.0)
Disagree	11	(11.2)	6	(35.3)	1	(7.7)	2	(11.8)	1	(3.9)	1	(4.0)
Neutral	25	(25.5)	7	(41.2)	4	(30.8)	4	(23.5)	3	(11.5)	7	(28.0)
Don't Know	10	(10.2)	3	(17.6)	3	(23)	0	(.0)	4	(15.4)	0	(.0)
Familiar with genetic testing												
Yes	52	(53.1)	9	(52.9)	10	(83.3)	9	(52.9)	12	(46.2)	12	(46.1)
No	46	(46.9)	8	(47.1)	2	(16.7)	8	(47.1)	14	(53.8)	14	(53.9)
Use of personal genetic information in health care is beneficial to patients												
Agree	71	(73.1)	9	(52.9)	7	(53.8)	13	(76.5)	21	(84.0)	21	(84.0)
Disagree	2	(2.1)	0	(.0)	1	(7.7)	0	(.0)	1	(4.0)	0	(.0)
Neutral	12	(12.4)	4	(23.5)	2	(15.4)	4	(23.5)	0	(.0)	2	(8.0)
Don't Know	12	(12.4)	4	(23.5)	3	(23.1)	0	(.0)	3	(12.0)	2	(8.0)
Undergoing genetic testing to find out if I am at risk for certain diseases												
Agree	59	(60.9)	3	(17.6)	7	(53.8)	11	(64.7)	20	(80.0)	18	(72.0)
Disagree	11	(11.3)	5	(29.4)	1	(7.7)	2	(11.8)	2	(8.0)	1	(4.0)
Neutral	21	(21.6)	6	(35.4)	3	(23.1)	4	(23.5)	3	(12)	5	(20)
Don't Know	6	(6.2)	3	(17.6)	2	(15.4)	0	(.0)	0	(.0)	1	(4.0)
Undergoing genetic testing to find out if a certain drug or treatment would work for my conditions												
Agree	59	(60.2)	2	(11.8)	5	(42.3)	13	(76.4)	19	(73.1)	20	(80.0)
Disagree	11	(11.2)	7	(41.1)	0	(0.0)	2	(11.8)	2	(7.7)	0	(.0)
Neutral	21	(21.4)	6	(35.3)	5	(26.9)	2	(11.8)	4	(15.4)	4	(16.0)
Don't Know	7	(7.2)	2	(11.8)	3	(23.1)	0	(.0)	1	(3.8)	1	(4.0)

Table 4. Qualitative supporting quotes, theme 1: familiarity and attitudes toward precision medicine

Codes	Quote
1.1. Knowledge	1.1.1. "I'll take a wild guess and think that it's using genetics to focus your use of medicine to treat things" (American Indian)
	1.1.2. "Determine if a certain medication or treatment will be better for that specific individual rather than a group….so it's more I guess precise precision health" (Chinese)
	1.1.3. "It's largely part of our culture to think that, because our grandma, parents, had something, then we will surely get it too. That's something very important" (Latino)
	1.1.4. "Genes could also be affected by environment, not only hereditary" (Chinese)
	1.1.5. "It's going to take more than us. You know somebody mentioned patient-centered homes or cares medical homes. I mean those terms have been thrown around for years at the MC" (Physician)
	1.1.6."The right drugs for the right person at the right time" (Physician)
1.2. Positive attitudes	1.2.1. "We're talking about early detection, which is the key" (African American)
	1.2.2. "These are preventive measures….this is the kind of medicine where you map your genes and see what your risks are" (Chinese)
	1.2.3. "It will help our future for our kids and our grandkids and everybody else" (Latino)
	1.2.4. "It's good because doctors can treat their patients the best way" (Vietnamese)
1.3. Negative attitudes	1.3.1. "I'm like suspicious of continued genocide. It's definitely paranoia, but it upsets me" (American Indian)
	1.3.2. "What are native people going to receive by participating in this? Are they going to be left by the wayside or are we going to have a repeat of history" (American Indian)
	1.3.3. "When it comes down to this particular population African Americans to participate it's about attacking… because older generations lost their trust" (African American)
	1.3.4. "This precision medicine is a bright new shining object …… patients who know about it may overestimate its efficacy and underplay side effects" (Physician)
	1.3.5. "With schizophrenia or psychosis there's probably no way for me to stop this from happening. There's always so much fear…..so I feel I am struggling with that" (Physician)

prevention and screening of diseases, followed by treatment of rare diseases as well as related to prenatal care (Table 5: Quotes 2.3.1 and 2.3.2). In each focus group at least one participant mentioned Angelina Jolie during discussions about genetic testing (Table 5: Quotes 2.2.2 and 2.2.3).

When asked about willingness to undergo genetic testing to screen or treat certain diseases, a majority of Latino, Chinese, Vietnamese and approximately half of African American participants were willing, compared with very few American Indians (18% for screening and 12% for treatment) (Table 3). During the focus group discussions, all African American, American Indian, Chinese, and some Latino and Vietnamese participants expressed concerns about undergoing tests without first being given a full understanding of the process and what would be done with their test results and DNA samples (Table 5: Quote 2.3.3). Some Vietnamese participants stated they would only consider genetic testing after discussing it with family members (Table 5: Quote 2.3.4).

Half of physicians mentioned that their patients would agree to undergo genetic testing if they prescribed it, while the other half mentioned that their patients might be skeptical about it. Fear of predisposition to certain diseases and discrimination were common concerns that physicians reported hearing from patients when they ordered genetic testing (Table 5: Quotes 2.3.5 and 2.3.6).

Theme 3: Precision Health Research

The majority of Chinese (65%), Latino (69%), and Vietnamese (68%) participants expressed their willingness to participate in precision health research (Table 3). In focus groups, interest and enthusiasm in participating in research involving genetic testing for disease prevention and treatment was evident (Table 6: Quote 3.1.1). However, some Chinese and a few Latino participants were worried about being experimental subjects and advocated

Table 5. Qualitative supporting quotes, theme 2: familiarity and attitudes toward genetic testing

Codes	Quote
2.1. Knowledge	2.1.1. "Most of the hospitals in the mainland China… they don't have this type of treatment method. Or there is no way for people to access this type of treatment, not too many people will understand this" (Chinese)
2.2. Famous celebrity	2.2.2. "Angelina Jolie, who made a widely publicized choice to undergo a double mastectomy after undergoing genetic testing" (American Indian)
	2.2.3. "People may have heard stories about Angelina Jolie who had a genetic test and then had a procedure. That's the extent. People know something exists but most of the Latino American community doesn't have access to this information" (Latino)
2.3. Attitudes	2.3.1. "These are preventive measures where you map your genes and see what your risks are" (Chinese)
	2.3.2. "When you become pregnant now a days they do a lot of genetic things to figure out with the baby" (African American)
	2.3.3. "I want to know what exactly they are doing" (African American)
	2.3.4. "I have the talk with family first" (Vietnamese)
	2.3.5. "Hopefully we can reassure all of those patients of the genetic information non-discrimination act and they are not allowed, they are not legally allowed to discriminate against based on their genetic information for employment or insurance" (Physician)
	2.3.6. "Afraid to find out that they have other diseases something worse than what they came for" (Physician)

for information about the type of research, process, risks, and benefits before deciding whether to participate. Chinese and Vietnamese participants discussed that younger generations and educated people would be more willing to participate in research as compared with older and less educated people (Table 6: Quote 3.1.2).

A little more than half of African American (54%) and American Indian (59%) participants reported that they either didn't know or were neutral about participation in precision health research. While 39% of African Americans reported that they would participate in precision health research, only 6% of American Indians reported they would be interested in participating. In focus group discussions, both African Americans and American Indians discussed their reluctance to participate in research as related to concerns about historical abuses, cultural factors, marginalization and/or racism. Some African American participants specified that they would only be interested in anonymous, non-experimental precision health research, and others said they would be interested in research led by African American researchers only. African American participants mentioned the Tuskegee experiment and Henrietta Lacks specifically as main reasons behind their reluctance

Table 6. Qualitative supporting quotes, theme 3: precision health research

Codes	Quotes
3.1. Positive attitudes	3.1.1. "It will help our future for our kids and our grandkids and everybody else" (Latino)
	3.1.2. "Younger generation are more willing to participate in research compared to older generations because they're less experienced in research and have less knowledge" (Vietnamese)
3.2. Negative attitudes	3.2.1. "We don't want to be guinea pigs" (African American)
	3.2.2. "Do you feel safe with research and trials? I don't think so" (African American)
3.3. Suggestions	3.3.1. "If precision medicine is going to be part of the future then one of the questions that comes to mind is to what extent are the information networks within the African-American community [are] going to be utilized" (Physician)
	3.3.2. "When you talk about being interested in doing this genomics research, gene sequencing, or even education and precision medicine, I think a lot of the doctors at this day and age… they go 'why would you want to do that?' or like 'what are you trying to accomplish?'" (Physician)
	3.3.3. "Until the last couple of years, right, there's not a lot of awareness within the communities about the lack of minority [patients] donating bone marrow and so I think educating the community is important" (Physician)

(Table 6: Quotes 3.2.1 and 3.2.2).

A majority of physicians expressed willingness to be involved in precision health research. In order to include racial/ethnic minorities in precision health, some physicians suggested: increasing physicians' and patient knowledge about precision health; encouraging clear communication strategies between patients and physicians; and building trusting relationships with the medical and research communities (Table 6: Quotes 3.3.1 to 3.3.3).

Theme 4: Concerns, Sources of Distrust and Challenges

Participants and physicians expressed different concerns pertaining to: 1) security and confidentiality of genetic information; 2) costs of genetic tests and precision medicine; 3) discrimination and disparities; 4) distrust of medical research and pharmaceutical institutions; 5) language barriers; and 6) physician's specialty.

Security and confidentiality of genetic information was a major concern for many participants, especially Chinese and American Indians, (Table 7: Quotes 4.1.1 & 4.1.2), and was also reported by physicians (Table 7: Quote 4.1.3). Participants expressed fear about data being shared with sources external to health care systems, including employers (primarily mentioned by Latinos) and insurance companies (Table 7: Quote 4.1.4).

Costs of genetic tests and precision medicine was another shared concern reported by physicians and participants across the five different groups and especially among Chinese, Latino

Table 7. Qualitative supporting quotes, theme 4: concerns, sources of distrust and challenges

Codes	Quotes
4.1. Security and confidentiality of genetic information	4.1.1. "They have to put that in writing to protect patient (American Indian)
	4.1.2. "I have no confidence, even Apple can be hacked" (Chinese)
	4.1.3. "Many people went and got their HIV test and there was initially a concern about the results becoming available to insurance companies" (Physician)
	4.1.4. "But there's computer hackers you know? People are hacking into everything bank accounts (and) medical records. (Latino)
4.2. Cost and affordability of genetic tests and precision medicine	4.2.1. "Compared to regular medicine, it would be more expensive…It's a "special service" focusing on every single person, and that will be related to insurance issue" (Chinese)
	4.2.2. "The problem is getting authorization from insurance companies" (Physician)
4.3. Discrimination and disparities	4.3.1. "A lot of the low income communities: we get the end of the stick" (African American)
	4.3.2. "What are native people going to receive by participating in this? Are they going to be left by the wayside or are we going to have a repeat of history?" (American Indian)
4.4. Distrust of medical and research and pharmaceutical institutions	4.4.1. . "It's evil…are you trying to use my data for cloning" (American Indian)
	4.4.2. "What are you going to do with this information once you have it? That would be my biggest question" (African American)
	4.4.3. "I need to think if I trust the organization doing the research" (Chinese)
	4.4.4. "I think my African American patients would be probably reluctant as we referred to because of the Tuskegee study you know most African Americans know about it or heard something about it" (Physician)
4.5. Language barriers	4.5.1. "Language barrier is really huge because sometimes even though they have translators they cannot express in the fullest way that they want" (Vietnamese)
	4.5.2. "We are so uncertain about what we're saying right we don't understand uncertainty as Physicians and how we understand what we're saying so it's very logical for them to be questioning our paradigm" (Physician)
4.6. Physician's specialty	4.6.1. "I agree if the Doctor is a specialist" (Chinese)
	4.6.2. "Some of those denials come back and say well these tests were supposed to be ordered by a specialist" (Physician) 4.6.3 "I think in primary care it's more difficult, the barrier is insurance coverage" (Physician)

Table 8. Qualitative supporting quotes, theme 5: cultural norms and beliefs

Codes	Quotes
5.1. Traditional medicine	5.1.1. "I'd go back home first to a medicine man. I would seek a medicine man first before I'd go to any modern civilization and medicine for healing and help" (American Indian)
5.2. Resilience	5.2.1. "Because we've been pushed down for so long… our genetic code has resiliency because we keep coming back, that's what makes us stronger…and that factors into our health" (American Indian)
	5.2.2. "Physically we are not built like white people…we can sustain more… you can they use our blood and genetics to modify so many things within health and stuff like" (African American)
5.3. Religion and spirituality	5.3.1 "I believe that we Mexicans are very religious" (Latino)
	5.3.2. "Whatever happen, its God given…and God gave your life, God decide everything if you get certain disease and you're going to die from it" (Vietnamese)
	5.3.3. "Are we trying to control how the world is supposed to be" (African American)
	5.3.4. "My body fluids are sacred as a Native or pre-American and so I don't want that out in the public domain for research or anything" (American Indian)
5.4. Taboos	5.4.1 "Taboo about talking about having a genetic disease there's potential" (Chinese)
	5.4.2 "My body fluids are scared as a Native or pre-American and so I don't want that out in the public domain for research or anything (American Indian)

and Vietnamese participants. All believed that precision health will not be affordable for all patients and, unless covered by insurance companies, its use would be limited as a result (Table 7: Quotes 4.2.1 and 4.2.2).

Participants worried that precision medicine might lead to discrimination and health disparities. Some African American participants discussed existing heath care disparities and stated that current treatments are based on research involving non-Hispanic Whites, which might not be relevant to them. Latino, Chinese, Vietnamese and some American Indian participants expressed a desire to undergo genetic testing only with clear laws and regulations that would protect them from discrimination. They were concerned about institutions prioritizing profit over helping patients and failing to distribute the benefits of their research to communities (Table 7: Quotes 4.3.1 and 4.3.2).

There were mixed opinions on the trustworthiness of physicians, researchers, and pharmaceutical institutions. While the majority of Vietnamese, Latino and Chinese trusted their physicians, American Indian participants were skeptical about physician knowledge and competence in precision health. African American participants expressed distrust of non-Hispanic White physicians relating to the Tuskegee experiment. Some American Indian participants distrusted physicians with concerns ranging from poisoning to involuntary cloning (Table 7: Quote 4.4.1). In addition to physicians' trustworthiness, many participants expressed distrust in individuals or institutions with access to their genetic information. Many African American and American Indian participants expressed concerns about potential harmful or profiteering intentions of genetic testing, which was also reported by physicians as a barrier to precision health (Table 7: Quotes 4.4.2 to 4.4.4).

Some Vietnamese participants expressed concern regarding language barriers that make it difficult to communicate clearly with their physicians about the reasons, processes, risks and benefits of genetic testing. (Table 7: Quote 4.5.1). Physicians also noted language barriers as a problem, often leading to skepticism among non-English speaking patients (Table 7: Quote 4.5.2).

Physician's specialty was an important matter for some Chinese participants who said they would only consider undergoing genetic testing if prescribed by a genetic specialist. Physician specialty was also reported by some physicians as a major barrier for prescribing genetic testing. They stated that although primary care physicians have a major role in disease prevention, genetic tests are not always covered by insurance unless prescribed by specialists, which could limit the implementation of precision health in primary care (Table 7: Quotes 4.6.1 to 4.6.3).

Theme 5: Cultural Norms and Beliefs

Diverse cultural norms and beliefs were reported by participants during focus groups. Some American Indian, African American, Chinese and Vietnamese participants expressed a clear preference for traditional medicine while other participants expressed a willingness to embrace precision health practices (Table 8: Quote 5.1.1). Many American Indian and some African American participants expressed a high level of confidence in the resilience of their own bodies that made them stronger than their non-native and non-African American counterparts. They attributed this resilience to survival of historical abuses. Multiple American Indian participants mentioned that living on their continent of origin made them uniquely equipped to deal with American diseases (Table 8: Quotes 5.2.1 and 5.2.2). Many Latino and some Vietnamese and African American participants viewed precision health as interfering with God's will (Table 8: Quotes 5.3.1 to 5.3.4). Many American Indian participants expressed an aversion to sharing bodily fluids for testing and considered their bodily fluids sacred, while many older Chinese participants reported discussing health matters and diseases in public as "taboo" (Table 8: Quotes 5.4.1 and 5.4.2).

DISCUSSION

This mixed methods study of diverse racial/ethnic minority communities' and physicians' views on precision health is a critical first step for precision health to have meaningful impact on health disparities. Our findings indicated that, while knowledge of precision health is low in the racial/ethnic minority communities included, some groups were enthusiastic about the approach, especially in as much as precision health considers influences on health in addition to genes (eg, environmental, behavioral, social factors). At the same time, significant concern was expressed by African American and American Indian participants about precision health practices and research based on past abuses in biomedical research. In addition, participants across the racial/ethnic groups and the physicians vocalized important concerns that need to be considered in order for precision health to have a meaningful impact on health disparities.

These results suggest that much work is needed to raise awareness about precision health in racial/ethnic minority communities. Familiarity with genetic testing was much higher, as evidenced by the number of participants across all five groups that mentioned the actress Angelina Jolie as an example of genetic testing to determine risk of hereditary breast and ovarian cancer. This suggests that the media may be able to play a role in increasing awareness about precision health. After learning about the definition of precision health, participants stressed that health is influenced by multiple factors in addition to genetics including socioeconomic status, health behaviors, neighborhood environment, and health care access. For precision health to be relevant for minority communities, it will be important that precision health research include these diverse factors.

Enthusiasm for precision health and precision health research varied remarkably between groups. Latino, Vietnamese, and Chinese participants were generally open to precision health and participation in precision health research. This may reflect a general acceptance of health care and research available in the United States or a lack of previous adverse experiences in US-based health care and research. In contrast, African American and American Indian participants demonstrated mistrust and skepticism. These significant

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concerns mean that researchers will need to make significant efforts to gain the trust of these communities, so they feel comfortable participating in precision health research. One approach to gaining trust, as brought up by African American participants, would be to increase the number of African American researchers conducting this type of research.

Diverse concerns were raised across all groups, including physicians, generally related to ways in which genetic information would be shared, possible implications of discrimination, and barriers in accessing precision health care due to costs, insurance coverage, and language barriers. Previous studies of community-based primary care physicians (n=488)[20] and African American college students (n=97)[21] documented similar concerns, especially related to discrimination and privacy. Similarly, participants across the groups discussed diverse cultural beliefs related to genetic testing and precision health care that may be relevant to consider when engaging racial/ethnic minority communities. Including community members early in the research process, ideally in the conceptualization of the research question, can ensure that diverse concerns as well as cultural and religious views are addressed. Additionally, these discussions indicate that cultural competency is necessary for physicians and researchers to establish open and clear communication about precision medicine.

Few community members or physicians were familiar with the Genetic Information Nondiscrimination Act of 2008 (GINA).[22] Similarly, a recent national survey reported that 79% of public respondents were unfamiliar with GINA, and of those who claimed to be familiar with the law, only 44% knew that it protected against genetic discrimination in health insurance, only 31% knew that it protected against employer discrimination, and 23% incorrectly thought it provided protection from life, disability, or long-term care insurance discrimination.[23] Raising awareness about this legislation may contribute to decreased fears about discrimination among community members and physicians.

Physicians offered recommendations for preventing widening disparities and to make precision health care and precision health research accessible: 1) increase physician training and knowledge about precision medicine and precision health; 2) conduct outreach to community members to increase knowledge; and 3) encourage clear communication strategies between patients and physicians to build trusting relationships and partnerships. Hauser and colleagues in the New York City region called for similar efforts to promote patient protections and effective adoption of precision medicine by physicians.[20]

Limitations of this study are related to the relatively small sample size of each racial/ethnic group and to the specific geographic region where the study was conducted. While this study provides important information on five racial/ethnic groups, future work could include additional minority groups, in-depth studies focused on one minority population, or research to understand if there are regional differences in attitudes and views on precision health.

Conclusion

This study highlights critical issues to address in conducting precision health research and implementing precision health approaches in minority communities. Immediate efforts should focus on increasing awareness and addressing concerns related to historical abuses, discrimination, cost, and language. Trusting community-university partnerships will be ideal for informing successful strategies to increase awareness and address concerns raised in the focus groups. Together, communities and their academic partners can work to ensure that precision health contributes to eliminating, rather than exacerbating, health disparities.

Conflict of Interest

No conflicts of interest to report.

Author Contributions

Research concept and design: Rosas, Vasquez, Garrick, Hattin, David, Evans; Acquisition of data: Rosas, Nasrallah, Park, Vasquez, Garrick, Hattin, Cho, Evans, Martin; Data analysis and interpretation: Rosas, Nasrallah, Park, Vasquez, Garrick, Hattin, Cho, Evans, McClinton-Brown, Martin; Manuscript draft: Rosas, Nasrallah, Vasquez, Garrick, Hattin, Cho, David, Evans, McClinton-Brown, Martin; Statistical expertise: Nasrallah, Garrick, Hattin, Martin; Acquisition of funding: Rosas; Administrative: Rosas, Park, Vasquez, Duron, Cho, David, Evans, McClinton-Brown; Supervision: Rosas, Park, Garrick

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