

Assessing Vietnamese American patient perspectives on population genetic testing in primary care: A community-engaged approach

Amy A. Lemke,^{1,8,*} Sarah H. Choi,² Vinh Dang,³ Tommy Q. Dang,⁴ and Joon-Ho Yu^{5,6,7}

Summary

Achieving health equity in precision medicine remains a critical challenge because of the continued underrepresentation of non-white populations in research and barriers to genetic services. The goal of this study was to explore Vietnamese American (VA) participant views toward incorporating genetics in routine healthcare to better serve the local VA community within an integrated health system offering primary care-based population genetic testing to adults for conditions that could be prevented or mitigated when detected early. We conducted semi-structured interviews from August–September 2021, with 22 individuals receiving primary care who self-identified as Vietnamese or VA, and employed rapid qualitative analysis (RQA) to identify key concepts. Community research team members participated in study design, data collection, RQA, and reporting. Findings from the interviews revealed that several participant perceived challenges to genetic testing, which included lack of information, fear of results impact, cost, and privacy concerns. Participants suggested various ways to overcome some of these barriers, such as decreasing the cost of testing, receiving information from a trusted physician, using preferred education strategies in the community, and having convenient access to testing. Study participants also shared a variety of trusted sources they would seek out for advice on genetic testing. This study with VAs identified barriers, facilitators, and messengers to offering genetic testing in a local healthcare context and demonstrated how community-engaged research coupled with RQA is a promising approach for healthcare institutions as they identify needs and tailor strategies for implementing population genetic screening programs in local ethnic communities.

Introduction

Precision medicine is being implemented in healthcare systems by offering population genetic screening to healthy individuals to increase awareness of disease risk, inform medication choice and dose, and enable early detection and prevention. A key challenge for its widespread implementation, as with all newer healthcare technologies, is the potential to develop and widen healthcare disparities. Achieving health equity in precision medicine remains a critical challenge because of the continued underrepresentation of racially and ethnically minoritized populations that have experienced historical trauma and structural inequities in research¹ and barriers to receiving genetic services.²

Limited existing research shows that Asian Americans (AAs) generally have positive attitudes towards genetic medicine and testing,^{3–6} but some AA populations frequently miss opportunities for early access to genetic counseling, testing, and disease prevention.⁷ As reported in previous studies, key facilitators for genetic testing with AAs focus on aspects of healthcare, including trust in healthcare providers and physicians,⁴ clear communication refraining from use of analogies and hypothetical ex-

planations,⁸ and availability at a low cost as well as insurance coverage.⁹

Barriers to genetic testing include healthcare system and individual factors. Reported healthcare- or systems-level barriers are limited medical interpretation for non-English-proficient individuals,^{9,10} cost and insurance coverage,^{3,11,12} and suboptimal referral.^{7,10} The latter was recently demonstrated by a difference in referral for genetic testing between non-Hispanic White individuals and other minoritized groups, including non-Hispanic Black, Hispanic, and Asian people. AAs have reported their own low awareness and knowledge of genetic services as well as general unfamiliarity and discomfort with western medicine.^{3,9,11} Additional psychosocial barriers relate to potential emotional trauma and anxiety and fear of discrimination and exploitation.^{3,13} These factors together often inform decisions to not pursue genetic testing³ and suggest a need for more culturally sensitive approaches to individual and family education and service provision.

Foundational to many of these barriers is the frequent monolithic treatment of “Asians.” AAs are often aggregated into a single, non-specific “Asian” category, particularly in genetic research, that often masks meaningful

¹Norton Children’s Research Institute, Affiliated with the University of Louisville School of Medicine, Louisville, KY 40202, USA; ²Neaman Center for Personalized Medicine, NorthShore University HealthSystem, Evanston, IL 60201, USA; ³Summit School Inc., Elgin, IL 60123, USA; ⁴Department of Family Medicine, Swedish Hospital – Part of NorthShore, Chicago, IL 60625, USA; ⁵Division of Genetic Medicine, Department of Pediatrics, University of Washington School of Medicine, Seattle, WA 98195, USA; ⁶Division of Bioethics and Palliative Care, Department of Pediatrics, University of Washington School of Medicine, Seattle, WA 98195, USA; ⁷Treuman Katz Center for Pediatric Bioethics, Seattle Children’s Hospital and Research Institute, Seattle, WA 98105, USA

⁸Lead contact

*Correspondence: amy.lemke@louisville.edu

<https://doi.org/10.1016/j.xhgg.2022.100134>.

© 2022 The Author(s). This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).



health differences between Asian ethnic groups and their understanding and views towards genetic services.^{2,14} In turn, aggregation precludes interpreting differences between ethnic populations' perspectives toward genetic services that may be relevant to geographical or location-specific communities. As the demographic characteristics of local ethnic communities continue to change, such generalizability to race may simply be inadequate to inform location-based healthcare systems. Ultimately, the lack of group-specific knowledge prohibits our understanding of genetic testing translation and its implementation in precision medicine.

Addressing individual- and system-level barriers to genetic testing may benefit from adopting a local ethnic community perspective. For example, Vietnamese Americans (VAs) are one of the fastest growing Asian subpopulations in the United States with a unique historical and cultural background that has involved multiple diasporic migrations.^{15,16} Despite their significant community presence, a recent systemic review identified only two articles that included VAs as a distinct subgroup, and none of the studies compared multiple AA subgroups.²

Community engagement provides a way for all stakeholders to participate in understanding the priorities of underrepresented ethnic minority communities^{2,17} but is often resource intensive and time consuming,¹⁸ given the growing diversity of the United States. Therefore, we adopted a community-engaged research (CEnR) approach coupled with rapid qualitative analysis (RQA) to explore VA participants' views toward incorporating genetics in routine healthcare to better serve the local VA community within a healthcare system implementing primary care-based population genetic testing.

Materials and methods

Setting and study design

In 2019, NorthShore University HealthSystem implemented a pilot primary care physician-genetics provider approach for population genetic testing and offered adult individuals, regardless of family history, no-cost genetic testing to enable risk identification, early detection, and prevention. The clinical-grade genetic testing included 60 genes associated with hereditary cancer and cardiac conditions, pharmacogenomic testing, and common trait information. Through this pilot program, testing was provided to over 10,000 individuals through their primary care physician in conjunction with their annual preventive care visit. Individual and provider experiences and outcomes from this initiative have been described previously.^{19,20} The program was expanded in the spring of 2021 and included primary care sites serving ethnic minority communities in north Chicago.

Based on the high level of interest by and established existing relationships with a north Chicago Vietnamese community, we elected to design a study to learn more about perceived barriers and facilitators to genetic testing in this community. We utilized a CEnR approach to inform our overall study design, including data collection, analysis, and write-up procedures.²¹ Our design

process was guided by quality standards for qualitative research and the Standards for Reporting Qualitative Research.^{22,23}

Local north Chicago Vietnamese community leaders were invited to participate in a focus group in May 2021 to discuss potential research questions, study design, and community education strategies surrounding genetic testing. Based on input from this group, we decided to engage Vietnamese community members who were seen for care at a well-established and respected neighborhood clinic in north Chicago (part of the integrated health system) to participate in our study. A trusted primary care physician at this clinic, who is Vietnamese and resides in this community, became a key member of the research team and helped recruit two other Vietnamese study team members. Training in community-based qualitative research was provided to the study team so that community members could also contribute to multiple aspects of the research study. This study was approved by the Swedish Hospital institutional review board.

Participants and recruitment

Participant inclusion criteria were that individuals must be aged 18 or older, received care at the north Chicago primary care clinic, and self-identified as Vietnamese or VA. Participants were recruited without consideration of health conditions or experience with genetic testing. Sequential, purposive sampling was utilized to identify participants during August and September 2021. A trained clinic staff member who spoke Vietnamese and English provided prospective participants with oral and written explanations using a recruitment flyer (Vietnamese or English) at the time of their clinic appointment. Participants were offered a \$50 gift card as compensation for their time. Upon completion of the interview, the gift card was mailed to the participant with a United States Postal Service (USPS) Receipt of Delivery form.

Data collection and procedures

Semi-structured interviews were used to assess views held by Vietnamese participants to better understand their perceptions of genetics and genomics-guided care. All interviews were completed by telephone because this was the participants' preferred method of conducting the interview. Many of the interviews were conducted in the evening, and the telephone interviews allowed more participant convenience and flexibility. At the start of the telephone interview, the study goal was reiterated, and informed consent information was read aloud to the participant. Agreement to proceed with the interview was considered implied consent. All study documents were developed in English and then translated into Vietnamese using a hospital-approved vendor for translation. The Vietnamese translated documents were also reviewed by study team members who speak and read English and Vietnamese for accuracy in the back-translation to the English versions.

Prior to initiating interview questions, a brief description of predictive genetic testing was read to the participant ([supplemental information](#)). Open-ended questions with probes were used to facilitate discussion, and closed-ended sociodemographic questions were also asked at the end of the interview ([supplemental information](#)). The English and Vietnamese translated discussion guide questions were pretested by English- and Vietnamese-speaking individuals to check for clarity and understanding. Interviews were conducted by a trained community member in Vietnamese or English, depending on participant preference. Theoretical saturation of key concepts,²⁴ where no new insights were emerging, was noted by completion of 22 interviews.

Table 1. Participant characteristics

	n	(%)
Sex		
Female	10	(45)
Male	11	(50)
Prefer not to answer	1	(5)
Age		
18–29	9	(41)
30–39	7	(32)
40–49	2	(9)
50–59	1	(5)
60–69	2	(9)
70 or older	1	(5)
Highest education level		
Less than ninth grade	2	(9)
9th–12th grade, no diploma	1	(5)
High school graduate or equivalent (GED)	5	(23)
Some college, no degree	2	(9)
Associate’s degree	1	(5)
Bachelor’s degree	9	(41)
Graduate or professional degree	2	(9)
Annual household income		
Less than \$20,000	4	(18)
\$20,000–\$39,999	3	(14)
\$40,000–\$59,999	1	(5)
\$60,000–\$79,999	5	(23)
\$80,000–\$99,999	1	(5)
\$100,000–\$139,999	2	(9)
\$140,000 or more	1	(5)
Prefer not to answer	5	(23)
Health insurance status		
Commercial/private health insurance	14	(64)
Medicaid or any kind of state or government-sponsored assistance	4	(18)
Medicare and Medicaid	2	(9)
No insurance	2	(9)
Health rating		
Excellent	2	(9)
Very good	7	(32)
Good	3	(14)
Fair	8	(36)
Poor	2	(9)

Data analysis

Interviews were recorded and transcribed verbatim in the original language by a transcription service. The Vietnamese transcripts were also reviewed by our Vietnamese-speaking study team members for accuracy of translation and interpretation. All Vietnamese transcripts were back-transcribed in English. The entire team was trained in RQA procedures and directed content analysis^{22,25–28} by an experienced investigator who has previously trained community members in qualitative research. RQA was utilized because this method has been shown to produce similar rigor and findings as traditional qualitative analysis, provides a systematic approach other than software coding, reduces time, and improves efficiency.^{29–32} A distinguishing feature of RQA is inclusion of community members as part of a multidisciplinary research team.³³

The RQA data reduction process involved creating topic names or “domains” that corresponded with the interview questions, and these domains were listed in a summary template used by the research team.^{34,35} Two team members completed template summaries for a subset of the transcripts and reviewed them together for similar summary styles and volume of information per domain. Differences were resolved, and when consistency was established, the team members worked independently to complete the remaining template summaries. Exemplary participant quotes were also included within each domain of the summary template. A final step involved development of a consolidated matrix to facilitate visual assessment of variation in each domain, note any gaps in information, and identify key concepts.³⁶ The entire research team jointly identified the emerging concepts related to each domain that was presented. Descriptive statistics were used to summarize responses to the sociodemographic questions.

Results

Participant characteristics

Twenty-two individuals participated in this study. Approximately half of the participants were male, and three-fourths were between the ages of 18 and 39 (range, 18 to 70 and older). Participating individuals reported a wide range of educational backgrounds and income levels. The vast majority indicated having health insurance (Table 1). All participants self-reported their race as Asian, and all but one indicated the country of origin as Vietnam, with a wide range of estimated United States arrival dates. Slightly over half (59%) reported their preferred language as Vietnamese (Table 2).

The community leaders we engaged specifically wanted us to ask participants how much violence they believe they experience because of race. Therefore, we asked, “Some people in the United States may have experienced violence because of their race or ethnicity and others may not have. How often do you fear that someone might threaten or physically attack you because of your race or ethnicity?” Six of 22 participants indicated that they sometimes, often, or always fear violence because of race.

Interview findings

Below we present the main findings that emerged from analysis of the key interview domains: (1) perceived

Table 2. Select participant migration characteristics

	n	(%)
Place of birth		
Vietnam	20	(91)
United States	2	(9)
County of origin		
Vietnam	21	(95)
China	1	(5)
Preferred language		
Vietnamese	13	(59)
English	8	(36)
Cantonese	1	(5)
Approximate year of arrival in the United States		
1970–1979	1	(5)
1980–1989	0	(0)
1990–1999	4	(18)
2000–2009	5	(23)
2010–2019	8	(36)
2020 or later	3	(14)
Prefer not to answer	1	(5)

challenges to genetic testing, (2) ways to overcome challenges of genetic testing, and (3) trusted sources for health information and genetic testing (Table 3).

Perceived challenges to genetic testing

Lack of information. A number of participants discussed how lack of information, or misinformation, can be a barrier to getting genetic testing in the Vietnamese community. One person noted: “I don’t think there are many people who know that. They simply go to the hospital for a general examination...But rarely do they care about genetic testing. I think the biggest reason why people refuse taking the genetic test is because they know very little, or not at all, about the test. I myself have never heard of it before.” (participant 16 [P16]). Others described how people with limited English proficiency and older individuals in the community may be more likely to face challenges in accessing information about genetic testing: “They are afraid that their English is not fluent enough...They are afraid that they won’t understand the terms.” (P02). There were also comments on how lack of information may lead to misinformation and distrust of the genetic testing technology and process. One participant explained that because people know little about genetic testing, “people do not know if they should trust it.” (P17). Another person described the fear that comes with misinformation: “Sometimes, people don’t understand thoroughly or correctly about it [genetic testing], so they are afraid of it. So, they would refrain from taking the test.” (P22).

Table 3. Key domains and participant perspectives

Domains	Participant perspectives
Challenges to genetic testing	lack of information
	fear of results impact
	costs to individuals
	privacy concerns
Ways to overcome challenges to genetic testing	free or reduced cost of testing or testing covered by insurance
	test information from trusted healthcare providers, including Vietnamese-speaking clinic staff and volunteers
	public education and awareness of genetic testing
	easy and convenient access to genetic testing
Trusted sources for health information and genetic testing	primary care doctor
	other healthcare providers (e.g., pharmacist, nurse, clinic staff, doctors on YouTube, etc.)
	family and friends
	reputable sources on the internet or via Google

Fear of results impact. The fear of knowing genetic test results and their implications often came up in interview discussions. More than half of the study participants talked about fear of experiencing stress, depression, or facing a reality they may not want to accept because of the genetic test results. One person indicated: “Vietnamese people, some are fearful, they are anxious that when they have to face diseases, they will not be able to stand it. They do not want to know. They think that, what will come, will come. If I’m ill, then I’ll die, there’s no need to worry. If I go for a medical exam and know the results, I will feel very depressed and [because of this] I will be more ill.” (P04). Another participant explained how fear of life disruption could be a factor in not learning about genetic test results. They described: “It’s like you are living your normal life, all of sudden one day you find out you have a disease, they feel very upset. They fear that they will no longer have any joy in their lives. So some people don’t want to know what diseases they might have.” (P13).

Some participants described that, because of their fear of results, they would prefer to wait and see whether a disease presents rather than have preemptive testing. One individual shared: “Many people that I know, like my uncle, they are really scared of seeing doctors. Because they think that if they discover that they have any illnesses, they would lose hope. So, they don’t want to find out. And instead, they would just wait until the symptoms show and then they would act.” (P22). In addition to fear of uncertainty, concern and fear about results impact on family was described by one person: “I don’t want to take the genetic testing, because I don’t want to face the truth. I don’t want to find out that I have cancer. Then I don’t know what I’m going to do. Then I might be a burden to my family

because [when] I keep thinking about cancer, like 90% [chance], I will die." (P08).

Costs for individuals. Cost of testing, cost of associated treatments, and cost in taking off time were also described as key barriers to genetic testing by several participants. In particular, one participant described the disincentive of cost of testing: "It [getting genetic testing] affects people's finances, so people don't want to go, because they don't have money. They don't even have money to buy food, why would they spend money to take the test? If the test is \$20–\$30, people may take it, but if it is \$100–\$200 for one test, I don't think someone with no medical problem would take the test." (P18). Regarding follow-up care, one person shared: "I think there are people who think that if they found out they're sick, they wouldn't be able to afford the treatment. So, they're scared and they just straight-up ignore it." (P16). Some participants further commented that there is a cost in terms of their time: "Because when we go for a medical checkup or a test, we lose time. We could use that time to work and earn money. If we don't work, we lose the income." (P04).

Privacy concerns. Participants reported varied views about privacy relating to genetic health information. One individual raised concerns about the potential for misuse of their genetic information: "Some people don't want their DNA out there being used for research and potentially getting in the wrong hands down the line. You know, maybe there's a bad doctor or a bad scientist or a bad corporation that wants to use that data." (P23). However, other individuals described how privacy would not be a concern. One participant shared: "The Vietnamese don't think much about privacy to be disclosed during medical procedures. The Americans always think about civil liberties and democracy, but the Vietnamese don't. They don't have the habit of thinking about it." (P02). Others described less of a concern about privacy and discussed belief that protections are in place for their health information.

Ways to overcome challenges to genetic testing

When asked what might help people overcome potential testing barriers and strategies for community education, study participants had a number of suggestions. Some mentioned that they would be more willing to have genetic testing if it was free, had a reduced cost, or was covered by their health insurance. Receiving information on genetic testing, particularly from their primary care doctors or a medical professional they find trustworthy and credible, was mentioned as a facilitator: "Family doctors can raise awareness about this really well because usually patients listen to their doctors' advice, what they should do, what they shouldn't do." (P04). A few participants also mentioned the need for Vietnamese interpreters or translators when explaining genetic testing information to those with limited English proficiency.

As lack of information was described as a large barrier to access of genetic testing, participants highlighted the

importance of community education to increase awareness of genetic testing in the VA community. One person shared some of the elements that they thought would be important to include when providing education content on genetic testing: "Education on any clear, concise, important concepts, so they can understand why the genetic testing is [important] and what the benefits behind it are." (P10). In addition, some participants added that convenience of testing would improve community access to genetic testing. They described being more willing to receive genetic testing if it was easy to access and did not take up too much of their time: "Increasing accessibility to these tests might encourage more people to get genetic testing. Target, they sell like, I think a testing kit in a place that's very accessible to a lot of people. Target has pharmacies and having a pharmacist be able to answer those questions too might be helpful." (P12).

Participants were also asked their opinions about what methods they thought would work best for providing information about genetic health care and testing. [Table 4](#) lists the various participant suggestions for preferred educational strategies.

Trusted sources for health information and genetic testing

Participants were asked who they seek out for advice on health and genetic testing. The trusted sources most often mentioned were healthcare providers such as primary care doctors, nurses, pharmacists, clinic staff members, or acquaintances with a medical background. One participant described their preference in speaking to their physician: "Asking my doctor is the best way. I can talk with my friends, but the most important person is the doctor. If the doctor thinks I should do it, I will do it. If it doesn't leave any effects or problems." (P01). Although the majority mentioned healthcare providers as a main source of advice, a few others mentioned family and friends. One participant described: "I will discuss this with my family and I will go for a genetic test. I tell my family everything, so they all know." (P20). Another person said they would talk to a friend first: "I will ask that person—my friend [who is a pharmacist]—'oh, should I do it or not?', and then after that, I will consult with my doctor." (P06).

Some participants noted that they would search the internet for advice on genetic testing. Sites mentioned were Google, PubMed, Centers for Disease Control and Prevention, and the National Institutes of Health. One participant described their strategy, "Well, I would say that Google is definitely one of the first starting points. I would go on there, search, read on WebMD, just sort of gather some general information. I don't think I would use Google as the deciding factor, whether or not to get tested. For something like that, it would need to still be run through with a doctor or, like, a pharmacist, someone qualified." (P07).

When probed, most of the participants expressed that they would not consult with a religious or a community leader for advice on health information and genetic testing

Table 4. Participant-suggested genetic health care and testing education strategies

Education strategy	Examples
Information from trusted healthcare providers	education provided by primary care provider or clinic staff during office visit
Advertisement on Vietnamese-language social media	create and upload short and easy-to-understand written or video posts on Facebook, Instagram, and/or Twitter publish informational ads on Google and medical-related or hospital websites promote online information events (e.g., webinars)
Advertisement in Vietnamese community newspaper or magazine	share real stories of people who have gone through the genetic testing process
Broadcasting on Vietnamese language TV, YouTube, and radio	information broadcasted by doctors or other qualified healthcare professionals
Education events at local clinic, pharmacy, or community organizations	Host question and answer (Q&A) sessions

because they did not have any medical background. However, two participants stated they would consider genetic testing if it was announced at the church or temple and another individual suggested that a person in a high-level position in a Vietnamese organization would be a good channel to raise awareness of genetic testing to the community.

Discussion

In the context of recent work on AAs and genomic medicine that call for more research, disaggregating data and addressing culturally, linguistically, and trauma-informed-specific needs in genetic services,^{2,17,37} we identified barriers, facilitators, and messengers for genetic screening in a local VA community healthcare context. Many of these testing barriers and facilitators have been observed across communities and populations.^{3,4,11,12} Consistent with CEnR principles, this study provided an opportunity for community members to participate in the research project lifecycle. The quick pace of this project depended most on community champions who guided each step and continue to serve as active research team members. Our use of RQA was integral to realizing the practical outcomes of CEnR. Thus, in addition to thematic findings, the CEnR process has yielded a partnership that will likely facilitate continued community engagement on genomic testing to benefit the community and healthcare system.

This CEnR approach enabled the team to identify practical considerations, such as how and who should provide education about genetic healthcare and testing to Vietnamese people in the healthcare institution. This approach offered insights that guided the development and implementation of interventions, including addition of at-home saliva-based genetic testing and adoption of culturally tailored educational and marketing materials. Specifically, the study team produced an advertorial on genetic testing that was distributed to

participants at a community event and was also published in a Vietnamese community magazine in print and online. Additional efforts to increase awareness of genetic testing included developing small and large informational posters that were displayed in primary care clinic exam and waiting rooms as well as a digital version that rotated on media walls across the hospital campus.

Although some identified barriers potentially can be addressed by provision of information, reducing costs, and protecting privacy, fear may be more elusive and persistent. Participants in our study characterized Vietnamese community members as fearful of being surprised and overwhelmed by the potential impact of genetic test results. This may reflect cultural beliefs that directly influence how genetic information is received by an individual. Given its prominence as a barrier to testing, further study is needed to distinguish whether their fear stems from a generalized fear of healthcare, a fear of identifying a disease, a fear of the genetic testing process, or another driving source. When identified, establishing its prevalence among VA people, among whom or which segments, and how it manifests in healthcare interactions would help to inform both strategy and tactics. For example, we anticipate that fear of racial violence could broadly impact access or whether individuals have bandwidth to pursue healthcare that might be perceived as optional or preventive. At a practice level, we might anticipate the question: when is a preference not to know an informed preference versus an uninformed misunderstanding, and how might that be addressed within a healthcare institution offering genetic screening?

In the context of this VA community, fear appears to be multidimensional and may be ubiquitous, given that 6 of 22 participants indicated that they felt some fear of violence because of race. Community research team members hypothesized that overcoming fear as a barrier may depend on one's perceived degree of control. Although fear of healthcare and, by extension, genetic testing is not unique, the community context of fear because VAs' structurally

bound experience of race warrants greater attention. Thus, if the outcome of genetic testing is perceived to be controllable or “outweighs” their fears and concerns, then people may be more accepting. However, if the outcome is perceived to be uncontrollable, individuals may be less interested in getting genetic testing. This hypothesis suggests that pre-test education on the genetic testing process and potential next steps following a testing result, such as treatment or prevention options, may be critical for utilizing genetic testing and information.

Another important point raised by our community research team members is the seeming inconsistency between participants’ fear of the impact of results and their trust in medical professionals. The practical question is who should educate, message, and offer genetic testing to members of the Vietnamese community. Medical professionals, including physicians, pharmacists, nurses, and specifically family and friends who worked in healthcare were cited as trusted and knowledgeable sources of information to aid individual decision-making about genetic testing. Therefore, community-based VA healthcare providers may offer an avenue for community education about genetic healthcare and testing. Given that a wide range of medical professionals may be solicited as information sources by Vietnamese people, coupled with the potential for misunderstandings about genetic testing and results, conveying accurate information about genetic testing and screening to the range of community health-related providers in the Vietnamese community beyond primary care providers may be an opportunity to address barriers and uptake.

Limitations

Because the relatively small number of participants, our findings may lack generalizability to VA populations in other locations. However, as a formative qualitative study, we sought to characterize the depth and range of perspectives from a circumscribed community. This particular set of study participants represents a segment of the local VA population in north Chicago who themselves likely differ in significant ways from the Vietnamese community in other areas of the country. Therefore, many of our findings are hypothesis generating and will help guide future research. It is also important to recognize the potential misinterpretation and translation of participant responses because of possible misunderstanding or lack of genetics knowledge by the translating linguist. This issue may have impacted participants’ understanding of interview questions as well as our understanding of responses when they were back-translated into English. This poses a common challenge in studies with non-genetics and medical professionals or laypeople across a range of linguistic populations.³⁸

Conclusion

This CEnR has identified barriers, facilitators, and messengers for genetic screening in a local VA community

healthcare context and, in doing so, demonstrated how CEnR coupled with RQA can be a promising approach for healthcare institutions as they identify needs and tailor strategies for implementing population genetic screening programs in local ethnic communities. Hypotheses generated from these findings, including the potential utility of delineating sources of fear associated with genetic testing, the potential to overcome fear through greater individual control over genetic information, and the promising role of Vietnamese healthcare providers in community genetic education, are important directions for future research.

Data and code availability

Materials and de-identified data presented in this paper may be made available by the corresponding author upon request.

Supplemental information

Supplemental information can be found online at <https://doi.org/10.1016/j.xhgg.2022.100134>.

Acknowledgments

We thank the clinic patients for their participation in this study. We also acknowledge VanNguyen Tran and Jenise Celestin for valuable contributions to this project. Funding for this study was provided by the Swedish Hospital Foundation.

Declaration of interests

V.D., T.Q.D., and J.-H.Y. have received compensation from NorthShore University HealthSystem for their consulting work on this project. A.A.L. was employed at NorthShore University HealthSystem during part of this study work.

Received: May 14, 2022

Accepted: August 3, 2022

References

1. Popejoy, A.B., and Fullerton, S.M. (2016). Genomics is failing on diversity. *Nature* 538, 161–164.
2. Young, J.L., Mak, J., Stanley, T., Bass, M., Cho, M.K., and Tabor, H.K. (2021). Genetic counseling and testing for Asian Americans: a systematic review. *Genet. Med.* 23, 1424–1437.
3. Glenn, B.A., Chawla, N., and Bastani, R. (2012). Barriers to genetic testing for breast cancer risk among ethnic minority women: an exploratory study. *Ethn. Dis.* 22, 267–273.
4. Rosas, L.G., Nasrallah, C., Park, V.T., Vasquez, J.J., Duron, Y., Garrick, O., Hattin, R., Cho, M., David, S.P., Evans, J., et al. (2020). Perspectives on precision health among racial/ethnic minority communities and the physicians that serve them. *Ethn. Dis.* 30, 137–148.
5. Ta Park, V., Kim, A., Cho, I.H., Nam, B., Nguyen, K., Vuong, Q., Periyakoil, V.S., and Hong, Y.A. (2021). Motivation to participate in precision health research and acceptability of texting as a recruitment and intervention strategy among Vietnamese

- Americans: qualitative study. *JMIR mHealth uHealth* 9, e23058.
6. Fisher, E.R., Pratt, R., Esch, R., Kocher, M., Wilson, K., Lee, W., and Zierhut, H.A. (2020). The role of race and ethnicity in views toward and participation in genetic studies and precision medicine research in the United States: a systematic review of qualitative and quantitative studies. *Mol. Genet. Genom. Med.* 8, e1099.
 7. Chapman-Davis, E., Zhou, Z.N., Fields, J.C., Frey, M.K., Jordan, B., Sapra, K.J., Chatterjee-Paer, S., Carlson, A.D., and Holcomb, K.M. (2021). Racial and ethnic disparities in genetic testing at a hereditary breast and ovarian cancer center. *J. Gen. Intern. Med.* 36, 35–42.
 8. Joseph, G., Pasick, R.J., Schillinger, D., Luce, J., Guerra, C., and Cheng, J.K.Y. (2017). Information mismatch: cancer risk counseling with diverse underserved patients. *J. Genet. Couns.* 26, 1090–1104.
 9. Cheng, J.K.Y., Guerra, C., Pasick, R.J., Schillinger, D., Luce, J., and Joseph, G. (2018). Cancer genetic counseling communication with low-income Chinese immigrants. *J. Community Genet.* 9, 263–276.
 10. Manriquez, E., Chapman, J.S., Mak, J., Blanco, A.M., and Chen, L.-M. (2018). Disparities in genetics assessment for women with ovarian cancer: can we do better? *Gynecol. Oncol.* 149, 84–88.
 11. Hann, K.E.J., Freeman, M., Fraser, L., Waller, J., Sanderson, S.C., Rahman, B., Side, L., Gessler, S., Lanceley, A.; and PROMISE study team (2017). Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review. *BMC Publ. Health* 17, 503.
 12. Ramirez, A.G., Chalela, P., Gallion, K.J., Muñoz, E., Holden, A.E., Burhansstipanov, L., Smith, S.A., Wong-Kim, E., Wyatt, S.W., and Suarez, L. (2015). Attitudes toward breast cancer genetic testing in five special population groups. *J. Health Dispar. Res. Pract.* 8, 124–135.
 13. Holzer, K., Culhane-Pera, K.A., Straka, R.J., Wen, Y.F., Lo, M., Lee, K., Xiong, T., Peng, K., Bishop, J., Thyagarajan, B., and Zierhut, H.A. (2021). Hmong participants' reactions to return of individual and community pharmacogenetic research results: "A positive light for our community". *J. Community Genet.* 12, 53–65.
 14. Gordon, N.P., Lin, T.Y., Rau, J., and Lo, J.C. (2019). Aggregation of Asian-American subgroups masks meaningful differences in health and health risks among Asian ethnicities: an electronic health record based cohort study. *BMC Publ. Health* 19, 1551.
 15. Budiman, A., and Ruiz, N.G. (2021). Key Facts about Asian Americans, a Diverse and Growing Population (Pew Research Center). <https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-americans/>.
 16. Harjanto, L., and Batalova, J. (2021). Vietnamese Immigrants in the United States (Migration Policy Institute). <https://www.migrationpolicy.org/article/vietnamese-immigrants-united-states>.
 17. Burke, W. (2021). Utility and diversity: challenges for genomic medicine. *Annu. Rev. Genom. Hum. Genet.* 22, 1–24.
 18. Lemke, A.A., Wu, J.T., Waudby, C., Pulley, J., Somkin, C.P., and Trinidad, S.B. (2010). Community engagement in biobanking: experiences from the eMERGE network. *Genom. Soc. Pol.* 6, 50.
 19. Lemke, A.A., Amendola, L.M., Thompson, J., Dunnenberger, H.M., Kuchta, K., Wang, C., Dilzell-Yu, K., and Hulick, P.J. (2021). Patient-reported outcomes and experiences with population genetic testing offered through a primary care network. *Genet. Test. Mol. Biomarkers* 25, 152–160.
 20. Lemke, A.A., Amendola, L.M., Kuchta, K., Dunnenberger, H.M., Thompson, J., Johnson, C., Ilbawi, N., Oshman, L., and Hulick, P.J. (2020). Primary care physician experiences with integrated population-scale genetic testing: a mixed-methods assessment. *J. Pers. Med.* 10, 165.
 21. Clinical and Translational Science Awards Consortium (CTSA) (2011). Principles of Community Engagement (U.S. Department of Health and Human Services).
 22. Miles, M.B., Huberman, A.M., and Saldana, J. (2018). *Qualitative Data Analysis: A Methods Sourcebook* (SAGE Publications).
 23. O'Brien, B.C., Harris, I.B., Beckman, T.J., Reed, D.A., and Cook, D.A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Acad. Med.* 89, 1245–1251.
 24. Starks, H., and Trinidad, S.B. (2007). Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual. Health Res.* 17, 1372–1380.
 25. Beebe, J. (2001). *Rapid Assessment Process: An Introduction* (Rowman Altamira).
 26. Hsieh, H.-F., and Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qual. Health Res.* 15, 1277–1288.
 27. McMullen, C.K., Ash, J.S., Sittig, D.F., Bunce, A., Guappone, K., Dykstra, R., Carpenter, J., Richardson, J., and Wright, A. (2011). Rapid assessment of clinical information systems in the healthcare setting. *Methods Inf. Med.* 50, 299–307.
 28. McNall, M., and Foster-Fishman, P.G. (2007). Methods of rapid evaluation, assessment, and appraisal. *Am. J. Eval.* 28, 151–168.
 29. Vindrola-Padros, C., and Johnson, G.A. (2020). Rapid techniques in qualitative research: a critical review of the literature. *Qual. Health Res.* 30, 1596–1604.
 30. Gale, R.C., Wu, J., Erhardt, T., Bounthavong, M., Reardon, C.M., Damschroder, L.J., and Midboe, A.M. (2019). Comparison of rapid vs in-depth qualitative analytic methods from a process evaluation of academic detailing in the Veterans Health Administration. *Implement. Sci.* 14, 11.
 31. Nevedal, A.L., Reardon, C.M., Opra Widerquist, M.A., Jackson, G.L., Cutrona, S.L., White, B.S., and Damschroder, L.J. (2021). Rapid versus traditional qualitative analysis using the consolidated framework for implementation research (CFIR). *Implement. Sci.* 16, 67.
 32. Taylor, B., Henshall, C., Kenyon, S., Litchfield, I., and Greenfield, S. (2018). Can rapid approaches to qualitative analysis deliver timely, valid findings to clinical leaders? A mixed methods study comparing rapid and thematic analysis. *BMJ Open* 8, e019993.
 33. Harris, K., Jerome, N., and Fawcett, S. (1997). Rapid assessment procedures: a review and critique. *Hum. Organ.* 56, 375–378.
 34. Hamilton, A.B., Brunner, J., Cain, C., Chuang, E., Luger, T.M., Canelo, I., Rubenstein, L., and Yano, E.M. (2017). Engaging multilevel stakeholders in an implementation trial of evidence-based quality improvement in VA women's health primary care. *Transl. Behav. Med.* 7, 478–485.
 35. Palinkas, L.A., and Zatzick, D. (2019). Rapid assessment procedure informed clinical ethnography (RAPICE) in pragmatic clinical trials of mental health services implementation: methods and applied case study. *Adm. Pol. Ment. Health* 46, 255–270.

36. Averill, J.B. (2002). Matrix analysis as a complementary analytic strategy in qualitative inquiry. *Qual. Health Res.* *12*, 855–866.
37. Popejoy, A.B. (2019). Diversity in precision medicine and pharmacogenetics: methodological and conceptual considerations for broadening participation. *Pharmgenomics Pers. Med.* *12*, 257–271.
38. Shaw, A., and Ahmed, M. (2004). Translating genetics leaflets into languages other than English: lessons from an assessment of Urdu materials. *J. Genet. Couns.* *13*, 321–342.