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ORIGINAL ARTICLE

Engaging Hmong adults in genomic and pharmacogenomic research: Toward reducing health disparities in genomic knowledge using a community-based participatory research approach

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Abstract Advancing precision medicine relies in part on examining populations that may exhibit unique genetic variants that impact clinical outcomes. Failure to include diverse populations in genomic-based research represents a health disparity. We implemented a community-based participatory research (CBPR) process with the Hmong community in Minnesota, who were refugees from Laos, in order to assess the feasibility of conducting genomic and pharmacogenomic-based research for genetic variants that are relevant to the Hmong community. Our Hmong Genomics Board, consisting of Hmong and non-Hmong professionals, used CBPR principles and built on previous formative research to create and implement culturally and linguistically appropriate informed consent processes for Hmong people at six community venues. The Board chose genetic variants for diabetes risk and warfarin response as relevant to the community. The Institutional Review Board approved aggregate but not individual return of results. Two hundred thirty-seven Hmong participants with mean (range) age of 30.2 (18–81) years and diverse levels of education (22% without and 75% with high-school education) provided saliva for genetic (DNA) analyses. Eighty-five percent of participants agreed to store DNA for future analyses, 82% agreed to share DNA with other researchers, and 78% agreed to be contacted for future studies. Twenty-five elders refused to participate because they wanted individual results. Aggregate results were shared with all participants. This CBPR approach proved highly successful to obtain informed consent and recruit a sample from the Hmong community for a genomic and pharmacogenomic study. Investment in the CBPR process may prove successful to address the gap of genomic information in under-represented communities.

Keywords Community-based participatory research · Genomics · Pharmacogenomics · Hmong

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Background

In order to advance the field of precision medicine, appropriate representation of all populations, including ethnic and racial groups, in genomic and pharmacogenomic-based research is warranted (Consortium 2012; Green et al. 2011; Haga 2010; Licinio 2001; Yu J-H and Burke W 2012). Failure to include diverse populations in such research represents a health disparity. However, challenges to participation by various populations in genomic research exist, especially in minority communities. These challenges include people's limited understanding about genetics, genomics, and clinical research; people's perceptions and beliefs regarding utility of genetic testing; people's distrust in the research process and in researchers

related to history of discrimination by medical personnel and researchers; and logistical barriers such as language, time, access, and simply not being asked to participate, which can all negatively influence community members' participation (George et al. 2014; Hartz et al. 2011; Millon Underwood et al. 2013; Rotimi and Marshall 2010). Novel approaches that address these challenges have the potential to increase community participation in genomic-based research.

The ethical issues that arise from conducting genomic-based research in communities with limited knowledge of science have led ethicists to identify necessary elements to be considered and included when obtaining informed consent from all communities (Mascalzoni et al. 2008; Rotimi and Marshall 2010). Similarly, these ethical concerns have led researchers to consider a variety of processes to obtain community input into genomic research and increase community interest in potential results (George et al. 2014; Green et al. 2011; Millon Underwood et al. 2013; Skinner et al. 2015; Yu J-H and Burke W 2012). These processes have included conducting community interviews, focus groups, and rapid ethnographic assessments (Skinner et al. 2015; Tindana et al. 2012) to identify perceptions and barriers to participate in community-based genetic studies; and working with communities through community advisory boards (Quinn 2004), community fora (Mascalzoni et al. 2008) and community consultations (Dickert and Sugarman 2005) to increase engagement of community members in conducting genomic studies. Several genomic studies have reported successful outcomes using various community engagement processes (Halverson and Ross 2012; Marsh et al. 2013; Marsh et al. 2010; Skinner et al. 2015; Tindana et al. 2012; Vreeman et al. 2012), and particularly in designing an informed consent process with appropriate vocabularies that address more complex ethical issues, such as whether or not genetic data should be given to participants (Lemke et al. 2012; Skinner et al. 2015).

In spite of a growing body of research that uses novel approaches to enhance community engagement, some of these approaches do not ensure community empowerment, or the equal sharing of the research responsibilities and results. Partnering with community members to conduct research via community-based participatory research (CBPR) could move the ethical processes one stage further to allow equal power sharing between researchers and community members throughout the research steps, from conceptualizing the study, to collecting and analyzing the data, and finally to communicating the results back to the community (Israel 2005; Israel et al. 1998). An interwoven CBPR partnership has the potential to identify and then address the social, cultural, logistical, and ethical issues that arise in conducting research focused on actionable outcomes (Chen et al. 2006; De las Nueces et al. 2012; George et al. 2014; Skinner et al. 2015).

In 2010, more than 66,000 Hmong lived in Minnesota (Pfeifer 2012), including original refugees from Laos who settled in the United States (US) after the Vietnam War ended in 1975, and their descendants. When Hmong people first arrived in Minnesota in the 1970–1990s, many did not trust medical providers or researchers and were concerned about providing blood and tissue samples as well as participating in general research and experimentation (Culhane-Pera et al. 2003). Over the past four decades, Hmong communities around the world have participated in few genomic-based research projects; their specific responses to genomic-based research are not well known (Xiong and Pepperell 2013). To address this lack of participation and uncertainty, we partnered with Hmong community members in a CBPR process, creating the West Side Hmong Genomics Board. We initially conducted a qualitative exploration through key informant interviews and focus group discussions to identify beliefs about heredity and genetics and reactions to participating in genomics research (publication pending).

In this article, we report on our CBPR partnership that built upon the previous formative research to create and implement a culturally and linguistically appropriate informed consent process for a community-based genetic study, in order to assess the feasibility of including the Hmong community in genomic or pharmacogenomic-based research investigations.

Methods

CBPR board

We (KCP and RS) recruited Hmong Genomics Board members in a snowball fashion amongst Hmong healthcare professionals and community leaders in St Paul MN because we assessed that the initial project needed people who understood the community as well as science, genetics, health, and medicines. Between 2007 and 2010, the CBPR West Side Hmong Genomics Board consisted of 2 non-Hmong members and 9 Hmong members; 8 women and 3 men; with a range of professions including 3 Hmong community leaders, 2 family physicians, 4 pharmacists, and 2 public health educators. Of the 9 Hmong Board members, 5 people were born in Southeast Asia and 4 were born in the US; 4 were high school graduates, 1 was college graduate, and 4 had professional degrees (in medicine, pharmacy, and public health).

The Board operated on CBPR principles of equal participation, transparent communication, defined roles, and shared decision-making, which occurred in a co-learning environment (Israel 2003). Board members participated in all decisions, deciding the focus of the genomic and pharmacogenomic questions, recruitment strategies, data collection processes, and data analyses. In addition, several Board members participated in the research steps. They designed the educational sessions, created two educational booklets about genetics and family history of diseases, wrote

and translated the informed consent forms, conducted the educational sessions, obtained informed consent, collected saliva samples, analyzed the DNA samples, and shared in the presentation of findings back to the community. Finally, the full Board provided a community perspective on the final genetic analyses and reports for Hmong community meetings, conference abstracts, and manuscripts.

Selection of genetic variants

The Board proposed considering several genes with known single nucleotide polymorphisms (SNPs) that contribute to disease risk and drug responsiveness, in order to ascertain which would likely be of interest to the Hmong community. Because of community members' concerns about dangers of warfarin and type 2 diabetes mellitus (T2DM), we selected relevant SNPs for the warfarin metabolizing gene CYP2C9 and the warfarin target gene VKORC1 (Johnson et al. 2011) and one SNP for the gene CDKN2A, which was reported to be associated with increased risk for T2DM (Saxena et al. 2007; Scott et al. 2007). Based on published guidelines (Johnson et al. 2011), we specifically investigated allele frequencies for three validated SNPs associated with altered response to warfarin (*CYP2C9*2*, *CYP2C9*3*, and *VKORC1*) (Johnson et al. 2011) and one SNP (rs10811661 *CDKN2A*) associated with increased risk for T2DM (Omori et al. 2008; Wu et al. 2008). We selected these genes to serve as concrete examples of genetic based drug response or disease risk factors for our purpose of engaging Hmong community members in this study and did not provide actionable information of value for anyone involved in this study, regardless of their past or current exposure to warfarin, current T2DM or risk for T2DM.

Culturally and linguistically appropriate informed consent processes

The Board decided to recruit Hmong adults (≥ 18 years old) with diverse ages, genders, levels of education and years in the US, in an effort to be inclusive of all community members. Reflecting upon our previous formative research results (Culhane-Pera et al. 2016), the Board members decided there needed to be a variety of details in the informed consent processes to accommodate adults' formal education levels, which are related to their scientific literacy, genetic knowledge, language fluency, numeracy, and literacy skills. Each participant who agreed to enroll in the study signed a written informed consent form in either English or Hmong or an oral consent form, and received $15. This study was approved by the University of Minnesota Committee on the Use of Human Subjects in Research, 0110M52021. The IRB denied our requests to provide participants with their unique individual genomics results unless we had trained genetic counselors on our team to give the information, which we did not. Hence, the consent process informed participants they would only receive aggregate of sample population results, rather than individual results.

We developed two informed consent processes: an in-depth process for people without high school education and an in-depth process for people with high school education. For the people without high school education, we delivered an hour-long group activity in Hmong language to engage people in an interactive discussion. We started by asking people about their concepts of heredity, and then we built upon those ideas that were consistent with scientific concepts of heredity as we presented about genetics and provided examples of genetic-based factors that influence health.

For Hmong adults with high school education, we implemented an hour-long interactive group curriculum in English (supplemented by Hmong as people desired) that reviewed basics of genetics, explained our rationale for including Hmong people in genetics and pharmacogenetics research, and discussed the impact genetics may have on the development of chronic diseases (such as T2DM) and responses to medicines as the focus of the genomic research. We used educational materials describing the role of genetics in chronic diseases, including the potential impact of common genetic variations, such as single nucleotide polymorphisms (SNPs). To create these materials, we interviewed six people with genetic-based diseases and adapted Genetic Alliance's toolkit "Does it Run in the Family?" with two English language brochures entitled "A Guide to Family Health History" and "A Guide to Understanding Genetics and Health" to highlight Hmong people's experiences with genetically influenced diseases (West Side Hmong Genomics Board 2008a, b).

For both groups, we explained important principles regarding federal research requirements about consent, confidentiality, and anonymity of data. We explained our specific IRB requirements that participants could receive aggregate results, but not individual results. We shared the possibility that any future genetic results might ultimately benefit the community but would not benefit individuals participating in this study at this stage. We stressed the difference between clinical services based on validated findings and discovery-oriented research conducted to increase community awareness about genomic and pharmacogenomic-based research. We designed consent forms to give participants the ability to indicate their willingness to permit storing un-identified DNA for 15 years for future analyses, sharing de-identified DNA with other researchers for similar types of research projects, and allowing the researchers to potentially contact them to participate in future research projects. We created written informed consent forms in fifth grade level English and in Hmong, and created an English/Hmong language form for people receiving and giving oral consent.

We attempted to increase trust in the research process by relating the scientific information to their personal

understanding of genetics, listening and responding to people's questions and concerns, giving Board names and contact information, highlighting the Hmong professionals and community leaders involved in conducting the research, promising to send them their results and then by giving their results to them.

Data collection

All participants answered 10 demographic questions, had their height and weight measured and were provided instructions on how to provide a sample of genomic DNA using saliva sample kit (DNA Genotek® Oragene, Ottawa, Ontario Canada). All subjects were provided with $15 for their participation.

Analyses

Descriptive statistics were used to describe participants' demographic characteristics, individuals' acceptance or rejection of participating in genomic analyses, body mass index (BMI), and frequency of genetic variations. The methods used for the extraction and processing of DNA obtained from saliva samples followed the instructions provided by the manufacturer of the kits (prepIT®.L2P reagent for DNA purification and ethanol protocol for DNA precipitation).

Results

Recruitment

Equipped with our two linguistically and culturally appropriate consent processes for genomic research, we recruited 135 Hmong adults from 5 separate venues—a Hmong community organization ($N = 56$), a medical clinic ($N = 24$), and Hmong student groups at 3 colleges/universities ($N = 55$). In addition, we modified the informed consent process from an interactive 1 hour-long process for sit-down groups to an interactive 15 minute process, in order to recruit people from educational booths at two regional Hmong conferences (the Minnesota Hmong College Student Association Conference and the Hmong National Development Conference). To the people who stopped at the booths, we described the study, discussed genetics in the Hmong community, and gave out copies of our Hmong versions of "A Guide to Family Health History" and "A Guide to Understanding Genetics and Health"(West Side Hmong Genomics Board 2008a; West Side Hmong Genomics Board 2008b). For the people interested in considering participation, we explained the written consent form process, and once signed, obtained the study information from an additional 102 participants.

Enrollment

A total of 237 Hmong adults signed the consent form to participate and donated a saliva sample for genetic analyses. (See Table 1) A mixture of community members agreed to participate: men and women; young, middle-aged, and older adults; people with and without diabetes; people without high school education and people with secondary school and university education. Of the 237 adults, 202 (85%) agreed to store their DNA for future analyses about any topics, 194 (82%) agreed to share DNA with other researchers about similar topics, and 185 (78%) agreed to being contacted for future research.

The recruitment and consent processes held at the community organizations, medical clinics, and student clubs resulted in a high level of participation. Participation rates in those settings were estimated to be about 85% of the people who attended the meetings to hear about the study. Participation rates for other venues varied from an estimate of about 75%

Table 1 Demographic characteristics of research participants

Participant characteristics ($N = 237$)	Results
Age	
Mean	30.3 years
Range	(18–81 years)
Median	22 years
Gender—% (N)	
Women	55.6% (132)
Men	44.3% (105)
Formal education—% (N)	
<High school	22.3% (53)
≥High school	75.1% (178)
Unknown	2.5% (6)
Years in USA	
Mean	15.57 years
Range	(3–31 years)
Birth country—% (N)	
USA	42.6% (101)
Southeast Asia	56.5% (134)
Unknown	<1% (2)
Spoken English skills—% (N)	
None/poor	22% (51)
Fair/good	19% (44)
Very good/excellent	58% (138)
Unknown	1.7% (4)
Self-reported medical history—% (N) ($N = 235$)	
Type 2 diabetes	13.2% (31)
Hypertension	6.3% (15)
Hyperlipidemia	5.9% (14)
Gout	5.1% (12)
Kidney stone	2.5% (6)

when held at Hmong conferences to a more substantial level of about 90% for those who approached our booth to learn about the study at Hmong conferences. From the community organization venue, 25 people declined, all of whom were over 50 years of age. When we inquired about their decision to not participate, they expressed their concern about not benefiting from the study: 'I want to know about my genes that you are testing, but you are not going to tell me.' 'How can you know my results and not tell me?' 'If it cannot help me, then why should I join?'

Aggregate SNP results

DNA was successfully extracted and analyzed from 236 of the total 237 saliva samples. We informed participants of aggregate results in three ways. We sent written materials in English and Hmong to home and email addresses as individuals preferred; we invited everyone to attend a group discussion of results (4 people attended); and we returned to four group settings where we had recruited people (1 community organization and 3 Hmong student groups). Specific study results of the allele frequencies for the genetic variants and participants' biological characteristics are reported elsewhere (Straka 2010).

For the genetic variant associated with increased risk of type 2 diabetes mellitus (*CDKN2A,* rs10811661), we informed participants that approximately 44% carried the single SNP associated with a 26–33% increased risk for developing T2DM and that this was not different than other populations made up of either a Han-Chinese (Wu et al. 2008) or Japanese populations, respectively (Omori et al. 2008). For the pharmacogenomic results associated with altered response to warfarin (based on analysis of *CYP2C9*2*, *CYP2C9*3*, and *VKORC1)*, we informed participants that the Hmong displayed a prevalence of individuals who may have a lower dosage requirement for the drug warfarin compared to non-Hmong. Specifically, approximately 30% of participants would need less than usual dose, and 2% would need more than usual dose (Gage et al. 2008; Klein et al. 2009), compared to a combined Han-Chinese and Japanese cohort (International HapMap Project 2010; Tham et al. 2006). For both genomic and pharmacogenomic results, we cautioned participants about the limited scope of translational significance of these observations, and provided general advice concerning reducing individual's risk to develop T2DM and discussing possible need for genetic testing should anyone be prescribed warfarin in the future.

Discussion

The CBPR-based West Side Hmong Genomics Board was a partnership with Hmong community members and researchers that created linguistically and culturally appropriate informed consent processes with educational materials and successfully enrolled 237 Hmong adults in a genetics/pharmacogenetics research project. The CBPR principles of equal participation, transparent communication, defined roles, and shared decisions, in a co-learning environment (Israel 2003), facilitated our movement beyond the more traditional superficial interaction between researchers and community members to a meaningful engagement and partnership. The CBPR processes used in this project appeared to be successful in addressing the historical challenges of research in minority communities and also addressing specific challenges to the Hmong community in a genetic-based research project.

Certainly, most of the study participants were young, had high school education, and had good or excellent English proficiency. However, older adults who had no high school education and poor or limited English skills also participated. These demographic characteristics of the total sample were influenced by our recruitment strategy; while we put significant time and effort into recruiting older people without high school genetics education, ultimately recruiting college students at conferences was easier and took less time. Hence, more high-school and college educated people participated than non-formally educated elders. Twenty-five elderly people who refused to participate expressed their concern that they would not learn their results, as the study would only return aggregate results and not individual results.

Dissemination of research results is also a core CBPR principle (Israel 2005). Whether to return aggregate results or individual results to genomic study participants is a controversial topic (Beskow et al. 2012; Beskow and O'Rourke 2015). Beskow et al. stated "providing aggregate results is not a substitute for meeting obligations concerning individual result". While our formative research indicated that people wanted to receive their personal results (Culhane-Pera et al. 2016), our IRB institution only approved sharing aggregate results. The rationale provided by our IRB was that given the absence of a CLIA certified laboratory completing the genotyping, and the absence of genetic counselors on the team to review the results with individuals, the Board could not return individual results in a meaningful manner. Although the first rationale was understood, the Board did not agree with the second rationale. The IRB letter stated: "Genetic results that are presented without the assistance of genetic counselor are essentially meaningless to subjects, and therefore, could possibly increase the risk of the study participation without a corresponding increase in benefit." Although a professor of genetic counseling agreed to help design our explanations, we did not have certified counselors available to present individual results face to face, so did not meet the IRB's requirement. The Board argued that genetic counselors would not necessarily be more effective than Board members, as they would need to work with Hmong interpreters; and while genetic counselors may be

useful for helping Hmong participants understand their risk for diabetes, their training concerning the interpretation and practical solutions for managing drug therapy choices and their training communicating with a varied Hmong community could be less effective than that which could be provided by members of the Board. However, the IRB was not persuaded to change their position.

The controversy of returning personal results versus providing aggregate genetic results to study participants is influencing regulatory bodies' decisions leading to conflicting approaches on communicating genetic results. Currently, the debate is being decided in favor of disclosing personal results. In the current study, the Committee on the Use of Human Subjects in Research's 2007 decision was based on National Human Genomic Research Institute's (NHGRI) 2003 federal recommendation policy that individuals should receive their results except when the results have unproven clinical validity, in which case the IRB can refuse to allow notification of individual results (National Human Genome Research Institute (NHGRI) 2003). In 2010, the National Heart, Lung, and Blood Institute (NHLBI 2010) expanded that decision to recommend that study participants *should* be offered individual results if the genetic result has important implications for health issues with substantial risks; the genetic finding is actionable; the analytic test is valid; the disclosure plan complies with laws; and participants want to receive individual results. In addition, individual results *may* be offered results if other conditions are met (National Heart Lung Blood Institute working group et al. 2010). Since then, studies have identified support for disclosing personal genomic results from genomic study participants (Allen et al. 2014; Bollinger et al. 2012; Halverson and Ross 2012; Overby et al. 2015; Trinidad et al. 2015), researchers (Appelbaum et al. 2015; Meacham et al. 2010), IRB committee members (Beskow and O'Rourke 2015; Dressler et al. 2012), ethicists and lawyers (Burke et al. 2014; Evans 2014; Thorogood et al. 2014; Wolf et al. 2015), and two genomics research networks (Jarvik et al. 2014). In addition, NHLBI (2010) recommended that "investigators conducting research with identifiable communities should engage the community on the return of aggregate and/or individual research results", and other researchers concurred (Lemke et al. 2012; Marsh et al. 2013; Overby et al. 2015; Trinidad et al. 2015).

In this specific identifiable ethnic population, participants expressed interest in learning about their results and in some cases declined to participate because, in their view, they would not directly benefit from the results of study, which the researchers knew. The IRB limitation on disclosing specific genomic results had a negative consequence on our study, with at least 25 elders refusing to participate because of it; other people may have felt similarly, but we lacked a mechanism to capture responses from non-acceptors at the student meetings and national conference. However, 237 people participated despite this limitation, so these 237 did not feel disenfranchised enough to refuse to participate. Nonetheless, the Board felt that many features of our research process supported explaining personal results: our CBPR process involved community members in every step of the research; our formative research interviewees said they wanted to know their personal results; participants' trust of the researchers was related to their obtaining their own results; our post-result process was designed to meet with people to explain their results individually; and the informed consent form could have offered participants a choice about obtaining their results. Some Board members felt the IRB had made an unethical decision that favored academic disciplines (genetic counselors over pharmacists and family physicians), medical institutions (IRB), and medical epistemology (genetic counseling) over community knowledge and desires. Still other members of the Board felt that there was enough uncertainty in the findings to not contest the IRB decision, noting that our findings of the genetic risks for cardiovascular diseases would have limited predictive power and that genotypes predicting potential altered drug metabolism would need to be validated before any formal interpretation could be considered (Relling and Klein 2011). Subsequent suspected genomic sources of contribution to other medical problems—specifically hyperuricemia and gout, which were of significant interest to our Hmong community members—were conducted utilizing this same sample population and sources of genomic DNA (Roman et al. 2016). Indeed, these initial studies are clearly of a "discovery" nature and findings from them would be considered only hypothesis generating. Of interest, both the results summarized in this paper and that of Roman et al. 2016, identify important differences in allele frequencies of SNPs governing predicted drug dosage (for warfarin) and risk for medical problems (such as hyperuricemia and gout) between the Hmong and other Asian populations. Given that these investigations are hypothesis generating at this stage, the Board ultimately decided to accept the IRB limitation, work to minimize the community concerns by explaining general results, and resolve to conduct future studies with genetic counselors so the IRB would allow us to give individual results to participants who wanted them. In addition, perhaps a change in IRB approach (NHLBI 2010) to listen to community members who are engaged in the research project will result in a different decision for future projects.

Limitations

This community-based genetic study represented a convenient sample of Hmong participants. By virtue of the study design, they were not necessarily representative of the Hmong community in Minnesota (where most research participants lived) or the United States (some conference attendees were from other states). In addition, our recruitment methods and

locations likely created a recruiting selection bias. We do not know to what extent uninterested people did not attend the group educational sessions of conference booth; we did not measure individuals' reactions to the study if they did or did not participate; and we did not evaluate people's reactions to obtaining the final study results in aggregate. Finally, we did not use any measurement of acculturation or ethnic identity that could have expanded upon our understanding of the sample. Nonetheless, the research participants included people of multiple characteristics from the community: age, gender, education level, birth country, and years lived in the United States.

Conclusion

In spite of these limitations, a CBPR process based on equal partnership with Hmong community members and non-Hmong researchers to create a culturally and linguistically appropriate consent process was successful in recruiting participants to a genomic/pharmacogenomic-based study. This CBPR project presents a research model that informed Hmong community members about genetic applications in disease prevention and management and medication effectiveness; and successfully recruited Hmong of a variety of ages and level of formal education in order to help the community. These initial steps have helped advance our capability of minimizing the inequity of genomic knowledge so that advancements in genomic-based medicine may be applied to the Hmong community. The investment in CBPR should be considered when genomic studies are conducted with communities in order to ultimately ensure equal access to valuable genomic information.

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Compliance with ethical standards

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Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval for research involving human participants All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of Minnesota institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the University of Minnesota Committee on the Use of Human Subjects in Research, 0110M52021.

Informed consent Informed consent was obtained from all individual participants included in the study.

References

Allen NL, Karlson EW, Malspeis S, Lu B, Seidman CE, Lehmann LS (2014) Biobank participants' preferences for disclosure of genetic research results: perspectives from the OurGenes, OurHealth, OurCommunity project. Mayo Clin Proc 89:738–746. doi:10.1016/j.mayocp.2014.03.015

Appelbaum PS, Fyer A, Klitzman RL, Martinez J, Parens E, Zhang Y et al (2015) Researchers' views on informed consent for return of secondary results in genomic research. Genet Med 17:644–650. doi:10.1038/gim.2014.163

Beskow LM, Fullerton SM, Namey EE, Nelson DK, Davis AM, Wilfond BS (2012) Recommendations for ethical approaches to genotype-driven research recruitment. Hum Genet 131:1423–1431. doi:10.1007/s00439-012-1177-z

Beskow LM, O'Rourke PP (2015) Return of genetic research results to participants and families: IRB perspectives and roles. J Law Med Ethics 43:502–513. doi:10.1111/jlme.12292

Bollinger JM, Scott J, Dvoskin R, Kaufman D (2012) Public preferences regarding the return of individual genetic research results: findings from a qualitative focus group study. Genet Med 14:451–457. doi:10.1038/gim.2011.66

Burke W, Evans BJ, Jarvik GP (2014) Return of results: ethical and legal distinctions between research and clinical care. Am J Med Genet C Semin Med Genet 166C:105–111. doi:10.1002/ajmg.c.31393

Chen DT, Jones L, Gelberg L (2006) Ethics of clinical research within a community-academic partnered participatory framework. Ethn Dis 16:S118–S135

Consortium, 1000 Genomics Project, Abecasis GR, Auton A, Brooks LD, MA DP, Durbin RM, Handsaker RE, Kang HM, Marth GT, GA MV (2012) An integrated map of genetic variation from 1,092 human genomes. Nature 491:56–65

Culhane-Pera K, Vawter D, Xiong P, Babbitt B, Solberg M (2003) Healing by Heart: Clinical and Ethical Case Stories of Hmong Families and Western Providers. Vanderbilt University Press

Culhane-Pera KA, Moua MK, Vue P, Xiaaj K, Lo MX, Straka RJ (2016) *Leaves Imitate Trees:* Minnesota Hmong concepts of heredity and applications to genomics research. Journal of Community Genomics. doi:10.1007/s12687-016-0284-2

De las Nueces D, Hacker K, DiGirolamo A, Hicks LS (2012) A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. Health Serv Res 47:1363–1386. doi:10.1111/j.1475-6773.2012.01386.x

Dickert N, Sugarman J (2005) Ethical goals of community consultation in research. Am J Public Health 95:1123–1127. doi:10.2105/AJPH.2004.058933

Dressler LG, Smolek S, Ponsaran R, Markey JM, Starks H, Gerson N et al (2012) IRB perspectives on the return of individual results from genomic research. Genet Med 14:215–222. doi:10.1038/gim.2011.10

Evans BJ (2014) The first amendment right to speak about the human genome. Univ Pa J Const Law 16:549–636

Gage BF, Eby C, Johnson JA, Deych E, Rieder MJ, Ridker PM et al (2008) Use of pharmacogenetic and clinical factors to predict the therapeutic dose of warfarin. Clin Pharmacol Ther 84:326–331

George S, Duran N, Norris K (2014) A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health 104:e16–e31. doi:10.2105/AJPH.2013.301706

Green ED, Guyer MS, National Human Genome Research I (2011) Charting a course for genomic medicine from base pairs to bedside. Nature 470:204–213. doi:10.1038/nature09764

Haga SB (2010) Impact of limited population diversity of genome-wide association studies. Genet Med 12:81–84. doi:10.1097/GIM.0b013e3181ca2bbf

Halverson CM, Ross LF (2012) Engaging African-Americans about biobanks and the return of research results. J Community Genet 3:275–283. doi:10.1007/s12687-012-0091-3

Hartz SM, Johnson EO, Saccone NL, Hatsukami D, Breslau N, Bierut LJ (2011) Inclusion of African Americans in genetic studies: what is the barrier? Am J Epidemiol 174:336–344. doi:10.1093/aje/kwr084

International HapMap Project (2010) http://hapmap.ncbi.nlm.nih.gov/cgi-perl/gbrowse/hapmap28_B36/.2014

Israel BA (2003) Commentary: model of community health governance: applicability to community-based participatory research partnerships. Journal of Urban Health 80:50–53

Israel BA (2005) Methods in community-based participatory research for health, 1st edn. Jossey-Bass, San Francisco, CA

Israel BA, Schulz AJ, Parker EA, Becker AB (1998) Review of community-based research: assessing partnership approaches to improve public health. Annu Rev Public Health 19:173–202. doi:10.1146/annurev.publhealth.19.1.173

Jarvik GP, Amendola LM, Berg JS, Brothers K, Clayton EW, Chung W et al (2014) Return of genomic results to research participants: the floor, the ceiling, and the choices in between. Am J Hum Genet 94:818–826. doi:10.1016/j.ajhg.2014.04.009

Johnson JA, Gong L, Whirl-Carrillo M, Gage BF, Scott SA, Stein CM et al (2011) Clinical pharmacogenetics implementation consortium guidelines for CYP2C9 and VKORC1 genotypes and warfarin dosing. Clin Pharmacol Ther 90:625–629. doi:10.1038/clpt.2011.185

Klein TE, Altman RB, Eriksson N, Gage BF, Kimmel SE, Lee MT et al (2009) Estimation of the warfarin dose with clinical and pharmacogenetic data. N Engl J Med 360:753–764

Lemke AA, Halverson C, Ross LF (2012) Biobank participation and returning research results: perspectives from a deliberative engagement in South Side Chicago. Am J Med Genet A 158A:1029–1037. doi:10.1002/ajmg.a.34414

Licinio J (2001) Pharmacogenomics and ethnic minorities. Pharmacogenomics J 1:85

Marsh V, Kombe F, Fitzpatrick R, Williams TN, Parker M, Molyneux S (2013) Consulting communities on feedback of genetic findings in international health research: sharing sickle cell disease and carrier information in coastal Kenya. BMC Med Ethics 14:41. doi:10.1186/1472-6939-14-41

Marsh VM, Kamuya DM, Mlamba AM, Williams TN, Molyneux SS (2010) Experiences with community engagement and informed consent in a genetic cohort study of severe childhood diseases in Kenya. BMC Med Ethics 11:13. doi:10.1186/1472-6939-11-13

Mascalzoni D, Hicks A, Pramstaller P, Wjst M (2008) Informed consent in the genomics era. PLoS Med 5:e192. doi:10.1371/journal.pmed.0050192

Meacham MC, Starks H, Burke W, Edwards K (2010) Researcher perspectives on disclosure of incidental findings in genetic research. J Empir Res Hum Res Ethics 5:31–41. doi:10.1525/jer.2010.5.3.31

Millon Underwood S, Buseh AG, Kelber ST, Stevens PE, Townsend L (2013) Enhancing the participation of african americans in health-related genetic research: findings of a collaborative academic and community-based research study. Nurs Res Pract 2013:749563. doi:10.1155/2013/749563

National Heart Lung Blood Institute working group, Fabsitz RR, McGuire A, Sharp RR, Puggal M, Beskow LM et al (2010) Ethical and practical guidelines for reporting genetic research results to study participants: updated guidelines from a National Heart, Lung, and Blood Institute working group. Circ Cardiovasc Genet 3:574–580. doi:10.1161/CIRCGENETICS.110.958827

National Human Genome Research Institute (NHGRI) (2003) NHGRI Policy Recommendations on Research Privacy Guidelines. http://www.genome.gov/11510216 Accessed May 31 2016

Omori S, Tanaka Y, Takahashi A, Hirose H, Kashiwagi A, Kaku K et al (2008) Association of CDKAL1, IGF2BP2, CDKN2A/B, HHEX, SLC30A8, and KCNJ11 with susceptibility to type 2 diabetes in a Japanese population. Diabetes 57:791–795

Overby CL, Maloney KA, Alestock TD, Chavez J, Berman D, Sharaf RM et al (2015) Prioritizing approaches to engage community members and build Trust in Biobanks: a survey of attitudes and opinions of adults within outpatient practices at the University of Maryland. J Pers Med 5:264–279. doi:10.3390/jpm5030264

Pfeifer ME, Sullivan J, Yang K, Yang W (2012) Hmong population and demographic trends in the 2010 Census and 2010 American community survey. Hmong Studies Journal 13:1–31

Quinn SC (2004) Ethics in public health research: protecting human subjects: the role of community advisory boards. Am J Public Health 94:918–922

Relling MV, Klein TE (2011) CPIC: clinical pharmacogenetics implementation consortium of the pharmacogenomics research network. Clin Pharmacol Ther 89:464–467. doi:10.1038/clpt.2010.279

Roman YM, Culhane-Pera KA, Menk J, Straka RJ (2016) Assessment of genetic polymorphisms associated with hyperuricemia or gout in the Hmong. Personalized Medicine 13(5):429–440

Rotimi CN, Marshall PA (2010) Tailoring the process of informed consent in genetic and genomic research. Genome Med 2:20. doi:10.1186/gm141

Saxena R, Voight BF, Lyssenko V, Burtt NP, de Bakker PI, Chen H et al (2007) Genome-wide association analysis identifies loci for type 2 diabetes and triglyceride levels. Science 316:1331–1336

Scott LJ, Mohlke KL, Bonnycastle LL, Willer CJ, Li Y, Duren WL et al (2007) A genome-wide association study of type 2 diabetes in Finns detects multiple susceptibility variants. Science 316:1341–1345

Skinner HG, Calancie L, Vu MB, Garcia B, DeMarco M, Patterson C et al (2015) Using community-based participatory research principles to develop more understandable recruitment and informed consent documents in genomic research. PLoS One 10:e0125466. doi:10.1371/journal.pone.0125466

Straka RJ, Yang Y, Lochungvu M, Lor M, Oetting WS, Yang P, Vue P, Culhane-Pera KA (2010) Comparisons of SNP frequencies for CYP2C9 and VKORC1 between Hmong and combined Han-Chinese and Japanese Cohorts Poster Session II (PII 1–84). Clinical Pharmacology & Therapeutics 87:S39–S65. doi:10.1038/clpt.2009.274

Tham LS, Goh BC, Nafziger A, Guo JY, Wang LZ, Soong R et al (2006) A warfarin-dosing model in Asians that uses single-nucleotide polymorphisms in vitamin K epoxide reductase complex and cytochrome P450 2C9. Clin Pharmacol Ther 80:346–355. doi:10.1016/j.clpt.2006.06.009

Thorogood A, Joly Y, Knoppers BM, Nilsson T, Metrakos P, Lazaris A et al (2014) An implementation framework for the feedback of individual research results and incidental findings in research. BMC Med Ethics 15:88. doi:10.1186/1472-6939-15-88

Tindana P, Bull S, Amenga-Etego L, de Vries J, Aborigo R, Koram K et al (2012) Seeking consent to genetic and genomic research in a rural Ghanaian setting: a qualitative study of the MalariaGEN experience. BMC Med Ethics 13:15. doi:10.1186/1472-6939-13-15

Trinidad SB, Ludman EJ, Hopkins S, James RD, Hoeft TJ, Kinegak A et al (2015) Community dissemination and genetic research: moving beyond results reporting. Am J Med Genet A 167:1542–1550. doi:10.1002/ajmg.a.37028

Vreeman R, Kamaara E, Kamanda A, Ayuku D, Nyandiko W, Atwoli L et al (2012) A qualitative study using traditional community assemblies to investigate community perspectives on informed consent and research participation in western Kenya. BMC Med Ethics 13: 23. doi:10.1186/1472-6939-13-23

West Side Hmong Genomics Board (2008a) A Guide to Family Health History. Does It Run In the Family? http://www.geneticalliance.org/sites/default/files/publicationsarchive/book1_westside.pd Accessed May 31 2016

West Side Hmong Genomics Board (2008b) A Guide for Understanding Genetics and Health. Genetic Alliance's Does it Run in the Family? http://www.geneticalliance.org/sites/default/files/publicationsarchive/book2_westside.pdf Accessed May 31 2016

Wolf SM, Burke W, Koenig BA (2015) Mapping the ethics of translational genomics: situating return of results and navigating the research-clinical divide. J Law Med Ethics 43:486–501. doi:10.1111/jlme.12291

Wu Y, Li H, Loos RJ, Yu Z, Ye X, Chen L et al (2008) Common variants in CDKAL1, CDKN2A/B, IGF2BP2, SLC30A8, and HHEX/IDE genes are associated with type 2 diabetes and impaired fasting glucose in a Chinese Han population. Diabetes 57:2834–2842

Xiong D, Pepperell CS (2013) Genetic research with Hmong-ancestry populations: lessons from the literature and a pilot study. Hmong Studies Journal 14:1

Yu J-H, Burke W (2012) GeneWatch Toward Inclusive Genomics. http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=432. Accessed May 31 2016