HHS Public Access

Author manuscript

Ethn Health. Author manuscript; available in PMC 2019 August 01.

Published in final edited form as:

Ethn Health. 2019 August ; 24(6): 694–704. doi:10.1080/13557858.2017.1346189.

Factors associated with participation by African Americans in a study of the genetics of glaucoma

Rupin Parikh, **Laura O'Keefe**, **Rebecca Salowe**, **Makayla Mccoskey**, **Wei Pan**, **Prithvi Sankar**, **Eydie Miller-Ellis**, **Victoria Addis**, **Amanda Lehman**, **Maureen Maguire**, and **Joan O'Brien**

Scheie Eye Institute, University of Pennsylvania, Philadelphia, PA, USA

Abstract

Objective—African Americans have been historically underrepresented in research studies. Our aim was to evaluate factors influencing enrollment in the Primary Open-Angle African American Glaucoma Genetics (POAAGG) study.

Design—Patients approached to enroll in the POAAGG study were asked to complete a 15-item survey addressing demographic characteristics, knowledge of genetics and glaucoma, and opinions on human research. Survey responses were compared between subjects who enrolled (Enrollers) and did not enroll (Decliners) in the POAAGG study.

Results—Enrollers (N= 190) were 3.7 years younger ($P = 0.007$) and had similar gender, education, and income level to Decliners ($N = 117$). Knowledge about genetics and glaucoma was similar between groups. Enrollers were more comfortable providing DNA for research studies (93.1% vs 54.1%; $P < 0.001$) and more likely to have participated in prior studies ($P = 0.003$) and consider participating in future studies ($P < 0.001$). Among Decliners, lack of time was the primary reason given for not enrolling.

Conclusion—To increase participation of African Americans in genetic research studies, efforts should be made to raise comfort with DNA donation.

Keywords

African Americans; African American recruitment; African American enrollment; clinical studies; genetic studies; minority research; glaucoma; glaucoma genetics

Introduction

African Americans have been historically underrepresented in research studies (Dresser 1992; Brown 1993; Sheikh 2005; Fisher and Kalbaugh 2011; Ford et al. 2013; Castillo-Mancilla et al. 2014). Participation of African Americans in clinical trials is much lower than this group's representation in the general population (Chandra and Paul 2003; Ford et al. 2013; Williams and Tellawi 2013). Specimens from African Americans are also underre-

Contact Joan O'Brien joan.o'brien@uphs.upenn.edu Scheie Eye Institute, University of Pennsylvania, 51 N. 39th Street, Philadelphia, PA 19104, USA.

Supplemental data for this article can be accessed doi:10.1080/13557858.2017.1346189

Disclosure statement: No potential conflict of interest was reported by the authors.

presented in biobanks and have less associated phenotypic information than specimens from non-Hispanic whites (Moorman et al. 2004; Millon-Underwood et al. 2013; Hagiwara et al. 2014).

There is some debate over the reasons for African Americans' underrepresentation in research. Some suggest that African Americans are less willing than other races to join research studies primarily due to past abuses such as the Tuskegee Syphilis Study (Gamble 1997; Reverby 2001; Suite et al. 2007; Rencher and Wolf 2013). Other researchers cite distrust of scientists, lack of knowledge about research, confusion over use of genetic data, and cultural differences between investigator and patients as barriers to African American recruitment (Shavers-Hornaday et al. 1997; Adams-Campbell et al. 2016; Frew et al. 2016). However, some studies have shown that African Americans are just as willing as non-Hispanic whites to join research studies (Wendler et al. 2005), with black patients citing ‘not being asked’ as the main reason for not previously enrolling in a study (Millon-Underwood et al. 2013). In order to ensure the generalizability of research results and promote inclusiveness, it is important to better understand recruitment incentives and trends in the African American population (Branson, Davis, and Butler 2007).

Previous research on African American participation in research has involved focus groups that evaluate ethical or personal issues influencing an individual's decision to join a hypothetical study (Sussner et al. 2011; Luque et al. 2012; Halverson and Ross 2012; Dash et al. 2014). There is a need to extend this research from hypothetical scenarios to real-world research studies, closely examining factors that influence recruitment. We addressed this need by investigating factors associated with enrollment in a subgroup of patients approached for enrollment in the Primary Open-Angle African American Glaucoma Genetics (POAAGG) study. The POAAGG study, which has enrolled 8192 African Americans as of 1 February 2017, investigates the genetic architecture of primary open-angle glaucoma (POAG) in African Americans (Charlson et al. 2015). Demographic information, knowledge of genetics and glaucoma, and opinions about human research were compared between a subset of patients who accepted and declined enrollment in the POAAGG study. An analysis of factors affecting enrollment will help to elucidate barriers to recruitment, create strategies to overcome these obstacles, and design future studies that are more sensitive to this population's needs.

Methods

POAAGG study population

The study design and the baseline demographics for the POAAGG study have been reported elsewhere (Charlson et al. 2015). In brief, candidates for the POAAGG study were approached during regularly scheduled visits to physicians at the Scheie Eye Institute of the University of Pennsylvania (UPenn) and its research sites in Philadelphia, Pennsylvania. Eligibility criteria for the POAAGG study included self-identification as black (African American, African descent, or African Caribbean) and age 35 years or older. Clinical research coordinators (CRCs) collected medical information, a consent form, and a DNA sample from eligible patients and provided them with a $10 gift card as compensation. Glaucoma specialists classified subjects as cases, controls, or suspects based on detailed

clinical criteria (Charlson et al. 2015). The POAAGG study protocol and consent statement were approved by the UPenn institutional review board (IRB). A subset of patients was also recruited from the Penn Medicine Biobank.

Customized recruitment methods

The POAAGG study made efforts to tailor recruitment methods to African Americans in Philadelphia. The Scheie Eye Institute, where the majority of POAAGG recruitment takes place, is located in a predominantly African American neighborhood in West Philadelphia. The Department is composed of 35% of non-European American ophthalmologists and the Glaucoma Service is led by an African American woman. CRC staff for the POAAGG study is also racially diverse, with 40% of current staff identifying as African American.

In 2014, the POAAGG study began to provide free glaucoma screenings for African American patients in a private screening room at the Scheie Eye Institute. These screenings were advertised through a series of posters in the local subway (SEPTA and through involvement of community leaders, including writers for African American newspapers (*Philadelphia Tribune*), pastors of African American churches, and hosts of African American radio programs. Interested community members called to schedule their free glaucoma screenings at the Scheie Eye Institute and eligible patients were enrolled in the POAAGG study. These patients were compensated for transportation costs and received a $10 gift card for enrollment. In addition, POAAGG study staff purchased a mobile van and fully-equipped it with glaucoma screening equipment, using a grant from the UPenn Hospital Board of Women Visitors. A glaucoma specialist and team of CRCs took this van to community centers, federally qualified health centers, retirement communities, and churches to evaluate these populations for glaucoma. Again, eligible patients were enrolled in the POAAGG study.

Survey development

A 15-item survey was developed based on previous reports that identified common perspectives on genetic research studies (Achter, Parrott, and Silk 2004; Hull et al. 2008; Kaufman et al. 2009; Rahm et al. 2013; Yu et al. 2014; Thiel et al. 2014). This survey consisted of seven true/false questions, four multiple choice questions, and four questions on demographics (Figure 1). The questions evaluated the following areas: overall opinion of genetic research studies (5), demographic information (4), understanding of genetics (2), understanding of glaucoma (2), and understanding of the POAAGG study (2).

Survey administration and data collection

All patients approached to enroll in the POAAGG study at University of Pennsylvania sites (Scheie Eye Institute, Perelman Center for Advanced Medicine) from February to May 2016 were asked to complete the survey (Figure 2). The survey was administered after POAAGG enrollment was completed or declined. Age, gender, and disease status were recorded for patients who declined both enrollment in POAAGG and completion of the survey.

Statistical analysis

Subjects who completed the survey were classified as either ‘Enrollers’ (enrolled in POAAGG study) or ‘Decliners’ (did not enroll in POAAGG study). A knowledge score was computed as the sum of correct responses for items 1, 2, 8, and 9. Comparison of means between groups was performed using a t-test, while the comparison of proportions used a chi-square test, utilizing a test for linear trend for ordered categories. All the statistical analyses were performed using SAS v9.4 (SAS Institute, Inc) with $P < 0.05$ considered to be statistically significant. Based on sample size calculations for detecting a difference in percentage between the Enrollers and the Decliners of 20% or more with an alpha error level of 0.05 and 80% statistical power, the goal was to enroll at least 116 patients in each group.

Results

A total of 492 patients were offered enrollment in POAAGG during the study period (Figure 2). All 190 patients who enrolled in the POAAGG study also completed the survey. Of the 302 patients who declined enrollment in the POAAGG study, 117 (38.7%) completed the survey and 185 (61.3%) declined the survey. Among patients declining POAAGG enrollment, the distribution of age and gender was similar between those completing the survey and those not completing the survey, with mean age of 66.5 and 67.6 years ($P = 0.38$) and percentage female of 69.6% and 65.0% ($P = 0.41$), respectively.

Enrollers in POAAGG were significantly younger than Decliners (62.8 ± 11.4 vs. 66.5 ± 10.6, $P = 0.007$), but education level and household income did not differ between groups (Table 1). A lower proportion of Enrollers than Decliners agreed that certain genes are associated with certain diseases (85.6% vs. 93.8%; $P = 0.03$; Table 2). However, the two groups had a similar proportion of correct responses to the other three knowledge items and similar mean knowledge scores. Enrollers were more likely to have participated in prior research studies (36.9% vs. 20.9%, $P = 0.003$), feel comfortable providing DNA for research studies (93.1% vs. 54.1%, $P < 0.001$), and consider participating in future research studies (88.0% vs. 61.1%, $P < 0.001$) (Table 2).

Decliners cited lack of time (49.6%), unwillingness to participate in any form of research (20.5%), and discomfort with genetic material being studied (16.2%) as reasons for not enrolling in POAAGG. The ‘other’ reasons for declining are detailed in Supplementary Table 1.

Subject responses were stratified by education level as high school or lower, some college, and Associate degree or higher (Supplementary Table 2). Higher education level was associated with higher mean scores on knowledge-based questions (3.1, 3.5, and 3.7, respectively; $P < 0.001$). The proportion of patients who agreed that government involvement would change their willingness to participate went down with increased education level (47.3%, 31.9%, and 33.3%, respectively; $P = 0.02$). The proportion who correctly understood the purpose of POAAGG increased with higher education (83.0%, 97.3%, and 97.6%, respectively; $P \leq 0.001$) and the proportion who believed that the findings of POAAGG would directly benefit them decreased with higher education (84.4%, 75.7%, and 72.3%, respectively; $P = 0.03$).

Subject responses were also stratified by income level as <$25,000, $25,000 to $49,999, and ≥$50,000 (Supplementary Table 3). Higher income level was associated with higher mean scores on knowledge-based questions (3.2, 3.4, and 3.6, respectively; $P < 0.001$). The proportion who correctly understood the purpose of POAAGG increased with higher income level (87.6%, 91.7%, and 95.8%, respectively; $P = 0.046$) and the proportion who agreed that government involvement would change their willingness to participate decreased with higher income level (44.1%, 44.3%, and 25.0%, respectively; $P = 0.01$).

Discussion

This study investigated factors associated with enrollment in a large research study on the genetics of glaucoma within African Americans, a population with an exceptionally high incidence of glaucoma (Weinreb and Khaw 2004). Demographic information such as gender, education level, and socioeconomic status were not associated with enrollment in our study. This finding was replicated in other genetic studies, such as the Black Women's Health Study, which showed that educational status and marital status did not differ between enrolled and non-enrolled patients (Adams-Campbell et al. 2016). Other non-genetic studies, however, reported positive associations between higher educational attainment and enrollment (Harris et al. 1996; Corbie-Smith et al. 1999; O'Malley et al. 2005; Blumenthal et al. 2010) and both higher (Sengupta et al. 2000; Advani et al. 2003) and lower (Gorelick et al. 1998) socioeconomic status and enrollment. These results suggest that while demographic characteristics may be associated with enrollment in some clinical studies, these factors play a lesser role in the decision to donate a DNA sample to a genetic study.

Knowledge of glaucoma and genetics also had a minimal effect on enrollment. Other studies have also found that increasing knowledge about genetics and the disease of interest had only minor effects on patient recruitment. For example, one study tested the effect of three educational sessions providing information about clinical trials and health disparities to a group of African Americans. After three and six months, the intervention group had no significant increase in intention to join clinical trials versus a control group who completed questionnaires (Frew et al. 2016). In addition, the Jackson Heart Study reported high acceptance of genetics research and willingness to enroll in the study, despite low to moderate levels of genetic knowledge (Walker et al. 2014).

Subjects who did not enroll in the POAAGG study were primarily distinguished by their discomfort in providing DNA for research studies. Many studies have cited mistrust in research as the most commonly identified barrier to study participation among African Americans (Kaufman et al. 2008; Bussey-Jones et al. 2009; Rivers et al. 2013). In fact, surveys have shown that only 25% (Mouton et al. 1997) to 44% (Millon-Underwood, Sanders, and Davis 1993) of African Americans view research in the United States as ethical. This underlying attitude of mistrust likely contributes to subjects declining to participate in the study.

It was interesting to note that ‘lack of time’ was the most common reason for patients to decline POAAGG enrollment. Patients did in fact have ample unfilled time to enroll, as they were approached during the 20–60 min interval between receiving drops to dilate their eyes

and seeing their physician. However, reassurance from CRCs that enrollment would not increase the time to see their physician or offers to arrange an early arrival at their next appointment typically did not alter willingness to participate. These experiences suggest that 'lack of time' may be a polite excuse for some patients, while the true reason for declining enrollment is discomfort, disinterest, or other reasons. We believe it is unlikely that unintentional microaggression towards African Americans (Sue et al. 2007) played a role; the study team took great care to hire culturally sensitive CRCs of diverse backgrounds and monthly enrollment averages of 10 CRCs over the past 18 months did not differ among ethnic groups (Asian American: 25.5 patients/month, African American: 25.7 patients/month, non-Hispanic white: 26.9 patients/month). Instead, survey results support an unwillingness to admit discomfort with DNA collection: while only 16% of Decliners turned down enrollment because they did not want genetic material studied, 46% reported not feeling comfortable with providing DNA.

Limitations of this study include the exclusion of 185 patients ('Double No' Group), who declined to complete the genetic ethics survey and enroll in the POAAGG study. It is possible that this group of patients would be the most opposed to research and have more extreme responses than the Decliners. We did confirm, however, that the excluded patients did not significantly differ in age or gender from the Decliners. Another limitation of the study is possible misinterpretation of the survey questions by patients. For example, CRCs noted that several patients did not understand what '<' or '>' or DNA stood for. Lastly, responses were confined by limited choices ('agree' or 'disagree').

This study suggests that increasing the comfort of African American patients in donating DNA will have the greatest influence on the enrollment of this population in genetic studies. There are several practical approaches that can be undertaken to achieve this goal. First, genetic investigators can ensure that the study team, including both physicians and CRC staff, has adequate representation of African Americans. Project teams that include members of the targeted minority community have been shown to extend cultural awareness and improve patient comfort level (Gallagher-Thompson et al. 2003; Williams and Tellawi 2013). In addition, genetic investigators can incorporate the physician into the enrollment process when possible, as positive relationships with providers are strong predictors of enrollment (Brown and Topcu 2003; Walker et al. 2014). Physicians for the POAAGG study have increased efforts to mention the study and answer patient questions during or after the appointment, setting the stage for the CRC to proceed with the introduction to the study and formal enrollment process. Next, patients can be provided with more information about the positive impact of the research study on the African American community. Learning about the positive impact of their enrollment from community members, rather than just study staff, may increase patients' comfort and motivation to join the study (Walker et al. 2014). For example, the POAAGG study is considering creating a short video of interviews from previous study participants, explaining their reasons for joining the study; this video could be shown on an iPad as part of the study introduction. Lastly, genetic studies can invest in relationships with African American community leaders and bring outreach events or screenings to areas of greatest need. African American churches and role models have been shown to be essential to the recruitment of this population (Frew et al. 2008, 2015; Langford, Resnicow, and Beasley 2015) and outreach is particularly important for study

retention (Yancey, Ortega, and Kumanyika 2006). We believe that these efforts will help provide greater comfort and familiarity with genetic studies, thereby increasing enrollment.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Funding: This work was supported by National Eye Institute [grant number 1RO1EY023557-01]; The Paul MacKall and Evanina Bell MacKall Trust; F. M. Kirby Foundation; The UPenn Hospital Board of Women Visitors; Research to Prevent Blindness.

References

Achter P, Parrott R, Silk K. 2004; African Americans' Opinions about Human-genetics Research. Politics and the Life Sciences. 23(1):60–66. DOI: 10.2990/1471-5457(2004)23[60:aaoahr]2.0.co;2 [PubMed: 16859381]

Adams-Campbell LL, Dash C, Palmer JR, Wiedemeier MV, Russell CW, Rosenberg L, Cozier YC. 2016; Predictors of Biospecimen Donation in the Black Women's Health Study. Cancer Causes & Control. 27(6):797–803. DOI: 10.1007/s10552-016-0747-0 [PubMed: 27106577]

Advani AS, Atkeson B, Brown CL, Peterson BL, Fish L, Johnson JL, Gockerman JP, Gautier M. 2003; Barriers to the Participation of African-American Patients with Cancer in Clinical Trials: A Pilot Study. Cancer. 97(6):1499–1506. DOI: 10.1002/cncr.11213 [PubMed: 12627515]

Blumenthal DS, Smith SA, Majett CD, Alema-Mensah E. 2010; A Trial of 3 Interventions to Promote Colorectal Cancer Screening in African Americans. Cancer. 116(4):922–929. [PubMed: 20052732]

Branson RD, Davis K Jr, Butler KL. 2007; African Americans' Participation in Clinical Research: Importance, Barriers, and Solutions. The American Journal of Surgery. 193(1):32–39. DOI: 10.1016/j.amjsurg.2005.11.007 [PubMed: 17188084]

Brown LS Jr. 1993; Enrollment of Drug Abusers in HIV Clinical Trials: A Public Health Imperative for Communities of Color. Journal of Psychoactive Drugs. 25(1):45–52. DOI: 10.1080/02791072.1993.10472590 [PubMed: 8483046]

Brown DR, Topcu M. 2003; Willingness to Participate in Clinical Treatment Research among Older African Americans and Whites. The Gerontologist. 43(1):62–72. [PubMed: 12604747]

Bussey-Jones J, Henderson G, Garrett J, Moloney M, Blumenthal C, Corbie-Smith G. 2009; Asking the Right Questions: Views on Genetic Variation Research among Black and White Research Participants. Journal of General Internal Medicine. 24(3):299–304. DOI: 10.1007/s11606-008-0883-7 [PubMed: 19101773]

Castillo-Mancilla JR, Cohn SE, Krishnan S, Cespedes M, Floris-Moore M, Schulte G, Pavlov G, Mildvan D, Smith KY. 2014; Minorities Remain Underrepresented in HIV/AIDS Research Despite Access to Clinical Trials. HIV Clinical Trials. 15:14–26. [PubMed: 24518211]

Chandra A, Paul DP III. 2003; African American Participation in Clinical Trials: Recruitment Difficulties and Potential Remedies. Hospital Topics. 81(2):33–38.

Charlson ES, Sankar PS, Miller-Ellis E, Regina M, Fertig R, Salinas J, Pistelli M, et al. 2015; The Primary Open-angle African-American Glaucoma Genetics (POAAGG) Study: Baseline Demographics. Ophthalmology. 122:711–720. [PubMed: 25576993]

Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. 1999; Attitudes and Beliefs of African Americans Toward Participation in Medical Research. Journal of General Internal Medicine. 14(9):537–546. [PubMed: 10491242]

Dash C, Wallington SF, Muthra S, Dodson E, Mandelblatt J, Adams-Campbell LL. 2014; Disparities in Knowledge and Willingness to Donate Research Biospecimens: A Mixed-methods Study in an Underserved Urban Community. Journal of Community Genetics. 5(4):329–336. DOI: 10.1007/s12687-014-0187-z [PubMed: 24771039]

Dresser R. 1992; Wanted Single, White Male for Medical Research. The Hastings Center Report. 22(1):24–29.

Fisher JA, Kalbaugh CA. 2011; Challenging Assumptions about Minority Participation in US Clinical Research. American Journal of Public Health. 101(12):2217–2222. DOI: 10.2105/ajph.2011.300279 [PubMed: 22021285]

Ford ME, Siminoff LA, Pickelsimer E, Mainous AG, Smith DW, Diaz VA, Soderstrom LH, Jefferson MS, Tilley BC. 2013; Unequal Burden of Disease, Unequal Participation in Clinical Trials: Solutions from African American and Latino Community Members. Health & Social Work. 38(1):29–38. [PubMed: 23539894]

Frew PM, del Rio C, Clifton S, Archibald M, Hormes JT, Mulligan MJ. 2008; Factors Influencing HIV Vaccine Community Engagement in the Urban South. Journal of Community Health. 33(4):259–269. DOI: 10.1007/s10900-008-9086-8 [PubMed: 18389351]

Frew PM, Omer SB, Parker K, Bolton M, Schamel J, Shapiro E, Owens L, et al. 2015; Delivering a 'Dose of Hope': A Faith-based Program to Increase Older African Americans' Participation in Clinical Trials. JMIR Research Protocols. 4(2):e64.doi: 10.2196/resprot.4072 [PubMed: 26036841]

Frew PM, Schamel JT, O'Connell KA, Randall LA, Boggavarapu S. 2016; Results of a Community Randomized Study of a Faith-based Education Program to Improve Clinical Trial Participation among African Americans. International journal of environmental research and public health. 13(1)doi: 10.3390/ijerph13010041

Gallagher-Thompson D, Solano N, Coon D, Arean P. 2003; Recruitment and Retention of Latino Dementia Family Caregivers in Intervention Research: Issues to Face, Lessons to Learn. The Gerontologist. 43(1):45–51. [PubMed: 12604745]

Gamble VN. 1997; Under the Shadow of Tuskegee: African Americans and Health Care. American Journal of Public Health. 87(11):1773–1778. [PubMed: 9366634]

Gorelick PB, Harris Y, Burnett B, Bonecutter FJ. 1998; The Recruitment Triangle: Reasons Why African Americans Enroll, Refuse to Enroll, or Voluntarily Withdraw from a Clinical Trial. An Interim Report from the African-American Antiplatelet Stroke Prevention Study (AAASPS). Journal of the National Medical Association. 90(3):141–145. [PubMed: 9549977]

Hagiwara N, Berry-Bobovski L, Francis C, Ramsey L, Chapman RA, Albrecht TL. 2014; Unexpected Findings in the Exploration of African American Underrepresentation in Biospecimen Collection and Biobanks. Journal of Cancer Education. 29(3):580–587. DOI: 10.1007/s13187-013-0586-6 [PubMed: 24243440]

Halverson CM, Ross LF. 2012; Incidental Findings of Therapeutic Misconception in Biobank-based Research. Genetics in Medicine. 14(6):611–615. DOI: 10.1038/gim.2011.50 [PubMed: 22261760]

Harris Y, Gorelick PB, Samuels P, Bempong I. 1996; Why African Americans may not be Participating in Clinical Trials. Journal of the National Medical Association. 88(10):630–634. [PubMed: 8918067]

Hull SC, Sharp RR, Botkin JR, Brown M, Hughes M, Sugarman J, Schwinn D, et al. 2008; Patients' Views on Identifiability of Samples and Informed Consent for Genetic Research. The American Journal of Bioethics. 8(10):62–70. DOI: 10.1080/15265160802478404

Kaufman D, Murphy J, Scott J, Hudson K. 2008; Subjects Matter: A Survey of Public Opinions about a Large Genetic Cohort Study. Genetics in Medicine. 10(11):831–839. DOI: 10.1097/GIM.0b013e31818bb3ab [PubMed: 19011407]

Kaufman DJ, Murphy-Bollinger J, Scott J, Hudson KL. 2009; Public Opinion about the Importance of Privacy in Biobank Research. The American Journal of Human Genetics. 85(5):643–654. DOI: 10.1016/j.ajhg.2009.10.002 [PubMed: 19878915]

Langford AT, Resnicow K, Beasley DD. 2015; Outcomes from the Body & Soul Clinical Trials Project: A University-Church Partnership to Improve African American Enrollment in a Clinical Trial Registry. Patient Education and Counseling. 98(2):245–250. DOI: 10.1016/j.pec.2014.10.018 [PubMed: 25468392]

Luque JS, Quinn GP, Montel-Ishino FA, Arevalo M, Bynum SA, Noel-Thomas S, Wells KJ, Gwede CK, Meade CD, Partners Tampa Bay Community Cancer Network. 2012; Formative Research on

Perceptions of Biobanking: What Community Members Think. Journal of Cancer Education. 27(1):91–99. DOI: 10.1007/s13187-011-0275-2 [PubMed: 21927867]

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. Nursing research and practice 2013. :749563.doi: 10.1155/2013/749563

Millon-Underwood S, Sanders E, Davis M. 1993; Determinants of Participation in State-of-the-art Cancer Prevention, Early Detection/Screening, and Treatment Trials among African-Americans. Cancer Nursing. 16(1):25–33. [PubMed: 8457983]

Moorman PG, Skinner CS, Evans JP, Newman B, Sorenson JR, Calingaert B, Susswein L, Crankshaw TS, Hoyo C, Schildkraut JM. 2004; Racial Differences in Enrolment in a Cancer Genetics Registry. Cancer epidemiology, biomarkers & prevention. 13(8):1349–1354.

Mouton CP, Harris S, Rovi S, Solorzano P, Johnson MS. 1997; Barriers to Black Women's Participation in Cancer Clinical Trials. Journal of the National Medical Association. 89(11):721–727. [PubMed: 9375475]

O'Malley AS, Forrest CB, Feng S, Mandelblatt J. 2005; Disparities Despite Coverage: Gaps in Colorectal Cancer Screening among Medicare Beneficiaries. Archives of Internal Medicine. 165(18):2129–2135. DOI: 10.1001/archinte.165.18.2129 [PubMed: 16217003]

Rahm AK, Wrenn M, Carroll NM, Feigelson HS. 2013; Biobanking for Research: A Survey of Patient Population Attitudes and Understanding. Journal of Community Genetics. 4(4):445–450. DOI: 10.1007/s12687-013-0146-0 [PubMed: 23605056]

Rencher, William C; Wolf, Leslie E. 2013; Redressing Past Wrongs: Changing the Common Rule to Increase Minority Voices in Research. American Journal of Public Health. 103(12):2136–2140. DOI: 10.2105/ajph.2013.301356 [PubMed: 24134384]

Reverby SM. 2001; More Than Fact and Fiction: Cultural Memory and the Tuskegee Syphilis Study. The Hastings Center Report. 31(5):22–28.

Rivers D, August EM, Sehovic I, Lee Green B, Quinn GP. 2013; A Systematic Review of the Factors Influencing African Americans' Participation in Cancer Clinical Trials. Contemporary Clinical Trials. 35(2):13–32. DOI: 10.1016/j.cct.2013.03.007 [PubMed: 23557729]

Sengupta S, Strauss RP, DeVellis R, Quinn SC, DeVellis B, Ware WB. 2000; Factors Affecting African-American Participation in AIDS Research. Journal of Acquired Immune Deficiency Syndromes. 24(3):275–284. [PubMed: 10969353]

Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC. 1997; Why are African Americans Under-Represented in Medical Research Studies? Impediments to Participation. Ethnicity & Health. 2(1-2):31–45. DOI: 10.1080/13557858.1997.9961813 [PubMed: 9395587]

Sheikh A. 2005; Why are Ethnic Minorities Under-represented in US Research Studies? PLoS Medicine. 3(2):e49. [PubMed: 16370583]

Sue DW, Capodilupo CM, Torino GC, Bucceri JM, Holder AM, Nadal KL, Esquilin M. 2007; Racial Microaggressions in Everyday Life: Implications for Clinical Practice. American Psychologist. 62(4):271–286. DOI: 10.1037/0003-066x.62.4.271 [PubMed: 17516773]

Suite DH, La Bril R, Primm A, Harrison-Ross P. 2007; Beyond Misdiagnosis, Misunderstanding and Mistrust: Relevance of the Historical Perspective in the Medical and Mental Health Treatment of People of Color. Journal of the National Medical Association. 99(8):879–885. [PubMed: 17722664]

Sussner KM, Edwards TA, Thompson HS, Jandorf L, Kwate NO, Forman A, Brown K, et al. 2011; Ethnic, Racial and Cultural Identity and Perceived Benefits and Barriers Related to Genetic Testing for Breast Cancer among at-Risk Women of African Descent in New York City. Public Health Genomics. 14(6):356–370. DOI: 10.1159/000325263 [PubMed: 21540561]

Thiel DB, Platt T, Platt J, King SB, Kardia SL. 2014; Community Perspectives on Public Health Biobanking: An Analysis of Community Meetings on the Michigan BioTrust for Health. Journal of Community Genetics. 5(2):125–138. DOI: 10.1007/s12687-013-0162-0 [PubMed: 23893769]

Walker ER, Nelson CR, Antoine-LaVigne D, Thigpen DT, Puggal MA, Sarpong DE, Smith AM. 2014; Research Participants' Opinions on Genetic Research and Reasons for Participation: A Jackson Heart Study Focus Group Analysis. Ethnicity & disease. 24(3):290–297. [PubMed: 25065069]

Weinreb, Robert N; Khaw, Peng Tee. 2004; Primary Open-angle Glaucoma. The Lancet. 363(9422): 1711–1720.

Wendler D, Kington R, Madans J, Van Wye G, Christ-Schmidt H, Pratt LA, Brawley OW, Gross CP, Emanuel E. 2005; Are Racial and Ethnic Minorities Less Willing to Participate in Health Research? PLoS Medicine. 3(2):e19.doi: 10.1371/journal.pmed.0030019 [PubMed: 16318411]

Williams MV, Tellawi G. 2013; Recruitment of Ethnoracial Minorities for Mental Health Research. Drugs. 67(2):236–244.

Yancey AK, Ortega AN, Kumanyika SK. 2006; Effective Recruitment and Retention of Minority Research Participants. Annual Review of Public Health. 27:1–28. DOI: 10.1146/annurev.publhealth.27.021405.102113

Yu JH, Harrell TM, Jamal SM, Tabor HK, Bamshad MJ. 2014; Attitudes of Genetics Professionals Toward the Return of Incidental Results from Exome and Whole-genome Sequencing. The American Journal of Human Genetics. 95(1):77–84. DOI: 10.1016/j.ajhg.2014.06.004 [PubMed: 24975944]

Opinion Survey

Mark whether you agree or disagree

	Agree	Disagree
1. I inherited my genes from my parents.	( )A	( )D
2. Certain genes are associated with certain diseases.	( )A	( )D
3. I have participated in research studies before.	( )A	( )D
4. I believe the findings of this study would directly benefit me.	( )A	( )D
5. I feel comfortable providing my genetic Information (DNA) for medical research studies.	( )A	( )D
6. If my DNA was eligible for another study in the future, I would consider participating.	( )A	( )D
7. Government involvement in a genetics research study (such as sponsorship or having access to data) would change my willingness to participate.	( )A	( )D

8. Glaucoma is (*Mark only 1 answer*):
   - ( )1 An eye infection that causes vision loss
   - ( )2 An eye disease that is contagious
   - ( )3 A disease, often with high eye pressures, that can cause vision loss or even blindness
   - ( )4 An eye disease that occurs due to diabetes

9. Glaucoma is caused by (*Mark only 1 answer*):
   - ( )1 Environmental factors such as pollution or exposure to metals
   - ( )2 Genes

10. The purpose of the study I was invited to join is (*Mark only 1 answer*):
    - ( )1 To research the genetic basis of glaucoma
    - ( )2 To treat my glaucoma

Answer only if you chose not to participate in the study:

11. I chose not to enroll in the study because (*Mark all that apply*):
    - ( )1 I do not have time
    - ( )2 I do not want my genetic material being studied
    - ( )3 I do not want to participate in any form of research
    - ( )4 Other: _____

Demographics:

12. Age: ___ years
13. Sex: Male ( )M Female ( )F
14. Your highest education level (*Mark only 1 answer*):
    - ( )1 Junior High School
    - ( )2 Some High School
    - ( )3 High School Diploma or GED
    - ( )4 Some College
    - ( )5 Associate's Degree
    - ( )6 Bachelor's Degree
    - ( )7 Post-graduate Degree
15. Household income (*Mark only 1 answer*):
    - ( )1 < $25,000
    - ( )2 $25,000-$49,999
    - ( )3 $50,000-74,999
    - ( )4 $75,000+

Figure 1. Survey administered to patients

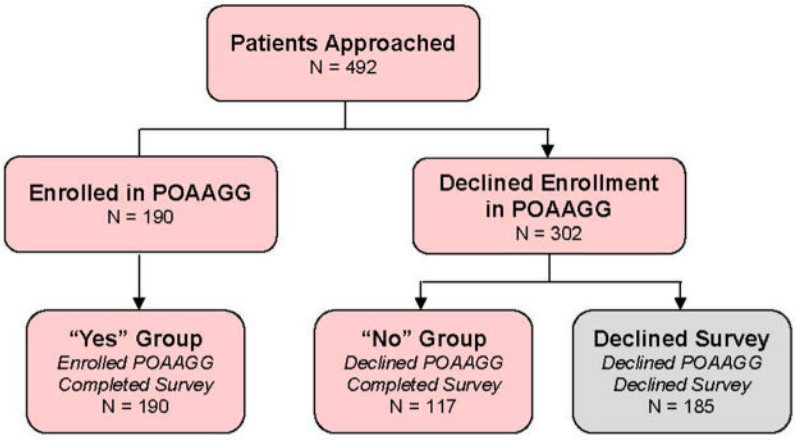

Figure 2. Flowchart of subjects: POAAGG enrollment and survey completion

Table 1

Comparison between Enrollers and Decliners of demographic characteristics.

	Enrollers (*N* = 190)	**Decliners (*N* = 117)**	***P* value**
Demographic characteristics			
Age (years)			0.007
N	183	112	
Mean (SD)	62.8 (11.4)	66.5 (10.6)	
Gender			0.95
Male	57 (30.5%)	35 (30.2%)	
Female	130 (69.5%)	81 (69.8%)	
Unknown/NA	3	1	
Highest education level			0.29
Junior High School	7 (3.8%)	6 (5.4%)	
Some High School	17 (9.2%)	17 (15.2%)	
High School Diploma or GED	56 (30.3%)	36 (32.1%)	
Some College	51 (27.6%)	23 (20.5%)	
Associate's Degree	20 (10.8%)	11 (9.8%)	
Bachelor's Degree	23 (12.4%)	9 (8.0%)	
Post-graduate Degree	11 (5.9%)	10 (8.9%)	
Unknown/NA	5	5	
Household income			0.44
<$25,000	80 (46.0%)	48 (49.0%)	
$25,000–$49,999	47 (27.0%)	26 (26.5%)	
$50,000–$74,999	25 (14.4%)	16 (16.3%)	
$75,000+	22 (12.6%)	8 (8.2%)	
Unknown/NA	16	19	

Table 2

Comparison between Enrollers and Decliners of knowledge about genetics and glaucoma and opinions about research.

Survey response	Enrollers (*N* = 190)	Decliners (*N* = 117)	*P* value
Knowledge Items, correct response, n (%)			
I inherited my genes from my parents.	177 (93.2%)	103 (88.8%)	0.18
Unknown/NA	0	1	
Certain genes are associated with certain diseases	161 (85.6%)	105 (93.8%)	0.03
Unknown/NA	2	5	
Glaucoma is a disease, often with high eye pressures, that can cause vision loss or even blindness	140 (75.7%)	73 (65.2%)	0.14
Unknown/NA	5	5	
Glaucoma is caused by genes	169 (90.4%)	100 (87.7%)	0.47
Unknown/NA	3	3	
Knowledge score			
1	4 (2.1%)	7 (6.0%)	
2	26 (13.7%)	12 (10.3%)	
3	49 (25.8%)	42 (35.9%)	
4	111 (58.4%)	56 (47.9%)	
Mean (SD)	3.4 (0.8)	3.3 (0.9)	0.13
The purpose of the study I was invited to join is to research the genetic basis of glaucoma	175 (92.6%)	100 (87.0%)	0.10
Unknown/NA	1	2	
Opinions on research, agree, n (%)			
I have participated in research studies before.	69 (36.9%)	24 (20.9%)	0.003
Unknown/NA	3	2	
I believe the findings of this study would directly benefit me.	152 (81.7%)	83 (74.1%)	0.12
Unknown/NA	4	5	
I feel comfortable providing my genetic information (DNA) for medical research studies.	176 (93.1%)	60 (54.1%)	<0.001
Unknown/NA	1	6	
If my DNA was eligible for another study in the future, I would consider participating.	162 (88.0%)	69 (61.1%)	<0.001
Unknown/NA	6	4	
Government involvement in a genetics research study (such as sponsorship or having access to data) would change my willingness to participate.	68 (36.2%)	51 (45.9%)	0.10
Unknown/NA	2	6	