Published in final edited form as:

Cancer Epidemiol Biomarkers Prev. 2014 August ; 23(8): 1649–1658. doi:
10.1158/1055-9965.EPI-13-1253.

Validating self-reported mammography use in vulnerable communities: findings and recommendations

Kristi L. Allgood¹, Garth H. Rauscher², Steven Whitman¹, Giselle Vasquez-Jones¹, and Ami M. Shah³

¹Sinai Urban Health Institute, Sinai Health System, Chicago, Illinois

²Division of Epidemiology & Biostatistics, University of Illinois at Chicago School of Public Health, Chicago, Illinois

³UCLA Center for Health Policy Research, University of California, Los Angeles. Los Angeles, California

Abstract

Background—Most health surveys ask women whether they have had a recent mammogram, all of which report mammography use (past two years) at about 70–80% regardless of race or residence. We examined the potential extent of over-reporting of mammography use in low income African-American and Latina women, and whether self-report inaccuracies might bias estimated associations between patient characteristics and mammography use.

Methods—Using venue based sampling in two poor communities on the west side of Chicago, we asked eligible women living in two west side communities of Chicago to complete a survey about breast health (n=2,200) and to provide consent to view their medical record. Of the n=1,909 women who screened eligible for medical record review, n=1,566 consented (82%). We obtained medical records of all women who provided both permission and a valid local mammography facility (n=1,221). We compared the self-reported responses from the survey to the imaging reports found in the medical record (documented). To account for missing data we conducted multiple imputations for key demographic variables and report standard measures of accuracy.

Results—Although 73% of women self-reported a mammogram in the last 2 years, only 45% of self-reports were documented. Over-reporting of mammography use was observed for all three ethnic groups.

Corresponding Author: Kristi L. Allgood, Epidemiologist II, Sinai Urban Health Institute, Sinai Health System, 1500 S. California Ave, K449, Chicago, IL 60608. 773-257-2525 (phone), 773-257-5680 (fax), kristi.allgood@sinai.org.

Kristi L. Allgood. Sinai Urban Health Institute, Sinai Health System, 1500 S. California Ave, K449, Chicago, IL 60608. 773-257-2525 (phone), 773-257-5680 (fax), Kristi.allgood@sinai.org.

Garth H. Rauscher. Division of Epidemiology & Biostatistics (M/C 923), UIC School of Public Health, University of Illinois at Chicago, 1603 West Taylor Street, Chicago, IL 60612. 312-413-4317 (phone), 312-996-0064 (fax), garthr@uic.edu.

Steven Whitman. Sinai Urban Health Institute, Sinai Health System, 1500 S. California Ave, K437, Chicago, IL 60608. 773-257-5661 (phone), 773-257-5680 (fax), steve.whitman@sinai.org.

Giselle Vasquez-Jones. Sinai Urban Health Institute, Sinai Health System, 1500 S. California Ave, K437, Chicago, IL 60608. 773-257-5960 (phone), 773-257-5680 (fax), suhi@sinai.org.

Ami M. Shah, MPH. UCLA Center for Health Policy Research, University of California, Los Angeles 10960 Wilshire Blvd., Suite 1550, Los Angeles, CA 90024. (phone) 310-794-2302, amishah@ucla.edu.

Conflicts of Interest: There are no conflicts of interest to disclose for any of the authors of this manuscript.

Conclusions—These results suggest considerable over-estimation of prevalence of use in these vulnerable populations.

Impact—Relying on known faulty self-reported mammography data as a measure of mammography use provides an overly optimistic picture of utilization, a problem that may be exacerbated in vulnerable minority communities.

Keywords

breast cancer disparities; mammography use disparities; validation of survey responses; vulnerable communities; breast cancer

Introduction

Most health surveys ask women whether they have had a mammogram and when they had their last one. Virtually all such surveys show that Black and White women are obtaining mammograms at about the same rate. For example, according to the web based prevalence and trend data the 2012 U.S. Behavioral Risk Factor Surveillance System (BRFSS) 74% of non-Hispanic White women, 78% of non-Hispanic Black women and 69% of Hispanic women reported receiving a mammogram in the past two years [1]. A community based program called the Racial and Ethnic Approaches to Community Health (REACH) found that in 2009, 80% of Black women and 77% of Latina women reported recent mammography use in Chicago neighborhoods [2]. These reports, and others like them, suggest that a substantial majority of women are getting mammograms routinely, have been doing so for several years and that there is no notable racial disparity.

Other studies have found, however, that self-reported health behaviors may be problematic because people tend to over-report desirable behaviors (e.g., exercise) and under-report undesirable behaviors (e.g., smoking) [3–6]. Many studies compared self-reported mammography histories with those documented from chart reviews [7–26] or other records (e.g., Medicare databases [27] or national mammography registries [28]). These studies, including a recent meta analysis, found a general tendency to over-report rather than under-report mammography use, and suggest that over-reporting might be greater in racial/ethnic minorities [29].

As part of the Helping Her Live intervention, a unique outreach and community navigation program aimed at increasing routine mammography use in two poor communities on the west side of Chicago, we conducted a baseline survey that asked about, among other things, prior mammography history [30]. The purpose of this survey was to not only find out how women report mammography usage, but also how well mammography and breast cancer is understood by women in these vulnerable communities as well as to verify self-reported mammography usage. The findings of the survey were to be used to inform the educational component of the intervention and not aimed to recruit women into the intervention. During the survey we also requested permission to examine medical records of the surveyed women, which allowed us to compare self-report with medical records information. Although such comparisons have been made before, very few have pursued this issue in

such vulnerable communities where one might expect low mammography rates and substantial over-reporting [8–9, 12].

The purpose of this analysis was to examine the potential extent of over-reporting and possibly underreporting of mammography use in these vulnerable populations, and to determine how self-report inaccuracies might bias estimated associations between patient characteristics and mammography use.

Materials and Methods

The communities

We interviewed women aged 40 and older who lived in the Chicago communities of Humboldt Park (HP) and North Lawndale (NL). HP is half Black, a quarter Mexican and a quarter Puerto Rican while NL is almost entirely Black [31]. Both communities are very poor [31,32]. Based on the 2010 American Community Survey 5-year estimates, the Median Household Income (MHI) for Chicago residents was about \$56,000. However in HP, a community that is in the process of gentrification, the MHI was about \$33,000; in NL the MHI was \$27,000 [32]. We targeted 500 women from each of the following four sectors of the two Chicago community areas: Non-Hispanic Black (NHB) women in NL; NHB women in HP; Puerto Rican women in HP; and Mexican women in HP.

The Survey

Thirteen female interviewers (6 Spanish speaking) who resided in the targeted communities were hired and trained to administer the survey. The 12-hour training involved discussions on how to conduct research studies, privacy and Health Insurance Portability and Accountability Act (HIPAA) rules, interviewing skills, and the general protocol for interviewing women in the community. In addition, each question including the response options and their meaning were thoroughly reviewed and interviewers practiced their skills through role-playing with trainers as well as piloting their skills with caregivers in the cafeteria of the hospital in which this program was housed. In each step, all interviewers were provided feedback to assure quality and systematic data collection. The survey was approved by the Mount Sinai Hospital Institutional Review Board.

We produced a comprehensive list of venues in the targeted areas that served women aged 40 years and older, and these venues served as the sampling frame. Examples of venues included local pharmacies, laundromats and grocery stores. Between March–June 2008, 3,199 women were screened for eligibility based on their age (40 yrs and over) and residence. Our interviewers were culturally matched to the sector in which the interviews were conducted. Interviewers were deployed at the various venues in each community area every day and there were very few instances where interviewers were shared across sectors. Adult women were screened for eligibility if they were at the venue at the same time as an interviewer. Interviewers completed 2,200 surveys and among them, n=144 respondents did not reside in either North Lawndale or Humboldt Park based on the self-reported address provided and were thus excluded (Figure 1).

Face-to-face interviews were conducted and responses were recorded on a paper-based instrument; each survey took about 20 minutes to complete. As an incentive, each respondent was given a \$20 gift card for a local business including Walgreens, CVS, supermarkets, and Wal-Mart. An additional 147 surveys were excluded due to missing data on race/ethnicity or reporting a race/ethnicity other than non-Hispanic Black, Mexican or Puerto Rican (final sample, n=1,909 women, Figure 1).

The survey included the following questions relevant to this analysis:

- “Have you ever had a mammogram or breast x-ray?” [33]
- “How long has it been since you had your last mammogram?” [33]
- “In what month and year was your last mammogram?” [33] For those who could not recall the month we also asked, “In what season was your last mammogram: winter, spring, summer or fall?” (new question)

In addition, women reported where they received their most recent mammogram, as well as any other facilities they used for primary or preventive care. We used this information to document prior mammogram histories during the past five years.

The validation sample

Each woman was asked to sign a HIPAA Authorization Form giving us permission to access her medical records at the specific facilities she reported; 1,566 of the 1,909 surveyed provided authorization (82%). Many of the 128 facilities listed on the authorizations were located out of state or had been reported by less than 10 women. We focused our abstraction efforts at the 18 facilities with more than 10 corresponding medical record authorizations, together representing 78% of the sample who gave us authorization. We requested medical records on the 1,221 women who provided a valid HIPAA Authorization Form and had at least one facility listed on the form (Figure 1).

The abstraction process

Data describing the facilities listed on the medical record authorization forms were entered into a Microsoft Access database that was linked to the survey responses. Before sending a request to the facility, each entry was cleaned by hand to ensure accuracy of the entries. Each facility received a request package, which was either hand delivered by a staff member of the project or mailed to a specific contact in the facility's Medical Records Department. Communication between the research staff and the mammography facility was ongoing as long as we were abstracting data from the site. Thus some sites required several requests prior to completion of the data collection.

For each of the 18 facilities from which we abstracted data, we created a protocol outlining the unique methods for that particular site. Abstractors were blinded to self-reported mammography status. Three sites allowed our staff to abstract data on site using an electronic medical record, while the remaining sites returned photocopies of the following (where available): breast imaging records for those who received a mammogram between 2003–present, mammography referrals, lists of appointments attended, pathology reports for breast tissue specimens and physician notes. For those who had no mammograms during this

time frame but who were past or current patients at the facility, we received the patient's medical record number and any breast imaging referral data (if available) or a memo from the facility stating that there were no breast images during the time period. If a patient we requested had never been seen at the facility listed on the HIPAA, a memo from the facility was provided stating that the records for the patient could not be located.

The abstractors collected information on any mention of a breast image documented in the medical record during the past five years that included: the image date and the procedure type (mammogram, ultrasound, etc.). Every record was later reviewed by a senior abstractor. A random sample of completed abstractions was also re-reviewed to ensure further accuracy of data collection. Each record was thus reviewed at least twice and some were reviewed 3 times. All data entry elements were independently reviewed by a second member of our team for accuracy, and a senior abstractor randomly performed a quality check on 10% of the records.

Data analysis and definitions

Data were analyzed using SAS statistical software v 9.1.3 and Stata version 12. We compared self-reported mammography in the 24 months prior to the date of the survey to corresponding documented history in the medical record (treated as the gold standard). For each self-reported versus documented screening history we identified: the number of positive reports that were documented as positive (true positives-TP); the number of positive reports that were documented as negative (false positives-FP); the number of negative reports that were documented as positive (false negatives-FN); and the number of negative reports that were documented as negative (true negatives-TN).

In order to assess the robustness of our results to potential selection bias due to incomplete record abstraction, we conducted multiple imputation analyses as follows. We started with the complete dataset of 1,909 eligible women, of whom 1,221 were included in our main analysis. Using the method of chained equations (ICE) as implemented by the *mi* command in Stata, we conducted multiple imputations to account for the missing values for self-reported mammography use (N=29), documented mammography use (N=688), education (N=25), and income (N=213). We set the three women with missing data on insurance status to the mode (uninsured). This method enables the analyst to choose an imputation model suitable for the distribution of each variable with missing data (e.g., logistic regression for binary variables) and to tailor the choice of predictor variables to each variable being imputed [34]. We created 20 imputed datasets of size 1,909. We then re-estimated our analysis models using Rubin's rules for combined estimation results across multiply imputed datasets [35].

We calculated measures to gauge the extent to which reliance on self-report might over- or under-estimate population prevalence of screening mammography. Reports to records ratio (RRR) was defined as the percent of positive mammogram self-reports divided by the percent of positive documented mammogram use. A value over 1 suggested over-reporting and a value below 1 indicated under-reporting. Reports to records difference (RRD) was defined as the difference between the percent of positive mammogram self-reports and the

percent of positive documented mammogram use. A value greater than 0 suggested over-reporting and a value below 0 indicated under-reporting.

We also calculated standard measures of self-report accuracy, including concordance, kappa, sensitivity (Se), specificity (Sp), positive predictive value (PPV) and negative predictive value (NPV) [36]. Extent of over-reporting was also assessed by calculating false positive rates (FPR) equal to one minus the specificity, with FPR=0 meaning no over-reporting, and FPR=0.5 meaning that half of all truly negative histories were reported as positive.

Results

We were able to abstract medical records from 1,221 (64%) of our eligible sample of 1,909 women; 343 women refused consent to medical record abstraction, and another 345 had documentation at a facility at which we did not abstract. Women who reported a mammogram in the prior two years were considerably more likely to have their medical records abstracted than women not reporting a prior history (72% vs. 50%, $p<0.0001$) (Table 1). Women in their 40s were less likely than older women to have records abstracted, and Mexican-American women were less likely than others to have their records abstracted. Uninsured women were the least likely, and Medicaid patients the most likely to have their records abstracted for this study. Women with less income or less education were more likely to have their records abstracted (Table 1). The data in Supplemental Table 1 suggest that those who had data abstracted were less likely to report having a mammogram in the last 2 years, more likely to be younger, more likely to be Mexican American, and more likely to be uninsured compared to those who did not have their data abstracted regardless of the reason for non-abstraction (Supplemental Table 1).

For the final sample of 1,221 women with interview and complete medical record data, three-fourths (73%) reported a mammogram in the past 24 months, but only 44% of these had a documented prior mammogram within two years (Table 2). Half the sample was NHB, and a fourth (23%) lacked any type of health insurance. More than half (55%) had annual incomes at or below \$10,000 (Table 2).

Table 3 presents the measures of accuracy by various demographic factors. Prevalence of mammography use via self-reports and documentation is presented before and after attempting to account for selection bias via multiple imputation methods; both sets of analyses yielded very similar results. Mexican and Puerto Rican women reported mammography use at higher rates than NHB women ($p<0.0001$). Reported use was lowest for women in their 40s compared to older women, and highest among uninsured and Medicare insured women and lowest for privately insured women. Reported use was also higher for women with more education and with more income. Associations were similar with respect to documented use although no longer statistically significant with respect to education and income (Table 3). Across all categories of all sociodemographic variables examined, mammography use estimates based on self-reports were considerably larger than the corresponding estimates based on medical record documentation (RRR ranged from 1.53 to 1.91; RRD ranged from 25 to 33 percentage points). (Table 4).

Accuracy estimates for Mexican and Puerto-Rican women were virtually indistinguishable from one another and so these two ethnic groups are combined in Table 4. Most of the inaccuracy in self-report appeared to be in the form of over-reporting, as seen by the low specificity and low positive predictive values overall and within racial/ethnic groups (Table 4). Latinas had a higher false positive rate, indicating greater over-reporting among Latina compared to NHB women. The higher apparent false positive rate remained even after adjusting for venue type, age, education, income, and health insurance type (Table 5).

Discussion

Our study demonstrated a considerable amount of over-reporting of mammography use in this sample of vulnerable populations, which was evident across levels of other sociodemographic variables and was accompanied by very little apparent under-reporting. We estimated that about 4 out of every 10 self-reported prior mammogram histories is over-reported (PPV=58%), and that more than half of all documented negative histories corresponded to a positive self-report (FPR=56%). The extent of over-reporting in our study appears to be greater than that estimated in most prior studies that have estimated over-reporting in terms of positive predictive value and/or false positive rate [29].

The level of over-reporting varied by race such that Mexican and Puerto Rican women, although culturally very distinct, were both more likely to over-report compared to NHB. False positive rates were also high in all three ethnic groups but were nearly 20 percentage points higher in Puerto Rican women and nearly 30 percentage points higher for Mexican women than for NHB women. Despite the disproportionate extent of over-reporting in Latina vs. NHB women, at the population level, racial/ethnic-specific estimates of mammography use were equally overly optimistic in all the ethnic minority groups: self-reports overestimated documented use by 27–30 percentage points across the three groups.

Very few prior studies have recruited people from community based venues and with a similar demographic makeup to our study [15–17]. One such study oversampled African Americans and Puerto Ricans at a community health center and reported similar concordance rates to our study (65% overall, 71% for NHB and 60% for Puerto Ricans) [17]. These women were already linked to a medical home, unlike many of the participants in our study.

Other studies that reported lower levels of over-reporting drew their samples from patients with access to care (e.g., members of insurance plans). For example, Caplan, et al, reported data on samples drawn from two different insurance plans and reported much less over-reporting than our study (PPV=0.88 and 0.84 respectively, and Sp=0.54 for both studies) [21, 22]. These findings suggest that there may be a difference in the amount of over-reporting based not only on race/ethnicity but also on access to care more generally.

Mammography is particularly vulnerable to forward telescoping of the dates of last mammogram [8–9, 19, 21, 29]. Women may recall a mammogram occurring sooner than it actually occurred based on the medical record. Depending on the extent of telescoping, this may cause an over-estimation of measures of accuracy. Some prior studies have included a

grace period to allow a woman to “forward-telescope” the date of her most recent mammogram by a few months and still be considered an accurate reporter. We chose not to include such a grace period. As a result, our estimates of over-reporting may be somewhat higher than from some other studies in part due to this difference in study design.

We estimated that about one out of every 20 documented mammograms went unreported (sensitivity=0.94). Consistent with most prior studies, the level of under-reporting of mammography use in our sample was far outweighed by the corresponding level of over-reporting [12, 21, 29]. The general interpretation is that there is little under-reporting regardless of the study methodology.

Strengths and Limitations

There are three overarching differences between the studies reviewed above and our study which lead to important strengths in our study. First, the sample size for our study (n=1,221) is more than three times that of most other similar validation studies. Second, the sample in our study includes women found at various community based venues rather than in clinics, health care insurance plans, or even one type of community based venue. As such, our sample represents a more disenfranchised sample of women, many of whom lack a medical home. Finally, unlike many studies, we gathered mammography histories on women regardless of how they reported mammography use. Due to the sample size and our strict adherence to our data collection methods, gathering this data was a substantial undertaking involving 18 hospitals in and around Chicago. Collecting data on negative self reports allows us to look at the whole picture of mammography reporting accuracy and reliability including negative predictive value, sensitivity and specificity.

In addition to these strengths there are some limitations worth noting. Women were asked to list all of the sites where they had received a mammogram in the last five years. Some women may not accurately recall where their most recent mammogram took place and could therefore be misclassified as a false positive when they were in fact a true positive, resulting in an over-estimate of over-reporting. This is a potential concern for all validation studies, because one can never validate a woman’s report of her last mammogram location. We tried to overcome this limitation by asking for all of her facilities for primary and preventive care, and requesting records from all of these facilities, including facilities that are contracted or sub-contracted with the State Early Detection Program, Illinois Breast and Cervical Cancer Program (IBCCP). Due to the issue of telescoping, extending the period beyond five years may have been warranted to have more documentation from medical records, which would have allowed a more complete assessment of the accuracy of self-report. However, we focused on the presence or absence of a mammogram within two years of the interview, and allowed a five-year window for documentation in the medical record.

It is possible that the environment of specific venues where women were interviewed, as well as the associated interview context, may have affected the quality of responses when compared to other studies where women were interviewed in a more controlled setting, though this is speculative. In addition, the face to face methodology might have introduced some bias. There is some evidence to support that there are very small, and not statistically significant, differences in responses regarding various colorectal cancer screening behaviors

when a survey is done face-to-face compared to other, more private, modes of survey data collection such as by telephone or by mail [37]. Unfortunately a similar study has not been conducted for other screening behaviors such as mammography; we can assume that the results would be similar.

Finally, women for whom we abstracted medical records were more likely to have reported a recent prior mammogram, to be older, be non-Hispanic Black or Puerto Rican, have health insurance, and have less income and education, than women for whom we did not abstract records. Some bias might have been introduced by excluding approximately 10% eligible respondents because the facility listed on the authorization was invalid according to our protocol (n=198, see Figure 1). While we attempted to account for potential selection bias in our analysis via multiple imputation, unmeasured selection factors may nonetheless have affected estimated results as with any study design. Of particular concern is the potential for under-ascertainment of documented mammography histories among recent Mexican immigrants, some of whom may have had a mammogram at a facility from which we did not abstract data. The FPR was 66% for the 1,221 women who provided authorization and whose records were abstracted. If the true (unobserved) FPR was similar for women who provided authorization but whose records were not abstracted (e.g. 66%) but was higher for women who refused HIPAA authorization (e.g. 80%) then the corrected FPR would be 68.5% instead of the observed estimate of 66%. Therefore, very little change in our outcomes and conclusions would be revealed under this scenario.

Implications

It has long been established that reliance on self-reports for estimating mammography use produces an over-estimate. Our results suggest that this problem is exacerbated in vulnerable ethnic minority populations. For many years researchers and clinicians have been misled by self-reported data. National surveys frequently publish self-reported data without adjusting for over-reporting of actual mammography usage [31, 38–40]. One of the Healthy People 2020 goals is to increase the proportion of women who have had a mammogram in the last two years to 84% [41]. According to numbers from the Behavioral Risk Factor Surveillance System (BRFSS), which was used as a baseline estimate, 73.7% had already reported a recent mammogram [1]. Stratifying these data by race reveals small disparities in reporting for the BRFSS survey. However, these small estimated disparities in self-reported mammography use are not consistent with the larger disparities in stage at diagnosis and mortality by race [42–44]. Thus, while self-reported data from surveys suggest that use is similar between racial/ethnic groups, albeit slightly lower among some minority populations, over-reporting among certain groups of women is masking an even lower rate of use. Research that relies on self-reported mammography usage data might be misleading due to these reporting differences. Therefore, studies of mammography behavior should not rely on self-reported mammography use data.

Acknowledgments

The authors would like to acknowledge the Avon Foundation for Women Breast Cancer Crusade for the support and generous funding. Specifically we would like to acknowledge Marc Hulbert, PhD, Executive Director of the Avon Breast Cancer Crusade, for encouraging our team to gather this data. For their immeasurable assistance in organizing the packets, entering and cleaning the data for this project we would like to acknowledge the following

Helping Her Live Community Health Workers: Ana Rosa Garcia, Wanda Rodriguez, and Celevia Taylor. Finally, we would like to thank the participants in the survey and especially those who agreed to allow us to view their medical record.

Financial Support: This work was supported by the Avon Foundation for Women Breast Cancer Crusade (grant number 05-2011-034, 05-2007-004). The recipients of this grant award were K Allgood, S Whitman, A Shah, G Vasquez-Jones. The Agency for Health Research & Quality (grant number 1 R01 HS018366-01A1). The recipient of this grant award was G Rauscher.

References

- Centers for Disease Control and Prevention [Internet]. Behavioral Risk Factor Surveillance System – Prevalence and Trends Data. Atlanta, GA: 2010. Available from: <http://apps.nccd.cdc.gov/brfss/race.asp?cat=WH&yr=2012&qkey=8481&state=US> [accessed January 2014]
- Centers for Disease Control and Prevention. Surveillance of Health Status in Minority Communities — Racial and Ethnic Approaches to Community Health across the U.S. (REACH U.S) Risk Factor Survey, United States, 2009. MMWR. 2011; 60:36.
- Ham SA, Ainsworth BE. Disparities in data on Healthy People 2010, physical activity objectives by accelerometry and self-report. Am J Public Health. 2010; 100:S263–S268. [PubMed: 20147669]
- Atienza AA, Moser RP, Perna F, Dodd K, Ballard-Barbash R, Troiano RP, et al. Self-reported and objectively measured activity related to biomarkers using NHANES. Med Sci Sports Exerc. 2011; 43:815–821. [PubMed: 20962693]
- Klein JD, Thomas RK, Sutter EJ. Self-reported smoking in online surveys: prevalence estimate validity and item format effects. Med Care. 2007; 45:691–695. [PubMed: 17571019]
- West R, Zatonski W, Przewozniak, Jarvis MJ. Can we trust national smoking prevalence figures? Discrepancies between biochemically assessed and self-reported smoking rates in three countries. Cancer Epidemiol Biomarkers Prev. 2007; 16:820–822. [PubMed: 17416777]
- Newell SA, Girgis A, Sanson-Fisher RW, Savolainen JJ, Hons BA. The accuracy or self-reported health behaviors and risk factors relating to cancer and cardiovascular disease in the general population – a critical review. Am J Prev Med. 1999; 17:211–229. [PubMed: 10987638]
- Paskett ED, Tatum CM, White DW, Hoen H, Case D, Velez R. Validation of self-reported breast and cervical cancer screening tests among low-income minority women. Cancer Epidemiol Biomarkers Prev. 1996; 5:721–726. [PubMed: 8877064]
- Champion VL, Menon U, Hollinden McQuillen D, Scott C. Validity of self-reported mammography in low income African American women. Am J Prev Med. 1998; 14:111–117. [PubMed: 9631162]
- Degnan D, Harris R, Ranney J, Quade D, Earp JA, Gonzalez J. Measuring the use of mammography: two methods compared. Am J Public Health. 1992; 82:1386–1388. [PubMed: 1415867]
- McPhee SJ, Nguyen TT, Shema SJ, Nguyen B, Comkin C, Vo P, et al. Validation of recall of breast and cervical cancer screening by women in an ethnically diverse population. Prev Med. 2002; 35:463–473. [PubMed: 12431895]
- Tumiel-Berhalter LM, Finney MF, Jaen CR. Self-report and primary care medical record documentation of mammography and pap smear utilization among low income women. J Natl Med Assoc. 2004; 96:1632–1639. [PubMed: 15622694]
- Powe BD, Cooper DL. Self-reported cancer screening rates versus medical record documentation: incongruence, specificity, and sensitivity for African American women. Onc Nurs Forum. 2008; 35:199–204.
- Clark CR, Baril N, Kunicki M, Johnson N, Soukup J, Lipsitz S, Bigby J. Mammography use among Black women: the role of electronic medical records. J Women Health. 2009; 18:1153–1162.
- Thompson B, Taylor V, Goldberg H, Mullen M. Mammography status using patient self-reports and computerized radiology database. Am J Prev Med. 1999; 17:203–206. [PubMed: 10987636]
- Lawrence VA, De Moor C, Glenn E. Systematic differences in validity of self-reported mammography behavior: a problem for intergroup comparisons? Prev Med. 1999; 29:577–580. [PubMed: 10600440]

17. Zapka JG, Bigelow C, Hurley T, Ford LD, Egelhofer J, Cloud M, et al. Mammography use among sociodemographically diverse women: the accuracy of self-report. *Am J Public Health*. 1996; 86:1016–1021. [PubMed: 8669504]
18. Ferrante JM, Ohman-Strickland P, Hahn KA, Hudson SV, Shaw EK, Crosson JC, Crabtree BF. Self-report versus medical records for assessing cancer-preventive services delivery. *Cancer Epidemiol Biomarkers Prev*. 2008; 17:2987–2994. [PubMed: 18990740]
19. McGovern PG, Laurie M, Margolis KL, Slater JS. Accuracy of self-report of mammography and pap smear in a low income urban population. *Am J Prev Med*. 1998; 14:201–208. [PubMed: 9569221]
20. Norman SA, Localio R, Zhou L, Bernstein L, Coates RJ, Flagg EW, et al. Validation of self-reported screening mammography histories among women with and without breast cancer. *Am J Epidemiol*. 2003; 158:264–271. [PubMed: 12882949]
21. Caplan LS, McQueen DV, Qualters JR, Leff M, Garrett C, Calogne N. Validity of women's self-reports of cancer screening test utilization in a managed care population. *Cancer Epidemiol Biomarkers Prev*. 2003; 12:1182–1187. [PubMed: 14652278]
22. Caplan LS, Mandelson MT, Anderson LA. Validity of self-reported mammography: examining recall and covariates among older women in a health maintenance organization. *Am J Epidemiol*. 2003; 157:267–272. [PubMed: 12543627]
23. Hiatt RA, Perez-Stable EJ, Quesenberry C, Sabogal F, Otero-Sabogal R, McPhee SJ. Agreement between self-reported early cancer detection practices and medical audits among Hispanic and Non-Hispanic White health plan members in northern California. *Prev Med*. 1995; 24:278–285. [PubMed: 7644451]
24. Armstrong K, Long JA, Shea JA. Measuring adherence to mammography screening recommendations among low-income women. *Prev Med*. 2004; 38:754–760. [PubMed: 15193895]
25. Gordon NP, Hiatt RA, Lampert DI. Concordance of self-reported data and medical record audit for six cancer screening procedures. *J Natl Cancer Inst*. 1993; 85:566–570. [PubMed: 8455203]
26. King ES, Rimer BK, Trock B, Balshem A, Engstrom P. How valid are mammography self-reports? *Am J Public Health*. 1990; 80:1386–1388. [PubMed: 2240315]
27. Holt K, Franks P, Meldrum S, Fiscella K. Mammography self-report and mammography claims: racial, ethnic, and socioeconomic discrepancies among elderly women. *Med Care*. 2006; 44:513–518. [PubMed: 16707999]
28. Cronin KA, Miglioretti DL, Krapcho M, Yu B, Geller BM, Carney PA, et al. Bias associated with self-report of prior screening mammography. *Cancer Epidemiol Biomarkers Prev*. 2009; 18:1699–1705. [PubMed: 19505902]
29. Rauscher GH, Johnson TP, Cho YI, Walk JA. Accuracy of self-reported cancer screening histories: a meta-analysis. *Cancer Epidemiol Biomarkers Prev*. 2008; 17:748–757. [PubMed: 18381468]
30. Hunt B, Allgood K, Sproles C, Whitman S. Metrics for the systematic evaluation of community-based outreach. *J Cancer Educ*. 2013; 28:633–638. [PubMed: 23857186]
31. Whitman S, Shah AM, Silva A, Ansell D. Mammography screening in six diverse communities in Chicago—a population study. *Cancer Detect Prev*. 2007; 31:166–172. [PubMed: 17418980]
32. American Fact Finder. American Community Survey, 5---year Estimates [Internet]. Washington, DC: U.S. Census Bureau; 2010. Available from: <http://factfinder2.census.gov/faces/nav/jsf/pages/searchresults.xhtml?refresh=t> [accessed November 2013]
33. Centers for Disease Control and Prevention [Internet]. National Health and Interview Survey, 2008. Atlanta, GA: Available from: ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Survey_Questionnaires/NHIS/2008/English/qadult.pdf [accessed January 2014]
34. Azur MJ, Stuart EA, Frangakis C, Leaf PJ. Multiple imputation by chained equations: what is it and how does it work? *Int J Methods Psychiatr Res*. 2011; 20:40–49. [PubMed: 21499542]
35. Little, RJA.; Rubin, DB. *Statistical Analysis with Missing Data*. New York: John Wiley & Sons, Inc; 1987.
36. Chmura Kraemer, H. *Evaluating Medical Tests: Objective and Quantitative Guidelines*. SAGE Publications, Inc; 1999.
37. Vernon SW, Tiro JA, Vojvodic RW, Coan S, Diamond PM, Greisinger, et al. Reliability and validity of a questionnaire to measure colorectal cancer screening behaviors: does mod of survey

- administration matter? *Cancer Epidemiol Biomarkers Prev.* 2008; 17:758–767. [PubMed: 18381467]
38. Breen N, Cronin KA, Meissner HI, Taplin SH, Tangka FK, Tiro JA, et al. Reported drop in mammography, is this a cause for concern? *Cancer.* 2007; 102:2405–2409. [PubMed: 17503429]
39. Centers for Disease Control and Prevention (CDC). . Cancer screening - United States, 2010. *MMWR.* 2012; 61:41–45. [PubMed: 22278157]
40. Selvin E, Brett KM. Breast and cervical cancer screening: sociodemographic predictors among White, Black and Hispanic women. *Am J Public Health.* 2003; 93:618–623. [PubMed: 12660207]
41. United States Department of Health and Human Services [Internet]. Healthy People 2020 Topics and Objectives: Cancer. Washington, DC: 2012. Available from: <http://healthypeople.gov/2020/topicsobjectives2020/pdfs/Cancer.pdf> [accessed November 2013]
42. Hirschman J, Whitman S, Ansell D. The Black:White disparity of breast cancer mortality: the example of Chicago. *Cancer Causes Control.* 2007; 18:323–333. [PubMed: 17285262]
43. Whitman S, Ansell D, Orsi J, Francois T. The racial disparity in breast cancer mortality. *J Comm Health.* 2011; 36:588–596.
44. Whitman S, Orsi J, Hurlbert M. The racial disparity if breast cancer mortality in the 25 largest cities in the United States. *Cancer Epidemiol.* 2012; 36:e147–e151. [PubMed: 22443886]

Figure 1.

Flow of the sample from survey screening to completed medical abstraction

HIPAA=Health Insurance and Portability Authorization Act Form

*Females aged 40 or over, self-reported address in one of the designated areas, spoken language is English or Spanish.

†Race/ethnicity is Non-Hispanic Black, Mexican or Puerto Rican, 40 yrs old, and resides in North Lawndale or Humboldt Park.

‡Valid facility name provided on HIPAA authorization and >10 women stated that they had a mammogram at the valid facility.

Table 1

Study characteristics of women whose medical records were abstracted versus not abstracted

	N	% Abstracted	Crude ¹ p-value	Adjusted ² p-value
Self-reported mammogram past 2 years			<0.0001	<0.0001
No	651	50		
Yes	1229	72		
Venue			0.003	0.003
Grocery store	272	60		
Healthcare center	263	67		
Community based organization	258	61		
Senior center	255	76		
Business	207	67		
Laundromat	172	60		
Church	140	56		
Other	124	62		
Park district	105	65		
Block club	71	58		
Government agency	26	54		
Beauty salon	16	63		
Age			<0.0001	0.007
40–49	696	58		
50–64	797	67		
65+	416	67		
Race/Ethnicity			<0.0001	0.016
Non-Hispanic Black (NHB)	954	66		
Mexican	419	55		
Puerto-Rican	536	68		
Health Insurance			<0.0001	0.015
Uninsured	511	55		
Medicare/VA	504	69		
Medicaid	510	72		
Private	381	58		
Education			0.018	0.095
< High School	872	67		
High School Grad	530	65		
> High School	482	59		
Income			0.002	0.027
Below \$10,000	934	65		
\$10,000–\$34,999	609	68		
\$35,000 and above	153	52		

¹ P-value from Chi-Squared test.² P-value from likelihood ratio test comparing multivariable models including all other variables in the table, versus without the variable of interest.

Table 2

Study characteristics of women with medical record documentation, N=1,221

	N	%
Self-reported mammogram past 2 years		
No	325	27
Yes	879	73
Documented mammogram past 2 years		
No	682	56
Yes	539	44
Venue		
Business	195	16
Park district	175	14
Other	164	13
Healthcare center	157	13
Block party	138	11
Community based organization	103	8
Senior center	79	6
Government agency	77	6
Grocery store	68	6
Beauty salon	41	3
Church	14	1
Laundromat	10	1
Age		
40–49	405	33
50–64	536	44
65+	280	23
Race/Ethnicity		
Non-Hispanic Black (NHB)	627	51
Mexican	229	19
Puerto-Rican	365	30
Health Insurance		
Uninsured	283	23
Medicare/VA	349	29
Medicaid	367	30
Private	220	18
Education		
< High School	580	48
High School Grad	345	29
> High School	284	23
Income		
Below \$10,000	604	55
\$10,000–\$34,999	412	38

	N	%
\$35,000 and above	80	7

Table 3

Prevalence of reported and documented mammography use in the last 2 years and estimation of over reporting by women's characteristics, N=1,221.

Measure	Reported				Documented				Over-estimate via self-reports			
	N	%	p-value	Imputed ²	N	%	p-value	Imputed ²	Raw ¹	RRR ³	RRD ⁴	Imputed ²
Overall	1,204	73		65	1,221	45		40		1.62	28	1.63
Age Group												
40-49 yrs old	398	67		54	405	35		30		1.91	32	1.8
50-64 yrs old	533	75	0.002	70	536	49	<0.0001	46		1.53	26	1.52
65 yrs old	273	78		73	280	49		47		1.53	27	1.55
Race/Ethnicity												
Non-Hispanic Black (NHB)	617	65		63	627	38		37		1.71	27	1.7
Mexican	225	82	<0.0001	64	229	51	<0.0001	43		1.58	30	1.49
Puerto Rican	362	81		70	365	51		45		1.59	30	1.56
Health Insurance Type												
Uninsured	219	81		72	220	50		46		1.91	29	1.57
Medicare/VA	343	79		75	349	51		49		1.52	27	1.53
Medicaid	361	71	<0.0001	66	367	43	<0.0001	40		1.61	27	1.65
Private	279	61		50	283	32		28		1.62	31	1.79
Education Level												
< High School	574	71		65	580	45		42		1.54	25	1.55
High School Grad	337	71	0.045	63	345	41	0.340	37		1.69	29	1.7
> High School	281	79		69	284	46		41		1.72	33	1.68
Income												
Below \$10,000	595	71		62	604	43		38		1.61	27	1.63
\$10,000-\$34,999	406	77	0.016	68	412	48	0.240	43		1.6	29	1.58
\$35,000 and above	80	84		72	80	50		45		1.68	34	1.6

¹ Complete case analysis.

² Estimated using Rubins rules on 20 multiply imputed datasets via chained equations.

³ RRR: Report to Records Ratio.

Table 4

Accuracy measures of self-reported mammography in the last 2 years, overall and by race/ethnicity

Measure	Overall (N=1,221) Value (95% CI)	Race/Ethnicity	
		NHB (N=627) Value (95% CI)	Latino (N=594) Value (95% CI)
Agreement (Concordance)	0.67 (0.64, 0.69)	0.69 (0.65, 0.73)	0.64 (0.60, 0.68)
Kappa	0.36 (0.32, 0.41)	0.43 (0.37, 0.48) *	0.26 (0.16, 0.36) *
Positive Predictive Value	0.58 (0.54, 0.61)	0.56 (0.51, 0.61)	0.59 (0.52, 0.66)
Specificity	0.44 (0.40, 0.48)	0.53 (0.48, 0.58) *	0.31 (0.23, 0.40) *
Negative Predictive Value	0.91 (0.87, 0.93)	0.94 (0.90, 0.97)	0.83 (0.68, 0.92)
Sensitivity	0.94 (0.92, 0.96)	0.95 (0.92, 0.97)	0.94 (0.88, 0.97)

NHB=Non-Hispanic Black

* Non-overlapping confidence intervals (CI) indicate significant differences.

Table 5

False positive rates by study characteristics

	N	Crude ¹		Adjusted ²	
		FPR ³	P-value	FPR ³	p-value
Age					
40–49	222	54		56	
50–64	246	56	0.170	56	0.740
65+	113	65		61	
Ethnicity					
Non-Hispanic Black (NHB)	325	47		47	
Mexican	94	72	<0.0001	76	<0.0001
Puerto-Rican	162	67		65	
Health Insurance					
None	164	47		46	
Medicare/VA	142	65		65	0.020
Medicaid	177	55	0.004	60	
Private	98	64		57	
Education					
< High School	269	55		53	
High School	174	53	0.070	57	0.110
> High School	138	65		65	
Income					
Below \$10,000	333	54		54	
\$10,000–\$34,999	208	60	0.130	59	0.350
\$35,000 and above	40	68		67	

¹ P-value from Chi-Squared test.² P-value from likelihood ratio test comparing multivariable models including all other variables in the table and venue type, with versus without the variable of interest.³ FPR, false positive rate, a measure of over-reporting equal to 1-specificity.