Increasing Utilization of Preventive Care in Asian American Women in Massachusetts

FINAL REPORT: SUBMITTED TO TISCH COLLEGE COMMUNITY RESEARCH CENTER AT TUFTS

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Questions

Research team

Size

Length

Recruitment

Location and equipment

Scribe guidelines

Facilitator guidelines

Facilitator role plays

Before a focus group starts

Facilitator welcome script (5 minutes)

Participant introductions (5 minutes)

Questions (80 minutes)

Facilitator closing

Facilitator and scribe review

Appendix IV: Presentation to TCRC 040816
Executive Summary

Screening is essential in detecting cancer in its early stages when it is easier to treat. Lack of health insurance has traditionally been a significant barrier to preventive care utilization. Despite health care reform that mandates free breast and cervical cancer screening, first in Massachusetts and later in the US through the Patient Protection and Affordable Care Act (ACA), barriers to preventive care still remain. To our knowledge, this study is the first to address cancer screening barriers for Asian American women residing in Massachusetts.

Reported rates of breast and cervical cancer screening for Asian Americans in Massachusetts differ depending on the analysis and indicate less of a discrepancy, if any, than when the proposal for this research was written. However, rates may differ for specific subgroups for which data is not available. Nonetheless, it is important to understand factors that facilitate or impede utilization of preventive services in order to achieve higher rates. This report covers research, guided by the principles of community-based participatory research (CBPR), exploring the reasons why Asian American women in Massachusetts who have insurance and access to care are not being screened for breast and cervical cancer at higher rates. Through ethnicity-specific focus groups with women who have insurance yet do not comply with screening guidelines, we sought to qualitatively explore Asian American women’s barriers to utilization of preventive services, particularly breast and cervical cancer screening. Our long-term goal is to reduce these barriers in order to increase cancer screening rates.

The most significant accomplishment of this research project is that we ran four focus groups with Chinese American, Vietnamese American, and South Asian American women, which are reported here. In order to plan and run these focus groups, and in support of our commitment to CBPR, we: 1) developed a Focus Group Facilitation Guide applicable to our specific research questions and designed to guide the planning and facilitation of any focus group; 2) trained community partners in focus group facilitation in three training sessions that included role play; 3) developed recruitment materials and a screening script for focus group participants of ethnic minority women; 4) developed Collaborative Institutional Training Initiative (CITI) training and trained community partners; and 5) presented findings at the Tufts Clinical and Translational Science Institute (CTSI) Together, Strengthening the Health of Chinatown: An Asian Health Symposium, a collaboration between Tufts academics and Asian American community partners.

In this report, we discuss our focus group findings, noting the limitations in terms of total participants, qualified participants, and adequate representation of the diversity of Asian women in Massachusetts. In summary, the focus group findings indicate that cultural beliefs, preventive care knowledge, and patient-provider attitudes influenced whether a woman would seek screening. Screening barriers included cultural norms about sexual activity and virginity, lack of knowledge about the risks and benefits of the breast and cervical cancer screenings, and lack of knowledge about how the tests were conducted and whether they were painful. Satisfaction with health care providers influenced their use of preventive care, such that women who were dissatisfied with their health care providers reported being less likely to
engage in timely screening and women who were satisfied with their health care providers reported being more likely to engage in preventive health. We found that when women feel healthy, they are less likely to see the value of screening; they furthermore question the merit of knowing whether they have cancer. In addition, women reported a lack of knowledge and confusion about recommended guidelines for breast and cervical cancer screenings. This was particularly notable since an October 20, 2015 change in the American Cancer Society mammography guidelines occurred during the same time we ran focus groups. Finally, we found that some women do not know that there is no charge for screenings and that cost can be a tipping point for some when added to the time and discomfort involved in getting screened. These focus group findings will inform the next steps of our research with Asian American women in Massachusetts and introduces new questions worthy of further exploration about the confusion about preventive care guidelines and cost.

Background

Diversity of Asian American women

The umbrella ethnicity “Asian” aggregates over 69 nationalities into one category. Each Asian ethic group is unique and differs in language, culture, and health beliefs, or practices. Thus, Asian American women are a diverse group, comprised of different subgroups and cultures representing each Asian country. Furthermore, the length of time individuals have been in the US and the type of community they live in vary considerably. In one focus group, in which the participants were all born in Vietnam, all lived in or near Randolph, MA, where there were many opportunities to be immersed in the Vietnamese language and culture, including attending the Vietnamese church where the focus group was held.

Across all the subgroups of Asian American women, screening rates vary, as do the reasons why each subgroup may or may not get screened. We focused on Vietnamese, Chinese, and South Asian subgroups for this study, but within each of these large subgroups are additional subgroups by region or country. Furthermore, within the US, there are state and regional factors that affect whether Asian American women receive breast and cervical cancer screening.

Demographic information for Asian Americans living in Massachusetts

It is important to understand the demographic composition of Asian Americans living in Massachusetts in order to understand their diverse backgrounds and experiences.

Where Asian Americans live

According to the 2010 US Census, Asian Americans made up 5.3% of the Massachusetts population. The three largest Asian groups in Massachusetts are Chinese, Indian, and Vietnamese. Table 1 shows the ten largest subgroups of Asian Americans in Massachusetts. Table 2 shows MA cities or towns with the largest number of Asian Americans by subgroup.
Table 1: Census 2010 › Number of Asian Americans residing in Massachusetts by Asian subgroup

<table>
<thead>
<tr>
<th>Asian American ethnic subgroups</th>
<th>Alone[1]</th>
<th>Alone or in combination with one or more other categories of same race [2]</th>
<th>Alone or in any combination[3]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chinese (Except Taiwanese)</td>
<td>118,164</td>
<td>122,443</td>
<td>131,846</td>
</tr>
<tr>
<td>Indian</td>
<td>77,177</td>
<td>79,093</td>
<td>85,441</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>42,915</td>
<td>45,380</td>
<td>47,636</td>
</tr>
<tr>
<td>Cambodian</td>
<td>25,387</td>
<td>26,934</td>
<td>28,424</td>
</tr>
<tr>
<td>Korean</td>
<td>24,110</td>
<td>24,723</td>
<td>28,904</td>
</tr>
<tr>
<td>Filipino</td>
<td>12,309</td>
<td>12,937</td>
<td>18,673</td>
</tr>
<tr>
<td>Japanese</td>
<td>9,224</td>
<td>9,808</td>
<td>15,358</td>
</tr>
<tr>
<td>Pakistani</td>
<td>6,205</td>
<td>6,525</td>
<td>7,071</td>
</tr>
<tr>
<td>Taiwanese</td>
<td>4,502</td>
<td>4,838</td>
<td>5,353</td>
</tr>
</tbody>
</table>

Source: Institute for Asian American Studies

Table 2: Census 2010 › Cities and Towns with Top 3 largest populations of Chinese Americans, Indian Americans and Vietnamese

<table>
<thead>
<tr>
<th>City or Town</th>
<th>Chinese Americans</th>
<th>Indian Americans</th>
<th>Vietnamese</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boston</td>
<td>25,921</td>
<td>8,489</td>
<td>11,670</td>
</tr>
<tr>
<td>Quincy</td>
<td>14,979</td>
<td>X</td>
<td>3,297</td>
</tr>
<tr>
<td>Malden</td>
<td>6,926</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Cambridge</td>
<td>X</td>
<td>4,129</td>
<td>X</td>
</tr>
<tr>
<td>Shrewsbury</td>
<td>X</td>
<td>3,261</td>
<td>X</td>
</tr>
<tr>
<td>Worcester</td>
<td>X</td>
<td>X</td>
<td>5,759</td>
</tr>
</tbody>
</table>

Source: Institute for Asian American Studies

NOTE: Black = 1 ranking; Red = 2 ranking; Blue = 3 ranking; X = Not in top ten
Language proficiency and median and per capita income across Asian American subgroups

Two indicators correlated with receiving preventive health care are English language proficiency and income levels. Table 3 shows that, with the exception of Korean-Americans (31.3%), less than 19% of Asian Americans in Massachusetts speak English only. With the exception of Indian Americans (18%), 33% to 58% of Asian Americans in Massachusetts report speaking English less than very well. In addition, Indian Americans in Massachusetts have both the highest per capita income rate, highest median household income, and lowest poverty level.

Table 3: U.S. Census › American Community Survey 2010-12: English usage at home and proficiency for selected Asian subgroups for persons 5 years and over in Massachusetts

<table>
<thead>
<tr>
<th></th>
<th>Chinese</th>
<th>Indian</th>
<th>Vietnamese</th>
<th>Cambodian</th>
<th>Korean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speak English only</td>
<td>17.9%</td>
<td>21.0%</td>
<td>8.3%</td>
<td>18.6%</td>
<td>31.3%</td>
</tr>
<tr>
<td>Speak a language other than English</td>
<td>82.1%</td>
<td>79.0%</td>
<td>91.7%</td>
<td>81.4%</td>
<td>68.7%</td>
</tr>
<tr>
<td>Speak English less than “very well”</td>
<td>44.7%</td>
<td>17.8%</td>
<td>58.0%</td>
<td>43.0%</td>
<td>32.9%</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Institute for Asian American Studies

Historical perspective on screening rates

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP), a program of the CDC, responds to cancer screening disparities between white women and Latina, Asian American, American Indian/Native American, and Black women. They created programs to ensure that women be screened, regardless of their race or ethnicity, and have access to early cancer detection. These programs included free breast and cancer screenings, outreach to underserved communities, and mobile screening vans.

Health insurance and breast and cervical cancer screening rates for Asian Americans in Massachusetts

In 2013, Behavioral Risk Factor Surveillance System (BRFSS) data showed for the three most recent years that 98.5% of Asian/Pacific Islanders had health insurance. Thus, access to health insurance or having to pay out-of-pocket should not be a screening barrier for Asian American women. [8]

As reported by the Massachusetts Department of Public Health (DPH), BRFSS data for 2014 for other preventive health indicators for Asian Americans include the following:
• **72.5% had a mammogram.** The percent screened for White, non-Hispanics was 82.6%, Blacks 74.4%, and Latinos 84.4%. As reported by the DPH, Asian American women in Massachusetts are less likely to have a mammogram than Latinos or Whites. [9]

• **84.6% had a Pap Smear test.** The percent screened for White, non-Hispanics was 74.1%, Blacks 69.1%, and Latinos 76.1%. Asian American women in Massachusetts have Pap tests at higher rates than other Massachusetts ethnic groups. [9]

• **4.4% could not see a doctor due to costs.** The percent that could not see a doctor for White, non-Hispanics was 5.4%, Blacks 10.9%, and Latinos 16.7%. [9]

However, Kaiser Fund reporting of BRFSS data for 2012-2014 presents a different picture. Using a methodology of averaging three years of data, Kaiser reports that Asian American and other ethnic groups have higher rates of screening and no notable ethnic differences.

• **89% had a mammogram.** The percent screened for White, non-Hispanics was 88%, Blacks 88%, and Latinos 84.4%. These data show that Asian American women in Massachusetts are just as likely to have a mammogram as other ethnic groups. [4]

• **96% had a Pap test.** The percent screened for White, non-Hispanics was 92%, Blacks 94%, and Latinos 93%. Kaiser data report that Asian American women in Massachusetts have Pap tests at a higher rate as other Massachusetts ethnic groups. [4]

• **15% of Massachusetts Asians and Native Hawaiian or Pacific Islanders did not have a regular provider.** [4]

**Health Centers as a source of care for Asian Americans**

Health centers play an important role in providing health care to the poor and uninsured, undocumented and documented immigrants, and the community at large. Health centers are public and private non-profit health care organizations that must comply with Federal requirements to:

• Serve a medically underserved population

• Provide appropriate and necessary services with fees adjusted on patients’ ability to pay (including no cost care for the indigent)

• Demonstrate sound clinical and financial management

• Governance by a board, most of whose members are served by the health center [10]

There are 49 health centers in Massachusetts, of which 34 qualify as Federally Qualified Health Centers (FQHC). The US Department of Health and Human Services defines FQHCs as

“Organizations receiving grants under Section 330 of the Public Health Service Act (PHS). FQHCs qualify for enhanced reimbursement from Medicare and Medicaid, as well as other benefits. FQHCs must serve an underserved area or population, offer a sliding fee scale, provide..."
comprehensive services, have an ongoing quality assurance program, and have a governing board of directors [10]."

In 2015, the Massachusetts League of Community Health Centers reported that Massachusetts health centers serve approximately 889,000 Massachusetts residents. In 2013, the Kaiser Family Foundation reported that FQHCs served 659,521 Massachusetts residents, of which 11.7% (77,164) were Asian [11, 12].

Table 4 shows that from 2011-2013, Massachusetts FQHCs have had decreasing cervical cancer screening rates. In 2013, FQHCs screened about two of three women for cervical cancer.

Table 4: Massachusetts FQHC cervical cancer screening rates—2011 - 2013

<table>
<thead>
<tr>
<th>Measure</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2011 - 2013 Trend: %Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical Cancer Screening</td>
<td>69.0%</td>
<td>65.6%</td>
<td>66.8%</td>
<td>-3.1%</td>
</tr>
</tbody>
</table>


**Screening and preventive services**

Preventive services are an effective way to address preventable disease like cancer and reduce the burden of disease through early detection. However, data indicates gaps in preventive care among Asian American women in Massachusetts, especially for low income, recent immigrant, and certain ethnic groups (e.g. Vietnamese Americans). These findings are noteworthy as insurance has not been a barrier in Massachusetts for many years due to health reform.

**Barriers to screening**

Studies examining primary care physician (PCP) perceptions of screening barriers identify those related to patients (e.g., lack of knowledge, motivation, fear, embarrassment); physicians (e.g., lack of belief in test efficacy); practices (e.g., time constraints to provide patient education); and system (e.g., lack of or inadequate insurance coverage) [13]. Hou and colleagues note that screening barriers common among Asians (nationally and internationally) include shyness, poor health knowledge, limited social support for use of preventive services, and fear of finding out one has cancer. The authors note transportation, lack of health insurance or physician referrals, and language as the screening barriers most relevant to Asian American women [14].

Women who have a regular place of care and receive routine health care are more likely to receive cancer screenings. Factors at the patient level that impede appropriate use of routine health care services include attitudes, beliefs, and knowledge that predispose people to avoid health care [15] and lack of awareness regarding what health insurance covers in terms of costs for preventive screening. [16]

Of note, length of US residency has been considered a factor associated with cancer screening rates, with shorter residency associated with lower screening rates, and longer residency associated with higher screening rates. However, a cross-sectional study of 851 Chinese, Korean, and Vietnamese Americans residing in Maryland showed that when health insurance
and having a regular physician were controlled for, the association between length of residency and cervical and breast cancer screening was no longer significant [6, 7].

**Incidence of breast cancer and breast cancer mortality rates 1999-2011**

CDC data show the incidence of breast cancer, the number of new cases each year, is rising slowly for all ethnicities after a lengthy period of decline. Figure 1 shows that nationally, Asian American women consistently have the second lowest incidence of breast cancer. From 2002 to 2011, there has been a slight upward trend in breast cancer incidence in Asian American women. This could reflect more people with cancer, or reflect more women being screened, thereby leading to more cases being identified. Nationally, breast cancer mortality rates for Asian American women are significantly lower than rates for whites, blacks and Hispanics. Figure 2 shows American Indians/American Natives (AI/AN) and Asian American/Pacific Islander (A/PI) women have the lowest breast cancer mortality rates. Other data such as age of onset and dietary habits may be worth considering especially if it shows differences for Asian American women.

**Figure 1: CDC – National breast cancer incidence rates, 2011**

![Figure 1](image1.png)

**Figure 2: CDC – National breast cancer mortality rates, 2011**

![Figure 2](image2.png)
Cervical cancer incidence and mortality rates in Asian American women

As shown in Figure 3, since 1999, the reported incidence of cervical cancer for Asian American women have been declining steadily. In 2011, Asian American women and American Indians/American Natives (AI/AN) shared the lowest cervical cancer incidence rates. Figure 4 shows that this is also true of cervical cancer mortality rates. Except for an increase in 2000 and 2001, Asian American women have had the second lowest or lowest mortality rates for cervical cancer.

Figure 3: CDC – National cervical cancer incidence rates, 2011

Figure 4: CDC – National cervical cancer mortality rates, 2011
In sum, from 1999 to 2011, Asian American women had:

- The lowest cancer screening rates for mammography but comparable to other ethnic groups for receiving a Pap test.
- The second lowest incidence rate for breast cancer.
- The lowest or second lowest incidence rate for cervical cancer from 1999-2011.
- Steadily decreasing cervical cancer mortality rates (from 2000-2009), but a slight increase between 2009-2011.

Interventions to increase breast and cervical cancer screening in Asian American women

There are factors that increase cancer screening for all women regardless of ethnicity or race, e.g., health insurance, no cost screenings, and having a regular place of health care, and a regular provider.

A 2012 systematic review of interventions to increase breast and cancer screening among Asian women both in the U.S. and internationally notes that Asian subgroup differences make comparisons and generalizability difficult, as do differences in study design and methodology. For their review, the authors included 37 observational studies, of which 18 had valid outcome measures. Of the 18 studies with outcome measures, eight were randomized control trials. Studies lacked information about long-term sustainability and cost-effectiveness. Nonetheless, the authors report the type of interventions likely to improve cervical and breast cancer screening among Asian women [19].

The authors found that successful interventions adapted standard interventions to be culturally sensitive, e.g., using bi- or tri-lingual outreach materials, and culturally appropriate messaging and materials. None of the published studies reviewed included innovative strategies to increase cancer screening. The authors also found interventions that used a combination of
strategies were more likely to be effective than a single-approach intervention. For example, the effectiveness of community-based or workplace-based group education programs increased when supplemented by other supports such as assisting women with scheduling and providing mobile screening services [19]. Interventions likely to be ineffective are home visits, media campaigns, and mailed culturally sensitive print materials with no other supporting calls or reminders [19].

Studies conducted with Vietnamese populations found that mass media campaigns that included a lay health worker component enhanced outcomes. Mass media campaigns alone were only modestly effective in increasing screening awareness, and did not increase women receiving a mammogram or Pap test. Interventions that targeted both the community and health care providers were more successful. These interventions included a multimedia campaign, patient registry, patient navigator system, and a reminder system [14].

Successful interventions for Chinese and Taiwanese Asian American women included direct mail and a follow-up phone intervention, direct mail and outreach workers providing logistical assistance, and a program that combined a community education program with patient navigators. The review did not report on interventions targeting Southeast Asian American women [14], highlighting a need to explore effective ways to increase screening in this group.

In sum, this review by subgroup found substantial evidence that culturally appropriate interventions could increase cancer screening rates among Asian American women. The authors suggest that community based interventions may be the best way to reach new immigrants and that using lay health workers reflecting the target subgroup were effective. When using media channels to promote screening, the authors suggest using locations where Asian American women go, such as Asian grocery stores [14].

**Policy and practice interventions**

A 2013 report issued by the National Academy for State Health Policy specifically addresses state and practice level policies and practices to increase cervical cancer screening in Federally Qualified Health Centers (FQHC) [11]. At the practice level, the report’s recommendations focus on improving screening rates through performance measurement, patient navigation, messaging and informational materials, and increasing accessibility through transportation assistance. At the policy level, the report’s recommendations focus on payment and financing to insure or screen more women and broader use of health information technology. Health information technology can help improve how practices track patient screening, create provider reminders, and measure provider assessment and feedback reports [20].

An important lesson learned is that FQHCs should establish a culture of quality improvement that involves all practice staff. Medical personnel must have a common understanding and commitment to improving screening. This includes knowing and understanding screening recommendations and eligibility guidelines for state-specific programs. Additionally, all must be committed to helping patients, especially underserved groups, understand the importance of screening and to helping patients make and keep screening appointments [20].
HEDIS cancer screening data for Massachusetts health plans

Commercial and public health plans are required to report National Committee for Quality Assurance’s (NCQA) Healthcare Effectiveness Data and Information Set (HEDIS) guidelines measures as part of their certification and licensing. HEDIS uses a core set of measures each year or every other year, as well as selected, additional measures. HEDIS measures use standardized methods of data collection, supporting meaningful comparisons across plans. Mammography (annual) and cervical cancer (biannual) screening rates are HEDIS requirements for health plans.

Without measurement, there can be no motivation for improvement. Conversely, it is possible that achieving a benchmark standard decreases incentive to go beyond the benchmark.

Nationally, the HEDIS 90th percentile for screening is 74.1% mammography and 72.5% for cervical cancer for all health plans. Current Massachusetts HEDIS screening rates for Asian American women are 76.1% for mammography and 84.6% for cervical cancer. Thus, Massachusetts health plans overall are exceeding national HEDIS standards for breast and cervical cancer screening. However, statewide HEDIS screening rates are not disaggregated by Asian American ethnicity, potentially concealing screening disparities across subgroups.

Women who are low-income, recent immigrants, or who have linguistic barriers are less likely to be screened for cancer. They are more likely to be insured through Medicaid, and to receive care at a community health center. Thus, we examine HEDIS screening rates for women with MassHealth insurance. For Medicaid health plans, the HEDIS requirement for both screenings is 75%, slightly higher than that of commercial plans. Figure 5 shows that in Massachusetts, health plans that serve MassHealth patients screened 72.5% of its members for cervical cancer; Figure 6 shows that MassHealth managed care plans had lower performance in 2013 than in 2011, although there is no statistical difference between the reporting years.

Figure 5: HEDIS 2013 Massachusetts health plan performance vs. benchmarks, cervical cancer screening
Cervical Cancer Screening

About this Measure
Cervical cancer is preventable with regular screening tests and follow-up. The USPSTF recommends women start cervical cancer screenings at age 21, or within three years of their first sexual activity, whichever comes first, followed by screenings every three years after that.

The Cervical Cancer Screening measure reports the percentage of women 21 to 64 years of age who received one or more Pap tests to screen for cervical cancer between 2010 and 2012. This measure can be collected with either the administrative (claims only) method, or the hybrid method (claims supplemented by medical record reviews). The PCC Plan and FCHP used claims only, while the other four MCCs (BMCHR HNE, NH, and NHP) used the hybrid method.

| Plan/Plan Group                          | 2013 Plan Performance | Benchmark
|-----------------------------------------|-----------------------|------------
| FALLOn COMMUNITY HEALTH PLAN            | 81.6%                 | 81.1%      |
| NEIGHBORHOOD HEALTH PLAN                | 81.1%                 | 81.1%      |
| NETWORK HEALTH                          | 79.0%                 | 81.1%      |
| BOSTON MEDICAL CENTER HEALTHNET PLAN    | 78.7%                 | 81.1%      |
| MASSHEALTH WEIGHTED MEAN                | 72.5%                 | 71.9%      |
| NATIONAL MEDICAID 75TH PERCENTILE       |                       | 71.9%      |
| NATIONAL MEDICAID 50TH PERCENTILE       | 64.1%                 |            |
| HEALTH NEW ENGLAND                      | 63.6%                 | 64.1%      |
| PRIMARY CARE CLINICIAN PLAN             | 62.4%                 |            |

↑ Rate is significantly above the 2013 National Medicaid 75th percentile
↔ Rate is not significantly different from the 2013 National Medicaid 75th percentile
↓ Rate is significantly below the 2013 National Medicaid 75th percentile

Source: MassHealth Managed Care HEDIS® 2014 Report
Figure 6: Comparison MassHealth HEDIS cervical cancer screening rates 2011 and 2013

Results

- 72.5% of female MassHealth managed care plan members aged 21 to 64 had a cervical cancer screening during the HEDIS 2013 measurement period. This Mass-Health weighted mean rate is statistically significantly higher than the national Medicaid 75th percentile rate of 71.9%.

- Four of the six Mass-Health plan rates were statistically significantly higher than the national Medicaid 75th percentile rate of 57.7%. Rates for HNE and the PCC plan were significantly lower than this benchmark.

- The PCC Plan’s 2013 rate was significantly below its 2011 rate. The other four plans with reportable 2011 rates (that is, excluding HNE) had 2013 rates that were statistically equivalent to their 2011 rates.

Source: MassHealth Managed Care HEDIS® 2014 Report

Figure 7 shows that in 2014, 71.2% of Massachusetts women ages 50-74 had a mammogram. This rate is not statistically different from the national HEDIS benchmark of 71.4. Both are above the national average of 64.9%. Figure 8 shows that all MassHealth managed care plans improved their mammogram screening rates from 2013 to 2014. In sum, health plans are meeting HEDIS screening benchmarks.
Figure 7: 2014 HEDIS plan performance vs. benchmarks mammogram screening rates, 2014

**HEDIS 2014 Plan Performance vs. Benchmarks**

<table>
<thead>
<tr>
<th>Plan</th>
<th>Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NEIGHBORHOOD HEALTH PLAN</td>
<td>75.5%</td>
</tr>
<tr>
<td>FALLON HEALTH</td>
<td>73.5%</td>
</tr>
<tr>
<td>NATIONAL MEDICARE 90TH PERCENTILE</td>
<td>71.4%</td>
</tr>
<tr>
<td>BOSTON MEDICAL CENTER HEALTHNET PLAN</td>
<td>71.3%</td>
</tr>
<tr>
<td>MASS HEALTHWEIGHTED MEAN</td>
<td>71.2%</td>
</tr>
<tr>
<td>PRIMARY CARE CLINICIAN PLAN</td>
<td>70.6%</td>
</tr>
<tr>
<td>TUFTS HEALTH PLAN - NETWORK HEALTH</td>
<td>69.9%</td>
</tr>
<tr>
<td>HEALTH NEW ENGLAND</td>
<td>66.0%</td>
</tr>
<tr>
<td>NATIONAL MEDICARE 75TH PERCENTILE</td>
<td>64.9%</td>
</tr>
</tbody>
</table>

↑ Rate is significantly above the 2014 National Medicaid 90th percentile
↔ Rate is not significantly different from the 2014 National Medicaid 90th percentile
↓ Rate is significantly below the 2014 National Medicaid 90th percentile

Source: MassHealth Managed Care HEDIS® 2014 Report

Figure 8: Comparison MassHealth HEDIS mammogram screening rates, 2013 and 2014

**Plan Rate Comparison to Prior Reporting Year**

<table>
<thead>
<tr>
<th>Plan</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHP</td>
<td>67.5</td>
<td>75.5</td>
</tr>
<tr>
<td>FH</td>
<td>71.8</td>
<td>73.5</td>
</tr>
<tr>
<td>BMCHP</td>
<td>64.7</td>
<td>71.3</td>
</tr>
<tr>
<td>PCCP</td>
<td>65.5</td>
<td>70.6</td>
</tr>
<tr>
<td>THP-NH</td>
<td>65.1</td>
<td>69.9</td>
</tr>
<tr>
<td>HNE</td>
<td>56.5</td>
<td>66.0</td>
</tr>
</tbody>
</table>

Source: MassHealth Managed Care HEDIS® 2014 Report

Results

- 71.2% of female MassHealth managed care plan members 50-74 years of age had a mammogram during the 27 months prior to December 31, 2013. This rate was statistically equivalent to the national Medicaid 90th percentile benchmark.
- Five of the six MassHealth plan rates were statistically equal to, or higher than, the 90th percentile benchmark rate of 71.4%. NHP's rate (75.5%) was statistically significantly higher than the benchmark, while FH, BMCHP, THP-NH, and HNE had rates that were statistically equal to the benchmark. The PCC Plan's rate of 70.6% was well above the national Medicaid 75th percentile rate of 64.9%, although it did not meet the 90th percentile.
Access to health insurance and preventive care

The passage of health reform in Massachusetts in 2006 increased access to care for uninsured Massachusetts residents and provided a model for national reform [1]. The Patient Protection and Affordable Care Act (ACA), passed in 2010, mandates universal health insurance coverage. Additionally, the ACA mandates that health plans offer mammograms and Pap tests free of charge [2].

Furthermore, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), a program of the Centers for Disease Control and Prevention (CDC) provides low-income, uninsured, and underserved women access to timely breast and cervical cancer screening and diagnostic services, e.g., clinical breast examinations, mammograms, Pap tests, pelvic exams, Human papillomavirus (HPV) tests, diagnostic testing for abnormal test results and referrals to treatment [3]. Congress created the NBCCEDP through the Breast and Cervical Cancer Mortality Prevention Act of 1990. Currently, the NBCCEDP funds screening services for breast and cervical cancer in all 50 states, the District of Columbia, 5 U.S. territories, and 11 American Indian/Alaska Native tribes or tribal organizations. Essentially, the ACA and NBCCEDP together ensure that women can receive breast and cancer screening regardless of their insurance, immigration, or economic status [3].

Asian American women

In Massachusetts, 97% of residents have health insurance and Asian Americans have the highest rate of health insurance coverage; only 3.1% of Asian Americans lack insurance as compared to 3.4% for white, 6.8% for black, and 10.6% for Latinos. [4] Despite high health insurance rates, rates of screening for breast and cervical cancer can be improved. This research project aims to explore why some insured Asian American women in Massachusetts do not seek screening. We set out to address the following questions:

1. What are the barriers at the individual level (e.g., lack of knowledge, motivation, fear, embarrassment), structural or process barriers, and barriers at the healthcare provider level for Asian American women to utilize preventive health behaviors and screenings, particularly screening for breast and cervical cancer?

2. How do Asian American women make decisions about their health in general and for breast and cervical health in particular?

3. What is the level of health literacy for breast and cervical health?

4. Do barriers differ by ethnicity, with a focus on Chinese, Vietnamese, and South Asian women, or are their other factors?

5. What people, programs, activities, or interventions can facilitate increased awareness and utilization of preventive services?
Our findings will inform the development of programs to increase screening and inform a larger intervention proposal application. This may entail program development, advocacy initiatives, or outreach and awareness campaigns for specific populations of Asian-American women.

**Project partners and project funding**

Dr. Lisa Gualtieri, assistant professor at Tufts School of Medicine in the Department of Public Health and Community Medicine, was Principal Investigator (PI) and Chien-Chi Huang, Executive Director of the Boston-based Asian Women for Health (AWFH), was co-investigator for this project. Dr. Tam Nguyen, Boston University School of Nursing, was an academic partner, and Dr. Gouri Banerjee, Saheli Boston, was a community partner, both introduced to the project by Ms. Huang. Drs. Nguyen and Banerjee have strong roots within the Vietnamese and South Asian communities, respectively.

A number of community members introduced through community partners, as well as Tufts University students and a summer intern, received focus group facilitator and/or CITI training, and some participated as facilitators, scribes, or participant recruiters.

Mardia Coleman, a graduate of Tufts University, served as research assistant on the project and conducted the literature review and wrote up study findings. Other Tufts University students who assisted in the study include Tariana V. Little and Daryl Mangosing. Kristen Daudelin, a summer intern, assisted in creating recruitment materials and developing CITI training. Priyanka Gupta, Wei (Cami) Chen, and Hien Vu assisted in multiple roles, including being facilitators and scribes. Dr. Karen Freund served as project mentor with in-kind support through an American Cancer Society Clinical Professorship.

This project was primarily funded by a grant from Tisch College Community Research Center at Tufts (TCRC). Dr. Nguyen provided additional support for this project from a separate grant, which covered the cost of gift cards for focus group participants and food at focus groups and training meetings.

**IRB review and approval**

The Tufts Medical Center and Tufts University Health Sciences Institutional Review Board (IRB) reviewed and approved this project with exempt status including recruitment materials and messaging. The review and resubmission process delayed the start of recruitment. The IRB furthermore approved a plan for CITI training for community partners that was not included in the original proposal or IRB submission.

**Methods**

**Guiding principles**

This research project is guided by the principles of community-based participatory research (CBPR), the form of community-engaged research wherein academicians and community
partners jointly guide the research project, from start to finish, through shared goals and complementary skills.

Because this research is formative and exploratory in nature, we used qualitative methods, in particular focus group discussions, to learn about barriers to utilization of preventive care. We aimed to obtain rich information from Asian American participants in order to identify next steps leading to culturally relevant, community-based interventions that could increase utilization of preventive services.

**Screening guidelines**
We used the United States Preventive Services Task Forces (USPSTF) [5, 6] and the National Committee for Quality Assurance’s (NCQA) HEDIS guidelines [7] for cervical cancer and breast cancer screening to determine the age group sought to participate in the focus groups. Both sets of guidelines recommend that healthy women with no risk factors receive a mammogram every 2 years starting at age 50, and a Pap test every 3 years starting age 21 or at the onset of sexual activity.

Of note, more than 90% of United States healthcare plans use HEDIS measures to assess and compare their performance regarding screening and other important performance measures. Because so many healthcare plans collect HEDIS data using a uniform measurement system, we consider HEDIS breast and cervical cancer screening data to be more accurate than self-reported BRFSS data. This is especially true in Massachusetts, where about 96% of residents have health insurance and public and private payers submit HEDIS data. Additionally, the number of Asian Americans who respond to the BRFSS survey is typically very low, precluding the ability to report informative data.

**Study population**
In order to be consistent with USPSTF and HEDIS guidelines, this project recruited English and non-English speaking Asian American women with health insurance ages 24-51 who had never had or had not received a Pap test in the last three years, and women ages 52-65 and who had never had or had not received a mammogram in the last two years. The choice of age range for Pap test is explained below. Women were eligible to participate if they met either criteria.

For study purposes, the lower cutoff age of 24 for Pap test screening was used because at age 21 women should start being screened and age 24 they are not adherent if they have never been screened. While women receive the Pap test at the start of sexual activity, we did not ask women under age 24 at what age they became sexually active because of the sensitive nature of the question.

We used the higher cutoff of age 51 for Pap test eligibility. While the USPSTF recommends screening through age 65, it was important for the research team to facilitate recruitment by community partners. By using a binary approach, 51 as an age limit for a Pap test and 52 as the entry age for a mammogram, we were able to use a recruitment script for inclusion/exclusion
criteria. Table 5 shows the inclusion criteria for focus group participants. Appendix I: Recruitment script provides the recruitment script we used.

We recruited Asian American women from three ethnic groups: Chinese-American, Vietnamese-American, and South Asian-American. South Asian women came from India, Pakistan, Bangladesh, Nepal, Bhutan, Maldives and Sri Lanka. The ability for participants to speak English was not a requirement because we trained Mandarin- and Vietnamese-speaking focus group facilitators, who all used the same Focus Group Facilitation Guide.

We chose these ethnic groups because Chinese-Americans are the largest Asian ethnic group in Boston and in MA, Vietnamese-American women are the second largest Asian ethnic groups in Boston, and South Asian-American women are the second largest Asian ethnic group in MA. It was important to have representation from multiple Asian countries given the diversity of cultural experiences and their potential impacts on health behaviors.

Table 5: Inclusion criteria for focus group participants

<table>
<thead>
<tr>
<th>Screening test</th>
<th>Age 24-51</th>
<th>Age 52 or older</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Pap test in the last three years</td>
<td>Eligible</td>
<td>No. Cut-off to facilitate ease of recruitment</td>
</tr>
<tr>
<td>No mammogram in the last two years</td>
<td>Not eligible, screening starts at age 50</td>
<td>Eligible</td>
</tr>
</tbody>
</table>

Asian American community study volunteers
Co-investigator Ms. Huang, academic partner Dr. Nguyen, and community partner Dr. Banerjee recruited volunteers from their ethnic communities to serve as recruiters, facilitators, and scribes for the focus groups. Volunteers represented each Asian-American subgroup and were fluent in English, Mandarin, or Vietnamese. We then recruited and trained Asian-American volunteers and one Tufts University graduate student in how to recruit and enroll study participants and how to conduct focus groups. The Focus Group Facilitation Guide is included here in Appendix III: Focus Group Facilitation Guide.

We held three separate two-hour sessions with community partners and volunteers where we reviewed the focus group protocol, principles of focus group leadership, guidance on facilitating focus group discussions, and how to manage time to ensure that all questions are asked at each session. The training included role playing and mock focus groups among research team members in order to provide feedback and debriefing. In a separate session, Dr. Gualtieri provided study volunteers with CITI training in research ethics. Some images from these sessions are included on the cover page of this report.

Additionally, Dr. Gualtieri shared the focus group training guide (in Appendix III: Focus Group Facilitation Guide) with community partners for their future use. She met representatives from other community organizations at the Tufts CTSI’s Together, Strengthening the Health of
Chinatown: An Asian Health Symposium and offered to provide them with the focus group facilitator training and/or guidelines.

Not all people who received focus group facilitation training and CITI training facilitated focus groups for our project, but all were trained and willing to. Given the CBPR nature of our research project, inclusion of Asian community partners was part of our effort to build research capacity in the community.

Recruitment methods
We aimed to recruit a convenience sample of Asian American women between the ages of 24 and 65 who had insurance coverage but had not followed the recommended screening guidelines for breast or cervical cancer screening. Our goal was to populate and run at least three focus groups. We developed promotional materials in English and traditional Chinese and a Facebook page, which are included in Appendix II: Recruitment materials (fliers and Facebook page).

We specified in promotional materials that participants would receive a $25.00 gift certificate for participation. While we did not specify it, we compensated participants who paid for parking, and, also, food was provided at all sessions.

We recruited focus group participants through the networks and affiliations of community partners, specifically: 1) Boston-based Asian Women for Health (AWFH) and its local and statewide network of collaborating organizations; 2) the Indian-American group Saheli Boston and its networks; and 3) the networks of Dr. Tam Nguyen, professor at the Boston College School of Nursing, who works closely with the Vietnamese community. We asked these organizations to post and distribute flyers both in paper, on websites and apps, email distribution lists, and to brief their members about the study. We distributed flyers in English and Traditional Chinese. Because South Asians in Massachusetts predominantly speak English, we used English language flyers to recruit South Asian women. We also used social media, including a study-specific Facebook page, http://facebook.com/TuftsStudy. Finally, we recruited at local events, including fliers at tables at local health fairs and Asian community events.

Study staff screened all potential respondents who called about the study to determine their eligibility and the Asian American subgroup to which they self-identified. Community groups conducted their own screening leading to providing study staff with names and contact information. Outreach was primarily in Boston and the Greater Boston area.

Focus group discussion methods
We recruited women who met either of the inclusion criteria. At each focus group, we provided participants with an explanation of the focus group purpose and their roles and rights in a script read by the facilitator. Participants were assigned a number and asked to provide demographic information prior to starting the focus group.
Because of the difficulties with recruitment and the lack of thorough screening processes, not all participants included in focus groups met the criteria. Since the unqualified participants had shown up in good faith and we only realized they were not qualified from the demographic forms, we did not think it was reasonable or hospitable to turn them away. We only hoped that we could learn about both facilitators and barriers to screening from them. Tables 7 and 8 show the screenings participants had received.

All focus groups had a facilitator and scribe and were audio recorded. We conducted four focus groups in total.

Analysis

Our original plan was to analyze the qualitative data collected at the focus groups using traditional qualitative analysis processes that have recently been labeled “immersion/crystallization” [1]. This process entails individually listening to the audio recordings, reading the transcripts, and taking analytic notes throughout the process. In addition, the data are typically discussed by the evaluation team to explore divergent interpretations and to arrive at a consensus for the findings.

While it is ideal to engage in the above process, it is also common practice for a dedicated scribe to take detailed notes during and after the sessions. Due to budget constraints, rather than transcribe and translate the recordings, we relied on notes from the focus group facilitators and scribes following the sessions. Some of the facilitators or scribes listened to the tapes to augment the focus group notes, a modification of the immersion/crystallization approach described below. Focus group recordings were reviewed by the facilitators, who used tables to describe major and minor themes for each question. The research teams then reviewed the themes and used a group process to interpret and finalize results.

Findings

Focus group recruitment

Recruitment proved challenging despite the many forms of outreach used and ultimately the recruitment challenges may be indicative of the limited number of women meeting the inclusion criteria. Also, the communities in which co-investigator Ms. Huang, academic partner Dr. Nguyen, and community partner Dr. Banerjee circulate may be largely filled with people who are more knowledgeable about health and thus more likely to be adherent to guidelines. They were however successful in recruiting volunteers from their ethnic communities to serve as recruiters, facilitators, and scribes for the focus groups.

Twenty-five women, all English-speaking, contacted us by phone or email to participate in the study through recruitment efforts. Of the eight who qualified for the study, four participated in focus groups. For the other four, we were not able to accommodate their needs in terms of location and time for sessions and one scheduled session was cancelled when all participants notified us they were unable to attend.
Additionally, we estimate that during recruitment, the study partners and staff talked with 3-4 times the number of women who wanted to participate but did not qualify. Community organizations assisted in recruiting the women who participated in the four focus groups.

Despite the best efforts of our study partners and a variety of direct and indirect outreach approaches, we found reaching women who were not up-to-date with breast or cervical cancer screening to be a challenge, not surprising given current screening rates. Study partners used multiple methods over four months to recruit focus group participants. As noted in the methods section, study partners used presentations, flyers, informational tables at local health fairs and Asian community events, postings on social media, and asking community organizations’ help in reaching out to their members. Study partners continually asked friends, neighbors, and community contacts if they knew of any women who might be interested in participating, describing the eligibility criteria.

The organizations with whom the study partners interacted regularly and whose membership includes Asian American women tended to have members who were concerned about health in general, the health of Asian American women overall, and their own health. These women tended to be more educated and had a regular health provider. As such, most of these women were up to date with screening tests and thus ineligible to participate in the study.

We found recruiting across a broad geographical region also presented problems. When qualified participants did contact the study, they often lived in disparate towns and could only attend at select times or days. At times, when we had enough qualified participants for a focus group, we could not get them together. Thus, we found that timing and location are of the essence when scheduling focus groups. When qualified participants had to wait for a focus group to be scheduled, or they had to travel, it was a barrier to participation.

We found seasonality to be another challenge. We started recruitment efforts in August, but did not begin to receive inquiries about the study until mid-September. It could be that summer vacations or lack of summer childcare were barriers. It could be also there needs to be a critical amount of repeated exposure to recruitment messages (flyers, emails, social media postings) before someone decides to contact the study for more information.

Study partner recruitment efforts based in the community through person-to-person contact with local groups or neighborhood churches were more successful in recruiting qualified study participants. Within the Chinese community, the most effective way was to tap into someone currently in that group and ask the person to ask around and see who fit the criteria, then ask the qualified participant to talk to their friends and family members. For instance, we had one woman who brought her mother and a friend to a focus group.

However, reaching into the community and using community partners to recruit and schedule presented challenges as well. One church serving the Vietnamese community offered to help us recruit from its congregation through contact with Dr. Nguyen. She provided the church with the study criteria. However, when we met the focus group participants, we found eight of the
nine of the women the church recruited were up to date with screening, e.g., not qualified to participate. Because the women had shown up and were willing to help us in good faith, we proceeded to conduct the focus group.

Finally, our study partners met a number of women aged 21-23 who had not received a Pap test. It was not clear if these women were eligible for screening (were sexually active) or if there were other barriers that kept them from having a Pap test.

**Focus group participants**
As of November 16, 2015 we conducted four focus groups; one in English, two in Mandarin Chinese, and one in Vietnamese. Tables 6-8 show focus group participant data.

Of the 25 total participants, 12 were technically ineligible. Ten women were current with preventive screening and nine of those were in the Vietnamese American focus group. In addition, two women did not have health insurance. The twelve women who were not qualified were included, because we did not know that they were not qualified until they were at the focus group, and it felt inappropriate to turn them away at that point. We still hoped that we could learn about both facilitators and barriers from them.

Table 6 shows that, of the twenty-five women participated in the focus groups, twelve were Chinese Americans, nine were Vietnamese Americans, three were Southeast Asian Americans, and one woman did not report her ethnicity (but we inferred from her answers during the focus group that she was South Asian). About half of the focus group participants spoke the language of their country of origin; about half spoke English and the language of their country of origin. A majority of participants reported having a usual place they receive health care.

The nine Vietnamese American women who did not qualify because they were current with preventive screening were members of the same congregation, spoke Vietnamese, and lived in or near Randolph, MA, the location of the church from which they were recruited. We saw this as an opportunity to learn about their experiences. We report on this focus group’s findings separately.

Each of the two Chinese-American focus groups had one participant who did not have health insurance and were not qualified participants. Neither listed having a usual source of healthcare. However, since these women had access to screening through ACA and NBCCEDP provisions, we did not see lack of health insurance as a reason to exclude their responses in our analysis. One focus group had a participant up-to-date with both screening tests.
Table 1: Focus group demographics—all participants

<table>
<thead>
<tr>
<th>Birth country (n=25)</th>
<th>China</th>
<th>India</th>
<th>Taiwan</th>
<th>Vietnam</th>
<th>Not reported</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participants</td>
<td>8</td>
<td>3</td>
<td>1</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years lived in the United States (n=22)</th>
<th>3 months-5 years</th>
<th>6-10 years</th>
<th>11-15 years</th>
<th>16-20 years</th>
<th>21-25 years</th>
<th>26-35 years</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participants</td>
<td>7</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Language spoken (n=22)</th>
<th>Chinese</th>
<th>English, Chinese</th>
<th>English, Hindi</th>
<th>English, other not specified</th>
<th>English, Vietnamese</th>
<th>Vietnamese</th>
<th>Vietnamese, Chinese</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participants</td>
<td>6</td>
<td>1</td>
<td>6</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age range (n=25)</th>
<th>24-41 (Pap test)</th>
<th>53-74 (mammogram)</th>
<th>Not reported</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participants</td>
<td>9</td>
<td>13</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Asian American ethnicity subgroup (n=25)</th>
<th>Chinese</th>
<th>Southeast Asian</th>
<th>Vietnamese</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participants</td>
<td>12</td>
<td>3</td>
<td>9</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you have a usual place of care? (n=25)</th>
<th>Yes</th>
<th>No</th>
<th>Not Reported</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participants</td>
<td>17</td>
<td>7</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Usual place of care (n=17)</th>
<th>Doctor</th>
<th>Doctor, Emerg Department</th>
<th>Doctor, Minute clinic</th>
<th>Emergency Department</th>
<th>Other</th>
<th>Not reported</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participants</td>
<td>12</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health insurance (n=25)</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participants</td>
<td>23</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2: Participant characteristics by focus group

<table>
<thead>
<tr>
<th>Date conducted</th>
<th># of participants</th>
<th># of qualified participants</th>
<th>Primary ethnicity</th>
<th>Language conducted</th>
<th>Age range</th>
<th>Location of focus group</th>
</tr>
</thead>
<tbody>
<tr>
<td>FG1: 10-11-15</td>
<td>9</td>
<td>0 (8 current mammogram; 1 not reported)</td>
<td>Vietnamese</td>
<td>Vietnamese</td>
<td>57-74</td>
<td>Randolph</td>
</tr>
<tr>
<td>FG2: 11-01-15</td>
<td>5</td>
<td>4 (1 no health insurance)</td>
<td>Chinese</td>
<td>Mandarin</td>
<td>25-56</td>
<td>Boston</td>
</tr>
<tr>
<td>FG3: 11-06-15</td>
<td>4</td>
<td>4</td>
<td>SE Asian</td>
<td>English</td>
<td>24-53</td>
<td>Boston</td>
</tr>
</tbody>
</table>
Focus group findings

Focus group 1

We conducted our first focus group in Vietnamese with nine Vietnamese women who were current with breast cancer and cervical cancer screenings. These women were recruited by a member of their church. Participants’ US residency ranged from 7-30 years.

- These women were well connected to health care. They all had family practice providers. Many saw their providers at six-month intervals. In some cases, frequency of appointments was due to having health problems. These women largely reported positive interactions with care providers.

- Participants appreciated and relied on health appointment reminders. Their doctors remind them of everything; for instance, when it is time to get a flu shot, to get other health tests or health screenings. The care practice typically provided phone reminders in Vietnamese.

- Participants reported having no major concerns about mammogram and pap tests. However, the women who stated they were widows in the group felt that their doctors were not as concerned about whether they received the Pap test. Also, there was an underlying belief among many participants that once a woman enters menopause or is no longer sexually active, she no longer needs to get regular pap smears.

- Overall, participants felt comfortable about screenings. There was some concern about experiencing pain when having screening tests. Some reported that the pain is less in the US than in Vietnam, but they did not say if it was because of the machine or technician.

- When confronted with a health concern, all the women reported consulting with their family and friends first (but mostly with family). If their family and friends suggest that they go to their primary care provider, they would. Participants also reported using the Internet to learn about their health (all websites mentioned were in the Vietnamese language). Internet searches were considered in addition to their doctor’s medical advice.

- Participants identified transportation as their biggest screening barrier because many did not drive. Participants reported they have support from family members, particularly their daughters, to drive them to and from screenings. Of note, one participant mentioned that her healthcare provider helped arrange transportation.

- Language skills were not seen as a barrier since they reported translation services as “pretty good”.

<table>
<thead>
<tr>
<th>Date conducted</th>
<th># of participants</th>
<th># of qualified participants</th>
<th>Primary ethnicity</th>
<th>Language conducted</th>
<th>Age range</th>
<th>Location of focus group</th>
</tr>
</thead>
<tbody>
<tr>
<td>FG4: 11-09-15</td>
<td>7</td>
<td>5 (1 no health insurance; 1 current Pap test)</td>
<td>Chinese</td>
<td>Mandarin</td>
<td>34-53</td>
<td>Boston</td>
</tr>
</tbody>
</table>
• Participants also reported cost as a possible barrier. They described being unsure if mammograms and pap smears were fully (100%) covered by their insurance, as they experienced situations in which some (other) services were only 80% covered.

• Participants’ advice for someone who does not want to get screened was to prevent health issues before it is too late. There was also a collective sense of “Chi em giúp nhau”, or wanting and needing to help and support each other. Several women suggested tapping into existing social networks to get women to encourage each other to get screened.

Focus group 2

The second focus group, conducted in Mandarin, comprised of four Chinese American women and one Taiwanese American woman, ages 25-56. Four women met study criteria because they had not received a Pap test in the last three years; one woman did not have a mammogram in the last two years. These women lived in a variety of cities surrounding Boston.

• When participants have concerns about their health, they try to heal themselves first. They may also talk to friends and family members and use the Internet.

• They reported they do not typically have a usual source of care or a regular health care provider. They do not get an annual physical. But, if participants felt they needed health care, they go to their community health center.

• These women reported that they typically get reproductive care information when they give birth, or when they have gynecological problems, such as vaginal discharge.

• Participants reported that they respond positively to reminders, particularly post cards. WeChat, an instant messaging service common in China, is their preferred communication channel.

• These women reported their impressions or experiences with mammograms and the Pap test as painful and undignified. They associated mammograms and the Pap test with unsympathetic technicians and long waits.

• Reported barriers to screening included:
  o Not knowing the screening guidelines
  o Feeling like they do not need a Pap test if they were not married or had only one sexual partner
  o Too much trouble to get an appointment
  o No need to get tested if you are healthy
  o No one told them to have a screening test
  o Not wanting to know if something bad will happen
- Lack of knowledge about the U.S. healthcare system
- Mistrust of providers and mixed experiences with them

Participants said that the following could increase screening awareness: in-person health education with professionals or peers; appointment reminders using postcards, phone calls or text messages; training providers to be more culturally sensitive and responsive; and a public awareness campaign using the media, billboards and subway ads.

Focus group 3

The third focus group, held in English, comprised of four Southeast Asian-American women, ages 24-30, who had not a Pap test in the last three years. Participants were all women born in India and now attending graduate school and/or working in the Boston area.

- Participants primarily use the Internet and the Google search engine to get information about their health questions or concerns. They report also talking with their parents or sisters, depending on the nature of the health concern.

- Each had a usual source of health care. Their provider provides them with reminders about routine health care. However, the group reported viewing health care as primarily curative, given their experiences in India, which differed from the U.S. norm of preventive care. Since they felt healthy, they did not see the value of screening but information from their provider could change that. They also discussed whether it was valuable to not know if you had cancer or to know early. One woman stated that, if she was screened, she would not tell her mother until she got the results so as not to cause needless worry.

- Participants knew the purpose of having a mammogram and Pap test, but did not know how they were done, what the tests cost, or if insurance covered the tests.

- Participants had misconceptions about why they might need a Pap test. Some thought a Pap test was sign of sexual activity and multiple sexual partners, or needed for those reasons. There was some concern that the invasive test would compromise virginity, a culturally valued status for Indian women. They agreed that being married supported the need for a Pap test, although those who mentioned being married had not had a Pap test.

- Participants wanted their doctors to tell them about the test, why it was needed, what the procedure entailed, including any level of pain, and the risks and benefits.

- In helping spread the word about why it is important to be screened, participants felt it would be important for women to know the consequences of having cancer, specifically gendered framing of consequences, like how cancer would affect women’s families. For instance, if you die from cancer, your children will become orphans; screening and early detection can help you live longer for your family. Participants felt “spreading the word”
through the community, having their health providers educate patients, and repetition of messaging would be effective to increase screening awareness.

**Focus group 4**

The fourth focus group, held in Mandarin, was with seven Chinese American women, ages 24-57. Five women were eligible because they had not received a Pap test in the last three years; one woman was because she had not had a mammogram in the last two years. One woman was up-to-date with all screening tests. One woman did not have health insurance. Participants had lived in the U.S. ranging from 5 to 22 years.

- Participants reported using a variety of approaches when they have health questions or concerns. When sick, they might try to “sleep it off”, take home remedies or Chinese medicines, or research their symptoms online. They may also see their primary care provider or visit the emergency department (ED). All of the women had a primary care provider.

- Participants reported that their doctors did not often provide them reminders about preventive tests or screening, for either themselves or their children. In contrast, they reported that their dentists provided them with reminders about dental preventive tests and screenings. One woman reported that in Hong Kong, “there are many ads and banners...to remind us about these services.” These women expressed a desire to receive reminders, both from their medical care providers and in community settings.

- Participants’ preferences for reminders included reminders in Chinese on WeChat; one respondent noted that MassHealth had set up a WeChat group for Asian seniors about their health. Other reminder preferences included ads in Chinese newspapers, mail reminders, texts, voicemails, and ads and banners in public spaces such as subways and bus stops.

- Some women returned to their homeland for physicals and preventive care. Many participants reported dissatisfaction with their U.S. primary care providers, especially at one community health center. They reported receiving inaccurate diagnoses from (generally) incompetent doctors who they perceived as often rude and impatient with them. These experiences led them to seek medical care at the ED. They felt that the ED had the resources to provide the tests needed for an accurate diagnosis and appropriate treatment.

- Participants’ experiences having a mammogram or Pap test were not much better. Many complained of insensitive, impatient mammogram technicians who ignored their complaints of pain and of doctors who conducted painful gynecological exams and Pap tests. It appeared that participants were not adequately prepared for what to expect from mammogram or Pap procedures. These experiences were barriers that kept them from having timely preventive tests.

- Other barriers to timely preventive tests included:
o Not having the time
o Not knowing if the tests are covered or covered in full by their health insurance
o Not knowing why the tests are necessary
o Not wanting to go to the doctor when you are not sick
o Not wanting to know if you are sick

• One woman reported that in the Chinese culture it is expected that a woman will have sexual relations with only one man; she associated the test with having multiple sexual partners.

• Respondents said supportive, reliable, and credible health providers would help them consider having preventive tests. They wanted to know the risks and benefits of the tests and what to expect from the procedures. They also wanted to be able to make informed choices as to whether or not they would be screened.

Findings by research question

1. What are the barriers at the individual level (e.g., lack of knowledge, motivation, fear, embarrassment), structural or process barriers, and barriers at the health provider level for Asian American women to utilize preventive health behaviors and screenings, particularly screening for breast and cervical cancer?

Overall, most of the respondents had a general understanding of the purpose of the two screening tests. However, some women feared getting a positive result to a screening test but others wanted to know so they could deal with it; some Chinese-Americans and Southeast Asian Americans felt that having a Pap test suggested multiple sex partners, which was culturally unacceptable.

However, the biggest barrier appeared to be at the practice level—doctors or technicians who participants perceived as rude or impatient, caused pain, and did not explain the purpose of the procedure or what to expect in terms of their state of undress, loss of dignity, or pain. Also some providers did not explain the side effects or risks of the procedure, so patients did not feel prepared for them or have clear expectations. Women who did not have satisfactory provider-interaction experience were not having screening tests. Additionally, dissatisfaction with their care provider seemed also to be a barrier to seeking screening.

Finally, each cultural and ethnic group had participants who did know not whether their health insurance covered preventive screenings in part or in full.

2. How do Asian American women make health decisions and what are the factors that influence their decision-making?
Women reported that they relied primarily on their doctor when they have health concerns; yet when they did not trust their doctor, some Chinese American women turned to the ED where they found the doctors and diagnostic tests they trusted. Women also reported consulting with family members and the Internet first, and a few turned to traditional medicines. Many women stated that because they felt healthy, they did not see the need for tests.

3. **What is the level of health literacy for breast and cervical health?**

It appeared most respondents had a general knowledge of the purpose of the tests, which is to discover cancer in its early states, while not necessarily knowing the specifics of how they were done. However, there were misconceptions about the Pap test in particular, e.g., that the tests were for women who had multiple sex partners or married women, or that post-menopausal women did not need to be screened. Some Chinese women wanted to know more about the risks and benefits. Many expressed lack of specific knowledge of the guidelines, which was highlighted following the change in the guidelines by the American Cancer Association for mammography. This took place partway through the focus groups, and women expressed concerns about not knowing which guidelines to listen to or why they were changed.

4. **Do barriers differ across the specific ethnicities that comprise Asian American women, particularly Chinese, Vietnamese, and South Asian women?**

Chinese American women were vocal about physical pain being a barrier to screening, but also pain or discomfort caused by insensitive doctors or mammogram technicians. They also expressed higher dissatisfaction with their health care providers and with the complexities of the health care system. They were used to better access to high quality, timely care in their native countries. As noted earlier, the Pap test has a connotation of multiple sexual partners, an unacceptable practice within the Southeast Asian or Chinese cultures. There was some discussion about the differences in care in “my country” and the US, one example being that a mammogram was more painful in Vietnam than in the US, although not specifying if this was due to equipment or technician.

5. **What people, programs, activities, or interventions can facilitate increased awareness and utilization of preventive services?**

Overall, all women wanted appointment reminders. They wanted reminders from their providers by mail or, if Chinese American, by WeChat. Chinese American women also wanted reminders posted in their community. Women wanted their doctors to explain the tests and the procedures. Some Chinese American women wanted their health care providers who they already know to conduct the tests and be sensitive to their pain.

Additional findings: The focus group discussions included questions that were highly pertinent and those they were curious about, such as how women with breast implants receive...
mammograms. Some topics were discussed with laughing. Family was an issue raised many times, in the context of mothers telling their daughters to be screened and vice versa, or what is communicated and when, such as telling mothers that a screening took place only after the results were received to save needless worry. Family played a role not only in reminders to be screened, but also in transportation to the appointment.

Discussion

Recruitment

Our recruitment efforts were most successful when we made connections at a more personal level, such as when a colleague knew someone who likely was not up-to-date with screening. We learned that traditional recruitment efforts—posting or disseminating study flyers, social media postings—reached people who wanted to participate but were not eligible. Further, women who are not current with screenings appeared to have few linkages with community organizations. Thus, using community organizations to increase screening awareness may not reach the intended audience. Other methods, such as peer education or community health educators, might hold promise.

Recruitment by community groups on the study’s behalf also had challenges. Time constraints among community groups interfered with their ability to effectively assess eligibility among potential participants.

When we did have qualified participants, we were hampered by the diverse locations where qualified participants lived, and the days and times participants could attend. Based on our experiences, we suspect that we should have concentrated efforts on a smaller geographic location where a large community of Asian American women reside.

Through the recruitment process, we learned there are Asian American undergraduate and graduate students who have not had a Pap test. We did not learn whether this was due to not meeting the screening guidelines regarding age, lack of access to preventive care, cultural beliefs, or other reasons. There is sparse literature that specifically addresses screening barriers among Asian American or South Asian American undergraduate or graduate students. This represents an area for future research.

Literature review

As previously noted, there is scarce literature to date on screening barriers in a post-ACA environment. To our knowledge, there is no existing literature that specifically addressed screening barriers or facilitators for Asian American women residing in Massachusetts. As such, this study adds to the literature and serves as a foundation for future research and interventions.

Screening rates for Asian American women residing in Massachusetts

Asian American women residing in Massachusetts may not be experiencing screening disparities. HEDIS data indicate that Massachusetts women overall are receiving Pap tests and mammograms at or above the HEDIS screening standard. However, health disparities by Asian
American subgroups warrant disaggregated analyses in statewide and national data sources and research studies. Asian American women who are not being screened might share similar characteristics with other women who are under-screened, e.g., lack of a regular place of care and lack of a regular provider. An area of future study is to request additional HEDIS data from the Massachusetts Office of Medicaid in order to examine screening rates by ethnicity, ESOL status and region. Another is to learn more about age of diagnosis for breast and cervical cancer, and mortality rates for these diseases.

**Screening barriers and facilitators**

Across all Asian American ethnicities, we found that cultural beliefs, provider practice and attitudes posed barriers to screening. Cultural norms about sexual activity and virginity, combined with a lack of knowledge about the risks and benefits of Pap test screening, were a screening barrier for Southeast Asian participants. Chinese women also associated the Pap test with sexual activity, which was associated with marriage and child-bearing.

Consistent with the literature, we found that in the Vietnamese focus group with qualified participants, women whose doctor scheduled their screening appointment for them and sent reminders, in their native language, were compliant with screening. These women largely reported liking their providers and feeling comfortable asking questions. By contrast, women who were dissatisfied with their health care providers reported not engaging in timely screening.

It appeared that the women who reported satisfaction with their providers sought health care at the same community health center (CHC). This particular CHC appeared to be following recommendations and guidelines for providing culturally appropriate care, engaging women in health care, and providing cancer screenings. Thus, we found that women who were satisfied with their health care providers were more likely to engage in preventive health.

Finally cost was perceived as a barrier and many women did not know that there was no charge or co-pay associated with preventive screening. When other barriers existed, such as the time to make, get to, and have an appointment for screening, cost should not be perceived as an additional barrier. This is worthy of further exploration and may be the case well beyond our study population of Asian American women.

**Policy**

While community organizations can help with increasing community preventive health awareness and cancer screenings, state and federal policies, quality improvement measures and quality reporting are drivers that establish the importance of cancer screenings. State, national, or accreditation initiatives to increase Asian American women screening rates could provide both the carrot and the stick (e.g., quality ratings, public reporting, other incentives) to encourage providers to make their practices more patient-centered in encouraging screening.
Screening guidelines

On October 20, 2015, the American Cancer Society (ACS) released new breast cancer screening guidelines [21, 22]. While the ACS guidelines are now closer regarding entry age for healthy women with average risk for breast cancer (age 45 vs. 50), the new screening guidelines are still not aligned with those of the USPSTF and NCQA. The discrepancy between USPSTF and NCQA recommendations and quality measures and the ACS could cause confusion among general audiences regarding guidelines in general, how they are determined, what is the research behind them, and why they change. Indeed, our focus group respondents generally were not aware of the entry age for breast cancer screening or of screening guidelines in general.

Taken together, this highlights the importance of patient-provider trust and the key role of physicians in informing and educating patients about guidelines in addition to scheduling screenings. It furthermore highlights the confusion people have about who creates guidelines and how, what to trust since they change, and how much personal knowledge they need about current guidelines. The confusion about guidelines is one worthy of further exploration.

Limitations

Literature review

There is a growing body of literature regarding cancer screening barriers and interventions to increase cancer screening for Asian American women. However, we could not find articles that include studies conducted after the implementation of the Affordable Care Act (ACA). The ACA effectively eliminates lack of health insurance and the ability to pay as screening barriers. Thus, reported screening barriers and facilitators may have shifted accordingly.

Studies conducted in urban areas with large immigrant and Asian populations are likely generalizable to Massachusetts. However, we could find no published studies that focused on understanding screening barriers or facilitators in Asian American women in Massachusetts.

The literature notes that Asian Americans are highly heterogeneous. Screening barriers and facilitators often are specific to certain subgroups that live in cities or regions with a specific set of health care resources and reported study results may not be generalizable.

Recruitment

Due to limitations of funding and staff resources, we did not reach into the Asian American community to the extent we would have liked, such as women living in more rural parts of Massachusetts. While our community partners worked hard to recruit across their networks, they did not have the resources to do more face-to-face recruitment. The study did not have the resources to go into the small shops and businesses where low-wage Asian American women work. These women may be less likely to have the resources to access timely health care, to have a regular source of health care, or a usual health care provider.

Regarding Pap test screening, we did not ask women under the age of 24 to participate in the study because of the sensitivity of asking young women if they were sexually active. There was a small risk of making women feel their choices about sexual behavior were not the norm.
Additionally, we did not that feel our volunteer recruiters had the training or desire to discuss this topic with potential participants due to its sensitive nature.

We shortened the age of Pap test screening to age 51, rather than following the recommendation to screen regularly until age 65. We did this to make it easier for our community partners to recruit study members. However, it is possible we missed potentially eligible study participants by doing so.

**Focus group findings**

Our focus group findings, while reflective of the literature, represent the experiences of a small number of Asian American women at a particular point in time. Each focus group reflected the experiences of women who receive care within a limited geographic area in Greater Boston and the providers with whom they interact within that area. We consider our findings important but possibly not be applicable to other Asian ethnic subgroups, or other Massachusetts regions, such as the rural areas we did not reach.

While we started to hear recurrent themes across the focus groups, especially across the two Chinese-American focus groups, we did not achieve response saturation. It is possible we would have achieved saturation had we conducted more focus groups or had a higher number of qualified participants. However, the heterogeneity of the Asian ethnic subgroups also could have prevented us from reaching saturation.

**Conclusion**

Consistent with the literature, we found similar and different views regarding health care and preventive screening among Asian sub-groups. Our results demonstrate that a one-size-fits-all approach to health education is unlikely to be successful in increasing preventive cancer tests and screenings among Asian American women in Massachusetts. Health care provider attitudes towards patients and how they educate patients can help women, regardless of ethnicity, have a positive experience about receiving health care and screening tests. Specifically, educating patients about the free cost of breast and cervical cancer screenings may increase utilization.

Participants expressed a desire for messages and reminders for attending screening appointments. They also expressed misconceptions and gaps in knowledge about the need for screening, regardless of ethnic subgroup. There is a need to provide education that reaches this audience and providing it on a broad level so that it reaches the family members who may then push other family members for preventive care; the most effective forms of education are a possible future direction for this research.

The study indicates the importance of two areas worthy of future research that may extend well beyond the Asian American population under study. One is the lack of knowledge about cost for preventive screening. This is important since it presents a perceived barrier that does not exist. Another is the confusion people have about who creates guidelines and how, which to trust since they change, and how much personal knowledge they need about current guidelines.
Study findings highlight participant preferences for intervention strategies. In addition to existing reviews, additional qualitative research could reveal promising approaches in culturally relevant, community-based interventions to increase utilization of preventive screenings among Asian American women. However, given the diversity of Asian American women, more focus groups in other parts of Massachusetts are needed. Specifically, a mixed-methods survey conducted within a defined and targeted geographic area can help to develop a better and accurate understanding of screening experiences and barriers, and ways to reach and engage vulnerable communities. In spite of its limitations, our exploratory study contributes to existing literature on Asian American women’s health and lays a foundation for future research.

**Acknowledgements**

This research was funded by Tisch College Community Research Center at Tufts (TCRC). We thank the many people, especially members of the Asian community, who supported, guided, and participated in this work. We especially thank our focus group participants for their time and insights. We thank the research team for their significant contributions to this study.
Table 3: All focus group participant demographic and health care data

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1 Highlighted cells show non-qualified subjects
References


8. Massachusetts Department of Public Health, *MassCHIP. Massachusetts Community Health Information profile*. 2013, Massachusetts Department of Public Health: Boston, MA.


Appendix I: Recruitment script

You are invited to take part in a focus group to support our research project, Increasing Utilization of Preventive Care in Asian American Women in Massachusetts. Dr. Gualtieri, an Assistant Professor at Tufts University School of Medicine, is the study’s principal investigator, and she is responsible for running the study. The purpose of this study is to learn about the reasons Asian American women may or may not decide to be screened for breast cancer or cervical cancer—have a mammogram or have a Pap test.

To be eligible for the focus group, you need to be between the ages of 24 and 65 and have not had a pap test in the last 3 years, or be over the age of 52 and have not had a mammogram in the last 2 years.

We will use the results of the study to improve health care for Asian American women, and to share what we learn with other health professionals through reports, articles or presentations.

The focus group will last 1 ½ hours. In the focus group, we will ask you to talk with the group about your experiences and beliefs about getting health care, where you get your health care, and reasons why you may or may not get screened for breast or cervical cancer. We will keep all the information you give us private.

In order to make sure we can get all of your answers, we will record the discussion and once we transcribe it we will destroy the recording. At the end of the focus group, we will give you a $25.00 gift card to thank you for your time and help. There are no direct costs to you to take part in the focus group.

Taking part in this focus group is entirely your choice. If you decide to participate in this focus group, you can choose to stop taking part at any time for any reason. You can answer all of the questions or some of the questions.

Nothing you do or say will affect your health care or any other services you may receive. However, your answers will help us improve health care for other Asian American women in Massachusetts.

Are you interested in helping us? We need to ask some questions to see if you are eligible.

A) Are you woman who is Chinese-American, Vietnamese-American, or South Asian-American and has health insurance?
   a. If yes, continue with (B)
   b. If no, not eligible

B) Are you between 24 and 65?
   a. If yes, continue with (C)
   b. If no, you are not eligible.

C) Have you had a pap test in the last 3 years?
   a. If yes, continue with (E)
   b. If no, continue with (D)

D) Have you gone through menopause or had a hysterectomy?
   a. If yes, continue with (E)
   b. If no, you are eligible.

E) Are you age 52 or older?
   a. If yes, continue with (F)
   b. If no, you are not eligible.

F) Have you had a mammogram in the last 2 years?
a. If yes, you are not eligible.
b. If no, you are eligible.

What is your preferred language?

Would you join a focus group in English if we do not have one in your preferred language?
Appendix II: Recruitment materials (fliers and Facebook page)

Are you an Asian American Woman?

We are conducting a focus group study on how Asian American women use screening and preventive care services in MA and need your help! Involvement includes attending a 1.5 hour focus group.

To be eligible, you must be Chinese American, Vietnamese American, or South Asian American and between 24 and 65 years of age. For more information or to enroll, please contact Mardi Coleman at 1-508-340-6123.

For any general questions about the study, please contact Principal Investigator, Lisa Guenther, PhD, MAH at 617-636-6690.

Preventive Care In Asian American Women in Massachusetts

Are you an Asian American Woman?

We are conducting a research study to learn more about use of screening for preventive care and need your help. Eligible participants will receive a $25 gift card.

To be eligible, you must be Chinese American, Vietnamese American, or South Asian American and between 24 and 60. Involvement in this study includes attending a 1½ hour focus group.

For more information or to enroll, please contact:
- Chinese women please call Chinh-Di Huang at 1-508-747-0171.
- Vietnamese women please call Tran Ngoc at 1-617-556-1969.
- South Asian women please call Abid Anwar at 1-508-324-6783.

Are you an Asian American Woman?

We are conducting a research study on how Asian American women use screening and preventive care services in MA and need your help! Eligible participants will receive a $25 gift card.

To be eligible, you must be Chinese American, Vietnamese American or South Asian American between 24 and 65 years of age. Involvement includes a 1.5 hour focus group.

For more information or to enroll, please contact: Mardi Coleman at 1-508-340-6123.

For any general questions about the study, please contact: Principal Investigator, Lisa Guenther, PhD, MAH at 617-636-6690.
Appendix III: Focus Group Facilitation Guide
Updated 5/31/16

Why this guide was created
Increasing Utilization of Preventive Care in Asian American Women in Massachusetts is a community-based research funded by Tisch College Community Research Center at Tufts (TCRC). Our research goal was to learn about barriers to utilization of preventive care in Asian-American women in Massachusetts.

Since no prior studies identified barriers with this population, we needed to conduct research and selected focus groups as the most effective way to receive in-depth input from many people. In general, focus groups are one of the best ways of learning what people think about a topic or set of topics and have advantages over surveys and key informant interviews. While surveys may have more respondents, their responses are typically to multiple choice questions and there is no opportunity for the depth or response or for follow-up questions. While key informant interviews can be easier to conduct and schedule, the discussion between focus group participants can spur more views and more responses can be elicited in a relatively short time compared to key informant interviews.

This guide was originally created to train community partners in focus group facilitation and to serve as the guide for the actual sessions. Our goal, beyond our own use, is to provide guidance to plan and run successful focus groups. The format we used (question, probe, and rationale) can be used to run focus groups for other research studies.

Planning focus groups
Focus groups require significant planning to prepare a submission to the IRB and to recruit, organize, run, and analyze the actual focus groups.

Questions
Planning the questions, and having a good flow and timing are important. If you are provided questions, make sure you are comfortable with them. Anticipate any areas where there may be questions or misunderstanding and be prepared with explanations. Note that the purpose of a focus group is not to educate, but you can provide handouts during the session if they help explain a concept, or provide educational materials at the end.

Conceptually, focus group questions are designed in an hourglass shape. Start with an easy, introductory question that helps get participants thinking generally about the question. The first question should encourage people to talk about something they know about. Subsequent questions require more thought and are more focused on what you hope to learn. The most difficult questions should be embedded in the middle. Then go back to broader questions that participants can more easily answer, such as suggestions and recommendations. The final questions also serve as way to conclude the focus group discussion and capture any final thoughts that may have been triggered in earlier discussion.
Research team
There are two roles described here: the scribe and the facilitator. Other members of the research team are involved in planning and analysis but typically do not come to focus groups because the number of people running and observing should not outnumber participants! The possible exception is the study PI if not the facilitator and wants to greet and thank people.

Size
The optimal focus group is 6-8 people with some diversity in composition so that discussion is rich. In addition to the participants, there will be you, the facilitator, and a scribe to take notes about key points. While many people might be interested in the focus group process and findings, it is best to reduce the number of observers and research staff in the room to increase comfort for participants.

Length
The optimal length is between 1 and 1 ½ hours to make it easier for people to fit it into their calendars and to maintain attention during the session without a break. Our sessions below were scheduled for 1 ½ hours. All ended on time or early.

Recruitment
Recruitment is the hardest part of planning a focus group, and try all approaches possible to reach your target audience, as approved by the IRB. Even when people sign up, they may not show up. Incentives (cash or gift cards) are a great way to promote a focus group (without being coercive, increase the likelihood they show up, and thank people for their time.

For groups of 6-8, it is best to recruit 8-9 people because of attrition. As part of the recruitment process, it should be made clear to participants that they should come alone to the focus group, without children or other family unless you can accommodate others or provide child care. Reminder calls or emails before the session are helpful.

Location and equipment
Select a convenient location with easy parking and public transportation access. If parking isn’t free, ideally people should be compensated for parking. Sometimes, it is easier to plan a focus group in conjunction with or immediately following another event.

Ideally use a large rectangular or oval table with comfortable chairs. Sit at the head of the table, and seat participants around the table. If possible, provide snacks and drinks on a side table.

Use a recording device that you test in advance for audio quality and that can record the entire session - most smartphones can do this. Ideally use two recording devices if possible in case one doesn’t work, and place them in two locations of the table to make sure everything is captured.

Scribe guidelines
The scribe has three responsibilities: to turn the recording device(s) on and off, to take notes, and to help the facilitator if needed. The scribe should test the recording device(s) in advance
and turn them on unobtrusively at the beginning and off at the end. The reason to be unobtrusive is that, even though participants have agreed to be recorded, the goal is for them to be as comfortable as possible and they are less likely to be if they are thinking about what they are saying or that it is being recorded.

Although the sessions will be recorded and transcribed, the scribe’s notes are valuable for the facilitator and the research team. A scribe should be unobtrusive and sit at the back or the room, not at the table, so participants are less aware of the notetaking. Paper or a computer can be used, but make sure the keyboard is a quiet one. Time stamp notes so that they can be synced with the recording if needed. Use the numbers on name tags for identification. Don’t write everything but catch the key points participants make. Review notes with the facilitator immediately following a session.

Finally the scribe keeps track of the time and indicates to the facilitator if a pacing change is needed to make sure all questions are covered.

Facilitator guidelines
The most important things to keep in mind when you facilitate a focus group are that 1) a focus group is about the participant’s opinions not yours, and 2) you elicit their opinions best by being warm, friendly, respectful, and non-judgmental.

Practice helps to prepare and increases your comfort. Run a mock focus group if possible! Become familiar with the questions you will be asking, so that, even if you read them, you seem knowledgeable and don’t detract from the conversational tone of the focus group. If you have any questions about the focus group design, address them in advance.

Arrive early and be calm and prepared. Dress professionally to show respect for your participants. Project confidence since it will help put participants at ease. Greet participants as they arrive. Always thank people at the beginning, at the end, and during, when appropriate. They are giving their valuable time and valuable opinions! You need to do this even if you don’t agree with what they say.

When the focus group starts, in addition to your words, use your facial expressions and body language to show that you are listening and attentive, but not to show your opinions. Don’t take notes, but develop good rapport in advance with the scribe so you can visually indicate important points to capture. As facilitator, you should immediately enhance the notes or take your own following the session before you forget key insights.

Make sure you always know the time so you can pace well, cover all questions, and end on time. Don’t interrupt a discussion, but tactfully move it along. Repeating a point or summarizing it shows you are listening, as does nodding. A clock on the wall is the least obtrusive way to keep track of the time.

A little humor can help but be careful never to offend. Self-deprecating humor is best since it is least likely to offend. Make eye contact and nod so people know you are listening, if culturally
appropriate. Be cognizant of your body language as a way of making people comfortable. Ice breakers can be a good way to start off and make people comfortable.

As facilitator, you are balancing between, on the one hand, trying to get people to forget they are in the artificial setting of a focus group in order to be comfortable and respond openly to questions, and, on the other hand, reminding people that you are hoping for answers to your questions. The time this balance is most apparent is when some or all participants are talking too much, too little, or at the same time.

The following covers the worst fears of facilitators and advice and phrasing to use if they happen:

1. The worst fear of facilitators is that no one will talk. If that happens, ask people more direct questions but be careful not to be offensive. Find subtle ways to do this that don’t explicitly point out that the person has been quiet or that other people have been contributing more. A phrase to use if someone isn’t speaking: “Do you agree with what others have said? Perhaps you could add your own perspective to help us gain a better understanding.”

2. The second worst fear is that one person will dominate. If someone dominates, ask others how they feel or say how much you appreciate one person’s views but you hope to hear from others as well. Use the focus group agenda to help move on. Try not to interrupt someone but wait until they pause. A phrase to use if someone is too talkative: “It is great to hear about your experiences but I want to make sure we hear from others before we move on to the next question.”

3. The third fear is that people will give cursory answers. If that happens, ask probing questions to learn more. A phrase to use if someone doesn’t go into detail: “What you said is very helpful and it would be great to understand why you think that.”

4. Another problem is “group think”, when one person says something and everyone nods. Deal with that by summarizing what you heard and asking if there are other views.

5. Everyone talking at once is another problem that can be culturally appropriate but not helpful in a focus group. Try phrases like, “Let’s make sure I captured what you said” or “help me by saying this one at a time so I don’t miss anything.” With phrases like these you are putting the onus on yourself, rather than seeming critical of them.

6. A final problem is misinformation. A facilitator’s role is not to educate, but a brochure can be provided at the end with accurate information.

**Facilitator role plays**

Practice running a focus group using role playing before a focus group is scheduled. Assign roles to participants such as talking too much or too little to practice skills in managing participants. Also practice the facilitator welcome and focus group questions.
Before a focus group starts
When people agree to participate during recruitment, participants should be provided with an identifying number. Have a sheet of names and ask people to sign in as they arrive (this also provides a record for the gift cards), welcome them, and hand them a name tag that has their identifying number. If part of your IRB submission, ask participants to complete a form for demographic responses that uses each participant’s identifying number. This number is used for all references to the participant henceforth. Additionally, you may have consent forms that participants must sign before the session starts that say they are agreeing to participate and understand the session is recorded but that all recordings will be destroyed following transcription. Request that people turn off their cell phones for the duration of the session. Make sure the scribe turns on the recording devices.

The following is the script and questions from the series of focus groups we ran. The timings were used to guide pacing. The words in italics are what the facilitator should say. Rewording it is fine as long as the same point is made.

Facilitator welcome script (5 minutes)
Thank you for coming today.

As you know, we have asked you to come tonight and tell us about some of your experiences with getting health care, in particular, why you may or may not decide to get a mammogram or a Pap test—to get screened for breast cancer or cervical cancer. Your answers will help us learn how you feel about these types of screenings, which are known as preventive care.

We want to remind you that we will keep private what you tell us tonight. We are recording the meeting so we don’t miss anything you say. After we listen to the recording and are sure we have written down correctly what you each said, we will destroy the recording. All written records will be available only to the research team.

We ask that you respect the privacy of everyone who is taking part in the focus group. You are free to tell others that you took part in a focus group and what the focus group was about. But, we ask that you not tell others the answers or opinions of the other focus group members.

You can decide not to answer a question or leave the focus group before it is over. We hope to hear from all of you and appreciate that you are taking the time to help us.

A focus group is a conversation — one person’s answers may trigger a new thought or idea — the more you talk with each other about the questions we ask, the more we’ll learn.

There are no right or wrong answers. We want to know what each one of you thinks about why you may or may not choose to have a mammogram or Pap test so we can understand better how to help other women. We hope to hear from all of you and appreciate your time.

Do you have any questions before we start?
Participant introductions (5 minutes)
Ask each person to say a little about themselves, such as where they are from. Introduce
yourself and the scribe. Having everyone say their first name and identifying number helps with
voice identification in the transcription.

Questions (80 minutes)
1. What do you do when you have health questions or concerns? (10 minutes)
   Probes: see a doctor, go to the ER or a clinic, ask a friend, which websites do you start with
   Rationale: This is an easy question for women to answer. Everyone is an expert on this
   subject. It’s also a conversation starter. It sets the stage for the rest of questions.

2. Where do you go for your health care? Do you have a doctor or health care provider that
   you see when you are ill? How about for your physical exam or for regular care? (10
   minutes)
   Probes: Do you see a doctor, nurse, acupuncturist, or herbalist? Do you use the emergency
department or a clinic for care? Why do you have a regular doctor or health professional
that you see, or why do you not have one?
   Rationale: Factors most predictive of screening are having health insurance, having a regular
place of care, and having a regular doctor. Many people use a minute clinic, urgent care or
the emergency department when they need immediate health care (flu shot, antibiotics,
stitches, etc.) College age women and young women who are thinking about becoming or
are sexually active may use Planned Parenthood for their health and/or women’s health
needs.
   NOTE: Here are recommended timeframes for physical exams for women. Younger women
may not have a place they go for a physical, because they don’t need to have one.
   Health screening - women - age 18 - 39: 2 health exams during your 20’s and 30’s.
   Health screening - women - age 40 - 64 every 1-2 years, depending on your health status.

3. When you go to the doctor, does he or she remind you it is time to get a flu shot, tests or
   screenings? How do you prefer to receive reminders – text message, postcard, email, phone
call, or other? (10 minutes)
   Probes: Does your doctor mention what is recommended given your age?
   Rationale: another highly predictive factor for receiving any type of preventive care is
having your doctor tell you should have it.

4. What is the first thing you think of when I say mammogram? What is the first thing you
   think of when I say Pap test? (10 minutes)
   Probes: not sure what they are, embarrassment, fear of test, fear of results, not sure what
the terms mean, discomfort, worries about cancer
Rationale: We want participants’ reactions to these screening tests. Some may not know what the tests are and that is fine. The next question gives participants specific information about the tests. The answers help us understand some of the barriers to screening.

5. Provide descriptions of what a mammogram and Pap test are. Pass around sheets with a description and images and make sure they are in the language of the focus group.

Has anyone talked to you about having a mammogram or pap test? Did you have a mammogram and do you remember when the last one was? Did you have a Pap test and do you remember when the last one was? (10 minutes)

Follow up questions: If mammogram or Pap test in the last 2 or 3 years: Did your doctor or another health care provider schedule an appointment for you? What helped you get tested?

Probes: Some issues might be scheduling, health professional explained tests, mobile mammography unit, Pap test is part of physical exam, materials are easy to read, someone comes with me to my appointment

Note: some women will not have had a mammogram because of age.

Rationale: We want to know situations that help women get screened. Having your doctor tell you it’s time for screening, or scheduling your screening test increases the likelihood you will follow through on screening.

6. Health care recommends that women get a mammogram every other year once they turn 50 and a Pap test every three years once they turn 21. Have you heard the recommended guidelines before? If you didn’t have a mammogram or Pap test ever or in the last few years following the guidelines, what are the main reasons? Do you know how to get one? (10 minutes)

Probes: Some of the reasons people don’t get screening include fear, embarrassment, pain, time, cost, not sure insurance covers it, don’t understand what’s involved, don’t know how to get one, language, culture, location

Rationale: This is the meat of our focus group. This information helps us think about what barriers exist. We’ll use some of this information in our wrap up questions.

7. Does anyone in your family get a mammogram or Pap test? How does that effect whether you get screened? (5 minutes)

Probes: Does your mother or sister? Do your friends?

Rationale: We got some really good information from this question at our focus group training and we’d like to learn more about this.

8. In Massachusetts, Asian American women have lower rates of getting mammograms and Pap tests. You’ve told us about a lot of reasons why you might not get a mammogram or
Pap test. What do you think are the biggest barriers to Asian American women getting a mammogram or a Pap test? (5 minutes)

Probes: Language, culture, someone to go with you

Rationale: We are closing out the session. Questions 8-10 are broader and less charged. It is always good to close out a focus group by asking people their advice.

9. Thinking about all that you have told us about reasons you may or may not get screened for cancer, what is your best advice for us to help women like yourselves to have mammograms and pap tests? (5 minutes)

10. Is there anything else you think we should know? (5 minutes)

Facilitator closing

Thank you for your help and time today. As a reminder, please do not share anything you heard from other participants in the focus group – please help us in keeping the confidentiality of this focus group.

Hand each participant a gift card. Thank them individually as you hand out gift cards.

Debrief with the scribe about both the focus group process and content, and capture key points that were made.

Facilitator and scribe review

Both the facilitator and scribe, as soon as possible following the conclusion of the focus group, should summarize what they learned. The following is the table we used.

<table>
<thead>
<tr>
<th>Name and role: recruiter, facilitator, scribe, or observer</th>
<th>Focus group recruitment, process, and learnings</th>
<th>What did you do and learn? Please complete below using your notes and impressions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment: when and where were you recruiting</td>
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<tr>
<td>Recruitment: what didn’t lead to qualified participants and why</td>
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<tr>
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<tr>
<td>Focus group process</td>
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<td>Focus groups description of participants, location, and date</td>
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<tr>
<td>For each of the following questions, what did you learn as facilitator or scribe and was it from all or some participants</td>
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<tr>
<td><strong>Introduction</strong></td>
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<tr>
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</table>
mammogram or Pap test. What do you think are the biggest barriers to Asian American women getting a mammogram or a Pap test?

Thinking about all that you have told us about reasons you may or may not get screened for cancer, what is your best advice for us to help women like yourselves to have mammograms and pap tests?

Is there anything else you think we should know?

Profile of research team

Role(s) you played

What was easy/rewarding?

What was difficult/frustrating?

What you learned?

Next steps you would like to be involved in, e.g., seeking funding, developing survey, presenting findings, writing journal paper
Appendix IV: Presentation to TCRC 040816

Increasing Utilization of Preventative Care in Asian American Women in MA

Research Team

PI: Lisa Guaitieri, PhD, ScM, Tufts University School of Medicine
Co-I: Chien-Chi Huang, Asian Women for Health
Community partner: Tam H. Nguyen, PhD, MSN/MPH, RN, Boston College School of Nursing
RA: Mardi Coleman, MS
Community Partners, Research Assistants, Facilitators, And Scribes:
- Gouth Banerjee, PhD, Sanofi Boston
- Tanana V. Little, MS
- Priyanka Gupta, MPH
- Wei (Can) Chen, MS
- Hien Vu
- Kristen Daudelin
- Daryl Manoosing, MPH
Mentor: Karen Freund, MD, MPH
Preventive Care

- Preventive services are an effective way to screen for disease and reduce the burden of disease through early detection
  - Example is mammography for breast cancer screening

- The Patient Protection and Affordable Care Act (ACA) mandate
  - Universal health insurance coverage
  - Health plans offer mammograms and Pap tests free of charge

Why are screening rates lower?

- We report on community-based research to explore factors influencing breast and cervical cancer screening behaviors among Asian American women in Massachusetts

- Despite high rates of health insurance, screening rates are lower than other ethnicities and we sought to learn why

- We conducted focus groups with Chinese, Vietnamese, and South Asian American women in MA
Barriers to Utilization of Preventive Care

- Primary care physicians (PCP) perceive barriers to screening
  - Patients: lack of knowledge, motivation, fear, and embarrassment
  - Physicians: lack of belief in test efficacy
  - Practices: time constraints
  - System: lack of or inadequate insurance and co-payments

Asian Americans in Massachusetts

- Preventive care
  - Asian Americans in MA have lowest rates of participation in preventive activities and breast and cervical cancer screenings
  - Even lower for low income and recent immigrants, also for certain ethnic groups: Vietnamese American

- Yet Asian Americans in MA are well-covered by insurance
  - Only 3.1% Asian American are without insurance compared to 3.4% for Caucasian, 6.8% for African-American, and 10.6% for Hispanic (2012)
Problem Statement

- We aim to explore why there is this disconnect between Asian American women having health insurance but not receiving screening for breast and cervical cancer at commensurate rates.
- Since access to care and being covered by insurance are not barriers to preventive health services for Asian American women in MA, what are the barriers?
- If we can identify barriers, we can start to address how to increase cancer screening.

Developed Set of Research Questions

1. What are the barriers (e.g., lack of knowledge, motivation, fear, embarrassment) for Asian American women to utilize preventive health behaviors and screenings, particularly screening for breast and cervical cancer?
2. How do Asian American women make health decisions and what are the factors that influence their decision making?
3. What is the level of health literacy for breast and cervical health?
4. Do barriers differ across the specific ethnicities that comprise Asian American women, particularly Chinese, Vietnamese, and South Asian women?
5. What people, programs, activities, or interventions can facilitate increased awareness and utilization of preventive services?
Funding

- Primarily funded by a grant from Tisch College Community Research Center at Tufts (TCRC)
- Dr. Tam Nguyen provided additional support, which covered the cost of gift cards for focus group participants and food at focus groups and training meetings
- Guided by the principles of community-based participatory research (CBPR)

Methods

- Project is formative and exploratory in nature
- Used qualitative methods – focus groups – to understand cultural and non-cultural barriers that influence Asian American women’s utilization of preventive services
- Ran 4 focus groups accounting for language and ethnicity with:
  - Chinese American women
  - Vietnamese American women
  - South Asian American women
To prepare

- Received exemption through Tufts Medical Center and Tufts University Health Sciences Institutional Review Board (IRB)
- Developed and refined **Focus Group Facilitation Guide**
  - How to plan and run focus groups and roles of facilitator and scribe
  - Welcome and closing scripts, questions, timing, and prompts
- Ran focus group facilitator trainings including role plays
- Developed and delivered IRB-approved CITI training to community partners
- Developed **recruitment script and recruitment materials**

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**Focus Group Facilitation Guide**

- **The worst fear of facilitators is that no one will talk**
  - A phrase to use if someone isn't speaking: “Do you agree with what others have said? Perhaps you could add your own perspective to help us help other women.”

- **The second worst fear is that one person will dominate**
  - A phrase to use if someone is too talkative: “It is great to hear about your experiences but I want to make sure we hear from others before we move to the next question.”

- **The third fear is that people will give cursory answers**
  - A phrase to use if someone doesn’t go into detail: “What you said is very helpful and it would be great to understand why you think that.”

- **Another problem is “group think”, when one person says something and everyone nods**
  - Summarize what you heard and ask if there are other views.

- **Everyone talking at once is another problem that can be culturally appropriate but not helpful in a focus group**
  - Try phrases like, “Let’s make sure I captured what you said” or “help me by saying this one at a time so I don’t miss anything.” With phrases like these you are putting the onus on yourself, rather than seeming critical of them.

- **A final problem is misinformation**
  - Our role is not to educate here, but we can provide a brochure at the end with accurate information.
Recruitment

- We recruited Asian American women from three ethnic groups: Chinese-American, Vietnamese-American, and South Asian-American

- The ability for participants to speak English was not a requirement
  - We trained Mandarin- and Vietnamese-speaking focus group facilitators, who all used the same Focus Group Facilitation Guide

<table>
<thead>
<tr>
<th>Screening test</th>
<th>Age 24-51</th>
<th>Age 52 or older</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Pap test in the last three years</td>
<td>Eligible</td>
<td>No. Cut-off to facilitate ease of recruitment</td>
</tr>
<tr>
<td>No mammogram in the last two years</td>
<td>Not eligible, screening starts at age 50</td>
<td>Eligible</td>
</tr>
</tbody>
</table>

Challenging to Recruit

- We recruited focus group participants through the networks and affiliations of community partners
  - Boston-based Asian Women for Health (AWFH)
  - Indian-American group Sahali
  - Networks of Dr. Tam Nguyen, who works closely with the Vietnamese community

- Asked them to post and distribute flyers both in paper, on websites and apps, email distribution lists, brief their members

- Used social media, including a study-specific Facebook page, [http://facebook.com/TuftsStudy](http://facebook.com/TuftsStudy)

- Recruited at local events, including fliers at tables at local health fairs and Asian community events
25 Participants in the 4 Focus Groups

<table>
<thead>
<tr>
<th>Date conducted</th>
<th># of participants</th>
<th># of qualified participants</th>
<th>Primary ethnicity</th>
<th>Language conducted</th>
<th>Age range</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>FG1: 10-11-15</td>
<td>9</td>
<td>0 (8 current mammogram; 1 not reported)</td>
<td>Vietnamese</td>
<td>Vietnamese</td>
<td>57-74</td>
<td>Randolph</td>
</tr>
<tr>
<td>FG2: 11-01-15</td>
<td>5</td>
<td>4 (1 no health insurance)</td>
<td>Chinese</td>
<td>Mandarin</td>
<td>25-56</td>
<td>Boston</td>
</tr>
<tr>
<td>FG3: 11-06-15</td>
<td>4</td>
<td>4</td>
<td>SE Asian</td>
<td>English</td>
<td>24-53</td>
<td>Boston</td>
</tr>
<tr>
<td>FG4: 11-09-15</td>
<td>7</td>
<td>5 (1 no health insurance; 1 current Pap test)</td>
<td>Chinese</td>
<td>Mandarin</td>
<td>34-53</td>
<td>Boston</td>
</tr>
</tbody>
</table>
Barriers contributing to lack of adherence to screening guidelines (1)

- Literature identifies barriers such as culturally insensitive/incompetent providers, which we found too
- Some factors we identified included
  - Not having the time
  - Not knowing why the tests are necessary
  - Not wanting to go to the doctor when you feel healthy
  - Not wanting to know if you are sick

Barriers contributing to lack of adherence to screening guidelines (2)

- Additional factors we identified included
  - Lack of knowledge about risks and benefits
  - Lack of knowledge about how screenings are conducted and whether they are painful
  - Concerns about impact of screening on virginity
  - Confusion about recommended ages for screening including misconceptions about the relationship between sexual activity and screening guidelines
  - Misconceptions about cost of screenings and not knowing if the tests are covered or covered in full by their health insurance
Broader issues

- Midway through our focus groups, on October 20, 2015, American Cancer Society mammography guidelines changed
- Served to highlight confusion about
  - Recommended ages for screening
  - Misconceptions about the relationship between sexual activity and screening guidelines
  - Who creates guidelines and how, and why are they always changing
- Misconceptions about cost of screenings
  - Given the number of barriers to screening adherence, shouldn’t cost be removed since it is no longer a barrier?

Today and tomorrow

Increasing Utilization of Preventive Care in Asian American Women in Massachusetts

Final Report: Submitted to Tufts College Community Research Center at Tufts

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- Kristina Dejardin
- Randi Marquardt, MPH

Mentor:
Karen Freund, MD, MPH

- Focus group facilitator training
- Develop, test, and deploy educational materials to reach
  - Patients
  - Caregivers
  - Providers
- Further discussion with Doug Brugge and Karen Freund
- Drafting paper to Journal of Immigrant and Minority Health