Published in final edited form as:
*J Cancer Educ*. 2012 December ; 27(4): 641–648. doi:10.1007/s13187-012-0423-3.

# Opportunities to reduce cancer barriers: Community town halls and provider focus groups

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## Abstract

This paper presents the findings from town hall meetings held with community residents and focus groups with healthcare providers. A total of five town halls (N=139) were conducted. Four were conducted in English and a fifth was conducted in Spanish to obtain the input of the local Hispanic community. Surveys were provided to town hall participants to assess their perceptions of cancer and screening as well as their cancer screening behaviors. Participants were asked questions designed to determine local gaps and needs in health and cancer care, and their attitudes regarding breast cancer resources, education, treatment and clinical trials. Additionally, four focus groups (N=45) were held with a wide range of providers to obtain their perspectives on barriers to breast cancer screening, local cancer prevention and care, and clinical trials. Results indicate gaps in local resources and support services, particularly in terms of education and integrated care.

## Introduction

Petersburg, Virginia is a vastly underserved area characterized by a declining population and high rates of poverty [14]. In comparison to the rest of the state, the Crater Health District, which includes Petersburg, has significantly higher mortality rates for breast, colorectal and lung cancers, fewer cancer diagnoses at the local stage, and a lower prevalence of screening behaviors [17]. In an effort to understand the contextual reasons undergirding cancer health disparities in this community, Project C.H.A.T. (Community Health Action Team) was established to conduct a cancer needs assessment in the area. C.H.A.T.'s long-term goal is to design and implement a cancer education program that is responsive to identified needs as it relates to cancer beliefs and attitudes and early detection, as well as breast cancer prevention, treatment, survivorship and research, in particular. To accomplish these goals, C.H.A.T. worked in close collaboration with Paint it Pink Petersburg, a community coalition composed of key government agencies, community organizations, local mammography

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centers, and state and local non-profit organizations. Multiple methods, including town hall meetings and focus groups, were used.

This paper presents the findings from town hall meetings with residents and focus groups with healthcare providers. Town hall meetings were chosen as an effective means for reaching large groups of local residents, men and women, while focus groups would be more feasible for recruiting health care professionals. In recent years, town halls have been used to obtain community opinion regarding a wide array of health concerns, including fetal alcohol spectrum disorders and asthma [18, 11, 19], as well as cancer [1, 7]. For example, town hall and focus groups data have been used to make major recommendations for increasing mammograms among black women [1].

## Research design

### Town halls

Five town halls were conducted. Four targeting the English speaking population were conducted in English. The fifth town hall targeted the small but growing Hispanic community and was conducted in Spanish [15]. Data collected during the town hall meetings included notes taken during the discussions and a survey completed by participants. The town hall and survey questions were translated into Spanish for the Hispanic town hall meeting. For verification purposes, all Spanish materials were back translated into English.

**Recruitment—**Petersburg is 79% African American [15], and the town halls reflected this demographic. Anyone over the age of 18 was invited to attend. The Community Health Educator recruited participants for the town halls primarily by posting flyers and establishing contacts through community representatives and organizations. The Paint it Pink Petersburg advisory board member played a significant role in assisting with recruitment. In addition to targeting neighborhoods and community groups, we used a snowball method. Community leaders and participants invited other members of their groups and communities to attend the town halls. We received IRB approval and a waiver of written informed consent. No identifying information was collected and no individual stipend was provided. Recruitment for the Hispanic participants was done exclusively from the church where the Hispanic town hall was held.

**Town hall meetings—**Surveys were administered at the beginning of each town hall and a cancer survivor gave a brief testimonial the end of each meeting. The four English town hall meetings were held at community locations, including a Parks and Recreations facility, the Department of Social Services, the local Food Bank, and a local civic club. The Hispanic town hall was held at a church that had a predominantly Spanish-speaking congregation. A select number of raffles were drawn at the town halls, and light refreshments were offered at all meetings.

Town hall meetings were facilitated by two experienced moderators. Moderators utilized a facilitator guide which included questions about (1) general health concerns in the community; (2) gaps in local breast cancer; (3) attitudes related to breast cancer resources, early detection, and treatment; and (4) attitudes toward clinical trials. Two research staff took detailed notes during the sessions. The research team met and provided written debriefing reports after each meeting, identifying the main discussion items from the town hall.

**Instruments—**The town hall survey assessed demographics, basic attitudes about cancer, and knowledge of cancer screening guideline and cancer resources in their community.

Questions examined perceptions of cancer in the community included, for example, “When compared to other health problems, how important is cancer?” Questions of screening knowledge and habits included, “At what age should a person first be screened for colorectal cancer?” and “Has a doctor recommended that you be screened for colorectal cancer?” All participants were asked questions about colon cancer, while women were asked additional questions about breast cancer.

**Data analysis—**Descriptive statistics from the survey data were obtained using SPSS version 19. For the qualitative town hall data, two coders independently read the notes taken by the research staff during the meetings. Each coder identified emerging codes and themes, then grouped these codes and themes by question and town hall location. The coders compared their summaries of codes and themes. Similar codes and themes were consistently identified. Discrepancies were resolved by a third coder who reviewed both the codes and the definitions.

The final data summary was used to create a condensed list of the major overlapping themes across the four English-conducted town halls. At each step of the data analysis process, there was discussion and consensus building around the emerging themes. The Hispanic town hall’s data analysis was completed in the same manner and we included a Spanish speaking coder. This analysis method has been utilized by other studies which included qualitative and survey data [10, 19].

### Health care providers

Four focus groups were conducted with providers who delivered health care services to breast cancer survivors and/or their families. The range of service providers included medical, radiation, pharmacy, oncology, mental health and social. We received a waiver of written informed consent from the IRB.

**Recruitment—**An open invitation was extended by the community health educator to providers via word of mouth, flyers, emails and face to face meetings. Sites or organizations where participants were recruited included hospitals, clinics, oncology groups and the Black nurses association. Once initial contact was made, a snowball method of recruitment occurred. Contacted providers reached out to others in their network.

**Focus groups—**The community health educator moderated the sessions. The facilitator guide included questions related to: (1) barriers and facilitators to breast cancer screening; (2) providers’ needs for delivering better care and services to cancer survivors and their families; (3) provider perspectives of community cancer needs, and differences by race and class?”; (4) provider perspectives about cancer prevention and care; and (5) provider attitudes towards clinical trials. Probes included, for example, “As a service provider, what are your needs in terms of providing better care to cancer patients and their families?” Notes were taken by two team members. The focus groups were conducted at one of the clinics or hospital of a participating member.

**Data analysis—**Codes and themes were identified using the notes taken during the focus groups. Two coders independently completed their data summaries of initial themes. Coders met to refine and finalize the codes. Agreement was high among the coders. The same process followed as described for the town halls. Themes from the town hall and provider data are discussed separately below.

# Results

## Surveys

**English speaking town hall—**The majority of those in attendance (95%) completed the surveys. Surveys were collected from 112 respondents from the four town halls. For some questions, not all 112 participants provided a response. The ages ranged from 20 to 80 or older. Almost half of the participants (n=55) were ages 40 to 64. The majority were female (n=98, 86%) and African American (n=102, 91%). Of the 99 who responded, 30% (n=30) reported earning less than $10,000 a year, and 42% (n=42) earned between $10,000 and $30,000 a year. Of the 101 who responded, 51% (n=52) reported living in a single-person household, though the average household size was 2.01 (*SD* = 1.43). Participants were also asked to report their health insurance plan (Table 1). Medicare was the most common type of health care coverage. Thirteen people reported having no health insurance. The majority indicated going to a private physician for their regular health care needs (Table 1).

**Cancer-related knowledge, beliefs and behavior:** Thirteen percent (n=14) reportedly have had cancer and 31% (n=35) have taken care of someone with cancer. Seventy-three percent (n=82) indicated knowing someone who has had cancer, and 8% (n=9) have neither had cancer nor known anyone who has had cancer. Two questions assessed the importance of cancer in the community. Of the 102 who responded, almost 70% (n=70) believed that cancer is a problem in their community. Eighty-four percent (n=92) of the 109 who responded indicated that cancer was extremely important in the community compared to other health problems, while only 3% (n=3) indicated that it was not important at all.

The vast majority of the 109 who responded (n=107, 98%) believed that cancer screening helps reduce cancer deaths. However, 43% of the 108 respondents said they did not know the age at which colorectal cancer screening should begin, and no one correctly responded that the first screening for colorectal should occur at age 50. Although, 19% (n=21) said it should occur at age 51. Female respondents were asked about the age for a first mammogram and, of the 95 participants who responded, 18% (n=17) said they did not know. No one correctly responded that the first screening should occur at age 40; though 28% (n=27) said it should occur at age 41.

Over half (n=61, 55%) indicated the doctor had recommended they be screened for colorectal cancer. Only 8% (n=5) said they did not follow the recommendation, due to fear and lack of insurance. Ninety-two percent (n=54) indicated following the doctor’s recommendation, and two did not respond.

Ninety-eight female participants completed questions related to breast cancer. Of the female respondents with known ages of 40 or older (n=84), the majority (n=78, 93%) had had a mammogram. Eighty-four women (86%) reported receiving a doctor recommendation to get a mammogram. Seventy-four (88%) followed through on the recommendation, seven (8%) did not, and three did not respond. Insurance was a deterrent for the seven who did not follow through. Of the 94 respondents, 86% (n=81) knew of a community location to get a mammogram.

**Hispanic town hall—**Surveys were collected from 27 participants attending the Hispanic town hall meeting. More than half were male (n=15, 56%). The majority were ages 20 to 39 (n=13, 48%) and 40 to 64 (n=12, 44%). One participant was over 64 and one did not respond. Of the 26 who responded, 46% (n=12) reported earning less than $10,000 a year, and 46% (n=12) reported an annual income between $10,000 and $30,000. The majority (n=19, 70%) indicated living with four to seven people in the same household (Mean=5.7, SD=2.28). Seventy-four percent reported not having any health care coverage (Table 1).

More than half (55.5%) reported using a community health clinic for their regular health care needs, with only 30% using a private physician (Table 1).

**Cancer-related knowledge, beliefs and behavior:** Only one participant indicated having had cancer, and five reported taking care of someone with cancer (19%). Forty-one percent (n=11) knew someone who had cancer, and 48% (n=13) had neither had cancer nor knew anyone who had cancer. Similar to the Non-Hispanic town halls, the majority (n=24, 89%) indicated that cancer is a problem in their community, and most (n=21, 78%) felt that cancer was extremely important relative to other health problems in the community.

The vast majority (n=25, 93%) agreed that screening helps to reduce cancer deaths. Forty-four percent (n=12) did not know the age when a person should first be screened for colorectal cancer, and no one correctly indicated 50 as the recommended age. Although, 15% (n=4) did indicate age 51. Five (19%) said their doctor had recommended they be screened for colorectal cancer, and four (80%) indicated following the recommendation.

Of the 12 females in the sample, none correctly indicated 40 as the recommended screening age for breast cancer; although three indicated age 41. Five (71%) of the seven women 40 or older had had a mammogram. The participants who reported receiving a physician recommendation to get a mammogram (n=5) were 40 or older, and four (80%) complied with the recommendation. Distance to the screening center, lack of a Spanish speaking doctor, and cost were reasons for the one participant not following the doctor’s screening recommendation. The majority (75%) did not know where to go to get a mammogram in the community.

## Town hall themes

At the beginning of each town hall, participants were asked to list their community health concerns and provide cancer with a ranking on the overall list. All groups stated that it would be high on the list; always within the top four health concerns, but never the leading concern. Many other health concerns were cited, including diabetes, AIDS and arthritis. When asked about general community health concerns, participants of two of the town halls focused on how men’s health concerns are often overlooked. The importance of focusing on men’s health was emphasized, as well as how women’s health often suffers because they tend to focus on other family responsibilities. Results from the Hispanic town hall had similarities and differences to those from the English speaking town halls. They expressed similar community needs in terms of education, transportation, support and finances, as well as a fear of cancer screening tests and diagnosis. They also indicated similar perceptions of clinical trials; although they indicated more willingness to participate. However, there were notable differences which are highlighted after the discussion of the major themes of the English town halls.

### English speaking town hall themes

**Cancer education and support:** Participants from all English-speaking town halls consistently mentioned the need for more education and support services. They indicated they would like information on cancer prevention and symptoms, along with education on nutrition. Barriers to care included a lack of financial support, adequate insurance, transportation and/or access to proper care. All groups stated that cancer patients need a great deal of support for themselves and their family. They emphasized a need for information regarding changes in appearance, as well as support and advice from a cancer survivor.

Participants indicated that they would like local cancer programs to be offered by members of the community. Members of one particular town hall wanted to see African American community members leading local programs. They also wanted educational materials to be easily accessible. Methods for doing this included placing materials in non-traditional locations, such as gas stations.

**Dissatisfaction with local care and resources:** The majority of attendees expressed a mistrust of the local medical community. There was an overall dissatisfaction with access to, and receipt of, medical care. Several provided personal negative experiences with misdiagnoses and with medical providers. For example, “They told my husband his pain was in his mind…he died six weeks later from bone cancer.” Many believed they did not receive adequate medical care because of certain stereotypes or stigmas that physicians associated with local residents. They specifically mentioned the “white flight,” which they said included competent physicians leaving the community. Another common theme was the need for improved communication between doctors and patients.

**Lack of knowledge regarding clinical trials:** Participants in every town hall associated clinical trials with being used as a human guinea pig. Participants cited fear of side effects (e.g., “Might wake up the next morning with a thumb growing out of your head”), receiving a placebo instead of treatment (e.g., “My heart is bleeding” for those receiving placebos), and having to sign away your rights (e.g., “If you aren’t offering the money offer the protection. I’d rather have the protection”). Many also believed that some in their community use clinical trials as an alternate source of income. For example, “A lot of people do it for financial gain.”

**Hispanic town hall themes—**The major additional themes that emerged from the Hispanic town hall included economic burden, cultural concerns and barriers to women’s health.

**Economic burden:** The lack of insurance and cost of medical care were indicated as the most important concerns related to women’s health, and were highlighted within the context of cancer survivors and their family. Additionally, the need to maintain employment and fear of losing a job for requesting time off were expressed barriers to participation in clinical research. Support of the extended family was emphasized as important for cancer survivors.

**Cultural and language concerns:** The language barrier was emphasized as a major difficulty in obtaining healthcare. There was a need for culturally and linguistically tailored resources and support, including the need for health information in Spanish and the need to communicate with medical professionals in Spanish. They also indicated the need for services that were tailored to specific Hispanic cultures, such as Mexican, Guatemalan or Columbian.

**Barriers to women’s health:** Finally, the barriers to acquiring healthcare for women were multiple, including finances, transportation and communication. When asked about the major concerns in the community relevant to breast cancer, one participant stated, “Everything related to having it – how to get to treatment, lack of transportation, how to communicate with the doctors…”

### Provider focus group themes

Forty-five providers attended one of four focus groups ranging from nine to 14 attendees each. The range of health care providers who attended included representatives from hospice and home care groups, mammography imaging centers, oncology centers and offices, local hospitals and the local university.

**Primary barriers to screening—**Primary barriers to breast cancer screening were associated with the lack of access to care and transportation, financial assistance, and lack of education. Provider groups focused on the personal responsibility of the patient in accessing resources. Three groups mentioned the patients' fear of cancer, diagnosis, or screenings. Providers also indicated that patients are not future oriented in relation to health concerns. There was a perception across the provider groups that patients are not interested in prevention. Three of the four groups stated that patients do not typically come in for regular check-ups, but rather wait until they are feeling ill or showing symptoms of illness. Providers in all groups stated that patients need to take charge of their own bodies, ask questions, and ensure that they get the answers they need from their physicians. One provider stated that he did not "want to put all responsibility on physicians, because it's not just their responsibility," while another stated that patients "don't take responsibility for their own health."

All groups mentioned that women seek medical help more readily than men. They also mentioned the needs of the Hispanic population in terms of access to care, financing, language barriers, and issues related to immigration status. Some providers expressed the belief that for certain populations, particularly of lower socioeconomic status, there is an element of shame in being diagnosed with cancer and having to ask for help. They also discussed how the elderly often need a stronger support system and are sometimes not treated as aggressively as younger patients.

Providers also indicated that there was a lack of education and information regarding the availability of local resources or support services for patients, including those that are financial. Providers cited not knowing where to send uninsured patients for screenings or treatment locally. Three of the four groups also mentioned poor patient-provider communication and a lack of personal relationships between patients and physicians.

**Lack of integrated care—**In relation to the needs of providers for providing better care, groups consistently mentioned the lack of local integrated and coordinated outreach efforts. The provider groups expressed a need for some type of designated patient navigator, which would benefit both patients and providers. Providers also indicated a need for more support services to assist patients. They stated that those working in healthcare, particularly physicians, often do not understand cultural barriers between themselves and particular populations. They suggested cultural competency training to alleviate some of these barriers and to improve doctor-patient communication.

Providers suggested a model of care that integrates medical care and education at one visit to aid in cancer prevention and screening. They also suggested doing more direct outreach to neighborhoods. However, while providers had suggestions for improving cancer prevention and care, they also expressed an overall sense of despondency regarding patient efficacy. All groups discussed their struggles with patients' non-compliance in detail. They indicated it is difficult for to get patients in for their screenings and follow-up appointments. One provider stated, "All I can do is tell her she needs to go," another that "if I find a lump I'm telling them to get an ultrasound…they are not going to get it."

**Clinical Trials—**Providers expressed that clinical trials should be made more available. They stated there are many misconceptions regarding clinical trials- even among providers- and that there is a need for more education for patients and providers on available trials.

## Discussion

Town halls with English and Hispanic speaking residents and focus groups with a range of health care providers assessed specific needs related to breast cancer disparities. The vast majority of participants across all town halls believed cancer was a major problem in their community and was an important concern. While they recognized that early detection of cancer can help save lives, no town hall participants correctly identified the appropriate age to begin regular screenings. The confusion about the correct age may be related to a lack of knowledge or could be reflective of some of the public discourse about the appropriate screening age and tests specific to some cancers. For example, specific to breast cancer, in November 2009, the US Preventive Services Task Force (USPSTF) released updated breast cancer screening recommendations [16] that triggered controversy and extensive media coverage [12]. Nevertheless, it is important to note that the majority who indicated that they received screening recommendations from their physicians followed through and obtained a screening. These results highlight the need for physicians to make screening recommendations when patients are in their office. Patients are likely to follow physician recommendations despite any confusion that may be caused by contradictory screening guidelines or lack of knowledge. Other research examining the use of mammography in Latina women also noted the importance of physician recommendation in whether or not women get screened for breast cancer [9].

Town hall results suggest that fear of screening and knowing that they have cancer affects women’s preventive behaviors. Multiple studies with African American and Hispanic women have noted the impact of fear on cancer screening [5, 3, 6, 4]. One study in particular highlighted that Latina women indicated higher levels of fear with regard to clinical breast exam screening in comparison to Caucasian women (Flynn, Betancourt, & Ormseth, 2011). This increased fear can impact subsequent clinical breast exam compliance.

Most of the town hall participants were low-income, with the majority indicating that they made less than $30,000 per year and many of those reporting an annual income of $10,000 or less. A larger percentage of Hispanic town hall attendees did not have health insurance. Further, a larger proportion of female Hispanic town hall participants were unable to identify where they could obtain a mammogram. This is of concern but not surprising given some of the other barriers mentioned. Furthermore, insurance status is one of the principal determinants of breast cancer screening, and this relationship is mediated by access to physician services as well as a physician’s recommendations to be screened [9].

Both groups emphasized a pronounced lack of available materials about cancer prevention, treatment and resources in their community. Hispanic participants also indicated a notable absence of cancer literature in Spanish, and emphasized the need for information in Spanish to recognize the ethnic diversity within the Spanish-speaking community. A limitation of this study is that we did not collect information about country of birth.

In addition to the major language barrier, the Hispanic town hall participants highlighted the significant economic barrier to both the individuals who seek preventive care or treatment as well as their family. Several suggested that language and economic barriers as well as immigration concerns cause a level of social isolation, which is further aggravated by a lack of knowledge about cancer and how it can be treated when detected early. The lack of extended family and social network support beyond that of the spouse and children was a concern. Research examining social support and breast cancer screening found that being Latina and born outside of the United States were associated with lower reported levels of social support [8]. Importantly, women reporting less social support were less likely to adhere to screening guidelines [8]. The overburdened role of Hispanic women within the family was also discussed as a barrier to seeking preventive care. Previous research suggest that parents in immigrant families may neglect their own health needs, so they can focus on their children's prosperity [2, 13]. Women, in general, may be more likely to focus their attention on the needs of their partner or children rather than their own health needs. This issue was similar to what English town hall participants discussed regarding men neglecting their health.

The majority of participants indicated that local health services were inadequate due to what they perceived as insufficient and poor quality of care. Participants suggested that their perception of the poor quality of health care and limited resources in this city was partly due to the changing racial demographic and the upsurge of providers born in other countries. Both the English and Spanish-speaking groups expressed a strong need for improved patient-physician communication. Furthermore, there was an overall lack of knowledge about clinical trials with several attendees providing specious information about trials.

Provider data, in several ways, corroborated findings from the community meetings. Providers indicated that the local health care delivery system was not comprehensive and needed coordination. They acknowledged both the dearth of patient resources as well as the many patient-level barriers. However, they underscored the importance of patient responsibility and their own frustrations with helping patients engage in regular preventive behavior, especially when certain resources were available. Finally, providers, with the exception of oncology staff, also reported a lack of knowledge about clinical trials.

The findings indicate that there is a strong need for more cancer education. Programs need to focus on providing education that is culturally specific and language appropriate. The information needs to be delivered by those with an understanding of the lived context of the groups they are attempting to reach. Furthermore, programming needs to focus on enhancing communication between provider and patient including increasing understanding of the multiple and complex barriers many poor residents encounter even when certain resources may be available. Finally, health programming must not assume that because resources are available that they are accessible. Engaging members of the targeted community as part of the planning and dissemination team will great enhance use of available as well as new resources.

## Acknowledgments

We would like to thank the town hall participants as well as the health care providers for sharing their views with us. We would also like to thank the members of the research team including Amber Cox, Carol Covington, Soyoung Hwang and Ellyn Leighton-Herrmann for their assistance with various parts of this project including recruitment, data analysis and/or assistance with manuscript preparation. Our appreciation is further extended to VCU Massey Cancer Center, Paint it Pink in Petersburg, the Petersburg Department of Social Services, and the Cameron Foundation for their support. This study was made possible by funding received from the National Cancer Institute (3U10 CA052784-20S2).

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## Table 1

Health Insurance and Regular Source of Care

| **Health Insurance** | **Non-Hispanic Town Hall N=112 (%)** | **Hispanic Town Hall N=27 (%)** |
|---|---|---|
| Employer health plan | 33 (29.5) | 4 (14.8) |
| Medicaid | 18 (16.1) | 1 (3.7) |
| Medicare | 51 (45.5) | 1 (3.7) |
| Military (Tri-Care) | 8 (7.1) | 0 (0) |
| No health insurance | 13 (11.6) | 20 (74.1) |
| Other | 14 (12.5) | 1 (3.7) |
| **Regular Source of Care** | | |
| Community health Clinic | 8 (7.1) | 10 (37.0) |
| Emergency Room | 16 (14.3) | 3 (11.1) |
| Health Department Clinic | 11 (9.8) | 3 (11.1) |
| Neighborhood Clinic | 4 (3.6) | 2 (7.4) |
| Private Physician’s Office | 78 (69.6) | 8 (29.6) |
| Other | 10 (8.9) | 6 (22.2) |