WHERE SCIENCE AND COMMUNITIES MEET:
A COMPARATIVE CASE STUDY OF STRATEGIES TO INCREASE CANCER SCREENING AMONG RURAL RESIDENTS

by

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ABSTRACT

Background: Cancer accounts for one in every four deaths in the U.S. Screening to detect cancer at an early stage when more favorable treatment outcomes are possible can reduce morbidity and mortality from cancer. Rural populations have some of the highest cancer incidence and mortality rates in the nation but particularly low screening rates. Understanding which strategies are effective for increasing screening in rural areas is essential to reduce this disparity; however, there is little evidence of best practice strategies to increase cancer screening among rural residents.

Purpose: The goal of this study was to assess and model best practice strategies for promoting cancer screening among rural populations.

Methods: The study used a retrospective comparative case study design and mixed methods, guided by a conceptual framework based on Social Ecological Theory and the Community Partnership approach to health promotion to assess strategies for promoting breast, cervical, colorectal, prostate, and skin cancer screening during 2006-2008 and related outcomes. Key informant telephone interviews (n=40) were conducted with community-based cancer coalition members (n=23) in three Appalachian states and cancer center or university-based community outreach program staff (n=17) in ten Appalachian states that serve rural populations. Key informants provided review and editing of their transcribed interview. Document
review conducted of program websites, two existing program databases, and
published literature was used to supplement the key informant data. Content analysis,
pattern matching, and triangulation of qualitative data were conducted and descriptive
statistics used for case descriptions and frequencies of screening strategies. The data
were compared against evidence-based strategies recommended by the U.S.
Preventive Services Task Force, Behavioral Risk Factor Surveillance System
(BRFSS) cancer screening data, and the study’s conceptual model. The findings were
then used to construct a best practices model of rural cancer screening strategies.

Results: Both cancer center-academic outreach programs and coalitions used
strategies to address multiple physical (environmental), structural, sociocultural,
individual, and programmatic barriers in their rural communities with demonstrated
screening success. Coalitions used more evidence-informed approaches but were less
cognizant of health behavior theories underlying such strategies; cancer center-
academic programs used more theory- and evidence-based programs and described
them by name. Other ‘best screening practices’ found include cancer screening
education for the public, community involvement in program development and
delivery, primary care clinics and mobile screening vans as intervention sites, ‘piggy-
backing’ programs onto other community events, targeting multiple conditions in a
health fair-type setting, and multiple component interventions.

Conclusion: Cancer screening in rural communities can be increased by strategies
that are evidence- and theory-based, involve community stakeholders in program
development and implementation, and address multiple barriers to cancer screening.
Areas for future practice and research include strategies and programs that aim to
increase physician recommendation of screening; increased, ongoing dialog and
feedback between community-based and cancer center/academic outreach programs;
recognition and testing of strategies developed by coalitions shown to effectively increase screening; systematic integration of community-academic partnerships into the mission of medical/academic institutions; sustained funding for rural cancer screening programs and mobile vans; and future study and analysis of power and class issues that persist in Appalachia.

Contributions: This research and the proposed best practices model help fill an important gap in rural cancer prevention and control, which may ultimately contribute to reducing cancer disparities in Appalachia and other rural areas.

This abstract accurately represents the content of the candidate’s thesis. I recommend its publication.

Signed

Mark B. Dignan
DEDICATION

I dedicate this thesis to my parents, who taught me the value of hard work, perseverance and resolve to attain my educational and life-long goals. I also dedicate this to my many family members, friends and colleagues for their support during the completion of this thesis.
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TABLE OF CONTENTS

Figures .................................................................................................................. xii
Tables .................................................................................................................... xiii

CHAPTER

1. INTRODUCTION: THE CASE FOR A RURAL CANCER SCREENING BEST PRACTICES MODEL ................................................................. 1
   Problem Statement .............................................................................................. 1
   Cancer Disparities in Rural Populations ............................................................. 2
   Barriers to Screening in Rural Communities ..................................................... 5
   Need for a Rural Best Practices Cancer Screening Model ............................... 7
   Purpose and Specific Aims ................................................................................. 10
   Study Propositions ............................................................................................ 11
   The Research Questions .................................................................................... 11
   Significance of the Study .................................................................................. 13
   Arrangement of the Thesis ................................................................................. 13

2. REVIEW OF THE LITERATURE .................................................................. 15
   The Burden of Cancer and Guidelines for Screening ....................................... 15
   Cancer Screening Strategies ............................................................................ 21
      Evidence-Based Strategies and Recommendations: 
      The Community Guide ................................................................................... 21
   A National Call to Action and Need for Theory-Based Screening and Prevention Models ................................................................. 30

viii
3. THEORIES SUPPORTING A RURAL CANCER SCREENING MODEL ........................................................................ 33
   Social Ecological Theory ...................................................................................................................... 33
   Roots of Social Ecological Theory ...................................................................................................... 33
   Application of Ecological Models to Health Promotion ...................................................................... 35
   The Community Partnership Approach .............................................................................................. 40
   Roots of the Community Partnership Approach ................................................................................. 40
   Principles of the Community Partnership Approach ........................................................................... 43
   Integrative Frameworks for Health Promotion .................................................................................... 45
   Conceptual Framework for the Study .................................................................................................. 47

4. RESEARCH DESIGN AND METHODOLOGY ..................................................................................... 48
   Study Design ....................................................................................................................................... 48
   Data Collection .................................................................................................................................... 49
     Key Informant Interview .................................................................................................................. 49
     Document Review ............................................................................................................................. 58
   Analysis ................................................................................................................................................ 59
     Overall Analytic Approach ............................................................................................................... 59
     Triangulation ..................................................................................................................................... 60
     Thematic Analysis .............................................................................................................................. 60
     Quantitative Analysis ......................................................................................................................... 61
     Comparative Case Analysis .............................................................................................................. 62
5. CASE STUDY FINDINGS: COMMUNITY-BASED
COALITIONS AND CANCER CENTER-ACADEMIC
OUTREACH PROGRAMS................................................................. 65
   The Research Sites and Key Informants................................. 68
   Cancer Foci and Target Audiences........................................... 71
   The Barriers Found to Cancer Screening Promotion.................. 73
      Physical Barriers............................................................... 74
      Structural Barriers............................................................ 75
      Social and Cultural Barriers.............................................. 80
      Individual Barriers.......................................................... 83
      Programmatic Barriers.................................................... 84
   The Definitions of Success in Rural Cancer Screening
   Programs.................................................................................. 85
   The Strategies Found for Promoting Cancer Screening in
   Rural Communities.................................................................. 87
      Overview of Strategies Found............................................. 87
      Program-related Strategies.................................................. 87
      Community Engagement Strategies..................................... 104
      Unsuccessful Strategies..................................................... 118
   The Findings Relative to the Community Guide’s
   Recommendations for Cancer Screening................................. 120
   Summary of Findings............................................................. 124

6. PROPOSED MODEL, FUTURE DIRECTIONS AND
CONCLUSION.................................................................................. 128
   Utility of the Conceptual Model and Changes Suggested
   by the Research......................................................................... 128
   The Proposed Best Practices Model of Rural Cancer
   Screening.................................................................................. 129
FIGURES

Figure

3.1 A Model Of The Determinants Of Health ....................................................... 38

3.2 Conceptual Framework For Determining A Rural Best Practices Cancer Screening Model ................................................................. 47

6.1 The Best Practices Model Of Rural Cancer Screening ........................................ 130
TABLES

Table
2.1 Recommended client-directed, provider-directed and multi-component intervention strategies for increasing breast, cervical, and colorectal cancer screening .............................................................. 25
2.2 Recommended strategies for preventing skin cancer ............................................. 28
2.3 Rural Healthy People 2010 cancer screening objectives ........................................... 31
3.1 Principles of community-based participatory research ........................................... 44
4.1 Factors related to rural cancer screening .............................................................. 50
5.1 Sample characteristics: coalition and cancer center-academic outreach programs, 2006-2008 .............................................................. 69
5.2 Cancer foci and target audiences of rural coalition and cancer center-academic outreach programs, 2006-2008 .............................................................. 72
5.3 Barriers to cancer screening in rural communities, 2006-2008 ................................ 73
5.4 Definitions of success in rural cancer screening promotion programs, 2006-2008 ........................................................................... 86
5.5 Funding sources of rural coalitions and cancer center-academic outreach programs, 2006-2008 ........................................................................... 89
5.6 Theoretical models and conceptual approaches used in rural cancer screening promotion programs, 2006-2008 ........................................................................... 95
5.7 Evidence-based and evidence-informed strategies used by coalitions and cancer center-academic outreach programs, 2006-2008 ........................................................................... 102
5.8 Community trust- and relationship-building strategies in rural cancer screening promotion programs, 2006-2008 ........................................................................... 105
5.9 Intervention sites in rural cancer screening promotion programs, 2006-2008 ........................................................................... 113
5.10 Intervention strategies in rural cancer screening promotion programs, 2006-2008 ........................................................................... 116
CHAPTER 1
INTRODUCTION: THE CASE FOR
A RURAL CANCER SCREENING
BEST PRACTICES MODEL

Problem Statement

Cancer is a group of over 100 diseases distinguished by the uncontrolled growth of abnormal cells. Cancer can result from internal factors (inherited gene mutations, hormones, immune disorders, and mutations that occur from metabolism) and external factors (tobacco, chemicals, radiation, and infectious agents) that can act alone, in combination, or in sequence to stimulate abnormal cell growth and proliferation of disease (American Cancer Society [ACS], 2008a). Age is a major risk factor, as 77% of all cancers are diagnosed in people age 55 and older. Once cancer spreads to major organs of the body and is not effectively treated, it can be fatal.

Cancer is the second most common cause of death in the U.S., exceeded only by heart disease, and accounts for one of every four deaths. In 2008, an estimated 1,437,180 new cancer cases of cancer will be diagnosed in the U.S. and 565,650 people are expected to die, more than 1,500 per day (ACS, 2008a). These estimates do not include carcinoma in situ of any site except urinary bladder, nor the more than one million new cases of basal and squamous skin cancers expected this year.

Cancer affects people of all racial, ethnic and socioeconomic groups; however, cancer rates are disproportionately higher among certain groups. These differences are described as cancer disparities, or cancer health disparities. Disparities, or inequalities, occur when members of certain population groups do not enjoy the same health status as other groups. The National Cancer Institute defines cancer health disparities as "differences in the incidence, prevalence, mortality, and burden of
cancer and related adverse health conditions that exist among specific populations groups in the United States" (National Cancer Institute [NCI], 2008a). Cancer disparities can involve biological/genetic, environmental, behavioral, and socioeconomic factors (Institute of Medicine [IOM], 2006). Most often, cancer disparities have been identified along racial and ethnic lines, but disparities extend beyond race and ethnicity to include residents of rural areas, women and children, the elderly, persons with disabilities, and other people who have inadequate access to health care and cancer-related services. Cancer disparities are measured by three health statistics: incidence (the number of new cancers), mortality (the number of cancer deaths), and survival rates (the length of survival following diagnosis of cancer) (Centers for Disease Control and Prevention [CDC], 2006).

**Cancer Disparities in Rural Populations**

People living in rural areas experience substantial cancer-related disparities overall compared to non-rural areas (Appalachia Regional Commission, 2006; Friedell, Linville, & Hullet, 1998; Friedell et al., 2001; Gamm, Hutchison, Linnae, Dabney, Dorsey, 2003; Gosschalk & Carozza, 2003; U.S. Department of Health and Human Services [DHHS], 2008). The negative effects of rural residence and poverty on cancer incidence and survival are well documented. For example, women living in low-income, rural geographical areas have a much greater risk of dying of cervical cancer than other women. Despite a steady decline in cervical cancer deaths in the U.S. overall, patterns of high cervical cancer mortality have persisted for decades among rural White women in Appalachia, African American women in the South, Hispanic women along the Texas-Mexico border, Northern Plains American Indians; Vietnamese American women; women in the central valley of California; and Alaska Natives (Freeman & Wingrove, 2005; Yabroff et al., 2005). Skin and lip cancer
mortality rates are known to be higher in rural areas (Monroe, Ricketts, & Savitz, 1992), likely attributable to increased sun exposure of rural residents, particularly farmers (Rosenman, Gardiner, Swanson, Mullan, & Zhu, 1995), and a lack of appropriate knowledge about precancerous and cancerous skin lesions (Moore et al., 2003; Mullan, Gardiner, Rosenman, Zhu, & Swanson, 1996).

Low survival rates due to late-stage cancer diagnosis are also disproportionately elevated in rural areas. Data for 1995-2000 from 30 population-based, central cancer registries in the U.S. revealed more diagnoses of late-stage prostate cancer in men residing in non-metro counties than those in metro areas, despite lower incidence rates overall (Jemal et al., 2005). Silverstein, Nietert, Ye and Lackland (2002) found that for residents in the Savannah River Region of the southeastern U.S., greater distance to the nearest hospital predicted diagnosis of advanced-stage lung cancer. Similarly, Parsons and Askland (2007) found increased distance to a primary care provider associated with diagnosis of late-stage colorectal cancer in rural Maine. Some studies suggest that late-stage disparities are even more pronounced among minorities in rural areas. For example, rural black women were often diagnosed with late-stage breast cancer than were black urban women or white women in both urban and rural areas (Amey, Miller, & Albrecht, 1997). However, women residing in lower socioeconomic, rural areas in Texas had significantly shorter survival times when diagnosed with early stage cervical cancer than women of higher socioeconomic status and urban residence (Eggleston, et al., 2006).

Appalachia, one of the largest rural geographical regions in the U.S., experiences significant cancer disparities and exemplifies the adverse effects of rurality and poverty on cancer-related outcomes. Appalachia is a 200,000-square-mile area that follows the spine of the Appalachian Mountains for 1,000 miles from southern New York to northern Mississippi. The Appalachian Region includes all of West Virginia
and parts of 12 other states: Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, and Virginia. Appalachia encompasses 410 counties and 23 million people, 42% of whom live in rural areas. U.S. census data for 1990 (the most recent data available for Appalachia overall) showed that only 68.4% of Appalachian adults aged 25 years and older were high school graduates, less than the national average of 75.2%; poverty rates in rural areas of northern and central Appalachia averaged 16%, exceeding the national average of 13.1%; and in central rural Appalachia, the poverty rate was nearly 27% (Appalachian Regional Commission, 2006). Research has demonstrated higher incidence rates (Hall, Jamison, & Coughlin, 2004; Hopenhayn, Bush, Christian, & Shelton, 2005; Lengerich et al., 2005; Wingo et al., 2008) and death rates (CDC, 2002; Hall, Rogers, Weir, Miller, & Uhler, 2000; Huang, Wyatt, Tucker, Bottorff, & Lengerich, 2002) from various types of cancer in Appalachia than the rest of the U.S. Data for 2001-2003, the most recent to be analyzed for Appalachia, showed higher overall cancer incidence rates in Appalachia than the national average, with particularly high rates of colorectal, lung, and other tobacco-related cancers (Wingo et al., 2008). The highest rates of lung and cervical cancer were in Central Appalachia; prostate, female breast, colorectal and selected other cancer sites were highest in Northern Appalachia; and Southern Appalachia had the lowest overall incidence rates within Appalachia but still higher than the rest of the U.S.

Other than avoiding tobacco and maintaining a healthy weight, following the recommended screening guidelines to detect cancer at an early stage when more favorable treatment outcomes are possible is critical to reducing one’s risk of dying from cancer (ACS, 2008a; Smith, Mettlin, Davis, & Eyre, 2000). Yet, screening rates for the types of cancer for which screening is available, including breast, cervical, and
colorectal, skin and prostate, are lower in rural areas of the U.S. overall than non-rural areas (e.g., Coughlin & Thompson, 2004; Coughlin, Thompson, Hall, Logan, & Uhler, 2002a; Coughlin, Thompson, Seeff, Richards, & Stallings, 2002b; Hall, Uhler, Coughlin, & Miller, 2002; Husaini et al., 2005; Lengerich et al., 2005; McElroy, Remington, Gangnon, Harihara, & Andersen, 2006; Yabroff, Ashbeck, & Rosenberg, 2007). Barriers to screening may be related to the physical environment, such as mountainous terrain and distance to health care facilities; structural in nature, including lack of medical facilities, cost and insurance issues, healthcare professional shortages and policy-level factors; social or cultural barriers related to group norms and beliefs about cancer, language issues, and mistrust of Western medicine; and individual-level barriers, including fear and lack of knowledge about cancer (Gosschalk & Carozza, 2003).

Barriers to Screening in Rural Communities

Access to health care is a major barrier for rural residents, due in part to substantial shortages of health care professionals in rural areas. Only 10% of U.S. physicians practice in rural communities, with more than 2,000 designated Health Professional Shortage Areas in rural and frontier areas in the U.S. and its territories, compared to only 910 in urban areas. Rural residents also have greater transportation difficulties reaching health care providers, often traveling great distances to reach a doctor or hospital (Amey et al., 1997; Arcury et al., 2005a; Arcury, Preisser, Gesler, & Powers, 2005b; Casey, Thiede, Call, & Klinger, 2001; Celaya, Rees, Gibson, Riddle, & Greenberg, 2006; Higginbotham, Moulder, & Currier, 2001; Silverstein, Nietert, Ye, & Lackland, 2002; Swan, Breen, Coates, Rimer, & Lee, 2003; Yabroff et al., 2005). Rural residents are more likely to be uninsured or underinsured (Brems, Johnson, Warner, & Roberts, 2006; Casey et al., 2001; Celaya et al., 2006; Cheng et
and have greater chronic illness, disability, fewer physician visits, and lower levels of preventive care than urban dwellers (Brems et al., 2006; Celaya et al., 2006; Cummings et al., 2002; Gosschalk & Carozza, 2003). Many people in rural communities lack knowledge about the need for screening and early detection (Jones, Shipp, Thompson, & Davis, 2005; Lantz, Weigers, & House, 1997; Michielutte et al., 1996; Moore et al., 2003; Tessaro, Mangone, Parkar, & Pawar, 2006); and have limited education, literacy, and health literacy (Brems et al., 2006; Celaya et al., 2006; Cummings et al., 2002; Gosschalk & Carozza, 2003; Thompson, Coronado, Neuhouser, & Chen, 2005; Yabroff et al., 2005). Many rural residents believe screening is not necessary in the absence of symptoms (Michielutte et al., 1996; Tessaro, et al., 2006); fear what may be found if they do get screened, or have fatalistic attitudes in believing that nothing can be done anyway if they do get cancer or that it is meant to happen (Kelly et al., 2007; Klabunde et al., 2005; Michielutte et al., 1996; Shell & Tudiver, 2004; Wolff et al., 2003). Adding to this is the evidence indicating that rural providers often fail to recommend screening to their patients (Kelly et al, 2007; Shell & Tudiver, 2004; Tessaro et al, 2006; Yabroff et al, 2005).

A major issue for public health agencies and networks is that these barriers rarely occur in isolation, requiring multiple-pronged approaches to facilitate screening behavior change. Thus, the challenges to addressing these barriers are many and complex. This complexity is illustrated by findings of a study conducted with 1,295 non-Hispanic white women in a rural, Appalachian area of western North Carolina. This study found that women with low knowledge, younger age, and low education were least likely to be screened for skin cancer. Cost, lack of symptoms, denial, fatalism, and fear of the stigma of cancer were all associated with low likelihood of
both prevention and early detection behaviors (Michielutte et al., 1996). Clearly, effective strategies are needed to overcome these barriers and increase screening if reductions in rural cancer disparities are to be achieved.

Need for a Rural Best Practices Cancer Screening Model

Community outreach programs have long been used to raise awareness and educate the public about cancer and the need for screening, and to offer reduced-cost and free cancer screening for those unable to pay. In recent years, there has been a growing trend in the use of participatory approaches and community-based participatory research (CBPR) to increase cancer screening in rural communities. The central tenet of CBPR is that inclusion of community stakeholders as equitable partners in all phases of community initiatives will more likely result in desired outcomes and sustainability of programs, because the specific needs, interests, values, and culture of the community are taken into account (Israel, Schulz, Parker, & Becker, 1998). The NCI (2008a) now promotes and in some initiatives requires CBPR as a method for reducing cancer disparities. In Appalachia, beginning in 1992 and with NCI funding, community-based cancer coalitions were formed in the Appalachian states of Kentucky, Pennsylvania, and West Virginia in collaboration with their three university partners as the Appalachia Leadership Initiative on Cancer (1992-2000) (Friedell et al., 2001). From 2000 to 2005 these academic-community partnerships continued to build capacity and began using CBPR as the Appalachia Cancer Network (2000-2005) (Coyne, Demian-Popescu, & Friend, 2006b; Davis, Armstrong, Dignan, & Norling, 2006a; Kluhsman, Bencivenga, Ward, Lehman, & Lengerich et al., 2006b; Lengerich, Rubio, Brown, Knight, & Wyatt, 2006a; Lengerich et al., 2005, 2004; Tessaro et al., 2006b; Vanderpool & Coyne, 2006a; Ward, Coffey Kluhsman, Lengerich, & Piccinin, 2006). The network has now
expanded to five academic-community partnerships in seven states as the Appalachia Community Cancer Network (2005-2010), using CBPR as a primary approach to reducing cancer disparities through education, training, and research (Appalachia Community Cancer Network [ACCN], 2008; Lengerich et al., 2006b). A number of other academic-community partnerships funded through the NCI’s Community Networks Program also are using CBPR in their programs (NCI, 2008a). In addition, a growing number of NCI-designated Comprehensive Cancer Centers are using CBPR in their community outreach programs with rural and other underserved populations (NCI, 2008b). It is notable that from 2002 to 2004 the percentage of the total National Institutes of Health budget for minority health and health disparities research activities, including CBPR, averaged 10.8% (range, 8.9%-11.9%) (IOM, 2006). Despite the committed efforts of community outreach programs and funding agencies, substantial strides in reducing cancer disparities have not yet been made.

Understanding which specific strategies are effective for increasing screening behavior is essential to reduce cancer disparities. Evidence-based approaches are currently disseminated through two major channels: the non-federal U.S. Preventive Services Task Force (Task Force) (2007) and a link on the Cancer Control P.L.A.N.E.T. (Plan, Link, Act, Network with Evidence-based Tools) open-access Web portal (NCI, 2008c). The Task Force is an independent panel of experts in primary care and prevention and one of the most comprehensive sources of evidence on cancer screening in the U.S. The Task Force regularly conducts systematic reviews of the literature on the effectiveness of screening interventions and publishes recommendations for cancer screening strategies based on these reviews in The Community Guide to Preventive Services (Breslow et al., 2008; CDC, 2008). Both print and online versions are available.
Cancer Control P.L.A.N.E.T. is a collaborative effort of the NCI, CDC, ACS, Substance Abuse and Mental Health Services Administration (SAMHSA), AHRQ, and Commission on Cancer. Research-tested intervention programs (RTIPS) products from selected, evidence-based programs are posted on Cancer P.L.A.N.E.T. These programs and materials can be downloaded and adapted to various audiences. The information is regularly updated as new evidence emerges from the literature. Currently, cancer screening RTIPS posted on Cancer Control P.L.A.N.E.T. include a small but growing number of evidence-based programs for breast, cervical, and colorectal cancer screening promotion; sun safety (skin cancer prevention); diet and nutrition; physical activity; patient informed decision-making; cancer survivorship; and tobacco control. However, there is a paucity of literature to date on evidence-based programs and strategies in rural populations. A number of community-based interventions have been tested with rural audiences, but most used a small sample size, weak evaluation methods, or were developed in response to very local conditions and thereby lack generalizability (Siegel, Berliner, Adams, & Wasongarz 2001).

In its *Making Cancer Health Disparities History Report*, the Trans-HHS Cancer Health Disparities Progress Review Group recommended that the U.S. Department of Health and Human Services should support the development, identification, dissemination, and delivery of “best practices” model approaches founded upon evidence-based guidelines, along with outreach strategies for cultural-, linguistic-, and literacy-specific cancer communications and health promotions in partnership with cancer survivors, caregivers, and community advocacy organizations (DHHS, 2004). Best practices in health promotion are programmatic activities and processes that are both evidence- and theory-based, reflect an understanding of the environment, and are most likely to lead to short- and long-term improved health
outcomes (Kahan & Goodstadt, 2001). Despite the growth in use of CBPR and funding to support cancer screening promotion programs, there is a paucity of literature on effective cancer screening strategies and substantial reductions in rural cancer disparities have not yet been made. A rural best practices model based on evidence-based guidelines is a critically needed tool to guide researchers and their community partners, public health agencies, funders and policy-makers in their collective effort to reduce cancer disparities in rural populations.

Purpose and Specific Aims

The purpose of this study was to determine and model best practice strategies to promote cancer screening in Appalachian and other rural communities. The research used a retrospective, comparative case study design with semi-structured key informant telephone interviews, document review, and both quantitative and qualitative data analyses. A conceptual framework based on Social Ecological Theory (Evans & Stoddart, 1990; Evans & Stoddart, 2003; McLeroy, Bibeau, Steckler, & Glanz, 1988; Stokols 1992, 1996;), the Community Partnership Approach (Green et al., 1995; Green & Mercer, 2001; Israel et al., 1998; Israel, Schulz, Parker, & Becker, 2001), and an Integrative Framework for Health Promotion (Best et al., 2003) guided the research.

The specific aims of this study were to:

Aim 1: Conduct key informant interviews and document review to determine strategies used by community-based coalitions and cancer center outreach programs to promote screening for breast, cervical, colorectal, prostate, and skin cancer among rural residents—the cancers for which screening methods currently exist.

Aim 2: Compare and contrast the extent to which these strategies have been successful or unsuccessful in promoting cancer screening.
Aim 3: Use the findings to construct a best practices model for promoting cancer screening in rural communities.

Study Propositions

1. Strategies that address multiple barriers to cancer screening more often result in completed screening among rural residents than strategies that address any single barrier alone.

2. Strategies that address multiple barriers to screening, with involvement of community members in developing and implementing those strategies, more often result in completed cancer screening among rural residents than strategies without community involvement.

The Research Questions

The research undertaken and reported herein sought to answer the following questions and sub-questions:

1. How can strategies used to promote cancer screening among rural residents be characterized? (Aim 1)
   a. To what extent have strategies that address barriers to screening been used? What specific barriers to screening were targeted?
   b. To what extent has a participatory approach been used to promote screening? What specific participatory strategies were employed?
   c. To what extent have health behavior theories or models been used? What specific theories or models were used?
   d. To what extent have evidence-based and evidence-informed approaches been
utilized to promote screening? What specific evidence-based strategies were used?

e. In what ways have funding level and funding sources influenced the choice of strategies used?

f. In what ways have federal, state or local policy influenced the choice of strategies used?

g. How do the cancer screening strategies used by community-based coalitions and cancer center outreach programs compare? How are they different? How are they similar? In what ways do they coincide?

2. To what extent have intervention strategies been successful or unsuccessful in promoting cancer screening among rural residents? (Aim 2)

a. How do community-based coalitions and cancer center outreach programs define success in their rural screening interventions?

b. To what extent has addressing barriers to screening contributed to the success of screening interventions?

c. To what extent have participatory approaches contributed to successful screening outcomes?

d. To what extent have health behavior theories or models contributed to successful screening outcomes?

e. To what extent have evidence-based and evidence-informed approaches contributed to successful screening promotion?

f. In what ways have funding level and funding sources contributed to successful screening efforts?
g. In what ways has federal, state or local policy contributed to the success of rural screening interventions?

h. How do the cancer screening outcomes of community-based coalitions and cancer center outreach programs compare? How are they different? How are they similar? In what ways do they coincide?

3. In a best practices model for promoting cancer screening among rural populations (Aim 3):

   a. What precipitating factors facilitate or inhibit cancer screening behaviors in rural areas?

   b. What evidence-based and evidence-informed strategies can positively impact the cancer screening behaviors of rural residents?

   c. What short- and long-term outcomes result from implementing strategies that effectively promote cancer screening in rural communities?

   Significance of the Study

   This research provides an important contribution to the literature by developing a best practices model to fill a critical gap in the toolbox of rural cancer prevention and control. If used and demonstrated by future interventions to effectively increase cancer screening and when replicated over time, the model may contribute to reducing the disparate burden of cancer in rural populations.

   Arrangement of the Thesis

   Chapter 2 presents a review of the literature related to cancer screening in rural populations and the need for a theory-based model for increasing cancer screening in rural communities.
Chapter 3 examines the relevance and application of theory to the study of cancer screening in rural communities and describes the integrated conceptual framework that guided this research.

Chapter 4 details the research design and methodology used in the research.

Chapter 5 presents the case study findings and describes the research sites and key informants; cancer foci and target audiences of both study groups; the barriers found to impede cancer screening; and how each study group defines success in their cancer screening programs. The strategies found for promoting cancer screening are presented and detailed, including program-related strategies, community engagement strategies, and unsuccessful strategies. The findings are then compared with the most current recommended strategies published in the *Guide to Community Preventive Services* (CDC, 2008), followed by a brief summary of the findings.

Chapter 6 discusses the utility of the study’s conceptual mode in light of the study’s findings and changes suggested by the research. A best practices model of rural cancer screening is then proposed. Strengths and limitations of the study are discussed and implications for future research and practice suggested. Finally, a plan for disseminating the study’s findings is outlined.
CHAPTER 2
REVIEW OF THE LITERATURE

Although progress has been made in reducing mortality rates and improving survival, further progress could be made if more people received screening for the most common types of cancer, which happen to be those for which screening is currently available: breast, cervical, colorectal, oral cavity, prostate, and skin cancer. Early detection for most of these cancers has been shown to reduce mortality (ACS, 2008a); for example, in 2006 the estimated number of premature deaths that could have been avoided through cancer screening ranged between 3% and 35%, depending on various assumptions (ACS, 2006). Beyond reducing the number of cancer deaths, screening can reduce cancer morbidity and treatment costs, since treatment for early-stage cancers is often less aggressive than for more advanced-stage cancers. As a context for the research reported herein, the summary that follows describes the burden of the most common forms of cancer and the national guidelines for screening and early detection of these cancers.

The Burden of Cancer and Guidelines for Screening

*Breast Cancer*

Breast cancer is the most common cancer among U.S. women and the second leading cause of cancer deaths in this population. The American Cancer Society (2008a) estimates that in 2008, 182,460 new cases of breast cancer will be diagnosed among U.S. women and about 1,990 new cases will occur in men. Of the 182,460, about 40,930 deaths are expected (40,480 women, 450 men). Despite enormous strides over the past three decades in screening, early detection, treatment success and extended survival overall, disparities in breast cancer incidence and mortality persist.
in the U.S. among certain populations, including minorities and those living in rural areas (e.g., Amey et al., 1997).

Mammography, the process of using low-dose X-rays to examine the human breast, is the “gold-standard” imaging technique that has been shown to reduce breast cancer mortality risk if detected early and with appropriate follow-up. For average-risk women in the general U.S. population, the American Cancer Society (2008a) recommends annual mammography beginning at age 40 and continuing for as long as a woman is in good health; clinical breast exam about every three years for women in their 20s and 30s and every year for women age 40 and over; and breast self exam for all women beginning in their 20s. Recommendations for high-risk women (lifetime risk greater than 20%) are magnetic resonance imaging (MRI) and a mammogram every year. Women at moderately increased risk (15% to 20%) lifetime risk should consult their physician about the benefits and limitations of adding MRI screening to their annual mammogram.

**Cervical Cancer**

In 2008, an estimated 11,070 new cases of invasive cervical cancer are expected among U.S. women and approximately 3,870 deaths from the disease (ACS, 2008a). Mortality rates have steadily declined over the past several decades in both white and African American women due to screening and early detection of pre-invasive lesions. However, cervical cancer disparities persist in Appalachia, especially in rural areas (Freeman & Wingrove, 2005; Hopenhayn et al., 2005; Huang et al., 2002; Lengerich et al., 2005). The primary risk factor for cervical cancer is infection with human papillomavirus (HPV); other risk factors for cervical cancer include beginning sexual intercourse at a young age, multiple sexual partners at any age, and tobacco smoking (ACS, 2008a).
The current “gold standard” for cervical cancer screening is the Papanicolaou (Pap) test, a simple procedure in which a small sample of cells are collected from the cervix and examined under the microscope to look for abnormal cervical cells. DNA tests to detect HPV strains associated with cervical cancer are sometimes used along with the Pap test, but are expensive and not commonly needed, since most cervical cancers grow very slowly and can be detected early with regular, less expensive Pap screening. The American Cancer Society (2008a) recommends that all women begin cervical cancer screening about three years after beginning vaginal intercourse and no later than age 21. Screening should be done every year with the regular Pap test or every two years with the newer, liquid-based Pap test. Beginning at age 30, women having three consecutive, normal Pap tests may be screened every two to three years, or every three years with either the conventional or liquid-based Pap test plus the HPV DNA test. Women age 70 and older having three consecutive, normal Pap tests and no abnormal Pap results in the past 10 years may stop cervical cancer screening. Women at higher risk (personal history of cervical cancer, DES exposure before birth, HIV infection or a weakened immune system) should continue annual screening as long as they are in good health. Women of any age who have had a total hysterectomy (including removal of the uterus and cervix) may stop cervical cancer screening unless the surgery was done as a treatment for cervical cancer or pre-cancer. Women who had a hysterectomy without removal of the cervix should continue to follow the guidelines above.

With regard to prevention, in June 2006, the U.S. Food and Drug Administration (USDA) licensed Gardasil®, the first HPV vaccine, but only for use in females aged 9-26 years. If administered prior to infection, the vaccine is highly effective in preventing persistent infection with HPV types 16 and 18, which are known to cause 70% of cervical cancers, and HPV types 6 and 11, which are known to cause 90% of
genital warts (Koutsy et al., 2002). In September 2008, the USDA approved Gardasil for females aged 9-26 years to prevent vaginal and vulvar cancer, also known to be caused by HPV types 16 and 18. Another vaccine (Cervarix) is currently awaiting approval by the European Agency for the Evaluation of Medicinal Products (ACS, 2008a). Men can also carry HPV; however, neither Gardasil nor any other vaccine is currently approved for use in men.

Colorectal Cancer

Colorectal cancer (CRC) is the third most common cancer and the third leading cause of cancer deaths among U.S. men and women. In 2008, an estimated 108,070 new cases of colon cancer and 40,740 cases of rectal cancer will be diagnosed and approximately 49,260 people will die from their disease (ACS, 2008a). Incidence of CRC has been declining overall for the past two decades, which partly reflects increased screening. The more rapid decline occurred in the most recent time period (1998-2004, 2.3% per year). However, research shows disparately high colorectal cancer incidence and mortality rates in Appalachia, especially in rural areas of Appalachia (Hopenhayn et al., 2005; Huang et al., 2002; Lengerich et al., 2005).

Early screening can detect and remove colorectal polyps before they progress to cancer and early-stage disease when treatment outcomes and survival are more likely. The American Cancer Society (2008a) advises that beginning at age 50, average-risk men and women should follow one of five testing schedules: 1) yearly fecal occult blood test (FOBT, take-home, 3-card method) or fecal immunochemical test (FIT, take-home 2-card method); 2) flexible sigmoidoscopy every 5 years; 3) annual FOBT or FIT plus flexible sigmoidoscopy every 5 years (combined testing is preferred over either of these options alone); 4) double-contrast barium enema every 5 years; or 5) colonoscopy every 10 years. Individuals at increased risk for colorectal cancer
should talk to their doctor about starting screening earlier than age 50 and/or undergoing screening more often.

Factors associated with increased CRC risk include age, as more than 90% of cases are diagnosed in people aged 50 years and older; a personal or family history of colorectal cancer and/or polyps; personal history of chronic inflammatory bowel disease; and certain inherited genetic mutations, such as in familial adenomatous polyposis (FAP) or hereditary non-polyposis colon cancer (HNPCC). Lifestyle factors, including obesity, physical inactivity, smoking, heavy alcohol consumption, a diet high in red meat, and low intake of fruits and vegetables are associated with increased risk of CRC. Research also shows that men and women who are overweight are at increased risk of developing and dying from colorectal cancer (ACS, 2008). Predictors of late-stage CRC have been demonstrated, including African American race (Polednak, 2000); low socioeconomic status, including less education and greater poverty (Cheng et al., 2001); lack of insurance supplemental to Medicare (Lee-Feldstein, Feldstein, & Buchmueller, 2002); living in medically underserved areas (Polednak, 2000); greater distance to a cancer center (Campbell et al., 2001) and to a primary care provider (Parsons & Askland, 2007); and rural residence (Fazio, Cotterchio, Manno, McLaughlin, & Gallinger, 2005).

Skin Cancer

Skin cancer is the most common cancer in the U.S. The American Cancer Society (2008a) estimates that more than 1 million unreported cases of basal cell or squamous cell cancers occur each year. About 62,480 new cases of melanoma, the most serious and lethal type of skin cancer, are expected in 2008, with 11,200 deaths from melanoma and 2,780 deaths from other non-epithelial skin cancers. Melanoma is primarily a disease of whites, as the rate of melanoma is more than 10 times higher in
whites than in African Americans. There is ample evidence that skin cancer incidence and mortality rates are higher among some rural populations compared to urban dwellers, especially farmers (Monroe et al., 1992; Moore et al., 2003; Mullan et al., 1996; Rosenman et al., 1995) and a lack of appropriate knowledge about screening and early detection (e.g., Michielutte et al., 1996).

Skin cancer is highly preventable and curable with early detection and treatment. The American Cancer Society (2008a) recommends avoiding exposure to the sun during midday hours (10 a.m. to 4 p.m.), wearing sunglasses and protective clothing that shades exposed skin, use of sunscreen with a sun protection factor (SPF) of 15 or higher, and avoiding use of tanning beds and sun lamps that emit additional sources of radiation. Children should be protected from the sun, as severe sunburn in childhood can significantly increase the risk for melanoma later in life. Early detection is primarily through recognition of changes to skin growths. Adults are advised to have a regular, dermatologic exam by a physician and thoroughly exam their skin regularly.

*Prostate Cancer*

Prostate cancer is the most frequently diagnosed cancer in men and the second leading cause of cancer deaths in men (ACS, 2008a). An estimated 186,320 new cases and 28,660 deaths are expected in the U.S. men in 2008. Both incidence and mortality rates of prostate cancer are significantly higher in African-American men than white men, for reasons that are not clear. Overall, incidence rates rapidly increased from 1988-1992, declined sharply from 1992-1995, and since 1995 have leveled off. These changes are attributable in part to screening with the prostate-specific antigen (PSA) blood test, which detects a protein made by the prostate gland in response to various conditions, including (but not exclusively) cancer. The only well-established risk factors for prostate cancer are age, ethnicity, and family history.
of the disease. Men living in rural areas have been shown to higher death rates and late-stage disease than those in urban areas and less prostate cancer knowledge (Jones et al., 2005) and lower prevalence of PSA screening (Bassett & Smyer, 2003; Jemal et al., 2005).

The American Cancer Society (2008a) recommends that beginning at age 50, men at average risk with at least a 10-year life expectancy should be offered an annual PSA blood test and digital rectal exam (DRE). Men at higher risk (African-Americans and men with one or more first-degree relatives diagnosed before age 65), should begin screening at age 45. All men should be given information on what is known and what is uncertain about the benefits and limitations of early detection and treatment of prostate cancer, in order to make informed decisions about screening. Despite these recommendations, there is an ongoing controversy about the lack of sufficient evidence to show that screening can decrease mortality for prostate cancer.

Cancer Screening Strategies

A large body of evidence has demonstrated that screening can reduce morbidity and mortality from some of the most prevalent types of cancer if detected at an earlier stage when treatment affords greater chances for survival. Less is known, however, about which strategies are most effective for increasing screening, particularly in rural areas.

Evidence-Based Strategies and Recommendations: The Community Guide

Since its inception in 1996, the Task Force on Community Preventive Services has been one of the nation’s leading authorities on evidence-based strategies and interventions for health promotion and disease prevention for a variety of health conditions, including cancer (CDC, 2008). The Task Force initially was convened by
the U.S. Department of Health and Human Services but is now a non-federal independent decision-making body. The Director of the Centers for Disease Control and Prevention appoints Task Force members, with supplemental staff and resources provided by the National Institutes of Health (NIH). The Task Force conducts periodic, systematic reviews of peer-reviewed, population-based interventions that focus on strategies to improve health-related, intervention outcomes. The Task Force issues recommendations for various categories of intervention strategies, based on the strength of the evidence in changing outcomes. Every stage of the review process follows standardized procedures, from intervention selection to literature search, review and analysis, and formulation of recommendations (Breslow et al., 2008). The methods and process used to perform these systematic reviews have been extensively described (Briss et al., 2000a; Truman et al., 2002; Zaza et al., 2000a, 2000b; cited in Breslow et al., 2008). Initially published in 2005, the recommendations are published as the Guide to Community Preventive Services (Community Guide) and made available on the Community Preventive Services website (CDC, 2008); and in peer-reviewed, public health journals. The Task Force uses three terms to describe their findings, defined as follows:

Recommended: The systematic review of available studies provides strong or sufficient evidence that the intervention is effective.

Recommended Against: The systematic review of available studies provides sufficient or strong evidence that the intervention is harmful or not effective.

Insufficient Evidence: The available studies do not provide sufficient evidence to determine whether or not the intervention is effective.
The Community Guide’s systematic reviews on cancer have included reviews on the effectiveness of community interventions to increase screening for breast, cervical, and colorectal cancers and reviews of economic evaluations for interventions that have effectively increased screening for those cancers (Breslow et al., 2008). Other reviews have focused on interventions to prevent skin cancer (e.g., Saraiya et al., 2004, cited in Breslow et al., 2008) and those designed to promote informed decision-making for cancer screening in communities and healthcare systems (Briss et al., 2004; cited in Breslow et al., 2008). At present, the Task Force does not recommend screening for lung and prostate cancers due to lack of convincing evidence to date that the benefits of screening outweigh the harms (U.S. Preventive Services Task Force [USPSTF], 2007; cited in Breslow et al., 2008). The Community Guide also has published many other reviews and recommendations with implications for cancer prevention, including reducing and preventing tobacco product use (CDC, 2000; Hopkins et al., 2001; Task Force on Community Preventive Services [Task Force], 2001; cited in Breslow et al., 2008); promoting oral health (CDC, 2001a; Task Force, 2002a; Truman et al., 2002; cited in Breslow et al., 2008); promoting physical activity (CDC, 2001b; Kahn et al., 2002; Task Force, 2002b; cited in Breslow et al., 2008); improving vaccine coverage, including hepatitis B vaccine (Briss et al., 2000b; CDC, 1999, 2005; Ndiaye et al., 2005a, 2005b; Task Force, 2000, 2005; cited in Breslow et al., 2008); and preventing HIV and STDs (Herbst et al., 2007; Task Force, 2007a, 2007b; cited in Breslow et al., 2008). Other reviews with implications for cancer prevention are planned or in progress, including promoting healthy nutrition, reducing unhealthy alcohol use, and additional reviews of interventions to prevent HIV and STDs. Information on these reviews can be accessed at: www.thecommunityguide.org (CDC, 2008).
Breast, Cervical, and Colorectal Cancer Screening

In July 2008, the Task Force released its most recent, cancer-related recommendations based on the most recent systematic reviews of the literature through 2004 (Baron et al., 2008a, 2008b, 2008c; Breslow et al., 2008; Glanz & Melvin, 2008; Hannon & Harris, 2008; Sabatino et al., 2008; Shepherd & Moore, 2008; Task Force, 2008; Yabroff et al., 2008). These recommendations include client-directed, provider-directed, and multi-component interventions for breast, cervical, and colorectal cancer (Table 2.1). Client-directed interventions address both increasing screening adherence and access to screening. In brief, for client-directed interventions, recommended strategies for increasing screening adherence are client reminders and small media (for breast, cervical, and colorectal cancer) and one-on-one education (for breast and cervical cancer); while those recommended for increasing access to screening include reducing structural barriers (for breast and colorectal cancer) and reducing out-of-pocket expenses (for breast cancer). For provider-directed interventions, provider reminders and provider assessment and feedback are recommended (for cervical cancer only). Multi-component interventions are also recommended (for cervical cancer only).

It is instructive to note that the Task Force used scientifically rigorous methods and selection criteria in making these important recommendations. First, reviews of cancer screening interventions were conducted only for cancers that convincing scientific evidence shows screening to improve health outcomes. Second, a standardized ranking process (Briss et al., 2000a, cited in Baron et al., 2008b) was used to prioritize three types of screening interventions that increase: 1) community demand (i.e., those that increase screening adherence behavior), 2) community access to screening by reducing client barriers, and 3) service delivery by health care providers (Baron et al., 2008b).
Table 2.1 Recommended client-directed, provider-directed, and multi-component intervention strategies for increasing breast, cervical, and colorectal cancer screening†

<table>
<thead>
<tr>
<th>Client-directed Interventions</th>
<th>Breast (Mammography)</th>
<th>Cervical (Pap test)</th>
<th>Colorectal (FOBT)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>To Increase Screening Adherence</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client reminders</td>
<td>Recommended</td>
<td>Recommended</td>
<td>Recommended</td>
</tr>
<tr>
<td>Client incentives</td>
<td>Insufficient Evidence</td>
<td>Insufficient Evidence</td>
<td>Insufficient Evidence</td>
</tr>
<tr>
<td>Mass media</td>
<td>Insufficient Evidence</td>
<td>Insufficient Evidence</td>
<td>Insufficient Evidence</td>
</tr>
<tr>
<td>Small media</td>
<td>Recommended</td>
<td>Recommended</td>
<td>Recommended</td>
</tr>
<tr>
<td>Group education</td>
<td>Insufficient Evidence</td>
<td>Insufficient Evidence</td>
<td>Insufficient Evidence</td>
</tr>
<tr>
<td>One-on-one education</td>
<td>Recommended</td>
<td>Recommended</td>
<td>Insufficient Evidence</td>
</tr>
<tr>
<td><strong>To Increase Access to Screening</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reducing structural barriers</td>
<td>Recommended</td>
<td>Insufficient Evidence</td>
<td>Recommended</td>
</tr>
<tr>
<td>Reducing out-of-pocket expenses</td>
<td>Recommended</td>
<td>Insufficient Evidence</td>
<td>Insufficient Evidence</td>
</tr>
</tbody>
</table>

**Provider-directed Interventions**

| Provider reminders | Recommended |
| Provider assessment and feedback | Recommended |
| Provider incentives | Insufficient Evidence |

**Multi-component Interventions**

| Multi-component interventions | Recommended |

† Source: CDC. Guide to Community Preventive Services, 2008

Strategies to increase adherence to screening were defined as:

- **client reminders**: letters, postcards or telephone messages to inform clients they are due or late for cancer screening
- **client incentives**: small, non-coercive financial or other rewards to encourage acceptance of screening
- **mass media**: informational messages delivered to large audiences via television, radio, billboards, or newspapers
• small media: informational messages delivered in pamphlets, brochures, leaflets, newsletters, letters, flipcharts, or videos

• group education: information or motivation delivered in a classroom or other group setting

• one-on-one education: information or motivation provided by one person to another, in person or by telephone

Strategies to increase access to screening were defined as:

• reducing out-of-pocket costs: reimbursing clients, providing vouchers, or increased third-party payment

• reducing structural or physical barriers (e.g., location, distance, inconvenient hours, dependent care, language and cultural differences): expanded clinic hours; establishing alternative screening sites; providing transportation, translational services, or scheduling assistance; and state or federally mandated laws to increase screening or coverage of screening

Strategies to encourage providers to deliver screening at appropriate intervals were defined as:

• reminders or checklists: informing providers when clients need screening tests

• assessment and feedback: evaluating provider performance in delivering a screening service to clients (assessment) and presenting providers with feedback on their performance

• provider incentives: monetary or non-monetary awards for client screening

Multi-component interventions were defined as studies that included more than one intervention strategy.

With regard to the applicability of these recommended strategies to rural populations, while some of the studies reviewed for the breast, cervical, and
colorectal cancer screening included rural populations, others did not. The Task Force suggested that the recommendations made through this systematic review should be generally applicable across a range of settings, but acknowledged that the evidence offers little insight into increasing access among people who have never been screened or who may be particularly hard to reach. Thus, a key question that remains to be answered is how screening can be made more accessible in rural and remote regions. The Task Force also suggested that the local context should be considered when identifying feasible intervention approaches to improve cancer screening, and that additional research is needed on all of the strategies examined.

Skin Cancer Screening

Based on previous systematic literature reviews, the Community Guide also lists recommendations for preventing skin cancer by reducing exposure to ultraviolet (UV) radiation (Table 2.2) (CDC, 2008). Recommended strategies issued for two types of behavioral strategies were improving “covering up” behavior by wearing protective clothing to block exposure to sunlight, and decreasing sun exposure by staying out of the sun during peak UV hours. In addition, sunscreen use was considered to be a secondary outcome, meaning that using sunscreen should be used in conjunction with the other two recommended strategies.

Three programs reviewed served as the evidence base for recommended school-related, sun protection strategies among children; while two programs served as the evidence base for recommended recreation-related, sun protection strategies among adults. All of these programs are currently listed as RTIPS on Cancer Control P.L.A.N.E.T. (NCI, 2008b).
### Table 2.2 Recommended strategies for preventing skin cancer

<table>
<thead>
<tr>
<th>Setting-Specific Interventions</th>
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</thead>
<tbody>
<tr>
<td>Education and policy interventions in primary schools</td>
<td>Recommended (to improve children’s “covering up” knowledge, attitudes, intent, and behavior)</td>
<td></td>
</tr>
<tr>
<td>Education and policy interventions in recreational and tourism settings</td>
<td>Recommended (to improve adults’ “covering up” knowledge, attitudes, intent, and behavior)</td>
<td></td>
</tr>
<tr>
<td>Educational and policy interventions in recreational settings</td>
<td>Insufficient Evidence (to improve children’s sun-protective behaviors)</td>
<td></td>
</tr>
<tr>
<td>Educational/policy interventions in child care centers</td>
<td>Insufficient Evidence</td>
<td></td>
</tr>
<tr>
<td>Educational/policy interventions in secondary schools/colleges</td>
<td>Insufficient Evidence</td>
<td></td>
</tr>
<tr>
<td>Interventions oriented to health care settings and providers</td>
<td>Insufficient Evidence</td>
<td></td>
</tr>
<tr>
<td>Educational/policy approaches in occupational settings</td>
<td>Insufficient Evidence</td>
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<tr>
<th>Target Population-Specific Interventions</th>
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</thead>
<tbody>
<tr>
<td>Interventions oriented to children’s parents or caregivers</td>
<td>Insufficient Evidence</td>
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</tbody>
</table>

<table>
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<tr>
<th>Community-wide Interventions</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mass Media and small media without other activities</td>
<td>Insufficient Evidence</td>
</tr>
<tr>
<td>Community-wide multi-component interventions</td>
<td>Insufficient Evidence</td>
</tr>
</tbody>
</table>

*Source: CDC. Guide to Community Preventive Services, 2008*

**Worksite Cancer Screening Intervention Strategies**

In addition to recommendations for breast, cervical, and colorectal cancer screening strategies described above, the Task Force provided guidance on how these
strategies can be implemented in the workplace. Based on its systematic reviews, the Task Force endorses the workplace as an ideal setting to disseminate evidence-based, cancer screening interventions (Hannon & Harris, 2008). The workplace provides opportunities such as on-site mammography and FOBT kit distribution; health educators brought into the workplace to provide cancer and screening-related education; annual worksite media campaigns coinciding with national campaigns; and reduction of out-of-pocket expenses for cancer screening through employer insurance programs. There remain many workplace-based strategies with insufficient evidence to recommend for or against them; however, the Task Force encourages future testing of various approaches to cancer screening promotion in the workplace.

Prostate Cancer Screening

One month following the issuance of its most recent recommendations for breast, cervical and colorectal cancer, in August 2008 the Task Force released its findings on prostate cancer in terms of defined levels of certainty about the net benefit of prostate cancer screening. These definitions apply to Task Force recommendations voted on after May 2007. In brief, based on the group’s most recent review of the literature, the Task Force concluded that the current evidence is insufficient to recommend screening for men of any age. In effect, for men younger than age 75 the benefits of prostate cancer screening are uncertain and the balance of benefits to harms have not yet been determined. For men age 75 and older, there is moderate certainty that the harms of prostate cancer screening outweigh the benefits.

Given the uncertainty and controversy around prostate cancer screening in men younger than age 75, the Task Force made suggestions for clinical practice that focus on informed decision-making. The Task Force recommends that before ordering a PSA test, providers should first discuss with the patient the potential but uncertain
benefits and the known harms of prostate cancer screening and treatment. The Task Force also recommends that providers should inform men about the gaps in the evidence and assist patients in taking their personal preferences into account before deciding whether to be tested.

The virtual lack of sufficient or strong evidence for prostate cancer screening and for some categories of barriers for breast, cervical, colorectal and skin cancer suggests the need for additional research. Future systematic reviews of the growing cancer screening literature will likely yield additional recommendations for strategies that can effectively increase cancer screening in both urban and rural populations.

A National Call to Action and Need for Theory-Based Screening and Prevention Models

The unequal burden of cancer has been described as not only a scientific and medical challenge, but also a moral and ethical dilemma (DHHS, 2004). The call has gone out through national initiatives and funding efforts for public health agencies, health care providers, academic researchers and communities of all racial, ethnic, rural and other underserved groups to partner in a national effort for: 1) reduced cancer disparities through increased routine cancer screening and early detection; 2) evidence-based, community interventions to be used to increase screening and modify risk behaviors; and 3) continued research efforts to recruit members of disadvantaged groups to clinical prevention, screening and treatment trials (CDC, 2006; DHHS, 2004; NCI, 2008a).

As part of this national effort, cancer is one of the leading rural health priority focus areas in the Healthy People 2010 initiative and its companion Rural Healthy People 2010 (DHHS, 2000; Gamm et al., 2003; Gosschalk & Carozza, 2003). Included in the Rural Healthy People 2010 plans are six cancer-related objectives for
rural populations, half of which are specific to cancer screening in rural areas (Table 2.3).

<table>
<thead>
<tr>
<th>Table 2.3</th>
<th>Rural Healthy People 2010 cancer screening objectives†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective 3-1.</td>
<td>Reduce the overall cancer death rate</td>
</tr>
<tr>
<td>Objective 3-11.</td>
<td>Increase the proportion of women who receive a Pap test*</td>
</tr>
<tr>
<td>Objective 3-12.</td>
<td>Increase the number of adults who receive colorectal cancer screening*</td>
</tr>
<tr>
<td>Objective 3-13.</td>
<td>Increase the proportion of women aged 40 years and older who receive a mammogram within the preceding two years*</td>
</tr>
<tr>
<td>Objective 3-14.</td>
<td>Increase the number of states that have statewide population-based cancer registries</td>
</tr>
<tr>
<td>Objective 3-15.</td>
<td>Increase the proportion of cancer survivors who are living five years or longer after diagnosis</td>
</tr>
</tbody>
</table>

†Source: Gosschalk & Carozza, 2003
*Objectives specific to cancer screening in rural populations

Another initiative, the NCI's Community Networks Program (CNP) administered by the NCI's Center to Reduce Cancer Health Disparities, is central to the NCI's efforts to reduce the unequal burden of cancer in the U.S. (NCI, 2008a). The Center supports the NCI Challenge Goal to eliminate suffering and death due to cancer, understand the causes of disparities, and reduce and eliminate inequities in the cancer burden among populations experiencing cancer disparities. The Center directs the implementation of initiatives that advance understanding of health disparities and integrates studies across the NCI's research divisions to identify scientific and policy areas that provide opportunities to reduce and eliminate cancer health disparities. In May 2005 NCI awarded $95 million in five-year grants to 25 institutions nationwide to participate in the CNP, including the seven-state Appalachia Community Cancer Network previously described. The major goal of the CNP is to reduce cancer health disparities through community-based participatory education, training, and research among racial/ethnic minorities and underserved populations.
In order to achieve these national objectives and reduce cancer disparities in rural populations, models of best practice strategies grounded in social science and health behavior theory are needed. The Community Guide recommendations are useful in providing some evidence-based strategies for increasing cancer screening across the general population. However, they are by no means comprehensive nor are they necessarily "best" practices, given that best practices by definition should be both theory- and evidence-based. Theory was largely absent from the evaluation criteria used in the systematic reviews used to make these recommendations. The interventions reviewed provided little insight into the applicability of screening strategies for hard to reach populations and gave no specific guidance about which intervention to select for a particular population or setting. In addition, these studies primarily focused on short-term changes in screening behavior and did not examine maintenance of regular screening or strategies that effectively sustain screening behaviors, once initiated (Baron et al., 2008b). The current study proposes a theory- and evidence-based best practices model which extends the existing literature to include strategies that are context- and culturally-sensitive to the everyday experiences of rural people. If used to design future interventions, the model could potentially help reduce cancer disparities in rural communities.
CHAPTER 3
THEORIES SUPPORTING A RURAL CANCER SCREENING MODEL

Social Ecological Theory

Since the mid-1800s, ecological theory has been advanced to explain the highly complex relationships among individuals, society, organizations, the built and natural environments, and personal and population health and well-being. The philosophical premise underlying ecological models is that behavior does not occur in a vacuum. Addressing multiple levels of behavior is thereby posited as a more comprehensive approach to health promotion. The defining feature of an ecological model is that it takes into account the physical environment and its relationship to people at individual, interpersonal, organizational, community, and policy levels (Stokols, 1992, 1996). As such, social ecological theory may be particularly appropriate and useful in conceptual models to guide cancer screening strategies and interventions for rural populations.

Roots of Social Ecological Theory

Beginning in the mid-1800s, ecological factors such as poverty and social class were studied in relation to health and disease; for example, the typhus epidemic, from which the host-agent-environment model evolved as the basis for public health analysis of infectious disease (McLeroy et al., 1988). There are traditions of ecological analysis of behavior within psychology. Sallis and Owen (1997) provide an overview of historical trends in the evolution of social ecological theory, based on previous reviews by McLeroy et al. (1988) and Stokols (1992, 1996). B. F. Skinner’s (1953) seminal studies showing that antecedent and consequent events in the observable environment directly controlled behavior was an influential forerunner of
current ecological models (Glanz, Rimer, & Lewis, 2002). Kurt Lewin (1936) first coined the term ecological psychology to describe the study of the influence of the outside environment on the person. Lewin’s view was of a limited role of the environment on behavior; in effect, that only a person’s perceptions of the external environment are important. Although the predominant contemporary explanations of behavior focus on cognitively-mediated determinants, there is a strong stream of psychological theory and research documenting direct, automatic environmental control of behavior (Bargh & Chartrand, 1999). Roger Barker (1968) developed the concept of behavior settings from his long-term observational studies of children in their everyday environments. Barker came to believe that behaviors could be predicted more accurately from knowing the situations that people are in, rather than from knowing about their individual characteristics (Wicker, 1979). Urie Bronfenbrenner (1979) focused on understanding the multiple levels of influence on behavior. Bronfenbrenner described three levels of environmental influences that interact with individual factors: the microsystem - interpersonal interactions in specific settings (e.g., with family members, social acquaintances, and work groups); the mesosystem – the interactions among various settings (e.g., family, school, and work); and the exosystem – the larger social system that can affect individuals and settings through economic forces, cultural beliefs and values, and political actions. Albert Bandura’s (1986) Social Cognitive Theory also shares some features with ecological models; specifically, that behavior is influenced by both personal and environmental factors. Despite Bandura’s rare reference in his writings to the role of the physical environment on behavior, contemporary models of health behavior based on Social Cognitive Theory posit multiple influences of the physical environment (e.g., Winett, King, Altman, 1989).
The early history of thought and research in the evolution of social ecological theory provides the foundation blocks upon which a model for cancer screening behavior change can be built. These building blocks include the influences on health behavior of the physical, economic, political, social and cultural environment; as well as knowledge, attitudes and beliefs of the individual and how the interactions of all of these factors can facilitate health behavior change.

*Application of Ecological Models to Health Promotion*

While the theory of ecological models evolved over a long period of time, the application of theory to health promotion programs has been a relatively recent development. Rudolph Moos (1980) first developed a social ecological model of health-related behavior that specified four categories of environmental factors as relevant for health: 1) physical settings, including features of both the natural environment (e.g., geography, weather) and of the built environment (e.g., buildings, urban design); 2) organizational factors (e.g., size and function of organizations such as worksites, schools, churches); 3) human aggregate factors (e.g., sociodemographic or sociocultural characteristics of people inhabiting an environment); and 4) social climate (i.e., perceived aspects of the social environment related to supportiveness of a social setting or clarity of expectations about the appropriateness of behaviors).

McLeroy, Bibeau, Steckler, and Glanz (1988) proposed an ecological model for health promotion that systematically categorizes behavioral factors into five levels of influence: 1) the individual level, including beliefs, values, education level, skills and other individual factors; 2) the interpersonal level, including interpersonal relationships between individuals; 3) the organizational level, which covers the way relevant institutions are organized and managed; 4) the community level, including the communities that individuals operate in (e.g. professional networks, associations,
neighborhoods), community attitudes, and the relationship among different institutions within communities; and 5) the policy level, which refers to policies and regulations affecting intervention participants and the institutions in which they function. The model assumes that appropriate changes in the social environment will produce changes (such as health behaviors) in individuals. Winett, King and Altman (1989) developed and published, in a pivotal book on health psychology and public health, a framework for integrating public health and psychological approaches to create more effective health interventions. This model proposed that the active involvement of community in designing and implementing interventions will enhance program delivery, improve the likelihood that change will be maintained at multiple levels, and encourage the ownership and control over community interventions, thereby leading to maintenance of the intervention beyond the external funding timeline. Cohen, Scribner, and Farley (2000) proposed a structural model of health behavior intended to move ecological theory from model building to the design and implementation of interventions. The model focuses on four categories of population-level structural factors that effect change in individual health behaviors: (1) availability of protective or harmful consumer products, (2) physical structures (or physical characteristics of products), (3) social structures and policies, and (4) media and cultural messages. The first three can directly influence individuals through facilitating or constraining behavior; while the fourth, media, operates by changing individual-level attitudes, beliefs and cognitions, as well as group norms. The authors also discuss the social distribution of environmental factors, risk behaviors, and adverse health outcomes and argue, as do Lynch, Smith, Kaplan, and House (2000), that socioeconomic disparities in health are largely attributable to differences in the material conditions of people's lives (Glanz et al., 2002).
One of the most important and highly influential applications of social ecological theory to public health can be found in the conceptual framework of the Healthy People 2010 U.S national health plan (Gamm et al., 2003). Initially articulated as the Healthy People 2000 plan (IOM, 1999), the Healthy People 2010 initiative is a set of national objectives and standards for researchers and practitioners to improve the public's health. The Healthy People 2010 field model includes objectives consistent with the ecological model of health promotion. Principles of social ecological theory as depicted in Evans & Stoddart's (1990, 2003) determinants of health model (Figure 3.1) were used to define the leading health indicators for the conceptual framework underlying Healthy People 2010. The model posits that the health and well-being of individuals and populations are products of individual or population risk factors and the role of medical care, and that health status and disease outcomes are determined by multiple factors both internal and external to the individual or population. These factors include the physical and social environments, genetic endowments, prosperity (wealth, poverty), individual behaviors and biology, health and function, disease, health care systems (including access to health care), and overall well-being. The schema also defines directions of influence and interaction among the various factors, in acknowledgement of the complex interrelationships and interactions among the multiple determinants of health. In addition, the model seeks to move health policy beyond health care policy alone to also include other health-related, social, political, and environmental policies, as well as characteristics and behaviors inherent in individuals and populations. The relationships among these many determinants of health suggest strategic points at which researchers or community groups can intervene to effect change in health status or disease outcomes.
Social ecological theory has been applied within multiple investigations of various health issues, including substance abuse (Kumpfer & Turner, 1990; Goodman, Wandersman, Chinman, Imm, & Morrissey, 1996); healthy lifestyles (Breslow, 1996); employee health (Stokols, 1996); and more recently within cancer control research. In the eight-year, community-based North Carolina Breast Cancer Screening Program for African American women in five rural counties, a social ecological framework was used to guide program development; data collection including program and individual service deliverer characteristics and external environmental influences; and evaluation (Earp, Altpeter, Mayne, Viadro, & O’Malley, 1995; Viadro, Earp. & Altpeter, 1997; Rauscher, Hawley, & Earp, 2005). Data from baseline (1993-1994), first (1996-1997), and second follow-up (2000) interviews with 336 White and 314 African-American rural women showed that physician recommendation was the strongest predictor of both initiation and
maintenance of regular mammography use; positive mammography attitudes and fewer personal barriers were strongly associated with initiation but not with maintenance (Rauscher et al., 2005). Kagawa-Singer, Park Tanjasiri, Lee, Foo, Ngoc Nguyen, Tran, and Valdez (2006) used an ecological and participatory action research approach (PAR) to reduce breast and cervical cancer morbidity and mortality rates among Asian American and Pacific Islander women by improving the capacity of community-based health centers that serve these women to deliver effective, culturally- and linguistically-appropriate breast and cervical cancer screening programs. Results from this research showed that PAR strategies and culturally-based techniques proved successful in maintaining scientific rigor, developing true community-researcher partnership, and achieving over 99% participation of their partnering community health outreach workers.

More recently, Woods, Montgomery, Herring, Gardner, and Stokols (2006) developed a social ecological model to examine which social factors (i.e., environmental, personal, person/environment interplay, Black culture and institutional policy) were predictive of prostate cancer screening among Black American men. Results showed that the physician's engaging communication style, encouragement to screen, the individual's positive interaction with healthcare staff, significant others, tailored social influences, and environmental factors were significantly and positively associated with prostate cancer screening in this population.

In further defining and applying the propositions of early social ecologists within the context of real-world situations, contemporary researchers have made important contributions to the understanding of the multiple determinants of health behavior. Thus, their collective efforts have strengthened social ecological theory and suggested
how specific strategies can be utilized to facilitate health behavior change, including cancer screening.

The Community Partnership Approach

In an editorial calling for more community outreach, Alan Leshner (2007), Chief Executive Officer of the American Association for the Advancement of Science and executive publisher of the journal Science, wrote:

There is a growing consensus that scientists must engage more fully with the public about scientific issues and the concerns that society has about them. Efforts that focus simply on increasing public understanding of science are not enough, because the problem is not merely a lack of scientific comprehension. In some cases, the public generally does understand scientific content in a fundamental way but still doesn't like it. Thus, the notion of public engagement goes beyond public education. We must have a genuine dialogue with our fellow citizens about how we can approach their concerns and what specific scientific findings mean. This kind of outreach is being encouraged by government agencies and private sources in Europe, Canada, and the United States.

In the field of public health, collaborative partnerships attempt to improve health-related conditions and outcomes and the well-being of entire communities. When diverse groups come together to achieve a common purpose, the outcome is often more effective for the targeted audience (e.g., Roussos & Fawcett, 2000). This is especially important for reaching underserved and high-risk populations in more effective ways.

Roots of the Community Partnership Approach

The Community Partnership Approach is an outgrowth of social ecological theory and practice, as recognition increasingly has been given to the involvement of
community stakeholders as partners in the research and program delivery process. The Community Partnership Approach is known by different terms, including “action research”, “participatory action research” (PAR), and “community-based participatory research” (CBPR). CBPR is the term most commonly used in the U.S., especially among governmental and public health agencies that have begun to address health disparities among disadvantaged populations. Many scholars use these terms interchangeably, given that all PAR methods share many underlying principles and core values (Wallerstein, 1999; Minkler, 2000). George, Green, and Daniel (1996) defined PAR as a “systematic investigation with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change.” Israel, Schulz, Parker, and Becker (1998) defined CBPR in public health as a partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process. In CBPR, all partners contribute their expertise and share responsibility and ownership of a program, resulting in a more comprehensive understanding of a health issue, which then facilitates putting that knowledge into action to improve the health and well-being of the community. To fully understand CBPR, it is instructive to examine the historical evolution of participatory action research into its modern-day application to health promotion.

The origins of action research reportedly stem from the work of psychologist Kurt Lewin around the close of World War II. Lewin emphasized the active involvement of people affected by the problem in research through a cyclical process of fact finding, action, and reflection, leading to further inquiry and action for change (Lewin, 1946; Minkler, 2000). More radical and innovative work was conducted in Third World countries of Latin America, India and Africa. In Latin America, Orlando Fals-Borda (1987) proposed community-based methods to motivate social
and economic change by empowering the "common" people, the basis for subsequent empowerment models of community research (Fals-Borda & Rahman, 1991). The dialogical method involving mutual learning and coupling of action-reflection of educator Paolo Freire (1974) in Brazil is considered a landmark in participatory frameworks, providing some of the philosophical underpinnings of more recent efforts, as well as the frameworks of sociological thought and communicative action provided by Jurgen Habermas (1979) from Germany.

The deep-rooted distrust of outside researchers among many local communities stems from the traditional approach of doing research on, and not with, the target community. Research often has been and continues to be viewed by many communities as colonizing efforts by powerful academic institutions that disallow the voices of those affected by the problem (Minkler, 2000). The Community Partnership Approach was initially used in the U.S. for research interventions to address cardiovascular disease and then extended to other health issues including cancer, HIV infection, and behavioral problems (e.g., Roussos & Fawcett, 2000; Blumenthal & DiClemente, 2003). With passage of the National Cancer Act of 1971 (P.L. 92-218), a promise was made to the American people to conduct the full spectrum of research and related activities necessary to prevent, control, and cure cancer. The President's Cancer Panel (NCI, 2008d) was thereby established and charged with monitoring and evaluating the National Cancer Program. The Panel is required to report at least annually to the President of the United States on impediments to the fullest execution of the program. The 2004-2005 Annual Report of the President's Cancer Panel made a number of recommendations about community participation in research:

1. Clinical and prevention research funding agencies should require community participation early in protocol design and in research implementation.
2. Research results must be shared with the individuals and communities that participate in clinical trials and other studies.

3. Clinical and prevention research grantees should be required to include as part of the grant application a plan for disseminating and sustaining new interventions into the community.

4. Existing community-based participatory models should be evaluated to determine the potential for adopting them in other geographic areas and populations.

*Principles of the Community Partnership Approach*

In contrast to the traditional “top-down” approach used in clinical research, CBPR in public health is based on a “bottom-up” approach and collaborative process involving academic/institutional researchers and community representatives (Figure 3.1) (Israel et al., 1998). Health-related CBPR focuses on social, structural, and physical environmental inequities through active involvement of community members, organizational representatives, and researchers in all aspects of the research process. Partners contribute their expertise to enhance understanding of a given health issue and integrate the knowledge gained with action to benefit the community involved. Successful CBPR develops sustainable relationships with partners at various levels within the community and provides resources (e.g. funds, training and possible employment opportunities) for the communities involved (Israel et al., 1998, 2001). CBPR endorses the same values of methodological rigor and ethical review as other research, but allows some flexibility in the research methods used to accommodate participation of community stakeholders. Fidelity (the degree of adherence to the study protocol) can thus be an issue in the CBPR approach, as community groups may not be used to, or understand the rigorous methods used in scientific inquiry. CBPR values literacy- and culturally-appropriate methods and
The ultimate goal of CBPR is to combine knowledge with action at the community level to achieve social change and improve the well-being of community residents.

<table>
<thead>
<tr>
<th>Table 3.1 Principles of community-based participatory research†</th>
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<tr>
<td>1. Recognizes community as a unit of identity</td>
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<td>2. Builds on strengths and resources within the community</td>
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<tr>
<td>3. Facilitates collaborative, equitable involvement of all partners in all phases of the research</td>
</tr>
<tr>
<td>4. Integrates knowledge and action for the mutual benefit of all partners</td>
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<tr>
<td>5. Promotes a co-learning and empowering process that attends to social inequalities</td>
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<tr>
<td>6. Involves a cyclical and iterative process</td>
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<tr>
<td>7. Addresses health from both positive and ecological perspectives</td>
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<tr>
<td>8. Disseminates findings and knowledge gained to all partners</td>
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<tr>
<td>9. Involves a long-term commitment by all partners</td>
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† Source: Israel et al., 1998

Beyond the general assumption that CBPR necessarily engages the lay community, Green, George, Frankish, Herbert, Bowie, and O’Neil (1995) raised the issue of whose participation needs to be solicited and incorporated in participatory research. Their assertion is that, if “community” includes other groupings of people sharing common characteristics or interests, there is a need and opportunity for undertaking participatory research with groups other than community residents. A broader application of participatory research is therefore urged in which the research is seen as systematic inquiry with the collaboration of all those affected by the issue being studied for the purposes of education, taking action, and effecting social or policy change. In this broader definition, collaborators may include not only the lay community and the researchers, but also public health practitioners, local agencies,
and policy makers (Green et al., 1995; Green & Mercer, 2001; Israel et al., 2001). Stakeholder involvement and participation are maximized when all partners are active throughout the study: in formulating research questions, selection of methods, analysis, interpretation, and application of findings. At minimum, stakeholders should be involved in the planning phase of the study to develop research questions and in the interpretation and application of the findings. This demarcation distinguishes participatory research from basic research, which typically involves only the researchers.

Clearly, as an outgrowth of social ecological theory and practice through participatory action for more than half a century in numerous countries and cultures, the Community Partnership Approach has been demonstrated as essential to influencing a community’s health status through participation, partnerships, and empowerment. The Community Partnership Approach should thereby be a core component of any model for health behavior change, particularly in rural communities.

**Integrative Frameworks for Health Promotion**

Finally, there is a growing movement towards the development and use of integrative frameworks as a more unified set of guidelines for health promotion planning and evaluation. Integrative frameworks incorporate multiple health behavior theories within a conceptual model and provide a comprehensive way to organize thinking about the many complex interactions between the multilevel factors involved in health promotion. The logic for using integrative frameworks is that they potentially can help close the gap between "best practice" guidelines for community health promotion and the reality of the way things work in the everyday world. For example, Best, Stokols, Green, Leischow, Holmes, and Buchholz (2003) proposed an
overarching theoretical framework for health promotion research that integrates four theoretical models: the Social Ecological model, the Life Course Health Development model, the PRECEDE-PROCEED model, and the Community Partnership model. The Community Partnership model in this integrative model reframed the literature to show three contrasting orientations to community partnering: those that emphasize empowerment, risk behavior, and interagency collaboration, with core values that define each orientation. The Empowerment orientation weights process heavily, the Behavior orientation weights outcome, and the Organization orientation weights structure. All three are needed for health promotion efforts. In addition, at least three kinds of partnering were envisioned for establishing and sustaining the collaborative health promotion community: collaboration among multidisciplinary health researchers, between multidisciplinary health researchers and community, and among community health organizations across local, state, national, and international levels. This systems-theory perspective suggests that a more comprehensive, participatory, and collaborative approach to health promotion is potentially more effective than narrowly targeted and less collaborative approaches.

An integrative framework that provides a unified set of guidelines by combining multiple theoretical approaches appears a fitting and most appropriate model for facilitating positive, cancer prevention and early detection behaviors in rural communities. Such a model would include the multiple-level, predisposing barriers and enabling factors that influence intention to be screened, but also consider how community member collaboration in developing and implementing interventions that meet the specific needs of their community can effectively increase and maintain regular cancer screening.
Conceptual Framework for the Study

A conceptual framework rooted in the integrated model just described was developed to guide the current research (Figure 3.2) and construct a best practices model for rural cancer screening, based on the study’s findings. This framework considers the various types of environmental factors that facilitate (predict) or inhibit (represent barriers to) screening behaviors (Social Ecological Theory), by which the choice of strategies used to intervene upon those factors can be made. Intervention strategies that use participatory collaboration (Community Partnership Approach) grounded in health behavior theory can facilitate change in screening behavior and longer-term cancer-related outcomes, including decreased cancer incidence, morbidity, mortality, and disparities. The Social Ecological Model frames the environment-behavior interaction as it relates to cancer screening in the rural setting. The Community Partnership Approach frames the intervention-behavior interaction for impacting screening behavior change. The integration of these models creates a comprehensive model against which the findings from this study can be fitted to construct a best practices model for rural cancer screening.

![Figure 3.2 Conceptual Framework For Determining A Rural Best Practices Cancer Screening Model](image-url)
CHAPTER 4
RESEARCH DESIGN AND METHODOLOGY

Study Design

This research used a retrospective, comparative case study design with key informant interviews and document review, with qualitative and quantitative evaluation methods to determine best practice strategies for promoting cancer screening in rural communities. "Cases" in this study were defined as rural, community-based cancer coalitions and cancer center community outreach programs east of the Mississippi River that serve a rural audience. The project was limited to the eastern half of the U.S. because it is largely encompassed by Appalachia, one of the largest, rural, geographical regions in the U.S., with some of the country’s highest cancer incidence and mortality rates and experiences significant cancer disparities. Appalachia also has one of the longest existing networks of rural, community-based cancer coalitions. In addition, the eastern U.S. is home to the majority of National Cancer Institute-designated Comprehensive Cancer Centers with outreach programs that serve a rural audience (NCI, 2008b). A conceptual framework based on Social Ecological Theory (McLeroy et al., 1988; Stokols, 1992, 1996; Evans & Stoddart, 1990, 2003), the Community Partnership Approach (Green et al., 1995; Israel et al., 1998, 2001; Green & Mercer, 2001), and an Integrative Framework for Health Promotion (Best et al., 2003) guided the research (Figure 3.2). The study was approved by the Scientific Review Committee of the Penn State Hershey Cancer Institute, the Institutional Review Board of the Penn State Milton S. Hershey Medical Center College of Medicine, and the Human Subjects Research Committee of the University of Colorado at Denver and Health Sciences Center (Appendix A).
Data Collection

The data were collected from October 2007 to August 2008 through key informant telephone interviews with community-based, cancer coalition members and cancer center outreach program staff and document review to supplement the key informant interview data. The key informant interviews were conducted by telephone in the Department of Public Health Sciences, Penn State College of Medicine, by the principal investigator (Ms. Kluhsman) and a research assistant (Ms. Diane Sheehan), a 2008 graduate of the Master's in Health Education Program at the Penn State University-Harrisburg campus. Ms. Kluhsman trained Ms. Sheehan on the study protocol and the interviewing, document review, and data coding processes.

Key Informant Interview

Development of the Key Informant Interview Instrument

The key informant interview instrument (Appendix B) was constructed using well-established, qualitative methods of inquiry (Spradley, 1979) and based upon comprehensive review of the cancer screening literature and the study's conceptual framework. A set of six general, open-ended, “grand tour” questions were developed as an in-depth, descriptive sequence of events to allow respondents to tell a narrative “story” about their cancer screening strategies used over the past three years (2005-2008) and the extent to which they were successful or unsuccessful, as defined by the respondent's respective coalition or cancer center outreach program and/or his or her personal definition of success. Additional “mini-tour” sub-questions were guided by probes to elicit finer details about the strategies used to promote cancer screening and the outcomes of their community interventions.

The interview instrument was designed to assess four distinct domains of factors related to rural cancer screening interventions: 1) Program demographics and
respondent characteristics; 2) Strategies to promote cancer screening; 3) Barriers to cancer screening; and 4) Outcomes of interventions using these strategies (Table 4.1).

<table>
<thead>
<tr>
<th>Table 4.1 Factors related to rural cancer screening</th>
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<tbody>
<tr>
<td>Domain 1 (Questions 1 and 3): Program and Respondent Characteristics</td>
</tr>
<tr>
<td>• Program service area demographics (5 factors): general location/rurality; racial/ethnic make-up; educational levels; poverty levels; industry/employment</td>
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<tr>
<td>• Respondent characteristics (4 factors): position/leadership role within the program; length of program service; primary discipline/profession; role in interventions</td>
</tr>
<tr>
<td>Domain 2 (Questions 2 and 4): Strategies to Promote Cancer Screening</td>
</tr>
<tr>
<td>• Cancer Screening Efforts (general) (4 factors): target audiences; targeted cancers; intervention sites; funding sources</td>
</tr>
<tr>
<td>• Cancer Screening Strategies in Past 3 Years (7 factors): intervention strategies; why/how strategies were chosen; how community was engaged/trust established/built; participatory approaches/extent of stakeholder involvement; recruitment strategies; health behavior theories/models; evidence-based approaches</td>
</tr>
<tr>
<td>Domain 3 (Question 5): Barriers to Screening</td>
</tr>
<tr>
<td>• Barriers to Cancer Screening (4 sub-domains of factors): Physical Barriers (e.g., geography, economy, physical structures); Structural Barriers (e.g., insurance/cost/poverty; availability of health care facilities and providers; transportation; provider recommendation of screening; policy-related issues); Social-Cultural Barriers (e.g., beliefs/myths about cancer; fatalism; language; cultural issues); Individual Barriers (e.g., fear/denial; knowledge/education/literacy</td>
</tr>
<tr>
<td>Domain 4 (Question 6): Outcomes of Interventions</td>
</tr>
<tr>
<td>• Definition of Success (3 factors): measures of success; reasons strategies were successful or unsuccessful; examples of successful and unsuccessful strategies</td>
</tr>
<tr>
<td>• Outcomes (2 factors): number of persons recruited/screened/diagnosed; influence of funding source and funding levels on outcomes</td>
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Pretest

After initial development, the key informant interview instrument and process were pretested with a small sample (n=7) of community-based cancer coalition
members in rural communities of northeast, northwest, and southwest Pennsylvania, and with cancer center outreach program staff that serve rural audiences in northeast, northcentral, and southcentral Pennsylvania. The recorded pretest interview (.WAV) files were sent via secure, electronic transfer to Dr. Jean Scandlyn for quality assurance; in effect, listening to all 7 interviews and providing feedback to the interviewers. The pretest results and quality assurance review confirmed that all types of cancer for which screening is currently available (i.e., breast, cervical, colorectal, prostate, and skin) should be included in the main study key informant interview, along with the three domains of barriers described above. Minor text changes were made and the main study interview instrument finalized.

*Development of the Data Coding Scheme and Coding Sheet*

Following the interview pretest, an initial data coding scheme was developed for construction of a Coding Sheet to be used as a tool to summarize the qualitative study data. The initial coding scheme was developed from *a priori* variables drawn from the study's conceptual model, the research questions, and key informant interview questions and then used to generate a list of potential thematic codes. The initial Coding Sheet was then drafted by formatting the list of thematic codes as a checklist with some additional, open-ended fields. This initial version of the Coding Sheet was used to code the pretest interview data and found to need only minor revisions. The second version of the Coding Sheet was then used to code the first five main study key informant interviews, again allowing for modifications, which resulted in a third version of the Coding Sheet. This process was repeated, as appropriate, throughout the data collection and coding period until a final version of the Coding Sheet emerged (Appendix C). With each new version of the Coding Sheet, previously coded data were recoded, as appropriate. Thus, all final coding of the key informant
interview and document review data was conducted through a rigorous methodology that strengthens internal validity and reliability of the study's findings. The data coding process is further described in the analysis section below.

Sample Eligibility and Identification

Key informant eligibility included male and female members of rural, community-based cancer coalitions in Pennsylvania and New York affiliated with the Appalachia Community Cancer Network at Penn State University (ACCN-PSU) and outreach program staff of National Cancer Institute (NCI)-designated Comprehensive Cancer Centers east of the Mississippi River that serve a rural population. Potentially eligible respondents were identified through the ACCN-PSU coalition database membership rosters, the NCI Cancer Centers Program website, and the websites of individual cancer center outreach programs. The initial sample pool was drawn from all 10 existing, ACCN-PSU member coalitions and 13 NCI-designated Comprehensive Cancer Centers assumed to serve a rural population (based on geographic location and website information). However, due to a potential accrual shortfall in both groups (especially coalitions) in the latter part of the accrual period, eligibility was extended to include additional coalitions in other ACCN regions, as well as cancer center- and university-based outreach programs that serve a rural audience but are not part of the NCI Cancer Centers Program. The final sample pool was thereby comprised of 78 potential respondents representing 12 community-based, Appalachian coalitions (n=50); 11 university-affiliated cancer center outreach programs (n=26) with and without NCI Comprehensive Cancer Center designation and/or funding through the NCI's Community Cancer Network Program; one university-based ACCN-affiliated outreach program that lacks a cancer center or medical school on their campus (n=1); and a county-based cancer center not affiliated
with either a university or NCI program (n=1). A more detailed description of the coalitions and outreach programs follows.

**ACCN cancer coalitions.** In recognition of the cancer disparities prevalent in Appalachia and other disadvantaged populations, beginning in 1992 the National Cancer Institute implemented a funding stream to address and reduce these disparities. Under the NCI-funded Appalachia Leadership Initiative on Cancer (ALIC) (1992-1999), community coalitions were formed in rural Appalachian counties of Pennsylvania and the southern tier of New York State, West Virginia, and Kentucky in collaboration with their academic partners at Penn State University, West Virginia University and the University of Kentucky (ALIC headquarters) to build capacity and begin delivery of cancer-related outreach to their local communities (Friedell et al., 2001). Through a second NCI funding cycle (2000-2005), the coalitions and their academic partners continued to build capacity as the Appalachia Cancer Network (ACN), adopted a conceptual model for community-based research, and intensified their community education and screening efforts (Lengerich et al., 2004). In the current, third cycle of NCI funding (2005-2010), the program has expanded to a five-region, seven-state network as the Appalachia Community Cancer Network (ACCN), with increased focus on cancer screening using evidence-based methods, cancer prevention, survivorship, and policy-related issues (ACCN, 2008; Lengerich et al., 2006b; NCI, 2008a). The ACCN is one of 25 Community Network Programs across the U.S. and its territories funded by the NCI’s Center to Reduce Cancer Health Disparities. Headquartered at the University of Kentucky Prevention Research Center, the ACCN is comprised by community coalitions and their university partners in the Appalachian regions of Kentucky (University of Kentucky), Pennsylvania and New York (Penn State University), Ohio (The Ohio State University), Virginia (Virginia Polytechnic Institute and State
University), West Virginia and Maryland (West Virginia University). The overall goal of the ACCN is to reduce cancer disparities in Appalachian communities through community-based education, research and training. The ACCN focuses its efforts primarily on cervical, lung, and colorectal cancers, all of which have high incidence and mortality rates in its seven-state service area. However, breast, skin, and prostate cancer also are targeted, given the disparately high incidence and mortality rates that persist for these cancers throughout the ACCN region.

Cancer center community outreach programs. The NCI Cancer Centers Program supports major academic and research institutions throughout the U.S. to sustain broad based, coordinated, interdisciplinary programs in cancer research (NCI, 2008b). These institutions are characterized by scientific excellence and capability to integrate a diversity of research approaches to focus on the problem of cancer. The NCI and its Cancer Centers Program are dedicated to the advancement of cancer research to ultimately impact on the reduction of cancer incidence, morbidity, and mortality. There are two types of NCI designations: NCI-designated Cancer Center and NCI-designated Comprehensive Cancer Center. To be recognized as an NCI-designated Cancer Center an institution must have a P30 Cancer Center Support Grant award. To qualify as an NCI-designated Comprehensive Cancer Center, the institution must meet multiple, specific criteria: 1) width and breadth of basic research, clinical research, and population and behavioral sciences research (including prevention and control); 2) strength of the interactions among the three major areas; and 3) a community outreach program that is knowledgeable about cancer incidence and mortality rates among both majority and special populations in its service area. The outreach program must conduct outreach efforts and activities that address the special problems of the community; use available expertise and resources to serve the community in ways that will reduce cancer incidence and
mortality; and evaluate the impact of its activities on clinical and public health systems within the center’s catchment area.

Sample Selection and Recruitment

Names and contact information of potential respondents in the sample pool were entered into a password-secure Excel spreadsheet on the principal investigator's personal computer, which served as the recruitment management system. From the sample pool list, three potential respondents representing various positions from each coalition (e.g., chairperson, community health agency representative, community volunteer) and cancer center outreach program (e.g., director, program manager, health educator) were randomly selected to receive an invitation to participate, with replacement. In effect, if someone refused, was found to be ineligible, or did not respond after multiple attempts, another potentially eligible person was selected. This purposeful, representative sampling strategy intended to strengthen generalizability of the study’s findings. The selection process occurred across three successive waves to allow sufficient time for the two interviewers to schedule and complete the interviews, due to other time commitments and professional responsibilities. The goal was to repeat the selection process until the target sample size (n=60 respondents; 30 per group) or saturation was reached.

Key informant recruitment materials (Appendix D) were mailed to potential participants, including: a letter of invitation from the principal investigator with a brief description of the study; the Informed Consent Statement (no signature required); a list of the five core interview questions; a bounce-back Acceptance-Refusal Form to accept or decline participation in the study; and a pre-paid/ pre-addressed return envelope to mail back the completed Acceptance-Refusal Form. Those who consented were asked to provide their preferred days/times, telephone
number to be used for the interview, and preferred method of initial contact (telephone or e-mail) to schedule the telephone interview. Upon receipt of the completed Acceptance Form indicating willingness to be interviewed, assignment to one of the interviewers was made. The assigned interviewer contacted the participant to schedule the interview at a time convenient to the participant. It is instructive to note that interview assignments were made alternately to the two interviewers as Acceptance Forms were received; however, in cases where the interviewer knew the respondent well enough for potential bias to occur (as decided by consensus between the two interviewers), assignment was given to the other interviewer. For both non-responders to the initial mailing and those who consented but were difficult to reach, one or more attempts per week were made by telephone or e-mail to reach potential respondents (Neuman, 1997, p.247). Contact attempts were made on different days of the week and various times of day, taking into account work schedules and possible vacation time, as the bulk of recruitment occurred in the summer. After one month of unsuccessful attempts, the potential respondent was ruled as a passive refuser, and no further contact attempts were made (Sears et al., 2003).

**Interview Procedures**

The interviews were conducted by telephone by Ms. Kluhsman and Ms. Sheehan and were expected to take approximately 35-40 minutes. The purpose of the study and consent provisions were briefly reviewed and explicit permission to tape record the interview obtained to assist subsequent transcription and help ensure accuracy of the transcribed data. If permission to tape record was denied, the interviewer did not turn on the tape recorder, but rather recorded the information manually, by pencil-paper only. However, as no one denied such permission, all interviews were recorded. The interview solicited information about screening strategies used to
promote cancer in rural communities during the past three years (2005-2008) (Appendix B). At the end of the interview (and if needed, based on accrual patterns), a snowball strategy was used to recruit additional participants by asking the respondent if any of their fellow coalition members or outreach staff might be interested in being interviewed. The recording device was turned off prior to any personal information being given.

**Incentives.** Within 1-3 days following completion of the interview, a $25.00 check was mailed to coalition participants in appreciation for their time. A similar financial incentive was not offered to the cancer center outreach program group, as professional courtesy in completing the interview was anticipated from these individuals.

**Respondent validation of the interview data.** As qualitative research is as much a reflection of the researcher as the research instrument, validation of the key informant interview data was critically important for this study (Crabtree & Miller, 1999). Thus, a “member check” validation technique (Lincoln & Guba, 1985) was used to maximize validity of the key informant data by recycling the transcribed interview back to respondents to review and corroborate (or disconfirm and correct) the printed transcript. A copy of the transcribed interview was mailed to each coalition and cancer center outreach program staff, generally within one month following the interview. The mailing included a cover letter and pre-paid, pre-addressed return envelope. Specifically, respondents were asked to make corrections and provide additional information or comments, as appropriate, on the transcript copy and then return their written comments to principal investigator Kluhsman by mail, e-mail or fax under confidential cover.

**Quality Assurance and Data Security.** Dr. Jean Scandlyn, Co-Chair of Ms. Kluhsman’s Dissertation Committee, provided quality assurance for the main study
Dr. Scandlyn has extensive experience in medical and social anthropology, social justice and marginalized groups, qualitative research, health behavior theory, and multicultural nursing. Her unique combination of expertise significantly enhanced the quality and delivery of the key informant interviews, as well as analysis and interpretation of the qualitative data. Four interviews (10% of the final study sample) were randomly selected for quality assurance. The de-identified, audio and transcribed computer files for each of the four interviews were transmitted to Dr. Scandlyn via secure, electronic transfer. Quality assurance measures included audio review of the recorded key informant interviews and visual review of each transcribed, coded interview (including a calculated Interrater Reliability coefficient for the two coders). These measures intended to strengthen validity and reliability of the data. As noted previously, all data were labeled with a study number; participants' personal contact information was maintained in an Excel spreadsheet by principal investigator Kluhsman; and all data stored in her password-secured computer and locked office to assure human subjects protections.

**Document Review**

Document review was employed as a second method of data collection to supplement and fill in the gaps of missing data from the self-reported, key informant interviews. Multiple sources were searched to identify and extract the data, including: 1) the ACCN-PSU coalition database, a password-secure, web-based application maintained by the ACCN-PSU research staff, including Ms. Kluhsman; 2) the five-region, ACCN data collection system; 3) websites of individual coalitions and cancer center outreach programs (where applicable); and 4) corresponding published literature through the PubMed web-based application (U.S. National Library of Medicine & National Institutes of Health, 2008). The data were coded
using similar methods as for the key informant interviews. Data coding processes are further detailed in the analysis section that follows.

Analysis

Overall Analytic Approach

A mixed methods approach was taken in this research, including: 1) qualitative analysis as the major methodology to conduct thematic analysis, coding, and comparison of the key informant interview and document review data, and 2) quantitative methods to provide descriptive statistics of the coded qualitative data. The overall approach followed the theoretical propositions that led to the case study (Yin, 1994). Thus, the data were examined through all phases of analysis in relation to the study’s research questions and conceptual framework (Figure 3.2) that arose from the review of the cancer screening literature and health behavior theory, respectively. Analyses were undertaken with care to avoid biasing the results, which can happen when, for example, a researcher subconsciously imposing his/her own world view or desired results on data provided by key informants. Established qualitative analytic techniques were purposefully employed to reduce the chance for bias, including systematic coding and cross-checking of the coding process and respondent validation. The goal of the analysis was to treat the evidence fairly, produce compelling analytic conclusions, and to rule out alternative explanations to the extent possible.

Four well-established methods of qualitative data analysis were used to evaluate the case study evidence: 1) triangulation (Denzin, 1978); 2) thematic analysis with iterative review and coding, using a template organizing style (Crabtree and Miller, 1999); 3) pattern matching (Yin, 1994); and 4) data organizing and display techniques that merge qualitative data and descriptive statistics from quantitative analysis (Miles & Huberman, 1984).
**Triangulation**

Triangulation has been identified as one method to help obtain rigor in qualitative research (Denzin, 1978). In triangulation, more than one source of data and analytic methods are used, along with cross-referencing of data, investigators and theories. Triangulation helps to reduce investigator bias, increase focus, and achieve comparable results. In this study, triangulation occurred by employing a conceptual model comprised by multiple theories that guided collection and coding (by more than one researcher) of data from multiple sources (key informants, document review); verification by key informants representing a range of positions, roles and perspectives; and comparison of the summary data with findings from systematic literature reviews (*Community Guide* recommendations) and national cancer screening data (BRFSS). Triangulation thus represents a major strength of this comparative case study.

**Thematic Analysis**

Thematic analysis and coding of the key informant interview and document review data were conducted to systematically examine, categorize, tabulate, and recombine the data for meaningful interpretation. Thematic analysis involved iterative review and coding of the key informant interview and document review data, using a template organizing style and categorical, *a priori* themes relative to the cancer screening literature, the study’s conceptual framework and research questions. This iterative process permitted the addition of new codes for themes as they emerged from the data (Crabtree & Miller, 1999).

As noted previously, data coding was performed by principal investigator Kluhsman and Ms. Sheehan as a second coder, who also assisted in conducting the key informant interviews and document review. Using the initial Coding Sheet
developed following pretesting of the key informant interview, the two coders independently coded the data and then regularly met to compare and reconcile their coding notes. This cross-checking of coding aimed to reduce subjectivity during data analysis (Barbour, 2001). Four consecutive sessions were held to review the coded key informant interview data (10 interviews per session), followed by five consecutive sessions to review the coded document data (5 sets of case documents per session). During each review session, the independent coding was compared and any coding disagreements reconciled through discussion and agreement of the appropriate code to be assigned. For new themes that emerged through the independent coding or review session, a new code was created as agreed upon by both coders, and the coding scheme revised, as appropriate. The revised coding scheme was then used to recode previously coded data, if appropriate, and for coding the next round of interview data. Thus, iterative review and coding of the data permitted continuous refinement of the Coding Sheet and thereby strengthened internal validity. Interrater reliability was calculated for each reconciled interview and case set of documents, targeting 95% agreement or 0.8 Cohen's kappa (Siegel & Castellan, 1988). After Coding Sheets were completed for individual key informants, a Case Summary Sheet was prepared for each coalition and cancer center case. The Case Summary Sheet consolidated codes of multiple key informants with any additional codes from document review for each site.

Quantitative Analysis

Descriptive statistics were used to help evaluate the case study evidence. A data spreadsheet was created using Microsoft® Office Excel 2003 (11.8211.8202) SP3, into which the data were entered for categorical themes corresponding to those on the Coding Sheet. Frequencies and percentages of case demographics, key informant
interview data, and document review data were calculated. These descriptive statistics were then used in conjunction with narrative data (e.g., salient quotes, examples of successful and unsuccessful strategies) from the case summaries to conduct comparative case analysis.

**Comparative Case Analysis**

Comparative case analysis relied upon the second two qualitative methods referenced above that have been widely used in qualitative research: pattern matching, which is especially useful for explanation building in a multiple case study design (Yin, 1984; 1994), and data organizing, display, and analytic techniques (Miles & Huberman, 1984) for meaningful interpretation of the study data.

*Pattern Matching*

All primary measures within the four domains of factors related to rural cancer screening interventions (i.e., program and respondent characteristics, screening strategies, barriers to screening, and intervention outcomes) were examined and compared across cases. Patterns that emerged from the data were compared against those that would be predicted by the conceptual model or by alternative explanations, which in this study includes recommended cancer screening strategies from the Community Guide and state-specific BRFSS screening behavior data. According to Yin (1984), the patterns may be related to the dependent or independent variables. If the patterns coincide, the results help strengthen the study’s internal validity.

*Comparison of screening strategies to Community Guide recommendations.* Screening strategies and other data reported by cases in this study were compared to those recommended by the U.S. Preventive Services Task Force and published in the Community Guide for breast, cervical, colorectal, and skin cancer, as described in Chapter 2. Despite the current lack of sufficient evidence for any particular screening
strategies to be made for prostate cancer, it is instructive to compare screening strategies reported in this study (as defined by the respondents and their programs) to similar strategies used in other interventions in the published cancer screening literature. Therefore, such comparisons were attempted for prostate cancer in this phase of the analysis.

Comparison of the findings to the Study’s Conceptual Model. Finally, the similarities and patterns found in the data were compared against those in the study’s conceptual model, including factors related to the physical environment, structural factors, sociocultural factors and individual factors in relation to intervention strategies, proximal outcomes, and longer-term outcomes.

Data Organizing, Display, and Analytic Techniques

Various methods were used to synthesize, visualize, and interpret the study data (Miles & Huberman, 1984). As described previously, the Case Summary Sheet provided a means to synthesize the key informant interview and corresponding document review data for each coalition and cancer center case. These data were entered into an Excel spreadsheet and descriptive statistics (counts, percentages) calculated. One frequency table summarized program and respondent demographics; another summarized percentages of different types (categories) of strategies used. To evaluate strategy effectiveness, a matrix table was created to list categorized strategies used by each case type (coalition, cancer center outreach program) and their corresponding screening outcomes. Tables also were used to separately display categorical examples of successful and unsuccessful strategies with related, salient quotes. Two additional tables presented comparisons of strategies reported in this study with Community Guide recommendations and state-specific BRFSS data, respectively. Finally, a flowchart was created and used to illustrate the fit of the data
with the study’s conceptual model, from which the proposed best practices model of rural cancer screening was developed.

In summary, the use of qualitative research, especially its application in multisite studies, requires robust data collection techniques, rigorous analytic methods appropriate to qualitative research, and systematic organization, interpretation and presentation of textual data. The methods used and described above were carefully selected to maximize credibility of the research and present the findings in a manner that will enhance their utility for researchers and community outreach groups.
CHAPTER 5

CASE STUDY FINDINGS: COMMUNITY-BASED COALITIONS AND CANCER CENTER-ACADEMIC OUTREACH PROGRAMS

The research undertaken and reported herein sought to answer the following questions and sub-questions:

1. How can strategies used to promote cancer screening among rural residents be characterized? (Aim 1)
   
   a. To what extent have strategies that address barriers to screening been used? What specific barriers to screening were targeted?
   
   b. To what extent has a participatory approach been used to promote screening? What specific participatory strategies were employed?
   
   c. To what extent have health behavior theories or models been used? What specific theories or models were used?
   
   d. To what extent have evidence-based and evidence-informed approaches been utilized to promote screening? What specific evidence-based strategies were used?
   
   e. In what ways have funding level and funding sources influenced the choice of strategies used?
   
   f. In what ways have federal, state or local policy influenced the choice of strategies used?
   
   g. How do the cancer screening strategies used by community-based coalitions and cancer center outreach programs compare? How are they different? How are they similar? In what ways do they coincide?
2. To what extent have intervention strategies been successful or unsuccessful in promoting cancer screening among rural residents? (Aim 2)

a. How do community-based coalitions and cancer center outreach programs define success in their rural screening interventions?

b. To what extent has addressing barriers to screening contributed to the success of screening interventions?

c. To what extent have participatory approaches contributed to successful screening outcomes?

d. To what extent have health behavior theories or models contributed to successful screening outcomes?

e. To what extent have evidence-based and evidence-informed approaches contributed to successful screening promotion?

f. In what ways have funding level and funding sources contributed to successful screening efforts?

g. In what ways has federal, state or local policy contributed to the success of rural screening interventions?

h. How do the cancer screening outcomes of community-based coalitions and cancer center outreach programs compare? How are they different? How are they similar? In what ways do they coincide?

3. In a best practices model for promoting cancer screening among rural populations (Aim 3):

a. What precipitating factors facilitate or inhibit cancer screening behaviors in
b. What evidence-based and evidence-informed strategies can positively impact the cancer screening behaviors of rural residents?

c. What short- and long-term outcomes result from implementing strategies that effectively promote cancer screening in rural communities?

This study used a retrospective, comparative case study design and mixed methods to determine best practice strategies for promoting breast, cervical, colorectal, prostate, and skin cancer screening in rural communities. The study was guided by a conceptual framework based on Social Ecological Theory and the Community Partnership Approach to health promotion. Data were primarily collected through key informant telephone interviews with members of rural cancer coalitions and staff of cancer center-academic outreach programs that serve a rural population; supplemented by document review of program websites, coalition databases, and published journal articles. Analyses included systematic coding and interpretation of data through thematic analysis, pattern matching, and triangulation; and descriptive statistics to report case characteristics and prevalence of screening strategies. The findings were compared to evidence-based strategies recommended and published in the Community Guide to Preventive Health Services by the U.S. Preventive Services Task Force, and to the study’s conceptual model. Finally, the findings were used to construct a best practices model of rural cancer screening strategies.

As a preamble to the research findings presented below, it is instructive to distinguish the various types of outcomes of rural cancer screening promotion interventions to be described. Thus, ‘screening-specific outcomes’ is defined as the number of completed screenings, as reported by key informants or found in document
review. The term ‘screening-related outcomes’ is defined as the number of individuals reached with a cancer-related message but not reported as having completed screening, as reported by key informants or found in document review (e.g., change in cancer-related knowledge, attitudes, intent to be screened, intent to receive HPV vaccination, unhealthy lifestyle behaviors). In addition, it is important to note that the more quantitative tables are intended to identify patterns, not to quantify differences and similarities among these groups. The many tables displaying so many frequencies and percentages may be confusing; the qualitative data tell a rich, more complete story.

The Research Sites and Key Informants

The initial sample pool consisted of 78 potentially eligible key informants from 13 cancer center-academic outreach programs and 12 community-based coalitions. All were contacted and of the 78, 32 (41%) refused, 5 (6.4%) were found ineligible (no outreach to rural audiences), and 1 (1.3%) was unable to be contacted after multiple attempts. Among the 32 who refused, 26 (81.3%) were coalition members and 6 (18.7%) were cancer center-academic program staff. Of these, one coalition member’s supervisor disallowed participation; another was too busy to participate; and all others provided no reason for refusal. As noted previously, accrual shortfalls resulted in modifying eligibility criteria to include a coalition in one other state and other types of cancer center-academic programs within Appalachia. The final sample of 40 (51.3%) key informants included 23 members of community-based cancer coalitions (n=11) in three states--Kentucky, Pennsylvania, and New York; and 17 staff of cancer center outreach programs (n=9) in 10 states--Alabama, Kentucky, Pennsylvania, Maryland, Mississippi, North Carolina, South Carolina, Tennessee, Virginia, and West Virginia (Table 5.1). All 11 community-based coalitions are affiliated with the NCI-supported Appalachia Community Cancer Network (ACCN,
Table 5.1 Sample characteristics: coalition and cancer center-academic outreach programs, 2006-2008*

<table>
<thead>
<tr>
<th>SERVICE AREA</th>
<th>Community-based Coalitions (n=11)</th>
<th>Cancer Center-Academic Outreach Programs (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>States</td>
<td>3 (KY, NY, PA)</td>
<td>10 (AL, KY, MD, MS, NC, PA, SC, TN, VA, WV)</td>
</tr>
<tr>
<td>Counties</td>
<td>27 (med 2; range, 1-8)</td>
<td>383 (med 23; range, 2-95)</td>
</tr>
<tr>
<td>Appalachian Counties</td>
<td>27</td>
<td>225</td>
</tr>
<tr>
<td>Rurality (rural/very rural)</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>White Majority</td>
<td>Majority</td>
<td>Varies</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>Growing</td>
<td>Growing</td>
</tr>
<tr>
<td>African American Pockets</td>
<td>--</td>
<td>Varies (range, 6% to 75%)</td>
</tr>
<tr>
<td>Amish/Mennonite; European immigrants; Native American; Other Pockets</td>
<td>--</td>
<td>Pockets</td>
</tr>
<tr>
<td>Employment</td>
<td>Predominantly blue collar: farming, manufacturing/industry, coal mining, timber, health care</td>
<td></td>
</tr>
<tr>
<td>High Poverty</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Low Education (high school or less)</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>High cancer incidence (overall)</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>High cancer mortality (overall)</td>
<td>11</td>
<td>9</td>
</tr>
</tbody>
</table>

*Source: Study Key informants

2006). All cancer center-academic outreach programs except one are university-based; four are affiliates of both an NCI-designated Comprehensive Cancer Center and an NCI-supported Community Cancer Network Program; two are affiliated with an NCI-designated Comprehensive Cancer Center only; one is associated with an NCI-funded Community Network Program only; and one is part of an integrated, statewide cancer prevention and control partnership. The one non-university, non-NCI affiliated site is a regional cancer center outreach program serving two rural
counties in southcentral Pennsylvania, primarily funded through a well-established, regional health care system. Collectively, the geographical service area of both study groups spans 410 counties, all of which were reported by respondents as being or encompassing largely rural and/or ‘very rural’ areas, with some small and some larger urban centers. All of the coalition counties and more than half of the cancer center-academic program counties are located in Appalachia. The median number of counties in the coalition case group was 2 (range 1-8), while the cancer center-academic group had a median 23 counties (range 2-95).

Although slightly more than half of informants in both study groups noted high cancer incidence and mortality rates among their populations, national data posted on Cancer Control P.L.A.N.E.T. (NCI, 2008b) confirmed high cancer incidence and mortality rates for all states examined in this study, particularly for breast, cervical, colorectal, and lung cancers. Consistent with the Appalachian region as a whole, the majority of the population in all 11 coalition service areas was described as White, with “pockets” of African-American, Asian, Native American, Amish/Mennonite, and other minorities. More than a quarter (27.3%) of coalitions and almost half of cancer center-academic programs reported a growing Hispanic-Latino immigrant population in their rural communities from Mexico and other Latin American countries. The cancer center-academic group described their counties as more racially and ethnically diverse, with higher proportions of African Americans ranging from 6% in a southwestern county of Pennsylvania to 65%-75% in much of Alabama and Mississippi. Both study groups described employment in their areas as predominantly farming, manufacturing, industry and other blue collar jobs; and small businesses, many of which were characterized as ‘mom and pop’ operations. Coal mining and timber were reported as major industries in several states (PA, KY, WV), along with automobile and parts manufacturers (e.g., Hyundai, Toyota), garment
factories, and poultry farms in more southern states (AL, MS, SC, TN, VA). Health care was cited as a major employer by about half of coalition respondents (54.4%) and cancer center-academic outreach staff (44.4%). More than half of coalitions and about a third of cancer center-academic programs have seen a migration out of jobs and young people from their regions in the past few years. High poverty rates and low median incomes prevail in 9 of the 11 coalitions’ service areas and 8 of the 9 cancer center-academic program regions. In one coalition’s home county in southern New York, 66.7% of the population has a median annual income of less than $30,000. More than half of both groups characterized the majority of their populations as less educated (high school or less), and just over a third of both groups described their service area as an aging population (50 and older). One cancer center respondent reported that their multi-county population in western Pennsylvania is the second oldest in the country, after the Dade County-Broward County area in Florida.

Cancer Foci and Target Audiences

When asked to describe their cancer screening program activities over the past 3 years, coalitions reported that their efforts have been focused primarily on breast cancer (100%); colorectal cancer (91.1%); skin cancer (72.7%); cervical, tobacco/oral/lung cancer, and prostate cancer (63.6%); nutrition (27.3%); ovarian cancer and physical activity (18.2%) (Table 5.2). Among cancer center-academic outreach programs, screening promotion efforts have targeted breast, cervical and colorectal cancer (100%); prostate and skin cancer (66.7%); nutrition (55.6%); and tobacco/oral/lung cancer, ovarian cancer, and physical activity (30%). The uninsured and underinsured as well as the rarely and never screened have been primary target audiences of both study groups. While the majority of cancer center-academic outreach programs have targeted White, as well as African-American and
Hispanic/Latinos in their screening promotion efforts, coalitions have focused primarily on White and Amish/Mennonite population in their rural communities. This is consistent with the demographic composition of each group’s service area.

Table 5.2: Cancer foci and target audiences of rural coalition and cancer center-academic outreach programs, 2006-2008

<table>
<thead>
<tr>
<th>CANCER FOCI</th>
<th>Coalitions (n=11)</th>
<th>Cancer Center-Academic Outreach Programs (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Breast</td>
<td>11</td>
<td>100.0</td>
</tr>
<tr>
<td>Colorectal</td>
<td>10</td>
<td>91.1</td>
</tr>
<tr>
<td>Skin</td>
<td>8</td>
<td>72.7</td>
</tr>
<tr>
<td>Cervical</td>
<td>7</td>
<td>63.6</td>
</tr>
<tr>
<td>Prostate</td>
<td>7</td>
<td>63.6</td>
</tr>
<tr>
<td>Lung/Oral/Tobacco</td>
<td>6</td>
<td>54.5</td>
</tr>
<tr>
<td>Nutrition</td>
<td>3</td>
<td>27.3</td>
</tr>
<tr>
<td>Physical activity</td>
<td>2</td>
<td>18.2</td>
</tr>
<tr>
<td>Ovarian</td>
<td>1</td>
<td>9.1</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Un/underinsured</td>
<td>11</td>
<td>100.0</td>
</tr>
<tr>
<td>Rarely/never screened</td>
<td>8</td>
<td>72.7</td>
</tr>
<tr>
<td>White</td>
<td>11</td>
<td>100.0</td>
</tr>
<tr>
<td>Amish/Mennonite</td>
<td>6</td>
<td>63.6</td>
</tr>
<tr>
<td>African American</td>
<td>2</td>
<td>18.2</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>2</td>
<td>18.2</td>
</tr>
<tr>
<td>Illegal Immigrants</td>
<td>2</td>
<td>18.2</td>
</tr>
<tr>
<td>Migrants</td>
<td>2</td>
<td>18.2</td>
</tr>
<tr>
<td>Native American</td>
<td>1</td>
<td>9.1</td>
</tr>
<tr>
<td>Other target audiences*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Women 18-26 (HPV); children, students (SKCA); Medicare recipients (BRCA, CXCA)</td>
<td>Coal miners, factory workers, veterans (CRC); Pregnant women, stay-at-home moms (BRCA, CXCA)</td>
</tr>
<tr>
<td>* Percentages not reported</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

72
The Barriers Found to Cancer Screening Promotion

When asked about barriers to cancer screening in their rural communities, key informants provided an extensive list of factors related to the physical environment (geography-related), structural (access-related), social and cultural (interpersonal and culture-related), individual (personal factors), and program-related barriers (Table 5.3).

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>BARRIER</th>
<th>Coalitions (n=11)</th>
<th>Cancer Center-Academic Outreach Programs (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Environment</td>
<td>Geography (mountains; few roads; poor roads)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Cost/insurance issues</td>
<td>10</td>
<td>91.1%</td>
<td>9</td>
</tr>
<tr>
<td>Transportation issues</td>
<td>(distance, gas prices, no public transportation)</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Lack organization capacity</td>
<td>(funding, staff)</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Lack health facilities</td>
<td>7</td>
<td>63.6%</td>
<td>6</td>
</tr>
<tr>
<td>Providers don’t recommend screening</td>
<td>6</td>
<td>54.5%</td>
<td>4</td>
</tr>
<tr>
<td>Provider shortage</td>
<td>5</td>
<td>41.8%</td>
<td>4</td>
</tr>
<tr>
<td>Follow-up difficult</td>
<td>(diagnosis/treatment)</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Competition (agency)</td>
<td>3</td>
<td>27.3%</td>
<td>0</td>
</tr>
<tr>
<td>Provider too busy</td>
<td>3</td>
<td>27.3%</td>
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<td>(specialists)</td>
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<tr>
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<tr>
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73
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<tr>
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<th>Cancer Center/ Univ. Outreach Programs (n=9)</th>
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<td></td>
<td>No symptoms, no screening</td>
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<td>Embarrassment</td>
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<tr>
<td></td>
<td>Program timing</td>
<td>2</td>
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**Physical Barriers**

While the physical environment—safe water, clean air, smoke-free workplaces, and safe neighborhoods—may commonly be thought of as contributing factors to good health, the effects of geography and specifically, topography, on health may not so often be considered. All key informants described the areas they serve as rural or very rural. Most coalitions (72.7%) characterized their service areas as large counties with small populations, fondly summarized by one respondent as, "People say there..."
are more cows than people." More than a third of coalitions (36.4%) and almost one-half (44.4%) of cancer center-academic programs described the topography of their service area as mountainous terrain, with few roads, poor roads, and long distances and travel times required to access health services. Travel distances of up to 100 miles, across state borders, and roads that make even short distances a major trek were commonly reported across both groups. Most respondents also stated that there is no public transportation in their rural areas, and over the past year this problem has been exacerbated by the dramatic rise in gas prices and downturn in the national economy. Thus, lack of transportation due to both physical factors (e.g., mountainous terrain, few roads, poor roads) and structural factors (e.g., cost and insurance issues, lack of transportation, lack of health care facilities, provider shortage) was one of greatest barriers to accessing cancer screening and other health services for these rural populations.

**Structural Barriers**

In addition to transportation, structural barriers most frequently reported by informants in both groups, in descending order of frequency, included cost and lack of adequate insurance (91.1% coalitions, 100% cancer center-academic programs); lack of organizational capacity in terms of adequate funding and staff to carry out their screening promotion interventions (72.7%, 77.8%); and lack of local health care facilities to meet the screening needs of rural residents (63.6%, 66.7%). Almost half of both study groups reported a shortage of health care providers in their service area, including primary care physicians and specialists.

A substantial number of key informants stated that many health care providers in their communities do not recommend screening for cancer to their patients (54.5%, 44.4%). These data are consistent with a 1993-1994 survey of White and African American women aged 52 years and older (n=1,933) in 10 rural North Carolina
counties that showed only 53% reported having received physician recommendation of screening mammography in the past year (O’Malley et al., 2001). Further, recommendation for mammography was found to be more frequent among women who had access to the health care system (i.e., had a regular physician and health insurance) and less frequent among women who were vulnerable (i.e., were older, had lower educational attainment, had lower annual family income). The data in the current study indicate that the lack of provider-recommended screening may be due in part or in combination with other factors, including providers being too busy (27.3% cancer center-academic programs, 18.2% coalitions); a shortage of providers in these rural communities (41.8%, 44.4%); and/or low screening reimbursement rates, as reported by 18% of coalitions. In addition, follow-up to screening for diagnostic care and treatment was reported as difficult (36.4%, 30%) and to pose an ethical dilemma for the coalition or outreach program in promoting screening for certain types of cancer. In effect, if there is no viable, local option for diagnostic care and treatment for people having an abnormal test result, program staff seem to be reticent to tell people that they should be screened. This quandary was often cited for colorectal cancer screening, as many rural communities in this study do not have an endoscopy center or trained gastroenterologists to perform colonoscopy. Informants also characterized follow-up care for cervical cancer as difficult. One cancer center informant in a southern state described their program’s experience with this issue:

*One of our biggest problems in our state is not getting the follow-up care for women screened for cervical cancer. We have great success in getting women of all SES levels, race, and ethnicities screened, but there are shortcomings in getting them into follow-up care because of capacity issues on the system level, where there are delays in getting colposcopy or other clinical procedures and treatment, so we need to be addressing the system while we’re doing this. So we work with some of these health systems to try to understand*
some of these barriers to completing the screening and follow-up care continuum.

A similar ethical dilemma occurred in outreach to undocumented Hispanic/Latino populations in several states, because undocumented persons are not covered for follow-up care under state-funded and other assistance programs. A coalition member in an Appalachian southern-tier county of New York State, which has a state-funded program for breast, cervical and colorectal cancer screening services and prostate cancer education for the uninsured, illustrated this dilemma in the following vignette:

We began focusing on screening minorities about 3 years ago. We applied for a Susan G. Komen grant for outreach to our Hispanic population and through this discovered that illegals wouldn’t be covered for treatment if diagnosed [with cancer]. We worked closely with a Texas-based foundation that would have provided [only] a minimal sum of money to help them. We went to the State Cancer Screening Program for advice, who said illegals should be encouraged to go back home for treatment. This was not a good answer or solution for our coalition. I would hate to diagnose someone with breast cancer and say, ‘Sorry about your luck, but you’re going to have to go back to Puerto Rico for treatment.’ So we stopped screening for Hispanic illegals but still provide education. We attend a ton of migrant health fairs. We’ve built a very good relationship and earned a lot of trust with that population and didn’t want to let that diminish, but at the same time had to let screening go without the ability to provide for follow-up treatment.

Another structural barrier revealed by a cancer center program director in rural Tennessee was that chicken production employers in her state tightly control access to their employees, who in the past have been largely, undocumented Hispanic/Latino immigrants from Mexico. These employers often block any attempts by public health staff to provide worksite cancer education and screening programs. Rural Hispanic/Latino populations were said to have fewer health care visits, not used to having a ‘medical home’, and they tend not to participate in public health programs.
These behaviors are likely due to concurring structural, sociocultural and individual factors, including undocumented status, migrant lifestyle, mistrust of Western medicine, individual behavior patterns, and language issues. Physician-patient mismatch in terms of ethnicity and gender also was reported as a barrier to screening for ethnic minorities; for example, a rural Hispanic woman seen by a White male physician may be a totally unacceptable situation for the woman, her husband, family members, and others in her social network. One cancer center program coordinator suggested that a systems-level change, such as having a promotor (an outreach worker in a Hispanic community who is responsible for raising awareness of health and educational issues) in attendance during the woman’s office visit might significantly improve this doctor-patient encounter and ultimately result in the woman being screened for breast, cervical or other cancer.

Another structural barrier reported by almost a quarter of cancer center-academic programs was that cancer screening in rural communities is not a priority for their home institution or partner hospitals. A cancer center outreach program coordinator for one of the longest-standing, 10th highest-funded comprehensive cancer centers in the U.S., which serves a large rural, multi-county area within 100-miles proximity of the institution, stated:

We’re not doing much cancer screening in rural areas and haven’t done much prevention and early detection. We haven’t had a cancer prevention and control person here, although we’re looking to hire someone. To meet the American College of Surgeons Commission on Cancer standards, we’ve always done a free skin cancer screening in May and a free prostate cancer screening in September here in [CITY NAME].... We’ve just begun to do some rural cancer education, but we’re not out there just yet....This takes administration buying into this and to have everyone agreeing that screenings are worth doing.
Administrative issues, such as funding priorities, requirements, and restrictions were reported as particularly problematic by a large majority (77.8%) of cancer center-academic programs and a smaller proportion (18.2%) of coalitions. Administrative burdens made worse by too little funding and staff can result in a ‘disconnect’ between communities and researchers or funding agencies if priorities and objectives of both groups are not in congruence. These barriers were illustrated by coalition members in two New York counties, relative to their state-funded breast, cervical and colorectal cancer screening and prostate cancer education program that recently mandated a reduction in education and outreach and increased administrative requirements:

The coalition started to reduce the number of women dying from breast cancer: the breast cancer mortality rate dropped over the past 5 years, although we're not totally responsible for that; it's a national trend. But because all of the data showed that and the state said it doesn't pay off, we slacked off on our community outreach & education, and we saw the rates go back up. We think we need to be doing MORE outreach & education; it [education outreach & screening] is a package deal. You have to keep the heat on these people, because let's face it, nobody wants to go looking for bad news every year, and that's what we're asking people to do: go have a cervical exam, go look for bad news, go have a breast exam, go look for bad news. Public health has really abandoned the idea of community outreach and education, in part because it's hard to justify spending the tax dollars on it because it's hard to measure.

During the past 2 to 3 years our program has seen a back slide due to administrative requirements, paperwork, credentialing of providers and screening sites, and cervical cancer follow-up protocols that take up a lot of our time—so much is involved in what we have to give to the Department of Health. Protocols for cervical are unbelievable because the national protocols & algorithms for follow-up have recently changed big time, and the state has tied in our funding with the extent to which the protocols are followed, and it's taking a lot to educate 'older school' providers with what those protocols are and what is best for their clients. Patients are thereby
being billed for services that aren't covered because the protocols weren't followed, so we've spent an exorbitant amount of time in sorting out bills and all of these tasks that have come for a limited number of staff to handle. We're hoping for a positive trend in the new grant year to achieving our screening goals, as the performance measures are intended to be more streamlined, and the credentialing and all of that lends credence to the program. But it's taken a lot of our time and a big learning curve against a much increased programmatic demand.

Social and Cultural Barriers

Social and cultural barriers were reported by respondents in both study groups for many of their targeted populations. More than half (55.6%) of cancer center-academic outreach programs and more than a third of coalitions (36.4%) spoke of 'family first' as a barrier to screening, with several meanings attributed to this issue by various rural populations. For low-income rural folks who have to travel a substantial distance to obtain health care, 'family first' was often reported to mean the choice between putting food on the table or providing other family needs and spending money on gas to travel to the doctor's office or community event to be screened (this barrier clearly overlapped cost as a structural barrier). As one respondent said of Latina women in her community,

Many Latinas are out of work right now, and because of the changes in the economy, they're incredibly concerned about trying to find work and meet their family's most basic needs. And getting to work is a need; going to the clinic unless you're dying is not.

Among rural Appalachian residents in Kentucky, 'family first' referred to traditionally strong family ties and the tendency to rely on family member knowledge and folk medicine for their health-related needs, rather than going to a doctor:

The cultural issue that people don't always seek health advice from health professionals; they'll ask their grandmother or aunt, or their father, or somebody else who may not know anything about it or have misconceptions
that they convey and say something like, 'All doctors do is give you bad news.' That's what my grandfather always used to tell me: 'Why go to the doctor? Have you ever had a doctor tell you anything good?' So there's just that sense that 'we'll take care of each other in the family or our community, and we don't need to seek help from health professionals. All they want to do is make money, or be in control, and that's their business. They don't care about us; they only want to make money.' So you've got all of that kind of stuff going on out there.

Among Hispanic/Latino populations, which similarly have a cultural tradition of strong family ties, 'family first' meant not wanting to do anything that would disrupt the family order:

*A younger Hispanic woman with small children who had inflammatory breast cancer [had] waited five months to get a mammogram. The fear and denial was huge. She didn't want to disturb the family and thought it would go away.*

In some instances, the meaning of ‘family first’ was less apparent, as in a vignette offered by another coalition member in a predominantly White, rural community:

*The mother of one of my staff who is a colorectal cancer survivor won’t do a FIT [fecal immunochemical test] screening. She’ll do anything for her children, but not for herself, so who knows what the barrier is there.*

Another sociocultural barrier coded as ‘stoicism and self-reliance’ defined in part by one coalition member, was the perspective among “rural, hardworking people that they don’t get sick, and therefore have no need to go to doctors and take care of their own” was reported by more than a third (36.4%) of coalitions. Cancer fatalism, both as a cultural and individual barrier, was cited by almost half of cancer center-academic outreach programs and more than a third of coalitions as highly prevalent across their rural populations regardless of race, ethnicity, or culture. As a philosophical view and situational state in which individuals feel powerless in the
... the belief that they're going to die of something, so they'd rather not know.

There's a fatalistic aspect in Appalachian culture here: 'If I'm going to die, I don't want to know' and 'It's God's will.'

... the perception of cancer as a death sentence. There is tremendous silence around colorectal cancer—the same as breast cancer 15 to 20 years ago—silence around cancer, or the 'Big C'. It's less of a barrier now than it once was for cancer, in general in North Carolina, although there are still a lot of people who are unfamiliar with colorectal cancer.

... the intrinsic fear that cancer is a death sentence. At the Lion's Club, participants didn't want to have a discussion on cancer.

Community mistrust and resistance were listed as a barrier to screening by 41.8% of key informants in coalitions and almost a quarter (22.3%) of cancer centers-academic programs: mistrust of health professionals among Appalachian residents, alluded to in the example above regarding reliance on family knowledge and folk medicine; mistrust of research and medicine among African Americans, which stems in part from the Tuskegee Syphilis Study (Freimuth et al., 2001); and community resistance to public health campaigns that encourage tobacco cessation. A poignant example of the latter was provided by a cancer center program director in West Virginia, which has the second highest tobacco smoking prevalence rate in the U.S. (NCI, 2008b):

*We conducted an evidence-based Delta Dental program that recruited dentists in a very rural county to promote oral screening and tobacco cessation. We addressed all of the barriers. We offered child care and gas vouchers. After 6 months, only one person had participated, and then we learned that the community had been taking down our program posters.*
The stigma of cancer as a cultural taboo or curse was reported by 36.4% of coalitions and 30% of cancer. Male gender also was cited by 27% of coalitions, as males reportedly “do not go to the doctor”. Those coalitions and cancer center programs that work with Amish populations reported Amish lifestyle and values as challenging; in effect, being a ‘closed’ community, many have Old Order Amish values and strong religious views, generally do not motor vehicles, and both women and men are very modest. In addition, one coalition member in a very rural county of Pennsylvania bordering West Virginia cited patriarchal attitudes as a major barrier for women in obtaining cancer screening: “...male domination. They want their women to be ‘barefoot and pregnant’, and women are afraid to do things on their own outside the home.”

Individual Barriers

As individual (personal) factors such as knowledge, beliefs and attitudes about cancer are rooted in cultural understandings and norms, individual-related barriers overlap with and often are difficult to separate from social and cultural barriers as previously described. In this research, fear and denial about cancer was unanimously reported by both study groups as one of the most prevalent individual and sociocultural barriers among their rural populations. Lack of knowledge about cancer and the importance of screening also were highly prevalent. Literacy issues were described as attributed to: 1) low reading ability among less-educated people; 2) low health literacy (e.g., “…one woman who heard her doctor talking about a cervical X-ray thought it was about her pelvic region’’); and 3) lack of technology literacy (e.g., computer, teleconference, and Webinar familiarity and skills). Other individual barriers to screening cited included ‘no treatment/no screening’--the perspective that “If I can’t afford treatment, then why be screened? It’s better not knowing”; screening as a non-priority for the target audience due to competing priorities; and
lack of perceived personal risk if there is no known family history of cancer. Similarly, ‘no symptoms/no screening’, the phrase used in this study for the lack of perceived personal risk in the absence of symptoms, was reported by more than a third (36.4%) of coalition informants and almost a quarter (22.3%) of cancer center-academic informants, which indicates the need for education. Additionally, despite the fact that Medicare covers the costs of most screening tests for breast, cervical, colorectal, and prostate cancer (ACS, 2008b), about a third (30%) of cancer center-academic programs stated that Medicare recipients do not take advantage of those benefits. Embarrassment was another less frequently but nonetheless important individual barrier, particularly related to the more invasive procedures used to screen for cervical, colorectal and prostate cancer. Modesty was an especially salient issue for the Amish population.

Programmatic Barriers

In addition to the a priori barriers to screening in the conceptual model that guided this research, programmatic (program-related) barriers emerged through the data as a distinct set of issues for both study groups. More than a third (36.4%) of coalitions and almost a quarter (22.3%) of cancer center-academic programs reported difficulty in tracking screening outcomes, in terms of whether people were actually screened following referral and whether they had a test result requiring follow-up diagnostic care and treatment. Difficulty in recruiting folks to educational and screening programs also was reported by both study groups, for many reasons both articulated and unknown. Among these, bad program timing stood out as a factor that diminished reach of screening-related interventions. Many other factors presented above—lack of transportation, cost and insurance, competing priorities, fear, beliefs, and cultural issues—were cited as barriers underlying low recruitment of individuals to cancer screening programs.
The Definitions of Success in Rural Cancer Screening Programs

Before presenting the strategies found to be used and successful (or less successful) in promoting cancer screening, it is instructive first to describe how the two study groups defined success in their cancer screening programs, as specifically asked in the telephone interview. While some informants gave their personal definition of success and that of their program or home institution (which were found to sometimes contrast), others made no such distinction; therefore, the summary that follows of how success was defined makes no such distinctions.

When asked to define how success is defined or measured in their outreach programs, the most frequently reported definition given by key informants in both study groups was the number of persons screened, diagnosed or treated early for cancer (Table 5.4). Other important measures of success for both groups were increased program capacity (72.7% and 77.8%) and increased cancer-related knowledge of their target populations (72.7% and 66.7%). Moreover, greater than half of coalitions (63.6%) and close to a third (30%) of cancer center-academic programs reported that if only one person’s life is saved by receiving a cancer-related message and being diagnosed and treated early, then that is success. Decreased cancer rates were more often cited as a measure of success by cancer center-academic programs (66.7%) than coalitions (36.4%), as well as quality of care and equal access to screening (55.6% vs. 27.3%). Other reported measures of success included the number of individuals reached and/or recruited; number of programs; increased sustainability; decreased cancer disparities; and timely provision of care from an abnormal screening result to diagnosis and treatment.

A number of other less frequently mentioned measures of success offered by both groups included: client satisfaction, number of partnerships; obtaining quality data;
and short-term gains. The meaning of this latter definition of success was given by a university researcher, who stated, "It's important when working with communities that they are able to see success in their efforts in pieces in order to stay engaged, rather than have to wait 5 years to see movement in rates." A coalition member similarly stated that short-term projects and gains were good, as coalition members are often volunteers with full-time jobs and are not able to commit to long-term projects.

| Table 5.4 Definitions of success in rural cancer screening promotion programs, 2006-2008 |
|---------------------------------|---------------------------------|---------------------------------|
| Definition                      | Coalitions (n=11)                | Cancer Center-Academic Outreach Programs (n=9) |
| Number screened/diagnosed/treated | 9 81.8                          | 8 88.9                          |
| Increased capacity              | 8 72.7                          | 7 77.8                          |
| Increased knowledge             | 8 72.7                          | 6 66.7                          |
| One person educated/screened/diagnosed/treated | 7 63.6                          | 3 30.0                          |
| Number reached/recruited        | 5 41.8                          | 3 30.0                          |
| Decreased cancer rates          | 4 36.4                          | 6 66.7                          |
| Quality of care/equal access    | 3 27.3                          | 5 55.6                          |
| Number programs                 | 2 18.2                          | 4 44.4                          |
| Increased sustainability        | 0 0.0                           | 4 44.4                          |
| Decreased disparities           | 0 0.0                           | 3 30.0                          |
| Timely screening to diagnosis/treatment | 0 0.0                          | 3 30.0                          |
| Client satisfaction             | 2 18.2                          | 2 22.3                          |
| Number of partnerships          | 1 9.1                           | 2 22.3                          |
| Quality data                    | 1 9.1                           | 1 11.1                          |
| Short-term gains                | 1 9.1                           | 1 11.1                          |
| Extent of community involvement | 1 9.1                           | 0 0.0                           |
| Number receiving comprehensive services | 1 9.1                           | 0 0.0                           |
| Number first-time screened      | 0 0.0                           | 1 11.1                          |
| Number remaining adherent       | 0 0.0                           | 1 11.1                          |
| New technology for rural communities | 0 0.0                           | 1 11.1                          |
| Number funded projects/mini-grants | 0 0.0                           | 1 11.1                          |
| Policy change to increase access| 0 0.0                           | 1 11.1                          |
| Translation/dissemination of evidence-based programs | 0 0.0                           | 1 11.1                          |
Although many of these measures were common to both study groups, a trend was observed in cancer center-academic programs being somewhat more focused on ‘big picture’, longer-term screening outcomes and coalitions focused on more proximal, shorter-term successes.

The Strategies Found for Promoting Cancer Screening in Rural Communities

Overview of Strategies Found

Numerous strategies used by the two study groups over the past three years in rural communities emerged from the study data, evidenced by a multitude of screening-related and screening-specific outcomes provided through the key informant interviews, their websites and publications, the ACCN-PSU coalition database, and the ACCN data collection system. As the reporting of these data could very well comprise several volumes, the narrative that follows will only highlight successful strategies and concepts that underlie those strategies with selected illustrative examples. It is also instructive to note a key finding of this study: rarely was a single strategy implemented in isolation by either group but was rather part of a multi-strategy (multiple component) approach to meet the specific needs of their target audiences.

Program-related Strategies

Whether conducted by ‘grassroots’ organizations or institutional programs, community-based cancer prevention and control interventions are subject to program-related influences, including the organization’s mission, capacity, and overarching approaches to implementing programs to improve cancer screening rates in their rural communities. The presentation of strategies found in this study thus begins with these program-related approaches and influences.
Program Mission: Four Foci

Four themes related to overall mission emerged from the key informant interview and document review data: 1) focus on increasing access to cancer education and screening services; 2) focus on decreasing cancer disparities; 3) focus on dissemination and translation of evidence-based programs and strategies; and 4) focus on survivorship across the cancer continuum. Both study groups were highly invested in increasing access to cancer education and screening, given that they all target the rural uninsured, underinsured, and minorities as underserved populations that experience significant cancer disparities. Not surprisingly when compared to coalitions, cancer center-academic programs more often reported reducing cancer disparities and dissemination and translation of research as objectives. About half of both groups perceived survivorship across the cancer continuum as important. Community education related to screening and early detection was a unanimous, primary goal of both groups. One NCI-funded Community Cancer Network Program director also reported that a key objective of their program is to link individual and systems-level barriers: “If we get people to change their [screening] behavior but there’s not a system in place that’s friendly and supports that behavior change, it’s a wasted effort.” This speaks to the ‘no treatment, no screening’ structural barrier previously described: if follow-up diagnostic care and treatment is not an available or viable option, then “Why be screened?” It also suggests the utmost importance of working at two levels to improve screening-specific outcomes, as this person described: the population (systems) level and the community (individual) level.

Capacity-building Strategies

Capacity-building strategies, defined as the processes of building a program’s infrastructure with adequate funding and staff to enable program implementation and
achieve desired outcomes, was reported as an important strategy by a large majority of cancer center-academic programs (88.9%) and almost half (41.8%) of coalitions. Capacity-building addresses structural-level barriers and includes such strategies as leveraging funding, training of program staff and volunteers, obtaining and using new technology to improve program delivery, and advocacy for policy-level decisions that enhance program delivery.

**Funding sources, strategies and influences.** A wide range of funding sources (Table 5.5), as well as funding levels and fundraising strategies (data not shown) were found for the two study groups. The CDC-funded, state-administered Breast and Cervical Cancer Screening Program was reported almost unanimously by both groups

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<tr>
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<td>27.3</td>
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<td>Foundation (private)</td>
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</tr>
<tr>
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</tr>
<tr>
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</table>

89
as a primary and "best source" of funding to screen the uninsured and underinsured for breast and cervical cancer, despite the challenges imposed by structural barriers including too little funding and quota restrictions to meet demand, and eligibility inconsistencies across states. West Virginia's Breast and Cervical Cancer Screening Program, for example, has been commended as, "one of the best" in the U.S.; and as previously reported, additional state funding in New York has enabled colorectal cancer screening and prostate cancer education to be added and integrated with the Breast and Cervical Cancer Screening Program, as well as follow-up diagnostic and treatment services for the uninsured. These programs have significantly increased screening among the low-income and uninsured rural citizens in the two states.

A large majority of cancer center-academic programs listed university (88.9%) and NIH/NCI (77.8%) funding as main sources of direct revenue; the Susan G. Komen Breast Cancer Foundation (55.6%); cancer center (44.4%); and leveraged funds though unspecified grants, business and industry, and their state legislature (30%, respectively). Except for university funding, most coalitions (77.8%) similarly reported NIH/NCI (primarily technical assistance and mini-grants through the ACCN) and other unspecified grants as a main source of revenue, with more than a third (36.4%) successful in leveraging funds through the Susan G. Komen Foundation, Lance Armstrong Foundation (in collaboration with the ACCN), and local fundraising activities. In addition, more than a quarter of coalitions (27.3%) received funding support from private foundations, community agencies, and a state-funded colorectal cancer screening program.

Budget amounts ranged from "meager funding" reported by several coalitions (with mostly donated time, materials and facilities for outreach activities) to millions of dollars funded through grants and other leveraged funds for cancer center-academic programs. An interesting theme revealed through the key informant
interviews was that funding level did not always match or well reflect program outcomes. For example, one coalition member said, "Our funding sources are mostly in-kind donations. We’ve had $59.00 in our checking account since May of 2003.” However, in 2007 this coalition managed to get over 200 women (many of whom were Amish) screened for breast and cervical cancer screening through their mobile screening van, other screening events, and a targeted mailing. They also used an adapted survey instrument to successfully complete a county-wide assessment of colorectal cancer-related resources and community needs and educated hundreds of people about the need for screening—all on a shoestring budget.

Similarly, it was interesting to hear a program director with an NCI-funded Community Cancer Network in Alabama and Mississippi say, “We’re eligible for 1.2 million per year, but that’s not very much when spread out over two states, 22 counties, and three universities. It’s a challenge but enables us to hire community volunteers.” Through an extensive network of lay helpers using a one-on-one, social networking approach, that program has successfully reduced the breast cancer disparity between African American and White women in part of its service area over the past several years and implemented numerous other programs in most of their counties.

Another program director of a university-based, statewide cancer consortium illustrated the lack of top-level funding support and how they were able to still develop a program through leveraged funds:

*NCI didn’t want to give us any money initially for our programs; eventually we got some, and it was only to go to [a few] specific counties. All of our funding was done through the State Breast and Cervical Cancer Screening Program and Cooperative Extension at the university (my department), and we funded a coordinator to manage the 11 counties that we focus on. We use a community-based approach, and my job is to take that theory and turn it upside down and see what will, and will not work in our specific population.*
It's a lot of translation of the research; it's what I am responsible for, and that's what we did in our program.

Three cancer center-academic programs in this study in North Carolina, South Carolina, and Tennessee have leveraged substantial amounts of funding from their state legislatures. The combination of university and NIH grants, private industry donations, alignment with their state cancer control plans, and building extensive community partnerships has enabled them to build strong, integrated statewide cancer prevention and control programs to increase cancer screening and decrease cancer disparities in their rural communities.

Several cancer center-academic programs have provided mini-grants to their community-based coalitions with demonstrated positive outcomes. For example, a program in West Virginia has leveraged substantial funds from the same private foundation for the past 8 years, much of which they have provided to their community partner groups as mini-grants to adapt and implement evidence-based, cancer education and screening programs. Likewise, among several Community Network Program mini-grant projects funded in Pennsylvania, one evidence-informed cervical cancer-related educational intervention resulted in significant increases in HPV-related knowledge and HPV vaccination intent among women aged 18-26. Another dissemination program is currently underway in three coalitions in Pennsylvania funded through mini-grants to replicate a successful program conducted by an Indiana County coalition which significantly increased mammography screening among low-income rural women recruited through food pantries.

Leveraged infrastructure grants have been especially successful for building program capacity for cancer center-academic programs. In addition to the southern two-state, NCI-funded Community Cancer Network Program that trained over 800 community lay health workers in part with infrastructure grants, a cancer center-
academic program in North Carolina has used funds from several large NIH infrastructure grants for building program capacity and providing mini-grants to its partner community groups:

We're only able to do what we do because of the funding through the CDC, NCI, and also LAF [Lance Armstrong Foundation] funding as a Center of Excellence on Survivorship—all of which are focused on building infrastructure for cancer prevention and control. If all of your research is for implementing research on specific topics, it's gonna take such a long time to build partnerships, because you're always asking community to come partner with you on this specific thing that they may not be too keen on—that they're interested in, but not as invested in--than if you had resources to be IN the community and build those relationships. And the infrastructure grants have allowed us to do that. In the last 3 years with these infrastructure grants, we're able to fund RFAs for community organizations to implement evidence-based community education or screening interventions that we think will enhance capacity for getting more people screened. Last year, we only had $40,000 total to disperse (8 groups for $5,000 each), but for some of these counties $5,000 is a huge amount of money. Three churches adopted the Body & Soul Program and our faculty worked with those churches to adapt the program. We unbundled the program and did only one part the first year, then submitted another proposal this year to add the peer advisor piece. We're also working with Morehouse, Emory, and the University of South Carolina to post an RFA ($20,000 per year; 2-year grant) that specifies five R-TIPS interventions, neatly lays out the Community Guide's recommendations for breast and cervical cancer screening promotion, and requires a Memorandum of Understanding that the funded community groups will work closely with university staff to adapt the program in both a feasible and recommended manner. The RFA also told them they can implement Body & Soul or Friend to Friend without a whole lot of adaptation, but they can also take bits and pieces from other R-TIPS. We're also helping to underwrite a Lay Health Advisor Conference in June. One motivation for this is that there's a proliferation of LHA [Lay Health Advisor] programs, but they don't give a whole lot of support for how to manage their programs and match their methods with some of the best evidence-based approaches. So we'll do a Lunch & Learn session at that conference about evidence-based approaches and trying to align your LHA program with recommended strategies; that will
be a Train-the-Trainer session with community lay health advisors, as well as program directors.

Thus, the contrast in funding levels among and between cases in this study is striking, and the lack of capacity in terms of funding and staff as reported by a large majority of both study groups suggests a key finding in this study: the need for additional and adequate NCI and other major funder support for both cancer center-academic outreach programs and community-based coalitions. A second key finding is that leveraged funds and mini-grants awarded to community groups can be successful strategies in achieving increased organizational capacity and sustainability, as well as favorable change in cancer screening rates.

New technology. Another program-related, systems-level strategy that emerged from the data was the use of new technology for cancer prevention and control efforts in rural parts of Appalachia. Given the often large geographical distance between cancer center-academic programs and coalitions with their other partner groups, the use of teleconferences and “Webinars” was reported by a few cases in both study groups as having strengthened their program efforts. For example, Webinar technology was used by the ACCN in partnership with the NCI’s Cancer Information Service Community Partners Program to successfully train coalition members and agency staff in Appalachian Kentucky, Pennsylvania, and New York on the NCI’s Using What Works program for using and adapting evidence-based programs. In addition, both teleconference and videoconference technology is now regularly used for ACCN Community Advisory Board meetings at the network and regional levels in addition to their annual, face-to-face meetings. The ACCN regional program in Virginia now has a state-of-the-art satellite video broadcast system that they use for both their quarterly statewide cancer coalition meetings and rural outreach. The system has been used by a physician to present sessions on clinical trials,
presentations on cancer surveillance, and data reporting and has been “very well received.” The system was constructed with successfully leveraged funds from a cancer center, a large health system, two universities, federal funds, and private donors. In North Carolina, teleconferencing has largely enabled establishment of a lay helpers program and has strengthened the program over the past few years. Thus, new technology appears to be a successful, strategic new tool for cancer prevention and control programs in rural communities.

**Theoretical and Conceptual Approaches**

In total, key informants named 11 theoretical and conceptual models that they use to guide their cancer-related program efforts, almost half of which were reported to have yielded successful outcomes (Table 5.6). Among these, all 11 coalitions and 7 of the 9 cancer center-academic programs reported that they have collaborated with their academic or community coalition counterparts in community-based participatory research, education and training, including training in evidence-based methods and

| Table 5.6 Theoretical models and conceptual approaches used in rural cancer screening promotion programs, 2006-2008 |
|---------------------------------|-----------------|-----------------|
| THEORY/ MODEL                   | Coalitions (n=11) | Cancer Center-Academic Programs (n=9) |
| Community-based participatory research*† | 11 100.0 | 7 77.8 |
| Social networking*†             | 4 36.4 | 5 55.6 |
| Faith-based health promotion*†  | 3 27.3 | 5 55.6 |
| Logic models                    | 3 27.3 | 0 0.0 |
| Social learning/ cognitive theory* | 3 27.3 | 2 22.3 |
| Diffusion theory*†              | 1 9.1 | 0 0.0 |
| Stages of Change*†              | 1 9.1 | 4 44.4 |
| Community capacity-bldg†         | 0 0 | 4 44.4 |
| Health belief model             | 0 0 | 4 44.4 |
| Empowerment†                    | 0 0 | 3 30.0 |
| Motivational interviewing       | 0 0 | 1 11.1 |

* Successful outcome resulted (coalition)
† Successful outcome resulted (cancer (center-academic program)
collaboration on mini-grants using evidence-based approaches. As previously noted, the coalitions in this study are all research partners in the ACCN. Each coalition has one or more representatives who serve on their local Community Advisory Board (CAB), and there is one representative from each of the five regional CABs on the Community Advisory Committee that advises and interacts with the Steering Committee of the Appalachian Community Cancer Network. Community-based participatory research is considered a prime directive of this network and the cornerstone of most ACCN interventions.

Social networking was an especially effective approach used by both study groups. The Community Cancer Network Program in Mississippi and Alabama, which has successfully reduced the breast cancer disparity among African American Medicare recipients in much of their service area, met this objective in part by using a one-on-one, social networking approach through their extensive community health workers network:

For folks we provide services to, we use the circle of influence network: people close to them, be they their church members, coworkers, neighbors, friends; anyone within that close social network. Those are the folks we try to approach first and we like to call those folks the 'low-hanging fruit'. And then we like to expand outside of their network to the 'higher-hanging fruit'. Those are the folks they don't know and don't have a relationship with; low-hanging fruit and high-hanging fruit. High hanging fruit are the ones that you can't readily get to. You're going to have to get on a ladder and you're going to have to really stretch and reach beyond your circle; you have to stretch yourself in order to reach these people.

In Kentucky, a coalition member is working with an academic researcher on a cervical cancer early detection and prevention program among faith-based groups, using a social networking approach with women in local churches to promote Pap testing and the HPV vaccine. A key informant from this coalition reported that
participation in the program has been tremendously successful: "We have so many women coming in now wanting Pap screening who say a girl at their church told them about it, they're having trouble keeping up with the demand. In our world, that is success."

Similarly, a Community Cancer Network Program in South Carolina partnered with African American churches to coordinate Witness Project events, using a social networking approach to share education and screening information with female church-goers:

With African American churches, we have been using the Witness [evidence-based] Project in collaboration with [researcher name] at Clemson University. Every time we go out, we recruit new women to come and be trained to serve as witnesses for breast cancer screening, lay helpers, and such. The Witness Project has been very well received among African Americans; so well that we can't keep up with the demand. We are booked through the Fall [interview date: June 26, 2008].

Another coalition member in Kentucky characterized their coalition as "a vehicle for Diffusion Theory in getting the message out to the community". In effect, the social networking approach used by the coalition to disseminate cancer screening messages through family members is very effective, because families in Appalachian Kentucky tend to be "tight-knit" and rely on family members for much of their health communication. In addition, Social Learning Theory helps dispel unhealthy lifestyle behaviors such as smoking, which in this population has long been a culturally-acceptable practice and norm:

If you tell one person and they tell another, and they tell another, this is an excellent way to get the message out. If one family member receives a health education message, they will hopefully tell another and that message will kind of ripple out across all family members. Also Social Learning Theory, because (and the coalition takes a stance that) people have to be taught that what they were raised with isn't always the best option. So we target younger
people especially and go back and say, 'Let's unlearn a little bit of the socialization; it's not necessarily OK to come out of church and light up a cigarette as soon as you step out the door, or go to the bingo hall on Saturday night and smoke—that's not necessarily the best option. So between Diffusion Theory and Social Learning Theory, I think we'll get it.

Community capacity-building models were used by a number of cancer center-academic programs to build integrated, statewide cancer prevention and control partnership programs in Tennessee, North Carolina, and South Carolina. For example, the TeamUp Tennessee: Cancer Education Program based at the University of Tennessee is a state and county partnership with the American Cancer Society's Mid-South Division, NCI's Mid-South Cancer Information Service, the Knoxville Affiliate of the Susan G. Komen for the Cure, the Tennessee Breast and Cervical Screening Program, and the University of Tennessee Extension.

Being university-based, we are viewed as credible and as leaders in our community, so we become very powerful change agents for our communities. Cooperative Extension is the critical player, as we are in every county in the state and resources are limited. And we don't sit in our office, because we're out there in the field. TeamUp has proven to be a very mobilizing body because we all have the same mission, share resources, do not duplicate efforts, and tailor our programs to the communities we serve. Many hospitals want to expand their outreach but don't have the capacity to get out and do it; and the American Cancer Society doesn't have field staff to get their message out. So the 'hub and wheel' structure provided by TeamUp, with Cooperative Extension as the conduit for outreach, being structured to facilitate groups and having the time and resources to coordinate these efforts, has made for a perfect relationship for statewide cancer prevention and control. The program has been very successful: statistically significant increases in cancer screening rates have been shown for all 11 counties as our activities have increased, and the network continues to grow. TeamUp's comprehensive approach has been cited by the state as exemplary, and our visibility within the state has substantially grown.
Use of the Transtheoretical Model of Change, or Stages of Change approach was reported by almost half of cancer center-academic outreach programs, one of which characterized their use of this and other models used as, "general health behavior models and behavior change: contemplation, pre-contemplation. In general, we pay attention to where they are in their stage of behavior; pretty general." In Kentucky, the state with the highest smoking rate in the U.S., a cancer center-academic researcher reported that they attempt to use theoretical approaches in everything they do, and they also follow the Transtheoretical Stages of Change Model to overcome the lack of knowledge barrier and to define success in their programs:

*We try to bridge the lack of knowledge and the willingness to move along the continuum of change, and that it’s OK to question the doctor, because people aren’t thinking about screening. It’s not on their radar screen, so we try to move them from pre-contemplation to contemplation, action, and sustaining their behavior.*

One of this program’s partner community coalitions has collaborated with another university researcher on a project using a community readiness model based on Stages of Change theory to evaluate a community’s readiness for tobacco-related policy change and determine stage-specific strategies to advance a community towards policy change. Although there is currently no available screening test for lung cancer and outcome data for this particular project is not yet available, the application of Stages of Change theory to community readiness for tobacco policy change holds great promise for reducing the disparate lung cancer incidence and mortality in Appalachian and other rural communities.

In West Virginia, recognizing that community pharmacists are among the most available and most trusted professionals in rural communities, a cancer center-academic program partnered with rural pharmacists to help educate community residents about colorectal cancer screening. The pharmacists attended three to four
educational sessions and received continuing education credits. Didactic education was provided on polyp transformation and Stages of Change Theory, as well as information on how to be agents of change. The project became the basis of a pilot study proposal with a small group of community pharmacists that was submitted for funding. Although no formidable outcomes resulted from this project, disseminating Stages of Change theory to potential change agents appears an important and innovative step towards increasing cancer screening in their communities.

Although use of theoretical models and conceptual approaches was found for both cancer center-academic programs and some coalitions, an observation made in the analysis of these data was that many of the coalitions actually use theory-based strategies but were not familiar enough with health behavior theory to articulate their efforts within these frameworks. For example, almost half of coalitions reported capacity-building as critical to the success of their outreach programs, yet none of these key informants framed their capacity-building activities in terms of theory. Another component in this ‘disconnect’ between researchers (‘science’) and communities may be that coalition members may not care as much about theory and conceptual models as what they can actively do to bring about health behavior change, as suggested by a coalition member in Kentucky in this vignette:

We’re not using any theoretical models; not in an overt way, anyway. I’m sure [researcher 1 name] is in her work, and I’m sure that [researcher 2 name] is.... I think it's a matter of, they are really sensitive to the fact that when they come to [community name], we don't really care about that stuff. I mean, I might care, but I'm an unusual member of this community, and I might care and want to hear about it for about 5 minutes, but that would be it and I wouldn't want to hear any more. Because it's not something that really drives people here; it's just way too abstract, developed by people that are not from here. It's foreign, not credible, not trustworthy, it's irrelevant. So the best thing to do, and I think it's what [researcher 1 and researcher 2] probably do, is that rather than talk it, they walk it. And that's what you have to do;
because that's what works. So they've done a good job, because I can't (laughs) give you any example of a presentation or anything that they've ever given to us as a community advisory group in terms of health education, behavior change theory, anything. What matters here is showing up, just being here. Rural people know this. It's really just teaching the people from [city name] that if you want to work effectively with us, you have to be here.

Researchers should heed the advice of this voice of the community; in effect, there are ways to use theory and conceptual approaches in collaborative programs with communities without preaching it. Framing theoretical concepts in lay terms that community members can easily understand, teaching by example, and 'being there' are extremely important. Nonetheless, the data in this study support theoretical and conceptual approaches as a best practice strategy in promoting cancer screening in these rural populations.

Evidence-based and Evidence-informed Strategies

The use and utility of evidence-based programs and evidence-informed strategies was found to vary widely between and across cases in this research (Table 5.7). A large majority of cancer center-academic programs (77.8%) reported using evidence-based approaches in their outreach programs, more than half of which strive "always" to use such practices. Of the two that have not used such strategies, both would like to but lack sufficient funding and staff to adopt these methods in their work. Evidence-based programs used by cancer center-academic programs included the Witness Project for African Americans and faith-based programs for Latinas in South Carolina, and the Body & Soul Program adopted by three churches in North Carolina. Evidence-based strategies recommended by the Community Guide were utilized by just over half (55.6%) of these cases, most of which were worksite interventions.
Table 5.7 Evidence-based and evidence-informed strategies used by coalitions and cancer center-academic outreach programs, 2006-2008

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<th>STRATEGY</th>
<th>Coalitions (n=11)</th>
<th>Cancer Center-Academic Programs (n=9)</th>
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<td>7 77.8</td>
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<td><strong>Community Guide recommended strategies</strong></td>
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<td>5 55.6</td>
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<td>7 77.8</td>
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<td>Tell A Friend*</td>
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</tr>
<tr>
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</tr>
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<td>2 22.2</td>
</tr>
<tr>
<td><strong>Witness Project†</strong></td>
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<td>2 22.2</td>
</tr>
<tr>
<td>Woman to Woman</td>
<td>1 9.1</td>
<td>0 0</td>
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* Successful outcome resulted (coalition)
† Successful outcome resulted (cancer [center-academic program])
▲ Majority were worksite interventions (both groups)

Among coalitions, a similar proportion (63.6%) also used evidence-based approaches, especially evidence-informed strategies; for example, adaptation of validated survey or questionnaire instruments. A coalition in Pennsylvania (cited previously) adapted an existing, validated questionnaire as a pretest and posttest instrument for their recent HPV education and vaccination promotion program, which demonstrated significant change in HPV- and cervical cancer-related knowledge and intent to obtain HPV vaccination among program participants. Two coalitions in northeastern and northwestern Pennsylvania adopted the American Cancer Society's evidence-based Tell A Friend program (listed on Cancer P.L.A.N.E.T.), resulting in over 500 completed breast cancer screenings per year in each of their counties. Yet another coalition in southwestern Pennsylvania adapted the Tell A Friend program to promote mammography among low-income women attending local food pantries in their county. Results showed 138 completed mammograms (a 28.2% increase in screening mammography in the county in 2005) and three women diagnosed and treated for breast cancer. The Witness Project and the Body & Soul program (both
listed on Cancer P.L.A.N.E.T.) are currently being implemented by a coalition in New York State, and several other coalitions were found to be working currently on adopting or adapting evidence-based programs.

A number of additional, evidence-based strategies used by one or more cases in both study groups included: targeted mailings; NCI-provided Consumer Health Profiles (detailed data on a community’s healthcare utilization, demographics, lifestyle and media preferences); and Woman to Woman, a program listed on Cancer P.L.A.N.E.T. designed to increase breast cancer and cervical cancer screening in the worksite setting.

It is instructive to note that while more than half of both study groups were trained on and/or used the Cancer Control P.L.A.N.E.T. web portal to locate evidence-based programs, the relative scarcity of such programs currently listed on P.L.A.N.E.T. was cited by many key informants as both disheartening and frustrating. A university-based program director in Tennessee attributed this dilemma as partly due to the ‘disconnect’ between researchers and communities, but also how their program was able to successfully adapt a program found elsewhere in the health literature for a rural population in their service area:

We intended from the beginning to utilize Cancer P.L.A.N.E.T., and we have a list of what we consider to be community-based, evidence-based programs. Unfortunately, for us, there wasn’t anything that dealt with White, Appalachian women; it was Korean women, African American women, and inner city women; nothing matched. However, we looked at one I think is called FOCUS, which didn’t do anything novel (I call it typical health education) but had a clinical [screening] component and an educational component with classes. So we adopted the multiple-strategy premise from that program and decided to have one activity that promoted the state’s Breast and Cervical Cancer Screening Program and one activity that did screening. The ‘Free Screening Day’ in multiple counties was our activity, which resulted in higher numbers of screening on that one day in those counties than we previously had in the whole year. So it was a very powerful
tool in reaching women. That was our evidence-based program, but what we were doing was basic health education, and we couldn’t use their materials because they targeted African American women. I think the problem in getting more evidence-based programs is that funded research aims to answer specific questions in a way that doesn’t allow sufficient flexibility to tailor a particular strategy or program to the targeted community or what the community even wants. So there’s a real clash in terms of what questions are answered, and the literature is not full of that kind of thing, because it doesn’t occur.

Clearly, the use of evidence-based programs and strategies is currently in its infancy, especially in rural communities. The key finding to report herein is that despite the paucity of recommended research-tested interventions and strategies, both community-based coalitions and cancer center-academic outreach programs increasingly have begun to embrace these methods with demonstrated success. Thus, evidence-based programs and strategies should be considered a best practice strategy for rural cancer screening promotion.

Community Engagement Strategies

A rich variety of community engagement strategies, defined as methods used to gain participation by members of the intended audience in cancer screening promotion programs, were revealed in this research. Community engagement strategies were found to fall within two domains, or categories: 1) trust and relationship-building strategies, and 2) recruitment and retention strategies. These strategies are further detailed, as follows.

Trust- and Relationship-building Strategies

By definition, human service programs are a social endeavor. Community engagement for program implementation in any setting begins with establishing trust and relationships, to facilitate entry into a community and foster participation of the
intended audience. The key informant interviews in this study were invaluable for delineating the various strategies for building trust and relationships in rural communities. Two subcategories of strategies related to this theme emerged from the data: participatory approaches and partnership networks (Table 5.8). It is instructive to note that, as with other categorical themes in this study, some of these strategies overlap with each other and are therefore non-discrete.

<table>
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<tr>
<th>Table 5.8 Community trust- and relationship-building strategies in rural cancer screening promotion programs, 2006-2008</th>
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<td><strong>PARTICIPATORY APPROACHES</strong></td>
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<td>Coalitions (n=11)</td>
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<td>Focus group*&lt;sup&gt;†&lt;/sup&gt;</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>Empowerment*&lt;sup&gt;†&lt;/sup&gt;</td>
</tr>
<tr>
<td>0</td>
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<tr>
<td>Lay helpers*&lt;sup&gt;†&lt;/sup&gt;</td>
</tr>
<tr>
<td>0</td>
</tr>
</tbody>
</table>
| * Successful outcome resulted (coalition)  
† Successful outcome resulted (cancer center-academic program) |
Participatory approaches. Community involvement in the development and implementation of screening initiatives was reported almost unanimously by all 11 coalitions and 7 of 9 cancer center-academic programs. Several strategies under the umbrella construct of community involvement were offered and illustrated. As a starting place, community assessment, defined as processes to determine the needs of the intended audience, was a strategy used by a large proportion of both study groups. Surveys were more frequently employed by cancer center-academic programs and effective for both engaging community member involvement and assessing community needs (data not shown). Survey assessments conducted by two coalitions were unexpectedly discovered as an effective educational tool, evidenced by feedback received from survey participants. Another coalition experienced an unanticipated gain in new members on their coalition as a result of a community assessment that they conducted.

Focus groups conducted with community members were especially useful for cancer center-academic programs to guide program development and implementation. Focus groups provided a forum for personal interaction with community members and to gather in-depth information about the community’s unique, social and cultural make-up and barriers to cancer screening from the community’s point of view. The information gleaned through focus groups guided program development and implementation, but also resulted in new partnerships and greater trust between program staff and community members. A university-based program director in North Carolina spoke of the value of focus groups in their work, evidenced in part by their successful lay helpers program that resulted in 456 low-income, White, African American and Hispanic women screened for breast and cervical cancer and 1,943 who received cancer-related health education:
Almost every project starts out with some focus groups in the local community to assess specific needs, perceptions about the health topic, and identify the opinion leaders in the community who we should be engaging. For example, so much of our work began with lay health advisor recruitment, asking women who they talked to for information, and then we turned to the people whose names were mentioned most often.

Identifying and engaging individual and organizational community champions and gatekeepers constituted another important strategy for building community trust and relationships. Community champions are defined herein as individuals or organizations that support, promote, or advocate for programs that seek to increase cancer screening among rural residents. Community gatekeepers are defined as individuals or organizations that facilitate (or impede) program entry into a given rural population. It is instructive to note that community champions and gatekeepers were found in some instances in this study to be indistinguishable, as some such individuals were found to be one and the same. A majority of both study groups reported successful outcomes resulting from engaging community champions and gatekeepers. Identifying and working with community champions and gatekeepers was particularly useful for interventions that targeted minority groups in rural communities. Some coalition key informants named members of their own coalition as community champions and gatekeepers. For example, a local school district superintendent in Kentucky who is a colorectal cancer survivor and member of the coalition served as a bridge between the coalition and local schools for implementation of a colorectal cancer education and screening initiative in their community. Among Amish populations community champions were reported to include trusted primary care physicians (e.g., “Dr. Diane”), university researchers and Department of Health immunization nurses, all of whom had a long history of trusted relationships with the Amish community. Yet another key informant and
community champion is a nurse practitioner and member of her local cancer coalition who maintains a very busy clinical practice, yet goes out regularly into the community to conduct cancer education and screening outreach. Since 2006 she has participated in 46 health fairs and collaborated with her coalition at many other community events and worksites, using a multiple component approach to target multiple conditions at each event. The result has been hundreds of community residents educated and screened for breast, cervical, and colorectal cancer, many of whom (and others) were also counseled on smoking cessation, nutrition, and physical exercise. Other examples of community champions and gatekeepers who played a key role in successful screening programs were identified, including: Amish elders, an Amish pastor's wife, and both Amish and non-Amish wives who attended cancer screening programs and then took FOBT kits home to their husbands, or recruited their husbands to colorectal and prostate cancer screenings; African American and Hispanic/Latino church pastors and leaders; and a Head Start pre-school program in rural New York attended by the children of migrant Hispanic/Latino vineyard workers, who the coalition worked with to enlist parents for cancer education and screening.

**Partnership networks.** Establishing, maintaining, and continually growing partnership networks emerged in this research as a central theme and crucial strategy for promoting cancer screening in rural communities. The data revealed somewhat different partnership networks of the two groups. Partnerships of cancer center-academic programs included more population-based, systems-level entities (e.g., state cancer control plans, state and national consortiums, other universities), while coalition partnership networks included more community-based, individual-level entities (e.g., local health agencies, businesses, civic organizations). However, partners common to both study groups included: their regional NCI Community
Cancer Network; local chapter(s) of the American Cancer Society; local health care providers, including hospitals, primary care practices, and individual healthcare professionals; state and local Department of Health; the CDC’s state-funded Breast and Cervical Cancer Program; the NCI’s Cancer Information Service; churches; the Susan G. Komen Breast Cancer Foundation; as well as local coalitions including those in the study sample and others (Table 5.8). In addition, Cooperative Extension was found to be the central and major partner in one cancer center-academic outreach program, which collaborates closely with the state’s Breast and Cervical Cancer Program. Among coalitions, in addition to other examples too exhaustive to list within the scope of this narrative, food pantries and the Lions Club were cited as major players in successful screening initiatives. Examples of these partnerships and their screening program outcomes are given, as follows.

Among cancer center-academic programs, an exemplary partnership network in West Virginia was comprised by the CDC/state-funded Breast and Cervical Cancer Screening Program, a major cancer center, university, regional division of the NCI-funded Appalachia Community Cancer Network (ACCN-WVU), and local healthcare providers and hospitals has resulted in approximately 16,000-18,000 women (20%-40% of those eligible) screened in the state each year for either initial or repeat, annual screening. In addition, the partnership was reported to be successful in screening many underserved rural residents for colorectal and prostate cancer (data not provided). A glimpse into the various partner roles and their inter-collaboration was provided by three key informant staff members involved in this partnership:

*The Breast and Cervical Cancer Screening Program serves all 55 counties in West Virginia. Funding comes from the CDC through the state to the cancer center, which maintains the public and professional education component of the program, as well as the partnership and collaboration piece. There are*
154 breast and cervical cancer screening providers and about 100 referral
providers around the state for the program.

ACCN [based at the university] doesn't engage in screening as a group, but
instead promotes other screenings through our partnerships; quite a bit
through the Breast and Cervical Cancer Screening Program. We partner with
hospitals and clinics for Paps, mammograms, clinical breast exams,
PSAs/DREs, and a lot of FOBTs/FITs. Locations for the free screenings
include clinics, federally approved health centers, and hospitals. Free Paps
are offered to women who don't qualify for the Breast and Cervical Cancer
Screening Program, and mammograms are offered in conjunction with other
screening events. FOBT/FIT is provided by the clinic or hospital. The hospital
takes on responsibility for follow-up care.

Through our many partnerships, we've increased screening for the rarely and
never screened and decreased time from screening to diagnosis and
treatment.

A second exemplary example is the statewide, "hub and wheel" TeamUp cancer
prevention and control partnership network in Tennessee (previously described). In
this network, the various partnership teams determine the strategies used to achieve
their goals. Initially, the NCI wanted all TeamUp partners to use a template (one
strategy) that would be consistent across all communities and populations for
increasing cancer screening, but as one respondent reported:

TeamUp recognized that a 'one size fits all' approach would definitely not
work for our 11 counties and resisted the use of a single template, because
communities are not all alike, and you can't put a footprint down and say,
'everyone's going to do it this way'. TeamUp has proven to be a very
mobilizing body because we all have the same mission, share resources, do
not duplicate efforts, and tailor our programs to the communities we serve.
Many hospitals want to expand their outreach but don't have the capacity to
get out and do it; and the same with the American Cancer Society that doesn't
have field staff to get their message out. So the 'hub and wheel' structure
provided by TeamUp, with Cooperative Extension as the conduit for outreach
and being structured to facilitate groups and having the time and resources to
coordinate these efforts, has made for a perfect relationship for statewide
cancer prevention and control. The program has been very successful: statistically significant increases in cancer screening rates have been shown for all 11 counties as our activities have increased, and the network continues to grow. TeamUp's comprehensive approach has been cited by the state as exemplary, and our visibility within the state has substantially grown.

Among coalitions in rural communities, partnerships were similarly shown as crucial to the success of their outreach and screening efforts. By definition, community-based cancer coalitions ARE partnerships, and partnership is the "fuel that drives everything we do." Many good examples of successful community partnerships were found in this research, many of which have already been noted in this narrative: churches, local healthcare providers, food pantries, schools, universities, the local Komen affiliate, civic organizations, businesses, Area Agency on Aging, drug and alcohol organizations, prisons, and other local health agencies. The local media was reported as another important partner in rural communities, in terms of both 'getting the word out' about the need for screening and available programs and events, but also media personnel being directly involved in the coalition's program planning including as coalition members. A coalition key informant in Kentucky illustrated this well:

A strength of our coalition is our relationship and work with the media, including a local TV station that has a sister station in Lexington and a representative on the coalition who is very community-oriented and focuses on health and the community. The station itself has a health focus and is very community-based, with a community Mountain Calendar, a regular Monday program called, 'Issues and Answers' on which the coalition has done programs on colorectal cancer and breast cancer, and other programming. We also use the local newspapers and radio stations. Because we're a small community and everyone knows everyone else, it's easy to get media representatives to come in and say, 'I'll take care of this for you.' So we have that media person built into our coalition.
This coalition-media partnership has been a key factor in the success of several screening-related events and initiatives, including an ACS Freedom Bus event hosted by the coalition, in which “tons of people” participated and were screened for breast, cervical, colorectal, and skin cancer; and a community-wide colorectal cancer campaign. With regard to this latter event, another key informant from the coalition reported:

That campaign was promoted through TV primarily by a young reporter who did things like went in for a colonoscopy, even though she was only about 30 years old. She talked about it on TV to educate the public and presented it in a culturally-sensitive way, since she’s from the community. So she reached a lot of people.

Based on these and many other examples found in this study, the data clearly demonstrate partnership networks as a best practice strategy for promoting cancer screening in rural communities.

Recruitment and Retainment Strategies

As the second major category of community engagement, strategies used to accrue rural residents into cancer screening initiatives (recruitment) and to promote continued participation in repeat programs and regular screening (retention) were demonstrated as crucial for improving cancer screening outcomes.

Intervention sites. The specific location of intervention sites was found to be particularly important for increasing access to screening. Site location was observed as interrelated with, and often dependent upon, the specific partnerships of the two study groups noted above. Although some intervention sites have been indicated in the previous narrative, the importance of site selection provides ample justification for the presentation of additional findings.
Both study groups selected a wide range of intervention sites over the past three years (Table 5.9). In terms of screening success, sites where both coalitions and

<table>
<thead>
<tr>
<th>INTERVENTION SITE</th>
<th>Coalitions (n=11)</th>
<th>Cancer Center-Academic Programs (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Primary care clinic*†</td>
<td>9</td>
<td>81.8</td>
</tr>
<tr>
<td>- Health fair/ health fair approach*†</td>
<td>9</td>
<td>81.8</td>
</tr>
<tr>
<td>- Hospital**†</td>
<td>9</td>
<td>81.8</td>
</tr>
<tr>
<td>- Mobile screening van**◊</td>
<td>7</td>
<td>63.6</td>
</tr>
<tr>
<td>- Worksite**†</td>
<td>7</td>
<td>63.6</td>
</tr>
<tr>
<td>- School/college*</td>
<td>6</td>
<td>54.5</td>
</tr>
<tr>
<td>- County/state health center*</td>
<td>5</td>
<td>41.8</td>
</tr>
<tr>
<td>- Church**†</td>
<td>4</td>
<td>36.4</td>
</tr>
<tr>
<td>- Cancer center†</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>- County fair</td>
<td>3</td>
<td>27.3</td>
</tr>
<tr>
<td>- Senior center</td>
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<td>27.3</td>
</tr>
<tr>
<td>- Conference/symposium facility*</td>
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<td>18.2</td>
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<td>- Federally-qualified health center</td>
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<td>9.1</td>
</tr>
<tr>
<td>- Farmers' grange</td>
<td>1</td>
<td>9.1</td>
</tr>
<tr>
<td>- Mexican-Latino celebrations</td>
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</tr>
<tr>
<td>- Amish health &amp; safety fair*</td>
<td>1</td>
<td>9.1</td>
</tr>
<tr>
<td>- ACS Freedom Bus*</td>
<td>1</td>
<td>9.1</td>
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<tr>
<td>- Courthouse</td>
<td>1</td>
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<tr>
<td>- Craft show</td>
<td>1</td>
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</tr>
<tr>
<td>- Floral shop</td>
<td>1</td>
<td>9.1</td>
</tr>
<tr>
<td>- Food pantries*</td>
<td>1</td>
<td>9.1</td>
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<tr>
<td>- Golf course</td>
<td>1</td>
<td>9.1</td>
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<td>- Barber shop/ beauty shop</td>
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<tr>
<td>- Laundromat</td>
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<td>- State health fair†</td>
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<td>- Wal-Mart</td>
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<td>0.0</td>
</tr>
<tr>
<td>- Water park/ beach</td>
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<td>0.0</td>
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</tbody>
</table>

* Successful outcome resulted (coalition)
† Successful outcome resulted (cancer [center-academic program])
◊ Lost funding/staff (for one or more cases, in one or both groups)
cancer center-academic outreach programs have been particularly successful in achieving desired cancer screening-specific outcomes included: primary care clinics and hospitals; mobile screening vans; worksites; churches; and some health fairs, especially an annual state health fair in Kentucky where “thousands were screened over the past few years”; and sites where a health-fair approach with multiple components was used to target multiple conditions and people were either scheduled or screened onsite. Cancer centers served as a favorable screening site for a majority of cancer center-academic outreach programs. Other successful sites for coalitions included: county and state health centers; food pantries (numbers screened previously cited); conferences where screening was offered (e.g., “more than 100” people screened at one annual, coalition-sponsored symposium); and the event that featured the American Cancer Society Freedom Bus in Kentucky (“tons of people were there”).

Mobile screening vans have been particularly successful in providing access to screening in rural communities. For example, cancer screening in rural communities of South Carolina has been primarily through a 40-foot mobile screening unit in existence since 1998 and a new unit purchased in 2007. Screenings are performed for breast (digital mammography), cervical, prostate, skin and oral cancer. In 2006, 1,378 screenings were completed; in 2007, this number rose to 1,632; and in the first three months of 2008, completed screenings totaled 1,596. Sustainability of the mobile unit has been built through leveraged funds from multiple sources (state-allocated federal funds, philanthropic gifts, the Nissan and Wachovia Foundations), and strong commitment from the university’s medical community. A medical director oversees all aspects of the van’s operations. Staffing includes two paid, nurse practitioners (one of whom specializes in breast and cervical screening, the
other in prostate screening); a full-time mammography technician; a phlebotomist; and two other staff who drive the van and register clients. In defining success in their outreach programs, one key informant said of this unit: “Success is asking if they would have gotten screened if mobile hadn’t come to their community; 64% of people say they wouldn’t have been screened if the mobile unit hadn’t been available.”

Based on the intervention sites found to be selected by these outreach programs, a key finding of this study is that “going where the people are”, particularly via mobile screening vans and easily accessible community sites, constitutes a best strategy for rural cancer screening programs. However, another sad and ironic finding is that many rural communities that once had mobile screening vans in the past no longer have this valuable screening resource because of lost funding and staff support. Clearly, with additional funding support and commitment by cancer centers and other key players, access to cancer screening could be much improved in rural communities.

**Intervention strategies.** A wide range of intervention strategies were used by the two study groups. A number of these were shown to be highly effective in promoting cancer screening (Table 5.10). *Community education* was unanimously used and considered or demonstrated by cases in both study groups to be an essential starting point for facilitating cancer screening and prevention behavior change. One-on-one education (the basis of social networking) was shown to be especially successful for screening mammography, as in the Alabama-Mississippi experience. Other educational strategies included group education to increase cancer-related knowledge and the need for screening, as well as to ‘demystify’ and ‘destigmatize’ cancer to erase misconceptions, myths, and fatalism. Two examples of the effectiveness of community education for screening promotion cited previously were: the Pennsylvania coalition’s HPV educational program for women aged 18-26 that
Table 5.10 Intervention strategies in rural cancer screening promotion programs, 2006-2008

<table>
<thead>
<tr>
<th>STRATEGY</th>
<th>Coalition (n=11)</th>
<th>Cancer Center-Acad. Programs (n=9)</th>
<th>STRATEGY</th>
<th>Coalition (n=11)</th>
<th>Cancer Center-Acad. Programs (n=9)</th>
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<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Comm. Educat.†</td>
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<td>- One-on-one*†</td>
<td>4</td>
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<tr>
<td>Multiple strategy approach*††</td>
<td>9</td>
<td>81.8</td>
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<tr>
<td>Target multiple conditions*††</td>
<td>8</td>
<td>72.7</td>
<td>6</td>
<td>66.7</td>
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<tr>
<td>Refer to BCCSP or CRC Program*††</td>
<td>8</td>
<td>72.7</td>
<td>9</td>
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<tr>
<td>Small Media: ^</td>
<td>8</td>
<td>72.7</td>
<td>4</td>
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<td>- Brochure/flyer</td>
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<td>4</td>
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<tr>
<td>- Radio**</td>
<td>7</td>
<td>63.6</td>
<td>1</td>
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<tr>
<td>- Word of mouth*</td>
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<td>- Local TV**</td>
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<td>- Payroll insert*</td>
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<td>9.1</td>
<td>1</td>
<td>11.1</td>
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<tr>
<td>Piggy back**</td>
<td>7</td>
<td>63.6</td>
<td>5</td>
<td>55.6</td>
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<td>2</td>
<td>22.3</td>
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<td>41.8</td>
<td>5</td>
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<td>1</td>
<td>11.1</td>
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<tr>
<td>Reminders*‡‡</td>
<td>5</td>
<td>41.8</td>
<td>1</td>
<td>11.1</td>
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</tbody>
</table>

* Successful outcome resulted (coalition) † Successful outcome resulted (cancer center/acad. program) ^ Unsuccessful outcome resulted (for one or more cases, in one or both groups) †† Community Guide-recommended strategy

resulted in significant change in HPV-related knowledge and intent to obtain HPV vaccination; and cancer center/university-led lay helper programs in Alabama,
Mississippi, and North Carolina that educated and screened hundreds of rural African American, Hispanic and White women breast cancer (Note: Other lay helper programs are currently in development by cancer center-academic programs in South Carolina and Kentucky). The central importance and role of community education for increasing cancer screening also was evidenced in faith-based initiatives, mobile screening events, conferences/symposia, and other venues. Clearly, the role of community education as a key strategy for promoting cancer screening cannot be understated.

A multiple-strategy approach was almost unanimously used by cases in both study groups in their screening outreach programs, with demonstrated successes in both groups. In these multi-component interventions, effective strategies included offering free screenings, primarily through referral to the CDC/state-funded Breast and Cervical Cancer Screening Program (in all states) and/or a state-funded colorectal cancer screening program (New York). Gas cards and other forms of provided transportation as an incentive for program participation helped reduce cost and transportation barriers. Small media, especially local newspapers, inserts in church bulletins and payroll checks, radio and TV, and especially word-of-mouth were found as effective strategies for recruiting people to screening programs and events and otherwise “getting the word out”. The strategy noted as “piggy back”—in effect, partnering a screening program with another community initiative or event as a way to maximize attendance and recruitment and to sometimes intentionally offer a ‘one-stop health shop’—was reported as an effective strategy by more than half of both study groups. Almost half of coalitions and one cancer center-academic program used client reminders, in the form of postcards, letters, and phone calls, and reported them as effective strategies. At least two cases (one in each study group) also encouraged provider reminders; for example, using their electronic medical medical record
systems to generate reminders for providers to counsel patients and reminder letters or phone calls to patients. Another especially important and effective strategy was to tailor programs, using literacy- and culturally-appropriate materials, settings and facilitators (e.g., visual materials featuring “Mariana’s story” and Spanish-speaking Promotoras in a Hispanic church for Hispanic or Latino audiences). Storytelling was reported as an effective trans-cultural strategy among the rural White Appalachian, Hispanic/Latino, and African American populations to educate and motivate people to be screened.

Unsuccessful Strategies

It is both instructive and useful to also examine strategies found not to work, as indicated in the table footnotes above. The most prevalent and informative, unsuccessful strategies found in this research will thus be summarized and illustrated, as follows.

Looking back at strategies reported by individual cases not to work, the first observation is that strategies reported as unsuccessful were far fewer than those that did work; in total, less than a dozen ‘unsuccessful’ strategies were noted or found. Among these, didactic lectures in community education programs, especially those wherein community members had to travel to attend the event had very low attendance. Some large media strategies including TV and radio campaigns reached tens of thousands of people but resulted in one or two persons screened. Financial incentives also were not effective. Cash payments to participants in one African American faith-based program raised ethical concerns of potential coercion. “Canned programs” and required use of a “program template” that prevented little adaptation or tailoring (as in the Tennessee experience) were also found as ineffective.

A second observation is that strategies that did not work for a few cases among the two study groups actually worked for most. In some cases, the unique mixture of
barriers to screening in the community, characteristics of the target audience, and programmatic factors (including personalities of intervention personnel) can create a situation in which "nothing seems to work". The following vignettes from two coalitions exemplify this theme. The primary screening-related goal of the first coalition was to promote mammography in a variety of ways, as described by an American Cancer Society coalition member:

Nothing seems to work for this coalition. We do a pink campaign in October for breast cancer, including decorating trees with lights and putting out donation canisters for the coalition. We identified non-compliant women and had them register to get on a van offered through the HealthyWoman [Breast and Cervical Cancer Screening] Program for a screening at the hospital during an afternoon. A local church donated the van. ACS provided money for lunch and the van and we publicized the event. We relied on the medical center to do the follow-up due to HIPAA rules and the coalition for word-of-mouth promotion. Two local restaurants had information on printed placements, and information was in the local newspaper. The results were disappointing: only four women were on the van. We tried year after year to get the van filled and couldn't. Awareness may have been more of an issue than transportation. Also, participants had to give up time. The coalition decided to hold a spaghetti dinner and hand out brochures at an information table, but people weren't interested in hearing the information when they were there to eat.

For a colorectal cancer screening program we did, the [name of lead group] relied on our coalition to share information with community peers, but it didn't get promoted. Five hundred placements were used to promote screening guidelines and the event, but there was no response. Techs at the hospital said they had no time. PAs at the hospital assured us that time would be given, but it didn't happen. And at the big street fair, there weren't any takers for the FOBT kits. People viewed them as unnecessary and uncomfortable. There was opposition to taking them. People here are 'scared to death' about cancer. The coalition likes to do big things but not the hands-on work. They won't spend the money they have but keep it in the bank. At meetings, I'm careful of my position because I'm there to support but not tell them what to do.
The experience of a second coalition illustrates how a potentially effective “piggy-back” strategy can backfire and prove to be unsuccessful in some situations, due to a competitive attitude (lack of a partnership spirit) among community agencies:

_The Vo-Tech school partners with our coalition on screening education and awareness. We’ve done skin cancer screenings every year, advertised through a newspaper article: where to pre-register; walk-ins also. Screenings are held at the Department of Health, and we have very high referral rates. We always tie in one screening event to another event; for example, the Pioneer Festival Relay for Life. However, this year ACS was very upset that we infringed on their territory, so we won’t do that again. This year we plan to tie in with the [other community name] event._

From these examples, it may be concluded that program strategies that work in one community may not always work in another, depending on the unique barriers to screening and the constellation of people, organizations, and commitment or inertia of local institutions and agencies that exist within the community.

The Findings Relative to the Community Guide’s Recommendations for Cancer Screening

As discussed in Chapter 2, the most authoritative research-tested, best practice cancer screening strategies against which this study’s findings can be compared are the Task Force-recommended strategies published in the Community Guide to Preventive Health Services. As a brief review, the Task Force found sufficient evidence to recommend the following strategies for increasing access and adherence to cancer screening:

- **For breast cancer (mammography):**
  - Client reminders
  - Small media
  - One-on-one education
  - Strategies that reduce structural or physical barriers
  - Strategies that reduce out-of-pocket expenses
For cervical cancer (Pap test):  
- Client reminders  
- Small media  
- One-on-one education  
- Provider reminders  
- Provider assessment and feedback  
- Multi-component interventions  

For colorectal cancer (FOBT):  
- Client reminders  
- Small media  
- Strategies that reduce structural or physical barriers  

For skin cancer (decreased sun exposure):  
- Education and policy interventions in primary schools (children)  
- Education and policy interventions in recreational & tourism settings (adults)  
- Sunscreen use (in conjunction with both strategies above)  

For prostate cancer (no specific screening recommended):  
- Informed decision-making  

Worksite interventions using the above strategies:  
- Onsite screenings, health educators, and media campaign  
- Reduced out-of-pocket expenses through employer insurance programs  

The majority of both study groups in this study employed one or more of these Community Guide-recommended strategies (Table 5.10), with impressive success in some programs’ screening outcomes. Many examples have been provided throughout this narrative. With respect to keeping this narrative within a reasonable length without sacrificing content, the following discussion of the study’s findings compared to the Community Guide’s recommended strategies will primarily focus on those relative to mammography screening.

Client reminders in the form of postcards, letters, and phone calls were used by almost half of coalitions and at least one cancer center-academic program, all of which included mammography screening. In New York State, client reminders are systematically generated by the newly integrated electronic system of the state-funded
Cancer Services Program, which substantially helps to increase breast, cervical, and colorectal screenings among the uninsured, as reported by two coalitions that administer the program in their counties. A coalition in western Pennsylvania collaborates with a patient navigator at the local hospital who places telephone reminder calls following screening recruitment events: "The calls help to generate a 30%-40% return rate [of a post-test that assesses cancer screening knowledge and intent]. Referrals go to the hospital and then the hospital follows-up with the primary care physicians."

The efficacy of client reminders and small media as part of a larger campaign to increase mammography screening was demonstrated in the following description, given by a cancer center-academic researcher in Kentucky, with supplemental information from document review:

For more than a decade, the Kentucky Cancer Program (KCP) [a statewide cancer control organization operated by two university-based cancer centers] has worked with the state’s First Ladies [governors’ wives] to reduce breast cancer deaths in the state. ‘Celebrate Your Birthday with a Mammogram’ is a statewide campaign begun by the KCP, First Lady Glenna Fletcher, and [a health care utilization management and quality improvement organization]. Through this initiative, more than 150,000 women ages 65-69 have received cards on their birthday from the Governor’s wife encouraging them to schedule an appointment with their health care provider for breast, cervical and colon cancer screenings. During the last two years, the cancer center organized 30 local parties attended by 2,600 women. The campaign also included TV and radio ads featuring the Governor’s wife promoting free and low-cost cancer screening for low-income women through the Kentucky Women’s Cancer Screening Program and Medicare. A social networking approach also is utilized: the birthday card message encourages women to bring a friend who has not been screened. At the ‘party’ event, each woman is given three birthday cards and asked to send them to three additional women. One-month follow-up reminder cards and a three-month follow-up telephone call are used to both encourage screening and assess compliance.
In addition to birthday cards as small media, informational messages delivered in brochures and flyers (with some exceptions), church bulletin and payroll inserts, local newspapers, radio and TV (with some exceptions), display boards, and DVDs/videos were shown to be effective in increasing mammography screening. Small media has been an important and effective strategy in the TeamUp Tennessee’s cancer screening efforts. In a pilot study, promotional strategies were employed to reach women with messages about the benefits of breast and cervical cancer screening using exhibits (39), newspaper articles (39), radio programs (29), and TV programs (5), resulting in 340,479 community contacts made. Cooperative Extension educators and county partners conducted 283 educational programs/events (mother/daughter teas, women’s teas, African American church service programs, Women’s Day fairs, church delivered educational programs, and health fairs), reaching 2,850 women. Overall, a significant increase in screening rates for women aged 50 through 64 was shown in all intervention counties, compared to control counties.

In another project in Tennessee, visual aids were found to be especially useful and effective with Hispanic and Latina women in promoting mammography screening:

*We conducted focus groups with Latina women to learn how they wanted to receive information about breast and cervical cancer and for their review of materials developed by the Department of Health. We learned that the use of images and visuals not targeted specifically to Latinas as an ethnic group (not being singled out) was a more powerful approach with this population. So we designed the educational materials using silhouettes instead of pictures of Latina women, and rather than talk about multiple risk factors we focused our message on being a woman and getting older as the biggest risk factor for breast cancer. This was more acceptable and less threatening. At the same time East Tennessee State University did some research that validated our project. Our program used the materials during the four years of our more recent study, and they are now being used throughout the state.*
Most of the remaining Community Guide recommended strategies for screening mammography, including one-on-one education, strategies that reduce structural or physical barriers (e.g., mobile mammography vans), those that reduce out-of-pocket expenses (e.g., referral to the CDC/state-funded Breast and Cervical Cancer Screening Program) and worksite interventions using these strategies have been well represented in this paper. The recommended strategies for cervical and colorectal cancer screening have also been well represented. The one exception, provider assessment and feedback for cervical cancer—in effect, evaluation of provider performance in delivering cervical cancer screening and feedback given to providers on their performance—was not reported or otherwise found in the analysis.

The value of evidence-based programs and the Task Force-recommended strategies are clear. However, the findings also reveal that other non-evidenced-based, ‘tried and true’ strategies used by outreach programs to increase cancer screening were found to work in the vast, rural Appalachian area represented in this study. Thus, it is not unreasonable to suggest that the strategies generated by, and shown effective through the passionate commitment and long-standing efforts of the eleven coalitions and nine cancer center/university-based outreach programs may very well be candidates for future designation as evidence-based approaches. Although beyond scope of this research, these community-based strategies represent important practice-based evidence worthy of further description and discussion.

Summary of Findings

In summary, comparisons between coalition and cancer center-academic outreach programs revealed similar but also differences in the definition of program success and strategies used to address barriers to screening. Cancer center-academic programs more often encountered system-level challenges, such as an inordinate
amount of administrative requirements, too little funding and staff and difficulty in obtaining screening for undocumented (immigrant) groups. In contrast, coalitions appeared to be challenged by more individual-level barriers, such as difficulty in tracking follow-up of abnormal screening tests, competition from other community organizations, and lack of provider recommendation of screening.

With regard to the ways in which the two study groups defined program success, the most common definitions to both groups included the number of persons screened, diagnosed and treated early and increased program capacity. However, cancer center-academic programs more often defined success in terms of population-based, long-term cancer health outcomes (e.g., decreased screening rates and disparities, increased sustainability); while coalitions more often cited individual-level, short-term outcomes (e.g., “one life saved”, increased knowledge, number of persons screened per event) as measures of success. This same pattern was observed for funding sources. While both groups almost unanimously named the CDC/state-funded breast and cervical cancer screening program as the best funding option for breast and cervical cancer screening, cancer center-academic programs tended to list large, population-based and institutional-level funding agencies as funding sources (e.g., Susan G. Komen Foundation, business/industry, state legislature, cancer center, university); while coalitions identified more local, community-level sources that focused on individual behavior change (e.g., small grants, donated time/materials/sites, American Cancer Society, fundraising). NIH/NCI were named by both groups as a major funding source; however, it is likely that for coalitions this meant NIH/NCI funding provided to the Appalachian Community Cancer Network, with which all 11 coalitions are affiliated.

A similar pattern was shown for use of theoretical models and evidence-based approaches. A large majority of both groups reported successes in using community-
based participatory research, social networking approaches (although more so by
cancer center-academic programs for the latter), and Cancer Control P.L.A.N.E.T.
However, coalitions used less theory (primarily Tell A Friend and targeted mailings)
and more evidence-informed strategies overall, while cancer center-academic
programs used more theory and evidence-based programs in general (e.g., Witness
Project, Body & Soul).

Finally, both between-group similarities and differences were found for
community- and trust-building strategies, choice of intervention sites, and other
specific intervention strategies. Effective strategies almost unanimously employed by
both study groups included community education; use of a multiple-strategy (multiple
component) approach to meet the specific needs of the target audience; community
involvement in program development and delivery; and primary care clinics as an
intervention site. Both groups also piggy-backed their programs onto other events
(coalitions more so); targeted multiple conditions; and hailed passion and
commitment as a necessary strategy. Coalitions, however, more often reported
partnerships with organizational champions and successful use of individual-and
community-level strategies, such as unpaid community volunteers, small media,
reminders and encouraging provider recommendation to ensure completed screening,
with programs delivered through mobile screening units, worksites, schools, health
fairs, and county fairs. Cancer center-academic programs, on the other hand, used
more population-based, formalized approaches and larger organizational partners
including faith-based and lay helpers programs; paid volunteers; and community
member training (including train-the-trainer programs), with greater program delivery
at churches, state health centers, and cancer centers than coalitions.

Finally, the data in this study demonstrate that multilevel approaches to cancer
screening (Study Proposition 1), with involvement of community members in the
development and implementation of those strategies (Study Proposition 2) can effectively overcome barriers and increase cancer screening in rural communities. However, the findings also indicate that strategic deficits remain among community-based coalitions and cancer center/academic outreach programs for achieving their cancer screening goals. As next described, a best practices cancer screening model is proposed to strengthen and assist these outreach programs in attaining their short- and long-term cancer prevention and screening objectives in rural populations.
Utility of the Conceptual Model and Changes Suggested by the Research

The conceptual model that guided this research (Figure 3.2) delineated the multiple levels of factors that can facilitate (predict) or impede (create barriers to) cancer screening, which when addressed through participatory interventions using health behavior models and strategies to overcome those barriers can contribute to health behavior change (screening) as a proximal outcome and to longer-term decreases in cancer morbidity, mortality, and disparities. The findings from this research corroborate these assumptions. The data also show multi-strategy approaches as a particularly effective strategy for increasing cancer screening in this study’s sample of rural residents. This finding is consistent with the literature that multi-strategy (multiple component) interventions are more effective than any single intervention strategy alone (Sin & St Leger, 1999; Sebaldt et al., 2007; USPSTF, 2007). Further, evidence-based programs such as those listed on Cancer Control P.L.A.N.E.T. (e.g., Witness Project, targeted mailings, Tell A Friend) and evidence-based strategies recommended by the Task Force in the Community Guide (e.g., worksite programs, small media, patient and physician reminders) were found in this study to decrease barriers to screening and increase screening behaviors and related outcomes, including knowledge, intent to screen, and primary prevention behaviors (HPV vaccination, tobacco cessation). Thus, the utility of the study’s conceptual model was confirmed by these evidence-based approaches and other successful strategies, which collectively suggest a best practices model to enhance the design and delivery of cancer screening outreach programs in rural communities.
The Proposed Best Practices Model of Rural Cancer Screening

The proposed best practices model of rural cancer screening is built upon: 1) productive interactions between community-based coalitions and cancer center-academic outreach programs, input and guidance from the community, and agreed-upon definitions of program success; and 2) strategies that build program capacity and engage community members in cancer screening (Figure 6.1).

**Cancer Center-Academic Outreach Programs**
- Congruent Measures of Success

**Program-Related Strategies**
- Mission & Program Foci
- Capacity-building Strategies
- Theory-based Models
- Evidence-based Approaches
- Community Education

**Community Coalition Outreach Programs**
- Community Engagement Strategies
- Trust & Relationship Building
- Community Involvement
- Partnerships & Networking
- Recruitment & Retainment Strategies
- Community Education

**Policy and Healthcare Systems Change**
- (Funding for screening)

**Individual Health Behavior Change**
- (Cancer screening)

**Healthcare Provider Behavior Change**
- (Screening recommendation)

**Long-term Health Outcomes**
- (Decreased cancer incidence, mortality, disparities)

*Figure 6.1 The Best Practices Model Of Rural Cancer Screening (Kluhsman, 2008)*
A central premise of this model is that these strategies are specifically chosen to address and overcome systems-level barriers (to increase access to screening), healthcare provider behaviors (increased barriers to screening at multiple levels. If successful, change in policy and healthcare systems, provider recommendation and performance of screening, and individual behavior (regular screening) change will occur. Theoretically, in the longer term change at these three levels will lead to decreased cancer incidence, morbidity, mortality, and disparities.

The model offers a recipe for increasing cancer screening in rural communities through collaborative interventions of cancer center-academic outreach programs and community coalitions. The first ingredient when beginning any new screening initiative is dialog between the two groups. As part of this dialog, a critical second ingredient is input and guidance from the community on program development, implementation and evaluation. Such input can occur through a community advisory committee, focus groups, and/or community opinion leaders. A third ingredient is a mutually agreed-upon measure (or measures) of success; in effect, the desired outcomes of the program or initiative. Congruent measures of success will help define program objectives, the roles of those involved, in program implementation, and the specific intervention strategies to be carried out. As the fourth ingredient, the strategies in the model are specifically targeted to screening-related barriers identified in the community. Program-related strategies are those that increase or insure the group’s capacity to achieve screening outcomes, shown by this research to include defining program foci (e.g., use of surveillance data, assessments, and Community Health Profiles to determine community needs); leveraged funding; selection of theoretical models known to work (community empowerment and capacity-building, social networking, faith-based health promotion, stages of change); and evidence-based approaches (programs on Cancer Control P.L.A.N.E.T.; Community Guide-
recommended strategies. Community engagement strategies include: building community trust and relationships (community gatekeepers; cultural sensitivity to decrease community-researcher ‘disconnect’, mistrust); community involvement (lay helpers, students, translators as trusted community members); partnerships and networking (with hospitals, providers, schools, local agencies); recruitment and retention strategies (going where the people are, mobile vans, gas card incentives to overcome geography and transportation barriers; one-on-one education to decrease fear/fatalism; free screening/referral to funded programs to overcome financial barrier; and using a multiple strategy approach to tailor a program, event, or health message to the specific needs of the target audience); and translation of models into messages that community members will relate to.

The benefits of this best practices model are many. The model can serve as a template to guide program development and implementation; offers insights into ways that outreach programs and coalitions can learn from each other; and provides a roadmap for building program capacity and synergy for effectively reducing cancer morbidity, mortality and disparities among rural people.

The proposed conceptual model could be tested in a two-group, quasi-experimental community screening promotion study, in which the type of cancer screening(s) targeted and the main outcome(s) are similar (e.g., colorectal cancer screening among rarely and never screened persons; and/or change in health care provider recommendation of screening; and/or change in a local hospital or cancer center agreeing to provide follow-up care for abnormal screening results). In this hypothetical study, the intervention ‘Group A’ might consist of a number of cancer center-academic outreach programs and their community coalition partners which collaboratively:
• identifies a community advisory committee to participate and guide the intervention from the earliest planning stage through dissemination

• selects the specific theoretical model(s), community partners, recruitment and evidence-based strategies to address the specific barriers to screening and tailor the intervention to the needs of the target population;

• maintains a collaborative approach throughout all phases of the study.

The comparison (control) ‘Group B’ might consist of a number of cancer center-academic outreach programs in counties without a cancer coalition, matched to the intervention group on rurality, county- or state-level BRFSS data for the specific targeted cancer(s), and sociodemographic characteristics of the target population (e.g., race/ethnicity, gender, education, income).

Strengths and Limitations

This study was strengthened by a large sample size (by qualitative inquiry standards) of cancer center-academic and community-based cancer outreach programs across a large, multi-state rural region of the eastern U.S. (Appalachia). Validity and reliability were enhanced by using multiple sources of data representing a three-year time period; multiple key informant perspectives in most cases; and multiple interviewers who also conducted systematic coding and analysis of these data. Study credibility is enhanced through expert review, oversight and assurance of sound scientific methods provided by senior researchers experienced in qualitative and community-based public health research. The investigator’s strong background in cancer prevention and control and community-based participatory research with medically underserved populations lends additional strength to the research.
This study is limited in being observational and included retrospective, self-report interview data subject to recall bias. Despite some racial and ethnic diversity in the study sample and their constituent populations, the predominantly White population of the Appalachian region limits generalizability to other rural areas. Generalizability was further limited by the sample of coalition key informants as representative mostly of Appalachian Pennsylvania and New York. The qualitative, interpretive nature of this research may have permitted interpretation bias in the study's analyses.

Implications for Future Research and Practice

Some of the many valuable lessons learned in this study for future research and practice are as follows:

1. Greater dialog and feedback between cancer center-academic outreach programs and community coalitions provides an opportunity to learn from each other and develop strategic plans and collaborative programs to overcome both program-related barriers and the barriers to screening among rural populations.

2. However, community-academic partnerships need to be systematically integrated into the mission of major academic medical institutions to achieve longer-term and sustained cancer health outcomes. Such partnerships can serve as a feedback loop and pipeline for outcome data to cancer center-academic programs and funding agencies.

3. Research-tested, evidence-based programs and strategies can increase cancer-related knowledge, first-time screening, and repeat screening among rural residents.

4. Despite the paucity of recommended, research-tested (evidence-based) interventions and strategies, both community-based coalitions and cancer center-academic outreach programs have embraced these methods with demonstrated success. In addition, coalitions can help generate important "practice-based" evidence that may result in improved screening among rural populations.
5. Many community coalitions that use evidence-based programs and strategies are not familiar with health behavior theories and research evidence underlying these approaches. Providing basic training in health theory and evidence-based approaches will reinforce their use of these methods and strengthen their grantwriting and fundraising efforts. In addition, many cancer centers are not familiar with effective methods of community engagement and would benefit from training in community engagement approaches to strengthen the reach and effectiveness of their work.

6. Institutional commitment to cancer screening as a priority area is crucial for improving cancer health outcomes in rural communities. Institutional support for local academic-community cancer control partnerships can be a cost-effective, mutually beneficial strategy for both the community and the institution.

7. Leveraged funds and mini-grants channeled to community groups can increase outreach capacity, cancer screening rates, and sustainability of programs.

8. Both cancer center-academic outreach programs and community coalitions suffer from chronic, inadequate funding and staff for achieving their cancer screening goals. Additional funding support is needed from the National Cancer Institute, state legislatures, and other funding agencies if reductions in rural cancer disparities are to be made.

9. Mobile screening units (i.e., “going where the people are”) are highly effective for increasing access and screening adherence in rural communities. As many rural communities that once had a mobile screening van no longer have this valuable resource because of lost funding and staff support, there is a need for greater funding and health systems change that support mobile screening vans in rural communities.

10. Although provider recommendation is known to be a strong predictor of screening compliance, lack of provider recommendation is a persistent problem in rural communities. Programs to increase physician recommendation should include complementary efforts to help physicians and patients address socioeconomic and other barriers to cancer screening.

11. Community trust is absolutely essential for rural cancer screening programs to successfully achieve their recruitment and retention goals. Pharmacists are among the most available and most trusted professionals in rural communities and
therefore can serve as agents of change in local cancer screening programs. Partnerships and networking with Department of Health immunization nurses and researchers with a long history or close relationship with the community, other community champions, gatekeepers, local health care providers, and community agencies can facilitate screening program success.

12. Program strategies that work in one community may not always work in another, depending on the particular barriers and characteristics of the community. Tailoring programs and use of culturally- and literacy-appropriate approaches are crucial for meeting the specific needs of people in rural areas.

13. Passion and commitment among program staff and strong community partnership networks are crucial to increasing program capacity and achieving increased cancer screening in rural communities.

14. The data in this research indicate a long-standing power and class differential in Appalachia as a more prominent issue than race and ethnicity. The strong pushback statements of community members in this study against medical hegemony suggest an area in need of further exploration in future research. These power issues should be examined through future, in-depth study and analysis.

Conclusion

The context of people’s lives determines their health behavior and consequently their overall health and well-being. This study provides a glimpse into the lives and struggles of everyday people living in rural areas and extraordinary insights into what public health practitioners can do to help improve the health status of our rural communities. During the telephone interviews conducted for this study, several key informants commented that the interview questions and dialog during the call helped them think about their programs in a different way and stimulated new ideas for planning, implementing or evaluating their interventions. The coding team created and coined a new thematic code from these recurring statements, ‘INTERVIEW AS MUTUALLY BENEFICIAL TO RESEARCHER AND KEY INFORMANT’. This single code perfectly mirrors the value and strength of the community partnership
approach for improving cancer-related outcomes in rural communities. We as public health workers and researchers must not only acknowledge but honor and fully embrace the community perspective and involvement in our rural health programs. In doing so we will gain a deeper understanding of the place where science and communities can and should meet to best serve and preserve the public’s good health.

Dissemination Plan

The findings from this study will be disseminated to the cancer coalitions and center-academic outreach programs that participated in this research; the University of Colorado Denver, the Penn State Hershey College of Medicine, and the National Cancer Institute that helped make this research possible; and to the public health community through a journal manuscript and conference presentations.
APPENDIX A
HUMAN SUBJECTS APPROVALS

• University of Colorado at Denver and Health Sciences Center
• Penn State Cancer Institute Scientific Review Committee
• Penn State Milton S. Hershey Medical Center College of Medicine
To: Brenda C. Klusman
From: UCD Human Subjects Research Committee
Subject: HRSC Protocol 2008-010
Title: WHERE SCIENCE AND COMMUNITIES MEET: A COMPARATIVE CASE STUDY OF COMMUNITY COALITION AND CANCER CENTER STRATEGIES TO INCREASE CANCER SCREENING AMONG RURAL RESIDENTS

Review/Panel: Expedited / Panel X
Review Date: 27 August 2007

Protocol Requires Minor Modifications
Reviewers see no problem or unacceptable risks in the protocol and consent, but stipulated changes in the protocol and/or consent form are needed. These are described in the attachments and reviewer comments. The proposal will not be approved until these stipulated changes are made and reviewed. To facilitate a timely review, please provide a cover letter itemizing your responses to each issue the reviewer has asked you to address. Please provide an edited copy of the Protocol/Protocol Summary (if applicable), and/or Consent Form (if applicable), with highlighted changes, and a clean copy of the consent form for the Co-Chair signature.

If the modifications are not received in COMIRB by Tuesday, 25 December 2007, your protocol will be WITHDRAWN. No research activities may begin on this protocol until final approval is received.

Comments:
PROTOCOL /APPLICATION:
1. Please confirm age range of participants.
2. Please explain methodology or plan for qualitative analysis.
3. Faculty advisor must be faculty with UCD or UCDHSC—please amend to include alternate advisor (Diane Fairdough or Debbi Main?).
4. Please provide study investigator's qualifications and experience with this population /research.
5. Explain whether women and minorities will be included to demonstrate equitable selection of study subjects.
6. This research will take place with external institutions—please provide a copy of that institutions IRB approval.

Dorothy Yates M.B.A.

Revised 23.05 2008-010 Panel X
Scientific Review Committee Notice of Review

Date of Review: July 31, 2007
Joseph J Drabick, MD, FACP, Chair

Protocol ID: Where Science and Communities Meet: A Comparative Case Study of Community Coalition and Cancer Center Strategies to Increase Cancer Screening among Rural Residents

Principal Investigator: Brenda Kluhsman, MS (HMC PHS)
Reviewer: Administrative Review

Discussion:
The above referenced study has undergone Administrative Review and is APPROVED by the Scientific Review Committee to proceed to IRB submission, if applicable.

Prepared/Saved 07.31.07
DATE: August 25, 2007
TO: Brenda Kieselman, Ph.D., Public Health Sciences (HMC)
FROM: Kevin Girod, M.D., Executive Chair
Institutional Review Board
RF: IRB Proposal No. 20070031 - Where Sexual and Community Men: A Comparative Case Study of Community Coalition and Center Center Strategies to Increase Cancer Screening Among Rural Residents

Confirmation of Exempt Status

Thank you for your application to the Institutional Review Board (IRB) for the above research. The activity was assessed for exempt status according to the policies of this institution and the provisions of applicable federal regulations. As submitted, the proposal was found not to require formal IRB review because the research met the criteria for exempt status according to the following category in the Code of Federal Regulations:

45 CFR 46.101(b)(2) - Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement, survey procedure, or observation of public behavior), unless: (i) Information obtained is recorded in such a manner that subjects cannot be identified directly or through identifiers linked to the subjects; and (ii) any identifiable link to subjects is maintained only by the investigator who conducted the research and who is responsible for the safety of the subjects; and (iii) the research activity is conducted in such a manner that the subjects are protected from risk of harm or risk of harm is not reasonably related to the potential or intended benefits (This category may NOT include_childhood vaccinations or the IDEA-regulated)

This determination was based on the research as described in your application and the following:

- Protocol Summary (dated 07/26/2007)
- Questionnaire - Key Informant Interview (received 07/27/2007). The research may involve only adults.
- No investigations for this research participated in the review determination.

Read this letter as evidence of IRB review and determination of exempt status for this research. Annual review of this research is not required provided the research is conducted as proposed. Therefore, all progress reports or IRB annual review letters will be issued.

The IRB requires notification and review in the following circumstances:

- Report any unanticipated problems involving risks to subjects or others that occur as a result of participation in this research.
- Report any proposed changes in the research activity that may alter the exempt status, outlined above. Prior IRB review is needed before such changes are initiated except where necessary to eliminate apparent immediate hazards to the subject.

Please include the IRB protocol number on any future documents submitted for this research. The Board appreciates your efforts to conduct research in compliance with the institutional policies and federal regulations that have been established for the protection of human subjects.

KGkm, Administrative Secretary
Key Informant Interview

Hello. This is [INTERVIEWER NAME] at the Penn State College of Medicine. I'm calling to complete our interview about cancer screening strategies used by your [coalition] [outreach program]

Is this STILL A GOOD TIME to complete the interview?

☐ Yes.... [CONTINUE]
☐ No.... [SCHEDULE CALLBACK TIME]: Date _____/_____/______
   Time: ____ AM / PM

Before we begin, I'd like to thank you again for your willingness to participate and briefly review the project:

• The purpose of this interview is to assess strategies used by community coalitions and cancer center outreach programs to increase cancer screening among rural residents during the past 3 years.
• About 60 individuals will participate in the study.
• The interview will take about 35-40 minutes. You may refuse to answer any question and end your participation at any time.
• Your identity will be kept completely confidential and will not be shared with anyone, or in any publication or presentation resulting from the study. The information you share will be not be coded or in any other way linked to your identity.

Do you have any questions?
[ANSWER QUESTIONS]

Do you give your consent to continue with the interview?

☐ No....Thank you for your time. [HANG UP]
☐ Yes [CONTINUE]

With your permission, I would like to tape record our interview to help assure that we accurately capture all of the information that you provide. The tape will be used only for the purpose of this research.

Do you give your permission for the interview to be tape recorded?

☐ No....OK, I will write your answers instead. [CONTINUE TO Q.1]
☐ Yes [TURN ON RECORDER; THEN CONTINUE TO Q.1]

Begin Time: ____ : ____ am / pm
Key Informant Interview Questions

[INTERVIEWER: Elaborate on any emergent themes beyond the questions and probes below. Maintain flexibility to follow narrative linkages for deeper meaning of participants' experiences.]

We are interested in learning how cancer screening is being promoted in rural communities.

1. How would you describe your [coalition's] [outreach program's] service area, in terms of its geography and population characteristics?
   Probes:
   - General location, rurality; Racial/ethnic make-up
   - Educational & poverty levels; Industry (blue-collar; white-collar)

2. Please tell me about your [coalition's] [outreach program's] cancer screening efforts with rural residents during the past 3 years.
   - Target rural audience(s)
   - Types of cancer targeted; Where screenings occurred
   - Funding sources (NIH, ACS, State Dept. of Health, foundations, etc.)

3. What has your role been in these screening efforts?
   Probes:
   - Position/leadership role in [coalition] [outreach program]
   - Length of service with [coalition] [outreach program]
   - Primary discipline/profession
   - Role in interventions

4. How would you describe the types of cancer screening strategies your [coalition] [program] has used with rural residents over the past 3 years.
   Probes:
   - Why/how these strategies were chosen
   - How community was engaged; trust established/built (e.g., community champion identified);
   - Participatory approaches; extent of stakeholder involvement
   - Recruitment strategies
   - Health behavior theories/models used
   - Evidence-based strategies/programs used
   - Examples (e.g., mobile screening units, partnerships w/local clinics/hospitals/agents; etc.)

5. Can you please describe the barriers to cancer screening in your rural communities, and how your [coalition]/[program] has addressed those barriers in your screening interventions?
   Probes:
   - Resources (e.g., insurance/financial costs/poverty; health care facilities; physicians/physician recommendation of screening; transportation; etc.)
   - Knowledge/attitudes/beliefs (e.g., education/literacy; cancer fatalism; myths about cancer; etc.)

6. How does your [coalition] [outreach program] define success in your rural cancer screening interventions, and how would you describe the successfulness of your program's cancer screening efforts in the past 3 years?
   Probes:
   - Measures of success
   - Reasons strategies were successful/unsuccessful
   - Examples of successful/unsuccessful strategies
   - Number of persons recruited/screened/diagnosed
   - Influence of funding source and funding levels

These are all the questions I have. Do you have any additional thoughts or questions? [PAUSE]

[If additional comments are needed, ask] Are there other staff in your program who I might contact for this interview? Name(s)/Phone #(s).

Thank you very much for your time. After the interview is transcribed, you may be asked to review the written transcript to confirm that it correctly states the information you shared. TURN OFF RECORDER.

End Time: [ ] [ ] [ ] am/pm

Version 2-10-05 (Final Amended: minor text changes only; per 35 pilot review)
## APPENDIX C
### DATA CODING SHEET

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<thead>
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<th>SERVICE AREA</th>
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<td>Population: (add if reported)</td>
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<tr>
<td>Single County: SINGLE COUNTY</td>
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<td>Breast BRCA</td>
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<tr>
<td>Multiple Counties: MULTIPLE COUNTIES</td>
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<td>Advocacy/Policy ADVOCACY</td>
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<td>Single State (list): SINGLE STATE</td>
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<td>Cervical CxCA</td>
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<td>Colorectal CRC</td>
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<td>Phyical Activity PHYS ACTIV</td>
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<td>Very Rural: VERY RURAL</td>
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<td>Lung/Tobacco LUNG/TOBACCO</td>
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<td>Employment/industry</td>
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<td>□ Partnerships/Networking PARTNERSHIPS/NETWORKING</td>
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<td>□ Cultural Sensitivity CULTURAL SENSITIVITY</td>
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<td>□ Demystify Cancer DEMYSTIFY</td>
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<td>□ Destigmatize Cancer DESTIGMATIZE</td>
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<td>□ Evaluation EVALUATION</td>
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<td>□ Low Literacy Materials LOW LIT MATERIALS</td>
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<td>□ Reminder Calls/Letters REMINDERS</td>
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<td>□ Short-term Projects/Gains SHORT-TERM PROJECTS/GAINS</td>
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<td>□ Target Multiple Conditions MULTIPLE CONDITIONS</td>
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*Unsuccessful Strategies (Go back through document, add double asterisk after code and to codes above)*

*Successful Strategies (Go back through document, add double asterisk after code and to codes above)*

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**Page 2**
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Page 3
Participant ID: ________

OTHER EMERGENT THEMES (Not listed above):

SUCCESSFUL STRATEGIES**

UNSUCCESSFUL STRATEGIES^^

SALIENT QUOTES (Highlight in yellow on transcript and summarize here):

Page # / Quote:

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APPENDIX D
KEY INFORMANT RECRUITMENT MATERIALS

- Cover Invitation Letter
- Consent Statement
- Interview Questions
- Acceptance-Refusal Form
[Date]

Dear [Ms] [Mr.]:

As you may know, cancer is a leading cause of death in the U.S., second only to heart disease. Cancer does not affect all populations equally. Some groups, including people living in rural areas, racial and ethnic minorities, and those without insurance or too little insurance coverage, are at greater risk to be diagnosed with cancer, to have a more advanced stage of disease, and to die from cancer.

Regular screening and early detection is one of the most important things people can do to reduce their chances of dying from cancer. Yet, screening rates are lower among disadvantaged people, especially in rural areas. A better understanding of the strategies that are effective in getting more people screened is needed if the death rates from cancer among rural and other disadvantaged populations are to be reduced.

I am writing to invite you to participate in a research study. The purpose of the study is to evaluate strategies used by community groups and cancer center outreach programs to promote cancer screening among rural residents.

If you participate, an interviewer from the Penn State College of Medicine will contact you and schedule a convenient time for you to complete a single, 35-40 minute telephone interview. The interview will ask about strategies used by your coalition or cancer center outreach program in your screening interventions during the past three years.

Please read the enclosed Summary Explanation of Research. After carefully reading the Summary, please complete and return the purple Acceptance/Refusal Form in the envelope provided to indicate whether or not you wish to take part in the study.

Thank you very much.

Sincerely,

[Signature]

Brenda C. Klusman, MSS, PhD (ABD)
Principal Investigator
SUMMARY EXPLANATION OF RESEARCH
University of Colorado at Denver and Health Sciences Center
Penn State College of Medicine, Penn State-Milton S. Hershey Medical Center

Title of Study: “Where Science and Communities Meet: A Comparative Case Study of Community Coalition and Cancer Center Strategies to Increase Cancer Screening among Rural Residents”

Principal Investigator: Brenda C. Khahsan, MSS, PhD Candidate
Other Investigators: Diane Sheehan, BA

You are being asked to volunteer to take part in a research study. Research studies include only people who choose to take part. This summary explains information about this research. You are urged to ask questions about anything that is not clear to you.

PURPOSE:
The purpose of this study is to learn more about strategies used by community coalitions and cancer center outreach programs to increase cancer screening among rural residents. The study is expected to last about one year. About 60 coalition members and cancer center outreach program staff are expected to participate.

PROCEDURES:
If you choose to participate, you will complete a one-time telephone interview. An interviewer from the Penn State College of Medicine will call or e-mail you to schedule a convenient time for you to complete the telephone interview. We ask that you choose a private setting to complete the interview. The interview will take about 35-40 minutes to complete and can be scheduled Monday through Saturday. With your verbal permission, the interview will be recorded as a computer audio file and electronically transcribed for analysis. Otherwise, the information you give will be noted by the interviewer using pen and paper only. You will be asked questions about cancer screening strategies used by your [Coalition] [Outreach Program] during the past three years.

RISKS:
There are few risks to you for being in the study. It is possible, but not likely, that your identity and contact information could be viewed by others not involved in the research. If this happens, any person(s) known to have seen your personal information will be asked to sign a Confidentiality Form promising not to reveal your information to anyone.

BENEFITS:
[Coalition Members] A $25 check will be mailed to you after completing the telephone interview to thank you for your participation. [Outreach Program Staff] You will not be paid for your
PROTECTION FROM RISKS:
Your name and personal contact information will be kept confidential and will not be used in any reports from this study. The information you give will be coded with a number instead of your name. The information you give and any records of your personal information will be kept in a locked file and/or password-secured computer file in the locked office of the principal investigator for three years (as required by the University of Colorado at Denver and Health Sciences Center), and then destroyed.

YOUR RIGHTS AS A RESEARCH PARTICIPANT:
You have the right to ask any questions you may have about this research. If you have questions or concerns now or later related to this research, you may contact the principal investigator, Ms. Brenda Kjohsman, at 717-531-5276 (e-mail: bck10@psu.edu).

If you have questions regarding your rights as a research participant or concerns about your privacy, you may call the research protection advocate in the Penn State-Milton S. Hershey Medical Center Human Subjects Protection Office at 717-531-5687.

You do not have to participate in this research. Taking part in this research study is completely voluntary. Your decision to participate or to decline the research will not result in any penalty or loss of benefits to which you are entitled.

There is no cost to you to participate. This study is funded in part by the Penn State College of Medicine and the University of Colorado at Denver and Health Sciences Center.

The principal investigator has no financial interest in this study and will not receive any financial benefit from conducting the study.

YOUR VOLUNTARY CONSENT TO PARTICIPATE:
Your return of the Acceptance/Refusal Form with the YES box checked and your personal contact information provided will imply your voluntary consent to participate in the study.

Your return the Acceptance/Refusal Form with the NO box checked will tell us that you do not consent to participate in the study.

This Summary Explanation of Research is yours to keep for future reference.
Interview Questions

INTERVIEW QUESTIONS

Brief Review of Study
- The purpose of this study is to assess strategies used by community coalitions and cancer center outreach programs to increase cancer screening among rural residents during the past 3 years.
- About 60 individuals will participate in the study.
- The interview will take about 35-40 minutes.
- You may refuse to answer any question and end your participation at any time.
- Your identity will be kept completely confidential and will not be shared with anyone, or in any publication or presentation resulting from the study.
- The information you give will be coded with a study number instead of your name.

Interview Questions
We are interested in learning how cancer screening is being promoted in rural communities.

1. How would you describe your [coalition's] [cancer center's] service area (geography, population characteristics)?
2. Please tell me about your [coalition's] [cancer center's] cancer screening efforts with rural residents during the past 3 years.
3. What has your role been in these screening efforts?
4. How would you describe the types of cancer screening strategies your [coalition] [cancer center] has used with rural residents over the past 3 years?
5. Can you please describe the barriers to cancer screening in your rural communities, and how your [coalition] [cancer center] has addressed those barriers in your screening interventions?
6. How does your [coalition] [cancer center] define success in your rural, cancer screening interventions, and how would you describe the success of your program's cancer screening efforts in the past 3 years?

Those are all the questions I have. Thank you for your time.

After the interview is transcribed, you may be asked to review the written transcript of our interview to confirm that it correctly states the information you provided.
Acceptance-Refusal Form

Study ID No.: 

**ACCEPTANCE/ REFUSAL FORM**

☐ YES, I wish to participate in the study.

☐ NO, I do NOT wish to participate.

**FIRST NAME** (please print)   **LAST NAME** (please print)

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**E-MAIL ADDRESS:** (Optional)

Thank you.
Please return this form in the pre-paid envelope.
BIBLIOGRAPHY


153


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164


