

## **The Northern Appalachia Cancer Network: Changing Cancer Research, Changing People's Lives**

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This article provides an overview of the Northern Appalachia Cancer Network at The Pennsylvania State University. The project was recognized with the 2009 Outreach Scholarship W. K. Kellogg Foundation Engagement Award for the Northeastern Region.

### **Setting the Context: The Pennsylvania State University (Penn State)**

**F**ounded in 1855, Penn State is a public research university with 87,000 students at 24 campuses throughout Pennsylvania. The largest of Penn State's campuses, University Park, is located in State College, a site chosen to be near the geographic center of the state. Located in south central Pennsylvania and ten miles east of Harrisburg, the capital of the Commonwealth of Pennsylvania, the Hershey campus is home to the Penn State College of Medicine, Penn State Hershey Cancer Institute, and the Penn State Milton S. Hershey Medical Center. As Pennsylvania's land-grant university, Penn State engages in collaborative activities with industrial, educational, and agricultural partners to generate, disseminate, integrate, and apply knowledge that is valuable to society.

### **Appalachia**

Appalachia is a geographically and culturally diverse region of 420 counties in 13 states from Mississippi in the south to New York in the north, coinciding with the Appalachian Mountains; 52 of Pennsylvania's 67 counties lie within Appalachia (Figure 1).

Appalachia has long been characterized as a rural region of the United States with high rates of poverty, isolation, and unemployment. This view of Appalachia has existed for decades; indeed, Appalachia was the setting where the War on Poverty in the 1960s was launched (*Appalachian Regional Commission, 2009*). Appalachia also is characterized by low health insurance coverage, poor health status, reduced access to primary and specialty health care, and

increased prevalence of behavioral risk factors (Halverson, Ma, & Harner, 2004). In terms of cancer, Appalachia has elevated incidence and mortality from cancers of the lung, colon, rectum, and cervix, as well as a high percentage of cancers diagnosed at a late stage when the prognosis is poor (ACCN, 2009; Huang, Wyatt, Tucker, Bottorff, Lengerich, & Hall, 2002; Lengerich, Tucker, Powell, Colsher, Lehman, Ward, Siedlecki, & Wyatt, 2005).

**Figure 1: Map of Appalachia**



### **How Penn State and Appalachia Decided to Partner**

In September 1992, Penn State was one of four academic institutions funded by the National Cancer Institute to form the Appalachia Leadership Initiative on Cancer (ALIC) (Couto, Simpson, & Harris, 1994). Of the four ALIC institutions, Penn State was the northernmost, and it became known as the Northern Appalachia Leadership Initiative on Cancer (NALIC). This initiative aimed to raise cancer awareness in rural communities in Appalachian Pennsylvania and New York through cancer-related outreach and education. The NALIC helped establish county-based cancer coalitions of lay and professional leaders from health, education, business, and civic and human service organizations, as well as cancer survivors and interested volunteers. With leadership at Penn State coming from the College of Agricultural Sciences, Cooperative Extension agents and the NALIC field staff provided technical guidance to the developing cancer coalitions.

## **The Northern Appalachia Cancer Network (NACN)**

Beginning in 2000, the NALIC shifted its focus from establishing new community cancer coalitions that raise awareness about cancer to enabling the existing coalitions to adapt and deliver evidence-based interventions. Evidence-based interventions are theory-based and have been found to change people's cancer-related behaviors and reduce cancer risk. Coincident with this shift in focus, the NALIC became known as the Northern Appalachia Cancer Network (NACN). In 2004, leadership for the NACN shifted from the Penn State College of Agricultural Sciences on the University Park campus to the Penn State College of Medicine and the Penn State Hershey Cancer Institute on the Hershey campus. The shift allowed the NACN to more fully benefit from cancer care and research of Penn State while maintaining its association with the College of Agricultural Sciences and Cooperative Extension.

In recent years, the NACN has further developed as a community-academic partnership to conduct community-based participatory research (CBPR). This transition has emphasized data-based assessment of cancer burden in coalition counties; measurement of the outcomes from evidence-based interventions; development and testing of new interventions; and active dissemination of intervention results. Consistent with the participatory approach of a community-academic partnership, the NACN is guided by a 27-member advisory committee. Each community cancer coalition has a primary representative to the advisory committee, often the chair of the coalition. Representatives of the coalitions hold local positions such as cancer administrator of regional hospital, Cooperative Extension agent, nurse, nurse practitioner, or director of a local nonprofit organization. The advisory committee also has representation from Penn State, health insurance companies, the American Cancer Society in New York and Pennsylvania, the Departments of Health in New York and Pennsylvania, and Comprehensive Cancer Control in New York and Pennsylvania (Lengerich, Wyatt, Rubio, Beaulieu, Coyne, Fleisher, Ward, & Brown, 2004; Lengerich, Rubio, Brown, Knight, & Wyatt, 2006).

### **Impact of the Northern Appalachia Cancer Network**

The long-term goal of the NACN is to measurably reduce cancer risk and improve cancer survivorship in rural, medically underserved areas of Appalachian Pennsylvania and New York. Using the CBPR approach, the NACN develops, implements, and

evaluates evidence-based interventions in rural communities and clinics. This approach allows community members and their organizations as well as clinical and academic partners to collaboratively work toward objectives that are important for the local community. The NACN seeks to make residents and communities healthier and more informed, with norms and policies that reduce cancer risk. Clinicians in the partnership seek to improve delivery of patient-centered and evidence-based medicine. Academicians want to contribute to scientific knowledge, manifested by funded research grants, scientific papers, national presentations, and training of students, who seek to hone their new skills and apply their new knowledge. While each partner may have a different objective, they share the goal of effectively reducing the cancer burden in Appalachian communities of Pennsylvania and New York.

### **The NACN's Community-Based Research**

The NACN research is prevention-oriented and relevant to the individual rural communities. The community identifies important health-related issues and helps develop research questions. Penn State brings expertise in study design, clinical medicine, protocol development, and data analysis. The research has been guided by health behavior theories, including the health belief model, theory of planned behavior, transtheoretical model of behavior change, social network theory, community coalition action theory, and the cognitive-social health information processing model. To help achieve local relevance, research sites have included schools, churches, senior centers, career centers, food pantries, primary care clinics, and rural hospitals. Literacy- and culturally-sensitive research materials are tailored to the unique needs of the community.

Examples of NACN programming and research projects are listed below.

- Developed and disseminated plans to enhance colorectal cancer survivorship in 18 Pennsylvania and New York counties (*Lengerich Kluhsman, Bencivenga, Allen, Miele, & Farace, 2007*).
- Documented over 1,300 community development, education, and cancer screening initiatives among NACN coalitions in 2000–2004, in which 1,951 of 3,981 individuals (49%) who were offered cancer screening completed the screening (*Kluhsman, Bencivenga, Ward, Lehman, & Lengerich, 2006*).

- Conducted focus groups to assess tobacco use and related social determinants in Northumberland County, Pennsylvania (*Branstetter, n.d.*).
- Conducted a population-based assessment of primary care providers' attitudes, beliefs, and patient recommendations related to the Gardasil vaccine for human papillomavirus (HPV) in Columbia, Snyder, Union, Northumberland, and Montour Counties (Pennsylvania) (*Huey, Clark, Kluhsman, Lengerich, & ACTION Health Cancer Task Force, 2009*).
- Assessed availability of the Gardasil HPV vaccine in public health departments and determined substantial variability in access, price, and utilization (*Katz, Reiter, Kluhsman, Kennedy, Dwyer, Schoenberg, Johnshon, Ely, Roberto, Lengerich, Brown, Paskett, & Dignan, 2009*).
- Conducted eight qualitative focus groups stratified by geography and sex among average-risk adult Latinos to identify barriers to colorectal cancer screening and to assess acceptability of available CRC screening options (*Garcia-Dominic, n.d.*).

Examples of the impact of community-based participatory research are listed below.

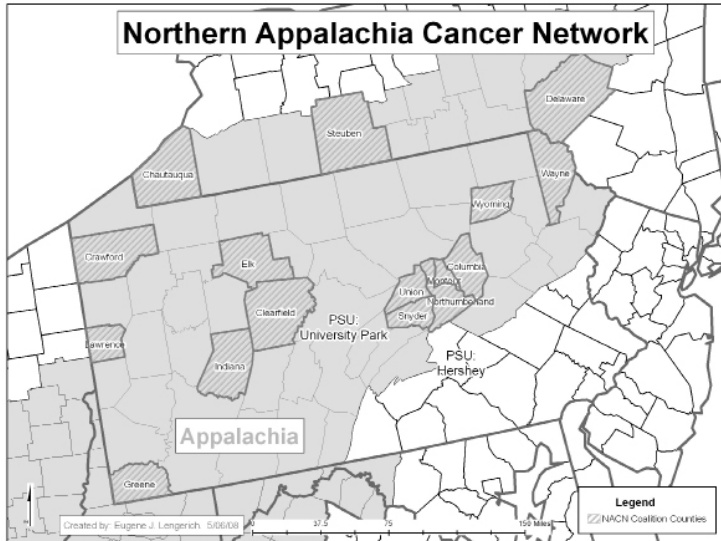
- Demonstrated through a randomized study that NACN coalitions can effectively disseminate messages and materials to increase the uptake of colorectal cancer screening (*Ward, Kluhsman, Lengerich, & Piccinin, 2006*).
- Increased mammography screening rates in Indiana County, Pennsylvania, among rarely or never-screened, low-income women who were recruited through food pantries (*Bencivenga, DeRubis, Leach, Lotito, Shoemaker, & Lengerich, 2008*).
- Increased HPV-related knowledge and HPV vaccination intent among women aged 18–26 in a five-county area (*Clark, n.d.*).
- Reduced the use of smokeless tobacco among male users through adaptation of an evidence- and community-based intervention (*Cushman, n.d.*).
- Demonstrated the feasibility and acceptability of a fecal immunochemical test with follow-up telephone barriers counseling intervention for increasing colorectal cancer screening in three rural, primary care clinics (*Kluhsman et al., n.d.*).

More about the impact of NACN's work on the communities it serves, as well as on the university students and faculty members in the network, is outlined in the sections below.

## **NACN's Impact on the Community**

Twelve community cancer coalitions are active in the NACN, including the ACTION Health Cancer Task Force, Central Susquehanna Colorectal Cancer Task Force, Crawford County Cancer Coalition, Coalition for People Against Cancer, Elk County Family Resource Network Cancer and Tobacco Education Coalition, Greene County Cancer Coalition, Indiana County Cancer Coalition, Lawrence County Cancer Coalition, Wayne County Cancer Coalitions, and Wyoming County Cancer/Tobacco Partnership in Pennsylvania; as well as the Chautauqua County Cancer Services Program Partnership, Delaware County Cancer Coalition, and Steuben County Cancer Services Program Coalition in New York. The 13 coalitions have more than 260 active members, including cancer survivors; community volunteers; and representatives of cancer control, health care, civic and community service organizations, and businesses.

**Figure 2: Northern Appalachia Cancer Network Map**



Through NACN training programs, coalition and community members have advanced their skills in the adaptation, delivery, and evaluation of evidence-based cancer initiatives. For example, a three-part 2009 webinar series provided guidance on health communication. *Working with the Media* taught development of public

health messages to which the media would respond and methods for effectively responding to reporters' questions. *Evaluating Health Promotion Efforts* addressed initiative evaluation, including reasons to evaluate, timing of evaluation, planning for evaluation, and collecting evaluation data. *Health Literacy* provided participants a better understanding of methods to develop clear, effective messages in understandable language. The three sessions were recorded and posted for replay. As evidence of the training and development, six NACN coalitions have written successful applications for external funding for community-based interventions in cancer prevention and control.

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### **NACN's Impact on Penn State Students and Faculty Members**

For undergraduate, graduate, and medical students, the NACN is a community-based laboratory in cancer prevention and control research. Several examples illustrate that the Northern Appalachia Cancer Network provides opportunities for student learning and research in a variety of disciplines.

In 2007, a Ph.D. candidate in Penn State Communication Arts and Sciences examined factors affecting rural women's intention to enter a clinical trial measuring electrodermal and electrocardiography changes. She found that the rural self-identity of the physician was associated with greater inclination of women to participate in a clinical trial ( $P < 0.05$ ) (Krieger, Parrott, & Nussbaum, 2010). In 2008, a medical student adapted the Indiana County Cancer Coalition's food pantry and mammography recruitment intervention study for delivery in four additional NACN coalitions. Also in 2008, two undergraduate students from Health Policy and Administration conducted a telephone- and Internet-based assessment of local sites for colorectal and breast cancer screening in central Pennsylvania.

Additionally in 2008, a staff member conducted her doctoral dissertation with NACN community coalition members, staff of National Cancer Institute (NCI)-designated Comprehensive Cancer Centers,



and NCI-funded Community Cancer Networks to determine best practices for increasing cancer screening in Appalachia (Kluhsman, 2009). In 2009, an NCI-funded postdoctoral trainee used her focus group findings on barriers to colorectal cancer screening among Latinos as preliminary data for a NCI-K01 training grant application of a randomized study

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to test the effect of social support on the uptake of colorectal cancer screening among Latinos. Additionally, working with students, the NACN has published estimates of the cancer incidence and mortality in Appalachian Pennsylvania and New York; conducted three public forums on cancer in Appalachian Pennsylvania and New York; and conducted two workshops

on community-based cancer research in Appalachian Pennsylvania and New York. Consistent with the participatory nature of CBPR, community members and students presented findings from their research at the two workshops. At the 2009 workshop, 97 people (mean age 44.9 years) attended, with 45.3% from rural counties.

Currently, the NACN includes faculty members from four Penn State colleges and an academic health center. Penn State faculty members on the NACN advisory committee have expertise in health communication, rural health, health services research, nursing, continuing education, epidemiology, population science, primary care, cancer treatment, and cooperative extension. This diverse professional background of NACN faculty has generated new interdisciplinary research related to cancer prevention and control through nutrition and physical activity, cancer screening and early detection, cancer survivorship, and uptake of cancer-related vaccines. The research of the NACN has helped position the Penn State Hershey Cancer Institute (PSHCI) as a leader in cancer prevention and control research in Appalachia, which is a major component of the PSHCI's 2010 application to the National Cancer Institute to be a designated cancer center.

No longer confined to the inflexible laboratory bench or the sterile hospital clinic, Penn State investigators, along with students, work with the NACN to test strategies that bring effective cancer prevention and control strategies to people in rural communities where they live and work and receive health care.



## **Lessons Learned and Best Practices**

Rural communities in Appalachia exhibit reduced access to health care and increased cancer burden. The NACN, a community-academic partnership, has used culturally relevant methods in a community-based approach to address the increased cancer burden in Appalachian communities in Pennsylvania and New York. This approach has reduced the risk of cancer for residents of rural communities. A community-based approach may be one of the few strategies to effectively address the cancer-related health disparities in Appalachia because of the limited access to medical centers and clinics in this area.

The NACN developed from an outreach effort focused on cancer awareness and education to an academic-community partnership focused upon cancer prevention and control research. The transition in focus took over 15 years. Funding agencies, community partners, and academic institutions must be prepared to invest in community-academic partnerships for an extended period of time to achieve similar results. University faculty should be prepared to invest the time necessary to establish a community-academic partnership before positive results will be realized, especially when their scholarly performance will be reviewed regularly for promotion and tenure.

Throughout its 18-year history, the NACN has learned that trust between the community and an academic health center must be engendered, and the profit-motivated model of health care delivery must not be permitted to enter discussions with community members. The NACN uses transparent and frequent communication in the context of its advisory committee, annual meetings, and frequent visits to coalitions. The NACN emphasizes shared values and goals.

In addition, the NACN has learned to nurture the network of community cancer coalitions despite their being spread across Pennsylvania and southern New York, a distance of over 400 miles. The NACN provides technical assistance to the coalitions through three field staff who are based in relative proximity to coalition counties. The NACN enhances communication through annual in-person workshops and periodic web-based training sessions.

### **NACN: Next Steps**

Future plans for the NACN are focused on enhancement and transferability. First, Penn State will expand the NACN's research

with externally funded, controlled studies intended to develop, implement, and evaluate evidence-based interventions. At present, there is a dearth of reports of studies showing a measurable reduction of cancer disparities among medically underserved populations. Most studies in health disparities have been limited to describing and quantifying cancer health disparities, rather than developing and testing methods to reduce the disparity. Studies by the NACN can make an important contribution to the scientific literature on community engagement and evidence-based interventions for cancer prevention research.

Second, Penn State intends to transfer the NACN experience to the catchment area of the Penn State Hershey Cancer Institute (PSHCI). The populations of the PSHCI catchment area are culturally diverse, including Caucasian, African American, Hispanic, Asian-related, and Native American individuals. Unlike NCI-designated cancer centers located in urban areas, the PSHCI serves a catchment area that includes communities widely dispersed along the urban-rural continuum, ranging from small towns and cities and their environs to the most isolated rural communities. Many communities have a high percentage of individuals who have limited access to health care services and have cancer-related health disparities.

### **Conclusion**

Despite multiple funding cycles and leadership changes, the NACN has developed into a community-academic partnership that includes one of the longest-running and most successful networks of community cancer coalitions in the United States (*Kluhsman et al., 2006; Wells, Ford, Holt, McClure, & Ward, 2004; Wells, Ford, McClure, Holt, & Ward, 2007*). The NACN has changed the approach to cancer research and training at Penn State. It promotes collaborative, community-based cancer research, especially research that is prevention-oriented and tailored to the specific needs of rural Appalachian communities in Pennsylvania and New York. The research questions and methods that emerge are generated by, and therefore highly relevant to, community members. The NACN has shifted the usual process of cancer studies away from solely understanding the genetic and cellular pathways in the development of cancer to a comprehensive understanding of the people and their interconnected biological, psychological, and sociocultural environments. Having positively affected the lives of people in rural, medically underserved communities and having brought a paradigm-shifting approach to cancer research and training, the NACN

is a seminal example of engaged scholarship at Penn State, where the mission includes improving “the well being and health of individuals and communities through integrated programs of teaching, research, and service” (*The Pennsylvania State University*, 2006).

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