

## ***"Starting the Conversation: Developing events to connect comprehensive cancer control coalitions and programs with underrepresented areas of their states"***



Kristine Harper Bowers and Joellen Edwards PhD, RN, FAAN  
East Tennessee State University College of Nursing

Appalachia is a federally defined geographic area in 420 counties of 13 states from Mississippi to New York. This region, where poverty, lower educational levels, and health disparities persist into the 21st century, exhibits rates of cancer, especially lung, skin and colorectal cancer that consistently exceed national and state levels. Appalachian culture, as described by project focus groups and supported in the literature, is characterized by deep family ties, deep identification with rural mountain culture and geography, religiosity, and self-reliance.

This foundation of Appalachian cancer health disparities helped us to devise strategies to reduce the cancer burden by engaging communities (individuals, state organizations, and health care providers) in locally-acceptable engagement modalities in local and rural settings to create opportunities for further conversation. Forums and roundtables were used to develop Cancer Communication Toolkits for communities to model the implementation of locally-generated workshops to facilitate discussion using storytelling, case scenarios, breakout sessions with guided discussions, and targeted evaluative techniques. Greater understanding about cancer prevalence and local strategies for fostering ongoing dialog with state agencies and organizations led to greater representation of rural areas in state cancer control plans. The development of the Toolkit and its publication and dissemination, and the lessons learned proved valuable in assessing the effectiveness of this strategy for developing greater communication in these 13 states.

### **Methods**

Mini grants awarded to organizations in 11 states encouraged greater inclusion of issues and local coalitions and organizations in state Comprehensive Cancer Control programs. Identified themes became the basis for further investigative reports. The website created as a public home to these toolkits describes how to conduct similar meetings and activities.

### **Products and Outputs**

The project culminated in a website with toolkits for community to use to create forum, roundtable and storytelling events to start conversations about cancer in underrepresented areas of their states, namely rural or remote counties which may not have rapport or resources with state comprehensive cancer plans or coalitions. This website is accessible as <http://www.etsu.edu/nursing/cc/>

Five issues became the basis of reports investigating the following topics:

1. Storytelling as a Cancer Communication Methodology
2. Successful Methods for Engaging Physicians and other Direct Health Care Service Providers in Appalachian Community Cancer Control Activities
3. Organization and Financial Support of Rural Cancer Care Navigation Models
4. Organizing, Quantifying Costs, and Documenting Benefits of Mobile Cancer Screening Units in Rural Areas
5. Communication about Cancer Combining Environment and Lifestyle Risk Factors

### **Conclusions**

We identified best practices in cancer control within regions as state cancer plans were presented to new audiences. We connected local with state cancer coalitions, and involved state cancer registries in the preparation and presentation of data. The meetings identified contributions and benefits of state and Appalachian community engagement in regional and state cancer control activities, facilitating new and important partnerships. Short-term outcomes: greater visibility of the Appalachian region written into state cancer plans, state and regional networking, forums and roundtables as models for engagement, new regional cancer data, new ways to present data to communities, new coalition members, new collaborations, and storytelling modalities that were perpetuated. Long-term outcomes: new partners identified for cancer control activities (schools, faith and rural organizations), new regional coalitions, forums and roundtables seen as best practice, awareness of differences in regional cancer care attitudes and beliefs, and use in cancer messaging and campaigns.