

# *Community Leader Responses to Dissemination Reports Regarding Regional Health Disparities*

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***RURAL APPALACHIAN CANCER DEMONSTRATION PROJECT***

## **ABSTRACT**

East Tennessee State University's Rural Appalachian Cancer demonstration Program (RACDP) has conducted a number of research activities and contributed to studies to identify and document health disparities in the Appalachian region. Findings from RACDP and other Appalachian regional studies were summarized and disseminated through a series of public meetings between April and December 2005. Over 100 community and health leaders attended in Tennessee and Virginia. Five presentations were made by the RACDP's Principal Investigator, twice in conjunction with the Investigator of an Appalachian Regional Commission regional disparities study. Written perspectives were requested from dissemination meeting participants in two states. A summary of the responses gathered at the conclusion of each meeting are summarized in this report.

Many findings about health disparities in the Appalachian region surprised participants. Most were not commonly known. Those participants who were regularly involved in public health employment or service on voluntary committees and boards recognized disparity issues but were unaware of the details. Participants suggested that the Program actively report disparity findings to the public and to health leaders using improved communication approaches to affect personal and community action to address those disparities.

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## FINDINGS

### ***Were you aware of the types of illnesses/diseases for which Appalachia might be considered a disparity population? If yes, tell how you learned about these?***

Responses indicated an overall awareness of disparities learned through professional and regional exposure, independent research, and participation on civic and social committees, professional workshops, attending other RACDP dissemination meetings, and reading the Appalachian Regional Commission website. Participants cited a lack of awareness of the details of the magnitude and specificity of disparities. The exposure to CDC or health department reports appeared to correlate with an increased understanding of disparity details.

### ***Did any findings surprise you?***

Participants reported surprise over some of the specific mortality rate findings (e.g., heart disease rates higher than cancer, pervasiveness of lung cancer, breast cancer in some Virginia counties, motor vehicle accident rates). Many were surprised about higher disparities among the region's African American population. Several participants noted variability of rates across the region (Central Appalachia compared with other parts of region) and some unique juxtapositions and inconsistencies (disparity changes at the "North Carolina line" and high outliers counties). The comparison of national mortality rates for breast (lower in Appalachia) and cervical (higher in Appalachia) cancer were generally reported to be surprising. There was interest in findings comparing cancer "death" rates with socioeconomic indicators. The evidence showing that disparities didn't always match-up with designated medically underserved areas was also frequently highlighted. Other respondents noted disappointment with incomplete data for African Americans and absence of mental health and substance abuse data.

### ***If you had to choose three disparity areas that ETSU and our partners should continue to explore, which would you choose? (Responses recorded by frequency):***

- Cancers (breast, cervical, lung)
- Relationship of cancer mortality to health behaviors (smoking, obesity)
- Appalachian disparity in premature deaths
- Changes in disparity patterns over time
- Recognizing differences by race for different diseases
- "Double disparity" for African Americans in Appalachia
- Relationship of education and economics/poverty to disparities
- How to communicate disparities messages to all the people involved in community health (religious groups, school system, and other parts of the social system)

- Look more closely into potential Hispanic paradox – do people who share in impoverished circumstances avoid the same adverse health outcomes?
- Relationship between statistics and environmental causes (e.g., water)
- Infant mortality
- All-disaster preparedness/emergency services
- Eldercare
- Health care access for those without resources such as insurance
- Pharmacy issues
- Diabetes
- Cardiovascular Disease

***What do you think are the biggest challenges to communicating cancer risk in this region?***

Notable challenges are epitomized in the responses: “What do people really hear” and “I wish I knew why they don’t listen”. Poverty, education levels, and health care access (both availability of services and financial access) are seen as barriers that promote regional disparities. Participants noted the importance of personal communication to “reach people where they are at” and suggested effective communication channels such as workplaces, churches, and social groups. Others cited the importance of engaging whole communities and promoting involvement in disparities campaigns. Confusion still remains about causes of some diseases (e.g., environmental risk factors and feelings that “everything causes cancer”).

A major communication challenge is a collective lack of understanding of why health and poor health outcomes are not a more immediate concern for individuals. Participants felt many Appalachian residents do not know about disease or see themselves not susceptible to disease. This leads to a lack of “motivation” to favorably weigh changing unhealthy behaviors or to seek health care when in “competition with more immediate daily issues.”

Participants called for a more thoughtful, regionally-appropriate and professional public education campaign about disparity issues. One challenge is to help people see the importance and worth of “spending time and resources” on themselves to be healthier. A “clear vision” is required to identify what needs to be communicated, to develop the “right message to really reach the audience you want,” and to create safe, trusting environments to assist in receiving and exchanging health information. Joint efforts should be formed between health professionals and “communicators” to achieve this.

**Now that you have seen the data, what should we do with it on a local, state, and national level?**

When compiling the participants' responses two themes stood out: "Promote access" and "Educate, educate, educate!" One suggestion to improve access involved use of health information technology to improve patient access to specialty, diagnosis, and patient education.

Health information technology could also enable coordination of care across state borders. Holistic approaches to health would also improve access. Public education programs are needed using multiple mediums and on multiple fronts incorporating public forums, newspapers, outreach to the faith community outreach, health professional education and legislative education. Additional public health attention and funding for health communication is needed. Reductions in publicly funded health service programs and eligibility (e.g., Medicaid, TennCare) should be recognized as detrimental to addressing disparities.

### **Exemplary “take home” messages to be shared about disparities**

- There are definite health care disparities in Appalachia and communicating this risk needs to be tailored to specific communities.
- The Appalachian region faces a bigger economic challenge from poor health than any other short-coming, including education.
- To make a difference, we all need to work together on education and prevention.
- We have two choices: Move out of the area or begin to move our bodies (exercise, lose weight). Be proactive and responsible for your health or be part of a disparity statistic.
- Both Appalachian regional and racial disparities exist here. Health disparities between blacks and whites need to be further prioritized and addressed.
- Research about the best ways to communicate health messages to different groups is valuable. We can not just send information to people and expect them to respond appreciatively. Sharing information is not enough!
- We must all cooperate to address these issues. Inactivity is not an ethical option.
- Things are bad and could be worse. There are lots of possibilities to translate these findings into action.
- People will go to great lengths not to lose something they have but are reluctant to work to gain something new. Present information about disparities that will motivate the region not to lose the image of “what’s right about Appalachia.”
- Use the impact of health disparities on future to touch heart of government officials.
- As professionals we need to recognize and study ‘disparities’ in our beliefs about the health of Appalachian people.
- Disparity maps “grab” people’s attention. These should be matched with qualitative stories related to the map’s numbers. Find a way to make the number’ human.
- How much money do we have or should we, as tax payers, spend to prevent cancer?
- Our region has higher mortality of middle aged adults. What should be done?
- Preventing disease and good health habits begin early. We should focus on changing eating habits in school cafeterias, mandate physical exercise in schools, and reform the reward system for schools to promote health of their students.
- Health care should be a system. Electronic records can actually help communication between specialists and primary care providers from rural areas to allow more services to be offered closer to home.

- Strengthen belief that many illnesses are preventable. You don't have to die from cancer.
- Primary care providers must be able to educate patients, encourage screening and treatment as recommended in findings.
- We can change!
- This (regional health disparities) is just the tip of the iceberg.....
- Start educating today; use word of mouth approach.