## COMMUNITY REPORT:

### INCREASING CLINICAL TRIAL ENROLLMENT IN NC COMMUNITIES

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**Did you know...**

- Cancer is the 2nd most common cause of death in North Carolina. Heart Disease is number one.
- Less than 3% of all adults with cancer have participated in cancer clinical trials. This small percentage is even lower for people of color and older people.
- 85% of U.S. cancer patients polled were unaware or unsure that cancer clinical trials were an option to consider.
- People in cancer trials vary rarely receive a placebo or fake medicine.
- In majority of clinical trials, participants receive state-of-the-art cancer care or care that is believed to be even better.

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### Cancer and Clinical Trials:

Everyone is affected by cancer. The North Carolina Central Cancer Registry estimates that one out of three North Carolina will develop cancer during their lives. In North Carolina 194,991 cases of cancer were diagnosed between 2000-2004. The number of people surviving cancer is increasing because of research advances. [http://www.cdc.gov/ohs/lists/ncancer.htm](http://www.cdc.gov/ohs/lists/ncancer.htm)

**How do you think this influences the effectiveness of cancer advances and treatments for all people with cancer?**

Cancer clinical trials help identify new ways to identify and treat cancer. Today, we have better cancer screening options and treatments because someone's family member participated in a cancer clinical trial.

These individuals may have participated in a treatment trial. Individuals with cancer who participate in a treatment clinical trial receive the best available treatment for cancer. They also help researchers to identify effective approaches to cancer care. In treatment cancer clinical trials, new approaches to cancer care are compared with the currently accepted forms of cancer care. People in cancer trials rarely receive a placebo or fake medicine.

These next pages share what we know about who participates in cancer clinical trials in North Carolina and how to find out about cancer research in your area.

In addition to treatment trials, there are other types of cancer trials:

- prevention trials, which study ways to prevent cancer,
- early detection/screening trials, help identify ways to improve early detection of cancer,
- diagnostic trials, which focus on ways to test for cancer or better identify it.

**IF YOU WANT TO KNOW MORE ABOUT CANCER CLINICAL TRIALS, ASK YOUR DOCTOR. YOU CAN ALSO REVIEW THE RESOURCES LISTED ON THE BACK.**
Who Participates in Cancer Clinical Trials in NC?

Between the years of 2000-2004, there were 194,991 cases of cancer diagnosed. Of all the individuals with cancer, less than 6% (10,275) participated in research to improve prevention, screening, diagnosis, or treatment of cancer. Fewer people participated in a cancer treatment trial. Nearly 5,000 people participated in a cancer treatment trial.

Should all adults with cancer participate in cancer clinical trials?

*What is most important is that individuals with cancer be offered the opportunity to participate in cancer clinical trials if they are interested and receive the information they need to make an informed decision.*

Participation in cancer clinical trials varies across all counties in the state. Clinical trial participation is above the national average (3%) in the dark green counties. Fewer people have participated in cancer clinical trials in the red counties.

**NCI Clinical Trial Enrollment:**
**Enrollment Rates in All NCI Treatment Trials, Adults (age 21+) 2003-2004**

- **Methods Summary:**
  - Rates are calculated as the total enrollment of individuals aged 21 or greater in NCI Treatment trials in years 2003-2004 according to the trial participants’ home county (reported by NCI) divided by the total newly diagnosed cases of cancer according to individuals’ home county (reported by NC Central Cancer Registry).
Focus Group Highlights

From July 2009 to September 2009, four focus group sessions were held with 30 African American male cancer survivors and caregivers. Sessions were held in Greensboro, High Point, Burlington and Siler City. The goal of the focus group was to better understand why African American males in Central NC are less likely to take part in clinical trials for cancer. Furthermore, participants were able to discuss things that would make them consider taking part in a clinical trial. Below are key findings that were common across the groups.

By participating in the focus groups, participants were able to learn more about some common misunderstandings about clinical trials. For example, most cancer clinical trials do not use a placebo, and clinical trial participants receive state-of-the-art care or new types of care that are believed to be even better. At the same time, participants were able to inform about their beliefs, values, and experiences, so that new and better systems of care can be developed.

Key Findings

<table>
<thead>
<tr>
<th>Opportunities to Take Part in Clinical Trials</th>
<th>Awareness about Clinical Trials</th>
<th>Accepting or Refusing to Take Part in Clinical Trials</th>
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<td>Participants talked about how they would respond to an opportunity to participate in a clinical trial. Participants:</td>
<td>Participants talked about the things that would make them not consider or consider participating in a clinical trial. Participants:</td>
<td>Participants talked about things that would cause them to accept or refuse actual participation in a clinical trial. Participants:</td>
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<td>• Would be open to participation if their doctor thought it was a good idea.</td>
<td>• Disliked the use of placebos and feared receiving one if taking part in a clinical trial.</td>
<td>• Were concerned about the cost of participating but would be more likely to participate if some costs were covered.</td>
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<td>• Would be open to participating if the study improved their health or the health of others like them.</td>
<td>• Did not want to feel like they were being used as “guinea pigs.”</td>
<td>• Were more willing to participate in a trial that involved providing information than participating in a treatment trial.</td>
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"I think it would be good to utilize centers of influence to spread awareness about this...They should be educated and informed about this and one of the reasons why we have the highest rate in the world, black males in prostate and colon cancer is a lack of just ignorance, just a lack of information." - Participant

"My father he died from cancer and I guess if they would have known a little more about it, it would have helped out. You know? He'd probably still be with me." - Participant
PROJECT SUPPORT

This community project was led by William Carpenter, PhD and is supported by the Carolina Community Network (CCN) and Project CONNECT, a part of the Carolina-Shaw Partnership for Eliminating Health Disparities. The CCN is a community-based collaborative of organizations and university faculty to address breast, prostate and colorectal cancer disparities among adult African Americans. The CCN is funded by the National Cancer Institute’s Center to Reduce Cancer Health Disparities. Project CONNECT collaborates with community organizations to encourage involvement in research among people of all backgrounds and explain why certain groups of people are faced with diseases and other illnesses more than others.

Educating Our Community About Clinical Trials

Resources

The following list of resources can provide you with more information about clinical trials including how to locate a clinical trial in your community. This information should be used together with advice from a health care professional.

American Cancer Society
Clinical Trial Matching Service
1-800-ACS-2345
http://clinicaltrials.cancer.org

To request a free educational workshop on cancer clinical trials for your church or organization, please contact one of the partners of Community Bridges to Cancer Clinical Trials

- Black Men’s Health Initiative Inc. www.bmhi.org
- Crossworks, Inc. www.crossworks.org
- NC Institutes for Minority Economic Development www.ncmed.com
- Project CONNECT www.connect.unc.edu (toll-free) 1-866-849-1579

National Cancer Institute
Cancer Information Service
1-800-4-CANCER (6237)
www.cancer.gov/clinical_trials/

National Institutes of Health
www.clinicaltrials.gov
You can also check with a local cancer center or Health care provider for cancer clinical trials in your area.