

The North Carolina Cancer Plan: A Living Plan for the People of North Carolina

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In our fast moving technological society, state cancer plans need to change frequently in order to remain current. North Carolina recognized this need and rose to the challenge. We are proud to be the first state in the country to develop a “Living Plan.”

The North Carolina Cancer Plan (referred to as the Plan in this commentary) is a current and evolving document designed to grow, develop, and account for progress that is made in accomplishing its goals and objectives. The Plan creates benchmarks or goals for individual programs to strive for and tracks progress toward these goals. Changes can be made to the Plan as often as necessary to keep it relevant and useful for our state in the fight against cancer. The Plan is available online at www.nccancer.com.

History

North Carolina's commitment to cancer prevention and control dates back to at least 75 years ago when the leadership of the North Carolina Medical Society identified cancer as a major public health issue and laid the foundation for future efforts. Shortly after World War II, the North Carolina Medical Society and the Women's Field Army (precursor of the American Cancer Society) worked successfully to have legislation enacted that created a cancer prevention and control component within North Carolina's

public health system. Coupled with local efforts in virtually every county of the state, many prevention, screening, and treatment programs were initiated. From then until the early 1990s, there were multiple commissions, task forces, and other officially convened groups that sought to coordinate North Carolina's cancer fighting efforts.

Finally in 1993, legislation was enacted that formally created the North Carolina Advisory Committee on Cancer Coordination

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and Control (NCAC). The North Carolina Comprehensive Cancer Program was designated to be its operational arm. Chief among NCAC's required duties was the development

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and implementation of a formal cancer plan for the state. Consequently, two 5-year plans were developed and published in 1996 and 2001.

New Directions

As the third 5-year plan was under development in early 2006, it was determined that a new strategy was needed. It has been said that the Plan had become “the destination and not the roadmap to get there.” From this assessment, the concept of the “Living Plan” was born. Rather than produce the traditional printed document, a more dynamic approach was adopted. The Plan had to be relevant, it had to be widely available, it had to have “buy-in” from all stakeholders, and it had to have the ability to grow, evolve, and to account for progress in meeting stated goals and objectives. It also had to be part of a process that encouraged the incorporation of comments and suggestions, thus helping the Plan to evolve.

The New Process

In order to create a new environment for Plan development, it became important to engage more participants significantly in the process. Although previous plans had included input from many stakeholders, the process was greatly expanded to reach out to more community-based organizations and individuals as well as those groups who had been involved in preparing earlier plans. It was also important to emphasize that the purpose of the Plan was to take action and not just to produce a document. Cancer survivorship (defined as beginning at the time of diagnosis and continuing through the entire cancer experience) had to be richly incorporated throughout the entire Plan. Citizens were encouraged to provide ideas for consideration and concerted efforts were made to identify and reach out to more people in the cancer community throughout the entire state. The ideas collected were then channeled to 1 of 3 subcommittees of the advisory committee—prevention, early detection, or care—for refinement and incorporation into a draft of the goals and objectives.

Supplementing this process was the creation of a national database containing over 800 goals and associated objectives gathered from virtually every state and US territory engaged in the development and implementation of cancer plans. Details from all published plans were abstracted and coded for relevant elements. This information was made available on a national Web site, www.CancerPlan.org, hosted by the Centers for Disease Control and Prevention, the National Cancer Institute, and the American Cancer Society. From this data, customized reports were created and provided to the 3 subcommittees. This activity allowed North Carolina to benefit from the collective wisdom and work of colleagues and peers throughout the country and greatly enriched the development of this state’s plan.

A draft of the new Plan was unveiled at the October 2007 meeting of the NCAC. Although more people had been included in the process, the draft plan resembled the previous

“I was diagnosed in 2006, at the age of 14, with leukemia. I went through a bone marrow transplant at Duke Hospital over Christmas. I am now turning 16 and have been in remission for over a year. I am still dealing with side effects from the treatment, but am progressing each day.”

**— Camille
Leukemia**

2 efforts and potentially had a similar outcome: a static addition to a library but not an action plan. At this point, evolving a new approach became an extremely important challenge.

Making the Transition to a “Living Plan”

The first major change that occurred was a commitment on the part of the Advisory Committee, the North Carolina Comprehensive Cancer Program, and the newly created North Carolina Cancer Partnership to embrace a different approach and to ensure that everyone’s voice was heard and given appropriate consideration. New strategies are now employed to implement this new approach, which is based upon the following principles:

- *Everyone matters.* Due consideration is given to anyone and everyone who wants to offer suggestions for the Plan’s goals, objectives, and strategies. To expand involvement, particularly from cancer survivors and caregivers, 18 work groups have been created to focus attention on specific

Table 1.
Major Themes in the North Carolina Cancer Plan

Access to Services
Alcohol Use
Cancer and the Environment
Clinical Trials
Cost and Financing
Data and Surveillance
Genetics
Health Behaviors: Nutrition, Physical Activity, Tobacco Use, and Infectious Agents
Palliative Care: Pain, Hospice, and End of Life Care
Professional Education and Awareness
Public Awareness
Site-Specific Cancers
Survivorship

cancer types, crosscutting issues (eg, disparities, clinical trials, professional education, and awareness), and populations (eg, survivorship, children, adolescents, and young adults). The work groups each prepare a report that fully describes their topic and make recommendations for planning, implementation, and policy that are transmitted to the advisory committee for subsequent incorporation in the Plan and for action.

- *Reaching out.* Countless presentations related to the North Carolina Cancer Plan have been made across the state. Additionally, from October 2007 through May 2008, approximately 3000 copies of the draft Plan have been distributed to individuals and organizations.
- *Your Plan is our Plan. Our Plan is your Plan.* Special efforts have been made to establish close ties with organizations that have a cancer agenda and to have them contribute to the North Carolina Cancer Plan and incorporate the Plan into their plans and activities. This includes organizations that provide funding for programs and projects and who have agreed to add the question, “How does your proposal relate to the North Carolina Cancer Plan?” to their requests for proposals or funding applications.
- *Do you see yourself in the Plan?* Individuals and organizations are asked this question. If they don’t see how the Plan is relevant to their mission or purpose, a request is made to tell us how we can make appropriate changes or inclusions.
- *Make change easy.* By keeping the Plan in a long-term draft form, changes can be made to reflect input from stakeholders and to incorporate rapid advancement and new knowledge in cancer prevention, early detection, and treatment.
- *Listen. Incorporate. Act.* In June 2007, approximately 150 cancer survivors, caregivers, and advocates came together and told us what was important to them and where the system could be improved. In June 2008, at a similar gathering of approximately 300 attendees, a report was delivered that described more than a dozen actions and accomplishments that had occurred as a result of what was discussed at the 2007 meeting.
- *Make the Plan accessible.* The Plan is accessible via www.nccancer.com and updates are posted as they are available. A project is currently in process that will create a Web-based, database-driven version of the Plan that will allow for individuals and organizations to create and print custom Cancer Plans based on specific factors that they select.

Evaluation

With the North Carolina Cancer Plan as our roadmap and reducing the burden of cancer as our destination, following a compass is essential. This is where evaluation and surveillance become important components of our program. Elements of the Plan must be measurable and, ultimately, efforts will be reflected in both the incidence and mortality rates of cancer in North Carolina.

Table 2.
Major Objectives Suggested in the North Carolina Cancer Plan

Creating and Enhancing Partnerships: Local, Regional, and Statewide
Determining and Implementing New Policies
Eliminating Disparities of All Types
Enhancing Professional Education and Involvement
Ensuring Health Care Access for All
Ensuring an Appropriate Workforce: Quantity, Quality, and Distribution
Increasing Data and Surveillance
Increasing Funding and Resources
Making Cancer Survivorship the Centerpiece
Making the Public More Aware and Engaged
Supporting Research and New Technology

The goals of evaluation are to determine whether particular projects or initiatives are effective and to understand why they failed or succeeded. Information from evaluation is used in planning to identify needs, define the burden of cancer, determine the prevalence of cancer-related risks, identify populations with greater needs, select strategies based on proven cancer control methods, and set appropriate goals and targets. Evaluation is also used to monitor the effectiveness of programs and progress toward goals, providing for their continued improvement. Data from evaluation and surveillance serve to educate the public, the health care community, and policy makers about cancer issues.

An evaluation protocol was created for the North Carolina Cancer Plan and the activities that flowed from it. Three different aspects are evaluated: process, impact, and outcome. Process evaluation determines the extent to which the strategies and activities proposed by the Plan are implemented as intended. This includes monitoring the planning and implementation process for the Plan as a whole as well as for individual strategies and projects. Process evaluation is used to document and analyze partner activities and provide information to improve ongoing implementation efforts.

Examples of impact evaluation include increasing access to services, changing behaviors, improving the quality of care, and achieving policy or environmental changes. The desired impacts of the Plan’s strategies are the objectives listed throughout the Plan which are measurable steps necessary to reach the Plan’s goals. In addition to evaluating and summarizing the impact of individual projects, there will be a regular review of progress toward meeting objectives.

Outcome evaluation involves systematic monitoring of defined program outcomes to assess how they change over time and the extent to which changes may be directly or indirectly

attributable to the program and its activities. Additionally, regular, systematic, and accurate assessment of the program and timely reporting of evaluation findings is important to the sustainability of the program.

In order to conduct an ongoing evaluation of the Plan, we rely upon several sources of data. First, data are collected by staff of the North Carolina Comprehensive Cancer Program and the NCAC in order to measure processes employed in the actual implementation of the Plan. These data are supplemented by impact and outcome measures that are obtained through the North Carolina Central Cancer Registry, North Carolina Behavioral Risk Factor Surveillance System (BRFSS), North Carolina Cancer Survey, National Cancer Institute's Surveillance Epidemiology and End Results (SEER), and the National Cancer Data Base (NCDB) of the Commission on Cancer of the American College of Surgeons. We also utilize special studies and research that are available for epidemiology and support for surveillance and evaluation through a contractual relationship with the School of Public Health at the University of North Carolina at Chapel Hill.

Opportunities for Involvement

In order for the North Carolina Cancer Plan to become the very best guide for reducing the burden of cancer for our citizens, it is essential that there always be opportunities for involving more stakeholders in our processes of development and implementation. Through this commentary and the other commentaries contributed to this issue of the *North Carolina Medical Journal*, we hope that more individuals will become aware of both the challenges and opportunities that cancer presents to North Carolina. We openly solicit comments, contributions, and participation. Please visit www.nccancer.com, write us an email, and join the efforts. Become involved and stay involved. Contribute to the Plan and be part of its implementation. Join us in reducing the burden of cancer for all the people of North Carolina. Be a local leader in this effort. **NCMJ**

"I have beaten the odds for more than 4 decades. After surviving cervical cancer in 1964, I then beat breast cancer. On April 18, 2001 my oncologist handed me what I considered to be a death sentence: stage IV inoperable non-small cell lung cancer in both lungs! "You might make it until Christmas," my physician told me. Well, I have celebrated 7 Christmases since my "death sentence." I had many rounds of chemo, 30 rounds of radiation, more chemo, and then Stereotatic Body Radiation (SBR). The last round of chemo did the trick; I have been cancer free since the last week of June 2005! It will soon be 3 years! I am still alive and kicking!"

*— Charlotte
Cervical, Breast & Lung Cancer*

"As a 59-year old, 4 year, stage III prostate cancer survivor, I feel fortunate to have a primary care physician who believes in PSA blood testing to detect prostate cancer. I have learned that my relationship with my family and friends define me as a person, not material possessions."

*— Richard
Prostate Cancer*