

## **IV. SURVEILLANCE AND APPLIED RESEARCH**

### **A. Goals**

Surveillance and applied research are integral elements of any public health initiative. Surveillance provides data items or indicators on diseases and populations affected by them in order to understand what is associated with diagnosis, health care outcomes, and numerous other variables. Applied research uses these data to better understand how initiatives can be designed to more effectively address and meet the needs of groups of people. For cancer survivorship, goals for this topic area include the following:

- Enhance the existing infrastructure to create a comprehensive surveillance system that can be used to understand the range of health issues that cancer survivors face and any differences between survivor groups based on demographic and medical variables.
- Thoroughly understand the factors associated with susceptibility to problems during each stage of cancer survivorship.
- Translate the research on cancer survivorship into practice by developing, implementing, and evaluating effective health intervention strategies.

**Surveillance and applied research** are the scientific tools of public health and are defined here and in Section II.C. as follows:

#### **Surveillance**

Cancer surveillance is the systematic collection, analysis, and use of cancer data. Information obtained through surveillance measures is critical for directing effective cancer prevention and control programs (CDC, 2001). Primary surveillance measures include cancer registries and several national and regional/state surveys. Cancer registries (NPCR, SEER) implement and maintain information systems designed to collect and manage data on each newly diagnosed case of cancer. National surveys, such as the NHIS and BRFSS, provide information on health attitudes, beliefs, and behaviors that could be used to help understand issues related to all stages of cancer survivorship.

#### **Applied Research**

Cancer survivorship research in a public health context would focus efforts on applying our knowledge of cancer and issues survivors face to the development of appropriate interventions. Understanding

specific structural, policy, or behavioral barriers to desired outcomes and evaluating programmatic efforts are other examples of applied research. Applied research investigates the extent to which these efforts effectively address survivor needs and provides findings that can guide further development of initiatives.

Prioritized needs for these components and suggested strategies for addressing them are presented in the following section.

## **B. Prioritized Needs and Suggested Strategies**

### **1. Enhance the existing surveillance and applied research infrastructure.**

Increasing the capacity of surveillance systems to capture information on health topics of interest can lead to a better understanding of diseases and the people affected by them. Effective survivorship research is dependent upon the integration and interaction of many information sources that serve as a strong and comprehensive infrastructure for study. A surveillance system that provides data on the long-term effects of cancer is critical to advancing survivorship. This need is described in detail in Section III of this *National Action Plan*.

### **2. Identify factors associated with ongoing health concerns of cancer survivors.**

As described in Section I, only within the past two decades have research and knowledge demonstrated that cancer is a disease a person can survive for many years after treatment. With their successful survival from cancer diagnosis and treatment, survivors are often faced with ongoing health concerns, such as heart problems, major disabilities, **lymphedema**, infertility, and others (NCI, 2002). Although there is understanding of the types of health problems cancer diagnosis and treatment may cause immediately, less is known about the long-term effects and how different people are affected by the services they receive. Some people may be prone to certain types of complications or long-term difficulties, but little is known that can help prevent or educate survivors on avoiding these problems. The extent to which diagnosis and treatment of cancer may impact the chances that a survivor will later develop other, secondary diseases is also unknown. Assessments of the potential for these problems can help guide delivery of health services to prevent or encourage early detection of other cancers and health complications (e.g., diabetes, heart disease) and thereby improve the quality of life for survivors. In addition, knowing the characteristics of survivors who are more prone to develop ongoing complications

can help researchers, policy and decision makers, program managers, and others to direct the development and implementation of survivorship services and programs that will address specific needs. Strategies to address this need include the following:

- Initiate research studies to identify characteristics associated with certain types of cancer and/or secondary health concerns.
- Identify modifiable behaviors (e.g., limited physical activity, poor eating habits) that can be targeted with interventions to reduce the likelihood of additional health problems.
- Once more is known about which characteristics render survivors susceptible to health problems (e.g., different age groups), develop **primary prevention** education programs to inform survivors about their susceptibility and any behavioral changes they can make to reduce their risk.

### **3. Determine programs and services that best address the needs of cancer survivors.**

Once more is understood about the health concerns survivors may face—particularly those that occur long after treatment ends—and the groups of survivors most susceptible to them, programs and services can be delivered to maximize the chances of optimum health among survivors during each stage of living with, through, and beyond cancer. These programs and services can include providing adequate screening for cancer recurrence (e.g., more frequent follow-up screening exams for those diagnosed with screen-detectable cancers than is recommended for the general population), follow-up surveillance of health concerns (e.g., frequent testing for heart problems among survivors of childhood cancers [IOM, 2003]), psychological and/or support group services, planning for possible infertility, and additional services that can be made strategically available to those most susceptible to recurring problems. More needs to be understood about the types of programs and services to provide survivors and the point in time at which these interventions would have the greatest positive impact. Importantly, the characteristics of those survivors most likely to benefit from delivery of developed services need to be identified. Strategies to meet this need include the following:

- Gain a better understanding of how cancer survivors interact with the health care system by conducting national surveys (e.g., NHIS, BRFSS) to delineate the services delivered, usage pattern, and any problems in these areas.

- Enhance collaborative efforts among academic researchers and state health departments to develop research projects to increase the body of knowledge about the care and services that can be provided to survivors to reduce susceptibility to additional health problems.
- Identify, evaluate, and disseminate findings of the most effective models of survivorship care.
- Incorporate lessons learned from this body of knowledge into state comprehensive cancer control plans.

#### **4. Conduct research on preventive interventions to evaluate their impact on issues related to cancer survivorship.**

**Preventive interventions** are those programs, activities, and services that identify areas of behavior that can be changed to reduce cancer recurrence and promote healthy lifestyles. The scope of preventive interventions includes, but is not limited to, reducing tobacco and alcohol use and sun exposure; improving nutrition, mental health, and early detection or follow-up, such as survivor self-advocacy; and increasing physical activity. This work is important not only for preventing other cancers and diseases but also for reducing cancer recurrence. Specific strategies for conducting this research include the following:

- Develop an inventory of existing preventive interventions.
- Evaluate programs in different public health settings to determine the effectiveness of a particular intervention and establish best practices for cancer survivors.
- Identify gaps in existing interventions through evaluation research.
- Develop interventions that address people at highest risk for developing other cancers and/or secondary health conditions.
- Conduct cost-effectiveness research of selected interventions.
- Customize communication to specific cancer survivor populations, with a specific focus on underserved communities, to increase awareness of available interventions and resources.

#### **5. Translate applied research into practice.**

Translating scientific research into practice is a crucial step in increasing the quality of life of cancer survivors. Research findings should be utilized to develop and implement programs and services that reduce negative health effects and promote long-term health benefits. In turn, these programs will benefit cancer survivors by

enhancing the health care services that they receive. The following strategies would begin to address this need:

- Incorporate cancer survivorship as an issue to address in the **Guide to Community Preventive Services** (Truman et al., 2000). This guide provides recommendations on preventive interventions that can be used in a community setting.
- Develop tools/methods for translating research findings so that the general public can understand and apply the knowledge to their everyday life.
- Use research findings to educate cancer survivors and others (including providers, organizations, and advocates) on survivorship issues.
- Disseminate research findings to health care professionals and survivors through public health and other organizations, using a variety of venues (e.g., Internet, mail).

## *Section IV Summary:*

### *Surveillance and Applied Research*

1. Enhance the existing surveillance and applied research infrastructure.
2. Identify factors associated with ongoing health concerns of cancer survivors.
3. Determine programs and services that best address the needs of cancer survivors.
4. Conduct research on preventive interventions to evaluate their impact on issues related to cancer survivorship.
5. Translate applied research into practice.



Daniel, Two-time Lymphoma Survivor



*“Survivorship is far more than living through cancer treatment — it’s who I am.”*