

III. CROSS-CUTTING NEEDS AND STRATEGIES

Four primary topic areas (see Section II.C.) for advancing cancer survivorship within the realm of public health have been identified:

- Surveillance and applied research
- Communication, education, and training
- Programs, policies, and infrastructure
- Access to quality care and services

Within these topic areas, five specific cross-cutting needs were identified.

I. Develop an infrastructure for a comprehensive database on cancer survivorship.

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 comprehensive database system could provide information on the ongoing health and other issues facing survivors. It could also provide the opportunity to follow survivors for many years after cancer diagnosis in order to better understand the long-term effects of having this disease. Enhancing the existing surveillance and research infrastructure can also ultimately lead to the development and implementation of strategies identified for other topic areas outlined in this National Action Plan. The following strategies focus on the specific data needs for cancer survivorship that have been identified to enhance the existing surveillance systems and applied research initiatives:

- Develop a national Work Group or Task Force composed of diverse organizations, representing private, nonprofit, and governmental agencies, to identify data needs for ongoing follow-up and confidential monitoring of cancer survivorship issues (e.g., treatment course and outcomes, quality-of-life indicators, long-term effects of diagnosis and treatment).
- Assess existing data on cancer survivors to identify gaps in order to determine areas of future research.
- Develop consensus on a set of data items or **indicators** used in the collection and analysis of cancer survivorship data, including data needed for long-term follow-up on survivors.

- Improve coordination among existing databases (e.g., NPCR, BRFSS, SEER), and add data variables or indicators where possible to collect supplementary information on cancer survivors.
- Develop a centralized resource center (i.e., clearinghouse) that includes linkages to all existing data sources and that provides for longitudinal data collection, monitoring, and follow-up.
- Increase the number and types of funding opportunities to enable a broader range of researchers to participate in survivorship surveillance activities.
- Use existing information technology to gather data on cancer diagnosis, treatment, and long-term issues and report the data in a timely manner.
- Provide widespread access to public data sets as quickly as possible to enhance research activities.

2. Develop, test, maintain, and promote patient navigation systems that can facilitate optimum care for cancer survivors.

Patient navigation is a tool that can be used to ensure that survivors understand their care and their process of care, and to enhance the delivery of optimum care. In these programs, health professionals and highly trained patient liaison representatives coordinate health care for patients and assist them in navigating the health care system. These navigators can provide information that will help educate the survivor about his or her health needs and concerns, ensure timely delivery of care, connect survivors with appropriate resources that will meet their needs, and provide general oversight to the delivery and payment of services for each survivor. Key strategies for developing and maintaining these programs include the following:

- Establish infrastructure of the patient navigation system, consisting of appropriate existing national organizations, to implement a national program with consistent delivery of services for cancer survivors.
- Promote universal input and buy-in by having patient navigation system co-branded and co-owned by all appropriate organizations.
- Identify existing types of patient navigation systems delivered in a variety of locations or through different mechanisms (e.g., rural, urban, on-line, print, telephone, clinical trials), and determine those that are considered **best practices**.

- Develop a database of existing and tested patient navigator tools/programs and educate survivors and others at the national, state, and community levels on their use.
- Plan, develop, and incorporate patient navigation systems into state comprehensive cancer control plans.
- Develop policies to require insurance coverage of patient navigation services.
- Develop effective patient navigator tools that address issues of disparity (e.g., race, ethnicity, education, geography, income, gender) among survivors.
- Encourage cancer survivors to volunteer their time (**in-kind**) to serve as individual navigators servicing other survivors.

3. Establish and /or disseminate clinical practice guidelines for each stage of cancer survivorship.

Clinical practice guidelines are defined by the IOM as

“...systematically developed statements to assist practitioner and patient decisions for specific clinical circumstances” (IOM, 1992).

These guidelines summarize the collective research on outcomes pertaining to one disease. When using the guidelines, physicians have to select from among the guideline recommendations those that seem most applicable to each individual’s care. In their statement, “Principles of Quality Cancer Care,” the Cancer Leadership Council emphasizes that all people with cancer need to have timely access to care that is based on the best available evidence (NCCS, 2003). Treatment options should include access to clinical trials, therapies to manage side effects, and services to help survivors and caregivers cope with emotional and practical concerns. Guidelines have been developed for the treatment of particular cancers, but they are not necessarily comprehensive in the sense of specifying care for survivors at each stage of cancer survivorship (e.g., monitoring survivors after treatment is completed, monitoring long-term health care). Guidelines are also in place to address end-of-life care so that survivors do not suffer from intense pain and discomfort during the final stages of life (IOM, 1997). The following strategies are proposed to systematically move toward quality and timely service provision so that guidelines are available throughout every stage of living with, through, and beyond cancer:

- Charge appropriate groups working on cancer survivorship issues (e.g., National Comprehensive Cancer Network, American Society of Clinical Oncology, NCCS) to develop clinical practice guidelines specific to each stage of cancer survivorship.

- Establish a centralized location for housing these guidelines (e.g., National Guidelines Clearinghouse, Cancer Information Service [CIS]).
- Develop both consumer and health care provider versions of each clinical practice guideline and disseminate through multiple channels and organizations.
- Require that programs funded by public health organizations include implementation of clinical practice guidelines (e.g., state cancer plans, CCC Programs).
- Ensure accessibility of services named in each clinical practice guideline.
- Conduct ongoing evaluation of guidelines and use results to assess utilization. Modify guidelines as needed.
- Provide training to cancer and non-cancer health professionals about guidelines to maximize workforce development.
- Ensure quality workforce by requiring ongoing training on such topics as cultural sensitivity and palliative care.
- Assess gaps in the health care workforce and develop strategies to recruit and retain quality service providers.

4. Develop and disseminate public education programs that empower cancer survivors to make informed decisions.

No one medical answer is right for everyone. Cancer survivors are faced with extremely difficult medical decisions at each stage of living with, through, and beyond cancer. In making difficult medical decisions, survivors need to thoroughly understand their options for care and why it is in their best interest to participate fully in the decision-making process. The informed decision-making process also enables physicians to more fully understand the attitudes and values of their patients, especially those with diverse cultural backgrounds. A growing body of research shows that when patients are well-informed and play a significant role in deciding how they are going to manage their health, the results are more positive. Informed patients feel better about the outcomes of the decision-making process and are therefore more likely to follow their providers' recommendations (Mulley, 1995). Key strategies for addressing this need include the following:

- Form a national Task Force to develop programs addressing public education among survivors, and create a multifaceted strategic plan around this issue.

- Identify existing resources available to survivors to facilitate informed decision making and advocacy skills, and develop programs or materials where information is lacking.
- Charge the national Task Force with implementing marketing strategies and a multimedia campaign to effectively educate survivors about issues and available education programs, using numerous modes for communication (e.g., Internet, print media).
- Disseminate and encourage implementation of best practices for enhancing informed decision making through a variety of venues (e.g., health care providers, advocacy groups, government agencies, legislators).

5. Conduct ongoing evaluation of all activities to determine their impacts and outcomes and ensure continuous quality improvement of services.

Evaluation planning and implementation are important processes in program development. The ultimate goals of these processes are to assess program implementation and outcomes, to increase program efficiency and impact over time, and to demonstrate accountability (CDC, 2001). According to CDC's "Framework for Program Evaluation in Public Health" (1999), program evaluation is an essential organizational practice in public health. The Framework proposes that evaluation is necessary to use science as a basis for decision making and public health action, expand the quest for social equity through public health action, perform effectively as a service agency, make efforts outcome-oriented, and be accountable (CDC, 1999). For evaluation to be effectively implemented, quality indicators need to be developed for programs and services so that progress toward articulated goals can be measured. These evaluation efforts should be continuous so that improvements can be made during all phases of program implementation. The following strategies could be used to comprehensively include evaluation and quality improvement in addressing all needs:

- Identify evaluation measures for each type of program or strategy implemented from the National Action Plan.
- Conduct theoretically-based and scientifically-grounded studies to assess implementation.
- Disseminate evidence-based program evaluation findings through public health organizations and other venues in order to maximize use of information.

Section III Summary: Cross-Cutting Needs for Cancer Survivors

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2. Develop, test, maintain, and promote patient navigation systems that can facilitate optimum care for cancer survivors.
3. Establish and / or disseminate clinical practice guidelines for each stage of cancer survivorship.
4. Develop and disseminate public education programs that empower cancer survivors to make informed decisions.
5. Conduct ongoing evaluation of all activities to determine their impacts and outcomes and ensure continuous quality improvement of services.

Jan, Breast Cancer Survivor



“Survivorship is the ultimate understanding of one’s purpose in life.”