

EXPLANATIONS OF PHRASES AND TERMS

Note: Listed below are explanations of phrases and terms that appear in the National Action Plan as bold text.

Access to quality care and services

Quality cancer care means ensuring that survivors have access to evidence-based (or proven to be successful) appropriate treatment. Services should be delivered in a timely and technically competent manner, utilizing good communication, shared decision making between the cancer survivor and health care providers, and in a cultural sensitivity manner across the continuum of care and throughout the remainder of life (IOM, 1999).

Access to quality treatment

Cancer treatment is complex and differs for each individual based on his or her specific situation and needs. Cancer survivors should have timely access to the latest and most effective treatments available. This would include clinical trials, if appropriate (Cancer Leadership Council, 2003).

Acute stage

The “acute” stage of survival begins with diagnosis and spans the time of further diagnostic and treatment efforts (Mullan, 1985).

Ancillary services

Professional services provided by a hospital or other inpatient health program. These may include x-ray, drug, laboratory, or other services (CMS, 2003).

Applied research

Use of surveillance data to better understand the extent to which interventions effectively address survivor needs and provide findings that can guide further development of initiatives.

Best practices

Programs that have been identified as effective through a standardized process using commonly agreed-upon criteria for rating their success (USDHHS, 2003).

Cancer

A term for diseases in which abnormal cells divide without control (NCI, 2003c).

Cancer Control PLANET

Plan, Link, Act, Network with Evidence-based Tools: a Web portal resource with links to resources for comprehensive cancer control (Cancer <http://cancercontrolplanet.cancer.gov>).

Cancer survivors

People who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends, and caregivers (LAF, 2003).

Case management

A process used by a doctor, nurse, or other health professional to manage a patient's health care. Case managers make sure that people receive needed services and track the use of facilities and resources (CMS, 2003).

Chronic disease

A disease that has one or more of the following characteristics: is permanent; leaves residual disability; is caused by nonreversible pathological alteration; requires special training of the patient for rehabilitation; or may be expected to require a long period of supervision, observation, or care (DEHA, 2003).

Clinical practice guidelines

Systematically developed statements designed to assist practitioner and patient decisions for specific clinical circumstances (IOM, 1992).

Clinical trials

Research studies, where patients help scientists find the best way to prevent, detect, diagnose, or treat diseases (NCI, 2003c).

Communication with the public

Communication with the general public and policy or decision makers about the issues surrounding cancer survivorship, which aims to create a societal understanding and acceptance of the growing population of cancer survivors and the issues they face.

Comprehensive cancer control

An integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention (primary prevention), early detection (secondary prevention), treatment, rehabilitation, and palliation (CDC, 2003b).

End-of-life care

Affirms life and regards dying as a normal process, neither hastening nor postponing death while providing relief from distress and integrating psychological and spiritual aspects of patient care. The goal of end-of-life care is to achieve the best possible quality of life for cancer survivors by controlling pain and other symptoms and addressing psychological and spiritual needs (Hospice, 2003).

Extended stage

The “extended” stage of survival begins when the patient goes into remission or has completed treatment (Mullan, 1985).

Guide to Community Preventive Services

The Community Guide summarizes what is known about the effectiveness, economic efficiency, and feasibility of interventions to promote community health and prevent disease. The Task Force on Community Preventive Services makes recommendations for the use of various interventions based on the evidence gathered in the rigorous and systematic scientific reviews of published studies conducted by the review teams of the Community Guide. Findings from the reviews are published in peer-reviewed journals and also made available on the internet at www.thecommunityguide.org.

Health care provider

A person who is trained and licensed to give health care. Also, a place licensed to give health care. Doctors, nurses, hospitals, skilled nursing facilities, some assisted living facilities, and certain kinds of home health agencies are examples of health care providers (CMS, 2003).

Healthy People 2010

Healthy People 2010 is a set of health objectives for the nation to achieve over the first decade of the new century. It can be used by many different people, states, communities, professional organizations, and others to help them develop programs to improve health (USDHHS, 2003).

Incidence

The number of new cases of a disease diagnosed each year (NCI, 2003c).

Indicator

A substitute measure for a concept that is not directly observable or measurable (e.g., prejudice, substance abuse). Also defined as a variable that relates directly to some part of a program goal or objective. Positive change on an indicator is presumed to indicate progress in accomplishing the larger program objective (PSAP, 2003).

Infrastructure

The systems, competencies, relationships, data and information systems, skilled workforce, effective public health organizations, resources, and research that enable performance of the essential public health services in every community (USDHHS, 2000).

In-kind

Contributions or assistance in a form other than money. Equipment, materials, or services of recognized value that are offered in lieu of cash (UCLA, 2003).

Living “beyond” cancer

Refers to post-treatment and long-term survivorship (LAF, 2003).

Living “through” cancer

Refers to the extended stage following treatment (LAF, 2003).

Living “with” cancer

Refers to the experience of receiving a cancer diagnosis and any treatment that may follow (LAF, 2003).

Lymphedema

A condition in which excess fluid collects in tissue and causes swelling. It may occur in the arm or leg after lymph vessels or lymph nodes in the underarm or groin are removed or treated with radiation (NCI, 2003c).

Metastasis

The spread of cancer from one part of the body to another. A tumor formed from cells that have spread is called a secondary tumor, a metastatic tumor, or a metastasis. The plural form of metastasis is metastases. Metastasized means to spread by metastasis (NCI, 2003c).

Morbidity

A disease or the incidence of disease within a population. Morbidity also refers to adverse effects caused by a treatment (NCI, 2004).

Pain and symptom management

Pain and symptom management refers to the provision of pain relief so that patients can tolerate the diagnostic and therapeutic procedures needed to treat their cancer (Foley, 1999).

Palliative care

Care given to improve the quality of life of patients who have a serious or life-threatening disease. Also called comfort care, supportive care, and symptom management (NCI, 2003c).

Patient navigation

A tool that can be used to ensure that survivors understand their care and their process of care and enhance optimum care. In these programs, health professionals and others coordinate health care for patients and assist them in navigating the health care system (<http://deainfo.nci.nih.gov/advisory/pcp/video-summary.htm>).

Permanent stage

The “permanent” stage is defined as a time when the “activity of the disease or likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested” (Mullan, 1985, p. 272).

Policies

Policies include legislation, regulations, ordinances, guidelines, and norms that establish an environment conducive to program implementation (NAAP, 1999).

Preventive interventions

Programs, activities, and services that identify areas of behavior that can be changed to reduce cancer recurrence or increase control and promote healthy lifestyles.

Primary prevention

Measures designed to combat risk factors for illness before an illness ever has a chance to develop (McGraw-Hill, 2003).

Programs

Programs are the actual implementation of specific interventions at the national, state, and community levels to address a public health problem (NAAP, 1999).

Provider training

Health care provider training aims to assure that providers are aware of the spectrum of services available to enhance quality of life throughout survivorship so that they may refer survivors to these services as appropriate.

Public health

Public health practice is the science and art of preventing disease, prolonging life, and promoting health and well-being (Winslow, 1923). The Institute of Medicine (IOM) has defined the mission of

public health as assuring conditions in which people can be healthy (1988). Public health's mission is achieved through the application of health promotion and disease prevention technologies and interventions designed to improve and enhance quality of life (PHFSC, 1994).

Qualitative data

A record of thoughts, observations, opinions, or words gathered/collected from open-ended questions to which the answers are not limited by a set of choices or a scale (PSAP, 2003).

Quantitative data

Numeric information that includes such items as type of treatment, amount of time, or a rating of an opinion on a scale from 1 to 5. Quantitative data are collected through closed-ended questions, where users are given a limited set of possible answers to a question (PSAP, 2003).

Risk

The probability that an event will occur (e.g., that an individual will become ill or die within a stated period of time or age) (Last, 1995).

Risk factor

Something that may increase the chance of developing a disease. Some examples of risk factors for cancer include age, a family history of certain cancers, use of tobacco products, certain eating habits, obesity, exposure to radiation or other cancer-causing agents, and certain genetic changes (NCI, 2003c).

Stakeholders

A stakeholder is someone who has a stake in an organization or a program. Stakeholders either affect the organization/program or are affected by it (PSAP, 2003).

Surveillance

Primary surveillance measures include cancer registries and several national surveys. Cancer registries implement and maintain information systems designed to collect and manage data on cases of cancer incidence. National surveys, such as the National Health Interview Survey (NHIS), provide information on health attitudes, beliefs, and behaviors that could be used to help understand issues related to cancer survivorship (CDC, 2003b).

Survivor education

The education of cancer survivors includes provision of information tailored to the particular stage of survivorship (Mullan, 1984).