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# Consensus Study Report HIGHLIGHTS

The National Academies of SCIENCES • ENGINEERING • MEDICINE CONSENSUS STUDY REPORT

DIAGNOSING AND TREATING ADULT CANCERS AND ASSOCIATED IMPAIRMENTS

# Diagnosing and Treating Adult Cancers and Associated Impairments

Cancer is the second leading cause of death among American adults after heart disease. An estimated 1.8 million new cases of cancer were diagnosed in 2020 and more than 600,000 cancer deaths occurred. However, improvements in treatment and earlier detection are leading to more cancer survivors—any living person with a history of cancer—from diagnosis until death. Half of all newly diagnosed cancer patients are working-age adults.

# Top 10 most common cancers among U.S. adults in 2020:

- Breast cancer
- Lung and bronchus cancer
- Prostate cancer
- Colorectal cancer
- Melanoma of the skin
- Bladder cancer
- Non-Hodgkin lymphoma
- Kidney and renal pelvis cancer
- Uterine cancer
- Leukemia

For many people who have been diagnosed with cancer, the cancer itself and its treatment can cause substantial adverse effects, referred to as **cancer-related impairments**, which

can be physiologic (e.g., pain, fatigue) or psychologic (e.g., depression, anxiety). They can affect an individual's ability to walk, stand, lift, carry, think, and work. Cancer survivors who are younger than 65 and who are unable to work because of such consequences may apply for disability benefits from the U.S. Social Security Administration (SSA); those older than 65 are not eligible for these benefits.

SSA has a five-step disability determination process, which includes a step that relies on the *Listings of Impairments*—health conditions considered severe enough to automatically qualify for disability benefits. To keep the disability listings for adult cancers up to date, SSA asked the National Academies of Sciences, Engineering, and Medicine to convene an expert committee to provide an overview of the diagnosis, treatment, and prognosis of selected adult cancers, particularly breast cancer and lung cancer. At the committee's request, SSA identified those cancers that

were most frequently listed as the primary diagnosis in disability claims for 2015–2019: breast cancer, lung cancer, colorectal cancer, head and neck cancers, pancreatic cancer, nervous system cancers, leukemia, lymphoma, liver or bile duct cancer, and ovarian cancer. The committee highlighted changes in the risk factors, incidence, treatment, and outcomes for these cancers, as well as for melanoma of the skin.

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#### CHANGING CANCER EPIDEMIOLOGY

The annual number of new cancer cases (incidence) among U.S. adults declined by approximately 21 percent between 1992 and 2017, and deaths from cancer declined by 43 percent. In 2020, 55 percent of the estimated 276,480 new **breast cancer** cases were expected to be diagnosed in women aged 64 years or younger. New cases of breast cancer among women older than 50 remained about the same over the past decade while its incidence in women under 40 has been rising. The incidence of **lung cancer** is decreasing. One-third of the estimated 228,820 lung cancer diagnoses in 2020 were among men and women aged 55 to 64 years. Non-small-cell lung cancer (NSCLC) and small-cell lung cancer (SCLC) account for 85 percent and 15 percent of all new cases, respectively.

Deaths from cancer have also fallen since 1991, primarily due to declines in mortality for breast, colorectal, prostate, and particularly lung cancer. Among the growing number of cancer survivors, estimated at 16.9 million in 2019, one-third are under 65 years. The population of cancer survivors will continue to grow due to earlier diagnosis and advances in treatments, but many survivors live with long-term impairments and functional limitations resulting from their cancer and its treatment that may affect their quality of life and ability to work.

## **SCREENING FOR, DIAGNOSING, AND STAGING CANCERS**

**Screening** can help to detect cancers early, when they are most likely to be cured. However, not all who are eligible are screened, and effective tests are not available for many cancers. **Diagnosis** may include pathological tissue examination, imaging studies, and other techniques, and involve a biopsy procedure—needle or surgical—to collect a tissue sample for microscopic examination to differentiate and stage the cancer and identify molecular biomarkers. Biomarker testing includes the analysis of DNA from cancer cells and other molecular tests. The increasingly common use of these new molecular and genomic assays to refine many cancer diagnoses can help to identify patients who may benefit from targeted treatments and to determine the best treatment strategy for a patient with cancer.

## **TREATING CANCER**

Each person's experience with cancer is unique, from the time of diagnosis, through treatment, to survivorship, and for many, to end of life. The cancer care trajectory depends on many factors, including type of cancer, how far the cancer has progressed, availability of and tolerance to treatments, and treatment outcomes (see Figure 1). Most cancers are treated with **local therapies** such as surgery and radiation (which are the most common), or ablation and embolization (which are less common). **Systemic therapies** such as chemotherapy, endocrine therapy, targeted therapy, immunotherapy, and stem cell therapy may also be used before or after surgery. Many systemic therapies beyond chemotherapy are now used to treat both early-stage and advanced cancer.



FIGURE 1 The cancer care trajectory.

**New and emerging treatments** for cancer are being developed for surgery, radiation, and systemic approaches. The committee defined new treatments as "therapeutic approaches adopted recently in clinical practice or established treatments for one cancer that are being studied for other cancers, and emerging therapies as novel therapeutic approaches under scientific investigation that have demonstrated promising results in early-stage

research, but have not yet been accepted as a standard of care." **Immunotherapies** represent an important and transformative class of new and emerging cancer treatments, as they can lead to prolonged disease-free survival for some cancers that respond poorly to conventional treatments. Although many new and emerging cancer therapies are improving survival, their long-term and late-onset effects are still poorly understood. Some newer treatment approaches are focused on reducing the toxicity and morbidity of conventional treatments; in time, these may become the standard of care as their effectiveness and safety become more evident.

#### **PROGNOSIS**

**Prognosis** refers to what a patient may expect over the trajectory of their cancer treatment and how long they might expect to live. While cancer survivors may live for years, the debilitating effects of their cancer and its treatments may make it difficult to function normally. In addition, many survivors with no evidence of cancer may later experience a cancer recurrence or they may develop new or subsequent primary cancers that may occur anywhere from months to years after the original cancer has been treated.

Because of improved treatments, current breast cancer survivors, including many with metastatic disease, have a longer life expectancy compared with prior cohorts of patients with breast cancer. The 5-year survival rate for people with the most common early-stage breast cancer is 94–99 percent. Lung cancer is one of the deadliest cancers, with more than half of people dying within 1 year of diagnosis. The 5-year survival rates across all stages of NSCLC and SCLS are only 24 percent and 6 percent, respectively. The high mortality rate is due to most people being diagnosed with advanced disease and to the high relapse rate even for those diagnosed in early stages. If diagnosed early, the 5-year survival rates increase to 57 percent for NSCLC, but to only 16 percent for SCLC.

#### **CANCER-RELATED IMPAIRMENTS**

The committee developed a list of long-term and late-onset impairments it considers as among the most common, disabling, and difficult to manage when the treatment goal is improved function. Comorbidities, symptom clusters, and other key factors alter the potential incidence and severity of cancer-related impairments. These impairments include:

• Pain

- Lymphedema
- Depression and anxiety

Gastrointestinal

- Cancer-related fatigue
- CachexiaCardiotoxicity
- impairments
- Musculoskeletal impairments
- Pulmonary toxicity
- Graft-versus-host disease
  Sleep disturbances

 Chemotherapy-induced peripheral neuropathy

- Cognitive impairments
- SSA's current cancer disability listings for adults do not reflect advances in cancer treatments and improved cancer survival rates or the growing number of cancer survivors who have impairments and functional limitations from a cancer or its treatment.

## **SURVIVORSHIP CARE**

**Survivorship care** provides cancer-related and supportive interventions that address the individual needs of each survivor. Challenges for survivorship care include the lack of resources, such as support and informational materials, in many outpatient care settings. Education efforts, including certification programs, are under way to expand training opportunities for health care providers to ensure that the long-term needs of cancer survivors are recognized and met during and after treatment.

## **CONCLUDING REMARKS**

The landscape for cancer diagnosis and treatment has changed dramatically in the past two decades. Discoveries in genetics and immunology have translated into improvements in diagnosis and treatments for many types of cancer. Pathologists now identify the unique expression of a tumor's genetic and immune features in biopsy tissue; this information, along with the anatomic extent of the cancer, can chart a personalized treatment plan for the patient. While these advances have contributed to improvements in cancer treatment outcomes, much less is known about the long-term and late-onset effects of these treatments compared with the conventional surgery, chemotherapy, and radiation approaches that have been used for more than 50 years. Managing cancer-related impairments and functional limitations as part of a patient-centered survivorship care program needs to be a lifelong process.

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