

I've completed my cancer treatment. Now what?



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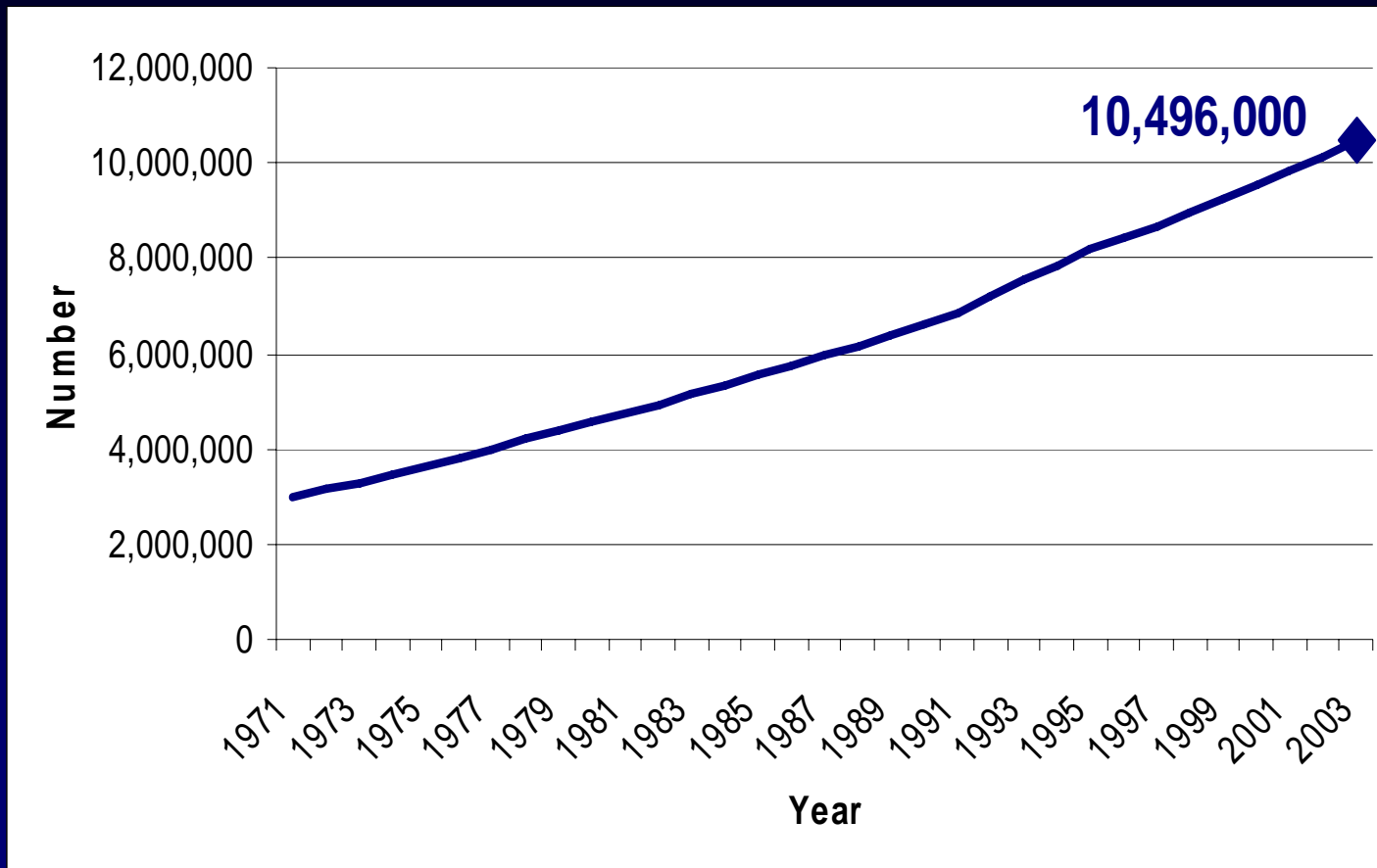
I've completed my cancer treatment. Now what?

- ◆ **Cancer Survivorship: Definition and Estimates**
- ◆ **Issues that confront survivors**
- ◆ **Efforts to address survivorship issues**

A Cancer Survivor is...

- ◆ A person who has been diagnosed with cancer *from the time of diagnosis through the remaining years of life*
- ◆ Family members, friends, and caregivers of those affected by cancer are acknowledged in survivorship

Estimated Number of Cancer Survivors in the U.S. 1971 to 2003



Data source: 2005 Submission. U.S. estimated prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2003 were based on the average of 2002 and 2003 population estimates from the U.S. Bureau of the Census

Reasons for increasing number of survivors

- ◆ Aging population
- ◆ Detection at earlier stages
- ◆ Improved treatment

Cancer Continuum

Prevention

Detection

Treatment

Survivorship

Palliation



Issues faced by Cancer Survivors

Physical

- Pain
- Fatigue
- Change in 'normal' functioning

Issues faced by Cancer Survivors

Medical

- Cancer Recurrence
- Late effects related to treatment
 - ◆ Second cancer
 - ◆ Osteoporosis
 - ◆ Heart Disease

Issues faced by Cancer Survivors

Psychological

- Fear of recurrence
- Anxiety about unknown
- Depression and sadness
- Sense of loss and vulnerability
- Inability to make long-term plans
- Positive effects
 - ◆ New appreciation of life
 - ◆ Sense of self-awareness and mastery

Issues faced by Cancer Survivors

Social

- Change in relationships
- Wanting time to spend with loved ones
- Communication about cancer

Spiritual

- Concerns about dying
- New perspective on personal spirituality
- Reframed sense of purpose

Issues faced by Cancer Survivors

Practical

- Caring for family
- Understanding own health care needs

Economic Issues

- Financial burden of health care costs
- Lost income from inability to work
- Inability to get insurance

Challenges for Providers

- ◆ Late effects are often unknown
- ◆ Lack of evidence for optimal follow-up care and surveillance
- ◆ Time constraints
- ◆ Medical training doesn't prepare for addressing psychosocial needs of patients
- ◆ Limited social services within practice setting
- ◆ Unaware of resources for survivors

Research Needs

- ◆ Follow-up care
 - What, when, who?
- ◆ How to optimize health after cancer treatment
- ◆ Health care delivery and access
- ◆ Evaluation of programs for survivors
 - What works, for whom, why?
- ◆ Understanding practical and economic consequences of cancer

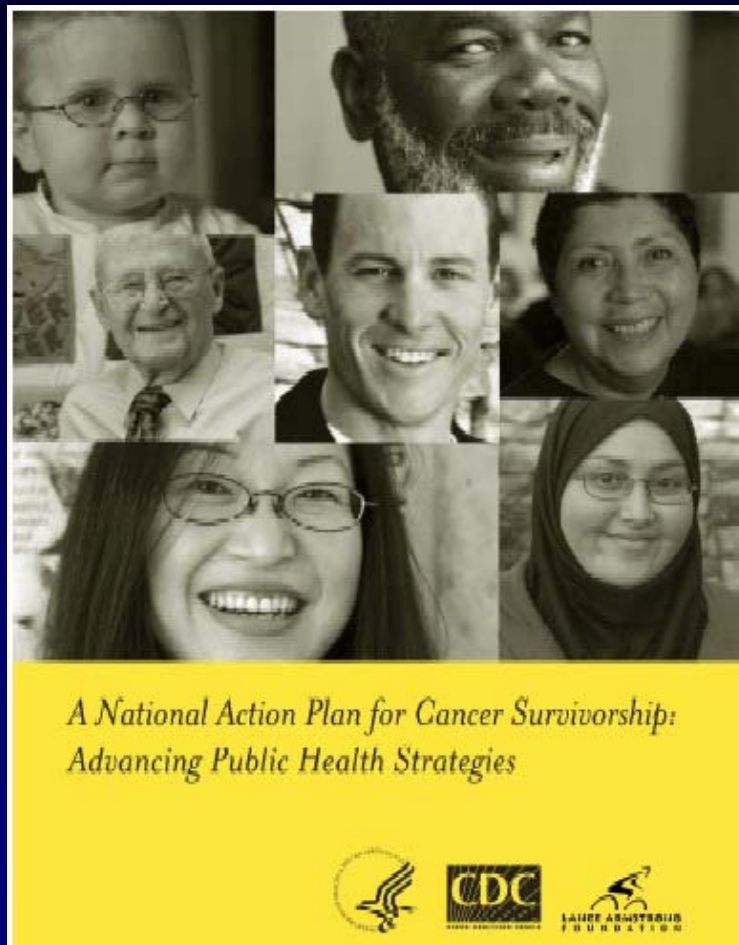
Challenges for Researchers

- ◆ Funding focuses on cause and treatment
- ◆ Study length is too short to include late-term effects
- ◆ Hard to find or include long-term survivors in studies
- ◆ Quality of Life measurement were developed to assess patients during and shortly after treatment
- ◆ Study populations may not reflect community

Efforts to address survivorship issues

- ◆ **A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies**
- ◆ **From Cancer Patient to Cancer Survivor: Lost in Transition**

A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies



- ◆ Input from ~100 experts in survivorship
 - Cancer Survivors
 - Clinical and behavioral science researchers
 - Federal agencies
 - State Cancer Control Coalitions
 - Non-profit and social service organizations
 - Advocacy groups
 - Policy makers

A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies

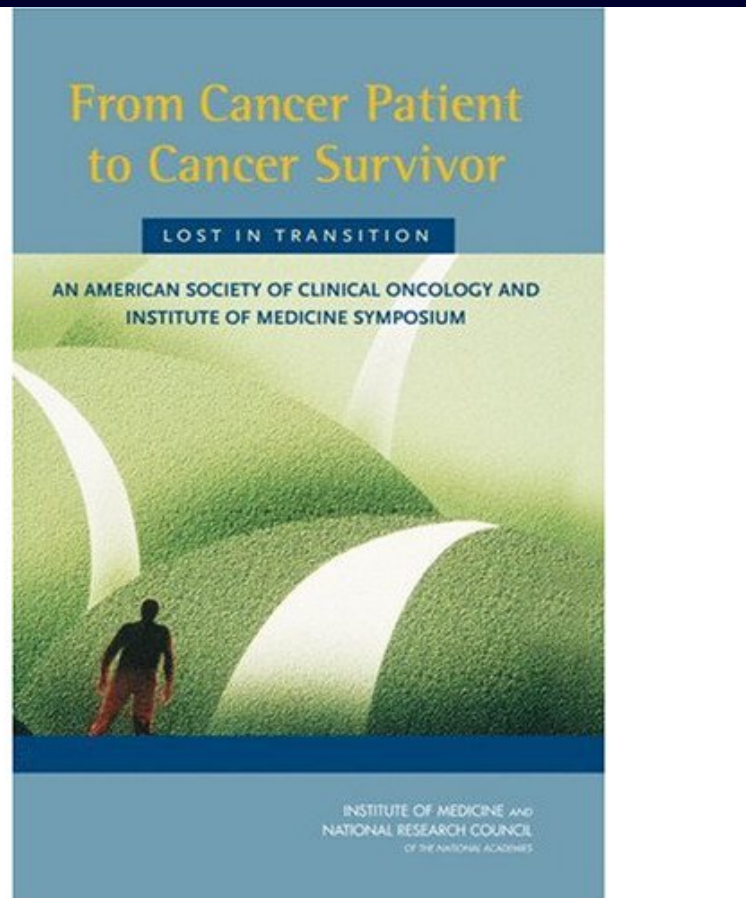
- ◆ Identifies cancer survivorship needs and proposes strategies for addressing those needs within four public health domains
 - Surveillance and Research
 - Communication, Education, Training
 - Programs, Policies, Infrastructure
 - Access to Quality Care and Services

A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies

Cross-Cutting Needs for Cancer Survivors

- ◆ **A comprehensive database on cancer survivorship**
- ◆ **Patient navigation systems**
- ◆ **Clinical practice guidelines for each stage of cancer survivorship**
- ◆ **Public education programs that empower cancer survivors to make informed decisions**
- ◆ **Evaluation of activities to ensure continuous quality of life and improvement of services**

From Cancer Patient to Cancer Survivor: Lost in Transition



◆ Intended for

- Cancer patients and their advocates
- Health care providers and their leadership
- Health insurers/plans
- Employers
- Research sponsors
- Policymakers

Institute of Medicine and National Research Council, 2006

From Cancer Patient to Cancer Survivor: Lost in Transition

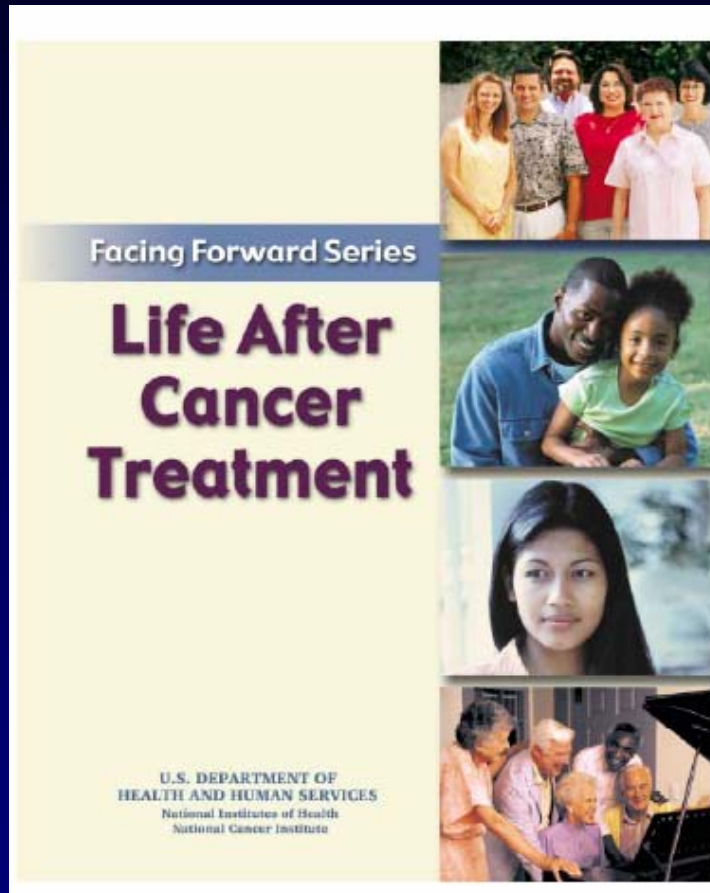
Goals of the Report

- ◆ Raise awareness of the medical, functional, and psychosocial consequences of cancer and its treatment.
- ◆ Define quality health care for cancer survivors and identify strategies to achieve it.
- ◆ Improve the quality of life of cancer survivors through policies to ensure
 - Access to psychosocial services
 - Fair employment practices
 - Health insurance

From Cancer Patient to Cancer Survivor: Lost in Transition

- ◆ **Recommendation: A “Survivorship Care Plan”**
- ◆ **A summary of information critical to the individual's long-term care**
 - **Cancer diagnosis, treatment**
 - **Potential consequences**
 - **Timing and content of follow-up visits**
 - **Tips on maintaining a healthy lifestyle**
 - **Ways to preventing recurrent or new cancers**
 - **Legal rights affecting employment & insurance**
 - **Availability of psychological & support services.**

Resources for Survivors



- ◆ **Facing Forward Series**
- ◆ **Developed by NCI**
- ◆ **Free**
- ◆ **Covers 'after cancer' topics**
 - **Getting Medical Care**
 - **Your Body**
 - **Your Mind and feelings**
 - **Social Relationships**
 - **Employment/Legal Rights**

Resources for Survivors

- ◆ **Lance Armstrong Foundation**
 - Worksheets for survivors to manage information
 - Video stories from survivors
- ◆ **American Cancer Society**
 - *I Can Cope* program
- ◆ **Cancer Care Incorporated**
 - Telephone education workshops
 - Financial assistance grants
- ◆ **National Coalition of Cancer Survivorship**
 - Advocacy
 - *Cancer Survivors Toolkit*

Summary

- ◆ **The number of cancer survivors is large and increasing**
- ◆ **Issues faced by survivors are recognized, but research on the best way to address them is lacking**
- ◆ **Late-effects of cancer and its treatment are still being characterized and evidence is needed to inform guidelines for follow-up care**
- ◆ **Resources on cancer survivorship are available through government and private organizations**

Extra slides

- ◆ The following slides were not presented, but may be of interest.

Risk of a Subsequent Cancer Diagnosis among Kidney Cancer Survivors

◆ Kidney

- Accounts for most subsequent cancer in survivors
- Higher risk among African-Americans

◆ Prostate, Bladder, Ureter

- May be related to increased urologic surveillance

◆ Thyroid

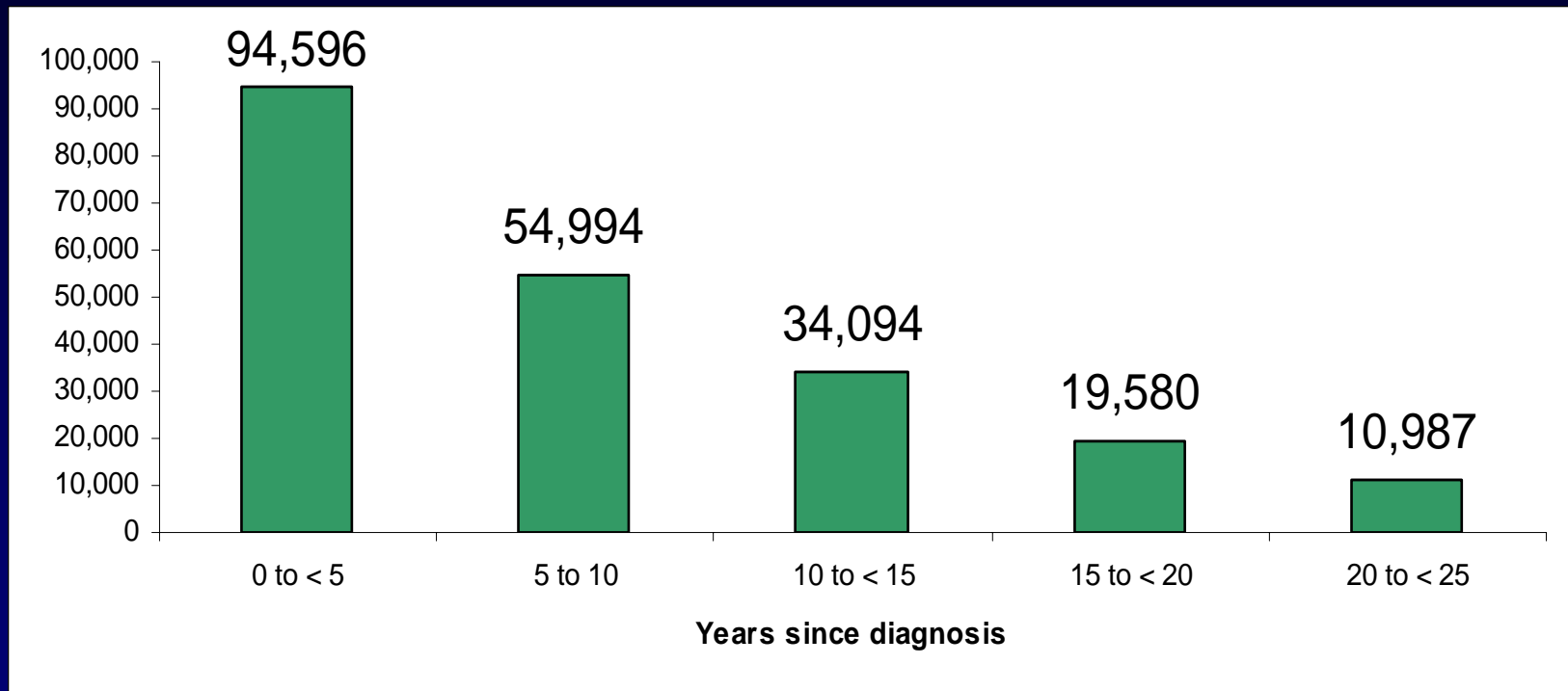
- 3-fold elevated risk, mainly in first year then declines

◆ Melanoma

◆ Leukemia

- Noted 1-4 years after kidney cancer diagnosis

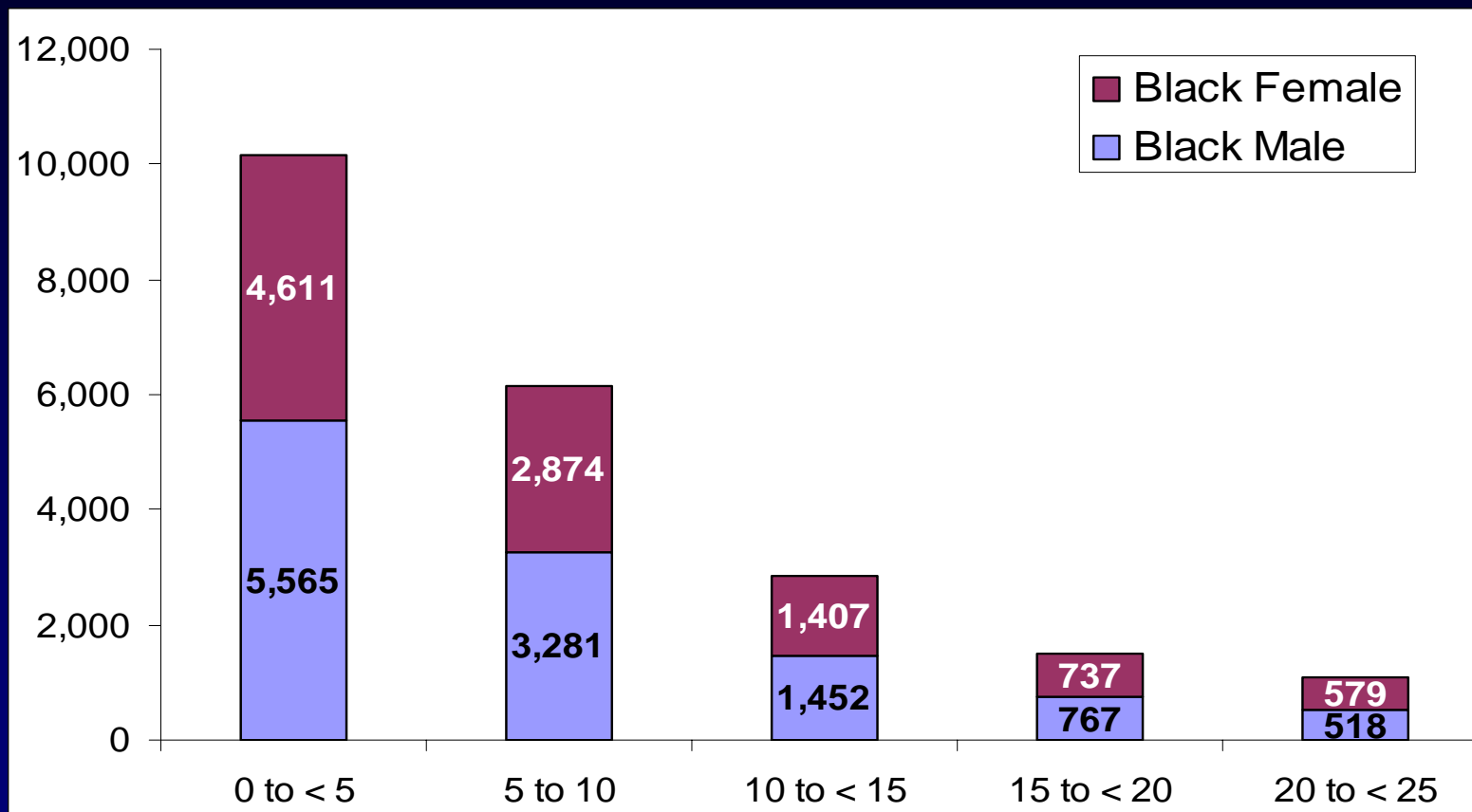
Kidney and Renal Pelvis Cancer (Invasive) Estimated Number of Survivors* = 230,148



*US 2003 cancer prevalence counts (SEER Cancer Statistics Review 1975-2003)

Kidney and Renal Pelvis Cancer

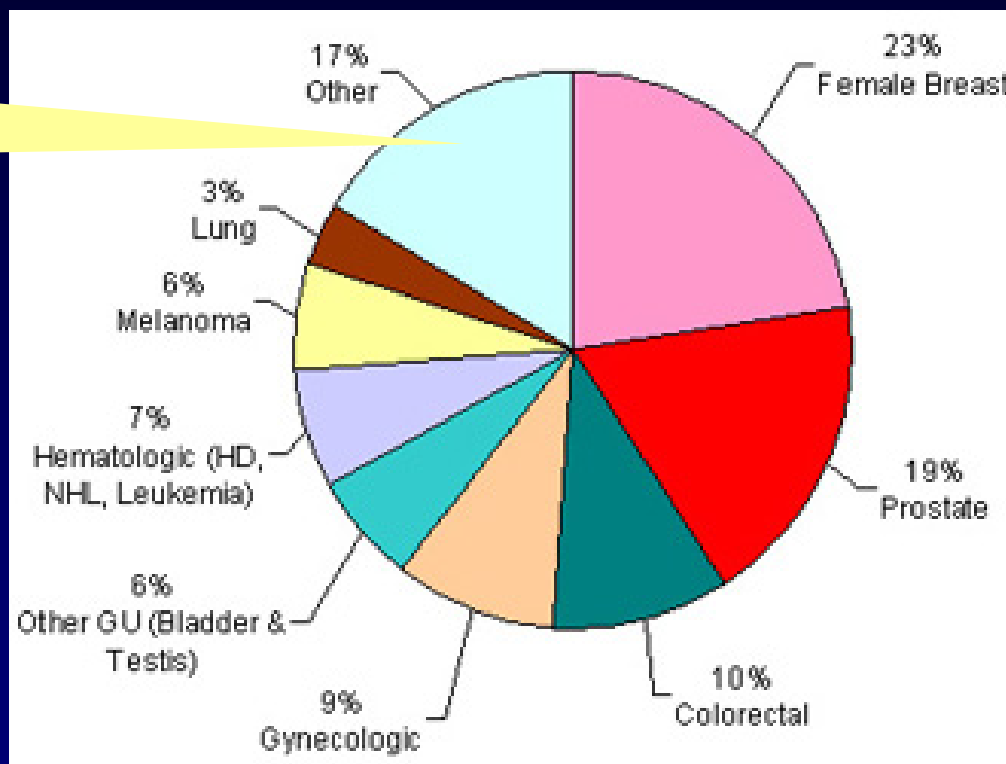
Estimated Number of African-American Survivors* = 24,142



*US 2003 cancer prevalence counts (SEER Cancer Statistics Review 1975-2003)

Distribution of cancer diagnosed among current survivors

2%
Kidney and
Renal Pelvis



Data source: 2005 Submission. U.S. estimated prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2003 were based on the average of 2002 and 2003 population estimates from the U.S. Bureau of the Census