

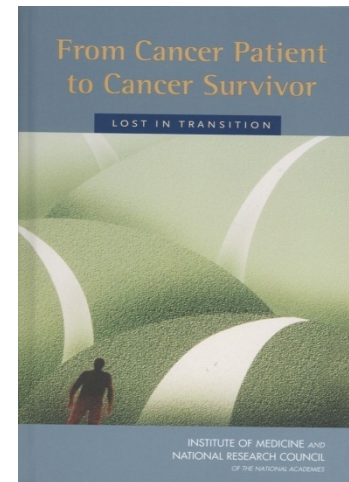
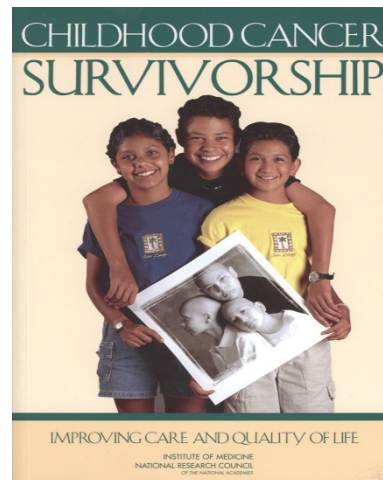
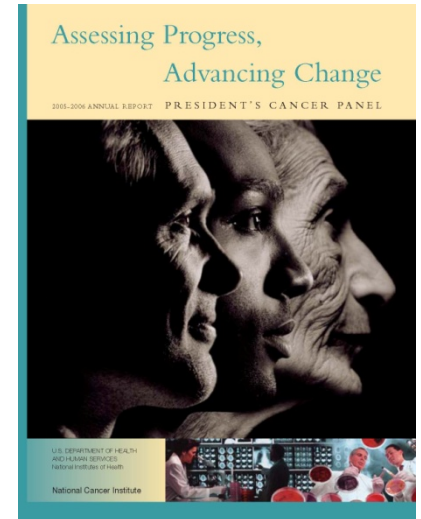
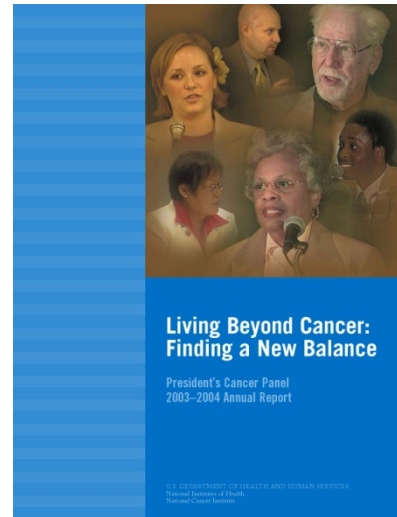
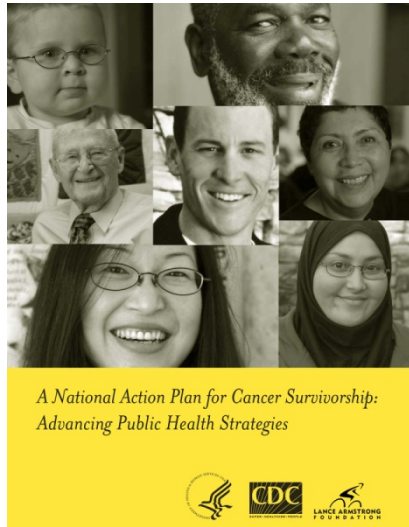


Cancer Survivorship: New Directions in Research and Care

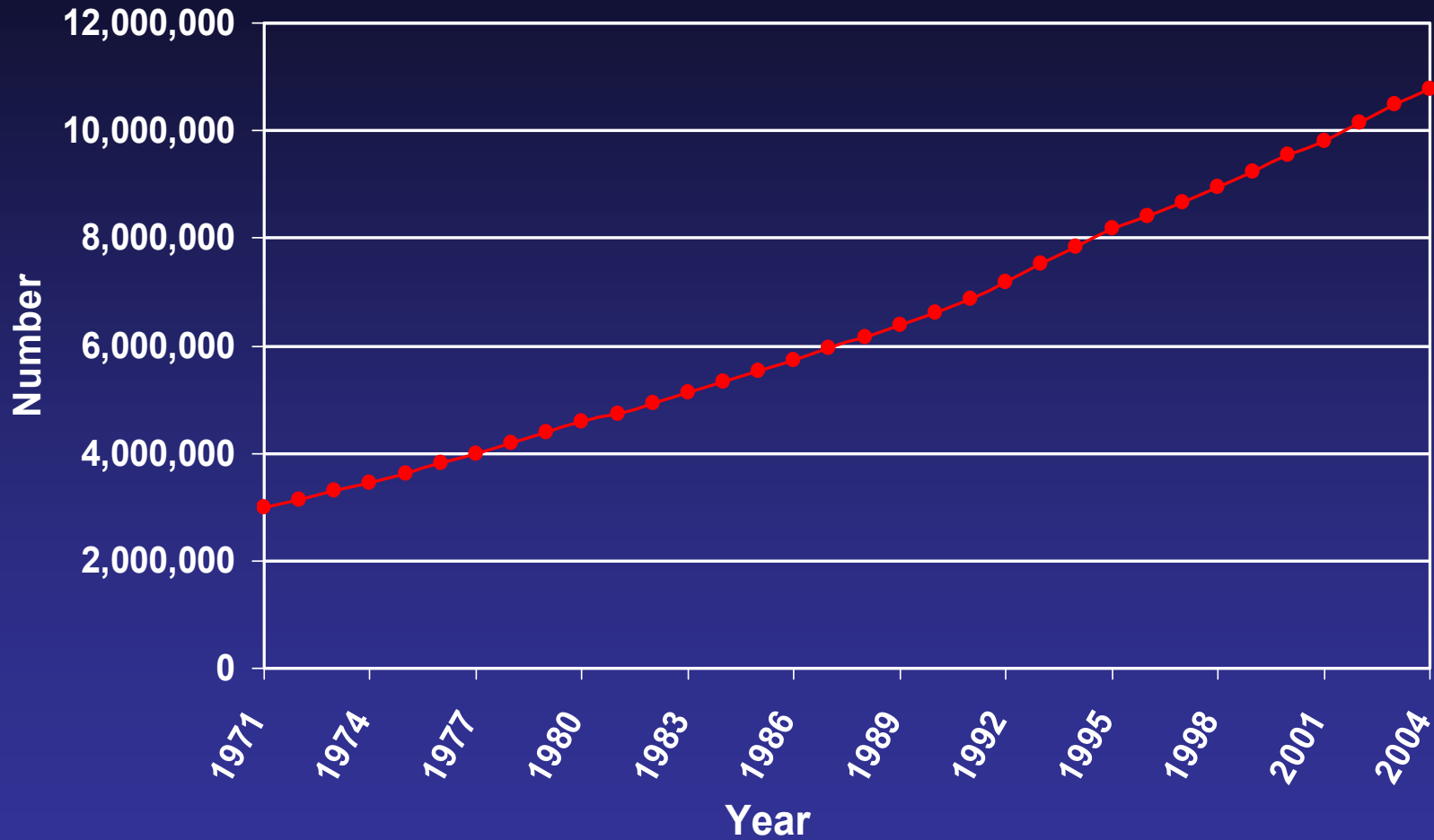
- **Office of Cancer Survivorship**
- **Julia H. Rowland, Ph.D., Director**
- National Cancer Institute • National Institutes of Health • DHHS



Major Reports on Survivorship



Estimated Number of Cancer Survivors in the United States from 1971 to 2004

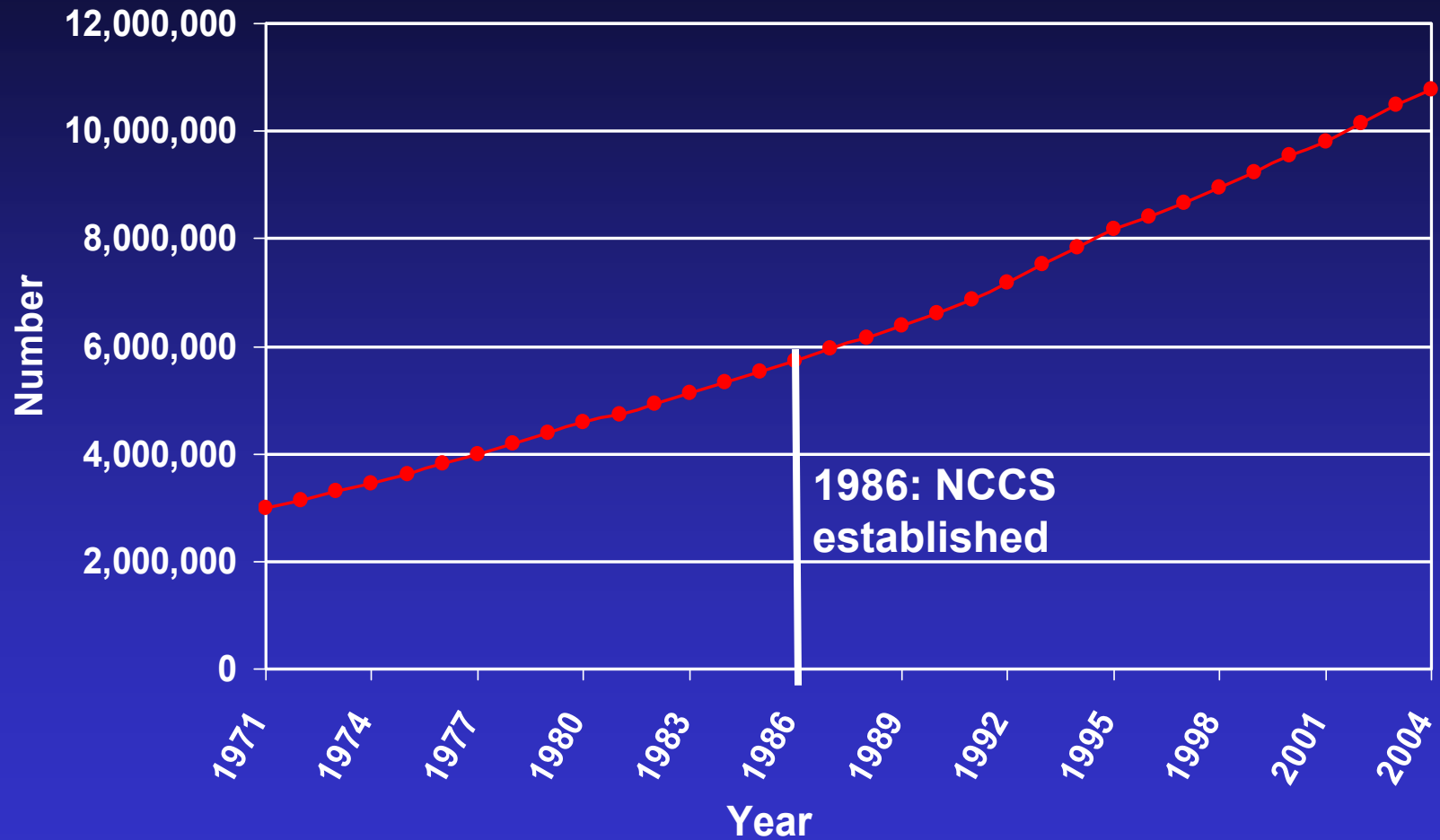


Data source: Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

What has contributed to this remarkable progress?

- Earlier detection
- New and more effective therapies, often including multimodal and multi-agent combinations
- More effective adjuvant and/or maintenance therapies
- Better supportive care
- Growing attention to long-term surveillance

Estimated Number of Cancer Survivors in the United States from 1971 to 2004



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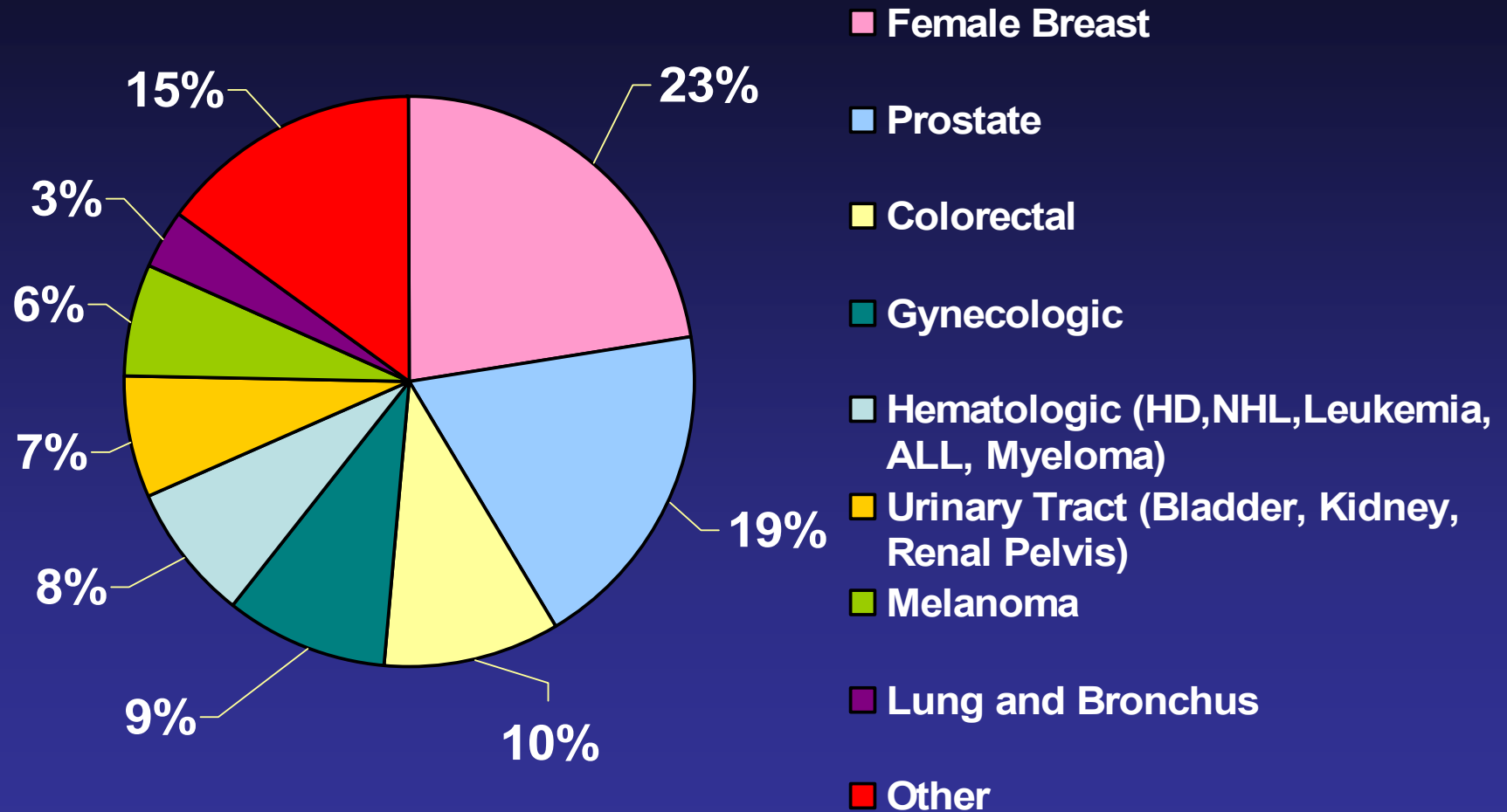
Definitional Issue: *Who is a Cancer Survivor?* **(NCCS)**

- ❖ **Philosophically, anyone who has been diagnosed with cancer is a survivor— from the time of diagnosis and for the balance of life**
- ❖ **Caregivers and family members are also cancer survivors**

Who Are Our Survivors?

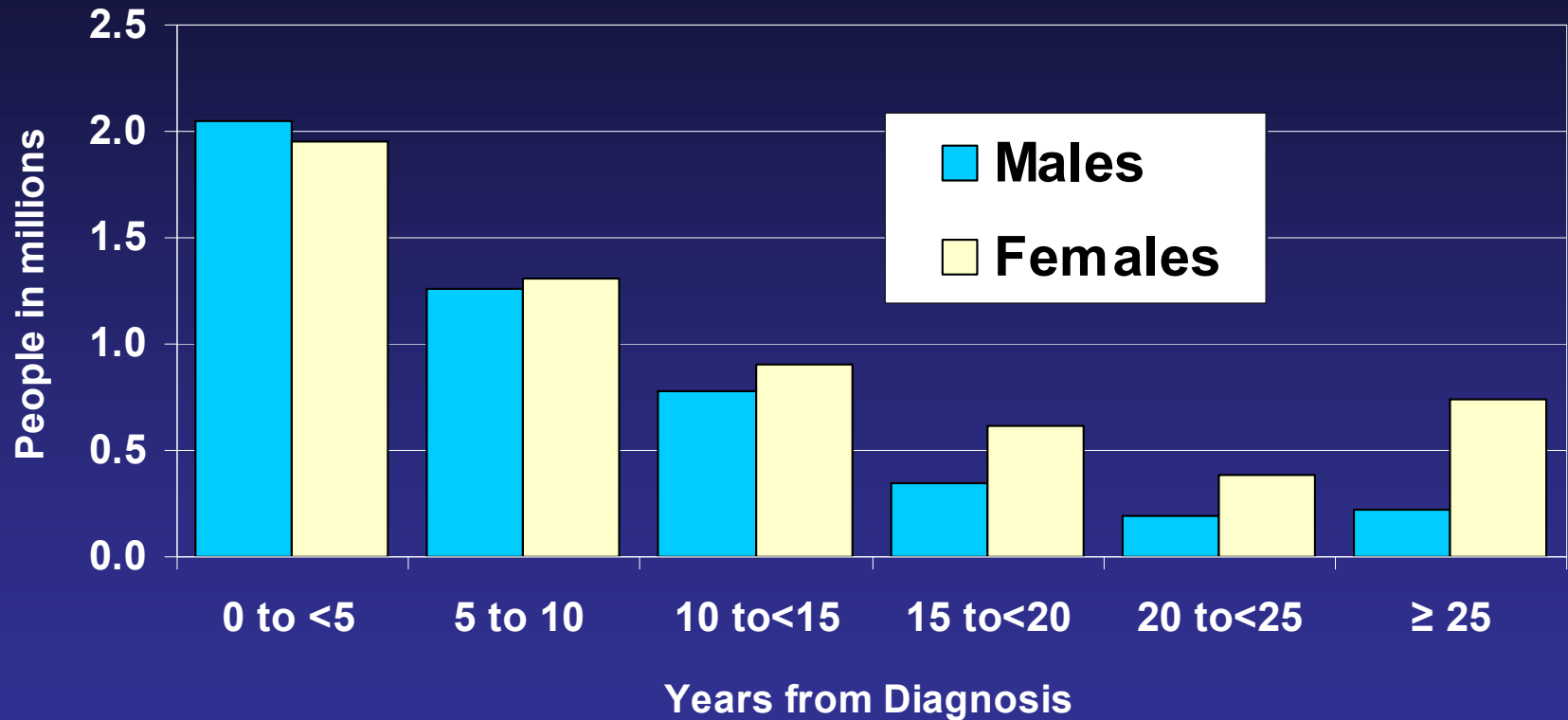


Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2004 by Site (N = 10.8 M)



Data source: Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

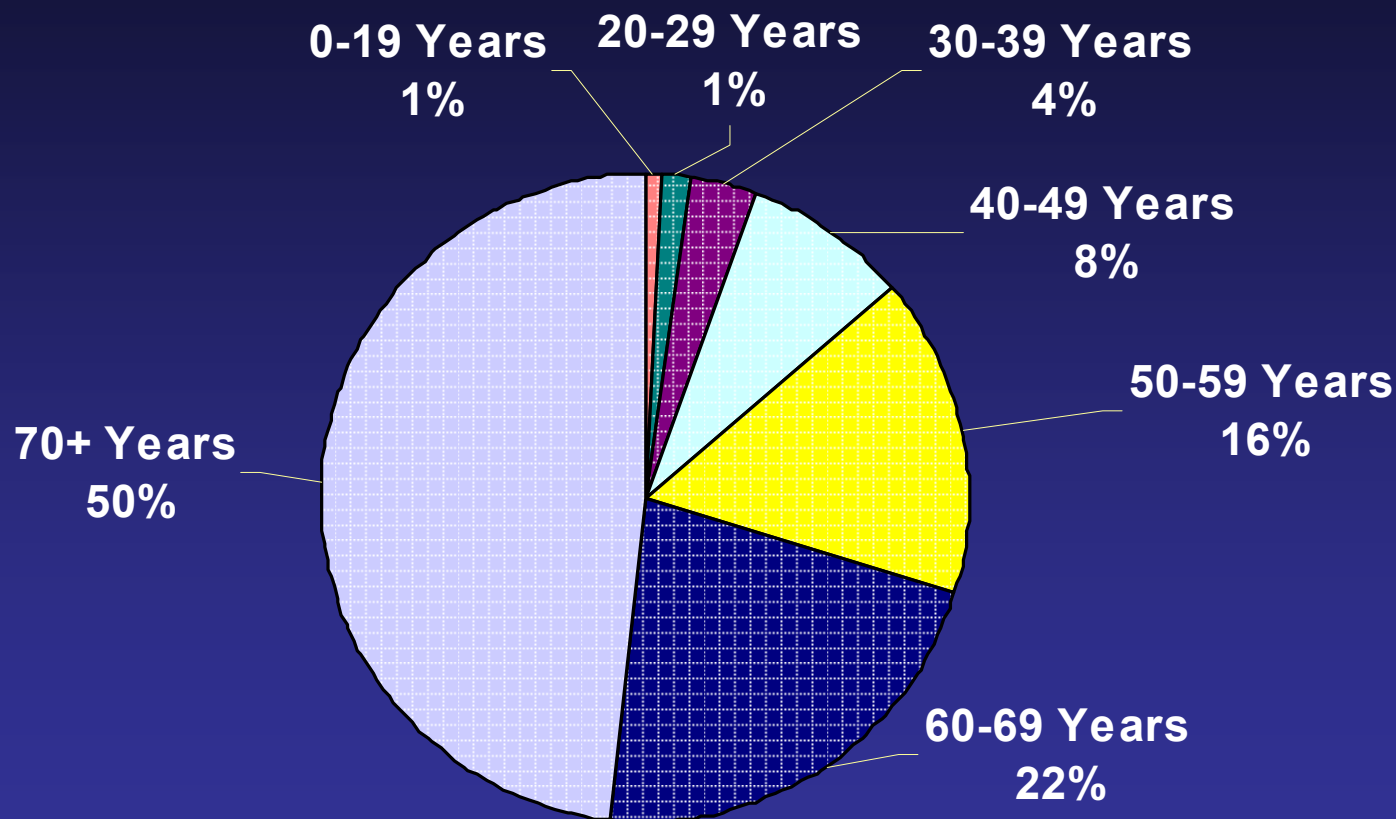
Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2004 by Time From Diagnosis and Gender (Invasive/1st Primary Cases Only, N = 10.8M survivors)



Data source: Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

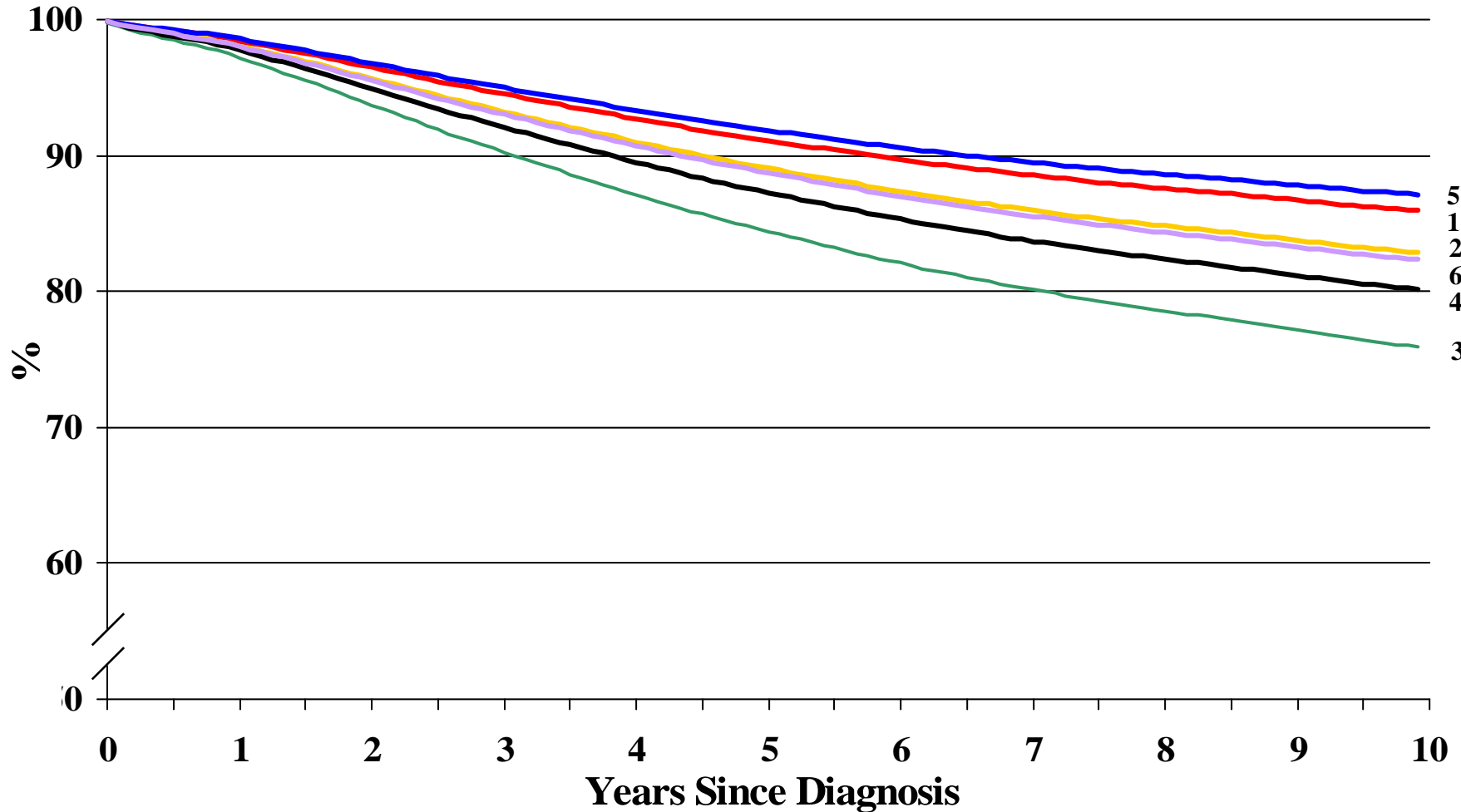
Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2004 by Current Age

(Invasive/1st Primary Cases Only, N=10.8M survivors)



Data source: Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

Female Breast Cancer Survival by Race/Ethnicity Adjusted by Age and Stage at Diagnosis SEER 1992 - 2000



The Changing Demography of Cancer Survivorship

- ❖ 66% of adults diagnosed with cancer today will be alive five years from now
- ❖ Among children, the 10 year relative survival rate is approaching 75%.
- ❖ Cancer for many has become a chronic illness
- ❖ Cancer is for most, a family illness
- ❖ Over 80% of all cancer patients are treated in the community



OCS Goals

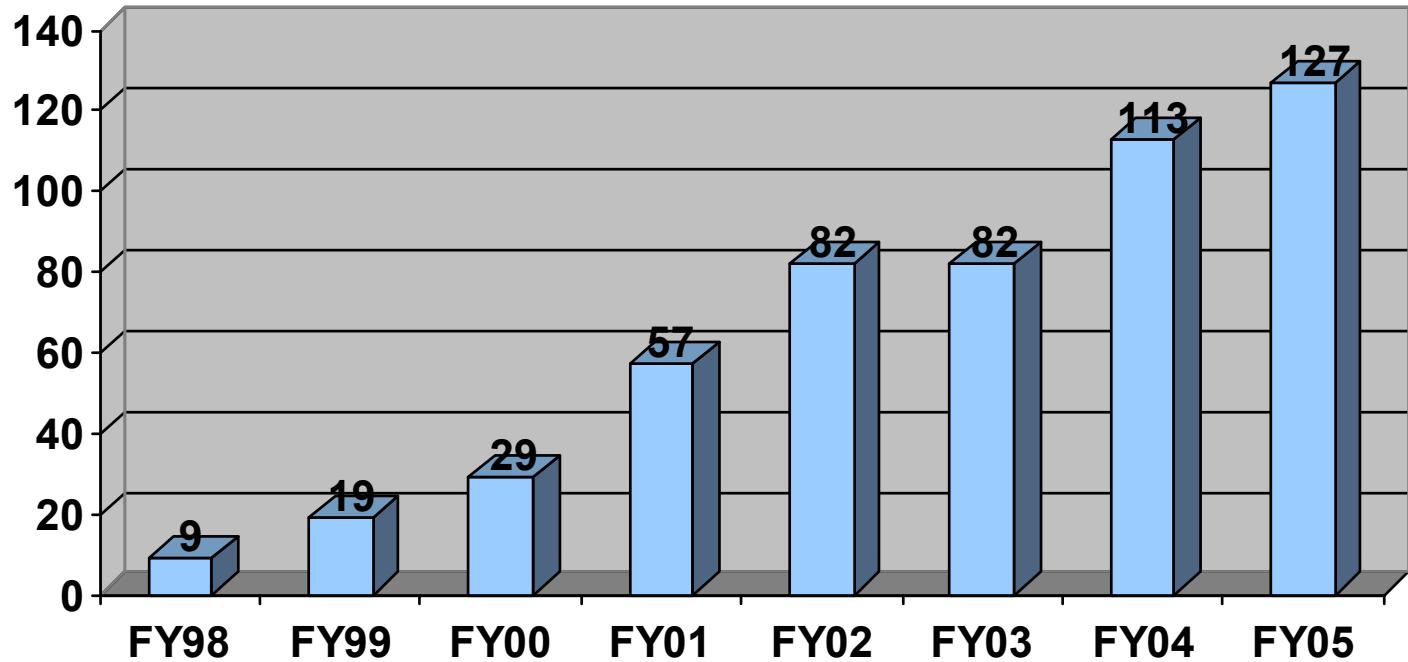
- ❖ The ultimate goal of the OCS is to enhance the length and quality of survival of all cancer survivors
- ❖ To provide a focus for the support of research that will lead to a clearer understanding of, and the ultimate prevention of, or reduction in, adverse physical, psychosocial, and economic outcomes associated with cancer and its treatment.
- ❖ To educate professionals who deal with cancer survivors about issues and practices critical to the optimal well-being of their patients. This educational commitment extends to cancer survivors and their families.

Definition: *What is Cancer Survivorship Research?*

Cancer Survivorship Research seeks to:

1. Identify, examine, prevent, and control adverse cancer- and treatment-related outcomes (such as pain, lymphedema, sexual dysfunction, second cancers, poor quality of life)
2. Provide a knowledge base regarding optimal follow-up care and surveillance of cancer survivors
3. Optimize health after cancer treatment

OCS Research Portfolio by Fiscal Year Total Grants



What is the Research Telling Us?



Lessons Learned From Clinical-Descriptive Research

- The majority of individuals successfully treated for cancer report adequate to good health-related quality of life following treatment — *Resilience!*
- *But...*
- Being disease free, does *NOT* mean you are free of your disease.
- Cancer can affect all aspects of a person's life.

Chronic and Late Effects of Cancer Treatment

- **Physical/Medical** (e.g., second cancers, cardiac dysfunction, pain, lymphedema, sexual impairment)
- **Psychological** (e.g., depression, anxiety, uncertainty, isolation, altered body image)
- **Social** (e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, return to school, financial burden)
- **Existential and Spiritual Issues** (e.g., sense of purpose or meaning, appreciation of life)

Second (third, fourth...) Malignancies

It is currently estimated that **756,467** people in the U.S. have been affected by more than one cancer diagnosis between 1975 and 2001; representing almost 8% of the current survivor population

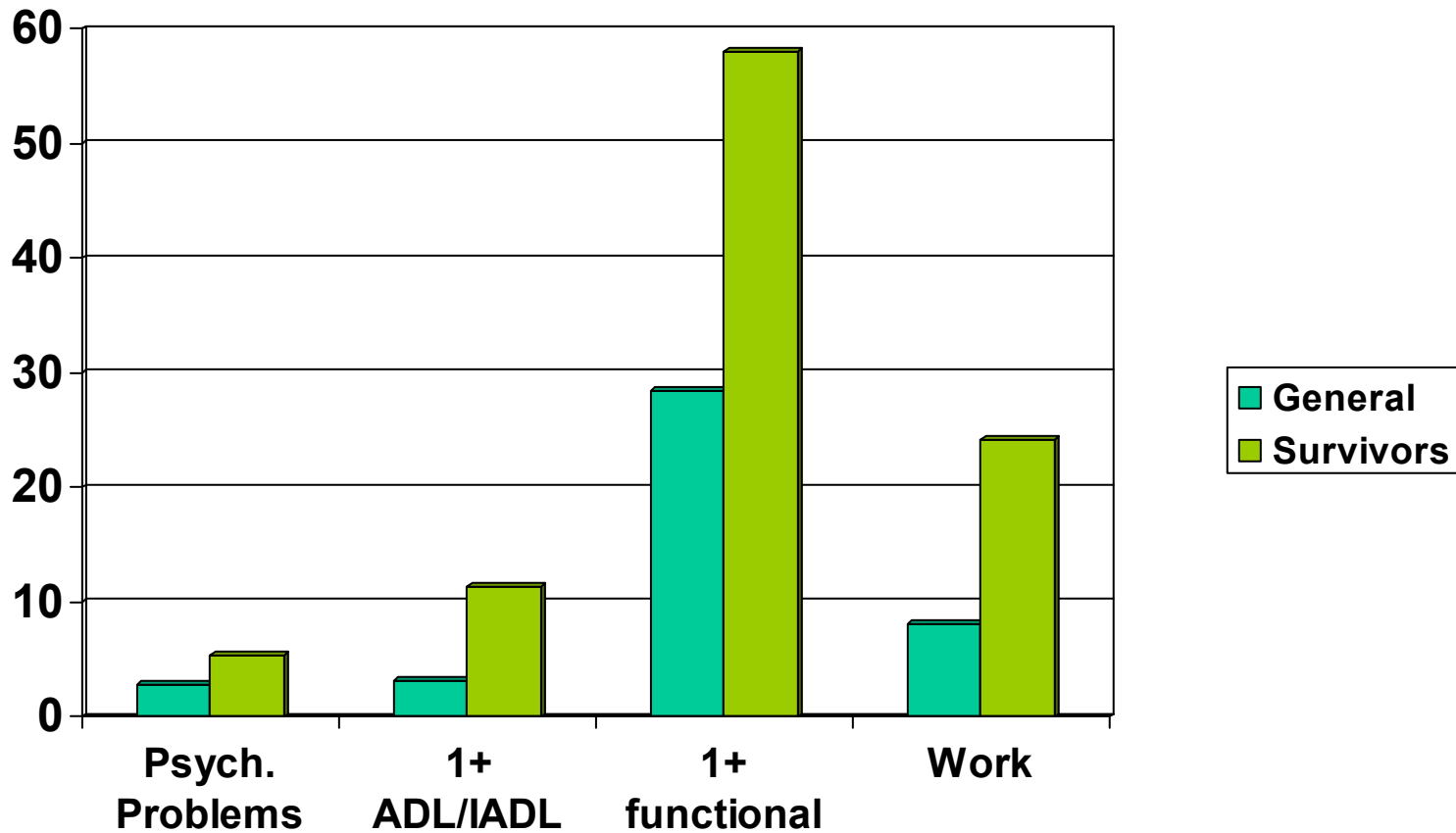
In 74% of cases these are cancers of a different site from the original diagnosis

Mariotto et al., *CEBP* 2007

Cancer Survivors at Increased Risk

- Disease recurrence/ new cancers
- Cardiovascular disease
- Obesity/Diabetes
- Osteoporosis
- Functional decline
- Poor quality of life

% with Limitations: Survivors vs. General Population



What are Survivors *Also* Telling Us?

- ❖ They want to know how to reduce the morbidity and mortality associated with their illness.
- ❖ They are also worried about the health of their family members.
- ❖ They want to work with their healthcare providers to address these issues, but are frustrated that these individuals often have little to offer them in this regard.
- ❖ The diagnosis of cancer may for many present a 'teachable' moment.

Potential Role of Lifestyle Modification

Source: Demark-Wahnefried

	Diet	Exercise	Smoking Cessation
<i>Depression</i>	✓	✓✓	
<i>Fatigue</i>	✓	✓✓	
<i>Adverse Body Composition</i>	✓	✓✓✓	✓
<i>Functional Decline</i>	✓	✓✓✓	✓✓
<i>Comorbidity</i>	✓✓✓	✓✓✓	✓✓✓

✓ Possible benefit ✓✓ Probable benefit ✓✓✓ Convincing benefit

What Does the Future Hold?



Priority Areas for *Cancer Survivorship Research -1*

Exploration of . . .

- “emerging” long-term and late effects (e.g., “chemo-brain”, neuropathies, CHF) – and interventions to prevent/ameliorate these
- the role of psychosocial/behavioral interventions in promoting health and adaptation

Priority Areas for *Cancer Survivorship Research - 2*

Exploration of . . .

- Impact of survivorship on the family/caregiver
- Economic outcomes; patterns/models of care (quality and cost of post-treatment care)
- Cancer communication
- Instrument development
- Aging and cancer interface
- Assessing outcomes in neglected groups (diverse peoples and cancer sites)

Future Directions in *Intervention Research -1*

- ❖ Screening for those at risk
- ❖ Targeting and tailoring interventions
- ❖ Appreciating the role of 'education' in all of these approaches
- ❖ Revisiting peer support

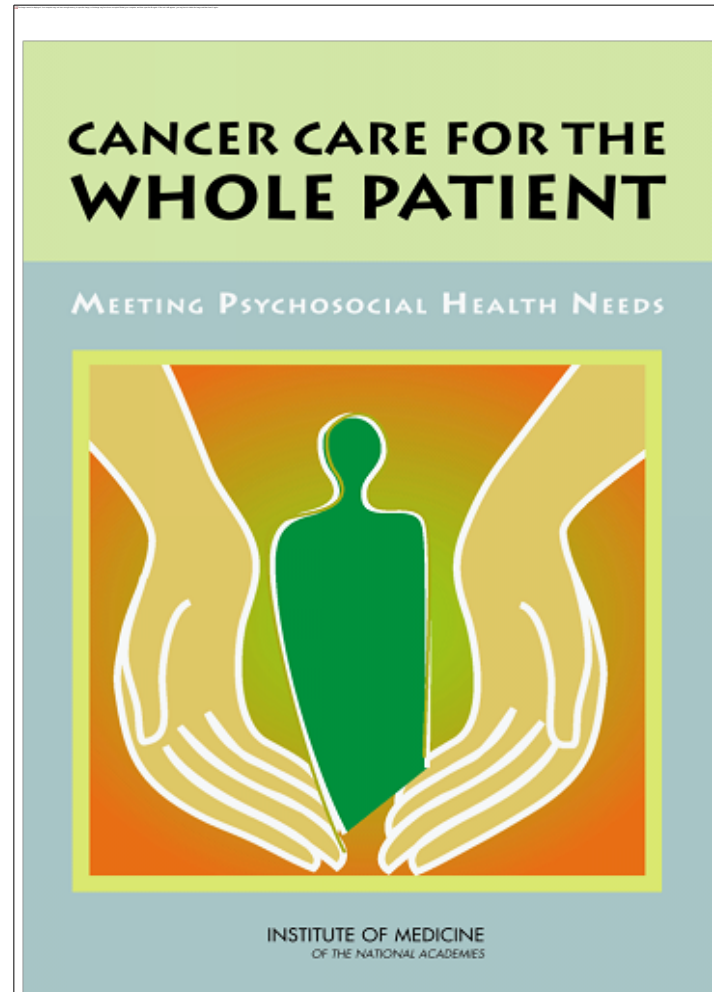
Future Directions in *Intervention Research -2*

- ❖ Exploring new technologies to collect data and deliver interventions (e.g., internet, PDAs)
- ❖ Evaluating the impact of interventions on health care utilization and costs and on medical outcomes (biological/physical)
- ❖ Developing new conceptual models as needed

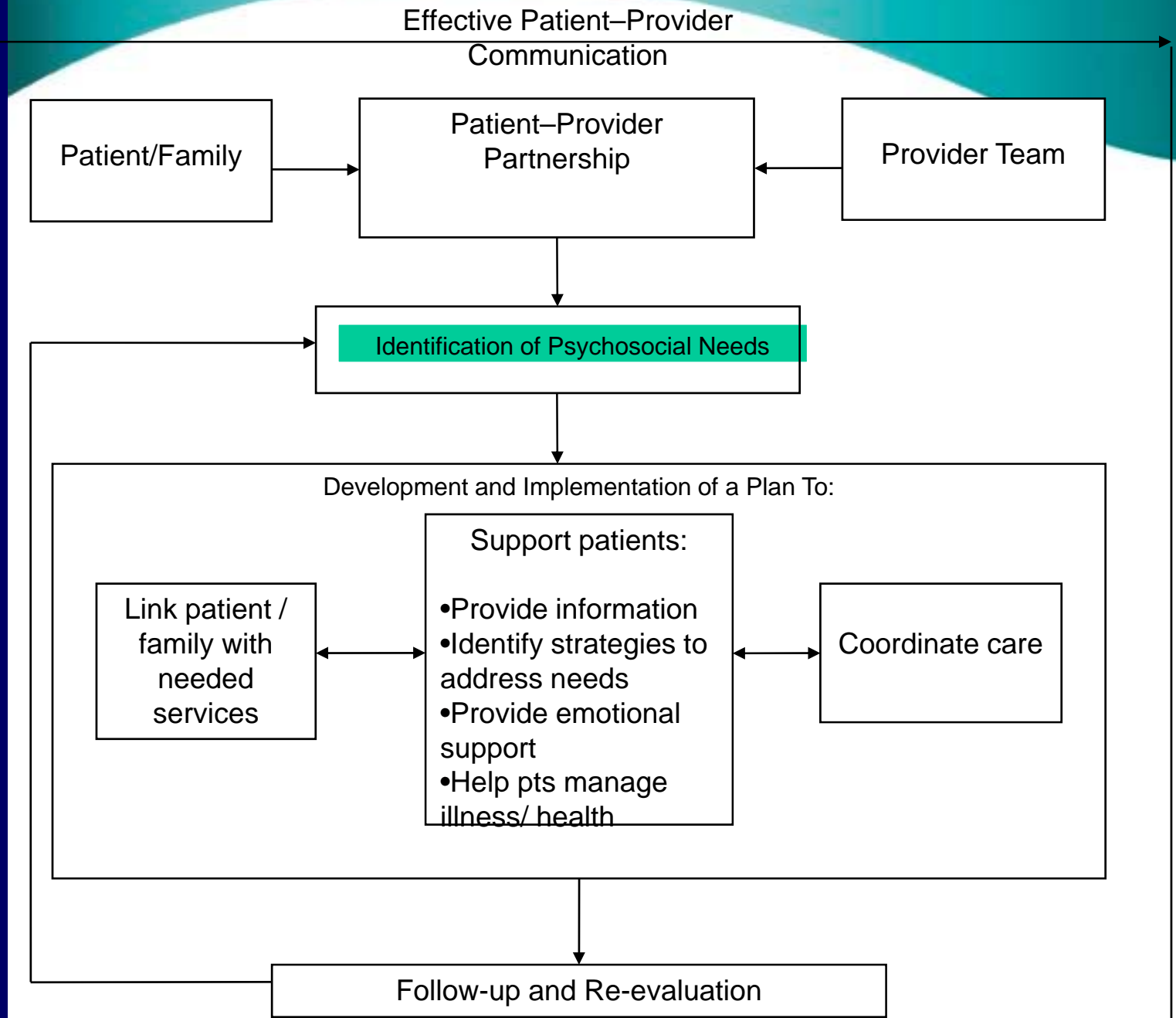
Selected Recommendations from the President's Cancer Panel

- Survivors should be counseled about the psychosocial effects of cancer and its treatment and referred to appropriate resources/services to address these.
- Fertility counseling should be provided to those of childbearing age.
- Support and guidance should also be given to family members and caregivers.

Addressing psychosocial needs
should be an integral part of
quality cancer care.



Model for the delivery of psychosocial health services.



National Cancer Institute

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PATIENT-CENTERED COMMUNICATION IN CANCER CARE

Promoting Healing and
Reducing Suffering

U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES
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of Health

Selected Recommendations from the President's Cancer Panel & IOM Reports

- When treatment ends, all survivors should receive a summary record that includes important disease characteristics and treatments received.
- In addition, they should be provided with a follow-up care plan incorporating available evidence-based standards of care.

Treatment Summary

- ❖ Type of cancer (dates of diagnosis and treatment, stage, tumor characteristics)
- ❖ Type(s) of treatment received
 - Surgery (nature, extent)
 - Chemotherapy (drugs, dose, delivery)
 - Radiation (dose, port, fractionation & schedule)
- ❖ Complications experienced (side effects, transfusions, recurrence/additional treatments, etc)
- ❖ Services used

Follow-up Care Plan

- ❖ Schedule of visits
- ❖ Provider(s) to deliver these
- ❖ Tests that may be needed (surveillance and prevention)
- ❖ Assessment and treatment/referral for side effects (e.g., lymphedema, menopausal symptoms, depression)
- ❖ Evaluation of health behaviors & promotion of healthy lifestyle

Adult Cancer Survivor Follow-Up Care Programs in the U.S.

- ❖ Relatively new effort (est. since 2000)
- ❖ Currently there are 13 such programs; 7 funded by Lance Armstrong Foundation
- ❖ All are affiliated with comprehensive cancer centers
- ❖ Models of care, staffing, services provided and patients/survivors seen vary widely
- ❖ Aware of need to evaluate both the value and effectiveness of services they are providing to ensure their sustainability and advance science of survivorship

Common Components of Care

- ❖ Surveillance for cancer spread or recurrence
- ❖ Prevention and detection of new cancers
- ❖ Screening and intervention for consequences of cancer (physical, psychological, social- including impact on school/work/economic status, partner & family relationships)
- ❖ Health promotion

What are the Implications for Survivors' Care?



Implications for Future Directions in *Clinical Care -1*

(or, what I learned in Pediatric Oncology)

- Pay attention to developmental/life-span issues
- Emphasize good communication in treatment decision-making and care
- Monitor and promote well-being across the survivorship trajectory
- Address the needs of family/caregivers

Implications for Future Directions in *Clinical Care -2*

- ❑ Developing guidelines for long-term follow-up (evaluating late toxicities)
- ❑ Leveraging models and delivery systems used for care in the setting of chronic illness (especially telemedicine & self-management; professional, non-profit organizations, peer counseling,)
- ❑ *Listening to survivors!*

Changing the Culture of Research and Care



The PATIENT is as important as the TUMOR

Challenges for the Future

- ❖ Keeping up with our expanding population of cancer survivors
- ❖ Identifying emerging survivorship issues and interventions to address these
- ❖ Delivering everything we know about survivorship care to all segments of our society
- ❖ Leveraging new technologies and delivery models to reach those in need of information and support
- ❖ Training the next generation of survivorship researchers and care providers

- ❖ *Doing all of the above without overwhelming the health care system physically or financially!*

Another Key Challenge for the Future...

❖ Identifying the Metrics to Measure our Success!

Specifically: How do we show that our investment in cancer survivorship research and programs is making a difference in peoples' lives, or the national burden of cancer?

Opportunities

- ❖ Growing attention to survivors' long-term well-being and follow-up care (as reflected in recent reports IOM, PCP, LAF/CDC)
- ❖ Commitment of growing numbers of researchers and clinicians to this area of cancer control science and practice
- ❖ Articulate and effective advocacy community!

Cancer Survivorship Research: *Mapping the New Challenges*

Save the Date

June 18-20, 2008
Grand Hyatt
Atlanta, GA



Watch for more details.
Conference Email: survivorship.conference@cancer.org

This conference is co-sponsored by the American Cancer Society's Behavioral Research Center, the National Cancer Institute's Office of Cancer Survivorship, and the Lance Armstrong Foundation.





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Cancer Survivorship Research

Cancer Control and Population Sciences

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Need Help?

Contact us by phone, Web, and e-mail
1-800-4-CANCER

Third Biennial Cancer Survivorship Research Conference
October 4-6, 2006



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What's New

[SAVE THE DATE: Cancer Survivorship Research: Embracing the Future - October 4-6, 2006, Bethesda, Maryland.](#)

Shortcuts

- [Video: The Excitement of Cancer Control Research, 2004-2005](#)
- [Funding Opportunities](#)
- [Active Research Portfolio](#)
- [Prevalence Figures](#)

New Reports

- [The President's Cancer Panel: Assessing Progress, Advancing Change - 2005-2006 Annual Report](#)
- [From Cancer Patient to Cancer Survivor: Lost in Transition - Institute of Medicine Report](#)