Estimated and projected number of cancer survivors in the United States from 1977-2022 by years since diagnosis
Source: de Moor et al, *CEBP*, in press March 2013
Women Alive Diagnosed with Breast Cancer by Current Age (US counts on January 1, 2008) (Invasive/1st Primary Cases Only, N = 2.6 Million Survivors)

Women Alive Diagnosed with Breast Cancer by Time Since Diagnosis (US counts on January 1, 2008) (Invasive/1st Primary Cases Only, N = 2.6 Million Survivors)

**Chronic Effects of Cancer Treatment**

- **Physical/Medical** (e.g., pain, fatigue, memory problems, lymphedema, sexual impairment, amputations)

- **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)
Cancer Survivors at Increased Risk for *Late* Effects

- Disease recurrence/new cancers
- Cardiovascular disease
- Obesity/Diabetes
- Osteoporosis
- Functional decline
- Poor quality of life
History of a movement...
• 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.
1. Diagnostic tests performed and results
2. Tumor characteristics (e.g., site, stage and grade, hormone receptor status, and marker information)
3. Dates of treatment initiation and completion
4. Surgery, chemotherapy, radiotherapy, transplantation, hormonal therapy, gene, or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any) indicators of treatment response, and toxicities experienced during treatment
Treatment Summary (per IOM) - 2

5. *Psychosocial, nutritional and other supportive services provided*

6. Full contact information on treating institutions and key individual providers

7. Identification of a key point of contact and coordinator of continuing care
Follow-up Care Plan (per IOM) - 1

1. The likely course of recovery from treatment toxicities, as well as the need for ongoing health maintenance/adjuvant therapy

2. A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed (and who should provide them)

3. Information on possible late effects and long-term effects of treatment and symptoms of such effects
Follow-up Care Plan (per IOM) - 2

4. Information on possible signs of recurrence and second tumors

5. Information on the possible effects of cancer on marital/partner relationship, sexual functioning, work, and parenting, and the potential future need for psychosocial support

6. Information on the potential insurance, employment, and financial consequences of cancer and, as necessary, referral to counseling, legal aid, and financial assistance
Follow-up Care Plan (per IOM) - 3

7. Specific recommendations for healthy behaviors (e.g., diet, exercise, healthy weight, sunscreen use, immunizations, smoking cessation, and osteoporosis prevention). When appropriate, recommendations that first-degree relatives be informed about their increased risk and the need for cancer screening (e.g., breast cancer, colorectal cancer, and prostate cancer).

8. As appropriate, information on genetic counseling and testing to identify high-risk individuals who could benefit from more comprehensive cancer surveillance, chemoprevention, or risk-reducing surgery.
9. As appropriate, information on known effective chemoprevention strategies for secondary prevention (e.g., tamoxifen in women at high risk for breast cancer)

10. Referrals for specific followup care providers (e.g., rehabilitation, fertility, or psychology), support groups, and/or the patients’ primary care provider

11. A listing of cancer-related resources and information (e.g., internet-based sources and telephone listings for major cancer support organizations)
Follow-up Care Plan (per IOM) 
Main Domains to Cover:

1. Surveillance for recurrence or new cancer
2. Assessment and treatment or referral for persistent effects (e.g., pain, fatigue, sexual dysfunction, functional impairment, depression, employment issues)
3. Evaluation of risk for and prevention of late effects (e.g., second cancers, cardiac problems, osteoporosis); health promotion
4. Coordination of care (e.g., including frequency of visits, tests and who is performing these)
What are the standards for survivorship care planning today?
ASCO (American Society of Clinical Oncology) Quality Oncology Practice Initiative (QOPI) Indicators

FU Care (2008):
- Was a treatment summary generated?
- Was a copy given to the patient?
- Was a copy given/sent to the provider(s)?
Standard 3.3:

1) A survivorship care plan is prepared by the principal provider who cared for the patient with input from the patient’s other care providers

2) The survivorship care plan is given to the patient on completion of treatment
CoC Standards: 2015

3) The written or electronic survivorship care plan contains a record of care received, important disease characteristics, and a follow-up care plan incorporating available and recognized evidence based standards of care, when available. *Minimum care plan standards should reflect those from the IOM Fact Sheet: Cancer Survivorship Care Planning.*
State of the “art” of SCP

• Of survivors diagnosed in the past 4 years, 58% stated they received some form of written instructions

• Despite the favorable view of these by providers and survivors
• Fewer than half (43%) of NCI designated centers deliver SCPs to breast and colorectal survivors
• Of those that do, NONE include all of the IOM recommended elements
Survivorship care planning

• Who should do this?
• When and where is this done?
• Are there evidence-based algorithms for care?
• What impact does this care planning have on: patients, providers, systems, burden of cancer

• **Who should provide what care to whom?** (Oncologists, PCP, CNP); role of medical homes?
Current Templates

❖ ASCO:

❖ Journey Forward:
  ❖ http://journeyforward.org

❖ LiveSTRONG:
  ❖ http://www.livestrongcareplan.org/
In spite of the uncertainties, there can still be good quality of life after cancer!