

DCCPS Research Resources for Studying Cancer Care in the Community Setting

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Purpose of This Overview



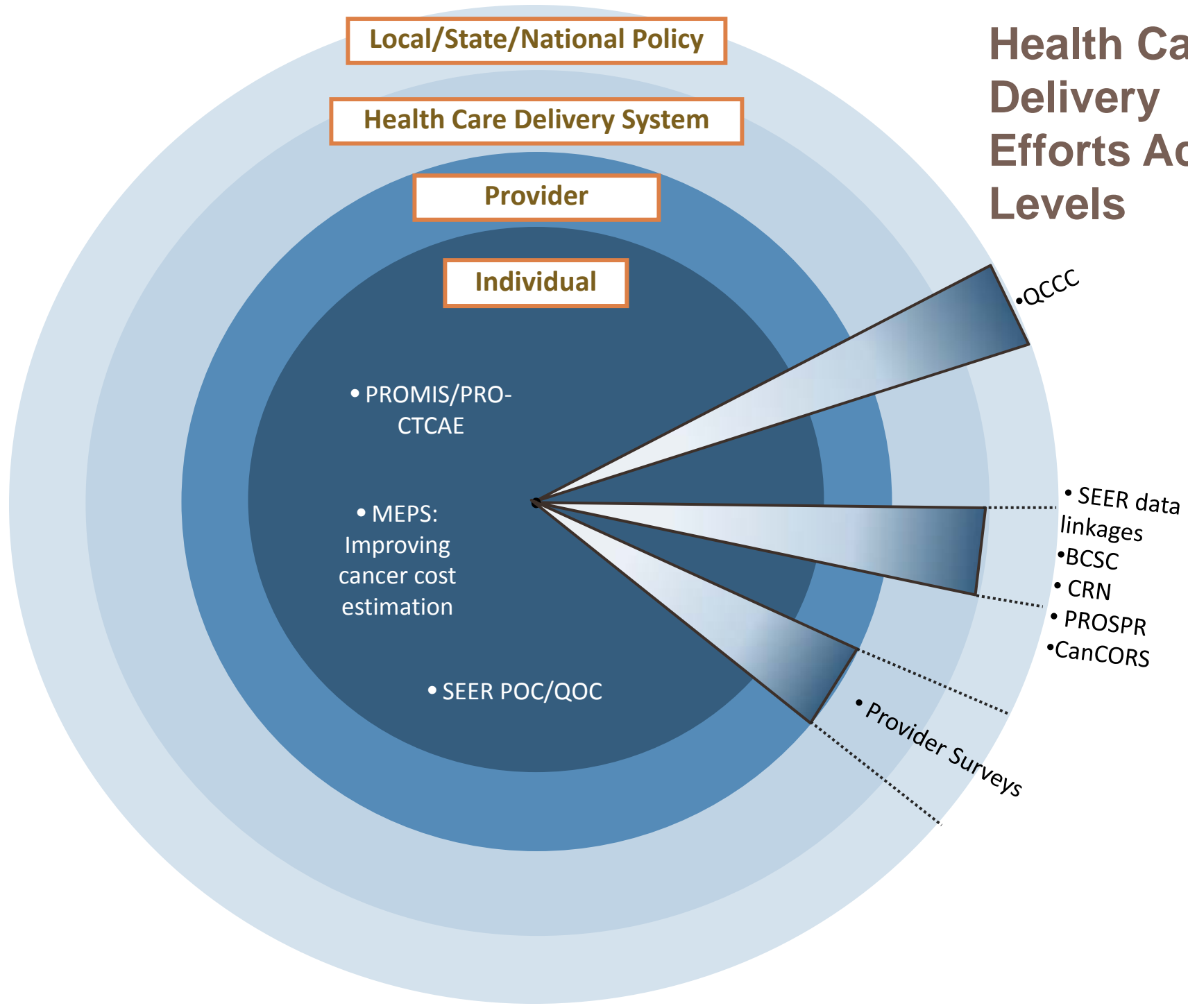
- Provide a sense of DCCPS efforts to develop multi-level and linked surveillance and research systems to evaluate cancer care delivery in the community setting
- Clarify the types of research issues that can be examined within these initiatives
- Describe how these initiatives interface with and are used by investigators within cancer centers, cooperative groups and other NCI initiatives
- Discuss how NCORP cancer care delivery research (CCDR) component will be distinctive from these other efforts

ARP's Mission



- Evaluate patterns and trends in cancer-associated health behaviors, practices, genetic susceptibilities, health services, economics, and outcomes, including patient centered outcomes.
- Monitor and evaluate these factors among the general population and specific populations in the U.S.
- Determine their influence on patterns and trends in cancer incidence, morbidity, mortality, survival, cost, and patient-reported outcomes.

Health Care Delivery Efforts Across Levels



Surveillance / Research Databases

- **Patterns of Care / Quality of Care Studies (SEER POC/QOC)**

<http://healthservices.cancer.gov/surveys/poc>

- Conducts augmented data collection from SEER cancer registries
- Documents national trends of initial cancer treatment

- **SEER-Medicare**

<http://healthservices.cancer.gov/seermedicare>

- Provides national data on longitudinal healthcare utilization, cost and outcomes, using Medicare data linked to SEER cancer registry data
- Allows linkage of data on patients to data on providers, hospitals, and area health care resources

- **SEER-Medicare Health Outcomes Survey (MHOS)**

<http://outcomes.cancer.gov/surveys/seer-mhos>

- Provides longitudinal national data on patient-reported outcomes, including data on health-related quality of life , functional status, smoking, and chronic conditions linked with cancer registry data

Patterns of Care / Quality of Care



- Common cancer sites routinely sampled
 - Early stage breast
 - CRC
 - Lung
- Other cancer sites sampled based on
 - New therapies/agents
 - Off-label use of agents
 - New biomarkers
 - Changes in guidelines
 - Suspected disparities in cancer
 - Previously collected/new collection

Age, Lack of Insurance, and Physician Specialty Effect Clinical Trial Enrollment for AYA Patients

	OR	95% CI
Age		
15-19	<i>Ref</i>	
20-24	0.56	0.29-1.07
25-29	0.28	0.10-0.73
30-34	0.43	0.19-0.96
35-39	0.32	0.15-0.69
Insurance		
Private	<i>Ref</i>	
HMO	0.69	0.39-1.23
Any Medicaid	0.77	0.36-1.64
Other	1.10	0.32-3.77
None	0.25	0.08-0.76
Unknown	0.12	0,01-1.66
Physician Specialty		
Hem/Onc only	<i>Ref</i>	
Ped Onc only	7.39	2.49-21.93
Ped Onc and other	3.69	1.63-8.36
Hem/Onc and other	1.01	0.53-1.94
Other/Unknown	0.47	0.14-1.59

- N=1,358 AYA patients with cancer (15-39 years)

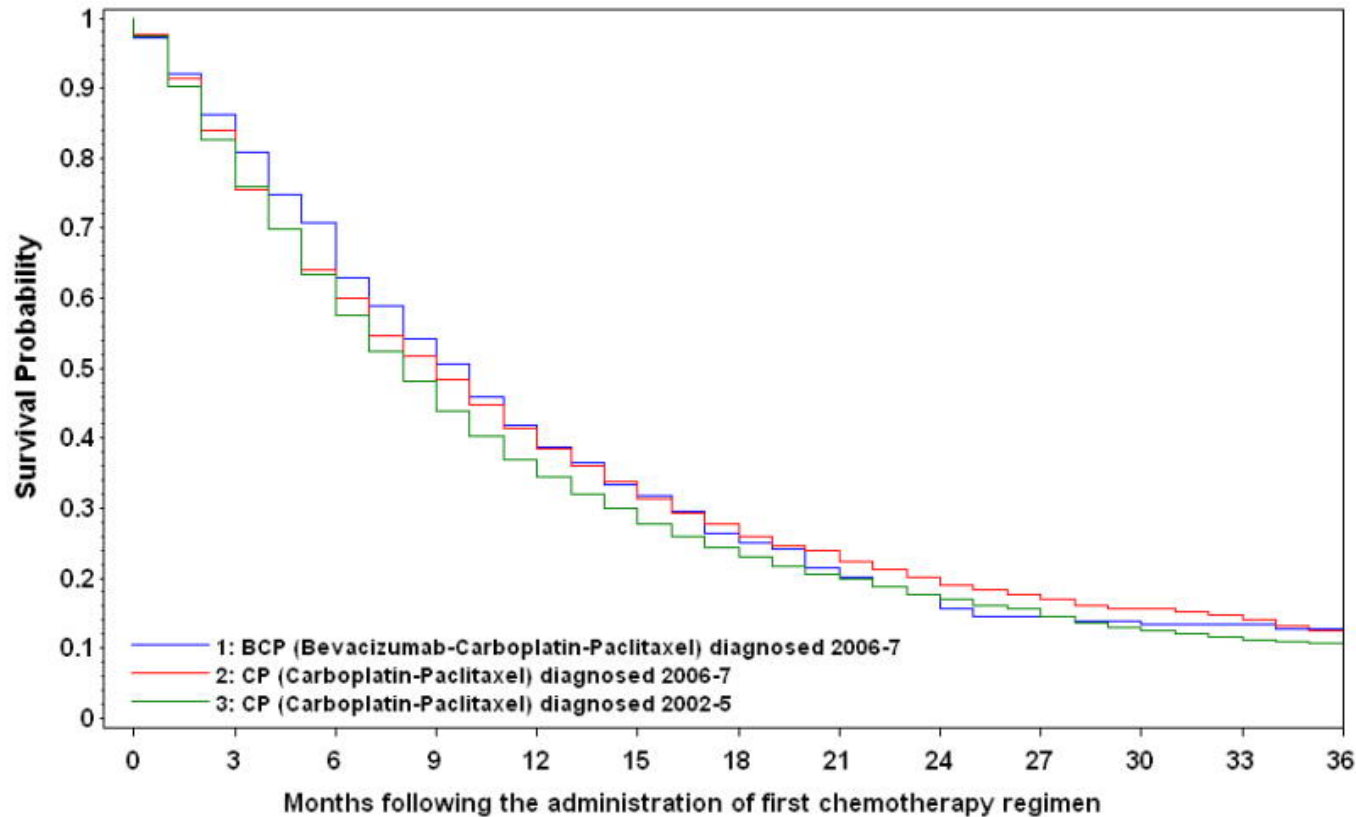
- 14% of AYA patients enrolled in clinical trial

SEER- Medicare



- SEER registries collect detailed data about date of diagnosis, clinical, demographic and cause of death information for persons with cancer
- Medicare data are longitudinal, with claims for all covered health services from the time of eligibility to death
 - Includes hospital, physician, outpatient, SNF, home health, and hospice services
- Over 750 articles utilizing SEER-Medicare database have been published in peer reviewed journals
- Three SEER-Medicare analyses published in April 2012 JAMA special issue on comparative effectiveness research

No Survival Advantage Observed by Adding Bevacizumab to Treatment



- N=4000 older adults diagnosed with non-small cell lung cancer between 2002-2007

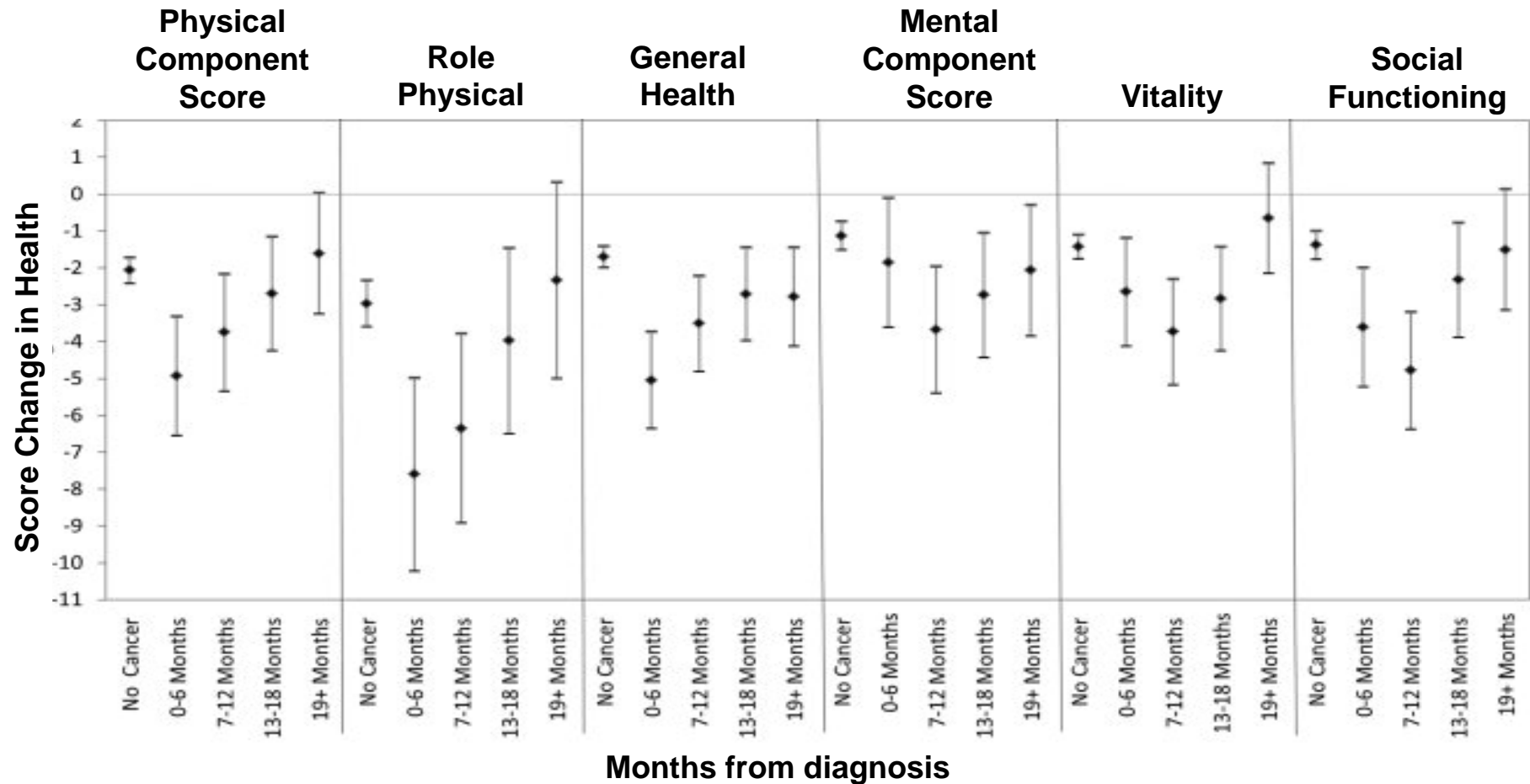
Kaplan-Meier Survival Curves for Medicare Beneficiaries Diagnosed with Advanced Non-Squamous Non-Small-Cell Lung Cancer, by Year of Diagnosis and First-Line Chemotherapy Administration with or without Bevacizumab

SEER-Medicare Health Outcomes Survey (SEER-MHOS)



- Provides longitudinal national data on patient-reported outcomes, including data on health-related quality of life , functional status, smoking, and chronic conditions linked with cancer registry data.
- Allows comparison between individuals with cancer and non-cancer controls
- SEER-MHOS Public Research Resource launched in 2011 to make these data accessible to researchers
- 12 SEER-MHOS data sets requested to date and 10 peer reviewed publications

Changes in Health-Related Quality of Life for Men with and without Prostate Cancer



N= 445 Medicare beneficiaries w/ prostate cancer diagnosis from 1998-2003; N=2225 controls
 Reeve et al. Cancer 2012 pg 5679-5687

MEPS Cancer Survivorship Survey

- Goal: address data gaps and improve research resources for estimating cancer burden, including financial burden
 - <65 population, privately insured, uninsured
 - Out-of-pocket expenditures including insurance premiums
 - Employment and productivity loss in cancer survivors and caregivers
- Survey completed by 1603 cancer survivors (90% response rate among MEPS participants)
- Items related to:
 - Access to cancer care
 - Changes in work because of cancer
 - Changes in caregiver work because of cancer
 - Financial burden
 - Medical debt/bankruptcy
 - Limitations in activities because of cancer
- Data available in 2013

Research Networks

- Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)

<http://healthservices.cancer.gov/cancors>

- Collaboration of 8 diverse research teams; enrolls 10,000 newly diagnosed patients with data from patients, surrogates, family caregivers, doctors, facilities, and claims
- Examines care delivered to patients with lung and colorectal cancer

- Cancer Research Network (CRN)

<http://crn.cancer.gov>

- Consortium of researchers affiliated with 10 community-based HMOs, covering 10 million people, 4% of US and 14% of all HMO patients
- Examines prevention, early detection, treatment, long-term care, & survivorship

Research Networks

- Breast Cancer Surveillance Consortium (BCSC) Research Resource

<http://breastscreening.cancer.gov>

- Network of 5 mammography registries with links to pathology and/or tumor registries, covering over 2 million women with 6.7 million mammograms and over 64,000 cases of breast cancer (linkage with Medicare data claims)
- Evaluates performance of screening mammography in the community

- Population-based Research Optimizing Screening through Personalized Regimens (PROSPR)

<http://appliedresearch.cancer.gov/networks/prospr>

- Supports research to better understand how to improve screening process (recruitment, screening, diagnosis, referral for treatment) for breast, colon, cervical cancer – planning to add lung as well
- Network of 7 research centers and SCC

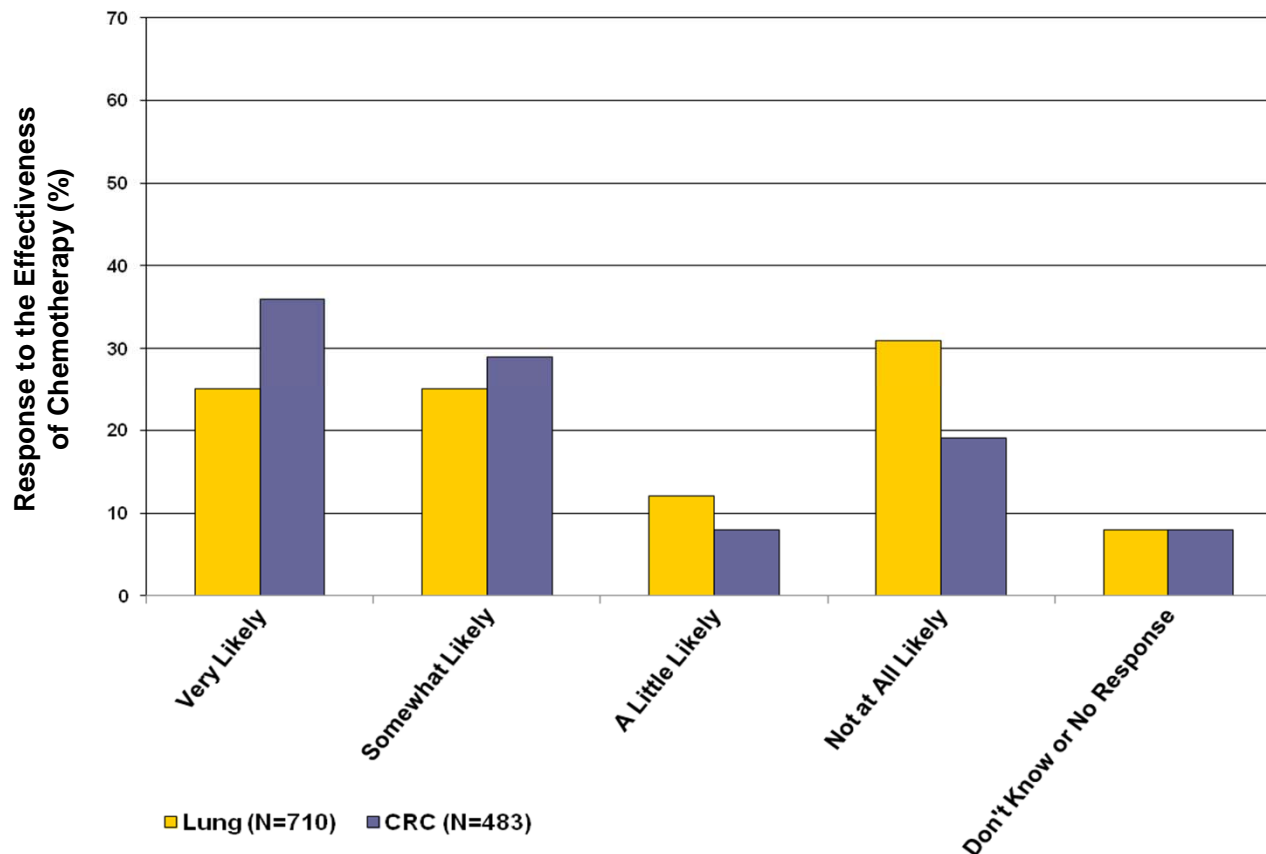
Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)



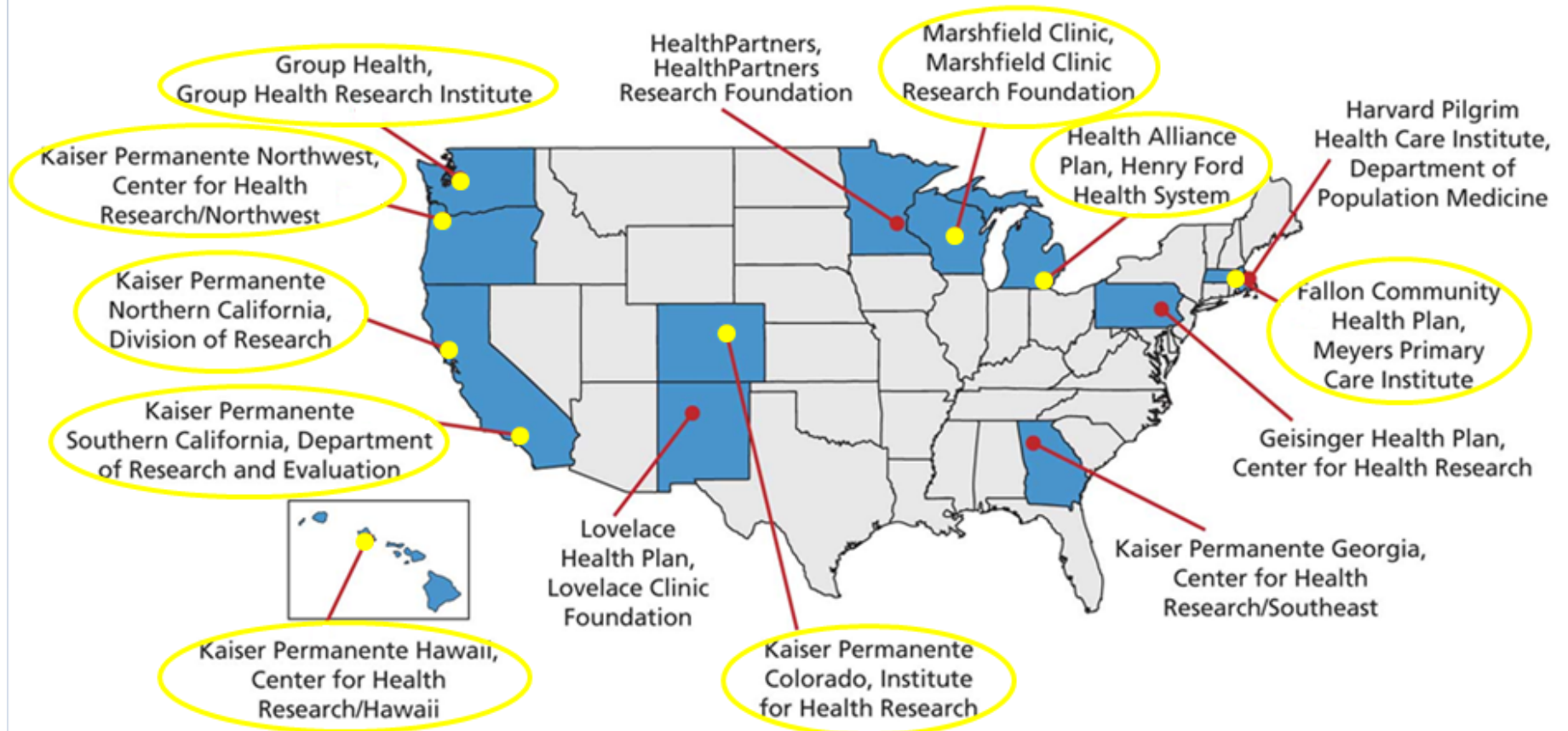
- 7 data collection sites, 1 coordinating center
- **Objective:** Evaluate determinants of quality of care and health outcomes among newly diagnosed lung and colorectal cancer patients and long-term survivors
- **Phase I:** Established cohort of ~10,000 newly dxed lung and colorectal cancer patients (dxed 2003-2005)
- **Phase II:** ~ 7 year follow-up of disease free survivors and those with advanced disease to be completed end 2012
- **Data collection:** patient, provider, and caregiver surveys; medical records

Patients with Advanced Lung or Colorectal Cancer are Overly Optimistic about Effectiveness of Treatment

Response to question: will chemotherapy cure your disease?

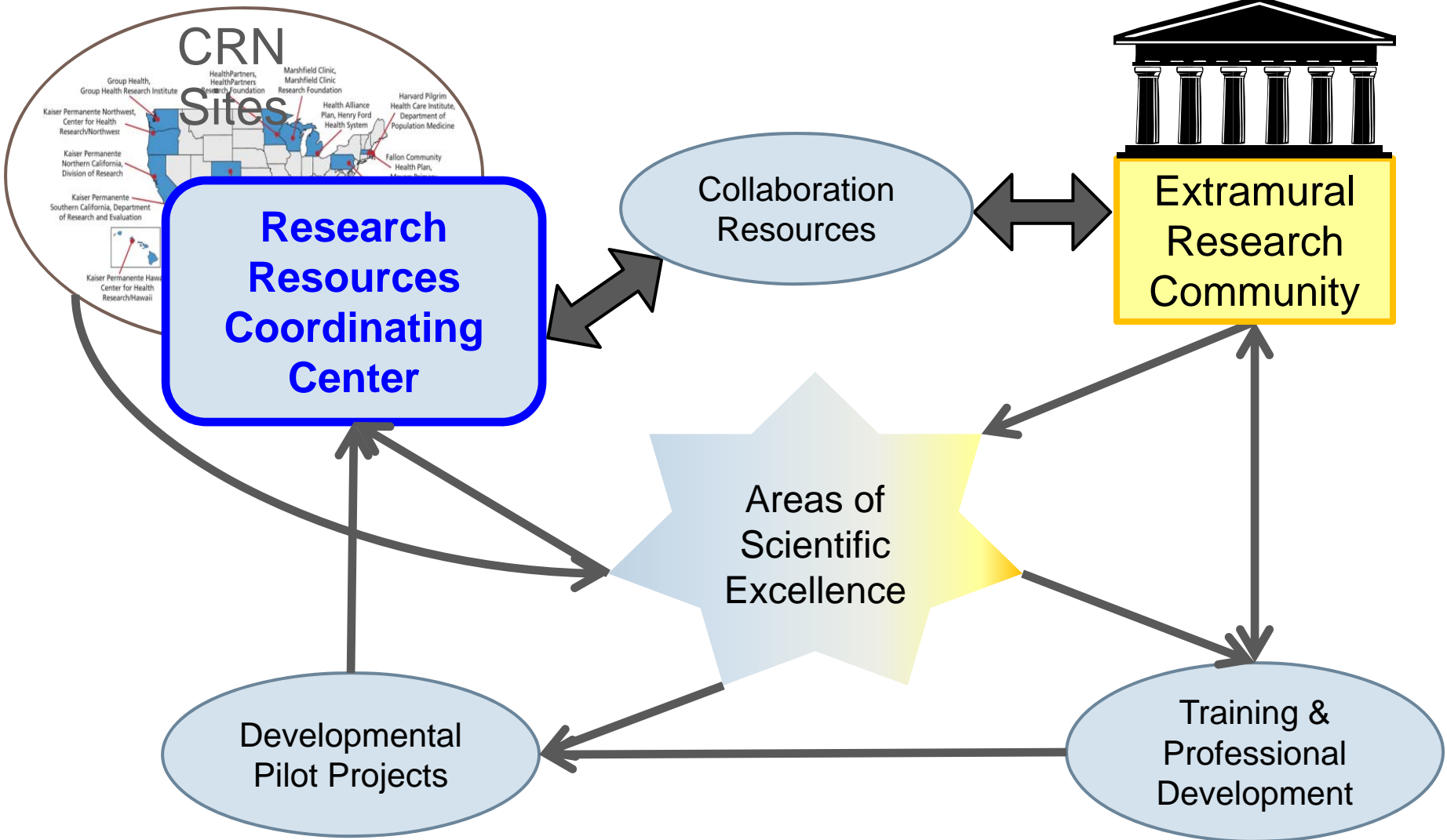


Cancer Research Network (CRN) Health Systems

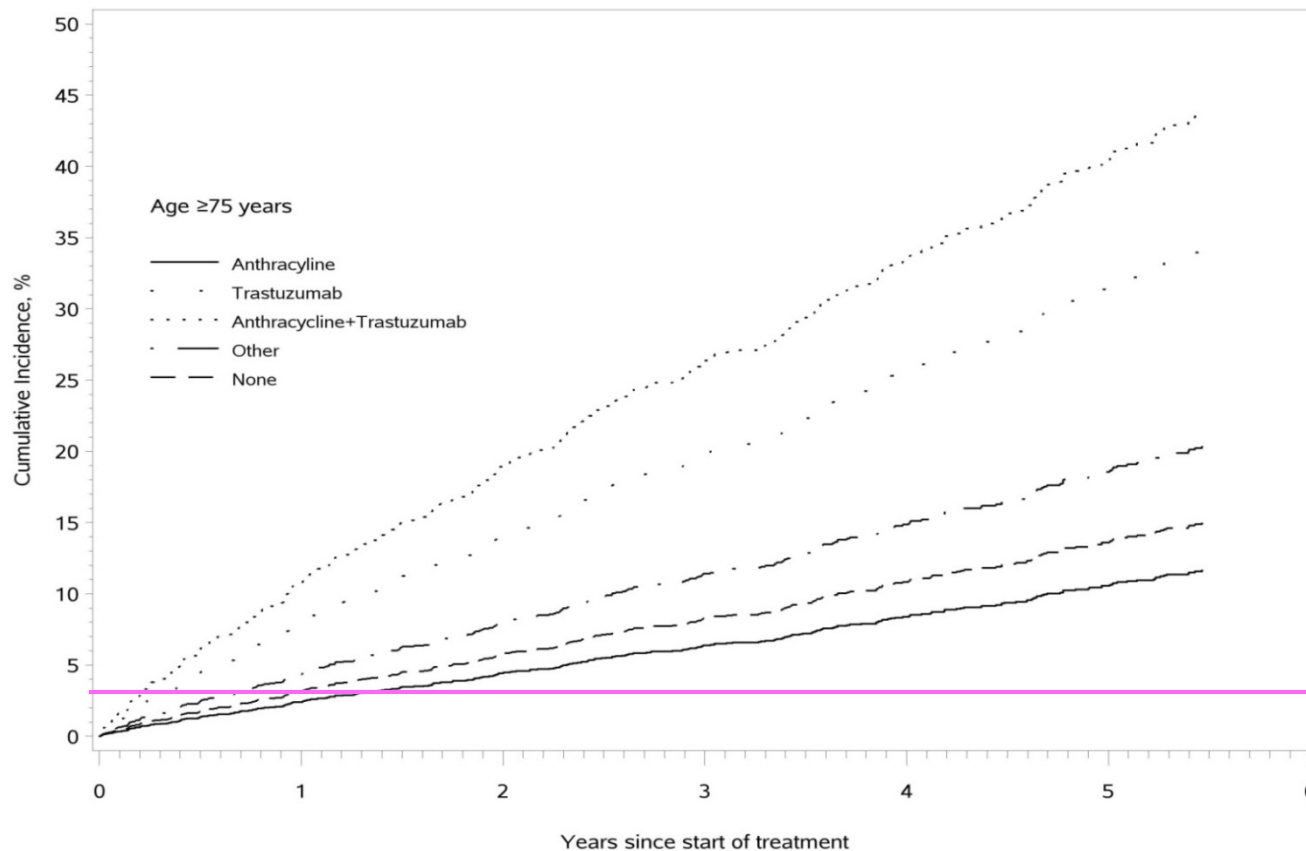


- ● CRN 3: 14 healthcare systems, 11 million individuals
- CRN 4: 9 healthcare systems, 10 million individuals

CRN Research Resource RFA Components



Heart Failure Much Higher in Older Women in Clinical Practice With A/T Breast Cancer Therapy

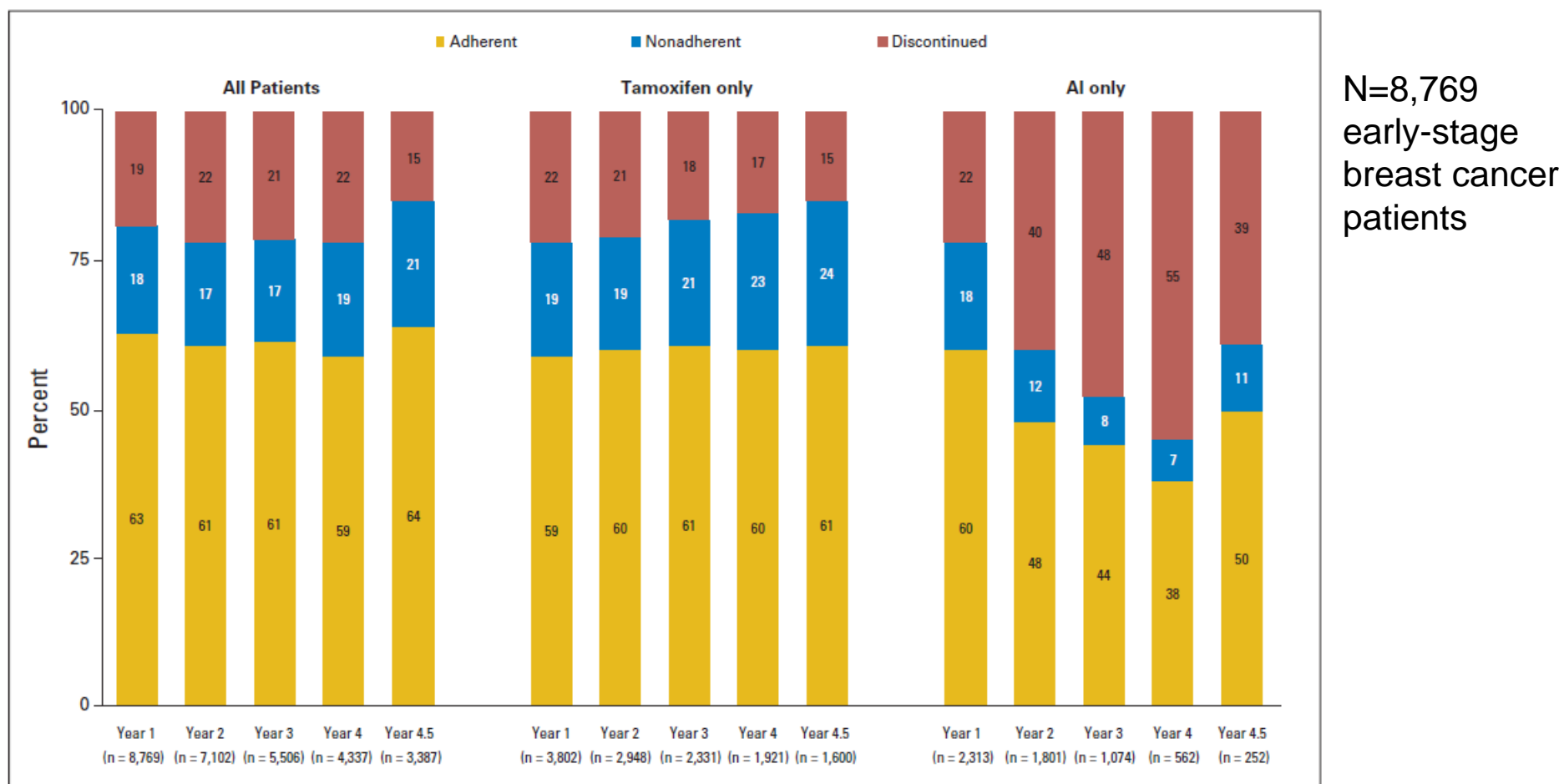


- N=12,500 women diagnosed with breast cancer from 1999-2007 at 8 CRN health systems
- Rate in RCTs is 2-4%

Bowles EA et al. JNCI 2012;104:1293-1305.

Heart failure measures developed by CVRN.

Early Discontinuation and Non-adherence to Adjuvant Hormonal Therapy



Integration with Other NCI Initiatives in Cancer Care

- Discussion with CTEP of cancer treatment and control studies and plans to hold joint discussions across funded groups regarding areas of priority
- Formal affiliations between initiatives
 - At least 8 CRN sites have active collaborations with Cancer Centers
 - Most of the CRN sites actively enroll patients to cancer treatment clinical trials through cooperative groups (NSABP, SWOG, RTOG, ACOSOG, ECOG, CTSU)
 - Investigators affiliated with CRN sites have helped recruit patients into prevention and screening trials (PLCO, NLST, SELECT)
- Interaction between CRN and DCTD on the potential for developing biospecimen inventory and acquisition efforts with linked clinical data

Integration with Other NCI Initiatives in Cancer Care

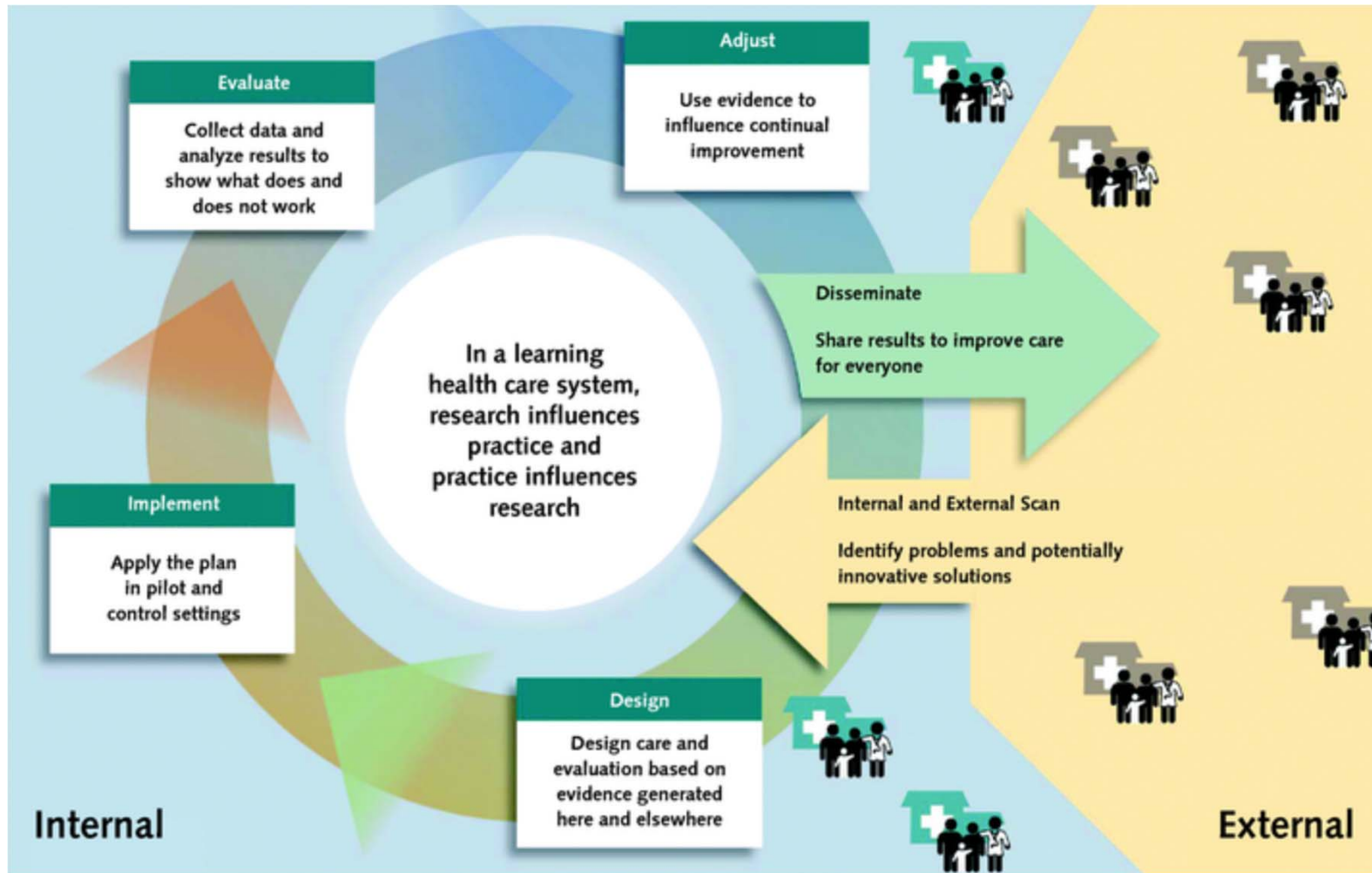
- Decisions on what cancer treatments to examine within SEER POC/QOC studies based on results from NCI trials
- Extensive use of DCCPS Research Resources by investigators within cancer centers, cooperative groups
 - Investigators from 54 NCI cancer centers have requested data for 543 SEER-Medicare projects
 - Participation in SEER-Medicare trainings
 - Investigators from cancer centers use BCSC data
- Experts across DCCPS community clinical care initiatives consulted on conceptual development of cancer care delivery component of NCORP

Integration with Other NCI Initiatives in Cancer Care



- Improved communication mechanisms to inform clinical research priorities
 - New investigational trials across care continuum
 - Studies of differential symptom burden in context of equivalent therapeutic benefit
- Potential to share lessons learned about building standardized data capabilities to support cancer care delivery research
- Natural experiments to study differences in approaches within integrated and non-integrated health systems to the delivery of cancer care

Care Delivery Research within Health Care Systems: Creating Rapid-Learning Health Care Systems



Examples:

- Primary Care Medical Home
- Tamoxifen treatment

How NCORP is Distinctive from Other Cancer Care Delivery Research Efforts



- NCORP aims to support delivery research that assures optimal therapies and system supports are available to improve patient outcomes
 - Emphasizes specialty providers and provider systems in communities often characterized by more care fragmentation
 - Integrates delivery research with NCI community-based clinical trials research to improve accrual or rapid dissemination of trial findings
 - Includes a focus on access and disparities in care beyond organized health care systems or insured care