DCCPS Research Resources for Studying Cancer Care in the Community Setting

Rachel Ballard-Barbash
Associate Director
Applied Research Program

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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

Local/State/National Policy

Health Care Delivery System

Provider

Individual

- PROMIS/PRO-CTCAE
- MEPS: Improving cancer cost estimation
- SEER POC/QOC

Provider Surveys

• SEER data linkages
• BCSC
• CRN
• PROSPR
• CanCORS

QCCC
Surveillance / Research Databases

- **Patterns of Care / Quality of Care Studies (SEER POC/QOC)**
  
  [http://healthservices.cancer.gov/surveys/poc](http://healthservices.cancer.gov/surveys/poc)
  
  - Conducts augmented data collection from SEER cancer registries
  - Documents national trends of initial cancer treatment

- **SEER-Medicare**
  
  
  - 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)**
  
  
  - 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

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<td>2.49-21.93</td>
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- N=1,358 AYA patients with cancer (15-39 years)
- 14% of AYA patients enrolled in clinical trial

Parsons et al. JCO 2011; 30: 4045-4053
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


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

Zhu et al. JAMA 2012;307:1593-1601
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

<table>
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<th>Months from diagnosis</th>
<th>Physical Component Score</th>
<th>Role Physical</th>
<th>General Health</th>
<th>Mental Component Score</th>
<th>Vitality</th>
<th>Social Functioning</th>
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Score Change in Health

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)**
  
  
  - 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)**
  
  
  - 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**
  
  
  - 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)**
  
  
  - 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 diagnosed 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

CRN Sites

Research Resources
Coordinating Center

Collaboration Resources

Extramural Research Community

Areas of Scientific Excellence

Developmental Pilot Projects

Training & Professional Development
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

Hershman DL, et al. JCO 2010; 28:4120-8

N=8,769 early-stage breast cancer patients
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