

Data Resources for Cancer Comparative Effectiveness Research

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CER: The New U.S. Health Policy Research Policy Paradigm

- American Recovery and Reinvestment Act of 2009 (ARRA)
- \$1.1 Billion for Comparative Effectiveness Research (CER)
 - \$300 Million for AHRQ
 - \$400 Million for NIH
 - \$400 Million for Secretary of Health and Human Services

What is CER?

- NIH Definition (preliminary): A rigor evaluation of the impact of different options that are available for treating a given medical condition for a particular set of patients. Such a study may compare similar treatments, such as competing drugs, or it may analyze very different approaches, such as surgery and drug therapy. Such research may include the development and use of clinical registries, clinical data networks, and other forms of electronic health data that can be used to generate or obtain outcomes data at they apply to CER.

What About Cost?

- Removed from NIH Definition
- Congressional Budget Office Definition: [adds] The analysis may focus only on the relative medical benefits and risks of each option, or it may also weigh both the costs and benefits of those options.
- Institute of Medicine Definition: [adds} The purpose of CER is to assist patients, clinicians, purchasers and policy makers to make informed health decisions.

NCI Data Resources to Support Health Economics and Policy Research

- **Patterns of Care**
 - Patterns of Care / Quality of Care Project
 - Cancer Care Outcomes Research & Surveillance Consortium (CANCORS)
 - SEER-Medicare
 - National Provider Surveys
 - HMO Cancer Research Network
- **Cost and/or Resource Use**
 - SEER-Medicare
 - HMO Cancer Research Network

Other Data Resources

- National Center for Health Statistics
 - National Health Interview Survey (periodically enhanced by NCI with Cancer Control Module)
 - Health System Encounter Surveys, e.g. National Ambulatory Care Survey, etc.
- Agency for Healthcare Research and Quality
 - Medical Expenditure Panel Survey
- Center for Medicare and Medicaid Services
 - National Health Expenditure Accounts
- Other Public and Private Data Sources
 - Summarized in Data Inventory in forthcoming (July, 2009) Medical Care Supplement: Health Care Costs: In Pursuit Of Standardized Methods And Estimates For Research And Policy Applications

Patterns of Care / Quality of Care Studies

- The Patterns of Care/Quality of Care (POC) initiative has three inter-related goals:
 - evaluate the dissemination of state-of-the-art cancer therapy into community practice;
 - disseminate findings in scientific journals and professional meetings; and
 - work with professional organizations to develop educational or training opportunities to improve the use of state-of-the-art cancer therapy in community practice.

Patterns of Care / Quality of Care Studies

- POC/QOC conducts enhanced collection of registry-based on cancer treatment using a sub-sample from all SEER registries.
- Most prevalent (breast, colorectal, lung, prostate) cancer organ sites are studied periodically and other sites are studied as determined by clinical experts at NCI.
- Special initiatives:
 - Prostate Cancer Outcomes Study
 - Cancers in Adolescents and Young Adults

Examples of POC/QOC studies

<u>Year of Diagnosis</u>	<u>Cancer Site</u>
1987-1991, 1995, 2000, 2005	Early Stage Breast
1991, 1995, 1997, 2000, 2005	In Situ Breast
1987-1991, 1995, 2000, 2005	B2 and C Colorectal
1991, 1996, 2002	Ovarian
1997, 2000, 2001	Cervix
1995, 1996, 2001	Melanoma
2006	AYA Initiative, e.g. Hodgkin, NHL, Germ, Osteosarcoma
1998, 2002	Prostate, PCOS Initiative

CANCORS

- Prospective longitudinal cohort of new diagnosed cancer patients, 5000 colorectal, 5000 lung cancer.
- Follow-up for one year on treatment patterns, quality of life, quality of care, using medical records, physician, patient and family caregiver interviews, link to Medicare files..
- Second phase, will examine, follow-up beyond one year, with special emphasis on newly emerging biological targeted therapies.

CANCORS Study Sites

Institution	PI(s)	Regions Covered
U. of Alabama - Birmingham	C. Kiefe, MD, PhD M. Fouad, MD	State of Alabama
Dana Farber Ca Institute	J. Weeks, MD R. Fletcher, MD	HMOs in 4 regions (subset of HMO/CRN)
Harvard + N. California Cancer Center	J. Ayanian, MD D. West, PhD	8 counties in San Francisco & Oakland, San Jose & Sacramento areas
U. of North Carolina - Chapel Hill	R. Sandler, MD	22 eastern/central counties in N. Carolina
U. of Iowa	R. Wallace, MD E. Chrischilles, PhD	State of Iowa
Veterans Health Admin.	D. Provenzale, MD M. Van Ryn, PhD	VAMCs in 14 cities
UCLA/Rand	K. Kahn, MD P. Ganz, MD	Los Angeles County
Dana Farber Ca Institute	D. Harrington, PhD	Data Coordinating Center

SEER-Medicare Linked Data

- The SEER-Medicare data are the result of the linkage of two large population-based sources of data: cancer registry data from NCI's sponsored cancer registries (SEER program) and Medicare claims from CMS
- The SEER registries collect detailed information about the 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. This includes hospital, physician, outpatient, SNF, home health, and hospice services.

Persons included in the SEER-Medicare Data

- 100% of patients in the SEER data who are found to be Medicare eligible; 1.8 millions cases
- 5% random sample of persons residing in the SEER areas who have not been diagnosed with cancer
 - These people can be used to create comparison groups as well as to create estimates of diagnostic testing and treatment practices in the entire population
 - Medicare files available for the non-cancer cases are the same as for the cancer cases

Potential Uses of SEER-Medicare Data

Cancer Control Continuum

Diagnosis/Treatment	Survivorship	Second Occurrence	Terminal
<i>Patterns of care</i>	<i>Late effects of treatment</i>	<i>Rates of second primaries</i>	<i>Use of hospice services</i>
<i>Perioperative complications</i>	<i>Post-diagnostic surveillance</i>	<i>Relationship of initial treatment to second primaries</i>	<i>Patterns of care during the last year of life</i>
<i>Volume outcomes studies</i>	<i>Treatment of prevalent cancers</i>		
<i>Extent of staging</i>	<i>Survival</i>		
<i>Comorbidities</i>			

← Health disparities, quality of care, and cost of care →

Comparison of SEER-Medicare and MEPS Estimates of Colorectal Cancer Treatment Cost

- We compared mean annual cost per prevalence case between SEER-Medicare and MEPS
 - SEER-Medicare:
 - Total healthcare cost: \$12,231
 - Cancer related cost: \$5,457
 - MEPS:
 - Total healthcare cost: \$18,359
 - Cancer related cost: \$11,614
- Why are cost estimates different?
 - MEPS includes more sources of payments and covered services (e.g., oral medications)
 - MEPS may preferentially identify cancer patients undergoing active care and miss cancer patients under routine follow-up

NCI National Healthcare Provider Surveys

- Periodic nationally representative surveys of health providers – physicians, health plan administrators – on selected topics related to cancer prevention, screening and treatment
- Question on provider knowledge of and attitudes toward clinical guidelines, provider policies and practices, reminder and tracking systems, health plan coverage policies, etc.
- High response rates, ranging from 55% - 80%

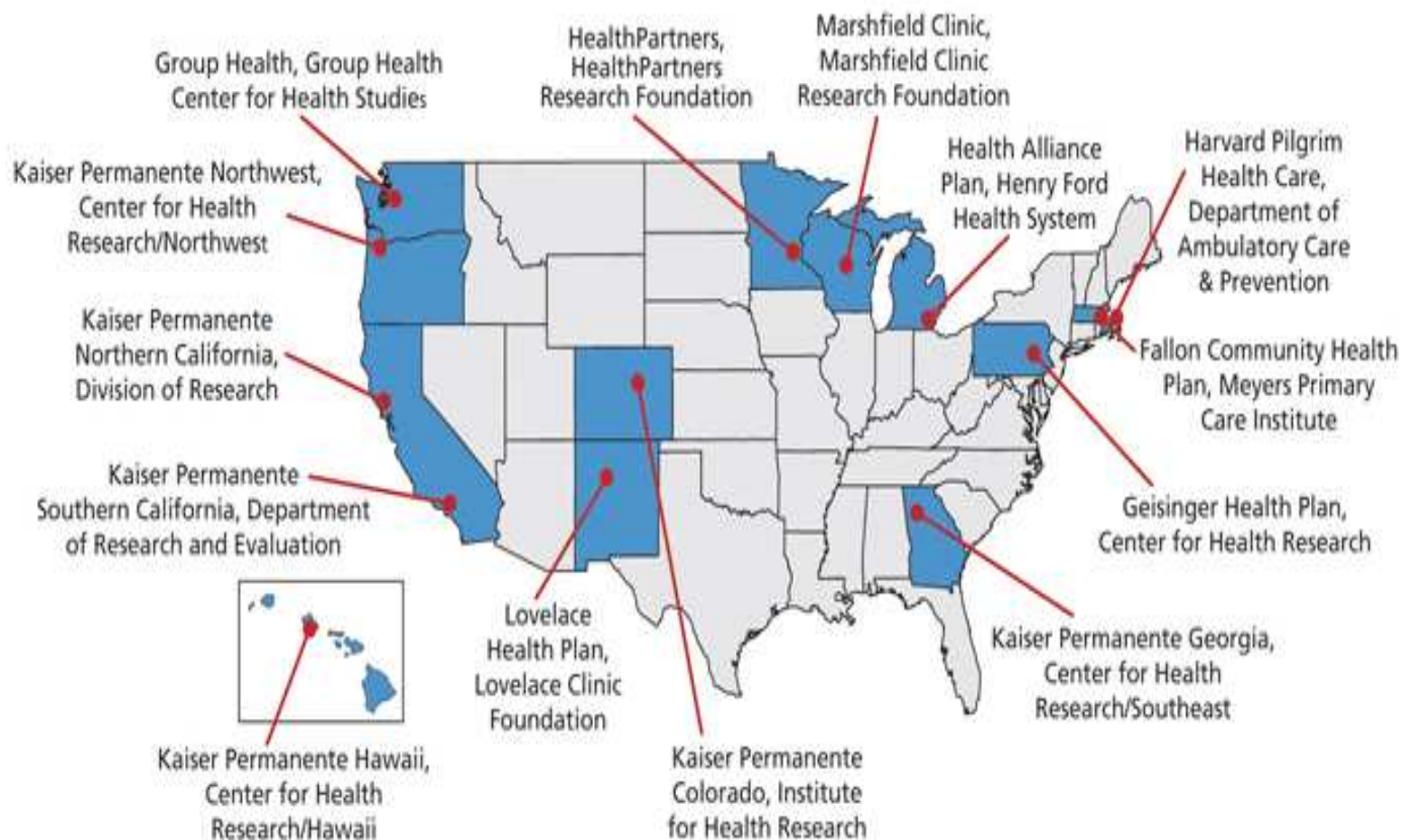
Topics of National Provider Surveys

- 1992: Mammography facilities
- 1999 -2000: Colorectal Cancer Screening
 - Primary care physicians
 - Specialty physicians
 - Health plans
- 2005: Colorectal Cancer Screening
 - Health plans
- 2006-7: Breast, Cervical, Colorectal and Lung Cancer Screening
 - Primary care physicians
- 2008: Energy Balance
 - Primary care physicians
- 2009: Cancer Survivorship
 - Primary care physicians
 - Oncologists

Cancer Research Network

- CRN consists of the research programs, enrolled populations, and data systems of 14 health maintenance organizations nationwide.
- The overall goal of the CRN, and the NCI initiative under which it was funded, is to use this consortium of delivery systems to conduct research on cancer prevention, early detection, treatment, long-term care, surveillance, and cancer communication and dissemination and implementation research. A portfolio of research studies encompasses cancer control topics ranging from modification of behavioral risk factors such as smoking to cancer care at the end of life.
- CRN research resources include automated data on healthcare resource use and cost, electronic medical records and health plan – patient web portals.

Cancer Research Network Sites



CRN DATA RESOURCES

Year of Availability for Key Data Resources

	GHC	GHS	HPHC	HPRF	HFHS	KPCO	KPG	KPH	KPNC	KPNW	KPSC	LCF	MCRF	MPCI
Automated Medical Record	2005	1995	1999	2004	1988	1997	2005	2004	2005 ^P	1997	2004	N/A	1994	2005
Administrative Data														
Membership	1989	1999	1999	1990	1980	1992	1995	1988	1976	1982	1988	1996	1995	1987
Outside Claims	1979	1999	1990	1990	1991	1993	1995	1995	1992	1989	1991	1996	1985	1987
Patient Scheduling	1984	1997	N/A	1990	1988	1992	1995	1992	1987	1985	1993	N/A	1991	1987
Deaths	1972	N/A	1983	N/A	1990	1989	1995	1985	1970	1979	1988	N/A	1992 ^P	N/A
Cost	1998	1999	1990	1990	1990	1997	1995	1995	1996	1998	1995	1999 ^P	1985 ^P	1988
Automated Clinical Data														
Outpatient Visits	1992	1995	1989 ^P	1990	1988	1992	1995	1995	1995	1987	1993	1996	1991	1987
Hospitalizations	1979	1993	1990 ^P	1990	1989	1991	1995	1988	1976	1985	1981	1996	1991	1987
Emergency Room	1992	1993	1990 ^P	1990	1988	1994	1995	1988	1995	1985	1993	1996	1991	1987
Pharmacy	1977	1985	1988 ^P	1990	1992	1993	1995	1992	1994	1989	1992	1996	1992	1987
Laboratory	1989	1995	1989 ^P	1994	1995	1994	1995	1988	1994	1993	1991	2000 ^P	1985	1990
Long-term Care	1992	N/A	1990 ^P	1990	1995	1994	1995	1995	N/A	1989	1995	N/A	N/A	1999
Home Health Care	1992	N/A	1990 ^P	1990	1995	1994	1995	1995	2002	1987	1995	N/A	N/A	1999
Radiology	1989	1994 ^P	1990 ^{R,T}	1990 ^T	1988 ^P	1992	1995	1991	1997	1989	1994	N/A	1974	1995
Pathology	1993	1987 ^P	1990 ^{R,T}	1990 ^T	1988 ^P	1994	1995	1995	1998	1970	N/A	N/A	1995	1995
Cancer Registry	1974	1980	1997	N/A	1972	1987	2004	1973	1973	1990	1988	1999	1990	N/A

Key

P = Partial

T = Text with search capability

N/A = Information not available in a single comprehensive datafile

CRN Burden Project

- CRN HMOs have variable types of patient-level data systems for healthcare resource use and costs
 - Internal encounter systems
 - Claims based systems
 - Outsourcing
- The CRN Burden Project will harmonize these systems with each other and with the Medicare claims system