ASPO Survivorship, Health Outcomes & Comparative Effectiveness Research Special Interest Group presents:

Connecting the dots: the creation and use of data linkages to study cancer survivorship and health outcomes research

The availability of "big data" in cancer research suggest the potential for new answers to long-standing questions about how to best deliver high quality care to cancer survivors. However, there are several challenges to creating linkages and caveats for their use. This webinar will provide case studies of the creation of new data linkages and discuss how best to leverage existing linkages for cancer control research.

Date: January 8, 2019
Time: 2:00pm-3:00pm ET
Link: https://cwru.zoom.us/j/929650435

Erin Kent, PhD
National Cancer Institute

Stephanie Wheeler, PhD, MPH
University of North Carolina, Chapel Hill

Betsy Shenkman, PhD
University of Florida

Karen Wernli, PhD
Kaiser Permanente

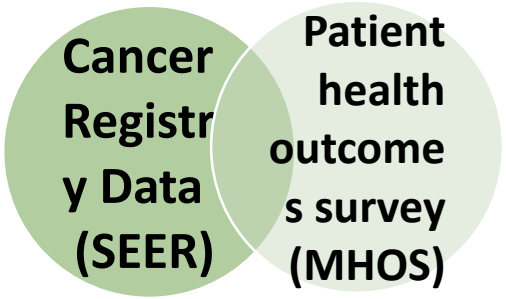
Kate Weaver, PhD MPH
Wake Forest University

NCI Linked Data Resources for Cancer Survivors

https://healthcaredelivery.cancer.gov/

SEER-MHOS Linked Data Resource

Surveillance, Epidemiology and End Results – Medicare Health Outcomes Survey



Survey includes:

- Health-related quality of life (SF-36, VR-12)
- Activities of daily living
- HEDIS effectiveness of care
- Patient-reported outcomes relevant for older adults with cancer

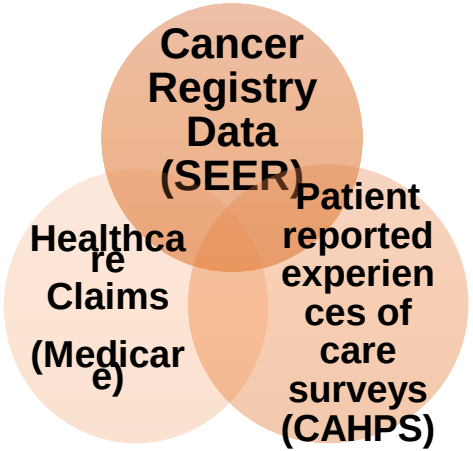
- Over **140,000 SEER-linked Medicare Advantage (HMO) beneficiaries***
- Over **2 million beneficiaries** without cancer
- **Designed to be longitudinal with baseline and follow-up surveys**, spaced two years apart, proportion with surveys before and after dx
- Over **80 data use agreements** and **45+ publications since** 2010 launch

No healthcare claims available in SEER-MHOS of medical care; Part D prescription drug claims under investigation though a feasibility study

https://healthcaredelivery.cancer.gov/seer-mhos/

SEER-CAHPS Linked Data Resource

Surveillance, Epidemiology and End Results – Consumer Assessment of Healthcare Providers and Systems



CAHPS survey includes:

- Doctor Communication
- Getting Needed Care
- Getting Care Quickly
- Care Coordination

- Over **205,000 cancer respondents**
- More than **724,000 non-cancer respondents**
- Medicare **claims** allow examination of aspects of healthcare utilization
- Over **10 data use agreements and 8+ publications** since 2015 launch
- Rich opportunities for research on patient experiences in cancer care delivery

https://healthcaredelivery.cancer.gov/seer-cahps/

https://aspo.org/annual-meeting/

ASPO 2019 Survivorship, Health Outcomes, and Comparative Effectiveness SIG March 11 Breakfast Session:

Multiple chronic conditions and care coordination among cancer survivors

Individuals are living longer with a history cancer, and many are dealing with other chronic conditions in addition to late/long-term effects from cancer and cancer treatment. The need to manage and coordinate health care services and communicating with a variety of healthcare providers can be challenging. This year's SIG will focus on research questions related to the coordination of care delivery for cancer patients with multiple chronic conditions.

ASPO Survivorship, Health Outcomes & Comparative Effectiveness Research Special Interest Group presents:

Connecting the dots: the creation and use of data linkages to study cancer survivorship and health outcomes research

I. Stephanie Wheeler, PhD, MPH, UNC Chapel Hill
Getting into the weeds: State-level data linkages for cancer prevention and control research

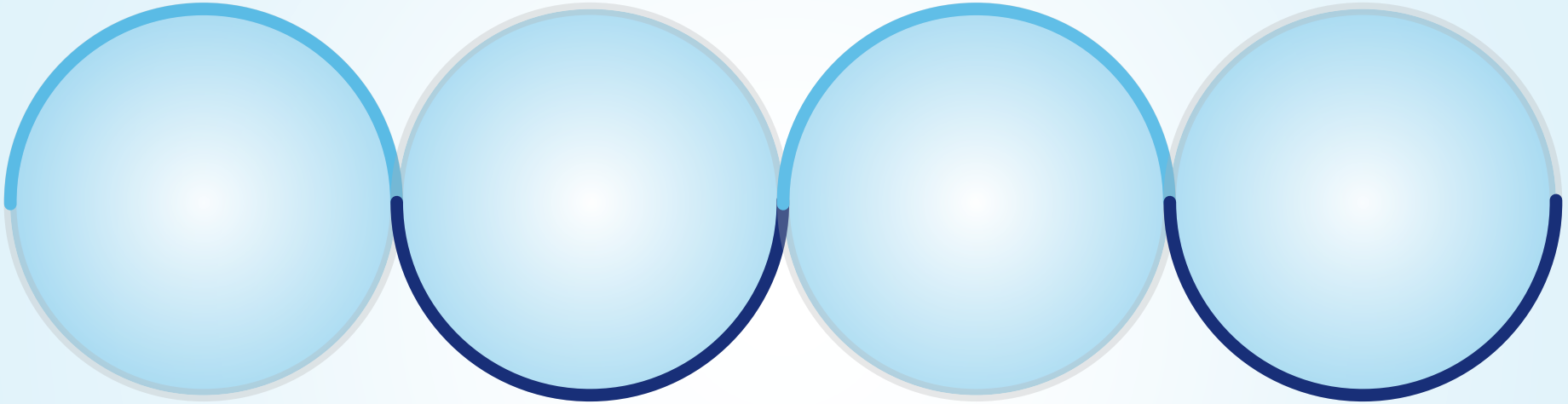
II. Betsy Shenkman, PhD, University of Florida
OneFlorida Cancer Control Alliance: leveraging linked private and public data for observational and clinical trials

III. Karen Wernli, PhD, Kaiser Permanente
Using Optum claims data in US cancer patients: an example in adolescent and young adults

Discussant, Q & A: Kate Weaver, PhD MPH, Wake Forest University

OneFlorida

Clinical Research Consortium



Inclusive of Diverse Populations

What Works Better for Whom Under What Circumstances?

Conducted in Real World Settings to Accelerate Translation to Practice and Adoption

The Science of Fostering the Uptake of Evidence-Based Best Practices Into Diverse Health Care Settings

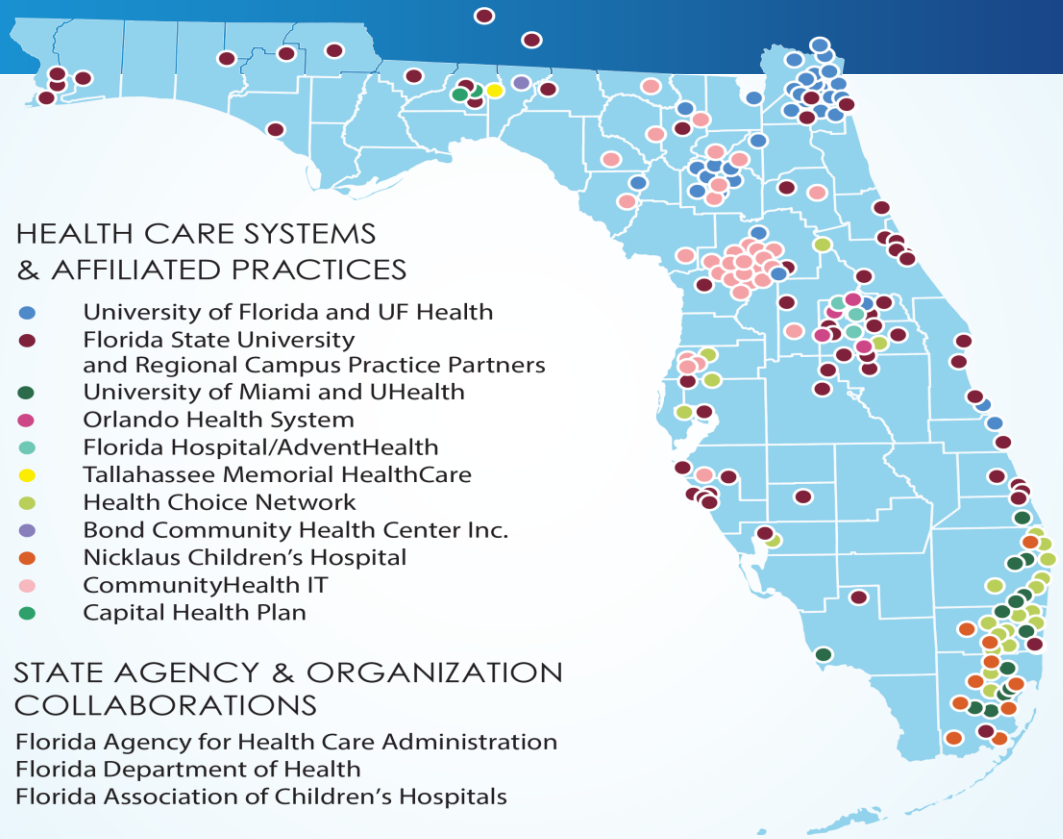
Learning Health System

Stakeholder Engagement: People, Clinicians, Health Systems, Payers, Industry

Real-World Evidence — What Is It and What Can It Tell Us?
N Engl J Med 2016; 375:2293-2297
DOI: 10.1056/NEJMsb1609216

FDA: Real World Evidence: Why is this happening now?

Real-World Evidence and Real-World Data for Evaluating Drug Safety and Effectiveness
JAMA. 2018;320(9):867-868. doi:10.1001/jama.2018.10136

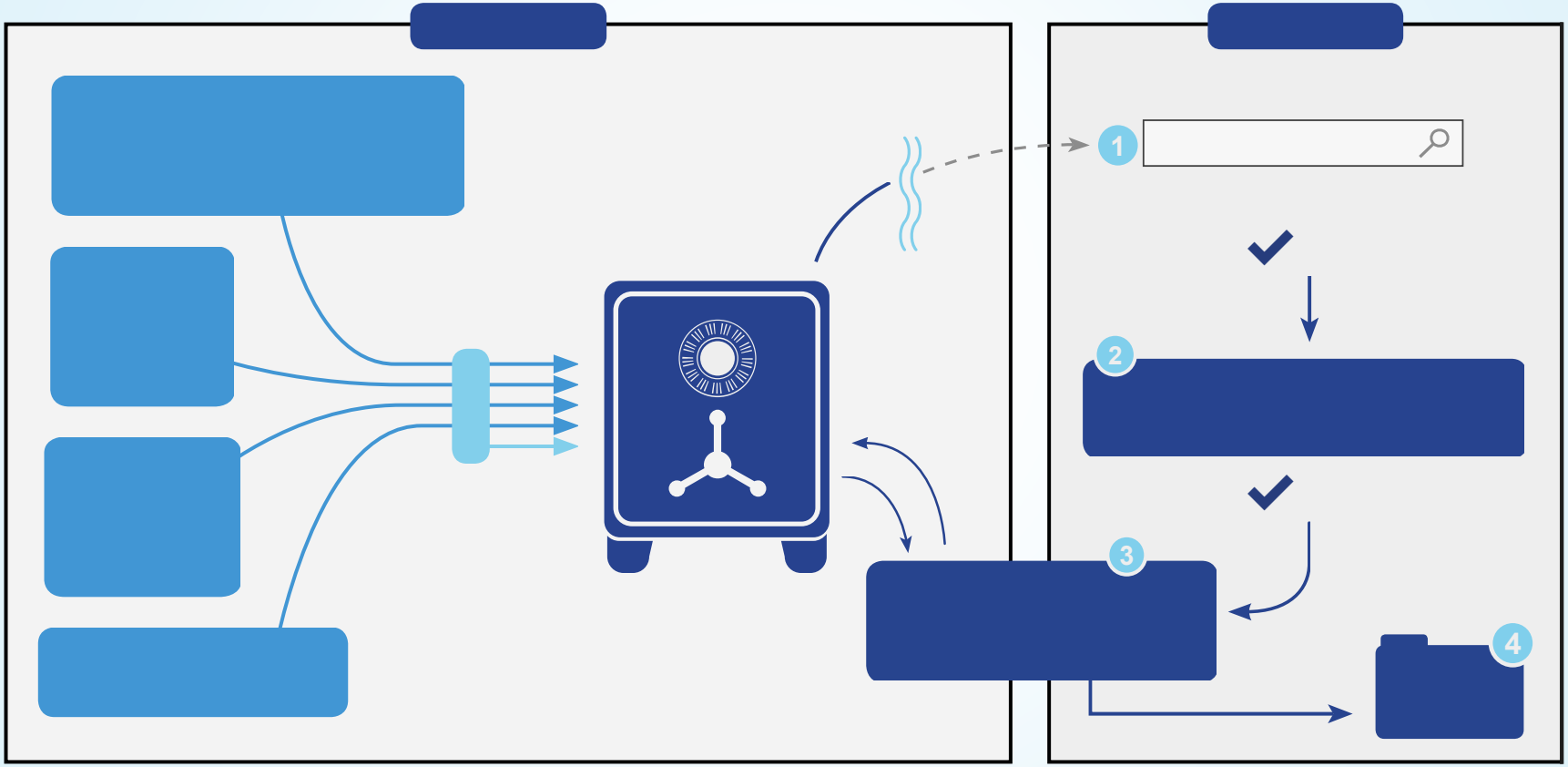


HEALTH CARE SYSTEMS & AFFILIATED PRACTICES

- University of Florida and UF Health
- Florida State University and Regional Campus Practice Partners
- University of Miami and UHealth
- Orlando Health System
- Florida Hospital/AdventHealth
- Tallahassee Memorial HealthCare
- Health Choice Network
- Bond Community Health Center Inc.
- Nicklaus Children's Hospital
- CommunityHealth IT
- Capital Health Plan

STATE AGENCY & ORGANIZATION COLLABORATIONS

Florida Agency for Health Care Administration
Florida Department of Health
Florida Association of Children's Hospitals


1
2
3
4

FUNDAMENTAL DATA

Demographic
- PATID
- BIRTH_DATE
- BIRTH_TIME
- SEX
- HISPANIC
- RACE
- BIOBANK_FLAG

HEALTH CARE DELIVERY DATA

Enrollment
- PATID
- ENR_START_DATE
- ENR_END_DATE
- CHART
- ENR_BASIS

Dispensing
- **DISPENSINGID**
- PATID
- **PRESCRIBINGID (optioal)**
- DISPENSE_DATE
- NDC
- DISPENSE_SUP
- DISPENSE_AMT

Death
- **PATID**
- **DEATH_DATE**
- **DEATH_DATE_IMPUTE**
- **DEATH_SOURCE**
- **DEATH_MATCH_CONFIDENCE**

Death Conditio
- **PATID**
- **DEATH_CAUSE**
- **DEATH_CAUSE_CODE**
- **DEATH_CAUSE_TYPE**
- **DEATH_CAUSE_SOURCE**
- **DEATH_CAUSE_CONFIDENCE**

MULTIPLE CONTEXT DATA

Vital
- **VITALID**
- PATID
- ENCOUNTERID (optioal)
- MEASURE_DATE
- MEASURE_TIME
- VITAL_SOURCE
- HT
- WT
- DIASTOLIC
- SYSTOLIC
- ORIGINAL_BMI
- BP_POSITION
- **SMOKING**
- TOBACCO
- TOBACCO TYPE

Conditio
- **CONDITIONID**
- PATID
- ENCOUNTEREDID (optioal)
- REPORT_DATE
- RESOLVE_DATE
- **ONSET_DATE**
- CONDITION_STATUS
- CONDITION
- CONDITION_TYPE
- CONDITION_SOURCE

Pro_CM
- **PRO_CM_ID**
- PATID
- ENCOUNTEREDID (optioal)
- PRO_ITEM
- PRO_LOINC
- PRO_DATE
- PRO_TIME
- PRO_RESPONSE
- PRO_METHOD
- PRO_MODE
- PRO_CAT

DIRECT ENCOUNTER DATA

Encounter
- ENCOUNTERID
- PATID
- ADMIT_DATE
- ADMIT_TIME
- DISCHARGE_DATE
- DISCHARGE_TIME
- PROVIDERID
- FACILITY_LOCATION
- ENC_TYPE
- FACILITYID
- DISCHARGE_DISPOSITION
- DISCHARGE_STATUS
- DRG
- DRG_TYPE
- ADMITTING_SOURCE

Diagnosis
- **DIAGNOSISID**
- PATID
- ENCOUNTERID
- ENC_TYPE
- ADMIT_DATE
- PROVIDERID
- PX_DATE
- PX
- PX_TYPE
- PX_SOURCE

Procedures
- **PROCEDURESID**
- PATID
- ENCOUNTERID
- ENC_TYPE
- ADMIT_DATE
- PROVIDERID
- PX_DATE
- PX
- PX_TYPE
- PX_SOURCE

Lab Result
- **LAB_RESULT_CM_ID**
- PATID
- ENCOUNTERID
- LAB_NAME
- SPECIMEN_SOURCE
- LAB_LOINC
- PRIORITY
- RESULT_LOC
- LAB_PX
- LAB_PX_TYPE
- LAB_ORDER_DATE
- SPECIMEN_DATE
- SPECIMEN_TIME
- RESULT_DATE
- RESULT_TIME
- RESULT_QUAL
- RESULT_NUM
- RESULT_MODIFIER
- RESULT_UNIT
- NORM_RANGE_LOW
- NORM_MODIFIER_LOW
- NORM_RANGE_HIGH
- NORM_MODIFIER_HIGH
- ABN_IND

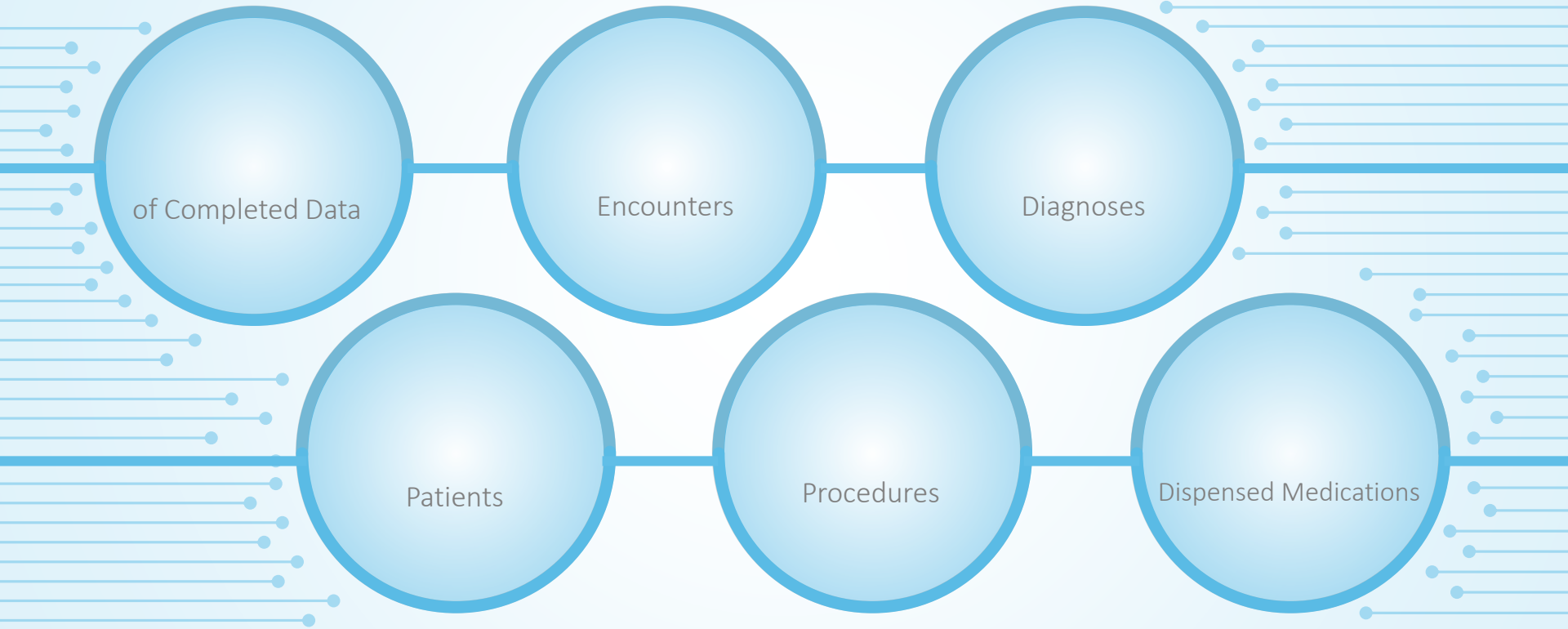
Prescribing
- **PRESCRIBINGID**
- **PATID**
- **ENCOUNTERID**
- **RX_PROVIDERID**
- **RX_ORER_DATE**
- **RX_ORDER_TIME**
- **RX_START_DATE**
- **RX_END_DATE**
- **RX_QUANTITY**
- **RX_REFILLS**
- **RX_DAYS_SUPPLY**
- **RX_FREQUENCY**
- **RX_BASIS**
- **RXNORM_CUI**

PCORnet TRIAL DATA

PCORnet Trial
- **PATID**
- **TRAILID**
- **PARTICIPANTID**
- **TRIAL_SITEID**
- **TRIAL_ENROLL_DATE**
- **TRIAL_END_DATE**
- **TRIAL_WITHDRAW_DATE**
- **TRIAL_INVITE_CODE**

PROCESS-RELATED DATA

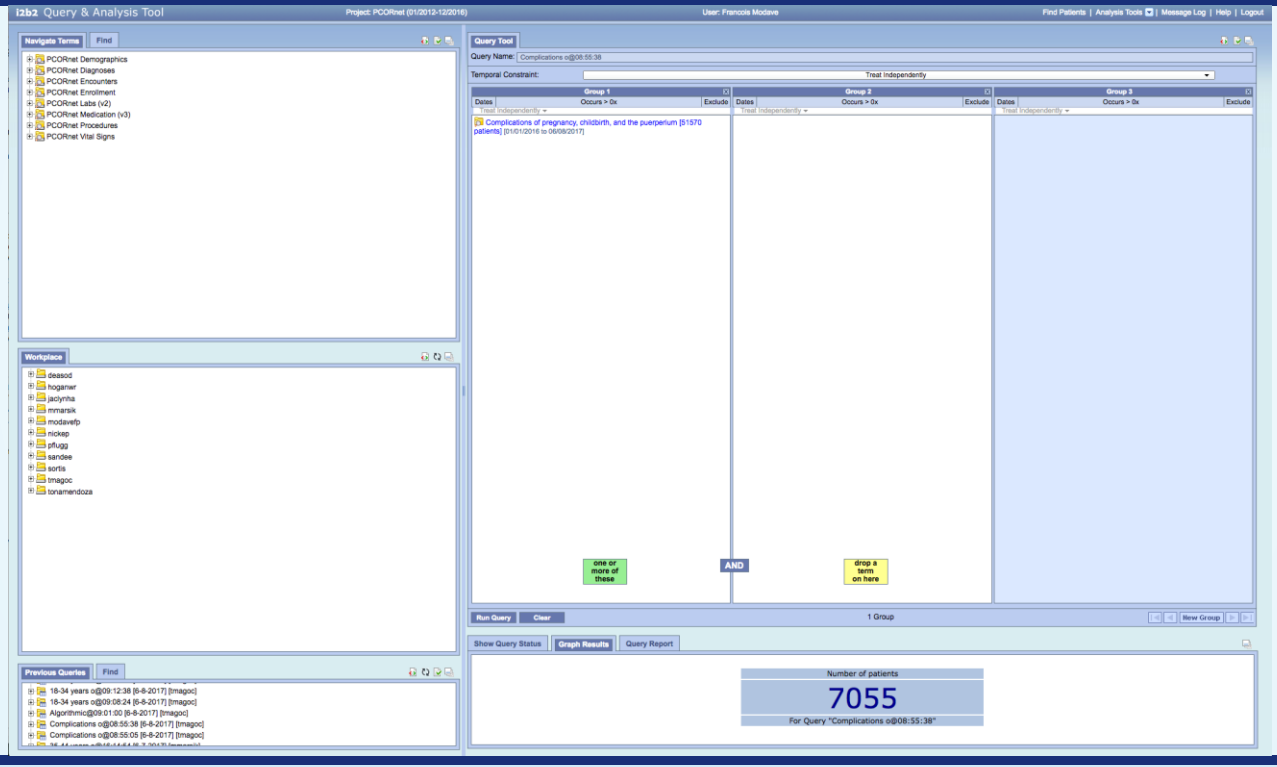
Harvest
- **NETWORKID**
- **NETWORK_NAME**
- **DATAMARTID**
- **DATAMART_NAME**
- **DATAMART_PLATFORM**
- **CDM_VERSION**
- **DATAMART_CLAIMS**
- **DATAMART_EHR**
- **BIRTH_DATE_MGMT**
- **ENR_START_DATE_MGMT**
- **ENR_END_DATE_MGMT**
- **ADMIT_DATE_MGMT**
- **DISCHARGE_DATE_MGMT**
- **PX_DATE_MGMT**
- **RX_ORDER_DATE_MGMT**
- **RX_START_DATE_MGMT**
- **RX_END_DATE_MGMT**
- **DISPENSE_DATE_MGMT**
- **LAB_ORDER_DATE_MGMT**
- **SPCIMEN_DATE_MGMT**
- **RESULT_DATE_MGMT**
- **MEASURE_DATE_MGMT**
- **ONSET_DATE_MGMT**
- **REPORT_DATE_MGMT**
- **RESOLVE_DATE_MGMT**
- **PRO_DATE_MGMT**
- **REFRESH_DEMOGRAPHIC_DATE**
- **REFRESH_ENROLLMENT_DATE**
- **REFRESH_ENCOUNTER_DATE**
- **REFRESH_DIAGNOSIS_DATE**
- **REFRESH_PROCEDURES_DATE**
- **REFRESH_VITAL_DATE**
- **REFRESH_DISPENSING_DATE**
- **REFRESH_LAB_RESULT_CM_DATE**
- **REFRESH_CONDITION_DATE**
- **REFRESH_PRO_CM_DATE**
- **REFRESH_PRESCRIBING_DATE**
- **REFRESH_PCORNET_TRIAL_DATE**
- **REFRESH_DEATH_DATE**
- **REFRESH_CAUSE_DEATH_DATE**

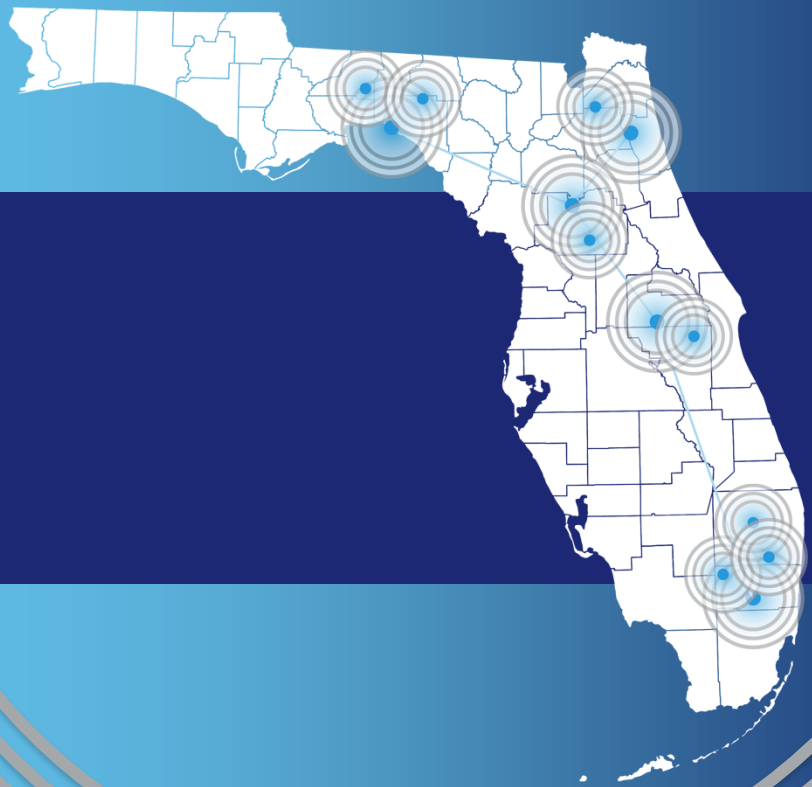

of Completed Data
Encounters
Diagnoses
Patients
Procedures
Dispensed Medications

Over 1.7M patients are de-duplicated

UFH	X	19,416	13,846	492,255	13,148	28,156	49,861	3150	235
ORL	19,416	X	3,331	136,315	789	2,526	211,875	1,924	2
UMI	13,846	3,331	X	205,274	800	2,034	8,124	52,093	3
FLM	492,255	136,315	205,274	X	43,131	98,291	357,096	238,686	244
TMA	13,148	789	800	43,131	X	121,697	1,570	424	1,509
TMC	28,156	2,526	2,034	98,291	121,697	X	4,777	863	2,077
AVH	49,861	211,875	8,124	357,096	1,570	4,777	X	3,424	9
NCH	3150	1,924	52,093	238,686	424	863	3,424	X	0
CHP	235	2	3	244	1,509	2,077	9	0	X

Uses i2b2 software over the Data Trust data to enable researchers to conduct anonymous queries on their own.





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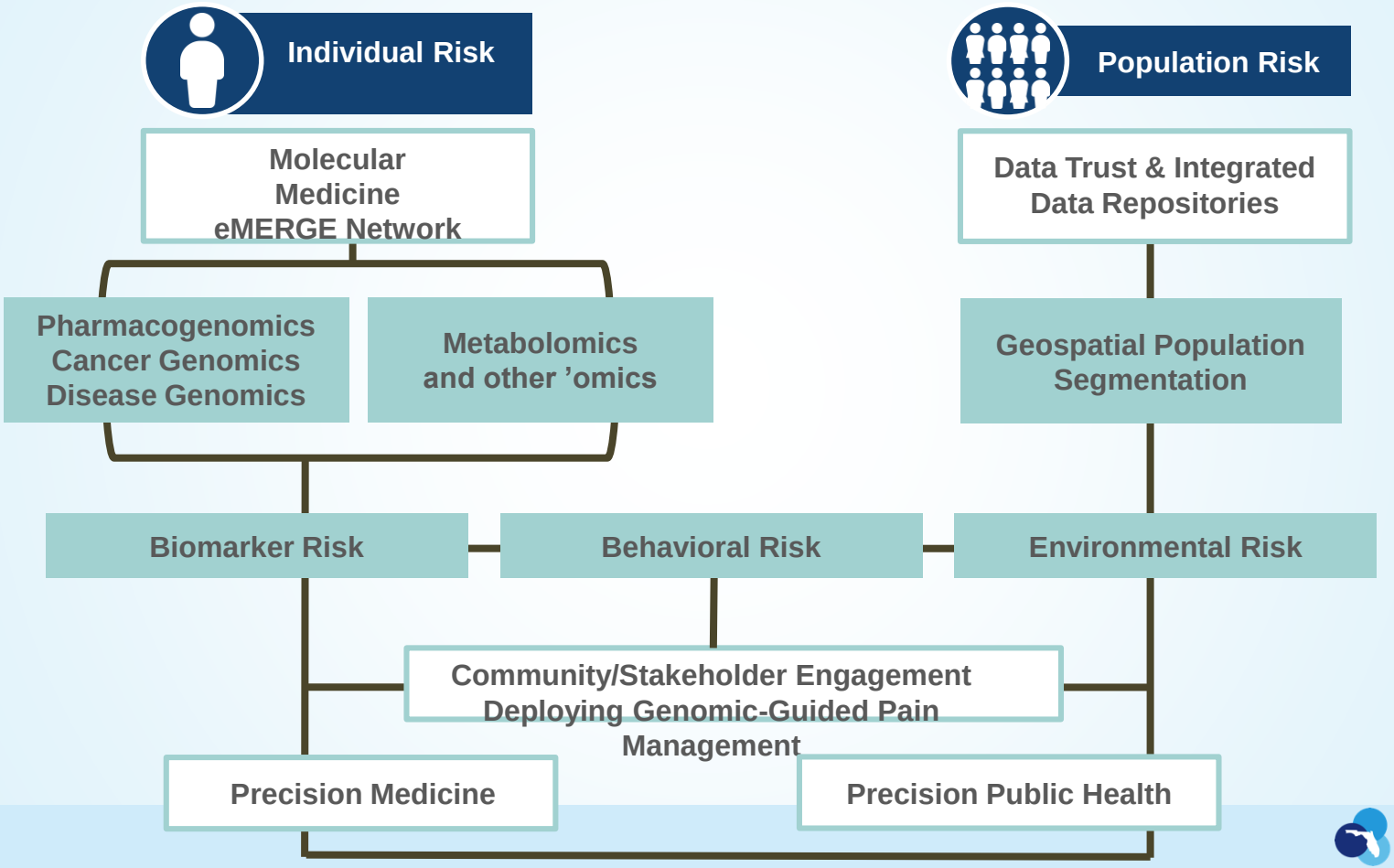
Clinical Research Consortium



OneFlorida Clinical Research Consortium

PCORI Rapid Cycle Research: Patterns of Use of Molecular Biomarkers and Targeted Cancer Therapies

- **Aim 1 (Use Characteristics).** In a cohort of patients with an invasive single primary solid tumor, describe the use of common molecular tumor and, in some cases, germline biomarker testing and associated targeted cancer therapies.
- **Aim 2 (Test Results).** In a subcohort of patients identify those who had molecular biomarker testing and for whom a test result was available, and determine whether the selected treatment was in accordance with the test result.
- **Aim 3 (Completeness and Outcomes).** Using the cohort from Aim 1 in sites with linked claims data, assess the completeness of the electronic health record derived data for identifying cancer treatments

NCI: Improving the Uptake of HPV Vaccine
PI: Stephanie Staras, PhD

- Goal to test interventions in diverse real world settings
- Used Data Trust to Identify Clinic Settings Considering
  - Vaccine Rates
  - Urban/Rural
  - Numbers of Teens, Young Adults

All of Us
THE FUTURE OF HEALTH BEGINS WITH YOU

The Precision Medicine Initiative

OneFlorida Clinical Research Consortium

- Using OneFlorida Data Trust
- Initial Recruitment: UM and UF (Gainesville and Jacksonville)
- Expansion to Advent Health

OneFlorida

Clinical Research Consortium

Getting into the weeds: State-level data linkages for cancer prevention and control research

Stephanie Wheeler, PhD MPH
Lineberger Comprehensive Cancer Center
Health Policy & Management
Gillings School of Global Public Health
University of North Carolina at Chapel Hill

Objectives

- Describe statewide data linkages being used for cancer prevention and control research
- Highlight how statewide linked cancer data can be used to identify population health problems and target potential solutions across the continuum
- Summarize with lessons learned/best practices for linking and leveraging state cancer data

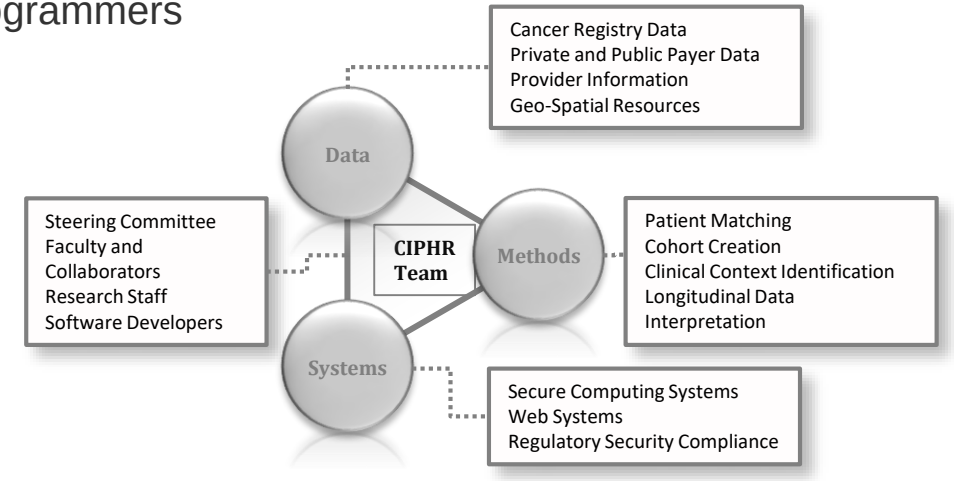
What do I mean by statewide cancer data linkages?

- Direct or probabilistic linkages among two or more secondary datasets that contain statewide cancer-related data:
  - Cancer surveillance (registry) data
  - Health insurance administrative claims and billing data
  - Healthcare resource, facility, and workforce data
  - Hospital discharge data
  - ED utilization data
  - Immunization records
  - DMV data
  - Sociodemographic and economic data
  - Bankruptcy filings

Developing Real World Linked Cancer Data Resources

Integrated, Inter-disciplinary team science

- Clinical domain experts
- Population/public health scientists
- Computer scientists/programmers
- Statisticians
- Database analysts



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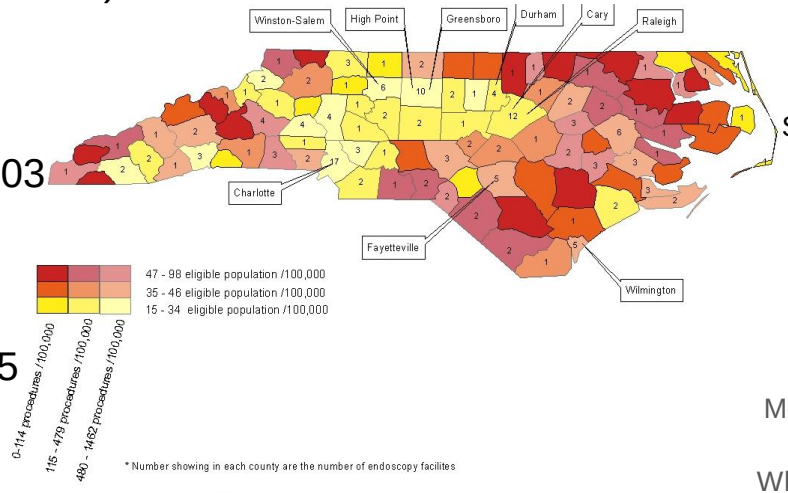
UNC Lineberger Cancer Information & Population Health Resource (CIPHR)

Unique linkages:
Cancer registry, multi-payer claims data (100% Medicare, 100% Medicaid, 70% private), SSI death index, other contextual data

Health Care Claims:
>6m persons since 2003
55% of NC population

NC Cancer Registry:
100% since 2003-2015
>650,000 cases

Cancer-cases claims:
85% of NC cancers
>552,000



Key collaborators
Chris Baggett
Laura Green
May Kuo
Public Health Faculty
Medicine Faculty

Shared resources
4 Systems developers
6 Analysts
1 program coordinator

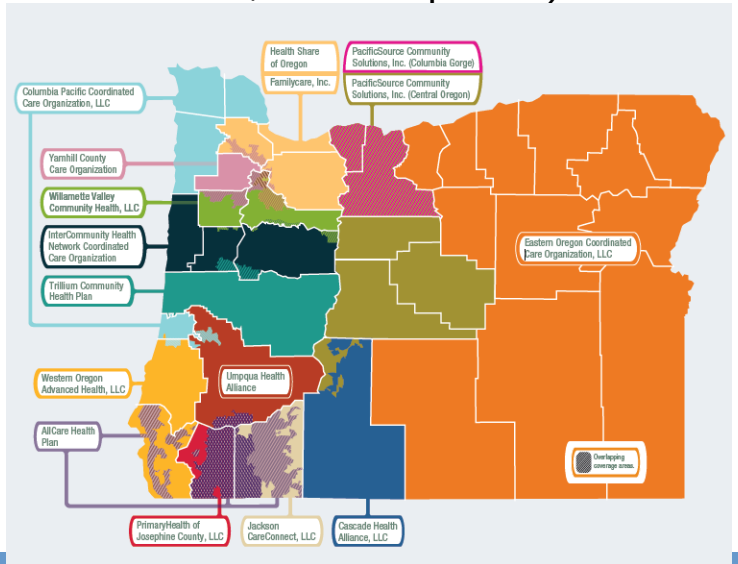
Key pubs (>60)
Meyer et al, NCMJ, 2014
Wheeler et al, H&P, 2014
Wheeler et al, Medical Care, 2013

UNC LINEBERGER

Oregon Health & Sciences University Center for Health Systems Effectiveness

Unique linkages:
Multipayer claims data (Medicaid, private insurers), other contextual data

Health Care Claims:
From 2007 for Medicaid; 2010 for private)



Key collaborators
John McConnell
Stephanie Renfro
Bonnie Lind
Public Health Faculty
Medicine Faculty

Shared resources
3 Health economists
5 Statisticians
3 Research assistants
1 program coordinator

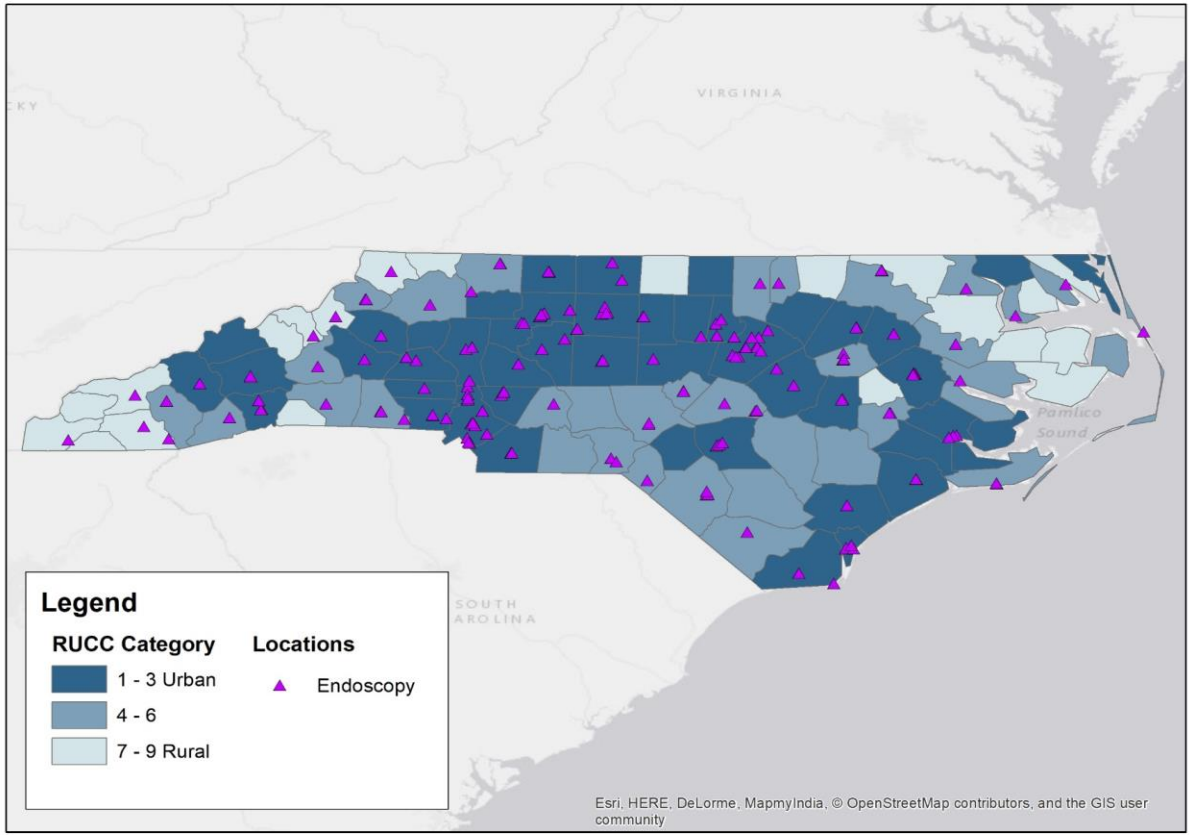
Key pubs (>52)
McConnell et al, Health Affairs, 2017
Davis et al, J of Rural Health, 2016
Charlesworth et al, JAMA IM, 2016

UNC LINEBERGER

Examples of Contextual Data to Augment State-level Cancer Registry-Linked-Claims

- Area Resource Files (ARF)
- Census/American Community Survey
- State Medical Facilities Plan Data
- State Pharmacy Association Data
- State Oncology Association Data
- RWJ County Health Rankings
- Public Health and Primary Care Networks
- National Association of County and City Health Officials (NAACHO)

Geolocating Endoscopy Facilities in NC



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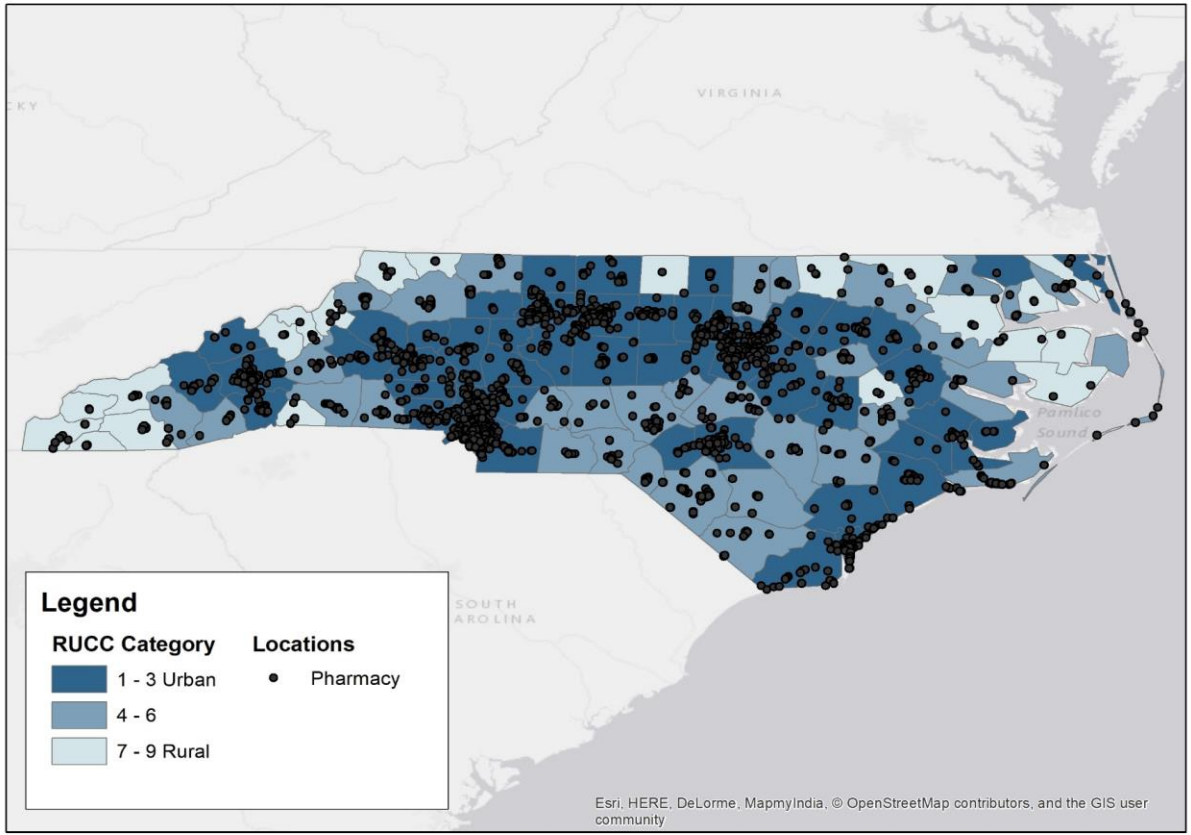
Geolocating Community Pharmacies in NC



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Geolocating American Cancer Society Primary Care Managers in NC

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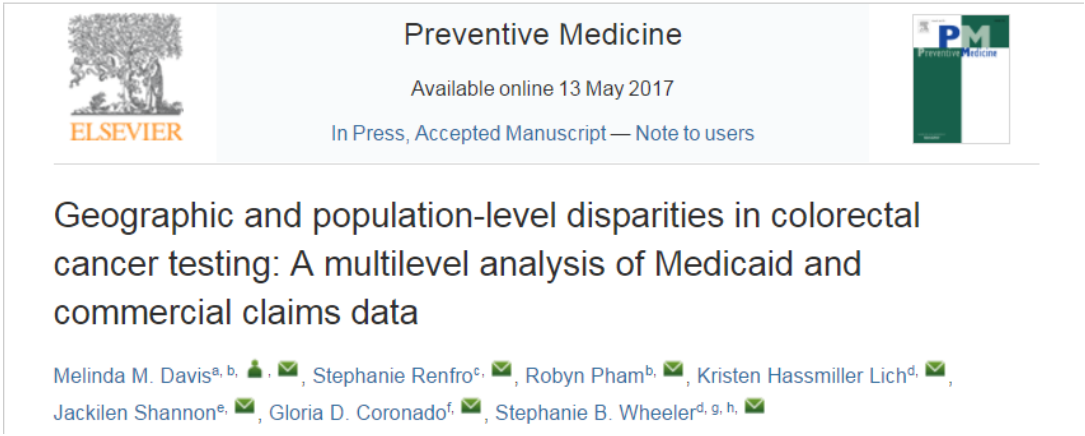
How Can State Data Linkages Be Useful?

- Identify geographic, socio-demographic and temporal trends in cancer risk factors (e.g., HPV vax), screening, incidence, mortality, care quality (e.g., surgery, chemo, radiation therapy), costs
- Identify and locate healthcare resources
- Identify social determinants of health outcomes
- Enable multilevel multivariable statistical and simulation modeling
- Target specific regions or sub-populations for interventions/implementation

Identifying geographic and socio-demographic correlates of colorectal cancer screening



ELSEVIER

Preventive Medicine

Available online 13 May 2017

In Press, Accepted Manuscript — Note to users

Geographic and population-level disparities in colorectal cancer testing: A multilevel analysis of Medicaid and commercial claims data

Melinda M. Davis[a, b], Stephanie Renfro[c], Robyn Pham[b], Kristen Hassmiller Lich[d], Jackilen Shannon[e], Gloria D. Coronado[f], Stephanie B. Wheeler[d, g, h]

ELSEVIER

Health & Place

Volume 29, September 2014, Pages 114–123

Regional variation in colorectal cancer testing and geographic availability of care in a publicly insured population ☆

Stephanie B. Wheeler[a, b, c, d], Tzy-Mey Kuo[b], Ravi K. Goyal[b], Anne-Marie Meyer[b], Kristen Hassmiller Lich[a], Emily M. Gillen[a], Seth Tyree[b], Carmen L. Lewis[b, c, e], Trisha M. Crutchfield[c, d],

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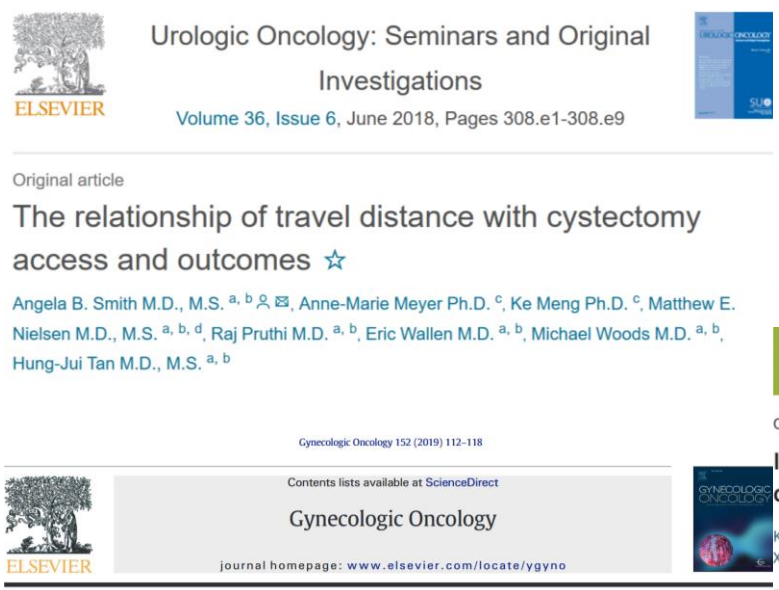
Identifying geographic and socio-demographic correlates of cancer treatment access & quality



Urologic Oncology: Seminars and Original Investigations

Volume 36, Issue 6, June 2018, Pages 308.e1-308.e9

Original article

The relationship of travel distance with cystectomy access and outcomes ☆

Angela B. Smith M.D., M.S. [a, b], Anne-Marie Meyer Ph.D. [c], Ke Meng Ph.D. [c], Matthew E. Nielsen M.D., M.S. [a, b, d], Raj Pruthi M.D. [a, b], Eric Wallen M.D. [a, b], Michael Woods M.D. [a, b], Hung-Jui Tan M.D., M.S. [a, b]

Gynecologic Oncology 152 (2019) 112–118

Contents lists available at ScienceDirect

Gynecologic Oncology

journal homepage: www.elsevier.com/locate/ygyno

Evaluating the urban-rural paradox: The complicated relationship between distance and the receipt of guideline-concordant care among cervical cancer patients

Lisa P. Spees [a,*], Stephanie B. Wheeler [b,c], Mahesh Varia [d], Morris Weinberger [b], Christopher D. Baggett [c,e], Xi Zhou [c], Victoria M. Petermann [f], Wendy R. Brewster [c,e,g]

[a] The Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, United States of America
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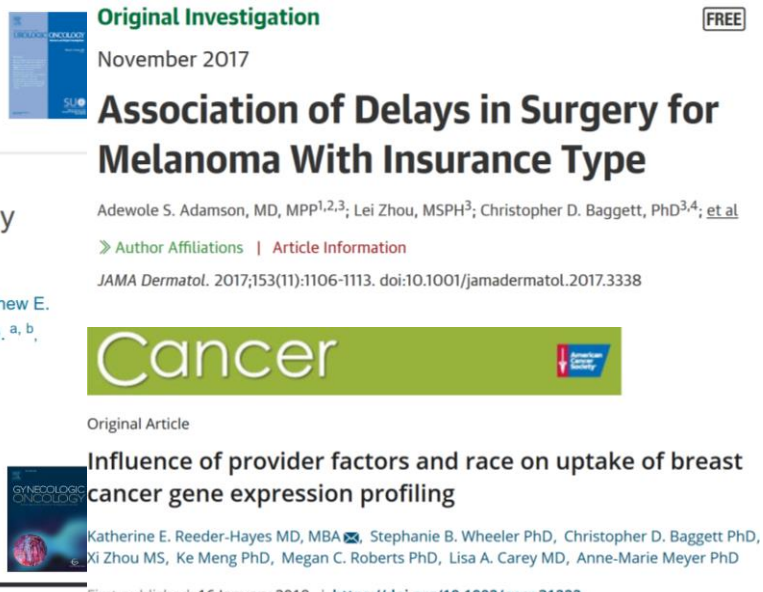
[f] School of Nursing, University of North Carolina at Chapel Hill, United States of America
[g] Department of Obstetrics & Gynecology, University of North Carolina at Chapel Hill, United States of America



Original Investigation

FREE

November 2017

Association of Delays in Surgery for Melanoma With Insurance Type

Adewole S. Adamson, MD, MPP[1,2,3]; Lei Zhou, MSPH[3]; Christopher D. Baggett, PhD[3,4]; et al

Author Affiliations | Article Information

JAMA Dermatol. 2017;153(11):1106-1113. doi:10.1001/jamadermatol.2017.3338

Cancer

Original Article

Influence of provider factors and race on uptake of breast cancer gene expression profiling

Katherine E. Reeder-Hayes MD, MBA, Stephanie B. Wheeler PhD, Christopher D. Baggett PhD, Xi Zhou MS, Ke Meng PhD, Megan C. Roberts PhD, Lisa A. Carey MD, Anne-Marie Meyer PhD

First published: 16 January 2018 | https://doi.org/10.1002/cncr.31222

Medical Care. 56(5):430–435, MAY 2018

DOI: 10.1097/MLR.0000000000000906, PMID: 29578953

Issn Print: 0025-7079

Publication Date: 2018/05/01

Care Coordination and Multispecialty Teams in the Care of Colorectal Cancer Patients

Justin G. Trogdon; Yunkyung Chang; Saray Shai; Peter J. Mucha; Tzy-Mey Kuo; Anne M. Meyer; Karyn B. Stitzenberg

UNC LINEBERGER

Identifying cancer care costs and cost-effectiveness of treatments and interventions

Published in final edited form as:
Breast Cancer Res Treat. 2017 November ; 166(1): 207–215. doi:10.1007/s10549-017-4386-2.

Medical costs of treating breast cancer among younger Medicaid beneficiaries by stage at diagnosis

Justin G. Trogdon[1], **Donatus U. Ekwueme**[2], **Diana Poehler**[3], **Cheryll C. Thomas**[2], **Katherine Reeder-Hayes**[1], and **Benjamin T. Allaire**[3]

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Breast Cancer Res Treat. 2017 July ; 164(2): 429–436. doi:10.1007/s10549-017-4249-x.

Journal of Endourology, Vol. 26, No. 8 | Laparoscopy and Robotic Surgery

Cost Analysis of Robot-Assisted Laparoscopic Versus Hand-Assisted Laparoscopic Partial Nephrectomy

James E. FergusonIII, Ravi K. Goyal, Mathew C. Raynor, Matthew E. Nielsen, Raj S. Pruthi, Paul M. Brown, and Eric M. Wallen

Published Online: 7 Aug 2012 | https://doi.org/10.1089/end.2011.0568

Breast cancer treatment costs in younger, privately insured women

Benjamin T. Allaire[1], **Donatus U. Ekwueme**[2], **Diana Poehler**[1], **Cheryll C. Thomas**[2], **Gery P. Guy Jr.**[2], **Sujha Subramanian**[1], and **Justin G. Trogdon**[3]

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 14, E18 FEBRUARY 2017

Cancer

Original Article | Free Access

Association between medical home enrollment and health care utilization and costs among breast cancer patients in a state Medicaid program

Racquel E. Kohler PhD, Ravi K. Goyal MS, Kristen Hassmiller Lich PhD, MHSA, Marisa Elena Domino PhD, Stephanie B. Wheeler PhD, MPH

First published: 19 August 2015 | https://doi.org/10.1002/cncr.29596 | Cited by: 4

ORIGINAL RESEARCH

Cost-Effectiveness Analysis of Four Simulated Colorectal Cancer Screening Interventions, North Carolina

Kristen Hassmiller Lich, PhD[1]; David A. Cornejo[2]; Maria E. Mayorga, PhD[2]; Michael Pignone, MD, MPH[3,4,5,6]; Florence K.L. Tangka, PhD[7]; Lisa C. Richardson, MD, MPH[7]; Tzy-Mey Kuo, PhD, MPH[3]; Anne-Marie Meyer, PhD[3,8]; Ingrid J. Hall, PhD, MPH[7]; Judith Lee Smith, PhD[7]; Todd A. Durham, MS[1]; Steven A. Chall, MS[9]; Trisha M. Crutchfield, MHA, MSIS[4,6]; Stephanie B. Wheeler, PhD, MPH[1,3,4]

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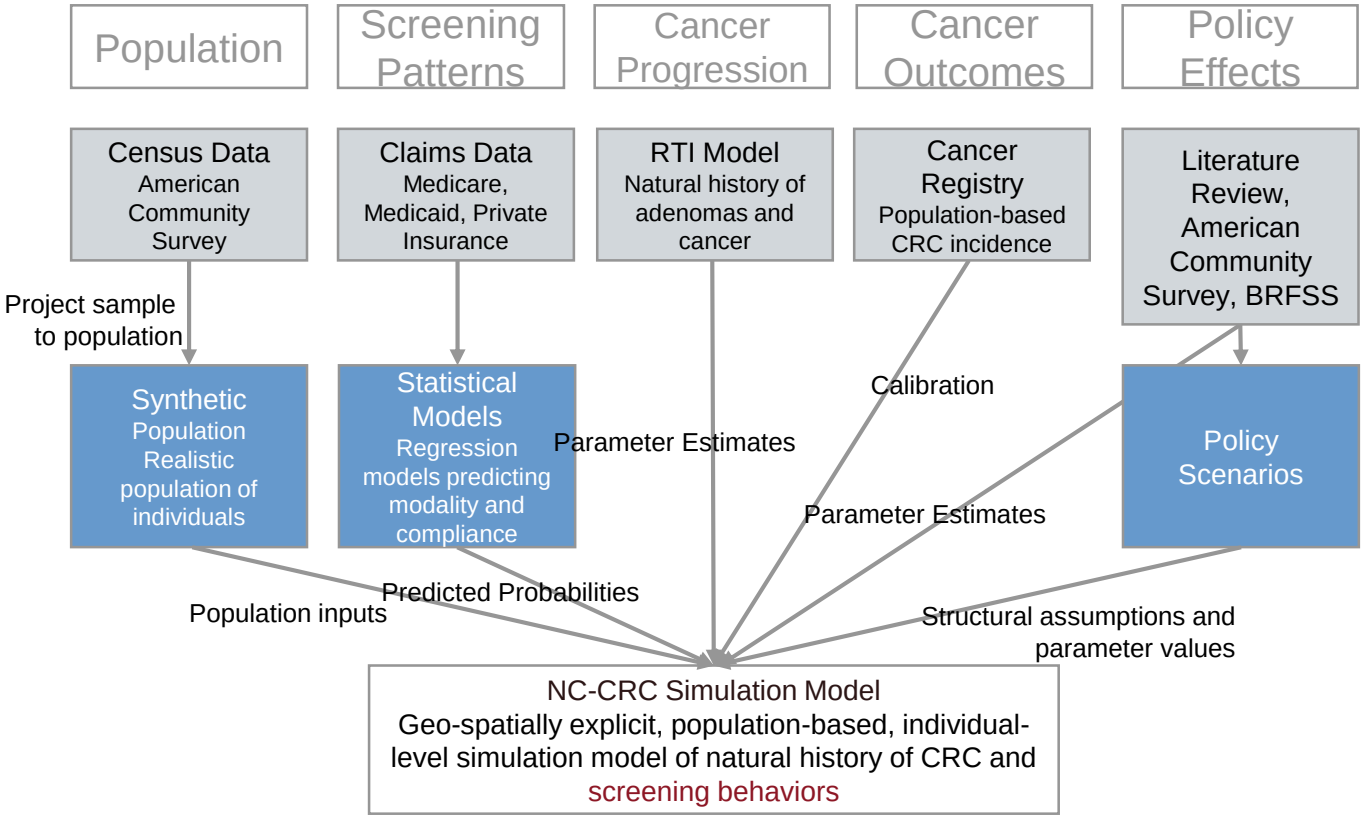
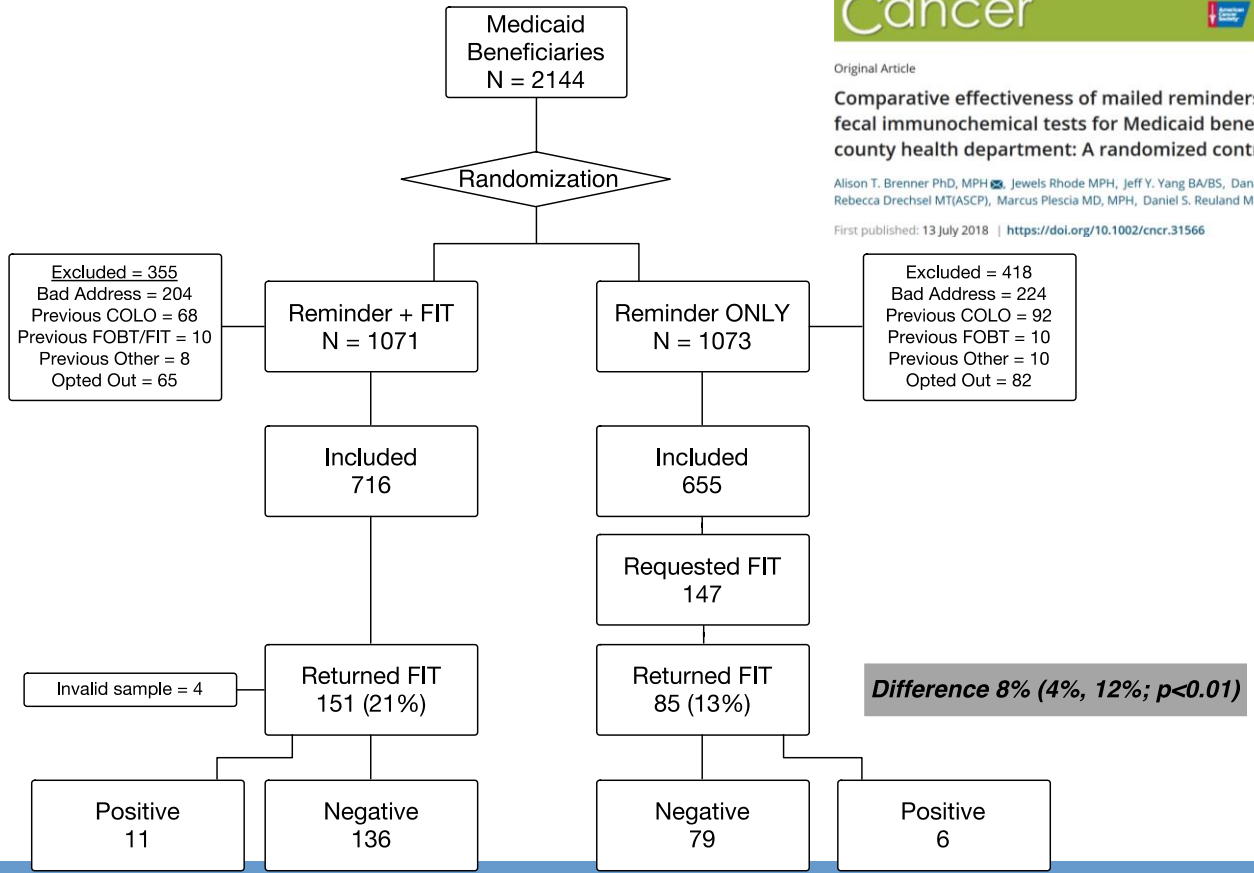
Enabling multilevel multivariable statistical and simulation modeling to project outcomes



Targeting specific regions or sub-populations for interventions/implementation



Cancer

Original Article

Comparative effectiveness of mailed reminders with and without fecal immunochemical tests for Medicaid beneficiaries at a large county health department: A randomized controlled trial

Alison T. Brenner PhD, MPH, Jewels Rhode MPH, Jeff Y. Yang BA/BS, Dana Baker RN, BSN, CCM, Rebecca Drechsel MT(ASCP), Marcus Plescia MD, MPH, Daniel S. Reuland MD, MPH ... See all authors

First published: 13 July 2018 | https://doi.org/10.1002/cncr.31566

Difference 8% (4%, 12%; p<0.01)

UNC LINEBERGER

Lessons Learned

- Dedicate resources to build data computing infrastructure, expertise & capacity
- Plan (& pay) for regular data updates
- Partner early and be a *good* partner! (eg, ROI)
- Explore probabilistic data linkages (SSN and name/address not always necessity)
- Develop multidisciplinary teams
- Consider unusual linkages (e.g., retail, environmental, financial, education, transportation and labor market data)

Thank you!

For more info, check out:

https://ciphr.unc.edu

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stephanie_wheeler@unc.edu

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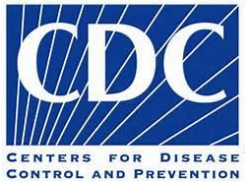


Using Optum claims data in US cancer patients: an example in adolescent and young adults

Karen J. Wernli, PhD
Associate Investigator
January 8, 2019

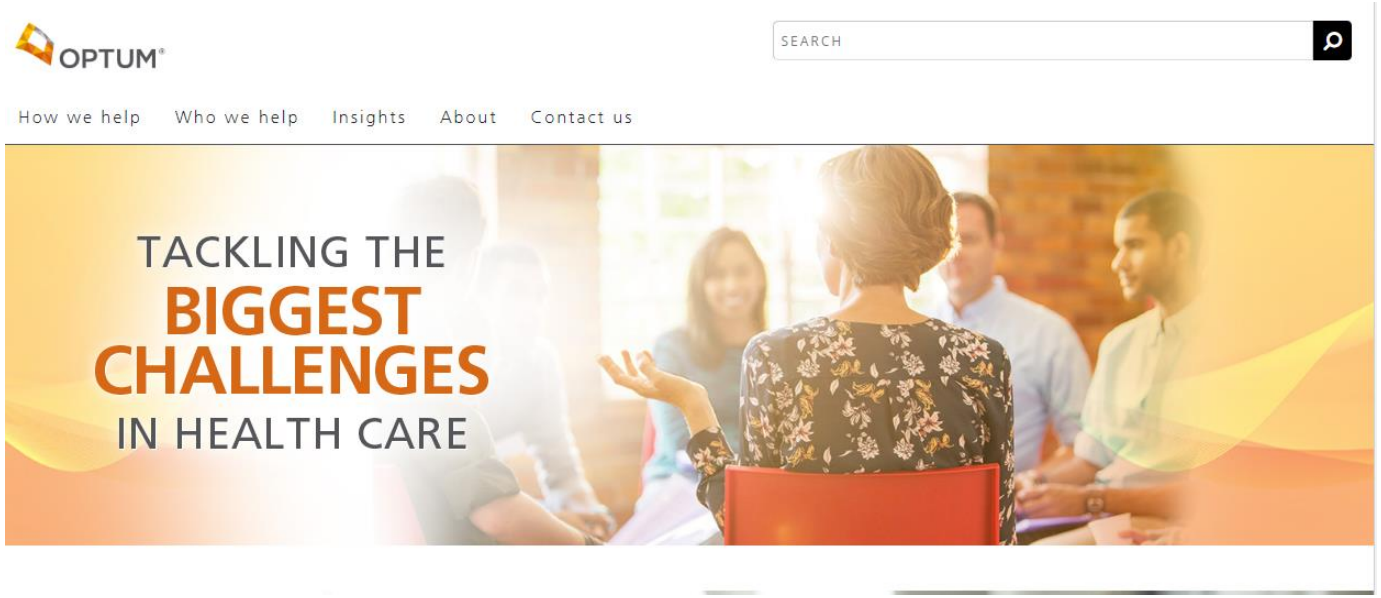
KAISER PERMANENTE®

Financial Disclosures

- Nothing to disclose

Challenge that I faced

Optum



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Current R21 specific aims

To assess variation in end of life among adolescent and young adult cancer patients, from 2001 – 2016 by time and geography, evaluating:

- Emergency department visits
- Hospitalizations
- Intensive Care Unit stays
- Surgery
- Receipt of chemotherapy

TABLE 2. Healthcare services at end of life by time period						
Measure	**Overall**	**2001 2004**	**2005 2008**	**2009 2012**	**2013 2016**	**Chi-square p-value**
Within 30 days of death						
≥2 ED visits	16.3%	15.3%	15.6%	16.3%	22.1%	0.01
Hospitalization	78.4%	-	77.3%	79.1%	80.7%	0.24
ICU stay	40.1%	35.8%	40.2%	42.7%	42.9%	0.004
Surgery	4.5%	4.4%	4.1%	5.1%	4.5%	0.63
Within 14 days of death						
Chemotherapy	12.0 %	12.5%	11.5%	12.0%	12.3%	0.90

TABLE 3. Healthcare services at end of life overall and by region and time						
Measure	**Overall**	**North-east**	**Mid-west**	**South**	**West**	**Chi-square p-value**
Within 30 days of death						
≥2 ED visits	16.3%	16.7%	16.6%	15.9%	16.9%	0.92
Hospitalization	78.4%	83.4%	78.2%	79.1%	74.3%	0.008
ICU stay	40.1%	41.9%	36.2%	42.6%	38.3%	<0.003
Surgery	4.5%	5.8%	4.0%	4.6%	4.5%	0.50
Within 14 days of death						
Chemotherapy	12.0%	13.0%	11.7%	12.2%	11.5%	0.87

What are these claims data good for?

- Healthcare data for commercially insured <65 years in all states and over time
- Patterns of healthcare utilization: time, geography
- Evaluation of change in care: chemotherapy, hospital
- Short-term outcomes
- Evaluating mortality

Caveats

- Lacking cancer diagnosis date, stage and tumor type
- Longitudinal analyses
- Limited confounders

Process

- In grant preparation, began speaking to Optum in support of purchasing claims data
- Optum provided a letter of support for application
- Work with an Optum programmer to build a cohort dataset
- Optum provides training of data to research team
- Optum available for additional data support as needed

Thank you

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