Cancer Care in Rural America: Research to Understand and Address Challenges

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Healthcare Delivery Research Program
Division of Cancer Control and Population Sciences
National Cancer Institute

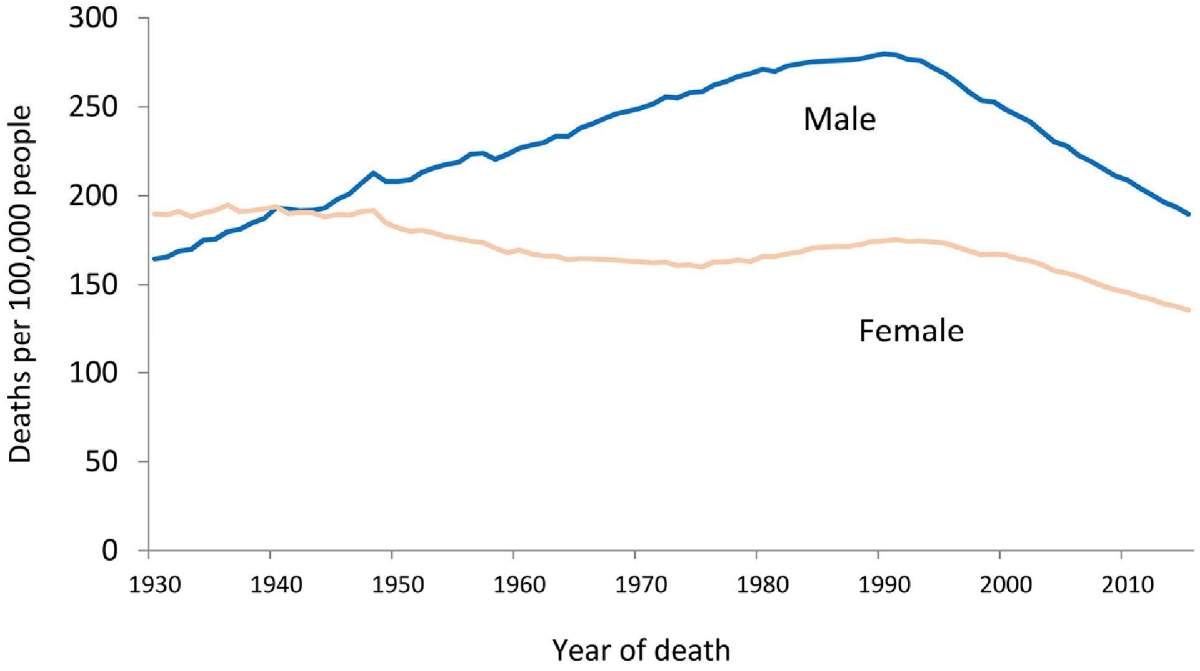
NOTHING WILL STOP US™

NATIONAL CANCER ACT 50 YEARS

…opportunity to commemorate the tremendous progress made in cancer research, consider the needs that remain, and affirm our unwavering commitment to patients.

- Ned Sharpless, MD, NCI Director

Age-Standardized Cancer Death Rates in the US



CA: A Cancer Journal for Clinicians, Volume: 68, Issue: 5, Pages: 329-339, First published: 10 July 2018, DOI: (10.3322/caac.21460)

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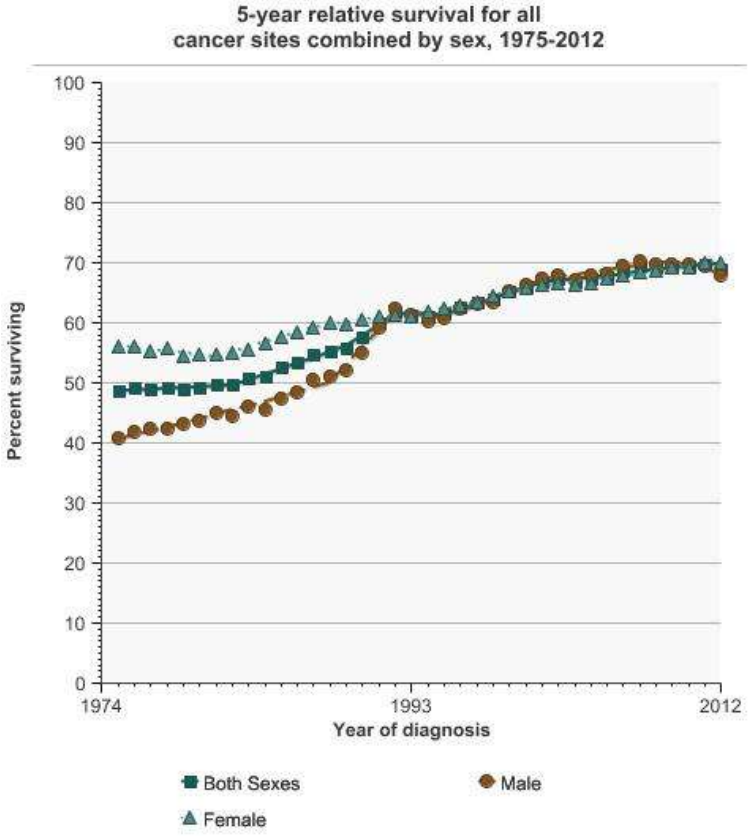


Source: SEER Program, National Cancer Institute. Underlying incidence data are from the SEER 9 areas (http://seer.cancer.gov/registries/terms.html).
Data are not age-adjusted.
Expected survival rates are derived from the U.S. Annual Life Tables.

NCIs Dedication to Health Disparities Research

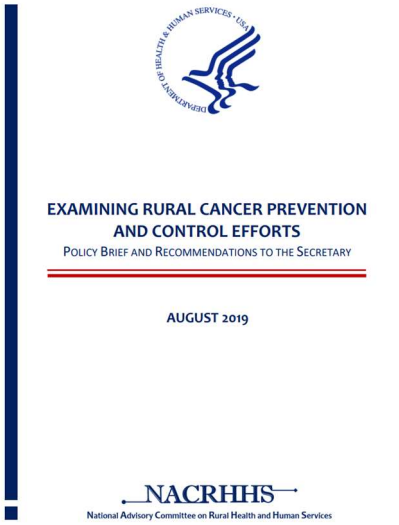
- The National Cancer Institute has designated reducing health disparities as a special challenge
- The **Division of Cancer Control and Population Sciences** (DCCPS) health disparities mission is to *monitor the differential burden of cancer among Americans and promote and conduct research that identifies and addresses the* ***economic, social, cultural, psychological, behavioral,*** *and* ***biological mechanisms*** *contributing to these disparities across the cancer control continuum and throughout the human lifespan*

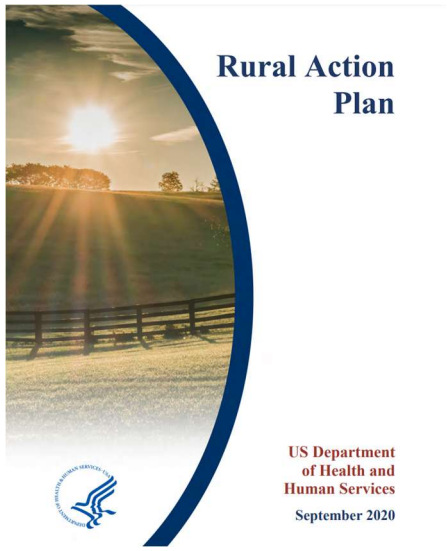
Trump Administration

By the authority vested in me as President by the Constitution and the laws of the United States of America, it is hereby ordered as follows:

Section 1. *Purpose*. My Administration is committed to improving the health of all Americans by improving access to better care, including for the approximately 57 million Americans living in rural communities. Americans living in rural communities face unique challenges when seeking healthcare services, such as limited transportation opportunities, shortages of healthcare workers, and an inability to fully benefit from technological and care-delivery innovations. These factors have contributed to financial insecurity and impaired health outcomes for rural Americans, who are more likely to die from five leading causes, many of which are preventable, than their urban counterparts. That gap widened from 2010 to 2017 for cancer, heart disease, and chronic lower respiratory disease.

Executive Order, 8/3/2020





Biden Administration

Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government

JANUARY 20, 2021 • PRESIDENTIAL ACTIONS

"It is therefore the policy of my Administration that the Federal Government should pursue a comprehensive approach to advancing equity for all, including people of color and others who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality."

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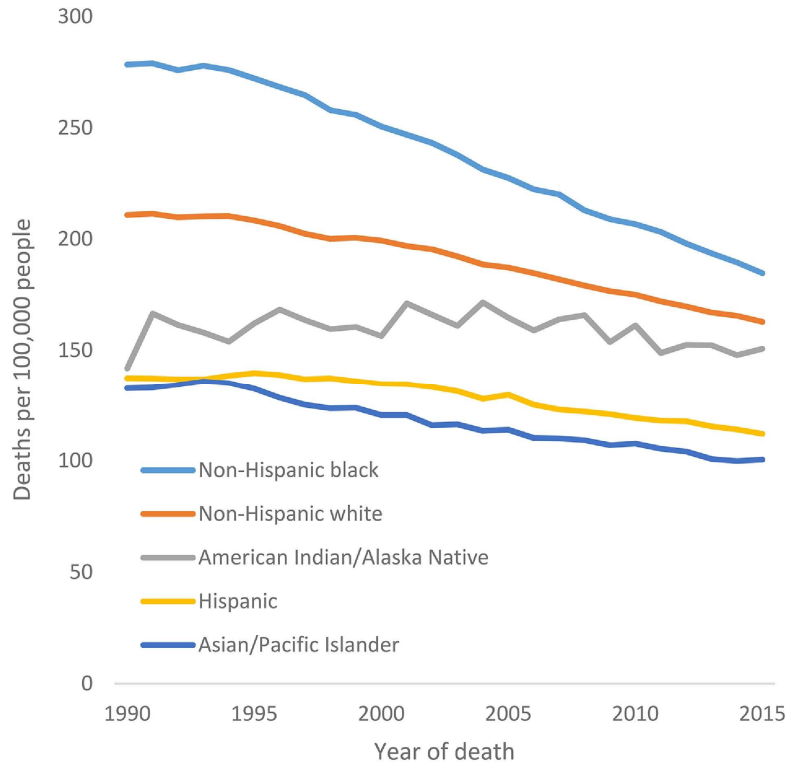
US Cancer Mortality by Race/Ethnicity



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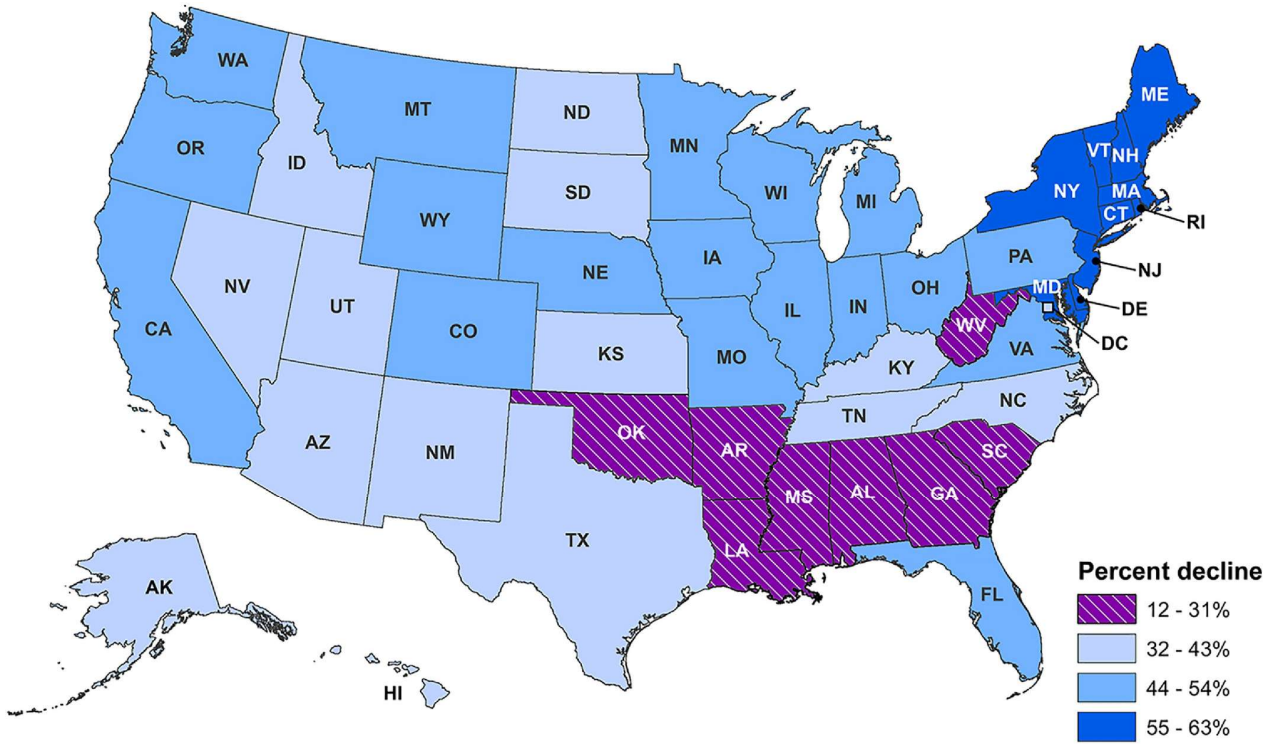
Decline in Colorectal Cancer Mortality Rate From 1980–82 to 2013–15



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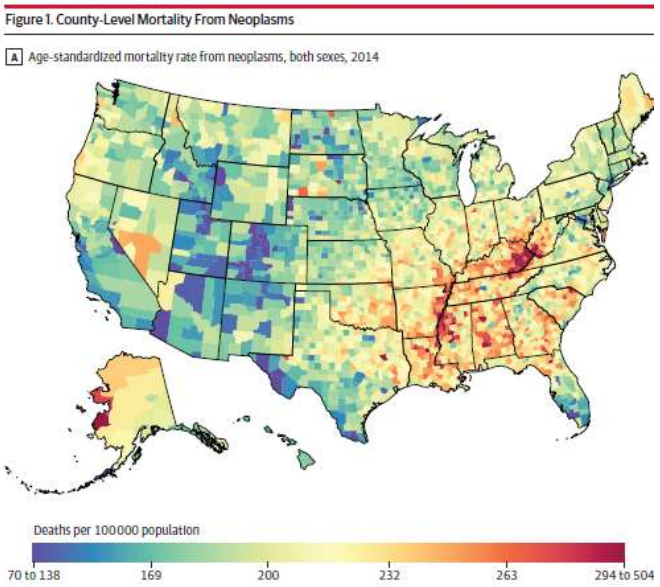
Overall Rural Cancer Burden

- Higher overall cancer incidence and mortality in rural versus urban areas
- Includes cancers for which prevention and/or early detection through screening are possible
  - Cervical
  - Colorectal
  - Lung
  - Melanoma
  - Oropharyngeal



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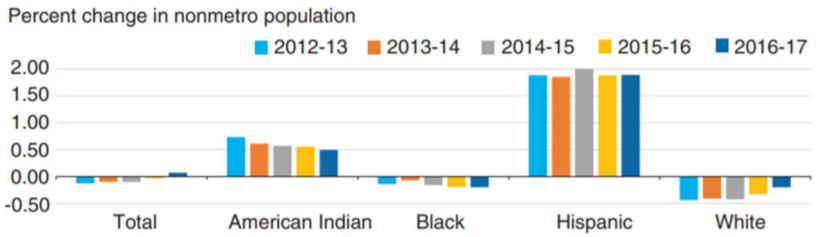
Growth in Rural Minority Populations

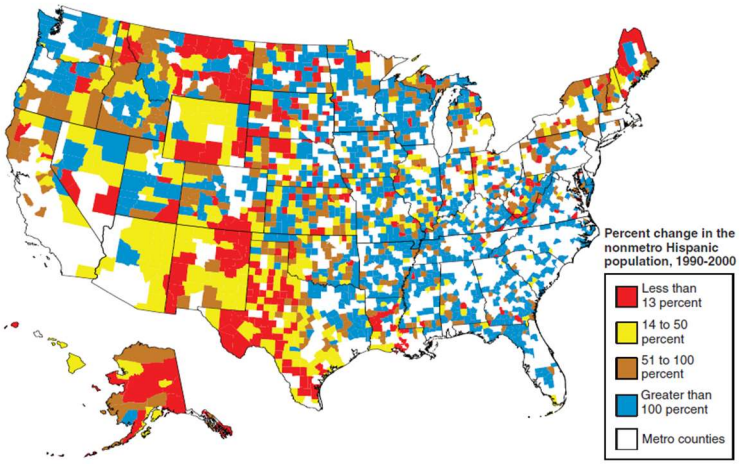
Improving nonmetro population trends since 2013 are mostly due to lower population loss among non-Hispanic Whites and stable growth among Hispanics



Note: Statistics for Whites, Blacks, and American Indians include only non-Hispanic residents. Residents included in the Hispanic category may be of any race. Groups with relatively few nonmetro residents (Asians, Pacific Islanders, and those reporting multiple races) are not included here.

Source: USDA, Economic Research Service using data from U.S. Census Bureau, Population Estimates Program.

Hispanic population growth is higher in the Southeast and Midwest



Source: Compiled by ERS using data from the 1990 and 2000 U.S. Censuses.

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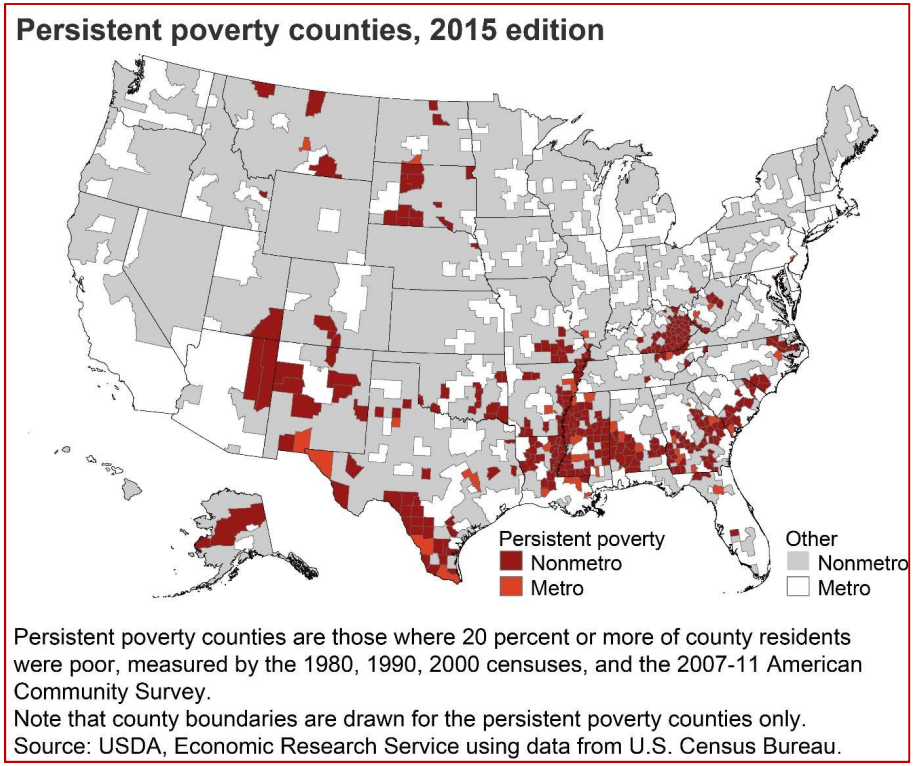
Persistent Poverty and Cancer

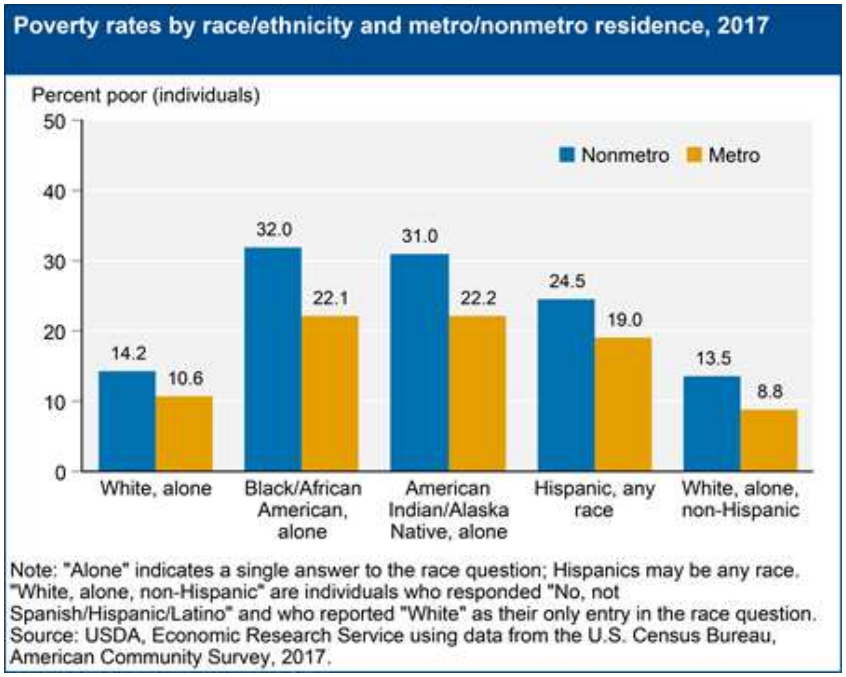
The study found that people who live in counties in the U.S. that experience persistent poverty are more likely to die from cancer than people in other counties. This risk was over and above the heightened risk seen in areas experiencing current—but not persistent—poverty.

- *CEBP. 2020 Oct; 29(10): 1949-1954.*



Persistent poverty counties are those where 20 percent or more of county residents were poor, measured by the 1980, 1990, 2000 censuses, and the 2007-11 American Community Survey.
Note that county boundaries are drawn for the persistent poverty counties only.
Source: USDA, Economic Research Service using data from U.S. Census Bureau.

https://www.cancer.gov/news-events/cancer-currents-blog/2020/persistent-poverty-increased-cancer-death-risk


Poverty rates by race/ethnicity and metro/nonmetro residence, 2017
Percent poor (individuals)
50
40
30
20
10
0
Nonmetro
Metro
14.2
10.6
32.0
22.1
31.0
22.2
24.5
19.0
13.5
8.8
White, alone
Black/African American, alone
American Indian/Alaska Native, alone
Hispanic, any race
White, alone, non-Hispanic
Note: "Alone" indicates a single answer to the race question; Hispanics may be any race. "White, alone, non-Hispanic" are individuals who responded "No, not Spanish/Hispanic/Latino" and who reported "White" as their only entry in the race question.
Source: USDA, Economic Research Service using data from the U.S. Census Bureau, American Community Survey, 2017.

Rural Challenges

- Higher poverty rates than urban areas
- Lower educational attainment
- Higher proportion of elderly
- Few resources for public health infrastructure
- Higher proportion of uninsured
- Geographic and social isolation
- Insufficient transportation
- Insufficient broadband access
- Higher medical mistrust
- Cancer-related fatalism
- Hospital closures
- Lack of access to health services; HPSAs

Rural Strengths

Individual, organizational, community, and cultural assets may be leveraged to inform intervention development

- Strong relationships and social networks
- Social support
- Resilience
- Values such as self-sufficiency, independence, and autonomy
- Strong local- and community-based organizations
- Connectivity across sectors/community cohesion

NCI DCCPS Rural Cancer Control Activities (Other than Funding)

Year	Activity
2016-2017	Emphasis on rural cancer disparities, Cancer Currents blogs
May 2017	Research Meeting: “Rural Cancer Control: Challenges & Opportunities,” University of Memphis School of Public Health, Memphis, TN
June 2017	CEBP* commentary: “Making the Case for Investment in Rural Cancer Control: An Analysis of Rural Cancer Incidence, Mortality, and Funding Trends”
October 2017	NCI Workshop: “Understanding Definitions of Rural/Rurality: Implications for Rural Cancer Control,” NCI Shady Grove
May 2018	Research Meeting: “Accelerating Rural Cancer Control,” NIH Natcher Auditorium
November 2018	CEBP* paper: “An Overview of the National Cancer Institute's Initiatives to Accelerate Rural Cancer Control Research” and “Opportunities and Challenges in Rural Cancer Research: An Epidemiologic Perspective”
August 2020	CEBP* paper: “Advancing Rural Cancer Control Research: NCI Efforts to Identify Gaps and Opportunities”
October 2020	CEBP* paper: “Persistent Poverty and Cancer Mortality Rates: An Analysis of County-Level Poverty Designations”

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**Cancer Epidemiology, Biomarkers & Prevention*

DCCPS Rural Funding Initiatives Across the Cancer Control Continuum

	NCORP (2014 & 2018)	Moonshot Initiatives (2018)	NCI-Des Ca Ctr Supplements (2018 & 2019)	Request For Applications (2019 & 2021)	R01 Grant Supplements (2020)	Program Announce. (2021)
[Capacity Building]	✓		✓		✓	
Etiology					✓	
Prevention					✓	✓
Detection		✓			✓	
Diagnosis	✓			✓		
Treatment	✓			✓	✓	
Survivorship	✓	✓		✓	✓	

THE CANCER CONTROL CONTINUUM

FOCUS

Etiology

- Environmental factors
- Genetic factors
- Gene-environment interactions
- Medication (or pharmaceutical exposure)
- Infectious agents
- Health behaviors

Prevention

- Tobacco control
- Diet
- Physical activity
- Sun protection
- HPV vaccine
- Limited alcohol use
- Chemoprevention

Detection

- Pap/HPV testing
- Mammography
- Fecal occult blood test
- Colonoscopy
- Lung cancer screening

Diagnosis

- Shared and informed decision making

Treatment

- Curative treatment
- Non-curative treatment
- Adherence
- Symptom management

Survivorship

- Coping
- Health promotion for survivors

CROSSCUTTING AREAS

Communications

Surveillance

Health Disparities

Decision Making

Implementation Science

Health Care Delivery

Epidemiology

Measurement

Adapted from David B. Abrams, Brown University School of Medicine

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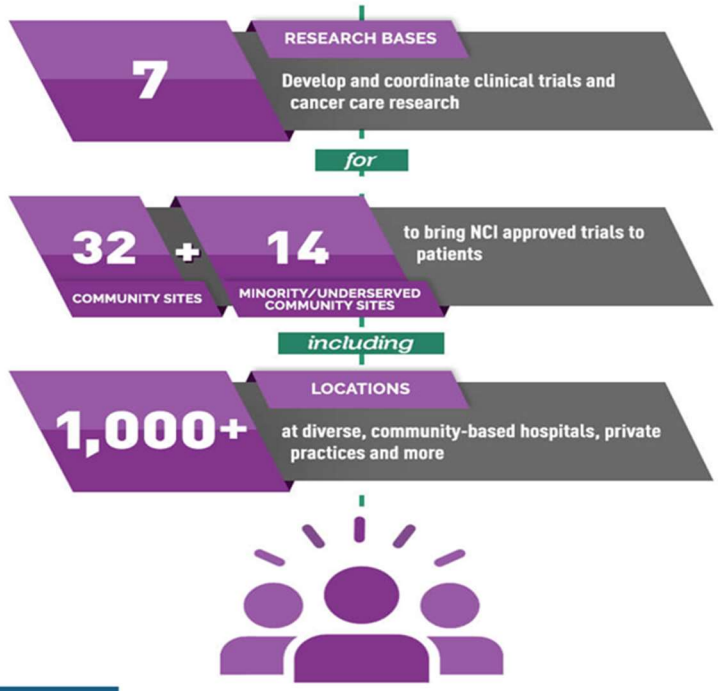
Diagnosis	✓			✓		
Treatment	✓			✓	✓	
Survivorship	✓	✓		✓	✓	

NATIONAL CANCER INSTITUTE

The **NCI Community Oncology Research Program (NCORP)** brings cancer research studies and results to patients in a variety of community settings across the United States.



NCI Community Oncology Research Program
A program of the National Cancer Institute of the National Institutes of Health

NCORP.cancer.gov

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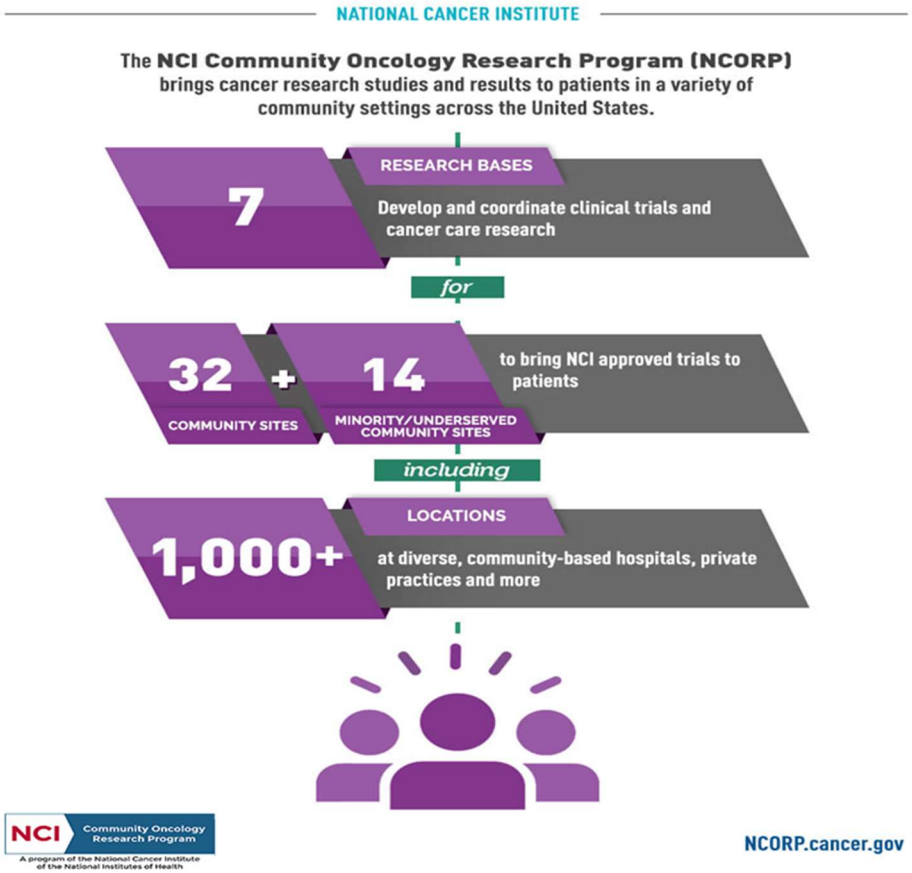

Cancer Care Delivery Research:

Improve clinical outcomes and patient well-being by **intervening** on **patient, clinician, and organizational factors** that influence care delivery with an emphasis on diagnosis, treatment, survivorship, and end-of-life care

Understand and address **health disparities**…both studies focused exclusively on disparities and the inclusion of disparities-related aims in studies with a broad focus

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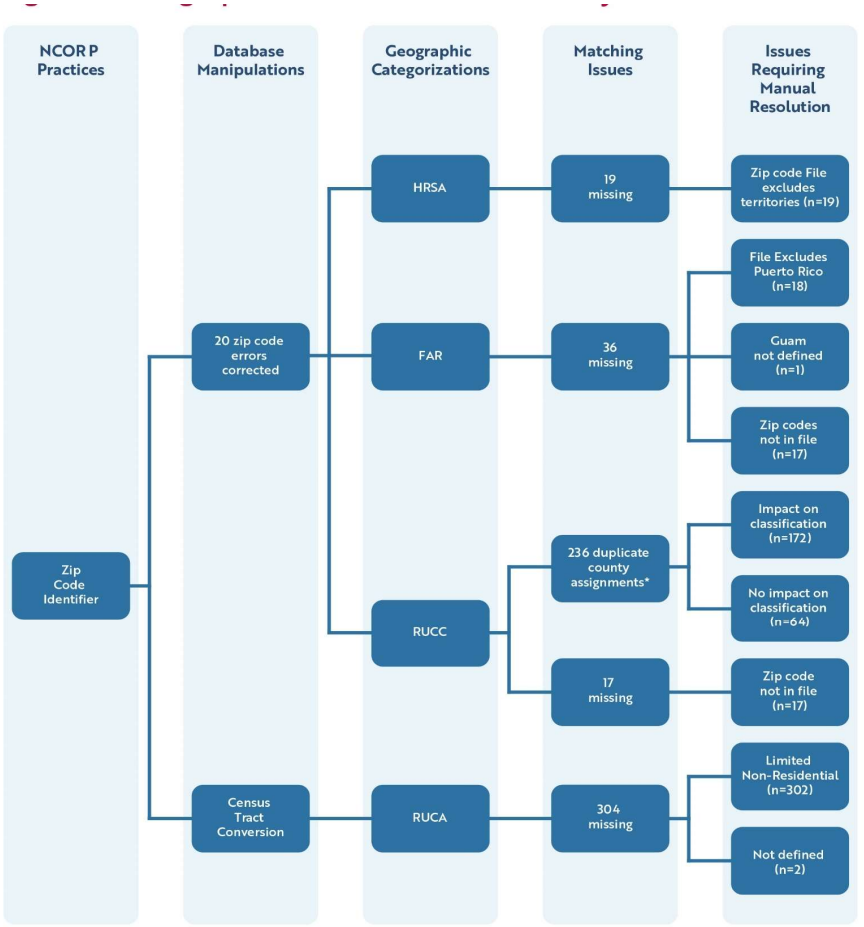
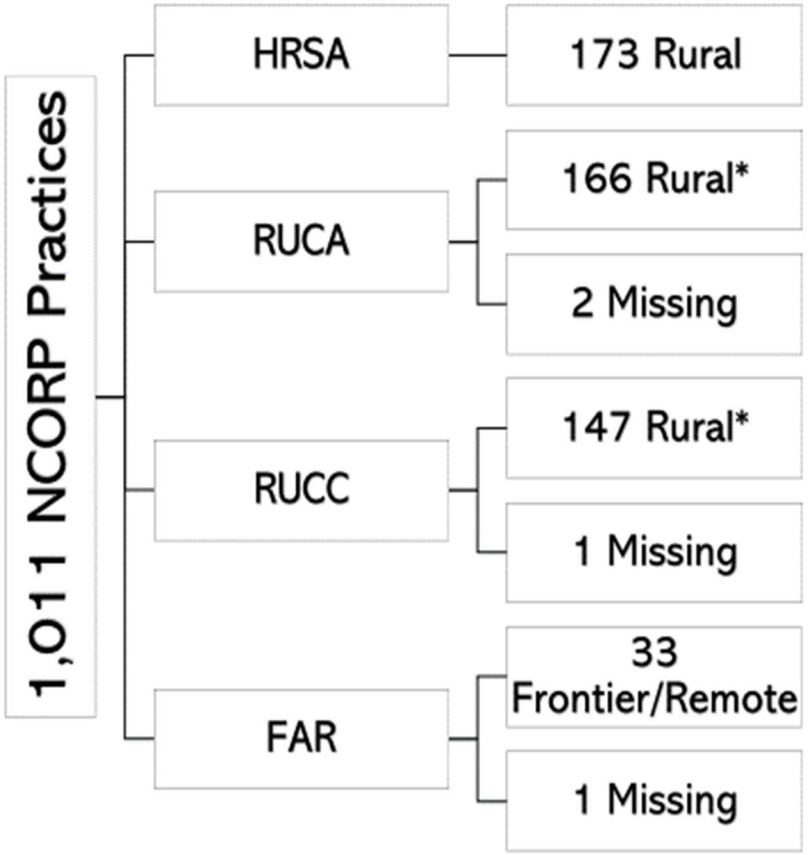
NCORP Rural Classification Process

(Led by Shellie Ellis, PhD, from the University of Kansas)



Rural Classification Results

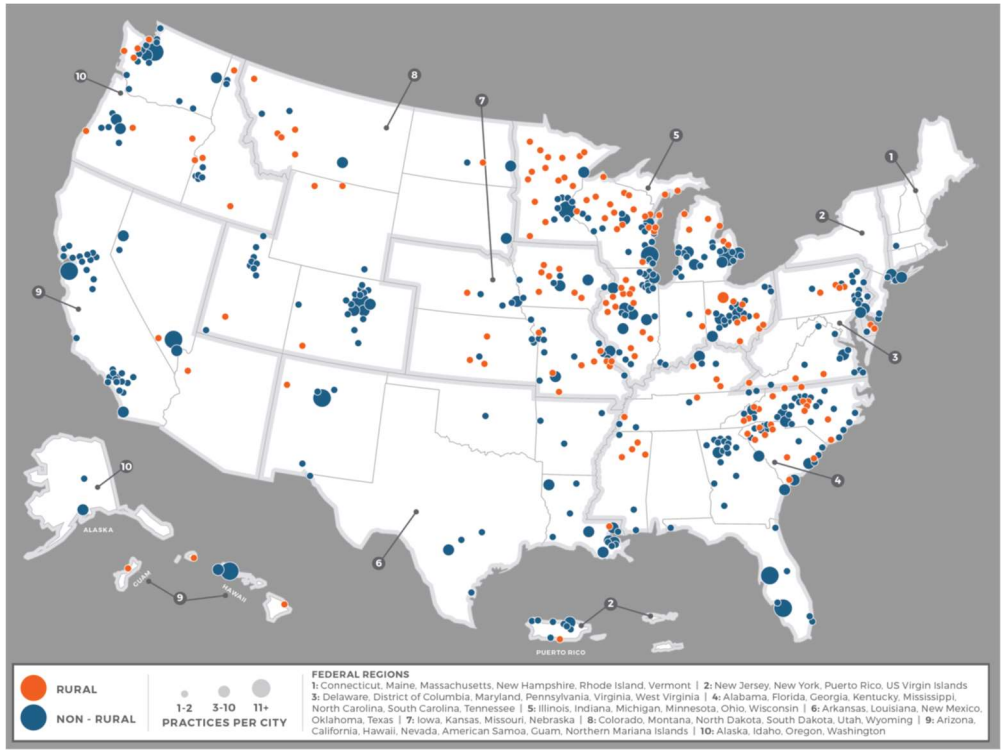


*Both RUCC and RUCA classified 1 practice as rural that was not identified by HRSA

How Rural is NCORP?

- 17% of participating practices
- 72% of NCORP Sites have at least one rural practice

- 2014 Funding

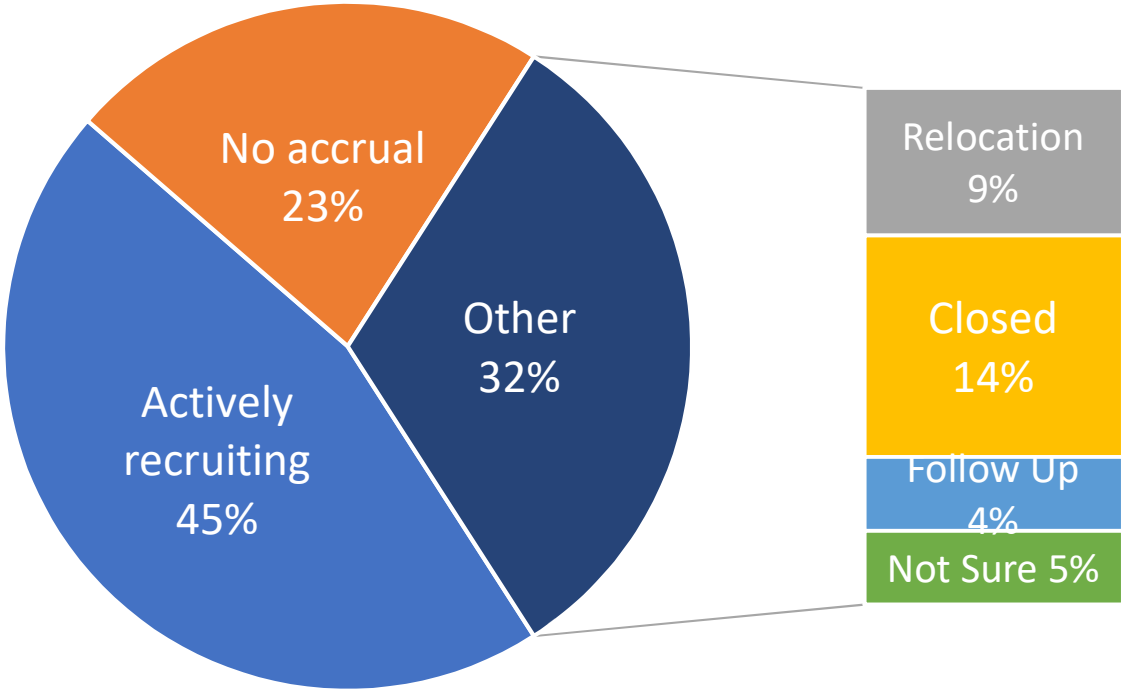


New in 2018

- University of Kansas Cancer Center -- first Minority/Underserved Community Site focused on rural populations

- MaineHealth Cancer Care Network [Scot Remick, MD]

Rural NCORP Practice Accrual to 22 CCDR Studies (n = 173)



NCI-Designated Cancer Center Supplements (2018 & 2019)

Develop and advance research capacity and collaborations with rural clinics to conduct research in cancer prevention and control.

Example: UT Southwestern Simmons Comprehensive Cancer Center

> Conduct a hybrid implementation-effectiveness intervention study to strengthen practice capacity to optimize result reporting, diagnosis, and referral to treatment for underserved, rural-residing individuals who screen positive for liver and cervical cancer and seek care in the South Texas US-Mexico border.

Accelerating Colorectal Cancer Screening and follow-up through Implementation Science

ACCSIS

Build the evidence base for multilevel interventions to increase rates of colorectal cancer screening, follow-up, and referral to care.

- Appalachia (University of Kentucky & Ohio State University)
- Rural populations and community health centers (University of North Carolina)
- Rural and frontier communities (Oregon Health Sciences University and Kaiser Permanente Northwest)
- Rural and urban populations (University of California at San Diego and San Diego Status University)

CANCER MOONSHOT
RESEARCH INITIATIVES

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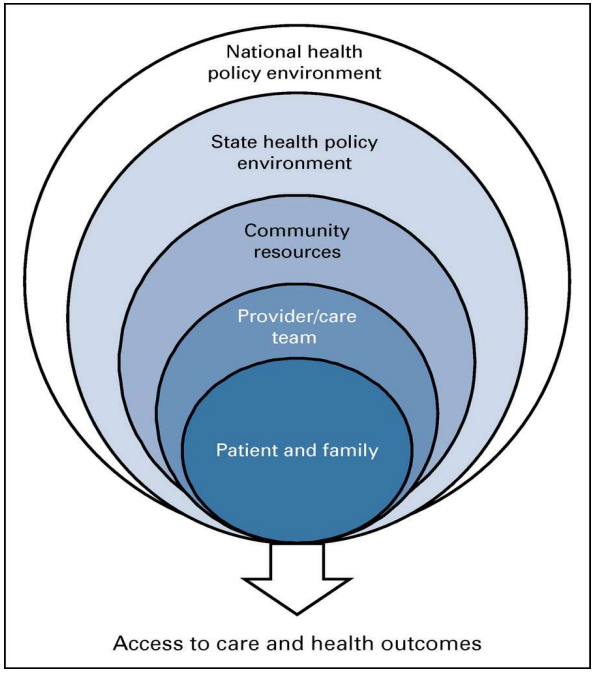
Factors at Multiple Levels Associated with Geographic Disparities in Cancer Care and Outcomes (Figure 2)



Published in: K. Robin Yabroff; Xuesong Han; Jingxuan Zhao; Leticia Nogueira; Ahmedin Jemal; *JCO Oncology Practice* 2020 16409-413.
DOI: 10.1200/OP.20.00352
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Improving the Management of Symptoms during and Following Cancer Treatment

IMPACT

Develop evidence that will guide efforts to improve symptom control for cancer patients during treatment and survivorship to build a foundation for effective cancer symptom management in routine clinical care.

- Small, rural, and community cancer centers (Dana-Farber Cancer Institute, Baptist Memorial Hospital and Dartmouth College [Sandra Wong, MD])
- Rural and urban populations (Mayo Clinic Rochester)

CANCER MOONSHOT
RESEARCH INITIATIVES

Administrative Supplements to Funded Grants (2020)

University of Colorado, Denver Parent Grant: Addressing Urban Rural Disparities in Cancer: The Case for Registry Expansion (CA229551)	Oregon Health & Science University Parent Grant: EXERCISING TOGETHER: A Randomized Controlled Trial of Partnered Exercise Training on the Health of Couples Coping with Cancer (CA218093)
University of Kansas Medical Center Parent Grant: Adaptive Intervention to Maximize Colorectal Screening in Safety Net Populations (CA188898)	Beckman Research Institute of the City of Hope Parent Grant: Epigenetic Damage in Women Living in LA Food-Desert Zip Codes (CA220693)
Vanderbilt University Medical Center Parent Grant: Enhancing Cancer Care Of Rural Dwellers Through Telehealth and Engagement (ENCORE) (CA240093)	Washington University Parent Grant: Implementing Multilevel Colon Cancer Screening Interventions to Reduce Rural Cancer Disparities (CA233848)

Request for Applications: Improving the Reach and Quality of Cancer Care in Rural Populations (RFA-CA18-026)

Improve the quality of cancer care in rural areas among low-income and/or underserved populations (intervention required)

- Financial navigation in community-based practices (University of North Carolina at Chapel Hill)
- Palliative care offered through community health workers (Massachusetts General Hospital)
- Practice facilitation and telemonitoring to enhance adoption of evidence-based practice guidelines for breast, colorectal, lung, and prostate survivorship care (University of Kansas)
- Telehealth access to molecular tumor board [physicians] and supportive care [patients] (Vanderbilt University)

Social and Behavioral Intervention Research to Address Modifiable Risk Factors for Cancer in Rural Populations (RFA-CA-20-051)

- Soliciting applications to develop, adapt, and test individual-, community- or multilevel interventions to address modifiable risk factors for cancer in rural populations.
- Applications should focus on primary prevention and assess and address one or more of the social and behavioral risk factors that contribute to cancer disparities in rural populations: tobacco use; diet, physical activity and weight; alcohol use; UV exposure; and HPV vaccination.
- Applications should also assess and address myriad social determinants of health, cultural factors, and health care and technology access barriers that may contribute to rural cancer disparities.
- **Next receipt date: January 18, 2022**

Rural-Urban Disparities in Behavioral Risk Factors for Cancer

- **Tobacco**
  - Higher rates of cigarette smoking and smokeless tobacco use
  - Rural youth are more likely to use tobacco products and use them more frequently than urban peers
- **Diet, Physical Activity & Weight**
  - Higher rates of obesity, lower rates of physical activity, and poorer diets in rural adults and youth
- **Alcohol**
  - Higher rates of alcohol abstinence in rural areas, but those who *do* drink have a higher prevalence of current alcohol disorder and of individuals exceeding daily alcohol limits
- **UV Exposure and Sun Protective Behavior**
  - Less likely to wear sunscreen, and higher indoor tanning use among rural teens
- **HPV Vaccination**
  - Rural HPV vaccination rates are 10% lower than in urban areas
  - Rural populations are less likely to know that HPV causes cervical cancer
  - Strong provider recommendations for HPV vaccination are less common in rural than urban areas

New Initiatives

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Persistent Poverty Supplement for NCI-Designated Cancer Centers

- Provide resources to support the time and effort of multidisciplinary teams at NCI-Designated Cancer Centers, in collaboration with clinics that serve underserved populations living in persistent poverty areas, to plan, implement, and sustain a cancer control research program that focuses on low-income and/or underserved populations
- Long-term goal is to develop the capacity for health care clinics and/or safety net providers to build cancer prevention and control research for the implementation of evidence-based programs and practices focused on low-income and/or underserved populations in persistent poverty areas

- *Applications must be submitted electronically via eRA Commons to the parent award (P30) using PA-20-272 on or before **May 21, 2021**.*

Request for Information (NOT-CA-20-080) Analysis of Responses to: Who can benefit from telehealth care?

- The removal of travel and time burdens may be especially beneficial for:
  - Specialty care (i.e., pediatric oncology, rehabilitation), as these sites may be more geographically dispersed than treatment sites for standard care
  - Medically-fragile patients
  - Patients with time constraints due to work, childcare, and/or eldercare responsibilities
  - Patients in rural and geographically remote areas

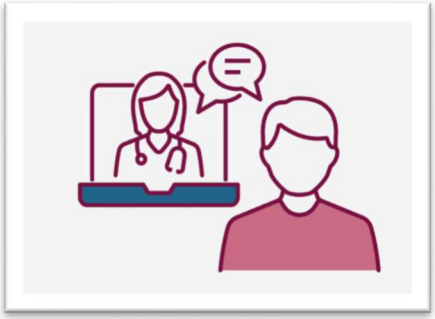
Request for Information (NOT-CA-20-080) Analysis of Responses to: Is access to telehealth care equitable?

- Factors affecting access include:
  - A lack of broadband internet connection
  - A lack of a compatible digital device (e.g., smartphones, computers)
  - Limited digital literacy
- Can partnerships with community organizations be established to minimize travel burden and/or provide reliable access to devices and/or the internet?

Centers on Telehealth Research for Cancer-Related Care RFA-CA-21-029 (P50 - Clinical Trial Required)

RFA Goals:

- Centers will generate and disseminate a robust evidence base for patient-centered, sustainable telehealth models of cancer care delivery.
- Each Center will leverage a clinical practice network able to support multiple cancer-focused telehealth research studies



Link: https://grants.nih.gov/grants/guide/rfa-files/RFA-CA-21-029.html
Informational Webinar: April 29, 2021 at 1pm (ET)

Receipt Date: July 20, 2021

Contact: Roxanne.Jensen@nih.gov

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Cancer Survivorship

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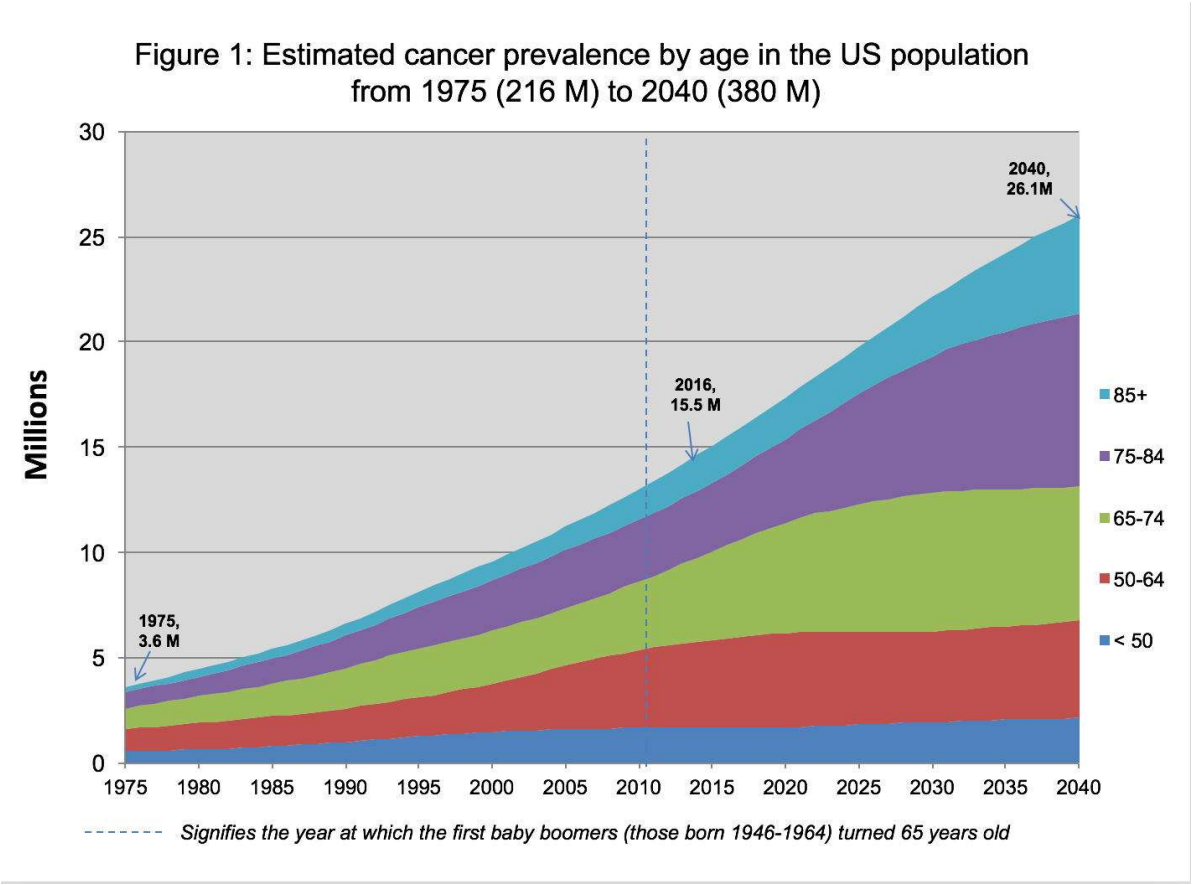
“Silver Tsunami”



Cancer Survivorship

- Can primary care providers play role in long-term management of cancer survivors, particularly those at low risk of recurrence?
  - Surveillance for recurrence
  - Screening for other cancers
  - Symptom management
  - Cancer-related cardiotoxicity

- Active area for us, with a number of active and upcoming funding opportunity announcements

Questions & Discussions

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