# Lessons and Opportunities to Spur Progress in Achieving Health Equity In Cancer Care: NIH's "Great Awakening"

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# "Great Awakenings" in American History

• First: 1730s and 40s

Second: 1820s and 30s

• Third: 1860s-90s

#### Themes

- religious revival: atonement for sins; a reckoning
- political mobilization: personal, emotional, shared experience
- products: Princeton Univ., abolitionism, social gospel
- murder as a catalyst: the murder of Elijah Lovejoy in 1837

# Prior Sparks, but no Fire (Yet)

- 1983: Gil Friedell becomes first director of UK Markey Cancer Center
- 1989: NCI director Sam Broder says "poverty is a carcinogen"
- 1994: Kahn & Prager "Interdisciplinary collaborations are a scientific and social imperative" The Scientist, July 11
- 1999: "The Unequal Burden of Cancer" IOM Report
- 2000: Acting NIH Director Ruth Kirschstein launches health disparities strategic initiative
- 2002: Centers for Population Health and Health Disparities P50s RFA

### Passive Resistance

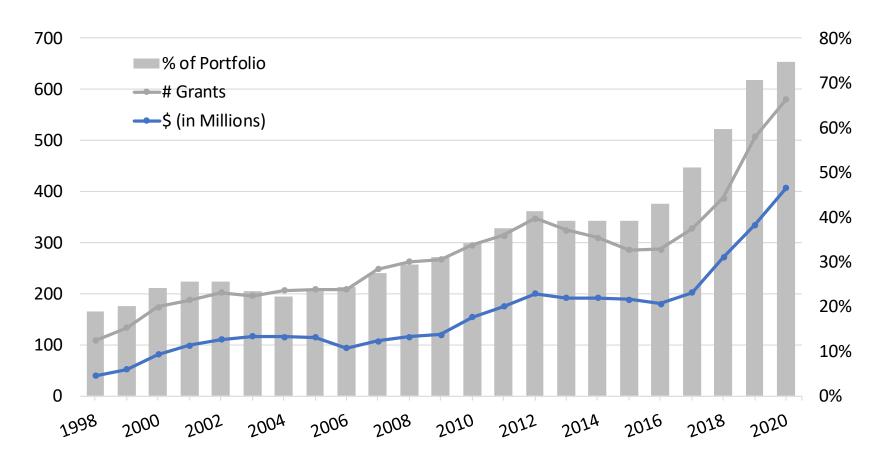
- Disciplinary Bias: ignorance and disrespect of the social sciences
- It's too big/hard/complex of a problem (i.e. not druggable)
- Not NIH's mission
- It's too political
- Healthcare delivery is about policy, not science
- The neglect of primary care in a specialty care-focused agency
- Multimorbidity in the real world vs. the clinical trials world

### Solutions

- Effective Informed Leadership
- Continued Integration of Social and Biomedical Sciences & Training
- Revitalize AHRQ to Significantly Expand Ambitious Open Access Peer-Reviewed Healthcare Systems Research
- Strengthen Equity-Relevant Peformance Measures and Standards
- Increase Support for and Flexibility of CDC's Cancer Control Programs
- Continue to Strengthen the NCI Cancer Centers Community Outreach and Engagement Requirements and Funding
- Greater Investment in HD and HE Research, Including Implementation Science, Policy Research and International Comparative Studies (see next slide)

### DCCPS HD Portfolio Trends, FY 1998-FY 2020

FY20 HD Summary			
Total HD Awards	Total DCCPS Awards	% HD	Dollars in Millions
580	767	75.6	\$407



# The NIH Awakening of 2020-21

- March, 2021: NIH Director Apologizes for Structural Racism
- Rapid proliferation of New Planning, Research, Training and Culture Initiatives (e.g. UNITE)

### Examples:

- September, 2021: FIRST (Faculty Institutional Recruitment for Sustainable Transformation) U54s and U24 Funded
- September, 2021: Transformative Research to Address Health Disparities and Advance Health Equity U01s Funded





cancer.gov • cancer.gov/espanol • cancer.gov/news-events/nca50

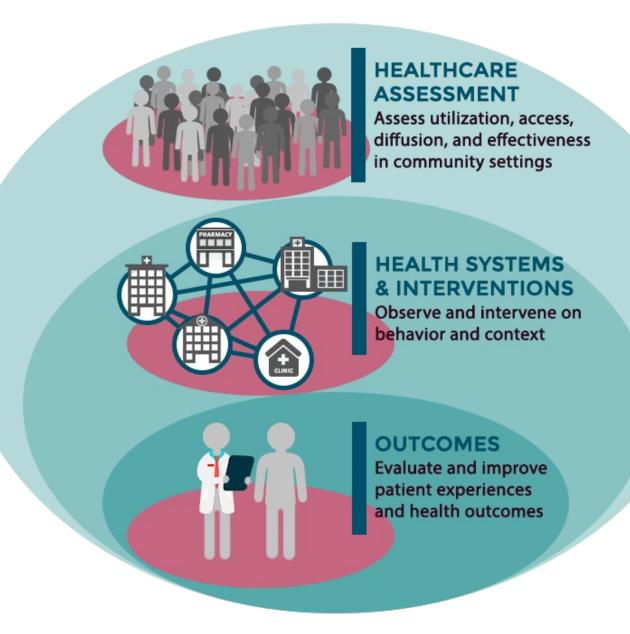
# Supplemental Slides

 Examples of Recent NCI Cancer Control Initiatives Related to Disparities and Equity

#### **HEALTHCARE DELIVERY RESEARCH PROGRAM**

Advancing innovative research to improve the delivery of cancer-related care.

- Health care delivery research at NCI is conceptualized as the study of cancer care, factors influencing care, and outcomes of care
- Cancer care refers to medical services offered across the cancer continuum, such as screening individuals not known to have cancer; treating cancer patients; following cancer survivors for recurrence; and providing psychosocial support at the end of life for patients and their caregivers





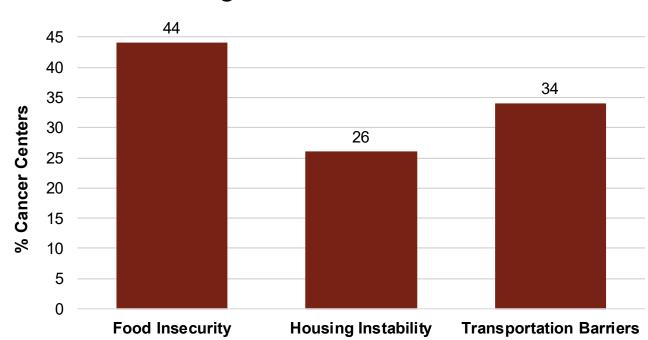
## A Survey of Diverse Cancer Settings

**Survey Goal**: The Healthcare Delivery Research Program conducted a survey to identify promising **approaches**, related **barriers**, and **recommendations** to improve organizational strategies to address social risks, specifically food insecurity, housing instability, and transportation barriers, in the context of cancer care delivery

Methods: Fielded July 9 - July 30, 2021 to 64 NCI-designated cancer centers and 46

NCORP sites (completion rate=81%)

% of NCI-designated cancer centers leading research initiatives designed to address food insecurity, housing instability, and/or transportation barriers



### Financial Navigation within NCI-Designated Cancer Centers

- Publication describes the availability of financial navigation services within the NCIdesignated cancer centers
- Data were obtained from the NCI Survey of Financial Navigation Services and Research, an online survey administered to NCI—designated cancer centers in 2019

"Cancer centers provide many financial services and resources.

However, there remains a need to build additional capacity to deliver comprehensive financial navigation services and to understand the extent to which patients are referred and helped by these services."



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Delivery of Financial Navigation Services Within National Cancer Institute— Designated Cancer Centers

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### Financial Navigation within NCI-Designated Cancer Centers

- Solicited supplement applications to P30 Cancer Center Support Grants for research to develop or expand capacity and infrastructure to deliver financial navigation services to cancer patients and their families
- 11 awards ~\$1,650,000 in funding
- Highlights
  - Investigators are conducting research to develop financial screening and service delivery programs and build upon ongoing financial navigation activities

Characterize facilitators and barriers to financial hardship screening and use information to develop and test a new screening tool

Scale up current model of symptom screening to collect information about financial hardship and document in the EHR

Implement an evidencebased financial navigation program in community practices and assess outcomes

# Accelerating Colorectal Cancer Screening and follow-up through Implementation Science (ACCSIS)

- Background: A Cancer Moonshot<sup>SM</sup> Initiative that supports research to build the evidence base on multilevel interventions to increase rates of CRC screening, follow-up, and referral to care
- Goal: Improving CRC screening, follow-up, and referral for care among populations that have low CRC cancer screening rates
- ACCSIS focuses on underserved groups, including racial/ ethnic minority populations, people living in rural areas
- Additional information: https://healthcaredelivery.cancer.gov/accsis/

# BLUE RIBBON PANNEL RECOMMENDATION G:

- Expand use of proven cancer prevention and early detection strategies
- Reduce cancer risk and cancer health disparities through approaches in development, testing and broad adoption of proven prevention strategies







### Research Centers

### **NU IMPACT**

- 6K patients, 1 health system
- 6 clinical practices
- English and Spanish-speaking patients receiving treatment with curative or non-curative intent or disease-free survivors
- Recruit from ethnically and racially diverse populations in metropolitan Chicago



### **SIMPRO**

- 13K patients, 6 health systems
- GI, GYN, lung cancer patients receiving surgery or chemotherapy for advanced disease
- Recruit from diverse populations in community and rural settings in ME, WV, NH, VT, TN, MS, and MA



### **E2C2**

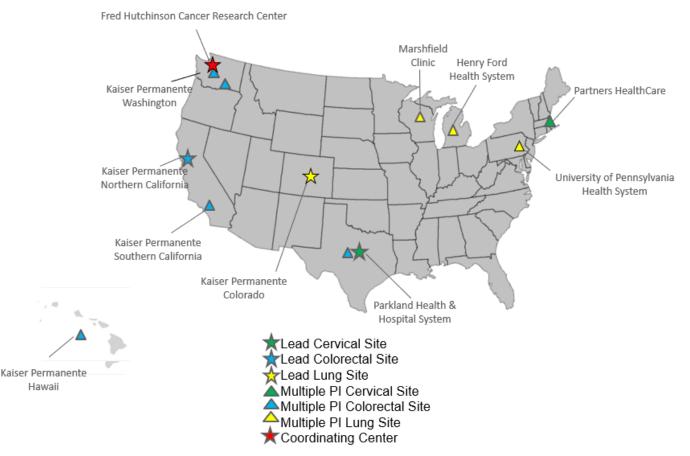
- 15K patients, 1 health system
- 21 care teams
- Patients on treatment, monitored, or survivorship care for solid tumors
- Recruit from rural populations in MN, IA, and WI



https://impactconsortium.org/



# Population-based Research to Optimize the Screening Process II (PROSPR II)



- Cervical, colorectal, and lung cancer
- Focus on underserved patient populations: e.g., racial/ethnic minorities, lower socioeconomic status
- Trans-PROSPR research to develop common conceptualizations and measures for assessing
  - Systems-level factors
  - Screening quality

# NCI Community Oncology Research Program (NCORP) Cancer Care Delivery Research (CCDR)

#### Background:

- A nation-wide network of over 1,000 community-based hospitals and practices, provides unique infrastructure to support research to improve care delivery in community hospitals and practices
- CCDR is a multidisciplinary science that seeks to improve clinical outcomes and patient well-being by intervening on patient, clinician, and organizational factors that influence care delivery

• 32 Community Sites

• 14 Minority/Underserved Community Sites

### Goal of CCDR in NCORP:

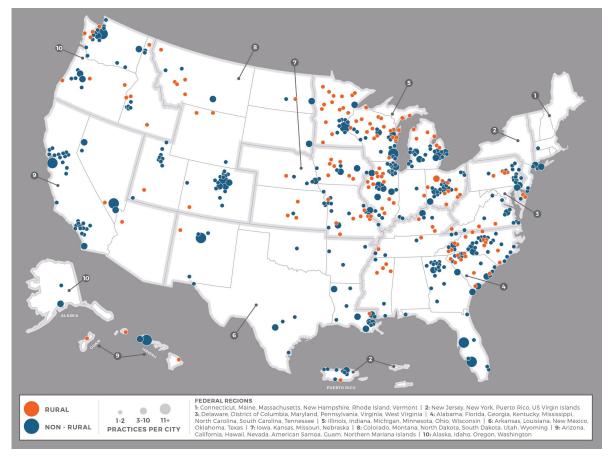
- To generate evidence that can be used to improve clinical practice, particularly through the evaluation of pragmatic interventions focused on clinicians, staff, and/or practices
- Committed to integrating health disparities research questions to studies, this includes both studies focused exclusively on disparities and the inclusion of disparities-related aims in studies
- Populations of interest: AYA, elderly, racial/ethnic minorities, sexual and gender minorities, rural residents
- Additional information: <a href="https://healthcaredelivery.cancer.gov/ccdr/">https://healthcaredelivery.cancer.gov/ccdr/</a>





### Capacity for Cancer Care Delivery Research in Rural America

- Rural cancer patients experience higher mortality and poorer quality of life outcomes than their urban counterparts and disparities are widening
- Mixed methods study of 22 rural NCORP practices to assess capacity for cancer care delivery research (CCDR)
  - 17% of NCORP practices are in rural areas
  - 73% of NCORPs included at least one rural practice among their affiliates
  - ~10% of all CCDR accrual originates from rural practices
- Research is needed to better understand urban-rural differences and develop ruralspecific care delivery innovations



More rural practices have been incorporated into NCORP in the most recent funding cycle



# Addressing Social Risks in Cancer Care Delivery Virtual Workshop

October 14, 15 and 18, 2021

A three-day virtual workshop focused on discussing the research needs for addressing social risks in cancer care, with a focus on food insecurity, housing instability, and transportation barriers

#### **Workshop Goals**:

- Describe the scope of research addressing social risks in the delivery of cancer care
- Identify effective and promising approaches for addressing social risks in cancer care
- Discuss challenges, gaps, and opportunities for future research in diverse cancer settings

Workshop brought together clinicians, researchers, community leaders, cancer patients, survivors, and advocates representing a broad range of experiences and expertise in this scientific area

Additional Information: <a href="https://events.cancer.gov/hdrp/ncisocialrisksmeeting">https://events.cancer.gov/hdrp/ncisocialrisksmeeting</a>



- RFA Goal: Improve the quality of cancer care in rural areas among low-income and/or underserved populations
- Focus: Strategies for delivering cancer care and treatment in rural areas

- 9 applications were selected for funding (two rounds of the RFA), including both observational and intervention studies focusing on:
  - Survivorship in rural primary care
  - Palliative care
  - Symptom management
  - Financial toxicity and navigation
  - Multi-level telehealth interventions
  - Community-based patient navigation for colonoscopy