STAKEHOLDER ENGAGEMENT TO REDUCE HEALTH INEQUITIES IN RURAL CANCER CARE

Hillary Lum, MD, PhD
Associate Professor of Medicine
Division of Geriatric Medicine
October 19, 2021
As a mentored member in the cancer prevention and control program, I am indebted to...

- P30 Aging and Cancer
- Community Outreach and Engagement Core
- P50 COISC3
- Rural Cancer Advisory Board
- CCTSI Dissemination Core
OUTLINE

• The Problem: Rural Cancer Disparities
• Two Rural Colorado Examples
• Commitment to Stakeholder Engagement
• The Road Forward
Persistent health disparities plague rural populations

- Greater mortality risks from multiple diseases, including cancer, cardiovascular disease, and drug-related injuries
- More likely to have low incomes, to have no more than a high school education, to be unemployed, and to be uninsured
Rural Cancer Mortality Disparity

• Healthy People 2020 objectives: to decrease cancer mortality to **161.4** deaths per 100,000 population

• As of 2015, this objective has been met in metropolitan counties.
  ▪ **157.8** cancer deaths per 100,000

• Yet, rural communities have been left behind.
  ▪ **180.4** cancer deaths per 100,000

https://www.cdc.gov/mmwr/volumes/66/ss/ss6614a1.htm?s_cid=ss6614a1_w
The Public Health Call to Action

Rural cancer control was one of several topics the National Advisory Committee on Rural Health and Human Services focused on in 2019. Policy recommendations from the meeting included:

1. Combine federal funding to implement and evaluate a rural patient navigation program
2. Increase funding for NCI’s Rural Cancer Control Program and related partnerships
3. Implement a national educational campaign to provide cancer related info to rural providers
4. Educate rural providers to use Medicare codes to enhance cancer care coordination
5. Require the assessment of rural-urban disparities and related goals and objectives in state cancer control plans

74% of Colorado Counties are Rural/Frontier

Colorado: County Designations, 2021

P50 COISC3 Slides
Lifetime Colorectal Endoscopy Rates

Screening and Risk Factors for Colorado by County
(2008-2010 County Level Modeled Estimate Combining BRFSS & NHIS)
Ever Had Colorectal Endoscopy (Sigmoidoscopy or Colonoscopy)
All Races (Includes Hispanic), Both Sexes, Ages 50+

Ever Had Colorectal Endoscopy
(Sigmoidoscopy or Colonoscopy)
(Percent of Respondents)
Quartile Interval
- 28.8 to 48.1
- > 48.1 to 51.4
- > 51.4 to 54.7
- > 54.7 to 60.1
- > 60.1 to 69.3
- Data Not Available

P50 COISC3 Slides
Mammography in Past 2 Years

Screening and Risk Factors for Colorado by County
(2008-2010 County Level Modeled Estimate Combining BRFSS & NHIS)
Had a Mammogram in Past 2 Years
All Races (includes Hispanic), Female, Ages 40+
Lung Cancer Screening Sites in Colorado by Rurality/Frontier Areas

Facility locations downloaded from the American College of Radiology (ACR) and the GO2 Foundation for Lung Cancer on 09/28/2021.

County designations as defined by the Colorado Rural Health Center as of January 2021.

Map composed by Amy Melles, Population Health Shared Resource, University of Colorado Cancer Center.

Slides Courtesy of Dr. Studts
Figure 3. Proportion eligible adults aged 55-80 years screened for lung cancer in the past year with low-dose computed tomography (LDCT) by state, 2018. US preventative services task force eligible adults were current or former cigarette smokers who quit within the past 15 years with a 30 or more pack-year smoking history and aged 55-80 years.

Local problems require local solutions that are based on community needs, available resources, and trusting and collaborative partnerships
NCI-designated Cancer Centers: How do we act locally?

https://www.cancer.gov/research/infrastructure/cancer-centers/find
• Involve Multiple Stakeholders
• Design for Real-World Life and Clinical Care
• Recognize the Importance of Health Equity

Image: https://tri.uams.edu/about-tri/what-is-translational-research/
Community Engagement Continuum

**Increasing Level of Community Involvement, Impact, Trust, and Communication Flow**

**OUTREACH**
- Some community involvement
- Communication flows from one to the other: to inform
- Provides community with information
- Entities coexist

**CONSULT**
- More community involvement
- Communication flows to the community and then back: answer seeking
- Gets information or feedback from the community
- Entities share information

**INVOLVE**
- Better community involvement
- Communication flows both ways, participatory form of communication
- Involves more participation with community on issues
- Entities cooperate with each other

**COLLABORATE**
- Community involvement
- Communication flow is bidirectional
- Forms partnerships with community on each aspect of project from development to solution
- Entities form bidirectional communication channels

**SHARED LEADERSHIP**
- Strong bidirectional relationship
- Final decision making is at community level
- Entities have formed strong partnership structures
- Broader health outcomes affecting broader community: bidirectional trust

Reference: Modified by the authors from the International Association for Public Participation
• Utilize existing data ... and develop new methods for working with small sample sizes

• Prioritize efforts to evaluate, adapt, and expand evidence-based interventions to rural areas using multidisciplinary research strengths

• Weigh the pros and cons of rural definitions and consider the interaction of geography with individual-level and regional factors

• Utilize an equity-based participatory implementation science approach to improve and align research and quality improvement efforts
Health Equity Implementation Framework

A determinants framework to explain factors relevant to implementation and disparities in health care:

- **Clinical Encounter**
- **Recipients**: Provider and staff culturally relevant factors
- **Recipients**: Patient culturally relevant factors
- **Societal Context**: Economies
- **Societal Context**: Physical Structures
- **Societal Context**: Sociopolitical Forces

OUTLINE

• The Problem
• Two Rural Colorado Examples
  • P50 Colorado Implementation Science Center in Cancer Control (COISC3), in partnership with Dr. Russ Glasgow et al
  • P30 Cancer and Aging Supplement
• Commitment to Stakeholder Engagement
• The Road Forward
Funded Transdisciplinary and Collaborative Research Centers

These 7 centers form the ISC³ network to advance implementation science by:

- Promoting the development of research centers that can build capacity to study high priority, emerging areas of cancer control implementation science
- Building implementation laboratories in diverse clinical and community settings
- Improving the state of implementation science measurement and methods
- Improving the adoption, implementation, and sustainment of evidence-based cancer control interventions through performing innovative pilot projects to determine best strategies for evidence-based cancer care
- Providing data and other resources to enhance and build the field of implementation science
- Sharing findings about implementation approaches with the cancer research community

...To reduce the burden of cancer by enhancing the design & delivery of cancer prevention and control interventions.
University of Colorado School of Medicine
Theme: Pragmatic Approaches to Cancer Prevention and Control in Rural Primary Care

Harvard T.H. Chan School of Public Health
Theme: Improving Community Health by Integrating Health Equity and IS for Cancer Control

Oregon Health & Science University
Theme: IS to Improve Cancer Screening and Prevention in Underserved Populations

University of Washington
Theme: Develop and Refine Innovative Methods for Optimization of EBIs in Cancer Control

Wake Forest School of Medicine/University of Massachusetts Medical School
Theme: Advance IS Through Technologies for Rapid Cycle & Real-time Deployment/Testing of Processes and Adaptations in Cancer Control

Washington University in St. Louis
Themes: Elimination of Cancer Disparities, Need for Rapid-cycle Studies, Systems Science Approaches to Enhance IS

University of Pennsylvania
Theme: Applying Behavioral Economics to Accelerate Deployment of EBIs for Cancer Care, Ensuring Equitable Delivery
Key Colorado ISC3 themes:

• Multiple stakeholder perspectives on values and cost that drive decision making

• Multi-faceted and multi-level context, and related adaptations

• Specific reach/implementation/ sustainability issues in rural primary care settings
Study Question: What are the perspectives persons with early dementia, care partners, and primary care team members in rural areas related to cancer screening shared decision making, including:

- Risks, benefits, and burdens of cancer screening in the context of dementia;
- Shared decision making involving persons with dementia and family care partners;
- Barriers to screening and dementia care in rural areas;
- Adaptations to primary care processes for cancer screening to meet the needs of persons living with dementia.
Methods

Setting: Four rural practices, selected from High Plains Research Network (Practice-based Research Network) and the National Research Network

Multiple stakeholder perspectives:
- Patients with early dementia (incl. Spanish speakers)
- Care partners of persons with dementia
- Primary care clinicians (MD, NP, PA)
- Primary care staff (care managers, RN, social workers)

Data Collection: Semi-structured interviews

Health Equity Implementation Framework. Woodward, Matthieu, Uchendu, Rogal, & Kirchner (2019)
Emerging Findings from Rural Primary Care

Theme 1: Providers reported engaging patients, regardless of dementia severity, and their care partners in discussions about cancer screening.

Theme 2: Providers adapted discussion of risks and benefits of cancer screening to the level of patient understanding by including simplified explanations, handouts, appointment follow up with clinical staff, and addressing topic at multiple visits.

- Providers also described shifting decision making to a care partner over time as patients lost decision making capacity.

Thank you: Ashley McDaniel, MA from VA South Central MIRECC
Emerging Findings from Rural Primary Care

Theme 3: As the patient loses the ability/capacity to make informed decisions and the care partner becomes more involved, providers noted significant considerations were given to the care partner’s perspective and values about the patient’s quality of life.

Theme 4: Patients and care partners who have personal or familial experiences with cancer tended to expect continued cancer screenings and shared decision making was not as prevalent.

Theme 5: Some providers noted a culture of distrust of the medical establishment in rural settings, which limits opportunities to engage in shared decision making about cancer screening.
OUTLINE

• The Problem
• Two Rural Colorado Examples
  • P50 Colorado Implementation Science Center in Cancer Control
  • P30 Cancer and Aging Supplement, in partnership with Dr. Liz Kessler, Dr. Dan Sherbenou, Dr. Anne Nederveld, Sarah Roberts
• Commitment to Stakeholder Engagement
• The Road Forward
# P30 Cancer and Aging Supplement

<table>
<thead>
<tr>
<th>Build</th>
<th>Build infrastructure to promote scientific exchange related to cancer and aging research</th>
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<tbody>
<tr>
<td>Identify</td>
<td>Identify geriatric assessment tools to extend evidence-based practice to community-based oncology and rural primary care practices</td>
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<tr>
<td>Capacity</td>
<td>Enhance capacity for patient-centered data collection in clinical research on cancer and aging</td>
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3P30CA046934-32S4 – Funded by NCI Supplement – Infrastructure Development and Team building for a Statewide Approach to Address Cancer and Aging in Colorado, PI Schulick
Rural Colorado Cancer and Aging Research

• **Aim 2.** Identify geriatric assessment tools that will support personalized care delivery based on physiological age instead of on chronological age and that can be implemented in rural oncology and primary care clinics.
  - Prioritize and centralize available frailty and geriatric assessment tools.
  - Determine acceptability and feasibility of geriatric assessment tools in community cancer prevention and care settings, starting locally and extending outward to rural oncology and primary care clinics.

• **Aim 3.** Pilot a Cancer Center resource for patient-centered data collection to facilitate bench-to-bedside-to-community research on cancer and aging.
• **Engagement:** 4 focus groups
  • 2 primary care – 11 providers
  • 2 oncology – 13 providers
  • Reviewed VES-13, G8, Medicare Wellness Exam, ADL, IADL

• **Operational Planning**
  • UCH Epic integration with G8
  • External providers (PEACHnet and Oncology Clinics)

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**Provider Responses**

- **G8**: 15 providers
- **VES13**: 10 providers
- **Medicare Wellness**: 5 providers
- **ADL/IADLS**: 5 providers

- **Positive**
- **Negative**
- **No Preference**
Providers who participated in the focus groups. N=24

Blue is primary care
Orange is oncology
• Pilot Implementation
  • 7 community providers trialed provider-assessed G8 for 3 weeks

• Input from Rural Cancer Advisory Board on a self-report G8
  • Developed patient-reported G4 (+4) to trial with UCH/Epic integration

• Evaluation
  • Review survey and interview results

• Next steps
  • MHC pilot for assessing G8 prior to UCHealth cancer clinic and Seniors clinic visit
    • Goal – available across UCHealth
  • Validate self-report vs. clinic-collected G8 in community clinics
    • Grant proposal under review
OUTLINE

• The Problem
• Two Rural Colorado Examples

• Commitment to Stakeholder Engagement
  • Community Outreach and Engagement Core, in partnership with Dr. Evelinn Borrayo, PhD, Associate Director, Community Outreach & Engagement
  • Rural Cancer Advisory Board
• The Road Forward
Provide comprehensive **up-to-date data** on the cancer burden, risks, and disparities in the catchment (Colorado).

Enhance and disseminate the **center’s research for impact** in reducing the cancer burden, risks, and disparities.

Engage communities in science, **education, and advocacy** to reduce cancer burden, risks, and disparities.
Purpose: Advise the UCCC on how to meaningfully engage the community in its cancer research, clinical care, and population-health efforts to better understand and address Colorado’s cancer burden, risks, & disparities.

Christi Cahill
Colorado Cancer Coalition

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Classique LLC

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St. Mary’s Medical Center

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Becky Selig, MSW
Colorado Department of Public Health & Environment

Emelin Martinez
Valley-Wide Health Systems

Caleb McNaughton
Highpoint Church

Eric Niemeyer
High Plains Community Health Center

Dianne Primavera
Lt. Governor State of Colorado

Rica Rodriguez
Vivent Health

Erika Serrano
Center for Health Progress

Stephanie Salazar-Rodriguez
Mile High Health Alliance

Jennifer Woodward, MSW
Colorado LGBTQ Health and Wellness Collaborative

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<tr>
<th>Project</th>
<th>Institution</th>
<th>Location</th>
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<tr>
<td>HPV Education and Patient Navigation Project</td>
<td>Denver Health Partnership</td>
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<td>HPV Educational Video</td>
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<tr>
<td>Colorectal Cancer Screening Navigation Research</td>
<td>Denver Health Partnership</td>
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<td>Rural Health Collaborative</td>
<td>Statewide</td>
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<td>Clinical Trials Education</td>
<td>Statewide</td>
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<td>Sun Smart Cancer Prevention Education</td>
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<td>Aging and Cancer Research Project</td>
<td>UC Health</td>
<td>Statewide</td>
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<td>Community Based Cancer Support Groups</td>
<td>Statewide</td>
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<td>Cancer Services Map</td>
<td>Statewide</td>
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<td>At Its Roots</td>
<td>Statewide</td>
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<td>Colorectal Exercise Study</td>
<td>CSU</td>
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<td>Esperanza en Español Spanish Head and Neck Clinical Trial Clinic</td>
<td>UC Health</td>
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<td>Breast Cancer Education Research Project</td>
<td>UC Health</td>
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<td>Spanish Radio Cancer Education</td>
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<tr>
<td>Rural Lung, Head and Neck Cancer Patient Navigation Intervention</td>
<td>Statewide</td>
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RESOURCE: Virtual Cancer Resources Map

- In collaboration with COE, CDPHE, Colorado Cancer Coalition, officially launched on January 11\textsuperscript{th}, 2021
- Provides information for resources such as:
  - Low and No Cost Cancer Screening
  - Genetic Counseling and Testing
  - Cancer Treatment
  - Cancer Patient Support and Survivorship Services
  - Palliative Care and Hospice Care
  - Clinical Trials
- Available in English and Spanish
- For hospital or clinic locations, insurance information is provided
- There is an “add my resource” option for any resources not currently featured on the map
Rural Cancer Advisory Board Members

- Established May 2021
- 10 Women Residing in Rural CO Communities
- Age range 40-75
- Race/Ethnicity:
  - 7 White
  - 3 Latina
- Various backgrounds: teacher, rancher, business retirees, etc.
RESOURCE: Rural Cancer Advisory Board

- May 19 Meet and Greet
- July 21
  - Presenter: Dr. Liz Kessler
    - Board members provided feedback and specific edits to a geriatric screening tool.
- September 15
  - Presenters: Dr. Jamie Studts and Erin Hirsch
    - Board members gave real time thoughts and opinions on introduction of a new lung cancer screening
- Upcoming Dates
  - November 10
  - January 19
  - March 16

Example Meeting Agenda

- 4:00–4:05 Welcome/Announcements
- 4:05-4:10 UCCC COE Update
- 4:10-4:20 Board Member Highlight
- 4:20-4:45 Building Research Skills
- 4:45–5:00 Break
- 5:00-5:30 Presentation
- 5:30-5:50 Feedback for Researcher
- 5:50-6:00 Closing Remarks/Questions
Desired Input from Rural Cancer Advisory Board

**GOAL:** Gather input for intervention design focused on engaging rural residents regarding lung cancer screening.

- Gauge awareness of lung cancer screening in rural areas (disproportionate burden due to smoking rates).
- Identify questions or concerns rural residents have about lung cancer screening.
- Gain insight into messaging, imagery, intervention approaches that will align with rural perspectives.

Courtesy of Dr. Jamie Studts, Erin Hirsch
Insights Gained from RCAB Meeting

Valuable Take Away Points

• Limited/non-existent awareness of lung cancer screening.

• Procedure experience, cost and benefit are very important.

• Trust, reputation, and legitimacy of healthcare critical from rural perspective.

• Collaboration with local clinicians and health departments needed.

• Imagery should portray benefit.

Next Steps

• Pilot grant application

• Foster relationships with rural clinicians and health systems to establish trustworthiness

• Educational and engagement opportunities
OUTLINE

• The Problem
• Two Rural Colorado Examples
• Commitment to Stakeholder Engagement
• The Road Forward
  • CCTSI Stakeholder Engagement Resources, in partnership with Dr. Bethany Kwan, PhD, MSPH, Director of D&I, Colorado Clinical & Translational Sciences Institute
Stakeholder Engagement

A bi-directional, longitudinal relationship between stakeholders and researchers that informs decision-making about research prioritization, conduct, and dissemination

Involves multiple stakeholder types to ensure the research is feasible, scientifically rigorous, and relevant

https://dicemethods.org/WhatIsStakeholderEngagement
<table>
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<tr>
<th>Stakeholder Group</th>
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<td>Patients and the public</td>
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<td>Providers</td>
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<td>Policymakers</td>
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<td>Purchasers</td>
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<td>Payers</td>
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<td>Product makers</td>
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<td>Principal investigators</td>
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Stakeholder Engagement Approaches

An organizing framework to establish with stakeholders at the beginning their role in decision-making related to the research activities.

More info at www.dicemethods.org
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<thead>
<tr>
<th>Stakeholder Engagement Methods</th>
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<tr>
<td>Tools, techniques, and processes to enact all of the “high-level” purposes of engagement</td>
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<tr>
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<td>Appreciative Inquiry</td>
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<td>Boot Camp Translation</td>
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<td>Citizen Juries</td>
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<td>Community Engagement Studios</td>
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<td>Concept Mapping</td>
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<td>Deliberative Polling</td>
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<td>Delphi Technique</td>
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<td>Human-Centered Design</td>
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<td>I-Corps</td>
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<td>Online Collaborative Platforms</td>
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<td>Online Communities</td>
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<td>Stakeholder Panels/Advisory Committees</td>
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More info at [www.dicemethods.org](http://www.dicemethods.org)
Partner with Stakeholders

- Identify and convene stakeholders
- Create reciprocal relationships
- Engage in bi-directional communication
- Elicit perspectives
- Make decisions over time and in partnership
Special thanks! Teamwork makes the dream work

• P30 Aging and Cancer (Kessler, Sherbenou, Nederveld, Roberts)
• Community Outreach and Engagement Core (Borrayo, Roberts, Pacheco)
• P50 COISC3 & Alzheimer’s (Glasgow, Bradley, Studts, Holtrop, Huebschmann, Nederveld, Carroll, Connelly, Oser, Bettcher, Hirsch, Ford)
• Rural Cancer Advisory Board (thanks to the COE and P50)
• CCTSI Dissemination Core (Kwan et al)
References

- American Cancer Society - Making the case for Health Equity
- Cancer Surveillance and Access to Care in Rural America Webinar, University of South Carolina Rural & Minority Health Research Center, February 4, 2020: https://www.ruralhealthresearch.org/webinars/cancer-surveillance