

# CANCER CENTER WITHOUT WALLS: ADVANCING PATIENT-CENTERED RESEARCH FOR CANCER CONTROL IN RURAL VA

PCORI ENGAGEMENT CONTRACT CONTINUED

MARCH 28, 2019

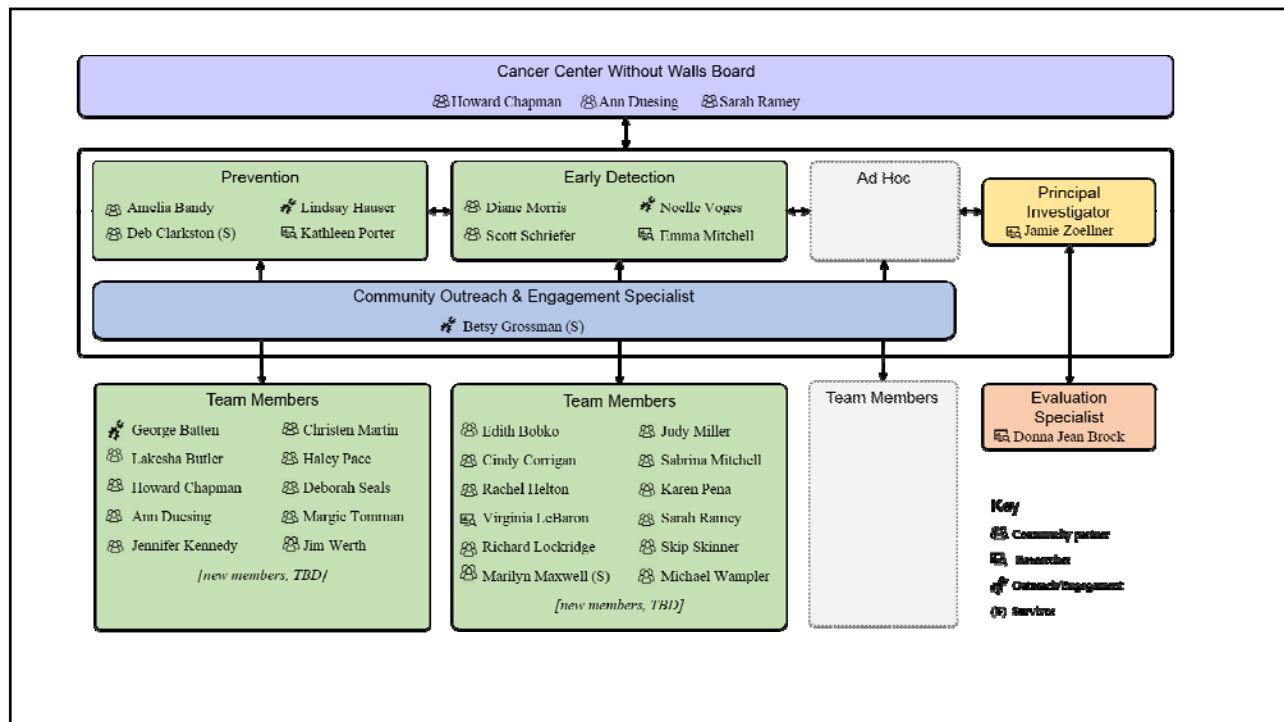


## THE BIG PICTURE AIMS & LONG-TERM OBJECTIVES

1. Build and strengthen the **research capacity** among members of **two Community Action Teams**, focused on Cancer Prevention and Early Detection, through relevant PCOR **skill-based trainings**.
2. Identify actionable, cancer PCOR priorities based on existing **local data and stakeholder/patient** input.
3. Advance the community capacity of Community Action Teams to **conceptualize, plan, mobilize resources, and execute cancer control** PCOR projects in their communities.

To accelerate the effectiveness testing, dissemination and implementation, and sustainability of culturally appropriate evidence-based cancer control interventions and programs in rural Appalachia.





## WHAT WILL OUR PRODUCTS BE?

- State-wide Virginia Cancer Plan contextualize and prioritized for our region
- Website
  - Increase awareness & collaboration
  - Training materials, specific to cancer control in Appalachia
- Competitive grant proposals
  - Interventions and programs selected and adapted to meet our needs

## MILESTONES FOR THIS 6-MONTH REPORTING PHASE (SEPT 2018- FEB 2019)

<b>Local press release #1</b>	Local press release of project launch	✓
<b>Develop Community Action Teams</b>	Activate 2 Community Action Teams: 1) Cancer Prevention and 2) Early Detection	✓
	CCWW CAB Meeting #1: PCORI Training #1: PCOR Principles 101	✓
<b>CCWW CAB Meeting #1</b>	CPPE Step #1: Problem assessments, identify root causes	✓
<b>CCWW Consent</b>	CCWW complete consent process	✓
<b>CCWW Capacity Assessment 1</b>	CCWW CAB completes Capacity Survey (time 1)	✓
	CCWW CAB Meeting #2: CPPE Step #1: Problem assessments, identify root causes (cont'd)	← Today!
<b>CCWW CAB Meeting #2</b>	CPPE Step #1: Create visual causal models	

### Southwest Virginia Residents Sought to Direct Region's Battle Against Cancer

*New UVA Initiative Helping Find Better Ways to Detect, Prevent Cancer*

CHARLOTTESVILLE, Va., Oct. 4, 2018 – A new University of Virginia Cancer Center initiative that will empower Southwest Virginia residents to lead projects to better detect and prevent cancer in the region. The effort has earned \$244,589 in funding from the Patient-Centered Outcomes Research Institute (PCORI).

With the funding in hand, the UVA Cancer Center Without Walls team is now seeking Southwest Virginia residents who will be trained to guide these cancer research projects.

Their goal is to address two cancer disparities in the Appalachian counties of Southwest Virginia:

- the lack of early screening and detection
- high death rates (between 15 and 36 percent higher compared with urban non-Appalachian residents) caused by later detection and lack of access to treatment and support programs

#### **Building Community Involvement**

This new initiative grew out of a community advisory board formed in 2013 for the UVA Cancer Center Without Walls, which works to improve cancer care for residents of Southwest Virginia. "The advisory board has been a sounding board for researchers," said Jamie Zoelner, PhD, RD, co-director of the Cancer Center Without Walls. "We hadn't sat down at the table with [the advisory board members] and said, 'What are your research priorities?'"

So over the past year, UVA Cancer Center team members met with the community advisory board to determine the board's priorities – which ended up centering on early detection and prevention – and to refine the application for funding through a PCORI contract.

"Mountain Empire Older Citizens is excited to serve on the Cancer Center without Walls Community Advisory Board and provide to leadership for the Early Detection Community Action Team," said Michael Wampler, executive director of Mountain Empire Older Citizens, Inc. "We are eager to help identify cancer-related priorities in southwest Virginia and expand community-based research opportunities."



**Want to take action to eliminate cancer in our  
community?**

### Join the Cancer Center Without Walls Advisory Board

The advisory board, sponsored by the UVA Cancer Center, is working to empower our community to lead projects that will better detect and prevent cancer in the region.

The initiative is seeking to add patients with cancer, cancer survivors and caregivers for cancer patients to the community action teams that live in the counties of Bland, Buchanan, Carroll, Dickenson, Grayson, Lee, Russell, Scott, Smyth, Tazewell, Washington, Wise and Wythe, along with the cities of Bristol, Galax and Norton. The initiative also aims to involve more oncologists, clinicians, researchers and policy makers who serve this region.

**Meetings are held quarterly throughout the region. Travel stipends are available.**

To learn more about the initiative, please contact Betsy Grossman at [elg6@virginia.edu](mailto:elg6@virginia.edu) or 276-376-3437.





## **CHARLOTTESVILLE LEADERSHIP TEAM MEETING**

- Dec 13
  - CACV Quarterly meeting
  - Community Partner Discussion
    - Virginia Department of Health (Amelia Bandy)
    - Tri-Area Community Health, Laurel Fork, VA (Howard Chapman)
    - Mountain Empire for Older Citizens, Inc, Big Stone Gap, VA (Dianne Morris)
    - Saltville Baptist Church, Saltville VA (Scott Schriefer)
    - Southwest Virginia Cancer Center, Ballad Health, Norton VA (Zilipha Cruz)
    - Community Member, Patty McAndrews (cancer survivor and caregiver)
  - UVA Partner Discussion
  - Cancer Center Tour
  - Holiday Party
- Dec 14
  - Cancer Control and Population Health Symposium




## PANEL DISCUSSION

- What do you see as the biggest opportunity within your organization and/or community to address or improve cancer control efforts?
  
- What do you see as the biggest barriers within your organization and/or community to address or improve cancer control efforts?
  
- If the sky was the limit and the resources were in place, what would be your top 2-3 priority programs or initiatives related to cancer control within your organization and/or community?



Opportunities	Barriers	Priorities
Expansion of Medicaid (especially for preventative services)	Difficult to reach geographically dispersed/isolated rural areas	Cost effective, localized screenings and prevention efforts (lung, breast, CRC, tobacco cessation, HPV vaccinations, genetic testing)
Influence and resources available from faith based organizations	Ineffective outreach with limited information on how to improve practices	Communication improvements between providers (EMR) and providers and patients (have the connection between prevention and early screening across all provider appointments)
Development of a statewide EMR	Culture of denial and resistance to change/fatalistic attitudes and fear/mistrust of cancer treatments	Data system that is continually updated and used to inform strategic plans and address barriers
Improving communication between patients and providers to increase the use of prevention and treatment services	Communication breakdowns between patients and providers (lack of follow up, importance of screenings, treatment advances..)	Align VDH plans to the state plan and develop operationalized procedures and trainings to achieve goals
E-health expansion of services to more remote areas	Health information systems do not communicate with one another	Pool research on how to better outreach to rural communities
	Lack of financial resources/ insurance to cover services	Integrate behavioral health into primary care health
	General lack of awareness about risk factors, detection, and treatment	SEM perspective on survivorship




**An Overview of Screening and Prevention Interventions for Rural Populations: *What Has Worked***

**February 15, 2019**  
12:00pm - 1:00pm

The UVA Cancer Center invites you to participate in this webinar as we explore previous screening and prevention interventions that have been successful in rural communities and how the presented interventions (and ones like them) might fit in your own community.


**Featuring:**  
**Emma Mitchell, PhD, MSN, RN**  
University of Virginia School of Nursing  
**Kathleen Porter, PhD, RD**  
University of Virginia Public Health Sciences



## **MILESTONES FOR NEXT 6-MONTH REPORTING PHASE (MARCH 2019- AUGUST 2019)**

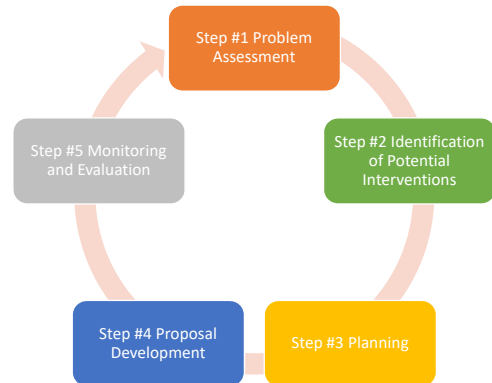
<b>Website Launch</b>	Launch Website	
<b>UVA PCOR training</b>	UVA PCOR training meeting	✓
	CCWW CAB Meeting #3: CPPE Step #1: Create visual causal models, con't CPPE Step #1: Prioritization	
<b>CCWW CAB Meeting #3</b>	CPPE Step #2: Identification and selection of potential interventions	
	CCWW CAB Meeting #4: PCOR training #2: Evidence synthesis on CPPE identified priorities	
<b>CCWW CAB Meeting #4</b>	CPPE Step #2: Identification and selection of potential interventions, con't	
<b>CCWW Capacity Assessment 2</b>	CCWW completes Capacity Survey (time 2) and qualitative interview Findings are disseminated back to CCWW CAB	

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## WHAT IS CPPE?

- Comprehensive Participatory Planning and Evaluation (CPPE)
- Action oriented approach designed to guide project planning and evaluation
- Each step is flexible
- Community involvement at every step increases motivation and co-learning, and ultimately the success
- ***Active participation by the community allows community expertise and priorities to drive the research***



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## CPPE & PCORI

- **Long-term goal:** Build and sustain capacity of rural Appalachian communities to prioritize, act on, and decrease cancer disparities.
- **Our process for choosing priorities will rely on:**
  - Existing local data
  - Stakeholder input – you and your expertise!



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## CPPE STEPS

- **Step 1: Problem assessment**
  - preliminary problem assessment
  - *causal analysis workshop (today!)*
  - supplemental data collection and model validation
  - causal model data analysis
- **Step 2: Identification of potential interventions**
- **Step 3: Planning**
- **Step 4: Develop proposals**
- **Step 5: Monitoring & evaluation**

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## NOVEMBER 1, 2018


- **Preliminary problem assessment**
  - Developed “community commitments” – how we want to work together
  - Gathered in action teams
    - Lack of Prevention
    - Lack of Early Detection
  - Worked through initial problem assessment by:
    - Identifying what is most meaningful / top priorities
    - Brainstorming causes
  - Sent research team home with all notes to compile and notice any themes

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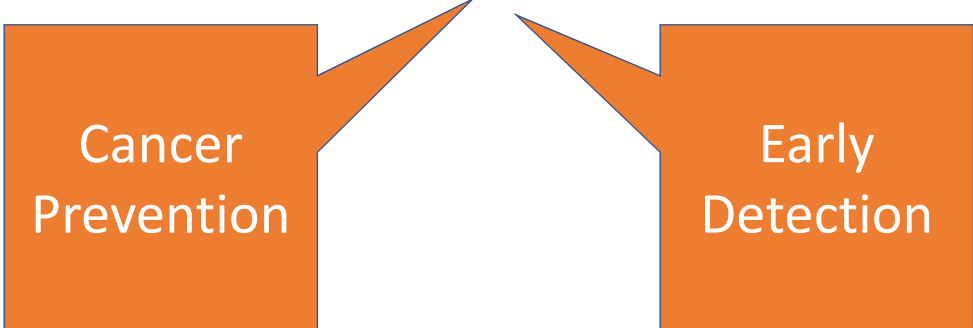
## PRELIMINARY PROBLEM ASSESSMENT BRAINSTORM



The image shows four sticky notes with handwritten text and diagrams. The top-left note asks 'What causes a lack of prevention?' and features a flowchart with blue and yellow boxes. The top-right note asks 'What causes a lack of early detection?' and also features a flowchart with blue and yellow boxes. The bottom-left note asks 'What is the most meaningful?' and has a diagram with orange and blue boxes. The bottom-right note asks 'What is the most meaningful?' and has a diagram with orange and blue boxes.


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## PRELIMINARY PROBLEM ASSESSMENT REPORTS



Two orange boxes are positioned side-by-side. The left box contains the text 'Cancer Prevention' and the right box contains 'Early Detection'. Both boxes have a pointed top edge that tapers towards the center, where they appear to meet or point towards each other.

**Next Step: Constructing Causal Models**

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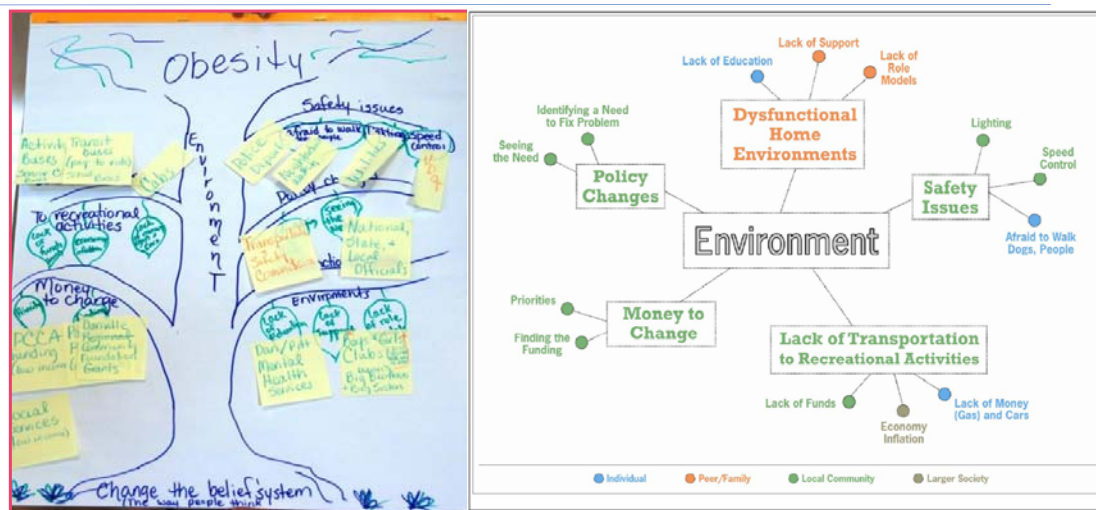
## CONSTRUCTING CAUSAL MODELS

Look at the original list of all brainstormed responses and the grouped responses.

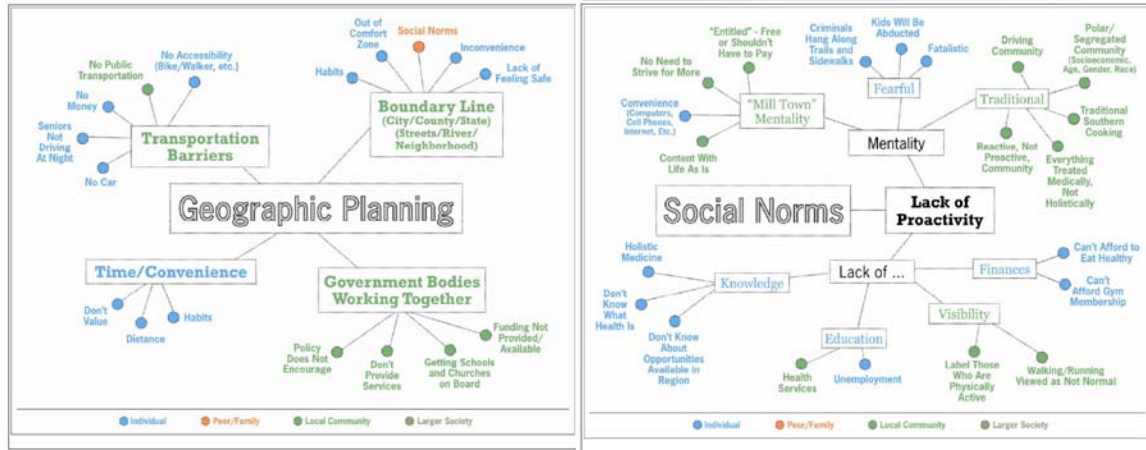
- What relationships do you see?
- How does all this information go together?
- Does the grouping fit your idea? If not, change it!
- What is missing related to the causes of **lack of cancer prevention** or **lack of early detection**?
- Put your ideas into a visual!



## OBESITY CAUSAL MODELS FROM DAN RIVER REGION



## OBESITY CAUSAL MODELS FROM DAN RIVER REGION



## CAUSAL MODELS FROM DAN RIVER REGION

Ended with 6 causal obesity-related models:

1. Physical activity
2. Nutrition
3. Social norms
4. Geographic planning
5. Environment
6. Education

From the prioritized causal models, three primary intervention ideas emerged including:

1. **community gardens to increase the accessibility of fresh/local foods**
2. **social support for physical activity**
3. **health-related social marketing campaigns**



## COMMUNITY COMMITMENTS

- Represent our area and people of our area as we know them.
- Take ownership of your expertise
- Think as if there is no box!
- Let people have time to talk. Try not to interrupt.
- Stay focused and on topic. Focus on the purpose of action teams: prevention, early detection.
- Be present.
- Judge-free zone. Be open to changing our minds. Notice pre-conceived notions.
- Have a willingness to share.

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## GATHER IN YOUR GROUP

- Prevention
- Early detection

During lunch, network and enjoy one another within your action group. As it fits, begin talking about what you see in the grouped responses. Notice:

- What relationships do you see?
- What influences what? What causes what?
- Draw, doodle, add question marks, arrows, exclamation points...





## CONSTRUCTING CAUSAL MODELS

Look again @ the responses. On your own, reflect:

- What relationships do you see?
- How does all this information go together?
- What would you change?
- What is missing?
- **STRATEGY:** Ask yourself,
  - How do these relate to lack of cancer prevention?
  - How do these relate to lack of early detection?

**GROUPED: What is the most meaningful for early detection?**

**HPV**

- Vaccinations increasing HPV vaccines
- Screenings cervical cancer screenings

**lung cancer**

- Need to address:
  - smoking cessation programs
  - lung cancer
- Screenings increase lung cancer screenings
- Understanding data
  - lung cancer mortality for this area compared to the rest of the state
  - most lung cancers are diagnosed at late stage

**CRC**

- Screenings
  - colorectal cancer mortality for Southwest Virginia- need to push for screenings and look at barriers for patients
  - CRC screening options (education)

**Breast cancer**

- Understanding data: # of mammograms received by women in our area
- Mammograms
  - increase mammogram screening
  - increase # of mammograms

**Prostate cancer**

- PSA testing
  - advice for PSA testing is "it's up to the patient" is concerning
  - recommendations against routine PSA have reduced screening rates
- Cost and accessibility issues
  - Cost of services- accessibility to live on affordable screenings for indigent populations
- Availability of services
  - no pediatric cancer data
  - regional super centers utilizing Telehealth to bring screenings to other communities

**Steps to improve effectiveness of early detection**

- Understanding/educating on health disparities
- Health outcomes -> social determinants of health
- Educate providers on early detection disparities
- Best ways for providers to communicate about cancer screening: how do patients perceive early detection? Do they think it's a PSA thing? Is that why have cancer?
- Collaboration: multi-centered screening conditions (reducing admin burdens for program development)

**GROUPED: What causes a lack of early detection?**

**Lack of knowledge about the value of screenings and available resources**

- lack of education
- lack of knowledge of available resources (i.e. Medicaid Expansion) & screenings
- lack of information to make an informed decision on screenings (i.e., pros & cons/mammogram) & education (i.e., HPV)
- lack of education regarding types of cancers and screenings
- lack of dissemination of information to health providers & educators
- lack of access to broadband information

**High-risk therapy choices**

**Fear, embarrassment, denial**

- embarrassed to have screenings
- fear of diagnosis tests
- fear they will get a positive screen / fear of diagnosis
- lack of awareness
- unwillingness to accept

**Cost**

- can't afford co-pay / cost of screenings
- economically distressed community / dwindling economy

**Lack of social support**

- lack of provider engagement
- lack of support from family

**Lack of providers and services (remote rural communities)**

- lack of resources
- lack of access to screening (distance, providers, screening technology)
- lack of access to care
- few PCP / tertiary care / specialists / specialized care
- available community resources for family cancer care
- pediatric education

**Lack of affordable transportation**

**Cultural beliefs & attitudes**

- lack of trust in medical establishment, distrust of large, urban-based programs
- culture of SWVA/Rapahannock, regional bias, misinformation, fear/anxiety, individual, don't want to be a burden on family

**Support & policies that hinder access to care**

- policies that hold back or are harmful to coverage or delivery of care
- lack of support to build regulatory approved programs

**Access to affordable care**

- lack of insurance

## CONSTRUCTING CAUSAL MODELS

- Gather into small groups, within your action team. *You decide – have at least 3 people in a group, and at least 2 groups.*
  - In your small group, share with one another what you see.
  - Begin to draw how this information relates to the lack of prevention or lack of early detection. You may create **more than one** causal model.
  - Use post-its, draw shapes and images.
- Remember, the causal model process is about you representing relationships that you see.
  - **How do these relate to lack of cancer prevention / early detection?**
    - What would you change? What needs to be added?
- Be brave – share your perspective, share your ideas.



## QUESTIONS. THOUGHTS. SUGGESTIONS??



## NEXT MEETING

### Next in-person meeting

- *Thursday, May 2*
- *Thursday, August 1*

### Interest in webinar this summer?

- *If so, what topic?*

