Concept Mapping of Implementation Research Priorities in Rural Cancer Control:

A Two-Phased Project

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Executive Summary

This project was conducted between May and November 2017 to provide perspectives for identifying cancer control research questions that address disparities in rural areas of the United States. The project transpired in two phases beginning with a research meeting entitled, Rural Cancer Control: Challenges and Opportunities," held at University of Memphis May 4-5, 2017[2]. The phase I meeting was planned by a multi-disciplinary panel of rural health experts including researchers, practitioners, and stakeholders, who identified critical areas of need within the context of implementation research across the cancer control continuum. Speaker presentations and panel discussions addressed these key areas and participants and attendees identified opportunities for future rural cancer control research within topics of prevention, emerging methods, information technology to address disparities, clinical research and quality of care, and improving access, engagement and care experiences. Summary of small group discussions during the conference lead to initial themes and topics statements for further development (described in Phase I).

The second phase of this project explored specific dissemination and implementation research questions that could inform future research opportunities developed and funded by the National Cancer Institute. Group concept mapping (GCM) was used to develop and create a visual map of foundational dissemination and implementation research questions relevant to rural cancer control. Participants from the phase 1 meeting provided additional content during an on-line brainstorming session by responding to a focus prompt: *To achieve measurable progress in Rural Cancer Prevention and Control, a comprehensive research and translation agenda would consider or include..*. Respondent statements were reviewed for responsiveness to the original focus prompt and merged with content from the Memphis meeting breakout sessions. Similar statements from Phase I and Phase II were combined and the final set was reduced to 107. These statements were then presented to 69 participants (researchers, intermediaries and practitioners) to be sorted into conceptually similar groups and rated on importance and current state of the research.

Results were analyzed to determine which statements were frequently grouped together, and which were not, by all participants in the sorting phase. Multi-dimensional scaling analysis was used to provide a visual representation of similarities and dissimilarities of the statements generated from the sorting phase. Coordinates for individual statements are generated and a two-dimensional point map was generated that shows the relation between all statements. Statements that were frequently grouped together (high correlation) are closer than statements that were not generally grouped together. Hierarchical cluster analysis was conducted to create a cluster map that shows how statements are grouped together and allowed themes to be identified Themes identified from the group concept mapping included: a need to leverage data and technology, define rural research context, adapt research approaches, use systems approaches in community, build trust and recognition, adapt models, identify care and access issues and focus on prevention and self-care (described in Phase II).

This report describes the outcomes from the two different phases of the project and provides a roadmap for implementation science research in rural cancer control, emphasizing the critical aspects of context and capacity to adapt current knowledge and models. Rather than suggesting the need for new structures and systems, the map suggests that integration of existing capacity and knowledge may provide the strongest approach to an informed and agreed-upon structure for implementation science in rural environments.

Concept Mapping of Implementation Research Priorities in Rural Cancer Control

Phase I *"Rural Cancer Control: Challenges and Opportunities"* Meeting Content Summary

Introduction

Although cancer mortality has decreased overall in the US, there are substantial differences among counties and distinct clusters of high mortality, with many of these clusters seen in rural, underserved regions. Widening cancer disparities in rural America may be due to limited access to health providers, a constrained and fragmented care delivery infrastructure, difficulty with continuity of care and coordinated communication among providers, few community resources to support early detection and preventive care, limited community health promotion opportunities, and constrained availability of internet and telecommunications --issues that are compounded as they overlay a generally older, sicker, and lower-income population found in rural areas[1].

To tackle these potential challenges, a national research meeting was organized to bring together a community of researchers to address the need to implement cancer prevention and control activities in rural areas. The meeting was planned by a multi-disciplinary panel of rural health experts including researchers and practitioners, who identified critical areas of need within the context of implementation research across the cancer control continuum. Presentations were invited to address cross-cutting content areas such as cancer surveillance, screening, care delivery, behavioral risk factors, health communication, and prevention interventions. The overarching purpose of the meeting was to identify opportunities for future rural cancer control research with specific goals of: 1) advancing research to address challenges in rural cancer control, particularly focused on dissemination and implementation of interventions and innovations that address disparities in rural populations; and 2) highlighting recent evidence to identify opportunities for future rural cancer control research that could be translated into effective interventions leading to prevention, diagnosis, and treatment of cancer.

The meeting entitled, "Rural Cancer Control: Challenges and Opportunities," was hosted at the University of Memphis, Memphis, TN and invited research leaders from academic, practice, non-profit advocacy and government settings to consider the issues related to cancer control and prevention in rural areas. With 125 registrants, representing 26 states and 61 organizations, the robust 2-day agenda on May 4-5, 2017 took advantage of the attendees' knowledge via plenaries, guided discussions, and panel presentations. In addition, attendees joined small group discussions on specific topics, to identify actions and considerations to address for future progress in rural cancer control and prevention.

Methods

Content analyses were conducted by Concept Systems Inc., to summarize the aggregated and analyzed output of all small group discussions and additional comments from the end-of-conference summary from meeting participants. Discussions provided a knowledge set emerging from the meeting.

Each small discussion was triggered by prompting questions, all preceded by this scene-setting vision: *Imagine 10-years from now, major improvements have been made in reducing cancer disparities in rural communities.*

Prompting questions for each subgroup discussion reflected major agenda topics of the Conference:

- Prevention Research in Rural Cancer Control: *What **prevention research** would have been implemented to achieve this?*
- Emerging Research Methods in Rural Cancer Control: *What **research methodology** would have supported this progress?*
- IT to Address Disparities in Rural Cancer Control: *What **digital health and oncology** informatics research would have been implemented to achieve this?*
- Clinical Research and Quality of Rural Cancer Care: *What **health care delivery research** would have been implemented to achieve this?*
- Improving Access, Engagement, Care Experiences: *What **research interventions** would have been implemented to achieve this?*

Data aggregation and review process

To represent attendee feedback, Concept Systems, Inc consultants aggregated input captured by moderators for all sub-group breakout sessions and the whole group discussion that capped the meeting, identifying about 180 individual items from the combined discussions. A draft prompt based on the meeting goals was used to shape and edit items for syntactic consistency for further content organization: **"To achieve measurable progress in Rural Cancer Prevention and Control, a comprehensive dissemination and implementation research agenda would consider or include…"** The resultant items were edited primarily for ease of understanding by those not in attendance with content kept as close to the original statements as possible.

 A keyword analysis of all items allowed topically similar items or ideas across small group discussions to be grouped, and to identify redundancies that typically exist when combining data from separate events on the same or similar topic. The process allowed content clarity to be observed, while suggesting edits for easy understanding of the items. 89 unique keywords resulted from the process. Linking items by keyword allowed easier identification of redundancies and reduced the set of ideas from about 180 to about 100.

A "Code word" structure was developed by observing the keywords in groups of related constructs, to help connect conceptually similar items into fewer but higher-order topical areas, for ease of understanding as idea sets. This process yielded 24 unique coded construct words, as a useful structure for summarizing the small group discussion content as an aggregate knowledge set.

Using both the breakout session topics and the code word analysis, Concept Systems, Inc developed a content frame that allowed a thematic approach to issues, ideas and recommendations on the meeting topics.

Summary Results: Feedback by themes across subgroups

Based on the topical analysis, several themes emerged as relevant in 3 or more of the subgroup discussions. This section describes cross-represented content, by theme. We identify the theme, indicate subgroups where related content was found, and provide examples of the comments from the subgroups.

Table 1: Legend for Small Group Topics.

Small Group Topic	Legend

Prevention Research	A
Emerging Research Methods	B
IT to Address Disparities	C
Clinical Research and Quality of Care	D
Improving Access, Engagement, Care Experiences	E

The emergence of 6 themes as cross-cutting topics is not surprising considering the agenda of the meeting. The specific comments in each theme, when taken as a group, provide both depth and specificity regarding elements on that theme.

Table 2: Themes appearing in 3 or more group feedback reports.

Theme	Small Group Topics
Collaboration	A, B, E
Context	A, D, E
Data	A, B, C, D, E
Interdisciplinarity	A, B, D, E
Information Tech (IT)	A, C, D
Methods	A, B, D, E

A representative sample of each topic area is captured in Table 3, below.

Table 3. Representative feedback within each cross-group theme.

Theme/Feedback
Collaboration
a strategic framework for network partners within the Cancer Prevention and Control Network (CPCRN) in considering evidence-based interventions.
care coordination between specialists and PCPs in rural settings and care transitions.
how to best build research interest and capacity among rural and community-based providers.
partnerships beyond agencies: NCI, CDC, Verizon, FedEx, etc.
the Health care Delta Network and NCORP, and whether other institutes can be involved.
where and when public/private partnerships are appropriate.
Context
a deep understanding of the wants and needs of people and communities.
a strengths-based lens rather than a deficiency lens, considering opportunities for innovation and impactful change through the strong social and community ties in many rural communities.
community delivered interventions: if a problem is in a community, the solution can also be in the community.
community reciprocity and what the community may gain.
demographic transitions and loss of social capital which are associated with increases in cancer mortality in rural areas.

engagement as a dimension of "care access".
engagement of rural patients, providers, and community partners.
identifying locale-specific attitudes or beliefs that might impact cancer control in rural communities.
more research that enables the exploration and appreciation of the variability among rural communities.
person-centered research on cost effectiveness via traditional funders like PCORI sponsorship, or NIH.
that uncertainty about program sustainability in communities impacts trust and the ability to do future work with community partners and community members.
the need to study adaptation of evidence-based interventions for implementation in other settings and update current knowledge.
Data and Data Integration
a virtual registry North American Association of Central Cancer Registries (NAACCR), Robert Wood Johnson Foundation (RWJF) Co. health rankings.
addressing the small sample size challenge by combining like areas; query for data availability (what can be combined?).
aggregation or pooling of data across studies.
data issues: timing and recency, ongoing collection and data storage.
determining what data can be combined when combining like areas.
how rapid social change affects the kinds of data and sources accessible to researchers.
identifying disparities hotspots and overlaying additional data from other variables to build a more complete picture.
identifying research measures that are distinct to rural environments on standard of care; quality of care and comparing (urban vs rural).
integrative data analysis that encompasses a small "n".
investigating patient reported outcomes and symptom management; often in rural areas "good patients" do not complain about symptoms.
privacy/confidentiality related elements like data use agreements, regulations and research priorities.
research into incentives for achieving optimal quality metrics.
small area estimation.
that data behind firewalls needs to be available.
that surveillance data may be useful even if not current.
the kinds of databases needed to understand rural spatial variables.
the rights of patients to donate their data.
the value of examining trends in surveillance data over time.
valid measures to characterize context, implementation, and adaptation.
Interdisciplinarity
a Center-based approach (critical mass) along with a phased approach, to recognize alignment with funding options.

guidelines for resource sharing among investigators and community partners.
multilevel and interdisciplinary research models.
multilevel approaches that include individuals and systems including parents, community, engaging multiple points and multiple populations.
that interdisciplinary research is critical for rural health given diverse elements that need to be considered.
Information Technology
adaptation of proven technologies to different conditions in rural research and translation.
geospatial data methods/mapping to enable visualization.
health information technology to address health -related workforce deficits.
health system informatics for patient experience.
identifying roles that information technology can serve.
implementing what works now in emerging Electronic Health Record systems, adapt proven techniques.
the conceptual framework that needs to be put in place for the next decade and the technology tools that can support it.
Methods
balancing the burden of implementing change vs the opportunity for success or good outcomes.
bridging community based participatory research, epidemiology and health services research systems.
bridging perspectives through CBPR for data generation, collection, use
common implementation standards across all settings.
detailed reporting and measurement of context and implementation processes to facilitate comparative effectiveness research and comparisons across heterogeneous rural contexts.
highlighting the importance of mixed methods.
how to scale up, test and adapt evidence-based interventions in context.
issues of fidelity in evidence-based interventions.
using digital science/communication science methods to understand decision making.
whether urban methods can be used or modified for use in rural areas.

Summary: Feedback by Subgroup Topic

This section contains an overview of the feedback from each topic session, listing themes that are present and providing representative content from each discussion. Recall that the filter for the statements is the focus prompt: **"To achieve measurable progress in Rural Cancer Prevention and Control, a comprehensive dissemination and implementation research agenda would consider or include…"** Feedback from each breakout topic heavily reflects the topic, as would be expected. Nevertheless, attendees contributed broader feedback that reflected their view of the connections among these topics, suggesting a systems basis for the development of this agenda going forward.

Breakout Topic A: Prevention Research in Rural Cancer Control

The first topic was more general than the feedback captured for the specifically focused breakout groups that followed. The sub-prompts for the discussion were:

- What new research evidence is **needed** to accelerate progress in prevention?
- What are the top 3-5 **research priorities** to accelerate progress in reducing rural cancer disparities?

Considering the broad topic of prevention research, captured items described collaboration, context, data, interdisciplinarity, and methods. Table 4 represents ideas that the group contributed to the prompts for Topic A.

Table 4: Feedback from Prevention Research Breakout Group Discussion

Topic A: Prevention Research
an infrastructure like a consortium to access and integrate funding.
community delivered interventions: if a problem is in a community, the solution can also be in the community.
highlighting the importance of mixed methods.
how rapid social change affects the kinds of data and sources accessible to researchers.
how to scale up, test and adapt evidence-based interventions in context.
issues of fidelity in evidence-based interventions.
multilevel approaches that include individuals and systems including parents, community, engaging multiple points and multiple populations.
the kinds of databases needed to understand rural spatial variables.
where and when public/private partnerships are appropriate.

Breakout Topic B: Emerging Research Methods in Rural Cancer Control

The group responded to these sub-prompts when considering emerging research methods:

- What research **methods are emerging** that are particularly compelling to address rural cancer disparities?
- What **methodological research** is needed to accelerate progress in rural cancer disparities?

The discussion showed a heavy emphasis on data, data integration and of course methods; in addition, collaboration, interdisciplinarity, patient focus and vision for rural cancer research were present. Table 5 is a representation of the ideas that emerged.

Table 5. Feedback from Emerging Methods Group

Topic B: Emerging Methods
a phased Center-based approach (critical mass), to recognize alignment with funding options.
a shared vision: where we believe things are going.
addressing the small sample size challenge by combining like areas; query for data availability to identify what can be combined.
an emphasis on more self-testing and a process for follow up: point of care, point of screening, etc.
bridging perspectives through CBPR for data generation, collection, use.
determine what data can be combined when combining like areas.
identifying disparities hotspots and overlaying additional data from other variables to build a more complete picture.
moving the focus from hotspots to peer modeling, from "bad" to "good" areas.
partnership--new and expanded to connect NCI, CDC, Verizon, FedEx, other systems.
that data behind firewalls needs to be available.
the value of examining trends in surveillance data over time.
whether urban methods can be used or modified for use in rural areas.

Breakout Topic C: IT to Address Disparities in Rural Cancer Control

Topic C is heavily represented in the cross-theme of Data in Table 3, above. The sub-prompts for the group's discussion were

- What new research evidence is needed to accelerate **progress in information technology and communications?**
- What are the top 3-5 research priorities to accelerate **progress in reducing rural cancer disparities?**

Emphasizing the purposeful application of IT to address disparities led to feedback that balanced objective data-driven issues and ideas with a recognition of the contexts in which disparities heavily affect the people. In addition to data and IT, items fell into several categories, including context, interdisciplinarity, methods and promising practices. Table 6 contains representative items on this topic.

Table 6. Feedback from IT to Address Disparities Group.

Topic C: IT to Address Disparities in Rural Cancer Control
a deep understanding of the wants and needs of people and communities.
achieving electronic health record (EHR) interoperability across the US including rural areas.
common implementation standards across all settings.
health information technology to address health -related workforce deficits.
health system informatics for patient experience.

identifying roles that information technology can serve.
identifying domains to study/support.
identifying research measures that are distinct to rural environments on standard of care; quality of care and comparing (urban vs rural).
information systems to provide the latest best practices to providers and teams.
integrative data analysis that encompasses a small "n".
investigating patient reported outcomes and symptom management; often in rural areas "good patients" do not complain about symptoms.
multilevel and interdisciplinary research models.
research into incentives for achieving optimal quality metrics.
that interdisciplinary research is critical for rural health given the diverse elements that need to be considered.
that surveillance data may be useful even if not current.
the conceptual framework that needs to be put in place for the next decade and the technology tools that can support it.
the rights of patients to donate their data.
using digital science/communication science methods to understand decision making.

Breakout Topic D: Clinical Research and Quality of Rural Cancer Care

Quality of Care emphasized locale-specific approaches, using tools and approaches including promising or best practices adaptation, electronic health records, and policy and payment structure's effect on efforts to increase quality. The sub-prompts the group considered were

- What research challenges would have been addressed to accelerate **progress in rural cancer care?**
- What are the top 3-5 research priorities to accelerate **progress in healthcare delivery** in reducing rural cancer disparities?

Table 7 includes items from the group discussion.

Table 7. Feedback from Quality and Care Discussion Group.

Topic D: Clinical Research and Quality of Rural Cancer Care
adaptation of proven technologies to different conditions in rural research and translation.
balancing the burden of implementing change vs the opportunity for success or good outcomes.
identify test 'models' for care delivery aligned with incentives under alternative payment models, via CMS innovation grants or other resources.
identifying locale-specific attitudes or beliefs that might impact cancer control in rural communities.
implementing what works now in emerging Electronic Health Record systems, adapting proven techniques.
observational studies on how cancer treatment is affected by ACOs or different payment structures.
policy-related drivers of high-quality care.

what mechanism works best for patients and providers to increase and maintain trust.

Breakout Topic E: Improving Access, Engagement, Care Experiences

A heavy emphasis on understanding the issues of access, trust and engaging people in context to improve care experiences was noted in this group. Sub-prompts to which the group responded were

- What new research evidence is needed to accelerate progress in **improving access to care**?
- What new evidence is needed to accelerate progress in **patient engagement** and improved **experiences of care**?

Contributors also discussed payment mechanisms, funding, policy impact on access, methods, and data for improving the care experience. Table 8 contains representative ideas from this discussion.

Table 8. Feedback from Access, Engagement and Care Group.

Topic E: Improving Access, Engagement, Care Experiences
a strengths-based lens rather than a deficiency lens, considering opportunities for innovation and impactful change through the strong social and community ties in many rural communities.
a whole person lens versus singular disease focus as critical for understanding cancer control and care delivery in rural settings.
articulating sustainability as a researchable problem.
balancing the research portfolio based on burden and opportunity in rural environments and recognizing existing levels of focus on certain cancers.
barriers to use of and access to palliative and other supportive care.
care coordination between specialists and PCPs in rural settings and care transitions.
delivering preventative care and facilitating patient-level behavior change in rural communities.
detailed reporting and measurement of context and implementation processes to facilitate comparative effectiveness research and comparisons across heterogeneous rural contexts.
differentiating cost effectiveness versus budget impact.
engagement as a dimension of "care access".
guidelines for resource sharing among investigators and community partners.
heterogeneity among rural settings and the impact on care delivery interventions.
how community partners are engaged, integrated, and paid as part of community-based interventions and community-care delivery system interventions.
how to best build research interest and capacity among rural and community-based providers.
how to best engage patients in their health in rural communities to help set norms and expectations for health.
how to best engage providers and community partners.
how to best support patients in modifying high risk behaviors in rural communities.
more research that enables the exploration and appreciation of the variability among rural communities.

person-centered research on cost effectiveness via traditional funders like PCORI sponsorship, or NIH.
studying and understanding program impact over longer time horizons than currently supported by 5-year funding mechanisms.
that access should be recognized as including more than physical location and insurance coverage in rural communities.
that conflicting definitions of "rural" affects who is eligible for funding and comparative research.
that research on care access and engagement for prevention and screening are also part of care delivery research.
that uncertainty about program sustainability in communities affects trust and the ability to do future work with community partners and community members.
treating policy and payment as context variables and examining the impact of these changes in rural settings.
valid measures to characterize context, implementation, and adaptation.
what models work best to sustain community-heavy interventions once initial start-up/grant period ends.

Implications

This overview of the breakout group content at the Rural Cancer Control and Prevention meeting contains representative items from each of the topic areas, and the crosstalk of major themes from group to group. It can assist future phases of research development in considering the high value ideas that surfaced through many different lenses during the meeting discussions, to support a continuation of purposeful planning for implementation research in rural cancer control and prevention.

Phase II. Concept Mapping of Rural Cancer Control Implementation Research Priorities

Introduction

The Rural Cancer Control (RCC) meeting summary provided an excellent collation of ideas and research topics that could potentially increase the implementation of interventions to address rural disparities in cancer outcomes. This second phase of the project was designed to expand the brainstorming content from the RCC meeting by including additional stakeholder participation, and then to conduct a concept mapping exercise to foster additional organization of research priorities. The goal was to further inform the development of a comprehensive dissemination and implementation research agenda to achieve measurable progress in rural cancer prevention and control to improve rural cancer disparities.

Methods

Concept mapping was conducted to examine specific research ideas that key stakeholders believed need to be addressed to increase the implementation of rural cancer control interventions. Concept mapping is a sequential, mixed-methods planning and evaluation approach that integrates qualitative processes (i.e., brainstorming, categorizing and rating ideas) with multivariate statistical analyses (i.e., creating a similarity matrix, multidimensional scaling, and hierarchical cluster analysis) to create visual representation of data.[34]

An on-line brainstorming activity was conducted in October of 2017 to expand the content from the RCC meeting breakout sessions. Researchers, health care practitioners and intermediaries (funders, advocates, etc.) were asked to respond to the following focus prompt, **"To achieve measurable progress in Rural Cancer Prevention and Control, a comprehensive dissemination and implementation research agenda would consider or include…"**

One hundred twenty-five Memphis meeting attendees were invited to participate in the brainstorming activity. These individuals were asked to share the invitation with additional colleagues so the total number of participants that received invitations is not known. Forty-two participants submitted 108 responses through anonymous logins on the project site during the 3 weeks that brainstorming was open. The statements generated during on-line brainstorming were reviewed for responsiveness to the original focus prompt and merged with content from the Memphis meeting breakout sessions (see Phase I report). Similar statements to those generated during the Memphis meeting were combined and the final statement set was reduced to 107 for the next phase of sorting and rating items.

A second invitation to participate in the sorting and rating phase of the mapping project was sent out to the 125 individuals that were invited to the brainstorming activity. Participants indicated whether they were a researcher (e.g., academic research, academic teaching, federal gov't research); practitioners (e.g., community-based education, hospital/clinic, managed care, private group practice, worksite); or an intermediary (e.g., advocacy, philanthropy/funding, federal gov't service, local government).

Participants were asked to review each statement and to create conceptual groupings on the concept mapping website. Each participant could create as many groups of statements as they felt necessary, providing a descriptive name for each grouping. Next, within these groupings, participants were asked to rate individual statements on a 4-point scale (1=relatively unimportant to 4=very/extremely important) on the *relative importance for improving implementation of rural cancer control interventions* and on a 3-point scale (1=not currently being addressed to 3=sufficiently being addressed) on the *degree to which they think the research is currently being addressed.*

Among the 69 total participants, 42 completed the sorting phase (34 researchers, 4 practitioners, 2 intermediaries, 2 "others") where conceptually similar topics were aggregated into categories. Forty-five participants (35 researchers, 5 practitioners, 2 intermediaries, 3 "others") completed ratings of the perceived importance of each research statement and 36 participants (28 researchers, 4 practitioners, 2 intermediaries, 2 "others") completed ratings of the perceived state of the current research for each statement.

Results

Using data from the sorting phase of the project, nonmetric multidimensional scaling was used to map points representing the 107 statements. A point cluster map was generated to display participant responses in a shared, aggregated conceptual structure (Figure 1). Key concepts within the cluster were used to label each grouping. The map yielded 8 initial clusters. A majority of the clusters, 6 of 8, representing "foundational" needs to the formation of a comprehensive dissemination and implementation research agenda in rural cancer control. The other 2 clusters were more focused on care specific research topics such as healthcare access issues and prevention and self-care interventions (figure 1).

Figure 1: Point Cluster Map of a Shared Conceptual Structure for Rural Cancer Control Implementation Research
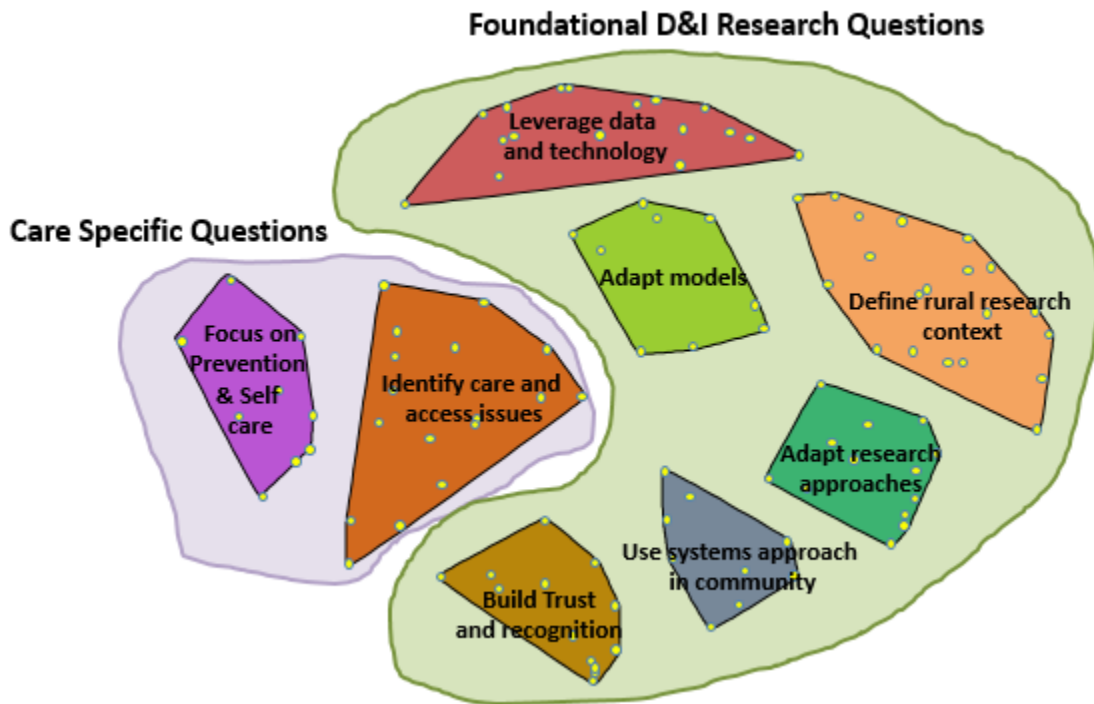
Identifying Research Gaps

By contrasting the cluster ratings of importance of a research topic with ratings of the perceived depth of existing research on a topic, potential gaps in the larger research agenda can be summarized. A

similarity matrix was constructed using rating data to create a relative pattern match between relative importance and the current state of research (Figure 2). The importance ratings for all research concepts ranged from 2.67 to 3.08 on a scale of 1-4. The current state of the research concept ratings similarly clustered with a range of 1.67 to 1.91 on a scale of 1-3. Highest ranked in importance was "Contribute to trust and recognition" which was rated third highest for state of the current research. Second highest in importance was "Use systems approach in community" which was rated as third lowest in current state of research.

Relative Pattern Match
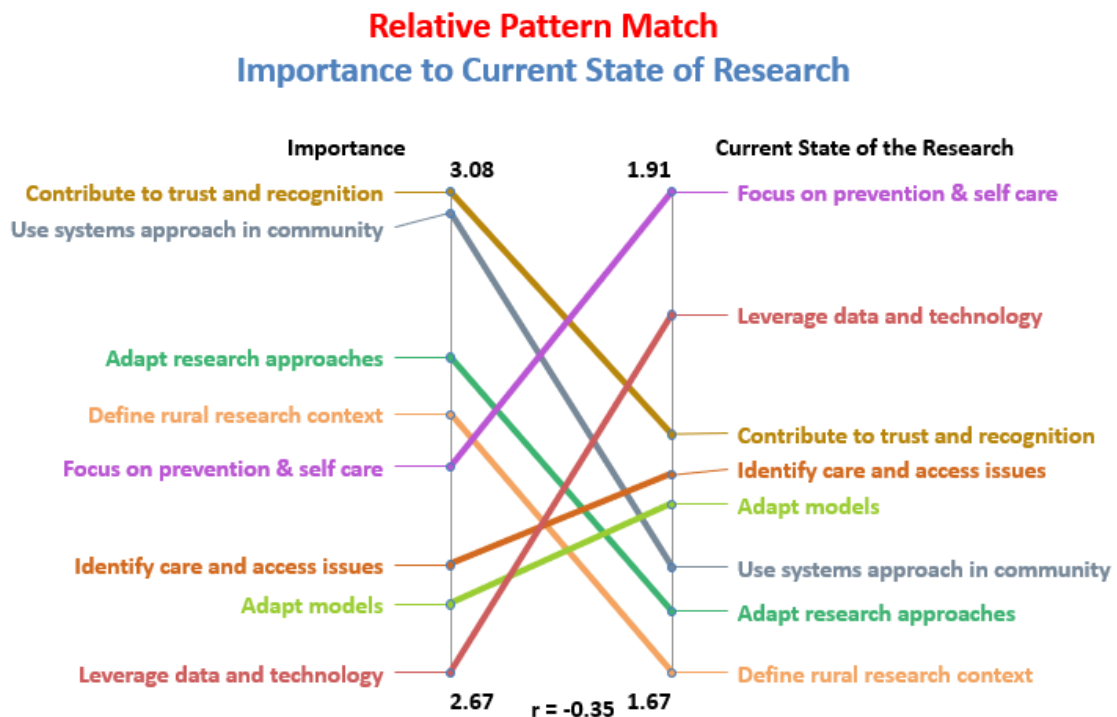### Importance to Current State of Research

Figure 2

Additional gap assessments were conducted using a "go-zone" analysis within each of the 8 conceptual cluster. Go-zone analyses provide a more detailed analysis of ratings by allowing comparison of statement ratings within clusters. Each statement within a cluster is compared on a bivariate plot that is divided into four zones. This study compares importance and current state of the research. The go-zone includes statements rated most important and low level of current state of the research. (Figure 3). By identifying the responses with both high importance and a low level of ongoing activities, the go-zones reflected participant perspectives of the high priority areas for which the gap in research should be closed. The statements for the "go-zones" of each cluster are provided in Appendix 1.

Go-Zones by Cluster

Figure with four quadrants:
- Top left (orange): High RATING 1 / Low RATING 2
- Top right (yellow): High RATING 1 / High RATING 2
- Bottom left (gray): Low RATING 1 / Low RATING 2
- Bottom right (green): Low RATING 1 / High RATING 2

Y-axis: Current State (High / Low)
X-axis: Importance (Low / High)

RATING 1 mean: will vary by cluster
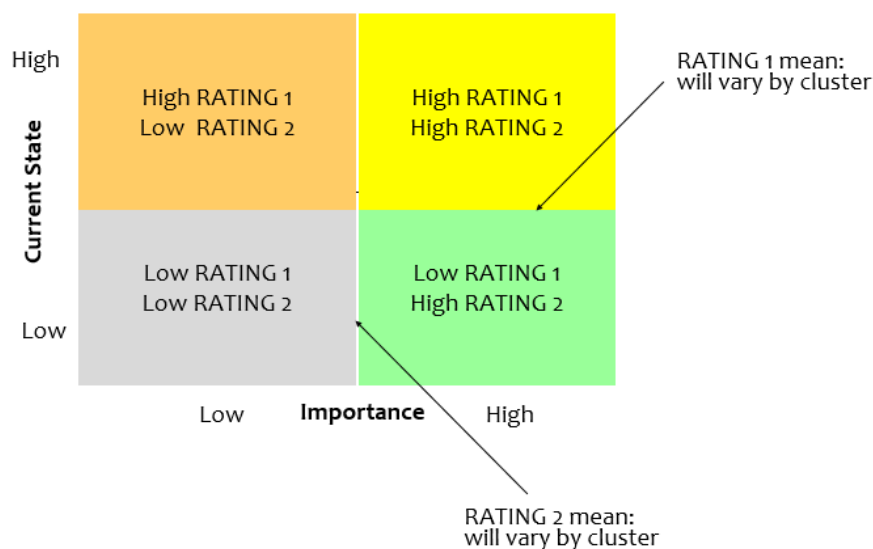RATING 2 mean: will vary by cluster

Figure 3

Results in each quadrant offer meaningful opportunities to understand the current state of research and areas considered of high importance to moving forward a research agenda in implementation of interventions for rural cancer control. The most expedient quadrant for consideration may be the "green zone" which indicates an area of high importance but that has less research information available (see Appendix 1). Summary results are presented within the two larger conceptual structures of 1) foundational issues for dissemination and implementation research agenda in rural cancer control and 2) care specific issues that will enhance progress in rural cancer control.

Foundational Issues for Dissemination and Implementation Research Agenda

The primary focus of the concept mapping project was to develop a comprehensive dissemination and implementation research agenda in rural areas. Six of the eight clusters include statements related to foundational issues related to developing this agenda. These six clusters are described below.

Leveraging Data and Technology

"Leverage Data and Technology" includes 17 statements overall (Appendix 1). This cluster was rated lowest out of the eight clusters on importance and second highest on current state of the research. While the rating on current state of the research gives the impression that sufficient research is underway that addresses data and technology issues for rural cancer control, five statements ranked in the "green zone" provide topics that are viewed as important and where the current state of the research could be enhanced. These topics include:

- *Achieving electronic health record interoperability across US including rural areas*

- *Linking heterogeneous data sets to support multilevel exploration of cancer disparities*
- *Confirming and addressing the digital divide in rural communities*
- *Information systems to provide the latest best practices to care providers and teams*

Define Rural Research Context

"Define Rural Research Context" includes 20 statements overall (Appendix 1). This cluster includes topics related to comprehensive behavioral and social epidemiology in rural geographies and populations as well as some measurement issues. This cluster is rated fourth in importance and lowest on the current state of the research. The ratings indicate that relative to the other topics, defining rural research context is a research area where additional work is necessary. Six statements ranked in the "green zone" provide topics that are viewed as important and where the current state of the research could be enhanced. These topics include:

- *Identifying research measures that are distinct to rural environments on standard of care; quality of care and comparing (urban vs rural)*
- *Identifying locale-specific attitudes or beliefs that might impact cancer control in rural communities.*
- *Research to examine factors that co-vary with rural/urban status that might a) be modifiable and b) explain WHY disparities exist not simply catalog them.*
- *Research enabling exploration and appreciation of variability among rural communities*
- *Detailed reporting and measurement of context and implementation processes to facilitate comparative effectiveness research and comparisons across heterogeneous rural contexts.*
- *How the unique social, physical, and cultural context of rural areas may differ from that of other types of areas so that evidence-based practices can be most effectively tested and implemented in rural communities*

Adapting Research Approaches in Rural Settings

The "Adapt Research Approaches" cluster focuses on research design considerations This cluster is rated second highest on importance and third lowest on current state of the research. Four statements ranked in the "green zone" provide topics that are viewed as important and where the current state of the research could be enhanced. These topics include:

- *Articulating sustainability as a researchable problem*
- *Heterogeneity among rural settings and the impact on care delivery interventions*
- *Studying program impact over the longer time horizon (than 5 yr.) funding mechanisms*
- *Multi-site demonstration projects*

Using Systems Approaches in Community

"Use Systems Approach in Community" cluster contains 9 statements (Appendix 1). The relative pattern match shows that this cluster is rated second highest on importance and third lowest on the current state of the research. Five specific statements ranked in the "green zone" provide topics that are viewed as important and where the current state of the research could be enhanced. These topics include:

- *Implement evidence-based interventions via coordinated efforts w/ cancer stakeholders*
- *How to best build research interest, capacity among rural and community-based providers*

- *Multi-level approach (patient, caregiver, community, etc.) to adapting evidence-based methods*
- *Strength-based lens rather than a deficiency lens, considering opportunities for innovation and impactful change through the strong social and community ties in many rural communities*
- *Multilevel approaches that include individuals and systems that engage at multiple points and multiple populations.*

Building Trust and Recognition to Support Research

The "Contribute to Trust and Recognition" cluster focuses on participatory, co-designed research processes and contains 12 statements (Appendix 1). This cluster is rated highest on importance and third highest on current state of the research. Three statements ranked in the "green zone" provide topics that are viewed as important and where the current state of the research could be enhanced. These topics include:

- *How partners are engaged, integrated, and paid as part of community-based interventions*
- *What models work best to sustain community-heavy interventions once initial start-up/grant period ends*
- *How to best engage patients in their health in rural communities to help set norms and expectations for health*

Adapting Models for Rural Research

The "Adapt Models" cluster is in the center of the map which indicates that it contains statements that bridge the ideas between the clusters that surrounds it. This cluster contains 9 statements (Appendix 1). This cluster is second lowest on importance and is rated the fourth highest (or fourth lowest) for current state of the research. Three statements ranked in the "green zone" provide topics that are viewed as important and where the current state of the research could be enhanced. These topics include:

- *Longitudinal patterns of care studies that identify where/how rural residents access care*
- *Access should be recognized as including more than physical location and insurance coverage in rural communities*
- *Adapting technologies known to work in global settings to rural US settings*

Care Specific Issues to Progress in Rural Cancer Control

Dissemination and implementation research doesn't happen in isolation. The concept mapping exercise identified additional research areas that need to be developed in rural cancer control specifically related to prevention, care and care access. The clusters included in this area are perceived to have more funded research than the topics related to dissemination and implementation research and are detailed below.

Identifying Care and Care Access Issues

The "Identify Care and Care Access Issues" cluster is located on the left center of the map and like the "Adapting Models" cluster, this cluster contains statements that bridge the ideas between the clusters that surround it. This cluster contains 17 statements (Appendix 1) and is fourth highest (or fourth lowest) on importance and is rated highest for current state of the research. Six statements ranked in

the "green zone" provide topics that are viewed as important and where the current state of the research could be enhanced. These topics include:

- *A whole person lens vs singular disease focus as critical for understanding cancer control and care delivery in rural settings*
- *Understanding and evaluating policies that impact health across government, systems and environment in rural settings*
- *Treating policy and payment as context variables and examining the impact of these changes in rural settings*
- *How to best support patients in modifying high risk behaviors in rural communities*
- *Support for rural providers to talk about clinical trials and link patients to trials*
- *Infrastructure like a consortium to access/integrate funding*

Prevention & Self Care in Rural Cancer Control

The "Focus on Prevention & Self Care" cluster contains 9 statements (Appendix 1). This cluster is second lowest on importance and is rated the fourth highest (or fourth lowest) for current state of the research. Two statements ranked in the "green zone" provide topics that are viewed as important and where the current state of the research could be enhanced. These topics include:

- *Resources to support follow-up and treatment for abnormal screening*
- *What are optimal roles for coordinating care between specialists, primary care practiced and community health workers*

Discussion

The Group Concept Map yielded a roadmap for implementation science research in rural cancer control, emphasizing the critical aspects of context and capacity to adapt current knowledge and models. Rather than suggesting the need for new structures and systems, the map suggests that integration of existing capacity and knowledge may provide the strongest approach to an informed and agreed-upon structure for implementation science in rural environments.

The cluster themes identified areas for research emphasis that included:

- Needs to leverage data and technology in rural areas

- Defining rural research context

- Adapting current research approaches for use in rural cancer control

- Using systems approaches in rural community

- Building trust and recognition in rural populations

- Adapting current research models for rural implementation

- Identifying care and access issues in rural communities

- Focusing on prevention and self-care for rural populations

The experience of the individual in context plays an important role in this map as well and helps balance the side of the map that suggests the need for data and models with the need for attention to trust building and community context. While Building Trust, Systems Approaches, Adapting Research, and Defining Rural Research Context were among the most important research areas, they were simultaneously rated with the greatest need for additional research so can provide a prioritization for future funding and collaborative initiatives.

The concept map can be used as a guide for future implementation research and rural cancer control research priorities. The perception of the current state of the research can be compared to current grant portfolio analyses and literature reviews to help focus future funding opportunities. It also provides a possible framework to evaluate whether future funded research proposals and publications address the research areas of greatest need and importance as identified by our sample of experts in rural cancer control.

Bibliography

1. Blake KD, Moss JL, Gaysynsky A, Srinivasan S, and Croyle RT. Making the case for investment in rural cancer control: An analysis of rural cancer incidence, mortality, and funding trends. *Cancer Epidemiol Biomarkers Prev*. 2017.

2. Kane M. Rural cancer control: Challenges and opportunities. Report from meeting at the University of Memphis School of Public Health. May 4-5, 2017.

3. Trochim WMK. Concept mapping: Soft science or hard art? *Eval Program Plann*. 1989;12(1):87-110.

4. Trochim WMK. An introduction to concept mapping for planning and evaluation. *Eval Program Plann*. 1989;12(1):1-16.

APPENDIX 1

Focus Prompt: To achieve measurable progress in Rural Cancer Prevention and Control, a comprehensive dissemination and implementation research agenda would consider or include…

Color Coding Key: Questions Location in Go-Zone Quadrants	
Quadrant Priority Ranking	**Description**
1	Relatively low level of current state of research/Relatively high importance
2	Relatively high level of current state of research/ Relatively high importance
3	Relatively high-level of current state of research/Relatively low importance
4	Relatively low level of current state of research/ Relatively low importance

Question #	Proposed Research Questions
	Leverage Data and Technology
1	achieving electronic health record (EHR) interoperability across the US including rural areas.
5	linking heterogeneous data sets (e.g., EHR, claims, and contextual variables from survey data) to support multilevel exploration of factors contributing to cancer disparities.
34	addressing the so-called digital divide or confirming if there is a digital divide in rural communities.
42	information systems to provide the latest best practices to providers and teams.
20	data issues: timing and recency, ongoing collection and data storage.
24	geospatial data methods/mapping to enable visualization.
32	implementing what works now in emerging Electronic Health Record systems and adapting proven techniques.
49	the kinds of databases needed to understand rural spatial variables.
72	identifying roles that information technology can serve
63	privacy/confidentiality related elements like data use agreements (DUA), regulations and research priorities.
64	health information technology to address health -related workforce deficits.
99	health system informatics for patient experience.
19	using bioinformatics approaches to determine how rural MDs access information.
41	a virtual Pulled registry North American Association of Central Cancer Registries (NAACCR), Robert Wood Johnson Foundation (RWJF) Co. health rankings.
57	a data catalog and integration infrastructure using state-of-the-art informatics methods such as ontologies and semantic data integration methods.
86	approaches to collect data from Accountable Care Organizations (ACOs) to study alternative payment models.

Question #	Proposed Research Questions
91	the rights of patients to donate their data.

Question #	Proposed Research Questions
	Define Rural Research Context
4	identifying research measures that are distinct to rural environments on standard of care; quality of care and comparing (urban vs rural).
23	research to examine what factors co-vary with rural/urban status that might a) be modifiable and b) explain WHY disparities exist not simply catalog them.
45	identifying locale-specific attitudes or beliefs that might impact cancer control in rural communities.
65	more research that enables the exploration and appreciation of the variability among rural communities.
67	detailed reporting and measurement of context and implementation processes to facilitate comparative effectiveness research and comparisons across heterogeneous rural contexts.
77	how the unique social, physical, and cultural context of rural areas may differ from that of other types of areas so that evidence-based practices can be most effectively tested and implemented in rural communities
17	geographic isolation including distance, transportation, adequate living resources, and technology / connectedness.
69	valid measures to characterize context, implementation, and adaptation.
83	measuring many different dimensions across rural areas including the technology environment, transportation, and other factors that affect health.
85	Acknowledgment that important contextual and social factors can significantly vary across short distances
53	that conflicting definitions of "rural" affects who is eligible for funding and comparative research.
79	a means to define and identify "bad areas" and "good areas" from cancer incidence perspective.
82	small area estimation.
88	addressing the small sample size challenge by combining like areas; query for data availability (what can be combined?).
95	highlighting the importance of mixed methods.
13	demographic transitions and loss of social capital which are associated with increases in cancer mortality in rural areas.
54	defining and selecting geographic areas that are similar for co-learning. i.e., case examples from one area being adapted for use in other similar areas.
75	using criteria for rural areas to try to identify "like" areas across the nation.
84	assessing internal US migration patterns to understand changing demographics (race/ethnicity/acculturation) within rural America.
94	how rapid social change affects the kinds of data and sources accessible to researchers.

Question #	Proposed Research Questions

	Adapt Research Approaches
14	articulating sustainability as a researchable problem.
33	heterogeneity among rural settings and the impact on care delivery interventions.
76	studying and understanding program impact over longer time horizons than currently supported by 5-year funding mechanisms.
90	multi-site demonstration projects.
30	the need to study adaptation of evidence-based interventions for implementation in rural settings.
58	how to scale up, test and adapt evidence-based interventions in context.
96	that interdisciplinary research is critical for rural health given the diverse elements that need to be considered.
27	issues of fidelity in evidence-based interventions.
29	Balancing he burden of implementing change vs the opportunity for success.
61	the design, implementation, testing and dissemination of appropriate HPV and cervical cancer prevention for rural citizens to address higher cervical cancer rates in rural vs urban communities.
2	an understanding that the scientific dissemination and implementation terms that we all use are not routinely used in rural settings or any practice settings and make them straightforward and common sense in rural areas.
9	demonstration projects as part of R01s.
62	balancing the research portfolio based on burden and opportunity in rural environments and recognizing existing levels of focus on certain cancers.

Question #	Proposed Research Questions
	Use Systems Approach in Community
35	implementing evidence-based interventions via coordinated efforts from all cancer stakeholders.
56	how to best build research interest and capacity among rural and community-based providers.
66	a multi-level approach (patient, caregiver, community, hospital, etc.) to adapting an evidence-based method.
74	a strengths-based lens rather than a deficiency lens, considering opportunities for innovation and impactful change through the strong social and community ties in many rural communities.
92	multi-level approaches that include individuals and systems including parents, community, engaging multiple points and multiple populations.
80	bridging community based participatory research, epidemiology and health services research (HSR) systems.
40	the ability to develop/support academic-community collaborations to ensure evidence-based interventions are implemented with timely technical assistance and traditional research projects).
98	a strategic framework for network partners within the Cancer Prevention and Control Network (CPCRN) in considering evidence-based interventions.
10	interventions to address limited use/access to palliative and other supportive care.

Question #	Proposed Research Questions
	Building Trust and Recognition
7	how community partners are engaged, integrated, and paid as part of community-based interventions and community-care delivery system interventions.
21	what models work best to sustain community-heavy interventions once the initial start-up/grant period ends.
51	how to best engage patients in their health in rural communities to help set norms and expectations for health.
3	strategies that actively engage and partner with community experts (patients, caregivers and lay community members) in a meaningful and sustainable way.
47	engaging local rural community stakeholders to assist in prevention messaging.
60	collaboration with comprehensive cancer control partnerships and state-level early detection programs funded through CDC.
78	engagement of rural patients, providers, and community partners.
101	leveraging local public health (PH) workforce (non CHES; peer support).
39	where and when public/private partnerships are appropriate.
55	guidelines for resource sharing among investigators and community partners.
70	community reciprocity and what the community may gain.
102	that uncertainty about program sustainability in communities impacts trust and the ability to do future work with community partners and community members.
106	what mechanism works best for patients and providers to increase and maintain trust.

Question #	Proposed Research Questions
	Adapt Models
46	longitudinal patterns of care studies that identify where/how residents of rural communities access care.
50	that access should be recognized as including more than physical location and insurance coverage in rural communities.
81	adapting technologies known to work in the global setting to rural US settings.
105	environmental factors, smoking rates, obesity rates, self-reported health.
107	adaptation of proven technologies to different conditions in rural research and translation.
97	investigating access to Clinical and Translational Science Awards (CTSA) by zip or county
22	the conceptual framework that needs to be put in place for the next decade and the technology tools that can support it.
26	studying the tools, databases, and approaches that national and global delivery services providers use, (like FedEx, IT networks, airports) to identify relevance - what works and what could work.
37	using digital science/communication science methods to understand decision making.

Question #	Proposed Research Questions
	Identify Care and Access Issues
11	a whole person lens versus singular disease focus as critical for understanding cancer control and care delivery in rural settings.
15	understanding and evaluating policies that impact health across government, systems, and environment in rural settings.
38	treating policy and payment as context variables and examining the impact of these changes in rural settings.
43	how to best support patients in modifying high risk behaviors in rural communities.
59	support for rural providers to talk about clinical trials to their patients and to link them to trials.
93	an infrastructure like a consortium to access/integrate funding.
6	utilizing evidence-based methods to increase prevention/screening (CRC, HPV).
12	models for delivering cancer care, particularly during treatment and survivorship.
71	that research on care access and engagement for prevention and screening are also part of care delivery research.
28	participation in CMMI models or other pilot projects that emphasize cancer prevention and/or control.
31	person-centered research on cost effectiveness via traditional funders like PCORI sponsorship, or NIH.
68	differentiating cost effectiveness versus budget impact.
89	observational studies on how cancer treatment is affected by ACOs or different payment structures.
25	a Center-based approach (critical mass) and perhaps a phased approach, to recognize alignment with funding options.
44	investigating patient reported outcomes and symptom management; often in rural areas "good patients" do not complain about symptoms.
87	the Health care Delta Network and NCORP - and whether other institutes can be involved.
100	new funding mechanisms of a "super" program contract/cooperative agreement idea.

Question #	Proposed Research Questions
	Prevention & Self Care
52	resources to support follow-up and treatment for abnormal screening.
103	what are optimal roles for coordinating care between specialists, primary care practice and community health workers.
36	addressing modifiable health behaviors (e.g., physical activity, dietary habits, smoking) along the cancer continuum from prevention through survivorship and end-of-life.
73	delivering preventative care and facilitating patient-level behavior change in rural communities.
8	provider education on cancer prevention and control.
16	reimbursement issues for high touch care and management/triage related to Medicare Access and Chip Reauthorization Act (MACRA) and Oncology Care Models (OCM) focus on value-based bundling.
18	identify test 'models' for care delivery aligned with incentives under alternative payment models, via CMS innovation grants or other resources.
48	reimbursement issues for portal communication/telehealth related to Medicare Access and Chip Reauthorization Act (MACRA) and Oncology Care Models (OCM) focus on value-based bundling.
104	an emphasis on more self-testing and a process to follow up - point of care, point of screening, etc.