Rural Cancer Control: A “Moonshot” Implementation Research Agenda

Lisa M Klesges, PhD, MS
August 23, 2018
Rural Cancer Disparities

Invasive Cancer Incidence, 2004–2013, and Deaths, 2006–2015, in Nonmetropolitan and Metropolitan Counties — United States

Making the Case for Investment in Rural Cancer Control: An Analysis of Rural Cancer Incidence, Mortality, and Funding Trends
Kelly D. Blake, Jennifer L. Moss, Anna Gaysynsky, Shobha Srivasan, and Robert T. Croyle

Ali H. Mokdad, PhD; Laura Dwyer-Lindgren, MPH; Cristina Fitzmaurice, MD, MPH; Rebecca W. Stubbs, BA; Amelia Bertozzi-Villela, MS, MS; Olivia Moncoff, MPH; Saghir Chaturvedi, MD; Christine Allen, BA; Mohsen Naghavi, MD, PhD; Christopher J. L. Murray, MD, DPhil

INTRODUCTION Cancer is a leading cause of morbidity and mortality in the United States and results in a high economic burden.

OBJECTIVE To estimate age-standardized mortality rates by US county from 29 cancers.
Rural Cancer Control Implementation Research

Rural Disparities
Cancer moonshot

Conduct implementation research to accelerate the adoption and deployment of sustainable, evidence-based cancer prevention and screening interventions at multiple levels and in different clinical and community settings.

Advance implementation science directed at fully integrating current evidence-based cancer prevention and screening interventions in 3 high priority, high impact areas: HPV vaccination, colorectal cancer (CRC) screening, and tobacco control.

To significantly impact cancer outcomes in the general population as well as among populations that experience persistent cancer disparities (e.g. low income, minority, rural, and other underserved populations).
Blue Ribbon Panel Recommendations, 2016

A. Establish a network for direct patient involvement
Engage patients to contribute their comprehensive tumor profile data to expand knowledge about what therapies work, in whom, and in which types of cancer.

B. Create a clinical trials network devoted exclusively to immunotherapy
Establish a cancer immunotherapy clinical trials network devoted exclusively to discovering and evaluating immunotherapy approaches.

C. Develop ways to overcome cancer’s resistance to therapy
Identify therapeutic targets to overcome drug resistance through studies that determine the mechanisms that lead cancer cells to become resistant to previously effective treatments.

D. Build a national cancer data ecosystem
Create a national ecosystem for sharing and analyzing cancer data so that researchers, clinicians, and patients will be able to contribute data, which will facilitate efficient data analysis.

E. Intensify research on the major drivers of childhood cancers
Improve our understanding of fusion oncoproteins in pediatric cancer and use new preclinical models to develop inhibitors that target them.

F. Minimize cancer treatment’s debilitating side effects
Accelerate the development of guidelines for routine monitoring and management of patient-reported symptoms to minimize debilitating side effects of cancer and its treatment.

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

H. Mine past patient data to predict future patient outcomes
Predict response to standard treatments through retrospective analysis of patient specimens.

I. Develop a 3-D cancer atlas
Create dynamic 3-D maps of human tumor evolution to document the genetic lesions and cellular interactions of each tumor as it evolves from a precancerous lesion to advanced cancer.

J. Develop new cancer technologies
Develop new enabling cancer technologies to characterize tumors and test therapies.
Rural Cancer Control Implementation Research

Venn Diagram:
- Rural Disparities
- Implementation Science

The diagram illustrates the intersection between rural disparities and implementation science, suggesting a research focus on understanding and addressing the unique challenges faced by rural communities in the context of cancer control implementations.
Implementing Successful Prevention Research
Emerging Research Methods
Data, Tools, Technology to Connect Rural Populations
Clinical Research and Quality
Improving Access, Engagement, Care Experiences
Public Health and Community Capacity: Aligning Research to Reduce Disparities

Imagine 10-years from now, major improvements have been made in reducing cancer disparities in rural communities...
At a Rural Cancer Control meeting (5/17) researchers identified opportunities for future research that can be translated into effective interventions leading to prevention, diagnosis and treatment of cancer. Ideas from that conference were expanded using group concept mapping.

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

Invited Online Brainstorming: Researchers, Health Care Practitioners, and Intermediaries to expand

L Klesges, C Vinson, M Kane, Rural Cancer Control Concept Mapping
Organizing Knowledge and Opinion

69 total Sorting Invitees
The Conceptual Framework

- Leverage data and technology
- Adapt models
- Define rural research context
- Adapt research approaches
- Use systems approach in community
- Identify care and access issues
- Contribute to trust and recognition
- Focus on prevention & self care

Point Cluster Map of Shared Conceptual Structure
8 initial clusters were extracted from the map of statements with 6 of the clusters describing “foundational” needs to formation of a comprehensive dissemination and implementation research agenda in rural cancer control

- Building an Understanding of the Rural Research Context
- Leveraging Data and Technology
- Adapting Existing Models for Rural Research
- Adapting Research Approaches in Rural Settings
- Applying Systems Concepts/Methods in Community
- Building Trust and Recognition to Support Research
- Address Care and Care Access Issues
- Preventive Care Focus in Rural Cancer Control
Relative Pattern Match
Importance to Current State of Research

Contribute to trust and recognition
Use systems approach in community
Adapt research approaches
Define rural research context
Focus on prevention & self care
Identify care and access issues
Adapt models
Leverage data and technology

Importance
Current State of Research

2.67
3.08
1.91
1.67

$r = -0.35$
Research of High Importance/ Less Known

**Rural Research Context** (e.g. from 6)
- Identifying research measures that are distinct to rural environments
- Research to examine factors that co-vary with rural/urban status
- Research enabling exploration and appreciation of variability among rural communities

**Leverage Data & Technology**
- 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

**Adapt Models**
- 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
Research of High Importance/ Less Known

**Adapt Research Approaches**
- 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

**Use Systems Approaches** (e.g. from 5)
- 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

**Build Trust and Recognition**
- How partners are engaged, integrated, and paid as part of community-based interventions
- What models work best to sustain community-heavy interventions once grant period ends
- How to best engage patients in their health in rural communities to help set norms and expectations for health
Research of High Importance/ Less Known

Identify Care and Access Issues (e.g., from 6)
- A whole person lens vs singular disease focus as critical for understanding cancer control and care delivery in rural settings
- Treating policy and payment as context variables and examining the impact of these changes in rural settings
- Support for rural providers to talk about clinical trials and link patients to trials

Prevention & Self-Care
- 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
“High Priority” Implementation Research

My Takeaways...public health systems view

- Systemic approaches....Learning Community Health System for identifying needs and understanding implementation research in context of rural community

- Designing and Supporting an “adaptive system” of rural health (cancer control) recognizing that cancer care delivery exists as part of a larger “social enterprise” driving health outcomes

- Participatory “co-design” or “user-designed” approaches to prevention and care delivery seeking understanding of local culture e.g., distance, connectivity

- Explore new opportunities for data, technology, communication, informatics to support person-centered care – can we “move information not people”
Aspirations for a better system design....

“...transform health care by moving from its historic “linear, deconstructed model” that falls along traditional disciplinary boundaries to a “complex, adaptive system” that drives better performance outcomes, and considers healthcare as a complex social process.”

--Paul Batalden, Institute for Healthcare Improvement
Care Redesign...Accountable Communities for RURAL Health System Transformation...

10 Rules to Accelerate Healthcare Redesign

• Change the balance of power. *Co-produce health and well-being in partnership with patients, families and communities.*

• Standardize what makes sense. *Standardize what is possible to reduce unnecessary variation and increase time available for individualized care.*

• Customize to the individual. *Contextualize care to an individual’s needs, values and preferences, guided by an understanding of what matters to the person in addition to “What’s the matter?”*

• Promote well-being. *Focus on outcomes that matter the most to people, appreciating that their health and happiness may not require healthcare.*

• Create joy in work. *Cultivate and mobilize the pride and joy of the healthcare workforce.*

Institute for Healthcare Improvement, Healthcare Executive NOV/DEC 2015
10 New Rules to Accelerate Healthcare Redesign

• Make it easy. Continually reduce waste and all nonvalue-added requirements and activities for patients, families and clinicians.

• Move knowledge, not people. Exploit all helpful capacities of modern digital care and continually substitute better alternatives for visits and institutional stays. Meet people where they are, literally.

• Collaborate and cooperate. Recognize that the healthcare system is embedded in a network that extends beyond traditional walls. Eliminate siloes and tear down self-protective institutional or professional boundaries that impeded flow and responsiveness.

• Assume abundance. Use all the assets that can help to optimize the social, economic and physical environment, especially those brought by patients, families and communities.

• Return the money. Give the money from healthcare savings to other public and private purposes.
Contributions of Implementation Science, Learning Health Care System, and Precision Medicine

Key Areas of Synergy
- Evolution of evidence base for precision medicine and implementation science
- Recognition of underuse and overuse of interventions
- Management of abundance of data

Optimal integration of effective diagnosis, prevention, and treatment
Understanding of multilevel context
Theories and strategies to drive health care improvement

Optimal use of genomics and behavioral data to drive clinical and patient decision making
Ongoing development of genomics evidence base
Personalized and population impact

Key Areas of Synergy
- Refresh cycle of evidence base
- Determination of degree of achievable personalization of care

Use of ongoing data to drive health system improvement
Focus on iterative and ongoing learning
All stakeholders participate

Robust, Sustainable Implementation Systems

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<tr>
<th>Point #</th>
<th>Characteristic</th>
<th>Implication</th>
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<tr>
<td>Systems Perspective</td>
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<tr>
<td>1</td>
<td>Context is critical</td>
<td>Research should focus on and describe context</td>
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<tr>
<td>2</td>
<td>Multilevel complexity</td>
<td>Most problems, and interventions are multilevel and complex</td>
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<tr>
<td>3</td>
<td>Focus on systems characteristics</td>
<td>More emphasis needed on interrelationships among system elements and systems rules</td>
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<tr>
<th>Robust, Practical Goals</th>
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<td>4</td>
<td>Representatives and reach</td>
<td>Focus on reaching broader segments of population and those most in need</td>
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<tr>
<td>5</td>
<td>Generalizability</td>
<td>Study generalization (or lack of such) across settings, subgroups, staff and conditions</td>
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<tr>
<td>6</td>
<td>Pragmatic and practical</td>
<td>Producing answers to specific questions relevant to stakeholders</td>
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<tr>
<td>7</td>
<td>Scalability and sustainability</td>
<td>From outset, greater focus on scale-up potential and likelihood of sustainability</td>
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<th>Research Methods to Enhance Relevance</th>
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<td>8</td>
<td>Rigorous</td>
<td>Identify and address plausible threats to validity in context of question. Greater focus on replication</td>
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<tr>
<td>9</td>
<td>Rapid</td>
<td>Approaches that produce faster answers</td>
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<tr>
<td>10</td>
<td>Adaptive</td>
<td>Best solutions usually evolve over time, as a result of informed hypotheses and mini-tests with feedback</td>
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<tr>
<td>11</td>
<td>Integration of methods; triangulation</td>
<td>For greater understanding, integrated Quantitative and Qualitative methods are often required</td>
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<tr>
<td>12</td>
<td>Relevance</td>
<td>Relevance to stakeholders should be top priority</td>
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<th>Flexibility</th>
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<td>13</td>
<td>Multiplicity</td>
<td>Encourage and support diverse approaches with the above characteristics (all models are wrong)</td>
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<tr>
<td>14</td>
<td>Respect for diverse approaches; humility</td>
<td>Different perspectives, goals, methods and approaches are needed. Continuing the same existing approaches will produce the same unsatisfactory results</td>
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Accountable Communities for **RURAL** Health System Transformation... to support cancer control research

Implementation research in health care, public health, and community settings to study care transformation and innovations in evidence-based cancer control interventions

Leverage community wisdom...future is **co-production** (Turakhia and Combs, 2017)

- Collaborative co-creation is the future of health research and health care interventions and delivery— and may have particular relevance for small populations/rural
- Focus on co-production and co-creation in our approaches, frameworks, and research methodologies
- Generating value together
  - Users and communities co-shape and co-make interventions /products /services
  - Such approaches prioritize and invest in collaborations with those most affected by data, research, interventions

Korngiebel, *Addressing the Challenges of Research with Small Populations*, NAM, 2018
Co-Mingling Methods – CBPR and Design Approaches....

Community-Based Participatory Research

Relationship building
- Determine or confirm priority

Engagement and admin work
- Intervention deployment and data collection

Data analysis
- Results review and dissemination

What next?

User-Centered Design for intervention creation

Generative and Formative research
- Iterative creation

Usability and user XP testing
- Revisions

Piloting → Deployment version

Dissemination and Implementation Research:
How might D&I be incorporated with these frameworks to enhance success?

Korngiebel, Addressing the Challenges of Research with Small Populations, NAM, 2018
Rural Cancer Control Implementation Research

Rural Disparities

Implementation Science

Connected Health
“Digital Access is becoming a super-determinate of health”

- Chairman Ajit Pai
Builds on Recommendations from PCP Report

Ensure Adequate Internet Access

**Action Item 4.1**
Support initiatives and programs to ensure that everyone in the United States has adequate Internet access if so desired.

**Action Item 4.2**
Support initiatives and programs to ensure adequate Internet access for all healthcare providers and organizations.

“Connect2HealthFCC is exploring the intersection of broadband, advanced technology and health and further charting the broadband future of health care – serving as an umbrella for all FCC health-oriented activities to help enable a healthier America.”
FCC and NCI team up to expand broadband access to cancer care in rural Kentucky

December 26, 2017
by John Fischer, Staff Reporter

The Federal Communications Commission (FCC) and the National Cancer Institute (NCI) are teaming up to enhance cancer care in rural communities by providing greater access to broadband technology.
L.A.U.N.C.H.
Linking and Amplifying User-Centered Networks through Connected Health

Focus on symptom management: Patrick et al achieved 50% reduction in preventable hospitalizations with this approach

People-Centered Design

Our major focus is design as a way of thinking, of focusing how people interact with complex systems and technology, and ensuring that we solve the right problem, the root issues that define the true needs of the people and groups that we serve.
Primary Objectives

- Demonstrate the value of an electronic safety net for patients and care teams through connected health technologies.
- Solve the “last mile problem” of extending benefits of current knowledge to all populations, especially in rural areas.
- Emphasize symptom management as Moon-Shot Compatible cancer focus.
- Move the needle on treatment burden (miles traveled, preventable complications, treatment coordination) and disease burden (through better adherence to treatment regimen and through early intervention on adverse symptoms).
- Create a platform for innovation and citizen participation.
L.A.U.N.C.H. Design Pad

LINKING AND AMPLIFYING USER CENTERED NETWORKS THROUGH CONNECTED HEALTH

Planning
Methods
Interventions
Micro Pilots
Technologies

Data Exploration
Literature Review
Population Data Review

Contextual Inquiry
Ethnographic Research
Technology Probes

Co-Design
Participatory Pilot Design
-Provider Centric
-Patient Centric
-Community Centric

Deploy/Observes
Participant Self Report
Observation & Assessment
Outcomes Monitoring

Evolve
LAUNCH PAD
Challenge based Pilots
PAD to support challenges

Scale
Large Scale Pilots
PAD Evolution
Lessons Learned

1.0
Initial phase to explore data on rural disparities, cancer treatment innovations, communication technology gaps and barriers

2.0
Preliminary ethnographic research engaging patients, providers, support network and community. First round needs, attitudes, barriers, then with technology probes prior to co-design of pilots

3.0
Participatory design around symptom management: micro pilots around distress reporting, connected health passive and active sensing

4.0
Agile Pilots for Symptom management integrating connectivity, sensing, reporting and collaboration technology form basis to understand requirements for Platform for Agile Development (PAD)

5.0
Preliminary data, ethnography, co-design and agile pilots set requirements for PAD: first “launch” with challenges and co-designed community based interventions

6.0
Scaling and evolution of PAD. Growth of an ecosystem of modular, open and interlocking parts from principles to policies to open-source software, open-APIs, technologies and standards
Currently 183 PBRNs nationally with over 29,000 practices, 150,000 clinicians, and 80 million patients
A national network that brings cancer clinical trials and cancer care delivery studies to people in their communities.
RESOURCES NCI

**Rural Cancer Control** ([https://cancercontrol.cancer.gov/research-emphasis/rural.html](https://cancercontrol.cancer.gov/research-emphasis/rural.html))
- Improving the Reach and Quality of Cancer Care in Rural Populations (RFA-CA-18-026)

- Integration of Individual Residential Histories into Cancer Research (R21, R01)

- Academic Research Enhancement Award (Parent R15)

- Collaborative Minority Health and Health Disparities Research with Tribal Epidemiology Centers (R01 Clinical Trial Not Allowed) (PAR-17-484); (R21 Clinical Trial Not Allowed) (PAR-17-483)
Implementation Science Centers for Cancer Control RFA

- 4-5 Research Centers
  - Implementation “Laboratories” Core
  - Methods Core
  - Principal Research Core
  - Network Cores

- 3 Advanced Centers P50 ($2M per yr); 2 Developing Center P20 ($1M per yr)
- FY19 Budget: $8M TC ($40M TC over 5 years)
- RFA on track for a Fall release
IS-C3: Advance Implementation Science (IS) in Cancer Prevention and Control

- Establish “implementation laboratories” in cancer in health care, public health, and community settings to study rapid innovations in evidence-based cancer control interventions
- Develop IS methods cores to fill gaps in measurement and study design
- Develop and execute innovative research pilots on optimal strategies to adopt, implement, and sustain evidence-based care and interventions
- Improve understanding of ethical issues related to implementation and de-implementation
- Develop data resources for an IS data ecosystem
- Disseminate lessons learned to grantees, health care systems, community settings, and key stakeholders in the field via a network core