What is ACCORDS?
Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a ‘one-stop shop’ for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally
## ACCORDS Upcoming Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Location</th>
<th>Presenter</th>
<th>Institution</th>
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<tbody>
<tr>
<td>January 11, 2023</td>
<td><strong>Hot Topics in Mixed Methods and Qualitative Research</strong></td>
<td>Ed 2 North 1107</td>
<td><strong>Danielle Varda, PhD</strong> (Vision Network Labs)</td>
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<td>January 23, 2023</td>
<td><strong>Methods and Challenges in Conducting Health Equity Research</strong></td>
<td>Ed 2 North 1103</td>
<td><strong>Danielle Beatty Moody, PhD</strong> (UMBC)</td>
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<td>January 25, 2023</td>
<td><strong>ACCORDS/CCTS View Community Engagement Forum</strong></td>
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<td>Pathways to Sustainability and Community Empowerment</td>
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<td>February 1, 2023</td>
<td><strong>Hot Topics in Mixed Methods and Qualitative Research</strong></td>
<td>Ed 2 North 1107</td>
<td><strong>Jeffrey Robinson, PhD</strong> (Portland State University)</td>
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<td>June 5-6, 2023</td>
<td><strong>COPH Con 2023</strong></td>
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<td><strong>Reassessing the Evidence:</strong> What is Needed for Real World Research and Practice</td>
<td>Registration opens January 2023</td>
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*all times 12-1pm MT unless otherwise noted
Basketball, Bloodlines, Bourbon, and Burley: Community-Engaged Research to Change the Lung Cancer Landscape in Kentucky

Presented by:

Jamie Studts, PhD
Basketball, Bloodlines, Bourbon, and Burley: Community-Engaged Research to Change the Lung Cancer Landscape in Kentucky

Jamie L. Studts, PhD

Professor of Medical Oncology
Scientific Director of Behavioral Oncology
Co-Leader of Cancer Prevention and Control
Co-Director of Population Health Shared Resource
Member, Thoracic Oncology Research Initiative
Faculty Disclosure/Transparency

- **Potential Perceived Conflicts of Interest**

- Provide consultation to J&J on an effort to increase engagement with lung cancer screening in novel settings.

- Serve on an Advisory Board for the Lung Ambition Alliance, which is supported by AstraZeneca.

- Provide consultation to Genentech regarding implementation of lung cancer screening.

- Member of the Scientific Leadership Council for the GO2 for Lung Cancer.

- Research funding from the National Cancer Institute, the American Cancer Society, the Bristol Myers Squibb Foundation, and the Centers for Disease Control and Prevention.
Facts & Figures 2022

**Incidence Trends**
- “From 2009 to 2018, the (lung cancer incidence) rate decreased by 2.8% per year in men and by 1.4% per year in women.”

**Mortality Trends**
- “Lung cancer mortality rates have declined by 56% since 1990 in men and by 32% since 2002 in women.”
- “…from 2015 to 2019, the rate decreased by about 5% per year in men and 4% per year in women.”

**Survival**
- “The 5-year relative survival rate for lung cancer is 22% overall (18% for men and 25% for women); 26% for NSCLC; and 7% for SCLC.”
Kentucky

Also Kentucky

University of Colorado Anschutz Medical Campus
Can-tuck-ee or Kain-tuck-ee?
<table>
<thead>
<tr>
<th>Kentucky is among the Top 5 worst states for:</th>
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</thead>
<tbody>
<tr>
<td>All site cancer incidence and mortality</td>
</tr>
<tr>
<td>Lung Cancer incidence and mortality</td>
</tr>
<tr>
<td>colorectal cancer incidence and mortality</td>
</tr>
<tr>
<td>Oral cancer incidence and mortality</td>
</tr>
<tr>
<td>Kidney cancer incidence and mortality</td>
</tr>
<tr>
<td>Cervical cancer incidence</td>
</tr>
<tr>
<td>Brain cancer incidence</td>
</tr>
<tr>
<td>Melanoma mortality</td>
</tr>
<tr>
<td>Leukemia mortality</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma mortality</td>
</tr>
<tr>
<td>Adults who currently smoke</td>
</tr>
<tr>
<td>Adults with no physical activity</td>
</tr>
<tr>
<td>Youth obesity</td>
</tr>
<tr>
<td>New Hepatitis C infections</td>
</tr>
<tr>
<td>People living in poverty</td>
</tr>
<tr>
<td>Adults without a bachelor’s degree</td>
</tr>
</tbody>
</table>
# Lung Cancer Epidemiology – Setting the Table

## Lung cancer *incidence* rate
- USA: 65.8 (men) 50.8 (women)
- Colorado: 43.1 (men) 38.5 (women)
- **Kentucky:** 104.6 (men) 76.9 (women)

## Lung cancer *mortality* rate
- USA: 44.5 (men) 30.7 (women)
- Colorado: 28.2 (men) 23.1 (women)
- **Kentucky:** 71.3 (men) 47.0 (women)

## Adult *smoking rate* (2020)
- USA: 12.5%
- Colorado: 14.5%
- **Kentucky:** 23.5%

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*Note: All rates are per 100,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.*

Figure 2. County-Level Mortality From Tracheal, Bronchus, and Lung Cancer

A. Age-standardized mortality rate from tracheal, bronchus, and lung cancer, both sexes, 2014.

Deaths per 100,000 population:
- 10 to 26
- 43
- 61
- 78
- 96
- 113 to 232

The lung cancer burden is not equally distributed across Kentucky.
The Commonwealth’s Cancer
#1 in Adolescent Smoking

#1 in Lung Cancer Mortality

#1 in Adult Smoking

#1 in Lung Cancer Incidence

The Colonel’s Not-So-Secret Recipe for Community Engaged Research in Kentucky.

Established Community Relationships
- Engage Trusted Partners

Windshield Time
- Travel to Community
- Travel where Partners Travel

Sustained Commitment
- Build Independent Relationships

Respect and Humility
- Listen
- Learn

Reliability
- Communication

trustworthiness
The Kentucky LEADS Collaborative

• Administrative Core

• Project 1: Provider Education

• Project 2: Survivorship Care

• Project 3: Prevention & Early Detection
The Kentucky LEADS Collaborative

- Community-Engaged
  - 14 unique implementation sites throughout KY
  - Over 100 additional community partners & organizations
  - Integration of community and medical advisory boards

- Interdisciplinary
  - Oncology, nursing, social work, palliative care, education, public health, communication, advocacy, psychology

- Multi-Level
  - Health Systems/Lung Cancer Screening Programs
  - Healthcare clinicians
  - Individuals diagnosed with lung cancer and caregivers

“Dedicated to reducing the burden of lung cancer in Kentucky and beyond through development, evaluation, and dissemination of novel, community-based interventions to promote provider education, survivorship care, and prevention and early detection regarding lung cancer.”
Kentucky LEADS Collaborative

Component 1:
Provider Education
The Great Kentucky Lung Cancer Screening Road Show

Bi-Directional Sharing of Cancer-Related Concerns, Perspectives, and DATA!

Annual Meetings (District Cancer Councils)
Approach to the District Cancer Council Meetings

- **Challenge**
  - BURDEN
    - KCR/SEER Data

- **Solution**
  - EVIDENCE
    - NLST Data

- **Relevance**

- **Community Engagement**

- **Implementation and Uptake**
The Kentucky Lung Cancer Screening Road Show (2013-2014)

- **Directly** reached hundreds of clinicians and engaged community members throughout the state
- **Indirectly** reached thousands of clinicians and community members through media coverage (e.g., tv, radio, newspaper)

Conclusions/Accomplishments

1. Tremendous engagement/attendance throughout the state
2. Significant interest in screening among clinicians and community
3. Pockets of apprehension, concerns, skepticism, and frank stigma
4. Recognition that extensive additional efforts would be needed
Provider Education Efforts

Four Educational Offerings:

1) Academic Detailing (January, 2016)
2) Large Group Presentations (February, 2016)
3) Online Training Course (April, 2016)
4) Webinars (March, 2017)
# REACH: Primary Care Clinicians and Staff

<table>
<thead>
<tr>
<th>Intervention</th>
<th>PCPs Educated</th>
<th>Non-PCPs Educated</th>
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<tr>
<td>Large Group Presentation</td>
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<td>Online Courses</td>
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<tr>
<td>Webinar</td>
<td>85</td>
<td>32</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1,403</strong></td>
<td><strong>1,273</strong></td>
</tr>
</tbody>
</table>

**Educational Efforts**

- **NP**: 511
- **PA**: 101
- **MD/DO**: 631

**Establishing Social Norms**
Kentucky LEADS Collaborative

Component 2:

Lung Cancer Survivorship
What level of interest do individuals with lung cancer have in psychosocial programs?

- Funded Randomized Clinical Trial for Lung Cancer Survivors, comparing supportive-expressive therapy (SET) and mindfulness-based stress reduction (MBSR). [circa 2001]

- Transitioned to a cross-sectional survey to generate some data addressing the psychosocial experience of lung cancer.
Who is the average lung cancer survivor?

- Male
- 70 years of age or older
- Substantial tobacco use history
- Likely to have military experience
- Multiple comorbidities
- May reside in a rural area
- May have economic constraints

Does this fit with our understanding of an individual who seeks a psychosocial survivorship interventions?

Person-Centered Approach
What is the experience of lung cancer survivors?

- Distressed
- Intrusive Physical Symptoms
- Socially Isolated
- Compromising Health Behaviors
- Stigma
- Remote – Lacking Access
- Disengaged
- Fatalism
- Lacking Access
Implementing Solutions to Improving Individual-Level Access to Services

Design for Efficacy?
Design for Dissemination?
Design for Acceptability!
Design for Adoption! (accessibility)
Development Process for the Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program

1) Convened an interdisciplinary team of clinicians, researchers, and advocates
2) Agreed to challenge assumptions/conventions regarding survivorship care
3) Reviewed literature and discussed practice knowledge base
4) Leveraged input from a diverse Community Advisory Board
5) Proposed and adopted fundamental principles and an approach that might enhance intervention acceptability
6) Selected module topics based on symptom burden and challenges
7) Designed clinician-participant engagement to be partnering and collaborative rather than educational
8) Integrated participant preferences into intervention delivery
Person or Patient-Centered Care Principles

• Partnering/Supportive Counseling Style
  • Rogerian/Motivational Interviewing
  • Coping with/Addressing stigma concerns
  • Empathy over education

• Shared Decision Making (SDM)
  • Adaptable (targeted and tailored content) that follows from Baseline Assessment and patient preferences
  • Effort to maximize survivor acceptability of the intervention
Precision Lung Cancer Survivorship

• The Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program is a *Precision Medicine* approach to Survivorship.

  • By design, the intervention *targets* the most prevalent and distress symptoms and challenges associated with a lung cancer diagnosis.

  • By integrating patient preferences, the intervention is *tailored* to the unique needs of the survivor, the preferred delivery method, and the desired level of involvement of the social support network.

*Modular Approach to Intervention Delivery – The Power to Choose*
What additional strategies were employed to enhance intervention acceptability?

1) Participants controlled their intervention content (menu).

2) Participants chose the order of the intervention content.

3) Participants chose whether or not to include a caregiver.

4) Participants chose the delivery platform. (in-person/phone)

5) Participants chose the frequency/duration of contact.
What efforts were made to achieve intervention accessibility and methodologic feasibility?

1) Trained local as opposed to centralized interventionists.

2) Sites choose the interventionists/survivorship care specialists.

3) Develop/evaluate a sustainable (web-based) training platform.

4) Support flexible delivery (e.g., in-person, telephone, telehealth).

5) Create a digital learning community to support intervention.

6) Provide technical assistance for sustainable delivery.
So, did it work?
The intervention acceptability signal was very encouraging!

- The trial was launched at 9 of the 10 planned sites.
- Accrual was uneven with some sites exceeding accrual expectations and others delayed in accrual.
Site Accrual Tracking – King’s Daughters Medical Center

Open to enrollment April 19, 2017
No accrual pause.
1) **Very encouraging results with regard to intervention acceptability.** (accrual of survivors, caregivers, and support from clinicians)

2) **Support for methodological feasibility.** (not discussed, but we collected complete data from approximately 50% of accrued participants (this was the goal, accounting for expected mortality).

3) **Data analysis examining preliminary efficacy data is ongoing.** (datasets are being cleaned and coded).

4) **Training program for clinicians was impactful and well-received.** (improving self-efficacy and empathy within lung cancer survivorship).

5) **Move forward with a proposed randomized controlled trial, including an evaluation of cost-effectiveness.**
Kentucky LEADS Collaborative

Component 3:
Prevention and Early Detection
Screening Rate Comparison, KY vs US (BRFSS, 2018)

- **27th** Colorectal Cancer Screening
  - Kentucky: 69.5% (US Rank: 27)
  - United States: 69.7%

- **29th** Breast Cancer Screening
  - Kentucky: 77.6% (US Rank: 29)
  - United States: 78.3%

- **26th** Cervical Cancer Screening
  - Kentucky: 80.2% (US Rank: 26)
  - United States: 80.2%
There have been noteworthy concerns regarding quality implementation of lung cancer screening.

In addition to supporting primary care, we need to work with LCS programs to facilitate implementation of high-quality LCS processes and smoothly translate results of the NLST and NELSON trials in routine practice.
Prevention & Early Detection (PD) Implementation Sites

1. Baptist Health, Lexington
2. Baptist Health, Paducah
3. Hardin Memorial Hospital and Cancer Center, Elizabethtown
4. Hazard Appalachian Regional Healthcare, Hazard
5. St. Elizabeth Healthcare, Northern Kentucky
6. King’s Daughters Medical Center, Ashland
7. Markey Cancer Center, Lexington
8. Owensboro Health, Owensboro
9. St. Claire Regional Medical Center, Morehead
10. Pikeville Medical Center, Pikeville
QUILS System 1.0

Assess Quality
(QUILS Index 1.0)

Feedback System
(QUILS Report 1.0)

Resource Portal
(QUILS Portal 1.0)

Technical Support
(QUILS Support 1.0)

Program Data Reporting

Program Policies and Practices Interviews

Table:

<table>
<thead>
<tr>
<th>Program</th>
<th>Screening Element</th>
<th>Maximum Score</th>
<th>Site Score</th>
<th>Eligibility</th>
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<tr>
<td>Target 1</td>
<td>Lung Cancer Screening</td>
<td>10</td>
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<tr>
<td>Target 2</td>
<td>Lung Cancer Screening</td>
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<td>5</td>
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<tr>
<td>Target 3</td>
<td>Lung Cancer Screening</td>
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<td>Target 4</td>
<td>Lung Cancer Screening</td>
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<td>5</td>
<td>Yes</td>
</tr>
<tr>
<td>Target 5</td>
<td>Lung Cancer Screening</td>
<td>10</td>
<td>5</td>
<td>Yes</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>75</td>
<td>5</td>
<td>Yes</td>
</tr>
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</table>

Summary Score: 75

Converted to 100

Program Domains:

- Screening
- Eligibility
- Site Score
- Maximum Score

Program 

- Lung Cancer Screening
- Target 1
- Target 2
- Target 3
- Target 4
- Target 5

Maximum Score: 10

Site Score: 5

Eligibility: Yes

Program Policies and Practices Interviews

Resource Portal (QUILS Portal 1.0)

Technical Support (QUILS Support 1.0)
QUILS Index 1.0 Overview, Domains, and Elements

**Screening Eligibility**
- Algorithm
- Frequency
- Duration

**Radiology Operations**
- Exposure
- LDCT Performance
- Results Reporting
- Nodule Management

**Team Operations**
- Clinical Team
- Review of Results

**Prevention Efforts**
- Tobacco Interventions
- Tobacco Targets
- Secondhand Smoke
- Radon Counseling

**Patient Education**
- Shared Decision Making
- Engagement and Retention

**Community Outreach**
- Marketing and Outreach
- Clinician Outreach
Kentucky LEADS Collaborative Prevention & Early Detection Study Schema

Data Sources for Evaluation
1) Team Member Interviews (Structured and Semi-Structured)
2) Program Surveys (Standardized IS Instruments)
3) Program Database Extraction (Enhanced Common Database)
Overall Baseline QUILS Score (0-100)

Baseline Average 67.8%

Overall Mean QUILS Scores Over Time (0-100)
National Lung Cancer Screening Uptake Landscape

**Kentucky**—the only state with substantial lung cancer burden that is also leading statewide LCS implementation.

(Fedewa et al., 2021)
Lung Cancer Screening Uptake in 2020

Top 3 States:
- Massachusetts: 19.7
- Kentucky: 17.7
- Maine: 13.9

Regional:
- Indiana: 7.9
- Tennessee: 7.5

Bottom 2 States:
- New Mexico: 1.9
- Nevada: 1.7

Uptake
Reduction in Late Stage Lung Cancer Diagnoses in Kentucky

• Stable at ~81% from 2009 through 2014

• Nearly 10% decline from 2014 to 2018!!
Learning Objectives

➢ Discover the burden of and disparities in lung cancer in Kentucky

➢ Explore use of community-engaged research methods to improve cancer outcomes, reduce cancer disparities, and pursue equity in Kentucky
The Colonel’s Not-So-Secret Recipe for Community Engaged Research in Kentucky.
Summary and Conclusion

- Kentucky has suffered persistent socioeconomic hardship alongside its substantial lung cancer burden.

- Kentucky’s sustained commitment to community-engaged research efforts created a unique opportunity for transformative change.

- Engaging with established partners, the Kentucky LEADS Collaborative developed, implemented, and evaluated a multilevel effort to reduce lung cancer in Kentucky.

- Community-engaged methods constituted the foundation and the load-bearing infrastructure for the Collaborative that has created the potential for
Second Faculty Disclosure/Transparency

- I think Bourbon tastes terrible.
- I don’t enjoy horse racing or horses.
- I have never smoked a single cigarette.
- I am slowly overcoming my dependence on Kentucky Basketball and allowing all of my emotions to be dictated by the outcome of the most recent game (or recruiting news if in the off-season), but until then…
Kentucky LEADS Collaborative

- **Component 1: Provider Education**
  - Educate and train primary care clinicians in Kentucky regarding implementation of innovations in lung cancer prevention, control, and care.

- **Component 2: Survivorship Care**
  - Develop and evaluate a novel lung cancer survivorship care program for survivors and caregivers.

- **Component 3: Prevention & Early Detection**
  - Facilitate implementation of high quality lung cancer screening throughout Kentucky.

Supported by a grant from the Bristol-Myers Squibb Foundation [501(c)3].
While individuals diagnosed with lung cancer in Kentucky face survivorship challenges, these are also opportunities.

Rural-Nonrural Inequity:
Significant differences in cancer incidence, mortality, and quality of life favor nonrural geographic areas and highlight the need for more focused attention on minorities.

Kentucky Cancer Registry, 2022: https://www.cancer-rates.info/ky/
Survivorship Care: Patient and Caregiver Intervention

• **Precision Intervention**:  
  - Built and implemented a novel psychosocial survivorship care intervention for individuals diagnosed with lung cancer and their caregivers (10 sites, 300 participants)

• **Four Key Domains**:  
  - Lung Cancer Basics  
  - Symptom Coping  
  - Psychosocial & Behavioral Concerns  
  - Caregiver Support
Lung Cancer Survivorship Randomized Controlled Trial

Objective 1. Test the **efficacy** of the Lung Cancer Survivorship Care Program to improve quality of life and other patient-reported outcomes (e.g., lung cancer treatment engagement, health behavior change)

Objective 2. Evaluate the impact of **caregivers as intervention partners** on lung cancer survivors’ quality of life outcomes

Objective 3. Measure the **cost-effectiveness** of the intervention relative to enhanced usual care
**Intervention Group.** Modular intervention – personalized, flexible, and collaborative sessions with a trained Survivorship Care Specialist

**Control Group.** Self-guided bibliotherapy – a more simplified, trimmed version of the intervention workbook
## Summary of QUILS Index Scoring Across Sites

### Consistently High
- **Eligibility**: Screening Eligibility Policy
- **Eligibility**: Screening Frequency & Duration Policy
- **Radiology**: LDCT Performance
- **Radiology**: Lung Nodule Identification
- **Radiology**: Structured Results Reporting
- **Radiology**: Lung Nodule Management Algorithm
- **Patient**: Engagement and Retention Methods
- **Community**: Provider Outreach

### Consistently Low
- **Prevention**: Tobacco Treatment Interventions
- **Prevention**: Tobacco Treatment Targets
- **Prevention**: Second-Hand Smoke Prevention/Education
- **Prevention**: Radon Prevention Education

### Inconsistent
- **Team**: Interdisciplinary Clinical Team
- **Team**: Team Review of Radiology Results
- **Patient**: Shared Decision Making
- **Community**: Responsible Marketing and Outreach
Kentucky LEADS Collaborative – Impact

- Clinician Education
- QUILS for LCS Programs

Impact

- Engagement
- Uptake
- Adherence
- Stage Shift
- Mortality Reduction
The Kentucky LEADS Collaborative efforts in lung cancer screening have embraced equity considerations since its initiation in 2014.

Continued efforts to encourage and support targeted and tailored efforts to meet needs of communities experiencing intersectional challenges to considering and accessing lung cancer screening.
Despite nation-leading rates of lung cancer screening uptake, there are areas of Kentucky that have not equally benefitted from lung cancer screening.
If we want these improved outcomes for individuals who have been diagnosed cancer, we need….

1) policy change to support appropriate access and fitting reimbursement models for service delivery and outcomes,

2) greater integration of transdisciplinary clinical teams that utilize bench players as well as our starters,

3) enhanced adaptation to contextual factors and application of precision approaches that utilize patient preferences, and

4) sustained commitment to improving broad outcomes of cancer care, including mortality, morbidity, quality of life, and well-being.