

# LUNG CANCER IN KENTUCKY

## A Primary Care Action Plan



**KENTUCKY**  
**LEADS**  
COLLABORATIVE

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**LUNG CANCER**  
EDUCATION • AWARENESS  
DETECTION • SURVIVORSHIP

LEADS PRIMARY CARE TASK FORCE

Primary Care Education Component  
University of Louisville  
2015





On behalf of the Kentucky LEADS Collaborative Primary Care Task Force, we are pleased to present “Lung Cancer in Kentucky: A Primary Care Action Plan.” Led by a provider education project team at the University of Louisville, the task force of distinguished primary care leaders was convened to guide the development of a statewide education program for Kentucky. Member passion and expertise culminated in recommendations that address comprehensive issues surrounding lung cancer care in our state. It is our hope that this document will generate action among the many individuals and organizations that can influence the prevention and management of this disease.

As Co-Principal Investigators, we would like to acknowledge the University of Louisville team responsible for this report and for the Kentucky LEADS primary care education efforts. They are Ruth Mattingly, MPA, Jorge Rios, MD, Celeste Worth, MCHES, Morel Jones, BA, and Margaret Oechsli, PhD. This team will be working with stakeholders to implement novel education programs to support primary care providers in the delivery of lung cancer care across the continuum.

The Kentucky LEADS Collaborative is a three-year initiative of the James Graham Brown Cancer Center, University of Louisville, the Markey Cancer Center, University of Kentucky, and the Lung Cancer Alliance. We are grateful to the Bristol Myers Squibb Foundation for funding this project and for giving us the opportunity to provide a forum to convene state leaders in primary care to produce this action plan. We would also like to thank our task force members and our partners for supporting Kentucky LEADS programs dedicated to reducing the burden of lung cancer in the Commonwealth.

Sincerely,

A handwritten signature in black ink, appearing to read "Connie Sorrell".

**Connie L. Sorrell, MPH**  
LEADS Co-Principal Investigator  
University of Louisville

A handwritten signature in black ink, appearing to read "Goetz H. Kloecker".

**Goetz H. Kloecker, MD, MSPH, MBA, FACP**  
LEADS Co-Principal Investigator  
University of Louisville



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## FOREWORD: A MESSAGE FROM THE TASK FORCE CO-CHAIRS

We are pleased to share this primary care action plan to improve the prevention, screening and treatment of lung cancer in Kentucky. The Kentucky LEADS Collaborative Primary Care Task Force came together for a two day consensus meeting in March 2015. Representatives from internal medicine, family medicine, thoracic surgeons, medical oncologists, pulmonologists, advanced practice nurses, insurers, health care systems, and professional organizations were presented a rare opportunity to analyze complex lung cancer issues and identify strategies to improve prevention and patient care.

This report presents five broad recommendations and potential strategic actions for consideration by stakeholders at the community and state levels. Some require immediate action, while others call for further clarification, analysis, or expert perspectives. The plan highlights the need for data collection, tool development for providers and patients, increased collaboration and communication among providers and systems, stronger policies and legislation, and provider education.

As task force co-chairs, we would like to express our appreciation the leadership of the University of Louisville project team from Kentucky Cancer Program and the James Graham Brown Cancer Center. We look forward to their upcoming continuing education offering for primary care providers, which will address many of the recommendations. We would also like to acknowledge the health care stakeholders who recognized the significance of this endeavor by appointing knowledgeable and passionate representatives to the task force. Finally, we wish to thank members for their time and participation in this project. Their enthusiasm and engagement has led to the development of a pivotal guide to reduce the burden of lung cancer in Kentucky over the coming years.

Unfortunately, Kentucky will continue to lead the nation in lung cancer mortality without concerted efforts at prevention, screening and treatment. We must remain committed to finding creative solutions to manage the entire spectrum of the process. It will take a united effort to reduce the toll of this disease; therefore, we applaud the continued commitment of all stakeholders to support the implementation of the plan.

Sincerely,



**Phillip F. Bressoud, MD, FACP**  
Governor, Kentucky Chapter of the  
American College of Physicians  
University of Louisville Healthcare  
Louisville, Kentucky



**Melissa L. Zook, MD, FAAFP**  
President, Kentucky Academy of Family Physicians  
London Women's Care  
London, Kentucky





# KENTUCKY LEADS COLLABORATIVE PRIMARY CARE TASK FORCE MEMBERS

## CO-CHAIRS

---

**Phillip F. Bressoud, MD, FACP**  
Governor, Kentucky Chapter  
of the American College of Physicians  
University of Louisville School of Medicine  
Louisville

**Melissa L. Zook, MD, FAAFP**  
President, Kentucky Academy of  
Family Physicians  
London Women's Care  
London

## MEMBERS

---

**Robert Adams, MD, FACCP, FACS, MPH**  
Owensboro Health Cardiothoracic Surgery  
Pleasant Valley Center  
Owensboro

**Timothy Jahn, MD**  
Chief Clinical Officer  
Baptist Health  
Louisville

**William T. Betz, DO, MBA, FACOFP**  
Senior Associate Dean for Osteopathic  
Medical Education  
University of Pikeville  
College of Osteopathic Medicine  
Pikeville

**James T. Jennings, MD**  
Medical Director, Adult Primary Care  
Norton Healthcare  
Louisville

**Roberto Cardarelli, DO, MPH, FAAFP**  
Chief of Community Medicine  
University of Kentucky College of Medicine  
Lexington

**Firas Koura, MD, MPH, FCCP**  
Pulmonologist  
Appalachian Regional Healthcare  
Kentucky Lung Clinic  
Hazard

**Julianne Z. Ewen, DNP, FNP-BC, APRN**  
President, Kentucky Coalition of Nurse  
Practitioners  
KentuckyOne Health Primary Care Associates  
Lexington

**Bryan Loy, MD, MBA**  
Vice President–Oncology, Laboratory,  
and Personalized Medicine  
Humana, Inc.  
Louisville

**Jeffrey M. Goldberg, MD, MS**  
Chief Medical Officer  
KentuckyOne Health  
Louisville

**Chrys Means, PA-C**  
Kentucky Academy of Physician Assistants  
Capital Medical Group West  
Frankfort

**Diane M. Harper, MD, MPH, MS**  
Chair, Family Medicine  
University of Louisville School of Medicine  
Louisville

**Attef Mikhail, MD**  
Radiologist  
Radiology Associates of Northern Kentucky  
Crestview Hills

**Bradley W. Housman, MD, FACOG**  
Vice President and Chief Medical Officer  
Baptist Health–Paducah  
Paducah

**Michael J. Murray, MD**  
Radiation Oncologist  
EC Green Cancer Center  
Hopkinsville

## MEMBERS (cont'd)

---

### **Madonna Ringswald, DO**

President, Kentucky Osteopathic  
Medical Association  
Director, Hospitalist Group  
Baptist Health-LaGrange  
LaGrange

### **Michael V. Smith, MD, FACC, FACS, FCCP**

Regional Vice-President, Medical Director  
Central Region Medicare/Anthem  
Atlanta

### **Tony Weaver, MD**

Assistant Dean, University of Kentucky  
Morehead Regional Site  
St. Claire Regional Medical Center  
Morehead

### **Joseph G. Weigel, MD, FACP**

Program Director of Internal Medicine  
Lake Cumberland Medical Associates  
Somerset

### **R. Brent Wright, MD**

Chair, Board of Trustees,  
Kentucky Medical Association  
Associate Dean for Rural Health Innovation  
University of Louisville School of Medicine  
Glasgow

### **Gary Kupchinsky, representing**

**Dr. Stephanie Mayfield Gibson, MD,**  
Kentucky Commissioner of Health  
Director, Division of Prevention  
and Quality Improvement

## MEMBER ORGANIZATIONS

---

*Anthem Blue Cross and Blue Shield*

*Appalachian Regional Healthcare*

*Baptist Health*

*Humana, Inc.*

*Kentucky Academy of Family Physicians*

*Kentucky Academy of Physician Assistants*

*Kentucky Chapter of American College  
of Physicians*

*Kentucky Coalition of Nurse Practitioners*

*Kentucky Commissioner of Health*

*KentuckyOne Health*

*Kentucky Medical Association*

*Kentucky Osteopathic Medical Association*

*Norton Healthcare*

*University of Kentucky College of Medicine*

*University of Louisville School of Medicine*

*University of Pikeville College  
of Osteopathic Medicine*

## PROVIDER EDUCATION TEAM

---

*University of Louisville*

### **Co-Principal Investigators**

**Connie L. Sorrell, MPH**

**Goetz Kloecker, MD, MSPH, MBA, FACP**

### **Co-Investigators**

**Ruth Mattingly, MPA**

**Jorge Rios, MD**

**Celeste Worth, MCHES**

**Morel Jones, BA**

**Margaret Oechsli, PhD**

## OTHER KENTUCKY LEADS STAFF

---

*University of Kentucky*

***Principal Investigator***

**Jamie Studts, PhD**

***Project Director***

**Allyson R. Yates, BS**

*Lung Cancer Alliance*

***Kentucky Field Coordinator***

**Angela Criswell, MA**

## FACILITATOR

---

**Judah Thornewill, PhD**

Chief Executive Officer

GroupPlus, Inc.

## CONSULTANT

---

**Samuel Cykert, MD**

School of Medicine

University of North Carolina–Chapel Hill



# INTRODUCTION

This report summarizes the Kentucky LEADS Collaborative Primary Care Task Force's proposed action plan for reducing the burden of lung cancer in Kentucky through primary care.

The task force's recommendations fall into five broad topic areas: tobacco cessation, lung cancer screening, management and treatment, survivorship, and continuing education. Within each topic, the proposed action items are categorized by audience: primary care provider (PCP) practices, hospitals and health systems, insurance providers, legislators and policymakers, and community partners. The action plan also identifies electronic health record (EHR) and data needs.

## BACKGROUND

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The Kentucky LEADS Collaborative (Lung Cancer Education, Awareness, Detection, and Survivorship) is a three-year effort to reduce the burden of lung cancer in Kentucky. The major goal of the project is to improve lung cancer care by increasing provider knowledge across the continuum of care, focusing on primary care physicians, nurse practitioners, and physician assistants.

This partnership of the University of Louisville (UofL), University of Kentucky (UK), and the Lung Cancer Alliance (LCA) is working to develop, evaluate, and disseminate novel, community-based interventions to promote provider education, prevention and early detection, and survivorship care of lung cancer. The three components are: Provider Education (UofL), Prevention and Early Detection (UK), and Survivorship Care (UK). Bristol-Myers Squibb Foundation funds the project.

The LEADS Provider Education Component, coordinated by the Kentucky Cancer Program at UofL, seeks to improve lung cancer prevention, care, and survivorship by developing, implementing, and evaluating a lung cancer continuing education program targeting PCPs throughout Kentucky.

## LUNG CANCER IN KENTUCKY

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In the commonwealth of Kentucky, an estimated 3,500 deaths are expected from lung cancer this year -- more than the 2,390 anticipated from breast, colorectal, prostate and pancreatic cancer, combined.<sup>1</sup> Kentucky leads the nation with the highest lung cancer incidence (122.9 and 80.7 per 100,000 in men and women, respectively<sup>2</sup>) and mortality rates (94.5 and 55.5 per 100,000 in men and women, respectively<sup>3</sup>). Moreover, Kentucky's lung cancer mortality rates are more than three-fold higher than those in Utah, which has the nation's lowest lung cancer mortality rates. Lung cancer survival rates are lower than for other cancers, with only a 17 percent five-year relative rate.

Kentucky's lung cancer rate is closely tied to its high adult smoking prevalence rate (26.5 percent), the second highest in the nation.<sup>6</sup> Nationwide, more than 87 percent of lung cancer deaths in men and 70 percent in women are attributable to smoking.<sup>7</sup> It has been estimated that radon causes ten percent, occupational exposures to carcinogens account for nine to 15 percent, and outdoor air pollution one to two percent.<sup>8</sup>

*\*Relative survival is a net survival measure representing cancer survival in the absence of other causes of death. For more information, see National Cancer Institute [http://seer.cancer.gov/seerstat/WebHelp/Relative\\_Survival.htm](http://seer.cancer.gov/seerstat/WebHelp/Relative_Survival.htm)*

## KENTUCKY LEADS COLLABORATIVE PRIMARY CARE TASK FORCE

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The LEADS Provider Education Component team at UofL created an external task force to examine lung cancer care across the continuum. The Kentucky LEADS Collaborative Primary Care Task Force was established and met in March 2015 to clarify the role of PCPs in lung cancer prevention, early detection, diagnosis, treatment, and survivor support; find ways to improve care delivery; identify educational messages; and determine how to most effectively disseminate educational messages and facilitate improvements.

The task force included 22 members who represent large health systems, insurance providers, academic medicine, primary care statewide organizations, state government, specialists involved in lung cancer care, and practicing PCPs. Several members had responsibilities for EHRs within either health systems or hospitals. All invited organizations accepted the invitation to participate. Task force members were enthusiastic and creative in their approaches to the challenges put before them. The task force was co-chaired by Phillip Bressoud, MD, governor of the Kentucky Chapter of the American College of Physicians, and Melissa Zook, MD, president of the Kentucky Academy of Family Physicians.

In preparation for the March task force meeting, the UofL project team conducted in-depth interviews with 28 PCPs across the state to identify current perceptions and practices regarding lung cancer prevention, screening, treatment, and survivorship. In addition, the team talked to PCPs about how they prefer to receive continuing education. Information gleaned from the interviews was presented at the meeting, and will guide development of the LEADS Provider Education Component continuing education programs.

Those interviewed were physicians in family practice and internal medicine, including medical doctors and doctors of osteopathic medicine. In addition, the team interviewed physician assistants and nurse practitioners in primary care. There was diversity among the interviewees in geographic location throughout Kentucky (i.e., urban/rural, north, south, east, west), age, gender, ethnicity, years in practice, type of practice, and economic status of patient populations.

Over the course of the two-day meeting, Primary Care Task Force members heard presentations on the severity of the lung cancer problem in Kentucky and analyses of five topics related to lung cancer (prevention, early detection, management and treatment, survivorship, and continuing education). Using this information, task force members drafted broad recommendations for primary care for each of the topics. They also were introduced to the Kentucky Cancer Program (KCP) “Pathfinder,” an online resource developed by the UofL Kentucky Cancer Program to link providers and patients with cancer resources in their local areas.

To assist them in their deliberations, task force members also were given summaries of results from the interviews with PCPs. The findings were organized by the five topic areas and included quotes that illustrated the complex challenges surrounding each issue. Endorsing the broad recommendations already drafted within the five topic areas, three discussion groups then proposed specific actions, with an emphasis on potential improvements related to lung cancer and health care delivery within primary care.

## KENTUCKY LEADS COLLABORATIVE PRIMARY CARE TASK FORCE (cont'd)

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The recommendations and actions developed by the task force go beyond the provider education scope of the Kentucky LEADS Collaborative Provider Education Component. The actions include recommendations for legislation, training and licensure policies, sharing of electronic health record data, and public education. Some actions suggested for PCPs are also followed by needed practice tools.

Additionally, task force members proposed establishing “Lung Cancer Centers of Excellence” to make low-dose helical computed tomography (LDCT) screening and specialized lung cancer care available in areas with poor access. As discussions evolved, they also suggested that the centers could serve as a point of contact for patient navigation and tobacco cessation resources. The proposed centers are referred to throughout the report. However, the task force focused primarily on the broad functions of the centers, rather than particulars, such as what entities would establish the centers (public or private) and how they would be funded.

This report serves as a summary of actions that merit serious consideration from legislators, government and nonprofit agencies, health systems, provider organizations, and others committed to tackling Kentucky’s significant lung cancer burden. Although this report is not intended to be a comprehensive plan, it does contain compelling ideas for further study and implementation, and reflects the knowledge, experience, and passion of the task force members. The UofL project team intends to disseminate this task force report widely to encourage a broad base of entities to consider the panel’s suggestions and, based on their merit, to elect to implement them to improve lung cancer control and care in Kentucky.

# LUNG CANCER PREVENTION

## TOBACCO CESSATION

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Primary care providers see an estimated 70 percent of smokers in their offices every year, and as a result, have an important opportunity to decrease smoking rates with office-based interventions.<sup>9</sup> Nearly 7 in 10 smokers want to quit, and more than 4 in 10 (42.7 percent) adult cigarette smokers reported attempting to quit in the past year.<sup>10</sup>

The U.S. Public Health Service (PHS) *Treating Tobacco Use and Dependence: 2008 Update*,<sup>11</sup> a clinical practice guideline, recommends that PCPs use the five A's (Ask, Advise, Assess, Assist, and Arrange) when treating patients with nicotine addiction.<sup>12</sup> Providers can increase cessation rates by asking patients about tobacco use at every office visit. According to the PHS, behavior modification can improve long-term smoking cessation success; even minimal (less than three minutes) provider advice on smoking cessation during an office visit can increase cessation rates.

Numerous effective medications are available for tobacco dependence. The PHS recommends clinicians encourage their use by all patients who attempt to quit smoking, unless medical contraindications exist, or among specific populations for which there is insufficient evidence of effectiveness. Seven first-line medications reliably increase long-term smoking abstinence rates. These include five nicotine replacement therapies in the form of a gum, patch, nasal spray, inhaler, and lozenge. The other two are prescription drugs, varenicline (Chantix) and bupropion (Zyban). Clinicians also may consider combinations of medications, as recommended in the PHS guideline.<sup>13</sup>

Telephone quitline counseling is another tobacco cessation strategy that is effective with diverse populations and has broad reach.<sup>14</sup> However, only about one percent of all tobacco users called the national 1-800-QUIT-NOW in fiscal year 2013.<sup>15</sup> Kentucky's Tobacco Quitline, part of the 1-800-QUIT-NOW service, offers free, one-on-one proactive coaching for tobacco users and accepts fax referrals and e-referrals. State officials would like to see significant increases in quitline usage. Therefore, Kentucky clinicians and health care delivery systems should both ensure patient access to quitlines and promote quitline use.

Tobacco cessation services also benefit another important population – patients who already have been diagnosed with cancer. Cancer patients who stop smoking after diagnosis experience medical advantages. Substantial evidence indicates that continued smoking may reduce the effectiveness of treatment and increase the likelihood of a second cancer. Continued smoking also may exacerbate the side effects of cancer treatment.<sup>16</sup>

It is important to note that tobacco cessation counseling is a central component of lung cancer screening. For example, the Centers for Medicare & Medicaid Services (CMS) requires that patients screened by LDCT also receive documented “counseling on the importance of maintaining cigarette smoking abstinence if former smoker; or the importance of smoking cessation if current smoker and, if appropriate, furnishing of information about tobacco cessation interventions.”<sup>17</sup>

Despite the PHS clinical practice guideline, in the 2010 National Health Interview Survey only half of smokers reported that they had received advice to quit from any health care provider.<sup>18</sup> Another study showed that only 36 percent of patients with lung cancer were counseled.<sup>19</sup>



## INTERVIEW FINDINGS

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Most PCPs interviewed said they ask all patients about tobacco use and advise smokers to quit. Few PCPs said they counsel cancer patients about the specific disadvantages of smoking related to their treatment. Only seven of 28 PCPs interviewed were aware of and refer patients to the Kentucky Quitline (1-800-QUIT-NOW). Individual PCPs who did not know about the quitline said they would refer patients to it. Some emphasized that, for it to be widely used across practices, the referral process must be very easy for their staff members. Many PCPs were not aware of existing community resources for smoking cessation efforts. All PCPs interviewed used EHRs, and most noted that it would be helpful to have EHR flags for tobacco use and lung cancer screening eligibility, showing an on-screen prompt with appropriate recommendations.

## RECOMMENDATION FOR PRIMARY CARE

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Prevent and treat tobacco use in primary care practices.

## ACTIONS

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### PRIMARY CARE PROVIDER PRACTICES

#### Provider Actions

- Use the KCP “Pathfinder” as a way to locate the nearest smoking cessation programs.
- Refer patients to smoking cessation programs and/or support groups and to the Kentucky Quitline (1-800-QUIT-NOW).
- Use the tobacco cessation billing guide.
- Use quick reference for interventions to assess patient behavior/addiction and link patients to appropriate tobacco cessation interventions.
- Request/accept academic detailing visits.†

#### Practice Tools

- Tobacco cessation billing guide that includes sample documentation of smoking cessation counseling required by CMS for lung cancer screening coverage.
- Quick reference for behavioral and pharmacological interventions.
- KCP “Pathfinder.”

### HOSPITALS AND HEALTH SYSTEMS

- Intervene with and offer resources to all tobacco users, in every stage of readiness to quit.

†Academic detailing is interactive educational outreach to physicians to provide unbiased, non-commercial, evidence-based information about medications and other therapeutic decisions, with the goal of improving patient care. It is usually provided to clinicians one-on-one in their own offices. The approach is based on the effective communication/behavior change/marketing approach used by pharmaceutical industry sales reps (“detailers”) to increase use of a company’s products. From: “Introductory Guide to Academic Detailing,” National Resource Center for Academic Detailing. [www.narcad.org/wp-content/uploads/2010/12/Academic-Detailing-Guide.pdf](http://www.narcad.org/wp-content/uploads/2010/12/Academic-Detailing-Guide.pdf)

## ACTIONS (cont'd)

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### INSURANCE PROVIDERS

- Eliminate copays for tobacco cessation pharmacotherapy and counseling. If removing copays is not possible, medications should be less expensive than e-cigarettes.<sup>‡</sup>
- Implement “Pay for Performance” to providers for tobacco cessation among patients.

### LEGISLATORS AND POLICYMAKERS

- Increase tobacco product taxes and use proceeds to fund health-related activities.
- Fund “Lung Cancer Centers of Excellence.”
- Legislate “Pay for Performance”<sup>§</sup> to providers for tobacco cessation among patients.

### COMMUNITY PARTNERS

- Work with community health workers, school clinics, parish health nurses, and other community-based resources to promote smoking cessation throughout communities.
- Engage fitness organizations to advertise smoking cessation quitlines.
- Develop age-appropriate education modalities for patients.
- Increase engagement of Kentucky youth in smoking cessation campaigns and programs.

### ELECTRONIC HEALTH RECORD (EHR) NEEDS

- Direct referral mechanism within the EHR to KY Quitline and/or smoking cessation counseling.
- Quality measures promoted in consultation with nonprofit organizations, such as the National Quality Form (NQF) and the National Committee for Quality Assurance (NCQA).
- “Best Practices Package” for EHRs that meets standards related to tobacco cessation.

### DATA NEEDS

- Details of tobacco cessation coverage by insurance carriers in Kentucky.

<sup>‡</sup> Since the 2008 guideline was issued, electronic cigarettes, known as e-cigarettes, have grown in popularity. E-cigarettes are battery-operated products that turn chemicals, including nicotine, into an aerosol that is inhaled by the user. E-cigarettes are reportedly used both as substitutes for cigarettes and as tools for quitting. However, their safety has not yet been fully evaluated.

<sup>§</sup> “Pay-for-performance” describes initiatives aimed at improving the quality, efficiency, and overall value of health care. These involve financial incentives to hospitals, physicians, and other health care providers to carry out such improvements and achieve optimal outcomes for patients. From: Health Affairs, [www.healthaffairs.org/healthpolicybriefs/brief.php?brief\\_id=78](http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=78)

# EARLY DETECTION OF LUNG CANCER

## LUNG CANCER SCREENING WITH LOW-DOSE HELICAL COMPUTED TOMOGRAPHY (LDCT)

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Recent evidence from the National Lung Screening Trial supports screening high-risk persons for lung cancer using low-dose helical computed tomography (LDCT).<sup>20</sup> High-risk persons are defined as those ages 55 to 74 years, who have cigarette smoking histories of 30 or more pack-years and who, if they are former smokers, have quit within the last 15 years.<sup>21</sup> LDCT is now the preferred screening method for lung cancer. Compared to chest radiography (CXR), LDCT screening reduced lung cancer mortality by 20 percent and all-cause mortality by 6.7 percent.<sup>22</sup> It also is important to note that screening with chest x-rays or sputum cytology does not reduce mortality from lung cancer in the general population or in ever-smokers, according to the National Cancer Institute.<sup>23</sup>

The U.S. Preventive Services Task Force (USPSTF) recommended screening with LDCT in December 2013, within the above parameters, but for ages 55 to 80.<sup>24</sup> CMS approved coverage of beneficiaries ages 55 to 77 years, effective February 5, 2015,<sup>25</sup> enabling high-risk patients with private and public insurance to have access to this potentially life-saving exam. CMS included a requirement that, before a lung cancer procedure, a Medicare beneficiary must undergo a lung cancer screening, receive counseling, and participate in a shared decision making (SDM)\*\* visit “to include benefits, harms, follow-up diagnostic testing, over-diagnosis, false positive rate, and total radiation exposure.”<sup>26</sup> CMS also set standards for radiology imaging facilities. In order to make quality screening more widely available, Kentucky screening programs need assistance in adopting and implementing practices that meet the CMS standards.

Screening for early detection of lung cancer holds tremendous promise because lung cancer symptoms usually do not occur until the cancer is advanced. Lung cancer diagnosed at early stages has better treatment outcomes, thus screening has the potential to improve survival and reduce mortality. The five-year relative survival rate for localized lung (and bronchus) cancer is 54 percent, compared to four percent when diagnosed at a distant stage.<sup>27</sup>

## INTERVIEW FINDINGS

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Only a few of the 28 PCPs interviewed currently follow the new screening guidelines. Many PCPs were unaware of the screening guidelines; others were unaware of insurance coverage for the screening. Several PCPs screen with chest x-rays. Three PCPs referred smokers for LDCT screening only if the patients requested it.

## RECOMMENDATION FOR PRIMARY CARE

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Identify and increase the number of high-risk patients screened for lung cancer.

*\*\*Shared decision making (SDM) is a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences. SDM honors both the provider's expert knowledge and the patient's right to be fully informed of all care options and the potential harms and benefits. This process provides patients with the support they need to make the best individualized care decisions, while allowing providers to feel confident in the care they prescribe. From: "What Is Shared Decision-Making?" Informed Medical Decision Foundation: [www.informedmedicaldecisions.org](http://www.informedmedicaldecisions.org)*

## ACTIONS

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### PRIMARY CARE PROVIDER PRACTICES

#### Provider Actions

- Identify patients eligible for screening and use an SDM approach to discuss.
- Request/accept academic detailing visits.
- Provide educational material to eligible patients (see Practice Tools, below)

#### Practice Tools

- Guide to SDM approaches.
- Patient education materials.
- KCP “Pathfinder.”

### HOSPITALS AND HEALTH SYSTEMS

- Identify patients eligible for screening and use an SDM approach to discuss.
- Increase screening access using mobile units, thereby bringing screening to the patient.
- Equip “Lung Cancer Centers of Excellence” with LDCT technology to serve patients in areas with high lung cancer incidence. Develop systems to ensure that the proposed centers can deliver same-day diagnostic services and discuss with patients next steps for evaluation and treatment.

### INSURANCE PROVIDERS

- Use claims data to identify patients at high risk for lung cancer.
- Use claims data to reach out to identified high-risk patients to encourage screening.

### LEGISLATORS AND POLICYMAKERS

- Mandate:
  - Insurance coverage for care that includes repetitive screening of nodules.
  - That EHR systems used in Kentucky flag patients eligible for screening.
  - Use of Kentucky Health Information Exchange (KHIE) to share data on incidence of patient screening among providers; share relevant data among providers.
  - Return of claims data to researchers to enable evaluation of outreach, screening, diagnosis, and treatment.
  - Kentucky Board of Medical Licensure development of a continuing education (CE) component on lung cancer screening, diagnosis, and treatment. Completion would be mandatory for licensure renewal.
- Establish Medicaid “Pay for Performance” standards for lung cancer screening.

## **ACTIONS (cont'd)**

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### **COMMUNITY PARTNERS**

- Develop a public education campaign on lung cancer screening in consultation with health communications experts. The campaign could include lung cancer patient testimonials about the value of early detection and treatment.
- Promote community education and awareness of lung cancer screening. Programs could include group presentations to age-appropriate audiences by community health workers or hospital groups.

### **ELECTRONIC HEALTH RECORD (EHR) NEEDS**

- “Best Practices” package for EHRs that meets standards related to lung cancer screening SDM, ordering, and tracking.

### **DATA NEEDS**

- Inventory of LDCT screening locations in Kentucky.

# LUNG CANCER MANAGEMENT AND TREATMENT

## ENHANCING COLLABORATION AND ACCESS FOR MULTIDISCIPLINARY CARE

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A host of issues surrounds lung cancer treatment. Despite improvements in treatment outcomes across all disease stages, many argue that lung cancer is under-treated, particularly among older patients.<sup>28,29</sup> A patient's educational level and socioeconomic status also may affect whether lung cancer is treated, as barriers such as transportation, lack of insurance, and caregiver availability, make treatment adherence difficult.

Under-treatment is sometimes attributed to nihilism from doctors, as well as from patients and their families, because of the false assumption that treatment offers little or no benefit due to the stage of the cancer, patient age, or other factors.<sup>30,31</sup> Some observers suggest that global anti-smoking efforts, which emphasize the link between smoking and lung cancer, have increased stigmatization of the disease.<sup>32,33</sup> Many presume that lung cancer patients, by smoking, caused their own disease, although genetic and environmental factors also contribute. Some have suggested that lung cancer patients are less likely than other cancer patients to be referred for oncology care, and that they receive less aggressive treatment than do other cancer patients.<sup>34</sup>

A literature review showed that stigma and nihilism about lung cancer outcomes might lead patients to delay reporting symptoms to clinicians and refuse recommended tests and treatments. This results from widespread perceptions that a diagnosis of lung cancer will inevitably result in death, and that lung cancer treatment is futile.<sup>35</sup>

In fact, the picture is not so bleak. Lung cancer death rates fell an average of 1.8 percent each year over 2002-2011,<sup>36</sup> concurrent with improvements in surgical techniques and combined therapies. Recent advances in lung cancer treatment include new, less invasive methods to surgically resect lung cancer, improvements in radiation delivery techniques, and the approval of new therapies that target a specific feature of the cancer and activate the immune system against the cancer.<sup>37</sup>

Palliative care is another area gaining attention. Emphasis is now on early initiation of palliative care, with one study showing that it actually added several months of survival for non-small cell lung cancer patients when started soon after diagnosis.<sup>38</sup>

Communication between PCPs and specialists about the management of patients with lung cancer is another key issue. Communication is often inadequate, with negative consequences for patients. One article noted that from diagnosis through primary treatment, patients report having significant informational and emotional needs that are often unmet.<sup>39</sup> Challenges that limit providers' ability to deliver effective care include "provider care discontinuities, information exchange problems, and gaps in provider role clarity that may be especially problematic within the context of managing comorbid health conditions."<sup>40</sup>

The roles and responsibilities of the PCP versus cancer specialists also are ill defined, leading to tremendous variation in how consistently patients are medically followed and managed once they are diagnosed with cancer. During the treatment phase, care administered by PCPs includes managing comorbid conditions, treating side effects of cancer treatment, evaluating and treating depression, and prescribing medications for pain management. Although studies have shown gaps and duplication in roles, additional research is needed into optimizing the provider relationships and patient care.<sup>41</sup>

## ENHANCING COLLABORATION AND ACCESS FOR MULTIDISCIPLINARY CARE (cont'd)

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Information technology, such as EHRs, has the “potential to facilitate delivery of efficient, coordinated, and appropriate follow-up care.”<sup>42</sup> However, many organizational, political, and technological hurdles exist to derail that eventuality. Other systemic or interpersonal approaches must be devised to ensure that patients are followed throughout the treatment and care phase.

Access is a critical factor in the ability of PCPs to successfully refer patients to specialty care. The task force included suggested actions related to access and transportation, although they are not directly related to the recommendation below. These actions are included to highlight their importance and encourage relevant audiences to address them.

## INTERVIEW FINDINGS

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Primary care providers interviewed usually refer patients with suspected lung cancer to pulmonologists. Once lung cancer is diagnosed, referrals to oncology and/or surgery were almost always made by the pulmonologists. The involvement of PCPs with their patients after diagnosis varied greatly. A few PCPs indicated they scheduled appointments with patients specifically to discuss their cancer treatment. However, most only saw patients when they presented for comorbid conditions or cancer treatment side effects. Some PCPs said they receive little or no communication from cancer treatment specialists about their patients’ treatment plan or progress. A few reported that they proactively ask cancer specialists for updates on their patient’s treatment.

PCPs interviewed were reluctant to say lung cancer is treated less aggressively than other cancers due to any bias related to stigma. However, fatalism was sometimes cited as a reason why patients do not seek treatment. Transportation and distance to treatment were the most frequently cited barriers to treatment.

## RECOMMENDATION FOR PRIMARY CARE

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Enhance collaboration between primary care PCPs and cancer specialists to improve patient care.

## ACTIONS

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### PRIMARY CARE PROVIDER PRACTICES

#### Provider Actions

- Keep abreast of advances in lung cancer treatment and potential benefits at all cancer stages.
- Request/accept academic detailing visits.
- Develop or use existing protocols for coordination of patient care and education from diagnosis through survivorship.
- Use KCP “Pathfinder” to link patients with appropriate resources.
- Provide educational material to eligible patients.

#### Practice Tools

- Simple protocol for care coordination.
- KCP “Pathfinder.”

## ACTIONS (cont'd)

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### HOSPITALS AND HEALTH SYSTEMS

- Use patient navigators and community health workers to facilitate communication between specialists and PCPs.
- Strategically identify geographic areas in which to establish proposed “Lung Cancer Centers of Excellence” for medical oncology care.
- Develop or use existing protocols to coordinate patient care and education from diagnosis through survivorship.
- Make specialist care available in areas of limited access to specialists.
- Develop a video conferencing network between PCPs and specialists and create incentives to encourage its use for care coordination.

### INSURANCE PROVIDERS

- Reform payment mechanisms to ensure coverage of lung cancer care coordination between multidisciplinary providers.

### LEGISLATORS AND POLICYMAKERS

- Define clear roles and responsibilities of all providers involved in the care of lung cancer patients. Responsibilities to be discussed may include:
  - Treatment options
  - Side effects management
  - Pain management
  - Follow-up laboratory testing
  - Timing of shifts in responsibilities among PCPs and specialists.
- Facilitate TeleHealth delivery to improve access to specialists and to address distance-to-care (transportation) issues.
- Strategically identify geographic areas in which to establish proposed “Lung Cancer Centers of Excellence” for lung cancer care.
- Legislate higher tobacco taxes to fund patient navigators at the proposed “Lung Cancer Centers of Excellence.”
- Establish a functional hotline and a web-based resource within proposed “Lung Cancer Centers of Excellence,” to quickly identify local providers within a region.
- Reform payment mechanisms to ensure lung cancer care coordination between multidisciplinary providers.
- Require cancer specialists to send copies of reports to PCPs



## **ACTIONS (cont'd)**

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### **COMMUNITY PARTNERS**

- Develop a mobile app (e.g., “Cancer Uber”) to increase the ability of volunteers to provide rides to cancer patients, and thus reduce the impact of transportation as a barrier to care.

### **ELECTRONIC HEALTH RECORD (EHR) NEEDS**

- EHR tracking of transmission between providers of tumor board summaries, office visit notes, and care team summaries.
- Kentucky Health Information Exchange (KHIE)-facilitated information exchange between providers.
- Physician Quality Reporting System (PQRS) metric for cancer care coordination defined at national levels and state health systems.
- More fluid information exchange without the hurdles of proprietary software and interfaces.

### **DATA NEEDS**

- State-wide analysis of the availability of lung cancer treatment, identifying underserved geographic areas.
- Study of patient navigation needs in rural versus urban areas.

# LUNG CANCER SURVIVORSHIP

## SUPPORTING LUNG CANCER PATIENTS AFTER DIAGNOSIS

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As of January 1, 2014, an estimated 430,090 men and women with a history of lung cancer were living in the U.S.<sup>43</sup> Although lung cancer survivors currently represent only three percent of all cancer survivors, that percentage will likely increase with the promise of earlier detection through LDCT screening and subsequent earlier and more successful treatment.

Cancer survivorship has many definitions. According to the National Cancer Institute, “An individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.”<sup>44</sup>

Although lung cancer survivors represent a small subset of the survivor population, they generally bear a heavier disease burden. The average patient is older (71 at diagnosis<sup>45</sup>), with more severe comorbid conditions, particularly those with a history of smoking.<sup>46 47</sup> Issues found in the literature related to medical management of lung cancer survivors include ongoing tobacco use, psychological distress, access to care, pain management, monitoring for cancer recurrence and new primary cancers, managing short- and long-term effects of treatment, and social support. In addition to social stigma, many lung cancer survivors battle impaired lung function, especially if they have undergone surgery.<sup>48</sup> These survivors live with fear of recurrence and, if they continue to smoke, are at an increased risk for additional smoking-related cancers, as well as other problems.<sup>49</sup>

For all cancer survivors, a lack of care coordination often leaves some or all medical and psychosocial issues inadequately, or not at all addressed.<sup>50</sup> Oncologists and PCPs differ in their beliefs regarding who provides specific aspects of care. Some providers are not deeply involved in psychosocial care. This underscores the need for better coordination of care, with PCPs and specialists working together to ensure that patients’ needs are met.<sup>51</sup>

Support groups have demonstrated benefits to cancer survivors. However, opportunities are limited for Kentucky lung cancer survivors, especially in rural areas, to share their common experiences, fears, and challenges. The high lung cancer mortality rate has been a barrier to the development of quality-of-life research, compared to studies of survivors of other cancers.<sup>52</sup>

The Kentucky Cancer Program recently launched an online version of its “Pathfinder: A Guide to Cancer-Related Resources,”<sup>††</sup> and is promoting it to providers to facilitate patient referrals. The website enables providers and patients to identify cancer prevention, screening, treatment, and support services within regions and counties of Kentucky.

To improve patient care, health, and quality of life after the primary cancer treatment, the Institute of Medicine recommended in 2005 that every cancer survivor have a comprehensive care summary and follow-up plan. The plan should reflect the survivor’s treatment and address myriad post-treatment needs.<sup>53</sup> In 2014, the American Society of Clinical Oncologists (ASCO) issued a simpler template for specialists to use in developing survivorship care plans.<sup>54</sup> ASCO stated that all cancer survivors benefit from a survivorship care plan to assist patients and their PCP in coordinating care. Further, ASCO encourages survivors who do not receive a plan to ask for one.<sup>55</sup> For an individual patient, the plan can facilitate coordination with their PCP, and make them aware of symptoms they should report and of potential long-term or late effects caused by their treatments.<sup>56</sup>

<sup>††</sup><https://netapps.louisville.edu/PathFinder>

## INTERVIEW FINDINGS

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Twenty of the 28 PCPs interviewed said they do not make referrals to support services for lung cancer survivors. Most stated that they thought that was the responsibility of the oncologists. When interviewers described the KCP “Pathfinder,” all PCPs said they would use the resource in their offices and recommend it to patients.

## RECOMMENDATION FOR PRIMARY CARE

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Improve care of lung cancer patients after diagnosis and treatment.

## ACTIONS

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### PRIMARY CARE PROVIDER PRACTICES

#### Provider Actions

- Refer patients to existing survivorship networks and resources.

#### Practice Tools

- KCP “Pathfinder.”

### HOSPITALS AND HEALTH SYSTEMS

- Increase access to lung cancer support resources. Create referral hotline at proposed “Lung Cancer Centers of Excellence.” Link relevant referral hotlines (e.g., United Way 211, Lung Cancer Alliance, American Cancer Society) to survivorship resources across Kentucky.
- Promote TeleHealth as a way to extend access to supportive care and services.
- Make survivorship resources easier for patients and PCP offices to navigate.
- Promote the use of KCP “Pathfinder.”
- Expand survivorship programs with rural outreach from major cancer centers and proposed “Lung Cancer Centers of Excellence.”
- Increase the number of qualified patient navigators.<sup>††</sup>
- Integrate patient care navigators into proposed “Lung Cancer Centers of Excellence.”

### COMMUNITY PARTNERS

- Increase access to lung cancer support resources. Link relevant referral hotlines (e.g., United Way 211, Lung Cancer Alliance, American Cancer Society) to survivorship resources across Kentucky.
- Make survivorship resources easier for patients and PCP offices to navigate.
- Develop a provider-focused mobile app for cancer survivorship resources.
- Promote use of the KCP “Pathfinder.” Conduct an intense marketing/awareness campaign surrounding the KCP “Pathfinder.”

<sup>††</sup> Patient navigators are a diverse group of lay people and health care professionals who assist patients at all stages of cancer care, from screening and diagnosis to treatment and survivorship.

## ACTIONS (cont'd)

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### ELECTRONIC HEALTH RECORD (EHR) NEEDS

- Questions within EHR products to address specific needs related to survivorship.
- EHR documentation related to patient social, clinical, and psychological support.
- Common data platform to share survivorship care plans with all members of the care team. The common data platform would use current EHR standards for efficiency of information exchange without creating additional workflow for clinicians and their offices.

### DATA NEEDS

- Inventory of existing survivorship networks across the state to promote them as resources.
- De-identified maps of lung cancer survivors across Kentucky.

## CONTINUING EDUCATION

### IMPROVING LUNG CANCER PATIENT OUTCOMES THROUGH PRIMARY CARE

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Primary care providers must treat a plethora of illness and diseases within a limited time for each patient. Furthermore, the lung cancer screening guideline is new, still somewhat controversial, and reimbursement for screening only began in January 2015, with an expansion the following month. Finally, while each PCP in Kentucky sees a multitude of patients eligible for screening each year, the average PCP only sees a few patients diagnosed with lung cancer annually.<sup>57</sup> Thus, coordination of care for that small number of patients is not likely to receive concerted attention from PCPs without systemic reminders, continuing education, and a healthcare environment that reinforces and rewards desired provider behaviors.

The Kentucky LEADS Provider Education Component team at UofL is charged with developing a continuing education (CE) program for PCPs to improve lung cancer care. According to the literature, CE is most effective if it is interactive, uses more than one method, involves multiple exposures to the messages, and focuses on outcomes deemed to be important.<sup>58</sup> Further, physician care and patient outcomes are most influenced when there is audit/feedback, academic detailing and outreach, and reminder systems.<sup>59</sup>

### INTERVIEW FINDINGS

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PCPs interviewed had mixed responses regarding preferences for CE platforms. Online courses were preferred for at least half, as long as they were available at any time, with a maximum one-hour commitment, and ideally broken into 10-15 minute segments. CE credit was reported to be essential. Seven PCPs were not at all interested in online CE offerings. Some recommended a half-day workshop that includes a tour of cancer treatment facilities, discussions on tobacco cessation (for all patients), and cancer resources.

### RECOMMENDATION FOR PRIMARY CARE

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Develop continuing education for PCPs on lung cancer care across the continuum.

## ACTIONS

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*Several of the following actions will be undertaken by the LEADS Provider Education Component. Others could be pursued by health systems, provider groups, and non-profit organizations.*

- Use a multi-modal approach to CE events. Engage community providers in education delivery. Develop webcasts, roundtables, and toolkits. Partner with state-level organizations and associations. Conduct academic detailing to PCPs, increasing reach by providing lunch, when possible.
- Disseminate CME/CEs with state organizations, insurers, and health systems.
- Create a primary care-specific tumor board that offers CME credit.
- Create free Self-Assessment Modules (SAMs) approved by the American Board of Family Medicine (ABFM).
- Develop lung cancer “TED Talks.” Make them available live and online.
- Create a performance improvement CME Maintenance of Certificate (MOC) on lung cancer screening. This could be created by and promoted through Area Health Education Centers (AHEC).
- Disseminate CME/CE programs through state organizations, insurers, and health systems.

## CONCLUSION

The issues presented in this report collectively demonstrate the heavy lung cancer burden in Kentucky and highlight the urgent need for improvement in areas of tobacco cessation, lung cancer screening, multidisciplinary care and collaboration, and survivorship care. The task force did not consider environmental factors such as radon during its discussions.

The Kentucky LEADS Collaborative Primary Care Task Force was convened to inform and enhance the efforts of the provider education team at UofL. These task force-endorsed recommendations and the accompanying action items will, where relevant, guide the development and implementation of the statewide continuing education program for PCPs. The resulting program also will improve lung cancer screening rates, increase tobacco cessation among lung cancer patients, increase referrals of lung cancer patients to treatment specialists and support services, enhance PCP knowledge of effective treatments and resources, and refer more lung cancer patients to survivorship programs and services.

Actions that fall outside of the scope of the provider education component will be pursued in partnership with other Kentucky LEADS Collaborative components, legislators, government and nonprofit agencies, health systems, provider organizations, and others. This report will be widely disseminated to stakeholders for action. Collective efforts will be required to significantly improve lung cancer prevention, screening, care, and survivorship in Kentucky.

# ACTIONS BY STAKEHOLDER AND SUBJECT

## ACTIONS

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### PRIMARY CARE PROVIDER PRACTICES

#### Provider Actions

##### Prevention

- Use the KCP “Pathfinder” as a way to locate the nearest smoking cessation programs.
- Refer patients to smoking cessation programs and/or support groups and to the Kentucky Quitline (1-800-QUIT-NOW).
- Use the tobacco cessation billing guide.
- Use quick reference for interventions to assess patient behavior/addiction and link patients to appropriate tobacco cessation interventions.
- Request/accept academic detailing visits.

##### Early Detection

- Identify patients eligible for screening and use an SDM approach to discuss.
- Provide educational material to eligible patients

##### Lung Cancer Management and Treatment

- Keep abreast of advances in lung cancer treatment and potential benefits at all cancer stages.
- Develop or use existing protocols for coordination of patient care and education from diagnosis through survivorship.
- Use KCP “Pathfinder” to link patients with appropriate resources.

##### Survivorship

- Refer patients to existing survivorship networks and resources.

##### Practice Tools

- Tobacco cessation billing guide that includes sample documentation of smoking cessation counseling required by CMS for lung cancer screening coverage.
- Quick reference for behavioral and pharmacological interventions.
- Guide to SDM approaches.
- Patient education materials.
- Simple protocol for care coordination.
- KCP “Pathfinder.”



## ACTIONS (cont'd)

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### HOSPITALS AND HEALTH SYSTEMS

#### Prevention

- Intervene with and offer resources to all tobacco users, in every stage of readiness to quit.

#### Early Detection

- Identify patients eligible for screening and use an SDM approach to discuss.
- Increase screening access using mobile units, thereby bringing screening to the patient.
- Equip “Lung Cancer Centers of Excellence” with LDCT technology to serve patients in areas with high lung cancer incidence. Develop systems to ensure that the proposed centers can deliver same-day diagnostic services and discuss with patients next steps for evaluation and treatment.

#### Lung Cancer Management and Treatment

- Use patient navigators and community health workers to facilitate communication between specialists and PCPs.
- Strategically identify geographic areas in which to establish proposed “Lung Cancer Centers of Excellence” for medical oncology care.
- Develop or use existing protocols to coordinate patient care and education from diagnosis through survivorship.
- Make specialist care available in areas of limited access to specialists.
- Develop a video conferencing network between PCPs and specialists and create incentives to encourage its use for care coordination.

#### Survivorship

- Increase access to lung cancer support resources. Create referral hotline at proposed “Lung Cancer Centers of Excellence.” Link relevant referral hotlines (e.g., United Way 211, Lung Cancer Alliance, American Cancer Society) to survivorship resources across Kentucky.
- Promote TeleHealth as a way to extend access to supportive care and services.
- Make survivorship resources easier for patients and PCP offices to navigate.
- Promote the use of KCP “Pathfinder.”
- Expand survivorship programs with rural outreach from major cancer centers and proposed “Lung Cancer Centers of Excellence.”
- Increase the number of qualified patient navigators.
- Integrate patient care navigators into proposed “Lung Cancer Centers of Excellence.”

## ACTIONS (cont'd)

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### INSURANCE PROVIDERS

#### Prevention

- Eliminate copays for tobacco cessation pharmacotherapy and counseling. If removing copays is not possible, medications should be less expensive than e-cigarettes.
- Implement “Pay for Performance” to providers for tobacco cessation among patients.

#### Early Detection

- Use claims data to identify patients at high risk for lung cancer.
- Use claims data to reach out to identified high-risk patients to encourage screening.

#### Lung Cancer Management and Treatment

- Reform payment mechanisms to ensure coverage of lung cancer care coordination between multidisciplinary providers.

### LEGISLATORS AND POLICYMAKERS

#### Prevention

- Increase tobacco product taxes and use proceeds to fund health-related activities.
- Fund “Lung Cancer Centers of Excellence.”
- Legislate “Pay for Performance” to providers for tobacco cessation among patients.

#### Early Detection

- Mandate:
  - Insurance coverage for care that includes repetitive screening of nodules.
  - That EHR systems used in Kentucky flag patients eligible for screening.
  - Use of Kentucky Health Information Exchange (KHIE) to share data on incidence of patient screening among providers; share relevant data among providers.
  - Return of claims data to researchers to enable evaluation of outreach, screening, diagnosis, and treatment.
  - Kentucky Board of Medical Licensure development of a continuing education (CE) component on lung cancer screening, diagnosis, and treatment. Completion would be mandatory for licensure renewal.
- Establish Medicaid “Pay for Performance” standards for lung cancer screening.

## ACTIONS (cont'd)

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### Lung Cancer Management and Treatment

- Define clear roles and responsibilities of all providers involved in the care of lung cancer patients. Responsibilities to be discussed may include:
  - Treatment options
  - Side effects management
  - Pain management
  - Follow-up laboratory testing
  - Timing of shifts in responsibilities among PCPs and specialists.
- Facilitate TeleHealth delivery to improve access to specialists and to address distance-to-care (transportation) issues.
- Strategically identify geographic areas in which to establish proposed “Lung Cancer Centers of Excellence” for lung cancer care.
- Legislate higher tobacco taxes to fund patient navigators at the proposed “Lung Cancer Centers of Excellence.”
- Establish a functional hotline and a web-based resource within proposed “Lung Cancer Centers of Excellence,” to quickly identify local providers within a region.
- Reform payment mechanisms to ensure lung cancer care coordination between multidisciplinary providers.
- Require cancer specialists to send copies of reports to PCPs.

### COMMUNITY PARTNERS

#### Prevention

- Work with community health workers, school clinics, parish health nurses, and other community-based resources to promote smoking cessation throughout communities.
- Engage fitness organizations to advertise smoking cessation quitlines.
- Develop age-appropriate education modalities for patients.
- Increase engagement of Kentucky youth in smoking cessation campaigns and programs.

#### Early Detection

- Develop a public education campaign on lung cancer screening in consultation with health communications experts. The campaign could include lung cancer patient testimonials about the value of early detection and treatment.
- Promote community education and awareness of lung cancer screening. Programs could include group presentations to age-appropriate audiences by community health workers or hospital groups.

## ACTIONS (cont'd)

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### Lung Cancer Management and Treatment

- Develop a mobile app (e.g., “Cancer Uber”) to increase the ability of volunteers to provide rides to cancer patients, and thus reduce the impact of transportation as a barrier to care.

### Survivorship

- Increase access to lung cancer support resources. Create referral hotline at proposed “Lung Cancer Centers of Excellence.” Link relevant referral hotlines (e.g., United Way 211, Lung Cancer Alliance, American Cancer Society) to survivorship resources across Kentucky.
- Make survivorship resources easier for patients and PCP offices to navigate.
- Develop a provider-focused mobile app for cancer survivorship resources.
- Promote use of the KCP “Pathfinder.” Conduct an intense marketing/awareness campaign surrounding the KCP “Pathfinder.”

## ELECTRONIC HEALTH RECORD (EHR) NEEDS

### Prevention

- “Best Practices” package for EHRs that meets standards related to lung cancer screening SDM, ordering, and tracking.

### Early Detection

- Develop a public education campaign on lung cancer screening in consultation with health communications experts. The campaign could include lung cancer patient testimonials about the value of early detection and treatment.
- Promote community education and awareness of lung cancer screening. Programs could include group presentations to age-appropriate audiences by community health workers or hospital groups.

### Lung Cancer Management and Treatment

- EHR tracking of transmission between providers of tumor board summaries, office visit notes, and care team summaries.
- Kentucky Health Information Exchange (KHIE)-facilitated information exchange between providers.
- Physician Quality Reporting System (PQRS) metric for cancer care coordination defined at national levels and state health systems.
- More fluid information exchange without the hurdles of proprietary software and interfaces.

## ACTIONS (cont'd)

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### Survivorship

- Questions within EHR products to address specific needs related to survivorship.
- EHR documentation related to patient social, clinical, and psychological support.
- Common data platform to share survivorship care plans with all members of the care team. The common data platform would use current EHR standards for efficiency of information exchange without creating additional workflow for clinicians and their offices.

### DATA NEEDS

- Details of tobacco cessation coverage by insurance carriers in Kentucky.
- Inventory of LDCT screening locations in Kentucky.
- State-wide analysis of the availability of lung cancer treatment, identifying underserved geographic areas.
- Study of patient navigation needs in rural versus urban areas.
- Inventory of existing survivorship networks across the state to promote them as resources.
- De-identified maps of lung cancer survivors across Kentucky.

### CONTINUING EDUCATION NEEDS

- Use a multi-modal approach to CE events. Engage community providers in education delivery. Develop webcasts, roundtables, and toolkits. Partner with state-level organizations and associations. Conduct academic detailing to PCPs, increasing reach by providing lunch, when possible.
- Disseminate CME/CEs with state organizations, insurers, and health systems.
- Create a primary care-specific tumor board that offers CME credit.
- Create free Self-Assessment Modules (SAMs) approved by the American Board of Family Medicine (ABFM).
- Develop lung cancer “TED Talks.” Make them available live and online.
- Create a performance improvement CME Maintenance of Certificate (MOC) on lung cancer screening. This could be created by and promoted through Area Health Education Centers (AHEC).
- Author and publish articles in Kentucky provider journals on lung cancer screening and care.
- Create a lung cancer speakers’ bureau for medical students, trainees, and medical staff.
- Disseminate CME/CE programs through state organizations, insurers, and health systems.

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# LUNG CANCER IN KENTUCKY

A Primary Care Action Plan

2015

LEADS PRIMARY CARE  
TASK FORCE



**KENTUCKY**  
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COLLABORATIVE

**LUNG CANCER**  
EDUCATION • AWARENESS  
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