



# Bridge to Good Living: Thriving Beyond Lung Cancer

Stephenie Kennedy-Rea, EdD (PI), Anne Swisher, PT PhD (Co-PI), Monika Holbein, MD (Co-PI)  
 Jim Keresztury, MBA, MSW, Adrienne Duckworth, MSN, and Abby Starkey, MS



## Program Background

The goal of the Bridge Program is to improve the overall coordination of care, increase quality of life, and decrease the consequences of treatment for patients diagnosed with lung cancer in the state of West Virginia. Patients are able to bridge the gap of cancer care from treatment to survivorship with the expertise of a multidisciplinary team.

## Lung Cancer in West Virginia

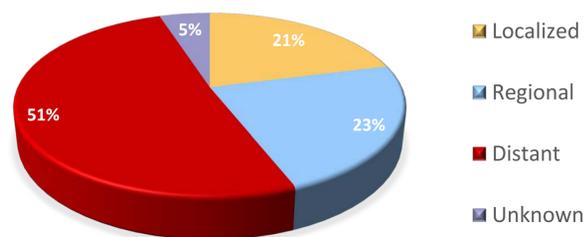
Lung cancer is the leading cause of cancer related deaths in West Virginia.

Half of all people with a lung cancer diagnosis also have distant metastasis<sup>1</sup>, because of this more people in West Virginia die of lung cancer than colorectal, prostate, and breast cancer combined<sup>1</sup>.

West Virginia is ranked among the top states in public risk factors for tobacco use<sup>2</sup>.

In 2014, the WV Board of Medicine reported an oncology shortage in 36 of the state's 55 counties<sup>3</sup>, as a result many residents rely heavily on services in adjacent states<sup>4</sup>.

PERCENTAGE OF LUNG CANCER CASES BY STAGE AT DIAGNOSIS, WEST VIRGINIA 2010-2014



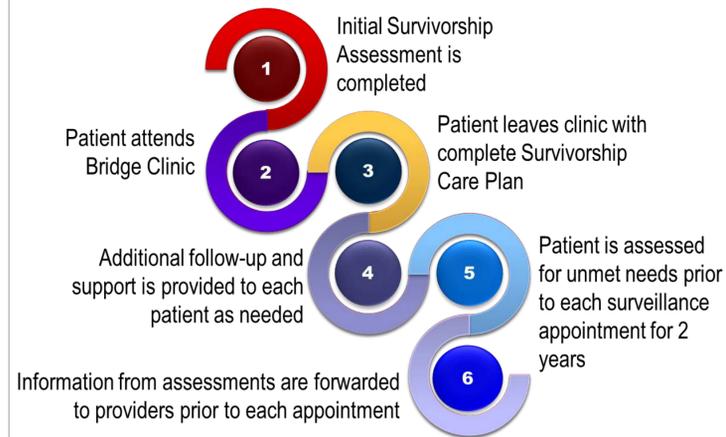
## Study Aims

**Aim 1:** Develop and implement a comprehensive survivorship model program for lung cancer patients completing definitive curative treatment.

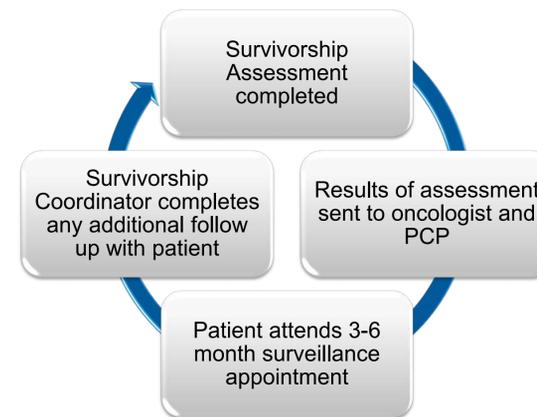
**Aim 2:** Develop and deliver a one-day, face-to-face training session for healthcare professionals addressing multiple areas of lung cancer.

**Aim 3:** Disseminate information about lung cancer survivorship and the model to the broader community of patients, families, providers, and advocates across West Virginia.

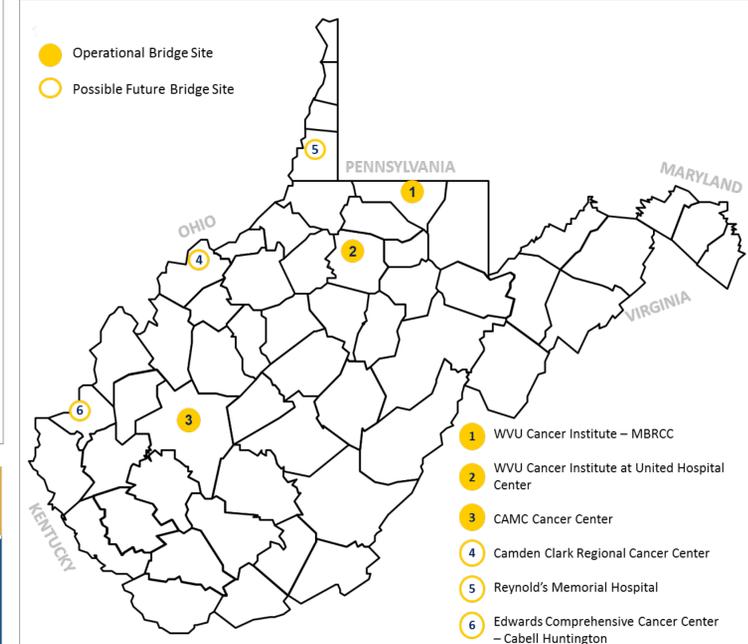
## The Bridge Clinic



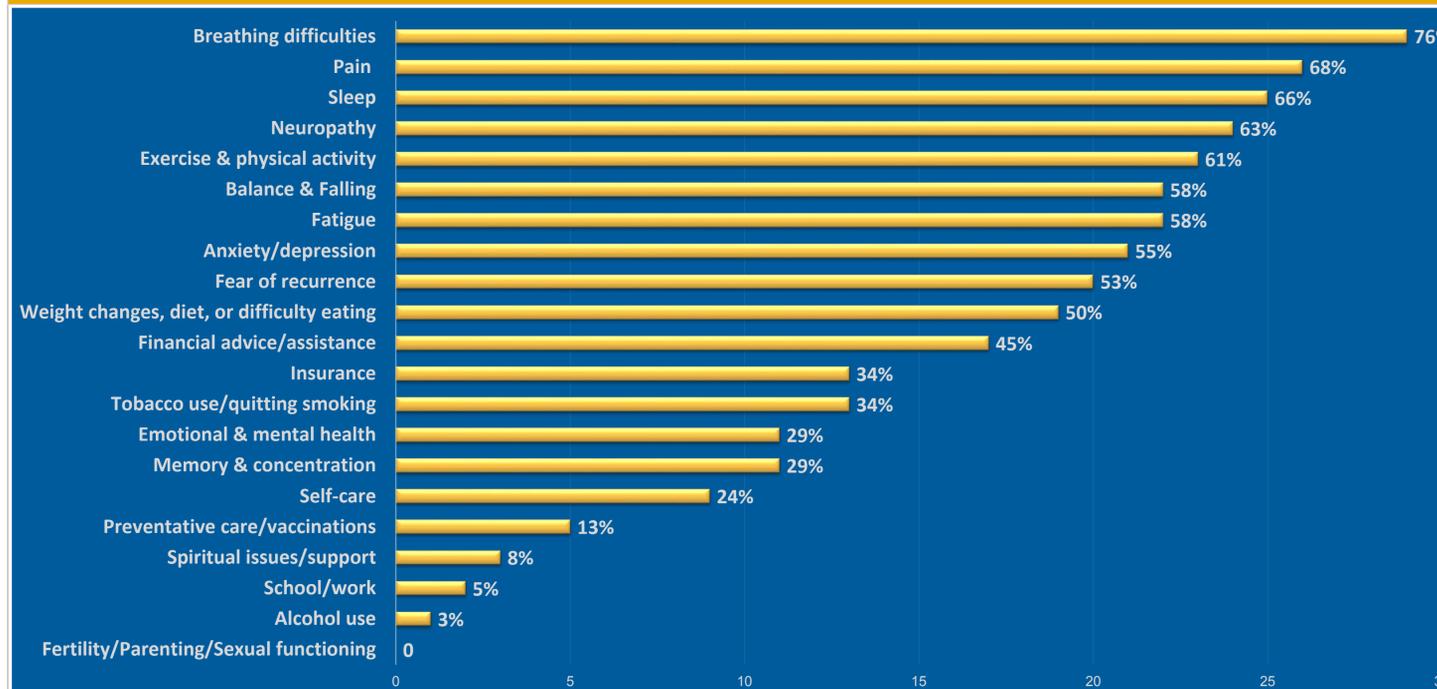
## Surveillance Cycle



## Partner Sites



## Lung Cancer Patient Needs Following Active Treatment

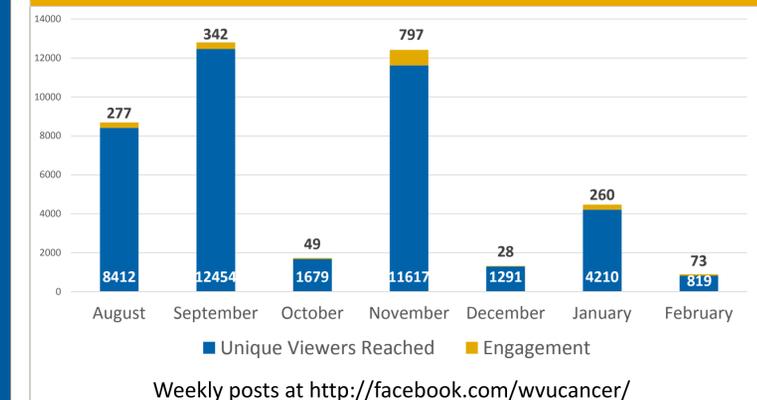


To date, 38 patients have been assessed. As a result of these assessments and consultation from a multi-disciplinary team, more than 50 referrals to community resources, social services, and other healthcare providers have been generated. The most common referral is for physical therapy. All patients surveyed identified at least one unmet need post-treatment.

## Screening to Survivorship: A New Look at Lung Cancer

In November 2017, a free continuing education conference was held in Morgantown, West Virginia with 115 total attendees. Continuing education credits were awarded to 52 participants, and 50 completed pre and post tests. The 2018 Lung Cancer Conference will have a policy focus. The conference will be held on November 1-2 at the WVU Erickson Alumni Center.

## Social Media Reach via Facebook



## Acknowledgements & References

- "Cancer Incidence." West Virginia Cancer Registry 2012. West Virginia Department of Health and Human Resources. Office of Epidemiology and Prevention Services. Web. Retrieved July 15, 2016.
- American Cancer Society. *Cancer Treatment & Survivorship Fact & Figures 2016-2017*. Atlanta: American Cancer Society; 2016.
- "Health Care in West Virginia." West Virginia Rural Health Association. October 2014. Web. Retrieved July 15, 2016.
- Swisher AK, Erickson M, Abraham J, Kurian S, Shannon V, Vona-Davis LC. Commentary: Overcoming barriers to physical activity in rural breast cancer survivors. *Rehabil. Oncology*. 2013; 31(4):32-5

The Bridge Program is supported fully by a grant from the Bristol-Myers Squibb Foundation's Bridging Cancer Care program. The Bridge Team would like to thank its collaborating partners in promoting the aims of this grant.



# Advancing Quality Lung Cancer Survivorship in South Carolina

**Principal Investigator:** Karen Kane McDonnell, PhD<sup>1</sup> ■ **Co-Investigators:** Jenay Beer, PhD<sup>3,4,8</sup>; Otis (Shaun) Owens, PhD<sup>3</sup>; Brandi R. Newsome, MD<sup>2</sup>; James William Hardin, PhD<sup>5</sup> ■ **Staff:** Tamara Church, MSW<sup>1</sup>; David Gallerani, MPH<sup>1</sup>; Samira Khan, MSW<sup>5</sup>  
**Consultants:** Linda E. Carlson, PhD<sup>6</sup>; Katherine R. Sterba, PhD<sup>7</sup> ■ **Students:** Dane Acena,<sup>9</sup> Amanda Bennett,<sup>1</sup> Kerry Breen,<sup>3</sup> Taylor Kennedy,<sup>8</sup> Elizabeth Regan,<sup>5</sup> Ligia Reyes,<sup>5</sup> Kasey Smith,<sup>8</sup> Lisa Webb<sup>1</sup>  
**Partners:** Upstream: A Center for Mindfulness Practice and Holistic Mental Health; Pam Gillam, MPA, Core for Applied Research & Evaluation<sup>5</sup>

<sup>1</sup>University of South Carolina (USC) College of Nursing <sup>2</sup>USC School of Medicine <sup>3</sup>USC College of Social Work <sup>4</sup>USC College of Engineering & Computing <sup>5</sup>USC Arnold School of Public Health <sup>6</sup>Dept. of Psychosocial Oncology, Tom Baker Cancer Centre, Calgary (Canada) <sup>7</sup>Medical University of South Carolina <sup>8</sup>University of Georgia <sup>9</sup>Benedict College

## LONG-TERM GOAL: Improve Clinical Outcomes for Survivors of Non-Small Cell Lung Cancer (NSCLC) and Their Family Members

### OBJECTIVE #1: Develop the Partners in Quality Lung Cancer Survivorship

A statewide network of clinical, community, and congregational stakeholders with an interest in advancing lung cancer survivorship

- ▶ **MAXIMIZE** community involvement and build capacity for survivorship care for patients with lung cancer and family members in South Carolina
- ▶ **COLLABORATE** with professionals from the American Cancer Society, American College of Surgeons' Commission on Cancer accredited cancer programs/centers, American Lung Association, Lung Cancer Alliance, SC Alliance of YMCAs, SC Cancer Alliance, SC Dept. of Health and Environmental Control (DHEC), SC Lieutenant Governor's Office on Aging, SC Non-Emergency Transportation Coalition, and SC Vocational Rehabilitation

### HIGHLIGHTS

**Established relationships** with cancer leaders across the state.

**Met with community leaders** to discuss survivorship priorities for patients, survivors, and families in South Carolina who are affected by a lung cancer diagnosis.

**Collected data** using two surveys (one for clinicians, one for patients/family members) and follow-up phone interviews.

**Prepared to present** data to key stakeholders at the first of three professionally facilitated meetings; objective is to create a strategic plan defining key survivorship priorities and recommended courses of action.



**16 ACOS COMMISSION ON CANCER-ACCREDITED PROGRAMS AND CENTERS**

**3 MEETINGS WITH KEY PARTNERS**



### OBJECTIVE #2: Adapt & Test the *Breathe Easier* Intervention

An exemplar intervention founded on the Mindfulness-based Cancer Recovery Program

- ▶ **ADDRESS** issues important to lung cancer survivors and their family members
- ▶ **DEVELOP** an intervention protocol with breathing exercises, mindfulness-based meditations, yoga (varying skill levels), and participant interaction components
- ▶ **TARGET** a dyad population; 1 dyad = 1 adult survivor of NSCLC (stage I, II, or IIIa) who has completed definitive treatment in past 5 years + 1 family member
- ▶ **ADAPT & EVALUATE** *Breathe Easier* as an interactive **mobile application** (simple prototype only); add content (varying skill levels: level I and level II)



▶ **TEST & EVALUATE** *Breathe Easier* as a face-to-face intervention:

• **FEASIBILITY** of a prospective, one group, mixed methods research design. Test recruitment, retention, intervention dose, adherence, and acceptability.

• **PRELIMINARY OUTCOMES:**

**Primarily**, greater symptom reduction immediately after intervention (less dyspnea, less fatigue, less stress)

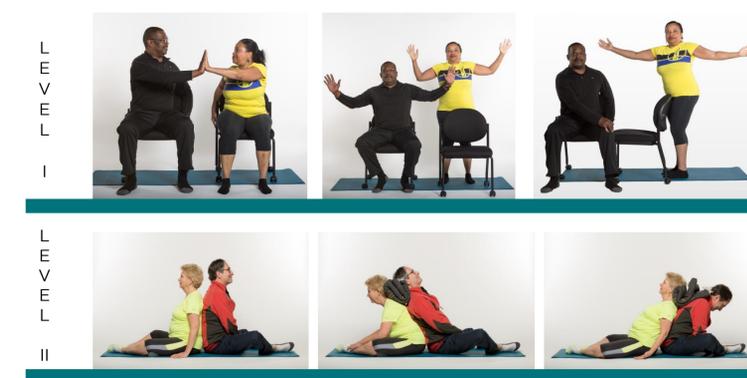
**Secondarily**, greater symptom reduction immediately after intervention (less anxiety, less depression, improved sleep quality)

### HIGHLIGHTS: FACE-TO-FACE

**Designed, developed, and initiated evaluation of a face-to-face**, 8-session, low-literacy, culturally sensitive group intervention and related materials. Evaluation plan is under way and focuses on feasibility and preliminary effects.



SAMPLE GENTLE MOVEMENTS:



#### Interim Feasibility Findings

**4 INTERVENTION ITERATIONS COMPLETED:**

- 3 level I (sitting yoga)
- 1 level II (standing/floor yoga)

**RECRUITMENT RATE: 42%**

**RETENTION RATE: 86%**

**INTERVENTION DOSE:** Measured by **2** protocols

**ADHERENCE:**

- **76%** among family members (range, 10–49 daily home assignments)
- **65%** among survivors (range, 5–48 daily home assignments)

**ACCEPTABILITY:** **100%** of participants agreed course materials were easy to read and use, learning breathing exercises and yoga helped them, and involving family was important

### MOBILE APP

**Designed, developed and planned evaluation of a mobile app prototype.** Using focus-group and personal-interview methodologies, the evaluation plan is scheduled to begin in April 2018 and will center on usability. Ease of use, content appeal, benefits and concerns, and cultural relevance will be examined.

"When we get too caught up in the busyness of the world, we lose connection with one another – and ourselves." – Jack Kornfield



Welcome to Breathe Easier, this is the main menu.



#### FOCUS GROUPS:

- Rooted in a community-based participatory research approach
- Will include lung cancer survivors and family members
- Will be consulted throughout app development process; will view and interact with simple prototypes

# Development of the Survive 2 Thrive Project: Lung Cancer Survivorship Care Program

Roy Hart, CEO; Jacinda Roach, PhD; Glenda Crump, COO; Key Britt, VP; Wilson Gaillard, Director; Roderick Givens, MD; Lindsey Rawls, RN; Elizabeth Walker, GS  
Mississippi Public Health Institute, Greenwood Leflore Hospital

## Background



**Survive 2 Thrive** is a partnership between Greenwood Leflore Hospital and the Mississippi Public Health Institute, with funding provided by the Bristol-Myers Squibb Foundation.

The diagnosis of cancer can be overwhelming. There are many new and confusing issues for lung cancer patients and their families or caregivers. The service area of Greenwood Leflore Hospital is comprised of residents who have higher levels of poverty, unemployment, and chronic disease incidence than any other area in Mississippi, which ranks among states with the highest levels of these conditions nationally.

**Survive 2 Thrive** has as its mission to improve the health outcomes and quality of life for patients at highest risk for, recently diagnosed with, or living with lung cancer among the priority population of the service area of Greenwood Leflore Hospital in the Mississippi Delta. Survive 2 Thrive seeks to accelerate the development, implementation, and evaluation of innovative models of prevention, detection, education, and survivorship care of lung cancer patients.

## The Burden of Lung Cancer

- Communities in the Mississippi Delta served by Greenwood Leflore Hospital are comprised of residents who suffer disparities in health equity due to poverty and lack of education, which translates into poor to no health literacy, lack of transportation for access to care, and a cultural dynamic that tends to increase risk and fails to support compliance to care.
- In the service area of Greenwood Leflore Hospital, 72.2% of the residents are African American. African Americans have the highest death rates and shortest survival rates of any racial and ethnic group in the United States for most cancers.
- The annual incidence of lung cancer per 100,000 population is highest among African Americans, and the highest lung cancer incidence is in the South (CDC). Minority and underserved populations are affected the most severely by lung cancer.
- Some older members of our priority population have accepted limited involvement in their medical care. Elderly lung cancer patients who are African American or from less educated communities are less likely to get the combination of chemotherapy and radiation that's linked to better survival odds. (*Journal of Clinical Pathways*)
- Many of our priority population do not value themselves highly enough to realize that health equity is the right of each individual to achieve optimal health care regardless of race; level of education; gender identity; sexual orientation; the job they have (or don't have); the neighborhood in which they live; or whether or not they have a disability.

## Study Aims

- AIM #1:** To improve the health outcomes and quality of life for patients at highest risk for, recently diagnosed with, or living with lung cancer among the priority population of the service area of Greenwood Leflore Hospital in the Mississippi Delta.
- AIM #2:** To reduce health disparities and improve health equity among the priority population of the service area of Greenwood Leflore Hospital in the Mississippi Delta.

## Research Methods

- Development of a sustainable program aimed at reducing lung cancer morbidity and mortality among underserved populations in the service area of Greenwood Leflore Hospital.
- Apply an evidence-based model of community health networkers to liaise and impact broad environmental and psychosocial challenges of the priority population.
- Utilize a multidisciplinary team to implement a patient-centered holistic approach to care that facilitates prevention of recurrent and new cancers; surveillance for metastasis, recurrence or secondary cancer; and assessment of medical and psychological effects.
- Utilize an intervention plan for the cancer survivor that addresses the consequences of cancer for the survivor and caregivers.
- Provide enhanced coordination of care for cancer survivors via the adoption of an evidence-based shared-care survivorship model.
- Evaluate effectiveness by measuring:
  - Number of participants with a documented care pathway service coordination plan
  - Estimated number of people in the target population
  - Number of educational materials provided
  - Number of educational opportunities
  - Number of target population reached
  - Number of participants retained in care
  - Number of referrals to community services
  - Number of home visits by community networkers

## Intervention Guiding Principles

### The Intervention is Designed to:

- Adhere to evidence-based protocols for lung cancer
- Be accessible to our underserved and difficult-to-reach population
- Exhibit a collaborative approach to ensure optimum access to care

### The Intervention Program is Targeted and Tailored:

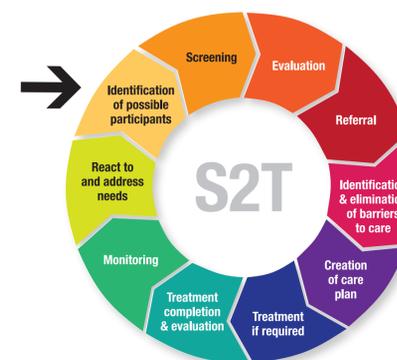
- Primary care providers current patient population
- Community awareness / outreach
- Program is tailored to individual needs through a shared decision-making process among the oncology physician, the oncology nurse navigator, community networkers, and the survivor and their caregivers.

### The Intervention Program is Adaptable:

- High risk individuals are identified through the medical delivery system.
- Screening processes are made available to advance early detection.
- Coordinated plans are offered to those identified.
- Barriers that are identified are removed.

## Survivorship Care Plan

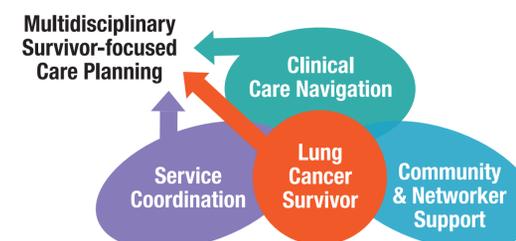
- Participants receive a personalized care plan that includes their health history, screening results, and care received.
- Education on lung cancer is provided.
- Treatment dates (chemo and radiation) are provided.
- Side effects of treatment (long and short term) are explained.
- Provider information is included for primary care physicians.
- Standard follow-up care is included.
- Referral sites are listed.
- Home visit questionnaires are administered.
- Self-management techniques are taught by community networkers during home visits.
- American Cancer Society support materials are included.



## Survivorship Care Specialist Training

The American Cancer Society provides specialized training in the area of lung cancer for our team. Learning objectives are:

- Create understanding of the lung cancer continuum.
- Describe lung cancer, the disease.
- Build knowledge of prevention and early detection measures for lung cancer.
- Increase awareness of the process of patient navigation.
- Discuss psychosocial aspects of cancer.
- Build skills for communicating with and navigating patients to resources.
- Increase knowledge of American Cancer Society resources.
- Facilitate communication among group to clarify roles and processes.



## Implementation Partner Sites

- Greenwood Leflore Hospital
- Greenwood Leflore Hospital Clinic Network
- Internal Medicine Associates - Greenwood, Mississippi

## Summary

The **Survive 2 Thrive Project** has propelled Greenwood Leflore Hospital into the forefront of lung cancer screening/care for the Mississippi Delta. Through the project's funds, Greenwood Leflore Hospital has:

- Obtained a 12-passenger van to provide transportation for our patients, most of whom are in dire need of affordable transportation for proper access to care;
- Purchased a data software tracking program, Nurse Nav. Oncology, allowing us to track our patients and pull data in a most efficient manner;
- Purchased low-dose cancer screening equipment for lung cancer;
- Purchased a Linear Accelerator for our Radiation Oncologist;
- Hired two pulmonologists; and
- Implemented \$99 low-dose lung cancer screening for the general public.

**Survive 2 Thrive** has made contact with 135 total patients. There are 93 patients in screening/surveillance. Of those 93, 16 are in surveillance (currently being followed by a pulmonologist for issues such as nodules, COPD, etc.) Sixty patients have actually received LDCT screenings. Of those 60, 16 have had recommended follow-up care (CTs, bronchoscopy, or PET scan.) Two of the screening patients received a cancer diagnosis due to the screening process. **Survive 2 Thrive** has reached 42 survivors, of which 15 are now deceased. These results have been obtained after 14 months of active operation.

## Learn More and Connect with Us

- <https://glh.org/services/survive-2-thrive>
- @greenwoodlefhospital
- Greenwood Leflore Hospital's Cancer Center  
Wilson Gaillard, Director: 662-459-7133

## Acknowledgments

Survive 2 Thrive is the result of a partnership between the Mississippi Public Health Institute and Greenwood Leflore Hospital in Greenwood, Mississippi.

Survive 2 Thrive is supported by a generous grant from Bristol-Myers Squibb Foundation's Bridging Cancer Care grant mechanism.



Additional support provided by Greenwood Leflore Hospital



# A Comprehensive Lung Cancer Patient Navigation Program (CLCPNP): A Review of Project Design and Preliminary Data

Dawn Wiatrek, PhD, Katherine Sharpe, MTS, & Octavia Vogel, MPH

## Background

In the United States, lung cancer is the leading cause of death from cancer (Siegel, 2015). Although lung cancer is the second most common cancer diagnosed in both men and women, the annual mortality burden of disease is larger than that of any other cancer. An estimated 224,210 new cases of lung cancer are expected in 2014, accounting for about 13% of all cancer diagnoses (American Cancer Society, 2015).

There are fewer survivors of lung cancer than other cancers such as breast or prostate, given the often asymptomatic nature of the disease and resulting diagnosis at a later stage (Poza, 2013). However, with the increased use of low dose computerized tomography (LDCT) screening for lung cancer, more cancers are being found early and at a treatable stage. This is resulting in an increased number of lung cancer survivors and it is imperative that models of survivorship care are established for this patient population.

As more survivorship care programs are implemented, it is becoming increasingly clear that there is not a single model for care delivery. While the first survivorship care programs were established at academic medical centers, survivorship care has now extended to community based practice (Miller, 2012). Yet there are opportunities to extend survivorship care further and provide the much needed access to information and support for lung cancer survivors. The Comprehensive Lung Cancer Patient Support Program (CLCPSP) is a multi-channel program designed to address the many challenges facing lung cancer survivors as they manage their illness.

## Program Goals

The primary goal of the CLCPSP is to provide an evidence-based, multi-level intervention that promotes high quality, patient centered coordinated care to lung cancer survivors living in the targeted geographic areas.

This will be accomplished by:

- Providing patient navigation services to reduce barriers and increase access to high-quality survivorship care for lung cancer survivors
- Empowering lung cancer survivors with the information, skills, confidence and support necessary to more actively participate in their health care
- Improving provider knowledge, understanding and skills related to provision of high quality, coordinated, patient centered survivorship care for lung cancer survivors.

## Target Population

The CLCPSP provides support to lung cancer patients in 8 states including:

- Alabama (2 cancer centers/hospitals)
- Georgia (3 cancer centers/hospitals, 1 navigator)
- Mississippi (4 cancer centers/hospitals, 1 navigator)
- Kentucky (7 cancer centers/hospitals, 1 navigator)
- Tennessee (1 hospital)
- North Carolina (20 cancer centers/hospitals, 1 navigator)
- South Carolina
- West Virginia (1 cancer center/hospital, 1 navigator)

## Program Design/Structure



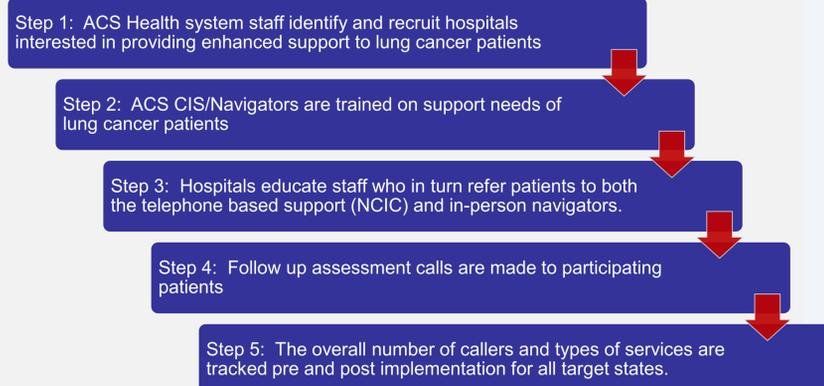
In developing the CLCPSP, the ACS was able to leverage existing national programs and resources to ensure the highest quality care was made available to patients. These included: **•Cancer Information Specialists at the American Cancer Society National Cancer Information Center (NCIC) (n=35)** who were trained on the unique needs of lung cancer patients and how to best provide telephone based lung cancer survivorship support ranging from cancer information to transportation and lodging

**•ACS funded hospital based navigators** in the 8 target states (n=12) who were trained on the unique barriers facing lung cancer patients across the continuum, and how to help empower patients to overcome these barriers.

**•ACS Health System Management teams** who met with representatives from over 40 cancer centers in the target states to share information about the program and promote the cancer information and resource navigation services.

**•The Cancer Survivorship Resource Center at the American Cancer Society** provided a variety of support materials and resources for cancer survivors, their loved ones, and health care providers. Through a partnership with NCI, the Survivorship Center recently launched a smart phone enabled website designed to provide easy access to critical survivorship information. ACS navigators and CIS have been trained on how to support patients interested in using this tool.

## Steps in the CLCPSP



## Training Overview

All training was developed and delivered by American Cancer Society content and medical experts, and delivered by an ACS oncologist and behavioral scientist. Pre/Post assessments were conducted by all navigators attending training

### Training Learning Objectives:

- Define the goals of the CLCPSP and the role of the patient navigator/CIS within the CLCPSP
- Understand the basics of lung anatomy, lung cancer screening/diagnosis, lung cancer treatment and treatment options.
- Describe supportive care, non-therapy options and follow-up care available/appropriate for lung cancer survivors and how to connect survivors to these resources
- Describe shared decision making concepts, including the role that an ACS navigator/CIS can play in making sure patients discuss their options with their health care provider (including clinical trials)
- Understand how to support the unique needs of lung cancer survivors including stigma, self-care and side effects
- Describe basic patient empowerment strategies and how to apply patient empowerment concepts/skills in the navigation setting
- Describe tobacco cessation, nutrition and physical activity resources for lung cancer survivors
- Understand how to best utilize springboard beyond cancer to support patients during and after treatment

## Provider/Cancer Team Training

Provider/cancer team training will be provided through a **Lung Cancer Survivorship ECHO clinic** to begin in May 2018 through April 2019. Cancer care teams are now being recruited for participation from the target 8 states. Each cancer care site participating will be asked to recruit at least one primary care facility with which they currently partner.

A core team of Subject Matter Experts is being recruited from the National Lung Cancer Roundtable. These SMEs will provide expert presentation and assist in the facilitation of case-based learning exercises in each session.

While the primary focus of the Lung Cancer Survivorship ECHO clinic will be survivorship, a variety of topics addressing the entire care continuum will be covered, highlighting the potential impact of decisions made at that phase on long term survivorship.

## Research Questions

Is it possible to increase our programmatic reach and number of lung cancer patients receiving services by increasing cancer center outreach and education about ACS navigation resources?

- Based on analysis of the total number of lung cancer patients served by ACS in the year prior to implementation, we estimated that during the 2 year implementation period of this grant (June 2017- May 2019), we could potentially reach between 15,000-20,000 lung cancer patients in the target states.

What are the most common barriers and resources received by lung cancer patients and how do these compare to other cancer types?

Do navigators and CIS report increased knowledge and confidence in supporting lung cancer patients following training?

Do patients receiving ACS navigation report increases in managing key barriers to care and key behaviors related to increased activation?

## Preliminary Data

Lung Cancer Patient Data Baseline/First Quarter			
All Services (Transportation, Lodging, Program referral, Navigation, Information)			
	Baseline (9/1/2016-8/31/2017) (Avg. Per Quarter)	Annual target: 10,000 (2500 per quarter)	First Grant Tracking Quarter (9/1/2017-11/30-2017) (percent of target achieved)
Patients receiving services in 8 target states	5354 (1338)	2500	1437 (57%)

- We are currently analyzing second quarter data, including the types of services received
- Navigators (n=12) reported increased understanding and confidence in being able to support lung cancer patients in all training areas.
- Surveys of patients receiving services are now underway and data will be available in the next 3-4 weeks

## Conclusions & Next Steps

While the quarterly target of 2500 was not achieved in the first quarter, additional activities are underway to help increase awareness of the program at all participating cancer centers. These include

- In-service presentations overviewing all ACS programs and services
- Lunch and learns with cancer care teams
- Navigator participation in ECHO teams to increase awareness of the type of support navigators can provide
- Development of print materials to share with patients

While the first quarter tracking did not begin until 9/1/2017, the in-person navigators were trained in May. This group reported an increase in the number of patients served during the first 6 months of the program.

We are currently planning a refresher training for all navigators and CIS.

During the initial 6 months of implementation 5 of navigator positions in the participating states were eliminated. We expect to see an increase in use of the NCIC-ACS resources at these sites.

## Acknowledgements

The CLCPSP is supported by a generous grant from the Bristol-Myers Squibb Foundation's Bridging Cancer Care grant mechanism.



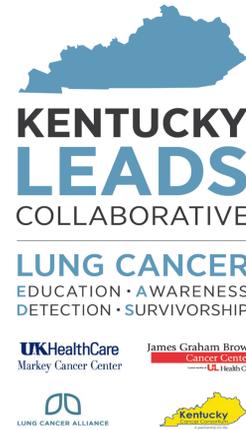
# Effects of an Online Training Program for Lung Cancer Survivorship Care Specialists: The Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program

J. L. Studts, PhD<sup>1</sup>; J. Burris, PhD<sup>1</sup>; M. Andrykowski, PhD<sup>1</sup>; T. Schapmire, PhD<sup>2</sup>; B. Head, PhD<sup>2</sup>; M. Rigney, LICSW<sup>3</sup>; A. Criswell<sup>3</sup>; S. Arnold, MD<sup>1</sup>; A. Yates<sup>1</sup>; C. Blair<sup>1</sup>; A. Christian<sup>1</sup>  
<sup>1</sup> University of Kentucky, <sup>2</sup> University of Louisville, <sup>3</sup> Lung Cancer Alliance

## Background

The **Kentucky LEADS Collaborative** (*Lung Cancer Education, Awareness, Detection, and Survivorship*) is a community-engaged effort developed by the University of Kentucky, the University of Louisville, the Lung Cancer Consortium to promote lung cancer survivorship in Kentucky.

In addition to the *Survivorship Care Program* Component, the **Kentucky LEADS Collaborative** is dedicated to addressing the burden of lung cancer within Kentucky through a community-engaged, multifaceted effort addressing *Provider Education and Prevention and Early Detection*.



## The Burden of Lung Cancer

*Individuals diagnosed with lung cancer face substantial burden*

**Lung Cancer Survivors are likely to experience:**

- 1) ...clinically-relevant levels of distress
- 2) ...prominent symptom burden
- 3) ...multiple health-compromising behaviors
- 4) ...substantial stigma as well as self-blame
- 5) ...lower levels of social support (complicated)
- 6) ...substantially *less* engagement and motivation for care
- 7) ...barriers to access care, survivorship care, in particular

## Introduction

Recent advances in early detection and treatment of lung cancer have created an emergent need for survivorship care interventions dedicated to supporting quality of life and reducing the burden of lung cancer following diagnosis. Based on principles of shared decision making and motivational interviewing, the Kentucky LEADS Collaborative developed a precision psychosocial intervention to address the unique experiences and challenges of individuals diagnosed with lung cancer and their caregivers. The aim of this study was to evaluate the impact of the first phase of a multicomponent program developed to train survivorship care specialists to deliver the new intervention.

## Research Methods

Participants included 20 Survivorship Care Specialists employed by 9 different lung cancer care facilities across Kentucky. Participants completed three waves of surveys evaluating their knowledge, attitudes, and practices regarding lung cancer survivorship care. After the baseline survey, participants received 10 hours of online training (i.e., oral presentations, slides, and video-recorded vignettes), and completed a second survey.

## Survivorship Care Specialist Training

Survivorship Care Specialists receive training, supervision, and consultation throughout the intervention via four mechanisms:

- The **online continuing education training** provides an introduction and overview to the theoretical foundations of the intervention as well as a detailed description of each module. The online training also includes video vignettes that demonstrate an aspect of each module.
- The **intervention training manual and workbook** offers additional details regarding the structure and content of the intervention, including sample activities and forms to be used in sessions.
- The **in-person intervention training** involves a group meeting with trainers and survivorship care specialists that provide in-depth discussion and preparation for implementation.
- The **online learning community** offers a platform for ongoing communication and supervision among survivorship care specialists.



## Participants

- Participants were female (100%), and were an average age of 45.84 (11.39) years.
- The majority of participants had nursing training (65%), with oncology social work (20%) and psychology represented (10%).
- Most participants (75%) practiced in a rural outpatient setting, and they had practiced for an average of 19.50 (10.46) years in their current profession.

## Measures

Participants completed self-report measures of background data, several measures related to lung cancer survivorship, and feedback regarding the online training program.

**Baseline Survey**  
 Demographic Questions  
 Practice Characteristics  
 Knowledge (Subjective)  
 Confidence in Practice  
 Comfort in Practice  
 Practice Intentions  
 Lung Cancer Attitudes  
 Lung Cancer Stigma  
 Lung Cancer Empathy  
 Lung Cancer Care Attitudes

**Subsequent Surveys**  
 Knowledge (Subjective)  
 Confidence in Practice  
 Comfort in Practice  
 Practice Intentions  
 Lung Cancer Attitudes  
 Lung Cancer Stigma  
 Lung Cancer Empathy  
 Lung Cancer Care Attitudes  
 Acceptability  
 Narrative Feedback

## Survivorship Care Module Topics

The Intervention consists of twelve modules, including one for Caregiver participants only:

1. Lung Cancer Basics
2. Navigating the Healthcare System
3. Coping with Pain
4. Coping with Fatigue
5. Coping with Sleep Problems
6. Coping with Distress
7. Coping with Shortness of Breath
8. Social Support
9. Clarifying Values and Making Decisions
10. Healthy Living
11. Tobacco Use
12. Caregiver Self-Care and Concerns



Participants receive workbooks that include background information as well as accompanying activities, materials, and resources supporting the focus of the module.

## Implementation Partner Sites

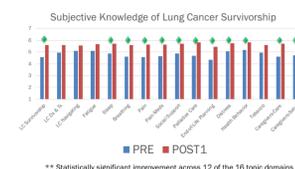


1. Baptist Health, Madisonville
2. Brown Cancer Center, Louisville
3. Ephraim McDowell Commonwealth Cancer Center, Danville
4. Hardin Memorial Hospital and Cancer Center, Elizabethtown
5. Hazard Appalachian Regional Healthcare, Hazard
6. King's Daughters Medical Center, Ashland
7. Markey Cancer Center, Lexington
8. Norton Cancer Institute, Louisville
9. Owensboro Health, Owensboro
10. St. Clair Regional Medical Center, Morehead

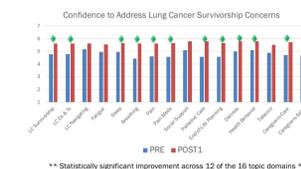
## Results

**All participants (100%) indicated that they would recommend the training program to a colleague and provided favorable narrative feedback.**

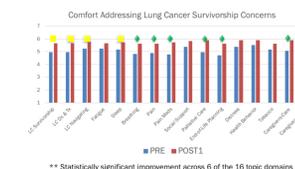
Participants reported substantially increased subjective knowledge of LC Survivorship.



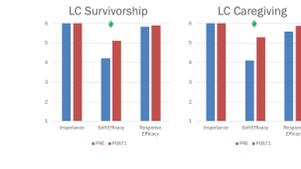
Participants reported consistently increased confidence to address LC Survivorship.



Participants reported generally increased comfort addressing LC Survivorship.

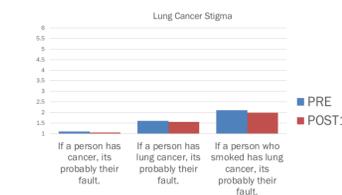


Participants reported more favorable attitudes toward LC Survivorship & Caregiving.

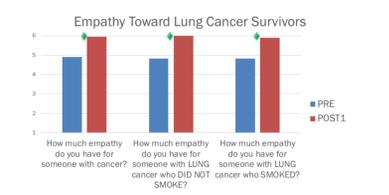


## Results

Participants reported no changes in LC stigma (very low).



Participants reported significantly increased empathy toward lung cancer survivors.



## Summary

- The **Kentucky LEADS Collaborative Survivorship Care Program** is a novel, precision survivorship care effort to promote quality of life and well-being among individuals diagnosed with lung cancer and their caregivers.
- **Preliminary conclusions...**
  - Strong, favorable response to online training
  - Significant improvement in knowledge
  - Significant improvement in comfort
  - Significant improvement in self-efficacy
  - Significant improvement in empathy
- **Limitations**
  - Small sample
  - No control condition
  - Short-term assessment
- **Future**
  - Evaluation of in-person training
  - Evaluation of impact throughout implementation

## Conclusions

Survivorship Care Specialists could play a central role in supporting quality of life following lung cancer, but little data is available to guide their training or clinical efforts. These early results suggest consistently beneficial effects of an online lung cancer survivorship training program designed to prepare individuals to provide precision psychosocial care to individuals diagnosed with lung cancer and their caregivers.

## Learn More and Connect with Us

- [www.kentuckyleads.org](http://www.kentuckyleads.org)
- [kyleads@uky.edu](mailto:kyleads@uky.edu)
- Kentucky LEADS Collaborative (Facebook)
- @KentuckyLEADS (Twitter)
- KentuckyLEADS (Instagram)

## Acknowledgments

- The KY LEADS Collaborative is supported by a generous grant from the Bristol-Myers Squibb Foundation's Bridging Cancer Care grant mechanism.



- Additional support provided by the Behavioral and Community-Based Research Shared Resource Facility and the Cancer Research Informatics Shared Resource Facility at the Markey Cancer Center, University of Kentucky, an NCI-designated Cancer Center (P30 CA177558).

# THE NATIONAL LUNG CANCER SUPPORT GROUP NETWORK: FINDING WHAT WORKS



MAUREEN RIGNEY, LICSW

## BACKGROUND

People diagnosed with lung cancer have greater unmet emotional needs and higher levels of distress than those diagnosed with other types of cancer.

Survivors often prefer lung cancer-specific groups to those for all cancers, but lung cancer groups can be challenging to start and maintain. At any given time, there are typically fewer than 100 lung cancer groups active in the US.

To increase the availability of support groups and learn more about the group process, the National Lung Cancer Support Group Network was created with these aims:

- Establishing seven groups in Tobacco Belt states
- Strengthening existing groups
- Connecting facilitators

New groups include assessment of group impact on quality of life, satisfaction and the value of participation. This part of the project ends in October of 2018 but other Network activities will continue.

## CONNECTING FACILITATORS

- Facilitators are kept up-to-date on the network through a quarterly e-newsletter.
- A formal mentorship program is being established to connect those starting groups with successful facilitators for support and tips.
- Based on survey results, a quarterly webinar series on topics of interest to facilitators is being designed.

## STRENGTHENING GROUPS

LCA provides personalized assistance to new/existing facilitators and offers the *Lung Cancer Support Group Troubleshooting Guide*, Created with the results of a survey of facilitators in the US, UK and Australia, the guide provides tips and creative solutions to overcoming the challenges of starting groups.

Available to new and existing facilitators, Network members were asked to share additional troubleshooting tips and best practices. The updated Guide will be available in June 2018.

## ESTABLISHING NEW GROUPS

With one exception, groups were started with no prior relationship with Lung Cancer Alliance. Overall project challenges included engaging facilities, overcoming suspicion and managing bureaucratic and IRB-related delays.

### Group #1: Gilda's Club, Nashville TN

**Successful.** Born of an existing relationship and actively supported by a survivor volunteer. The project end was February 2017 and the group remains very active.

**Lessons learned:** Established relationships and trust speed the process. The support of a long-term survivor, this setting and their support group expertise were invaluable.

### Group #2: Merit Health, Jackson MS

**Unsuccessful.** Started by a passionate but novice facilitator in a problematic region, it lasted less than four months.

**Lessons learned:** A general cancer support group need to exist. Enthusiasm doesn't insure success. Place matters.

### Group #3: Cornucopia Cancer Support Center, Durham NC

**Reorganizing.** Ideally located in an independent support center with dedicated, professional facilitators in an area that draws from three major cancer centers has only had five attendees over time.

**Lesson learned:** Sometimes everything is right and the group still struggles.

### Group #4: West Virginia University Cancer Center, Morgantown WV

**Rebuilding.** 18 individuals attended over time but the group failed to consistently coalesce. Latest facilitator seems dedicated.

**Lessons learned:** Consistent facilitators is vital. A doctor champion is helpful.

### Group #5: Northeast Georgia Medical Center, Gainesville GA

**Reorganizing.** 12 individuals attended over time. Attendee death had a strong impact. Lack of institutional/marketing support.

**Lessons learned:** A system with several locations may find more support through moving the group.

## ESTABLISHING NEW GROUPS, CONT'D

### Group #6: Redmond Regional Medical Center, Rome GA

**Unsuccessful.** Only two individuals attended over time.

**Lessons learned:** Facilitators need to recognize the time and dedication successful groups require. A community needs assessment would have helped.

### Group #7: Greenville Health Systems, Greenville SC

**Successful.** Eager, engaged attendees. Institutional support. Dedicated facilitator who brought two group members to the LCA Advocacy Summit in 2017.

**Lesson learned:** Sometimes everything is right and the group thrives.

### Group #8: University of South Carolina, Columbia SC

**Successful.** Filling a gap left by prior lung cancer group. Motivated individuals, many of whom already knew each other. Institutional support. Dedicated facilitator. Pleasant setting.

**Lesson learned:** The best groups truly meet the needs of the community.

**OVERALL lesson learned:** Once committed, facilitators are hesitant to give up on a group.

## RESEARCH METHODS

New groups survey participants via pencil-and-paper questionnaires, using a pre/post test design,

The baseline questionnaire includes:

- CancerSupportSource@(CSS)-15 Distress Screening Tool
- Positive Affect Scale of PANAS
- UCLA 3-item Loneliness Scale

Follow-up questionnaires, administered after six months of attendance, include:

- CSS-15 Distress Screening Tool
- Positive Affect Scale of PANAS
- UCLA 3-item Loneliness Scale
- Additional self-efficacy measures
- 14 questions on group helpfulness

## DEMOGRAPHICS TO DATE

All groups include lung cancer survivors, spouses/partners and other loved ones.

Seventy-seven participants completed the baseline questionnaire. Seventeen have thus far completed both baseline and follow-up questionnaires. Of those 17, most were:

- Patients/survivors (82%)
- Diagnosed at stage III or IV (59%)
- White (94%)
- Female (59%)

Reasons for non-completion included the participant:

- Dropped out of the group
- Died
- Had not yet reached 6 months
- Declined to complete the follow-up questionnaire

## RESULTS TO DATE

These results only reflect the 17 completed baseline and follow up questionnaires.

### Self-Efficacy

100% agreed or strongly agreed that after attending the group, they felt confident in:

- Asking their healthcare team questions about treatments and side effects
- 99% (n=16) agreed or agreed strongly that after attending the group, they felt confident in:
- Making treatment decisions
  - Accessing information and resources

### Helpful Group Experiences

Highest scores were reported for:

- Feeling a sense of belonging
- Receiving support and encouragement
- Developing

Lowest scores were reported for:

- Feeling as though they confronted difficult problems
- Talking about recurrence fears

**100% said they would recommend the group to others.**

## COMMENTS

Participants are invited to include comments on their group experience at 6 month follow-up.

***This is a loving, supportive, encouraging and inspiring group.***

***It helps to be in the company of fellow travelers.***

***It's reassuring to be around others that are in similar situations to share and hear what someone else may have experienced and helps relieve stress levels.***

***Every lung cancer patient needs this.***

## CONCLUSION

Although thus far, only 17 baseline and follow-up questionnaires have been submitted, these results suggest positive potential impact and benefit of lung cancer support groups, particularly with regard to improving quality of life through reductions in distress.

## THANKS

- Dr Joanne Buzaglo and colleagues at the Cancer Support Community's Research and Training Institute for their data analysis.
- All the facilitators who work so hard to improve the lives of the lung cancer community
- Bristol Myers-Squibb Foundation for their support of this project.

## CONTACT

MAUREEN RIGNEY, LICSW  
Director of Support Initiatives  
mrigney@lungcanceralliance.org