

Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program: A Model for Lung Cancer Survivorship Care

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Objective

- Introduce the Kentucky LEADS Collaborative
- Introduce the Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program as a model for supporting quality of life, symptom management, and behavior change following a diagnosis of lung cancer
- Present early feedback regarding the feasibility and acceptability of the program





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\$7.0 million grant from BMSF

- Lung Cancer
- Education
- Awareness
- Detection
- Survivorship



Bristol-Myers Squibb
Foundation



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Kentucky LEADS Collaborative

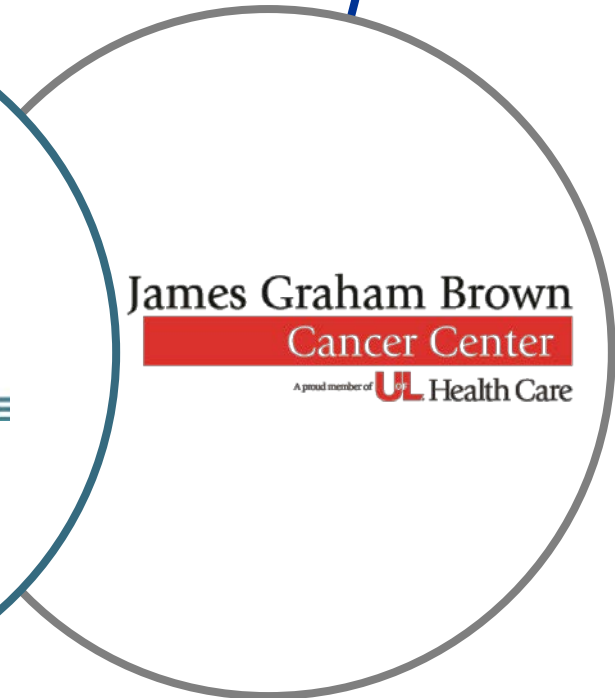
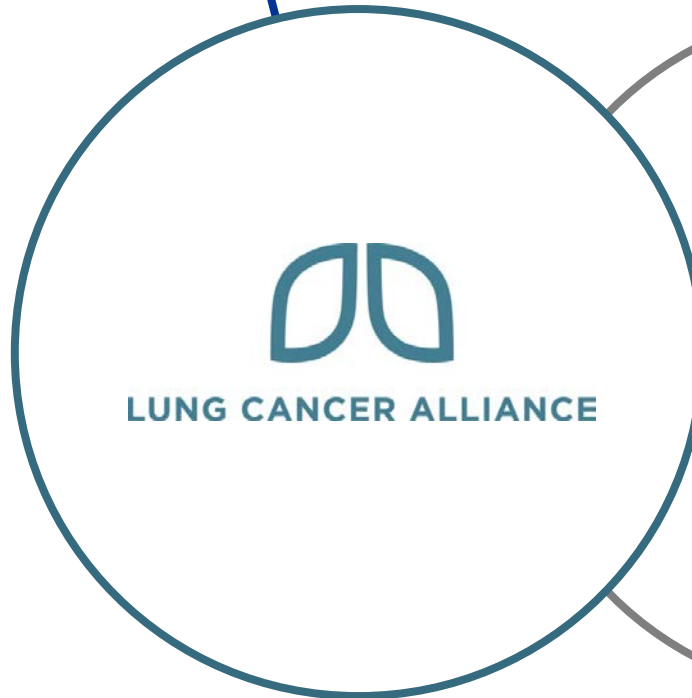
“Dedicated to reducing the burden of lung cancer in Kentucky and beyond through development, evaluation and dissemination of novel, community-based interventions to promote provider education, survivorship care and prevention and early detection regarding lung cancer.”

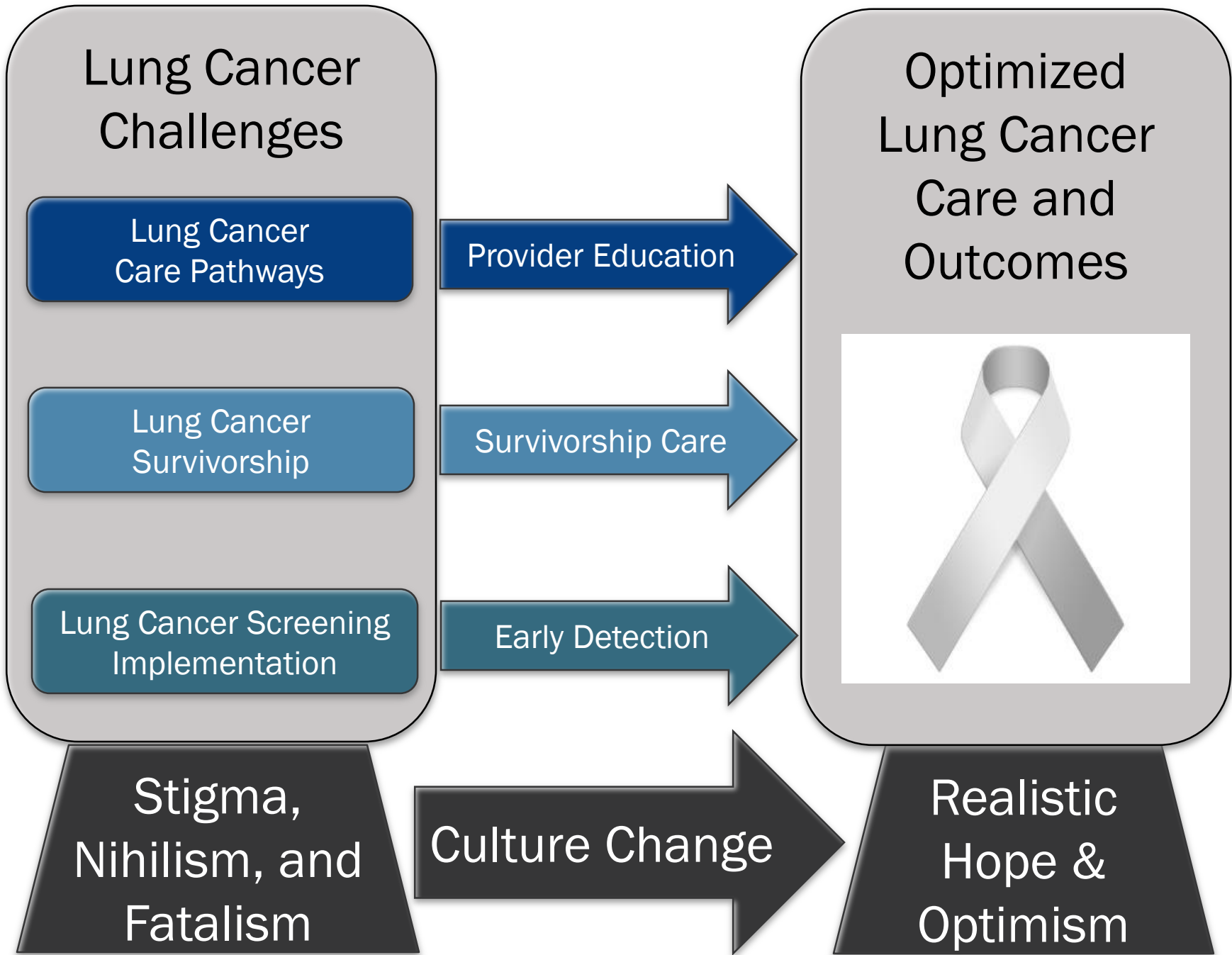


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Lung Cancer Challenges

Lung Cancer Care Pathways

Lung Cancer Survivorship

Lung Cancer Screening Implementation

Provider Education

Survivorship Care

Early Detection

Stigma, Nihilism, and Fatalism

Culture Change

Optimized Lung Cancer Care and Outcomes



Realistic Hope & Optimism

Kentucky LEADS Collaborative

Fundamental Principles

■ Community-Engaged

- Over 15 implementation sites throughout KY
- Over 20 additional community partners & organizations
- Integration of community and medical advisory boards

■ Interdisciplinary

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

■ Multi-Level

- Healthcare providers
- Individuals diagnosed with LuCa and Caregivers
- Health Systems/Lung Cancer Screening Programs

The Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program



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THREE QUESTIONS

What is the experience of lung cancer survivors?

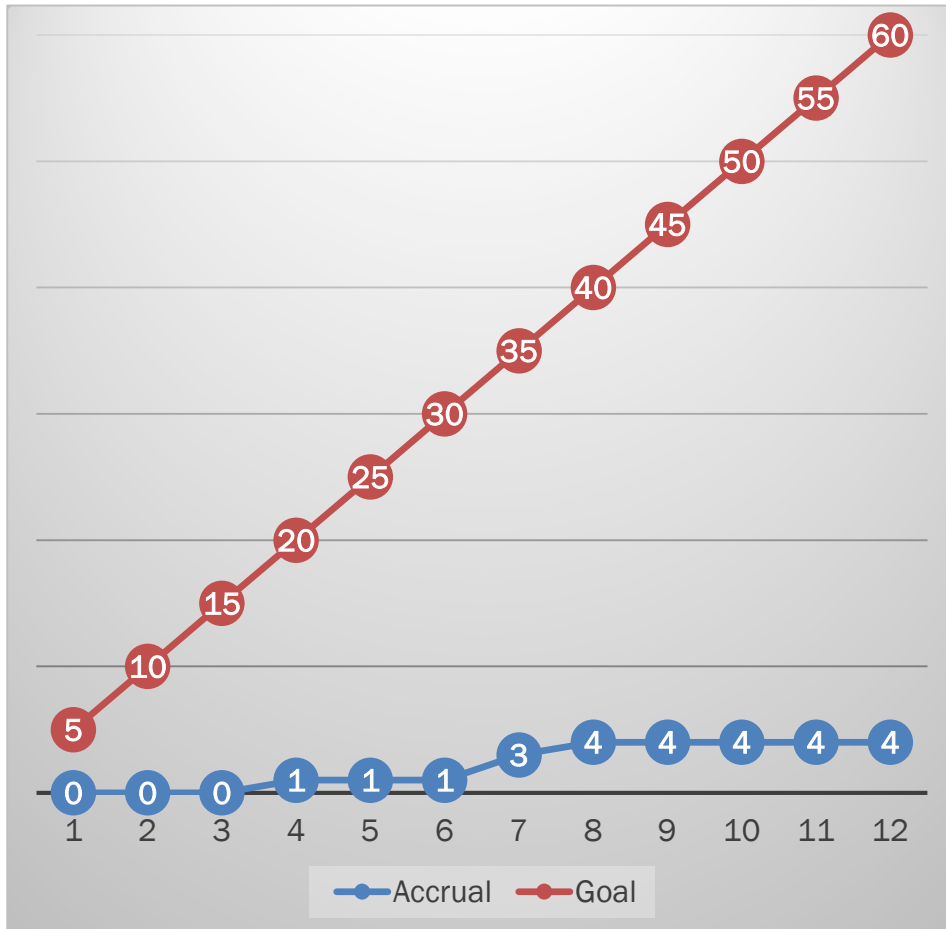
What would we like the experience of lung cancer survivors to be?

How should we approach lung cancer survivors?

**Why
focus
on
*Lung
Cancer
Survivors?***

- Incidence burden
- Innovations in care
- Symptom burden
- Unique community
- Opportunity for innovation
- Opportunity for impact
- Stubbornness

What level of interest do individuals diagnosed with lung cancer have in psychosocial programs?



- ❖ Funded Randomized Clinical Trial, comparing supportive-expressive therapy (SET) and mindfulness-based stress reduction (MBSR).
- ❖ Transitioned to a cross-sectional survey to generate some data addressing the psychosocial experience of lung cancer.

Survivorship Care (SC) Team

University of Kentucky

- Jamie L. Studts (PI)
- Michael Andrykowski (Co-I)
- Robin Vanderpool (Co-I)
- Jessica Burris (Co-I)
- Cynthia Robinson (Co-I)
- Susanne Arnold (Co-I)
- Courtney Blair (PD)
- Amy Christian (RA)
- Allyson Yates (Project Manager)



University of Louisville

- Tara Schapmire (Co-I)
- Barbara Head (Co-I)



Lung Cancer Alliance

- Maureen Rigney (Co-I)
- Angela Criswell (KFC)

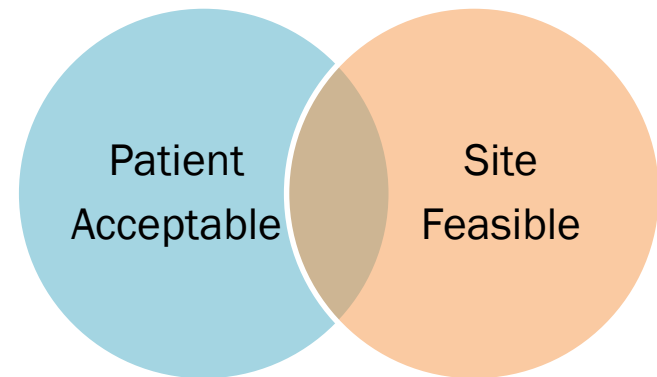


Survivorship Care Intervention

Guiding Principles

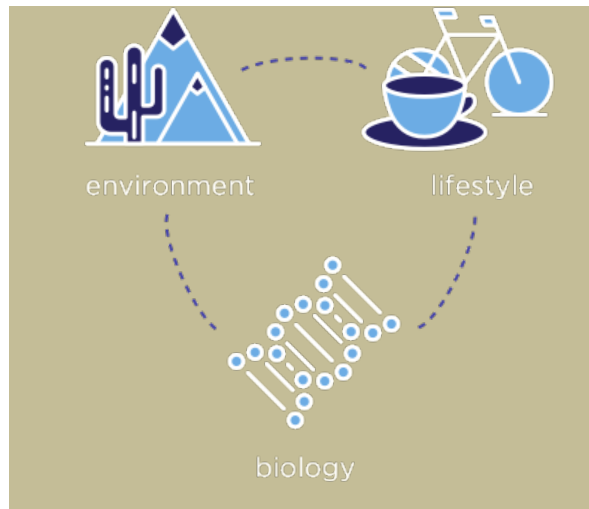
■ *Designed for Dissemination*

- Acceptable
- Feasible
- Intervention Delivery
 - In-person, telephone, telemedicine, other
- Interventionists
 - Any survivorship care specialist identified by site
- Targeted and Tailored Content
 - Lung cancer targeted
 - Patient/Caregiver tailored (survivor/provider)



Precision Medicine

is an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.

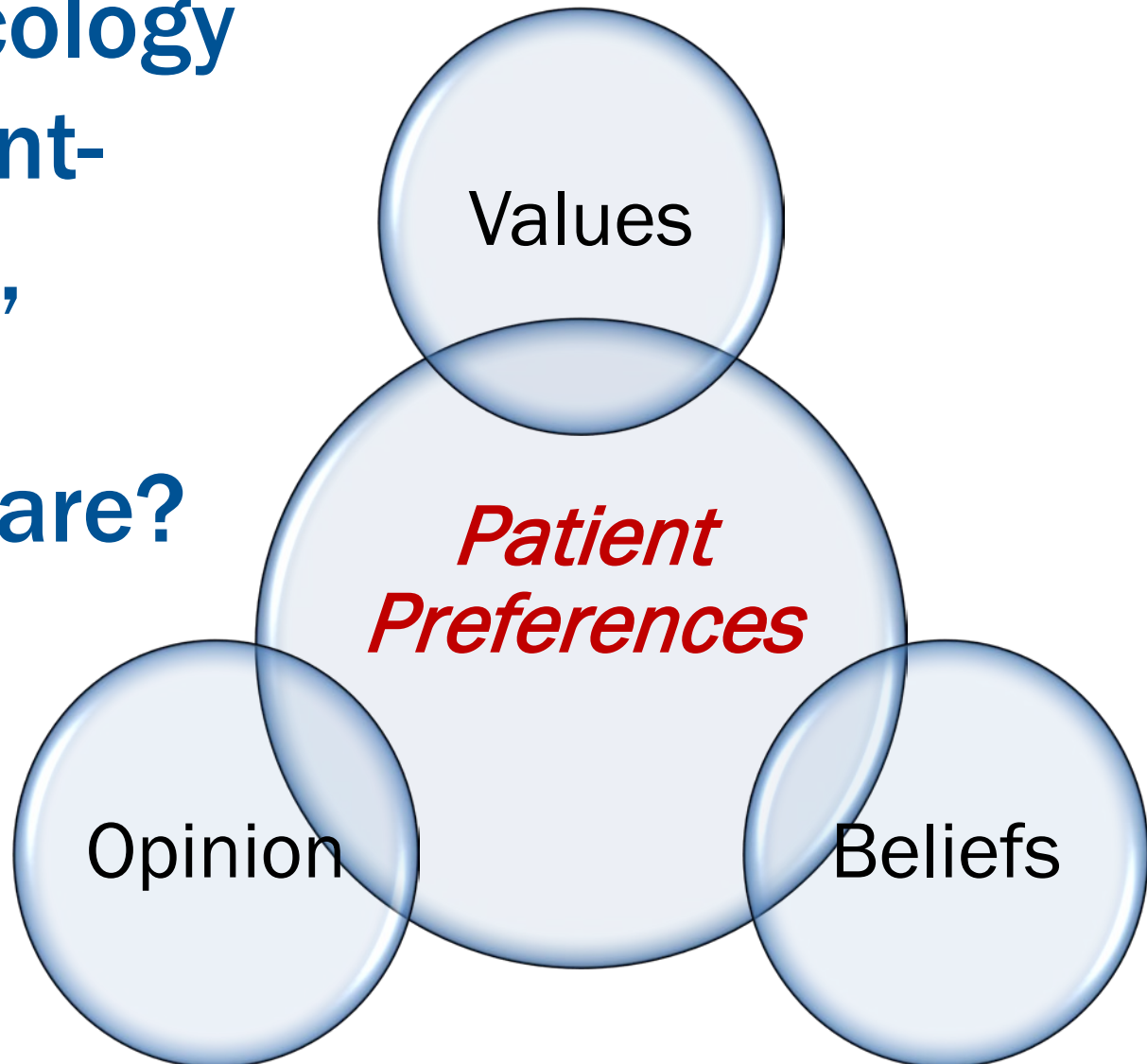


NATIONAL CANCER INSTITUTE PRECISION MEDICINE IN CANCER TREATMENT

Discovering unique therapies that treat an individual's cancer based on the specific genetic abnormalities of that person's tumor.

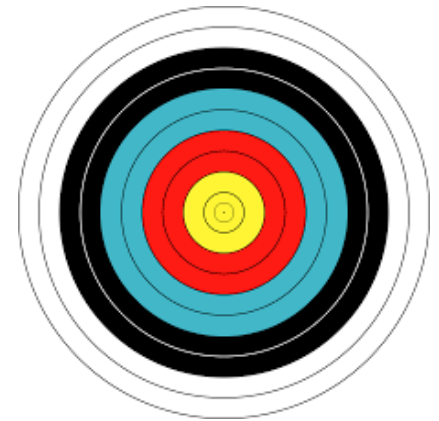


How might precision
medicine/oncology
apply to patient-
centered care,
including
survivorship care?



Precision Survivorship Care

- The Kentucky LEADS Collaborative Lung Cancer Survivorship Care Program is a *Precision Medicine* approach to Survivorship.
 - By design, the intervention *targets* the most prevalent and distress symptoms and challenges associated with a lung cancer diagnosis.
 - By integrating patient preferences, the intervention is *tailored* to the unique needs of the survivor, the preferred delivery method, and the desired level of involvement of the social support network.



Patient-Centered Care Principles

■ Partnering/Supportive Counseling Style

- Rogerian/Motivational Interviewing
- Coping with/Addressing stigma concerns

■ Shared Decision Making (SDM)

- Adaptable (targeted and tailored content) that follows from Baseline Assessment and patient preferences
- Effort to maximize survivor acceptability of the intervention



Motivational Interviewing (MI)

Motivational interviewing is a skillful clinical style for eliciting patients' own good motivations for making behavior change in the interest of their health.

- Rollnick, Miller, & Butler (2007) Motivational Interviewing in Health Care.

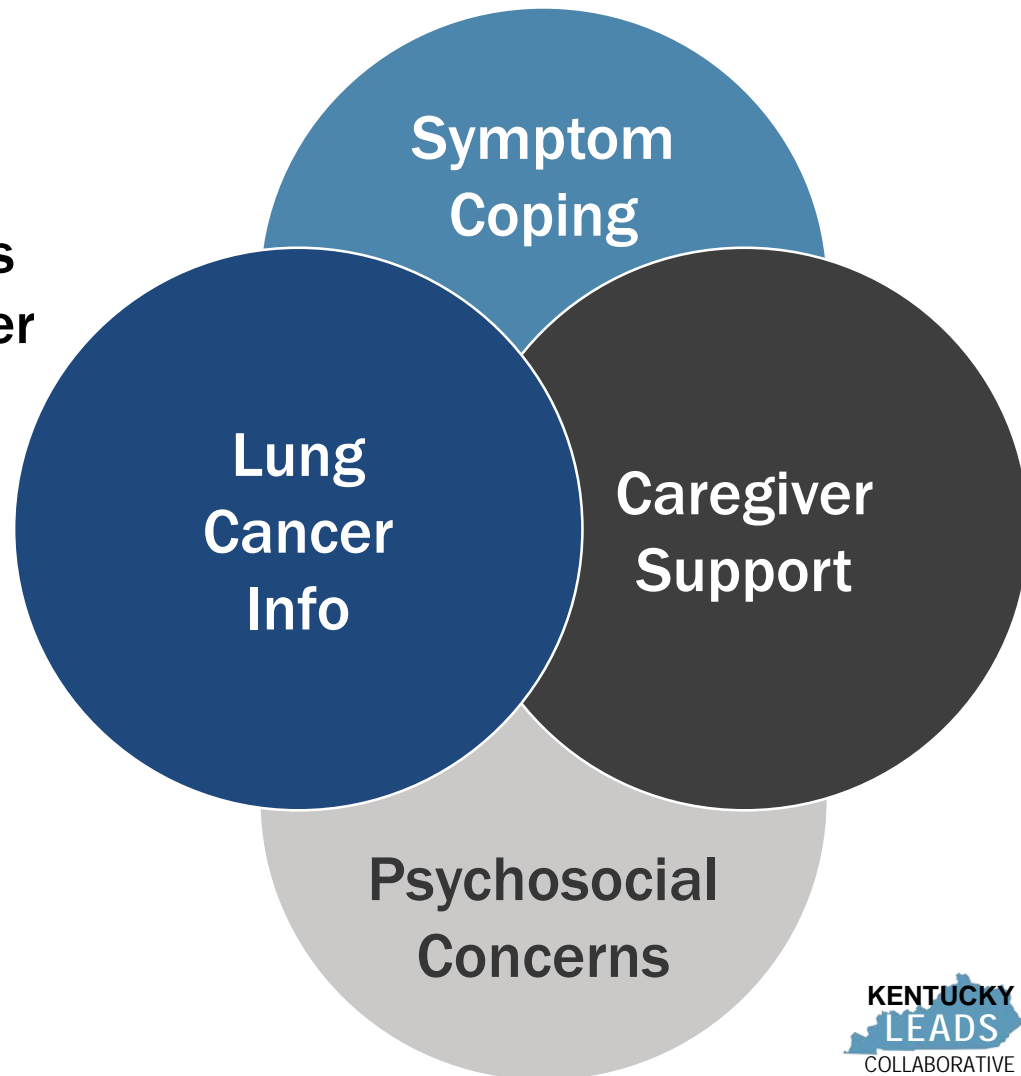
Shared Decision Making (SDM)

- Shared Decision Making (SDM) is a collaborative process that allows patients and their providers to make health care decisions together. It takes into account the best clinical evidence available, as well as the patient's values and preferences.
- SDM is a process, not a goal. The goal is better health decisions to achieve outcomes that matter most to the patient. SDM is a way to reach that goal.
- A proven process to incorporate the patient's voice in health care decisions, shared decision making is the pinnacle of patient-centered care.

Survivorship Care (SC)

Patient and Caregiver Intervention

- Built and implementing a novel psychosocial survivorship care intervention for individuals diagnosed with lung cancer and their caregivers (10 sites, 300 participants)
- Four key domains
 - Lung cancer info
 - Symptom coping
 - Psychosocial concerns
 - Caregiver support



Patient Modules (Session Topics)

- 1) Lung Cancer Basics
 - 2) Navigating the Healthcare System
 - 3) Coping with Pain/Addiction Concerns
 - 4) Coping with Fatigue
 - 5) Coping with Sleep Problems
 - 6) Coping with Shortness of Breath
 - 7) Coping with Distress
 - 8) Social Support
 - 9) Values and Decision Making
 - 10) Healthy Living
 - 11) Tobacco Use
 - 12) *Caregiver Concerns and Self-Care*
-
- Lung Cancer Info (2)
- Symptom Coping (4)
- Psychosocial Concerns (5)
- Caregiver Support (1)

Survivorship Care (SC) Aims and Hypotheses

- We hypothesize that the LC Survivorship Care Intervention and Training Program will:
 - 1) improve quality of life, better symptom control, increase tobacco treatment, and reduce distress among lung cancer survivors.
 - 2) improve quality of life, increase tobacco treatment, and reduce distress among family members/caregivers of individuals diagnosed with lung cancer.
 - 3) increase self-efficacy and skills in providing lung cancer survivorship care among program providers (e.g., nurses, social workers, navigators, psychologists, etc.).

Survivorship Care (SC) Program Acceptability and Feasibility

- Determine program *acceptability* among LC survivors
 - Participant program recommendations to others
 - Participation satisfaction ratings
 - Percentage of planned modules delivered to survivors
- Determine methodological *feasibility* of the study design and procedures for coordinating center and implementation sites
 - Intervention accrual rate
 - SC specialists intervention feasibility
 - Participant survey completion rate
 - Participant drop-out rate
 - Participant missing data rate

This trial is registered with [clinicaltrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02989974) ([NCT02989974](https://clinicaltrials.gov/ct2/show/study/NCT02989974)).

Survivorship Care (SC) Specialist Training Program

Online CE
Intervention
Training

Training
Manual

In-Person
Module
Training


Learning
Community

- A sustainable companion training program to support KY LEADS SC Specialists in their work with the program.

- Training Program
 - Online CE Program
 - Training Manual
 - Survivor/Caregiver Workbook

SC Specialist Treatment Manual & Survivor Workbook

Kentucky Lung Cancer
Survivorship Care Program




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Survivorship Care Specialist Manual

428 “spell-binding” pages

Kentucky Lung Cancer
Survivorship Care Program



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Survivor Workbook

270 “riveting pages”

Survivor and Caregiver Eligibility & Accrual Process

■ Inclusion Criteria

- History of lung cancer diagnosis
- Anyone over age 18 with a diagnosis of lung cancer
- Ability to communicate verbally in English

■ Exclusion Criteria

- Serious mental illness that would preclude participation
- Substance abuse that would preclude participation

■ Accrual Process

- Within the standard site process
- Preferred:
 - Oncologist recommendation → research coordinator and SC Specialist contact

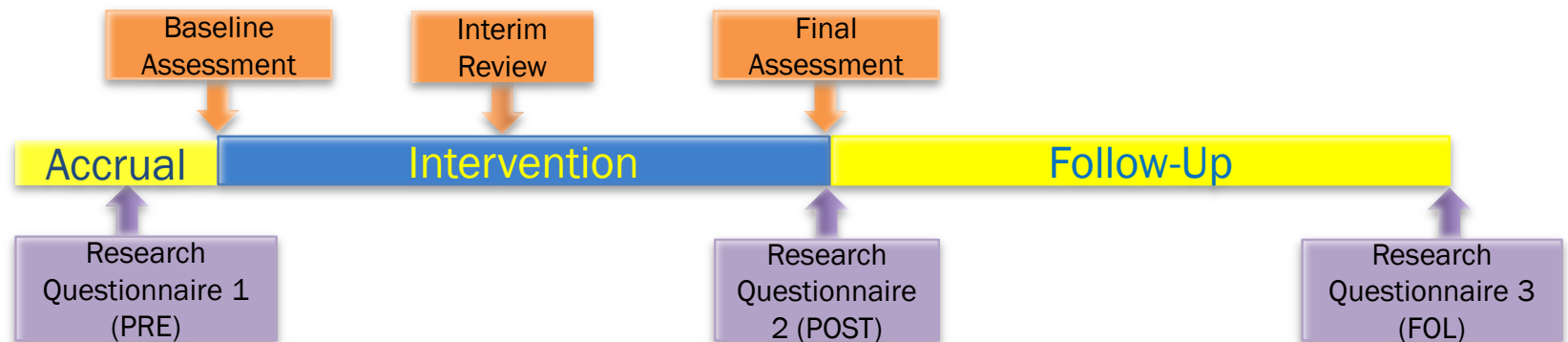
Survivorship Care Specialist and Research Coordinator Trainings

- Online, in-person Trainings, and ongoing peer supervision
- Successfully trained 20 Survivorship Care Specialists from 9 sites across Kentucky.
- Successfully trained 12 Research Coordinators from 9 sites.
- Some cross-trained professionals.
- Offering additional trainings as new folks come on board at implementation sites



SC Intervention Research Plan (N=300)

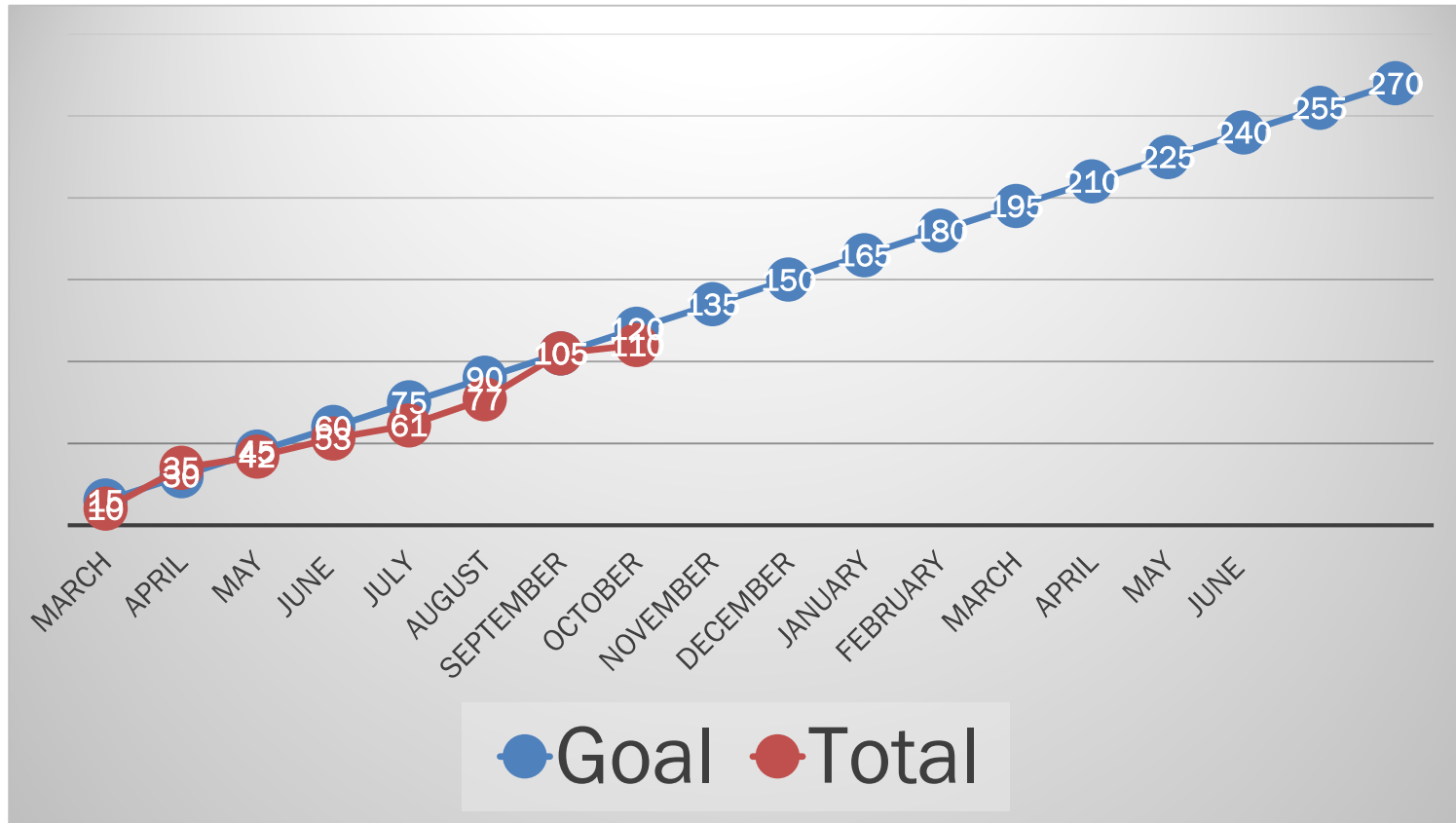
- Survivors/Caregivers (N=30 per site)
 - Quality of Life (multiple domains to match intervention)
 - Pre, Post, 6-month Post-Baseline follow-up
 - Key Informant Interviews with subset (2 per site)



What have we learned so far?

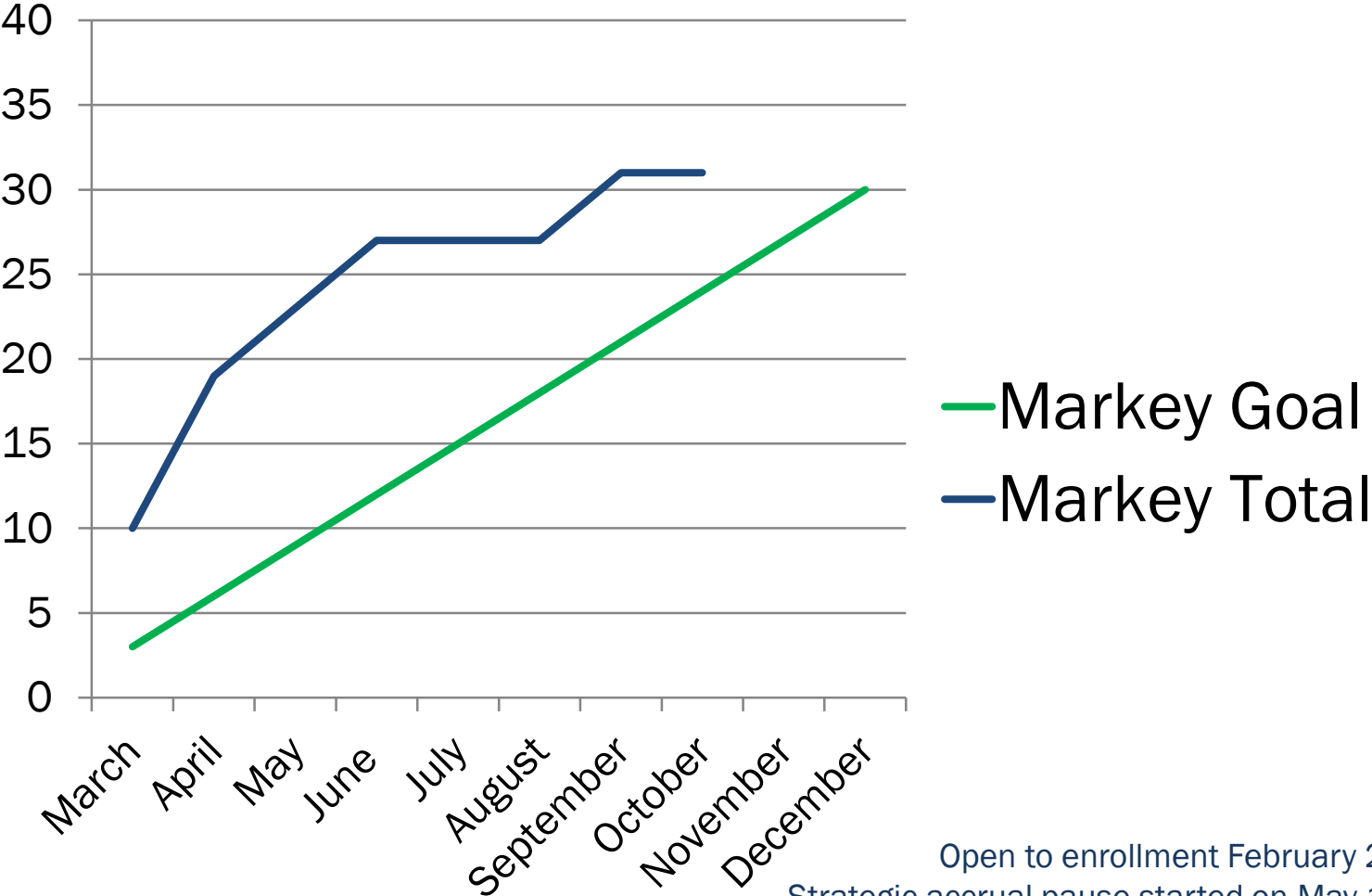


The early signal on intervention acceptability is encouraging.



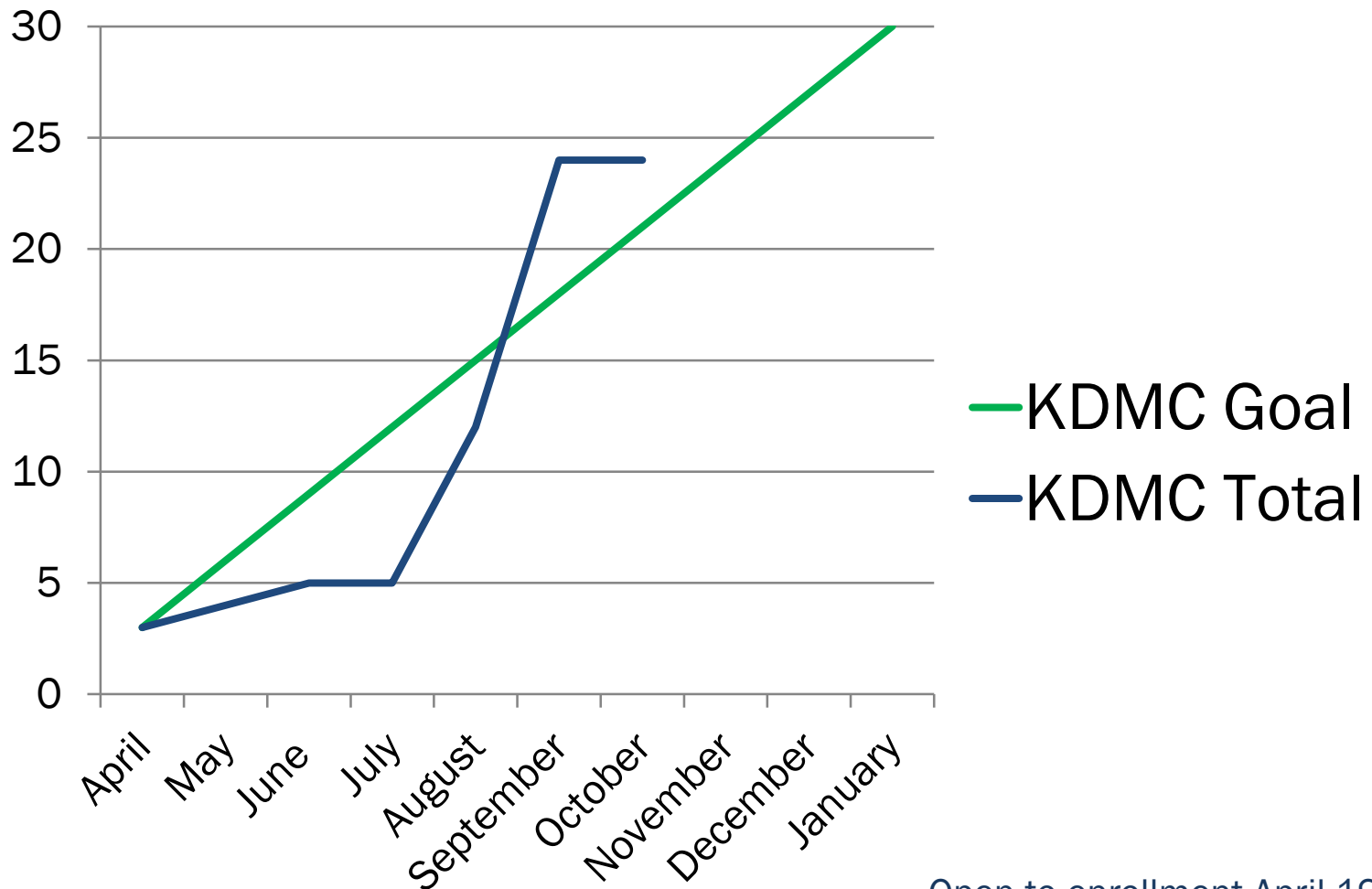
The trial has been launched at 8 of the 10 sites, but accrual has been uneven with some sites rapidly exceeding accrual expectations and other delayed in accrual.

UK Markey Cancer Center (09) Accrual Tracking



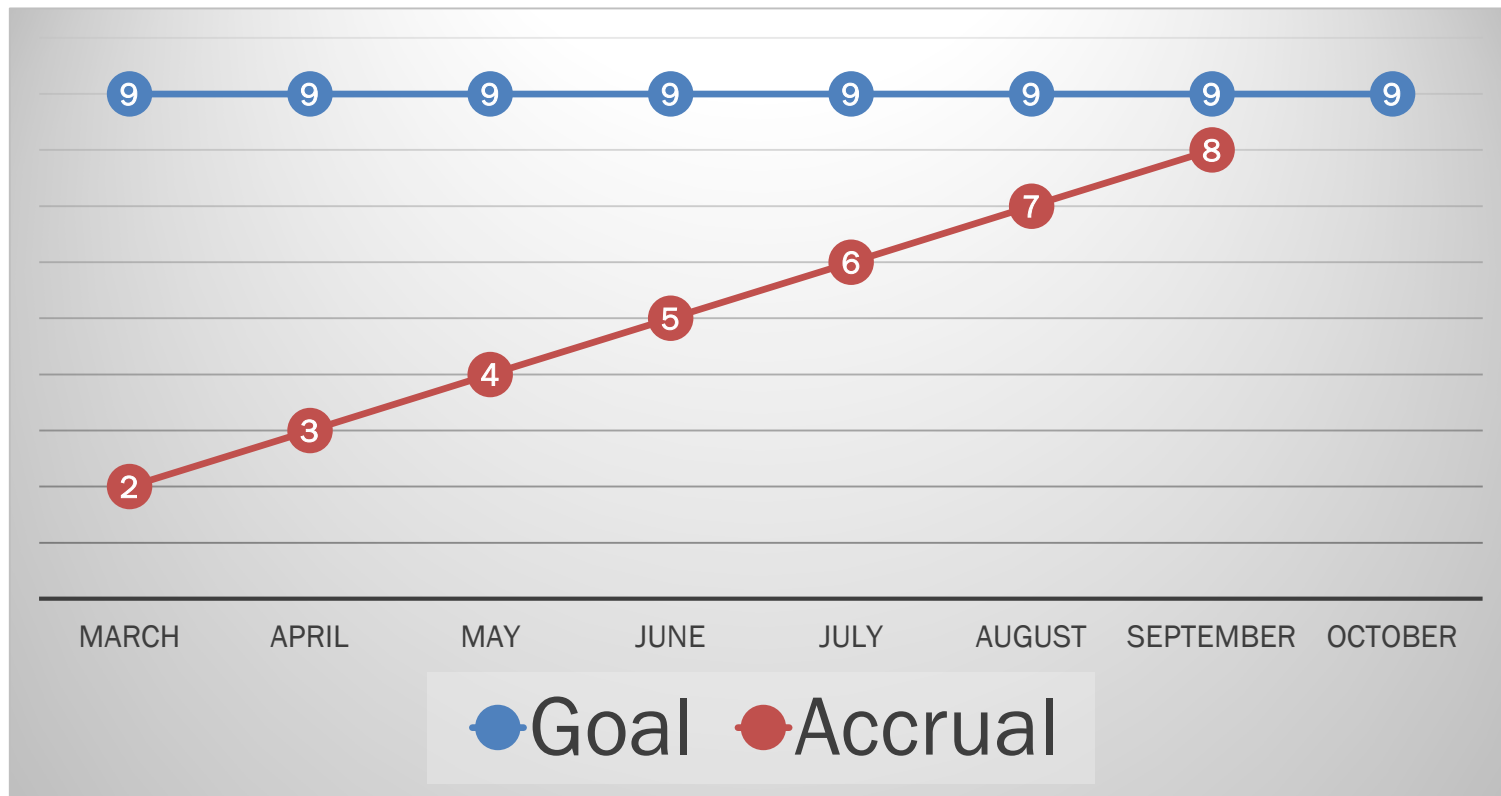
Open to enrollment February 20, 2017
Strategic accrual pause started on May 11, 2017
Strategic accrual continued until current

King's Daughters Medical Center (05) Accrual Tracking



Open to enrollment April 19, 2017
Currently on accrual pause.

The early signal regarding intervention feasibility is also quite favorable.



The trial has been launched at 8 of the 10 sites, achieving a rate of one additional site per month.

Survivorship Care Implementation 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. Owensboro Health, Owensboro
9. St. Claire Regional Medical Center, Morehead

Response to the survivorship care specialist training platform has been consistently positive.

- High favorable training satisfaction ratings from SC Specialists after online training and in-person training.
- Statistically significant increases in SC Specialist knowledge on 12 of 16 training program module topic areas.
- Statistically significant improvements in SC Specialist confidence in 11 of 16 training program module topic areas.
- Statistically significant improvements in reported empathy among SC Specialists.

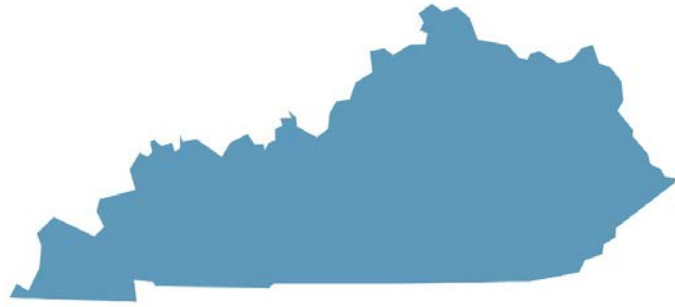
Summary

- Program development complete, but...
- Intervention training complete, but...
- Project implementation nearly complete....
- Project accrual... ongoing
- Preliminary conclusions...
 - ▢ Strong acceptability signal (accrual)
 - ▢ Strong feasibility signal (specialists)
 - ▢ Next... adherence?
 - ▢ Next... efficacy?



Conclusions (Preliminary)

- Lung cancer survivors and caregivers have unique needs that warrant novel intervention approaches.
- We have developed a precision survivorship care intervention that seeks to address the unique needs of lung cancer survivors and caregivers.
- Survivorship Care Specialists can be trained to address the unmet survivorship needs of lung cancer survivors and caregivers.
- Preliminary indicators of intervention acceptability and methodological feasibility have generated enthusiasm.
- Ongoing research will evaluate additional indicators of feasibility (program delivery and completion) and preliminary efficacy to guide subsequent research efforts.



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A special member of **UL** Health Care



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

Connect with us:

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