Advancing Quality Lung Cancer Survivorship in South Carolina

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Care Collaborations & Patient Support

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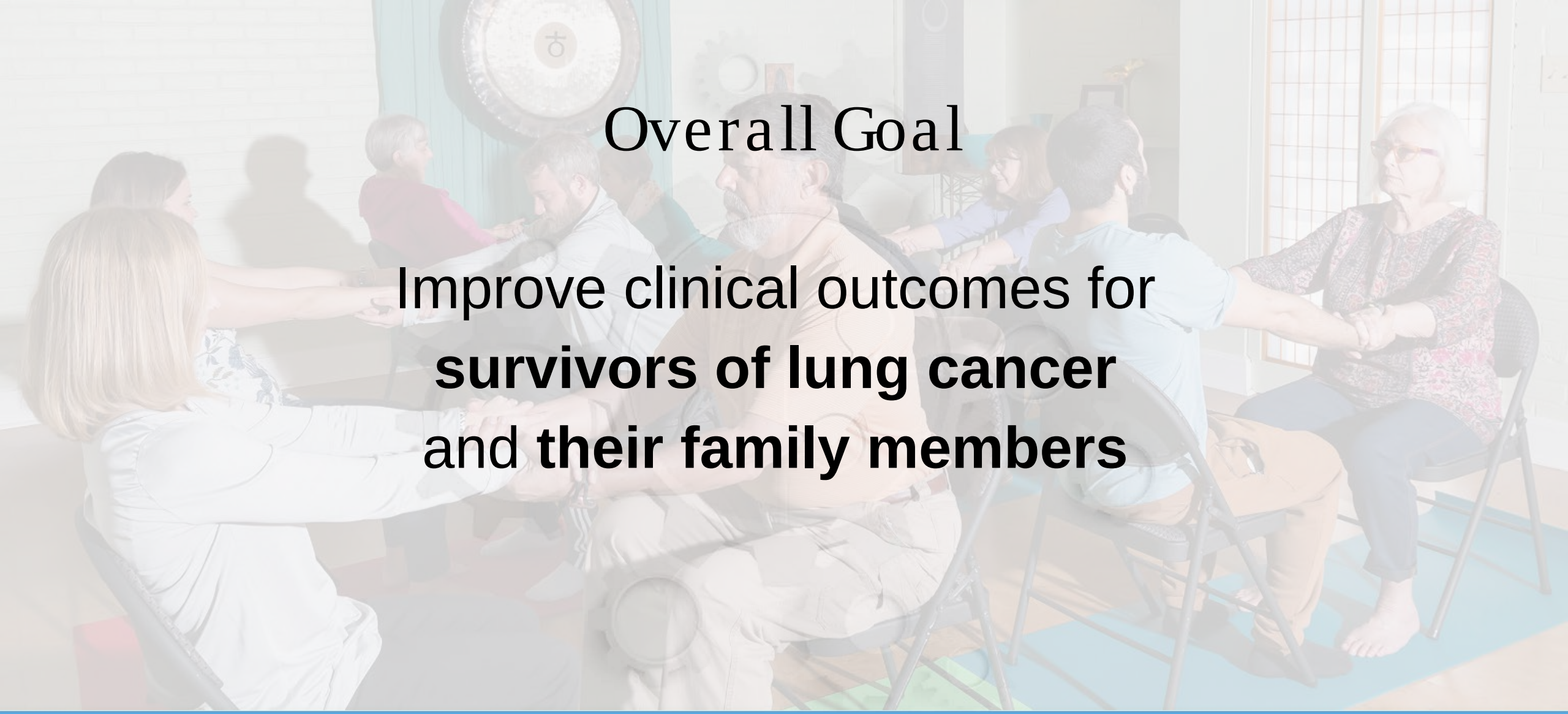

Overall Goal

Improve clinical outcomes for
survivors of lung cancer
and **their family members**

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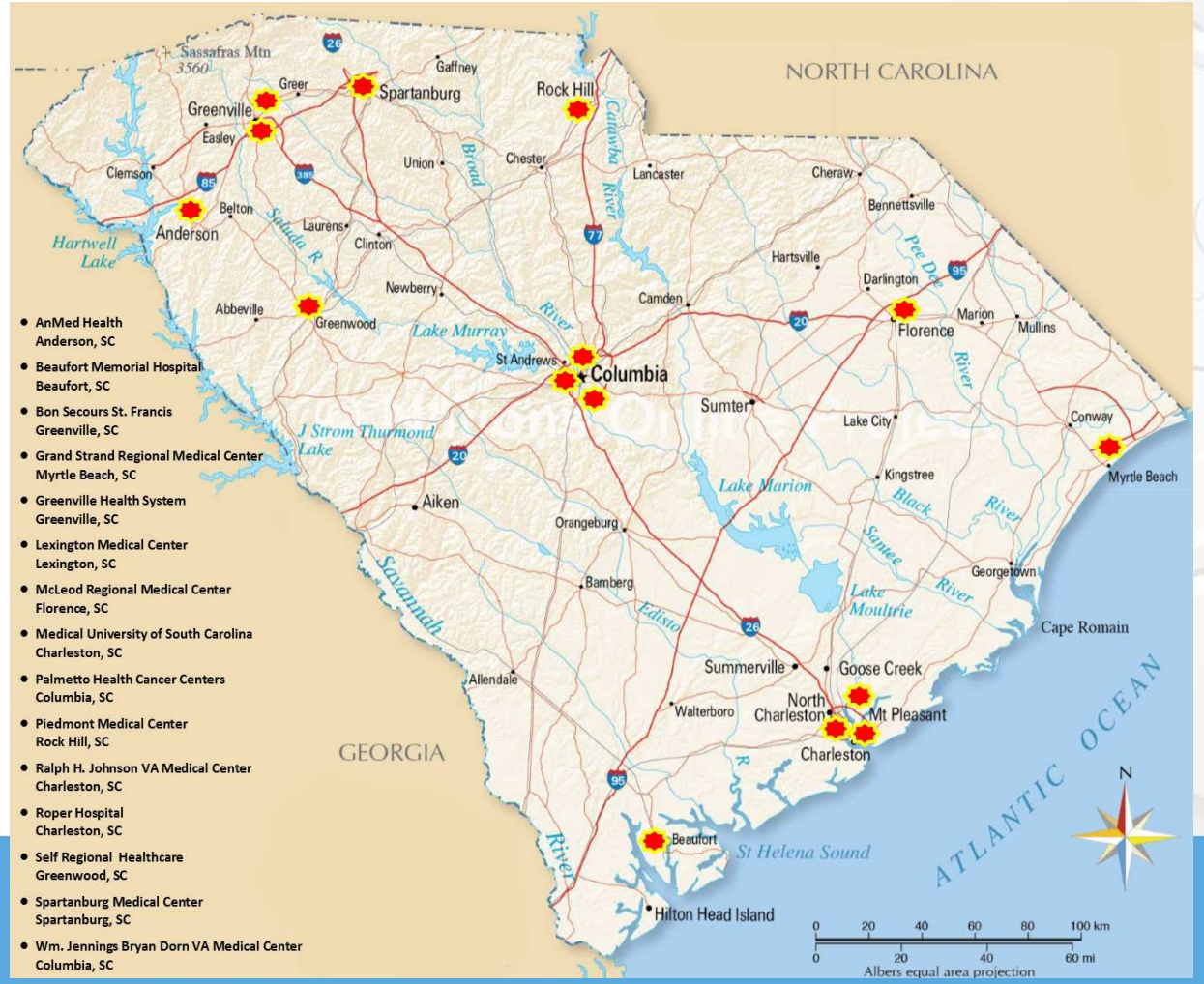
Objective #1

Develop the Partners in Quality Lung Cancer Survivorship (PIQ)

- Statewide network of community and clinical stakeholders
- Maximize community involvement and build capacity for survivorship care services in SC

Strategic Planning Process (4 Phases)



Phase 1 Collecting data from providers statewide **→100% response**

Phase 2 Interviewing survivors and family members by phone **→ 4 regions**

Phase 3 Establishing mission, vision, and values

Phase 4 Identifying objectives, goals, and priorities

→ What can we do to facilitate change in the next 3 years?

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Outcome: Strategic Goals

#1 Establish and communicate supportive community resources and evidence-based practices to enhance the care and support of survivors with lung cancer and their families.

#2 Increase the recognition and diagnosis of COPD as the major comorbidity for persons with lung cancer

#3 Increase the recognition of COPD as a risk factor for lung cancer among PCPs and the value of targeting this high-risk group for lung cancer screening

#4 Increase awareness and demand among the public of the availability of lung cancer screening in South Carolina

Objective #2a

Adapt and test the *Breathe Easier* intervention

- **Foundation**: Evidence-based Mindfulness-based Cancer Recovery program
- **Content** (8 weeks):
  - Breathing exercises
  - Mindfulness-based meditation
  - Sitting yoga + standing/floor yoga
  - Participant interaction
- **Tailored**: Addresses issues important to survivors of lung cancer and their family members
- **Research design**: Prospective, one-group, repeated measures, sequential, mixed-method
- **Feasibility**: Measured recruitment, retention, adherence, acceptability, and intervention dose
- **Preliminary outcomes**: Measured exercise capacity, dyspnea, fatigue, sleep quality and quantity, and stress

Adherence

Factors	Expectation	Actual: Survivors	Actual: FMs
Attendance[1]	80% (8 weeks) 70% (3-hr retreat)	91% 78%	90% 83%
Breath. Ex.	15.6 min/day (5 weeks)	15.8 min/day	20.9 min/day
Meditations	18.2 min/day (6 weeks)	19.5 min/day	23.7 min/day
Gentle Movements	31.5 min/day (4 weeks)	25.6 min/day	24.9 min/day

Acceptability

FM = Family Member

Acceptability Statements[2]	Survivors n (%)[3]	FMs n (%)[3]
Booklet easy to read	49 (96%)	55 (95%)
Audio recordings easy to use	49 (91%)	57 (93%)
Sharing my thoughts w/ others was comfortable	52 (97%)	58 (95%)
Learning gentle movements helped	52 (98%)	53 (90%)
Involving a family member important to survivor	53 (98%)	54 (89%)

[1] Calculated without 4 dropouts (no attendance after consent appointment).
[2] Acceptability measured by a data collection form "Acceptability Evaluation" adapted with permission from P. J. Hollen, PhD, RN, FAAN.
[3] Responses "strongly agree" and "agree" combined.

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Preliminary Outcomes

Measure	Mean for Survivors (SD) N = 21	Mean for FMs (SD) N = 21	Comparisons
Exercise Capacity (measured with 6-Minute Walk Test)	**n = 17**	**n = 16**	**n = 33**
Pre-Intervention 6-Minute Walk Test	305 m (95.9)	234 m (90.3)	271 m (98.6)
Post-Intervention 6-Minute Walk Test	328 m (108.2)	247m (84.7)	288.7 m (104.5)
	t = 0.17, df = 16, p < .05*	t = 0.36, df = 15, p < .05*	t = 0.09, df = 32, p < 0.5

*Paired t-tests results.

Significant

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Preliminary Outcomes

Measure	Survivors	FMs	Comparisons
Dyspnea Scores[1]	N = 23 T1 = 10.68 T2 = 7.16	N = 23 T1 = 6.44 T2 = 5.28	N = 46 p = 0.05 (Group) p = 0.12 (Time)
Fatigue Scores[2]	N = 23 T1 = 32.0 T2 = 39.3	N = 23 T1 = 36.0 T2 = 39.6	N = 46 p = 0.80 (Group) p = 0.07 (Time)

Note. T1 = Pre-Intervention; T2 = Post-intervention

[1] **Dyspnea** measured with FACIT-Dyspnea 10-item Short Form. [2] **Fatigue** measured with FACIT Fatigue Scale (v. 4)

Significant difference by group

Objective #2b

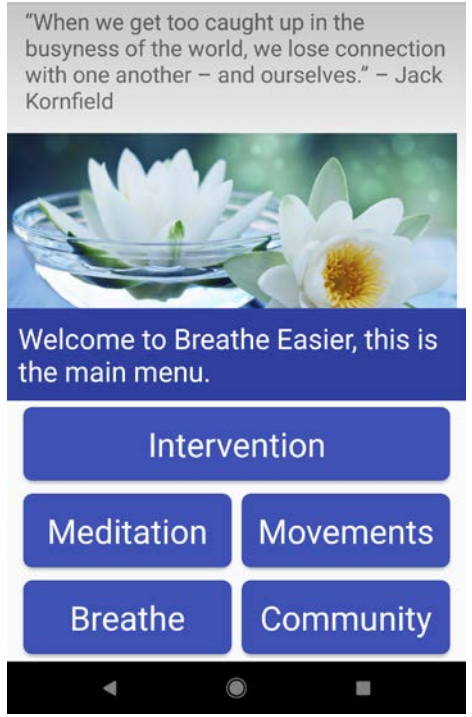
Adapt *Breathe Easier* to an interactive mobile application (prototype)

- Provides support for behavior change and symptom reduction regardless of the setting
- 3 development & evaluation phases:

  Phase I: Adaptation to mHealth app prototype — user-centered design

  Phase II: Focus group evaluation of usability and acceptance

  Phase III: Interviews with African-American subset of survivors and family members to assess cultural sensitivity of app



Outcomes

- Users were pleased with the **user-friendly** design of the app including the aesthetic appeal, navigation layout, and display of content, but offered **recommendations for improvement** (e.g., larger font; adding online community feature)
- Potential **health outcomes**, **privacy concerns**, and **comparison** to in-person interventions influence app usefulness and acceptance
- App was **culturally sensitive** to African Americans, with **minimal changes recommended** (e.g., adding more images to demonstrate exercises; adding upbeat music)
- African Americans less concerned about the cultural sensitivity of the information as they are about receiving **clear survivorship information**

Summary of Project Results to Date

Established new support groups and network

- Statewide stakeholder network and strategic plan for improved services for survivors of lung cancer + their families & friends
- Breathe Easier Club in Columbia, SC — led to other supportive care service providers in the community
- Cancer Support Community Interest Groups in 3 regions (existing group in 4th region)

→ ***Infrastructure in place and important connections made; some challenges to overcome still***

Adapted and tested the *Breathe Easier* intervention

- 2 intervention protocols, participant handbook and assignment journal, audio series
- Train-the-trainer curriculum

→ ***Strong feasibility and promising preliminary outcomes***

Developed a working mobile app prototype for *Breathe Easier*

- Cultural sensitivity evaluated by dyadic interviews

→ ***Strong acceptability and usability determined by focus group research***

Conclusion

- Mindfulness-based Cancer Recovery interventions hold great promise for improving the lives of racially diverse survivors of lung cancer and family members.
- An mHealth app will increase accessibility. Already, is in demand. However, special consideration of app design is needed to ensure future acceptance and longer-term usage.

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Key Lessons

- Coordination of clinical partners across state takes considerable time and resources
- COPD (#1 comorbidity) has a major impact on QOL of survivors in SC
- Patients and family members interested in services to reduce symptom burden
- Patients aren't being referred to supportive care (i.e. palliative care, pulmonary rehabilitation, home-based care) even when it's covered by insurance
- Family members may have impaired physical and emotional health also
- Transportation is a critical issue for rural and a substantial barrier
- Sensitivity to literacy levels, hearing and seeing capabilities, physical limitations, and oxygen users is paramount

Patient Story: Anthony Bookman

- Suffered 2 bouts with NSCLC, resulting in complete removal of his right lung followed by chemotherapy and radiation treatments.
- Afterward, dealt with debilitating shortness of breath and exhaustion just from getting dressed each day. Embarrassment about his symptoms led him to live primarily as a shut-in, only venturing from home once a week for worship.
- Took part in *Breathe Easier* with his pastor and found the exercises and interactions with other survivors invaluable. His lung capacity improved, oxygen use dropped, and he felt encouraged. Now leads a Bible study, delivers Meals on Wheels, and is pursuing a part-time job.

> *"The program taught me to slow down and appreciate the simple things we can do on our own. … I've learned to expect more of myself than I did before I started the class. … It's been fun to see myself improve, and I'm looking to do so much more." –Bookman*

Next Steps ~ 2019

1. Implementing Strategic Objectives.

2. Testing the “Train the Trainer” Breathe Easier curriculum with professionals around the state.

3. Looking for funding source to complete transition from working prototype to functional Breathe Easier App!

Bridge to Good Living: Thriving beyond Lung Cancer

West Virginia University Cancer Institute

Stephenie Kennedy-Rea

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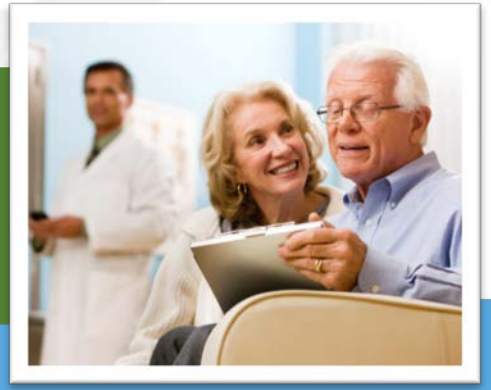
Project Goals and Summary

Develop and implement a comprehensive survivorship model program for lung cancer patients

Train health professionals on emerging lung cancer research related to coordination of care and survivorship

Disseminate information about lung cancer survivorship to patients, families, and health care providers



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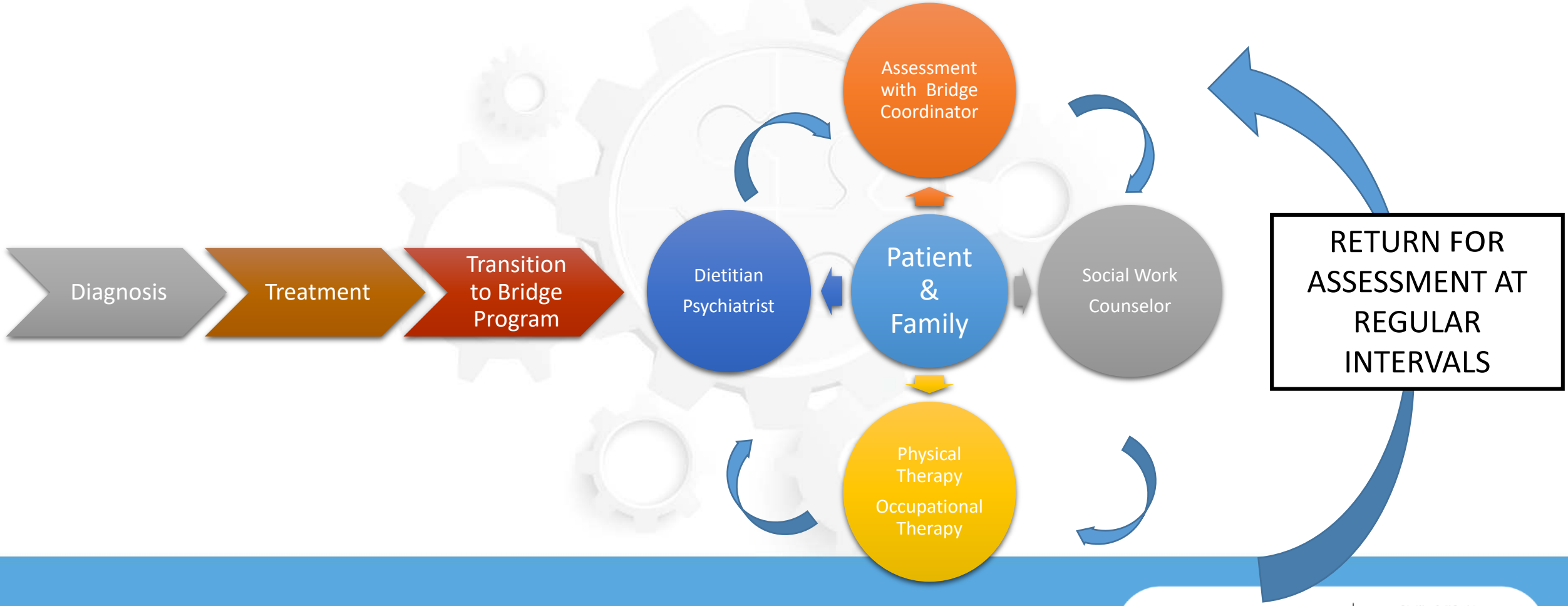
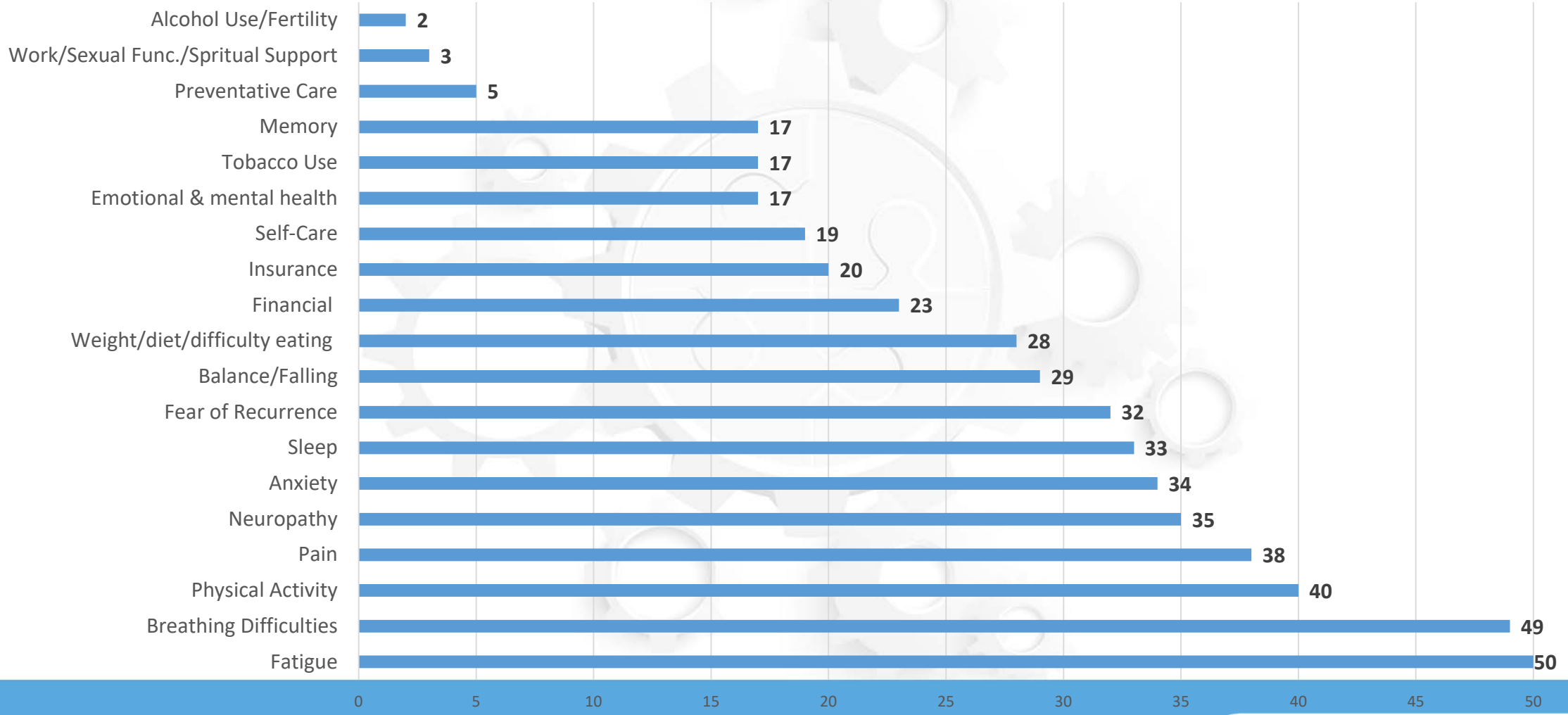
Service Flow of Implementation Model



Results: Identified Needs at the Conclusion of Treatment



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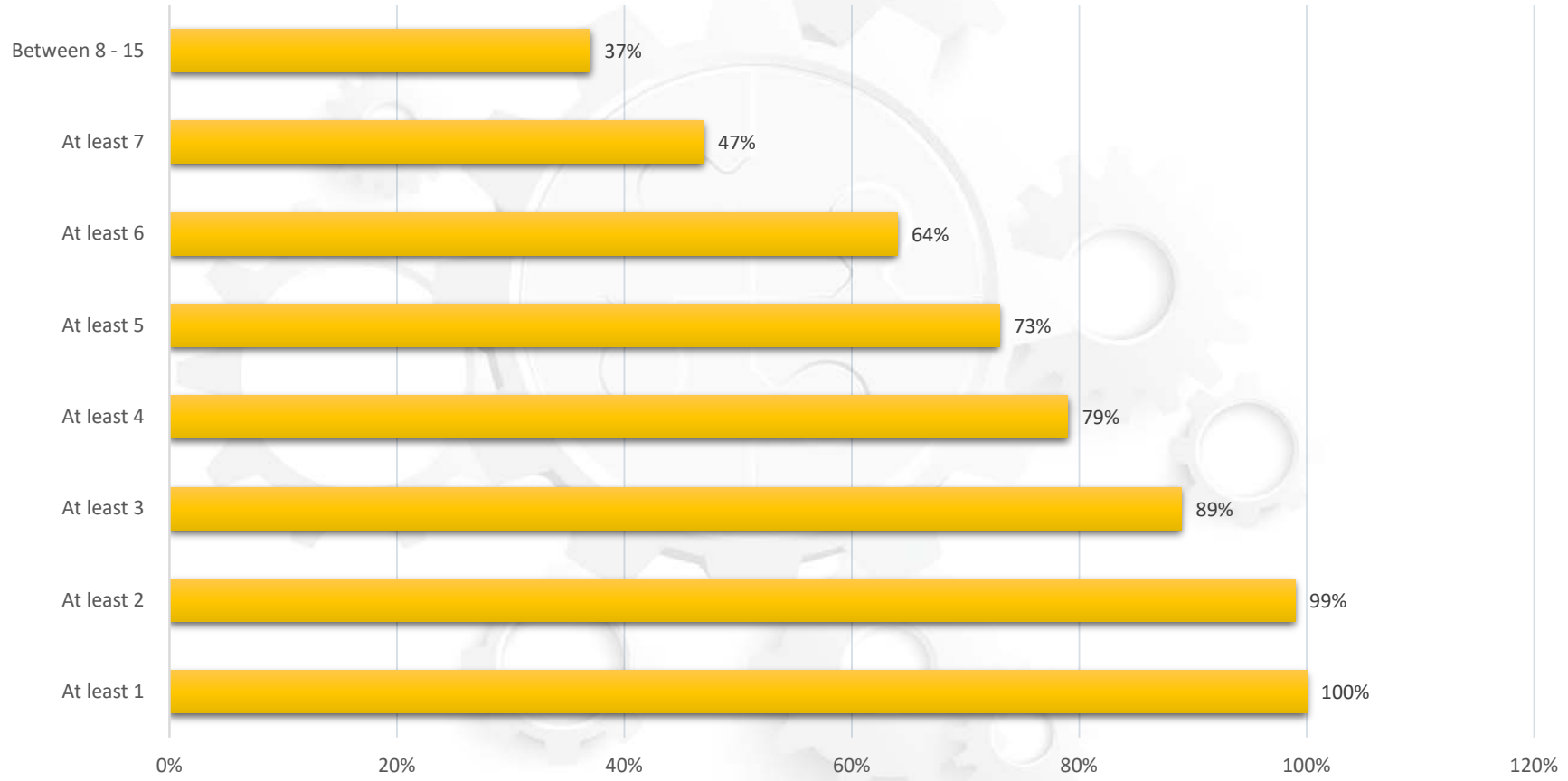
Results: Percentage of Patients and Number of Identified Needs



Additional Project Results

	Bridge Program Patients	Non-Bridge Patients
Average Pack Years	39	44
Hospitalization result of recurrence	100%	100%
ED Visit Leading to Hospitalization • Called to Triage Prior to ED Visit (communication, comfort with seeking care)	88% **50%**	88% **29%**
Travel >1 Hour for Care/Visit	42%	52%
Survivorship Care Plan	**100%**	**38%**
Visit Frequency/Compliance	~88%	~88%
Decrease in # of Unmet Needs	**93%**	**N/A**

Key Lessons

- Language matters
- Strong institutional support is a vital component
- Successful survivorship programs must continually assess how things are working
- No one-size-fits all when implementing survivorship care
- Survivorship programs require flexibility
- Lung cancer patients ending active treatment report a high level of unmet needs and require increased time for assessment and planning

Patient Story and Experience

- James – Stage III Lung Cancer Patient
- Uninsured
- Active prior to treatment
- PT/OT referral
- Transportation challenges
- Therapy and $40 gas card made all the difference

Wild Card

- Plan for sustainability early in the development of programs
- Return on investment discussion
  - Difficulty retrieving data from medical health records
  - Consider revenue from referrals
  - Demographic of cancer survivors is changing

Dr. Dawn Wiatrek, PhD
Strategic Director, American Cancer Society-ECHO Survivorship

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Project Goals and Summary

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.

To accomplish this goal we will work with cancer centers within **8 target states to**:

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

NCIC/Navigation Flow

Regional ACS staff educate hospitals on services and referral process

Hospital staff refer patients to navigation or NCIC

Services delivered by navigator to patient

Services delivered by NCIC to patient

ECHO Flow

Experts prepare and deliver content

HUB sites participate as learners, presenting cases for discussion

Patients receive enhanced quality of care from HUB sites

Project Results to Date

	Target (Based on previous year numbers+20% increase)	First full grant measurement year
NCIC/Hospital Referral project & Navigation		
Number of services provided to lung cancer patients in 8 target states	16,000 per year (4000 per quarter)	11,151
Number of unique patients receiving lung cancer services from ACS in 8 target states	8000 (est. 2 per patients-most patients receiving info service + at least 1 other)	5359
Number of hospitals in 8 states referring	30	25
Most Common Services Received (Not including General Info)		
Personal Health Manager		29%
Transportation		19%
Lodging		17%
Wigs/gift items		15%
Navigation		9% (655)

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ECHO Structure and Participation Data

- 13 sessions with topics including:
  - Lung cancer screening
  - Innovations in treatment for early stage and late stage cancers
  - Disparities in care
  - Managing symptoms/comorbidities (prehab/rehab)
  - Post-treatment Survivorship
  - End of Life/Hospice care
- Over 20 expert faculty and facilitators
- 8 community cancer centers regularly participating
- Assessments on each session (CEUs provided)
- Small grants offered to improve implementation of lessons learned

Lessons learned and next steps

Recruitment of Spoke sites can be challenging:

- Working directly with individual cancer centers is not always the most efficient approach
  - For cancer centers that are part of a larger system (Duke affiliates, Sara Cannon, US Oncology) working directly with leadership in the system may help improve participation
- Individual Cancer Centers may want to receive CE from experts that are familiar with their area/region (cultural differences/concerns etc)
- Offering small grants to promote implementation of lessons learned can be used to promote participation
- Challenging to get entire cancer team to attend sessions (timing of sessions is important)
- Survey for interest in topics prior and during the ECHO to ensure you are on the right track

Don't stop after a single clinic

- How do we use the resources created to continue to improve quality care

Patient Story and Experience: An ECHO Story

Case Study:

- 57 yr old male patient w/history of drug use and mental illness
- Possibly homeless
- Prostate Cancer Survivor
- Diagnosed with early stage lung cancer
- Failed to show up for 3 pre-op appointments, so treatment plan changed to radiation

Recommendations/Discussion

- Patient never received clear information on his diagnosis
- With high risk for no show patients, there should be a protocol for pre-op visits
- Radiation typically requires more frequent visits so unclear on why this was the alternative
- Discussion on shortages in skilled surgeons/protocols etc. and increases in early stage lung cancers
- Potential collaborations with major cancer centers that can minimize in-patient time and travel through telemedicine

Veterans Affairs Based Comprehensive Lung Cancer Survivorship Program

Institute for Medical Research
Durham VA Medical Center

Scott Shofer MD. PhD, Alisa Hassinger PA-C, Jordan Stafford MS, Robert Kundich BA, Anne Mathews MD, Scott Swartzwelder PhD

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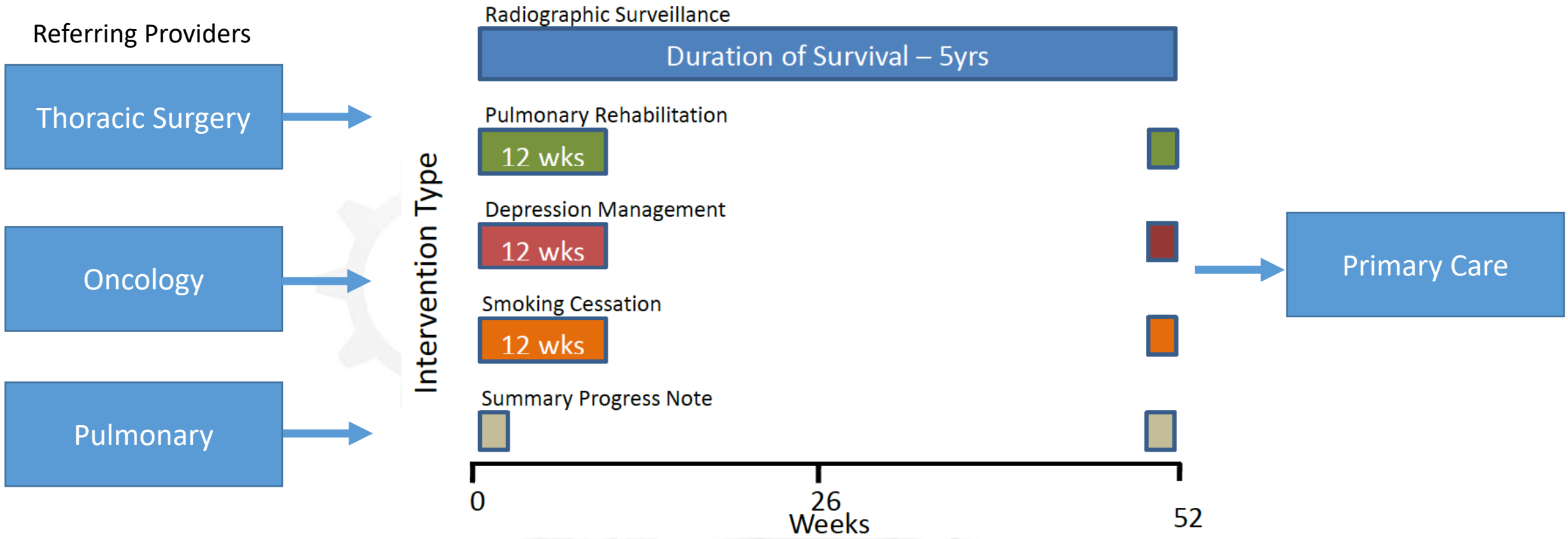
Project Goals and Summary

- A comprehensive telehealth based program for patients with lung cancer targeting commonly encountered problems of dyspnea, depression, and tobacco abuse. The program also aims to improve outcomes by using EMR based tools to ensure appropriate surveillance for recurrent disease. Interventions include:
- Home-based Pulmonary Rehabilitation
  - 12 week program with weekly contact by telephone or Skype meetings
  - COPD Medication optimization
  - Nutritional intervention
- Depression and Anxiety Management
  - Medication optimization
  - Weekly phone contact with Cognitive Behavioral Therapy
- Tobacco cessation
  - Low cost medication and nicotine replacement
  - Weekly coaching interactions
- Electronic monitoring of radiographic surveillance

Service Flow Map



Project Results to Date

Demographic Information

Number of Participants =11

	Number	Percentage
Gender		
Male	10	91
Female	1	9
Age		
50-59	2	18
60-69	5	45
70-79	4	36
Race		
Caucasian	7	64
Black	4	36
Tumor Stage		
IA	4	36
IB	6	54
IIIA	1	9

Project Results to Date

Baseline Clinical Data

Number of Participants=11

	Number	Percentage
Smoking Status		
Current	2	18
Previous	8	82
Never	1	9
Frailty Status (n=9)		
Non-frail	3	33
Pre-frail	5	45
Frail	1	11
Mental Health Status		
HADS Score ≥8	6	54
PHQ-9 ≥5	6	54
Psychiatric Diagnosis	9	82
COPD Status		
No Diagnosis	2	18
Mild	1	9
Moderate	6	54
Severe	2	18

Project Results to Date

Patient Participation by Program Component

Number of Participants =11

	Number	Percentage
Pulmonary Rehabilitation	11	100
Mental Health	3	27
Smoking Cessation	1	9

Pulmonary Rehabilitation Walk Data

N =4*

*Pt data selected by length of program participation

	Avg Steps Week 2	Avg Step Week 3	Avg Step Week 4	Increase 1 Month
Patient 1	375	645	507	58%
Patient 2	554	751	613	33%
Patient 3	7386	8467	7531	2%
Patient 4	1330	**	4926	36%

**Data Unavailable

Key Lessons

- Veterans are willing to accept participation in an exercise program
- Rates of completion are better than we anticipated but not as good as we would like
- Veterans are less willing to accept mental health services
- PTSD is more common than we anticipated in this group and has significant adverse effects on the remainder of their care

Patient Story and Experience

- Mr. W.
  - 71 yo male Dx with Stage IB adenocarcinoma of the lung s/p Right upper lobectomy 7 months prior to enrollment in the program
  - Pt described symptoms of dyspnea with minimal activities such as showering or walking to the mailbox
  - Pt expressed increasing symptoms of depression, anxiety, and has the feeling he is a burden to his family
  - Other diagnoses include GOLD B COPD, PTSD, Morbid Obesity
  - Initial Assessment Metrics
    - mMRC Dyspnea score 4
    - PHQ-9 24 (significant depression)
    - 6 min walk 149 meters
    - COPD Assessment Test 38/40

Patient Story and Experience

- Mr. W.
  - At completion of the program he notes significant improvement in his symptoms of SOB
  - His anxiety related to his breathing is now managable
  - He has increased his daily activity as measured by his pedometer by 50%
  - Completion Assessment Metrics
    - mMRC Dyspnea score 4 → 3
    - PHQ-9 24 → 20
    - 6 min walk 149 m → 205 m
    - COPD Assessment Test 38/40 → 30/40