

PATIENT CENTERED CARE
ePROs Monitoring in Thoracic Surgery and Oncology Patients
July 12

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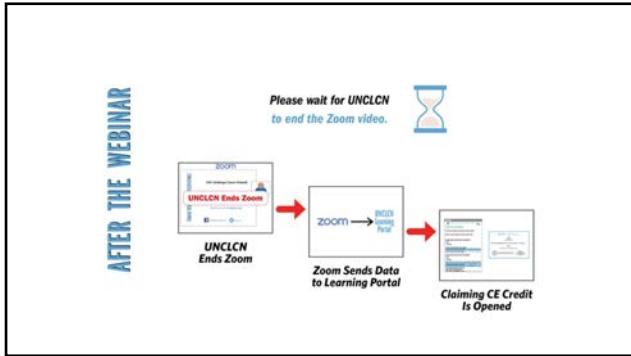
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PATIENT CENTERED CARE

Gita Mody, MD, MPP

ePROs Monitoring in Thoracic Surgery and Oncology Patients

July 12

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OUR PRESENTER



Gita Mody, MD, MPH

Dr. Gita Mody is an Adjunct Assistant Professor at the UNC Gillings School of Global Public Health with the Public Health Leadership Program. She received her M.D. at Washington University School of Medicine in St. Louis and received her M.P.H. in Clinical Effectiveness from the Harvard School of Public Health. As an Assistant Professor in the UNC Department of Surgery and Director of Thoracic Surgical Oncology, her clinical expertise is in caring for lung cancer patients, who are amongst the most vulnerable and underserved groups in North Carolina. Her major research interest is in optimizing quality of life and other patient-centered outcomes in patients with chronic illness through studying the implementation of digital health and other complex interventions. Her training in comparative effectiveness research, patient-reported outcomes measurement, and implementation science are synergistic, and she is well-versed with experimental and pragmatic study designs. Her current and prior work is funded through grants from the National Heart, Lung and Blood Institute (NHLBI) - American College of Surgeons (ACS), and the Thoracic Surgery Foundation (TSF). She is passionate about global equity in health and actively engages in training the next generation of clinical scientists from low-resourced settings through her work in the Malawi Cancer Outcomes Research Program.

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ePRO is the abbreviation for "electronic Patient-Reported Outcome".

True 0%

False 0%

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DISCLOSURES

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ePROs Monitoring in Thoracic Surgery and Oncology Patients
UNC Lineberger Cancer Network Webinar | July 12, 2023

 **Gita N. Mody, MD MPH**
Assistant Professor of Surgery
Director of Thoracic Surgical Oncology
UNC Department of Surgery
Lineberger Comprehensive Cancer Center



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Disclosures

Research funding and advisor for Sivan Ltd.

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Objectives

1. Describe symptom burden of thoracic surgical and oncologic conditions and treatments
2. Review reasons and methods for patient-reported outcomes monitoring
3. Discuss implementation of PRO monitoring in thoracic patients' survivorship care

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Thoracic surgery

- Thoracic surgery includes the esophagus, mediastinum, trachea and chest wall.



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Chest diseases treated with surgery

- Emphysema
- Dysphagia
- Gastroesophageal reflux disease
- Tumors of the lung, esophagus, chest wall, mediastinum
- Tracheal anomalies
- Diaphragm disease
- End-stage lung disease requiring transplantation
- Benign chest wall abnormalities

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Types of thoracic surgery

- Approaches
 - Open
 - Minimally invasive
 - Video Assisted Thoracoscopic Surgery (VATS)
 - Robotic Assisted Thoracoscopic Surgery (RATS)
 - Uniportal thoracoscopic surgery
- Procedures
 - Pulmonary resection
 - Wedge resection
 - Segmentectomy
 - Lobectomy
 - Pneumonectomy
 - Thymectomy
 - Diaphragm plication and repair
 - Chest wall resection
 - Lymph node biopsy
 - Decortication and Pleurodesis
 - Esophagectomy
 - Paraesophageal hernia repair




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Lung Cancer Statistics


Common Types of Cancer	Estimated New Cases 2021	Estimated Deaths 2021
1. Breast Cancer (Female)	281,550	43,600
2. Prostate Cancer	248,530	34,130
3. Lung and Bronchus Cancer	235,760	131,880
4. Colorectal Cancer	149,500	52,980
5. Melanoma of the Skin	106,110	7,180
6. Bladder Cancer	83,730	17,200
7. Non-Hodgkin Lymphoma	81,560	20,720
8. Kidney and Renal Pelvis Cancer	76,080	13,780
9. Uterine Cancer	66,570	12,940
10. Leukemia	61,090	23,660

Lung and bronchus cancer represents 12.4% of all new cancer cases in the U.S.



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Lung Cancer Statistics

- 1 in 5 cancer deaths 
- Average age at diagnosis: **70 years**
- New lung cancer **cases and deaths are decreasing**
 - Reduction in smoking
 - Earlier detection
 - Treatment advances

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Stages of Lung Cancer

Of new cases, **17%** are diagnosed with local disease, **22%** at regional state, and **56%** with distant disease.

I stage II stage III stage IV stage

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What is the most common treatment for early-stage lung cancer?

0%	0	Surgery
0%	0	Radiation
0%	0	Observation

Start the presentation to see live content. For screen share software, share the entire screen. Get help at pollen.com/help

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Majority of Early-Stage Lung Cancer Patients Undergo Surgical Therapy

76.7% of those with Stage I disease

83.8% of those with Stage II disease

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Lung resection

- Employed for diagnosis, treatment, and palliation of lung cancer and other thoracic conditions.
- >80,000 lung resection procedures are performed annually in the United States.
- Pulmonary lobectomy is increasing by 1.7% per year.




Image credit: Memorial Sloan Kettering Cancer Center

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Approaches to lung resection

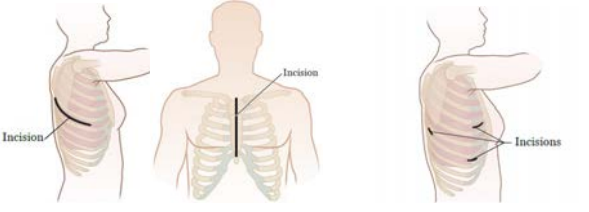


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Extent of lung resection

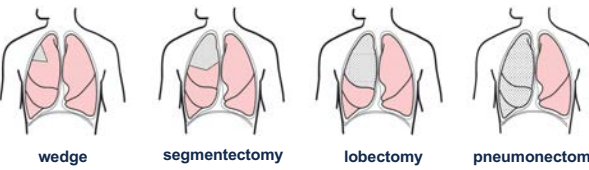
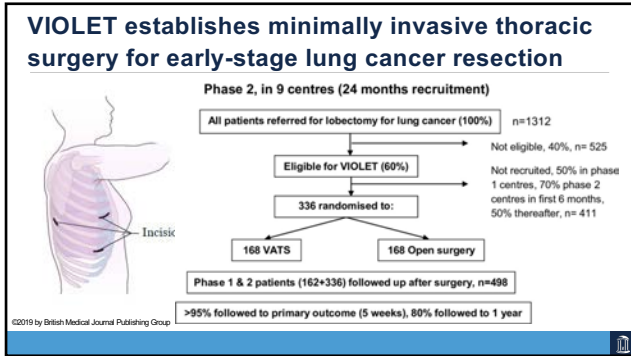
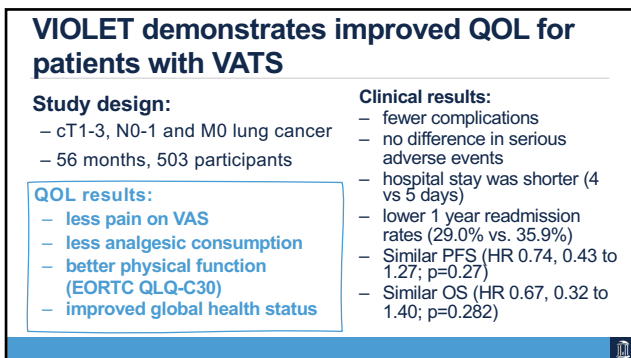


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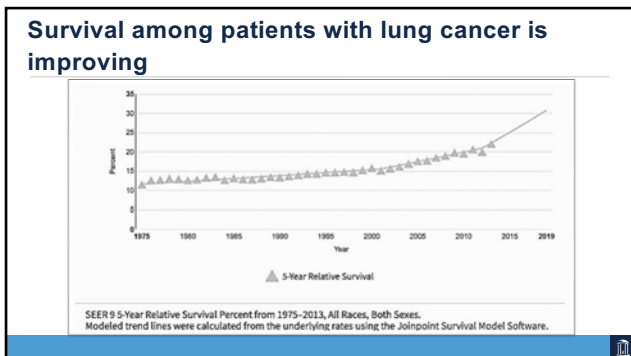
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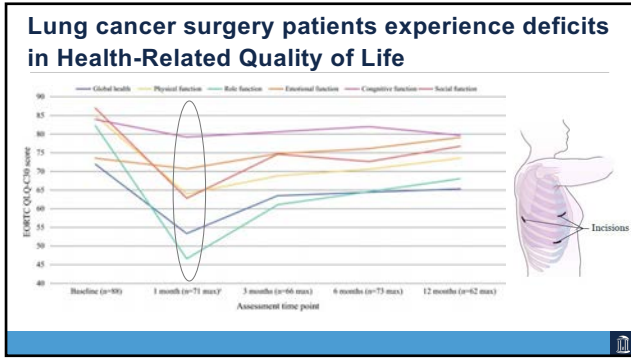
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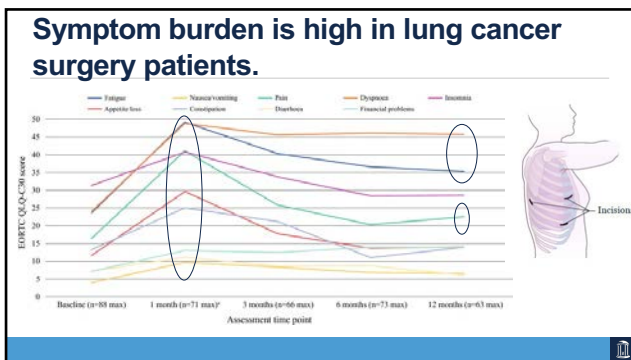
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Audience question

- Shortness of breath is a short term postoperative symptom after lung cancer surgery?
 - A. True
 - B. False

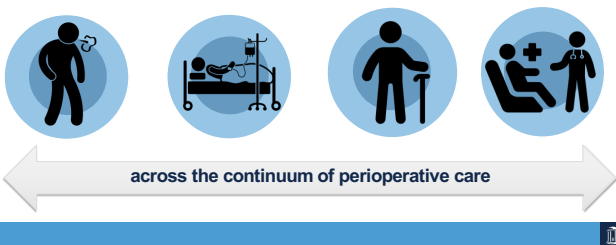
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Lung cancer surgery patients' HRQOL priorities



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When should HRQOL be measured?





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Thoracic surgery patients report gaps between preop expectations and postop HRQOL

10 semi-structured interviews with elderly patients

1 year after thoracic surgery

 Unexpected duration of physical recovery time

 Eventual return to baseline physical function

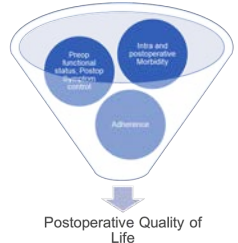
 Improvement in emotional HRQOL

Mody GN, Bennett A, Jain M, Kerain C, Jakkach M, Frain L. Geriatric patient experience after thoracic surgery: how to help older patients avoid the hospital? Presented by Mody GN at ASCO QOL 27th Annual Conference, October 2020

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Quality of Life experiences after thoracic surgery are multifactorial

- How do the outcomes thoracic surgery patients experience contribute to their postoperative quality of life?
- How do the expectations of patients contribute to their postoperative quality of life?



Postoperative Quality of Life

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Systematic review on HRQOL after lung cancer surgery identified numerous publications

Identification

7,054 studies imported for screening

2,893 duplicates removed

4,261 studies screened

3,024 abstracts excluded


1,239 full texts assessed for eligibility

802 full texts excluded

367 full texts retained

214 texts excluded from final analysis

153 articles focused on QOL analysis



Dr. Aurelie Merlo, PGY 6

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Postoperative Symptom Burden in Patients Undergoing Lung Cancer Surgery

153 items - Long-term quality of life - categorized by theme:

- 34 items - Longitudinal trajectory of QOL**: How does QOL change over time after lung cancer surgery?
- 49 items - Risk factors for poor QOL**: What are the risk factors that predict poor QOL after lung cancer surgery?
- 4 items - Relationship of poor performance QOL to outcomes**: How does poor performance QOL impact outcomes after lung cancer surgery?
- 13 items - Articles validating QOL instruments and cross-sectional studies that do not classify outcomes**: Articles validating QOL instruments and cross-sectional studies that do not classify outcomes.
- 54 items - Symptom burden**: What is the symptom burden after lung cancer surgery?

Original Article

Postoperative Symptom Burden in Patients Undergoing Lung Cancer Surgery

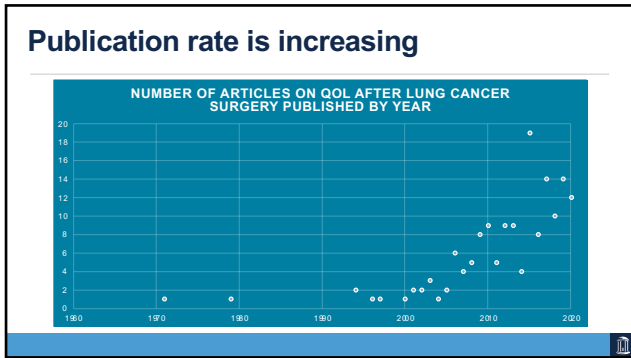
Abstract

Background: Previous studies on quality of life (QOL) after lung cancer surgery have identified a long burden of symptoms postoperatively. We first performed a systematic review of QOL in patients undergoing surgery for lung cancer. It included longitudinal studies focusing on symptom burden and QOL.

Objectives: To perform a systematic review of studies addressing symptom burden in patients undergoing surgical resection for lung cancer.

Methods: We searched multiple medical research databases for longitudinal research on self-reported QOL in cancer patients undergoing and in studies about QOL and symptom experiences after lung cancer surgery. The search strategy was based on the PRISMA search protocol through multiple iterations of the strategy and protocol according to the PRISMA 2020 reporting guideline.

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Measurement approaches vary

Quality of Life: Outcome Measures and Frequency Used in the 54 Included Articles

SF-36 or SF-12	17
EORTC QLQ-C30 or LC-13	11
Hospital Anxiety and Depression Score	11
Subjective data	6
Acceptance of Illness Scale; American Thoracic Society Questionnaire; Athens Insomnia Scale; Baseline Dyspnea Index; Reclaiming Questionnaire; Brief Fatigue Inventory; Brief Pain Inventory; Center for Epidemiologic Studies – Depression Scale; Control Preferences Scale; Coping Inventory; Decisional Conflict Scale; Douleur Neuropathique 2 or 4; Experiences in Close Relationships Scale II; Functional Assessment of Cancer Therapy – Lung; General Sleep Disturbance Scale; Godin Leisure Time Exercise Questionnaire; Herth Hope Questionnaire; Impact of Event Scale; Karnofsky Performance Scale; Lee Fatigue Scale; Leeds Assessment of Neuropathic Symptoms and Signs; Leicester Cough Questionnaire; Lung Cancer Symptom Questionnaire; MD Anderson Symptom Inventory; Medical Coping Modes Questionnaire; Medical Outcomes Study Social Activity Limitations Scale and Symptom Assessment Scale; Mental Adjustment to Care Scale; Mini-Mental State Examination; Multidimensional Scale of Perceived Social Support; Multidimensional Fatigue Symptom Inventory – Short Form; Numeric Rating Scale; Patient-Reported Outcomes Measurement Information System Tools; Perceived Family Support Scale; Physical Activity Questionnaire; Pictorial Patient Experience; Pittsburgh Sleep Quality Index; Posttraumatic Growth Inventory; Post-Traumatic Stress Disorder Checklist Civilian Version; Profile of Moods Questionnaire; Self-Administered Comorbidity Questionnaire-19; Self-Efficacy Scale; Stress Thermometer; Social Support Scale; State-Trait Anxiety Inventory; Symptom Distress Scale; Toronto Mindfulness Scale; Veterans RAND 12-Item Health Survey; Visual Analogue Scale; 12-item World Health Organization Disability Assessment Schedule 2.0	<5

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Key findings

- Symptom burden is high before and after surgery.
- Pain, dyspnea, cough, fatigue, depression, anxiety are most studied symptoms.
- Pre-surgery symptoms are a risk factor for symptom acuity and persistence after surgery.
- Symptom burden is a predictor of postoperative QOL.

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Objectives

- Describe symptom burden of thoracic surgical and oncologic conditions and treatments
- Review reasons and methods for patient-reported outcomes monitoring**
- Discuss implementation of PRO monitoring in thoracic patients' survivorship care

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Who should report on HRQOL?



- Patients at risk for lung cancer
- Comparison of Health Utility Scores for common postoperative conditions

Outcomes	Utility Score* (95% CI)
Pain requiring 2 wk of hospitalization	0.83 (0.74-0.90)
Anxiety requiring bronchoscopy therapy	0.90 (0.72-0.98)
Ventilator dependence for 3 d	0.79 (0.68-0.93)
Ventilator dependence for 7 d	0.74 (0.66-0.82)
Ventilator dependence for 15 d	0.66 (0.57-0.75)
Ventilator dependence for 30 d	0.56 (0.45-0.68)
Permanent ventilator dependence with estimated survival of 6 mo	0.10 (0.04-0.16)
Acute myocardial infarction	0.49 (0.40-0.58)
Can walk only two city blocks without stopping	0.48 (0.40-0.56)
Current activity level reduced by half	0.44 (0.37-0.51)
Oxygen dependence	0.33 (0.26-0.40)
1 mo of nursing home placement followed by a one-block walking distance (increase of 100 ft)	0.30 (0.25-0.37)
Need assistance with activities of daily living (dressing)	0.19 (0.13-0.25)
Limited to bed to chair entrance	0.17 (0.11-0.23)
Progressive lung cancer	0.17 (0.10-0.24)
Permanent nursing home placement	0.16 (0.10-0.22)

*Utility scores range from 0 representing death to 1 representing perfect health.

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Who should report on postoperative HRQOL?

Clinician-reported Outcomes	Patient-reported Outcomes
	

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Patient-Reported Outcome Measure (PROM)

- Measurement based on report that comes directly from patient about status of patient's health condition **without amendment or interpretation of patient's response**
 - New FDA guidance in 2020



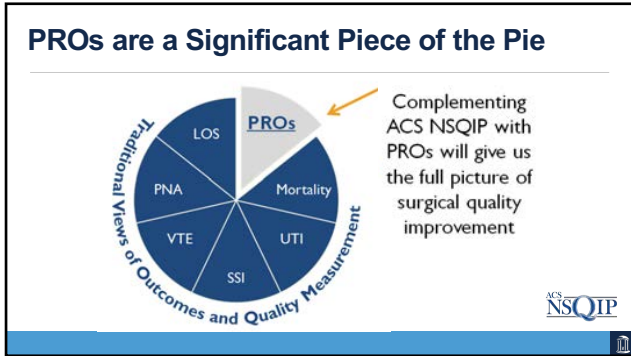
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What is a Patient-Reported Outcome (PRO)?

Based on a report that comes **directly from the patient** about the status of the patient's health condition without amendment or interpretation of the patient's response

- Developed with patient and clinician input
- Evidence of psychometric testing for validity and reliability

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Is it a PROM? Questions to ask:

- **Low bar**
 - Does it measure a health concept appropriate for direct patient report?
 - Does it measure perceptions of how a patient feels or functions, beliefs about a health concept, or experience?
- **Higher Bar**
 - Were items or instrument developed with patient and clinician input?
 - Psychometric, validity, reliability evidence?

Image credit: Cartoonstock.com

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Why does measuring PROs matter?

"For patients, there is much more to success than alive or dead, complication, no complication.

How often have we heard 'They said my hip replacement went well, **but I am now housebound**,' or 'He says I have a good flow rate in my bypass graft, **but I still get pain after 10 metres**.'


Vallance-Owen, BMJ 2008

Image credit: Adobe Stock (iStock)

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How to measure PROs?

PRO (tool):	PROM (instrument)
Symptoms:	St. George's Respiratory Questionnaire (SGRQ)
Functional status:	Patient-Reported Functional Status (PRFS)
Health-Related Quality of Life:	EORTC QLQ-C30
Self-efficacy for managing condition:	PROMIS Self-Efficacy



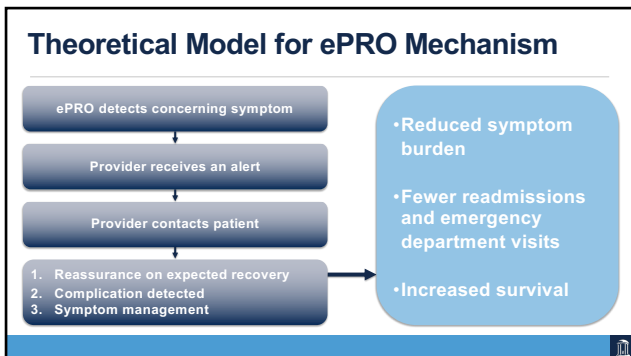
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Patient-Reported Outcomes version of The Common Terminology Criteria For Adverse Events (PRO-CTCAE™)
QUICK GUIDE TO THE ITEM LIBRARY*

Oral	Respiratory	Neurological	Sweat/Water	Genital
Dry mouth S	Shortness of breath S	Numbness & tingling S	Headache S	Aches and pains S
Difficulty swallowing S	Cough S	Dizziness S	Fatigue S	Diarrhea S
Mouth/throat sores S	Wheezing S			
Crusting at the corners of the mouth (cheilitis/cheilosis) S	Chest/Circulatory	Visual/Perceptual	Mood	Decreased libido S
White quality changes P	Shortness of breath S	Burned/irritated S	Anxious FS	Delayed orgasm P
Hoarseness S	Heart palpitations FS	Floating/lymph P	Discouraged FS	Unable to have orgasm P
	Catamenia	Wet/dry eyes S	Sad FS	Pain/discomfort intercourse S
	Rash P	Ringing in ears S		
Taste changes S	Skin dryness S	Attention/Memory	Genitourinary	Miscellaneous
Decreased appetite S	Acne S	Concentration S	Irregular periods/ovulation P	Breast swelling and tenderness S
Nausea FS	Hair loss A	Memory S	Swelling P	Bruising P
Vomiting FS	Itching S		Missed expected menstrual period P	Clots FS
Heartburn FS	Weak P	Pain	Vaginal discharge A	Increased sweating FS
Gas P	Hand/foot weakness S	General pain FS	Vaginal dryness S	Decreased sweating P
Bloating FS	Nail loss P	Headache FS	Painful urination S	Hot flashes FS
Hiccups FS	Nail ridging P	Muscle pain FS	Urinary urgency H	Ribcaged FS
Constipation S	Sensitivity to sunlight P	Joint pain FS	Urinary frequency FS	Pain and swelling at injection site P
Diarrhea P	Redness/irritation P	Swollen lymph nodes S	Change in usual urination P	Body odor S
Abdominal pain FS	Redness/swelling P	Swelling P	Urinary incontinence FS	
Rectal incontinence FS	Redness/irritation P	Speech/swallowing P		
	Skin darkening P			
	Speech/swallowing P			

*Complete library of items available at: <https://healthoncology.cancer.gov/pro-ctcae>

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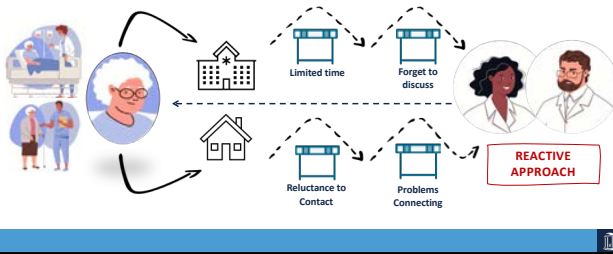
What is a electronic PRO monitoring?

Collects PROs on repeated intervals via:
Paper
Kiosk
Tablet
Home phone (IVR)
Phone call

- Delivers PROs to clinicians
 - Alerts (email, Epic, text message)
 - Symptom reports

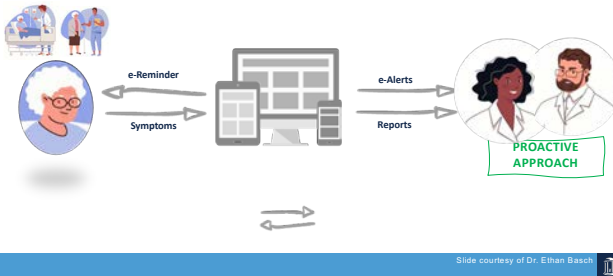
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Standard Approach to Postoperative Symptom Monitoring



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Alternative: Systematic Post-discharge Symptom Monitoring using ePROs



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Collection of Patient-Reported Outcomes (PROs) can be done remotely and in real-time.

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Evidence for PRO effectiveness in advanced oncology

- PROTECT was a multicenter cluster randomized trial.
- To evaluate ePRO symptom monitoring vs. a usual care control group
- Community oncology practices in the US national network of the Alliance for Clinical Trials in Oncology were invited to participate.
 - Consecutively approach and enroll up to 50 adults with any type metastatic cancer receiving treatment with chemotherapy, targeted oral therapy, and/or immunotherapy if they understood English, Spanish, or Mandarin.
 - Patients with indolent lymphoma or acute leukemia or who were receiving hormonal monotherapy were excluded.

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Lung cancer patients undergoing PRO monitoring within the PROTECT study

- Adults ≥18 years old
- Advanced/metastatic disease
- Systemic therapy at community oncology sites
- Weekly PRO-CTCAE survey
- Opportunity for write-in symptoms
- Automated system (+reminders)
- Alerts for severe, very severe or increasing symptoms
- 3-month satisfaction survey

Weekly electronic PRO survey delivery and reminder schedule.

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Baseline characteristics of patients with lung cancer v. patients with other cancer types

	Lung cancer (n=118)	Other cancers (n=475)	p value
Age (mean, sd)	64.4 (9.9)	61.9 (11.9)	0.03
ECOG score (n, %)			0.002
0	41 (34.7%)	211 (44.5%)	
1	59 (50.0%)	218 (46.0%)	
2	14 (11.9%)	44 (9.3%)	
3	4 (3.4%)	1 (0.2%)	
Comorbidities* (n,%)			0.02
0-1	67 (56.8%)	323 (68.0%)	
2-4	51 (43.2%)	152 (32.0%)	
Education			0.06
Up to 8th	2 (2%)	8 (1.7%)	
9th to 11th	12 (10%)	23 (4.9%)	
High School/GED	39 (33%)	134 (28.8%)	
Some College	39 (33%)	131 (28.2%)	
Associates Degree	5 (4%)	34 (7.3%)	
College Degree	12 (10%)	79 (17.0%)	
Advanced Degree	8 (7%)	56 (12.0%)	

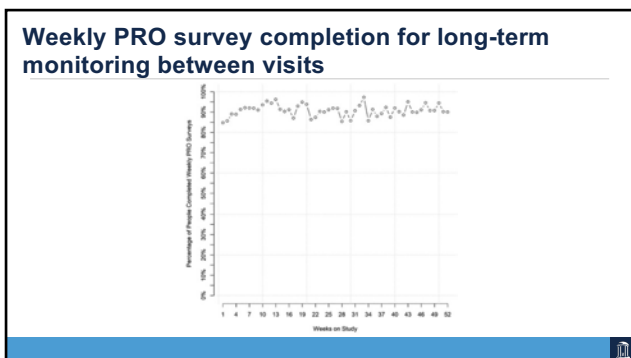
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Demographics of lung cancer patients choosing IVR for PRO monitoring

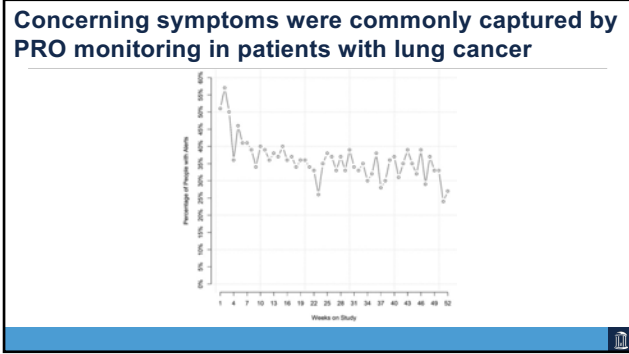
	IVR (n=47)	Web-based (n=71)	p value
Age (mean, sd)	65.28 (9.59)	63.87 (10.13)	0.45
Gender (n, %)			0.563
Male	18 (38.3%)	31 (43.7%)	
Female	29 (61.7%)	40 (56.3%)	
Education*			0.009
Up to 8th	1 (2.2%)	1 (1.4%)	
9th to 11th	8 (17.0%)	4 (5.6%)	
High School/GED	21 (45.7%)	18 (25.4%)	
Some College	12 (26.1%)	27 (38.0%)	
Associates Degree	2 (4.3%)	3 (4.2%)	
College Degree	0 (0.0%)	12 (16.9%)	
Advanced Degree	2 (4.3%)	6 (8.5%)	
Prior computer/device use			<0.001
Never	17 (36.2%)	2 (2.8%)	
Ever (once a week to daily)	30 (63.8%)	69 (97.2%)	
Prior email use			<0.001
Never	26 (55.3%)	5 (7.0%)	
Ever (once a week to daily)	21 (44.7%)	66 (93.0%)	
Prior internet use			<0.001
Never	21 (44.7%)	2 (2.8%)	
Ever (once a week to daily)	26 (55.3%)	69 (97.2%)	

*1 missing response

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Concerning symptoms were commonly captured by PRO monitoring in patients with lung cancer

Symptom Type	% (n = 118)	Mean continuous duration (weeks)*	Mean reported weeks**
Pain	83.1%	2.87	8.3
Reduced Activity	58.5%	1.98	4.99
Diarrhea	51.7%	1.34	3.51
Reduced Appetite	51.7%	1.16	2.28
Dyspnea	50.8%	2.02	5.28
Constipation	47.5%	1.07	2.20
Nausea	48.3%	1.28	3.65
Fallen	43.2%	1.23	2.55
Insomnia	39.0%	1.29	3.89
Depression	37.3%	1.58	4.93
Vomiting	22.0%	1.06	2.27
Financial Toxicity***	15.3%	n/a	n/a

*Mean continuous duration is calculated as the average number of consecutive weeks a concerning symptom was reported, per patient.
 **Mean reported weeks is calculated as the total number of weekly records a concerning symptom was reported, averaged over the number of patients who reported such a symptom.
 ***Financial Toxicity was collected every 4 weeks

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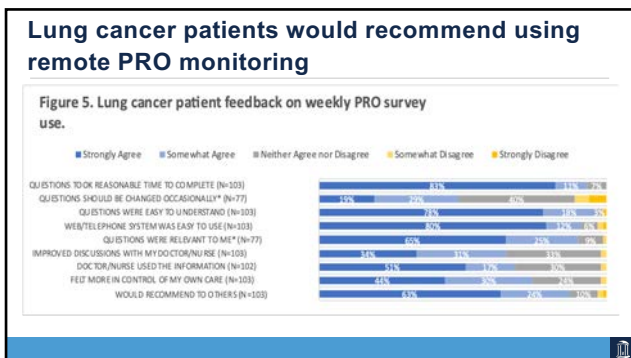
69

Alerts to providers for concerning symptoms led to intervention

Intervention	n	% (n=1470)*
Coached patient to self-manage or treat symptoms	270	18.4%
Prescribed or changed medications (supportive drugs and/or cancer treatment)	162	11%
Expedited a clinic appointment	68	4.6%
Ordered imaging and/or laboratory test(s)	28	1.9%
Referred to the emergency department	11	0.7%
Planned to address concern at next clinic visit	281	19.1%

*More than one intervention may have been taken per alert.

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- ### PRO-TECT Lung Conclusions
- Remote PRO monitoring was feasible in lung cancer patients in the setting of a pragmatic trial.
 - Lung cancer patients on treatment experience a high-symptom burden, which can be detected by PRO surveys.
 - Practice nurses and providers were able to respond to PRO alerts with various management strategies.
 - Real-world experience and best implementation strategies are needed going forward.

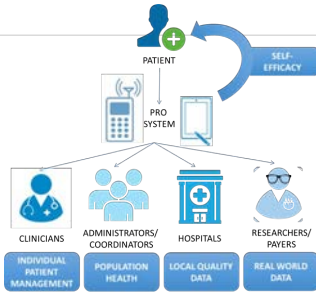
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Objectives

1. Describe symptom burden of thoracic surgical and oncologic conditions and treatments
2. Review reasons and methods for patient-reported outcomes monitoring
3. **Discuss implementation of PRO monitoring in thoracic patients' survivorship care**

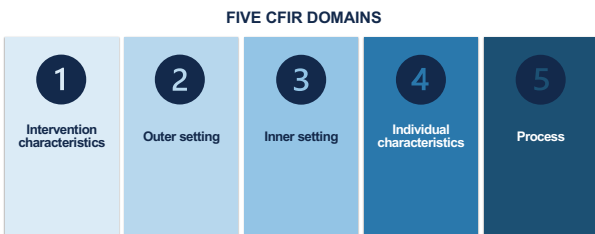
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Value of PRO Data in the Electronic Medical Record

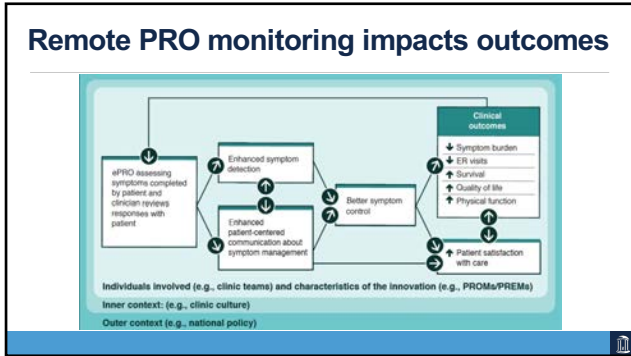


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Consolidated Framework for Implementation Research (CFIR)



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- ### Organizations increasingly advocate for PRO integration
- Center for Medicare and Medicaid Services (CMS)
 - National Quality Forum (NQF)
 - National Institutes of Health (NIH)
 - National Cancer Institute (NCI)
 - US Food and Drug Administration (FDA)
 - American College of Surgeons (ACS)
 - American College of Chest Physicians (ACCP)
 - Center for Medical Technology Policy (CMTP)
 - Patient-Centered Outcomes Research Institute (PCORI) created by Affordable Care Act

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UNC Health Care System & UNC Hospitals

- State-owned, not-for-profit medical system
- Affiliated with UNC-Chapel Hill School of Medicine
 - Academic teaching hospital
 - Tradition of public health & service within the community and beyond

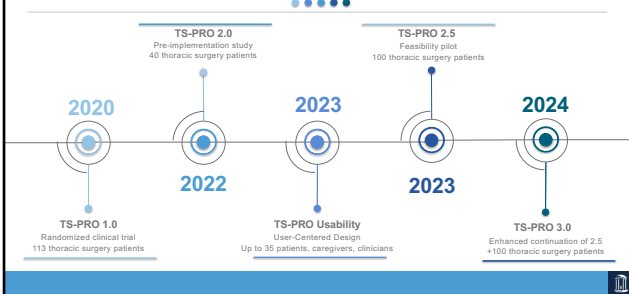
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Multidisciplinary Thoracic Oncology Program

- MTOP at UNC Hospitals organized in 1993
- Patients who need testing for - or have been diagnosed with - lung cancer, mesothelioma, and other thoracic malignancies
- Care team includes:
 - surgery
 - pulmonary medicine
 - medical and radiation oncology
 - thoracic radiology
 - pathology
 - oncology nursing

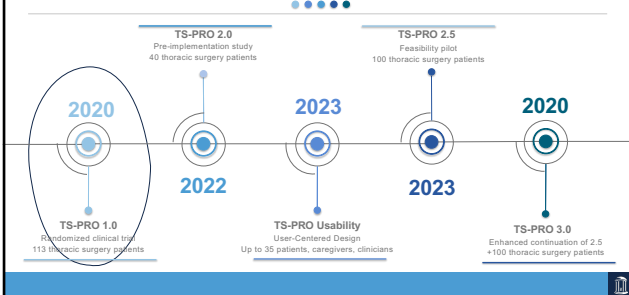
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A Timeline of TS-PRO Studies at UNC



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TS-PRO 1.0



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TS-PRO 1.0 enrollment

- Recruited **preoperatively** from the UNC MTOP
- April 2020-February 2022
- Eligibility criteria
 - 18 years of age or older
 - English-speaking**
 - Presenting for elective inpatient thoracic surgery
 - Able and willing to complete **web-based** symptom survey



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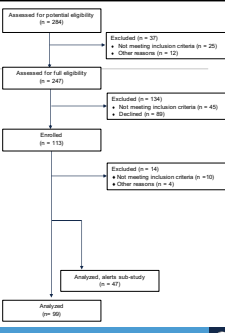
TS-PRO 1.0 Symptom Reporting via automated ePROs

- Via UNC PRO-Core
- Web-based
- Email invitations to complete surveys sent per schedule
 - Automated email reminders
 - Study-team reminders by telephone as needed

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TS-PRO 1.0 Enrollment

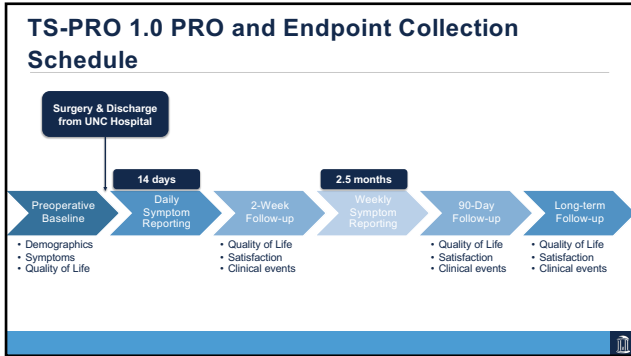
- 56% agreed to participate
- 113 enrolled and randomized
 - 57 passive monitoring
 - 56 active monitoring
- 99 participants began ePRO monitoring



```

graph TD
    A[Assessed for potential eligibility (n = 284)] --> B[Assessed for full eligibility (n = 247)]
    A --> E1[Excluded (n = 37)  
• Not meeting inclusion criteria (n = 25)  
• Other reasons (n = 12)]
    B --> C[Enrolled (n = 113)]
    B --> E2[Excluded (n = 136)  
• Not meeting inclusion criteria (n = 45)  
• Declined (n = 91)]
    C --> D[Analysed, overall sub-study (n = 45)]
    C --> E3[Excluded (n = 68)  
• Not meeting inclusion criteria (n = 10)  
• Other reasons (n = 58)]
    D --> F[Analysed (n = 99)]
  
```

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TS-PRO 1.0 Demographic Characteristics

	Active Arm (n=56)	Passive Arm (n=57)	Combined (n=113)
Male gender, n (%)	24 (42.9)	18 (32.7)	42 (37.8)
Age, mean ± sd	56.6 ± 13.6	63.1 ± 13.7	60.0 ± 14.0
Race, n (%)			
White	37 (67.2)	42 (77.8)	79 (72.5)
Black or African American	11 (20.0)	8 (14.8)	19 (17.4)
Native American or Alaskan Native	4 (7.3)	1 (1.9)	5 (4.6)
Native Hawaiian or Pacific Islander	0 (0.0)	0 (0.0)	0 (0.0)
Asian	0 (0.0)	2 (3.70)	2 (1.8)
Other	2 (3.6)	1 (1.9)	3 (2.8)
Prefer not to answer	1 (1.8)	0 (0.0)	1 (0.9)

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No demographic differences (refused vs. agreed)

	Approached (n=202)	Agreed (n=113)	Refused (n=89)	p-value
Age (years), mean (SD)	61.1 (14.1)	60.0 (14.0)	62.4 (14.3)	0.113
Male, n (%)	83 (41.5)	42 (37.8)	41 (46.1)	0.252
Ethnicity, n (%)				
Hispanic	3 (1.5)	2 (1.9)	1 (1.1)	1.00
Race, n (%)				
White	146 (73.7)	79 (72.5)	67 (75.3)	0.336
Black or African-American	38 (19.2)	19 (17.4)	19 (21.4)	
Native American/Alaska Native	6 (3)	5 (4.6)	1 (1.1)	
Native Hawaiian/Pacific Islander	1 (0.5)	-	1 (1.1)	
Asian	3 (1.5)	2 (1.8)	1 (1.1)	
Other	3 (1.5)	3 (2.7)	-	
Prefer not to answer	1 (0.5)	1 (0.9)	-	

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TS-PRO 1.0 Clinical Characteristics

	Active Arm (n=56)	Passive Arm (n=57)	Combined (n=113)
BMI	30.15 ± 7.8	28.44 ± 6.5	29.30 ± 7.2
FEV1, mean±sd	87.05 ± 20.5	79.14 ± 23.2	83.06 ± 22.1
DLCO, mean±sd	83.25 ± 21.5	73.93 ± 21.2	78.37 ± 21.7
CAD, n (%)	53 (94.6)	47 (85.4)	100 (90.1)
Diabetes, n (%)	10 (17.9)	5 (9.1)	15 (13.5)
HTN, n (%)	30 (53.6)	33 (60.0)	63 (56.8)
PVD/PE/DVT, n (%)	6 (10.7)	4 (7.3)	10 (9.0)
Smoking, current, n (%)	5 (8.9)	9 (16.4)	14 (12.6)
Smoking, ever, n (%)	31 (58.9)	38 (69)	71 (64.0)
Lung cancer, n (%)	13 (23.6)	25 (45.5)	38 (34.5)
Malignancy, n (%)	28 (50.0)	37 (88.5)	65 (59.1)

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TS-PRO 1.0 Surgery Types

	Active Arm (n=56)	Passive Arm (n=57)	Combined (n=113)
Wedge, n (%)	19 (38.0)	16 (32.6)	35 (35.4)
Segmentectomy, n (%)	1 (2.0)	1 (2.0)	2 (2.0)
Lobectomy, n (%)	10 (20.0)	16 (32.7)	26 (26.3)
Pneumonectomy, n (%)	1 (2.0)	2 (4.1)	3 (3.0)
Chest wall repair, n (%)	3 (6.0)	3 (6.1)	6 (6.1)
Diaphragm repair, n (%)	4 (8.0)	2 (4.1)	6 (6.1)
Thymectomy, n (%)	2 (4.0)	3 (6.1)	5 (5.1)
Biopsy, n (%)	7 (14.0)	4 (8.2)	11 (11.1)
Other, n (%)	5 (5.05%)	3 (6.00%)	2 (4.08%)

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TS-PRO 1.0 ePRO Participation Levels

Post-discharge timing	High (>80%*)	Moderate (50-80%*)	Low (1-49%*)	None (0%*)	Total
Daily survey delivery (14 surveys)					
Day 1-7	34%	27%	17%	22%	100%
Days 8-14	37%	28%	13%	22%	100%
Weekly survey delivery (11 surveys)					
Weeks 3-4	64%	10%	0%	26%	100%
Weeks 5-8	51%	25%	6%	18%	100%
Weeks 9-12	49%	20%	7%	24%	100%

*% of post-discharge ePRO surveys completed

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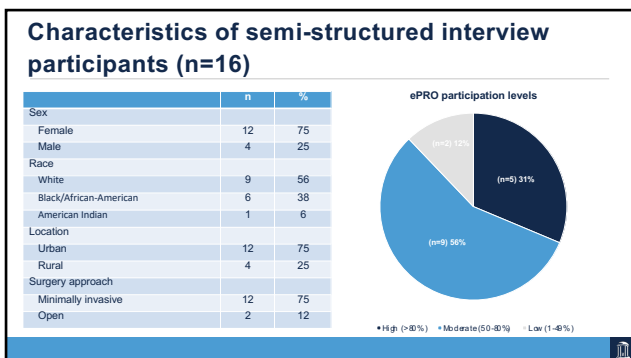
Predictors of ePRO Participation Level

	None	Low (0-50% survey completed)	Medium (50-80% completed)	High (>80% completed)	p-value
Overall	12 (12.1)	27 (27.3)	18 (18.2)	42 (42.4)	0.155
Active monitoring	4 (33.3)	12 (44.4)	13 (72.2)	21 (50.0)	
Passive monitoring	8 (66.7)	15 (55.6)	5 (27.8)	21 (50.0)	
Gender					0.179
Male	6 (50.0)	13 (50.0)	7 (38.9)	11 (26.2)	
Female	6 (50.0)	13 (50.0)	11 (61.1)	31 (73.8)	
Race					0.339
White	7 (58.3)	15 (55.6)	13 (72.2)	32 (76.2)	
Black	3 (25.0)	8 (29.6)	4 (22.2)	4 (9.5)	
Other	2 (16.7)	4 (14.8)	1 (5.6)	6 (14.3)	
Education					0.064
No college degree	9 (90.0)	15 (71.4)	5 (35.7)	19 (55.9)	
College degree or more	1 (10.0)	8 (28.6)	9 (64.3)	14 (41.2)	
Other	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.3)	
Marital Status					0.009
Not married or partnered	8 (72.7)	4 (19.0)	7 (50.0)	9 (25.7)	
Married or partnered	3 (27.3)	17 (61.0)	7 (50.0)	26 (74.3)	
Computer Frequency					0.148
Seldom or never	2 (18.2)	2 (10.0)	0 (0.0)	1 (2.9)	
Daily or often	9 (81.8)	18 (90.0)	14 (100.0)	34 (97.1)	
Smoke					0.015
Never	1 (8.3)	6 (22.2)	8 (44.4)	21 (50.0)	
Smoking ever	11 (91.7)	21 (77.8)	10 (55.6)	21 (50.0)	

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- ### TS-PRO 1.0 Patient Interview Methods
- 30–60-minute audio-taped telephone interview
 - Semi-structured interview guide:
 - Section 1. Barriers and Facilitators Encountered During Study
 - Section 2. Enrollment Experience
 - Section 3. Experience with Clinician Contacts due to Alerts (Active Monitoring Arm only)
 - Section 4. Closing

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Qualitative analysis by COM-B domains

Capability

Theme 1. **Symptoms** and physical functioning during surgical recovery were **barriers** to ePRO assessment completion.

"There was days where I was feeling awful and I didn't complete the survey, but it was because of how I was physically feeling, not because of I didn't wanna do the survey, if that makes sense."

"I think I was just mainly exhausted, and it was that [the surveys] were helpful and..."

"... a couple of weeks that I didn't complete [the surveys] ... was at the beginning because I was still going through a little bit of, I guess, side effects from the surgery, so I really wasn't doing a lot of things on the computer or on the internet at that time. That was the only time."

Callouts: "Is daily too often?", "Doing assessments when feeling better?"

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Qualitative analysis by COM-B domains

Opportunity

Theme 2. **Adequate access** to the required **technology** was a barrier to completing web-based ePROs for a few participants.

"Well, my daughter, I was usin' her email, and it wouldn't let her login... see, my daughter do that, and she live [elsewhere], so I'd rather be called on the phone to answer any survey."

"...I live in the country. If anything, the service is a little slow, but as far as loggin' in and answerin' the questions and stuff it was no problem."

"It's just I tried to log in on my phone, and it wouldn't—you know, it just wouldn't go to that website..."

Callout: "Offer telephonic even if have internet?"

95

Qualitative analysis by COM-B domains

Opportunity

Theme 3. Participants reported ease of completing the ePRO assessments.

"[The surveys] weren't that long, so they weren't time consuming at all."

"The questions and the answers were self-explanatory. It was pretty simple, pre the questions."

Theme 4. Patients preferred engagement on ePRO participation with the **surgical care team**.

"Yeah, [the surgeon] told me when we were in office, they asked me and then sent the person in...I did it more for the surgeon than if you would've hit me blind, I probably would've questioned it more... I guess it gave it legitimacy, with the surgeon [telling me]."

Callout: "Busy clinicians?"

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Qualitative analysis by COM-B domains

Motivation Shorten or tailor ePRO?

Theme 5. Participants reported **irrelevant or repeated** ePRO monitoring questions.

"I think also because the surgery didn't really turn out the way that it was expected, that I think a lot of the questions didn't really apply to me because, like I said, [surgery] didn't really do what it was supposed to do."

"I think it was aimed [at someone with more extreme symptoms]—I came back negative for cancer... and I'm in overall good health. I don't want to say [the surveys were] monotonous because you—] can see where the questions need to be asked and in the time frame that they're asked. It was just for me, it was just asking a lot of questions that I wasn't running into..."

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Qualitative analysis by COM-B domains

Motivation Tie to perioperative teaching or discharge process?

Theme 6. Participants reported a lack of clarity on ePRO assessment **integration with routine clinical care.**

"I don't know. I don't know if [my care team] see the survey, if they don't see the survey, I don't know."

"Well, I think, to begin with, I thought it was all part of the care there at UNC. I guess after talking to them, I realized that it was a study that was bein' done separate."

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Qualitative analysis by COM-B domains

Motivation

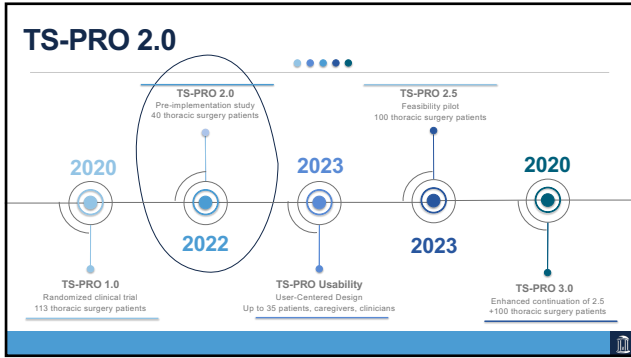
Theme 7. Participants reported increased awareness of their symptoms and recovery with ePRO use.

"I think it's beneficial because it makes you think about how you're feelin'. Again, I was goin' through so much that I think it was crucial, really, to make sure there wasn't major problems with me."

"[The questions] gives the patient time to really think about what symptoms that they may be having. They may not think about it at the moment, but when they're filling out the survey, they have a chance to think about how they're feeling... it was good [the surveys] continue to come so that if [symptoms] do come, I can write 'em down, and then hopefully someone from the team would reach out and ask me, "When did they start? How are you feeling? Do you feel like you need to come in?" Follow-up questions like that."

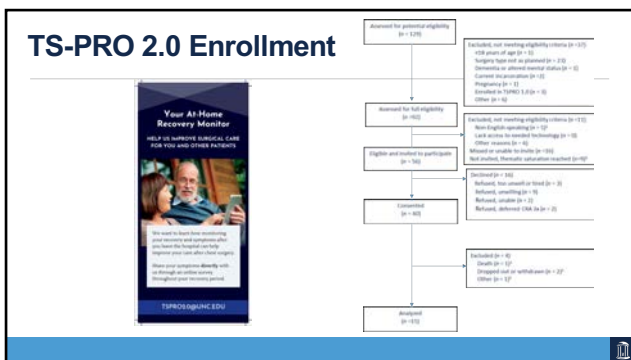
"[The surveys help] you keep up with yourself, plus you feel like you have support from another ... source."

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Audience question

- Which barriers affect ePRO implementation in your clinic?
 - A. Support from staff
 - B. Provider buy-in
 - C. Patient buy-in
 - D. All of the above
 - E. None! We already do ePRO monitoring!!

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Acknowledgements: clinical care team






Ben Halthcock Jason Long Lauren Hill Bernice Newsome Julia Coleman

IG CT Residents

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Acknowledgements: funding

- NIH National Heart, Lung, and Blood Institute (K23HL157765)  National Heart, Lung, and Blood Institute
- American College of Surgeons Foundation  AMERICAN COLLEGE OF SURGEONS
- Sivan Innovation 

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Acknowledgements

1. Slide contributions: Ethan Basch, Angela Smith, Amanda Gentry
2. UNC Pro Core

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For more information, please visit our website:

Patient-Centered Perioperative Care Research Laboratory at UNC



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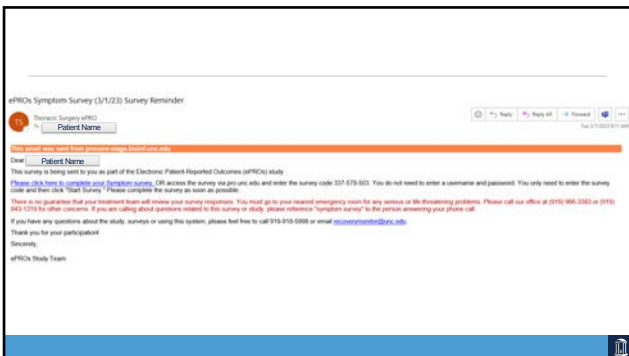
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Questions: gita_mody@med.unc.edu

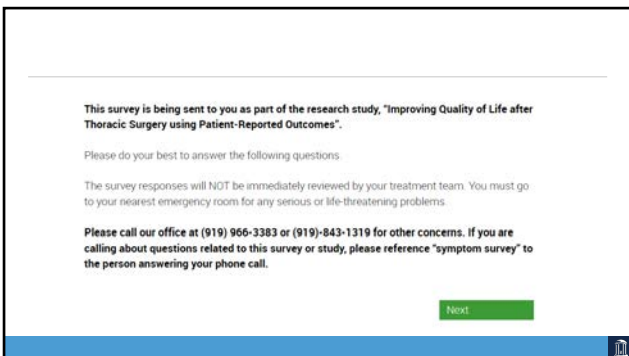
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Your Quality of Life
We are interested in some things about you and your health. Please answer all of the questions yourself by selecting the option that best applies to you. There are no right or wrong answers. The information that you provide will remain strictly confidential.

Next

115

Do you have any trouble taking a short walk outside the house?

Not at all
A little
Quite a bit
Very much

Next

116

During the past week, were you limited in doing either your work or other daily activities?

Not at all
A little
Quite a bit
Very much

Next

117

How would you rate your overall health during the past week?

1 2 3 4 5 6 7
Very Poor Excellent

Next

118

As you recover from your thoracic surgery, you may experience various symptoms and/or side effects. For each question, please select the ONE box that best describes your experiences over the past **24 hours**, so we can understand your preoperative symptoms.

Next

Department of Surgery

119

In the last **24 hours**, what was the SEVERITY of your CONSTIPATION at its WORST?

None
Mild
Moderate
Severe
Very severe

Next

120

In the last **24 hours**, how **OFTEN** did you feel a **POUNDING OR RACING HEARTBEAT** (PALPITATIONS)?

- Never
- Rarely
- Occasionally
- Frequently
- Almost constantly

Next

121

Do you have any other symptoms that you wish to report?

No
 Yes

If yes, please describe:

Next

122

This survey is complete. Thank you!

Note: This survey is used for research. If you have severe symptoms or health issues that you think need medical attention, it is important you contact your doctor directly.

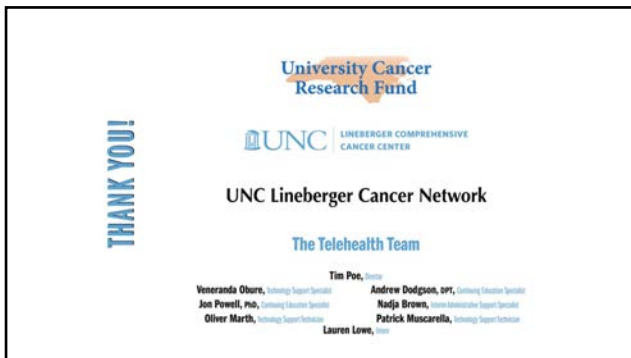
You must go to your nearest emergency room for any serious or life-threatening problems.

Please call our office at (919) 966-3383 or (919) 843-1319 for other concerns. If you are calling about questions related to this survey or study, please reference "symptom survey" to the person answering your phone call.

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SELF-PACED, ONLINE COURSES



ADVANCED PRACTICE PROVIDER
Parenting with Cancer
 Justin Yopp, PhD



RESOURCES BY PRACTICE
The Ketogenic Diet for Brain Tumor Patients: A Phase 1 Trial and Beyond
 Jethro L. Hu, MD



PATIENT CARE/CLINICAL CARE
Cancer Pathology: How Diagnosis Drives Treatment
 Yuri Fedoriv, MD

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THANK YOU FOR PARTICIPATING!

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