Bridging Survivorship and Symptom Monitoring: Building Sustainable Systems of Care across the care journey

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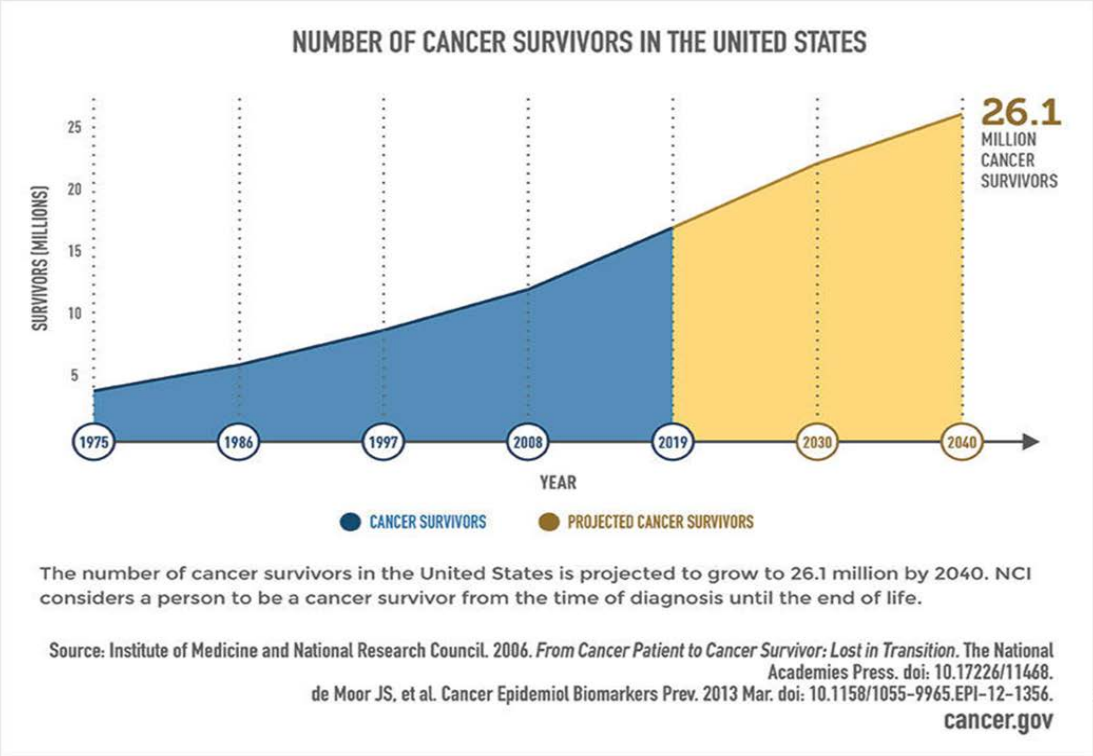
Objectives

- -To understand the science around survivorship and symptom management in cancer care
- -To develop some knowledge in implementing programs around survivorship and symptom management
- -To develop an awareness around the barriers in implementing survivorship and symptom monitoring programs

Cancer Survivors



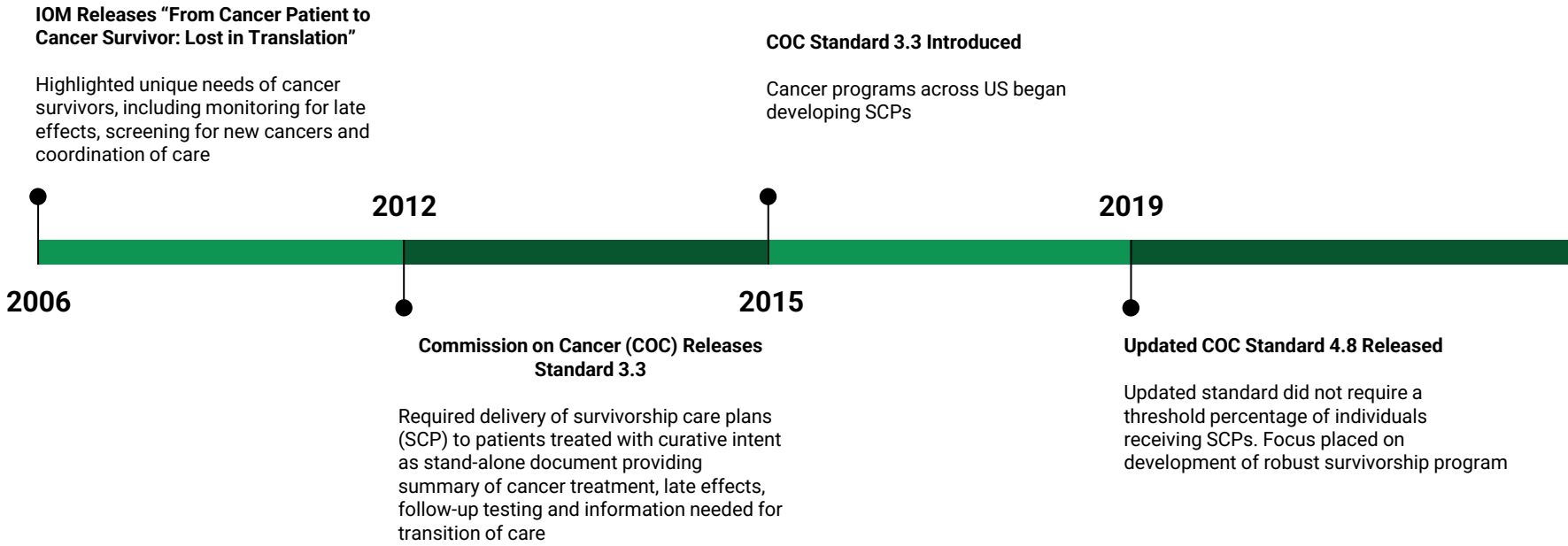
NCI definition of a cancer survivor: any individual with a diagnosis of cancer from the time of diagnosis through the trajectory of their life

Cancer Survivors and Overall Health

- Increased risk of excess morbidity and mortality in cancer survivors, but also gaps in care
  - Higher rates of treatment-related health conditions, including subsequent malignancies, cardiovascular disease, stroke
  - Gaps in care are multifactorial
    - Lack of knowledge of late effects
    - Loss to follow up from the primary oncology team,
    - Lack of regular primary care, the need to navigate critical transitional life milestones (e.g., educational pursuits,
    - Increased psychosocial and supportive care needs
    - Un/underinsurance

- Growing recognition of survivorship needs has led to development of National Standards for Cancer Survivorship Care
- Gaps in knowledge of survivorship care receipt and best practices for delivering tailored survivorship care

History of Survivorship Care and Care Plans



Mann, Nekhlyudov. J Can Surv. 2024
Blaes et al, JCO OP 2020

National Standards for Cancer Survivorship Care

•Mollica et al, J of Cancer Survivorship. 2024 Aug;18(4):1190-1199

National Standards for Cancer Survivorship Care

•Mollica et al, J of Cancer Survivorship. 2024 Aug;18(4):1190-1199

ASCO Guidelines & Metrics

ASCO Guideline Frameworks

Routine Clinical Integration: ASCO strongly endorses embedding ePROs into standard oncology practice to drive proactive symptom control.

Integrative Oncology Guidelines: Joint ASCO/SIO guidelines recommend evidence-based non-pharmacologic interventions (acupuncture, mindfulness, yoga) tracked via PROMs for pain, fatigue, and anxiety.

Quality Performance Measures

QOPI Integration: ASCO developed PRO Performance Measures (PRO-PMs) evaluating both outcome metrics (e.g., proportion with severe chemotherapy nausea) and care processes.

Value-Based Benchmarking: Uses structured patient self-reports to establish quality benchmarks across community and academic cancer centers.

Lai-Kwon et al, *Am Soc Clin Oncol Educ Book* **44**, e438512(2024)
Rocque et al, JCO 2026

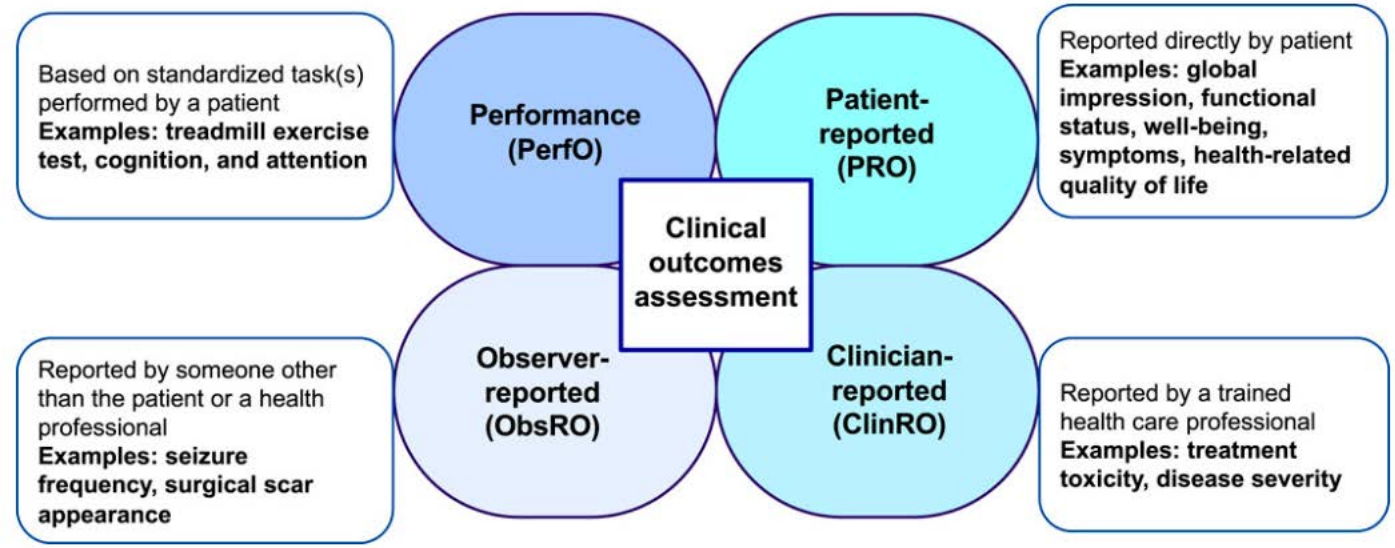


Fig 1. Types of clinical outcomes assessment.[3]

Lai-Kwon et al, *Am Soc Clin Oncol Educ Book* **44**, e438512(2024)
Rocque et al, JCO 2026

Financial Toxicity & Burden

Expanding Beyond Physical Symptoms

Modern symptom literature emphasizes that physical side effects intersect heavily with psychosocial distress and financial hardship.

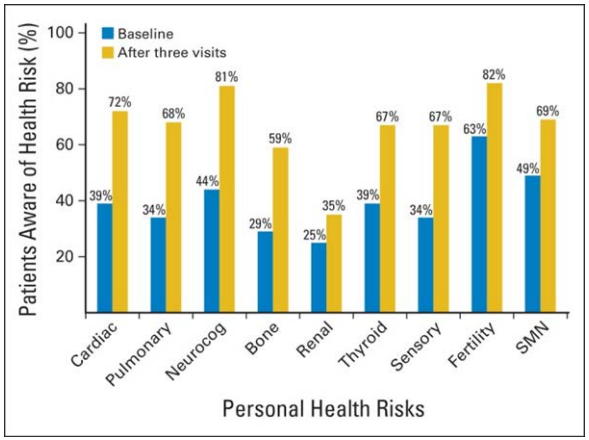
Out-of-Pocket Expenses: High treatment costs predict medication non-adherence and lower quality of life.

Holistic Screening: PRO instruments now screen for financial toxicity (COST tool), mood disorders, and caregiver burnout.

Navigational Support: Automated alerts connect distressed patients with financial counselors and social work teams.

What evidence is there to support survivorship and symptom management?

Survivorship Care Improves Knowledge about Followup and Improves Long Term Screening

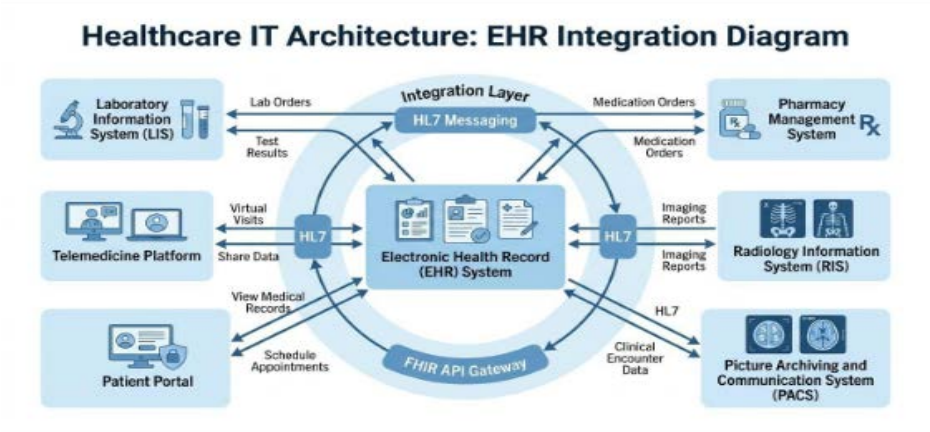


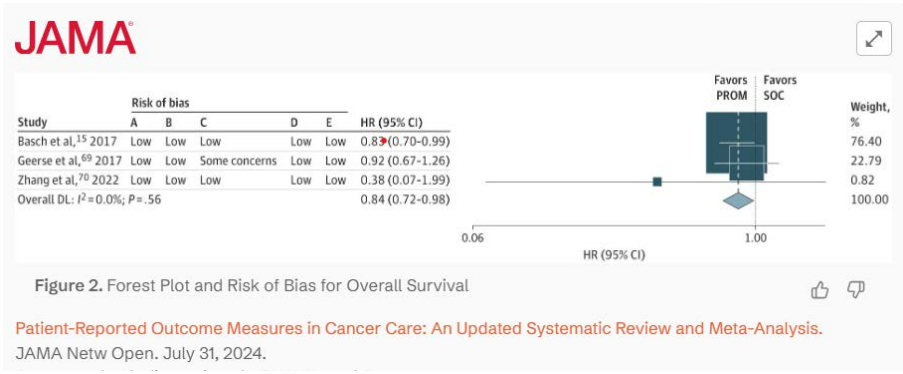
Breast cancer and CV screening outcomes by use of LTFU clinic

Variable	All patients N=41		No LTFU clinic N=18		LTFU clinic N=23		p value
	N	%	N	%	N	%	
Screening for breast cancer							0.71
No	8	19.5	4	22.2	4	17.4	
Yes	33	80.5	14	77.8	19	82.6	
Mammogram only							0.11
No	24	58.5	8	44.4	16	69.6	
Yes	17	41.5	10	55.6	7	30.4	
Any MRIs							0.003
No	21	51.2	14	77.8	7	30.4	
Yes	20	48.8	4	22.2	16	69.6	
Dual screening							0.02
No	26	63.4	15	83.3	11	47.8	
Yes	15	36.6	3	16.7	12	52.2	
MRI recommended							0.002
No	12	29.3	10	55.6	2	8.7	
Yes	29	70.7	8	44.4	21	91.3	
CV screening							0.007
No	13	32.5	10	55.6	3	13.6	
Yes	27	67.5	8	44.4	19	86.4	

Landier W, Chen Y, et al, JCO 2015
Baxstrom K, Blaes AH. Support Care Cancer 2018

eSyM Trial: Background & Rationale




JAMA

Study	Risk of bias A	B	C	D	E	HR (95% CI)	Weight, %
Basch et al,[15] 2017	Low	Low	Low	Low	Low	0.83 (0.70-0.99)	76.40
Geerse et al,[69] 2017	Low	Low	Some concerns	Low	Low	0.92 (0.67-1.26)	22.79
Zhang et al,[70] 2022	Low	Low	Low	Low	Low	0.38 (0.07-1.99)	0.82
Overall DL: I^2 = 0.0%; P = .56						0.84 (0.72-0.98)	100.00

Figure 2. Forest Plot and Risk of Bias for Overall Survival

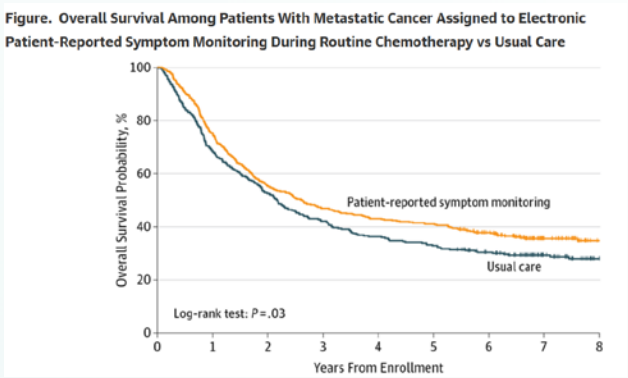
Patient-Reported Outcome Measures in Cancer Care: An Updated Systematic Review and Meta-Analysis.
JAMA Netw Open. July 31, 2024.

Hassett et al. Pragmatic trial eSYM using cluster randomized trial design

Survival & Tolerability Gains

+5.2

Months Median Survival Benefit



Landmark Trial Findings (Basch et al.)

Overall Survival: Routine ePRO tracking during chemotherapy demonstrated a statistically significant survival gain compared to standard care.

Extended Therapy Duration: Proactive symptom detection enabled patients to tolerate active cancer treatments longer at therapeutic doses.

Reduced ER Visits: Early nursing intervention triggered by ePRO alerts led to a 7% absolute reduction in emergency room visits.

Basch et al, JAMA 2017;318;(2):197-198.

Clinical Benefits Comparison

National cluster-randomized trial data confirm that digital PRO monitoring confers significant advantages in physical functioning, overall health-related quality of life, and symptom control in community oncology settings.

Lizan et al, Cancers 2021

SIMPRO Consortium & Implementation

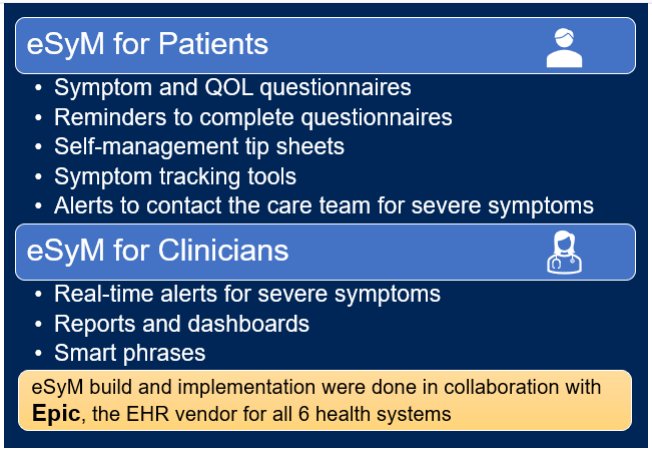
Consortium Collaboration

Six diverse health systems collaborated within the SIMPRO Consortium to build and deploy eSyM across academic CCCs and community cancer networks.

Institution	Description
BAPTIST	Community cancer network
Dartmouth Health	Academic medical center / NCI designated CCC
Legorreta Cancer Center, Brown University	Academic medical center
WVU Cancer Institute	Primary/academic cancer center
MaineHealth Cancer Care Network	Primary center/Community cancer network
Dana-Farber Cancer Institute	Academic medical center / NCI designated CCC

Epic EHR Integration

eSyM build and clinical workflow integration were developed directly in collaboration with Epic, standardizing symptom tracking across centers.



Prior analyses of the eSyM study found…

Reach

- After implementation, ≈50% of patients used eSyM to report symptoms

Symptom Burden

- **Implementation** of eSyM was associated with reduced symptom burden for fatigue and anxiety, with clinically meaningful differences observed among surgical patients.

Acute Care Utilization

- **Implementation** of eSyM was NOT associated with acute care utilization across all 6 health systems, but there was heterogeneity with significant effect seen at some sites
- After implementation, **use of eSyM** to report symptoms was associated with a 9-22% reduction in ED visits and a 20-39% reduction in hospitalizations

eSyM Reporter vs Non-Reporter OS

Primary evaluation: No difference in survival in all comers

Secondary Evaluation Findings

Among post-implementation cohorts, patients who actively used eSyM to report symptoms experienced significant overall survival benefits:

- **Chemotherapy:** 78.2% OS (Reporters) vs 65.2% (Non-reporters) — Adjusted Diff -10.0%.
- **Surgery:** 96.6% OS (Reporters) vs 92.3% (Non-reporters) — aHR 0.58 (P < 0.001).

Fostering engagement is critical.

Survivorship Care Plans

- Several nonrandomized studies have suggested benefits including increased knowledge, surveillance, coordination of care and patient/stakeholder satisfaction, but significant heterogeneity in study design and outcome measurement exist.
- A review of 13 randomized controlled trials showed SCPs did not improve physical, functional and psychological well being outcomes.
- More recently, pediatric cancer survivors may have improved overall survival when actually followed with SCP. Our prior work, receipt of SCPs results in higher levels of knowledge about cancer treatment.

Ji, X., Williamson Lewis, R.S., et al, JNCI 2026.
Nissen MJ, Tsai ML, Blaes AH, et al. J Cancer Surviv. 2012 Mar;6(1):20-32.
Nissen MJ, Tsai ML, Blaes AH, et al, . J Cancer Surviv. 2013 Jun;7(2):211-8.
Baxstrom K, Peterson BA, Lee C, Vogel RI, Blaes AH. Support Care Cancer. 2018 Jul;26(7):2361-2368.

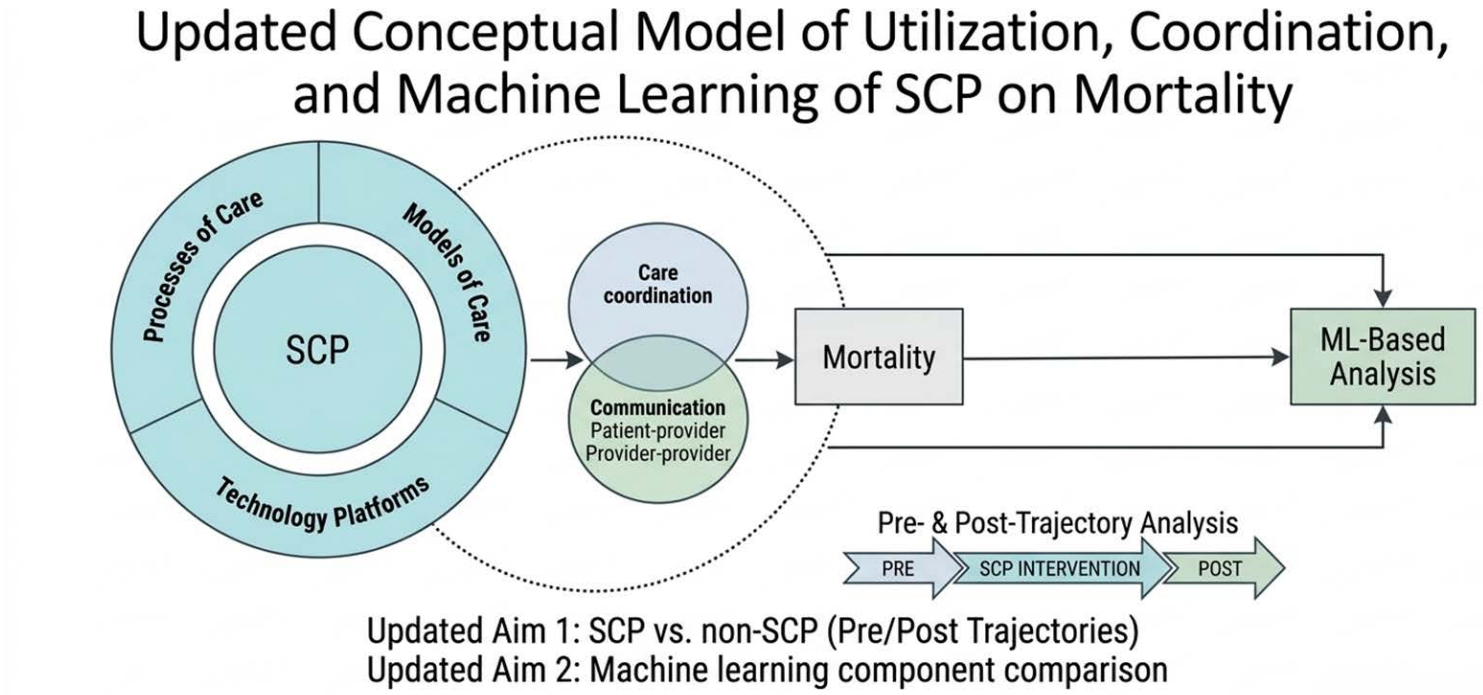
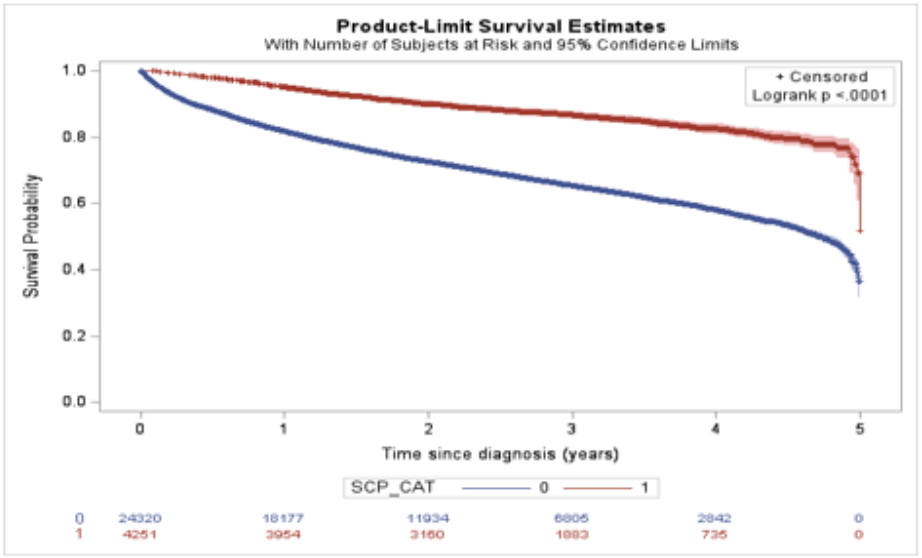
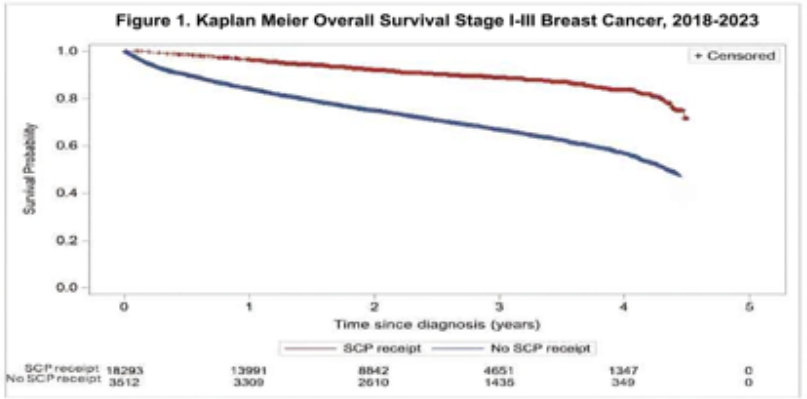


Figure 2. Updated conceptual model of utilization, coordination of SCP, pre/post trajectories, ML-based analysis, and impact on mortality. (Adapted from Pary et al.)

Survivorship Care Plans and Overall Mortality





SCP receipt and reduced overall mortality (Hazard Ratio 0.48, Confidence Interval 0.49-0.53; p<0.0001).

Similar results across almost all disease types, and by age at diagnosis (AYA), stage of disease

U48DP006834(PIs Blaes/Marmor/Laska)
P30CA077598-26 (Pis Blaes/Parsons

Blaes et al, ASCO Quality 2026

Understanding the impact of survivorship care on health outcomes in cancer survivors

- **<u>Aim 1:</u> Identify risk factors for underutilization of survivorship care (SC) in AYA survivors, and assess alignment with National Standards for Cancer Survivorship Care**
  - EHR linkage of AYA and cancer registry
  - Examine survivorship visit (outcome)
  - Online patient survey (risk factors, perceived barriers)
  - Alignment of standard

- **<u>Aim 2</u>: Identify strategies to address barriers to survivorship care and optimize programmatic alignment with National Standards.**
  - Key informant interviews health system leaders, providers, AYA survivors (utilizers and nonutilizers)

Figure 1: Measures to be collected adapted from standards

Theme	Specific entity	Data Source (score)	
		EHR	Patient survey
Cancer care follow up			
	Follow up care for at least five years	✓ (0,1)	
	Monitoring for late effects and chronic conditions	✓ (0,1)	
	Referrals to specialists for chronic conditions or prevention of chronic conditions	✓ (0,1)	
Survivorship care access			
	Survivorship / LTFU program visit	✓ (0,1)	
	Receipt of survivorship care plan	✓ (0,1)	
Access to specialty care	Specialty care appointment	✓ (0,1)	
Risk of recurrence or new cancers assessed	Genetics and/or screening for second cancers	✓ (0,1)	
Care planning process, shared goals of care, advanced care planning and coordination with other providers	Primary care visit		✓ (0,1)
Lifestyle/Wellbeing/ psycho-oncology			
	Tobacco use, diet/nutrition counseling, promoting physical activity	✓ (0,1)	✓ (0,1)
	Nutrition, OT/PT, PMNR, sexual health, fertility services, dental services	✓ (0,1)	
	Financial hardship/toxicity addressed Social work referral	✓ (0,1)	
	Emotional/psychologic assessment	✓ (0,1)	✓ (0,1)
	Social work/return to work/school		✓ (0,1)
Total score (15)		11	4

P30CA077598-26.
Co-PIs: Anne Blaes and Helen Parsons

Structural and Systemic Barriers

Financial & Insurance Obstacles

Payment/reimbursement issues and insurance-related barriers affecting care access

Geographic & Service Access

Challenges related to facility location, driving distance, and available services, particularly in rural populations

Health System and Institutional

Barriers

- Interdisciplinary care and knowledge gaps
  - Limited awareness or integration of survivorship care guidelines
- Institutional deprioritization of survivorship care
  - Reduced focus and resource allocation for post-treatment care
- Health system complexities
  - Logistical efficiencies like referral process barriers, scheduling challenges
- Fragmented care transitions
  - Pediatric to adult oncology

Facilitators

- Comprehensive survivorship care
- Holistic care
- Normalizing survivorship care
- Provider education
- Referring provider buy-in
- Survivorship procedures and processes
- Utilizing technology (e.g., virtual care)

Rick T, … Blaes AH, Parsons, H. Cancer Medicine 2026

- **“I feel fairly fortunate that my oncologist was focused on survivorship care and did refer me to someone to talk to, as well as physical therapists.” - Participant 6**

- **“I feel like I’m just out on my own. My doctor is not engaged in supportive care.”**

- **“I’ve been in treatment for 11 years. And right now, it's the longest I've ever made it, 4 months, without going to the doctor. It was once a month for probably 10 years. I highly recommend therapy.”**

Real implementation of Survivorship Care and Symptom Reporting (ePROs)

Cancer Survivorship Care - University of Minnesota

- University of Minnesota
- Univ of Minnesota Physicians
- Masonic Cancer Center
- MHealth Fairview

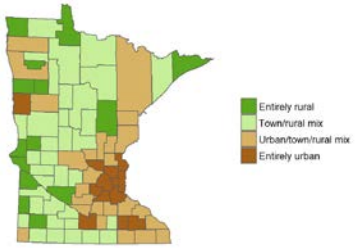


Figure 2: The Minnesota State Demographer analyzed census tracts to determine what type of mix is within each county, providing a more nuanced story for Greater Minnesota when analyzing economic and demographic trends. (Data: MN Demographer's Office)

Adult Cancer Survivors

Consultative LTFU Clinic

Individuals > 5 years dx

2009

→ Initially MD, APP

↓

With changes in understanding survivorship care across the trajectory of cancer care, LTFU clinic has been maintained

→ Survivorship care embedded within disease teams*

↓

Goal: connecting patients to supportive care services, implementation of research

→ Project specific embedded research*

Dr Tara Rick, PA-C, PhD**

Embedded within our APPs, disease teams

Kaia Verich, RN, BAN, OCN*

Dr Anne Blaes, MD MS

** Clinical care: Supported by our Serviceline partner
Research: Grants, philanthropy, MCC, institution

Digital ePRO Triage Workflow

Enrolled in eSYM at the time of starting new chemotherapy

1. Survey Trigger

Automated SMS/email notification prompts patient weekly between visits.

2. Self-Report

Patient completes PRO-CTCAE survey via mobile app or web portal.

3. Auto Analysis

System scores responses; severe scores trigger real-time clinical alert.

4. Care Action

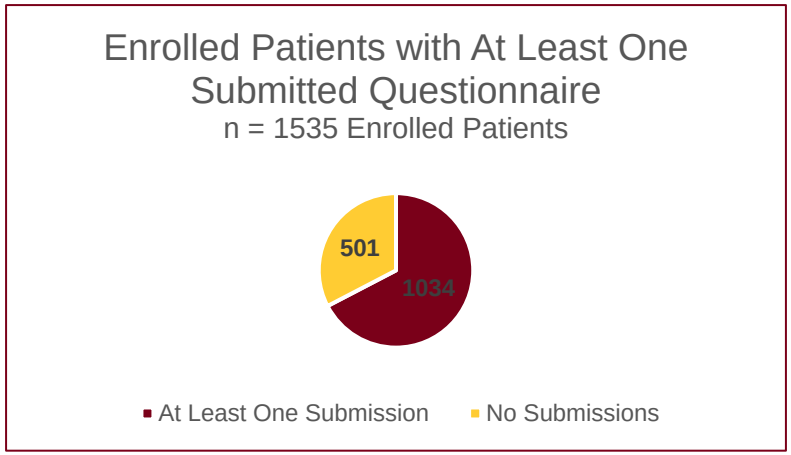
Triage nurse reviews alert, contacts patient, and adapts treatment plan.

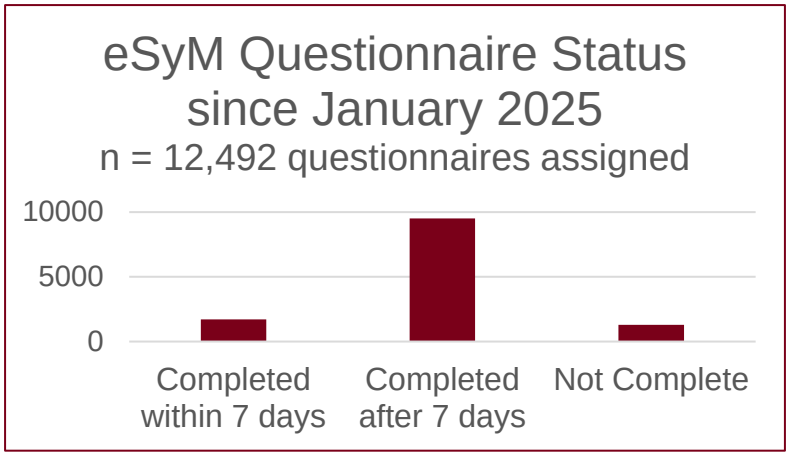
3. Educational platforms on symptom mgmt

eSyM Patient Enrollment and Engagement

-5,640 patients have been eligible for eSyM enrollment between 1/1/2025 – 7/31/2026. 1,535 patients, or 27%, have been enrolled.

-Of the 1,535 patients enrolled since January 2025, 1,034, or 67% of patients have completed at least one questionnaire.



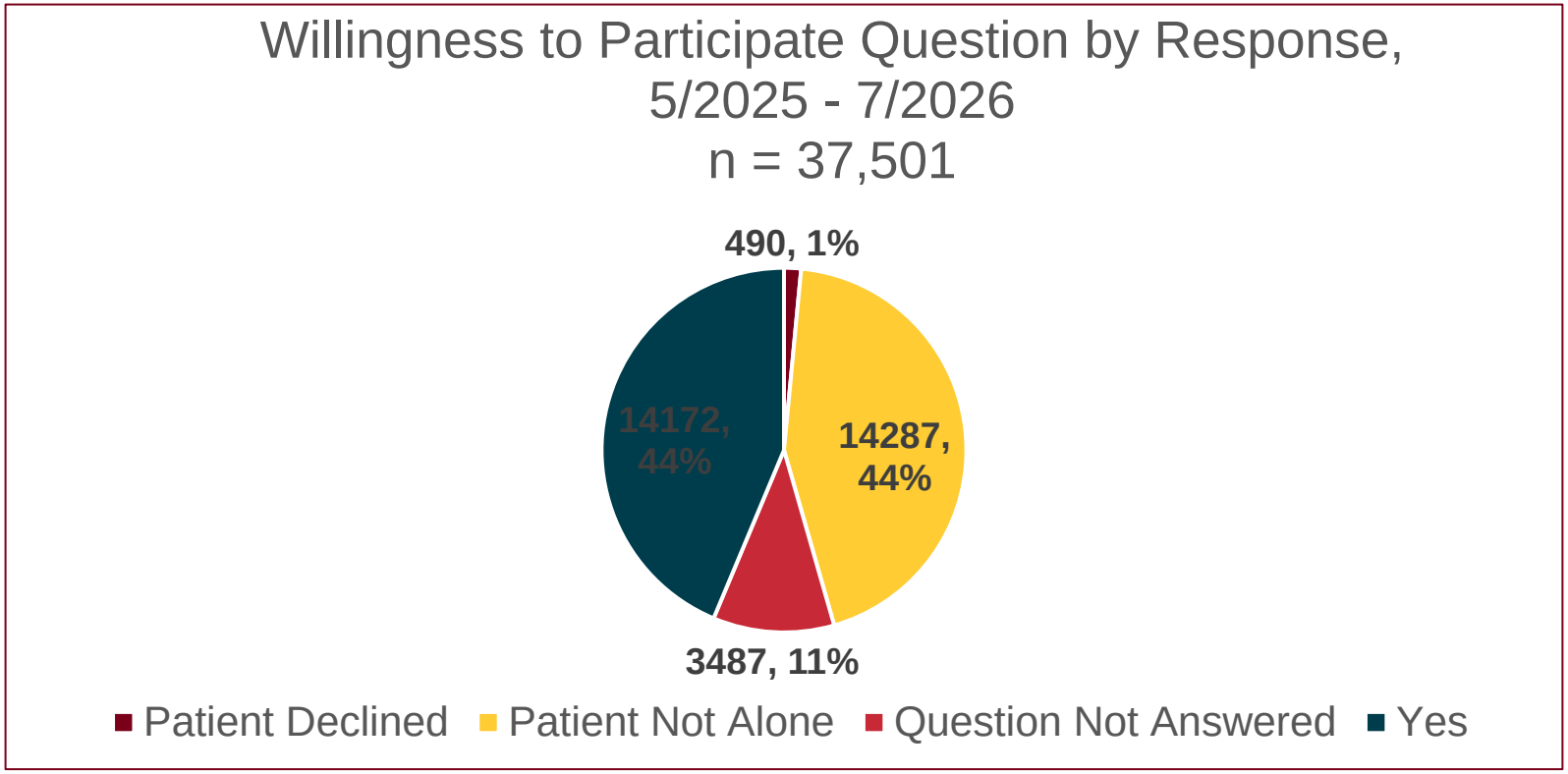


Q1 2026 eSyM Activity Summary

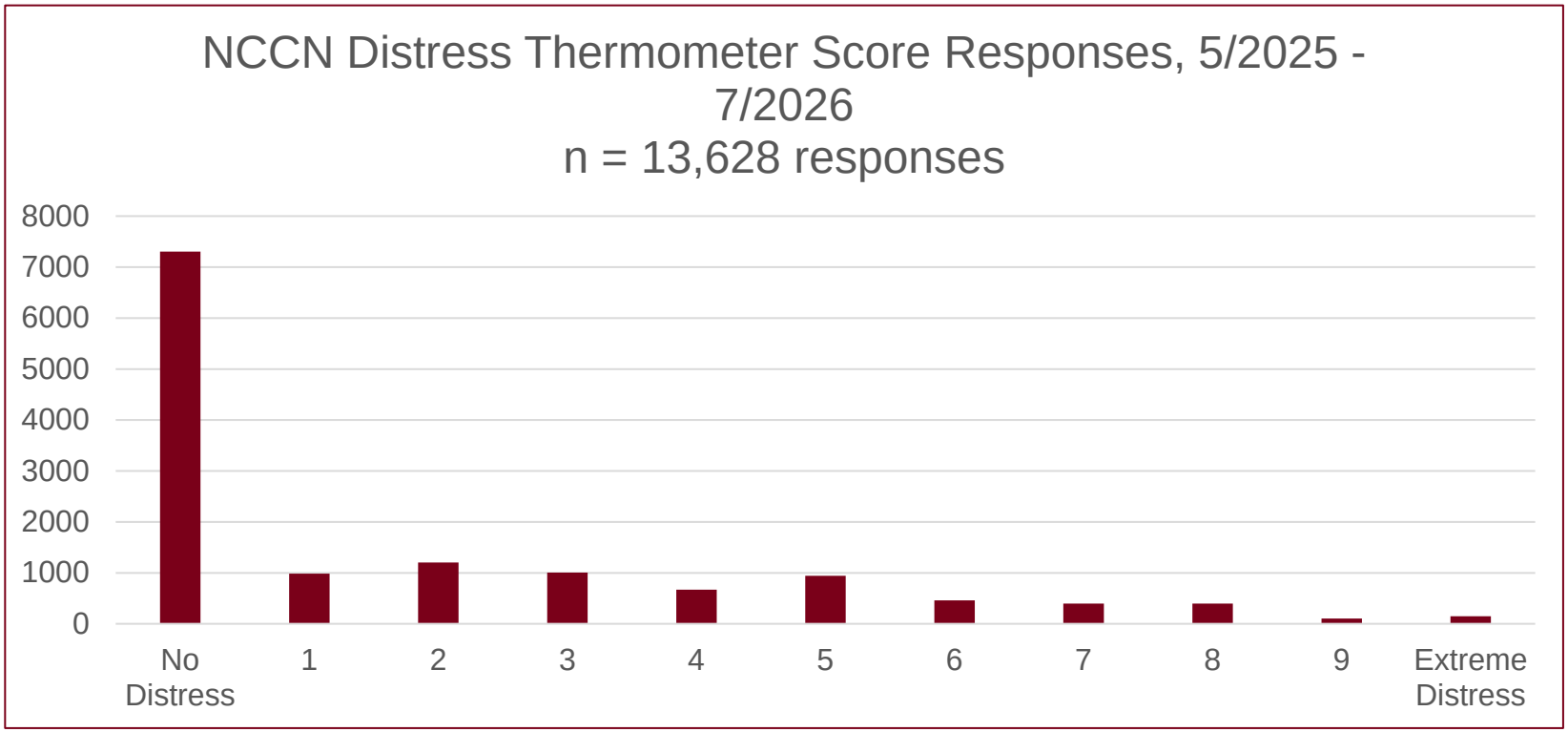
- 12% of questionnaires included a report of at least one severe symptom
  - Top severe symptom ratings include pain, fatigue, difficulty sleeping, anxiety, constipation

- 1,324 education tasks were assigned
  - 864, or 64%, of the tasks were complete
    - Top education task assignments include managing wellbeing, rash, pain, fatigue, numbness and tingling

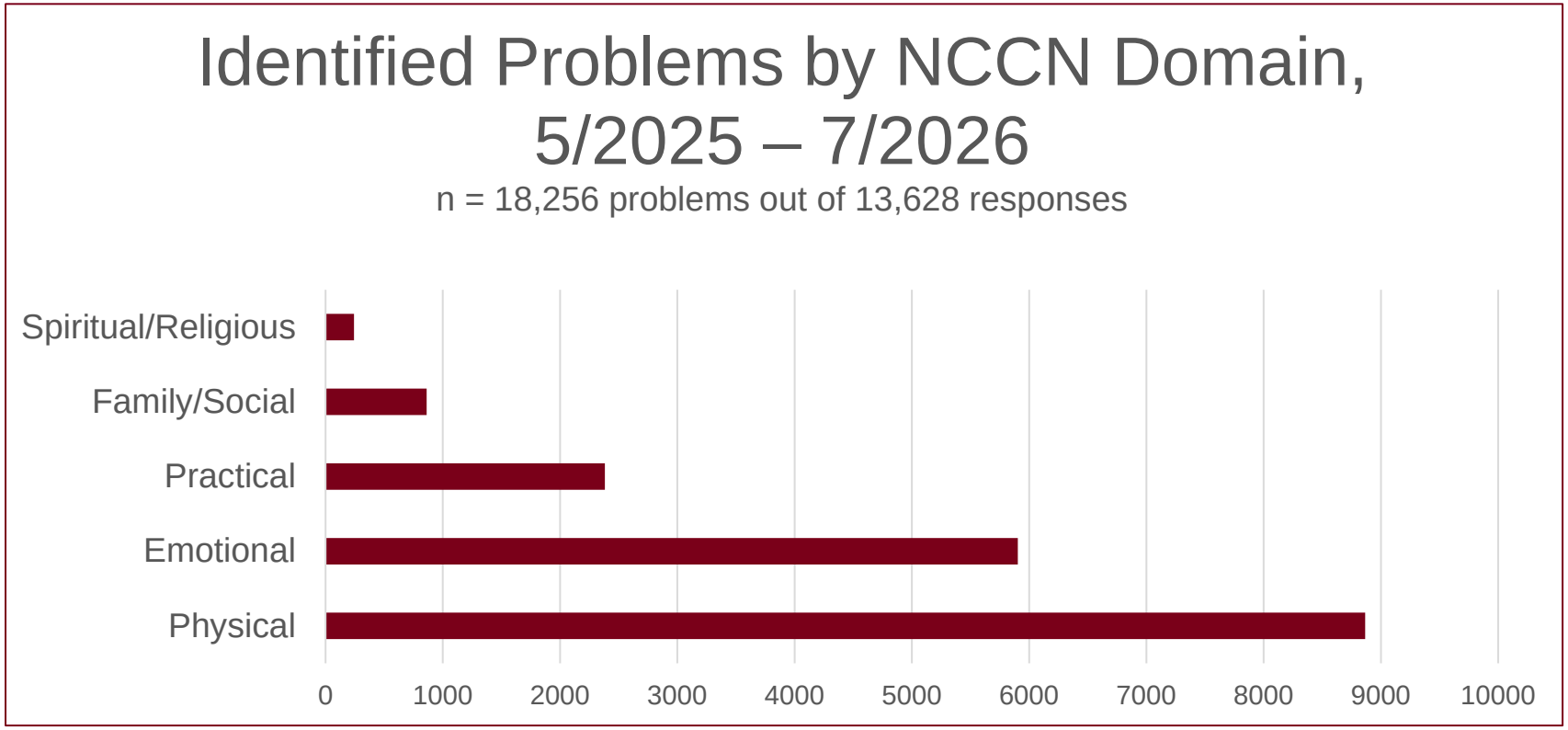
NCCN Distress Thermometer Participation



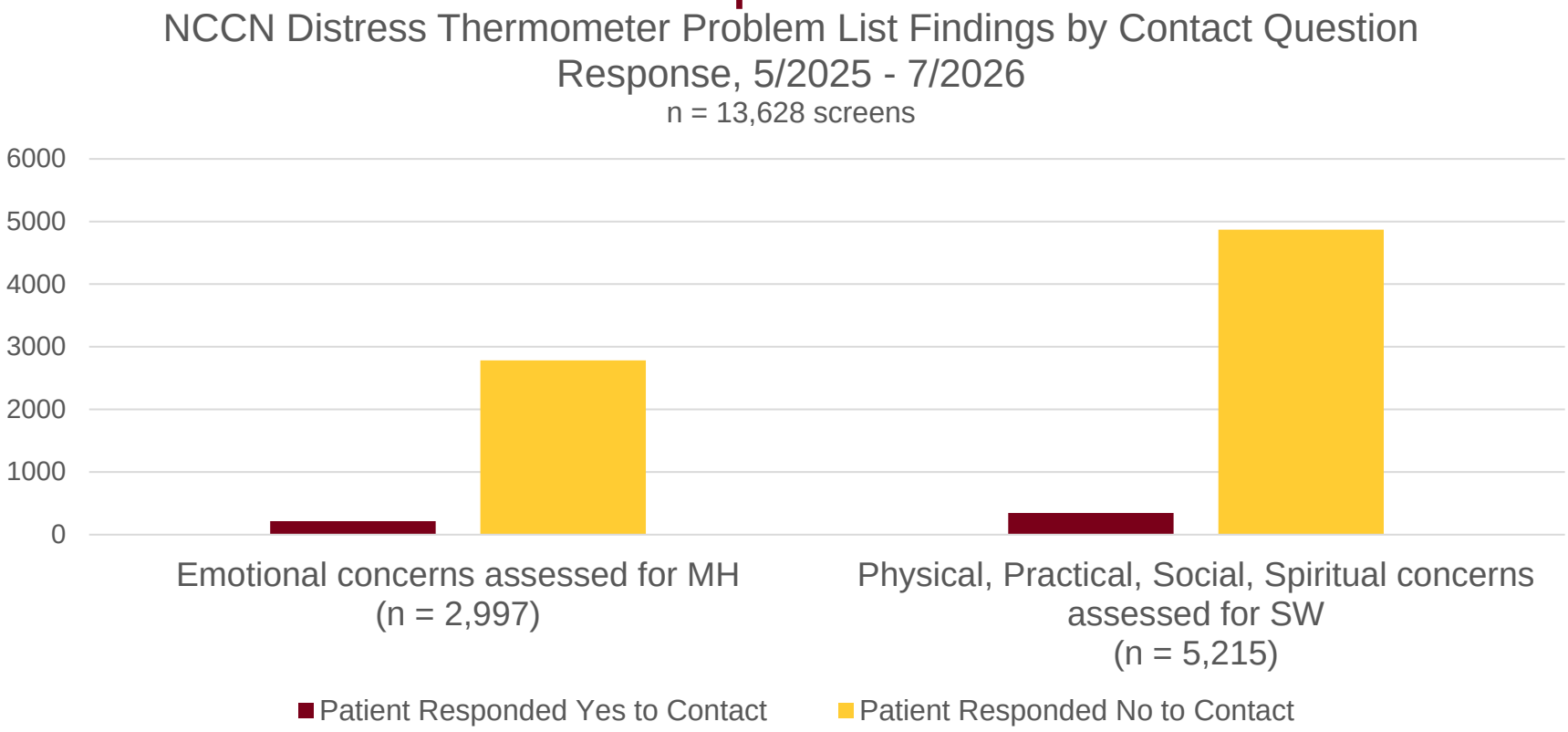
NCCN Distress Thermometer Responses



NCCN Distress Problem List Findings



NCCN Distress Problem List Findings and Related Responses



Next Steps for NCCN Distress Thermometer

- Removal of ‘patient not alone’ option in rooming documentation
- Discussion around use of ipads in clinics for patients to complete it independently, or assignment in MyChart prior to visit
- Consider impact of patient level barriers such as survey fatigue, preferred language, role of caregiver in completing surveys, etc

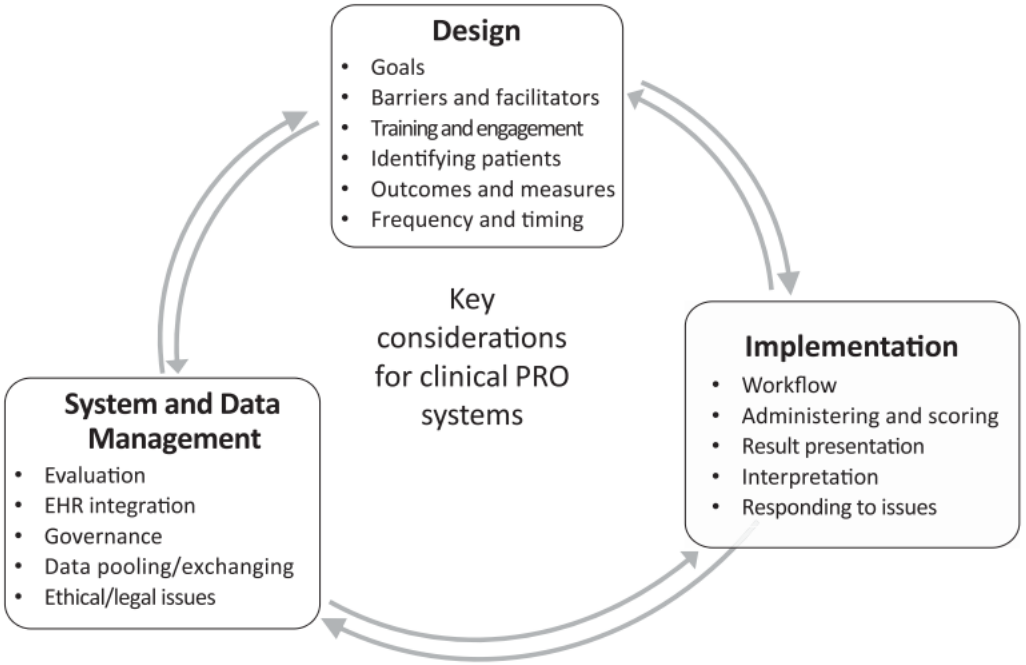


FIG 4. Key considerations for integrating PROs into clinical systems.[66] EHR, electronic health record; PROs, patient-reported outcomes.

Oncology Supportive Care Services

OVERVIEW

Any cancer journey impacts your mind, body, and spirit. The supportive services below are available to help enhance your experience, wellness, and quality of life. Please speak to your care team if you would like to access any of these services as part of your current cancer treatment. Your health plan may require a referral from your provider in order for charges to be covered by your plan. Please speak to a representative from your health plan to learn what services require a referral from your care team, and what services are covered by insurance.

AVAILABLE SERVICES

Cancer Rehabilitation: Our cancer rehabilitation program includes a physical medicine and rehab (PM&R) physician, physical and occupational therapists, and speech language pathologists, all of whom have specific training and experience working with cancer survivors. They will evaluate your individual needs and goals, while working with you and your cancer care team to develop a personalized treatment plan, which may include things like improving your ability to function physically and

MORE INFORMATION

If you are interested in learning more general information about these services, please scan the QR code and enter your information to have one of our survivorship nurses connect with you or visit the M Health Fairview Cancer Care webpage at mhealthfairview.org/thecareforcancer.

costs of living, empowering you to learn about options for managing medical bills, or connecting you with a financial assistance navigator for health insurance support. Please contact your cancer care team and ask to speak with an oncology social worker.

Health and Wellbeing Questions Assistance*: The University of Minnesota offers different websites to support the health and wellbeing of all people: the Cancer Survivorship Program, the Earl E. Bakken Center for Spirituality & Healing, and Taking Charge of Your Survivorship. On these sites, you can find safe and reliable information on topics such as mindfulness,

Survivorship Education Opportunities

- For Patients and Caregivers**
  - Annual Survivorship Conference – 20th year
    - 400-500 attendees
  - Thrive Educational Series
    - Spring/Fall series
    - Online Access at https://survivorship.umn.edu
  - Monthly webinars nurses/APPs/MDs
    - RN credits CME

R13CA278261
Blaes
**MCC Led; others are a partnership

Survivorship Standard Service Reviews

2022	2023	2024	2025
Acupuncture	Nutrition	Breast Cancer Rehab	Survivorship Long Term F/U Clinic
PM&R/Cancer Rehab	Living Beyond Breast Cancer	Sexual Health	Cardio-Oncology
Survivorship Care Plans	Survivorship Care Plans	Social Work	Mental Health

*SCPs were done routinely for all completing curative intent therapy til 2023

Cancer Survivorship Program – Clinical Program

Table 3 Successes, challenges, and future directions

	Successes	Challenges	Future direction
Clinical	• Unique model that prioritizes individualized cancer survivorship care across the lifespan • Separate survivorship groups working together in a team approach (childhood, adult, BMT) • Leadership buy-in • Dedicated MD/APP champions and program manager • Electronic health system support • COVID-19 pandemic served as a catalyst for the rapid adoption of virtual care, which has reduced geographical barriers to care	• Engagement of primary oncologists and primary care in utilizing cancer survivorship and smooth transitions • Lack of consistent guidelines in adult cancer survivors • Translating the action items of the SCP into provider orders • During the early COVID-19 pandemic, services were temporarily paused as they were considered lower priority	• Introduce cancer survivorship early in the cancer continuum • Enhance the diversity of our patient populations, such as those who live in rural areas, gender, racial, and ethnic minorities, and patients living with cancer by working community outreach and engagement • Expand on areas of expertise within our program, such as focusing on cardio-oncology, aging, and sexual health • Implementing a learning health-care system to enhance efficiency and accessibility for our patients
Education	• Leveraging of community and philanthropic partnerships has increased patient resources, shared knowledge, enhanced community engagement and increased reach and impact • Unique educational programs for researchers, medical trainees, clinical workforce (RNs, APPs, MDs)	• Organization of patient education materials on several web pages across our research programs and clinical partners	• Creating centralized e-learning modules for our patients • Centralizing educational programs for clinical staff
Research	• Bidirectional research infrastructure is well-established addressing research questions raised by patients, allowing patient participation in research activities on multiple levels	• Challenges compiling data across programs due to the differing data points collected by each program • Financial support to leverage databases and research teams	• Utilizing consistent tools to measure outcomes across the program to track progress • Leveraging research programs to establish a Research Center for Cancer Survivorship Across the Lifespan

Rick T…Blaes AH, J Cancer Survivorship 2

Opportunities in real world implementation

Despite strong evidence, full implementation of ePROs, Distress thermometers and survivorship care face several ongoing challenges:

- **EHR Integration:** Integrating ePRO platforms into Electronic Health Record (EHR) workflows without creating "alert fatigue" for oncology teams.

- **Data Actionability:** Ensuring clinical teams have clear protocols for acting on intermediate-severity PRO reports.

- **Equity & Accessibility:** Designing digital PRO tools that accommodate low digital literacy, language barriers, and sensory or cognitive impairments.

Opportunities in real world implementation

- Challenges with measurements of survivorship and supportive care (particularly in analyzing large data sets EHR, claims data, etc)

- Are there opportunities with community resources as well in an effort to reduce barriers and address patient concerns?

Conclusion

- Engagement in care, whether through survivorship or ePROS, improves overall cancer outcomes
- With the growing number of cancer survivors, there continues to be opportunity to augment survivorship and supportive care needs, including PROs and supportive care needs
- Meeting the patient at the right time with the right resources remains a challenge

Questions?

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