



# The Patient Voice: Living With and Beyond Cancer in Rural Communities ECHO

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Thursday June 11, 2026

*This project was funded in part by the Centers for Disease Control and Prevention NU58DP007218.*

# Housekeeping Items



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**Please type your full name - *First Name, Last Name- organization and email into the Chat Box.*** If you're in a room with others, please add all names in the Chat for accurate attendance.

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This session is being recorded, and a link will be e-mailed to attendees and posted on the NYS Cancer Consortium Website ([nyscancerconsortium.org](http://nyscancerconsortium.org))

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Use the buttons in the *black* menu bar to unmute your line and to turn on your video.  
**If you do not wish to have your image recorded, please turn OFF the video option**

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Do NOT share any personal health information (PHI) about any patient.

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If you have a question, please type it in the Chat Box any time during this presentation.

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# Today's Agenda



Topic	Facilitator/Presenters	Time
<b>Welcome &amp; Introductions</b>	Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP	10 mins
<b>Background Information</b>	Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP	10 mins
<b>Case Presentation(s)</b>	Maureen Killackey, MD, FACS, FACOG	15 mins
<b>Discussion/Questions, Answers &amp; Solutions?</b>	Maureen Killackey, MD, FACS, FACOG	20 mins
<b>Feedback Survey &amp; Wrap Up</b>	Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP	5 mins

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# Introductions



**Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP**

**Director, Ph.D. Program in Nursing**  
Department of Doctoral Studies Stony Brook University School of Nursing



**Maureen Killackey, MD, FACS, FACOG**

**Chair, NYS Cancer Advisory Council and American College of Surgeons Commission on Cancer Site Reviewer, Bassett HealthCare**



*Speakers have no disclosures or conflicts to report.*

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# Introductions



**Christina Crabtree-Ide, PhD, MPH**  
**Director of Population Health Outreach**  
Roswell Park Comprehensive Cancer Center



**Tessa Flores, MD**  
**Medical Director of Cancer Survivorship and Screening**  
Roswell Park Comprehensive Cancer Center



*Flores has no disclosures or conflicts to report. Crabtree-Ide reports funding support from Genentech, and stock ownership of Danaher, Fortive, Vontier, and Veralto Corps.*

# The New York State Cancer Consortium

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*Working Together,  
Reducing Cancer,  
Saving Lives*



Visit us at  
[nyscancerconsortium.org](https://nyscancerconsortium.org)



We work together to implement the **NYS Comprehensive Cancer Control Plan** and reduce the burden of cancer through the following activities:



Increase public knowledge of the Consortium and Plan



Collaborate to achieve Plan goals and objectives



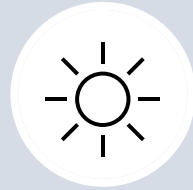
Share progress, insight and expertise



Track progress on cancer indicators tied to the Plan

# Consortium Action Teams

- Learn about the latest updates in state-wide cancer prevention efforts
- Promote Plan priorities through webinars, trainings, or workshops
- Collaborate with team members to achieve Plan goals



Skin Cancer



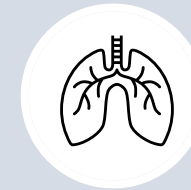
Colorectal Cancer



Environmental  
Carcinogens



HPV Coalition



Lung Cancer



HEAL (Healthy  
Eating Active  
Living)



**Survivorship**

Survivorship ECHO Program



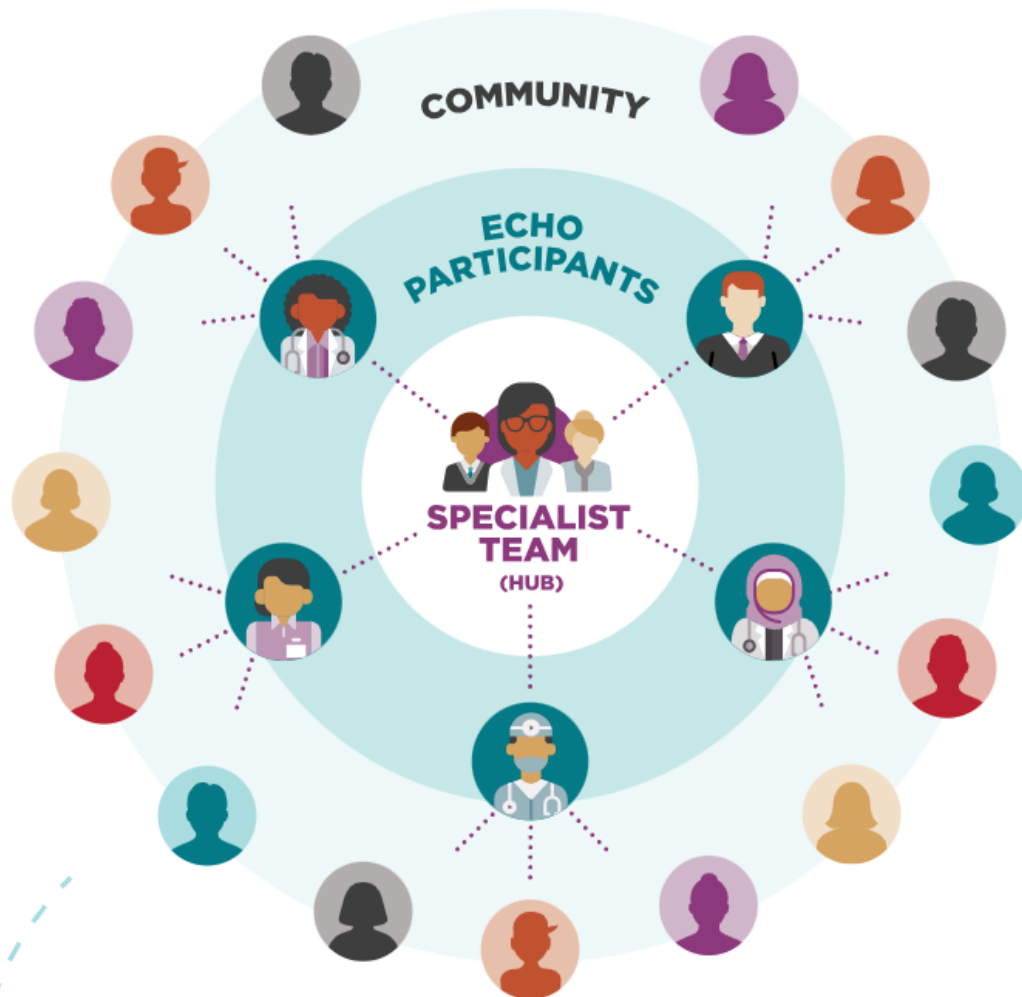
Visit us at  
[nyscancerconsortium.org](https://nyscancerconsortium.org)

# What is a Project ECHO?

Extension for Community Healthcare Outcomes



**All Teach, All Learn**



**We call it “all teach, all learn.”**

ECHO participants engage in a virtual community with their peers where they share support, guidance and feedback. As a result, our collective understanding of how to disseminate and implement best practices across diverse disciplines continuously improves and expands.

# PROJECT ECHO

*Moving Knowledge Not People*



**Survivorship ECHO Series: January 11 – June 13, 2024**  
**FREE Educational Series, CME Credits**  
**NYS Cancer Consortium, NYS Survivorship Action Team**  
**Supported by CDC Grant and SUNY Upstate for CME Credits**

## WHO CAN JOIN?

**Primary care teams** providing care to rural and underserved/under-resourced populations in NYS

Any **multi-disciplinary teams** who care for cancer survivors in NYS

**All sessions in this series will be held on the 2<sup>nd</sup> Thursday of the month**

Session 1: Introduction and Survivorship 101		Session 4: Survivorship Lifestyle Behaviors	
<b>January 11, 2024</b> 12-1:00pm	Maureen Killackey, MD, FACS, FACOG Tessa Flores, MD Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP <b>Facilitator:</b> Christina Crabtree-Ide, PhD, MPH	<b>April 11, 2024</b> 12-1:00pm	Mara Ginsberg, Esq. Timothy Korytko, MD <b>Facilitator:</b> Christina Crabtree-Ide, PhD, MPH
Session 2: Survivorship Teams		Session 5: Survivorship and Sexual Health	
<b>February 8, 2024</b> 12-1:00pm	Tessa Flores, MD Gregory P. Rys, NP Maura Abbott, PhD, AOCNP, CPNP-PC, RN <b>Facilitator:</b> Maureen Killackey, M.D.	<b>May 9, 2024</b> 12-1:00pm	Kristin Sobieraj, PA <b>Facilitator:</b> Tessa Flores, M.D.
Session 3: Medical Issues in Survivorship		Session 6: Supportive Care in Survivorship	
<b>March 14, 2024</b> 12-1:00pm	Craig D Hametz, MD, FACC, FASE, FASNC Tessa Flores, MD <b>Facilitator:</b> Maureen Killackey, M.D.	<b>June 13, 2024</b> 12-1:00pm	Anne Moyer, PhD Robin Eggeling <b>Facilitator:</b> Christina Crabtree-Ide, PhD, MPH

## [Register Here](#)

**CME Credit Awarded\***  
**1 AMA-PRA Category 1 Credit per session**  
 \*With completion of clinic evaluation survey



**Incentives**  
 Clinic/Provider teams who complete the 6 session ECHO program will receive a \$100 incentive



The session will be audio and video recorded. Your participation confirms your consent to this recording/photography. To ensure HIPAA compliance, patient information must remain de-identified for presentation during clinic.

# Survivorship Community Engagement Forums



## 2024: Rural Cancer Survivorship Across the Continuum

- Rural setting catchment area >> NCI designated Cancer Center

## 2026: Enhancing Rural Survivorship Care: Patient Perspectives on Navigating Healthcare Needs in Rural Communities, the Patient Voice

- Rural setting catchment area>> Multidisciplinary community hospital

### Topics explored:

- Care Coordination & Communications
- Barriers/Access to survivorship care
- Quality and Availability of care
- Impact of rural living on survivorship care & biggest challenges
- What healthcare providers should understand about their experience as a cancer survivor living in a rural community

# Improving Navigation for Cancer Survivors in Rural Communities

## OVERVIEW

This learning series will provide guidance and best practices to improve patient navigation for cancer survivors in rural communities throughout New York State. Over the course of three sessions, participants will learn how patient navigation impacts the survivor's quality of life; navigation best practices with a focus on rural settings; and the navigator's role.

## WHO CAN JOIN?

This series is open to Patient Navigators, Medical Assistants, Physician Assistants, Licensed Practical/Vocational Nurses (LPN/LVN), Registered Nurses (RN) and those at primary care sites that assist patients with overcoming barriers to receiving survivorship care.

## SESSION OVERVIEW

**All sessions take place on Thursdays from 12:00 – 1:00pm**

**MAY 8<sup>th</sup> | Transitions in Survivorship; Finding the Way**

**MAY 22<sup>nd</sup> | Navigating Communications in Survivorship Care**

**JUNE 5<sup>th</sup> | Navigating Legal & Financial Issues in Survivorship Care**

## REGISTRATION

[Register Here](#) or scan the QR code to register. For more information, please visit the Consortium website. **Pre-registration is required to attend. Attendees must commit to all three sessions.**



**CE Credits Awarded\***  
**AAPA CME, CNE, and CEU 1 Credit per session**  
 \*With completion of clinic evaluation survey

# Survivorship Community Engagement Forum

## Focus Group Findings on Care Coordination and Communication

### Person-Centered Care and Human Connection

- "Focus is lost on them as a person – it's all labs and what is entered into the computer. The human touch is gone"
- "My own doctor doesn't have time for me"
- Face to face is "best" "I'm not just data-see me not the computer"

### Challenges in Care Coordination and Fragmentation of Services

- "Feeling of disconnect between specialties and primary care"
- Information gaps after diagnosis-inadequately prepared for how sick they would feel, long-term side effects, or lifestyle changes.
- Fragmentation often forces "patients coordinate" their own care, even for complex situations
- Strong demand for summaries, "cliff notes," or care maps to support continuity.

# Survivorship Community Engagement Forum

## Focus Group Findings on Care Coordination and Communication

### Provider Understanding, Continuity, and Access to Specialists

- Need consistent provider who knows their history; desire for stability in seeing the same care provider
- Need better access to timely specialist appointments
- Gaps in specialized care "not all specialists we have access to have sufficient expertise with oncology"
- Larger healthcare systems patients felt like "a number" due to pressure on doctors

### Emotional Impact and Fear of Recurrence

- Pervasive fear amplifies the need for reliable coordination and empathetic communication, as any perceived lapse in care exacerbate anxieties
- Need better handoffs to survivorship providers
- Desire for proactive support and reassurance during transitions in care

# Session 1: Coordination and Communication

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June 11, 2026 | 12:00 - 1:00pm

**Moderator:** Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP

**Presenter:**

Maureen Killackey, MD, FACS, FACOG

# Learning Objectives

1. Identify communication barriers for cancer survivors in rural communities.
2. Identify coordination of care challenges for rural cancer survivors.
3. Describe best practices and resources needed for effective communication and collaboration between primary care providers, patient navigators and the oncology team

# Session One Case Study #1



## Patient Hx

- 52 yo female
- Lives alone in a rural area of NYS, no public transportation
- 1 adult son lives distantly
- Well-educated, managerial position with good income and insurance
- Diagnosed with triple negative breast cancer at rural facility by surgical oncologist who relocated during pt's therapy
- Neoadjuvant chemo/ICI therapy
- Interest in surgical clinical trial at NCI cancer center
- Continued chemo/ICI & RT after surgery

## Key Elements

- Housing , transportation & caregiving challenges
- Leave of absence from work; privacy issues
- Consult at NCI center=>shared care
- Neoadjuvant Rx given at rural facility; surgery to be done at NCI
- Many appts, many co-pays
- Lack of clarity & coordination: Where/when do I get labs, imaging, followup? Game plan?
- Feeling disconnect between sites, specialties & primary care
- Unaware of local/rural resources
- Patient falls through the cracks

## Barriers/Challenges

- Who is my doctor, team?
- Has PCP been kept in the loop?
- Financial toxicity
- When to return to work, concerns about workplace reception, ability
- Cognitive decline
- Due to physician staffing changes, loses initial rural Onc team
- No local Caregiver
- Unaware of the need for post op continued therapy (Info gaps)
- Who manages side effects of therapy – eg Derm?
- Next steps – eg followup team, Port removal? Surveillance?

# Session One Case Study #1



## Discussion & Questions

- When do we introduce survivorship care, transition, identify individual in that role
- How do we navigate staffing changes, while maintaining patient/caregiver trust in care, including unfavorable test results?
- What is the best practice for incorporating personalized & time appropriate Care Coordination
- How do we ensure good case management for pts

- Who is my doctor, team?
- Has PCP been kept in the loop?
- Financial toxicity
- When to return to work, concerns about workplace reception, ability
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- Due to physician staffing changes, loses initial rural Onc team
- No local Caregiver
- Unaware of the need for post op continued therapy (Information gaps)
- Who manages side effects of therapy – eg Derm?
- Next steps – eg followup team, Port removal? Surveillance?

# Session One Case Study #2



## Patient Hx

- Male, 70's
- Lives w/wife, farmers in remote area
- 1<sup>st</sup> cancer: melanoma, 2015
- 2<sup>nd</sup> cancer: delayed diagnosis, emergency surgery=>CRC
- 3<sup>rd</sup> cancer: prostate

## Key Elements

- Caregiver wife
- Concerns about maintaining farm
- Geographic, travel challenges during therapy
- Multiple physicians, ?communication & coordination
- Multiple cancers: impact on family & their risk

## Barriers/Challenges

- Exhausted patient, "3 cancer are enough"
- Exhausted caregiver, stoic, committed, frustrated
- Financial concerns
- Multiple clinical providers, varying levels of knowledge, interest – "Who is my doc? Who do I trust?" Delayed diagnosis #2

# Session One Case Study #2

## Discussion & Questions

- Is there a mechanism in place to assess caregiver burden?
- How do we navigate staffing changes, while maintaining patient/caregiver trust in care, including unfavorable test results?
- What is the best practice for incorporating culturally sensitive and time appropriate Care Coordination for end-of-life resources and/or Goals of Care conversations?
- How do we ensure good case management for pts with late disease (including financial toxicity)?

## Barriers/Challenges (Reference)

- Exhausted patient, “3 cancer are enough”
- Exhausted caregiver, stoic, committed, frustrated
- Financial concerns
- Multiple clinical providers, varying levels of knowledge, interest – “Who is my doc? Who do I trust?” Delayed diagnosis #2



# Open Discussion: Questions, Answers and SOLUTIONS?



[Brief Report](#) | [Brief Report](#)

## Nearly All Cancer Survivors Return to Primary Care

Laura C. Pinheiro, Mangala Rajan, Monika M. Safford, David M. Nanus and Lisa M. Kern

The Journal of the American Board of Family Medicine July 2022, 35 (4) 827-832; DOI: <https://doi.org/10.3122/jabfm.2022.04.220007>

## Spectrum of Disciplines Involved in Survivorship Care



## Interdisciplinary Survivorship Care Providers



Diagnosis, screening assessment, treatment, rehabilitation, survivorship or palliative care



Nurses and APNs cut across the whole spectrum of care and survivorship trajectory

### National Comprehensive Cancer Network (NCCN)

**Dr. Tessa Flores!**

**By Topic:**

- Anthracycline-induced cardiac toxicity
- Anxiety and depression
- Cognitive function
- Exercise
- Fatigue
- Healthy lifestyles
- Immunizations and infections
- Menopause-related symptoms
- Pain
- Sexual function (female/male)
- Sleep disorders

### The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, & Young Adult Cancers

**By Topic:**

- Any Cancer Experience
  - Psychosocial, Fatigue, Sleep, limitations in healthcare access, subsequent malignancy, malignancy risk offspring
- Blood/Serum Products
- Chemotherapy
- Radiation
- Hematopoietic Cell Transplant
- Surgery
- Other Therapeutic Models
- General Health Screening

### American Society of Clinical Oncology (ASCO)

**By Topic:**

- Anxiety and depression
- Cardiac dysfunction
- Chronic pain
- Fatigue
- Fertility preservation
- Neuropathy
- Palliative care

**By Cancer Site:**

- Breast (ASCO/ACS)

### American Cancer Society (ACS) Survivorship Care Guidelines for Primary Care Providers

**By Topic:**

**Holistic:**

- Care coordination
- Health promotion
- Long-term and late effects
- Nutrition and physical activity
- Screening
- Surveillance

**By Cancer Site:**

- Breast (ACS/ASCO)
- Colorectal
- Prostate
- Head and neck



# Open Discussion: **SOLUTIONS?**

# Components of a Survivorship Care Plans and/or Treatment Summaries

Tissue diagnosis, stage,  
treatment plan and  
dates of treatment,  
toxicities experience

Expected short-and  
long-term side effects of  
therapy

Surveillance plan for  
recurrence and  
secondary cancers

Recommendations for  
late term monitoring

Listing of providers  
responsible for care  
with contact  
information

Evaluation of  
psychosocial needs

Preventative, health  
promotion behaviors

Follow-up care and  
referrals

THE GEORGE  
WASHINGTON  
UNIVERSITY

WASHINGTON, DC

## Advancing Patient-Centered Cancer Survivorship Care

Adapted from the National Cancer Survivorship Resource Center

[www.cancer.org/survivorshipcenter](http://www.cancer.org/survivorshipcenter)

Dr. Maureen Killackey, GWU External Advisory Board, CoC Project

Development of this presentation was made possible by cooperative agreement #5U55DP003054 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not represent the official views of the Centers for Disease Control and Prevention. The views expressed here do not necessarily reflect the official policies of the U.S. Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. government.

# SOLUTIONS-continued



- Navigation –many models
- Personalized, “wrap around care”
- Early introduction to Survivorship, Transitions  
Integrate Palliative Care Services
- Expand workforce, care team  
Care team: Clinical, financial, legal, spiritual  
psychosocial support
- Peer to Peer support



# SPECIAL ANNOUNCEMENT

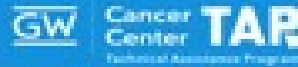


GW Cancer Center



The GW Cancer Center is a training and technical assistance provider of the Centers for Disease Control and Prevention (CDC) National Comprehensive Cancer Control Program.

**NEW**



## Getting Paid for Patient Navigation Special Topics in Patient Navigation: Getting Paid for Patient Navigation



**Free Online Training**

Estimated completion time



- 0.50 Contact hours for nursing
- 0.50 AMA PRA Category 1 Credit™
- 0.50 CHES®/MCHES®

This 30-minute training provides a 2026 update on CMS requirements to bill for patient navigation services.

[Go to training](#)

# Upcoming Session Dates

**June 18<sup>th</sup>**  
12 – 1:00pm

Session 2: Access and  
Availability in Rural  
Survivorship Care

**June 25<sup>th</sup>**  
12 – 1:00pm

Session 3: Navigating  
Health Information in  
the Digital Age



# Thank you for attending

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Please complete the  
session evaluation

