Beyond Surviving to Thriving: A Key Challenge for Cancer Survivorship

Julia Rowland, PhD
Smith Center for Healing & the Arts
Washington DC
ASPO 50th Anniversary Webinar

What I will cover…

- A brief history of cancer care in the US
- What changed?
- Where we are today
- Where we need to be headed as we look to the future…

The Dream of Yesterday

National Cancer Act of 1971

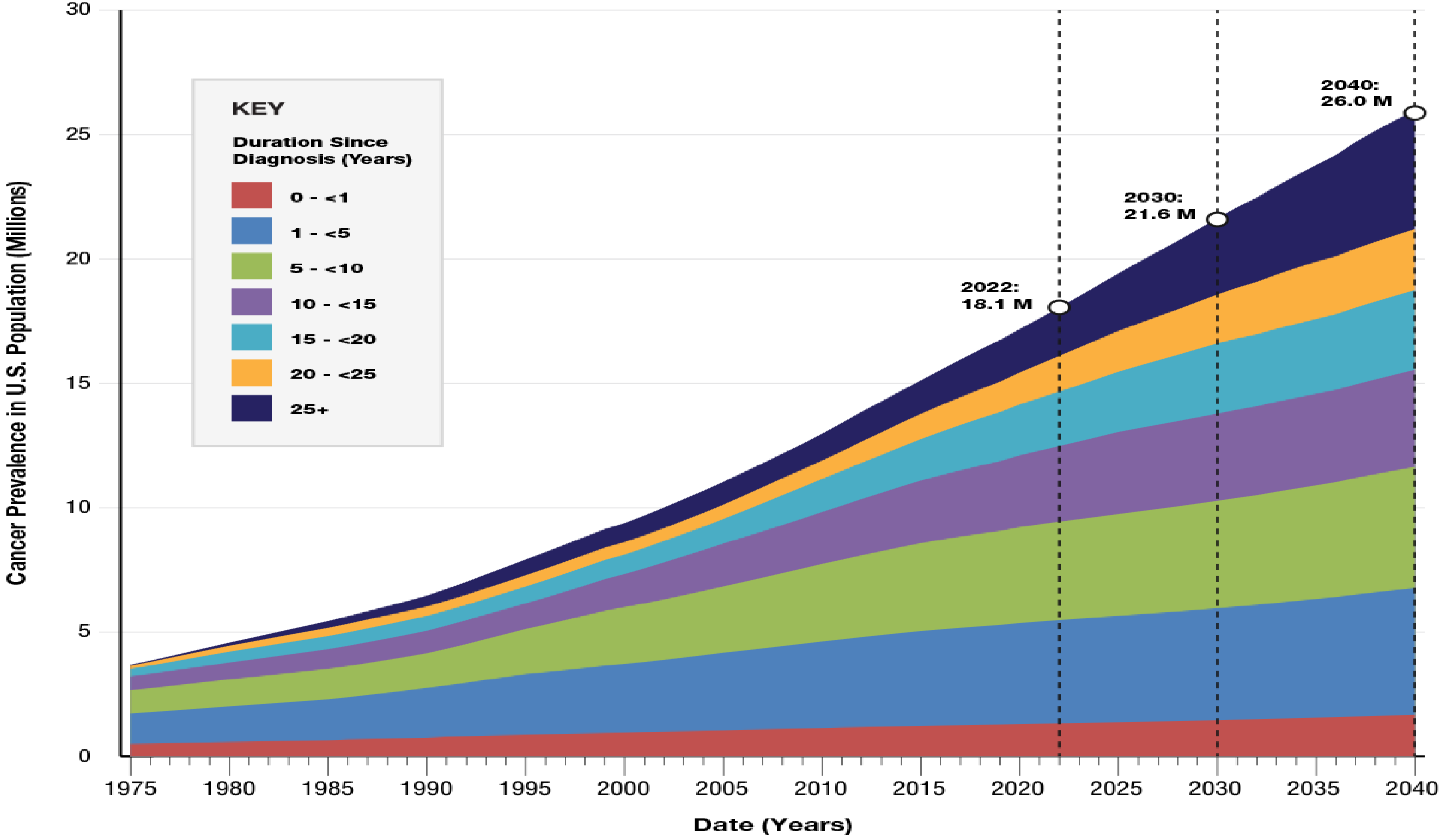
President Richard Nixon signs National
Cancer Act on December 23, 1971

“Make the Conquest of Cancer a National Crusade”

State of the Art of Cancer Care in 1971

- Fewer than half of those diagnosed could expect to be alive in 5 years
- Cancer treatments were still relatively few, frequently ineffective, and produced serious, often poorly controlled side effects (life-threatening anemia, nausea, vomiting, pain, disfigurement)
- Care was delivered largely in the hospital setting over days, sometimes weeks and months
- The focus on care was helping individuals survive the treatment or die of — not live with — their illness
- Patients (and their loved ones) were not expected to be equal partners in care; treatment decisions were made largely by physicians or the medical team

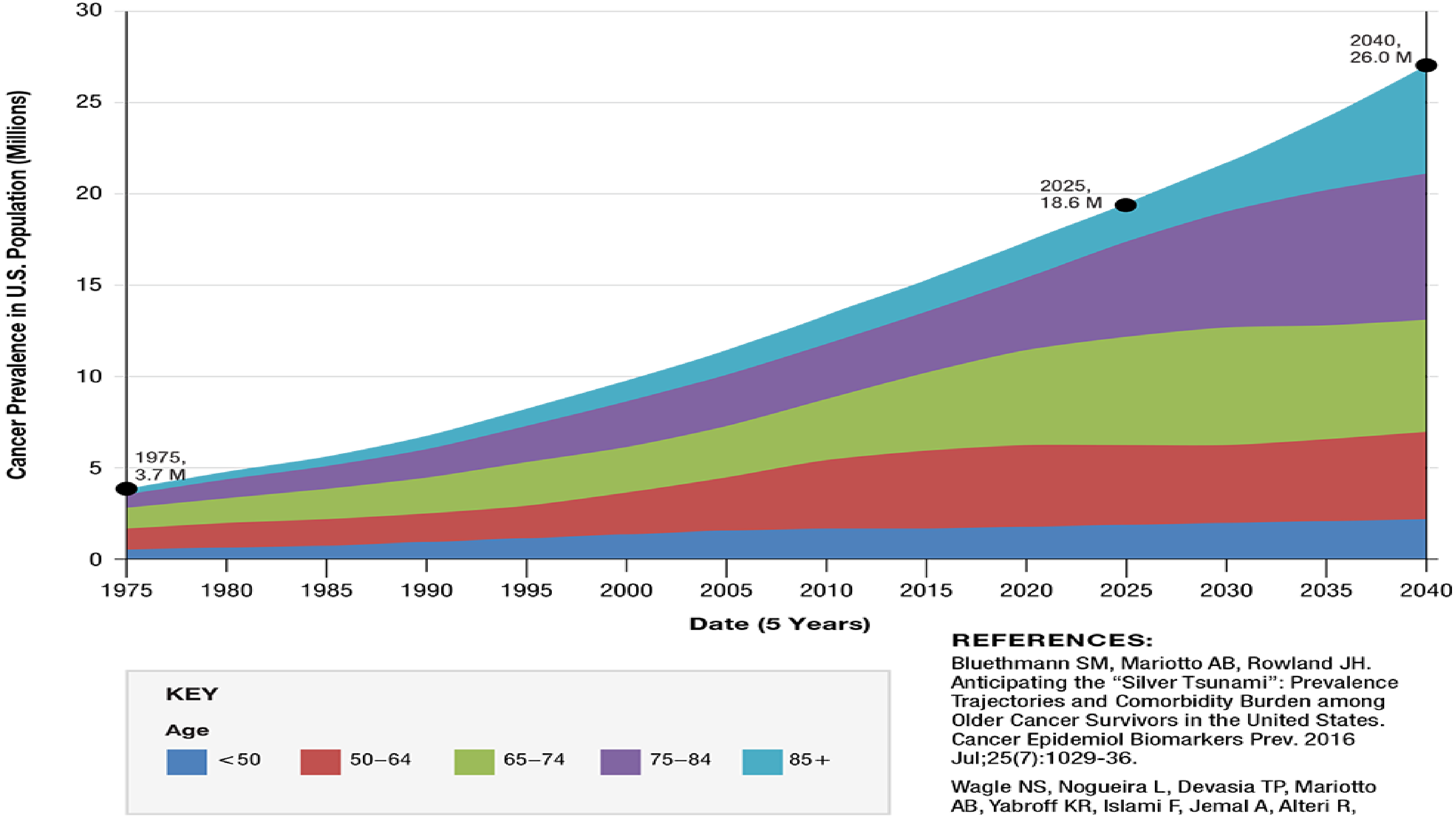
Number of Cancer Survivors in the United States, by Calendar Year and Time Since Diagnosis



REFERENCE:

Tonorezos E, Devasia T, Mariotto AB, Mollica MA, Gallicchio L, Green P, Doose M, Brick R, Streck B, Reed C, de Moor JS, Prevalence of Cancer Survivors in the United States, JNCI: Journal of the National Cancer Institute, 2024; https://doi.org/10.1093/jnci/djae135

Cancer Prevalance and Projections in U.S. Population from 1975–2040, by Age



REFERENCES:

Bluethmann SM, Mariotto AB, Rowland JH. Anticipating the “Silver Tsunami”: Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors in the United States. Cancer Epidemiol Biomarkers Prev. 2016 Jul;25(7):1029-36.

Wagle NS, Nogueira L, Devasia TP, Mariotto AB, Yabroff KR, Islami F, Jemal A, Alteri R, Ganz PA, Siegel RL. Cancer treatment and survivorship statistics, 2025. CA Cancer J Clin. 2025 May 30

State of the Art of Cancer Care 2026

- Of individuals diagnosed today,70% can expect to be alive in 5+ years
- Treatments for cancer are often complex and multi-modal and increasingly include oral meds, targeted and immunologic drugs
- Cancer patients receive most of their care in the outpatient setting, largely in the community (versus big cancer centers)
- Cancer for many has/will become a chronic illness
- There is an expectation that patients – and their families – will be actively engaged partners in care

How did we get here? Drivers of Success…

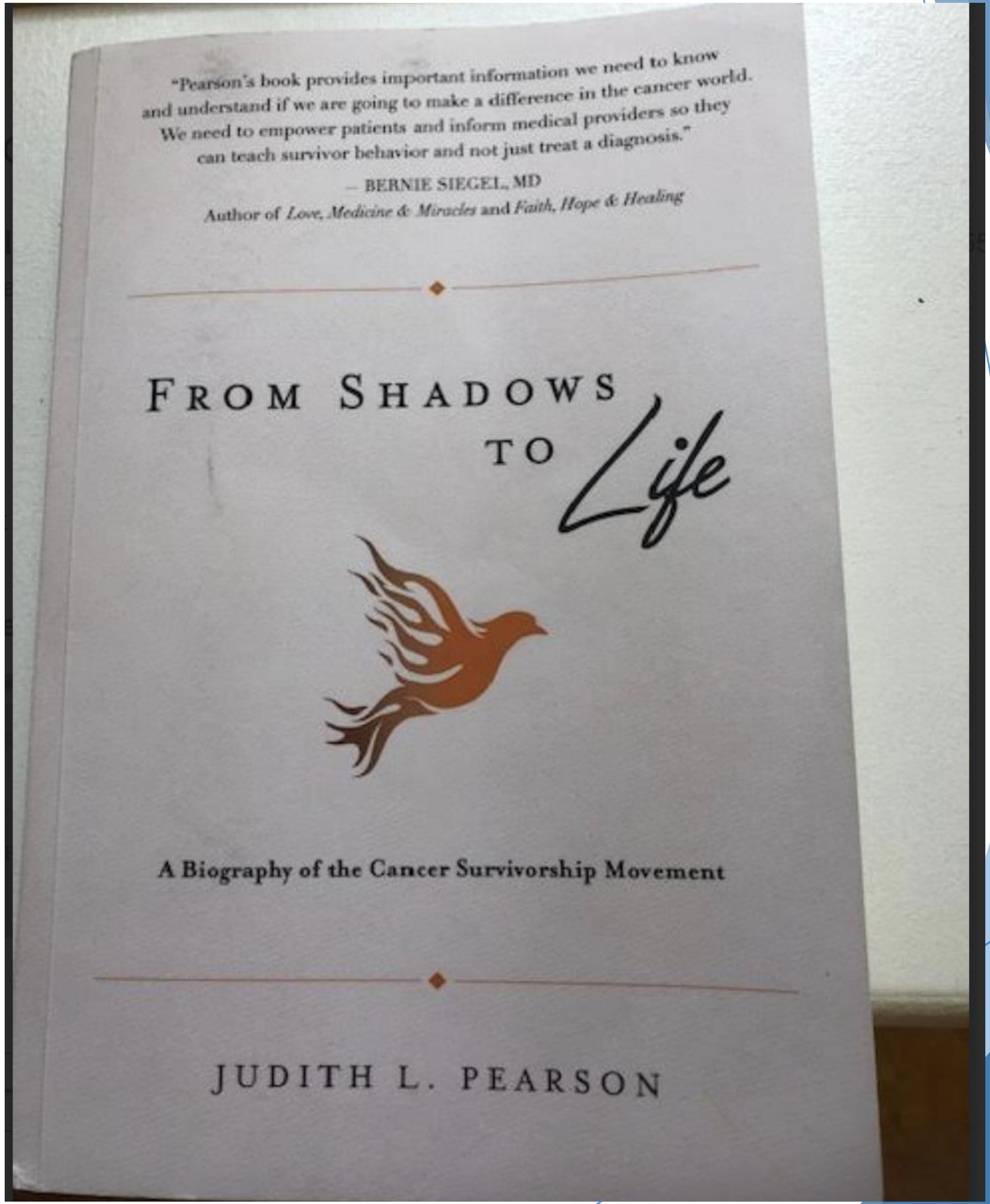
- Earlier detection
- More and improved efficacy of treatments available
- Better supportive care
- ***Growing attention to long-term and late-effects of cancer and its treatments***
- ***The rising voice of survivorship champions***

Founders of the NCCS, 1986

From Shadows to Life. A Biography of the Cancer Survivorship Movement

By Judith Pearson

Lincoln Square Books, 2021



"Pearson's book provides important information we need to know and understand if we are going to make a difference in the cancer world. We need to empower patients and inform medical providers so they can teach survivor behavior and not just treat a diagnosis."

— BERNIE SIEGEL, MD

Author of *Love, Medicine & Miracles* and *Faith, Hope & Healing*

FROM SHADOWS TO *Life*

A Biography of the Cancer Survivorship Movement

JUDITH L. PEARSON

NCCS: Three Key Contributions

1. Redefining the term ‘cancer survivor’
2. Recognizing “post-treatment” as a unique phase of care and championing the need to study and address the challenges it presents
3. Advocating for the creation of the Office of Cancer Survivorship, at NCI

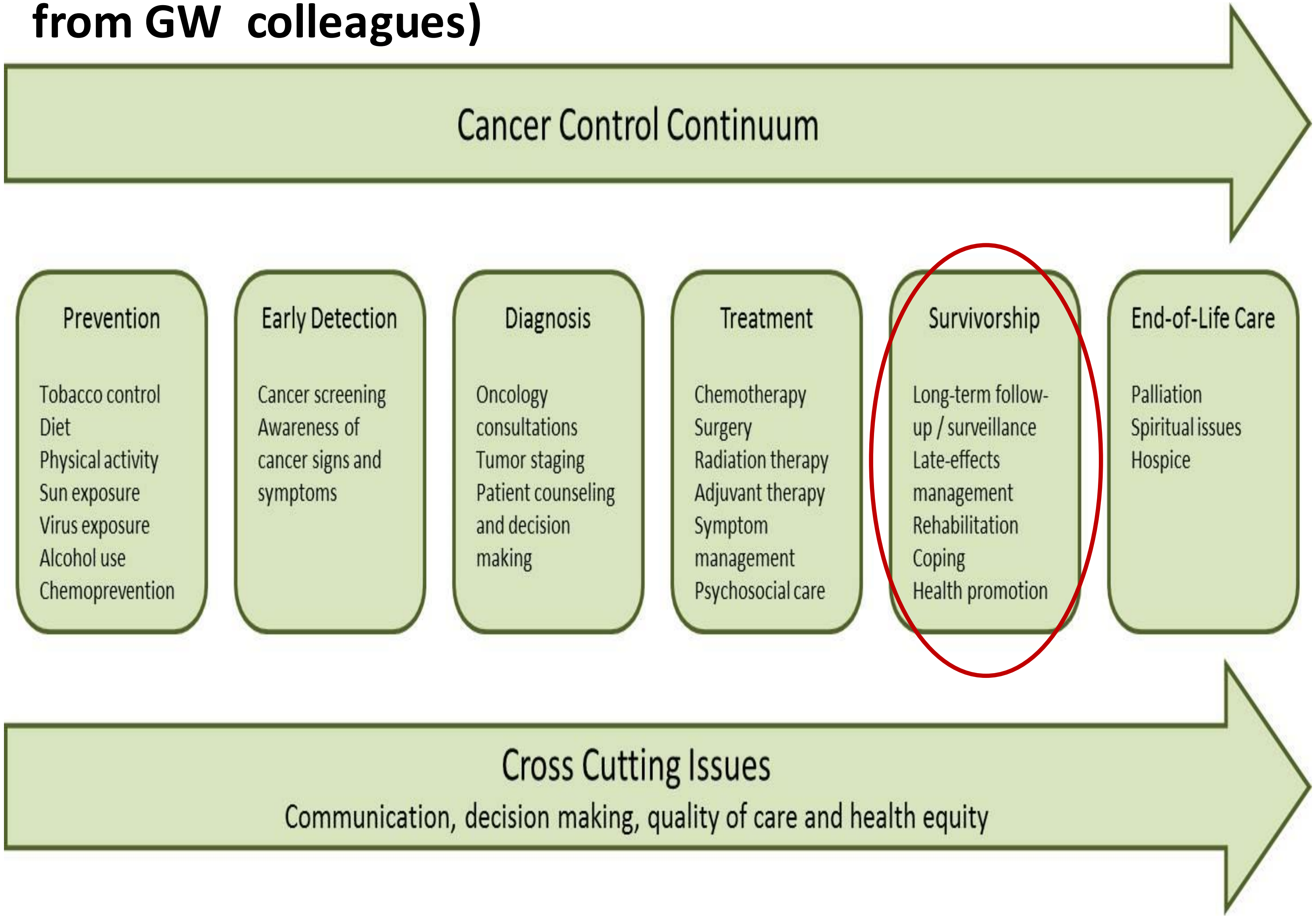
NCCS Redefined what it meant to be a **CANCER SURVIVOR**

- Anyone who has been diagnosed with cancer is a survivor --- from the time of diagnosis and for the balance of life
- Caregivers and family members are also cancer survivors

Changing the Culture of Research and Care

The PATIENT is as important as the TUMOR

NIH/DCCPS Model (modified from Abrams with input from GW colleagues)



Cancer Control Continuum

Prevention
- Tobacco control
- Diet
- Physical activity
- Sun exposure
- Virus exposure
- Alcohol use
- Chemoprevention

Early Detection
- Cancer screening
- Awareness of cancer signs and symptoms

Diagnosis
- Oncology consultations
- Tumor staging
- Patient counseling and decision making

Treatment
- Chemotherapy
- Surgery
- Radiation therapy
- Adjuvant therapy
- Symptom management
- Psychosocial care

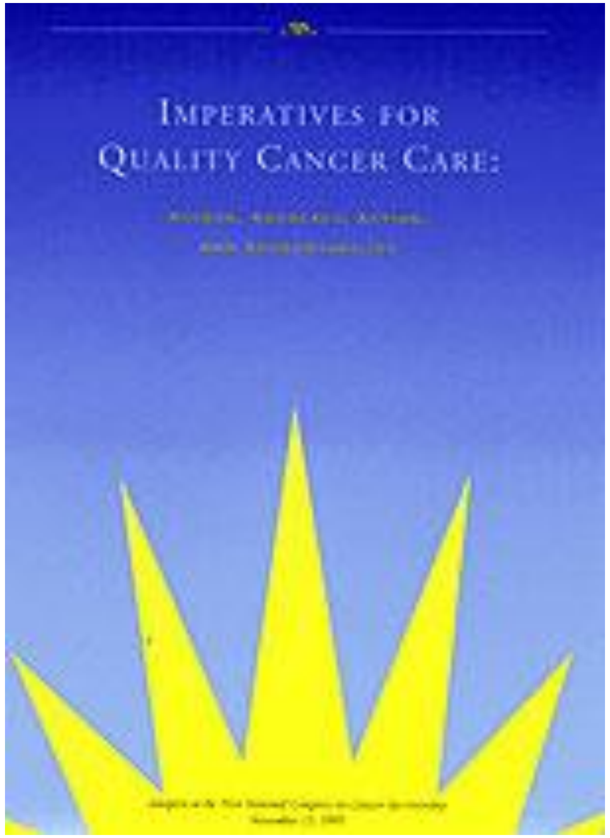
Survivorship
- Long-term follow-up / surveillance
- Late-effects management
- Rehabilitation
- Coping
- Health promotion

End-of-Life Care
- Palliation
- Spiritual issues
- Hospice

Cross Cutting Issues

Communication, decision making, quality of care and health equity

1st Cancer Survivorship Report



IMPERATIVES FOR
QUALITY CANCER CARE:

- *Imperatives for Quality Cancer Care: Access, Advocacy, Action and Accountability* (1996)
- NCCS released after the First National Congress for Cancer Survivorship meeting in Washington, D.C. in 1995 that defined, for the first time, quality cancer care from the patient's perspective
- ***OCS established in response to this report***

“[Survivors] have special psychological, physical, and health care counseling needs that we are only beginning to understand…the [OCS] will support the much needed research that will help cancer survivors deal with the problems they face even after their cancer is cured.” ***President Clinton, October 27, 1996, at the Rose Garden ceremony to formally announce the launch of the OCS.***

OCS established in 1996

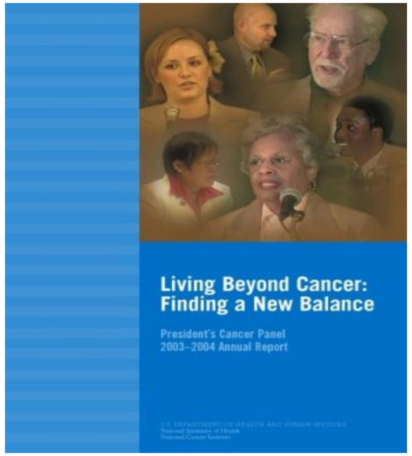
- **Mission**: To improve quality of life as well as length of survival of all those diagnosed with cancer
- **Activity:** OCS accomplishes its mission through --
    - *Support, direction and conduct of research* a) identifying and addressing the long-term and late consequences of cancer and its treatment; b) delineating best practices in post-treatment care of survivors; and c) optimizing survivors' health behavior after cancer
    - Promotion of training of researchers and clinicians skilled at conducting survivorship research and caring for the growing population of survivors
    - Dissemination of information to professionals who treat cancer patients, to survivors, and to the public concerning the problems and needs as well as appropriate care of cancer survivors and their families

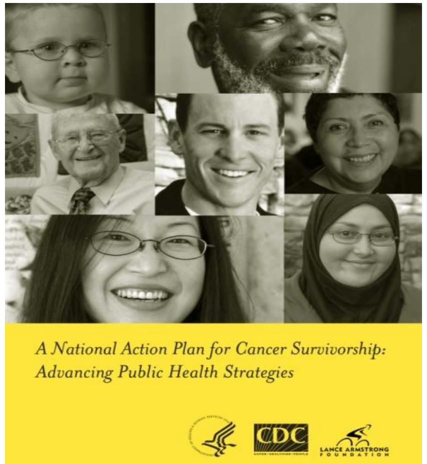
Building on the shoulders of giants

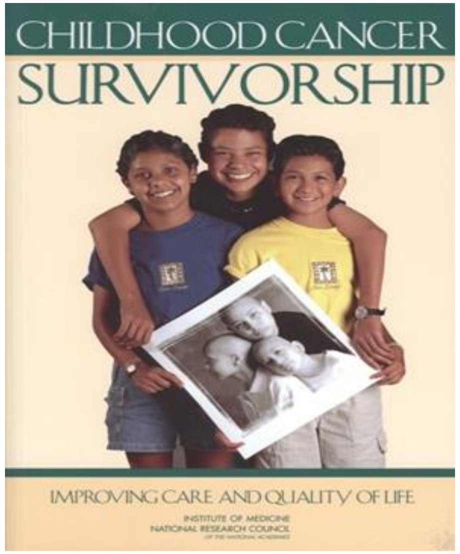
- Ellen Stovall, NCCS CEO & President

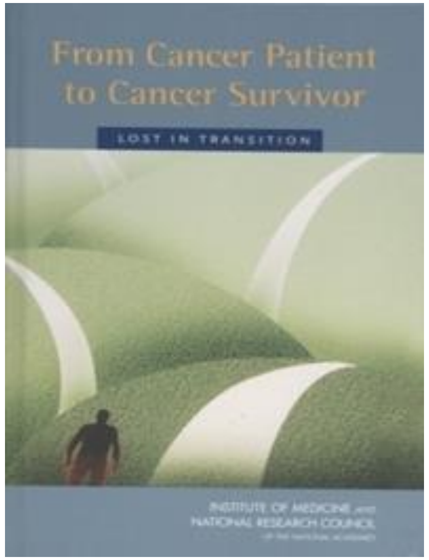
- Anna Meadows, MD, 1st OCS Director, 1996-99

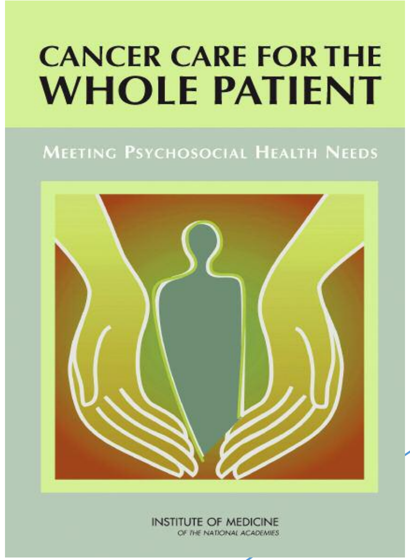
National Visibility of Cancer Survivorship


Living Beyond Cancer: Finding a New Balance
President's Cancer Panel
2003–2004 Annual Report


A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies


CHILDHOOD CANCER SURVIVORSHIP
IMPROVING CARE AND QUALITY OF LIFE
INSTITUTE OF MEDICINE
NATIONAL RESEARCH COUNCIL


From Cancer Patient to Cancer Survivor
LOST IN TRANSITION
INSTITUTE OF MEDICINE and
NATIONAL RESEARCH COUNCIL


CANCER CARE FOR THE WHOLE PATIENT
MEETING PSYCHOSOCIAL HEALTH NEEDS
INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Lessons Learned

- Everyone’s course is unique
- ”It’s not over when it’s over!”
- Cancer has the potential to impact every aspect of an individual’s life: physical, cognitive, emotional, social, spiritual, existential

Long-term/Chronic effects of cancer

- **Physical/Medical** (e.g., pain, fatigue, memory problems, lymphedema, sexual impairment)
- **Psychological** (e.g., depression, anxiety, uncertainty/fear of recurrence, isolation, altered body image, poor QOL)
- **Social/Economic** (e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, return to work and/or school, financial burden)
- **Existential and Spiritual Issues** (e.g., sense of purpose or meaning, appreciation of life)

Cancer Survivors are Also at Risk for *Late Effects*

- ***Disease recurrence/ new cancers; 20% of new cancers occur in patients with a cancer history***
- Cardiovascular disease
- Obesity/Diabetes
- Osteoporosis
- Functional decline
- Poor quality of life

Lessons Learned

- Everyone’s course is unique
- ”It’s not over when it’s over!”
- Cancer has the potential to impact every aspect of an individual’s life: physical, cognitive, emotional, social, spiritual, existential
- Cancer is a family illness

What we know about caregivers…

- Family/informal cancer caregivers are ‘in the room’ with patients, influence decisions and affect care
- They provide vital support as well as direct care, including oversight of medication, visits, wound care
- They often feel ill-prepared for their roles
- Well-being of survivors and their caregivers often parallel one another; dyadic co-dependency
- **They often neglect their own health in the process of caregiving**
- Their numbers, like survivors, are growing!

Kent EE et al., *Cancer* 2016

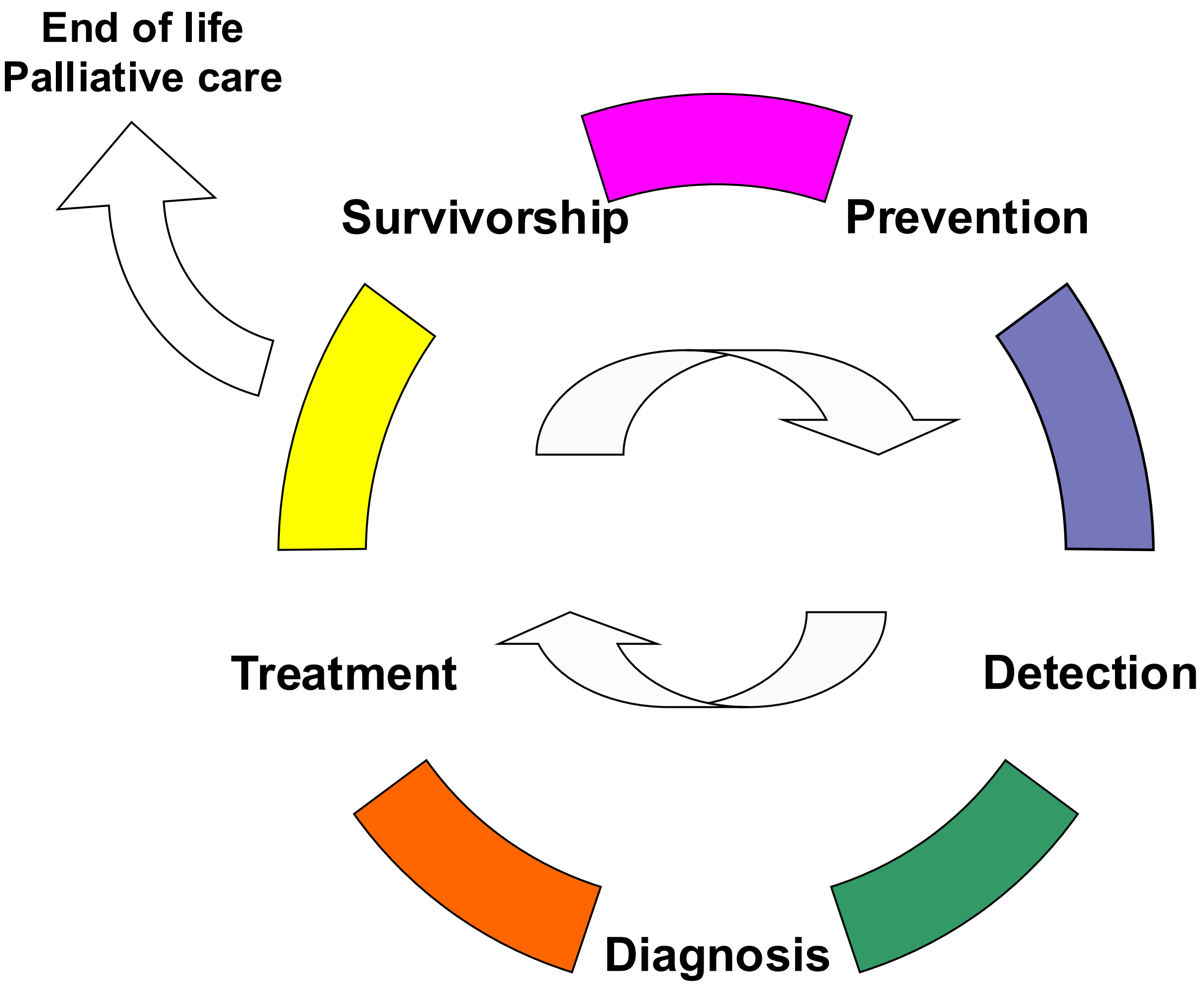
Lessons Learned

- Everyone’s course is unique
- ”It’s not over when it’s over!”
- Cancer has the potential to impact every aspect of an individual’s life: physical, cognitive, emotional, social, spiritual, existential
- Cancer is a family illness
- ***Cancer may be a “teachable moment”***

Why the interest in survivors' health behaviors?

- Growing number of cancer survivors who…
- Are living longer
- Are older, and also aging
- Often gain wt, stop exercising during Rx
- Are at risk for a number of co-morbid health conditions (and may also have a history of others)
- Are asking for help in reducing cancer-related morbidity and mortality
- Can benefit from health promoting inventions

Cancer Control Continuum
"Revisited"



Rowland & Bellizzi, Hematol Oncol Clin North Am, 2008

Pursuit of a Healthy Lifestyle: A Critical Frontier in Survivorship Research & Care

Physical Activity

Smoking Cessation

Sunscreen Use

Alcohol Moderation/Elimination

Balanced diet

Recommended Screening / Vaccine Uptake

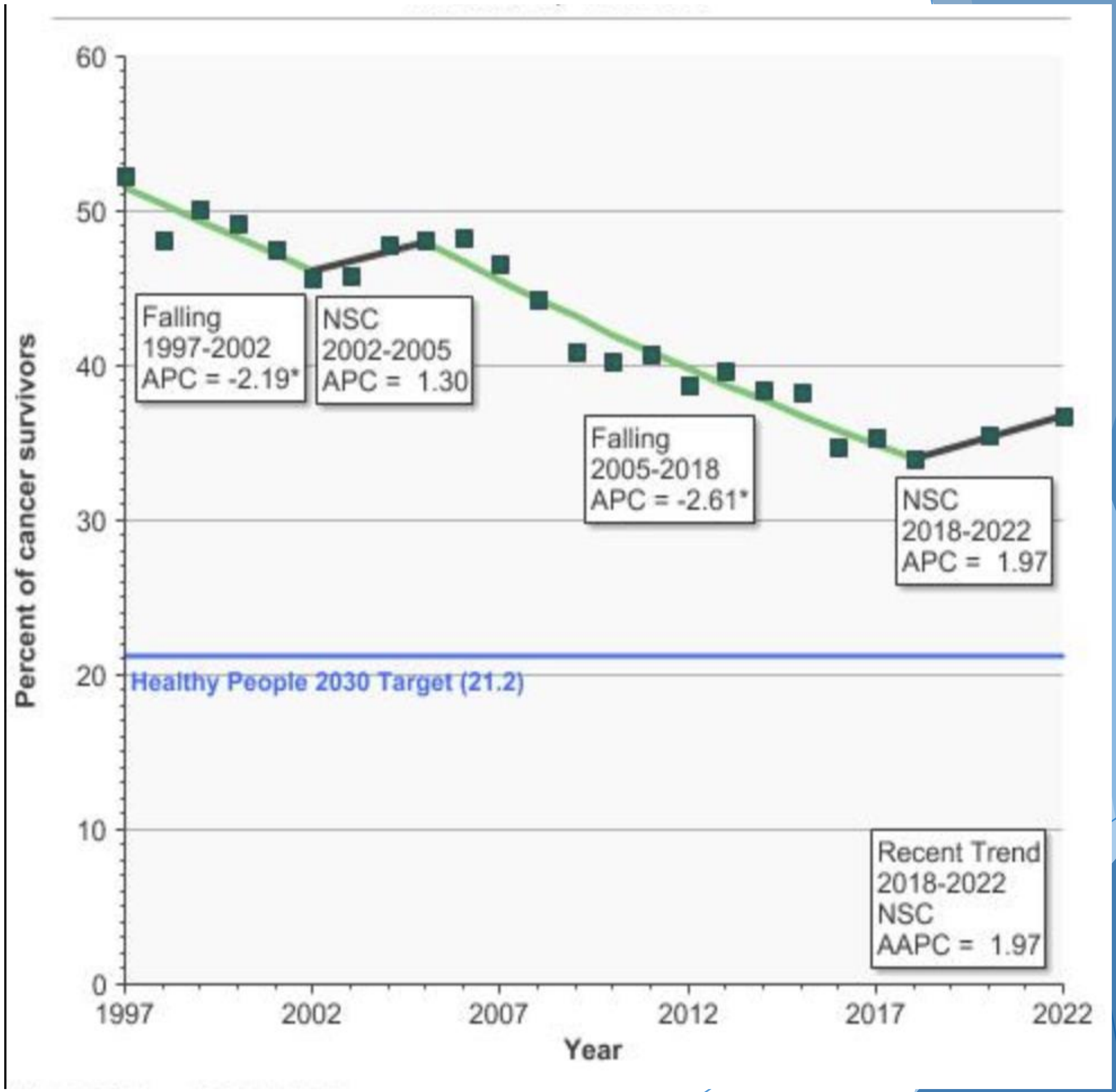
Social engagement

Percentage of cancer survivors 18 years and older reporting ***no*** physical activity in their leisure time: Both Sexes, 1997-2022

Source:

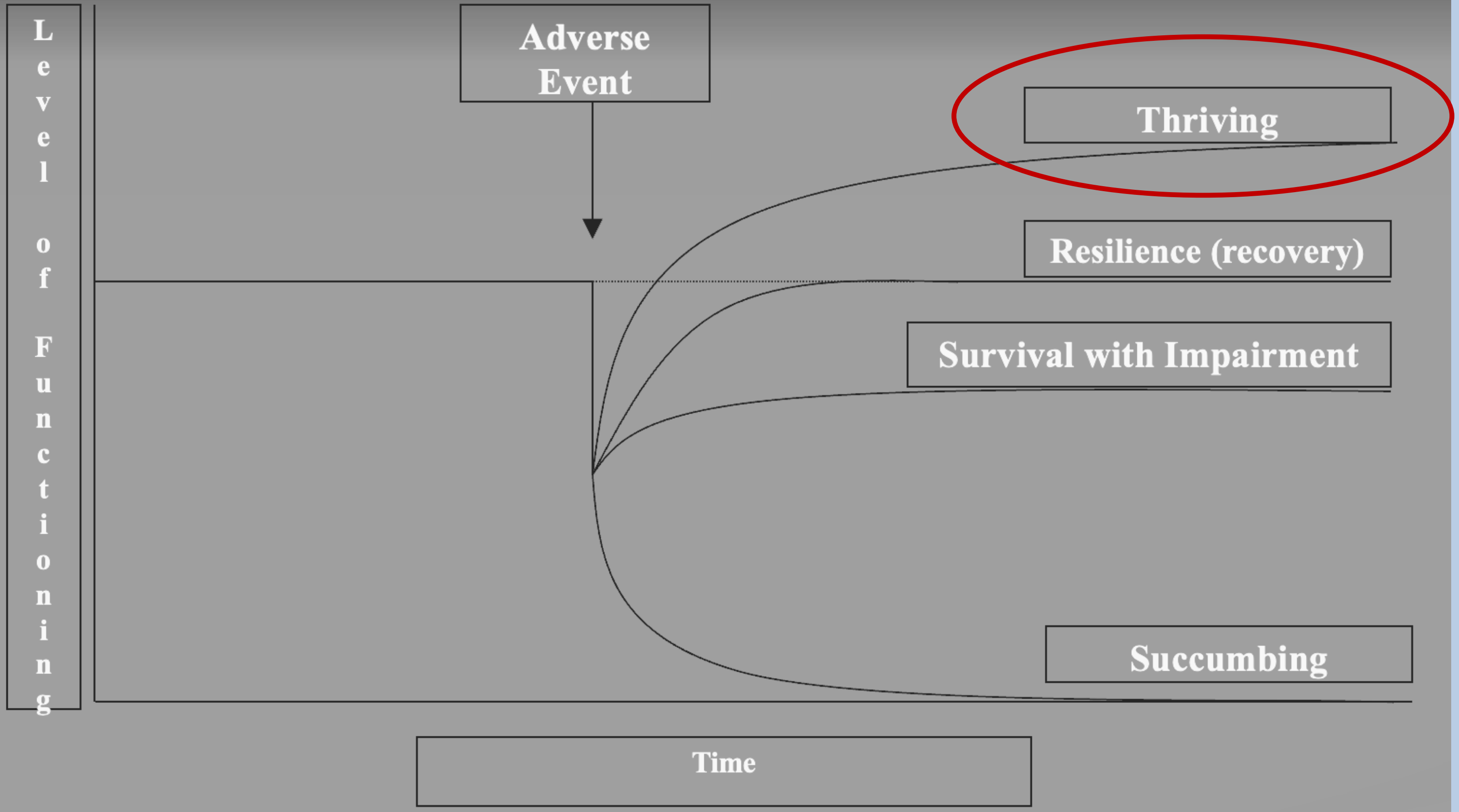
Cancer Trends Progress Report

(Accessed: June 2, 2026)



Healthy People 2030 Goals: *Cancer*

- ***Reduce new cases of cancer and cancer-related illness, disability and death***
- Reduce the overall cancer death rate — C-01
  (With specific goals for breast, colorectal, prostate)
- Increase the proportion of survivors who are living 5 years or longer after cancer — C-11
- Increase quality of life of cancer survivors. — C- R01
- Increase the proportion of people who discuss interventions to prevent cancer with their providers — C-R02



Adapted from : O'Leary & Ickovics, 1995

“Nothing about me without me!”

Happy 50th Birthday ASPO

Happy 40th Birthday Cancer Nation

&

Happy 30th Birthday OCS!!

Thank You!

Julia@smithcenter.org

Northwestern Medicine®
Feinberg School of Medicine

Advancing Community-engaged Approaches and Equity in Rural Cancer Survivorship Research

Marquita Lewis, PHD, MPH, MS
Northwestern University
Department of Medical Social Sciences
Robert Lurie Comprehensive Cancer Center

CIRCLE RESEARCH CENTER

Community-engaged Initiatives for Rural health, Cancer survivorship, and Lasting Equity

The CIRCLE Research Team is committed to building deep partnerships relationships with rural clinical teams and communities to intentionally collaborate with community partners to co-create strategies that center community priorities and improve equitable access to care.

Research Focus: Community-to-Clinic

Burden of Rurality

10%
of US health providers

>80%
are considered mental health shortage areas

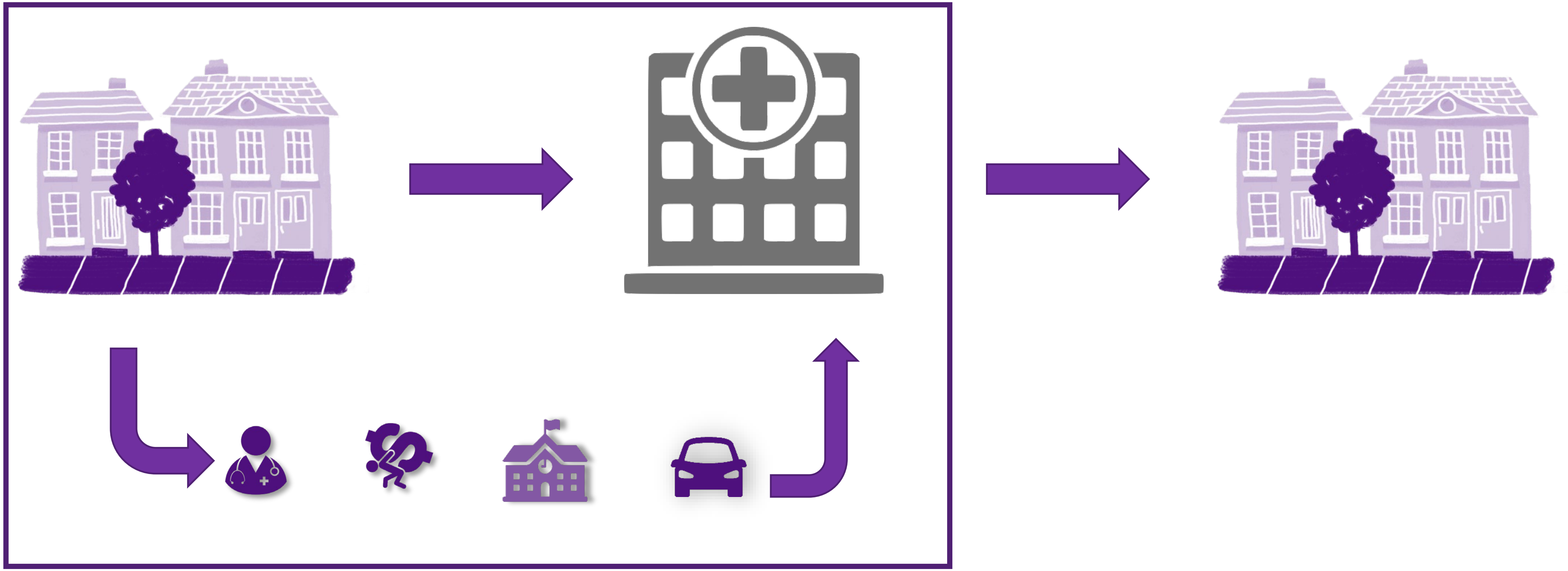
>150
hospital closures since 2010

25%
of rural residents are ≥65 years

22%
lack high-speed internet

70%
telehealth uptake from 2019-2022

Research Focus Community-to-Clinic



Glutton for punishment or just ironic

- Community-engaged, which takes forever
- Qualitative researcher, which takes forever
- Rural health researcher, living in Chicago
- Digital health researcher who just got a smart phone

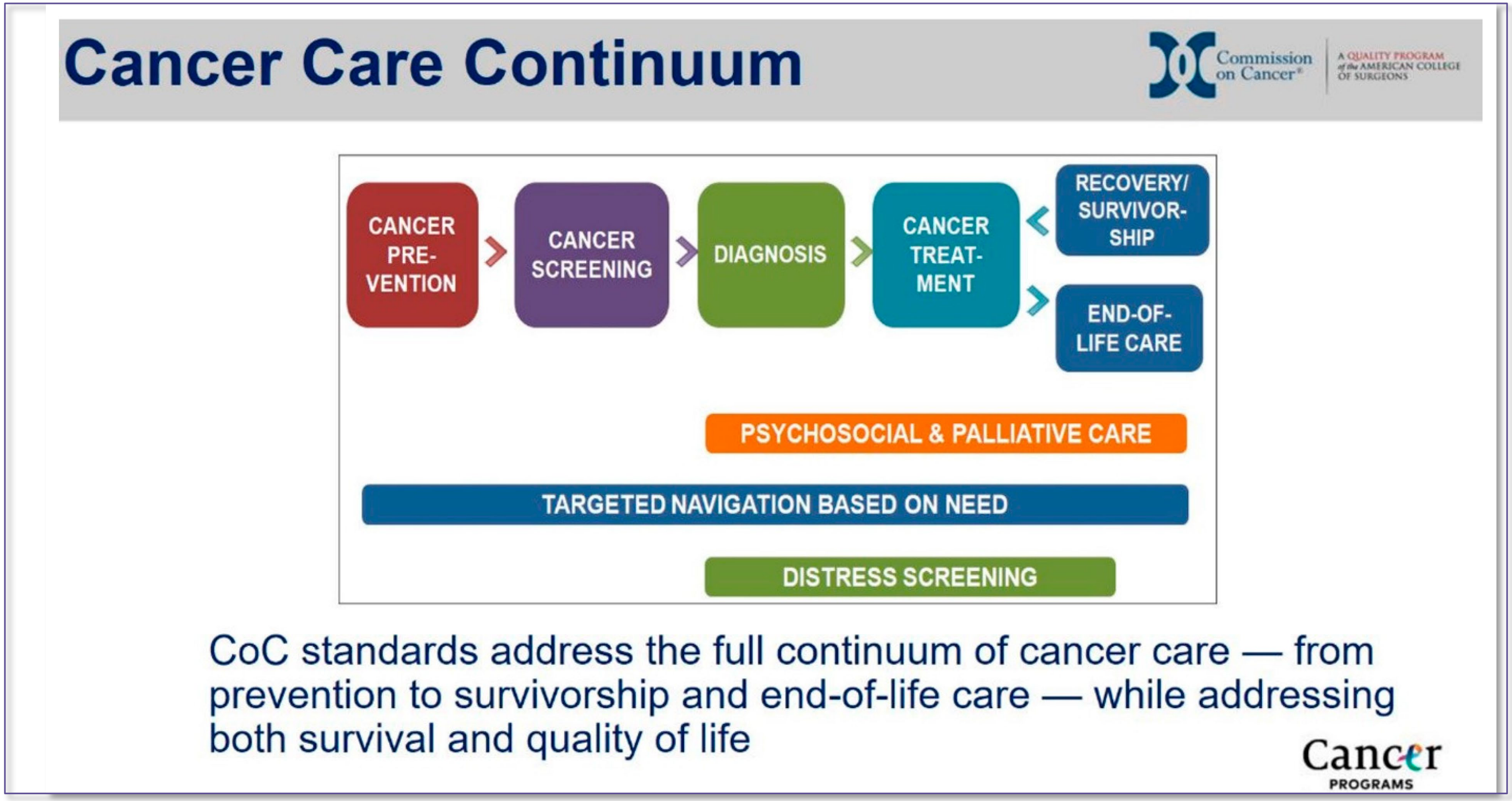
Community Engaged Research

- Approach for conducting research in a collaborative way
- Bidirectional exchange of expertise between academics (scientific experts) and communities/stakeholders (local, cultural, practice experts) that results in informed decision-making about design/conduct/use of research.

Types of Community Engagement

- Community health presentations
- Community Advisory Boards
- Lived experience panels
- User-centered design approaches
- Co-Design Approaches
- Community-partner-led investigations

The model of the cancer care continuum and health equity



Cancer Care Continuum

Commission on Cancer®
A QUALITY PROGRAM of the AMERICAN COLLEGE OF SURGEONS

CANCER PREVENTION
CANCER SCREENING
DIAGNOSIS
CANCER TREATMENT
RECOVERY/ SURVIVORSHIP
END-OF-LIFE CARE

PSYCHOSOCIAL & PALLIATIVE CARE

TARGETED NAVIGATION BASED ON NEED

DISTRESS SCREENING

CoC standards address the full continuum of cancer care — from prevention to survivorship and end-of-life care — while addressing both survival and quality of life

Cancer PROGRAMS

Why community-engaged in rural

Structural inequities

Survivorship affects all
aspects of life

Rural residents are
aging in place

Community is a rural
superpower

Funded Projects

Community Engaged Approaches

	CENTRAL 2020	CONNECT 2021	SYNERGY 2021	BRIDGE 2024	Rural Black Men's Project
Qualitative analysis	✓	✓		✓	✓
Community Advisory Boards		✓	✓		
User-Centered Design		✓			
Co-Design Approaches				✓	
Community-led partnerships					✓

CENTRAL Study (2020)

PROBLEM:

- Lung cancer is the most diagnosed cancer type among US adults.
- Rural residents have a lower 5-year survival rate than urban survivors.

STUDY PURPOSE:

- Interview rural lung cancer survivors to assess their cancer survivorship needs.

Community Engaged Approach

✓ *Qualitative Interviews*

Results

Frustrations and uncertainty regarding unexpected barriers

a) barriers to adhering to clinical posttreatment survivorship care recommendations

b) barriers to daily living

> You don't really realize that you're gonna need that help with your food, and eating, and your bedsheets, and getting in and out of the bath or whatnot, or going on - doing your errands, picking up your medicine

---

Strategies to improve delivery of posttreatment information

a) communication needs to be clear and specific

b) modes of communication were diverse but needed to be convenient and direct

> You want your surgeon to say, “You're gonna be in the hospital for five days…You don't want your surgeon to say you might be in the hosital for five days, but maybe we can get you home in three days…human nature says we're going home in three days,.

Results

Strategies to remain positive and respond to emotional concerns of survivorship care

a) self-reliance

b) a responsive care team

c) strong social networks

Like I was not Joe - Joe Blow that walked in off the street that they'd never seen in their life. I felt like I was family from the - I mean, from day one.... They, uh - they made the experience good. You know, if I cried, they were there to, uh, support me.

Corresponding to the impact of engaging and patient-centered care teams

a) stress management

b) pain management

Well, after I got out of the hospital, if it wasn't for my daughter-in-law, I would probably starve to death because I was in a lot of pain and stuff. And she come and made sure I got my bath and fed me, brought me meals and stuff"

Lessons Learned

- Helpful for a needs assessment and establishing partnerships
- Covid-19 exposed digital divide
- Emotional concerns were apparent, but challenging to gauge

Next steps

- Deeper dive into strategies to improve survivorship care
- Explore emotional concerns and the digital divide

The CONNECT Study

PROBLEM:

- Reduced utilization is an access barrier
- Digital health tool development does not include the voices of rural and older adults
- Telehealth is part of the tapestry of rural healthcare

STUDY PURPOSE:

- Develop a telehealth concierge for rural older cancer survivors (ROCS) with cancer related distress

Community Engaged Approach

- ✓ *Qualitative Interviews*
- ✓ *Community Advisory Board*
- ✓ *User-Centered Design*

Developing a telehealth concierge for rural older cancer survivors with cancer-related distress

Cancer-related distress is a complication of cancer that includes psychological distress or anxiety arising from a diagnosis or disease management.

Telehealth has the potential to improve access to cancer care and mental health supports

Rural older adults face **usability barriers.**

Rooper et al,, 2024

Research Aims

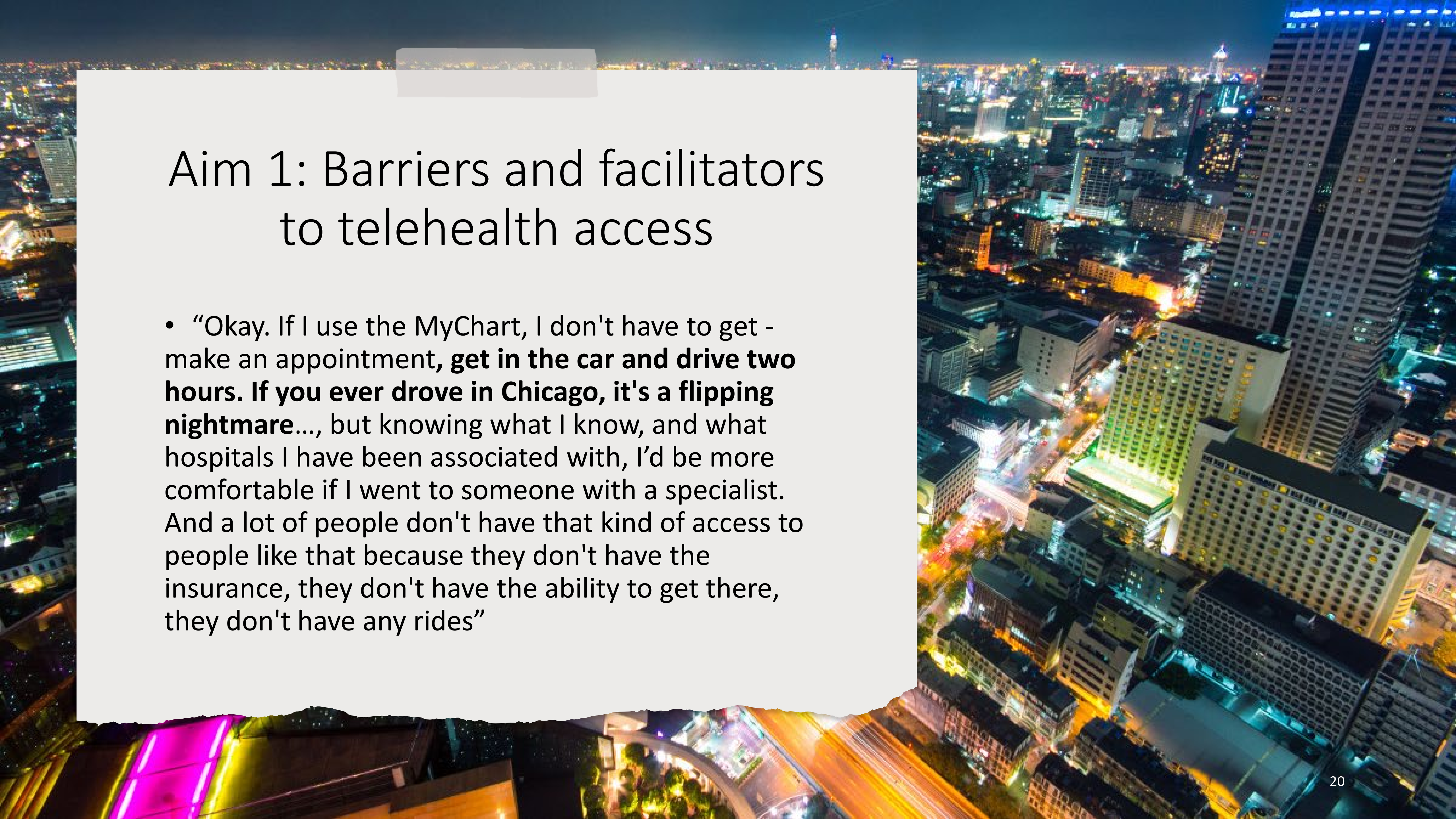
Aim 1: Learn about the facilitators and barriers of when accessing telehealth and mental support services.

Aim 2: Develop tool prototype

Aim 3: Test the usability of the tool

User-centered design approach

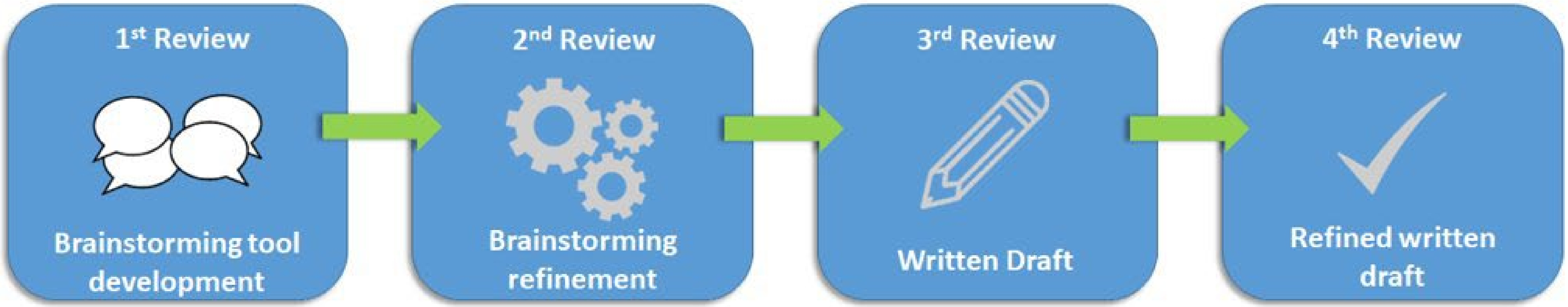
- Focuses on the user's needs and goals throughout the design process
- Enhanced User Satisfaction
- Improved usability
- Reduced costs



Aim 1: Barriers and facilitators to telehealth access

- “Okay. If I use the MyChart, I don't have to get - make an appointment**, get in the car and drive two hours. If you ever drove in Chicago, it's a flipping nightmare**…, but knowing what I know, and what hospitals I have been associated with, I’d be more comfortable if I went to someone with a specialist. And a lot of people don't have that kind of access to people like that because they don't have the insurance, they don't have the ability to get there, they don't have any rides”

Aim 2: Digital Tool Development



1st Review

Brainstorming tool development

2nd Review

Brainstorming refinement

3rd Review

Written Draft

4th Review

Refined written draft

Lessons Learned

- Centering ROCS voices in technology design
- Desired real-time assistance
- Older adults are not averse to technology, but need supports

Next steps

- Finish the prototype with additional technical assistance supports
- Test efficacy

BRIDGE STUDY (2024)

PROBLEM:

- Building from CONNECT's usability findings
- Findings suggested synchronous, real-time assistance
- Test efficacy and equity

STUDY PURPOSE:

- Assess the efficacy and sustainability of the updated CONNECT

Community Engaged Approach

✓ Qualitative Interviews
✓ Co-Design Approach

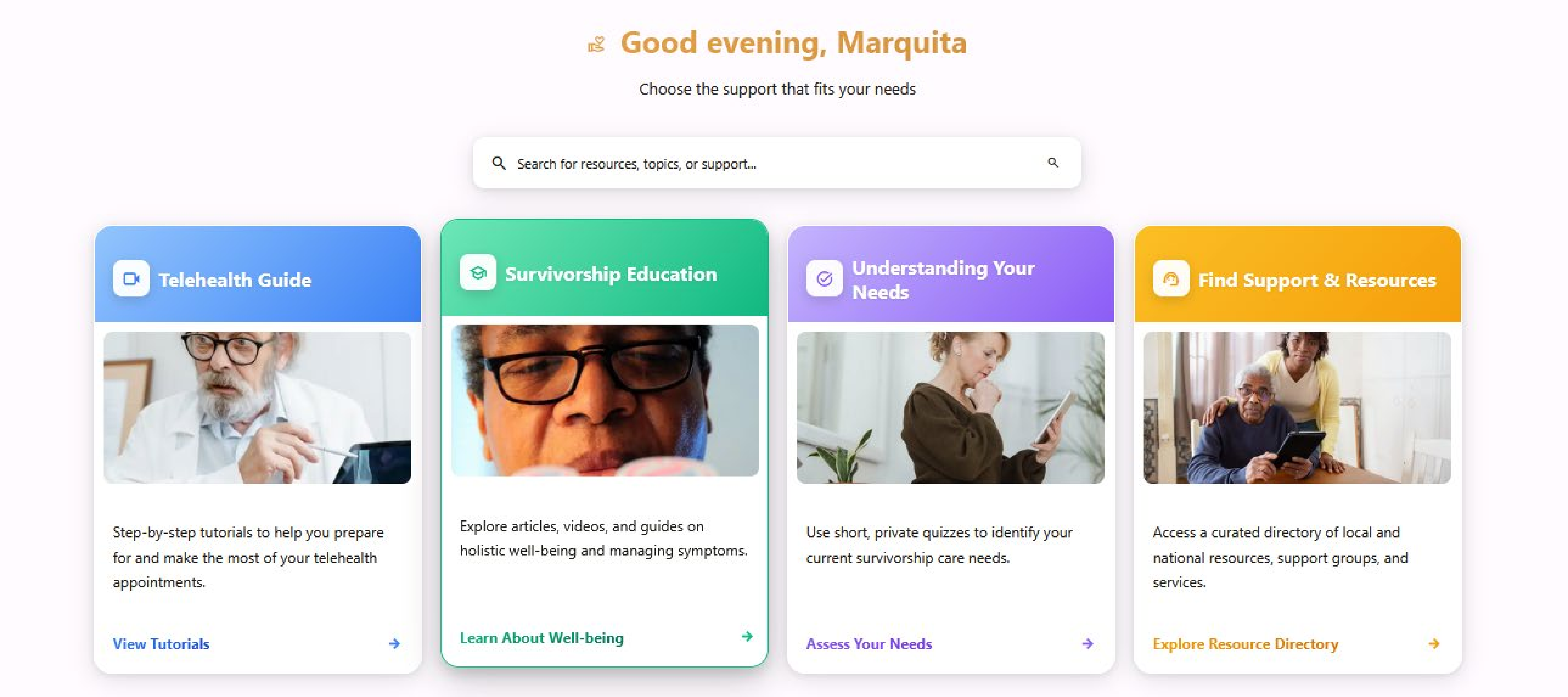
Research Aims

Aim 1: Finalize prototype development with synchronous caregiver communication and a Co-Design team. N=30

Aim 2: Test efficacy of BRIDGE compared to usual care with ROCS-Caregiver dyads (N=274 per arm)

Aim 3: Test sustainability

Bridge Website



Good evening, Marquita

Choose the support that fits your needs

Telehealth Guide

Step-by-step tutorials to help you prepare for and make the most of your telehealth appointments.

Survivorship Education

Explore articles, videos, and guides on holistic well-being and managing symptoms.

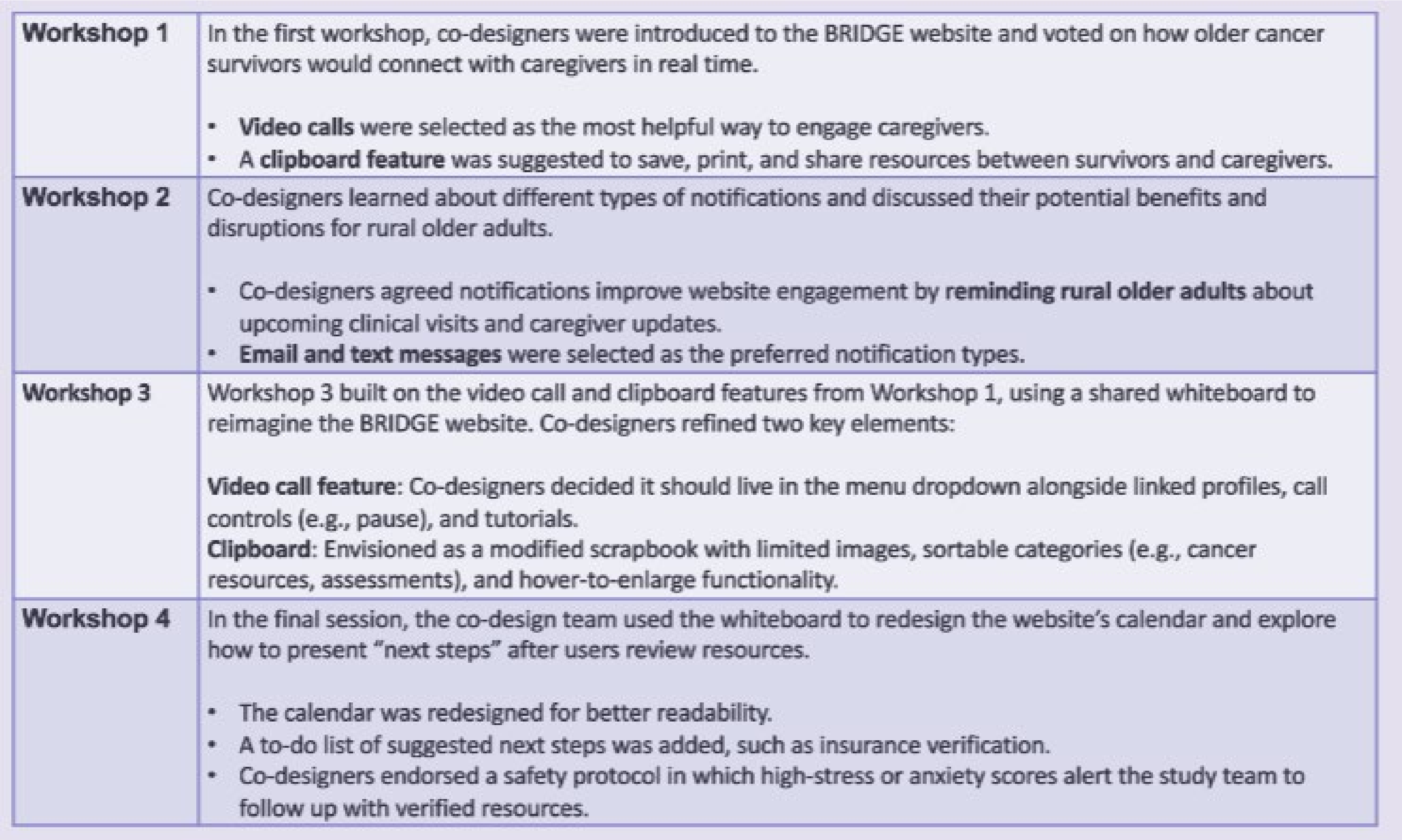
Understanding Your Needs

Use short, private quizzes to identify your current survivorship care needs.

Find Support & Resources

Access a curated directory of local and national resources, support groups, and services.

Co-Design Process and Findings (N=30)



Workshop 1	In the first workshop, co-designers were introduced to the BRIDGE website and voted on how older cancer survivors would connect with caregivers in real time. • **Video calls** were selected as the most helpful way to engage caregivers. • A **clipboard feature** was suggested to save, print, and share resources between survivors and caregivers.
Workshop 2	Co-designers learned about different types of notifications and discussed their potential benefits and disruptions for rural older adults. • Co-designers agreed notifications improve website engagement by **reminding rural older adults** about upcoming clinical visits and caregiver updates. • **Email and text messages** were selected as the preferred notification types.
Workshop 3	Workshop 3 built on the video call and clipboard features from Workshop 1, using a shared whiteboard to reimagine the BRIDGE website. Co-designers refined two key elements: **Video call feature**: Co-designers decided it should live in the menu dropdown alongside linked profiles, call controls (e.g., pause), and tutorials. **Clipboard**: Envisioned as a modified scrapbook with limited images, sortable categories (e.g., cancer resources, assessments), and hover-to-enlarge functionality.
Workshop 4	In the final session, the co-design team used the whiteboard to redesign the website's calendar and explore how to present "next steps" after users review resources. • The calendar was redesigned for better readability. • A to-do list of suggested next steps was added, such as insurance verification. • Co-designers endorsed a safety protocol in which high-stress or anxiety scores alert the study team to follow up with verified resources.

Next Steps

Usability Testing

Remove unnecessary tasks from your to-do list and move on

Finalize tool

Tool deployment and remove bugs

Efficacy Testing

Temporarily pause the task that not need to be handled right away

Sustainability Assessment

Quickly accomplish the task that requires only a few minutes to complete

QUALITATIVE METHODS THROUGH A PARTICIPATORY LENS

DR. MARQUITA LEWIS

DR. IDA SALUSKY

AUGUST 25TH & 27TH
SEPTEMBER 1ST 3RD & 17TH

PARTICIPANTS WILL LEARN

- Foundational skills in qualitative research, including core principles and how qualitative and quantitative approaches differ
- To select and apply effective data collection methods aligned with participatory research approaches
- Practical analytic strategies for producing credible, trustworthy qualitative findings
- To effectively communicate qualitative insights with impact to both academic and nonacademic audiences

SCAN TO REGISTER:

Join Dr. Marquita Lewis and Dr. Ida Salusky for an introduction to using qualitative methods in research design and grant proposal development with a focus on participatory research. This virtual training will help build essential theoretical and methodological skills to conduct rigorous qualitative research.

APPLICATION INFORMATION

This training is ideal for early career investigators, postdocs, staff, community partners interested in research, and faculty developing grants with qualitative components.

Submit a CV, biosketch, or resume. Also, include a description (up to 250 words) of what do you want to get out of the training and any grant proposal ideas that you plan to integrate qualitative methods.

- 4 HALF DAYS (10AM-1PM 8/25, 8/27, 9/1, 9/3)
- 1 FULL DAY (10AM-3:30PM 9/17)
- $1,500 FOR SCHOLARS
- $100 FOR COMMUNITY PARTNERS (FULL DAY ONLY)

EMAIL MATERIALS TO:
MSS_EDUCATION@NORTHWESTERN.EDU

Qualitative Methods Short Course

SCAN TO REGISTER:

For more information: Email mss.education@northwestern

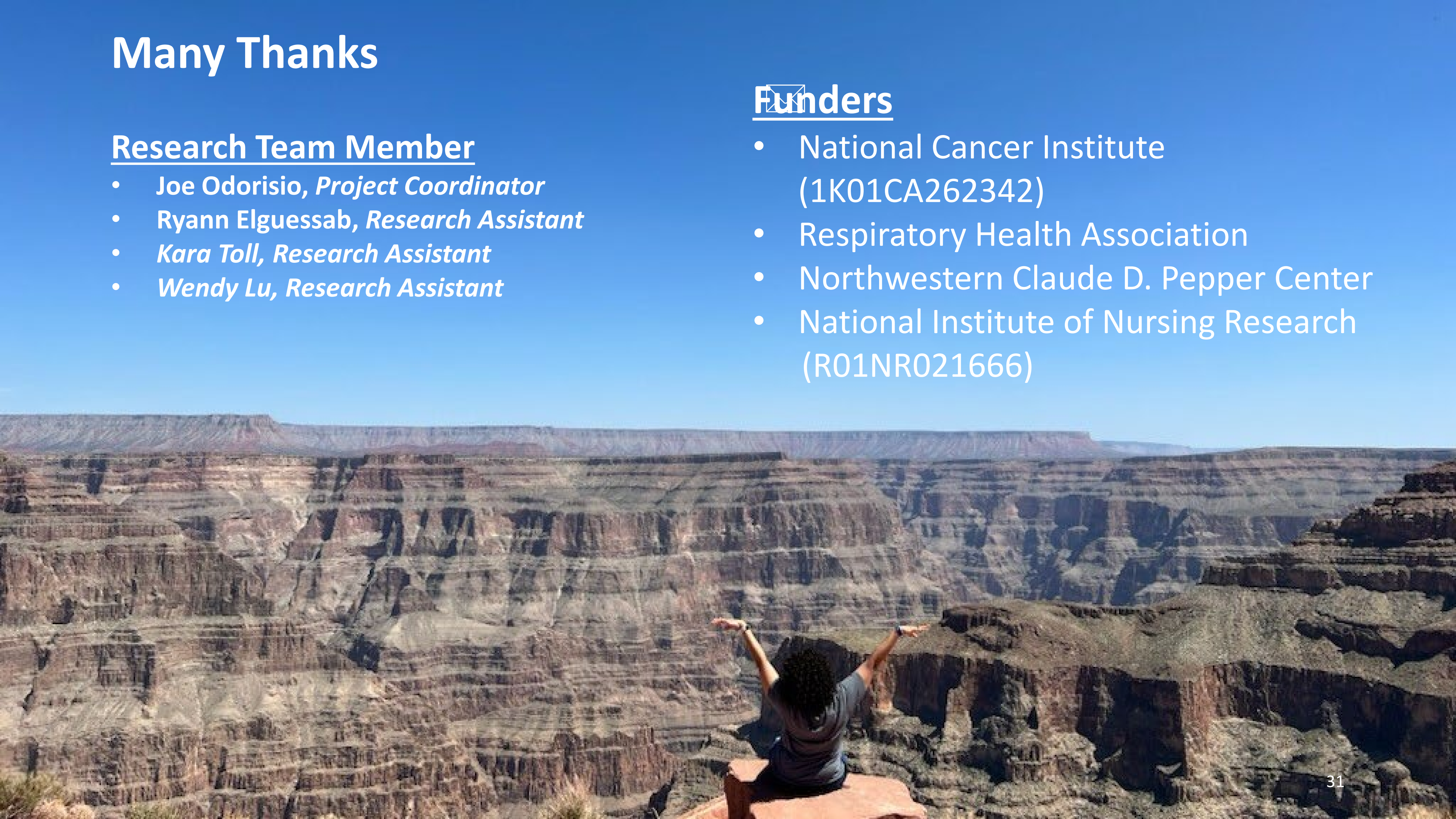
Practical Insights

- FOLLOW YOUR VALUES!!!!!
- “Make new friends, but keep the old”
- Have a mentorship team of:
  - Advocates: People who talk good about you behind your back
  - Coaches: Those who are “walking” with you and who can talk about the day-to-day and big pictures
  - Sponsors: Those who will invest in you (e.g., put you on grants)
- Have mentors that you want to grow-up and be like
- There are plenty of good ideas that go unfunded, but good stories rarely do—learn how to craft a good story
- NO. That’s a complete sentence.

Things I wish I was better at

- KNOWING WHEN TO ASK FOR HELP
- FOLLOW-THROUGH
- RESEARCH TEAM/LAB MANAGEMENT
- WORK-LIVE BALANCE/INTEGRATION/MIRACLES

Many Thanks



Research Team Member

- **Joe Odorisio, *Project Coordinator***
- **Ryann Elguessab, *Research Assistant***
- ***Kara Toll, Research Assistant***
- ***Wendy Lu, Research Assistant***

Funders

- National Cancer Institute (1K01CA262342)
- Respiratory Health Association
- Northwestern Claude D. Pepper Center
- National Institute of Nursing Research (R01NR021666)

QUALITATIVE METHODS THROUGH A PARTICIPATORY LENS

DR. MARQUITA LEWIS

DR. IDA SALUSKY

AUGUST 25TH & 27TH
SEPTEMBER 1ST 3RD & 17TH

PARTICIPANTS WILL LEARN

- Foundational skills in qualitative research, including core principles and how qualitative and quantitative approaches differ
- To select and apply effective data collection methods aligned with participatory research approaches
- Practical analytic strategies for producing credible, trustworthy qualitative findings
- To effectively communicate qualitative insights with impact to both academic and nonacademic audiences

SCAN TO REGISTER:

Join Dr. Marquita Lewis and Dr. Ida Salusky for an introduction to using qualitative methods in research design and grant proposal development with a focus on participatory research. This virtual training will help build essential theoretical and methodological skills to conduct rigorous qualitative research.

APPLICATION INFORMATION

This training is ideal for early career investigators, postdocs, staff, community partners interested in research, and faculty developing grants with qualitative components.

Submit a CV, biosketch, or resume. Also, include a description (up to 250 words) of what do you want to get out of the training and any grant proposal ideas that you plan to integrate qualitative methods.

- 4 HALF DAYS (10AM-1PM 8/25, 8/27, 9/1, 9/3)
- 1 FULL DAY (10AM-3:30PM 9/17)
- $1,500 FOR SCHOLARS
- $100 FOR COMMUNITY PARTNERS (FULL DAY ONLY)

EMAIL MATERIALS TO:
MSS_EDUCATION@NORTHWESTERN.EDU

Qualitative Methods Short Course

SCAN TO REGISTER:

For more information: Email mss.education@northwestern

marquita.lewis-thames@northwestern.edu

Survivorship & Advocacy For Childhood Survivors & AYA’s

Life After Cancer

Diagnosed with Ewing's Sarcoma

Summer 2000
Age 12

live for today

Childhood cancer at a glance over 365 days

- Chemotherapy every 14 days alternating two chemo regimens.
  - 3 day hospital stay
    - VDC/IE Vincristine, Doxorubicin, Cyclophosphamide
  - 5-6 day hospital stay
    - IE Ifosfamide and Etoposide
      - Chemo side effects included
      - Nausea & Vomiting
      - Mouth Sores
      - Hair loss
      - Constipation & Hemorrhoids
      - Brittle bones (broken tail bone)
      - Fatigue & easily exhausted

Childhood cancer at a glance over 365 days

- 10 days of neupogen shots for blood counts in between chemo sessions
- Twice weekly blood draws
  - If low, either platelets or blood transfusions administered
- Major back surgery to excise tumor & rib resection
- Scans every 3 months
- Physical Therapy
- Steroids that made me gain 40 lbs & look like a balloon

Experiences & Resources available

Provided by local and national non-profits I got to experience for Childhood cancer survivors

- **Jay Fund**
  - **NSYNC concert in limo**
  - **Holiday parties**
- **American Cancer Society**
  - **R.O.C.K. weekend**
  - **R.O.C.K. Scholarships**
- **Camp Boggy Creek**
  - **Attended week long summer camp x 4**
- **Child Cancer Fund**
- **Dreams Come True**
  - **Family trip to Alaska that included private mushing lesson (dog sled) & opportunity to participate in opening ceremonies for the Iditarod & ride in the first 10 miles**
- **Sunshine Kids**
  - **Week long trip to Tampa, Daytona & Orlando featuring beach activities & theme parks**

Experiences & Resources available

Clinic & Hospital stays offered additional in house resources for children

- Arts & Crafts
- Playroom
- Teen talk & pizza nights (group therapy)
- Video Games, Card & Board Games
- Movie Nights
- Parties
- Holiday Celebrations

Professionals who felt like family

- Child life specialists
  - Who threw you a party for end of chemo
  - Always had activities & a friendly face
  - Made signs for your hospital room
  - Would come visit in hospital
- Social Workers
  - Gave both patients & families support
- Therapists
- A team of Doctors who listened & cared

Life After Cancer

Volunteering

Giving Back

Staying Involved

Keeping touch with friends & healthcare professionals

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"The best way to find yourself is to lose yourself in the service of others."
-Gandhi

"Life's most persistent and urgent question is, what are you doing for others?"
-Martin Luther King Jr.

"Start where you are. Use what you have. Do what you can."
-Arthur Ashe

Over 80,000 Adolescents & Young Adults (AYA ages 15-39) are diagnosed with cancer every year.

AYA’s are more likely to have late stage diagnosis.

AYA’s are navigating high school, college, first careers, relationships, marriages, buying your first house, starting a family…a cancer diagnosis is disruptive and isolating.

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https://www.cancer.gov/types/aya

Live For Today Programs

Member Support
Group Events
Life Adventures
Healthy Living
Mental Health

Member support happens through

- Peer Dialogue
- Group Events
- Community Connections

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Life Adventures

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Mental Health & Healthy Living

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Survivorship Challenges

- Fertility
- Cognitive & Intellectual
- Physical limitations
- Fear of recurrence
- Secondary Cancer
- Damage to major organs such as heart, lungs, & brain
- Mental Health
- General Wellness with diet & exercise
- Maintaining Jobs
- Relationships
- Friendships
- Finding purpose
- Follow up care
- Insurance
- Financial Stability
- Mourning a life you once had & coming to terms with your “new” normal
- Comorbidity

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Ways the healthcare community can aid in survivorship

- Long term care patient advocates
- Develop programming specific for Survivor challenges
- Provide access to resources outside the hospital/clinic
- Be honest about potential outcomes & long term effects
- Discuss quality of life
- Encourage families to stay involved in post treatment care
- Educate on diet & nutrition
- Stay open minded to safe holistic approaches
- Bridging the gap between children's care to adult care
- Encourage health living/wellness
- Acknowledge that disparities & comorbidities are part of it
- Remember that when a patient finishes treatment, their cancer journey does not end and support is always needed

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Thank you for listening!

Contact us:

Kaitlyn Ash

kaitlyn@live-for-today.org

Live For Today Foundation
www.live-for-today.org