Cancer Caregiving in the Community
Today’s R2R Cyber-seminar will begin at 2 PM ET

Erin Kent
PhD, MS
Epidemiologist and Program Director,
Outcomes Research Branch,
National Cancer Institute

Kristen Cox Santiago
MS
Senior Director, Policy & Advocacy,
Cancer Support Community

Allison Harvey
MPH, CHES
Senior Manager, Health Care Professional Education,
George Washington Cancer Institute

WebEx can call you at the number of your choice, or call your computer.

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1-855-244-8681
Access code: 732 523 450

RESEARCH TO REALITY
NATIONAL CANCER INSTITUTE
Cancer Caregiving in the Community

Research to Reality Cyber-Seminar Series November 2016
## Cancer Caregiving in the Community

<table>
<thead>
<tr>
<th>Erin Kent</th>
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Cancer Caregiving in the Community
NCI Research to Reality Cyber-Seminar
November 28, 2016

Erin E. Kent, PhD, MS
Epidemiologist and Program Director
Outcomes Research Branch, Healthcare Delivery Research Program
Division of Cancer Control and Population Sciences
National Cancer Institute
Informal Caregivers

- Individuals that assist family members/friends by providing care which is:
  - typically uncompensated
  - usually in the home setting
  - involving significant efforts for extended time
- Caregiving can require demanding tasks, including:
  - Monitoring for side effects
  - Managing symptom burden
  - Treatment decision-making
  - Care coordination
  - Triage
  - Administering medication
  - Technical medical tasks
  - Managing patient’s financial and social obligations
Informal caregiving

- In 2015, an estimated 43.5 million U.S. adults served as a caregiver
- This care was valued at $470 billion
Cancer-specific caregiving

- Unique aspects of caregiving in the context of cancer
  - Rapid deterioration of health
  - High levels of emotional stress
  - Multi-modal therapies
  - More and more outpatient/home care
  - Recurrence, and fear of recurrence
For the vast majority of respondents, being diagnosed with cancer caused distress. The impact of cancer on their family was most often reported as being extremely stressful. In all aspects of life mentioned in this survey, respondents aged 25 to 54 years were significantly more likely than those aged 55 years and older to report being highly or extremely distressed.

### Cancer-Related Distress

#### 25-54 Years Old (n=267)

- The impact of your cancer on your family: 48%* highly or extremely distressed, 28% somewhat distressed, 24% not at all or slightly distressed.
- How you feel physically: 42%* highly or extremely distressed, 30%* somewhat distressed, 29% not at all or slightly distressed.
- Finances: 40%* highly or extremely distressed, 29%* somewhat distressed, 31% not at all or slightly distressed.
- Ability to work: 39%* highly or extremely distressed, 28%* somewhat distressed, 33% not at all or slightly distressed.
- Ability to do things you love to do: 38%* highly or extremely distressed, 24%* somewhat distressed, 38% not at all or slightly distressed.
- How long you expect to live: 35%* highly or extremely distressed, 30%* somewhat distressed, 35% not at all or slightly distressed.

#### 55 and Older (n=238)

- The impact of your cancer on your family: 20% highly or extremely distressed, 28% somewhat distressed, 52% not at all or slightly distressed.
- How you feel physically: 13% highly or extremely distressed, 20% somewhat distressed, 67% not at all or slightly distressed.
- Finances: 19% highly or extremely distressed, 14% somewhat distressed, 66% not at all or slightly distressed.
- Ability to work: 16% highly or extremely distressed, 10% somewhat distressed, 74% not at all or slightly distressed.
- Ability to do things you love to do: 14% highly or extremely distressed, 20% somewhat distressed, 66% not at all or slightly distressed.
- How long you expect to live: 14% highly or extremely distressed, 15% somewhat distressed, 71% not at all or slightly distressed.

*Indicates statistically greater at 90% confidence level

11. How distressed (anxious, extremely upset, or in emotional pain, for example) have you been due to the impact cancer has had on the following aspects of your life?
Estimated cancer prevalence by age in the U.S. population


©2016 by American Association for Cancer Research
CANCER CAREGIVING IN THE U.S.
An Intense, Episodic, and Challenging Care Experience
To compare individuals who report caregiving for an adult who has cancer to those who care for adults with other illnesses

- Burden of care
- Hours per week caregiving
- Communication with healthcare providers
- Making end-of-life decisions
- Emotional stress

http://www.caregiving.org/cancer/
Cancer Caregiving in the U.S.

- **Dataset**: Caregiving in the U.S. 2015
- **Design**: Nationally representative study of adults, age 18+, conducted in late 2014 using GfK’s probability-based online KnowledgePanel®
- **Sample size**:
  - 111 caregivers identified cancer as the main problem or illness requiring care
  - 1,164 non-cancer caregivers
- **Analysis**: Bivariate comparisons using t-tests for means with equal variances and and independent z-tests for proportions (unpooled) were used.

http://www.caregiving.org/cancer/
Results

- **Main findings:**
  - Approximately 2.8 million adults serving as a caregiver to an adult with cancer in the U.S.
  - 62% of cancer caregivers are in high burden situation
  - Average time per week caring: 32.9 hours
  - 43% report performing complex medical/nursing tasks without any prior preparation
  - 50% reporting high emotional stress
  - 25% reporting high levels of financial strain

http://www.caregiving.org/cancer/
Results: Demographics

- **Cancer-caregivers:**
  - Gender: 58% Female
  - Race/ethnicity:
    - 65% White, non-Hispanic
    - 16% Hispanic
    - 11% African-American, non-Hispanic
    - 8% Asian, non-Hispanic
  - Marital status: 62% married

- **Non-cancer caregivers:**
  - Gender: 60% Female
  - Race/ethnicity:
    - 61% White, non-Hispanic
    - 17% Hispanic
    - 13% African-American, non-Hispanic
    - 6% Asian, non-Hispanic
    - 3% Other
  - Marital status; 56% married
Results: Age Distribution

Age of Care Recipient

Median age:
Cancer: 69
Non-cancer: 73

Age of Caregiver

Median age:
Cancer: 52
Non-cancer: 51

*\( p < 0.05 \)
Results: Duration of Care

Cancer caregivers (n=111)

- < 6 months: 38%
- 6 months- 1 year: 29%
- 1-4 years: 24%
- 5-9 years: 6%
- 10 years+: 3%
Average: 1.9 y*

Non-cancer caregivers (n=1,164)

- < 6 months: 29%
- 6 months- 1 year: 19%
- 1-4 years: 26%
- 5-9 years: 13%
- 10 years+: 13%
Average: 4.1 y

*p < 0.05
Results: % Assisting with ADLs and IADLs

**Average #ADLs:**
- C: 2.4 (SE = 0.20)
- NC: 1.6 (SE = 0.05)

**Average #IADLs:**
- C: 4.6 (SE = 0.17)
- NC: 4.2 (SE = 0.06)

**ADLs**
- Incontinence
- Bathing
- Feeding
- Getting Dressed
- Toileting
- Beds/Chairs

**IADLs**
- Arranging services
- Managing finances
- Meds/Pills/Injections
- Meal Prep
- Groceries/shopping
- Housework
- Transportation

* *p < 0.05*
Results: Burden of Care

Cancer caregivers (n=111)
- 62% High Burden
- Average: 3.4*

Non-cancer caregivers (n=1,164)
- 38% High Burden
- Average: 2.8

*p < 0.05
Results: Tasks and Preparation

- **Non-cancer caregivers (n=1,164)**
- **Cancer caregivers (n=111)**

- **Does tasks & was well prepared**
  - Non-cancer: 28%
  - Cancer: 28%
  - *p < 0.05

- **Does tasks, not prepared**
  - Non-cancer: 43%
  - Cancer: 42%
  - *p < 0.05

- **Does not do tasks**
  - Non-cancer: 27%
  - Cancer: 42%

- 55% of non-cancer caregivers do medical/nursing tasks
- 71% of cancer caregivers do medical/nursing tasks

*Non-cancer caregivers (n=1,164) Cancer caregivers (n=111)*
### Results: Help with key activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Cancer Caregiver (n=111)</th>
<th>Non-Cancer Caregiver (n=1,164)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communicating with healthcare professionals (doctors, nurses, social workers) about his/her care</td>
<td>82%*</td>
<td>62%</td>
</tr>
<tr>
<td>Monitoring severity of recipient’s condition to adjust care accordingly</td>
<td>76%*</td>
<td>66%</td>
</tr>
<tr>
<td>Advocating for him/her with health care providers, community services, government agencies</td>
<td>62%*</td>
<td>49%</td>
</tr>
</tbody>
</table>

*p < 0.05
### Results: Help with key activities

As a caregiver, on which of the following do you feel you need more help or information…

<table>
<thead>
<tr>
<th>Activity</th>
<th>Cancer Caregiver (n=111)</th>
<th>Non-Cancer Caregiver (n=1,164)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing your emotional and physical stress</td>
<td>43%</td>
<td>42%</td>
</tr>
<tr>
<td>Making end-of-life decisions</td>
<td>40%*</td>
<td>21%</td>
</tr>
<tr>
<td>Keeping care recipient safe at home</td>
<td>33%</td>
<td>42%</td>
</tr>
<tr>
<td>Managing his/her incontinence or toileting problems</td>
<td>15%</td>
<td>11%</td>
</tr>
<tr>
<td>Managing his/her challenging behaviors, such as wandering</td>
<td>10%</td>
<td>13%</td>
</tr>
<tr>
<td>Finding non-English language educational materials</td>
<td>5%</td>
<td>5%</td>
</tr>
</tbody>
</table>

* *p < 0.05
Results: Emotional Stress of Caregiving

Cancer caregivers (n=111)
- 7% Not at all stressful
- 18% Slightly stressful
- 24% Moderately stressful
- 31% Highly stressful
- 19% Very stressful

Non-cancer caregivers (n=1,164)
- 16% Not at all stressful
- 20% Slightly stressful
- 26% Moderately stressful
- 22% Highly stressful
- 16% Very stressful

50%* Highly stressed
37%* Highly stressed

* p < 0.05
Additional resources on cancer caregiving research
Intervening with cancer caregivers to improve patient & caregiver health outcomes and optimize healthcare utilization: PAR-16-317 (R01), PAR-16-318 (R21)

- Fund interventions that support the success of informal cancer caregivers for adult cancer patients, as measured by the following outcomes:

1. **Improved patient health:**
   Physical and psychosocial outcomes, quality of life

2. **Improved caregiver well-being:**
   Lower burden, higher capacity and quality of life

3. **Optimized healthcare utilization:**
   Improved oral medication adherence; reduced emergency room visits, hospitalization and hospital readmissions; lower rates of infection; timely medication refills; better adherence; use of supportive/palliative care service; primary care visits

Next due date: April 11, 2017
Palliative Care Needs of Individuals with Rare Advanced Diseases and Their Family Caregivers: PAR-17-018 (R01), PAR-17-018 (R21), NINR/NCI FOA

- Expand knowledge and increase the evidence base for palliative care in advanced rare diseases, including rare cancers, and to improve well-being and quality of life among seriously ill individuals and their family caregivers.

- Qualitative, mixed methods, observational, quasi-experimental, and experimental designs with focus on individual- and family-centered outcomes encouraged.

- Goal: Examine unique physical and psychosocial issues related to end-of-life and palliative care that may present among adults with advanced rare cancers* and their family/informal caregivers, including but not limited to:
  - Psychological distress
  - Prognostic uncertainty,
  - Social isolation
  - Decisional regret
  - Decision-making in an emotional and ambiguous context.

*(those with an incidence of fewer than 150 per million per year or approximately 40,000 cases or fewer) (Greenlee, 2014)
National Academies of Medicine Study of Caregiving in Older Adults (September), 2016

Selected Recommendations:

1. (1) Establishment of a National Family Caregiver Strategy

2. (1-f): Expansion of data collection infrastructure across HHS on the experiences of family caregivers

3. (1-g): Multi-agency research program to evaluate caregiving interventions in community and real-world settings
Additional Areas for Future Research/Development

- Population-based studies

- Items on national surveys:
  - HINTS V items
  - 24 states fielded 8-item caregiving module in 2015

- Longitudinal studies
- Dyadic analysis
- More needed research in underserved groups
Caregiving legislation in action

- **Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (S. 1719/ H.R. 3099):**
  - Require Secretary of HHS to create a national strategy to support family caregivers

- **Caregiver Advise, Record, Enable (CARE) Act:**
  - *Record* identity of caregiver upon hospital admission
  - *Advise* caregiver prior to discharge
  - *Enable* caregivers by involving and instructing them in discharge planning
The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.

CARE Act goes into effect:
- Oklahoma, 11/5/14; Colorado, 5/8/15; New Jersey, 5/12/15; West Virginia, 6/8/15; New Mexico, 6/17/15; Mississippi, 7/1/15; Virginia, 7/11/15; Arkansas, 7/22/15; Connecticut, 10/11/15; Nevada, 10/1/15; Maine, 10/15/15; Puerto Rico, 12/31/15; California, 1/1/16; Indiana, 1/1/16; New Hampshire, 1/1/16; Oregon, 1/1/16; Illinois, 1/27/2016; Utah, 2/10/16; Rhode Island, 3/1/16; Nebraska, 3/30/16; New York, 4/23/16; Washington, 6/9/16; Wyoming, 7/11/16; Michigan, 7/12/15; Louisiana, 8/1/16; Maryland, 10/1/16; Minnesota, 1/1/17; Hawaii, 7/1/17; Virgin Islands, TBD; Washington D.C.: TBD

**Updated on 6/21/2016**
Caregiving: puts the focus on families

An individual doesn’t get cancer; a family does.
-T. T. Williams
1 out of 3 cancer patients in active treatment reported having no caregiver

CancerCare Patient Access and Engagement Report, 2016
R2R Cancer Caregiving in the Community
November 29, 2016
Kristen Cox Santiago
OUR MISSION:
To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.
Service Delivery

- 46 centers, 120 satellite locations
- Cancer Support Helpline®
- CancerSupportSource®
- Open to Options®
- Frankly Speaking About Cancer®
- Online Support: The Living Room®

“It is just the greatest place; I have found support, friends and new ways to meet the challenge of having cancer.”
“The emotional support I got from the Cancer Support Community allowed me to draw positive energy from people who were going through what I was going through.”

Kelly, Cancer Experience Registry

"The way they listened to me patiently without judgment, consoling my ocean of tears, gently offering a supportive ear and tender advice, and understanding the enormous stressors on caregivers, is a service that is **priceless**. The *Cancer Support Helpline* was truly a **LIFELINE** for me."

Malaya Cooks, Caregiver & Helpline Caller
Frankly Speaking About Cancer

Caring for a Loved One

Family members, spouses, partners and friends who take on a caregiving role have a unique relationship to cancer. Caregivers see and experience firsthand how deep and wide cancer’s emotional impact can be. They learn how quickly life can become complicated and constrained by a cancer diagnosis. They become attuned to a new reality of making appointments, managing treatments and deciphering insurance forms and medical fees.

It is not all too often, often don’t “see” how much you, the caregiver, are doing. Your loved one is in the midst of the orbit of cancer care, and friends and family members often do not recognize the toll it is taking. Caregivers need support and resources to carry them through the journey.

As a caregiver, you are likely to experience a wide range of feelings, fluctuating between anger, despair or from camaraderie to loneliness and all in one day. On the following pages you will find information that will help you understand your role as a caregiver and help address your own needs.

When a Woman You Care About has Breast Cancer

People who care about someone with cancer can be active participants in enhancing their health and well-being and their loved ones and nurture their relationships through and beyond the cancer experience.

People who care about someone with cancer can be active participants in enhancing health and well-being.
Research and Training Institute
Experts in the Cancer Patient Experience

• The first and only Institute in the U.S. dedicated to psychosocial, behavioral and survivorship research and training
• Led by a PhD behavioral psychologist and staffed by a multidisciplinary team of clinical and research professionals
Cancer Experience Registry®

• First cancer Registry in the world designed to:
  – Understand the full impact of the patient and caregiver experience with cancer
  – Positively influence each individual’s cancer experience
  – Develop programs to help the nation’s health care systems be more responsive to the needs of cancer survivors and caregivers
  – Accelerate and enhance the productivity of research and treatment to improve the lives of those living with cancer

• Currently 10,800 participants (and growing!)
The Evolution of the Registry:
Specialty Registries

The General Cancer Experience Registry
Metastatic Breast Cancer (MBC)
Breast Cancer

Multiple Myeloma (MM)
Chronic Myeloid Leukemia (CML)

Caregivers
Lung Cancer
Melanoma

Prostate Cancer
Gastric Cancer

Chronic Lymphocytic Leukemia (CLL)
Caregivers: Multiple Myeloma

2013 2014 2015 2016
Top Areas Needing Help as a Caregiver

Please tell us how much help you need /needed... (n=97)

- Managing feelings of guilt: 30.9%
- Navigating the health care system: 32.3%
- Providing emotional support for...: 34.7%
- Getting support for myself: 38.2%
- What emotional resources are...: 43.4%
- What state and federal benefits...: 44.3%
- Managing feeling overloaded...: 45.4%
- What financial resources are...: 45.4%
- Managing stress: 46.7%
- Understanding the patients...: 47.4%

% needing “quite a bit” or “very much” help
Caregivers are Highly Involved in Medical Care and Health Interactions

- Coordinating health insurance: 47.2%
- Administering treatment: 50%
- Finances: 55.2%
- Transportation: 62.9%
- Coordinating medical care: 62.6%
- Treatment decision making: 75.9%
- Going to medical appointments: 84.3%
- Providing emotional support: 95.3%

n = 108

% “Quite a bit” or “Very much” involved
Caregiving Self-Efficacy

Overall confidence in ability to care for patient: 72.3%

Confidence in providing emotional support: 58.5%

Confidence in delivering medical care: 58.5%

% “quite a bit” or “very much” confident

n=94; Remaining % “not at all,” “a little bit,” or “somewhat” confident
“...Place the oxygen mask on yourself first before helping small children or others who may need your assistance.”
CancerSupportSource® Caregiver
Four Themes and Sample Items

<table>
<thead>
<tr>
<th>Emotional Concerns*</th>
<th>Caregiving Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling sad or depressed</td>
<td>Managing household/family activities</td>
</tr>
<tr>
<td>Worrying about the future</td>
<td>Getting info about patient care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self-Care</th>
<th>Patient Well-Being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise/being physically active</td>
<td>Patient’s pain/physical discomfort</td>
</tr>
<tr>
<td>Eating and nutrition</td>
<td>Changes in patient’s mood/behavior</td>
</tr>
</tbody>
</table>

*Includes 4-item subscale to assess risk for clinical level of depression
CSC & The Cancer Moonshot

Kim Thiboldeaux
CEO, Cancer Support Community

Educate & Empower
Patient's about Clinical Trials

Patients are our True North
<table>
<thead>
<tr>
<th>CSC Redondo Beach</th>
<th>GC Twin Cities</th>
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<tbody>
<tr>
<td>CSC Santa Monica</td>
<td>CSC Greater St. Louis</td>
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<tr>
<td>CSC Delaware</td>
<td>GC Kansas City</td>
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<tr>
<td>CSC Greater Miami</td>
<td>CSC Montana</td>
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<tr>
<td>UF Health Cancer Center-</td>
<td>CSC Central New Jersey</td>
</tr>
<tr>
<td>Orlando Health</td>
<td>CSC Greater Cincinnati-Northern Kentucky</td>
</tr>
<tr>
<td>GC South Florida</td>
<td>CSC Central Ohio</td>
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<tr>
<td>CSC Atlanta</td>
<td>CSC Greater Lehigh Valley</td>
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<tr>
<td>OSF Saint Francis Medical Center</td>
<td>CSC Greater Philadelphia</td>
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<tr>
<td>CSC Central Indiana</td>
<td>Greenville Health System</td>
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<tr>
<td>GC Evansville</td>
<td>GC Nashville</td>
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<tr>
<td>GC Quad Cities</td>
<td>Whitman-Walker Health Clinic</td>
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<td>GC Metro Detroit</td>
<td>GC Madison</td>
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<tr>
<td>CSC Greater Ann Arbor</td>
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</tbody>
</table>
CSC Affiliate and CCC Partnership

• Caregiver needs are integrated into programs and services
• Webinars for state coalitions
Thoughts/Questions?

So that no one faces cancer alone®
Supporting Cancer Survivors through Comprehensive Cancer Control Programs

Research to Reality
Cancer Caregiving in the Community
November 29, 2016
Caregivers and Survivorship

• National Cancer Institute considers “family members, friends, and caregivers [as] part of the survivorship experience.”

• Cancer caregivers may also experience lower quality of life, psychosocial distress, trouble with relationships and lack of support (Mellon, Northouse & Weiss, 2006; Mosher et al., 2016; Trudeau-Hern & Daneshpour, 2012)
Role of Comprehensive Cancer Control (CCC) Programs

• Public health needs of cancer survivors is a priority area for National Comprehensive Cancer Control programs and coalitions (Seef, 2010)

• GW Cancer Center released Supporting Cancer Survivors through Comprehensive Cancer Control Programs resource in September (http://bit.ly/2016SurvivorshipReport)

• Resource provides an introductory education about post-treatment survivorship needs, offers potential benchmarks that could be included in state cancer plans and identifies systems-level opportunities for supporting survivors and caregivers
## Examples of Benchmarks & Potential Measures

<table>
<thead>
<tr>
<th>Benchmark</th>
<th>Measure</th>
</tr>
</thead>
</table>
| Increase use of Cancer Survivorship, Sexual Orientation and Gender Identity (SOGI), Anxiety and Depression and Caregiver Modules in BRFSS concurrently | Number of cancer caregivers participating in module  
Number of cancer caregivers participating in module  
Identification of cancer survivor and caregiver needs at state level |
| Provide educational opportunities for survivors and caregivers to increase awareness of resources to address lifestyle, psychosocial and financial concerns through multiple channels to reach diverse and hard to reach populations | Number of survivors and caregivers engaged/educated  
Learning outcomes based on event objectives |
| Support local health departments in implementing survivorship activities into their programs | Number of activities delivered focusing on post-treatment cancer survivors and caregivers  
Number of resources distributed  
Number of cancer survivors and caregivers reached |
Conclusion

- CCC programs and coalitions are uniquely positioned to address survivor and caregiver needs.

- The Institute for Patient-Centered Initiatives and Health Equity (formerly the GW Cancer Institute) will continue to support CCC programs in their efforts through technical assistance made possible with a 5-year cooperative agreement with the Centers for Disease Control and Prevention.
Join the Research to Reality and George Washington Cancer Institute

Supporting Cancer Survivors through Comprehensive Cancer Control Programs

COFFEE BREAK WEBINAR

TUESDAY, DECEMBER 13TH
2 PM ET

This 20-minute conversation with lead author Allison Harvey will explore findings of the report and systems-level opportunities for supporting cancer survivorship in surveillance and applied research; communication, education and training; programs, policies and infrastructure; and access to quality care and services

Come with your questions and share your perspective.
Questions for Our Speakers?
Tell Us About Your Experience!
Use the Q&A Feature on the right of your screen.

Erin Kent
*PhD, MS*
Epidemiologist and Program Director, Outcomes Research Branch, National Cancer Institute

Kristen Cox Santiago
*MS*
Senior Director, Policy & Advocacy, Cancer Support Community

Allison Harvey
*MPH, CHES*
Senior Manager, Health Care Professional Education, George Washington Cancer Institute
• A link to a feedback survey will be sent to all registrants shortly.
• Continue the discussion on our Research to Reality Community of Practice: researchtoreality.cancer.gov

We will be sending more information about the December 13th “Coffee Break” webinar to all registrants tomorrow morning.