

Welcome!

2019 Cancer Policy & Advocacy
Team (CPAT) Symposium
#CPAT19



NATIONAL COALITION
FOR CANCER SURVIVORSHIP



#CPAT19

NCCS Cancer Policy & Advocacy Team

- 2014: Inaugural training
- 2015: Added Hill Day; expanded from annual training to year-round program of engagement
- 2016: Included medical students from the Cancer in the Under-Privileged, Indigent, or Disadvantaged (CUPID) program
- 2017: Advocated to protect Affordable Care Act (ACA) during repeal efforts
- 2018: Advocates participated in press conference on pre-existing conditions



Who Has Attended All Six Years?



Valerie Fraser

Five-Year Attendees



Rebecca Esparza

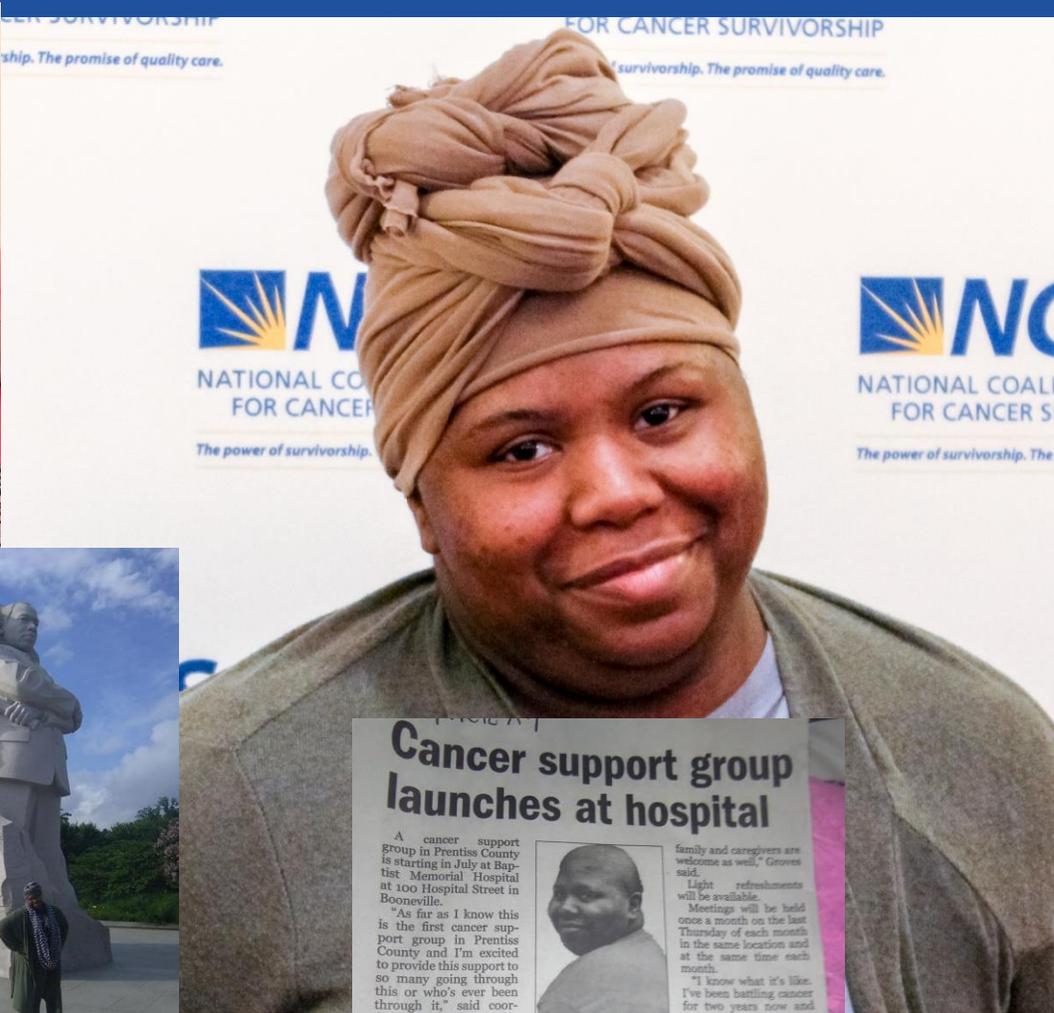


Liza Fues



Desirée Walker

Jennifer Groves (1986-2018)



Cancer support group launches at hospital

A cancer support group in Prentiss County is starting in July at Baptist Memorial Hospital at 100 Hospital Street in Booneville.

"As far as I know this is the first cancer support group in Prentiss County and I'm excited to provide this support to so many going through this or who's ever been through it," said coordinator Jennifer Friar Groves of Booneville.

Groves, 31, is currently battling stage 4 breast cancer that has spread to her liver and brain.

The first support group meeting is set for Thursday, July 26 from 6 p.m. to 7 p.m. at Baptist Memorial Hospital in Booneville on the first floor classroom beside the gift shop.

family and caregivers are welcome as well," Groves said.

Light refreshments will be available.

Meetings will be held once a month on the last Thursday of each month in the same location and at the same time each month.

"I know what it's like. I've been battling cancer for two years now and it never gets easier but it helps having support and being able to talk to people who truly understand," she said.

She said sponsors and donations are still needed. Those having questions or needing more information should contact Groves at 662-416-7324 or by email at Jennifer.friargroves86@gmail.com.

Jennifer Friar Groves of Booneville is the coordinator for a cancer support group starting in Prentiss County.



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Agenda Overview – Day 1

- We have a packed agenda!
- There are a few breaks – take additional breaks if you need them.
- Advocate Panel
- Health Policy Outlook for 2019
- Keynote - Disparities in Cancer Care and Outcomes

Agenda Overview – Day 1

- Communications Breakouts
 - Your Story in a Nutshell (for first-time attendees) – Madison Room
 - Media Training – Telling Your Story
- Congressional Cancer Survivors Caucus
 - Congressmen Mark DeSaulnier (D-CA) & Buddy Carter (R-GA)
- Staging Your Impact – Meeting with Policymakers
- Grief and the Cancer Care Journey

Agenda Overview – Day 1

- Break/Reception – Ballroom I
- Dinner
- Improving Doctor/Patient Communication

Agenda Overview – Day 2

- Breakfast
- Hill Prep & Rally
 - Congressman Jamie Raskin (D-MD)
 - Congresswoman Debbie Wasserman Schultz (D-FL)
- Hill Meetings

Updates on NCCCS Projects



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Elevating Survivorship

A patient- and advocate-led initiative to improve survivorship care in the United States

- Launched Speakers Bureau & Survivorship 101 presentation template
- Recruited 10 Elevate Ambassadors from across the US to engage in projects to improve survivorship care at the local level
- Trained Elevate Ambassadors in April 2019 in Arlington, VA



Survey Results – Treatment Experiences

- Patients report many physical and emotional side effects. Fatigue and anxiety top the list of both the most common and long term effects. These are also among the most severe side effects reported by patients.
- However, patients report that while healthcare providers are helpful at addressing their physical side effects such as nausea and vomiting, HCPs are far less helpful at addressing fatigue, anxiety, depression and cognitive effects.

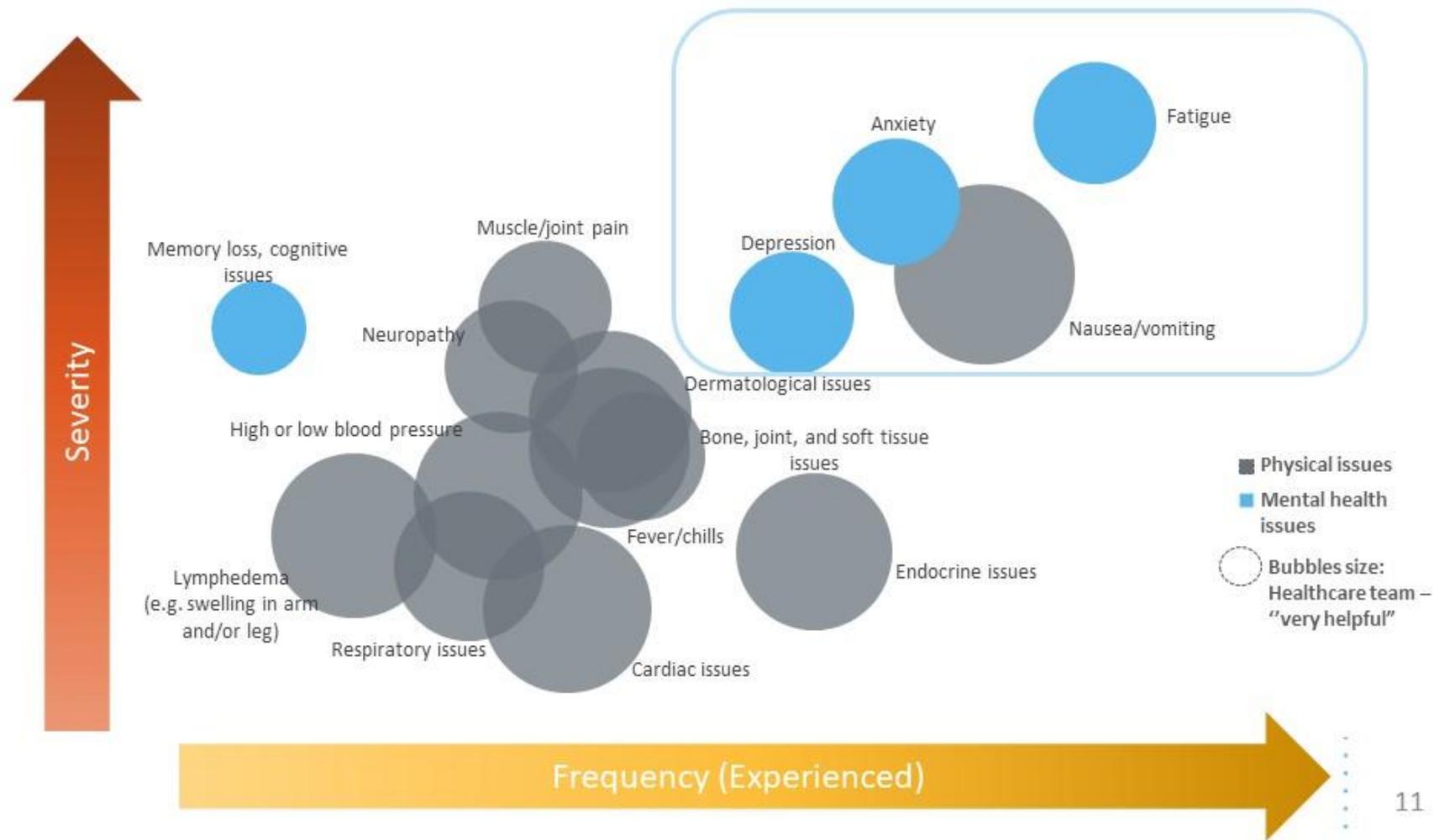
Survey Results – Post-Treatment Experiences

- Few feel very prepared for the transition to post-treatment, nor informed about how to manage their health post-treatment.
- While most patients have spoken to a healthcare provider about post-treatment care, over half say they asked their doctor/HCP, and far fewer say their provider initiated these conversations.
- Satisfaction with post-treatment care is varied, with few describing it as excellent. As a result, more rely on online sources for information rather than their HCPs.

Survey Results – Survivorship Needs

- When asked to identify their level of concern about a range of issues, financial issues tops the list (getting/keeping health insurance, having financial support), followed by managing ongoing side effects, uncertainty about the future, and having the energy to make it through the day.
- There is clearly a disconnect between patient concerns and support from HCPs. Less than a third rate their HCP as “very helpful” on their top issues.
- Many are interested in survivorship resources, especially programs for managing long-term symptoms, but few say these are available from the HCPs today.

Providers are more helpful with nausea and vomiting, but less helpful with key side effects like fatigue, anxiety, and depression



I wish I had known....

- Patients say they wish they had known more about the severity of side effects and long term management; mental health side effects; and fertility/sexual health side effects.

More information about immunotherapy and the possible side effects.
-Immunotherapy patient, In Tx Recurrence

I wish I had known about fertility preservation.
- Metastatic Cancer patient

How living with the fear of recurrence or metastasis can be exhausting, but CAN be managed, through diet, exercise and support groups.
- In Treatment for Initial Diagnosis

*I wish the oncologist would have told me it was 'normal' to experience **pain, fatigue, and depression** with cancer.*
- Completed Tx

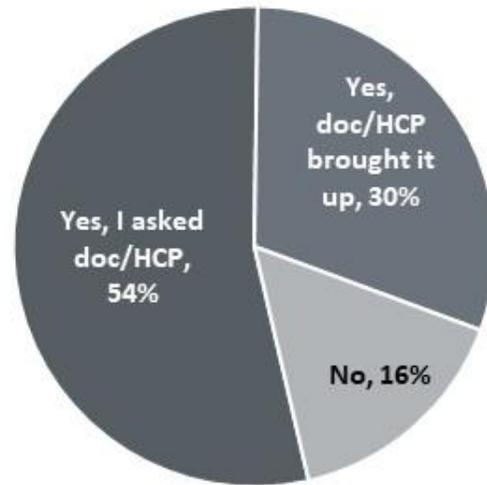
*Long term survivorship issues such as **loss of libido** and its effect on marriage, how to handle **lasting aches and pains**, value of exercise to **mental health**.*
- Completed Treatment

*The **mental side** of things would be worse after treatment is finished.*
-Immunotherapy patient, Completed Tx

Half initiate conversations with their healthcare team about post-treatment

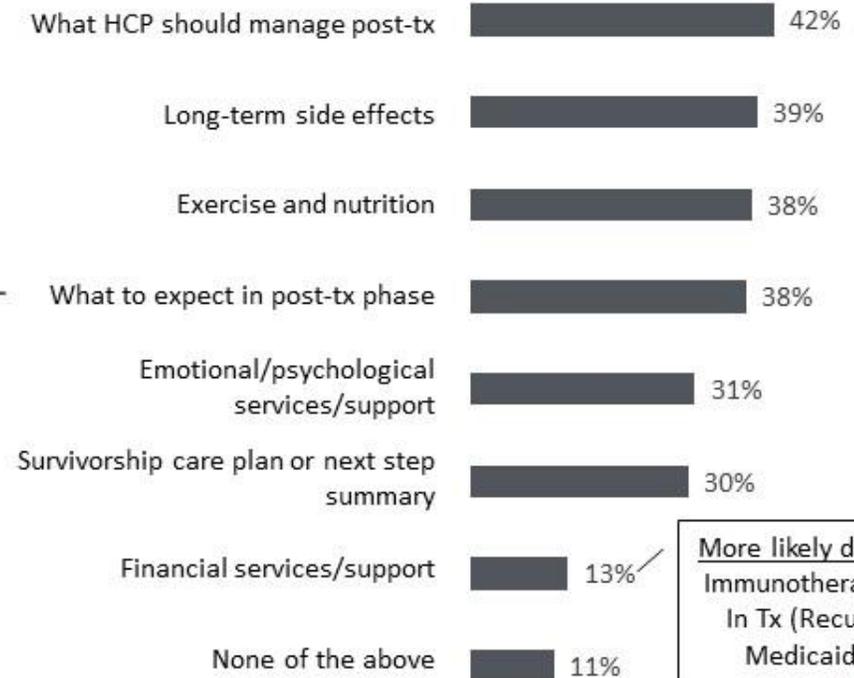
- Who is responsible for post-treatment care is the topic most discussed. Few discuss financial services/support, survivorship plans, or emotional support.

84% have spoken with doctor/HCP about post-treatment



More likely provider-initiated:
 Immunotherapy: 44%
 In Tx (Recur): 42%
 Stage 2: 42%

Which of the following did you discuss/receive from your doctor/HCP about transition to post-treatment? (select all)

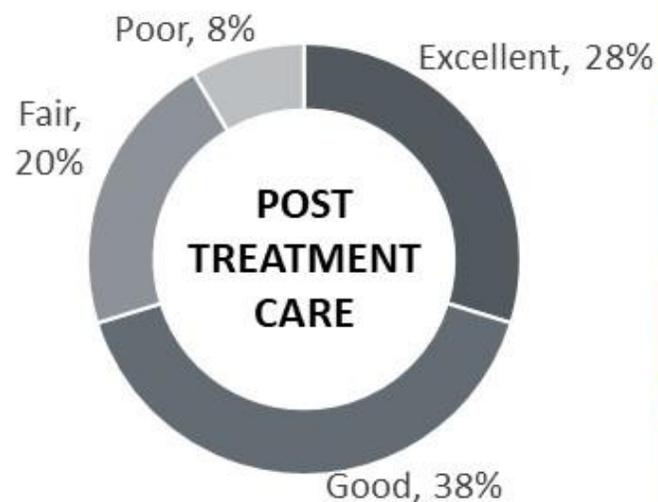


More likely discussed:
 Immunotherapy: 21%
 In Tx (Recur): 22%
 Medicaid: 23%

Patients are mixed on the quality of their post-treatment care

- Just a quarter describe it as “excellent,” and in open-ended questions, many voice concerns about getting enough attention and preparation from their providers.

How would you evaluate your post-tx care?



Satisfaction levels were consistent across audiences

In their own words...

I think there are "survivorship" issues that should really be discussed as part of treatment, not just when treatment ends.

-Completed Tx

Once I was out of active treatment, I was no longer be considered a priority to my oncology team.

-Immunotherapy patient, Completed Tx

Survivorship was harder than treatments.

-Immunotherapy patient, Completed Tx

*I wish that my healthcare team would address survivorship issues and long term effects of my cancer diagnosis. At this point I am just told to call if there are any changes in the way that I feel, this leaves me **feeling uneasy and uncertain** about the future of my health.*

-Immunotherapy patient, In tx reoccurrence

Wrap-up: Key Areas of Need

- There are many ways that NCCS and its partners can impact the survivorship needs of diverse groups of cancer patients.

1

Mental health side effects (depression and anxiety) are common and last well beyond treatment, yet are not well addressed by healthcare providers. Patients say emotional support is a big area of need post-treatment – from mental health counseling to support groups.

2

While many are discussing post-treatment with their healthcare providers, these conversations are mostly logistical (i.e. who will manage post-treatment care). As a result, many rely on online sources for information and support, and indicate they need more resources.

3

Insurance coverage, financial support, and long term symptom management are top patient concerns. There is also high interest in access to resources/programs for these issues through HCPs. However, few HCPs are currently providing them and many patients wonder where they can go to get these supports.

4

Younger patients (18-39) and more vulnerable populations (low income, Medicaid, in poor health) have higher levels of concern across a range of issues. More vulnerable populations are also less likely to say their HCPs have been helpful with these issues.

5

Immunotherapy patients are more satisfied with their post treatment experiences. They are significantly more likely to report feeling prepared and informed, and while they share many concerns around financial and emotional issues, they also report higher levels of help from HCPs in dealing with these challenges.

Survivorship Checklist

OBJECTIVE:

Empower cancer survivors to take charge of their care with a simple checklist to navigate the complexities of cancer survivorship



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CANCER SURVIVORSHIP CHECKLIST

What You Need to Know When You Have **FINISHED TREATMENT**



This checklist provides an overview of important information and actions to help you manage your health after you have completed treatment for cancer.

CARE PLAN

- Ask for a written treatment summary and care plan for me and my primary care provider. This should include what my treatment was and plans for future tests and visits.
- Discuss with my health care team important topics, including:
 - What recovery from my treatment will be like,
 - Any physical or emotional concerns I still have after treatment ends,
 - Short- and long-term treatment side effects and actions to take when symptoms arise,
 - Screening for recurrence or for new cancers,
 - Diet, exercise, or other health recommendations.
- Have plan clearly explained by a member of my oncology care team so that I can understand it.

HEALTH CARE

- Discuss with my oncology team who will manage my care after treatment ends – a member of the oncology team, my primary care physician, or both together using the care plan.
- Discuss how my care will be coordinated with my primary care doctor. Ensure my primary care provider understands required follow-up care specific to my diagnosis and treatment.
- Schedule all necessary appointments and get copy for reference.

EMOTIONAL/MENTAL HEALTH

- Discuss my emotional or psychological concern (including anxiety, depression, or other worries).
- Ask for support or counseling for emotional, or relationship issues.
- Identify support groups or patient advocacy where I can get support.

FINANCIAL HEALTH

- Discuss financial concerns with my care team especially if financial concerns may make me to follow my post-treatment care rec.
- Ask for resources for financial support, if needed.
- Discuss any concerns regarding getting health insurance.
- Request information regarding my right Family and Medical Leave Act (FMLA) to my caregivers.
- Discuss whether I am facing any problem at school as a result of my treatment.
- Discuss whether I am dealing with:

For additional questions, please visit www.canceradvocacy.org/checklist
The Survivorship Checklist has been supported by an educational grant from Bayer HealthCare Pharmaceuticals Inc.



CANCER SURVIVORSHIP CHECKLIST

What You Need to Know When You Are **IN TREATMENT**



This checklist provides an overview of important information and actions to help ensure you are receiving the care that is best for you. This side of the checklist provides suggestions for key information and questions to ask when you have been diagnosed with cancer or are receiving treatment for cancer.

SHARED DECISION-MAKING

- Have a family member or friend attend appointments with me to provide support, ask questions, and take notes.
- Get a full explanation of my diagnosis and chance of recovery.
- Share with my doctor what is most important to me, so my goals can be included in my treatment plan.
- Discuss my treatment options, including the benefits and side effects (both short-term and long-term) of each.
- Discuss the pros and cons of participating in a clinical trial.
- Seek a second (or third) opinion if it will make me feel more comfortable about my decision.
- If I may wish to have children in the future, discuss my fertility options before treatment.

CARE PLAN

- Ask for a written plan of care, including:
 - Frequency of treatments and tests,
 - Side effects I should expect and how to manage them,
 - Any disruptions I should expect to my work, family or other responsibilities,
 - Resources I can use to understand the diagnosis and treatment better,
 - How and when to contact my care team if I have questions or concerns.
- Have plan clearly explained by a member of my oncology care team so that I can understand it.
- Discuss involvement of caregivers and my preferences for how I would like to be treated.

HEALTH CARE

- Ask if I will need someone to drive me to the treatment(s), and ask for help if transportation is an issue.
- Discuss diet, exercise, or other health recommendations.

EMOTIONAL/MENTAL HEALTH

- Discuss my emotional or psychological concerns (including anxiety, depression, or other worries).
- Ask for support or counseling for emotional, sexual, or relationship issues.
- Identify support groups or patient advocacy groups where I can get support.

FINANCIAL HEALTH

- Ask for information about the costs of treatment.
- Discuss financial concerns with my care team if financial concerns may make it hard to follow my treatment plan.
- Ask for resources for financial support, if needed, health insurance.
- Talk to my employer or school if I need to take time off.
- Request information regarding my rights under the Family and Medical Leave Act (FMLA). This also applies to my caregivers.
- Discuss whether I am facing any problems at work or school that may get in the way of my treatment. Discuss whether I am dealing with any discrimination.

CAREGIVER(S)

- Ask how a caregiver can get help or training if needed to care for me at home.

For additional questions, please visit www.canceradvocacy.org/checklist
The Survivorship Checklist has been supported by an educational grant from Bayer HealthCare Pharmaceuticals Inc.



Quality Measurement

Redefining Functional Status (RFS) Project

- Convened committee of 10 cancer survivors, representing different cancers and stages of disease, as well as Technical Expert Panel (TEP) of oncologists and quality measurement methodologists
- Conducted RAND Delphi survey process to reach consensus regarding priority areas for quality measurement related to functional status
- Convened patient committee for two-day meeting to discuss survey results and priorities for measurement, as well as additional recommendations

Quality Measurement

Redefining Functional Status (RFS) Project

- Prioritized outcomes for measurement of RFS
 - Physical function, pain, fatigue
 - Cognitive functional, mental health, emotional health, depression
 - Independence, control, resilience, grief
 - Overall quality of life
- Currently evaluating validated surveys for best alignment with the conceptual definition
- Next step will be to develop patient-centered specifications for RFS outcome measures

Engaging CPAT Members

- Nominations
- Media opportunities
- Webinars/Facebook Live
- Facebook Group
- CPAT Chronicles

cpat@canceradvocacy.org

