

# GW Cancer Institute

THE GEORGE WASHINGTON UNIVERSITY

## Generation and Dissemination of Evidence (GATE), an Oncology Community of Practice (CoP)

### Ask the Expert Session 1: Summary Discussion Notes

#### Dissemination and Implementation of Survivorship Care Plans: Benefits, Challenges and Future

December 14, 2015

#### Experts



**Sarah Birken, PhD** is an assistant professor in the Department of Health Policy and Management in the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. She received her MSPH and PhD from the University of North Carolina at Chapel Hill in Health Policy and Management and her BA from the University of California, Berkeley in Women's Studies with Phi Beta Kappa honors. Dr. Birken's primary research interests are health care organization and delivery; the dissemination and implementation of innovations; quality improvement; and organizational behavior in cancer care. Currently, she is studying the dissemination and implementation of survivorship care plans in US cancer programs. She has won awards for distinguished scholarly achievement, such as the Academy of Management's Health Care Management Division Best Paper

Based on a Dissertation. Dr. Birken has several peer-reviewed empirical and theoretical publications in highly ranked health services journals and a national presence in the cancer survivorship and dissemination and implementation research communities. She has experience in community health, quality improvement consulting, and academic settings. She has taught courses including Health Services Research Study Design and a doctoral seminar in Organizational Theory and Health Care Organizations.



**Elizabeth Hatcher, MSN, APRN, FNP-BC** is a Nurse Practitioner with the Division of General Internal Medicine at the George Washington University (GW) Medical Faculty Associates. She received a Bachelor of Arts degree in Psychology at Emory University in 2000. In 2010, she completed a Bachelor of Science in Nursing degree at The University of Tennessee at Chattanooga. In 2015, Elizabeth earned a Master of Science in Nursing, Family Nurse Practitioner degree at the GW School of Nursing. She is board certified as a Family Nurse Practitioner by the American Nurse Credentialing Center (ANCC). Elizabeth gained patient care experience as a Nurse Technician I, PRN at the Memorial Hospital in Chattanooga, Tennessee. In her most recent position, she was a Survivorship Project Manager at The George Washington University Cancer Institute, where she

navigated individual post-treatment cancer survivors through the healthcare system; collaborated with multi-disciplinary teams to coordinate "Thriving After Cancer Adult Survivorship Clinic" to provide survivorship care plans, as well as providing education courses to post treatment patients at GW and its surrounding community. Elizabeth has two publications and has presented at a number of forums locally and regionally.



**Liza A. Fues, JD** is a Patient Advocate at the George Washington University (GW) Cancer Institute and a 30-year survivor of breast cancer. At the GW Cancer Institute, she is helping to develop an online policy, systems, and environment tool to help address inequities in cancer care. Prior to joining the GW Cancer Institute, she was the Project Manager supporting the National Cancer Institute's State Cancer Legislative Database Program and an attorney with a large firm. She is an active volunteer with the American Cancer Society. She did not receive a care plan at the time of her cancer diagnosis.

## **Presentations**

A PDF document of the presentations given by each expert is available for download

<https://smhs.gwu.edu/cancergate/events/ask-expert-survivorship-care-planning>

## **Questions, Answers, and Discussion**

Following each expert presentation, a question, answer and discussion session was held. The following is a summary of each of these sessions.

- Question: How can one help to coordinate care plans and engage physicians, other health care providers, patients, and others engaged in a patient's care?
  - Dr. Birken noted that ideally, everyone engaged in a patient's survivorship care plan is aware of everything that is going on with the patient and knows what the team members are doing as well. There are no set rules for doing this but proponents of care plans advocate for them as a common sense approach to get everyone on the same page so that they know what has been done, what everyone is currently doing and what is going to be done in the future. Many studies that have been done on the topic expect a lot out of a survivorship care plan. Alone, it may be unlikely that a survivorship care plan will be able to achieve those intended outcomes. It may be more important to think about implementation. For example, having a nurse practitioner sit down with a survivor and talk through the survivorship care plan is an important component. Additionally, making sure that the specialists' information is on the plan and making sure that the primary care provider is connected to the patient as well is critical. Implementation is as vital as the survivorship care plan itself.
- Question: What do survivorship care plans look like in the different settings?
  - A participant who works at a non-profit community hospital system spoke about her experience with care plans as being fraught with frustration and a small degree of success. She says only about 1% of patients want to come in and discuss the plan. Thus, she is unsure that the plans are really meeting the patients' needs and is unsure what exactly their needs are. If the plans aren't resonating with survivors, she questioned if they are really needed. The participant did mention that there is a certain subset of patients, such as breast cancer survivors, who are very mobilized and motivated and seek out what they need. It seems possible that motivated patients like this may utilize their plan and meet with the intended providers to implement it. It seems like plans are not "one size fits all" and the approach taken may be different for different patients.
  - Dr. Birken agreed with the participant that it is important to analyze what specific plans are right for patients. Dr. Birken spoke about another study she is working on about an intervention for prostate cancer survivors. The intervention looks at an addendum at the end of a care plan that includes a web-link intended for patient use online at home. The link provides evidence-based information for patients, and does so in the privacy of their home where they don't have to work with a provider. Classes and other educational tools are important to look at in addition to, or in lieu of, care plans and all of the models should be rigorously tested.
  - A participant from California said that she works with a significant amount of retired and military patients. From 2012 to 2015 her workplace created about 400 care plans. The participant believed that patients who are in the military and are transferring to another location or those who live in a different place part-time appreciate having a care plan so all of their information is in one document for other care providers they see. However, the patients who live in the same place all the time don't seem to care about a plan as much.
  - A participant from a hospital setting said that research to support the timing of when the care plan should be shared with a patient as well as surveillance guidelines are available. However, there is not a lot of research to support the recommendations that exist. In her experience, she has found issues with patients having physician fatigue in all of the follow-ups recommended in their guidelines. Patients may also have

- trouble affording the numerous co-pays when they go to all of the recommended follow-up appointments. The participant said that she believes it would be helpful to have more information about follow-up care.
- Dr. Birken acknowledged that there are many dimensions that still need to be investigated. Many variables need to be taken into account and it will take time to figure out what will work in certain situations. Research has indicated that guidelines are not evidence-based, which can be aggravating to practitioners. Dr. Birken says that she is currently collaborating with a student who is developing a meta-guideline to synthesize the useful pieces of existing guidelines, which will be vetted by experts in the field of survivorship. She hopes that it will help to create more helpful guidelines than those that currently exist.
  - Question: Are you billing for your visits with patients? How are you doing that? What is your compliance in patient follow-up? Have you had issues with it?
    - Ms. Hatcher explained that she is billing as a visit in internal medicine. The nurse practitioner bills for delivering the care plan as a comprehensive follow up visit. She explained that they get a lot of positive feedback from patients and survivors who are coming in. In the past, it has been a challenge to get the systematic referrals from the oncologists. She believes that the patients will see it as important if their providers support it.
    - A participant said that she asks survivors who come in for visits what they have heard about the survivorship clinic and what their expectations are. Seventy-five to eighty percent of the patients respond that they are there because their doctor referred them. The participant said that where she works they are also struggling to get physician buy-in to let them know that patients are finishing therapy so she knows to get started on a care plan.
    - Another participant said that one thing that has been done in her a medical group that is well-received by patients is approval to get combination visits where the patients come in, pay one co-pay, see their physician for their follow-up visit and then if they are able to stay longer, they are able to have another appointment to talk about their care plan and any survivorship needs. This is more convenient for the patient.
  - Question: As a patient, do you have any suggestions about how we can determine the effectiveness of care plans and their process? The participant asking currently uses a survey but says it doesn't seem to be a very good way of getting feedback.
    - Ms. Hatcher says that the clinic looking to do a survey as well, but agrees that it is not a great way to get feedback. She says the clinic also uses postcards that are left with patients as a way to get feedback. The results give providers feedback about the value of the clinic. The postcard has a simple rating system from 1-10 asking patients about their experience along with space for a note to the provider about their experience. It's anecdotal feedback but it is helpful because it is given to the patient right after the visit when their appointment is still fresh in their mind.

### **Expert-recommended resources:**

- **Resources from Elizabeth Hatcher:**
  - CoC Standard:  
<https://www.facs.org/publications/Newsletters/coc-source/special-source/standard33>
  - NAPBC Standard:  
<https://www.facs.org/~media/files/quality%20programs/napbc/2014%20napbc%20standards%20manual.ashx#page=59>
  - Comparison of CoC and NAPBC standards:  
[https://www.ons.org/sites/default/files/Comparison\\_CoC\\_NAPBC\\_SurvivorshipStandards.pdf](https://www.ons.org/sites/default/files/Comparison_CoC_NAPBC_SurvivorshipStandards.pdf)
  - ASCO Template:  
<http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>
  - Journey Forward:  
<http://www.journeyforward.org/>
  - NCCN Guidelines:

- [http://www.nccn.org/professionals/physician\\_gls/f\\_guidelines.asp#supportive](http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#supportive)
- **Resources from Liza Fues** (*Modified from Memorial Sloan Kettering Cancer Center*  
<https://www.mskcc.org/referring-physicians/survivorship/survivorship-care-plan>)
  - ACS Guidelines:  
<http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/toolsforhealthcareprofessionals/index>
  - American Society of Clinical Oncology:  
[Care plan templates, guidelines for breast and colorectal cancer follow-up](#)
  - Journey Forward:  
[Tool for developing care plans based on ASCO recommendations](#)
  - National Comprehensive Cancer Network:  
[Disease-specific treatment follow-up guidelines](#)  
Registration is required, but access to these guidelines is free
  - Live**Strong** Care Plan, Powered by Penn Medicine's OncoLink:  
[Patients can develop their own care plan to be reviewed by their healthcare team](#)
  - Memorial Sloan Kettering Cancer Center:  
[Treatment summary and care plan](#)