

National Comprehensive Cancer Control Program
Technical Assistance and Training Regional Workshop
Session II: Survivorship Notes
AL, IL, KY, MS, TN
February 24, 2021

CDC Facilitators: Chris Stockmyer

GW Cancer Center Facilitators: Mandi Pratt-Chapman, Dao Duong, Liza Fues, Ruta Brazinskaite

ACS Facilitators: Sarah Shafir, Katie Bathje, Todd Tyler

Other National Partnership representatives: Leslie Given (Strategic Health Concepts)

Introduction

Representatives of programs associated with CDC Program Consultant Jamila Shields and Elliane Yashar, along with coalition representatives from Illinois, Kentucky, Mississippi and Tennessee, attended a virtual survivorship workshop convened by the GW Cancer Center and ACS. Please note that Alabama representatives were not able to attend the workshop.

There were 4 learning objectives:

- Identify **potential barriers to implementing survivorship goal(s) in your state**
- Develop **strategies to address identified barriers**
- Utilize **resources to start an action plan to implement your survivorship goal(s)**
- **Exchange ideas and network with other state CCC program and coalition representatives**

Discussion: What was your top survivorship priority coming out of Session I? Were there any progress or changes made to this priority?

- **Illinois:** No changes made since the last session. Their top two survivorship priorities were getting information and resources so people can understand expectations of survivorship and empowering and engaging survivors.
- **Kentucky:** Their top three survivorship priorities were empowered and engaged patients, meaningful communication between providers and patients, and access to a full spectrum of care. The coalition has started a survivorship committee that has goals aligned with the prioritized areas mentioned.
- **Mississippi:** Working on different survivorship objectives with their workplan, including prostate cancer survivorship efforts. The coalition is moving forward with their health coaching program, progressing with a survivor's retreat in May, and working on needs assessments.
- **Tennessee:** Top survivorship priorities were mental health care and social support and empowered and engaged patients. The coalition is working on a final approval of a breast cancer project in Memphis, developing their Year 5 APR to include healthy brain initiatives, and supporting survivorship programs already in place, such as those provided by the YMCA and Cancer Support Community.

After states completed the first breakout activity identifying root causes of their survivorship priority areas, they were asked to report out on their finalized problem statement and prioritized cause.

- **Kentucky**
 - **Problem Statement:** Patients are not aware of resources for basic needs in the community.
 - **Prioritized Cause:** Lack of internet access, especially in rural areas
 - Other causes discussed
 - Lack of communication by programs not sharing resources
 - Survivors facing challenges with getting back on their feet
 - Survivors not prioritizing self-care
 - Limited transportation resources

- **Mississippi**
 - **Problem Statement:** There is a lack of health promotion resources for cancer survivors.
 - **Prioritized Cause:** There is a big need to launch health promotion products to those who can use it.
 - In regards to their digital health coaching program for survivors, there may be a lack of awareness of the program itself, so working on dissemination strategies and improving communication efforts.
 - The coalition emphasized that survivorship is not a destination so reframing health as a journey may potentially increase awareness at the patient and provider level.
 - Other causes include having rural areas with limited access to resources, which can be addressed by looking at different program modalities (i.e., computer, phone, print material).
 - Mentioned that mistrust can be a barrier to raising awareness and discussed ways to reach survivors via patient navigators, referral methods, and other modes of communication.

- **Tennessee**
 - **Problem Statement:** Patients with low health literacy experience health disparities at a higher level and the provider's ability to impact is limited.
 - **Prioritized Cause:** Limited resource access and provider education.
 - Other causes
 - Rural vs urban challenges
 - Changing screening guidelines, which can be addressed by empowering patients to inquire about these changes.
 - Access to resources. Cancer resources are only offered via in-person health educators, thus, there may be gaps with lack of virtualization.
 - Education levels, such as low high school graduation rates. Coalition is looking at modifying provider communication to address health literacy issues.
 - Provider education and confidence, which can be affected by time limitations on visits, missed educational opportunities, and urgent need to discuss palliative care more frequently.

Group Discussion with Liza Fues, GWCC: Engaging and Empowering Survivors within Your Coalition

What are some ways to better engage and empower survivors within your coalition? What type of information and/or resources can help cancer survivors understand expectations of survivor engagement within your coalition?

- Tennessee's stakeholder analysis revealed that many individuals intend to be active or peripheral participants, so they are finding more ways to improve their survivor population among stakeholders.
- Mississippi utilizes their annual survivorship conference and retreat to gather ideas and learn more about survivors' needs; this information can be used to shape survivorship goals.
- **Tips and Tricks**
 - Consider why do you want survivors? Are you expanding to caregivers and family members?
 - Think of the value proposition
 - Helps volunteers feel like they're giving back, helping people, making a difference, and paying it forward
 - Use search engines to look for volunteers, such as Volunteer Match
 - If coalitions have a website, consider having a form specifically for survivors to sign up to be a volunteer
 - When seeking volunteers, be specific in their activities. Are activities focused on advocacy, staffing events, or simply providing a survivor perspective?
 - Specify time commitment and make it easy for survivors to sign up. Use online forms and/or social media messages to provide up to date contact information for a point person to follow up with interested survivors
 - Make sure there is some form of training (i.e., 1:1, small group) to talk about expectations of having a survivor perspective, so people joining the coalition feel that they have something to offer. Include an overview of any workgroups and/or task forces and define any entities or acronyms.
 - Additionally, coalitions can have a dedicated member train and interact with new survivors joining the table.
 - Resources
 - Articles
 - [5 Ways to Recruit More Volunteers for your Nonprofit](#)
 - [Prospective Volunteers Are Closer than You Think](#)
 - Websites for Recruiting Volunteers
 - [VolunteerMatch](#)
 - [Create the Good](#)
 - [Idealist](#)
 - Examples of websites that make it easy to volunteer
 - [National Coalition for Cancer Survivorship](#)
 - [American Cancer Society](#)

- [American Cancer Society Cancer Action Network](#)

End of Session Feedback: What went well and what could be done differently?

- Some comments: “Liza’s info was so helpful. Great ideas and insight to engage survivors.”
“There could be an entire training on recruiting and retaining survivors in a meaningful way.”
- Mississippi thought that this session was more geared to coalition efforts. They also liked resources and targeted conversation for survivorship.
- Recommendations: more sessions or a forum to facilitate dialogue among state directors, possibly have sessions where states can check in in regards to their survivorship goals and activities
- Note that these tools and steps can be used for other priorities and help build internal capacity to convene on similar topics with your own coalitions!