

SURVIVORSHIP INTEREST GROUP BREAKOUT SESSION - NOTES

When a child is first diagnosed with cancer, survivorship is the ultimate goal. There are more childhood cancer survivors than ever before, but toxic treatments lead to many complications and unique challenges that need to be addressed. The Survivorship Interest Group's Breakout Session examined three separate initiatives that have the potential to impact and help our childhood cancer survivors, their families, and the nonprofit organizations and medical professionals that serve them.

THE HOPE PORTAL (www.hope-portal.org) is a centralized and comprehensive database that connects patients, survivors, and their families to childhood cancer resources and support service organizations quickly and efficiently. In order to keep the Hope Portal an updated and valuable resource, we encourage nonprofit organizations to: add your organization to the Hope Portal; customize and update your profile; embed the Hope Portal onto your website; recommend the Hope Portal to other organizations; and tag "Survivorship" if your organization offers services and/or programs for this population. In addition, the Family Support and Survivorship Interest Groups are launching the Hope Portal State Liaison project, which would provide volunteers with an opportunity to network with the childhood cancer community in their particular state. For this project, we are looking for a volunteer from each state to:

- Connect with treatment centers in your state to raise awareness about the Hope Portal as a valuable resource for their patients, survivors and families.
- Connect with nonprofits in your state to encourage them to join the Hope Portal and reach more patients, survivors and families, including at least two organizations that offer survivorship resources, programs, and services.

Finally, we discussed the various ways that the Survivorship Interest Group is diligently working on expanding the number of organizations that offer survivorship resources on the Hope Portal, including: addressing organizations currently on the Hope Portal that have not marked "Survivorship", but do offer services to this population; adding and contacting new organizations that fit within the current structure; and a future project to create a new "Survivorship" section with new search categories on the Hope Portal.

BETTER TOGETHER is a multi-phase project for childhood cancer survivors and their caregivers, regardless of their age or stage of survivorship. There are four phases to this project and we are currently working on the first two, which were addressed in this breakout session. **Phase 1** consisted of building a database of organizations that offer resources, programs, and services to survivors and their caregivers. This database includes all of the "Survivorship" organizations from the Hope Portal, but it is also more expansive because it includes many other organizations that do not fit the current structure or categories of the Hope Portal. We have added 125 organizations so far, but the database will continuously grow. We are now working on the **Phase 2** of this project - launching a navigator program, "**CAC2 Connection**", which will provide a personalized approach to connect survivors and their caregivers, as well as nonprofit organizations and medical professionals serving this population, with organizations that provide resources, programs, and services. We envision CAC2 Connection to exist on the CAC2 Survivorship page, where a survivor, caregiver, nonprofit organization, or medical professional would submit a question about finding an organization to assist with a specific survivorship challenge, such as finding a support group for young adult survivors, finding various college scholarship, or discovering an adventure camp for a survivor and their family. Within a defined period of time, a trained navigator would search the database to find organizations fitting the particular need or concern. This phase has been submitted to CAC2's Project Incubator, and we will be working through that process and waiting for approval. Additionally, we had a "Happy Hour" session at the end of the Summit on CAC2 Connection, and I have attached the handout that we created to further explain this program.

We are looking for volunteers to help with Better Together and CAC2 Connection to:

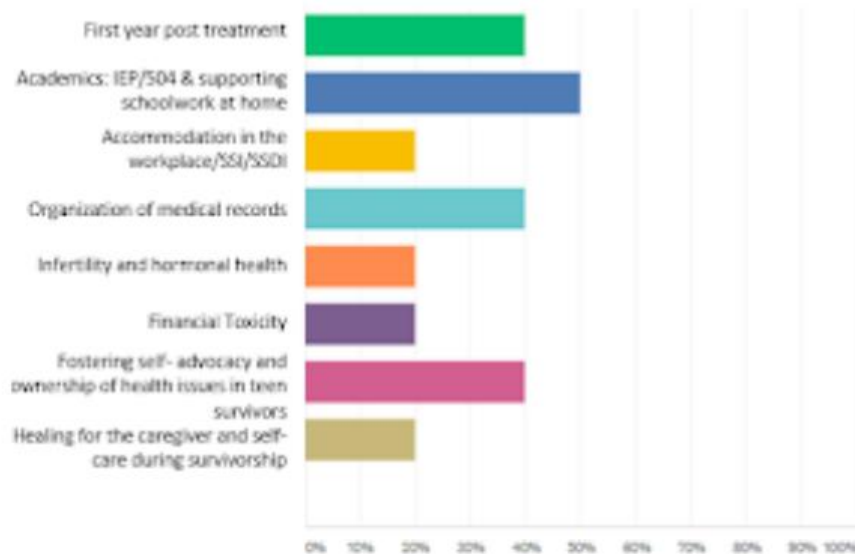
- Help us build our database by emailing us any organizations that serve childhood cancer survivors and/or their caregivers
- Help us with building CAC2 Connection
- Sign up to become a navigator!

THE SURVIVORSHIP TOOLKIT is our newest project and the general purpose of it is to provide additional and more thorough resources for survivors and their families that address some of the challenges and issues that this population faces. The Toolkit would be accessible through the Coalition Against Childhood Cancer’s website to childhood cancer survivors and their families, and CAC2 member organizations and medical professionals can both provide the Toolkit’s resources to their own community of survivors and their families. The Toolkit would also allow them to better understand some of the challenges of childhood cancer survivorship. There is a vast array of survivorship topics that we could consider, but in order for the Toolkit to be successful, we want to *start* by addressing one key area and providing meaningful support for it.

In order to determine the direction of the Survivorship Toolkit, we conducted several polls and had a very interactive, energetic discussion about each topic. First, we asked the attendees which survivorship challenges they first wanted to address with the Toolkit. The results revealed that academics was the top topic, followed closely with a three-way tie between: addressing the first year post-treatment; organization of medical records; and fostering self-advocacy and partnership of health issues in teen survivors. There was discussion about the focus of academics and how the Toolkit could break this topic down into appropriate subcategories to provide assistance to all of the identified populations. This could make it a comprehensive resource for a variety of situations, side effects, age groups, and length of time as a survivor.

Out of all of the survivorship challenges, what do we first want to address with the Survivorship Toolkit?

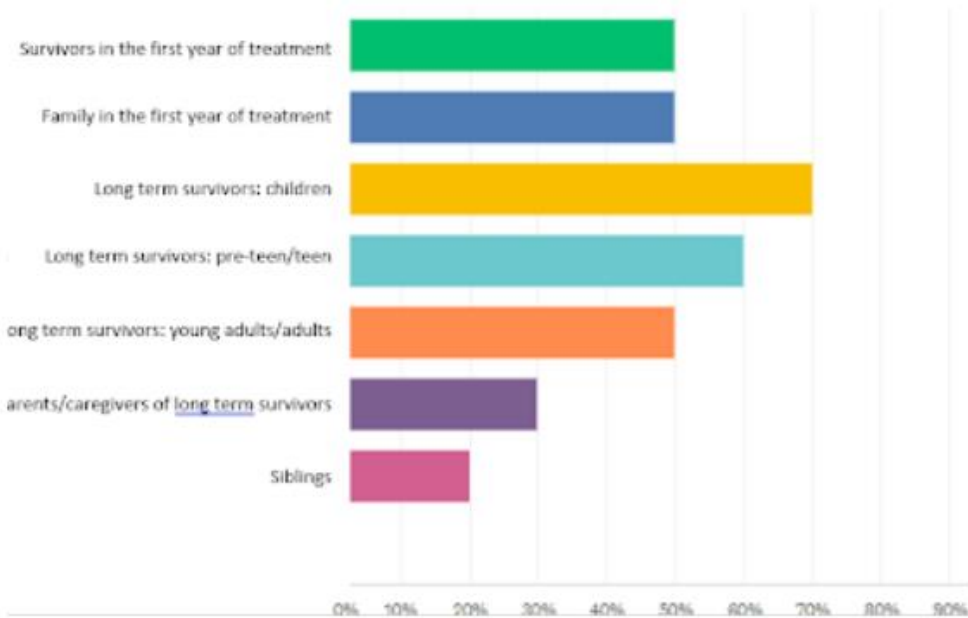
Answered: 10 Skipped: 0



Next, we asked the attendees about which population that they would like to address immediately, and survivors of varying ages was the resounding answer. Addressing survivors that were children took the top spot, followed closely by survivors in their pre-teens/teens. The conversation after this poll question discussed the possibility to expand the population to include parents who advocate for survivors that cannot do it themselves.

What population would you like to address immediately?

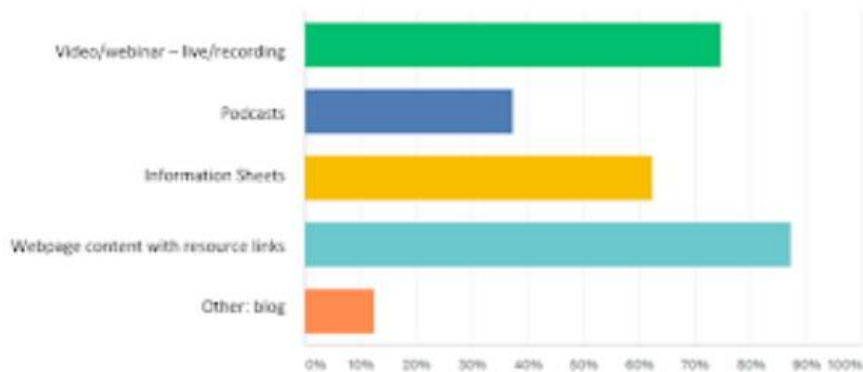
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The third poll examined the content of the Survivorship Toolkit, and attendees expressed an interest for the Toolkit to include webpage content with resource links. By order of popularity, they also expressed an interest for the Toolkit to include: videos/webinars, either live or recorded; information sheets; podcasts; and blogs.

What format(s) should we consider to provide information for the Survivorship Toolkit?

Answered: 8 Skipped: 0



We are looking for like-minded members to work on the Survivorship Toolkit and join further discussions on discuss what we want to address and include. Once that is decided, we also need volunteers speak with various professionals and organizations to create the elements of this toolkit. The attendees were polled about how frequently they wanted to meet to discuss the Survivorship Toolkit and other Survivorship Interest Group initiatives, and the results revealed a strong desire to meet monthly. *We will be sending out an email shortly to determine the date and time of the first meeting!*

If you are interested in becoming involved in any of these projects, joining our meetings, or receiving emails about the Survivorship Interest Group, please email Mariah Forster Olson, the Survivorship Interest Group Lead, at: survivorship@cac2.org.