In this lecture we’re going to talk about the Passport for Care. This is a clinical decision support tool for care providers and a resource site for survivors of childhood cancer. My name is ZoAnn Dreyer, and I am a pediatric oncologist at Texas Children’s Cancer Center, and the Director of the Long-Term Survivor Program.
Learning Objectives

At the completion of this course the learner will be able to:

- List recommendations of the Institute of Medicine that are considered critical for proper cancer survivor care.
- Explain the value of the PFC to long-term survivor patients.
- Describe the uses and benefits of the clinician portal and survivor website sections of the PFC, including the survivor care plan generated from PFC.
- Appraise the impact of information generated for survivors on their care and interactions with their providers.

At the completion of this course, the learner will be able to: 1) list the recommendations of the Institute of Medicine that are considered critical for proper cancer survivor care; 2) be able to explain the value of the PFC, or Passport for Care, to long-term survivor patients; 3) describe the uses and benefits of the clinician portal and the survivor website sections of the PFC, including the survivor care plan generated from the PFC; and 4) appraise the impact of this information generated for survivors on their care and their interactions with their providers.
The participant benefits include the following. What can this tell me about my everyday practice? By understanding the Passport for Care Survivor website, you can see what the survivor receives as follow-up care recommendations, and then you can help screen for and manage any potential late effects.

Why doesn’t the survivor just go to an oncologist?

- Some survivors are no longer followed by their oncology providers or may not be able or wish to be followed by a “cancer clinic” and don’t want to be associated with a “cancer clinic.” But if they are in the Passport for Care, they can bring you, the primary care provider a guide to follow for their care.

Why can’t I, as the PCP, see the survivor’s Passport for Care page myself?

- The survivor’s page is password protected so the survivor is in charge of their information, but it serves as a great communication tool for you and your patients.
How can the primary care provider benefit from the Passport for Care? You will be provided with follow-up care recommendations, appropriate and necessary follow-up care. Accurate screening and prevention guides are provided. It’s a communication tool, the provider to the patient, and the provider to the long-term survivor expert. It has definite educational benefits, both for you and for the provider, and offers excellent guidelines for transitional care.
In 2006, the Institute of Medicine made recommendations for what every cancer survivor should have -- a care plan that contains the following critical elements. There should be information on the patient’s cancer diagnosis and the treatments received. There should be recommendations regarding follow-up evaluations. There should be guidelines for preventative practices and healthcare maintenance. There should be information on helpful resources, such as advocacy, counseling, insurance, et cetera.
A recent study of twenty thousand childhood cancer survivors found that of those survivors two-thirds reported at least one medical condition, and of those twenty-five percent, had a serious medical complication, and you can see whether you’re looking at all patients with cancer, or the different subgroups of cancer. This was a very uniform finding.
Based on the recommendations of the Institute of Medicine, the Passport for Care was developed. And why was that developed? Because the Institute of Medicine report from cancer patient to survivor identified gaps and care for survivors, and made the following recommendations. They recommended that providers establish cancer survivorship as a distinct phase of cancer care, that they develop and provide a summary of treatment and survivorship care plan to each survivor, that healthcare providers use systematically developed, evidence-based, clinical practice guidelines, assessment tools, and screening instruments to help identify and manage the late effects of cancer and its treatment in cancer survivors.
The Passport for Care is an online, Internet-based resource for both clinicians and survivors. The Passport for Care includes a clinician portal and a survivor website. It is a collaborative effort. Follow-up care guidelines developed by the Children’s Oncology Group Long Term Care subcommittees are provided by experts across the country for general provider and oncologist use and understanding. Developed, launched and hosted by the CCIT – Center for Collaborative and Interactive Technologies at Baylor College of Medicine and Texas Children’s Cancer Center, the Passport for Care assists providers in delivering comprehensive quality care to long-term survivors of childhood cancer with complex treatment histories.
Issues affecting childhood cancer survivors, or cancer survivors in general, include medical late effects, lack of consistent long-term medical follow-up, psychosocial issues, employment issues, insurance issues, and discrimination.
Challenges to follow up for childhood cancer survivors include a number of different things. They frequently change healthcare providers. They go off to college. They grow up and go on to their adult life. Primary care doctors are not generally familiar with survivor issues. There is a lack of easily accessible follow-up medical information for these survivors, and there is no mechanism available that alerts survivors to new medical findings that relate to them. The Passport for Care addresses these by offering long-term care guidelines and recommendations for screening individualized to the survivor’s characteristics and treatment history, accessible to the patient, to give to providers a guide to follow for follow-up care.
The Children’s Oncology Group guidelines are evidence-based and consensus-based. There are actually fourteen multidisciplinary task forces. You can see in this picture a representation of the classic guidelines that we use in the Children’s Oncology Group. There are a hundred and fifty-six treatment-based guidelines. There is survivor education. This is updated every five years by experts and a PDF is published online. The Passport for Care is the individualized, online resource, which easily links the survivor and the provider to the Children’s Oncology Group long-term follow-up guidelines.
The Passport for Care has a dual use -- it is used by the clinician providing the long-term survivor care, as a free, web-based resource that provides a portable treatment summary, individualized recommendations for care, professional educational opportunities. The data, the treatment summary, is entered by the oncology clinic. The survivor website provides survivors with a free, Web-based resource for personalized treatment summaries, lists the potential effects based on prior therapy, individualized follow-up recommendations for monitoring late effects, and diagnosing late effects. Only survivors can access their own personal page.
What is the status of the Passport for Care website and the worksites currently using it? The Clinician Portal was launched in 2008 for data entry and clinician use throughout the United States. There are over a hundred and twenty-five Children’s Oncology Group institutions currently using the portal. Nearly twenty thousand survivors have had their treatment data entered in this Passport for Care. The Survivor Website was launched in limited clinics in January of 2015. It’s in the process of a staged national rollout to all COGs websites by mid-2015. Enrollment strategies are in development. Local patients are accessible. Loss to follow-up patients can be challenging, and we’re working on user features that may be needed in the future.

### Status of the Passport for Care Sites

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<th>Clinician Portal</th>
<th>Survivor Website</th>
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<tr>
<td>Launched in 2008 for data entry and clinician use</td>
<td>Launched to limited clinics January, 2015</td>
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<td>Over 125 COG institutions using the portal</td>
<td>Staged national rollout to all COG sites by mid 2015</td>
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<td>19,500+ survivors have been entered</td>
<td>Enrollment strategies in development</td>
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<td>Local patients accessible</td>
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<td>Lost to follow-up patients challenging</td>
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<td>Adding user features as needed</td>
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What’s an overview of the Passport for Care? The Passport for Care includes a basic treatment summary with basic medical information. It does not replace the medical record. It is not meant to be a complete medical record, but includes the demographics, the patient’s diagnosis, the prior therapies, relapses, cumulative doses of radiation, and the things that are relevant for managing a long-term survivor. It also includes links to the follow-up care guidelines, as well as resources for the survivors as they move forward.
The Passport for Care Clinician Portal includes the treatment summary, the online accessible care plan, and a printable output. You can print health care guidelines, specific guidelines, and general guidelines. You can actually review the evidence based on evidence rating systems. References are provided and linked to Medline abstracts and there are downloadable survivor educational resources, as well, called “Health Links,” which you can see representations of on this slide.
A recent user survey was completed asking for what percentage of survivors was the Passport for Care being used. Of those who responded, forty-two percent enter a hundred percent of survivors. Almost thirty-two percent felt that seventy-five percent of survivors were using the Passport for Care, and they were using it with them. Thirteen percent felt that approximately fifty percent of survivors coming for a visit were using the Passport for Care, and so on. Only a very small percent did not use the Passport for Care at all.
In the users’ survey, the users were asked, “To what extent does the Passport for Care significantly impact survivor care?” Forty-one percent felt that they adhered more closely to the Children’s Oncology Group guidelines because of the ease of using the links with Passport for Care. Seventy-eight percent felt that the survivors were receiving much more comprehensive care as it relates to long-term survivors. Forty-four percent felt that there were increased conversations and increased ease of conversation with survivors regarding the risks of their treatment. Ninety percent of the users were either very satisfied or generally satisfied with the Passport for Care.
What does the Survivor Website offer? Survivors have a direct access to their data in the Passport for Care. The development process included focus groups with survivors to understand their needs. It is optimized now for anytime access by smart phones, tablets, or computer. Enrolling survivors through their oncology clinic is extraordinarily easy. Survivors who are lost to follow up are a challenge to reach. Includes printable PDF of follow-up recommendations to share with other care providers.

- Clinical data must be entered
- Need secure access code to enroll
- If data not in, mechanisms in development for obtaining treatment summary

What does the Survivor Website offer? Survivors have a direct access to their data in the Passport for Care. The development process included focus groups with survivors to understand their needs. It is optimized now for anytime access by smart phones, tablets, or computers. Enrolling survivors through the Oncology Clinic is extraordinarily easy. Survivors who are lost to follow up have been a challenge to reach and sometimes create difficulties for entering their data. The survivor website includes printable PDFs of follow-up care guidelines and recommendations to share with others to share with their providers. The clinical data must be entered, and that is entered securely with a code within the Oncology Clinic. If the data has not been entered, mechanisms are in development for obtaining treatment summaries for those patients. Again, a representation of the survivor website is presented.
The survivor portal has a number of different sections, as you can see here, and previously described, including the treatment summary, guidelines for healthcare follow up, general history and educational resources. It also includes follow-up care plan views where links are made directly from the type of therapy a patient received to the type of guideline that is necessary for providing optimal care.
The treatment summary includes information that’s been entered by the oncology clinic or the treating institution. It’s printable. It’s downloadable as a PDF, and you can update the contact information easily.
The follow-up care plan has a number of different views, including linking the therapy received, whether it’s a drug, or radiation, or surgery, with the potential late effect, and the risk, and the surveillance studies required.
There are also health links provided, which the survivor can use and provided in basic English, describing the drug they received and the risks associated with that.
In addition, there’s information for the doctor. It includes the basic treatment summary, again, the healthcare guidelines, dependent on what the basic therapies were the surveillance studies required.
How can the primary care provider benefit from the Passport for Care? It provides complete follow-up care recommendations, appropriate and necessary follow-up care, accurate screening and prevention guides easily accessible. It is a wonderful communication tool between the provider and the patient, and the provider and the long-term survivor expert. It offers educational benefits to the survivor and the provider, and offers guidelines for transitional care.
How do the survivors feel about the survivor website? Here are just a few comments from some of our survivors. "This is great. I could have used it five years ago. I really, really like this. It’s a great tool. I can give this to my new primary care doctor. They’re always afraid of taking care of me.”
A manuscript was published recently in “Nature Reviews,” which highlighted the childhood cancer survivor care program and the development of the Passport for Care.
The Passport for Care also offers navigation services, and this includes a nurse navigator, who is available at a help desk, contact information for the Passport for Care, and guides to survivors and care providers. It supports providers in understanding and appreciating follow-up care needs and necessity for screening. It provides survivorship educational resources for care providers available online by email link and by phone. It interacts with the cancer treatment centers across the country to get survivors familiar with and into the Passport for Care. And lastly, primary care providers may directly contact the navigator at the website.