



## Clinical Decision Support Tool for Care Providers and A Resource Site for Survivors of Childhood Cancer



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 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.

## CME Participant Benefits

- **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, 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 you patients.



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 the oncologist? Some survivors are no longer followed by their oncology providers, or may not be able to see or wish to be followed by a cancer clinic. They don't want to be associated with a cancer clinic. But if they're in the Passport for Care, they can bring you, the primary provider a guide to follow for their care. Why can't I, as the primary care provider, 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 PCP benefit from the PFC

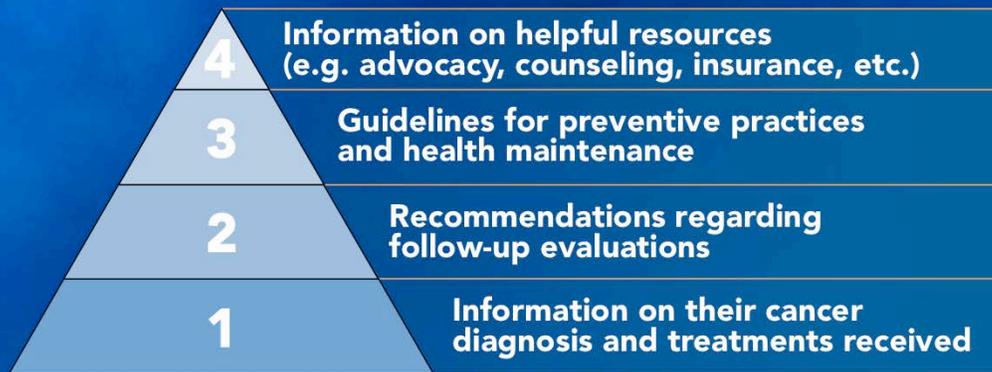
- **Follow-up care recommendations**
  - ▶ Appropriate and necessary follow-up care
  - ▶ Accurate screening and prevention guide
- **Communication tool**
  - ▶ Provider to patient
  - ▶ Provider to long-term survivor expert
- **Educational benefits**
- **Guidelines for transitional care**



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.

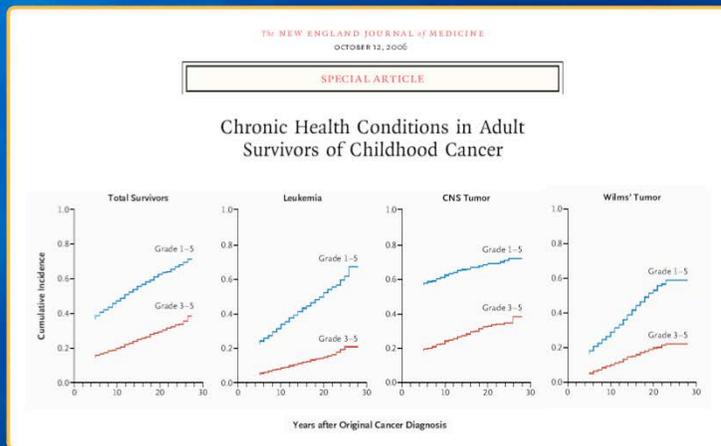
# The Institute of Medicine Recommendations

Every cancer survivor should have a care plan that contains:



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.

# Medical Issues Facing Survivors



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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.

## The Passport for Care: Why?

Designed to implement the Institute of Medicine's recommended care plan

- 2005 IOM report "*From Cancer Patient to Survivor - Lost in Translation*" identified gaps in care for survivors and recommended:
  - ▶ Providers establish cancer survivorship as a distinct phase of cancer care
  - ▶ Develop and provide a Summary of Treatment and a Survivorship Care Plan to the survivor
  - ▶ Health care providers use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment



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 identify and manage the late effects of cancer and its treatment in cancer survivors.

## The Passport for Care Clinician Portal and Survivor Website: A collaborative effort

- Follow up care guidelines developed by the Children's Oncology Group Long Term Care subcommittees
  - ▶ Guidelines 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
  - ▶ Assists providers in delivering comprehensive quality care to long term survivors of childhood cancer with complex treatment history



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 include long-term care subcommittees focused on each and every organ system potentially at risk from childhood cancer therapy. These guidelines are provided by experts from across the country for the general care provider and oncologist for understanding risks. The Passport for Care was developed, and launched, and hosted by the Center for Collaborative and Interactive Technologies at the Baylor College of Medicine and Texas Children's Cancer Center. The Passport for Care assists providers in developing comprehensive quality of care to long-term survivors of childhood cancer with complex treatment histories.

## Issues Affecting Cancer Survivors

- Medical late effects
- Lack of consistent long-term medical follow-up
- Psychosocial
- Employment
- Insurance
- Discrimination



Issues affecting childhood cancer survivors, or cancer survivors in general, include medical late effects, lack of consistent long-term medical follow up, psycho-social issues, employment issues, insurance issues, and discrimination.

## Challenges to Follow-up for Childhood Cancer Survivors

- Frequent changes in health care provider
- Primary care MDs not familiar with survivor issues
- Lack of easily accessible follow-up medical information
- No mechanism that alerts survivors to new medical findings that relate to them

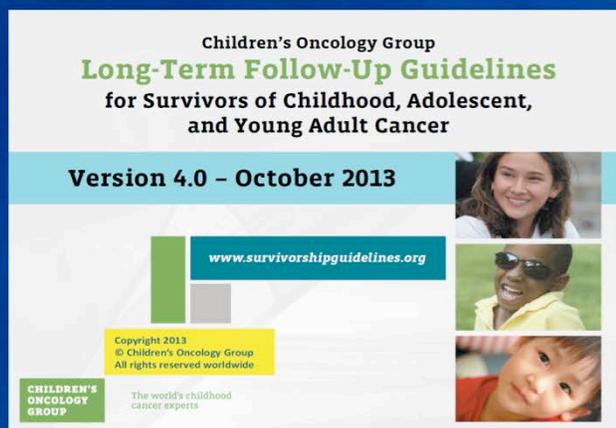
PFC addresses these by offering long-term care guidelines and recommendations for screening individualized to the survivor's characteristics and treatment history, accessible to the patient, to give to providers to guide follow-up care



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 finds that may 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 providers a guide to follow for follow-up care.

# Children's Oncology Group Guidelines

- Evidence and consensus-base
- 14 multidisciplinary taskforces
- 156 treatment-based guidelines
- Survivor education
- Updated every 5 years
- A PDF is published online
- PFC is the individualized online resource



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.

# Passport for Care – dual use



## Clinician Portal

Provides long-term survivor providers a free Web-based resource for:

- Portable treatment summary
- Individualized recommendations for follow-up and preventative health care based on COG guidelines
- Professional educational opportunities
- Data entered by oncology clinic



## Survivor Website

Provides survivors with a free Web-based resource for:

- Personalized treatment summary
- List of potential late effects based on individual cancer treatment history
- Individualized follow-up recommendations for monitoring of potential late effects
- Only survivor has access to their "page"



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.

## Status of the Passport for Care Sites

### Clinician Portal

- Launched in 2008 for data entry and clinician use
- Over 125 COG institutions using the portal
- 19,500+ survivors have been entered

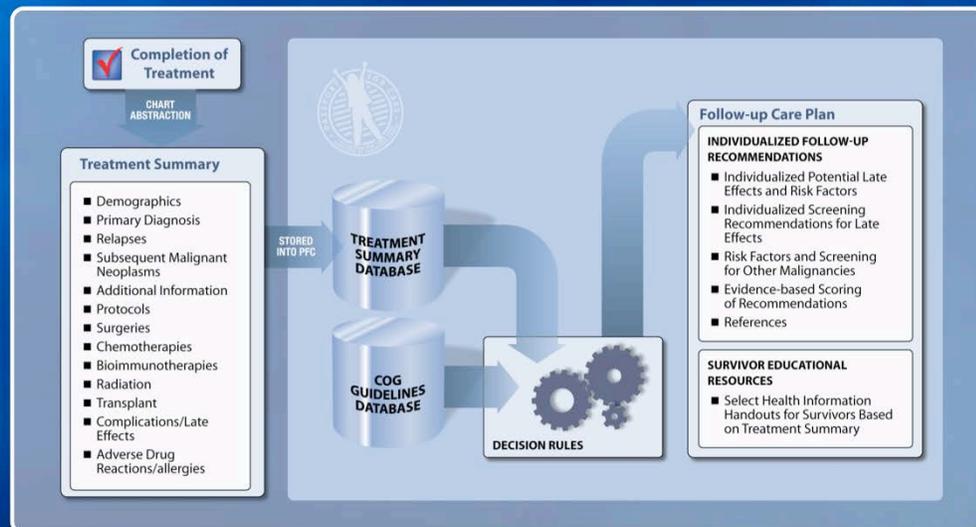
### Survivor Website

- Launched to limited clinics January, 2015
- Staged national rollout to all COG sites by mid 2015
- Enrollment strategies in development
- Local patients accessible
- Lost to follow-up patients challenging
- Adding user features as needed



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.

# Overview of the Passport For Care

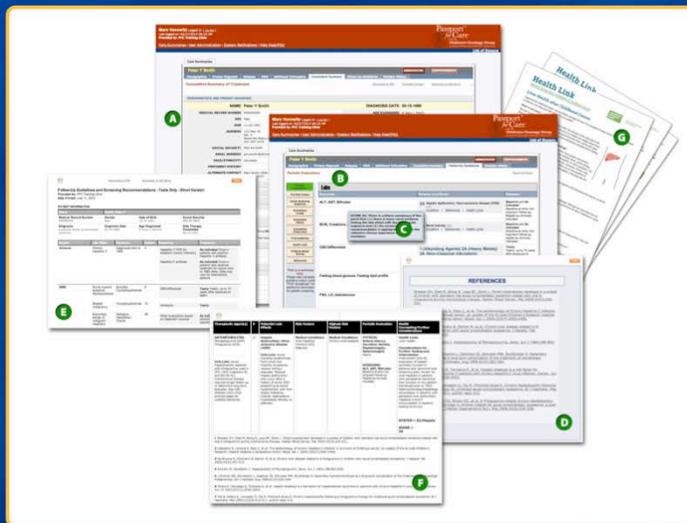


What's an overview of the Passport for Care? The Passport for Care includes a basic treatment summary with basic medical information. It does not replace the medical record. It is not meant to be a complete medical record, but includes the demographics, the patient's diagnosis, the prior therapies, relapses, 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.

## PFC Clinician Portal

### Clinician Portal pages:

- A. Treatment summary
- B. Online accessible care plan
- C. Printable output
- D. Specific guidelines
- E. Evidence rating
- F. References for each guideline linked to MEDLINE abstracts
- G. Downloadable survivor education resources (Health Links)



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.

## PFC Users Survey\*

### For what percentage of survivors is the PFC being used?

N = 45/70 clinics = 64%



\* Survey conducted in 2013 (N=45/70 clinics = 64%)

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.

## PFC Clinician Portal Users Survey\*

### To what extent does PFC significantly impact LTS care?

- Adhere more closely to COG guidelines: 41%
- Give more comprehensive info to LTS: 78%
- Increased conversations with LTS re risks: 44%
- 90% of users were very satisfied (60%) or generally satisfied (29%) with the PFC

\*Survey conducted in 2013



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.

# Survivor Website

- Survivors have direct access to their data in the PFC
- The development process has included focus groups with survivors to understand their needs
- Optimized for anytime access by smart phone, tablet, or computer.
- Enrolling survivors through their oncology clinic
- 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.

# Survivor Portal Sections

**Treatment Summary**

Your treatment summary is your cancer treatment history up to the date of the completion of your treatment. It does not contain any subsequent treatments or health changes. The summary is only as complete as the information provided by your Long Term Survivor clinic or treatment clinic. It does not contain a full medical history. This summary is used to generate your long-term follow-up guidelines.

**About John Doe**

Cumulative Record Number:	John Doe	Emergency Contact Name:	
Medical Record Number:	2	Emergency Contact Phone:	
Date of Birth:	06/05/1987	Prepared By:	Testing Clinic
Gender:	male	Prepared By:	Testing Clinic
Home/Work Address:			
Address:	123 Main Street Houston, TX 77001		
Email:			

**Primary Diagnosis**

**Follow-Up Care Plan**

Your follow-up care plan was developed for you based on your treatment history and the Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers developed by the Children's Oncology Group (COG). Your treatment history was used to determine which of the guidelines were most relevant to you. These recommendations do not replace the judgment of your doctor or clinician.

View by: **Personal Link (New)** | Type of Treatment | Body System Affected | Test or Exam Frequency

Body system primarily affected	You may be at risk for
Cardiovascular	Thrombosis, vascular insufficiency, elevation of serum LFT or the heart
Central Nervous System (CNS)	Clinical neurocognitive, memory, hearing/visual deficits
Dental	Dental procedures, dental procedures, dental procedures
Dermatology	Dermatologic changes, hair loss, hair loss
Endocrine/Metabolic	Growth hormone deficiency, hypogonadism, hypogonadism

**What is Passport for Care?**

Passport for Care is a summary of your cancer treatment history, individualized follow-up recommendations for screening and managing potential late effects, educational materials, and a notebook to create and store information.

**Treatment Summary**  
Your treatment summary is your cancer treatment history. This summary is used to generate your long-term follow-up care plan.

**Follow-Up Care Plan**  
Recommendations for screening and management of late effects that may potentially arise as a result of the cancer treatment that you received as a child.

**Your Notes**  
Create notes to remember details related to your treatment history or to remind you of things you'd like to bring up with your doctor.

**Your Notes**

ADD NEW NOTE

NOTE TITLE (REQUIRED)

NOTE DATE (REQUIRED)

NOTE CONTENT (REQUIRED)

This is not a medical record and does not communicate with your provider.

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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.

# Treatment Summary

Information is entered by the oncology clinic or treating institution

- ▶ Printable
- ▶ Downloadable as a PDF
- ▶ Can update contact information



Passport for Care

Information for Your Doctor | Demos/Help | Sign Out

Treatment Summary | Follow-Up Care Plan | Your Notes

### Treatment Summary

Download as PDF | Print

Your treatment summary is your cancer treatment history up to the date of the completion of your treatment. It does not contain any subsequent treatments or health changes. The summary is only as complete as the information provided by your Long-term Survivor clinic or treatment clinic. It does not contain a full medical history. This summary is used to generate your long-term follow-up guidelines.

#### About John Doe

Cumulative Summary for:	John Doe			
Medical Record Number:	2	Emergency Contact Name:		
Date of Birth:	Oct 03, 1997	Emergency Contact Phone:		
Gender:	male	Provided By:	Testing Clinic	
Race/Ethnicity:		Prepared By:		
Address:	123 Main Street Houston, TX 77001		Date Prepared:	
Email:				

#### Primary Diagnosis

Diagnosis Category:	Leukemia	Date of Primary Diagnosis:	Jul 10, 2000
Diagnosis:	Acute lymphoblastic leukemia	Date Therapy Completed:	Jan 24, 2009
Primary Site:		Age at Diagnosis:	6-1/12 years, months
Laterality:		Present Pertinent History:	

#### Surgeries - 1 surgery entered

Date	Procedure	Site	Laterality	Surgeon/Institution	Comments
Jul 10, 2000	Central venous catheter				

#### Chemotherapies - 7 chemotherapies entered

Drug Name
Asparaginase
Dexamethasone

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.

# Follow-Up Care Plan: Views

Follow-up recommendations are based on Children's Oncology Group comprehensive guidelines.



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.

# Health Links

**Follow-Up Care Plan**

Your follow-up care plan was developed for you based upon your treatment history and the Long Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers developed by the Children's Oncology Group (COG). Your treatment history was used to determine which of the guidelines were most relevant to your case. These recommendations do not replace the judgment of your doctor or clinician.

**View by:** Potential Late Effect | **Type of Treatment** | Body System Affected | Test or Exam Frequency

**All Cancer Survivors**

**You may be at risk for:** Your doctor may suggest these tests or examinations

Adverse Psychosocial/OSL Effects	Psychosocial assessment with attention to educational and/or vocational progress, social withdrawal			
Fatigue	Psychosocial assessment			
Limitations in healthcare and insurance access	Psychosocial assessment, with attention to healthcare and insurance access			
Mental health disorders: Depression, Anxiety, Post-traumatic stress, Suicidal ideation	Psychosocial assessment with attention to depression, anxiety, post-traumatic stress, suicidal ideation	Yearly	Emotional Issues	
Psychosocial disability due to pain	Psychosocial assessment	Yearly	Chronic Pain	
Risky behaviors	Psychosocial assessment	Yearly	Emotional Issues	

**Radiation**

You received or were exposed to radiation: Head/Brain - Central (whole brain)

You may be at risk for:	Your doctor may suggest these tests or examinations:	How often:	Learn more:
Brain malignancies	Some pain (especially in irradiated field)	Yearly	
Pain of bones in irradiated field	Pain of bones in irradiated field	Yearly	
Brain tumor (benign or malignant)	Headaches, Vomiting, Cognitive, motor or sensory deficits, Seizures and other neurologic symptoms	Yearly	
Cataracts	Neurologic exam	Yearly	
	Evaluation by ophthalmologist	As indicated	Cataracts

## Health Link

**Healthy Living after treatment of childhood cancer**

### Educational Issues Following Treatment for Childhood Cancer

Treatment for cancer during childhood or adolescence may affect educational progress due to prolonged absence or reduced energy levels that frequently occur during treatment. In addition, some types of cancer may require therapy to control or prevent spread of the disease to the brain and/or spinal cord (central nervous system). This therapy can sometimes affect memory and learning abilities. Parents and teachers should be aware of potential educational problems that may be related to cancer treatment so that children and teens at risk can be watched closely and given extra help if the need arises.

**What increases the risk of educational problems?**

Factors that may place children and teens at increased risk for difficulties in school include:

- Diagnosis of cancer at a very young age
- Numerous or prolonged cancer diagnoses
- A history of learning problems before being diagnosed with cancer
- Cancer treatment that results in reduced energy levels
- Cancer treatment that affects hearing or vision
- Cancer treatment that results in physical disabilities
- Cancer therapy that includes treatment to the central nervous system (see below)

**Are children and teens with certain types of cancer at higher risk of developing educational difficulties?**

Yes, children and teens with the types of cancer listed below are more likely to have received treatments that may affect learning and memory. Since treatments for these types of cancer vary widely, not everyone who was treated for these cancers is at increased risk.

- Brain tumors
- Tumors involving the eye or ear
- Acute lymphoblastic leukemia (ALL)
- Non-Hodgkin's lymphoma (NHL)

**What types of treatment place children and teens at higher risk for learning and memory problems?**

- Methotrexate—if given in high doses intravenously (IV) or injected into the spinal fluid (intrathecal (IT) or intracranial (IC))
- Cyclophosphamide—if given in high doses intravenously (IV)
- Surgery involving the brain
- Radiation to any of the following areas:
  - Brain (overall)
  - Craniospinal region (medical area behind the shoulders)
  - Total body irradiation (TBI)
  - Craniopharyngeal or chiasmatic (may affect hearing)

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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.

# Information For Your Doctor

**Information For Your Doctor**

Your information on Passport for Care is most helpful when you share it with your doctor. For your convenience, clicking the buttons below, you can download (as a PDF) or print your Treatment Summary and your Follow-Up Plan.

[Download Info For Your Doctor](#) [Print Info For Your Doctor](#)

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Dictionary of Cancer Terms. Adapted from the National Cancer Institute's Dictionary of Cancer Terms.

**Treatment Summary**

Your treatment summary is your cancer treatment summary up to the date of the completion of your last treatment. It does not include any subsequent treatments or health changes. The summary is only as complete as the information provided by your Long-term Survivor clinic or treatment clinic. It does not contain a full medical history. The summary is used to generate your long-term follow-up guidelines.

**About John Doe**

Complete Summary for:	John Doe	Emergency Contact Name:	
Medical Record Number:	2	Emergency Contact Phone:	
Date of Birth:	Oct 03, 1987	Provided By:	
Gender:	male	Date Prepared:	
Name/Title:			
Address:	123 Main Street Houston, TX 77001		
Email:			

**Primary Diagnosis**

Diagnosis Category:	Leukemia	Date of Primary Diagnosis:	Jul 10, 2010
Diagnosis:	Acute lymphoblastic leukemia	Date Therapy Completed:	Jan 24, 2011
Primary Site:		Age at Diagnosis:	6/10 years
Laterality:		Present Patient History:	

**Surgeries** - 1 surgery entered

Date	Procedure	Site	Laterality	Surgeon/Institution	Comments
Jul 10, 2010	Central venous catheter				

**Chemotherapies** - 7 chemotherapy entered

Drug Name	Start Date	End Date	Comments
Asparaginase			
Acute lymphoblastic leukemia			

**Recommended Testing**

Sorted by: Tests or Exams

Test/Exam	Frequency	Evaluation by oncologist	Evaluation by nephrologist
As indicated			
As indicated			

**Explanation of Recommended Testing (Including History and Physical)**

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 PCP benefit from the PFC

- Complete follow-up care recommendations
  - ▶ Appropriate and necessary follow-up care
  - ▶ Accurate screening and prevention guide
- Communication tool
  - ▶ Provider to patient
  - ▶ Provider to long-term survivor expert
- Educational benefits
- Guidelines for transitional care



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.

## Survivor Website: What the Survivors are saying about the PFC

"This is great, I could  
have used it five years  
ago"

– T.P.  
Mom of survivor

"I really, really, like  
this, it is a great  
tool!"

– J.J.  
Dad of Survivor

"I can give this to my new  
primary care doctor, they are  
always afraid of taking care of  
me"

– T.C.  
Survivor



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."

## Passport Progress



The screenshot shows the top portion of a web page from Nature Reviews Clinical Oncology. At the top left is the logo for "nature REVIEWS CLINICAL ONCOLOGY". Below this is a navigation bar with "Paediatric cancer" selected. To the right of the navigation bar, it says "Focus issue: December 2014 Volume 11, No 12" and has links for "Perspectives" and "Reviews". The main title of the article is "Childhood cancer survivor care: development of the Passport for Care". Below the title are the authors: "David G. Poplack, Michael Fordis, Wendy Landier, Smita Bhatia, Melissa M. Hudson & Marc E. Horowitz". There are also links for "Affiliations", "Contributions", and "Corresponding author". At the bottom of the article preview, it says "Nature Reviews Clinical Oncology 11, 740–750 (2014) | doi:10.1038/nrclinonc.2014.175" and "Published online 28 October 2014".

A manuscript was published recently in “Nature Reviews,” which highlighted the childhood cancer survivor care program and the development of the Passport for Care.



## Passport For Care – Navigation Services

- Nurse Navigator – [svp-helpdesk@bcm.edu](mailto:svp-helpdesk@bcm.edu)
- Contact available on Passport For Care site
- Helps guide survivors and care providers to long term survivor care experts
- Helps survivors link to their original treatment facility and information to streamline entry into Passport For Care
- Supports survivors in understanding and appreciating follow-up care needs and necessity for screenings
- Provides survivorship educational resources for care providers
- Available online, by email link, and by phone
- Interacts with cancer treatment centers across the country to get survivors familiar with and into the Passport for Care Survivor website
- PCP's may directly contact the navigator at [svp-helpdesk@bcm.edu](mailto:svp-helpdesk@bcm.edu)



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.