



Survivorship Care Plans: Integrating Kentucky Cancer Registry Data into Journey Forward

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Objectives

- Outline changes in Commission on Cancer (CoC)-accreditation requirements around survivorship care plans (SCP)
- Describe Kentucky Cancer Registry's (KCR) project for helping to facilitate these SCP requirements
- Introduce Journey Forward (JF) SCP templates
- Demonstrate how to use KCR's new web-based application for using data from Cancer Patient Data Management System (CPDMS) to **start** a SCP using JF templates

Cancer Survivorship Care Planning

“Every cancer survivor should have a comprehensive care summary and follow-up plan once they complete their primary cancer care that reflects their treatment and addresses a myriad of post-treatment needs to improve their health and quality of life.”

Background

- Changes in CoC-accreditation requirements (Standard 3.3)
 - In 2015, SCPs required for 10% of patients who are treated with curative intent and have complete active therapy.
 - Annual increase in percentage:

2015	2016	2017	2018	2019
10%	25%	50%	75%	100%

- At a minimum, SCPs **must include** a treatment summary and follow-up care plan.
- Of note, National Accreditation Program for Breast Centers is requiring **50%** of eligible breast cancer patients receive SCP by 2015.
- Need to increase health facilities' capacity to generate and deliver SCPs.
 - Tools and assistance from external organizations can help cancer programs implement new standard

Background

- Using data from **electronic sources** may enhance reliability and validity of information included in SCPs, and improve staff efficiency and effectiveness in preparing them.
- 83% of hospital cancer registry staff (54/65) responding to a recent survey indicated they would be interested in adopting the Journey Forward SCP template at their hospital if some of the data fields could be prepopulated.
- Recent in-depth interviews with cancer patient navigators and oncology nurses also indicate support of this approach; respondents would welcome its introduction into their practice.

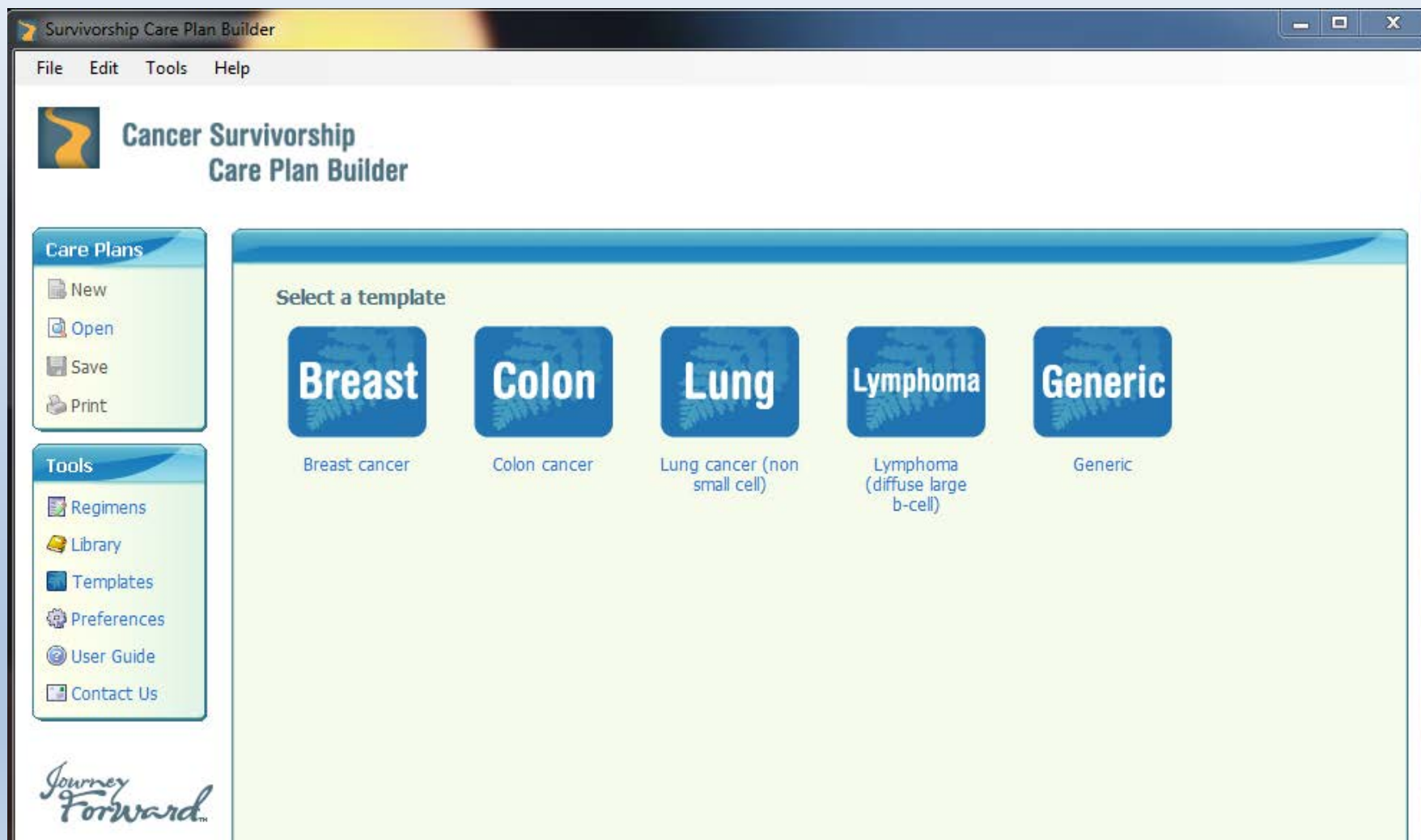
Background

- Kentucky Cancer Registry to the rescue!
 - KCR has developed a web-based application that exports relevant data from the Cancer Patient Data Management System (CPDMS) into JF, providing a starter-template for a SCP
- UK Markey Cancer Center pilot grant awarded January 2015 to evaluate implementation of KCR application
 - Collaboration between UK, KCR, KCC, and 3 case study sites in central and eastern KY.



- Free survivorship care plan builder available for download:
<http://www.journeyforward.org/professionals/journey-forward-tools-overview>
- Site-specific templates available for breast, colon, lung and lymphoma. A customizable generic template is available for other types of cancers and a prostate template is expected soon from JF.
- Components of a JF SCP:
 - Care team information
 - Background information on diagnosis, staging, comorbid conditions
 - Treatment summary
 - Schedule for follow-up care (ie. surveillance)
 - Psychosocial assessment
 - Information on symptom management, late effects of treatment

SCP Builder Interface



Creating a plan in the SCP Builder

Survivorship Care Plan Builder

File Edit Tools Help

Cancer Survivorship Care Plan Builder

Care Plans

- New
- Open
- Save
- Print

Tools

- Regimens
- Library
- Templates
- Preferences
- User Guide
- Contact Us

Journey Forward

MCM0001692600

Breast cancer Survivorship Care Plan

[General information](#) | [Background information](#) | [Treatment plan](#) | [Treatment summary](#) | [Follow-up care](#)

Care plan prepared by

Care plan prepared on

Practice site

Patient name

Medical record number

Patient phone (home)

Patient phone (cell)

Patient email

Age at diagnosis

Date of birth

Care Team

	Name	Phone	Email
Support contact	<input type="text"/>	<input type="text"/>	<input type="text"/>
Hematologist/oncologist	<input type="text"/>	<input type="text"/>	<input type="text"/>
General/breast surgeon	<input type="text"/>	<input type="text"/>	<input type="text"/>
Radiation oncologist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Plastic surgeon	<input type="text"/>	<input type="text"/>	<input type="text"/>
Primary care physician	<input type="text"/>	<input type="text"/>	<input type="text"/>
OB-GYN	<input type="text"/>	<input type="text"/>	<input type="text"/>
Nurse/nurse practitioner	<input type="text"/>	<input type="text"/>	<input type="text"/>
Mental health/social worker	<input type="text"/>	<input type="text"/>	<input type="text"/>
Coordination of care	<input type="text"/>	<input type="text"/>	<input type="text"/>

Next >

Sample Plan



Cancer Survivorship Care Plan

SAMPLE

This Survivorship Care Plan will facilitate cancer care following active treatment. It may include important contact information, a treatment summary, recommendations for follow-up care testing, a directory of support services and resources, and other information. [1]

Survivorship Care Plan for Breast Cancer

Prepared by: Martha Trout on 6/17/2012 at Pleasant Valley Cancer Center

General Information

Patient Name	Jane Plummer
Date of birth	6/17/1965
Age at diagnosis	47
Support contact	Tom Plummer

Care team

Hematologist/oncologist	Dr. Howard
General/breast surgeon	Dr. Jones
Radiation oncologist	Dr. Smith
Plastic surgeon	None
Primary care physician	Dr. Wells
OB-GYN	Dr. Innes
Nurse/nurse practitioner	Martha Trout
Mental health/social worker	Susan Green
Coordination of care	

Background Information

Family history	None
Genetic testing	Not applicable
Other health concerns	History of cervical cancer at age 29
Echocardiogram or MUGA result	EF = 82%
Additional comments	Had annual mammogram in April 2011 which showed cyst only. Found lump under arm in August while out fishing. Jane elected to have bilateral mastectomies due to her history of cystic lumps in both breast.

Left breast	
Definitive breast surgery	Mastectomy on 1/12/2011
Sentinel node biopsy	No
Axillary dissection	Yes, 1/12/2011
Lymph nodes	13 removed, 3 positive
Tumor type & stage	Infiltrating ductal, T3 (Tumor is more than 5 cm (2 inches) across), N2 (Cancer has spread to 4 to 9 lymph nodes under the arm, or cancer has enlarged the internal mammary lymph nodes)
Pathologic stage	Stage III (Locally advanced cancer with small, moderate or large tumor and lymph node involvement)
ER status	Positive
PR status	Positive
HER2 status	Positive

Treatment Plan & Summary

Patient's height	64 in	
	Pre-treatment	Post-treatment
Patient's weight	127 lb	120 lb
Patient's BSA	1.61 m ²	1.57 m ²
Patient's BMI	21.8	20.6
Date last menstrual period	9/24/1994	
Comments	Due to size of tumor in breast and painful, matted nodes under arm, neo adjuvant selected. During work-up for possible clinical trial, a CT scan was done with no evidence of metastatic disease.	Skin on left chest wall was excoriated and needed dressings with silvadene until healed.

Regimen	Paclitaxel, Carboplatin		
Treatment on clinical trial	No		
	Therapeutic agents	# cycles	% dose reduction
	Paclitaxel	6	0
	Carboplatin	6	0

Biologic therapy	Planned: Yes, Administered: Yes
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Sample Plan

Ejection fraction	Pre-biologic therapy: 84% (9/2/2010), Most recent: 82% (12/23/2011)
Biologic therapy treatment dates	9/27/2010 -12/23/2011
Pre-operative chemo administered	Yes
Chemotherapy treatment period	9/27/2010 -1/3/2011
Possible side effects of regimen	Anemia, Cardiac symptoms, Fatigue, Hair loss, Infertility, Low blood count, Menopause symptoms, Muscle aches, Nausea/vomiting, Neuropathy
Reconstruction	Planned: No, Completed: No
Radiation therapy	Planned: Yes, Completed: 3/25/2011, dose: 60 gy
Growth factor given	Yes
Serious toxicities during treatment	Neutropenia
Hospitalization for toxicities	No
Neurotoxicity impairing activities	No
Reason for stopping chemotherapy	Completed therapy
Disease status at end of treatment	Tumor shrinkage as it was given neo-adjuvantly
Endocrine therapy	Anti-estrogen: tamoxifen
Endocrine therapy timing	5 years, starting 4/11/2011

Follow-Up Care

UPON SCREENING, THE PATIENT HAS BEEN DETERMINED TO HAVE THE FOLLOWING ISSUE(S):

Patients – Please consult your health care provider for medical advice specific to you before using any medications, supplements, or other products, and before beginning any lifestyle program.

Chief patient concern	Concerns about risk of recurrence
Needs/Concerns	Suggested intervention(s)
Concerns about risk of recurrence	Patients need to know that these feelings are normal, and they won't cause the cancer to come back. • Referral for cognitive behavioral therapy or counseling • Referral to support group, e.g. American Cancer Society (www.cancer.org , 800-227-2345), Cancer Support Community (www.wellnessandcancer.org , 888-793-9355)
Fatigue	• Regular physical activity (e.g., walking 20 minutes daily) • Evaluation for hypothyroidism, anemia, depression

Test	Frequency	Provider to contact
Medical history/physical exam: Yrs 1-3	Every 3 months	Dr. Howard
Medical history/physical exam: Yrs 4,5	Every 6 months	Dr. Howard
Post-treatment mammography	Not needed	Dr. Innes
MRI		Provider decision

Pelvic examination	Every year	Dr. Innes
Breast self-examination	Every month	

Preventive care recommendations	Bone health, Colon cancer screening, Exercise
Comments on follow-up care	Jane worked throughout her treatment, taking time off only for her surgery. Her two grandsons were her focus on getting through treatment and surviving as she didn't want to miss a day with them.

Possible Late Effects of Treatment

You may experience the following effects after cancer treatment.

- **Surgery:** Numbness, weakness, pain, loss of range of motion (ROM), or arm swelling (lymphedema)
- **Chemo/Biotherapy:** Fatigue, ovarian failure with associated menopausal symptoms, neuropathy, cognitive dysfunction, weight gain, psychological distress, and sexual dysfunction; increased risk of leukemia (after anthracycline based therapy), osteoporosis from premature ovarian failure, increased risk of cardiac dysfunction secondary to anthracycline and/or trastuzumab.
- **Radiation:** Breast pain, fibrosis, telangiectasia, atrophy, poor cosmetic outcome.
- **Hormone therapies:**
 - Tamoxifen—hot flashes, increased risk of blood clots, uterine cancer, and stroke.
 - Aromatase inhibitors—increased risk of osteoporosis and fracture.

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Life After Cancer Treatment: Managing Fatigue

"If I could stop feeling so tired all the time, I think I'd be fine. I've started getting used to everything else."—Rosa

Some cancer survivors report that they still feel tired or worn out. In fact, fatigue is one of the most common complaints during the first year of recovery.

Rest or sleep does not cure the type of fatigue that you may have. Doctors do not know its exact causes. The causes of fatigue are different for people who are receiving treatment than they are for those who have finished.

- Fatigue during treatment can be caused by cancer therapy. Other problems can also play a part in fatigue, like anemia (having too few red blood cells) or having a weak immune system. Poor nutrition, not drinking enough liquids, and depression can also be causes. Pain can make fatigue worse.
- Researchers are still learning about what may cause fatigue after treatment.

How long will fatigue last? There is no normal pattern. For some, fatigue gets better over time. Some people, especially those who have had bone marrow transplants, may still feel energy loss years later.

Some people feel very frustrated when fatigue lasts longer than they think it should and when it gets in the way of their normal routine. They may also worry that their friends, family, and coworkers will get upset with them if they continue to show signs of fatigue.

Getting Help

Talk with your doctor or nurse about what may be causing your fatigue and what can be done about it. Ask about:

- How any medicines you are taking or other medical problems you have might affect your energy level
- How you can control your pain, if pain is a problem for you

Sample Plan

- Exercise programs that might help, such as walking
- Relaxation exercises
- Changing your diet or drinking more fluids
- Medicines or nutritional supplements that can help
- Specialists who might help you, such as physical therapists, occupational therapists, nutritionists, or mental health care providers

Coping with Fatigue

Here are some ideas:

- **Plan your day.** Be active at the time of day when you feel most alert and energetic.
- **Save your energy by changing how you do things.** For example, sit on a stool while you cook or wash dishes.
- **Take short naps or rest breaks between activities.**
- **Try to go to sleep and wake up at the same time every day.**
- **Do what you enjoy, but do less of it.** Focus on old or new interests that don't tire you out. For example, try to read something brief or listen to music.
- **Let others help you.** They might cook a meal, run errands, or do the laundry. If no one offers, ask for what you need. Friends and family might be willing to help but may not know what to do.
- **Choose how to spend your energy.** Try to let go of things that don't matter as much now.
- **Think about joining a support group.** Talking about your fatigue with others who have had the same problem may help you find new ways to cope.

End Notes

Note 1: *Important caution.*

This is a summary document whose purpose is to review the highlights of the cancer chemotherapy treatment plan for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and adjuvant chemotherapy in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

The novel SCP Application

- At least **one-fourth** of the fields in each JF template can be prepopulated from CPDMS data using the new SCP application.
- The SCP application is now available and will require **collaboration with facility registrars.**
- Users may **query** patients using data included in cancer abstracts such as MRN, SSN, patient name, dates, stage, etc.
- Once a patient(s) is identified, there is an export feature, which exports relevant data into the JF template that has been chosen; the template can then be opened in the JF software program securely on a user's local computer for **completion and additional tailoring.**
- **Tracking feature** within the SCP application (patient/date and time/user)

Demonstration

Next steps

- Official launch: **June 1, 2015**
 - Expect to continue refinements over next 9-12 months
- Feedback welcomed!
 - Regarding the application itself as well as internal SCP policies and procedures in place at various facilities
- Plans are in place to integrate other SCP vendor templates in the future, based on feedback from users and additional funding
- Application technical assistance available from KCR informatics staff: **scpsupport@kcr.uky.edu**
- REDCap webinar evaluation survey

General Questions? Contact Us!

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