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1. **I've heard and seen references to the Kentucky Cancer Registry's (KCR) "Survivorship Care Plan (SCP) application" and "Journey Forward". Are they the same thing?**

    No. **Journey Forward (JF) is a suite of electronic survivorship care planning tools** developed through a collaboration between the National Coalition for Cancer Survivorship, University of California at Los Angeles (UCLA), Oncology Nursing Society, Anthem, and Genentech; it is not a product of the Kentucky Cancer Registry (KCR). One tool offered by JF is the Survivorship Care Plan Builder, a **free** online software that contains site-specific (breast, lung, colon, and lymphoma) and generic survivorship care plan templates that may be tailored to individual patients.

    The Kentucky Cancer Registry has developed an *independent, companion* web-based application for Kentucky hospitals that will facilitate the generation of survivorship care plans using the JF software described above. KCR's application exports cancer patient data collected and maintained by KCR (ie., treatment and staging information) directly into the pre-selected JF SCP template, which opens in JF's SCP Builder software. Further data entry and tailoring may then be completed by the user *in the JF software* before the plan is given to the patient.

2. **How do I get Journey Forward on my computer?**

    Journey Forward's SCP Builder software may be downloaded for **free** at: http://www.journeyforward.org/get-started-with-the-survivorship-care-plan-builder

    You may want to work with local IT staff regarding administrative download rights.

3. **Who can use KCR's Survivorship Care Plan application? How can I obtain access to the application?**

    The application may be used by personnel at health care facilities in Kentucky that report data on cancer cases to the Kentucky Cancer Registry. A variety of personnel who are involved in survivorship care planning may wish to access the application, including (but not limited to) hospital registrars, patient navigators, and oncology nurses. Access requests should be sent via email as described below:

    If you are a registrar, please send an email to scpsupport@kcr.uky.edu to request access and carbon-copy your regional coordinator.

    If you are a patient navigator, nurse navigator, or other clinical staff we encourage you to reach out to the registry staff at the healthcare facility where you work in order to start a conversation about collaborating to use the application. **Your registry contact may be able to generate initial SCP plans for you, or may submit an access request to KCR on your behalf** so that you may use the application yourself. If you do not know your registry contact, please let us know the hospital facility you work and we will send you an email with his/her name and contact information.

4. **Where does the patient information that gets exported into JF's templates come from?**

    The Kentucky Cancer Registry maintains the state-wide Cancer Patient Data Management System (CPDMS) software that all Kentucky hospitals use to report cancer diagnoses and treatment information. This hospital registry data from CPDMS is used to pre-populate a portion of the fields in a given JF SCP template.

5. **I don't use Journey Forward – can I still use the application?**

   Although many survivorship care plan templates and software packages exist, currently, **the KCR application only supports Journey Forward**. Additional SCP templates and vendors (ie., Livestrong, ASCO) may be supported in the future.

6. **How timely is the data provided by KCR? How up-to-date is the data that gets exported into the JF template?**

   KCR requires that data on cancer cases be reported to the registry within 180 days (6 months). However, turn around varies by facility and may be impacted by factors such as registrar caseload. Many facilities consistently abstract cases before the 180 day timeframe.

   After a cancer case has been abstracted by a hospital registrar, KCR ensures that reporting requirements have been sufficiently met before the abstract is considered "complete." **The KCR SCP application will only export data from cancer abstracts considered complete.** If a registrar updates something on a "complete" abstract, the updated information is immediately available, and therefore can be exported in JF.

7. **Is there any chance the information exported from KCR into the JF SCP is incorrect or inaccurate? I think some of the information that was prepopulated in the JF template is wrong – what should I do?**

   There are two reasons that the data in the JF template generated using KCR's SCP application may be incorrect.

   First, the data carried into the JF starter template from KCR's SCP application reflects what is currently recorded in the CPDMS; data incorrectly recorded in CPDMS will thus be inaccurate on the JF template.

   Second, there may be a technical error in the mapping of variables collected by the registry into the specific data fields contained within JF's templates.

   If you notice inaccurate data in the JF template, please contact your facility's registrar to alert them of the error. Registrars, please communicate with KCR so that the source of the inaccuracy can be determined.

   Please take care to review all information exported from KCR's SCP application into the selected JF SCP template. The JF SCP template generated using KCR's application is a *starting point*, NOT a final product.

8. **How much of the JF templates can be filled in with data from KCR? Do you plan to increase the number of fields that can be pre-populated?**

   Although it varies by template, **at least one quarter of the fields contained in a JF template can be prepopulated using data collected by KCR.** Close to one third of the fields in JF's breast cancer template can be prepopulating using KCR's SCP application. KCR will continue mapping data from CPDMS into the JF SCP templates, but it is important to note that not all of the template fields can be prepopulated using registry data.

9. **Why are most of the fields blank when I open the SCP in JF? Why can't all of the fields be populated?**

   KCR does not collect all of the data included in the JF templates. For example, KCR collects data on staging and treatment for each cancer case, but does not collect data on biometric variables like height and weight of the patient. Furthermore, details for follow-up care and information about possible late effects of treatment are **intended to be tailored to individual patients by a member of their clinical team**. SCPs are often tailored

through a combination of professional opinion and/or one-on-one conversation between patients and their care providers.

10. **How can I tell if a patient in the database needs a SCP?**

Healthcare facilities frequently have their own protocols for determining which patients need to receive an SCP. For example, facilities who are accredited by the [ACOS Commission on Cancer (CoC)](#) may define "survivor" differently from facilities who are not CoC-accredited. As a result of this variability, KCR's SCP application does not have a single mechanism for definitively identifying patients who need an SCP in a way that matches each facility's unique protocol.

However, several features of the application have been designed to help facilities to this end – namely, the criteria on which patients at a facility are queried. For example, patients may be queried according to criteria like staging, and patient lists within the SCP application indicate whether or not treatment has been received by each individual. These criteria may help identify patients who are ready to receive an SCP.

Additionally, the SCP application has a history tracking feature so that application users can determine if a JF starter SCP template was previously created for a patient. Application users can see the time and date of previously generated JF templates for each patient, as well as the application user associated with each download.

11. **I need to create an SCP for a patient who has been seen and/or treated at multiple facilities. Will the KCR SCP application pull data from all of those facilities into the JF template?**

Not necessarily. Application users are provided access to a limited set of patient databases, namely databases maintained by the hospital registries where they work. **Accordingly, the data exported into a JF template using the KCR SCP application contains only information maintained by the application user's hospital registry.**

12. **Are all cancer patients at my facility in the SCP application database? What should I do if I can't find a patient who needs a SCP in the database?**

All cancer cases at the facility where you work who have an abstract considered complete by KCR will be accessible in KCR's SCP application. There may occasionally be patients who require an SCP but whose KCR abstract is pending completion. These patients will not be "discoverable" in the KCR SCP application; the application may not be used to generate starter JF SCPs for these patients.

13. **How can I tell if someone has already created a SCP for a patient using KCR's application ?**

KCR's SCP application has several tracking features that will help you identify patients for whom the SCP application has previously been used to generate a JF template.

When the KCR SCP application is used to generate a JF SCP template for a patient, the patient list is automatically updated so that the date, time, and username associated with the download are recorded are made visible in the under the column "created." The information displayed in the patient list reflects the most recent download for each patient.

Additionally, the "history" tab in the top left hand side of the application contains a running list of all JF SCP templates generated for patients in the user's available databases.

The application tracks downloads made by all application users who have access to the same database.

Note: The history tracked by the KCR SCP application ONLY identifies when the application was used to generate a starter JF SCP template. It does NOT track changes to the SCP that were made within the JF software (ie. additional tailoring completed by clinical staff) after the starter template was generated, and does NOT track whether a SCP was delivered to a patient.

14. **I know my patient had surgery/treatment/etc, but that information doesn't appear in the JF starter template that I open from the application. Why?**

    The Kentucky Cancer Registry does not collect all of the data included in the JF templates. For example, Information about care and treatment obtained at a facility outside of your own may not be exported into the JF starter SCP template. Application users are provided access to a limited set of patient databases, namely databases maintained by the hospital registries where they work and the data included within those databases. Accordingly, the data exported into a JF template using the KCR SCP application contains only information maintained by the application user's hospital registry, which may or may not include details on care obtained elsewhere.

15. **I just created a JF template for my patient using the KCR application – can I give it to the patient now? What else do I need to do?**

    NO. **What opens in the JF software after selecting "create" in the KCR SCP application is a *STARTER* SCP template. It is incomplete and needs additional data entry and tailoring before it is ready to be delivered to a patient.**

    The Kentucky Cancer Registry does not collect all of the data included in the JF templates. For example, KCR collects data on staging and treatment for each cancer case, but does not collect data on biometric variables like height and weight of the patient. Furthermore, details for follow-up care and information about possible late effects of treatment are intended to be tailored to individual patients by a member of their clinical team. SCPs are often tailored through a combination of professional opinion and/or one-on-one conversation between patients and their care providers.

16. **I created a JF starter template for a patient, but someone else is going to finish it. How can I share it with him/her?**

    Once a JF starter template has been generated for a patient using the KCR SCP application, there are several ways that it can be shared with others. Each healthcare facility can decide what method works best for them.

    The file can be saved within the JF software itself. Anyone else editing the SCP within JF **MUST** have the JF software program loaded on to their computer in order to open the JF files.

    Alternatively, the JF file may be saved as a PDF or Word Document to a local drive or a shared network at your facility. If saved to a shared drive/network, others who have access to the same network may access the document from different computer work stations.

    It is important to note that KCR's SCP application does NOT track or save any additional data entry and tailoring that was performed after the JF starter SCP template was initially generated. Changes made the initial

JF starter template can ONLY be saved within the JF software or to the Word/PDF document kept on a local computer drive or shared network.

17. I started a SCP for a patient in the past, but I need to change/update some of the information. Can I make changes to the SCP template I downloaded before?

If no additional information was entered into the JF starter SCP template after it was initially generated, you can simple create another JF starter template from the KCR SCP application.

If additional information was entered from within the JF software (ie. biometrics, follow-up care recommendations, late effects, etc), then you must open the JF, Word of PDF file to which that additional information was saved. KCR's SCP application does NOT track or save any additional data entry and tailoring that was performed after the JF started template was initially generated. Changes made the initial JF starter template can ONLY be saved within the JF software on a local computer or shared drive, or to the Word/PDF document kept on a local computer drive or shared network.

18. What does "Date of diagnosis" mean?

The date of diagnosis is the date of first diagnosis of this cancer by a recognized medical practitioner.

19. What does "Date of 1st contact" mean?

The date of first contact is the date of the facility's first inpatient or outpatient contact with the patient for diagnosis or treatment of the cancer.

20. What does "Date Completed" mean?

"Date complete" refers to the most recent date on which the cancer abstract was considered "complete" by the Kentucky Cancer Registry. **It does NOT mean the date the SCP was created, completed, or delivered.**

21. I want to create an SCP for a patient who had melanoma skin cancer, but I only see site-specific templates available for lung, colon, breast, and lymphoma. What should I do?

The generic template may be used for all cancers not covered by the site-specific templates. Simply select "generic" as the care plan template before creating the starter template.

22. Do I have to use the site-specific cancer templates for all breast, lung, colon, and lymphoma cancer cases, or can I use the generic template?

No. If preferred, the generic template may be used for all cancer sites.

23. Do the site-specific templates cover all types of breast/lung/colon/lymphoma cases?

Not always. The lung cancer template is intended for non-small cell carcinoma. The lymphoma template is intended for diffuse large B-cell.

24. I created a SCP in the application, but when I click "open," it doesn't open. What should I do?

If the download SCP template will not open, it is more than likely a technical issue with JF on your local computer. You will need to contact your local IT staff to help resolve this.

Please note: In order to open the JF SCP starter template, you must have the JF SCP Builder software downloaded onto your computer. Journey Forward's SCP Builder software may be downloaded for free at: http://www.journeyforward.org/get-started-with-the-survivorship-care-plan-builder

25. Can I put something in the SCP that isn't included in any of the specific fields on the JF template?

Yes. The Journey Forward SCP includes several fields where you can enter any additional information that you and the patient feels is important. Please see "Frequently Asked Questions" on JF's website:

http://www.journeyforward.org/faq-page

26. I'm having a problem with JF. Who should I ask for help?

For technical problems with JF, please check with the IT staff at your hospital facility.

For general questions about JF capabilities, consult the JF website for resources such their FAQ and a troubleshooting guide with much more detailed information about the JF software. You may also contact JF directly through the "contact" link on their website.

Links to these resources are provided below:

The JF website: http://www.journeyforward.org/

The JF FAQ: http://www.journeyforward.org/faq-page

The JF contact link: http://www.journeyforward.org/form/my-care-plan

27. I'm having a problem with KCR's SCP application. Who should I ask for help?

For problems with KCR's SCP application, please send an email to scpsupport@kcr.uky.edu. Your questions will be answered promptly.