

# Cancer Patient Navigation-Data Survey Report:

*What Data do you collect?*

*What Data is most important?*



**March 18, 2014**

Information provided for this report came from an online survey developed in partnership with the Kentucky Cancer Consortium and numerous organizations throughout Kentucky. Please see page 13 for a list of contributing partners who worked on this project.

The survey was disseminated through REDCap to the Kentucky Cancer Consortium- Kentucky Cancer Patient Navigation Network (KCPNN).

**Participation Rate= 69%** (37 completed surveys/54 invited) Note: The online survey link was sent to the KCPNN listserv which lists 54 nurses and navigators.

## **Summary**

### **General Information**

- The majority of survey respondents were located in **Non-Hospital settings** (n=21, 57%).
- The most frequently indicated method for collecting data was using:
  - 1) **Excel** (n=13, 35%)
  - 2) Custom-made software; Handwritten paper only (n=7, 19%)
- The most frequently indicated section of the cancer care continuum that patient navigators focused on was **Treatment** (n=26; 63%).
- Regardless of the section of the cancer care continuum, patient navigators indicated the following data was frequently collected:
  - 1) **Patient linked with appropriate community resources** (n=24; 59%)
  - 2) Insurance status of patient; Number of patients navigator per navigator; Type of encounter (n=22, 54%)
  - 3) Number of patient referrals (n=20; 49%)

### **Screening Data**

- Most common Screening data collected:
  - 1) Date enrolled into navigation (n=17; 41%) **most indicated piece of data collected**
  - 2) Date screening test completed (n=16; 39%)
  - 3) Date referred for screening; Date screening test scheduled (n=15; 37%)
- Most important Screening data:
  - 1) Increase the percentage of patients who complete a screening (n=15; 37%) **most indicated important data**
  - 2) Increase in the number of patients seen at your institution/organization (n=9; 22%)
  - 3) Initial contact until screening test completion (n=8; 22%)

## Early Detection/Diagnosis

- Most common Early Detection/Diagnosis data collected:
  - 1) Date diagnostic test completed; Stage at diagnosis (n=14; 34%)
  - 2) Date diagnostic test scheduled (n=13; 32%)
  - 3) Date patient informed of diagnostic test result; Number of patients lost to follow-up (n=11; 27%)
- Most important Early Detection/Diagnosis data:
  - 1) Initial contact until date of cancer diagnosis (n=11; 27%)
  - 2) Abnormal screening test reported until diagnostic test scheduled; Initial contact until diagnostic test or biopsy completed; Data on connecting underserved patients to navigation services (n=10; 24%)
  - 3) Initial contact until diagnostic test or biopsy scheduled (n=9; 22%)

## Treatment

- Most common Treatment data collected:
  - 1) Recommended surgery performed; Recommended chemo received &/or completed (n=13; 32%)
  - 2) Recommended radiation therapy received/completed (n=11; 27%)
  - 3) Standard of care delivered, NCCN guideline adherence; Primary care provider or medical home/treatment team notified &/or oncology records shared (n=10; 24%)
- Most important Treatment data:
  - 1) Initial contact until date treatment initiated (n=14; 34%)
  - 2) Increase in the number of patients seen at your institution/organization (n=13; 32%)
  - 3) Consult with oncology provider until first treatment date (n=10; 24%)

## Survivorship

- Most common Survivorship data collected:
  - 1) Provide information on support groups (n=8; 20%)
  - 2) Patient receipt and understanding of survivorship care plan (n=7; 17%)
  - 3) Adherence to clinical follow-up recommendations once treatment is completed; Provide direct emotional support to patient (log time spent doing so, or how often); Date of last follow-up (n=5; 12%)
- Most important Survivorship data:
  - Patient reported barriers to care until barriers adequately addressed; Increase in the number of patients seen at your institution/organization (n=6; 15%)
  - Cancer diagnosis until survivorship care plan discussed with patient; Cancer treatment completion until survivorship care plan discussed with patient; Increase in healthy preventive behaviors at follow-up (i.e., quit smoking, exercise, eat healthy, etc.) (n=5, 12%)

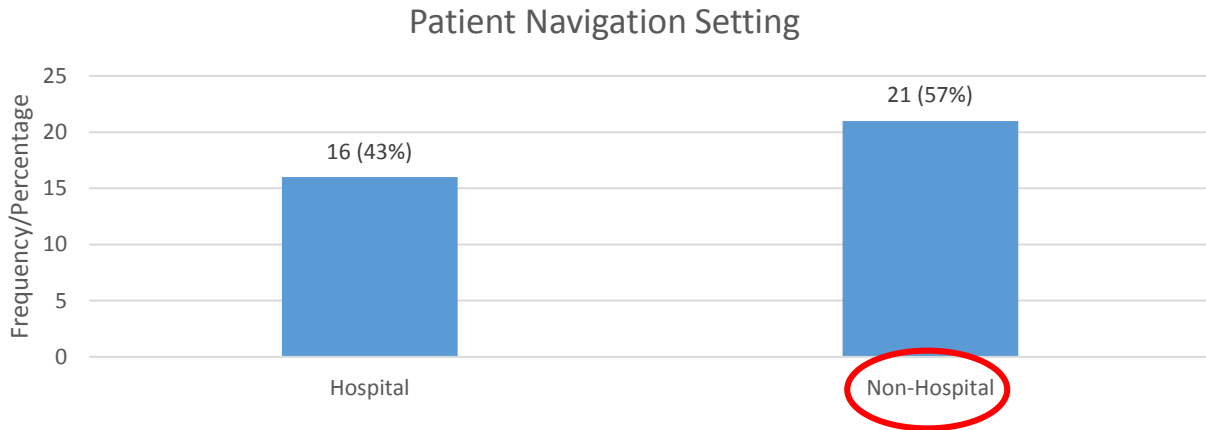
## Final Comments

- Numerous patient navigators reported that they are in the **planning phase** of their program's development.

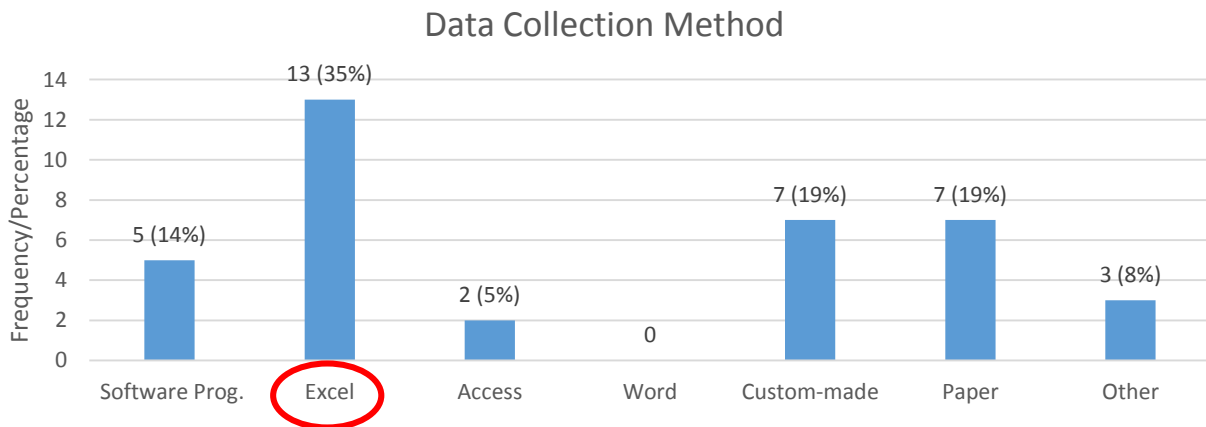
## Detailed survey responses:

### Information on Your Patient Navigation Program

For what type of organization do you provide cancer patient navigation services?



How do you currently collect the data regarding your cancer navigation services? Select the ONE answer that best applies to your program.



Software Prog.= Computer software program

Excel= Microsoft Excel spreadsheet

Access= Microsoft Access database

Word= Microsoft Word

Custom-made= Custom-made software

Paper= Hand-written paper only

Other

Computer software programs reported to be used by navigators:

- MosaiQ
- We use Omnicare which has a segment for navigation {Reported by 2 partners}.
- Adverttek
- Bridge/CDP

Other comments/programs:

- We have interdepartment forms that I can share. We also have an excel spreadsheet that follows those forms. We also use OMNI for data tracking and collection. I also used a different system making use of an Excel spreadsheet. Now all of that is tracked in Mosaiq.
- MEDITECH
- Our webmail service has a task option, each patient is added as a new 'task', and we move review dates up as needed.

**Choose the section of the cancer continuum that you navigate. Select the ONE answer that best applies to your program. Note: Patient Navigators reported working with patients on more than one section of the continuum of care.**

Ranking	Response	Frequency/Percentage
1	<b>Treatment</b>	<b>n=26; 63%</b>
2	Screening	n=22; 54%
3	Early Detection/Diagnosis	n=20; 49%
4	Survivorship	n=15; 37%

**Regardless of the cancer continuum section (Screening, Early Detection/Diagnosis, Treatment, Survivorship) you navigate cancer patients on, which of the following data does your cancer patient navigation program collect? Select ALL that apply.**

Ranking	Response	Frequency/Percentage
1	<ul style="list-style-type: none"> <li>• Patient linked with appropriate community resources</li> </ul>	n=24; 59%
2	<ul style="list-style-type: none"> <li>• Insurance status of patient</li> <li>• Number of patients navigated per navigator</li> <li>• Type of encounter (in person, phone, letter)</li> </ul>	n=22; 54%
3	<ul style="list-style-type: none"> <li>• Number of patient referrals</li> </ul>	n=20; 49%
4	<ul style="list-style-type: none"> <li>• Patient reported barriers to care</li> </ul>	n=17; 41%
5	<ul style="list-style-type: none"> <li>• Number of uninsured and underinsured patients navigated</li> </ul>	n=16; 39%
6	<ul style="list-style-type: none"> <li>• Number of patients provided with educational materials and information</li> </ul>	n=13; 32%
7	<ul style="list-style-type: none"> <li>• Patient satisfaction scores</li> </ul>	n=11; 27%
8	<ul style="list-style-type: none"> <li>• Time spent addressing a particular barrier (minutes/hours, etc.)</li> <li>• Other</li> </ul>	n=7; 17%
9	<ul style="list-style-type: none"> <li>• Health literacy of patients measured</li> </ul>	n=3; 7%

Other Comments included:

- Appointments with MD's and hospitals; high risk factors; patients lost to system or not qualified for the program; numbers for each county served; when follow-up visits need to be made
- Date of birth, race, smoker, employment, referral source, detail notes of encounter
- Direct services provided. Type of service, value of service. (many specific patient supplies listed along with other connections made on behalf of the patient). Notes

regarding each patient with description of latest discussion(s) with dates. Referrals given.

- Data is not collected.
- When at the cancer center, we tracked all of that. Now at the Breast Center, we track what is checked plus that dates of appts and provider names to track who we are referring to as well. We give educational materials to all patients.
- Treatments given, surgeries, test

<b>Screening Data</b>
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Which of the following **SCREENING** related data does your cancer patient navigation program collect? Select **ALL** that apply.

<b>Screening Data Collected</b>		
<b>Ranking</b>	<b>Response</b>	<b>Frequency/Percentage</b>
<b>1</b>	• Date enrolled into navigation	n=17; 41%
<b>2</b>	• Date screening test completed	n=16; 39%
<b>3</b>	• Date referred for screening • Date screening test scheduled	n=15; 37%
<b>4</b>	• Date screening test results are read/reported • Primary care provider or medical home/treatment team notified/records shared	n=13; 32%
<b>5</b>	• Date patient informed of screening test result	n=12; 29%
<b>6</b>	• Number of patients lost to follow up	n=10; 24%
<b>7</b>	• Number of missed appointments	n=9; n=22%
<b>8</b>	• Other	n=2; 5%

Other Comments Included:

- 4. Pts have appropriate f/u for abnormal CT's. 5. Smoking Cessation for those who have screens.

Which (5) cancer patient navigation SCREENING outcomes are MOST important to your organization? Select up to five outcomes.

<b>Most Important Screening Outcomes</b>		
<b>Ranking</b>	<b>Response</b>	<b>Frequency/Percentage</b>
1	<ul style="list-style-type: none"> <li>Increase the percentage of patients who complete a screening</li> </ul>	n=15; 37%
2	<ul style="list-style-type: none"> <li>Increase in the number of patients seen at your institution/organization</li> </ul>	n=9; 22%
3	<ul style="list-style-type: none"> <li>Initial contact until screening test completion</li> </ul>	n=8; 20%
4	<ul style="list-style-type: none"> <li>Scheduled screening until screening is completed</li> <li>Test results are read/reported until the patient is informed of test result</li> </ul>	n=7; 17%
5	<ul style="list-style-type: none"> <li>Data on connecting underserved patients to navigation services</li> </ul>	n=6; 15%
6	<ul style="list-style-type: none"> <li>Personal stories from patients directly affected by your services</li> <li>Patient reported barriers to care until barriers adequately addressed</li> </ul>	n=5; 12%
7	<ul style="list-style-type: none"> <li>Referral for screening until screening is scheduled</li> </ul>	n=4; 10%
8	<ul style="list-style-type: none"> <li>Completion of screening until test results are read/reported</li> <li>Negative screening test result until date of NEXT regular screening test appointment kept</li> </ul>	n=3; 7%
9	<ul style="list-style-type: none"> <li>Increase in patient satisfaction scores over a period of time</li> <li>Initial contact until referral for screening</li> </ul>	n=2; 5%
10	<ul style="list-style-type: none"> <li>Increase in percentage of patients connected with financial assistance</li> <li>Other</li> </ul>	n=1; 2%

Other Comments Included:

- Reason for missed or canceled appt. For example, financial reason, chose another facility etc.
- No show rates, last attempt letter given, cancelled appointments

<b>Early Detection/Diagnosis Data</b>
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Which of the following EARLY DETECTION/DIAGNOSIS related data does your cancer patient navigation program collect? Select ALL that apply.

<b>Early Detection/Diagnosis Data Collected</b>		
<b>Ranking</b>	<b>Response</b>	<b>Frequency/Percentage</b>
1	<ul style="list-style-type: none"> <li>Date diagnostic test completed</li> <li>Stage at diagnosis</li> </ul>	n=14; 34%
2	<ul style="list-style-type: none"> <li>Date diagnostic test scheduled</li> </ul>	n=13; 32%
3	<ul style="list-style-type: none"> <li>Date patient informed of diagnostic test result</li> <li>Number of patients lost to follow-up</li> </ul>	n=11; 27%
4	<ul style="list-style-type: none"> <li>Number of missed appointments</li> </ul>	n=10; 24%
5	<ul style="list-style-type: none"> <li>Primary care provider or medical home/treatment team notified/records shared</li> </ul>	n=9; 22%
6	<ul style="list-style-type: none"> <li>Name of professional organization's guidelines adhered to for diagnostic test</li> <li>Date diagnostic test results are read/reported by pathologist</li> </ul>	n=8; 20%
7	<ul style="list-style-type: none"> <li>Other</li> </ul>	n=2; 5%

Other Comments Included:

- Barriers addressed with details provided
- Data not collected

Which (5) cancer patient navigation EARLY DETECTION/DIAGNOSIS outcomes are MOST important to your organization? Select up to five outcomes.

<b>Most Important Early Detection/Diagnosis Outcomes</b>		
<b>Ranking</b>	<b>Response</b>	<b>Frequency/Percentage</b>
1	<ul style="list-style-type: none"> <li>Initial contact until date of cancer diagnosis</li> </ul>	n=11; 27%
2	<ul style="list-style-type: none"> <li>Abnormal screening test reported until diagnostic test scheduled</li> <li>Initial contact until diagnostic test or biopsy completed</li> <li>Data on connecting underserved patients to navigation services</li> </ul>	n=10; 24%
3	<ul style="list-style-type: none"> <li>Initial contact until diagnostic test or biopsy scheduled</li> </ul>	n=9; 22%
4	<ul style="list-style-type: none"> <li>Patient reported barriers to care until barriers adequately addressed</li> </ul>	n=7; 17%
5	<ul style="list-style-type: none"> <li>Increase in the number of patients seen at your institution/organization</li> </ul>	n=6; 15%
6	<ul style="list-style-type: none"> <li>Personal stories from patients directly affected by your services</li> </ul>	n=4; 10%
7	<ul style="list-style-type: none"> <li>Increase in patient satisfaction scores over a period of time</li> <li>Increase in percentage of patients connected with financial assistance</li> </ul>	n=3; 7%
8	<ul style="list-style-type: none"> <li>Other</li> </ul>	n=1; 2%

Other Comments Included:

- Data not collected



<b>Treatment Data</b>
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Which of the following TREATMENT related data does your cancer navigation program collect? Select ALL that apply.

<b>Treatment Data Collected</b>		
<b>Ranking</b>	<b>Response</b>	<b>Frequency/Percentage</b>
<b>1</b>	<ul style="list-style-type: none"> <li>Recommended surgery performed</li> <li>Recommended chemo received/completed</li> </ul>	n=13; 32%
<b>2</b>	<ul style="list-style-type: none"> <li>Recommended radiation therapy received/completed</li> </ul>	n=11; 27%
<b>3</b>	<ul style="list-style-type: none"> <li>Standard of care delivered, NCCN guideline adherence</li> <li>Primary care provider or medical home/treatment team notified/oncology records shared</li> </ul>	n=10; 24%
<b>4</b>	<ul style="list-style-type: none"> <li>Hospice referral completed</li> </ul>	n=8; 20%
<b>5</b>	<ul style="list-style-type: none"> <li>Number of patients given information on clinical trials</li> <li>Number of patients enrolled in clinical trials</li> <li>Palliative care referral completed</li> </ul>	n=7; 17%
<b>6</b>	<ul style="list-style-type: none"> <li>Number of patients leaving the cancer center for treatment elsewhere</li> <li>Date patient referred to supportive care provider following distress measurement tool</li> </ul>	n=6; 15%
<b>7</b>	<ul style="list-style-type: none"> <li>Reason patient/family decline treatment</li> </ul>	n=5; 12%
<b>8</b>	<ul style="list-style-type: none"> <li>Date patient completed distress measurement tool</li> <li>Potential long term/late effects shared with patient</li> </ul>	n=4; 10%
<b>9</b>	<ul style="list-style-type: none"> <li>Reasons for missed cancer therapy days</li> <li>Number of unavoidable admissions/ER visits</li> <li>Reason for non-participation in clinical trials if offered/patient eligible</li> </ul>	n=3; 7%
<b>10</b>	<ul style="list-style-type: none"> <li>Radiation therapy days missed</li> <li>Length of [hospital/cancer center] stay</li> </ul>	n=2; 5%
<b>11</b>	<ul style="list-style-type: none"> <li>Other</li> </ul>	n=1; 2%

Other Comments Included:

- Services provided for support, items given, resources given are all documented.

Which (5) cancer patient navigation TREATMENT outcomes are MOST important to your organization? Select up to five outcomes.

<b>Most Important Treatment Outcomes</b>		
<b>Ranking</b>	<b>Response</b>	<b>Frequency/Percentage</b>
<b>1</b>	<ul style="list-style-type: none"> <li>Initial contact until date treatment initiated</li> </ul>	n=14; 34%
<b>2</b>	<ul style="list-style-type: none"> <li>Increase in the number of patients seen at your institution/organization</li> </ul>	n=13; 32%
<b>3</b>	<ul style="list-style-type: none"> <li>Consult with oncology provider until first treatment date</li> </ul>	n=10; 24%
<b>4</b>	<ul style="list-style-type: none"> <li>Patient reported barriers to care until barriers adequately addressed</li> <li>Increase in percentage of patients who complete treatment</li> <li>Increase in patient satisfaction scores over a period of time</li> </ul>	n=8; 20%
<b>5</b>	<ul style="list-style-type: none"> <li>Cancer diagnosis until date treatment began</li> <li>Increase in percentage of patients connected with financial assistance</li> </ul>	n=7; 17%
<b>6</b>	<ul style="list-style-type: none"> <li>Cancer diagnosis until consult with oncology provider</li> <li>Reduced time intervals between treatment modalities (surgery to radiation, chemo to surgery/radiation, etc.)</li> <li>Data on connecting underserved patients to navigation services</li> </ul>	n=6; 15%
<b>7</b>	<ul style="list-style-type: none"> <li>Personal stories from patients directly affected by your services</li> </ul>	n=5; 12%
<b>8</b>	<ul style="list-style-type: none"> <li>Cancer diagnosis until distress measurement screen completion</li> <li>Distress measurement screen completion until completed referral to supportive care provider (if appropriate)</li> </ul>	n=3; 7%
<b>9</b>	<ul style="list-style-type: none"> <li>Date of terminal diagnosis until hospice referral completed</li> </ul>	n=1; 2%
<b>10</b>	<ul style="list-style-type: none"> <li>Other</li> </ul>	n=0

<b>Survivorship Data</b>
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Which of the following SURVIVORSHIP related data does your cancer patient navigation program collect? Select ALL that apply.

<b>Survivorship Data Collected</b>		
<b>Ranking</b>	<b>Response</b>	<b>Frequency/Percentage</b>
1	<ul style="list-style-type: none"> <li>Provide information on support groups</li> </ul>	n=8; 20%
2	<ul style="list-style-type: none"> <li>Patient receipt and understanding of survivorship care plan</li> </ul>	n=7; 17%
3	<ul style="list-style-type: none"> <li>Adherence to clinical follow-up recommendations once treatment is completed</li> <li>Provide direct emotional support to patient (log time spent doing so, or how often)</li> <li>Date of last follow-up</li> </ul>	n=5; 12%
4	<ul style="list-style-type: none"> <li>Recurrence data</li> </ul>	n=4; 10%
5	<ul style="list-style-type: none"> <li>Survival data</li> </ul>	n=3; 7%
6	<ul style="list-style-type: none"> <li>Quality of life assessed (ex: FACIT, PROMIS, Impact of Cancer Scale, etc.)</li> <li>Record patient's current preventive behaviors and ways they optimize wellness, and counsel on healthy preventive behaviors</li> </ul>	n=2; 5%
7	<ul style="list-style-type: none"> <li>Number of patients lost to follow-up</li> </ul>	n=1; 2%
8	<ul style="list-style-type: none"> <li>Other</li> </ul>	n=0

Which (5) cancer patient navigation SURVIVORSHIP outcomes are MOST important to your organization? Select up to five outcomes.

<b>Most Important Survivorship Outcomes</b>		
<b>Ranking</b>	<b>Response</b>	<b>Frequency/Percentage</b>
<b>1</b>	<ul style="list-style-type: none"> <li>• Patient reported barriers to care until barriers adequately addressed</li> <li>• Increase in the number of patients seen at your institution/organization</li> </ul>	n=6; 15%
<b>2</b>	<ul style="list-style-type: none"> <li>• Cancer diagnosis until survivorship care plan discussed with patient</li> <li>• Cancer treatment completion until survivorship care plan discussed with patient</li> <li>• Increase in healthy preventive behaviors at follow-up (i.e. quit smoking, exercise, eat healthy, etc.)</li> <li>• Increase in patient satisfaction scores over a period of time</li> </ul>	n=5; 12%
<b>3</b>	<ul style="list-style-type: none"> <li>• Increase the percentage of patients who attend post-treatment follow-up appointment</li> <li>• Decrease in distress measurement scores during patient's treatment</li> <li>• Increase in percentage of patients connected with financial assistance</li> <li>• Data on connecting underserved patients to navigation services</li> <li>• Personal stories from patients directly affected by your services</li> </ul>	n=4; 10%
<b>4</b>	<ul style="list-style-type: none"> <li>• Cancer treatment completion until first follow-up appointment</li> </ul>	n=3; 7%
<b>5</b>	<ul style="list-style-type: none"> <li>• Increase in Quality of Life scores after patient receives navigation</li> </ul>	n=2; 5%
<b>6</b>	<ul style="list-style-type: none"> <li>• Other</li> </ul>	n=0

## **Final Comments**

**We would like to hear from you! Please feel free to provide us with any comments about your patient navigation program, data you collect, or outcomes that you measure.**

- Patient navigation is a big part of the care that the clients get at this clinic. The client will be given all the information/guidance needed for the complete care necessary.
- We are in the infancy stage of starting a navigation program and while many of the choices are appealing and seem very appropriate to be tracking, at this point we are only tracking very basic data.
- I also collect second opinions, ratio kept. I collect stages, pathology information and when patient discussed in conference.
- Would like more info on resources (businesses, names of people to contact, etc.) in the area that would help the patient and the navigator throughout the screening process.
- number of pt's in cs, fp and pn programs in relation to Paps. Treatment f/u plans from referred providers.
- n/a
- Do not have formalized patient navigation program. RN coordinates needed services.
- We are still in the planning stages of this.
- We are still in the process of trying to put a navigation process in place rather than a navigator due to limit funding.

**Many thanks to the partners who contributed to this survey and report:**

- Katie Bathje: Kentucky Cancer Consortium
- Jessica Jones: Kentucky Cancer Consortium
- Jenita Lyons: Norton Healthcare Centers for Prevention and Wellness
- Amy Morgan: Appalachian Regional Healthcare
- Jaclyn Nee: Kentucky Cancer Registry
- Jaime Rafferty: Kentucky Cancer Program-West
- Christy Roberts: Norton Cancer Institute
- Ashley Teague: Kentucky Cancer Program-East
- Carla Terrell: Owensboro Health