

Priority Needs of Kentucky Cancer Survivors: Results of an Online Survey of the Kentucky Cancer Consortium Survivorship Committee

December 2009; 25 respondents

In December 2009, the Kentucky Cancer Consortium sent an invitation to take an online survey to 35 partner organizations on the Kentucky Cancer Consortium Survivorship Committee membership list. 25 partners responded.

In 2004, the Centers for Disease Control and Prevention (CDC) collaborated with the Lance Armstrong Foundation and key partners to identify and prioritize cancer survivorship needs within a public health context. Through this partnership, "[A National Action Plan for Cancer Survivorship](#)" was developed.

The National Action Plan identified priority needs within four public health areas: surveillance and applied research; communication, education and training; programs, policies and infrastructure; and access to quality care and services.

Five cross-cutting needs were identified through the development process. For the purposes of this survey, the five needs were re-worded into Kentucky-specific statements. Respondents were asked to choose their level of agreement with each of the statements, based on their experience in working with cancer survivors in Kentucky (Strongly Agree, Agree, Neither agree nor disagree, Disagree, Strongly Disagree)

After identifying five cross-cutting needs for cancer survivors, the "National Cancer Action Plan" also listed 17 'Priority Needs'. Respondents of the Kentucky survey were then asked how "urgent" they saw those needs (Urgent Need, Average Need, or Lesser Need) for cancer survivors in Kentucky.

The needs are listed below in order of most urgent to least urgent, as perceived by the 25 respondents (cancer survivorship professionals). While all the needs are important, respondents were asked to consider what is already 'happening' around these needs and how much more needs to be done in the state of Kentucky.

1. Educate policy-makers about cancer survivorship issues.

- a. 20 of 25 respondents saw need as "urgent" or "above average" in urgency

2. Education decision-makers about economic and insurance barriers related to health care for cancer survivors.

- a. 20 of 25 respondents saw need as "urgent" or "above average" in urgency

3. Establish integrated multidisciplinary teams of health care providers for cancer patients.

- a. 20 of 25 respondents saw need as "urgent" or "above average" in urgency

4. Educate health care providers about cancer survivorship from diagnosis through long-term and end-of-life care.

- a. 20 of 25 respondents saw need as "urgent" or "above average" in urgency

- 5. Teach survivors how to access and evaluate available information.**
 - a. 19 of 25 respondents saw need as “urgent” or “above average” in urgency
- 6. Kentucky cancer survivors have adequate access to patient navigation systems that facilitate optimum care.**
 - a. 19 of 25 respondents “Strongly disagreed” or “disagreed” with this statement.
- 7. Identify factors associated with ongoing health concerns of cancer survivors.**
 - a. 19 of 25 respondents saw need as “urgent” or “above average” in urgency
- 8. Identify and implement programs proven to be effective (i.e. best practices).**
 - a. 18 of 25 respondents saw need as “urgent” or “above average” in urgency
- 9. Implement evidence-based cancer plans that include goals and strategies for all stages of cancer survivorship.**
 - a. 18 of 25 respondents saw need as “urgent” or “above average” in urgency
- 10. Translate applied research into practice.**
 - a. 18 of 25 respondents saw need as “urgent” or “above average” in urgency
- 11. Develop strategies to educate the public that cancer is a chronic disease people can and do survive.**
 - a. 18 of 25 respondents saw need as “urgent” or “above average” in urgency
- 12. Assess and enhance provision of palliative services to cancer survivors.**
 - a. 18 of 25 respondents saw need as “urgent” or “above average” in urgency
- 13. Empower survivors with advocacy skills.**
 - a. 17 of 25 respondents saw need as “urgent” or “above average” in urgency
- 14. Establish and/or disseminate guidelines that support quality and timely service provision to cancer survivors.**
 - a. 17 of 25 respondents saw need as “urgent” or “above average” in urgency
- 15. Develop infrastructure to obtain quality data on all cancer management activities to support programmatic action.**
 - a. 16 of 25 respondents saw need as “urgent” or “above average” in urgency
- 16. Conduct research on preventive interventions to evaluate their impact on issues related to cancer survivorship.**
 - a. 14 of 25 respondents saw need as “urgent” or “above average” in urgency
- 17. Determine programs and services that best address the needs of cancer survivors.**

- a. 14 of 25 respondents saw need as “urgent” or “above average” in urgency
- 18.** Kentucky cancer patients keep track of their own treatments and ask questions about follow-up care.
 - a. 13 of 25 respondents disagreed with this statement
- 19.** Enhance the existing surveillance and applied research infrastructure.
 - a. 12 of 25 respondents saw need as “urgent” or “above average” in urgency
- 20.** Kentucky cancer survivors have adequate access to public education programs that empower them to make informed choices.
 - a. 11 of 25 respondents disagreed with this statement
- 21.** Kentucky health care providers utilize Cancer Survivorship Care Plans with their patients. (i.e., ASCO currently has Survivorship Care Plans available for Breast and Colon Cancers)
 - a. 7 of 25 respondents Strongly disagreed or disagreed with this statement
- 22.** Kentucky has an infrastructure for a comprehensive database on cancer survivorship.
 - a. 5 of 25 respondents Strongly disagreed or disagreed with this statement
- 23.** Organizations that work with cancer survivors in Kentucky evaluate activities to determine their impacts and outcomes and ensure continuous quality improvement of services.
 - a. 1 of 25 respondents Strongly disagreed or disagreed with this statement