

Attachment 3c: Frequently asked questions (FAQs)

Disparities in Distress Screening among Lung and Ovarian Cancer Survivors Centers for Disease Control and Prevention (CDC)

Frequently Asked Questions and Answers (FAQs) For Healthcare Facilities

If you have questions, contact Theresa Famolaro or Diane Ng
([800 NUMBER], [CDCScreening@westat.com])

GENERAL QUESTIONS

1. Who is sponsoring this project?

The Centers for Disease Control and Prevention (CDC) is sponsoring this project.

2. What is the purpose of the study?

The purpose of the study is to examine the extent to which disparities exist in distress screening and follow-up among cancer survivors in cancer treatment facilities and programs across the county. The project seeks to understand the facilitators and barriers to the process of incorporating distress screening and follow-up treatment in the care of ovarian and lung cancer survivors.

3. Who is Westat?

Westat is a research company that has contracted with CDC to assist them with the design and implementation of the study. Westat will work with participating healthcare facilities to collect the necessary data.

4. How does this study define a cancer survivor?

The CDC defines cancer survivors as “people who have been diagnosed with cancer and those in their lives who are affected by the diagnosis, including family members, friends, and caregivers.” The National Cancer Institute (NCI) states that a “cancer survivor is one who remains alive and continues to function after overcoming difficulties or life-threatening diseases like cancer.”¹ This study will specifically target survivors of lung and ovarian cancer from the beginning of their diagnosis.

¹¹ Shapiro, et al, (2009). The LIVESTRONG survivorship of excellence network. *Journal of Cancer Survivors*, 3(1), 4-11.

5. Why is the study focusing only on lung and ovarian cancer survivors?

Lung and ovarian cancer survivors are known to have low 5-year survival rates. According to the National Academies of Sciences, Engineering, and Medicine (formerly known as the Institute of Medicine, or IOM), ovarian cancer is considered one of the most lethal types of cancers.² Therefore, CDC believes that it is imperative to develop a greater understanding about the types of services they receive during their course of treatment and follow-up care.

6. What types of data will you collect?

At the patient level, we will collect data related to patient demographics, cancer diagnosis and treatment, and receipt of distress screening - name, address, birth date, Social Security Number will not be collected. At the facility level, we will collect data on the processes and protocols related to implementing distress screening. A small number of participating healthcare facilities will be invited to participate in an interview and focus group to increase contextual understanding of facilitators and barriers to distress screening and follow-up processes.

7. How will the results be used?

Results of this study will provide valuable information on addressing the psychosocial needs of ovarian and lung cancer survivors. Additionally, this study will provide CDC's National Comprehensive Cancer Control Program (NCCCP) with information to assist with the development of information, resources, technical assistance, and future evidence-based interventions to improve the quality of life of these survivors. Since 1998, NCCCP has helped reduce the burden of cancer in the United States and U.S. Territories by creating coalitions, reviewing cancer burden, prioritizing cancer control strategies, and creating and implementing cancer plans. For more information about NCCCP visit <https://www.cdc.gov/cancer/ncccp/about.htm>. Furthermore, findings will be used to evaluate the need for policy, systems and/or environmental change to enhance the landscape of quality of life services for cancer survivors in communities at large.

8. Which accreditation agencies have approved this study?

This study has been approved by the American College of Surgeons (ACS) Commission on Cancer (CoC) as fulfilling requirements for *Standard 4.7 Studies of Quality*. Participating CoC-accredited healthcare facilities may participate for credit.

9. What other organizations are involved with this study?

²² National Academies of Sciences, Engineering, and Medicine. (2016). Ovarian cancers: Evolving paradigms in research and care. Washington, DC: The National Academies Press. doi: 10.17226/21841

This study was informed by input from the Patient Centered Research Collaborative (PCRC), a research cooperative group comprised of oncology social workers, patient advocates, and academic researchers.

HEALTHCARE FACILITY ELIGIBILITY

1. What types of healthcare facilities can participate?

Healthcare facilities that offer cancer services for ovarian or lung cancer including distress screening, have fully implemented Electronic Health Records (EHRs), have been in operation for 12 months, and have a bed size of 25 beds or more can participate in the study. We will be implementing the study in 50 healthcare facilities.

2. Our healthcare facility also treats other forms of cancer. Can we share other cancer cases that are not ovarian or lung cancer?

This study focuses on ovarian and lung cancer cases because patients with these cancers have low five-year survival rates and organizations such as the National Academies of Sciences, Engineering, and Medicine have recently emphasized the need to increase the understanding of ovarian cancer. Additionally, lung cancer patients/survivors are under-represented in the psychosocial literature. For the purposes of this study, we will not request information about other cancer types.

TIME AND HEALTHCARE FACILITY RESPONSIBILITY

1. How will Westat collect EHR data?

There are a couple of options. One option is to work with your IT department to extract data coded by your healthcare facility cancer registry in the healthcare facility EHR. Additionally, we may request extracts of data that are not coded (such as information that is found in progress notes, scanned documents, and other formats) in order to gain information related to the receipt of distress screening and follow-up. Other options include secure remote access to your EHR system by study staff or onsite abstraction of your EHR distress screening data by healthcare facility or external staff.

2. How will Westat collect the qualitative data?

We will conduct one key informant interview and one focus group from a sample of the participating healthcare facilities. The key informant interview will take place with a healthcare facility administrator, while the focus group will consist of a mix of medical providers, social workers, and consult staff who are involved in distress screening.

Interviews and focus groups will take place through a video call and we will record audio with consent.

3. When does the EHR abstraction begin and end?

The EHR abstraction will take place from spring of 2019 through fall of 2019.

4. What will be the point of contact's responsibility?

The point of contact (POC) will participate in conference calls to understand the purpose of the study, and provide information about healthcare facility characteristics such as ovarian and lung cancer cases, and distress screening practices. Westat will work with the POC to ensure that healthcare facilities have completed Institutional Review Board (IRB) application materials, signed documentation to ensure the protection of personal health information (PHI), and have appropriate procedures in place to share healthcare facility EHR data.

5. Will you require any healthcare facility staff time? If yes, how much time?

The study will require minimal staff time. Specific responsibilities of healthcare facility staff include those mentioned above for the POC, and the coordination of processes to obtain the EHR. Healthcare facility staff or providers selected to take part in the key informant interview and focus group will require approximately 1 - 1.5 hours, and will receive a monetary thank you of \$100 and \$60, respectively, upon completion.

6. How much will this study cost our healthcare facility?

There is no direct cost to the healthcare facility.

SECURITY AND CONFIDENTIALITY

1. How will you protect our healthcare facility's EHR data?

- A Limited Dataset for extracted data, not containing names, addresses, birth dates, or Social Security Numbers, will be transmitted to Westat via a secure file transfer protocol (SFTP).
- In addition, participating healthcare facility may sign a Business Associates Agreement (BAA) that protects the confidentiality of your healthcare facility's EHR data and the identity of your healthcare facility. The BAA will also provide guidance on how we will use the data in the study.

BENEFITS TO PARTICIPATING HEALTHCARE FACILITIES

1. Why should we participate? What are we going to get in return?

- For each participating healthcare facility, CDC will develop an individual healthcare facility feedback report that allows you to compare your healthcare facility to other participating healthcare facilities with regard to distress screening.
- Participating healthcare facilities will receive credit for *Standard 4.7 Study of Quality* by the American College of Surgeons (ACS) Commission on Cancer (CoC).
- Your participation will add to the body of knowledge regarding distress screening for cancer patients that will ultimately improve the quality of life of cancer survivors.
- Healthcare facility qualitative interview and focus group respondents will receive a monetary thank you for their participation, \$100 and \$60 respectively.