Attachment 5d: Key informant interview guide and informed consent

Centers for Disease Control and Prevention

Disparities in Distress Screening among Ovarian and Lung Cancer Survivors Study

Key Informant Interview Guide

Form Approved
OMB Control # 0920-XXXX
Expiration Date: XX/XX/20XX

Collection of this information is authorized by The Public Health Service Act, Section 411 (42 USC 285a). Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private to the extent provided by law. Names and other identifiers will not appear in any report of the study. Information provided will be combined for all study participants and reported as summaries. You are being contacted to participate in this data collection so that we can further understand how psychosocial distress screening practices are implemented for lung and ovarian cancer survivors.

Public reporting burden for this collection of information is estimated to average 60 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30329; ATTN: PRA (0920-XXXX). Do not return the completed form to this address.

INTRODUCTION

Hi [NAME OF INTERVIEWEE]. Thank you for taking the time to talk with us today. The purpose of this interview is to develop a richer understanding of the distress screening procedures among ovarian and lung cancer patients and survivors at [NAME OF HEALTHCARE FACILITY/PROGRAM]. Today's questions are all about your perceptions and views on topics such as your healthcare facility's policies on cancer care, processes for distress screening and follow-up procedures etc. Please keep in mind that there are no right or wrong answers. We are NOT looking for any specific responses from any respondents. These questions are only to help us get a glimpse into how things work at your healthcare facility.

CONFIDENTIALITY/INFORMED CONSENT

This session will last approximately 1 hour.

Everything we talk about will be kept secure to the extent permitted by law. With your permission, we would like to record our conversation. We use it solely as a backup to our notes and destroy it at the end of the study. It will not be shared beyond our internal team at Westat.

Your participation is completely voluntary, and you have the right to stop at any time or to refuse to answer any question.

Your responses to these questions will not be shared outside of the evaluation team. In our summary findings, your responses will be combined with other people's responses, so your answers will never be attributed to your name. We may use quotes from you or other key informants in our reports, however, in such cases, they will not be linked to any names or identifiers.

Do you agree to continue with the interview?

[*OBTAIN INFORMED CONSENT*]

We would like to record this interview so that we can be sure to accurately capture your responses. A recording would only be reviewed by a small number of Westat staff members. If you do not agree to have the interview recorded, we can still conduct the interview without turning on the recorder.

Would it be okay with you if we record this interview?

[*OBTAIN CONSENT TO RECORD SESSION*]

[*IF CONSENT IS GIVEN TO RECORD, THEN SAY WHILE RECORDING*]*:*

Okay, just for confirmation, you have agreed to participate in this interview and have agreed to allow us to record this session. You understand that your responses will be kept secure, you can refuse to answer any questions, and you can stop the interview at any time. Is that correct?

INTERVIEW QUESTIONS

1) Overview of the Program/Facility/Service

a) Facility level information [*TO BE PRE-POPULATED AS MUCH AS POSSIBLE*]

i) Type of facility
ii) Year established
iii) Region served
iv) Organizational structure (affiliate centers)

b) Respondent level information [*ASKED ONLY IF INFORMATION HAS NOT BEEN OBTAINED FROM PRIOR COMMUNICATIONS*]

i) What is your title/role at [HEALTHCARE FACILITY NAME]?
ii) How long have you been doing this type of work or related work?

2) Policies on Cancer Care

a) What are some organizational policies and practices that have been implemented at your healthcare facility surrounding distress screening? [*INTERVIEWER TO REVIEW HEALTHCARE FACILITY DISTRESS SCREENING PROTOCOL*]

Probes:

i) How long has your facility implemented routine distress screening?
ii) To what extent is Psychosocial Distress Screening practices among cancer patients and survivors[1] implemented in your facility?
iii) Does this apply for all patients, or only certain diseases/clinics? What might be some differences between ovarian and lung cancer survivors than it is for others?
iv) Is this process consistent across disease centers/clinics/satellite locations?

b) How does your facility define a "pivotal medical visit"? Are they similar for all patients?

[11] 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."

3) Processes for Distress Screening, Referral & Follow-up Care

a) **Screening**

What is the process for identifying psychosocial needs of patients at [HEALTHCARE FACILITY NAME]?

Probes:

i) What Distress Screening tool(s) is/are used at your healthcare facility?

ii) What are the distress thresholds for this(these) screening instrument(s)? Why were the specific thresholds selected?

iii) How is screening administered? Who administers the screening? Where do the screenings typically take place (e.g. waiting rooms, chemotherapy session)?

iv) Is the screening process any different for ovarian and lung cancer survivors than it is for others?

b) Referral and Follow-up Care

What are the different types of psychosocial services available at [HEALTHCARE FACILITY NAME]? How are patients generally linked to these types of services?

4) Procedural issues with Documentation/Medical Records

a) How is distress screening, assessment, referral and/or follow-up documented?

b) What are the processes you know of that are in place to monitor the screening and follow-up for each patient?

c) How is the whole process overseen and reviewed?

Probe:

i) Are there regular reporting procedures for distress screening and their results (i.e. for your unit/healthcare facility)?

5) Implementation (Challenges and Facilitators)

a) What are some factors at [HEALTHCARE FACILITY NAME] that facilitate or make it difficult to screen patients?

b) Do you think [HEALTHCARE FACILITY NAME] has the adequate (staff) capacity to provide distress screening, referral and follow-up?
c) What are some of your best practices relating to distress screening, referral, and follow-up care)? Are they any different for the procedures for ovarian and lung cancer survivors?
d) What are your thoughts about the overall impact that distress screening has on the patient's care?
e) What types of improvements to the distress screening process at [HEALTHCARE FACILITY NAME] could be made to help sustain it for the long term?
f) What high-level support do you need to help improve processes/outcomes? [How might CDC's NCCCP be able to provide support)?

6) Context

a) Other questions specific to the facility or respondent