

Appendix G. West 1 Postbaseline Survey, Including the SCQI

Appendix G:
Week 1 Post---Baseline Survey including
Survivorship Care Quality Instrument

Week 1 post baseline survey

Please complete the survey below.

Thank you!

Assumptions

- o This is the first time survivors have visited the survivorship program
- o The impact we are examining is the visit itself and any follow up from the time of the visit to 6 months

RA: Hello, my name is X, and I'm a research assistant at the George Washington University. I'm following up with you about the study you enrolled in last week called Evaluating Cancer Survivorship Care Models. Do you have some time now to complete your one week follow up survey?

We anticipate the survey should take between 30 and 45 minutes over the phone. When you are done we will send you a \$15 gift card in appreciation for your time. Please answer each question to the best of your knowledge. Before I get started, do you have any questions?

[Introduce study] Survivorship care is a type of care that many cancer centers are developing to support patients like yourself, who have completed treatment for their cancer, but who still require cancer-related follow-up care. The questions I'm about to ask you will be about your experience during your first survivorship visit. We are defining a "survivorship visit" as the time you spent with any provider during your initial visit to help you get the care and services you need for your cancer follow-up and overall healthcare. This may include the time you spent with your doctor or nurse, a patient navigator, a financial specialist or anyone else whom you saw during your first survivorship visit.

RA: Now I'm going to ask you a series of questions about your first survivorship visit:

Date of survey completion:

(mm-dd-yyyy)

During your first survivorship visit, who did you see? (Select all that apply)

- An oncologist
- A primary care clinician/internist
- A surgeon
- A nurse practitioner
- A nurse
- A social worker/case manager
- A psychologist or psychiatrist
- Health behavior or self-management specialist
- patient navigator or nurse navigator
- A financial specialist
- Another cancer survivor
- A physical therapist/rehabilitation specialist
- nutritionist/dietitian
- An exercise trainer
- Other (please specify)

Indicate 'other' provider

Approximately how long did your entire survivorship visit last (excluding wait time and the time you

) spend completing the first survey)?

((HH:MM))

Do you currently have a primary care provider who is not your oncologist?

- Yes
- No
- Not applicable
- Don't know

Domain 1: Care coordination and transitions in care

Is the same cancer doctor who was in charge of your treatment also in charge of your care now that you are done treatment?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did your doctor or nurse seem informed and up-to-date about the care you got from other clinicians related to your cancer care?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did it appear to you that your clinician had your medical files related to your cancer care on hand?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did your clinician review the medications you are using, including medicines prescribed by other clinicians?

- Did not discuss it
 Briefly discussed it
 Discussed it with me in detail
 Not applicable
 Don't know

During your survivorship visit, did your doctor or nurse offer to arrange other doctors' visits or tests that you needed?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you have a discussion with your doctor or nurse about whether you feel ready to move your cancer care to your primary care doctor or nurse?

- Did not discuss it
 Briefly discussed it with me
 Discussed it with me in detail
 Not applicable
 Don't know

During your survivorship visit, did you receive instructions on how to move your cancer care from your cancer doctor to your primary care doctor or nurse?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

How well do you think all of your doctors have stayed informed of your health now that you are receiving survivorship services?

- Not at all
 Somewhat
 Extremely
 My cancer doctor is my survivorship doctor
 Don't know

Domain 2: Provision of Full Spectrum Care

During your survivorship visit, did you receive a complete physical exam with medical history?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During the survivorship visit, did you receive resources and/or referrals that can help you manage the symptoms related to the long and late term effects of your cancer?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During the survivorship visit, did you receive resources and/or referrals that can help you get regular exercise and/or physical activity?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you receive the resources, services, and/or referrals that can help you achieve a healthy diet and healthy eating habits?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you receive information and/or a referral to rehabilitation services, such as physical therapy, for cancer-related issues?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you and your doctor or nurse talk about specific things you could do to improve your health or prevent recurrence of cancer such as getting exercise, quitting smoking, and limiting alcohol consumption?

- Did not discuss it
 Briefly discussed it with me
 Discussed it with me in detail
 Not applicable
 Don't know

During your survivorship visit, were you referred to another doctor or specialist for any other medical problems you might be having related to your cancer?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Domain 3: Health Insurance Issues

During your survivorship visit, did you get the help you needed, such as information or a referral, to better understand your health insurance coverage for medical services?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you get the help you needed, such as information or a referral, to better understand insurance coverage options for prescription or non-prescription drugs?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you get the help you needed, such as information or a referral, to deal with insurance claims?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Domain 4: Mental Health and Social

During your survivorship visit, did you and your doctor or nurse talk about getting emotional or social support related to the impact of your cancer, its treatment and/or the lasting effects of treatment?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you and a doctor or nurse talk about getting emotional or social support to help you deal with what life is like after treatment?

- Did not discuss it
 Briefly discussed it with me
 Discussed it with me in detail
 Not applicable
 Don't know

During your survivorship visit, did you and a doctor or nurse talk about getting emotional or social support to help you deal with changes in your relationships with your spouse/partner, family, and others?

- Did not discuss it
 Briefly discussed it
 Discussed it with me in detail
 Not applicable
 Don't know

During your survivorship visit, were you referred to another doctor or specialist for any kind of emotional concerns?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Domain 5: Empowered and Engaged Patients

During your survivorship visit, did you feel included in all decisions about your cancer-related follow-up care?

- Not at all
 Slightly
 Somewhat
 Very
 Extremely
 Not applicable
 Don't know

During your survivorship visit, did your doctor or nurse ask you what your most important problems are or what you are most worried about?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did your doctor or nurse help you think about how you might solve these problems?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

(Select 'not applicable' if survivors said 'no' to last question indicating they their doctor didn't ask what was most important to them.)

During your survivorship visit, did you set goals and a short term action plan to help you manage your cancer-related follow-up care and improve your overall health?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Domain 6: Information and Resources

During your survivorship visit, did you discuss with your doctor or nurse the need for regular follow-up care and screening now that your treatment is over?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you discuss with your doctor or nurse any late or long-term side effects of cancer and your treatment that you may still be experiencing or may experience later?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did your doctor or nurse offer you a summary document that listed the treatment you received for your cancer?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did your doctor or nurse offer you a written assessment and follow-up care plan? (A care plan is a document that sets out your needs and goals for caring for your cancer after treatment has ended.)

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Domain 7: Communication with Physicians

During your survivorship visit, did your doctor or nurse give you easy to understand instructions about what to do to take care of your health now that your cancer treatment has ended?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you feel your doctor or nurse always treated you with courtesy and respect?

- Not at all
 Slightly
 Somewhat
 Very
 Extremely
 Not applicable
 Don't know

During your survivorship visit, did you feel your doctor or nurse explained the reasons for any medical tests you might need related to your follow-up care?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did you feel you had enough time to ask your questions and voice your concerns about your cancer-related follow up care?

- Not at all
 Slightly
 Somewhat
 Very
 Extremely
 Not applicable
 Don't know

During your survivorship visit, did you feel your doctor or nurse listened carefully to you about concerns you have about your health and cancer-related follow-up care?

- Not at all
 Slightly
 Somewhat
 Very
 Extremely
 Not applicable
 Don't know

Domain 8: Productive Interactions

During your survivorship visit, did someone provide you with information about who to contact if you are experiencing a medical problem or concern now or in the future?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

(*Select 'N/A' if the survivor already knew who to contact/was provided that info at an earlier date)

During your survivorship visit, did you and your doctor or nurse decide together if you should transition your care from your oncologist to your primary care doctor or nurse?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, did your doctor or nurse help you make informed choices about your cancer- related follow-up care?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

During your survivorship visit, do you feel you and your doctor or nurse shared responsibility for solving problems and setting goals related to your cancer follow-up and overall health?

- Not at all
 Slightly
 Somewhat
 Very
 Extremely
 Not applicable
 Don't know

Domain 9: Medical Home

Do you feel the survivorship services provide holistic care? In other words, your doctors and nurses treat you as a whole person looking at all of the problems you might have and not just the cancer?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Do you feel you can get advice quickly from your doctors and nurses outside of visits?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Do you feel the survivorship services include everything needed to provide complete medical care in the post-treatment phase of your cancer care?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

As far as you know, is your medical information maintained in a computerized system like an electronic health record (For example, a digital version of your paper chart that includes all of your medical history)?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Are your laboratory, other test results and medical records online for you to see?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Is there a team of doctors and nurses, such as an oncologist, patient navigator, social worker, and others, that work together to address all of your healthcare needs?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Do you feel you have a point of contact who is helping you coordinate all of your cancer-related follow-up care?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

RA: Now I'm going to ask you questions about your satisfaction with the care you received at the survivorship clinic.

Would you recommend the survivorship services to any family or friends who are survivors of cancer?

- No, definitely not
 Yes, somewhat
 Yes, definitely
 Not applicable
 Don't know

Using any number from 0 to 10, where 0 is the worst possible and 10 is the best possible, what number would you use to rate your survivorship visit?

I am very satisfied with the care I received at the survivorship visit.

- Strongly disagree
 Disagree
 Uncertain
 Agree
 Strongly agree

RA: I would like to know how confident you are in doing certain activities. For each of the following questions, I'm going to ask you to choose the number that best corresponds to your confidence that you can do the tasks regularly at the present time, with 1 being "not confident at all" and 5 being "totally confident."

(Prompt: Remind the participant of the scale extremes 1=not confident at all 5=totally confident after the first few topics and continue to do so throughout the survey as needed)

How confident are you that you can deal with physical symptoms or health problems related to the lasting effects of your cancer?

- 1 Not at all confident
 2
 3
 4
 5 Totally confident

How confident are you that you can deal with emotional distress related to the lasting effects of your cancer?

- 1 Not at all confident
 2
 3
 4
 5 Totally confident

How confident are you that you can ask for help for problems related to the lasting effects of your cancer without feeling guilty?

- 1 Not at all confident
 2
 3
 4
 5 Totally confident

How confident are you that you can handle any fears about your cancer returning?

- 1 Not at all confident
 2
 3
 4
 5 Totally confident

How confident are you that you can identify changes in your body related to a return of cancer?

- 1 Not at all confident
 2
 3
 4
 5 Totally confident

How confident are you that you can call a healthcare provider if you notice a symptom that may be related to the return of cancer?

- 1 Not at all confident
- 2
- 3
- 4
- 5 Totally confident

How confident are you that you can deal with the health care system and get the care you need when you need it?

- 1 Not at all confident
- 2
- 3
- 4
- 5 Totally confident

How confident are you that you can get the medical care you need without being set back financially?

- 1 Not at all confident
- 2
- 3
- 4
- 5 Totally confident