

Impact of Cancer Scale Tool



This tool is provided courtesy of Brad Zebrack, PhD, University of Southern California School of Social Work.

The *Impact of Cancer Scale Tool* has 82 items that cover 10 different domains of people's lives that seem to be affected by cancer. There are five positive impact subscales and five negative impact subscales.

The following citations, which provide additional information about the *Impact of Cancer Scale Tool* instrument and its development, have been provided by Dr. Zebrack:

- Zebrack BJ, Ganz PA, Bernaards CA, Petersen L, Abraham L. Assessing the impact of cancer: development of a new instrument for long-term survivors. *Psycho-Oncology*. 15(5):407-421.
- Zebrack B, Yi J, Petersen L, Ganz P. (In Press). The impact of cancer and quality of life for long-term survivors. *Psycho-Oncology*.

EMPLOYMENT

1. Are you fully retired from paid employment?

_____ 1 Yes → *go to NEXT PAGE*

_____ 2 No



2. Were you employed and earning income at some time during the last 12 months?

_____ 1 Yes _____ 2 No → *go to NEXT PAGE*



Please circle the number for each statement below that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
3. I am concerned about not being able to work if I were to become ill again.....	1	2	3	4	5
4. Concerns about losing health insurance keep me in the job I have now.....	1	2	3	4	5
5. I worry about being forced to retire or quit work before I am ready.....	1	2	3	4	5

LIFE OUTLOOK

We are interested in knowing about your personal views or perspectives on life. Given your life **as it is now**, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. Because of cancer I live each day one at a time.....	1	2	3	4	5
2. I feel grateful to be alive.....	1	2	3	4	5
3. I feel like time in my life is limited.....	1	2	3	4	5
4. I learned something about life because of having had cancer.....	1	2	3	4	5
5. Having had cancer makes me feel unsure about my future.....	1	2	3	4	5
6. I worry about my future.....	1	2	3	4	5
7. I am afraid to die.....	1	2	3	4	5
8. I can accept my mortality, that I am going to die someday.....	1	2	3	4	5
9. I feel like time in my life is running out.....	1	2	3	4	5
10. Having had cancer has made me realize that time is precious.....	1	2	3	4	5
11. Having had cancer has strengthened my religious faith or my sense of spirituality.....	1	2	3	4	5

YOUR BODY AND YOUR HEALTH

We are interested to know how having had cancer **NOW** affects your body and your health, if at all.

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I do not take my body for granted since the cancer.....	1	2	3	4	5
2. Having had cancer has made me more concerned about my health.....	1	2	3	4	5
3. I am more aware of physical problems or changes in my body since having had cancer..	1	2	3	4	5
4. Other health problems not related to cancer bother me more than having had cancer.....	1	2	3	4	5
5. I worry about my health.....	1	2	3	4	5
6. I accept the changes my body has gone through as a result of cancer and its treatment.....	1	2	3	4	5
7. I worry about the cancer coming back or about getting another cancer.....	1	2	3	4	5
8. New symptoms (aches, pains, getting sick or the flu) make me worry about the cancer coming back.....	1	2	3	4	5
9. Having had cancer makes me feel uncertain about my health.....	1	2	3	4	5
10. I am concerned that my energy has not returned to what it was before I had cancer....	1	2	3	4	5
11. I am bothered that my body cannot do what it could before having had cancer.....	1	2	3	4	5
12. I worry about how my body looks.....	1	2	3	4	5

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
13. I feel disfigured.....	1	2	3	4	5
14. I sometimes wear clothing to cover up parts of my body I don't want others to see.....	1	2	3	4	5
15. Having had cancer has made me take better care of myself (my health).....	1	2	3	4	5
16. Having to pay attention to my physical health interferes with my life.....	1	2	3	4	5
17. I am unable to think or remember things like I used to.....	1	2	3	4	5

FEELINGS ABOUT CANCER

Given your life as it is **NOW**, how do you feel about having had cancer?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I consider myself to be a cancer survivor.....	1	2	3	4	5
2. I feel a sense of pride or accomplishment from surviving cancer.....	1	2	3	4	5
3. I learned something about myself because of having had cancer.....	1	2	3	4	5
4. I am angry about having had cancer.....	1	2	3	4	5
5. I feel guilty for somehow being responsible for getting cancer.....	1	2	3	4	5
6. I feel that I am a role model to other people with cancer.....	1	2	3	4	5
7. As time goes on, having had cancer becomes less important to me.....	1	2	3	4	5
8. Having had cancer has made me feel old.....	1	2	3	4	5
9. I feel guilty today for not having been available to my family when I had cancer.....	1	2	3	4	5
10. My sense of myself as a cancer survivor has lessened over time.....	1	2	3	4	5
11. My life would be better today if I had not had cancer.....	1	2	3	4	5
12. Having had cancer has been the most difficult experience in my life.....	1	2	3	4	5

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
13. Having had cancer has not been as big a deal as other things that have happened in my life.	1	2	3	4	5
14. I view having had cancer as a private experience.....	1	2	3	4	5
15. I wish to forget about having had cancer.....	1	2	3	4	5
16. I am constantly reminded that I had cancer....	1	2	3	4	5
17. Something good has come from having had cancer.....	1	2	3	4	5
18. I think the doctors should have done a better job treating my cancer.....	1	2	3	4	5
19. Now that my treatment has ended I feel like my cancer doctors are not interested in my well-being.....	1	2	3	4	5

MEANING OF CANCER

Given your life as it is now, how much do you agree or disagree with each of these statements about cancer?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I wonder why I got cancer.....	1	2	3	4	5
2. It is important for me to know why I got cancer.....	1	2	3	4	5
3. Having had cancer turned into a reason to make changes in my life.....	1	2	3	4	5
4. Because of cancer I have become better about expressing what I want.....	1	2	3	4	5
5. Because of cancer I have more confidence in myself.....	1	2	3	4	5
6. Having had cancer has given me direction in life.....	1	2	3	4	5
7. I feel like cancer runs my life.....	1	2	3	4	5
8. Because of having had cancer I feel that I have more control of my life.....	1	2	3	4	5
9. I have financial problems that are related to having had cancer.....	1	2	3	4	5
10. Within the past year I have had difficulty getting my health insurance to pay some of my medical bills.....	1	2	3	4	5

ACTIVITIES AND RELATIONSHIPS

This section includes questions about your social activities and about important relationships in your life.

Given your life as it is now, how much do you agree or disagree with each of the following statements? (*Circle the number for each statement that best describes how much you agree or disagree with the statement.*)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I place a higher value on my relationships with family or friends than I did before having had cancer.....	1	2	3	4	5
2. I feel a special bond with people with cancer..	1	2	3	4	5
3. Because I had cancer I am more understanding of what other people may feel when they are seriously ill.....	1	2	3	4	5
4. Having had cancer has made me more willing to help others.....	1	2	3	4	5
5. I feel that I should give something back to others because I survived cancer.....	1	2	3	4	5
6. I worry about friends dying from cancer.....	1	2	3	4	5
7. Having had cancer has made me feel alone...	1	2	3	4	5
8. Having had cancer has made me feel like some people (friends, family, co-workers) do not understand me.....	1	2	3	4	5
9. I am concerned about my children getting cancer.....	1	2	3	4	5
10. Uncertainty about my future affects my decisions to make plans (examples: work, recreation/travel, get married, get involved in relationships, have a family, go to school).....	1	2	3	4	5
11. Having had cancer has motivated me to make plans for dying (get my affairs in order).....	1	2	3	4	5

Circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
12. Having had cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family).....	1	2	3	4	5
13. On-going cancer-related or treatment-related symptoms (for example bladder or bowel control, lymphedema, hair loss, scars, infertility, premature menopause, lack of energy, impotence/sexual problems, aches, pain or physical discomfort) interfere with my life.....	1	2	3	4	5

14. Are you currently married, living together as married, or in a significant relationship?

_____ 1 Yes → go to **QUESTION 19 on NEXT PAGE**

_____ 2 No



Given your life as it is now, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
15. Uncertainties about my health or my future have made me delay getting married or getting involved in a serious relationship.....	1	2	3	4	5
16. I wonder how to tell a potential spouse, partner, boyfriend, or girlfriend that I have had cancer.....	1	2	3	4	5
17. I am concerned about how to tell a spouse, partner, boyfriend, or girlfriend that I may not be able to have children.....	1	2	3	4	5
18. I worry about not having a spouse, partner, boyfriend, or girlfriend.....	1	2	3	4	5

STOP HERE

Please answer the following questions ONLY if you are **currently married, living together as married, or in a significant relationship. Otherwise, please stop.**

Given your life as it is now, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
19. I am open and willing to discuss my cancer with my spouse/partner.....	1	2	3	4	5
20. My spouse/partner is open and willing to discuss my cancer with me.....	1	2	3	4	5
21. Uncertainty about my health has created problems in my relationship with my spouse/partner.....	1	2	3	4	5
22. I worry about my spouse/partner leaving me if I were to become ill again.....	1	2	3	4	5

Impact of Cancer Version 1 (IOC) Scoring Instructions

Last updated 2/5/08

The Impact of Cancer Version 1 (IOC) is an instrument assessing quality of life and other aspects of long-term cancer survivorship. Development of the IOC is described in:

Brad J. Zebrack, Patricia A. Ganz, Coen A. Bernaards, Laura Petersen, Laura Abraham. Assessing the Impact of Cancer: Development of a new instrument for long-term survivors. Psycho-Oncology 2006; 15(5): 407-421.

The IOC uses 41 items taken from a longer 81-item questionnaire, which is also described in Zebrack et al. (2006). The 41 items form 10 subscales and two higher order scales, one positive and one negative. A list of the 41 items, along with item numbers matching those in the paper, can be found at the end of this document.

A respondent indicates his or her agreement with each item on a 5-point scale where 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree and 5 = strongly agree. Each subscale is computed by taking the mean of the responses for items in the subscale. A higher score on a subscale means stronger endorsement of that content area. In order to score any subscale, at least half of the items comprising the subscale should be non-missing; otherwise the subscale should be scored as missing. The higher order positive and negative scales are scored as the mean of subscale scores comprising the scale.

How to score the 10 IOC subscales:

Physical: Health Awareness (4 items)
Mean of ioc15, ioc16, ioc17, ioc29

Physical: Body Changes (5 items)
Mean of ioc24, ioc25, ioc26, ioc27, ioc28

Psychological: Positive Self-Evaluation (8 items)
Mean of ioc33, ioc34, ioc37, ioc54, ioc55, ioc63, ioc64, ioc65

Psychological: Negative Self-Evaluation (4 items)
Mean of ioc35, ioc36, ioc39, ioc40

Existential: Positive Outlook (3 items)
Mean of ioc07, ioc13, ioc14

Existential: Negative Outlook (4 items)
Mean of ioc08, ioc09, ioc10, ioc12

Social: Life Interferences (3 items)
Mean of ioc30, ioc72, ioc73

Social: Value of Relationships (2 items)
Mean of ioc61, ioc62

Meaning of Cancer (5 items)
Mean of ioc43, ioc51, ioc52, ioc53, ioc56

Health Worry (3 items)
Mean of ioc19, ioc21, ioc22

How to score the two higher order positive and negative scales:

Higher Order Positive Scale

Mean of subscales Physical: Health Awareness, Psychological: Positive Self-Evaluation, Existential: Positive Outlook, Social: Value of Relationships, Meaning of Cancer

Higher Order Negative Scale

Mean of subscales Physical: Body Changes, Psychological: Negative Self-Evaluation, Existential: Negative Outlook, Social: Life Interferences, Health Worry

Item Descriptions (for the 41 items included in the subscales; item numbers reference Zebrack et al. (2006))

ioc07 I learned something about life because of having had cancer
ioc08 Having had cancer makes me feel unsure about my future
ioc09 I worry about my future
ioc10 I am afraid to die
ioc12 I feel like time in my life is running out
ioc13 Having had cancer has made me realize that time is precious
ioc14 Having had cancer has strengthened my religious faith or my sense of spirituality
ioc15 I do not take my body for granted since the cancer
ioc16 Having had cancer has made me more concerned about my health
ioc17 I am more aware of physical problems or changes in my body since having had cancer
ioc19 I worry about my health
ioc21 I worry about the cancer coming back or about getting another cancer
ioc22 New symptoms make me worry about the cancer coming back
ioc24 I am concerned that my energy has not returned to what it was before I had cancer
ioc25 I am bothered that my body cannot do what it could before having had cancer
ioc26 I worry about how my body looks
ioc27 I feel disfigured
ioc28 I sometimes wear clothing to cover up parts of my body I do not want others to see
ioc29 Having had cancer has made me take better care of myself (my health)
ioc30 Having to pay attention to my physical health interferes with my life
ioc33 I feel a sense of pride or accomplishment from surviving cancer
ioc34 I learned something about myself because of having had cancer
ioc35 I am angry about having had cancer
ioc36 I feel guilty for somehow being responsible for getting cancer
ioc37 I feel that I am a role model to other people with cancer
ioc38 As time goes on, having had cancer becomes less important to me
ioc39 Having had cancer has made me feel old
ioc40 I feel guilty today for not having been available to my family when I had cancer
ioc43 Having had cancer has been the most difficult experience in my life
ioc51 I wonder why I got cancer
ioc52 It is important for me to know why I got cancer
ioc53 Having had cancer turned into a reason to make changes in my life
ioc54 Because of cancer I have become better about expressing what I want
ioc55 Because of cancer I have more confidence in myself
ioc56 Having had cancer has given me direction in life
ioc61 I place a higher value on my relationships with family or friends than I did before having had cancer
ioc62 I feel a special bond with people with cancer
ioc63 Because I had cancer I am more understanding of what other people may feel when they are seriously ill
ioc64 Having had cancer has made me more willing to help others
ioc65 I feel that I should give something back to others because I survived cancer
ioc72 Having had cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family)
ioc73 On-going cancer-related or treatment-related symptoms interfere with my life