Long-Term Follow-Up Study

University of Minnesota The Denver Children's Hospital Children's Hospital of Pittsburgh Children's Hospital at Stanford University Dana-Farber Cancer Institute Children's National Medical Center U.T.M.D. Anderson Cancer Center Memorial Sloan Kettering Cancer Center Texas Children's Hospital University of California at San Francisco Seattle Children's Hospital & Medical Center Toronto Hospital for Sick Children St. Jude Children's Research Hospital Children's Hospital of Columbus Roswell Park Cancer Institute Mayo Clinic Children's Health Care - Minneapolis Children's Hospital of Philadelphia St. Louis Children's Hospital Children's Hospital of Los Angeles UCLA Medical Center Miller Children's Hospital Children's Hospital of Orange County Riley Hospital for Children-Indiana University UAB/The Children's Hospital of Alabama University of Michigan-Mott Children's Hospital Children's Medical Center of Dallas

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WOMAN'S EMOTIONAL WELL-BEING INTIMACY SURVEY

As part of the Long-Term Follow-up Study, we are asking for your help to better understand the impact of cancer or similar diseases and their treatment on emotional well-being and sexual functioning. In a survey we sent you previously, you agreed to consider participating in a study about this subject matter. Participation in this aspect of the study involves answering a series of questions that will take approximately 30 minutes to complete.

Previous research studies suggest that some women cope well after treatment for cancer or similar illnesses during childhood and adolescence, while others experience difficulties in their psychosexual adjustment. We hope to be able to more accurately describe the issues adult females face. This information will help us better understand the needs of individuals previously treated for cancer or similar illnesses, as well as future patients with these diseases.

Some of the information requested in the questionnaire is of a personal nature. You are free to leave blank any question you are uncomfortable answering. As with all other aspects of your participation in the Long-Term Follow Up Study, information will be kept strictly confidential.

Your help in this very important project is greatly appreciated. If you have any questions or concerns, please call the Long-Term Follow-up Study office at the University of Minnesota at 1-800-775-2167

Today's date:		
	(Month/dav/year)	

02575

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use the No. 2 pencil enclosed (Please do not use pen).

2. Completely darken your answers, that is, fill in the full circle.

CORRECT ♠ ® ⓒ ■ INCORRECT ※ ♥ • •

3. Make no stray marks of any kind. Other than your responses, please keep the form as clean as possible. Erase

Instructions: The first section of questions asks about your views of your current health and overall well-being. This information will help us to better understand how you feel and how well you are able to do your usual activities. Answer each question by marking the response that most closely fits your situation. Please read the instructions and items carefully. If you are unsure about how to answer a question, please give the best answer you can.

cleanly any answer you wish to change. Do not use "white-out".

A .1	In general, would you say your health is: (Mark one) ① Excellent	A.4 During the <u>past 4 weeks</u> , have you had any of the following problems with your work or other regular
	② Very good	daily activities as a result of your physical health?
	③ Good	(Mark one number on each line)
	④ Fair	No —
	⑤ Poor	Yes —
		a. Cut down on the amount of time you spent
		on work or other acitivities ① ②
A.2	Compared to one year ago, how would you rate your	
	health in general now? (Mark one)	b. Accomplished less than you would like ① ②
	Much better now than one year ago	,
	② Somewhat better now than one year ago	c. Were limited in the kind of work or other
	3 About the same as one year ago	activities ①②
	Somewhat worse now than one year ago	activities
	Much worse now than one year ago	d. Had difficulty performing the work or other
	Widen worde new than one year ago	
		activities (for example, it took extra effort) ① ②
A.3	The following items are about activities you might do	
	during a typical day. Does your health now limit you	A.5 During the past 4 weeks, have you had any of the
	in these activities? If so, how much? (Mark one number	following problems with your work or other regular
	on each line)	daily activities as a result of any emotional problems
	No, Not Limited At All	(such as feeling depressed or anxious)?
	Yes, Limited A Little	(Mark one number on each line)
	Yes, Limited A Lott	No ——
	ACTIVITIES Tes, Elimited A Lot	Yes —
	a. Vigorous activities, such as running, lifting	a. Cut down on the amount of time you spent
	heavy objects, participating in strenuous	on work or other activities ①②
	sports ① ② ③	b. Accomplished less than you would like ① ②
	b. Moderate activities, such as moving a	c. Didn't do work or other activities as
	table, pushing a vacuum cleaner, bowling	carefully as usual 12
	or playing golf ① ② ③	
	c. Lifting or carrying groceries 123	
	d. Climbing several flights of stairs ① ② ③	A.6 During the past 4 weeks, to what extent has your
	e. Climbing one flight of stairs ① ② ③	physical health or emotional problems interfered with
	f. Bending, kneeling, or stooping ①②③	your normal social activities with family, friends,
	g. Walking more than a mile	neighbors, or groups? (Mark one)
	h. Walking several blocks ① ② ③	① Not at all
	i. Walking one block	② Slightly
	j. Bathing or dressing yourself ① ② ③	3 Moderately
	jg or arooting yourself thin the time to the	Quite a bit
		5 Extremely

A .7	How much <u>bodily</u> pain have you had during the <u>past</u> 4 weeks? (Mark one)	A.10 How TRUE or FALSE is each of the following statements for you? (Mark one number on each line)
	1 None	
	Very mild	Definitely False —
	3 Mild	
	Name of the state	Mostly False —
	Moderate One of the control	Don't Know
	§ Severe	Mostly True —
	Very severe	Definitely True
A.8	During the past 4 weeks, how much did pain interfere	a. I seem to get sick a little easier than
	with your normal work (including both work outside the home and housework)? (Mark one)	other people 12345
	1) Not at all	b. I am as healthy as anybody I know ① ② ③ ④ ⑤
	② A little bit	b. Tallias licality as anybody i know 0 0 0 0
	Moderately	1000
	Quite a bit	c. I expect my health to get worse ① ② ③ ④ ⑤
	1000	
	(5) Extremely	d. My health is excellent ① ② ③ ④ ⑤
A.9	These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u> . For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u> - (Mark one number on each line)	Instructions: In this next section, we will ask you to focus on some physical symptoms that some cancer survivors may experience. Because we are surveying a broad range of individuals who received a variety of medical treatments, some of the issues may apply to you whereas others will
	None of the Time ——	not.
	A Little of the Time	We are interested in knowing the extent to which you have
	Some of the Time	been bothered by any of the following problems DURING
		THE PAST FOUR WEEKS. For each physical symptom
	A Good Bit of the Time	listed below, please mark the appropriate number on each
	Most of the Time	line, using the scale below.
	All of the Time	into, doing the bodie bolow.
	a. Did you feel full of pep?	
	a. Did you leef fall of pep!	No, Not At All
		No, Not Much
	b. Have you felt very nervous? 1 2 3 4 5 6	Yes, Sometimes —
		During the past Yes, Definitely —
	c. Have you felt so down in the dumps	four weeks
	that nothing could cheer you up? ① ② ③ ④ ⑤ ⑥	B.1 I wake early then sleep badly for the
		rest of the night ①②③④
	d. Have you felt calm and peaceful? 1 2 3 4 5 6	
		B.2 I get very frightened or panic feelings
	e. Did you have a lot of energy? ① ② ③ ④ ⑤ ⑥	for apparently no reason at all 1234
	f. Harris constant alexander of the	2000
	f. Have you felt downhearted	B.3 I feel miserable and sad 1234
	and blue? ① ② ③ ④ ⑤ ⑥	
		B.4 I feel anxious when I go out of the house
	g. Did you feel worn out?	on my own ① ② ③ ④
	h. Have you been happy? ① ② ③ ④ ⑤ ⑥	B.5 I have lost interest in things ① ② ③ ④
	i. Did you feel tired?	B.6 I get palpitations or a sensation of
	g	"butterflies" in my stomach or chest 1234
		butternies in my storiator of thest
		B.7 I still enjoy the things I used to 1234
		2000
		B.8 I feel life is not worth living 1 2 3 4

B.11 I am restless and can't keep still ① ② ③ ④

No, Not At All

No, Not Much

Yes, Sometimes

Yes, Definitely

During the past four weeks ...

B.12	I am more irritable than usual ① ② ③ ④
B.13	I worry about growing old ① ② ③ ④
B.14	I have headaches ① ② ③ ④
B.15	I feel more tired than usual ① ② ③ ④
B.16	I have dizzy spells
B.17	My breasts feel tender or uncomfortable ① ② ③ ④
B.18	I suffer from backache or pains in my limbs
B.19	I have hot flashes
B.20	I am more clumsy than usual
B.21	I feel rather lively and excitable 1234
B.22	I have abdominal cramps or discomfort ① ② ③ ④
B.23	I feel sick or nauseated ① ② ③ ④
B.24	I have lost interest in sexual activity ① ② ③ ④
B.25	I have feelings of well-being
B.26	I have heavy periods 1 2 3 4
B.27	I suffer from night sweats ①②③④
B.28	My stomach feels bloated ① ② ③ ④
B.29	I have difficulty in getting off to sleep ① ② ③ ④
B.30	I often notice pins and needles in my hands and feet
B.31	l am satisfied with my current sexual relationship (please omit if not sexually active)
B.32	I feel physically attractive ①②③④
B.33	I have difficulty concentrating ①②③④
B.34	As a result of vaginal dryness, sexual intercourse has become uncomfortable (please omit if not sexually active)

No. Not At All —	
NO, NOLALAII	
No, Not Much	
Yes, Sometimes ——	
Yes, Definitely ——	

Durin	ıg tl	ne p	ast
four v	wee	ks .	

	Tour moone
B.35	I need to pass urine/water more frequently than usual
B.36	My memory is poor 1 2 3 4
B.37	Is it very difficult for you to cope with any of the above symptoms? 1 Yes (If so, which ones? Please specify below.) 2 No

 Very Descriptive

 Moderately Descriptive

 Not at all Descriptive
 0 1 2 3 4 5 6

 C.2 Uninhibited
 0 1 2 3 4 5 6

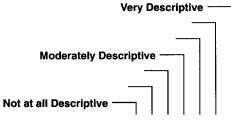
 C.3 Cautious
 0 1 2 3 4 5 6

 C.4 Helpful
 0 1 2 3 4 5 6

 C.5 Loving
 0 1 2 3 4 5 6

 C.6 Open-minded
 0 1 2 3 4 5 6

 C.7 Shallow
 0 1 2 3 4 5 6



	Not at all Descriptive —
C.8	Timid 0 1 2 3 4 5 6
C.9	Frank 0 1 2 3 4 5 6
C.10	Clean-cut 0 1 2 3 4 5 6
C.11	Stimulating 0 1 2 3 4 5 6
C.12	Unpleasant 0 1 2 3 4 5 6
C.13	Experienced
C.14	Short-tempered ① ① ② ③ ④ ⑤ ⑥
C.15	Irresponsible ① ① ① ② ③ ④ ⑤ ⑥
C.16	Direct ① ① ② ③ ④ ⑤ ⑥
C.17	Logical ① ① ② ③ ④ ⑤ ⑥
C.18	Broad-minded ① ① ② ③ ④ ⑤ ⑥
C.19	Kind 0 1 2 3 4 5 6
C.20	Arousable ① ① ② ③ ④ ⑤ ⑥
C.21	Practical 0 1 2 3 4 5 6
C.22	Self-conscious 0 1 2 3 4 5 6
C.23	Dull ① ① ② ③ ④ ⑤ ⑥
C.24	Straight forward ① ① ② ③ ④ ⑤ ⑥
C.25	Casual 0 1 2 3 4 5 6
C.26	Disagreeable
C.27	Serious 0 1 2 3 4 5 6
C.28	Prudent
C.29	Humorous 0 1 2 3 4 5 6
C.30	Sensible 0 1 2 3 4 5 6
C.31	Embarrassed ① ① ② ③ ④ ⑤ ⑥
C.32	Outspoken 0 1 2 3 4 5 6
C.33	Level-headed (0 (1) (2) (3) (4) (5) (6)
C.34	Responsible 0 1 2 3 4 5 6

Very Descriptive —	٦
Moderately Descriptive —	
Not at all Descriptive —	

C.35	Romantic	0123456
C.36	Polite	0123456
C.37	Sympathetic	0 1 2 3 4 5 6
C.38	Conservative	0 1 2 3 4 5 6
C.39	Passionate	0 1 2 3 4 5 6
C.40	Wise	0 1 2 3 4 5 6
C.41	Inexperienced	0 1 2 3 4 5 6
C.42	Stingy	0 1 2 3 4 5 6
C.43	Superficial	0 1 2 3 4 5 6
C.44	Warm	0 1 2 3 4 5 6
C.45	Unromantic	0123456
C.46	Good-natured	0 1 2 3 4 5 6
C.47	Rude	0 1 2 3 4 5 6
C.48	Revealing	0 1 2 3 4 5 6
C.49	Bossy	0 1 2 3 4 5 6
C.50	Feeling	0123456

Instructions: The next section covers material that is sensitive and personal. These questions are very important in understanding how medical treatment affects one's body and sexuality. If you are unable or do not wish to answer any question, you may leave it blank and go on to the next. Some questions ask about your experience, thoughts and feelings, while others ask about how treatment has affected your intimate relationships. Please answer each question honestly and accurately. Be assured that your responses will be kept completely confidential. Answer the following questions by choosing the most appropriate response for the past month.

D.1 Do you currently have a sex partner?

- 1) Yes
- 2 No

D.2 Have you been sexually active during the past month?

- 1 Yes (Go to Question D.4)
- 2 No (Go to Question D.3)

	I am too tired. I am not interested.	in the past month. (By arousal, we mean the physical and emotional responses in your body and mind that tell you that you are feeling sexually excited):
	I have a physical problem that makes sexual relations difficult or uncomfortable.	and you are recoming containly exercisely.
	My partner is not interested.	More than once a day ——
	My partner is too tired.	Once a day ——
	My partner has a physical problem that makes sexual	2 or 3 times per week ——
	relations difficult or uncomfortable	Once a week —
	7 I do not have a partner as this time.	2 or 3 times —
	Other (please describe)	Once
	W	Not at all —
		a. Dreams or fantasy
D.4	During the past month, how frequently have you had	b. Masturbation
	sexual thoughts, fantasies, or erotic dreams?	c. Touching, hugging, holding,
	(Please mark the most appropriate response.)	kissing 0 1 2 3 4 5 6
	Not at all	d. Petting and foreplay 0 1 2 3 4 5 6
	① Once	e. Vaginal intercourse 0 1 2 3 4 5 6
	② 2 or 3 times	f. Other sexual activity 0 1 2 3 4 5 6
	③ Once a week	(please specify below):
	4 2 or 3 times per week	
	⑤ Once a day	
	More than once a day	
D.5	Using the scale below, indicate how frequently you have felt an interest or desire to engage in the following specific activities in the past month. (This question is about your thoughts, desires or wishes, not about how you feel during sexual activity.) (For each item, please mark one number that is closest to your experience):	D.7 Using the scale below, indicate how frequently have you engaged in the following sexual activity in the past month. More than once a day —— Once a day ——
		2 or 3 times per week ——
	More than once a day —	Once a week —
	Once a day	2 or 3 times ——
	2 or 3 times per week ——————————————————————————————————	Once ——
	2 or 3 times —	Not at all ——
	Once —	
	Not at all	a. Dreams or fantasy
	NOC 411 4 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	b. Masturbation
	a. Dreams or fantasy	c. Touching, hugging, holding,
	b. Masturbation	kissing 0 1 2 3 4 5 6
	c. Touching, hugging, holding,	d. Petting and foreplay 0 1 2 3 4 5 6
	kissing 0123456	e. Masturbation with a partner 0 1 2 3 4 5 6
	d. Petting and foreplay 0 1 2 3 4 5 6	f. Vaginal intercourse 0 1 2 3 4 5 6
	e. Vaginal intercourse 0 1 2 3 4 5 6	g Other sexual activity 0 1 2 3 4 5 6
	f. Other sexual activity ① ① ② ③ ④ ⑤ ⑥	(please specify below):
	(please specify below):	
		D.8 During the past month, who has usually initiated sexual activity? (Please mark the most appropriate response.)
		① I do not have a partner (Go to Question D.24)
		I have not had sex with a partner during the past month
		② I usually have initiated activity
		My partner and I have equally initiated activity
		My partner usually has initiated activity
		The state of the s

D.6 Using the scale below, indicate how frequently you

have become aroused by the following sexual activity

D.3 I am not sexually active because: (Mark all that apply)

(i) I have never been sexually active.

D.9	During the past month, how have you usually responded to your partner's sexual advances? (Please mark the most appropriate response.) 1 No sexual advances during the past month 2 Usually refused 3 Sometimes refused 4 Accepted reluctantly 5 Accepted, but not necessarily with pleasure		Usually, about 75% of the time Sometimes, about 50% of the time Seldom, less than 25% of the time Not at all i. Sharp pain inside or outside your
D 10	Usually accepted with pleasure Always accepted with pleasure		vagina
D.10	During the past month, have you felt pleasure from any sexual activity? 1 I have had no sexual activity in the past month 2 I have not felt any pleasure 3 Seldom, less than 25% of the time 4 Sometimes, about 50% of the time		(please specify below):
	Usually, about 75% of the time Always felt pleasure	D.14	Do you use vaginal lubricant? ① No ① Yes, sometimes ② Yes, almost always
D.11	During the past month, has the frequency of your sexual activity with a partner been: (Please mark the most appropriate response.) 1 Less than I desired 2 As much as I desired 3 More than I desired	D.15	Using the scale below, indicate the frequency with which the following factors have influenced your level of sexual activity during the past month.
			Usually, about 75% of the time
			Sometimes, about 50% of the time
D.12	In the past month, how often have you reached orgasm (climax) during sexual activity?		Seldom, less than 25% of the time——
	I have had no sexual activity in the last month.		Not at all
	② I have not experienced orgasm.		I have not had a partner
	3 Seldom, less than 25% of the time.		a. My own health problems (for
	Sometimes, about 50% of the time.		example, infection, illness) 12345
	5 Usually, about 75% of the time.		b. My partner's health problems 0 1 2 3 4 5
	I always experienced orgasm.		c. Conflict in the relationship 0 1 2 3 4 5
			d. Lack of privacy
D.13	How frequently in the past month have you had the problems listed below?		e. Other (please specify below): 0 1 2 3 4 5
	Always		<u></u>
	Usually, about 75% of the time ——		
	Sometimes, about 50% of the time——	D.16	During the past month, how frequently have you

Seldom, less than 25% of the time-

e. Difficulty reaching orgasm..... ① ② ③ ④ ⑤ g. Painful penetration or intercourse ① ② ③ ④ ⑤

a. Lack of wetness in your vagina as

become wet and slippery as you

h. Vaginal bleeding or irritation after

b. A long time for your vagina to

Not at all -

(0) (1) (2) (3) (4) (5) tly have you been able to communicate your sexual desires or preferences to your partner? (Please mark the most appropriate response.) ① I have been unable to communicate my desires or preferences 1 Seldom, about 25% of the time 2 Sometimes, about 50% of the time

4 I was always able to communicate my desires or

3 Usually, about 75% of the time

preferences

D.17	Overall, how satisfied have you been with your sexual relationship with your partner? (Please mark the most appropriate response.)	D.24 Overall, how in sexual activity response.)
	Very satisfied Somewhat satisfied	Not at all implementation Somewhat up
	Neither satisfied nor dissatisfied	Neither impo
	Somewhat dissatisfied	3 Somewhat ii
	Very dissatisfied	Very importa
		D.25 Mark the number
D.18	Overall, how satisfied do you think your partner	that best descr
	has been with your sexual relationship? (Please	① Entirely hete
	mark the most appropriate response.)	2 Largely hete
	1 Very satisfied	experience
	② Somewhat satisfied	③ Largely hete
	Neither satisfied nor dissatisfied	experience
	Somewhat dissatisfied Norw dissatisfied	4 Equally hete
	Very dissatisfied	5 Largely hom experience
		Experience Largely hom
D 19	Please rate how satisfied you have been with your	experience
D. 10	ability to share warmth and intimacy in the past month	7 Entirely hom
	by marking the number from 0 - 10 (0 = not at all	Entiroly Non
	satisfied, 10 = extremely satisfied).	
		Thank you for comp
	Not at all 0 1 2 3 4 6 6 7 8 9 19 Extremely	responses will be ke comments that you your experiences o
_		questionnaire, plea
D.20	Please rate how comfortable you have been with touching, hugging or holding your partner in the past month by marking the number from $0 - 10$ ($0 = not$ at	or on a separate pi
	all satisfied, 10 = extremely satisfied).	
		Use this space for a
	Not at all 0 1 2 3 4 5 6 7 8 9 19 Extremely	
D.21	How satisfied are you with the overall appearance	
	of your body? (Please mark the most appropriate response.)	
	① Very satisfied	
	② Somewhat satisfied	
	Neither satisfied nor dissatisfied	
	Somewhat dissatisfied Very dissatisfied	
D.22	Please rate how interested you have been in sexual	
	thoughts, feelings, or actions in the past month by	
	marking the number from 0 - 10 ($0 = not$ at all interested, $10 = extremely$ interested).	
	Not at all 0 1 2 3 4 5 6 7 8 9 10 Extremely	After completing t using the en
D 33	Please rate the extent to which sexual activity has	Long-
<u>ال</u>	been satisfying for you in the past month by marking	Dep
	the number from $0 - 10$ ($0 = not$ at all satisfying,	Uni
	10 = extremely satisfying).	420 De
		l Mir

nportant a part of your life is your ? (Please mark the most appropriate

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er that corresponds to the statement ribes your sexual experience.

erosexual

erosexual, but some homosexual

erosexual, but considerable homosexual

erosexual and homosexual

nosexual, but considerable heterosexual

nosexual, but some heterosexual

nosexual

pleting this questionnaire. All your ept strictly confidential. If you have any would like to share with us regarding or additional responses to this se feel free to write them on this page ece of paper.

Use this space for any additional comments you may have.		

this questionnaire, please return by closed envelope, and mail to:

> Term Follow-Up Study artment of Pediatrics iversity of Minnesota laware St. SE, MMC 715 Minneapolis, MN 55455

Again, thank you for your help and your participation in this study!

Extremely

Satisfying

Not at all 0 1 2 3 4 5 6 7 8 9 10