SJLIFE

Women's Health Questionnaire

The following questionnaire addresses personal subject matter on topics including fertility, puberty, and sexual health/functioning. These important quality of life issues have not been well studied among survivors of childhood cancer. By completing this questionnaire, you will help us better understand these issues which could one day lead to improved prevention and treatment options.

All adult SJLIFE participants are being asked to complete this questionnaire. Be assured that your participation is voluntary and you may choose to answer all, some, or none of the questionnaire items. Your responses will be kept confidential so please do not put <u>any</u> identifying information (like name, age, or date of birth) on this questionnaire. Once completed, please seal the questionnaire in the attached envelope and drop it off in the questionnaire box in the SJLIFE clinic. Thank you in advance for your participation.

Today's date:		/		/				
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INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

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 a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging. If you must erase answers, erase them completely.
- 2. When marking boxes, make an x inside the box.
- 3. Make no stray marks of any kind. Please keep the form as clean as possible.
- 4. Written responses must stay within the boxes provided.
- 5. Once you have completed the questionnaire, please place it in the attached envelope and drop it off in the SJLIFE questionnaire box in clinic.

ESTROGEN THERAPY

Estrogen is the female hormone made by the ovaries. It can be given to patients to start puberty (puberty is defined as the physical changes that allow a girl's body to change into a woman's body) or can be used in older females who have low blood levels of estrogen. Estrogen can also be used with other female hormones as a form of birth control.

A 1.	Have you ever been treated with estrogen?
	□Yes
	□ No Go to Question B1, next page.
	☐ I don't know
A2.	Were you treated with estrogen therapy <u>during puberty</u> (puberty in girls is typically around ages 10-11 and leads to increase in size of breasts and development of pubic hair)?
	□Yes
	□No
	☐ I don't know
A3.	Were you treated with estrogen to prevent signs and symptoms of menopause (hot flashes, vaginal dryness, bone loss and/or decreased sex drive)?
	□Yes
	□No
	☐ I don't know
A4.	Were you treated with estrogen or other hormones to prevent pregnancy?
	□Yes
	□No
	☐ I don't know
A5.	Was your treatment with estrogen
	□ continuous
	☐ interrupted (stopped and started again)

A6. How many <u>years</u> (in total) have you been on estrogen? Do not count years in which your estrogen therapy was stopped.				
Years				
A7. Are you <u>currently</u> on e	strogen?			
☐ Yes				
□No				
A8. How have you received (Mark all that apply)	l estrogen treatments?			
☐ Injections (shots)	☐ Skin patch			
☐ Pills	☐ Vaginal ring			
☐ Gel/Cream				
A9. At what age did you sta	art estrogen?			
Age in years				
A10. If you took estrogen a at what age did you la	nd it was discontinued, st <u>stop</u> taking estrogen?			
Age in years				
A11. If you stopped taking you stop? (Mark all th				
☐ I stopped the medicir taking it				
☐ My doctor told me to	stop			
	scription for the medicine			
☐ Other reason If Other reason, explain				
ii Other reason, explain	•			

BODY IMAGE

On this scale you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and mark the response which comes closest to the way you have been feeling about yourself during the past week.

During the past week 31. Have you been feeling self-consciou about your appearance?	A Not at all S	uite a	a bit	
about your appearance?	Not at all <u>S</u>	little		
about your appearance?	<u>s</u>			
about your appearance?				
as a result of your disease or treatme				
 Have you been <u>dissatisfied</u> with your appearance when dressed? 				
 Have you been feeling <u>less</u> feminine a result of your disease or treatment 				
 Have you been finding it <u>difficult</u> to loat yourself naked?				
36. Have you been feeling less sexually attractive as a result of your disease treatment?	or			
37. Have you been <u>avoiding</u> people beca of the way you felt about your appearance?				
88. Have you been feeling the treatment left your body less whole?				
39. Have you felt <u>dissatisfied</u> with your b	ody? □			
310. Have you been <u>dissatisfied</u> with the appearance of a scar(s)?	🗖			
311. At the present time, do you have any of the following?		No	Ye 	s
Persistent hair loss]
Scarring or disfigurement of the hear or neck region (including the face)]
Scarring or disfigurement of the chest or abdominal region]
Scarring or disfigurement of the arm or legs (including an abnormally sho arm or leg)	rt			1
Walk with a limp		_		
Loss of an arm or a leg	· · · · · ·]
Loss of an eye				
Other]

PERCEPTIONS

It is common for people to have different ideas about their own chances of experiencing certain medical problems. Please answer the next few questions by marking the answer that best describes your own opinions.

C1. Mark the response that best describes your risk compared to other women your age never diagnosed with cancer or a disease like cancer.

	Much more					ore	
	Slightly more						
	About the sam						
	Slig	htly	less				
	Much	less					
a. Infertility							
b. Sexual dysfunction							
c. Low estrogen levels							

If you answered <u>Slightly more</u> or <u>Much more</u> to any of the medical problems listed above, continue with the next question. Otherwise, skip to Question D1, next page.

C2. If you think you have increased risk (you answered <u>Slightly more</u> or <u>Much more</u> in Question D1) for having infertility, sexual dysfunction, or low estrogen due to cancer or a similar illness, please mark the reasons from the choices below. If you do not feel that you are at increased risk for a medical problem, mark "Not applicable".

I think I am at increased risk because of . . . (Mark all that apply)

The kind of surgery I needed for my cancer or similar illness						
The kind of radiation I received						
The kind of chemotherapy I received						
The type of cancer or an illness like cancer that I had						
Not applicable						
a. Infertility						
b. Sexual dysfunction						
c. Low estrogen levels						

C3. If you consider yourself at risk for infertility, sexual dysfunction, and/or low estrogen, how did you learn of your increased risk?

(Mark all that apply)

	Another way							
	Information you found on the internet							
	Printed information							
	Your gynecologist							
	Your general practit	ioner	/inte	rnist				
	Yo	ur fa	mily					
	Your oncolo	gist						
	Not applicable							
a. Infertility								
b. Sexual c	dysfunction 🗖							
c. Low estr	rogen levels							
If anothe	er way, please specify	·.						

C4. If told by a healthcare professional about potential problems with fertility, sexual functioning, and/or low estrogen, when did you receive the information? (Mark all that apply)

	After treatment in another setting						
After treatment in a long-term follow-up program/ cancer survivor program							
	After treatment, by your oncologist						
At the time of treatment							
At the time of diagnosis							
		Not applicable					
a. Infe	rtili	ty □					
b. Sex	ual	${\it dysfunction.} \ldots \ldots \square$					
c. Low estrogen levels □							
If in	If in another setting, please specify.						

RELATIONSHIP/MARITAL SATISFACTION SCALE

D1. Are you <u>currently</u> married or in a significant relationship?					T
☐ Yes					p
□ No →	Go to	Question E1.			F
Please mark the answers that iter			em	which best	I
D2. How well do	es yo	our partner m	eet <u>y</u>	your needs?	
1	2	3	4	5	
Poorly		Average		Extremely well	'
D3. In general, h		atisfied are y	ou v	vith your	
1	2	3	4	5	
		. 🗆			١.
Unsatisfied		Average		Extremely satisfied	'
D4. How good is	your	relationship	con	npared to most?	
<u>1</u>	2	3_	4	5_	
Poor		Average		Excellent	
D5. How often d relationship	-	ı wish you ha	dn't	gotten into this	1
<u>1</u>	2	3_	4	<u>5</u>	
 	Ш	. 🗆	Ц	□	
Never		Average		Very often	
D6. To what exte			onsh	nip met your	l
<u>1</u>	2	3_	4	5_	
		. 🗆			
Hardly at all		Average		Completely	
D7. How much o	lo you	u love your pa	artn 4	er? 5	
	Ĺ	, ,	T I	ū	
Not much	_	Average		Very much	
D8. How many p	roble	_	in y	our relationship?	
1	2	3	4	5	
		. 🗆		□	
Very few		Average		Very many	

FERTILITY AND FERTILITY PRESERVATION

The next set of questions will ask about your fertility, pubertal development, sexual development, and quality of life. You may feel these questions are personal. Please be reassured your responses will remain confidential.

E1.	Do you know your fertility status?
	□Yes
	□No
E2.	Have you and a partner ever <u>tried</u> to become pregnant?
	□Yes
	□ No
E3.	Have you ever had difficulty (it took more than 1 year) becoming pregnant with a partner?
	□Yes
	□No
	☐ I don't know
E4.	Were you able to have all the children you wanted thave?
	☐ Yes
	□ No
E4a	. If no, which of you wanted more children?
	☐ I wanted more children but my partner(s) did not
	☐ My partner(s) wanted more children but I did not
	☐ We both wanted more children but we could not have more

É5.	If more children were wanted, what were the reasons for not having more children? (Mark all that apply)	E9. If you were evaluated by a fertility specialist, was a problem identified?				
	☐ I was unable to have more children (female infertility)	☐ Yes —				
	☐ I had other health issues related to my cancer treatment that made us decide not to have more children	□No				
	☐ I had other health issues <u>not</u> related to my cancer treatment that made us decide not to have more children	If yes, please specify.				
		E10. Have you/your partner engaged in treatment for fertility problems?				
	☐ My partner had other health issues that made us decide not to have more children	☐ Yes				
	☐ My partner and I tried but could not become pregnant, we do not know the reason why	□ No				
	☐ There were issues other than health that kept us from having more children (social/financial)	E11. If yes, what type of treatment? (Mark all that apply) ☐ Insemination				
	If there were other issues, please specify.	☐ Ovulation Drugs				
		☐ In Vitro Fertilization (IVF)				
		☐ Other				
		If Other, please specify.				
E6.	Have you or a male partner ever been evaluated for infertility?	E12. Do you have any concerns about your fertility				
	☐ Yes ☐ No	(your ability to have/produce biological children in the future)?				
	☐ I don't know	□No				
E7.	If you or your partner were evaluated for decreased	□Yes				
	fertility, was a problem identified?	☐ Not sure				
	☐ Yes. A fertility problem was found in my partner.☐ Yes. A fertility problem was found in me.	E13. Were you/are you at risk for premature ovarian failure (early menopause) due to cancer				
	☐ Yes. A fertility problem was found in both me and my partner.	treatment?				
	□ No	☐ Yes ☐ No ☐ I don't know				
	☐ I don't know	E14. Did you undergo oocyte cryopreservation (egg freezing) before you received cancer therapy?				
E8.	Were you personally evaluated by a fertility specialist?	☐ Yes ☐ No ☐ I don't know				
	☐ Yes☐ No☐ Go to Question E10.	E15. Did you undergo oocyte cryopreservation (egg				
	If yes, which kind of physician?	freezing) <u>after</u> you received cancer therapy?				
		☐ Yes ☐ No ☐ I don't know				
		E16. Did you undergo ovarian tissue freezing/cryopreservation before you started cancer treatment?				
	If yes, how old were you at the time of evaluation? Age in years	☐ Yes ☐ No ☐ I don't know				

Please! Do not mark below this line

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E17. Regardless of what you decided, were you offered fertility preservation before, during, or after your cancer treatment? (Mark all that apply)	F5. In general, how often do you or your partner use a condom during sex? (Select only one response.)		
□ No 	☐ Not applicable because I have never had sex		
☐ Yes, before treatment	□ Never		
☐ Yes, during treatment	☐ Rarely		
☐ Yes, after treatment	☐ Sometimes		
PUBERTY AND SEXUAL DEVELOPMENT	☐ Often		
	☐ Always		
F1. Was the onset of your puberty (The onset of puberty in females is characterized by pubic hair and breast development.)	F6. My previous sexual experiences have been with (Mark all that apply)		
☐ Early compared to others your age	☐ The opposite gender - men		
☐ Normal compared to others your age	☐ The same gender - women		
☐ Late compared to others your age	☐ Both genders- men and women		
F2. Were hormones needed to start your puberty?	☐ Myself- I have masturbated		
□Yes	☐ None of the above		
□No	☐ No reply		
F3. Have you had sexual intercourse?	F7. My sexual experiences in the <u>last year</u> have been with (Mark all that apply)		
□ Yes ¬	☐ The opposite gender - men		
☐ No If no, Go to Question F6.	☐ The same gender - women		
If yes, at what age did you first have intercourse?			
	☐ Both genders- men and women		
Age in years	☐ Myself- I have masturbated		
F4. Did you or your partner use a condom at last	☐ None of the above		
intercourse?	☐ No reply		
□No	F8. How many sexual partners have you had in the last		
☐ Yes Go to Question F5.	month?		
E40 If you did not you a condem of loca			
F4a. If you did not use a condom at last intercourse, what method did you or your			
partner use to prevent pregnancy?	F9. How many sexual partners have you had in the <u>last</u>		
(Select only one response.)	year?		
☐ No method was used to prevent pregnancy			
☐ Birth control pills	F10. How many sexual partners have you had in your		
☐ IUD (such as Mirena or ParaGard)	lifetime?		
☐ Implant (such as Implanon or Nexplanon)			
☐ Shot (such as Depo-Provera)			
☐ Birth control patch (such as Ortho Evra)			
☐ Birth control ring (such as NuvaRing)			
☐ Sponge (such as Today Sponge)			
☐ Spermicide			

Please! Do not mark below this line -

SEXUAL ACTIVITY

The following are questions commonly used by doctors to assess sexual function in females. They are standardized questions asked in a standardized fashion.

These next questions are sensitive and personal. They are very important in understanding how your medical illness or treatment affects your self and your body. Some questions ask about your own experiences, 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 are totally confidential.

G1.	Have you been sexually active in th	e past yea	ır
	(alone or with a partner)?		

☐ Yes	→ Go to Question G3.
□ No	

G2. I have not been sexually active in the <u>last year</u> because . . . (Mark all that apply)

DC	ause (mark an that appry)					
	I have never been sexually active		→	Go to Question		,
	I am too tired			Question	ı G	*
	I am not interested					
	I have a physical problem that ma difficult or uncomfortable	kes	se	exual rela	tior	1
	My partner is not interested					
	My partner is too tired					
	My partner has a physical problem relations difficult or uncomfortable		at r	makes se	€XU	а
	Other					
	If Other, please specify.					

3 3.	Have you been sexually active in the
	past month (alone or with a partner)?

Yes
No

G4. In the <u>past month</u>, how frequently have you had sexual thoughts, urges, fantasies, or erotic dreams? (Please mark the one item that is closest to your experience.)

Not at all
Once

2	or	3	times

	_		_		_	1
ш	2	or	J	times	а	week

G5. Using the scale below, how frequently have you felt an interest or desire to engage in the following specific activities in the past month?

	(This question is										
	about your desire				Мо	re tha	an on	ice a	day		
	to engage , <u>not</u>		Once a day								
	about how you feel during sexual		2 to	3 tin	nes p	er w	eek				
	activity.)			Once	e a w	eek					
	(For each item,		2 to	3 tin	nes						
	please mark the response that is		0	nce							
	closest to your	Not at	all								
	experience):										
a.	Dreams or fantasy			Ġ							
b.	Masturbation										
c.	Touching, hugging,		_	_	_	_	_	_	_		
	holding, kissing			П	П	П		Ш			
d.	Petting or foreplay										
e.	Vaginal intercourse										
f.	Other sexual activity										
	If Other, please specify.										

G6.	How frequently have you become aroused by the
	following sexual activity in the past month?

(By arousal, we mean				Moı	e tha	an once a day					
the physical and emotional responses	Once a day										
in your body and mind	2 to 3 times per week										
that tell you that you are feeling sexual.)			Once	a w	eek						
(For each item,		2 to	3 tin	nes							
please mark the		O	nce								
response that is closest to your experience):	Not at	all									
a. Dreams or fantasy			<u></u>		$\dot{\Box}$		Ġ				
b. Masturbation											
c. Touching, hugging, holding, kissing											
d. Petting or foreplay											
e. Vaginal intercourse											
f. Other sexual activity											
If Other, please specify.											

G7. In the <u>past month</u>, have you felt pleasure from any sexual activity?

☐ I have had no sexual activity in the past month	
☐ I have not felt any pleasure	

- $\hfill\square$ Seldom, less than 25% of the time
- $\hfill\square$ Sometimes, about 50% of the time
- $\hfill\square$ Usually, about 75% of the time
- ☐ Always felt pleasure

G8. Using the scale below, how frequently have you engaged in the following activities in the past month?

	More than once a day												
(For each item,	Once a day												
please mark the	2 to 3 times per week												
response that is closest to your													
experience):		2 to	3 tin										
		Oı	nce										
	Not at	all											
a. Dreams or fantasy													
b. Masturbation													
c. Touching, hugging, holding, kissing		. 🗆											
d. Petting or foreplay													
e. Masturbation with parti	ner												
f. Vaginal intercourse													
g. Other sexual activity													
If Other, please specify	-												

G9. In the <u>past month</u>, how often have you reached orgasm (climax) during sexual activity?

- ☐ I have had no sexual activity in the last month☐ I have not experienced orgasm
- ☐ Seldom, less than 25% of the time
- $\hfill\square$ Sometimes, about 50% of the time
- ☐ Usually, about 75% of the time
- ☐ I always experienced orgasm

G10. When you have orgasms (climax), how intense have they been in the <u>past month</u>?

- $\hfill \square$ I have had no sexual activity in the last month
- ☐ I have had no orgasms in the last month
- ☐ My orgasms were very mild
- ☐ My orgasms were fairly mild
- ☐ My orgasms were fairly strong
- ☐ My orgasms were very strong

G11. How easy or difficult has it been for you to have orgasms (climax) in the past month?										G14. Please rate the extent to which sexual activity has been satisfying for you in the past month by marking a number from 0 to 10 (0=Not at all satisfying															
	\square I have had no sexual activity in the last month)=Ex						(0			ou.	o. yg		
	□lh	nave ha	e had no orgasms in the last month																						
	☐ It was very difficult to have orgasms; it took a litime and a lot of concentration													0 t at a		2	3	4	5	6	7	8		10 trem	
	☐ It was fairly difficult; it took a while													isfyii	ng								Sa	atisfy	ing
	☐ It v	was fai	rly ea	sy									G1:								actor		uenc	е	
☐ It was very easy												yc	our s	exua	l act	ivity	in th	e <u>pa</u>	st mo	nth?					
G12. How frequently in the <u>past month</u> have you had the problems listed below? ALSO, MARK THE BOX IN THE LAST COLUMN if the problem stops your sexual activity.											if							imes,	about	about 50% of	of the		Alw time	ays	
	Always Does th problem																			No	t at all				
	Usually, about 75% of the time											your rent					I have	not h	nad a	partne	er				
	Sometimes, about 50% of the time										sex	rual vity?	I have not had a partner												
		Seldom	, less t	than 2	5% of t	he ti	ime				(30	//	a.	Му	own	heal	lth			[) <u> </u>	Ġ			
					Not a	t all					Yes	No	b.	Му	part	ner's	heal	th		٠					
a. Va	ginal	drynes activity.	ss dur	ing									C.				-		-	_ -					
		sexual				ш	ч	ш	ч	ш			d. Other												
de	sire.													II O	tner,	pieas	e spe	есіту.							
		tightne																							
		ring pe urse					П	П	П	П															
e. An	xiety	about	your s	sexua	ıl								'												
		nance to orga											G1		e yo					arried	d or p	artne	r rel	atio	nship
g. Va	ginal	bleedi netratio	ng or				_				_	_			NO, I	do n	ot ha	ve a	poss	sible	\rightarrow	Go t	o Qu	estio	n H1,
int	ercou	ırse												ı	oartn	er						next	page	Э.	
		ed sen	,																	ve a past	oartne year	er, an	d we	HA\	/E
		ain ins gina				_	_	_	_												partne		t we	HAV	E
		roblem													NOI	beer	ı sex	ually	activ	e this	past	year			
		please				_		_					G1	be	en a	ble t	о со	mmı	ınica		reque our se	-		-	
		se rate														ve be eren		nabl	e to c	comm	nunica	ite m	/ des	ires	or
		ıghts, f narkind													Selo	dom,	less	than	25%	of th	e time	Э			
	by marking a number from 0 to 10 (0=Not at all interested, 10=Extremely interested).										☐ Sometimes, about 50% of the time														
]] 🗆				l Usu	ally,	abou	t 75%	% of t	the tir	ne				
	ot all estec	_	3	4	5	6	7		8	9	Extre) emely ested				s alv eren		able	to co	mmu	nicate	e my	desir	es oi	

Please! Do not mark below this line

•							l .						
For each item,			Very		1.0		G25. I feel depressed about symptoms that keep me from enjoying sexual activity?						
please mark the response that is	Som	iewna	t sati	stied			☐ Rarely or none of the time						
closest to your	Neither satisfied nor o		- 1	Н			☐ Some or a little bit of the time						
experience:	Somewhat dissa	tisfie	d	Н			☐ Occasionally or a moderate amount of time						
	Very dissatisfie	d I		Н			☐ All of the time						
G18. Overall, how you been with	your sexual						G26. I sometimes feel too distressed to engage in sexual activity?						
•]					☐ Rarely or none of the time						
G19. Over the past	4 weeks, how you been with						☐ Some or a little bit of the time						
your sexual re	elationship with						☐ Occasionally or a moderate amount of time						
] [] [☐ All of the time						
	tner has been with	J [_			G27. Problems with my sexual performance cause me distress?						
G21. Over the past							☐ Rarely or none of the time						
satisfied do y partner has b							☐ Some or a little bit of the time						
		_ _] 🗆				☐ Occasionally or a moderate amount of time						
							☐ All of the time						
have been with		are arkin satis	warm g a r fied, □	nth a num □ 9	ber		Sexual Dysfunction Therapy H1. Have you ever received medical treatment for sexual dysfunction like vaginal dryness, itching, or pain (not infection-related) during sex?						
Satisfied					trem atisfi		□ No ↓						
you have bee	t 4 weeks, please rate with touching, huby marking a numbe comfortable, 10=Ext	ggir er fr	ng or om 0	hole to 1	ding I0	l							
0 1 2 Not at all Comfortable	3 4 5 6	□ 7			☐ 10 tremanforta	-	H2. Have you ever tried/received complementary or alternative medical treatment (herbal supplements or acupuncture, for example) for sexual dysfunction?						
G24. I feel positive	about my sexual re	elatio	nshi	ip?			□ No ↓						
☐ Not in a se	xual relationship						If yes, what treatment(s)?						
☐ Rarely or n	one of the time												
☐ Some or a	little bit of the time												
☐ Occasiona	lly or a moderate amo	ount	of tin	ne									
☐ All of the ti	me						H3. Have you <u>ever</u> had psychological treatment (talk therapy) for issues related to sexual dysfunction?						
							□Yes						
							□No						

Please! Do not mark below this line

dysfunction.	Use this space for any additional comments you may have:
I1. Is there anything you wish you had been told at the time of your diagnosis and treatment regarding your future fertility or sexual functioning? (use additional pages if necessary)	
I2. Is there anything you wish you had been told in a follow up cancer visit regarding your future fertility or sexual functioning? (use additional pages if necessary)	
I3. Is there anything you wish to know now regarding fertility or sexual functioning? (use additional pages if necessary)	
	Thank you for participating.

Finally a few questions about how you think survivors of childhood cancer and similar illnesses could best

be informed about their risk (if any) of sexual

Please! Do not mark below this line

We are always interested in your

input.