LTFU
Long-Term Follow-Up Study

Men's Health Questionnaire

St. Jude Children's Research Hospital
Children's Healthcare of Atlanta/Emory University
Children's Hospital at Stanford
Children's Hospital of Columbus
Children's Hospital of Orange County
Children's Hospital of Philadelphia
Children's Hospital of Los Angeles
Children's Hospital of Pittsburgh
Children's Hospitals & Clinics of Minnesota, Minneapolis and St. Paul
Children's Medical Center of Dallas
Children's National Medical Center
City of Hope National Medical Center
Dana-Farber Cancer Institute/ Children's Hospital Boston
Loma Linda University
Mattel Children's Hospital at UCLA
Mayo Clinic
Memorial Sloan-Kettering Cancer Center
Miller Children's Hospital
Riley Hospital for Children - Indiana University
Roswell Park Cancer Institute
Seattle Children's Hospital & Medical Center
St. Louis Children's Hospital
Texas Children's Hospital
The Denver Children's Hospital
Toronto Hospital for Sick Children
UAB/The Children's Hospital of Alabama
University of California at San Francisco
University of Michigan - Mott Children's Hospital
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The LTFU Men's Health Study is funded by

LIVESTRONG
LANCE ARMSTRONG FOUNDATION

Puberty, sexual development, infertility, and quality of life are important areas to study and understand in young adult survivors of pediatric cancer and other childhood illnesses. In a survey we sent you previously, you indicated your interest in participating in a study with this subject matter. Questions like these have already been asked of the female cancer survivors in the LTFU cohort. Important findings came from the female health questionnaire - for example the risk of premature menopause in female survivors of pediatric cancer and other childhood illnesses. This finding has been used to change clinical practice and counseling to female survivors of pediatric cancer and other childhood illnesses.

So, now it is your turn to teach us more about the health of male survivors of pediatric cancer and other childhood illnesses. Participation in this aspect of the study involves answering a series of questions that will take approximately 30 minutes to complete. You may feel these questions are very personal. Please be reassured your responses will remain confidential. We appreciate your willingness to answer this questionnaire.

Sincerely,

The LTFU study staff

Today's date: 20 / /

Please! Do not mark below this line

Survey #007

6450074196

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.

GENERAL HEALTH QUESTIONS

A1. Have you seen a physician for a routine physical (not due to a serious or severe medical problem) in the last year?

☐ Yes

☐ No → ***Go to Question B1.***

A2. If yes, in the last year have you seen . . .
(Mark all that apply)

☐ General Practitioner (such as a family practice or internal medicine doctor)

☐ Oncologist (cancer specialist)

☐ Cancer survivor doctor

☐ Other Specialist (such as a cardiologist, endocrinologist, etc.)

If Other Specialist, what kind?

RELEVANT MEDICAL HISTORY

Some medical problems or their treatments can interfere with men's health. Below are some questions on specific medical problems.

B1. Have you been diagnosed with any of the following medical problems?

	Yes	No
a. Depression	☐	☐
b. Obsessive Compulsive Disorder	☐	☐
c. Other Major Psychiatric Illness (for example, schizophrenia or paranoia)	☐	☐
d. Spinal injury	☐	☐
e. Prostate disease (enlarged prostate, prostate surgery, prostate cancer)	☐	☐

If yes, what prostate problem(s)?

Please! Do not mark below this line

	Yes	No
B2. Have you ever had problems with addiction to alcohol or drugs?	☐	☐

If yes, with what substance?

☐ Alcohol ☐ Drugs

If yes to drugs, please specify which drugs.

B3. Have you ever had any of the following surgeries?		
a. Prostate surgery	☐	☐
b. Pelvic surgery	☐	☐
c. Penis surgery	☐	☐
d. Testicular surgery	☐	☐

If yes to any of these surgeries, what kind of surgery(ies) did you have and why?

Testosterone Therapy

Testosterone is the male hormone made in the testes. It can be given to patients to start puberty (puberty is defined as the physical changes that allow a boy's body to change into a man's body) or can be used in older males who have low blood levels of testosterone.

B4. Have you ever been treated with testosterone?

☐ Yes

☐ No → ***Go to Question B11.***

☐ I don't know

B5. Were you treated with testosterone therapy during puberty (puberty in boys is typically around age 11 and leads to increase in size of the testes, growth of the penis, development of pubic hair, underarm hair and facial hair)?

☐ Yes

☐ No

☐ I don't know

B6. Are you currently on testosterone?

☐ Yes

☐ No

B7. How have you received testosterone treatments? *(Mark all that apply)*

☐ Injections (shots) ☐ Skin Patch

☐ Pills ☐ Inside the mouth patch

☐ Gel

B8. At what age did you start testosterone?

☐☐

Age in years

B9. If you took testosterone and it was discontinued, at what age did you stop taking testosterone?

☐☐

Age in years

B10. If you stopped taking testosterone, why did you stop? *(Mark all that apply)*

☐ I stopped the medicine because I did not like taking the medicine

☐ My doctor told me to stop

☐ I no longer had a prescription for the medicine

☐ Other reason

If Other reason, explain.

Erectile Dysfunction Therapy

Erectile dysfunction is a sexual problem characterized by the inability to develop or maintain an erection of the penis. Treatment for erectile dysfunction can include medicines taken by mouth, medicines that can be given as injections, mechanical devices like pumps, and surgery.

B11. Have you ever received treatment for erectile dysfunction?

☐ Yes

☐ No → *Go to Question C1.*

B12. Have you ever been treated with a medicine for erectile dysfunction - like Viagra, Cialis, Levitra, Muse, Edex or Caverject?

☐ Yes

☐ No

If yes, what medicine(s)?

B12a. When did you begin treatment for erectile dysfunction?

☐☐ ☐☐☐☐

Month (mm) **Year (yyyy)**

B12b. Are you currently on treatment for erectile dysfunction?

☐ Yes

☐ No

B13. Have you ever had surgery for erectile dysfunction?

☐ Yes

☐ No

If yes, what surgery(ies)?

B13a. Date of First Erectile Dysfunction Surgery

☐☐ ☐☐☐☐

Month (mm) **Year (yyyy)**

B14. Have you ever had other medical treatment for erectile dysfunction (e.g., mechanical pump)?

☐ Yes

☐ No

If yes, what treatment(s)?

B14a. Date of First Medical Therapy for Erectile Dysfunction

☐☐ ☐☐☐☐

Month (mm) **Year (yyyy)**

PUBERTY AND SEXUAL DEVELOPMENT

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

C1. Was the onset of your puberty . . . *(The onset of puberty in males is characterized by development of pubic hair, increase in size of testes and increase in size of penis.)*

☐ Early compared to others your age

☐ Normal compared to others your age

☐ Late compared to others your age

C2. Have you ever ejaculated? *(Ejaculation is the ejecting of semen from the penis. Ejaculation may occur during intercourse, masturbation or spontaneously during sleep - a nocturnal emission or "wet dream".)*

☐ Yes

☐ No

If yes, at what age did you first ejaculate?

☐☐

Age in years

Please! Do not mark below this line

C3. Have you had sexual intercourse?

☐ Yes

☐ No

If yes, at what age did you first have intercourse?

☐☐

Age in years

C4. My previous sexual experiences have been with . . . *(Mark all that apply)*

☐ The opposite gender - women

☐ The same gender - men

☐ I have only masturbated

☐ I use sexual videos, internet, etc.

☐ None of the above

☐ No reply

C5. My sexual experiences in the last year have been with . . . *(Mark all that apply)*

☐ The opposite gender - women

☐ The same gender - men

☐ I have only masturbated

☐ I use sexual videos, internet, etc.

☐ None of the above

☐ No reply

Fertility

C6. Have you and a partner ever tried to become pregnant?

☐ Yes

☐ No → ***Go to Question C17 .***

C7. Has a female partner ever had difficulty (it took more than 1 year) becoming pregnant by you?

☐ Yes

☐ No

☐ I don't know

C8. Were you able to have all the children you wanted to have?

☐ Yes → ***Go to Question C10.***

☐ No

C8a. *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

C9. If more children were wanted, what were the reasons for not having more children? *(Mark all that apply)*

☐ I was unable to father more children (male infertility)

☐ I had other health issues related to my cancer treatment that made us decide not to have more children

☐ I had other health issues not related to my cancer treatment that made us decide not to have more children

☐ My partner was not able to become pregnant (female infertility)

☐ My partner had other health issues that made us decide not to have more children

☐ My partner and I tried but could not become pregnant, we do not know the reason why

☐ There were issues other than health that kept us from having more children (social/financial)

If there were other issues, please specify.

C10. Have you or a female partner ever been evaluated for infertility?

☐ Yes

☐ No → ***Go to Question C14.***

☐ I don't know

Please! Do not mark below this line

C11. If you or your partner were evaluated for decreased fertility was a problem identified?

- ☐ Yes. A fertility problem was found in my partner.
- ☐ Yes. A fertility problem was found in me.
- ☐ Both of the above
- ☐ No
- ☐ I don't know

C12. Were you personally evaluated by a fertility specialist?

- ☐ Yes
- ☐ No → *Go to Question C14.*

If yes, which kind of physician?

If yes, how old were you at the time of evaluation?

☐☐
Age in years

C13. If you were evaluated by a fertility specialist was a problem identified?

- ☐ Yes
- ☐ No

If yes, please specify.

C14. Have you ever had semen (sperm) analysis?

- ☐ Yes
- ☐ No → *Go to Question C17.*
- ☐ I don't know

C15. On the semen analysis was your sperm count . . .

- ☐ Normal
- ☐ Low
- ☐ I don't know

C16. On the semen analysis was the motility (movement) of your sperm . . .

- ☐ Normal
- ☐ Low
- ☐ I don't know

Sperm Preservation

C17. Were you offered preservation of your sperm by freezing before you started cancer treatment?

- ☐ Yes
- ☐ No → *Go to Question D1.*
- ☐ I don't know

C18. Did you choose to freeze your sperm?

- ☐ Yes → *Go to Question C20.*
- ☐ No
- ☐ I don't know

C19. If you did not choose to freeze your sperm why did you decide not to? *(Mark all that apply)*

- ☐ I was too young at the time of diagnosis
- ☐ I was told not to try to freeze sperm

If so, who told you not to?

- ☐ I did not know how to freeze sperm and could not find out how to freeze sperm
- ☐ I was worried about my future health and my ability to be a father
- ☐ I was worried about passing on cancer to my child
- ☐ I was worried about having a child damaged by my cancer
- ☐ I was worried about having a child damaged by my cancer treatment
- ☐ Sperm freezing was too expensive
- ☐ I didn't believe it was the right thing to do
- ☐ Other reason

If Other reason, please specify.

Go to Question D1.

Please! Do not mark below this line

C20. Have you tried to use your frozen sperm to fertilize an egg?

- ☐ Yes
- ☐ No → *Go to Question C24.*
- ☐ I don't know → *Go to Question D1.*

C21. How many times have you tried to use your frozen sperm?

- ☐ 1 time
- ☐ 2-5 times
- ☐ > 5 times

C22. How many times has a pregnancy resulted from the use of your frozen sperm?

- ☐ None have resulted
- ☐ Once
- ☐ Twice
- ☐ Three times
- ☐ More than three times

C23. How many babies have been born from use of your frozen sperm?

- ☐ None have resulted
- ☐ One
- ☐ Two
- ☐ Three
- ☐ More than three

Go to Question D1.

C24. If you did not use your frozen sperm why did you decide not to use them? *(Mark all that apply)*

- ☐ I did not know how to use the banked sperm
- ☐ I was worried about my health and my ability to be a father
- ☐ I was worried about passing on cancer to my child
- ☐ I was worried about having a child damaged by my cancer
- ☐ I was worried about having a child damaged by my cancer treatment
- ☐ It was too expensive
- ☐ I did not believe it was the right thing to do
- ☐ Other

If Other, please specify.

QUALITY OF LIFE / SYMPTOMS

Quality of life is important when thinking about men's health. Please choose the single best answer to each of the following questions.

D1. In general, would you say your health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

The following questions are about activities you might do during a typical day. In the <u>past 4 weeks</u>, has your health limited you in these activities? If so, how much?

D2. <u>Moderate activities</u>, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No, not limited at all

D3. Climbing <u>several</u> flights of stairs

- ☐ Yes, limited a lot
- ☐ Yes, limited a little
- ☐ No, not limited at all

During the <u>past 4 weeks</u>, how often have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

D4. <u>Accomplished less</u> than you would like

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Little of the time
- ☐ None of the time

D5. Were limited in the <u>kind</u> of work or other activities

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Little of the time
- ☐ None of the time

During the past 4 weeks, how often have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

D6. Accomplished less than you would like

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Little of the time
- ☐ None of the time

D7. Did work or other activities less carefully than usual

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Little of the time
- ☐ None of the time

D8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all
- ☐ A little bit
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

These questions are about how you have felt during the past 4 weeks. 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 past 4 weeks…

D9. Have you felt calm and peaceful?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Little of the time
- ☐ None of the time

D10. Did you have a lot of energy?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Little of the time
- ☐ None of the time

D11. Have you felt downhearted and depressed?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Little of the time
- ☐ None of the time

D12. During the past 4 weeks, how often has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ Little of the time
- ☐ None of the time

Please indicate how true each statement has been for you during the past 7 days.

Mark only one answer for each problem and try not to skip any items.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
E1. I feel fatigued.	☐	☐	☐	☐	☐
E2. I feel listless ("washed out")	☐	☐	☐	☐	☐
E3. I have trouble starting things because I am tired	☐	☐	☐	☐	☐
E4. I have trouble finishing things because I am tired	☐	☐	☐	☐	☐
E5. I am able to do my usual activities . .	☐	☐	☐	☐	☐
E6. I am frustrated by being too tired to do the things I want to do	☐	☐	☐	☐	☐
E7. I have to limit my social activity because I am tired	☐	☐	☐	☐	☐

Please! Do not mark below this line

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.

F1. For each of the following medical problems mark the response that best describes your risk compared to other men your age never diagnosed with cancer or a disease like cancer.

	Much more	Slightly more	About the same	Slightly less	Much less
a. Infertility	☐	☐	☐	☐	☐
b. Low testosterone levels	☐	☐	☐	☐	☐
c. Sexual dysfunction	☐	☐	☐	☐	☐

If you answered *Slightly more* or *Much more* to any of the medical problems listed above continue with the next question. Otherwise, skip to Question G1.

F2. If you think you have increased risk (you answered *Slightly more* or *Much more* in Question F1) for having any of the medical problems in Question F1 because you had cancer or a similar illness, please mark the reasons you think you are at increased risk 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. Low testosterone levels	☐	☐	☐	☐	☐
c. Sexual dysfunction	☐	☐	☐	☐	☐

F3. If you consider yourself at risk for infertility, low testosterone, and/or sexual dysfunction, how did you learn of your increased risk?
(Mark all that apply)

	Another way	Information you found on the internet	Printed information	Your general practitioner/internist	Your family	Your oncologist	Not applicable
a. Infertility	☐	☐	☐	☐	☐	☐	☐
b. Low testosterone levels	☐	☐	☐	☐	☐	☐	☐
c. Sexual dysfunction	☐	☐	☐	☐	☐	☐	☐

If another way, please specify.

F4. If told by a healthcare professional about potential problems with fertility, low testosterone levels, and/or sexual functioning, 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. Infertility	☐	☐	☐	☐	☐	☐
b. Low testosterone levels	☐	☐	☐	☐	☐	☐
c. Sexual dysfunction	☐	☐	☐	☐	☐	☐

If in another setting, please specify.

Please! Do not mark below this line

SEXUAL ACTIVITY

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

These questions are sensitive and personal. They are very important in understanding how your medical illness or treatment affects yourself 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 the PAST YEAR (alone or with a partner)?

- ☐ Yes → *Go to Question G3.*
- ☐ No

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

- ☐ I have never been sexually active
- ☐ I am too tired
- ☐ I am not interested
- ☐ I have a physical problem that makes sexual relations difficult or uncomfortable
- ☐ My partner is not interested
- ☐ My partner is too tired
- ☐ My partner has a physical problem that makes sexual relations difficult or uncomfortable
- ☐ I do not have a partner at this time
- ☐ Other

If Other, please specify.

→ *Go to Question G4.*

G3. Have you been sexually active in the PAST MONTH (alone or with a partner)?

- ☐ Yes
- ☐ No

G4. In the PAST MONTH, 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
- ☐ Once a week
- ☐ 2 or 3 times a week
- ☐ Once a day
- ☐ More than once a day

Continue on next page

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 to engage, not about how you feel during sexual activity.)

(For each item, please mark the response that is closest to your experience):

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy	☐	☐	☐	☐	☐	☐	☐
b. Masturbation	☐	☐	☐	☐	☐	☐	☐
c. Touching, hugging, holding, kissing	☐	☐	☐	☐	☐	☐	☐
d. Petting or foreplay	☐	☐	☐	☐	☐	☐	☐
e. Intercourse (penetration with a partner)	☐	☐	☐	☐	☐	☐	☐
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 the physical and emotional responses in your body and mind that tell you that you are feeling sexual.)

(For each item, please mark the response that is closest to your experience):

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy	☐	☐	☐	☐	☐	☐	☐
b. Masturbation	☐	☐	☐	☐	☐	☐	☐
c. Touching, hugging, holding, kissing	☐	☐	☐	☐	☐	☐	☐
d. Petting or foreplay	☐	☐	☐	☐	☐	☐	☐
e. Intercourse (penetration with a partner)	☐	☐	☐	☐	☐	☐	☐
f. Other sexual activity	☐	☐	☐	☐	☐	☐	☐

If Other, please specify.

G7. In the PAST MONTH, have you felt pleasure from any sexual activity?

- ☐ I have had no sexual activity in the past month
- ☐ I have not felt any pleasure
- ☐ Seldom, less than 25% of the time
- ☐ Sometimes, about 50% of the time
- ☐ 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?

(For each item, please mark the response that is closest to your experience):

	Not at all	Once	2 to 3 times	Once a week	2 to 3 times per week	Once a day	More than once a day
a. Dreams or fantasy	☐	☐	☐	☐	☐	☐	☐
b. Masturbation	☐	☐	☐	☐	☐	☐	☐
c. Touching, hugging, holding, kissing	☐	☐	☐	☐	☐	☐	☐
d. Petting or foreplay	☐	☐	☐	☐	☐	☐	☐
e. Intercourse (penetration with a partner)	☐	☐	☐	☐	☐	☐	☐
f. Other sexual activity	☐	☐	☐	☐	☐	☐	☐

If Other, please specify.

G9. In the PAST MONTH, how often have you reached orgasm (ejaculation) 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
- ☐ Sometimes, about 50% of the time
- ☐ Usually, about 75% of the time
- ☐ I always experienced orgasm

Please! Do not mark below this line

G10. When you have orgasms (ejaculations), how intense have they been in the PAST MONTH?

- ☐ 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 (ejaculations) in the PAST MONTH?

- ☐ I have had no sexual activity in the last month
- ☐ I have had no orgasms in the last month
- ☐ It was **very difficult** to have orgasms; it took a long time and a lot of concentration
- ☐ It was **fairly difficult**; it took a while
- ☐ It was **fairly easy**
- ☐ It was **very easy**

G12. How frequently in the PAST MONTH have you had the problems listed below?
ALSO, MARK THE BOX IN THE LAST COLUMN if the problem stops your sexual activity.

	Not at all	Seldom, less than 25% of the time	Sometimes, about 50% of the time	Usually, about 75% of the time	Always	Does the problem stop your current sexual activity? Yes	No
a. Difficulty getting an erection. . .	☐	☐	☐	☐	☐	☐	☐
b. Lack of sexual interest or desire.	☐	☐	☐	☐	☐	☐	☐
c. Losing an erection during sexual activity.	☐	☐	☐	☐	☐	☐	☐
d. Delayed ejaculation	☐	☐	☐	☐	☐	☐	☐
e. Anxiety about your sexual performance.	☐	☐	☐	☐	☐	☐	☐
f. Unable to achieve orgasm. . . .	☐	☐	☐	☐	☐	☐	☐
g. Pain during penetration or intercourse.	☐	☐	☐	☐	☐	☐	☐
h. Other problem with sexuality . .	☐	☐	☐	☐	☐	☐	☐

If Other, please describe.

G13. Please rate how interested you have been in sexual thoughts, feelings, or actions in the PAST MONTH by marking a number from 0 to 10 (0=Not at all interested, 10=Extremely interested).

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Not at all Interested — Extremely Interested

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, 10=Extremely satisfying).

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Not at all Satisfying — Extremely Satisfying

G15. How often did the following factors influence your sexual activity in the PAST MONTH?

	I have not had a partner	Not at all	Seldom, less than 25% of the time	Sometimes, about 50% of the time	Usually, about 75% of the time	Always
a. My own health	☐	☐	☐	☐	☐	☐
b. My partner's health	☐	☐	☐	☐	☐	☐
c. Conflict in my relationship	☐	☐	☐	☐	☐	☐
d. Other	☐	☐	☐	☐	☐	☐

If Other, please specify.

G16. Are you currently in a married or partner relationship that could be sexual?

- ☐ NO, I do not have a possible partner → *Go to Question H1.*
- ☐ YES, I am married or have a partner, and we HAVE been sexually active this past year
- ☐ YES, I am married or have a partner, but we HAVE NOT been sexually active this past year

Please! Do not mark below this line

G17. Over the past 4 weeks, how frequently have you been able to communicate your sexual desires or preferences to your partner?

- ☐ I have been unable to communicate my desires or preferences
- ☐ Seldom, less than 25% of the time
- ☐ Sometimes, about 50% of the time
- ☐ Usually, about 75% of the time
- ☐ I was always able to communicate my desires or preferences

G18. Overall, how satisfied have you been with your sexual relationship with your partner?

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied

G19. Over the past 4 weeks, how satisfied have you been with your sexual relationship with your partner?

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied

G20. Overall, how satisfied do you think your partner has been with your sexual relationship?

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied

G21. Over the past 4 weeks, how satisfied do you think your partner has been with your sexual relationship?

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied

G22. Over the past 4 weeks, please rate how satisfied you have been with your ability to share warmth and intimacy with your partner by marking a number below from 0 to 10 (0=Not at all satisfied, 10=Extremely satisfied).

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 1 2 3 4 5 6 7 8 9 10

Not at all Satisfied — Extremely Satisfied

G23. Over the past 4 weeks, please rate how comfortable you have been with touching, hugging or holding your partner by marking a number from 0 to 10 (0=Not at all comfortable, 10=Extremely comfortable).

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 1 2 3 4 5 6 7 8 9 10

Not at all Comfortable — Extremely Comfortable

ERECTILE FUNCTION

These questions are specifically about erectile function and are frequently used by doctors to determine adequacy of erectile function and patient response to erectile treatments. Questions H1 to H15 are in reference to the last 4 weeks . . .

Please pick the single best answer

H1. In the past 4 weeks, how often were you able to get an erection during sexual activity?

- ☐ No sexual activity → *Go to Question H11.*
- ☐ Almost never/never
- ☐ A few times (much less than half the time)
- ☐ Sometimes (about half the time)
- ☐ Most times (much more than half the time)
- ☐ Almost always/always

Please! Do not mark below this line

H2. In the past 4 weeks, when you had erections with sexual stimulation, how often were your erections hard enough for penetration?

- ☐ Almost never/never
- ☐ A few times (much less than half the time)
- ☐ Sometimes (about half the time)
- ☐ Most times (much more than half the time)
- ☐ Almost always/always

H3. In the past 4 weeks, when you attempted sexual intercourse, how often were you able to penetrate (enter) your partner?

- ☐ Did not attempt intercourse → *Go to Question H9.*
- ☐ Almost never/never
- ☐ A few times (much less than half the time)
- ☐ Sometimes (about half the time)
- ☐ Most times (much more than half the time)
- ☐ Almost always/always

H4. In the past 4 weeks, during sexual intercourse, how often were you able to maintain your erection after you had penetrated (entered) your partner?

- ☐ Almost never/never
- ☐ A few times (much less than half the time)
- ☐ Sometimes (about half the time)
- ☐ Most times (much more than half the time)
- ☐ Almost always/always

H5. In the past 4 weeks, during sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?

- ☐ Extremely difficult
- ☐ Very difficult
- ☐ Difficult
- ☐ Slightly difficult
- ☐ Not difficult

H6. In the past 4 weeks, how many times have you attempted sexual intercourse?

- ☐ One to two attempts
- ☐ Three to four attempts
- ☐ Five to six attempts
- ☐ Seven to ten attempts
- ☐ Eleven+ attempts

H7. In the past 4 weeks, when you attempted sexual intercourse, how often was it satisfactory for you?

- ☐ Almost never/never
- ☐ A few times (much less than half the time)
- ☐ Sometimes (about half the time)
- ☐ Most times (much more than half the time)
- ☐ Almost always/always

H8. In the past 4 weeks, how much have you enjoyed sexual intercourse?

- ☐ No enjoyment
- ☐ Not very enjoyable
- ☐ Fairly enjoyable
- ☐ Highly enjoyable
- ☐ Very highly enjoyable

H9. In the past 4 weeks, when you had sexual stimulation or intercourse, how often did you ejaculate?

- ☐ Almost never/never
- ☐ A few times (much less than half the time)
- ☐ Sometimes (about half the time)
- ☐ Most times (much more than half the time)
- ☐ Almost always/always

H10. In the past 4 weeks, when you had sexual stimulation or intercourse, how often did you have the feeling of orgasm or climax?

- ☐ Almost never/never
- ☐ A few times (much less than half the time)
- ☐ Sometimes (about half the time)
- ☐ Most times (much more than half the time)
- ☐ Almost always/always

H11. In the past 4 weeks, how often have you felt sexual desire?

- ☐ Almost never/never
- ☐ A few times (much less than half the time)
- ☐ Sometimes (about half the time)
- ☐ Most times (much more than half the time)
- ☐ Almost always/always

Please! Do not mark below this line

H12. In the past 4 weeks, how would you rate your level of sexual desire?

- ☐ Very low/none at all
- ☐ Low
- ☐ Moderate
- ☐ High
- ☐ Very high

H13. In the past 4 weeks, how satisfied have you been with your overall sex life?

- ☐ Very dissatisfied
- ☐ Moderately dissatisfied
- ☐ About equally satisfied and dissatisfied
- ☐ Moderately satisfied
- ☐ Very satisfied

H14. In the past 4 weeks, how satisfied have you been with your sexual relationship with your partner?

- ☐ Very dissatisfied
- ☐ Moderately dissatisfied
- ☐ About equally satisfied and dissatisfied
- ☐ Moderately satisfied
- ☐ Very satisfied

H15. In the past 4 weeks, how do you rate your confidence that you could get and keep an erection?

- ☐ Very low
- ☐ Low
- ☐ Moderate
- ☐ High
- ☐ Very high

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 testicular or sexual dysfunction.

H16. Is there anything you wish you had been told at the time of your diagnosis and treatment regarding your future fertility or testicular function or sexual functioning? (use additional pages if necessary)

H17. Is there anything you wish you had been told in a follow-up cancer visit regarding your future fertility or testicular function or sexual functioning? (use additional pages if necessary)

H18. Is there anything you wish to know now regarding fertility or testicular function or sexual function? (use additional pages if necessary)

Please! Do not mark below this line

We are always interested in your input in the follow-up study.
Use this space for any additional comments you may have:

When you have completed this questionnaire please return it to us in the enclosed envelope.

Mail to:

LONG-TERM FOLLOW-UP STUDY
St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
332 N. Lauderdale St.
Memphis, TN 38105-2794

Thank you!

St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder
Finding cures. Saving children.

Please! Do not mark below this line

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