



about
skin cancer

ADVANCING SURVIVORS' KNOWLEDGE

LTFU
Long-Term Follow-Up Study



HARVARD
T.H. CHAN

SCHOOL OF PUBLIC HEALTH
Department of Social and
Behavioral Sciences

Thank you very much for your participation in this important study. If you prefer, you can complete this survey online at www.stjude.org/ltfu-ASK12. Your log-in ID is your birth date and your password is:

At the end of the survey, there is a HIPAA Authorization Form. We are requesting this new HIPAA Authorization Form to assist us with planned medical chart review.

You can also complete the survey over the phone with a trained interviewer by calling the study team toll free at 1-800-775-2167.

If you have any questions, please call the study team at 1-800-775-2167 or via email at LTFU@stjude.org.

Your generosity in participating is greatly appreciated.

Sincerely,

The LTFU study staff

Today's date:

| | | | | | | | | | |
|----------------------|----------------------|---|----------------------|----------------------|---|----------------------|----------------------|----------------------|----------------------|
| <input type="text"/> | <input type="text"/> | / | <input type="text"/> | <input type="text"/> | / | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| M | M | | D | D | | 2 | 0 | 1 | |
| | | | | | | Y | Y | Y | Y |

Please! Do not mark below this line

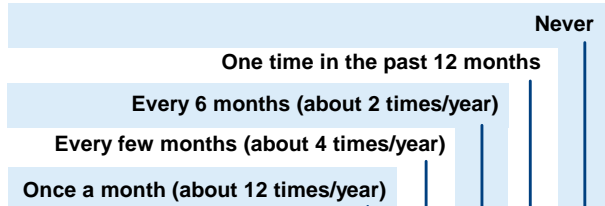
Survey #191

2758485267

A. SKIN CHECK PRACTICE

A1. In general, would you say your health is...

- Excellent
- Very good
- Good
- Fair
- Poor



A2. In the past 12 months, how often did you carefully check your whole body (including the skin on your back and back of your legs) for any sign of skin cancer?

A3. In the past 12 months, how often did you have a partner, close relative, or friend help you carefully check your whole body (including the skin on your back and back of your legs) for any sign of skin cancer?

A4. In the past 12 months, have you asked your regular healthcare provider* or your dermatologist to examine your whole body for skin cancer? (Select all that apply)

- Yes – I asked my regular healthcare provider
- Yes – I asked my dermatologist
- No

**Your regular healthcare provider is the person you see most frequently for your regular care. This can be your primary care physician (PCP), a general practitioner (GP), a family doctor, an oncologist or any doctor, a nurse practitioner (NP), or a physician assistant (PA), but does not include your dentist.*

For questions A5-A15, we are asking about only the past 2 months.

A5. How many times in the past two months have you carefully checked your whole body (including the skin on your back and back of your legs) for any sign of skin cancer?

- Never
- Once
- 2 or more times

Thinking back over the past 2 months, what areas of your skin, if any, have you carefully checked for warning signs of skin cancer? Please select a response for each area of your skin below.

Checked for skin cancer over the past 2 months?

| | Yes | No |
|--|--------------------------|--------------------------|
| A6. The front of your body from the waist up . . . | <input type="checkbox"/> | <input type="checkbox"/> |
| A7. The front of your thighs and legs | <input type="checkbox"/> | <input type="checkbox"/> |
| A8. The bottom of your feet | <input type="checkbox"/> | <input type="checkbox"/> |
| A9. Your calves | <input type="checkbox"/> | <input type="checkbox"/> |
| A10. The backs of your thighs | <input type="checkbox"/> | <input type="checkbox"/> |
| A11. Your buttocks | <input type="checkbox"/> | <input type="checkbox"/> |
| A12. The lower parts of your back. | <input type="checkbox"/> | <input type="checkbox"/> |
| A13. Your upper back | <input type="checkbox"/> | <input type="checkbox"/> |
| A14. Your scalp | <input type="checkbox"/> | <input type="checkbox"/> |

A15. How many times in the past two months have you had someone (such as a partner, close relative, or friend) help you carefully check your whole body (including the skin on your back and back of your legs) for any sign of skin cancer?

- Never
- Once
- 2 or more times

Please! Do not mark below this line

B. SKIN CANCER SELF-CHECKS

For the next set of questions, we are asking about skin-checks that you or someone helping you may have done. This would not include skin exams that may have been performed by your regular healthcare provider or any other provider.

B1. In the past 12 months, have you noticed any moles that have any of the following characteristics? (Please select all that apply)

- Asymmetrical (half of the mole looks different from the other half)
- Border irregularities (the outside edges of the mole are not round)
- Color differences (more than one color, for example different colors of tan and brown, red, black, blue/gray, or white)
- Diameter is bigger than ¼ inch or 6 mm (equal to or wider than the size of a pencil head eraser)
- Evolving (changed size, color or shape)
- New mole (that wasn't there before)
- Looks different from other moles around it
- I have not noticed any moles with the above characteristics

B2. In the past 12 months, have you noticed any of the following characteristics anywhere on your skin? (Please select all that apply)

- An unexplained whitish scar-like area
- A shiny bump or nodule
- A reddish patch or irritated area
- A persistent non-healing sore
- A pink growth with a slightly elevated rolled border and crusted indentation in the center
- None of the above characteristics

→ **Go to Question C1a on page 4.**

B3. In the past 12 months, what did you do the first time you noticed any of the these characteristics from B1 and/or B2 on your skin? (Select all that apply)

- Contacted my regular healthcare provider for a skin exam
- Contacted my dermatologist for a skin exam
- Asked someone else to look at it (a partner, close relative, or friend)
- Looked at the ASK study materials to compare my mole or spot
- Decided to watch to see if it changed before taking any action
- Decided to wait until my next appointment with my regular healthcare provider to talk to him/her about it
- Other

If Other, please specify.

Continue on next page...

C. HEALTH & HEALTH CARE PROVIDER EXAMINATIONS

Please tell us about your regular healthcare provider and other providers that you may have seen in the past 12 months. Your regular healthcare provider is the person you see most frequently for your regular care. This can be your primary care physician (PCP), a general practitioner (GP), a family doctor, an oncologist or any doctor, a nurse practitioner (NP), or a physician assistant (PA), but does not include your dentist.

C1a. Who is your regular healthcare provider now?

- A primary care provider; this includes primary care physician (PCP), general practitioner (GP), family doctor, nurse practitioner (NP), or a physician assistant (PA)
- An oncologist
- A cancer survivorship care provider
- An obstetrician or gynecologist (OB/GYN)
- Another type of specialist

Provider name:

Office name:

Address:

City, state, zip:

Phone #:

C1b. How many visits have you had to these providers in the past 12 months?

| | 0 visits | 1-2 visits | 3-5 visits | 6 or more visits |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| A primary care provider ; this includes primary care physician (PCP), general practitioner (GP), family doctor, nurse practitioner (NP), or a physician assistant (PA)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| An oncologist | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| A cancer survivorship care provider | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| An obstetrician or gynecologist (OB/GYN) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Another type of specialist | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

C2. Please tell us if you received any of the following medical exams or procedures in the last 12 months from any provider.

| | Received in last 12 months? | |
|---|-----------------------------|--------------------------|
| | Yes | No |
| MALES AND FEMALES | | |
| Flu shot | <input type="checkbox"/> | <input type="checkbox"/> |
| Blood pressure check | <input type="checkbox"/> | <input type="checkbox"/> |
| FEMALES ONLY | | |
| Physical exam to screen for breast cancer | <input type="checkbox"/> | <input type="checkbox"/> |
| Mammogram to screen for breast cancer | <input type="checkbox"/> | <input type="checkbox"/> |
| Pap smear to screen for cervical cancer | <input type="checkbox"/> | <input type="checkbox"/> |

For the next group of questions, please focus your answers on your regular healthcare provider.

In the past 12 months, when you had a routine visit with your regular healthcare provider, did you...

Not applicable, I did not have a routine visit with my regular healthcare provider

| | Yes | No | Not applicable, I did not have a routine visit with my regular healthcare provider |
|---|--------------------------|--------------------------|--|
| C3. Prepare a list of questions for him/her? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C4. Ask about cancer screenings that you might need? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C5. Ask questions about the things you want to know and/or things you don't understand? ... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

For the next group of questions, please answer about things that either your regular healthcare provider or your dermatologist may have done or told you in the past 12 months. (Please select all that apply)

In the past 12 months, has your regular healthcare provider or your dermatologist... (Select all that apply)

| | Yes – my regular healthcare prov | Yes – my dermatologist | No |
|---|----------------------------------|--------------------------|--------------------------|
| C6. Told you that you were at risk for skin cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C7. Told you to check your skin for warning signs of skin cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C8. Showed you how to check your skin for warning signs of skin cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

C9. In the past 12 months, has your regular health care provider or your dermatologist examined the area where you had radiation treatment for signs of skin cancer? (Please select all that apply)

- Yes – My regular healthcare provider examined the area
- Yes – My dermatologist examined the area
- No
- Not sure if my regular healthcare provider or my dermatologist examined the area
- Not sure where I had radiation treatment

C10. In the past 12 months, has your regular health care provider or your dermatologist carefully examined your whole body for any sign of skin cancer? (Please select all that apply)

- Yes – My regular healthcare provider examined my whole body **→ Go to Question C12.**
- Yes – My dermatologist examined my whole body **→ Go to Question C12.**
- No
- Don't know

C11. In the past 12 months, has your regular health care provider or your dermatologist examined any part of your skin for any sign of skin cancer? (Please select all that apply)

- Yes – My regular healthcare provider examined part of my skin
- Yes – My dermatologist examined part of my skin
- No
- Don't know

C12. In the past 12 months, has your regular health care provider or your dermatologist noticed an unusual mole(s) or worrisome mark(s) or spot(s) on your skin?

- Yes
- No **→ Go to Question C14.**
- Don't know **→ Go to Question C14.**

C13. How long did it take from the time your regular healthcare provider or your dermatologist noticed an unusual mole(s) or worrisome mark(s) or spot(s) to the time your provider told you the diagnosis?

- He/She provided a diagnosis during the appointment
- Less than 2 weeks
- 2 to 4 weeks
- 1 to 3 months
- Greater than 3 months
- Pending, still waiting for diagnosis

→ [Go to Question C14.](#)

C14. In the past 12 months, how many skin exams, either of your whole body or any part of your skin, have you received from any healthcare provider or dermatologist?

- 0 → [If 0, go to Question C18 on page 12.](#)
- 1
- 2
- 3
- More than 3

We would like to know about each of those skin exams. Please complete the questions below for each of the exams you have had in the past 12 months. If you have had more than 3 skin exams in the past 12 months, please tell us about the first 3 exams in the questions below.

C15. First exam

Who completed the first exam?

- Primary care provider
- Dermatologist
- Oncologist
- Survivorship care provider
- Obstetrician/Gynecologist
- Other specialist

Is this your regular healthcare provider?

- Yes
- No

Contact information for the Provider who completed the exam:

| |
|-------------------|
| Name: |
| Address: |
| Address: |
| City, state, zip: |
| Phone #: |

Date of exam: / /
M M D D Y Y Y Y

What prompted the exam? (Select all that apply)

- It was part of a routine visit
- I requested a special appointment
- I was referred for this exam

Were you fully undressed for this exam?

- Yes
- No
- Not sure

How much of your body was examined?

- My whole body
- Just a part of my body

What was the outcome of this exam?

(Select all that apply)

- No concerns → Skip to Question C16, if you had a second exam. If not, skip to Question C18.
- Watch and check again later → Skip to Question C16, if you had a second exam. If not, skip to Question C18.
- Referral to specialist
- Biopsy (a small sample taken for further evaluation) or Excision (complete removal of the mole or area of concern)

If you were referred to a specialist, did the first (referring) doctor follow-up with you after the exam?

- Yes
- No
- Not sure
- I was not referred to a specialist

If a biopsy(s) was taken or an excision(s) completed at this visit, we would like to know about each one of those procedures. If you have had more than 3 biopsies and/or excisions during this visit, please tell us about the first 3.

| What was the result of biopsy/excision 1? | What was the result of biopsy/excision 2? | What was the result of biopsy/excision 3? |
|--|--|--|
| <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ | <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ | <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ |
| If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below. <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement | If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below. <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement | If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below. <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement |

Please! Do not mark below this line

C16. Second exam

Who completed the second exam?

- Primary care provider
- Dermatologist
- Oncologist
- Survivorship care provider
- Obstetrician/Gynecologist
- Other specialist

Is this your regular healthcare provider?

- Yes
- No

Contact information for the Provider who completed the exam:

(Select if same provider as first exam and skip Contact information here.)

| |
|-------------------|
| Name: |
| Address: |
| Address: |
| City, state, zip: |
| Phone #: |

Date of exam:

| | |
|--|--|
| | |
|--|--|

 /

| | |
|--|--|
| | |
|--|--|

 /

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

M M D D Y Y Y Y

What prompted the exam? *(Select all that apply)*

- It was part of a routine visit
- I requested a special appointment
- I was referred for this exam

Were you fully undressed for this exam?

- Yes
- No
- Not sure

How much of your body was examined?

- My whole body
- Just a part of my body

What was the outcome of this exam?

(Select all that apply)

- No concerns → *Skip to Question C17, if you had a third exam. If not, skip to Question C18.*
- Watch and check again later → *Skip to Question C17, if you had a third exam. If not, skip to Question C18.*
- Referral to specialist
- Biopsy (a small sample taken for further evaluation) or
Excision (complete removal of the mole or area of concern)

If you were referred to a specialist, did the first (referring) doctor follow-up with you after the exam?

- Yes
- No
- Not sure
- I was not referred to a specialist

Continue on next page...

If a biopsy(s) was taken or an excision(s) completed at this visit, we would like to know about each one of those procedures. If you have had more than 3 biopsies and/or excisions during this visit, please tell us about the first 3.

| What was the result of biopsy/excision 1? | What was the result of biopsy/excision 2? | What was the result of biopsy/excision 3? |
|--|--|--|
| <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ | <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ | <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ |
| <p>If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below.</p> <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement | <p>If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below.</p> <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement | <p>If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below.</p> <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement |

Please! Do not mark below this line

C17. Third exam

Who completed the third exam?

- Primary care provider
- Dermatologist
- Oncologist
- Survivorship care provider
- Obstetrician/Gynecologist
- Other specialist

Is this your regular healthcare provider?

- Yes
- No

Contact information for the Provider who completed the exam:

(Select if same provider as first second exam and skip Contact information here.)

| |
|-------------------|
| Name: |
| Address: |
| Address: |
| City, state, zip: |
| Phone #: |

Date of exam:

| | | | | | | | | | |
|----------------------|----------------------|---|----------------------|----------------------|---|----------------------|----------------------|----------------------|----------------------|
| <input type="text"/> | <input type="text"/> | / | <input type="text"/> | <input type="text"/> | / | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| M | M | | D | D | | Y | Y | Y | Y |

What prompted the exam? *(Select all that apply)*

- It was part of a routine visit
- I requested a special appointment
- I was referred for this exam

Were you fully undressed for this exam?

- Yes
- No
- Not sure

How much of your body was examined?

- My whole body
- Just a part of my body

What was the outcome of this exam?

(Select all that apply)

- No concerns → Skip to Question C18.
- Watch and check again later → Skip to Question C18.
- Referral to specialist
- Biopsy (a small sample taken for further evaluation) or
Excision (complete removal of the mole or area of concern)

If you were referred to a specialist, did the first (referring) doctor follow-up with you after the exam?

- Yes
- No
- Not sure
- I was not referred to a specialist

Continue on next page...

If a biopsy(s) was taken or an excision(s) completed at this visit, we would like to know about each one of those procedures. If you have had more than 3 biopsies and/or excisions during this visit, please tell us about the first 3.

| What was the result of biopsy/excision 1? | What was the result of biopsy/excision 2? | What was the result of biopsy/excision 3? |
|--|--|--|
| <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ | <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ | <input type="checkbox"/> No significant finding, normal mole (benign) <input type="checkbox"/> Atypical/unusual mole <input type="checkbox"/> Actinic keratosis <input type="checkbox"/> Seborrheic keratosis <input type="checkbox"/> Basal cell cancer <input type="checkbox"/> Squamous cell cancer <input type="checkbox"/> Melanoma-in-situ <input type="checkbox"/> Melanoma <input type="checkbox"/> Unsure <input type="checkbox"/> Pending <input type="checkbox"/> Other (specify) _____ |
| <p>If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below.</p> <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement | <p>If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below.</p> <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement | <p>If scarring from this biopsy or excision lasted more than 2 months, please rate on a scale from 0 to 5 below.</p> <input type="checkbox"/> 0 No scarring/disfigurement <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 Much scarring/disfigurement |

Please! Do not mark below this line

C18. In the past 12 months, did you have any other visits, tests or procedures related to your skin?

- Yes
 No **→ Go to Question C19.**

If yes,

C18a. What tests or procedures did you have done (related to your skin)?

The next few questions are about health insurance and healthcare costs.

C19. Do you have health insurance?

- Yes
 No **→ Skip to Question C23.**

C20. Do you have the same health insurance that you did 12 months ago?

- Yes
 No

C21. During the past 12 months, have you delayed seeking any medical care because of worry about the cost of the co-payment (co-pay)?

- Yes
 No

C22. Does your health insurance plan require prior authorization or a referral for you to see a dermatologist?

- Yes
 No
 Unsure

C23. In the past 12 months, have you had to pay any out-of-pocket costs for visits, tests or treatment related to an unusual mole or spot on your skin, a pre-cancerous mole or spot, or a mole or spot that was diagnosed as cancer?

- Yes
 No **→ Skip to Question D1.**
 Unsure **→ Skip to Question D1.**

If yes,

C23a. How much have you paid in out-of-pocket costs over the last 12 months for care related to unusual, pre-cancerous or cancerous moles or spots on your skin? Out-of-pocket costs include co-payments or coinsurance for physician visits, tests, medications and other treatment.

- Less than \$50
 \$50-\$100
 \$101-\$200
 \$201-\$500
 More than \$500

Continue on next page...

D. SUN & TANNING BEHAVIOR

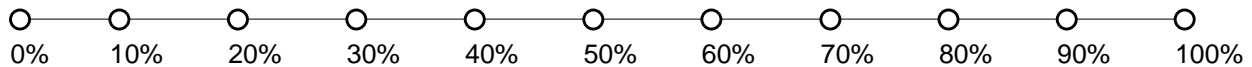
For the following questions please think about your behavior over the last 12 months and answer for that time period only.

D1. When the weather was warm and sunny, how many hours in a typical 7-day week (Monday - Sunday) did you usually spend sunbathing (over the last 12 months)?

- 0 hours weekly [→ Go to Question D3.](#)
- 1-3 hours weekly
- 4-9 hours weekly
- 10+ hours weekly

D2. When you sunbathed, how frequently did you use sunscreen (with at least SPF 15) that covered your body (over the last 12 months)?

(Please fill in a circle above a number from 0% to 100% of the time)

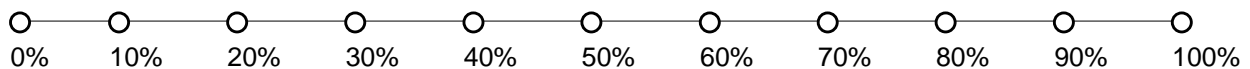


D3. When the weather was warm and sunny, how many hours in a typical 7-day week (Monday - Sunday) did you usually spend in the sun doing something other than sunbathing (such as working, exercising, walking, gardening, etc.) over the last 12 months?

- 0 hours weekly [→ Go to Question D6.](#)
- 1-3 hours weekly
- 4-9 hours weekly
- 10+ hours weekly

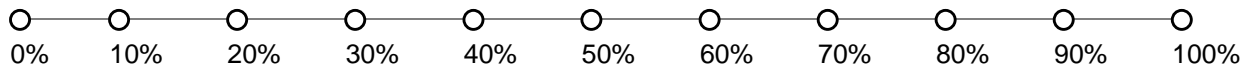
D4. When you spent time in the sun other than sunbathing, how frequently did you wear a hat or visor to keep your head or face protected from the sun (over the last 12 months)?

(Please fill in a circle above a number from 0% to 100% of the time)



D5. When you spent time in the sun other than sunbathing, how frequently did you seek shade or use sun protection such as sunscreen (with at least SPF 15) or a long-sleeve shirt (over the last 12 months)?

(Please fill in a circle above a number from 0% to 100% of the time)



D6. How many times have you tanned indoors in the past 12 months?

- 0 times → Go to Question D8.
- 1-2 times
- 3-10 times
- 11-24 times
- 25 times or more

D7. In the past 12 months, how many times did you get redness from tanning indoors, that lasted a day or more?

- Never
- 1 time
- 2 times
- 3 times
- 4 times
- 5 or more times

D8. In the past 12 months, how many times did you get redness from the sun that lasted a day or more?

- Never
- 1 time
- 2 times
- 3 times
- 4 times
- 5 or more times

E. SKIN CANCER KNOWLEDGE

E1. Have you heard of the 'ABCDE' rule for detection of melanoma?

- Yes
- No

E2. Melanoma is a serious type of skin cancer. Please identify the warning signs for melanoma. *(Please select all that apply)*

- A mole that is perfectly round
- A mole that looks different from other moles around it
- A mole with even borders
- A mole that is light brown or tan
- A mole that has changed
- Don't know

F. RISK BELIEFS

In the following questions, when we say skin cancer we are referring to the three major forms of skin cancer - basal cell cancer, squamous cell cancer, and melanoma.

F1. Compared to the average person your age and gender, would you say that you are:

- Less likely to develop skin cancer
- About as likely to develop skin cancer
- More likely to develop skin cancer
- Much more likely to develop skin cancer

F2. What do you think is the chance that you will develop skin cancer at some point in the future?

- Very unlikely
- Unlikely
- Moderate chance
- Likely
- Very likely

F3. Being diagnosed with skin cancer would be:

- Not at all serious
- A little serious
- Somewhat serious
- Quite serious
- Very serious

G. ROLE OF SPOUSE/PARTNER/RELATIVE/FRIEND IN HEALTH HABITS

G1. Does your spouse/partner/relative/friend help you with the following?
(Select all that apply)

| | Yes | No |
|--|--------------------------|--------------------------|
| Learn about my health problems | <input type="checkbox"/> | <input type="checkbox"/> |
| Talk to the doctor for me | <input type="checkbox"/> | <input type="checkbox"/> |
| Schedule appointments for me | <input type="checkbox"/> | <input type="checkbox"/> |
| Help me make medical decisions. | <input type="checkbox"/> | <input type="checkbox"/> |

H. ATTITUDES ABOUT CHECKING YOUR SKIN

Please indicate how you feel about the following statements.

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |
|---|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| H1. I can do a thorough skin check for skin cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H2. It is important that I check my whole body, not just the areas that are usually exposed to the sun, for signs of skin cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H3. I know what I am looking for when I check my skin for skin cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H4. I don't want to check my skin because I do not want to find something concerning. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H5. It is hard to remember to check my skin for skin cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H6. I feel comfortable having a partner/close relative/friend check the back of my body for warning signs of skin cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H7. I would be more likely to check my skin regularly if my regular healthcare provider encouraged me to | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H8. I don't check my skin for skin cancer because my doctor does it for me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H9. <u>During the next 2 months</u> , I plan to carefully check my skin for skin cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

How confident are you that you can:

| | Extremely confident | Quite confident | Somewhat confident | A little confident | Not at all confident |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| H10. Tell the difference between melanoma and freckles or moles? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H11. Check the moles (and any other worrisome marks or spots) on your upper back by yourself or ask someone to look for you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H12. Check the moles (and any other worrisome marks or spots) on the back of your lower legs by yourself or ask someone to look for you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| H13. Ask your regular healthcare provider for a skin examination at least once a year? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

I. MANAGING YOUR HEALTH

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally. Your answers should be what is true for you and not just what you think others want you to say. If the statement does not apply to you, select N/A (Not applicable).

| | Strongly agree | Agree | Disagree | Strongly disagree | N/A |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 11. When all is said and done, I am the person who is responsible for taking care of my health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Taking an active role in my own health care is the most important thing that affects my health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. I am confident I can help prevent or reduce problems associated with my health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. I know what each of my prescribed medications does | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please! Do not mark below this line

| | Strongly agree | Agree | Disagree | Strongly disagree | N/A |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 15. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. I am confident that I can tell a doctor concerns I have even when he or she does not ask | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. I am confident that I can follow through on medical treatments I may need to do at home | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. I understand my health problems and what causes them | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. I know what treatments are available for my health problems . . . | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 110. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 111. I know how to prevent problems with my health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 112. I am confident I can figure out solutions when new problems arise with my health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 113. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

ASK STUDY MATERIALS

The following questions are focused on the Advancing Survivors' Knowledge (ASK) About Skin Cancer Study materials. We would like to know what you thought about the print materials, texts and website that were available to you as an ASK participant.

J. ASK PRINT MATERIALS

J1. Did you receive the ASK print materials in the mail?

- Yes
- No → **Go to next section, ASK Text Messages.**
- Do not remember receiving materials in the mail → **Go to next section, ASK Text Messages.**

J2. How many of the ASK print materials did you read?

- All of them
- Some of them
- None of them → **Go to next section, ASK Text Messages.**

J2a. Please check the materials you read:

- "Your skin cancer risk" brochure
- "An appointment checklist"
- "Your step-by-step skin self-check guide" folded poster
- "Your DermLite and how to use it"

J3. Did you look at the ASK print materials again after reading them for the first time?

- Yes
- No
- Not sure/Don't remember

J4. After receiving the ASK print materials, what did you do (besides reading them)?

(Select all that apply)

- Visited the ASK website
- Did a skin self-check
- Used the DermLite lens to look at my skin
- Shared them with others
- None of the above
- Other

If Other, please describe.

Please! Do not mark below this line

J5. After receiving the ASK print materials...
(Select one answer)

- I made an appointment to have a complete skin exam
- I thought about making an appointment for a complete skin exam but it was hard to find time
- I decided to wait until my next scheduled appointment to ask for a complete skin exam
- I recently had received a complete skin exam by my regular healthcare provider or dermatologist, so I didn't do anything
- I was not too concerned about my skin cancer risk so I did not do anything
- None of the above
- Other

If Other, please describe.

J6. If you saw your doctor, did you use the ASK appointment checklist to prepare for the appointment?

- Yes
- No
- Not sure/Don't remember
- I did not see my doctor

J7. If you saw your doctor, did you discuss any of the things that you learned from the ASK print materials with him or her?

- Yes
- No
- Not sure
- I did not see my doctor

K. ASK TEXT MESSAGES

K1. Did you receive the ASK text messages?

- Yes
- No → Go to next section, ASK Website.
- Not sure → Go to next section, ASK Website.

K2. How many of the 13 ASK text messages did you read?

- All of them
- Some of them
- None of them

K3. How did you feel about the number of ASK text messages you received?

- There were too many
- There were just enough
- There were too few

K4. In general, how did you feel about the timing of the delivery of ASK text messages you received?

- ASK text messages were delivered at a convenient time
- I would have preferred the ASK text messages to be delivered: *(Please select all that apply)*
 - Earlier in the day
 - Later in the day
 - On weekdays only
 - On weekends only
 - Other

If Other, please describe.

K5. As a result of receiving the ASK text messages, did you do any of the following?
(Select all that apply)

- Read the ASK Study print materials
- Visited the ASK Study website
- Did a skin self-check
- Used the DermLite lens to look at my skin
- Made an appointment for a physician skin exam
- None of the above
- Other

If Other, please describe.

L. ASK WEBSITE

L1. Did you visit the ASK website (www.askaboutskeincancer.org)?

Yes → **Go to Question L2.**

No

L1a. If you did not visit the ASK website, please tell us why not? (*Select all that apply and skip to next section, General Questions About ASK Materials*)

- Could not remember my log in information/did not want to log in
- I had enough information from the print materials
- I was too busy; not enough time
- I don't have access to/don't spend much time on a computer and/or the internet
- Other

If Other, please explain.

L2. What was the primary reason you visited the ASK website? (*Select one answer*)

- To learn about different types of skin cancer
- To learn how to do a skin self-exam
- To view images of skin cancer
- To learn about skin cancer prevention
- To learn about my risk for skin cancer
- To upload photos
- Other

If Other, please explain.

L3. Please tell us any problems you encountered with the ASK website. (*Select all that apply*)

- Not applicable- I did not encounter any problems
- I did not like having to log in
- The site was difficult to navigate
- The information on the website was difficult to understand
- Other

If Other, please describe.

L4. I would have liked if the ASK website had provided more information about:

L5. Please check any of the actions you took after visiting the ASK website. (*Select all that apply*)

- Looked at my skin for signs of skin cancer
- Used the DermLite lens to look at my skin
- Made an appointment with my regular healthcare provider or dermatologist for a complete skin exam
- Looked at other websites about skin cancer
- Talked to friends and/or family about skin cancer
- Talked to my doctor(s) about skin cancer
- The ASK website did not make me want to do anything else
- Other

If Other, please describe.

M. GENERAL QUESTIONS ABOUT ASK MATERIALS

M1. Which ASK resource was the most useful in helping you look at your skin?

- Website
- Print materials
- Text messages
- The DermLite lens attachment for my smartphone or tablet
- None of the ASK materials were helpful for me

M2. Which ASK resource was the most useful in helping you ask your doctor to look at your skin?

- Website
- Print materials
- Text messages
- None of the ASK materials were helpful for me

M3. Were the ASK Study materials the first time that you learned about your risk for skin cancer?

- Yes
- No

N. DERMLITE QUESTIONS

N1. Did you receive the DermLite lens and attachment for your phone or tablet at the beginning of the study?

- Yes [→ Go to Question N2.](#)
- No [→ END OF SURVEY. PLEASE COMPLETE HIPAA FORM ON PAGE 21.](#)

N2. Would it have been helpful to you if there was an ASK study staff person reaching out to you on how to use the DermLite lens?

- Yes
- No

N3. Did you use the DermLite to look at your skin?

- Yes [→ Go to Question N4.](#)
- No [→ Go to Question N3a.](#)
- Not sure [→ Go to Question N3a.](#)

N3a. Please indicate any reason that you did not use the DermLite to look at your skin?

(Select all that apply)


- I did not have any moles or spots that concerned me
- I could not attach the DermLite to my phone or tablet
- The DermLite process seemed too time consuming
- I decided to go directly to my regular healthcare provider or dermatologist for a complete skin exam
- I wasn't confident that I could identify a potential skin cancer
- I am not very "tech savvy"; not sure I could make it work
- Other

If Other, please explain.

N4. Did you ask anyone to help you use the DermLite lens to look at your skin?

- Yes
- No

N5. Did you take any photos of your skin using the DermLite?

- Yes [→ Go to Question N6, next page.](#)
- No 

N5a. Please indicate any reason you did not use the DermLite to take any photos of your skin?

- I did not have any moles or spots that concerned me
- It was too difficult to take a photo of the moles or spots that concerned me (could not reach)
- The instructions were confusing
- I could not get the DermLite to work
- Other

If Other, please explain.

END OF SURVEY. PLEASE COMPLETE HIPAA FORM ON PAGE 21.

N6. Did you upload photos to the ASK website?

- Yes  [Go to Question N7.](#)
- No

N6a. Please indicate any reason that you did not upload photos.

- I could not log in to the ASK website
- The instructions were confusing
- I was worried about security/confidentiality on the ASK website
- I could not find the Photo Repository on the ASK website
- It seemed too complicated to upload a photo
- When I saw the photo, I was not concerned
- I decided to go directly to my regular healthcare provider or dermatologist for a complete skin exam
- Other

If Other, please explain.

N7. Did you receive the findings of the photo(s) that you uploaded to the ASK Study website from your regular healthcare provider?

- Yes
- No

N8. What device did you use to upload photos to the ASK website? (*Select all that apply*)

- Smartphone
- Tablet
- Computer



HIPAA Authorization Form

If you sign this form, you are giving St. Jude Children's Research Hospital permission to use or disclose (give out) medical information. It will allow St. Jude and LTFU Researchers to get copies of certain parts of your (your child's) medical record that we may need to review, such as treatment history for your (your child's) childhood illness, records for later illnesses, or health screenings.

LONG-TERM FOLLOW-UP STUDY HIPAA¹ AUTHORIZATION TO USE AND DISCLOSE HEALTH INFORMATION FOR RESEARCH

- 1. Purpose.** As a research participant and at my request, I give Greg Armstrong, M.D., M.S.C.E., and the researcher's staff permission to use and disclose my (my child's) health information for a research project called Long-Term Follow-Up (LTFU) Study.
- 2. Individual Health Information to be Used or Disclosed.** My (My child's) health information that may be used or disclosed for this research may include my (my child's) medical records.
- 3. Who May Disclose My (My Child's) Health Information?** During this study, my (my child's) health care information may be released to the researcher and the researcher's staff by the hospitals, clinics, and health care providers who have treated me.
- 4. Who May Receive My (My Child's) Health Information?** The health information disclosed by researchers and information given by me during the research study may be received and used by Greg Armstrong, M.D., M.S.C.E., the researcher's staff, LTFU collaborators, the LTFU Biopathology Center (Columbus, OH), the LTFU Biorepository (Cincinnati, OH), the LTFU Radiation Physics Center (Houston, TX), the LTFU Statistical Center (Seattle, WA), the Memorial Sloan-Kettering Cancer Center (NY, NY), the Dana Farber Cancer Institute (Boston, MA), ClientTell (Valdosta, GA), and the Harvard T.H. Chan School of Public Health (Boston, MA).
- 5. Right to Refuse to Sign this Authorization.** I do not have to sign this form. If I decide not to sign the form, I may not be allowed to take part in this study. However, my decision not to sign this form will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.
- 6. Right to Revoke.** I can change my mind and revoke (take back) this authorization (permission) at any time by sending a written notice of my decision to Dr. Greg Armstrong, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Memphis, TN 38105. If I take back my permission, the researcher may use and disclose only the protected health information already collected for the research study. No further health information about me will be collected by the researcher or disclosed to the researcher for this study.
- 7. Possible Re-disclosure.** After my (my child's) health information is given out under this authorization form, there is a chance that it might be re-disclosed outside this study and no longer covered by this form. However, I understand that the research team and the St. Jude Institutional Review Board (IRB) are very careful to protect my (my child's) privacy and limit the use of information that can identify me (my child). (The IRB is the committee that reviews studies to be sure that the rights and safety of those taking part in the study are protected.) In addition, the LTFU study maintains a Certificate of Confidentiality from the National Institute of Health to protect the identity of research subjects.

For those taking part in the research study who are not legal adults, this authorization form will expire when they become legal adults (unless the person taking part in the study has appointed a legal guardian to provided authorization). A new form will be required when the child becomes a legal adult. For a legal adult taking part in this study, this authorization (permission) expires at the end of the study.

I am the research participant, or I am legally authorized to act on behalf of the person taking part in the study.

I have read this information and have received a copy of the form.



Printed name of research participant

Signature of research participant or legal guardian

Printed name of legal guardian

Describe how the person signing has authority to act on behalf of the research participant

Date



¹HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.

Please! Do not mark below this line

Thank you for taking the time to complete your survey!

This page left intentionally blank

This page left intentionally blank