

LTFU

Long-Term Follow-Up Study

Summer 2019

Update

More knowledge, more power

Little was known about what it meant to be a survivor of childhood cancer when the LTFU Study began in 1994. You've helped change that.

To continue learning how to protect survivors' health during the decades after treatment, we will launch the next follow-up survey in August 2019.

Convenient The survey will roll out first to participants for whom we have email addresses. (Paper surveys will be mailed later.) By saving the survey icon onto a smart phone or other device, you can simply tap your home screen to start or continue answering questions.

Update or provide your email address for easy access to the new survey. Visit ltfu.stjude.org and click on "Update Your Info."

Comprehensive This survey collects a detailed update of information about your health. It's important for us to know if things have changed, and just as important to know if they stayed the same! Your responses become even more important with each additional year of follow-up.

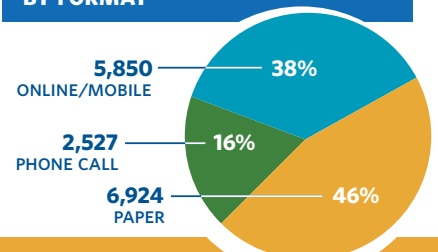
Let's keep learning, together!

2017/2018 survey preferences

Each LTFU Study participant is unique—and each survey makes a unique contribution to advancing scientific knowledge. To make it as easy as possible for you to complete follow-up surveys, we offer a variety of formats. This graph shows how many participants used each of the formats for the recently completed survey.

We will continue to enhance the survey completion options, based on your suggestions and feedback from the Participant Advisory Council (PAC) (see page 2).

NUMBER OF SURVEYS COMPLETED, BY FORMAT



A NOTE FROM US

The most recent LTFU Study follow-up survey has officially closed, and in just a few months, new knowledge about survivorship will be in the hands of doctors, survivors, and researchers. **Check out the infographic on page 2** that shows what we do with your data.

Every response matters

More than 74% of the study's survivor participants and 61% of their siblings completed the survey. Each of the 15,000 completed surveys contains valuable information. LTFU's detailed, continuously updated data is what makes it such a powerful research resource. Thanks to you, we know more than ever before about how to promote survivors' health.

New survey is launching!

The LTFU Study research team is working hard to finalize the next follow-up survey, which will launch in August 2019. This survey is important because it will comprehensively update participants' health information. Strong response rates increase the accuracy and usefulness of research results. **Read "More knowledge, more power" to learn more.**

Thank you!

On behalf of the LTFU Study team, I want to thank every LTFU participant for your ongoing dedication to advancing knowledge about survivor health.

Greg Armstrong, MD
Principal investigator

We're glad you asked...

What happens to my survey after I return it?

You mailed back your paper survey, completed your telephone interview, or hit "Submit" if you responded online/mobile. What then?

If you're curious about what we do with your data, here's a look behind the scenes.



TRACK

As soon as your completed survey is received at the LTFU Coordinating Center at St. Jude Children's Research Hospital in Memphis, TN, we log it into our tracking database—and we stop sending you reminders!



STORE

Information from online/mobile surveys and telephone interviews is directly stored in our database. Paper surveys are scanned to translate the filled-in "bubble" answers into digital code; handwritten responses are transcribed and coded. Then the paper surveys are stored in locked cabinets in a secure facility at the Coordinating Center.



MERGE

When we close the survey, all of the data are combined to create a single data set. Each survey collection period lasts about two years. Completing your survey soon after receiving it can help shorten the survey collection period.



RELEASE

As soon as the results are released, you start making a difference. LTFU data are:

- **Shared with physicians** around the world through scientific publications and conference presentations, to enhance their knowledge about how to provide the best medical care to survivors.
- **Used by researchers** launching new studies to learn more about a specific issue, or to investigate ways of improving survivor health.
- **Communicated to survivors** so they have the knowledge they need to prevent or manage late effects. Information is published in the LTFU newsletter, on our website (ltfu.stjude.org), and in HealthLinks published by the Children's Oncology Group (childrensoncologygroup.org).

CLEAN

The entire data set is carefully reviewed by statisticians at the LTFU Statistical Center at Fred Hutchinson Cancer Research Center in Seattle, WA to make sure it is complete and accurate. This takes about three months. Then the data are ready to be used.



Update or provide your preferred email address

To be notified of the next survey via email, please take a minute to confirm your contact information.

- Visit ltfu.stjude.org and click on "Update Your Info"
- Call us toll-free at 800-775-2167
- Email us at LTFU@stjude.org

LTFU PAC update

More than 100 participants volunteered for the LTFU Participant Advisory Council (PAC) after reading about it in the last newsletter (Winter 2019, online at ltfu.stjude.org).

PAC members are already helping to shape the study by sharing their suggestions on how to improve communication about the LTFU follow-up surveys. We are grateful for their insights!

Study participants who are willing to share their ideas and opinions can still join the LTFU PAC. We will reach out on an as-needed basis to people who signed up. There's no time commitment. To volunteer, please email your interest to ltfu@stjude.org.

Skin cancer early detection practices among survivors

Skin cancer is the most common second cancer among childhood cancer survivors treated with radiation, and one of the most treatable if detected early. But many survivors are missing an important opportunity to protect their health, LTFU Study research found.

A unique opportunity

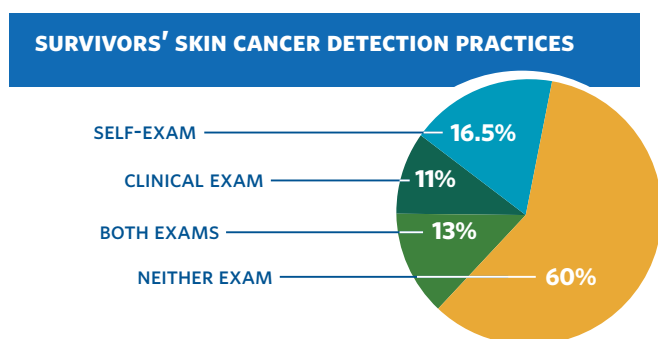
Skin cancer is the easiest cancer to detect early because it's the only cancer we can actually see. Current

follow-up guidelines recommend that survivors treated with radiation regularly check their skin for changes, and receive a skin exam by their health care provider during their annual check-up. Early detection and treatment can help survivors live longer, healthier lives.

LTFU researchers recently published data from 728 participants in the ASK (Advancing Survivors' Knowledge) About Skin Cancer Study, which assessed survivors' adherence to skin cancer screening guidelines.

What we learned

When asked how many times in the past two months they had carefully checked their skin, and whether, in the past 12 months, a health care provider had examined their whole body, here's how they responded:



What you can do

Ask your health care provider for a whole-body skin examination: Providers are more likely to screen when requested to do so by their patients.

Learn how to examine your skin: Learn how to do a monthly skin self-examination to detect any



ADVANCING SURVIVORS' KNOWLEDGE

changes using the ABCDE (Asymmetry, Border, Color, Diameter, Evolution) rule. More information about how to check your skin is provided by the Centers for Disease Control: www.cdc.gov/cancer/skin/basic_info/symptoms.htm

Practice sun safety: Stay in the shade, wear protective clothing outdoors, and apply water-resistant sunscreen (a minimum of 30 SPF) every two hours even when it's cloudy. Avoid tanning beds!



Citation: Geller A, Keske R, et. al. Skin cancer early detection practices among adult survivors of childhood cancer treated with radiation. *Journal of Investigative Dermatology*, April 2019

Latest LTFU publications

Here's a sampling of more LTFU Study research published since the beginning of 2019.

Journal of Investigative Dermatology, April 2019
Genome-wide association study in irradiated childhood cancer survivors identifies HTR2A for subsequent basal cell carcinoma.

Psycho-Oncology, April 2019
Sleep, emotional distress, and physical health in survivors of childhood cancer.

Journal of Clinical Oncology, March 2019
Therapy-related cardiac risk in childhood cancer survivors.

International Journal of Radiation Oncology, February 2019
Hyperthyroidism following radiation therapy for childhood cancer: a report from the Childhood Cancer Survivor Study.

A complete list of all published research can be browsed on the LTFU website: lftu.stjude.org