

Coordinating Center Report

CCSS Investigator Meeting

June 14, 2023

CCSS

Childhood Cancer
Survivor Study



St. Jude Children's
Research Hospital

An NCI-funded Resource

- Provide a staffing overview
- Discuss the core activities of the CCSS Coordinating Center
- Update regarding the myLTFU participant portal
- Review priorities for the next 5 years

Primary role: coordinate the daily activities of the study

3 main teams within the Coordinating Center:

- Project coordination, recruitment, survey administration, biologic specimen and medical record collection, coding
 - Led by Shani Alston, CCSS Project Coordinator
- Phone-based recruitment and data collection, participant tracing
 - Led by Dayton Rinehart, Call Center Coordinator
- Survey creation, database design, data cleaning, myLTFU portal development
 - Led by Chris Vukadinovich, Director of Data and Systems

Serve as the central liaison for all support facilities, committees, working groups, collaborating sites, and external investigators

Coordinate Follow-Up Surveys

- Administer questionnaires to 22,000+ active participants every 2 – 3 years
- Paper, online, and phone survey completion options
- Format, mail, process, code, transcribe, scan
- Reminders (lots of reminders!)
 - Email, text messages, phone calls, mailings

Follow-Up 7 Survey Status

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Participants Invited

Survivors (N = 17,552)

	<u>n</u>	<u>% of Invited</u>	<u>% of Completed</u>
Total Completed	11,745	66.9%	
Completed Online	8,008	45.6%	68.1%
Completed by Mail/Paper	3,028	17.3%	25.8%
Completed by Phone	709	4.0%	6.0%
Non-Responder	5,500	31.3%	
Refused Survey	92	0.5%	
Refused Further Contact	215	1.2%	
<hr/>			
Survey Period: 8/19 – 12/21			

Follow-Up 8 Survey Status – In Progress

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Participants Invited

Survivors (N = 18,104)

	n	% of Invited	% of Completed
Total Completed	7,860	43.4%	
Completed Online	6,636	36.7%	84.4%
Completed by Mail/Paper	980	5.4%	12.5%
Completed by Phone	244	1.4%	3.1%
Non-Responder	10,083	55.7%	
Refused Survey	36	0.2%	
Refused Further Contact	125	0.7%	
Survey Period: 4/22 – Present			

External investigator-initiated studies (ancillary studies)

- Project coordination
- Recruitment
- Data collection
- Regulatory requirements

Subsequent neoplasm confirmation

- Obtain pathology reports/records to histologically confirm reported conditions

Biologic specimen collection

- Oragene (saliva) kits
- Blood sample for participants with a subsequent malignant neoplasm
- Somatic tumor tissue for subsequent malignant neoplasms
- Blood sample for participants with a chronic health condition/matched controls

Collection of DNA: Oragene

- Completed kits go to CCSS Molecular Biology Support Center in Cincinnati
- Front-end \$25 Target gift card

Kits Sent	Overall Survivors (n = 19,198)		Overall Siblings (n = 4,002)	
	<i>N</i>	<i>% of Sent</i>	<i>N</i>	<i>% of Sent</i>
Returned	10,409	54%	1,643	41%
Refused	1,486	7%	325	8%
Pending	5,164	27%	1,408	35%
In Tracing	1,636	9%	581	14%
Deceased	503	3%	45	1%

Participant tracing

Data checks and quality control for survey data

Maintain participant and researcher websites

Participant communication and education in coordination with the CCSS Education Committee (M. Hudson, Chair)

- Newsletters 3 – 4 times per year
- Study results
- Respond to requests and questions
- Liaison with Participant Advisory Committee

Sample Participant Newsletter

CCSS

LTFU

Long-Term Follow-Up Study

Spring 2023

Update

Every day our hearts beat more than 100,000 times, pumping about 2,000 gallons of blood throughout our bodies. Keeping our hearts healthy and strong is one of the most important things we can do to take care of ourselves and prevent heart disease, which is the leading cause of death in the US.

This issue features two LTFU studies with excellent names—CHIP and SALSA—that are exploring how to promote the heart health of childhood cancer survivors. This research aims to discover how communication and support can help survivors become

warriors for their own health. Inside,

A NOTE FROM US

you'll also find resources and tools that can help you be that warrior.

Our Fall 2022 issue focused on colorectal cancer (CRC) and survivorship, another timely and important health topic. While it was being printed, Hollywood celebrity Ryan Reynolds shared his CRC screening experience in a YouTube video that has been viewed more than one million times. During his colonoscopy, his doctor detected and removed a precancerous growth. "This was potentially lifesaving for you," his doctor told him.



The video is part of a public awareness campaign promoting colorectal cancer screening. If you missed the LTFU newsletter or haven't seen the video, here are the links:

- **LTFU newsletter:** Through the myLTFU portal or online at lftu.stjude.org
- **Youtube:** bit.ly/3Q6Cn0f

We always welcome your feedback. Let us know what topics you'd like us to focus on in future issues of the LTFU Update by calling 1-800-775-2167 (8 a.m. to 5 p.m. CST) or emailing lftu@stjude.org.

Greg Armstrong, MD
Principal Investigator



"The goal of these two studies is to help childhood cancer survivors become more aware of how their treatment may have affected their heart, and what they can do to stay healthy," says Eric Chow, MD, a researcher and pediatric oncologist at Fred Hutch Cancer Center in Seattle, Washington.

Survivorship and heart health

LTFU research is exploring new ways to increase awareness of survivors' unique risks for heart disease and discover how best to protect their heart health.

"More than 85% of children with cancer are now surviving beyond five years and they are living longer, healthier lives," says Eric Chow, MD, Co-Chair of the LTFU Study Chronic Disease Working Group. "However, some radiation and/or chemotherapy treatments can increase their risk of developing heart disease earlier than the general population.

"Survivors who received these treatments are more likely, at a younger age, to develop high blood pressure, diabetes, or high cholesterol—conditions that can lead to heart disease. The good news is that, once detected, they can be treated. The goal of our research is to help survivors become more aware of how their treatment may have affected their heart, and what they can do to stay healthy."

CHIP: An intervention for survivors and their PCPs

The CHIP (Communicating Health Information and Improving Coordination with Primary Care) Study was launched five years ago. "Many of today's survivors were treated a long time ago, and they may have forgotten, or perhaps they never received, important details about the types and doses of chemotherapy or radiation treatment they received," says Dr. Chow.

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LTFU

Long-Term Follow-Up Study

Fall 2022

Update

This issue of LTFU Update focuses on colorectal cancer (CRC). CRC is increasing in the general population, and the risk is higher still for childhood cancer survivors who received abdominal or pelvic radiation.

The good news is that colorectal cancer is preventable, and is curable with early detection and treatment.

The information in this newsletter is provided to help you understand your CRC risk, screening guidelines, and the importance of timely screening. We wholeheartedly encourage you to protect your health with CRC screening.

A NOTE FROM US

What our research is doing

This issue highlights what LTFU Study researchers are doing to better understand childhood cancer survivors' CRC risk. The SPIRES Study is exploring how mobile health apps can be used to increase survivor and health care provider knowledge of the CRC screening recommendations.

The LTFU study is also working with survivorship researchers around the world to better understand which survivors are at risk for CRC.

Survey status

The information you have contributed to the LTFU Study over the years provides the basis for today's screening recommendations for childhood cancer survivors. Today, your participation is more important than ever so we can continue to advance survivorship care.

The current LTFU Study survey is available. This survey includes important topics such as health updates, unmet survivorship needs, and medical care. Print surveys are being mailed to participants who prefer it to the online option. The survey also continues to be available through your myLTFU portal. Please call our toll-free number at 1-800-775-2167 or email us at lftu@stjude.org if you have any questions.

We are grateful for your continued dedication and vital contributions. Greg Armstrong, MD
Principal Investigator



What you need to know about... Colorectal cancer

Colorectal cancer (CRC) is the second leading cause of cancer death in the US. When diagnosed early by screening tests, CRC is more likely to be cured than cancer diagnosed after symptoms have developed during later stages of the disease. CRC is a type of cancer that develops in the colon (large intestine) or the rectum (the section of the large intestine closest to the anus). Among the general population, screening recommendations have been adjusted because of an increase in CRC rates among younger adults. Factors like family history and lifestyle affect everyone's cancer risk. While we can't change our family history, healthy changes to diet and activity levels can decrease our risk. (See page 2 to learn more.)

Abdominal or pelvic radiation increases risk

Everyone is at risk for colorectal cancer, but the risk is more than ten times higher for childhood cancer survivors who were treated with abdominal or pelvic radiation. [continued on page 2](#)

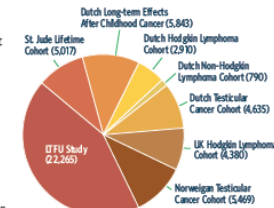
I-SCRY: International "team science"

The LTFU Study has joined forces with seven other international research groups to learn more about CRC among survivors of childhood cancer. By merging the data from these eight cohorts, I-SCRY can analyze detailed information about treatment from more than 51,000 survivors.

An enormous impact on survivor health

I-SCRY will give researchers a better sense of which survivors are more likely to develop CRC. What they learn may help refine the recommendations for screening, prevention, and intervention strategies.

Thanks to the participants in these groups, the results of this study could have an enormous impact on the health of childhood cancer survivors.



I-SCRY creates a "super-cohort" of more than 51,000 multi-national survivors of childhood, adolescent, and young adult cancer.

Childhood Cancer Survivor Study

An NCI-funded resource

Goals:

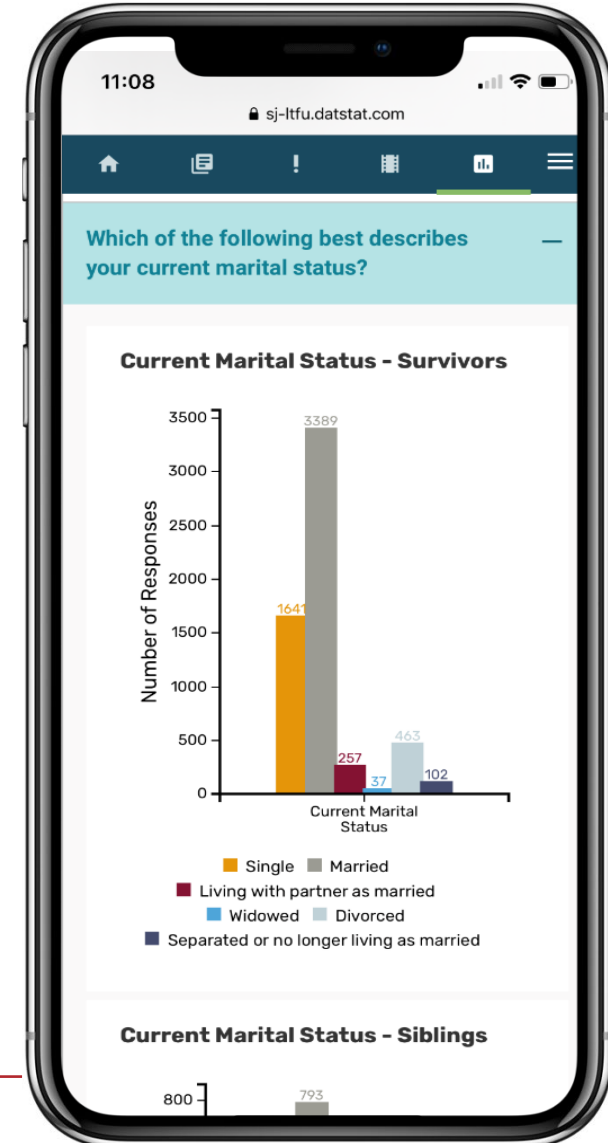
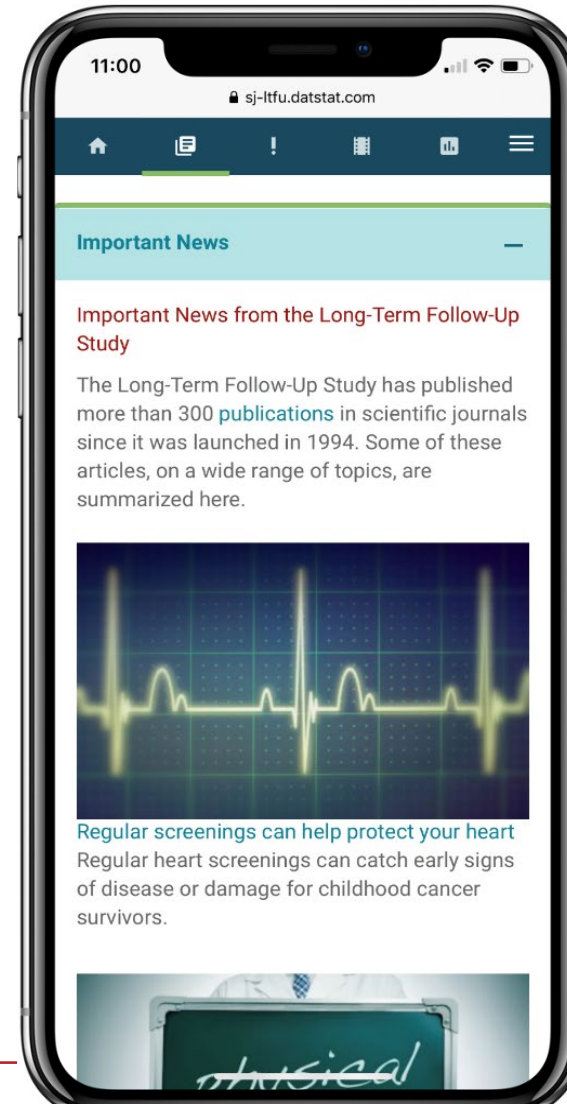
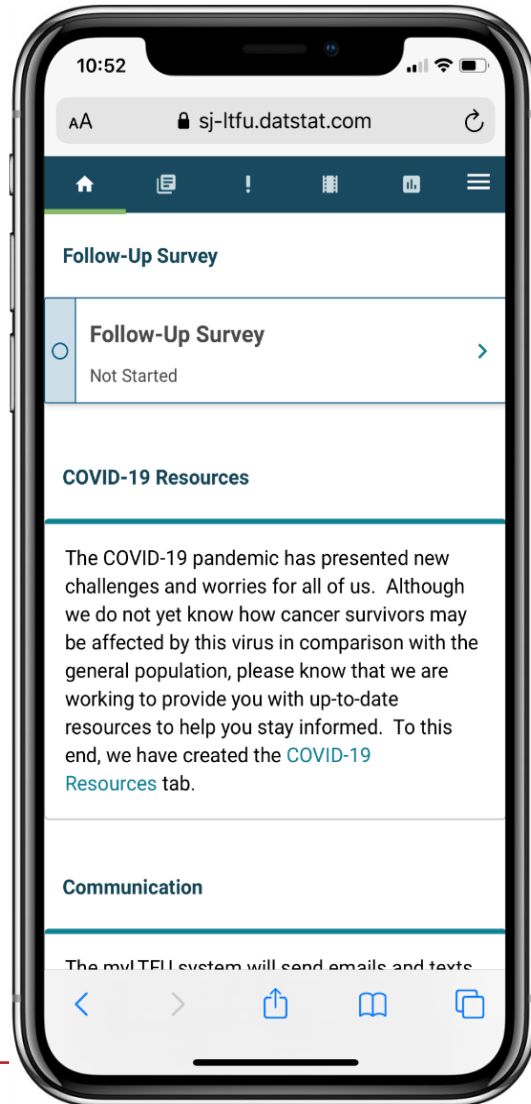
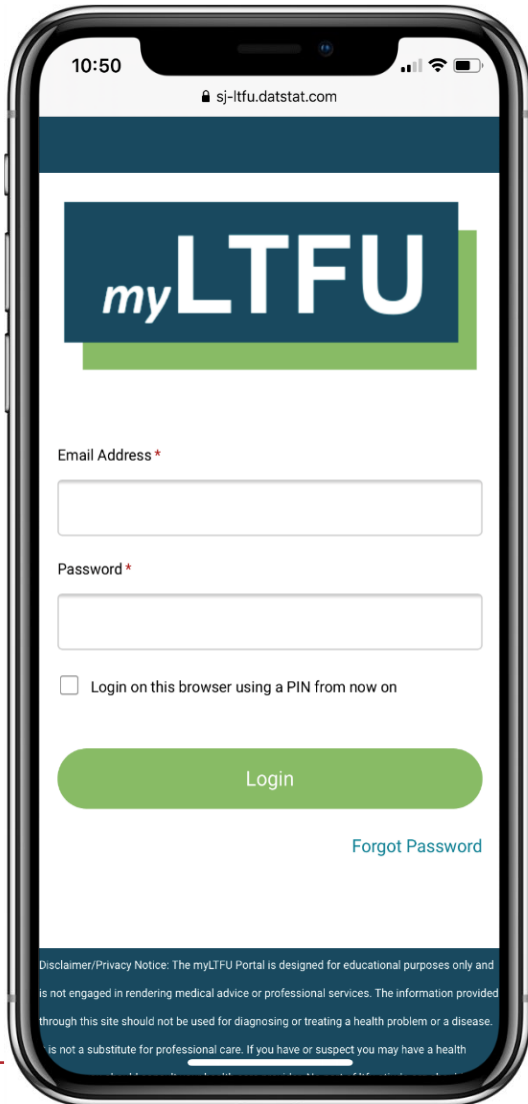
- Implement a flexible, mobile participant portal that can remotely collect self-report and sensor-based data
- Scalable and adaptable system architecture to reliably curate large quantities of data
- Automate study processes
- Dynamic coordinator interface/dashboard for the study team
- Foster participant engagement and communication
- Establish a pool of participants available for mHealth and intervention studies

Utilize the DatStat Connect platform to create a mobile-friendly web portal accessible by smartphone, tablet, or PC

- Participants can bookmark site and save shortcut/icon to mobile device
- Administer online consents, forms, and surveys
- Upload files to the study team
- Schedule messaging (emails and texts) and data collection activities
- Provide participant resources
 - Recommended websites; newsletters; brief study results/updates; live survey results
- Coordinator portal

myLTFU Sample Screenshots

CCSS



Invited participants to the portal with the Follow-Up 7 survey

12,207 survivors (67%); 2,176 siblings (54%) have activated their account

Seven active ancillary studies including three randomized, controlled intervention trials that utilize myLTFU

Priorities – Next 5 Years

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- Administer two follow-up surveys to the cohort
- Conduct an in-home assessment of 1000 participants to examine frailty/aging
- Administer online cognitive assessment to the cohort
- Conduct National Death Index search
- Continue subsequent neoplasm adjudication
- Continue collecting blood and tumor tissue specimens
- Coordinate recruitment and data collection for ancillary studies
- Continue participant engagement efforts while minimizing burden