

Completing the Circle: Lay Summary of Protocol Results for Study Participants

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Why have lay summaries of protocol results?

The success of clinical trials (protocols) includes developing strong, valued partnerships with participants and their families through the life cycle of a study. Our Patient Family Advisory Council identified the inability to communicate study results to participants as an important gap in this relationship. We developed and implemented a project to provide a lay summary of study results to patients and families through the St. Jude website. Providing our families with a lay summary of protocol results not only meets a need, it also creates a deeper bond between our families and our research. Figure 1.



Figure 1.



What is the Patient Family Advisory Council?

The Patient Family Advisory Council (PFAC), comprised of parents of St. Jude patients, represents the patient and family community and partners with our staff to enhance patient family-centered programs at St. Jude. The St. Jude Comprehensive Cancer Center works closely with the PFAC, seeking their input and feedback on research ideas, as well as community needs, and providing education about clinical trials.

How did we do it?

1 Engage Stakeholders

- Communications Department
- Patient Experience Office
- Biomedical Library
- St. Jude *clinicaltrials.gov* coordinator
- Internet Team
- Principal investigators
- PFAC

2 Define Applicable Clinical Trials

- St. Jude investigator-initiated clinical trials
- Peer-reviewed published results
- NCT number from *clinicaltrials.gov*

3 Outline Lay Summary Content

- Why the study was done
- When it was done
- What the study consisted of
- What we learned from it
- What the next research steps were as a result of that study
- How the study's findings affected the participants
- Contacts for obtaining more information
- Where results were published

4 Determine Key Factors for Success

- Ensure consistency in format and language across all lay summaries
- Write in lay language
- Solicit and incorporate feedback from the PFAC
- Address the ethnic and language diversity of our patient population by posting the lay summaries in English and Spanish

5 Define & Execute the Process

- Develop list of St. Jude investigator-initiated, *clinicaltrials.gov*-registered studies
- Identify trials from list with publications
- Draft lay summary based on published results
- Engage principal investigator to review and approve the summary
- Publish English and Spanish versions on *stjude.org*

What has been accomplished?

Currently, 18 lay summaries in both English and Spanish are available through the St. Jude website.

How are the lay summaries communicated to the study participants and their families?

- Surveyed PFAC members on their knowledge of this new initiative
- Featured in **Your Voice** parent newsletter
- Increased accessibility by providing information and links to the summary at multiple locations
 - a. Education section of the patient/parent app
 - b. Patient/Family Advisory Resource Section of the St. Jude website

What's next?

- Optimize our search engine on the St. Jude website so the results from a particular study can be easily found
- Explore ways to notify when there is a new clinical trial result posting
- Assess impact through surveys and website hits

