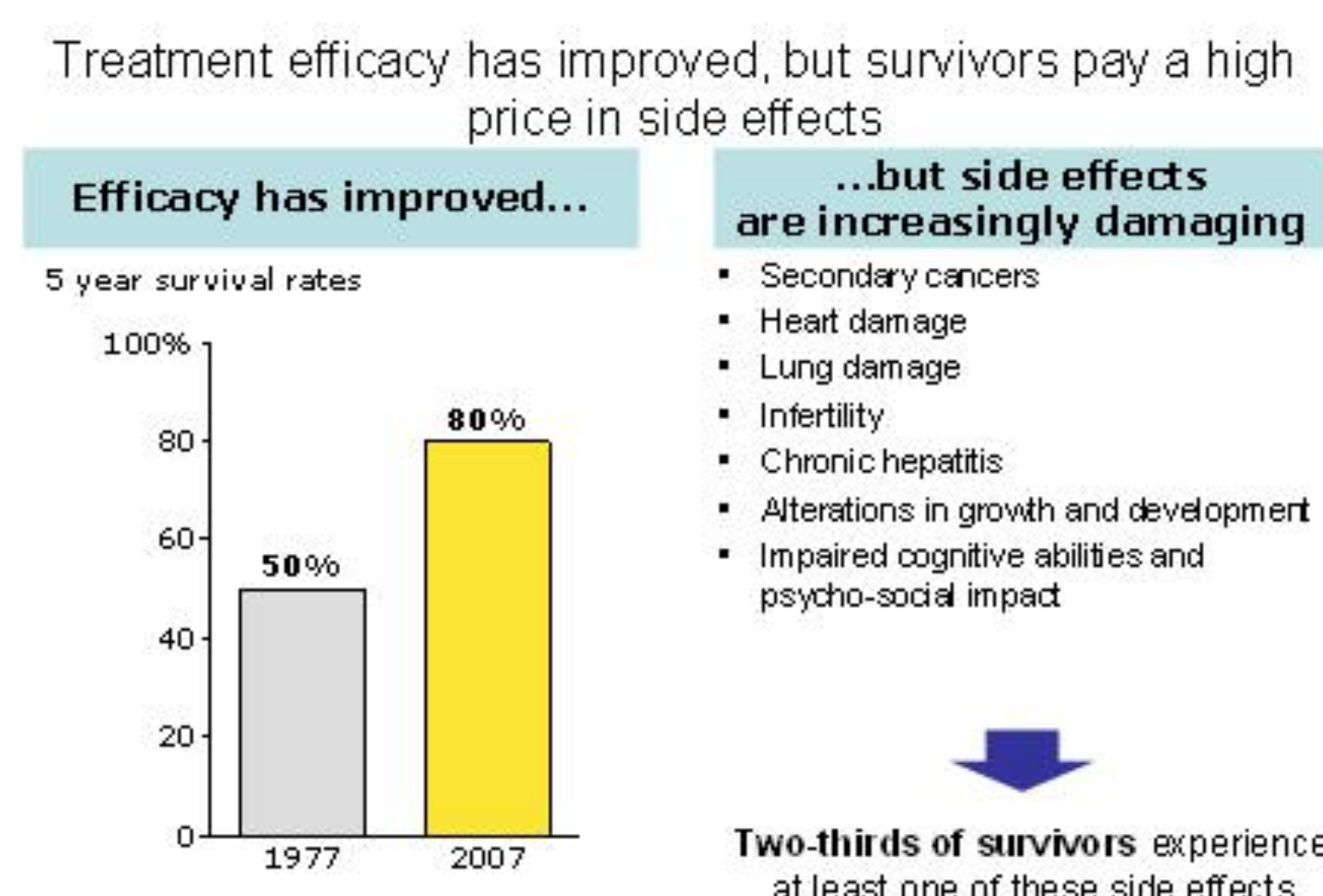


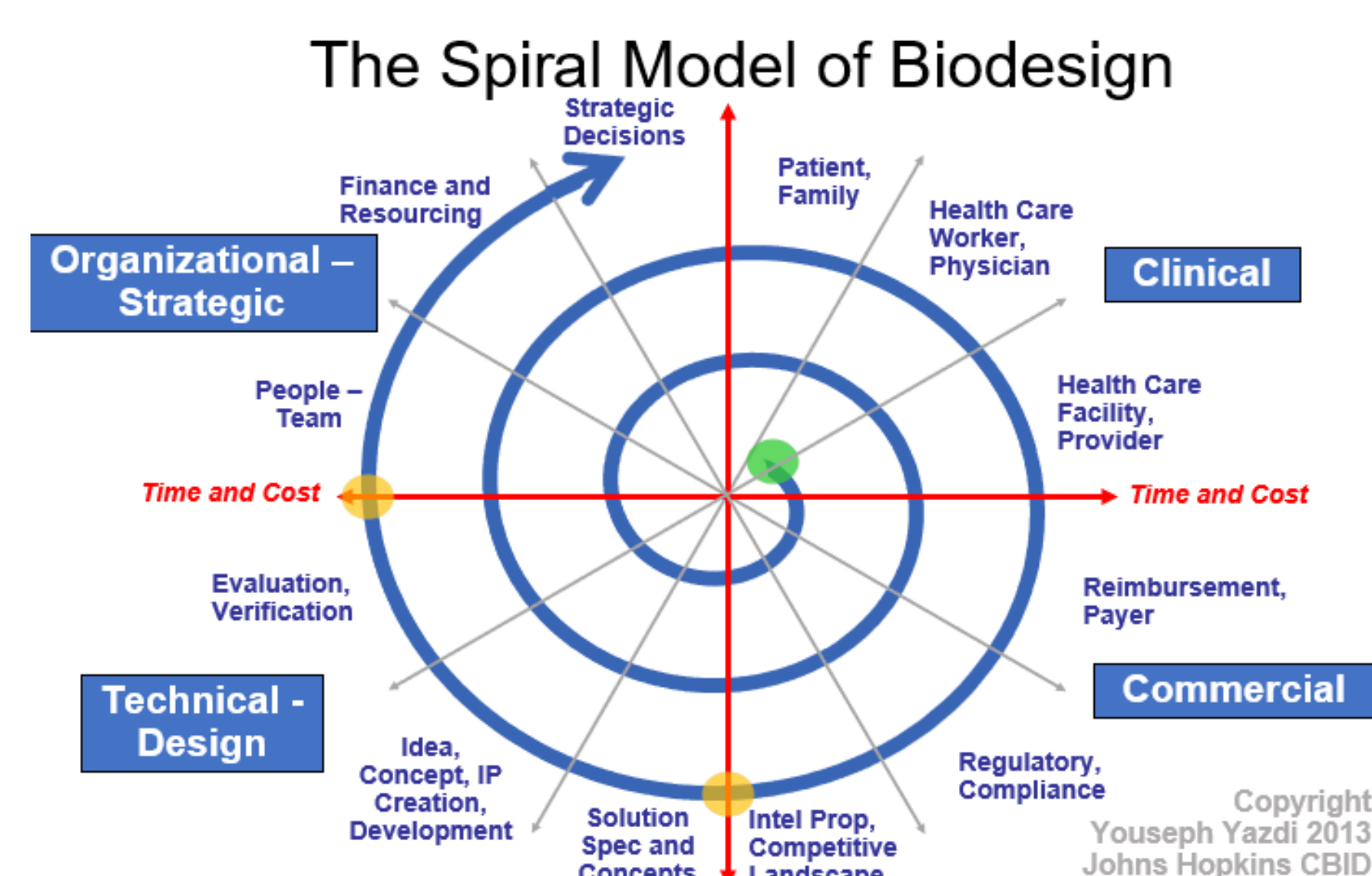
BACKGROUND

- Each year, the parents of approximately 16,000 children across the United States will hear the words "your child has cancer."
- Though the physical aspects of pediatric cancer treatment are unforgiving (chemotherapy, steroids, bone marrow transplants, etc.), the psychosocial impacts that come with enduring this treatment can be devastating for both the patient and those around them.
- ~73% of pediatric cancer survivors experience post-traumatic stress symptoms (PTSS)
- ~99% of families of survivors have at least one member experiencing PTSS
- Therefore, I identified a means to improve the psychosocial effects that come with the pediatric cancer experience
- Under the supervision of Dr. Theodore Moore, MD in the Pediatric-Hematology Oncology clinic at UCLA, I validated the need for such an intervention with stakeholder interviews and clinical observation in concordance with the biodesign process from the Sling Health Summer Biodesign Program



METHODS

- An initial solution concept for improving the psychosocial effects of the pediatric cancer experience was identified and created prior to the start of this ethnographic research
- However, in order to confirm the practical need for such a solution, clinical observation and interview-based validation with 4 different types of stakeholders within the pediatric hematology-oncology clinic were conducted



- The initial need was confirmed and refined into a needs statement formulated to be measurable and appropriately scoped; several additional needs were also identified and followed the same process
- Needs prioritization criteria were selected and applied to all needs discovered in clinic and ultimately confirmed the initial need as the top need
- With confirmation of the legitimacy of the need for the solution concept, a clinical research study is in the process of being designed to test the solution's efficacy in the target patient population

RESULTS

Breadth of Clinical Immersion

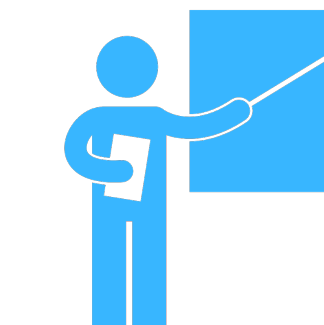
42 hrs
of clinical immersion and ethnography

4
different types of stakeholders interviewed

10 hrs
of stakeholder interviewing & discussions



attending & fellow physicians



child education specialists



nurse practitioners

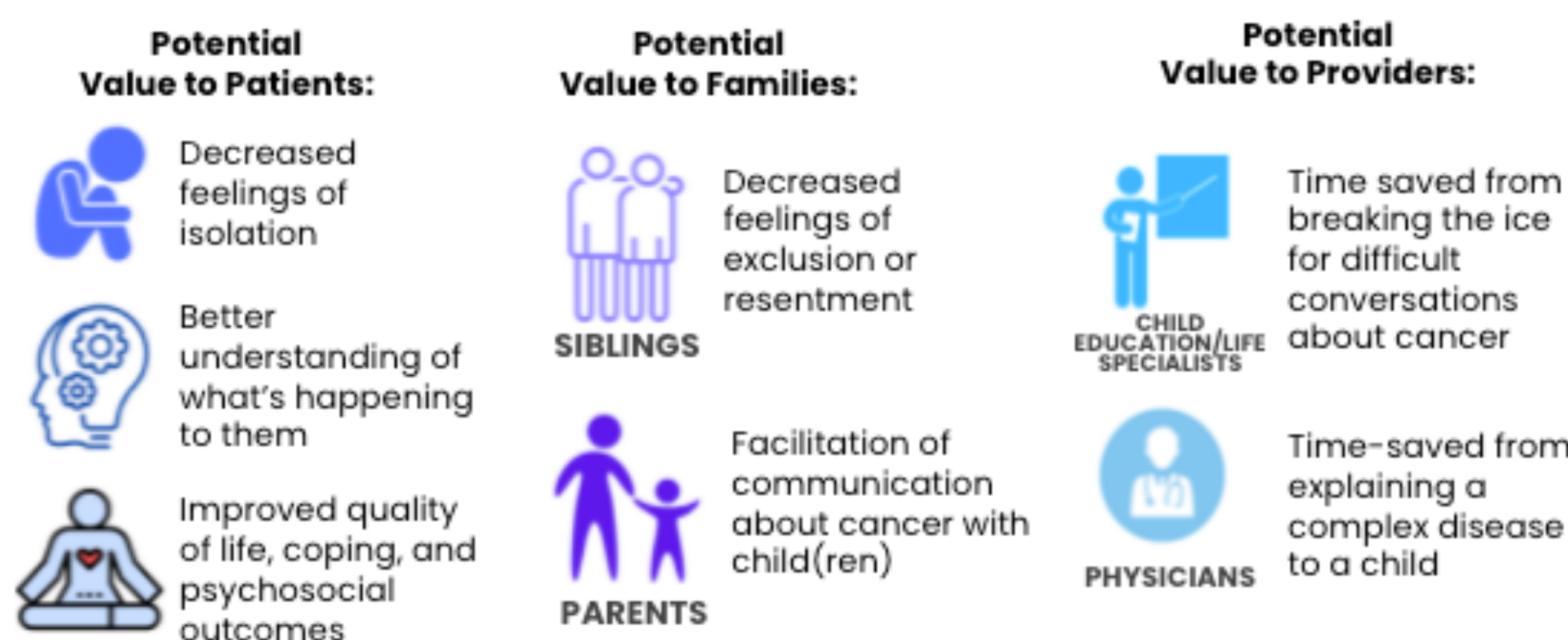
validated the proposed need:

Pediatric cancer patients need a fun way to engage with their disease in order to improve their confidence, autonomy, and understanding of cancer during treatment and reduce adverse mental health effects during/after treatment.

Additional Needs Identified & Validated

- Young adult hematology-oncology patients need a more accessible way to get connected with adult healthcare providers when transitioning from pediatric care in order to prevent adverse health effects.
- Adolescent hematology-oncology patients need a way to improve medication adherence during treatment in order to prevent adverse health effects.

Value Proposition & Potential Impact for meeting the proposed need



DISCUSSION

The top need was first discovered following my personal experience as a pediatric cancer patient over 10 years ago. I found that I lacked a fun and light-hearted way to engage with my disease that included my friends, family, and classmates, and that resulted in feelings of isolation, loss of control, and anxiety.

- Through the biodesign process, I was able to not only better define this need and its scope, but also validate the need through interviews with stakeholders and clinical observations.
- The key stakeholders identified for this project were attending physicians, nurse practitioners, and child education/child life specialists because they are the populations that work most closely with the target patient population.
 - Validation feedback: **meeting this need could help...**
 - patients (+ families) feeling stripped of control over their health
 - children & young adults having a hard time coping with their diagnosis and the effects of treatment
 - patients (+ families) struggling to feel empowered and motivated when they encounter setbacks in treatment
 - siblings feeling excluded when their sibling is sick

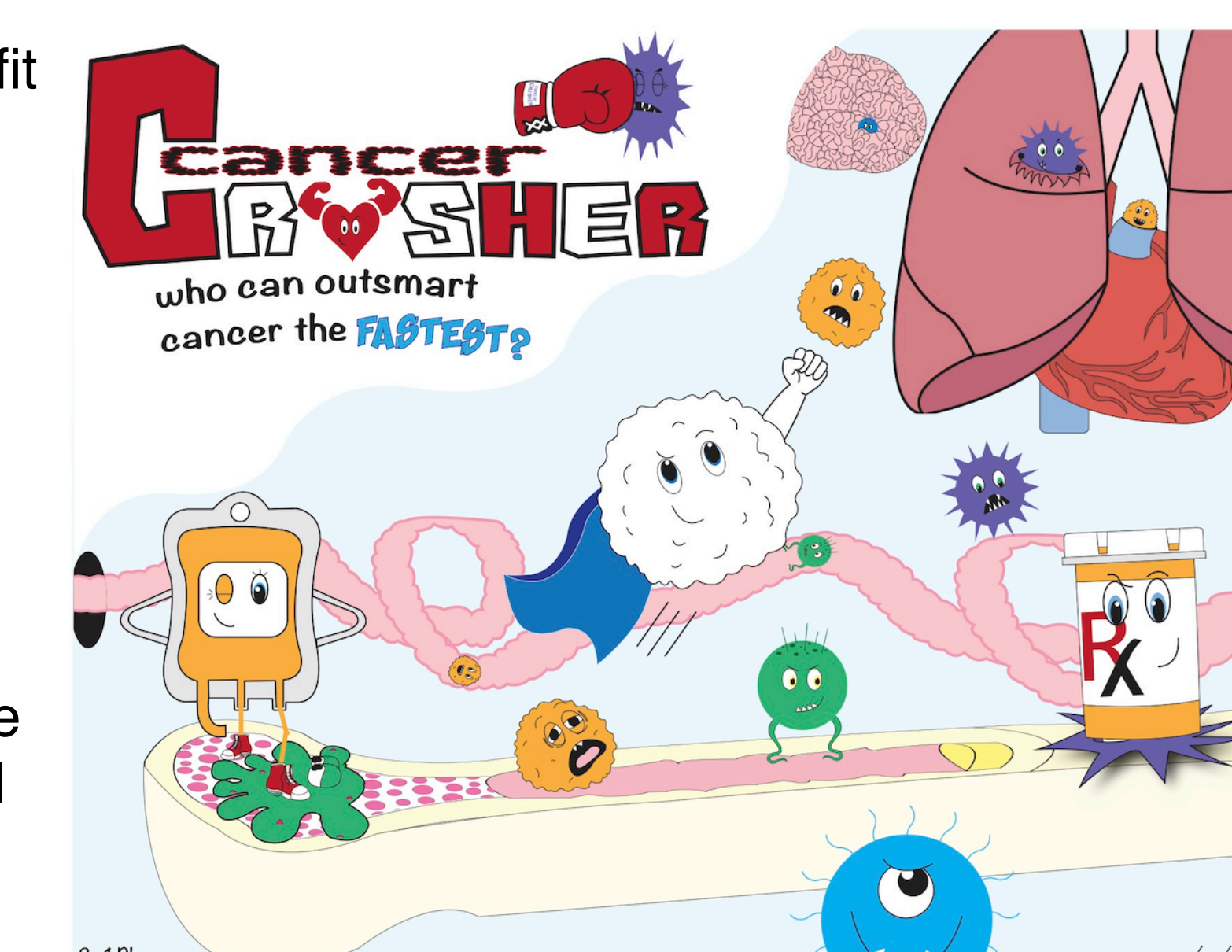
FUTURE DIRECTIONS

A preliminary solution concept had been developed prior to this ethnographic research, but it was imperative to start at the beginning of the process to ensure that the solution would actually be meeting an important need.

Based on stakeholder feedback, it became clear that a solution to meet this need would need to:

- be easily-digestible for young children
- provide a sense of entertainment and fun for young children
- provide an educational benefit that could be understood by young children

Based on the data collected through clinical observation and stakeholder interviews, it appears that the preliminary solution concept would be successful at meeting the top need. However, additional clinical research with the solution concept will be conducted in order to better quantify the size of the impact.



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- Marusak HA, Harper FW, Taub JW, Rabinak CA. Pediatric cancer, posttraumatic stress and fear-related neural circuitry. Int J Hematol Oncol. 2019
- Anne E. Kazak, et.al, Posttraumatic Stress Disorder (PTSD) and Posttraumatic Stress Symptoms (PTSS) in Families of Adolescent Childhood Cancer Survivors, Journal of Pediatric Psychology, Volume 29, Issue 3, April 2004