Category: Community Outreach and Engagement & Diversity, Equity, and Inclusion – Work in progress

Educational Informatics on the Assent Processes of Oncology Research to Children & Adolescents With Cancer

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1. Background

Clinical trials are critical to discovering new options for diagnosing, preventing, and treating cancer. Clinical trials allow researchers to assess the safety and efficacy of potential new treatments across lifespan. The effectiveness of treatments varies by individuals, especially children, given their physiological differences. Additionally, enrolling children in clinical trials presents a unique set of challenges including obtaining consent from guardians and assent—affirmative agreement to participate in research—from children. Despite the importance of obtaining assent from pediatric participants, current processes often fail to engage them directly, leading to a lack of understanding of clinical trials for children with cancer.

2. Goals

Our primary goal was to increase clinical trial enrollment in pediatric oncology clinical trials for youth (ages 6-12). Specifically in our project, we aimed to:

- Create a visually engaging and interactive resource to aid in understanding, address fears, and promote education
- Ensure representation of diverse characters to increase inclusivity and promote a sense of
- familiarity among pediatric patients from various backgrounds, thereby addressing disparities in health care access and participation
- Promote autonomy and empower younger children as part of the decision-making process by explaining clinical trials in simplified terms

3. Solutions and Methods

Our analysis of current assent forms revealed challenges in comprehension due to complex medical terminology and a lack of connectivity. To address these issues, we developed an interactive comic book tailored for pediatric oncology patients, simplifying concepts and enhancing engagement. The novel approach includes a visual glossary defining clinical trial terms and images depicting conditions across different skin tones. Moreover, the inclusion of racially and ethnically diverse characters aims to foster representation and inclusivity. This solution provides a coherent and engaging experience by utilizing relevant storylines, lively illustrations, diverse characters, and interactive features, with the intent to aid in understanding and address potential fears, while remaining informative and accurate.

4. Outcomes

Preliminary findings indicate positive feedback from Yale research professionals regarding the comic book's potential effectiveness in enhancing inclusivity and raising clinical trial awareness among a pediatric oncology population. This communication approach acknowledges the importance of children's autonomy, a guiding ethical principle in clinical research, and empowers children in their decision-making. We expect the comic book will address challenges to enrolling children by simplifying complex information and enhancing engagement through representation of diverse characters fostering inclusivity, and ensuring all children feel represented and understood. By using tools such as the comic book, researchers can create a more inclusive and empowering environment for children, ultimately improving their experiences and outcomes in pediatric oncology clinical trials.

5. Lessons Learned and Future Directions

Future directions include obtaining feedback from Yale Cancer Center Community Advisory Board and Cultural Ambassadors to incorporate into the next iteration. Moreover, we will seek to gather feedback from children to ensure alignment with their interests and needs, while fostering education among pediatric patients and families. We plan for widespread dissemination through collaboration with health care professionals, researchers, and community stakeholders. Ultimately, our efforts will improve information accessibility, encourage trial participation, and contribute to pediatric oncology research advancement locally and globally.