Patient Engagement in the CHAMP Leukemia Intervention Trial Development

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Executive summary

Objectives

Aim 1: To understand the baseline practice of laboratory diagnosis and monitoring prognosis of patients with leukemia at the Pediatric Oncology Unit of Uganda Cancer Institute (UCI), Kampala, Uganda.

Aim 2: To develop and implement an evidence-based algorithm for laboratory investigation, diagnosis, and monitoring treatment response for leukemia in children at the UCI, Kampala, Uganda

Activities

Developed a 15-member Community Advisory Board (CAB); engaged patients and caregivers through workshops, refined diagnostic algorithms, trained patient advocates, and integrated patient feedback through continuous feedback loops for improved leukemia diagnosis and treatment monitoring.

Outcomes

Inclusion of patient-centered endpoints in trial evaluation. Improved healthcare worker training in leukemia diagnostics and patient communication. Improved understanding of the challenges faced by patients and their caretakers during the diagnosis and pathological monitoring of treatment response.

Challenge

Leukemia is the most common childhood cancer in Uganda, yet diagnostic inefficiencies, fragmented communication, and limited patient engagement have led to delayed diagnoses and poor treatment adherence. The CHAMP Leukemia Intervention aims to address these gaps by developing a patient-centered diagnostic and treatment monitoring algorithm.

CHAMP Leukemia

- Established a 15-member Community Advisory Board (CAB) with childhood leukemia survivors, caregivers, and healthcare workers.
- Conducted two consultative workshops with patients and caregivers to identify barriers to timely diagnosis.
- Trained patient advocates to engage meaningfully in the trial process.
- Defined patient-prioritized endpoints such as diagnostic timelines, treatment initiation rates, and quality of life indicators.

Incorporating feedback

- Patient feedback shaped trial design, ensuring cultural appropriateness and relevance, i.e., refinement of the research questions, defining clinically relevant endpoints from the perspective of patients (patient satisfaction and diagnostic turn around time), and patient-friendly graphic materials explaining the trial.
- Input from caregivers led to the inclusion of patient-friendly educational materials like graphics for participant recruitment and infographics explaining leukemia diagnostic and treatment monitoring journey.
- Identified barriers in referral pathways and inconsistencies in diagnosis, leading to process improvements.
- Developed a standardized diagnostic algorithm incorporating real-world patient experiences.

Impact on study design

- Improved healthcare worker training in leukemia diagnostics and patient communication.
- Enhanced protocol design incorporating patient and caregiver feedback, e.g., feedback led to streamlined diagnostic and treatment monitoring pathways and identified clinically relevant endpoints such as reduced diagnostic turnaround time and caregiver satisfaction.
- Strengthened patient-centered research by integrating real-world needs into trial evaluation.
- Enhanced trial design by incorporating culturally sensitive approaches and accessible communication.
- Strengthened patient involvement through continuous input from the Community Advisory Board (CAB).
- Fostered trust and collaboration between researchers, patients, and caregivers for future clinical trials.

Conclusions

- The patient engagement process in the CHAMP Leukemia Intervention has ensured that the proposed clinical trial in Uganda is clinically sound and responsive to patient and parent/primary caregiver needs.
- This can ensure the trial informs strategies to improve leukemia diagnosis, treatment monitoring, and overall patient care, leading to improved overall survival.
- This model can be replicated in other low-resource settings to enhance childhood cancer outcomes, for example, (1) establishing pediatric oncology-focused community advisory boards (with representatives like survivors & parents) for clinical trials within institutions, (2) training and empowering patient Advocates, (3) participatory research by organizing co-design engagement sessions with people with lived experience with pediatric leukemia when designing clinical trials, and (3) cross-country knowledge sharing and regional collaborations.

1 **Applying for the pre-application grant**

2 **Activities proposed**

3 **Outcomes & incorporating them back into endpoint and trial design**

Providing pre-application funding for patient involvement

A new grant mechanism called “pre-application grants” has been launched. These small grants are to close the funding gap for patient experts to provide input to the development of a grant application/protocol.

We are aiming at supporting patient organizations during this early phase with a budget. The budget should be planned to cover travel costs to preparatory meetings and the work time invested by staff or patient experts. This work should be carried out as a preparation step prior to the submission of a clinical research grant application to RTFCCR

4 **Conclusion**

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