The Need for Data Integration and Collaboration for Improved Pediatric Cancer Registry: Lessons Learned from the National Cancer Control Programme Integrating Children, Adolescents, and Young Adults (NCCP ICAYA)

Background

Data integration remains a critical challenge in pediatric cancer care in Nigeria, where fragmented information systems and limited collaboration hinder effective policymaking and resource allocation. The WHO St. Jude NCCP ICAYA initiative highlighted the need for coordinated data systems to support better outcomes for children, adolescents, and young adults (CAYA) with cancer.

Aim

This study explores lessons from the NCCP ICAYA program and its influence on Nigeria’s efforts to establish a comprehensive pediatric cancer registry, with a focus on ongoing work in Nigeria

Methods

We conducted a qualitative review of sessions and stakeholder engagements from the NCCP ICAYA program, focusing on themes of data integration, institutional collaboration, and applicability to national registry development.

Results

The NCCP ICAYA initiative significantly deepened awareness of the importance of a unified pediatric cancer registry. It underscored the value of cross-sector collaboration and real-time data sharing across healthcare institutions. These insights have informed the ongoing development of a national, population-based pediatric cancer registry capturing incidence, treatment, and outcomes. Collaboration among the Federal Ministry of Health, Lagos University Teaching Hospital, and NGOs such as The Dorcas Cancer Foundation has been notably strengthened through the initiative.

Conclusion

The NCCP ICAYA program has played a pivotal role in advancing data integration and stakeholder collaboration in Nigeria’s pediatric oncology landscape. Lessons from the initiative have shaped the foundation for the Pediatric Cancer Registry and offer a scalable model for national implementation to improve childhood cancer care outcomes in Nigeria.