CNS TUMOR BOARD: LESSONS LEARNT AND FUTURE TREATMENT OF CHILDREN WITH CENTRAL NERVOUS SYSTEM NEOPLASMS IN SRI LANKA

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BACKGROUND: To enhance the quality of care available for children with central nervous system (CNS) tumors across the world, a systematic evaluation of service delivery capacity is needed to identify gaps in pediatric neuro-oncology and prioritize interventions. To that end, we created the PediAtric Neuro-Oncology Resource AssessMent Aid (PANO-rama) tool. METHODS: PANORAMA development consisted of three phases: operationalization, consensus building, and piloting. PANORAMA was designed to have domains that capture the elements of the pediatric neuro-oncology care continuum using assessments which were weighted according to their importance. Responses were ordinarily scored to reflect adequacy of satisfaction. PANORAMA was revised based on feedback at various phases to improve its relevance, usability, and clarity. RESULTS: The operationalization phase identified thirteen domains using 252 questions. The consensus phase included validating the identified domains, questions, and scoring by fifteen experts (six pediatric oncologists, three radiation oncologists, two neurosurgeons, two radiologists, and two pathologists). The validated PANORAMA domains were national context, hospital infrastructure, organization and service integration, human resources, financing, laboratory, neurosurgery, diagnostic imaging, pathology, chemotherapy, radiotherapy, supportive care, and patient outcomes. Seventy-six questions were added during the expert review. PANORAMA was piloted at thirteen institutions in twelve countries, representing diverse patient care contexts. Face validity was assessed using the correlation between the estimated score by respondents and calculated PANORAMA scores for each domain (r = 0.67; p < 0.0001). Piloting eliminated two questions. CONCLUSIONS: PANORAMA was developed following a systematic approach, leading to a relevant tool to evaluate the core elements of pediatric neuro-oncology service capacity. PANORAMA will be distributed to facilitate quantitative evaluation of institutional services, allowing for prioritization and benchmarking with centers at the local, regional, and international levels.