

# Unseen and unheard: African children with cancer are consistently excluded from clinical trials

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Cancer in Africa has been described as a runaway train as it now kills more Africans than malaria.<sup>1,2</sup> There are an estimated 1 million new cases of cancer on the continent every year and this is expected to double by 2030.<sup>3</sup> Cancer in Africa is characterised by high mortality and the disparity between mortality rates in Africa and high-income countries (HIC) is most striking for childhood cancers with mortality rates as high as 80% compared with 20% in HICs like the USA and Canada.<sup>4</sup> Despite the stark disparity in burden (85% of childhood cancers occur in low and middle-income countries<sup>5</sup>) and mortality rates of childhood cancers in Africa, access to clinical trials, which are vital for the development of effective and safe therapeutics and treatment, remains unacceptably low for African children.

Over the last two decades, clinical trials have played a key role in improving survival rates for children with cancer in HICs.<sup>6</sup> For example, in England, patients with cancer enrolled in clinical trials have significantly higher survival rates than similar patients with cancer who are not enrolled in trials.<sup>7</sup> The National Comprehensive Cancer Network has stated that clinical trials are the best way to manage patients with cancer.<sup>2,8</sup> Unfortunately, this is not possible for most African countries where very poor prognosis has been linked to late presentation, malnutrition, treatment abandonment, lack of proper supportive services and need for drug dose modification. Undoubtedly, all these factors significantly affect low survival rates of childhood cancers in Africa and must be addressed systematically by strengthening health systems.<sup>5,9</sup> However, the molecular and genetic composition of cancer types, which can influence treatment options, is often neglected in discussions on how to tackle childhood cancers in Africa.

Important ethnic differences exist in the prevalence and outcomes of childhood cancers. In their recent review, Eche and Aronowitz observed that despite Black children having lower risks of acute lymphoblastic lymphoma (ALL), 15 of the

16 studies they reviewed reported inferior survival rates for Black children with ALL compared with their White and Hispanic counterparts.<sup>10</sup> In agreement with this, epidemiological studies of children with leukaemia conducted in the USA and UK observed that unfavourable prognostic characteristics were more common in ethnic minorities compared with White, non-Hispanic children possibly contributing to disparities in survival of minority children with ALL.<sup>11,12</sup>

Oncology clinical trials are crucial for developing novel and safe tools for the prevention, diagnosis, screening and treatment of cancer. Unfortunately, Africa seems to be largely excluded from cancer research. Although the continent accounts for 17% of the world's population, only 2% of participants of genomics studies are of African descent compared with 78% of European ancestry.<sup>13</sup> Even more alarming, only 0.06% of analysed data from the UK Biobank were from people of African ancestry.<sup>14</sup>

The exclusion of African populations in childhood cancer research is deeply troubling. A review of cancer clinical trials in Africa found that only 20 of 54 African countries surveyed hosted clinical trials with the majority in four countries: Egypt, South Africa, Algeria and Kenya.<sup>1</sup> Only 109 cancer clinical trials were being conducted in Africa with a population of 1.2 billion people compared with over 6800 in the USA with a population of 328 million.<sup>15</sup> Regrettably, the exclusion of African participants from the majority of clinical trials means that a large proportion of paediatric patients with cancer are not represented in the very research efforts aimed at combating these diseases.

Children are still excluded from the few cancer clinical trials available in Africa. Currently, most ongoing cancer clinical trials in Africa are funded by academic institutions and pharmaceutical companies based in the USA, Switzerland and Egypt.<sup>1</sup> The top sponsor is Hoffmann-La Roche, a Swiss pharmaceutical company. However, it is likely that very few of these clinical trials focus

on childhood cancers as the top cancers studied are breast, cervical, lung and gastrointestinal.

The untoward exclusion of African children in clinical trials occurs mainly due to a perceived lack of research capacity in Africa. Clinical research activity in many African countries remains low mainly due to limited research and development (R&D) funding. Despite their political commitment to spend at least 2% of gross domestic product (GDP) on R&D, collectively, African countries only spend about 0.5% of their GDP on R&D compared with the 2.2% global average.<sup>16</sup> Ngoma and Ngoma have argued that where resources are limited, policymakers tend to view cancer research as a luxury rather than a necessity.<sup>17</sup> As a consequence, there are few dedicated and skilled research teams which coupled with unreliable internet access, poor or no access to scientific literature, inadequate regulatory structure and poor-quality assurance result in an overall lack of capacity to implement cancer research projects and meet international Good Clinical Practice standards. These factors, together with therapeutic misconception among the general public, prevent more home-grown cancer clinical trials on the continent.

Despite the considerable challenges involved, the combination of a fast-growing, largely treatment-naïve population, large burden of disease and the greatest human genetic diversity of any region in the world, Africa is actually uniquely suited for clinical research. Increasing the number of clinical trials conducted in Africa will certainly require African governments to dedicate considerable resources towards scientific capacity building in their respective countries; however, the key to success will be greater collaboration and integration across the continent. More collaboration is needed between African researchers, research sites and regulatory bodies.<sup>18</sup> Collaboration between national regulatory bodies to reduce the bureaucratic challenges in conducting trials in 54 different African countries with 54 different regulatory jurisdictions will make Africa a lot more attractive to clinical trial sponsors. Similarly, collaboration between African researchers across sites can yield better science and foster mentorship and training opportunities. Collaboration between research sites across the continent and the world can also help standardise treatment protocols/guidelines and improve efficiency allowing for local evidence-based solutions to be generated and more easily shared and implemented.

The conspicuous absence of African children from cancer clinical trials highlights the global disparities that exist in cancer research and care. This disparity must be addressed if the WHO global initiative for childhood cancers is to achieve its goal of at least 60% survival for all children with cancer by 2030.<sup>19</sup> This will not be an easy task, but the battle against childhood cancers will be fought in Africa and is not one the world can afford to lose.

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