

# Medicine needs of children not addressed in the National Cancer Strategic Framework: insights from a triangulation study

Iris R. Joosse<sup>1</sup>, Hendrika A. van den Ham<sup>1</sup>, Aukje K. Mantel-Teeuwisse<sup>1</sup>, Fatima Suleman<sup>2</sup>

<sup>1</sup> Utrecht WHO Collaborating Centre for Pharmaceutical Policy and Regulation, Utrecht Institute for Pharmaceutical Sciences, Utrecht University,

<sup>2</sup> WHO Collaborating Centre for Pharmaceutical Policy and Evidence Based Practice, School of Health Sciences, University of KwaZulu-Natal

<https://doi.org/10.61473/001c.118489>

---

## South African Health Review

Vol. 26, 2023

---

### Aim

A better understanding of the scope of the National Cancer Strategic Framework (NCSF) could lead to improvements aiding the framework's ultimate objective of reducing the burden of cancer. Accordingly, this report evaluates whether the 2017-2022 NCSF adequately addressed issues related to childhood cancer treatment, in particular paediatric oncology medicines.

### Methods

To identify determinants of current access to childhood oncology medicines in South Africa, in-depth interviews were conducted with 29 stakeholders in South Africa's public and private healthcare sectors. Key health system stakeholders included policy makers and regulators, medical insurance scheme informants, medicine suppliers, healthcare providers and civil society stakeholders. Identified barriers were categorised according to the components of the pharmaceutical value chain, and combined with a health systems approach to acknowledge the linkages of medicines with other building blocks of the health system. Identified barriers were then compared to the limitations and interventions as discussed in the 2017-2022 NCSF to identify areas for improvement in the framework.

### Findings

Three recurrent gaps in the NCSF in relation to childhood cancers were identified, representing a range of issues throughout the pharmaceutical value chain: 1) childhood cancers are neglected compared to adult cancers, in both the policy arena and the organisation of healthcare services; 2) there are particular challenges for childhood cancers due to their rarity, thus requiring targeted interventions (e.g., regulatory incentives, tailored pricing solutions, and customised evidence requirements by decision-making bodies); and 3) children must be accompanied by a caregiver during treatment, causing several social and financial issues for their families.

### Conclusions

There is a pressing need for a strategic cancer plan that makes proper provisions for children. Such an endeavour must commence with acknowledging the areas in which childhood cancers are different from adult cancers, and which demand targeted intervention in an update of the NCSF.

## Introduction

Childhood cancer comprises a diverse range of heterogeneous cancers that manifest in children and adolescents.<sup>1</sup> These cancers differ from cancers affecting adults in two

key aspects. First, they have a distinct aetiology, different tumour biology and microscopic appearance, and primarily arise in developing tissues and organs. Second, childhood cancers are often aggressive and marked by rapid growth over a short time.<sup>2</sup> Paradoxically, their rapid growth also renders them more susceptible to

chemotherapy compared to many adult cancers. Timely initiation of treatment, which may also include surgery and radiotherapy, often holds the potential for a cure.<sup>1</sup>

In South Africa, approximately 1 000 children under the age of 19 receive a cancer diagnosis every year.<sup>3</sup> However, this figure is believed to account for less than half of those who develop cancer.<sup>4</sup> Despite the relatively small number of children affected by childhood cancers, the disease is an emerging challenge in South Africa and other low- and middle-income countries (LMICs).<sup>4,5</sup> Survival rates of approximately 50% for childhood cancers in South Africa as compared to those in some high-income countries (reported to be as high as 80-90%)<sup>6</sup> are of great concern.<sup>7,8</sup> Known reasons for these poorer survival rates are diverse, and include late diagnosis of the disease, a lack of treatment capacity at healthcare facilities, physical obstacles to using healthcare services, and barriers in accessing cancer medicines through unaffordable prices, stock-outs, and discontinued manufacturing of essential medicines.<sup>9-11</sup>

The 2017-2022 National Cancer Strategic Framework (NCSF) was intended to guide health legislation and policy-making for cancers at all levels of the health system, through outlining key interventions and establishing a single platform to coordinate the different activities and stakeholders.<sup>4</sup> As the core framework and development plan, the NCSF should have included all those affected by the disease, including children. Although the NCSF identified childhood cancer as a national priority, policy analyses conducted in the context of other LMICs have shown that policy directives for childhood cancers are often vague, hindering progress and resource allocation.<sup>12-14</sup> Hence, this report evaluates whether the 2017-2022 NCSF adequately addressed issues related to childhood cancer, and identifies specific concerns for this population for future policy-development. Considering that childhood cancers are more reliant on chemotherapy than adult cancers,<sup>1</sup> the paper focuses on paediatric oncology medicines in particular.

## Methods

Data source and method triangulation<sup>15</sup> were employed to contextualise quantitative and qualitative data generated in prior research to the NCSF, using the following data sources:

### Quantitative data derived from an analysis of policy documents

Alignment of key pharmaceutical processes in the context of essential childhood cancer medicines was studied through a comparison of the World Health Organization's (WHO) Model List of Essential Medicines for Children (EMLc); the registered health products database of the South African Health Products Regulatory Authority (SAHPRA); the National Essential Medicines List (NEML), and relevant tender documents for antineoplastics and supportive medicines.<sup>16</sup>

### Qualitative data generated through individual in-depth interviews with stakeholders in the pharmaceutical value chain

A health systems analysis was conducted to identify barriers and facilitators in access to childhood cancer treatment and medicines in South Africa. Twenty-nine semi-structured, in-depth interviews were conducted with professional stakeholders in the pharmaceutical value chain, including policy makers and regulators (n = 7), medical insurance scheme informants (n = 5), medicine companies and suppliers (n = 7), healthcare providers (n = 6), and civil society stakeholders (n = 4).<sup>17</sup> Interviews were conducted between September and November 2022 and questions covered aspects related to governance, financing, social aspects and service, and medicine delivery. The barriers and facilitators identified were categorised according to a recently developed framework that covers core processes within the pharmaceutical value chain and broader health system, i.e., policy and legislation, medicine regulation, public financing and pricing, selection, reimbursement, procurement and supply, healthcare delivery, dispensing, and use.<sup>18</sup>

### Qualitative data derived from focus group discussions with caregivers of children with cancer

Four semi-structured focus group interviews (three in the public sector context and one in the private sector) were conducted with caregivers of children with cancer to explore their experiences in accessing and using cancer services.<sup>19</sup> A total of 22 caregivers (20 caregivers of children receiving care in the public health care system and two in the private sector) participated in the sessions, organised in October and November 2022. Participants were asked about the cancer journey, the impact of the diagnosis and treatment on their lives and that of their family, whether they received support, their experiences in accessing care services, financial experiences and costs incurred, and any unmet needs during the cancer journey.

Barriers in access to childhood cancer care identified in each source were extracted and triangulated to create a complete overview of barriers in access to childhood cancer treatment, and then compared to the limitations and interventions as proposed in the 2017-2022 NCSF.<sup>4</sup> Identified barriers were perceived as addressed if any reference was made to the barrier in the NCSF, whether literally or implied, in either the limitations, the description of different service delivery platforms, or in the proposed strategies and goals. A reference did not need to be specific to childhood cancers, but could be more general.

Subsequently, the authors engaged in a consensus process by leveraging the data and explanations provided in the individual studies to assess which barriers predominantly affect treatment of childhood cancers and hence require particular intervention, and which is-

sues have broader implications yet warrant special consideration regarding their impact on children.

## Findings

A total of 59 barriers, differing in size and impact on access to childhood cancer treatment and medicines, were identified through the triangulation of policy documents, stakeholder interviews, and focus group sessions. The barriers include some unique to childhood cancer, alongside obstacles applicable to other cancers or populations, as well as general health system challenges that also have an impact on childhood cancers.

Twenty-five of the barriers arising from the research are acknowledged in the NCSF. Nonetheless, five of those barriers require additional intervention to ensure access for children as well. Of the 34 barriers not addressed in the NCSF, six predominantly affect children and hence require specific intervention to ensure access. Another 11 barriers have broader implications for the general population, but nonetheless warrant special consideration in the context of childhood cancer so as not to neglect their needs. Although general action may still be needed to address the remaining 17 barriers, no specific intervention for children would be required. An overview of all barriers assessed, as well as whether they are acknowledged in the NCSF, and whether they require specific intervention or consideration for children, is provided in [Table 1](#).

The next sections exclusively outline those barriers that require particular intervention or consideration in the context of childhood cancers.

## Policy and legislation

Several professional stakeholders indicated that no concrete political priority is given to childhood cancer, resulting in a lack of targeted strategies for childhood cancers. This is most likely due to the small number of children affected compared to adults. Some of the barriers are inherent to rare diseases (described in more detail below), and specific interventions for cancers affecting smaller patient numbers, incorporated within the larger strategic framework, are thus appropriate.

Within national legislation, stakeholders also highlighted significant issues with the Single Exit Price (SEP) policy. Specifically, they expressed dissatisfaction with the policy, since the underlying basis on which launch prices are determined by manufacturers remains non-transparent. The policy also induces higher pricing due to external reference pricing schemes by other countries. Additionally, although pharmaceutical suppliers indicated willingness to provide medicines at lower prices to small patient populations based on compassionate grounds, the current pricing policies offer no flexibility for discounting. A permanent price reduction is not desired by manufacturers because the SEP policy requires the launch and subsequent changes in prices to be made public, and manufacturers are not willing to have a lower

price made visible to other countries. Exemptions, such as permitting discounting for rare diseases, may provide particular opportunities to amend the SEP policy.

## Medicine regulation

To encourage registration of orphan medicines, stakeholders indicated that there is a need for regulatory incentives such as expedited approvals, exemptions from importation requirement (including post-importation testing and local packaging requirements), or reductions of value-added taxes (VAT), all of which could increase access to some of the innovative childhood cancer medicines.

Section 21 provides an alternative access pathway for medicines that are not (yet) registered in the country (or medicines that were deregistered) on a named patient basis. Several essential childhood cancer medicines are only accessible through this pathway. Some suppliers even indicated they prefer this access pathway for small patient populations, given that the SEP policy does not apply to Section 21 medicines and discounted prices are thus possible. However, this pathway was also associated with increasingly higher pricing for small patient groups, because the relative contribution of additional costs for freight, post-importation testing, and local packaging increases when the patient population decreases. Additionally, considerable delays in acquiring the products may occur due to administrative processes, the time it takes to ship them from Europe or the Americas to South Africa, and subsequent clearance by Customs. Increasingly higher pricing and further delays could be avoided if exceptions were in place for rare diseases such as childhood cancers.

Finally, although deregistration of older products was highlighted as a problem in the NCSF, the issue has a particular impact on children because treatment of childhood cancers is so reliant on those traditional chemotherapeutics.

## Public financing and pricing

Childhood cancer medicines are primarily listed on the NEML for tertiary and quaternary level of care, and therefore financed through the National Tertiary Services Grant (NTSG). No specific part of the budget is allocated to childhood cancers. This budget may also be used to acquire medicines that are not on the NEML. In practice, healthcare professionals indicated that they were unable to access the NTSG budget when attempting to acquire medicines for childhood cancer treatment because the budget had been exhausted elsewhere. Considering that childhood cancer medicines are confined to the NTSG, children are particularly affected by the lack of transparency of NTSG spending and potentially inequitable allocation.

The previous system of temporary care grants has been abolished. If it were reinstated, care grants could be awarded to families of children undergoing cancer treatment to cover the additional costs associated with

Table 1. Barriers in access to childhood cancer treatments acknowledged in or missing from the NCSF, and those requiring specific intervention or consideration for children

| Barriers identified through triangulation                                     | Addressed in NCSF?        | Attention required?        |
|-------------------------------------------------------------------------------|---------------------------|----------------------------|
| <b>Health information systems</b>                                             |                           |                            |
| Lack of monitoring taking place for cancers                                   | √                         | -                          |
| <b>Policy and legislation</b>                                                 |                           |                            |
| Lack of political priority given to childhood cancers                         | x                         | !                          |
| Policy-making to implementation gap                                           | √                         | -                          |
| Lack of multi-stakeholder engagement in policy-making                         | √                         | -                          |
| Transparency and pricing problems in SEP policy                               | x                         | ?                          |
| Medicine patent laws have various shortcomings                                | √                         | -                          |
| <b>Medicine regulation</b>                                                    |                           |                            |
| More regulatory efficiency needed to avoid duplication                        | x                         | -                          |
| Need for regulatory incentives or exemptions                                  | x                         | !                          |
| Medicines not registered or older products deregistered                       | √                         | ?                          |
| Issues in pricing and reimbursement of section 21 medicines                   | x                         | ?                          |
| <b>Public financing and pricing</b>                                           |                           |                            |
| Concerns about allocation of provincial budgets                               | √                         | -                          |
| No transparency in spending of Tertiary Services Grant                        | x                         | !                          |
| No temporary care grants for families                                         | x                         | !                          |
| Medicine or equipment donations are not sustainable                           | x                         | -                          |
| Medicines are high priced                                                     | √                         | -                          |
| Alternative payment models needed for innovative products                     | x                         | -                          |
| No formal Health Technology Assessment process                                | x                         | -                          |
| <b>Selection</b>                                                              |                           |                            |
| Review of tertiary Essential Medicines List (EML) needed                      | x                         | !                          |
| High evidence requirements for EML                                            | x                         | !                          |
| Oncology medicines should be classified as vital on EML                       | x                         | -                          |
| New additions to the EML can be unfunded mandates                             | x                         | -                          |
| Lack of Standard Treatment Guidelines for childhood cancers                   | x                         | !                          |
| Concerns about decision-making of Pharmaceuticals and Therapeutics Committees | x                         | ?                          |
| <b>Reimbursement</b>                                                          |                           |                            |
| Incomplete insurance coverage for cancers                                     | √                         | -                          |
| Members forced to leave insurance plans                                       | x                         | -                          |
| Grey areas in what must be minimally insured                                  | x                         | -                          |
| More clarity in regulations needed                                            | x                         | -                          |
| Concerns about decision-making for ex-gratia payments                         | x                         | -                          |
| <b>Barriers identified through triangulation</b>                              | <b>Addressed in NCSF?</b> | <b>Attention required?</b> |
| <b>Procurement and supply</b>                                                 |                           |                            |
| Process issues with national tender system                                    | √                         | -                          |
| Alternative procurement strategies needed                                     |                           | ?                          |

| Barriers identified through triangulation                                        | Addressed in NCSF?        | Attention required?        |
|----------------------------------------------------------------------------------|---------------------------|----------------------------|
| Lack of urgency from procurement team                                            | ×                         | ?                          |
| Concerns about buy-outs of medicines                                             | ×                         | -                          |
| Unavailability and stock-outs of medicines                                       | ✓                         | -                          |
| Poor distributions systems                                                       | ✓                         | -                          |
| <b>Healthcare delivery</b>                                                       |                           |                            |
| Lack of diagnostic capabilities leading to late diagnosis                        | ✓                         | -                          |
| Inadequate referral systems including repeated transfers                         | ✓                         | ?                          |
| Primary healthcare level training inadequate in public sector                    | ✓                         | -                          |
| Primary healthcare level insufficiently utilized in private sector               | ×                         | -                          |
| Lack of healthcare professionals across healthcare levels                        | ✓                         | -                          |
| Lack of formal training and accreditations for childhood cancers                 | ✓                         | !                          |
| Lack of diagnostic and radiology resources                                       | ✓                         | -                          |
| Lack of psychosocial support                                                     | ✓                         | -                          |
| Lack of priority given to palliative care services                               | ✓                         | -                          |
| Delays in care or defaulting owing to complementary and traditional care         | ✓                         | -                          |
| Child-specific services not catered for                                          | ×                         | !                          |
| <b>Dispensing</b>                                                                |                           |                            |
| Gaps in safe and controlled preparing and administering of medicines             | ×                         | ?                          |
| Lack of clinical responsibility of pharmacists                                   | ×                         | -                          |
| Use(r)                                                                           |                           |                            |
| Inability to travel owing to financial strain                                    | ✓                         | ?                          |
| Symptomatology accepted as part of life                                          | ✓                         | -                          |
| Normal functioning family and work life disrupted                                | ×                         | ?                          |
| Defaulting on treatment                                                          | ✓                         | -                          |
| Frustration with healthcare system                                               | ×                         | -                          |
| Dietary requirements owing to cancer treatment                                   | ×                         | ?                          |
| <b>Barriers identified through triangulation</b>                                 | <b>Addressed in NCSF?</b> | <b>Attention required?</b> |
| Cross-cutting themes                                                             |                           |                            |
| Advocacy needed at all levels                                                    | ×                         | -                          |
| Lack of awareness on and preparedness for childhood cancers                      | ✓                         | !                          |
| Lack of awareness on health system components                                    | ×                         | -                          |
| Lack of knowledge on bone marrow donations                                       | ×                         | ?                          |
| Inequities in care and services provided                                         | ×                         | -                          |
| Lack of funding for non-governmental organisation that provide critical services | ×                         | -                          |

(✓) = Confirmed or implied in analysis of limitations or proposed interventions; (×) = Not confirmed in analysis of limitations or proposed interventions; (!) = Specific intervention required for childhood cancers; (?) = Warrants special consideration regarding impact on childhood cancers; (-) = Does not require particular intervention or consideration for childhood cancer.

treatment. At this time, only children with a permanent disability, such as those who have had a limb or eye removed due to cancer, qualify for a permanent disability grant. However, this excludes most children with cancer.

These findings demonstrate that particular advocacy is needed for children about this issue.

## Selection

With the inception of the NEML and Standard Treatment Guidelines (STGs), public healthcare in South Africa has been rationalised and limited resources have been used effectively. With that, the NEML and STGs are key in providing access to medicines, thus essential childhood cancer medicines missing from the NEML lead to a cascade of complications. Policy-makers and regulators indicated that the current tertiary/quaternary NEML is still adult-dominated, and limited attention has been paid to paediatric indications since inception of the list. They advised that a thorough review of the completeness of the NEML is necessary, with active involvement from paediatric oncologists, along with development of STGs for some of the more prevalent childhood cancer types to increase accountability and access.

Paradoxically, stakeholders indicated that it is difficult to have paediatric oncology medicines added to the NEML due to the strict criteria and evidence requirements applied by the Selection Committee. It is widely known that clinical evidence in children is often missing or weak, which is even more pronounced for rare diseases.<sup>2</sup> In many cases, expert opinion constitutes the core type of evidence, which is not accepted by the Committee. Therefore, the high evidence requirements preclude orphan medicines from being added to the NEML.

If medicines are not included on the NEML, access to them can only be attained after approval from an institutional or provincial pharmaceuticals and therapeutics committee (PTC), usually paid for from the NTSG. The PTC appraises a request based on the justifications provided by the healthcare provider and the evidence presented. This process is associated with numerous obstacles, in addition to the issues associated with accessing the NTSG budget. Specifically, stakeholders expressed concerns because the PTC members often have no expertise in childhood cancers. It was felt that medicines for childhood cancers were not getting approved because the committee members did not understand the urgent need for these medicines. Additionally, high evidence requirements, similar to those for the NEML, preclude these medicines from approval. Finally, there is no transparency and consistency in the decision-making of the PTCs, and the process can be delayed for up to four weeks. As such, revised and transparent procedures are necessary to facilitate better access to cancer medicines not listed on the NEML, including paediatric oncology medicines.

## Procurement and supply

To increase manufacturers' interest in the South African market, and that of other countries in the region, the possibilities for multi-country pooled procurement should be investigated. This is particularly relevant for diseases with small patient numbers, such as childhood cancers.

In addition to this, healthcare professionals who were interviewed experienced a lack of understanding and ur-

gency from other professionals involved in the procurement of medicines. It was felt that impending stock-outs were not communicated timeously by members of procurement teams and that little effort was made to resolve any issues urgently. The usually aggressive childhood cancers are specifically impacted by this perceived lack of understanding and efficiency. Additional training of professionals working in the procurement and distribution chain is needed, as well as more efficient set-up of the procedures involved.

## Healthcare delivery

Many barriers to the delivery of cancer services were already addressed in the NCSF, but three barriers require special intervention or consideration for children. First, inadequate referral pathways may have a more pronounced impact on children because childhood cancers are treated in public sector facilities concentrated in the Western Cape and Gauteng. Hence, some children and their caregivers need to travel long distances, often crossing provincial borders, for treatment. This further disrupts family life and hampers frequent commuting between the treatment facility and the place of residence. Additionally, caregivers indicated that multiple referrals from facility to facility were needed during the diagnosing, staging and treatment of the cancer. These put considerable strain on families, particularly since travel is associated with high costs. The NCSF recognises that more efficient referral pathways are needed and that the secondary level of care may be skipped for cancers. To avoid delays and reduce strain on caregivers, this special population could be considered as a test group if alternative referral pathways are tested.

Second, the lack of skilled healthcare professionals was highlighted in the NCSF, which includes a significant lack of nurses specialised in childhood oncology and paediatric oncology pharmacists. Contributing to this shortfall, there is a particular deficit of training programmes and opportunities in this critical field, significantly impacting the quality of care. Establishing continuous development tracks with periodic retraining and retesting is imperative to maintain consistent skills in childhood oncology nursing and pharmacy.

Healthcare providers noted a third substantial gap: some hospitals, although offering childhood oncology services, do not specifically cater to the needs of children with cancer. A striking example is the closing of hospital pharmacies over the weekend, even though some paediatric chemotherapy regimens continue over the weekend. This constitutes an urgent organisational gap that needs to be addressed locally.

## Dispensing

Healthcare professionals expressed that there are gaps in the preparing and administering of oncology medicines, including those for children. Safe administration may be threatened because staff are not adequately trained to administer chemotherapy to children. In ad-



dition to this, the quality of oncology medicines may be compromised because the controlled environment needed to prepare these medicines, such as a laminar airflow cabinet, is not available in all treatment facilities. This particularly affects small-scale private sector cancer facilities as well. Additionally, healthcare providers indicated that when pharmacy services are not continuously available, medicines may be prepared by untrained individuals in an uncontrolled environment. Children are at greater risk for compromised quality of care because they typically depend on liquid or intravenous dosages forms.

## Use

Financial strain was emphasised as an important concern by caregivers due to travel requirements and the specific dietary requirements of children undergoing chemotherapy. Because children are typically accompanied by a caregiver, an added burden stems from double travel expenses and the necessity for caregivers to arrange their own accommodation and cover their own food expenses. Although non-governmental organisations provide significant assistance to caregivers through accommodation facilities and meals, caregivers continue to experience considerable strain. Moreover, their professional life and their family's dynamics may be disrupted due to continued absence. This, in turn, exerts emotional and psychological pressure on the caregiver and the child. The need for nutritional and financial support, for example through temporary care grants, (see 'Public financing and pricing') was thus highlighted.

## Awareness

Awareness raising and education campaigns were highlighted as key interventions in the NCSF, yet this study identified a significant gap in their scope because campaigns aimed at lifestyle interventions and screening are of minimal relevance for childhood cancers. Through the discussions with caregivers, it became evident that many South Africans are not aware that cancer can also affect children. This lack of awareness, among both the general public and healthcare professionals working in primary healthcare, makes timely diagnosis less likely. There are important opportunities to increase awareness of childhood cancer by actively engaging schools and other early childhood development systems.

Finally, bone marrow transplantations are lifesaving therapies for some childhood cancers, but a general lack of awareness and knowledge on this topic, among caregivers of recipients and especially potential donors, was identified as an important barrier. To broaden access to this life-saving therapy and enable more children to benefit from bone marrow transplantations, an expanded pool of donors, especially from non-white racial backgrounds, is essential.

## Discussion

Analysis of the 2017-2022 NCSF revealed a range of gaps, indicating that although the framework provided a general understanding of overarching issues along the pharmaceutical value chain, it failed to address the specific needs of children. Essentially, the gaps can be distilled into three aspects: 1) a tendency to neglect childhood cancers compared to adult cancers; 2) the distinct challenges arising from the rarity of childhood cancers require targeted interventions; and 3) children are typically accompanied by a caregiver during treatment, putting additional emotional and financial strain on their families. The findings underscore the need for a strategic cancer plan that arranges appropriate measures for children across the health system, as well as for medicines specifically.

The neglect of childhood cancer was evident along the value chain, spanning the policy arena, regulatory and selection processes, and extending to the organisation of healthcare services. However, the omission of childhood cancer from the broader cancer agenda is paradoxical. Despite being consistently emphasised as a priority, the NCSF is adult-dominated and fails to propose any interventions or strategies specifically tailored to address the unique needs of children. This irony becomes more apparent when considering the NCSF's own emphasis on prioritising curable cancers to optimally allocate limited resources, a category that includes childhood cancers,<sup>1</sup> and the Constitutional obligation to realise children's health.<sup>20</sup>

The deficient policy commitments to childhood cancer are in line with findings in other LMICs, where vague directives have previously been described and highlighted.<sup>12-14</sup> Historical prioritisation of communicable diseases over non-communicable diseases has contributed to this deficiency.<sup>14</sup> The desirability and feasibility of expanding access to non-communicable diseases and smaller patient populations and the attitudes of South African policy-makers therein should be explored. At the same time, there are also reports of LMICs that have succeeded in creating political priority for childhood cancers and establishing sustainable financing<sup>21</sup> in which civil society engagement was instrumental. Additionally, childhood cancer, with its relatively high cure rates in a manageable patient pool, could function as a test cohort for cancer policy interventions, for it has been hypothesised that successful childhood cancer programmes may have a positive spill-over effect to benefit adult cancers.<sup>22</sup> This could ensure improved access for both populations.

To enhance prioritisation, there needs to be recognition that childhood cancers are distinct from adult cancers and may have different requirements. While there are notable similarities and interventions that could benefit other cancers, it is crucial not to overlook issues exclusive to children or those affecting them differently. In the present study, the key items that are of specific concern for children and warrant attention have been high-

lighted. Without this recognition, proper provisions cannot be made for this special population in an updated strategic framework.

The rarity of childhood cancers poses challenges in access but at the same time provides opportunities through numerous policy instruments such as regulatory incentives, tailored pricing solutions, and customised evidence requirements by decision-making bodies.<sup>23</sup> However, fundamental to such prioritisation is an operational definition of what constitutes a rare disease in the South African context. Notably, any interventions aimed at childhood cancers could thereby extend benefits to other rare diseases, mitigating some of the challenges associated with those diseases and promoting more equitable access.<sup>24,25</sup>

The emotional and financial toll of childhood cancer on families has been described in the context of other LMICs and was confirmed in the present study.<sup>26-28</sup> Although the NCSF acknowledged the financial, geographical, and logistical barriers associated with cancer treatment, this study hypothesises that these barriers have a more significant impact on families faced with childhood cancers. This impact can be attributed to the highly concentrated provision of childhood cancer care and the fact that these patients are typically accompanied by a caregiver who requires food and accommodation. Temporary care grants should be reinstated and nutritional support programmes introduced to relieve the pressure on these children and their families.

A notable strength of this study's approach lies in the triangulation of quantitative and qualitative data derived from three distinct methodologies. This resulted in a comprehensive overview of barriers to access for childhood cancer treatment, allowing for a meaningful comparison with the NCSF. In line with the NCSF, a health system perspective was adopted. However, by specifically focusing on the medicines in the health system, this research was able to uncover barriers that might have otherwise been overlooked. Although the study was on barriers specifically relevant to children, the analysis also uncovered a range of barriers that apply to adult cancers, revealing opportunities for further expansions of the framework to the general population.

This study inherits limitations from the data sources utilised. Furthermore, during stakeholder interviews, clarity was not always achieved regarding whether identified barriers were specific to children or had broader implications. In such instances, a consensus approach was employed by the authors to deduce the barrier's impact, introducing a potential for different interpretations of the data.

## Recommendations

In order to improve survival and reduce the burden of childhood cancer on South African families, representation of issues that affect children in a future update of the NCSF is key. This begins with acknowledging that childhood cancers are a distinct group of cancers requiring targeted interventions. Fundamental therein, is a clear operational definition for rare diseases and orphan medicines, facilitating prioritisation in the pharmaceutical value chain. To further improve access to childhood cancer medicines, there is a need for flexible pricing solutions and exemptions from importation requirements, as these medicines cannot benefit from bulk purchasing. Additionally, multi-country pooled procurement should be investigated, taking into account the learnings of previously failed and successful attempts in other regions.<sup>29</sup> To ensure sufficient budget for procurement of childhood cancer medicines, NTSG spending must be made transparent to assure its equitable allocation. Given its crucial role in ensuring access to medicines, a thorough review of the NEML regarding childhood cancer medicines is urgently needed, and the benefit of STGs for prevalent childhood cancers should be explored. Furthermore, PTC procedures, including their evidence requirements, expertise of committee members, and administrative processes, must be amended for swift and equitable access. The implementation of continuous training programmes on childhood cancer medicines, whether for nurses, pharmacists, or supply chain staff, is pivotal in delivering high-quality care and should be initiated promptly. Broader health system interventions include nutritional and financial programmes which are urgently needed to alleviate strain on children and their families. Finally, awareness programmes targeting childhood development systems will provide important opportunities for earlier diagnosis.

## Conclusion

The findings of this study exposed a tendency within the 2017-2022 NCSF to overlook the distinct challenges associated with childhood cancers and the medicines needed to treat them. The aspects in which childhood cancer medicines are different from adult cancer medicines should be acknowledged and warrant special provisions in a future update of the NCSF. Without this recognition, proper arrangements cannot be made to improve access to childhood cancer medicines, nor can the Constitutional obligation to ensure children's health be realised.



## Abbreviations

Published: October 01, 2024 CAT.

| Abbreviation | Description                                        |
|--------------|----------------------------------------------------|
| EMLc         | Essential Medicines List for Children              |
| LMIC         | low- and middle-income countries                   |
| NCSF         | National Cancer Strategic Framework                |
| NEML         | National Essential Medicines List                  |
| NTSG         | National Tertiary Services Grant                   |
| PTC          | Pharmaceuticals and Therapeutics Committee         |
| SAHPRA       | South African Health Products Regulatory Authority |
| SEP          | single exit price                                  |
| STG          | standard treatment guidelines                      |
| WHO          | World Health Organization                          |



This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CCBY-NC-4.0). View this license's legal deed at <https://creativecommons.org/licenses/by-nc/4.0> and legal code at <https://creativecommons.org/licenses/by-nc/4.0/legalcode> for more information.

## References

1. World Health Organization. *CureAll Framework: WHO Global Initiative for Childhood Cancer. Increasing Access, Advancing Quality, Saving Lives*. World Health Organization; 2021. <https://www.who.int/publications/i/item/9789240025271>
2. Kattner P, Strobel H, Khoshnevis N, et al. Compare and contrast: pediatric cancer versus adult malignancies. *Cancer Metastasis Rev*. 2019;38(4):673-682. doi:[10.1007/s10555-019-09836-y](https://doi.org/10.1007/s10555-019-09836-y)
3. National Cancer Registry. *Cancer in South Africa: 2020. Full Report*. National Institute for Communicable Diseases; 2020. <https://www.nicd.ac.za/centres/national-cancer-registry/cancer-statistics/>
4. Department of Health. *National Cancer Strategic Framework for South Africa 2017-2022*. National Department of Health; 2017. <https://knowledgehub.health.gov.za/elibrary/national-cancer-strategic-framework-south-africa-2017-2022>
5. Magrath I, Steliarova-Foucher E, Epelman S, et al. Paediatric cancer in low-income and middle-income countries. *Lancet Oncol*. 2013;14(3):e104-116. doi:[10.1016/S1470-2045\(13\)70008-1](https://doi.org/10.1016/S1470-2045(13)70008-1)
6. Allemani C, Weir HK, Carreira H, et al. Global surveillance of cancer survival 1995-2009: analysis of individual data for 25,676,887 patients from 279 population-based registries in 67 countries (CONCORD-2). *Lancet*. 2015;385(9972):977-1010. doi:[10.1016/S0140-6736\(14\)62038-9](https://doi.org/10.1016/S0140-6736(14)62038-9)
7. Stones DK, De Bruin GP, Esterhuizen TM, Stefan DC. Childhood cancer survival rates in two South African units. *S Afr Med J*. 2014;104(7):501-504. doi:[10.7196/samj.7882](https://doi.org/10.7196/samj.7882)
8. Poyiadjis S, Wainwright L, Naidu G, Mackinnon D, Poole J. The Saint Siluan warning signs of cancer in children: impact of education in rural South Africa. *Pediatr Blood Cancer*. 2011;56(2):314-316. doi:[10.1002/pbc.22853](https://doi.org/10.1002/pbc.22853)
9. Mattila PO, Babar ZU, Suleman F. Assessing the prices and affordability of oncology medicines for three common cancers within the private sector of South Africa. *BMC Health Serv Res*. 2021;21(1):661. doi:[10.1186/s12913-021-06627-6](https://doi.org/10.1186/s12913-021-06627-6)
10. Modisakeng C, Matlala M, Godman B, Meyer JC. Medicine shortages and challenges with the procurement process among public sector hospitals in South Africa: findings and implications. *BMC Health Serv Res*. 2020;20(1):234. doi:[10.1186/s12913-020-05080-1](https://doi.org/10.1186/s12913-020-05080-1)
11. Meyer S, Nqabeni G, Tsotetsi N. *Access to Cancer Medicines in South Africa. Cancer Alliance Report CA03/2021*. Cancer Alliance; 2021. <https://canceralliance.org.za/wp-content/uploads/2021/06/Access-to-Cancer-Medicines-SA-April-2021-v3.pdf>
12. Petricca K, Kambugu J, Githang'a J, et al. Access to essential cancer medicines for children: a comparative mixed-methods analysis of availability, price, and health-system determinants in east Africa. *Lancet Oncol*. 2023;24(5):563-576. doi:[10.1016/S1470-2045\(23\)00072-4](https://doi.org/10.1016/S1470-2045(23)00072-4)
13. Boateng R, Petricca K, Tang B, et al. Determinants of access to childhood cancer medicines: a comparative, mixed-methods analysis of four Caribbean countries. *Lancet Glob Health*. 2021;9(9):e1314-e1324. doi:[10.1016/S2214-109X\(21\)00287-4](https://doi.org/10.1016/S2214-109X(21)00287-4)
14. Boateng R, Renner L, Petricca K, Gupta S, Denburg A. Health system determinants of access to essential medicines for children with cancer in Ghana. *BMJ Glob Health*. 2020;5(9):e002906. doi:[10.1136/bmjgh-2020-002906](https://doi.org/10.1136/bmjgh-2020-002906)
15. Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. *Oncol Nurs Forum*. 2014;41(5):545-547. doi:[10.1188/14.ONF.545-547](https://doi.org/10.1188/14.ONF.545-547)
16. Joosse IR, van den Ham HA, Mantel-Teeuwisse AK, Suleman F. Alignment in the registration, selection, procurement and reimbursement of essential medicines for childhood cancers in South Africa. *BMJ Glob Health*. 2023;8(9):e012309. doi:[10.1136/bmjgh-2023-012309](https://doi.org/10.1136/bmjgh-2023-012309)
17. Joosse IR, van den Ham HA, Mantel-Teeuwisse AK, Perumal-Pillay VA, Suleman F. Access to childhood cancer medicines in South Africa: a health systems analysis of barriers and enablers. *J Pharm Policy Pract*.
18. Joosse IR, van den Ham HA, Mantel-Teeuwisse AK, Suleman F. A proposed analytical framework for qualitative evaluation of access to medicines from a health systems perspective. *BMC Research Notes*. 2024;17(1):159. doi:[10.1186/s13104-024-06764-1](https://doi.org/10.1186/s13104-024-06764-1)

19. Joosse IR, van den Ham HA, Mantel-Teeuwisse AK, Suleman F. The caregiver's experience of childhood cancer treatment in South Africa. *J Pharm Policy Pract.* 2024;17(1):2312382. doi:[10.1080/20523211.2024.2312382](https://doi.org/10.1080/20523211.2024.2312382)
20. Buchner-Eveleigh M. Children's rights of access to health care services and to basic health care services: a critical analysis of case law, legislation and policy. *De Jure Law J.* 2016;49(2):307-325. doi:[10.17159/2225-7160/2016/v49n2a6](https://doi.org/10.17159/2225-7160/2016/v49n2a6)
21. Denburg AE, Ramirez A, Pavuluri S, et al. Political priority and pathways to scale-up of childhood cancer care in five nations. *PLoS One.* 2019;14(8):e0221292. doi:[10.1371/journal.pone.0221292](https://doi.org/10.1371/journal.pone.0221292)
22. Gupta S, Howard SC, Hunger SP, et al. Treating childhood cancer in low- and middle-income countries. In: Gelband H, Jha P, Sankaranarayanan R, Horton S, eds. *Cancer: Disease Control Priorities*. 3rd ed. The International Bank for Reconstruction and Development / The World Bank; 2015. doi:[10.1596/978-1-4648-0349-9\\_ch7](https://doi.org/10.1596/978-1-4648-0349-9_ch7)
23. Gammie T, Lu CY, Babar ZU. Access to orphan drugs: a comprehensive review of legislations, regulations and policies in 35 countries. *PLoS One.* 2015;10(10):e0140002. doi:[10.1371/journal.pone.0140002](https://doi.org/10.1371/journal.pone.0140002)
24. Adachi T, El-Hattab AW, Jain R, et al. Enhancing Equitable Access to Rare Disease Diagnosis and Treatment around the World: A Review of Evidence, Policies, and Challenges. *Int J Environ Res Public Health.* 2023;20(6):4732. doi:[10.3390/ijerph20064732](https://doi.org/10.3390/ijerph20064732)
25. United Nations General Assembly. *A/RES/76/132. Addressing the Challenges of Persons Living with a Rare Disease and Their Families*. United Nations; 2021. <https://digitallibrary.un.org/record/3953765?ln=en&v=pdf>
26. Islam MZ, Farjana S, Efa SS. Impact of childhood cancer on the family: evidence from Bangladesh. *Heliyon.* 2021;7(2):e06256. doi:[10.1016/j.heliyon.2021.e06256](https://doi.org/10.1016/j.heliyon.2021.e06256)
27. Rativa Velandia M, Carreño Moreno SP. Family economic burden associated to caring for children with cancer. *Invest Educ Enferm.* 2018;36(1):e07. doi:[10.17533/udea.iee.v36n1e07](https://doi.org/10.17533/udea.iee.v36n1e07)
28. Kasahun GG, Gebretekla GB, Hailemichael Y, Woldemariam AA, Fenta TG. Catastrophic healthcare expenditure and coping strategies among patients attending cancer treatment services in Addis Ababa, Ethiopia. *BMC Public Health.* 2020;20(1):984. doi:[10.1186/s12889-020-09137-y](https://doi.org/10.1186/s12889-020-09137-y)
29. Parmaksiz K, Bal R, van de Bovenkamp H, Kok MO. From promise to practice: a guide to developing pooled procurement mechanisms for medicines and vaccines. *J Pharm Policy Pract.* 2023;16(1):73. doi:[10.1186/s40545-023-00574-9](https://doi.org/10.1186/s40545-023-00574-9)