

# Statement by Civil Society Organizations in Uganda on Budget Allocation for Palliative Care Services for the Financial Year 2019/2020

submitted to:

The Deputy Speaker of Parliament | The Chairperson Committee on Health

Written By: Organizations Working on Palliative Care, Human Rights and Budget Advocacy

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## HIGHLIGHTS ON DEVELOPMENT OF PALLIATIVE CARE IN UGANDA

### THE GAP

- No standalone Palliative Care policy
- No Monitoring and Evaluation framework to guide or monitor implementation of services.
- Public health structure still prefers institutionalized care as opposed to home care which is the most suitable model for PC provision
- Training of Palliative Care providers is not adequate.
- Trained Palliative Care providers not recognized by public civil service structures.

### BUDGET ALLOCATION

- Palliative Care has no direct funding or vote in the national budget.

### WHAT HAS WORKED

- Integration of Palliative Care in the National Health Sector Strategic Plans.
- Inclusion of Palliative Care in the National Minimum Health Care Package.
- Local production of Oral Liquid Morphine which is available free of charge to all in need,
- Allowing specially trained nurses to prescribe morphine for pain control
- Introduction of the Advanced Diploma in Palliative Care Nursing

### THE NEED

Increasing double burden of diseases and conditions that require Palliative Care. eg. Non- Communicable Diseases (NCDs) estimated to account for **33%** of all deaths in 2016, 32,617 new cancer cases and 21,829 cancer deaths in 2018.

Only **4.8%** of the public hospitals have fully integrated Palliative Care services.

Morphine consumption was reported to be 0.3853 mg/capita in 2015, way below the African mean of 0.728mg/capita and global mean of 5.42mg/capita.

## 5 RECOMMENDATIONS TO GOVERNMENT

- Expedite development of the National Palliative Care Policy.
- Consider direct funding for Palliative Care Services at National and Local Government level.
- Invest in Palliative Care training.
- Recognize palliative care specialty in the civil service structure.
- Proposed National Health Insurance Scheme (NHIS) should cover all conditions that require Palliative Care.
- Government supports Private Not for Profit institutions to strengthen home/ community care for Palliative Care patients and their families.

## Definition of Palliative Care

Palliative care is “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and thorough assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>1</sup>

### Palliative Care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;<sup>2</sup>

The World Health Organization (WHO) and the Worldwide Hospice Palliative Care Alliance (WHPCA), in the Global Atlas of Palliative Care at the End of Life, identified the diseases that require palliative care for adults and children to include cancer, cardiovascular/heart, HIV/AIDS and liver and kidney diseases, among others.<sup>3</sup> The majority of adults in need of palliative care have chronic diseases such as: cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). There is evidence to show that early palliative care interventions improve survival and patient outcomes and, for this reason, should be provided from the point of diagnosis<sup>4</sup>.

## Guiding frameworks

In 2014, the World Health Assembly (WHA67.19) passed a resolution on strengthening palliative care as a component of comprehensive care throughout the life course.<sup>5</sup> The May 2017 WHA70.12 resolution on cancer also commits Governments to provide pain relief and palliative care to their citizens.<sup>6</sup> The African Union (AU) Common Position on Controlled Substances and Access to Pain Medications speaks to the availability of narcotic drugs and psychotropic substances to provide relief from pain and suffering associated with serious chronic illnesses.<sup>7</sup>

Palliative care is a component of Universal Health Coverage (UHC), which has a central place in achieving the Sustainable Development Goals (SDGs) by 2030.<sup>8</sup>

<sup>1</sup> World Health Organization, 2015. Palliative care is an essential part of cancer control. Accessed online at: <http://www.who.int/cancer/palliative/en/>

<sup>2</sup> World Health Organisation (WHO) 2004 access on <https://www.who.int/cancer/palliative/definition/en/>

<sup>3</sup> &3 World Health Organization and Worldwide Hospice Palliative Care Alliance, 2014. Global Atlas of Palliative Care at the End of Life. Accessed online at: [http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)

<sup>4</sup> Temel J., Greer J., Gallagher E, et al, 2010. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. New England Journal of Medicine 363(8). [pdf] Available at: <http://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678>

<sup>5</sup> World Health Assembly, May, 2014. Sixty-Seventh World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course. Accessed on <http://www.oeci.eu/Attachments%5CA6>

<sup>6</sup> United Nations General Assembly, September 2011. Political Declaration of the High-Level Meeting of the General Assembly of the General Assembly on the Prevention and Control of Non-Communicable Diseases. Accessed online [http://www.un.org/ga/search/view\\_doc.asp?symbol=A/66/L1](http://www.un.org/ga/search/view_doc.asp?symbol=A/66/L1)

<sup>7</sup> World Health Assembly, May, 2017. Seventieth World Health Assembly. Cancer prevention and control in the context of an integrated approach. Available at: <http://www.who.int/cancer/media/news/WHA58%2022-en.pdf?ua=1>

# Brief History and Progress of Palliative Care in Uganda

The provision of palliative care services in Uganda commenced in 1993 with the establishment of Hospice Africa Uganda (HAU). In 1999, the Palliative Care Association of Uganda (PCAU) was established to provide leadership and coordination of civil society efforts towards the integration of palliative care in the country's health care system working collaboratively with the Ministry of Health. Uganda has realized several milestones. Palliative care has been integrated in Uganda's Health Sector Strategic Plans since 2004. It is included in the National Minimum Health Care Package (NMHCP).

Through a Public Private Partnership (PPP), the Government of Uganda and Hospice Africa Uganda have an understanding for the production of oral liquid morphine which is available for patients in need free of charge. Uganda was the first country in the world to allow specially trained nurses to prescribe morphine for pain control. The WHO and WHPCA mapping of the levels of global palliative care hails Uganda for advanced integration of palliative care into health care system.<sup>9</sup> In 2015, the Quality of Death Index published by the Economist Intelligence Unit ranked Uganda as the second in Africa after South Africa and 35<sup>th</sup> globally out of the 80 countries studied.<sup>10</sup>

## The High Need for Palliative Care Services and the Unmet Gap

Uganda, like other sub-Saharan countries, faces an increasing double burden of diseases and conditions that require palliative care. For example, in the WHO 2018 Country Profiles, Non-communicable Diseases (NCD) were estimated to account for 33% of all deaths in Uganda in 2016. The Ministry Health also revealed that in 2018, there were 32,617 new cancer cases and 21,829 cancer deaths in Uganda. These conditions require palliative care.<sup>11</sup>

Only 11% of those who need pain control and palliative care access it in Uganda<sup>12</sup>. The country's Health Sector Development Plan 2015/16 - 2019/20, shows that palliative care services are being offered in only 4.8% of the public hospitals in the country.<sup>13</sup>

The report by the Uganda Human Rights Commission points out various gaps in the provision of palliative care services<sup>14</sup> Uganda lacks a standalone palliative care policy to guide the implementation of palliative care services. The entire public health structure emphasizes institutionalized care as opposed to home care which is the most suitable model for palliative care provision in countries like Uganda.

<sup>9</sup> World Health Organization, Questions & Answers on Universal Health Coverage. Available at: <<http://www.who.int/contracting/documents/QandAUHC>>.

<sup>10</sup> The Economist Intelligence Unit. The 2015 Quality of Death Index. Ranking palliative care across the world. <https://eiperspectives.economist.com/sites/default/files/2015>.

<sup>11</sup> World Health Organization - Non communicable Diseases (NCD) Country Profiles, 2018. Accessed on [https://www.who.int/nmh/countries/uga\\_en.pdf?ua=1](https://www.who.int/nmh/countries/uga_en.pdf?ua=1)

<sup>12</sup> Knaul FM, et al. Alleviating the access abyss in palliative care and pain relief - an imperative of universal health coverage: the Lancet Commission report. Accessed on <http://www.thelancet.com/commissions/palliativecare>

<sup>13</sup> Ministry of Health of the Republic of Uganda, September 2015. Health Sector Development Plan, 2015/16 - 2019/20.

<sup>14</sup> The 20th Annual Report, Uganda Human Rights Commission accessed on <http://uhrc.ug/reports>

There is no monitoring and evaluation framework for palliative care services. In addition, there is inadequate training of palliative care providers which is coupled with the fact that the public civil service structure does not recognize the few qualified health workers in the field of palliative care.<sup>15</sup> In 2015, Uganda's morphine consumption was reported to be 0.3853 mg/capita, which is below the Afro mean of 0.728mg/capita and global mean of 5.42mg/capita.<sup>16</sup>

## Budget Allocation to Palliative Care

According to the 2018 Africa scorecard on domestic financing for health adopted by the African Union<sup>17</sup>, countries aspiring for UHC needed to have a government expenditure on health of more than \$86.3 per capita (target 1) and 5% of their GDP (target 2). Only 11 African countries met target one and 2 countries met target two, excluding Uganda. Two African countries met the Abuja 2001 Declaration target of spending more than 15% of annual government budget on health, still excluding Uganda. For majority of African countries (89%) including Uganda, out of pocket health payments were more than 20%, which means that according to the WHO, there is financial catastrophe or impoverishment caused by health payments in these countries. In Uganda, Government only met 13.43% of total spending on health, households and employers 46.71% and development partners 39.86%.

In order to achieve the national development agenda, the health sector has pledged to keep focusing on, among others, the delivery of palliative care services to all Ugandans. However, the budget landscape does not sufficiently align to this aspiration. Palliative care has not realized direct funding or vote in Uganda's national budget. In the Budget Framework Paper for the 2019/20 financial year,<sup>18</sup> there are significant budget cuts that touch the provision of palliative care. The proposed Uganda Cancer Institute (UCI) budget for the FY 2019/20 is projected to decrease by UGX 30.561 billion (33.513%) from UGX 91.192 billion in FY 2018/19 to UGX 60.631 billion.

This absurdly comes at a time when there is a growing need for palliative care in this sphere. Be that as it may, the future funding prospects for the UCI further promise nothing but gloom. The downward spiral in funding continues as projections for financial years 2020/21 and 2021/22 reflect UGX 30.7 billion and UGX 33.2 billion respectively in budget allocation. This retrogression in funding is unjustified in a state that is faced with lack of essential medicines, medical equipment and human resource to tackle the growing cancer cases. See figure 1 for UCI budget details.

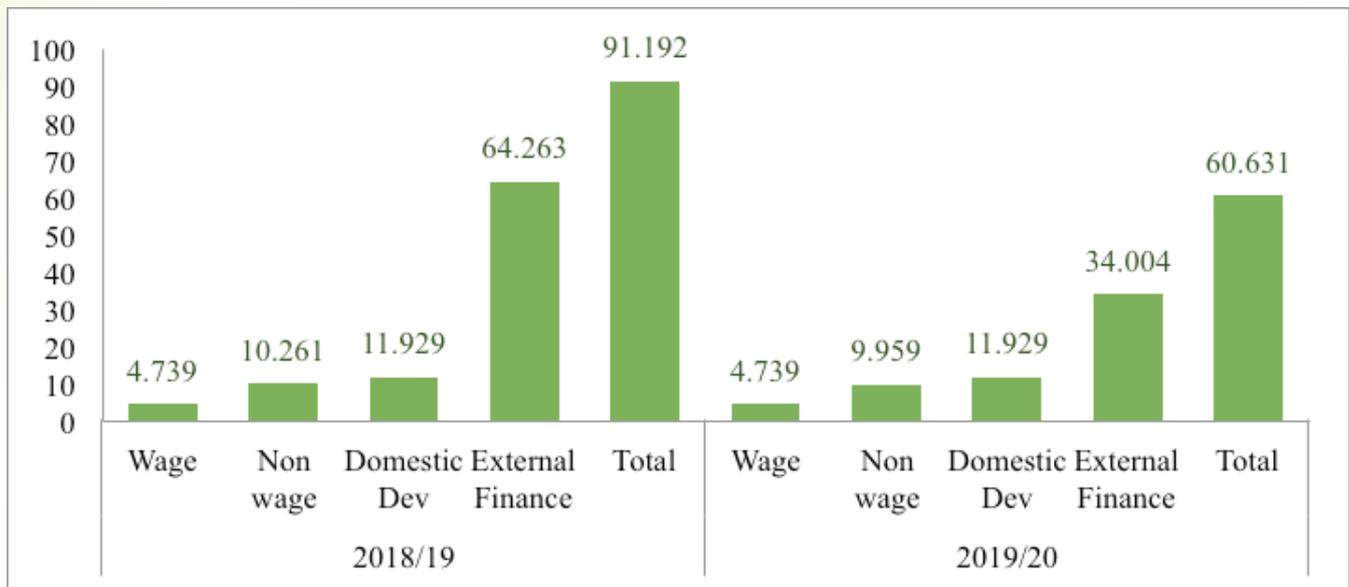
<sup>15</sup> Jagwe J, Merriman A. Uganda: Delivering Analgesia in Rural Africa: Opioid Availability and Nurse Prescribing. *Journal of Pain and Symptom Management*. Vol. 33 No. 5 May 2007. [https://www.jpmsjournal.com/article/S0885-3924\(07\)00118-2/pdf](https://www.jpmsjournal.com/article/S0885-3924(07)00118-2/pdf)

<sup>16</sup> International Narcotics Control Board; World Health Organization population data: By Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2015

<sup>17</sup> African Union and the Global Fund, 2018. Africa Scorecard on Domestic Financing for Health, 2018. [online] <http://aidswatchafrica.net/index.php/africa-scorecard-on-domestic-financing-for-health/document/75-2018-africa-scorecard-on-domestic-financing-for-health-english/12>

<sup>18</sup> <http://budget.go.ug/budget/sites/default/files/National%20Budget%20docs/National%20Budget%20Framework%20Paper%20FY%202019-20.pdf>

**Figure 1: Uganda Cancer Institute Budget for FY 2018/19 and proposed 2019/20**



Source: Ministry of Finance, Planning and Economic Development.

The table above, also shows that external finance exceed domestic financing for the two financial years. In financial year 2019/20, even if the external funding is projected to reduce, it is still higher than domestic financing. Relying on external financing for UCI is unsustainable as it is susceptible to shocks like sudden reduction in funding as it is projected to happen for the FY 2019/20.

**The Health Sector Ministerial Policy Statement for FY 2016/17 on Vote 104 for the Ministry of Health shows that UGX 155M (One hundred fifty five million shillings) had been allocated for Palliative Care Activities. This was indicated for Clinical and Public Health under Programme 07 of Clinical Services. Much as the amount was low given the role expected of the Ministry of Health in ensuring adequate integration of Palliative Care in the entire health care structure, the Health Sector Ministerial Policy Statement for FY 2019/20 did not indicate any amount for Palliative Care Activities. This is despite the fact that Palliative Care is included in the Uganda National Minimum Health Care Package (UNMHCP) as per the Health Sector Development Plan 2015/16 - 2019/20. Without direct budgetary allocation to Palliative Care Activities, it would be difficult to actualize such plans.**

In a nutshell, apart from providing budgetary information on cancer and HIV/AIDS services, Uganda's national budget has meagre regard for the need to specifically allocate a vote to palliative care; the net effect of which is difficulty in tracking performance and ultimately failure to take measured steps towards averting the challenges that face the broader provision of palliative care services as earlier mentioned.

## Snapshot Comparison with East African Countries

Rwanda was the first African country to pass a stand-alone national palliative care policy<sup>19</sup>. The country has national guidelines for palliative care and funding for palliative care in the National Health budget.<sup>20</sup> Palliative care is therefore included in the country's National Health Insurance Scheme.<sup>21</sup> The Ministry of Health of Rwanda has a dedicated person for palliative care activities. Only Kenya among the East African countries reported morphine consumption per capita (2.1459mg/capita) in 2015 above the Afro mean (0.728mg/capita), although still below the global mean of 5.42mg/capita.<sup>22</sup> Palliative care is included in the National Cancer Plan, National HIV plan.

The country also has a person dedicated to coordinate palliative care activities nationally.<sup>23</sup> Tanzania has a National Palliative Care Policy Guideline and palliative care is included in the National Cancer Plan and HIV plan, with the country having a National Coordinator for palliative care at the Ministry of Health. The country undertakes the local production of oral liquid morphine for pain relief, although no dedicated funding is yet included in the national health budget.

## Recommendations

In order to improve palliative care service provision in Uganda the undersigned organizations recommend that:

- a) Government fast tracks the development, approval and ensure funding for the implementation of the National Palliative Care Policy.
- b) Government initiates steps to progressively realize direct funding for palliative care services in Uganda. There should be a vote for palliative care in the future national budgets of Uganda.
- c) Government considers investing in human resources for palliative care by training palliative care providers at all levels.
- d) The Health Service Commission and other relevant bodies should recognize palliative care as a medical, nursing and allied health workers specialty and therefore recruit and retain palliative care specialists in service at least up to Health Centre IV level.
- e) While considering to pass the National Health Insurance Scheme (NHIS) Government should ensure that the scheme covers all conditions that require palliative care.
- f) Government considers deliberate funding to Private Not for Profit Standalone Hospices to strengthen home and community care among palliative care patients and their families.

<sup>19</sup> Luyirika E.B.K, Namisango E, Garanganga E et al. Best practices in developing a national palliative care policy in resource limited settings: lessons from five African countries. *ecancer* 10 652 / <https://doi.org/10.3332/ecancer.2016.652>. <https://ecancer.org/journal/10/652-best-practices-in-developing-a-national-palliative-care-policy-in-resource-limited-settings-lessons-from-five-african-countries.php>

<sup>20</sup> The APCA African Palliative Care Atlas 2017 [https://www.africanpalliativecare.org/images/stories/pdf/APCA\\_atlas.pdf](https://www.africanpalliativecare.org/images/stories/pdf/APCA_atlas.pdf)

<sup>21</sup> African Palliative Care Association, 2018. East African Documentary on palliative care. <https://www.youtube.com/watch?v=HGZlBtkNms&t=24s>

<sup>22</sup> Same as 15

<sup>23</sup> Same as 18

# Organizations that endorsed this Statement:



The **Initiative for Social and Economic Rights (ISER)** is a registered Non-Governmental Organisation (NGO) which seeks to promote the effective understanding, monitoring, implementation, accountability and full realisation of Economic and Social Rights (ESRs) in Uganda and the East African region. <https://www.iser-uganda.org/>



**African Palliative Care Association (APCA)** was formally founded in Tanzania in 2004 and established in 2005 in Kampala. APCA's mission is to ensure that palliative care is widely understood, integrated into health systems at all levels, and underpinned by evidence in order to reduce pain and suffering across Africa.



The Palliative Care Association of Uganda (PCAU) is the National Association for Palliative care in Uganda, registered as a Non-Governmental Organization (NGO) in 2003. PCAU envisions access to Palliative Care for all patients and families in need in Uganda. PCAU works towards the integration of palliative care in the Uganda Health Care System through advocacy, capacity building, research and resource mobilization. <https://pcauganda.org/>



The **Center for Health, Human Rights and Development (CEHURD)** is a Non-governmental Organization pioneering the justiciability of the right to health in the East African Region. CEHURD works towards ensuring that public health laws are used as principle tools for the promotion and protection of public health of the vulnerable populations in the East African region. CEHURD realizes this through an integrated program of litigation, advocacy, and action research. CEHURD concentrates its efforts on vulnerable populations such as women, children, orphans, sexual minorities, HIV/AIDs, persons with disabilities, refugee populations. <https://www.cehurd.org/>



**Uganda Network on Law, Ethics and HIV/AIDS (UGANET)** was established in 1995 to bring together organizations and individuals who are interested in advocating for the development and strengthening of an appropriate policy, legal, human rights and ethical response to Health and HIV/AIDS in Uganda. <https://uganet.org/>



**The Coalition for Health Promotion and Social Development (HEPS-Uganda)** is a health and human rights non-governmental organization which envisions a society in which all Ugandans can exercise their health rights and responsibilities. Established in the year 2000, HEPS-Uganda is a coalition of health consumers, health practitioners, Civil Society Organizations (CSO's) and Community Based Organizations (CBOs) that works to ensure equitable access to health services with special focus on access to essential medicines for all Ugandans. <https://www.heps.or.ug/>



**Hospice Africa Uganda (HAU)** was founded by Dr. Professor Anne Merriman in 1993 to address the overwhelming unmet need for palliative care in Africa. Having chosen Uganda for the model, with an ethos with the patient and family at the Centre of all, an affordable culturally appropriate model for Africa was developed. <http://uganda.hospiceafrica.or.ug/>



**Uganda cancer society** is an umbrella organization established in 2011 with a current membership of about 40. The mission of UCS is to coordinate civil society efforts for a systematic contribution towards effective cancer control in Uganda through fostering collaborative advocacy, awareness creation, capacity building, research and patient support. <https://www.ugandacancersociety.org/>



**Kawempe Home Care (KHC)** is a not for profit organisation that was started in July 2007 by a group of devoted health professionals. KHC's Mission is to improve the quality of life for people living with HIV/AIDS, TB, and or cancer through the creation of sustainable community based model of holistic care which comprises of treatment, prevention and support. <https://kawempehomecare.org/>

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