JOINT CIVIL SOCIETY REPORT ON PALLIATIVE CARE IN UGANDA
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Brief profile of submitting Organisations

1. **Palliative Care Association of Uganda (PCAU)** is the National Association for Palliative care in Uganda, registered as a Non-Governmental Organization (NGO) in 2003. The mission of PCAU is to support and promote access to palliative care for patients and families in need through the integration in health care systems, education, training and evidence based practices and advocacy.

2. **African Palliative care Association (APCA)** was formally founded in Tanzania in 2004 and established in 2005 in Kampala. APCA's mission is to ensure 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.

3. **Kawempe home care (KHC)** was started in July 2007 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**.**

4. **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.

5. **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.

6. **The Initiative for Social and Economic Rights (ISER)** is a registered national non-governmental organization in Uganda founded to ensure the full recognition, accountability and realization of social and economic rights primarily in Uganda and the East African region.

KEY WORDS: *PALLIATIVE CARE; RIGHT TO HEALTH; CANCER INSTITUTE; MONITORING AND EVALUATION; UNIVERSAL HEALTH COVERAGE; LACK OF DISAGREGGATED DATA; ESSENTIAL MEDICINES*

EXECUTIVE SUMMARY

1. This report discusses the realization of the right to palliative care in Uganda, highlighting key challenges faced in accessing palliative care. It makes recommendations on how to strengthen access to palliative care so as to fully realise the right to health.

2. Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.[1] Palliative care is required for a wide range of diseases for adults[2] and children.[3]

3. The government of Uganda through the Ministry of Health and civil society working in the area of palliative care have realised key milestones in the provision of palliative care in the country. Uganda was ranked the best in Africa.[4] In the October 2015 Quality of Death Index published by the Economist Intelligence Unit, Uganda was second in Africa and 35th globally out of the 80 countries studied.

4. Despite these milestones, there are 300,000 people in Uganda that need palliative care and only 10% of them can access it. This figure does not take into account the needs of families where the lack of palliative care leads to exacerbation of poverty, social stigma, and family breakdown.[5] Only 4.8% of hospitals offer palliative care services.[6] Palliative care provision is even more limited in private health facilities. None of the 29 private hospitals in Kampala district has a palliative care unit or team constituted, and they tend to rely on referrals to Hospices. Moreover, the palliative care services provided are predominantly medical and the provision of psychosocial or spiritual care is often unavailable yet effective palliative care requires a holistic approach.

5. The limited provision of palliative care is the result of: an inadequate legal and policy framework to provide strategic planning resulting in a fragmented approach to service delivery; lack of monitoring and evaluation; limited training of palliative care providers; and the lack of essential drugs.[7]

METHODOLOGY

6. This report was developed after consultation with civil society organisations in Uganda working on palliative care and the right to health. A meeting was convened by Palliative

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[1] Definition of Palliative Care by the World Health Organization (WHO) http://www.who.int/mediacentre/factsheets/fs402/en/

[2] 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%).

[3] Children, particularly those born with congenital abnormalities and others who suffer from childhood cancers, HIV/ AIDS and several other illnesses, also need palliative care.

[4] WHO/WHPCA Global Palliative Care Atlas Jan 2014

[5] Draft National Palliative Care Policy – Uganda.

[6] Health Sector Development Plan 2015/16-2019/20 at p.40.

[7] 2014 The HIV/AIDs Uganda Country Progress Report 2014 p.49, Uganda AIDS Commission (UAC).

Care Association Uganda, the Africa Palliative Care Association and the Initiative for Social Economic Rights (ISER), bringing together palliative care practioners to discuss key challenges faced in realising access to palliative care in Uganda and to identify emerging issues to include in report. The report was validated by civil society working on palliative care.

NORMATIVE FRAMEWORK

7. Uganda has ratified a wide range of international and regional human rights treaties related to the enjoyment of the highest attainable standard of physical and mental health ('right to health').[8] Palliative care is fundamental to realising the right to health and the rights of the child and denial of it can result in cruel and degrading treatment. The United Nations (UN) Committee on Economic, Social and Cultural Rights asserted that "States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons…. to preventive, curative and palliative health services."[9] The UN Committee on Economic, Social and Cultural Rights has affirmed the importance of "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity."[10] The UN Committee on the Rights of the Child has stated that access to pediatric palliative care is a human right.[11] Both the UN Special Rapporteurs on Health and Torture have explained, "[t]he failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment."[12] The government of Uganda through the line Ministry of Health acknowledges Palliative Care in key health sector policies like the Health Sector Development Plan 2015/16-2019/20, the HIV/AIDS strategic plan and the Health Sector HIV Comprehensive Communication Strategy.

ACHIEVEMENTS, BEST PRACTICES, CHALLENGES AND RECOMMENDATIONS

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[8] WHO Factsheet on Health & Human Rights in Uganda http://www.who.int/hhr/news/hhr_factsheet_uganda.pdf Accessed February 2016

[9] UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, E/C.12/2000/4, para. 34 (Aug. 11, 2000)

[10] Committee on Economic, Social and Cultural Rights, General Comment 14, para. 25.

[11] UN Committee on the Rights of the Child, General Comment No.15, The right of the child to the enjoyment of the highest attainable standard of health, CRC/C/GC/15, April 17, 2013, http://tbinternet.ohchr.
org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=5&DocTypeID=11, para. 25.

[12] Nowak M and Grover A, Special Rapporteur on Torture and Special Rapporteur on the right to the highest attainable standard of health, Letter to Her Excellency Ms. Selma Ashipala-Musavyi, Chairperson of the 52nd Session of the Commission on Narcotic Drugs, December 10, 2008, p. 4www.hrw.org/sites/default/files/related_material/12.10.2008%20Letter%20to%20CND%20fromSpecial%20Rapporteurs.pdf.

I. INADEQUATE LEGAL AND POLICY FRAMEWORK

A. The Lack of A Policy to Guide Palliative Care Results in A Fragmented Approach to Palliative Care

8. The inadequate provision and access to palliative care reflects the lack of a national policy on palliative care to guide the development and sustainability of palliative care service delivery and to provide the framework for the integration of palliative care services into the health care system. The absence of the policy has contributed to a fragmented approach to palliative care service delivery[2] with over 80% of all Palliative Care Services offered in urban areas leaving out people in families in rural areas who are in need.

9. The Ministry of Health in partnership with civil society organisations working on palliative care has drafted a National Palliative Care Policy however the policy has stagnated at the Ministry of Health for more than twelve months. Fast tracking the National Palliative Care Policy would go a long way in strengthening palliative care by guiding and streamlining the planning, budgeting, implementation and evaluation of palliative care services in the country.

10. ***Recommendation: The Government should fast track the development and approval of the National Palliative Care Policy.***

B. Lack of explicit mention of Statutory instrument Number 24: The National Drug Authority (Prescription and Supply of Certain Narcotic Analgesic Drugs) Regulations, 2004 Hinders Access to Essential Medicines.

11. In recognition that Nurses form the backbone of Health Care workers in Uganda [3], the high doctor to patient ratio and with the minimal numbers of doctors with palliative care knowledge in 2004, government issued an instrument authorizing qualified Nurses and Clinical Officers to prescribe and supply the narcotic analgesic Drugs specified in the Schedule (Morphine). However, in 2015, Uganda passed the Narcotic Drugs and Psychotropic Substances (Control) Act which does not explicitly reaffirm the statutory instrument number 24 of 2014.

12. ***Recommendation: While drawing regulations for the new Act, the government should recognize the use of narcotics for medical purposeS and reaffirm statutory instrument Number 24 of 2015.***

C. Failure to Implement World Health Assembly Resolution Detrimentally Affects Integration of Palliative Care Services At All Levels Within Healthcare System

13. Uganda is a signatory to the World Health Assembly resolution of May 2014 which requires all governments to integrate Palliative Care into its health systems at all levels in order to honor the rights of citizens to quality palliative care. This involves ensuring the service at all levels from grassroots in the community to the regional and national hospitals, increasing budgetary allocations, capacity building and ensuring adequate trained human

resources and that essential medications are universally available.[13] However, the WHA resolution has not been implemented nor have any steps been taken to put in place guidelines for its implementation.

14. ***Recommendation: The Government should put in place practical steps and guidelines for the implementation of the 2014 World Health Assembly Resolution on the strengthening of palliative care as a component of integrated service at all levels within the continuum of care in order to make progress towards honoring the human rights of palliative care patients who are exceptionally vulnerable.***

II. CHALLENGES WITH SERVICE DELIVERY

A. Lack of Monitoring and Evaluation of the Provision of Palliative Care Services Affects the Quality of Services Provided

15. Monitoring and evaluation of services provided is essential for maintaining standards of service delivery. The Ministry of Health has worked with the Palliative Care Association of Uganda (PCAU) to accredit a total of 208 health facilities, of which 49 are private, to stock oral morphine. Before accreditation, facilities have to fulfil requirements including having at minimum: an eligible morphine prescriber; safe storage facilities including a lockable cupboard; and supportive administration at the facility**.** Despite this progress, less than 50% of health centers in the Country are accredited to offer palliative care services. Morphine is distributed to Public health facilities by a government entity, the National Medical Stores (NMS), and to Private facilities by the Joint Medical Stores (JMS). Whereas this Public Private Partnership (PPP) extends oral liquid Morphine to patients free of charge, there are various challenges facing the morphine supply chain. Such challenges stems from the lack of knowledge about the availability and use of morphine among a cross section of health workers, pharmacists and the public.

16. Recommendation: The Government should establish a palliative care country team headed by the Ministry of tasked with ensuring the monitoring and evaluation of the Morphine Supply Chain.

B. Inadequate Training of Palliative Care Providers Results in Limited Access to Palliative Care

17. There is need to invest, retain, recruit and train palliative care service providers at all levels. Palliative has been integrated in the medical and nursing curricula of some schools in Uganda and it is examinable. A number of health professionals have therefore been introduced to the basic concepts of palliative care through introductory certificate courses run by civil society organisations like Hospice Africa Uganda, Mildmay Uganda and the Palliative Care Association of Uganda (PCAU). However, not all health teaching institutions have courses on palliative care due to the lack of trained tutors and lecturers.[14] To ensure a sustainable supply of palliative care practitioners, there is need for inclusion of

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[13] Sixty Seventh World Health Assembly, *Strengthening Of Palliative Care As A Component Of Comprehensive Care Throughout The Life Course,* Resolution WHA 67.19. (24 May 2014): http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

[14] Draft National Palliative Care Policy – Uganda

palliative care in the curriculum of training schools for medical, nursing and clinical officers. Pre-service training in-service training in palliative care should also be emphasized.

18. Moreover, while the government has accredited and recognizes the training in palliative care at diploma and degree level, the recruitment and employment structure does not recognize palliative care practitioners as specialists. Palliative care specialists are often transferred from accredited facilities to other facilities where palliative care is not offered thereby not utilizing their skills which curtails there motivation to further their education and training.

19. Recommendation: The Government should invest in human resources for palliative care by training palliative care providers at all levels and the Health Service Commission should recognize palliative care as a medical, nursing and allied health workers specialty.

C. Lack of Disaggregated Data on Palliative Care Which Is Needed for Decision Making and Resource Allocation

20. During Uganda's UPR in 2011, Uganda received a recommendation to take steps to ensure that well functioning health information systems are in place which combine disaggregated data from facilities, administrative sources and surveys, to enable effective monitoring of progress. The government has taken commendable steps to develop data collection tools for palliative care. In the 2011 review of the Health Management Information System (HMIS), national indicators for palliative care were included to guide the monitoring and evaluation of services. A palliative care data collection tool has also been developed based on the key priority and evaluation areas outlined in the World Health Assembly Resolution of May 2014.[15] However, there is no readily available data on the provision of palliative care nor on the number of people living with moderate or severe pain. Yet disaggregated data is essential to guide decision-making, programme development and resource allocation for palliative care services.

21. Recommendation: The Government should strengthen Health Information Systems to generate, collect and disaggregate data on palliative care and morphine use, and distribute to stakeholders for proper decision making on Palliative Care.

D. Inadequate Access to Essential Medicines

22. Uganda has made progress in increasing access to essential medicines for palliative care. It was the first country in the world to amend statutory instruments to allow non-
Physician to prescribe oral morphine for, the WHO medication of choice for moderate to severe pain. Through a public-private partnership mechanism between the Government of Uganda and Hospice Africa Uganda, oral morphine is locally reconstituted and distributed through the existing medicines distribution system for free. Despite this the essential medicines that accompany Morphine to erase side effects are not provided free in all public and private facilities caring for palliative care patients.

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[15] Ibid.

23. Recommendation: The Government should review the essential medicines list to include essential palliative care medicines other than morphine. These include adjuvants and laxatives.

E. The Lack of An Autonomous Cancer Institute

24. The Health Sector Development Plan 2015/16-2019/20 notes that the number of lives lost to cancer is increasing significantly, 100% more than in 1990.[16] With a population of 34 million, Uganda has only 20 oncologists yet the demand for these experts has grown with an annual load of more than 60,000 new cases in Uganda alone.[17] Uganda Cancer Institute (UCI) is the only facility that provides specialized treatment for cancer and palliative care is an essential part of cancer treatment. Yet it lacks adequate resources. UCI receives UGX 10 billion annually, which is insufficient given the demand for the services it provides.[18] Having it as an autonomous body would enable it to receive better funding from internal and external sources.

25. Recommendation: The Government should establish the Uganda Cancer Institute as an autonomous body by an Act of Parliament and fund it appropriately to enable it to work closely with all stakeholders across the spectrum from prevention, early diagnosis, treatment, cure and palliation as standard integrated services.

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[16] Health Sector Development Plan 2015/16-2019/20
[17] http://health.go.ug/projects/uganda-cancer-institute
[18] http://observer.ug/news-headlines/37452-we-can-treat-90-of-cancers-at-mulago-uci-director