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Supplementary appendix

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Miami DeclarAction to close the access abyss in palliative care and pain reliefⁱ

April 6, 2018

Preamble

WE, the critical mass of palliative care civil society organizations, representing all world regions, and a group of concerned, informed and committed global citizens and researchers, are inspired by the many opportunities to effectively and efficiently evoke change to ***close the access abyss in palliative care and pain relief***.¹

This DeclarAction is the outcome of the global launch symposium, at the University of Miami on April 5-6 of 2018, of the report of The Lancet Commission on Global Access to Palliative Care and Pain Relief,¹ and is our contribution towards meeting the goals of World Health Day 2018 (April 7, 2018).

We affirm that addressing the access abyss in palliative care and pain relief is essential to achieving Universal Health Coverage (UHC) and Sustainable Development Goal (SDG) target 3.8., Article 5 of the Universal Declaration of Human Rights and Article 7 of the International Covenant on Civil and Political Rights, which prohibit torture, inhuman or degrading treatment or punishment, and protect access to adequate palliative care and pain relief.² The realization of better health for all is unimaginable and cannot be achieved without addressing the suffering and pain of ill health. Expanding access to palliative care and pain relief must not, however, be in substitute to treatment, but rather as part of ensuring care across the continuum.

Building on earlier efforts,^{3,4} the Lancet Commission estimated that more than 61 million people experienced serious health-related suffering (SHS) in 2015, 80% of which lived in low- and middle-income countries (LMICs). This figure includes 5.3

ⁱThis DeclarAction was designed and drafted by Felicia Marie Knaul, Richard Horton, Afsan Bhadelia, Julio Frenk, and Liliana De Lima with input from Natalia M. Rodriguez, Xiaoxiao Jiang Kwete, and Julia Olson. It was reviewed by all participants of the Global Launch Symposium of the Lancet Commission Report on April 5-6, 2018 in Miami, FL, and their comments were compiled and integrated to produce this final document.

million children. Yet, the majority had little or no access to palliative care, not even to oral immediate-release morphine for pain relief. Much of this burden is due to neglect, and lack of access to prevention and treatment, such that 63% of deaths with SHS could be avoided in LMICs. This is a global health crisis and an ethical failure that the world can no longer continue to ignore.¹

Indeed, inexpensive and cost-effective interventions that comprise an essential package of palliative services exist. Yet, they are mostly available to individuals living in high-income countries (HICs) and a fortunate few living in LMICs who can access these services. The Lancet Commission, working with the Disease Control Priorities Project,⁵ demonstrated that this essential package is globally affordable. For low-income countries, the Essential Package of palliative care health services for adults and children is about 3% of the cost of an essential UHC package.⁶

The relief of pain is at the core of palliative care and hence the essential package. Yet, access to inexpensive opioid medicines is a public health challenge and an equity imperative. Opiophobia – heightened fear of non-medical use and addiction to opioids – has caused devastating restrictions on clinically necessary prescription of pain relief medication. Due to this and other barriers, global and national policies are skewed mostly toward limiting access with little or no regard for the suffering of millions, especially the poor, leaving them to live and die in pain.

The time for equivocating on so urgent a task has passed.

Transitioning Health Systems to Volume and Value

A paradigm shift in the guiding pillars of medicine and public health is transitioning health systems to expand the focus from the **volume** of services delivered to increasing the emphasis on the **value** generated by health care. Such a fundamental transition to volume **and** value must include avoiding pain and suffering.

The huge unmet burden of SHS speaks to a deplorable deficit in health system performance. Until now, most health systems have rewarded the quantity of services delivered to improve access rather than the quality of services delivered to maximize impact. There is growing recognition that assessments of performance using volume-based, versus value-based, indicators without including patient priorities compromise the fundamental human right to live without avoidable suffering and pain.

In addition to improved population health outcomes, the concept of value in health systems is centered on both clinical outcomes and patient experience, which represent the technical and the interpersonal dimensions of quality, respectively.⁷

Freedom from avoidable pain and suffering is a crucial element of both. Therefore, palliative care and pain relief are essential to achieving the transition to volume and value.

Commitments and Calls to Action

Commitment and action are paramount to reducing the burden of SHS amenable to health interventions and meet the 2030 Agenda. We, advocates and researchers, ***commit ourselves and call upon our global, regional and national leaders*** to immediately and urgently act in the following six areas to close the access abyss in palliative care and pain relief:

- I. Accelerate progress to provide universal access to a publicly financed and fully integrated essential package of palliative care health services
 - We commit to:
 - Disseminate the Lancet Commission results on the Essential Package of palliative care and pain relief services to effect change
 - Develop an augmented package, starting with a focus on children
 - Mobilize broader civil society to demand access to the Essential Package
 - We call upon:
 - World Health Organization (WHO), the World Bank, regional development banks and UNICEF to provide normative guidance, technical assistance and financing to ensure safe and universal access to the Essential Package
 - WHO, the World Bank, regional development banks and UNICEF to work together to aggregate demand for opioid medicines to help make the best reported international prices available to all countries as well as to stabilize prices through better negotiating capacity
 - Pan American Health Organization (PAHO) to expand use of its Strategic Fund to undertake pooled purchasing of opioid medicines to aid countries in making the Essential Package available to all
 - National governments to allocate the necessary public financing to ensure access to all citizens to the Essential Package
 - Countries and the international community to promote equitable access for vulnerable populations groups, including the poor, children, elderly, disabled, mentally ill, indigenous groups, the lesbian, gay, bisexual and transgender (LGBT) communities,

migrants, refugees and displaced persons, prisoners, and individuals in complex humanitarian crises

- Private sector to levy equitable pricing and to advance research and development to generate frugal innovation
- Faith-based organizations to facilitate efforts to expand access to the Essential Package

II. Create balanced global and national policies on access to opioid medicines for pain relief to enable effective public health practice and policy-making

○ We commit to:

- Share the information on SHS with the International Narcotics Control Board (INCB)
- Create tools, based on local needs, to provide countries with full knowledge of the evidence generated by the Lancet Commission
- Generate materials to address opiophobia that fuels the pain crisis

○ We call upon:

- INCB to make use of the tools developed by the Lancet Commission, and especially the SHS framework to have an improved measure of estimating the need for opioids analgesics for medical use
- National governments, with assistance from international organizations, to put into practice the Lancet Commission's recommendations to restrict influence of for-profit entities in tendering, procuring, and marketing of opioids
- Government agencies and educational institutions to implement palliative care including evidence-based prescription and use of opioid medications in the curricula of medical and nursing schools
- Countries and their respective ministries of health to convene interinstitutional advisory groups, including diverse stakeholders, to uphold and promote effective palliative care and pain relief policies

III. Transition health systems to focus on volume and value in ways that incorporate palliative care and pain relief to achieve UHC

○ We commit to:

- Develop appropriate metrics and indicators, with account of existing efforts and in partnership with national governments, that adequately value the relief of pain and suffering to patients and caregivers

- Engage in national, regional and global initiatives focused on improving health system performance and UHC to ensure the inclusion of palliative care and pain relief
- Disseminate relevant data to countries, bilateral and multilateral organizations to advance integration of and reporting on palliative care
- We call upon:
 - Global institutions working on UHC, and especially WHO, the World Bank and UNICEF, to incorporate universal access to palliative care in their policies and programs
 - National governments to anchor health system performance in value and ensure that this includes the relief of pain and suffering
 - Advocacy movements focused on related causes such as non-communicable and chronic diseases, women’s empowerment, children’s well-being, human rights, forced migration and humanitarian crises, to name a few, to incorporate the need for palliative care and pain relief into their priority-setting
 - Communications partners to develop accessible materials with applicable, context-specific messaging to build public awareness on the principle of balance

IV. Implement accountability frameworks to evoke change

- We commit to:
 - Develop accountability frameworks that encompass the value of alleviating SHS through access to the Essential Package
 - Adopt, as leading palliative care civil society organizations, these frameworks and conduct shadow monitoring of the performance of our global, regional and national health systems
- We call upon:
 - International health financing institutions, bilateral and multilateral organizations, and national governments to put into practice the use of accountability frameworks to catalyze coverage and improve quality of palliative care
 - WHO to follow on the 2014 resolution WHA67.19⁸ to generate country action plans that include palliative care and accountability mechanisms with indicators and targets for corrective action

V. Organize and mobilize evidence through research and implementation science

- We commit to:

- Develop and apply metrics, taking into account existing measures, to incorporate the alleviation of pain and suffering and for setting priorities
 - Promote knowledge exchange among countries by undertaking research on policies and interventions
 - Partner with the Lancet, as well as regional and national palliative care associations, and professional organizations to generate annual reports with country by country estimates of SHS, disaggregated by gender, and published around world hospice and palliative care day
 - We call upon:
 - Donor organizations, international financial institutions, and WHO to support the development and application of a multi-institutional initiative to develop appropriate metrics, building on existing work, for priority-setting
- VI. Negotiate a balanced and action-oriented public health agenda that embodies global collective action**
- We commit to:
 - Produce global public goods, such as standardized training materials and guidelines for palliative care and pain relief, and disseminating them through a global knowledge exchange across various languages
 - Build knowledge on palliative care and train various cadres of healthcare professionals in its delivery to address needs of all age groups
 - Advocate for meaningful policies and partner with national governments and other relevant organizations to develop inclusive global and national policy frameworks
 - We call upon:
 - Global health institutions to incorporate this DeclarAction into relevant decision-making platforms, such as the United Nations High-Level Meetings on NCDs (2018) and UHC (2019), as well as celebrations of the 40th anniversary of the Alma Ata Declaration on Primary Care

¹ Knaul FM, Farmer PE, Krakauer EI, et al on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *The Lancet* 2018; 391(10128): 1391-1454 (Online, October 12, 2017). Accessible at: [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)32513-8/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32513-8/fulltext)

² Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/10/44, January 14, 2009. Accessible at: <http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.44AEV.pdf>

³ Foley KM, Wagner JL, Joranson DE, Gelband H. Pain control for people with cancer and AIDS. In: Jamison DT, Breman JG, Measham AR, et al, eds. *Disease Control Priorities in Developing Countries*, 2nd edn. Washington, DC: The International Bank for Reconstruction and Development, The World Bank; New York, NY: Oxford University Press, 2006.

⁴ Connor SR, Bermedo MCS. *Global atlas of palliative care at the end of life*. Geneva: World Health Organization, Worldwide Palliative Care Alliance, 2014.

⁵ *Disease Control Priorities* re. *Disease Control Priorities*, 3rd edition. Accessible at: <http://dcp-3.org/>

⁶ Watkins D, Qi J, Horton S. Costs and affordability of essential universal health coverage in low- and middle-income countries. DCP3 Working Paper Series Working Paper #20. Seattle, WA: University of Washington, 2017.

⁷ Donabedian A. Evaluating the quality of medical care. *Millbank Memorial Fund Quarterly* 1966; 44: 166–206.

⁸ WHO. WHA67.19. Strengthening of palliative care as a component of comprehensive care throughout the life course. Geneva: World Health Organization, 2014.