IAHPC ADVOCACY NOTE
For International, Regional, and National Partners and IAHPC Members

World Health Organization Executive Board Meeting #144
Geneva, January 24-31, 2019

Introduction - Why we need you!

The Executive Board (EB) of the World Health Organization (WHO) is composed of 34 Member States, elected for three-year terms. The main functions of the Board are to give effect to the decisions and policies of the World Health Assembly (WHA), to advise it and generally to facilitate its work. The 144th meeting of the Executive Board (EB144) will convene in Geneva on January 24-31, 2019. The current members of the EB are listed here and they will all be present. Member states not currently members of the EB also send delegations to the meeting, and your country may be represented by one of these.

During the meeting, the EB members are entitled to comment first on agenda items and propose changes or new initiatives. All other countries are entitled to comment after the EB members, followed by interventions of representatives of NGOs in official relations with WHO, such as the International Association for Hospice and Palliative Care (IAHPC). The IAHPC is a global, membership organization in formal relations with WHO and in consultative status with the Economic and Social Council of the United Nations. In this capacity, the IAHPC sends delegates to participate in the meetings at WHO and other UN organizations. Comments by civil society are usually limited to 3 minutes.

Regional and national palliative care associations are key partners of the IAHPC and of country delegations at these and in other meetings of the WHO and the WHA. IAHPC can invite its members to participate in its delegation to the WHO meetings. However, it is the member states who have the greatest leverage to suggest changes in texts and documents, which is why we need strong partners at the national level who are willing to work and collaborate with their governments - in other words, be strong advocates for palliative care. This is why we need you!

The advocacy team at IAHPC has put together this document that will help you learn more about the next WHO EB, learn about some resources, and learn how to become a better palliative care advocate to advance relevant policies in your country.

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I. General Recommendations

Be active on social media! Register for a Twitter account if you don't have one already, learn to use it using the hashtags #palliativecare #hpm #hpmglobal to connect with clinical and advocacy networks with shared interests. Follow @IAHPC, @WHPCA, @ICPCN as well as your corresponding regional association (ALCP for Latin America, APCA for Africa, APHN for Asia, EAPC for Europe) and your national palliative care organization.

Read the Policy and Advocacy column in the IAHPC monthly newsletter and consider contributing your story, with challenges and successes.

Introduce yourself and your organization to the representative of the WHO country office and cultivate a relationship with him/her and with the corresponding focal point for NCDs and Medicines. For more information on the WHO country offices see here.

Consider joining the IAHPC, your respective palliative care regional association and your national palliative care association if you have not done so already. Also, consider joining the World Medical Association and advocate that they include palliative care in their interventions, press releases, reports, etc., with uptake of Lancet Commission Recommendations and the recommendations of the Astana Declaration.

Contact Dr. Katherine Pettus, the IAHPC Advocacy Officer if you have any questions or need additional guidance and support. Dr. Pettus can set up a Skype call or a tutorial if you are interested in learning more on how to do advocacy with your national delegation.

II. Specific Recommendations: Advocacy Process for WHO EB144

Identify which government officials from your country will be attending EB 144. Sources of this information are the Ministry of Health or State Department in your country, or your country's mission office in Geneva here. Review the document: "How to Use this Advocacy Note." It contains sample letters and messages to government and WHO country contacts.

This is where your relationship with a key person in your Ministry of Health comes into play, as it is helpful to direct your advocacy communications to someone who already knows you! The goal is to have your country delegation pick up at least some of your message. Member states listen to one another in meetings such as the EB, so when your country shares its learning experience, it can help others understand how to begin integrating palliative care. In preparation for the meeting, our national associations partners can:

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- **Draw** their government contact's attention to the topics below and discuss how each is relevant to the specific situation in your country.
- **Educate** them about what they (your) government is doing to improve access to palliative care and controlled meds. *They may not know!* (You may need to suggest text for the speeches being prepared. Offer to do so. We will help on request.).
- **Cultivate** a collaborative relationship with a key person in your Ministry of Health who can provide you with information into reports to be presented at the EB. If possible, organize an informal policy dialogue. Your Association can develop your own advocacy agenda that is relevant for your context, to share with those policymakers. This should align with the agenda of the WHO meeting, and can align with our proposed statements. You can propose text (one or two sentences).
- **Request** to be included on your national delegation for WHO EB or the World Health Assembly in May.

The members of this delegation need to be informed about your Associations' efforts to provide palliative care in your countries. You are their key informants! IAHPC can provide evidence about palliative care and essential medicines directly to WHO at meetings such as the EB and WHA, *and* we can inform our membership (you) about relevant agenda items.

III. WHO EB144 Agenda items relevant to palliative care and access to pain treatment and care.

The following are the specific items in the agenda EB144 that are relevant to palliative care and the comments that IAHPC will be presenting. We have also included a line with the recommendations to national associations. If you belong to your national palliative care association, share this with your colleagues and set a strategy and steps to advocate with your national delegation to WHO EB144. *We would like as many country comments as possible to mention palliative care and controlled medicines as per your country context, addressing the agenda comments below.*

1. Item 5. Proposed Program Budget: 2020–2021: Thirteenth General Programme of Work, 2019–2023 WHO Impact Framework. http://apps.who.int/gb/ebwha/pdf_files/EB144/B144_5-en.pdf

Overall Context - Thirteenth General Programme Of Work, 2019–2023
Item 7. "According to the investment case for WHO, hitting the triple billion targets would result in 30 million **lives saved**, 100 million **healthy life years improved** and 2–4 % **economic growth** in

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low- and middle-income countries over the five-year implementation period of GPW 13 (2019–2023)."

IAHPC response: The focus is on disease eradication, health emergencies, and redirecting resources to country level.

- National budgets should strengthen health systems to allow for integration of prevention, promotion, treatment, rehabilitation, **and palliative care**. They should not perpetuate the disease-centered, "rescue medicine" model that leaves millions behind in severe health related suffering each year.

- Palliative care should be included on the WHO Country Officer's priority lists.
  Given the new emphasis on devolving resources to countries, this is an important communications channel for policy implementation. Georgia tells us that palliative care is not on the priority list, so the WHO CO cannot act to support implementation efforts, even though palliative care is now in all the normative and technical documents coming from the Secretariat. How do we bridge that information and implementation disconnect?

National associations can ask

1) What percentage of the budget goes to health and to education, and
2) How much will be invested in palliative care development as part of Primary Health Care.
    a. If the response is "none," or is inadequate, you can offer to assist by supplying evidence about the number of palliative care providers in your country, issues with access to education and essential medicines, etc, and a proposed draft budget based on the Lancet Commission Essential Package. IAHPC can help with this!
3) To work with the WHO Country officer and your MoH to strengthen your health system by integrating palliative care according to regional and global guidelines.

2. Outcome 1.1. Improved access to quality essential health services
Box 1. Targets Associated with Outcome 1.1
"Increase access to quality essential health services (including promotion, prevention, curative, rehabilitative and palliative care) with a focus on primary health care, measured using a UHC index"

3. Outcome 1.3. Improved access to essential medicines, vaccines, diagnostics and devices for primary health care
Box 3. Targets Associated with Outcome 1.3
Increase the availability of oral morphine in facilities caring for patients in need of this treatment for palliative care at all levels from 25% to 50%

IAHPC response: These targets need to be placed in a health system strengthening context that describes serious health-related suffering (SHS) (per the Lancet Commission Report) and includes

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the WHO Concept of Balance for internationally controlled substances. Improvement of affordable access to other essential controlled medicines, including methadone, requires adequate workforce training and quality monitoring. A quantity prescribed indicator alone violates the principle of balance and can result in the further stigmatising of opioid medications.

National associations can ask whether their ministry of health would like technical support to estimate the amount of Serious Health Related Suffering in your country, and match it with consumption of controlled medicines (i.e. opioids such as morphine) on the WHO Palliative Care List. The technical reports and data are available on the University of Miami website and contain SHS data disaggregated by country.

You can then work with the International Narcotics Control Board and IAHPC to implement appropriate training curricula for implicated workforce and estimates for rational stocking and dispensing. Your health ministries can then report on this indicator to future WHO EBs and WHAs.

4. EB 144/11 **Implementation of Agenda 2030**

IAHPC response: IAHPC thanks the Secretariat for the Report's attention to internationally controlled essential medicines, emphasises Lancet Commission Report recommendation of essential package and cost to countries in range of income levels. We will support implementation efforts, including for primary care, in order to deliver on commitments of Astana Declaration.

National associations can request their country delegations to apply for technical support from the Secretariat in order to implement the recommendations of the Lancet Commission Report and to comply with WHA 67/19 and Declaration of Astana.

5. EB 144/17 **Access to medicines and vaccines Report by the Director-General**

IAHPC response: IAHPC thanks the Secretariat for the Report and references to controlled medicines. IAHPC participated in the Roadmap process. We will assure the Secretariat that IAHPC will continue to work with them on refining indicators in the context of balanced drug policies in order to follow recommendations of UNGASS2016, working with WHO EMP division, Service Delivery and Safety, UNODC and INCB.

The following is a problematic sentence in the Report:
i. [WHO will provide] "Support for improved forecasting and quantification of controlled medicines to avoid *over-stock* and support for strengthened capacity of prescribers and dispensers to ensure the quality of service and minimize the risk of diversion."

IAHPC and our members identifies stockouts and *understock* as the usual problems.

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We have a **question** about the following deliverable:
ii. "Support for the development of national policies and regulations to ensure access, appropriate prescribing, dispensing and use of controlled medicines, including guidance on optimizing relevant legislation and support for strengthening the capacity of prescribers and dispensers to ensure access and quality of service and minimize the risk of diversion."

What form will this "support" take? In the light of Astana, will countries be supported improve regulations to help train and empower family doctors?

National associations can request their delegations to
1) Ask the Secretariat for clarity on these issues
2) Offer to form working teams to assist ministries with development of national policies and regulations to ensure balanced policies to improve access (etc.) to controlled medicines
3) Request that the EMP's 2018 Annual Report contain information about access to controlled medicines for palliative care in relation to the Lancet Commission Report on Serious Health Related Suffering.

6. EB144/18 **Medicines, vaccines and health products: Cancer medicines**

IAHPC response: IAHPC will thank the Secretariat for the Report and remind member states that there is a separate list of *essential medicines for palliative care* that are useful for cancer patients, and that these include internationally controlled essential medicines, unavailable in more than 70% of countries. We request the Secretariat to prepare a similar Report on pricing and access to controlled medicines and will collaborate using our evidence base, the Opioid Price Watch.

National associations can request their delegations to instruct the Secretariat prepare a similar Report, in collaboration with INCB and civil society, analyzing pricing and availability of internationally controlled essential medicines for the treatment of pain, palliative care, anesthesia, obstetrics, mental health, substance use disorder, trauma, etc. This will be essential to implement Target 3.8 (SDGs), Astana Declaration, and the WHA 67.19.

7. EB 144/36 **FENSA – Engagement with non-state actors**

IAHPC response:
1) IAHPC will thank the Secretariat and assure them that we will help achieve the triple billion goal by mobilizing our civil society membership who can provide expert consultation to governments on how to implement PC in their countries.
2) IAHPC will ask through the Chair why the Secretariat of the Medicines and Vaccines Program effectively marginalizes the reports and inputs of our organization, which is in official relations and regularly submits reports and recommendations on improving access to internationally controlled essential medicines. The recently released WHO Essential Medicines & Health Products Annual

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Report for 2017 ignores the recommendations and suggestions made by IAHPC and other civil society organizations for balanced language and attention to the Lancet Commission Report data on severe health related suffering in every WHO member state.

Associations can request that delegation statements on this issue

1) Describe collaboration between governments and providers, and ongoing efforts to develop balanced policies regarding access to internationally controlled essential medicines for palliative care.
2) Mention they plan to work with WHO Country Officers and Regional Offices to improve access, and ensure that palliative care implementation is on all countries' priority lists.

8. EB 144/52 **Reports of Advisory Bodies**:

IAHPC response: We will thank the 40th Expert Committee on Drug Dependence (ECDD) for recommending that tramadol *not* be place under international control in one of the schedules of the drug control conventions. IAHPC's survey of our membership provided evidence that such a recommendation, *given inadequate access to morphine in 70% of the world,* would add significant burden to patient suffering. Tramadol remains the last "unscheduled" medicine available to primary care practitioners and oncologists in many countries.

We will request that the Secretariat take a position that ECDD should

- Not be asked to review tramadol for a seventh time
- Change its name to reflect the WHO concept of balance to ensure access for the rational use of essential medicines (including those placed under international control) and the WHO approved, non-stigmatising language around substances under international control [the word "Drug" is particularly egregious]
- Ensure inclusion of a palliative care expert, and practitioner who treats chronic pain in outpatient settings in low-income countries in future Committees
- Revive EMP activities to promote access to controlled medications for the treatment of pain, substance use disorder and other indications like dyspnoea (the former Access to Controlled Medications Programme).

National associations can request that their delegations include these points in their statements. Below are some helpful tools.

Applicable official WHO documents and policies

Two official documents apply: The Style Guide and the Lexicon on Drug and Alcohol Dependence. The ICD-10 (-11) contains definitions that should be applied in other WHO publications. The Style Guide and the Lexicon are not cross-referenced and should be modernized for consistent policies. It is Department of EMP policy that the word "medicines" is the correct term for referring to these substances, not "drugs."

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"Drug" is an ambiguous word; particularly when it is used to refer to an internationally controlled medicine. Imprecise terminology and use of the word "drugs" interfere with efforts to promote their availability for medical purposes.

IV. Resources and References

- Declaration of Astana
- IAHPC Advocacy Page
- IAHPC Presentation at 40th Expert Committee on Drug Dependence, 2018
- IAHPC Language Matters edited by Willem Scholten, PharmD
- Knaul FM, Farmer PE, Krakauer EL, et al, on behalf of the Lancet Commission on Global Access to 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. Lancet 2017; published online Oct 12. http://dx.doi.org/10.1016/S0140-6736(17)32513-8
- Scholten, W., Simon, O., Maremmani, I., Wells, C., Kelly, J. F., Hämmig, R., & Radbruch, L. (2017). Access to treatment with controlled medicines rationale and recommendations for neutral, precise, and respectful language. *Public health*, *153*, 147-153.

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