

IAPO's response to the Draft Global Strategy



WHO IGWG Draft Global Strategy and Plan of Action on Public Health, Innovation and Intellectual Property

The International Alliance of Patients' Organizations (IAPO) strongly supports the World Health Organization's (WHO) efforts to develop a global strategy to address the lack of safe and effective medications for many patients around the world and especially those suffering from diseases and conditions that have been "neglected" by pharmaceutical research and development for a variety of reasons. IAPO agrees with WHO's identification of two main barriers to effective treatment for many patients: lack of innovative therapies and lack of access to therapies that have been developed. Finally, we concur that the former barrier must be addressed by providing incentives to stimulate research and development into treatments for neglected diseases, while the second barrier must be addressed by reducing the gap between the costs of therapies and the funds available to purchase them.

General Comments

IAPO is committed to engaging in the discussion on this issue; however, we must express our significant disappointment that patients and patient groups have not been actively encouraged to participate and offered the necessary support to do this effectively from the outset of this process. Now, given the announced timeframe of the Intergovernmental Working Group on Public Health, Innovation and Intellectual Property, there is insufficient time for patient groups to inform themselves and consult with each other regarding the important and complex issues and potential measures outlined in the strategy.

The draft plan does not specifically refer to patients or patient groups amongst the key stakeholders yet patients are a key stakeholder and there are many patient groups, including IAPO, that are committed to actively participate in health policy issues, at international, national, and regional levels. A fundamental premise of patient-centred healthcare is that patients and patient groups are involved in all stages of healthcare decision-making, including setting of international policy. Patients and patients' organizations deserve to share the responsibility of healthcare policy-making and performance monitoring through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre.

Conclusions and Recommendations

IAPO is concerned that debate around these issues has become polarised by different stakeholders as developed versus developing economies or, more versus less stringent intellectual property regimes. This has the potential to create conflict between patients with chronic illnesses and patients with infectious diseases when, in fact, what should operate to the benefit of all patients, is access to good healthcare, including safe and effective treatments. These different interests have neglected the

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perspective of the key stakeholder: “*patients*”. We urge the WHO and all stakeholders to show leadership and take meaningful action to ensure that patients and patient groups are given a central role in future discussions while recommending that member countries should consult with patients’ organizations and patients and include their opinions in their own responses.

Across these areas, we would like to see studies into the impact on patients of the measures proposed in the draft global strategy conducted in order to inform all stakeholders particularly patients and patient groups to make better quality decisions on this important issue. The results should be made available to patients and patient groups in an appropriate format according to health literacy principles, as outlined here: www.patientsorganizations.org/healthliteracy