



World Cancer Leaders' Summit

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A MEMBERSHIP ORGANISATION
FIGHTING CANCER TOGETHER

Meeting report on the Public Private Dialogue on access to cancer medicines: a better way forward

As governments are moving towards Universal Health Coverage (UHC), systemic bottlenecks towards access to quality cancer medicines have become one of the most pressing issues in the global and national policy agenda. Affordable cancer treatment has recently been the topic of discussion by policymakers, civil society, and industry. Taking this momentum forward, it is timely for the cancer community to have an open, inclusive, constructive, and evidence-based dialogue focused on access to cancer medicines, on the key systemic barriers for access, and potential solutions that can be pursued collectively by different stakeholders for the wellbeing of patients and sustainability of cancer care.

There are several key issues to be addressed to advance this agenda. These include procurement and supply chain issues, existing mechanisms to bring innovations to healthcare systems and patients, alignment of R&D priorities with patient needs, and pricing and payment policies, all of which affect access to medicines. Recognising the complexity of the issue and the multiple components in the ecosystem that affect access to medicine, UICC organised a public private dialogue (PPD) at the 2019 World Cancer Leaders' Summit, focusing on identifying and raising awareness on key barriers and prioritising policy directions and health sector solutions that can contribute to better patient outcomes in a sustainable manner.

The PPD started with a passionate call for access to timely treatment from Alexandra Nunez, a patient rights advocate with Tour Rosa.

She mentioned that challenges to care include access to accurate and timely diagnosis, quality of treatment, access to the treatment facility itself and trained health care professionals- the lack of which eventually lead to suboptimal health outcomes. Alexandra also mentioned that in order to aspire to Universal Health Coverage, it is important to engage the relevant stakeholders with decision-making authority in all arenas, both in public and private sectors to address the political, economic and regulatory barriers.

Following Alexandra Nunez's intervention, other members of the panel including representatives from the UN, civil society and the private sector, provided their views on the barriers surrounding access to medicines and what the possible solutions could be. The outcome from the panel discussion as well as the breakout sessions where over 100 participants took part, is summarized in this report based on the key areas identified. These discussions focused on the major barriers to access and how the cancer community can work together to find solutions to improve access to treatment. For details of the panel and session sponsors, please see Annex 1.

From the onset, key themes emerged from the panel member interventions which also resonated with participants at the breakout sessions. The key barriers highlighted were pricing policy frameworks, weak health systems and inadequate procurement practices and supply chain. It was a frank discussion where concerns were raised, and priorities debated. These barriers raised during the interventions by the speakers and the participants are grouped by themes below;



Speakers

The panel was facilitated by Esteban Burrone from Medicines Patent Pool and the panellists for this session included;

- **Alexandra Nunez, President,**
Asociación Tour Rosa
- **André Ilbawi,**
Cancer Control Officer,
World Health Organization
- **Gaëlle Krikorian,**
Head of Policy,
MSF Access Campaign
- **Dávid Dankó,**
Managing Director,
Ideas & Solutions (I&S)
- **Rosa Giuliani,**
Chair Global Policy Committee,
ESMO
- **Greg Perry,**
Assistant Director,
IFPMA

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Pricing policy frameworks

André Ilbawi from WHO opened the discussion on pricing policies by mentioning that there is inadequate public financing for universal access to essential medicines and this results in significant out-of-pocket spending. Limited pricing policies, market entry barriers where registration of the product can take years and restricted negotiating capacity to get the lowest possible prices are some of the reasons behind not being able to afford a sustained supply. WHO then highlighted the purpose of their technical report on cancer medicines pricing and the WHA resolution on improving the transparency of markets for medicines, vaccines and other health technologies², in framing the global debate on pricing and advocated for efficient pricing policies.

Gaëlle Krikorian with Médecins Sans Frontiers Access Campaign (MSF) then provided MSF's perspective on access barriers. MSF's work on access to medicines is rooted in their medical operations and supports people in their own projects and beyond. In this regard, they mentioned their entry into cancer care with their first programme set up in Mali for cervical and breast cancer.

MSF also acknowledged the importance of the WHO documents mentioned in the WHO presentation and outlined the main tenets of MSF's Access Campaign, highlighting that the main barrier to access is the lack of transparency on the pricing of cancer medicines, particularly transparency related to the cost of R&D. It was mentioned that R&D for medicines benefit from tax rebates, public funding etc and this should be reflected in the pricing of medicines. The lack of transparency around intellectual property which has led to market monopolies, especially for novel therapies, is also a key aspect of this debate around transparency which MSF emphasized should be addressed. MSF urged a socially responsible contract between the public and private sectors as the first step towards ensuring equitable access.

The conversation on pricing policies then shifted to the issue of reimbursement of cancer drugs, Dávid Dankó, an expert on reimbursement policies, mentioned that as funds are never enough to reimburse all novel therapies, trade-off decisions need to be made, and these should be based on the value of novel therapies. There are different approaches across countries and health care systems to establishing the value of therapies. One approach is economic evaluation where cost-effectiveness and budget impact are considered. Another approach is the analysis of comparative effectiveness where the emphasis is on added clinical benefit against the most commonly used active comparator or comparators. Here, economic considerations are typically introduced later during pricing negotiations. A third approach consists of multi-criteria assessment where economic factors, clinical value and other possible sources of value are taken into consideration when a pricing or reimbursement decision is taken. Each approach comes with its list of strengths and possible shortcomings.

Dr Dankó also mentioned that negotiations between the industry and governments (payers) will continue to be a part of the pricing and reimbursement process. The challenges of these negotiations could be overcome with agreements on negotiated access, managed entry agreements, and also alternative sources of funding.

The IFPMA also raised the issue of addressing 'price mark ups' on medicines in the distribution chain.

1. <https://apps.who.int/iris/bitstream/handle/10665/277190/9789241515115-eng.pdf?sequence=1&isAllowed=y>

2. http://apps.who.int/gb/ebwaha/pdf_files/WHA72/A72_ACONF2Rev1-en.pdf

3. <https://www.msfaccess.org/about-us>

Weak health systems

Following discussion on pricing policies, another key barrier highlighted was the need to strengthen health systems. Most health systems strengthening interventions ignore interconnections between the system components of medicines and health financing, human resources, infrastructure etc. Consequently, access to medicines is addressed through fragmented approaches⁴.

Greg Perry from The International Federation of Pharmaceutical Manufacturers Association (IFPMA) highlighted the fact that as access is a shared responsibility and access to health care is a human right, more investment is needed from all relevant sectors. And for the moment, that investment mainly comes from the private sector.

The IFPMA then stressed the need for substantially improving domestic (re)allocation of resources focusing on health as a vital first step. This would enable much needed investment in prevention and awareness campaigns, timely screening for early diagnosis, infrastructure and training and retention of the health work force etc.

Rosa Giuliani from the European Society for Medical Oncology (ESMO) further advocated for the need of more resources to ensure a country's ability to offer patients access to the best possible quality of cancer care within their UHC package.

Additional and equally important barriers identified at the breakout session with regard to health systems included a lack of appropriately trained health care professionals and lack of health insurance schemes resulting in substantial out of pocket payments for treatments (especially for novel therapies).



4. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3794462/>

Inadequate procurement and supply chain

The IFPMA mentioned that although most of the cancer medicines listed on the WHO Model List of Essential Medicines (WHO EML) are off-patent and exist as generics and biosimilars, they are often not available in many LMICs. The WHO EML is growing, and the 2019 list includes many patented innovative medicines, and the challenges to access still remain the same. Therefore, another key barrier is an inadequate procurement system and a fragmented supply chain.

WHO talked about the inefficiencies in procurement and supply chain management, highlighting the impact of absent or outdated treatment guidelines on prescribing practices and frequent stockouts due to inefficient forecasting and abandoned care due to improper follow up. WHO also mentioned the discord between country selection and the WHO EML. This means that countries do not list the recommended medicines for procurement.

Formulating a UN response requires breaking down the components of access. Some components include; improving medicines selection via the WHO Expert Committee on the Selection and Use of Essential Medicines and the costing tool to support high-impact treatment regimens.

Cancer medicines constitute about 30% of substandard and falsified (SF) products reported to WHO. Access and quality go hand in hand. Therefore, ensuring quality through the WHO prequalification programme, which designates pharmaceutical companies as reliable and a platform for substandard and falsified (SF) medicines testing and reporting are two mechanisms to ensure quality.

WHO mentioned improving procurement via pooled procurement models by the UNDP and UNICEF. This would provide support to countries in negotiating a better price and also support with regulatory system strengthening ultimately guaranteeing a sustained supply of medicines.

Stressing the importance of a sustained supply of medicines, ESMO highlighted the various initiatives and tools they have made available to improve treatment. These include access to over 80 guidelines for health care professionals and patients, a report on shortages of cancer medicines in the European region, development of a scale to assess the magnitude of clinical benefit for the novel therapies and the uptake of biosimilars.

ESMO then stressed that barriers to access should be divided in terms of access to innovative treatments and access to inexpensive medicines. Countries should have a national EML list based on the WHO EML and develop procurement systems to protect these medicines from shortages. ESMO also mentioned the importance of having guidelines for healthcare professionals and patients.

The IFPMA also stressed the need to create regulatory reliance as this would enable speedier regulatory authorisation for both established and innovative treatments and efficient procurement practices which are vital in improving access to generics and biosimilars.



Discussion on solutions

As the session moved onto the groups discussing possible solutions at the breakout sessions, it was acknowledged that cancer is a very complex disease and needs to be addressed as such and examples that work in communicable diseases may not always be extrapolated to cancer. A national cancer strategy with all the components of cancer control – screening, early diagnosis, access to novel and effective treatment and palliative care are needed at every level of health care facility.

Initial steps toward ensuring cancer control should be the revision of the National Cancer Control Plans (NCCPs) and investing in data systems (cancer registries).

With regard to solutions towards sustainable pricing, participants discussed the need to establish alternative pricing mechanisms, taking forward the options included in the WHO report on cancer medicines pricing. Developing methodologies to compare prices in different countries and move towards a system that's more transparent, was also discussed.

The need for more transparency around intellectual property issues, especially patent status of novel therapies was also discussed.

While some participants felt more work was needed on transparency of pricing policies in order to negotiate better prices in the procurement of medicines, others felt focus on supply chain and health systems strengthening was more urgent in the provision of comprehensive care for cancer.

Therefore, with regard to health systems strengthening, participants stressed the need to keep UHC high on the political agenda, by setting targets and making the case for investment in cancer control.

It was stressed that for early diagnosis and treatment to be consistent, health infrastructure and capacity building should be supported. Ways to take this forward include; training and retention policies for health care professionals, the decentralisation of treatment and care by cascading some aspects of care (for example palliative care) down to the primary health care (PHC) level.

With regard to expanding health insurance, it was suggested to explore the mechanism of channelling taxes and for employers to contribute towards insurance schemes to ease the burden of out of pocket expenses on health.

Participants felt that clear and reliable data to forecast patient needs was the first step towards efficient procurement and a robust supply chain. The second point that everyone agreed on was that all the medicines listed on the WHO EML should be available in countries.

It was mentioned that enforcing transparent procurement practises and establishing long term purchasing agreements for both established and innovative treatments would ensure a sustained supply of medicines. Participants also mentioned exploring the possibility of pooling procurement as a mechanism to combine resources, negotiating better agreements while also benefiting the suppliers.

Regulatory systems play a key role in ensuring the safety, efficacy and quality of medicines. Very often national regulatory bodies do not have the capacity to do this. The lengthy processes of registering products in a country can sometimes take up to 5 years leading to a delay in procurement. Therefore, the need for regulatory systems strengthening and capacity building was an important point stressed by most participants.

The importance of stimulating and sustaining local production and technology transfer was also raised (with a focus on those medicines listed on the WHO EML).

The need for an efficient and sustainable supply chain was also discussed. Mechanisms of ensuring this include, putting in place appropriate forecasting mechanisms, appropriate storage facilities and information systems (with efficient alert systems) and regulated distribution networks supported by trained staff.

Conclusion



Access to timely and quality assured treatment is the collective responsibility of governments, patient organisations, civil society and the private sector. All the plenary speakers and participants agreed with stressing the importance for equity and always placing the patient at the centre.

Furthermore, the issue of transparency was mentioned in different contexts, particularly the need for increased transparency from the industry and likewise from governments. The need to pool resources and share best practises was also seen as vital in making the most of sparse resources.

An open and ongoing dialogue is key between relevant stakeholders and UICC will continue to provide a platform to keep the momentum focussed on this discussion. UICC will also take these discussions forward at the regional and county levels. Furthermore, UICC in collaboration with

partners, has done extensive work on analysing NCCPs. An updated and comprehensive NCCP was highlighted as being a key first step in ensuring access to treatment. In this regard, UICC is able to offer technical assistance to countries to develop and update their NCCPs.

UICC will also develop master courses on some of the issues identified above and continue work at the country level through its Cancer Advocates Programme.

In conclusion, collaboration and shared understanding at the national and international levels between governments, the pharmaceutical sector, patient groups and all other key stakeholders is key in moving towards a common goal of building resilient and sustainable health systems.



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