

The Johannesburg Declaration
A civil society declaration on the UN Secretary-General's High-Level Panel on
Access to Medicines

March 17 2016

The UN system – and governments and people around the world – are poised on the threshold of a historic opportunity to redress the policy incoherence and imbalance that exists with respect to health technologies between the justifiable interests of inventors and trade rules on the one hand and international human rights law and public health on the other.

A system of financing biomedical research and development that relies upon the grant of monopolies - and the search for profits through high prices - produces innovation gaps, inefficiencies, and distortions in the development of new health technologies, as well as avoidable death and suffering due to high prices and lack of access to health technologies.

Twenty years ago, the WTO TRIPS Agreement created global standards for intellectual property that have been used to exclude competitors from offering more affordable health products. Since then industry and certain countries defending their interests have relentlessly pursued ever-higher standards of patent, data/regulatory, trade secret, and other intellectual property protections through free trade agreements, investment treaties, diplomatic pressure, misleading technical assistance, litigation and retaliatory measures.

The UN Secretary-General's High-Level Panel on Access to Medicines has been established to consider bold, evidence-based alternatives to the distortions and excesses of the current system – new mechanisms both for sustainably incentivizing research and development that focuses on the health needs of all people and for ensuring affordable access to the benefits of medical advances.

Civil society organizations from around the world write this Declaration to encourage the High-Level Panel to seize this opportunity to make path-breaking recommendations for reform and revolution in global and national systems for supporting research and development of needed health technologies and for subsequently guaranteeing equitable and affordable access to safe, efficacious, and well-adapted technologies for all persons, in all countries, for all health conditions.

Based on a review of the contributions and participation in consultations held in London and Johannesburg, civil society urges the High-Level Panel to recognize the following principles and to adopt the following recommendations:

Principles

The human right to health which includes access to and the creation of essential health technologies is paramount. Although medical innovators, creators, and researchers are entitled to material and reputation benefit for their research and development efforts, monopolies that transform into high prices are not required for the realization of those benefits. The UN Special Rapporteur in the Field of Cultural Rights recently affirmed that there is no human right to patent protection, stating, “where patents and human rights are in conflict, human rights must prevail.” Similarly, the UN Human Rights Council and the Special Rapporteur on the Right to Health have both affirmed that the right to health supersedes intellectual property protections.

Medical research should focus on the medical needs of all people, including the unmet needs of those whose medical conditions have been neglected in the current system. Global and national mechanisms should be strengthened and expanded to track human health needs and to help prioritize research and development efforts. At the same time, there needs to be ample support for research that expands our understanding of biomedical science, building the scientific foundation for new medical technologies, and for research that adapts products to the needs of specific populations and locales.

All governments have a duty to invest public resources in basic science and in medical research and development and to ensure efficient and effective systems of private research and development as well. Public funding whether through grants, contracts, innovation inducement prizes, or other incentive mechanisms and research subsidies must be adequate, sustained, and responsive to health needs, and policies should maximize the benefits to the public. To the extent possible, and where appropriate, coordination mechanisms should be established for national, regional, and global R&D efforts.

The costs of medical research and development should be delinked from the price of health technologies. Health technologies should be produced efficiently and where possible competitively either by the private or public sector.

Medical research and development should be conducted with maximum transparency and with meaningful support for open-source and collaborative efforts. Siloed and secret research, hidden for the purpose of private benefit, is subject to misrepresentation, wasteful or redundant research efforts, and unethical experiments, and should therefore no longer be encouraged or tolerated.

Clinical trials to test the safety and efficacy of medical technologies should be independently evaluated and conducted to ensure proper research design, objective weighing of evidence and transparency. Subject to measures to protect the privacy of patients, the results of all clinical trials should be accessible to researchers and the public, in order to expand access to knowledge and enable the data to be evaluated by others.

Governments have a duty to ensure that all people have equitable and affordable access to needed health products. When intellectual property (especially patents, data/regulatory rights, copyright, and trade secrets) creates barriers to access knowledge, and limits both

the freedom to innovate and affordable access to health technologies, it (including the intellectual property related to research platforms, base technologies and final medical products) must be reformed and progressively eliminated.

Recommendations:

We strongly support and echo the recommendations of the Global Commission on HIV and the Law and of the UN Special Rapporteur in the Field of Cultural Rights for the UN High Level Panel “to review and assess proposals and recommend a new intellectual property regime for pharmaceutical products that is consistent with international human rights law and public health requirements, and simultaneously safeguards the justifiable rights of inventors.” We call on the UN High Level Panel to make strong recommendations in this regard.

Governments must increase their investments in medical research and development, including basic science, and develop norms and systems that prioritize R&D towards patient-driven health needs, promote transparency and coordination of efforts, and ensure affordability and access to medicines.

Governments should progressively promote new R&D funding systems that rely on grants, prizes, and other incentives that delink R&D costs from the price of medical technologies. To facilitate and accelerate these reforms, the UN Secretary General should start a process for governments to negotiate a global R&D agreement to ensure robust levels of R&D funding, and reform or eliminate incentive systems that use the grant of monopolies.

Governments must ensure transparency in every aspect of the pharmaceutical market, including but not limited to prices, sales, R&D costs and outcomes.

No country should make TRIPS-plus demands in trade agreements or through diplomatic or other political pressures. All existing trade agreements with TRIPS-plus provisions should be amended or suspended to remove such provisions. Similarly, no country should make or continue provisions in investment agreements that allow investor-state-dispute-settlement with respect to IP or other investment claims based on health products. All existing trade agreements and intellectual property regimes should be interpreted to prioritize human rights and the right to health and access to health technologies.

All countries should adopt legally permissible TRIPS flexibilities into relevant and national and regional law and they should use such flexibilities to give effect to the obligation to ensure access to medicine for all. Countries should expand the use or adopt mandatory or presumptive compulsory licensing provisions for health technologies, and apply such safeguards to patents, data/regulatory rights, copyright, and trade secrets.

Governments should devise universal access systems that ensure equitable and affordable access to safe, efficacious, and well-adapted health technologies for all health conditions. They should ensure that all people receive the benefits of medical advances.

Signed by:

Treatment Action Campaign

SECTION27

People Living with Cancer

Cancer Association of South Africa (CANSA)

Advocates for Breast Cancer

Cancer Alliance South Africa

South Africa Federation for Mental Health

NCD Alliance South Africa

HealthGap

ITPC-Global

ITPC-MENA

Initiative for Medicines, Access & Knowledge (I-MAK)

STOPAIDS

Third World Network

Treatment Action Group (TAG)

ACCESS (France)

Delhi Network of Positive People (DNP+)

ITPC-South Asia

AIDS Access Foundation

Thai Network of People Living with HIV/AIDS

FTA Watch

Positive Malaysian Treatment Access & Advocacy Group (MTAAG+)

Knowledge Ecology International (KEI)

The Young Professionals Chronic Disease Network

The Sunflower Fund

ARASA

Wings of Hope Cancer Support

KELIN - Kenya