CALL TO ACTION!
FROM HIV TO BROADER HEALTH - THE FIGHT IS FAR FROM OVER!

International Treatment Preparedness Coalition (ITPC) Meeting
Bellagio, Italy
30 June - 03 July 2014
This Call to Action is the result of a three-day meeting of 23 community leaders at the Bellagio Centre, Italy. The International Treatment Preparedness Coalition (ITPC) convened the meeting with support from the Rockefeller Foundation and Pangaea Global AIDS.

The Bellagio meeting brought together a diverse mix of academics, health practitioners, activists and policy makers, including HIV and human rights activists; government sector representatives; people who work on health systems strengthening and primary health care; experts in Tuberculosis (TB) and Hepatitis C (Hep C); and people with experience working on access to medicines and intellectual property rights. In sum – a diverse group united by a common passion for the right to health.

The meeting aimed to reflect on how to strengthen broader health systems through the HIV response, and particularly through community-driven HIV responses. ITPC wanted to examine how the many successes and achievements of the HIV movement could be applied to health system debates. The objectives were to examine the value and challenges of integrating with other social justice movements; strategise about how to capitalise on the expertise of the HIV advocacy movement; learn from how community-based HIV service delivery approaches can improve broader health systems; and identify how to continue to strengthen community-led systems as HIV care is further incorporated into primary health care.

Reflecting on the successes of the AIDS movement while ringing the alarm bell

First hand accounts from around the globe reveal that the AIDS movement has connected community actors at global, regional, national and local levels, resulting in an unparalleled health access movement. Innovative funding mechanisms have been developed specifically for HIV; we have won some battles with pharmaceutical companies; and communities are engaged in health care in a way we have never seen before. Community systems were strengthened to bridge the gap between communities and health services; more people are on treatment; governments are increasingly accountable on health commitments; and people are better able to claim their rights. HIV has made headway in terms of integrating with and strengthening services for other areas of health such as sexual and reproductive health and rights (SRHR), TB and Hep C. Members from the meeting revealed that in their countries, the AIDS movement was already shifting to take on a more expansive health agenda.

However, the news from meeting participants – all of whom are working on the frontlines – was also that the AIDS movement is in great peril, with serious implications for curbing the epidemic and for extending the movement’s work to advance broader health concerns. Despite UNAIDS’s fast-track modeling¹ that discusses the possibility to end the AIDS epidemic by 2030, current realities make that future unlikely. If we are to build on the successes of HIV to increase access to primary health care, we need to first ensure that the response to the disease doesn’t flounder and fail.

The precarious state of the movement emerged as somewhat of a surprise in Bellagio— in terms of the real depth and severity of the crisis among many groups working on HIV— and so the meeting became an emergency summit to figure out how to move forward, while still broadening our vision for the future. Despite our immense successes, and the new ‘end of AIDS’ rhetoric from global health institutions, the fight is far from over.

… WE ADDRESS REALITY

¹ For more information:
Despite massive successes we know that the ‘end of AIDS’ is not yet in sight. Even in contexts where successful advocacy and community systems have improved HIV-related health outcomes, people continue to die from inadequate health care delivery. Health systems are weak or broken; funding is declining or not going to the right places; civil society has become fragmented; and structural drivers are not adequately addressed. At the global level, international organizations mired in bureaucracy churn out targets, toolkits and donor reports – and move further away from real discussion of the barriers to ending AIDS on the ground. We offer the following reality check - because unless we are honest with ourselves, we can never ‘end AIDS’.

The HIV movement is now an industry. As civil society has evolved and joined forces with international institutions, it has diluted our ability to hold our governments and other actors accountable. We have lost our anger, and our ability to address politics and power which we did so skillfully in the early days of HIV. We are buying into the rhetoric around ‘the end of AIDS’, ‘reduced funding’, ‘country ownership’ and the ‘burden of disease’ (i.e. the move away from supporting the most affected populations outside of sub-Saharan Africa) without a fight.

Donors retreat from HIV with no strategy for how communities will receive life saving medicines and services in their wake. The very rhetoric around the end of AIDS allows donors to redirect funds to other issues, when cuts in HIV funding are seriously impacting a sustainable HIV response at a country level. Several developed country donors no longer have AIDS as a development priority. An example of the impact of this can be seen in Uganda where The AIDS Support Organization (TASO), the pioneer HIV civil society organisation in Uganda and the largest indigenous HIV/AIDS service provider in Sub-Saharan Africa, is downsizing from 100 to 50 staff as they have lost 30% of their income. Successful community mobilisation around HIV has led to a lot of rhetoric about the importance of NGOs and community engagement, but very little real support to ensure that their activities are sustained.

We are operating in a climate where we are told global funding is declining, but we know that it isn’t always about a lack of money – money is often wasted and directed to the wrong places. The global military spend for 2012 was 1.7 trillion and we know that the US...
government spends more on defence than China, Russia, Saudi Arabia, France, UK, Germany, Japan and India combined.

There is a global call for national governments to take greater responsibility and to maintain health services without heavy dependence on external aid, i.e. a move towards ‘country ownership’. Whilst the theory is good, in terms of governments taking more responsibility and being accountable for the right to health for their own people, we know that ‘country ownership’ really means government ownership. The reality is that the most politically, socially and economically marginalised groups are the first to fall off government agendas once donor backs are turned. This issue is increasingly pronounced as countries graduate from low-income status (LICs) to middle-income status (MICs), often rendering them ineligible for foreign aid. For example, Botswana is now classified as an upper MIC and most of the bilateral donors have left, leaving the Global Fund as the only donor. In some MICs, governments would prefer to pay for commodities rather than uncomfortable human rights work. UNAIDS is predicting that huge funding gaps will remain in LICs and MICs between 2015 and 2020. Recent Global Fund allocations move away from investing in MICs despite their high disease burden and critics of the Global Fund tell us that money is not tracked well in country, often stays at treasuries and is misappropriated.

Pharmaceutical companies hold as much power as ever, and are increasingly negotiating behind closed doors. We still have an international intellectual property framework that seriously impedes access to medicines. Trade barriers to drug access have not decreased and once first line generic ARTs became more affordable, we seemed to think the job was done. This is particularly challenging for MICs who are mostly left out of access programmes initiated by the pharmaceutical industry.

Everyone talks about a human rights approach – but no one does it. Human rights in practice have fallen off the public health agenda. Lip service is often paid to ‘human rights’ based HIV interventions, but we know that on the rare occasion they appear in national HIV plans, they are often not costed or budgeted; nor incorporated in M&E systems. Critical enablers and rights-based approaches are neglected in a context where they are urgently needed to enable potentially far-reaching bio-medical advances, such as Treatment as Prevention (TasP) and Pre-exposure Prophylaxis (PreP).

We talk about getting people on the right ARVs, monitoring procurement systems, and building the capacity of communities to hold their government to account for health spending, neglecting to mention that these goals cannot be achieved when basic human rights remain out of reach, such as the rights to water and sanitation. There is growing intolerance for the registration and activism of local civil society, and many people remain in situations where their sexual identity or behaviours leave them criminalised and marginalised without access to essential prevention and treatment services. Yet we are without strategies to address these monumental barriers to progress.

Weak health systems prevent progress on HIV. Even if we are successful in our advocacy for ART, HIV and TB services, people will still die if we continue to focus on a single health problem leaving their diverse health needs unaddressed. For example, despite the many successes we heard about in Zimbabwe, we also heard how the Ministry of Health is drastically under-funded; and operating with a

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2 Source: UNAIDS May 2012
30 year old structure and limited numbers of doctors and nurses due to ‘brain drain’. There are stockouts and, although ARVs are offered free of charge, patients have to pay for associated costs, for example consultations, lab services and other medicines. Volunteers and community health workers are extremely overburdened.

**The focus on HIV treatment often neglects the big picture.** Money for treatment is seen as a necessary investment, but often little consideration is given to the related costs in terms of time and money, or whether there is an enabling environment. People will not access testing and treatment if they don’t have treatment literacy, understand treatment regimes and are in an environment where access to testing and treatment is restricted by stigma, discrimination and criminalisation. The critical enablers need to be in place: legal services for key populations, harm reduction programmes for people who use drugs; gender empowerment programmes; and legal reform to change discriminatory laws.

**WE RADICALLY STRENGTHEN OUR MOVEMENT**

In light of the problems outlined above, participants at the meeting came up with some core areas for action. Together we must:

**Re-engage politically**

Challenge influential normative health institutions such as UNAIDS and WHO to:
- Provide critical data on the impact of low funding levels on the HIV response and broader health outcomes.
- Provide guidance to countries to set priorities given that they have limited money to meet the new UNAIDS targets.
- Position human rights and civil society as the core of successful HIV and broader health responses – even if it flies in the face of more conservative governments and donors.

**Invest in activism and cultivate smarter advocacy strategies**

As a movement, we urgently need to reignite the political and moral fires that led us to develop the successful activism over the past decade that led to big wins – such as HIV treatment expansion. We must also engage strategically with the media and view it as part of our role to provide them with evidence to inform their reporting. We need to advocate for:
- Continued investment in community systems and community engagement for broader health issues.
- Greater government accountability in terms of reaching key populations, human rights interventions and in terms of addressing structural drivers (in response to the ‘country ownership’ agenda).
- Affordable and quality-assured medicines and laboratory commodities for diagnostics and monitoring.
- Efforts to address the negative impacts of ‘brain drain’ on the capacity of health systems.
- Money and resources for issues of civil and political rights such as the rights of people living with HIV; freedom of expression; transparency of public resource spending; sexual orientation; gender inequity; discrimination and criminalisation; and long-term legal reform.
- Well-researched national guidelines for diseases other than HIV.
- Funding and political will to support critical enablers, for example, legal services for key populations, harm reduction, empowerment programmes for women, law reform to improve access to services.

**Document what works**
We know we have a lot to be proud of, but we need to continually strengthen the evidence base if we are to apply similar strategies to the strengthening of broader health systems. For example, we need to document how the AIDS movement:

- Reduced drug prices
- Positioned human rights at the centre of the public health agenda
- Influences broader social justice issues
- Works to integrate HIV with TB, Hep C and SRHR and other health services.
- Mobilises communities to bridge the gap between marginalised groups and health services.

**Analyse funding streams and re-direct resources to communities**

While participants took note of the fact that international donors are retreating from HIV at the same time as increased investment is needed to scale-up treatment access, there was also a shared sense that existing resources are not spent effectively. We need to monitor funding sources and identify when they are supporting ineffective programmes. We must:

- Carry out critical analysis of where current funding for health is going and why civil society and community responses are still under resourced.
- Argue that we can help governments to save money and provide them with the evidence that we can succeed in this role.
- Engage strategically in the funding debates: use evidence to prove what we do works, including costing and financial analysis; and present the results of community engagement models in a way that reveals ‘value for money’ to donors. At the same time, be wary of realigning our work to fit global donor priorities instead of being driven by the real needs on the ground.
- Use the Investment Framework model to cost all parts of the response, including a critical analysis of the impact of donor-imposed “graduation” (i.e. transition of countries from low-income to middle-income status) on access to treatment and health outcomes at a country level; and the impact of corruption and inappropriate allocation of resources.
- Revisit our Global Fund advocacy strategy, and question the overall Global Fund model to ask big picture questions about how the Global Fund is resourced and whether the Global Fund in its current form meets the needs of our constituents.
- Explore untapped resources and opportunities to diversify funding, to lessen dependence on donor governments and raise funds for activism. At a national level, explore innovative models for fund raising, e.g. the AIDS levy in Zimbabwe and a program raising funds from citizens through mobile phone contributions in other countries.

**Campaign together to increase access to medicines**

Overly protective intellectual property (IP) protection is the emerging human rights crisis of our time. Many countries now spend a significant portion of their national health budget on medicine procurement, including HIV treatment, yet still cannot purchase the appropriate quantity of high quality medicines because of the prohibitive costs. IP continues to be the one issue that unites us all and that we can organise around. We need to think through global strategies to build a new community-driven IP movement to ensure generic production; research and development; access to medicines and diagnostics; and TRIPS advocacy.

**Shape the future of community responses**

We know it is crucial to invest in community responses, including community systems, because it is the only way to ensure accessibility and acceptability of services. But we need to prove community responses work; we must build a body of evidence; define what
community systems should look like; and propose strategies to tackle some of the barriers and issues we know communities face.

- Provide evidence for the vital role communities play in strengthening health systems and linking communities to services.
- Develop strategies to utilise the experiences and expertise of community-based HIV service delivery approaches to improve access to and engagement in wider health services.
- Develop strategies to strengthen health and community systems to support continued scale up of HIV treatment and prevention services, as HIV care is further incorporated into primary care.
- Aim for community systems that are able to reach populations governments are unwilling to reach. In order to do this, communities must be able to play a watchdog function and speak out when needed. Resourcing these communities will be challenging however.

Re-invigorate the movement for treatment education

Treatment literate patients – those that know and understand the different medicines they take, the different medical options they have and the broader socio-economic and political context of HIV – initiate treatment earlier and are more likely to stay on treatment for the long run. But treatment education projects are often no longer funded and there is little appetite from donors and national agencies to resource such programmes. As civil society, we know that treatment literacy is crucial for successful and sustainable treatment programmes. We need to:

- Re-conceptualize treatment education to make it more acceptable as a funding priority for donors and national governments.
- Engage with diverse partners – such as movements for the environment, democracy, and women's rights – to support community led treatment education programmes.

Unite! Who will be our allies, comrades and share our voice?

We are not the only ones facing these issues and certainly not the only ones with a motive for universal access to treatment and the right to health for all, but civil society is fragmented. We need to:

- Build partnerships with other movements, such as the various social justice movements, and organisations facing the same issues. This is critical so that in a post 2015 framework, whatever the new development goals, we are united and at the centre of health service delivery and access. We have learned valuable lessons from joining forces with the LGBTI and sex worker movements; at the same time we are mindful of the lessons we have learned in terms of challenges of integration with other movements.
- Link with and make synergies with other development issues such as social protection, education and legal reform.

To call attention to the reality of ending AIDS, meeting participants decided to take action at the International AIDS Conference in July 2014 in Melbourne, Australia. Participants developed placards and postcards based on ‘AIDS will only end when...’ and gathered community perspectives from around the world to inform the creation of the cards. At the IAC opening ceremony, a diverse coalition of organizations, including ITPC, Health GAP, International Civil Society Support and others marched to the stage to display a unified, powerful message.
SUCCESSFUL EXAMPLES OF HOW HIV HAS STRENGTHENED HEALTH SYSTEMS AND IMPLICATIONS FOR THE FUTURE

People are now living with HIV, but dying of other illnesses such as TB. The AIDS experience has provided us with lessons, models and many evidenced-based strategies and interventions which can be applied to health care access beyond HIV. Lessons learned from HIV programmes are already being applied to other diseases, for example, diabetes and malaria. Below are the core lessons learned from AIDS.

AIDS activism revolutionized health funding through bringing communities to the decision-making table and supporting bottom-up funding models.

For example:

• The development of the Global Fund, with its emphasis on community and civil society engagement in its governance and implementation. This has linked the local to the global and enabled advocacy in donor countries to be informed by what is actually happening within communities. For example, the Global Fund Advocates Network (GFAN) recruited, connected and mobilised advocates, activists and affected communities in the South and the North to build a global social movement to demand health for all and to communicate the urgent need for, and to demand full funding of, the Global Fund.

• The AIDS response has given rise to new ways of funding health systems at a community level: in Western Kenya, communities have leveraged mobile phone technology to raise funds, while in Zimbabwe an AIDS levy has resulted in additional resources.

• ITPC developed grant systems through the HIV Collaborative Fund that were based on the premise that the people most affected have the best knowledge of their needs and should shape funding priorities. This was an innovative model that was able to support groups that are often unregistered; with little or no organisational structure; but are working to respond on the ground. The model continues today in the form of ITPC’s community grantmaking programs.

The AIDS movement transformed drug pricing and access to treatment and diagnostics. Issues of generic production, research and development, access to affordable drugs and TRIPS advocacy united activists and resulted in numerous policy changes. For example:

• In India, people living with HIV and other health groups such as cancer advocates opposed patents with support from legal practitioners. Global activists also supported national advocacy efforts to incorporate TRIPS flexibilities into national legislation, successfully pressurising Indian parliamentarians to ensure that they considered the implications of national law on access to generics globally.

• A coalition of HIV and harm reduction activists emerged in the past two years to advocate for universal access to Hep C treatment. This coalition has drawn on the lessons learned from the HIV treatment movement, and they are employing similar rights-based strategies: community mobilisation; peer-led interventions; and fighting discrimination.
• Treatment literacy programmes have resulted in community members having information on ARVs and ARV regimes; the importance of adherence; understanding lab results; and better communication with health service providers. This has also enabled people living with HIV to engage in informed advocacy. An example of this is in China, where treatment education has led patients to pressure the government to phase out the toxic drug Stavudine (DT4). Lessons learned from HIV treatment education could also be applied to TB.

• In Thailand the community movement has organised around Free Trade Agreements that would affect access to multiple drugs and has moved from HIV into broader advocacy around social justice.

The AIDS response altered the public health paradigm to operate within a human rights framework. This is one of our movement’s greatest achievements. For example:

• We have insisted that medical practitioners and policy makers reflect on health services within a human rights framework, which not only acknowledges people’s right to access safe and quality health services, but also notes the importance of communities holding their governments accountable, and the responsibilities of governments to provide accessible, available, affordable and good quality health services to all.

• Various marginalised, stigmatised and criminalised groups have found a voice and a platform through HIV to lobby for their right to health services, for example people who use drugs, LGBTI and sex workers.

• In 2011, the Investment Framework (IF) model that was widely endorsed by global health institutions took a human rights approach to the HIV response, noting that successful responses are universal, equitable, inclusive, foster participation, ensure informed consent and accountability. The IF is testimony to our advocacy efforts, as it asserts that critical enablers increase the impact of basic programme activities by overcoming limiting factors such as stigma, poor health literacy and punitive legal environments. The IF also lists examples of social enablers.

• A young movement of TB activists is now working to integrate HIV and TB in line with the Global Plan to Stop TB, 2011-2015. Learning from HIV, they are building evidence around TB in the same way we have done around HIV and the access movement, i.e. how to go from public health to a more human rights-based approach.

“Other than the discovery of the virus and the development of drugs and diagnostic, every single advance that has successfully addressed AIDS since the beginning of the epidemic has been made by people living with AIDS. We stepped in where our government failed. People with AIDS created safer sex, needle exchange programmes, the concept of confidentiality approaches to HIV testing to protect human rights, and transformed clinical research and drug development by demanding to be included in processes to set up research priorities.”

David Barr, HIV activist and one of ITPC’s founders
AIDS offered alternative service delivery models that are now applicable across health issues. Through the response to HIV, we now understand the crucial role of communities in health system strengthening and service delivery. Communities become empowered to monitor and hold their governments accountable; participate in service-delivery decision-making; and create demand for services. The need to bridge the gap between community members and health systems has also acted as a catalyst for the decentralisation of HIV services, bringing health care interventions closer to those who need them. For example:

- The HIV response led to the development of innovative models, such as peer outreach and task shifting. Through these innovations, services have been extended to vulnerable, stigmatised and criminalised populations, linking them to health and other social services. In Kenya, where there’s a chronic shortage of doctors, we see examples of task shifting, where Advanced Practice Clinical Officers are taking on some of the tasks traditionally carried out by doctors. HIV outreach workers in Western Kenya also now carry machines for blood pressure and for glucose testing to make sure that while they are reaching people in remote areas, they are also addressing other health issues.

- HIV has strengthened health-related processes and systems in some contexts. For example, in Zimbabwe, the introduction of ‘Quality Improvement’ programmes for HIV have increased the capacity of health workers to use data to monitor performance at site level; and laboratory infrastructure procured through AIDS funding is also being used for non-HIV patients. Engagement with the community also led to decentralised services; multidisciplinary outreach programmes for ARV rollout; community representatives on Health Centre Committees; electronic patient tracking systems; improvements in commodity security; and ‘expert patient’ trainers.

- At a community level, BONELA is employing proven rights-based HIV approaches to address a poor-performing community TB care program in Botswana. Through the TB Buddy Project, Community Advocates are offered incentives to provide one-on-one supervised DOTS (Directly Observed Treatment) support to individual TB patients. This has improved treatment completion and cure rates, reduced defaulter rates; and significantly strengthened the performance of the Community TB Care Programme, as is reflected in national data.

WHERE DO WE GO FROM HERE?

The Bellagio meeting was a critical opportunity to review where we are as an AIDS movement. The many successes we have all seen on the ground, together with biomedical advances and data showing increased treatment coverage, have fuelled the ‘end of AIDS’ concept and its accompanying rhetoric. But at the Bellagio meeting we were able to take a closer look that revealed we still have a long way to go. We now stand at a turning point, which given the right strategies, partnerships and coherence offers communities the opportunity to create a new global health movement to ensure universal treatment access and the right to health for all.

This meeting was the starting point.
BELLAGIO MEETING PARTICIPANTS

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