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Agenda item 3

UNAIDS-Lancet Commission Working Group 2 Discussion Paper
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How can the experience of the AIDS response serve as a transformative force in global health and development?

INTRODUCTION

This Working Group is charged with extracting key learning from the successes and failures in the global responses to AIDS and transforming these into lessons that can be used to support more effective responses to global health and development. The goals of this process are:

- To reinvigorate the response to AIDS, and;
- To indicate how these lessons can be transformative beyond AIDS

To achieve these goals, it is necessary to document and understand what happened over the past three decades and then to assess and review how to revitalize successful approaches, to learn from errors, and to build on the learnings from AIDS to secure effective responses to other development and global health challenges. It is equally important to ensure that the global response to AIDS remains on track and has maximum impact by reinvigorating those approaches that have served the global AIDS movement well. Ideas and experiences shared by Working Group members, and derived from preliminary literature reviews, served as the basis for the identification of several key themes and innovations in the HIV response that should be useful to drive effective responses in other areas. Six core themes are briefly described below (with some illustrative examples) and offered to the consultation process for input and ideas. Participants in the consultations are kindly invited to comment on the following:

- Are these themes a good reflection of the key innovations?
- Should some be excluded?
- Are there other key innovations which are not included?
- Are there other good examples of successes? And examples of where things have not worked?
- How can these examples serve to inspire and inform other health and development challenges? Which are transferable?
- What are the opportunities for enhancing learning and improving other responses?
- What are the barriers to learning across these sectors and issues?
- How can the learning be carried forward?
- Can new technologies and approaches be employed to transfer knowledge and enhance understanding?
Theme 1: Activists and Advocacy

1.1. No other global health movement has been so deeply grounded in advocacy by individuals directly affected by the health condition. From the very earliest days (before HIV had been isolated and AIDS named) people with GRID/HTLVIII/LAV/HIV/AIDS were outspoken and strident in making their needs vociferously known. And while activists living with the virus were central to driving the response, AIDS advocacy drew strength from a wider base of activism. In the 1980s, the gay movement was political and global, and spawned important activist groups, such as ACT-UP (the AIDS Coalition To Unleash Power). Activist doctors, celebrities (e.g., Elton John, Elizabeth Taylor), and other high profile supporters (such as Kenneth Kaunda, Kofi Annan) spoke out about the personal effect AIDS had on their lives and demanded quality services and a stronger response. As the impact in Africa became deeper, local advocacy groups were formed, such as Uganda’s TASO (The AIDS Support Organisation) and South Africa’s Treatment Action Campaign (TAC).

MSF (Médecins sans Frontières) has played an important, and innovative, advocacy role alongside grassroots groups such as TAC in South Africa. MSF has put in place pilot projects that proved that high quality treatment scale-up is viable. In tandem TAC members – mostly people living with HIV - showed the fierce demand for services through public demonstrations and activism.

1.2. A remarkable feature of the AIDS response has been the contribution of confrontational activists on the outside and “briefcase activists” working within the system to get results. In this way people living with HIV took control of scientific findings and became central to shaping the “products” - such as treatment guidelines and “patient” information - that had historically been the preserve of the medical profession. Activists, in particular people living with HIV, played a central role in educating each other, and transformed the care system. Activists exposed the double-standards and profit-driven motives of the pharmaceutical industry, forcing a dialogue on this aspect of health care, highlighting the injustices in the system, and offering a constant critique as well as pushing the global pharmaceutical industry to recognize that engaging with the users of their products is essential at the development stage as well as when products come to market.

1.3. Activism has given voice to people – especially those from the grassroots, often the poor and marginalised – forcing the powerful to listen. It has faced stigma and discrimination head on, slowly re-shaping attitudes towards the virus and the communities most affected. There was a similar trajectory with breast cancer over the past 30 years, moving from a stigmatised condition that could not be spoken about to something which is discussed in public. AIDS activism has catalyzed an evolving inclusiveness of communities as well as individuals beyond the disease. The shift to increasing tolerance of diversity, and growing acceptance of homosexuality in some countries – including moves to legalise gay marriage - can be traced back to the AIDS movement.
Discussion Questions: To what extent are the lessons from activism relevant to other health conditions? How can activism build accountability? Is it realistic for people with other chronic or life threatening diseases to form similar coalitions? Has AIDS activism built on pre-existing political movements (e.g. the global gay movement) that do not underpin other illnesses?

Theme 2: Chronic care and prevention

2.1. The AIDS response is becoming a leading example of a chronic condition being tackled in a global co-ordinated way – both for treatment and care, and also for prevention. The chronic care and management of HIV should provide a good lesson, as well as a platform, for other diseases and broader health issues moving forward. While some of the best services were delivered through parallel systems - that can place a strain on weak health systems - there are nevertheless lessons to be learned from the innovative ways they evolved to deliver chronic care management services. The fact of delivering effective care for a chronic health condition, and retaining people in services, may have elements that could serve as an important model for cross-learning with other health issues, notably for non-communicable diseases (NCDs).

2.2. The AIDS response has also changed thinking about the health system by, for example, bringing health services out of the clinic and into the community by TASO in Uganda - a development that made it clear that communities are part of the health system. Task shifting and sharing, and the employment of peer educators and mentors – for example the Mentor Mothers model of Mothers2Mothers (an African organisation started in South Africa) - are novel approaches that could prove to be highly transferable.

2.3. Lessons from the chronic care of HIV disease are matched by prevention approaches that also require constant and repeated effort (these could be called "chronic prevention"). These demonstrate that ongoing health promotion interventions are achievable, for example the success of promoting the consistent, on-going use of condoms by sex workers and by gay communities. While not unique to HIV and AIDS, acknowledging the real (albeit complex) successes of maintaining significant behavioural change is important for other conditions that cannot be avoided through a simple one-off bio-medical intervention. A unique feature of HIV-related behaviour change and prevention interventions is the visibility it has brought to discussions about sexual practices. The AIDS response has forced dialogue on sexuality and identity into the public domain - an innovation that has resonance across other health and human rights issues.

“What we heard before was that health was seen as a service provided by highly trained specialists. We sought to create partnerships with non-medical personnel. One thing the AIDS response taught us is that we can and should use non-medical people. They can do counselling and testing in communities, etc.”
Minister Ramsammy, Guyana
2.4. HIV prevention (as well as the broader response) has shown how to engage with marginalized populations and the value of doing so. Health has been the entry point for engagement, and has led to new ways of considering and addressing human rights issues. By working with and through communities, the health response to HIV has moved human rights in new and better ways to address gender equality, sexual and reproductive rights, as well as directly addressing legal and “moral” obstacles that prevent engagement with populations that are criminalized as well as marginalized. Human rights demands have followed in the wake of health arguments.

Discussion Questions: What are the opportunities for developing new models of chronic care for other conditions, building on community models of care and support? What lessons can be learnt from existing approaches to diabetes and other chronic health conditions to enhance further the response to AIDS and other global health issues? How do human rights, sexuality and global health issues work together to deliver more effective responses?

Theme 3: Evidence and data

3.1. Data have been used in many ways. Epidemiology has helped to understand the epidemic, to target and then expand interventions (by focusing on “hotspots” and conducting “Know Your Epidemic” studies) and is an important accountability measure. Data have been “demystified” through the AIDS response. Communities have learned to gather, interpret and use data, increasing their ability to hold people to account and to improve the way services are brought to local level.

3.2. UNAIDS has played a key role in gathering and publicising accurate data about HIV and AIDS and the diverse impacts of the epidemics. Fundamental to the use of evidence and data has been the importance of building credibility – and ensuring that misconceptions are corrected. UNAIDS has often taken bold steps – to ensure that governments and other stakeholders are informed about the real impact of the epidemic (however “politically” unpalatable) and also to correct misunderstanding. After two decades of the response, UNAIDS took the bold decision to issue a correction to the global epidemic statistics. It was feared that this move – highlighting that previous reports had over-estimated rates of HIV in some cities and countries – might undermine public confidence. In fact, it enhanced credibility and confidence by demonstrating an openness to “mistakes” that in turn emphasised the reliability of the revised projections.

3.3. And there have been novel approaches to data-gathering, not just using the formal approaches of epidemiology and science. Communities can play a key role in data
gathering, and they may often identify innovative approaches that drive problem solving processes and new responses, as well as information gathering. For example, in an area of high malnutrition, a community health worker approached mothers who had children that were not malnourished in order to understand and gather information about what they were doing to maintain the health of their children. This data was then applied and used for interventions to reach other families.

3.4. Data have also been used successfully to make the case for political and financial investments in the response, and to drive accountability by keeping track of whether promised interventions have been delivered, and if so whether they have been successful. Numbers have been used cleverly to tell the story, with communication messages working across several fronts. Such messages have made the case not only in terms of rates of death and illness, but also defining the economic impact, security threat, etc. Media messaging and branding has been clever, very professional and used to great effect. Ideas have been disseminated through a range of channels, not just through words but using literature, the arts, movies, books, advertising campaigns, the Red Ribbon and the Quilt to speak to emotions as well as to the mind.

In Guyana building information systems was critical. As well as surveillance, effort was put to ensuring that information systems reach people. For example, the pastor in a village has access to information so he can talk to his people and local politicians can see how relevant information affects his people.

"When you speak to a villager, he knows how diabetes is ravaging his community. It was HIV that brought models and practices that are now benefiting us across the board."

Minister Ramsammy, Guyana

**Discussion Questions:** What are the lessons from HIV and AIDS data-gathering that could best serve other health conditions? How can the approaches to using data be utilised to persuade, to plan programmes and for accountability? What are the best techniques for using data? What are the roles for new technologies?

**Theme 4: Partnership and collaboration**

4.1. Partnership has been a core feature of effective responses to AIDS – it is the hallmark of Australia’s successful control of HIV, and a founding principle of the Global Fund to Fight AIDS, Tuberculosis and Malaria. Partnership means that real people living with the disease have been at the centre of the response from the outset. As equal partners they have been able to secure legitimacy, share power and to give voice to the real concerns and experiences of those most affected. And they have brought a multitude of skills and approaches and engaged these so that people access HIV

South Africa has a cross-sectoral approach engaging all key government ministries, union leaders, faith leaders, people living with HIV, the private sector and civil society. The South African National AIDS Council has a broad range of members, each representing different sectors of society as well as government departments. Moving beyond health has been important and transformative.
information and services in all relevant parts of their lives. Multi-sectoral working – bringing together all relevant government departments, private sector, civil society, people living with HIV – has meant that HIV is addressed in the many ways it affects communities and individuals. The principle of “Health in all policies” has integrated responses to HIV across all government departments in countries with effective responses. Fundamental to the multi-sectoral approach has been recognition of the social determinants of HIV, including how poverty drives health inequities and the uneven progress of the disease.

4.2. This partnership approach has led to a radical approach of sharing power and responsibility that also means mobilising, sharing and making the best use of resources. One of the important innovations of the AIDS response was to get serious financing to civil society. This has meant that most affected communities - including people living with HIV - have had control of some of the resources and been able to target them towards areas that would otherwise have been overlooked.

4.3. The importance of partnership within the AIDS response has also been balanced by an “Exceptionalist” approach. This approach is based on recognition of the differences between HIV and other health conditions, with one of the most important overall distinctions being that HIV has direct impacts on so many sectors and aspects of life. The response would likely not have moved so quickly if the approach had been to work patiently through broader, more generalist approaches such as health systems strengthening. This balance may now need to shift to sustain the AIDS response as well as to strengthen other efforts.

4.4. One of the consequences of Exceptionalism and the rapid prominence of AIDS was fragmentation and duplication. Building on broader aid effectiveness principles, the AIDS movement stressed the importance of coordination, developing the concept of The 3 Ones to stress the importance of aligning national efforts behind One Strategy, One Coordinating body and one Monitoring and Evaluation (M&E) system. This has led most countries to develop National Strategic Plans (a model already used by some other health conditions), providing clarity of national leadership, driving political attention, and securing greater credibility through stronger monitoring systems.

**Discussion Questions:** What is the ideal balance between an Exceptionalist and an integrated response to AIDS? Do other global health and development issues need a focused response or should they be integrated across broader issues? How can partnership and multi-sectoral working be used to intensify the effectiveness of responses to other health and development issues?
Theme 5: Political leadership

5.1. Key moments drive political leadership, which in turn drives national action and programme scale-up. Influences on politicians are multiple, and include smart advocacy and effective use of data to drive arguments. Appealing to different issues has proved useful: economic growth, security threats, population impact, and national pride are among the many approaches in this regard. The role of activism in driving early political leadership cannot be underestimated. As political commitment grows, inevitably activism wanes. Ongoing advocacy rooted in the most affected countries of the Global South is essential for sustaining political leadership, especially as HIV epidemics are better controlled in the North. Countries with successful responses are often characterised by high-level political leadership for the AIDS response that drives decision-making, partnership and resource allocation. This political will is active and sustained, ensuring that there is accountability for actions – and intervention where there is inaction – as well as laudable policies and strategies.

5.2. Global solidarity has been important, and can drive political leadership, either through international agreements and accords, or through perceptions of international interest and fear of being shamed for insufficient action. In 2001, the UN held its first Special Session on AIDS (UNGASS) following growing international momentum with key milestones often tracked through the International AIDS Conferences. For example, at the 1996 conference in Vancouver, scientists revealed that highly active antiretroviral treatment (HAART) was possible; two years later in Geneva there were early efforts to try to “bridge the gap” between those rich countries where HAART was scaling up and the majority world with HIV which had no access. This was an important mind shift, and by 2000 global attention fixed firmly on the Durban conference and the denialist policies of the government with the highest AIDS burden. The interventions of key individuals – including people living with HIV – led to a global outcry of emotion and a resulting call for

Following the coup in 1992, the new Thai government created a National AIDS Committee (NAC), headed by the Premier– the first time in the world that a NAC had leadership by a Head of State. The government brought in important stakeholders from non-health sectors and became open to new evidence. This was invaluable for understanding HIV, and allowed for civil society, science and public health to engage in the leadership addressing the epidemic.

New leadership in South Africa across various sectors led by the President, H.E. Mr Jacob Zuma, the Deputy President and Chair of SANAC, H.E. Mr Kgalema Motlanthe, and the Minister of Health, Dr Aaron Motsoaledi worked as a collective with civil society, led by Steve Letsike, and all the other sectors to mobilize the country through the HIV Counselling and Testing campaign. Since that time notable achievements include:

- 18 million people were offered HIV testing over 18 months (8 million were also tested for TB);
- Today 90% of all health facilities are used to test and treat people with HIV – in 2009, just 10% were; and
- Task-shifting has been emphasized. Nurses have been trained and empowered to handle most HIV-related services.
science to focus on where the needs were greatest and the responses that were known to work resulted in a step change in the response.

5.3. The 2001 UNGASS and the UN Declaration, which led to the creation of the Global Fund as a “war chest for AIDS”, and the UN Security Council debate on AIDS – the first time the Security Council had addressed a health issue – were all landmark events heralding a global shift in attention and a substantial increase in resources. The World Health Organization (WHO) committed to achieving 3by5 (3 million people on treatment by 2005) and in 2005 the G8 and then the UN committed to *Universal Access to AIDS treatment, prevention and care by 2010*. That commitment in some way formed the basis for the current push for Universal Health Coverage. UNAIDS is now driving global mobilization around the vision of *Three Zeros*: Zero new HIV infections, Zero AIDS-related deaths and Zero Discrimination. All of these global statements and events are significant in that they create space for more effective national action and drive accountability efforts.

In Rwanda there is an annual meeting for local Mayors with President Paul Kagame. The Mayors must provide reports and updates on how they are delivering AIDS services. These are closely interrogated by the President, and challenged for accurate data and focus. This has created national buy-in and accountability for a scaled-up response.

In 2001, the new Guyanese Minister of Health reached out to parliamentarians and others to consider how to get civil society and other sectors involved in the HIV response. This was prompted by the 2001 UNGASS. Much of the population did not see the importance because they did not understand how AIDS affected them. The health Minister “personalized” the issue by telling people that an effective HIV response is in the best interests of themselves and their families.

**Discussion Questions:** How can these bold actions be applied in the post-2015 development agenda? What new global goals will drive the AIDS response moving forward? How can political leadership prepare health and community systems to handle the needs of the 15 million people currently on ART, and the millions more that will start treatment? As the response scales up – and if the Three Zeros are achieved - will the institutions and structures that have been created need to adapt to address more diseases? What can other global health and development issues learn from the impact of these global goals on political leadership? Is there a risk of “goal fatigue”? How can advocacy be sustained to maintain political momentum and accountability?
Theme 6: Money

6.1. One of the key dynamics of the response has been the substantial global resources for AIDS, and the rapid scale-up in contributions by donors. Soon after the 2001 UNGASS there was a “tipping point” when global contributions to the AIDS response shifted from the millions to billions.

6.2. These funds were raised in an unprecedented manner, mostly from traditional sources of development assistance. In addition foundations have mobilised and disbursed substantial volumes of finance, and the private sector has also played an important role, including through novel approaches such as the Project (RED) partnership that raises awareness as well as funds. Other innovative financing includes the “airline tax”, where contributions from flight ticket sales in several countries have been used to create UNITAID.

6.3. In 2002 the Global Fund was created, and it has now grown to be the most significant source of financing for programmes on AIDS, TB and malaria in most affected countries. The Global Fund is an innovative model for development financing, founded on a partnership model that shares power between donors and implementers, and emphasises country ownership as a core value, as well as stressing the importance of funding being based on performance. Alongside the Global Fund, the most important source of external finance for the AIDS response is the US government’s PEPFAR programme – the largest programme on health ever created. Both programmes have emphasised “country ownership”, but also have been criticised at times for the style of relationship between donors and recipients.

6.4. On top of these substantial increases in donor assistance, there has been a huge growth in domestic financing for AIDS responses, especially in middle-income countries. This bodes well for the sustainability of the response, and underscores the importance of shared responsibility for AIDS responses.

Discussion Questions: How can the substantial new global programmes for HIV - the Global Fund and PEPFAR - inform global health? Could these instruments expand to take on board additional health concerns? Are similar vertical programmes needed? If so, what can be learned from the challenges with these complex instruments, as well as their impact in directing new resources to the countries and programmes in greatest need? How can the concept of “country ownership” be translated into a transformative relationship between those in need of funds and the providers of development assistance – both to sustain an effective response to AIDS and to inform the global health agenda going forward? What are the best approaches to sustain and build country ownership through domestic financing as well as innovative financing mechanisms?
Working Group 2 – List of Members

Co-Chairs: Dr Mark Dybul, Executive Director, The Global Fund to Fight AIDS, Tuberculosis and Malaria
Minister Aaron Motsoaledi, Minister of Health (South Africa)

Commissioners: Justice Edwin Cameron, Justice, Constitutional High Court (South Africa)
Ms Helen Clark, Administrator, United Nations Development Programme (UNDP) (represented by Mandeep Dhaliwal, Director, HIV, Health and Development Practice, Bureau for Development Policy)
Ms Svitlana Moroz, Board Chairwoman Svitanok Club, All-Ukraine Network of People Living with HIV (Ukraine)

Special Envoy: Dr Speciosa Wandira-Kazibwe, United Nations Secretary-General’s Special Envoy for HIV/AIDS in Africa (Uganda)

Members: Minister Kesetebirhan Admasu, Minister of Health (Ethiopia)
Dr Chris Beyrer, Director, Johns Hopkins Fogarty AIDS International Training and Research Program and Johns Hopkins Center for Public Health & Human Rights and Associate Director, Center for Global Health (USA)
Minister Agnes Binagwaho, Minister of Health (Rwanda)
Minister Fenton Ferguson, Minister of Health (Jamaica)
Mr Anand Grover, Special Rapporteur, United Nations Human Rights Council, Office of the High Commissioner for Human Rights (UNHCR)
Professor Chip Heath, Professor of Organizational Behavior, Stanford Graduate School of Business (USA)
Dr Dominique Kerouedan, Founder and Scientific Advisor of the Concentration in Global Health, Paris School of International Affairs (France)
Mr Donal Brown, Head of Global Funds Department, Department for International Development (UK) (represented by Jane Miller, MDG Team Leader and Senior Regional Health Advisor, Department for International Development, UK)
Dr Carole Presern, Executive Director, World Health Organization Partnership for Maternal, Newborn and Child Health (Switzerland)
Ms Selina Lo, Senior Editor, The Lancet (China)
Minister Leslie Ramsammy, Minister of Agriculture (Guyana)
Ms K. Sujatha Rao, Former Union Secretary, Ministry of Health and Family Welfare and former Director General, National AIDS Control Organization (India)

Writers: Mr Jeff Hoover, Associate, and Ms Robin Gorna, Director, AIDS Strategy, Advocacy and Policy (ASAP) (UK)

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