Civil society demand for accountability to achieve the 90-90-90 targets: lessons from Eastern and Southern Africa

Asia Russell[a], *Maureen Luba*[b], *Kenneth Mwehonge*[c], *Richard Lusimbo*[d], *Maureen Milanga*[a], *and Matthew M. Kavanagh*[a,e]

Purpose of review
Civil society demand for accountability has long been a critical component of the AIDS response. In the age of 90-90-90 HIV treatment goals, civil society advocacy has continued, but often in new forms. In particular, civil society accountability at the intersection of national policy and global health financing has taken on increasing importance, but has not been well documented.

Recent findings
Civil society demand for accountability is a key to addressing both the insufficient progress toward '90-90-90' HIV treatment goals and the gap in democracy in HIV policymaking particularly prevalent in the context of internationally financed HIV programming. Civil society can serve three vital functions for accountability: unlocking decision-making processes monopolized by powerful funders through North–South networks; challenging dominant ideas that justify status-quo policies; and 'venue shifting' to institutionalize new, more open spaces for policymaking.

Summary
The functions of civil society demand for accountability have played key roles in improving the AIDS response in several countries in East and Southern Africa. Dramatically scaling-up capacity for civil society advocacy is necessary in the near term to achieve global HIV goals.

Keywords
advocacy, antiretroviral treatment, civil society, global health, policy

INTRODUCTION

In 2016, the United Nations General Assembly adopted, by consensus, a commitment to achieving the 'Fast Track' 90-90-90 targets: ensuring that 90% of people with HIV know their status, 90% of those have access to treatment, and 90% of those have suppressed viral load by 2020 [1]. These targets deliberately focused on accelerated scale-up of quality HIV treatment coverage capable of virologic suppression because defeating HIV will otherwise not be possible. This is a particularly important priority for global political commitment because cost implications of treatment scale-up have historically undercut leaders' commitment.

The most recent data show, however, that the end of HIV is not on track: AIDS mortality has stalled at 940 000 people per year. Although a record 21.7 million people are on treatment – an increase of 2.3 million last year – in the next 3 years an additional 2.8 million people must be added each year, but there are no new commitments to increase resources [2]. Meanwhile some regions are losing ground – with no reduction in AIDS-related mortality in eastern Europe and central Asia since 2010 and a 11% increase in deaths from AIDS-related illness in the Middle East and North Africa over the same period [2].

In response to these concerning trends, expanding effective civil society demand for accountability and advocacy is critical at the national and global level to drive both increased resources and increased

[a]Health Global Access Project, Kampala, Uganda and Nairobi, Kenya, [b]AVAC, Lilongwe, Malawi, [c]Coalition for Health Promotion and Social Development, [d]Sexual Minorities, Uganda and [e]Georgetown University, Washington, DC, USA

Correspondence to Asia Russell, Health Global Access Project, 81 Prospect St, Brooklyn, NY 11201, USA. E-mail: asia@healthgap.org

Curr Opin HIV AIDS 2019, 14:41–45
DOI:10.1097/COH.0000000000000516

1746-630X Copyright © 2018 Wolters Kluwer Health, Inc. All rights reserved.

Copyright © 2018 Wolters Kluwer Health, Inc. All rights reserved.

KEY POINTS

- Civil society demand for accountability is a key to addressing both the insufficient progress toward '90-90-90' HIV treatment goals and the democratic gap in HIV policymaking particularly prevalent in the context of internationally financed HIV programming.
- Civil society can serve three vital functions for accountability: unlocking monopolistic decision-making processes through North–South networks; challenging dominant ideas that justify status-quo policies; and 'venue shifting' to institutionalize new, more open spaces for policymaking.
- These functions have played key roles in improving the AIDS response in several countries in East and Southern Africa.
- Dramatically scaling up capacity for civil society advocacy is necessary in the near term to achieve global HIV goals.

impact of existing resources. Activism has, since the earliest days of the pandemic, been a critical component of the AIDS response – generating political will, improving accountability, and challenging vested interests and status-quo thinking [3–5]. In the age of 90-90-90, civil society advocacy has continued, but often in new forms. In particular, civil society demand for accountability at the intersection of national policy and global health financing has taken on increasing importance in the 90-90-90 era, but has not been well documented.

Studies have shown civil society engages in a variety of functions in global health policymaking [6,7]. As advocates, civil society is involved throughout the policy-making process – from setting the agenda to formulating policy, implementation, and evaluating effectiveness [8]. Activists in global health help draw attention to key issues and force policymakers to act [9] – providing compelling moral arguments for action and introducing novel policy alternatives [10]. Civil society engages long after priorities have been set – helping shape the details of policy, influence how programs are run, and watchdog programs' expenditures, quality, and respect for rights [7,10–13]. Insufficient attention has been paid, however, to the role of civil society throughout the policy process in global health financing initiatives [14▪].

In many of countries with high HIV rates, priority setting, policy making, and implementation related to the 90-90-90 goals occur in spaces that bridge the national and global. International financing initiatives like the US President's Emergency Plan for AIDS Relieve (PEPFAR) and the Global Fund to Fight HIV, Tuberculosis and Malaria (Global Fund) have a strong, and at times decisive, role in all parts of the governance process [15,16]. Indeed, in many high-burden HIV countries, external financing represents the majority of funding for HIV – with decisions made by donor officials in a complex, often closed process with varying degrees of input from national actors. This phenomenon extends far beyond HIV – with the old emphasis on national sovereignty decreasingly helpful in understanding governance in a contemporary context with a proliferation of new political actors and authorities [17]. Scholarship, however, has paid insufficient attention to civil society's engagement at this intersection of national and global health policy.

A REVIEW OF CIVIL SOCIETY DEMAND FOR ACCOUNTABILITY

We focus here on reviewing the ways in which civil society demand for accountability for 90-90-90 goals has functioned at this juncture, drawing on case studies from several countries in East and Southern Africa where national and PEPFAR policymaking has been critical. Overall, we have found advocacy led by people with HIV and their allies has taken on a new relevance and urgency in the 90-90-90 era. Although these examples of advocacy precede agreement on the 90-90-90 targets, they represent benchmarks indicating what is possible in the context of flat or declining funding and harmful policies that reject scientific evidence.

We find that successful advocacy in this space has performed three important functions: unlocking closed decision-making processes, in particular through North–South advocacy networks; challenging dominant ideas that have justified status-quo policies; and 'venue shifting' to institutionalize new, more open spaces for global health policymaking. As such, we draw on policy literature and 'punctuated equilibrium' theory that explains policy change and the role of 'policy entrepreneurs' in change-making as a theoretical framework for our review effective HIV advocacy for 90-90-90 [18,19].

Activists build pressure based on deployment of community evidence using dynamic campaigns that have the immediate goals of both changing funding levels and strategies of funders, while illustrating the actual community burden of funding cuts and flat funding. In recent country cases, these approaches have resulted in necessary shifts in funder actions that have the potential to improve program impact while securing increased HIV funding.

Copyright © 2018 Wolters Kluwer Health, Inc. All rights reserved.

Opening closed policymaking cycles through North–South advocacy

Policymaking on technical issues like the details and shape of the HIV response are rarely given attention by political leaders – and instead, critical decisions are often delegated to smaller, closed groups that political scientists call 'monopolies' because they seek to exercise control over policy without outside attention [18]. In global HIV, government and funding agency officials often take life-or-death decisions out of the view of scrutiny – calling them too complex for discussion with political leaders or affected communities. This has been particularly true within bilateral financing initiatives like the PEPFAR program – where final spending decisions lie entirely with US government staff and, until recently, the formal planning process was a closed dialogue between country-based and Washington, DC-based US government officials [20]. Country Operational Plans (COPs) – the outcome of that formal planning process – were confidential documents. This was particularly problematic as PEPFAR financing – which flows directly to implementing nongovernmental organizations – is the largest source of HIV funds in many countries. For years, this was considered legitimate – a technical issue – despite long-held principles that people living with HIV have a right to be engaged in policymaking that affects them [21,22]. A coalition of activists successfully pushed to gain access to these plans and to insert themselves into the policy-making process – delegitimizing what had been a closed process. Coalitions of advocates nationally and globally have formed a flexible network in order to prioritize new approaches to holding funders accountable for their priorities and strategies.

An early example of this national and international advocacy collaboration through 'North–South' solidarity came in Uganda. In 2012, it was the only PEPFAR 'focus country' reporting rising HIV incidence – due in part to moving too slowly in scaling up treatment. Uganda attracted scrutiny when PEPFAR decided to 'cap' new treatment enrollees [23]. Although officials at the time denied it was happening, advocates helped uncover evidence of this decision, written in a memo to service providers, and used effective advocacy to secure a new trajectory of treatment scale-up [24]. But assessment of recent Country Operational Plans (then only available surreptitiously or in redacted form) by advocates indicated that core treatment and prevention strategies had not changed. The results of the 2011 Uganda AIDS Indicator Survey underscored advocates' concerns – for example, rates of sex with a condom between noncohabitating partners decreased by nearly 20% between 2005 and 2011 [25].

Civil society continued pushing both the Ministry of Health and PEPFAR to expose the consequences of an off track response – through face-to-face advocacy meetings, a high profile press conference, and community level assessment of gaps in service delivery that made it impossible for local technocrats to contain [26]. It attracted political attention both in Uganda and in Washington, DC – including by US Ambassador Eric Goosby, political leader of the PEPFAR program – which finally changed policy. By 2012, the Uganda COP was 'red lighted' for insufficient quality and responsiveness to the reality of the national epidemic. It was revised substantially, and that expectation of scrutiny from Washington DC helped trigger a new standard in approaching COP development and implementation.

Challenging powerful ideas that justify status-quo policies

Policy often remains stuck, even when failing, because a powerful idea maintains the status quo – one that causes higher level officials to dismiss calls for change [27]. Policymakers come to accept the way an issue is framed for long periods, perhaps even taking it for granted that the current policy is the best possible, until advocates successfully challenge that narrative using their moral authority and innovative approaches that directly engage those who hold decision-making authority. Advocacy approaches to advance 90-90-90 goals have played a role in highlighting the critical issues that have been ignored and submerged. This approach relies on a mapping and calculation of the costs of unmet community need for quality treatment scale-up, starting from an assessment of current HIV epidemiology, and contrasting these priorities with the interventions funded by national governments and donors.

In Malawi, advocacy by civil society has illustrated this function. In 2012, a small coalition of advocates came together to challenge the continued use of the antiretroviral stavudine in HIV programs after it had been eliminated from WHO-recommended regimens because of side effects that people living with HIV (PLHIV) in Malawi had long complained about [28,29]. The decision had been taken largely because donor officials had questioned the cost effectiveness of switching quickly – a powerful idea in an AIDS program long run on minimal funding with a focus on low-cost models. Activists, however, effectively reframed this question to focus on retention and adherence: side effects were undermining the effectiveness of the program and switching drugs was needed to respect the rights of PLHIV

1746-630X Copyright © 2018 Wolters Kluwer Health, Inc. All rights reserved.

Copyright © 2018 Wolters Kluwer Health, Inc. All rights reserved.

and the improve outcomes. Through letters, meetings, and phone calls, a coalition of groups inside Malawi and in the United States successfully lobbied PEPFAR and the Global Fund to support a switch – a move that quickly triggered a switch by Malawian policymakers [30].

That coalition then faced a similarly powerful idea as their attention turned to the PEPFAR program – which for years remained committed to funding primarily technical assistance and capacity building rather than direct services like medicines and healthcare worker salaries despite rate-limiting gaps and a rising PEPFAR budget. This was based on the idea that doing so was a 'sustainable,' appropriate role for PEPFAR funding [31]. Starting in 2015, activists reframed the debate in terms of gaps in the AIDS response and low-impact vs. high impact interventions – pushing for increased amounts of PEPFAR funding be used for direct services. Although informally many actors agreed with the civil society analyses, they chose not to raise them. Civil society, therefore, moved to 'auditing' the national HIV response and PEPFAR contribution – documenting that, in fact, PEPFAR had grown to be the single largest source of HIV funding in the country [32]. Activists then documented, in writing, the gaps in to achieving 90-90-90 with particular focus on the striking lack of workforce capacity [33]. At first, PEPFAR officials in Lilongwe responded that funding public sector healthcare workers' salaries was against sustainability policies – but as activists in Malawi were connected to activists in Washington, DC, they were able to quickly determine PEPFAR's stance in other countries was quite different. Working with the Ministry of Health, the Clinton Health Access Initiative, and others, they built a clear case that human resources were the rate-limiting factor, showed that PEPFAR was not addressing this crisis, and brought their case to political leaders in both the Malawian and US government. By the end of 2016, the 'outsider' independent voices and their pressure through letters, lobbying, and a press conference made headway. PEPFAR shifted policy and, over the last several years, has funded hundreds of new nurses, pharmacists, and community health workers – which have been crucial in speeding up ART and improving program quality [34].

Venue shifting to gain political support

A third major function of civil society in the context of 90-90-90 has been expanding the 'venues' for policymaking – that is, finding a decision setting that offers the best prospects for reaching their policy goals and open for participation [35]. As discussed above, PEPFAR COPs have been reconstructed in recent years as US leaders responded to calls to open the process. Activists in numerous countries have seized this opportunity to help co-construct the new PEPFAR process, inserting themselves into decision-making in important ways that provide new opportunity to overcome bad policies.

In Kenya, for example, key population advocates have been particularly adept at venue shifting to secure expanded programming for sex workers, MSM, people who inject drugs, and others where targets have been inadequate. The official estimated total MSM in Kenya, for example, was for years set by the National AIDS Control Programme at a number representing just 0.4% of all adult men – an estimate far below reasonable evidence [36]. This estimation justified artificially low targets for service delivery – allowing programs to claim high 'coverage' while reaching less than 20 000 people in a country with over 13 million adult men. As national technical officials opposed changing the estimate, Kenyan activists shifted their focus into two important venues: the writing group for the Global Fund concept note and the PEPFAR Country Operational Planning process. Mobilizing evidence and support from leading researchers, they captured the attention of political appointees in the US government, the Global Fund board, and the Kenyan government. By shifting venues, they were able to pressure leaders into setting higher targets for service delivery in externally financed programs – even as the population size estimates remained low. By 2018, PEPFAR and the Global Fund were together funding programs to reach 52 000 MSM – double the prior estimated population [37].

CONCLUSION

The world faces a crossroads in the AIDS response: accelerate and achieve the 90-90-90 goals by 2020 or fail to prioritize the lives of millions? HIV/AIDS policymaking, target-setting, and financing are life-and-death matters but, as we have described, critical decisions are often buried in bureaucracy with powerful ideas mobilized to deflect political attention from some of the most important issues in the AIDS response. Civil society demand for accountability is a key to addressing both the insufficient progress toward 90-90-90 and the democratic gap in HIV policymaking particularly prevalent in the context of internationally financed HIV programming. We have shown that civil society can serve three vital functions for demand for accountability: unlocking monopolistic decision-making processes through North–South networks; challenging dominant ideas that justify status-quo policies;

Copyright © 2018 Wolters Kluwer Health, Inc. All rights reserved.

and 'venue shifting' to institutionalize new, more open spaces for policymaking. Together these functions have played key roles in improving the AIDS response in several countries in East and Southern Africa. The same is true in a variety of countries – and could be true throughout the world. Civil society demand for accountability, however, is insufficiently resourced and too-rarely considered integral to achieving HIV goals. Reversing this trend and dramatically scaling up capacity for civil society advocacy is not just helpful, but likely necessary in the near term. Issues ranging from reversing the flat mortality trends, ramping up TB services through roll out of bedaquiline and the new rapid urine-based test for lipoarabinomannan (LAM) antigen, ensuring access to new AIDS drugs like dolutegravir, shifting to differentiated service models, scaling up key population programs, and increasing ambition for PrEP programming are all areas that will need to be addressed in the next few years – and each will require greater civil society demand for accountability for success.

Acknowledgements

Although the writing of this article was not funded by external sources, the authors acknowledge funding from the MAC AIDS Fund that has supported elements of the advocacy described.

Financial support and sponsorship

None.

Conflicts of interest

There are no conflicts of interest.

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

- ■ of special interest
- ■■ of outstanding interest

1. United Nations. Political declaration on HIV and AIDS: on the fast-track to accelerate the fight against HIV and to end the AIDS epidemic by 2030. 7 June 2016.
2. UNAIDS. Global AIDS update 2018: miles to go. Geneva: UNAIDS; 2018.
3. Smith RA, Siplon PD. Drugs into bodies: global AIDS treatment activism. Connecticut, USA; 2006.
4. Mbali M. South African AIDS activism and global health politics. New York: Palgrave Macmillan; 2013.
5. Kapstein E, Busby J. AIDS drugs for all: social movements and market transformations. Cambridge, UK; 2013.
6. Frenk J, Moon S. Governance challenges in global health. N Engl J Med 2013; 368:936–942.
7. Lee K. Civil society organizations and the functions of global health governance: what role within intergovernmental organizations? Glob Health Gov 2010; 3:.
8. Sabatier PA, Weible C. Theories of the policy process. Colorado, USA; 2014
9. Smith SL, Shiffman J. Setting the global health agenda: the influence of advocates and ideas on political priority for maternal and newborn survival. Soc Sci Med 2016; 166:86–93.
10. Smith J, Buse K, Gordon C. Civil society: the catalyst for ensuring health in the age of sustainable development. Glob Health 2016; 12:40.
11. Parker RG. Civil society, political mobilization, and the impact of HIV scale-up on health systems in Brazil. J Acquir Immune Defic Syndr 1999 2009; 52(Suppl 1):S49.
12. Buse K, Eba P, Sigurdson J, *et al.* Leveraging HIV-related human rights achievements through a Framework Convention on Global Health. Health Hum Rights 2013; 15:E96–E110.
13. Taylor AL, Alfven T, Hougendobler D, *et al.* Leveraging nonbinding instruments for global health governance: reflections from the Global AIDS Reporting Mechanism for WHO reform. Public Health 2014; 128:151–160.
14. ■ Gómez EJ. Civil society in global health policymaking: a critical review. Glob Health 2018; 14:73.

A literature review of the important role of civil society in shaping policies in global health.

15. Biesma RG, Brugha R, Harmer A, *et al.* The effects of global health initiatives on country health systems: a review of the evidence from HIV/AIDS control. Health Policy Plan 2009; 24:239–252.
16. Cohn J, Russell A, Baker B, *et al.* Using global health initiatives to strengthen health systems: a civil society perspective. Glob Public Health 2011; 6:687–702.
17. Haas PM. Is there a global governance deficit and what should be done about it. Geneva: Ecologic; 2003.
18. Baumgartner FR, Breunig C, Green-Pedersen C, *et al.* Punctuated equilibrium in comparative perspective. Am J Polit Sci 2009; 53:603–620.
19. Green-Pedersen C, Walgrave S. Agenda setting, policies, and political systems: a comparative approach. Chicago, USA; 2014.
20. Kavanagh MM, Baker BK. Governance and transparency at PEPFAR. Lancet Glob Health 2014; 2:e13–e14.
21. Morolake O, Stephens D, Welbourn A. Greater involvement of people living with HIV in healthcare. J Int AIDS Soc 2009; 12:4.
22. Wright J. Only your calamity: the beginnings of activism by and for people with AIDS. Am J Public Health 2013; 103:1788–1798.
23. Don McNeil. At front lines, AIDS war is falling apart. New York Times. 9 May 2010.
24. HIV treatment access in Uganda: a report from the ground. Science Speaks [Internet]. 2010 Apr 21; Available at: http://sciencespeaksblog.org/2010/04/21/hiv-treatment-access-in-uganda-a-report-from-the-ground/.
25. Ministry of Health of Uganda. Uganda AIDS Indicator Survey [Internet]. 2011. Available at: health.go.ug/docs/UAIS_2011_KEY_FINDINGS.pdf.
26. The change we need to end AIDS in Uganda: a civil society analysis of the state of Uganda's AIDS response [Internet]. Kampala; October 2012. Available at: https://d3n8a8pro7vhmx.cloudfront.net/healthgap/pages/102/attachments/original/1406056764/shadow_report_final_PF.pdf?1406056764.
27. Baumgartner FR. Ideas and policy change. Governance 2013; 26:239–258.
28. Antigone Barton. Groups to Global Fund, PEPFAR: Support switch from toxic treatment. Science Speaks [Internet]. 2012 Aug 15; Available at: https://sciencespeaksblog.org/2012/08/15/groups-to-global-fund-pepfar-support-switch-from-toxic-substandard-drug/.
29. Andrieux-Meyer I, Clayden P, Collins S, *et al.* Why it's time to say goodbye to stavudine. . .everywhere. S Afr J HIV Med 2012; 13:17–19.
30. Trapence G, Banda E, Russell A. Letter to Global Fund General Manager Gabriel Jaramillo and Global AIDS Coordinator Eric Goosby. 2012 (copy of letter on file with author).
31. PEPFAR. Malawi Country Operational Plan. Washington, DC: U.S. Department of State; 2015.
32. Kavanagh MM. Getting more PEPFAR funds to clinics and communities in Malawi and Zimbabwe [Internet]. Health GAP. Available at: https://www.healthgap.org/getting_more_pepfar_funds_to_clinics_and_communities_in_malawi_and_zimbabwe.
33. Archangel Nzangaya. US to pay Malawian health workers for 3 years. Malawi24 [Internet]. 29 November 2017. Available at: https://malawi24.com/2017/11/29/us-pay-malawian-health-workers-3-years/.
34. Health Global Access Project. Activism delivers real impact at the 2016 PEPFAR COP Reviews [Internet]. 2016 May. Available at: https://www.healthgap.org/activism_at_2016_cop_reviews.
35. Pralle SB. Venue shopping, political strategy, and policy change: the internationalization of Canadian forest advocacy. J Public Policy 2003; 23: 233–260.
36. PEPFAR. Kenya Country Operational Plan COP. Washington, DC: U.S. Department of State; 2016.
37. Health Global Access Project. 2017 PEPFAR Country Operational Plans: Civil Society AIDS Activists Pushing Toward Higher Impact [Internet]. New York; 2017 May. Available at: https://www.healthgap.org/pepfarcop17wins.

1746-630X Copyright © 2018 Wolters Kluwer Health, Inc. All rights reserved.

Copyright © 2018 Wolters Kluwer Health, Inc. All rights reserved.