Valuing the central role of community AIDS

2018 conference meeting: summary report

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Introduction

On Wednesday the 25th of July the Australian Research Centre in Sex, Health & Society (ARCSHS) at La Trobe University, in conjunction with UNAIDS and GNP+ hosted a meeting titled: "*How do we maintain and evidence the crucial role of community-based organisations (CBOs) in the global response to HIV*?"

This brief report summarises the rationale for the meeting, provides an overview of presentations made, offers a summary of group discussions and outlines potential avenues for further collaboration.

As the HIV response adapts to the largest and most significant developments in HIV prevention in over 20 years, it is timely to investigate and articulate the diverse ways in which community organisations influence and impact the epidemic. While the emergence of PrEP and treatment as prevention (TasP) have undoubtedly helped to reduce incidence of HIV transmission in some populations, there is much to do in ensuring these technologies reach those who need them most and that no one is left behind. Peer and community-based organisations will be crucial to this effort given their capacity to engage with marginalised or hard-to-reach populations. Peer and community-based organisations will also continue to be the central force ensuring equity of healthcare and treatment access, while contributing to the broader sexual health and well-being of HIV affected people in a myriad of other ways through individual, community and policy-based initiatives.

However, the evidence base that clearly demonstrates this crucial role is limited, complicated by the significant challenges inherent to complex, community-embedded ways of working. In an increasingly biomedical era, the role of peer and community organisations and social and behavioural interventions has been called into question by funders, with reductions in funding already documented across the globe.

Meeting objectives

With the challenges outlined above in mind, the objectives of this meeting were as follows:

1. To examine ways of better evidencing the crucial role that peer and community-based organisations play in the global HIV/AIDS response;
2. To share developments in demonstrating the quality and impact of peer and community-based organisations;
3. To discuss and action ideas relating to the role of peer and community organisations in the HIV response generated during the AIDS2018 conference.

Attendees

The meeting brought together a range of key organisations in the community-led response to HIV. Our aim was to identify and discuss innovative means of evidencing the central role of community organisations at this critical juncture in the epidemic. In all over 80 people attended the seminar and a further 40 people took part in the group discussions that followed.

The meeting included attendees from nearly twenty countries, including: Australia, Botswana, Canada, France, Germany, Hungary, India, Indonesia, Jamaica, Lebanon, Netherlands, South Africa, Switzerland, Taiwan, Thailand, Uganda, Ukraine, UK and USA. Also represented were a variety of sectors within the global HIV response, including peer and community led organisations, PLHIV groups, health service providers, researchers, funders, and government. The contribution of so many individuals helped shape a very lively and engaging discussion into how best community-led organisations respond to an environment in which funding can be precarious, and one in which funders do not always have access to data that demonstrates their crucial value.

Presentations

The meeting began with opening remarks from **Laurel Sprague** from UNAIDS and **Adam Bourne** from ARCSHS. These were followed by a ten-minute address by **Amukelani Maluleke** from Treatment Action Campaign (TAC) (tac.org.za) in which he outlined the crucial role of TAC as a peer led organisation in the HIV response in South Africa and the challenges they often faced in providing government and funders precise evidence as to their impact. These remarks were followed by **Graham Brown** (ARCSHS) and **Suzy Malhotra** (Living Positive Victoria) who gave an in-depth account of an ongoing project led by ARCSHS to better evidence the role of community and peer-led organisations in the Australian HIV response. Utilising a systems theory approach, this project – What Works and Why (W3: www.w3project.org.au) – identified four key functions of peer led organisations in Australia and positioned these within the broader community and structural environment.

Group tasks

After a general discussion on the presentations, the meeting formed four groups for more in-depth discussion on the following questions:

1. What approaches have you/your organisation utilised to help evidence the role and impact of your community or peer-led?

   - What tool or methodologies you have been using? What has worked well?

   - What have been the barriers and enablers of evidence generation?

2. What are the next steps? How can we ensure a better evidenced role in the global HIV response moving forwards?

Summary of discussion

A lengthy and diverse discussion occurred within each of the four working groups. These have been collated, along with reflections raised in plenary discussion, into the following four themes:

1. The collective impact of community-led responses

Participants highlighted that many organisations had good evaluation of individual projects and programs. However, the real value may be in drawing together the evaluations across multiple community organisations to demonstrate broader impact at a community and structural level, their role within the response, and ways to represent this to stakeholders and funders. Questions/issues that arose included:

- Opportunities and challenges to draw together all evaluations into one central & shared database;
- What changed? What was the transformation?
- Community definitions of impact.
- Identifying capacity to undertake such collective impact assessment.

2. Common/clear indicators of influence/advocacy

Many participants felt most existing M&E indicators prioritised outputs and impacts related to individuals, but few indictors related to broader community and structural level changes. The presentation on the W3 Framework generated significant discussion on the need for common and clear indicators of influence in both community as well as policy and health systems. These needed to be developed and incorporated into their standard reporting to funders, so the crucial role of peer and community organisations can be more accurately reflected on a routine basis. Questions/issues that arose included:

- The need to identify practical dashboard indicators relating to role and effectiveness of peer and community led organisations;
- The need for community and multicounty engagement in development of indicators;
- Engaging with funders regarding the alignment of these indicators with their theories of change or strategic plans
- The need to trial the indicators at multiple levels (state/province, country, regional level);
- The community needs to be the driver in the development of indicators, and how such data is to be collected and used.

3. National, Regional, and Global Networks to mobilise and share

Participants identified the potential for national, regional, and global networks to draw together common indicators, case studies, and mobilise resources to build collective evidence of the impact of community and peer led organisations. Such networks would have particular value where multiple organisations are funded for community development, health promotion and advocacy purposes within the same country or region. Questions and issues that arose included:

- Understanding and presenting collective impact is important when advocating for funding;
- A network would further facilitate the identification and building of collective impact narratives;
- Identify and share/promote evidence of good programs, case studies etc;
- How best to showcase the role of individual community organisations in highlighting significant case studies, and their evaluation mechanisms in a collegiate manner?;
- Ensuring that communities are able to drive the creation of evidence of collective impact (rather than this being solely determined by funders).

4. Financial and logistical implications of data collection for community-led organisations

Participants emphasised that they recognised the value of indicators to report their unique impact, they also highlighted this would have significant financial and logistical implications to them in order to collect and report such information to their funders or build evidence of a broader collective impact. In an era of reduced budgets for community programming, it was important that resourced were not drawn from already limited M&E budgets.

- Ensuring sufficient resourcing of M&E in in funding of community led organisations;
- Ensuring workforce capacity to sustain and meaningfully use data from M&E for advocacy and service design and delivery.

Next steps

We have been really encouraged by the strong engagement with the topic and the high number of invitees who were able to attend. We invite people to let ARCSHS know if you would like to be part of the continuing discussion and actions after the meeting (email: david.OKeeffe@latrobe.edu.au).

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