



How do we value the role of the community responses to HIV?

ARCSHS Workshop at SKPA Meeting: summary report

August 2019, Bangkok

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Summary

The mobilisation of communities is central component of an effective response to HIV. However, often the complex role community led organisations play in strengthening community systems and guiding HIV policy and strategies is often not well articulated or demonstrated. In an environment of competing priorities and reducing investment, it is increasingly important to build the evidence of the value of community led organisations in the HIV response.

On Friday the 2nd of August 2019, the Australian Research Centre in Sex, Health & Society (ARCSHS) at La Trobe University, in conjunction with the Australian Federation of AIDS Organisations (AFAO) hosted a meeting in Bangkok, Thailand, titled: "How do we value the role of the community responses to HIV?" The meeting sought to reaffirm the crucial role that community organisations play in the global HIV/AIDS response and begin discussions on ways to collectively build the evidence to demonstrate this role.

The meeting was held immediately after the AFAO Sustainability of HIV Services for Key Populations in Asia (SKPA)¹ initiate discussions with a range of country and regional based community organisations who were already meeting together. The meeting was intended to initiate discussions with an initial group who were available on this date, and then broaden the discussion to organisations who were not able to attend.

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.

Context

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. For example- while the emergence of pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP) have undoubtedly helped to reduce incidence of HIV transmission in some populations in some countries, 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, and their expertise in leadership, advocacy and community-led action on health, human rights, and social justice. 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.

The Opportunity

There are many initiatives emerging to respond to this challenge, and to increase the visibility and evidence for the role of peer and community organisations.

For example – The What Works and Why (W3) Project in Australia has been collaborating with HIV peer and community organisations to develop a framework and tools to enable these organisations to adapt, scale-up and demonstrate their impact in rapidly changing community and policy environments. Some of our funding bodies

¹ AFAO is the Principal Recipient for the *Sustainability of HIV Services for Key Populations in Asia (SKPA)* program, funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria. The program aims to promote sustainable HIV services for key populations by addressing barriers to the provision of services and programs at scale.

have expressed interest in exploring how this community led research approach may be strategically useful for peer and community organisations and networks in Asia and the Pacific.

We are committed to the central role of community in the HIV response and so before we continue these discussions with potential funders, we are keen to initiate discussions first with key community organisations and networks in the region. We would like to understand the work and needs of organisations in Asia and the Pacific and see if there is interest in forming a coalition to strengthen the collective evidence for peer and community organisations in the HIV response.

Meeting Objectives

With the above in mind, the objectives of this meeting were:

1. To reaffirm the unique and crucial role that community organisations play in the global HIV/AIDS response, and the evidence required to demonstrate this;
2. To discuss ways that community organisations can demonstrate the community and policy level impact of their role;
3. To identify interest in a collaborative consortium proposal to funders that could:
 - Enhance the evidence building capacity and resources within community organisations and networks; and
 - Work at a regional or network level to draw together common evaluation indicators, case studies and resources to build collective evidence of the impact of community organisations in the HIV response in Asia and the Pacific.

Attendees

The meeting brought together 27 participants from a range of key organisations in the community-led response to HIV in Asia and the Pacific. 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 30 people attended the workshop and took part in the group discussions that followed.

The meeting included attendees from countries, including: Australia, Bhutan, Laos, Mongolia, Papua New Guinea, Philippines, Sri Lanka, and Timor Leste. 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 workshop began with opening remarks from **Leo Kenny** from AFAO and a presentation by **Graham Brown** from ARCSHS. **Graham Brown** posited the question, “How do we value the role of the community responses to HIV?”, and provided an example of work in this area, the What Works and Why Project (W3: www.w3project.org.au) in Australia.

The W3 Project is supporting community and peer-led programs in Australia to adapt, scale-up and demonstrate their impact in rapidly changing community and policy environments in Australia. Utilising a systems theory approach, the W3 Project identified four key functions to articulate the role of community and peer-led organisations within their community and policy environment:

- Engagement: How the community organisation maintains up to date knowledge of the diversity and dynamism of needs, experiences and identities in its communities.

- Alignment: How the program picks up signals about what's happening in its policy and service sector environment and uses this to better understand how it works or what may need to change.
- Learning and Adaptation: How the program constantly adapts and refines its understanding and approach based on insights from engagement and alignment.
- Influence: How the program uses existing community, social and political processes to influence and achieve improved outcomes in both their communities and the policy and service sector.

Through the presentation Dr Brown discussed the experience of peer organisations in Australia who had drawn on the W3 Project approach, generating the following:

- Supporting the collection of data that is more meaningful to peer and community organisations,
- Increasing peer staff confidence and motivation in using peer evaluation methods,
- Capturing the unique impact of peer-led health promotion,
- Building stronger evidence of role of community organisations contributions to the HIV response,

From the presentation participants were invited to respond either by way of questions or comments. This generated a discussion which is summarised in the following dot points drawn from facilitation and participant submitted notes.

- There is a need to acknowledge the role of human rights and community mobilisation in any community response.
- CBOs have built long term credibility and trustworthiness within their communities.
- Peer-designed and peer-delivered programs emerge from recognition that the community knows what it wants better than anyone else - no community, no credibility
- Peer programs have the ability and insight to support their communities in many ways that professionals and organizations may not be able to. Despite their lack in the same level of professional training as doctors and organization personnel, their role should not be overlooked or dismissed.
- Often there is an underestimation of community resilience, and there is a need to invest in this resilience.
- There is pressure from funders to achieve short-term goals when CBOs work long term in their communities.
- There is a need to increase the visibility of the role of the community organisations to all parties; the challenge is how to gather evidence demonstrate the role and impact of CBOs and how their programs are adapting and changing with their communities and with the epidemic.
- Such evidence is vital for operating in an environment with decreasing donor funding
- The collection of more meaningful data included that data which often already collected but can be used more meaningfully. For example, collecting and valuing community insights which emerge in team meetings. Outreach workers finding out what's happening on the ground and feeding it back to managers who adjust the programs or support advocacy.
- Challenges for CBOs is the knowledge of what's happening on the ground in peer outreach getting back to the larger organisation.
- Community organisations are often working in "stigmatized engagement" – such as NSP. The stigmatisation of the work can reduce the outreach and effectiveness of programs. Therefore, educating and advocacy towards broader community, policy and service sector is important for programs to improve effectiveness.
- Communities alone may lack the necessary credibility to change in laws, policy, and resources. The role of alignment with allies to change systems, such as advocacy to influence someone else to change policy.
- There was recognition in the practical use of models such as W3 and interest in identifying how we go about applying this model.
- Suggestions that W3 approach may be useful in CBOs articulating and undertaking community monitoring – a way to collect and understand perspectives from key populations

Workshop Discussion

The participants then divided into four small groups to reflect on the presentation and discussion to date, and share the experiences of their own organisations through the following guided questions:

- Describe a time when you heard from your community that something needed to change?
- How did you hear that? From who did you hear that?
- What did you do with it? What happened next?
- What were the barriers/enablers to creating change?
- What did you learn from this?

Then as a small group they discussed

- What were common learnings and experiences?
- What might help you demonstrate this crucial role that you're playing in a systematic way?

The groups fed back to the large group some of their insights. This generated a wide-ranging discussion. The notes from the small group and whole group discussions, as well as participant's notes contributed after the meeting, have been collated into five key themes described below.



Summary of discussion

1. The role of using data and community insights to achieve more meaningful evaluation and demonstrate the role of community

Many of the attendees noted that they already collect a vast array of data but did not use it as meaningfully as perhaps they could. Demonstrating the quality, impact, and effectiveness of peer programs requires proper data collection and analysis: however, this does not necessarily mean an increase in data collection, rather the process of analysing programs in a way that may reveal useful insight. Some spoke of the need to translate the community knowledge into a resource that can be used in advocacy. Similar to translating research into policy and practice, we need to recognise and value community knowledge and consider innovative ways of translating this into policy and practice.

2. Need to increase capacity for CBOs to better use their community insight and evidence in advocacy

Many of the attendees felt that their community organisations engaged and worked well within their communities, however challenges arose when they needed to reach out to allies or attempted to influence key funders or government officials. Concerns relating to stigma and discrimination related to HIV were strong in the delivery of community led services across many jurisdictions, and were coupled with the illegality and/or stigmatisation of drug use, sexuality and sex-work.

Consideration needs to be made for country-specific values when attending to these issues. Some attendees highlighted the human rights versus community safety issue when discussing problems in their nation. Some felt there is a need to couch their approach in a rights-based language framework, with others feeling an economic and community safety argument would work better in their context.

3. Building sector wide capacity to prepare collective evidence and demonstrate the value of a community led response

Many attendees saw themselves as champions of changes in their sector but do not have either the capacity or funding to measure success beyond general outcomes required by the funder. An often-reported experience was that they implemented programs well, and had credibility among affected communities, but the capacity to collect and use evidence was limited for some. Many felt that by working with others as a coalition that they may be better equipped to demonstrate a broader impact at a systematic level.

Developing viable monitoring and evaluation indicators which are meaningful to the work of community organisations would be very timely. The concern was that if community sector does not come up with meaningful indicators first, then funders or government may develop and implement indicators which are less meaningful or effective in reflecting the impact of community organisations.

4. Investing in the long term strengthening and sustainability of CBOs

Attendees emphasised that limited resources were a barrier to them achieving the capacity to collect and analyse indicators of achievement in a systemic way. There was an acknowledgement that without significant funding in both training of staff, and investment in systems, that any evidence collected may not be sustained into the long-term and have very little meaningful use for organisations.

There was also concern that funders were reluctant to fund such projects and their priority was to demonstrate immediate outcomes in the health and well-being of participants. Again, the issue of trusted allies and having access to funding to support such an approach was a key issue to implementing ongoing intervention or program evaluation.

5. Opportunity to support SKPA² goals in sustainability and to articulate community monitoring

² The *Sustainability of HIV Services for Key Populations in Asia (SKPA)* program, funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria, aims to promote sustainable HIV services for key populations by addressing barriers to the provision of services and programs at scale.

The feedback from participants highlighted there were valuable entry points to engage and draw on the W3 framework. Particularly in relation to longer term sustainability of community networks beyond the life of the SKPA program, and what needs to be better documented and measured. This included

- the need for community organisations to articulate and undertake community monitoring to guide project planning and the process of directing efforts, and
- the opportunity to broaden the monitoring and evaluation approach to look at more meaningful indicators and data beyond the current framework, and how we demonstrate the added value of community led responses.

Next steps

Recommendation

Participants agreed to form a small working group to generate a Community/Research partnership proposal for funding to support:

1. CBOs to build the evidence of the community response at an organisation and at a sector level; and
2. building capacity of CBOs to prepare/use this evidence – we need to make the evidence usable and persuasive in advocacy

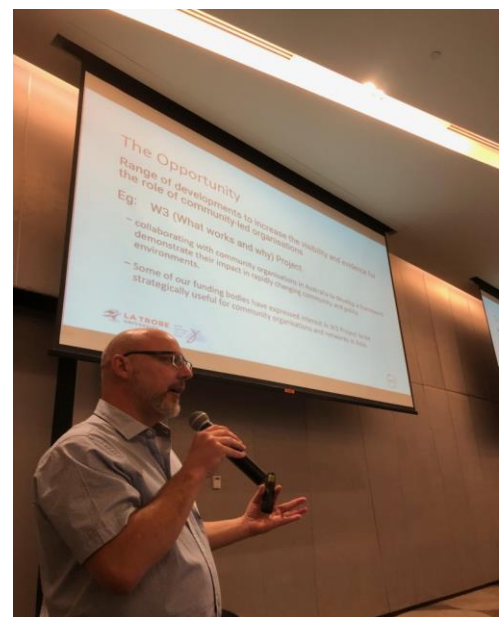
Similar to research translation of research into policy and practice, we need to translate community knowledge and insights into policy and practice

The above proposal is expected to be submitted in 2020.

The SKPA project and ARCSHS agreed to continue discussions regarding the contribution the W3 Framework could make to articulating and supporting community monitoring outcomes of the SKPA project.

Tasks

1. Report reviewed by participating organisations for feedback and then released (or a summary version released).
2. ARCSHS to invite nominations from attending organisations as well as other invited organisations to be part of a small working group to develop a funding proposal to progress this work.
3. ARCSHS collaborates with working group in the writing of the proposal and developing partnership governance and identifying lead organisation for the proposal.



Acknowledgements

We thank all the participants for providing their time and insights to the workshop.

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