Representation and Participation of Key Populations on Country Coordinating Mechanisms (CCMs) in Six Countries in Southern Africa

Final Report

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of the Global Fund

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Preface

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This report is one of several Aidspan reports available at www.aidspan.org/page/research. Other reports recently published by Aidspan include:

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Acronyms

CCM	Country coordinating mechanism
CSO	Civil Society Organization
IDU	Injecting Drug User
KAP	Key Affected Population (s)
MSM	Men who have sex with men
NGO	Non governmental organization
PLWD	People living with disease
SOGI	Sexual Orientation and Gender Identities
SW	Sex worker

Executive Summary

Introduction: This survey is intended to help CCMs, those interested in their composition and outputs, and other stakeholders understand the status, opportunities and challenges that remain for key populations[1] and their representatives on the CCMs. Many changes have been initiated over the past few years as CCMs adapt to the changing model emerging from the Global Fund. One of the most talked about changes are the increasing requirements to address the needs of key populations that are considered at high risk of transmitting and being infected.

Background: While presence of some key populations representatives on most CCMs is now standard, their ability to contribute, and the quality of their participation in the processes of these bodies remains unclear. Traditionally, key population representatives work from within networks of persons living with/affected by the diseases. These individuals are rarely made office bearers and have often in the past been seen as somewhat token CCM members. Their participation and influence in the CCM processes remains unclear.

Methods

This survey, conducted in August 2014 using semi-structured interviews, asked questions of the leaders of the CCMs about KAPs reps, and asked those reps what their experiences were of recent engagement. The CCMs represented in this study include those in Swaziland, Lesotho, South Africa, Botswana, Zimbabwe, and Zambia. The main recommendations for improving the participation of KAP (both their representatives and the self-identifying individuals themselves) are presented below.

Recommendations:

1. CCMs can do a better job of communicating the agenda and outcomes of their deliberations – this means both the CCMs need to communicate to their members and the members need to communicate to their constituencies.
2. CCM management should be able to call all meetings in a planned and methodical way. No member should say they were called to meetings with only a few days to prepare.
3. Advancing the professionalization of the KAPs through their organizations or through individuals – but the reps must prepare themselves as well as they can for every meeting.
4. Continuity of presence is important – we are not sure how to ensure this in the dynamic and often political context of CCM representation.
5. Improved data, and improved understanding of those data, are needed for all key populations to better inform interventions.
6. Some CCMs may need to consider more seats for particularly hard hit KAPs, or those who cannot be represented by "multi-purpose" CSOs or networks.
7. Stigma for many KAPs remains a major challenge in all societies. CCMs may not necessarily be the place to solve this problem, but the suggestion of bringing on religious or other community leaders might help alleviate some of the issues.
8. The recognition of the lack of protection under legal framework is universal, but will take time and effort to change. Meantime, continued strengthening and education at all levels of the health system that provides diagnosis, treatment, care and support must continue to be a priority.

[1] Key population is used as an abbreviation of "key affected population" – both terms appear to be used interchangeably in the technical literature.

Introduction

In August 2014, Aidspan conducted a study to document the attitude, participation and some experiences of key affected population (KAP) representatives on Country Coordinating Mechanisms (CCM) in six Southern African countries. As the national coordinating and oversight body of Global Fund grants, CCMs play an important role in hosting and coordinating country dialogues, development of concept notes, selection of grant recipients, oversight of Global Fund grant implementation and reporting.

The Global Fund now requires that CCMs show evidence of membership of key populations affected by the epidemic. Current understanding based on the Fund's 2014 CCM guidelines includes the following as KAPs: women and girls, men who have sex with men (MSM), people who inject drugs (PWID), transgender people, sex workers (SW), prisoners, refugees and migrants, people living with HIV, adolescents and young people, orphans and vulnerable children (OVC), and populations of humanitarian concern. The Fund also provides the following definition of who qualify as KAPs under its Key Populations Action Plan (2014-17) "(1) the group faces a higher epidemiological impact of a disease, (2) faces lower access to key services and needs for whatever reason, or (3) faces criminalization, marginalization or exclusion that hinders access to key services or basic human rights."

While the presence of some KAP representatives on most CCMs is now standard, their ability to contribute, and their quality of participation in the processes of these bodies remains unclear. Traditionally, KAP representatives work from within networks of persons living with or affected by the diseases. These individuals are rarely made office bearers and have often in the past been seen as somewhat token CCM members. Their participation and influence in the CCM processes remains unclear. An Aidspan study conducted in August 2014 used a series of key informant interviews to analyze attitudes of the leaders of the CCMs and the key population representatives on the CCMs in Swaziland, Lesotho, South Africa, Botswana, Zimbabwe, Zambia.

Background

The Global Fund's model is designed to direct resources to priority areas that ensure the greatest impact. The Fund does this by using various country level systems, most notably the Country Coordinating Mechanisms (CCMs). CCMs are meant to be constituted by consensus among various multi-sectoral stakeholders or constituencies, particularly those actively involved in the fight against HIV and AIDS, Malaria and Tuberculosis. Like the Global Fund board, CCMs are intended to be driven by principles of democratic decision-making, inclusive participation, strong national ownership, mutual accountability, openness and transparency and a commitment to achieving the greatest possible results and efficiency with the money used.

CCMs are the key channel at national level who are responsible for coordinating the development of proposals (now called concept notes), identifying principal grant recipients and overseeing the implementation and reporting of the grants. The CCM membership is constituted of government, bilateral/multi-lateral technical partners and non-states actors including civil society, faith based organizations and the private sector. Members may be grant implementers.

Because of the key role that the Global Fund expects the CCMs to play in defining and managing the grant development process; and because the Fund wants to see strong impact using what has been called "smart programming" (ie programmes that reach the most affected populations, and therefore have the biggest impact), the Fund has reorganized the eligibility and assessment criteria for the CCMs. This has affected the eligibility requirements, the performance assessments and the ways in which the products (the concept notes) are being reviewed.

Current responsibilities include: ensuring adequate representation of people living with the diseases and key affected populations; monitoring feedback from non-CCM members, particularly on oversight issues; and ensuring proper representation of all non-state actors on the CCM, with evidence of a transparent and documented selection process.

Under the new rules, the CCM is also expected to show evidence of membership of key and affected populations.

The Fund acknowledges that the definition of “key population” varies depending on the diseases and the epidemiological context. The current definition of KAPs is based on the Fund’s Gender and Equality, the Sexual Orientation and Gender Identities (SOGI) strategy and the new Key Populations Action Plan (2014-17). The action plan uses the following basic factors to determine if a group falls under a key and affected population: (1) That the group faces a higher epidemiological impact of a disease, (2) faces lower access to key services and needs for whatever reason, or (3) faces frequent human rights violations, systematic marginalization or criminalization, and thence exclusion that all may increase vulnerability and risk and hinders access to key services. The Fund notes that in certain contexts, where, for example, certain groups may face risks if exposed publically, then the CCM (in order to be eligible) must show evidence of how it is going to get fair representation of those groups, even if self-identifying individuals cannot be physically present.

A summary of work conducted between 2012 and 2014 on the presence and participation by key population representatives on CCMs was summarized in September 2014 in a publication by Aids Accountability International [5,6]. This provided important themes for this study as it was one of the first attempts to summarize the level of representative of KAPs on the CCMs in southern Africa. The themes that emerged were similar to the main themes Aidspan used to define the guidelines for the key informant interviews: coordiantion, capacity, consultation and preparation. Aidspan did use the earlier publications to guide the study. The main difference was that Aidspan was asking what was the quality of participation: were individuals able to and did they know how to get their ideas on the table and into the concept notes.

History of key affected populations and presence in the Global Fund’s ecology:

From its founding, the Global Fund has made various efforts to create a common understanding of who qualify as KAPs. To trace those efforts to define and focus funding and support for KAPs, we explored key documents and policies. It is possible to trace some milestones within requirements and guidelines issued as recommendations or minimum standards, or more recently as strongly worded eligibility requirements.

The Global Fund’s use of the term "vulnerable" was present in key Global Fund documents and board decisions in 2002 during the 2nd Board Meeting, where funding eligibility was discussed. More direct reference made in formal guidance to CCMs about specific categories of KAPs such as women, children and vulnerable groups, and people living with HIV begun in 2003 during the Fund’s 4th and 5th board meetings.

In 2007, the Board asked the Fund’s Secretariat to recommend how vulnerable groups can be effectively represented on CCMs and asked how they can meaningfully participate in the work of CCMs. Then in 2008, specific terminology of key and affected populations began to be used. The guidelines for CCMs issued that year included representation from KAPs for the first time:

> “11. In order to ensure vulnerable and marginalized groups are adequately represented, the Global Fund strongly encourages CCMs to consider how to improve the representation and participation of representatives from such groups on the CCM, taking into account the scale of the national epidemic of the three diseases and the key affected populations in the national context.
>
> 12. The Global Fund recommends that all countries strive to include the following actors in their CCMs:

- Academic/Educational Sector;
- Government;

- NGOs/Community-Based organizations;
- People living with HIV/AIDS, TB and/or Malaria;
- Key Affected Populations****
- Private Sector;
- Religious/Faith-Based organizations;
- Multilateral and Bilateral Development Partners in-country.

The membership of the CCM should comprise a minimum of 40 % representation of the nongovernment sectors such as NGOs/community based organizations, people living with the diseases, key affected populations**, religious/faith-based organizations, private sector, academic institutions (see Annex 1 on "the types of civil society and private sector representation most relevant to the work of CCMs".

The CCM guidelines issued almost annually after 2008 used similar language to the 2008 Guidelines, and didn't change much until 2011. Then in 2011 the guidelines said:

"CCMs should ensure the representation of key affected populations (refer to footnote 2) taking into account the socio-epidemiology of the three diseases and the national context. The Global Fund Sexual Orientation and Gender Identities (SOGI) strategy provides additional guidance in this regard for populations most-at-risk for HIV." Although this was in the guidelines, it was not part of the wording of the six minimum requirements.

The 2011 guidelines were the first to contain "minimum standards" and "standards" as well as formal requirements, but none of these focused on representation from KAPs. These guidelines were adopted at the Board meeting in May 2011.

The latest CCM guidelines (2013 – 14), which form the basis of the CCM performance assessment tool, include a revision to the wording of Requirement 4, which reads as follows:

"The Global Fund requires all CCMs to show evidence of membership of people that are both living with and representing people living with HIV, and of people affected* by and representing people affected by Tuberculosis ** and Malaria*** as well as people from and representing Key Affected Populations****, based on epidemiological as well as human rights and gender considerations.

* Either people who have lived with these diseases in the past or who come from communities where the diseases are endemic.

** In countries where Tuberculosis is a public health problem or funding is requested or has previously been approved for Tuberculosis.

*** In countries where there is on-going evidence of Malaria transmission or funding is requested or has previously been approved for Malaria

**** The Secretariat may waive the requirement of representation of Key Affected Populations as it deems appropriate to protect individuals"

Further elements under the Fund's eligibility requirements for CCMs include several sections that describe how the CCM should ensure representation of key populations:

- Requirement number 1: "Clearly document efforts to engage key affected populations in the development of concept notes, including most-at-risk populations."

Separate from the *requirements*, the Global Fund has also instituted a set of standards, which are based mostly on best practice. The set identified below are now part of the CCM performance framework. This will become compulsory starting January 2015. These standards also provide guidance on KAPs as follows:

- Linked to requirement number 4:

◊ "CCMs should ensure the representation of key affected populations taking into account the socio-epidemiology of the three diseases and the national context. The Global Fund Sexual Orientation and Gender Identities strategy provides additional guidance in this regard for populations most-at-risk for HIV".

◊ The CCM has balanced representation of men and women (the Global Fund Gender Equality Strategy clarifies how women and girls are key affected groups in the context of the 3 diseases).

Work by both GNP+ and more recently by ICASO to support engagement of KPs by CSOs showed that one of the biggest elements CCMs need to focus on was improving communication and feedback, engagement of a wide range of actors, including on-CCM and developing policies that provide greater clarity of roles by different actors, improved rotation and sharing of tasks on CCMs or related technical working groups.[2] *[3,4,]* Finally, ongoing reporting from countries going through the experience of having a full country dialogue (the precursor to the development of a concept note), and the actual development of the concept note is just beginning. One of the first countries to experience this in what was called the early applicant group – was Zimbabwe[7]. Their experience of participation and the extra needs that were required for the KAPs was written up in 2014 and several of the points including in this report were expanded on by the individuals interviewed on Zimbabwe's CCM.

Methodology

A review of key documents from the Global Fund and any external studies (case studies, research papers etc) was done to provide the research team with the focus areas, the main questions and probes with which to develop a guide for the qualitative interviews.

A guide for the qualitative review was developed and tested internally and externally, and revised before being given to 17 individuals. These individuals were purposively sampled from a list of all the members of the CCMs, and a rolling snowball sampling method was used to make sure that the KP representatives, the CSOs with relevant experience and role on the CCMs, and the leadership of the CCMs were all contacted. A listing of the CCM leadership including focal persons was obtained from the Global Fund's CCM website, and Aidspan used its list of contacts to ensure all relevant members (including some past members) were included on the final sample frame.

Emails introducing the study, the interviewer and the concept behind the research were sent to all those on the list whom Aidspan felt would know who the right people to speak to about this project. We requested short interviews to ensure they understood the study and that we were talking to the right people. Despite the short notice of this study, the majority agreed to be interviewed, and by the end of the process, using "snowball sampling" to reach the most relevant individuals, we had interviewed 21 people. Out of these a few only gave us contacts for further information (3), so we did not count these as full interviews; and 1 interview did not produce any relevant information as the person was not on the CCM. This interview was not included in the analysis. The team emphasized that the survey was anonymous, so the results presented here are only identified by gender, not by country, since it would then be simple, with so few people, to identify the respondents. Informed consent was sought for each interview.

Analysis: With 17 semi-structured questionnaires completed by Skype or phone, the results were transcribed and analysed by coding the main ideas into key themes and drawing out proposed strategies or solutions where relevant. Our analysis of these themes, presented here, was enhanced by our understanding of the context. We have joined the results and discussion points coming from those findings to ease the reading of these results. We have also considered what was not talked about or mentioned, and occasionally this meant returning to the interviewees if we felt there was need to get more information.

[2] ICASO (2013). Effective CCMs and the Meaningful Involvement of Civil Society and Key populations.

Results

A total of 17 individuals were interviewed and these included 11 men and six women, spread evenly across the countries – with three or four interviewees from the six countries: Zimbabwe, South Africa, Swaziland, Zambia, Botswana and Lesotho. These included chairs, vice-chairs, members, and administrators of the CCMs. Among the constituencies of interest we included members of CCMs who were either representing key populations or were NGO representatives with experience on the CCMs. We interviewed a few multi- or bilateral donor representatives who either sit on the CCMs, or who work closely with them. The interviewees' years of experience on the CCMs ranged from two weeks or two months to 9 years.

A few of the respondents were former-CCM members recommended to us as knowledgeable on the subject of KAPs participation. The individuals interviewed came from many professions: activists, lobbyists, medical professionals, directors of network organizations, journalists and lawyers. There were only two who self-identified themselves as gay. None identified themselves as sex workers, transgender or IDUs, but several KP representatives said they were their spokespeople. Two interviewees identified themselves as disabled. In total there were nine KAP representatives, including those who represent the interests of girls and women (3).

The interviews usually lasted about 30 minutes, and respondents were asked a series of questions about participation on CCMs and their perspective on the inclusiveness of ideas that came from KAPs, and what the remaining challenges were for KAPs. They were asked how many meetings they had attended in the past 12 months. This was to ascertain their level of engagement and knowledge of the CCMs functions roles and actions. The majority (14) had attended 3 and 12 meetings in the last year. A few responders said they had only attended one or two meetings, while one person had attended more than 15.

Results with discussion by thematic or focal area:

Presence and Quality of Representation of Key Populations

All the CCMs in this region now have KAP representatives, and several have more than one. Many of those we interviewed felt that this was a positive shift in how the KAPs were being represented on the committees but most seemed to think that there was room for improvement. As one former CCM member put it: "This year KAPs are represented by 2 organizations, unlike before…. A lot of change is happening". [Female, Administrator].

But while the KAP representation has increased on these committees, there is a mixed picture as to whether these individuals are actually actively engaging in CCM meetings and related committees, or whether they are being heard. Several individuals confirmed that in the past, many CSO representatives tended to be quiet during CCM meetings. "My experience has been that civil society tends to not contribute as much as they should." [Female, CSO].

Two other recently appointed KP representatives both shared the sentiment that previous KP reps were not very vocal, implying that they were (vocal). While one senior administrator confirmed that "The MSM rep [that we now have] is very vocal." (Male, Senior administrator) And a CSO rep with many years experience said: "I have seen this [situation] evolve with time - before the civil society was not vocal at meeting –we were just told what to do, no orientation workshops were conducted, but we are no longer spectators now, we know our roles and improving as we move on." [Female, CSO]

> Finding and Discussion:
>
> The finding suggests that not only are KAPs now present on the CCMs, but they are no longer quiet (even where they used to be). But just because one is vocal does not necessarily translate into meaningful engagement through getting ideas noted and interventions or programmes included to meet the needs of ones constituency.

Quality of contribution to KAP planning and related processes:

All KAP reps interviewed felt that they could and did speak up and that they are heard in general. But when asked if they had evidence that what they said was being taken seriously, most only spoke in general terms. A few gave examples such as:

> " I feel I have shaped national policy through getting more protective materials and more access to services into the system and getting some money set aside in the concept note to try to change the legal environment [for homosexuality, IDUs and sex work]" (Male, Administrator).

When asked for more specific cases where their contributions were included several noted that the process was still underway (it was too early to tell). One shared a case where a concept note had already been submitted.

> "[Our] concept note had sections on sex workers to have training on the establishment of support clubs. It also included the training of sex workers as peer educators and had budget lines for advocacy, for example, for engagement with policy makers to improve the legal frameworks." (Female, CSO rep).

> Finding and Discussion:
>
> The finding suggests that while many CCMs have created space for the KAPs to be heard, and that some evidence is emerging that their needs are being more directly entered into the concept notes, that this is only just beginning. It was hard to get specifics on this point as the representatives seemed more comfortable talking in general terms. We tried to get specific, concrete examples of change that had occurred as a result of the KAP presence, but found few examples. We hypothesize about what might be contributing to this below.

Multiple roles/ too many hats:

Several respondents felt that KAP representatives often found (or find) themselves wearing more than one hat –representing multiple groups of KAPs, usually with different needs. Two KAP reps pointed out that they had to represent LGBTI, sex workers and IDUs, but they had been elected to represent either women and girls or disabled persons.

Another CSO rep for a CCM told us this about the link between resources and representation:

> "There are competing factors when KPs want to elect their representatives- for example, MSM have many other organizations and are fighting over who should legitimately represent them. Since there is no direct fund from the CCM to organizations, some are leaving because there is no funding they are getting." (Female, CSO rep and administrator).

> Finding and Discussion:
>
> The issue of individuals having to represent multiple groups is an important challenge, and not one that presents an easy solution. The definition of KAP used by the Global Fund in its guidelines says that the CCM can pick KAP representatives from several groups and does not stipulate further than this, nor does it name a number. Obviously, there is an (unwritten) intention that the type of KAP selected for the CCM should bear some relationship to the epidemiological profile of the country, but the requirements go no further than giving a list of possible KAPs. The rest is up to the country. How countries go about solving this question is obviously up to them, at this stage. It is not clear whether more seats should be opened for more KAPs, or should certain epidemiological factors drive the selection process.

Lack of Data or Evidence for KAP interventions:

There were several times when the question of whether the KAP needs and ideas were being heard and recorded through to the concept note development stage were jeopardized either because there remains resistance at the governmental level, or, because of a lack of data or evidence so the drafters of the concept notes are unable to pursue these ideas.

In discussion around the acceptability of having a gay man on the CCM, one KAP representative said that resistance continues:

> "thereis a lack of cooperation form the other constituencies (on the CCM) because they feel that the key populations are time-wasters." (Male, KP rep)

Another talked about how well the experience of being consulted was working. He said "we have demanded that the government address the issues of access and protective materials, and we've asked for increased resource allocation." But then he added: "we are currently doing research to get data on HIV prevalence amongst sex workers." (Male, KP rep). In other words his ideas were being taken up, but they had to get more information (HIV prevalence data amongst SWs).

> Finding and Discussion:
>
> The issue of lack of evidence is important too – and it may well explain why some of the participation of the KAP representatives is perceived as a "token" at times. If data are still lacking, for example, on something as basic as HIV prevalence amongst a key population like sex workers, then the drafters of the concept notes may well be tempted to see the KAPs as "time-wasters." Clearly more attention to good quality evidence of effective work for advocacy is needed in this context. See also the finding below on whether or not the KAP sit on the technical working groups that feed information to the CCMs.

Technical capacity to attract and present the evidence:

Another member with several years as a CSO rep on the CCM said that despite being "at the writing table" she was frustrated by the fact that:

> " most CBOs don't do systematic evaluations… you find that the concept note that I was working on could not propose an activity for scaling to the national level because … when asked where it worked, we were not sure." (Female, CSO rep)

She added to this argument by saying – at times "our CBOs don't share [their experiences] if they have a model that is working, they don't share for fear that someone will steal their ideas." (Female, CSO rep).

So in terms of quality of participation, there was almost unanimous feeling that the KAP representatives are beginning to speak out, but some felt this was still only "paper" representation or "tokenism." When we tried to find out who was to blame for this situation some felt it was the "problem of the legal environment", others say it is the personality of the individuals. But the example above shows that in some situations the KPs may well be being heard, but whether those ideas are being transferred into the concept notes is dependent on this like evidence and competing priorities. More evidence of these issues are given below under challenges.

Mechanics of inclusion/exclusion:

Respondents were asked to name ways in which they have been included or excluded. Several individuals said they were frequently invited late to key meetings, which meant they had little time to prepare. One newly appointed individual said: "I was notified late for the meeting, and had no time to prepare, so my participation was almost nil." The late invitation and late papers also hinder those who are meant to be representing large constituencies from consulting with members, usually scattered across the country.

> Finding and Discussion:
>
> A poorly prepared member of a large constituency is highly likely to do a poor job of representing their stakeholders. Thus, expect poor communication and feedback as a frequent complaint. This point is a "low hanging fruit" i.e. an easy means of improving the quality of representation by members of the KAPs. This point should also be taken up with a general point about the need for improving (and tracking evidence of) communication between the CCM and its members – including feedback from constituency meetings, rapid publication of the minutes of meetings etc...

The breadth and complexity of the constituencies was also referred to as a barrier whereby one individual said that they are expected to represent "people who are scattered all over this country, yet I have no resources for communication… so how can I get them to come together with an agenda."

Another important factor which may exclude KP's from contributing much to the concept notes is that although they are being invited to sit on large, CCM related committees, they are not considered "technical" by their peers. Therefore, they are often

not invited to technical subcommittee meetings, such as technical working groups where critical planning, prioritization, discussion and debate is done, and then fed into CCM discussions and subsequently into the concept note.

> 、I actually feel [this] could be the biggest weakness that civil society has… you feel that [unlike] the government entity they (CSOs) should have actually focused before coming to the meeting but [they can't] because they are not participating actively in the [technical] subcommittees…. In my country, the CCM makes most of the decisions but the technical arguments are done at the subcommittee level. [As a result] … civil society's participation is disjointed…. At the subcommittee, that's where important decisions are made and feedback [gotten]…so you see how important the technical subcommittees are and not many of our civil society organizations or the KPs realize that." (Female, CSO rep).

The same respondent illustrates the problem of disjointed representation by saying there is often a lack of continuity in who attends the meetings and how information received is shared. She illustrated this vividly:

> "I will give you an example… the WHO representative on our CCM has been serving their two terms on the CCM fully – the same person comes every time. But when you look on the civil society end or the key population reps, people come and go, the moment you have started to learn, to understand, the next thing people start having vendettas against you, and kick you out of there." (Female, CSO rep)

She continued:

> [When I] am sitting there [in the technical sub-committees] do I then pass the key issues to the person that is going to the CCM? In some situations, organizations (CSOs) send junior officers to go to the subcommittee meetings, and they don't necessarily pass on to their bosses the important information, and it is those bosses who go to the main CCM meeting. I find this to be a disservice." (Female, CSO rep)

Finding and Discussion:

The findings in this section show a need for improvement by KAP members in making the system work for them. The comments made about lack of presence on technical working groups, or about limited technical capacity to engage effectively in these meetings are important. They illustrate how the KAP representatives are perceived by others and are also a reflection of how technical or non-technical KAP reps are and thence how much information they can absorb and deliver. Part of this technical ability is shown in the lack of continuity in their engagement in meetings (which may also be linked to low incentives and commitment levels, or to the political or organizational context in which they work). High levels of continuity lead to dependability, a growth in confidence by the members themselves and hopefully a more consistent flow of information to their constituencies. This finding is probably linked to the problems many KAP find in accessing and presenting appropriate evidence or data; even where they do present data those data may not be considered credible. Especially if they are not sitting on the technical working groups then by definition, they are absent when these data on the transmission risks and access to services for KAP are discussed (if they are).

Communication within and between the CCMs and their members' constituencies:

Feedback of information and/or communication between CCM secretariats, the wider CCM membership and between those CCM members and their constituents remains a challenge. Several respondents (KPs) did not know if their ideas have been used in concept notes as the feedback mechanism remains patchy from inception to the production of the final document. Some blame the CCM itself for not feeding information outwards, others were specific saying that the CSO representatives ability to "disseminate information to their constituencies regarding their attendance at the meetings was very limited" (Female, CSO rep).

Another CCM member pointed out that without resources to help with the feedback, these KP representatives, who are often either poorly paid, or even volunteers, simple don't have the time or money to spend time giving feedback to those they represent. For example, when asked why a CSO representative might not be giving good or regular feedback to their constituency, she said:

> "It could be they don't have money. Most CBO sitting at the CCM are volunteers. So how do you ask volunteers to give feedback to the constituency that they are representing. Whereas somebody like NACC they have the money, when they go back to their organization, its easier to get word out. They have it easy." (Female, CSO rep)

Some CCM members showed knowledge of what had gone into the proposals but weren't sure of the details, so couldn't feed them back to constituencies. For example, one person said they were sure "that more resources had been set aside for protective materials such as lubricants or harm reduction kits (needles) but he was "not sure how much had been allocated because the budget process was not open." (Male, KP rep)

Finally, several responses were noted by some of the CCM members interviewed regarding continued gaps in information on the CCM eligibility requirements.

> Finding and Discussion:
>
> It appears that improvements in communication between the CCM members and their constituencies are still needed. Large constituencies, weak or patchy feedback mechanisms and few resources all appear to be part of the problem. But the finding that suggests that some CCM members had general but not detailed knowledge about interventions is important. This may reflect poor attention by the members themselves during finalization of the concept note or may indicate obscure systems such as the final budgeting or grant negotiation processes. Most comments made on this shows evidence that many CSO CCM members do not know exactly what is being allocated to which programme until long after the process is finalized.

Triggers for change

Respondents were asked what they felt had triggered a change in the composition and receptiveness of the CCM to KAPs. Nearly all cited the "orientations" held by the Global Fund Secretariat staff over the past year for the CCMs and their constituencies during country dialogue. Another said that there had been explicit "awareness creation forums for KPs" held over the past few years to ensure the KPs reps were better informed about the whole process. The same CCM member told us about the "capacity building forum like the Women for Global Fund" that has "helped us to ask the right questions and fully engage." (Female, CSO).

One person praised the access to technical assistance funding and support that has enabled country dialogue processes to proceed more smoothly and broadly than before. Another cited the benefits that had accrued to both the CSO and KP constituencies from such technical support and described how CSO engagement in the concept note development process had become more organized and articulate by using a priority setting method developed by AIDS Accountability International. AAI has supported countries to produce Civil Society Priorities Charters, which are advocacy tools used to advocate to Country Coordinating Mechanisms (CCM) for inclusion in concept notes to the Global Fund. These documents in some countries have also helped streamline focus by CSOs within national planning and budgeting processes.[3]

> Finding and Discussion:
>
> The findings here suggest this change in the representation of KAPs on CCMs has come from a variety of sources – probably the Global Fund's orientation for the NFM have been the most important element. But other sources have clearly helped. We did not explicitly ask whether any of the change had come from within the countries but we do know of several cases in southern Africa where initiatives to include the MARPs began several years ago.

Lack of legal framework

Only one country (South Africa) has a legal framework that explicitly protects gay men and transgendered people[4]. So all KAPs in this study when asked to talk about the existing challenges, based their responses around the lack of legal framework in their countries, as being one of the most significant barriers to human rights protection and access to services.

One representative from a human rights group said, "We have a major challenge with the legal environment… and we need a legislative review of the whole situation." Another senior administrator of a CCM said "we see good will [in terms of legislative support] coming from the government

[3] http://www.aidsaccountability.org/?page_id=10280&projectid=922

[4] The SA Constitution/Bill of Rights states in section 9.3: The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

but some key populations are not yet recognized legally. The penal code has not been amended to cater for people like MSM or LGBTI." (Woman, CSO). So clearly the lack of legal protection or the fact that homosexuality is illegal, remains an issue for the majority of these countries.

However, nearly all of them also made two additional points. First, that even in South Africa where there is legal protection for MSMs, there continues to be a lot of discrimination in "the wider community". So, there is a recognition that legal protection is only a first step. In SA, one member said, "The legal environment is progressive but we have a problem at the community level with cultural and social factors that continue to be a hindrance." This would illustrate the continuing fear and stigma that many or most MSM continue to operate under, including, presumably on the CCM.

One rep said that "stigma and discrimination remain a huge challenge despite everything [done]" (Male, KP rep). And another representative observed:, "Communities are more hostile now than the government. We need to do a lot of sensitization at the community level so that they can embrace us [KAPs]." (Male KP rep). And another experienced rep for the CSO constituency said, "Key population groups are only free to engage in 'safer spaces' for example in their support groups rather than in formal meetings."

A second point raised in this context and that was pointed out by several respondents, when they said that despite the lack of legal protection, many societies do provide theoretical universal access to care and services for all their citizens. So under this provision of services is possible for all including LGBTI, MARPs and those marginalized by society in general. As one representative put it:

"Currently the provision of health services should [be] and is non-discriminatory and there is the issue of patient-doctor confidentiality. But we will not shy away from procuring all the supplies required by the medical practitioners in order to meet the needs of their clients including KAP…they will just present their medical problems as is the case, but not necessarily to say for example, I am an member of MSM…" (Male, administrator)

Finding and Discussion:

The findings here suggest the lack of a legal framework is important for several reasons for the quality of participation by KAPs. First, it means that the CCMs have to provide a "safe space" that protects members from victimization under a harsh legal framework. This links to a continued lack of understanding or lack of tolerance (or worse) for MSM, IDUs or Sex workers which limits how open the KAP reps can be on the CCMs. Second, things may well be changing for these groups and the suggestion that the attitude of government people is no longer a major issue (at least in one setting) but attitudes do not change overnight. Third, even in the context of South Africa, which does have legal protection, the situation in the surrounding communities remains challenging for these groups. Finally, protection against discrimination via promise of universal health care and the provision of non-discriminatory health care in many settings is promising and needs as much support as possible.

Conclusions:

Clearly there has been a great deal of effort to try and make these CCMs more inclusive and better able to represent the needs of the KPs but more remains to be done.

Some of the major themes emerging from this survey show that progress has been made in including KP representatives onto the CCMs, but their participation is inhibited by their ability to speak out and engage authoritatively and knowledgeably. Even when vocal, their ideas may lack credibility if they are not backed by relevant and appropriate evidence. Communication is clearly an issue from within the CCM, and between members of the CCM and their constituencies.

Recommendations:

1. CCMs can do a better job of communicating the agenda and outcomes of their deliberations – this means both the Secretariats of the CCMs need to communicate to their members early and the members need to communicate to their constituencies. This may well need more resources to be effective.
2. CCM management should be able to call all meetings in a planned and methodical way. No member should say they were called to meetings with only a few days to prepare.
3. Advancing the professionalization of the KAPs through their organizations or through individuals – but the reps must prepare themselves as well as they can before every meeting. Requiring all "Alternate members" to attend all meetings is another strategy, which should ensure better continuity and communication by the representatives of each constituency.
4. Continuity of presence is important – we are not sure how to ensure this in the dynamic and often political context of CCM representation. Strategies are being tried in other countries whereby there are frequent between-meeting gatherings by the KAP representatives take place. These groups are also pushing themselves to reach out to the wider networks in the region to gain better knowledge of specific areas.
5. Improved data are needed for all key populations reps to better inform interventions in all locations.
6. Some CCMs may need to consider more seats for particularly hard hit KAPs, or those who cannot be represented by "multi-purpose" CSOs or networks.
7. Stigma for MSM, IDU and sex workers remains a major challenge in all societies. We do not think the CCMs are necessarily the place to solve this problem, but maybe the suggestion of bringing on religious leaders or other community leaders might help alleviate some of these issues.
8. The recognition of the lack of protection under legal framework is universal, but will take time and effort to change. Meantime, continued strengthening and education at all levels of the health system that provides diagnosis, treatment, care and support must continue to be a priority. Safe spaces within CCMs and technical working groups can be an alternative in the meantime.

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Annex A: Interview Guides

Key population representatives and their participation on CCMs – a rapid study

Intro: My name is _________________. I work for Aidspan. Aidspan,the independent observer of the Global Fund and is doing a study of the presence and quality of participation by key population representatives on the CCM s in the African southern region. We know this is changing on many CCMs and we want to document this at a regional level, starting with southern Africa.

This is of course a voluntary study – there is nothing you will gain from being a part of it – and you are welcome to stop it at any time. Your views are important for the world of the Global Fund to hear, and we would appreciate it if you could give me a few examples in the responses to my questions below.

Duration: I do not expect this to take more than 15 minutes of your time. We are looking for perspectives as to the participation of other CCM members and by yourself as an individual.

Anonymous: When we write up these results - no individuals or countries will be identified by name.

No.	Question	Probe 1	Probe2	Notes for interviewer
	Names: Organization:			
1	How long have you been on the CCM? _____(months or years)? How were you selected?			If less than 6 months, ask for as much detail as possible but also ask for the name of the person who represented KPs before them so that you can follow up with another interview. It will also be a good idea to compare the 2 experiences…
2	What is your position on the CCM?			
3	Which key population do you represent?	How long have you formally represented this population (the particular KP)?	Do you work for an organization which has a focus on KPs? Do you identify as a member of the KP?	
4	Can you tell me about your general experience(s) on the CCM?	How would you describe your experience of being a member of the CCM? (Good, bad, neutral)	Have you been heavily involved in the general processes of the CCM?	Make note of any particular phrases that provide insight into their participation or perceptions of participation and ensure to tie these into the questions asked later in the interview.
5	Do you attend the meetings whenever they are called? (Yes, No , Sometimes)	How many meetings have you attended?	Are you aware of any other meetings that take place which you are not invited to?	
6	Have you contributed during meetings in the last 12 months? (Often, Sometimes, Rarely, Never)	Can you give me an example of a time that you have contributed in a meeting?		
7	Do you feel that your contributions and the information which you provide/volunteerisgenerally acted upon and used?	Can you give me an example or examples of times when this has happened?	***(If a concept note is close to completion or has been submitted)*** Can you see evidence of your contribution(s) in the concept note(s)?	
8	***(If no contribution in meetings is alluded to)*** What makes it difficult for you to contribute in CCM meetings?	Can you give me an example or examples of times when this has happened?		
9	Have you been part of the detailed planning for the development of your country's concept note? (Yes, No)	What part(s) of the concept note development process have you been involved in?		Find out if they were part of the country dialogue – if yes, how engaged were they?
10	You represent ______ - Do you detect a change in the responsiveness of CCM members to your constituency"? (Yes, No, Somewhat)	If yes, how?	Can you give me an example?	

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This is of course a voluntary study – there is nothing you will gain from being a part of it – and you are welcome to stop it at any time. Your views and experiences are important for the world of the Global Fund to hear, and we would appreciate it if you could give me a few examples in the responses to my questions below.

Duration: I do not expect this to take more than 15 minutes of your time. We are looking for perspectives as an individual who is part of the CCM leadership

Anonymous: When we write up these results - no individuals or countries will be identified by name.

No.	Question	Probe 1	Probe2	Notes for interviewer
	Names: Organization: Date:	Other Job outside CCM?		
1	how long have you been on the CCM? What is your occupation or position outside the CCM?			If less than 6 months, ask for as much detail as possible but also ask for the name of the person who represented KPs before them so that you can follow up with another interview. It will also be a good idea to compare the 2 experiences...
2	What is your position on the CCM?	How long have you held this position?		
3	Do you attend all the CCM meetings which are called? (Yes No Sometimes)	How many meetings have you attended in the last 12 months?		
4	Can you tell me about the type of participation and level of contribution by different CMM members?	Do some members contribute more or less in meetings?		We want to find out whether it is a CCM which has vibrant/in-depth discussions or whether meetings are more for endorsing decisions already made...
5	Is there a strategy in place for involving key populations onyour CCM? (Yes No Not sure)	*If yes;*Can you tell me some more about the strategy? *If no;* Are there any plans to develop a strategy for KPs?	Do you have any other comments on the involvement of KPs on your CMM?	
6	Is there a representative for KPs on the CCM at the moment?	Yes No		
7	Do you feel the key populations representative(s) engage and contribute in meetings? (Yes No Sometimes)	Can you give me an example of when they have contributed significantly in a meeting?	Where and when do the KP representatives most likely to engage?	
8	Does the involvement of KP representatives help with the development of the concept note? (Yes, No)	Can you give me an example of this?		
9	Have the contributions and the engagement in proceedings of the CCM by KP representatives changed over time? (Yes, No, Not sure)	Can you give me an example or examples of this change?		
10	Have there been any changes in the legal environment within your country that may support or hinder the presence and outspokenness of key population representatives in the CCM in the past 12 months? (Yes, No, Not sure)	Can you tell me some more about these structural changes in your country?		
11	Are there challengeswith how your CCM meets the Global Fund's eligibility criteria for key pops to be represented on the CCM? (Yes, No, Not sure)	How does your CCM meet the criteria in your context?		

Independent observer
of the Global Fund

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