In-depth Thematic Studies

During the month of October 2016, a Community Action and Leadership Collaborative (CLAC)-affiliated researcher conducted 19 extensive independent interviews with key and vulnerable populations and community respondents. CLAC members themselves identified the interviewees to ensure representation of all disease cohorts and geographies relevant to the Global Fund, and their involvement in the thematic areas of exploration. Interviews averaged 90 minutes in length and were, by necessity, flexible to ensure capture of the dynamics specific to respondent experiences. A vetted list of qualitative open-ended questions guided the discussions. The views presented here are not necessarily CLAC's, but represent those of the respondents, further endorsed by in-country community consultations.

To maintain confidentiality, as requested by interviewees, quotes are anonymous, and editorial liberties taken to further mask identity and ensure narrative flow.

The CLAC is a unique collaboration between AIDS and Rights Alliance for Southern Africa (ARASA), the Global Network of People Living with HIV (GNP+), Global Action for Trans* Equality (GATE), the Global Forum on MSM and HIV (MSMGF), the Global Network for Sex Work Projects (NSWP), the International Network of People Who Use Drugs (INPUD), and the International Treatment Preparedness Coalition (ITPC). The collaboration between these regional networks supports a deep understanding and connection with key populations to strengthen expertise in the areas of HIV and tuberculosis, treatment access, human rights and community engaged. www.clac.cab.

**Thematic Study 3: Community Engagement in Gathering, Interpreting, and Utilizing Evidence**

**Summary**

Programmatic monitoring for quality and impact, and community watchdogging of national program implementation, are both important components of grant processes. The Global Fund model supports the idea of community watchdogging, and encourages key and vulnerable population involvement in monitoring, towards facilitating ownership, sustainability, and opportunities to improve overall health outcome quality and impact. Towards this, the Global Fund advises monitoring to be included within grants and, together with global key population networks, is exploring other potential sources of funding for independent, community-led monitoring and watchdogging. Further, the importance of engaging in a broader range of data processes to improve advocacy, participation, and programmatic results beyond monitoring or watchdogging was felt to be overlooked.

This thematic study describes the experiences shared by interviewees regarding processes around monitoring, watchdogging, and gathering and using evidence. Examples are provided using respondent quotes of how communities are supported in these areas, and suggestions are provided on shifting the emphasis of their engagement from monitoring or watchdogging to gathering, interpreting, and effectively using data (e.g., epidemiological, behavioral, size estimation, programmatic, human rights violation and gender-balance-related, needs assessments) in advocacy.

The desire for long-term and comprehensive support to build and strengthen community capacity in all data processes was unanimous. While global networks and academic learning institutions (universities) have provided some communities with technical support and resources, there remains an overarching **lack of donor understanding or support** in this area, possibly due to the **lengthy time and resource commitments** necessary to do it right. Other lingering **challenges** include:

1. Overarching **confusion by communities around their roles** in programmatic monitoring and implementation watchdogging, and resulting frustrations

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2. **Costs** (*time, financial, human resources*) and risks to communities involved in some programmatic monitoring and watchdogging activities, including those that compromise ability to speak out on findings (e.g., status as a recipient of grant funds)

3. **Lack of governmental transparency** or willingness to disclose information needed for monitoring or watchdogging

4. Difficulty getting **governmental ‘endorsement’ of data** that are community generated or do not support political desires or positions

Areas for replication found to better engage communities in data processes in all phases of grant cycles include:

1. Better define ‘monitoring’ and ‘watchdogging’
   1.1 Clarify the purpose of monitoring and watchdogging
   1.2 Identify monitoring roles and responsibilities (communities, country coordinating mechanisms/CCMs, fund portfolio managers/FPMs, external oversight bodies without potential conflicts of interest)
   1.3 Mitigate and protect communities from watchdogging risks
   1.4 Underwrite costs (time, financial, human resource) for both community monitoring and watchdogging

2. Proactively support communities to overcome monitoring and watchdogging barriers
   2.1 Support leaders to identify problems and find solutions in partnership with other key stakeholders
   2.2 Ensure access to requisite information
   2.3 Assist communication and information dissemination processes

3. **Promote community-desired involvement in all aspects of evidence generation** to:
   3.1 Address concerns about data quality, confidentiality, and gaps
   3.2 Bolster advocacy and engagement with long-term mentoring and skills development in the areas of:
      - Data collection (protocol and questionnaire development, field data collection)
      - Interpretation (analysis)
      - Utilization (including distribution)

4. **Ensure appropriate evidence generation timing** so that current data are supporting processes appropriately and sequentially, starting with IBBS and national strategic planning

**1. Better Define Monitoring and Watchdogging**

Interviewees responded to questions about monitoring and watchdogging in a variety of ways: they were either not engaged, had never thought about or been approached about being engaged, had only limited experience monitoring or watchdogging, had no desire to be engaged, and in some cases, wanted to be more engaged.

1.1 *Clarify monitoring and watchdogging purposes and expectations*

There is widespread confusion about what monitoring or watchdogging entail. While no clear definitions of either exist, monitoring is an option proposed by the Global Fund as part of program implementation, focused on outputs and outcomes, accepted by most stakeholders, and entitled to receive financial and programmatic support. Monitoring provides evidence about the quality, appropriateness, and impact of service provided. Watchdogging, on the other hand, is a largely Western civil society construct combining the concepts of monitoring and advocacy. The purpose of watchdogging is to gather evidence for action. The actions typically involve advocacy, community mobilization, and lobbying—to push for the changes needed to overcome human rights, gender, and other obstacles faced by key and vulnerable populations. Subsequently, watchdogging is often viewed negatively and even as
a threat by some governments and PRs. Watchdogging can be included within a grant as part of the community based monitoring interventions. Most regional grants a number of grants at country level do include community monitoring. While supported on paper by the Global Fund, watchdogging is largely voluntary and underfunded. **There is a need for a clear and concise definition of each, endorsed by communities and key stakeholders, and delineating roles and responsibilities.**

The nuances between community engagement in monitoring and watchdogging tend to blend, particularly for those with little or no prior experience with either. Many felt little incentive to engage in monitoring or watchdogging when their perception was that communities were being purposely excluded from other aspects of the grant process and national response to the three diseases. **There is a feeling that true, unbiased monitoring rarely occurs, and that watchdogging has little real impact.** “There is not much motivation from communities to do [monitoring or watchdogging] because it has never led to anything” was a common sentiment. While it was commonly felt that communities have a role to play in monitoring and watchdogging, this role should not be prioritized or come at the expense of diluting the significant roles they play in many other areas of the grant process.

### 1.2 Identify monitoring roles and responsibilities

Interview responses regarding who, when, and how monitoring should occur, were conflicted and even contentious.

- **Should communities be involved?** “We have a bad habit of assuming key populations should monitor rollout. It is necessary, because otherwise it is just the PR’s word and that cannot always be trusted, but we must think it through from the community perspective.” Some question why communities should care about numerical monitoring findings when they have little to do with realities as experienced by them on the ground. “Monitoring is only happening as part of the process of implementation, and then it is only capturing quantitative indicators of delivery: how many condoms, how many activities, etc.” “Monitoring is all about outputs and making sure money is making an impact. Because of this focus, the Global Fund doesn’t care about the other nuances of engagement, or other monitoring results.” One respondent reported collecting success stories as part of monitoring, which were ultimately “of no interest” to the country team. **The Global Fund’s concept of impact and actual impact on the ground are at odds. The level of impact they desire is not reaching communities. They only want quantitative numbers to show impact. This is a waste of monitoring money.”**

- **What about country coordinating mechanisms (CCM)?** “Monitoring should not be an activity of the CCM but an actual on-the-ground activity. What is happening now is technical, quantitative monitoring. No wonder monitoring is underperforming. **Nobody is doing other kinds of monitoring – qualitative monitoring.** They are too scared. Or unsure how to proceed without it coming back to slap them.” Officially, monitoring should be the responsibility of the CCM oversight body, as this is where different technical working groups report monitoring findings. There are concerns, however, for “the oversight committee on the CCM includes stakeholders and it is difficult for them to present honest monitoring.” “We have a strategic monitoring committee, but civil society is only included on this committee if they are perceived as agreeing with the government. The committee must be subjective. Outside of this committee there is no informal monitoring process.” **Many feel that the CCM is the last platform where monitoring results will be true and honest.**

- **How should fund portfolio managers be involved?** This is an area where specific criticism is lobbied, for many blame FPMs directly for the perceived failure of good monitoring intentions. “Most FPMs are careerists, and they are only assessed in allocation and disbursement of money, with little care about other implementation factors. The only way to change this is if it concerns their personal job security.” “**Everything is tied to quantitative indicators so things like capacity strengthening and systems strengthening, which are more subjective, are lost.** It is hard to count advocacy.” “We get so caught up in counting meetings and how many attended that we forget whether the real
issues are resolved. And the Global Fund never comes back to ask, either.” There was a suggestion by several respondents to add a specific key performance indicator (KPI) to “show if key [and vulnerable] populations were receiving Global Fund funds, how often, and the quality of the FPM’s direct meeting with them,” rather than just assessing for the quantitative experience of service end users. “The FPM will never have a whole picture unless there is personal motivation to meet with the direct beneficiaries and recipients.”

Ultimately, several respondents suggest that external parties are best placed to oversee monitoring. For example, “The CRG (Community Rights and Gender Department) has an important role to monitor and talk to people and get feedback, and maybe to package indicators that could affect the level of funding, because FPMs do not all work closely with civil society and are not aware of implementation and impact.” The CRG is not involved on-the-ground, however, leading some to suggest that in some situations, “external monitors, like election monitors, might be necessary.” While the PR has a mandate to provide monitoring data, if they control monitoring, “then there might be a conflict of interest.” Further, “Monitors must be separate from the PR, SRs (sub-recipients), and SSRs (sub-sub-recipients). That way there isn’t any fear from threats that funding will be cut” if unflattering monitoring data are reported. While there was agreement that monitoring be overseen by an external body, “they must be internal to [or understand] the issues in the country.” This is a hard combination to find.

1.3 Mitigate and protect communities from watchdogging risks

Unlike programmatic monitoring, watchdogging is viewed widely as risky business for communities. “We are dealing with humans who might take findings personally and make it challenging for us. Yes, we fear reprisal and backlash. We have seen it and we fear it.” Engaging in watchdogging is felt to expose key and vulnerable populations to further vulnerabilities, causing them to be viewed with suspicion, anger, and hostility, and leaving them open to blame, blackballing, and even threats when repercussions from the Secretariat result. A common perception is that “if we expose negative findings, we [country or organization] might be excluded from future the Global Fund opportunities. My organization did not receive funding for several years because we publicly called the PR out on things.” Several feel that engaging in watchdogging and advocacy erodes community ability to engage more fully in the country dialogue process, by pitting them against other stakeholders including the government. “It becomes difficult to gain access to information, of form partnerships and collaborations, when you are seen as tattle-telling to the Global Fund.” In some extreme contexts, “we do not have the right to own a perspective different from the government, and must align with government policies and actions or be labeled a terrorist or enemy, and persecuted. The legal environment is hostile against traitors, and we risk human rights violations and worse, so we are not involved in any watchdogging activities.”

The ultimate fear is that reporting or advocating on negative findings concerning the government or PR, particular findings about community exclusion (which was felt by respondents to be the ultimate purpose of watchdogging), will cause the Global Fund to withdraw funding. “Civil society is scared that funding will end if gaps in engagement are revealed, so they are not willing to watchdog.” Funding withdrawal “will hurt us the most.” The consequences of monitoring or watchdogging should not be “black or white, but graduated, with restrictions and withholdings” that do not penalize the whistle blower more than the accused.

As with monitoring, several respondents question whether communities should lead watchdogging efforts, as traditionally conceived. Rather, “Impartial oversight from groups not directly involved in the Global Fund grant implementation ensures a live feedback loop from the field to central that will not put the reporter in jeopardy,” removes the risk of the Global Fund or PR influence, and “will allow things to get changed and impact to be achieved.”
1.4 Underwrite costs (time, financial, human resource)

Community monitoring and watchdogging both take time and resources. Where communities are involved in monitoring, respondents report they are aware of only limited resources available from the Global Fund to cover expenses. Many respondents are under the impression that organizations self-fund most monitoring efforts.

Watchdogging, as outside of the Global Fund mandate, does not have earmarked resources. Assuming community organizations will watchdog because “it is the right thing to do” fails to appreciate the prerequisite structures, funding, technical skills, and tools to do so, including mechanisms to ensure that information is available to them and protections from persecution in place. Most community organizations operate on limited funding, and voluntarily endangering their access to scarce resources is seen as suicidal. “Who is paying for watchdogging to happen? Most key population-led organizations hardly have enough funds to manage their day-to-day operations. They are doing amazing work on limited funds, but if they are expected to watchdog and look at quality of service, levels of discrimination, reception at clinics, they need support to do this, and not just financial but technical support.” In some cases, communities receive targeted resources and technical support from private foundations, global or regional networks or consortiums, and multilaterals (Robert Carr Network Fund/RCNF, CLAC, ITPC, MSMGF, NSWP, UNAIDS) to pursue watchdogging and advocacy. These global networks have extensive reach, and a significant benefit is that they can produce quality and accurate data, report negative or threatening findings, facilitate dialogue, and advocate from the outside-in for change, taking the pressure of local organizations.

2. Support Communities to Overcome Monitoring and Watchdogging Barriers

Several respondents note valuable lessons learned from watchdogging and monitoring repercussions, which forced them to change their approach to the entire country dialogue process, from aggressor to solution finder. Interestingly, these same respondents are the ones in support of heightened community monitoring and watchdogging roles. “Watchdogging and advocacy are often shied away from because they are seen as volatile activities, but they can quite simply be vocalization of challenges encountered, engaging with healthcare staff or other stakeholders about service delivery, and building social accountability within communities.” A common theme amongst their positive monitoring and watchdogging experiences is the presence of dynamic leadership – lacking in examples from more pessimistic or impasive respondents.

2.1 Support leaders to identify problems and find solutions in partnership with other key stakeholders

Strong leaders facilitate processes whereby their communities analyze their watchdogging actions, constructively criticize their approaches, and course-correct. “We are not spies obsessed with reporting the failures of the government or PR. We must not go to war with them. In order to build trust and make progress, we must discuss and communicate timely solutions and ways forward. Otherwise, watchdogging is not benefiting us.” Further, “When we are always seen as the enemy, we will fail. When we use fire, we miss the point and do not get what we want. Same when we weep. These are not good approaches. We should be friendly. Currently, we are seen as problem solvers because we changed our approach and worked with the PR and other stakeholders instead of against them to find solutions. We no longer make demands... we now approach situations with technical [advocacy] skills and patience so that we are included and seen as a partner, and are supported in gaining our rights.”

In order to pursue proactive watchdogging and community-led monitoring, rather than reactive, communities need “a cascade system of learning that addresses methods and processes and the Global Fund policies from regional to national to community levels, to ensure a critical mass” have the knowledge and skills and confidence to pursue activities. “Support cannot be piecemeal. It needs to be a 100% effort,
with technical assistance, training, support channels, and resources.” Interpersonal communication skills are needed to build relationships and trust, to gain sustained access to necessary information. “We realize the process is not easily facilitated or supported, but token engagement in watchdogging without tools or skills is simply not working.”

2.2 Ensure access to requisite information

A key monitoring concern is that communities do not know what information they need, how to access it, or how to analyze it to understand what it might show. “The Global Fund needs to intervene in this area more,” being mindful that PRs and governments may feel threatened by monitoring. In most communities, “CCM and Global Fund processes are only really understood by those directly involved or employed by them. If key populations do not understanding what is happening, how can they even ask for information to monitor?”

In some examples, information appears not to exist. “There is no data being collected [or shared] because the government doesn’t want to look bad.” In other cases, governments object to the idea of transparent information. “The government doesn’t believe that the Global Fund or civil society should be interfering in private country affairs. They say they don’t want to disclose sovereign information of the state, and that it is confidential.” In Tunisia, for example, this issue alone caused the government to delay signing their Global Fund grant by a year, with devastating consequences for community members.

In some countries, community treatment Observatorios, community animators, and other community watchdog bodies integrate officially into national strategic plans, which means they became part of grant implementation by default. “Infiltration into national strategic planning processes ensures ownership and sustainability,” and facilitates access to information. These bodies, and additionally external community taskforces (see Thematic Study 2), further sanction community feedback, inform advocacy to effect change, and force governmental accountability.

2.3 Assist communication and information dissemination processes

Questions concerning monitoring and watchdogging findings abound, including what to do with them, how to present them, and who to present them to. Without a mechanism for communicating feedback, monitoring and watchdogging are wasted efforts. Most communities do not even know who is funding what, so they don’t know who to provide findings or report concerns to.”

For watchdogging, a hierarchical chain of reporting, supported by the Global Fund Secretariat, is needed. “The Secretariat needs to step in more, especially for issues in which the government is the violator, and partners are afraid to come forward and speak for fear of persecution.” For monitoring, there is a desire that the PR introduce a mechanism they can feed information in to and out of, to clean up what is currently described as a “disorganized” monitoring and reporting process. This suggestion, however, raises concerns amongst as to whether the PR can be trusted to submit ‘bad’ monitoring results to the FPM, and the need for the mechanism be transparent and directly viewable by the FPM and all contributors. A further suggestion is for easy channels (external to the CCM) for communities to report directly to the Global Fund, quarterly at a minimum.

Several note that methods unrelated to the Global Fund hierarchy no longer work as effectively when disseminating information (mainly from watchdogging) and informing advocacy. In the not-too-distant past, social media was the avenue of choice to ‘publish’ findings and advocate for course corrections; but, “there is too much information out there now,” and postings on social media (Facebook, Twitter) are not as effective anymore. “Nobody is paying attention, and there is very little impact.” To really scale up and maximize monitoring and watchdogging efforts, “we need to utilize Mobile alerts, web forums, dialup lines, and other [newer] modern methods,” opine a few. Others counter that, “the reality is that many places do not have electricity, email, telephone services, Skype access, and there are huge language issues.”
3. Promote Community Involvement in All Aspects of Evidence Generation

All respondents unanimously and passionately desire community involvement in broader data processes (e.g., epidemiological, behavioral, size estimation, programmatic, human and gender rights-related, needs assessments). The results are similar to monitoring and watchdogging, namely facilitating opportunities for communities to improve overall health outcomes through heightened advocacy ability, but with less perceived risk or pressure. “Data are needed to get money to communities, and money is needed to get data from communities.”

3.1 Address concerns about data quality, confidentiality, and gaps

“When we came into the Global Fund process, we learned that every number counted – even the wrong numbers. They have a huge impact on funding and activities.” Amongst respondents, there was broad recognition that bad epidemiological data, particularly population size estimations, affected communities for years.

Respondents described bad data as:

- **Not reflecting realities accurately.** Bad data often fails to involve community members in the collection, interpretation, or distribution of findings – in other words, does not engage community members. Ironically, **data processes lacking community engagement are determining the level of engagement offered to those same community members** through, for example, representation on the CCM and other national strategic planning and disease response processes. **Data resulting from processes lacking community engagement is easier to manipulate in support of political agendas of popular desires.** This is especially true when it involves a controversial or criminalized population. In one country, “misconstrued data shows that populations of men who have sex with men are declining, a politically and culturally desirable finding that has led the government to argue successfully for less funding allocated to men who have sex with men-related programming in Global Fund grants.” Because of examples like this, several respondents question the Global Fund’s true intentions when it comes to community engagement “rhetoric.” “The Global Fund is supporting repressive governments when they trust manipulated and inaccurate data and reports from those seeking to hide key population numbers. Repressive governments control the flow of information, not the prevalence of diseases, and the Global Fund should know this. If they were really for promoting community engagement, they would be demanding better data” and data engaging communities in all aspects of generation.

- **Missing data.** In countries where data are simply absent, some communities “are not invited to attend meetings or participate at all, because we cannot prove our existence.” “The government is hopeful that we will disappear.” “Bad or missing numbers mean we are discounted as unimportant for investment.” “Some community members are left out of the process due to a lack of data collected about them. For youth, this is especially challenging because they are minors. **We need specific data to ensure key populations are targeted with activities and funding,”** and are allowed a chance to participate. **“Data are the foundation of all community engagement.** Activism is dying in many communities because there is not data or evidence to back up advocacy agendas. We cannot argue for benefits without evidence. This is not specific to one region, one stakeholder, or one topic, but cross-cutting and experienced by all key populations in all countries.”

- **Lacking confidentiality** results in further concerns for, or actual increases in, stigmatization and discrimination of individuals or communities.

There is broad consensus that **community involvement in data processes helps ensure that data are accurate, rigorous, reflective of their realities, non-harmful, and used to inform advocacy agendas.** Having solid baseline data (epidemiological, bio-behavioral, size estimation) supports key and vulnerable population positions, requests, and priority needs. Unfortunately, communities do not have the background needed to engage in this type of rigorous research, and it is perceived as not being a
Global Fund priority area. “The Global Fund rejected our proposal to build data capacity. They also rejected our program proposal because we did not have data to support our needs.” Yet, individual country examples where data processes are being supported show monumental results. “It allowed us to work together and approach the government and support our advocacy agendas, and our demands were met. This made a huge difference on the ground.”

3.2 Bolster Advocacy and Engagement with Long-term Mentoring and Skills Development

There is an urgent need to train and involve community members in protocol and questionnaire development, data collection in the field, interpretation and analysis, distribution, and utilization. There is also a need to recognize that this is not a quick process, and requires long-term commitment. “You cannot build data capacity in a few months. It takes years.” Specifically, key and vulnerable populations, their organizations and networks, should be trained and then contracted to generate evidence on their specific communities, being the ones who know their realities the best. “This is the only way to collect true, reality-based data. Obviously, this must include capacity and skills building and resourcing.”

- Improve data collection skills. Respondents were quick to provide multiple examples of how bad data collection methods produced inaccurate findings. This includes a lack of community involvement in protocol and questionnaire development and field data collection. “When I pointed out errors in the questionnaires, the national AIDS representative shouted at me in front of the FPM that I was too young to make comments, though it was my job as part of the CCM oversight committee.” “I pointed out a number of problems with the IBBS questionnaires. They were not reflective of the issues of men who have sex with men, sex workers, or people who use drugs in the country. There were also problems with the data collection methods. They wanted to ask questions in groups of 25-50 people, with no confidentiality. Key populations will not answer honestly under these conditions. In the end, nobody listened to my suggestions, or those of any other key populations. Nothing was changed, and the survey went forward. As a result, the findings show ‘accurately’ things that the homophobic government is now using to pull back support including for prevention efforts. They say that the data supports their actions. This data fed into national plan prioritizations, and then the concept note, so prevention activities are grossly inadequate. When we are not involved as key players in data collection, there is too much chance that the data will not be rigorous and will be usable against us.”

Several respondents said they took matters into their own hands, seeking and securing both short- and long-term data collection support through regional and global networks. In one example, “We searched to find who was writing about our issues. We then lobbied those researchers directly to help us strengthen our own capacity to do our own research and produce our own data.” This community is now getting direct mentorship from those researchers. In another example, “We applied for and received grant funding to work with researchers in a [foreign] university, who are training our staff. We hired research assistants and their capacity to conduct research is being built under university staff supervision.” Communities need technical assistance to ensure that community-generated data are rigorous and high quality. “We need training, and we need to know how to formulate questions personalized to our local level.” Most felt that regional and global networks must have ownership in these processes, and to endorse community findings. Further value is added “if findings are comparable across a region, then the regional network could use it to lobby and put regional pressure on national governments.”

- Improve interpretation skills. Once data are collected, community members need further training and mentorship on analyzing and interpreting findings. “Civil society does not have much research background, and analysis does not come easy.” In the case of the community receiving university support, “our researchers are now coming back from the field, keying in data, and working with mentor researchers to analyze and write up findings.” All felt it vital that community members themselves
own the analysis, for “how else will we learn?” “When we do the work ourselves, the results belong to us and will be used by us. It is important that we own the data, and understand what it tells. Other donors like PEPFAR ask us to participate in data collection, but then they analyze it for us rather than building our capacity to do it ourselves.”

Data collection and interpretation will not work if it is an ad hoc activity. “We need routine, not reactive, data systems. We need to be collecting information weekly and monthly in districts,” not just when there are last minute demands for evidence. There need to be regular meetings to jointly analyze data and discuss what data shows. “This can be what is there, and what is not. Both are important.” Community participatory research and analysis usually elicits a groan, but “when communities are an active part of the analysis, they understand and know the value of it,” and are able to take the findings forward in advocacy and into grant discussions.

- Improve utilization skills. Respondents felt a need to be able to “profile our evidence better so that we can utilize it more effectively.” For example, tightening the gaps between data collection and data needs, ensuring that data are endorsed, and knowing how to communicate findings and advocate for action in the most effective manner. Community utilization of quality data facilitates stronger advocacy and discourse on the situation of key and vulnerable populations. “We need the evidence from data collection and research to support our positions, our requests, our priority needs. We need a solid baseline” that is recognized officially. This is important in the context of transitioning as well. “Evidence will help the government prioritize both with and without donor funding, and will clearly identify areas with need that cannot be ignored” (see Thematic Study 4).

The International Treatment Preparedness Coalition (ITPC) successfully implements a long-term system of community consultative groups (CCG) supported to engage in all stages of the data process. “The added value from the CCGs is that they now have the data, they own the data, and they participate more as a result of the data. They see what is in the data for them – this is the value of their participation. All Global Fund applications require data to supplement and support programming. CCGs identify what information is available, and fill the gaps.” CCGs are one successful example of community engagement in data processes whose replication was requested by respondents seeking for ways to push for their greater inclusion based on epidemiological evidence. The MSMGF’s Speaking Out advocacy training was another, with modules on how to best utilize data to position advocacy processes.

4. Ensure Appropriate Evidence Generation Timing

Respondents were quick to point out that building upon existing activities leads to greater success. Engagement in national strategic planning processes nearly always ensures that key and vulnerable population issues are addressed during concept note development, budgeting, and subsequently implementation – which in turn hopefully provides watchdogging and other data to support greater prioritization of community issues in the next strategic plan. However, “when priorities are set by governments based on the national strategic plan, which was based on IBBS several years old by the time the concept note was written, it really doesn’t matter how much the community is engaged now, for the level of support is fixed.”

It is one thing to strengthen the data process, but another to do so at the right time. Respondents report that data collection processes, particularly larger bio-behavioral surveys and size estimation exercises, are often not timed to coincide well with the timeline from national strategic plan to concept note. One notes, “We completed the IBBS (integrated bio-behavioral surveillance study) just five days before signing the grant, so this new evidence was not usable by the current grant, and will be outdated by the time of the next grant.”

Further, data collection is often conducted under pressure and at the last minute. “When evidence is missing or data are needed, we hear about from the PR (principle recipient) and it is always urgent.
This is a bad way to do things.” “We need a better roadmap so we are prepared. We need help anticipating data needs, and the roadmap can help us plan and gather evidence ahead of time.” To have the most impact, this roadmap needs to ensure that communities are “involved all the way back to the IBBS process, which is the basis for prioritizing needs during strategic planning,” which feeds into concept note development. When this ordering is followed, new data and studies will be completed in time for the beginning of the next cycle of planning, grant making, and implementation.