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Perspective

A change long overdue: Integrated biological & behavioural surveillance surveys to prioritize sub-national levels for measuring HIV prevalence & behavioural trends

It is current practice to use national integrated biological and behavioural surveillance (IBBS) surveys for estimating the trends and burden of HIV disease and examining the effectiveness of different interventions in key populations and the lower-risk general population, based on guidance developed some time ago[1]. These surveys are time consuming and resource intensive, often requiring inputs from external technical experts, which makes them even more unsustainable for use at shorter intervals. While they satisfy the expectations of funders and national policymakers by measuring HIV trends at the national level among key and general populations, such data can, at best, be not very informative and, at worst, be misleading in guiding sub-national priorities and responses[2]. This is a significant issue in large disparate geographies. These costly national surveys do not always provide the information programmes need to measure progress and adapt to shifting needs in a timely manner. In decentralized health systems, local level data are critical for local ownership and action.

HIV in Asia disproportionately affects different population groups and locations, among which there can be considerable variations in one country[2]. For example, despite a national HIV prevalence of more than one per cent among the general population, the Thai HIV epidemic was never generalized. It was initially driven by high prevalence of HIV amongst sex workers (up to nearly 30%) and injecting drug users (around 50%), and later men who have sex with men and in the partners of these key populations, indicating that the prevention and treatment response should be focused on them[3]. Large variations of HIV amongst these populations across districts required local data[2].

A successful response to HIV depends on good planning and mounting a community-led response[4]. However, community involvement is often lost as these surveys fail to galvanize the local community to improve its response by really understanding what is going on and how they can influence it - despite the colossal investment of a national IBBS survey.

Implementing an IBBS to collect relevant information for HIV is exceptionally challenging in the Asian context since key population groups are routinely criminalized and face extreme levels of stigma. A fullscale IBBS places a premium on recruiting unbiased samples, which can more reliably track trends over time. Since reaching out to most of the key population members in a defined geographical area is difficult, specialized probability sampling methods, including respondent-driven recruitment and venue-based cluster sampling, are used for IBBS. Typically, samples recruited from a specific geographic area are too small to provide reliable local estimates. Instead, these data are analyzed as part of a national level sample. While community-based organizations (CBOs) mobilize participants, they do not in turn receive relevant information that would allow for mid-course corrections in service delivery or prioritization. Analysis can usually be done only at the national level, which tends not to capture the high level of geospatial variation in the disease burden or behavioural patterns. To ensure that CBOs are integral to implementing any IBBS, there must be a focus on ensuring that questions and information required by CBOs and non-government organizations are effectively collected and disseminated.

An alternative model of local IBBS of different risk groups and geographic locations that are more

sustainable is possible at a lower cost, which can give faster local-level results to assess the current situation and identify weaknesses with the interventions in that area[4]. When aggregated to a national level, such results can also give insights at the national level, similar to a national IBBS.

The national IBBS conducted in India (2014-2015) apparently received the highest level of funding in a single country globally. The main finding from the HIV surveillance from different rounds in India has been that overall, there has been a decline in prevalence nationally. However, this top-level finding masks the fact that prevalence has risen in several states, including a drastic increase in the prevalence of HIV in the State of Mizoram[5]. Furthermore, after two to three years of collecting and compiling data, local community groups involved in the survey could not even be given information about weaknesses in their interventions, missing a huge opportunity to empower them with local knowledge.

In contrast, local IBBS surveys have often been more effective in addressing this need. When such surveys were conducted in sites such as Manipur for PWID (persons who inject drugs)[6], Mysore for SW (sex worker)[7] or MSM (men who have sex with men) in Mumbai, they immediately informed the local community groups and planners about the extent of coverage of different interventions, changes in behaviour or prevalence of HIV as well as utilization of services in that local community. This further reinforces the understanding that interventions and sustained behavioural change for HIV are best achieved through community engagement, involvement and community-led interventions. Local IBBS surveys emphasize locating a community's need as central to the response to HIV. However, instead of supporting local surveys in each intervention site across the country, national IBBS became the norm.

Similar experiences have been recorded in Bangladesh, Indonesia, Pakistan and the Philippines. A national IBBS constituted through multiple local IBBS surveys could be a game changer in India as well as other large countries and could mobilize action at the local level - to end HIV and achieve sustainable development goal (SDG) - 3.3 on time.

In this article, we have described the weaknesses of national IBBS frameworks that prioritize nationally representative samples. We advocate for replacing them with frameworks that focus on local IBBS, noting that local surveys can be aggregated to obtain trends and data at the national level as needed. It is critical that countries plan IBBS surveys that are designed first and foremost to provide high-quality data in local geographic areas that have been prioritized based on epidemiologic relevance and programmatic need. These local IBBS surveys can contribute to a national IBBS sample, to which a limited number of non-priority areas can be added if desired, to ensure that the national sample reflects the national situation. However, this sub-national strategy recognizes that community-led local-level surveys are much more empowering and valuable, and international technical agencies such as UNAIDS, WHO and CDC should review current guidance.

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