

HOW DO COMMUNITIES MEASURE THE PROGRESS OF LOCAL RESPONSES TO HIV/AIDS

In an AIDS-competent society, people are dealing effectively with AIDS where they live and work because they accept the reality of HIV/AIDS, they assess how HIV/AIDS is affecting their lives and work, and they are adapting to live positively with HIV/AIDS.

This Technical Note aims to describe a synthesis of global learning on methods whereby communities measure the progress of local responses to HIV/AIDS. How do social groups know they become AIDS-competent? Through three steps:

1. Communities own the problems and find solutions (para. 1): they assess their progress in owning the process, or identifying and solving their problems
- Participatory Rural Appraisals (PRA), e.g. "Risk Mapping", are useful tools for this purpose.
2. Communities measure progress (para. 2): they monitor the reduction in HIV, STDs, TB and opportunistic infection incidence and prevalence, and the improvements in behavioural and attitudinal changes.
- Communities and Districts know through surveillance systems and the Health Management Information System (HMIS) the scope of their problems locally and how they evolve, including the accompanying behavioural and attitudinal changes.
3. Ultimately, the quality of life of individuals improves (para. 3): communities assess improvement in the quality of their lives, and that of specific groups.

Key Concept

Local monitoring of HIV/AIDS is a process for measuring results in a stepwise fashion. It is defined as the routine tracking of priority information about HIV/AIDS, either formal (e.g. mapping, surveillance and HMIS, quality of life) or informal (e.g. indicators of progress developed by the social groups).

Through local partnerships, people and communities can assess the HIV/AIDS situation, and understand how AIDS affects their lives. Consequently, they can act and learn from their collective actions and partnerships.

"Behaviour change in the end will have to be the decision of the individuals." (Freire, 1983)

Local partnerships on HIV/AIDS are a people-centred interaction between the key social groups (the communities) in the living environment including home and neighbourhood, the service providers, and the facilitators catalysts (Key Note, January 2000).

Local monitoring allows, ultimately, to know how to access resources of prevention, care and support in communities.

Common Features to Measuring the Progress of Local Responses to HIV/AIDS

A number of key operating common features listed next allow communities to measure the progress of Local Responses to HIV/AIDS, in addition to the specific ones outlined later:

- Monitoring is linked to action: local experiences guide both action and research
- Monitoring instruments are sensitive to local responses
- Assessments are conducted by communities in order to internalise and own the process and enhance the responses against the HIV/AIDS epidemic
- Communities are involved in all cases in the discussion and use of qualitative and quantitative data, and, in the collection of new measures where they do not exist, or they contribute to some of those
- Local monitoring of HIV/AIDS epidemic and behavioural changes are part of a broader involvement of communities in HIV/AIDS responses
- Surveillance and monitoring data are presented to communities and to local policy-makers, in ways that enhance their relevance for community groups and local planning, using appropriate presentation methods.

1. Assessing progress in the communities' development of their autonomy

Specific Features

- Assess whether the communities and the vulnerable individuals are autonomous in their decisions to take action for behaviour change
- Assess as well the environment under which the autonomy is developed and sustained.

Status of development for Measuring Progress on Local Responses to HIV/AIDS

A tool to enable communities to create a supportive environment and reduce social vulnerability is the mapping of behaviours ("Risk Mapping"), based on the experiences in Magu District, Tanzania. This is a process in which community sub-groups (e.g. women, men, youth, specific groups) identify and visualise places where sexual risk behaviour actually occurred in their villages. The groups then discuss the problems faced in avoiding risk behaviour and proposed action that could create a supportive environment. Future developments encompass the updating of mapping in changing communities, and mapping techniques documenting strengths and opportunities as well.

Mapping is an example of one the participatory methods which can help communities to become owners of the process, and convert awareness into action, consequently creating a supportive environment for behaviour change.

Besides the mapping tool, different Methodologies for Active Participation (MAP) exist to assess progress in the communities' development of their autonomy. Those can be complementary to mapping, and can bring about a positive provocation to the ongoing local community conversation.

As part of the development of their autonomy, communities develop their own indicators that are measurable, achievable and practical. They are collected, analysed, and interpreted by and for the beneficiaries' use in order to improve the services.

There is a need to develop new indicators to assess the local responses' sustainability, and to assess and monitor the progress of contextual factors (e.g. socio-economic, cultural, norms, local laws), and effectiveness of local partnership (e.g. shared respect for the community specific situations).

2. Monitoring the reduction in HIV incidence and prevalence and improvement in behavioural change

Specific Features

- Local monitoring emphasises an ongoing use of surveillance data at local levels, stimulating communities to analyse their specific factors of vulnerability and of risk, in order to understand the benefits of prevention and control actions and responses (local planning and management)
- Reduction of stigma around HIV/AIDS is an essential part of the action: local monitoring (e.g. "VCCCCTS", or the forgotten "C" in Voluntary Counselling and Testing) and involvement of People Living with AIDS may reduce stigma by breaking the silence around HIV/AIDS and stimulating action in communities
- Generating data on the HIV/AIDS epidemic as close to the communities as possible requires that HIV testing be made available and accessible to more local areas by using simple and easy testing methods, accompanied by systems for quality assurance
- Discussions that are part of the ongoing community conversation (often indirectly linked with home care) need to be facilitated in a context of counselling characterised by a relational team approach with community groups
- Capacity of local communities for a wider confidentiality needs to be affirmed, to the extent that shared confidentiality happens at the discretion of the local community. This is a safe situation in which personal secrets are known to others in the living environment but they do not always need to be verbalised. This form of confidentiality is often issue centred rather than focused on specific persons
- Health professionals have a pivotal role because they have privileged access to HIV/AIDS and related information. Mechanisms in place ensure to maintain confidentiality of individuals, families and communities tested and test results. Training in participatory approaches as well as relevant epidemiological and statistical support is essential. Finally, regular supportive supervision of health centre staff is also essential.

Status of development for Measuring Progress on Local Responses to HIV/AIDS

A mix of quantitative and qualitative methods and tools can best measure progress with the combination of various surveillance systems (biological and behavioural), accompanied by the Health Management and Information System.

The best balance of these methods and tools still need further simplification and testing for the use of Local Responses.

3. Assessing the improvement in the Quality Of Life (QOL) of people, including that of specific groups

Specific Features

- People concerned are asked for their own perception of quality of life
- People Living with AIDS and AIDS patients and those symptomatic and asymptomatic with HIV infection, as well as the general population of 'well' people are able to respond
- Questionnaires address quality of life issues that are relevant to the people concerned so that they are culturally sensitive to their needs, should be culturally coherent, and should be available in the local language(s)

Status of development for Measuring Progress on Local Responses to HIV/AIDS

The Division of Mental Health at the World Health Organisation (WHO) developed both a generic and an HIV specific WHOQOL-questionnaire for the measurement of quality of life of people with many diseases and conditions and for HIV infected people respectively.

The WHOQOL is a self-assessment tool designed to measure the quality of life of those with chronic diseases, high risk groups like refugees and migrants, care-givers and well people (a generic scale). The questionnaire addresses seven domains of quality of life (physical, psychological, level of independence, social relationships, environment, spirituality/religion/personal beliefs, and the spiritual beliefs of PLWHA).

This instrument is not yet designed for use at the local level. It may, nevertheless, be adapted and simplified for the purpose of measuring Local Responses.

This Technical Note will need updating again in the near future due to the rapidly changing situation of Local Responses, and what is learned about measurement.

Further readings:

1. "Assessment of autonomy of individuals and communities involved in HIV/AIDS"

Dick Schapink, Venance Nyonyo, Japheth Ng'weshemi, Françoise Jenniskens and Gabriel Mwaluko, TANESA Programme, Tanzania and Royal Tropical Institute, the Netherlands, 1999

For more information: J. Ng'weshemi, jngweshemi@africaonline.co.tz

2. "Process Approach Guide to HIV/AIDS risk behaviour mapping: Magu District experience 1996-1998, (TANESA), Tanzania"

V. Nyonyo, D. Mayunga, C. Pervilhac, J. Ng'weshemi, G. Mwaluko, June 2000

For more information: J. Ng'weshemi, jngweshemi@africaonline.co.tz

3. "Local monitoring of HIV/AIDS: a review of selected experiences and indicators for measuring HIV/AIDS epidemic and behavioral change at local level."

Halima Dao, May 2000

For more information: Bernhard Schwartlander, UNAIDS: schwartlanderb@unaids.org

4. "Evaluation Guide to Monitoring and Evaluation for National AIDS Programmes"

UNAIDS/WHO/USAID/Measure, 2000

For more information: Bernhard Schwartlander, UNAIDS: schwartlanderb@unaids.org

5. "Guidelines for Second Generation HIV Surveillance"

UNAIDS/WHO, WHO/CDS/EDC/2000.5

For more information: Bernhard Schwartlander, UNAIDS: schwartlanderb@unaids.org

6. "Measuring Quality of Life in HIV and AIDS", 2000

LOCAL RESPONSES TO HIV/AIDS

Local communities across the world are dealing effectively with AIDS where they are and where learning can change the reality of HIV/AIDS. They do so as they find AIDS is affecting their lives and work and become engaged to live positively with HIV/AIDS.

The Local Monitoring Note aims to describe a synthesis of global learning on methods whereby communities measure the progress of local responses to HIV/AIDS. How do social networks they become AIDS-competent? Through their own communities own the problems and find solutions (para. 1), they assess their progress in solving the problems, or identifying and solving their problems.

Participatory Rural Appraisal (PRA) - eg. "Risk Mapping" are work tools for this purpose.

Communities measure progress (para. 2), they measure the reduction in HIV, STDs, TB and opportunistic infection incidence and prevalence, and the improvements in behaviour and quality of life.

Communities and partners learn through surveillance systems and the Health Management Information Systems (HMIS) the scope of their problems locally and how they evolve, including the accompanying socio-cultural and structural changes.

Ultimately, the quality of life of individuals improves (para. 3), communities assess their own extent in the quality of their lives, and that of specific groups.

Key Concept

Local monitoring of HIV/AIDS is a process for increasing evidence in a stepwise fashion. It is defined as the routine tracking of activity information about HIV/AIDS, either formal (eg. surveys, surveillance and HMIS, quality of life) or informal (eg. indicators of progress developed by the social groups).

Through local participation, people and communities can assess the HIV/AIDS situation and understand how AIDS affects their lives. Consequently, they learn and learn from their experiences, attitudes, and relationships.

"Progressive change in the end will have to be the domain of the individual." (Freud, 1967)

Local partnerships on HIV/AIDS are a people-centred interaction between the key social groups (ie. communities) in the living environment including home and workplace-based, the service providers, and the facilities/enterprises (Key Note, January 2000).

Local monitoring allows, ultimately, to know how to access resources of prevention, care and support in communities.