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**HOW CAN WE  
MONITOR PROGRESS  
IN PROVIDING  
HIV-RELATED  
CARE AND SUPPORT?**

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SEPTEMBER 2013

STOPAIDS is the network of UK agencies working since 1986 to secure an effective global response to HIV and AIDS. With 80 members behind us, we raise a united voice to rally and maintain the UK's leadership in the global response to HIV. Together with people living with HIV, we fight for a global response that respects, protects and fulfils human rights. We give decision-makers the proof – and the push – they need to make the right, smart choices to help improve the lives of the millions of people around the world needing HIV treatment, prevention, care and support.

STOPAIDS achieves its impact through its membership, which works directly with more than 130 million people worldwide, and by engaging decision-makers through the development of policy, identifying best practice, lobbying and conducting public campaigns. Over three decades STOPAIDS has helped to secure high level international commitments to universal access as well as UK government leadership in the response. We have advanced the international development NGO sector's work, driving the uptake of the latest and most effective approaches to tackling HIV. We have pressed pharmaceutical companies to open up access to generic versions of their HIV medicines and we have partnered with leading UK parliamentarians throughout this time.

[www.stopaids.org.uk](http://www.stopaids.org.uk) [info@stopaids.org.uk](mailto:info@stopaids.org.uk) Twitter [@STOPAIDS](https://twitter.com/STOPAIDS)

Report written by Roger Drew

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## BACKGROUND AND INTRODUCTION

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In 2008, the Care and Support Thematic Group of STOPAIDS produced a report entitled *What do We Really Mean by 'Care and Support'?*

This report sought to establish a common understanding and terminology related to care and support. It included a section on indicators for monitoring care and support but concluded that available indicators were deficient in many ways. The report concluded that a representative range of indicators is vital for supporting the development and measuring the impact of care and support programmes and policies.

Since that time, the thematic group has been actively engaged in trying to come up with a set of indicators that can be used to monitor HIV-related care and support. This work was recognised in 2010 when the thematic group was asked to co-lead, along with the United Nations Children's Fund (UNICEF), the care and support element of the 2010 review of indicators used to monitor the 2001 Declaration of Commitment adopted by the United Nations General Assembly Special Session (UNGASS) on HIV. This review identified that, despite the large overall number of care and support indicators being monitored by agencies at some level, very few were of sufficient quality to meet the MERG indicator standards and so be considered viable indicators for international level monitoring. This lack of good quality, standardised care and support indicators was also confirmed by a web-based survey on current practises in national monitoring.

So, from 2011 until 2013, the thematic group has been implementing a project to test care and support indicators in two countries, South Africa and Zambia. As a result of that work, the thematic group is now able to present here a step-by step monitoring framework and a

set of indicators that can be used to monitor HIV-related care and support. This document focuses mainly on analysis at the national level but the approaches discussed could be adapted for sub-national level and/or used for analysis across countries. It is primarily aimed at NGOs working on HIV-related issues in one or more low-income countries. However, it is expected that this publication will be of interest to others including national governments, funding agencies, multilateral organisations, academics, national NGOs and community-based organisations. More details of the process followed are documented in the final project report (FPR).

## A MONITORING FRAMEWORK

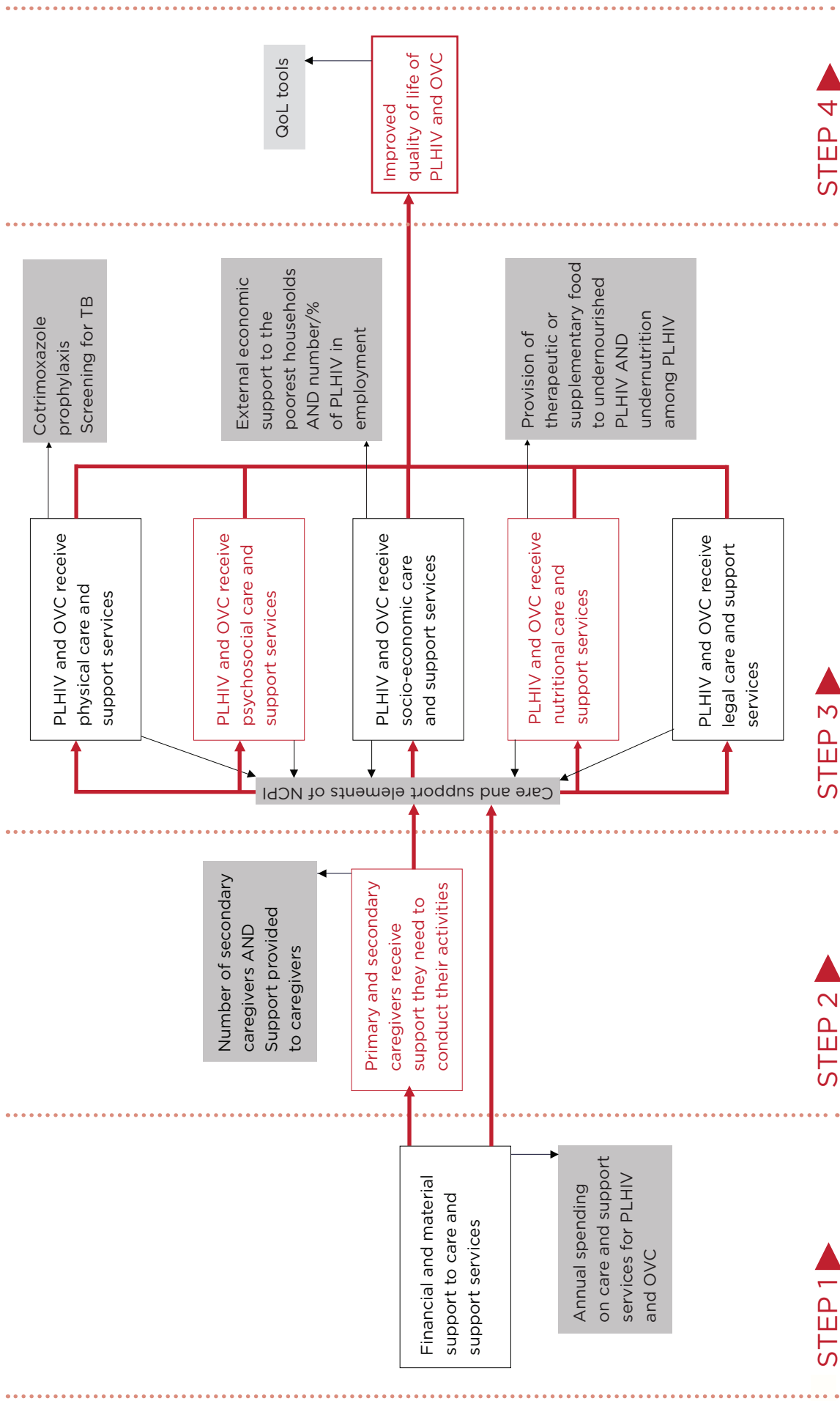
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In order to monitor HIV-related care and support, it is helpful to have a monitoring framework which shows what resources are provided for care and support, what activities are conducted with those resources and the results they have. Figure 1 presents a simple and quite general monitoring framework in diagrammatic form. It includes suggested indicators for monitoring a number of different elements of the framework and sub-divides the monitoring process into four steps. This framework may need to be modified and adjusted to be relevant to particular settings in which care and support are provided.

This monitoring framework is based on five domains of care and support – physical, psychosocial, socio-economic, nutritional and legal. It also recognizes three key target groups of care and support – people living with HIV (PLHIV); orphans and vulnerable children (OVC); and caregivers.

Essentially, the framework consists of a theory of change model in which financial and material resources are used to provide a

**FIGURE 1** FRAMEWORK AND PROPOSED INDICATORS FOR MONITORING HIV-RELATED CARE AND SUPPORT SERVICES AS USED FOR TESTING INDICATORS



range of care and support services to PLHIV and OVC both directly and through primary and secondary caregivers (see Box 1). Care and support services are depicted as having five components - physical, psychosocial, socio-economic, nutritional and legal. The expected result of providing these services is improved quality of life for both PLHIV and OVC.

### **BOX 1**

#### **STOPAIDS DEFINITIONS OF CAREGIVER**

*(from Past Due: Remuneration and Social Protection for Caregivers in the Context of HIV and AIDS: Policy Brief: March 2012)*

**Primary caregivers** are both adults and children who care for other family members in their homes.

**Secondary caregivers** are community caregivers or other health workers who work as individuals or staff (paid or volunteer) of clinics, non-governmental organisations (NGOs) and faith based organisations (FBOs).

The framework is not intended to capture everything related to care and support. Like all models, it is highly-simplified and aims to represent a much more complex reality. It has limitations, such as not clearly distinguishing between financial and material resources from within a community and external resources, e.g. from donors. As a result, it may appear that the model implies that no care and support services can be provided without material and financial resources from donors. This is not the case. However, it is hard to imagine what care and support services can be provided in the absence of any material and financial resources, e.g. from within the community, from local and national government or from donors. Key advantages of the model as presented are simplicity and clarity. Both these features would have been compromised by seeking to capture additional levels of complexity.

The model is based on certain assumptions. For example, it is assumed that provision of financial and material support will result in delivery of care and support services. However, there could be some circumstances, e.g. outbreaks of war/conflict, in which this might not happen. The model therefore assumes that an external environment exists which is conducive to the delivery of these services.

Palliative care is not shown as a separate component or element of the model. This is partly because of widely divergent views of what constitutes palliative care and how it should be defined. However, the main reason is that many elements of palliative care are captured across the framework within various elements.

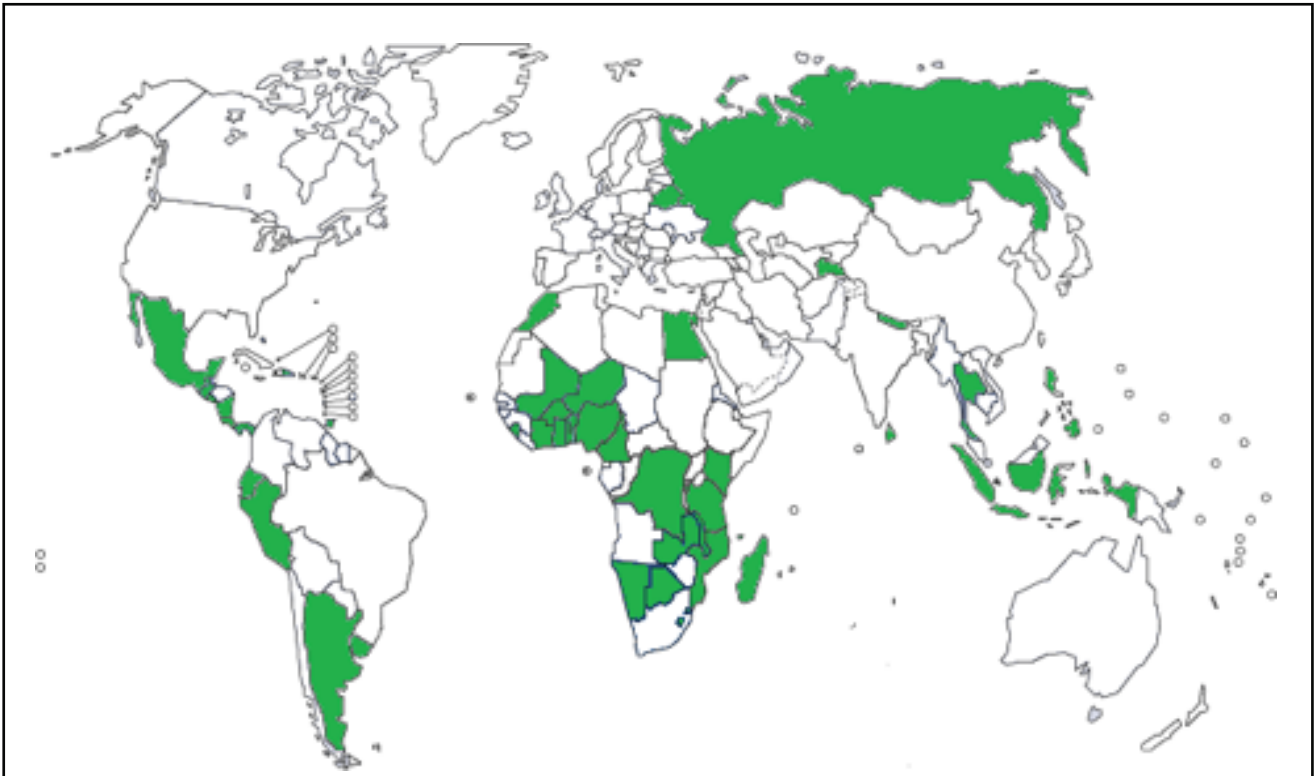
## **STEP 1: MEASURING FINANCIAL AND MATERIAL SUPPORT TO CARE AND SUPPORT SERVICES**

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The first step in monitoring care and support is to measure the financial and material support available for care and support activities. This may be possible at national level in countries that have conducted a National AIDS Spending Assessment, which uses a National Funding Matrix to assess spending on the response to HIV across a number of different categories, including some related to care and support. As of July 2013, National AIDS Spending Assessments are available for 42 countries on the UNAIDS website<sup>1</sup> (see Figure 2).

STOPAIDS has developed a tool (see Annex 1 of FPR) which shows how to map different line items within the funding matrix, onto different care and support categories.

One challenge is that care and treatment are joined together as one main category of HIV spending in the funding matrix. There is a sub-category for antiretroviral therapy (ART).



**FIGURE 2** COUNTRIES THAT HAVE CONDUCTED NATIONAL AIDS SPENDING ASSESSMENTS  
(SOURCE UNAIDS WEBSITE; JULY 2013)

The tool assumes that spending on care and support can be calculated by subtracting the reported spending on ART from the reported total spending on care and treatment. The tool assumes that most of this spending is on physical care, apart from specified categories focused on psychological treatment and support services and nutritional support associated with ART. Additional spending on care and support is included in other categories of HIV spending including:

- Orphans and vulnerable children -this is shown in the funding matrix as a separate funding category
- Social protection and social services (excluding OVC) - the mapping tool assumes that this is analogous to the socioeconomic domain of care and support
- Enabling environment - the mapping tool assumes that this is analogous to the legal domain of care and support

The main advantage of this approach is that

data is already available for a significant number of countries. In some cases, countries have data available over a number of years (see Box 2).

However, there are some challenges with this data. These include:

- The assumption that countries allocate HIV spending in the same way as each other and over time.
- Limitations of data quality - the accuracy of figures reported by countries depends on the accuracy and completeness of figures reported by agencies and organisations.
- Excessive complexity of the line items within the funding matrix. As a result, these may not be relevant to all countries.

Given these concerns, caution is needed in interpreting figures from National AIDS Spending Assessments, particularly where comparisons are made across countries. More detail of how data from National AIDS

## **BOX 2** NATIONAL SPENDING ON CARE AND SUPPORT: DATA FROM TEN COUNTRIES

STOPAIDS has used this method to analyse spending on HIV-related care and support in ten African countries – Botswana, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, Swaziland, Tanzania and Zambia. In summary:

- Overall spending on HIV-related care and support increased from 2003 to 2010
- On average, more than one third of HIV spending is focused on care and support
- Most care and support spending is focused on orphans and vulnerable children and the physical care of people living with HIV
- There is relatively little spending on some domains of care and support including psychosocial, socio-economic and legal
- But, spending on nutritional support to ART is a significant and growing expenditure in some countries, e.g. Mozambique
- Reported spending on psychosocial support was very low, less than 1% of all spending on care and support overall. The country with the highest level of reported spending on psychosocial support was Swaziland

Spending Assessments can be used to track national spending on care and support is available in Annex 5 of the FPR.

## **STEP 2: ASSESSING WHETHER CAREGIVERS RECEIVE THE SUPPORT THEY NEED TO CONDUCT THEIR ACTIVITIES**

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Financial resources are not the only type of resources needed for HIV-related care and support. Human resources are even more vital. In 2012, STOPAIDS published a policy brief<sup>2</sup> on remuneration and social protection for caregivers in the context of HIV and AIDS. This recognised that, in sub-Saharan Africa, an estimated 90% of care for people living with HIV is done in the home by family or community-based caregivers. The policy brief distinguished between ‘primary’ and ‘secondary’ caregivers (see Box 1).

Although it might be useful to know the number of primary caregivers in a community or country, there are considerable difficulties in

measuring this. First, there does not appear to be an agreed definition of the term. Some use the term ‘primary’, as STOPAIDS does, to denote first line carers. However, others use the term to denote main carer. Other differences include who care is being provided for and the time period during which care may have been provided. Second, there is no readily available mechanism for collecting this information. Although censuses in some high-income countries, e.g. the UK, do ask about primary caring responsibilities, this does not appear to be the case in low- and middle-income countries. Given this, it is probably not feasible to routinely measure the number of primary caregivers in a particular community or country.

It may be easier to get information on the number of secondary caregivers in a community or country as their contribution is more formalised. However, there may be differences in definition between countries. For example, in South Africa, this appears to be defined narrowly by government as those who receive a stipend for such activities. In Zambia, civil society organisations define this more broadly as those who have been



trained to provide such services. In general, it is preferable to measure those who actually provide services rather than all those who have ever been trained in this area. More detail of how the number of secondary caregivers can be measured is available in Annex 5 of the FPR. Where such figures are available, they should be compared with some proxy measure of level of need, such as the total population of a country and/or the estimated number of people living with HIV in the country.

It may be useful to assess periodically the support provided to caregivers. Areas which might merit such assessment include the caring roles the caregivers are expected to carry out and the extent to which they:

- Are provided with the equipment they need
- Have access to transportation
- Receive financial compensation for their activities
- Are able to refer people to other services
- Feel valued

While it would be possible to develop a tailored questionnaire for this purpose, there are already multiple questionnaires being used for similar purposes internationally. Between 2011 and 2013, STOPAIDS reviewed 12 questionnaires used in work with caregivers. This work concluded that the questionnaire that best fitted the identified needs was the Community Health Worker Assessment and Improvement Matrix (see Annex 2 of the FPR). Although this matrix is intended for use among community health workers, it could be extremely relevant for those working with secondary caregivers. To be used in this context, it would require some modification and further testing. STOPAIDS would be interested in hearing from any organisations conducting such modifications and testing of this tool to find out more about the process and results. More detail concerning questionnaires for secondary caregivers is available in Annex 5 of the FPR.

## STEP 3: MEASURING THE EXTENT TO WHICH PLHIV AND OVC RECEIVE CARE AND SUPPORT SERVICES

The third step focuses on the extent to which PLHIV and OVC receive care and support services across five domains - (a) physical; (b) psychosocial; (c) socio-economic; (d) nutritional and (e) legal.

The National Commitments and Policies Instrument (NCPI) can potentially provide information on care and support across each of these domains. It is completed every two years by national governments and representatives of civil society as part of Global AIDS Response Progress Reporting. Questions cover a wide range of topics. The vast majority of countries provide data to UNAIDS for NCPI (see Figure 3).

STOPAIDS has identified questions in the NCPI of relevance to care and support (see Annex 4 of the FPR). These questions cover three main areas:

- The country's legal and human rights environment in which the national response to HIV is provided. These questions cover issues such as the extent to which the national HIV strategy and development plans address important issues of human rights, stigma and discrimination; the provision of legal protection for key populations and vulnerable groups; and the extent to which laws and policies act as obstacles to an effective HIV response. There are more questions of this type for civil society than for government.
- The provision of treatment, care and support in the country. Questions include an assessment of the extent to which specific care and support services are implemented. They also allow both government and



**FIGURE 3** COUNTRIES THAT SUBMITTED A RESPONSE TO NCPI IN 2012 (SOURCE UNAIDS WEBSITE; JULY 2013)

civil society opportunity to rate national treatment, care and support services overall.

- The provision of services for orphans and vulnerable children.

Summary data related to care and support for ten countries is presented in Box 3. More detail of how data from NCPI can be used to monitor care and support is available in Annex 5 of the FPR.

### STEP 3A: Measuring the extent to which PLHIV and OVC receive physical care and support services

Physical care and support services are a major and important part of all care and support services provided to PLHIV and OVC. For PLHIV, prevention and treatment of opportunistic infections is particularly important. Providing PLHIV with

Cotrimoxazole preventive therapy can prevent a significant number of deaths and illnesses. Measuring the extent to which those who require Cotrimoxazole receive it can provide an indication of the extent to which PLHIV and OVC receive physical care and support services. Data is available for a large number of countries and is reported to WHO regularly. In 2010, 76 countries reported this data to WHO and in 2012 56 countries did so. This indicator is also tracked by some major funders, such as the Global Fund and PEPFAR. However, these agencies all have slightly different definitions of this indicator<sup>3</sup> which makes understanding and comparison of data more complex. To understand data reported against this indicator it may be helpful to be clear as to:

- What time period is being considered? Is it ever received Cotrimoxazole, received in the last year or received on last visit?
- Who is being considered? Adults? Children? Both?
- How is eligibility for Cotrimoxazole defined?

**BOX 3** WHAT CAN NCPI TELL US ABOUT CARE AND SUPPORT? DATA FROM 10 COUNTRIES

STOPAIDS has used this method to analyse spending on HIV-related care and support in ten African countries – Botswana, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland and Tanzania. In summary:

- All countries had a wide range of policies in place related to HIV care and support. However, there were some blind spots in most countries in terms of restrictive laws and policies relating to some key populations, particularly men who have sex with men.
- There was a gap between having human rights policies in place and ensuring these were implemented. For example, when asked to rank policies, laws and regulations and their implementation on a ten point scale, civil society respondents gave an average ranking of 6.60 and 5.22 respectively in 2012 (as compared to 5.64 and 4.45 in 2010). Although most countries had independent national institutions for the promotion and protection of human rights, very few had performance indicators or benchmarks for human rights.
- There was variation in the availability of key care and support services across countries, by year and by respondent. Overall, services that were commonly available included HIV testing and counselling for TB patients and Cotrimoxazole prophylaxis for people living with HIV. Services that were less commonly available included nutritional support for people receiving ART, psychosocial support for PLHIV and their families and HIV care and support in the workplace.
- On average, reported coverage for OVC programmes was around 40%, although there was wide inter-country variation, e.g. between 7 and 95% for government respondents in 2010.
- Average ranking on a ten point scale for provision of HIV-related care and support rose slightly from 2010 to 2012 for both government (7.82 in 2010 to 8.00 in 2012) and civil society respondents (7.50 in 2010 to 7.60 in 2012).
- Average ranking on a ten point scale for provision of OVC services fell slightly from 2010 to 2012 for both government (6.80 in 2010 to 6.56 in 2012) and civil society respondents (6.50 in 2010 to 6.40 in 2012).

There may be national guidelines which may be based on international guidance, e.g. from WHO<sup>4</sup>. Is it possible to know the number of people eligible to receive Cotrimoxazole or is some kind of proxy needed, e.g. people diagnosed with HIV but not yet receiving ART?

More detail of how data related to Cotrimoxazole preventive therapy can be used to monitor care and support is available in Annex 5 of the FPR.

Similarly, TB is a major cause of death among

PLHIV. Screening for TB is recommended for PLHIV and the extent to which this is done can provide an indication of the extent to which PLHIV and OVC receive physical care and support services. Data is available for a large number of countries and is reported to WHO annually. For example, 53 countries reported 2011 data to WHO. This indicator is also tracked by some major funders, such as the Global Fund and PEPFAR. However, these agencies have slightly different definitions of this indicator<sup>5</sup> which makes understanding and comparison of data more complex. To understand data reported against this

indicator, it may be helpful to be clear as to:

- What precisely does TB screening involve?
- Who is being considered? Adults? Children? Both?
- Whether TB screening is being conducted among those newly-diagnosed with HIV or among all people with HIV? Does this match with the denominator being used for this indicator?

More detail of how data related to TB screening can be used to monitor care and support is available in Annex 5 of the FPR.

It may be possible to get data for other physical care and support services for PLHIV, for example, the extent to which pain is managed effectively. However, indicators are not well-developed in other areas and data is not as widely available as for the two indicators presented here.

### STEP 3B: Measuring the extent to which PLHIV and OVC receive psychosocial care and support services

Psychosocial support for PLHIV and OVC is recognised as important. Such services include the provision of counselling beyond the post-test period and the provision of peer support through support groups led by people living with HIV. STOPAIDS is concerned that this area of care and support is under-recognised and under-funded. It is therefore important that the extent to which these services are provided is monitored. However, it has proved difficult to identify robust indicators for this purpose, with the exception of relevant data that can be extracted from NCPI. This remains a significant gap area.

### STEP 3C: Measuring the extent to which PLHIV and OVC receive socio-economic care and support services

Socio-economic support for PLHIV and OVC is recognised as an important issue, although this is increasingly provided through social protection mechanisms focused on the poorest and most vulnerable people in a country, rather than providing stand-alone services for PLHIV or OVC.

There is an indicator within the Global AIDS Response Progress Reporting set which captures the provision of external economic support to the poorest households. Details of this indicator are available on <http://www.indicatorregistry.org/node/865>. This indicator has evolved over the years. Changes include focusing on economic support as opposed to multiple forms of support and considering the poorest households rather than those specifically affected by HIV. Collection of data requires some form of household survey, such as a DHS. It is unclear how available data is on this indicator. In the 2012 report on the global AIDS epidemic, UNAIDS did not report on this indicator. A brief review of narrative reports for 12 countries<sup>6</sup> showed that none of them reported data for this indicator in 2012. In some cases, e.g. South Africa and Swaziland, the narrative reports did contain other material relevant to this issue. In some cases, e.g. Malawi, the report noted that the country had been able to report on the previous indicator but was not now able to do so since the definition had changed<sup>7</sup>.

Information about the employment status of PLHIV compared with the population overall could provide useful contextual information about the socio-economic status of PLHIV. It could also potentially provide information about the benefits of HIV-related care and support programmes. Relevant data is available in countries that have conducted

a DHS which included HIV testing. However, when STOPAIDS reviewed available data for six countries<sup>8</sup> no differences were found between PLHIV and the general population either overall or when men and women were considered separately. This finding differs from other studies, e.g. from Spain, where it has been found that employment probability was lower among people living with HIV than among others. Employment probability was further reduced among symptomatic HIV patients and among those with AIDS.

More detail of how data related to employment among PLHIV can be used to monitor care and support is available in Annex 5 of the FPR.

### STEP 3D: Measuring the extent to which PLHIV and OVC receive nutritional care and support services

Good nutrition is of critical importance for people living with HIV, including those receiving antiretroviral therapy. It is possible to monitor progress in this area by measuring the proportion of people living with HIV who are undernourished and by monitoring the proportion of those who receive therapeutic or supplementary food.

PEPFAR has information available for the number of undernourished PLHIV provided with therapeutic or supplementary food in some countries, particularly in Africa (see Figure 4). However, countries are only just starting to report to PEPFAR the number of people living with HIV who are undernourished.



**FIGURE 4** COUNTRIES IN WHICH PEPFAR HAS INFORMATION ABOUT PROVISION OF SUPPLEMENTARY AND THERAPEUTIC FOOD TO PLHIV (SOURCE USAID)

More detail of how data related to nutrition among PLHIV can be used to monitor care and support is available in Annex 5 of the FPR.

### STEP 3E: Measuring the extent to which PLHIV and OVC receive legal care and support services

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Legal support for PLHIV and OVC is recognised as an important area, e.g. in addressing issues related to stigma and discrimination. It is therefore important that the extent to which these services are provided is monitored. However, it has proved difficult to identify robust indicators for this purpose, with the exception of relevant data that can be extracted from NCPI. NCPI has a very strong focus on legal and human rights issues, so is highly relevant to this area.

## STEP 4: ASSESSING IMPROVEMENTS IN THE QUALITY OF LIFE OF PLHIV AND OVC

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The ultimate purpose of providing care and support to both PLHIV and OVC is to improve their quality of life. However, it is relatively unusual for care and support programmes to systematically track improvements in clients' quality of life and the reasons for this.

There are a number of possible tools for assessing quality of life among PLHIV and OVC. These include:

- EQ-5D<sup>9,10</sup>
- WHO-QOL<sup>11,12,13</sup>
- The CAFOD “batteries” tool<sup>14,15</sup>
- The African Palliative Outcome Score (APCAPOS)<sup>16,17,18</sup>

#### **BOX 4** POTENTIAL TOOLS FOR ASSESSING THE QUALITY OF LIFE OF PLHIV AND OVC

**EQ-5D** is a quality of life tool widely-used in Europe. It assesses health-related quality of life in five dimensions - mobility; self-care; usual activities; pain/discomfort and anxiety/ depression. Its use is well-documented but its analysis focuses fairly narrowly on health and requires use of abstract numerical scales.

**WHO QOL** is a quality of life tool which asks more than 25 questions using a five point scale. Scores are then calculated for six health domains - physical; psychological; level of independence; social relationships; environment; and spirituality, religion and personal beliefs. It has been widely used and has a broader approach to health than EQ-5D. It has specific questions on some sensitive topics and has been particularly adapted for HIV. Like EQ-5D, it requires use of abstract numerical scales.

**The CAFOD batteries tool** was specifically designed by an international NGO to be user-friendly. It is based on the metaphor of a rechargeable battery and does not require high levels of literacy or numeracy to use. It is completed using a conversational style and is quick to complete. However, it has not been widely used beyond CAFOD and its use has not yet been formally documented, e.g. in a peer reviewed journal.

**The African Palliative Care Outcome Score** is a quality of life tool based on 10 items addressing physical and psychological symptoms, spiritual, practical and emotional concerns, and psychosocial needs of the patient and family. It has been validated and was specifically developed for the African context. It is reported to be quick and easy to use. However, use has been limited to palliative care contexts.

Brief details of these tools and their relative merits are presented in Box 4.

STOPAIDS would be interested in hearing from any organisations conducting such testing of any of these tools to find out more about the process and results. More detail concerning the use quality of life tools in monitoring the results of care and support is available in Annex 5 of the FPR.

## CONCLUSIONS

Care and support for PLHIV and OVC are essential elements in an effective response to HIV. In 2008, STOPAIDS published a document which tried to define more fully what precisely is meant by care and support. It raised the

issue of how effective delivery of care and support could be monitored. However, this has been hampered by the very limited availability of effective monitoring tools.

This document seeks to provide these. It does this, first, by presenting a simple, four-step monitoring framework which starts with financial and human resources available for care and support and seeks to track how these can be used to improve the quality of life of PLHIV and OVC. It also presents a number of indicators that can be used within this framework. These indicators have been tested and reviewed by an independent indicator review panel. In some areas of care and support, e.g. psychosocial, it has proved extremely difficult to identify good quality, specific indicators. These remain important gap areas that merit further work.

## REFERENCES

<sup>1</sup> <http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/nasacountryreports/>

<sup>2</sup> See <http://stopaids.org.uk/wp-content/uploads/2013/08/UK-AIDS-Consortium-policy-briefing-remuneration-of-caregivers.pdf>

<sup>3</sup> See [http://www.indicatorregistry.org/search/apachesolr\\_search/cotrimoxazole](http://www.indicatorregistry.org/search/apachesolr_search/cotrimoxazole)

<sup>4</sup> See <http://www.who.int/hiv/pub/guidelines/arv2013/download/en/index.html>

<sup>5</sup> See [http://www.indicatorregistry.org/search/apachesolr\\_search/tb?page=2](http://www.indicatorregistry.org/search/apachesolr_search/tb?page=2)

<sup>6</sup> Botswana, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Tanzania, Uganda and Zambia

<sup>7</sup> Previously the indicator was the percentage of very sick persons whose households received social/material support in the past 30 days

<sup>8</sup> Kenya, Lesotho, Malawi, Mozambique, Swaziland and Zambia

<sup>9</sup> See <http://www.euroqol.org/>

<sup>10</sup> Robberstad, B and Olsen, J.A. (2010) *The Health-related Quality of Life of People Living with HIV/AIDS in Sub-Saharan Africa: A Literature Review and Focus Group Study* See <http://www.resource-allocation.com/content/8/1/5>

<sup>11</sup> See [http://www.who.int/mental\\_health/publications/whoqol/en/](http://www.who.int/mental_health/publications/whoqol/en/)

<sup>12</sup> For a specific description of WHOQOL BREF see <http://>

[www.who.int/substance\\_abuse/research\\_tools/en/english\\_whoqol.pdf](http://www.who.int/substance_abuse/research_tools/en/english_whoqol.pdf)

<sup>13</sup> One member of the IRP provided extensive information on how WHOQOL had been adapted for use in Estonia – see Rütel, K. (2009) *HIV Epidemic in Estonia: Injecting Drug Use and Quality of Life of People Living with HIV* Doctorate Dissertation, Tartu University Press, 162; Rütel, K., Uusküla, A., Minossenko, A. and Loit, H-M. (2008) *Quality of Life of People Living with HIV and AIDS in Estonia* Central European Journal of Public Health 2008; 16(3), pp111-115; Rütel, K., Pisarev, H., Loit, H-M. and Uusküla, A. (2009) *Factors Influencing Quality of Life of People Living with HIV in Estonia: A Cross-Sectional Survey* Journal of the International AIDS Society 2009; 12:13

<sup>14</sup> CAFOD (2010) *Assessing the Quality of Life of People Living with and Affected by HIV: A Participatory Approach: Batteries Methodology*

<sup>15</sup> Drew, R. (2011) *Thematic Review: CAFOD's International Work in HIV-related Care and Mitigation*

<sup>16</sup> See [http://www.africanpalliativecare.org/index.php?option=com\\_content&view=article&id=135&Itemid=41](http://www.africanpalliativecare.org/index.php?option=com_content&view=article&id=135&Itemid=41)

<sup>17</sup> Harding, R., Selman, L., Agupio, G., Dinat, N., Downing, J., Gwyther, L., Mashao, T., Mmoledi, K., Moll, T., Sebuyira, L.M., Panjatovic, B. and Higginson, I.J. (2010) *Validation of a Core Outcome Measure for Palliative Care in Africa: the APCA African Palliative Outcome Scale* Health and Quality of Life Outcomes 2010, 8:10 <http://www.hqlo.com/content/8/1/10>

<sup>18</sup> APCAPOS was also considered as a potential indicator in the section on pain management (see p36). However, it was discounted from this section because it was considered too complex for prospective testing in South Africa and Zambia, and has a much broader focus than pain management only.