

Challenges of monitoring and evaluating paediatric HIV care

Background

In recent years there has been significant progress in increasing access to antiretroviral therapy (ART) for children living with HIV in developing countries. By the end of 2008 it was estimated that 275,700 children (38% of those in need) were receiving ART. This was an increase of 77,700 children from the end of 2007. Ensuring quality of care is a challenge for programmes which are under high pressure to increase coverage quickly. Monitoring and evaluation (M&E) has been identified as a key strategy to scale up and improve service quality because:

- It defines priorities for service provision and regular feedback motivates health workers (“what is reported on is done”)
- It shows progress, allows meaningful target setting, and justifies resource allocation
- It identifies gaps and allows an assessment of what needs to be done to improve services

In order to assist governments to monitor progress, WHO and UNICEF recently reviewed and revised existing guidance on M&E of services for preventing mother-to-child transmission (PMTCT), paediatric ART and HIV care and support. They recommend 12 indicators for national governments to monitor and evaluate their programmes (see box 1).

National reporting of coverage of paediatric HIV services has improved

in recent years. More than 100 low-income countries have consistently reported on paediatric HIV treatment and care since 2006, which is up from 58 in 2004 (see figure 1).

This policy brief discusses key challenges for monitoring and evaluating paediatric HIV treatment and care. These were identified at a workshop held in Uganda in May 2009, involving providers, researchers and policy-makers from Uganda, Zambia, Malawi and Zimbabwe. Representatives from Ministries of Health and focal persons for M&E of paediatric services and PMTCT programmes participated.

Weaknesses of the recommended indicators

It is notable that only 1 of the 12 WHO indicators focuses on paediatric care of HIV-infected children after infancy, rather than on PMTCT and infants. Thus none of the core indicators mention HIV testing of older children presenting to acute care settings such as hospitals and malnutrition units where the proportion of children with HIV is high. Similarly, although the number of infants receiving cotrimoxazole is an indicator, this is not extended to older HIV-infected children who also require cotrimoxazole. None of the recommended indicators address adolescents aged 15 to 18 years, who need a high level of support. The percentage of previously undiagnosed pregnant women tested for HIV during pregnancy would be useful, as

identifying women newly tested HIV positive determines entry in PMTCT.

Some of the recommended indicators maybe hard to measure, such as 5 (percentage of HIV-positive pregnant

Key Points

- Monitoring and evaluation of HIV services for children is important
- WHO have developed indicators for PMTCT and paediatric HIV programmes, however these indicators do not focus sufficiently on paediatric care of HIV-infected children after infancy
- The key challenges to monitoring and evaluating of paediatric HIV programmes are related to :
 - Data quality
 - Harmonisation of indicators between countries
 - Measuring of the impact of treatment programmes
- Any efforts to address these challenges need to take into account the pressure on health workers caused by the shortage of human resources

Box 1: WHO recommended national indicators for monitoring and evaluation of PMTCT and paediatric HIV care and treatment (source UNICEF 2009)

1. Existence of national policies and guidelines in line with international standards for the prevention of mother-to-child transmission
2. Percentage of health facilities that provide antenatal care services with both HIV testing and ARV for the prevention of mother-to-child transmission on site.
3. Percentage of pregnant women who were tested for HIV and received their results
4. Percentage of HIV-positive pregnant women who were assessed for ART eligibility.
5. Percentage of HIV-positive pregnant women who received ARV to reduce the risk of mother-to-child transmission
6. Percentage of infants born to HIV-positive women (HIV-exposed infants) receiving ARV prophylaxis to reduce the risk of mother-to-child transmission (by regimen: single- or multi-drug).
7. Percentage of infants born to HIV-positive pregnant women who are started on cotrimoxazole prophylaxis within two months of birth.
8. Percentage of infants born to HIV-positive women who received an HIV test within 12 months of birth.
9. Percentage of HIV-exposed infants who are exclusively being breastfed, replacement fed or mixed fed at 3 months.
10. Percentage of HIV-positive women of reproductive age receiving HIV care and treatment services with unmet need for family planning services.
11. Percentage of infected infants born to HIV-positive women.
12. Percentage of HIV-positive children aged 0–14 who are currently receiving ART.

women, who received ARV to reduce the risk of MTCT) and 6 (percentage of infants born to HIV-positive women receiving ARV prophylaxis to reduce the risk of MTCT). When ARVs for mother or infant are handed out to women to be administered at home it doesn't necessarily mean that they are actually taken.

It would be useful to split these data on Indicator 8 (Percentage of infants born to HIV-positive women who received an HIV test within 12 months of birth) into those tested between 0–<6 months and 6–12 months and by test type (virological and antibody). The aim should be to diagnose HIV early in infancy as by 12 months many

HIV-infected infants born to HIV-positive mothers will have died.

On the one hand, there is an understandable desire of policymakers to base decisions on more and better evidence. On the other hand, health workers are under intense pressure in many low-income settings due to staff shortages and high patient numbers. It is important therefore that the number of indicators they have to keep records of is limited to a manageable amount. Participants at the workshop came to a consensus that priority should be given to getting good quality harmonised data on the following key WHO indicators for M&E strategies:

Key terms

Standardised system: A single way of collecting national data based on standardised forms

Active data collection: Data are collected by the central unit from standardised forms during regular visits.

Passive data collection: Data are sent by sites to the central unit

- Indicator 5. Percentage of HIV-positive pregnant women who received ARV to reduce the risk of mother-to-child transmission.
- Indicator 8. Percentage of infants born to HIV-positive women who received an HIV test within 12 months of birth.
- Indicator 12. Percentage of HIV-infected children aged 0–14 who are currently receiving ART.

Monitoring and Evaluation of paediatric HIV treatment and care in Malawi, Uganda, and Zambia

In Malawi, Uganda and Zambia M&E systems have a single standardised way of collecting national data based on standardised forms for HIV testing, PMTCT, diagnosis, management and follow-up of HIV exposed infants, and ART. In Zambia data collection is active for all services. Uganda uses a combination of active and passive data collection. In Malawi, data are collected actively for ART service, while for other services data collection is passive.

Many of the indicators used by these countries were similar to those recommended by WHO (see box 1). However, there are also major differences between the recommended indicators and country indicators, and between the indicators used in different countries. For example, countries use different denominators for

indicator 5: the number of identified HIV positive women (Uganda), the estimated number of HIV-infected pregnant women (Zambia), or the total number of HIV-infected women, which includes pregnant women newly tested for HIV in labour and delivery, and those with previously identified positive status (Malawi). The denominator for core indicator 7 is the estimated number of HIV-infected pregnant women giving birth (Zambia) and the total number of HIV-exposed infants identified (Malawi). Different definitions and data sources affect the comparability of data between countries.

Challenges of monitoring and evaluating HIV services for children

In addition to the difficulties in comparing data across countries, as discussed above, there are several key challenges for programmes in terms of monitoring and evaluating HIV services for children.

Data quality

Ensuring that data collected is in good quality is challenging, particularly for interventions related to PMTCT which involve several different services or departments and may depend on data from parallel M&E systems (e.g. HIV- care and treatment, PMTCT, maternal and child health, and family planning services). Longitudinal follow-up of HIV-exposed infants and their mothers is often patchy, as it depends on patient held records which are sometimes lost. Some data are collected passively and they are usually not as rigorously checked as actively collected data.

Ensuring that reports created from data provided by health workers and lower level managers are regularly fed back to these levels helps to motivate staff to provide good quality data. It will also enable them to make use of the data to improve their services. Parallel M&E systems should be integrated.

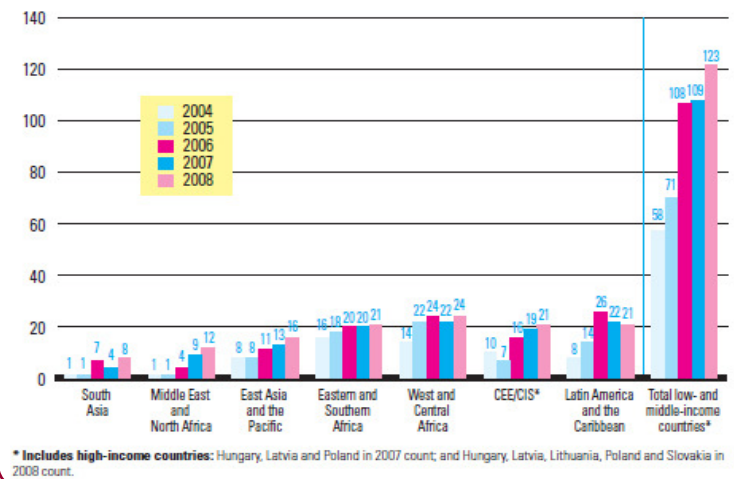
Little measurement of impact

There is very little use of M&E systems to measure health outcomes of interventions among children in routine M&E of national programmes. However, data on outcomes is important since it allows programmes to identify progress or areas for improvement, is useful for resource allocation decisions, and helps to justify expenditure on a particular programme. For example, there are hardly any data on the survival and retention of children on ART. It is also important that indicators are valid: that they measure what they purport to measure. Measurement of impact is of particular importance at a time when there are concerns about the availability of donor resources to maintain programmes including supply chains and availability of paediatric ARV formulations, due to the financial crisis.

Pressure on human resources

There are many demands on the time of health workers, whose main focus is service provision. Data collection is usually not of highest priority for front line staff. Therefore M&E systems should aim to collect data on fewer, but meaningful, indicators. There is a need for evaluating these indicators to determine their validity and how they relate to longer-term outcomes. Any changes to M&E systems should focus on selecting, prioritising and harmonising existing indicators and tools. The introduction of new indicators is only justifiable if indicators are meaningful to the

Figure 1. Number of low and middle-income countries reporting on key data on PMTCT and paediatric HIV care and treatment, 2004-2008 (Source: UNICEF 2009)



staff collecting and documenting the data and the meaningfulness clearly outweighs staff's additional efforts. If data on additional indicators are needed, sentinel sites could be used, rather than every facility, as an alternative.

Age-bands for data collection are too broad

Programme data is often collected in broad age-bands. Grouping data for children aged 0-14 years masks the differences in biological and social needs within this age group and different indicators may be important for different age groups. For example, 14 year olds will respond to interventions such as ART very differently to infants, complex diagnosis of HIV infection is limited to the first 12-18 months of life and M&E of health interventions in adolescents is hardly possible with existing age bands. Disaggregating data into smaller age-bands (e.g. 0-18 months; 18 months – 5 years; 5-10 years; 10-14 years; 14-18 years) may help programme managers to target interventions more effectively in some situations.

Recommendations for national policy makers and programme managers

- Feedback reports created from data provided by health workers and lower level managers to those who provided the data, to help encourage quality data, and use of the data to improve services
- Integrate parallel M&E systems
- Use active rather than passive data collection for a small number of key indicators to ensure quality
- Use sentinel sites to collect any additional data that is needed, such as data on outcomes and different age bands

Credits

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Recommended Readings

World Health Organisation, UNICEF (2008): Scale up of HIV-related prevention, diagnosis, care and treatment for infants and children: A programming framework. World Health Organisation, Geneva.

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Peersman G, Rugg D, Erkkola T, Kiwango

Recommendations for international policy makers

- Revisit the current recommended national indicators for monitoring and evaluation of PMTCT and paediatric HIV care and treatment, to include more focus on paediatric care of HIV-infected children after infancy
- Provide clear guidelines for the definitions of recommended indicators, and the numerators and denominators that should be used, to encourage harmonisation and comparability, but ensure country ownership
- Identify evidence-based indicators that are specific to different age groups

Recommendations for funders

- Use national M&E indicators rather than imposing additional or different indicators for programmes, as human resources for collecting M&E data are scarce
- Encourage more uptake of existing funds available for evaluation, particularly to measure outcomes of paediatric HIV services, and provide additional funds where there are gaps

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About Evidence for Action

Evidence for Action is an international research consortium with partners in India, Malawi, Uganda, UK and Zambia, examining issues surrounding HIV treatment and care systems.

The research is organised in four key themes:

1. What “package” of HIV treatment and care services should be provided in different settings?
2. What delivery systems should be used in different contexts?
3. How best should HIV treatment and care be integrated into existing health and social systems?
4. How can new knowledge related to the first three questions be rapidly translated into improved policy and programming?

Partners:

International HIV/AIDS Alliance, UK
Lighthouse Trust, Malawi

London School of Hygiene and Tropical Medicine, UK

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