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# Estimation of orphanhood due to AIDS and non-AIDS causes and the impact of intervention programmes

Report of a meeting of the UNAIDS Reference Group on Estimates, Modelling and Projections held in Baltimore, USA, July 12<sup>th</sup> 2007

## TECHNICAL REPORT AND RECOMMENDATIONS



Joint United Nations Programme on HIV/AIDS

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The meeting of the UNAIDS Reference Group on Estimates, Modelling and Projections (the 'Epidemiology Reference Group') was organised for UNAIDS by the UK secretariat of the Reference Group ([www.epidem.org](http://www.epidem.org)) based at Imperial College London. Participants of the meeting are listed at the end of this document. The recommendations in this document were arrived at through discussion and review by meeting participants and drafted at the meeting.

Dr Peter White, London, October 2007.

## Introduction

### *The Reference Group on Estimates, Modelling and Projections*

The Joint United Nations Programme on HIV/AIDS (UNAIDS) *Reference Group on Estimates, Modelling and Projections* exists to provide impartial scientific advice to UNAIDS, the World Health Organization (WHO) and other United Nations and partner organisations on global estimates and projections of the prevalence, incidence and impact of HIV/AIDS. The Reference Group acts as an 'open cohort' of epidemiologists, demographers, statisticians, and public health experts. It is able to provide timely advice and also address ongoing concerns through both *ad hoc* and regular meetings. The group is co-ordinated by a secretariat based in the Department of Infectious Disease Epidemiology, Imperial College London ([www.epidem.org](http://www.epidem.org)).

### *Aim of the meeting*

The aim of this meeting was to bring together experts to produce recommendations on the complex topic of estimation of orphanhood due to AIDS and non-AIDS causes and estimation of the impact of intervention programmes.

### *Approach*

The meeting featured both presentations of recent data and group discussions, which focused on specific technical issues. Presentations and discussion topics are listed in Appendix I.

The meeting was attended by 19 experts (see Appendix II for a list of participants). Each contributed, not only data, insights and analysis, but also worked hard to produce a set of recommendations, drafted at the meeting. We would like to thank them for their hard work and attendance at the meeting.

The recommendations drafted at Reference Group meetings give UNAIDS and WHO guidance on how best to produce estimates of HIV/AIDS, an opportunity to review current approaches and also help to identify information needs (earlier reports are published on the Reference Group website [www.epidem.org](http://www.epidem.org)). This transparent process aims to allow the statistics and reports published by UNAIDS and WHO to be informed by impartial, scientific peer review.

# **Estimation of orphanhood due to AIDS and non-AIDS causes and the impact of intervention programmes**

## ***1. Discrepancies between orphanhood measured in DHS/MICS and modelled by Spectrum using population projections using life tables, fertility assumptions***

A review of DHS data on number of orphans has found consistently that the reported number of maternal orphans is lower than the estimated number of maternal orphans estimated by UNAIDS (Spectrum). Spectrum projections of orphan estimates overestimate the number of maternal orphans across several countries in Sub-Saharan Africa, when compared with cross-sectional DHS surveys, by 30-100%, independent of the particular country's HIV prevalence. The overestimation of maternal orphans was consistent across age groups (0-4, 5-9 10-14), although more pronounced in the 0-4 year age group and occurred in all 22 countries in sub-Saharan Africa that had DHS data. This discrepancy was similar in size for countries with very low adult HIV prevalence rates (e.g., Senegal) and those with high prevalence (Zimbabwe) suggesting that the discrepancy is not due to the AIDS estimate. There is no corresponding discrepancy for paternal orphans.

Possible explanations for this discrepancy include incorrect assumptions regarding female mortality/fertility and child mortality in the Spectrum projections or inaccurate enumeration of female deaths and child births/deaths in the demographic surveys. DHS may under-estimate maternal orphans due to under-reporting, with adopted children being reported as the biological children of the adoptive parent.

## ***2. Estimations of AIDS orphans based on DHS surveys***

The Demographic and Health Survey program collects several pieces of information that can be used to estimate the number of orphans and the number of maternal AIDS orphans. From the household roster of members and over-night visitors, maternal, paternal, and double orphans are determined directly by asking the household respondent whether the parents of each child under 18 years of age are alive. This is the primary source of information on orphans, which can be classified by age, sex, relationship to head, type of area and region of residence, schooling, and level of wealth, as well as nutritional status. In high HIV prevalence countries, support given to households with orphans is asked.

A second source of information on orphanhood is given by the sibling history portion of the individual women's and men's interviews that is included in many DHS surveys. In the sibling history, for each sister who died at age 12 years or more, the number of children to whom she gave birth is asked. Given her age at death, estimates of survival probabilities can be applied to these births to estimate the number of surviving children (maternal orphans) of the dead mothers.

Based on DHS data for HIV status (in most sub-Saharan countries and some other countries), a third source of information on estimates of maternal orphans can be obtained from a model which estimates the fertility of mothers who died of AIDS and of the mortality of their children. For example, given the prevalence rate of Kenya, 193 maternal AIDS orphans are estimated per 10,000 women age 15 to 49 years.

## ***3. Tanzania in-depth site comparison of DHS versus demographic surveillance***

The results of the Tanzanian DSS survey were compared with DHS estimates in 3 sites with different socio-economic characteristics, finding close agreement.

However, since DSS sites are not nationally representative, their data cannot be used to generalise. AIDS and non-AIDS orphans cannot be distinguished in the DSS data. The problem of potential under-reporting of orphans by adoptive parents was recognised.

#### ***4. Discrepancies between UN models and DHS survey estimates: insights from analyses of Manicaland survey data***

Data collected in Manicaland, a province in eastern Zimbabwe, as part of an HIV prevention and monitoring project have been used to explore possible sources of bias in orphan estimates. Since these data are longitudinal, more-detailed information about the orphan status of each participant is available compared with the simpler, cross-sectional demographic surveys.

It was found that paternal orphan status was more likely than maternal orphan status to be missing or unknown from each round of the Manicaland surveys. However, over time greater inconsistency was found in reporting of maternal orphan status (30%) than paternal orphan status (15%), with some individuals being reported as orphans and then subsequently 'reverting' to non-orphan status – suggesting that cross-sectional surveys may under-estimate true numbers of orphans. These differences may explain some of the observed discrepancy between DHS estimates of maternal orphan prevalence and the UNAIDS projections. When more-detailed questions regarding parental survival status are used, the consistency of reporting increases over time for all types of orphans.

Decreases in fertility amongst HIV positive women are assumed in the UNAIDS projections but no adjustments are made for possible decreases in fertility amongst HIV negative, terminally ill women. Comparisons of prevalence of current pregnancy between those reporting serious ill health and those reporting good health or minor illness, amongst HIV negative women in Manicaland, revealed no statistically significant differences. However, further investigation is required to rule out the possibility that fertility is reduced amongst women suffering illnesses other than AIDS.

#### ***5. Effect of using different life tables, or other demographic parameters***

The estimated number of orphans depends to some extent on adult mortality levels but also on the levels of child mortality. Overestimating or underestimating either of these components will have an impact on the estimated number of orphans.

Changing the model life table, for example from CD-North to CD-South, has been found to have a substantial impact in reducing the adult mortality levels. Choosing the adequate model life table may help reduce the gap in the estimated number of orphans in some countries, as provided by different sources, but this may not be the appropriate or only solution in all countries where differences have been encountered. In countries highly affected by the HIV/AIDS epidemic, the calibration of other parameters may also contribute in reducing the gap in the number of orphans.

Further work needs to be done to examine the effect of sex-ratios in the models and to determine how much of the discrepancies are due to differences in estimates of non-AIDS deaths vs AIDS deaths.

## **6. Methods to estimate AIDS orphans outside of sub-Saharan Africa**

The methodology for estimating AIDS orphans in SSA assumes that the fertility of those dying from AIDS is similar all other adults, except for the fertility-inhibiting effect of HIV infection. In low-level and concentrated epidemics a large portion of AIDS deaths are among population groups that may have very different fertility from the rest of the population: IDU, MSM and sex workers. Estimates of AIDS orphans need to be adjusted for this difference. The adjustment may be based on rates of fertility, sexual activity or marriage.

Key questions are:

- How does past fertility of those dying from AIDS differ from the rest of the population?
- How does likelihood of double orphans differ from the rest of the population?
- To what extent are data available on fertility, sexual activity or marriage rates for key populations?
- Is an additional adjustment needed for double orphans?

## **7. Fertility in most-at-risk populations (MARPs)**

To estimate orphanhood due to AIDS in countries with concentrated epidemics, an important question is, do the MARPs have the same fertility as the “general population? Typically, it has been assumed that many MARPs have lower fertility rates, especially IDUs and MSM.

There are very few data, and marriage rates look like being the most useful and widely-available. Other useful data are the proportion of female sex workers who have children. However, there are many limitations, including many studies not controlling for age. (For MSM, there are often data on their numbers of female sexual partners, but these partnerships do not necessarily result in parenthood.) Data on fertility rates for clients of sex workers are often not available.

It was noted that in concentrated epidemics the relative frequencies of maternal and paternal orphans are likely to be different from generalised epidemics.

It was commented that condom use in Africa has been found to have no effect on fertility rates because condoms are used in sexual partnerships which are not intended to produce children.

## **8. Estimating the impact of adult ART on orphanhood**

With the advent of wider distribution of anti-retroviral therapy (ART), it is important to see what the impact of adult ART is on the numbers of orphans. Simplified methods were developed to try to estimate these impacts for the PEPFAR focus countries. Alternative estimates can be obtained using Spectrum by running scenarios with and without adult ART. Recent changes in the assumptions behind Spectrum also will have an impact on the estimates.

As ART provision increases, there will be a shift in the stage of infection of individuals commencing therapy, towards earlier stages. This will affect mortality rates and therefore life-years gained through ART.

Since ART increases rates of non-AIDS orphanhood - by delaying parents' death due to AIDS, so exposing them to greater cumulative risk of death due to a non-AIDS cause – it was recommended that *total* rates of orphanhood should be estimated and ART's impact on those total rates examined.

It was noted that PMTCT programmes increase AIDS orphans by averting juvenile mortality due to HIV, resulting in children out-living their HIV-infected mothers.

Since orphanhood is delayed rather than averted unless it is delayed until after the child has reached adulthood, providing estimates of both prevalent numbers of orphans and years of orphanhood averted was recommended.

## **9. Recommendations**

### Reconciling DHS and model estimates

- Examine effects of non-AIDS mortality updates in Spectrum 2007 vs DHS/MICS: do discrepancies persist?
- Compare DHS household summary estimates of orphanhood with estimates of orphanhood derived from sibling history.
- Compare Male/Female adult HIV prevalence, mortality and fertility from DHS vs Spectrum.
- Examine numbers of children ever born for males and females at their average age of AIDS death.
- Examine if survival of HIV+ women is longer than currently assumed.
- Are there urban/rural differences in fertility apparent in DHS data?
- Examine age-gaps in monogamous, long-term relationships in DHS.
- Repeat regression analysis of dual AIDS orphanhood.
- Perform more-detailed analysis of longitudinal data on orphanhood from the Manicaland study. Specifically, more sensitivity and specificity analyses, and how often is child's mother a foster parent?
- Examine mortality of orphans.
- Compare DHS and DSS data.

### Adjusting for fertility in concentrated epidemics

- Finalise review and summary of fertility among MARPS.
- Patterns of marriage may need to be used to estimate fertility of MARPs, and should be validated where possible.
- Comparison needs to be made between numbers of children born & surviving for adults in MARPs and for the general population as sampled in population-based surveys.
- To estimate the numbers of AIDS orphans in Spectrum, add the facility to increase specification of factors (e.g. proportion of different MARPS constituting the epidemic; and fertility of these groups in the country), perhaps only supplying an output if factors are specified or defaults actively selected.
- Examine at what level adjustments need to be made. Should they be generic (region-specific), rather than country-specific, due to data limitations? Where data are available, country-specific patterns should be examined (e.g. younger age of East European & Chinese IDU, although these differences would not be an issue if age-structured data are used).

### Methods for estimating orphanhood averted by ART

- Two measures are recommended: (i) Difference in prevalence of orphans (due to AIDS and non-AIDS causes combined, since ART increases rates of non-AIDS orphanhood), and (ii) Years of orphanhood averted (i.e. 'orphan-free years gained', the extra years lived as not an orphan over a period).
- An additional measure (if agencies would find it useful) could be numbers of children who would have become orphans but did not because they reached 18 years of age before their parent(s) died.
- Calculation is to be done in Spectrum by comparing runs with and without ART.
- Future work should examine the effects of (i) PMTCT & ART/Ctx in children (which increases orphanhood by averting the child's dying before the mother) and (ii) adult ART (increasing fertility).

# Appendix I: Meeting Agenda

## Thursday July 12th: Estimation of orphanhood and of orphanhood due to AIDS

Start	Duration	Subject	Speaker
900	25	Opening remarks	Peter Ghys
<b>Session 1 - Estimation of orphanhood due to AIDS and non-AIDS causes. Chair: Geoff Garnett</b>			
925	30	Discrepancies between orphanhood measured in DHS/MICS and modelled by Spectrum using population projections using life tables, fertility assumptions	Roeland Monash / Neff Walker
955	35	Tanzania in-depth site comparison of DHS versus demographic surveillance	Robert Mswia
1030	15	<i>Coffee break</i>	-
1045	20	Discrepancies between UN models and DHS survey estimates: insights from analyses of Manicaland survey data	Laura Robertson
1105	45	Estimations of AIDS Orphans based on DHS Surveys	Shea Rutstein
1150	20	Effect of using different life tables, or other demographic parameters	Francois Pelletier / Neff Walker
1210	35	Discussion	-
1245	75	<i>Lunch</i>	-
1400	15	Methods to Estimate AIDS Orphans Outside of Sub-Saharan Africa	John Stover
1415	25	Fertility in high risk groups	Neff Walker
1440	15	Potential methods to estimate reductions in HIV mortality and orphanhood due to ART	Ray Shirashi
1455	30	Estimates of the Impact of Adult ART on Orphanhood	Peter Johnson / Michelle Sherlock
1525	20	Discussion	-
1545	15	<i>Coffee break</i>	-
<b>Discussions. Chair: Neff Walker</b>			
1600	90	Discussion	-
1730	-	Close	-

## Appendix II: List of Participants

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