

# GUIDELINE ON HIV DISCLOSURE COUNSELLING FOR CHILDREN UP TO 12 YEARS OF AGE



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## SUMMARY DECLARATIONS OF INTEREST

All members of the Guideline Group were asked to complete a WHO declaration of interest form. Six people declared potential conflicts of interest:

Abbie Jung worked for an organization with interest in the area of the outcomes of the meeting (Médecins sans Frontières from 2006-2008). Winnie Kalyesubulya declared that the outcomes from the meeting would benefit the interests of people with whom she has substantial common personal, financial or professional interest. Fabienne Hejoaka declared that she has been paid for consulting work and has received support (grants and in non-monetary support) for research related to the outcomes of the meeting, from the Bernard van Leer Foundation. Paul Montgomery declared that he has received support from the John Fell Fund, University of Oxford, for research related to the outcomes of this meeting. Nathan Tumwesigye declared that he works for the African Network for Care of Children Affected by HIV/AIDS (ANECCA) that provides HIV care to children and disclosure is part of the package of care provided. Rachel Baggaley-Faussett declared that the organization she worked for, Christian AID, received support for research in work on orphans and vulnerable children.

The Steering Group did not consider any of these declarations to be reason for a Guideline Group member to recuse themselves. Thus, all participants were involved in development of the guidelines.

Declarations of interest forms also were collected from the non-WHO peer reviewers. No peer reviewer declared a potential conflict of interest.

This report and associated appendices and other materials appear on the World Health Organization web site at <http://www.who.int/hiv/topics/vct/en/index.html>



## ABBREVIATIONS AND ACRONYMS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>AFRO</b>	Africa Regional Office
<b>ANNECCA</b>	African Network for Care of Children Affected by HIV/AIDS
<b>ART</b>	Antiretroviral therapy
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CDI</b>	Children's Depression Inventory
<b>CBCL</b>	Child Behavioural Checklist
<b>CHELSEA</b>	Children, health, education, ladies, senior citizens, environment, awareness
<b>CHW</b>	Community health workers
<b>CI</b>	Confidence interval
<b>GFATM</b>	Global Fund to fight HIV/AIDS, Tuberculosis, and Malaria
<b>GRADE</b>	Grading of Recommendations Assessment, Development and Evaluation
<b>GRC</b>	Guidelines Review Committee
<b>HCW</b>	Health care worker
<b>HIV</b>	Human Immunodeficiency Virus
<b>HTC</b>	HIV testing and counselling
<b>IAS</b>	International AIDS Society
<b>M&amp;E</b>	Monitoring and evaluation
<b>NSA</b>	National Strategy Application
<b>NGO</b>	Non-governmental organization
<b>PEPFAR</b>	U.S. President's Emergency Plan for AIDS Relief
<b>PICO</b>	Problem / Intervention / Comparison / Outcome
<b>PMTCT</b>	Prevention of mother-to-child transmission of HIV
<b>RR</b>	Relative risk
<b>RO</b>	Regional Office
<b>SARA</b>	Sustainable AntiRetroviral Access Program
<b>UN</b>	United Nations
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNICEF</b>	United Nations Children's Fund
<b>USAID</b>	U.S. Agency for International Development
<b>WAG</b>	Women's Action Group
<b>WHO</b>	World Health Organization

# EXECUTIVE SUMMARY

## Purpose of the guideline

The World Health Organization (WHO) has developed guidance for health care workers on how to support children up to 12 years of age and their caregivers with disclosure of HIV status. Health care workers (HCWs) know that disclosure decisions are complex because of stigma, social support concerns, family relations, parenting skills and concern about children's emotional and maturational ability to understand and cope with the nature of the illness. HCWs challenged by the complicated issues facing HIV-affected families are often without the support of definitive, evidence-based policies and guidelines on when, how, and under what conditions children should be informed about their own or their caregivers' HIV status. Consequently, many health care workers around the world are uncertain how to counsel clients about the disclosure process. Thus, they may often miss opportunities to assist parents in dealing with these issues and explaining to parents the need for HIV testing and counselling for all their children. The lack of disclosure ultimately adversely affects the well-being of the child, including access to paediatric HIV treatment and care and adherence to treatment.

Health care workers are often without the support of definitive, evidence-based policies and guidelines on when, how, and under what conditions children should be informed about their own or their caregivers' HIV status.

This guidance is intended as part of a comprehensive approach to ensuring child well-being—that is, the physical, emotional, cognitive and social well-being of the developing child—following the child's own diagnoses of HIV or that of a parent or close caregiver. Disclosure is crucial to the continuum of HIV care.

## Key findings

A comprehensive review of the literature, undertaken to find evidence to support recommendations, reached the following conclusions:

### *Disclosure to children of their own HIV status*

- There is evidence of health benefit (e.g. reduced risk of death) and little evidence of psychological or emotional harm from disclosure of HIV status to HIV-positive children. Immediate emotional reactions dissipate with time and respond to programme interventions.
- Disclosure of diagnosis, as described by published researchers and by practitioners, is not an isolated event but rather a step in the process of adjustment by the child, caregivers, and the community to an illness and the life challenges that it poses.

### *Disclosure to children of their parent's or caregivers' HIV status*

- There is evidence of benefit to health for HIV-positive and HIV-negative children of HIV-positive caregivers if the caregiver discloses to them.
- The concerns of some caregivers that disclosure leads to increased behavioural problems in children and decreases the quality of the relationship are not supported by children's reports about their reactions to disclosure of their caregivers' HIV status. Even by parents' reports, anticipating and preparing for the understandable initial emotional reactions can improve the child's responses, and responses improve with time.

- There appears to be no harm to caregivers when they disclose their status to their children or wards.

### Special considerations

- Since many of the potential benefits of disclosure are health benefits, e.g. increased adherence to treatment, efforts to increase the availability and accessibility of treatment should accompany disclosure initiatives.
- Stigma is a major barrier to disclosure of HIV status to children. Caregivers fear that children will face stigma. This fear often delays their decisions to disclose. In preparing for full disclosure, parents/caregivers and health workers need to help children manage the stigma of being infected or affected by HIV. Also, the scale-up of antiretroviral therapy (ART) will oblige health systems to take a more systematic and practical approach to addressing stigma. Reducing stigma should make disclosure easier and thus increase the uptake of treatment, adherence to medication, and coping with HIV-related symptoms and the side effects of treatment. (See box, "Why the concern about stigma?" p. 35.)
- There is evidence that, in the absence of adequate support and community tolerance, public or inadvertent disclosure may adversely affect the well-being of children in HIV-affected families. Creating school and community environments where discrimination is unlikely is an important adjunct to the disclosure process. Initiatives to protect privacy and to institute policy, laws, and norms preventing discrimination and promoting tolerance and support will help create environments where disclosure is less problematic.
- Attention is needed to the benefits of marshalling multiple sources of support, both personal (e.g. children's friends, caregivers' peers) and institutional (e.g. schools), for disclosure and the challenges that follow. This is especially the case because disclosure can take place over a period of time, in the course of several different conversations, in different settings with different people, and in response to new events (e.g. death of a family member).
- Children often express concern for, and wish to support, their HIV-positive caregiver. Children need truthful information, appropriate to the child's understanding, as to how the parent/caregiver is feeling and to have their fears and concerns addressed.
- How disclosure takes place may vary from culture to culture and from place to place, depending on available resources and caregivers' desires and concerns. The elements of an intervention described in this report can provide guidance to health care workers on how to support a disclosure process that does the least harm and promotes well-being (1,2). It can be adapted to different geographic areas and resource environments. Adaptation is important because HIV-positive children are coping not only with HIV but also with multiple circumstances that affect their development, particularly in areas highly affected by HIV, and should receive support to come to terms with living with HIV.

Efforts to increase the availability and accessibility of treatment should accompany disclosure initiatives.

## Key Recommendations

1. Children of school age<sup>1</sup> should be told their HIV positive status; younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure.

*Strong recommendation, low quality of evidence*

2. Children of school age should be told the HIV status of their parents or caregivers; younger children should be told this incrementally to accommodate their cognitive skills and emotional maturity.

*Conditional recommendation, low quality of evidence*

3. The decision on who will disclose to the child should be guided by the intent to improve/promote the child's welfare and minimize the risk to his or her well-being and to the quality of the relationship between child and parent/caregiver.

*Conditional recommendation, absent evidence*

4. Initiatives should be put in place to enforce privacy protection and institute policy, laws and norms that prevent discrimination and promote tolerance and acceptance of people living with HIV. This can help create environments where disclosure of HIV status is easier.

*Strong recommendation, low quality of evidence*

## Topics for further research

Members of the Guideline Group discussed several issues in need of additional research:

- Who can best convey a child's HIV status to the child? For example, outcomes can be compared among disclosure by a parent/caregiver, by a health care worker or by a parent/health care worker team. Do HIV-positive caregivers perceive more distress in their children than the children themselves say that they experience? Which better predicts health behaviour and child and family adjustment following disclosure—the caregiver's perceptions or the child's report?
- Does rehearsal of HIV-related discussions and social disclosure<sup>2</sup>, compared with no social disclosure, result in better outcomes of disclosing a child's or parent/caregiver's HIV-positive status to the child?
- By what criteria can parents and children identify safe or trusted persons who can assist with preparing for disclosure and talking about HIV-related issues?
- In specific cultural and economic contexts, what are specific practices that may provide resources or else create challenges to HIV-infected children and their parents/caregivers? What types of support does a child need after disclosure?

<sup>1</sup> In this document, school-age children are defined as those with the cognitive skills and emotional maturity of a normally developing child of 6-12 years.

<sup>2</sup> "Social disclosure" means disclosure beyond the immediate family to a larger circle of family, friends and others in social networks.

Guideline Group members also urged further research to: (1) determine the impact of full disclosure on a child's mental health; (2) determine the impact of full disclosure on the child-parent/caregiver relationship; and (3) outline a process for assessing health care workers' competence and confidence in assisting parents/caregivers with disclosure.

## **Conclusion**

Article 17 of the United Nations *Convention on the Rights of the Child* (3) states that every child should have “access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health”. While the published evidence, as assessed by the GRADE process, is of low quality, the programmatic experiences of the Guideline Group members and the external peer reviewers strongly support the recommendations that were developed, which endorse disclosure to children as vital to their well-being and health.

The availability and roll-out of treatment for adults and children highlights the need to address disclosure, which supports uptake of, and adherence to, treatment. At the same time, the availability of treatment affects messages about the future health of the child and/or the parent/caregiver since, where treatment is available, an HIV-positive diagnosis is no longer inevitably associated with poor outcomes.

The concept of disclosure covers a wide range of behaviours. There is a need to identify necessary steps in the process of disclosure—especially, naming the infection and providing support with managing stigma.

# 1. INTRODUCTION

Despite great progress in expanding access to antiretroviral therapy (ART) in recent years, progress in paediatric HIV counselling and testing—the gateway to such treatment—has lagged. As of 2009 an estimated 2 500 000 children under four years of age were living with HIV. Of these, the great majority—2 300 000—live in sub-Saharan Africa (4). Of the estimated 1 276 000 children under 15 years of age in need of ART, just 356 400, or about 28%, are on treatment (5), while 37% of eligible adults are on treatment (4).

Limited documentation of the experience of counselling services for children, particularly in settings of limited resources, makes it difficult for health care workers (HCWs) to meet the needs of children and their parents or caregivers. Therefore, the World Health Organization (WHO) has collaborated with its partners to develop recommendations on counselling children and their caregivers on HIV disclosure and HIV status. This guidance on disclosure, presented here, is intended to contribute to a comprehensive approach to ensuring child well-being (that is, the physical, emotional, cognitive and social well-being of the developing child) following their own diagnoses of HIV or that of a parent or close caregiver. This report also summarizes the available relevant evidence and its quality.

## 1.1 Objectives

The recommendations in this document complement related guidelines published by WHO, including the *WHO recommendations on the diagnosis of HIV infection in infants and children* (6) and *Antiretroviral therapy for HIV infection in infants and children: Towards universal access. Recommendations for a public health approach: 2010 revision* (7), as well as the WHO/UNAIDS *Guidance on provider-initiated HIV testing and counselling in health facilities* (8).

The objectives of the guideline development process were to review the evidence and then determine what recommendations could be developed to:

- Provide age-appropriate counselling for children
- Recommend who should disclose to children and how best to do this
- Extract useful counselling advice for a child's parents or caregivers
- Identify relevant costs related to health care workers' support to parents/caregivers with disclosure of HIV-positive status to a child.
- Propose ways to build capacity for the implementation of this intervention.

## 1.2 Target audiences and scope of the guidelines

This document is intended for health workers and programme managers involved in paediatric HIV counselling, testing, treatment and care services at health facility and community levels. The recommendations focus on counselling for disclosure to children who are 12 years of age or less of HIV status—their own or their parent/caregiver's. While all involved in development of the guideline agreed that HIV counselling for adolescents needs equal attention, 12 years was chosen as the upper age limit to ensure that young children would receive sufficient attention. In this document school-age children are defined as children aged 6–12 years rather than 6–11 years, as is common in published studies.

## 1.3 Background

Worldwide, AIDS is estimated to be the eighth leading cause of death among adolescents ages 15–19 and the sixth leading cause of death among those ages 10 to 14. In countries with high HIV prevalence, however, AIDS takes a relatively greater toll (9). Children with HIV disease have been called “the missing face of AIDS” because, more often than adults, they lack basic health care and they have been “missing from global and national policy discussions” (10).

Recent research documents the complex psycho-social issues related to disclosure of a child's or caregiver's HIV status. Research on disclosure of HIV status, including to whom and under what conditions, has been called “a vital part of research on families and HIV/AIDS” (11) because of the need to design evidence-based family interventions that guide caregivers on whether, how, and when to disclose (12). With the increase in access to ART, several social and behavioural science researchers now define HIV as a chronic disease with multiple effects on families (12,13,14,15). Research on disclosure to children will increasingly take place in this context.

An extensive review of the literature, including literature on the effects of disclosure, was conducted to support the development of guidance on HIV disclosure “best practices”. Until recently, most research on HIV disclosure to children (of the child's or the parent/caregiver's HIV status) focused on the correlates of disclosure, patterns of disclosure (16), the differences between disclosers and non-disclosers, the experiences of parents or caregivers with HIV, their decisions whether or not to disclose and their reasons for these decisions, the child's perceived reaction (17), and children's internalizing and externalizing behaviours post-disclosure. In the clinical sphere research has investigated the knowledge and attitudes of HCWs and the effects of disclosure/non-disclosure on children's treatment adherence (18,19). Most of this research has explored the predictors of mothers' disclosure practices and intentions. To date, the findings have been mixed, providing caregivers and HCWs with inconsistent guidance. While studies have looked at the rationales for and predictors of disclosure, what is disclosed and the effects of disclosure, beyond recognizing its challenges, is little understood.

Studies point to the contextual challenges facing caregivers as they grapple with the complicated decision of disclosure to children. For example, disclosure of HIV often amounts to a disclosure of stigmatized behaviours associated with transmission routes. Parents/caregivers' feelings of shame and their fear of inadvertent disclosure and stigma tend to discourage them from revealing their own or their children's HIV status (20). Concealing HIV status, however, may lead to or exacerbate depression, worry and other negative mental health outcomes, potentially interfering with treatment and affecting family life, including parenting ability and the child's social and academic life, e.g. school performance (21,22,23,24).

Concealing HIV status may lead to or exacerbate depression, worry and other negative mental health outcomes, potentially interfering with treatment and affecting family life.

For HIV-positive parents and caregivers, decisions about disclosure to children can complicate a challenging family situation further (25). They must take on the added responsibility for their children's illness management, including medication initiation and adherence, and coping with HIV-related symptoms and treatment side effects—responsibilities that often increase parental stress (16). They may need to plan for the future care of their children in the midst of family or community rejection.

Disclosure leads to extended discussions as the implications of having HIV in the family unfold. Such discussions do not occur as a discreet, one-time event, but instead they occur over time. Children have questions and worry about what will happen to them in the course of their own disease; for both HIV-positive and well children, what will happen to them if their caregiver is ill or dies; who will take care of them; how HIV is transmitted; and other concerns. They may be confronted by stigma, discrimination or bereavement. Thus, disclosure is a process of many conversations over time and may call for information, reassurance and planning. The act of disclosure includes a number of specific steps of explanation, including naming the condition.

Indeed, HCWs know that disclosure decisions are complex because of HIV-related stigma, mental health and social support concerns, family functioning including parenting and communication skills, and worry about children's emotional and maturational ability to cope with and understand the nature of the illness. HCWs challenged by the complicated issues facing HIV-affected families lack the support of definitive, evidence-based policies and guidelines on when, how, and under what conditions children should be informed about their caregiver's or their own HIV-positive status. Thus, they may be uncertain how to counsel clients about the disclosure process, and they miss opportunities to assist parents with these issues, including convincing parents of the need for HIV counselling and testing of all of their children. Ultimately, these missed opportunities adversely affect the child's well-being, including access to paediatric HIV care. Delay in initiation of the process of disclosure increases the difficulty of eventual disclosure. Additional evidence for guidelines on paediatric HIV disclosure counselling could significantly improve health care for children and their caregivers who are living with HIV disease worldwide.



## 2 METHOD

### 2.1 Identification of need

In August 2008 content analysis of published and draft WHO documents promoting access to HIV care for infants, children and adolescents identified the need for evidence-based guidelines for paediatric HIV counselling (26). Following the WHO Guideline Review Committee process, a steering group convened in September 2008 to discuss possible literature review questions and propose the membership of the Guideline Group, an international panel of people with knowledge and expertise in working with children infected and affected by HIV, that would formulate recommendations. A consultant to WHO (H. Schünemann), expert on the training for and application of the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) process, provided input early on. Following the development of a preliminary report on the evidence found and evaluated, the Guideline Group met in June 2009 under the guidance of its Chair, Prof. Lorraine Sherr, the Group further defined the scope of the guidelines and called for reviews and analyses to support recommendations (27,28).

The Guideline Group agreed that guidance for disclosure to children ages 12 and under constituted an unmet need and that disclosure to adolescents over 12 years required further and separate attention. Participants discussed the guideline development process at length, especially the quality of the evidence presented to inform this process. There was general acknowledgement of the low quality of evidence presented, according to GRADE assessment, and Group members expressed concerns about gaps in the quantity and scope of the literature accessed, specifically that it did not include some sources of information such as anthropological data and grey literature.

In addition, there were many questions about the applicability of GRADE in the psychological and social fields, specifically because these data are not easily categorized into dichotomous groupings (e.g. in ethnographic studies). As these studies are seldom randomized, controlled trials, the GRADE methodology rates evidence from studies in these fields as low or very low quality.

### Steps in developing WHO recommendations and on HIV disclosure counselling

1	Scoping of current and draft WHO guidelines and tools on HIV prevention, treatment and care for infants, children and adolescents	August 2008
2	Development of PICOT <sup>3</sup> questions for review of evidence	November 2008
3	WHO Guidelines Review Committee (GRC) approval of proposed process	December 2008
4	Selection of the Guideline Group	January-March 2009
5	Retrieval of evidence, evaluation and synthesis of systematic review, preparation of GRADE profiles and summaries of evidence	January 2009
6	Consultation meeting of the Guideline Group to formulate draft recommendations	June 2009
7	GRC secretariat recommendation to expand the search for studies conducted in resource-limited settings	June 2009
8	Further systematic literature review and preparation of GRADE profiles to include additional searches of grey literature	March-December 2010
9	Review by Guideline Group, peer review of recommendations and principles	March-April 2011
10	Final GRC approval of summary of evidence	September 2011
11	Publication and dissemination	November 2011

In the ensuing discussions between the GRC Secretariat and the Guideline Group, there was a reiteration of the fact that quality of evidence is only one of four considerations used to determine the strength of recommendations. The other three considerations—benefit/risk balance, values and preferences, and costs—allow upgrading the strength of recommendations when the evidence is weak. Participants noted that the additional evidence from published and unpublished studies and programme reports presented at the consultation meeting on the work of Guideline Group members confirmed the findings of the systematic review.

On request of the Guidelines Review Committee secretariat, the search for literature was expanded to find additional studies conducted in resource-limited settings. Given their experience in the field, many of the participants did not believe there would be much additional evidence found. There was eventual agreement, however, that the additional search could be useful to the development of guidelines and could inform the design of appropriate health services.

<sup>3</sup> PICOT = Population, Intervention, Comparison, Outcome, Time—the elements of a well-constructed research question designed to define the search for evidence.

## 2.2 PICOT questions emerging from initial steps and reviews

### *Question 1: Full disclosure versus non-disclosure*

- 1.1 Do HIV-positive children 12 years and under **whose HIV status** is disclosed to them display equal or greater well-being than those children who are not disclosed to?
- 1.2 Do children 12 years and under who get the **HIV-positive status of their parent/caregiver** disclosed to them display equal or greater well-being than those children who are not disclosed to?

### *Question 2: Disclosure by the caregiver versus by other persons*

- 2.1 Do HIV-positive children 12 years and under **whose HIV status** is first disclosed to them by their parent/caregiver display equal or greater well-being than those children disclosed to by others (e.g. a health care worker [HCW], a parent-HCW team, another family member, or inadvertent or public disclosure)?
- 2.2 Do children 12 years and under **whose caregivers' HIV status** is first disclosed to them by the caregiver display equal or greater well-being than those children disclosed to by others (e.g. a health care worker [HCW], a parent-HCW team, another caregiver, another family member, or inadvertent or public disclosure)?

### *Question 3: Identifying a safe person with whom the child or caregiver can freely discuss HIV-related issues*

- 3.1 Is there benefit for **HIV-positive children** 12 years and under when they or their caregivers have identified “safe” persons with whom the child can discuss, or the caregiver can practice discussing, disclosure and unfolding HIV-related issues compared with HIV-positive children 12 and under who have no identified “safe” persons?
- 3.2 Is there benefit for children 12 years and under from families with **an HIV-positive caregiver** when they or their caregivers have identified “safe” persons with whom to discuss or to practice discussing disclosure and unfolding HIV-related issues compared with children 12 and under from families with an HIV-positive caregiver who have no identified “safe” persons?

### *Question 4: Assistance from HCWs specially trained in disclosure to children versus assistance from HCWs with standard training*

- 4.1 Is there benefit to **HIV-positive children** 12 years and under when discussions with caregivers about HIV-related issues and disclosure of the child's HIV status are initiated or assisted by an HCW who has received enhanced training on disclosure to children versus discussion initiated or assisted by a HCW with standard training?
- 4.2 Is there benefit to children 12 years and under when discussions with caregivers about HIV-related issues and disclosure of the **parent's or caregiver's HIV status** are initiated by an HCW who has received enhanced training on disclosure to children versus discussion initiated by a HCW with standard training?

In the report of findings and the recommendations that follow, Questions 1 and 4 take special account of developmental and contextual/cultural issues. Findings and recommendations for Questions 2 and 3 take special account of the issues that unfold before and after disclosure (e.g. the caregiver's HIV knowledge, the child's curiosity about medications, immediate and longer-term emotional reactions, plans for family care during the caregiver's illness or after death, what to tell others about the child's or caregiver's illness, preparation for adolescence, and potential HIV transmission risk). Both the scope and the draft PICOT questions led to the literature review and analyses that follow.

### 2.3 Literature review

**Purpose.** The literature review serves two purposes: (1) locating empirical literature that examines the outcomes of disclosure of (a) the child's own HIV-positive status to children 12 and under and (b) a caregiver's HIV-positive status to children 12 and under (generally referred to in this report as outcome studies); and (2) outlining issues and observations obtained through clinical, policy, and small qualitative studies and through review articles (generally referred to in this report as *background literature*).

**Scope of the review.** Published articles and peer-reviewed abstracts were searched. Documents that included, but were not exclusively about, children 12 and under were retained (articles that included children 10–18, for example). Book chapters, letters, and dissertations were not included. The literature search built upon the previous literature review and extended the search window by a year to June 30, 2010. Because HIV is a serious chronic illness, classic articles about disclosure of other chronic illness conditions or about children's understanding of illness at different ages were included.

**Procedure.** All staff members were oriented to issues in HIV disclosure through review articles and chapters, to literature review procedures under the direction of a health librarian, and to qualitative research synthesis and quantitative meta-analysis through readings and on-line trainings. Under the direction of a health librarian, the search terms and databases previously developed were both replicated and extended. The extension consisted of identifying the 10 articles judged by senior staff to be most relevant to the topic of disclosure to children 12 and under and then adding any key words associated with those articles that were not previously used into an additional search.

Two research assistants independently carried out the literature review. After removing duplicates and obviously irrelevant publications, the assistants, with the help of senior staff, triaged publications into three categories: (1) *outside the scope*, (2) *included background articles*, and (3) *possible studies of outcomes*.<sup>4</sup>

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4 Appendix A summarizes the search strategy. Appendices to this report will be found online at <http://www.who.int/hiv/topics/vct/en/index.html>

**Literature identified.** Two hundred fifty-five articles were identified. Fifty-four of these were classified as *outside the scope* because of passing or no mention of disclosure, no youth 12 or under, or lack of clarity in content or design (e.g. unclear as to whose status is being disclosed)

One hundred forty articles were initially considered *background*, with seven of these providing reflections on what respondents felt were the ideal circumstances for disclosure. Excluded empirical outcome studies (N=32, see below) were retained since many contributed background.

Finally, 61 articles provided empirical data, potentially focused on *outcomes relevant to health and well-being*. Senior staff independently read and made decisions about inclusion of these articles, with disagreements resolved by discussion or consultation with content or methods experts.

*Included empirical outcome studies.* Twenty-nine studies were retained for analysis; 15 focused on outcomes of disclosure of the child's HIV status and 15 on outcomes for disclosure of the caregiver's HIV status (one study reported on both child and caregiver status disclosure). Many empirical articles concentrated on predictors of disclosure rather than outcomes. Outcome studies have special importance, because the first question to answer in developing guidelines on disclosure to children is whether disclosure does harm or creates benefit. Also, because children change emotionally, behaviourally and cognitively as they mature, longitudinal studies and studies that control for age have special importance.

Child age, disclosure—the focus of our inquiry—and outcomes are sometimes intertwined. The older children are, the more likely they are to have been disclosed to; the more likely they are to develop emotional or behavioural problems and, if not on treatment, to have developed neurocognitive delays; for perinatally infected children, the older they are, the more likely that their own HIV disease has progressed or else responded to new treatments, and the more likely that they are to have experienced the illness or death due to HIV of someone close; likewise, the more time that has passed, the more likely that a caregiver's HIV has progressed or the more effective that treatment has become.

Because HIV or its treatment may have some neurocognitive effects, mental health outcomes that are responsive to life events (e.g. anger, sadness) were chosen over mental health outcomes that are likely more biologically based (e.g. psychiatric hospitalization). Finally, throughout the developmental literature it has been noted that caregivers' and children's reports about children's feelings and distress can diverge (29,30). Several studies suggest that parents who are distressed see more distress in their children (31,32). Thus, children's self-reports about feelings or distress may be more immediate than caregivers' reports. While some authors cited here routinely combine sources of information (25), most are limited to only child or only caregiver self-reports on symptomatology. Where children's feelings are concerned, inter-rater reliability between sources is often low. The better measures ask about specific feeling states and well-described symptoms.

*Excluded empirical outcome studies.* Studies that were not analysed concentrated on predictors of disclosure as opposed to outcomes; were among a series of articles about the same data set (the data that were more recent, reported on a larger sample size, or more clearly focused on disclosure were chosen for analysis); or failed to differentiate between those disclosed to and those not. Studies that had insufficient power to detect what existent literature would characterize as a likely change in outcome (e.g. from 50% to 90% adherence)—that is, studies that had sample sizes insufficient to detect a stable effect—also were excluded from analysis.

Citations for all 255 studies are available on the WHO HIV department web site at <http://www.who.int/hiv/topics/vct/en/index.html>, each with indication of the category to which it was assigned and a brief description highlighting the rationale or rationales for inclusion or exclusion.

## 2.4 Analysis

Complete copies of the 140 background studies and 61 empirical studies were obtained.

**Background literature.** Literature was classified as addressing disclosure of caregivers' HIV status or children's HIV status or both. A brief overview of approach and major themes was prepared by one senior investigator and confirmed by the second. Summaries of literature referenced in this report refer back to the complete text.

**Outcome studies.** Analysis proceeded according to methods endorsed by the Cochrane group (33) and utilized their software, Review Manager 5 and GRADEpro 3.6.

Population. Studies included hospital/clinic-attending caregivers or children, children in communities with high prevalence of HIV, and children from infancy through adulthood (with samples always including children 0–12 years) from 24 countries and territories worldwide.

Intervention. The intervention was naturally occurring *full* disclosure (that there was a serious illness and it was HIV) documented by interview. The contrasting condition thus was partial (e.g. that there is an illness) or absent disclosure. In one case (34) a standardized disclosure support intervention was piloted; it was given to all eligible families attending a clinic.

Comparisons. The Summary of Findings tables in the appendices report on unique comparisons.

For children's HIV status the comparisons were between (1) outcomes for HIV-positive children who were disclosed to and those who were not; and (2) outcomes for HIV-positive children before and after disclosure. Wherever possible, outcomes are reported in terms of relative risk—that is, was an outcome more or less likely in the group that had been disclosed to than in the group that had not been disclosed to? In the remaining cases mean differences in measures are reported. In the interpretation of mean differences, it is important to note not only statistical significance but also the nature of the scale for which the mean difference is calculated. A 1-point difference, for example, means something quite different when a scale has only five points than when the scale has a range of 0 to 100 points.

Additional tables and figures<sup>5</sup> synthesize children's reports of immediate and longer term reactions to disclosure. Change over time—because such reports are not independent of one another (the same person may be reporting on two different occasions)—require special handling statistically. Where these procedures are not used in the original article, illustrative tables of percentages, rather than Summary of Findings Tables, are presented. Similarly, complex analyses with many covariates and interaction terms are difficult to summarize across studies. Here, too, illustrative additional tables were used.

For caregivers' HIV status the comparisons were between children's and some caregivers' outcomes for (1) caregivers who disclosed and those who did not and (2) pre- to post-disclosure. Additionally, comparative data were available for (3) children identified in the community as HIV-affected compared with those who were not—what may be termed inadvertent, public or presumptive disclosure. Additional tables for caregivers' HIV disclosure/source of disclosure describe the prevalence and degree of immediate and long-term reactions to disclosure.

Outcomes. The outcome variables included health (e.g. death rates, adherence to treatment, HIV testing of children, self-assessment of life quality), standardized and brief self-reports of mental health (e.g. depression) or emotion (e.g. sadness) and, in some cases, assessment of social reactions (e.g. bullying, perceived social support).

Grading the quality of evidence. The highest quality of evidence in the GRADE system is assigned to randomized, controlled clinical trials. Because disclosure in the 29 graded studies was always a naturally occurring event (no one was randomized to be told or not told about HIV status), the studies were classified as observational. The highest grade usually assigned to observational studies is “moderate”. Only in two instances, both with extensive longitudinal follow-up, stable results, and statistical controls for common covariates, was the quality of the evidence rated as high.

## **2.5 Consensus, external review and updating**

The GRADE evidence assessment process was applied to the studies on all of the PICOT questions. It was not always possible, however, to develop GRADE profiles when data and information to calculate the necessary risk ratios were lacking. The initial ranking of the evidence for each question was collectively done by the consultants responsible for the systematic review and shared with members of the Guideline Group. Risk/benefit tables were developed during the consensus meeting, and these were again shared with all the Guideline Group members for any additional input when they reviewed the literature review report. The final recommendations take into consideration the quality of the evidence, cost, feasibility and the values and preferences of the caregivers and health care providers as assessed by the Guideline Group members. Concerns raised by a member of the Guideline Group who had been through the experience of having a child undergo HIV testing and disclosure of HIV status were factored into the recommendations.

5 To be posted on <http://www.who.int/hiv/topics/vct/en/index.html>.

The Guideline Group members received the systematic literature review report by e-mail and sent back comments to the group or directly to the WHO technical officer. Recommendations and consideration of cost, values and preferences, and benefits and harms were reviewed through e-mail correspondence. Comments were considered and addressed in subsequent drafts that were sent out again to the Group for their review. External reviewers were then invited to make their contributions to the document, and the Steering Group considered their input and incorporated it where appropriate.

The final recommendations and the risk/benefit profiles are consistent with those first proposed at the consensus meeting in June 2009.

## **2.6 Dissemination and future support**

Following clearance by the GRC, the guidelines with recommendations have been posted on the WHO web site at <http://www.who.int/hiv/topics/vct/en/index.html>. Dissemination of the document is taking place on the Internet and via e-mail. The GRADE tables and the risk/benefit tables are being posted on the WHO web site along with the full text of the systematic literature review report. Members of the Guideline Group and WHO implementing partner agencies have been asked to share the findings more widely with colleagues in the field.

## **2.7 Review and development of other materials**

A 4-page technical brief summarizing interventions to expand HIV testing and counselling for children, including these recommendations, is being posted on the WHO web site and can be printed easily for dissemination at technical meetings. WHO colleagues working on related guidelines and tools (ARV treatment, infant and child diagnosis, prevention of mother-to-child transmission) have been alerted to incorporate these recommendations and principles into their documents. Operational and training materials for use at district-level health facilities have been developed in the HIV department at WHO; upcoming revisions will incorporate the recommendations and principles on disclosure support from this guideline.

## **2.8 Future revision**

It is expected that the recommendations in this document will be revised in 2014 following a review of their implementation and programme experience.



## 3 FINDINGS

### 3.1 PICOT Question 1: Full disclosure versus non-disclosure

#### QUESTION 1.1:

*Do HIV-positive children 12 years and under whose own HIV status is disclosed to them display equal or greater well-being than those children who are not disclosed to?*

#### Summary of findings<sup>6</sup>

Comparing children disclosed to with those not disclosed to

*Health outcomes: death, CD4 decline, adherence to medication.* A Romanian study (35) found less than half the risk of death over a 3-year period (RR=.44, 95% CI .2-.99, p=.05, moderate quality of evidence) among children ages 5–17 years who had been disclosed to compared with HIV-positive children who were not disclosed to. The effect persisted after controlling for age. In this retrospective chart review, the authors found cases with 15% CD4 declines over the follow-up period to be slightly, but not significantly, less likely among those disclosed to (RR=.81, 95% CI .5–1.32, n.s., low quality of evidence). The authors hypothesized that both health effects were due to greater compliance with health monitoring. Data from five studies of children ages 2–18 years (19, 36, 37, 38, 39), conducted in Italy, Togo, Uganda and the United States, indicate a nearly 20% greater rate of adherence to ARV medication regimens among children whose HIV-positive status had been disclosed to them compared with children who were in treatment but had not been told their status, as measured by various indicators. The finding was not statistically significant (RR=1.18, 95% CI .88–1.57, n.s., low quality).

A Romanian study found less than half the risk of death over a 3-year period among children ages 5–17 years who had been disclosed to compared with HIV-positive children who were not disclosed to.

*Mental health: psychological distress, depression, general anxiety, separation anxiety.* In a meta-analysis of two studies in France and Zambia (40, 41), significantly fewer 5- to 15-year-old HIV-positive children who had been disclosed to self-reported psychological distress (RR=.64, CI .41–1.00, p=.05, low quality) than did HIV-positive children not disclosed to. In several US studies of moderate quality, there were no significant combined or singular mean differences between HIV-positive children disclosed to and those not disclosed to on measures of depression/dysthymia (ages 6–13) (26, 42), general anxiety (ages 6–11 years) or separation anxiety. Several of the mental health studies had appropriate controls, e.g. matched for gender, caregiver symptoms and other factors.

<sup>6</sup> See Appendix B for Summary of Findings and GRADE Tables comparing children disclosed to with those who are not disclosed to, online at <http://www.who.int/hiv/topics/vct/en/index.html>

### Comparing before and after disclosure<sup>7</sup>

In a prospective, longitudinal, multi-city United States study following paediatric cases (ages 5–20) three years before and three years after disclosure, Butler *et al.* (43) found no significant changes after disclosure in caregiver reports on child well-being on four *health* measures (general health, distress related to symptoms, physical functioning, health care utilization), *mental health* (psychological status) and *social behaviour* (social role functioning). This work was graded moderate to high in quality.

Unfortunately, no study identified assessed social isolation, stigma and other societal reactions pre- to post-disclosure for HIV-positive children learning their own status.

However, three additional tables<sup>8</sup> look at (1) the prevalence of the immediate emotional reactions of children, (2) reactions at six months in one intervention study, and (3) results of the Butler *et al.* (43) study when covariates and interaction of disclosure point and elapsed time are assessed. This third table shows that there are still no significant changes pre- to post-disclosure in the outcomes listed in the Summary of Findings Table after taking account of multiple factors such as viral load, gender, ethnicity and primary caregiver.

*Immediate reactions of HIV-positive children as reported by the children themselves.* Across four studies (22, 25, 34, 44) representing over 150 children ages 5–19 years in three countries or territories (Puerto Rico, Thailand, United States), the predominant reaction is sadness and worry (reported by 35.9% of children), followed by neutral/normal (28.2%), shocked (16.0%), angry (14.7%), confused (8.3%) and positive (e.g. relief, 6.4%).

*Reactions six months post-intervention.* Blasini *et al.* (34) designed and piloted a health care staff/caregiver intervention to support disclosure of a child's HIV status. Follow-up six months later found a dissipation of children's confusion and anger, a reduction of negative emotions, and an increase in feelings of normality (70.0%) and in positive emotions (47.5%).

### ***Special considerations regarding the developmental stages of children***

The clinical and observational literature on children's developmental understanding of HIV and AIDS supports earlier literature on children's developmental ability to understand illness in general (45). This body of literature suggests that children's understanding of illness, including its causes and consequences, increases as children grow older (46, 47, 48). Studies of children in developing (49) and developed countries (43, 50) confirm the notion that increased understanding of illness and death is related to cognitive development. For example, Peltzer *et al.* (49) found in Black South African children that the older children expressed more strategies for staying well, could describe AIDS, and knew more objective signs and symptoms of illnesses, including AIDS, than younger children.

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<sup>7</sup> See Appendix C for Summary of Findings and GRADE Tables on health outcomes in children before and after disclosure.

<sup>8</sup> See Appendix D.

When disclosing to children, whether about their own or their caregiver's HIV disease, those presenting information should consider children's cognitive-developmental ability to understand what is being said. Childs *et al.* (51) suggest that disclosure that is not tailored to the child's understanding of illness and the consequences of medication can be a barrier, like non-disclosure, to treatment adherence. Using Piaget's stages (pre-logical—ages 2–6, concrete-logical—ages 7–10, and formal logical—ages 11 and up), Bibace and Walsh (46) propose that caregivers and HCWs tailor their explanations of illness to children's perception of cause and effect and of contagion as well as to their sense of control, largely determined by their cognitive-developmental age (which is not always synonymous with their chronological age).

Those disclosing HIV status to a child should consider the child's cognitive-developmental ability to understand what is being said.

By school age<sup>9</sup> children have both experienced and understand illness(46). With regards to HIV, now thought of as a chronic illness where ART is widely available, they also understand concepts that assist with full disclosure, such as how illness might come about and the importance of taking care of oneself (34, 29, 35, 47, 48). Various perspectives point to this stage of development, which generally takes place at 6 to 8 years of age. For example, in a non-HIV-related study of children ages 5–9 in London, Lansdown and Benjamin (50) found that by the age of eight or nine most children were able to fully understand the concept of death, and more than half of 5-year-olds had a partial or full understanding. Also, studies report better psychosocial adjustment to illness among paediatric cancer patients told of their illness early—at a mean age of 5.7 in one study (17, 52) and among youth in the 1990s who were told their HIV-positive status at ages between 6 and 11 (53). Since, globally, the age of informed assent for participation in clinical trials is seven years (54), it is appropriate that guidelines for disclosure distinguish between children under seven and older children. Such an approach is consistent with the 1999 recommendation by the American Academy of Pediatrics that school-age children should be informed about their HIV status (55) and the HIV clinical guidelines of New York State (56). All these various perspectives emphasize that maturity, rather than simply chronological age, is what matters and that the outcome of disclosure, at any age, will be more positive when family and health care providers agree about the process and support it. In any case, the average age at which disclosure takes place has been dropping as HIV treatment has become more widely available and more effective (43).

In addition, recent research strongly suggests that disclosure should be viewed as a process that occurs over time rather than a discrete event when the child's or the caregiver's illness is named (47, 57, 58). HIV raises continuing issues and implications for the child and other family members: feeling ill, diagnosis, disclosure to others, treatment, adherence, relationships to friends and community, planning for the future and adjusting to the illness at different life stages, such as entering adolescence and encountering the potential for new transmission risks. The available evidence appears to support a process-oriented approach to disclosure,

9 In this document "school age children" refers to children ages 6–12 years.

consistent with the child's developmental ability to understand the information disclosed. At the same time, it is important to tailor disclosure to cultural context.

QUALITY OF EVIDENCE: LOW

**Conclusion:** There is evidence of health benefit and little evidence of psychological or emotional harm in the disclosure of HIV status to HIV-positive children. Expected and understandable initial emotional reactions dissipate with time and may respond to interventions.

**Recommendation:** Children of school age should be told of their HIV-positive status; younger children should be informed incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure. Disclosure can be seen as a step in the process of adjusting to an illness and the life challenges it poses.

**QUESTION 1.2:**

*Do children 12 years and under who get the HIV-positive status of their parent/caregiver disclosed to them display equal or greater well-being than those children who are not disclosed to?*

**Summary of findings**

Comparing children disclosed to with those not disclosed to<sup>10</sup>

*Health outcomes: testing of children, adherence to medication.* In an Ugandan study with a small sample (N=52) (59), the investigators found that children who had had their caregivers' HIV status disclosed to them seemed more likely to have been tested for HIV themselves than children who had not been disclosed to (RR=8.36, 95% CI 0.47 to 147.77, n.s., low quality). The study included infants to adults (ages 1–36 years); the effect was stronger among children 12 and under (RR=12.14, CI .66–222.01, n.s.) but even less stable, given the smaller sample size. Polisset et al. (38)

HIV-positive children were significantly more likely to adhere to treatment if they had been told about their caregivers' HIV-positive status

found in their Togo sample that HIV-positive children, ages 6–15, of HIV-positive caregivers were significantly more likely to adhere to treatment, as measured by caregivers' 4-day and 1-month reports of no missed doses, if they had been told about their caregivers' HIV status (RR=1.53, CI 1.03–2.26, p=.03, low quality).

*Social outcomes: plan for future care communicated to child.* In Sweden, among African immigrant children of ages from infancy to 17 years, those who had been told their caregivers' status were more than three times more likely to have been told about a plan for their future care than to those who had not been told their caregivers' status RR=3.66, CI 1.0–3.27, p=.05, low quality) (60).

<sup>10</sup> See Appendix E for Summary of Findings and GRADE tables comparing children to whom the HIV status of a parent was disclosed with those not disclosed to.

*Child mental health: caregivers' and children's reports of child problems.* Two studies used caregivers' reports to derive total scores for the Child Behavioral Checklist (CBCL) or an adapted version of this measure (61,62). Together, these studies, involving children from infancy to 18 years of age in the United States and across 10 Western European countries, indicate a significantly higher level of perceived problems among children who had been told their caregivers' HIV status ( $p=.009$ , low quality) than among those who had not. In contrast, two studies using children's reports on the externalizing scale or subscales of the CBCL found lower scores ( $p=.03$ , low quality) for children whose caregivers' HIV status had been disclosed to them. These two studies, both conducted in the United States, sampled 6- to 11-year-olds (63, 64).

*Caregivers' mental health: depression and perceived social support for personal/private feelings.* Murphy et al. (63) also looked at outcomes for mothers who had and those who had not disclosed their status to their children. Using a standardized scale, they found no significant difference in maternal depression, but they did find that HIV-positive mothers who had disclosed felt that they had more social support for their personal/private feelings ( $p=.01$ , low quality).

#### Comparing before and after disclosure<sup>11</sup>

*Mental health: comparison of mothers' and children's reports about internalizing and externalizing behaviours and relationship quality.* In a prospective longitudinal study conducted in the United States, Shaffer et al. (65) followed 6- to 11-year-old children from before disclosure through 12 to 20 months after disclosure. They compared three key outcomes—internalizing behaviour, externalizing behaviour and perceived relationship quality—for children whose mothers' HIV status was or was not disclosed to them. The authors also compared mothers' and children's reports about these three key variables. Children's reports did not significantly change pre- to post-disclosure for any of these outcomes. Mothers' reports, however, indicated significantly negative changes after disclosure in children's externalizing behaviour ( $p=.0126$ , low quality) and decreased relationship quality ( $p=.04$ , very low quality).

*Children's understanding of HIV.* In the Shaffer study (65) the children whose parents' or caregivers' HIV status was disclosed to them demonstrated a significantly higher level of understanding of the causes of HIV than children who were not disclosed to ( $p=.047$ , low quality).

There were no studies found that report on social reactions—e.g. discrimination or support—for children of disclosure of the caregiver's HIV-positive status.

Findings about community awareness of caregiver's HIV status and the effect of this awareness on children will be discussed under Question 2.<sup>12</sup>

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11 See Appendix F for Summary of Findings and GRADE tables comparing outcomes in children before and after disclosure of the parent/caregiver's HIV status.

12 See Appendix G for additional tables on immediate and longer-term reactions post-disclosure.

Summary data across studies are not available to describe children's self-reports of immediate reactions to disclosure of their caregivers' HIV status. However, there are data on parents' description of the prevalence of immediate emotional/cognitive reaction across several studies and data from two studies on how severe such reactions are and whether they are perceived to change over time.

*Immediate reactions of children to caregivers' HIV disclosure as reported by caregivers.* Across four studies (62, 66, 67, 68) representing nearly 270 children ages 1–18 from 12 countries (South Africa, United States, 10 Western European countries), the predominant reactions were sadness (41.6%), worry (23.4%), emotionally neutral or no reactions (18.2%), and mature reactions (16.7%), with less than 6% reporting other reactions (e.g. anger, confusion). In her study Nostlinger (62) does not define “mature reaction”, but her discussion suggests that it may mean adopting a caring or concerned role appropriate to older children.

*Changes in severity of children's reactions over time as reported by caregivers.* Two studies reported on the severity of children's reactions to caregivers' disclosure and their change over time. Data from Delaney et al. (69) and Tompkins (68) indicate that immediate reactions of worry, sadness, shock, confusion and anger decrease over time. “Over time” is not defined in the Delaney study, but the mean time in the Tompkins study is 3.7 years. Reactions initially and over time were not extreme.

### ***Special considerations about caregivers' disclosure***

Among children's reactions to learning caregivers' HIV-positive status are immediate concerns about the caregiver's well-being. Children may become appropriately protective or, if these concerns are not addressed, overly protective of their caregiver. Qualitative studies describe children hugging and consoling the caregiver. Also, uninfected children may fear contagion if they do not understand the nature of HIV transmission (66,69). Osborne notes that children's misconceptions and fears about transmission of HIV can be addressed with educational interventions (48). *Since reactions change over time, with and without intervention, it will be very important for researchers to keep consistent track of time since diagnosis.*

The data presented here suggests that caregivers tend to see more distress in their children than the children say that they experience. Future studies may want to compare how well caregivers' and children's own reports of their distress predict subsequent child health behaviour and child and family adjustment.

QUALITY OF EVIDENCE: LOW

**Conclusion:** There is evidence of health and life planning benefit for the children, with and without HIV, of HIV-positive caregivers if the caregiver discloses to them. There is some perception by caregivers that their children's behavioural problems increase and the quality of the relationship decreases after disclosure. These perceptions are not verified by children's self-reports. Parents do report that expected and understandable initial emotional reactions improve with time. Disclosing appears to pose no harm to caregivers.

**Recommendation:** Children of school age should be told of their caregivers' HIV status; younger children should be informed incrementally to accommodate their developing cognitive skills and emotional maturity. Children may need to be reassured as to how the parent/caregiver is feeling and have fears and concerns addressed.

**Research recommendation:** Investigate whether caregivers perceive more distress in their children than the children say they experience.

### 3.2 PICOT Question 2: Disclosure by the caregiver versus disclosure by other persons

#### QUESTION 2.1:

*Do HIV-positive children 12 years and under whose own HIV status is disclosed to them by their parent/caregiver display equal or greater well-being than those children disclosed to by others (e.g. a health care worker [HCW], a parent-HCW team, another caregiver, another family member, or inadvertent or public disclosure)?*

There are few data that address the effects of different sources of disclosure to children of their HIV-positive status.

Lesch et al. (47) report that caregivers of HIV-positive children may be more likely to engage in partial rather than full disclosure due to uncertainty about children's attitudes and emotional stress, whereas HCWs are more likely to favour full disclosure because of the positive consequences, such as improved coping, treatment adherence, and autonomous decision-making. In a study of delayed disclosure, Instone (70) also observes that HCWs favoured full disclosure to children more than parents did. Similarly, De Baets et al. (71) found that CHWs favoured full disclosure but were less willing to discuss grief.

Several hospital- or clinic-based interventions utilize HCW-caregiver teams to disclose children's HIV status to them (see PICOT question 4, section 3.4).

QUALITY OF EVIDENCE: ABSENT

**Conclusion:** There are no comparative studies shedding light on which individuals or teams can best disclose to a child his or her HIV status. There is some indication that HCWs may see more value in full disclosure than caregivers do and that caregivers may presume certain negative types of child reactions.

Evidence may be lacking as to who best can tell a child about the child's HIV-positive status, or, indeed, what would be the ideal characteristics of the person making the disclosure. Still, the principles of human rights, as stated in the Convention on the Rights of the Child (3), provide guidance: The choice must be made in the best interests of the child.

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

—*Convention on the Rights of the Child*

**Recommendation:** The decision on who will disclose to the child should be guided by the intent to improve/promote the child's welfare and minimize the risk to his or her well-being and to the quality of the relationship between child and parent/caregiver.

**Research question:** Who should convey a child's HIV status to the child? Is there a role for the HCW in this process, and, if so, what this role should be?



### QUESTION 2.2:

***Do children 12 years and under whose caregivers' HIV status is disclosed to them by the caregiver display equal or greater well-being than those children disclosed to by others (e.g. a health care worker [HCW], a parent-HCW team, another caregiver, another family member, or inadvertent or public disclosure)?***

Aside from the Summary of Findings table (see Appendix G) on public or inadvertent disclosure, there are few data that address the effects of different sources of disclosure to children about their caregivers' HIV status. In fact, there are no comparative studies shedding light on what individuals or teams should best convey a caregiver's HIV status to a child.

At the family level a study in the United States found that HIV-positive mothers wanted to take the leading role in making decisions about disclosure of their HIV status to their children (69). These mothers' perceptions of their children's ability to understand and accept the disclosure guided their decisions. Similarly, in a study of Thai children age 6 and older receiving ART found that the majority (57%) of caregivers preferred to be the one who disclosed the caregiver's HIV status, while 43% said they needed the assistance of a HCW (44).

QUALITY OF EVIDENCE: ABSENT

**Conclusion:** There are no comparative studies shedding light on what individuals or teams can best convey a caregiver's HIV status to a child, although caregivers most often say they wish to lead disclosure.

**Research recommendation:** Support and conduct research on the outcomes of current disclosure protocols compared with more detailed protocols that address who should disclose, what is disclosed, and when to disclose a caregiver's HIV status to the child.

#### ***Additional considerations: inadvertent public disclosure of a caregiver's HIV-positive status***

Disclosure of a parent/caregiver's HIV status can be inadvertent and public rather than intentional and family- or health-care-centred<sup>13</sup>. Clearly, communities are often aware that a child is affected by HIV<sup>14</sup> because of the child's circumstances, particularly if the child is orphaned or not living with parents. Indeed, several studies (72, 73, 74) have recruited HIV-affected children to participate through their identification by the community, based on the presumed cause of death of a parent, orphan status, or living arrangements in orphanages, foster homes or group homes. Work by Ishakawa *et al.* (75) in schools in Thailand and by a set of researchers working in rural Chinese communities (74, 76) shed light on the social and psychological effects of such "presumptive" disclosure.

13 See Appendix H for Summary of Findings and GRADE tables on community awareness that a child is HIV-affected compared with community controls.

14 HIV-affected children are children whose lives have been affected by HIV infection, whether their own or that of someone close to them, such as a parent.

*Social effects: experience of bullying and traumatic life events.* Together, data from Ishakawa et al. (75) and Li et al. (76) suggest that 6- to 18-year-old children identified as HIV-affected report a greater likelihood of being bullied or threatened than their community peers of similar age (RR=1.65, 95% CI 1.09–2.05, p=.02, low quality). In the Ishikawa study the authors noted that school personnel were not aware that discrimination against HIV-affected children was a problem. In an HIV-affected rural community in China as well (76), such children were likely to experience a higher number of traumatic life events not obviously related to HIV, such as accidental injury, physical or sexual abuse, being separated from family, or divorce of parents (p<.00001, low quality).

*Psychological effects: depression, loneliness, self-esteem, future expectations (general), hope for future (specific).* Using standardized measures and adjustments for age, sex and family socioeconomic status, Fang et al. (74) found significantly more negative psychological effects for HIV-affected children were more likely to experience negative psychological states than comparison with community controls (p=.02 to <.00001, moderate quality). Orphans and those otherwise identified as HIV-affected were combined for these analyses; effects were generally negative for both groups but generally greater for orphans.

QUALITY OF EVIDENCE: LOW

**Conclusion:** There is some evidence that general community awareness that a child is HIV-affected may adversely affect these children's well-being, in the absence of adequate support and community tolerance.

Fear of negative social reactions has long been cited as a barrier to disclosure (25, 77). As the above referenced studies and the observations by Cluver and Orkin (72), Delva et al. (73) and Mbaye et al. (77) underscore, such fears may have some foundation. Using policy, law and social norms to prevent discrimination may be an integral part of promoting disclosure and enhancing HIV care (77, 78).

**Recommendation:** Initiatives to protect privacy and institute policy, laws and norms preventing discrimination and promoting tolerance and support will help create environments where disclosure of caregivers' status is less problematic for the child. Such initiatives should accompany interventions encouraging and supporting disclosure.

### Why the concern about stigma?

The word “stigma” is derived from the Greek word for “brand”, or “mark”. This “mark” was associated with a lower position in life and was characterized by fear and shunning by others, often leading to feelings of unworthiness in the person being stigmatized. Shame and the experience, or even the expectation, of reproach lead people to stay away from others and to become socially isolated. Thus, stigma and social isolation go hand in hand.

Disclosure of either a child's HIV-positive status or the parent's status can burden the child with coping with stigmatization. In HIV-related situations stigma has been associated with depression and makes it less likely that a person with HIV will enter treatment or, if treated, will keep appointments and take medicines as scheduled. HIV-positive children may not even want to go to school or may believe they do not deserve to reach their goals in life. Being stigmatized may give others an excuse for bad behaviour such as bullying. HIV stigma may be presumptive—that is, in a highly affected community anyone who is ill is assumed to have HIV or anyone who has HIV is assumed to have become infected through drug use or illicit sexual behaviour (79, 80, 81, 82, 83).

HIV-related stigma may be internal stigma, received stigma or stigma by association. Internal stigma refers to perceptions of the self, social withdrawal, self-exclusion and fear of disclosure. Received stigma refers to neglect by others, their fear of contagion, avoidance, rejection, labelling, pestering, negative attitudes and hostility, abuse and gossip. Stigma by association refers to a child being stigmatized, for example, because a parent is HIV-positive. Stigma can be increased by policies that are discriminatory (e.g. immigration rules, discrimination allowed in hiring and firing). Stigma can occur at national, local, institutional, community, family and interpersonal levels (78, 80, 83).

### Interventions

Programs to reduce stigma and increase positive interactions with persons living with HIV have addressed communities, workplaces, health care workers, students in school, families and persons living with HIV themselves. Several interventions have proved effective (84, 85).

Effective interventions can fall into any of four categories: information, skill building, counselling/support, and testimonials from people living with HIV (84, 85). Caregivers may delay disclosure to a child for fear that the child will have negative feelings about himself or herself or for fear of others' reactions. Children, like adults, need help to cope with real or expected reactions from others. Children should be taught specific skills to strengthen their ability to cope with the various forms of stigma (20, 80).

### 3.3 PICOT Question 3: Identifying a safe person with whom the child or caregiver can freely discuss HIV-related issues

#### QUESTION 3.1:

*Is there benefit for HIV-positive children 12 years and under when they or their caregivers have identified “safe” persons with whom to discuss or practice discussing disclosure and unfolding HIV-related issues compared with HIV-positive children 12 and under who have no identified “safe” persons?*

There are few data that addresses the effects of having “safe” persons with whom to discuss disclosure and other HIV-related issues.

Recently, some researchers have been including “social disclosure” as a variable in their studies (16, 86). Social disclosure is defined as disclosure that a person is HIV-positive or that a family is HIV-affected to a larger circle of family, friends and others in social networks—for example, health care personnel or school personnel—who may assist in dealing with HIV-related issues. The “social disclosure” variable is being used as a possible predictor of disclosure to others outside the social disclosure circle and of outcomes of disclosure.

*Safe HCWs.* There is some evidence in the literature suggesting that caregivers who may be distressed about disclosing their child’s HIV status benefit from practicing their disclosure conversations with a HCW (34, 87). In a pilot study by Blasini *et al.* (34) of a disclosure protocol, caregivers of perinatally infected children in Puerto Rico participated in a pre-disclosure intervention. They received assistance from HCWs with HIV information and psychosocial aspects of disclosure. Participants reported positive outcomes. Children were not more depressed, for example, and caregivers felt relieved post-disclosure (see Question 1.1).

*Safe friends.* In a longitudinal study of 8- to 18-year-olds, Sherman *et al.* (88) observed positive effects on well-being when children disclosed to friends. The authors note that such disclosure may be particularly important in the transition to adolescence.

*Safe school personnel.* Several studies have described the prevalence of disclosure to school personnel and considered whether such personnel, particularly school nurses, should be informed of a child’s HIV-positive status so that they can be prepared to give support when disclosure takes place—particularly if it is inadvertent (89, 90, 91, 92, 93). Studies of the outcomes of such disclosures may be particularly important; several authors have noted that school problems—attendance, misbehaviour at school, bullying or being bullied—are associated with a child’s HIV-positive status (61, 72, 74, 94, 95). Finding opportunities to take medication at school can be a problem, as well.

QUALITY OF EVIDENCE: ABSENT

**Conclusion:** Literature suggests that HCWs and friends can help children cope with learning their HIV-positive status. The literature on the role of school personnel is mixed. The prevalence of school-related issues for children suggests that this is an important area for study. An empirical literature on a wider circle of social disclosure needs to be developed. It may prove beneficial to identify other “safe” persons outside the family.

**Research recommendation:** Investigate what roles social disclosure (and its component individuals or institutions, e.g., schools) and rehearsal of HIV-related discussions play in the outcomes of disclosure of a child’s HIV-positive status?.

**QUESTION 3.2:**

*Is there benefit for children 12 years and under from families with an HIV-positive caregiver when their caregivers have identified “safe” persons with whom to discuss or practice discussing disclosure of their HIV-positive status to a child and unfolding HIV-related issues compared with children 12 and under from families with an HIV-positive caregiver who have no identified “safe” persons?*

The context and social support for adult disclosure of HIV status has focused almost exclusively on effects for the adults (86). To our knowledge, there are no outcome data that focus on effects on children 12 and under, although work by Rotheram-Borus and colleagues (96), whose sample is largely adolescents and who therefore have been told their caregivers’ status, could be applied to the younger age group.

QUALITY OF EVIDENCE: ABSENT

**Conclusion:** There is little guidance on this topic regarding fostering positive outcomes for children. The literature suggests benefits for adults.

**Research recommendation:** Investigate what roles social disclosure (and its component individuals or institutions) and rehearsal of HIV-related discussions play in the outcomes of disclosure to children of their caregivers’ HIV-positive status.

### 3.4 PICOT Question 4: Assistance from HCWs specially trained in disclosure to children versus assistance from HCWs with standard training

#### QUESTION 4.1:

*Is there benefit to HIV-positive children 12 years and under when discussions with caregivers about HIV-related issues and disclosure of the child's HIV status are initiated by a HCW who has received enhanced training on disclosure to children versus discussion initiated by a HCW with standard training?*

Both the resources for and the desire for assistance from HCWs or other service providers regarding disclosure may vary greatly from culture to culture and place to place.

One pilot study of disclosure of child HIV status (34) involving HCWs has been completed and has obtained positive results.<sup>15</sup> A hallmark of this pilot intervention is offering the caregiver a choice of methods for disclosure, e.g. HCW-assisted or assisted by family as the caregiver deems appropriate. The concept of multiple pathways for the process of disclosure could be adapted elsewhere to local circumstances and local services.

#### Health care workers assist disclosure: a pilot intervention

In Puerto Rico an intervention described by Blasini *et al.* (34) involves health care workers in disclosure of young people's HIV status to them. The intervention incorporates training of HCWs and offers caregivers the choice between a caregiver/family and a caregiver/HCW disclosure strategy.

#### Health care workers' roles and responsibilities

The health care workers' roles and responsibilities in disclosure include the following:

- Respect the disclosure event by scheduling an appointment with family and staff members chosen by the patient (child or caregiver) whom they trust and with whom they feel comfortable.
- Notice and attend to the feelings presented by all family members before disclosure.
- Share the diagnosis quickly; do not "beat around the bush".
- Keep medical facts to a minimum, describing HIV infection as a chronic illness (explain in further detail over the course of time).
- Use language appropriate to the developmental and cognitive level of the child.
- Accept and foster silence, as the youth needs time to process the important information being given.
- Respect and promote the sharing of feelings and support by family members and staff toward the child, and let the child express his or her feelings and needs.
- Explore the child's knowledge about his/her health, HIV/AIDS and other chronic illnesses.
- Assess the youth's coping skills, family and peer support, school/work progress, skills and interests.

<sup>15</sup> See Additional Tables, Question 1.1, in Appendix B.

## Health care workers assist disclosure: a pilot intervention

### The process

The intervention involves the following steps:

1. Health professionals are taught to support caregivers' decisions whether to disclose the HIV diagnosis, and they respect the family's timing. They do not rush the disclosure process but instead stay alert and sensitive to the families' feelings and needs as they evolve through the phases of disclosure.
2. The health professionals are taught to respect caregivers' reasons to fear and resist the disclosure process.
3. The family receives a detailed explanation of the disclosure model before disclosure.
4. During educational sessions the staff member prepares family members to answer embarrassing or painful questions that children are likely to be asked (e.g. about sexual practices or drug use).
5. The team of health professionals assists caregivers in revealing other family secrets first, such as adoption.
6. Caregivers who have disclosed to their youth with good psychological adjustment serve as peer supporters to other caregivers.
7. Staff members must consider the stage of HIV and the child's medical condition because fear, pain and fatigue further compromise the child's and family's emotional energy levels during the disclosure process. They avoid disclosure during a medical crisis or acute illness.
8. Emphasizing confidentiality, the staff member engages the patient in a "partnership" based on confidence and trust.
9. Throughout the sessions the staff member ensures that the child seems curious and ready to learn more about his/her medical condition.
10. When the patient is ready to know more about his/her medical condition, the patient can choose which family and staff members he/she wants present at the disclosure session.
11. The staff member embraces the child and family members as a token of joining them in their journey through the disclosure process.
12. The staff member gives the child or adolescent an HIV educational cartoon book.

A search for other interventions, programs, or protocols—ongoing or in development—yielded the suggestion from Menon et al. (41) that a child peer-support component be included among the supports for disclosure, in addition to support from caregiver-peers and HCWs.

QUALITY OF EVIDENCE: ABSENT

**Conclusion:** No comparative studies have been completed comparing standard versus enhanced training.

**Research question:** What are models of suitable interventions to support disclosure to children of their own and their caregivers' HIV-positive status? What are the outcomes of implementing these interventions?

The core elements of trainings from Blasini et al. (34) and this guidance document can be applied to design, implement and further test a disclosure model and an accompanying HCW training model. Recommended elements are (1) choice of culturally appropriate and available resources to assist the disclosure process, (2) communication appropriately geared to children of different ages, (3) providing caregivers and children with information they need to know about HIV and its treatment, (4) preparing caregivers for the short- and long-term emotional reactions of their children, (5) developing a plan for child and caregiver to disclose to others, (6) preparing caregivers to answer questions that children may have over time and to choose “safe” staff members or others with whom to discuss issues, and (7) preparing caregivers to engage in life-planning with children. Any intervention and its training must cover reduction of stigma and protection of privacy.



#### QUESTION 4.2:

*Is there benefit to children 12 years and under when discussions with caregivers about HIV-related issues and disclosure of the parent/caregiver's HIV status are initiated by HCWs who received enhanced training as compared with HCWs who have standard training?*

Aside from the Rotheram-Borus study (15) with caregivers of older children rather than HCWs, to our knowledge no studies comparing standard and enhanced training have been completed and published.

Several authors (15,77, 97, 98) have described protocols for disclosure of caregivers' HIV status to children. Some have emphasized addressing stigma, planning for the child's future ("succession planning") and dealing with bereavement as issues in the unfolding process of HIV-related discussions. An additional set of protocols for disclosure of the child's HIV-positive status to the child are under development (99, 100), while Evans *et al.* (101) have described development of a hospital-based disclosure protocol for both children's and caregivers' HIV status.

QUALITY OF EVIDENCE: ABSENT

**Conclusion:** No studies have been completed comparing enhanced and standard training.

**Research question:** What are models for suitable training of HCWs to assist disclosure?

Core elements can be extracted from training models for support of caregivers' status disclosure, protocols described in the literature, and this guidance document to design, implement and further test an HCW training model. Models may closely resemble those for disclosure of child HIV status, but with additional emphasis on obtaining support for caregivers, dealing with stigma, dealing with institutions such as schools, and on life planning and challenges including bereavement.

## 4. CONCLUSION

The roll-out and increasing availability of antiretroviral treatment for adults and children brings into focus the need to address disclosure, which supports the uptake of, and adherence to, treatment. In this context the WHO Guideline Group agreed unanimously on the need for guidance on disclosure and determined to develop recommendations for health care workers on how to support children and their parents/caregivers with disclosure of HIV status. While the published evidence, as analysed by the GRADE process, is of low quality, the programmatic experiences of the Guideline Group members and the external peer reviewers support the recommendations developed.

In the course of discussion members of the Guideline Group noted key challenges faced during disclosure, which include HIV-related stigma; changing caregivers and caregiver roles; high mobility of children between families; vulnerable caregivers (e.g. grandparents and young siblings); homelessness; institutional care; the high burden of care on health care workers and families due to concomitant diseases, poverty and multiple episodes of bereavement within families; and parents' and HCWs' inadequate child/parent counselling knowledge, skills and support.

The Guideline Group members pointed out key success factors observed in their work experience. These include adequate caregiver preparation and continued support; a shared appreciation for the process of disclosure on the part of both the primary caregiver and health-care worker; the primary caregiver's acceptance of her or his own HIV status; honest answers to children's queries (tailored to a child's developmental age and communicated in the language the child understands best); use of age-appropriate, child-friendly counselling tools; a supportive community and social environment including protective laws and policies; and adequate social support including peer support for caregivers, children and families.

Programme implementers continue to find evidence of the adverse impact that the absence of disclosure or the lack of preparation for disclosure has on prevention, treatment and adherence outcomes. There are areas in which additional study should be done to better inform the design of interventions and to improve the quality of disclosure of HIV status to children. Even while such research is underway, WHO will work with governments and other implementing partners that provide health services to children to disseminate the recommendations presented here and to adapt them to geographic and cultural contexts.

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