Legal, ethical and counselling issues related to HIV testing of children

HIV counselling and testing of children: Implementation guidelines

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1. Introduction

1.1 Purpose of guidelines

These guidelines set out in more detail the requirements for HIV counselling of children in the context of existing legislation and policy. They give information about:

- The counselling of children of different ages and developmental levels and assessing a child’s capacity to give informed consent;
- Pre- and post-test counselling for children and for parents and caregivers of children unable to consent independently;
- Follow-up and referral of children and/or parents or caregivers;
- Client-initiated or voluntary counselling and testing and provider-initiated counselling and testing as applied to children;
- Counselling guidelines relative to disclosure of HIV status by and to children;
- Key qualities and competencies required for HIV counselling of children;
- The physical environment and use of appropriate materials in work with children and young people.

HIV Counselling and Testing (HCT) is the most important entry point for HIV-related treatment, care, support and prevention. The HIV epidemic in South Africa is “significant” amongst children. By 2007 32,940 children (under 15 years) in South Africa were estimated to be living with HIV and AIDS but not on treatment (Department of Health,
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2008). These facts highlight that every effort must be made to facilitate HIV testing in this population within the framework of applicable legislation and policy.

1.2 Legal and policy framework

**The Children’s Act (No. 38 of 2005)**

The Children’s Act defines a child as any person under the age of 18 years. This definition spans newborns and infants, early childhood from about two to six years, middle childhood and adolescence (defined by the World Health Organisation as being from 10 to 18 years).

The Act states that every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning the child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.

Furthermore, the Children’s Act, 13 (1) stipulates that every child shall have access to information on:
(a) health promotion and the prevention and treatment of ill-health, disease, sexuality and reproduction; and
(b) the causes and treatment of his or her health status.

The right of a child to participate in decision-making related to his/her own healthcare is an important principle guiding interactions between the healthcare provider, the child and his or her parent or caregiver, including counselling.

With regard to HIV testing, the Children’s Act (sections 130 and 132) specifies that a child may be tested for HIV when it is in the best interests of the child and informed consent has been given by the child, or a parent or caregiver, if necessary. This requires “proper (pre- and post-test) counselling by an appropriately trained person”.

The Children’s Act (section 132) further specifies that counselling should be directed at the child if he or she has sufficient maturity to understand the benefits, risks and social implications of an HIV test; in other words, is capable of giving informed consent. If a child’s parent or caregiver is aware of the possibility of testing, he or she should also be involved in counselling. In the case of children who are not sufficiently mature to understand the benefits, risks and social implications of an HIV test (most commonly, children under 12 years), the parent or caregiver may give consent following counselling.

**The National HIV Counselling and Testing (HCT) Policy Guidelines (“the national policy”)**

The national policy provides for different models for the delivery of HCT, specifically, client-initiated counselling and testing (CICT) or voluntary counselling and testing (VCT), and provider-initiated counselling and testing (PICT), both of which can be applied in the case of children, subject to the requirements of proper counselling as indicated above.
2. Defining counselling

2.1 General

Broadly speaking, counselling can be defined as:

“…a facilitative process in which the counsellor working within the framework of a special helping relationship uses specific skills to assist children and young people to help themselves more effectively. This involves helping the person to cope with their emotions and feelings as well as helping them make positive choices and decisions.” (Gillis, 1994)

Counselling a child involves good communication skills and the ability to build a relationship of trust between the child and the healthcare provider.

BASIC GUIDELINES FOR COUNSELLING A CHILD:

- Create a safe space that is private and quiet.
- Establish a relationship with the child by showing an interest in his or her world.
- Meet the child at his or her level.
- Use language that is appropriate for the child’s level of insight, understanding, education and emotional readiness.
- Show respect for the child’s needs, feelings and responses.
- Listen attentively to what the child is saying.
- Help to put the child’s feelings into words.
- Be calm, unhurried and caring in your interactions with the child.
- Find appropriate ways to help a child express him or herself, e.g., stories, books, drawings or games.
2.2 Pre- and post-test counselling

In the context of HCT and regardless of the model of delivery (VCT or PICT), counselling involves as a minimum pre- and post-test counselling.

- **Pre-test counselling:**
  A process during which a person undergoes confidential counselling before testing so that he or she can make an informed choice about whether to test in order to learn his or her HIV status. Counselling provides an opportunity for discussion about HIV/AIDS, including the risk of infection and means of protection, and allows individuals to think about the implications of a negative or positive test result, as well as strategies for coping with the test result.

- **Post-test counselling:**
  This is provided to help people understand the test result as well as the implications of the results and to consider and plan any follow-up action that is required. It helps children and their parents or caregivers to explore options about who to share the results with and how this might be approached.
3. Counselling children of different ages

Approaches to HCT of children are influenced by the age and stage of development of the child. It is important to be aware that there is considerable overlap between successive stages of development and that counselling should be attuned to the developmental level and needs of the individual child, rather than being determined solely by the chronological age of the child.

Developmental level may also be affected by a child’s circumstances; for example, experience of caring for a sick relative or living on the street may encourage the development of knowledge and skills ordinarily associated with a later age or stage of development. The healthcare provider should therefore ensure that counselling takes into account the need for information designed specifically for children of different ages and the use of techniques that are appropriate for the child’s age and stage of development.

3.1 Infancy and early childhood

Counselling and testing of newborns and infants is addressed with the parents or caregivers. This also holds true for young children under the age of about seven years since they have a limited comprehension of disease and disease progression. From the age of about seven years children begin to develop a better understanding of health and illness and should be involved in the counselling and testing process.
3.2 Middle childhood

Middle childhood (roughly seven to 10 years) is an important time for cognitive, social and emotional development. Children in middle childhood are learning to read, write and do arithmetic at school. They are also more independent and able to express a variety of different emotions.

In the context of pre- and post-test counselling the healthcare provider should be guided by an appreciation that children at this stage of development are interested in how the body functions and will understand cause, effect and transmission of HIV. Information should be clear and straightforward. The ability to read means that children in middle childhood are likely to have many questions. Myths and misconceptions may exist and counselling provides an important opportunity for the healthcare provider to rectify these.

This stage of development also heralds increasing curiosity about sex, and children in middle childhood may experiment with various sexual activities such as sex play with same or opposite sex friends – although this is not likely to involve adult sex acts, e.g., vaginal or anal penetration – and occasional masturbation.

By helping children to appreciate the implications of HIV for many aspects of health and encouraging them to take responsibility for their own healthcare, the provision of appropriate pre- and post-test counselling in middle childhood can lay the groundwork for responsible attitudes and behaviours in adolescence.

3.3 Adolescence

Adolescence is a time of transition to adulthood. It is characterised by rapid physical growth when the reproductive organs start to function and secondary sexual characteristics (e.g., breast development) are evident. Besides physical development the adolescent’s cognitive ability develops quantitatively and qualitatively during this period. Considerable development is also evident in the social and moral spheres. For example, adolescents have a clearer idea of right and wrong, which is sometimes influenced by the values and codes of their peers. Although the onset of puberty is generally considered a marker of a child’s entry into adolescence, emotional and cognitive functioning characteristics of middle childhood may persist for some time.

In the context of pre- and post-test counselling the healthcare provider should be guided by the knowledge that adolescents have a more complex understanding of the causes of illness and are able to appreciate that, given certain circumstances, anyone can be infected with HIV. Adolescents are able to understand the consequences of HIV and can appreciate the role of medication and a healthy lifestyle for maintaining wellness in an HIV-positive individual.

Young people in South Africa are considered to be at risk of HIV infection due to factors such as sexual exploration, experimentation with alcohol and drug use and other risk behaviours associated with perceptions of invulnerability. In addition, factors such peer pressure, concurrent sexual partnerships, gender-based violence and transactional sex increase the risk of infection in this population. These issues may need to be addressed in counselling adolescents.

Adolescents know much more about how the human body functions and about sexuality and reproduction, but often still have misconceptions, or are influenced by myths common in their social circle. A tendency towards peer group conformity can lead to high-risk behaviours. In pre-and post-testing counselling sessions, regardless of whether the adolescent admits to sexually risky behaviour, risk reduction needs to be addressed. Healthcare providers should communicate in a direct, clear and frank manner, using appropriate terminology.

Remember that there is an overlap between these stages of development so counselling should focus on the needs and developmental stage of each child, rather than their physical age.
4. Assessment of best interests and capacity to give informed consent

A child (as young as 12 years or, in certain cases, even younger) may be tested without the assistance or consent of a parent or caregiver, provided that testing is in the best interests of the child and the child has given informed consent for testing after pre-test counselling. However, since age is not always a reliable indicator of a child’s cognitive and emotional maturity and capacity to give informed consent, the healthcare provider has a responsibility to assess capacity to give informed consent in children, whether they are over or under 12 years. Similarly, whether or not testing is in the best interests of the child should be assessed in every case.

KEY CONCEPTS: THE CHILD’S BEST INTERESTS

Testing is generally in the best interests of a child if it promotes the child’s physical and emotional welfare, for example, through permitting access to appropriate treatment and care, or encouraging risk reduction. However, it is necessary to assess whether there are any reasons why testing may, at a particular time, not be in the best interests of the child.

The following are some reasons that could justify a decision not to test a child:

- significant emotional distress (to the extent that the child cannot, even with support, participate meaningfully in the assessment process, or would be unlikely to cope with a positive result);
- imminent risk to the safety of the child where the child has indicated that a positive result could provoke a harsh response from a member of the child’s family or other social unit;
- lack of social support to assist the child to cope with a (positive) result and its implications and no means to remedy the lack.
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The above implies that, in certain circumstances, a child who requests HIV testing (or for whom a healthcare provider recommends testing) may be refused testing at that time on the grounds that he or she does not have sufficient knowledge, understanding or appreciation of the implications of testing to give informed consent independently of adult support, or that his or her circumstances are such that testing is not in his or her best interests at the time.

Assessing capacity to give informed consent and whether testing is in the child’s best interests at that time involves a process of interaction between the healthcare provider and the child in order to explore a range of factors. These include:

- the child’s ability to engage with the counselling process (behaviour and mental state);
- the child’s capacity to learn or convey to the healthcare provider a basic understanding of HIV and the implications of HIV and testing (knowledge);
- the child’s capacity to think logically through issues (e.g., possible implications of testing);
- the emotional state of the child;
- the extent to which the child is testing voluntarily; and
- the kinds of support that would be available if the child tested positive.

The outcome of the assessment process could be summarised in the following way:

<table>
<thead>
<tr>
<th>Definitely has sufficient capacity to consent</th>
<th>Probably has sufficient capacity to consent</th>
<th>Probably does not have sufficient capacity to consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely in best interests taking into account his/her circumstances</td>
<td>Probably in best interests taking into account his/her circumstances</td>
<td>Probably not in best interests taking into account his/her circumstances</td>
</tr>
</tbody>
</table>

Generally, a decision to allow a child to test or not shouldn’t be based on a single factor or aspect of the assessment process (e.g., the child’s response to a specific question).

Rather, the decision should be made on the basis of observation and appraisal throughout the assessment process, providing a basis for an overall judgement of whether the child has sufficient capacity to consent and whether testing is in the child’s best interests, taking into account his or her particular circumstances at the time.

KEY CONCEPTS: CAPACITY FOR INFORMED CONSENT

To give informed consent, the child must have knowledge and understand and appreciate any harm or risk of the test itself, as well as the benefits, risks and social implications of testing. In other words, the child must be able to foresee the possible outcomes and implications of testing. This requires not only sufficient cognitive maturity, but also emotional stability and willingness to accept support, sufficient to be able to cope with the test result, especially if it is positive.
An assessment that aligns with either of the first two columns would imply that the child should be allowed to test.

Where the assessment overall is in line with the last column, testing should be deferred, with the possibility that the decision not to allow testing at that time may be reversed on further assessment, even within a fairly short space of time (e.g., when the effect of inhalant drugs has worn off, or when a child who is extremely distressed has recovered his or her composure).

In exceptional circumstances, an assessment may result in contradictory findings regarding capacity to consent versus best interests. Specifically, it may be found that the child has sufficient capacity to consent, but that testing does not appear to be in the child’s best interests. In these circumstances, if a child has been assessed as having sufficient capacity to consent, this factor should generally take priority; however, in extreme circumstances (e.g., imminent risk of violence to the child if the child tests positive, or clear suicidal intent), testing may be refused, even though the child has been found to have capacity to consent.

It is important that any decision to refuse the child testing on a particular occasion should be taken with care and after careful consultation with the child, bearing in mind:

- the need to respect and promote the child’s sense of agency and control;
- the barriers that the child will have had to overcome in coming for testing;
- the likelihood of the child having been exposed to risk (and possibly of continuing HIV exposure);
- the fact that refusing testing will block access to treatment if required.

To encourage careful and consistent decisions, assessments should, if possible, be discussed with a senior colleague before the child is informed of the outcome. Difficult cases and decisions to refuse testing should always be discussed with a registered professional colleague (e.g., social worker, nurse) before the child is informed of the outcome.

The assessment may be undertaken before or as part of pre-test counselling. Where a decision is made to refuse to allow a child to test on a particular occasion, the reasons must be conveyed to the child honestly and respectfully, using an approach appropriate to the child’s level of development and emotional state. In the case of children who do go on to test, post-test counselling is essential.

A decision not to allow the child to test should be accompanied by a referral for further counselling and, if appropriate, provision of a new date for HCT. Depending on the child’s circumstances, the involvement of a parent or caregiver to assist him or her in the consent process could also be discussed with the child.
5. Pre- and post-test counselling of children

The national policy makes provision for information sessions in which basic information about HIV and AIDS is provided in a group format. These may be appropriate for older children, especially adolescents. However, group pre-test sessions do not replace individual pre-test counselling where the child’s specific understanding of the information should be reviewed and additional information provided if appropriate. If a group session has been held, the individual counselling session can be briefer and focus specifically on the child’s understanding of issues covered in the group session, risks for HIV infection and the implications of testing.

5.1 Pre-test counselling

Healthcare providers should consider the following when conducting pre-test counselling with children 12 years old or younger who have sufficient maturity to give informed consent for testing:

<table>
<thead>
<tr>
<th>WHAT</th>
<th>HOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Build a relationship of trust</td>
<td>Be supportive, non-judgemental, respectful, explain role of healthcare provider, stress confidentiality.</td>
</tr>
<tr>
<td>Allow time</td>
<td>Children may require more time than adults; make provision for this.</td>
</tr>
<tr>
<td>Establish a contract</td>
<td>Explain purpose and process of pre- and post-test counselling (including assessment of capacity and best interests if part of counselling); discuss confidentiality and limits to confidentiality (including requirement to report sexual activity).</td>
</tr>
</tbody>
</table>
### 5.2 Post-test counselling

The following guidelines may be used for the post-test counselling of children:

<table>
<thead>
<tr>
<th>WHAT</th>
<th>NEGATIVE RESULT</th>
<th>POSITIVE RESULT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclose result to child (and any caregiver involved in pre-test counselling)</td>
<td>Give the result; explain meaning of result.</td>
<td>Give the result clearly and gently; explain meaning of result.</td>
</tr>
<tr>
<td>Provide support</td>
<td>Discuss feelings related to the result.</td>
<td>Give time to absorb news and ask questions; help young person to cope with emotional responses.</td>
</tr>
<tr>
<td>WHAT</td>
<td>NEGATIVE RESULT</td>
<td>POSITIVE RESULT</td>
</tr>
<tr>
<td>------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Discuss support systems</td>
<td></td>
<td>Review pre-counselling strategy plan; address immediate and long-term support; discuss implications of result for family or other social unit; encourage involvement of parents or guardians or other older supporter.</td>
</tr>
<tr>
<td>Discuss implications of knowing status</td>
<td>Review acquisition and transmission of infection; discuss risk reduction plans.</td>
<td>Review means of transmitting infection and ways to prevent re-infection; address safety and risk reduction as appropriate; stress availability of treatment, care and support; discuss positive living.</td>
</tr>
<tr>
<td>Discuss disclosure of results.</td>
<td>Discuss need to share the result with others.</td>
<td>Discuss to whom, how and when the results could be disclosed.</td>
</tr>
<tr>
<td>Discuss implications of results.</td>
<td>Discuss the window period and need for further regular testing, especially where high risk behaviour is involved.</td>
<td>Discuss any fears or problems the young person might foresee e.g., stigma, rejection; discuss dealing with these.</td>
</tr>
<tr>
<td>Make the appropriate referrals.</td>
<td>Assess need for referral to medical and/or psychosocial services; provide information or refer to community-based resources.</td>
<td>Arrange for follow-up counselling; refer for clinical management and care; give information or refer to community-based resources.</td>
</tr>
<tr>
<td>Follow-up on referrals</td>
<td></td>
<td>Check whether referrals have been acted on; if not, undertake confidential effort to renew contact with child.</td>
</tr>
</tbody>
</table>

### 5.3 Follow-up counselling and referrals

Regardless of the test outcome, children will benefit from follow-up counselling sessions where concerns or issues that may have emerged during post-test counselling can be discussed. For example, concerns about the involvement of parents/caregivers may be addressed and the young person helped to find ways in which to approach this.

The healthcare provider further needs to assist the child to work out priorities in relation to the child’s concerns, to make effective referrals where necessary and assist with the uptake of such referrals in order for the individual to benefit from available care and support services, especially when these are not provided by the facility concerned. The child may need care and support in the various areas indicated below.

- Medical
- Nutritional
- Social
- Legal
- Economic
- Psychological

It is important that the healthcare provider has a good knowledge of community resources and is able to refer appropriately, taking into account factors such as the age and developmental level of the child, language and culture. The ability of the healthcare provider to ensure that referrals also reflect the stated needs of an individual and that resources can be easily accessed, make uptake more likely.
Needs may include: medical evaluation, care and treatment, particularly in the case of an HIV-positive result; reproductive health services, including STI (sexually transmitted infection) screening and care; mental health services, for example where a child is having difficulty adjusting to a positive result; and services for the treatment of drug and alcohol abuse. Age-specific support groups, if available, could also be valuable.

Referrals should be discussed with the child and consent obtained prior to information being given to any other party, either verbally or in writing. The healthcare provider should further ascertain whether the child has accessed the recommended service and, if not, make a confidential follow-up.

5.4 Counselling where children are under 12 years or not sufficiently mature to consent

In instances where the child is under 12 years of age and has been assessed to be of insufficient maturity to give informed consent, or, even if aged 12 or older, has been assessed as lacking the mental capacity to give consent independently, consent must be obtained from a parent or caregiver or other parties designated by the Act.

In such cases the child should nevertheless be included in the counselling process in a manner that is appropriate to his or her level of understanding and the child’s assent to test should be obtained.

KEY CONCEPTS: WHAT IS ASSENT?

Assent refers to the willingness of a child to be tested, usually expressed verbally to the healthcare provider. It is obtained by explaining in a manner appropriate to the child’s age and stage of development why and how testing will be conducted. This implies that a single means of obtaining assent will not be appropriate for all children and that the healthcare provider should adopt a flexible approach. This should include being flexible about whether to see the child alone for at least part of the counselling session in order to allow the child to ask questions or confide information that he or she may be unwilling to share in the presence of a parent or caregiver.

The healthcare provider should document that the child has given assent. Assent from the child must always be accompanied by informed consent from the parent or caregiver. Where a child has given assent to testing, it is important that he or she is involved in post-test counselling in a manner appropriate to his or her age and stage of development. The question of whether to disclose the child’s status at this time needs to be addressed with the parent or caregiver in pre-test counselling and prior to discussion with the child (see also 9.1: Disclosure of a child’s HIV-positive status to the child).

In the case of infants and very young children who are too young to provide assent, informed consent is obtained from a parent, caregiver or another party designated in the Children’s Act and the focus of pre- and post-test counselling is the adult concerned. However, even young children need to be engaged in testing in ways that address their psychological and emotional needs. Thus toddlers benefit from having a simple explanation of what is happening and having their parent or caregiver present in a supportive role during testing.
6. Pre- and post-test counselling of parents or caregivers

Specific guidelines for counselling parents or caregivers of HIV-exposed infants (or where the mother’s HIV status is unknown) with respect to testing and infant feeding are provided in the national PMTCT policy and guidelines.

However, an important general principle in counselling parents or caregivers is that counselling should address not only the issue of testing the child, but, in order to encourage appropriate support for the child, should also take into account the perceptions, feelings and needs of the parent or caregiver.

6.1 Pre-test counselling guidelines

- Tailor the counselling approach to accommodate considerations such as the person’s relationship to the child (e.g., parent, caregiver or sibling) and his or her level of education.
- Build a positive relationship with the parent or caregiver and establish a counselling contract.
- Provide information on the purpose of counselling and testing, including the risks, benefits and social implications of testing. This should include the following:
  - Establish what the parent or caregiver knows about HIV and testing and provide further information as needed (including that knowing the status of a child who may have been exposed to HIV will promote optimal management of the child’s health and, in the case of infants, may enhance the chances of survival);
  - Discuss the implications of a positive or negative result for the child and significant others in the child’s life (including the implications of a positive result for a parent whose own HIV status is unknown);
  - Raise awareness of HIV-related prevention (including PMTCT), treatment, care and support services, either within the facility or through referrals;
  - Emphasise confidentiality of the test results;
6.3 Declining to give consent for testing

A parent or caregiver may decline to give consent to test a child and this decision should be respected by the healthcare provider. In the case of refusal, counselling should always be undertaken with the parent or caregiver in order to ascertain and respond to any fears, concerns or beliefs that might be an obstacle to the provision of consent. Where it is deemed that a parent or caregiver is withholding consent unreasonably and against the best interests of the child, an application may be made to the Children’s Court for consent (see National Policy on HIV Counselling and Testing, 7.1.3).

Healthcare providers may also decide on the basis of an assessment that it is not in a child’s best interests to test. In these circumstances, the child and/or parent or caregiver should receive counselling and the appropriate referrals should be made and a new date given for HCT.
7. Models of HIV counselling and testing (HCT)

HCT models include:
- Client-initiated counselling and testing (CICT) (more commonly known as voluntary counselling and testing or VCT); and
- Provider-initiated counselling and testing (PICT).

In the provision of HCT for children, healthcare providers can employ both models, but should take account of the specific requirements for counselling children and/or their parents and caregivers.

**Client-initiated (voluntary) counselling and testing (CICT or VCT)**

Client-initiated or voluntary counselling and testing has been widely used as a model for the provision of HIV counselling and testing in South Africa. This is a client-initiated approach, meaning that a child or the parent or caregiver of a child wanting to have the child tested will actively seek out facilities that offer HIV testing.

**Provider-initiated HIV counselling and testing (PICT)**

Also called the “opt in” approach, PICT has been introduced as a means of increasing uptake of HCT. In this model, healthcare providers recommend HCT to clients (children or their parents or caregivers) attending a healthcare facility. The decision to accept or reject the recommendation to test remains with the client. PICT services are offered as a routine standard of care, regardless of the reason for presenting at a health facility.

In both CICT/VCT and PICT models, counselling must include:
- pre-test counselling to explain the purpose and possible implications of an HIV test;
- informed consent;
- post-test counselling to discuss test results; and
- follow-up counselling.
7.1 Counselling in the context of CICT/VCT

In the case of children or young people, voluntary counselling and testing would generally be targeted at groups such as vulnerable children, for example, children who have been sexually abused, street children or children who have to take care of ill family members; young people or couples who are sexually active; young men who have sex with men (MSM); young, pregnant women; and individuals at risk through injecting drug use (IDUs); and young sex workers.

Children or young people who voluntarily seek counselling and testing have usually faced a number of obstacles in coming forward, e.g., limited access to facilities or censure for being sexually active. It is therefore essential that they are treated with respect and sensitivity, and afforded professional and confidential services. However, they may also present on the basis of peer pressure to test, without sufficient understanding of what it is that they are requesting. Proper pre- and post-test counselling and an assessment of capacity to consent and whether testing is in their best interests is essential.

Special considerations when adopting a VCT approach

<table>
<thead>
<tr>
<th>Children over 12 years or under 12 years (with sufficient maturity)</th>
<th>Parents or caregivers considering consent to test a child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confirm age of child.</td>
<td>Check relationship to child, determine that person is legally authorised to give consent for testing.</td>
</tr>
<tr>
<td>Recognise the child’s right to test independently; ensure child has not been coerced into testing.</td>
<td>Assess parent/caregiver relationship with child.</td>
</tr>
<tr>
<td>Acknowledge the child’s courage in seeking the service.</td>
<td>Explain necessity for informed consent from parent/caregiver (or child, if aged 12 years and sufficiently mature); depending on child’s age emphasise need for his or her involvement in the counselling process, e.g., consent or assent to test; discuss with parent/caregiver appropriate ways of involving child.</td>
</tr>
<tr>
<td>Explore the reason the child wants to test and explain need for informed consent.</td>
<td>Explore reasons for wanting to test child.</td>
</tr>
<tr>
<td>Explain child’s right to confidentiality and consent for disclosure.</td>
<td>Explain parent/caregivers right to confidentiality and consent for disclosure.</td>
</tr>
<tr>
<td><strong>Children over 12 years or under 12 years (with sufficient maturity)</strong></td>
<td><strong>Parents or caregivers considering consent to test a child</strong></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Discuss benefits of familial or other support; if appropriate, explore reasons for not wanting involvement of a parent/caregiver; encourage involvement of parent/caregiver or other older supporter.</td>
<td>Explore possibility of disclosure to others, e.g., family members where this would benefit child.</td>
</tr>
<tr>
<td>Assess risks, perceptions and factors influencing vulnerability.</td>
<td>Assess parent/caregiver perceptions related to child’s risk of HIV infection.</td>
</tr>
<tr>
<td>Use opportunity for health education, specifically regarding risk reduction; where appropriate, recommend testing of sexual partner.</td>
<td>Use opportunity to explore available support, e.g., medical follow-up, psychosocial support; where appropriate, address benefits of VCT for parent/partner/child’s siblings.</td>
</tr>
<tr>
<td>Based on observations during counselling, assess child’s capacity to give informed consent and whether testing is in the child’s best interests; if concerns, discuss with senior colleague.</td>
<td>Based on information obtained during counselling, assess whether testing is in the child’s best interests; if concerns, discuss with senior colleague.</td>
</tr>
<tr>
<td>Refer as appropriate to medical services, support groups, nutritional guidance, sexual and reproductive health.</td>
<td>Identify needs and make appropriate referrals.</td>
</tr>
<tr>
<td>Plan for further counselling session and follow up confidentially if necessary.</td>
<td>Plan for further counselling session and follow up confidentially if necessary.</td>
</tr>
</tbody>
</table>

### 7.2 Counselling in the context of PICT

A provider-initiated approach to HCT is recommended for children who might be at particular risk of HIV infection. This includes:

- HIV-exposed infants
- abandoned babies
- infants younger than 18 months
- infants older than 18 months
- breastfed babies of HIV-positive mothers
- children not identified by PMTCT (Prevention of Mother-to-Child Transmission) programmes
- child survivors of sexual assault
- young people who are sexually active or involved in high-risk behaviours.

**PICT provides an opportunity for the early identification of HIV and provision of the appropriate prevention, treatment, care and support and is a recommended approach with young people. Pre-test counselling is an essential component of the process to ensure informed consent for testing.**
Apart from the routine offer to test, healthcare providers should be cognisant of high risk groups including:

- Young people who are sexually active;
- Young people at high risk for infection, e.g., those with STIs, drug abusers, etc.;
- Young people with signs, symptoms and medical conditions suggestive of HIV infection;
- Pregnant adolescents;
- Young people who have been the victim of rape or sexual abuse.

Children, especially those under the age of 12 years, attending a health facility are generally accompanied by a parent or caregiver. Healthcare workers should routinely suggest HIV testing to parents and caregivers and recommend HIV testing of children where there is reason for concern. For example:

- Exposure in pregnancy, labour or breastfeeding;
- A child showing signs and symptoms of HIV illness;
- A child showing signs and symptoms of an STI;
- A child that is malnourished;
- A child who is known to have lost one or both parents to AIDS; or
- A parent/parents known to be HIV-positive.

Special considerations when adopting a PICT approach

<table>
<thead>
<tr>
<th>Children over 12 years or under 12 years (with sufficient maturity)</th>
<th>Parents or caregivers considering consent to test a child</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Confirm age of child.</strong></td>
<td>Check relationship to child; confirm that person is legally authorised to give consent for testing.</td>
</tr>
<tr>
<td><strong>Explain reason why PICT is being recommended.</strong></td>
<td>Explain reason why PICT is being recommended.</td>
</tr>
<tr>
<td><strong>Advise child of right to give informed consent for testing on his/her own.</strong></td>
<td>Discuss necessity for giving informed consent with parent/caregiver.</td>
</tr>
<tr>
<td><strong>Explain that decision to test is voluntary and discuss right to decline test; give assurance that this will not affect provision of future treatment, care and support; in case of refusal, ascertain reasons and respond to incorrect beliefs; encourage return.</strong></td>
<td>Advise parent/caregiver of his/her right to refuse testing; give assurance that this will not affect provision of future treatment, care and support; in case of refusal, ascertain reasons and respond to incorrect beliefs; encourage return.</td>
</tr>
<tr>
<td><strong>Advise child that she/he may voluntarily include a parent or caregiver in the counselling process; discuss the benefits of such involvement.</strong></td>
<td>Depending on the child’s age emphasise need for his/her involvement in the counselling process, e.g., consent or assent to test; discuss with parent/caregiver appropriate ways of involving child.</td>
</tr>
<tr>
<td><strong>Children over 12 years or under 12 years (with sufficient maturity)</strong></td>
<td><strong>Parents or caregivers considering consent to test a child</strong></td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>Based on observations during counselling, assess child’s capacity to give informed consent and whether testing is in the best interests of the child; where concerns, discuss with senior colleague.</td>
<td>Based on information obtained during counselling, assess whether testing is in the child’s best interests; if concerns, discuss with senior colleague.</td>
</tr>
<tr>
<td>Where appropriate, recommend testing of sexual partner.</td>
<td>Recommend testing for parents/siblings of child.</td>
</tr>
<tr>
<td>Explain child’s right to confidentiality and consent for disclosure; explore possibility of disclosure to trusted adult where this would benefit the child.</td>
<td>Explain parent/caregiver’s right to confidentiality and consent for disclosure; explore possibility of disclosure to others, e.g., family members where this would benefit the child.</td>
</tr>
<tr>
<td>Provide age-appropriate information, e.g., pamphlets.</td>
<td>Provide information, e.g., pamphlets.</td>
</tr>
<tr>
<td>Assess needs and refer as appropriate.</td>
<td>Assess needs and refer as appropriate.</td>
</tr>
<tr>
<td>Plan for further session and follow-up confidentially if necessary.</td>
<td>Plan for further session and follow up confidentially if necessary.</td>
</tr>
</tbody>
</table>
8. Special provisions

The Children’s Act refers to HCT in the context of child survivors of sexual assault. The Act makes provision for the testing of children in situations where a healthcare provider or individual outside of a healthcare setting may be at risk of HIV infection due to accidental exposure to a child’s body fluids, e.g., blood. Pre- and post-test counselling under these circumstances is discussed below.

8.1 HCT for child survivors of sexual abuse

Disclosure of sexual abuse to a healthcare provider by a child or adolescent can occur in the course of HCT. A child or adolescent may also request VCT as a result of sexual abuse and fears concerning the possibility of HIV infection.

Knowing about a sexual offence immediately places the healthcare worker under a legal obligation to report the offence to the police, with or without the consent of the child.

The healthcare provider is also required to report any physical abuse or neglect of a child that might become apparent during HCT to a designated child protection organisation or the provincial Department of Social Welfare.

In support of this requirement the law limits the rights of the child or adolescent to confidentiality in cases that involve abuse or sexual offences. In the context of HCT it is important for the healthcare provider to ensure that the child fully understands the reason for this limitation, for example, that reporting is necessary to secure the child’s safety and protection. The child should be given information about the procedures involved. In addition, the risk of HIV infection as a result of sexual abuse should be addressed where appropriate.
The child’s age and developmental stage will generally determine his or her understanding of the experience of sexual abuse. The younger the child, the less likely it is that he or she will appreciate the meaning and possible outcomes of a sexual encounter or relationship. As the child develops and acquires more advanced cognitive abilities, the ways in which he or she makes sense of sexual abuse will change. This influences the impact of the abuse on the child, for instance, a younger child may find it difficult to trust adults, whilst an older child could feel responsible for the abuse and may grapple with feelings of guilt. The impact of sexual abuse on a child is also significantly affected by the nature of adult reactions and support.

Understanding these differences can assist the healthcare provider in giving the appropriate support and information during the counselling process. In addition, it is important to make the appropriate referrals.

Sexually abused children will require ongoing counselling by an experienced healthcare practitioner and will need to be supported through procedures such as a medical examination and any subsequent legal processes.

Guidelines for healthcare provider following disclosure of sexual abuse during HCT:

- Believe the child; children do not usually lie about sexual abuse;
- Do not be judgemental;
- Do not respond with shock;
- Avoid asking too many questions and probing for details;
- Let the child tell his or her story using terms with which he or she is familiar;
- Tell the child that it is not his or her fault that the abuse occurred (children are often afraid that they may be blamed, disbelieved or rejected as a result of their disclosure);
- Talk to the child about who else will need to be told and ask who he or she thinks should know;
- Without scaring the child, discuss what needs to happen as regards reporting the abuse;
- Tell the child what kinds of protection and support (e.g., in relation to the perpetrator, or engaging with the family, or finding alternative accommodation) will be available to him or her, including through referral.
8.2 HIV testing following occupational or other exposure to a child’s body fluids

The national policy states that a child may be tested for HIV if the healthcare provider is at risk of HIV infection as a result of exposure to the child’s body fluids. In the case of exposure outside of the healthcare setting, a court order is required to test the child.

Under these circumstances, the provision of voluntary consent is not a pre-requisite for testing. However pre- and post-test counselling should still be conducted with the child or adolescent, with the involvement of a parent or caregiver if the child so chooses. In the case of young children who do not have sufficient maturity to understand the implications of an HIV test, pre- and post-test counselling should be undertaken with the child and his or her parent/caregiver.

Counselling should be conducted in a manner appropriate to the child’s age and stage of development. In the case of a young child who may not understand modes of transmission, full disclosure of the reason for testing may not be helpful and could result in the child feeling that he or she has done something wrong. A more general and simple explanation, like the one overleaf, may suffice.

**KEY CONCERNS:**

- A key concern is the legal obligation placed on the healthcare provider to report sexual offences, in particular, consensual sexual intercourse involving children under the age of 16 years. This requirement undermines provisions of the Children’s Act which give children right of access to health promotion and the prevention of diseases; the right to test independently; confidentiality of their health status; and confidential access to contraception and advice. Healthcare providers’ concerns about possible obligations relating to sexually active children as well as the fears of young people that they might be reported represent a significant obstacle to frank and open discussion about risk and prevention.

- From an ethical point of view, it is necessary to inform children at the outset of contact with them about the obligation to report (e.g., when explaining limits to confidentiality during pre-test counselling). In any circumstances that suggest that reporting may be required, it is recommended that healthcare providers always consult with a more senior colleague before doing so. If a decision to report is taken, the child must be informed in advance and provision made to provide ongoing counselling and other support and protection for the child.
In the case of HCT with the older child, the healthcare provider should ascertain how much the child knows about HIV and build on this to explain the reason for testing.

What the counsellor could say:

“I know that the clinic sister took some blood earlier (invite child to talk about this). Blood tests are important to check if everything is ok. When nurses or doctors take blood they are very careful, for example, they wear gloves. Do you know why that is? (Allow child to answer, assess knowledge and introduce discussion of HIV, transmission and precautions). Although a person can be very careful, there can be accidents and that’s what happened just now. Sister accidentally pricked herself with the same needle that she had used to take your blood...”

Guidelines for testing as a result of exposure to a child’s body fluids:

- Help the child to relax by asking him or her general questions, for example, about his or her interests;
- Emphasise that the exposure to the child’s body fluids was accidental;
- Assure the child that he or she has done nothing wrong;
- Assure the child that there will be no repercussions for him or her;
- Reassure the child that the need to have an HIV test is a precaution and represents standard practice when a person is accidentally exposed to someone’s blood or other body fluids;
- Reassure the child that the need for an HIV test following accidental exposure to the child’s body fluids by a healthcare provider could happen to anyone at any time.

The results of an HIV test should be conveyed to the affected healthcare provider and discussed with the child or adolescent and/or his or her parent or caregiver during post-test counselling. In the case of a positive result, referral should be made to the appropriate services for management and support.
9. Disclosure of a child’s HIV status

The Children’s Act (Section 133) includes strict safeguards on disclosure of a child’s HIV-positive status to others. Children of 12 years, or under 12 years and capable of consent, are entitled to exercise the right to confidentiality. In other words, they can decide who should know their HIV status.

The national policy on HCT recommends that a person who tests HIV-positive should be encouraged to disclose his or her HIV status to at least one other person as a means of obtaining support, including for adherence to treatment. Although not a requirement to access treatment, healthcare providers should therefore address disclosure (whether with the child or a parent or caregiver) as part of the pre- and post-test counselling process.

In the case of children, an additional and often a prior concern is the issue of disclosing a child’s status to the child. Many parents and caregivers find it hard to disclose the child’s status to the child. Whilst healthcare providers should respect their wishes and views, involvement of the child should be encouraged and supported with appropriate disclosure strategies as the child develops.

9.1 Disclosure of a child’s HIV-positive status to the child

Disclosure is understood here as the process of telling a child that he or she has HIV. However, this cannot be a “once-off” conversation and further counselling is essential to help the child cope with knowing his or her diagnosis and develop strategies for living a healthy life.

Disclosure of a child’s status may take place with the child on his or her own if the child is over the age of 12 or under 12 years, but capable of providing informed consent to test. Alternatively, it could involve the parent or caregiver, or a designated individual/organisation if the child is under the age of 12 but not capable of providing consent.

The extent of knowledge and understanding and the emotional responses of the child during pre-test counselling will generally serve as a guideline for the most appropriate means of disclosing a child’s status to him or her in post-test counselling. Information from a parent or caregiver who has been involved in the counselling process can also be of assistance in deciding how to disclose to the child and in how much detail.
9.2 Disclosure to pre-school children

Consent for HIV testing of children under six years of age will generally be obtained from a parent or guardian or other legally designated individual or organisation. This means that such a person or organisation will also have the right to maintain confidentiality or to disclose a child’s status, including to the child him- or herself. However, even very young children can be given simple answers appropriate to questions they may ask about their involvement in treatment, thus providing a platform for later, gradual disclosure along the lines outlined above.

9.3 Disclosure to children under the age of 12 years or incapable of providing consent

The healthcare provider should emphasise to the parent or caregiver the benefits of disclosure, especially to children in middle childhood. The decision of a parent or caregiver not to disclose a child’s status to him or her should be respected. Nevertheless, follow-up counselling is recommended in order to explore feelings, and identify and address any obstacles that might be in the way of beginning the disclosure process.
Guidelines for healthcare provider:

- Explore the parent or caregiver’s views and feelings about disclosure to the child;
- Emphasise the advantages and disadvantages of disclosure both for the child and the parent and caregiver, e.g., treatment adherence, sexual activity, control over when and how disclosure takes place;
- Talk about the possibility of disclosure to family members, school teachers, etc.;
- Talk about different ways of disclosing to the child;
- Plan for further counselling if the parent or caregiver does not want to disclose.

9.4 Disclosure to children over 12 years, and under the age of 12 years who are capable of consent

In the case of adolescents, i.e., a young person of between 10 to 18 years, disclosure to the child should be relevant and appropriate to the age and information needs of the child. The healthcare provider should discuss possible disclosure to others, including a sexual partner if relevant, but should respect the decision that the young person makes. Assurance of support and willingness to help should be given, but healthcare providers should take care not to seem intrusive.

9.5 Disclosure of the child’s status to others

The decision to disclose a child’s status to others rests entirely with the child if he or she is over 12 years or under 12 years and of sufficient maturity to have consented to testing. Such a child has the legal right to confidentiality about his or her status and disclosure may only take place with his or her consent.

The healthcare provider may, without using pressure or coercion, encourage disclosure to a trusted adult where this is likely to be in the best interests of the child. The child’s decision must, however, be respected.

Guidelines: Levels of disclosure

An understanding of the different levels of disclosure is important in the disclosure process. In this regard, the following are useful:

- **Non-disclosure**: The child fears negative outcomes from disclosure and does not want to reveal his or her status to anyone.
- **Shared confidentiality**: The child is prepared to reveal his status to a parent, caregiver or trusted adult with the understanding that that person will not disclose to others without being given permission by the child.
**Voluntary disclosure:** The child is prepared to share information about his or her HIV status with others. This may take the form of partial or full disclosure.

**Partial disclosure:** The child will only reveal his or her status to certain people, for example, a family member.

**Full disclosure:** The child is prepared to reveal his or her status more widely, for example, within a support group.

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**Guidelines: Disclosing to others**

The following guidelines are relevant when counselling children around disclosure to others:

- Make the level of discussion equal to the child’s age and developmental level.
- Help the child to express his or her feelings.
- Find out about the child’s sources of support.
- Help the child to think about disclosure to others.
- Discuss the implications of disclosure, including the benefits and risks.
- Discuss the implications of disclosure to an inappropriate person or group.
- Ask the child who they think should be told.
- Help the child to think about how and when they should reveal their status.
- Help the child to anticipate and prepare to deal with responses, e.g., role-play in preparation for disclosure.
- Do not put pressure on the child to disclose.
- Arrange follow-up counselling.
10. Qualities and competencies required for HIV counselling of children

Healthcare providers undertaking pre- and post-test HIV counselling of children should have a good understanding of child development, i.e. the physical, mental, emotional and social processes that characterise development. This is because children will have different needs at different stages of their development, for example, adolescents will require detailed information about HIV and AIDS, whilst younger children are likely to be overwhelmed by too much information.

There should also be an understanding that development can be adversely affected by a variety of factors, including HIV infection, and that age and level of development are therefore not necessarily identical. There may also be differences in level of development in different areas, for example, age-appropriate capacity to understand and think, but less maturity in expressing and managing feelings or social interaction.

In order to counsel effectively, healthcare providers must also talk and interact differently with children of different ages and levels of development. For example, hand puppets may be useful for counselling younger children, whilst role-play might be more appropriate for older children. In addition, the healthcare provider’s understanding of child development will allow sound and accurate assessment of the child’s capacity to participate in the counselling process.

High levels of emotional warmth, developed interpersonal skills and knowledge of how, when and where to refer children for treatment, care and support are also pre-requisites for pre- and post- test counselling of children.

Healthcare providers involved in counselling children should undergo training to assist in developing the above qualities and competencies. They should also receive mentoring and supervision to ensure the implementation of their training to an acceptable standard and support in dealing with the stressful nature of the work.
The physical environment is important in the context of counselling. A private, quiet and comfortable counselling space where there will be no interruptions is necessary to facilitate the counselling process. Materials should include appropriate information and educational materials. Depending on the age and developmental stage of children seen in the service, materials such as pencils, crayons, storybooks or puppets that may aid the counselling process should be standard-issue equipment.

### A youth-friendly service

The National Policy on HIV Counselling and Testing states that HCT services must be youth-friendly. Recommendations for the provision of a youth-friendly service (YFS) include:

- **Facility location**: a safe environment that is accessible by public transport;
- **Facility hours**: convenience (hours do not conflict with school or work);
- **Facility administration**: services offered by appointment as well as through drop-ins, short waiting time;
- **Facility environment**: privacy and confidentiality;
- **Facility staff**: service providers in a similar age range, with an understanding of youth-friendly pre- and post- test counselling and adolescent development;
- **Provision of a range of services**: a “one-stop shop”, including sexual and reproductive health counselling or linkages to agencies offering appropriate support;
- **Peer education**: availability of peer education and counselling;
- **Publicity**: creating awareness of services available;
- **Affordability**: services that are free or affordable;
- **Youth participation**: encouraging young people to identify their needs and preferences and to participate in design of programmes.
References

Boswell, D. & Baggaley, R. (June 2002). Voluntary counselling and testing (VCT) and young people: A summary overview. USA: Family Health International.


APPENDIX A: Model Informed Consent Forms

Version 1: Children able to give informed consent

**INFORMED CONSENT FOR HIV TESTING**

*(to be read to and discussed with client after pre-test counselling and signed by client before testing)*

I, .................................................................................. am ..................................... years old.

I have been given information about HIV and AIDS and have been able to talk about what this means to me.

I have been told about how the HIV test works and what it can and cannot tell about whether I have HIV.

My healthcare worker and I also talked about the possible benefits and drawbacks of testing, both for my healthcare and for relationships and interactions with other people if I test positive. We also talked about the possibility of telling certain people that I have been tested, especially if the test shows I have HIV, and ways I could do this.

I understand that I do not have to have an HIV test and that whether I test or not, I will still be able to get treatment, care and support if I need it.

I understand that if the test shows that I have HIV, I will be given support and helped to get the healthcare I need.

I have been able to ask questions and get answers that I understand.

I have been given enough time to think about this decision and I agree that I want to be tested for HIV.

__________________________________________________________

Name of person giving consent (print): .......................................................... 

Signature/mark: .......................................................... Date: ............................... 

__________________________________________________________

Name of person taking consent (print): ..........................................................

Signature: .......................................................... Date: ...............................
INFORMED CONSENT FOR HIV TESTING

(to be read to and discussed with client after pre-test counselling and signed by client before testing)

I, ...................................................................................... am the parent/caregiver of
...................................................................................... who is aged ......................... years.

I confirm that I have been given information about HIV and AIDS, including how the HIV test works.

My healthcare worker and I have discussed possible benefits and drawbacks of my child being tested for HIV, both for his/her healthcare and for relationships and interactions with other people if s/he tests positive. We also talked about the possibility of telling certain people about my child’s test and ways we might do this.

I understand that I do not have to agree to my child having an HIV test and that whether s/he is tested or not, s/he will still be able to get treatment, care and support if s/he needs it.

I understand that if the test shows that my child is HIV-positive, we will be given support and helped to get the healthcare s/he needs.

I confirm that my questions have been answered satisfactorily.

I have been given enough time to think about this decision and I agree to allow my child to be tested for HIV.

______________________________
Name of person giving consent (print): .....................................................................................

Signature/mark: ................................................................. Date: ...........................................

______________________________
Name of person taking consent (print): .....................................................................................

Signature: ................................................................. Date: ...........................................