

# HIV testing guidelines for children of HIV positive parents and/or siblings in the UK and Ireland

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These guidelines are intended to assist healthcare professionals with the process of HIV testing for children and young people with HIV-infected parents or siblings. Some families may require more time than others to come to a decision to test their child for HIV. A multidisciplinary approach may be required when dealing with more challenging situations. Also refer to '[Don't forget the children](#)' document

Healthcare professionals involved in the process of testing children and young people for HIV following the risk of horizontal transmission (e.g. community sharps injuries, unprotected sexual intercourse etc.) should refer to the CHIVA Post-exposure prophylaxis (PEP) guidelines. <http://chiva.org.uk/professionals/health/guidelines/pep/young-pep-ref.html>

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## 1. Introduction

A significant number of children born to HIV-infected parents, living in the UK and Ireland, remain untested [1, 2]. Some of these children could be infected with HIV and have survived through childhood to adolescence without significant symptoms.

A survey up to the end of 2005 identified 38 adolescents diagnosed with HIV at  $\geq 13$  years of age with a median CD4 count of  $< 250$  cells/mm<sup>3</sup> [1]. These young people contracted HIV perinatally (mother to child transmission). 11/38 infected adolescents developed an AIDS defining illness before or within 2 years of diagnosis. 32/38 started antiretroviral therapy (HAART), within a year of their HIV diagnosis in most cases.

Furthermore, despite the national implementation of preventive measures of mother to child transmission (MTCT), Tookey et al. conducted an audit between 2002 and 2005 in the UK and Ireland and identified 87 HIV infected children [2]. 54/87 of these infected children were born to undiagnosed mothers who either declined antenatal testing or seroconverted during pregnancy. Prolonged breastfeeding was also an important risk factor for MTCT when maternal HIV status was unknown.

Yet, a number of HIV-infected parents are reluctant to test their children for HIV despite the increasing knowledge about HIV and improved prognosis with highly active antiretroviral therapy (HAART) [3]. Some of the main reasons for refusing testing of the child are:

- the child being well
- fear around disclosure of parental HIV diagnosis to the child
- stigma / isolation / guilt
- inability to cope with a positive result.

BHIVA UK guidelines for HIV testing (2008) underline the importance of early HIV diagnosis for better outcomes including reduced mortality and morbidity, better response to HAART and improved public health issues related to HIV transmission [4].

With an increasing number of HIV positive pregnant women and the issues around immigration, testing children in higher risk population groups is paramount [5, 6].

In the updated guidelines for HIV testing (2008), The Medical Foundation of AIDS and Sexual Health (MedFASH) and the British HIV Association (BHIVA) reinforce the fact that [4, 7]:

“It is within the competence of all clinicians and appropriately trained healthcare workers to obtain consent and perform an HIV test. There is no need for special counselling skills beyond those required for routine clinical practice”.

## **2. Transmission of HIV**

The majority of children living with HIV acquired the virus from their mothers either in utero, at delivery, or through breastfeeding (refer to [BHIVA / CHIVA Guideline on the Management of HIV infection in pregnant women](#))

Children and young people may also acquire HIV horizontally (see [CHIVA's post-exposure prophylaxis guidelines](#))

- through unprotected sexual intercourse with an infected person or through sexual abuse.
- through sharing needles, syringes or other equipment during intravenous drug use
- following administration of infected blood, blood products or organ transplantation (rare in UK since screening of blood and organs)
- through sharp injury from used equipment with evidence of fresh contaminated blood.

It is in the best interest of any infant/child/young person thought to be at significant risk of exposure to HIV infection to be tested. This includes all those with parents and/or siblings who are HIV-infected. Testing is only urgent in children who are at risk of rapid disease progression (especially those under 1 year of age) or those who are symptomatic (see flowchart).

## **3. Consent**

In the UK and Ireland, children are defined as those under 18 years old [8, 9]. The age, legal aspect and process of obtaining informed consent may vary from one country to another and depends on the child's capacity to consent, the medical treatment and the child's social situation [10]. Informed consent is required in all cases prior to HIV testing; this should be given voluntarily.

Please refer to the following documents and weblink for further information:

- Seeking consent: working with children.  
[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4067204.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4067204.pdf)
- A Good Practice Guide on consent for Health professionals in NHS Scotland.  
[http://www.sehd.scot.nhs.uk/mels/HDL2006\\_34.pdf](http://www.sehd.scot.nhs.uk/mels/HDL2006_34.pdf)
- Consent to medical treatment in Ireland: an MPS guide for clinicians.  
<http://www.medicalprotection.org/Default.aspx?DN=f74874e6-80ec-46e1-830e-3927f22ed592>
- Fraser guidelines of competence.  
[http://www.nspcc.org.uk/inform/research/questions/gillick\\_wda61289.html](http://www.nspcc.org.uk/inform/research/questions/gillick_wda61289.html)

The Department of Health (2001) suggests it would be good practice to involve the parent/carer with legal responsibility unless the young person does not want that to happen [11].

The involvement of the person with parental responsibility is particularly relevant when testing a young person of HIV positive parentage because there may be concerns over parental diagnosis being disclosed. Therefore, both the young person and the parent/carer may need additional support and reassurance from the healthcare professional.

It should never be assumed that parental responsibility systematically falls with the mother. It would be deemed good practice to involve both parents where appropriate.

The Children Act (1989) promotes the participation of children in giving consent to procedures. Their involvement in discussions on testing should be encouraged where it is felt appropriate and following in-depth discussion with the person/s holding parental responsibility [9].

Whilst consent should be obtained from the parent/legal guardian it is good practice to get 'assent' from the child, i.e. they are aware that a blood test is going to be done and have some explanation of the reason for doing it.

Wherever possible it might be useful to involve young people, who are Fraser competent in the consent process for testing even if their parents are undecided or have not given their consent.

Nevertheless, full disclosure of parental HIV diagnosis to the child is not always appropriate or necessary (i.e. age dependent). This should be discussed and agreed with the person holding parental responsibility prior to discussing the test with the child.

### **3.1. Looked after child / unaccompanied minors**

Refer to CHIVA's Guideline for the testing of looked after children who are at risk of a blood-borne infection:

<http://chiva.org.uk/professionals/health/guidelines/testing/lookedafter.html>

For children looked after by social services, parental responsibility may be shared between parent/s and the Local Authority. Individual Local Authorities commonly have their own policies around good practice with regard to HIV testing of children which can be referred to for guidance.

Consideration should be made for the birth parents, especially mothers, as a positive result will have a significant impact not only on the child but also on one or both parents.

### **3.2. Parental refusal to consent to testing**

This is a difficult area to address and will vary considerably with each case.

Each case should be assessed on its individual issues but should take into account both the child's best interest and parental concerns [8, 9, 13, 14, 15].

Difficulties in obtaining parental consent may arise for the following reasons:

- the parent may be newly diagnosed and not fully accepting their own diagnosis
- parental experience of, or perception of, negative consequences if HIV diagnosis becomes known
- the parental cultural background where HIV is associated with significant stigma
- fear of rejection from children/partner
- fear of parental disclosure to the child leading to the child sharing the information with others

- parent is 'not ready' for the child (dependent on age) to know about what they might be tested for
- "my child looks well so doesn't need testing"
- the adult healthcare professional may not be confident enough to re-visit the issue with each subsequent clinic visit.

Despite the above, the welfare of the child is paramount (Children Act 2004) and must remain at the forefront of any discussion [16]. HIV positive parents, aware of their status, are in a position to be monitored and access treatment in order to achieve and maintain a good level of health. Their children should be afforded the same level of care.

#### **4. Timeline for testing (see flowchart)**

##### **4.1. Infants**

Infants (less than one year of age) infected with HIV are at risk of rapid disease progression to AIDS or death. Antiretroviral treatment of HIV infected infants should be started as soon as possible, ideally before the development of any symptoms. Any infant at risk of HIV infection must be HIV tested as a matter of urgency. An HIV DNA PCR or HIV viral load should be done if the child is < 18 months of age.

##### **4.2. The Asymptomatic child**

An upfront and honest discussion with the parent/guardian with legal responsibility on the reasons for testing the child should be initiated.

Parents may be offered sufficient time to come to terms with the prospect of testing their child for HIV (i.e. 6 months maximum). Parents should also be informed that they will be expected to engage with the clinical team during these 6 months.

If the parents are not fully ready to test their child, additional time (i.e. 6 months maximum) may be granted with a definitive deadline providing the child remains asymptomatic.

Any parent/guardian refusing to engage within the 6 month time scale will be informed of the need to refer the child to local social services for further action (e.g. court order) as an issue of safeguarding the child's wellbeing. In addition, professionals involved in the process of testing the child for HIV should discuss ways of approaching the family with the paediatric HIV specialist team and a multidisciplinary meeting may be necessary.

### **4.3. The acutely ill / symptomatic child**

Where a child is hospitalised or frequently unwell with symptoms suggestive of HIV infection, a more direct approach will need to be taken and consent for testing agreed within a much shorter time scale. This will depend very much on the severity of the presenting illness; this could be in a range of immediate testing to 4 weeks post admission to the hospital. Discussion with local specialist paediatric services and referral to social services is recommended in case of parental refusal.

These time lines are designed to guide the practitioner and are in no way mandatory.

Each case should be assessed by the multidisciplinary team working with the child and their family on an individual basis and action taken accordingly.

## **5. Confidentiality**

The BHIVA testing guidelines (2008) state that 'HIV testing has historically been an exception and treated differently to testing for other serious medical conditions' [4]. Like any other medical condition, the general principles of confidentiality should be adhered to by any healthcare professionals and not just doctors, as laid down by the General Medical Council (GMC) (2004) [17].

*'Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to give doctors the information they need in order to provide good care'.*

Even though HIV is now treatable and considered a chronic condition there is still stigma associated with an HIV diagnosis. For this reason, families should be assured of confidentiality at both the pre- and post-test discussion. Parents of a positive child may also need to be reassured of confidentiality around their own diagnosis if they are not yet willing, or it would be age inappropriate, to disclose to their child.

Older children who have consented for an HIV test may decide to get their result in confidence. It is highly recommended to involve parents, for support as well as the need for them to consider an HIV test if their own status is unknown.

## **6. Procedure for testing**

### **6.1. Where to obtain an HIV test?**



HIV testing can be obtained in the community from GPs and health centres, GUM clinics, voluntary agencies and outreach centres. Most large cities have specialist centres or large paediatric units who will give advice and/or deal with referral to local paediatricians specialising in HIV.

## **6.2. Who can test?**

Any competent clinician (GPs, nurses, midwives, registrars, health advisers, etc.) can obtain verbal informed consent and perform an HIV test. Written informed consent is not recommended. However, the discussion and verbal consent must be documented in the medical notes, dated and signed by the person obtaining consent.

## **6.3. Who should be offered a test?**

- All children / young people where a parent or sibling is known to have HIV or may have died of an HIV associated condition
- where no documentation of the child's previous negative HIV test result is provided
- a child whose father has HIV and mother's HIV status is unknown (it may be better to determine mother's HIV status if possible, before making the decision to test the child)
- children / young people with signs and symptoms consistent with an HIV diagnosis
- children / young people newly arrived in the UK from high-prevalence areas if test indicated
- children / young people who are presented for fostering/adoption where there is any risk of blood-borne infections.
- Children of HIV infected parent diagnosed after the child was born, even if the mother had a negative antenatal test. This is due to the risk of seroconversion or HIV infection during pregnancy or breastfeeding (unless evidence of maternal negative HIV status post-delivery or post-breastfeeding)

## **6.4. Which test to use?**

Children < 18 months should be tested for genomic evidence of HIV by PCR with repeat confirmatory PCR if initial test is positive

Children > 18 months, as for adults, should have an HIV antigen/antibody test:

- 4<sup>th</sup> generation Assay (recommended) test for HIV antibody and P24 antigen simultaneously; which reduces the time between infection and HIV detection to 1 month
- 3<sup>rd</sup> generation Assay: HIV antibody only detection; time between infection and HIV detection is 6 weeks minimum
- Point of care test (POCT) (where available) should be used with caution. Only CE-marked POCT kits must be used and a nominated accredited pathology laboratory should assist with governance issues and quality assurance of the test process. Any reactive test result must be confirmed by a serological test (i.e. false positive result). The use of venous blood in POCT is recommended as experience in practice shows that families may refuse a confirmatory test if POCT is reactive. Perform POCT as well as taking a sample of venous blood. Send venous blood sample for HIV antigen/antibody test if POCT result is reactive, discard blood sample if negative. Healthcare professionals using POCT must be trained in accordance with local and national guidelines on the use of POCT

## **7. Pre-test discussion**

The pre-test discussion is to establish informed consent for HIV testing of the infant/child/young person. This should ideally involve both parents and where appropriate the child or young person.

Regardless of the age of the child/young person and prior to organising an appointment for the child, an initial conversation with the person with parental responsibility would clarify how much information about the test parents are prepared to disclose. This is to clearly establish whether or not they want to disclose their own diagnosis (if applicable).

Parents should be allowed enough time (i.e. weeks or months –see above) to reflect on the initial conversation if necessary. Negotiation on how much information about the test the child should know helps them feel empowered and actively involved in the decision to test.

Discussion with HIV infected parents accessing adult specialist care should be initiated in the adult department and appropriate referral to paediatric services made following parental agreement to test the child for HIV. This is to ensure adequate parental follow-up through the

process of testing if parents need more time to reach an agreement. Paediatric specialist services should assist the adult clinician with the discussions

It is never good practice to test children, whatever their age, without them having a reason why a blood test is being carried out.

For the primary school aged child, it is usually possible to negotiate at least a partial truth; for example 'your parents agree that you should have a blood test to check for any germs or viruses in your blood' or 'we would like to check how strong your body is to fight infections.'

For older children (>12 years old), families should strongly be encouraged to openly discuss the test with their child. When dealing with HIV-infected parents, strong objection from parents to disclose their own diagnosis should not prevent the child from being tested. A full explanation including the words 'testing for HIV' is in their best interests.

In practice, healthcare professionals have used different strategies to test young people for HIV without disclosing parental HIV status. "Health check" including HBV, HCV and HIV testing, as well as sexual health screen may be possible with older children. Nevertheless, parents should be warned and anticipate that children may ask questions about the reasons for the need of a "health check".

The pre-test discussion should include:

- Reasons and benefits for testing (risks of transmission, prognosis, treatment available in UK).
- When possible, a full history of child's health including birth and country of origin, breastfeeding, past medical history, transfusions, etc., should be obtained. The discussion should also include information about the family (e.g. status of other parents, siblings) and refer appropriately.
- Consequences for not testing the child (i.e. risks of becoming unwell, death).
- Any concerns raised by the family (e.g. disclosure to the child or partner, fears of positive result, family issues).
- How and when the test result will be given and confirm contact details.
- As most children with HIV have acquired the virus from their mother, testing a child has huge implications for the family, as a positive test is likely to indicate the mother

is positive and her partner and other children may also be infected, also requiring an HIV test. .

### **7.1. Cultural / religious / personal issues**

Parents/carers should be given every opportunity to voice their concerns and questions about testing their child so they feel included in the process and understand the reasons fully. Negotiation is paramount as some parents may find the decision difficult to make. It is usually possible to achieve a balance which respects parental views whilst being clear that the evidence from the UK experience shows that testing their children for HIV is the best protection of their child's future health.

Where interpreters are required it is generally best to avoid using other family members or friends because of the issues around confidentiality.

### **7.2. How will the result be given?**

An appointment should be arranged in order to give the result to the family. When possible, results should be given by the health professional that carried out the procedure. Waiting for an HIV test result is a very anxious time for families. Therefore, arrangement should be made to give the result in a timely fashion.

Results of an HIV test whether positive or negative should not be given by mail, telephone or email. However, results may be given by phone in exceptional circumstances (e.g. family living out of area). Parents/guardian must clearly understand the risks of getting a positive result by phone with no immediate support.

Young persons should be given some time to consult in private. This is to allow any discussion related to personal issues including sexual health. Parents accompanying the young person should be made aware of this procedure. Information on confidentiality should be emphasised to the young person.

Children under 16 years old who are sexually active should be assessed according to Fraser guidelines. Refer to [The Society of Sexual Health Advisers' Manual – working with specific groups](#).

## **8. Post-test discussion**

The result should be given face to face in a confidential environment and in a clear and direct manner. If the family's first language is not English, consideration should be given to the use of an appropriate confidential translation service.

Regardless of the test result, meet with the parent/legal guardian prior to discussing result with the child. This is to contain any reaction from the parent that could upset the child.

However, the test result may be given to young people in confidence and further discussion on extending disclosure to significant family members must take place.

### **8.1. Test result negative**

- Advise on health promotion (e.g. sexual health, PEP) according to age then discharge from the clinic
- allow the child/young person to ask any questions or share concerns
- offer the possibility of a follow up appointment or a phone call to talk about the testing again where necessary. This may be important for those children who have had HIV named as part of the testing procedure and who may have concerns about their parents' diagnosis. Refer to appropriate services (i.e. GP, HIV counsellor, paediatric HIV team, psychology department) where necessary.

Children born to HIV-infected mothers known to have been breastfed should be tested for HIV at a minimum of 3 months following the last day of breastfeeding.

### **8.2. Test reactive or equivocal** (mainly children/adolescents who are sexually active)

These clients may be sero-converting and management of re-testing may be complex. Such individuals should be promptly referred to specialist care. Inform the family/young person of the need for referral to the paediatric HIV team for further follow-up.

### **8.3. Test result positive**

If the child is aware that the test was for HIV, meet both the child and legal guardian to discuss results and follow up.

If the child is not aware of HIV test, meet with legal guardian prior to discussing result with the child. This is to contain any reaction from the parent that could upset the child.

Reassure and allow the family to reflect on the positive result but link into appropriate services.

Refer the family promptly to appropriate specialist services. It is recommended that any child testing positive for the first time is seen by a specialist (HIV clinician, specialist nurse, sexual health adviser) at the earliest possible opportunity, preferably within 48 hours and certainly within 2 weeks of receiving the result. A child/young person under 16 years old should be seen by someone who has paediatric experience.

## **9. Conclusion**

Testing children of HIV-infected parents or siblings is paramount regardless of parental age, gender, sexual orientation, etc. This is to prevent disease progression and poor health outcomes of undiagnosed HIV positive children. Health care professionals should feel confident discussing such issues with clients from high-risk population groups and undertaking HIV testing. The relevant healthcare centre should be contacted to confirm the child is uninfected or an HIV antibody test should be repeated when there is no proof of a previous negative result.

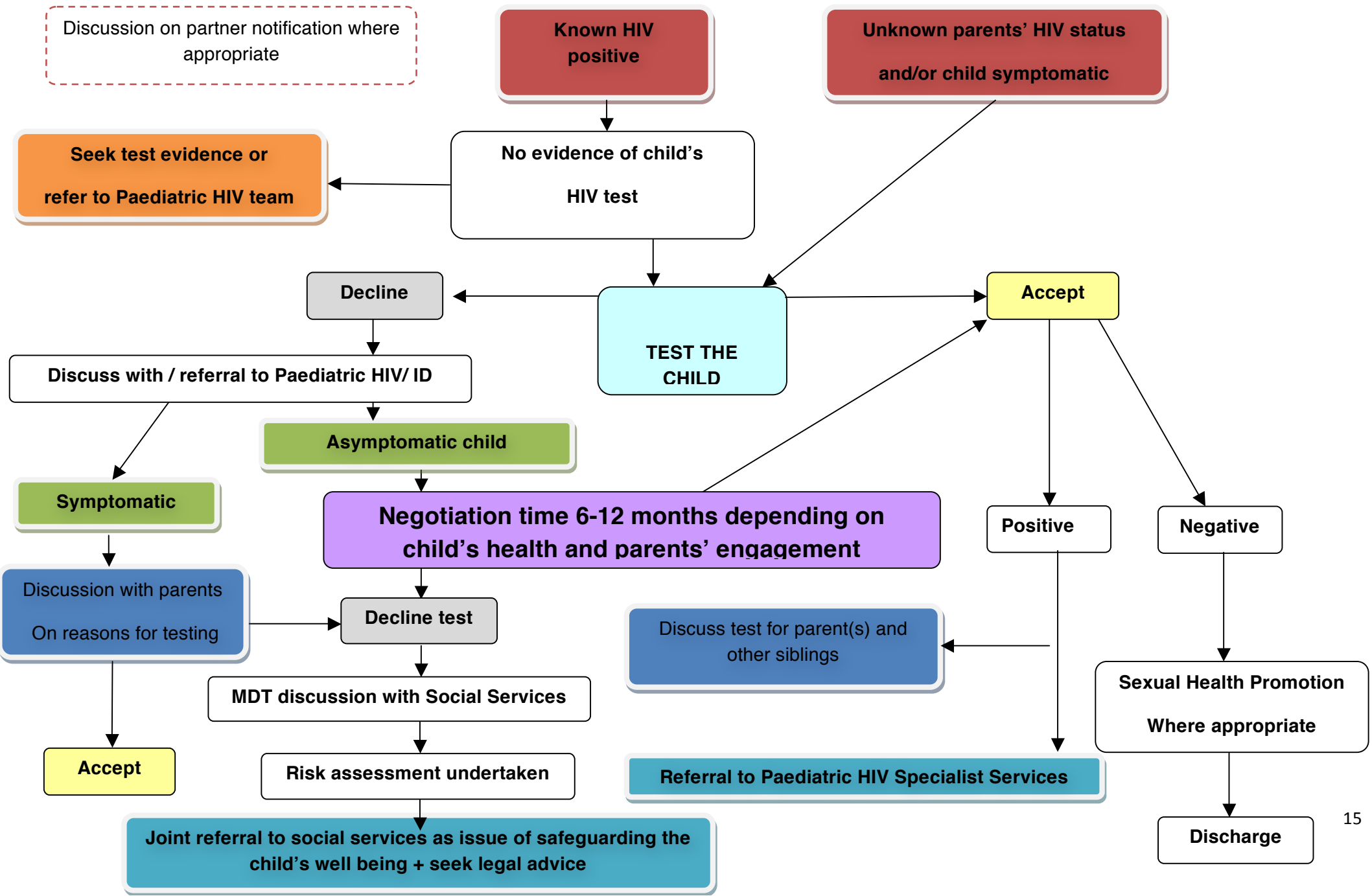
Regular multidisciplinary meetings with the presence of an adult HIV clinician, a paediatric specialist nurse, paediatrician, social worker, psychologist and any other healthcare professionals directly involved with the process of testing is recommended. This is to discuss any issues related to those families in follow up and highlight any difficulties with getting the child tested. The communal decision to refer the child to social services for additional support may be relevant.

Close work in collaboration between adult and paediatric services with effective communication is therefore paramount.

Appropriate referral to HIV specialist services is preferable when dealing with difficult situations (i.e. reluctant parents). Refer to CHIVA network.

<http://chiva.org.uk/professionals/health/networks/index.html>

**HIV testing pathway For children of HIV infected parents and/or siblings**



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