

HIV testing guidelines for children of confirmed or suspected HIV positive parents

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Introduction

A significant number of children born from HIV positive parents, and living in the UK and Ireland, remain untested^{1,2}. Many of these children could potentially be infected with HIV and survive through childhood to adolescence without any symptoms.

Recent findings¹ identified 38 adolescents diagnosed with HIV at 13 years of age and above to the end of 2005 with a median CD4 count of < 250 cells/mm³. These young persons 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 preventative measures of mother to child transmission (MTCT), an audit conducted by Tookey and co-workers² between 2002 and 2005 in the UK and Ireland identified 87 HIV infected children. 54/87 infected children were born from undiagnosed mothers who either declined antenatal testing or seroconverted during pregnancy. Prolonged breastfeeding was also an important risk factor of MTCT when maternal HIV status was unknown.

Many HIV-infected parents are reluctant to test their child for HIV³ despite the increasing knowledge about HIV and improved prognosis with highly active antiretroviral therapy (HAART). Some of the main reasons for refusing testing the child are:

The child being well

Fear around disclosure of parent HIV diagnosis to the child

Stigma / isolation/guilt

Inability to cope with a positive result

Recent BHIVA 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 transmission⁴.

With an increasing number of HIV positive pregnant women⁵ and the issues around immigration, testing children in higher risk population groups is paramount.

In the updated guidelines for HIV testing (2008)^{4, 6}, The Medical Foundation of AIDS and Sexual Health (MedFASH) and the British HIV Association (BHIVA) reinforce the fact that

“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”.

Transmission of HIV

The majority of children living with HIV acquired the virus from their mothers either in utero, at delivery or through breastfeeding (vertical transmission): <http://www.bhiva.org/cms1221368.asp>

Children and young people may also acquire HIV horizontally:

[http://chiva.org.uk/health/guidelines - pep](http://chiva.org.uk/health/guidelines-pep)

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 or blood products or organ transplantation (rare in UK since screening of blood and organs)

Through sharp injury from used equipment with evidence of fresh 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 or siblings, who are HIV infected.

Testing is only urgent in children who are at risk of rapid disease progression or who are symptomatic (see appendix 1).

Consent

In the UK and Ireland, children are defined as those under 18 years old (UN Convention on the Rights of the child 1989 and Children Act, 1989)^{7,8}.

Informed consent is required in all cases prior to HIV testing; this should be given voluntarily. Some of the issues that may arise are addressed below, including practical guidance:

Young people over 16 years

Under English law, young people aged between 16 and 18 years old are assumed to have the capacity to consent to medical treatment in the same way as adult and therefore have the legal right to consent to their own medical treatment (Family reform Act 1969); but unlike adults, the refusal of treatment can be overridden by a person with parental responsibility or the court.

This is done on the basis that the welfare of the young person is paramount. If a young person over 16 years old gives consent, it is not necessary to gain consent from a person with parental

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

The involvement of the person with parental responsibility is particularly relevant when testing a young person of HIV positive parentage, as there may be concerns over parental diagnosis being disclosed, which may require additional support to the young person as well as reassurance to the parent/carer by the healthcare professional.

Children and Young People less than 16 years

A child or young person under 16 years old can give consent to treatment if they are classed as what was historically known as 'Gillick competent' but more widely referred to as Fraser guidelines or competence.

http://www.nspcc.org.uk/Inform/resourcesforprofessionals/InformationBriefings/gillick_wda61289.html

This essentially means, a child who has sufficient knowledge to enable them to understand fully the nature and implications of having an HIV test also have the capacity to give their consent. As for children over 16 years old, it is not only good practice but also prudent to involve those with parental responsibility.

The Non Competent Child

If a child lacks the capacity to consent either due to age or mental capacity, the consent of one parent/carer with parental responsibility is sufficient. Clarification should be sought on who holds parental responsibility and this should be documented.

As most children will acquire HIV from their mother it is likely that she will hold parental responsibility and therefore maternal consent should be sought although it would be deemed good practice to involve both parents where appropriate.

However, it should never be assumed that parental responsibility falls with the mother.

The Children Act (1989) promotes the participation of children in giving consent to procedures and 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.

It can help to remember that 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.

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.

Looked after child/Unaccompanied minors

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

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 the mother as a positive result will have a significant impact not only on the child but also on one or both parents.

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 and should take into account.

The rights of the child

Children Act 1989

Working together to Safeguard Children 2006

UN Convention on the Rights of the Child.

Article 2 or 6 - the right to life.

Article 24 – the right to the highest attainable standard of health.

The rights of the parent

Disclosure of a parent's HIV status infringes his/her right to medical confidentiality.

It also infringes his/her right to respect for his private life under article 8 (European Convention on Human Rights, 1954).

To make their own decisions regarding their children's medical treatment.

Parents' rights are not absolute- they can be infringed if necessary to protect the child's own rights. But only if infringement is proportionate to the risk (i.e. is there a less aggressive method of dealing with the situation?).

Difficulties in obtaining 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 known

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. After all, the HIV positive parent, who knows their status, is in a position to be monitored and start effective treatment at an optimum time to achieve and maintain a good level of health, and therefore their child should be afforded the same level of care.

Timeline for testing (Appendix 1)

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. A time line prior to referring the child to social services should be discussed (i.e. 6 months). Parents should be informed that they will have to engage with relevant healthcare services (e.g. GP, Paediatric HIV Team, HIV counsellor...) during these 6 months. If the parents are not fully ready to test their child, an additional 6 months may be granted with a definitive deadline provided the child remains asymptomatic.

Any parent 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 as an issue of child protection.

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.

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

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

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. 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)⁹. *Confidentiality: protecting and providing information*⁷.

'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 consented for an HIV test may decide to get their positive 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 status unknown.

Where to obtain an HIV Test

In the community, HIV testing can be obtained from GP and Health centres, GUM clinics, Voluntary agencies and outreach centres. Most large cities have specialist centres or large paediatric units who would give advice and/or deal with referral to local Paediatricians specialising in HIV.

Procedure for testing

Who can test?

Any competent clinician (GP's, Nurses, midwives) can obtain informed consent and perform an HIV test.

This should be documented in the case notes and may be verbal or written, dated and signed by the person obtaining consent.

Who should be offered a test?

All Children/young person 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

Children whose father has HIV and mother's HIV status is unknown.

Children/young people with signs and symptoms consistent with an HIV diagnosis

Children/young person newly arrived in the UK from high-prevalence areas

Children/young person who are presented for fostering/adoption where there is any risk of blood-borne infections.

Pre-test discussion

The pre-test discussion is to establish informed consent for HIV testing of the infant/children/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 organizing 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) 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.

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 (e.g. Your parents agree that you should have a blood test to check for any germs or viruses 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. Strong objection from parents to disclose their diagnosis should not prevent the child from being tested. a full explanation including the words 'testing for HIV' is in their best interests

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...)

As most children with HIV have acquired the virus from their mothers, 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.

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.

How the result will 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.

Results of an HIV test whether positive or negative must not be given by mail, telephone or email.

Young persons should be entitled 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 Gillick competences criteria.

<http://www.ssha.info/public/manual/index.asp>

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 utilisation of an appropriate confidential translation service.

Test result negative:

Advice 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 to talk about the testing again where necessary. This may be important for those children who have had the HIV named as part of the testing procedure and who may have concerns about their parents' diagnosis.

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

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 service

Refer the family promptly to appropriate specialist services. It is recommended that any children 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 16years should be seen by someone who has paediatric experience.

Which test to use?

Children < 18 months should be tested for genomic evidence of HIV by PCR.

<http://www.bhiva.org/cms1221368.asp>

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

4th generation Assay (recommended) test for HIV antibody and P24 antigen simultaneously; reduce the time between infection and HIV detection to 1 month

3rd 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. Send venous blood sample for HIV antibody test if POCT result is reactive, discard blood sample if negative. Healthcare professionals using POCT must be trained in accordance with local guidelines

Conclusion

Testing children of confirmed or suspected parental HIV positive status 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 in their daily practice with discussing such issues with their clients from high risk population groups and undertake HIV testing of existing offspring. An HIV antibody test should be repeated in absence of the proof of a previous negative result.

Appropriate referral to HIV specialist services experienced in paediatric/family HIV is preferable when dealing with difficult situations (i.e. reluctant parents...) Refer to the CHIVA network for advice

<http://chiva.org.uk/networks>

Also see 'Don't forget the Children' document (ref)

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