

# 'Don't Forget the Children'

Guidance for the HIV testing of  
children with HIV-positive parents

## MISSION STATEMENT

*The HIV status of all the children of known  
HIV-positive adults in the UK should be known  
as a matter of clinical urgency*



# 'Don't Forget the Children'

Guidance for the HIV testing of  
children with HIV-positive parents

British HIV Association • Children's HIV Association • British Association for Sexual Health and HIV

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**'Don't Forget the Children'**

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1 Mountview Court • 310 Friern Barnet Lane • London N20 0LD

Tel: 020 8446 8898 • Fax: 020 8446 9194 • Email: [info@mediscript.ltd.uk](mailto:info@mediscript.ltd.uk)

# 'Don't Forget the Children'

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## Executive summary

### The current situation

- Undiagnosed HIV is a well-recognised problem in the UK among adults and is associated with late presentation and increased morbidity and mortality. It is less well understood in children.
- The children of HIV-positive adults attending HIV services are a readily accessible group of children at risk of HIV infection.
- There is a current lack of robust protocols in place to ensure that children at risk of HIV infection are identified and tested.
- Many children with vertically acquired HIV (HIV infection passed from mother to child) will become symptomatic within the first 1–2 years of life; however, some may remain asymptomatic well into adolescence.
- The morbidity of vertically infected children is reduced by HAART even when children are overtly asymptomatic or only showing sub-clinical signs of disease. Undiagnosed HIV infection in children is a significant cause of potentially avoidable morbidity and mortality.
- Children of HIV-positive parents in the UK who were born abroad are those most at risk of undiagnosed paediatric HIV infection as they are less likely to have had antenatal HIV testing and treatment.
- In law the safety of the child is paramount, although laws also protect the privacy of parents regarding their own medical information.
- HIV testing of children is clearly in the medical interests of the child and, in the majority of cases, testing the children of HIV-positive parents is straightforward. However, if the parents consistently refuse, thereby putting the child at risk of having undiagnosed HIV infection, it may become a child-protection issue and need to involve the courts.
- Parents may have major concerns about testing their children for HIV, relating to fear of disclosure, stigma, guilt and the inability to cope with their child receiving an HIV-positive diagnosis.

### Recommendations for Standards of Care

1. All adult HIV services, including statutory and voluntary, as well as NHS and social services, must have protocols and procedures in place to ensure that all children of HIV-positive parents are tested for HIV.
2. A multi-sector, multidisciplinary team needs to be identified for each HIV service, or network, and be responsible for setting up protocols and managing cases if and when they arise.
3. Where an adult HIV service has no nearby specialist paediatric HIV services, referral and advice pathways will need to be developed which include the regional HIV paediatric lead.
4. All HIV units will need to perform a 'look back' exercise to establish the HIV status of any children whose HIV-positive parents attend that service.
5. All HIV services need effective operational procedures and information systems to monitor this process comprehensively.
6. All new HIV-positive patients attending adult HIV services should have any children identified, tested and the information clearly documented.
7. There need to be joint protocols in place between health and social care to manage those cases where parents initially refuse, in order that these cases may be dealt with sensitively and appropriately. A clear pathway of referral needs to be identified within the multidisciplinary team.
8. All healthcare professionals have a duty to ensure the safety of children, so if the child is persistently being put at risk by not being tested then there is a clear threshold for referral to child safeguarding services.
9. Appropriate follow-up support should be provided for all children and parents, regardless of the test outcome, to help with disclosure or adjustment issues that may arise subsequently.

## Introduction

*Any infant/child/young person thought to be at significant risk of HIV infection, including all those with parents or siblings who are HIV infected, should be tested*

*UK National Guidelines for HIV Testing 2008, Appendix 5: Testing infants, children and young people*

Undiagnosed HIV infection is a significant problem in the UK. Much attention has been given to the problem of undiagnosed HIV-positive adults, though the proportion of these adults who remain unaware of their HIV infection has remained largely unchanged over the last few years. Antenatal HIV testing and diagnosis has been a great success and shows what can be achieved with a focused and well targeted strategy. There appears to have been less attention given to identifying undiagnosed HIV-positive children.

Undiagnosed HIV infection leads to a significant risk of increased morbidity and mortality in adults and children alike. This report came into being as a direct consequence of the death of a 10-year-old child who had undiagnosed HIV infection all his/her life. This child was diagnosed HIV positive only hours before death. This report is particularly concerned with increasing the level of HIV testing in a well defined, readily accessible group at significantly increased risk of HIV infection – those

children whose parents have been diagnosed HIV positive and are currently receiving HIV care at adult centres in the UK.

The 14th Annual British HIV Association (BHIVA) Conference took place several weeks after SP died in spring, 2008. Several presentations were made referring to this case and audience discussion revealed that the majority of HIV units did not have robust systems for identifying and testing the children of the HIV-positive adults attending their clinics. It also became clear that there were many practical concerns about how to achieve this goal.

As a direct result of this, BHIVA, the Children's HIV Association (CHIVA) and BASHH (British Association for Sexual Health and HIV) came together with a small steering group, including representatives from the voluntary sector, to organise a multi-sector, multidisciplinary conference entitled 'Don't Forget the Children'. The aim of the conference was to explore the issues from a multidisciplinary perspective, reach a

### The case of SP

SP was 10 years of age and had a chronic medical condition. SP became unwell one evening, was taken to hospital the following morning and subsequently admitted, with general malaise and a low-grade fever, indicating a probable infection. SP's condition gradually deteriorated during the next few hours.

The parents were asked if the child had any other underlying health issues and at this point, they disclosed that they were HIV positive and had been diagnosed 6 years earlier. SP had never been HIV tested and had an urgent HIV test that came back positive. SP's condition continued to deteriorate rapidly, which resulted in a transfer to the Paediatric Intensive Care Unit. SP went into a coma and died shortly afterwards – less than 48 hours after the initial presentation to the hospital.

Further investigation, after SP's death, showed that SP's mother had been advised to have SP tested for HIV. This had been discussed with her doctor and a nurse-counsellor at the time of her initial HIV diagnosis. She declined to allow SP to have an HIV test at that time as she felt that her child was well, and she herself was not in the right frame of mind. She was already struggling to deal with the issues and felt that she could not cope with having her child HIV tested in case the result came back positive. After further discussion she agreed to have her child tested for HIV at a later date.

It does not appear that either the parents or the HIV team looking after them raised the issue again. It is possible that SP would not have died had his/her HIV status been known 6 years earlier.

(The real initials of this child have not been used.)

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consensus on the way forward and develop guidance for HIV care providers and planners as to how best to achieve this.

Money was raised from the Department of Health and the pharmaceutical industry to ensure that attendance at the conference would be free. Additional funding was granted by the Elton John AIDS Foundation to produce a report on the issues and the changes that need to occur in practice.

'Don't Forget the Children' was held on Wednesday 10 December, 2008 and was attended by over 160 participants including those from adult and paediatric HIV care, social services, voluntary sector services, People Living with HIV (PLHIV), legal experts and epidemiologists. The structure and content of this report reflect the structure of the conference and the discussions that took place.

**Section One** sets out the epidemiological and clinical background to the problem, including how many children are likely to be positive, which groups are at high risk and the consequences of late diagnosis.

**Section Two** looks at the relevant legal and child safeguarding issues and highlights the duties and responsibilities of those working with families and children.

**Section Three** offers practical responses and guidance.

**Section Four** sets out case studies and ways to support families in having their children tested.

**Section Five** offers recommendations.

The **Appendices** include a pathway to testing and an information sheet for patients.

***Throughout this report, reference to the testing of children for HIV is taken to apply principally to birth children. The need or otherwise to test step-, adopted or fostered children should be assessed individually according to the risks outlined in 1.1.3.***

## Section One: Clinical presentations

This section is closely based on presentations given at the 'Don't Forget the Children' conference and provides background epidemiological and clinical information about HIV and its clinical presentation in children in the UK. The original presentations can be accessed online [1].

*The most dangerous HIV in the UK is undiagnosed HIV*  
Participant, 'Don't Forget the Children'

### Summary

- It is difficult to assess the number of undiagnosed children based on currently available information, although the number of undiagnosed infected UK-born children currently aged over 10 is likely to be small.
- HIV-positive children can survive into their teens before developing symptoms, although most will become ill in the first year or two of life.
- Most HIV-infected children in the UK were born abroad in countries of high HIV prevalence, most notably Sub-Saharan Africa.
- Two-thirds of HIV-positive infants in the UK are born to HIV-positive women who remain undiagnosed throughout pregnancy. Sixty percent of infants born to undiagnosed women die, compared to 20% of infants born to diagnosed women.
- It is paramount that infants born to mothers with HIV are diagnosed before they develop symptoms.
- If there is a positive parent or sibling, then the child needs to be tested.

### 1.1 The UK epidemiology of undiagnosed HIV infection in children

Infants whose mothers are diagnosed with HIV before or during pregnancy are usually tested soon after birth, and are not breastfed. In 2000–2006 1.2% of infants became HIV infected when the mother had been diagnosed HIV positive prior to, or during pregnancy. Although young children of newly diagnosed women are likely to be tested, it is less clear what happens to older children.

#### 1.1.1 HIV-infected population in the UK (HPA, 2007)

There were approximately 56,000 people living with diagnosed HIV in the UK in 2007, including 20,000 women. Another 21,000 individuals were estimated to be HIV positive but remained undiagnosed and so did not know that they were HIV positive. About 7,700 individuals were newly diagnosed in 2007, of whom 55% (4,260) acquired their infection heterosexually.

### 1.1.2 How many HIV-infected adults have children?

This number is unknown. Several factors need to be taken into account, including the age profile of the HIV-infected population and differing fertility rates in different ethnic groups. Information from local audits (see 1.3) can be very useful in this analysis.

#### 1.1.3 Children at significant risk of having undiagnosed HIV infection in the UK

- Children of diagnosed HIV-positive women and men
- Siblings of diagnosed HIV-positive children and young people
- Children of undiagnosed HIV-infected parents
- Children born abroad, especially in high-prevalence countries
- Unaccompanied refugee and asylum-seeking children
- 'Looked after' children
- Children living abroad whose HIV-infected parents are UK residents
- Children with non-vertically acquired infection

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## 1.1.4 Children with diagnosed HIV in the UK

There were 772,000 infants born in the UK in 2007.

- Of these, about 1,230 had mothers with diagnosed HIV. About 1% of these mothers' infants are likely to be infected, and most will have been diagnosed within a year.
- 70–120 undiagnosed women probably gave birth. About 30% of their infants are likely to be infected, and about a third have probably already been diagnosed.

## 1.1.5 Older children

To date, about 1,700 children under the age of 16 have been diagnosed with HIV in the UK. Of these, 95% (1,600) were 'vertically infected' (where the HIV passes from mother to child), and just under 50% were born abroad. In 2007 about 1,000 under-16s were being seen for HIV care. This included about 80 newly diagnosed children, of whom about 60% were born abroad.

**Table 1:** Age at diagnosis: children diagnosed since 2000 in the UK, reported to NSHPC by September 2008



P. Tookey, DFTC

## 1.1.6 Audit of perinatal transmission of HIV in England 2002–2005 [2]

This audit was based on a review of 3,400 infants born to HIV-infected women in England over a 4-year period, reported to the NSHPC by March 2006; 87 HIV-infected children were identified. No transmissions occurred from diagnosed HIV-positive women who had optimal care and undetectable viral load at delivery.

Thirty percent of infected children were born to women diagnosed at or before delivery.

- Likely contributory factors included failures of communication, concurrent infections in pregnancy, late diagnosis and/or premature delivery.
- To date, two children are known to have died and 20% of survivors have had an AIDS-defining illness.

Seventy percent of infected children were born to undiagnosed HIV-positive women.

- In some cases antenatal testing was not offered or was declined.
- At least 15% of mothers had a negative antenatal HIV test, so seroconversion (primary HIV infection) must have occurred later in pregnancy, or after delivery during breastfeeding.
- To date, nine children are known to have died and 60% of survivors have had an AIDS-defining illness.

Adverse social circumstances were reported in many families, including mental health issues and problems with housing and immigration.

## 1.1.7 The audit's recommendations

The audit made thorough recommendations [3] which include:

- Reducing the length of 'turnaround' time for getting the result of the HIV test
- The testing of unbooked women at delivery with a 'rapid' HIV test
- Postnatal care including the administering of PEP, and not breastfeeding
- Testing the family of any woman who tests positive antenatally.

## 1.2 The consequences of undiagnosed HIV in children

In infancy there is a high risk of rapid HIV progression and death, which is why HAART should be started immediately [4]. It is therefore important that HIV-positive infants and children are diagnosed and receive medical care urgently.

### 1.2.2 Mortality

Data from the USA offer information on the mortality rates of HIV-infected children aged 5–14 years of age (PACTG 219). Despite HAART (Highly Active Antiretroviral Therapy), HIV-infected children still have a more than 30-fold higher death rate than HIV-uninfected children of the same age.

### 1.3 An audit on the knowledge of their children's HIV status in HIV-positive mothers attending a genitourinary medicine clinic in the UK [5]

An audit was undertaken of HIV-positive women attending the GUM outpatient clinic of a district general hospital in the UK over a 4-month period.

**Table 2:** Children diagnosed with HIV in the UK since 1998 (n = 815)

Age at Diagnosis	At diagnosis CD4 < 15% and / or CD4 <200	One year after HAART CD4 < 15% and / or CD4 <200	Newly diagnosed start HAART and died within 1 yr
0-1 yr	22%	2.7%	11
2-4 yrs	33%	7%	1
5-9 yrs	33%	11%	6
10+ yrs	54%	27%	1

- Data were gathered using a survey method with a proforma filled in by a clinician during consultation.
- The survey looked at 297 women. They were found to have 217 children under 16 years of age between them. Of these 217 children, only 58 had been tested for HIV.

Reasons given for not testing the children were:

- For 43/52 (82%) of mothers: the perception that physical wellbeing is incompatible with HIV infection. This was the only reason given by 16/43 (32%).
- For 29/52 (56%) of mothers: fear of disclosure
- For 22/52 (42%) of mothers: the inability to cope with a positive diagnosis
- For 20/52 (38%) of mothers: the fear of feeling guilty if the child was diagnosed positive

The audit concluded that the HIV status of the majority of the children of the HIV-positive parents attending that GUM service was unknown. At re-audit a year later, 68% of the children were still untested.

#### 1.4 An analysis to establish the information on late diagnosis of perinatally acquired HIV [6]

The aim of this analysis was to describe the clinical features and modes of presentation in adolescents with vertically acquired HIV infection diagnosed at 13 years and above in the UK or Ireland. The data sources were paediatric surveillance to September 2007 (NSHPC and CHIPS) and adult surveillance to December 2005 (HPA and SOPHID).

Forty-two young people were located through this analysis, of whom:

- 20% had their HIV diagnosis delayed for more than a year
- 20% were at an advanced stage of disease at diagnosis
- 50% had CD4 <200 cells/ $\mu$ l
- 50% were asymptomatic

The analysis concluded that a significant number of young people with vertically acquired HIV infection are surviving childhood, without treatment, to be diagnosed in adolescence.

#### 1.5 Conclusion

The number of undiagnosed HIV-infected children in the UK is difficult to assess, yet there are a significant number of children of HIV-positive parents who remain untested and, of these, a proportion are likely to be HIV positive.

Parents face a number of barriers to testing their children, including the belief that a healthy child cannot be HIV positive. Other reasons include guilt and fear of disclosure.

Untested HIV-positive children can and do survive into adolescence, symptom free and undiagnosed. They remain at risk, however, of increased morbidity and mortality due to late diagnosis.

The limited data available suggest that only a minority of the children of HIV-positive adults receiving HIV care in the UK have been HIV tested. This leaves the untested children at risk of the complications of untreated HIV infection and AIDS. The testing of the children of these HIV-positive adults should be undertaken as a matter of urgency to reduce the risk of unnecessary morbidity and mortality associated with late presentation of HIV.

## Section Two: Legal issues

**This section sets out the legal framework for the issues relating to testing children for HIV. Utilising the law in the context of testing the children of HIV-positive mothers should only happen once all other avenues are explored through a multidisciplinary approach.**

*Parents have rights; but so do their children*  
Speaker, 'Don't Forget the Children'

### Summary

- The welfare and safety of the child are paramount.
- Both parent and child have rights protected by UK law: these include the right to confidentiality of medical information and the right to life.
- The right to confidentiality can be infringed 'in the public interest' to avoid a serious risk to others, but this must not be undertaken lightly.
- If an older child is deemed competent to consent on their own behalf to a test, they must be fully and appropriately informed of all relevant information prior to giving their consent.
- It is important to work with the parents to negotiate the testing of children and find mutually acceptable ways forward, preserving the family unit wherever possible.

### 2.1 *Re C (HIV test) [1999] 2 FLR 1004*

To date there has only been one reported case in UK law regarding HIV and testing a child, which was a baby born to an HIV-positive mother in 1999. The parents refused testing and medication. The case went to both the High Court and the Court of Appeal. Both judgements talked about the child's rights.

The first judge referred to the UN Convention of the Rights of a Child (Articles 6 and 24), but as this is not part of domestic law, and therefore not binding, both judgements referred to Section 1 of the Children Act 1989, which makes the child's welfare paramount. Under this, they granted a specific issue order authorising tests on the baby. It is important to note that although these judgements occurred after the Human Rights Act 1998, the act was not implemented until 2000 and therefore a judgement today would need to take this Act into account.

### 2.2 **Rights and the law**

Both a parent and a child share the same rights under domestic law, such as the right to medical confidentiality. Children are also protected by the provisions of the Children Act 1989.

Children and parents are additionally protected

by the rights listed in the European Convention on Human Rights (ECHR), which was made part of UK law by the Human Rights Act 1998 (implemented in 2000) [7]. Particularly relevant to the issue of testing is Article 2 (the right to life) which places on state authorities a positive obligation to protect a person's life, whatever their age, and Article 8 (the right to respect for private life and personal privacy) which includes the right to medical confidentiality.

### 2.3 **Medical confidentiality**

Article 8 of the ECHR reinforces the common law principles of medical confidentiality. It protects parents against infringements of their privacy, including disclosure of their medical information. But such disclosure may be justified to protect the rights of others, such as the child, as long as the infringement is 'necessary' and proportionate to the risk of not making the disclosure.

In this respect, ECHR law mirrors the UK's common law defence for infringing medical confidentiality, 'in the public interest'.

Government guidance on information-sharing and infringing a patient's confidentiality states that this may be justified 'in the public interest' to avoid a serious and identifiable risk to another

individual [8]. The risk to the child may be considered to fall under this, yet all other possibilities must be explored first to justify this decision.

In relation to medical confidentiality, it should be remembered that a parent might object to their child being informed of their HIV status without first gaining the parent's consent. Similarly, an older child might object if parents, school teachers or social workers, etc. are informed of their HIV status without their consent.

## 2.4 Other rights parents have

Article 8 of the ECHR gives parents various other important rights:

- To make their own decisions regarding their children's medical treatment;
- To enjoy intimate family life with a child – this could be infringed by attempts to prevent a mother breastfeeding if this were an issue;
- To enjoy a child's company – this could be infringed by the local authority implementing a care order and removing the child from his or her family.

More specifically, if doctors ignore a parent's refusal to allow a child to be tested for HIV, the parent might claim that these rights under Article 8 had all been infringed. Such infringement could be justified, but only if the action taken was necessary and proportionate to the risk involved. The fact that it was taken to promote the child's best interests would be of great relevance. Therefore all other possibilities should be explored first, before breaching the parent's rights.

## 2.5 A child's rights under children's legislation

The Children Act 1989 states that the best interests of the child should be the paramount consideration in any court decision on the upbringing of the child. The Act imposes specific duties on local authorities to protect children. Under Section 17, local authorities have a general duty to safeguard and promote the welfare of the children within their area who are in need. A general principle underpinning local authorities' legal obligations is that wherever possible children should be brought up and cared for within their own families.

The Children Act 2004 provides a new framework for children's services in England and

Wales. Section 11 places the duty on relevant bodies to make arrangements to ensure that their functions are discharged having regard to the need to safeguard and promote the welfare of children. Safeguarding arrangements made by local authorities may include guidance for local authority practitioners on information sharing – see Information Sharing: Guidance for practitioners and managers (DCSF 2008).

If a child is likely to suffer significant harm if not removed from parents and/or tested or treated, the local authority may apply to the courts for an Emergency Protection Order (EPO) under Section 44 (Children Act, 1989) which thereby allows the local authority to remove the child from the home and gives the local authority shared Parental Responsibility (PR) with the parents to make arrangements for and give consent to testing and treatment.

EPOs are a short-term solution, only lasting 8 days, thereby ensuring that before there is further intervention, the matter is placed back before the court. If the child is likely to suffer significant harm through the parents' refusal, the local authority may apply for a care order under Section 31 (Children Act, 1989) thereby acquiring legal authority to remove the child on a long-term basis and consent to treatment. Since all such steps might be opposed by the parents as being an unnecessary and disproportionate infringement of their own rights under Article 8 ECHR (see above), the local authority should first explore all other ways of engaging the parents and obtaining their agreement to testing and treatment.

## 2.6 Consent to testing: infants and younger children

Infants and young children are not competent to consent to treatment themselves and doctors therefore need legal authority from someone with PR. This can be either the mother or father (or the local authority in the instances stated above).

## 2.7 Consent to testing: older children

Under the concept of *Gillick* competence, older children may consent on their own behalf to medical treatment if they are considered to be of sufficient maturity and judgement to enable them to understand what is proposed [9]. (*Gillick* competence is broader than *Fraser*

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competence; the Fraser guidelines relate specifically to competence for consenting to contraceptive treatment.)

A child need not necessarily be of a specific age to be deemed Gillick competent to consent to HIV testing and treatment. But they must be appropriately informed about what they are being tested for [10]. In practice, this can be challenging if the parent does not want to disclose their diagnosis to the child. Documented agreement of the child as well as the parent should be obtained. The Department of Health has produced guidance on this in 'Consent: A guide for children and young people (2001)' [11].

As has been stated throughout, the parents have rights too. Informing the child of the parent's status without the parent's consent will infringe the parent's right to medical confidentiality and must be carefully justified. It may be that this matter will need to be discussed with legal representatives to explore the legal

options. It is essential to work with parents to negotiate ways forward that do not isolate them but also ensure the child's rights are upheld. Section 4 offers examples of successful approaches that have previously been used to negotiate the successful testing of Gillick-competent children where the parent does not at that point want to disclose their own HIV status (see 4.1.2).

For children of all ages, if a parent refuses to allow the child to be tested or if a Gillick-competent child refuses to be tested, appropriate legal advice should be sought and as a last resort the case will need to be referred to the courts.

### **2.8 Conclusion**

Both parents and children have rights in UK law, but if a case goes to court, the court will always give the child's welfare paramount consideration. All other avenues should be explored prior to court action.

## Section Three: Practical responses

For the vast majority of families, testing their children for HIV will be relatively straightforward if approached correctly. In many cases, the extra support will provide an opportunity for the family to address issues that they are already preoccupied with, such as pre-existing anxiety about the child's HIV status and disclosure. The challenge in more difficult cases will be to find common ground between the professionals and the parents. This section suggests practical tools for the testing of, and for monitoring the testing of, children of HIV-positive parents.

### Summary

- A clear procedure needs to be developed and followed when testing children of positive parents.
- Adult services need to develop robust information systems to record and monitor the process of testing all the children of their positive patients.
- Services should have an agreed multidisciplinary pathway in place for testing children that includes plans for all eventualities.

### 3.1 Testing children

The UK National Guidelines for HIV Testing 2008 [12] sets out that a person, which includes a child, should now be able to be tested for HIV in a number of medical settings.

In the light of the case of SP and the conference, CHIVA has now produced *HIV testing guidelines for children of confirmed or suspected HIV-positive parents (2009)* [13]. These are comprehensive guidelines specifically on the testing of children of HIV-positive parents. The guidelines suggest a 6–12-month timescale of negotiation, depending on the age and health of the child and the support needed by the parent(s). This timescale may appear somewhat arbitrary but it is useful to note the date when the issue is first raised. This then provides a 'ticking clock' which can help keep the process focused and under review. Where young infants (0–1 year of age) are concerned, the timescale is more urgent as the risk of disease progression in the first year of life is high. Each case should be viewed individually, but the actions taken within this process of supporting a parent to test their child need to acknowledge the child protection issue that refusal to test presents.

In summary, these guidelines cover the following:

- Consent, including Gillick competence (see 2.7)
- Parental refusal and a timeline for testing
- Confidentiality and testing
- Who can test, and the procedure that needs to be undertaken during the process of testing.

The process of testing needs to include considering the importance of the follow-up care for families after testing has taken place. A positive diagnosis could have a major impact on the family, as could a negative diagnosis where the child now has new information about the family's HIV status and may need support to manage this.

### 3.2 Monitoring the testing of children with HIV-positive parents

Adult services from both health and social care need an appropriate information system to record basic data and track the testing of children of HIV-positive parents if at risk. This information system needs to be able to:

- Proactively manage the cohort of possible parents (including gay and bisexual men and women who may also have children)
- Proactively manage ongoing cases with a view of the 'ticking clock'
- Have clear thresholds to escalate referrals to the next level of responsibility when necessary. Ultimate local responsibility rests with the local safeguarding children board (LSCB).

### 3.3 A pathway to testing

Alongside the information system, an agreed multidisciplinary parent pathway needs to be clearly established. This should have the capacity to:

- Acknowledge that different cases will need different types of intervention and that all need proactive management.

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- Be straightforward, the goal being the immediate testing of children, or a mutually agreed deferral for an agreed set period.
- Support more complex cases and have the mechanisms in place for more intensive involvement and family support where required.
- React appropriately in cases of absolute parental refusal and potential risk to the child. These cases need to be identified early on for intensive multidisciplinary support and prompt involvement of the multidisciplinary team to, where possible, avoid a child protection referral.

Where negotiation with parents is needed, the person primarily responsible for this will depend on the available personnel in each different setting. HIV paediatric nurses are experienced in this area, but in some settings, such as GUM clinics, it may be experienced health advisers who will take the lead. Utilising the skills in a multidisciplinary team and engaging more experienced centres in complex cases will all support the process.

Appendix Four sets out a flow chart to support the planning of the pathway to testing the children of HIV-positive parents.

### 3.4 Conclusion

There should be clear joint protocols in place between health and social care, working with both adults and children and relating to information-sharing and the testing of children of HIV-positive parents. These should include seeking legal advice if it is not possible to secure a parent's agreement to testing and/or treatment, and involve a multidisciplinary approach to include voluntary sector and peer support.

Robust monitoring systems need to be put in place so that the progress to testing of all children of HIV-positive parents can be followed up and action taken when necessary.

The protocol should include a pathway developed in advance by a multidisciplinary team, which will facilitate joint working, clarify roles and cover all eventualities.

## Section Four: Supporting families

Supporting families in having children tested for HIV should be seen as a journey in which a child protection referral after ongoing refusal to test is a last, but necessary resort. The key is in communicating with the parents, that all practitioners are able to clearly explain in a confident and non-blaming way why testing is important and the benefits of including the child in this process. This section offers possible cases presented at the conference, discussion on ways to take these forward and guidance on talking through possible issues with parents.

*The build-up may take a little longer than we would like it to be, but the reality is, if and when done properly, the impact especially should the child test positive – which can be a nightmare for parents – is much more manageable.*

HIV-Positive Mother, 'Don't Forget the Children'

### Summary

- Cases:
  - My children are both well, so they can't have HIV
  - Teenage children
  - Children who do not live in the UK
  - Have the children actually been tested?
  - Prayer will heal my children.
- A checklist for talking to parents
- Issues that arise may include fear, guilt, disclosure and the child being well

#### 4.1.1 Case: My children are both well, so they can't have HIV

A mother has tested positive for HIV. When asked, she says she has two children aged five and seven but both are well and she feels they do not need to be tested.

##### Response:

- A well child does not mean an HIV-negative child.
- Explain the risk factors.
- Make reference to the mother's symptom-free time.
- As the children are young, disclosure is not an issue.
- Insistence that HIV was acquired after children's birth can only be accepted with evidence of the mother having a negative HIV test after breastfeeding.
- Possible option of obtaining consent through father.
- Use a multidisciplinary approach to support mother through the process.

#### 4.1.2 Case: Teenage children

*I would always say that I am seeing you for a general health check. I discuss health and general issues and explain the blood tests are for infections like HIV and hepatitis – I have not yet been asked 'why HIV?'*

Participant, DFTC

A mother tests positive for HIV and has two children who are 13 and 15 years of age. She refuses to allow them to be tested, as she is worried they will ask too many questions, and she does not want them to discover her HIV status.

##### Response:

- A well child does not mean an HIV-negative child.
- Explain the risk factors.
- The children are Gillick competent (see 2.7) so will need to be fully informed.
- Utilise the multidisciplinary team to support the mother to agree to a mutually acceptable way to test her children.

- ❑ Encourage the mother to share her diagnosis with her children – they will be more likely to support her than let her down. Being open with them may help her in coming to terms with her HIV.

*The key is working with the parents to find ways forward... In older children, a plausible explanation could be 'as you were born abroad, we would like to test you for a variety of blood-borne viruses which are more common where you were born, such as hepatitis B (the importance of that is that it can affect your liver); HIV (which can be treated); and a full blood count (to see if you're anaemic)'.*

Participant, DFTC

### 4.1.3 Case: Children who do not live in the UK

A mother tests HIV positive through routine antenatal screening. When asked if she has children, she says she does but they live in her country of origin.

#### Response:

- ❑ As with children living in the UK, explain the risk factors.
- ❑ Knowing a child's status is best, wherever they live.
- ❑ There may be issues around relatives being unaware of the HIV status of the mother.
- ❑ The child can be tested next time they visit the mother, or the next time the mother visits the country of origin.
- ❑ Where possible, testing should not be delayed, especially if the child is suspected to be symptomatic.
- ❑ There is no statutory obligation towards children living outside the UK.

### 4.1.4 Case: Have the children actually been tested?

A baby is seen postnatally for testing. The family

arrive and there are two older siblings. When asked, the mother says the two older children have both been tested, but she cannot say where or when.

#### Response:

- ❑ If there is no record, then a 'repeat' test must be undertaken. The parent can be told the benefits of testing and also that the hospital needs to have a record that the child has been tested and the result of this test.
- ❑ Consent issues will vary on the age of the children (see 4.1.1 and 4.1.2, above).

### 4.1.5 Case: Prayer will heal my children

A mother who is HIV positive says that she does not believe her children need to be tested as she has had a prayer healing session for them, so God will look after them.

#### Response:

- ❑ Approach this sensitively: negotiation needs to be non-judgemental.
- ❑ The hospital needs to have a record that the child has been tested and the result of this test.
- ❑ Use a multidisciplinary approach to appropriately support the mother.
- ❑ Have information about prayer and medicine available for the mother to read.
- ❑ Balance the risk factors and the benefit of testing the children with the time needed to negotiate with the mother.

*We had a mother who is HIV positive. Two weeks before a scheduled caesarean section, she told healthcare workers that she had been cured through prayer. The healthcare workers talked to her and finally got her agreement to be re-tested and that if she was still positive, she would start taking her medicine again and have her caesarean as planned.*

Participant, DFTC

*Social workers are usually involved in assisting adult clients to repatriate children from abroad with their mothers. We usually have the discussion about testing children prior to their entry into the country in these cases.*

*It is also good to pinpoint a period of time when families are not in crisis. Once they have their immigration status confirmed and they are not homeless, not fighting for benefits or worrying where their next meal is coming from. Once a family or a mother has had time to come to terms with her own HIV diagnosis we have found they are more conducive to discussing testing their children. Building that relationship and understanding the pressures are vital in gaining parents' confidence.*

Participant, DFTC

## 4.2 Talking to parents about testing their children

*Every time our appointment for testing came I would spend sleepless nights agonising over what the result would be... It was and remains one of the most difficult things I have had to deal with in all my years of being diagnosed.*

HIV-Positive Mother, DFTC

It is important to explain to the parent that it is routine for all children of HIV-positive parents to be tested and if a parent claims a test has been undertaken, there must be a record of the test and its result for each child who lives in the UK.

### Check list

- Raise the issue; stress that this is routinely discussed with all HIV-positive parents.
- Explain the facts on the possibility of a positive diagnosis, depending on the child's age.
- Acknowledge and, where possible, alleviate the parent's fears.
- Work in partnership with the parent to agree the process of testing.
- Use a multidisciplinary approach to ensure the parent has all the support they need during the process including involving peer and voluntary sector support.
- Plan for all outcomes, which include the support and information needs of the child if told the parent's diagnosis.

### 4.2.1 Barriers to testing children

Acknowledging and alleviating the parent's fear and guilt will ensure the best outcome in most cases. Possible barriers include:

#### The parents fear disclosing their diagnosis to the child

- If a child is young, reassure the parent this is not an issue.
- If the child is Gillick competent (see 2.7) then discuss the options with the parent and agree the way forward. If the plan involves not fully disclosing the parent's status at testing, plans must be made for a positive result and how then the parent's status will be explained to the child.

### What if the child is positive?

- Reassure the parent that HIV is a manageable illness. It is better to know so the child's health can be monitored and maintained.

*The women I work with who have positive children often feel themselves to be very separate from those that do not. There is a great deal of guilt, and the emotional burden of vertical transmission on a mother is huge.*

Participant, DFTC

### Fear that the child will tell others the parent's diagnosis

- Reassure the parent that on the whole children will recognise the importance of confidentiality.
- In adolescents it has been reported in many cases that the child is already aware of their parent's diagnosis prior to being told.

### Disclosing to other health professionals

- Fully inform the parents of where the record of the child's test will be kept and who will have access to this information.
- Reassure them that no one will be informed about the test unless the result is positive, and explain who would then need to be told.

### Fear of meeting others at hospital visits

- Acknowledge the parent's fears of 'being seen' and support them with developing strategies to deal with these situations, such as how they would explain why they are at the hospital that day.

### Disclosure to partner

- The priority in this situation is always having the child tested. Discuss whether at this point partner notification is necessary for testing the child.
- Talk through possible outcomes and how these will impact on telling a partner. Involve peer support or a health adviser to support the parent in the process of notifying their partner.

### The child is well

- Refer to the parent's asymptomatic period and explain that a well child may make a

## 'Don't Forget the Children'

positive diagnosis less likely, yet there still is a risk.

- If there is a possibility the child is sexually active, stress the risk of onward transmission and the urgency of the test.

### 4.3 Multidisciplinary approach

If a parent needs additional support, use a multidisciplinary approach including, where possible, voluntary sector and peer support. This will ensure that the level of support and information needed by that particular parent is available during and after that time and that they feel in control of the process.

*Women can see health workers as 'professionals' and so there won't be the same relationship as a voluntary sector organisation can establish. So use us from the beginning, not just to mop up afterwards.*

Speaker from Voluntary and Community Sector, DFTC

### 4.4 Conclusion

Work in partnership and fully engage the parent in the process. Offer additional support and find compromises in agreed timelines that allow the parent to have the time they need whilst ensuring the best outcome for the child.

If a parent refuses testing, it is vital to use a multidisciplinary approach to support the parent and child. It may be that a social worker or support worker can spend the time and develop the relationship needed to ensure the child is tested. A joint protocol will ensure that pathways are in place for all eventualities.

## Section Five: Recommendations

- 5.1** All adult HIV care provider and support services, including the NHS and social services in the statutory sector, and those in the voluntary sector, must have protocols and referral pathways in place to ensure that all the children of HIV-positive parents are tested for HIV.
- 5.2** The negotiation time allowed with parents needs to be weighed against the child's age and health.
- In the case of infants and symptomatic children, a test must occur immediately.
  - Where the child is too young for consent, a guide of 6 months is felt to be acceptable.
  - In the case of asymptomatic non-sexually active young people, it is felt that up to a year is acceptable.
  - For sexually active young people, the possibility of onward transmission makes testing urgent.
- 5.3** All HIV services must have protocols and procedures in place for the testing of children of HIV-positive parents. In planning the response to refusal to testing, a multidisciplinary team should be involved and their roles in managing the testing of children clearly set out. The team should include, where possible, members of the adult HIV services, a named paediatric consultant and paediatric clinical nurse specialists, specialist midwives, health advisers, voluntary sector, peer support workers and social workers. They will also need to liaise with the local safeguarding children board (LSCB).
- 5.4** Where an adult HIV service has no nearby specialist paediatric HIV service, referral and advice pathways will need to be developed in line with the local configuration and include linking in with regional paediatric HIV services.
- 5.5** Procedures should include a clear pathway, which includes a 'ticking clock' starting when the issue is first raised with the parents, setting out who is responsible at what time, and at which point the local safeguarding children board should be involved.
- 5.6** All HIV units and services need to 'look back' and establish the HIV status of any children whose HIV-positive parents attend that service. This will be time consuming but is essential in ensuring these children's wellbeing.
- 5.7** All HIV units and services should develop effective systems to audit enquiries to patients about the testing of children; and to ensure that this process is comprehensively executed and monitored, and the test information is appropriately and securely recorded.
- 5.8** All new patients or service users should be asked about their children and, in the case of health, informed that protocols require that all children of HIV-positive parents are tested for HIV is at risk, and that this is recorded on the patient's confidential records.
- 5.9** Cases where parents refuse a test for their child/ren need to be managed especially closely, and support from a more experienced centre may be required in some cases.
- 5.10** All healthcare professionals have a duty to ensure the safety of children, so if the child is persistently being put at risk by not being tested then there should be a clear threshold for referral to child safeguarding services.

## Appendix One: Acknowledgements

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*'This document is not exhaustive but we believe that it gives thorough guidance and advice on the issues that it covers. It is part of a continuing process and we hope that it will provide a practical starting point for professionals in a variety of different settings to develop an informed approach to the issue. It is also hoped that this report will lead to further work in this area.'*

Ms Magda Conway and Dr Christopher Wood

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## Appendix Two: Abbreviations

ART	Antiretroviral Therapy
BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
CHIPS	Collaborative HIV Paediatric Study
CHIVA	Children's HIV Association
DFTC	'Don't Forget The Children' Conference
ECHR	European Convention on Human Rights
EJAF	Elton John AIDS Foundation
EPO	Emergency Protection Order
GUM	Genitourinary Medicine
HAART	Highly Active Antiretroviral Therapy
HPA	Health Protection Agency
ID	Infectious Diseases
LSCB	Local Safeguarding Children Board
MDT	Multidisciplinary Team
NSHPC	National Study of HIV in Pregnancy and Childhood
PEP	Post-Exposure Prophylaxis
PLHIV	People Living with HIV
PR	Parental Responsibility
SOPHID	Survey of Prevalent HIV Infections Diagnosed
STARHS	Serological Testing Algorithm for Recent HIV Seroconversion

## Appendix Three: Patient Information Sheet

### Why it is important to test your child for HIV

#### **Why should I test my child for HIV?**

We now have very effective treatment – anti-retroviral therapy (ART) – which means that if a person knows they have HIV, their health can be monitored and this medication can keep them well. The most dangerous thing for an HIV-positive child or adult in the UK is not knowing they have HIV. If you don't know your child's diagnosis and they do have HIV, they could become very ill. If you, and we, know their diagnosis, we can start their treatment and keep them well.

#### **How do children get HIV anyway?**

The main way children become infected with HIV is through mother-to-baby transmission during pregnancy, delivery or breastfeeding, if the woman is HIV positive at that time. Other than that, HIV can be transmitted through sexual contact, sharing of needles or contact with infected blood. It does not get passed on through ordinary household contact.

#### **My child is healthy – why should I worry – surely it would have shown up by now if they were infected?**

Both adults and children with HIV can remain well with no outward signs for years, until the HIV weakens their immune system. (The immune system is the body's defence against illness and infections.) When the immune system becomes weak, the person becomes very vulnerable to HIV-related disease, so they can suddenly have dangerous, or potentially fatal illnesses.

Although most children born with HIV will start to show signs of illness before the age of 5, there are a number of children who remain perfectly healthy up to the age of 10, 15 or even occasionally 20 years. Therefore the only way to be sure that a child born to parents with HIV is not infected, is to have a test.

#### **I don't know when I became HIV infected.**

If a child's mother has tested HIV negative in a later pregnancy (*subsequent* to this child) then she was not HIV positive during pregnancy or breastfeeding of *this* child. However, unless that fact is clearly established, then this child and any siblings need to be tested by the paediatric team.

#### **I do not want my child to know about my HIV infection – how can they be tested without finding out?**

This is a concern for many parents. If the child is young, then those doing the test simply need your permission. Talk to the paediatrician about the test and you may want to talk to a peer support worker or your doctor about what a positive test result will mean to you.

If the child is older and can give their own permission for blood tests, you will need to work out with the paediatrician a way in which the test can be undertaken, where you feel comfortable about what your child is told, but at the same time your child knows what they are being tested for.

This is a difficult time, but the people supporting you have done this many times before and can help you through it. Talk to a peer support worker or your doctor about what can be said, and also what you will say to your child if their test is positive.

#### **Why is this really so important – can't we wait until they show some signs of infection before testing them?**

This is important, and we shouldn't wait. There have been a number of cases where children have become very ill, or have actually died, because they were not diagnosed with HIV in time.

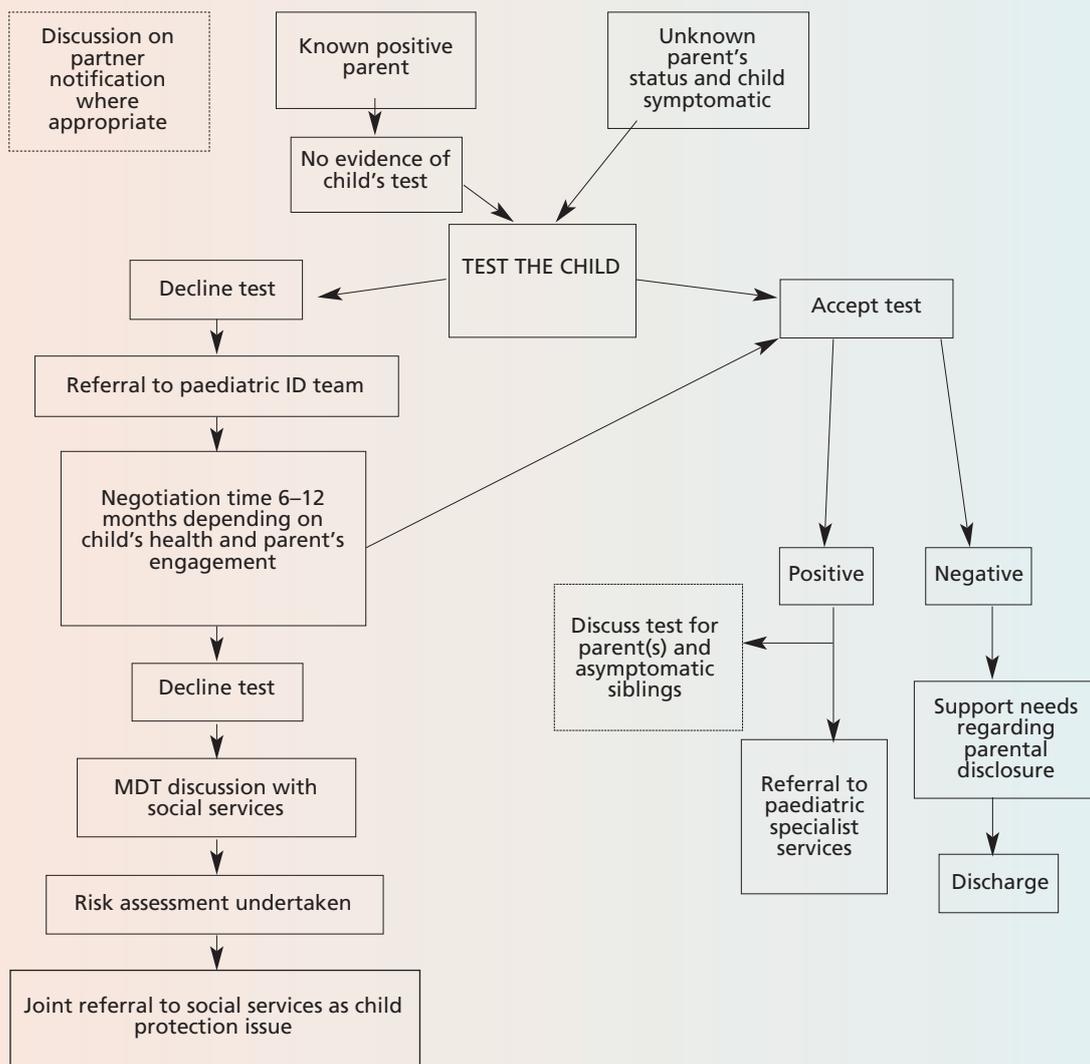
HIV testing of all children born to HIV-positive parents, and in particular mothers with HIV, can be a lifesaving action and should be done in every case. Therefore these children, even if they look healthy and feel healthy and however old they are, should have a test to make absolutely sure that they are HIV negative.

Most children tested in this way will be HIV negative. Those who are HIV positive need to be diagnosed as soon as possible. The medication really works, but if we don't know, we can't use it to keep them well.

**If you want more information about children and HIV, including services that support families, please visit [www.chiva.org.uk](http://www.chiva.org.uk) or ask your nurse or doctor about services available in your area.**

## Appendix Four: Parent's Pathway

The Parent's Pathway: Supporting parents to have their UK-resident children tested for HIV



## Appendix Five: References

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