

# **GUIDELINES FOR THE TESTING OF LOOKED AFTER CHILDREN WHO ARE AT RISK OF A BLOOD-BORNE INFECTION**

---

## **Introduction**

It is a statutory requirement that looked after children have a comprehensive health assessment, as it is acknowledged that they have unmet health needs and could be at risk of a wide range of health problems.

This Practice Note, produced by a health/social care working party involving BAAF, the Children's HIV Association (CHIVA) and the National Children's Bureau (NCB), aims to provide social care and children's health care workers with:

- multi-agency guidance to address the health needs of looked after children who could be at risk of blood-borne infections;
- information on Hepatitis B (HBV), Hepatitis C (HCV) and Human Immunodeficiency Virus (HIV);
- information on syphilis (another blood-borne infection) where relevant;
- guidelines on consent and confidentiality;
- procedures for how to identify, assess, test and refer children at risk of blood-borne infections.

Blood-borne infections cause treatable diseases, so risk factors should be considered in a comprehensive health assessment. These infectious diseases (transmitted from person to person) often cause fear in both professional and lay groups. Consequently, individuals and families face stigma, discrimination and social exclusion. This is particularly the case with HIV.

All professionals working with looked after children need to be familiar with these guidelines.

## **Why test?**

It is important that any test carried out on a child is done in the best interests of the child, which should be decided in the context of a comprehensive paediatric assessment. Due to advances in the treatment of blood-borne infections, there are real advantages in determining the status of children who may have been exposed to infection.

It is recommended that all children up to 18 years of age who are at risk of blood-borne infections should be tested. Children who have contracted blood-borne infections from their mothers can remain well for many years.

Without treatment and monitoring, all of these blood-borne infections can cause children to become severely ill, and put them at risk of death. For some infections, for example, HIV, younger children are at particularly high risk if they remain untreated; therefore, if risk factors are identified, testing in this group should be carried out with more urgency.

The working party rejected universal screening of looked after children for blood-borne infections because it was agreed that these infections should be identified like any other disease, according to individual risk factors.

---

Due to the stigma attached to blood-borne infections, families are often very worried, and sometimes reluctant, when the subject of testing their children is raised. However, in most cases, with accurate information, parents' and carers' fears can be alleviated. As these cases may be complex, it is essential that discussion with parents is carefully planned and advice from the local paediatrician or paediatric specialist (paediatrician or nurse with training or expertise in paediatric infectious diseases) is sought. Due to the complexity of these issues, it is important to ensure interpreters are provided when required.

### **Raising the concerns of possible blood-borne infections with the parents, and child when appropriate**

The needs assessment carried out by the social worker should routinely involve the gathering of information about family health and lifestyle. If, as part of this assessment, there are concerns about risk factors for blood-borne infections, it is essential that these concerns are raised with a health care professional with appropriate training or experience, before discussing these concerns with the parent or carer. The health care professional can advise on the risks and the need for testing and how to approach the family. Appendix 1 contains essential information in order to make this referral.

Consent for testing for blood-borne infections must **always** be obtained by a health care professional with appropriate training or experience. Although the most suitable professional may vary depending on local practices, the important consideration is that they have the appropriate information and experience, or are able to access advice about blood-borne infections from a paediatric specialist.

### **Blood-borne infections and how they are transmitted**

In addition to the risk factors detailed for each infection, when assessing children from abroad, health care professionals should give

consideration to the prevalence of each infection in the country of origin. However, the risk of blood-borne infections in children from low prevalence areas should not be ruled out (see the websites listed at the end of this Practice Note for more information).

### **HIV (Human Immunodeficiency Virus)**

#### **What is HIV?**

HIV is a virus that attacks the body's immune system making it vulnerable, over time, to infections that a healthy immune system would fight off. Medical treatment for HIV infection is now available to control the disease and prevent infections. Children under one year of age are at high risk of severe disease and death, even if they have few symptoms, and therefore need to be tested more urgently.

#### **Transmission of HIV**

The vast majority of children who have HIV acquire the virus from their mothers (vertical transmission), either in the womb, at delivery or through breastfeeding. *The risk of mother to child transmission of HIV is 25%.*

Other, much rarer, routes by which the infection may be spread (horizontal transmission) are:

- through unprotected sexual intercourse (including oral sex) with an infected person, or through sexual abuse;
- through sharing contaminated needles, syringes or other equipment during intravenous drug use, or needle stick injury;
- through blood transfusions in a country where blood donations are not screened for HIV (all blood donations in the UK are screened for HIV);
- by invasive medical/dental treatment using non-sterile instruments/needles (this may be of particular concern abroad).

HIV is **not** spread by social contact and daily activities, e.g. coughing, sneezing, kissing, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

---

## **Intravenous drug users (IVDU) HIV seropositivity**

Unlinked anonymous testing of current and former IVDUs in 2005 in England, Wales and Northern Ireland was 1.6% (Wales 1.6%, Northern Ireland 2%, England 1.1% and London 3.2%). The prevalence of HIV amongst IVDUs in Scotland who had undergone voluntary testing was 0.9%.

## **HBV (Hepatitis B Virus)**

### **What is HBV?**

HBV is a virus that causes inflammation of the liver, which can result in liver cell damage that may lead to scarring of the liver (cirrhosis) and increased risk of liver cancer in some people. The risk of liver cancer is much higher in children infected at birth. Unlike individuals infected in later life, where 90–95% clear the virus completely, 90% of infants infected at birth do not clear the virus and are at risk of the long-term problems described above. HBV is much more easily transmitted by blood-borne routes than HIV. A small proportion of people with HBV are highly infectious. HBV is preventable by immunisation.

### **Transmission of HBV**

Children and young people can acquire HBV:

- from mother to child at delivery. *The risk of mother to child transmission of HBV is 20–90%*;
- through unprotected sexual intercourse with an infected person, or through sexual abuse;
- through sharing contaminated needles, syringes or other equipment during intravenous drug use, or needle stick injury;
- through a blood transfusion in a country where blood donations are not screened for hepatitis (all blood donations in the UK are screened for HBV);
- by invasive medical/dental treatment using non-sterile instruments/needles (this may be of particular concern abroad).

Other, less common routes by which the infection may be spread are:

- from non-sterile equipment used for tattooing and cosmetic piercing;
- by sharing razors and toothbrushes (which may be contaminated with blood) with an infected person.

There are rare reports of transmission of HBV between people living in the same house. These reports relate to individuals who are highly infectious. Unless someone is highly infectious, HBV is **not** spread by social contact and daily activities, e.g. coughing, sneezing, kissing, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

## **Intravenous drug users (IVDU) HBV seropositivity**

Unlinked anonymous testing of current and former IVDUs in 2005 in England, Wales and Northern Ireland showed that 19% had antibodies to HBV core antigen (anti-HBc), a marker of previous or current HBV infection (Wales 7.5%, Northern Ireland 9.7%, England marked regional variation: Yorkshire and Humber 5.5%, North West 31%). In Scotland, 6% of the 372 reported cases of HBV were from IVDUs, a huge reduction from the 30% of cases reported in 1999.

## **HCV (Hepatitis C Virus)**

### **What is HCV?**

HCV is a virus that causes inflammation of the liver. Of people with HCV infection, 15–45% will clear the virus. The majority of people infected will get only mild liver damage. However, in 5–20% of people HCV progresses over 20–30 years to cause serious liver damage.

### **Transmission of HCV**

Children and young people can acquire HCV:

- through sharing contaminated needles, syringes or other equipment during intravenous drug use, or needle stick injury;

- through a blood transfusion in a country where blood donations are not screened for hepatitis (all blood donations in the UK are screened for HCV).

Other, less common routes by which the infection may be spread are:

- from mother to child at delivery. *The risk of mother to child transmission of HCV is 6% (increased to 10–15% in mothers co-infected with HIV).* Currently there is no proven association between breastfeeding and HCV transmission;
- through unprotected sexual intercourse;
- from non-sterile equipment used for tattooing and cosmetic piercing;
- by invasive medical/dental treatment using non-sterile instruments/needles (this may be of particular concern abroad);
- by sharing razors and toothbrushes (which may be contaminated with blood) with an infected person.

HCV is **not** spread by social contact and daily activities, e.g. coughing, sneezing, kissing, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

#### **Intravenous drug users (IVDU) HCV seropositivity**

Unlinked anonymous testing of current and former IVDUs in 2005 in England, Wales and Northern Ireland was 42% (Wales 18%, Northern Ireland 28%, England 44%). Prevalence of HCV amongst IVDUs in Scotland who had undergone a voluntary HIV test was 44%.

#### **Are any other body fluids infectious?**

Urine, faeces, saliva, sputum, tears, sweat and vomit do not carry a risk of HIV, HBV or HCV infection, unless they are contaminated with blood.

### **Syphilis**

#### **What is syphilis?**

Syphilis is a bacterial infection. When acquired sexually, syphilis initially causes sores and then

progresses to give rashes and generalised symptoms. Over many years, untreated syphilis can cause serious damage to many systems in the body and may result in death.

Congenital syphilis (babies and children who acquire syphilis from their mothers during pregnancy) can result in multi-system organ damage (e.g. to the brain, bones, teeth and eyes). Congenital syphilis is preventable by treating the mother with antibiotics in pregnancy, or the baby soon after birth. An infant infected with syphilis in the womb may appear unwell at birth, but may look well and only present with symptoms later, in early childhood.

#### **Transmission of syphilis**

Children and young people can acquire syphilis:

- from mother to child in the womb. *The risk of mother to child transmission of syphilis is 70–100%;*
- through unprotected sexual intercourse or sexual contact with an infected person or through sexual abuse;
- through a blood transfusion in a country where blood donations are not screened for syphilis (all blood donations in the UK are screened for syphilis).

Syphilis is **not** spread by social contact and daily activities, e.g. coughing, sneezing, kissing, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

### **Documentation**

The next two sections look at some of the important issues to consider when obtaining consent for testing, and when to disclose information pertaining to testing, and to whom. It is very important that a full and contemporaneous record details not only the actual decisions made, but also documents the reasons for decisions and the information used to make these decisions.

---

## Obtaining consent to test for blood-borne infections

Except for emergency situations where the wellbeing of the child could suffer if testing/treatment is not provided immediately, informed consent is required before carrying out the blood tests. It is therefore essential that everybody working with a child being tested for blood-borne infections knows who has parental responsibility (or parental responsibilities and rights in Scotland), and whether the child has capacity to consent, since these are a prerequisite to the power to consent. Verbal and written information should be provided to explain the benefits of the tests (see the information leaflets reproduced in Appendices 2 and 3). An appointment should be offered for the parent/s with parental responsibility/ies to discuss the tests with the doctor or nurse taking the test. Children must be given an age-appropriate explanation of what tests are going to be undertaken, as well as the procedures involved.

Some of the issues around consent for children and young people are addressed below.

- As most children with blood-borne infections have acquired the infection from their birth mothers, identifying infection in a child is likely to indicate that the mother is also infected. Therefore, confirming infection in a child has implications for the whole family, as a positive test is likely to mean that the mother is positive and that her partner and other children may also be infected. The pre-test discussion should ideally involve both parents and, where appropriate, the child or young person. Every effort should be made to organise this appointment. If circumstances result in the birth mother not being involved in pre-test discussions, consideration needs to be given to informing her that the child is being tested, determining if she wishes to know the results and, if so, who will give her the results.
- Testing for blood-borne infections needs to be done in the context of a comprehensive assessment by a paediatrician or paediatric specialist.
- Consent for testing for blood-borne infections is considered best practice and should be obtained by the health professional testing the child. Verbal consent is adequate but must be documented in the notes.
- Further advice about tests for blood-borne infections can be obtained from the paediatrician or paediatric specialist.

## Who can give consent for the child?

This depends on:

- the child's legal status and who holds parental responsibility/ies;
- whether the child lives in England, Wales, Northern Ireland or Scotland.

The details for each country are set out in Appendix 5. The situations covered are:

- i. Local authority has full parental responsibility/ies.
- ii. Local authority shares parental responsibility/ies with the parent/s.
- iii. Parent/s have sole parental responsibility/ies.
- iv. Abandoned baby.
- v. Children and young people who are under 16.
- vi. Children and young people who are 16 and over.

See also Appendix 4 for a flowchart guideline for testing looked after children for blood-borne infections.

## Confidentiality and disclosure

Information about the health or medical history of an individual is confidential to the person concerned and must be protected by local procedures. The legal position is set out in the Data Protection Act 1998 and the Human Rights Act 1998. Confidential information can only be disclosed in limited circumstances. The protection of client confidentiality is particularly important in relation to blood-borne infections because HIV, and to some extent HBV, HCV and syphilis carry a stigma which may lead to

---

discrimination against individuals with these infections.

There are many circumstances where those involved in caring for a child (e.g. schools and other support services) do not require knowledge that the child has a blood-borne infection.

However, sometimes knowledge of blood-borne infections is important for the child's medical or emotional wellbeing. The Data Protection Act 1998 and guidance recognises that there are circumstances where persons involved with the child may need that information for the purpose of the child's care.

Before disclosing information about blood-borne infections to any agency or individual, the following matters need to be taken into account in reaching a decision.

- Is disclosure in the best interests of the child, and if so, why?
- What information needs to be disclosed and to whom?
- Do those with parental responsibility/ies or the competent child consent to the disclosure?
- Are there risks to the carers/agency staff if the information is not disclosed?
- What are those risks?
- What is the ability of those receiving the information to maintain confidentiality?

In the event that there is objection on the part of the parent or competent child and, having taken such information into account, the local authority is still of the view that the information should be disclosed, then the objecting party should be given adequate opportunity to seek legal advice before the information is disclosed. In all such cases, the local authority should seek legal advice before disclosure.

## **When to test looked after children**

The scenarios listed below are the most common situations identified by the BAAF/CHIVA/NCB working party where concerns about the risk of

transmission of blood-borne infections were identified. It is obviously impossible to cover every potential situation, therefore the most important component of this document is to improve working relations between health and social care, so that advice can be sought as and when situations occur. Early communication is always preferable, particularly in the case of blood-borne infections, where tensions may be running high due to the stigma attached to these. This early communication will help avoid misinformation and inappropriate handling of situations which can make future dealings with families very difficult.

It is important in all situations that as little time as possible should elapse before getting the results back to carers, families, and children, because of the anxiety caused by testing. In addition, this is especially important in the case of young infants found to have HIV or syphilis infection who need to be referred to a specialist urgently for treatment. If untreated, they are at high risk of long-term irreversible damage.

Information on which blood tests need to be carried out, and when, is detailed in the section titled 'Practicalities of testing children for blood-borne infections'.

## **Specific case scenarios**

### **a) Abandoned baby**

*A newborn infant was found by a member of the public at a local church. They contacted the police, who brought the baby to the Accident and Emergency Unit. The nursing staff in A&E contacted social care.*

*Although the baby was well and had a normal medical examination, because of the lack of any information about the mother, blood tests were taken for HIV, HCV, HBV and syphilis. The blood tests showed that the baby had been exposed to HBV, therefore she was given immediate immunisation against HBV to prevent infection.*

In a newborn infant, testing for blood-borne infections is a medical emergency as

---

interventions and treatments can prevent transmission to the baby. All babies abandoned in the first five days of life, with limited or no information about their parents, are considered high risk and need to be seen urgently within 24 hours by a paediatrician, because preventative treatment can still be administered (for syphilis, HIV and HBV). After this time, preventative treatments are unlikely to be effective; however, babies with blood-borne infections would benefit from monitoring and treatments. Therefore it is imperative that the baby is screened for all the tests the mother would usually have in the antenatal period (syphilis, HIV, and HBV). It is also advisable to screen for HCV even if it is not part of the routine antenatal screening.

Testing for blood-borne infections in newborn babies is complicated, especially when there is limited or no maternal information. It also requires more than one set of blood tests. See the section titled 'Practicalities of testing children for blood-borne infections' for more information.

#### **b) Infant born to a mother with no antenatal care**

*Mary came to A&E in labour on a Friday evening. She had received no antenatal care, so in accordance with the local guidelines she had urgent blood samples taken for all the routine antenatal screening tests. The provisional HIV test was positive and the on-call paediatrician was informed. A second test was requested in order to confirm the first positive test (a confirmatory test). However, Mary was not informed what the test was for. Mary continued to breastfeed her son and the second positive test result was given to her 24 hours after her son was born. Mary agreed to stop breastfeeding and her son was started on antiretroviral medications.*

*Although it is routine to get a confirmatory test when an HIV positive result is received, in a case such as this where immediate action and interventions can help prevent infection, action should be taken after the first positive result. This would have enabled Mary and her son to receive*

*immediate appropriate medication and her son would not have been breastfed.*

*Happily, in this case subsequent blood tests showed Mary's son to be HIV negative. Even when post-exposure antiretroviral therapy is not started immediately after birth, it may be effective up to 72 hours after birth.*

Infants or children of mothers who have not had their antenatal booking blood tests (or are unaware of their results) will need screening for all the tests their mother would usually have had (syphilis, HIV and HBV). Although HCV is not a routine antenatal booking blood test in all areas, screening should be considered where there are identified risks.

#### **c) Child born to a mother with continuing risk of acquiring blood-borne infections in pregnancy**

*Sarah was placed in foster care shortly after birth. Sarah's mother was a known intravenous drug user (IVDU). After a year it was decided that Sarah should be placed for adoption. The medical adviser who undertook her pre-adoption health assessment noted that although Sarah had negative tests for HCV and HBV at 12 months of age, she had not been tested for HIV. Sarah's mother had been tested for all blood-borne infections at antenatal testing and tested negative. However, as it was known that Sarah's mother had continued to inject throughout pregnancy and breastfed for five days, it was advised that Sarah also needed to be tested for HIV. Consent was obtained from Sarah's birth mother and Sarah tested negative.*

It is important to be aware that antenatal blood tests are taken at 12–18 weeks, so it is possible for women to acquire infection later in pregnancy after the booking tests, for example, by continuing IVDU or having unprotected intercourse throughout pregnancy. HIV infection acquired during pregnancy is associated with a very high risk of mother to child transmission due to high levels of the virus in the blood. Therefore, in cases where professionals are

---

aware of these risks during pregnancy, the mother needs to have repeat blood tests for blood-borne infections and syphilis to allow for interventions to prevent mother to child transmission. If the woman is in labour, urgent blood tests need to be taken. If the mother refuses to be tested, then the newborn baby needs to be tested. To allow for interventions, these tests need to be carried out in the first days of life. If the mother refuses testing of the baby, urgent legal advice must be sought.

In older babies and children it is important to bear in mind that, despite a negative antenatal test at 12–18 weeks, if the mother has been at continued risk of blood-borne infections during pregnancy, then the child is at risk of infection and therefore should be tested after birth (see ‘Practicalities of testing for blood-borne infections’ later in this leaflet).

**d) Children whose parent is a known intravenous drug user (IVDU)**

*Steven was a healthy four-year-old in foster care when his case was discussed at an adoption panel. During the consideration of his case, the social worker shared new information that his birth mother had been an intravenous drug user. The medical adviser recommended that Steven be tested for blood-borne infections.*

*Steven’s birth mother was contacted and gave verbal consent for him to be tested. All Steven’s tests were negative. The paediatrician contacted Steven’s birth mother and gave her the results.*

*It was not a medical emergency to test Steven, which allowed more time to gather information and to contact Steven’s birth mother in accordance with good practice.*

All children who have a parent (either mother or father) who is an IVDU need to be tested for HCV, HBV, HIV, and syphilis. It is a common misconception in these cases that HIV is the most important test. In fact, HCV and HBV are currently the most common infections in drug users (see information on seropositivity rates in ‘Blood-borne infections and how they are

transmitted’, earlier in this Note). Although not transmitted by IVDU, where high risk activity has occurred, screening for syphilis should be undertaken.

**e) Children where there are concerns about parental drug use and possible IVDU**

All children need a comprehensive assessment by a paediatrician. Every child should be considered on an individual basis. If there are concerns from the history, or symptoms of syphilis, HIV, HBV or HCV, then the paediatrician should liaise with the paediatric specialist.

**f) Testing children in cases of sexual abuse and sexual exploitation**

All children need a comprehensive assessment by a paediatrician with experience in the assessment of children who have been sexually abused. This should include an assessment of risk for blood-borne infections.

**g) Children where information on one parent or both parents is incomplete/inadequate**

All children need a comprehensive assessment by a paediatrician. Every child should be considered on an individual basis. If there are concerns from the history, or symptoms of syphilis, HIV, HBV or HCV, then the paediatrician should liaise with the paediatric specialist. If there is no information about the parent/s, then testing should be considered in the best interests of the child.

**h) Unaccompanied asylum-seeking children from abroad**

*When 15-year-old Celia arrived from the Democratic Republic of Congo (DRC) as an unaccompanied asylum-seeking young person, she was very quiet and withdrawn. It was suggested by her social worker that an HIV test should be included in her initial health assessment because it was felt that she may have been at risk due to the high prevalence of HIV in the DRC.*

*During the initial assessment with the paediatrician and an interpreter, little information was gained. Celia was seen in*

---

*two further appointments during which she revealed that she had suffered multiple bereavements and had some symptoms of post-traumatic stress disorder. Celia was referred to the Child and Adolescent Mental Health Service (CAMHS) for emotional and psychological support.*

*During the appointments, Celia also told the paediatrician that she had had consensual sexual activity in the DRC, and a referral to Genito-Urinary Medicine (GUM) was made for a later date.*

*It took some time for Celia to reveal information about her past. Recognising the often considerable vulnerability of unaccompanied asylum-seeking children and young people is important when assessing them. Celia's risks of blood-borne infections needed to be considered in relation to all her needs, and her need for emotional support was more pressing at the outset.*

All unaccompanied asylum-seeking children and young people (UASC) need a comprehensive assessment by an appropriate health care professional. Often there is a lack of background history and it may take time to develop a trusting relationship in order to obtain information.

The prevalence of viral infections varies in different countries and many UASC arrive from countries where blood-borne infections are highly prevalent. A large number of them will have experienced rape and torture and some will have worked as commercial sex workers either before, en route to, or following arrival in the UK. Others will have been in consensual sexual relationships. In these cases, a full sexual health assessment should be completed; ideally, this should be carried out in the context of a comprehensive assessment, and in association with local GUM services. In the absence of a history of sexual activity, but where blood-borne infection is suspected, paediatricians should liaise with the paediatric specialist.

A number of factors should be taken into account with UASC and sexual health screening.

- **Interpreters** Face-to-face interpreting should be carried out with sensitive attention to gender, ethnicity, etc, to ensure an appropriate interpreter is chosen.
- **Trauma** Relating events around rape and torture may be extremely traumatic for the child or young person. Information should be shared with other professionals when appropriate to avoid the child or young person having to repeat the information.
- **Time** The child or young person may need extensive counselling to convince them of the benefits of screening for blood-borne infections. For many, blood-borne infections are highly stigmatising, and HIV in particular is viewed by many as a death sentence.
- **Confidentiality** It is particularly important for UASC that information should be shared sensitively and only in their best interests.

#### **i) Young people who are looked after**

*Gareth, a 15-year-old living in a children's residential unit, was referred to the local paediatrician for looked after children, for testing for blood-borne infections, because new information came to light that his mother was a long-term intravenous drug user. When the paediatrician saw Gareth and was given more information from the key worker, it transpired that he had been staying away from the care home and admitted to heavy drinking and smoking cannabis.*

*Gareth was referred to CAMHS because of concerns about depression, and was given an appointment for a later date at the local GUM clinic. When he had his full sexual health screen two months later, he tested negative for all blood-borne infections, but positive for chlamydia, for which he was appropriately treated.*

*Even though Gareth was 15 years old, it was appropriate that he was tested for blood-borne infections because there are*

---

*young adults who are in good health despite being infected with blood-borne infections at birth. Additionally, as in this case, it is important to be aware that many young people are sexually active and this is a risk factor for blood-borne infection (as well as other sexually transmitted infections). However, like the case of Celia in h), testing for healthy children in this age group is not an emergency, and so should be prioritised in accordance with the young person's needs.*

*Prior to attending the GUM appointment with Gareth, his key worker had discussed with her line manager how to maintain Gareth's confidentiality. In accordance with agency policy, the key worker shared Gareth's test results only with her line manager, as had been agreed beforehand.*

It is imperative that the young person's confidentiality is respected at all times. Disclosure of information regarding the young person's health needs should be done in discussion with the young person and in their best interests. The designated key worker or another trusted individual should attend the appointment. The staff member should be fully briefed about confidentiality procedures. This includes recording of the young person's health information and ensuring that wider access to the information is protected.

**Young people at risk of blood-borne infections from birth** Children who are infected at birth with blood-borne infections can be in good health, with no symptoms, into their late teens and early adulthood. Therefore testing should be considered in this group when risk factors are identified as they will still benefit from medical interventions.

**Young people who are sexually active** Young people who are sexually active are at risk of acquiring blood-borne infections and other sexually transmitted infections. Testing for blood-borne infections should be done in this age group as part of a sexual health assessment which is usually best provided by GUM services for young people.

#### **j) Foster carers with a blood-borne infection**

*When Emma was three years old and in foster care, she was due to be returned to her birth father when her foster father disclosed to social care that he was HIV positive. Concerns were subsequently raised by social care that Emma may have been at risk of contracting HIV. The concerns were based on her being in the same household as an HIV positive adult. No other risk of transmission had been identified.*

*Using local medical advice, a court order was obtained to test Emma for HIV. The local HIV team who were approached to test Emma were concerned that there was no need to test as no risks of transmission of HIV had been identified. Therefore they declined to test Emma. The case went back to court with appropriate medical advice and the court order was revoked.*

*Testing in this case would not only have put Emma through an unnecessary medical intervention, but would have breached the foster carer's confidentiality due to the duty to inform Emma's birth father of the order to test for HIV.*

There is a negligible risk to children cared for in the homes of carers with HBV, HCV or HIV. HIV and HCV are **not** transmissible by living in the same house. There are reports of transmission of HBV between people living in the same house but they are rare and are associated with highly infectious status. Transmission can be prevented by vaccinating children cared for by HBV infected foster carers. All foster carers need to be given education about simple infection control measures that reduce the risk of the spread of diseases (universal precautions).

In deciding whether to disclose a foster carer's blood-borne infection status to a third party (including the parent), the local authority should always seek legal advice since the decision involves weighing up the duty of confidentiality owed to the foster carer, and his or her human rights, and the rights of the child, the parents and other third parties.

---

In reaching a decision to disclose, the local authority must apply the following test:

Has the foster carer given their consent to that disclosure?

**OR**

If the foster carer objects, the local authority needs to weigh up the following competing factors and decide on balance whether there is a particularly serious pressing need for disclosure and, if so, the extent of the disclosure appropriate and necessary for that purpose.

The factors to be taken into account are:

- the risk posed to the child or others by non-disclosure – this will often be based on medical evidence as to the likelihood of the child or others contracting the infection;
- whether the information is needed in the course of litigation;
- the duty of the local authority to share relevant information with the parents.

It should then be decided whether in the circumstances of the case these factors outweigh the carers' right to privacy.

If the local authority decides that there should be disclosure, then the foster carer should be given advance notice and the opportunity to challenge the decision to disclose.

#### **k) Foster carer caring for children with blood-borne infections**

- All foster carers need to be given education about simple infection control measures that reduce the risk of the spread of diseases (universal precautions).
- All short-term foster carers who accept children as emergency placements, and the foster carers' families, should be offered HBV immunisation. Permanent foster carers (and their families) who accept a child known to be at high risk for HBV should also be offered immunisation.

- When a child with infectious HBV is placed with a family, the family members should all be offered HBV vaccination.
- In principle, it is important that foster carers are informed of a child's health care needs. For children with blood-borne infections, it is important that proper consideration is given to what information is divulged, as covered above under the paragraph relating to confidentiality. This needs to be re-evaluated every time the child changes placement.
- When the local authority is deciding whether to disclose such information, it should take into account that it is more important for the foster carers to be told this information if the child is in a long-term foster placement, on medication, or is significantly immunocompromised and therefore at risk of infection.
- If a child's status is unknown or if they are uninfected but their parent has a blood-borne infection, the local authority must consider disclosure of that information to other third parties. In doing so, it should apply the test set out in section j) above.
- If a child with a blood-borne infection is placed with a foster carer who is informed of the child's health needs, extra information on blood-borne infections, transmission and social and medical considerations should be given. This is to protect the child from harm and to ensure that the foster carers are equipped to give children the care they need.
- Information on any medication prescribed for a child, and contact details for their health care professionals, are imperative to safeguard the child. Specialists working with the child will be happy to help in these situations.
- Foster carers looking after children with blood-borne infections need to be informed that the child's diagnosis is to be treated with the strictest confidence and they should not disclose it to others (see 'Confidentiality and disclosure' earlier in this leaflet).

---

## D) Adoption

- All prospective adoptive parents should receive information about HIV, HBV and HCV as part of their preparation process.
- If a child being placed for adoption is known to have HIV, HBV or HCV, the adoptive parent/s need to be informed at the outset as a preliminary issue before the identity of the child is revealed. The adoptive parent/s should also be given information and counselling about the implications of these infections for the child's health, and the availability of services.
- If a child being placed for adoption is known to have HBV, the adoptive parent/s must be informed about the need to have members of their family household vaccinated.
- If a member of the child's family has HIV, HBV or HCV, but the child does not, the test for deciding whether to disclose that information is the test set out in j) in relation to disclosure of a carer's medical status.
- Where the history of the birth parents gives rise to serious concern that a child could have HIV, HBV, HCV or syphilis, the paediatrician or paediatric specialist should be consulted, and testing of the child be requested.

Once a comprehensive health assessment has been completed and no risk factors for HIV, HBV or HCV have been identified, there is no need to carry out testing prior to adoption or at the request of the adoptive parents.

### **Practicalities of testing children with blood-borne infections**

It is always useful to liaise with your local laboratory to ensure the appropriate blood samples are taken.

#### **Testing children under 18 months of age**

Diagnosis of blood-borne infections in young children is made more complicated by the presence of maternal antibodies which are

passed to the child through the placenta. The presence of antibodies in a child under 18 months therefore does not necessarily signify HIV, HCV or HBV infection in the child. Additionally, there have been rare cases of infants who have negative antibodies but are shown to be infected on PCR (polymerase chain reaction – a test which detects the presence of the virus itself in the blood). These cases occur when mothers have been infected in late pregnancy and consequently have not transferred maternal antibodies to the baby. Therefore, if maternal status is unknown in a child under 18 months, both an antibody test and PCR tests for HIV and HCV need to be taken. In the case of HBV, in addition to antibody testing, a test for the presence of surface antigen should be done. Ideally, when sending HIV PCR tests, a maternal sample should be sent as well, to ensure that the baby's virus is identifiable by the test centre. Subsequently, a second PCR sample should be sent for verification.

To exclude a diagnosis of syphilis, the infant should be tested for syphilis antibodies. If the screening syphilis ELISA test is positive, then the laboratory will undertake the treponemal and non-treponemal tests (different tests in different labs – you need to determine which are done locally). An infant born to a mother who has had syphilis and been treated in the past, or who had active syphilis during pregnancy will have a positive antibody test, and interpretation should be discussed with the microbiology team. If the mother has been previously treated, then the baby will have passive transfer of maternal antibodies which will disappear over the first year of life. If the baby has been infected, then the antibody response will remain and the titre may increase, so treatment will be required. The urgency of deciding about when to treat depends on whether there is any history about the mother or not, and whether the baby has any symptoms of disease. This can be discussed with the paediatrician or paediatric specialist.

#### **Testing children over 18 months of age**

For children over 18 months, HIV, HCV and syphilis infections are identified by taking an

---

antibody test. By this age the child will have lost maternal antibodies and therefore any antibody identified will signify that the child is infected. For HBV, an antibody and HBsAg (hepatitis B surface antigen) should be requested.

Antibodies normally take a few weeks to appear after the virus enters the body. This is known as the window period. Therefore, it is not possible, with an antibody test, to find out if infection has occurred immediately after a possible risk event. Testing can be carried out immediately which will identify if a child already has infection, but will need to be repeated at three months (for HIV, HCV and syphilis) and six months (for HBV).

Tests for HIV, HCV, HBV and syphilis can be ordered by the community or hospital paediatrician. Alternatively, the paediatric specialist will be happy to carry out the pre-test information-giving and testing.

### **Giving the results**

The person who had the pre-test discussion with the family should, wherever possible, give the results. An appointment to give the results should be made at the time of testing and the results should be given as soon as possible. If any of the results are positive, the information should be given in a clear and sympathetic way. Allow time for the young person or carers to react to the news. Listen to their response and help them talk through what it means. Provide information about the infection but be aware that it may be difficult for anyone to take in this information whilst upset. In the case of HIV, it is very important to explain that HIV is a treatable disease now, and not a death sentence as many people still believe.

It is important to identify who will support the family and help them to think about who else they would like to be told. Contact numbers should be given and an early follow-up arranged with the appropriate specialist. Parents are referred to adult teams for testing.

## **Insurance**

Members of the working party highlighted that professionals involved with children at risk of blood-borne infections sometimes voice concerns that testing can affect future insurance and mortgage policies.

In guidelines written in conjunction with the British Association for Sexual Health and HIV (BASHH) in 2003, the Association of British Insurers now recommends to its members that they no longer ask if people have had a test or counselling for blood-borne infections and ask only about positive results. Therefore, testing children for blood-borne infections should have no negative implications for their future.

## **Useful websites**

### **Hepatitis**

The World Health Organisation website gives data on prevalence at [www.who.int/health\\_topics/hepatitis/en/](http://www.who.int/health_topics/hepatitis/en/)

The Health Protection Agency website gives data on prevalence in the UK at [www.hpa.org.uk/infections/topics\\_az/hepatitis\\_c/data.htm](http://www.hpa.org.uk/infections/topics_az/hepatitis_c/data.htm)  
[www.hpa.org.uk/infections/topics\\_az/hepatitis\\_b/data.htm](http://www.hpa.org.uk/infections/topics_az/hepatitis_b/data.htm)

### **HIV**

The World Health Organisation website gives data on prevalence at [www.who.int/health\\_topics/hiv\\_infections/en/](http://www.who.int/health_topics/hiv_infections/en/)

The Health Protection Agency website gives data on prevalence in the UK at [www.hpa.org.uk/infections/topics\\_az/hiv\\_and\\_sti/stats/hiv/prevalence/default.htm](http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/stats/hiv/prevalence/default.htm)

The United Nations website gives information on HIV/AIDS at [www.unaids.org](http://www.unaids.org)

The Children's HIV Association website gives information on children with HIV in the UK at [www.chiva.org.uk](http://www.chiva.org.uk)

---

## BAAF

British Association for Adoption and Fostering (BAAF)

Saffron House, 6–10 Kirby Street  
London EC1N 8TS  
Tel: 020 7421 2600  
www.baaf.org.uk

7 Cleeve House, Lambourne Crescent  
Cardiff CF14 5GP  
Tel: 029 2076 1155

40 Shandwick Place  
Edinburgh EH2 4RT  
Tel: 0131 220 4749

Botanic House, 1–5 Botanic Avenue  
Belfast BT7 1JG  
Tel: 028 9031 5494

## References

BAAF (1991) *Children Act 1989: Consent to Medical Treatment for Children*, Practice Note 23, London: BAAF

BAAF (1998) *Consent to Medical Treatment for Children in Scotland*, Practice Note 38, London: BAAF

BAAF (1999) *Hepatitis and HIV: Issues related to substitute care, foster care, residential care and adoption*, Practice Note 39, London: BAAF

Centers for Disease Control and Prevention – www.cdc.gov

Community Health South London NHS Trust (2001) *HIV and Children: Interagency guidelines for good practice*, London: Community Health South London NHS Trust

Conway M (2005) *HIV in Schools: Good practice to supporting children infected or affected by HIV*, London: National Children's Bureau

Day L, Hamujuni-Smith B and Hart D (2000) *Child Protection and HIV: Recommendations for good practice*, London: The Pan London Local Authority Children and Families HIV Consultation Forum

Department of Health (1989) *The Children Act (c.41)*, London: HMSO

Department of Health (2002) *Promoting the Health of Looked After Children*, London: HMSO

Department of Health (2003) *Screening for Infectious Disease in Pregnancy: Standards to support the UK antenatal screening programme*, London: HMSO

Department of Health (2005) *Children in Need and Blood-Borne Infections: HIV and hepatitis*, London: HMSO

Department of Health (2005) *Family Planning Association Syphilis Leaflet*, London: HMSO

Department of Health (2007) *Immunisation against Infectious Disease*, "The Green Book", www.dh.gov.uk/en/policyandguidance/healthandsocialcaretopics/greenbook/dh\_4097254

Donaghy S (2004) *HIV Testing of Children and Young People*, www.chiva.org.uk

General Medical Council (1995) *HIV and AIDS: The ethical considerations*, London: GMC

Harrow Council (2005) *Policy Statement on HIV and AIDS: People First policy and practice memorandum 1.7*, London: Harrow Council

Health Protection Agency (2006) *Shooting Up: Infections among injecting drug users in the United Kingdom*, October 2006 update, London: HPA, www.hpa.org.uk

Office of Public Sector Information (1998) *Data Protection Act*, London: HMSO

Office of Public Sector Information (1998) *Human Rights Act*, London: HMSO

Tudor-Williams G (2004) *Post-Exposure Prophylaxis (PEP): Guidelines for children exposed to blood-borne infections* (adapted from guidelines originally drafted by Dr Delia Bethell), www.chiva.org.uk

## Essential information for referral to paediatrician/ paediatric specialist for testing for blood-borne infections

(To be completed by social worker prior to referral)

### Patient details (or patient label)

Name \_\_\_\_\_ DOB \_\_\_\_\_

Address \_\_\_\_\_

NHS No \_\_\_\_\_ CHI \_\_\_\_\_

Tel \_\_\_\_\_ Mobile \_\_\_\_\_

### GP details

Name \_\_\_\_\_

Address \_\_\_\_\_

Tel \_\_\_\_\_

### Social worker details

Name \_\_\_\_\_

Address \_\_\_\_\_

Tel \_\_\_\_\_

Consent to inform GP of results? Yes / No

**Carer's details** \_\_\_\_\_ **Parent** \_\_\_\_\_

Carer's name \_\_\_\_\_ Name \_\_\_\_\_

Relationship \_\_\_\_\_ Address \_\_\_\_\_

Who has parental responsibility/ies? \_\_\_\_\_

Will parent attend the appointment? Yes / No Tel \_\_\_\_\_

Who else is aware that testing is taking place? \_\_\_\_\_

### Reason for referral

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### Who is to be informed of the results?

\_\_\_\_\_

\_\_\_\_\_

Signed \_\_\_\_\_ Designation \_\_\_\_\_ Date \_\_\_\_\_

# Parent/carer information leaflet

Your child/the child you are caring for has been assessed by a paediatrician (children's doctor) and they have requested that your child have a blood test. The blood test is looking for the following infections: hepatitis B; hepatitis C; Human Immunodeficiency Virus (HIV), and syphilis. Hepatitis B, HIV and syphilis are all tested for routinely during pregnancy. Many areas also test for hepatitis C during pregnancy.

### Information on these infections

#### What is hepatitis B virus?

Hepatitis B is a virus that causes swelling and loss of function (inflammation) of the liver, which can result in damage that may lead to scarring of the liver and increased risk of liver cancer in some people.

#### What is hepatitis C virus?

Hepatitis C is also a virus that causes swelling and loss of function (inflammation) of the liver. The majority of people infected will get only mild liver damage. However, in some people hepatitis C progresses over 20–30 years to cause serious liver damage.

#### What is HIV?

HIV is a virus that attacks the body's defence against infection (immune system) making it vulnerable, over time, to infections that a healthy immune system would fight off.

#### What is syphilis?

Syphilis is a bacterial infection that in adults initially causes sores and then progresses to give rashes and generalised symptoms. Over many years, untreated syphilis can cause serious damage to many systems in the body and may result in death. Congenital syphilis (babies and children who acquire syphilis from their mothers during pregnancy) can result in multi-system organ damage (e.g. to the brain, bones, teeth and eyes).

#### Why would the child have these infections?

Children who have these infections usually have had the infection transmitted from their mother

while in the womb, during labour or while being breastfed. This means that when infection is found in a child, their mother more often than not has the same infection as well. It is therefore important that parents understand this and have the appropriate information and time for questions before testing on the child is carried out. There are other less common ways in which a child could have acquired the virus and these can be discussed as well.

#### Why is it useful to know if your child has an infection in the blood?

Due to improvements in the treatment of hepatitis B, hepatitis C, HIV and syphilis infections, there are real advantages in finding out whether children (and adults) have these infections. Children who have contracted these infections from their mothers can remain in good health for many years. However, without treatment and monitoring, all of these infections can cause children to become severely ill, and put them at risk of death.

#### Practicalities of testing

Your child will be seen by the children's doctor for the blood to be taken and the results will be ready usually within two weeks. A follow-up appointment for the results will be arranged at the first appointment. Prior to your child's appointment, it has been arranged for you to have an appointment with the children's doctor so that you can discuss the implications of testing your child and what this means for you. In this meeting you can also discuss how you would like to receive the results of your child's blood tests.

Your appointment date is:

Your child's appointment date is:

If you have a problem attending this appointment please call and rearrange on:

Your child's GP will be informed of the results. If you have concerns about this, please discuss with your doctor and social worker.

## Young person information leaflet

You have been assessed by a paediatrician (children's doctor) and they have requested that you have a blood test. The blood test is looking for the following infections: hepatitis B; hepatitis C; Human Immunodeficiency Virus (HIV), and syphilis.

### Information on these infections

#### What is hepatitis B virus?

Hepatitis B is a virus that causes swelling and loss of function (inflammation) of the liver, which can result in damage that may lead to scarring of the liver and increased risk of liver cancer in some people.

#### What is hepatitis C virus?

Hepatitis C is also a virus that causes swelling and loss of function (inflammation) of the liver. The majority of people infected will get only mild liver damage. However, in some people hepatitis C progresses over 20–30 years to cause serious liver damage.

#### What is HIV?

HIV is a virus that attacks the body's defence against infection (immune system) making it vulnerable, over time, to infections that a healthy immune system would fight off.

#### What is syphilis?

Syphilis is a bacterial infection that in adults initially causes sores and then progresses to give rashes and generalised symptoms. Over many years, untreated syphilis can cause serious damage to many systems in the body and may result in death. Congenital syphilis (babies and children who acquire syphilis from their mothers during pregnancy) can result in multi-

system organ damage (e.g. to the brain, bones, teeth and eyes).

#### Why would you have these infections?

Children who have these infections usually have had the infection transmitted from their mother during pregnancy or after birth. These infections are passed from person to person by sexual intercourse, or from sharing needles or other equipment when using drugs.

#### Why is it useful to know if you have an infection in the blood?

Due to improvements in the treatment of hepatitis B, hepatitis C, HIV and syphilis infections, there are real advantages in finding out whether you have these infections. Children and young people who have contracted these infections from their mothers can remain in good health for many years. There are treatments available for these infections that enable people to have healthy lives. However, without treatment and monitoring, all of these infections can cause people to become severely ill or even die.

#### Practicalities of testing

You will be seen by your doctor or nurse for the blood to be taken and the results will be ready usually within two weeks. At this appointment you can discuss the tests in more detail.

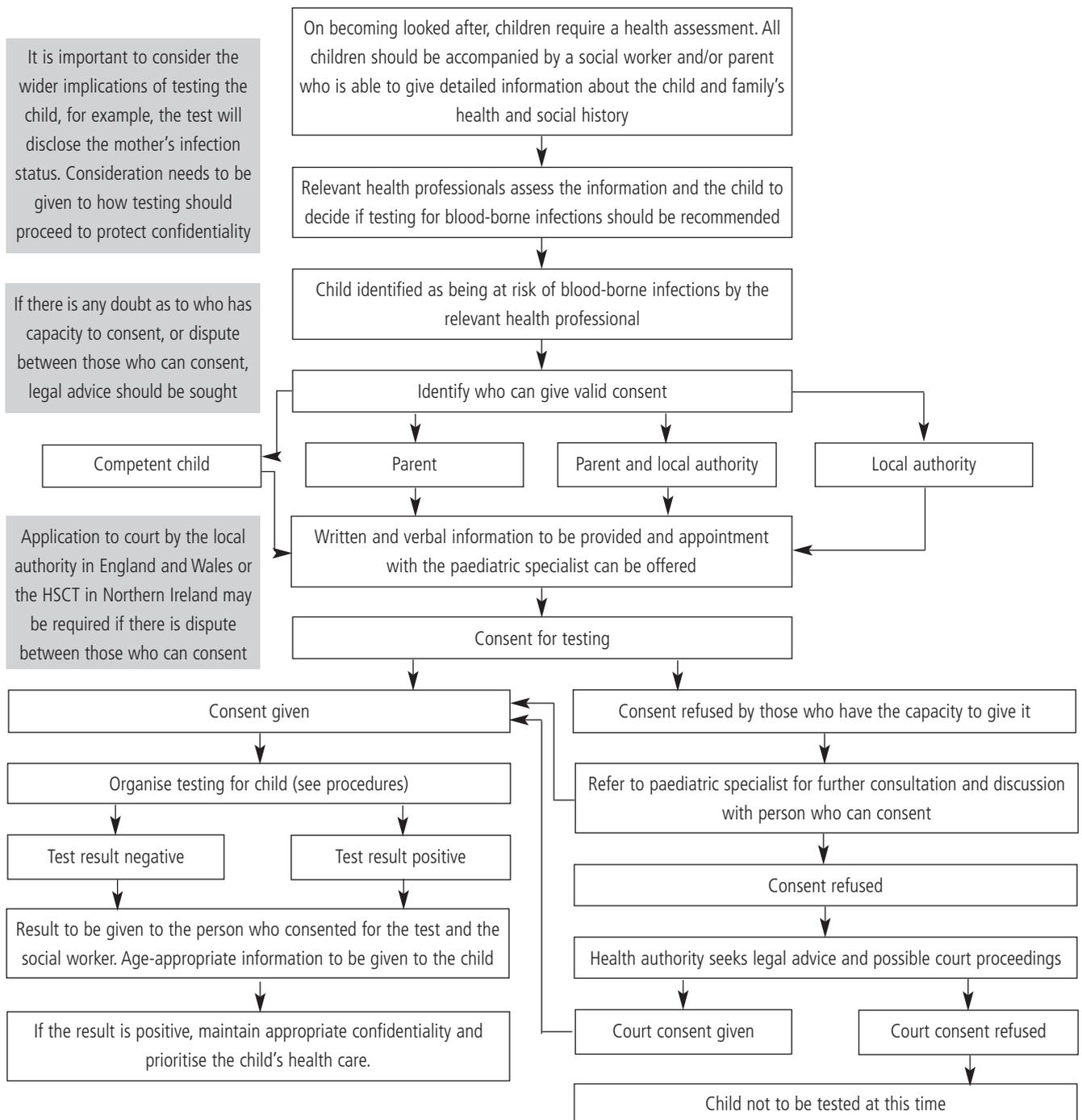
Your appointment date is:

If you have a problem attending this appointment please call and rearrange on:

Your GP will be informed of the results. If you have concerns about this, please discuss with your doctor and social worker.

# A guideline for testing looked after children for blood-borne infections

- For a newborn baby, this procedure should be urgently expedited as the baby needs an urgent assessment by a paediatrician within 24 hours to allow preventative treatment.
- Information regarding the intention to test, the recommendation to test and the test result is confidential. It should not be disclosed to carers, agencies or other third parties without due consideration (see ‘Confidentiality and disclosure’ earlier in this leaflet).
- This is a guideline. Each case will be different. The decisions are primarily medical and legal. Appropriate advice should be sought.



## Who can give consent for testing and treatment?

### Country-specific information

This appendix covers the different rules about who may consent for testing and treatment, depending on:

- where the child is in the UK; and
- the child's legal status, i.e. in what way the local authority and/or others are involved with the child.

The rules about consent and the types of orders, etc, vary between:

- England and Wales;
- Northern Ireland;
- Scotland.

It should be remembered that there are cases where the child's status (i.e. type of order, etc) has been determined in one of the four UK countries, but that he or she is placed in another. In such cases, the law applying to consent will be that of the country where the child is placed at the time the consent is sought. However, the status of the child, and whether or not the local authority holds parental responsibility/ies, will still be determined by the law of the country where any order was made and which continues to affect the child.

### I. England and Wales

#### i. Local authority has full parental responsibility

There are still occasions when a local authority may have full responsibility for a child in England and Wales, even if the local authority is not an English or Welsh one. Although freeing orders cannot be obtained in England and Wales under the Adoption and Children Act 2002, there are still children who are subject to freeing orders granted under the previous legislation. In addition, freeing orders are still obtainable in Scotland and Northern Ireland and children from there may be placed in England and Wales (for further details see the relevant country in this appendix).

When a local authority (or NI Health and Social Care Trust (HSCT)) has full parental responsibility/ies, it is its consent which is needed, if the child is not capable of consenting – see v. and vi. below.

#### ii. Local authority shares parental responsibility (PR) with the parent/s

There are a number of legal orders which give a local authority parental responsibility (PR) which it shares with the parent/s. The main ones are care orders under the Children Act 1989 and placement orders. Under the latter, PR is also shared with prospective adopter/s under the Adoption and Children Act 2002.

In cases where the child does not have capacity to consent himself or herself, the decision rests with those who have parental responsibility. The decision to consent to testing a child for blood-borne infections should be made jointly between those who have PR. Where there is agreement between those with parental responsibility, there are no difficulties in proceeding.

However, there may be some circumstances where a local authority considers it inappropriate to consult with the parent/s. In those cases, the local authority should seek legal advice before proceeding, and consideration must be given to the rights of parent/s to know their own infection status. Furthermore, where there are current court proceedings, any children's guardian appointed in the proceedings should also be consulted in relation to testing.

If one party with parental responsibility refuses to consent to testing, an appointment should be offered with the paediatric specialist as further information and advice will often result in agreement to the tests.

Where there is an unresolved dispute between those who have PR, the situation is more complicated, and legal advice should be sought since it may be necessary to apply to court for the issue to be resolved.

---

Decisions made by those with PR or the court are to be made on the basis of what is in the best interests of the child.

### **iii. Parent(s) have sole parental responsibility**

There are situations where the parent/s retain full parental responsibility, for example, where the child is accommodated by a local authority on a voluntary basis. If there are concerns about the child's risk factors for blood-borne infection but the parent/s of a child without capacity to consent refuse testing, the paediatric specialist should be consulted. As stated earlier, if the child is asymptomatic then there is time to work with families. Usually, with accurate information and expert support, families will agree to testing. In rare cases applications may be made to court for the issue of consent to be resolved.

### **iv. Abandoned baby**

In the case of an abandoned baby, there is an absence of persons with parental responsibility. Under the Children Act 1989, a local authority has the duty to safeguard the baby's welfare and a power to do what is reasonable to safeguard the baby's welfare. This would include consenting to tests on the recommendation of medical practitioners. In the case of a newborn baby, this assessment should be carried out within 24 hours (see the specific case scenario for an abandoned baby earlier in this leaflet).

### **v. Children and young people under 16**

A child or young person under 16 years old can give consent to treatment if he or she is "Gillick competent". This means that a child or young person who has sufficient understanding and maturity to comprehend fully the nature and implications of having tests for blood-borne infections will also have the capacity to give his or her own consent. The position if he or she refuses is as set out below in relation to young people who are 16–18 years old.

### **vi. Children and young people who are 16 and over**

Young people aged 16 or 17 can consent to their own medical treatment, under the terms of the

Family Law Reform Act 1969. If a young person of 16 or 17 gives consent, it is not necessary to get consent from an adult with parental responsibility but it would be good practice to involve the parent/s, unless the young person doesn't want this. If a young person aged 16–18 refuses consent, legal advice should be sought.

## **II. Northern Ireland**

### **i. Health and Social Care Trust (HSCT) has full parental responsibility**

An HSCT may have full responsibility for a child in terms of a freeing order under the Adoption (Northern Ireland) Order 1987. In addition, children from England, Wales and Scotland who are subject to a freeing order may be placed in Northern Ireland (for further details see the relevant country in this appendix).

When an HSCT, or a local authority from elsewhere in Britain, has full parental responsibility, it is the Board's (or authority's) consent which is needed, if the child is not capable of consenting – see v. and vi. below.

### **ii. HSCT shares parental responsibility with the parent/s**

There are a number of legal orders which give an HSCT parental responsibility (PR) which it shares with the parent/s. The main ones are care orders or interim care orders under the Children (Northern Ireland) Order 1995.

In cases where the child does not have capacity to consent himself or herself, the decision rests with those who have parental responsibility. The decision to consent for testing a child for blood-borne infections should be made jointly between those who have PR. Where there is agreement between those with parental responsibility, there are no difficulties in proceeding.

However, there may be some circumstances where an HSCT considers it inappropriate to consult with the parents. In those cases, the HSCT should seek legal advice before proceeding, and consideration must be given to

---

the rights of parent/s to know their own infection status. Furthermore, where there are current court proceedings, any guardian *ad litem* appointed in those proceedings should also be consulted in relation to testing.

If one party with parental responsibility refuses to consent to testing, an appointment should be offered with the paediatric specialist as further information and advice will often result in agreement to the tests.

Where there is an unresolved dispute between those who have PR, the situation is more complicated and legal advice should be sought since it may be necessary to apply to court for the issue to be resolved. It is possible to proceed with medical treatment with the consent of only one party with PR, but this would not be advisable in the situations covered by this Practice Note.

Decisions made by those with PR or the court are to be made on the basis of what is in the best interests of the child.

### **iii. Parent/s have sole parental responsibility**

There are situations where the parent/s retain full parental responsibility, for example, where the child is accommodated by an HSCT on a voluntary basis. If there are concerns about the child's risk factors for blood-borne infection but the parent/s of a child without capacity to consent refuse testing, the paediatric specialist should be consulted. As stated earlier, if the child is asymptomatic then there is time to work with families. Usually, with accurate information and expert support, families will agree to testing. In rare cases applications may be made to court for the issue of consent to be resolved.

### **iv. Abandoned baby**

In the case of an abandoned baby, there is an absence of persons with parental responsibility. Under the Children (Northern Ireland) Order 1995, an HSCT has the duty to safeguard and

promote the baby's welfare, but no specific powers to do what is reasonable to safeguard the baby's welfare, although these could be implied. These powers could include consenting to tests on the recommendation of medical practitioners. In the case of a newborn baby, this assessment should be carried out within 24 hours (see the specific case scenario about an abandoned baby earlier in this Note).

### **v. Children and young people under 16**

A child or young person under 16 years old can give consent to treatment if he or she is "Gillick competent". This means that a child or young person under 16 who has sufficient understanding and maturity to comprehend fully the nature and implications of having tests for blood-borne infections will also have the capacity to give his or her own consent. The position if he or she refuses is as set out below in relation to young people who are 16–18 years old.

If the child or young person under 16 does not have the necessary understanding and maturity, then the consent of someone with PR is required.

### **vi. Children and young people who are 16 and over**

Young people aged 16 or 17 can consent to their own medical treatment, under the terms of the Age of Majority Act (Northern Ireland) 1969. If a young person of 16 or 17 gives consent, it is not necessary to get consent from an adult with parental responsibility, but it would be good practice to involve the parents, unless the young person does not want this. If a young person aged 16–18 refuses consent, the refusal may be overridden by a person with PR or by a court, but legal advice should be sought.

If a young person over 16 does not have the necessary understanding and maturity, then the consent of someone with PR is required.

---

### **III. Scotland**

#### **i. Local authority has full parental responsibilities and rights**

A local authority may have responsibilities and rights because of a freeing order or a parental responsibilities order (PRO). Freeing orders are still obtainable in Scotland under the Adoption (Scotland) Act 1978, at least until the Adoption and Children (Scotland) Act 2007 comes into force at the end of 2008 or early in 2009. In addition, children from Northern Ireland and England and Wales may be placed in Scotland. Freeing orders are still obtainable in Northern Ireland and although they cannot be obtained in England and Wales under the Adoption and Children Act 2002, there are still children who are subject to freeing orders granted under the previous legislation.

In addition, local authorities in Scotland may obtain full parental responsibilities and rights (except the right to agree or not to adoption) through parental responsibilities orders (PROs) under Section 86 of the Children (Scotland) Act 1995, although these will be abolished when the 2007 Act comes into force.

When a local authority (or HSCT) has full parental responsibilities through a freeing order or a PRO, it is its consent which is needed, if the child is not capable of consenting – see v. and vi. below. However, if the child or young person is capable of consenting, it is his or her consent which is needed, not the authority's or HSCT's – see v. and vi. below.

#### **ii. Local authority shares parental responsibilities with the parent/s**

At present, there is no order whereby local authorities in Scotland share responsibilities and rights with parents. However, this will occur when permanence orders are granted under the Adoption and Children (Scotland) Act 2007, when that Act comes into force at the end of 2008 or early 2009.

#### **iii. Parent/s have sole parental responsibilities and rights**

There are situations where the parent/s retain all parental responsibilities, for example, where the child is accommodated by the local authority on a voluntary basis or the child is subject to a supervision requirement. If there are concerns about the child's risk factors for blood-borne infection but the parent/s of a child without capacity to consent refuse testing, the paediatric specialist should be consulted. As stated earlier, if the child is asymptomatic then there is time to work with families. Usually, with accurate information and expert support, families will agree to testing.

If the child does not have capacity to consent, the parent refuses consent and the child is subject to a supervision requirement, the hearing may be asked to override the refusal by adding a condition to the requirement. In rare cases, an application may be made to a court for the issue of consent to be resolved. However, if the child or young person is capable of consenting, it is his or her consent which is needed, not the parent's – see v. and vi. below.

#### **iv. Abandoned baby**

In the case of an abandoned baby, there is an absence of persons with parental responsibilities. Under the Children (Scotland) Act 1995, a local authority has a duty to safeguard and promote the baby's welfare but no specific powers to do what is reasonable to safeguard the baby's welfare, although these could be implied. These powers would include consenting to tests on the recommendation of medical practitioners. In the case of a newborn baby, this assessment should be carried out within 24 hours (see the specific case scenario for an abandoned baby earlier in this leaflet). General medical tests should be carried out and this could arguably include testing on the recommendation of medical practitioners.

---

**v. Children and young people under 16**

Under s.2(4) of the Age of Legal Capacity (Scotland) Act 1991, children and young people under 16 have the right to consent to their own medical treatment 'where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment'. Although it is good practice to involve the parents or others with parental responsibilities, it is the child's consent which matters when the medical practitioner is satisfied that he or she is competent. Parental refusal cannot override the competent child's consent. And the competent child's refusal

cannot be overridden by the consent of the parent.

**vi. Children and young people who are 16 and over**

In Scotland, a young person who is 16 or older is a full adult for the purposes of medical consent, under the Age of Legal Capacity (Scotland) Act 1991. The parent (or local authority or HSCT) has no right to consent or not consent on his or her behalf or to override a refusal to consent by the young person. If the young person is not capable of consenting, legal advice should be sought about how consent for an incapable adult may be obtained.

---

## **Disclaimer**

*Earlier drafts of this document were widely circulated during consultation; however, this Practice Note supersedes all previous drafts.*

This Practice Note was written by Marthe Le Prevost, Paediatric HIV Clinical Nurse Specialist, and Dr Amanda Williams, Consultant Paediatrician.

Further contributions were made by the BAAF/CHIVA/NCB working party, including the authors and Dr Christine Arnold, Associate Specialist; Dr Thérèse Bennett, Associate Specialist; Amanda Ely, NCB; and Florence Merredew, Health Group Development Officer, BAAF, in consultation with BAAF colleagues Deborah Cullen, Frances Nicholson and Alexandra Plumtree.

## **Acknowledgements**

Special thanks go to Dr Hermione Lyall, Chair of Children's HIV Association of UK and Ireland; Dr Ximena Poblete, Consultant Paediatrician; and Kathy Robinson, Senior Solicitor, Brent Legal Department.

We would also like to acknowledge the invaluable contributions of members of the BAAF Health Group Advisory Committee and Dr Suzanne Anderson, Paula Bell, Janet Connellan, Cheryl Dunn, Anne Edwards, Liz Jamieson, Naima Khan, Dr John McSorley, Dr Nermin Muhialdin, Dr Sepali Wijesinghe and Dr Maryam Zahir of Brent and Harrow.

© BAAF, 2008

Published by British Association for Adoption and Fostering, Saffron House, 6–10 Kirby Street  
London EC1N 8TS

**[www.baaf.org.uk](http://www.baaf.org.uk)**

*Charity no 275689 (England and Wales) and SC039337 (Scotland)*