PRACTICE NOTE 76

Guidelines for the testing of looked after children and young people at risk of blood-borne infections

Introduction

Blood-borne infections (BBI) are caused by micro-organisms (viruses or bacteria) that are carried in blood and cause disease in people. The infections covered in this guidance are Hepatitis B (HBV), Hepatitis C (HCV), Human Immunodeficiency Virus (HIV), and syphilis.

The original BAAF (now CoramBAAF) Practice Note on blood-borne diseases, Practice Note 53 (2008) was produced by a health/social care working group involving BAAF, the Children's HIV Association (CHIVA) and NCB (National Children's Bureau). This updated Practice Note has been produced by a CoramBAAF working group, including CHIVA. It aims to provide social care and children's health care workers with:

- multi-agency guidance to address the health needs of looked after children and young people who could be at risk of blood-borne infections;
- information on HBV, HCV, HIV, and syphilis;
- 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 diseases that are treatable, so as is the case with the general population, whenever risk factors for these diseases are identified, **testing should be offered at the earliest opportunity to ensure treatment is not delayed**.

All professionals working with vulnerable children and young people, looked after children and young people, and care leavers need to be familiar with this guidance.

The diseases in brief

	What is it?	How common is it?	How treatable is it?
HIV	A virus that attacks the body's immune system, making it vulnerable, over time, to infections that a healthy immune system would fight off. HIV is less easily transmitted than HBV or HCV. The virus does not clear spontaneously.	The most recent estimate suggests there were 105,200 people living with HIV in the UK in 2019. In 2020, 2,210 children were reported to be living with HIV in the UK. https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/hiv/	HIV cannot be cured, but antiretroviral (ART) medication provides long-term control and prevents illness. The vast majority of people living with HIV on treatment reduce the amount of virus in their blood so that it becomes undetectable, and they then do not pass on the virus by sexual transmission routes. Life expectancy now is the same as the general UK population.
Hepatitis B	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. 90–95% of those infected as adults clear the virus completely. The risk of liver cancer is much higher in children infected at birth because 90% of these	0.4% of women tested antenatally had HBV infection. (Green Book, 2019). www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book#the-green-book 180,000 people in the UK are living with chronic HBV infection.	Most adults infected clear the virus completely with no intervention. If an individual goes on to develop chronic infection, they need ongoing monitoring. There are various medications that can control symptoms.

	infants do not clear the virus. HBV is much more easily transmitted than HIV. A small proportion of people with HBV are highly infectious. HBV is preventable by immunisation.	https://britishlivertrust.org.uk/information-and-support/living-with-a-liver-condition/liver-conditions/hepatitis-b/	Vaccination for HBV is now part of routine vaccination schedule for babies. Newborn babies at high risk of contracting HBV from their mother should be vaccinated at birth to prevent infection and have follow-up to confirm HBV status.
Hepatitis C	A virus that causes inflammation of the liver. Of people with HCV infection, 15–50% will clear the virus. The majority will get only mild liver damage. However, in up to 30% of people, HCV progresses over 20–30 years to cause serious liver damage and increased risk of liver cancer.	PHE estimates that 143,000 people are living with HCV. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/831155/Hepatitis_C_in_the_UK_2019_report.pdf	In some individuals, the virus will clear with no intervention. If not, most people can be treated with medication and the virus can be completely cleared.
Syphilis	A bacterial infection. When acquired sexually, syphilis initially causes sores and then progresses to cause 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 occurs in babies and children, who acquire syphilis from their mothers during pregnancy, and can result in multi-system organ damage (e.g. to the brain, bones, teeth and eyes). 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.	There are 7,000 new UK cases per year (PHE, 2018). The incidence is increasing.	Syphilis will not go away on its own. It can be treated and completely cleared with medication. Congenital syphilis is preventable by treating the mother with antibiotics in pregnancy, or the baby soon after birth. There are increasing cases of congenital syphilis but overall it remains rare.

How are these infections passed from one person to another (transmitted)?

These micro-organisms can transfer from one person to another in **blood**, **semen** or **vaginal fluid**.

Vertical transmission routes (mother to baby)	**HIV**	**Hepatitis C**	**Hepatitis B**	**Syphilis**
Mother in pregnancy or delivery	√ 25% risk if mother untreated, and breast feeds, falling to 0.28% for women diagnosed and treated before birth and avoiding breastfeeding. The vast majority of children with HIV acquired it from their mothers.	√ (main risk at delivery) Approx. 5% risk if mother has active infection.	√ 90% risk if mother is highly infectious. Infant vaccination and maternal	√ 70–80% risk if mother untreated

			treatment reduce transmission.	
Breastfeeding	√ In the UK, mothers with HIV are advised not to breastfeed. However, women who are virologically suppressed on cART with good adherence and who choose to breastfeed should be supported to do so, but should be informed about the low risk of HIV transmission through breastfeeding in this situation. www.bhiva.org/pregnancy-guidelines	X	X	X
Horizontal transmission routes				
Sexual intercourse (including oral sex) with infected person	√	√ (low risk in heterosexual relationships)	√	√
Sexual abuse/exploitation/ assault	√	√	√	√
Intravenous drug use/ sharing contaminated needles, equipment	√	√	√	X
Intranasal drug use (ongoing research)	X	Recently suggested	X	X
Blood transfusion in countries where blood is not screened	√	√	√	√
Medical equipment/invasive procedure with unsterilised equipment	√	√	√	X
Non-sterile equipment, piercing and tattoos	X	√	√	X
Toothbrush or razor contaminated with blood and shared	X	√	√	X
Sporadic infection in high prevalence area (e.g. in institutions and in between children)	X	X	√	X

See the NHS website for further details: https://www.nhs.uk/conditions/.

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 visibly contaminated with blood.

These diseases are not transmitted by social contact and daily activities, e.g. coughing, sneezing, kissing, holding hands, or sharing bathrooms, swimming pools, toilets, food, cups, cutlery and crockery.

Household/family contact

A note about HBV vaccination

If someone has recently been infected with HBV, they may be in an "acute" phase of the disease where the virus is more likely to spread by the routes described in the table above. Therefore household members, where an individual has HBV, are offered vaccination against HBV.

Many individuals have already received HBV vaccination (mainly children since 2017). The vaccination is now given routinely to all infants in the UK as part of the national childhood immunisation schedule (from 2017). Some individuals have been vaccinated due to workplace or travel protection.

Why test?

It is important that any test carried out on a child is done in their best interests. 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 can remain well for many years, even if acquired at or before birth.

Without treatment and monitoring, all of these blood-borne infections can cause children to become ill, have impact on their quality of life and can be life-limiting. It is important to initiate treatment early, particularly in younger children. Thus if risk factors are identified, testing in this group should be carried out urgently.

The working party which authored this guidance 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. However, as all of these infections are potentially life-threatening and treatable, there should be a low threshold for testing.

Due to the nature of blood-borne infections, those concerned are often very worried when the subject of testing is raised. However, in most cases, with support and the provision of accurate information, fears can be put into context and alleviated, as treatment is now an option. These cases may be complex. It is essential that discussion with all concerned is carefully planned and advice sought from local specialists where needed. It is important to support the individuals involved, particularly where English may not be their first language, and interpreters should be provided when required.

Testing for blood-borne infections is a normal part of health care today. Looked after children and young people and their parents may have been tested for these infections before children come into care. It is important that complete health histories are available to avoid duplication or unnecessary testing.

Confidentiality is extremely important. Individuals and families managing and living well with these health conditions still report experiencing stigma, discrimination and social exclusion.

Antenatal screening

Most blood-borne infections in infants and children occur as a result of vertical transmission from their mother. It is therefore important to understand what screening is offered to pregnant women.

In the UK, pregnant women are offered routine blood tests for HBV, HIV and syphilis at booking (usually around 12 weeks). These tests can be repeated later in pregnancy if it is identified that women are exposed to further risks of infection. Testing for HCV in pregnancy is offered on a selective, not a routine, basis where specific risk is identified. The main situation is when a woman and/or her partner are past or current IV drug users or have arrived from a high risk country.

Where women are identified as having a blood-borne infection, their care in pregnancy and the care of their infant, partner and other children will be managed by maternity and neonatal/paediatric and infectious disease services.

In the UK, most women with HIV are diagnosed prior to or in early pregnancy, and effective treatment ensures that infection in their child is nearly always prevented.

Raising the concerns of possible infections

Health and social care professionals may identify risk factors (see table below) at any point in the child's life. When risk factors are identified, the practitioner will need to seek advice from an appropriate health professional, e.g. the LAC health team, GP, or local paediatric or paediatric infectious diseases team.

Social workers must ensure that they share information about parental lifestyle and risk factors with the health team in a timely manner. Good communication between health and social care is essential.

The statutory health assessments offered to children and young people in care also offer a valuable opportunity to review whether children have been exposed to any risk and to take any action needed.

In some situations, a child may be **exposed to a risk where immediate assessment and attention (within 72 hours) can prevent an infection developing post exposure**. This is particularly the case with HBV (where immediate vaccination can prevent infection), and HIV (where post-exposure prophylaxis can be given).

Risk factors/situations that require further assessment/where testing for a child may be recommended

All of these infections are potentially life-threatening and are treatable – so have a low threshold for testing.

Parent risk factors	Child/young person risk factors
Birth mother has unknown blood-borne infection status • Not present/available • Unknown mother • Did not receive antenatal tests (declined or pregnant in another country) Birth mother had routine pregnancy screen but transmission risks identified in later pregnancy or during breastfeeding, such as unprotected sexual intercourse. New information that birth mother/father has a diagnosed blood-borne infection Parents are IV drug users Birth mother and father have unknown lifestyle risks	IV drug use Victim of sexual abuse/exploitation Unprotected sexual intercourse. Needle stick injury Has experienced female genital mutilation (FGM) Unsafe tattoos and piercings Injury received, such as human bite Refugee/unaccompanied asylum-seeking child (UASC)

In addition to the risk factors detailed in the table above, when assessing children from abroad, health care professionals should give consideration to the prevalence of infections in the child's country of origin. However, the risk of blood-borne infections in children from low prevalence areas should not be ruled out (see websites listed at the end of this Practice Note for more information). When all the circumstances have been considered, **a health professional may recommend testing for blood-borne infections.**

The actual process for blood-borne infection screening/carrying out blood tests will vary across the UK according to service provision. **Local guidelines/pathways should be agreed**, to give practitioners guidance on making a referral for testing (see Appendix 1).

There are some situations where risk factors for blood-borne infections in a child have been identified but where **it may be possible to test the birth mother instead, and exclude infection in the child. Social workers must prioritise contacting the birth mother.**

Consent and record keeping

The next two sections of text explore some of the important issues to consider when obtaining consent for testing for blood-borne infections, and when to share information pertaining to testing, and with 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 them.

Consent for testing looked after children and young people for blood-borne infections must always be obtained by a health or social 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, and are able to access advice about blood-borne infections from appropriate paediatric specialists.

Obtaining consent to test for blood-borne infections

- Except for emergency situations where the health of the child is likely to suffer if testing/treatment is not provided immediately, informed consent is required before carrying out the blood tests. Consent must be obtained without delay and should not become a reason to defer testing. It is therefore essential that everyone working with a child being tested for blood-borne infections knows who has **parental responsibility (PR)** (or parental responsibilities and rights in Scotland), and **whether the child has capacity to consent, since these are prerequisites to the power to consent**. Verbal and written information should be provided to explain the benefits of the tests (see information leaflets in Appendices 2 and 3).
- Best practice is that an appointment (video, telephone or in person) should be offered for the parent/person with parental responsibility/ies to discuss the tests with the doctor or nurse recommending them. However, in some circumstances a social worker with appropriate training can obtain informed consent from a parent in a written form (see sample form in Appendix 1).

- It is not always appropriate or possible to include all those with PR in discussing the tests. It is acceptable to obtain informed consent from one party with PR. For more information, see https://www.nhs.uk/conditions/consent-to-treatment/children/.
- Children must be given an age-appropriate explanation of what tests are going to be undertaken, as well as the procedures involved and information on relative risk and benefits of testing, including risk of untreated infection. If children have capacity to do so, their consent should be taken and documented. Verbal consent is adequate but must be documented in the notes. Gillick guidelines should be followed where a child/young person has capacity to give consent. See https://learning.nspcc.org.uk/child-protection-system/gillick-competence-fraser-guidelines.
- The statutory Initial Health Assessment for a looked after child is an opportunity to consider the need for blood-borne infection testing, and it is important to prioritise obtaining consent at this point if the child is accompanied by a parent/other adult with PR.

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

- Sometimes young people and those with PR ask for "time" to consider testing. This will need to be managed on a case-by-case basis, and advice should be obtained from a paediatric specialist about the risks of delaying testing. (See the GMC case study set out here: https://www.gmc-uk.org/ethical-guidance/learning-materials/parent-refuses-consent---part-one.)
- As most children and young people with blood-borne infections have acquired them from their 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 are at risk. Best practice is that the pre-test discussion should ideally involve both parents (not necessarily together) and, where appropriate, the child or young person. If family circumstance are such that the mother is not 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. Local pathways should describe how the mother is informed of test results and, in the event of a positive test result, is signposted to appropriate services for herself.
- Attempting to have discussions with or locate a mother should not delay testing for a child (where the child/young person themselves or another party is giving consent to the tests). Where a parent is known to be living with a blood-borne infection, but does not consent for this information to be given to the child, there is a duty not to breach the parent's confidentiality while giving a reasonable explanation to the child for why testing is recommended.

Who can give consent for the child?
(where the child is not able to give consent themselves)
This depends on:

- the **child's legal status and who holds PR**; and
- whether the child lives in England, Wales, Northern Ireland or Scotland, as legal orders vary between the nations.

The details for each country are set out in Appendix 4.
The situations covered are:

- Local authority shares PR with the parent/s (court orders)
- Parent/s have sole PR
- Abandoned baby
- Children and young people who are under 16
- Children and young people who are 16 and over

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 2018 and an individual's privacy rights in 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 that 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 well-being. The Data Protection Act 2018 and guidance recognises that there are circumstances where those 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 PR or the competent child/young person 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? Consider use of a confidentiality agreement.

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 shared, then the objecting party should be given adequate opportunity to seek legal advice before the information is shared. In all such cases, the local authority should seek legal advice before disclosure.

Case examples

The scenarios listed below are the most common situations identified by the authorial working group 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 guidance is to encourage positive working relations between health and social care, so that advice can be sought as and when situations occur. Early communication is always preferable; misinformation and inappropriate handling of situations 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'.

Risk of vertical transmission/newborn babies

a) 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 IV drug user. 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. Sarah's mother was not contactable, the local authority had PR and gave consent for testing Sarah.

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 initial routine tests, e.g. by continuing IV drug use 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.

b) Abandoned baby

A newborn infant was found by a member of the public. They contacted the police, who brought the baby to the Accident and Emergency Unit. The nursing staff 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.

Risk of vertical transmission/older children

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.

c) Child whose parent is a known intravenous (IV) drug user

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 Steven's mother had been an IV drug user. The medical adviser recommended that either Steven's mother or Steven himself should be tested for blood-borne infections.

Steven's mother was contacted. She did not wish to be tested herself but gave consent for Steven to be tested. All Steven's tests were negative. Steven's mother was informed of the results. It was not a medical emergency to test Steven, which allowed more time to gather information and to contact Steven's mother in accordance with good practice.

All children who have a parent (either mother or father) who is an IV drug user 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.

d) Birth parents diagnosed with HIV

Bella was a six- year-old placed with prospective adoptive parents. Her social worker received new information that Bella's birth mother had recently disclosed that she had HIV. Bella had not been tested and Bella's prospective adoptive parents now requested that she be tested. On discussing the case with the LAC health team, the social worker mentioned that the birth mother had another baby who was 18 months old. Further consultations with the birth mother revealed that she was tested in this pregnancy for blood-borne infections, including HCV, and all tests were negative at that time. It was decided that there was no need to test Bella.

Horizontal transmission risk

e) Testing children in cases of sexual abuse and sexual exploitation

Ben was a 14-year-old who had been raped at the age of 12. He disclosed the rape to his current foster carers. Ben was reluctant to see any health professionals; however, he agreed to see the LAC nurse for his review health assessment. The LAC nurse explained the risks of blood-borne infections and the benefits of testing. Ben chose to attend the sexual health clinic, where staff arranged for screening with his informed consent.

Where there is late disclosure and a young person or child has declined specialist examination and assessment, blood-borne infection testing should be offered as part of ongoing care. (If a child/young person is seen at a sexual assault referral centre (SARC), need for screening will be considered and arranged if necessary.)

f) Young people who are sexually active

Lorna was 15 years old and lived with foster carers. She had been on a school trip and had unprotected sexual intercourse with a young person that she met on the trip abroad. She told her foster carer, who arranged for her to attend the local sexual health service and accompanied her at her request.

Young people who are sexually active and have unprotected sexual intercourse are at risk of acquiring blood-borne infections and other sexually transmitted infections. Testing for blood-borne infections should be considered in this age group with young people's informed consent, as part of a risk-based sexual health assessment which is usually best provided by sexual health services for young people.

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.

g) Unaccompanied asylum-seeking minors from abroad

When 15-year-old Celia arrived in the UK from Botswana 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 Botswana.

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 (PTSD). 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 Botswana, and a referral to the sexual health clinic 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. Emotional support should be provided whilst offering screening.

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 infections varies in different countries, and many UASC come from, and/or travel through, countries where blood-borne infections are highly prevalent. A large number of them will have experienced rape and/or torture. In highly endemic areas, HBV can spread via horizontal transmission between children.

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 sexual health services. In the absence of a history of sexual activity, but where blood-borne infection is possible, paediatricians should consider the risk factors, e.g. mother to baby transmission, and, if appropriate, arrange for testing with the young person's consent. **Screening for HBV, HCV, HIV and syphilis should be strongly considered in this group of young people. Testing for other infectious diseases such as tuberculosis, and for worm infections such as schistosomiasis, should also be considered.** 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 and ethnicity to ensure that an appropriate and trained 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.
- **Arrangements for giving results**: these should include ensuring that an appropriate interpreter is present (particularly if there is a positive test result).

Practicalities of testing children with blood-borne infections

It is important to refer to local procedures and pathways (see Appendix 1). Health professionals should refer to local guidelines and take advice from the local virology team/laboratory.

Tests for HIV, HCV, HBV and syphilis can be ordered by a variety of health professionals, community or hospital paediatricians, GPs or other clinical services. Blood may actually be taken in a number of different settings dependent on local arrangements.

Blood tests for infectious diseases broadly look for two markers in the blood: presence of the virus/bacteria itself (antigen or genetic material), or the antibodies that the body produces in response to an infection. The exact types of blood test used may vary between laboratories; new tests are developed and become available regularly.

Blood tests required will depend on the child's age. Depending on the child's age, length of time since possible exposure, and type of disease, repeat tests may be required to check for infection and obtain definitive results.

Where infections in a pregnant mother are known, testing the infant and any treatment required will be arranged by maternity/neonatal services.

Testing children under 24 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 24 months therefore does not necessarily signify syphilis, HIV, HCV or HBV infection in the child.

HBV, HBC and syphilis transferred maternal antibody is usually lost by 18 months, but HIV antibodies may persist to 22 months. Negative antibody tests can exclude infection; however, if an infant has positive antibody tests, they will need other tests looking for the virus/bacteria in the blood. Blood should be taken for both to minimise blood tests and visits, and the laboratory notified to carry out a PCR test if there is a positive antibody.

- HIV antibody testing should be done with fourth generation combined antigen-antibody assay.
- HIV testing in infants is with HIV DNA/RNA PCR test when there is a positive antibody test.
- HCV testing should include RNA PCR testing when there is a positive antibody test.
- HBV viral load (DNA PCR) should be done if there is evidence of chronic HBV infection.

If initial screening tests are positive, urgent discussion with a specialist should take place to ensure correct further testing, interpretation and management.

Testing children over 24 months of age

For children over 24 months, HIV, HCV and syphilis infections are identified by taking an antibody test. By this age, the child will usually have lost maternal antibodies and therefore any antibody identified will signify that the child is infected.

For HBV, HBsAg (Hepatitis B surface antigen) and HBV antibodies (Hepatitis B surface antibody and core antibody) should be requested (https://bit.ly/3sZp1Ne).

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. Following a recent exposure risk, testing can be carried out immediately that will identify if a child already has infection, but it will need to be repeated at three months. HIV testing (preferably with a fourth generation combined antigen and antibody test) can be repeated earlier, at two months post-exposure.

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, and it may be advisable for positive results to be given by a paediatric infectious diseases consultant. 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.

This Practice Note cannot cover all situations. Practitioners should always contact locally identified specialist/lead professionals for advice where needed and can use the resources listed below. CoramBAAF members may also contact the CoramBAAF Advice Line.

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Working Group

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Useful websites

NHS Choices
www.nhs.uk/conditions/#

Screening tests in pregnancy leaflet
www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief

The Green Book (vaccinations guide)
www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book#the-green-book

Lab Tests Online
https://labtestsonline.org.uk/tests-index

Hepatitis

Children's Liver Disease Foundation
https://childliverdisease.org/liver-information/childhood-liver-conditions/hepatitis-b/

World Health Organisation data on prevalence
www.who.int/topics/epidemiology/en/

Public Health England
www.gov.uk/government/collections/hepatitis-b-guidance-data-and-analysis
www.gov.uk/government/collections/hepatitis-c-guidance-data-and-analysis

HIV

CHIVA (Children's HIV Association) provides information about HIV and children/young people living with HIV
www.chiva.org.uk

Useful information for people living with HIV
http://i-base.info/

AVERT provides information about HIV and testing
www.avert.org/public-hub

World Health Organisation provides data on prevalence
www.who.int/topics/epidemiology/en/

Unaccompanied asylum-seeking children

Royal College of Paediatrics and Child Health
https://www.rcpch.ac.uk/resources/refugee-unaccompanied-asylum-seeking-children-young-people-guidance-paediatricians

Collaborative HIV Paediatric Study
www.chipscohort.ac.uk/

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APPENDIX 1

Developing a local Pathway/Guideline

A local Pathway/Guideline should be developed by a multi-agency group. Key professionals to be involved would include: LAC health professionals (commissioner and provider), maternity and neonatal services, paediatrics/paediatric infectious diseases, virology/laboratory, sexual health services, and children's social care. There should be agreement on who will take the lead for development and review of the Pathway/Guideline. This could be the designated LAC health team with the paediatric infectious disease team.

Key areas to cover

- Local points of contact for advice/lead professionals identified.
- Advice on how consent will be obtained and recorded, and exemplar consent and referral forms to be used (see below).
- Devising of/agreement on local information leaflets for children, young people and parents.
- Agreement on a referral pathway.
- Following discussions with the local laboratory/virology, details of the exact blood tests that need to be requested.
- Consideration of providing sample blood test report forms for health professional use.
- Review of guideline timescales.
- Signposting to training opportunities.

Example referral form

Essential information for referral to health professional to discuss testing for blood-borne infections
(To be completed by social worker)

Patient details (or patient label)

Name

DoB

Address

NHS No | CHI

Tel | Mobile

GP details	**Social worker details**
Name	Name
Tel	Mobile
Address	Address
Email	Email

Carer's details	**Parent/s**
Carer's name	Name
Relationship	Address

Who has parental responsibility?

Reason for referral

Who else is aware that appointment is taking place?

Will parent attend the appointment? Yes / No

Would parent like to be contacted by phone Yes / No | Tel

Signed | **Designation**

Date

Example consent form

Consent form: blood-borne infections

I, , have parental responsibility for

(child's name)

(child's DoB)

I give permission for him/her to have a blood test to screen for blood-borne infections (Hepatitis B, Hepatitis C, HIV and syphilis).

I have had information about these tests given to me and had the opportunity to discuss them. I understand what is being tested for and the implications of the results.

Parent / Guardian (delete as appropriate)

Name

Signature

Date

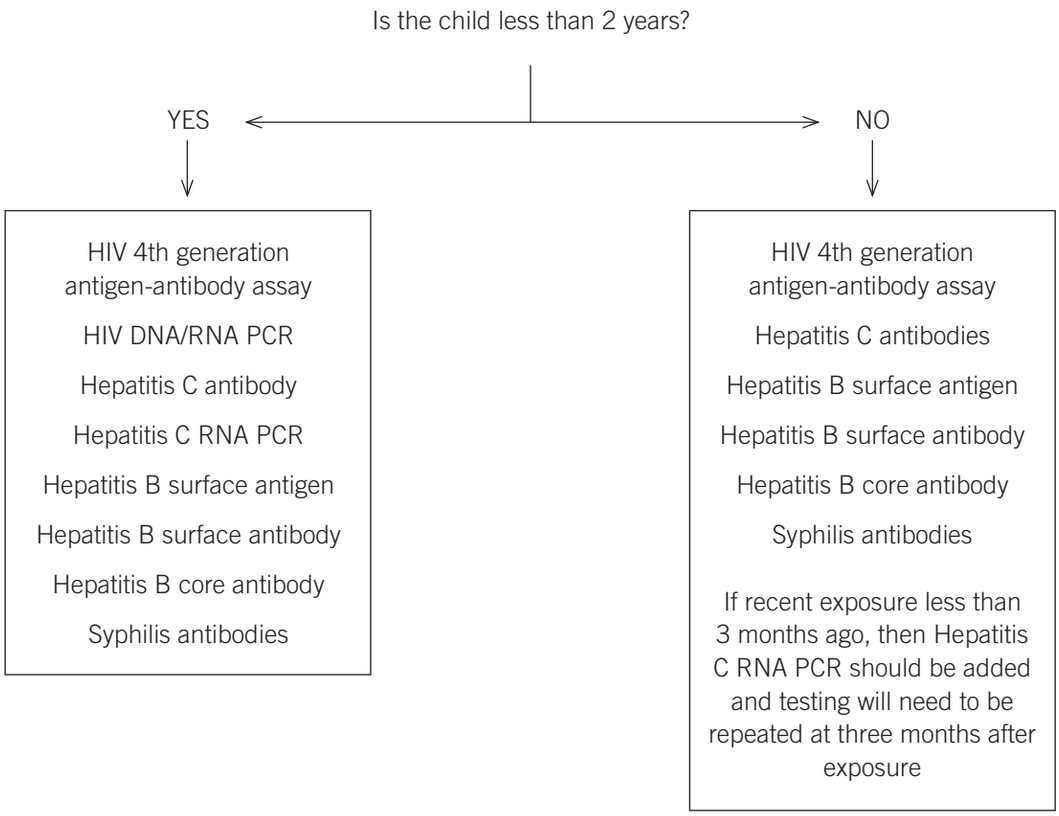
If Children's Services has parental responsibility, and a service manager signs the form, every effort must be made to ensure that the parent/s have been given the information about the blood test and every effort has been made to obtain their consent.

Example: Completing the blood tests – Advice Notes

(Note: timescale for testing may need to be altered if the child had received post-exposure prophylaxis with antiretroviral drugs or immunisation for Hepatitis B.)

www.chiva.org.uk/files/1215/4454/3739/CHIVA_PEP_2017.pdf

Identify specific local requirements to include on blood form. If there is an ongoing risk of exposure, e.g. episodes of going missing/IV drug abuse, consider Hepatitis B vaccination.



APPENDIX 2

Example information leaflet

There are many examples of locally developed leaflets (some available online) that can be used; these might already be available in your local area.

Below is some suggested example wording if you are developing your own information leaflet.

Parent Information Leaflet

Your child has been assessed by a health professional 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 occurs in babies and children who acquire syphilis from their mothers during pregnancy. It can result in damage to many organs in the body (e.g. to the brain, bones, teeth and eyes).

Why would my child have these infections?

Children who have these infections usually have acquired them 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 their 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.

Hepatitis B, HIV and syphilis are all tested for routinely during pregnancy. Some areas also test for Hepatitis C during pregnancy. However, even if a mother has had these tests early in pregnancy and had negative results, there may be a chance that she has been infected later in pregnancy.

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. Once the infection is found, these infections can be monitored, treated and sometimes cured, so it is in your child's best interest to be tested.

Practicalities of testing

(insert local arrangements for appointments and arrangements for results)

Your appointment date is:

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

APPENDIX 3

Example information leaflet

Young Person Information Leaflet

You have been assessed by (insert name of health professional), 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 damage to many organs in the body (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?

There are real advantages in finding out whether you have these infections, as all of the infections have good treatments. Once the infection is identified, it can be monitored, treated and sometimes cured, and people are able to have healthy lives. Treatment is likely to work better the earlier an infection is detected. Without treatment and monitoring, all of these infections can cause people to become severely ill or even die prematurely. You can be infected at birth and remain well for many years.

Practicalities of testing

You will be seen by (insert local information) for the blood to be taken and the results will be ready (insert local arrangements for timescales and arrangements for results)

Your appointment date is:

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

APPENDIX 4

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. whether the child is subject to a court order and in what way the local authority and/or others share parental responsibility/ies for the child.

The rules about consent and the types of orders, etc, vary slightly between England and Wales, Northern Ireland and Scotland.

There may be situations where the child's legal status (i.e. type of order) has been determined in one of the four UK countries, but the child is placed (living) 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 legal 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.

England and Wales

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

There are three legal orders that give a local authority parental responsibility (PR), which it shares with the child's parent/s. These are care orders and interim care orders under the Children Act 1989, and placement orders (authority to place a child for adoption) under the Adoption and Children Act 2002. Under a placement order, PR is also shared with prospective adopter/s, when the child is placed in their care.

If the child is subject to an emergency protection order or interim care order and testing is being considered, the court should be told so that it can make any directions it considers to be necessary.

When the child is under these orders, if the local authority is exercising PR in relation to testing without the child's parents' consent, it must be satisfied that it is necessary to do so to safeguard and promote the child's welfare (Children Act 1989, s.33(3) & (4)). The local authority must inform the parent/s of their decision and reasons, and it must consider the rights of parent/s to know their own infection status.

Where there are current court proceedings, any children's guardian appointed in the proceedings should also be consulted in relation to testing and the court informed of any proposals or disagreement.

It is not necessary to have the consent of both of the child's parents, and the rights of each parent to confidentiality about their health data must be considered. If one party with PR 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, legal advice should be sought without delay, 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 made on the basis of the child's welfare being paramount; in other words, the child's welfare is the primary consideration.

ii. Parent/s have sole parental responsibility

There are situations where the parent/s retain PR, for example, where the child is accommodated by a local authority on a voluntary basis (s.20, Children Act 1989 in England, and s.76 of the Social Services and Well-being (Wales) Act 2014). If there are concerns about the child's risk factors for blood-borne infection, and the parent/s of a child without capacity to consent refuse to permit their child to be tested, the paediatric specialist should be consulted. As set out earlier, if the child is asymptomatic, there is time to work with families, but a time limit for resolution should be agreed. Usually, with accurate information and expert support, families will agree to testing. In rare cases, an application may be made to court for the issue of consent to be resolved. The health professionals and local authority will need to discuss whether the local authority or the health trust issues the court application.

iii. Abandoned baby

In the case of an abandoned newly born baby or an unaccompanied child without capacity to consent, there is an absence of known persons with PR. Under the Children Act 1989, a local authority in England or Wales has a duty to safeguard a child's welfare and a power to do what is reasonable to achieve this, including consenting to tests on the recommendation of medical practitioners.

iv. Children and young people under 16

A child or young person under 16 years old can give consent to treatment if they are "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 their own

consent. If they refuse, the local authority and the health professionals should consider seeking legal advice, having regard to the urgency and necessity for testing.

v. Children and young people who are 16 and over
Young people aged 16 or 17 in England and Wales can consent to their own medical treatment under s.8 of the Family Law Reform Act 1969. If they give consent, it is not necessary to get consent from an adult with parental responsibility, but it is good practice to consider involving the parent/s, unless the young person does not want this. If a young person aged 16–18 refuses consent, legal advice should be sought, having regard to the urgency and necessity for testing.

Northern Ireland

i. Health and Social Care Trust (HSCT) has full parental responsibility
An HSCT may have sole responsibility for a child in terms of a freeing order under the Adoption (Northern Ireland) Order 1987. When an HSCT, or a local authority from elsewhere in Britain, has full PR, it is the Trust'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 that give an HSCT 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 themself, the decision rests with those who have PR. The decision to consent for testing the 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.

iii. Parent/s have sole parental responsibility
There are situations where the parent/s retain full PR, 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 refuse consent to test and the child or young person does not have capacity, 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 may 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 Practice Note).

v. Children and young people under 16
A child or young person under 16 years old can give consent to treatment if they are "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 their own consent. The position if they refuse 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 PR, but it is 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 or directions obtained from a court.

Scotland

i. Parent/s retain the right to give or refuse permission for medical examination or treatment
In Scotland, only a court can remove Parental Rights and Responsibilities (PRRs), and this will happen at the end of the permanence process, under a permanence order or adoption order. Up until that point, the PRRs are retained by the parent who is:

- the child's mother;
- the father, where the parents are married or where the father has been registered on the child's birth certificate after 4 May 2006;
- the father, where the mother has agreed to this and it has been legally recorded or where the court has granted PRRs in respect of the child.

Other individuals may hold PRRs where these have been granted by the court.

ii. Parent/s refuse permission for testing
Where the child is accommodated by the local authority on a voluntary basis, for example, the parent/s continue to retain their PRRs just as do parents whose children are

not looked after. 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. Usually, with accurate information and expert support, families will agree to testing.

In rare cases, an application may be made to the court for the issue of consent to be resolved. The Health Board, rather than the local authority, would petition the court to obtain an order overriding the parents' refusal to consent. The guiding principle for the court in cases involving a child is to consider what decision would be in the child's best interests.

However, if the child or young person is capable of consenting, it is their consent that is needed, not the parent's – see v. and vi. below.

iii. Children's Hearings may suspend parents' PRRs
Where a child is subject to an order issued by a Children's Hearing, the local authority is responsible for implementing the order.

A measure may be added to some orders if it is necessary for the protection, guidance, treatment or control of the child and it represents the minimum intervention into the child's life. The measure may be a requirement that the local authority arranges a specified medical examination or treatment for the child.

iv. Local authority obtains PRRs
The local authority may apply for and be granted a permanence order under which they obtain PRRs. The permanence order will have a range of ancillary provisions in relation to the making of decisions about the child, such as who consents to medical examinations and treatment. These may be shared with foster carers, but it is very unlikely that the court would continue to allow rights relating to decision-making about the child's health to remain vested in the parents.

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 parent/s or others with parental responsibilities, it is the child's consent that matters when the medical practitioner is satisfied that they are 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/s, local authority or medical board has no right to consent or not consent on their 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.

vii. Abandoned baby
In the case of an abandoned baby, there is an absence of knowledge of those with PRRs. Under the Children (Scotland) Act 1995, a local authority has a duty to safeguard and promote the baby's welfare and it is implied that they take any reasonable and proportionate action necessary to discharge this responsibility.

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 Practice Note). General medical tests should be carried out and this could arguably include testing on the recommendation of medical practitioners.

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