



National Children's  
Bureau



# Practice guidance: supporting young people with HIV testing and prevention

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## Glossary of terms and abbreviations

**AIDS** (Acquired Immune Deficiency Syndrome) is an advanced stage of HIV infection, and is characterised by health conditions that develop when the body's immune system is severely weakened. AIDS can be avoided in most cases by modern HIV treatment. The term is infrequently used these days.

**BBV** Blood-borne virus.

**BASHH** British Association for Sexual Health and HIV.

**BHIVA** British HIV Association.

**Children and young people** are both used to describe individuals under the age of 18, since this is the age limit to which most professional duties discussed in this document extend. The use of 'young people' specifically acknowledges adolescence and indicates content that may usefully guide approaches taken with young adults.

**CHIVA** Children's HIV Association.

**FGM** (Female genital mutilation) refers to procedures that intentionally alter or cause injury to the female genital organs for non-medical reasons. FGM is illegal in the UK.

**HIV** (Human Immunodeficiency Virus) is a virus that causes an infection affecting the body's immune system. Advances in HIV treatment have made it possible for people to live long, healthy lives with HIV. See 'Appendix: An overview of HIV, hepatitis B and hepatitis C' for further information (p30).

**IPEDs** (Image and performance enhancing drugs) are substances that promote weight loss, change skin colour, build muscle or allow longer, harder training. These include anabolic steroids, human growth hormone, and tanning agents.

**Looked after children** are individuals under the age of 18 who are 'looked after' by their local authority under the Children Act 1989 (also known as children in care).

**Men who have sex with men** is a term often used in public health to refer to men who engage in same-sex sexual activity. It includes men who do not identify themselves as gay or bisexual.

**PEP** (Post-exposure prophylaxis) is a course of anti-HIV drugs that, when started as soon as possible within 72 hours of exposure to HIV, can dramatically reduce the likelihood of infection.

**Prevalence** refers to the proportion of a population found to have a particular condition or risk factor.

**STI** Sexually transmitted infection.

**Transgender** is an umbrella term for various people who experience a mismatch between their gender identity and the sex that they were assigned at birth.

**Unaccompanied asylum seeking child** is defined as an individual aged under 18 (at the time of submitting an asylum application) who is separated from both parents, is not being cared for by an adult who in law or by custom has responsibility to do so, and is applying for asylum in their own right (Home Office 2016).

**Vertical transmission** refers to the transmission of HIV from a mother to her child during pregnancy, birth or breastfeeding.

## Introduction

This document aims to enhance professionals' confidence at recognising and responding to potential risk of HIV infection for children and young people. It covers identification of the need for HIV testing; referral for testing; support throughout the process; support for children and young people who receive a positive HIV diagnosis; and ongoing management of risk with young people, whatever their HIV status.

Establishing infection risk and testing for infections are within the role of qualified health professionals and are covered by clinical guidance. This practice guidance is for professionals who do not provide HIV testing, treatment or advice as part of their day-to-day work. It is primarily intended for those working outside health settings, such as social workers or voluntary sector practitioners.

This document considers children and young people who may be more vulnerable than others to HIV infection, or experience additional barriers to accessing services, due particular behaviours, circumstances or inequalities. These include looked after children; children and young people who have been coerced into sexual activity; boys and young men who are involved in sexual activity with men; and young people who inject drugs.

This guidance focuses on HIV and the specific issues associated with it. However, it may also be helpful in informing approaches taken to children and young people at risk of other sexually transmitted infections (STIs) and blood-borne viruses (BBVs). Despite key differences between infections, issues that may overlap include exposure risk, testing processes and social impacts. See also 'Appendix: An overview of HIV, hepatitis B and hepatitis C' (p30) and 'Sources of information and support' (p26).

### HIV and children and young people in the UK

By the end of 2014, 536 children aged 0-14 and 2,776 young adults aged 15-24 were accessing HIV care in the UK. Of all the individuals accessing HIV care in the UK, 1,703 are believed to have acquired HIV through vertical transmission (from mother to child during pregnancy, birth or breastfeeding); about two-thirds of these are aged 15 or above (PHE 2015a; CHIPS 2015).

Public Health England data (PHE 2015a) revealed 32 new HIV diagnoses in 2014 in children aged under 15 and 727 in young adults aged 15–24 years<sup>1</sup>. Routes of transmission among 15-24 year olds were sex between men for 60% of cases; heterosexual contact for 23%; and injecting drug use for 0.6% (PHE 2015b). For almost all the remaining cases, HIV was either acquired through vertical transmission or the route of transmission is unknown/unreported. Both the proportion and number of new HIV diagnoses among men who have sex with men aged 15–24 years have increased in recent years (Yin and others 2014).

#### Case examples

There may be future opportunities to add examples of individual cases and professional responses to this document. We are particularly keen to feature young people's own voices. If you wish to share an example or content created by young people that relates to HIV testing and prevention, we would like to hear from you. Please contact Emily Hamblin at [ehamblin@ncb.org.uk](mailto:ehamblin@ncb.org.uk).

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<sup>1</sup> Numbers will rise somewhat as further reports are received for recent years.

## How does HIV testing and support for children and young people feature in your professional work?

All those involved in supporting young people's health and wellbeing should have general awareness of sexual health and should promote safer sex and awareness of risks relating to drug use. Professionals' safeguarding duties are explained in broader terms by the statutory guidance *Working together to safeguard children: A guide to inter-agency working to safeguard and promote the welfare of children* (HM Government 2015b).

It is important that children and young people's needs relating to the risk of HIV are specifically considered by those who:

- are involved in health assessments for looked after children, including unaccompanied asylum seeking children
- have legal responsibilities around promoting and protecting the health and wellbeing of looked after children
- provide specialist support in which HIV risk factors for children and young people regularly feature.

All those working with children and young people should consider the possible risk of HIV infection if an individual is believed to be, or have been:

- involved in unprotected sexual activity, especially when other risk factors are present
- experiencing non-consensual sexual activity and/or sexual exploitation
- sharing equipment used to prepare or take psychoactive or image and performance enhancing drugs (IPEDs).

The following section explores specific considerations for children and young people who may be more vulnerable than others to HIV infection, or experience additional barriers to accessing services, due to particular behaviours, circumstances or inequalities. Content under several headings may be relevant to a given young person.

### Looked after children

*Promoting the health and well-being of looked after children: Statutory guidance for local authorities, clinical commissioning groups and NHS England* (DfE and DH 2015) explains legal responsibilities for the health of looked after children (individuals under the age of 18 who are in local authority care). It states that:

The corporate parenting responsibilities of local authorities include having a duty under section 22(3)(a) of the Children Act 1989 to safeguard and promote the welfare of the children they look after [...] This includes the promotion of the child's physical, emotional and mental health and acting on any early signs of health issues (p6).

Social workers therefore have an important role in promoting the health and welfare of looked after children, and their responsibilities are detailed in the guidance. They are expected to contribute to the formulation and implementation of health plans for looked after children and to pass information about any health needs or behaviours which could pose a risk of harm to the child. Young people leaving care to transition into adulthood must also be able to continue to obtain the health advice and services they need. The guidance explains the relevant duties of health professionals, social workers and personal advisers to ensure effective transitions for care leavers.

Looked after children may face higher likelihood of exposure to HIV than their peers due to:

- overlapping risk factors for HIV infection and for becoming looked after (for example, parental substance use, sexual abuse)

- higher prevalence of certain behaviours that increase HIV risk amongst looked after children than the non-care population (for example, unprotected sex), along with increased chances of missing out on mainstream sex education (Fallon and others 2015)
- increased vulnerability to sexual exploitation and abusive relationships (HM Government 2009).

Occasionally a child who is looked after may require HIV testing where vertical transmission (from mother to child) is considered possible. All children with a mother and/or father known to be living with HIV require testing. This applies regardless of the child's age, as some young people with lifelong HIV will nevertheless have remained well without treatment, and not experience symptoms. In some cases, a mother's HIV status may not be known to herself, the child and/or services. This may happen if the mother has not disclosed her HIV diagnosis, has not been diagnosed, lives abroad, or has died.

The particular issues relating to testing looked after children for HIV are explored in *Guidelines for the testing of looked after children who are at risk of a blood-borne infection* (BAAF and others 2008). These guidelines recommend testing for HIV and BBVs 'in the best interests of the child, which should be decided in the context of a comprehensive paediatric assessment' that considers individual risk factors. Current UK HIV testing guidelines (BHIVA 2008) and Children's HIV Association guidelines (CHIVA 2014) advise health professionals on testing any children of HIV-positive parents.

See also 'Confidentiality' (p16).

## Unaccompanied asylum seeking children

As an unaccompanied asylum-seeking child would usually enter local authority care (see above), they should have a comprehensive health assessment carried out by a medical practitioner. A health assessment conducted according to guidance from the Royal College of Paediatrics and Child Health should take into account what has happened to the individual before entering the UK, en route and at their final destination (RCPCH 2016). Paediatricians are advised to sensitively review sexual health and possible experiences of rape or sexual exploitation. Assessments should also consider the prevalence of communicable diseases in the individual's country of origin (RCPCH 2016).

For unaccompanied asylum seeking children who have lived in areas of high HIV prevalence (see also below), it may not be possible to be certain about their potential historical exposure to HIV, including from their mothers. Whilst most babies who acquire HIV from their mothers will become ill in the first year or two of life, some survive into their teens before developing symptoms.

## Children and young people from communities disproportionately affected by HIV

HIV is much more prevalent in other parts of the world than in the UK, particularly in sub-Saharan Africa. Access to HIV prevention interventions, testing and treatment is poor in some settings. Children and young people born, or with parents born, in these regions may have had increased risk of exposure to HIV than the general UK population.

Families and young people from communities disproportionately affected by HIV should be able to access to HIV-related information and support that is culturally appropriate and relevant. Community-led services have an important role in providing this (for example, see NAT 2014a).

Current UK HIV testing guidelines (BHIVA 2008) recommend that HIV testing is considered for children newly arrived in the UK from high-prevalence areas, including unaccompanied minors.

HIV testing and treatment in England is free for anyone who needs it, regardless of their immigration status.

## Girls and young women who have undergone female genital mutilation (FGM)

Girls and young women may have been exposed to HIV if they underwent FGM procedures alongside other girls and unsterilised surgical instruments were used; the long-term health implications of FGM can also include potential increased risk of STIs including HIV (WHO 2015). Health professionals should lead on responding to needs relating to exposure to HIV, but other professionals may play an important part in referring to health services and providing emotional support and education relating to HIV.

## Children and young people for whom sexual abuse, exploitation or assault is a concern

The needs of children and young people who have, or may have, experienced sexual abuse, exploitation or assault require sensitive understanding and care. This may include attending to a host of psychosocial as well as physical health issues. Potential exposure to HIV and other infections should certainly be considered. The likelihood of exposure and transmission depends on a range of factors, and appropriate health professionals should make any judgements about an individual's requirements for testing in accordance with guidelines (BASHH 2010; BASHH 2012).

If a child or young person discloses recent sexual abuse, exploitation or assault, taking swift action to help them access appropriate services can help to reduce their STI risk (see 'The importance of timely HIV testing' on p11); allow broader clinical and psychosocial needs and the risk of unplanned pregnancy in girls to be addressed; and enable forensic evidence to be gathered.

## Boys and young men engaging in same-sex sexual activity

Boys and young men involved in sexual activity with other males will be diverse in terms of the frequency and nature of their sexual activity; the number and ages of their partners; their use of condoms; and whether sexual activity is consensual. Research suggests that one in three victims of child sexual exploitation are male (Cockbain and others 2014).

In the UK in 2014, one in 20 men who have sex with men aged 15-44 were estimated to have HIV; in London, the figure was one in 11 (Skingsley and others 2015). Public Health England attributes the high prevalence and incidence of HIV and STIs in this population to partnership patterns, along with the risks associated with anal sex without condoms (PHE 2014a). PHE also notes links with mental health inequalities affecting men who have sex with men, and high levels of drug and alcohol use. For men who practise chemsex<sup>2</sup>, the odds of sexual behaviour with a risk of HIV and STI transmission may be increased (Bourne and others, 2014).

PHE recommends that men who have sex with men should have a full HIV and STI screen at least annually, or every three months if having condomless sex with new or casual partners (Skingsley and others 2015).

Boys and young men who are sexually attracted to males, whether sexually active or not, need access to relevant information on HIV and sexual health. Research from NAT (2015) suggests that young men who are attracted to men are not well catered for by school sex education provision and, in common with the general population, lack knowledge of HIV transmission, prevention and testing. NAT's findings suggest that many young men who experience same-sex attraction do not look for information about HIV or see it as relevant to them. Those who feel same-sex attraction but identify as heterosexual are significantly less likely than those who identify as gay or bisexual to seek information, advice and support around sex, relationships and HIV.

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<sup>2</sup> Chemsex is 'commonly understood to describe sex between men that occurs under the influence of drugs taken immediately preceding and/or during the sexual session [...] The drugs most commonly associated with chemsex are crystal methamphetamine, GHB/GBL, mephedrone and, to a lesser extent, cocaine and Ketamine' (Bourne and others, 2014)

## Transgender young people

Globally, transgender people are among the populations most affected by HIV. Widespread stigma and discrimination can affect both an individual's likelihood of being exposed to HIV and access to appropriate healthcare, information and support (Interagency Working Group on Key Populations 2015). However, collection of data on HIV in transgender people in the UK is currently in its early stages, with no data publicly available, and there is little documented knowledge about the particular HIV prevention and support needs of trans young people in the UK. Relevant organisations and resources are signposted in 'Sources of information and support' (see p26).

## Young people who use psychoactive or image and performance enhancing drugs (IPEDs)

Patterns of drug use in the UK are constantly evolving, and vary greatly according to local populations. In 2015 Public Health England concluded that 'the changing patterns of psychoactive drug injection are increasing risk' (PHE and others 2015). Due to harm reduction interventions, HIV prevalence amongst people who inject drugs is low, but young people who share equipment to inject any kind of drugs are at risk of HIV and other BBVs. All young people who inject or snort drugs need access to relevant information and support around harm reduction and safer sex.

The latest available data from Public Health England (PHE 2014b; PHE 2015c) suggest that a minority of individuals aged under 25 who inject psychoactive or image and performance enhancing drugs report sharing equipment. Self-reported consistent condom use is also low amongst both users of psychoactive drugs and of IPEDs. Users of IPEDs often do not see themselves as drug users or recognise their risk of infection (Kimergård and McVeigh 2014).

HIV testing guidelines (BHIVA 2008) recommend that people who inject drugs get tested for HIV annually or more frequently if they have clinical symptoms of recent infection (see 'The importance of timely HIV testing' on p11).

## Children and young people with learning or physical disabilities

Research shows that disabled children are three times more likely to experience abuse, including sexual violence, than non-disabled children; the risk is even greater for some groups (Jones and others 2012; Sullivan and Knutson 2000). Disabled children and young people face additional barriers to getting their needs and views comprehended, believed and addressed adequately; their opportunities to learn and communicate about issues relevant to safeguarding and sexual health may also be limited (Miller and Brown 2014; DCSF 2009).

National guidelines on STIs and related conditions in children and young people (BASHH 2010) advise that, where children and young people are unable to communicate partially or fully due to learning or other disabilities, and require sexual health services, they may need alternative ways of accessing services and/or independent advocates (as it is possible that their carer could be an abuser).

## Young people whose sexual partners are known to have HIV

The likelihood of a person living with HIV passing the virus on during a single act of sex is low, and is significantly dependent on their 'viral load'. Viral load refers to the amount of HIV in a person's blood. It can be reduced by effective HIV treatment to a level at which it is 'undetectable' by viral load tests. Evidence shows that having a low viral load substantially lowers the risk of HIV transmission even with repeated sex over a long period of time. However, missing doses of antiretroviral therapy (medication that controls HIV) may increase the risk of HIV transmission.

Monitoring viral load is an integral part of the healthcare provided to people living with HIV, as is addressing needs for information and support relating to safer sex and relationships.

Condoms, when used correctly and consistently, are highly effective in preventing the transmission

of STIs including HIV, as well as unwanted pregnancies.

Partners of people living with HIV should get tested regularly for HIV and other STIs.

See also 'Ongoing management of risk with all young people' (p22).

## Establishing and responding to the need for HIV testing in a child or young person

This section outlines where information about a child or young person's behaviour or circumstances should prompt consideration of risk of HIV and, if necessary, support for them to access appropriate services.

A range of guidance supports health professionals to determine whether a child or young person needs testing for particular STIs and BBVs. These are signposted in 'Sources of information and support' (p26). One key document is the British Association for Sexual Health and HIV *United Kingdom National Guideline on the Management of Sexually Transmitted Infections and Related Conditions in Children and Young People* (BASHH 2010)<sup>3</sup>.

The BASHH guideline describes how the risk of a child or young person acquiring an STI is dependent on a wide range of factors. An individual's need for testing can only be assessed by suitably trained professional, and there are some scenarios when testing should be considered as a matter of course (for example, pregnancy or sexual assault).

Once a child or young person's potential need for STI/BBV testing has been identified, professional responses will depend on locally available services, and should make use of established referral pathways. Key considerations for individuals include legal status (for example, as a looked after child) and requirements for forensic evidence in cases of suspected sexual abuse or assault. The BASHH guideline notes that 'the young person's (and their parent/carer's) psychological and social needs' should be taken into account when scheduling examinations.

Young people may need encouragement, signposting or other support to access sexual health services. Testing for STIs is best presented to young people as a normal, routine part of taking care of their health. Brook advises young people who are having sex to get screened and tested for STIs once a year (including within long-term relationships); after unprotected sex; before having sex with a new partner; or if deciding to stop using condoms with a new partner (Brook 2015).

When recording, sharing or acting upon information about safeguarding concerns, it is important to include relevant details about risk behaviours or potential exposure to infection, as disclosed, in line with established procedures.

### The importance of timely HIV testing

Highly effective HIV treatment is available in the UK. People living with HIV can stay well long-term if they begin their HIV treatment at the appropriate time. Left untreated, the impacts of HIV on health are serious and ultimately life-threatening, so early diagnosis is extremely important. This is especially the case for young children, who often experience faster HIV progression than adults.

Like most STIs, HIV can be initially asymptomatic. However, if a young person reports risk factors for acquiring HIV or potential recent exposure and, around the same time, complains of flu-like symptoms or feeling generally unwell, they should be referred for HIV testing without delay. Symptoms including fever, rash, headache, aches and pains, and tiredness are common within about a month following HIV infection. National HIV testing guidelines (BHIVA 2008) emphasise that testing during this period presents a unique opportunity to ensure early diagnosis and prevent onward transmission, which is more likely shortly after infection.

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<sup>3</sup> The BASHH guideline is primarily directed at the management and care of young people under the age of 16 years, but is also applicable to young people aged 16-18 who have learning difficulties or who are 'vulnerable'. Otherwise, adult guidelines generally apply to young people over the age of 16.

## Post-exposure prophylaxis (PEP)

If a child or young person has been at significant risk of HIV exposure within the past 72 hours, they should attend a sexual health service or Accident & Emergency department urgently, as post-exposure prophylaxis (PEP) medication can dramatically reduce the likelihood of infection when taken as soon as possible within this time period. PEP is only prescribed when the risk of exposure to HIV is considered significant, and must be taken for 28 days.

## Communication about testing

Children and young people, with or without their parents, will receive information about testing for HIV and any other infections during a pre-test discussion with an experienced health professional (see 'The process of testing children and young people for HIV' on p13). Before this point, other professionals can play a key role in facilitating access to these discussions by:

- giving accurate messages that HIV is a serious but manageable long-term health condition
- encouraging children and young people, and their parents/carers as appropriate, to engage with relevant services (see Figure 1).

Importantly, diagnosing a young person's HIV enables contacts who may also be at risk to be identified and offered testing, and prevention of vertical transmission when young women are diagnosed during pregnancy. This can be discussed with young people during the testing process, but may induce anxiety. The young person's own need for HIV testing is of primary importance, and communication about testing should focus on its benefits for them personally.

## Consent to testing

In the UK, testing for STIs and BBVs, including HIV, is voluntary and confidential.

Clinicians should lead on addressing any issues around consent to testing, including discussions with parents.

The legal framework on consent to medical investigations or treatment for children and young people is covered in detail by the General Medical Council publication *0-18 years: Guidance for all doctors*. It addresses children and young people's capacity to consent; the need to encourage those with capacity to involve their parents in making important decisions, whilst respecting their rights; and the law regarding those who lack capacity to consent.

### Benefits of HIV testing

If the result is positive:

- Treatment is available and starting at the right time protects health
- Can prevent the infection being passed on to others
- Can get help and support, including from peers who have received the same diagnosis

If the result is negative:

- Peace of mind
- Opportunity to get information and support to reduce future risk.

Figure 1

## The process of testing children and young people for HIV

The testing process, and other assessments and interventions that may happen alongside it (for example, relating to pregnancy, safeguarding or health promotion), will vary according to an individual's needs and circumstances. Children, young people, their caregivers and/or their partners may experience high levels of anxiety during the HIV testing process and whilst awaiting results; therefore clear, accessible information and emotional support are essential.

There can be a gap between the time an individual gets an infection and when it will show up on tests: this is called the 'window period' and for HIV it varies between individuals and tests used, but is usually one to three months. Young people should not delay testing, but may be encouraged to retest later to confirm results. Services providing testing can advise.

### Access to HIV testing

Where a child or young person is tested for HIV will depend on local provision, referral pathways, and their individual needs. Settings may include:

- Paediatric outpatient services, including paediatric HIV services
- Genitourinary Medicine (GUM) or sexual health clinics
- Accident & Emergency departments (which may also provide PEP in cases of significant recent risk of exposure to HIV – see p12)
- Community settings such as local HIV organisations
- Services addressing specific needs and circumstances, for example, Sexual Assault Referral Centres, drug treatment services; antenatal care; and termination of pregnancy services
- GP surgeries.

Young people aged over 16 will most commonly be tested for HIV in sexual health settings. Pre-pubertal children are normally tested in paediatric healthcare settings. Post-pubertal young people aged under 16 may be seen in children's or adult's settings.

Paediatric HIV treatment services have specialist expertise in addressing the physical, emotional and social impacts of HIV on children and young people. They are therefore often well-placed to providing testing for young people under 18 whose risk of HIV is significant, as well as for younger children. These services are also a valuable source of information and advice for professionals.

The availability of specialist paediatric HIV services depends on local HIV prevalence, but national networks have been set up to ensure all children and young people living with HIV have access to appropriate care (see [www.chiva.org.uk](http://www.chiva.org.uk) for details).

### Self-testing and self-sampling

CE-marked self-testing kits (which provide results directly to the user within minutes) are available for HIV, as are self-sampling kits (which allow the user to collect and send a sample for laboratory analysis). However, kits circumvent the face-to-face discussions with healthcare professionals that can be beneficial (see below) and are recommended for HIV results for children under 16 and other vulnerable individuals (BHIVA 2008).

## What a child or young person can expect from HIV testing

### Pre-test discussion

These conversations led by health professionals should:

- enable exploration of young people's risk factors and sexual history, as relevant
- explain testing procedures and turnaround times for results
- address concerns
- establish consent
- provide information about HIV infection and treatment.

Such conversations should be sensitive to particular circumstances. For example, when vertical HIV transmission is considered possible, the child or young person's awareness of HIV within the family will be an important consideration.



### Testing procedures

HIV testing can be done by taking a blood sample from the arm or a pin-prick of blood from the finger. Sometimes an oral swab may be taken instead. The availability of different tests varies across settings.

Babies who require HIV testing because their mothers are known to be HIV-positive are tested at birth and again after six weeks and twelve weeks, to check directly for the HIV virus in the blood. At 18-24 months, infants have a different test to confirm that their mothers' antibodies to HIV are no longer present. If there are any HIV antibodies present in a child at age 24 months, this will be because the child has HIV. This final test will also detect cases in which infants acquire HIV through breastfeeding after a negative test at 12 weeks of age.



### Post-test discussion and delivery of results

At the time of testing, clear information should be given about how and when results will be conveyed and any need for repeat testing.

'Rapid tests' can provide results within minutes.

Where samples are tested in a laboratory, the waiting time varies. It is usually 1-2 working days, though can take around one week.

Negative results from laboratory tests may be available by text message, phone or post. Positive test results will require confirmation with a repeat blood test.

Positive results for HIV should always be delivered to a young person face-to-face by a suitable health professional. Detailed discussions about the implications of their diagnosis and next steps will either happen at this point, or after swift onward referral to specialist healthcare (BHIVA 2008).

When conveying a positive HIV diagnosis to a child in a paediatric setting, clinical staff should follow CHIVA guidelines on *Talking to children about HIV in health settings* (2014). Key principles include:

- Talking to young children with HIV about their health and HIV diagnosis in partnership with the child's parent or carer, and striving to answer children's questions truthfully
- Supporting children's learning about HIV and processing of their own diagnosis over time

- Helping children and families to access support and information about HIV outside clinic visits.

Upon receiving a positive HIV diagnosis, many people initially fear that they will die. Children and young people are likely to need time, information and support to understand HIV as a treatable long-term condition, and develop strategies for living well with HIV. Professionals involved in a young person's life beyond healthcare settings are well-placed to help, both in the days and weeks following a diagnosis and in the longer term. See 'Post-diagnosis support' (p20).

## Key issues

### Confidentiality

The General Medical Council advises that 'a confidential sexual health service is essential for the welfare of children and young people. Concern about confidentiality is the biggest deterrent to young people asking for sexual health advice. That in turn presents dangers to young people's own health and to that of the community, particularly other young people.' (GMC 2007).

Respecting the confidentiality of individuals' HIV information is extremely important for meeting legal duties around information-sharing; reducing the risk that people will experience stigma and discrimination; providing reassurance; and ensuring proportionate responses to risk. HIV can be transmitted in a limited range of circumstances that do not include day-to-day social contact, and highly effective treatment is available for people living with HIV.

Following confidentiality protocols and relevant guidance can help protect children and young people's information before, during and after testing for HIV and other STIs/BBVs.

#### Access to confidential STI testing for young people under 16

The General Medical Council's document *0-18 years: guidance for all doctors* explains that contraceptive, abortion and STI advice and treatment can be legally provided to young people under 16 without parental knowledge or consent, provided that:

- they understand all aspects of the advice and its implications
- the doctor cannot persuade the young person to tell their parents or to allow them to tell the parents
- in relation to contraception and STIs, the young person is very likely to have sex with or without such treatment
- their physical or mental health is likely to suffer unless they receive such advice or treatment, and
- it is in the best interests of the young person to receive the advice and treatment without parental knowledge or consent.

#### Information about children and young people's infection status

Local practice varies in terms of which health professionals beyond the HIV team are able to access records including individuals' HIV information. All information in medical records should be treated as confidential, including information on HIV, BBVs and STIs.

A range of guidance supports health professionals to meet their legal and professional duties in relation to sharing information about a child or young person's infection status or risk. Key points include:

- Children under 16 at risk of, or who have, an STI, or 16-18 year olds deemed vulnerable, should have their views sought and usually give consent before information is shared outside the healthcare team. The overwhelming considerations in decisions about information-sharing are the care of that young person and the need to act in her/his best interests to protect their emotional and physical health (BASHH 2010, p14).
- Doctors can disclose relevant information about a child or young person's sexual activity 'when this is in the public interest'. If they are involved in abusive or seriously harmful sexual activity, doctors must share relevant information with appropriate people or agencies, such as the police or social services (GMC 2007, para 65).
- Infringing confidentiality, including that of adults, 'in the public interest' can be justifiable and legal where the failure to do so would result in a child being placed at risk of harm (GMC 2007 paras 47-50; GMC 2009a paras 36-39; HM Government 2015a).
- Outside health, informing other professionals or individuals of a child or young person's HIV

diagnosis should only happen with the parents', and if age appropriate, the child or young person's consent, and where it is in the individual's best interest. There is no obligation to automatically inform any other institution, for example, school, that a child has HIV (CHIVA 2013; Conway 2015).

Professionals working within and outside health services may sometimes need to be assertive and capable of resisting pressure to inappropriately disclose children and young people's HIV information.

*Information sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers* (HM Government 2015a) sets out golden rules and key principles for information sharing. It states that information sharing should be necessary, proportionate, relevant, adequate, accurate, timely, secure and recorded.

### **Sharing of information about looked after children**

Department of Health guidance on *Children in Need and Blood-borne Viruses: HIV and Hepatitis* (DH 2004, s5, paras 16,18-19) states that local authorities sharing information about looked after children and other 'children in need'<sup>4</sup> should provide non-directive and sensitive information appropriate to individual needs, describing the advantages and disadvantages of disclosing infection status. The guidance acknowledges that occasionally it may be considered necessary to go against the wishes of the child or parents, because the child is at risk of significant harm if disclosure is not made; there is a legal requirement for the information to be disclosed; or public interest requires disclosure, for example in order to prevent others being put at serious risk. In this case, the child and/or parents should be told what will happen and given a written explanation of the reasons for overruling their wishes. Legal advice may be needed in such a scenario.

Statutory guidance on *Promoting the health and wellbeing of looked after children* (DfE and DH 2015) states that, in obtaining consent to seek information on a child or young person's health status or history from other parties, or to disclose information about the individual, 'a key consideration will be determining whether the child is competent to give consent or whether consent should be sought from a person with parental responsibility'. The guidance states that the principles used to establish children and young people's capacity to consent to medical treatment should also apply to consent to information sharing, and outlines these. If a competent child does ask for their confidence to be kept, this 'must be respected unless disclosure can be justified on the grounds of public interest: for example, because there is reasonable cause to suspect that the child is suffering, or is likely to suffer, significant harm'.

For children and young people who acquired HIV or hepatitis from their mothers in early life, sharing information about their diagnosis necessarily reveals their mother's infection status. This has particular implications when sharing information about looked after children. The statutory guidance (DfE and DH 2015) advises that:

Where disclosure of a child's information might reveal information about other individuals (e.g. parents, family), consent should be sought from these individuals as well. Where it is not practicable to seek consent or where the individual is not competent to give consent, it is important to consider whether disclosure would be justified in the 'public interest' (e.g. to protect others from a risk so serious that it outweighs the individual's right to privacy). Decisions to disclose information in the public interest must be taken on a case by case basis, and should always be fully documented.

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<sup>4</sup> A 'child in need' is defined under the Children Act 1989 as a child who is unlikely to reach or maintain a satisfactory level of health or development, or their health or development will be significantly impaired, without the provision of services, or the child is disabled. Social workers assess individual children referred to the local authority to establish whether they are children in need and therefore eligible for services.

## Anti-stigma practice

People living with HIV still face stigma and discrimination in the UK. Media portrayals and public perceptions of HIV are too often outdated, framing HIV as a 'death sentence' and reflecting myths about HIV transmission that are without scientific basis (NAT 2014b). These misconceptions affect the lives of people living with HIV and can also be compounded by racism, homophobia and prejudices relating to drug use, poverty and sex work.

In recent decades, great strides in HIV treatment and prevention have made HIV into a treatable long-term health condition. HIV is included within the definition of disability in the Equality Act 2010, which means that people living with HIV are protected from discrimination from the point of diagnosis.

Children and young people who are living with HIV should not be subject to health and social care responses that are markedly different to those responses given to children living with other chronic illnesses (Ely 2012). It is important, therefore, that professionals working with children and young people are sensitive to, and able to challenge, HIV-related stigma in all scenarios.

### Reflecting accurate information about HIV

Professionals should recognise the limits in their knowledge and remit, make use of accessible information to address gaps, and involve practitioners with specialist expertise (see 'Sources of information and support' on p26).

### Focusing on behaviours, not identities

UNAIDS guidelines on HIV terminology (UNAIDS 2015) state that 'risk is defined as the risk of exposure to HIV or the likelihood that a person may acquire HIV. Behaviours, not membership of a group, place individuals in situations in which they may be exposed to HIV, and certain behaviours create, increase or perpetuate risk.'<sup>5</sup> Some children and young people will be more vulnerable than others to being exposed to HIV, due to their social circumstances or health inequalities.

### Modelling openness and confidence

Children and young people may hear stigmatising messages about HIV from family, peers, the media, and even teachers, as well as via the internet and social media. Practice guidance from CHIVA (Ely 2012) explains the importance of these being counteracted by professionals:

There is a need for professionals to support a normalisation of HIV, in an effort to address the persistence of stigma, which is supported by ongoing practices of avoidance of open conversations about HIV in both health and social care settings. Such practices can be viewed as mirroring spheres of secrecy which already surround HIV in many communities, and, without meaning to, can support a context where HIV is seen as very different and ultimately something to fear. The child will then take on this fear and therefore not be sufficiently equipped with the tools they need to live well with HIV.

It is important that children and young people can have open, comfortable and non-judgmental conversations about HIV with the professionals supporting them. Confidence is an important element of enabling these conversations, and is linked to the ability to reflect accurate information about HIV.

CHIVA provides guidance for health and social care professionals on talking to children and young people living with HIV about their HIV (Ely 2012; Melvin and Donaghy 2014).

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<sup>5</sup> The UNAIDS terminology guidelines mention coercion, discrimination and violence, though not in relation to the word 'behaviour'. It should be acknowledged that individuals do not always have agency, or the opportunity for consent, in situations where they are exposed to HIV.

## **Positive and holistic approaches to young people's sexual health and wellbeing**

Professional practice that supports young people to develop positive sexual identities and relationships can be informed by the World Health Organization's definition of sexual and reproductive health (WHO 2006) as:

A state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

This definition applies whatever a person's HIV status. *Guidance on the management of sexual and reproductive health for adolescents living with HIV* (HYPNet and others 2011) proposes that 'discussions with HIV-positive adolescents need to focus on the fact that sexual relationships are possible, achievable and to be expected'.

## Post-diagnosis support

Individuals' responses to receiving an HIV diagnosis vary widely and evolve over time. Reactions may include denial, shock, relief, numbness, anger and loneliness. Links between HIV, social exclusion and poor mental health (BPS and others 2011) make supportive professional responses to HIV diagnoses in children and young people extremely important. Some young people may already be struggling with narratives of self-blame and negative self-talk.

Health professionals delivering a child or young person's HIV diagnosis will link them to HIV healthcare immediately. Whether an individual receives HIV care in a paediatric or adult setting will be determined according to their age, maturity, needs and wishes, and available provision. Adult services should provide care in accordance with BHIVA treatment guidelines (2015); children's services should follow CHIVA Standards of Care (CHIVA 2013) and paediatric clinical guidelines. Paediatric and adult services each have advantages and disadvantages for young people, and professionals from each need to work together to meet young people's needs effectively.

As with other chronic conditions, living with HIV can present difficulties for children and young people and affect many areas of their life; for example, feeling different from peers, difficulties adhering to strict medication regimes, doubts and worries about their future. Children and young people diagnosed with HIV also face high levels of stigma – internalised, feared or enacted – and often experience other disadvantages and vulnerabilities in their lives. These may be associated with mental and emotional health problems (YoungMinds 2016).

Standards for psychological support are available for both adults and children living with HIV (BPS and others 2011; CHIVA and others 2014). The children and young people's standards explain that, since HIV is now a manageable long-term condition, the emphasis of psychological support is on 'adjusting to changing life and developmental demands':

These include the ordinary developmental tasks of managing school and learning, gaining independence and autonomy, navigating changing relationships with family and peers, and preparation for adulthood: including managing psychosexual and emotional changes as well as future employment and careers.

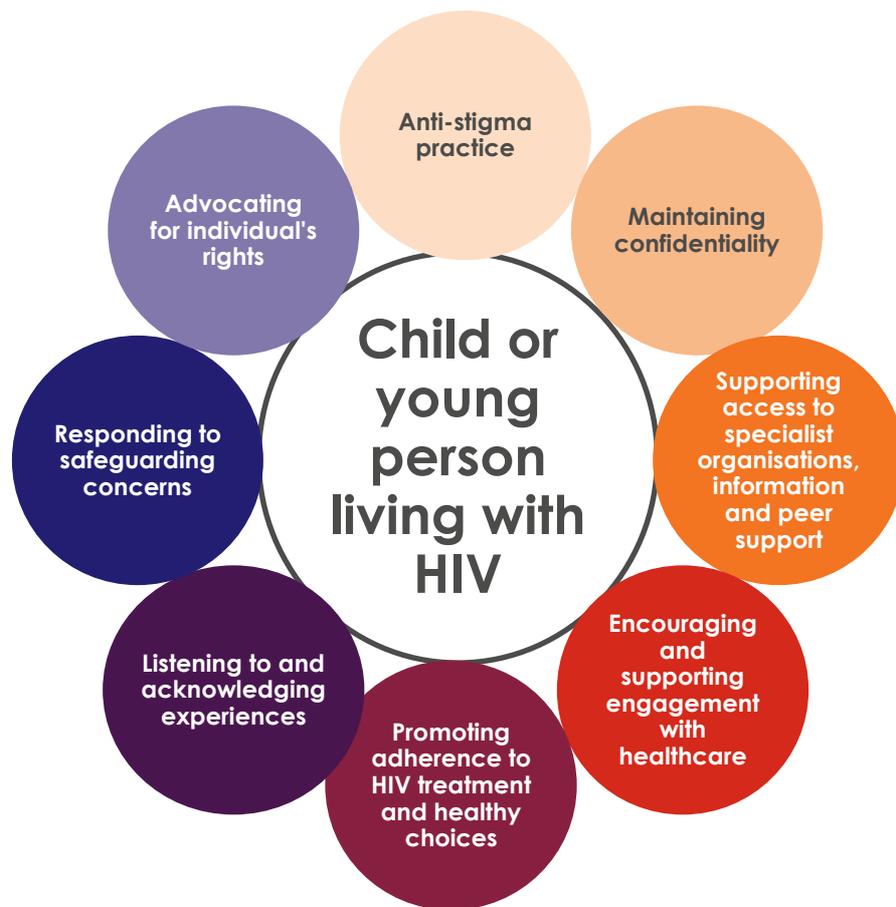
Professionals providing HIV treatment and care for children and young people are expected to regularly monitor their psychological wellbeing and developmental needs and actively follow up concerns.

A wide range of professionals can respond to children and young people's emotional and psychological needs around HIV, as these change over time. Some ways in which those working outside HIV healthcare and support services can do this are shown in Figure 3.

### Key messages for young people newly diagnosed with HIV and their families

- HIV is a treatable long-term condition, not a death sentence
- Taking medication is an important part of this
- HIV shouldn't stop you achieving your goals including working and having children
- The stigma around HIV is often based on fear and inaccurate information
- Taking care of yourself when living with HIV is really important
- People are living long, healthy, full lives with HIV
- Help and support is available, including from peers who have received the same diagnosis.

Figure 2



**Figure 3**

Specialist HIV professionals can also help other practitioners to support children and young people within the remit of particular roles.

It is important to emphasise that there is very little that HIV can prevent a child or young person from doing.

Parents, carers and partners may also need help to adjust to an individual's HIV diagnosis.

See 'Sources of information and support' (p26) for resources for professionals, young people and parents, and signposting to services.

## Peer support

Evidence from young people who have grown up with lifelong HIV, as well as from adults living with HIV, shows that peer support can be instrumental in helping individuals to cope with an HIV diagnosis and manage the impact of HIV on their lives. CHIVA *Standards of Care* (2013) present peer support as an important element of HIV care and support, helping families and young people 'escape isolation, renew and strengthen their self-esteem and become partners with services in treatment and care decisions'.

**'I can't even begin to describe [...] You can just be you and everyone there loves you for who you are and it's time to take medication and everyone's doing it at the same time.'**

**Young person participating in a residential support camp (quoted in Hamblin 2011)**

Young people who have acquired HIV in adolescence can still benefit from meeting young people who have had HIV since birth or early childhood, and/or older adults living with HIV.

## Ongoing management of risk with all young people

Whether young people test positive or negative for HIV, health professionals should lead on responding to their needs relating to:

- Medical treatment, including supporting adherence to HIV treatment when required
- Preventing future risk of STIs, BBVs and unwanted pregnancy
- Preventing transmission of STIs or BBVs to others
- Young people's understanding of, attitudes to and control over risk
- Strategies to assist young people to escape abusive situations
- Information on contraception choices, reproductive health and pregnancy, taking into account individuals' infection status
- The effects of behaviours and choices on health, for example, smoking, diet, drug and alcohol use
- For young people diagnosed with HIV, education about their condition, how it affects them, how to manage its impact, and how to protect themselves and their partners – this is a long-term process
- Whether, when and how to disclose an HIV diagnosis to current or potential partners.

This should be done in accordance with guidelines (for example, BASHH 2010; HYPNet and others 2011; CHIVA 2013; HM Government 2015b). Professionals should only attempt to support or advise young people to the extent that their job role and experience allows. Responses should be informed by leadership from sexual health and HIV professionals that is direct, current and specific to the individual concerned.

Calm, non-judgmental responses to information about young people's risk behaviours will help keep communication open. This is crucial as awareness of how risk factors may change or persist for a young person can help to identify when they may need testing or other health or safeguarding interventions.

All young people should receive positive, consistent messages about how to reduce their risk of acquiring STIs and BBVs (see Figure 4), with additional support where necessary. The presence of other STIs can increase the risk of HIV transmission, so timely diagnosis and treatment of other STIs is important for young people regardless of their HIV status.

### Young people at ongoing high risk of exposure to infections

Some young people will face particular challenges in preventing exposure to HIV and other infections. This may be due to violent or coercive behaviour from other people. Young people at ongoing high risk of infection will need additional support.

Knowing about post-exposure prophylaxis (PEP; see p12), including when, where and how to access it, can be particularly important for HIV prevention.

Pre-exposure prophylaxis (PrEP), which is a

### Key messages for all young people

As far as you possibly can:

- Use condoms correctly and consistently
- Avoid sharing equipment to prepare or take drugs
- Seek help urgently if you think you might have been exposed to *any* infection through sexual activity or sharing equipment used to take drugs – or if you have symptoms
- Consider STI testing regularly, depending on your risk of being exposed to infections, or when you have a new partner.

Figure 4

course of drugs taken before exposure to HIV, has been shown to be effective at preventing HIV infection. As of May 2016, it is not available through the NHS on prescription, but may in future provide an HIV prevention option for people at highest risk.

## Young people living with HIV

### Avoiding passing on HIV

Sexual activity in young people living with HIV does not in itself present automatic cause for concern or require HIV healthcare professionals to share information (see 'Confidentiality' on p16 and 'Positive and holistic approaches to young people's sexual health and wellbeing' on p19).

Consistent condom use is recommended for sexually active young people living with HIV, as it is for other young people, to protect themselves and their partners from STIs and avoiding unwanted pregnancy.

Having a high 'viral load' (amount of HIV measurable in the blood) increases the risk of HIV transmission. By reducing an individual's viral load, HIV treatment not only benefits their health but also makes them less likely to pass on HIV. Knowing this may motivate young people living with HIV to take their medication, and increase their peace of mind if condom use is not always possible for them during vaginal or anal sex.

People living with HIV can have children without passing HIV on to their partner or child, with effective HIV prevention interventions and support.

### Disclosing HIV to sexual partners

There is no automatic requirement for young people living with HIV to disclose their diagnosis to all sexual partners. There are complex emotional, social and legal issues involved in whether, when and how people living with HIV disclose their HIV status to current or potential partners.

Guidelines for paediatric healthcare professionals (HYPNet and others 2011) emphasise the need for timely sexual health education and support around negotiating sexual relationships, including disclosure of HIV to sexual partners. They advise that:

- HIV positive adolescents should ideally disclose their status to sexual partners even when they are having protected sex. This will allow partners to make their own risk assessment and will ease discussions about post exposure prophylaxis (PEP) (see p12).
- If an HIV positive adolescent is having unprotected sex or there has been a risk of exposure (e.g. condom splits) they need to disclose their HIV status to that partner so that they can obtain PEP to lessen the risk of HIV transmission.

In reality, young people living with HIV may not feel able to disclose their diagnosis to sexual partners. These situations call primarily for support and education from the young person's clinic team. The team will also weigh the best interests of their patient against any need for disclosure of information in the 'public interest', taking into account specific risks, the circumstances and relevant professional guidelines (for example, GMC 2009b; BASHH 2010; HYPNet and others 2011; Phillips and others 2013). The nominated practitioner for child protection and other agencies should be involved as required. Some relevant considerations are addressed below, in 'Confidentiality' (p16) and in 'Young people whose sexual partners are known to have HIV' (p9).

### Violence and discrimination

Young people diagnosed with HIV may experience discrimination from peers, families, communities, educational institutions and services including healthcare providers. Maintaining confidentiality and providing effective support as appropriate (see 'Post-diagnosis support' on p20) will help to protect young people from this and ensure their rights are respected.

Some young people will be in situations where there is a risk of violence or aggression from partners, perpetrators of abuse or others if their infection status becomes known. Evidence from around the world, particularly into women's experiences (for example, Sophia Forum 2013; Salamander Trust

2014) suggests that individuals' HIV diagnosis can be used against them in abusive situations to make threats, establish power, and control access to resources and support.

Where such possibilities exist, appropriate professionals should work with the young person to anticipate and prevent them. Guidelines for paediatric healthcare professionals (HYPNet and others 2011) advise on the need to identify possible sexual violence, exploitation or domestic violence and who to involve.

Maintaining young people's confidentiality can protect them. HIV professionals can also suggest strategies individuals can use to keep their own HIV information private, often based on ways that other young people living with HIV manage this.

### **Criminal responsibility for HIV transmission**

In some specific circumstances, people living with HIV can be prosecuted for 'reckless' or 'intentional' transmission of the virus to an individual to whom they have not disclosed their HIV status. Prosecutions are rare and no young people under 18 have yet been prosecuted in the UK. However, accusations and police investigations do happen, which can be traumatic for all young people involved and their families. Figure 5 presents a case study that highlights the importance of informed and measured responses to legal concerns about HIV transmission.

#### **Case example: 'Lee'**

Lee had unsafe sex with his girlfriend to whom he had not disclosed his HIV status.

He was concerned about the event and shared it with staff at his children's home; they in turn reported it to the social services' duty social work team. The duty team referred it to their manager and a child protection response was undertaken regarding the girl. There was a panic response, immediate action was considered necessary, strategy meetings were held between different managers within the children's service and a significant number of social services staff then learnt about Lee's HIV status.

The girl's parents learnt what had happened and began proceedings to prosecute for reckless transmission of HIV under Section 20 of the Offences Against the Person's Act 1861, although there was no evidence that transmission of HIV had taken place.

Lee was referred to a specialist legal advisor. After this meeting he panicked and went straight to the police station and handed himself in.

The police did not know what to charge him with and so charged him with sexual assault, although the girl was the same age as him and at this stage was still untested.

The girl concerned was later tested by an adult sexual health service. She tested negative for HIV. Her parents and the police dropped all charges.

This incident highlighted the widespread lack of awareness and understanding of HIV among statutory services and, in this instance, the police. Misunderstandings about risks meant that management decisions within children's services were based on a panic response. Equally, the police were ill-equipped with awareness and understanding and quickly criminalised the behaviour of the young man, even though no criminal offence had taken place and there was no knowledge that HIV had been transmitted.

Case study from: Ely, A (2008) *Looking after HIV: Considering the needs of HIV positive looked after children*. National Children's Bureau

**Figure 5**

If supporting a young person around an accusation, either against them or being made/considered by them, advice should be sought at the earliest opportunity from:

- the National AIDS Trust or Terrence Higgins Trust (see 'Sources of information and support' on p26)
- the young person's healthcare team, as appropriate.

NCB and CHIVA have produced tailored information on legal rights and responsibilities for young people living with HIV<sup>6</sup>.

All young people will benefit from open, comfortable, non-judgemental conversations about HIV and approaches that do not exceptionalise HIV.

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<sup>6</sup> Available at <http://www.chiva.org.uk/youth/hiv-facts/law/> and <http://www.ncb.org.uk/lifelinks/your-life-leaflets>

## Sources of information and support

### Information on HIV and related health topics

Many of these websites include information for both professionals and the public, including young people and their parents/carers. Many provide specialist information addressing specific behaviours or circumstances.

Children's HIV Association (CHIVA)	<a href="http://www.chiva.org.uk">www.chiva.org.uk</a>	Children and young people living with HIV
NCB's Children and Young People HIV Network	<a href="http://www.ncb.org.uk/hiv">www.ncb.org.uk/hiv</a>	Children and young people living with HIV
National AIDS Trust (NAT)	<a href="http://www.natf.org.uk">www.natf.org.uk</a> <a href="http://www.lifewithhiv.org.uk">www.lifewithhiv.org.uk</a> <a href="http://www.hivaware.org.uk">www.hivaware.org.uk</a> <a href="http://www.mycaremyvoice.org.uk">www.mycaremyvoice.org.uk</a>	Public awareness, policy and rights relating to HIV
Terrence Higgins Trust (THT)	<a href="http://www.tht.org.uk">www.tht.org.uk</a> <a href="http://www.tht.org.uk/itstartswithme">www.tht.org.uk/itstartswithme</a> <a href="http://www.tht.org.uk/friday-monday">www.tht.org.uk/friday-monday</a>	Sexual and reproductive health, HIV, sexuality and gender
NAM	<a href="http://www.aidsmap.com">www.aidsmap.com</a>	HIV
Brook	<a href="http://www.brook.org.uk">www.brook.org.uk</a>	Young people's sexual health and wellbeing
NHS Choices	<a href="http://www.nhs.uk">www.nhs.uk</a>	Health
FPA	<a href="http://www.fpa.org.uk">www.fpa.org.uk</a>	Sexual health, including for people with learning disabilities
Sex Education Forum	<a href="http://www.sexeducationforum.org.uk/resources/resources-for-sre.aspx">www.sexeducationforum.org.uk/resources/resources-for-sre.aspx</a>	Resources for sex and relationships education
Get Your Rights	<a href="http://www.getyourrights.org">www.getyourrights.org</a>	Children and young people's rights in the NHS
AYPH Be Healthy	<a href="http://www.ayph-behealthy.org.uk">www.ayph-behealthy.org.uk</a>	Young people's health participation, including for those affected by child sexual exploitation
Hepatitis C Trust	<a href="http://www.hepctrust.org.uk">www.hepctrust.org.uk</a>	Hepatitis C
Children's Liver Disease Foundation	<a href="http://www.childliverdisease.org">www.childliverdisease.org</a>	Liver diseases in children, including hepatitis C
YoungMinds	<a href="http://www.youngminds.org.uk">www.youngminds.org.uk</a>	Young people's mental health and wellbeing

Gendered Intelligence	<a href="http://www.genderedintelligence.co.uk">www.genderedintelligence.co.uk</a>	Trans young people
Stonewall Youth	<a href="http://www.youngstonewall.org.uk">www.youngstonewall.org.uk</a>	LGBTQ young people
Disrespect Nobody	<a href="http://www.disrespectnobody.co.uk">www.disrespectnobody.co.uk</a>	Healthy relationships for young people
IPED Info	<a href="http://www.ipedinfo.co.uk">www.ipedinfo.co.uk</a>	Image and performance enhancing drugs
Talk to Frank	<a href="http://www.talktofrank.com">www.talktofrank.com</a>	Confidential drugs information and advice
Outsiders	<a href="http://www.outsiders.org.uk">www.outsiders.org.uk</a>	Disabled people's sexual health and wellbeing
British Institute of Learning Disabilities	<a href="http://www.bild.org.uk/information/relationships">www.bild.org.uk/information/relationships</a>	Information for people with learning disabilities
The Who Cares? Trust	<a href="http://www.thewhocarestrust.org.uk">www.thewhocarestrust.org.uk</a>	Health and wellbeing information for looked after children and care leavers
African Health Policy Network	<a href="http://www.ahpn.org.uk">www.ahpn.org.uk</a>	Health and wellbeing for the UK's African population

### HIV and sexual health services for children, young people and families

Children's HIV Association (CHIVA)	<a href="http://www.chiva.org.uk">www.chiva.org.uk</a> <a href="http://www.chiva.org.uk/professionals/regional-networks/">www.chiva.org.uk/professionals/regional-networks/</a> <a href="http://www.chiva.org.uk/youth/find-support/hiv/">www.chiva.org.uk/youth/find-support/hiv/</a>	Delivers services nationally and online; provides details of paediatric HIV healthcare services and local voluntary organisations
Body & Soul	<a href="http://www.bodyandsoulcharity.org">www.bodyandsoulcharity.org</a>	HIV support services in London, with nationwide support offered remotely
Positively UK	<a href="http://www.positivelyuk.org">www.positivelyuk.org</a>	HIV support services in London and nationwide peer mentoring
NHS	<a href="http://www.nhs.uk/Livewell/Talkingaboutsex/Pages/Ineedhelpnow.aspx">www.nhs.uk/Livewell/Talkingaboutsex/Pages/Ineedhelpnow.aspx</a>	Sexual health services for young people
NAM e-atlas	<a href="http://www.aidsmap.com/e-atlas">www.aidsmap.com/e-atlas</a>	HIV service finder
Brook	<a href="http://www.brook.org.uk">www.brook.org.uk</a>	Young people's sexual health and wellbeing
Terrence Higgins Trust (THT)	<a href="http://www.tht.org.uk">www.tht.org.uk</a>	Sexual and reproductive health and HIV

## Practice guidance and standards for health and social care professionals

<a href="#"><u>CHIVA Standards of Care for Infants, Children, and Young People with HIV</u></a>	CHIVA, 2013	<a href="http://www.chiva.org.uk"><u>www.chiva.org.uk</u></a>
<a href="#"><u>Standards of care for people living with HIV</u></a>	BHIVA, 2013	<a href="http://www.bhiva.org"><u>www.bhiva.org</u></a>
<a href="#"><u>Psychological Management of Children and Young People Living with HIV: Standards for Care</u></a>	CHIVA, British Psychological Society and Paediatric Psychology Network, 2014	<a href="http://www.chiva.org.uk"><u>www.chiva.org.uk</u></a>
<a href="#"><u>Standards for psychological support for adults living with HIV</u></a>	British Psychological Society, BHIVA and Medical Foundation for AIDS & Sexual Health	<a href="http://www.bhiva.org"><u>www.bhiva.org</u></a>
<a href="#"><u>Working together to safeguard children: A guide to inter-agency working to safeguard and promote the welfare of children</u></a> (This guidance links to other guidance relating to specific groups of children and young people, or issues affecting them)	HM Government, 2015	<a href="http://www.gov.uk"><u>www.gov.uk</u></a>
<a href="#"><u>Information sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers</u></a>	HM Government, 2015	<a href="http://www.gov.uk"><u>www.gov.uk</u></a>
<a href="#"><u>0-18 years: guidance for all doctors</u></a>	General Medical Council, 2007	<a href="http://www.gmc-uk.org"><u>www.gmc-uk.org</u></a>
<a href="#"><u>Confidentiality</u></a>	General Medical Council, 2009	<a href="http://www.gmc-uk.org"><u>www.gmc-uk.org</u></a>
<a href="#"><u>Confidentiality: disclosing information about serious communicable diseases</u></a>	General Medical Council, 2009	<a href="http://www.gmc-uk.org"><u>www.gmc-uk.org</u></a>
<a href="#"><u>Treat Me Like This guidelines</u></a> developed by young people for HIV healthcare providers	CHIVA, 2015	<a href="http://www.chiva.org.uk"><u>www.chiva.org.uk</u></a>
<a href="#"><u>Open And Honest Practice When Working With Children</u></a> by Amanda Ely	CHIVA, 2012	<a href="http://www.chiva.org.uk"><u>www.chiva.org.uk</u></a>
<a href="#"><u>Talking to children about HIV in health settings</u></a> by Diane Melvin & Sheila Donaghy	CHIVA, 2014	<a href="http://www.chiva.org.uk"><u>www.chiva.org.uk</u></a>
<a href="#"><u>HIV transmission, the Law and the work of the clinical team, January 2013</u></a> by Matthew Phillips, Mary Poulton, BHIVA and BASHH	BHIVA and BASHH, 2013	<a href="http://www.bhiva.org"><u>www.bhiva.org</u></a>
<a href="#"><u>Promoting the health and wellbeing of looked after children: Statutory guidance for local authorities, clinical commissioning groups and NHS England</u></a>	Department for Education and Department of Health, 2015	<a href="http://www.gov.uk"><u>www.gov.uk</u></a>
<a href="#"><u>Looking after HIV: Considering the needs of HIV positive looked after children.</u></a> by Amanda Ely	NCB, 2008	<a href="http://www.ncb.org.uk"><u>www.ncb.org.uk</u></a>
<a href="#"><u>HIV in Schools: A good practice guide to supporting children living with and affected by HIV</u></a> by Magda Conway	NCB and CHIVA, 2015	<a href="http://www.chiva.org.uk"><u>www.chiva.org.uk</u></a>

## Clinical guidelines

This list indicates the range of guidance that informs how health professionals meet children and young people's needs relating to sexual health and HIV. Making connections with local HIV healthcare providers and voluntary organisations is recommended (see above for details).

<a href="#"><u>UK National Guidelines for HIV Testing</u></a>	BHIVA, BASHH and British Infection Society, 2008	<a href="http://www.bhiva.org"><u>www.bhiva.org</u></a>
<a href="#"><u>UK National Guideline on the Management of Sexually Transmitted Infections and Related Conditions in Children and Young People</u></a>	BASHH, 2010	<a href="http://www.bashh.org"><u>www.bashh.org</u></a>
<a href="#"><u>BASHH CEG 2015 summary guidance on tests for Sexually Transmitted Infections</u></a>	BASHH, 2015	<a href="http://www.bashh.org"><u>www.bashh.org</u></a>
<a href="#"><u>BASHH Recommendations for Testing for Sexually Transmitted Infections in Men who have Sex with Men</u></a>	BASHH, 2014	<a href="http://www.bashh.org"><u>www.bashh.org</u></a>
<a href="#"><u>Guideline for consultations requiring sexual history taking</u></a>	BASHH, 2013	<a href="http://www.bashh.org"><u>www.bashh.org</u></a>
<a href="#"><u>UK National Guidelines on safer sex advice</u></a>	BASHH and BHIVA, 2012	<a href="http://www.bashh.org"><u>www.bashh.org</u></a>
<a href="#"><u>Post-Exposure Prophylaxis (PEP) Guidelines for children and adolescents potentially exposed to blood-borne viruses</u></a>	CHIVA, 2015	<a href="http://www.chiva.org.uk"><u>www.chiva.org.uk</u></a>
<a href="#"><u>UK National Guideline for the Use of HIV Post-Exposure Prophylaxis Following Sexual Exposure (PEPSE)</u></a>	BASHH, 2015	<a href="http://www.bashh.org"><u>www.bashh.org</u></a>
<a href="#"><u>HIV testing guidelines for children of HIV positive parents or siblings in the UK and Ireland</u></a>	CHIVA, 2014	<a href="http://www.chiva.org.uk"><u>www.chiva.org.uk</u></a>
<a href="#"><u>PENTA Guidelines for treatment of paediatric HIV-1 infection 2015: optimizing health in preparation for adult life</u></a>	Paediatric European Network for Treatment of AIDS, 2015	<a href="http://www.penta-id.org"><u>www.penta-id.org</u></a>
<a href="#"><u>British HIV Association guidelines for the treatment of HIV-1-positive adults with antiretroviral therapy 2015</u></a>	BHIVA, 2015	<a href="http://www.bhiva.org"><u>www.bhiva.org</u></a>
<a href="#"><u>Guidance on the management of sexual and reproductive health for adolescents living with HIV</u></a>	HIV in Young People Network, CHIVA, BASHH and BHIVA, 2011	<a href="http://www.hypnet.org.uk"><u>www.hypnet.org.uk</u></a>
<a href="#"><u>Refugee and unaccompanied asylum seeking children and young people: paediatric health assessment</u></a>	Royal College of Paediatrics and Child Health, 2016	<a href="http://www.rcpch.ac.uk"><u>www.rcpch.ac.uk</u></a>
<a href="#"><u>UK National Guidelines on the Management of Adult and Adolescent Complainants of Sexual Assault</u></a>	BASHH, 2011 (updated 2012)	<a href="http://www.bashh.org"><u>www.bashh.org</u></a>
NICE guidance and quality standards	National Institute for Health and Care Excellence	<a href="http://www.nice.org.uk"><u>www.nice.org.uk</u></a>

## Appendix: An overview of HIV, hepatitis B and hepatitis C

This table summarises key information about the blood-borne viruses HIV, hepatitis B and hepatitis C, which can be transmitted in similar ways. It is important to note that exposure to an infection does not inevitably lead to transmission. The degree of risk depends on a range of factors relating to the individual concerned and the circumstances in which exposure occurs.

See 'Sources of information and support' (p26) for signposting to detailed and up-to-date information on these and other infections.

There can be a risk of different infections associated with sexual activities besides vaginal or anal penetrative sex (for example, oral sex, sharing sex toys, or sexual activities involving blood or faeces). Some of these risks are theoretical or negligible, whilst others are more substantial. Sexual health professionals can advise. Condoms, dental dams and hygiene measures can protect against most risks.

	HIV	Hepatitis B	Hepatitis C
<b>What is it?</b>	HIV stands for the Human Immunodeficiency Virus. HIV attacks the body's immune system, undermining the body's defence against diseases. HIV can be asymptomatic for years but, without medication, people living with HIV eventually develop 'AIDS-defining' diseases including tuberculosis, pneumonia or some types of cancer. AIDS (Acquired Immune Deficiency Syndrome) is a syndrome – a collection of different signs and symptoms – that characterise an advanced stage of HIV infection.	<p>Hepatitis B is a blood-borne virus.</p> <p>Hepatitis B is more infectious than HIV and hepatitis C. The majority of people infected with hepatitis B in adulthood are able to fight off the virus and fully recover within one to three months (acute infection), after which they have lifelong immunity. Babies and children with hepatitis B are more likely to develop a chronic infection (90% of babies and 20% of older children with hepatitis B, compared with 5% of adults) (NHS 2016).</p> <p>Hepatitis B often doesn't cause obvious symptoms in the acute phase. Chronic hepatitis B infection can cause life-threatening liver damage and liver cancer.</p>	<p>Hepatitis C is a blood-borne virus that can lead to cirrhosis of the liver, primary liver cancer or liver failure.</p> <p>Around one quarter of people who acquire hepatitis C will clear the virus naturally within six months. In others, the virus will develop into long-term (chronic) infection.</p> <p>Symptoms can take years or decades to occur.</p>

	HIV	Hepatitis B	Hepatitis C
<p><b>Main transmission routes in the UK</b></p> <p>These are not exhaustive lists of possible routes of transmission. The frequency of infection via different routes depends on their relative risk and is context-specific.</p>	<ul style="list-style-type: none"> <li>• Anal sex without a condom</li> <li>• Vaginal sex without a condom</li> <li>• Mother to child during pregnancy, birth or breastfeeding (rare in the UK)</li> <li>• Using shared, unsterilised needles and other equipment for injecting drugs (rare in the UK, though when exposure occurs, it is more likely to result in infection than sexual exposure)</li> </ul>	<ul style="list-style-type: none"> <li>• Anal sex without a condom</li> <li>• Vaginal sex without a condom</li> <li>• Using shared, unsterilised needles and other equipment for injecting or snorting drugs.</li> <li>• Mother to child, usually during or after birth.</li> <li>• Household transmission can occur through sharing toothbrushes or razors that may be contaminated with blood.</li> </ul>	<ul style="list-style-type: none"> <li>• Using shared, unsterilised needles and other equipment for injecting, smoking or snorting drugs. Around 90% of the hepatitis C infections diagnosed in the UK will have been acquired through injecting drug use (PHE and others 2015).</li> <li>• Anal sex without a condom</li> <li>• Vaginal sex without a condom (very rare)</li> <li>• Mother to child transmission during pregnancy or birth (occurs in around one in twenty babies born to mothers with hepatitis C).</li> </ul>
<p><b>Treatment and cure</b></p>	<p>Progress in HIV treatment has made it possible for people to live long, healthy lives with HIV and to recover from AIDS, so long as they take daily medication. However, there is no cure for HIV.</p>	<p>Acute hepatitis B doesn't usually require treatment.</p> <p>Treatment can help control chronic hepatitis B and prevent liver damage, although it won't necessarily cure the infection. Some people need lifelong treatment to control hepatitis B.</p>	<p>Highly effective treatments have recently become available for adults with hepatitis C infection, offering significant chance of cure.</p> <p>Treatment options for children are currently more limited, but it is likely that these newer treatments will soon be available.</p>
<p><b>Testing</b></p>	<p>Usually blood sample sent for laboratory testing. See p14.</p> <p>Antenatal screening is offered to all pregnant women.</p>	<p>Blood sample sent for laboratory testing.</p> <p>Antenatal screening is offered to all pregnant women.</p>	<p>Blood sample sent for laboratory testing.</p> <p>Antenatal screening is not currently routine.</p>

	<b>HIV</b>	<b>Hepatitis B</b>	<b>Hepatitis C</b>
<p><b>Prevention</b></p> <p>Measures that apply to healthcare services or providers of tattooing or body piercing are not included.</p>	<p>There is no effective vaccine.</p> <p>HIV can be effectively prevented through the use of condoms for anal and vaginal sex and dental dams for oral sex; HIV treatment (which reduces infectiousness); and not sharing equipment for injecting drugs.</p> <p>Post-exposure prophylaxis (PEP; see glossary on p4) can reduce the risk of infection after recent exposure. <i>Pre</i>-exposure prophylaxis (PrEP), which can reduce the risk of HIV infection if taken <i>before</i> exposure to HIV, is not available through the NHS on prescription at the time of writing. PrEP may in future provide an HIV prevention option for people at highest risk.</p> <p>Vertical HIV transmission (from mother to child) can be effectively prevented through HIV treatment, managed vaginal birth or planned caesarean section, and not breastfeeding.</p>	<p>Hepatitis B can be prevented by not sharing equipment used to prepare or take drugs; using condoms; and not sharing items such as razors or toothbrushes that might be contaminated with blood.</p> <p>A hepatitis B vaccine is available for people at high risk of the infection.</p> <p>Emergency treatment after recent exposure (with the vaccine or hepatitis B immunoglobulin) can help reduce the risk of infection.</p> <p>Immunisation of babies at birth can prevent babies born to mothers with hepatitis B from acquiring the infection and developing chronic hepatitis B infection.</p>	<p>There is no vaccine.</p> <p>Hepatitis C can be prevented by not sharing equipment used to prepare or take drugs; using condoms with new partners or for sexual activities involving likely exposure to blood; and not sharing items such as razors or toothbrushes that might be contaminated with blood.</p> <p>Prevention of vertical transmission is not currently possible, though the risk of transmission is lower than for HIV and hepatitis B.</p>

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