



CHIVA Standards of Care for Infants, Children, and Young People with HIV (Including infants born to mothers with HIV)

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Supporting text for Standards

UK Paediatric HIV Population

As of the end of March 2017, a total of 927 patients were alive and in active follow-up at a Paediatric clinic in the UK or Ireland. Approximately half of these children have been born abroad and the median age of the cohort is around 14 years. All children diagnosed with HIV in the UK and Ireland is reported to the NSHPC (National Study of HIV in Pregnancy and Childhood) and is followed up as the Collaborative HIV Paediatric Study (CHIPS) cohort. The data set is updated annually through clinician reporting; thus, we have excellent up-to-date information on the epidemiology of Paediatric HIV in the UK as well as annual updates on case management which are evaluated regularly to improve patient care.

The vast majority of children and young people with HIV in the UK were infected through mother-to-child transmission. Approximately 50% of children and young people with HIV currently live within Greater London, and the proportion living elsewhere in England is growing; there are also smaller cohorts in Ireland, Scotland and Wales. Overall, mortality among children and young people with HIV has reduced considerably since the introduction of highly active antiretroviral therapy (HAART) in 1997. High uptake of antenatal testing reduced transmission rates from diagnosed women, improved survival following initiation of HAART and later age at presentation among those born abroad mean that the average age of perinatally infected children and young people in the UK and Ireland continues to rise.

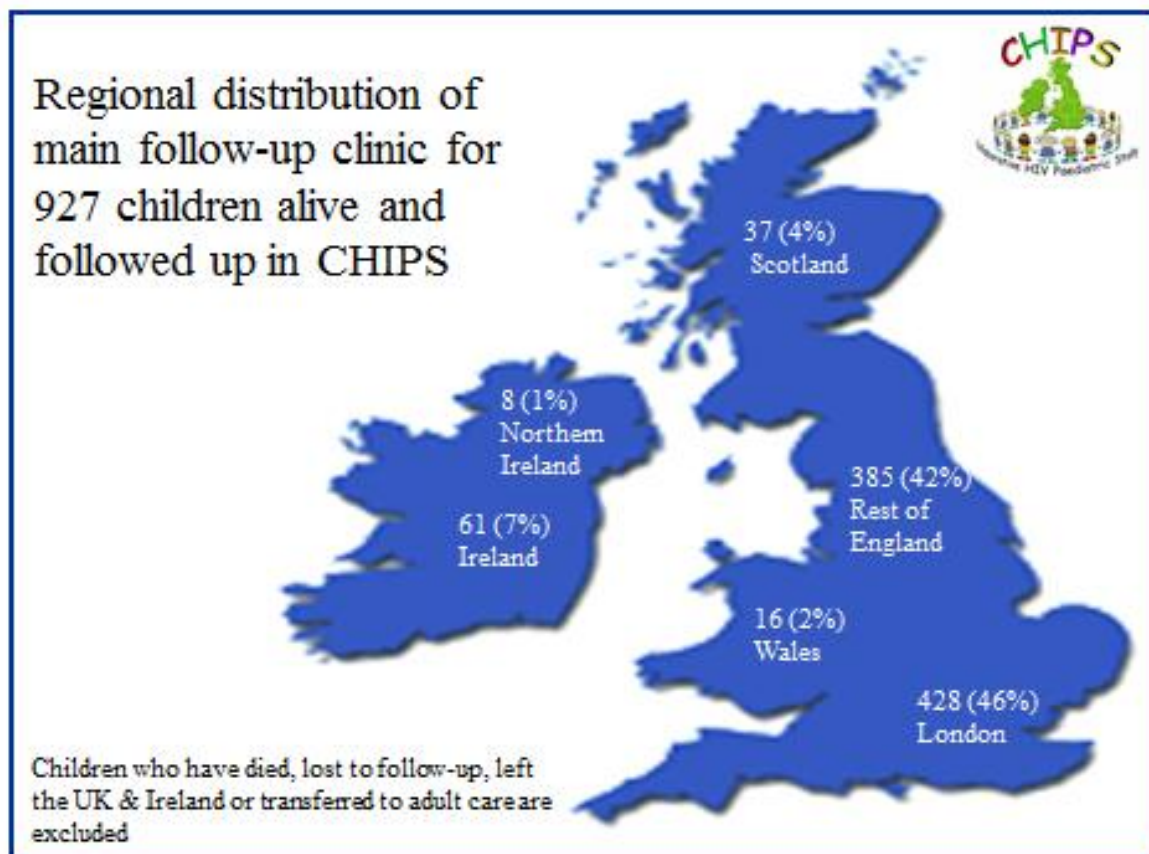
HIV has become a chronic condition of childhood with the likelihood of long-term survival; therefore, development of appropriate services for long-term survivors is an important consideration for the adult services taking over their care.

New Cases of Paediatric HIV

A very small number of perinatally-infected children are still diagnosed with HIV in the UK each year. This is despite the widespread availability of effective interventions to prevent mother to child transmission, which have reduced the rate of mother-to-child transmission in the UK and Ireland from 0.46% in 2010-2011 to 0.27% in 2012-2014 (NSHPC data). Infected infants, especially those born to mothers who were not diagnosed by the time of delivery, suffer significant morbidity and mortality. Undiagnosed infants presenting with rapidly progressive HIV, and associated diseases such as primary pneumocystis

pneumonia (PCP), disseminated CMV or HIV encephalopathy, are at high risk of death or permanent disability during their presenting illness before it is possible to start them on HAART. Older children and young people presenting with very advanced HIV and very low CD4 counts have more commonly been born abroad and are at risk of death from opportunistic infections prior to starting combination therapy. The numbers of this latter group remain relatively small. Yet both of these high-risk groups of children require intensive input of complex medical care: to treat their opportunistic infections, to establish antiretroviral therapy with concomitant difficulties of poly-pharmacy and drug side-effects, and to manage the risk of immune reconstitution syndromes. The family and social circumstances of children and young people with HIV are also often complex, with multiple needs that must be managed alongside the medical HIV care.

The CHIPS data (March 2017):



Testing of mothers in pregnancy and infants born to mothers with HIV

Over 1100 births per year to women diagnosed with HIV in or before pregnancy are reported annually to the NSHPC <http://www.ucl.ac.uk/nshpc/>. The vast majority of these infants receive appropriate interventions to reduce mother-to-child transmission including: antiretroviral therapy in pregnancy, decision on type of delivery (i.e. plans for vaginal delivery or caesarean section), post-exposure prophylaxis to the infant, and formula feeding. Management in pregnancy should follow the BHIVA guidelines for management of HIV in pregnancy. Few infants born in the UK now acquire vertically transmitted HIV (<10 per year) with more than two thirds of these infants being born to mothers who were not diagnosed with HIV before the birth. The mothers whose infants are infected despite maternal diagnosis before delivery are generally diagnosed late in pregnancy and/or have sub-optimal viral suppression due to adherence difficulties and/or drug resistance. If these babies are diagnosed with HIV prior to the onset of opportunistic infections, they can be started on HAART and PCP prophylaxis, reducing their risk of rapid disease progression by 75% or more.

As a result of the national 'opt out' strategy of antenatal testing for HIV implemented in 2000, more than 97% of pregnant women in the UK are tested antenatally. It is of concern, however, that some women who decline antenatal testing appear to be at increased risk of being HIV positive and some women who are HIV antibody negative at booking subsequently acquire HIV during pregnancy or breastfeeding. Therefore, all women need good sexual health information in pregnancy to avoid the risk of acquiring HIV and transmission to the infant during pregnancy or breastfeeding.

As there is a duty of care to babies themselves upon their birth, it is recommended that babies born to mothers who have declined all offers of testing should be offered a screening antibody test as soon as possible after birth. If this is refused, then consultation with paediatric safeguarding team and wider MDT including tertiary Infectious disease center consultation may result in a decision to refer to Social care to assess the risks to the infant and whether a threshold to seek an order to test the baby against parental wishes is met.

More than half of all pregnant women living with HIV are aware of their infection before conception. Early attendance for antenatal care should be encouraged to facilitate optimal management of known HIV infection and to optimise outcomes for both mother and child.

Effective treatment for HIV in children and young people

HAART is extremely effective for the management of Paediatric HIV. In the CHIPS cohort over 75% of children on first-line HAART have full viral suppression, but this requires a high level of adherence. Treatment of children is complex, as appropriate drug formulations for babies, toddlers, young and older children are not always available making dosing difficult. Data on appropriate drug dosing and metabolism at different ages is also scarce for many of the drugs, especially for infants and younger children, and close monitoring of adherence is required.

Supportive management for children on long term HAART is complex and requires long term endurance from children, their carers and the treatment team; the challenges evolve over the Paediatric age range. The success of antiretroviral medication is dependent on adherence to therapy. A high degree of adherence to treatment with HIV drugs is required or drug resistance can develop rapidly. First-line therapy is most likely to result in a favourable outcome with undetectable viral load and effective immune reconstitution, if adherence is achieved.

Children are likely to require life-long treatment and as there are a limited number of antiretroviral drugs available, supporting adherence to treatment is essential for a successful outcome. In addition, the formulations available for younger children are limited. Effective adherence support requires a multi-disciplinary approach, regular review and individualised adaptation over time.

Children require developmental and age appropriate knowledge about HIV and its management. Given that HIV remains a highly stigmatised disease, the process of learning about HIV is a key area in the management of children and families; education about HIV must be undertaken sensitively and carefully and must occur over time. Ideally naming should occur in primary school years with an aim to continue to increase self-esteem and self-knowledge throughout care in preparation for transition from paediatric into adolescent and adult care.

As the numbers of children, especially young children, with HIV fall, tertiary centers with expertise in paediatric HIV should be involved in supervising or liaising about the treatment of all infected children. This is particularly important in complex cases, including drug resistance and interactions, poor adherence and, persistent refusal to test.

Optimising transition to adult services

Transition is defined as the purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centered to adult orientated health care systems. The success of antiretroviral medication has transformed paediatric HIV infection into a chronic health condition, with children surviving well into adulthood and thus increasing numbers transiting into adult services. Assuming the numbers of new patients entering paediatric HIV care continue to decline or remain at a constant average, it is estimated that the cohort will halve in size by 2020 (CHIPS data). The process of preparation for transition should begin in middle childhood and progress through adolescence, at a pace appropriate for the individual child and their family, culminating with transfer to adult HIV services.

Reference should be made to CHIVA Guidance on Transition for adolescents living with HIV, Caroline Foster 2017.

http://www.chiva.org.uk/files/2814/8587/2242/CHIVA_Transition_Guidelines2017.pdf

Health education and promotion are integral parts of the transition process and include negotiating relationships, sexual health education, vaccination and support (AALPHI trial; http://www.ctu.mrc.ac.uk/our_research/research_areas/hiv/studies/aalphi/).

HYPNet/CHIVA/BASHH/BHIVA Guidance: Guidance on the management of sexual and reproductive health for adolescents living with HIV 2011 should be followed.

http://www.chiva.org.uk/files/3914/2857/9880/Guidance_on-sexual-health.pdf

Specific attention must also be given to education regarding preventing secondary transmission as well as to the young person's reproductive options and contraception due to drug interactions.

Children's HIV Association (CHIVA) & Children's HIV National Network (CHINN)

The Children's HIV Association of the UK and Ireland (CHIVA) exists to support healthcare and other professionals in the management and support of children and families with HIV. CHIVA has a well visited website (www.chiva.org.uk) where a range of professional's access information and guidance on the management of the common problems faced by children with HIV. CHIVA has also developed its website for young people and for parents/carers promoting youth and family-friendly information and peer support. For children and young people with HIV, CHIVA provides a dedicated website accessed through a secure login; www.ifonlyyouknew.org.uk. CHIVA carries out direct work with children and young people with HIV focusing on peer support and HIV education programmes. These include



CHILDREN'S HIV ASSOCIATION

the CHIVA national support camp for young people with HIV positive young people (11-16 year-old), which offers them the opportunity to learn about living well with HIV in a supportive environment whilst developing a peer support network. The national support camp includes a Camp Leader programme for young adults with HIV (aged 18-24) who attend camp as peer mentors.

The Children's HIV National Network (CHINN) was inaugurated in 2005 and was established to formalise the support network of specialist expertise in paediatric HIV care, linking all local centers and regional networks to a lead specialist center to ensure access to specialist care for all children and young people living with HIV in the UK. The number and configuration of centres specialising in care of Paediatric and adolescent HIV may change across the UK as the number of HIV-infected children living in the UK declines.

Standards of Care for Children and Young People Living with HIV

The CHIVA Standards of Care for Children and Young People with HIV

In 2009, CHIVA developed the first set of Standards of Care for infants, children and young people infected with HIV and for infants born to mothers with HIV. They were revised and expanded in 2013. The age profile of the paediatric cohort of HIV infected patients continues to rise over time, as fewer HIV-infected babies are born in the UK due to the effectiveness of measures to prevent mother-to-child transmission. Coupled with this, the clinical and wider needs of this patient group mean that the Standards warrant review, accommodating changes in the commissioning and financial environment, and the structure of the NHS across paediatric and adult care.

The Standards delineate

- Appropriate clinical pathways of care
- Multi-disciplinary team working
- The role of the Children's HIV National Network.

In addition, all health, social care and educational professionals must always work together to ensure that appropriate measures are taken to safeguard children from harm.

The Standards set out in this document are broadly in line with those set out in BHIVA Standards for the care provided for adults living with HIV in the UK, and provides a set of Standards which are specific, concise statements about the care that a child or young person living with HIV in the UK should expect to receive. No single model of delivery of care is proposed nor is a “one size fits all” model advocated; rather care provision should be tailored to local arrangements and networks whilst aiming for equality of access to care that reaches the appropriate standards. Clear care pathways through Paediatric and transition HIV services at local, regional and national levels need to be secured to ensure that all children and young people living with HIV receive the care they need.

The scope of CHIVA Standards

The scope of CHIVA Standards of care begins with the unborn infant exposed to HIV in utero from the age of viability, subject to maternal choices. The scope then extends from the moment of birth when the child gains its own rights for optimal care, throughout the Paediatric age range until they progress through the transition process to adult services, at an age and stage appropriate to the individual.

Care for children and young people living with HIV extends beyond their own medical needs and is frequently coloured by parental and familial issues, be they financial, housing, immigration, or socially related. The Standards also incorporate the needs of children and young people to be assured access to appropriate services that ensure that their psychosocial, educational, cognitive and emotional and social needs are met.

To ensure that services providing care for children and young people living with HIV are relevant, appropriate, accessible and family-centered, the Standards include mechanisms for user engagement in service design and delivery. Maintaining and enhancing knowledge about Paediatric and adolescent HIV via both epidemiological/ public health surveillance and research is a vital component of care, which is included in this set of Standards.

Aims of the CHIVA Standards

These Standards aim to inform

- Service providers throughout the UK who are involved in any aspect of the delivery of health care to children and young people living with HIV, from antenatal care through to transition to adult care.
- Commissioners who have responsibility for commissioning health care for children and young people living with HIV.
- Families and carers living with HIV about the expected standards of the HIV related healthcare for children and young people.

This set of Standards is complementary to the BHIVA Standards of Care for Adults Living with HIV (2013)

Standard 1:

Best Practice for Prevention of Mother-to-Child Transmission of HIV

Pregnant women with possible or confirmed HIV infection should have access to diagnostic tests and interventions to prevent mother-to-child transmission, as early as is possible during pregnancy, and where such interventions are not provided during pregnancy they should be provided as early as possible to the infant after birth.

Quality statements

- The management of HIV in pregnancy and the perinatal period should follow the current version of the British HIV Association guidelines for the management of HIV infection in pregnant women. It gives comprehensive details on treatment plans and the different clinical scenarios which can occur during pregnancy, including the emergency scenarios, e.g. unbooked delivery or premature delivery.
- Optimising the prevention of mother-to-child transmission of HIV requires a multidisciplinary team including midwifery, obstetrics, adult genito-urinary medicine/infectious diseases, virology, primary care, neonatology and paediatric infectious diseases teams. All complex cases should be involved paediatric HIV specialists through the CHINN network.
- The multidisciplinary team may additionally involve social work, voluntary services, housing, peer support and other key workers, depending on psychosocial and practical needs of the HIV-infected pregnant woman that may impact on positive health management.
- This team should meet regularly to plan for the progress of all the pregnancies under their care.
- All women with HIV must have a birth plan for prevention of transmission, produced in a timely fashion and available to the labour ward and neonatal team. A woman should have a copy of their own birth plan in case of unexpected events.
- Appropriate planning of interventions including HAART, mode of delivery, post-

exposure prophylaxis to the infant and mode of infant feeding, needs to be established in good time such that the woman can be commenced on therapy in time to achieve an undetectable viral load and significantly reduce the risk of transmission.

- Formula feeding should be recommended, and infant feeding in the context of HIV should be discussed well before the birth.
- All trusts that provide care for HIV-infected pregnant women should have a designated HIV lead for midwifery, obstetrics and paediatrics.
- All women whose HIV status is unknown should be recommended to have an antenatal HIV test in pregnancy to enable interventions to reduce the risk of mother-to-child transmission.
- Women who decline antenatal HIV testing should be encouraged to review this decision and should be referred rapidly to a specialist midwife/screening coordinator for further discussion.
- Women who present late in pregnancy or in labour without having had an HIV test should be recommended to have a rapid HIV test.
- Where babies are born to mothers who have declined all HIV testing in pregnancy, antibody testing of the infant as soon as possible after birth is strongly recommended. Safeguarding considerations must be applied for the best interest of the child and advice sought as appropriate.
- Infants born to HIV-positive mothers must be followed up under paediatric care to ensure they complete the prescribed course of post exposure antiretroviral prophylaxis, are monitored for adverse effects and have blood tests performed to determine whether viral transmission has occurred. Follow up must continue until HIV antibody tests become negative, usually by 18-24 months of age, or HIV infection is diagnosed and specialist paediatric HIV care is assured.

Standard 2:

Paediatric Diagnostic Testing for HIV

All babies, children and young people attending healthcare services (primary, secondary and tertiary care) should be offered diagnostic tests for HIV in accordance with current national guidance. A low threshold for testing is advocated.

Quality statements

- All children at risk of HIV infection should have an HIV test according to the National HIV testing guidelines 2008.
- All children born to women living with HIV, including those born prior to the woman being diagnosed with HIV, should be assessed for risks of vertical transmission and tested for HIV infection when they are resident in the UK. The residency of all untested children who are judged to have been at risk of vertical HIV transmission should be reviewed regularly (at least annually).
- Infants (less than 1 year old) thought to be at risk of HIV infection should be tested as a matter of urgency so that the infant can be commenced on PCP prophylaxis and antiretroviral treatment to reduce the risk of HIV disease progression.
- Paediatric services must have a local policy of how HIV testing is managed, how results are recorded and given to families, and how support is organised when children are found to be infected. Teams must ensure that families have a clear understanding of the testing process.
- Diagnosis of HIV infection in children over the age of 18 months is by an HIV antibody test, as for adults.
- Infants known to have been exposed to HIV during pregnancy should be tested by amplification of the virus genome (DNA or RNA PCR or other amplification methods). This is because all infants born to mothers with HIV will have trans-placentally acquired maternal antibody, which can be detected in the infant up to 18-24 months of age.

- Infants presenting with symptoms of possible HIV infection before the age of 18 months but not known to have been exposed to HIV in utero should have an initial HIV antibody test, to be confirmed by a PCR test if positive. This will have implications on parent's HIV status as well.
- Positive HIV test results should always be confirmed with repeat testing.
- Multi-disciplinary support from specialist paediatric HIV services should be provided for families where an infant or child has a positive HIV test.

Standard 3:

Paediatric HIV Disease Management – Referral to Paediatric/Adolescent HIV Services

Children and young people with HIV, whether newly diagnosed or arriving in the UK having previously been diagnosed with HIV, should be referred urgently for care to a specialist Paediatric HIV service run by appropriately trained practitioners with expertise in HIV within 2 weeks.

Quality statements

- Management of children with HIV in the UK should be according to the current version of the PENTA (Paediatric European Network for the Treatment of AIDS) guidelines (<http://penta-id.org>).
- All infants (less than one year) diagnosed with HIV should be started urgently on anti-retroviral treatment and co-trimoxazole prophylaxis due to their risk of rapid disease progression.
- Starting treatment is now recommended for all children regardless of age, CD4, viral load etc.
- Children presenting with symptomatic HIV require urgent appropriate management of both their HIV and any presenting opportunistic infection.
- Initiation or changes to combination antiretroviral therapy for any individual should always be discussed in a treatment meeting (also known as a "virtual clinic"), either locally or virtually via the CHINN.
- As ART is evolving rapidly, all children, including those with suppressed HIV infection on treatment, should have their treatment regularly reviewed by an MDT or in a treatment meeting to assess whether any less toxic regimens may be available for possible simplification of the regimen.
- Expert paediatric pharmacy support for clinicians treating children with HIV should be available locally or via the CHINN network.
- Expert virological support for clinicians treating children with HIV should be available locally or via the CHINN network.
- All families require multi-disciplinary support to help with developing in-depth

knowledge about the child's infection, their treatment and support for adherence to the drug regimen.

- Where appropriate, families and children should be offered the opportunity to participate in PENTA (<http://penta-id.org/hiv/>) or other antiretroviral treatment trials.
- Clinical management of children with HIV should be in line with guidelines available on the CHIVA website. These include:

1. Baseline investigations

<http://www.chiva.org.uk/guidelines/baseline-investigations/>

2. CHIVA PEP

<http://www.chiva.org.uk/guidelines/chiva-pep-2015/>

3. Immunisation

<http://www.chiva.org.uk/guidelines/immunisation/>

4. Mother to child transmission

<http://www.chiva.org.uk/guidelines/mother-child-transmission/>

5. Monitoring Neurological outcomes

<http://www.chiva.org.uk/guidelines/monitoring-neurological-outcomes/>

6. Naming HIV at a younger age: CHIVA statement

<https://www.chiva.org.uk/guidelines/naming-hiv-younger-age-chiva-statement/>

7. PENTA Treatment guidelines

<http://www.chiva.org.uk/guidelines/penta-treatment-guidelines/>

8. Paediatric dosing: ICHT 2018

https://www.chiva.org.uk/files/9815/2959/2889/ICH_Paed_HIV_Dosing_2018_FINAL_-_for_external_distribution.pdf

9. Sexual and Reproductive health

<http://www.chiva.org.uk/guidelines/sexual-and-reproductive-health/>

10. Taking HIV medicines and adherence
<http://www.chiva.org.uk/guidelines/adherence/>

11. Testing for HIV
<http://www.chiva.org.uk/guidelines/testing/>

12. TB-HIV Coinfection
<http://www.chiva.org.uk/guidelines/tb-hiv-coinfection/>

13. Talking to children about HIV in clinic: guidance for health professionals
<https://www.chiva.org.uk/guidelines/talking-children-about-hiv-clinic-guidance-health-professionals/>

14. Transition
<http://www.chiva.org.uk/guidelines/tr/>

15. Vitamin D guideline
<http://www.chiva.org.uk/guidelines/vitamin-d-guideline/>

16. Unwell Child with HIV and opportunistic infections
<http://www.chiva.org.uk/guidelines/advanced-diseases-and-other-infections/>

17. Checklists and Proformas: aids for clinic
<http://www.chiva.org.uk/guidelines/clinic-forms/>

18. Young people
<https://www.chiva.org.uk/youth/>

19. Psychological standards of care
http://www.chiva.org.uk/files/4514/2900/7023/Psychological_Standards_for_Care.pdf

Standard 4:

Specialist Multi-disciplinary Paediatric HIV Treatment & Care - Outpatient & Inpatient

Children and young people with HIV should attend a Paediatric outpatient HIV service(s), should have the HIV infection monitored and treated safely in accordance with CHIVA and PENTA guidance, and be able to access a comprehensive range of multi-disciplinary services. Services must have follow up and transfer arrangements that ensure children and young people with HIV are retained in specialist care.

When inpatient care is needed for the management of proven or suspected complications of HIV infection or its treatment, admission to a paediatric ward should be readily accessible and should be provided by appropriately trained staff under the supervision of a consultant led multi-disciplinary paediatric HIV team.

Children and young people living with HIV should receive care and support which promotes their mental, emotional and cognitive wellbeing and is sensitive to the unique aspects of living with HIV.

Quality statements:

- Services for infants, children and young people with HIV should be led by a suitably qualified consultant in paediatric infectious diseases or a suitably trained consultant paediatrician with a special interest in HIV.
- A multidisciplinary team is required to care for children and adolescents with HIV.
- The team should include support from paediatricians, specialist paediatric nurses, pharmacists, virologists, psychologists, physiotherapists, social workers, and dieticians. Some of these professionals will provide direct involvement and be part of the core clinic team others will be accessed through referral or consultation.
- The core team should meet regularly to plan and review the progress of children under their care.

- The multidisciplinary team should liaise closely with the following groups also working with families with HIV: adult HIV physicians caring for parents, midwives and obstetricians caring for pregnant women, GPs and health visitors in primary care, educational institutions, social workers, voluntary sector and any other team / clinicians involved in the care of children and families with HIV.
- Services must take account of the psychological, neuro-developmental and learning needs of infants, children and young people, and provide developmentally appropriate support for: learning about HIV, coping with living with HIV and its treatment, as well as coping and adjusting to other difficulties or impairments or significant social changes, losses or deaths within the family.
- Clinicians caring for children with HIV should undertake an in-depth annual review of the holistic management of each child, including: growth and development, HIV disease parameters, HIV treatment, adverse events and side effects of treatment. There should also be a screen for changes in family circumstances, educational progress and psychological issues and appropriate onward referral for more specialist assessment or interventions when needed.
- Where possible, combined outpatient family care should be offered so that parents and children can be treated within the same clinic visit.

Psychology support

- Psychological support should be developmentally appropriate and integrated into the ongoing health care that all children and young people with HIV receive.
- Psychological support should take account of family and cultural contexts as well as health parameters.
- Psychological support should be provided in the form of a tiered or stepped care model as described in both the Psychological standards for Adults with HIV (2011) and in the Psychological Management of Children and Young People living with HIV: Standards of care (2014).
http://www.chiva.org.uk/files/4514/2900/7023/Psychological_Standards_for_Care.pdf . This model allows for the basic psychological support needs of all children with HIV and their families to be met by a wide range of health professionals and support agencies. More complex psychological needs including individuals requiring specialised psychology assessment or interventions, such as counselling or therapy, are in the next tier and should be provided by appropriately

trained personnel following a clear referral pathway.

- All newly referred children with HIV should have a social and psychological review which includes a developmental, learning or progress screen within the first 2 months of engagement with an HIV service.
- Children and young people living with HIV should have access to regular screening to identify any changes to their psychological support needs and referred on for more comprehensive assessment and interventions with other services when it is required. This screening should happen annually or following events known to trigger or exacerbate psychological distress or cognitive difficulties.
- Onward referral to meet specific psychological needs will require knowledge of available local generic psychology services such as CAMHS, educational or neuropsychology as well as specialist paediatric or HIV psychology services and should include clear referral pathways and documentation about uptake and outcome.
- Older children and young people should also be regularly screened by the paediatrician for symptoms of depression, anxiety or stress disorders, and risk of self-harm, substance misuse as well as other behavioural or cognitive difficulties influencing health and wellbeing or capacity to consent or make health care decisions.
- Psychological assessment and therapy should be provided by practitioners who are appropriately trained and have demonstrated required competencies.

Standard 5:

Safe Antiretroviral prescribing - Effective Medicines Management

Children and young people living with HIV should be prescribed antiretroviral drugs by an appropriately qualified clinician and receive treatment and monitoring with such drugs that follows current CHIVA and PENTA guidance.

Quality statements

- Antiretroviral treatment should only be prescribed for children and young adults by a Paediatric HIV specialist.
- Antiretroviral prescribing competencies must be maintained on a continuing basis and there should be evidence of CPD in the clinician's appraisal process to ensure this requirement is met.
- Treatment should be prescribed in line with current CHIVA and PENTA guidelines.
- Information relating to HIV treatment for children and young people should be recorded alongside other medical conditions.
- Medication review should be undertaken at each clinic visit.
- Paediatric HIV services must include the involvement of a suitably trained pharmacist and engage in regular multi-disciplinary 'drug meetings' to review all antiretroviral and non-HIV medication taken by each child or young person. The frequency of drug meetings should be monthly to quarterly based on clinic frequency /and caseload.
- Paediatric HIV services have a duty to participate in regular monitoring of efficacy and safety of antiretroviral prescribing locally, regionally and nationally.
- All prescribing must be accompanied by appropriate psychosocial support and, children should be followed up in a paediatric clinic with experience of antiretroviral use.

Standard 6:

Adherence support

Children and young people with HIV who are prescribed antiretroviral drugs should receive individually-tailored support to assist them to achieve a high level of adherence to their medication regimen(s); this should be provided by appropriately experienced individual(s) within the multi-disciplinary paediatric HIV team.

Quality statements

- Current guidance on adherence should be followed: 'Protocol to Enhance Adherence' 2011
http://www.chiva.org.uk/files/1714/2858/0390/Protocol_to_enhance_adherence.pdf
- Guidance for young people on managing taking HIV medicine should be followed.
http://www.chiva.org.uk/files/7214/5207/8528/Guidance_for_Young_People_on_Managing_Taking_Medication.pdf
- There should be an identified individual (usually the Paediatric HIV Clinical Nurse Specialist) who will lead on work with families to provide information about drug treatment, prepare children and families for drug treatment, and arrange follow up.
- In centres supported by a Paediatric HIV pharmacist, they will also play an important role in leading treatment and adherence support.
- Before starting therapy, a plan needs to be made for pre-treatment discussion, starting treatment and follow up. This may be in clinic or at home, and with telephone contact. The voluntary services and peer support available should be utilised to promote adherence.
- Before starting treatment, there should be discussion with the family and multidisciplinary team to identify family beliefs around drugs and identify any issues regarding parental drug adherence (if appropriate). An assessment should be made about any issues within the child or family's life, which might impact on adherence (e.g. other members of the household not aware the child has HIV infection).
- There should be a contact plan for unexpected problems with adherence/ side effects, so that families are aware of how and when to seek advice in case of a

problem with medication occurring in or out of hours.

- Adherence to prescribed medication should be re-assessed at each contact or clinic visit. Ongoing access to adherence support within and outside the clinic setting should be offered throughout the duration of a child or young person's ARV therapy.
- Provision of adherence support should recognise that support will be required more intensively at certain stages, which are predictable: when starting treatment, for infants, toddlers, and adolescents, when changing antiretroviral medication and when changing formulation (e.g. liquids to tablets). Provision should also be made for unpredictable crises, which may or may not be related to drug treatment: parental illness, side effects, and social, housing and immigration issues etc.

Standard 7:

Talking to Children & Naming HIV Infection

In managing information-giving and naming of an HIV diagnosis to the child, the work should be undertaken as a process taking place over a period of time appropriate to the child's their age and level of understanding, and in partnership with the family. CHIVA statement on naming HIV to younger children should be followed: (http://www.chiva.org.uk/files/5614/5261/8934/CHIVA_statement.pdf) and associated practice guidance 'Talking to children about HIV in health settings' 2014 (http://www.chiva.org.uk/files/7914/7627/7970/Talking_to_children_about_HIV_in_health_settings-1.pdf)

Quality statements:

- There should be a multidisciplinary health team approach to talking to children with HIV about their health, in partnership with their carers. Where centres do not have access to the full multidisciplinary team, specialist advice and input should be sought through the CHINN network. When possible, carers and children should be connected with voluntary services and peer support to build skills and confidence in discussing HIV and health with family members.
- The lead worker should undertake an assessment of the child and family's needs around HIV. Assessing the child's readiness to have their HIV named to them should begin from the age of 6. It should focus on the child's own need for information and consider their capacity to understand it. Most children should have HIV named to them by the age of 9.
- From the assessment, an individualised plan should be developed for the care and support needed to enable the child to learn more about their health diagnosis.
- The naming plan should be reviewed and updated regularly.
- Children and young people should have ongoing explanations about their health relevant to their ongoing development and information needs.
- The majority of children should have had an open discussion about having HIV

during their primary school years. Consideration of an individual child's need to have HIV named should begin at the start of their schooling and be assessed on an individual basis. The majority of children should know they have HIV before they start secondary school. Where carers are reluctant to discuss HIV with their child, the child's needs and rights to health information should be the paramount consideration. Reasons underlying the carers' reluctance should be explored and addressed sensitively. Professional modeling of confidence around the children's need and right to know the name of their health condition is important.

- After telling the child that they have HIV, discussions need to continue to build upon the child's understanding of HIV and sexual health.
- Collaborative work with voluntary organisations and social care HIV specialist agencies that can support this work of building and establishing the child's understanding of HIV should be undertaken where possible.
- Evaluation of each child's level of understanding of their illness and the plan of naming should always be part of the multidisciplinary team meeting discussion.
- There should be clear and up-to-date documentation in the child's medical notes on the child's understanding of their illness pre- and post-naming, the naming plan and the name of the lead worker.
- All carers should be offered support and advice around how to talk with their child about their health condition and HIV. Consistent with WHO guidelines, this support should also encourage naming HIV to non-infected children.
- All children, young people and families should be encouraged to share their diagnosis to all their other healthcare professionals including their GPs, because ignorance of the HIV status may hamper the provision of effective healthcare and may put the child or young person at significant risk of harm (see GMC guidance, "Confidentiality: disclosing information about serious communicable diseases").
- Outside health, informing other professionals or individuals of a child's HIV diagnosis should only happen with the parents', and if age appropriate, the child's consent, and where it is in the child's best interest. There is no obligation to automatically inform any other institution, e.g. nursery or school, that a child has HIV.
- Members of the multi-disciplinary team should actively support families who decide to inform other professionals and should offer up-to-date information on HIV for

- The child's HIV diagnosis should not be shared with other professionals without the family's permission, except in exceedingly rare situations where children may come to harm if the family's confidentiality is not breached ([See guidance from the General Medical Council Confidentiality case study: Serious communicable diseases - Should a doctor override a patient's objection to disclosure of their HIV status?](#)). Such action should only be taken after consideration by the multi-disciplinary team.

Standard 8:

Sexual Health, Secondary HIV Prevention & Reproductive Health

Children and young people living with HIV should receive care that promotes and maintains good sexual health.

Addressing matters of sexual health, secondary HIV prevention and reproductive health should begin in paediatric services when appropriate to a young person's age and developmental stage, but in advance of the time at which they become sexually active, wherever possible.

Quality Statements

- Sexual health education and assessment should be part of the education and naming programme for young people with HIV and this should be delivered by appropriately trained individuals, ideally including a sexual health adviser. Young people must be provided with the opportunity to discuss sexual health without a carer present.
- The sexual health needs of young people with HIV positive and neurocognitive / learning difficulties or physical disability should be considered specifically and individually. Expert guidance should be sought where needed.
- Young people should expect to be taught how to protect themselves and others from acquiring sexually transmitted infections through collaboration with, and access to, specialist services for sexually transmitted infection.
- Young people with HIV should be made aware, sensitively but directly, of their legal position on HIV transmission and how to protect themselves from risk of prosecution. For further information, please refer to <https://chiva.org.uk/youth/hiv-facts/hiv-and-law/> Sexual health professionals and voluntary sector outreach services for young people should be utilised where appropriate and involved in the multidisciplinary care team wherever possible. Reference should also be made to Standard 7: Sexual Health and Secondary HIV Prevention in the BHIVA Standards of Care for Adults Living with HIV 2013 and also the HYPnet sexual health guidelines <http://www.hypnet.org.uk/pages/guidelines.php>

Standard 9:

Transition to Adolescent & Adult HIV Specialist Services

Adolescents and young people living with HIV should have an individualised care plan to transition them to adult services over time, as is appropriate to their age, developmental stage and social circumstance.

Quality statements

- Generic national guidance on transitional care should be followed (see web links below). Many hospital trusts will also have local transition procedures.
- Every young person should have an individualised plan for transition for each young person following CHIVA Transition guidance
<https://www.chiva.org.uk/guidelines/tr/>
- A lead for transition should be identified in both adult and paediatric services.
- Every young person should have a comprehensive paediatric discharge summary completed before transfer to adult services. This should include presentation, treatment history, immunological and virological response, drug resistance mutations, allergies including to antiretrovirals and adherence patterns, long-term toxicities, co-existing medical and psychological issues, and educational and family and social history. The summary should be discussed with the young person prior to transfer and they, the adult service and paediatric service, should have a copy.
- The views of adolescents and young adults should be represented in policy and on-going service developments. Services should refer to the national Children's Bureau report <https://www.ncb.org.uk/resources-professionals> and to the Treat Me Like This Youth guidelines
http://www.chiva.org.uk/files/1014/5079/3341/Guidance_for_Clinics_on_Transition.pdf
- Parents and carers should be supported in enabling young people to gradually achieve independence. Involvement of local patient groups and voluntary services should also be strongly encouraged to improve planning and provision of clinical care.

- Paediatric HIV services should actively work with adult services to ensure they are youth friendly and that cross-service support and liaison is available throughout the transition process to meet the needs of individual young people.

National Transitional Care Guidance

- Reference should be made to Transition from children to adults' services for young people using health or social care services, NICE guidelines [NG43] Published date: February 2016. <https://www.nice.org.uk/guidance/ng43>.
- Royal College of Paediatrics and Child Health (2003) The Intercollegiate Working Party on Adolescent Health. Bridging the gaps: health care for adolescents. <http://rcpch.adlibhosting.com/files/Bridging%20the%20Gaps%20-%20Health%20Care%20for%20Adolescents%202003-06.pdf>
- National service framework for Children Young People and Maternity Services (2004) <http://www.dh.gov.uk>
- Adolescent Transition Care. Guidance for nursing staff. Royal College of Nursing (2004) <http://www.rcn.org.uk>
- National service framework for long term conditions (2005) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198114/National_Service_Framework_for_Long_Term_Conditions.pdf
- You're Welcome quality criteria: Making health services young people friendly (2007) <http://www.dh.gov.uk>
- A transition guide for all services. Key information about the transition process for disabled young people (2007)
- Transition: moving on well (2008). <http://www.dh.gov.uk>

Standard 10:

Access to, and Competencies of, Multidisciplinary Specialist Paediatric HIV Team

Children and young people living with HIV should receive care overseen by a Consultant Paediatrician who is a specialist in HIV and provided by practitioners with appropriate competencies within a suitable and recognised governance and management structures.

Quality statements

- All members of the multidisciplinary team caring for children, families and pregnant women with HIV, should maintain up to date knowledge of this rapidly evolving field.
- All members of the MDT should have appropriate experience and training in safeguarding children.
- All members of the multidisciplinary team should regularly attend and participate in local and national CPD-accredited educational and training events (e.g. local CHINN meetings, biannual CHIVA / BHIVA / NHIVNA national meetings and other relevant meetings).
- Doctors, clinical nurse specialists and pharmacists leading a local MDT should have completed formal training in paediatric HIV care such as the PENTA/ESPID European training course for Paediatric HIV
<https://penta-id.org/education/trinforpedhiv/>
- The involvement of a multidisciplinary team is essential for the holistic care of infants, children and young people with HIV and their families. Issues which need to be specifically addressed for children with HIV and their families include adherence support, naming of HIV diagnosis to both the infected child and affected children within the family and transition to adult care.
- Paediatricians leading HIV services should be accredited or have an interest in paediatric infectious diseases or be appropriately experienced and trained in the management of children with HIV. The team should include support from:

paediatric and adult clinical nurse specialists, pharmacists, psychologists, physiotherapists, social workers and dieticians. In addition, access to expertise from paediatric speech and language therapy, occupational therapy, child development teams and community paediatric services should be available when required.

- There should be easy access to support and advice from social care and voluntary services.
- Some units may have few infected children but may care for an increasing local population of pregnant women with HIV. There should be an identified multidisciplinary team locally (including adult reproductive and sexual health / genito-urinary medicine, midwifery, obstetrics, Paediatrics and HIV clinical nurse specialist), with access to specialist advice from a wider multidisciplinary team (including specialist adult and paediatric HIV nurses and doctors) at a larger centre within the CHINN network. This wider team will be required particularly where there are complicating factors such as complex social problems, adherence issues, late booking, complications of pregnancy or multi-drug resistance (see 2.3 Standards of Care for Prevention of Mother-to-Child Transmission).
- In units where there is no 24hr paediatric infectious diseases or HIV consultant cover, access to protocols for the management of children with HIV must be available (examples are available on the CHIVA website: <http://www.chiva.org.uk/professionals/health/networks/index.html>). These should include simple guidelines for the assessment and treatment of HIV infected children, instructions on how to access notes or recent blood results, either locally or from the unit where the child's HIV care takes place, and principles of antiretroviral therapy. Guidance should be clear to any local clinician that 24-hour advice from the lead HIV care centre is always available; a contact phone / e-mail list should be actively maintained. These should be accessible and known to clinicians in all units.

Standards for staffing of units providing care for HIV-infected children

- The staff required for the care of children in families with HIV depends on the local case load which includes:
 - HIV infected children
 - Infants being born to pregnant women with HIV
 - The local adult HIV cohort. Centres must identify all the children of HIV positive adults and make sure that they have access to an HIV test

- Testing of other groups of children e.g. following the use of post-exposure prophylaxis or where testing is to be done in complex situations such as for looked after children or following sexual abuse.
- The original CHIVA Standards (2010) made specific staffing recommendations for different caseloads. As service configurations change, firstly in London and then outside London, these suggested staff to patient ratios may change. Pending such changes, suggesting staffing ratios from the 2010 Standards remain as a useful guide.

Table of suggested staffing of different cohorts

Cohort of children and young people	Required staffing	Minimum staffing levels (whole time equivalents)
Over 80	HIV consultants in paediatric infectious diseases	2
	HIV paediatric clinical nurse specialists	2
	Psychologist / mental health worker	1
	Pharmacist	1
	Dietitian	0.2 – 0.4
	Physiotherapist	0.2
	Data manager / service coordinator	1
30-80	HIV consultants in paediatric infectious diseases	1
	HIV paediatric clinical nurse specialists	1 – 2
	Psychologist / mental health worker	0.2 – 0.5
	Pharmacist	0.5
	Physiotherapist	0.2
	Data manager / service coordinator	0.5 – 1
Fewer than 30	HIV consultants in paediatric infectious diseases (or general Paediatrician with interest in infectious diseases)	0.5 – 1
	HIV paediatric clinical nurse specialists	0.5 – 1
	Psychologist / mental health worker	0.2
	Pharmacist	0.2

- In different centres the proportion of the case load may vary, some centres having more HIV infected children and others a larger adult cohort with more pregnancies etc. Working with the adult cohort and pregnant women is a very considerable part of the role of the paediatric HIV clinical nurse specialist.
- Staff to patient ratios for multi-disciplinary care in paediatric HIV units is difficult to stipulate but it must be recognised that the ratios required will be higher than for adult HIV services. In some centres, geographic and other factors may result in the need for much higher staff to patient ratios than the national average.
- Referral pathways for more specialist assessment or interventions e.g. neurocognitive difficulties need to be established in accordance with local or regional resources/ services.

Training for other Professionals

- Paediatric units caring for children and families with HIV should lead local training about HIV for all health, social care, and educational professionals coming into contact with families. This is very important as there continues to be stigma and misinformation surrounding HIV which may affect families, especially when seeing professionals other than the HIV team.
- Units should maintain a log of training sessions undertaken.

Standard 11:

National Surveillance & Audit Programmes

Services providing care for children and young people living with HIV should participate in national surveillance and audit programmes.

Quality statements

- All infants who are born to mothers with HIV should be reported to the National Study of HIV in Pregnancy and Childhood <http://www.ucl.ac.uk/nshpc/>
- Clinicians caring for children with HIV should report annually requested clinical data to the CHIPS cohort so that local parameters may be compared with national parameters (e.g. proportion of children on treatment, proportion of children with full viral suppression etc.) Local practices should be reviewed if there is a divergence of local and national parameters.
- Use of combination antiretroviral therapy during pregnancy should be reported to the International Antiretroviral Pregnancy Registry (APR). This Registry is important as it collates data on congenital abnormalities in infants born exposed to antiretrovirals in utero (www.apregistry.com). Although aggregated UK data from the NSHPC is sent to the APR, this is less detailed than the data which can be supplied directly by clinicians. Thus, to obtain optimal data on antiretroviral exposure in pregnancy, each local team should report to both the NSHPC and the APR.
- HIV-infected young people newly diagnosed over the age of 15 should be reported to the HIV and AIDS Reporting Section at the HIV and AIDS Reporting System (HARS) Public Health England (<https://www.gov.uk/guidance/hiv-surveillance-systems>)
- Clinicians caring for children with HIV should participate in local and national audits of HIV paediatric management and amend their local practices in the light of audit findings. This includes participating in the CHIVA annual audit programme.
- Clinicians caring for pregnant women with HIV should report every pregnancy to the National Study of HIV in Pregnancy and Childhood (<http://www.ucl.ac.uk/>

nshpc/) and should participate in local and national audits of HIV management in pregnancy, and amend their local practices in the light of audit findings.

- Significant antiretroviral, or other, drug toxicities should be reported through the national "Yellow Card" scheme to the Medicines and Healthcare products Regulatory Agency, MHRA <https://yellowcard.mhra.gov.uk/> and on CHIPS forms.
- Any serious untoward events such as an unexplained case of vertical HIV transmission should be reported through to the appropriate trust risk management scheme and a risk assessment undertaken. Learning points from such events should be disseminated to all the team members to improve care for the future.
- Network and local meetings should highlight any important clinical governance issues identified in relation to best care for children and families with HIV and instigate action plans where necessary to improve care.
- Professionals involved in looking after children with HIV should at least attend one meeting a year (CHIVA, regional or national network conference) to update their knowledge.

Standard 12:

Engagement & Involvement of Service Users, Non-HIV Specialists, Voluntary Organisations, Social Care and HIV in Schools

Children and young people living with HIV and their families / carers should have opportunities to be actively involved in decisions about to their healthcare. They should also have opportunities to be involved in their design, planning and delivery.

Families should be encouraged to consent to their GP, health visitor and dentist being informed about the diagnosis of HIV in a child in order that information about the child's health can be communicated and appropriate advice and care can be given in primary care.

All professionals working with children and families with HIV need to be aware of, and work within national and local child protection procedures <https://www.nspcc.org.uk/>

Where possible engage with voluntary sector organisations available who provide support and services for children and families with HIV

Clinical governance procedures and practices must be formulated and observed within each service, under the overall responsibility of the lead clinician.

Quality statements

Involvement of local service users

- Young people's input into service planning and evaluation should be actively solicited; where this is difficult, for example due to small numbers, their parents/carers and voluntary organisations can also be referenced as well as the opinions of young people with HIV from regional and national user organisations such as the CHIVA Youth Committee <http://www.chiva.org.uk/about/who/youth.html>.
- Expert patient programmes for young people and parents should also be encouraged.

Involvement of health and wider services in paediatric HIV service planning and provision

- GPs and the primary health care services should be actively engaged in the care of children and families with HIV, incorporating annual mapping of referral pathways to paediatric HIV services.
- Strong links should be established with the commissioners responsible for the whole HIV pathway (HIV prevention and care and support) and HIV treatment and care.

Working with community and primary care services

- Appropriate information and contact details should be given to the family by the hospital paediatric team caring for the child in order to aid easy communication and allow advice to be easily sought. This is especially important because the degree of knowledge of paediatric HIV varies amongst health care professionals.

Joint working with social care

- When a child is diagnosed with HIV, there should be a holistic assessment of the needs of the child, including the need for referral and assessment by social care, who may be able to provide appropriate support for the child and family as a child in need.
- In larger centres there may be a member of the multidisciplinary team from social care who will be introduced to the family as part of the team. Where social care is not integrated within the MDT, assessment of families' social care needs should be discussed within the MDT and appropriate referral made with consent from the family.

Safeguarding

- Professionals working with children and families with HIV should foster close links with local safeguarding teams to allow advice and discussion of difficult situations at an early stage.
- Difficult cases regarding specific issues such as parental beliefs about HIV, consent to testing or treatment for children, and education and naming of HIV to children, should be discussed within the multidisciplinary team and CHINN network. Voluntary and social services working with the family should be involved in these

discussions. Appropriate discussion may take some time before progress on resolving the issue can be made. However, a time-limit must be agreed for each case within the multidisciplinary team when the case should be escalated to the safeguarding team and social care or legal input as indicated. Excellent multidisciplinary documentation must be maintained in such complex cases.

- Where there is a significant risk to the health of a child which cannot be addressed by in-depth multidisciplinary discussion with the family then a discussion with local safeguarding leads as part of the local Trust safeguarding procedures will need to take place and subsequent referral to social care under child protection/safeguarding procedures may be needed. This may arise where a child is unwell and consent is not given for appropriate diagnostic tests or treatment, or where the child is under 1 year when there is urgency to test because of the risk of rapid disease progression or opportunistic infection.
- Safeguarding issues are complex and should be discussed with Lead Centres within the local paediatric HIV network and with local Paediatricians with expertise in child protection.
- Local legal teams may need to be involved and advice sought.
- Appropriate consideration needs to be given to the need for wider disclosure of HIV diagnosis to other professionals. This should be done only in the best interest of the child and usually with parental consent. It should be explicit that not all professionals dealing with the family need to be aware of the HIV diagnosis.

Third Sector groups – partnerships with voluntary agencies

- Units caring for children and families with HIV should be aware of these services and provide information to families, so that they can access these services if they wish, see CHIVA website:

<https://www.chiva.org.uk/professionals/resources/guidance-service-development/>

Units should have specific referral pathways in place. Families may initially not wish to engage with outside agencies, but this should be readdressed at intervals.

- Peer support for families should be encouraged as it can be highly effective in helping them to gain knowledge and confidence in the management of their HIV. Peer support helps families and young people escape isolation, renew and strengthen their self-esteem and become partners with services in treatment and care decisions. Many organisations can be engaged to encourage positive living, with life skill training to support positive self-management.
- Mapping of referral pathways to the voluntary sector for e.g. peer support and wider HIV-related support provision should be maintained to provide updated and accurate information about services when required.
- CHIVA national support camp should be discussed with all families of eligible children (living with HIV aged 11-16) families should be supported to consider this peer support and HIV education opportunity for their child. Refer to information on the CHIVA website to support these discussions.

HIV in Schools

- School needs to be a place where it is safe to be living with HIV and where families feel safe to share this information. An HIV-friendly school can be achieved through a holistic approach that promotes a caring, supportive and inclusive environment. As those with HIV fear negative judgements, direct reference to HIV in school' policy documents and other relevant communications with parents/carers (along with other health conditions) will ensure that all those in the school community are aware of the school's position in wanting to support a child living with or affected by HIV.

http://www.chiva.org.uk/files/9114/4976/8872/HIV_in_Schools.pdf

- It is important that all staff discuss, and are aware of, the procedures for HIV disclosure, before it happens. This presents the opportunity to: ensure that staff's HIV knowledge is up-to-date; reassure staff by repeating information about routes of transmission; and firmly establish the need for confidentiality. It may be helpful to get support from a local health promotion unit, health advisors from local sexual health clinics, or a local paediatric infectious diseases nurse or doctor. (HIV in Schools; A good practice guide to supporting children living with and affected by HIV)

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Glossary of terms and abbreviations

Adherence: The extent to which a patient's action matches the agreed recommendations. Non-adherence may limit the benefits of medicines, resulting in lack of improvement or deterioration and the emergence of drug resistant strains of HIV.

Adherence support: Mechanisms and interventions that help families match the agreed interventions, allowing the child or young person to take the correct dose of the correct drug at the correct time.

AIDS (Acquired Immunodeficiency Syndrome): A clinical syndrome, characterised by a susceptibility to a number of infections and malignant conditions, which is the result of the immune system damage caused by HIV.

Amplification of the virus genome: The production of multiple copies of a particular gene – used in the diagnosis of HIV infection, particularly in babies and children less than 18 months of age, who also have maternal HIV antibodies which cross the placenta.

Antiretroviral therapy (ART, ARVs, HAART): Drugs, usually taken in combination with each other that suppress the activity of HIV by inhibiting viral replication.

Antiretroviral Pregnancy Registry: An international registry that collates data on congenital abnormalities in infants born exposed to antiretrovirals in pregnancy – www.apregistry.com.

BHIVA: British HIV Association – information at www.bhiva.org.

CAMHS: Child and Adolescent Mental Health Services – NHS provided services for children in the mental health arena in the UK.

CCT: Certificate of Completion of Training (formerly CCST, Certificate of Completion of Specialist Training). Advanced post-graduate qualification in an individual specialty typically completed 5 or more years after qualifying as a medical practitioner. Ordinarily required for entry to the Specialist Register, which is in turn required for eligibility to apply for NHS consultant posts.

CD4 Cells / CD4 Count: The class of white blood cells known as CD4 T-helper lymphocytes which are the target cells for HIV infection and subsequent damage. The CD4 count is the number of these lymphocytes in the blood.

CHINN: Children's HIV National Network.

CHIPS: Collaborative HIV Paediatric Study – national annual clinician reported data on HIV parameters in all HIV infected children and young people allowing comparison of local and national parameters.

CHIVA: The Children's HIV Association – information at <https://www.chiva.org.uk/>

Clinical governance: A systematic approach to maintaining and improving the quality of patient care within a healthcare system.

CMV: Cytomegalovirus – a viral infection that is associated with HIV infection.

Cognitive: The mental process of knowing including aspects such as awareness, perception, reasoning and judgement.

Cohort: A group of people (children or young people) who have a disease – in this case HIV infection.

Continuing Professional Development (CPD): An ongoing commitment to learning in various forms, which maintains knowledge and skills, and which enhances professional standards of work. This is an obligatory component of most professions.

Consultant: Except where nurse consultants are mentioned explicitly, the word 'consultant' is used in this document to refer to medical consultants.

Designated: A specified place or person that is identified for a certain purpose of responsibility.

DoH: Department of Health.

Epidemiological surveillance: Continuously gathering, analysing and interpreting data about diseases such as HIV and disseminating the conclusions of the analyses to relevant organisations.

Drug interaction: A situation in which a substance – often another drug – affects the activity of a drug ie. the effects of the drug may be increased or decreased or a new effect may occur that neither drug produces on its own.

ESPID: European Society for Paediatric Infectious Diseases – information at www.espid.org.

GU or GUM: Genitourinary medicine – the medical specialty relating to the diagnosis and management of sexually transmitted infections (including HIV) and other genital conditions in men and women.

HAART: Highly Active Antiretroviral Therapy.

HIV: Human immunodeficiency virus.

HIV antibody test: The standard initial test for HIV infection in adults and children over the age of 18 months, which detects the presence of antibodies to HIV in the blood.

HIV drug resistance: The ability of HIV to overcome the drugs used in its treatment.

HIV encephalopathy: HIV associated Central Nervous System pathology leading to structural damage of the brain and / or impaired function or development in children.



CHILDREN'S HIV ASSOCIATION

HIV network: A collaboration between network providers to ensure children and young people living with HIV have equity of access to appropriate care - in paediatric HIV the networks exist in the form of CHINN – the Children's HIV National Network.

HIV prevalence: The number of cases of HIV infection in a given population at any one time.

HIV resistance mutations / assay: A test to identify the presence of changes within the genetic make-up of HIV which can lead to drug resistance.

HPA: Health Protection Agency – information at <http://www.hpa.org.uk>.

Infectious Diseases (ID): The branch of paediatrics that specialises in the diagnosis and management of infectious diseases.

Immune reconstitution syndrome: In some cases of HIV associated immunosuppression, the immune system begins to recover in response to treatment but then responds to a previously acquired opportunistic infection with an overwhelming inflammatory response, making the symptoms worse.

Immunosuppression: A reduction in the activity or effectiveness of the immune system, leaving the child or young person more susceptible to a range of infections.

JCHMT: Joint committee on Higher Medical Training, which oversees medical training and works with specialist advisory committees for each specialty to develop their curricula for training leading to CCT.

Mother to child transmission / Vertical transmission: The transmission of an infection or other disease from a mother to her child.

MRCOG: Membership of the Royal College of Obstetrics and Gynaecology (basic post-graduate qualification typically completed 2 years after qualifying as a medical practitioner).

MPRCP: Membership of the Royal College of Physicians (basic post-graduate qualification typically completed 2 years after qualifying as a medical practitioner).

Multidisciplinary team (MDT): A group of representatives from several different professional backgrounds and areas of expertise. The membership should include key professionals who will contribute to improving and maintaining health for the patient population being served. Members may not all be in the same place at the same time and may operate within a virtual network.

Naming of HIV infection (previously Disclosure): Children and young people should have ongoing discussions about their health condition appropriate to their age and level of understanding, aiming for most children to have had HIV named to them before they are 9.

Neonatology: The branch of paediatrics that deals with the care, development and diseases of the newborn infant.

NHIVNA: National HIV Nurses - <https://www.nhivna.org/>

NSHPC: National Study of HIV in Pregnancy and Childhood. This is a confidential national (UK and Ireland) reporting scheme for pregnancies in women who are HIV positive and for babies born to HIV positive women and other HIV positive children.

Onward transmission: When a virus / infection is passed on from one individual to another.

Opportunistic infection: An infection that will usually only occur in a child or young person with a compromised immune system.

PCT: Primary Care Trust.

Peer support: Peer support is a supportive relationship in which people who share something come together, this may be having the same health condition or coming from a similar community. Peer support is based in the belief that relationships with shared experiences are often a helpful context in which to receive social and emotional support with a focus on learning and growth.

PENTA: Paediatric European Network for the Treatment of AIDS – a collaboration between paediatric HIV centres in Europe, which leads clinical research into the treatment of HIV infection in childhood.

Perinatally infected: An infection, caused by a bacteria or virus, that has passed from a mother to her baby during pregnancy or delivery.

PMETB: Postgraduate Medical Education and Training Board – a statutory body which promotes, sets and enforces standards for medical training.

Polypharmacy: The use of multiple medications by a child or young person.

Post Exposure Prophylaxis (PEP): Immediate HIV therapy, started within 72 hours and usually continued for 4 weeks, following a high-risk HIV exposure, including birth to an HIV positive mother. The aim is to reduce the risk of acquiring HIV infection.

Primary pneumocystis pneumonia (PCP): A serious pneumonia caused by *Pneumocystis carinii* which is associated with HIV infection and can be rapidly fatal in undiagnosed or untreated infants with HIV infection. Prophylaxis against PCP can be given as the antibiotic Septrin (Cotrimoxazole).

Prophylaxis: Treatment that is given to prevent the occurrence of an infection.

Protocols: Detailed plans of medical treatments, procedures or experiments.

Psychosocial: Relating to the combination of psychological and social behaviour.

Safeguarding procedures: Procedures that protect children from maltreatment, prevent impairment of children's health and development and ensure that children grow up in circumstances consistent with the provision of safe and effective care.

Serious untoward event / incident (SUI): An event which is out of the ordinary or unexpected with the potential to cause harm and / or attract public or media interest.

SHA: Strategic Health Authority.

Stepped care model: A model with four essential levels of psychological support provision for people living with HIV, based on levels of need.

STI: Sexually transmitted infection.

Stigma / Stigmatised disease: The prejudice, negative attitudes, abuse and maltreatment that is directed towards some people and families living with HIV.

Tertiary care: Specialised consultative care, usually on referral from primary or secondary care personnel, by specialists working in a centre that has personnel and facilities for special investigation and treatment.

Third trimester: The last 12 weeks of pregnancy.

Transition: The purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centred to adult-orientated health care systems.

TB: Tuberculosis – an infection due to *Mycobacterium tuberculosis* which is associated with HIV infection.

Viral load (VL): The quantity and activity of HIV in a child or young person's blood, usually measured by a test that determines the number of copies per ml.

Virtual clinic: Provision of expert advice by a multidisciplinary panel of experts from a specialist treatment centre on the therapeutic treatment options for a child or young person by a clinician at the same or different centre via on-line and other ICT-based remote management systems.

Yellow card scheme: The UK system for collecting information on suspected adverse drug reactions to medications.