

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

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Section 1-Background to HIV infection in children in the UK - 2009

UK Paediatric HIV Population

In the UK there are currently around 1300 children infected with HIV. Approximately half of these children have been born abroad and the median age of the cohort is around 11 years. All children diagnosed with HIV in the UK are reported to the NSHPC (National Study of HIV in Pregnancy and Childhood) and are followed up as the CHIPS cohort (Collaborative HIV Paediatric Study). The data set on these children is updated annually, thus CHIVA have excellent current information on the epidemiology of paediatric HIV in the UK as well as annual updates on case management. Recent mathematical modelling (2009) of the UK paediatric HIV population growth over the last 5 years by the CHIPS team has demonstrated a nationally relatively stable population number for the next 5 years ahead (for further information contact www.chipscohort.ac.uk) with relatively equal numbers of new patients entering the cohort as older children transition to adult care.

The vast majority of children with HIV in the UK are infected through mother-to-child transmission. Approximately 50% of infected children currently live in and around Greater London, and the proportion living elsewhere in England is growing, there are smaller cohorts in Ireland, Scotland and Wales. Overall mortality among children with HIV has reduced considerably since the introduction of highly active antiretroviral therapy (HAART). High uptake of antenatal testing, reduced transmission rates from diagnosed women, improved survival following 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 or Ireland continues to rise.

HIV has become a chronic condition of childhood with the likelihood of survival well into adult life; therefore, development of appropriate services for long term paediatric survivors has become an important goal for the 21st century.

New Cases of Paediatric HIV

Unfortunately, there are still a small number of perinatally HIV infected children diagnosed in the UK each year (less than 1-2%) who 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 during their presenting illness before it is possible to start them on combination therapy. Older children and young people presenting with very advanced HIV and exceedingly low CD4 counts, usually from abroad are also at risk of death from opportunistic infections prior to starting combination therapy, however, these numbers remain relatively small. Both of these high risk groups of children require a high input of complex medical care to treat their opportunistic infections and to establish antiretroviral therapy with concomitant difficulties of poly-pharmacy, drug side-effects and the risk of immune reconstitution syndromes.

Infants born to Mothers with HIV

Over 1200 births per year to women diagnosed with HIV in or before pregnancy are reported annually to the 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 (e.g. planned caesarean section); post-exposure prophylaxis to the infant; and formula feeding. A very small number of infants born in the

UK now acquire vertically transmitted HIV (approximately 30-40 per year) with around 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 and/or have had inadequate treatment. If these babies are diagnosed with HIV prior to the onset of opportunistic infections, they can be started on combination antiretroviral therapy and PCP prophylaxis and, as a result, the risk of rapid progression of disease is reduced by 75% or more.

Significant efforts via national 'opt out' strategy to optimise antenatal testing for HIV over the last 10 years have resulted in more than 95% of pregnant women in the UK being tested antenatally. However, 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 should receive good sexual health information in pregnancy, to avoid the risk of acquiring HIV. Any woman who has refused the antenatal HIV test offer should be encouraged to reconsider her decision, and rapid testing should be available in the antenatal clinic for late booking women as well as on the labour ward for untested women. In areas of increased HIV seroprevalence the possibility of third trimester repeat testing for negative women should be considered.

Efficacy of Treatment for HIV in Children

Combination therapy is extremely effective for the management of paediatric HIV. In the CHIPS cohort more than three-quarters of children on 1st line HAART have full viral suppression, but this requires a high level of adherence (>95% of doses). Treatment of children is complex, as appropriate formulations for babies, toddlers, young and older children are not always available. 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 drug levels may be required.

Supportive management for children on long term HAART is complex and requires long term endurance from children, their carers and the treatment team. Effective support for adherence requires a multi-disciplinary approach. Children require developmental / age appropriate knowledge about HIV and its management. The process of learning about HIV is a key area in the management of children and families, and education about HIV must be undertaken sensitively and carefully over time, to enable children living with this infection (a stigmatised disease) to develop and maintain high self-esteem and self-knowledge prior to transition from paediatric into adolescent and ultimately adult care.

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 health professionals in the management of children and families with HIV. CHIVA has developed a website (www.chiva.org.uk) where healthcare professionals can access information and guidance on the management of most of the common problems that occur for children with HIV. CHIVA is now expanding the role of the website to develop a site for young people and their parents so that peer support can be encouraged.

The Children's HIV National Network (CHINN) was inaugurated in 2005. CHINN was established to formalise a support network of specialist expertise to colleagues who may

be caring for only a few children. Local providers who are part of regional Networks have been allocated a lead centre to engage with if an HIV child presents. The 3 specialist centres, all based in London are St George's, Imperial College Healthcare Trust and Great Ormond Street Hospitals. For more detail on Network arrangements please refer to Appendix.

The CHIVA Standards of Care for Children with HIV

The CHIVA Standards of Care for Children and Young People with HIV and for Infants Born to Mothers with HIV will delineate the following:

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

These standards, assume that all care should follow the basic tenets of the "National Service Framework for Children and Maternity" (www.dh.gov.uk) and "Every Child Matters" (www.everychildmatters.gov.uk). 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.

Section 2 - Best care of HIV infected children & best practice for prevention of mother to child transmission

2.1 – Standards of care for HIV testing and diagnosis

1. 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 (www.bhiva.org).
2. Women who decline antenatal HIV testing should be encouraged to review this decision and should be referred to a specialist midwife for further discussion.
3. Women who present late in pregnancy or in labour without having had an HIV test should be recommended to have a rapid HIV test.
4. Where babies are born to mothers who have declined an HIV test in pregnancy, the parents or carers should be strongly recommended to have the infant tested as soon as possible after birth.
5. All children at risk of HIV infection should be recommended to have an HIV test according to the National HIV testing guidelines 2008 (www.bhiva.org)
6. 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 prophylaxis against PCP and antiretroviral treatment to reduce the risk of HIV disease progression.

7. Units must have a local policy of how HIV testing is managed, how results are given to families, and how support is organised when children are found to be infected.
8. Adequate multi-disciplinary support for families where an infant or child has a positive HIV test must be provided.

2.1.1- Blood tests for the diagnosis of HIV in babies and children

1. Diagnosis of HIV infection in children over the age of 18 months is by an HIV antibody test, as for adults.
2. Diagnosis of HIV infection in infants requires amplification of the virus by DNA or RNA PCR or other amplification methods. This is because all infants born to mothers with HIV will have transplacentally acquired maternal antibody which can be detected in the infant up to 18 months of age
3. Positive HIV test results should always be confirmed with repeat testing.

2.2 – Standards of care for HIV disease management

1. More than half of all HIV-infected pregnant women are aware of their infection before conception. Early attendance for antenatal care should be encouraged to facilitate optimal management.
2. 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 (www.pentatrials.org)
3. CHIVA treatment pathways for infants, children (1-12 years), and adolescents should be followed. The appropriate pathway for a child at any one time, whether standard or complex, will depend on: the age of the child; the level of immune suppression; the treatment required; the developmental status; and the complexity of the social circumstances (see appended pathways).
4. All infants (less than one year) diagnosed with HIV should be started urgently on anti-retroviral treatment due to their risk of rapid disease progression.
5. For children over one year of age, the need for anti-retroviral treatment is dependant on HIV symptoms, CD4 count and viral load (See PENTA guidelines www.pentatrials.org).
6. Children presenting with symptomatic HIV require urgent appropriate management
7. Appropriate therapy is according to the age and weight / surface area of the infant / child.

8. 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 network.
9. Expert paediatric pharmacy support for clinicians treating children with HIV should be available locally or via the CHIN network.
10. Expert virological support for clinicians treating children with HIV should be available locally or via the CHINN.
11. 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 regime.
12. Where appropriate families and children should be offered the opportunity to participate in PENTA or other antiretroviral treatment trials.
13. Treatment for opportunistic infections should follow protocols for opportunistic infections found on the CHIVA website
<http://www.chiva.org.uk/health/guidelines/treating-oi>.
14. Clinical management of children with HIV should be in line with guidelines available on CHIVA website <http://www.chiva.org.uk/health/guidelines>. These include:
 - a. Baseline and routine follow up investigations for HIV in infants / children
 - b. Guidelines for many common presenting syndromes
 - c. Appropriate immunisation schedules for children with HIV
 - d. Protocols to enhance adherence, including how to help young children learn to swallow pills.
 - e. Advice on monitoring developmental progress and outcomes in children with HIV.

Pathways of Care for Children and Young People with HIV

1. 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.
2. A multidisciplinary team is required to care for children and adolescents with HIV.
3. The team should include support from: paediatricians; specialist nurses, pharmacists, psychologists, physiotherapists, social workers, and dieticians.
4. The team should meet regularly to plan and review the progress of children under their care.
5. 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 bodies; and any other team / clinicians involved in the care of children and families with HIV.

6. Where possible, combined outpatient family care should be offered so that parents and children can be treated within the same clinic visit.
7. Services must take account of the psychological and cognitive developmental needs of infants, children and young people, and undertake developmentally appropriate support for: learning about HIV; coping with living with HIV; as well as coping with death and loss within the family.
8. An individual transitional care plan should be developed for each young person to facilitate a smooth, timely and appropriate transition from paediatric to adult care (see transitional care guidelines on the CHIVA website (www.chiva.org.uk)).
9. Paediatric services must liaise closely with adult multidisciplinary HIV services and a lead for transitional services should be identified.
10. Services for young people born with HIV should be developed according to the “HIV Young Person’s Network” (HYPNet) guidelines (available via the CHIVA website (www.chiva.org.uk)).
11. 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; family circumstances; educational progress etc.

2.3 – Standards of care for Prevention of mother to child transmission

1. The management of HIV in pregnancy and the perinatal period should follow the current version of the British HIV Association (BHIVA www.bhiva.org) guidelines which give 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.
2. To optimise the prevention of mother to child transmission of HIV, a multidisciplinary team including midwifery, obstetrics, adult GU/Infectious Diseases, neonatology and paediatric infectious diseases is required.
3. The team should meet regularly to plan for the progress of all the pregnancies under their care.
4. 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.
5. Appropriate planning of interventions including combination antiretroviral therapy, 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.

6. Units caring for HIV infected pregnant women should follow the recent recommendations of the national audit of infants born to mothers of infected infants born in the UK between 2002 and 2005 (www.nshpc.ucl.ac.uk).
7. All Trusts, which provide care for HIV infected pregnant women, should have a designated HIV lead for midwifery, obstetrics and paediatrics.

2.4 – Standards of care for Reporting of cases

1. All infants born to mothers with HIV should be reported to the National Study of HIV in Pregnancy and Childhood (www.nshpc.ucl.ac.uk).
2. Use of combination antiretroviral therapy during pregnancy should be reported to the International Antiretroviral Pregnancy Registry. 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 complete than the data which can be supplied directly by clinicians). So, to obtain optimal data on antiretroviral exposure in pregnancy each local team should report to both the NSHPC and the APR.
3. All children diagnosed with HIV should be reported to the NSHPC. Subsequent to this HIV infected children will enter the CHIPS cohort and clinicians will be requested to complete an annual follow-up on the child, detailing growth, development, HIV symptomatology, HIV treatment, HIV viral load and CD4 counts and adverse events (www.nshpc.ucl.ac.uk, www.chipscohort.ac.uk).
4. HIV infected young people newly diagnosed over the age of 15 should be reported to the HIV and AIDS Reporting Section at the HPA (www.hpa.org.uk)

2.5 – Standards of care for Post-exposure prophylaxis beyond the neonatal period

1. Children may be exposed to HIV accidentally through blood exposure, e.g. needle stick, or sexually via consensual or non-consensual sex. Post-exposure prophylaxis, where appropriate, should be made available to children and young people according to the current version of the CHIVA guidelines (www.chiva.org.uk).
2. Treatment must be accompanied by appropriate psychosocial support and ideally, children should be followed up in a paediatric clinic with experience of antiretroviral use.

2.6 – Standards for Clinical Governance and audit of Local and National Practice

1. 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 practises should be reviewed if there is a divergence of local and national parameters.
2. In any clinic cohort, at least 75% of children on first line combination antiretroviral therapy should have fully suppressed viral load after 12 months.

Clinicians caring for children with HIV should participate in local and national audits of HIV paediatric management, and amend their local practises in the light of audit findings. This includes participating in the CHIVA annual audit programme. Clinicians caring for pregnant women with HIV should participate in local and national audits of HIV management in pregnancy, and amend their local practises in the light of audit findings.

3. Significant antiretroviral, or other, drug toxicities should be reported through the national “Yellow Card” scheme to the Medicines and Healthcare products Regulatory Agency (MHRA) (www.mhra.gov.uk).
4. Any serious untoward events 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.
5. 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.

2.7 – Standards for Acquiring, Maintaining and Updating HIV knowledge

1. 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
2. All members of the multidisciplinary team should regularly attend and participate in local and national CPD accredited educational and training events (e.g. London CHIVA meetings, local network meetings, bi annual CHIVA / BHIVA / NHIVNA national meetings etc).
3. Doctors, clinical nurse specialists and pharmacists leading a local MDT should have completed the PENTA/ESPID European training course for Paediatric HIV “Tr@informedHIV” (www.pentatrials.org)

Section 3 - Multi-disciplinary team and multi-agency working for families with HIV

3.1 General Principles

The expertise of adult HIV physicians is invaluable, and essential for the smooth transition in the adult setting. However paediatricians should lead the holistic care required for children growing and developing with HIV. Care must be family centred and close collaboration with adult HIV services and antenatal services are essential.

1. 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, disclosure of HIV diagnosis to both the infected child and affected children within the family and transition to adult care.
2. Hub services should be led by a paediatric infectious diseases consultant. Spoke / local services may be led by a general paediatrician with a special interest in HIV. The team should include support from: specialist paediatric nurses, 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.
3. There should be easy access to support and advice from social care services.
4. In Lead / Hub HIV Care Centres it would be expected that all the members of the multidisciplinary team are located in one centre. However for smaller units the complement of the team will vary. All units should have a lead paediatrician and nurse, with access to local paediatric support services and easy access to a Networked specialist HIV Centre with multidisciplinary team services
5. 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 GUM, midwifery, obstetrics, and paediatrics), 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 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 pregnancy and prevention of MTCT).
6. 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; www.chiva.org.uk). 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 actively maintained. These should be accessible and known to clinicians in all units.

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

The number of staff required for the care of children in families with HIV depends on the local case load which includes:

- 1) HIV infected children
- 2) Infants being born to pregnant women with HIV
- 3) 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.
- 4) 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.

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.

A range of patient numbers is given for each centre (this is dependent on the number of patients not the case mix), the number of Staffing and outpatient clinics required will need to be adjusted accordingly

As part of the commissioning process, HIV care centres within the CHIN Network will be designated appropriately as **Lead Hub, Regional Hub, Spoke or Local** HIV care centres. Appropriate staffing levels for centres are described below. A few larger London spoke Centres have evolved with larger numbers of patients than described below and staffing levels should be appropriate for the numbers of patients. This may be more in line with staffing levels described for Regional Hub units.