CHILDREN'S CHIVA HIV ASSOCIATION

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

1.1 UK Paediatric HIV Population

In the UK there are currently around 1300 children infected with HIV. Approximately half of these children were 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 dataset 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 predicted a nationally relatively stable population number for the next 5 years (for further information contact www.chipscohort.ac.uk) with equal numbers of new patients entering the cohort as older children make the 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 and 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.

1.2 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 cell 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.

1.3 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 the 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 HIV-negative women should be considered.

1.4 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 first-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.

1.5 Children's HIV Association (CHIVA) and 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 with which to engage if an HIV-infected child presents. The three 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 the Appendix.

1.6 The CHIVA Standards of Care for Children with HIV

These CHIVA Standards of Care are for infants, children and young people infected with HIV and for infants born to mothers with HIV. They 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 and 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 they 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.
4. All infants (less than 1 year) diagnosed with HIV should be started urgently on antiretroviral treatment due to their risk of rapid disease progression.
5. For children over 1 year of age, the need for antiretroviral treatment is dependent on HIV symptoms, CD4 cell 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 CHINN.
9. Expert paediatric pharmacy support for clinicians treating children with HIV should be available locally or via CHINN.
10. Expert virological support for clinicians treating children with HIV should be available locally or via 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 regimen.
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 www.chiva.org.uk.
14. Clinical management of children with HIV should be in line with guidelines available on the CHIVA website (www.chiva.org.uk). These include:
    - Baseline and routine follow-up investigations for HIV in infants/children;
    - Guidelines for many common presenting syndromes;
    - Appropriate immunisation schedules for children with HIV;
    - Protocols to enhance adherence, including how to help young children learn to swallow pills;
    - Advice on monitoring developmental progress and outcomes in children with HIV.

2.2.1 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 dietitians.
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) 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 (www.bhiva.org).
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 report *Perinatal transmission of HIV in England 2002–2005* (www.chiva.org.uk/health/publications/perinatal) (the full report is available only via the NHS computer network at www.esussexaiau.nhs.uk/docs/specialised/verticaltransmissionfullreportoctober2007.pdf).
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 must 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 can 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 must 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 cell 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 practices should be reviewed if there is a divergence of local and national parameters.
2. In any network cohort, at least 75% of children on first-line combination antiretroviral therapy should have fully suppressed viral load after 12 months.
3. 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.
4. Clinicians caring for pregnant women with HIV should participate in local and national audits of HIV management in pregnancy, and amend their local practices in the light of audit findings.
5. 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).
6. Any serious untoward events should be reported 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.
7. 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, biannual 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@inforpedHIV" (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 is 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 dietitians. 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 the 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* 2.3 *Standards of care for prevention of mother-to-child transmission*).
6. In units where there is no 24-hour paediatric infectious disease 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, and a contact phone/e-mail list should be 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 staff and outpatient clinics required will need to be adjusted accordingly.

As part of the commissioning process, HIV care centres within CHINN 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.

Staffing, structure and function of HIV centres for children

Provider	Cohort of patients	Team	Outpatient Clinics	Network Clinics	Inpatients	Research & Development	Audit	Patient User Participation
Lead Hub Centre	More than 100 HIV-infected children in follow-up More than 30 infants born to HIV-positive mothers per year Has an associated adult HIV cohort of > 2000 patients	2 WTE HIV paediatric infectious disease consultants (including lead clinician for the network) 2–3 WTE paediatric HIV clinical nurse specialists 0.2–0.4 WTE dietitian 1 WTE psychologist 1 WTE pharmacist 0.2–0.4 WTE physiotherapist 1 WTE data manager/ coordinator	At least 2 one-stop MDT clinics per week with support from the adult HIV team for adult patients	Outreach support for linked local clinics	Referral centre for patients from the network with major infections, organ disease, complex opportunistic infections, management of complex drug treatments/ side effects	Active role in the development and review of clinical protocols as well as in translational research to improve HIV clinical care	Active in delivering national CHIVA audit cycle and maintenance of the audit cycle of services for local CHINN	Engagement with patients, families and carers to ensure services based on needs – patient satisfaction surveys/age-appropriate focus groups etc.
Regional Hub Centre (A few larger London spoke centres will require levels of staffing equivalent to regional hub centres depending on patient numbers)	25–99 HIV-infected children in follow-up More than 20 infants born to HIV-positive mothers per year Has an associated adult HIV cohort of > 1000 patients	1 WTE HIV paediatric infectious disease consultant (including lead clinician for the network) 1–2 WTE paediatric HIV clinical nurse specialists 0.5 WTE psychologist 0.2–0.5 WTE pharmacist 0.5–1 WTE data manager/ coordinator	1–2 one-stop MDT clinics per week with support from the adult HIV team for adult patients	Possible outreach support for linked local clinics	Referral centre for patients from the network Major infections and organ disease should be discussed with London Lead Centre	Active role in the development and review of clinical protocols as well as in translational research to improve HIV clinical care	Participate in CHIVA audit cycle and lead some audits for local CHINN	Engagement with patients, families and carers to ensure services based on needs – patient satisfaction surveys/age-appropriate focus groups etc.
Spoke Centre (A few larger London spoke centres will require staffing levels equivalent to regional hub centres)	10–25 HIV-infected children in follow-up More than 10 infants born to HIV-positive mothers per year Has an associated adult HIV cohort of 500–1000 patients	0.5 WTE HIV paediatric infectious disease consultant or general paediatrician with interest in infectious diseases 0.5–1 WTE paediatric HIV clinical nurse specialist 0.2 WTE psychologist 0.2 WTE pharmacist	0.5–1 one-stop MDT clinics per week with support from the adult HIV team for adult patients	Possible joint local clinics with network or lead centre 2–4 times per year	Inpatients may be managed locally, in liaison with regional hub/ London Lead Centre Severe infections or other complex problems should be referred to regional hub/ London Lead Centre	Participate in network lead projects	Participate in CHIVA audit cycle and local network audits	Engagement with patients, families and carers to ensure services based on needs – patient satisfaction surveys/age-appropriate focus groups etc.
Local Centre	Up to 10 HIV-infected children in follow-up Up to 10 infants born to HIV-positive mothers per year Has an associated adult HIV cohort of up to 500 patients	Named paediatrician with interest in infectious diseases 0.5–1 WTE paediatric HIV clinical nurse specialist	One paediatric clinic every 2–4 weeks with support from adult HIV team for adult patients	Possible joint clinic with network/lead centre 2–4 times per year	Inpatients may be managed locally, in liaison with regional hub/ London Lead Centre Severe infections or other complex problems should be referred to regional hub/ London Lead Centre	Participate in network lead projects	Participate in CHIVA audit cycle and local network audits	Engagement with patients, families and carers to ensure services based on needs – patient satisfaction surveys/age-appropriate focus groups etc.

WTE, whole time equivalents

3.3 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.

3.4 Managing disclosure of the HIV diagnosis, to the child and to others

Disclosure to a child about their HIV diagnosis is a process which needs to take place over a period of time, in partnership with the family. CHIVA Practice Guidance *Talking to children about their health and HIV diagnosis* should be followed (www.chiva.org.uk).

1. 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 could be sought through CHINN.
2. A lead worker should be identified who will coordinate the work around disclosure with the family and child.
3. The lead worker should undertake an assessment of the child and family's needs around disclosure to the child.
4. 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.
5. The disclosure plan should be reviewed and updated regularly.
6. Children and young people should have ongoing explanations about their health condition appropriate to their age and level of understanding. This knowledge should be built upon in stages over time (see Disclosure Table www.chiva.org.uk).
7. The majority of children should have had an open discussion about having HIV by the time of transfer to secondary school. Exceptions should be documented, along with the plan for ongoing appropriate interventions to advance the child's knowledge.
8. After telling the young person that they have HIV, discussions need to continue to build upon the young person's understanding of HIV and sexual health.
9. The child's level of understanding of their illness and the plan of disclosure should always be part of the multidisciplinary team meeting discussion.
10. 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 disclosure plan and the name of the lead worker.
11. All parents/carers should be offered support and advice around how to talk with their child about their health condition and HIV.

Adequate information and resources should be available for healthcare professionals around talking to children about their health and HIV (*see* Disclosure Table www.chiva.org.uk). Disclosure to other professionals or individuals about a child's HIV diagnosis should only happen with the parents', and if age-appropriate, the child's consent, in partnership with the family and where it is definitely 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 MDT can actively support families during disclosure to other professionals, and offer up-to-date information on HIV for them, e.g. for teachers or social workers.

The child's HIV diagnosis should not be disclosed to 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. Such action should only be taken after consideration by the MDT.

3.5 Adherence support

The success of antiretroviral medication is dependent on adherence to therapy. HIV drugs require a high degree of adherence to treatment 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. Children are likely to require lifelong 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.

Adherence support will be required more intensively at certain stages which are predictable (when starting treatment; for infants, toddlers, and adolescents; when changing antiretrovirals [ARVs]; when changing formulation e.g. liquids to tablets). In addition there will be unpredictable crises which may or may not be related to drug treatment (illness in a parent, side effects, and social, housing and immigration issues).

1. CHIVA guidance on adherence should be followed (www.chiva.org.uk).

2. 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.
3. In centres supported by a paediatric HIV pharmacist, they will also play an important role in leading treatment and adherence support.
4. 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. In some areas there are community paediatric/HIV services trained in adherence, and ongoing support can be offered at home.
5. 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).
6. 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.

3.6 Transition and optimal adolescent care for young people born with HIV

1. Transition is defined as 'the purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centred to adult orientated health care systems' (Blum RW, Garell D, Hodgman CH *et al*. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health*, 1993, **14**, 570–576).
2. Generic national guidance on transitional care should be followed (see 3.6.1 National Transitional Care Guidance Resources). Many hospital trusts will also have local transition procedures.
3. The majority of HIV-infected children are infected by mother-to-child transmission and considered as children living with a chronic health condition. The success of antiretroviral medication means that children are surviving with HIV into adulthood with increasing numbers making the transition to adult services. This process of preparation begins in middle childhood and progresses through adolescence at a speed appropriate to each child and their family and culminates at the point of transfer to adult services. (This section does not apply to young people who acquire HIV during adolescence, most of whom receive care from adult services).
4. It is essential that there is an individualised plan for transition for each young person following CHIVA and HYPNet guidelines (www.chiva.org.uk).
5. A lead for transition should be identified in both adult and paediatric services.
6. Health education and promotion are an integral part of the transition process including negotiating relationships, safe sex education and vaccination. HYPNet/CHIVA guidance: Sexual health for young people with perinatally acquired HIV 2009, currently under preparation, should be followed (www.chiva.org.uk).
7. Each young person who makes the transition should have a comprehensive paediatric discharge summary completed before transfer to adult services. This should include presenting and treatment history, immunological and virological response, drug-resistance mutations, allergies including to antiretrovirals, long-term toxicities, co-existing medical issues and a psychosocial, educational and family history. The summary should be discussed with the young person prior to transfer and they, the adult and paediatric service should have a copy.
8. The views of adolescents and young adults should be represented in policy and ongoing service developments. Parents and carers should be supported in enabling young people to gradually achieve independence. Local patient groups should be strongly encouraged to improve clinical care.

3.6.1 National Transitional Care Guidance Resources

- Royal College of Paediatrics and Child Health (2008). Adolescent Health Project www.rcpch.ac.uk/education/projects-and-programmes/adolescent-health-project
- National service framework for children, young people and maternity services (2004) www.dh.gov.uk
- Adolescent transition care. Guidance for nursing staff. Royal College of Nursing (2004) www.rcn.org.uk
- National Service Framework for long term conditions (2005) www.dh.gov.uk
- You're Welcome quality criteria: Making health services young people friendly (2007) www.dh.gov.uk
- Department of Health (2006). Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145

- Department of Health (2008). Transition: moving on well www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_083592
- Transition Information Network. www.transitioninfonetwork.org.uk

3.7 Working with community and primary care services

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.

- The level of knowledge about paediatric HIV varies even within health care professionals, and therefore appropriate information should be provided and contact details given for the hospital paediatric team caring for the child, in order to aid easy communication and allow advice to be easily sought (*see* CHIVA website www.chiva.org.uk).

3.8 Joint working with social care and safeguarding

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 lead/network 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. In other centres the referral will need to be made to the appropriate local social care team after consent from the family.

3.8.1 Safeguarding

1. All professionals working with children and families with HIV need to be aware of, and work within national and local child protection procedures www.safeguardingchildren.org.uk; www.everychildmatters.gov.uk
2. Professionals working with children and families with HIV should foster close links with local child protection teams to allow advice and discussion of difficult situations at an early stage.
3. Difficult cases regarding specific issues around parental beliefs about HIV, consent to testing or treatment for children should be discussed within the multidisciplinary team and with the lead centre. Appropriate discussion may take some time before progress on accepting a diagnosis of HIV can be made.
4. Good multidisciplinary documentation should be maintained in these complex cases.
5. Where there is a significant risk to the health of a child, which cannot be addressed by in-depth multidisciplinary discussion with the family (including peer support groups where appropriate), then a discussion with social care within safeguarding procedures will need to take place and subsequent referral under child protection 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.
6. These 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.
7. Local legal teams may need to be involved and advice sought.
8. 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 interests 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.

3.9 Third sector groups – partnerships with voluntary agencies

1. There are many voluntary organisations both local and national providing excellent support and services for children and families with HIV.
2. 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 www.chiva.org.uk). Families may initially not wish to engage with outside agencies, but this should be readdressed at intervals.
3. Peer support for families 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. Many organisations encourage positive living, with life skill training courses.

3.10 Working with commissioners for HIV services

1. Paediatric and maternity HIV services must work closely with HIV commissioners to optimise funding support for clinical care.
2. Appropriate performance indicators and outcome measures should be negotiated with the commissioners to monitor clinical care.

SECTION 4 The Children's HIV National Network (CHINN)

Standard: All children with HIV should be managed within the Children's HIV National Network (CHINN).

4.1 The Children's HIV National Network

Networks for the care of children infected with HIV were established in London by the London HIV Consortium Paediatric Sub-Group in 2004 (*Paediatric HIV – Developing Paediatric HIV Clinical Networks 2004*). Following this the Department of Health and the specialised services commissioners group established paediatric HIV networks for children outside London in the Children's HIV National Network (CHINN) review in 2005.

- The London Networks are:
  Northwest London (Lead – Imperial College Health Care NHS Trust);
  Northeast London (Lead – Great Ormond St Hospital for Children NHS Trust);
  South London (Lead – St George's Healthcare NHS Trust).
- Direct London linked spoke centres link directly with outreach from the existing London networks.
- The CHINN Regional Networks are:
  North East England;
  North West England & North Wales;
  Midlands;
  South West England & South Wales;
  Scotland;
  Northern Ireland.
- Each CHINN Regional Network links with one of the London Lead Centres. The exception is Northern Ireland which links directly with Dublin.
- Some regions have joint regional hub centres (e.g. in the South West & South Wales where Bristol and Cardiff are the regional network centres), see Appendix. However, each regional network has one lead paediatrician.

4.2 Clinical governance

The lead paediatrician for the regional network takes responsibility for clinical governance within the network.

- Each regional network should have local referral protocols and have clear pathways of patient care to ensure the highest quality of care.
- Each network should have regular meetings for training, collaborative audit and research.

4.3 Networked care

- The lead paediatrician for the regional network needs to be actively involved in planning and delivering the care for all children in the network in collaboration with paediatricians in the other Network HIV Care Centres and the London Lead Centre.
- Initiation or changes to combination antiretroviral therapy for any individual should always be discussed in a treatment meeting, either locally or virtually via the London Lead Centre.
- For effective shared care, copies of clinic letters and discharge summaries should be sent to the London Lead Centre paediatrician.

SECTION 5 Appendix

The Children's HIV National Network			
Regional Networks	Linked Lead Hubs	Regional Network Hub (some rotate)	Local Centres
North East	St George's Hospital	Sheffield	Leeds
		Newcastle	Huddersfield
			Whitehaven
			Bradford
			Middlesbrough
			Calderdale
			Harrogate
North West & North Wales	Imperial College Healthcare NHS Trust	Manchester	Stoke-on-Trent
		Liverpool	Preston
			Blackpool
Midlands	St George's Hospital	Birmingham	Coventry
			Leicester
South West & South Wales	St George's Hospital	Cardiff	Exeter
		Bristol	Torquay
Scotland	Imperial College Healthcare NHS Trust	Edinburgh	Dundee
		Glasgow	Inverness
Northern Ireland	Dublin	Belfast	

Direct London linked centres		
Lead Hubs	Spoke Centres	Local Centres
Imperial College Healthcare NHS Trust	Chelsea & Westminster	Ealing
	North West London Hospitals NHS Trust	Cambridge
		Ipswich
	Lewisham	Reading
	Luton & Dunstable	Nottingham
	Wexham Park Hospital Slough	Derby
		Great Yarmouth
	Milton Keynes	
	Oxford	
	Northampton	
Great Ormond Street	North Middlesex	Royal London
	Newham	Peterborough
		Southampton
		Southend
St George's	Evelina Children's	Eastbourne
	King's	Brighton
	Mayday	Guildford
	Woolwich	Dover – via King's
		Chatham, Kent – via Evelina

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