

Review of The Children's HIV National Network (CHINN) 2014

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Background

Following the London review of Paediatric HIV services in 2004, in the following year, a review of the service provision for children living with HIV outside of London was undertaken and as a result, the Children's HIV National Network (CHINN) was established. Since then, the numbers of children infected with HIV in the UK have stabilised at around 1200, with the median age of the cohort increasing to around 13 years, with a predicted stable population number for the next five years from the Collaborative HIV Paediatric Study (CHIPS) cohort.

Distribution of cases within the UK however, has changed, from 70% of the cohort in 2004 living within London, to an equal distribution of children now living outside London as within – therefore working in Networks has become increasingly more important, particularly in the more geographically remote areas.

The aim of the Paediatric HIV service is to provide consistent, effective and appropriate family centred care which ensures that children remain safe and well and have access to the same standards of care wherever they live in the UK. Currently, care is provided to children both inside and outside London by regional/ hub and local centres who follow CHIVA and PENTA guidelines, with access to regional educational meetings and national conferences and tertiary centre advice when required via virtual clinics. Within London there are three tertiary centres who provide national advice : St Mary's, St George's and Great Ormond Street hospitals. The changing nature of Paediatric HIV infection, with a possible decline in numbers in the future, means that formal, networked arrangements for care will continue to be required to protect quality, improve productivity and continue to enable access to care relevant to local needs. Arrangements for care must be documented to make it clear to patients and care providers how pathways operate. All patients need to have access to a multidisciplinary team, although in some parts of the country this may only be delivered in the regional/hub centres. In more geographically remote areas, commissioning arrangements will be with the regional/hub centres. Staff to patient ratios for multidisciplinary care in paediatric HIV are difficult to stipulate but ratios will be higher than

for adult services – guidance is included with in the CHIVA Standards of Care 2013 document.

In 2013, the NHS Commissioning Board took over the commissioning of specialised services, with Paediatric HIV care being commissioned alongside Adult HIV care. Clarification of the formal networked arrangements which form part of the service specification, has therefore become necessary, to look at current patient locations and inform future commissioning processes.

Structure of Current Regional Networks

There are currently five regional networks within England – North East, North West, Midlands, South and South West and London and South East with differing commissioning arrangement in each area. In geographically remote areas, the regional/hub centres are responsible for the majority of the care, whereas in other areas (Midlands) more formal commissioning has led to the development of both regional/hub centres and lead centres with appropriately trained staff. In some regions (South West) staff from the regional/hub centre travel to the local centres to conduct regular clinics. Perinatal care of mothers with HIV and their babies continues to take place in most hospitals across the UK, with advice available from the regional/ hub and tertiary centres for complex cases. There are currently around 1300 pregnancies per year reported to the National Study of HIV in Pregnancy and Childhood (NSHPC). Each network has developed a governance framework including network meetings, collaborative audit and research and, in some cases, dashboard data looking at clinical outcomes.

Networks

North East

Regional/hub centres:

Newcastle

Sheffield

Leeds

Local centres:

Calderdale / Huddersfield

North West

Regional/hub centres:

Liverpool (Alder Hey)

North Manchester

Local centres:

Stoke on Trent

Blackpool

Midlands

Regional/hub centres:

Leicester

Birmingham Heartlands

Lead centres:

Nottingham

Northampton

Derby

Local centres:

Coventry

Wolverhampton

South West

Regional/hub centres:

Bristol

Southampton

Local centres:

Plymouth

Truro

Gloucester

Bath

Swindon

Taunton

Yeovil

Exeter

Torbay

Poole

London and South East

South

Regional/hub centres:

St Georges – tertiary centre

Kings

Evelina

North

Regional/hub centre:

St Marys – tertiary centre

Local centres:

Chelsea and Westminster

Ealing

Northwick Park

North Central / East

Regional/hub centre:

Great Ormond Street – tertiary centre

Local centres:

Newham/ Royal London/Barts/Whipps Cross

North Middlesex

Direct London Linking Centres

Luton

Milton Keynes

Oxford

Wexham Park

Reading

Brighton

Peterborough

Portsmouth

Chelmsford

Colchester

Salisbury

Norwich

Future Commissioning Issues

- Area Teams, particularly in the East and London and the South East will need to decide how payment is made for children who receive care in the London tertiary centres and whether these numbers are included in those of the tertiary centres. Funding for drugs must also be considered
- Payment for complex perinatal advice / care of pregnant women and their babies is unclear but will need to continue in most hospitals across the country
- Funding for CNS posts may be reviewed , particularly if numbers of patients decline and may need to be partially funded by individual providers
- Governance arrangements need to be clear – particularly where advice is given by the tertiary centres
- Providers of paediatric care need to be linked to adult centres to avoid problems with transition and increased morbidity and mortality in young adults
- Providers / networks should give consideration to providing an Annual report to inform commissioners of current activity and performance
- Transition and networked social support are thought to be essential components of the network

References

Children's HIV National Network Review 2004

Service Specification Specialised HIV Services (Children) B06/S/b 2013

CHIVA Standards of Care for Infants, Children and Young People with HIV 2013