



British HIV Association



Standards of Care

for People Living with HIV
2013

Dr Esse Menson

Honorary Secretary and Standards Lead,
Children's HIV Association (CHIVA)



CHIVA Standards of Care 2013
for
Infants, Children & Young People
with HIV
~ including infants born to mothers with HIV



CHIVA Standards of Care 2013

~ what does it mean for
children & families?



Scale of paediatric HIV



- 1,200 vs 80,000
 - numbers **small**
 - consequence, impact, management challenges **large**
- Stable number ~ changing profile
- Family matter
- Changing needs over time
- Lifelong chronic condition
 - complex patients graduating to adult services



UK paediatric HIV



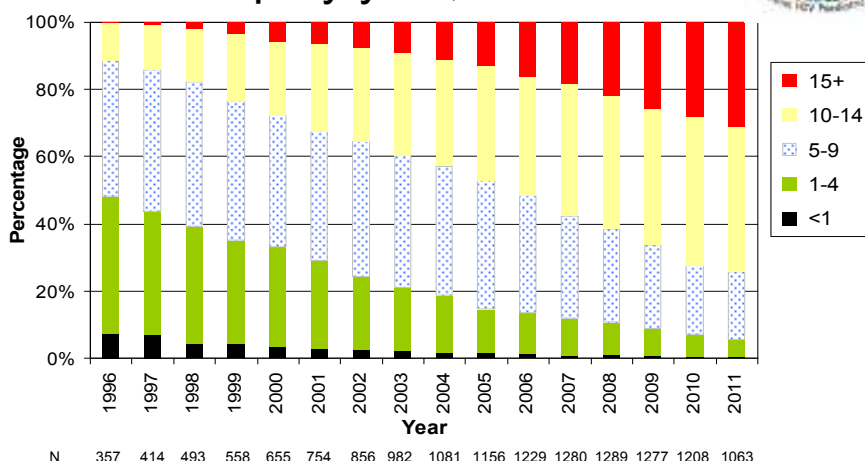
- 1,200 children
 - **Half born abroad**
 - Immigration and parent / carer considerations

- **Mode of infection**
 - Well, older children at diagnosis
 - Aging cohort
 - Particular challenges

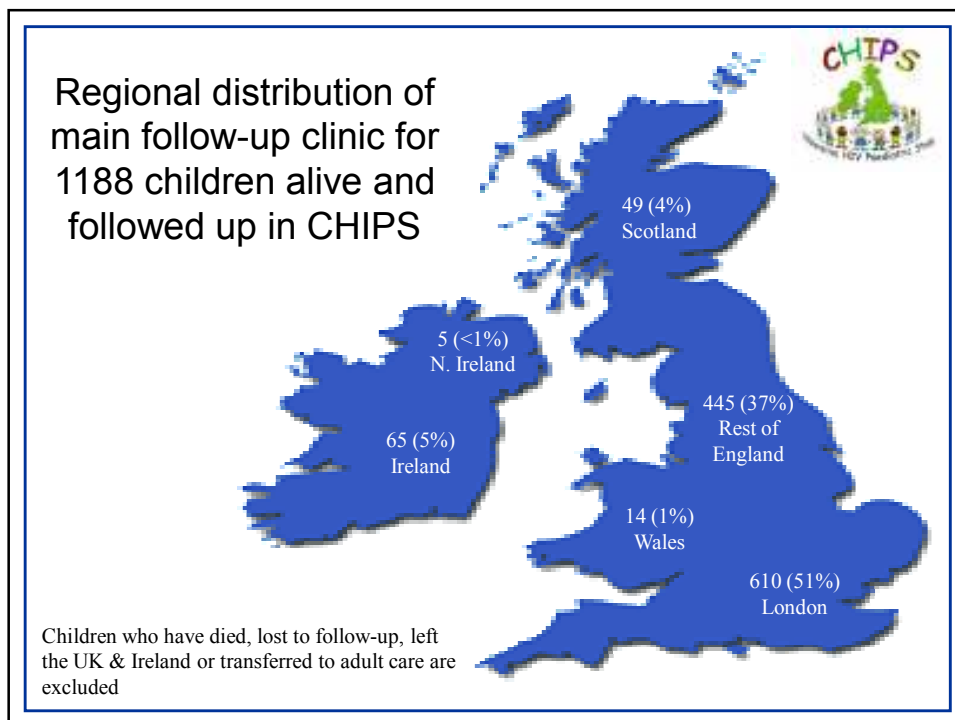
- **Geographic location**
 - In London vs out
 - Changes over time
 - Access to care & support services



Age* of children in paediatric follow-up by year, 1996-2011



- Age = age at start of the year or age at presentation
- Data are for children & young people receiving paediatric care; those who have transferred to adult clinics are not included here.



New cases of Paediatric HIV



- Success story of pMTCT
 - Better but not solved
 - New challenges
- Perinatal cases
- Risk periods
- Advanced disease in childhood
- Family & social matters
- Changing expectations



Antenatal care of exposed babies



- 1,300 births per year to diagnosed women
- Opt out of testing & safeguarding
- Paediatric challenges of diagnoses in pregnancy



Effective paediatric HAART



- Formulation difficulties
 - Perils of overdosing & underdosing?
 - Palatability
- Plea to pharma
- Complexities of resistance during paediatric ages



Collaborative HIV Paediatric Study CHIPS



- **Since April 2000**
- Multi-centre cohort study of HIV+ children UK & Ireland
 - describes clinical, laboratory and treatment data
 - describes use of paediatric HIV services
- **Collaboration between**
 - 65 clinics
 - PENTA trials
 - National Study of HIV in Pregnancy and Childhood
 - MRC Clinical Trials Unit
- Primary funding
 - NHS London Specialised Commissioning Group



Children's HIV National Network (CHINN) Review 2005

CHIVA Standards of Care 2013

~ what does it mean for children & families?

Standards for

- service providers
- commissioners
- families, young people & children



Standards of care – adults ... children

12 Standards of Care for People Living with HIV

- Standard 1: HIV testing and diagnosis
- Standard 2: Access to, and retention in, HIV treatment and care
- Standard 3: Provision of outpatient treatment and care for HIV, and access to care for complex comorbidity.....
- Standard 4: Safe ARV prescribing: Effective medicines management ..
- Standard 5: Inpatient care for people living with HIV.....
- Standard 6: Psychological care.....
- Standard 7: Sexual health and identification of contacts at risk of infection.....
- Standard 8: Reproductive health.....
- Standard 9: Self-management
- Standard 10: Participation of people with HIV in their care.....
- Standard 11: Competencies
- Standard 12: Information for public health surveillance, commissioning, audit and research.....

- Standard 1: Best Practice for **Prevention of Mother-to-child Transmission of HIV**
- Standard 2: Paediatric Diagnostic Testing for HIV
- Standard 3: Paediatric HIV Disease Management - Referral to Paediatric & Adolescent HIV Services
- **Standard 4: Specialist Multi-disciplinary Paediatric HIV Treatment & Care - Outpatient & Inpatient**
- Standard 5: Safe ARV prescribing - Effective Medicines Management
- **Standard 6: Adherence Support**
- **Standard 7: HIV Education & Naming**
- Standard 8: Sexual Health, Secondary HIV Prevention & Reproductive Health
- **Standard 9: Transition to Adolescent & Adult HIV Specialist Services**
- Standard 10: Access to, and Competencies of, Multidisciplinary Specialist Paediatric HIV Team
- Standard 11: National Surveillance & Audit Programmes
- Standard 12: Engagement & involvement of Service Users, Non-HIV Specialists, Voluntary Organisations & Social Care

pMTCT Best Practice



- Maternal rights, fetal considerations
- Mutli-disciplinary care
 - across health
 - voluntary organisation
- Successes ... with caution
- Interventions plus support & enabling
- Completing follow up until antibody-negative



Managing Paediatric HIV



- Multi-disciplinary, integrated care
- Standardisation of geographic differences
- Age & stage appropriate care
- Guidelines
 - CHIVA
 - PENTA
 - Monitoring
 - Support provision incl mentoring





The screenshot shows the CHIVA HIV Association website. The header includes the logo and a navigation menu with items: Home, About Us, Professionals, Parents, Youth, Support Camp, Donate, Resources, and Latest. The main content area is titled "Professionals" and features two callout boxes: "Health" (for those providing care) and "Support" (for those offering help). A sidebar on the left contains a menu and a calendar for November 2012. An announcement at the bottom right seeks health care professionals for a survey.

CHILDEREN'S
chiva
HIV ASSOCIATION

Select Language
Powered by Google Translate

Home About Us Professionals Parents Youth Support Camp Donate Resources Latest

▸ About CHIVA
 ▾ Professionals

- HIV Health
- Regional networks
- Resources
- Support
- Children & youth services

 ▸ Parents
 ▸ Youth
 ▸ Support Camp
 ▸ Get involved

Health
 For those providing health care for families living with HIV, from Infectious Diseases Specialists to A & E Doctors and Nurses.

Support
 For those offering help to families living with HIV, including social workers and voluntary sector, schools and housing.

November 2012 #
 Mon Tue Wed Thu Fri Sat Sun
 1 2 3 4
 5 6 7 8 9 10 11
 12 13 14 15 16 17 18
 19 20 21 22 23 24 25
 26 27 28 29 30

[Request a secure log-in](#)

Announcement:
 We are looking for health care and other professionals working with families living with HIV to complete a short survey based on The Children's Society Inquiry into the asylum support system.
[Click here to take survey](#)

Adherence Support



- Pre-start preparation
- Age & stage appropriate support
- Child – carer(s)
- Multi-disciplinary, multi-agency
- Support delivery within the home
- Continual re-evaluation



Education & Naming



- “Families first”
- Rights & needs of child
- Multi-disciplinary, multi-agency work based on families’ needs
- Age & stage appropriate talking
- Evaluation of understanding
- Siblings and onward disclosure
- Information to other professionals



Different ways young people found out about HIV in their family

Submitted by Anonymous on Fri, 04/11/2011

"I found out by reading a letter. Mum knew but she did not react in a bad way. The information I got about HIV was just from letters until I joined the group where I found out more".

"I blocked out how I found out as I was very young. Since then, I have found out more information on HIV".

"The health professionals informed me and my sister and I thought my mum was going to die. I ran away for a few hours, as I needed space".

"Mum told me when I was 8/9 years old. I didn't mind. She explained it all to me, the pros and cons, and that everything was going to be fine".

"When I was told about it I felt like my whole world was turned upside down, I didn't talk, just sat there stunned then I just walked up stairs and went to bed. The next morning I came down stairs as if nothing had happened."



HIV in Schools

Good practice guide to supporting children
infected or affected by HIV

Magda Conway

Sexual health education



- Begins in paediatric services
- Right to be seen without carer
- Promote and maintain good sexual health
- Secondary HIV prevention
- Reproductive health and options

Pregnancy in adolescence



blue sky
TRUST

Responding to HIV in the North East
challenging stigma • reducing transmission • improving lives

T4Y
THINK FOR YOURSELF

WOULD YOU LIKE **SUPPORT** IN EQUIPPING YOUNG PEOPLE TO MAKE HEALTHY CHOICES ABOUT **RELATIONSHIPS AND SEX?**

T4Y raises the self esteem and aspirations of young people by equipping them with the skills and information they need to make healthy relationship choices.

T4Y delivers interactive courses and workshops in schools and youth settings using creative elements such as drama, art and dance. T4Y specialises in consulting young people about their relationships and sex education needs.

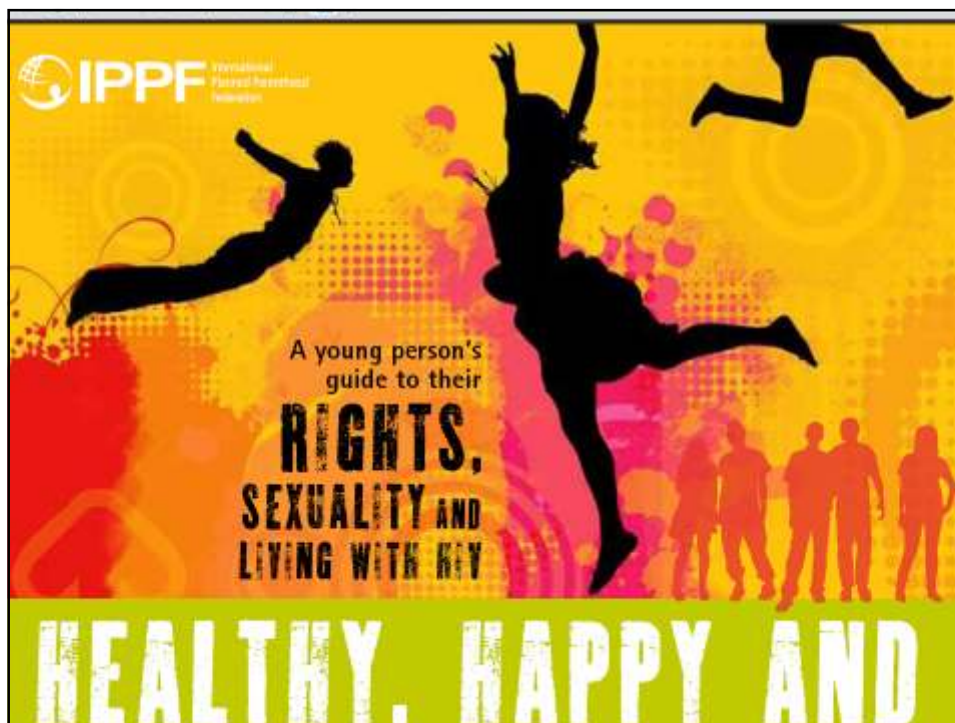
Outcomes of T4Y include:
Reduced risk taking behaviour
Reduced teenage conceptions
Delayed early sex

Topics delivered include:
HIV awareness
Sexually transmitted infections
Assertiveness and peer influence

BODY & SOUL. life, love & hiv

Home About Us Contact Us What's On

Can you turn about HIV in the FACTORY? Play the game, watch the film, try the quiz, learn the facts.



Transition



- Delivering a 'process not an event'
- Planning & provision
- Regional differences – standards
- User involvement
 - views of young people
 - peer support & mentoring
- Life transitions



[About CHVA](#) | [Home](#)
[Professionals](#) | [Parents](#)
[Youth](#)
[Support Camp](#)

- Why a camp?
- At camp
- Does it work?
- Camp leaders
- Volunteer-Key worker
- Donate to the support camp

Support camp

Submitted by Paul Dudgeon on Nov, 10 (2012)



"I learned that I can conquer my fears and though I may feel alone, I am not." (Young person, camp 2012)

"I got to meet people with the same thing as me, because where I live it just felt like it was just me" (Young person,



cwac

CHILDREN WITH AIDS CHARITY

[home](#) | [blog](#) | [about](#) | [contact](#)

donate NOW





The History of Children With AIDS Charity

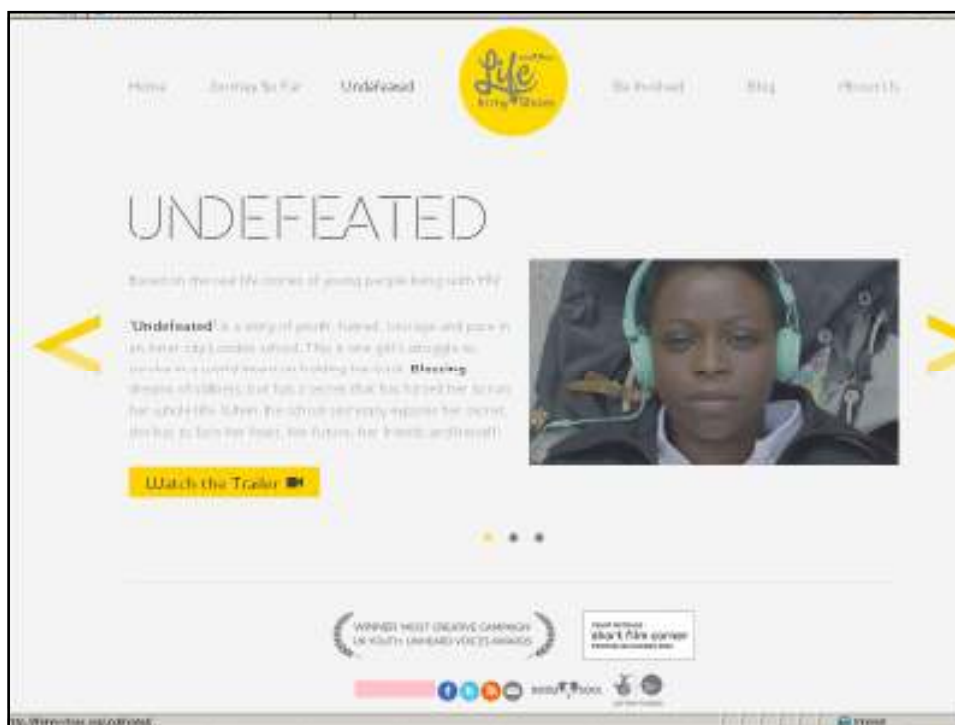
1991 a Specialist Paediatric HIV Service was established at St Mary's Hospital in Paddington, London.

Rebecca Handet, whose daughter Sasha was being cared for at St Mary's, met Jo Dodge, the coordinator of the service, to discuss the shortage in the existing provision of services for children Infected and Affected by HIV. Being white, middle-class and Jewish, Rebecca shattered all HIV-positive stereotypes, having become infected with HIV through a blood transfusion in her second pregnancy, before blood was screened for the virus.

hardship

transport

education



Paediatric HIV & family

CHILDREN'S
Chiva
HIV ASSOCIATION

- Family focus
- Family lead
- Family sensitive
- Family empowered
- Child / young person at centre



INCLUDE PROGRAMME
Change for Families affected by HIV

The Child Social Work Foundation

You are in: Home > Resources > Supporting young carers in families affected by HIV

Home About us Events and training Young Carers Services **Resources** Guidance

Professional Resources

Families affected by HIV

- Identifying and supporting
- Awareness Raising and Training
- Stigma and Discrimination
- Disclosure and Confidentiality
- Immigration and Asylum
- Education Professionals
- Social Care
- Health Care
- Young Carers Professionals

Supporting young carers in families affected by HIV

The toolkit has been funded by the [Elihu John AIDS Foundation](#) and provides information, resources and good practice guidance about supporting young carers affected by HIV.

What do young carers affected by HIV want?

Young carers affected by HIV are calling for:

- Specialist HIV and young carers training sessions for all teachers, education professionals, social care and health professionals
- Have lessons about HIV and the impact on family members and young carers in schools
- Raise awareness of young carers affected by HIV all the time not just on World Aids day

[Supporting young carers in families with HIV](#) - Information for HIV professionals

RESOURCES

HIV SERVICES IN YOUR AREA

YOUNG CARER SERVICES IN YOUR AREA

Just Normal Young People
Supporting young people living with HIV in their transition to adulthood
A report from the Children and Young People HIV Network

Emily Hamblin

HIV

Children, HIV, Asylum & Immigration

An overview of the current situation for children living with HIV and insecure immigration status

Magda Conway

December 2006



POSITIVELY UK

A national charity championing the rights of people living with HIV

Home
Policy
Women
Information
Men
Get Involved
Youth
About Us
Health
Contact Us

You are here:

>> Youth

Want to Talk?

Want to talk to another person living with HIV? Call the peer support helpline on 020 7713 0222, weekdays 10am to 5pm, Thursdays until 8pm.

Want to support Positively UK?

[Donate](#)

Youth

Positively UK has a new service for 16-24 year olds living with HIV. The service is led by young people also living with HIV. Together with clinics across London we aim to support you during your move from child to adult health services and care. If you are dealing with a new diagnosis, or coming to terms living with HIV, and would like the right support, and information.

Please contact us on: 0207 713 0444
Monday to Friday 10am to 4pm
Thursdays 10am to 8pm.
Or email Maureen at mikswanuk@positivelyuk.org

Want To Get Involved?

We are currently recruiting volunteers to be youth peer mentors. As a youth peer mentor you'll befriend another young person, providing a listening ear, support with managing their HIV, relationships and co-ordinating small befriending groups. Full training and support is provided. If you are interested please contact fraser@positivelyuk.org.



Talksafe

What it's all about?

terrence HIGGINS TRUST

About Talksafe

Talksafe is a safe place to get the answers that matter to you - learn more, get advice from a mentor your own age or talk to a counsellor. Just click on your age group to get started. [Read more](#)

10 to 12

13 to 15

16 to 18

CHIVA Standards of Care 2013

~ what does it mean for
children & families?

- Standards for**
- service providers
 - commissioners
 - families, young people & children



CHILDREN'S
chiva
HIV ASSOCIATION

ACKNOWLEDGEMENTS

CHIVA Standards of Care 2013
for
Infants, Children & Young People with HIV
~ including infants born to mothers with HIV



British HIV Association



Standards of Care
for People Living with HIV
2013

Launch Event

Thursday 29 November 2012
Royal College of Physicians, London

