

# Living with HIV

## Supporting HIV positive students in higher education

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National Children's Bureau

Student Health Association Conference

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# Children and Young People HIV Network



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for children

- Free email-based membership for professionals concerned with the impact of HIV on UK children and families
- Based at research and development charity the National Children's Bureau
- Policy and practice development, participation work etc.
- 2010-2013 Department of Health funded project on transition into adulthood.

[www.ncb.org.uk/hiv](http://www.ncb.org.uk/hiv)

# Young adults living with HIV in the UK, 2013 (PHE data)



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## Young adults accessing HIV care

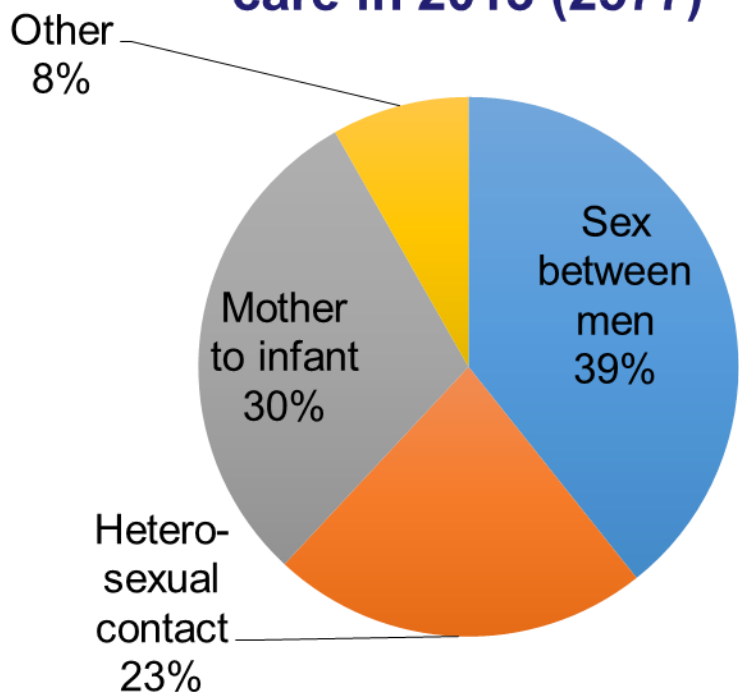
Age	Men	Women	Total
16-19	323	293	616
20-24	1332	629	1961
Total	1655	922	<b>2577</b>

## New diagnoses amongst young adults

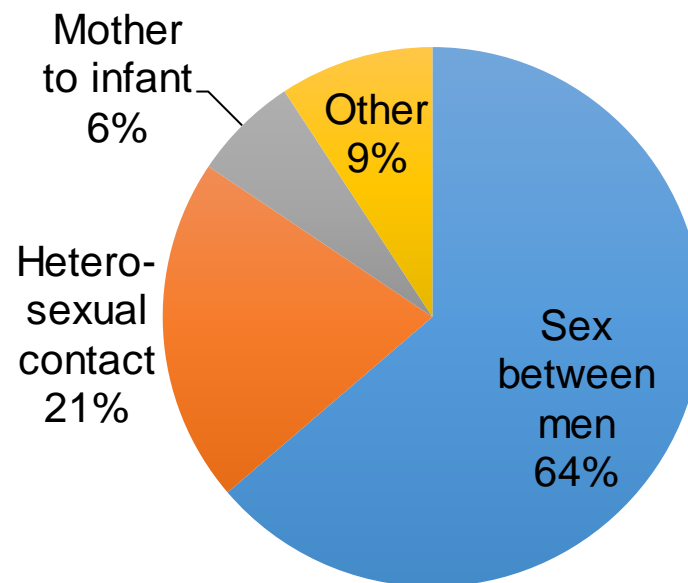
Age	Men	Women	Total
16-19	-	-	147
20-24	-	-	578
Total	568	157	<b>725</b>

# How did they acquire HIV?

**Young adults accessing HIV  
care in 2013 (2577)**



**Young adults diagnosed in  
2013 (725)**



# What do they know about (their) HIV?

## Young adults with lifelong HIV

- In 2007, the average age at which children learnt their own HIV positive status was 12.
- Large volume of complex information about HIV and its physical, psychological and social implications.
- In 2014, 88% clinics delivering paediatric HIV care provided sexual health education.

# What do they know about (their) HIV?

## Young men who are attracted to men

National AIDS Trust *Boys who like boys* research with young men (14-19):

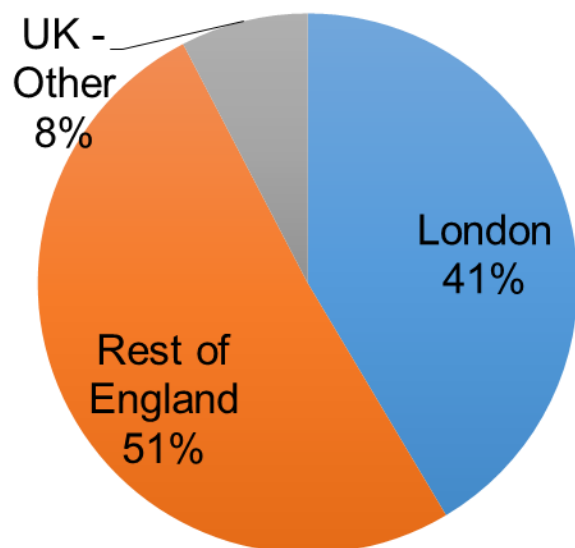
- 75% didn't get any information about same-sex relationships at school
- 33% didn't get any information on HIV transmission and safer sex
- over a quarter were not clear how HIV was passed on
- 43% were satisfied that they knew enough about HIV.

# Where are they?

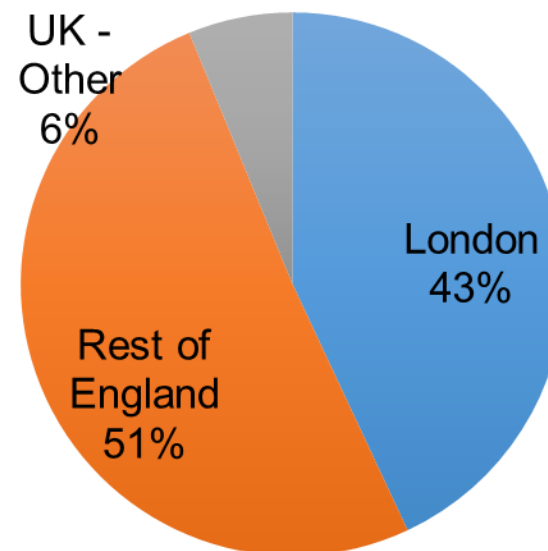


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## Young adults accessing HIV care – place of residence

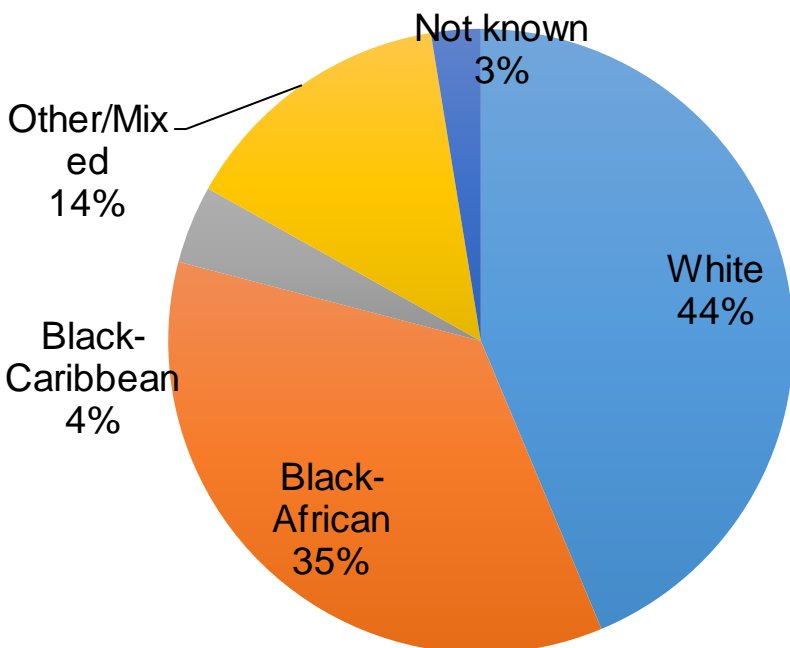


## Young adults newly diagnosed – place of diagnosis



# Ethnicity and region of birth

## Young adults accessing HIV care in 2013 (2577)



Individuals who have accessed paediatric HIV healthcare in the UK:

- 8 in 10 are Black African
- 5 in 10 were born abroad.

Newly diagnosed young adults:

- 49% born in UK
- 15% in rest of Europe
- 13% Africa.



# Background



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Students may have experienced:

- migration
- poor access to (optimal) HIV treatment
- bereavement, illness, caring responsibilities
- stigma and discrimination in UK and international contexts
- compounded isolation in areas of low HIV prevalence.

# HIV stigma and discrimination

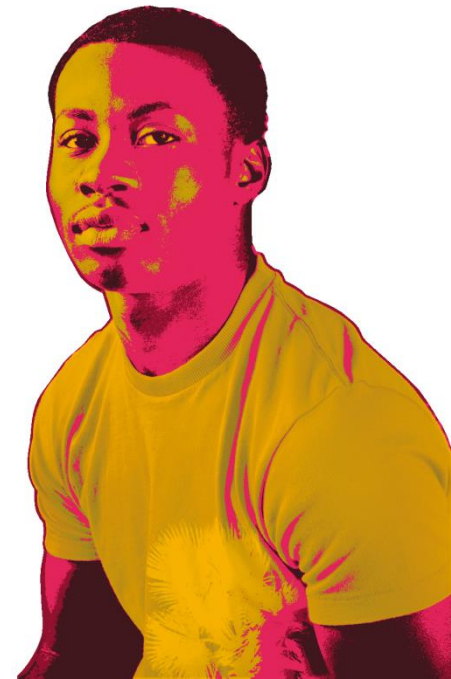
- Public misconceptions
- 'Outside of the HIV clinic, people living with HIV experience stigma and discrimination in healthcare settings with alarming frequency' (NAT)
- HIV positive children are still as risk of exclusion from schools
- The Offences Against the Persons Act
- Internalised stigma.

# ‘Peter’



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- Lifelong HIV acquired from his mother
- Family from sub-Saharan Africa
- Both parents died during his childhood
- Sibling carer
- Social services involvement.



# Beginning college/university...

- May not have considered HIV when planning for HE
- May be unaware that support is available for fluctuating or less visible impacts
- May be unaware of legal rights under the Equality Act 2010, not relating to the label 'disabled'
- Aware of discrimination in education and healthcare settings.



*Image from THT.org.uk*

**‘Peter’**



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*‘I didn’t really think about my HIV status when I picked my university. [...] Initially I didn’t tell anyone, as I wasn’t fully aware of what I would need.’*



# What may students present with? Mental health



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- Increased risk of mental health issues
- Pressure points: diagnosis, ill health, family ill health/death, starting/changing treatment or care, disclosing HIV status, new relationships

In young people with vertically-acquired HIV:

- HIV treatment refusal the most common behaviour indicating psychological distress
- 22% formal psychiatric diagnosis
- 1/3 of those without formal diagnosis had behaviours indicating psychological distress (HYPNet)



# What may students present with?

## Impact of long-term HIV and treatment



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**Bamford A., Lyall H. *Paediatric HIV grows up: recent advances in perinatally acquired HIV***

*There has been a shift in focus beyond ensuring survival into adulthood, towards **optimisation of health status** throughout childhood and adolescence in preparation for **healthy and productive adult life**.*

*Challenges still remain in the management of these young adults, a proportion of whom were diagnosed in pre/early ART era. **Triple class resistance, long-term drug toxicity, psychopathology, complex adherence issues** (often starting in early life), **learning difficulties/neurodisability** and **poor retention in care** can all add to patient complexity.*

AALPHI study participants ( $\geq 16$  years, ever received paediatric HIV care in the UK/Ireland):

- 25% ever had an AIDS-defining condition
- Most on ART with good CD4 and viral load status.



# HIV treatment

- Good adherence crucial for long-term health and treatment options (95% aim)
- Can involve high pill burden, unpleasant taste, side effects like diarrhoea, long-term toxicity
- *Why bother when I feel fine?*





# What may students present with?

## Sexual and reproductive health



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### **Young adults 16-25 with vertically acquired HIV:**

- 56% sexually active
- One quarter of these reported suboptimal condom use
- One sixth a past STI
- 40% had disclosed their HIV status to current partners
- 82% had partners who tested for HIV
- Half had attended for post-exposure prophylaxis

(HYPNet)

### **Young men who have sex with men**

- Quarter of STI diagnoses among MSM reported from men aged 16-24 years in 2012

(PHE)

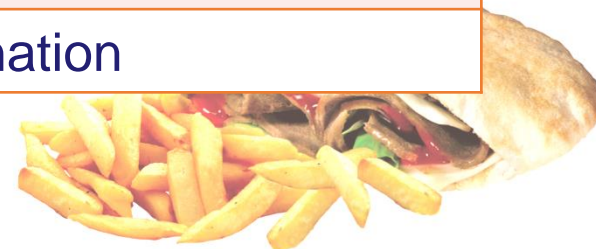
# HIV, health and the student lifestyle

Factor	Impacts
Irregular routine	
Smoking, poor nutrition, erratic sleep etc.	
Alcohol and drugs	
Sexual partners and relationships	
Academic pressure	
Shared accommodation	



# HIV, health and the student lifestyle

Factor	Impacts
Irregular routine	Treatment adherence
Smoking, poor nutrition, irregular sleep etc.	Immunity; side effects; long-term outcomes
Alcohol and drugs	Drug interactions; vomiting after taking meds; disinhibition and unsafe sex
Sexual partners and relationships	Negotiating sex; disclosing HIV; peer pressure; risks/concerns around transmission
Academic pressure	Mental health, cognitive functioning, HIV symptoms and side effects
Shared accommodation	Disclosure; discrimination



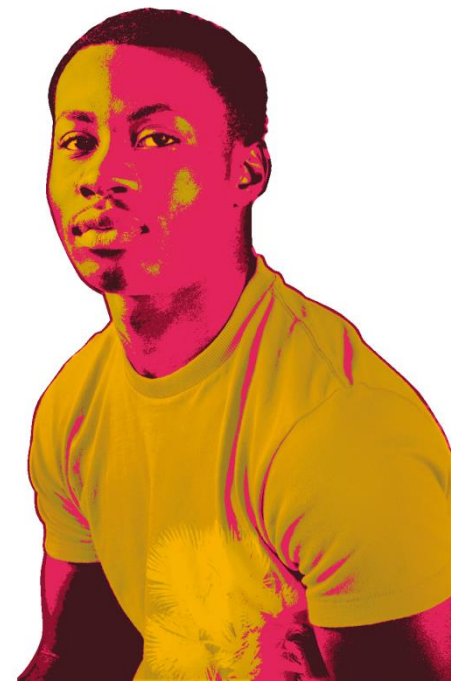
# ‘Peter’



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*‘When I got there a lot of new experiences happened – a lot of pressures. I ended up telling tutors and other people that I didn’t really need to tell.’*

Peter transferred to a university nearer to support networks; disclosed HIV.



## Peter's advice

- The importance of having someone *'who you can check in with, who knows you and believes in you'*
- Continuity
- Help to prepare for university: what young adults can expect; their support needs; what is available.
- Felt it was probably best to disclose HIV to universities *'as you never know when your health may deteriorate and affect your education.'*
- *'It's the inability to ask for help that can mess you up.'*

# Ways of supporting HIV-positive students




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**What ways might be  
relevant for your role?**

# Ways of supporting HIV-positive students

Recognise that students may:

- have recently entered adult HIV care; feel close to paediatric HIV practitioners; and/or wish to retain care in familiar centre
- access GP and sexual health services without disclosing HIV
- not remember all the information you give them
- see HIV prevention differently.

A stylized illustration of a young woman with dark hair tied back, wearing a blue top. She is looking towards the right. A large orange speech bubble originates from her mouth.

*'I get to the uni where I know that there's going to be support around me [...] I'm not far away from home, I'm not far away from my hospital.'*

# Ways of supporting HIV-positive students

Help them to:

- decide where to access their HIV care; ideally someone local should know about their HIV - GUM clinic or GP
- access psychosocial and/or peer support from HIV organisations.

*'I have so much love coming from different ways when you come, meeting people who are just the same as you, who feel, who seek acceptance from the world but they don't know how to get it.'*





# Encouraging students with HIV to share this with student health services

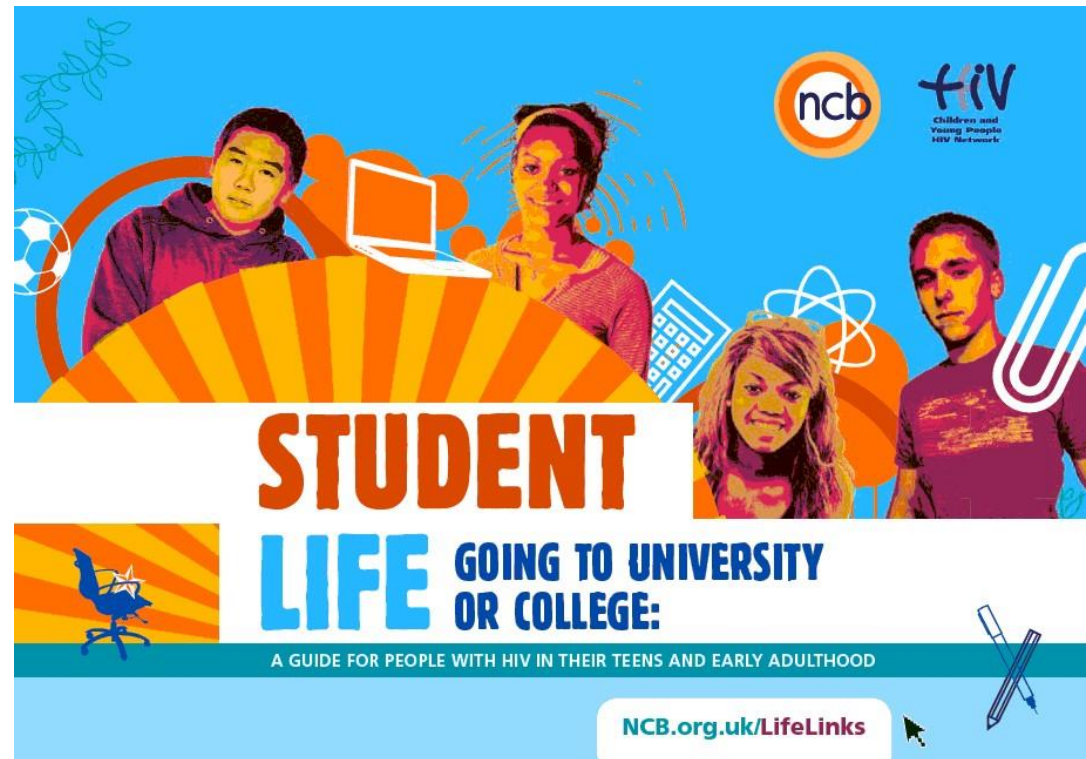


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- Give clear information and assurance about confidentiality
- Enable students to give evidence of the impact of their health condition without naming it – some never will
- Help students to communicate about their HIV with a single trusted individual
- Proactively mention HIV in:
  - broader work on health, wellbeing and equality
  - specific HIV awareness activities
  - policies, procedures, and literature for students
- NAT report, *HIV Patient Information and NHS Confidentiality in England*, 2014 [www.nat.org.uk](http://www.nat.org.uk)



- **Student Life**
- **Working Life**
- **Independent Life**
- **Life and Rights**  
(discrimination,  
confidentiality,  
criminalisation)
- **Life Looking Forward**  
(transition)
- **Sharing in Life** (disclosing  
HIV – produced with  
CHIVA)



# Studying with HIV

A website for people who work with students, and HIV practitioners supporting young adults

[www.ncb.org.uk/studying-with-hiv](http://www.ncb.org.uk/studying-with-hiv)



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## Studying with HIV

Checklist

Introducing HIV

HIV and young adults

Responding to  
disclosures of HIV

Students experiencing  
difficulties

Exploring a student's  
support needs

College or university  
and local services

Administration and  
practical support

Emotional and  
pastoral care

Health services

Student-led services  
and activities

## Administrative and practical support services

### Academic and financial support

People with HIV can experience fluctuating symptoms; young people in families affected by HIV may also take on caring responsibilities for family members; and individuals and families living with HIV are disproportionately affected by poverty. Whatever an HIV positive student's current situation, the possibility of accessing extra help, extensions, time out from their studies, or financial assistance if they need it should be mentioned to them.

Private access to a computer is extremely important for students who have HIV, as extensive and up-to-date information and advice about living with HIV is available online, and can help them manage HIV's complex, ever-changing and significant impact on their lives. People can be extremely conscious of others discovering that they visit HIV websites. If students cannot afford their own computer and would like one, assisting them with this should be a priority.

### Accommodation

Some of the older drugs used to treat HIV need to be kept refrigerated. This is now uncommon but could be an issue for students living in university residences, given that they may wish to keep their HIV diagnosis private. In such cases, private access to a fridge should be arranged.

Having HIV and wanting to keep it private adds an extra level of stress to communal living at university. Students with HIV risk discrimination and disregard for confidentiality from housemates who do not understand

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# Studying with HIV: Downloadable information sheet

## Information for students



### HIV and other relevant services and information

#### **NCB.org.uk/LifeLinks**

A web directory to help you find information and support on all aspects of life as a young adult, as well as HIV. LifeLinks contains links and helpline numbers as well as step-by-step advice for certain situations, for example if you've had unprotected sex. You can also download our *Student Life* leaflet here – it's all about how to manage student life when you have HIV.

#### **CHIVA.org.uk**

The Children's HIV Association hosts a secure website for young people with HIV aged 24 and under, with information and social networking.

#### **MyHIV.org.uk** and THT Direct

Free information and interactive tools, online counselling and advice, anonymous question-answering, and community forums provided by THT at MyHIV.org.uk.

#### **Struggling to keep track of your meds?**

Get an app called *iDiary*, designed by young people with HIV in Leicester to help remember treatment doses and hospital appointments, or try the medication reminder tool on [MyHIV.org.uk](http://MyHIV.org.uk).

#### **Been sick?**

If you're sick within an hour of taking your meds, you need to take them again.

#### **Want to know about alcohol, drugs and HIV?**

Go to [MyHIV.org.uk](http://MyHIV.org.uk).

#### **Wondering what to have for dinner?**

Visit [FoodChain.org.uk](http://FoodChain.org.uk) for tips on using nutrition to feel well and stay healthy with HIV.

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Where we work

Policy & evidence

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LifeLinks

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HIV information and support

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Relationships and personal life

Study, work and travel


Independent living

Rights and safety

In Scotland, Wales or Northern Ireland?

Your Life leaflets

Young people's stories



LifeLinks

Welcome! If you have a question or comment about *LifeLinks*, or to report broken links, please email [HIV@ncb.org.uk](mailto:HIV@ncb.org.uk)

I need help!

If you're in immediate danger, call 999 for emergency services.

- [I have an urgent issue relating to HIV](#)
- [I have another urgent issue or want to talk to someone now](#)

I want information or support

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Have you seen our  
YOUR LIFE leaflets?

You can read our leaflets online. We hope you find them useful. Please let us know what you think by completing our feedback survey (and enter a prize draw to win a £15 Amazon gift certificate!)

YOUR LIFE leaflets

What's your story?

If you've dealt with any of the issues covered on this website, and want to share your story anonymously with other young people, please get in touch!

Find out more

# Guidelines



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- British HIV Association (BHIVA) *Standards of care for people living with HIV 2013*  
<http://www.bhiva.org/standards-of-care-2012.aspx>
- BHIVA guidelines (antiretroviral therapy, management of HIV infection in pregnant women etc.)  
<http://www.bhiva.org/guidelines.aspx>
- *HIV Patient Information and NHS Confidentiality - A policy report, 2014* – National AIDS Trust  
<http://www.nat.org.uk/media/Files/Publications/Jan-2014-HIV-Patient-Confidentiality-NHS.pdf>
- *HIV Transmission, the Law and the Work of the Clinical Team, 2013* – BHIVA position paper  
<http://bhiva.org/Reckless-HIV-Transmission-2013.aspx>
- Children's HIV Association (CHIVA) standards and guidelines  
<http://www.chiva.org.uk/professionals/>
- *Paediatric European Network for Treatment of AIDS (PENTA) guidelines for treatment of paediatric HIV-1 infection 2015: optimizing health in preparation for adult life*  
<http://onlinelibrary.wiley.com/doi/10.1111/hiv.12217/pdf>
- *Guidance on the Management of Sexual and Reproductive Health for Adolescents Living with HIV 2011* – HIV in Young People Network (HYPNet), CHIVA, British Association for Sexual Health and HIV (BASHH), BHIVA: <http://www.chiva.org.uk/guidelines/young-people/>
- *Standards for psychological support for adults living with HIV 2011* – British Psychological Society (BPS), BHIVA and Medical Foundation for AIDS & Sexual Health (MedFASH)  
<http://www.bhiva.org/StandardsForPsychologicalSupport.aspx>

**Thank you for listening.**

**We are grateful to the young adults who shared their experiences.**

**[www.ncb.org.uk/studying-with-hiv](http://www.ncb.org.uk/studying-with-hiv)**

**[hiv@ncb.org.uk](mailto:hiv@ncb.org.uk)**





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[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/339041/MSM\\_Initial\\_Findings\\_GW2014194.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/339041/MSM_Initial_Findings_GW2014194.pdf)