

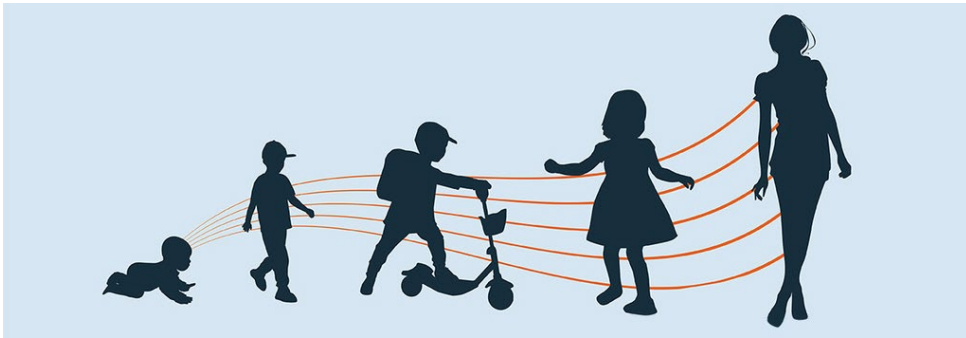
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# Growing up with HIV - the role of stigma

Katie Warburton

University of Central Lancashire, and CHIVA youth committee



# Growing up with HIV: The role of stigma

CYC  
CHIVA Youth Committee

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## Conflict of Interest

In relation to this presentation I declare that we have no conflict of interest

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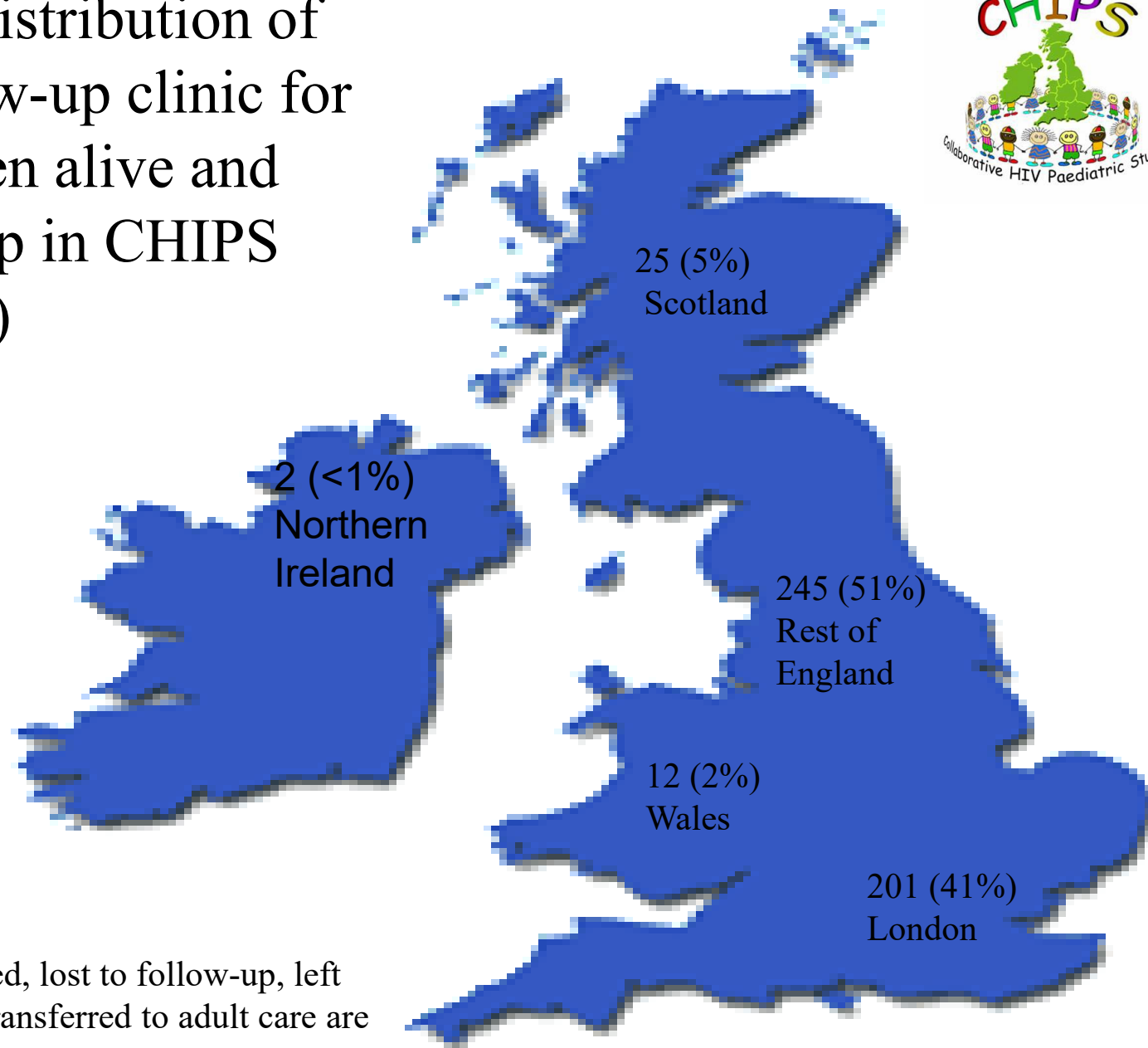


# The Plan

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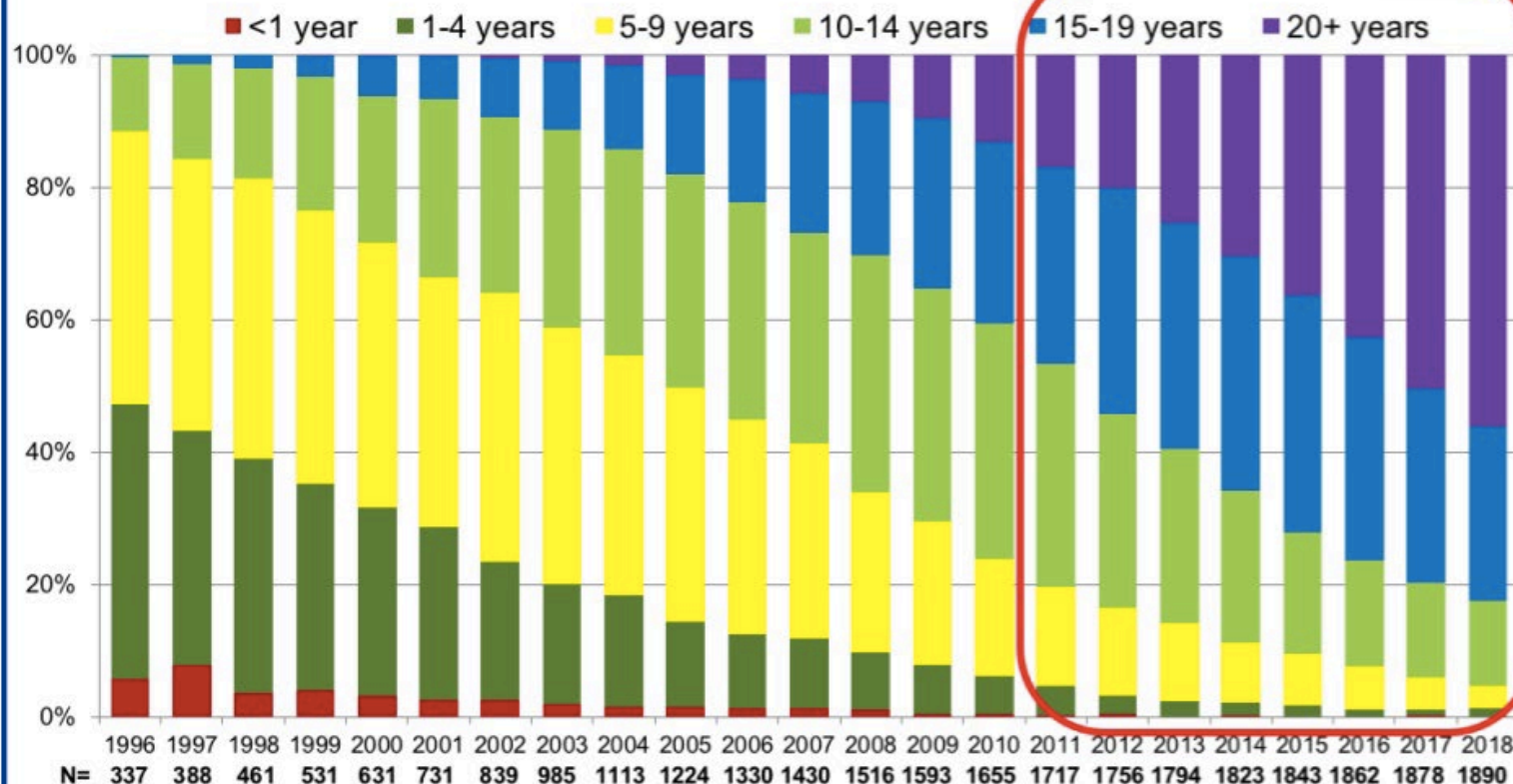
- Set the scene
- Remember that children are not young adults
- Consider some (but not all) of the challenges growing up with HIV
- Challenge yourself to make a difference

# Regional distribution of main follow-up clinic for 489 children alive and followed up in CHIPS (2021 data)



Children who have died, lost to follow-up, left the UK & Ireland or transferred to adult care are excluded

## Age of UK/Irish cohort of patients with HIV acquired in childhood, 1996-2018



Note: Data are for all children and young people alive who ever presented to medical services in the UK/Ireland, including children who have since transferred to adult care; those who subsequently died or were lost to follow-up are excluded from the year of death or loss to follow-up. All paediatric patients included, from date of first presentation to medical services in the UK, regardless of mode of acquisition (91% perinatal). CHIPS includes all diagnosed HIV-infected children known to be living in the UK/Ireland, of whom 58% were born abroad. Data for 2018 are incomplete as subject to reporting delay.

# Children newly diagnosed with HIV in the UK and Ireland between 2000 and 2018: Poster 66

## a population- level overview

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### BACKGROUND

- In recent years the UK & Ireland (UK/I) vertical HIV transmission rate (VTR) has declined to <0.3% among pregnant women diagnosed with HIV. Very few transmissions to diagnosed women still occur in the UK/Ireland, with the majority of children seen for HIV care now being born to undiagnosed women or born abroad.
- We explore the changing characteristics of children diagnosed with HIV and seen for care in the UK/Ireland in 2000-2018 using two observational population-level surveillance datasets

### RESULTS

- 1606 children were diagnosed between 2000-18; annual number of new diagnoses peaked at 157 in 2003, declining to 20-50 since 2012-18 ( $p<0.001$ ), Figure. The proportion of children born abroad increased from 63% (2000-04) to 73% (2012-18) ( $p<0.01$ ).
- Median [IQR] diagnosis age declined from 2.4y [0.3,4.9] <2005 to 0.3y [0.1,1.6] in ≥2010 among domestic-born, versus 9.2y [5.9, 12.3] and 3y [2.3, 4.5] in children born abroad, respectively.
- The proportion with children with CDC Stage C at diagnosis declined from 32% (2000-04) to 12% (2015-18) among domestic-born, and 20% to 15% among children born abroad, respectively.

Table: Characteristics at time of UK/Ireland diagnosis by place of birth

	Born UK/I (n=549)	Born abroad (n=1057)	p-value
<b>Acquisition: vertical</b>	532 (98.2%)	920 (96.3%)	0.05
<b>Ethnicity:</b>			
Black African	388 (71.5%)	925 (88.3%)	
White	50 (9.2%)	28 (2.7%)	
Other	105 (19.3%)	(9.0%)	<0.001
<b>Maternal HIV diagnosis:</b>			
Before pregnancy	43 (8.1%)	12 (1.4%)	
During pregnancy	87 (16.3%)	20 (2.4%)	
After pregnancy	402 (75.6%)	813 (96.2%)	<0.001
<b>Reason for child's diagnosis:</b>			
Child symptomatic	205 (37.5%)	419 (41.2%)	
Mother diagnosed	169* (31.0%)	124** (12.2%)	
Other family member diagnosed	166 (30.4%)	443 (43.6%)	
Other	6 (1.1%)	30 (3.0%)	<0.001
<b>Median age at diagnosis, years [IQR]</b>	1.5 [0.3,4.9]	8.6 [5.3,12.0]	<0.001
<b>CDC Stage C at diagnosis</b>	144 (26.2%)	179 (16.9%)	<0.001

### ART INITIATION

**UK/Ireland-born children:** 90% (491/545) were ever on ART; the median time from HIV diagnosis to ART initiation was 0.7y [0.2, 3.2] overall and declined from 0.9y [0.2, 4.1] <2005 to 0.4y [0.06, 1.4] in children diagnosed ≥2015 ( $p=0.002$ ).

**Children born abroad and diagnosed in the UK/I:** 87% (674/779) were ever on ART; median time from diagnosis to ART initiation was 1.2y [0.3, 3.7] overall and declined from 1.3y [0.3, 4.1] in children diagnosed 2000-04 to 0.3y [0.1, 0.4] in children diagnosed ≥2015 ( $p=0.002$ ).

**Children previously diagnosed abroad:**

Overall 26% (271/1057) of children born abroad were known to have been diagnosed abroad, increasing over time (Figure). 60% (162/271) started ART prior to entry to UK/I. Median age at ART start in the country of origin of 5.4 [2.2, 8.4] years. In contrast, for children diagnosed but not treated abroad, median age at ART start was 10.9 [7.3, 4.0] years.

\*143/169 UK/I born children diagnosed as a result of antenatal screening (from the pregnancy resulting in the transmission or a subsequent pregnancy)

\*\* 9/124 of those born abroad were diagnosed in UK/I as result of antenatal screening in subsequent pregnancy

### METHODS

- All children aged <16 years at HIV diagnosis are reported to the Integrated Screening Outcomes Surveillance Service (ISOSS), part of Public Health England's Infectious Diseases in Pregnancy Screening Programme. Children are followed up longitudinally in the Collaborative HIV Paediatric Study (CHIPS) whilst in paediatric HIV care.
- Descriptive statistics summarise characteristics of children diagnosed with HIV between 2000-18 at first diagnosis in UK/Ireland by place of birth (domestic versus abroad) and calendar year of diagnosis. Age of diagnosis is described by year of birth.

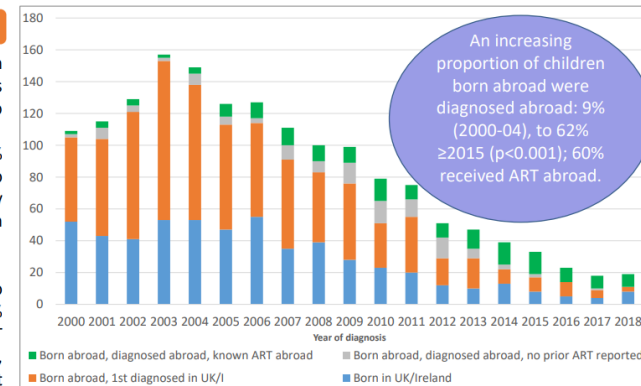


Figure: Number of children diagnosed with HIV in UK/Ireland by place of birth, diagnosis and treatment

### CONCLUSIONS

- The decline in new paediatric HIV diagnoses reflect the success of prevention of VT domestically and globally. In the UK specifically there is an uptake of over 99% of the HIV screening test in pregnancy, supported by the work of the Infectious Diseases in Pregnancy Screening Programme. An increasing proportion of children born abroad are now arriving already diagnosed and treated.
- Initiatives to increase ascertainment of HIV status in children have included the 'Don't forget the children' campaign in the UK/I. The antenatal screening programme offers a further opportunity for sibling testing both for children born in the UK/I and abroad.
- Paediatric HIV surveillance remains vital to ensure this vulnerable population receives high quality specialist care and optimal health outcomes.

#### FUNDING AND GOVERNANCE

ISOSS is funded by Public Health Infectious Diseases in Pregnancy Screening Programme. CHIPS is funded by NHS England. Patient data is collected under legal permissions granted to PHE under Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002

#### ACKNOWLEDGEMENTS

Thanks to respondents who report to ISOSS and CHIPS and to the rest of the current ISOSS and CHIPS teams. Any views expressed are those of the authors and not necessarily those of the funders.

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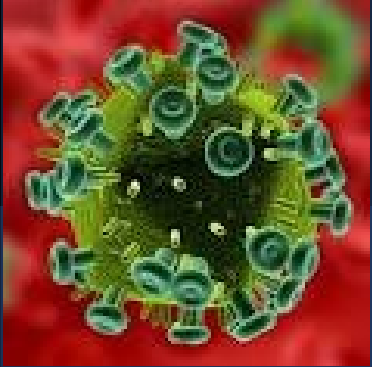
# Children's Rights

- The best interests of the child must be paramount in decisions about a child
- Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously
- Every child has the right to the best possible health

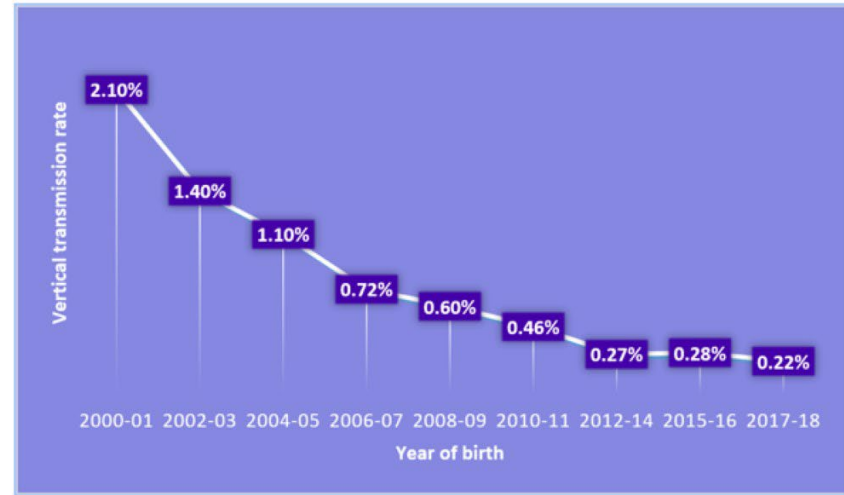
(UN Convention of the Rights of the Child, 1989)



# Testing (during or before pregnancy)



Vertical transmission in UK, 2000-2018



Data for 2000-11 from Townsend *et al.* AIDS 2014; data for 2012-14 from Peters *et al.* CID 2016; data for 2015-16 from Peters *et al.* HIV Drug Therapy Glasgow 2018; data for 2017-18 from Peters *et al.* CROI 2021

# Testing

Don't forget the children

- Implications of a positive result
- Unable to cope with positive result
- Child / Adolescent is well
- Age of young person
- Feeling of guilt
- Fear of disclosing own diagnosis
- Fear of child disclosing to others





# STIGMA!



# Naming HIV to Children

- “Health practitioners should consider telling children that they have HIV from the age of 6, taking into account their cognitive capacity and any current social considerations, aiming for most children knowing the name of their diagnosis before the age of 9. Health practitioners should lead this, in collaborative partnership with carers and voluntary sector and social care services”



# STIGMA!



Sharing – within households

# Sharing – with others

Family

Friends

School

Partners

Work

“My brother  
doesn’t know,  
we share a  
bedroom”

“I’m growing  
up with a  
sexually  
transmissible  
infection”

“I live a  
constant lie”

“I want to tell my  
best friend but  
my Mum says no”





# STIGMA!



# Taking meds is complex

- Unaware of diagnosis
- Hiding medication
- Sleep overs
- School trips



# STIGMA!

# CHIVA Youth Committee





# Our challenge to you

- Watch Life Growing Up  
[https://www.youtube.com/watch?v=HHfW\\_uVzx8g](https://www.youtube.com/watch?v=HHfW_uVzx8g)
- Educate someone
- Offer to talk about HIV at your local school
- Share CHIVA approved resources
- Remember that the experiences of young adults who have grown up with HIV are different. Ask about when they found out about HIV and how that made them feel?

You have  
No Idea

Any Questions?