Growing up with HIV: Reflecting on 30 years through a child health lens

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Chiva

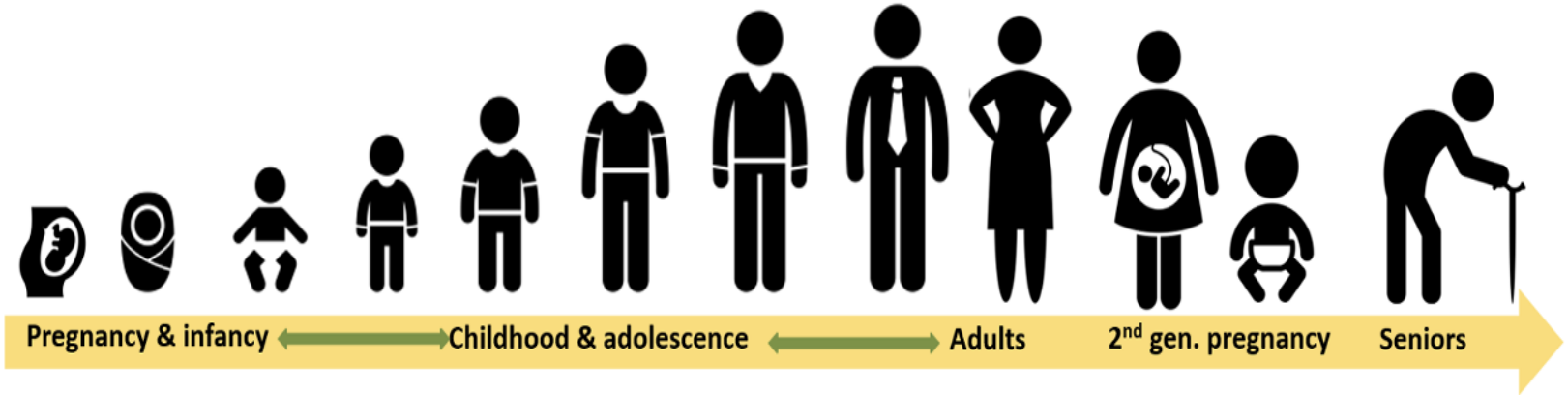
GROWING TOGETHER FOR HEALTH AND HAPPINESS

No conflicts of interest

No photos or recording of shared video and audios please

Plan

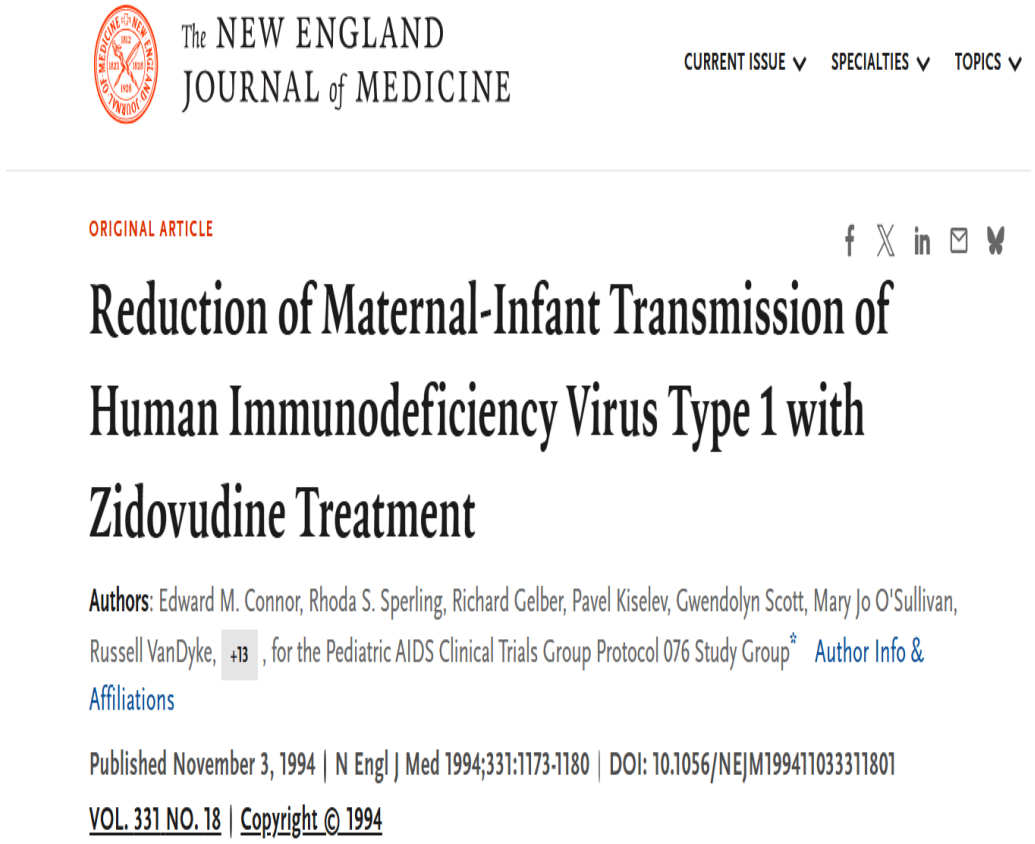
- Vertical transmission
- Medicines
- Psychosocial support
- Challenges
- Looking ahead (where next?)



Vertical transmission

- ✓ Vertical transmission in England remains below 0.4% (women diagnosed before delivery) (2016-2023) (Peters et al, 2026)

- ✓ BHIVA guidelines (2025) on the management of HIV in pregnancy and the postpartum period



The NEW ENGLAND JOURNAL of MEDICINE

CURRENT ISSUE SPECIALTIES TOPICS

ORIGINAL ARTICLE

Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment

Authors: Edward M. Connor, Rhoda S. Sperling, Richard Gelber, Pavel Kiselev, Gwendolyn Scott, Mary Jo O'Sullivan, Russell VanDyke, +13 , for the Pediatric AIDS Clinical Trials Group Protocol 076 Study Group* Author Info & Affiliations

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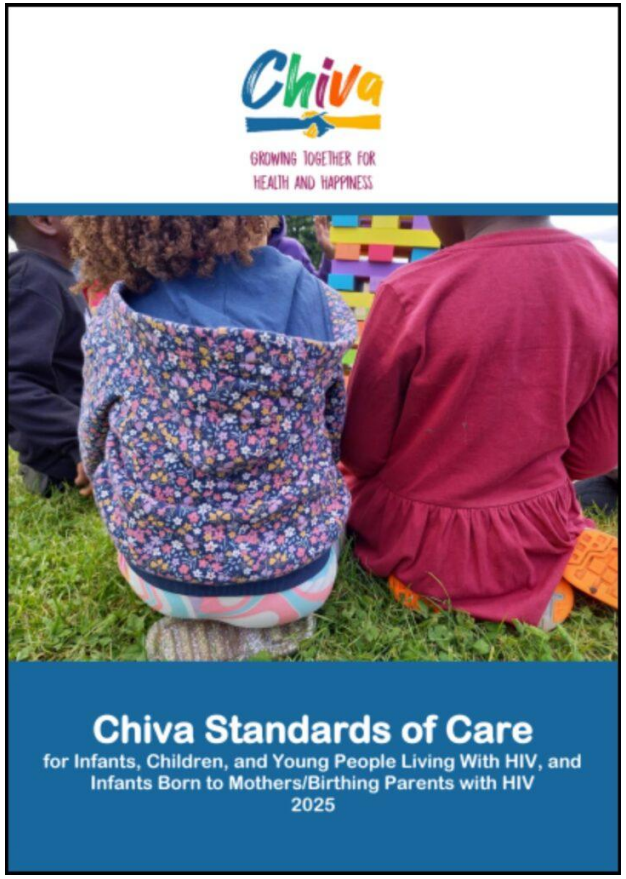
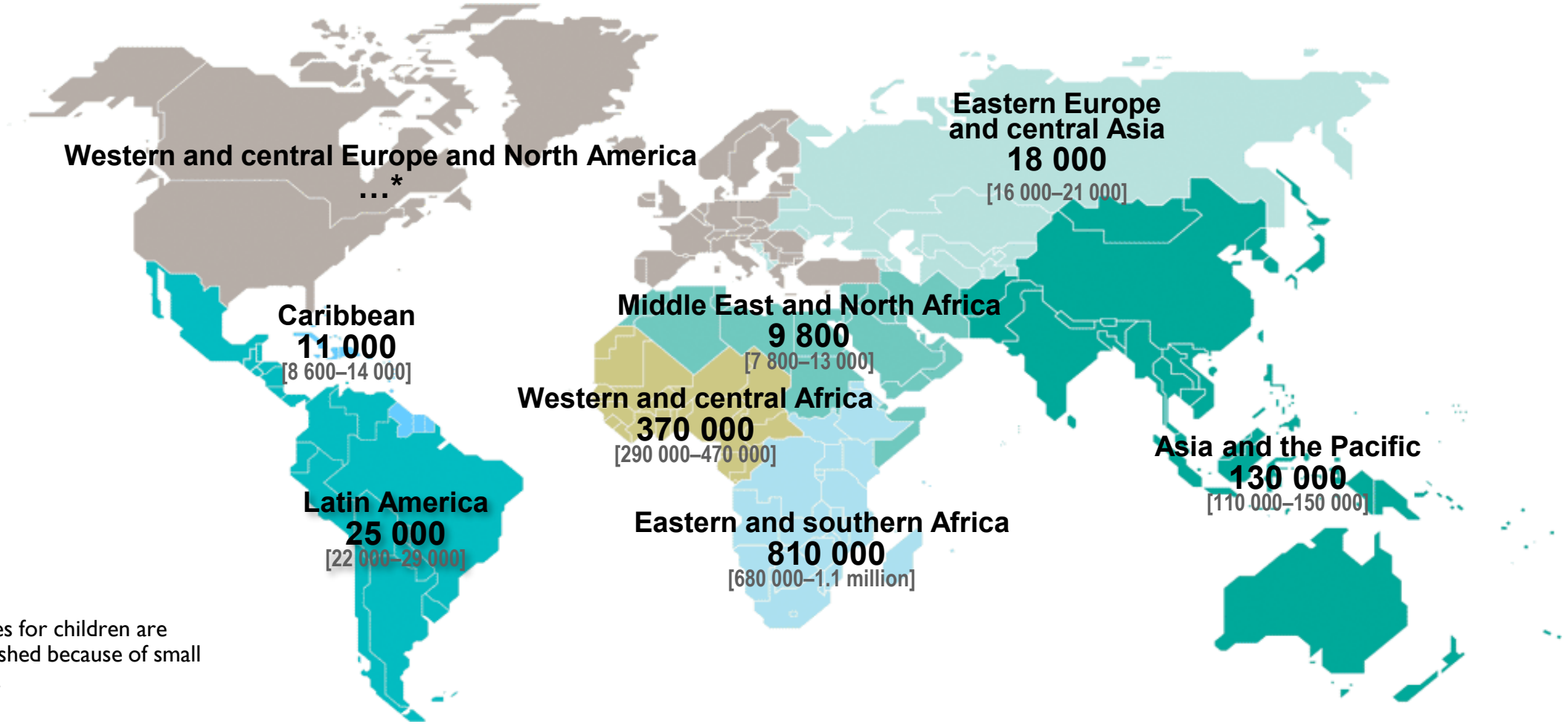
Children are not small adults

- Anatomically and physiologically different
- Organs still developing
- Growing
- Infants can become sick very quickly
- Viral loads higher and higher for longer
- Higher absolute CD4 count (percentage less variable)
- Metabolism different
- Pharmokinetics different
- Availability, tolerability, acceptability different
- Growing up with HIV
- Most likely other family members living with HIV



Children (<15 years) estimated to be living with HIV | 2024

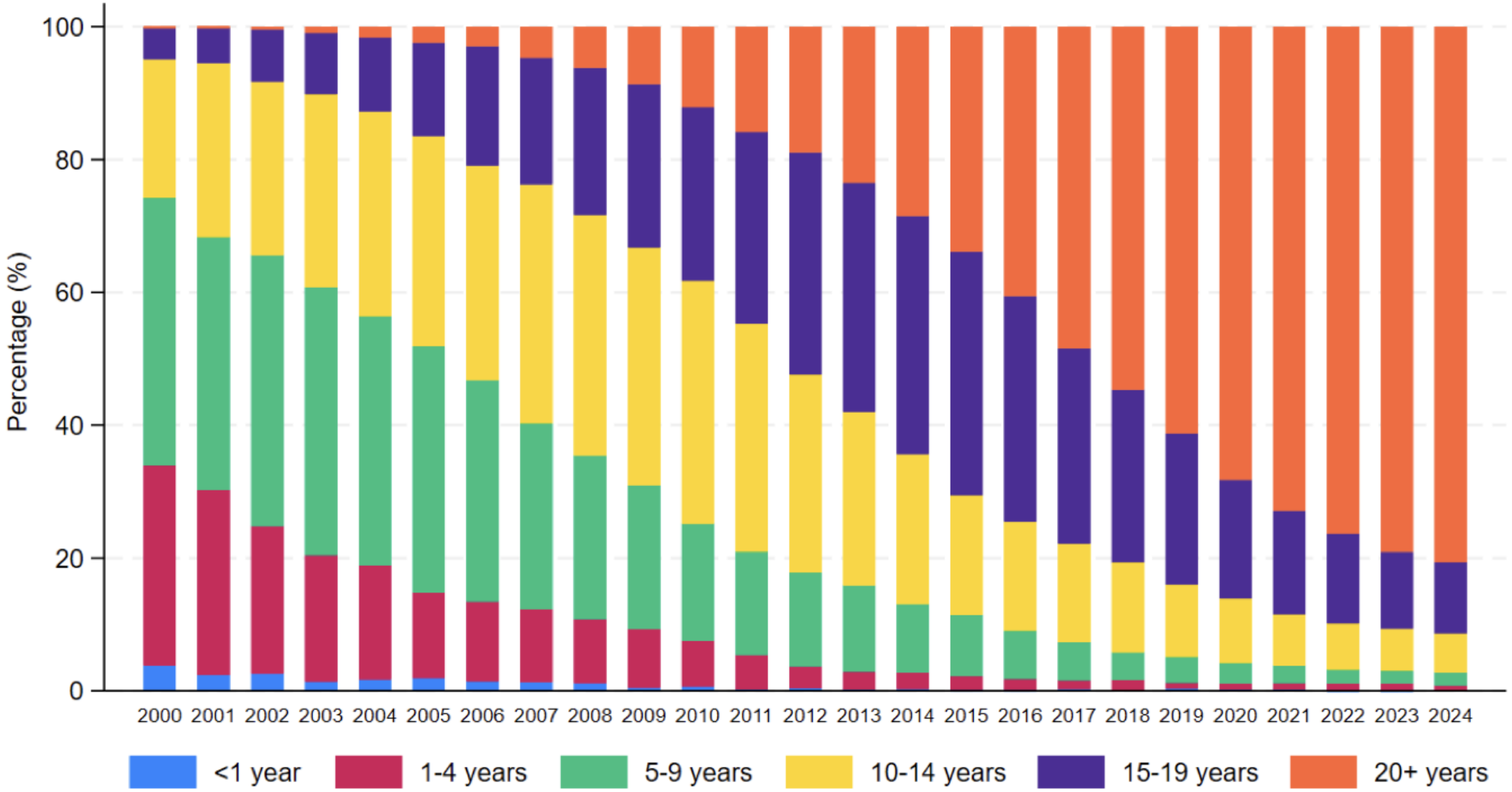


*Estimates for children are not published because of small numbers.

Total: 1.4 million [1.1 million–1.8 million]

Source: UNAIDS 2025 epidemiological estimates

Age distribution of people in England with HIV diagnosed in childhood (n=1,569), 2000-2024

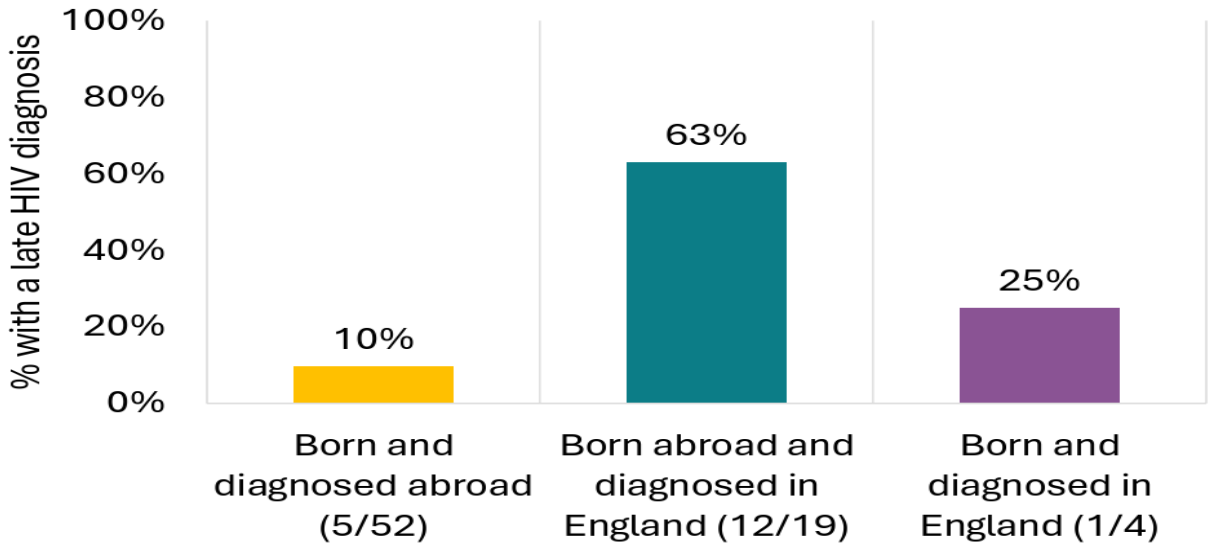


Late Diagnosis

CYP presenting with a late HIV diagnosis

- 24% (18/75) of CYP presented with a **late HIV diagnosis***
- Proportions of late diagnoses were highest among children born abroad and diagnosed after arriving in England (63%,12/19)
- Median CD4 count at presentation was 126 cells/mm^3 (IQR 79-322 cells/mm^3)
- 94% (17/18)** were on ART at most recent report

***1 CYP not on ART at time of reporting, but due to start ART*



**Late diagnosis was defined by the presence of an AIDS-defining condition at presentation, and/or:*

- *≥5 years old: CD4 ≤350 cells/mm^3*
- *1-5 years old: CD4 <500 cells/mm^3*
- *<1 year: CD4 <750 cells/mm^3*

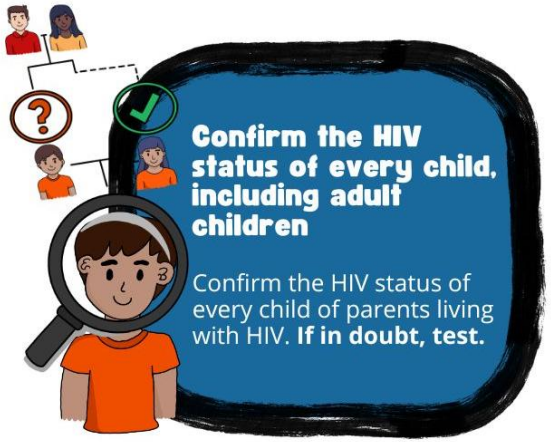
Testing and treatment 95-95-95

- In 2025, 88% [70–>98%] of all people living with HIV knew their HIV status. Among people who knew their status, 89% [71–>98%] were accessing treatment. And among people accessing treatment, 95% [76–>98%] were virally suppressed.
- **Among children aged 0–14 years the 95–95–95 targets were 64%, 84%, 85%**

UNAIDS, 2025

Don’t Forget the Children 2026

The HIV status of all children of adults living with HIV, including adult children, should be known and confirmed as a matter of clinical urgency

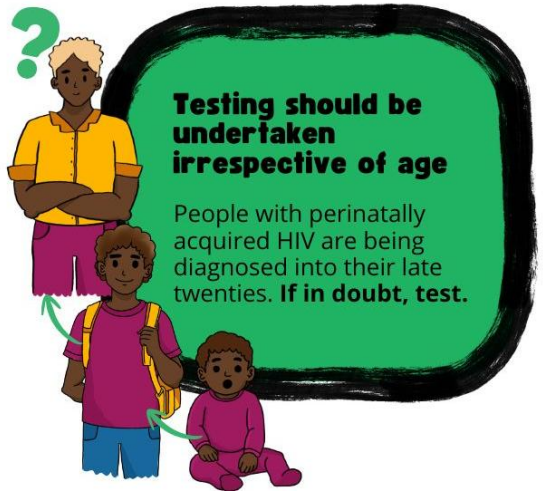


Confirm the HIV status of every child, including adult children

Confirm the HIV status of every child of parents living with HIV. **If in doubt, test.**

See the proof

Verbal reassurance is insufficient. Misunderstandings can occur regarding whether an HIV test has been done, so documentation should be reviewed. **If in doubt, test.**



Testing should be undertaken irrespective of age

People with perinatally acquired HIV are being diagnosed into their late twenties. **If in doubt, test.**

Review testing annually

Children and young people may join a family later or move to the UK after the parent’s diagnosis. An annual review should include checking that you have an accurate list of a person’s children. **If in doubt, test.**

A message from the Chiva Youth Committee, who are young people growing up with HIV

Every child deserves to grow up healthily. Early testing can help identify when someone has been born with HIV or acquired HIV in early life. This early detection means each person can receive the right medication and benefit from a long-term healthcare plan.

Overall, this helps protect children and young people from serious long-term illnesses linked to HIV. The benefit of this is that the child will have a happy, long, and healthy life.
No child should be forgotten!

If in doubt, test!

Scan to download the full document (final draft) from Chiva.org.uk/tools

BHIVA British HIV Association

nhivna National HIV Nurses Association

BASHH British Association for Sexual Health and HIV

The medicine journey

- ✓ IV AZT used in children and effective (Pizzo et al, 1988)
- ✓ 1990 FDA approved AZT for children
- ✓ In 2003 triple and quadruple therapy changed hospital admissions, morbidity and mortality significantly in the UK (Gibb, 2003, Judd et al, 2007)
- ✓ CHER Trial – initiate treatment straight away (Viorali et al, 2008)
- ✓ ODESSEY. CHAPAS, BREATHER
- ✓ CARES, MOCHA, IMPALA, LATA – injectables trials

- ✓ **PENTA / EACS Treatment Guidelines**

PENTA / EACS:
Initiation of ART in Children and Adolescents

- We recommend the initiation of ART in all children and adolescents diagnosed with HIV
- We emphasise the need for urgent diagnosis and initiation of treatment for infants diagnosed with HIV, due to their high risk of rapid disease progression
- We endorse the "U=U" campaign (undetectable (defined as VL < 200 copies/ml for > 6 months) = untransmissible) for sexual transmission of HIV, which is particularly relevant to sexually active adolescents and is a motivational message to enhance adherence and prevent onward HIV transmission
- Although viral suppression markedly reduces transmission, there is no definitive evidence confirming that "U=U" can be applied to vertical transmission (including transmission through breastfeeding)

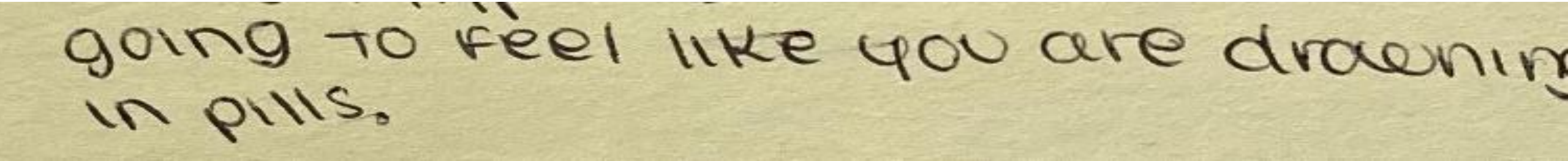
Medicines are an anguish

“if I don’t take it I sometimes I used to think like **maybe I don’t have it lets just not take it**”

“that’s when like sleepovers then became a thing and then it was harder for me at first cos it was like I have to take medicine and my mum would be like oh **you can’t go you can't go but I’d have to be like having to hide the fact that I take this medication which was kinda hard**”

“it’s just like death death death and it needs to stop”

“the pressure of like doctors being judgemental with you and I feel like cos at one point I stopped taking mine for like a year and I was getting problems a bit ill but like I wasn’t seeing it myself and I was going to my appointments the doctors were like its very easy to take medication like its just one pill a day its not as easy as you think it is like doctors cant relate to what you feel and how your day to day life is with HIV”



Perinatally acquired HIV - some issues needing attention

- **Rates of viral suppression are lower** in young adults with perinatally acquired HIV when compared to adults with non perinatally acquired HIV

- **Rates of disengagement in care are higher** in young adults with perinatally acquired HIV than in older adults with horizontally acquired HIV - early years following transition to adult care is a particular time of risk for disengagement

- **Rates of triple class drug resistance are higher** in adults with PHIV, when compared to aged-matched adults with NPHIV

- **Evidence of poorer outcomes** (single clinic cohort study)

- Psychosis x 6 compared with age-matched peers, not living with HIV (Malik et al, 2017)
- 21% diagnosed with anxiety or depression
- Mortality & Malignancy associated with advanced HIV

Emerging clinical complexities (despite viral suppression)

Cardiometabolic

Subclinical cardiac and vascular changes

Cardiomyopathy

Cardiac fibrosis and inflammation

Higher rates of hypertension/diabetes

Adverse bone health

Respiratory

Higher rates of chronic lung disease
- Clinical or radiological

U.K. 47% abnormal chest x-ray
- 8% bronchiectasis or bronchiolitis

U.S. higher rates fixed airways obstruction

Sexual and reproductive health

Higher rates of HPV persistence

Reduced fertility

Third generation outcomes:
- Preterm delivery
- Low birth weight/S-G-A
- HIV exposed uninfected infants?

Neurocognitive and mental health

Legacy effects of advanced HIV on cognition

Higher rates of mental health disorders:
- Anxiety
- Depression
- Psychosis
- PTSD

Henderson Trop Med ID 2024, Majonga Curr Op HIV/AIDS 2024, Rakhamina Curr Op HIV/AIDS 2024, Mallik Curr Op HIV/AIDS 2025.

Psychosocial considerations

Impacts on social relationships and personal relationships

Challenges for young people **around starting sexual relationships**

HIV as a 'family experience'

- Secrecy
- Isolation

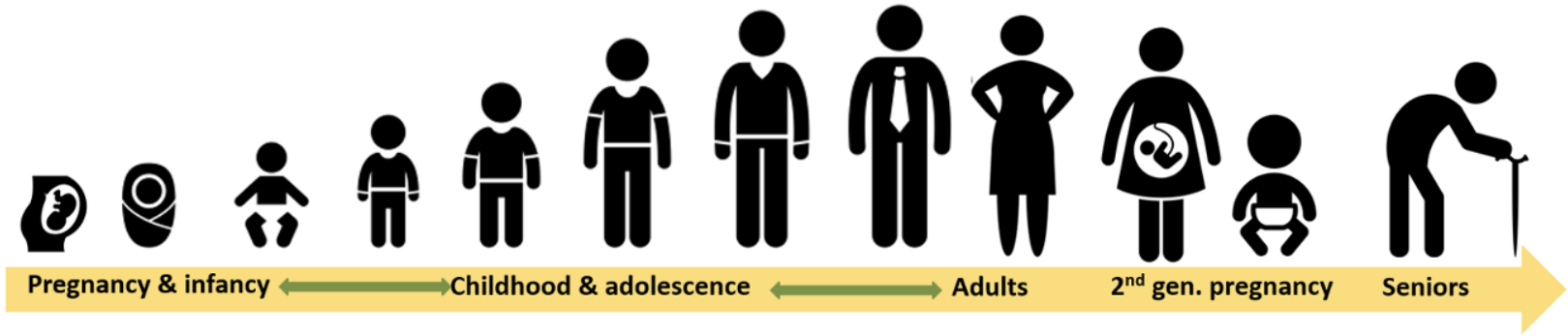
Adverse Childhood Experiences

Increased focus on need to understand long term outcomes

•People born with HIV are getting older – this is a massive success, in UK most are now adults

•Long-term clinical outcomes are starting to emerge, suggesting potential co-morbidities which may be related to lifelong HIV and ART exposure

•Important gaps in understanding identified concerning long term outcomes – to understand what living with perinatally acquired HIV looks like in the fourth decade



Developing a social model to address psychosocial well being

- **Empowerment** – equipping young people with knowledge & skills, ensuring they have opportunities to have their voices heard
- **Building confidence & skills** for young people
- **Creating Peer Support opportunities** & community building activities
- **Developing a Life Span approach** to delivering care and support
- **Enhancing wider public understanding of HIV**

Intergenerational Stigma

AIDS CARE
2026, VOL. 38, NO. 6, 1253–1267
https://doi.org/10.1080/09540121.2025.2609896

It's time to tell: early naming of HIV to children can break the cycle of intergenerational stigma and reduce self-stigma.

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ABSTRACT

Children living with HIV are not routinely informed of their HIV diagnosis: open communication is not yet standard global practice (Warburton et al., 2022). This article presents data from a qualitative study aimed at establishing an evidence-based approach to telling children they are HIV positive. An arts-based narrative inquiry methodology was used. Sixteen young people and ten parents were recruited via voluntary sector organizations in the United Kingdom and shared their experiences through focus group participation. Participants used arts resources to create something of their choice as a vehicle to share their untold stories. Creative pieces made by participants included masks and boxes illustrating the experiences of stigma and self-stigma and highlighting the need felt by participants to hide HIV. Stigma prevents HIV-related conversations and creates self-stigmatization. Secrecy in family homes exacerbates self-stigma and a cycle of intergenerational stigma, as a new concept, was identified in the narratives. The burden of hiding a health diagnosis is an overwhelmingly negative experience for children and their families. Early naming of HIV and open communication will reduce the weight of self-stigma and intergenerational stigma experienced by children and families. It is time to break the cycle of stigma.

ARTICLE HISTORY
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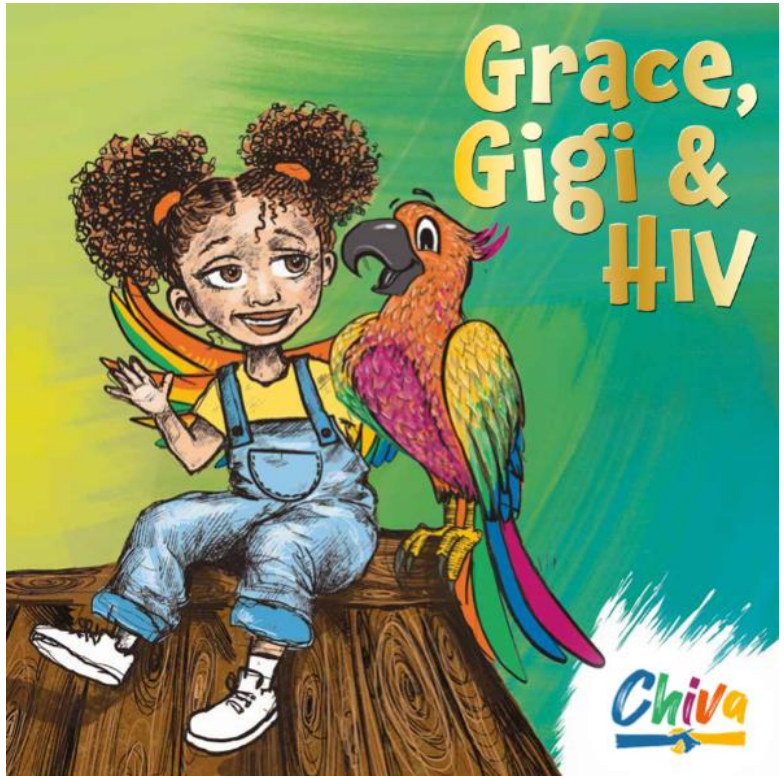
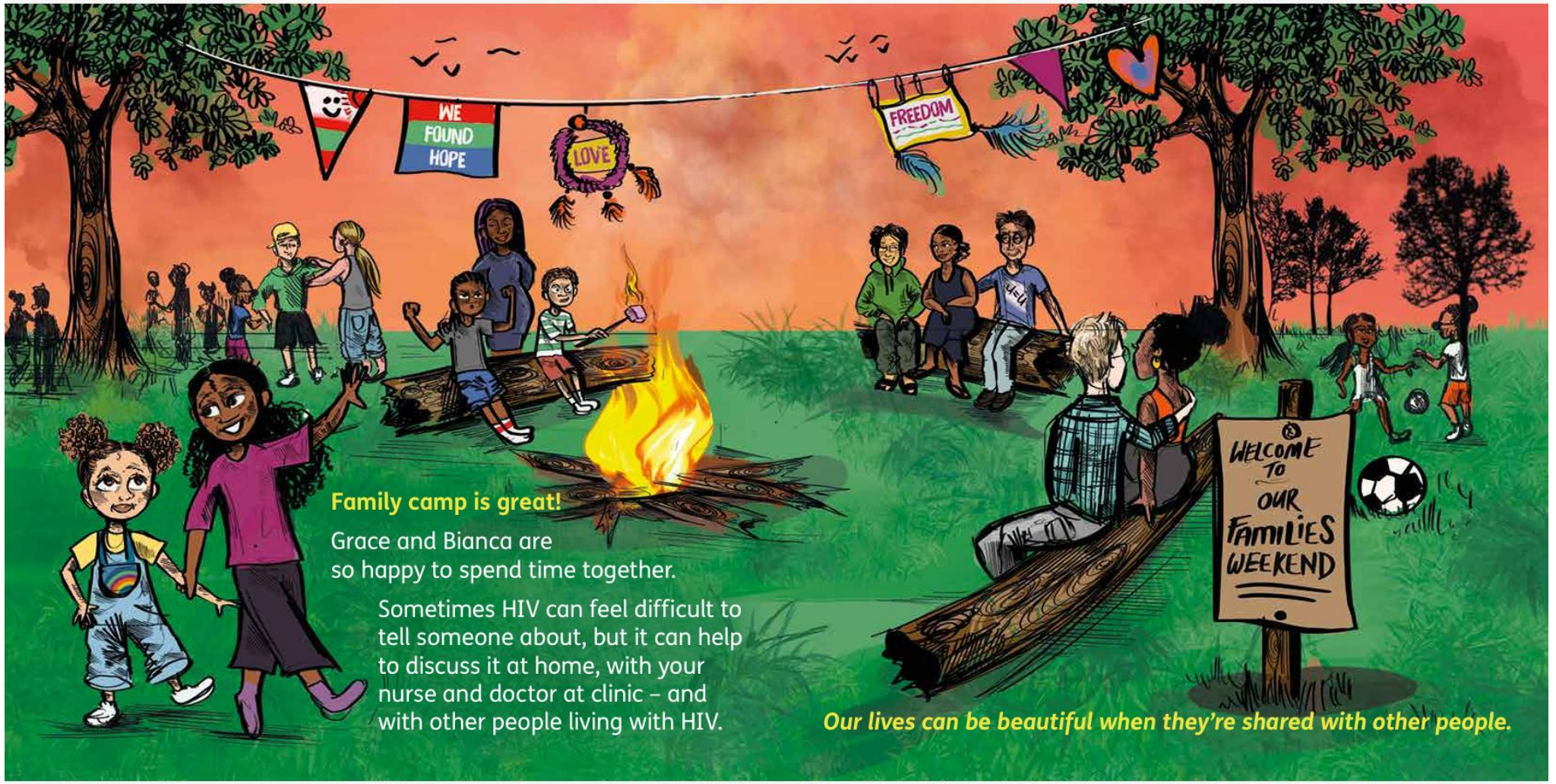
KEYWORDS
HIV; children; disclosure; stigma; good health and well being

Talking about HIV to children

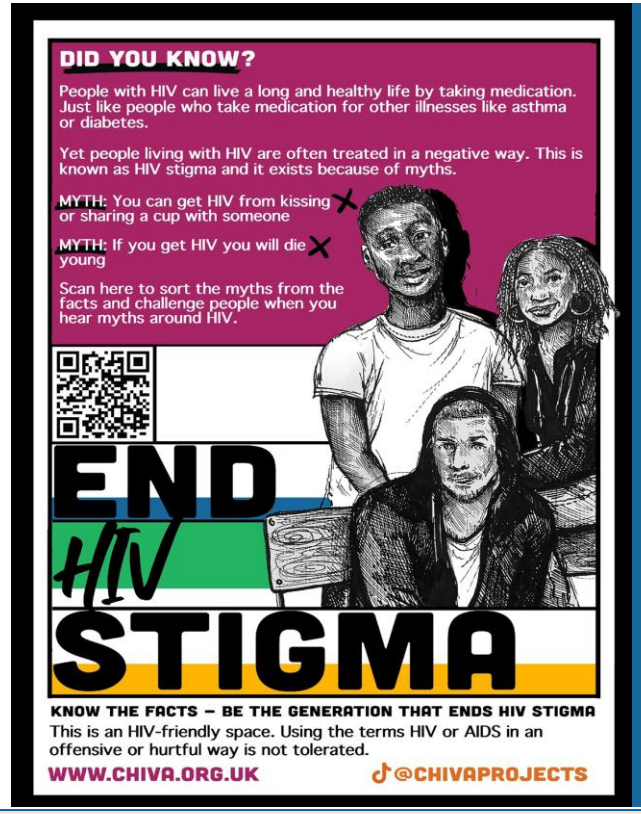


Families weekends



Youth Participation

- Chiva Youth Committee (CYC)
- Youth peer roles in projects
- Project leadership roles for former participants
- Camp Leaders at F2B Camp
- Campaigns & Resource development

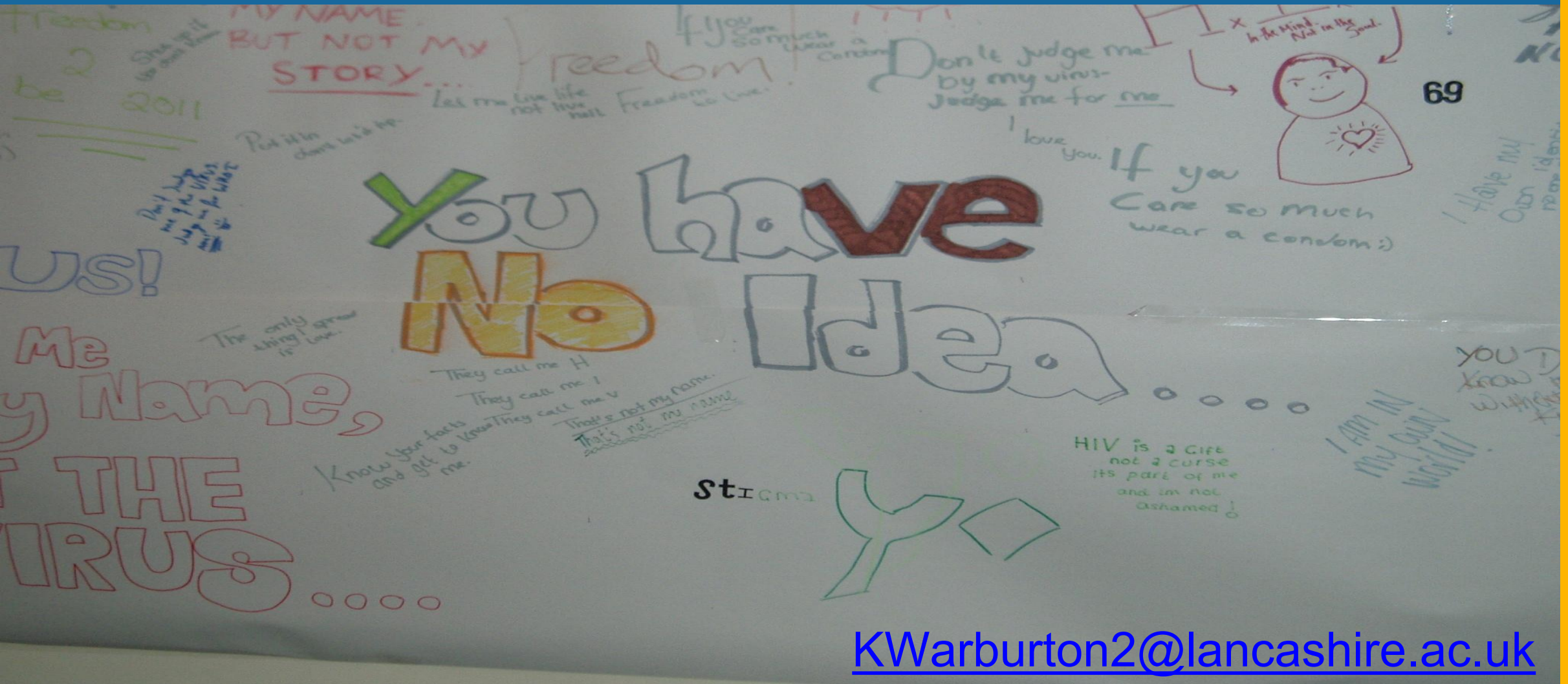


Chiva Current Strategic Objectives

- Develop comprehensive and integrated support into adulthood
- Assess the impact of Chiva's support programmes
- Enhance public awareness and understanding of HIV
- Ensure young people participate fully in the research agenda and evidence generation
- Enhance professional understanding of best practices in HIV
- Influence the research and policy agenda

Mission: To ensure that children, young people and young adults growing up with HIV become healthier, happier and more in control of their own futures.

Thank you for listening



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