



Growing up with HIV

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Conflicts of Interest

- Nil

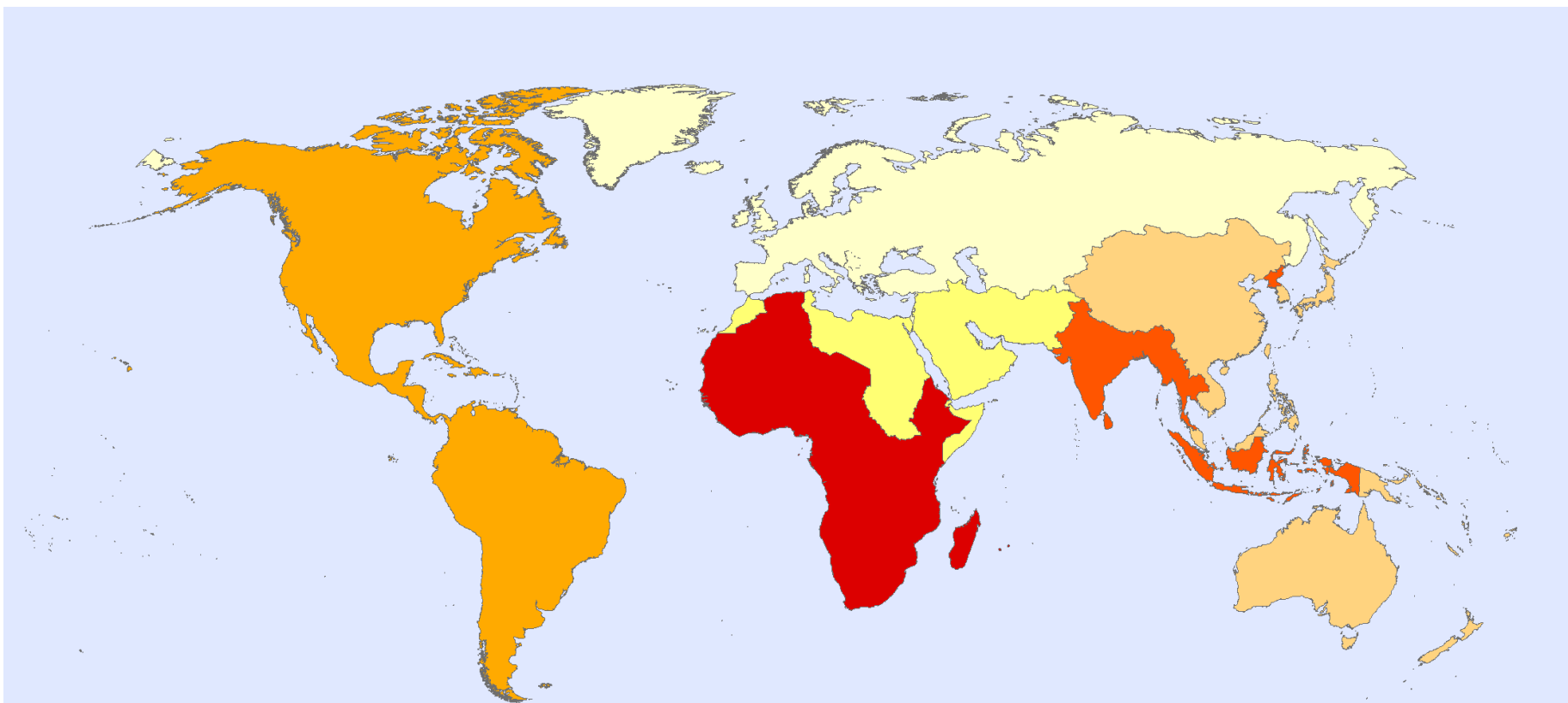
Global burden

- 2011 34 million people living with HIV worldwide
- 2011 3.3 million children living with HIV are under 15 yrs
- In 2007 adolescents and young adults 15-24yr accounted for 45% of new HIV infections worldwide



Children (<15 years) estimated to be living with HIV, 2011

By WHO region



Number of children by WHO region

Europe: 13 000 [11 000-15 000]	Americas: 63 000 [48 000-79 000]
Eastern Mediterranean: 33 000 [23 000-45 000]	South-East Asia: 140 000 [120 000-160 000]
Western Pacific: 36 000 [30 000-43 000]	Africa: 3 100 000 [2 700 000-3 400 000]

Total: 3 300 000
[3 100 000-3 800 000]

0 875 1,750 3,500 Kilometers

The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

Data Source: World Health Organization
 Map Production: Public Health Information
 and Geographic Information Systems (GIS)
 World Health Organization



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Ageing Cohort Globally

- 2.1 million children <15 yrs

Ferland et al 2010. Survey of children accessing HIV services in a high prevalence setting: time for adolescents to count?

~ 25,000 Zimbabwean children - 25% 10-14yrs
17% 15-19yrs

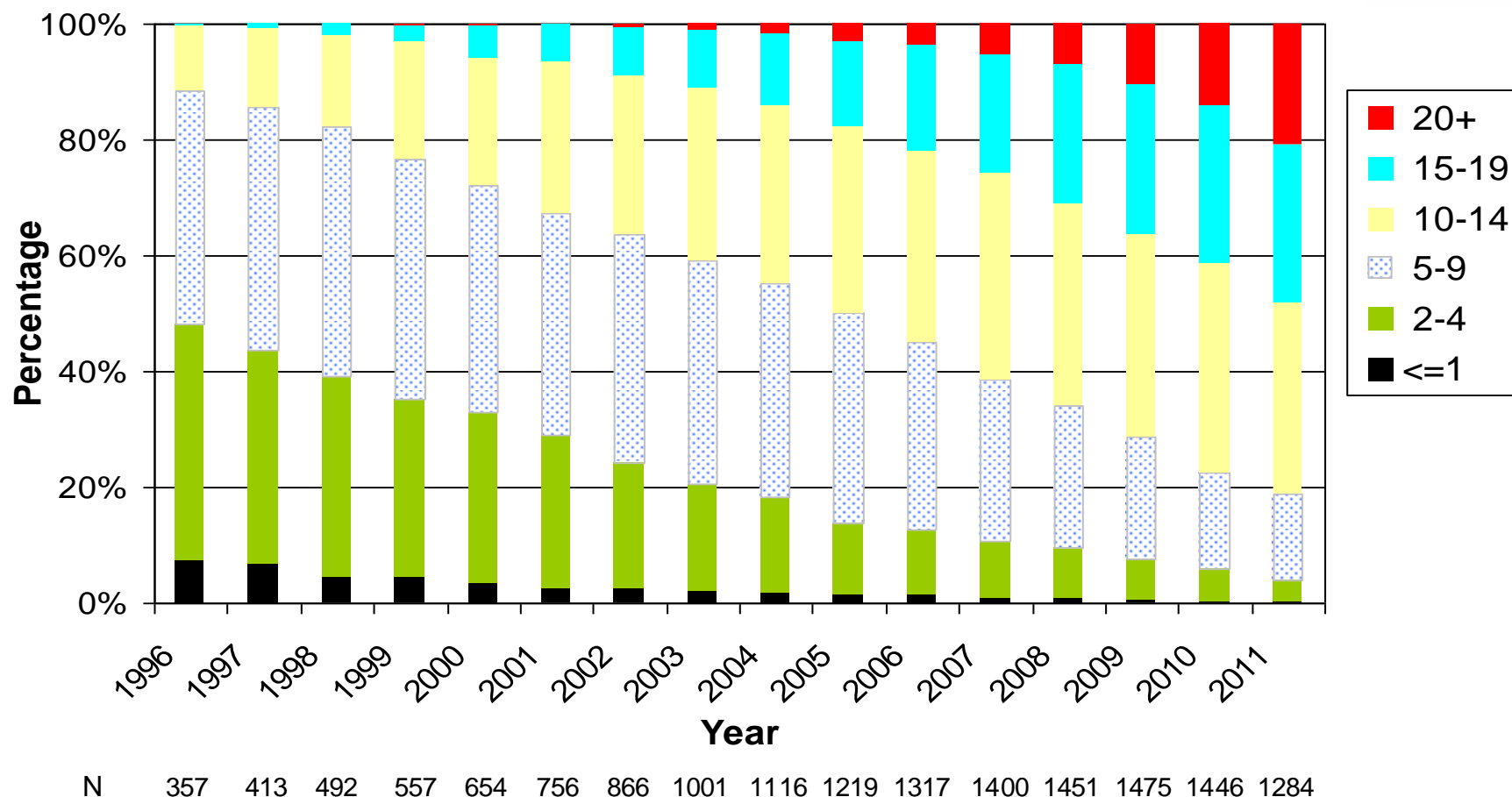
CHIPS UK Data March 2010

- 1,645 children
- 520 aged 15+
- 206 transferred to adult care



Median age HIV infected European paediatric cohorts
>10yrs

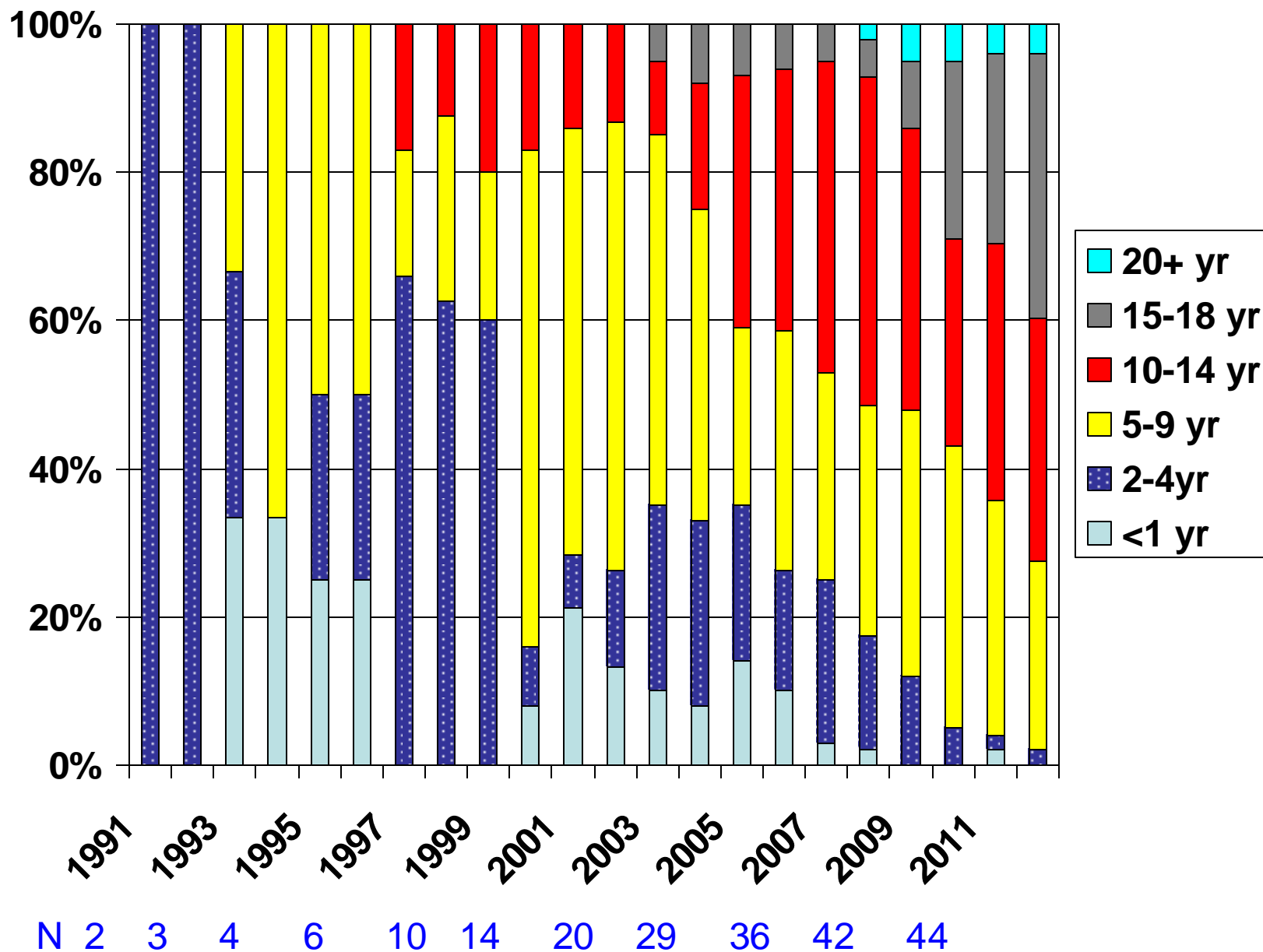
Age* of children including those transferred to adult care by year, 1996-2011

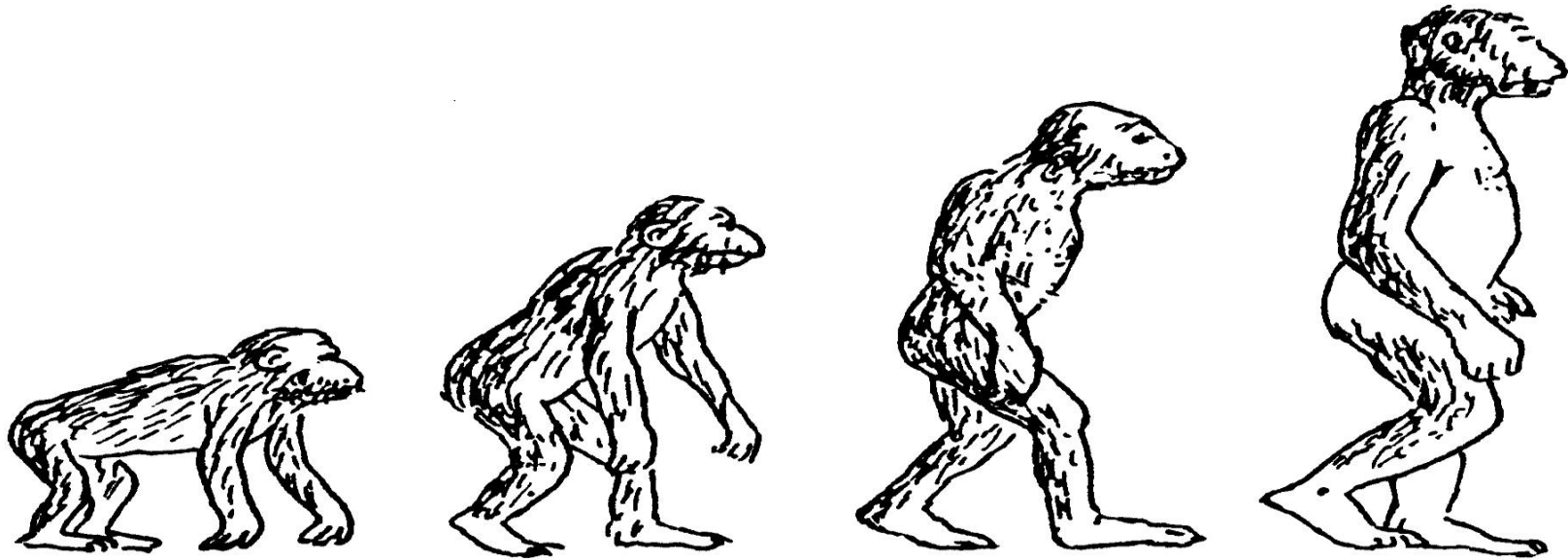


Data are for all children and young people in CHIPS (excluding those who have died or who are lost to follow-up) as well as young people in CHIPS who have transferred to adult care

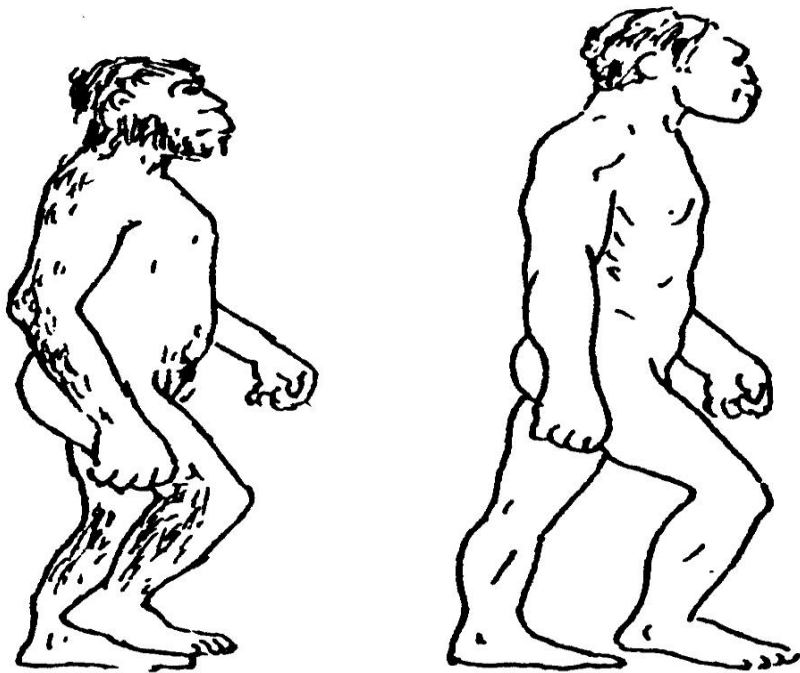
Starship Children's Hospital HIV clinic data

Age of children including those transferred to adult care by year, 1991-2012





Adolescents



Time of change:

Downside: Increases in

- ✗ Challenging behaviours
- ✗ Disaffection with school
- ✗ Risk taking –drugs, alcohol etc.
- ✗ Pregnancy & STD's
- ✗ Depression
- ✗ Self harm

Upside: opportunities for

- ↑ Friends
- ↑ Relationships
- ↑ Freedom
- ↑ Creativity: music, clothes, dance
- ↑ Developing identity and control
- ↑ Excitement and fun often without responsibility

Adolescence

The Youth2000 Survey Series

Dr S Denny and Adolescent Health Research Team

1. National Secondary School Student Surveys

2001 - 9,699 adolescents

2007 - 9,107 adolescents

2012 - 8,500 adolescents

2. School Climate Surveys

2007 School Climate

2012/13 School Climate

3. Alternative Education Surveys

2009 - 335 adolescents

2000 – 268 adolescents

4. Teen Parent Unit Survey

2006 - 220 adolescents

5. Wharekura Survey

2007 – 22 kura and 677 taiohi*

10 YEARS OF THE YOUTH HEALTH
AND WELLBEING SURVEYS:
WHAT HAVE WE LEARNT?

www.youthresearch.auckland.ac.nz

School of Population Health, University of Auckland

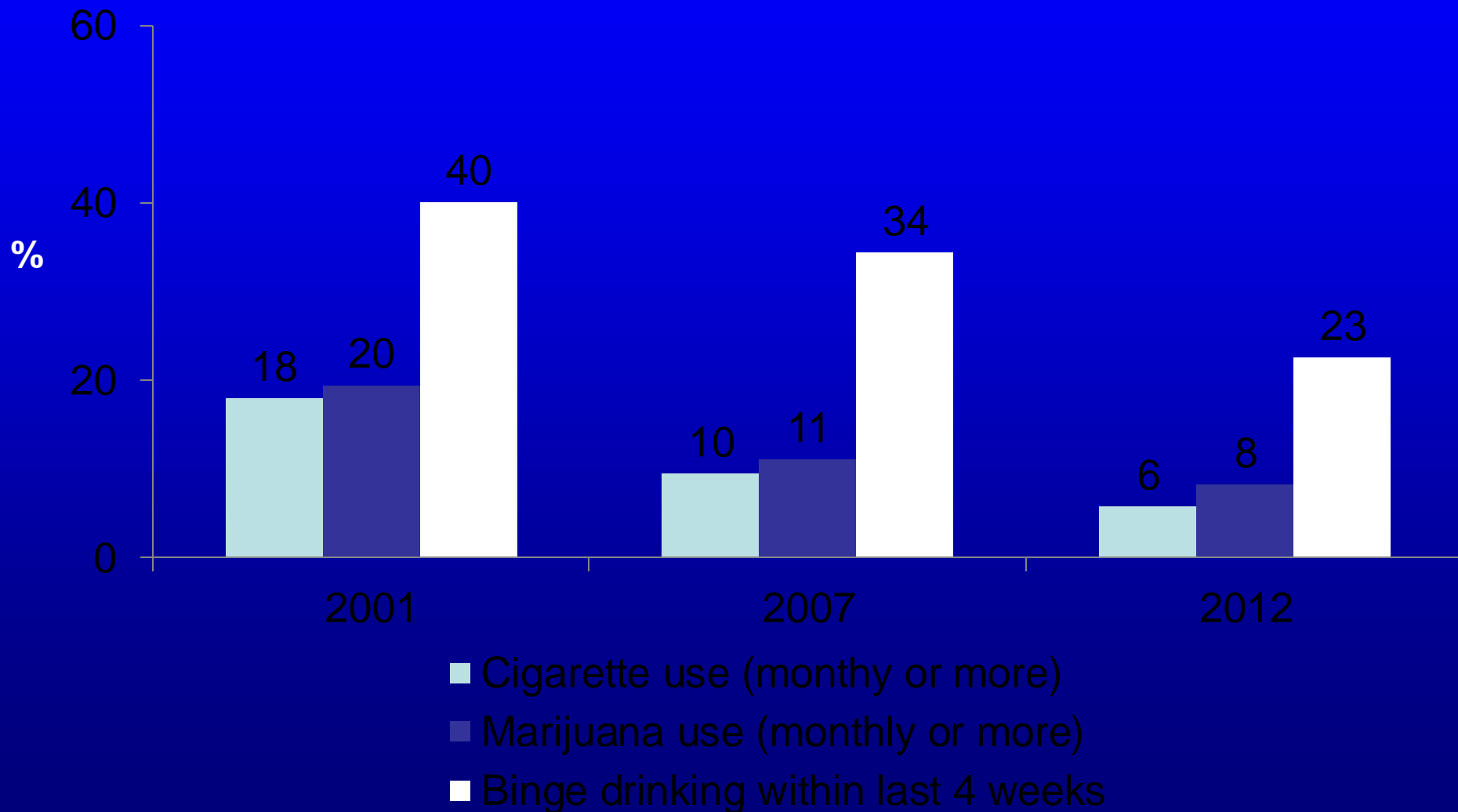
*confidential report

The Youth 2000 survey series

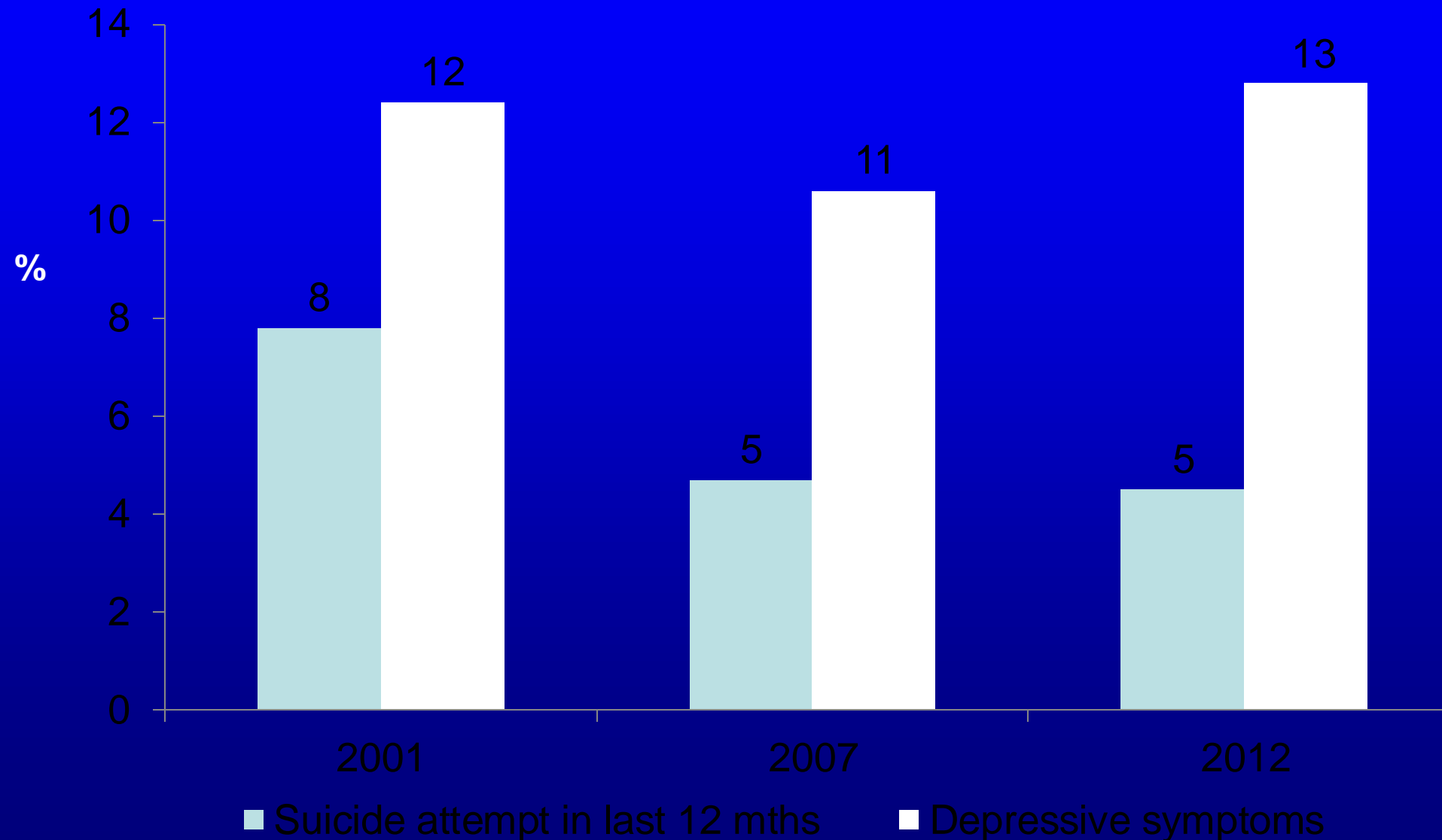
Violence



Substance use



Suicide attempts & depressive symptoms



Sexual and reproductive health



Greater rate of risky behaviours in youth with chronic conditions

- 2002 Swiss multicentre Adolescent survey 7548 16-20yr olds
760 with chronic illness vs 6493 healthy controls
- Daily smoking OR* 1.18 (1.01, 1.38)
- Illegal drugs 1.23 (0.94, 1.60)
- Early sexual debut 1.26 (0.97, 1.63)
- Eating disorder 1.26 (0.93, 1.71)
- Violent acts 1.29 (1.06, 1.56)
- Antisocial acts 1.35 (1.14, 1.59)
- Alcohol misuse 0.99 (0.83, 1.17)
- more likely to report 3 or ≥ 4 simultaneous behaviours

* Adjusted for age, gender, academic track, parents education, health perception and depression

Case: 17 yr old

Diagnosed at 2yrs

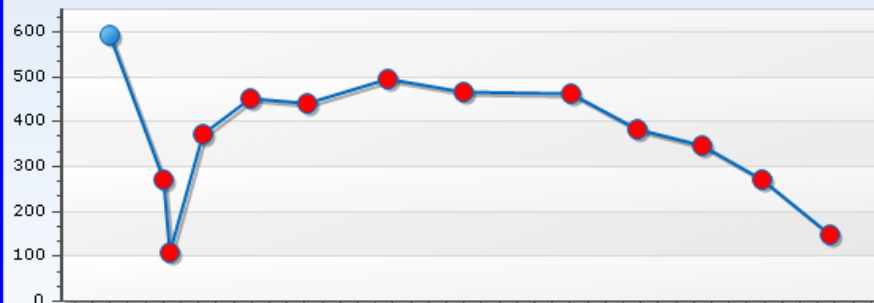
CD4 420 (26%) VL 307,000

- Mother HIV +, sib HIV -, father left
- “family is under considerable stress and turmoil”
- “happy child but very overactive”
- Zidovudine, lamivudine, nelfinavir started
- “excellent adherence” CD4 1510 VL 39750
- Recurrent fever - antibiotic prescription not filled “ on too many drugs already”
- CD4 1140 (44%) VL 57000
- Move to live with extended family
- Counselling, significant behavioural/financial difficulties

Progress

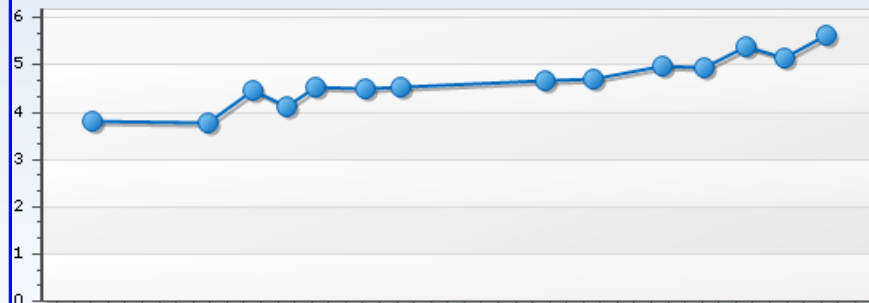
- Few health issues, good attendance at clinic
- “Excellent” drug adherence reported
- Number of different ART combinations, CD4 1175 (31%) VL 69 (183, 8710, 19000)
- Stopped ART, multiple behavioural/adherence issues
- Community & hospital social supports offered

Immunodeficiency Markers:



— Absolute CD4

HIV Viral Load:



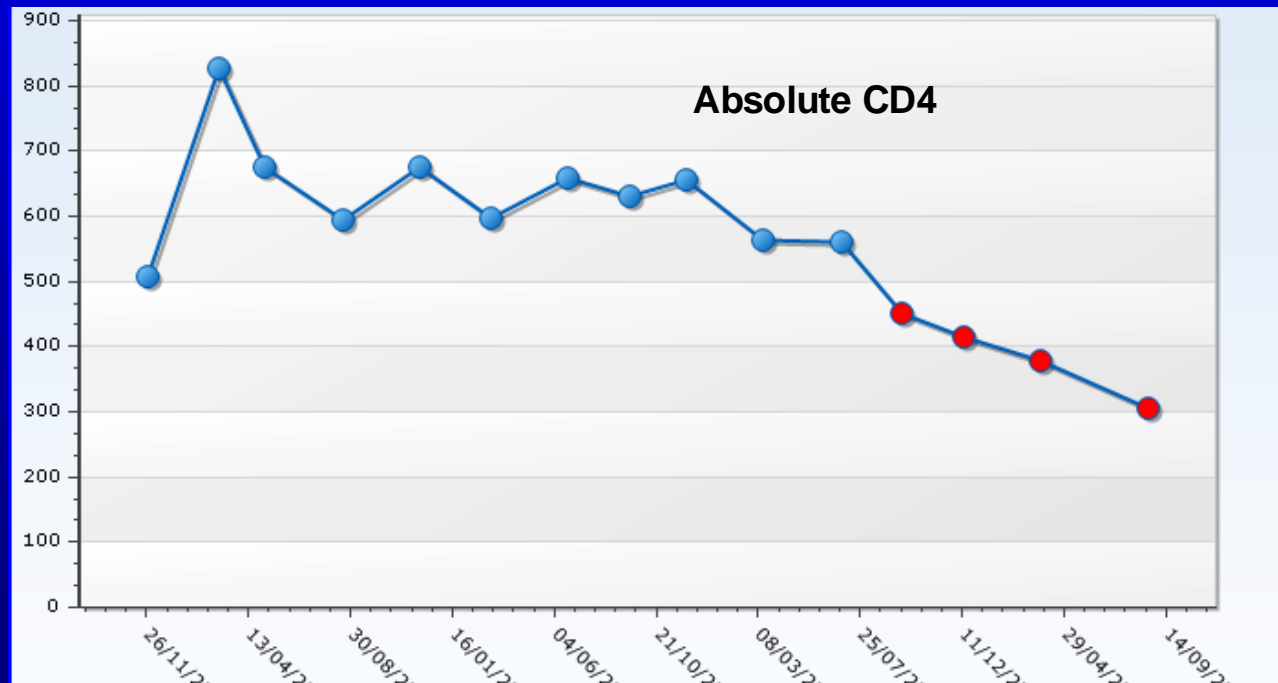
— HIV RNA log copies/ml

Case: 17years

- Transitioned to adult care
- CD4 declining $147 \times 10^6/l$, VL > 100000 off ART, multi-drug resistant virus
- HAART restarted
- Poor school attendance
- Binge drinking
- Marijuana use
- Sexually active
- Left home, no fixed income

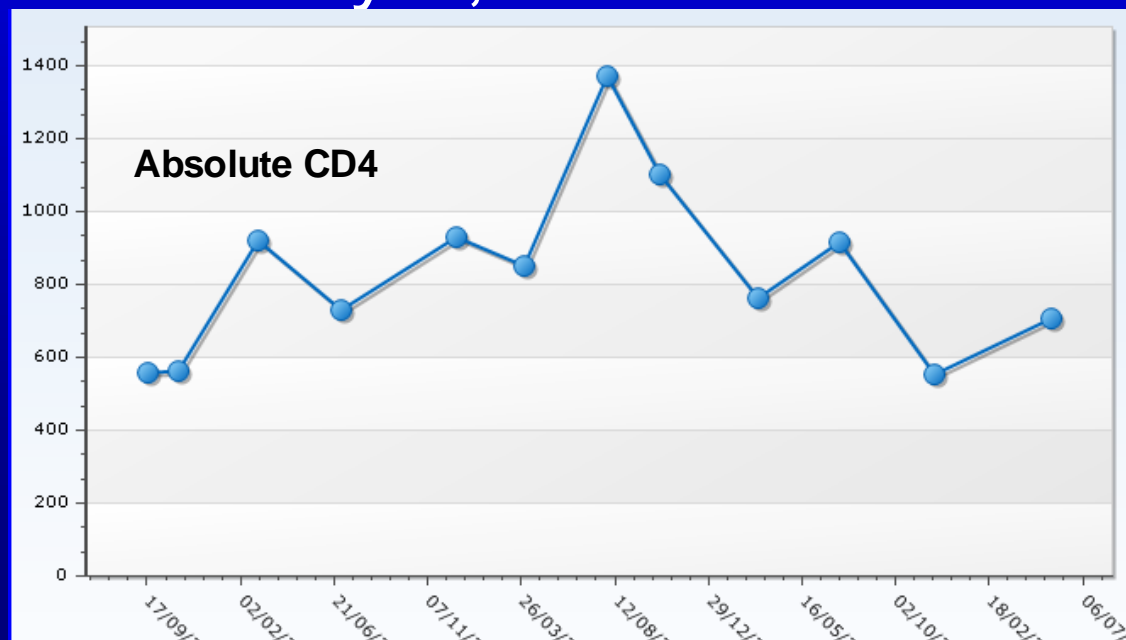
16yr old

- Diagnosed 9 yr old CD4 663×10^6 , VL4226 copies/ml
- No antiretrovirals started
- Stable clinical course until recently



18 yr old

- Diagnosed 3yr old, CD4 713×10^6 (18%), VL67370 copies/ml (log 4.8)
- HAART started ZDV, 3TC, nevirapine
- No significant illnesses, fully viral suppressed for 14 yrs, remains on same ARTs



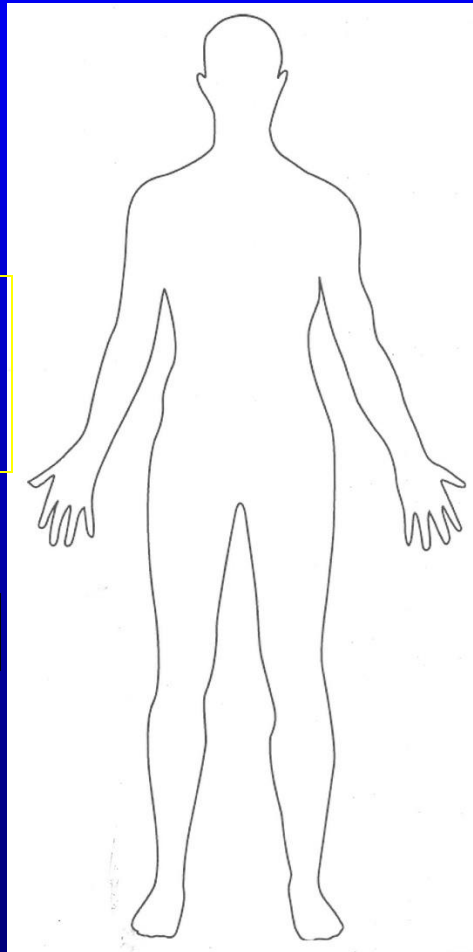
Unique situation of children being born with a transmissible disease and a chronic life-limiting disease

Multigenerational illness

Negotiating first (and every) relationships/SI with an STI

Complex psychological needs

Cultural adjustments



Stigma and secrecy

Chronic ill health in childhood

Immigration, poverty, employment

Adherence to medication

Longterm S/E HIV and ARVs - MDR

Prefrontal cortex maturation - 3rd decade

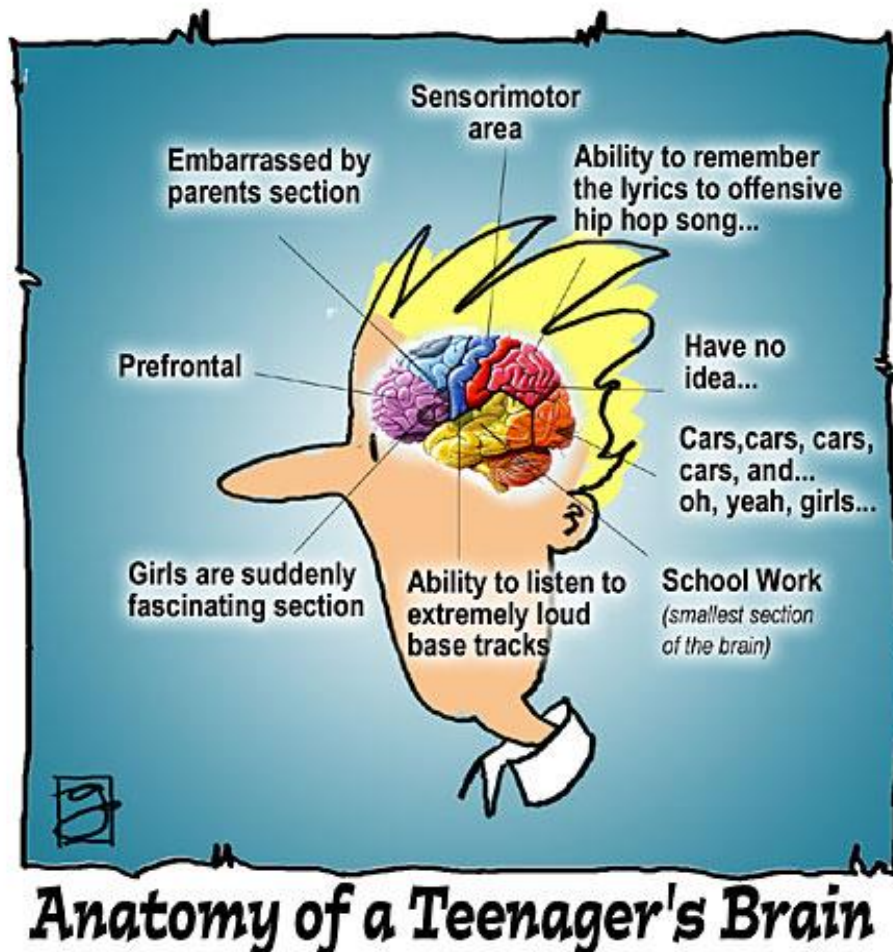
- impulse control, planning, emotional regulation
- Prefrontal cortex: decision making/ reasoning/impulse control matures into early 20s

Infantile encephalopathy- hypertonic diplegia

Chronic HIV exposure

Social factors – deprivation, malnutrition, isolation

Longterm exposure to ART
± in-utero exposure



Neurocognitive and Psychiatric Outcomes

- 81 adolescents median age 15 yrs
- Weschler IQ - normal range
- Psychiatric illness 48%, multiple 18%
- Learning disability 42%, learning support 38% (16% mental health hospitalisation)

BUT if prior AIDS: Lower IQ ($p=0.002$)- below average range

19x multiple psychiatric diagnoses

4x mental health treatment.

Psychiatric Hospitalisations

- PACTG219C prospective cohort study of -1808 HIV-infected, 1021 neg children
- 25 <15yrs hospitalised for psychiatric reasons
- 6.17/1000 person-years cf general paed population
1.7/1000 person-yrs
- Over all ages 32 hospitalised –
 - depression (16) and behavioural disorders (8), suicide attempt/ideation (6) most common
- 15 multiple hospitalisations, median age of first hospitalisation 11 yrs

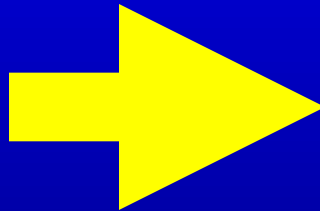
Adolescent History taking - peer and self HEADSS adolescent screening tool

- **Home - Living**
- **Education and employment - Social services**
- **Activities - youth offending**
- **Drug use, alcohol, smoking, other**
- **Sexuality**
- **Suicide/Depression- mental health and self harm**

Medical Issues



1993



antiretroviral drug chart Drugs licensed in the European Union - February 2010

Generic name	Trade name	Formulation	Standard adult dose	Pharmacokinetics	Major side-effects	Food restrictions
Nucleoside reverse transcriptase inhibitors (NRTIs)						
3TC	Epivir	200 and 300mg tablets	200mg twice a day or 300mg once a day	2	Common: Nausea, vomiting, diarrhoea, headache, abdominal pain, myalgia, rash, tendinitis	Take with or without food
Abacavir	Zenpep	300mg tablets	300mg twice a day or 600mg once a day	2	Common: Rash, nausea, vomiting, diarrhoea, fever, headache, loss of appetite, tendinitis, hypersensitivity reaction	Take with or without food
AZT/zalcitabine	Retovir	200 and 300mg capsules	300mg twice a day	2	Common: Nausea, vomiting, flatulence, headache, dizziness, weakness, loss of appetite	Take with or without food
d4T/didanosine	Zeniv	25, 50, 75 and 100mg capsules	People over 60kg: 400mg twice a day People under 60kg: 300mg twice a day	2	Common: Peripheral neuropathy, nausea, vomiting, diarrhoea, rash, tendinitis	Take with or without food
d4T/didanosine	Videx	25, 50, 100, 150 and 200mg tablets	People over 60kg: 400mg twice a day People under 60kg: 300mg twice a day	2 or 4 (increased if co-administered with zalcitabine)	Common: Peripheral neuropathy, nausea, vomiting, diarrhoea, rash, tendinitis	Take at least two hours after eating or drinking anything except water
d4T/didanosine	VidexEC	125, 250, 250 and 500mg tablets	People over 60kg: 400mg twice a day or 300mg twice a day People under 60kg: 300mg twice a day	3 or 2	Common: Peripheral neuropathy, nausea, vomiting, diarrhoea, rash, tendinitis	Take at least two hours after eating or drinking anything except water
FTC/emtricitabine	Emtriva	200mg capsules	300mg twice a day	1	Common: Nausea, vomiting, diarrhoea, abdominal pain, headache, dizziness, weakness, rash	Take with or without food
Nucleoside reverse transcriptase inhibitors (NRTIs)						
tenofovir	Virad	300mg tablets	300mg once a day	1	Common: Nausea, vomiting, diarrhoea, dizziness, loss of appetite, headache, rash	Take with food
INSTI/NRTI fixed dose combinations						
3TC/FTC	Combivir	Tablet comprising 300mg 3TC and 150mg FTC	One tablet twice a day	2	See 3TC and FTC	Take with or without food
3TC/abacavir	Bictevir	Tablet comprising 150mg 3TC and 150mg abacavir	One tablet twice a day	2	See 3TC and abacavir	Take with or without food
3TC/abacavir	Kivexa (EU)	Tablet comprising 300mg 3TC and 150mg abacavir	One tablet twice a day	3	See 3TC and abacavir	Take with or without food
FTC/tenofovir	Peppi	Tablet comprising 300mg FTC and 300mg tenofovir	One tablet twice a day	3	See FTC and tenofovir	Take with food
INSTI/NRTI/NRTI fixed dose combinations						
FTC/tenofovir/abacavir	Atrine	Tablet comprising 300mg FTC, 300mg tenofovir and 150mg abacavir	One tablet once a day	3	See FTC, tenofovir and abacavir	Take without food
Non-nucleoside reverse transcriptase inhibitors (NNRTIs)						
Etravirine	Symtu	200mg capsules	400mg twice a day	1	Common: Rash, dizziness, fatigue, diarrhoea, abdominal pain, headache, tendinitis, myalgia, weakness	Take on an empty stomach, preferably at bedtime
Etravirine	Isentrop	200mg tablets	400mg twice daily	4	Common: Rash, dizziness and nausea Rare: Hypersensitivity reaction	Take with food
Nevirapine	Viramune	200mg tablets	600mg once a day for two weeks then 400mg once a day or 200mg twice a day	2	Common: Liver toxicity, skin rash, nausea, vomiting, headache, diarrhoea, abdominal pain	Take with or without food
Protease inhibitors						
Atazanavir	Reyata	150, 225, 300 and 400mg capsules	300mg with 300mg ritonavir twice a day	2.5	Common: Nausea, diarrhoea, rash, abdominal pain, headache, hyperbilirubinaemia	Take with food
Darunavir	Prezista	200, 300 and 400mg tablets	600mg with 100mg ritonavir twice a day	6	Common: Diarrhoea, nausea, headache	Take with food
Fosamprenavir	Scelvir	700mg tablets	700mg with 100mg ritonavir twice a day	4.5	Common: Lymphadenopathy, nausea, vomiting, diarrhoea, rash, abdominal pain, headache, dizziness, fatigue, loss of appetite	Take with or without food
Indinavir	Crixivan	200, 333 and 400mg capsules	800mg three times a day	6	Common: Kidney stones, abdominal pain, loss of appetite, dark stools, loss of weight, nausea, vomiting, diarrhoea, rash, headache, dizziness, weakness, tendinitis	Take one hour before or two hours after food or take with food
Lopinavir/ritonavir	Kaletra	Tablet comprising 400mg lopinavir and 80mg ritonavir	Two tablets twice a day or 700mg three times a day	4	Common: Lymphadenopathy, related liver enzyme increases, nausea, vomiting, diarrhoea, abdominal pain, rash, headache, tendinitis	Take with or without food
Nelfinavir	Viracept	250mg tablets	1200mg twice a day or 700mg three times a day	10	Common: Lymphadenopathy, nausea, vomiting, diarrhoea, rash, headache, dizziness, weakness, tendinitis	Take with food
Ritonavir	Norvir	300mg capsules and 200mg tablets	600mg twice a day or 300mg three times a day	3	Common: Lymphadenopathy, nausea, vomiting, diarrhoea, rash, headache, dizziness, weakness, tendinitis	Take with food
Saquinavir	Invirase	200mg capsules and 100mg tablets	600mg with 100mg ritonavir twice a day	6.5	Common: Lymphadenopathy, nausea, vomiting, diarrhoea, rash, headache, dizziness, weakness, tendinitis	Take with or without food
Tyrosinase	Aptivase	200mg capsules	600mg with 100mg ritonavir twice a day	8.5	Common: Lymphadenopathy, nausea, vomiting, diarrhoea, rash, headache, dizziness, weakness, tendinitis	Take with food
Integrase inhibitors						
TLD integrase	Fostemsavir	Tablet	Tablet of 150mg under the skin twice a day	Common	Rash, dizziness, headache, nausea, vomiting, diarrhoea, abdominal pain	No food restrictions
CCR5 inhibitor						
Maraviroc	Celselt	250, 500mg tablets	300mg twice a day or 150mg twice a day with 100mg ritonavir	2 - 4	Common: Headache, dizziness, nausea, vomiting, diarrhoea, rash, headache, dizziness, weakness, tendinitis	Take with or without food
Integrase inhibitor						
Raltegravir	Isentrop	400mg tablets	400mg twice a day	2	Common: Headache, dizziness, nausea	Take with or without food

*Formulation(s) shown. † Includes ritonavir co-formulation.
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2012

Medical Issues



Increased risk of cancers

Adherence



Metabolic abnormalities:
body image
bone density

Mitochondrial toxicity

Delayed puberty/short stature



Multidrug resistant virus

Long exposure to ART/HIV



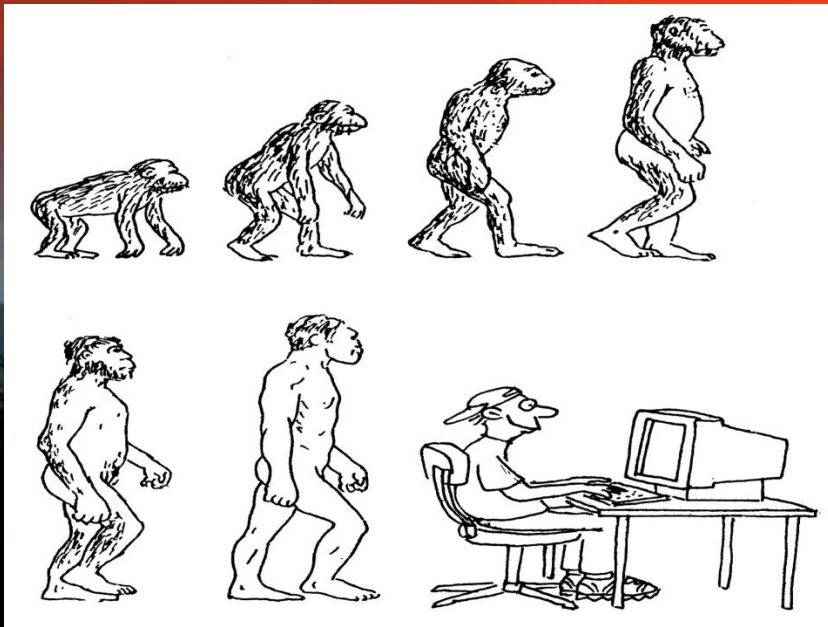
Paediatric adherence impact on adult life

- Case note review of young people 18-25yr, receiving both paed and adult care – 34 paHIV

	Good paediatric adherers n=15	Poor paediatric adherers n=19
CD4 <200 at last follow up	0	9
Virology	(1) rebound (14) VL<50	(2) VL<50, CD4 >200 for >50% of time on ART
AIDS diagnosis (death)	0	4 (2)

Poor adherer - reported >10% of ART doses missed

Good adherer > 90% ART doses taken



Evidence in chronic disease

- Renal transplantation: 35% lost graft within 36 months of transfer
Watson A 2000
- Congenital heart disease: 1 in 5 deaths “avoidable”
Somerville J 1997
- Diabetes: 10-69% no medical f/up after paediatric care
Pacaud D 1996, Frank M 1996, Kipps 2002
- Better attendance when young person has met adult team prior to transfer
Kipps 2002

Transition

“Transition: getting it right for young people” www.dh.gov.uk 2007

'A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems'

Age appropriate approach flexible to individual needs of the adolescent

Resilience

Coping strategies

Independence

Social supports



Transition Process

- Occurs over **years**
- Partnership between:
 - Young person
 - Carer
 - Paediatric & Adult Multi disciplinary team services
- Tailored to the individual young person, recognition of maturity of the child
- Encourage to develop autonomy and self management skills with dedicated team responsible for transition
- Parents need to handover care, allow teenager to become the decision maker

Need for acknowledgement of the individual



Acknowledging HIV

Knowledge & opportunities

Appropriate involvement of
parents/caregivers

Appropriate supports offered/privacy

Acknowledge sexual activity/drug/alcohol use

There's more to life than HIV

Not too much information

Enabling independence and
respecting confidentiality

Not assuming sexual activity

Encourage autonomy & self esteem

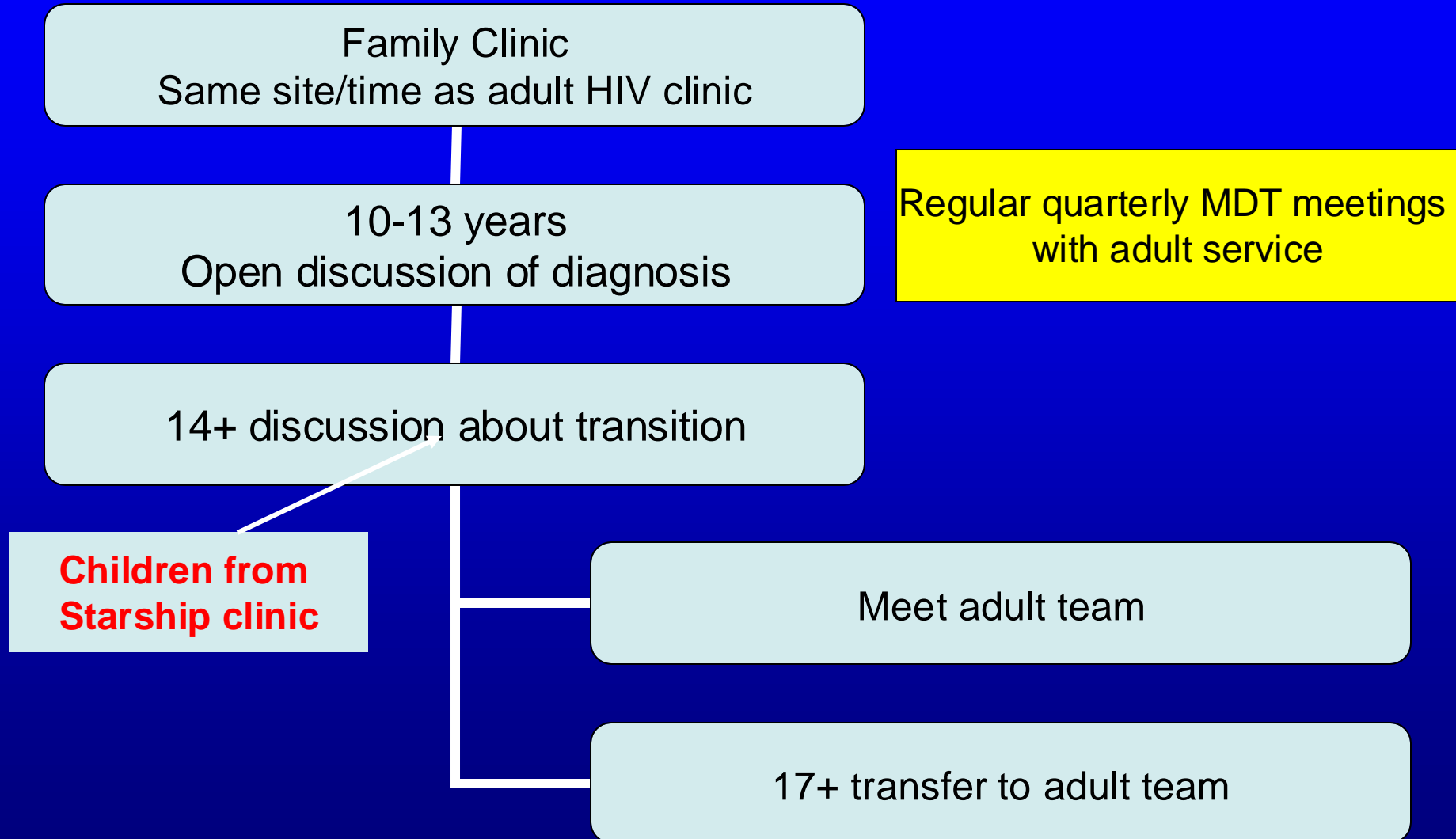
Models of Transition

- Several models for transitioning young people to adult services
 - Family clinics: integration
 - Specialist services: handing over
 - Specialist services: separate youth clinic
- Model chosen will depend on variety of factors – resources, numbers

Transition plan

- Full review of clinical history
- Identify other assessments/resources needed
- Update on knowledge of HIV and confidentiality
- Sexual health discussion
- Parents/caregiver support
- Discussion on where/when/who
- Introduce to adult service providers
- Shared/joint meeting with staff
- Handover for other services

Transition at Starship Children's Hospital



Transition at Starship Children's Hospital

Benefits:

- family-centred care
- 1 hospital visit per family
- family issues can be dealt with
- easier transition

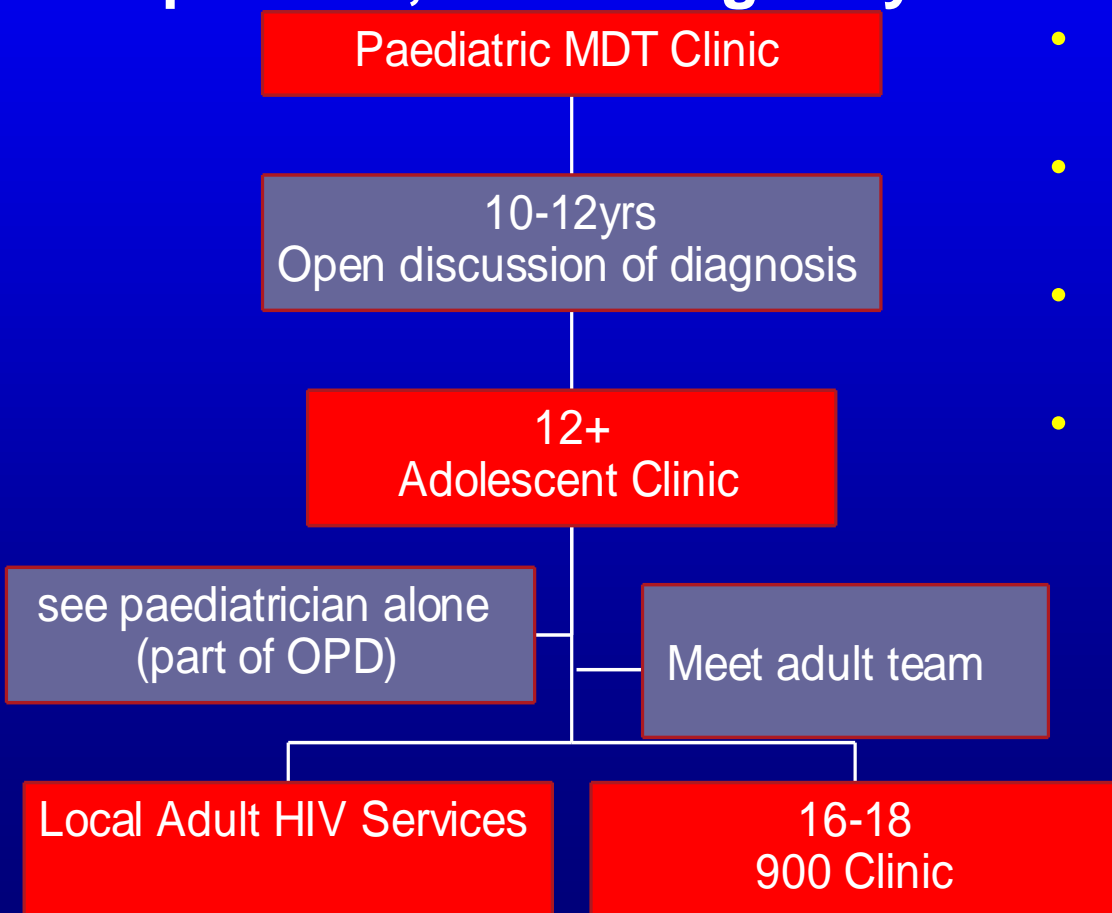
Disadvantages:

- longer duration
- adult clinic not setup for children
- child can disrupt adult visits
- confusion over clinic sites for other clinic visits



Transition care services for young people

**Questionnaire on transition,
21 patients, median age 19yr**



- 68% transition positive effect on their health/well-being
- 95% felt their transition was an easy process
- All were happy with their young person OPD care
- 1/3 happy with their care as adult inpatients
- Being treated as an individual, comprehensive management explanations and encouragement to develop independence were cited as strongly important

Health outcomes following transfer to adult services

- Retrospective 2006-11, n = 58, median age 20 (17-24),
- 20% severe immunosuppression (CD4 <200)
- 25% admitted - 4 due to ODs, OIs (2), CVA (1)
- 2/58 died (end stage disease, & sepsis, declined ART)
- High rates of co-morbidity, including depression
- Despite attending for MDT follow up there is a small group of young people who remain off ART with low CD4 counts
- But not all bad news:
85 % of those who take ART are undetectable

A silhouette of a person is captured mid-jump, leaping over a deep canyon. The scene is set against a dramatic sky at sunset or sunrise, with warm orange and yellow hues near the horizon and cooler blue and purple tones higher up. The person's arms are outstretched forward, and their legs are bent in a dynamic jumping pose. The rocky edges of the canyon are visible in the foreground, framing the bottom of the scene.

Resilience, confidence, hope

Conclusion

- HIV is a chronic disease of childhood with a varied path
- Transitional Care should be planned, purposeful and positive - there is no “right way”
- Need to maintain engagement in health care and acknowledge the complexities of adolescence
- HAART is good, **Adolescents are great**

Acknowledgments

- Dr Caroline Foster, 900 Clinic, Dr Hermione Lyall, St Mary's Hospital, London
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