National HIV Nurses Association

BASLNF
British Association for the Study of the Liver Nurse Forum

NHIVNA Pre-conference Study Day

'Current Issues in HIV, Hepatitis and other Blood-borne Viruses'

In collaboration with BASLNF

Royal Armouries International, Leeds

17 June 2015

17th Annual Conference of the
National HIV Nurses Association (NHIVNA)

National HIV Nurses Association

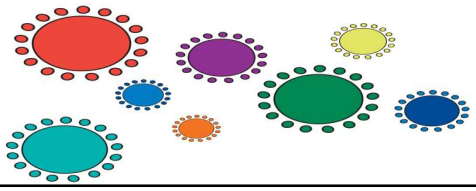
Katie Rowson

MRC Clinical Trials Unit at UCL, London

17 - 19 June 2015 - Royal Armouries International, Leeds

Prevention of MTCT through Pregnancy Support

Katie Rowson
Paediatric Nurse Specialist



NHS
North West
Perinatal and Paediatric HIV Network

Support through Pregnancy

The Liverpool Way

- Monthly pregnancy MDT's
- Regular contact
- Home visits
- Hospital visits

Why is support needed

- Allows a person to talk about their thoughts and feelings
- Issues can be discussed in a safe environment
- Provides assistance to deal with negative thoughts and ideas
- Supportive mechanism to deal with 'bad news'

Diagnosis in Pregnancy …

- Loss of “normality”
- Temporary loss of hope
- Loss of expectations (conscious and unconscious)
- Chaos and loss of control
- Physical pain
- Guilt at failure or inability to protect one’s own child

Effective management = <1% of babies infected

Mother to Baby Transmission

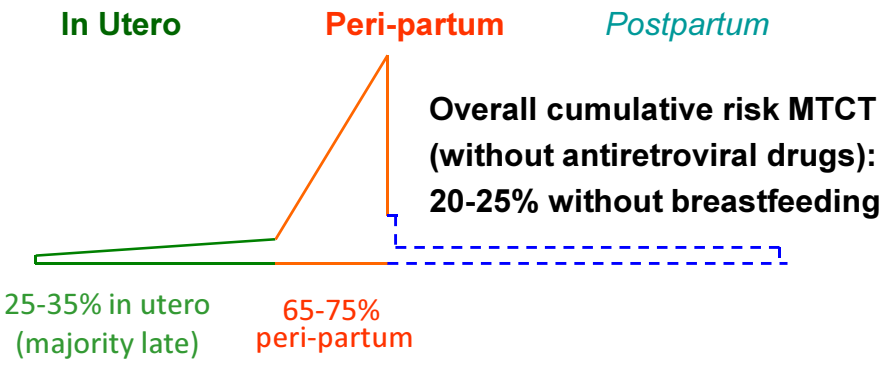
- Majority of children in UK transmitted HIV from their mother
- Now preventable in 99% of births
- Mother undetectable viral load
- Bottle feeding (UK) (Please note CHIVA Breastfeeding Statement)
- Baby has ART for 4/52
- Viral Load day of delivery, 6/52, 3/12
- Ab test 18mnths – 2 years

MTCT: from 25% to < 1%

- Before 1994: 25%
- 1994 - 1996: 8%
- 1996 - 1998: 2%

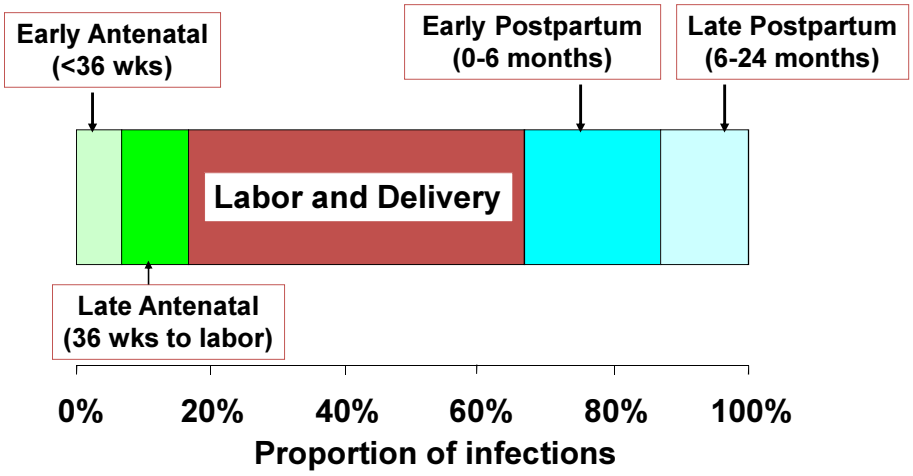
- Modern HAART: <1% transmission

Timing of Mother-to-Child Transmission of HIV with no breastfeeding



The majority of transmissions occur in the intra-partum period

Timing of Mother-to-Child Transmission of HIV with breastfeeding and no ARV prophylaxis



Maternal Risk Factors for Peri-Natal HIV Transmission (Pre-ACTG 076)

- Increased illness severity
- Maternal drug use
- Low vitamin A levels/Anaemia
- International settings
- Pre-term delivery
- Breast-feeding

UCL

How children acquired infection

2384 paediatric infections reported to NSHPC
1986 – September 2011

Mother-to-child transmission	1972
Blood factor treatment	267
Blood/tissue transfer	61
Other/undetermined	84

- About 15% of all infected children ever reported in the UK and Ireland are known to have died
- About 11% have left the country or are otherwise lost to follow up

MRC Centre of Epidemiology for Child Health

NSHPC

UCL

National Study of HIV in Pregnancy and Childhood

NSHPC

April 2014 Update

Obstetric and paediatric HIV surveillance data from the UK and Ireland

Principal Investigator: Pat Tookey

Population, Policy and Practice Programme,
UCL Institute of Child Health, London

www.ucl.ac.uk/nshpc

UCL

Mother-to-child transmission of HIV

- In the UK, if an HIV positive pregnant woman is unaware of her infection status, her baby has a roughly 1 in 4 chance of being infected
- Effective interventions substantially reduce the risk of mother-to-child transmission of infection, but can only be offered to pregnant women who are aware of their HIV infection
- Using antiretroviral therapy (ART) antenatally, during delivery and for the infant, appropriate mode of delivery, and avoiding breast feeding can reduce rates of mother-to-child transmission to under 1%

MRC Centre of Epidemiology for Child Health

NSHPC

Low rates of mother-to-child transmission of HIV: UK & Ireland 2000-2006

Townsend *et al.* AIDS 2008; 22:973-81

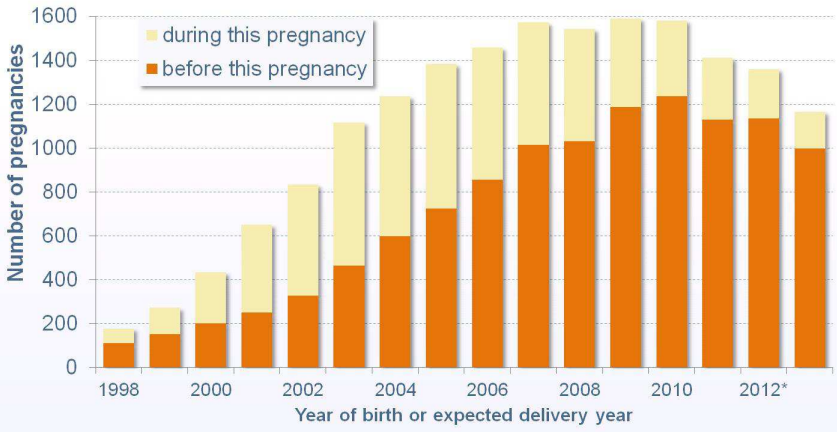
Group	Number of transmissions	MTCT rate
Overall	61/5151	1.2% (CI 0.9-1.5%)
2000-2002	23/1456	1.6%
2003-2006	38/3695	1.0%
At least 14 days HAART	40/4864	0.8%
ZDV monotherapy + PLCS	0/464	0.0%
HAART + PLCS	16/2286	0.7%
HAART + SVD	4/559	0.7%
VL<50 copies/ml	3/2117 (*2 with evidence of in utero transmission)	0.1%

ZDV: zidovudine
PLCS: planned lower caesarean section
SVD: spontaneous vaginal delivery
VL: HIV viral load

National Study of HIV in Pregnancy and Childhood NSHPC

Timing of maternal HIV diagnosis

UK & Ireland 1998-2013



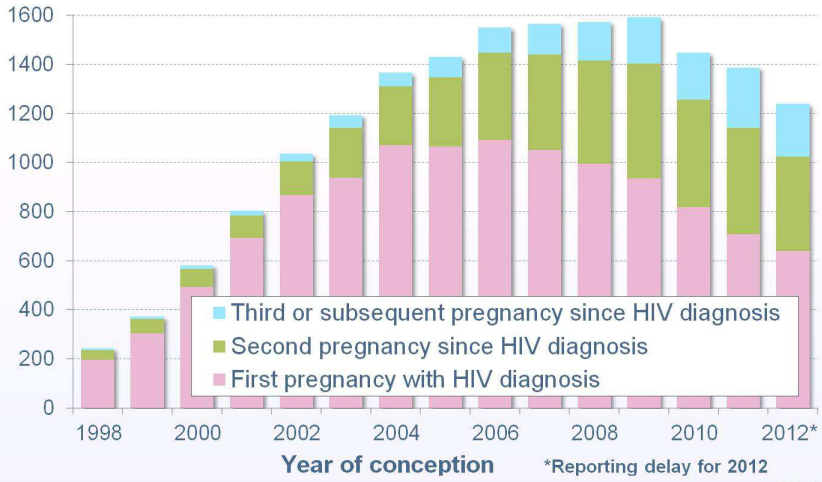
UK & Ireland pregnancies (all outcomes) reported to NSHPC by March 2014**

* latest years subject to reporting delay
** includes data from all NSHPC reporting sources

National Study of HIV in Pregnancy and Childhood NSHPC

Sequential pregnancies by conception year, 1998-2012

Pregnancies reported by end March 2014, UK and Ireland



National Study of HIV in Pregnancy and Childhood

Antiretroviral therapy in pregnancy in the UK & Ireland

- Among pregnancies in previously diagnosed women nearly 60% were on ART at conception (~40% of all pregnancies in women diagnosed before delivery)
- Most previously untreated / undiagnosed women start ART in pregnancy, usually between 23 and 30 weeks
- About 98% of diagnosed pregnant women take ART
  - wide variety of drug combinations and timing of treatment
- Beneficial effects of ART in reducing mother-to-child transmission are clear

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Antiretroviral therapy and congenital abnormalities, infants born in the UK and Ireland, 1990-2007

- Overall congenital abnormality rate – 2.8% (232/8242)
  - 2.1% excluding 59/232 with minor abnormalities
  - Consistent with 2-3% reported for major birth defects in England
- **No evidence** of a significant association between exposure to ART and prevalence of abnormalities (p=0.69)
  - 2.8% in 498 unexposed infants
  - 3.1% in 1708 infants exposed to ART in 1st trimester
  - 2.7% in 5427 infants exposed to ART in 2nd/3rd trimester
- No difference in abnormality rates by class of ART exposure in the 1st trimester
- Findings consistent with international Antiretroviral Pregnancy Registry, and other European studies

Townsend et al. AIDS 2009; 25:519-524

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Infection status of children

Born to women diagnosed with HIV before delivery in **UK & Ireland**, reported by March 2014*

Year of birth	Infected	Indeterminate	Uninfected	Total
Pre 1990	20	18	144	182
1990-99	91	123	754	968
2000	7	29	340	376
2001	10	60	489	559
2002	10	53	661	724
2003	11	57	942	1010
2004	10	55	1035	1100
2005	14	54	1160	1228
2006	9	53	1236	1298
2007	9	57	1341	1407
2008	9	53	1312	1374
2009	6	74	1319	1399
2010	5	118	1299	1422
2011	6	234	1002	1242
2012	4	560	648	1212
2013	0	646	330	976
2014	0	43	3	46
Total	221	2287	14015	16523

*774 infected children born in the UK or Ireland to women who were undiagnosed at the time of delivery have also been reported

National Study of HIV in Pregnancy and Childhood NSHPC

Key Points

- Transmission can only be prevented if we are aware of mums diagnosis so every pregnant woman should be HIV tested
- If a lady refuses testing it should be re-offered
- Foetus has no human rights - Do you need to test at birth
- Complicated cases should be discussed with regional teams at the earliest point of concern
- what should you give the baby? Do you need SS involvement?
- If a lady has tested negative in pregnancy don't rule out HIV in a symptomatic child (or adult)

UCL

Pregnancies in perinatally infected young women

HYPNet case note review in selected UK centres 2010

HYPNet HIV in Young People Network

- 42 pregnancies in 30 women with perinatal/early childhood infection
- Median age at first pregnancy 18, (range 14-22)
- 50% highly treatment experienced
- Detectable viral load close to delivery in 7/21 live births; one infant HIV infected
- 81% of pregnancies reportedly unplanned
- In half of pregnancies partners reportedly unaware of maternal HIV status
- 36% of 42 pregnancies electively terminated, 14% miscarried

Kenny *et al. HIV Medicine 2012*,13:304-8

National Study of HIV in Pregnancy and Childhood NSHPC

Transition
Supporting Young People

MARIA DOWIE

CLINICAL NURSE SPECIALIST

PAEDIATRIC & ADOLESCENT HIV

LEEDS GENERAL INFIRMARY

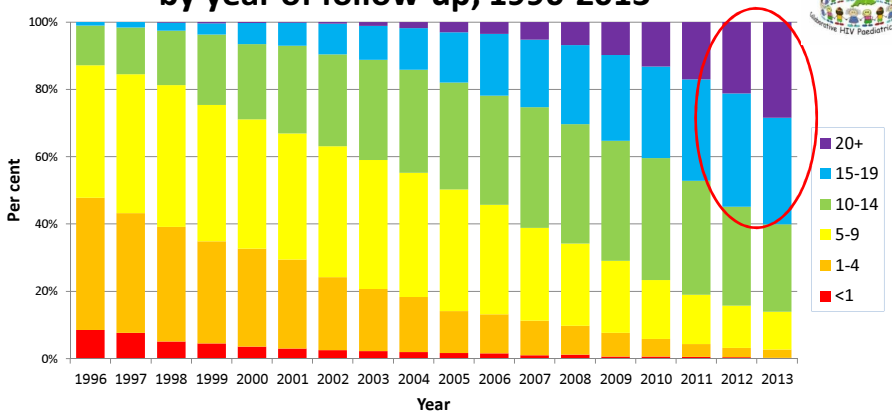
Katie Rowson
AALPHI Research Nurse
MRC Clinical Trials Unit at UCL
Lecturer in Children's Nursing
University of Central Lancashire

Ruth
CHIVA
Youth Committee

National Study of HIV in Pregnancy and Childhood
NSHPC

Age of UK/Irish children with HIV by year of follow-up, 1996-2013

CHIPS



N	389	514	671	891	1150	1357	1509	1607	1645								
	433	577	779	1027	1251	1444	1569	1646	1541								

Note: Data are for all children and young people alive who were ever in follow-up from 1996 onwards, 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 infections are included, regardless of mode of acquisition (94% perinatal). CHIPS includes all diagnosed HIV-infected children known to be living in the UK/Ireland, of whom ~55% were born abroad. Data for 2013 are incomplete as subject to reporting delay.

Growing up

- World Health Organisation Definitions:
  - Young people =10-24 years
  - Adolescents = 10-19 years

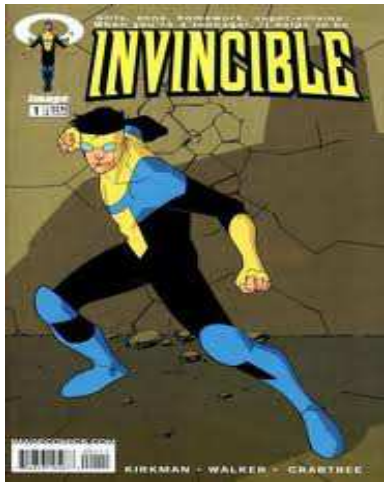
Different needs:

- Medically
- Socially
- Physically
- Emotionally

- More support than any other group?

Being a Teenager ....

- Be responsible
- Think for yourself
- Growing Up
- Having Fun
- More freedom
- Being Independent
- Start Work
- Lots of things change
- I'm always right



What is Transition?

"transition is the purposeful, planned movement of adolescents & young adult with chronic physical & medical conditions from child centred to adult orientated health care systems" (Blum et al 1993)

"transition of care from paediatric to adult setting is not specific to HIV……..However, there are important differences for young people living with HIV which may make this process more difficult" (Lyall 2007)

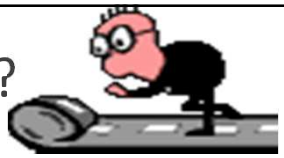
Why is it Different?

- ❖Stigma & Discrimination
- ❖Confidentiality/secrecy
- ❖Medication
- ❖Complexities of additional medical needs
- ❖Complexities of additional socia

Do you want to know how I feel?

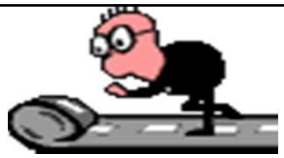
- Got to suss out ya friends ……
- I know everything but I'm too worried t have sex
- I expect a painful death…..
- School trips are soooo hard …..
- Feel like I'm keeping something from my friends and my friends are everything …..
- People that talk about HIV or AIDS at school make it hard …..
- It's a 24 / 7 secret …..
- I worry that people's attitudes and love would change if they know I had HIV ….

How do we do this?



- Transition from child-centred to adult orientated health care systems (Blum et al, 1993)
- The National Service Framework for Children, Young People and Maternity Services (DOH, 2004)
- Bridging the Gaps: Health care for Adolescents (RCPCH, 2003)
- A transition guide for all services (2007)
- Transition: getting it right for young people Improving the transition of young people with long term conditions from children's to adult health services (2006)
- Transition: Moving on Well (DOH, 2008)
- You're Welcome – Quality criteria for young people friendly health services (DOH, 2011)
- ACT. The Transition Care Pathway. (2007)
- Growing up Matters (CSCI, 2007)
- Lost in transition (RCN, 2008)

How do we do this?



- Adolescent Transition care (RCN, 2004)
- Growing ?Up, Gaining independence priiples for Transition of HIV care (Lyall, 2003)
- Coping and psychological adjustment in adolescents with vertically acquired HIV (Sopena et al, 2010)
- Supporting change: Successful transition of young people who have grown up with HIV infection: guidance for services (Melvin et al, 2007)
- Young people in the United Kingdom and Ireland with perinatally acquired HIV: the paediatric legacy for adult services (Foster et al, 2009)
- Growing up with HIV (Dorrell et al, 2009)
- CHIVA guidance on Transition for Adolescent's living with HIV (Foster , C 2010)
- Young People living with HIV and the transition from children's to adult services (Howell & Hamblin, 2011)
- Just Normal Young People (Hamlin, 2011) (NCB)

When it goes wrong ....

- ❖Lost to follow up
- ❖Increased morbidity
- ❖Increased mortality
- ❖Treatment failure
- ❖Drug resistance
- ❖Why – need more support, too much change, financial pressures, cognitive impairement, want to be "normal" .....

Young People previously 'transitioned'

- 10 cases reviewed
  2 transferred out
  8 stayed at the same hospital
- 25% attended more than half their appts in last 2 years
- 3 out of 8 adherent to treatment

What's on my mind?

Today but sometimes The Future ...

These meds …..

Relationships .....

Can I – have a family, have a career ….

Medication

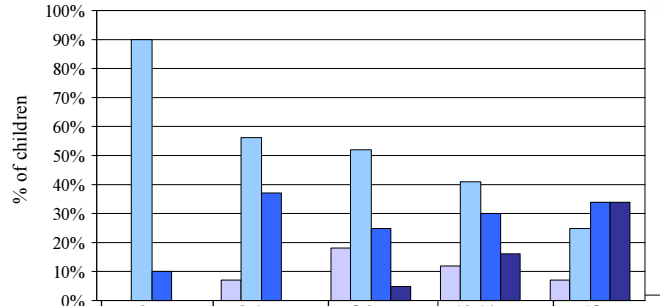
I've not missed any Doctor ...

I'm fine without my meds

They make me ill ..... No chance I'm taking 'em...

Their under lock 'n' key at my house

Not weekends



No. of children	< 2 years	2-4 years	5-9 years	10-14 years	≥15 years	Total (%)
Naive	2 (25%)	2 (6%)	26 (14%)	56 (13%)	19 (6%)	105 (11%)
1-4 drugs	6 (75%)	17 (55%)	80 (44%)	175 (40%)	92 (27%)	370 (37%)
5-7 drugs	0 (0%)	12 (39%)	63 (35%)	132 (30%)	108 (31%)	315 (32%)
8+ drugs	0 (0%)	0 (0%)	11 (6%)	74 (17%)	124 (36%)	209 (21%)
Total	8 (100%)	31 (100%)	180 (100%)	437 (100%)	343 (100%)	999 (100%)

Reasons for non-adherence

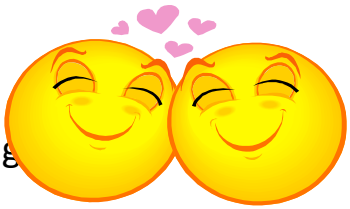
- Just Forget
- Taste, Size, Frequency and Amount of
- Beliefs, Culture, Religion
- Past experience
- Family Life, Support, Role Model
- Routine, Stress
- Young carer
- Exams
- Social Life, want to be "normal", weekends, alcohol, recreational drugs
- Don't feel unwell
- Reminder of diagnosis
- Understanding of diagnosis and medication
- Side Effects

Things that help ....

- Calendars
- Alarms
- Texts
- Parent / carer
- Routine e.g. brushing teeth
- Labelling syringes
- Home Support
- Direct Observational Therapy by family member
- Education / knowledge of diagnosis / Understanding
- Support groups / 1-to-1

Relationships and Sexual Health

- Sexual Debut with a Sexually Transmittable Disease
- Advice – leaflets, staff, websites, groups, peer support
- Practical advise – e.g. How to put a condom on
- Reviews – clinic sheet / annual review / smears
- Condoms
- Criminalisation
- PEP-SE
- Open conversations –non-judg



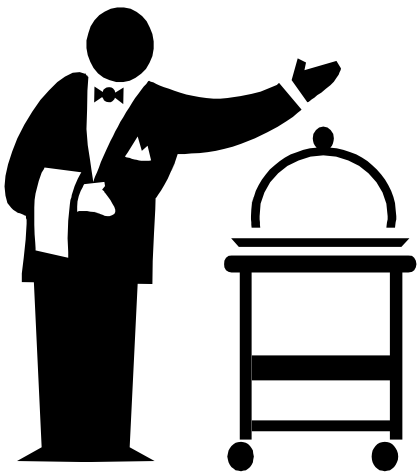
Questionnaire

"We want a Young Person's Clinic"

- Everyone agreed that they wanted a transition clinic
- Everyone thought it should be in the adult setting
- Everyone agreed there should be later appointments (4-7pm)
- The clinic should have a name
- Criteria - Young People know their diagnosis, want to come to this clinic, happy to be seen alone

Young People want ....

- An area without crying babies
- Text reminders
- A safe space
- Teen friendly environment
- Private toilets
- Better explanations from doctors
- Less waiting time
- Food and Drink



What's Important to Young People ...

- Confidentiality and Trust
- Clear explanations
- Involvement in decision making
- That we're taken seriously
- Comfortable environment

What do Young People know about HIV?

- Understands CD4 Counts & Viral Load:
- Understands routes of HIV transmission:
- Understands how antiretroviral treatment works: condom:
- Understands legal implications of HIV & transmission:
- Knows where to get advice / support:

- 0 1 2 3 4 5 6 7 8 9 10

Clinic Sheet

•Education/work:
• Who knows about your HIV?
•
•Alcohol u/wk
•Cigarettes /day
•Drug use
•
•Discussions held today (✓)
•Steps in HIV & Sexual Health Knowledge
•How is HIV spread from person to person
•What increases the risk of HIV transmission
•How MTCT works to prevent infant infection
•How to have safe sex
•How to use a condom
•What contraception is best for them
•How to get PEPSE
•How to access more information about HIV + sexual health
•How to access peer support
•Legal implications of HIV & transmission

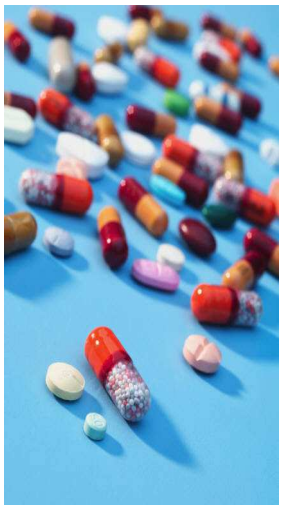
Living with:

Menarche yrs
LMP
Coitarche yrs
Contraception

ARV Situation

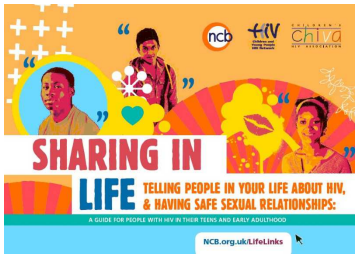
❖30/35 on treatment
❖3 off / interruption (adherence)
❖2 naive

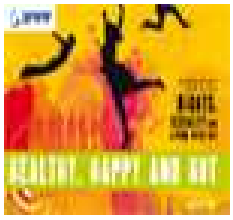
❖1/3 need additional help with meds
❖2 on weekly visits
❖10 on first line therapy



Additional Support

- Additional physical / medical input = 7
- Social work involvement = 9
- Peer support = 20
- Intensive Medication support = 4
- Cognitive Impairment = 5
- Caring responsibility = 2
- Live independently = 5





Questionnaire 2 years on …

- 17 young people completed questionnaires
- 16 over 15 years of age
- Majority use public transport to attend
- 100% happy with time
- ½ remember appt – prefer a text or call as a reminder

Questionnaire 2 years on …

- What's good about clinic?
  staff, health info, peers, seeing friends
- What's important?
  staff attitudes, information, confidentiality
- What could make it better?

faster, see same Doctor, group sessions at clinic, £100 for having bloods done!

- 7/17 not worried about going to adult clinic
- 13/17 state meds are their own responsibility
- 11/17 would phone nurses if running out of meds
- Young people stated that health information should be given at clinic or peer support group by nurse, doctor or peer support staff (2 out of 17 said parents)

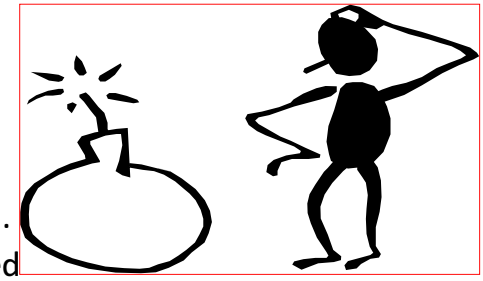
What do Young People know about HIV?

- Understands CD4 Counts & Viral Load:
- Understands routes of HIV transmission:
- Understands how antiretroviral treatment works: condom:
- Understands legal implications of HIV & transmission:
- Knows where to get advice / support:

- 0 1 2 3 4 5 6 7 8 9 10

Challenges ….

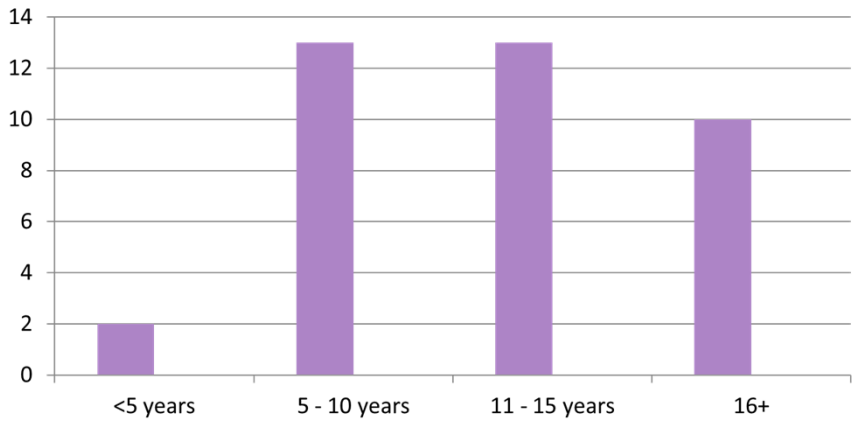
- ❖ Attendance / DNA rate
- ❖ Don't use clinic area frequently
- ❖ Patient numbers increasing therefore clinics over full
- ❖ Prep time
- ❖ Roles
- ❖ Cervical Smears
- ❖ HPV vaccines
- ❖ Consider offering drop in …..
- ❖ Additional Support is needed
- ❖ Extra support during quicker transitions such as pregnancy
- ❖ Buy in from all involved health and social care professionals



Getting ready for adolescence!

Paediatric and adult HIV services

Young people attending Leeds clinic from within West Yorkshire



Transition process….

- Individualised, flexible
- Choices, decision making
- Coordinated multidisciplinary approach
- Communication
- Parental support
- Timing - Chronological, developmental and 'social' age
  - Health status, other issues i.e. immigration
  - Readiness of young person/parent

Pre transition discussion	12 – 14 years
Process to commence	14 – 16years
Transition	16 – 18 years

Model in Leeds

Transition Clinic

- Parental and adolescent questionnaires
- Transition results from adolescent questionnaire:
  - Accessing an adolescent/transition clinic – 5 yes 1
  - Introduction to adult team - 5 yes 1 not sure
  - Age of transition: 14 – 16yrs - 2, 16+ yrs – 4
  - Location – majority Children's Out Patients
  - Time of clinics – early evening clinic - majority
  - Other services accessible via clinic
    - Dental,
    - Counselling/psychology
    - Pharmacist
    - Dietitian
    - Contraception

The Transition Clini

- May 2010 clinic commenced!! Originally 'The family and Young People's Clinic'
- Joint monthly clinic which runs until 6pm - paed/adult consultant, pharmacist, psychologist and CNS
- All young people have an individualised Transition plan

  age of transition, seen without parents, medical history, treatment, adherence, disclosure, SRE, accessing adult services, voluntary sector
- Transition out of area – individualised, flexible – i.e. Offer of attending initial consultation at local centre

Future

- *Evaluation* - to ensure the service continues to meet the needs of young people across the region – Audit, ongoing discussion, implementation of Annual Reviews and Team away day
- *Together4Life* – adolescent support group
- *Stepping Up Day*
- *Development of a Young People's HIV Clinic for 16 – 25year olds*. Currently monthly MDT meetings, database development

Leeds Teaching Hospitals

Adolescent forum – provision/development of high quality transition services, newly appointed Adolescent/Transition Nurse, pilot document for national benchmarks for transition 2014

youthhealthtalk.org
healthtalkonline.org

Advice to doctors and nurses

"We have lived with our condition most of our lives so we know as much as you do. Please acknowledge our understanding"

"It is important for young people to have a say in their treatment"

"Talk to us and not just our parents. Give us the opportunity to talk to us away from our parents"

"Don't see us as just the patient but see us as teenagers with other things going on in our lives"

"Try to see things from our perspective"

"Be compassionate and sensitive"

CHIVA
CHILDREN'S HIV ASSOCIATION

- Ruth
- CHIVA Youth Committee Representative

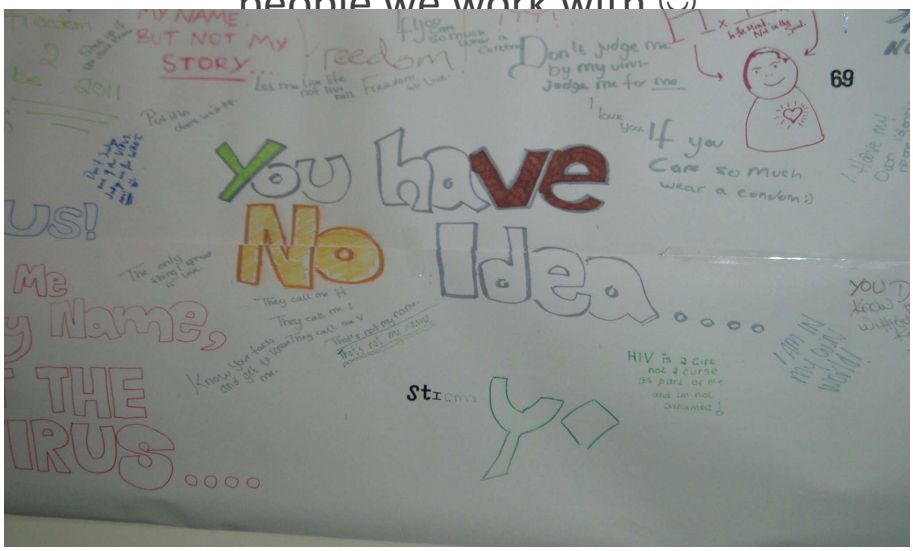
Young People's Experience of Transition

- It was ok as I already knew the team
- There was no process; my next appt was in the adult clinic
- Scary – scared of the unknown
- Harder to trust new people; I used to be able to ask anything
- I need help to manage my meds, remember my appts and that
- It's boring
- I was able to move when I felt ready; no rush

Top Tips ….
CHIVA Youth Committee

- R – respect us
- E – Everyone is Different
- S – simple Language
- P – be patient
- E – comfortable Environment
- C – Communication – be clear and don't presume
- T – Too personal – ask about my life; don't jump in with the sex questions

With thanks to the wonderful young people we work with ☺



National Study of HIV in Pregnancy and Childhood

NSHPC

Life after CHIPS: CHIPS+ and AALPHI update

Katie Rowson
AALPHI Research Nurse
MRC Clinical Trials Unit at UCL
(With Thanks to
Marthe Le Prevost)

CHIPS
Collaborative HIV Paediatric Study

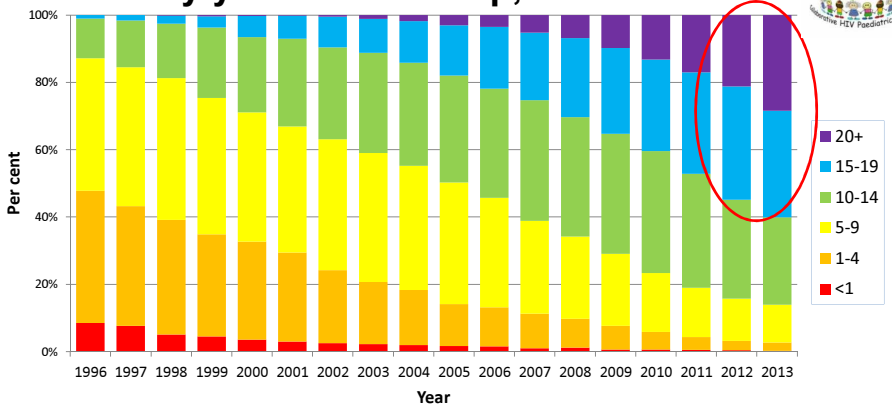
talk to ALFIE

Talk outline

- CHIPS+
  - introduction
  - progress to date
- AALPHI
  - recruitment update
  - cohort characteristics
  - anxiety and depression analysis
- Next steps…

National Study of HIV in Pregnancy and Childhood

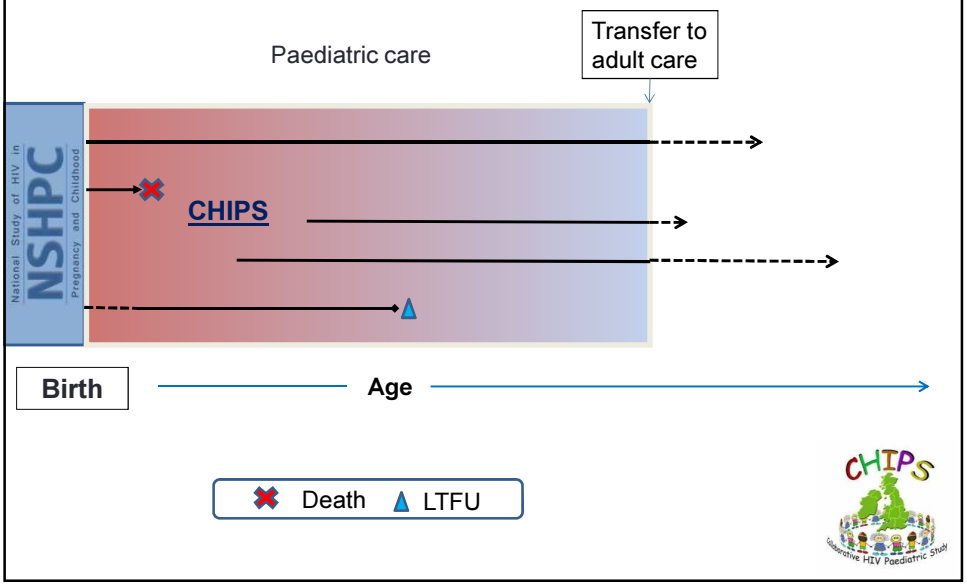
Age of UK/Irish children with HIV by year of follow-up, 1996-2013



N	389	514	671	891	1150	1357	1509	1607	1645								
		433	577	779	1027	1251	1444	1569	1646	1541							

Note: Data are for all children and young people alive who were ever in follow-up from 1996 onwards, 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 infections are included, regardless of mode of acquisition (94% perinatal). CHIPS includes all diagnosed HIV-infected children known to be living in the UK/Ireland, of whom ~55% were born abroad. Data for 2013 are incomplete as subject to reporting delay.

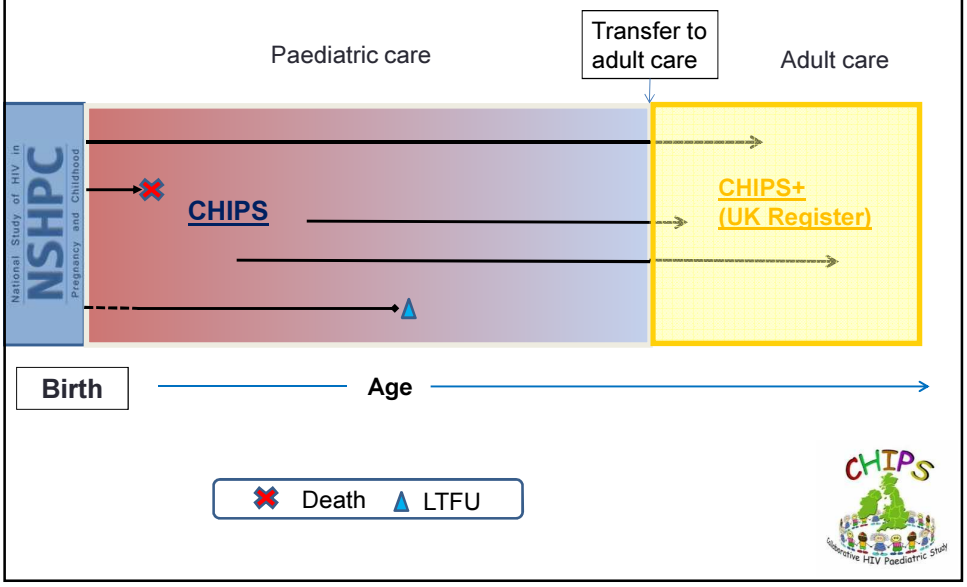
Follow-up of children with HIV

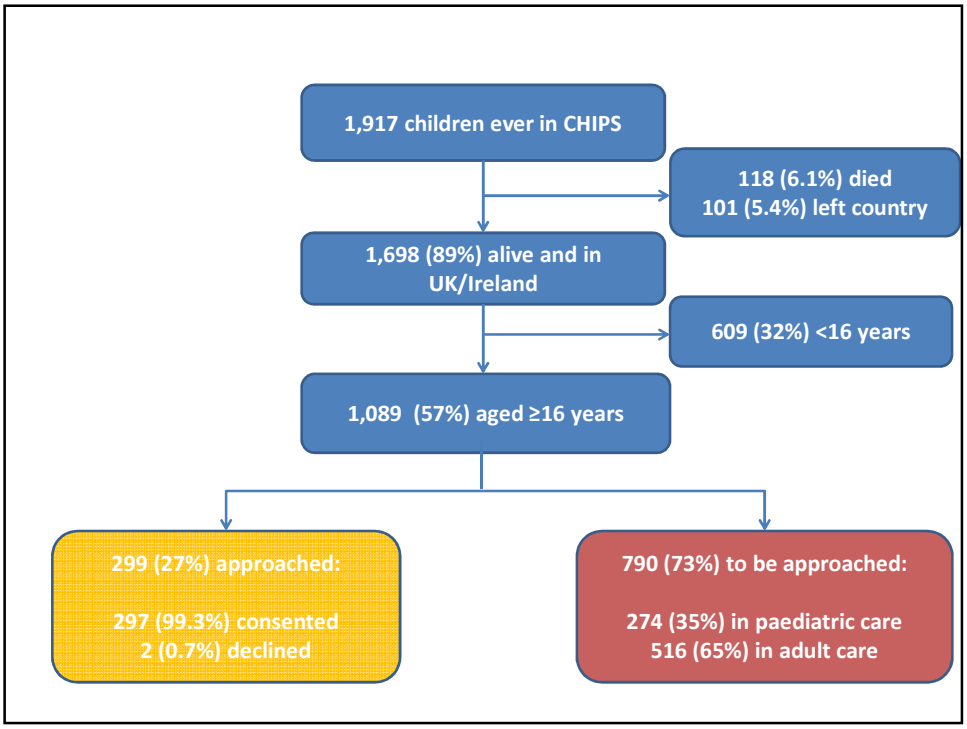


Aims: Extending CHIPS to CHIPS+

- To establish a paediatric-adult cohort study of perinatally HIV infected patients ever followed in CHIPS → CHIPS+
- Assess long term outcomes of perinatally HIV infected young people in adulthood
- Annual follow up form: CD4, VL, ART history, CDC events, hospitalisation, pregnancy, serious non AIDS events
- Inclusion criteria: Age ≥16 years; ever received HIV care in a paediatric clinic in the UK/Ireland
- Requires consent at age ≥16 years

Follow-up of children with HIV





Adolescents and Adults Living with Perinatal HIV

AALPHI

AALPHI

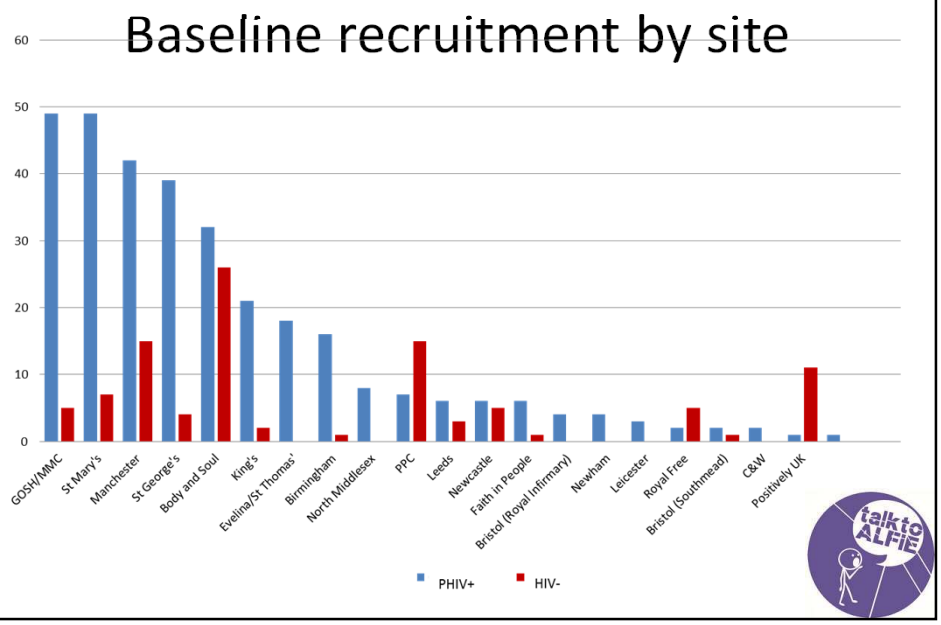
- 5 year cohort study carrying out face-to-face interviews with perinatally HIV infected (PHIV) and HIV affected (HIV-) young people
- 5 key domains: neurocognitive, cardiac, metabolic, sexual and reproductive health and anthropometry and bone composition
- Inclusion criteria:
  - PHIV (n=300): 13-21, paediatric care in UK, willing to give a blood sample
  - HIV- (n=100): 13-23, willing to have an HIV test, awareness of HIV in the family, living in the same household as positive participant or have an HIV positive parent, sibling, friend or partner

Interview 1

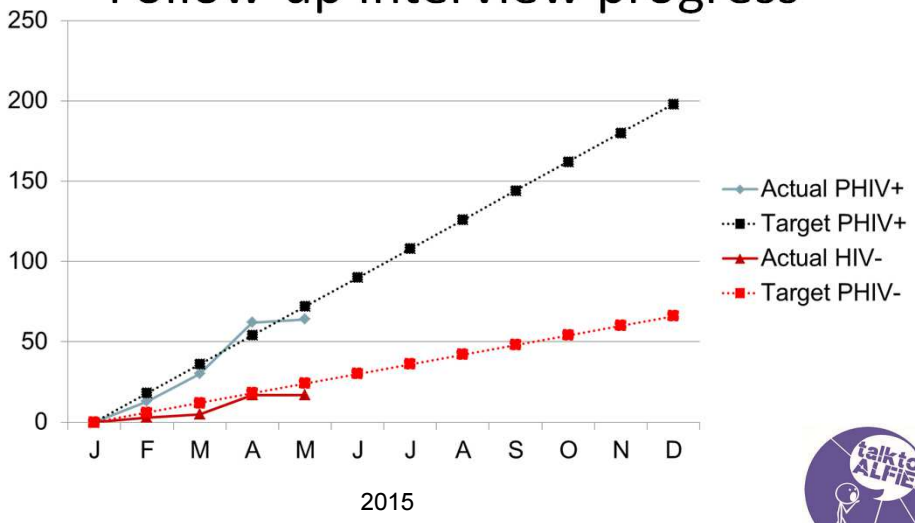
We have enrolled:

318 perinatally HIV infected
and
101 HIV negative young people

THANK YOU!



Follow-up interview progress



AALPHI cohort characteristics

Socio-demographics

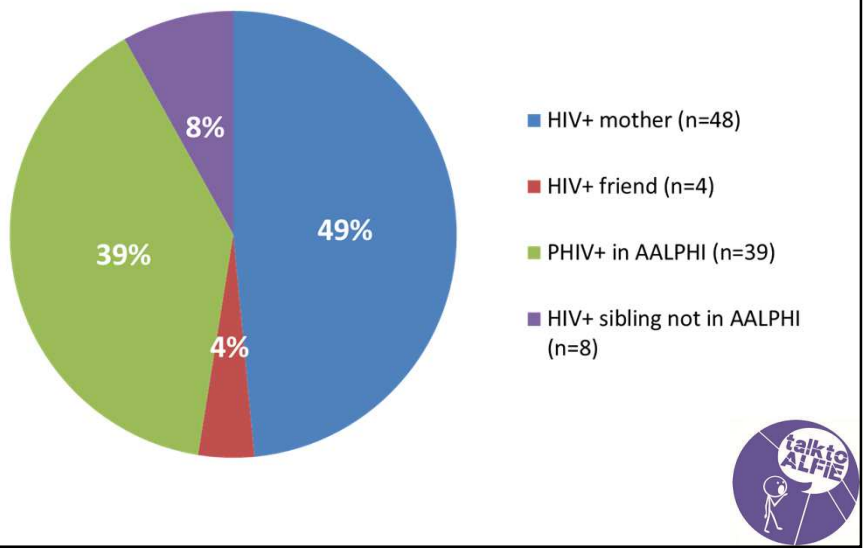
	PHIV+ (n=315)	HIV- (n=101)	Total (n=416)	CHIPS ≥13
	n (%) or median [IQR]			
Males	128 (41 %)	32 (32 %)	160 (38 %)	(48%)
Age, years	16 [15, 18]	16 [14, 18]	16 [14, 18]	18 [15-21]
Ethnicity				
Black	270 (86 %)	74 (73 %)	344 (83 %)	(78%)
Other	44 (14 %)	27 (27 %)	71 (17 %)	(22%)
Born abroad	185 (59 %)	48 (48 %)	233 (56 %)	(54%)
Recruited in London	230 (73 %)	76 (75 %)	306 (74 %)	(62%)
Parent died	108 (35%)	24 (24%)	132 (32%)	-
Median age at disclosure	12 [11, 13]			-

Counselling and self-harm

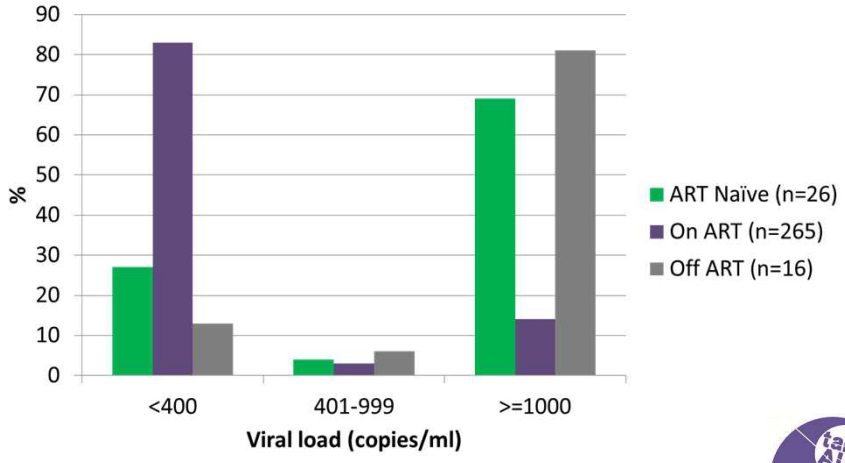
	PHIV+ (n=287)	HIV- (n=97)	Total (n=384)
	n (%)		
Ever self-harmed (19% in ALSPAC*)	36 (13%)	19 (19%)	55 (14%)
Thought life not worth living	113 (40%)	39 (40%)	152 (40%)
Thought about killing themselves (16% in ALSPAC*)	67 (23%)	24 (25%)	91 (24%)
Referred to mental health service	22 (8%)	6 (6%)	28 (7%)
Referred to counselling/psychol	79 (28%)	25 (26%)	104 (27%)

*Source: ALSPAC 2012

Relationships of HIV- to PHIV+

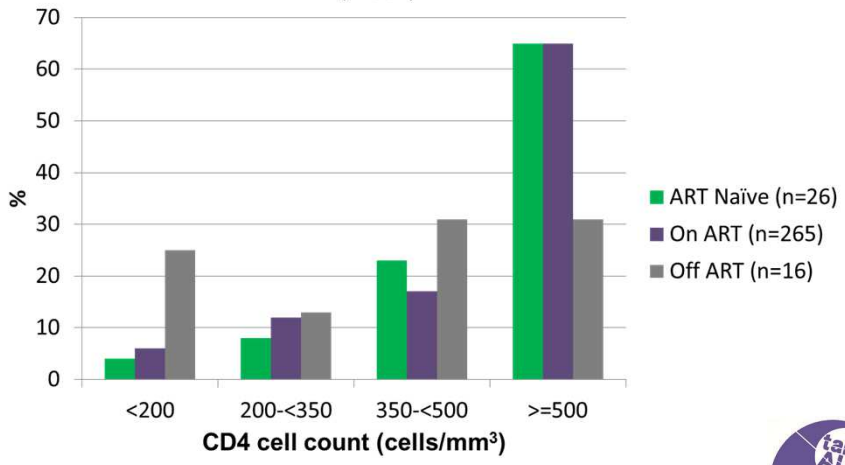


Most recent VL by ART status (n=307)

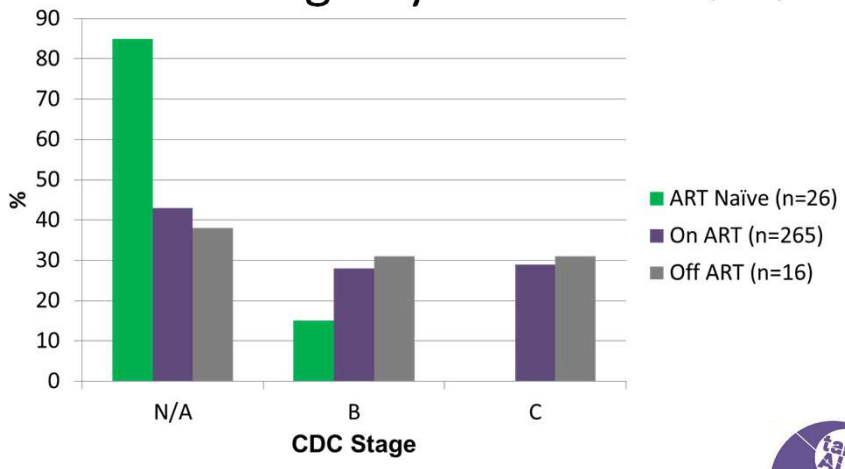


Most recent CD4 by ART status

(n=307)



Clinical stage by ART status (n=307)



Anxiety and depression in AALPHI

- Few studies have investigated anxiety and depression in perinatally HIV-infected young people (PHIV) and HIV negative (HIV-) controls.
- The role of HIV is unclear with some studies showing increased depression and/or anxiety in PHIV and HIV- young people compared to population norms
- This is the first study of anxiety and depression in a large UK cohort of PHIV and HIV-

Methods

- Participants in this analysis:
  - 290 perinatally HIV infected
  - 99 HIV negative
- Neurocognitive/ psychosocial battery (computer assisted interviewing) including:
  - Hospital Anxiety and Depression Scale (HADS)
  - Rosenberg Self-Esteem Scale (self esteem)
  - PedsQL Pediatric Quality of Life (PedsQL) Inventory

Hospital Anxiety & Depression Scale (HADS)

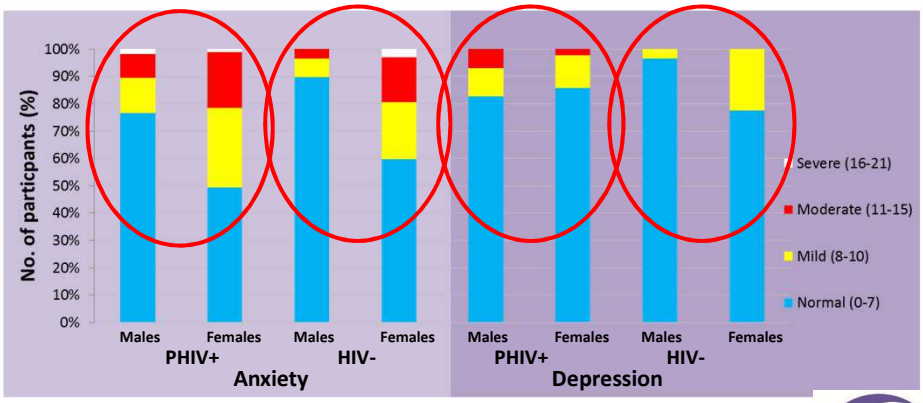
- Very commonly used scale
- 14 item scale (7 anxiety, 7 depression)
- Each item has 4 possible responses
- Participant is asked to choose one response which best describes their feelings
- Two scores, one for anxiety, one for depression

Analysis

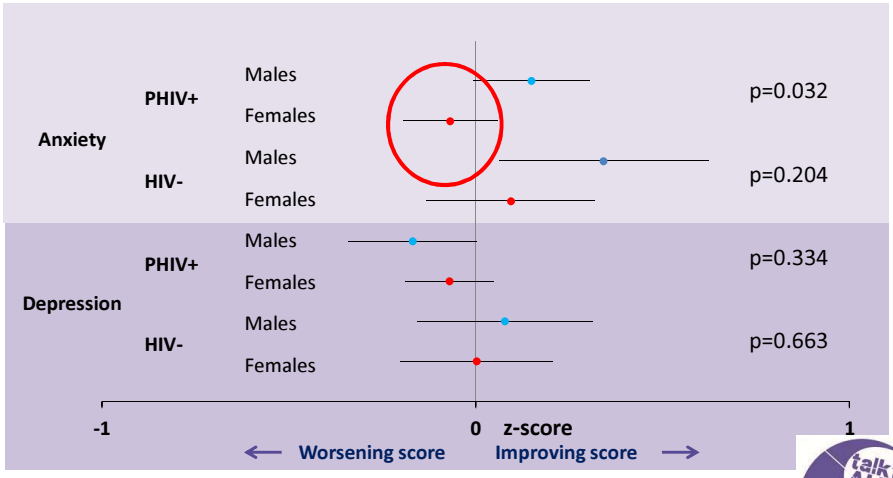
- z-scores calculated using normative sex-adjusted data for UK young adults aged 25-29yrs*
  - z-score>0 = above average score compared to norms
  - z-score<0 = below average score compared to norms
- 2 multivariable models for anxiety & depression separately
- Predictors:
  - A priori: PHIV v HIV-, baseline age, sex, ethnicity, born outside UK
  - Psychosocial: parent death, fostered/adopted, current education/employ, who living with, whether parent in work, PedsQL, self-esteem, self-harm, ever felt life not worth living, disclosure, deprivation, alcohol, smoking and drugs
  - PHIV+ only: year 1st presented, nadir/current CD4, age starting ART, current ART status, ever/current EFV use

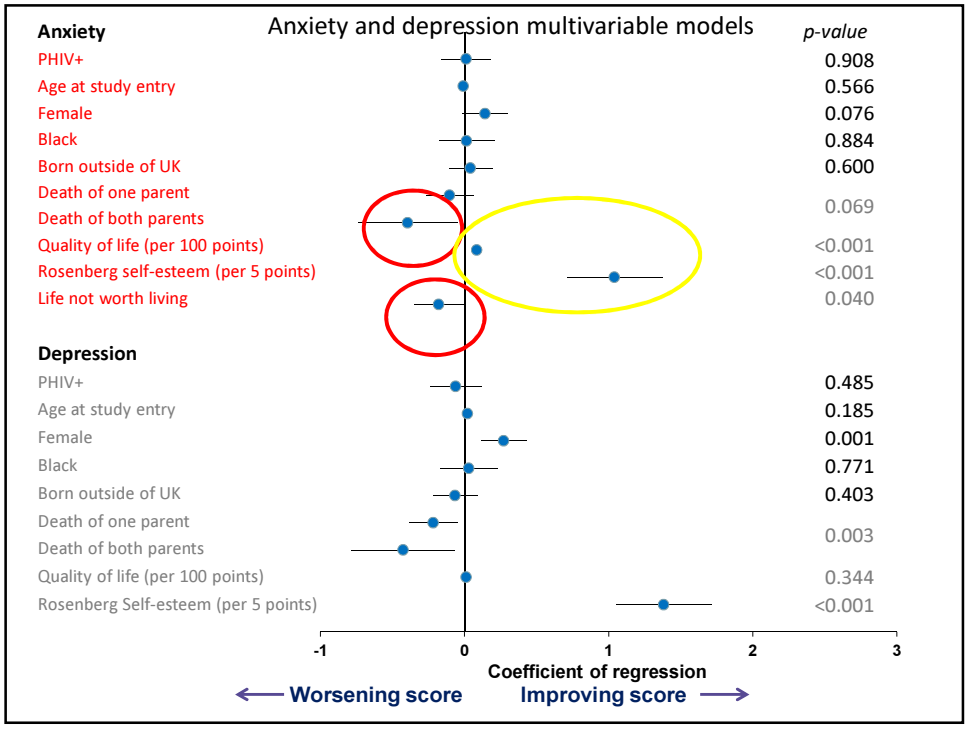
*Qual LifeRes 2015;24:391-9

HADS scores by group and sex



HADS mean z-scores (95%CI) by group and sex




Anxiety and depression multivariable models
Anxiety
PHIV+
Age at study entry
Female
Black
Born outside of UK
Death of one parent
Death of both parents
Quality of life (per 100 points)
Rosenberg self-esteem (per 5 points)
Life not worth living
Depression
PHIV+
Age at study entry
Female
Black
Born outside of UK
Death of one parent
Death of both parents
Quality of life (per 100 points)
Rosenberg Self-esteem (per 5 points)
p-value
0.908
0.566
0.076
0.884
0.600
0.069
<0.001
<0.001
0.040
0.485
0.185
0.001
0.771
0.403
0.003
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<0.001
-1
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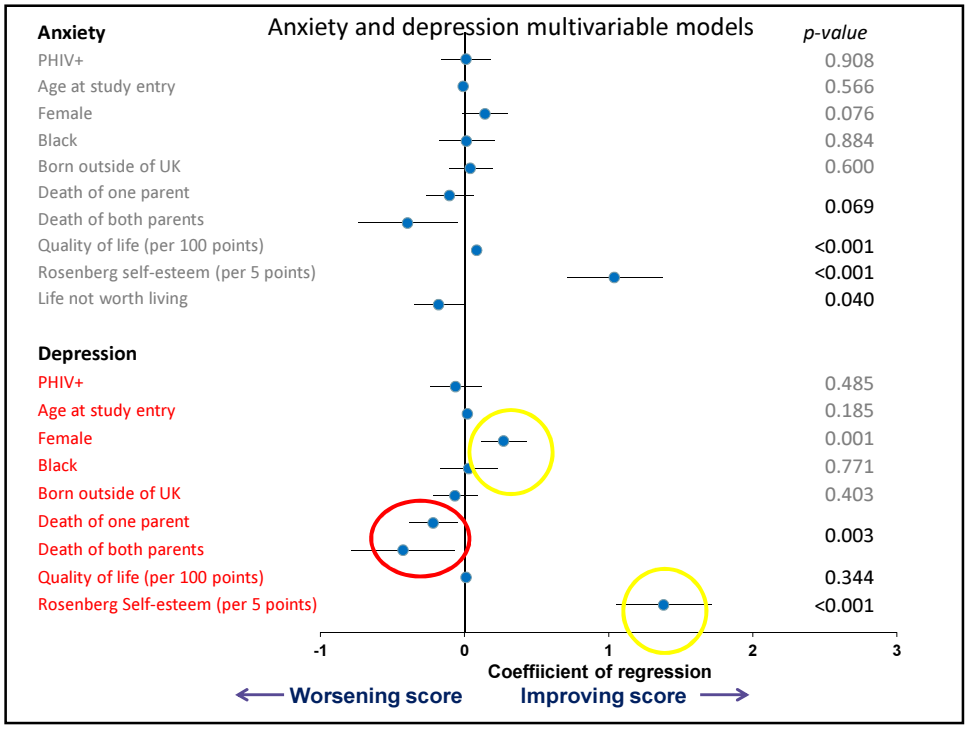
1
2
3
Coefficient of regression
Worsening score
Improving score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1
2
3
Coeffiicient of regression
Worsening score
Improving score

Conclusions of the HADS analysis

- No differences were found between PHIV+ and HIV- for anxiety and depression scores.
- Parental death and thinking life was not worth living were associated with **poorer** scores.
- For anxiety improved QoL and self-esteem and for depression improved self-esteem are associated with **better** scores - so appear protective.
- Findings suggest that many HIV+ young people express feelings of anxiety and depression but [illegible] are similar to HIV- controls and the UK populat[illegible]

Next steps for AALPHI and CHIPS+

- AALPHI
  - Lots more analysis – wealth of data!
  - Complete interview 2
  - Future funding for further follow-up
  - Face-to-face vs remote (phone /internet)
- CHIPS+
  - Study coordinator and data manager to be employed
  - Clinics will be contacted when in place

We thank all young people, parents and staff from the clinics and voluntary services in AALPHI.

- UCL Project team: A. Judd, M. Le Prevost, A. Mudd, A. Nunn, K. Rowson, K. Sturgeon.
- Investigators: M. Conway, K. Doerholt, D. Dunn, C. Foster, D. Gibb, A. Judd (PI), S. Kinloch, N. Klein, H. Lyall, D. Melvin, D. Pillay, K. Prime, T. Rhodes, C. Sabin, M. Sharland, C. Thorne, P. Tookey.
- UCL Data Services: C. Diaz Montana, K. Fairbrother, M. Rauchenberger, N. Tappenden, S. Townsend.
- Neurocognitive subgroup: A. Arenas-Pinto, C. Foster, A. Judd, D. Melvin, A. Winston.
- Steering Committee chairs: D. Gibb, D. Mercey
- NHS clinics (named alphabetically): LONDON: Chelsea and Westminster NHS Foundation Trust, F. Boag, P. Seery; Great Ormond Street Hospital NHS Foundation Trust, M. Clapson, V. Noveli; Guys and St Thomas' NHS Foundation Trust, A. Callahgan, E. Menson; Imperial College Healthcare NHS Trust, C. Foster, A. Walley; King's College Hospital NHS Foundation Trust, E. Cheserem, E. Hamlyn; Mortimer Market Centre, Central and North West London NHS Foundation Trust, R. Gilson, T. Peake; Newham University Hospital, S. Liebeschuetz, R. O'Connell; North Middlesex University Hospital NHS Trust, J. Daniels, A. Waters; Royal Free London NHS Foundation Trust, T. Fernandez, S. Kinloch de Loes; St George's University Hospitals NHS Foundation Trust, S. Donaghy, K. Prime. REST OF ENGLAND: Alder Hey Children's NHS Foundation Trust, S. Paulus, A. Riordan; Birmingham Heartlands, Heart of England NHS Foundation Trust J. Daglish, C. Robertson; Bristol Royal Infirmary, University Hospitals Bristol NHS Foundation Trust, J. Bernatoniene, L. Hutchinson, University Hospitals Bristol NHS Foundation Trust, M. Gompel, L. Jennings; Leeds Teaching Hospitals NHS Trust, M. Dowie, S. O'Riordan; University Hospitals of Leicester NHS Trust, W. Ausalut, S. Bandi; North Manchester General Hospital, Pennine Acute Hospitals NHS Trust, P. McMaster, K. Rowson; Royal Liverpool and Broadgreen University Hospitals NHS Trust, M. Chaponda, S Paulus.
- Voluntary services (named alphabetically): Blue Sky Trust, C. Dufton, B. Oliver; Body and Soul, A. Ash, J. Marsh; Faith in People, I. Clowes, M. Overton; Positively UK, M. Kiwanuka, A. Namiba; Positive Parenting & Children, N. Bengtsson, B. Chipalo.
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We thank the staff, families & children from all the hospitals who participate in CHIPS:

Republic of Ireland: Our Lady's Children's Hospital Crumlin, Dublin.
UK: Birmingham Heartlands Hospital, Birmingham; Blackpool Victoria Hospital, Blackpool; Bristol Royal Hospital for Children, Bristol; Calderdale Royal Hospital, Halifax; Central Middlesex Hospital, London; Chase Farm Hospital, Middlesex; Chelsea and Westminster Hospital, London; Coventry & Warwickshire University Hospital, Coventry; Derbyshire Children's Hospital, Derby; Derriford Hospital, Plymouth; Ealing Hospital, London; Eastbourne District General Hospital, Eastbourne; Glasgow Royal Hospital for Sick Children, Glasgow; Great Ormond St Hospital for Children, London; Halliwell Children's Centre, Bolton; Harrogate District Hospital, Harrogate; Hillingdon Hospital, London; Hinchingbrooke Hospital, Huntingdon; Homerton University Hospital, London; Huddersfield Royal Infirmary, Huddersfield; Ipswich Hospital, Ipswich; James Cook Hospital, Middlesbrough; James Paget Hospital, Great Yarmouth; John Radcliffe Hospital, Oxford; King's College Hospital, London; Leeds General Infirmary, Leeds; Leicester Royal Infirmary, Leicester; Luton and Dunstable Hospital, Luton; Mayday University Hospital, Croydon; Milton Keynes General Hospital, Milton Keynes; Newcastle General Hospital, Newcastle; Newham General Hospital, London; Ninewells Hospital and Medical School, Dundee; Norfolk & Norwich Hospital, Norwich; North Manchester General Hospital, Manchester; North Middlesex Hospital, London; Northampton General Hospital, Northampton; Northwick Park Hospital, London; Nottingham City Hospital, Nottingham; Queen Alexandra Hospital, Portsmouth; Queen Elizabeth Hospital, Woolwich; Queens Medical Centre, Nottingham; Raigmore Hospital, Inverness; Royal Alexandra Hospital, Brighton; Royal Belfast Hospital for Sick Children, Belfast; Royal Berkshire Hospital, Reading; Royal Children's Hospital, Aberdeen; Royal Cornwall Hospital, Truro; Royal Devon and Exeter Hospital, Exeter; Royal Edinburgh Hospital for Sick Children, Edinburgh; Royal Free Hospital, London; Royal Liverpool Children's Hospital, Liverpool; Royal London Hospital, London; Royal Preston Hospital, Preston; Salisbury District General Hospital, Salisbury; Sheffield Children's Hospital, Sheffield; Southampton General Hospital, Southampton; St George's Hospital, London; St Luke's Hospital, Bradford; St Mary's Hospital, London; St Thomas' Hospital (Evelina Children's Hospital), London; Torbay Hospital, Torquay; University Hospital Lewisham, London; University Hospital of North Staffordshire, Stoke On Trent; University Hospital of Wales, Cardiff; West Cumberland Hospital, Whitehaven; Wexham Park, Slough; Whipps Cross Hospital, London; Whittington Hospital, London; Wythenshawe Hospital, Manchester.

Extra slides

PedsQL

	PHIV (n=287)	HIV- (n=98)	p-value*	Norms	Overall p-value
Category	mean (sd)	mean (sd)		mean (sd)	
(1) Physical functioning	80.6 (15.1)	83.8 (14.9)	0.071	89.1 (12.7)	
(2) Emotional functioning	67.4 (20.8)	69.5 (21.5)	0.399	80.2 (18.0)	
(3) Social functioning	86.5 (15.6)	88.4 (14.1)	0.271	90.3 (12.6)	
(4) School functioning	65.2 (20.8)	75.1 (17.3)	<0.001	81.5 (17.4)	
Psychosocial summary score (2-4)	73.0 (15.5)	77.7 (14.7)	0.009	74.2 (16.4)	0.981
Overall total score (1-4)	74.9 (14.3)	79.2 (13.7)	0.010	74.7 (16.5)	0.067

Higher score = better quality of life; * t-test comparing PHIV to HIV-

Rosenberg self-esteem

	Agree/ Disagree	PHIV+ (n=290)	HIV- (n=99)	p-value
Person of worth on equal plane	Strongly agree or agree with statement	90%	92%	0.689
Number of good qualities		91%	92%	0.781
Able to do things as well as others		90%	91%	0.787
Positive attitude towards myself		86%	87%	0.859
Satisfied with myself		81%	82%	0.804
Inclined to feel I am a failure	Strongly disagree or disagree with statement	79%	82%	0.537
Do not have much to be proud of		72%	81%	0.071
Wish I had more respect for self		59%	58%	0.805
Feel useless at times		52%	62%	0.087
Think I am no good at all		60%	66%	0.287

Rosenberg self-esteem

Group	n	mean	sd	p-value
PHIV+	290	20.4	5.6	0.927
HIV-	99	20.5	5.9	
Norms	2,353	27.3	3.5	<0.001

Higher score = better self-esteem; * t-test comparing PHIV to HIV-

National HIV Nurses Association

BASLNF
British Association for the Study of the Liver Nurse Forum

NHIVNA Pre-conference Study Day

'Current Issues in HIV, Hepatitis and other Blood-borne Viruses'

In collaboration with BASLNF

Royal Armouries International, Leeds

17 June 2015