Kids to adults: tracking perinatally infected youth as they transition to adult care - the UK/Ireland experience

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Background

• In 2013, estimated 3.2 million children <15 years living with HIV\textsuperscript{1}

• 2.1 million adolescents (10-19 years) living with HIV\textsuperscript{2}

• HIV/AIDS is the 2nd leading cause of death among adolescents globally and 4th leading cause of DALY lost

• In Europe/US - growing proportion of perinatally infected (PHIV+) patients surviving to adulthood\textsuperscript{3} but few studies continue follow up after transfer to adult care

• Recent studies suggest increased risk of hospitalisation/ mortality after transfer to adult care\textsuperscript{4} and after pregnancy\textsuperscript{5}, but limited to small sample sizes

Follow-up of all HIV infected children in the UK/Ireland

Followed since birth

Diagnosed after birth

Birth 2y 13y 16y

Paediatric care
Adult care

Death  LTFU  End of paed care
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.
Aims

• To establish a life course cohort study of PHIV+ patients ever followed in CHIPS → CHIPS+

• Assess long term outcomes of PHIV+ 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
Extending follow-up of PHIV+ patients

CHIPS

CHIPS+ (UK Register)

AALPHI

NSHPC, SOPHID, UK Resistance Dataset

National Study of HIV in Pregnancy and Childhood

UK born

Diagnosed after birth

Birth 2y 13y 16y ≥21y

Paediatric care

Adult care

Death LTFU
Results

1917 children ever in CHIPS

1698 (89%) alive and in UK/Ireland

1089 (57%) aged ≥16 years

118 (6.1%) died
101 (5.4%) left country

609 (32%) <16 years

299 (27%) approached:
297 (99.3%) consented
2 (0.7%) declined

790 (73%) to be approached:
274 (35%) in paediatric care
516 (65%) in adult care
## Results (n=288, as of Nov 2014)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
<th>or median [IQR]</th>
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<tbody>
<tr>
<td>Sex, female</td>
<td>161 (56%)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity: Black African</td>
<td>240 (83%)</td>
<td></td>
</tr>
<tr>
<td>Mode of infection: Perinatal</td>
<td>274 (95%)</td>
<td></td>
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<tr>
<td>Median age at start of ART (n=267)</td>
<td>7.5 [3.3-11.9]</td>
<td></td>
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<tr>
<td>Median current age</td>
<td>18.9 years [17.5-20.9], range 16-32</td>
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<tr>
<td>Median CD4 cell count/mm(^3) (n=237)</td>
<td>570 [406-782]</td>
<td></td>
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<tr>
<td>Ever CDC stage C</td>
<td>73 (25%)</td>
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<tr>
<td>ART status at last visit: On ART</td>
<td>242 (84%)</td>
<td></td>
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<tr>
<td>Off ART</td>
<td>24 (8%)</td>
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<tr>
<td>Naive</td>
<td>21 (7%)</td>
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</tbody>
</table>

76% VL<50 copies
Summary

• Two thirds of PHIV+ in CHIPS are now ≥16yrs, of whom a quarter have consented to long-term follow-up

• Of those enrolled, most were on ART with good CD4 and VL status, but there may be a selection bias towards regular clinic attenders

• Qualitative and economic sub studies to assess outcomes by types of transition to adult care ‘model’

• Need your help to trace and enrol all perinatally infected patients transferred to adult care to maximise coverage

• Data critical to inform future treatment and care
Acknowledgements

Study participants and clinics

MRC CTU at UCL

AALPHI: A. Nunn, K. Sturgeon, A. Mudd

CHIPS: D. Dobson, C. Cook, A. Tostevin, L Harper

Data Management: K Bellenger

UCL Data Services: C. Diaz Montana, K. Fairbrother, M. Rauchenberger, N. Tappenden, S. Townsend, D. Johnson, E.Little

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