

# National Study of HIV in Pregnancy and Childhood

## Quarterly Update

Royal College of Obstetricians & Gynaecologists

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Between June 1989, when the study was set up, and the end of April 2007, 8155 pregnancies (in 6613 women) were confirmed (Table 1); 287 of these pregnancies occurred before the start of the surveillance and were reported retrospectively.

**Table 1: Pregnancy outcome for 8155 confirmed reports**

Live birth	6387	Maternal death in pregnancy	3
Stillbirth	82	Went abroad before delivery	107
Spontaneous abortion	386	Lost to follow-up	90
Termination	609		
Ectopic pregnancy	24	Expected to continue to term	467

### Follow-up of ART- exposed uninfected children: Findings from the CHART study

Most uninfected children born to diagnosed women in the UK are exposed to antiretroviral therapy (ART) in fetal and early life. In the CHART study, we explored the feasibility of using clinic-based follow up to investigate any association between ART exposure and adverse health events; a report on recruitment and follow up is being prepared. CHART was carried out 2002-2005 and funded by the Medical Research Council; thank you to all the families and health professionals who contributed.

Two papers were published in April (see page 3 for details). In one, we reported findings from a survey of parents' and health professionals' views on long term follow up. Four potential follow-up strategies were outlined: clinic-based, postal contact, telephone contact, and data linkage with no direct contact.

Most respondents thought follow up was a good idea, and virtually all parents wanted to be told if a potential health risk associated with ART exposure was identified. However, a third of parents and nearly half the professionals strongly objected to at least one of the options; parents were most negative about postal contact, and health professionals about clinic-based contact. It will be challenging to identify a

strategy that meets with general approval, but data linkage is likely to be most feasible way forward.

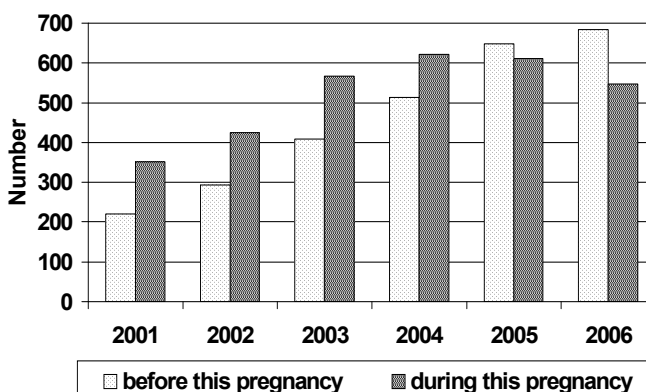
The second paper describes a data linkage protocol that has already been established: reports to the NSHPC are linked to routinely collected cancer and death notifications, a process known as 'flagging'. By the end of 2005, 95% (>2600) of reported children born 2001-2004 in England or Wales (uninfected or indeterminate infection status) had been flagged.

Fourteen deaths (3 uninfected and 11 indeterminate children) and no cancers have been recorded to date; several deaths were associated with prematurity or congenital abnormalities, and some were in children who had not been exposed to ART.

In the long term we will be able to look at cancers and deaths in relation to the prospectively collected data on ART exposure in fetal and early life. Length of follow up is limited at this stage, and the most important message from this publication is the high success rate of the flagging process in a situation where names are not available and anonymity needs to be preserved.

### Timing of diagnosis of maternal infection

Since 2001, the proportion of women reported who were diagnosed during their current pregnancy declined, from just over 60% in 2001 to about 45% in 2006. This is probably because women who were previously diagnosed antenatally are now returning for subsequent pregnancies. High uptake of antenatal testing remains vital, not only for women having their first baby in the UK, but also for those who tested negative in a previous pregnancy.



## Audit of HIV-infected infants in England

During 2006 we carried out an audit of the circumstances surrounding cases of perinatal transmission of HIV in England between 2002 and 2005; this audit was conducted in collaboration with the London HIV Consortium, the Audit Information & Analysis Unit for Specialised Services and CHIVA.

About 90 infected infants, reported to NSHPC by the end of March 2006, were included; about a third were born to diagnosed women, and two thirds to undiagnosed women. Data provided routinely through the NSHPC surveillance were available for all the women and their infants.

We asked notifying clinicians to provide additional data on each case, including whether antenatal testing was offered and accepted, and further information on the management of pregnancy and delivery, any concurrent illnesses in the woman, and any other relevant issues during pregnancy. The response rate exceeded 90%, and the data are currently being analysed; a report will be available later this year. Thank you again to everyone who provided additional information and completed the forms.

### Antiretroviral Pregnancy Registry's Interim Report

Last year we contributed summary tables to the Antiretroviral Pregnancy Registry (APR) showing types of congenital abnormality according to maternal antiretroviral therapy in pregnancy.

This year we have provided two updated tables, which will appear in their Interim Report in July. The report will be available on the APR website:

[www.apregistry.com/who.htm](http://www.apregistry.com/who.htm)

**Table 2: Pregnancies in HIV infected women**

Reporting period	Response rate (%)	Confirmed cases *	Not yet confirmed
1989 - 1999	94-96	1360	0
2000 - 2002	95-96	2031	109
2003	93	1059	49
2004	93	1268	51
2005	93	1184	175
Jan - Mar 2006	93	320	76
Apr - Jun 2006	93	279	110
Jul - Sep 2006	88	241	143
Oct - Dec 2006	77	126	124

\* An additional 287 pregnancies occurred before the start of the surveillance and were reported retrospectively.

### Tables 2 and 3

These tables show the response rates by reporting period, and by country and English region.

All pregnancies in women known to be HIV-infected should be reported, regardless of when the diagnosis was made, and whether or not the woman plans to continue to term.

Please remember to return any outstanding forms and green cards. Thank you very much for your continued involvement and for all your hard work!

**Table 3: Response rate to quarterly reporting scheme**

Country / Region	No. of units	Response rate (%)	
		Jul-Sep 2006	Oct-Dec 2006
England	187	92	80
<i>London</i>	31	94	74
<i>North</i>	61	89	79
<i>Midlands &amp; East</i>	45	96	82
<i>South</i>	50	92	82
Wales	13	77	77
Scotland	18	78	78
N Ireland	13	100	85
<b>UK total</b>	<b>231</b>	<b>90</b>	<b>80</b>
Ireland	18	56	39
<b>Total</b>	<b>249</b>	<b>88</b>	<b>77</b>

### How the NSHPC works

**Obstetric reports** to the NSHPC are made through RCOG, and **paediatric reports** through the British Paediatric Surveillance Unit (BPSU). These, and additional direct reports to the NSHPC, are combined and processed at the Institute of Child Health, London.

Paediatric follow up is initially through the notifying paediatrician and then depends on the infection status of the child and the unit looking after them. We continue to seek annual follow up information on infected children either from the notifying paediatrician, or with their agreement, through CHIPS (the Collaborative HIV Paediatric Study), our collaboration with the MRC Clinical Trials Unit and the units caring for infected children.

## Conferences

NSHPC data on mother-to-child transmission of HIV in the UK and Ireland between 1990 and 2004 were presented at the Conference on Retroviruses and Opportunistic Infections (CROI) in Los Angeles, USA, in February. The poster is available, along with the abstract, on the CROI website:

[www.retroconference.org/2007/](http://www.retroconference.org/2007/)

A summary of maternal and paediatric HIV issues presented at CROI was compiled by Claire Townsend and colleagues for the "Women, Children and HIV" website. This summary is available at:

[www.womenchildrenhiv.org/wchiv?page=pi-croi-2007](http://www.womenchildrenhiv.org/wchiv?page=pi-croi-2007)

Claire Townsend also attended the 11th International Workshop on HIV Observational Databases in Monte Carlo, where she gave an oral presentation on the risks and benefits of HAART (highly active antiretroviral therapy) in relation to premature delivery and mother-to-child transmission, based on NSHPC data.

NSHPC data, and findings from CHIPS (Collaborative HIV Paediatric Study, the follow-up of infected children in the UK and Ireland) were also presented at the Royal College of Paediatrics and Child Health's Spring Meeting in York (see box, right).

Finally, the NSHPC contributed data to three abstracts being presented at the British HIV Association (BHIVA)'s Annual Conference in Edinburgh (see box, right).

### Recent publications

Cortina-Borja M, Williams D, Cubitt WD, Tookey PA, Newell M-L, and Peckham CS. HIV1 subtypes in pregnant women in the UK. *Int J of STD and AIDS* 2007;18(3):160-2

Hankin C, Lyall H, Peckham C, Tookey P. Monitoring death and cancer in children born to HIV-infected women in England and Wales: use of HIV surveillance and national routine data. (Research Letter) *AIDS* 2007; 21(7):867-869

Hankin CD, Newell M-L, Tookey P. Long-term follow-up of uninfected children born to HIV-infected women and exposed to antiretroviral therapy: survey of parents' and health professionals' views. *AIDS Care* 2007; 19(4): 482-486

Townsend CL, Cortina-Borja M, Peckham CS, Tookey PA. Premature delivery in HIV-1 infected women taking antiretroviral therapy in the UK and Ireland (1990-2005) *AIDS*, in press 2007

**Ethics and funding** - The NSHPC is currently funded by the Health Protection Agency and has London Multi-Centre Research Ethics Committee approval (Ref: MREC/04/2/009; January 2004).

### Conference abstracts

#### CROI, Los Angeles, USA, February 2007

Townsend et al. Mother-to-child transmission of HIV in the UK and Ireland, 1990-2004. *Poster 761.*

#### 11<sup>th</sup> International Workshop on HIV Observational Databases, Monte Carlo, March 2007

Townsend et al. Premature delivery, vertical transmission and antiretroviral therapy in HIV-infected pregnant women in the UK and Ireland. *Oral*

#### RCPCH Spring Meeting, York, March 2007

Townsend et al. Vertically acquired HIV infection in the UK and Ireland in the era of routine antenatal testing (2000-2005). *Arch Dis Child* 2007; 99(suppl\_1): A80-A87. *Abstract G/THUR/ALL6. Oral*

Doerholt et al. Morbidity, mortality and response to treatment in perinatally HIV-infected children in the UK and Ireland, 1996-2006: a prospective cohort study. *Arch Dis Child* 2007; 99(suppl\_1): A80-A87. *Abstract G/THUR/ALL5. Oral*

#### BHIVA Conference, Edinburgh, April 2007

Tosswill et al. An audit of laboratory diagnosis of HIV-1 infection in infants born to HIV-1 positive mothers in the UK. *Oral*

Thornton et al. High prevalence of HIV-1 in women who terminate their pregnancies: data from the Unlinked Anonymous Prevalence Monitoring Programme. *Oral*

Roedling et al. Pregnancy and mode of delivery in HIV positive women at two London Centres – have the BHIVA pregnancy guidelines led to an increase in vaginal deliveries in women with undetectable viral load? *Oral*

**NSHPC team** - Pat Tookey (principal investigator), Janet Masters (NSHPC co-ordinator), Claire Townsend and Barbara Willey (researchers), Icina Shakes (administrative assistant), Kate Francis (temporary staff).

**NSHPC slides** - A regularly updated powerpoint presentation of the NSHPC data is available. Please email us to request a copy.

## Children born to HIV infected women

These tables include data from the paediatric reporting scheme, which runs in parallel to the obstetric scheme. Paediatric data are collected via the British Paediatric Surveillance Unit (BPSU) of the Royal College of Paediatrics and Child Health (RCPCH), through its orange card system. (For further information, please see <http://bpsu.inopsu.com/>)

**Table 4: Children born to HIV infected women and reported by March 2007**  
Infection status and region of first report

	Infected	Indeterminate	Uninfected	Total reported	Known to have died *
England total	1417	1392	4694	<b>7503</b>	228
<i>London</i>	934	654	3017	<b>4605</b>	166
<i>North</i>	157	218	496	<b>871</b>	30
<i>Midlands and East</i>	189	290	742	<b>1221</b>	21
<i>South</i>	137	230	439	<b>806</b>	11
Wales	17	20	40	<b>77</b>	2
Northern Ireland	5	9	16	<b>30</b>	1
Scotland	66	67	278	<b>411</b>	22
Ireland	78	62	753	<b>893</b>	20
<b>Total</b>	<b>1583</b>	<b>1550</b>	<b>5781</b>	<b>8914</b>	<b>273</b>

\*excludes deaths in children known not to be infected

Table 4 includes 434 young people born before 1990; 233 were uninfected and 60 of those are known to have died. Approximately 9% of children in Table 4 were born outside the UK and Ireland.

**Table 5: Children born in the UK and Ireland to diagnosed women \***  
Year of birth and infection status (reports to the end of March 2007)

	UK			Ireland			Total (UK & Ireland)
	infected	indeterminate	uninfected	infected	indeterminate	uninfected	
<b>pre 1990</b>	14	20	104	6	0	40	<b>184</b>
<b>1990-96</b>	72	85	315	4	5	28	<b>509</b>
<b>1997</b>	7	7	79	0	0	7	<b>100</b>
<b>1998</b>	4	14	111	0	0	16	<b>145</b>
<b>1999</b>	4	15	187	0	1	12	<b>219</b>
<b>2000</b>	6	31	293	0	1	48	<b>379</b>
<b>2001</b>	5	67	410	3	2	80	<b>567</b>
<b>2002</b>	12	57	546	1	4	115	<b>735</b>
<b>2003</b>	6	84	780	4	6	139	<b>1019</b>
<b>2004</b>	10	122	861	1	9	103	<b>1106</b>
<b>2005</b>	11	322	761	0	24	81	<b>1199</b>
<b>2006</b>	8	549	437	0	6	53	<b>1053</b>
<b>2007</b>	0	51	2	0	2	0	<b>55</b>
<b>Total</b>	<b>159</b>	<b>1424</b>	<b>4886</b>	<b>19</b>	<b>60</b>	<b>722</b>	<b>7270</b>

\* 642 infected children born to women who were undiagnosed at the time of delivery have also been reported

In Table 5, although 22% of children born since 2000 are currently described as indeterminate (pending test results), at least 98% are likely to be uninfected, since they were born to diagnosed women.