

Lost to follow-up HIV-exposed indeterminate children in the UK and Ireland

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BACKGROUND

- The current HIV vertical transmission rate among diagnosed women is <0.3% in the UK and Ireland, based on children with known infection status
- The status of a small number of HIV-exposed children remains unknown due to a range of factors
- BHIVA guidelines state that all HIV-exposed infants should be tested at birth, 6 & 12 weeks, with a final 18 month antibody test to establish infection status

METHODS

- The National Study of HIV in Pregnancy & Childhood (NSHPC) has collected data on pregnancies in women with HIV and their children since 1989
- Data collected includes infant diagnostic test results and current contact status
- Where no PCR test at or after 12 weeks is reported, we define an infant's HIV status as indeterminate. Loss-to-follow-up (LTFU) was defined based on respondent report
- We describe children born to HIV-diagnosed women in the UK and Ireland from 2009 onwards and reported to the NSHPC by the end of 2017 as LTFU before infection status was confirmed
- Of 9854 livebirths reported by 31-12-2017, 16% (1623) were indeterminate, including 28 who died. Of the surviving 1595 indeterminate children, 245 (15%) are aged >2 years; data is currently being sought on 132/245 (Fig 1)

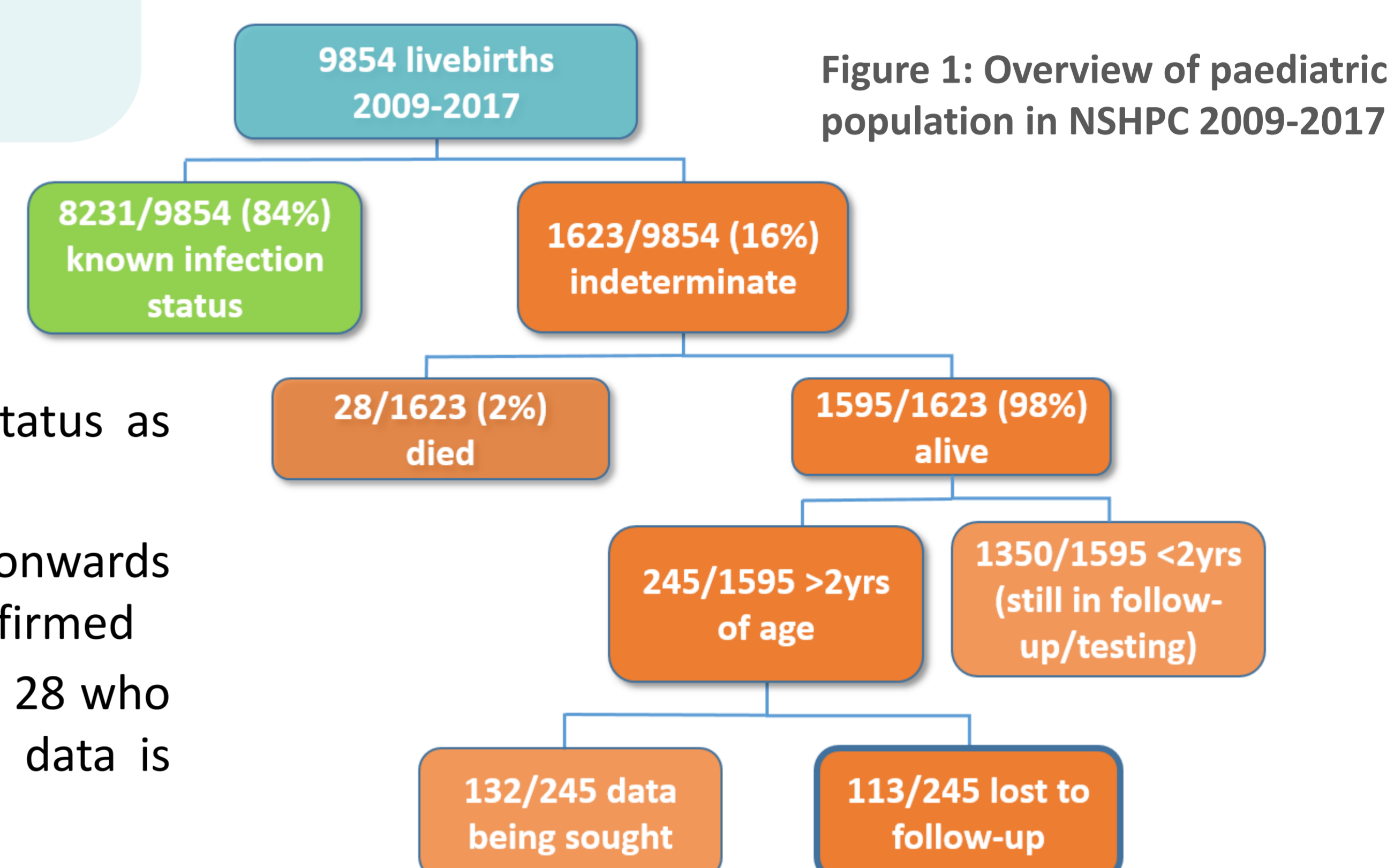
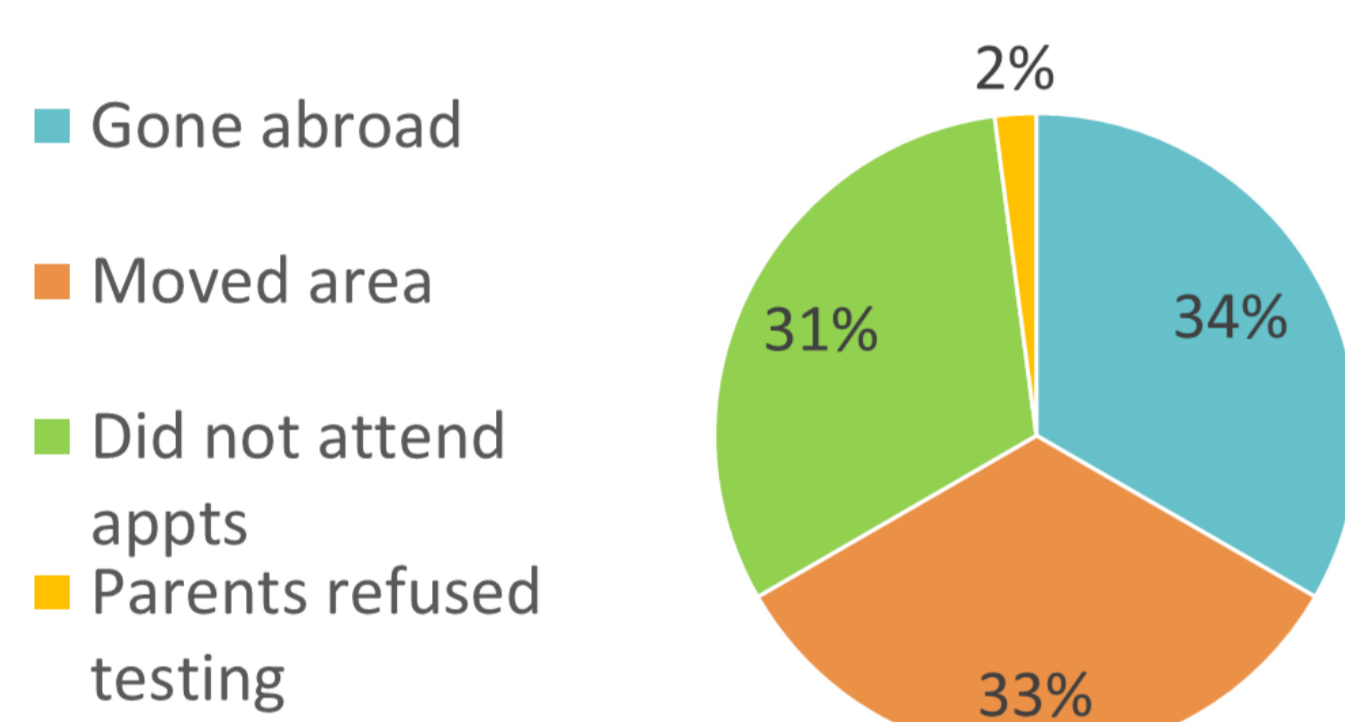


Figure 1: Overview of paediatric population in NSHPC 2009-2017

RESULTS

113 indeterminate children >2years of age were reported as **lost to follow-up**. Among these LTFU children aged >2 years, **76% (86/113) had only a birth PCR test**, with the remainder only having birth and 6 week PCR tests

REASON FOR LOSS TO FOLLOW-UP



Reason for LTFU was only known/provided in 48/113 cases. Among these, a third of children were reported to have **gone abroad**, a third **moved area** and 31% did **not attend appointments** despite chasing. In one case the parents were reported as refusing testing (Fig 2).

Figure 2: Reason for loss to follow-up

ISSUES IN PREGNANCY

Half of mothers **booked late for antenatal care** and over a fifth delivered with **detectable viral load** (Fig 3)

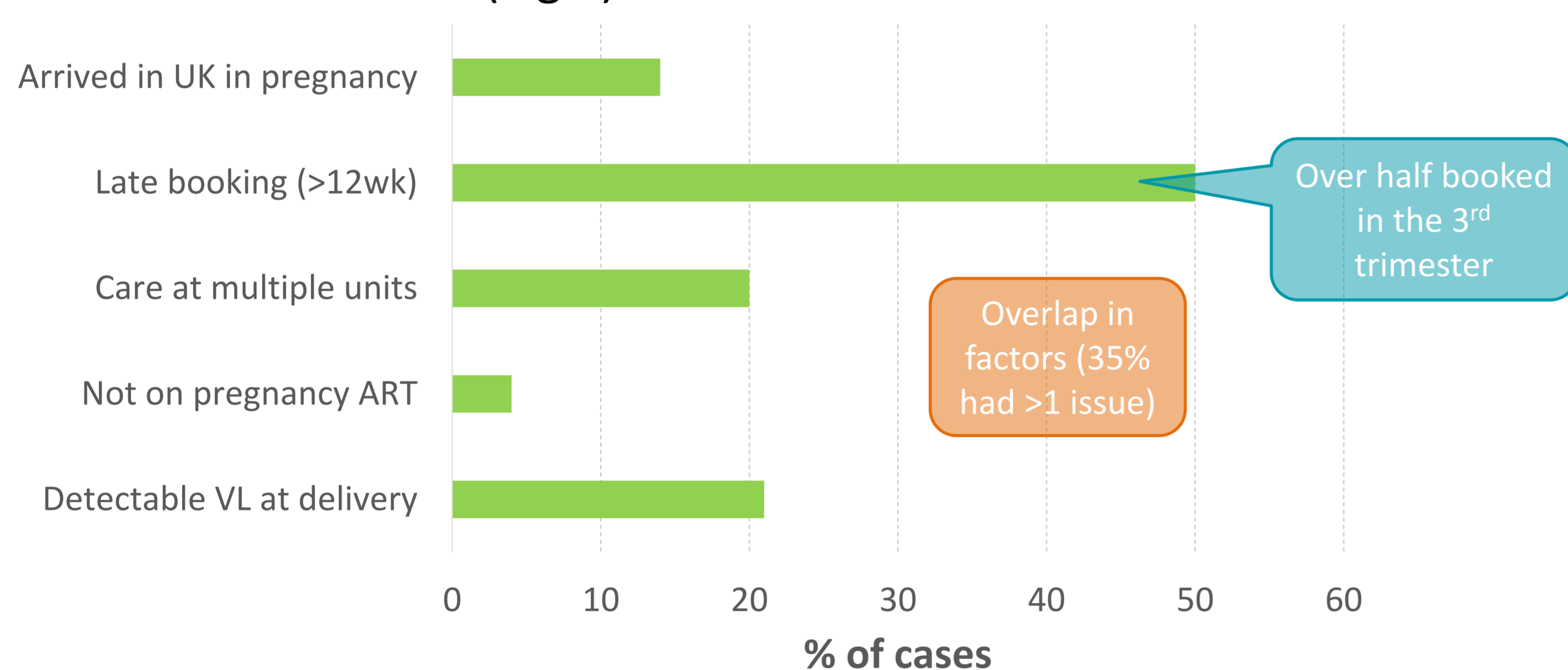


Figure 3: Proportion of cases with sub optimal PMTCT interventions reported

- Late booking and poor adherence were also found to be contributing factors in perinatal transmissions by the recent NSHPC audit

CONCLUSIONS

- Nearly half of HIV-exposed indeterminate children born in the UK and Ireland currently aged over 2 years of age have been reported as LTFU
- The NSHPC's surveillance across maternity and paediatric units highlights the presence of engagement issues likely related to LTFU, e.g. the high rates of mothers with late antenatal booking and detectable viral load
- A multi-disciplinary approach, with communication of any issues in maternity care to paediatric services, may provide opportunities to anticipate and address potential disengagement

MATERNAL DEMOGRAPHICS

Compared to mothers of children with known infection status, a higher proportion of those with children LTFU were: in their first pregnancy and diagnosed with HIV in pregnancy (Table 1)

Table 1: Maternal characteristics for those with known infection status v indeterminate & LTFU (births 2009-2017)

Characteristic	Known infection status (n=8231)	Indeterminate & LTFU (n=113)	P-value (χ^2)
Ethnicity	(n=8222)	(n=110)	0.41
Black African	6160 (75%)	88 (80%)	
White	1378 (17%)	16 (15%)	
Other	684 (8%)	6 (5%)	
Country of birth	(n=8159)	(n=109)	0.09
UK/Ireland	1217 (15%)	10 (9%)	
Abroad	6942 (85%)	99 (91%)	
HIV acquisition	(n=7666)	(n=102)	0.37
Heterosexual	7348 (96%)	98 (96%)	
Injecting drug use	125 (1.5%)	3 (3%)	
Other	193 (2.5%)	11 (1%)	
Timing of diagnosis	(n=8231)	(n=110)	0.03
Before pregnancy	6792 (83%)	82 (75%)	
During pregnancy	1439 (17%)	28 (25%)	
Parity	(n=6121)	(n=76)	0.04
Primiparous	1816 (30%)	31 (41%)	
Coinfections	877 (13%)	10 (11%)	0.60

A fifth arrived within 12mths of pregnancy

Median maternal age was 32yrs (IQR: 27, 36) same as NSHPC as a whole

SIBLINGS (excluding twins)

- 11/113 children had **one or more siblings previously LTFU**
- 5/113 siblings had **gone abroad** before infection status was established
- 2/113 had older siblings who were **HIV-positive**

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