The family HIV testing pathway; ensuring prioritisation and follow up

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Background:

Our trust serves an urban population (Total cohort size 5000). Following a serious incident (SI) investigation into the late diagnosis of an HIV positive child, the Family HIV testing pathway was redesigned and a look-back exercise of the patient cohort initiated.

Methods:

A dedicated HIV health adviser post was created to lead this process. The HIV testing pathway for untested children was rewritten with involvement of the safeguarding team.

A new AIDS diagnostic code was implemented in pathology for post-mortem diagnoses with a monthly report sent to the HIV department.

Traffic light system for assessing urgency of HIV testing timeline (see table 1): Time zero is from the time we knew about an untested child.

Table 1:

BLUE LIGHT – Same day testing	***Partner in late stage of pregnancy >24/40** ***** Child currently an inpatient**
RED LIGHT - Testing within 1 month	*Partner in early stage of pregnancy *child at home but frequently ill *untested baby <1yr old
YELLOW LIGHT - Testing within 4-6 months	*child at home and currently well (institute safeguarding protocol by month 4, resolve by month 6)
GREEN LIGHT - Test within 3-6 months	*sexual contacts not known to be pregnant

A local community event was held in conjunction with a third sector organisation to raise awareness of the importance of partner and child testing.

Patients are being identified in batches:

Tier 1: Women living with HIV who may have untested children.

Tier 2: Males living with HIV who may have untested partners and children

Results:

Results to date: 1601 patients have been identified in Tier 1 across three sites. Tier 2 – 474 men from site 1 identified so far.

Tier 1 cohort - single site data: 530 women **(age 18-65**) 18-25 (7), 26-35 (71), 36-45(187), 46-55 (215), 56-65 (50)

241 (45%) with children in UK who have been tested

151 (28%) documented no children

3 (0.5%) declined to give details of their children's testing status as now adults

12 (2%) with children abroad and are untested.

123 (23%) who have children considered not at risk of vertical transmission due to HIV acquisition timeline of mother.

1 child was referred to child safeguarding team and subsequently tested negative.

2 children referred to Paediatric teams - 1 tested negative, the other had tested HIV positive before joining parent in UK.

3 referrals to GP for child testing - 2 carried out and tested negative, 1 declined involvement as young person 18yr old.

0 children were newly diagnosed during this period.

Conclusion:

- The majority of patients to date have engaged with the process.
- The appointment of a dedicated Health adviser has been crucial for leading, supporting and facilitating this process.
- This on-going piece of work requires the support of the HIV MDT and Trust safeguarding team