

BACKGROUND

- ✦ An audit of HIV positive mothers attending the family clinic at St George's Hospital (SGH) in 2003 identified that 20% of their children resident in the UK were untested for HIV¹
- ✦ National guidance for testing children born to HIV positive parents has been produced by BHIVA^{2,4}, CHIVA^{3,4} and BASHH⁴ and has now been widely adopted. This states that adult HIV services must have protocols and procedures for testing any infant, child or young person thought to be at significant risk of HIV infection including all those with parents or siblings who are HIV infected
- ✦ The National BHIVA audit in 2009 looked at adult HIV clinics' policies and practice on testing children of adult HIV positive patients. 88% had a standard procedure for identifying children of newly diagnosed adults but only 24% sites had reliable systems to check whether children of previously diagnosed mothers were tested
- ✦ SGH now have a rigorous testing policy, enhanced follow up and clear procedures in place, resulting in early identification of children at risk. Since January 2009, results of prospective testing of all children of HIV positive mothers attending SGH for the first time, and at risk, have been clearly recorded on our in-house database

AIMS

- ✦ To identify that all children of HIV positive mothers attending SGH for the first time, and at risk, are being tested for HIV
- ✦ To perform a 'look back' to check the HIV status of children of existing HIV positive mothers at SGH

METHODS

- ✦ A multidisciplinary team (MDT) of doctors, nurses and health advisers from the paediatric and adult HIV service were convened to facilitate this process
- ✦ All women registered at the Courtyard HIV Clinic, SGH between 1/1/09-1/1/12 were identified using Sophid data. Information was collected on a standardised paper proforma from patient notes or face to face interviews including; number of women with children, ethnicity, total number of children and if tested for HIV, status of tested children, age and country of residence of children, mothers' reason for not testing children. Data was transferred and stored on a secure, in-house electronic database. Data was also prospectively collected from face to face interviews with all newly diagnosed HIV positive women since 1/1/09
- ✦ Our focus to date during the 'look back' phase has been children <18yrs living in the UK
- ✦ All untested children identified were discussed at our MDT and appointments for testing in the Children's Outpatient dept were set up with the Paediatric nurses
- ✦ For women identifying that their children had already been tested for HIV elsewhere, Health Advisers have contacted these clinics to verify test results

RESULTS (see Fig 1.)

- ✦ 627 women were identified
- ✦ Information was gathered on 603/627 (96%)
- ✦ 482/603 (80%) were Black African, 54 (9%) White British and 30 (5%) Black Caribbean
- ✦ 476/603 (79%) mothers had 1056 children
- ✦ 30/1056 (3%) were not considered at risk of being HIV positive, mostly due to the mother having a verified HIV negative test after childbirth
- ✦ 1026/1056 (97%) children were potentially at risk
 - ✦ 665/1026 (65%) had been tested for HIV
 - ✦ 76/665 (11%) had already tested HIV positive and were known to our service
 - ✦ 589/665 (88%) were HIV negative
- ✦ 361/1026 (35%) were untested or of unknown testing status
 - ✦ 300/361 (83%) were untested aged ≥ 18yrs
 - ✦ 61/361 (16%) were untested aged <18yrs
 - ✦ 21/361 (6%) were untested aged <18yrs and living in the UK (circled Fig 1.)
- ✦ Reasons given by mothers for children remaining untested included concerns about parental HIV disclosure, feelings of guilt should the child test positive, the child being medically well or too old to test
- ✦ Since our 'look back' and rigorous prospective testing of all children of newly diagnosed mothers in 2009 began, no children have yet tested HIV positive

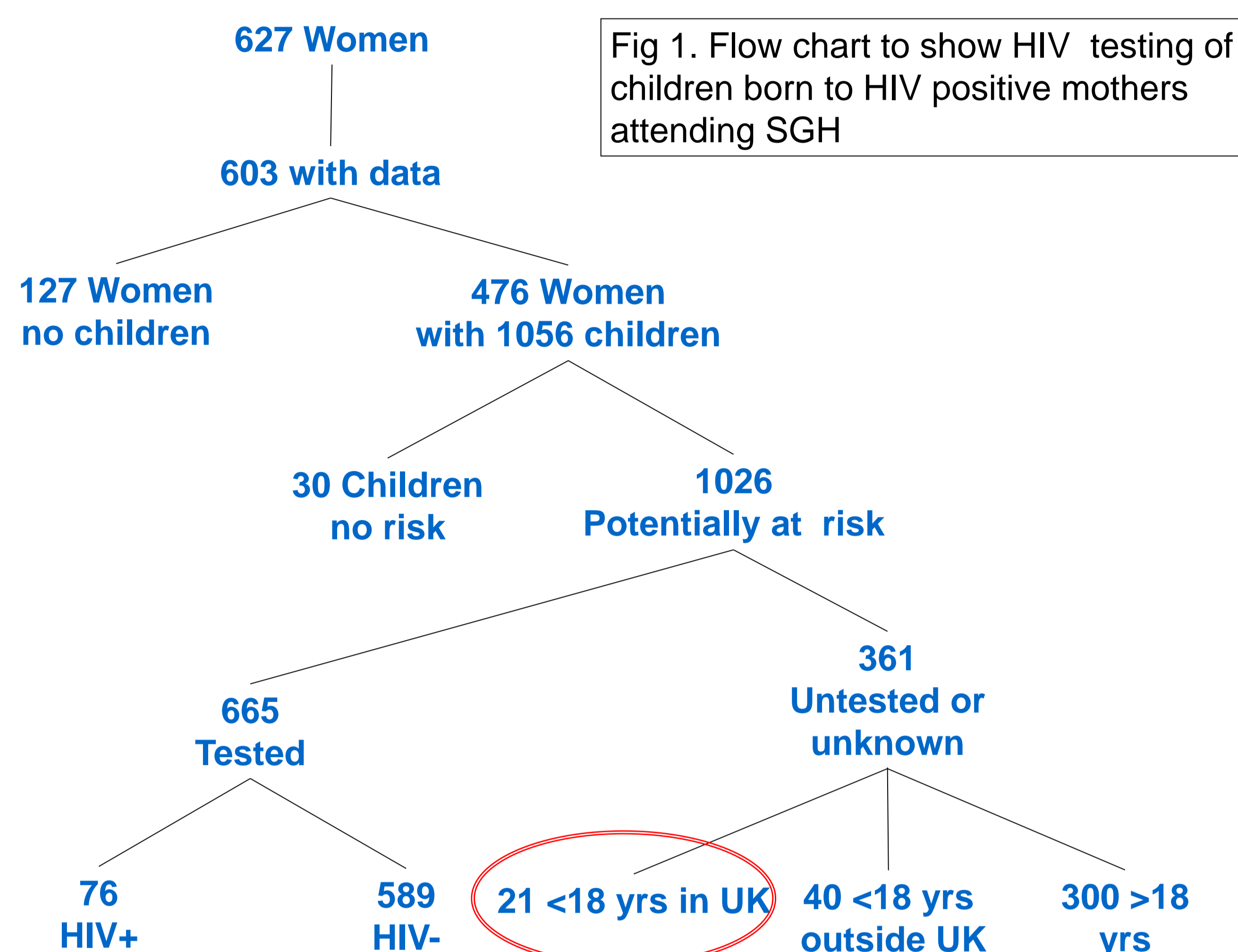


Fig 1. Flow chart to show HIV testing of children born to HIV positive mothers attending SGH

DISCUSSION

- ✦ Despite our large cohort of women and children, 94% children aged <18yrs and living in the UK have been tested for HIV
- ✦ Those who remain untested are:
 - ✦ children >18yrs
 - ✦ children living abroad
 - ✦ children not at risk, for example born before maternal risk
- ✦ Untested children <18 yrs (21/361; circled Fig 1.) are on our database and are being actively followed up in our MDT through the 'look back' process
- ✦ To date we have focused on the <18's living in the UK as it is potentially a safeguarding issue if children at risk of HIV infection are denied access to testing. They are also an easily accessible group
- ✦ Outstanding and difficult cases, often where mothers decline to test their children, are discussed at our MDT every 3 months. There is a clear pathway for referral to social services, should this be necessary
- ✦ Follow-up support is offered to all children and parents to help with disclosure or adjustment issues
- ✦ Qualitative interviews to explore the testing process with mothers who have tested their children with relative ease compared with those who initially felt resistant, are due to be carried out later this year
- ✦ At SGH most children are tested with a venous blood sample however an audit from St Mary's Hospital has shown an advantage to point of care testing (POCT) in reducing parental anxiety whilst waiting for test results⁵. More widespread use of POCT may help to facilitate future testing

RECOMMENDATIONS

- ✦ All healthcare professionals have a duty to ensure the safety of children and ensure safeguarding issues are addressed
- ✦ All services need to be aware of, and follow, existing national guidelines for child testing which can be adapted to suit local needs
- ✦ MDT working should be routine
- ✦ Follow-up support should be provided for all children and parents to help with disclosure or adjustment issues
- ✦ There is currently no national data on the numbers of children tested for HIV since the introduction of national guidance. We would welcome a national BHIVA audit to explore this further

REFERENCES

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