

Confidentiality and Non-Disclosure can affect Enrolment, Follow-up and Adherence to Antiretroviral Therapy in Ugandan Children

Findings from the ARROW (AntiRetroviral Research for Watoto) trial

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THE ISSUE

HIV infected children depend on adults for their care, but non-disclosure of the child's HIV status between care-givers may affect the child's treatment in terms of adherence to Anti-Retroviral Therapy (ART) and attendance to clinics

BACKGROUND

- 🚫 The ARROW trial is evaluating monitoring strategies and first-line ART in 1200 HIV-infected children from 3 sites in Uganda (n=800) and one in Zimbabwe (n=400) [see poster MOPE0191]
- 🚫 At enrolment, contact details are obtained and the child's home is visited
- 🚫 The care-givers, commonly mothers, are asked if they have disclosed the child's HIV status to their spouses



FINDINGS

Out of 622 children screened
110 mothers (18%)
had not disclosed the child's HIV status to the father

Refused consent for ARROW (n=30)

Recruited to ARROW (n=80)

- Amongst the 30 mothers who refused consent for ARROW,
- 🚫 3 opted not to start their child on ART
 - 🚫 One child died in the process

- Amongst the 80 children recruited to ARROW,
- 🚫 Five mothers declined home visits
 - 🚫 Mothers gave wrong contact details, making it difficult to locate children who missed clinic appointments
 - 🚫 Two children have been lost to follow up
 - 🚫 Two children missed appointments because their fathers questioned the frequency of clinic visits, while one father denied that their child was HIV-infected and threatened violence if the child received care
 - 🚫 Mothers may hide ART from fathers, and this, coupled with missed visits, leads to poor adherence.

LESSONS LEARNED and NEXT STEPS

- 🚫 Disclosure of a child's HIV status to both primary care-givers should be encouraged prior to enrolment into a clinical trial
- 🚫 Use of a trusted third party to work with both care-givers during the disclosure process is often helpful
- 🚫 Adherence and follow-up become problematic if only one care-giver knows the child's HIV status and the care-giver dies

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