



Disclosure of their HIV status to HIV-infected children participating in the ARROW trial in Entebbe, Uganda

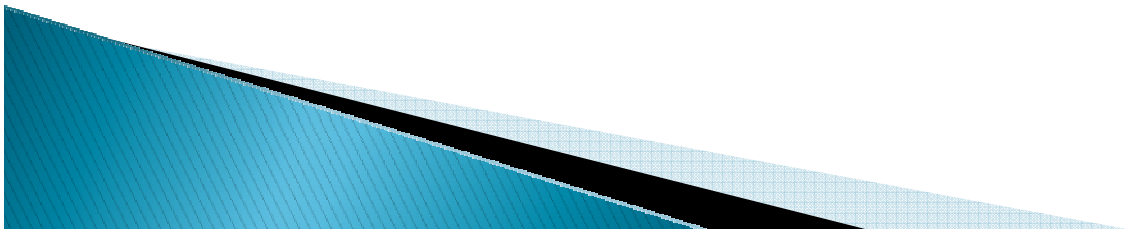
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on behalf of the ARROW Trial Team

4th National Paediatric HIV/AIDS Conference
September 2010

ISSUES



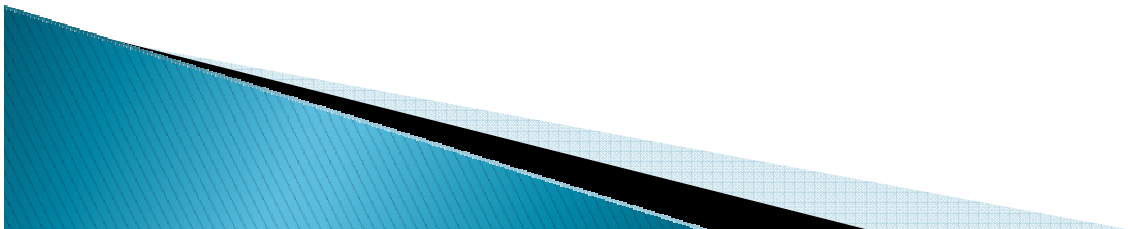
- ▶ HIV-infected children depend upon adults for their HIV-related care
- ▶ It has been suggested that knowledge of HIV status among older children may improve adherence to anti-retroviral therapy (ART)
- ▶ The Ugandan National ART guidelines recommend children aged ≥ 8 years be informed of their HIV status
- ▶ There are few documented experiences of disclosure of HIV status to children on ART



PROGRAMME DESCRIPTION(1)



- ▶ ARROW is a clinical trial evaluating monitoring strategies and first-line ART in HIV-infected children from Uganda and Zimbabwe
- ▶ Informed consent to participate in ARROW was given by the child's primary carer
- ▶ Assent to participate in the trial is given at 13 years



PROGRAMME DESCRIPTION (2)

Counselling session



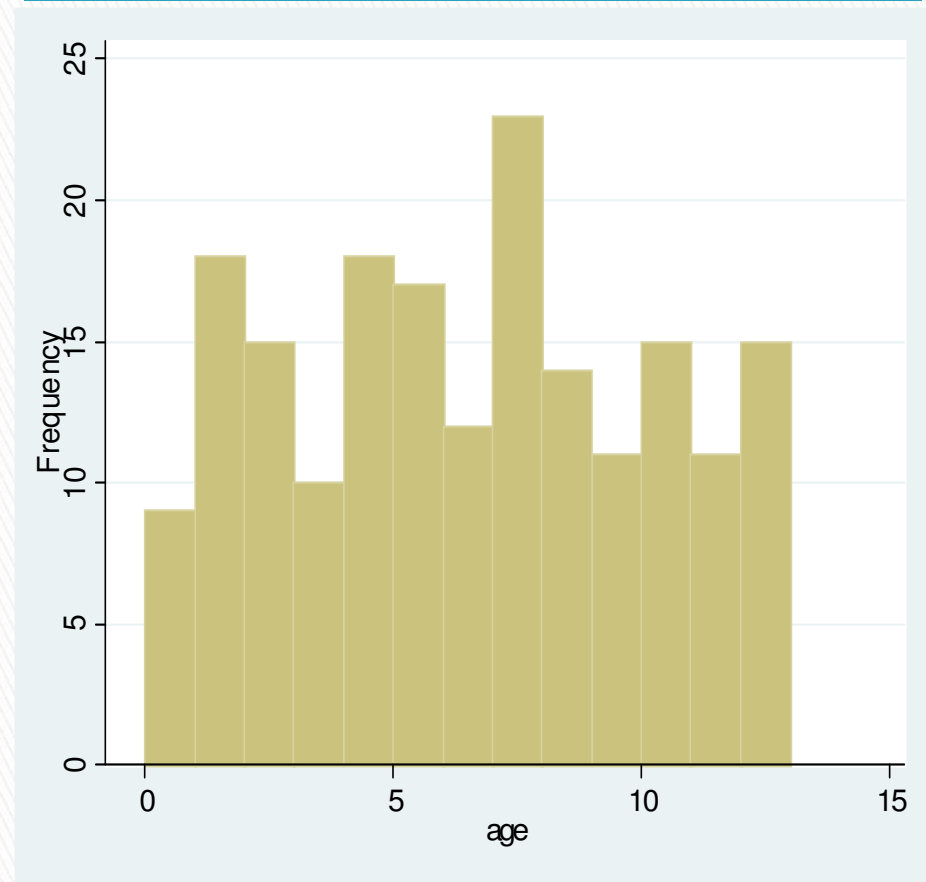
- ▶ The trial counselors encourage carers of children ≥ 8 years to disclose to them their HIV status at home
- ▶ The counselors also offer the option of assisted disclosure in the clinic

PROGRAMME DESCRIPTION (3)



- ▶ **189** children were recruited to ARROW -Entebbe
 - Median age 6.6 (IQR:3.7 - 9.2); 88 boys/101 girls)
 - None of them knew their HIV status at enrolment.
- ▶ **178** children are in active follow up

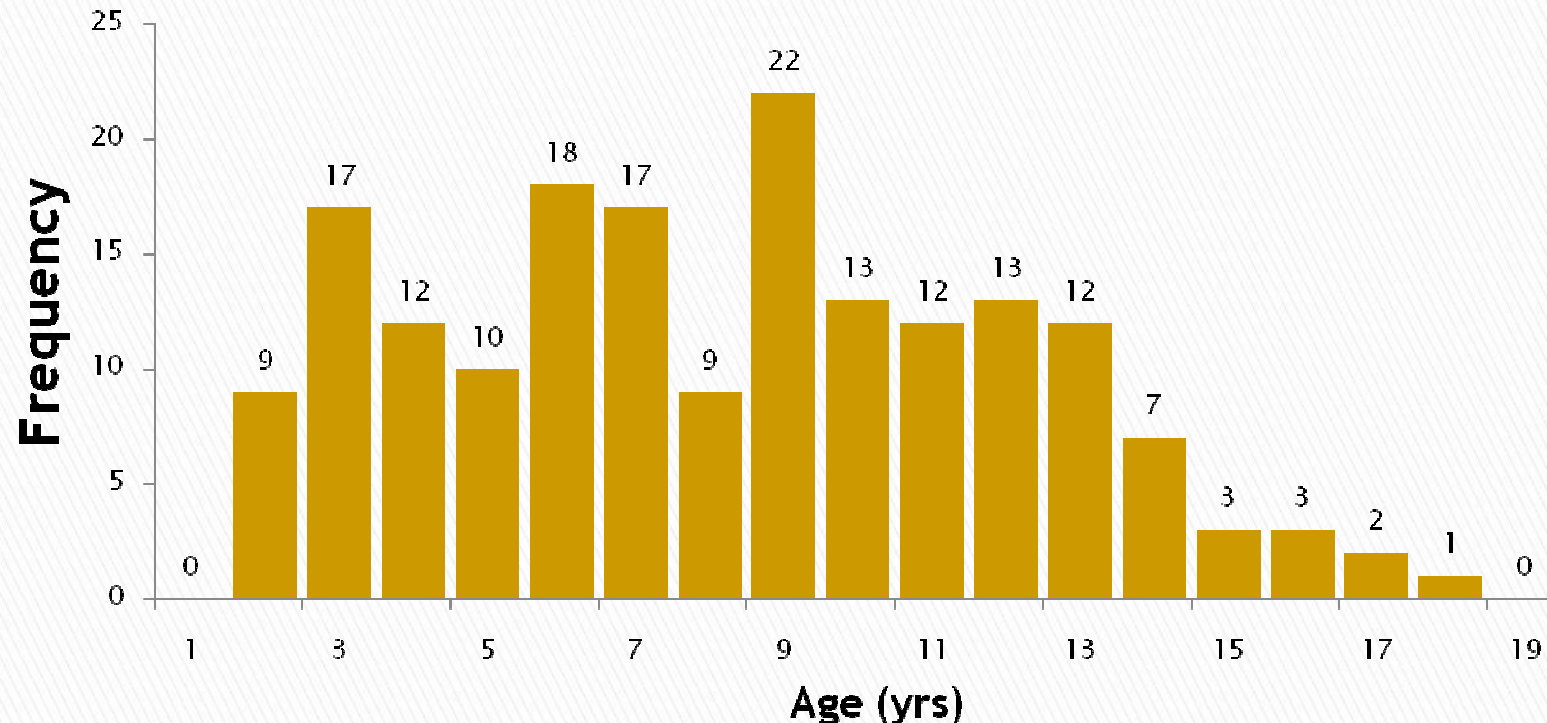
Age of children at enrolment in Entebbe, Uganda



PROGRAMME DESCRIPTION (4)



Age distribution at the Entebbe site by May 2010



- ▶ There are 97 children ≥ 8 years and the disclosure process has been started in 81 (84%) and is ongoing



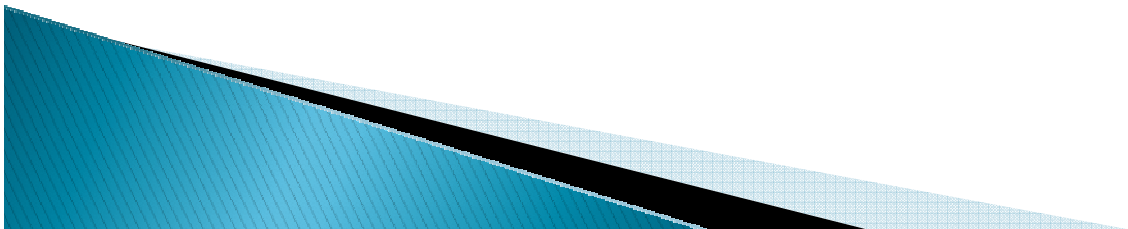
PROGRAMME DESCRIPTION (5)

- ▶ Over the past two years,
 - **81 children (79/81 aged ≥ 8 years)** have learnt their HIV status through assisted disclosure
 - **2 children aged 7 years** were also informed of their status as both had been asking questions about tablet taking.
- ▶ **50/81 (61.7%)** carers were biological parents,
 - mostly on ART
 - who found disclosure easier than non-biological guardians who understood little about HIV.
- ▶ Information supplied through guidance and support from counselors was central to the success of the assisted disclosure process.
- ▶ Carers reported that information received during the disclosure process has helped improve children's adherence to ART.

LESSONS LEARNED



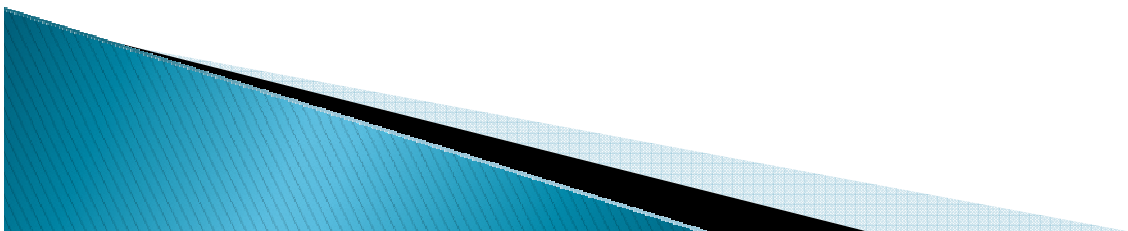
- ▶ Disclosure of their HIV status to children on ART aged ≥ 8 years is an ongoing process which appears fundamental for maintaining adherence to ART
- ▶ Carers, especially non-biological parents, frequently require professional support to disclose to the children their HIV status



CONCLUSIONS



- ▶ Disclosure of a child's HIV status by all primary carers should be encouraged and be part of the training given to HIV health care workers



ACKNOWLEDGEMENTS



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- ▶ The ARROW Trial teams at:
 - MRC/UVRI, Entebbe
 - Joint Clinical Research Centre, Kampala
 - Mulago Hospital, PIDC
 - UZ College of Health Sciences, Harare, Zimbabwe
 - MRC - CTU, London, UK
- ▶ The ARROW Trial Steering Committee, Data Monitoring Committee, Endpoint Review Committee
- ▶ ARROW funders: MRC UK, UK DfID
- ▶ GlaxoSmithKline (GSK) for trial drugs