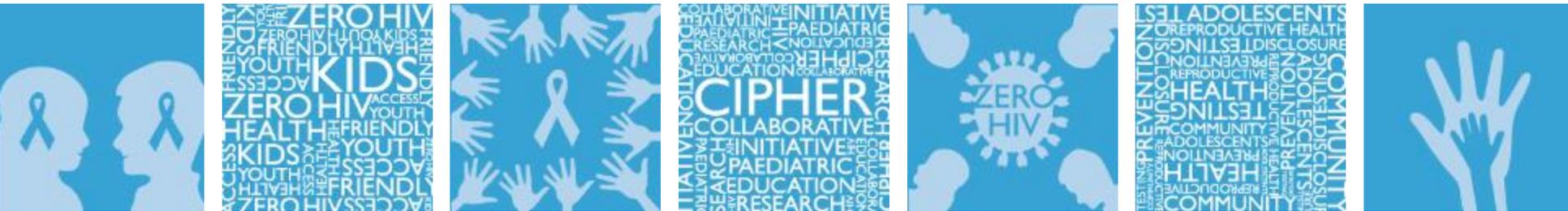


# The Collaborative Initiative for Paediatric HIV Education and Research (CIPHER)

Marissa Vicari, IAS



*The implementation of this project was made possible through an unrestricted grant from ViiV Healthcare. The content and structure of the project has been guided by paediatric experts convened by the IAS.*



## Goal

Optimizing clinical management and delivery of services to infants, children and adolescents affected by HIV in resource limited settings, through advocacy and research promotion.

## Objectives

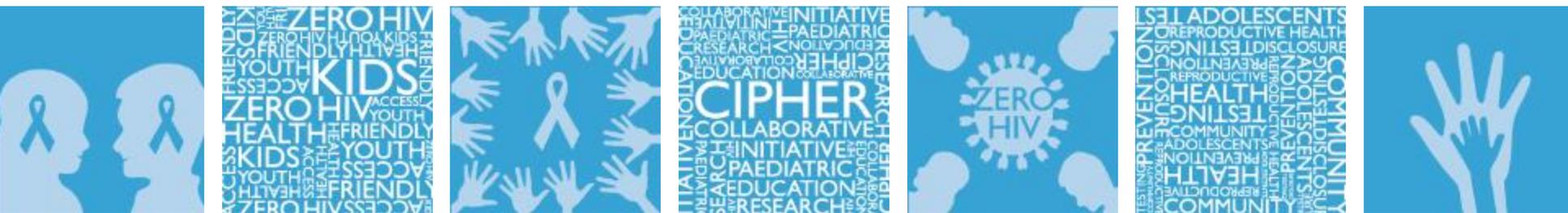
- Addressing **targeted research gaps** to optimize service delivery and clinical management
- Strengthening paediatric HIV **cohort collaboration** to support evidence-informed decision making
- **Advocacy and outreach** (2014)

- 2012: CIPHER founded as 2-year flagship IAS paediatric initiative
- Guided by paediatric HIV experts convened by the IAS
- Activities developed 2012 – 2013
  - Needs Assessment: clinical and operational research gaps
  - Research Grant Programme
  - Global Cohort Collaboration
  - Online Paediatric HIV Cohort Database
  - JIAS Special Issue: Perinatally HIV-infected Adolescents
- End 2013: paediatrics an IAS priority, branded as CIPHER
- 2014-2015: current activities expanded, new activities
  - Viral load monitoring, adolescents, young key populations, roundtable discussions ...



# CIPHER Online Paediatric HIV Cohort Database and Global Cohort Collaboration

Annette Sohn, TREAT Asia – amfAR



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# Paediatric HIV Cohort Database



- Online, searchable database
- Platform for cohort collaboration
- Source of information for researchers, funders, policy makers

Launched on World AIDS Day 2013

[www.ias-cipher.org](http://www.ias-cipher.org)



To date:

- 30 cohorts/networks, representing ~250,000 infants, children and adolescents in 59 countries
- 389 unique visitors, 742 total visits, from 50 different countries

Next steps and ideas:

- Analysis tools: Summary tables, epidemiology tool, disaggregation of data by WHO weight bands
- Additions: Link to online paediatric HIV resource library (with UNICEF), blog for sharing information,

**What information would be useful to you?**

- Paediatric HIV Cohort Investigator Consultation, 13-15 May 2013
- Participating cohorts/networks
  - IeDEA (Southern, Central, West and East Africa; CCASAnet; TREAT Asia)
  - EPPICC (including PMTCT and Eastern European cohorts)
  - Médecins Sans Frontières (MSF)
  - Baylor International Pediatric AIDS Initiative (BIPAI)
  - International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT) P1074
  - Pediatric HIV/AIDS Cohort Study (PHACS)
  - Optimal Models/ICAP

***Representing ~250,000 infants, children, and adolescents***

- ✓ **Global epidemiology of adolescents with perinatal HIV infection**
- ✓ **Duration of first-line ART in children**
- ✓ **Capacity building:** scholarships for data analysis with core analysis center
- **Perinatal pregnancies:** determining pregnancy outcomes among HIV-infected adolescents (including health-status of infants), retrospective data collection; descriptive, characteristics, not a lot of data available
- **Hepatitis B/C:** cross-sectional prevalence blood testing survey, POC assays, selected sites, regional representation (\$)

# Tabled research gaps

- **Tenofovir toxicity monitoring**
  - Short and long-term health impact
- **Cost-effectiveness modelling**
  - Developing a paediatric cost-effectiveness model
- **Mapping the use of ARVs**
  - Formulations, procurement patterns, strategies for stock outs
- **Disclosure**
  - To patients and partners
- **Early infant diagnosis**
  - Operational research on programmatic strategies
- **Physical and cognitive development among adolescents**
  - Physical development/puberty onset
- **HIV-exposed, uninfected infants and children**
  - For comparative studies, health outcomes after ARV exposure
- **Cancer incidence**

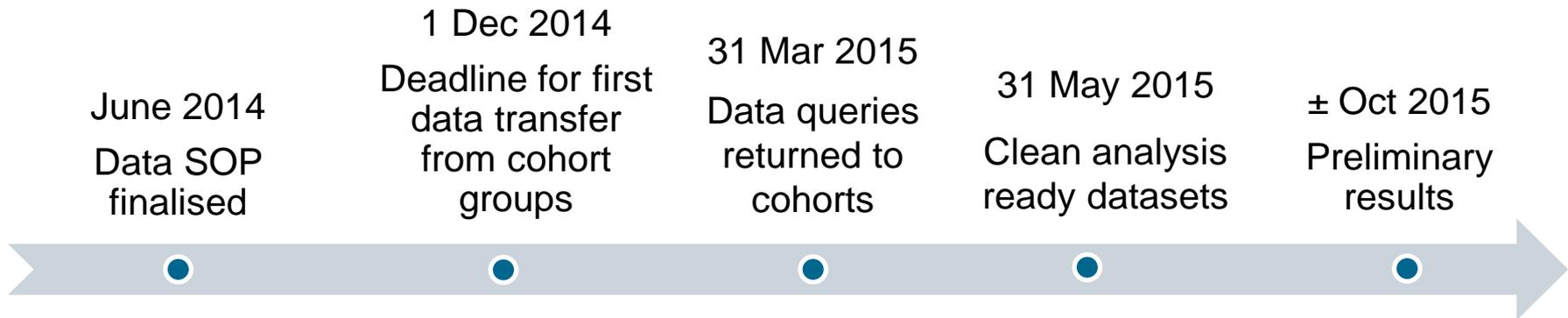
- Priority research topics
  - Time on first-line ART: Estimate incidence of treatment switch to second-line ART and associated factors; describe regimen use and durability
  - Adolescent epidemiology: Describe the global epidemiology of perinatally HIV-infected adolescents and compare outcomes across regions
- To be studied through a new, global pediatric cohort collaboration, supported by CIPHER (2014-2016)
- Data and analysis centres
  - CIDER (IeDEA Southern Africa), PI: Mary-Ann Davies
  - MRC UCL (EPPICC), Ali Judd
  - CBAR HSPH (PHACS), George Seage III

# Approach to data management & analysis for CIPHER Cohort Projects



- Collaborative & capacity building
  - data centre is a partnership of 3 institutions including a partner from a resource-limited country with high burden of pediatric HIV
- Capacity-building scholarship for PhD/post-doc mentored by lead paediatric HIV cohort statisticians.
- Huge and complex task of combining data across multiple cohort networks with different structures
- Consultative development of SOP for data transfer & harnessed existing resources for data harmonization (e.g. HICDEP)
- Use of metadata to understand network or individual cohort characteristics and account for these in analyses
- Data-sharing agreements

# Timelines and challenges



- Tight timeline
- Diversity of cohort network structures and settings
  - data centre will work with each network to assist with extraction/transfer most appropriate for their structure.
- Missing data/different levels of detail on certain variables, e.g. mode of transmission
  - use of variables with subcodes to allow for different data granularity and sub-analyses in cohorts with additional detail.