IAS

International AIDS Society

11th Symposium on Children and Adolescents with Perinatal HIV Exposure

Meeting report

Hosted by IAS – the International AIDS Society – in collaboration with Penta – Child Health Research, Mass General Brigham, Paediatric-Adolescent Treatment Africa (PATA) and the United Nations Children's Fund (UNICEF)

IAS 2025 pre-conference | 13 July 2025 | Kigali, Rwanda

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Content

Executive summary

On 13 July 2025, IAS - the International AIDS Society - in collaboration with Penta – Child Health Research, Mass General Brigham, Paediatric-Adolescent Treatment Africa (PATA) and the United Nations Children's Fund (UNICEF), hosted the 11th Symposium on Children and Adolescents with Perinatal HIV Exposure as a pre-conference event at IAS 2025, the 13th IAS Conference on HIV Science, in Kigali, Rwanda, with the theme, *Taking action to ensure that children and adolescents with perinatal exposure thrive*. The symposium brought together 130 researchers, healthcare providers, policy makers, funders and community representatives to discuss emerging evidence and interventions to improve the health and well-being of this underserved population.

The objectives of the symposium were to:

1. Present the latest scientific findings on the health, development and well-being of infants, children and adolescents with perinatal HIV exposure.
2. Inform health, policy and programming for infants, children and adolescents with perinatal HIV exposure by sharing evidence-based recommendations and learnings from best practices.
3. Foster networking opportunities for early-career researchers, policy makers, programme management staff and advocates working with infants, children and adolescents with perinatal HIV exposure.

Over 90% of survey respondents rated the clarity of the objectives and design and delivery of the symposium as either very good or excellent.

Background

Significant progress has been made in preventing vertical HIV transmission. As of 2024, it is estimated that nearly 16 million children under the age of 15 globally have been perinatally exposed to HIV, but did not acquire HIV[1]. However, an increasing and consistent body of evidence highlights associations between perinatal HIV and antiretroviral drug exposure during gestation and elevated vulnerability to adverse health outcomes. These include increased rates of adverse birth outcomes, infectious morbidity, mortality, impaired growth and suboptimal neurodevelopmental and cognitive outcomes compared with peers born to individuals without HIV[2].

Since 2017, the Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) of the IAS, in collaboration with WHO, UNICEF, PHACS, Mass General Brigham and PATA, has convened meetings to understand why infants, children and adolescents who are exposed to HIV are not consistently thriving to their fullest potential. This is the largest annual forum for policy and scientific dialogue around children and adolescents with perinatal HIV exposure.

[1] UNAIDS. AIDS Info - Global data on HIV epidemiology and response. https://aidsinfo.unaids.org/

[2] Understanding challenges and optimising outcomes of children with perinatal HIV exposure. JIAS Volume 26, Issue S4. Available here.

Welcome session

Claude Mambo Muvunyi, Director General of the Rwanda Biomedical Centre and Professor of Clinical Microbiology at the University of Rwanda, welcomed the participants to Rwanda. He acknowledged the global progress in reducing new paediatric HIV acquisitions, resulting in a 60% increase in the number of children under 15 who were perinatally exposed to HIV. While this reflects the success of prevention programmes, he stressed the urgent need to address the health and developmental challenges faced by children with perinatal HIV exposure. This population faces higher vulnerability to infectious morbidity, poor growth and developmental delays.

With no data yet on long-term outcomes of this population into adulthood, critical questions remain about future health issues. Framing the meeting as the world's largest forum dedicated to this population, he reaffirmed the need for a "thrive agenda" – one that prioritizes early identification of vulnerable children and delivers the support necessary for them to reach their full potential.

"Ensuring these children thrive is not only a matter of individual human rights, but also a strategic investment in strengthening communities and the long-term human capital of countries with high HIV prevalence."

Claude Mambo Muvunyi

Session 1: Leveraging routinely collected health data to improve outcomes of infants and children with perinatal HIV exposure

This session, facilitated by Agnes Ronan, Head of Programmes for PATA, focused on how routinely collected health systems data can be used to understand and improve outcomes for infants and children with perinatal HIV exposure.

The session featured two presentations, followed by a panel discussion.

Leveraging routinely collected health systems data to understand outcomes of children with perinatal exposure and assess interventions to improve outcomes – The CHERISH Study

The first presenter, Mary-Ann Davies, Public Health Medicine Specialist with the Western Cape Provincial Department of Health and Wellness in South Africa and Paediatric Clinical Epidemiologist at the University of Cape Town, presented the National Institute of Child Health and Human Development (NICHD)-funded Children HIV-Exposed Uninfected - Research to Inform Survival and Health (CHERISH) study. The study highlights the value of leveraging routinely collected health systems data, rather than establishing parallel research systems, to monitor long-term outcomes across the life course and evaluate interventions aimed at improving health trajectories for children with perinatal HIV exposure.

The study found that infants with perinatal HIV exposure had a higher prevalence of low birth weight (<2,500g) and higher rates of neonatal and infant mortality than those not exposed, especially among infants whose mothers initiated antiretroviral treatment (ART) in pregnancy or experienced ART interruptions during pregnancy. These findings are consistent with prior evidence. As none of the children were exposed to dolutegravir (DTG) during gestation (which is part of the currently recommended initial treatment for all persons living with HIV, including pregnant women), further research is needed to assess whether earlier maternal ART initiation or DTG use during pregnancy may reduce these risks.

Leveraging routinely collected health data to identify infants and children at risk for suboptimal health and development outcomes

Megan Song McHenry, paediatrician and Associate Professor of Paediatrics at the Ryan White Centre for Paediatric Infectious Disease and Global Health, Indiana University School of Medicine, presented on the neurodevelopmental outcomes of children with perinatal HIV exposure. While children with perinatal HIV exposure have an increased chance of poor health and developmental outcomes, not all of them will have adverse outcomes, raising the critical question of how to identify those most vulnerable in resource-limited settings. Megan described the implementation of a neurodevelopmental screening programme in western Kenya, which was developed through community engagement and integrated into maternal-child clinics. The model used mentor mothers to administer screening, followed by assessments and referrals where needed. While feasible, the approach faced challenges: locally derived screening items had poor psychometric performance; sensitivity and specificity were low; training and monitoring requirements were high; and clinic time pressures made additional screening difficult.

As a potential solution, Megan highlighted the use of routinely collected health data to develop risk prediction scores for neurodevelopmental outcomes. The Tabiri study in Kenya demonstrated that such variables performed better than traditional screening questions. Current work includes validating risk scores in larger populations and applying machine learning to refine predictive models. She emphasized that leveraging routine health data to automate risk screening holds promise, but requires further development of health system capacity for referral and care pathways. Advances in this area could optimize care for children affected by HIV and benefit child health globally.

Panel discussion

The panel featured Vivian Nyamande, a mentor mother with Zvandiri supporting young mothers living with HIV in Harare, Zimbabwe, and Loyce Maturu, an advocacy advisor. The discussion centred on the importance of psychosocial support, stigma reduction and the role of lived experience in shaping interventions for children with perinatal HIV exposure.

Vivian Nyamande emphasized the need for caution when using routine health data to identify vulnerable children, noting the potential for further stigmatization of mothers and families affected by HIV. She highlighted that some of the language used in existing tools and programmes can be stigmatizing for young mothers, underscoring the importance of involving them in the design and wording of tools to ensure sensitivity and acceptability. Vivian also stressed the critical role of mentor mothers in engaging and supporting young mothers through peer-to-peer connection, sharing lived experiences and modelling resilience.

Loyce Maturu noted that while prevention of vertical HIV transmission programmes have been largely successful, major gaps remain in providing holistic care for children and families. She shared her personal journey of growing up with HIV, the loss of her parents and brother, and experiencing stigma, abuse and household instability, all of which impacted her confidence and mental health. She described concerns about stigma linked to health records (for example, the notation of nevirapine at birth on immunization and growth cards), which could affect how children are treated in early childhood centres. She also highlighted challenges created by non-disclosure in extended families, which can limit the monitoring and support of children's developmental milestones.

Both panellists shared advice for healthcare providers, stressing that the focus should extend beyond achieving a negative HIV test result for the child. Treatment as prevention and infant prophylaxis alone is not sufficient as families also need accurate information, psychosocial support and reassurance that their fears and anxieties will be addressed.

Session 2: Mental well-being of children and adolescents with perinatal exposure to HIV

This session, facilitated by Renata Sanders, the Division Chief of the Craig-Dalsimer Division of Adolescent Medicine at The Children's Hospital of Philadelphia and Professor of Pediatrics and Medicine, turned attention to the often-overlooked mental health needs of children and adolescents with perinatal HIV exposure.

The session featured two presentations, followed by a discussion.

DISC: Disclosure intervention to support caregivers. Findings from a Botswana-based disclosure study

Kedibonye Lephoi Thankane, a research study nurse with the Botswana Harvard Health Partnership, presented findings from the Botswana-based Disclosure Study, which explored the dynamics of HIV status disclosure within families and co-designed tools to support the process.

The findings revealed that disclosure was often adolescent driven, with young people prompting the conversation and mothers sharing their status before they felt fully prepared. Adolescents frequently played a supportive role, encouraging their mothers' adherence to treatment. Some adolescents, however, expressed uncertainty about their own HIV status as disclosure typically focused only on the mother's diagnosis and not on the adolescent's in utero HIV exposure.

Barriers to disclosure included mothers perceiving their adolescents as too immature or unable to keep the family's HIV status confidential, feeling unprepared to initiate the conversation, and fearing the mental health impact of disclosure. Persistent stigma in schools, where HIV is still associated with thinness or hair loss, further discouraged disclosure. Facilitators included mothers' self-acceptance, strong mother-adolescent relationships, partners' support, and adolescents' maturity and HIV knowledge.

Participatory workshops indicated that mothers preferred cartoon-based videos and peer support groups as disclosure tools.

Optimizing mental health in adolescents growing up in households affected by HIV: The Friendship Bench model

Thandiwe Mashunye, Head of Programs and Government Relations at Friendship Bench Zimbabwe, presented on community-based models for addressing adolescent mental health in households affected by HIV, highlighting their scalability and cultural relevance.

The Friendship Bench model began with 14 community grandmothers, trusted figures within the social fabric, who draw on their life experience to support others. The model is structured around three phases:

1. Kuvhura pfungwa (opening the mind):
   Creating a safe space for individuals to share and identify their challenges

2. Kusimudzira (uplifting):
   Encouraging individuals to generate their own solutions

3. Kusimbisa (strengthening):
   Building resilience and equipping individuals with critical skills to address future challenges

This approach provides a structured yet culturally grounded framework for delivering mental health support at the community level.

Panel discussion

The panel featured Janviere Uhiriwe Gihozo, a young adult with perinatal HIV exposure, and her mother, Potamienne Komezusenge, a member of the Rwanda Network of People Living with HIV. They shared their personal journeys navigating HIV and stigma in their community.

Potamienne described how she and her husband were diagnosed with HIV after losing their fourth child to illness. This had a mental health toll on them. With the support of healthcare providers and the prevention of vertical transmission programme, they went on to have a child without HIV, choosing to breastfeed to maintain the mother-child bond. Today, her daughter is thriving and pursuing studies in software development.

Janviere heard about her mother's HIV status from the community before being told by her parents, which led to anxiety about becoming an orphan. At school, she faced exclusion from peers who knew her family was affected by HIV and was burdened with questions about HIV from classmates. Misinformation in the curriculum, such as the teaching that "everyone with HIV will die", deepened the sense of isolation. In response, her father became a peer educator, working in schools and communities to share accurate information on HIV and treatment. This helped reduce stigma and improved understanding among students and community members.

Session 3: Evidence to inform action

This session, facilitated by Victoria Chuwa, Health and HIV Specialist at UNICEF Rwanda, featured two oral abstracts presented by scholarship recipients, followed by a debate on whether children and adolescents with perinatal HIV exposure require long-term follow-up and dedicated funding and support.

Oral abstract 1 – Gestational exposure to an efavirenz-containing compared to a dolutegravir-containing antiretroviral regimen is associated with lower anthropometrics at 18 months of life among children HIV-exposed uninfected in Botswana

Gosego Masasa, Head Nurse of the FLOURISH study, Botswana Harvard Health Partnership in Botswana, presented study findings from the evaluation of growth outcomes at 18 months among children with perinatal HIV exposure, drawn from the Botswana-based Tshilo Dikotla and FLOURISH studies.

The study showed notable differences between those exposed to efavirenz (EFV) and dolutegravir (DTG). Female infants in the EFV group had lower weights and, overall, children exposed to EFV demonstrated lower weight-for-age and weight-for-length z-scores compared at 18 months of life with the DTG group. Male infants exposed to EFV were also observed to be shorter than those exposed to DTG. Despite these differences, there were no significant variations between the groups in rates of stunting, wasting or being underweight. Adjusted analyses confirmed that EFV exposure was associated with lower mean weight-for-age and weight-for-length z-scores. Additional factors influencing growth included birth weight-for-age z-scores, maternal age at delivery and preterm birth.

Oral abstract 2 – The association between low birth weight and neurocognitive development and the impact of exposure to HIV in utero

Christabell Mdhulu, Study Psychologist at the Blantyre Malaria Project in Malawi, presented results from the REFINE study investigating the impact of HIV exposure on child neurocognitive development.

The analysis highlights important differences in the impact of low birth weight between children exposed and unexposed to HIV. Using the Malawi Developmental Assessment Tool (MDAT) to assess social, fine motor, language and gross motor skills, its findings showed that children exposed to HIV had lower birth weights and were more likely to experience gross motor, fine motor and social delays. Females were more affected by social delays while children in rural areas showed greater motor delays. Low birth weight was strongly associated with neurodevelopmental challenges, with affected children being three times more likely to have fine motor and language delays and twice as likely to have overall developmental delays. Notably, the type of delays varied by HIV exposure status: unexposed children with low birth weight primarily had social delays whereas exposed children had broader impairments across fine motor, gross motor and overall MDAT scores. These findings suggest that low birth weight has a disproportionately greater impact on neurodevelopmental outcomes among children exposed to HIV perinatally.

Debate – Children and adolescents with perinatal HIV exposure require long-term follow-up and dedicated funding and support

Priscilla Tsondai, Technical Lead for Paedaitric HIV (CIPHER) at the IAS, moderated a debate on the need for long-term follow-up and dedicated funding for children and adolescents with perinatal HIV exposure.

Laurie Gulaid, UNICEF's Regional Advisor for HIV and Sexual and Reproductive Health Rights for Eastern and Southern Africa, argued that siloed, vertical programmes are inherently exclusionary and risk reinforcing discrimination. She emphasized that not all children perinatally exposed to HIV who did not acquire HIV face equal risks for poor outcomes. Rather, factors such as low birth weight, extreme poverty, food insecurity and maternal illness are key drivers and are shared by many other vulnerable children. Laurie cautioned that targeted follow-up may heighten stigma, exacerbate mental health challenges and add financial and programmatic burdens. Instead, she called for equity-driven approaches that build scalable screening tools and systems to identify, monitor and care for all children and adolescents most vulnerable to poor health outcomes.

Jane Mutanga, an independent consultant from Zambia and former CIPHER Fellow, made the case for sustained long-term funding to address perinatal HIV. While not all children have equal vulnerability, she emphasized the importance of targeted interventions for those most vulnerable, supported by dedicated funding. She highlighted the "HIV-negative myth", noting that even children with perinatal exposure who are HIV-free face a higher likelihood of infectious diseases, increased mortality, growth and developmental delays, adolescent mental health challenges, potential metabolic complications and unknown long-term effects of antiretroviral therapy exposure. Jane argued that a "wait and see" approach is costly and dangerous, pointing to drugs used in the past and later found to have severe side effects. She acknowledged the challenges posed by shrinking healthcare budgets and competing priorities, but underscored opportunities for progress. These include early identification of vulnerable children through simple screening tools, caregiver education and involvement, global consensus on sustained funding, and research and investments in systems strengthening and capacity building.

Closing remarks

Sonia Lee, Branch Chief of the Maternal and Pediatric Infectious Disease Branch at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), gave the closing remarks. She highlighted the significant progress made since the symposium's inception in 2015. Initially convened to share data on immune, growth and morbidity differences between children born with and without perinatal HIV exposure, the symposium has since expanded to complement research findings by leveraging routinely collected health data to measure outcomes, guide policy and identify children in need of additional support, while ensuring that community voices and lived experiences are central.

She highlighted the importance of mental well-being and disclosure experiences among mothers and adolescents and the value of community-based models like the Friendship Bench for mental health support.

This year's symposium also emphasized nurturing the next generation of researchers, with early-career scholars presenting their work, and introduced a debate format to encourage dialogue on the extent of long-term support needed for children exposed to HIV. Looking ahead, participants were encouraged to provide feedback to shape future innovation. The event closed with gratitude to partner organizations for their financial support and well wishes for those attending IAS 2025.

Conclusion and way forward

The 2025 symposium reinforced the urgent need to prioritize children and adolescents with perinatal HIV exposure in global and national health agendas. Key themes that emerged included the importance of:

- Leveraging data for action and accountability
- Addressing mental health as a core component of care
- Challenging stigma in schools, communities and health systems
- Ensuring ongoing programmatic and financial support for children and adolescents with perinatal HIV exposure who are HIV-free

The IAS and its partners are committed to continuing this vital conversation and translating these insights into concrete policy and programming efforts to ensure that all children and adolescents with perinatal HIV exposure not only start life HIV-free, but thrive.

To ensure accessibility and dissemination of knowledge and facilitate a broader reach and continued learning beyond the event, presentations from the symposium have been made available on IAS+.

Finally, the 12th symposium will take place as a pre-conference at AIDS 2026, the 26th International AIDS Conference in Rio de Janeiro, Brazil, and virtually in July 2026.

Acknowledgements

We express our gratitude to the 11th Symposium on Children and Adolescents with Perinatal HIV Exposure Organizing Committee, as well as the session chairs and speakers who significantly contributed to and supported the facilitation of the symposium. Sincere appreciation is also extended to the IAS Communications team for handling all the symposium communication and design aspects. We are also grateful to the sponsors, including IAS, Penta – Child Health Research, Mass General Brigham, Paediatric-Adolescent Treatment Africa (PATA), UNICEF, ViiV Healthcare, CHOP Global Health Center and Penn Center for AIDS Research (CFAR), whose support played a crucial role in making the 11th Symposium on Children and Adolescents with Perinatal HIV Exposure possible. Finally, we extend our thanks to all the participants whose active engagement and contributions enriched the discussions of the symposium.

Sponsors

Supporting resources

9th Symposium on Children and Adolescents with Perinatal HIV Exposure

Session recording

10th Symposium on Children and Adolescents with Perinatal HIV Exposure

Session 1 | Session 2 | Session 3

Annex 1. Programme

Leveraging routinely collected health data to improve outcomes of infants and children with perinatal HIV exposure		
Chair: Agnes Ronan		
9:00 – 9:05	Introduction and housekeeping	Agnes Ronan
9:05 – 9:10	Opening remarks	Claude Mambo Muvunyi
9:10 – 9:25	Leveraging routinely collected health systems data to understand outcomes of children with perinatal exposure and assess interventions to improve outcomes – The CHERISH Study	Mary-Ann Davies
9:25 – 9:40	Leveraging routinely collected health data to identify infants and children at risk for suboptimal health and development outcomes	Megan McHenry
9:40 – 10:00	Panel discussion	Agnes Ronan Vivian Chitiyo Loyce Maturu

Mental well-being of children and adolescents with perinatal exposure to HIV		
Chair: Renata Sanders		
10:15 – 10:25	Session outline	Renata Sanders
10:25 – 10:35	Findings from the Botswana-based Disclosure Study	Kedibonye Thankane
10:35 – 10:45	Friendship bench– Identifying viable models to optimize mental health of adolescents growing up in households affected by HIV	Thandiwe Mashunye
10:45 – 11:00	Q&A	Renata Sanders (Facilitator) Kedibonye Thankane Thandiwe Mashunye
11:00 – 11:15	Discussion	Renata Sanders (Facilitator) Janviere Uhiriwe Gihozo Potamienne Komezusenge

Session 3: Evidence to inform action		
Chair: Priscilla Tsondai		
11:45 – 11:50	Session outline	Victoria Chuwa
11:50 – 12:00	Gestational exposure to an efavirenz-containing compared to a dolutegravir-containing antiretroviral regimen is associated with lower anthropometrics at 18 months of life among children HIV-exposed uninfected in Botswana	Gosego Masasa
12:00 – 12:10	Oral Abstract 2 - The Association Between Low Birth Weight and Neurocognitive Development and the impact of Exposure to HIV in Utero	Christabell Mdhluli
12:10 – 12:40	Debate – Children and adolescents with perinatal HIV exposure require long-term follow-up and dedicated funding and support	Priscilla Tsondai (Moderator) Laurie Gulaid Jane Namangolwa Mutanga
12:40 – 12:45	Closing remarks	Sonia Lee