

Meeting Report

Adolescent Transition Workshop

28 March 2015, Catania, Italy



Hosted by the Collaborative Initiative for Paediatric HIV
Education and Research of the International AID Society and the
IeDEA Network Coordinating Center, Vanderbilt University
<http://www.iasociety.org/CIPHER>



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INTRODUCTION AND BACKGROUND

As the HIV epidemic matures and antiretroviral treatment (ART) is scaled up in resource-limited settings, children with HIV are reaching adolescence in greater numbers and are surviving into adulthood. This growing population of adolescents with perinatally acquired HIV is faced with a spectrum of clinical issues and challenges around adherence to ART. In addition to the complexities of a chronic illness, adolescents living with HIV undergo rapid physical and psychological development, and often face a range of psychosocial challenges.¹

Globally, more than three million children are living with HIV, and 90% of them live in sub-Saharan Africa. In 2012, an estimated 2.1 million adolescents (10-19 years of age) were living with HIV in low- and middle-income countries.² Most worrying, HIV-related deaths in adolescents continue to rise despite declines in other age groups.^{3,4} In addition, transition from paediatric to adult care may be associated with an increased risk for mortality in this population although there is limited evidence.⁵

At the 18th International Workshop on HIV Observation Databases (IWHOD)⁶ held in 2014, the topic of adolescent transition out of paediatric-care settings was flagged as critical during a plenary discussion on adolescents living with HIV. The Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) of the International AIDS Society (IAS) as an important platform that could support cohorts in better understanding what is happening to adolescents as they attempt to transition and access adult care services. Participants requested having a stand-alone meeting to focus exclusively on transition at the 19th IWHOD.

As the platform for the largest cohort collaboration in paediatric HIV research, CIPHER is an appropriate vehicle to address the knowledge gaps around adolescent transition into adult care. Its existing mission is to optimize clinical management and delivery of services to infants, children and adolescents affected by HIV in resource-limited settings through advocacy and research promotion. Key CIPHER objectives include promoting and investing in targeted research to address priority knowledge gaps in paediatric HIV, coupled with convening stakeholders and establishing collaboration mechanisms to strengthen communication, knowledge transfer and exchange among paediatric HIV cohorts. In addition, CIPHER is making efforts around advocacy and outreach to support evidence-informed clinical, policy and programmatic decision making. CIPHER was launched as a two-year research initiative in 2012 with the generous support of an unrestricted grant from ViiV Healthcare's Paediatric Innovation Seed Fund. With continued funding from founding sponsor ViiV Healthcare and with support from Janssen Pharmaceuticals, CIPHER has grown to be a flagship programme of the IAS.

In May 2013, the CIPHER Cohort Collaboration was formed. This global network of observational paediatric HIV cohorts/cohort networks is the largest to date and represents about 250,000 infants, children and adolescents affected by HIV. The collaboration is currently running studies on two critical research gaps in paediatric HIV: the durability of first-line ART in children; and the global epidemiology of perinatally HIV-infected adolescents.

¹ Hazra R, Siberry GK, Mofenson LM. Growing up with HIV: children, adolescents, and young adults with perinatally acquired HIV infection. *Annu Rev Med.* 2010;61:169-85.

² [Global Report, 2013. UNAIDS](#)

³ Bekker LG, Hosek S. HIV and adolescents: focus on young key populations. *J Int AIDS Soc.* 2015 Feb 26;18 (2 Suppl 1):20076.

⁴ [The Gap Report, 2014. UNAIDS](#)

⁵ Fish R, Judd A, Jungmann E, O'Leary C, Foster C; HIV Young Persons Network (HYPNet). Mortality in perinatally HIV-infected young people in England following transition to adult care: an HIV Young Persons Network (HYPNet) audit. *HIV Med.* 2014 Apr;15(4):239-44.

⁶ The objective of IWHOD is to bring together junior and senior researchers from both developed and developing countries working on cohorts of patients with HIV, to present in an informal, closed-meeting format their latest findings and work in progress and allow open discussions on common issues of cohort methodology, techniques and statistics. For more, click here: <http://newsite.iwhod.org/>.

The workshop on adolescent transition was held in conjunction with the 19th IWHOD in Catania, and was co-hosted by the IAS and the INCC. It included a series of presentations to better understand transition of adolescents living with HIV into adult-care settings.

Workshop objectives

1. To establish a baseline on how paediatric HIV cohorts are tracking, or planning to track, [adolescents](#) from paediatric settings into adult care
2. To encourage cohorts that do not have any mechanisms in place currently to collaborate and develop action points to address this topic soon
3. To identify research gaps in adolescent transition within cohorts
4. To have consensus on a broad-stroke research agenda in adolescent transitioning.

In order to prepare for the workshop in Catania, the CIPHER [online database](#) was an important source in identifying which cohorts were working on adolescent transition or were planning to address the issue in the future. A survey was distributed to cohort investigators included in the CIPHER database to develop the scope of the workshop. Each cohort was asked to describe the following:

- Current/planned activities on adolescent transition
- Tools, protocols, technologies and material used to track data
- Challenges and barriers identified in working with adolescent transition
- Research gaps in adolescent transition
- Identification of main needs and ways forward.

SETTING THE SCENE

Models in estimating the HIV epidemic among adolescents

Mary Mahy (UNAIDS, Geneva) provided an overview of the work at UNAIDS on modelling the HIV epidemic among adolescents living with HIV and touched on some of the challenges and limitations with current estimates. Most new HIV infections in adolescents worldwide were reported in girls (64%) in 2013 (Table 1).

| | |
|---|---|
| Number of adolescents living with HIV | 2.1 million (1.9-2.3 million) (45% boys) |
| Number of new adolescent HIV infections | 250,000 (210,000-290,000) (36% boys) <ul style="list-style-type: none"> • limited to 15-19 year olds, not enough data to estimate infections in 10-14 year olds |
| Number of AIDS deaths among adolescents | 120,000 (100,000-130,000) |

Source: UNAIDS 2013 estimates

Table 1. Global estimates of HIV in adolescents

UNAIDS estimates on the global burden of HIV are based on country-level data, with 25 countries accounting for 80% of new adolescent infections and five accounting for 57% of new infections (South Africa, India, Indonesia, Nigeria and Mozambique). Spectrum, a software developed in the US, is the basis for the UNAIDS estimates (<http://www.epidem.org>) for which the assumptions are revisited annually. UNAIDS and partners support country teams, made up of national epidemiologists, and monitoring and evaluation (M&E) experts, in creating country-level Spectrum files, which are then provided back to UNAIDS.⁷

Mahy described how the total number of new HIV infections in children is estimated using a variety of data and adjustments (Figure 1), how prevalence data are translated into incidence data, and how that prevalence is distributed by age brackets of five years. Participants noted that the model does not differentiate between perinatally HIV-infected and other adults over the age of 15 years.

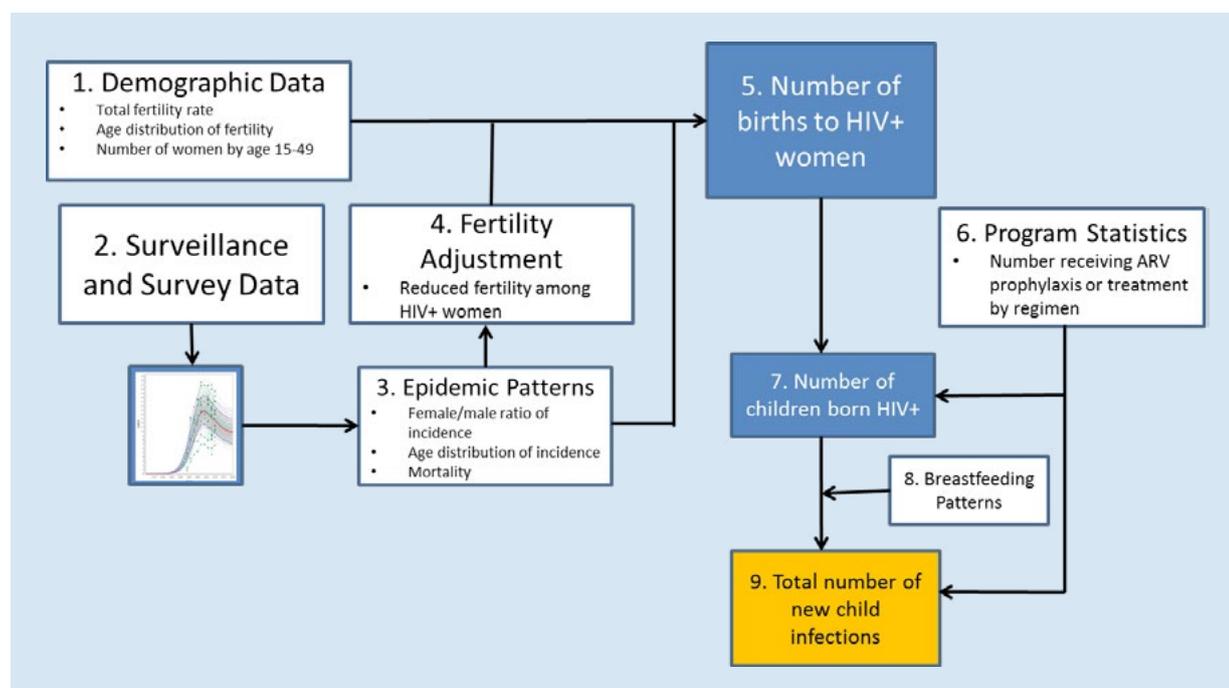


Figure 1. Spectrum process to determine paediatric HIV incidence

⁷ Country teams use the software tool Spectrum (www.futuresinstitute.org) and the AIDS Impact Module to estimate the impact of the HIV epidemic.

The paediatric model in Spectrum tracks infections by CD4 category and timing of infection (perinatal, 0-6 months, 7-12 months, 12+ months after birth) and recognizes different survival rates based on when children are infected. Distribution of HIV-infected children not on ART by CD4 count and CD4 percent is based on the HIV Paediatric Prognostic Markers Collaborative Study and Cross Continents Collaboration for Kids.⁸ Estimates of rates of transition from one CD4 “bin” (category) to another are based on CD4 percentage distribution; survival among those not on ART is based on data from Marston⁹ (e.g., children infected later in life progress more slowly to death), and these rates are linearly projected out to match what is known about adults’ survival rates. Mahy emphasized that there is the limited data available for five to 14 year olds. Of note, the survival of young children is being examined in relation to survival in young adults.

Data from the International Epidemiological Databases to Evaluate AIDS (IeDEA) have been used to estimate region-specific parameters on survival of children on ART in the Spectrum model.

One key piece of information, particularly for adolescents and which the model is not currently capturing, is when children initiate ART (as the number of adults receiving ART includes those 15 years and older and the value for children is all people <15). Countries are being encouraged to obtain accurate numbers of those receiving ART by age group as the software currently distributes the proportion receiving ART to those who are clinically eligible. As a result, Spectrum currently cannot accurately estimate AIDS deaths by age group among children.

Mahy concluded her overview of Spectrum by highlighting the need for collaboration by workshop participants, especially on the following data gaps:

- Data on children not on ART are currently not available.
- Rates of progression among children infected perinatally versus those infected as adolescents do not exist (although they are not necessarily difficult to get).
- Better data on when children start on ART are needed, including median age at start of ART.
- Data on retention in care for adolescents are lacking. Although the IeDEA data, which is used to estimate survival among children on ART, reflect drop out, country-specific information on this variable might improve the estimates for adolescents.
- Obtaining more real data against which to validate models would be valuable (e.g., prevalence estimates among adolescents or programme data, such as numbers on ART).

Participants noted that they would share data and that there are cross-sectional data, HIV surveys and other resources coming out of the US Centers for Disease Control and Prevention that could be useful to the UNAIDS modelling estimates.

⁸ Data provided by David Dunne (unpublished).

⁹ Marston M, Becquet R. Net survival of perinatally and postnatally HIV-infected children: a pooled analysis of individual data from sub-Saharan Africa. *Int J Epidemiol.* 2011 Apr; 40(2): 385–396. Published online 2011 Jan 18.

PATA Study: What is happening on the ground in adolescent-specific HIV treatment services?

Heleen Soeters from Paediatric AIDS Treatment for Africa (PATA, South Africa) described a WHO-commissioned study¹⁰ reviewing the availability of specialized and appropriate HIV treatment and care services for adolescents in sub-Saharan Africa at the facility level. A cross-sectional survey (with quantitative and qualitative items) was developed from a variety of stakeholders (including in French and Portuguese), with a total of 218 facilities in 23 countries across sub-regions responding to the survey. The actual sample number of adolescents living with HIV in care across the sample was 57,299, and the adjusted estimate across all regions was 80,072 when adjusting for missing data using regional averages.

Facilities were asked about major barriers to adolescent treatment and care, with non-adherence and treatment resistance identified as the two most important barriers. Others included non-disclosure to adolescent, socio-economic challenges (e.g., transportation costs and food insecurity), inadequate resources and stigma. Although the majority of facilities use the WHO definition of “adolescent”¹¹, 26% of facilities do not have a working definition of “adolescent” whatsoever. Of concern, very few facilities capture data for perinatal infection and 25% of facilities are not recording any of the following: a) perinatal infection; b) pregnancy; c) patients who sell sex; d) patients who inject drugs; and e) men who have sex with men.

In terms of records of treatment outcomes, most facilities (80%) do not disaggregate by age and 43% record virologic suppression. An estimated 45% of facilities also do not have a clear determination of what adherence is and how to measure it, and 39% are not using guidelines/protocols for adherence.

About 87% of facilities provide some form of adherence counselling and 67% provide other services to improve adherence, 49% of which provide peer support, activities and clubs. With regard to the content of adherence counselling, the focus is more on adherence behaviour and the more superficial aspect of adhering. As such, there is a gap in counselling around the actual drivers of (non)adherence, including living positively, disclosure support and social support. Notably, only 11% of facilities have adherence strategies in counselling.

In terms of adolescent-specific service delivery, the most common model was a dedicated clinic day or time. For transitioning, 51% of facilities were found to guide transition, with mean age of transition at 18 years. It was also observed that psychosocial issues were not adequately addressed during transition. An estimated 46% of facilities reported that they catered to special needs of HIV-infected pregnant adolescents, although it appeared that it was only prevention of mother-to-child transmission (PMTCT) services. Lastly, 63% of facilities provided sexual and reproductive health (SRH) services. Based on the PATA findings, the following points should be considered as part of a research agenda in adolescent transition:

- Standardization of a common definition of adolescence is needed.
- Data systems should be strengthened to enable age disaggregation and development of adolescent-friendly protocols, services and systems.
- Protocols for managing non-adherence, standards and methods for determining non-adherence and strategies for adherence support in treatment failure must be in place.
- Clear definitions are lacking, as are protocols around transition and retention in adolescents.
- Peer support groups, activities and clubs are a promising approach and should be explored.
- Sexual and reproductive health services, including meeting the special needs of pregnant adolescents living with HIV, are not being adequately addressed.

¹⁰ This study did not include prevention, and only focused on adolescents who are HIV infected, be it perinatally (during pregnancy, labour and breastfeeding – vertical transmission) or postnatally (horizontal transmission). The clinics sampled in this study did not distinguish between these groups.

¹¹ “Adolescents” are defined as persons between the ages of 10 and 19.

Research gaps in adolescents living with HIV: the WHO perspective

Martina Penazzato (WHO, Geneva) described the complexities and challenges of HIV infection in adolescents, highlighting the range of issues around poor adherence and sexual reproductive health needs. From a WHO perspective, adolescents living with HIV are a prioritized population whose treatment and care issues require specialized focus. Notably, WHO convened a technical meeting¹² in September 2014 and examined gaps on key pieces of work that should be addressed in the next set of WHO treatment guidelines due to be published in 2015.

For treatment outcomes in adolescents, systematic reviews were conducted to determine the proportion of virologically suppressed adolescents. For service delivery, a literature review of 11 studies was undertaken, with only three studies being randomized clinical trials; it found that few interventions include peer support, directly observed therapy or counselling. Despite the limited number of studies identified out of 13 years of research, some promising interventions were identified for adolescents failing treatment or having problems with adherence.

WHO also considered real-world data and supported the PATA situational analysis (described earlier in this report). In addition, young people are being engaged in the WHO process. For example, an online survey of 400 adolescents living with HIV highlighted challenges on adherence and concerns about side effects, emphasizing how they disrupt their lives and how, as a result, unplanned treatment interruptions are common.

WHO has engaged in an ongoing mapping exercise to summarize continuing research on adolescents living with HIV. Thirty-nine studies have been identified, 25 of which are treatment focused. Key topics of current research include better understanding of the epidemiology, use of new drugs, long-term side effects (e.g., treatment sequencing on managing second-line failure), alternative strategies, co-morbidities (e.g., HPV) and mental health issues. As part of this mapping exercise, a total of 17 intervention studies on service delivery have been identified, with only one transition study being planned. Most of the work happening is on areas of disclosure, linkage to care and adherence. Importantly, disclosure studies are not addressing disclosure from adolescents to others.

From the WHO perspective, it is important that development of guidelines strikes a balance on simplification, harmonization, optimization and scale up, all of which should be data driven. Based on the 2014 consultation, it was recognized that the issues specific to adolescents, particularly around transition, are being lost in technical discussions, which often focus either on children or on adults. In sum, adolescent transition has not been addressed and WHO is prioritizing this gap.

In terms of the role of observational cohorts in shaping guidance, the CIPHER collaboration is providing an important platform for much-needed research while the role of adult cohorts has yet to be clarified. Penazzato emphasized that in order to ensure continuity in research across the age spectrum, adolescents must be included from the onset of study design.

In identifying the relevant research gaps that can support WHO recommendations, a number of service delivery questions remain.

¹² Meeting report can be accessed here: <http://www.who.int/hiv/pub/arv/consultation-hiv-treatment-adolescents/en/>.

adolescent-friendly services
minimum package of care
integration of SRH
pregnant adolescents
disclosure
transition
adherence (understanding and interventions)
incentives
psychosocial tools
treatment literacy

WHAT IS THE ROLE OF THESE SERVICE DELIVERY INTERVENTIONS IN ADOLESCENT CARE?

In generating and appraising evidence on adolescent outcomes, a number of methodological challenges persist, including inconsistent age definitions, small sample sizes, not differentiating adolescents by mode of transmission, non-time-updated cohorts, lack of age-disaggregated outcomes, selective reporting of outcomes, inconsistency in application of interventions to participants, failure to identify and appropriately adjust for potential confounding variables, lack of comparison groups, and selective outcome reporting.

Discussion

Transitioning pregnant young women on lifelong ART is a key challenge, and this population was described as “doubly vulnerable” from a service delivery standpoint. There was a suggestion to further understand how facilities identified by PATA are actually carrying out transitions of their adolescents. It was also underscored during the discussion that according to data from Malawi, younger women are at greater risk for loss to follow up in Option B+ programmes.¹³

National surveillance systems: the UK experience

Pat Tookey (University College London, UK) provided an overview of how adolescent transition is being considered and captured in existing national surveillance systems in the United Kingdom. Since 1990, there has been comprehensive observational active surveillance of obstetric and paediatric HIV in the UK and Ireland through the National Study of HIV in Pregnancy and Childhood (NSHPC). The NSHPC has two complementary active reporting schemes: paediatric HIV cases are reported from clinics and through British Paediatric Surveillance Unit orange card reports; and obstetric respondents report all pregnancies in women with diagnosed HIV infection. There is substantial feedback to respondents and HIV networks to maximize coverage and case ascertainment (>95%).

There are a number of ongoing UK-based studies of paediatric/perinatally acquired HIV, with the Collaborative HIV Paediatric Study (CHIPS) being a hallmark follow-up study of all HIV-infected children under care in the UK and Ireland. CHIPS is recognized for its optimized surveillance. In the UK, there is some transition into adolescent-specific clinics, and some adolescents transition into adult clinics. The Adolescents and Adults Living with Perinatal HIV (AALPHI) cohort study is a consented study nested in general surveillance, which includes adolescents aged 13-21 years, (n=300 HIV-infected plus 100 HIV-negative sibling/household controls). CHIPS+ is a new consented study that will follow up all those in CHIPS as they turn 16 years and will try to answer the transition question of whether adolescent-friendly services are superior to adult services regarding both qualitative and quantitative components.

¹³ Tweya H et al. Understanding factors, outcomes and reasons for loss to follow-up among women in Option B+ PMTCT programme in Lilongwe, Malawi. *Trop Med Int Health*. 2014. <http://www.ncbi.nlm.nih.gov/pubmed/25087778>

In terms of data linkage for HIV-exposed uninfected infants, HIV-infected children and HIV-positive pregnant women, different routes exist in the UK (e.g., direct data transfer from the NSHPC to CHIPS), as highlighted in Figure 2. Notably, approximately 90% of births from 2000 to 2010 to HIV-positive women reported to NSHPC have been matched to national birth registration data; the long-term aim is monitoring cancers and death in individuals who were exposed to HIV and specific antiretroviral drugs or regimens in fetal life.

One of the primary ethical challenges for adolescent research is disclosure of status to study participants (namely adolescents). In the UK, some of the cohort efforts are funded through public health surveillance, but funding gaps persist and continuity of funding is not guaranteed.

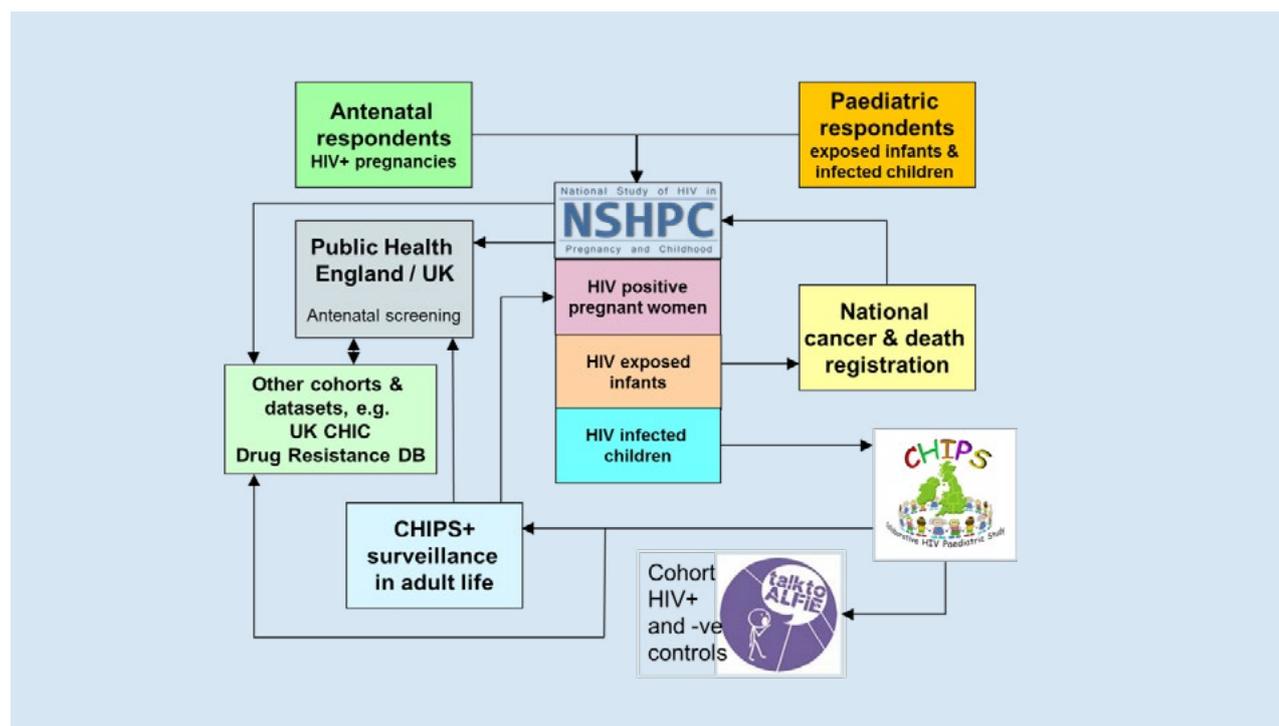


Figure 2. Data flows to and from the National Study of HIV in Pregnancy and Childhood (NSHPC), the confidential national (UK and Ireland) active reporting scheme for pregnancies in HIV-positive women, babies born to HIV-positive women, and other children with HIV infection, and linked to other studies of children and adults with perinatal HIV. Further information is available at www.ucl.ac.uk/nshpc.

HOW PAEDIATRIC HIV COHORTS ARE ADDRESSING ADOLESCENT TRANSITION: Current and planned work

European Pregnancy and Paediatric HIV Cohort Collaboration (EPPICC)

Ali Judd (Medical Research Council Clinical Trials Unit, University College London, UK) provided an overview of EPPICC, which is composed of 25 cohorts in 15 countries in Europe and Thailand, reflecting a significant amount of work being undertaken in this network. Across EPPICC, there is a wide variety of approaches on linking paediatric HIV cohorts to national adult surveillance systems. Strong linkages are in place in Belgium, Spain and the UK, where particular emphasis has been given to adolescent transition. In other countries, such as France (where there are similar cohorts of adolescents, like AALPHI), linkage to adult surveillance is currently not in place, although it should be possible. The Swiss cohort is an example of complete integration of paediatric and adult cohort data systems. In addition, for some hospitals, databases are actually considered cohorts. Figure 3 highlights how linkage between paediatric and adult cohort datasets is possible in many countries throughout the European continent and also Thailand.

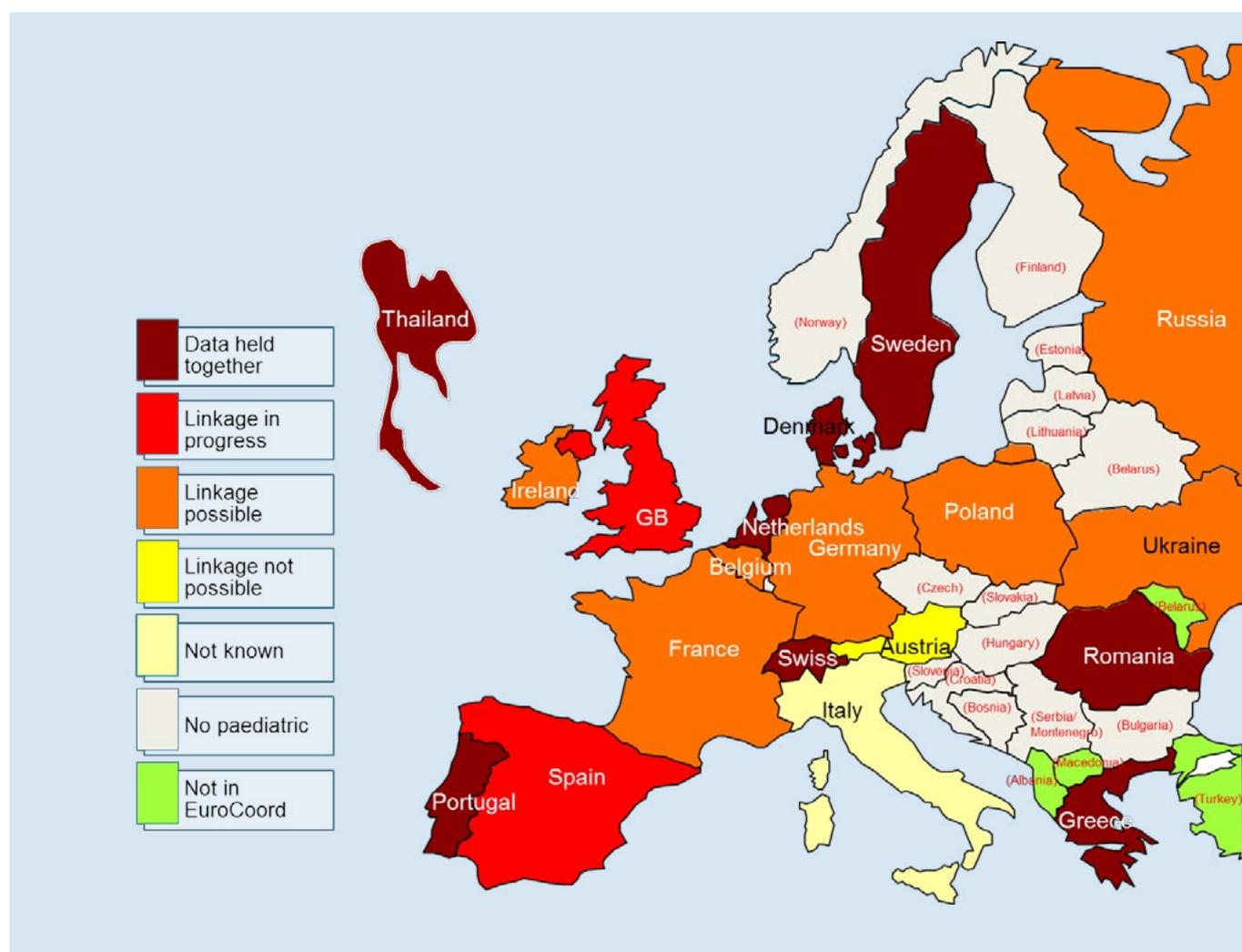


Figure 3. How data linkages between paediatric and adult HIV cohorts are being carried out across EPPICC countries

There is a range of challenges, particularly as different countries are at different stages of cohort development. Gaining consent to track adolescents as they transition out of paediatric cohorts is a major issue as ethical approval may be needed to follow them into adult care. Linking adult and paediatric datasets once consent is in place is another element that has to be addressed. For example, pseudo-anonymized identifiers for the same person may be different in adult and paediatric cohorts, and linkage may not be straightforward if the adult cohort is not national. There is also a need to determine how to measure loss to follow up of adolescents during or after transition.

As noted, data linkage is taking place across many EPPICC sites, whereby adolescents are consenting into adult cohorts, whether those are adapted adult cohorts or new adolescent-specific cohorts. Furthermore, there have been strong efforts to involve adolescents themselves in research consultations, as has been done in AALPHI with a sock puppet [YouTube video](#). In the UK, CHIPS+ is also aiming at a broader analysis of intervention effectiveness by answering whether adolescent-focused clinics are more cost effective with better health outcomes than standard adult clinics.

In identifying underlying needs and strategic ways forward, the research community has to appreciate how paediatric and adult data should be held together. Importantly, there must be buy-in from adult clinicians, as well as paediatricians, in the process of optimizing transition for adolescent populations.

leDEA West Africa Collaboration (WADA/pWADA)

Valériane Leroy (INSERM, Université Victor Segalen Bordeaux, France) outlined the ongoing work in leDEA pWADA, a collaboration of adult and paediatric HIV care cohorts, consisting of 11 sites for children in seven countries. Currently, an estimated 12,000 children under the age of 16 are being followed up, 20% of whom are adolescents. For transition of adolescents to adult care in west Africa, there are significant gaps in knowledge, with only one out of 11 pWADA clinical sites having both paediatric and adult HIV care services. In general, sites have very limited experience in data linkage and optimizing data systems at the facility level. National surveillance programmes have unique identifiers, which are not linked to leDEA (pWADA). There is also no specific information on transfer to adult care within pWADA.

What is known is concerning, particularly a very high rate of loss to follow up and lack of adherence in adolescents.¹⁴ Interestingly, there are cases where children do not want to transition to adult cohorts, even up to 21 years of age, as these children feel much more comfortable and familiar with the health care workers in their paediatric-care settings.

In 2011, a multidisciplinary consultation on adolescents took place in Dakar, Senegal, which explored how to address adolescent transition and the use of support groups, including adolescent peers, after transfer into adult settings. COHADO, a multicentre cohort nested in paediatric pWADA sites of HIV-infected adolescents in west Africa, has included 300 adolescents in two pilot sites (Cote d'Ivoire and Togo). The purpose of this cohort is to design, pilot and implement prospective data collection specific to HIV-infected adolescent issues within pWADA.

A complex set of challenges and barriers persist in west Africa, and Leroy emphasized that a multidisciplinary approach will be required to prepare adolescents for transition into adult-care settings. Of note, clinicians surveyed in sites across pWADA reported that they require up to three years in preparing adolescent transition to adult-care setting. Lack of disclosure remains problematic, and in west Africa, a large proportion of adolescents living with HIV do not know their status.¹⁵

¹⁴ Ekouevi DK, Azondekon A, Dicko F, Malateste K, Toure P, Eboua FT, Kouadio K, Renner L, Peterson K, Dabis F, Signate-Sy H, Leroy V, for the leDEA pediatric West African Database to evaluate AIDS (pWADA). 12-month mortality and loss-to-program in antiretroviral-treated children: The leDEA pediatric West African Database to evaluate AIDS (pWADA), 2000-2008. *BMC Public Health*. 2011 Jun 30;11(1):519.

¹⁵ Meless GD, Aka-Dago-Akribi H, Cacou C, Eboua TF, Aka AE, Oga AM, Bouah B, Eugene M, Moh C, Arrive E, Timite-Konan M, Leroy V, Group P-CS. Notification of HIV status disclosure and its related factors in HIV-infected adolescents in 2009 in the Aconda program (CeP8Ref, CHU Yopougon) in Abidjan, Cote d'Ivoire, The PRADO-CI Study. *Journal of the International AIDS Society*. 2013;16:18569

There are currently no youth-friendly tools, protocols or technologies used to prepare adolescents for transfer in pWADA sites, and there is a paucity of education and training in this area. In addition, there is a general sense that quality of care should be improved. What is at times overlooked is the cost associated with transitioning to an adult clinic: adolescents often have to incur the costs of laboratory tests.

In terms of research, there is an urgent need to assess interventions aimed at helping adolescents cope with their HIV care.

leDEA Southern Africa

In what appears to be one of the more integrated systems in sub-Saharan Africa, **Mary-Ann Davis** (University of Cape Town, South Africa) provided an overview of leDEA Southern Africa (leDEA-SA), which includes six countries in southern Africa and a total of 16 cohorts. All but three cohorts combine paediatric and adult cohort data within a single dataset, and can therefore readily track long-term outcomes, (e.g., loss to follow up, death and transfers out of paediatric clinics) (Figure 4), undertake adolescent analyses, and participate in leDEA multiregional adherence and disclosure analyses. Nevertheless, nearly one in five adolescents will transfer their care between 10 and 13 years of age, indicating that transition is an important issue despite having many combined cohorts.

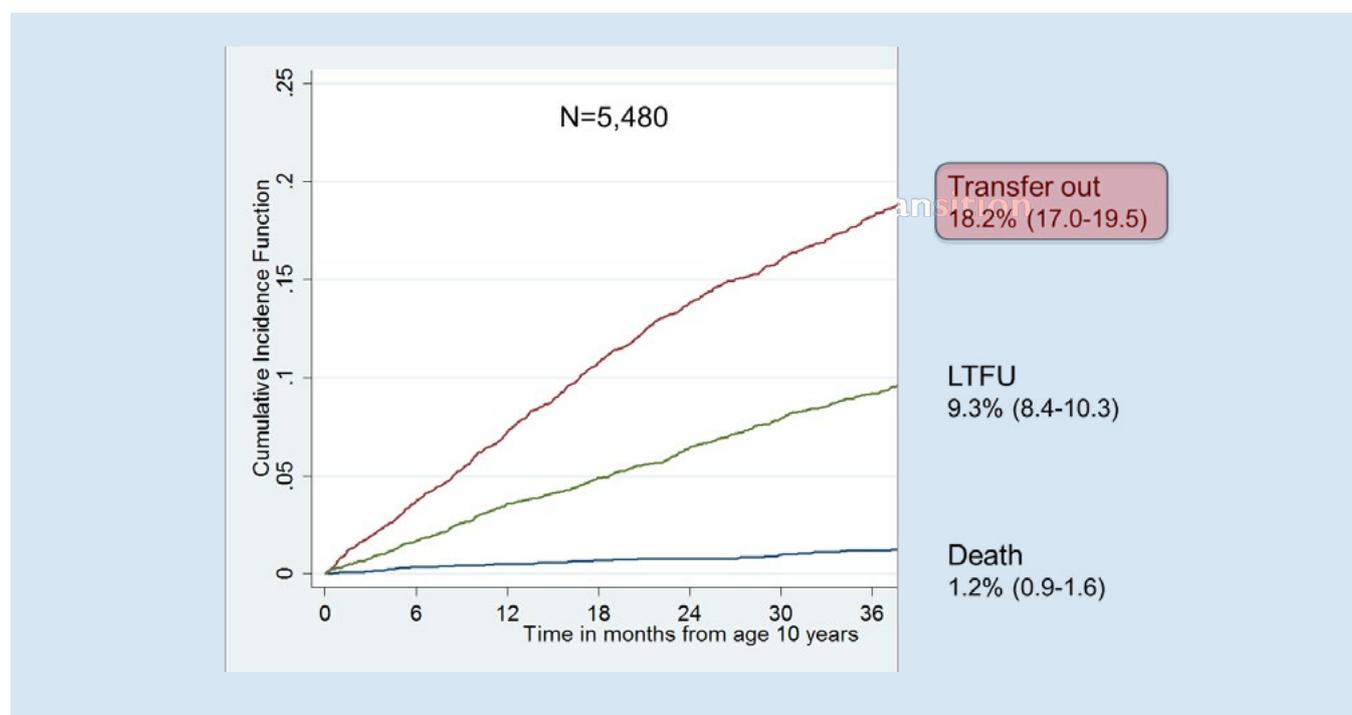


Figure 4. Incidence of adolescent-specific outcomes in leDEA-SA study participants.

LTFU: lost to follow up

In the Western Cape Province of South Africa, each patient (including all adolescents) has a unique patient identifier, and there is a linked data system for all HIV care (with visits captured in the HIV Electronic Register, or eRegister, data systems). The model for consolidating patient data in the Western Cape, highlighted in Figure 5, is used in all clinical systems, and thereby essentially offers a province-wide data repository. The model considers all patients who remain in the province.

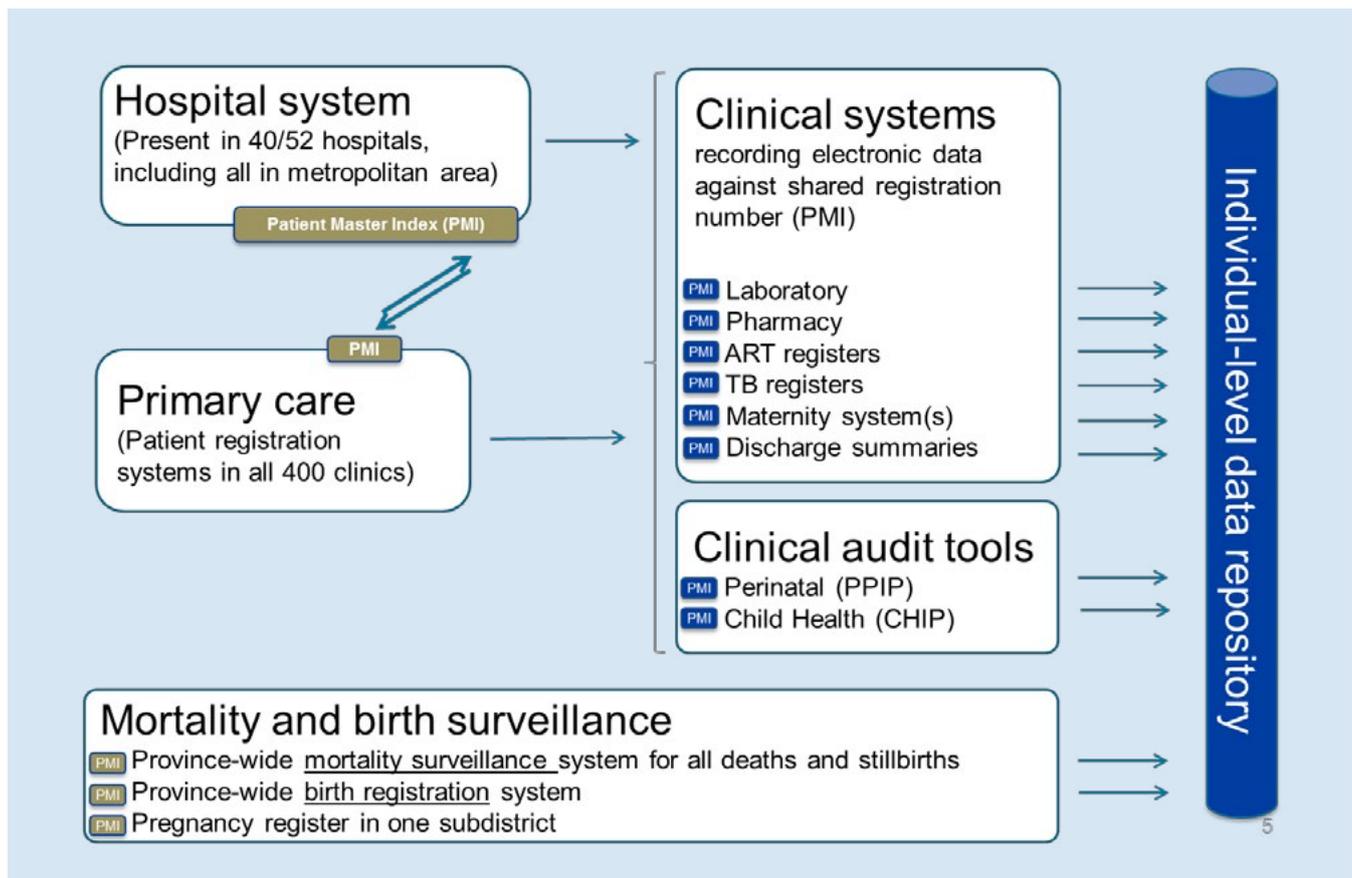


Figure 5. Model for consolidating patient data in the Western Cape, South Africa

In the Western Cape, there are ongoing efforts to use this system to understand reasons for continuing HIV-related deaths. This has been done successfully for adults, and an update for all deaths from 2011 to 2013, including children, adolescent and adults, will be conducted. The National Health Laboratory Service (NHLS) in South Africa is being utilized as well to examine adolescent-specific elements. This is being led by the Health Economics and Epidemiology Research Office at the University of Witwatersrand (HE2RO), associated with the Thembalethu cohort, which is using probabilistic linkage of NHLS data to create a “virtual HIV cohort”. In addition, there is linkage of NHLS data to individual HIV cohorts to evaluate adolescent HIV outcomes, including levels of retention and transition between sites using longitudinal laboratory history to track entry into and out of care.

Davies described how adolescent-specific surveillance is lacking in most countries, although in South Africa, some of its linkage projects will feed into national surveillance. She also highlighted some work from Malawi, where pre-ART and ART programmes fall under national surveillance. In closing, Davies outlined some of the critical steps needed to optimize adolescent transition, including:

- Strengthening intra-operability of data systems and capacity for linkage
- Enhanced data collection in combined cohorts around time of adolescent transition
- Strengthening links between paediatric and adult cohorts.

leDEA East Africa

Rachel Vreeman (Indiana University School of Medicine, USA) provided an overview of current activities around adolescent transition in leDEA East Africa. There are a total of 10 clinical programmes in east Africa (Kenya, Tanzania, and Uganda), with more than 85% of an estimated 41,000 children coming from the Academic Model for the Prevention and Treatment of HIV/AIDS (AMPATH) cohort. It is becoming increasingly clear that there is already considerable activity around service delivery in leDEA East Africa, with some work happening around transitioning, although it may not necessarily be stated as such.

ART adherence in east Africa is also being addressed as strategies to measure adherence in children are being validated and research is being expanded to look at service delivery and site-level issues. In addition, cohort investigators are looking at adherence prospectively across all leDEA sites. There is also some ongoing research around status disclosure; within leDEA East Africa sites, approximately half of children living with HIV have not been told that they are HIV positive.

In terms of adolescent-specific transition efforts, all but one clinical programme in leDEA East Africa has a cohort of both adult and paediatric patients. In the majority of sites, children and adults are cared for within the same clinics, and paediatric cohort data are integrated with adult data. Vreeman pointed to the contribution by some of their sites to the Kenyan national surveillance data; however, continuity into adulthood is not maintained.

Regarding best strategies to mediate transfer and transition, some key issues were flagged, namely: a) disclosure of status; b) the need for more implementation science; and c) identifying how to ensure adolescents have responsibility over their medication, coupled with adherence.

leDEA Caribbean, Central and South America (CCASAnet)

Rachel Vreeman also described how CCASAnet, which includes sites in Argentina, Brazil, Chile, Haiti, Honduras, Mexico and Peru, has been addressing adolescent transition in that region. Haiti has the only dedicated adolescent HIV clinic in the region and tracks patients through all linked clinics. CCASAnet sites have reported a number of challenges. For example, adolescents living with HIV report fear of transition, noting how they are intimidated by the adult clinic atmosphere. This is also described by adolescents in leDEA East Africa. There are particular concerns around safe sexual practices and family planning, information that paediatricians usually do not provide. It is often the case that once adolescents find themselves in adult clinics, adult providers assume that they have received this information.

Among the CCASANET sites, many opportunities were identified through the pre-meeting survey of cohort investigators, such as improving referral and counter referral mechanisms among paediatric, adolescent and adult clinics, and also offering more community-based ART refill options so adherence is not solely dependent on clinic attendance.

leDEA Asia-Pacific

Annette Sohn (TREAT Asia – amfAR, Thailand) described the Asia-Pacific experience in the projects currently underway in the region under the umbrella initiative, “Making Adolescents Count” (Figure 6). For example, the STAY cohort is going to examine how youth are actually transitioned by collecting data based on annual in-person visits (e.g., questionnaires, lab tests) and also biannual online/mobile surveys. There is collaboration underway to conduct an adolescent services survey, translated into 13 languages, of paediatric clinics across the region (beyond leDEA networks) whose results will be compared with African data from the PATA analysis (described earlier in this document). The Youth ACATA programme aims to identify young advocates living with HIV and to train them, which is in line with leadership development efforts promoted under the UNAIDS “All In” initiative. Sohn emphasized the current global momentum on adolescent issues, which can help facilitate what is happening in adolescent care and transition.

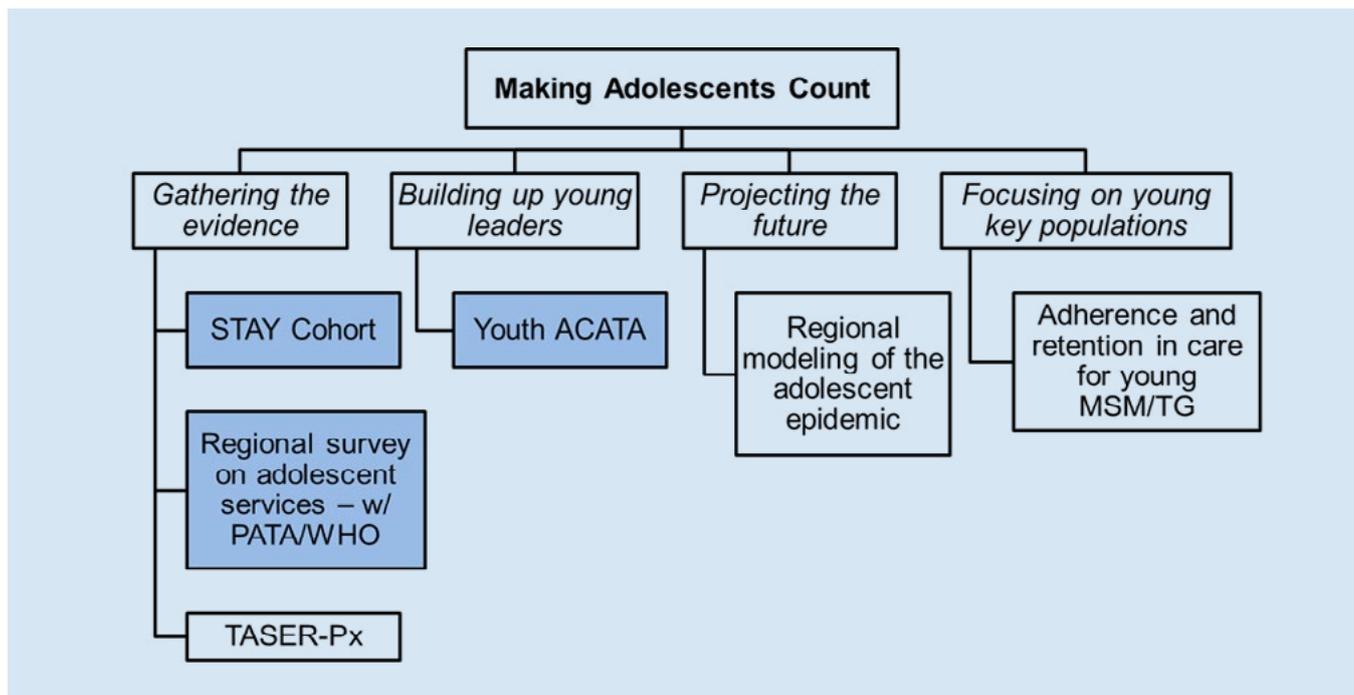


Figure 6. Projects from leDEA Asia-Pacific addressing adolescent transition

Regarding challenges in transition, there is a level of disinterest among some adult clinicians in addressing the special needs of adolescents living with HIV since adolescents constitute a minority of their adult care patients. Consequently, such adult settings do not have social support services tailored to adolescents. Moreover, adolescents generally want to be in care settings with other adolescents.

Data harmonization remains a key element, and Sohn described how their group is examining other protocols, such as AMP-Up from PHACS. leDEA Asia-Pacific investigators are also exploring REDCap and Google as survey platforms. Importantly, there are major knowledge gaps in adolescent transition in Asia-Pacific, as highlighted in other presentations. There were calls for more input from social scientists, who have not been part of the network in Asia, especially in addressing mental health and resilience. There is a lack of psychiatrists, especially those who may have some interest or training in HIV in children. There are also not enough data to advise advocacy at the regional level.

Jamaica Paediatric Perinatal and Adolescent HIV/AIDS Programme (JaPPAAIDS)

Celia Christie-Samuels (University of West Indies, Jamaica) presented ongoing efforts to optimize transition in adolescents enrolled in JaPPAAIDS. In Jamaica, children across all disciplines (including HIV/AIDS) are routinely transitioned into adult care within the public sector at the age of 12 years. Caregiver support is a key predictor in successfully carrying out transition into adult-care settings. In two paediatric sites, children are kept there until 24 years old. The Jamaica experience on adolescent transition involves holistic management, with great focus on the service delivery implementation. Currently, a ViiV Healthcare-funded initiative is studying specialty care and transition of adolescents living with HIV.

There is also intensive tracking of transition, coupled with training of adult physicians and paediatricians in adolescent HIV/AIDS transition. Transition involves the use of psychologists (which is in contrast to the Asia-Pacific experience). Christie-Samuels described the JaPPAAIDS experience in adolescent transition as a “Jamaican model”, adding that there are plans to upscale this to the other sites in Jamaica.

Pediatric HIV/AIDS Cohort Study (PHACS)

George Seage (Harvard University, USA) offered the American experience on adolescent transition based on PHACS, a cohort study initiated in 2005 that has sought to address the long-term safety of fetal and infant exposure to ART, and to investigate the effects of perinatally acquired HIV in adolescents. PHACS currently has an Adolescent Master Protocol (AMP) in place: at the age of 18, all AMP participants are offered enrolment to AMP-UP and re-consented as adults. Seage noted that some study participants refuse to re-consent.

PHACS investigators spent a number of years conducting in-depth interviews with participants, funders and other actors to develop AMP. They are now looking to extend this protocol into a less intensive long-term follow-up study called AMP-UP, and are aiming to recruit up to 600 perinatally HIV-infected adolescents; 196 are currently enrolled. As part of this new study, a large amount of data is being collected. Participants will be conducting an online survey based on Illume software, which takes on average 35 minutes to complete, and is user friendly. The survey itself includes eight modules: demographics; health and health care; sexual behaviour; recent sexual behaviour; reproductive health; life events/quality of life; substance use; and adherence to therapy.

Seage explained that when adolescents are asked about satisfaction during the transition process, the most satisfied with care are those who have actually transitioned. PHACS currently does not collaborate with adult cohorts since there is no adult cohort that can enrol most PHACS participants. In addition, Seage spoke about the fragmentation of the American health care system, in contrast with somewhere like South Africa where data integration between paediatric- and adult-care settings is more optimized. As a result, there currently is no national surveillance system in the US that tracks transition into adult health care for young people with perinatally acquired HIV or for other chronically ill young people.

In PHACS, questions administered before and after transition to adult HIV care include:

- Have adolescents discussed the process of transitioning with paediatric/adolescent clinic staff?
- Which written transition materials have they reviewed?
- Have adolescents been assessed in terms of their ability to manage medications and health care appointments and satisfaction with the care they receive at their clinic (both pre- and post-transition)?

Furthermore, cohort investigators are looking at clinical outcomes and quality of life after completion of transition to adult HIV care, as well as factors associated with successful transition. In terms of challenges and barriers around adolescent transition, Harvard is piloting some approaches to transition, as has been used by the Nurses' Health Study and the Framingham Heart Study. As flagged in preceding presentations, adolescent researchers and clinicians have to be cognizant of the sensitivities around consent.

ART outcomes among adolescents living with HIV in Ethiopia

Degu Jerene (Addis Ababa University, Ethiopia) gave an overview of a CIPHER-sponsored project, an ongoing collection of data in eight facilities in two regions in Ethiopia, as part of a cohort of children and adolescents living with HIV (n=2,058). Adolescent transition is a specific variable (age of transition) in this cohort. Currently, cohort investigators are examining the organization of clinical care for adolescents (stand-alone or integrated child-adolescent-adult clinics). They are also trying to better understand the role of age at transition, and socio-demographic and clinical factors that impact on transition in this population. Jerene also highlighted an existing collaboration with one adult cohort site that has been tracking enrolled patients since 2003.

In terms of challenges around data collection/maintenance and research, there is a high resource need to maintain high-quality data in Ethiopia. From a service delivery standpoint, the care of adolescents is not adequately addressing underlying psychosocial issues given the limited mental health support in place. This echoes the experience in the Asia-Pacific.

The current tools include an Access-based database at each site, where unique identifiers are included. A site logbook for cross checking and standard operating procedures are also being utilized (e.g., for data abstraction).

As HIV in adolescence is an understudied area, some priority research questions include:

- Models of care: what is appropriate?
- Defining the optimal age of transition into adult care
- How can treatment adherence and retention in care be improved?
- What is the incidence of TB and other co-infections in adolescents?

Paediatric cohort of HIV-positive children followed by the Ambulatory Treatment Center of Brazzaville

Martin Herbas Ekat (Ambulatory Treatment Center of Brazzaville, the Republic of the Congo) presented The Ambulatory Treatment Center of Brazzaville in the Republic of the Congo, which was created in 1994 and includes a cohort of 220 children as of December 2014. The centre provides psychosocial support through several activities (such as individual consultations, discussion groups of teenagers, “sorties thérapeutiques” (therapeutic outings), home visits and family mediation) to adolescents living with HIV. Individual consultations are focused on adherence and disclosure of serological status.

Discussion groups for adolescents are led by a psychologist addressing the challenges encountered in adolescence. The centre also plays a role in family mediation, particularly for those adolescents who have been stigmatized, and there are attempts to re-integrate adolescents into their homes.

All centre participants, including adults and children, have a medical record, which is updated at each visit; quarterly reports are sent to the country's HIV department. [Santia](#) is the software now in place to follow up cohort participants in Brazzaville. There is a need to have better tools to assess adherence in adolescent populations as strategies involving counting of tablets at the follow-up visit are not optimal. In addition, existing tools and algorithms for diagnosis of treatment failure in adolescents are not sufficient. For example, measuring viral load every six months, the standard tool in determining failure, is sometimes not available in their setting.

In Brazzaville, co-trimoxazole prophylaxis (CTXp) is administered irrespective of disease stage, CD4 cell count or use of ART up until the age of 14 years. Cohort investigators are interested in ascertaining the cost effectiveness of CTXp in adolescents, particularly around reductions of morbidity and mortality, and improvements in growth.¹⁶ Lastly, there is a need to evaluate the benefit and cost of viral load monitoring in improving the question of care in adolescents.

¹⁶ Church JA, Fitzgerald F, Walker AS, Gibb DM, Prendergast AJ. The expanding role of co-trimoxazole in developing countries. *Lancet Infect Dis.* 2015 Mar;15(3):327-339.

HICDEP: HIV Cohorts Data Exchange Protocol overview

A brief overview on the HIV Cohorts Data Exchange Protocol ([HICDEP](#)) was presented by **Bruno Ledergerber** (University Hospital Zurich, Switzerland). HICDEP is a protocol that allows for simple sharing of data across HIV cohorts by providing a standard format for datasets. It is being used by several major HIV cohort collaborations, including Concerted Action on SeroConversion to AIDS and Death in Europe (CASCADE), the Collaboration of Observational HIV Epidemiological Research in Europe (COHERE), EuroSIDA and paediatric networks, such as the Paediatric European Network for Treatment of AIDS (PENTA) and EPPICC. The specification now consists of 27 tables in a relational structure covering most medical aspects of HIV patients' histories used in clinical research, including paediatric aspects. Several collaborations have contributed to definitions, and there are efforts now to collaborate with partners outside Europe.

Of relevance to this workshop, mother-to-child information captured in HICDEP includes obstetrics, child delivery and abnormality of new-borns. Specific variables within these HICDEP tables can be reviewed in order to determine which specific data items or tables could capture adolescent transition.

RESEARCH GAPS

In 2013, WHO's [Guidance for HIV testing and counselling and care for adolescents living with HIV](#) outlined specific areas of priority research on interventions focusing on adolescents. In addition, WHO's technical consultation on adolescents and HIV last year further identified research gaps in clinical monitoring, service delivery interventions, drug optimization and the role of community. The following research gaps are specific to adolescent transition, and were identified based on a survey of the paediatric HIV cohorts registered on the CIPHER online database and discussion at the Adolescent Transition Workshop. From its inception, CIPHER has focused on addressing outstanding research gaps in both clinical research and operational/implementation science. A key recommendation coming out of the workshop was the need to follow up adolescents over the long term and to systematically capture clinical and operational outcomes after they transition into adult-care settings.

Clinical research gaps (please refer to Table 2)

1. Long-term ART outcomes

- The long-term impact of paediatric ART on physical and cognitive development of adolescents living with HIV remains a key priority for research. A [needs assessment](#) by CIPHER in 2013 has already flagged this research gap and identified key areas, including metabolism, bone mineral density and other clinically relevant laboratory and biological markers in adolescents.
- In addition to this workshop and the 2013 needs assessment, an Industry Liaison Forum/CIPHER [roundtable meeting](#) at AIDS 2014 also identified the need to longitudinally track efficacy, tolerability, safety and resistance to ARVs.

2. HIV-1 viral load (VL)

- As the key goal of ART is to achieve and maintain durable viral suppression, there is a need to better understand VL outcomes, including levels of VL suppression in adolescents, particularly as they transition

out of paediatric-care settings and into adult care.

3. Mental health

- Not enough mental health outcomes are being captured for paediatric and adolescent cohort participants. Underlying mental health conditions, such as depression and anxiety, are associated with a variety of other outcomes, including adherence and treatment interruption. Psychiatric care is often not prioritized in many paediatric settings in resource-limited countries, and therefore mental health is not captured as an outcome in most studies.
- Workshop participants recognized that appropriate controls should be in place when mental health outcomes are measured.

4. Pregnancy

- Accurate rates of pregnancy in adolescent females as they transition out of paediatric cohorts in resource-limited settings currently do not exist.

5. Sexual and reproductive health (SRH)

- Outcomes on SRH of adolescents are insufficient and critical in order to support policies, programmes and services, which remain inadequate in responding to their SRH needs.

6. Resilience

- Measuring levels of resilience in adolescents along the cascade of transition is identified as providing important insight into how certain adolescents cope with a variety of issues, including their own HIV status.

7. Mortality

- Measuring mortality (e.g., alive/dead as a dichotomous variable) as a variable of key interest in cohorts should be urgently prioritized, particularly across various time points post-transition.

8. Cotrimoxazole prophylaxis (CTXp)

- In cohort settings, such as Brazzaville, CTXp is administered irrespective of disease stage or CD4 cell count or use of ART, until the age of 14 years. It is important to assess the duration of protection and tolerability of such long-term CTXp use and also to capture these outcomes during and after transition in adolescents receiving CTXp.

9. New drugs

- In the context of treatment optimization, use of new ART agents should include consideration of how adolescents can benefit, especially as they transition into adult-care settings.

10. Disease progression

- Differences in rates of progression among adolescents infected perinatally versus those infected behaviourally as adolescents are not well understood. Capturing this as part of systematic cohort research, including during transition, can be particularly informative to UNAIDS modelling estimates.

11. Importance of collecting mode of HIV transmission

| Research gap in adolescent transition | Workshop Cohorts | | | | | | | | | | Other partners | |
|---------------------------------------|------------------|-------------------|----------|-------------------|----------------|----------|---------|-------------|-------|----------|----------------|-----|
| | EPIICC | leDEA East Africa | leDEA SA | leDEA West Africa | leDEA CCASAnet | leDEA AP | Jamaica | Brazzaville | PHACS | Ethiopia | UNAIDS | WHO |
| Adherence | | • | | • | | | | • | | • | | • |
| Retention in care | | • | | • | | | | | | | • | |
| Psychosocial support | | • | | | | | • | | | | | • |
| Mental health | | • | • | | | | | | • | | | |
| Predictors of successful transition | | | | | | | • | | • | | | |
| Reproductive health | | | | • | | | | | | | | • |
| ART status (on or off) | | | | | | • | | | | | | |
| HCW needs | | | | | | | • | | | | | |
| Optimal age of transition | | | | | | | | | | • | | |
| Best model of care | | | | | | | | | | • | | |

Table 2. Clinical HIV research gaps in adolescent transition identified by workshop cohorts, UNAIDS and WHO

Operational/implementation research gaps (please refer to Table 3)

1. Adherence

- Limited evidence is available on assessing effective strategies, interventions and models of care that are most optimal in supporting adherence among adolescents and in transitioning adolescents from paediatric to adult ART programmes. Studies have indicated that adherence is poorer in adolescent populations than in adult or pre-adolescent populations.^{17, 18}

2. Retention in care

- Strategies that aim to minimize loss to follow up and promote retention in care for adolescents during and after transition remain to be evaluated.

3. ART status (on/off)

- At all points of the transition cascade, cohorts should be measuring the ART status of their adolescent participants.

4. Predictors of successful transition

- From a service delivery standpoint, barriers to transitioning adolescents are often outlined. However, there is currently no evidence on what approaches or interventions can ensure a successful transition out of paediatric HIV care.
- Understanding adolescents' perception of ideal transition management can offer important insight for researchers and practitioners.

5. Needs of health care worker (HCW)

¹⁷ Sabin CA, Smith CJ, d'Arminio Monforte A, Battegay M, Gabiano C, Galli L, et al. Response to combination antiretroviral therapy: variation by age. *AIDS*. 2008; 22(12): 1463-73.

¹⁸ Nachega JB, Hislop M, Nguyen H, Dowdy DW, Chaisson RE, Regensberg L, et al. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa. *J Acquir Immune Defic Syndr*. 2009; 51(1): 65-71.

- There is insufficient training for HCWs to manage adolescents during the transition process.
6. Psychosocial support
 - Implementation science is lacking on how to develop more effective programmes and health systems that can enhance emotional, mental and social outcomes for adolescents and young adults.
 7. Optimal age of transition
 - There is wide variability across paediatric HIV cohorts for when adolescents transition into adult care. The age at which transition begins is an important variable, which has yet to be addressed in the context of cohort research.
 8. Best model of care
 9. When do children and adolescents start ART?
 - Better data is needed to ascertain at what age and CD4 count adolescents initiate treatment.
 10. Adult clinician buy in
 - To enhance service delivery interventions, adult clinicians can provide insight into what they consider to be challenges, barriers and potential solutions for transitioning adolescents into their own care settings.

| Research gap in adolescent transition | Workshop Cohorts | | | | | | | | | | Other partners | |
|--|------------------|-------------------|----------|-------------------|----------------|----------|---------|-------------|-------|----------|----------------|-----|
| | EPPICC | IeDEA East Africa | IeDEA SA | IeDEA West Africa | IeDEA CCASAnet | IeDEA AP | Jamaica | Brazzaville | PHACS | Ethiopia | UNAIDS | WHO |
| Long term ARV outcomes, post transition | • | • | | | | • | • | | • | | | |
| Viral load; viral load suppression | | | • | | | • | | | | | | |
| Pregnancy | | | • | | | | | | | | | • |
| New drugs | | | | | | | | | | • | | • |
| Resilience | | | • | | | | | | | | | |
| Mortality | | | | | | • | | | | | | |
| Cotrimoxazole prophylaxis | | | | | | | | • | | | | |
| Disease progression between perinatally infected vs. behaviorally infected | | | | | | | | | | | • | |
| When do children start ART? | | | | | | | | | | | • | |

Table 3. Operational HIV research gaps in adolescent transition identified by workshop cohorts, UNAIDS and WHO

DISCUSSION POINTS

Rohan Hazra (US National Institutes of Health, NICHD, USA), as moderator of the workshop discussion, provided a summary of the key themes and issues emerging out of the cohort presentations.

- Additional data would help inform estimates from UNAIDS modelling.
 - More reliable national and global estimates could inform all the other research currently being conducted or being planned.
 - Research gaps identified by UNAIDS for this workshop should be considered alongside those flagged by each of the cohorts.
- Great examples of linking to surveillance systems exist, as in South Africa and the UK.
 - Identify what is available in one's setting and how it can be expanded to track adolescents based on how other settings have succeeded in monitoring transition.
- Mobility of young people cannot be underestimated.
 - Adolescents living with HIV and receiving care are not a static patient population that happen to transition physically at the same facility.
 - Cohorts have to consider strategies in maintaining contact with adolescents as they prepare to transition out of paediatric settings, with some minimal follow up in place in order to have a "bird's eye view".
 - More intensive research can be conducted once adolescents are transitioned, particularly in looking at clinical, including psychosocial, outcomes of interest.
- True engagement with young persons has yet to be realized.
 - Investigators have to consider how they can engage with young adults to inform research by having a better understanding of their experiences and needs, particularly with respect to resilience.
 - A key step is to move beyond research by empowering adolescents and identifying their educational needs.

Every cohort presentation highlighted the issue of **adherence**; although as a research area this is critical, Hazra called for more action around service delivery interventions to support adolescents in adherence. Moreover, he stressed that the research community should recognize and understand how needs vary according to age. **Mental health** was also another important topic addressed by the cohort investigators participating in the workshop.

Importantly, a topic of priority is the **SRH of adolescent females** as it is becoming increasingly evident that this is a special population. Under the leadership of actors like WHO, a research agenda around transition for service delivery has to be in place to drive guidance and to maximize treatment outcomes in this population (Figure 7). CIPHER is a key platform that can support the development of this research agenda, given its unique position and ability to coordinate and align efforts by its cohort partners.



Figure 7. How to address research gaps in adolescent transition in the context of normative guidance and policy making (adapted from Martina Penazzato’s presentation at the workshop)

PRIMARY SUGGESTIONS: How can this group make a difference?

Workshop participants provided insight and feedback on how they as a group could support some activities based on the general themes, research gaps outlined and key topics around adolescent transition.



Suggestion 1: Common definition of transition and outcomes

Across the literature on transition, papers use different outcomes and measurements. Workshop participants felt there was an opportunity to have a consensus definition of adolescent transition and to define specific outcomes that the group deemed most important.

Suggestion 2: Key indicators for national and global reporting

Once there is consensus on the most appropriate definition of adolescent transition and the most important outcomes associated with this transition, the group recognized that cohorts should capture the major key indicators required for national and global reporting. Furthermore, UNAIDS could better define with partners and CIPHER colleagues what additional pieces of information can be derived from paediatric HIV cohorts that can support global policy makers.

Suggestion 3: Common analytical plan

Despite some existing data on transition available for analysis, the group recognized that a high-level common analytical plan was lacking. Therefore, bringing cohorts together as a follow up to this workshop would be a critical step, and the group identified next year’s IWHOD meeting as the point by which this analytical plan would be fully developed.

In addition, the development of such an analytical plan would need buy in from cohorts and a deeper conversation around the technicalities. The following are some of the outstanding objectives of the development process:

- To determine how long the transition period should be
- To build a cascade of transition covering the critical outcomes of interest
- To identify what tools would be relevant to support the development of the plan.¹⁹

Suggestion 4: Engaging adult cohort investigators and adult clinicians

The issue of the role of adult cohorts in these discussions and the need to engage them was raised. There are strong examples of linkages happening between paediatric HIV cohorts into adult-care settings, namely in east Africa, the Western Cape and the UK. It was emphasized that adult cohorts need to have the variable, “perinatally acquired HIV infected”, as a baseline in their data systems. In addition, greater communication with adult cohort investigators would be constructive.

Suggestion 5: Data harmonization

The group could focus on settings already doing data linkages, as was shown in the Western Cape. A proposal was put forth to create a working group that could better understand how such linkages could be scaled up. Existing platforms, such as PHACS, which is particularly detailed, could be examined, and then the group could consider what is feasible at a broader basis.

- Action point: an exercise in harmonization between PHACS and AALPHIE
- Specific variables within these HICDEP tables can be reviewed in order to determine which specific data items or tables could capture adolescent transition.

NEXT STEPS

Near term

The IAS welcomed the idea of continuing these discussions during the CIPHER Global Cohort Collaboration Meeting on San Servolo Island, Venice, Italy, in May 2015, alongside the 2015 Paediatric European Network for Treatment of AIDS-Infectious Diseases (PENTA-ID) meeting. As there is a need to scope out research priorities more systematically and with greater precision around the actual research questions, this working group meeting would be a concrete follow-up activity coming out of this workshop.

Medium term

It is important to brainstorm how to link more effectively with existing and parallel activities, such as “All In”²⁰ and PEPFAR’s prevention-based DREAMS initiative (Determined, Resilient, AIDS-free, Mentored, and Safe Women).²¹ There is an opportunity to harmonize, where possible, the data needs that feed into M&E across initiatives.

¹⁹ PHACS colleagues noted that they would gladly share their surveys with other CIPHER workshop participants.

²⁰ UNAIDS, UNICEF and partners launched “All In” in Kenya this year. It is a new platform for action to drive better results for adolescents by encouraging strategic changes in policy and engaging more young people in the effort.

²¹ PEPFAR and its partners work with partner countries selected to participate in DREAMS to provide a core package of evidence-based interventions that have successfully addressed HIV risk behaviours, HIV transmission and gender-based violence.

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