RESEARCH FOR AN AIDS FREE GENERATION:

A GLOBAL RESEARCH AGENDA FOR ADOLESCENTS LIVING WITH HIV

Worldwide, there were an estimated 2.1 million [1.4 million - 2.6 million] adolescents (10-19 years old) living with HIV in 2016, with 150 adolescents dying from AIDS-related causes every day[1]. Between 2000 and 2015, annual AIDS-related deaths declined for all age groups except adolescents, where mortality more than doubled from 18,000 to 41,000[2].

In 2016, there were an estimated 260,000 [150,000-340,000] new HIV infections among adolescents. In sub-Saharan Africa, two out of three newly infected adolescents aged 15-19 years were girls[3]. With the successful scale up and effectiveness of antiretroviral therapy (ART), children living with HIV are surviving and growing into adolescence. This increasing population requires ongoing support to remain in care and adhere to ART, as well as to manage the changes related to adolescence.

Adolescents living with HIV are in urgent need of improved approaches to address their specific health needs. Evidence indicates higher rates of loss to follow up[4,5], and poor adherence[6], as well as increased needs for psychosocial support[7]. This population group continues to be underserved by current HIV services and have significantly worse access to and coverage of ART[8]. Despite a rapidly growing area of HIV research, a considerable amount of effort is still needed to inform the understanding of what works for this population. Improving outcomes for adolescents and reaching global targets for an AIDS FREE generation by 2030[9] will require evidence-based interventions and policies. These should take into consideration the developmental stage of adolescence while comprehensively addressing the multiple needs of adolescents living with HIV and actively engaging them in their own healthcare. To overcome these barriers and challenges in a context of increasing funding constraints, targeted research is urgently required to bridge identified research gaps and inform policy on adolescent HIV.

The World Health Organization (WHO) and the Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) of the International AIDS Society (IAS) have undertaken a global research prioritization process. Through broad engagement with stakeholders, a global research agenda has been established, which is aimed at guiding work and maximizing available resources. The agenda is comprised of priority research themes in the areas of testing, treatment and service delivery for informing global policy change, and improving outcomes for adolescents living with HIV.

Targeted research is urgently required to bridge identified research gaps and inform policy on adolescent HIV.

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METHODS

This process was based on the Child Health and Nutrition Research Initiative (CHNRI)[10] methodology for setting priorities in health research, and was guided by a working group of experts in paediatric and adolescent HIV[11].

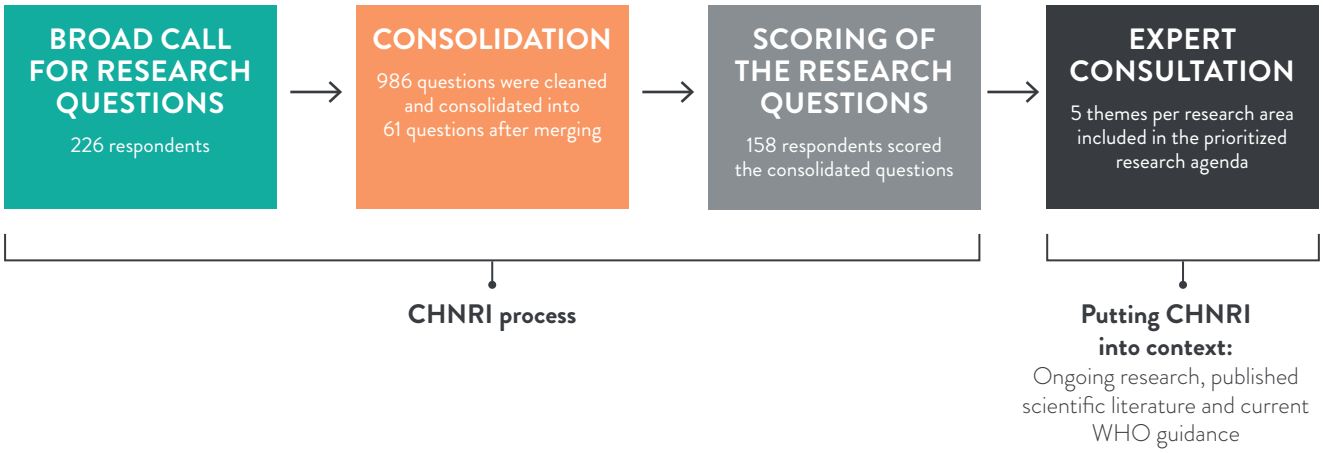
The main steps included:

A broad call for research questions: A survey calling for priority research questions and planned/ongoing studies was sent to a broad range of stakeholders[12].

Consolidation: Submitted research questions were cleaned and consolidated through a thematic content analysis.

Scoring of the research questions: Respondents to the first survey were asked to score the consolidated lists of research questions against pre-defined CHNRI criteria, resulting in a prioritized list.

Expert consultation: To form the final research agenda, an expert consultation of researchers, UN organizations, civil society and community representatives, was held to review the top 10 ranked questions for testing, treatment and service delivery in the context of ongoing research, published scientific literature and current WHO guidance. Themes, rather than questions, were used for the final agenda.



TEN KEY CONSIDERATIONS

FOR IMPLEMENTATION OF THE RESEARCH AGENDA

The following considerations, which emerged from the research prioritization process, should be taken into account when implementing the prioritized agenda for adolescents:

- **Strengthen national monitoring and evaluation systems** to obtain relevant disaggregated data (age, sex, region, mode of transmission) for accurate monitoring of progress and challenges, informing policies and effective programme planning.
- **Improve programmatic data** to help assess the implementation of ongoing service delivery and determine what works best in specific contexts.
- **Recognize adolescence as a developmental stage of life** within service delivery models.
- **Assess the effect of social determinants of health** to ensure successful scale up of HIV services and positive individual outcomes.
- **Increase participation of adolescents,** civil society and community-based organizations as key stakeholders, especially in implementation research, advocacy and service delivery.
- **Develop innovative approaches to trial design and implementation** to maximize their added value and expedite results.
- **Overcome reluctance of including adolescents in studies** due to issues of consent or concerns around study retention to ensure that data relevant to this age group are gathered.
- **Use observational data** and big data collaborations to inform policy and programme decision making.
- **Utilize modelling** as an important tool to help bridge data gaps and optimize existing data.
- **Innovate clinical and implementation science** to provide new tools for more effective care for adolescents living with HIV.

TOP RESEARCH PRIORITIES
FOR ADOLESCENT HIV

TESTING

- Strategies and interventions to improve access to and uptake of HIV testing services, and factors that impact their success
- Strategies and interventions to improve linkage of newly diagnosed adolescents to HIV treatment, and factors that impact their success
- Safe and acceptable strategies or interventions to improve access to and uptake of HIV testing services for adolescents from key populations
- Consent policies and practices to facilitate access to and uptake of HIV testing services in adolescents
- Safety, acceptability, feasibility and effectiveness of self-testing

TREATMENT

- Effective monitoring approaches and strategies to improve adherence among adolescents and factors that impact their success
- Safety, efficacy and acceptability of novel drug delivery systems
- Prevention and clinical management of co-infections, particularly tuberculosis
- Optimal sequencing of ART in adolescents
- Impact of HIV infection and ART on short- and long-term outcomes of adolescents, in particular non-communicable diseases

SERVICE DELIVERY

- Interventions to improve retention in care and factors that affect their success
- Strategies or interventions to improve sexual and reproductive health outcomes in adolescents living with HIV
- Strategies or interventions to support pregnant adolescents living with HIV and improve both maternal and child health outcomes
- Service delivery models to improve outcomes along the HIV cascade, including peer interventions and differentiated service delivery models
- Psychosocial support strategies or interventions to improve individual and programmatic outcomes

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A CALL TO ACTION

Stakeholders involved in clinical and operational research in adolescent HIV can support the successful implementation of this agenda by actively engaging with the established priorities and integrating them into their activities in the following ways:

FUNDERS

- Utilize the agenda to guide funding priorities.
- Focus available resources on research areas that will have the greatest impact on reducing the adolescent HIV.

IMPLEMENTERS AND PROGRAMME MANAGERS

- Improve and integrate information from routine monitoring systems to help evaluate and learn from ongoing activities and new strategies.
- Apply lessons learned from programmes in similar settings or different countries.

POLICY MAKERS

- Guide adolescent HIV research to inform policies at country level.

Involve adolescents living with HIV and the community in a meaningful and responsible way

RESEARCHERS

- Integrate relevant elements of the research agenda into ongoing and future research.
- Engage and partner with programme implementers to effectively assess the outcomes of service delivery models focused on adolescents.
- Reduce research overlap and maximize resources by informing others in the research community about ongoing and future projects.

CIVIL SOCIETY AND COMMUNITY-BASED ORGANIZATIONS

- Engage with the agenda and promote community participation in research, particularly operational research, and programme support.
- Advocate for implementation of the research agenda to improve outcomes in adolescent HIV.

For more information on the research agendas and the process that was followed, please visit:
https://www.iasociety.org/CIPHER

[1] UNICEF, UNAIDS and WHO Global AIDS Monitoring Data, 2017.

[2] UNICEF, For Every Child End AIDS, Seventh Stocktaking Report, 2016.

[3] UNICEF, UNAIDS and WHO Global AIDS Monitoring Data, 2017.

[4] Lamb R, Fayorsey R, Nuwagaba-Birbonwoha H, Viola V, Mutabazi V, et al. High attrition before and after ART initiation among youth (15 – 24 years of age) enrolled in HIV care. AIDS. 2013; 27: 559-68.

[5] Auld A, Agolory S, Shiraishi R, Wabwire-Mangen F, Kwesigabo G, et al. Antiretroviral therapy enrolment characteristics and outcomes among HIV-infected adolescents and young adults compared with older adults — Seven African countries, 2004 –2013. MMWR. 2014 Nov; 63(47): 1097-1103.

[6] Nachega J, Hislop M, Nguyen H, Dowdy D, Chaisson R, et al. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in southern Africa. JAIDS. 2009 May; 1 (51): 65-71.

[7] Denison J, Banda H, Dennis A, Parker C, Nyambe N, et al. "The sky is the limit": adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. J Int AIDS Soc. 2015; 18(1): 19358.

[8] WHO, Report of the consultation on the treatment of HIV among adolescents, 2014.

[9] PEPFAR, UNAIDS, UNICEF, WHO, Start Free, Stay Free, AIDS Free, A super-fast-track framework for ending AIDS among children, adolescents and young women by 2020, 2016.

[10] Rudan, I, Gibson JL, Ameratunga, S, El Arifeen, S, Bhutta ZA, et al. Setting priorities in Global Child Health Research Investments: Guidelines for Implementation of the CHNRI Method, Croat Med J, 2008, 49(6): 720-733.

[11] The scope of the exercise included testing, treatment and service delivery for adolescents. Preventive interventions were not within the scope of this exercise.

[12] Including researchers, policy makers, implementers, healthcare providers, networks of young people living with HIV and community representatives.

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