





#### **MEDIA STATEMENT:**

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# The invisible generation – why are the deaths of adolescents living with HIV being forgotten?

New coalition calls for urgent response to expand treatment and care for adolescents living with HIV

The World Health Organization released a report last week that reveals HIV is the second leading cause of death amongst adolescents aged 10-19 globally, and the number one cause in Africa. Adolescents are increasingly dying at a time when HIV-related deaths are decreasing for all other age groups.

In light of this stark statistic, a new coalition was formed to catalyze immediate change in the HIV response for adolescents. Networks of people living with HIV, HIV treatment organisations and youth groups have united with researchers, clinicians and global health agencies to address gaps in the treatment and care needs of adolescents living with HIV, including the intellectual property barriers that prevent adolescents from accessing essential medicines. Key organizing partners include the Global Network of People Living with HIV (GNP+), the Global Network of Young People Living with HIV (Y+), the International Treatment Preparedness Coalition (ITPC), The PACT for Social Transformations in the AIDS response, and UNAIDS.

"The needs of adolescents living with HIV have been ignored for too long," said Suzette Moses-Burton, Executive Director of GNP+. "The problems we are facing today, which include the increasing number of HIV-related deaths among adolescents, are due to the failure of the HIV response to provide optimal treatment for children, as well as to understand their specific requirements on disclosure, adherence, and other support needs as they transition to adolescence and adulthood."

The coalition has outlined six key areas to improve access for the 2.1 million adolescents living with HIV globally to ensure that their rights to health and dignity.

#### The coalition calls for:

1. Increased access to HIV testing

The majority of adolescents are still unaware of their status and often present at health facilities with a severely compromised immune system. Provide convenient, appropriate and preferred testing options, lower the age of independent consent and create demand by expanding promising practices.

2. Expanded treatment options for adolescents

The lack of effective and easy-to-administer paediatric formulations affects children into adolescence as long-term ART side effects and drug resistance due to sub-optimal treatment regimens take effect. Lack of treatment, monitoring and support services, and the high cost of second— and third—line

<sup>&</sup>lt;sup>1</sup> World Health Organization 2014







regimens, create

adherence issues.

# 3. Adapting health services to adolescents' needs

Adolescence is a time of critical transition resulting in unique needs – specialist approaches are needed for treatment education and treatment fatigue, social and adherence support, stigma-free sexual and reproductive health services, and to improve transition to adult care services.

#### 4. Mobilising social support

Adolescents and families need more information and guidance for HIV disclosure, to assess risk and manage reactions from friends, family and sexual partners, especially in the context of countries that criminalize HIV non-disclosure, transmission and exposure. Stigma and discrimination, including self-stigma, remain huge challenges.

## 5. Empowering adolescents

Adolescents need to be meaningfully involved in reviewing, adopting and implementing the WHO 2013 ART guidelines in countries, as well as in the design and delivery of services, and in the crafting of messages directed at them.

### 6. Better data to improve policies and programmes

Higher-quality data and ongoing research on adolescent outcomes are urgently needed, disaggregated by gender, key population and age group, in order to facilitate the creation of global evidence for international guidelines. Research should also investigate causes and issues around treatment failures and loss-to-follow-up.

Christine Stegling, Executive Director of ITPC, a global network of advocates working on treatment access, said: "Adolescents living with HIV today are simply running out of options as second- and third-line HIV treatment regimens remain unaffordable and unavailable in many countries. We need to foster a broad movement that cuts across sectors to ensure the success of this agenda and prevent the unnecessary deaths of adolescents living with HIV."

Lumumba El-nasoor Musah, Co-chair of the SRH working group of Y+, said: "Young people and adolescents living with HIV are at the heart of our strategy – they are the very ones who know how services can be better shaped to suit their needs, and what is missing from current services."

To read more about the coalition, please access the full statement here: [include link to outcome document]

## -ENDS-

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For more information

about how you and your organisation could get involved in this coalition please contact: ALHIVcoalitionforaction@gmail.com