Addressing challenges facing adolescents in knowing and managing their HIV status in sub-Saharan Africa
Adolescents frequently fall between the cracks of paediatric and adult HIV care services, and large proportions of ALHIV do not know their status. Treatment adherence among adolescents is generally lower and treatment failure rates are comparatively higher than in other age groups. Sadly, the main barriers are the psychosocial circumstances in which adolescents live, the deeply entrenched stigma surrounding HIV, adolescents’ limited personal resources and dependence on caregivers, and the health systems which are unprepared to address the specific needs of ALHIV.

This policy paper was conceived at a joint LSHTM-Sentebale roundtable meeting in July 2017; three young people from Lesotho and Botswana presented their personal experiences and challenges of living with HIV to an audience including Prince Harry, leading HIV researchers, and senior staff from organisations such as UNAIDS, PEPFAR and the Global Fund to Fight AIDS, TB and Malaria. This paper profiles some promising approaches to address challenges and barriers identified by ALHIV, which are divided into three categories. Under services and environment, we discuss approaches for addressing health system barriers to ALHIV accessing testing and treatment; in language and discourse, we consider messaging about HIV/AIDS as experienced by ALHIV, including public health campaigns that resonate with ALHIV, interventions seeking to mitigate stigma, and sensitive and sanguine ways to talk about and disclose HIV status. Finally, under agency, we consider approaches that aim to boost resilience, self-efficacy, knowledge and awareness, and mental wellbeing among ALHIV that can empower them to live happy, healthy and productive lives.

This brief is aimed at organisations working with ALHIV who wish to implement evidence-based programmes. The paper provides a snapshot of some promising interventions in sub-Saharan Africa profiled in the recent literature (2010 onwards). It is crucial that interventions make a difference not only to the treatment outcomes but also to the quality of life of ALHIV. Such interventions need not be complex or costly, if they are sustainable, and listen to and work closely with young people living with HIV and their communities.

In 2016, around two million adolescents aged 10–19 years were living with HIV, nearly 85% of whom live in sub-Saharan Africa. An estimated 260,000 adolescents were newly infected with HIV globally in 2016. In sub-Saharan Africa, three in four new HIV infections among 15–19 year olds were among girls, and HIV-related illnesses remain the second leading cause of death for young women aged 15–24 years in Africa. Adolescents living with HIV (ALHIV) include both those perinatally infected and those infected sexually, and these young people face distinct challenges at all stages of the HIV care pathway including diagnosis, linking to HIV care services, staying in care and maintaining treatment.

I want to give a sense of hope that there is still life if you are HIV-positive [...] I have a vision of keeping the next generation alive

Kananelo
22, Lesotho

"Psychosocial support’ addresses psychological and social issues experienced by people living with HIV (WHO definition).

"Many highly effective interventions evaluated and reported on before 2010 or from regions outside sub-Saharan Africa are not covered in this paper. Prevention interventions or approaches are only considered when they concern secondary prevention or onward transmission of HIV. As the emphasis of the paper is on psychosocial support interventions, it does not consider biomedical approaches that could improve adherence such as the development of long-acting antiretroviral drugs, or interventions to reduce their side effects."
### Health services

**“The health services are open during school hours and we don’t have the time to go for check-ups”**

### Promising approaches and interventions

- **Peers** can be used as facilitators within school-based networks.
- **Social networking platforms** can be used to engage with adolescents.
- **Language and discourse** can be used to improve understanding and acceptance of HIV.

### Challenges expressed by ALHIV

- **“The soap opera MTV Shuga has helped reduce stigmatising attitudes, and to recast HIV as a chronic manageable disease”**

### Promising approaches and interventions

- **Home-based testing and counselling** can improve access to care.
- **Targeted education and training** can improve knowledge and skills.
- **Participatory workshops** can improve awareness and knowledge.
- **Psychosocial support groups** can improve access to care and support.
- **Social networking platforms** can be used to engage with adolescents.

### Poverty

- **Economic empowerment programmes** can reduce stress and improve well-being.
- **Peer support groups** can improve access to care.

### Language and discourse

- **Language to discuss a sexually transmitted, incurable infection rarely, requires a socially acceptable, private, healthy, and sensitive language**.
- **Social networking platforms** can be used to engage with adolescents.
- **Language and discourse** can be used to improve understanding and acceptance of HIV.

### Improving parent-child communication through structured programmes

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### Challenges expressed by ALHIV

#### Age of consent

Age of consent at 18 may restrict access to HIV testing and counselling services for those under 18. Barriers to adherence may be specific to adolescents, as their needs and experiences differ from adults. In countries like South Africa and Uganda, the age of consent is 18, which may limit access to HIV testing and counselling services for minors.

#### Mental health impacts of living with HIV

Mental health problems can negatively impact on adherence. In both adolescence and later life, barriers may include perceived stigma, perceived discrimination, and difficulty in self-control and resilience. The prevalence of mental health disorders is often high among ALHIV, and mental health impacts may particularly impact on mental distress experienced by adolescents affected by HIV.

#### Non-medical barriers to adhering to HIV medication

Non-medical barriers to adhering to HIV medication include lack of disclosure, perceived stigma, and peer pressure. Adherence to medication may be particularly challenging for adolescents who may be at particularly high-risk of mental distress. Victimization through bullying and discrimination may be at particularly high risk of mental distress.

### Promising approaches and interventions

#### Contact with community-based organisations

Contact with community-based organisations can improve adherence. These organisations can provide support and guidance to ALHIV, helping them to navigate the complexities associated with taking medication over a long period. They can also provide education and support about the importance of adherence, addressing the difficulties associated with taking medication daily.

#### Participatory activities

Participatory activities, such as digital storytelling, where ALHIV narrate their experiences on film, can reduce anxiety among ALHIV and improve their understanding of the difficulties associated with taking life-long treatment. These activities can foster self-understanding, self-control, and resilience, and help to improve adherence.

#### SMS messaging

SMS messaging can be an effective way to improve adherence. It can be used at weekly intervals rather than daily intervals to improve treatment continuity. However, acceptability of SMS reminders may not always be high, and factors such as educational level, disclosure, and access to internet can influence their effectiveness.

### Recommendations for implementing organisations

- Recognise that adolescents living with HIV (ALHIV) face unique challenges that are different to those facing children and adults.
- Ensure psychosocial support is reaching ALHIV as they transition into adult care.
- Adopt a human rights-based approach to testing, care, viral suppression, and supporting mental wellbeing of ALHIV.
- Recognise the crucial role of peers, caregivers, families, teachers, and communities, and equip them to best support ALHIV.
- Emphasise that ALHIV, while a heterogeneous group facing myriad challenges, can live healthy, happy, and productive lives.
- Empower ALHIV to lead, participate in and shape youth-friendly services, policies and research.

### Agency

- Find ways to sensitively discuss sex, dating and relationships for ALHIV, as this is a clear gap in current interventions.
- Interventions need to consider and address the contextual and structural factors (e.g. unstable family structures, poverty, marginalisation) which limit ALHIV’s ability to manage their status.
- Look to reach the “hard-to-reach”, marginalised ALHIV who may not be using any kind of formal or informal health service.
- The evidence base around adolescents to support ALHIV needs to be strengthened, through participatory and action-oriented research to overcome key barriers (e.g. stigma, among ALHIV, marginalisation of certain ALHIV groups).
- Tailor media, campaigns and approaches used in interventions to age range, geographical/cultural context (and potentially) mode of HIV infection in order to enhance their sustainability and scalability.
This paper is intended to profile promising approaches and good practices for supporting ALHIV to overcome psychosocial, ethico-legal and structural challenges associated with knowing and managing their HIV status. One limitation must be stressed, namely that many of the approaches discussed above are preliminary studies of feasibility or acceptability, and are yet to be tested at scale or in other contexts. Furthermore, many of the studies rely on a small sample of adolescents and have methodological issues. There is particularly limited research on the adherence, retention in care and treatment outcomes of young people from marginalised populations. Nonetheless it is hoped that the approaches profiled will spark some new ideas to integrate into existing or new programmes, or inspire collaborations with the organisations involved. The paper looked only at promising interventions for ALHIV in sub-Saharan Africa, but ALHIV themselves or organisations working with them may wish to learn from interventions in other parts of the world or with other groups.

The complexity of needs faced by ALHIV requires a holistic approach that takes account of factors at all levels of the health and social system that adolescents are part of, including their family, their broader community and the policy environment which can facilitate their wellbeing. Some of the most effective interventions work closely with caregivers or families, and emphasise resilience and the possibility of ALHIV to live healthy, happy and productive lives. That said, it is crucial that the human rights of ALHIV are front and centre, to ensure that adolescents can access testing and link quickly to care in cases where their home or economic circumstances may directly or indirectly limit engagement with HIV services. It is also crucial that the needs of adolescents who do not engage at all – perhaps because of marginalisation, disability, or lack of awareness, resources or independence – are considered and included when planning support interventions.

Most crucially, the literature consistently demonstrates that programmes and services need to step up the engagement of adolescents in programming, going beyond token involvement to listen to youth in meaningful and profound ways. This may involve uncomfortable or unfamiliar conversations about adolescents’ rights, consent, autonomy and sexuality, but these can underpin the most transformative initiatives. It is important to recognise that adolescents do not live their lives in healthcare facilities, and effective models of supporting ALHIV need to move away from a predominant focus on access to drugs to addressing the interlocking complexities of the family, community, school, work or social environments in which adolescents are situated. Adolescents living with HIV can thrive just like any of their HIV-negative peers in all walks of life, but only when provided with support and opportunities that enable them to overcome the challenges they face.

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A call to action

HIV needs to be treated exactly the same as any other disease, and between us hopefully we can eradicate the stigma and give these young people an opportunity to stand up and say, I’ve lived it [...] and I want to come forward and make a difference.

Prince Harry at LSHTM-Sentebale roundtable, July 2017

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