RESEARCH REPORT

Needs, Challenges and Opportunities:
Adolescents living with HIV in Zambia

International HIV/AIDS Alliance
Alliance Zambia
Southern African AIDS Trust
Network of African People living with HIV/AIDS

March 2011
ACKNOWLEDGEMENTS

The investigators in this study would like to acknowledge the participation and assistance provided by the individuals and institutions that contributed to this project.

We established a number of research partnerships to conduct this project, including Alliance Zambia, Southern African AIDS Trust (SAT) Zambia, and NZP+ (the Network of Zambian people living with HIV). The study also benefits from existing links between the Alliance and the Evidence for Action (EFA) Research Programme Consortium, an international research partnership led by London School of Hygiene and Tropical Medicine (LSHTM), and working with Southern African research institutions (in Zambia, Malawi, South Africa). In addition, a core advisory group was established amongst these partners to coordinate and conduct the research.

We are grateful to these institutions for the ongoing support and resource mobilisation through the duration of the study. Thanks also go to the research assistants recruited for data collection, and personnel at Alliance Zambia and the International HIV/AIDS Alliance, who launched and coordinated the study, in particular Dr Fabian Cataldo, Choolwe Haamujompa and Robert Haloba. Comments on earlier drafts of the report were very much appreciated from Cecilia Khara, Programme Officer, East and Southern Africa, International HIV/AIDS Alliance.

The study was supported through the Alliance Africa Regional Programme (ARP), with funding from the Swedish development agency (Sida).

Finally, we acknowledge and are immensely grateful for the contribution of participants. Their openness and honesty make this study possible.

Ian Hodgson, PhD
Principal Investigator
International HIV/AIDS Alliance, UK
March 2011

Contributing authors: Ian Hodgson (International HIV/AIDS Alliance), Choolwe Haamujompa (Alliance Zambia), Gitau Mburu and Julia Ross (International HIV/AIDS Alliance).
Table of Contents

ACKNOWLEDGEMENTS .......................... ii
ACRONYMS AND ABBREVIATIONS .......... v
EXECUTIVE SUMMARY ........................ vi
  RESEARCH SUMMARY AND BACKGROUND ........................................ vi
  DESCRIPTION OF THE PROJECT .................................................. vi
  FINDINGS ................................................................. vi
  DISCUSSION AND IMPLICATIONS .......................................... vii
1. INTRODUCTION ............................. 2
  1.1 Summary ......................................................... 2
  1.2 Background and Rationale ...................... 2
  1.3 Literature review ........................................... 3
  1.4 Working definitions ....................................... 5
    Adolescence ......................................................... 5
    Sexual and Reproductive Health (SRH) ........ 5
    Research Partnerships ......................................... 5
2. STUDY OBJECTIVES AND DESIGN ......... 7
  2.1 Aim, objectives and research questions .......... 7
    Objectives .......................................................... 7
    Research questions ............................................. 7
  2.2 Study Design .................................................. 8
    Study Sites ........................................................ 8
  2.3 Data Collection ............................................. 9
    Recruitment ....................................................... 10
    Inclusion Criteria ............................................... 11
    Exclusion Criteria ............................................... 11
    Description of respondents’ context .............. 11
  2.4 Ethics ............................................................. 12
    Participant Reimbursement ......................... 12
  2.5 Study limitations .......................................... 12
3. FINDINGS AND ANALYSIS .................. 14
  3.1 The psychosocial and SRH needs of an adolescent LHIV .... 14
    3.1.1 Relationships .............................................. 15
    3.1.2 Treatment ............................................... 17
    3.1.3 Knowledge of sexual and reproductive health, family planning and HIV ... 17
    3.1.4 Living the life of a young person with HIV .......... 19
    3.1.5 What are the needs? ...................................... 23
  3.2 The impact of accessing HIV and SRH services .......... 25
    3.2.1 Benefits of services .................................... 25
    3.2.2 Relationships with service providers ............ 26
    3.2.3 Information – nature and challenges ............ 28
3.3 Effectiveness of services: relationship between the needs of adolescents and availability
and nature of service provision 31
Case Study: Family planning and older respondents 32
3.3.1 Perceived problems with services 32
3.3.2 Need for adolescent-friendly services 34
3.3.3 Service recommendations: respondents 35

4. Discussion and Recommendations: What the Evidence Tells Us 37
4.1 Key findings 37
4.2 Discussion 37
The centrality of effective services 38
Barriers 39
Informing transition 39
4.3 Recommendations 40
4.3.1 Personal 40
4.3.2 Community 40
4.3.2 Organisational 40
4.3.3 Policy 41
4.3.4 Specific issues to track in Phase II 42

5. Gathering Qualitative Data: Lessons Learnt 44
5.1 Preparing for the study 44
5.2 Collecting the data 44
5.3 Analysis 45

References 46

Appendices 48
Appendix 1: Demographic details of respondents 48
Appendix 2: Dissemination meeting 49
# ACRONYMS AND ABBREVIATIONS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ALHIV</td>
<td>Adolescent living with HIV</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>CBO</td>
<td>Community Based Organisation</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-based Care</td>
</tr>
<tr>
<td>HCP</td>
<td>Health care provider</td>
</tr>
<tr>
<td>IHAA</td>
<td>International HIV/AIDS Alliance</td>
</tr>
<tr>
<td>INGO</td>
<td>International Non-Government Organisation</td>
</tr>
<tr>
<td>LSHTM</td>
<td>London School of Hygiene and Tropical Medicine</td>
</tr>
<tr>
<td>LHIV</td>
<td>Living with HIV</td>
</tr>
<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NAP+</td>
<td>Network of African People living with HIV/AIDS</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
</tr>
<tr>
<td>PLHIV</td>
<td>People Living with HIV</td>
</tr>
<tr>
<td>SAT</td>
<td>Southern African AIDS Trust</td>
</tr>
<tr>
<td>SRH</td>
<td>Sexual and reproductive health</td>
</tr>
<tr>
<td>SSI</td>
<td>Semi-structured interview</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>United Nations Joint Programme on AIDS</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY

I want to know if I can have a boyfriend because every time I ask my mum she tells me not to.
I would also love to learn about safe sex, and safe motherhood (14 year old girl, Lusaka)

RESEARCH SUMMARY AND BACKGROUND

The aims of this qualitative study, carried out in 2010, were twofold. The first was to explore and document psychosocial, sexual and reproductive health (SRH) needs of adolescents (10-19) living with HIV in Zambia. The second aim was to identify gaps between these needs and existing SRH and HIV-related initiatives and services currently available to young people. Funding for the study was through the Alliance Africa Regional Programme (ARP) with financial support from the Swedish development agency (SIDA).

The need for this study arose out of concerns that growing numbers of adolescents living with HIV are not receiving consistent, age-appropriate support from HIV services especially in relation to sexuality, relationships and tailoring lifestyles around their HIV status. In addition, as antiretroviral treatment (ART) is rolled out and access becomes more viable, adolescents living with HIV require increasingly sophisticated interventions to ensure that the benefits of ART are maximised.

It is vital to gather evidence about the experience of young people living with HIV, the nature and quality of services, and the extent to which adolescents and young people access and benefit from these services in Zambia, and elsewhere in southern Africa.

DESCRIPTION OF THE PROJECT

Qualitative data were generated through semi-structured interviews and focus groups with: young people living with HIV (116); Key Informants, including medical and nursing staff and counsellors (38); and parents/guardians (21). Three Zambian regions were selected – Lusaka (urban), Kitwe (urban) and Kalomo (rural). Interviews conducted in health centres and NGO offices.

Adolescents living with HIV were selected on the basis of their age (10-19), and current enrolment in HIV services for treatment and monitoring in the three regions.

An advisory research group supervised data collection, analysis and report writing and dissemination of results, and the local ethics committee at the University of Zambia granted ethical approval.

FINDINGS

Following qualitative, inductive analysis of data, the findings provide a number of insights into the experiences of living as an adolescent living with HIV, the nature and effectiveness of HIV service providers, and the intersection of the two.

A number of themes emerged in the data, including:

- **Immediate social networks:** for ongoing support, close social networks (especially families) have a significant impact on the ability of young people to adhere to treatment, and coming to terms with their HIV diagnosis (positively and negatively).
- **Diagnosis:** being diagnosed with HIV is traumatic, and where parents are also infected there are additional difficulties if disclosure of parents’ and the young person’s status is poorly managed.
• **Impact:** HIV – either directly or by proxy - affects significantly the agency of young people. Choices are affected, and the need to acquiesce more strictly with safe sex and ART adherence potentially creates a more difficult experience of adolescence. Many adolescents however are determined not to let HIV change their lives – and many aspire to marriage and having children.

• **Information:** Young people are often seeking information – they are expectant – and service providers in some instances are clearly unable to meet the informational requirements of young people. Tailored and participatory events addressing informational and social needs are appreciated greatly.

• **Integrated adolescent-friendly services:** HIV support services vary in their capacity to meet the needs of this group. Medical support (i.e. around treatment) is generic, but addressing the social and psychological needs more fragmented. Respondents in the lower age groups have relatively limited insights into some aspects of SRH, and also what support is available. Services that are welcoming, empowering and willing to share specific information about individual needs are highly valued.

**DISCUSSION AND IMPLICATIONS**

The data confirm that for young people, living with HIV amplifies the need for effective support and guidance, and as they move from child to adolescent to adult, there is a range of HIV-related factors impacting on their day-to-day lives. This study identifies key interventions that could improve the effectiveness of HIV service providers, on three levels:

• On the personal level, young people living with HIV must be encouraged and motivated to access local support groups and providers of psychosocial support in their community. Whilst this of course cannot be compulsory, evidence suggests meeting with experts and other affected people can help offset some of the problems around adherence, and lack of people (outside of the family) to discuss some of the more complex aspects of HIV infection.

• On the organizational level, service providers delivering HIV, SRH and psychosocial interventions can play an active role in facilitating earlier testing of children at risk of HIV, and also supporting the process of disclosure – of the child’s own status and of the parents’. There is also potential for greater integration between service providers and parents/guardians, promoting integrated and seamless support. This will help ensure that messages related to HIV and SRH are accurate and consistent. Finally, information cohesion (organisation, family, media, and faith-based) can go a long way in ensuring an end-user (the young person) is not presented with conflicting messages.

• On the level of policy, funding adolescent-friendly HIV and SRH services in both urban and rural settings should be a key priority. Adequate support must be available for clinic-based health care workers and NGOs as they support young people. In many ways this client group is the most complex, subject to rapid social and physical transition, and ongoing assessments must be in place to ensure services meet the need of an adolescent at each point in their development.

*There is no place for us as children to get information. Here [at the clinic] children are scared - even me. I don’t like this place because my mum died here (15 year-old boy, Kalomo)*
1. **INTRODUCTION**

*Adolescence being the difficult age that it is, the teenagers [living with HIV] encounter difficulties of a more personal nature such as self-awareness, defining their identity, building their peer group, making plans for the future, dealing with their sexuality. Generally, taking the step from childhood to adulthood is hard in more ways than one and generates inner conflicts materialized in confusion, identity crisis, stress, etc. From this point of view, they are not different from any other normal teenager* (World Health Organisation 2009, p4)

1.1 **Summary**

This research aimed to explore issues linked to adolescents living with HIV in Southern Africa. It was planned in collaboration with The International HIV/AIDS Alliance (Africa Regional Programme), The Southern African AIDS Trust and The Network of African People living with HIV/AIDS in Zambia. The aim of the study was twofold: to explore and document the current psychosocial and SRH needs of young people and adolescents living with HIV (aged 10 to 19 and living in Zambia); and to elicit and identify gaps between these needs and existing SRH and HIV-related initiatives and services currently available to young people.

The research questions were organised around the need to improve programmatic work and services focusing on adolescents living with HIV. This study is the first phase of two, focusing on three sites in Zambia. A second phase is planned, which will conduct the research in three other Southern African countries (Malawi, Zimbabwe and Mozambique), working in close collaboration with existing networks of PLHIV and local research partners.

The research provides an evidence-based approach to influence current programming strategies and local/international policies, and will involve some capacity strengthening for regional partners.

1.2 **Background and Rationale**

Three decades into the HIV epidemic, children and young people remain among the worst affected, yet all too often at the periphery of the world’s response (UNICEF 2009). Adolescents\(^1\) living with HIV, whether they have been exposed to HIV perinatally, during infancy or youth, face serious challenges that make transition to adult care particularly difficult. Many of the children currently in early adolescence were diagnosed to have HIV before effective treatment was available and initially were not expected to survive beyond early childhood. Health systems and HIV service providers have yet to improve and adapt their services in light of the growing number of young people living with HIV. In Zambia for instance, many young adults (up to 20 years old) living with HIV continue to be treated within paediatric services which are not adapted to the transitional needs between childhood and adulthood, and which consequently do not address adequately these adolescents’ needs around SRH, safer sex practices and contraception methods.

In the lives of young people, HIV is a complex phenomenon, affecting the development of their sexual identity and reproductive health in very specific ways. Difficulties in accessing SRH and HIV health services tailored to meet the needs of adolescents often results in marginalisation of this group, who are frequently ending up being treated in either paediatric or adult services. It is estimated that among low and middle-income countries as many as 60 per cent of all adolescent

---

\(^1\) Defined here within the 10-19 age group (see section 1.4)
pregnancies and births are unintended (Onifade 1999), and the presence of an STI leads to a decline in health and an increase in the likelihood of HIV transmission and re-infection for these adolescents.

As anti-retroviral therapy (ART) becomes increasingly available, young people living with HIV need tailored support to adopt healthy sexual behaviours. The current psychosocial and SRH support provided by existing formal health providers does not fully recognise the complexity of the issues faced by young people. Good, comprehensive HIV care includes not only the prescribing of antiretroviral treatment, but also must include general healthcare, ongoing psychosocial support and counselling, care for other STIs, gynaecologic care and family planning (Zeichner & Read 2005).

According to a framework that has been used to assess the extent to which countries respond to the SRH needs of their youth, one important factor is also the accessibility of services and prescription contraceptives (Hock-Long, Herceg-Baron et al. 2003). Adolescents living with HIV require intense counselling relating to their reproductive health including their desire for pregnancy, contraceptive practice, and decisions and choices if an unintended pregnancy occurs (Zeichner & Read 2005). Furthermore, a growing set of evidence indicates that local support networks of PLHIV (both formal and informal) have the potential to provide young people and adolescents with more suitable and effective options in terms of SRH and HIV services, in contexts in which the formal health system does not offer an adequate response to those needs.

1.3 Literature review

Comprehensive services for adolescents living with HIV in low-income settings are underdeveloped, as paediatric and adult services remain ill equipped to deal with the complex needs of this group. Improved effectiveness and availability of ART has contributed to increased numbers of infected children reaching adolescence (Bakeera-Kitaka, Nabukeera-Barungi et al. 2008; Birungi, Obare et al. 2009), and nearly half of new transmissions worldwide occur among young people aged 10 to 24 – many of whom are unaware of their HIV status (MacPhail, Pettifor et al. 2008). Therefore, in addition to supporting long-term survivors of HIV, there is a need to reduce barriers to testing and provide comprehensive support for those that test positive. Adolescents living with HIV require support in issues related to disclosure, social integration, sexuality, treatment adherence, and mental wellbeing. A review of the literature on adolescents living with HIV revealed that sexual and reproductive health (SRH) and psychosocial support were areas most neglected by services for this group. These findings were based on 34 academic articles and 11 reports that were derived from a literature search utilising five databases.

In terms of psychosocial support, the literature highlights the need for high quality, ongoing counselling in order to: help young people accept a seropositive diagnosis; aid in disclosure to family, friends and sexual partners; provide support for mental health issues, such as depression, anxiety, and suicidal ideations; and offer support regarding issues related to stigma and discrimination (Strydom & Raath 2005; Wright, Lubben et al. 2007; MacPhail, Pettifor et al. 2008; Mayekiso 2008).

Existing counselling services are often poor, and ongoing counselling is not frequently offered as part of VCT (MacPhail, Pettifor et al. 2008). One study on the attitudes of South African youth to VCT found that the absence of ongoing support acted as a barrier to testing, since not knowing one’s status was perceived to be better than having to bear the burden of one’s seropositivity alone (MacPhail, Pettifor et al. 2008). This attitude was linked to a fear that an HIV positive diagnosis would compel one to commit suicide, an issue that was also flagged in a Malawian study of the link between HIV and mental health (Wright, Lubben et al. 2007). Counselling could help in this regard,
by helping adolescents come to terms with their diagnosis and provide ongoing support. A number of studies noted that disclosing to sexual partners was rare, and that despite its challenges disclosing to family and friends was much more common (Ayres, Paiva et al. 2006; Bakeera-Kitaka, Nabukeera-Barungi et al. 2008; Birungi, Obare et al. 2009; Ezekiel, Talle et al. 2009). Adolescents living with HIV require ongoing support to develop skills and strategies for disclosing to sexual partners.

Adolescents that are long-term survivors of HIV may have particular needs associated with what it means to be an adolescent living with HIV compared to a child living with HIV. These issues may be related to the timing of having their HIV status disclosed to them by a parent or caregiver, and feelings of confusion and mistrust that may emanate from situations where there has been a lack of open communication about HIV (Abadia-Barrero & Larusso 2006). A study of children living in institutionalised care found that adolescents showed a poor understanding of the implications of HIV for their lives and displayed cynicism regarding treatment adherence and risks to their health (Abadia-Barrero & Larusso 2006).

According to Dago-Akribi and Adjoua (2004) adolescents need to understand their treatment, have the opportunity to discuss the difficulties of adherence, and be offered encouragement and support. As adolescents negotiate the transition from childhood to adulthood, they may require additional support in order to confront issues related to stigma and discrimination, anxieties about the future, and depression (Ayres, Paiva et al. 2006).

The SRH needs of adolescents living with HIV are largely unmet, resulting in widespread misconceptions and misinformation regarding fundamental aspects of prevention and reproductive life (Ayres, Paiva et al. 2006; Birungi, Obare et al. 2009). There is a prevailing assumption that adolescents living with HIV should abstain from sex and relationships; however, a Ugandan study found that many of these adolescents are sexually active or desire to be in a relationship but employ poor preventive practices (Birungi, Obare et al. 2009). Secondary prevention should be a priority with this group; adolescents should be provided with clear and accurate information about HIV transmission, viral load, HIV re-infection and STIs, and should be supported in developing skills to negotiate disclosure and consistent condom use. Another Ugandan study investigating the sexual risk reduction needs of adolescents living with HIV found that ‘adolescents’ motivation for protection was identified on a continuum between hope and fear’ (Bakeera-Kitaka, Nabukeera-Barungi et al. 2008). These adolescents expressed a fear of pregnancy, re-infection and infertility, and a desire to procreate in the future. The aspiration to have a future family was mentioned in the literature as a source of hope for adolescents living with HIV (Ayres, Paiva et al. 2006; Bakeera-Kitaka, Nabukeera-Barungi et al. 2008; Birungi, Obare et al. 2009). These hopes and fears draw attention to the importance of both sexual health and family planning support for this group.

Given the complex process of sexual identity building in adolescence, young people living with HIV require support in dealing with their sexual development and sexual feelings (Dago-Akribi & Adjoua 2004; Birungi, Obare et al. 2009). For this reason, SRH should be provided in conjunction with psychosocial support. A Brazilian study of children and adolescents living in institutionalised care indicated that a lack of support renders adolescents prone to sexual risk-taking behaviours, as these adolescents may exhibit a poor understanding of HIV and its implications on their lives and pessimism about their future (Abadia-Barrero & Larusso 2006). Therefore, adolescents living with HIV require tailored and ongoing support to adopt healthy sexual behaviours.
Overall, services for young people living with HIV – often uncomfortably situated in either paediatric or adult facilities – need to become better equipped to deal with the specific needs of adolescents. For example, there is a need for VCT facilities to become more youth-friendly, as negative perceptions of VCT can act as a barrier to testing (MacPhail, Pettifor et al. 2008). In a context where VCT is the gateway to the long-term management and treatment of HIV (MacPhail, Pettifor et al. 2008, p ), it is important to reduce barriers to early diagnosis and treatment by addressing adolescent concerns regarding confidentiality, negative attitudes of health staff, and poor quality counselling services (Langhaug, Cowan et al. 2003; Rassjo, Darj et al. 2007; MacPhail, Pettifor et al. 2008; Matthews, Hellard et al. 2009). Furthermore, there is a need to develop innovative VCT strategies that strengthen familial and peer networks before and after VCT, and that link young people back into their families and communities and into treatment and care (Denison, McCauley et al. 2008). Referral networks should also be put in place to enable access to psychosocial support, legal assistance, and HIV treatment and care (MacPhail, Pettifor et al. 2008).

1.4 Working definitions

Adolescence

Adolescence is the transitional period between childhood and adulthood. It begins with the biological changes associated with puberty and proceeds through a process of psychosocial changes. Each aspect of maturation does not develop at the same rate. We will use the World Health Organisation (WHO) definition of adolescents as children and young people between the ages of 10-19 years.

Sexual and Reproductive Health (SRH)

Sexual and reproductive health relates to and includes family planning, maternal and newborn health, the prevention of STIs, the promotion of sexual health, the prevention and management of gender-based violence, the prevention of unsafe abortion, and post-abortion care².

The relationships between HIV and sexual and reproductive health are well recognized. The overwhelming majority of HIV infections are sexually transmitted or associated with pregnancy, childbirth and breastfeeding. Underlying social and economic factors such as poverty and gender inequality contribute to both HIV transmission and poor sexual and reproductive health. By linking initiatives for sexual and reproductive health and HIV multiplies opportunities for preventing and treating sexually transmitted infections including HIV, providing family planning and maternal and child health services, and providing treatment and care for PLHIV.

Research Partnerships

This research was developed jointly by Alliance Zambia, the International HIV/AIDS Alliance secretariat, the Southern African AIDS Trust and the Network of African People living with HIV.

We established a number of research partnerships to conduct this project. In Zambia (Phase I of the study), a partnership was established between the Alliance Zambia, SAT Zambia and NZP+ (the Network of Zambian people living with HIV). The study also benefits from existing links between the Alliance and the Evidence for Action Research Programme Consortium, an international research partnership led by London School of Hygiene and Tropical Medicine (LSHTM), and working with

---

² Rapid Assessments Tool: SRH and HIV Linkages (IPPF,UNFPA,WHO,UNAIDS,GNP+,ICW and Young Positives)
Southern African research institutions (in Zambia, Malawi, South Africa). A core research group was established amongst these partners in order to coordinate and conduct the research.

In addition, an advisory research group was established in Zambia to include a range of other local institutions and organizations in the development of the study. The advisory group has representation from the Network of Zambian People living with HIV, the University Teaching Hospital, the National AIDS Council, the Ministry of Health, the Ministry of Sport, youth and Child Development, the National Youth Forum, the Zambia TB related AIDS Project (ZAMBART), International HIV/AIDS Alliance and the Southern African AIDS Trust (SAT).

Capacity strengthening was provided to partners, through training in research proposal development, qualitative and quantitative research methods, data analysis, and training in communication and writing skills to disseminate and present research results. There was also an opportunity for colleagues preparing for the second phase of the project to attend the dissemination event for this study (see Appendix 2, page 49).
2. STUDY OBJECTIVES AND DESIGN

2.1 Aim, objectives and research questions

The aims of this qualitative study, carried out in 2010, were twofold. The first was to explore and document psychosocial, sexual and reproductive health (SRH) needs of adolescents (10-19) living with HIV in Zambia. The second aim was to identify gaps between these needs and existing SRH and HIV-related initiatives and services currently available to young people. Funding for the study was through the Alliance Africa. This would provide evidence to inform and support policy and service development.

Objectives

The specific objectives of the study were:

- To explore and document the current psychosocial and SRH needs of a representative sample of adolescents living with HIV
- To understand the impact of accessing ART and SRH/HIV related services on the formation of sexualities and SRH needs of adolescents.
- To understand the relation between these needs and the availability, perception and quality of services, and to further understand how these services and interventions cope with a growing number of adolescents – more specifically in the areas of SRH, family planning and contraception, positive prevention, and safer sex practices.
- To provide an evidence-based approach to understand the needs of adolescents and how these needs can be addressed

Research questions

Research questions formulated for the study fall broadly into two areas: the needs and challenges of adolescents living with HIV, and the availability and suitability of services.

Needs and challenges of adolescents living with HIV

a. Needs assessment of adolescents living with HIV
   - What are the specific needs of adolescents living with HIV with regards to SRH services?
   - What are the daily ‘challenges’ identified by adolescents in relation to accessing information, SRH, care and treatment services?
   - What resources do adolescents use to gain information about living with HIV, contraception and SRH?

b. Knowledge and attitudes towards existing SRH and HIV-related services
   - What knowledge do adolescents have of where to seek help, attend services and get advice on safer sex behaviours or treatment adherence?
   - What is the nature of the relationships between adolescents and the services they have access to? How do they judge these services and what kind of interactions do they have with the staff?
   - How do adolescents articulate their experiences of accessing SRH services? Do they feel entitled to (more) services and support (including safer sex advice, mentorship, and disclosure support)?
   - How do adolescents perceive their personal access to HIV related services?

c. Impact of SRH services
   - How do current SRH activities impact on adolescents living with HIV?
     - How do ART and other treatment regimens impact on the adolescents’ personal development and on forming sexualities?
Availability and suitability of services

b. Assessment of existing services
- What are the current services and interventions available to these adolescents in three different sites (two urban and one rural) in Zambia?
- What efforts are currently in place to provide adolescents-friendly services (facility based and ‘community’ interventions)?
- How are services and interventions (facility based and ‘community’ interventions) taking into account the specific needs of these adolescents?
- What minimum standards and local/national policies exist in each setting for HIV-related services working with adolescents living with HIV?

c. Barriers and Challenges to providing SRH and HIV-related services to adolescents
- What challenges exist for service providers who are aiming to work with adolescents?
- Are there services that exist but are not adapted or not accessed and why?

d. Impact of interventions and policies
- How are we to modify policy, programmes, and efforts at health interventions so as to improve the linkages between needs of adolescents and the availability of suitable services and interventions adapted to young people?

2.2 Study Design

Study Sites
Three study sites were selected in Zambia on the basis of the presence of ART centres in which some adolescents are currently enrolled, and through the partnership between Alliance Zambia and SAT Zambia. It was felt that in order to insure a broad representation of the circumstances of adolescents living in different contexts, these sites should be selected across urban and rural areas, and amongst different districts and provinces of Zambia. Consequently, we identified three sites where adolescents are currently enrolled in HIV and SRH-related services and interventions: Kalomo, Kitwe and Lusaka districts as shown below:

Figure 1: Regions chosen for data collection
Kalomo Site
Kalomo is a rural district situated in the Southern Province, approximately 360km from Lusaka. Adolescents in Kalomo were recruited through the Kalomo district Hospital and a number of interventions conducted by NGOs and CBOs currently working with Alliance Zambia (Kalomo Mumuni Centre, Kalomo Interdenominational Youth Christian Fellowship, Let’s Build Together, Sikwazwa).

Kitwe Site
Kitwe is located in the Copperbelt province, 365km from Lusaka. Adolescents were identified through two clinics (Luangwa and Mopani Clinics), and through the Twafwane Christian Community Centre (SAT partner), a CBO focused on home-based care and also working with adolescents.

Lusaka Site
In Lusaka, the study identified adolescents through the paediatric ward at University Teaching Hospital (UTH), where a number are currently accessing HIV related services and ART. We will also identify some adolescents through the work of Face-to-Face Foundation (SAT partner) and through the Ng’Ombe Home Based Care CBO (Alliance Zambia partner).

2.3 Data Collection
The research design is cross-sectional and observational, drawing mainly on a qualitative approach through a number of methods such as semi-structured interviews, focus groups and personal narratives.

Semi-structured interviews were conducted in each of the three sites of the study. Potential respondents living with HIV were identified through their access to ART treatments and/or specific NGO and CBOs. Interview guides were adapted to ensure questions matched the age group of adolescents, and broadly organised around key themes. These included: personal circumstances of adolescents; their needs in terms of support for issues linked to HIV and SRH; their knowledge and
attitudes towards existing services and interventions; and an assessment of the impact that current activities have on the development of their sexualities and SRH needs.

Interviews were recorded and transcribed. The research team also collected relatively small number of life histories and narratives to capture individual experiences in a less structured way and to allow for the emergence of new categories of data in relation to personal circumstances over a longer period of time.

Interviews were conducted with a range of Key Informants. These include service providers for SRH activities and health professionals who work closely with adolescents living with HIV. These interviews included questions around:

- Their assessment of the suitability of current services in relation to what they perceive as the needs of adolescents
- Any current barriers or challenges to providing SRH and HIV services and interventions which are adapted for adolescents living with HIV
- The type of policies and interventions that may be useful to put in place to provide SRH and HIV ‘adolescents friendly’ services

A small number of focus groups were conducted in each setting with adolescents living with HIV (gendered focus groups), their parents or guardians, and SRH and HIV service providers. Focus groups were limited in number, allowing us to identify and explore issues relating to potential gaps between the needs of adolescents living with HIV and the services and interventions that are currently available to them.

Finally, researchers conducted observations throughout the course of data collection. These included confidential field notes focusing on their experiences in interacting with the various research participants, and on the nature of relationships and social interactions on the ground (e.g. between adolescents themselves, with their parents or guardians, and between adolescents and health providers). These observations feed into the analysis, providing first hand observations of the different types of social interactions between adolescents, service providers and other actors related to SRH activities.

Recruitment

Research participants were selected in each site at the onset of the study for the qualitative data collection. In order to ensure that we represent the experience of a wider range of young people in Zambia, half of the adolescents will be identified through their existing relations with the work of NGOs, CBOs, and networks of PLHIV, whilst the other half will be identified through local treatment centres (i.e. local clinics or ART centres). Adolescents were also contacted via CBOs, NGOs and ART centres will be asked if they would like to be part of the study and will be explained the aim as well as procedure of data collection. CBOs, NGOs and ART centres selected participants based on the inclusion criteria for adolescents.

The needs of young people vary according to age, sex, class, religion and culture, urban or rural residence and whether they are in school or out of school, married or unmarried, sexually active or

---

3 See full details of respondents in Appendix 1, page 48
4 A follow up knowledge, attitudes and practices (KAP) survey is planned, to identify further issues for inclusion in further studies
not (Onifade 1999). Likewise, programmes designed to meet diverse needs are clearly shaped by social and economic factors and we will attempt to capture and reflect as much as possible the range of experiences of these local realities. For this reason, we selected and interviewed adolescents in two age groups: 10-14, and 15-19. We sought as far as possible a gender balance for the collection of data, and adolescents from a range of backgrounds within a given area, so as to cover various socio-demographic characteristics (e.g. adolescents in and out of school, some supported by household and others living on their own, male and female, and ranging from age 10 to 19).

**Inclusion Criteria**

- Adolescents between 10 and 19 years old
- Living with HIV
- Fully aware they are living with HIV
- Gender (study includes male and female respondents)
- Willingness to participate
- Parental or guardian approval granted
- Adolescents are linked to an ART centre or an NGO/CBO (i.e. accessing HIV and SRH related treatment and services)

**Exclusion Criteria**

- Adolescents who are not aware of their HIV status
- Individuals who have not disclosed to their families and household members
- Adolescents currently experiencing emotional distress, mental illness
- Reluctance or refusal to be involved in the study or refusal from parent/guardian

Other research participants include a small number of parents or guardians of adolescents, as well as health workers who work closely with adolescents in each study site. We adopted a convenience sampling approach in order to identify and recruit those who will be participating in focus groups and interviews.

**Description of respondents’ context**

Respondents selected for this study include:

- Adolescents living with HIV (n=116 – including interviews and focus groups)
- Key Informants, including medical and nursing staff, and counsellors (n=38)
- Parents/guardians (n=21)

The majority of interviewed respondents living with HIV (n=58) claimed not to be in current relationships. Those who were in relationships stated they were not sexual, though a very small number of those in their late teens were in permanent relationships or married, and already had children (n=6). With these respondents, it is likely they were infected during their earlier teenage sexual encounters. For younger respondents, more likely to have been infected from birth, they often were unable to state when they found out they were HIV positive, or how they had become infected. Rarely (n=2), the narrative of respondents suggests that sexual partner does not know their status.

Of the 58 interviewees, a significant number of respondents (n=28) are considering having children at some time in the future. In this group, insights into family planning and reproductive health ranges from very limited to highly informed. Younger adolescents tended to have limited knowledge, claiming not to understand the terminology.
2.4 Ethics
This study, given its sensitive topic, and participant age, was especially cognisant of the need to protect adolescents living with HIV, and their families. The usual consideration for privacy, confidentiality and sensitivity were especially robust in this study. Training was provided on the collection of sensitive data, and child protection, for all investigators and research assistants throughout the project, and the core research and advisory groups were involved throughout to ensure the study was conducted in accordance with current policy and guidelines. Each research collaborator signed that they understood, and would abide by, the Code of Conduct on Child Protection. All participant information containing names and other personal identifiers was stored securely, and anonymised where possible.

The research proposal was granted ethical approval by the local ethics committee at the University of Zambia (UNZA), the Research Steering Committee of the International HIV/AIDS Alliance, and the institutions and organisations involved in the study (i.e. research partners and study sites).

In order to ensure appropriate and ethical informed consent, information sheets were provided for the parents/guardians of potential respondents, and after a suitable time for consideration (including discussion with the adolescent) a form for assent was signed by the parent/guardian allowing the participant to be recruited to the study.

Participant Reimbursement
Participants were not paid to take part in the study, though where appropriate a small gratuity for travel and a meal was available.

2.5 Study limitations
This study is essentially qualitative in nature, based on text-based data. Though the findings do include a consideration of available services, the data are based on methods that gather the perceptions of respondents, and as such cannot be generalised beyond people included in this study. This provides a rich insight into the lived experiences of respondents, and it is intended that further survey-based data gathered at the end of the interview/focus group cycle (not included in this report) will provide a more quantitative perspective.

Second, this design provides a snapshot of perceptions, at a given time. A more longitudinal approach, ideally following the introduction of specific (improved) interventions, which is able to track developments and impact over time, would provide a more detailed picture of how services are able to meet the needs of adolescents. For example, tracking the benefit of SRH information provided for a 12-year-old girl, and then monitoring the nature of her experiences, sexuality and reproductive health to age 19.

Third, the respondents for this study were recruited because they already access services (so, are aware of their HIV status). They have therefore already entered the health system. There are inevitably those who are unaware of their status, and may not benefit from the more specialised education and support available to respondents in this study (albeit of varying quality). What is their experience?
Lastly, in certain areas (Lusaka in particular) there are more female than male respondents. Whilst overall the division was close to equal, in Lusaka findings are skewed due to gender imbalance.
3. FINDINGS AND ANALYSIS

Data were analysed using NVIVO software to sort, code and categorise the qualitative data – a vital tool for processing large amounts of qualitative materials (Bazely 2007). In preparation for the analysis, the key research questions were reviewed and initial codes inserted into NVIVO. Data were initially allocated broad-based themes corresponding to the aims of the study, and then re-visited inductively (using analytic induction, as discussed by Silverman 2001), to reveal additional elements.

A number of key themes emerge from the analysis, broadly referring to the initial research questions, but also generating a variety of further stable categories, giving insights into the nature of living with HIV as a young person, and of support provision.

The findings section below provides details of the analysis within the domain of two essential groups: ‘being’ - the experience of living with HIV as a young person (including knowledge, treatment, relationships, sexuality and the impact of HIV on the daily life); and the effectiveness of services (including information and support).

3.1 The psychosocial and SRH needs of an adolescent LHIV

Living with HIV presents a range of psychosocial challenges for young people as they transition through adolescence, and face issues around sexuality and reproductive health. ‘Growing up’ is clearly a vital part of adolescence, and young people are experience major physical, emotional and social changes. HIV is yet another factor threatening to impact on their lives as they move through the process of disengagement with the family and engagement with the ‘world’ of adults. Being HIV positive means this process is skewed, and as a result HIV could be yet another controlling mechanism. There is also the growing impact of sexuality:

*The feeling of suddenly going for boys, I never had that feeling before so when I started experiencing those emotions it was very confusing (Lusaka, FGD, PLHIV)*

HIV and SRH services are in place for a number of reasons, and problems in this context often have the same root causes, such as limited access to information, gender inequality, and social marginalisation. They also share many of the same aims: learning about one’s HIV (or other) status, and promoting safer sex with reproductive choice. Integration of these services and optimising their commonalities is a key aim within public health, and if effective they can be central in providing HIV testing and treatment, disseminating accurate and current information on issues around living day to day with HIV, and ensuring that sexualities are negotiated successfully.

The data reveal a number of themes providing a rich insight into some of the difficulties faced by this group, including:

- The need for **effective and meaningful relationships** – these feature throughout the respondents comments, and for adolescents having no one to talk with, or problems with boy/girl friends, making friends at the ART clinic, are all significant to the person’s day-to-day lives
- The challenges of **treatment**, ensuring appropriate adherence for viral suppression
- Issues around **living the life of a young person with HIV**, such as emotional needs (supporting an adolescent affectively as he/she negotiates adolescence), including stigma and self stigma
(‘reputation’), and living in a society which ‘is not agreeable to talking about sexual issues with their children’

- Generally, issues around agency underpin many of their experiences – how much influence does an adolescent living with HIV have on their immediate physical and social space, and destiny?

3.1.1 Relationships

*My family is the only support I have – when I am down I talk to my mum and sister: I don’t talk to anyone about how I am feeling – I keep it to myself (10 year old girl, Lusaka)*

**Family**

The discussions reveal beneficial and supportive, but also fractured and fragmented family structures. The majority of respondents are orphans, having lost one or both parents, and being cared for by other members of the extended family. Many are also living in large family groups, and the phenomenon of multiple caregivers is, as perceived by service providers, a significant threat to unified and consistent support. For the adolescents, instances where they have sought support from aunts and grandparents suggest relatives who are not parents are able to provide input. There is also evidence of problematic relationships with family members – either through parents being too close, or relatives’ lack of empathy leading to non-consensual disclosure, or inappropriate guidance on relationships and sexual safety.

For many respondents their parents, or a close relative, are the first point of contact for support and guidance in times of particular need. There is evidence of less effective relationships between young people and their parents/guardians, for whilst the family can clearly be a positive influence on the life of a young person living with HIV, respondents describes a number of instances where the family has been less than helpful. These circumstances include delaying information about an HIV diagnosis, providing flawed information, or (in one case) a mother complaining to a school about providing sex education. Delaying information about diagnosis is also linked to another phenomenon, where parents refuse to disclose their own status, and young people (on learning that HIV is spread through sex) become confused (they are not sexually active). In these circumstances there is perplexity – reducing agency and heightening anxiety.

Relationship with parents and significant others, as revealed in this study is comprised of a number of factors. Fears of disclosure from parent to child are indicated, and when a child is receiving drugs for a diagnosis he/she is unaware of, service providers are limited in what information they can provide for the child:

*I started suspecting that I was very sick in 2006 when I had meningitis. My mother never really told me that I had the HIV virus. I always used to wonder what was wrong with me because I was always getting sick and becoming very thin. Only me, my mum and dad always take medicine but my young sister does not, so this always puzzled me. So my mother finally explained to me that I am sick in 2009 and that is why I always feel sick and have to take medicine everyday (14 year old girl, Lusaka)*

**Problems in the family**

Problems within the family are not only focused around disclosure of the adults’ status or discussions on sexuality. Fractured family structures pose additional threats, and for one health care
provider, “one of the main problems is that most of these children are orphans; they live with
aunty’s, uncles or grandparents, so for them access to information is difficult because they are not
free with these people”. This respondent (18 year old boy) describes the situation for him:

“I’m living with my brothers; when dad and his 1st wife divorced, he married my mum. She
died when I was 3, so I was with my dad, and then he got married again and I was living with
my step mum. He died 2004, when I was in grade seven and I was writing my exams then.

According to Key Informants, multiple carers mean that a child may not have a “fixed, stable home”,
and constantly moving distorts the consistency of information, because “not all of those relatives
had genuine concern for the child”.

Parents sometimes try to restrict the lives of children they have told about their diagnosis:

“I am scared of having a boyfriend because my mum has told me not to have a boyfriend. She
says it is bad for someone in my condition (14 year old girl, Lusaka)

Friendships and relationships
These are central to the lives of adolescents – many respondents describe the different
circumstances they face; some are able to maintain ‘normal’ relationships, and have many friends
both at school and around their home. Others are less connected, with one commenting that she
feels “isolated”, and having “no one to talk to” (14 year old female). For many adolescents, there is
sadness that they cannot attend school – and linked to their desire for information, missing school
for any reason is seen as a thing to avoid if possible.

Having friends to talk to is an important benefit, where this is available: “Talking to my best friend
about it helps a lot” (11 year old girl, Kitwe).

Impact of HIV on relationships
The impact of HIV on relationships can be significant for some: “being in a relationship when you
have HIV is difficult”. For one respondent looking towards the future, “it won’t be easy to get
married to someone who is negative – [it is possible] only if the person accepts you, and that’s not
so easy nowadays” (male, 19 years old). The permanence of an HIV status does weigh on
adolescents’ minds:

“It means you are HIV positive for the rest of your life, and you should take care of yourself. As
in a relationship you would have to be with the same person for the rest of your life (16 year
old girl, Kitwe)

There is also fear that they will experience loss if they disclose:

“I have a boyfriend at the moment but it is not a sexual relationship. He does not know about
my status. I am scared of telling him because he might leave me (19 year old female, Lusaka)

Respondents do comment on the extra stress of being HIV positive and in a relationship. Conversely,
many of the younger respondents comment that having HIV will not impact overall on their
relationship with a boy/girlfriend – in the sense that they still expect to have such relationships at
some time. Most respondents claim they are not currently in relationships, indicating that their
anticipation of the impact of HIV is based on anticipation: when they do begin to ‘date’ potential sexual partners, their willingness to disclose could lessen.

3.1.2 Treatment

Since I started taking my medicine my health has improved tremendously. I am no longer weak; I do not get any opportunistic infections (19 year old female)

The majority of young people interviewed receive ART, and they are quick to acknowledge that the treatment is life saving, keeping the virus at bay. For younger respondents, being on treatment improves health to the extent they are able to return to school. Many of the needs of an adolescent, whether they are HIV infected or not, are generic, but the experience of living with HIV brings a range of additional stresses on a young person, and the impact of ART can be significant, altering relationships. For example: ‘I cannot hang out with my friends because I have to be home by six to take my medicine’ (18 year old female), or because of side effects: “I started taking my ART last week and I am still finding it difficult, especially swallowing the pills: I actually throw up”.

Support from the family

Supporting adolescents in taking their ART falls to family members or guardians outside of the clinic – and indeed this is what Key Informants consider one of the most effective ways of guaranteeing young person maintains adherence.

Effective relationships with adults are crucial to ensure that they are able to prompt and remind the respondents to take ART: “my mother always encourages me to take my medicine” (19 year old girl). When a respondent is not in a support group, the role of the family is especially significant for the young person, especially if they are sick. This is not always a parent, but could be an aunt or a grandparent.

Dealing with a daily regime requiring careful adherence is for most respondents something they are used to, though not without some difficult times, due to side effects. One – not typical, though worth noting here – simply threw away his treatment, refusing to conform to advice about taking the medication, returning only when his symptoms became severe.

3.1.3 Knowledge of sexual and reproductive health, family planning and HIV

At what age should we start talking about these things with our children? I feel yes we should talk with them but when do we start? (FGD, parents, Lusaka)

Knowledge – defined as the state or act of knowing – indicates that information has been processed. Information, for the purposes of this discussion, is the ‘package’ of facts transmitted between two parties. Levels of awareness and understanding amongst respondents do vary. Some deny any knowledge of issues beyond a basic understanding of HIV – though this response is more usual in younger respondents. The majority are aware of essential details, such as the need for condoms to protect against HIV, but a number lack more sophisticated insights into the nature of reproductive health and family planning. Some suggest it is “not yet time” to have such information.

Sources of information

Respondents describe a range of information sources, and a valuable method of providing support and information is through peer educators. Peer education is a valid and valuable way to maximise
on affected people engaging with others empathetically, and in this study the role of peer educators in schools and organisations is confirmed as providing a vital and valued resource. For this respondent – not receiving peer support – this could be a potentially vital source of information, for:

> It is not ok for me [to talk about sex and sexuality] because I feel shy to meet old people and talk about issues like sex with them (12 year old male, Kalomo)

Other general sources of information on HIV and reproductive health for participants include: school; clinic – usually around written literature (including details of services that are available); local agencies; friends; TV and radio; newspapers. Generally, respondents are aware of how HIV spreads; their knowledge of prevention of re-infection suggests an awareness of how condoms prevent HIV transmission. However, insights into more sophisticated matters, such as general sexual health and family planning, is more varied. The main sources of this information are the clinic, peer education events, or schools. Younger children tend to have vague – or no – ideas about family planning, and for older children some deny any knowledge, and others confirm it includes issues around child spacing, and preventing unwanted pregnancies (methods of contraception). A number of respondents claim not to know about family planning, and some responses suggest the concept of family planning may be ambiguous:

> Family planning is about how to sweep, clean plates and the surrounding area (11 year old male, Kitwe)

Data also suggest that awareness and understanding of family planning may be gender related – many of the male respondents have less insight than female respondents, who typically have a better level of knowledge, certainly around the child spacing, and the need to protect children from HIV infection.

**CASE STUDIES: Peer support**

Peer support groups are a valuable resource for information, and for respondents describing their experiences, comments suggest in this context their value for informing and educating is high. Here, a 19 year old (male) describes information on family planning received from one peer education group:

> In family planning there are traditional and modern methods. In modern methods we have the pill, intrauterine devices, injectables, male condom, female condom, and traditional methods include periodic abstinence and withdrawal.

To contrast, a younger (10 year old) respondent who attends no groups, and talks only to her ‘aunty’ describes her frustration at not being able to access information:

> I have tried to ask them for information but they will not give it to me. I do not know if I want to have children, and I do not have any information about family planning because I do not know what this is.

Whilst this is perhaps an age-related distinction, it raises a question about how and when information should be provided – and at age 14 this female respondent also confirms the value of peer support groups:
At hospital we have a peer support group – it involves children who are around my age and are living positively. We talk about our experiences about living with HIV, and the support we have been getting. Also, they give us information about HIV.

**CASE STUDY: Coping alone**

Rarely amongst responses however, there are clear indications of risk: for one 19 year old participant living in Lusaka, she has not disclosed to her partner (with whom she has already one child), and also is unwilling or unable to access support services. She takes oral contraceptives but appears not to use condoms. This particularly sad case suggests that high-risk participants are clearly not ‘reached’ appropriately – information may be available, but using that information in practice is limited. Her agency is restricted and she is mostly alone:

> I do not get any support in terms of counselling or support groups. The only time I was ever offered counselling was when I found out about my status [2 years before]. Otherwise there is no one who really offers me support. The only family that I have is my grandmother and she is not always there so I’m by myself most of the time (19 year old female, living in Lusaka)

Regarding specific knowledge about the transmission of HIV, as mentioned above there is general understanding about how HIV is transmitted – and avoiding re-infection is (for girls) by “not sleeping with boys”), or “abstaining from sex”, and use of condoms. There was concern from healthcare providers that those children not attending school miss out on vital informational support, and here a respondent confirms this:

> There is this programme in the school that teaches us about being safe. [This] should not only be in school but in the community; they should increase those people to come and sensitize us, because most of the people really don’t know about the services here. (16-year-old girl, Kitwe)

### 3.1.4 Living the life of a young person with HIV

Right now I am feeling fine but yesterday I was not feeling so well. Every day is different. Sometimes I wake up feeling fine, and other days I am not so fine. I usually experience a lot of body pains. My health does not usually affect my day-to-day activities, only when I am very sick that is when I don’t do what I normally do (14 year old girl, Lusaka)

> My illness does not stop me from leading a normal life, apart from when I feel very sick. That is when I am not able to do most things. (19 year old female, Lusaka)

Living with HIV for this group is a central theme of the research, and a range of responses illustrate the complex factors facing this group:

- Disclosing status to boy/girlfriend: “I am scared of telling him because he might leave me” says one 19 year-old girl
- Restricted growth due to HIV – “I thought everyone who looked at me knows my status...for this reason I even stopped going to school”
Being diagnosed with HIV

Initial diagnosis and its impact are understandably traumatic in a young person’s life. Respondents describe a range of situations where and how they discover their HIV status – in some cases they were tested almost by default when accompanying another family member to an HIV test. Their responses – fear, depression, seeking a cause – were often determined by the nature of the initial diagnosis and availability of immediate and subsequent counselling.

Reactions from respondents are tinged with trauma and sadness: “when I had my first counselling session it was devastating” (FGD, PLHIV). Another was “really depressed”, and for a 19 year old girl, she “cried and cried”. The data also include references to suicidal thoughts. Asked how HIV affects one respondent, she states:

In most cases I feel sad about myself...I feel lack of confidence and sometime I even feel like, I can just feel like I can just kill myself to get rid of all this. (16-year-old girl, Kitwe)

How young people discover their status arises in a number of ways. Some are tested because a sibling or parent is also infected. Not knowing, but realising others did know (usually parents) is especially difficult for some: “the fact my family kept this from me made me feel very sad”, leading to difficult family relationships – “during this period I hated my mother” (who by this time had died of an AIDS-related illness). For one 16 year old, lack of counselling support after her diagnosis led to her “not having anyone to talk to and explain the way (she) was feeling”. And here, a 14-year-old girl describes her difficulty in finding out about her diagnosis:

I discovered I was HIV positive in 2008 – I was 12 years old. My father told me I had the virus; my mother did not to tell me – every time I asked her what was wrong with me she would not tell me. When I found out about my status I was shocked and felt very sad. (14 year old girl, Lusaka)

Prior preparation through generating a broad understanding of HIV in the home can help – for an 18 year old respondent, he and his uncle had been talking about HIV for a while, so when he was eventually tested he “stopped getting scared”.

CASE STUDY: Discovery

This narrative provides insights into the impact of diagnosis, where there are a number of actors, and how the manner of disclosing to the adolescent affects the overall process:

By then I was sick. My dad had already been on ART some months, and then he told me that he would end this sickness once and for all, but I didn’t really understand what he was talking about.

So the following morning, we came here and I saw a poster. I was thinking ‘why are we here?’ but I didn’t ask. Then we went into the VCT room, and I was counselled, and knew then that I was going to have an HIV test. My dad and I were told to come back on Friday.

When we came back it was on the 18th of December, and that’s when I found out that I was HIV positive. Well, it wasn’t actually easy because by then I remembered the information I used to receive - that ‘if you have HIV you are going to die any moment from now and it’s the end of the world you just have to give on life’.
But the nurse advised me that it’s not the end of the world: “You still have a long way to go. Being HIV positive doesn’t mean your dreams are shattered; you should have strength to pull through”. That’s how I recovered. (11 year old girl, Kitwe)

Disclosure

Here, a health care provider describes issues around disclosing to a boy or girlfriend:

[Disclosure] is a huge challenge for adolescents. About half of the girls and boys that come here are involved with people who are HIV negative and they all don’t want to disclose their status for fear of being dumped. (FGD, health care providers, Lusaka)

Deciding when, how and who to disclose is a significant part of the life of a young person living with HIV. We see in these respondents’ examples of where this decision has been taken away from them or reluctance to share their status from expected stigma.

So I started taking and living a secret life and all (18 year old male, Lusaka)

Well because I no longer see myself as being negative which is what I used to do before, I have certain limitations. If for example I had a girlfriend, we would not do certain things and when I tell her my status, she would put in certain barriers in our relationship. (19 year-old male, Lusaka)

Fears of stigma are well documented in the literature, and for an adolescent this is an especially amplified phenomenon, impacting potentially on relationships at a time when transition from childhood to adulthood is by itself turbulent and stressful.

Disclosure is predicated on certainty of infection, and as discussed elsewhere, this is not always confirmed for respondents until later in adolescence. Telling other people can be stymied by fears of stigma, and even for respondents in relationships, their partners are not always aware – “I’ll tell him when we get married”. The fear of being rejected leads some not to disclose their status; some respondents were currently in a sexual relationship practicing safe sex, though not all.

Some take a sophisticated view of HIV, disclosing to a partner, but refusing sex (leading in one case to the partner leaving). Selective disclosure seems the option of choice – telling family but not friends at school. This option is wise, as according to another respondent:

There is no one I can trust – they may start discriminating because there are still some people that have a misconception and don’t have the right information about HIV (19 year old male, Lusaka)

Living a ‘secret’ life as a person with HIV is not an unusual phenomenon for PLHIV, and the role of services supporting this group must include initiatives enabling young people to develop realistic notions of their illness, their place in society, and sufficient preparation for transition into adulthood.
Need for normality: HIV as a negative force

Some of the respondents are determined to take control of their lives – indeed, a number state they seek normality, to be like other young people. Others are more reactive, less willing or able to influence their lives. Perhaps as an illustration, HIV is a force leading to deviation from a routine trajectory, into a world dominated by treatment, altered social interaction, and a consideration of sexuality requiring awareness of ‘real’ danger to self or others (rather than imagined danger, which underpins education around sexual health).

In spite of this, many respondents are planning for future times – indeed their hopes and dreams are similar to many other young people; marriage; children; and employment. They steer towards a goal that in spite of their diagnosis is still very much in their sight. Indeed, many of the female respondents comment specifically on their need for more information on pregnancy and child spacing. Hopes are also verbalised for “medicine to heal me completely” (11 year old male), and this aspiration of survival is powerful throughout the responses in this study.

There is for some an acceptance, and commitment to living a life that is ‘normal’; and they are fatalistic: “It has happened and there is nothing I can do about it”. And for a 14 year old girl, “my outlook on life is usually optimistic, and I usually wake up looking forward to a new day”. These are those who are coping, and this is often a personal characteristic rather than one relating specifically to services. For some, being “positive does not make the relationship different” (this is a 10 year old girl speaking, very “optimistic about life”). This particular respondent also looks forward to having a boyfriend so ‘she has someone to talk to’. Generally, respondents feel that having a relationship should not be affected by an HIV status, and for those diagnosed at an earlier age, they seem to adapt more effectively than those who discover their status later on (an experience also complicated by feeling they have been deprived of full knowledge).

Stigma

Stigma for a person living with HIV of any age is a constant threat, and the impact on relationships has already been addressed. Fear of general stigma is certainly very real (hence reluctance to disclose). For one, “a lot of people make fun of me at school” (16 year old male). The problem of families reacting negatively is flagged in a number of responses – “when we are all seated at the table, they start to say all sorts of things” (16 year old girl, Kitwe – living not with her parents, but with extended family). In one extreme example, where an aunt (guardian) found out about a girl’s status, she proceeds to disclose to “anyone who cared to listen”. The respondent continues:

This was very painful for me because I thought that it was my right to disclose to people about my status. I felt that my rights were violated. I actually cried. She went to the extent of telling people that I am sick because my mother was a prostitute and she brought this disease upon her brother. I feel like my aunt does not love me, because of her behaviour towards me, when I am taking my medicines she will look at me in a funny way (FGD, PLHIV, Lusaka)

Stigma is reported by one focus group as where children are not given plates in the home, or there is verbal abuse. There is also expected stigma (self stigma, or internalised stigma) that seems an almost greater threat, especially with a boy/girl friend. One Key Informant suggests young people living with HIV “would rather hide their status...they always think that people will react badly once they find out
about their status”. Health care providers in one region report of a girl neglected by her family: she is covered in sores, and no one will touch her. The same respondent also reports children being denied food, thus affecting adherence to ART (source: Key Informant, Kalomo).

A secondary impact of stigma is reluctance of parents to disclose to their children. As described by Key Informants at one clinic, this is due in part to a parent not fully accepting his or her own status. In one case a mother LHIV is described as taking her 6 month old HIV positive child to a clinic many miles from home, so that she would not be recognised in her own village. This also impacts on the timing of when a child is informed of her/her status. Cases are described where a child discovers the traumatic and mortal nature of HIV before they are informed about their own status – leading to “confusion”. Elsewhere, a stepmother is described as denying that she is with her stepdaughter saying she is “keeping the tablets” for a child living in another house.

These narratives, though anecdotal (and in some cases likely to be atrocity stories\(^5\)), are validated by comments suggesting skewed notions of HIV in communities and potential risk. This is not always the case however: one 19 year-old female comments: “I shared my status with my good friends, and they were very understanding”. Sadly, not disclosing (and not coming to terms with a diagnosis) can lead to young people avoiding the necessary support and information required to ensure safer sex and living healthy lives. Here, a respondent describes his role in advocating for better awareness – and also the anomalous situation of others suspected his status before he did:

\begin{quote}
At first, before I knew I was HIV positive, the people I live with started separating things such as plates a spoon cup. They gave me a spoon, they gave me a plate a cup like separating them each day when am eating. They left me alone to eat.

But since I knew I was HIV positive, I started thinking that is the reason they are treating me this way. Fortunately I had that knowledge, and I didn’t know what they knew more about HIV. So, I gave them some advice about things they should know, and they have stopped treating me differently. Now we all use the same things (18 year old male, Kitwe).
\end{quote}

3.1.5 What are the needs?

Based on the discussions above, we can see that there are a number of specific needs facing ALHIV. Support during diagnosis and disclosure is vital – assisting the adolescent to process potentially shocking information, and coming to terms with their altered life, not only for themselves, but in the impact on parental relationships if infected perinatally. This can add an additional burden of parental mortality.

There is also the need for ongoing support for treatment adherence – we have seen that a significant proportion of support is from the immediate family. If fragmented family structures, or guardians unable to focus adequately on the young person’s requirements, threaten this support, then the effectiveness of ART is limited. This is especially so if the parents have not disclosed their own status – how can they tell their children why they are taking medication, if by telling them this would raise questions about the origin of the HIV infection?

\(^5\) Descriptions of events, partly exaggerated to illustrate a personal viewpoint.
Agency
A key element underpinning much of the respondents’ descriptions of their lives and their relationships is that of agency – how much control and influence they have on their circumstances. For adolescents, gradually moving towards a state of independence is part of the growing process, and on the evidence of this study, HIV has the potential for negative impact on an adolescent’s capacity, potentially restricting social, psychological and personal development.

This intersects with a number of factors across the data, including stigma that denies full integration, and access to information – either about living with HIV, or the ‘limbo’ period between suspecting something may be amiss (either seeing relationships change, or experiencing the signs and symptoms of opportunistic infections), and finding out about their HIV status. Cases are reported by respondents confirming that some adolescents accessing treatment are not aware of their status, and when they are informed, this leads to a desire for more information about the source of their infection: seeking some reason – or blame – for their diagnosis. For respondents infected vertically, and whose mother is still alive, a positive diagnosis places strain on mother-child relationships. Not knowing where they got the virus – if not from the parents – is also traumatic, and health care providers describe incidents where teenagers become pregnant, find they are HIV positive, but the father of the child is HIV negative.

HIV has become another power over their lives: for one (male) respondent, this is especially difficult: “everyone wants you not to do this or that – they are protecting you, like you are fragile – to that, eat the right way, do limited physical work. You cannot drink or smoke or have a normal life”.

Sexuality
Sexuality is a key part of a young person’s life: experiencing bodily changes and seeking relationships with potential partners. They are unlikely not to engage in sexual activity just because knowledge is lacking, though respondents were generally aware of the need for condoms to prevent re-infection and pregnancy, or alternatively abstain completely because condoms might not work. Interestingly, this was an approach promoted by at least one INGO working in Kitwe, and repeated by a respondent in the same area. The pressure to engage in sex – especially for girls – is ever-present:

So far I have dumped three guys because they were pressuring me into having sex with them and I am not ready for it. I fear that I might infect them or re-infection may occur because I do not know what they have but at least I know my status. (19 year old female, Lusaka)

Crucially, respondents cannot always talk with parents about sexuality – “it’s against our tradition for parents to talk with their children about matters of sexuality” (FGD, parents, Lusaka) – and this limitation is complicated by the influence of ‘tradition’ preventing effective discussions about sexuality, and sexual health (and also, more specifically, HIV and the source of the infection).

“ We do not have a society that is supportive” according to one health worker, and one instance, where a HCP had discussed sex with a young person, her mother “came to the hospital and shouted at us”. Fears about talking about these key issues have a significant negative impact on the nature of support. Embarrassment at dealing with sexuality is confirmed by one FGD respondent (a parent) suggests:
Yes, sometimes our children come to us and they are confused; and when they do we shun them and just shut them out; the girl might want to have sex...and if you don’t have time to talk with them that what is happening is normal and how to handle it, (they are) left to themselves and the people out there, who advise them to go and practice. (FGD, parents, Lusaka)

3.2 The impact of accessing HIV and SRH services

Most providers are not child-friendly environments (FGD, PLHIV, Kitwe)

Services exist to protect the slide of young people (in this case) towards illness, isolation, and (as a public health measure) protect the infected person – and others – from the consequences of unsafe sex when one or other person has HIV. Broadly, HIV services available for ALHIV include clinics providing treatment and some psychosocial support, NGOs (such as World Vision, Face to face Foundation, NZP+), groups working at the community level (such as the Ng’Ombe home based care agency in Lusaka), peer educators, and school-run meetings such as Anti-AIDS Clubs. Each serves a distinct purpose, though for clinics opportunities for interventions are highest: their constituency is ‘captive’, attending regularly at between 1 and 3 monthly intervals. For respondents receiving treatment (the majority), interactions in this health care setting are a regular and demanding part of their lives.

This section focuses on:

- The benefits of services, as identified by respondents – what are the strengths and positive experiences of accessing HIV services?
- The nature of provided by services information – the value of information, the source, and also the potential damage of flawed information

3.2.1 Benefits of services

I really like going to the centre to be with friends, because we talk (16-year-old girl, Lusaka)

The benefits of using services are confirmed by respondents in a number of ways. Here, the experience is very positive:

I belong to a support group and every time I feel like I need someone to talk to I know who to go to. The support group sometimes arranges workshops at NZP+, they help to strengthen us and help us to learn as we mingle with others who are also positive like I am. I enjoy having such workshops and I wish to have more of them. (16-year-old girl, Kalomo)

According to the respondents (ALHIV and KIs), the benefits attending clinics are described as:

- Meeting people who are friendly and welcoming
- Meeting other people living with HIV of a similar age
- For counseling and support when diagnosed, or emotionally low
- Attending workshops on HIV, family planning, and life skills
- As a resource for asking questions, and learning more about HIV
- For food supplements
- Providing monetary support for school attendance
- Pay for medical procedures

The notion that the local clinic is a safe haven is strong – respondents see it as a place to ask questions, meet their peers, and receive attention and support, with no risk of stigma:
At the hospital we have a peer support group, it involves children who are around my age and are living positively. We talk about our experiences regards living with HIV; we talk about the support that we have been getting, they also give us information on HIV/AIDS, and they also tell us that it is possible to have children even though you are positive. They make us feel like we are normal children and are not sick. I enjoy these meetings very much and would like to have more of these meetings (14 year old female, Lusaka)

At the centre I get to meet people who are my age and are sick, and this gives me relief. I am able to talk to my friends because they are going through the same things that I am going through (15 year old girl, Lusaka)

Home-based care services (HBC) provide additional support, and local churches are also involved in some areas, for example in Kitwe, providing sessions run by the parish priest who would:

...invite all those people working in clinics to come and help us out, both people that are negative and positive, to give us information we need about the STIs and other diseases (15 year old girl, Kitwe)

Respondents confirm that services are a key part of their life as an ALHIV, though a full range of services are not available at all centres, and not all respondents access services that are available. For some respondents they are aware but don’t attend – here, they depend on their family for social support, or the church:

The only support I get is from my grandmother and sometimes people from church to come and see me when I am sick (11 year old girl, Lusaka)

For others, they are certain that their local facility does not provide (for example) such support groups or workshops.

3.2.2 Relationships with service providers

What I have learnt is that people around me are the ones that can help – but they should be positive in their mind (16 year old male, Kalomo)

Welcoming, friendly and informative services are important, and effective relations with service providers are a key to reaching this target population. For one parent, “adolescents are very sensitive – if you do not approach them nicely they will leave and never come back, and then will go and tell their friends that the hospital is not a place to go”. Positive interactions are invaluable. Likewise, negative reactions can be potentially damaging – for young people and their parents:

[Children] don’t always feel well treated, because sometimes you are late taking them, and then treatment support workers will shout with no regard to you as a parent, and our children feel offended. The hospital is supposed to be a place where we should feel safe but we are sometimes scorned by these health workers in the presence of the child you have taken. How do you expect this adolescent to feel? (FGD, Parents, Kalomo)

Indeed, this is confirmed by respondents – one who suggests that:

We are strict with them as children, so maybe when they come [to the clinic] the first thing you do is start shouting at them: “Why did you do this?” Then afterwards you realize that
you are not supposed to shout, and then you embrace them. [When that happens] the relationship is not that good. (Key Informant, health care worker, Kitwe)

Being at a clinic can be comforting: for one 11 year old boy, staff are “God sent; without them we would not survive”. Positive comments about relationships with service providers are epitomised in this comment: “other than my mother, they are the only people I can confide in” (19 year old female, Lusaka), illustrating the importance of an effective, therapeutic interaction. In this difficult transitional age, having connections is vital: “I do not keep secrets from my doctor – I always tell him exactly what I’m feeling” stated one 14 year-old girl. The contribution of other (external) agencies providing events in the clinics, such as ‘Youth Alive’, is seen very positively, because:

They came to talk to us about a lot of things involving HIV – keeping ourselves healthy, and protecting ourselves from other diseases (12 year old female, Lusaka).

Respondents also appreciate information on life skills – and where these are available (for example in Lusaka) the support meetings and training in knitting and sewing are valued. Generally, younger adolescents seem especially appreciative of clinic services: “I am happy with the services I receive from the centres. I go to the hospital once every month. I am welcomed, and enjoy going there” (12 year old girl, Lusaka).

Pressures of work can impact on the nature of this relationship. We have noted that there are staff who ‘shout’ at young people, and here we see the need to interact with so many adult patients impacts on the care of adolescents:

At the ART clinic we try to be as friendly as we can with adolescents but you will agree with me that much as we provide a service to them, they still see us as a doctor, or a nurse or a treatment support worker. Sometimes we have a lot of pressure, especially with adult clients, so you find that you lose your temper. Adolescents became victims of that due to the fact we attend to them at the same time (FGD, HCP, Kalomo)

A consequence of less effective relationships with service providers is poor information exchange, and an emphasis on physical rather than psychosocial needs. Respondents report interactions as rushed, where they “shout”, or where age-specific information is unavailable, leading to less understanding of SRH and HIV – especially for those not attending support groups or NGO events:

Most providers if you access medication from them all they ask is how are you feeling and draw your blood that’s all - no information sharing or meetings (FGD, PLHIV, Kitwe)

Even for those HCP who are willing to discuss issues, getting young people to honestly talk about their experiences is difficult – as with all adolescents, there is reluctance to talk about private lives:

From experience we have noticed that during workshops most of the adolescents will claim that they are not doing it. They will admit to being in a relationship, but they will not admit to it being a sexual relationship. (FGD, HCP, Lusaka)
3.2.3 Information – nature and challenges

The information that I get is sufficient but I would love to learn some more
(14-year-old girl, Lusaka)

Section 3.1.3 addresses general levels of information awareness – and here we discuss effectiveness of services in providing information for maintaining appropriate levels of sexual and reproductive safety, and family planning. For many adolescents, engaging in sexual activity is something they do because “everyone else is doing it”, and then they do, they have little or no idea of the consequences” (Key Informant, Kalomo). Indeed, many respondents and Key Informants confirm challenges in Kalomo – perhaps because of its rural status – in disseminating information successfully, failing to address lack of understanding of key issues amongst adolescents.

HIV and SRH support services form the locus of correct and accurate informational resources, and a core aim of this study is to explore levels of awareness around sexual and reproductive health. But the family also is a vital resource, though guilt and confusion can prevent effective information exchange in this context:

The adolescent may need someone to talk to, but the parents cannot because of stigma surrounding the disease. It’s a sexual disease, so they believe they did something wrong in sex, and the parents cannot talk about what they did, and so we have a generation conflict. This is a normal occurrence, made worse as the young person cannot talk to their peers because it is a secret. So what I see is the information on how important it is to take your drugs, clear the wrong impression that you did something wrong or your parents did something wrong (Key informant, Lusaka)

The barriers to accessing information are also around the stigmatised nature of SRH – even if adolescents are motivated to seek information, the very act can be discouraged by fear of judgement:

The other challenge is reputation. We fear to go and look for information because we are worried about what other people will think of us. In most cases we choose not to go looking for information. (Focus group, PLHIV, Lusaka)

There is also a disadvantage from the parental role that HCP sometimes adopt, in the sense that they become too close to be able to provide objective information:

Another reason as to why we health care providers are not able to provide information is that we develop a close bond with these children. As a result we develop a relationship of mother-child, and when this happens we fail to tell them certain things because now we think of them as our children. (FGD, HCP, Lusaka)
Awareness of availability of HIV and SRH services

A number of respondents claimed not to be aware of available services, though these were generally the younger children. Older children – 13-14 onwards – seemed more cognisant of what support was available in the local community in addition to the ART clinic. This example from a 17-year-old girl in Kitwe illustrates:

Q. What services do you receive when you come to the clinic, related to HIV and sexual reproductive health?
A: We sometimes have workshops here
Q. What’s your opinion of these services?
A. I think they are good, they should continue

Respondents (ALHIV) in focus groups were able to list, after some brainstorming, locations in their regions where they can access help and support – but it was a common perception in these groups that though these locations do provide services (for treatment, care and support), there is still a need to be adolescent focused to make them truly effective. This is considered further in section 3.3.3.

Communicating directly with young people is vital – “The doctor did not directly explain things to me – I wish he had. He was only talking with my mother.” (15 year-old girl, Lusaka)

Information quality

Access to information, correcting flawed information, and ensuring that adolescents properly understand details are an ongoing challenge. For one HCP ALHIV sometimes “have the mind of a very young child”, and age-specific information is necessary and required. There is a keen desire for information amongst many respondents, and their wish for accurate and understandable material – especially amongst the older children – is a common response to the question ‘What information do you require?’

Key informants confirmed that the role of clinical and support services (including NGOs) is to provide information about sex, safe sex, contraceptives and family planning, and ensure that the information is not conflicting: “our messages should be the same”. A parent taking part in a focus group concurs: “we need [the services] to tell the truth, because if they go out and discover the truth they will call their mother a liar”.

Information requirements: respondents

In addition, Information requested by respondents includes (divided into ‘younger’ and ‘older’ adolescents to illustrate):

Younger (10-14)

- A lot of things, like growing up with HIV and AIDS (12 year old boy)
- Life skills (14 year old girl)
- Information that isn’t just for “old people” (10 year old boy)
- More about HIV, safe sex safe motherhood, child spacing (14 year old girl)
- Marriage and not infecting a husband, kissing and whether this spreads the virus (14 year old girl)
- Issues around longevity and dying – “I am scared of dying” (14 year old girl)
Older (15-19)

- Pregnancy, safe sex and family planning (15 year old girl)
- About adolescence and HIV generally (14 year old boy)
- Availability and access to support groups (19 year old girl)
- Life skills
- Information on things ‘other than just giving us medicine’ (15 year old girl)

For one 14 year old girl, there is concern: “I really have a lot of worries and questions”, and (perhaps more poignantly):

*I also want to know if I can have a boyfriend because every time I ask my mum she tells me not to. I would also love to learn about safe sex, and safe motherhood (14 year old girl, Lusaka)*

Some centres do provide information, but for another 14-year old girl, she wants to discuss and learn more about basic facts, because “it is very relevant information”. Another respondent suggests that:

*I think all we need to know is how to live positively as young people growing up with HIV (15 year old male, Kalomo)*

There are examples of good practice, benefiting adolescents living with HIV across the region. Respondents attending one centre in Lusaka receive information about “the adventure of life” – that life does not end with HIV, and a lot of things that can be achieved. For a 15-year-old respondent, “I enjoy these things because they encourage us”. Though this same respondent also requested additional, specific information about pregnancy and family planning, indicating that even where information and support begin to address issues around living with HIV, there is still the need for insights into long term issues for (in this case) women. In addition, there is evidence that schools provide flawed information, and according to one HCP FGD, children are sometimes told, “living with HIV, they would die”. Teachers according to these respondents should be “taught child psychology so that they know how to handle children”.

In Kitwe, the SOS Children’s Clinic is acknowledged as a useful source of support and information, though not all respondents are able to access this service.

**Bad information**

Flawed information is actually recognised by many respondents, and here 19-year old comments on her limited knowledge, and questionable sources:

*I don’t know a lot about HIV/AIDS. The little information I have I just pick up from what people say about the disease; and I also learnt some of it from school. I learn about it from my friends mostly [but] I’m not sure if what they are saying is true or not (19 year old female, Lusaka)*

Younger respondents are also aware that they can be exposed to flawed information:
I do not trust some of the information that I get from my friends because sometimes it is the wrong information: it is not correct (FGD, female PLHIV, Lusaka)

Information about treatment is also prone to being skewed. Family members can be a source of conflicting information, for example grandmothers who are “unwilling to accept advice” (FGD, health care provider, Lusaka). In addition, there are potentially conflicting messages from the media, or the church:

They are sometimes told to stop this medication and just be on prayers – so in our setting they are told to use a condom, but in another they are told it’s a sin. We do have conflicting messages. (Key Informant, Lusaka)

Respondents also comment that at times there is “too much information”, or that they don’t have enough information on sexual health (this is reflected in comments from the Key Informants, also concerned about the lack of information in this area).

Lack of information
Comments from respondents confirm that there is sometimes a lack of information about HIV, though inquisitiveness of respondents about finding out more about HIV is not necessarily age-related. Younger respondents, and older children, seek further information. Here, a 10 year old girl comments:

I have tried to ask them for more information but they did not give me enough. What they told me was not very useful. I would love to have more access to information and life skills. I do not have any information about family planning - I do not even know what family planning is. (10-year-old female, Lusaka)

This response is mirrored elsewhere – there is a desire for details about HIV, and how it impacts on their lives. There is concern from respondents and Key Informants that those who are not able to attend school (often because both parents are dead and there is no one to ‘sponsor’ them). Though in this dataset it is not possible to attribute effects to specific causes, many of the respondents who themselves have children, dropped out of school at an early age, often around grade 7 (so 12, or 13 years of age).

Ensuring adequate informational (and other) support is available for these young people already entering adulthood (and having children of their own) but who may still be relatively immature, could be problematic (which ‘group’ are they members of?). This problem is not unique to developing world systems – knowing where to ‘fit’ a young adult into western health services is also a difficult consideration in some cases.

3.3 Effectiveness of services: relationship between the needs of adolescents and availability and nature of service provision

Each time I am at the hospital I feel low, especially when I see sick people (16-year-old girl, Kalomo)
We see above some of the needs of adolescents living with HIV, and issues around access. How effective, for the respondents LHIV, and the Key Informants with in-depth knowledge of the context, in addressing the needs and requirements of this group? Specifically:

- What are the problems with accessing services, and what do they contribute?
- What are the recommendations for HIV services, from the perspective of service users, and also Key Informants working in the field?

**CASE STUDY: Family planning and older respondents**

As mentioned in section 2.3, a small number of respondents in their late teenage years (so still technically adolescents) are in permanent relationships, and have already been pregnant.

In the case of one particular respondent, an 18-year-old female, the complexities of living on the cusp between adulthood and adolescence is illustrated well. Dropping out of school at grade 7 (14 years old), she claims not to have used a method of family planning, and already had one child. She is currently pregnant, and discovered her HIV status when pregnant with her first child 2 years previously. She has some knowledge of family planning, and reproductive health, and that condoms can prevent HIV transmission. Asked why she doesn’t use any method for preventing pregnancy, she states:

> When I had my first child I thought that why should I get injectables when I am alone [her partner was away]? So I was just saying to myself that I will go later. Then when he came back that’s when I thought that I should go and get injected but [I didn’t], so that’s how we have this one.

Condoms are provided at her clinic, though because she is not yet on ART, she only attends at 6 monthly intervals for a CD4 test. She hopes she can prevent the child becoming HIV positive:

> Now what I want is to be on medication so that the child escapes the virus.

Her (intermittent) partner knows about her HIV status, but he “refuses to go to a clinic”. She feels happy about her interactions with care providers, though wishes that she could “know more” about HIV and reproductive health.

The challenge for services in this context is that though this person is still an adolescent (transitioning into adulthood, with a non-permanent relationship), her needs are very much of an ‘adult’ nature, and deciding where to ‘slot’ her is likely to be difficult. She needs support not only because of her status, and her need for antenatal interventions, but also in her relationship with the child’s father, and continuing requirement for general information. How can non-clinical support be provided? And what should be its nature?

**3.3.1 Perceived problems with services**

> Seats are mostly occupied by adults (FGD, PLHI, Kalomo)

> Some are very good people; some are cruel (12 year old boy, Kalomo)

> But when you go for a workshop we sit on nice chairs (10 year old boy, Kitwe)

Perceived problems with services are identified by respondents, and here we see that living with HIV, and its complexities, are not always addressed even in workshops arranged for PLHIV:
Q: So, why would you want to be a womaniser?
A: Because I thought no one would accept me
Q: But there a lot of people who are positive and are married
A: Yes I have heard of them but they only discovered after marrying. I would love to see a couple where they bring them in and say ‘Look I am positive and my wife is negative’.
Q: But don’t you talk about these things in your workshops?
A: No, because we only talk about adherence (19 year old male, Lusaka)

Key informants indicate their concern about certain aspects services, especially the nature of information that adolescents LHIV receive, and the limited services available in less urban areas (particularly those served only by mobile ART clinics). Key informants from a major clinic in Lusaka comment that retention rates outside of the centre may be less – “I don’t want to think what is happening in the district clinics”.

In addition, the difficulties in tailoring services for adolescents – because they fall between children living with HIV (perhaps requiring a more pedagogic approach), and adults, whose requirements for information and support are likely to be around supporting families, being regularly sexually active, and as an older person more able to process conceptually the threats they face.

This comment is reflecting on concerns at this clinic that due to the large numbers of adolescents they deal with, they feel constrained in providing additional support. There is a desire for more localised groups, illustrated here by a respondent who involved at his local school in the anti-AIDS club, and is happy to seek information from nurses, but feels there could be more done:

Here we don't have youth groups where a young person like me can go and get information or share what I have. We rely on people like you [the interviewer] when you bring us drugs and sometimes booklets (17 year old boy, Kalomo)

Attending support groups – seen as a key benefit for those attending (albeit with issues around providing age-appropriate support) – is by no means universal, and for those wishing additional networks, this creates a vacuum:

I do not belong to any support group. I wish I could because it would help me to talk to people who are sick like me (19 year old female, Lusaka)

In the cases of groups that are functioning, there is a desire for them to be better integrated, focusing on social aspects of living with HIV:

They are good but I would want to have more interaction on the social side so that we get to know each other because there are some people we saw once and never saw again (19 year old male, Lusaka)

Regarding information, we have already seen that information about HIV and living with HIV can be limited, depending on the source and regularity. For many Key Informants commenting in this study, adolescents require information because they will “explore” anyway, and they need more information than simply about drugs. There is also concern that (as commented above) information may be flawed, and “adolescents don’t have the correct information at all” (FG respondent, HCP). There may also be “conflicting messages”, and clinics focusing on treatment alone are unable to
provide additional support that is the main activity of agencies working specifically in ongoing interventions – such as male circumcision, discussions around reproductive health, and teenage pregnancies (KI, PPAZ). Fitting treatment regimes with lifestyle is an ideal way to encourage adherence, but when support services are unable to do this effectively, the result can be serious. This is confirmed by a Lusakan PLHIV, who comments that she:

...was given the drugs, but when I got home I just could not take them...because I didn’t accept that I was positive, and at the end of 8 months I threw the drugs away. Then I got very sick and my CD4 dropped to 1% (19 year old female, Lusaka)

3.3.2 Need for adolescent-friendly services

[We] do not understand fully the services we are receiving (FGD, PLHIV, Kitwe)

Sometimes I don’t feel free [to talk] especially here at the hospital. They sometimes bring very sick old people on the bicycle and wheelbarrow, then when they teach they just teach us together with old people (12 year old male, Kalomo)

Providing adolescent-friendly services is perhaps the greatest difficulty for agencies working in the field. Key Informants working in clinics acknowledge these limitations:

At times it may not be easy to ensure that the interactions with them are child friendly – it’s difficult to maintain when adults surround you. We used to have a youth friendly corner, but due to lack of funding it has died a natural death. There needs to be a full time person trained specifically to deal with adolescents. But there isn’t (FGD, HCP, Kalomo)

This is especially so when a clinic has low numbers of children attending for treatment – it is difficult to allocate resources to such a small group. Adolescents are certainly perceived as having specific needs – in many ways above and beyond the needs of adults – but for clinics faced with large numbers of patients, capacity simply isn’t available:

When there are very few people to deal with a large community you can only commit so much time to an individual (HCP, Kalomo)

There are times when there is limited privacy for discussion – highlighted by males LHIV in particular. There was also evidence that the respondents LHIV felt there was a lack of age specific information, and a tendency to conflate all age groups into a single meeting, which can be problematic:

Sometimes when we meet as adolescents at least we can meet as adolescents, but then you find people of 14, 12 and even 8, and you cannot talk about certain things [for example] sex (17 year old male, Lusaka)

Some respondents were scared of the medical and nursing staff – “I see children here scared when they come in” (17 year old male Kalomo) – though at the same time wishing for more “adults to talk to” (10 year old female, Kalomo). And poorly tailored attempts at connecting with young people who are already withdrawn can fail to reach those needing support the most:

It would be good if everyone would get involved in [support group] discussions...health care workers try talking to [the quieter members groups] but this makes it worse and they withdraw further (11 year old female, Lusaka)
For some respondents, the ART clinic can be frightening for other reasons – including the proximity to a mortuary (Kalomo), or memories evoked following the death of a parent who attended the same clinic (Kitwe). Another source of anxiety at the clinic is the presence of so many adults:

*You see a lot of people at the clinic – daddies, mummies, uncles, and aunties – all receiving treatment. The children then look afraid. We have a lot of needs, but services are few.* (18 year old male, Kitwe)

ALHIV in rural areas, waiting for the mobile clinic to arrive, feel at times especially isolated – not only because of their need for treatment, but also because they have no person to talk with about current concerns, and staff have limited time:

*People come and do things so fast because they want to go back fast – they talk fast, write drugs, and then say “next”* (16 year old male, Kalomo)

This raises a key question: are counsellors and care givers available when needed? For some, this is not the case, though when attending at clinic, interactions with knowledgeable health workers is highly valued, and noticeable when absent:

*Care is given at appointed time in a month – sometimes you may require care, but then you find the carer went for a workshop, or they are sick* (FGD, PLHIV, Kitwe)

### 3.3.3 Service recommendations: respondents

*The most important things adolescents who are living positively need are: love, support and care* (19 year old female)

When asked specifically about factors that could improve the delivery and effectiveness of services, there were a range of responses, from both PLHIV and Key Informants.

#### Information

Synchronising information between services and parents/carers is flagged as a key element in the data, and informing *parents* about appropriate SRH and HIV information is a vital way to ensure consistency and support. Parental/carer and service providers suggest this could be a key strategy (especially given that the first point of contact is the parent/guardian):

*We as parents are also to some extent not aware about SRH information that can help adolescents living with HIV* (FGD, Parents, Kalomo)

*Parents need to work hand in hand with the care providers. They should meet halfway [and] play their part, and when they come to the clinic, we the caregivers should be able to ask what information they have given their child* (FGD, health care providers, Lusaka)

A key barrier to involving parents effectively is that many will not have disclosed their diagnosis to the children – and appropriate management of disclosure for both must be a key recommendation for all programmes.

---

6 This young person has no parents, and lives with his ‘aunty’ – one example where additional service support is particularly required
Being ‘normal’

Detailed information about growing up as a ‘normal’ person – indeed, when young people confirm the benefits of services, often this is the terminology that is used:

They make us feel like we are normal children and are not sick. I enjoy these meetings very much and would like to have more of these meetings (14 year old girl, Lusaka)

For the ALHIV themselves, there was agreement across the dataset of many fundamental elements that would enable services to meet their needs appropriately. From younger respondents, there was general satisfaction about the services they receive, though this could be due to their being willing to ‘put up’ with elements that older participants would find less satisfactory.

Interactions with services were judged by respondents on the welcome they receive when attending the clinic – for one 11-year-old boy “just greeting me” is his recommendation. Specific requests for an adolescent-friendly service were verbalised by many, and – linked with the comment in section 3.2.3 about the need for age-specific information, respondents comment that receiving information that they understand is important.

Service logistics

Respondents comment on a range of issues specifically around the environment of the health centres, and the management of consultations. There is a general desire to reduce the time that young people are required to wait, and in addition to be “seen first”, and “separated from old people” (12 year old male, Kalomo). As discussed above, queuing for long periods is difficult, especially for young people, difficult, and keeping this to a minimum may reduce anxiety. There is little for them to do whilst queuing, and whilst some did comment that in certain locations support group meetings are held during this time, there are also substantial numbers who are simply waiting, and for those who are concerned about being seen outside the clinic, this adds an extra layer of unease. For one respondent, queuing presents other threats:

There are times when people sick with malaria come and watch you. There are also drunkards who start talking saying “those are taking ART….we found them”. It would be better to get drugs without people knowing (19 year old female, Kitwe)

In addition, more ‘dynamic’ events and information delivery when these are available offer a vital connection with young people, especially when the only contact they have with an ‘expert’ is when attending for treatment. Repetitive and unfocused messaging is ineffective.

There are clearly issues around resources flagged in the findings, including: lack of sufficient space, so making privacy difficult and lack of opportunity to “be together and chat how to live positively” (19 year old make, Lusaka); shortage of staff; and funding (in one location) for specific, adolescent-friendly areas. Services are at times overwhelmed by meeting the needs of adults attending for treatment and support, and respondents’ comments suggest this detracts from the additional and refined interventions required to meet the needs of adolescents which may not be addressed sufficiently by activities shaped by adult needs.
4. DISCUSSION AND RECOMMENDATIONS: WHAT THE EVIDENCE TELLS US

We need to capture them earlier. We are not capturing the children and I think the earlier you do this the easier it becomes when a child is exposed to information from an early age. It becomes easier than asking a 16 year old who you have never sat down with and have never talked to; they will be very apprehensive, with preconceived ideas (Key Informant, Kalomo)

4.1 Key findings

- **Immediate social networks**: for ongoing support, close social networks (especially families) have a significant impact on the ability of young people to adhere to treatment, and coming to terms with their HIV diagnosis (positively and negatively).

- **Diagnosis**: being diagnosed with HIV is traumatic, and if parents are also infected there are additional difficulties if disclosure of parents’ and the young person’s status is poorly managed.

- **Impact**: HIV – either directly or by proxy – affects significantly the agency of young people. Choices are less, and being encouraged to acquiesce more strictly with safe sex and ART adherence guidelines potentially creates a more difficult experience of adolescence, as well as the additional factors affecting relationship negotiation.

- **Information**: Young people in this study are often seeking information – they are expectant – and HIV service providers in some instances are clearly unable to meet the social and informational requirements of young people. Tailored and participatory events are appreciated greatly.

- **Integrated adolescent-friendly services**: support services vary in their capacity to meet the needs of this group – medical support (i.e. around treatment) is generic, but addressing the social and psychological needs is more fragmented (with NGOs and other external facilities playing a key role). Respondents in the lower age groups seem lacking especially in essential insights and the full range of provision. Services that are welcoming, empowering and willing to share specific information about individual needs are highly valued.

4.2 Discussion

*Treat young people as young adults, not big children (World Health Organisation 2009)*

We see from the comments above, adolescents living with HIV face many issues around sexuality, social and family structure, social integration and adhering to treatment. These are all woven into the fabric of respondents’ lives. On the basis of this study, HIV and SRH services, whilst providing in some areas an effective framework of support, are also failing to meet the entire range the needs of ALHIV.

Figure two displays some of the key issues and needs facing ALHIV emerging from this study, and highlights factors of which HCPs and CBOs should be aware if services for this group are to be effective.
The centrality of effective services

The quality of HIV services available to adolescents living with HIV has a significant impact on their ability to negotiate adolescence safely. We see from other recent studies (World Health Organisation 2009) the importance of programmes that are engaging, focus on young people, and enable an adolescent LHIV to enter adulthood empowered and informed. This must remain one of the core aims of HIV services. Failure to address sufficiently the developmental needs of ALHIV could lead to increased risk of ill health and (ultimately) risk to the community.

Also, it is vital that in assessing the needs of a particular young person, this is done based on their social and intellectual development, rather than simply their physical, given that young people develop at different rates. An effective relationship between HIV services and parents adds to the positive influences and resources for the PLHIV, and will synchronise (for example) information provision. Evidence from these interviews suggest that those respondents who are less able to connect with staff at the ART clinic – and also who claim not to have attended additional workshops or NGO-hosted events – have less knowledge and understanding of SRH and HIV than those with more functional relationships with experts.

There is no doubt that services available for young people are a vital and integral part of an enabling framework, providing material and social support, information about a range of relevant topics, and medical treatment. Some of the clinics in this study are – perhaps inevitably – medicalised, though respondents report the positive nature of being able to ask questions of ‘experts’ about their treatment and their HIV infection, if the context is conducive to such interactions, and personnel willing to engage. Other – more social – needs appear to be met more patchily, and given that HIV services for young people provide in many cases a safe haven, and a place where young people can meet with friends, then it is vital that these facilities are available at a level that addresses more personal needs. Based on this sample of respondents, the positive impact of home based care is clearly a beneficial feature, and the model in Kitwe (Twafwane Christian Community Centre) and the

---

**Figure 2: Key needs of ALHIV emerging from the study**

<table>
<thead>
<tr>
<th>SOCIAL NETWORK</th>
<th>INFORMATION</th>
<th>HIV SPECIFIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Supportive family structure (or similar)</td>
<td>• Living with HIV; and implications</td>
<td>• Proper management of diagnosis and disclosure</td>
</tr>
<tr>
<td>• People to ‘talk to’</td>
<td>• Planning for the future</td>
<td>• Ease of ART</td>
</tr>
<tr>
<td>• Friends of a similar age and facing similar challenges</td>
<td>• Understandable and directed information</td>
<td>• Engagement with service providers</td>
</tr>
<tr>
<td>• Preparation for relationships with boy/girl friend</td>
<td>• Age-appropriate material</td>
<td>• Assistance with balancing - ART, future planning, social integration, psychosocial and physical development</td>
</tr>
<tr>
<td></td>
<td>• Peer support for information processing</td>
<td></td>
</tr>
</tbody>
</table>

---

**INFORMATION**

- Living with HIV; and implications
- Planning for the future
- Understandable and directed information
- Age-appropriate material
- Peer support for information processing

**HIV SPECIFIC**

- Proper management of diagnosis and disclosure
- Ease of ART
- Engagement with service providers
- Assistance with balancing - ART, future planning, social integration, psychosocial and physical development

---

**SOCIAL NETWORK**

- Supportive family structure (or similar)
- People to ‘talk to’
- Friends of a similar age and facing similar challenges
- Preparation for relationships with boy/girl friend

---

**INFORMATION**

- Living with HIV; and implications
- Planning for the future
- Understandable and directed information
- Age-appropriate material
- Peer support for information processing

---

**HIV SPECIFIC**

- Proper management of diagnosis and disclosure
- Ease of ART
- Engagement with service providers
- Assistance with balancing - ART, future planning, social integration, psychosocial and physical development

---

**Figure 2: Key needs of ALHIV emerging from the study**
Lusakan Ng’Ombe Based Care service are cited as especially helpful, offsetting the intrinsic medicalised approach of ART clinics.

Barriers

<table>
<thead>
<tr>
<th>SERVICES</th>
<th>CONTEXT</th>
<th>ADOLESCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Not adolescent friendly</td>
<td>• Unsupportive social setting</td>
<td>• Not attending available services</td>
</tr>
<tr>
<td>• Medicalisation of clinics</td>
<td>• Social stigma</td>
<td>• Misunderstanding</td>
</tr>
<tr>
<td>• Information is poorly given</td>
<td>• Peer pressure</td>
<td>• Not applying what information and support recommends</td>
</tr>
<tr>
<td>• Failure to track all adolescents</td>
<td>• Unsupportive - or absent - family network</td>
<td>• Not aware of diagnosis</td>
</tr>
<tr>
<td>• Not all adolescents have access to support</td>
<td></td>
<td>• Stress of diagnosis</td>
</tr>
</tbody>
</table>

Figure 3: Summary of barriers

Figure three presents some of the barriers to accessing and benefiting from services, as identified in this study. As can be seen, a number of these factors are outside the control – agency – of adolescents.

Providing an effective service and support to adolescents, across the full age range, from different backgrounds and experiences of living with HIV, is a significant test. The findings in this study highlight a number of specific factors that mitigate the effectiveness of support mechanisms. Getting young people to access services in the first place can be problematic – this study confirms respondents who are aware that support exists, but which they choose not to access.

Urban versus rural

The study also suggests contrasts between urban and rural areas, as described by some respondents. In Kalomo (rural), comments refer to intermittent contact with support services, and especially for those unable to attend school, there is a risk that ALHIV lack access to sufficient information, though activities of local support groups - when ALHIV are able to access them – and NGO activities (e.g. with NZP+) are cited as especially helpful.

Informing transition

Times when ALHIV require most support – being informed of their diagnosis, and (in some circumstances) learning of the diagnosis of their parents – is one of the transitions (from not knowing, to knowing, an HIV status) where interventions are crucial. Some respondents state they are “just told”, whilst others commented that relationships with their parents were jeopardised from the knowledge the virus was likely derived from their mother.
As to schools and education, a number of respondents are not attending school due to lack of money, or (perhaps more worrying) because the expense is seen as unnecessary, given the perceived limited life span of the young people. Schools are potentially an important source of information on general issues around sexual health and family planning, and though some respondents experience stigma, education is broadly beneficial. Local agencies such as the Face-to-Face Foundation provide material support, and this approach is clearly one that can maximise the likelihood of children attending school.

Any consideration of the lived experience of this group must consider the entropy that HIV generates. Though many of these respondents confront HIV aggressively, and refuse to let a diagnosis alter their lifestyle, there can be little doubt that being infected is always at the back of their minds – requiring constant attention (treatment, constant vigilance regarding safe sex, and altered family structures as a product – in most cases – of one or both parents already having died of HIV, and fears of mortality). Relaxing attention to one or more of these factors leads to negative consequences that, for other non-infected adolescents, may be less of an issue.

4.3 Recommendations

On the basis of this study, medical aspects of support tend to be stronger than the social. A range of additional activities can be put in place to address this inequity, and there are specific recommendations can be made to address weaknesses, at the personal, community, organisational and policy levels.

4.3.1 Personal

Adolescents living with HIV must be encouraged – and motivated – to access local support groups, and providers of social support available in their community. Though it is inappropriate to make this compulsory, meeting with experts and other affected people can help offset some of the problems around adherence, not having people (outside of the family) to talk with and discuss some of the more complex aspects of HIV infection.

4.3.2 Community

Data from the study confirm that in some regions, support for ALHIV is limited, especially where the local clinic provides only medical support. Community organisations currently supporting adults living with HIV should consider targeted, adolescent-friendly activities to ensure that psychosocial needs are addressed, especially for those living in less structured home situations. Respondents confirm that NGO interventions (especially organisations such as NZP+, who have capacity and resources) are beneficial – especially the social interventions. In more isolated communities, enhancing ART adherence support and information hubs could fill gaps left by intermittent service provision in such areas.

4.3.2 Organisational

Improving the quality of adolescent-friendly services – a key factor for many respondents – would have a hugely positive impact. Local organisations (both clinical and NGO) should also advocate for earlier testing of children who are most at risk of being infected, in negotiation with parents/guardians. This enables earlier diagnosis; provision for treatment, and more timely information on safe sex and better preparation for disclosing to the child their status. Even the provision of separate treatment days for adults and children – where this is possible – could have a
profound impact on the quality of support for young people. The need for effective local services is particularly vital if the family structure is also fragmented. Here, young people could miss out on essential information on adherence, safer sex and general issues around HIV. Focused, targeted interventions are required for these particularly vulnerable individuals.

Second: Services can provide advice and information on negotiating disclosure, especially to potential sexual partners. This was identified as a key fear by respondents, and by supporting the PLHIV in addressing fear of stigma, and self-stigma, could make their disclosure more effectively managed.

Third: Support for parents as they disclose to their children their own status. Respondents report anger and confusion around their own status, and lack of understanding about the source of their infection when their parent(s) have not disclosed. Workshops and one-to-one counselling sessions for parents would make this process less traumatic for both parents and their children.

Fourth: Working in partnership with families/guardians. Parents and guardians have a range of responsibilities towards adolescents LHIV – supporting ART adherence, timely disclosure (if relevant) of their own HIV status, being a resource for information. Other needs – for example medical, and some social – are addressed by HIV services (both clinical and non-clinical). It is imperative that parents/guardians and HIV services work in harmony, and develop mutual trust for their combined support of adolescents LHIV. Instances in the data where this has been difficult confirm that for the young person, lack of cohesion in support leads to increased confusion and frustration.

Lastly: ALHIV should be informed of and invited to support groups to address psychosocial aspects of HIV. The study reveals a number of respondents who are unaware of such initiatives and for all people living with HIV (as revealed in a study undertaken by Alliance Uganda in 20107), groups and networks have a significantly positive experience.

4.3.3 Policy
Providing, and funding, adolescent-friendly services in both urban and rural settings should be a key priority for policy makers, as well as ensuring there is adequate support for clinic based health care providers and NGOs as they support adolescents LHIV. In many ways this client group is the most complex, subject to rapid social and physical transition, and ongoing assessments must be in place to ensure services meet the need of an adolescent at that point in their development. This study suggests that support in rural Kalomo may be less effective that urban Kitwe and Lusaka.

In addition – from a policy and organisation perspective – working towards information cohesion (organisation, family, media, and faith-based organisations) can go a long way in ensuring an end-user (the young person) is not presented with conflicting messages – the example of INGOs promoting abstinence in contrast to use of condoms for safer sex illustrates this issue. Children and young people are presented with a range of data to process, and services must take a lead on reducing dissonance and promoting consistency.

This context of HIV care delivery would benefit clearly from the development of guidelines for best practice. Supporting this vulnerable client group is complex, and with the constant strain in

delivering HIV services across the age range, the special needs of ALHIV are — as this study suggests — at risk of being overwhelmed, unless interventions are pro-active and designed specifically for this age group. Special considerations must be given for:

- **Avoiding generic approaches**: Refining services to ensure that young people do not receive generic, adult oriented interventions which are in many ways unsuitable
- **Addressing the nature of family and community support**: How can children and adolescents who are often living in fractured family structures be better supported?
- **Information**: Ensuring that information provision around safer sex, family planning and treatment adherence is prioritized in planning and funding. Clearly, this is also a key part of supporting all PLHIV, but for adolescents their transitional and malleable life-world makes them especially vulnerable to losing control of their health and safety — and that of others
- **Clinical settings**: Producing guidelines addressing specifically the needs of children and young people — drawing on the successes (and positive experiences of respondents in this study), and addressing the weaknesses

### 4.3.4 Specific issues to track in Phase II

As mentioned in section 1.1, this is the first of a two-phase project, and a number of issues emerge from the findings (and others were identified at the dissemination meeting — more details about the event is in Appendix 2), which can feed into designing the next stage. There are two broad areas: logistics and design, and findings to follow up.

#### LOGISTICS AND DESIGN

- More robust tracking of differences in the needs identified that are facing 10-14 year olds, and 15-19 (so, disaggregating the two age groups). This also applies to rural vs. urban
- Training events for research assistants are highly beneficial, and for Phase I, there was clear evidence that their preparation had positive impact on the nature and quality of the data collected.
- For Phase I, descriptive information was gathered about the nature and extent of services. Whilst this was certainly useful, further details would be valuable in order to explore in more depth the association between adolescents’ needs, and the impact of local services in meeting them.
- The original proposal included the use of a KAP survey, to provide background information supporting the qualitative data. As can be seen in this report, these data are not included, partly due to time constraints (data were collected, but not processed). This information could be valuable for Phase II, though benefits cannot be evaluated at this stage.
- Planning dissemination workshops for communities from which the data were collected.
- As mentioned in the limitations section (2.5), there was a gender imbalance in some areas (more females than males). Research assistants commented this was simply because there were fewer males attending clinics and centres. Phase II should consider ways to ensure that this is less of an issue.

#### FINDINGS – TO EXPLORE FURTHER

- Some adolescents recruited for Phase 1 have no parents (lost to AIDS), and no aunties and uncles (traditionally a key resource for information on SRH and family planning). These children in particular are at risk of missing out on effective information and support if agencies fail to identify them.

42
• Disclosure continues to be a huge issue – further insights into its impact (not only in disclosing a positive HIV status, but also being informed of diagnosis) would be extremely valuable, as well as identifying ways that the process can best be supported.

• The impact of culture and tradition in Phase I did not dominate, though it is vital to track this in Phase 2, for anecdotal evidence suggests this is a central issue in determining the shape and nature of information. For example, how much are adolescents able to be told about SRH and family planning within their immediate family? How openly can people discuss the issues?

• Phase 1 respondents include some older adolescents (17-19), already with children of their own. Phase 2 should explore for specific issues and challenges facing ‘mature’ adolescents, as compared with younger
5. **GATHERING QUALITATIVE DATA: LESSONS LEARNT**

This study gathered qualitative data from a large cohort of young people (59 semi structured interviews; and an additional 54 participating in FGD), living with HIV and Key Informants in three regions of Zambia. The sensitive nature of the topic, plus the difficulties interviewing young people about very personal aspects of their lives inevitably posed a number of challenges to successful completion of this study. In addition, the qualitative nature of this study provides rich insights into the lived experience and context of young people, providing important benchmarks for their perceived needs, though inevitably gives less detail of cause and effect, which would require a different research design.

There are a range of lessons learned from carrying out this study, and these will be useful in designing the second stage of this research, planned for three countries – Malawi, Zimbabwe and Mozambique.

5.1 **Preparing for the study**

From its inception, this study has been a partnership, between local agencies (NZP+, SAT, Alliance Zambia), government and academic institutions. This collaboration ensures that the study is valid and that key stakeholders are engaged with the process.

The University of Zambia bio-ethics research committee gave ethical approval, and compiling the application for approval adhered to appropriate ethical guidelines regarding the conduct of research activity, and the protection of children.

5.2 **Collecting the data**

For this study, research assistants were recruited and trained in qualitative data collection during a one-week event early in 2010. Training included interviewing skills, transcribing, and ethical issues.

When reviewing transcriptions, it was helpful to have details not only of the respondent, but also the conduct of the interview. As with all data collection, contextual distractions pose a threat to quality and sensitivity, and in this study a number of factors were noted:

- Local ‘noise’ – other training events
- Respondents misunderstanding the question
- Respondents not understanding the meaning of the questions – for example, this 10 year old female interviewee from Lusaka: *I do not have any information about family planning because I do not even know what family planning is*
- Keeping children with short attention spans focused whilst ensuring they feel secure and safe
- Distractions from mobile phones
- Respondents simply too shy or embarrassed to share their experiences – this tends to be an issues with the younger children
- Respondents uneasy about being overheard

---

8 Interviewing children is always challenging, and in some instances focus groups can resolve individual embarrassment, especially with very young children. Useful guidelines are found in: *So You Want to Involve Children in Research?* Stockholm, Save the Children, 2004
• Respondents becoming emotional – in these situations the interview was always halted, and the interviewee given the option to terminate the interview

The interviews were also an opportunity for young people to gather more information about HIV and sexual health – interviews always ended with an opportunity for the interviewee to ask questions themselves, and many took the opportunity to seek more information: from the interviewer, or a member of staff if available.

5.3 Analysis

Qualitative data, by its nature, generates a large amount of data. Output from this study comprised ninety-two individual documents, and though the use of software such as NVIVO is invaluable in sorting and coding text, the process of analysis can be – is – time consuming. This study has been delayed for a number of reasons, meaning that final coding and analysis was put back towards the end of the funding cycle.

For future studies, planning sufficient time for this important part of the research process is vital; otherwise significant findings can be missed in the pressure to disseminate findings within the available timescale. In addition, a number of documents were limited in their usefulness, due to time limitations in the field, or nature of respondent responses, and as a result, there is always the risk that findings are skewed toward one location or another. Though this is not necessarily a problem within the qualitative domain (which seeks descriptive, rather than empirical evidence), there is a need that data is sufficiently detailed to gain a valid interpretation of what people and groups may be experiencing.
REFERENCES


## APPENDICES

### Appendix 1: Demographic details of respondents

<table>
<thead>
<tr>
<th>Site</th>
<th>Young people and adolescents living with HIV</th>
<th>Health providers (including NGOs)</th>
<th>Parents or Guardians</th>
</tr>
</thead>
</table>
| 1 Kalomo | **12 SSI** (5 male, 7 female):  
- 10-14: n = 8 (3 male, 5 female)  
- 15-19: n = 4 (2 male, 2 female) | 5 Key Informant SSI:  
- Medical x 2  
- Counselor  
- Nurse x 2 | 1 FGD (n=8) |
|    | FGD1 (n=5) – Ages 15-17 – mixed (3 male, 2 female)  
FGD2 (n=8) – Ages 10-14 – mixed (4 male, 2 female) | FGD (n=8) [from DoT, VCT, counsellor, MCH, Out Patient dept] | |
|    | Narrative 1: 17 year-old male  
Narrative 2: 15 year old male | | |
| 2 Kitwe | **24 SSI** (15 male, 9 female):  
- Ages 10-14: n = 10 (9 male, 1 female)  
- Ages 15-19: n = 14 (6 male, 8 female) | 6 Key Informant SSI:  
- Admin  
- Nurse x 2  
- Medical x 2  
- Counselor | 1 FGD (n=8) |
|    | FGD1 (n=12) – Ages 10-14 – mixed (6 male, 6 female)  
FGD2 (n=12) – Ages 15-19 – mixed (7 male, 5 female) | | |
|    | Narrative 1: 15 year old male  
Narrative 2: 18 year old male | | |
| 3 Lusaka | **22 SSI** (9 male, 13 female):  
- Ages 10-14: n = 8 (8 female)  
- Ages 15-19: n = 14 (9 male, 5 female) | 3 Key informant SSI:  
- Medical  
- NGO x 2 | 1 FGD (n=5) |
|    | Narrative: 19 year old female | FGD1 (n=7) [including nurses and counsellors]  
FGD2 (n=9) [general HCP] | |
|    | FGD1 (n=3) – Ages 10-15 - female  
FGD2 (n=7) – Ages 15-19 - female  
FGD3 (n=3) – Ages 10-15 - female  
FGD4 (n=5) – Ages 14-19 - female | | |
| Totals | **116 (53 male, 63 female)**  
- Ages 10-14: n=52 (22 male, 30 female)  
- Ages 15-19: n=64 (28 male, 36 female) | **38** | **21** |
Appendix 2: Dissemination meeting

A dissemination meeting was held in Lusaka on the 15th March 2011, for partners to the project, other stakeholders, and those who were involved in collecting the data.

The meeting comprised of an overview of the current context of adolescents living with HIV in Zambia, and an ‘interview’ one affected adolescent who shared her personal insights into some of the key issues she faces in her day to day life.

The meeting also provided an excellent opportunity for feedback on the preliminary findings (presented in PowerPoint format), and recommendations for further programming. There were also helpful comments about the implementation of Phase II of the project, where the research is being rolled out to Zimbabwe, Malawi and Mozambique.

Around thirty-five people, representing various agencies and HIV advocates, as well as members of the advisory board and Alliance Zambia, attended the meeting. The media were also in attendance, and two attendees were interviewed for Muvi TV, which aired that evening. A feature article is also planned for the Zambia Daily Mail by another journalist at the meeting.

A follow up event, designed as a capacity-building exercise, was arranged to follow the main meeting. The aim was to discuss general issues around the management of a large study such as this, and also to address specific issues that could inform the design and execution of the next phase. Ten people attended this meeting, including a researcher who would be managing Phase II in Zimbabwe. The topics included: ethics; collecting and analysing qualitative data; and the need for effective dissemination of findings back to the communities from where data were collected.