Adolescent Topics

Adolescents and HIV: Definitions and Disaggregation

DISCUSSION PAPER

MannionDaniels

Contents

Executive summary

"Too old for paediatrics and often deemed too young for adult health services, many adolescents fall through the cracks at a time they most need our attention." - Anthony Lake[1]

Adolescents are recognised as a critical target group for interventions to tackle HIV and other public health priorities. Despite this, there is currently a lack of clarity and consistency in how adolescents are defined and how HIV data about adolescents are disaggregated.

Clear definitions and disaggregated analysis of quantitative data are important for designing and implementing impactful programmes and policies. Disaggregated data has the potential to help stakeholders:

- Identify the subgroups in most need or at most risk;
- Identify the subgroups that are currently underserved;
- Determine resource allocation for different geographical locations;
- Understand how well a programme is performing; and
- Estimate the impact of a programme or policy.

This paper summarises challenges in the way adolescents are currently defined and disaggregated when it comes to quantitative data including surveys, surveillance, routine data and models. It also proposes solutions for broader discussion. In this paper disaggregation refers to both analysis within smaller age ranges and by other factors, such as sex and school attendance. The geographical focus for this paper was eastern and southern Africa.

Defining adolescence

The definition of adolescence commonly given for use with quantitative data is 10-19 years old. However, the more commonly used age range for data about adolescents or young people is 15-24 years old. These two age ranges do have the advantages of being well known and of conforming to the common data analysis approach of grouping people into five-year age bands. However, their shortcomings include:

- The characteristics and needs of 10-year-olds are very different to those of 19-year-olds. Since so much change occurs so rapidly during adolescence, it is questionable whether such wide age ranges are the most useful way to look at data for programming and policy.
- Adolescence is more than an age range, it is a collection of life transitions that include changes in biology and in social roles. These transition points occur at different ages for different people and in different contexts.

Challenges of disaggregating adolescent data

Adolescent HIV data is currently disaggregated to varying degrees depending on the data source. Each data source presents different challenges to achieving more disaggregated data. Some of the main challenges covered in the report include the following:

- Survey & surveillance sample sizes: National surveys generally provide the most scope for disaggregated adolescent data. However, such analysis is not consistently done as sample sizes are seldom large enough for this kind of disaggregation, particularly for sub-populations such as provinces or regions.
- Defaulting to five- and 10-year age bands: Since change occurs rapidly during adolescence, and at specific life transition points, broad age ranges hide a lot of important information.

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1   UNAIDS, To End The AIDS Epidemic, Start Focusing On Adolescents, available at http://www.unaids.org/en/resources/presscentre/featurestories/2015/february/20150217_oped_all-in, 2015

- Using disaggregation factors appropriate to adults: The factors by which data should be disaggregated for adolescents are different from adults. For example, it is particularly useful to disaggregate adolescent data by school attendance and by household structure where possible.

- Routine service data are aggregated: It is rare to find service data specific to adolescents even though this information is often in the patient records. The challenge is that most management information systems require that patient-level data is aggregated on paper before being sent up the reporting chain.

- Models limited by underlying data and assumptions: If models are based on data that is aggregated, or the models aggregate populations into five-year bands to avoid more complex modelling, they often cannot provide accurate disaggregated estimates.

- The exclusion of 10- to 14-year-olds: 10- to 14-year-olds are under-represented in much of the data. This is thought to be partly due to the challenging ethical requirements of collecting data from children and the lack of technical skills required to work with younger age groups.

Recommendations

Defining adolescence

There are definitions of adolescence that avoid the challenges of crude age ranges and attempt to capture the experience of adolescence in terms of life transitions. However, these may not be practical for quantitative data.

A common and useful compromise is to use more refined age ranges that do not overlap with each other and that separate adolescence into three meaningful stages – early adolescence, middle adolescence and young adulthood. There are various options for the age ranges that correspond to these stages. One option that is consistent with common data analysis practices is to use five-year age bands such that early adolescents are 10- to 14-year-olds, middle adolescents are 15- to 19-year-olds and young adults are 20- to 24-year-olds. Where possible, further subdivision of these bands has been shown to yield useful results.

Disaggregating adolescent data

- Adolescent-specific data collection: Ideally, it would be possible to establish adolescent-specific data sources using adolescent-appropriate data collection methods, samples and analysis. Adolescent-specific data collection methods do exist, and can be learned from and replicated.

- Make existing data go further: The scarcity of resources available often makes adolescent-specific data collection unrealistic. However, much can be done with existing data sources. Re-analysis of existing data can be performed based on an understanding of the needs of those that work on adolescent HIV. Data repositories that make this data more widely available could facilitate this further analysis.

- Advances in current practices: Particularly to increase representation of 10- to 14-year-olds in data, it is useful to support survey teams and ethics committees to ensure that younger adolescents are not systematically excluded from data collection. Technological advancements, including the establishment of patient level databases for routine service data, can facilitate analysis of adolescent specific and disaggregated service data.

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
DHS	Demographic and Health Survey
DFID	Department for International Development
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored and Safe Women
EHPSA	Evidence for HIV Prevention in Southern Africa
ESA	Eastern and southern Africa
HAVEG	HIV AIDS Vaccines Ethics Group
HMIS	Health Management Information System
HIV	Human Immunodeficiency Virus
MIS	Malaria Indicator Survey
PEPFAR	United States President's Emergency Plan for AIDS Relief
PHIA	Population-based HIV Impact Assessment
SDGs	Sustainable Development Goals
STI	Sexually Transmitted Infection
TRREE	Training and Resources in Research Ethics Evaluation
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNFPA	United Nations Population Fund
VMMC	Voluntary Male Medical Circumcision
WHO	World Health Organisation

1. Introduction

Recent years have seen a global recognition of the importance of tackling HIV among adolescents[2]. Adolescence is a period of transition from childhood dependence to adult independence. It is a time of rapid change in terms of biology, psychology and social roles. Adolescents are often in a particularly vulnerable position in society due to this transition. During this period, many adolescents begin to experiment with their sexuality and other behaviours including drug use[3]. They may also experience various forms of exploitation, or suffer from inadequate access to information and services due to their social status, economic circumstances or social stigmas.

HIV prevalence data indicate that adolescents are a group left behind by HIV prevention programming, particularly in sub-Saharan Africa. An estimated 670,000 aged 15-24 years were newly infected with HIV in 2015, including 250,000 15- to 19-year-olds. More of half of the world's newly infected 15- to 19-year-olds were in eastern and southern Africa[4]. Treatment for adolescents is also challenging: AIDS-related deaths among adolescents grew from 71,000 in 2005 to 110,000 in 2012 globally despite a decline among other age groups in the same period.[5]

It must be noted that adolescence is not only a period of vulnerability and risk, or a transition into adulthood. It is an important life stage in itself. The changes that can result in vulnerability also make adolescence a time of discovery and opportunity. Adolescence is a formative period when health trajectories can be shaped towards positive health outcomes. As such, it represents a particularly important opportunity for public health interventions targeting not only HIV, but a range of other health challenges [6].

The issue of disaggregation

The broad data on adolescent HIV mask variations and subgroups amongst adolescents at particular risk or with specific needs. For example, in Kenya the HIV prevalence for 14-24-year-old females (3%) masks great differences in prevalence between girls aged 15-19 years (1.1%) in comparison with young women aged 20-24 years (4.6%).[7] South Africa is another example of striking age and gender differences in HIV risk in younger age cohorts. While 5.6% of females ages 15-19 were found to be living with HIV in 2012, only 0.7% of males in these age group tested HIV-positive. Prevalence among females aged 20-24 years jumped to 17.4%, and was also three times higher than in their male counterparts aged 20-24 (5.1%).[8] Other subgroups of adolescents have differing vulnerability, such as the relatively poor, those in rural areas versus urban areas, those in- or out-of-school, or married and unmarried adolescents.[9]

Our ability to disaggregate data on adolescent HIV, both by age and by other factors, is limited and so prevents a better understanding of subgroups among adolescents in eastern and southern Africa (ESA). We also lack clear information on the proportions of adolescents with HIV that acquired the virus perinatally, or during infancy via breastfeeding, and those that acquired it during adolescence via unprotected sex.[10]

2   UNAIDS, Adolescent Girls and Young Women, available at: http://www.unaids.org/sites/default/files/media_asset/02_Adolescentgirlsandyoungwomen.pdf, 2014

3   UNICEF, The State of the World's Children 2011, available at: http://www.unicef.org/adolescence/files/SOWC_2011_Main_Report_EN_02092011.pdf, 2011

4   https://data.unicef.org/topic/hivaids/adolescents-young-people/#, 2016

5   UNAIDS, 'Towards an AIDS-Free Generation', 2013, p83, http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/20131129_stcktaking_report_children_aids_en.pdf, Idele, P, a Gillespie, T Porth, C Suzuki, M Mahy, S Kasedde, and others, 'Epidemiology of HIV and AIDS among Adolescents: Current Status, Inequities, and Data Gaps', Journal of Acquired Immune Deficiency Syndromes, 66/SUPPL. 2 (2014), S144–53

6   The Lancet, Adolescence: A Foundation for Future Health, available at: http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(12)60072-5.pdf, 2012

7   Kenya AIDS Indicator Survey Report, 2012. http://nacc.or.ke/wp-content/uploads/2015/10/KAIS-2012.pdf

8   Simbayi L, Shisana O, Rehle T, et al. South Africa National HIV Prevalence, Incidence and Behaviour Survey, 2012. Cape Town: Human Sciences Research Council, 2014.

9   Idele, P, a Gillespie, T Porth, C Suzuki, M Mahy, S Kasedde, and others, 'Epidemiology of HIV and AIDS among Adolescents: Current Status, Inequities, and Data Gaps', Journal of Acquired Immune Deficiency Syndromes, 66/SUPPL. 2 (2014), S144–53

10 Ibid, S144-53

This hampers our understanding of who is at particular risk, specific needs of subgroups of adolescents, and what groups, contexts or behaviours might most beneficially be targets for programmatic interventions. In recognition of this, global HIV prevention policies from UNAIDS, WHO and other agencies have urged stakeholders to improve data systems to allow for more disaggregation of the adolescent population[11].

Nevertheless, there is currently a lack of clarity and consistency around how surveillance systems, surveys and monitoring and evaluation efforts should be modified to cater to this underserved group. A further complicating factor is that the group referred to as 'adolescent', a term used throughout the HIV prevention field, is defined in different ways by different stakeholders. Furthermore, people going through adolescence are also often lumped in with other broad categories that may not reflect their needs, such as 'children', 'adults' or 'youth', depending on the focus of the organisation.

About this paper

EHPSA commissioned MannionDaniels Limited[12] to produce a report on the issue of disaggregation of data on adolescents. It aims to contribute to, and broaden, the regional debate on issues affecting the design of research, policy and programming for HIV prevention for adolescents. This discussion paper is a summary of the key issues in the report. The full report and evidence briefs are available at:
http://www.ehpsa.org/critical-reviews/age-disaggregation

The first section of this paper summarises the definitions of adolescence currently in use and how they relate to quantitative data. It offers some ways forward on a common approach to defining adolescence in the ESA region.

The second section summarises the main HIV indicators, their data sources and what they can tell us about adolescents in ESA. It also outlines the challenges that prevent a more detailed breakdowns of adolescent HIV data from being used, and the solutions that can help us overcome those challenges.

Methods

This discussion paper triangulates information from three sources: a review of published literature; discussions with experts on adolescence; and case studies focused on three selected countries - Malawi, South Africa and Tanzania.

• Consultations with experts: 59 experts were consulted via telephone or in-person meetings. Experts were identified via the networks of the authors of this paper and through recommendations of the experts themselves.

• Literature review: A wide range of literature was consulted including the toolkits and surveillance guidelines of multilateral and donor organisations; major agency and national government HIV progress reports; HIV modelling documentation; and relevant journal articles. Additional data from the three focal countries was accessed including routine data reports, national survey and surveillance reports and youth policies.

• Country case studies: The selection of countries was based on their diverse HIV prevalence levels and trends and their ability to provide a range of insights into the topics.

Limitations

This paper focuses on definitions of adolescence and the challenges of disaggregating quantitative data. It does not attempt to provide a nuanced understanding of the adolescent experience and its associated vulnerabilities.
In addition, the experts consulted for this paper may not represent the views of all those working in this field.

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11 WHO, 'Adolescent HIV Testing, Counselling and Care: Monitoring, Evaluation and Research', available at http://apps.who.int/adolescent/hiv-testing-treatment/page/monitoring_evaluation_and_research, accessed August 2016

12 www.manniondaniels.com

Similarly, the breadth of issues covered in this paper, combined with the huge amount of documentation and literature available on each of these subjects covered in this paper, means that not all literature relating to these topics could be reviewed. Finally, while the three case study countries provided useful insights, they may not be fully representative of the diverse countries and communities in the region.

2. Current definitions

'Depending on the agency or governmental body, a 15-year-old in eastern and southern Africa will be categorised as a child, an adult, an adolescent, a young person and a youth.'

Overlapping definitions

Adolescents are defined as aged 10-19 years by the WHO and UNICEF. This definition is shared by many governments in the region and has been adopted by various NGOs and research institutions.

Data relating to HIV commonly reflect the 15- to 24-year-old population. UNAIDS often refers to 'adolescents and young people', defined as ages 15-24 [13], and this is the age range used for the UNGASS indicator relating to young people. Despite AIDS Indicator Surveys being described as surveys of 'adolescents and adults', their samples do not include 10- to 14-year-olds[14]. Various UN agencies and USAID are focused on 'youth' or 'adolescents and youth', including for HIV programming, which they define as 15- to 24-year-olds or 'young people' defined as 10- to 24-year-olds[15] [16].

Most ESA countries have set the age of majority at 18, which means that under-18s are legally classified as children. UNICEF similarly categorises children this way. In routine data, service indicators are often divided between ages 0-14 years and 15 years and up, effectively including 15-year-olds as adults.

Ten- to twenty-four-year-olds are therefore included in a variety of groupings, but these groupings may be based more on the needs of agencies and data analysts than the actual needs and risks faced by different subgroups within the age range.

Depending on the agency or governmental body, a 15-year-old in the ESA region will be categorised as a child, an adult, an adolescent, a young person and a youth.

Being categorised into various broad groups has a number of implications. Adolescents are likely to be the target of a range of services, policies and programmes designed to include anyone from infants to the elderly.

It must be noted that overlapping definitions are necessary. Younger adolescents are also children, and should benefit from the same protections. Older adolescents are also adults and must bear adult responsibilities. However, since adolescents are already subsumed into these other broad categories, it is important that the definitions of adolescence that we use to distinguish them from other children and adults do represent their specific needs. Where possible, categorisations layered on top of 'children' and 'adults' should avoid being overly broad, and should not overlap with each other. The issue is not that the 10-19 and 15-24 age ranges overlap with childhood and adulthood, but that they themselves are broad and overlap with each other.

Categories that span the child-adult cut-off point of 18 are also problematic. For example, 18- to 19-year-olds are adults that are categorised as adolescents and grouped in with children, while 15- to 17-year-olds are children that are categorised as youth and grouped in with adults.

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13 UNAIDS, Adolescent Girls and Young Women, available at http://www.unaids.org/sites/default/files/media_asset/02_ Adolescentgirlsandyoungwomen.pdf, 2014

14 The DHS Program, AIS Methodology, available at http://dhsprogram.com/What-We-Do/Survey-Types/AIS-Methodology.cfm#CP_ JUMP_16323, accessed August 2016

15 UNDESA, 'Definition of Youth', United Nations Department of Economic and Social Affairs, 2009, 2014, 1–7

16 USAID, Youth in Development: Realising the Demographic Opportunity, available at https://www.usaid.gov/sites/default/files/ documents/1870/Youth_in_Development_Policy.pdf, 2012

The 10-19 age range

The standard definition of adolescents as 10-19 year olds used by WHO and UN agencies is the period of life that encompasses the main changes and transition points of the adolescent experience[17]. It is useful because it has been widely taken up by other organisations and projects as their official definition of adolescence, and consistent terminology facilitates communication. This definition also conforms to the norm among data analysts of using five-year bands to group people by age. A standard age range allows for comparability in data, policies and programme designs.

However, as with any strict definition of a diverse group, it also has a number of important limitations in addition to the issue of overlapping with other age categories described above. These are:

- Age range too wide. This wide age range groups together people at very different life stages. The attributes and needs of 10-year-olds are dramatically different to those of 19-year-olds, and their policy and programming needs will be very different. The prevalence and incidence of HIV among early adolescents, middle adolescents and young adults is also very different.

- Rarely used in presentation of data. While this definition has been adopted by a variety of international agencies and national governments, it is sporadically used in practice – largely negating the benefit of having a standard definition.

- Life stage, not age: The start and end points of adolescence are not only determined by age. For example, adolescence is generally considered to start with the biological changes of puberty which tend to occur at different points between the ages of 10 and 15-years old[18]. Adolescence is thought to end with physical maturation combined with the transition to adult social roles[19]. Both these start and end points vary with individuals and contexts.

Definitions beyond age

There are alternative definitions of adolescence in use that may be more appropriate for understanding the complexities of adolescence. For example, DFID's youth policy takes a 'lifecycle approach' to youth, defining it as 'the period of time during which a young person goes through a formative transition into adulthood'. Taking a lifecycle approach is valuable because it allows us to go beyond defining young people by age to identifying what it means to become an adult by other defining moments - such as getting a job, marrying or becoming a parent. It also enables us to take into consideration cultural and country contexts, and to examine the broader social, economic, political, physical, emotional and cultural changes that the transition to adulthood involves."[20]

To be usable as a definition for quantitative data analysis, a clear set of criteria would be needed to categorise people. Given the complex interplay of factors that demarcate adolescence from adulthood, it is unclear whether it would be possible to create a strict definition of the endpoint of adolescence. Furthermore, there would be the risk that comparable data could not be presented on adolescent HIV from different contexts if this context-specific and nuanced definition is used.

A lifecycle approach is useful therefore, in developing a qualitative understanding of the true nature of adolescence. It can also help us to interpret quantitative data by understanding how factors such as education and marriage fit into adolescence as a complex period of transition. However, it cannot replace age range definitions used to categorise people as adolescents for quantitative data.

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17 Canadian Paediatric Society, Age Limits and Adolescents, available at http://www.cps.ca/documents/position/age-limits-adolescents, 2003

18 The Lancet, Pubertal Transitions in Health, available at http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(07)60366-3.pdf, 2007

19 The Lancet, http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(07)60366-3.pdf, 2007

20 Department for International Development, Putting young people at the heart of development: The Department for International Development's Youth Agenda, available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/548247/DFIDyouthagendaapproach3.pdf, 2016

Compromise proposal

The limitations of both the age based and life-stage based definitions of adolescence illustrate that there is a tension between the complex and context-specific nature of adolescence, and the need for a simple and standard definition for the purposes of quantitative data.

There is no current solution which will both fully capture adolescence and be usable for categorising people in quantitative data. Instead, we can aim to address the other limitations of the 10-19 definition described above – that it is too broad, that it overlaps with other age range categories and that in practice it is rarely used to present data.

A common approach is to focus on three stages – early adolescence, middle adolescence and young adult-hood – and to use these stages in place of the broad and overlapping groups 'adolescence' and 'youth'.

Early adolescence: Members of this group are entering puberty, and experience the associated rapid chang-es in biology and social roles and expectations. Most in this group have a developing interest in sex but not reached sexual debut, with some important exceptions. Relationships with peers become increasingly important[21].

Middle adolescence: The physical changes are less dramatic for this group, though changing social relation-ships and roles become increasingly important[22]. Members of this group are starting to have sex, with levels increasing markedly in the later years. This causes HIV incidence to increase, though it tends to remain rela-tively low, especially among males in the region.

Young adulthood (or late adolescence): This group is largely sexually active and out of school. Young adults are becoming more emotionally stable and achieving increased independence. They are more likely to be married, have children, and work. In most contexts, HIV incidence among this group is higher than for early and middle adolescents.

There is no standard set of age ranges corresponding to these three stages. Different organisations and experts use different age ranges. The most common is to use the standard five-year age bands to define the three groups:

- Early adolescence – 10-14 years

- Middle adolescence – 15-19 years

- Young adulthood – 20-24 years

The graphic below shows how the use of mutually exclusive age ranges that match the child-adult cut-off could reduce the risk of people being lost in definition overlap.

Figure 1: Proposed definitions of adolescence

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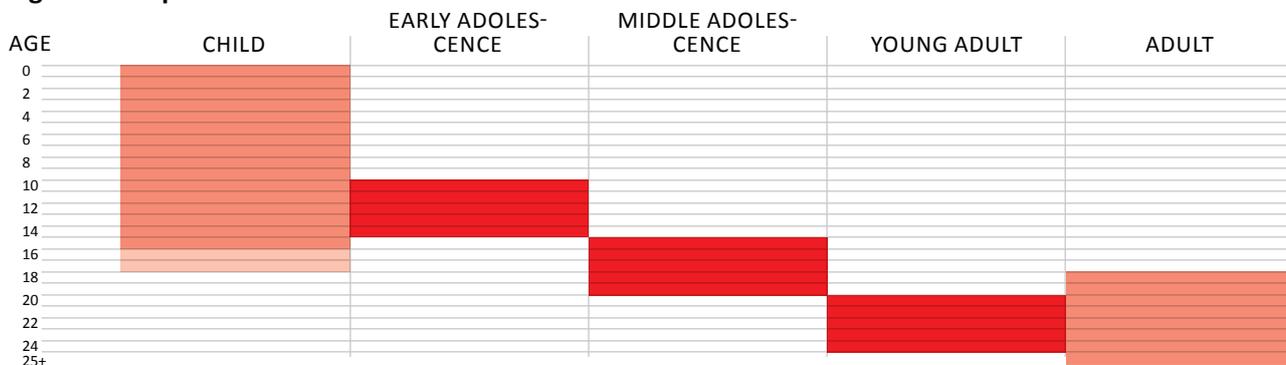
21 Ibid.

22 Ibid.

3. Disaggregation, challenges and solutions

3.1 Indicators and data sources

Indicators tell us about the direction and scale of the epidemic. The way that an indicator should be disaggregated depends on how the data is to be used. For example:

- Prevalence and incidence data: Disaggregated prevalence data help us understand who has a current need for treatment. In younger age groups, change in prevalence between ages can also give an indication of risk of new infections. However, incidence data, which measures new infections more directly, is important to give an understanding of the current risk of infection faced by different age groups. This is particularly useful for identifying groups to be targeted for prevention activities.

- Data on knowledge and behaviours: Disaggregated data about knowledge can tell us who is in need of further education and who has been left behind in education efforts. Disaggregated data on behaviours, such as condom use and multiple sexual partners, inform us of who is likely to be at heightened risk of infection.

- Service data: Routine data on service provision is used to inform management decisions at all levels, ranging from procurement of items such as family planning supplies, to performance monitoring. Routine data are also important for estimating the coverage of services, factors affecting uptake and adherence to services. Understanding how specific groups are receiving services would allow the health system to better serve those groups.

There are different data sources which can provide information for different indicators and allow for disaggregation and grouping in different ways. These include national surveys, Antenatal Clinic surveillance; key population surveillance; routine service data; studies and research projects; and Spectrum or other model estimates.

Different data sources present varying levels of disaggregation:

- National survey reports tend to present the most disaggregation, and have been more standardised across countries than other data source reports.

- Key population surveillance presents inconsistent disaggregation and often excludes under-18s.

- Routine service data reporting is the least disaggregated and data specific to adolescents is usually not provided.

3.2 Limitations of standard grouping strategies

It is common to provide disaggregation of results by demographic factors such as age, sex, marital status, race, education and occupation. These may be relevant for grouping adolescents, but there are differences in how we should disaggregate these factors for adolescents.

The most important example is age groups. As discussed above age ranges are commonly too wide to allow for a proper understanding of adolescence. One solution is to first analyse data by year of age, rather than automatically creating multi-year bands. This allows users of the data to see any specific ages in people's lives where risks appear to change.

Age grouping is not the only case where standard grouping practice can cause losses in information. If age data is does not differentiate by sex, important differences between young men and women may not be reflected. Other factors such as type of residence, being sexually active, and having multiple partners, may also benefit from a more nuanced disaggregation.

3.3 Additional disaggregation factors

While the standard demographic factors by which data are commonly disaggregated for adults are also relevant to adolescents, there are other factors that are of particular importance. These include school attendance and household structure, which have been shown to influence HIV risk.[23]

The first step towards a solution is to ensure that the required data, such as school attendance and household structure, are collected where this would be possible and useful – especially in national surveys, key population surveillance and relevant research studies. The second step is to make disaggregation of adolescent data by these factors standard by including them in report templates and M&E guidelines.

3.4 Exclusion of 10- to 14-year-olds

National surveys such as DHS and AIS make a huge contribution to our broader understanding of HIV epidemics. However, the 10- to 14-year age group is generally excluded from national surveys, ANC surveillance, key population surveillance and Spectrum modelling.

Since most 10-14 year olds have not reached sexual debut, it may be considered justifiable that data on them are not collected. However, there are a number of reasons that data on 10-14 year olds are important:

- Many adolescents with HIV, including 10-14 year olds, were infected at infancy. This group has specific needs.
- Approximately 10%, 15% and 14% of early adolescents in Tanzania[24], Kenya[25] and Malawi[26] respectively have reached sexual debut. A systematic review found consistent associations between early sexual debut and HIV[27].
- Early adolescence is an important opportunity to influence future trajectories[28]. It is important that programmes working with this group are armed with knowledge and behaviour data about them.

There are valid ethical and technical considerations of working with children aged 10-14 which may lead to the exclusion of this group from some studies. However, challenges have been overcome in a number of programmes. Examples include the Population-Based HIV Impact Assessments (PHIA)[29], that include data on under 15-year olds as part of data collection encompassing the whole household[30], and The Global Early Adolescent Study[31] whose focus is 10- to 14-year-olds.

Strategies to allow inclusion of 10- to 14-year olds include:

- Adolescent-specific data collection;
- Household data collection; and
- Retrospective interviewing of older adolescents.

Researchers may however require additional guidance on matters such as the ethical approval process and interviewing young adolescents.

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23 Tanzania THMIS 2011 dataset and Malawi DHS 2010 dataset, available at dhsprogram.com

24 HIV/AIDS and Malaria Indicator Survey 2011-2012 – Tanzania, available at http://dhsprogram.com/pubs/pdf/AIS11/AIS11.pdf, 2013

25 Demographic and Health Survey 2014 – Kenya, available at https://dhsprogram.com/pubs/pdf/FR308/FR308.pdf, 2015

26 Demographic and Health Survey 2010 – Malawi, available at https://dhsprogram.com/pubs/pdf/FR247/FR247.pdf, 2011

27 NCBI, Is early sexual debut a risk factor for HIV infection among women in sub-Saharan Africa? A systematic review, available at http://www.ncbi.nlm.nih.gov/pubmed/23176109, 2012

28 NCBI, A conceptual framework for early adolescence: a platform for research, available at http://www.ncbi.nlm.nih.gov/pubmed/24486726, 2013

29 large-scale national surveys currently being implemented in Malawi, Zimbabwe, Zambia, Uganda and Swaziland

30 http://phia.icap.columbia.edu/

31 Global Early Adolescent Study, available at: http://www.geastudy.org/

3.5 Small sample sizes

Sample sizes are one of the determinants of how precise the results of a survey or surveillance will be. In some studies, the sample sizes are not large enough to allow for disaggregation of results within in the youth age groups that would be most useful to programme designers and policy makers.

Solutions to this issue include:

•   Using much larger sample sizes; and

•   Oversampling adolescents without inflating other groups.
In the final analysis, it is important to recognise that samples in existing, large-scale national surveys may not be suitable to achieving anything more than a big picture snapshot of adolescent HIV.

3.6 Limitations of models

The disaggregation presented by models is limited. For example, Spectrum includes results for 15- to 24-year-olds as a separate group. However, more detailed breakdowns of estimates into smaller age groups or by other factors are more difficult to obtain. This is because, in the past, models have been constrained by available input data. These have meant there would be limited benefits, but substantial challenges, of building routine models to provide more definition in narrower age bands of adolescents and youth.

Models, including Spectrum, are regularly improved upon and updated. The assumptions and source data that models can use are also progressing and becoming more detailed and accurate. For example, the PHIA surveys will use large samples that include adolescents, providing us with a powerful data source with which to calibrate modelled estimates.

3.7 Limitations of routine service data/HMIS

Most HMIS in ESA provide data on testing and treatment services for children and adults (usually children are categorised as those aged 0-14 years old, and adults are those 15 years and above). Deviations from this are rare but do exist – for example Malawi's quarterly reports include HIV testing and counselling figures for 15-24 year olds. In general, there are no figures specific to adolescents, let alone data split by sex or other factors.

Data on age, sex and in some cases other factors, are collected at the facility level for each patient, but this data generally does not go beyond the facility.

There are several strategies for dealing with this challenge:
Revisit original records: Data can be extracted by visiting a sample of facilities and reviewing patient records. This will enable the creation of a dataset with age and sex variables. This dataset can then be analysed with any combination of age- and sex- disaggregation required, as well as geographical disaggregation. Such exercises are being undertaken in both Malawi and Tanzania as a collaboration between UNICEF and the national governments.
Sentinel sites: A sample of sentinel sites can be selected for more intensive data collection. Additional resources can be put into technology, training and other resources to make the collection of additional, rigorous data easier, and provide access to un-aggregated raw data.
Patient level databases: It is possible to use computer-based management information systems in facilities to create patient-level databases. If these databases include a demographic record for each individual patient with their sex and age, it should be possible to produce disaggregated service figures. Other disaggregation factors can also be used if they exist in the databases.

3.8 Lack of data accessibility

The data on adolescents that can be easily accessed, or that has been widely disseminated, is only the tip of the iceberg of the data that has already been collected. Reports from national surveys and surveillance do include chapters or sections dedicated to adolescents or youth with varying degrees of detail. However, these are often a relatively small part of longer reports, and do not appear to be well known or used. Policy-

makers and programmers would benefit from access to adolescent-specific information without having to go through a variety of long adult-focused documents to find it.

Various efforts are being undertaken to rectify this. Data analysis or re-analysis can be accompanied by a specific dissemination plan to reach programmers and policymakers. There are also other ways of providing access to data beyond reports. One example is StatCompiler[32], which allows the public to produce a large variety of tables and graphs based on DHS data, depending on their requirements. Such tools can be enhanced to cater to the requirements of adolescent-focused users[33].

3.9 Lack of nuanced understanding

The standard large-scale data sources used for understanding HIV epidemics may not be all that is needed to further our current understanding HIV among adolescents. For example, most surveys and surveillance provide detailed data about one moment in time. Snapshots of indicators, useful disaggregation and best data collection methods, can only provide limited insights into the complex dynamics of adolescent vulnerability. Routine service data also includes only basic facts about a person's characteristics and service uptake. Therefore, these sources are not necessarily well suited to providing insight into the interaction of biological, psychological, and social transitions that can result in adolescent vulnerability.

The broader takeaway point is to manage our expectations of what each data source can provide. Many alternative approaches such as qualitative methods and longitudinal studies are used successfully to answer these questions.

3.10 Lack of disaggregation by mode of infection

Routine data and survey data cannot usually distinguish between adolescents infected during infancy and during adolescence. Whether an adolescent was infected during infancy or adolescence has different implications for risk, treatment adherence and prevention efforts. Distinguishing between them in survey, surveillance and routine service data would therefore be useful[34]. However, global reporting currently does not distinguish between the groups.

Currently the main methods available to us to estimate the number of perinatally HIV infected adolescents are modelling or estimates from longitudinal cohort studies. Surveillance systems could be designed to systematically track perinatally HIV infected adolescents.

3.11 The limitations of simple disaggregation

Programme implementers often wish to use disaggregated data to determine the factors that cause adolescent vulnerability. However, many analyses do not easily allow for such inferences. Firstly, the simple cross-tabulations usually presented in data show associations, not causality. In addition, multivariate analyses are required to exclude effects of confounding, and are often not done.

For example, programmers may want to see whether being relatively poor results in higher vulnerability, and therefore higher HIV prevalence. Simple cross-tabulation of wealth and HIV prevalence may indicate that the wealthiest are at a higher risk of HIV than poorer groups. However, when adjusted for urban/rural residence, this association may disappear, implying that living in urban areas is the real risk factor, not being wealthier.

This issue comes back to the variety of ways in which data is used. There is nothing incorrect about showing that those in higher quintiles have higher HIV prevalence. For example, it may be useful to know that to reach

32 http://www.statcompiler.com/

33 USAID, Youth Data Collection in DHS Surveys: An Overview, available at http://dhsprogram.com/pubs/pdf/OP9/OP9.pdf, 2014

34 Journal of the International AIDS Society, The changing epidemiology of the global paediatric HIV epidemic: keeping track of perinatally HIV-infected adolescents, available at http://www.jiasociety.org/index.php/jias/article/view/18555/3055, 2013

people living with HIV with certain messages or services, it is important to use communication channels that are relevant to both the wealthier and poorer parts of the population. However, there is a problem if this over-simplified analysis is used to infer the causes of higher HIV prevalence. Data should be presented in ways that suit the specific question that is being asked.

There are widely-used ways to adjust for confounding, including multivariate analysis techniques.

However, there is a basic conundrum here: the way that sample sizes are determined, data is analysed and presented should be based on how the data is to be used. In the case of HIV data from surveys and surveillance, it is used in a variety of ways and is "general purpose" data, unlike research studies focused on a specific question. To collect data and present analyses that would cover all the potential uses would require larger, more expensive samples, and would also make reports unwieldy.

3.12 More effective use of existing data

There are two strategies that can be employed to overcome the limited use of existing survey data:

- Ensure that reporting templates and guidelines present results that are appropriate to the priority needs of data users. This requires consultation to determine the most important ways that the data is used.
- Provide access to raw data. This allows analysts to produce results appropriate to specific needs. There are examples where data sources, such as surveillance datasets or datasets from research studies, have been made available in data repositories[35]. Expanding such efforts would ensure that data can be analysed and presented to meet the myriad needs of programmers and policymakers.

4. Conclusions

The response to the challenges of defining and disaggregating adolescence will be largely driven by the needs of advocates, planners, programmers and service providers. Adaptations will have to balance what is desirable with what is feasible given the practical challenges raised by the diversity of data collection methodologies, increased workloads, increased costs and, potential for lower cost effectiveness, when we seek to refine information further. Thus, reaching agreement on what questions are priorities to answer, and which produce 'nice to have' information, will be a key first step to deciding what disaggregation of routine or other data and analyses should be undertaken.

Defining adolescence

Overlapping and broad additional categories layered on top of the child and adult categories make the specific needs of adolescents less visible and less clearly defined. This makes it more difficult to target and design interventions to use scarce resources to maximum effect.

For most data collection and reporting purposes, rather than using the 'adolescent' and 'youth' categories, we propose standardisation and wider use of three stages of adolescence – early adolescence, middle adolescence and young adulthood. These stages better group together people with similar needs and experiences, and are mutually exclusive.

The standard age ranges corresponding to these stages can either adhere to the current standard five-year age bands (10-14, 15-19, 20-24) or we can attempt to base them on years of age that correspond to life transition points. However, as we have seen there are challenges in generalising life transition points.

A practical solution would be to stay with five-year age bands for most purposes, as they are already so commonly used. However, to address certain issues, data and analyses of risk and needs in relation to transition

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35 African Population and Health Research Center, Central Data Catalog, available at http://aphrc.org/catalog/microdata/index.php/catalog

stage rather than age, or in addition to it, may provide useful insights to programmers and service providers. Where policy and planning questions require, and samples are large enough, it may also be useful to collect data and produce analyses for individual years or groupings of years. Strategic choices will, in addition, have to be made about whether to change routine data collection systems, or whether to use non-routine studies or sentinel sites to explore more nuanced disaggregation and inform decisions about whether it is worthwhile to change routine systems.

Disaggregating adolescent data

The calls for more disaggregated data on adolescents can be partially met by pushing existing data further. This includes:

•   Analysing data based on the needs of the relevant programmers and policymakers rather than using the standard approaches applied to adult analysis;

•   Greater consistency about how adolescent data is disaggregated, analysed and presented;

•   Disseminating adolescent data to those that work with adolescents;

•   Disaggregating survey data by key adolescent-related variables such as school attendance and household structure;

•   Ensuring datasets are made available for further analyses to explore more issues and trends than might have been possible in initial studies;

•   Presenting important figures by year of age to identify changes within age groups that can be masked when defaulting to five-year age bands; and

•   Providing extra resources to increase sample sizes, numbers of variables and analyses to resolve persisting uncertainties about trends and relationships between key variables such as schooling, pregnancy and HIV risk.

Many of these improvements have been achieved in the past with efforts that could be replicated. Strategies include:

•   Consulting programmers and policy-makers through well-designed processes to identify analyses that would most benefit their work:

•   Re-analysing or revisiting existing data sources to create adolescent-specific publications using adolescent-appropriate disaggregation factors and methods;

•   Re-analysing survey, surveillance and research data, when the raw data is accessible; and

•   Disaggregating routine service data through the use of data extraction exercises, sentinel sites or patient level databases.

Further improvements could be gained with additional data collection exercises, though these are likely to require more resources. These include:

•   Supporting survey teams and ethics committees to ensure that 10- to 16-years-olds are represented in datasets; and

•   Conducting adolescent-specific data collection exercises where adolescent-appropriate data collection methods, samples and analysis can be used, including the use of qualitative and longitudinal study designs where needed.

The content and opinions as expressed within this document are those of the authors and do not necessarily reflect the opinion of UK aid, DFID, Sida, NORAD or that of the programme managers, Mott MacDonald

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