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**Wellbeing among adolescents and young adults in sub-Saharan  
Africa: a mixed methods study of their wellbeing construct, its  
health correlates and association with access to HIV treatment**

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## **Abstract**

Improving wellbeing among adolescents and young adults aged 15 to 34 years forms an integral part of universal health coverage and sustainable development in sub-Saharan Africa (SSA). However, data on the wellbeing effects of policies and programmes for this age-group remain scarce, despite this being a key Sustainable Development Goal. The lack of evidence on wellbeing determinants and measures are key barriers to the design and evaluation of wellbeing policies and programmes. This thesis contributes towards informing wellbeing measures for policy evaluations and identifying policies and programmes that may be effective in promoting wellbeing among this population.

In this thesis I aim to investigate appropriate measures and health determinants of wellbeing among adolescents and young adults in SSA. Using a mixed-methods research design, I first identify the correlates and experiences of wellbeing among young people living with HIV via a mixed-method review. Thereafter, I apply econometric techniques to investigate the relationship between health (mental and physical) and wellbeing; and subsequently examine whether scale-up of HIV treatment, a key public health policy in this setting, has been associated with any wellbeing gains among young people as they transition into adulthood. Lastly, I qualitatively explore the local understandings and experiences of wellbeing among young people living with and without HIV.

In my review, I find that social support and belonging were key correlates of wellbeing, and that acceptance and belonging within networks were key in shaping experiences suggestive of wellbeing. In my econometrics study, I find that poor mental health and physical health are negatively associated with wellbeing, and that HIV treatment access is strongly positively correlated with wellbeing. My qualitative study suggests that social integration and social contribution are key dimensions of young people's wellbeing in this setting. Overall, my thesis supports the use of multi-dimensional

relational wellbeing measures for this population. Evaluation of multi-sectoral HIV policies on wellbeing among adolescents and young adults are warranted.

## **Declaration by candidate**

I, Darshini Govindasamy, confirm that the work presented in this thesis is my own. Where information has been derived from other sources; I confirm that this has been indicated in the thesis.

I have read and understood the School's definition of plagiarism and cheating given in the Research Degrees Handbook. I have acknowledged all results and quotations from the published or unpublished work of other people.

I declare that no copy editing and/or proof-reading services were availed by me in the preparation of this thesis. I have exercised reasonable care to ensure that the work is original and does not to the best of my knowledge break any UK law or infringe any third party's copyright or other intellectual property right.

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**DATE:** 09 January 2020



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## List of Definitions

**Adolescents-** people between the ages of 10 to 19 years <sup>1</sup>

**Youth-** persons aged 15 to 24 years <sup>2</sup>

**Young people-** people between the ages of 10 to 24 years <sup>3</sup>

**Young adult-** people between the ages of 20-24 years <sup>4</sup>

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<sup>1</sup> Source: World Health Organization (WHO). 2014. Health for the World's Adolescents. A second chance in the second decade [Online]. Geneva Switzerland: WHO. Available: <http://apps.who.int/adolescent/second-decade/> [Accessed 28 March 2017].

<sup>2</sup> Source: United Nations (UN). 2020. Definition of Youth. <https://www.un.org/esa/socdev/documents/youth/fact-sheets/youth-definition.pdf>. (accessed 02 June, 2020)

<sup>3</sup> Source: World Health Organization (WHO). 2014. Health for the World's Adolescents. A second chance in the second decade [Online]. Geneva Switzerland: WHO. Available: <http://apps.who.int/adolescent/second-decade/> [Accessed 28 March 2017].

<sup>4</sup> Source: United Nations General Assembly (A/36/215 and resolution 36/28, 1981)- <https://www.un.org/development/desa/youth/what-we-do/faq.html>. [Accessed 02 June 2020]

## List of Abbreviations and Acronyms

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
BMI	Body Mass Index
DALY	Disability-Adjusted Life Year
FE	Fixed effects
FGD	Focus-group discussion
GDP	Gross Domestic Product
HICs	High income countries
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council
IDI	In-depth interview
KII	Key informant interview
LMICs	Low- and middle-income countries
LSHTM	London School of Hygiene and Tropical Medicine
NIDS	National Income Dynamics Study
OECD	The Organisation for Economic Co-operation and Development
PLHIV	People living with HIV
POLS	Pooled ordinary least squares regression
PWB	Psychological wellbeing
QoL	Quality of life
RE	Random effects
SA	South Africa
SAMRC	South African Medical Research Council
SDG	Sustainable Development Goals
SSA	Sub-Saharan Africa
Stats Sa	Statistics South Africa
SWB	Subjective wellbeing
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	The United Nations Development Programme
UNICEF	The United Nations Children's Fund
USD	United States Dollar
WHO	World Health Organization
YPLHIV	Young people living with HIV
ZAR	South African Rand

# **Chapter 1: Background to the study**

## **1.1 Chapter introduction**

In this chapter I highlight the main background literature that supports this thesis. I first introduce the importance of investment in the wellbeing of adolescents and young adults (15-24 years) in sub-Saharan Africa (SSA), both from an economic and public health perspective, and situate these within the current policy landscape. Subsequently, I examine reasons for focusing on wellbeing as an outcome measure in public policy evaluation. I then draw attention to the main health issues encountered by adolescents and young adults in SSA and its likely implications for their wellbeing.

## **1.2 Rising population of young people in Africa-implications for public health policy**

In 2019, Africa was home to nearly one-fifth (221 million) of the 1.2 billion young people aged 15-24 years worldwide. It is estimated that by 2065, this population size will almost double (UN, 2019). Demographic models predict that the African continent will experience substantial demographic transitions in the next decade, with its relatively large youth (15-24 years) population moving into working age, and its share of the working-age population becoming larger than the non-working-age population (Agbor et al., 2012, Ahmed et al., 2016). Based on this demographic transition, results from economic modelling studies indicate that there is potential for this region to achieve a demographic dividend (i.e. a positive economic growth potential) (Bloom et al., 2017).

However, studies suggest that attainment of this economic benefit, linked to the rising youth population, will require greater policy investment among this population, particularly public health policies that address broader aspects of quality of life such as wellbeing (Bloom, 2012, Patton et al., 2016). This will help ensure a healthy and educated cohort of young adults who enter into the labour market.

This demographic shift does pose a challenge to health policy and systems in SSA, as currently the quality of life of young people is a neglected health policy and programme area (Kabiru et al., 2013). Presently, adolescents and young people in this region are faced with a triple burden of disease, with high risk of mortality and morbidity related to infectious diseases (i.e. HIV/AIDS), non-infectious diseases (e.g. mental health, nutritional disorders), and injury and violence (Azzopardi et al., 2019, Kassebaum et al., 2017). Total disability-adjusted life years (DALYs) attributed to this disease burden range from 14-29 million per 100 adolescents within sub-Saharan African countries (Azzopardi et al., 2019). These conditions are likely to negatively impact young people's wellbeing, an indicator of whether one is thriving across multiple life domains (Adler and Seligman, 2016), given the strong link between health and wellbeing (Layard et al., 2014, Steptoe, 2019). However, there is limited research on the effects of health policies and programmes on the wellbeing among adolescents and young adults in this region (Plan International, 2019, OECD, 2018). Universal health coverage forms an essential part of attainment of Sustainable Development Goal (SDG) 3 "Improving health and wellbeing for all ages". However, at the recent high-level meeting on Universal health coverage at the United Nations General Assembly, it was reported that adolescents and young adults were overlooked (The Lancet Child and Adolescent Health, 2019).

Informing health policy decisions on wellbeing for adolescents and young adults in SSA is challenging as often data on this age-group is aggregated with adult data (Patton et al., 2016). More importantly, wellbeing indicators, grounded in wellbeing theory, are not routinely collected by health programmes in this region (Azzopardi et al., 2019). Few health policy evaluations go beyond narrow biomedical indicators and examine broader quality of life outcomes such as wellbeing. Furthermore, there is lack of clarity on how to define and measure wellbeing for this population. Guidance on wellbeing measures and an assessment of the health determinants of wellbeing could be an important first step in directing health policies and programmes to support youth wellbeing.

Below, I review the literature on the application of wellbeing as a quality of life outcome measure in economics and policy evaluations.

### **1.3 Wellbeing as a measure of quality of life in policy evaluations**

The social psychology literature defines quality of life as a multi-dimensional construct consisting of both subjective (i.e. wellbeing) and objective components (e.g. living standards). Thus, wellbeing is seen as one of the components of quality of life (Cummins, 2005). Wellbeing is not the absence of mental illness (e.g. absence of depression or anxiety) but rather it denotes positive mental health. It is a multi-dimensional construct focused on emotional (e.g. balance of positive and negative affect), psychological (ability to find meaning, purpose) and social functioning (social integration). Mental illness focuses on disease symptomatology, and thus wellbeing is a distinct phenomenon (Keyes et al., 2002; Westerhof & Keyes, 2010).

Nearly 46 years have passed since Richard Easterlin's pioneering economic research highlighted the value in applying wellbeing measures to assess quality of life (Easterlin, 1974). However, academic and policy interest in this area has only grown in the past two decades (Frey, 2019, Diener and Seligman, 2018, McGregor and Pouw, 2016, Layard, 2006)

A key focus of welfare economics is the allocation of resources to maximise human welfare (i.e. the benefit gained from consumption of goods and services). Traditional economic measures of human welfare (e.g. Gross Domestic Product (GDP)) have been strongly criticised for focusing on the monetary value of goods and services in the formal market (Aitken, 2019). In 2009, the landmark report by the Stiglitz-Sen-Fitoussi Commission on the Measurement of Economic Performance strongly recommended that policy evaluations adopt a wellbeing approach to human welfare and complement

standard economic growth measures with wellbeing measures (Stiglitz et al., 2009). According to Stiglitz et al. (2009), as part of a global shift from economic production towards people centred-development and sustainability, this approach would provide a more holistic account of the impact of policies on social progress as wellbeing measures are able to capture the non-material aspects of people's lives such as the welfare obtained from social relationships and other psychological facets (i.e. competence, autonomy).

Several additional benefits of adopting a wellbeing approach in policy evaluations have been outlined in the literature which include: 1) measuring wellbeing, based on how it is locally defined and valued, could guide resource allocations in line with societal values (Mcgregor and Pouw, 2016); 2) it allows for the study of the net effect of various policies on individual welfare (Odermatt and Stutzer, 2017, Clark et al., 2019); 3) it can be used to study the determinants of welfare both at an individual and societal level (Odermatt and Stutzer, 2017, Clark et al., 2019); 4) multi-dimensional self-reported wellbeing measures can help captures diversity in experiences of quality of life by age, gender and generations (Stiglitz et al., 2009). A major critique of the use of a self-reported wellbeing approach for the assessment of welfare is centred around evidence which shows that people adapt to life events, in that gains and losses in wellbeing are followed by adaptation back to baseline levels of wellbeing (Kahneman et al., 1999, Sen, 1999). Hence, after a negative event people could revise their reports of wellbeing and this may not be reflective of their actual experiences. However, econometric analyses based on longitudinal datasets have shown little to no adaptation for certain life events such as poverty (Clark et al., 2008), unemployment (Clark et al., 2016), and disability (Oswald and Powdthavee, 2008), which has reinforced confidence in the use of this approach to examine welfare.

Currently, improving the wellbeing of nations is at the core of several international development policies such as the SDGs (Goal 3) (UN, 2016), and UNICEF's Global Social

Protection Programme Framework (UNICEF, 2019). Whilst the promotion of wellbeing among its citizens as a government objective has only recently become a national priority for many high-income countries (United Kingdom, Canada, Sweden, Australia, New Zealand), it has been the guiding principle of economic development in Bhutan since the 1970s (Bates, 2009). Several low- and middle-income countries (LMICs)<sup>1</sup> have appointed Ministers of Happiness to oversee policies and programmes that seek to promote societal wellbeing (Sachs et al., 2019). In addition, there has been strong advocacy in the United Kingdom to incorporate wellbeing measures into routine government monitoring systems (Clark et al., 2019), with establishment of a What Works Centre for Wellbeing that aims to inform decision-making on policies to increase community wellbeing (What Works Centre for Wellbeing, 2019). Accounts of national wellbeing data in the United Kingdom have already helped move funding towards policies targeting mental health (Clark et al., 2018). Furthermore, the New Zealand government has recently proposed the use of wellbeing measures to guide budget allocation and priority setting (Anderson and Mossialos, 2019). Whilst robust research has informed wellbeing measures for policy evaluations in high-income countries (Dolan et al., 2011), research on appropriate measures for LMICs is scarce.

Literature on the associations between health policies or programmes and wellbeing in SSA has only recently emerged, specifically in the area of HIV/AIDS (Deaton et al., 2010), sex workers (Ito et al., 2018), gender empowerment (Ferrari, 2016) and ageing (Steptoe et al., 2015). However, there is limited evidence on the relationship between public health policies on youth wellbeing in SSA. Poor health is one of the strongest predictors of wellbeing in adolescence. Wellbeing during adolescence and young adulthood is a strong predictor of positive health, education and employment outcomes in adulthood (Layard et al., 2014). Thus, evaluating public health policies

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<sup>1</sup> Defined according to the World Bank's Country Classification. Source: World Bank. 2019. World Bank country and lending groups [Online]. World Bank Data Help Desk Washington (DC). Available: <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups> [Accessed 16 October 2019].

based on improvements in wellbeing could help identify policies to promote short- and long-run economic gains (Clark et al., 2019).

## **1.4 Disease burden and potential links to wellbeing among youth in SSA**

### **i) HIV/AIDS**

Globally, SSA accounts for the largest number of adolescents living with HIV (1.46 million) (UNICEF, 2019) and young people living with HIV (YPLHIV) (2.8 million) (UNAIDS, 2019a). Despite wide scale-up of life saving HIV treatment, antiretroviral therapy (ART), AIDS-related illness remains the leading cause of mortality among 15-24 year olds in eastern and southern SSA (UNAIDS, 2017)<sup>2</sup>. In 2018, young women aged 15-24 years accounted for 26% of new infections in this region (UNAIDS, 2019). Evidence over the past decade has highlighted the sub-optimal ART access (Desmonde et al., 2018) , treatment adherence (Kim et al., 2014), retention in HIV care (Enane et al., 2018), and health related quality of life (Vreeman et al., 2017) among this population. Young people living with HIV encounter a complex mix of health, economic and social problems namely drug side-effects, co-morbidities, learning difficulties and changing caregivers, including social isolation due to HIV-related stigma (Lowenthal et al., 2014, Bernays et al., 2014, Toska et al., 2019, Sherr et al., 2018, Casale et al., 2019). HIV-related stigma is a known negative correlate of wellbeing (Hutton et al., 2013b, Greeff et al., 2010, Sanjuán et al., 2013), and likely lowers wellbeing among this population by negatively affecting physical and mental health.

To date, outcomes in HIV policy evaluations are based on narrow treatment measures. Yet, recent studies highlight the need to examine broader quality of life measures such as wellbeing (Lazarus et al., 2016, Webster, 2019). However, there is lack of guidance on how to appropriately measure wellbeing, specifically for YPLHIV who may have different needs compared to young people not living with HIV. In Chapter 6, I present

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<sup>2</sup> This is the most recent statistic for the age-group 15-24 years



findings from my mixed method review through which I sought to understand the health and socio-demographic correlates and experiences of wellbeing among YPLHIV. In addition, in chapter 8, I highlight findings from my qualitative study that explored how wellbeing differed by age, gender and HIV status among YPLHIV aged 15-24 years.

The scale-up of ART in this high HIV burden region has been impressive and is associated with gains in health-related quality of life among adults living with HIV (Beard et al., 2009). Furthermore, studies suggest that improved ART access is associated with positive labour market outcomes (Thirumurthy and Zivin, 2012, Rosen et al., 2014, Larson et al., 2013) and spillovers in terms of growth and educational investments among children living in households affected by HIV (Zivin et al., 2009, Lucas and Wilson, 2013). This policy may also be associated with positive spillovers in terms of wellbeing. However, there is lack of evidence on the wellbeing gains of this policy, particularly among youth. In Chapter 7, I present findings from my evaluation of the relationship between South Africa's ART scale-up policies and wellbeing among youth aged 15-24 years.

## **ii) Mental health**

Mental illness is one of the strongest negative predictors of wellbeing. Robust data on the disease burden of mental health conditions among adolescents and young adults is limited in SSA (Erskine et al., 2017). However, evidence from an earlier systematic review of community-based studies in SSA suggest that mental health problems among 0-16 year-olds is substantial (pooled prevalence of psychopathology 14.5%) (Cortina et al., 2012). In a recent multi-national study in SSA, Kilburn et al. (2018) found that between 33% and 64% of rural youth aged 15-25 years in Kenya and Tanzania, respectively, possessed symptoms suggestive of depression. Similarly, a study conducted in peri-urban South Africa, reported that 33% of adolescents aged 14-19 years screened positive for probable depression (Barhafumwa et al., 2016). Whereas in a South African study conducted among peri-urban young adults aged 18-30 years, the prevalence of depressive symptoms appeared to be substantially higher, with

72.0% of women and 74.8% of men who reported moderate or high levels of symptoms (Gibbs et al., 2018).

More recently, resilience, defined as one's ability to draw on resources in their socio-ecological context in order to adapt to adversity or vulnerability (Ungar, 2006, Masten, 2001), has become the focus of HIV adolescent programmes in SSA, in an effort to adopt a strengths-based focus on mental health (Skovdal and Daniel, 2012). Few studies have examined resilience patterns and risk for mental illness among young people. However, two studies conducted in South Africa among younger adolescents aged 10-15 years living with HIV found that resilience was negatively correlated with behavioral problems (Kuo et al., 2019, Bhana et al., 2016). In the international literature, wellbeing has been shown to mediate the effects of resilience on depression among young people (Burns et al., 2011). In addition, resilience has been shown to mediate the pathway between social exclusion and life satisfaction (Arslan, 2019).

Mental illness likely affects wellbeing by negatively impacting mood and social relationships (Layard et al., 2013). However, there is a gap in knowledge on the relationship between poor mental health and wellbeing among adolescents and young adults (Owen et al., 2016). In Chapter 7, I present results from my econometric analysis of panel data that examined the relationship between depressive symptom and youth wellbeing in South Africa.

### **iii) Physical health**

Poor physical health, particularly among young people, is negatively correlated with wellbeing (Proctor et al., 2009). Anthropometric data highlight the high levels of undernutrition (stunting or thinness), and even higher levels of overnutrition (overweight or obesity) among adolescents in this region (Caleyachetty et al., 2018). This double burden places adolescents at high risk of non-communicable diseases

(Christian and Smith, 2018) that are associated with negative wellbeing (Steptoe, 2019). Underweight among adolescents is also associated with symptoms suggestive of depression (Cortese et al., 2009) and an HIV positive status (Frigati et al., 2019). Adolescents and young adults who are underweight are likely to experience stigma and social exclusion as overweight is the more socio-culturally desired body image in this region (Prioreshi et al., 2017, Poobalan and Aucott, 2016). In a review examining the correlates of malnutrition among adolescents in SSA, authors found that being male and living in a rural area were positively associated with stunting (Keino et al., 2014). In a more recent national survey, 44% of adolescents aged 15-18 years reported being dissatisfied with their body image, which likely has implications for their self-esteem and overall wellbeing (Mchiza et al., 2015, Gitau et al., 2014). Furthermore, among rural South African youth, undernutrition was associated with perceptions associated with illbeing (Pedro et al., 2016). To date, no study has explored the relationship between underweight and wellbeing among youth in this setting. In Chapter 7, I also present findings from my econometric analysis investigating the relationship between underweight and wellbeing among youth in South Africa.

## **1.5 Conclusion**

Physical and mental health are key factors that determine wellbeing across the life course. The high morbidity among adolescents and young people in SSA and psychosocial impacts of these conditions coupled with the lack of services to support their broader needs, suggests that wellbeing among this group is compromised. This could have serious consequences for future economic growth and sustainable development in this region.

Firmly placing young people high on the Universal Health Coverage and SDG agenda requires the provision of economic evidence to inform resource allocation decisions that support their wellbeing. The robustness of this evidence could be improved by ensuring that wellbeing measures used in evaluations are aligned with local understanding of wellbeing and that selection of health policies are based empirical national-level data on the determinants of wellbeing. Hence, the impetus for this PhD study was to contribute towards guidance on appropriate wellbeing measures and evidence on health determinants of wellbeing to inform policy and programme development in this area.

## **Chapter 2: Thesis overview**

### **2.1 Chapter introduction**

In this chapter I provide a justification for this research, and then detail the aims and objectives of this thesis. I then describe my design approach, geographic setting and thesis structure. I close this chapter by detailing my role and the outputs from this thesis.

### **2.2 Justification for this thesis**

Wellbeing measures, as conceptualised in the field of social psychology, are now one of the recommended measures for assessing the broader impacts of public policies on social progress (Stiglitz et al., 2009). Several governments have integrated these measures into policy monitoring systems (Sachs et al., 2019). Ranking policies based on their impact on wellbeing could help decision makers understand which policies to invest in to meet the needs of populations (Clark et al., 2019). However, wellbeing measurement in economics has mainly considered unidimensional subjective wellbeing measures that evaluate how one is feeling towards life, with limited focus on psychological wellbeing measures, which assess functioning across multiple domains of life (Frey, 2019). Applying a multidimensional measurement approach may be more valuable for assessing the impact of multi-sectoral policies. To date, wellbeing measurement and its application in health policy evaluations have been limited to high-income settings. In this thesis I seek to provide the evidence to fill this research in gap for adolescents and young adults in SSA.

### **2.3 Thesis aim and objectives**

I aim to investigate appropriate measures and the health determinants of wellbeing among adolescents and young adults in SSA.

To achieve the primary aim, this study sought to meet the following objectives:

1. Identify the correlates and lived experiences of wellbeing among YPLHIV.
2. Examine the relationship between poor mental health and physical health on youth wellbeing.
3. Examine the relationship between ART scale-up policies on youth wellbeing.
4. Explore how wellbeing is locally understood and experienced among young people living with and without HIV.

I address the following research questions:

1. What are the dimensions that constitute wellbeing among young people living with and without HIV in SSA?
2. What are the most appropriate measures for capturing wellbeing among young people living with and without HIV in SSA?
3. What types of public health policies and programmes could be considered for promoting wellbeing among adolescents and young adults in SSA ?

## **2.4 Study design: Mixed methods**

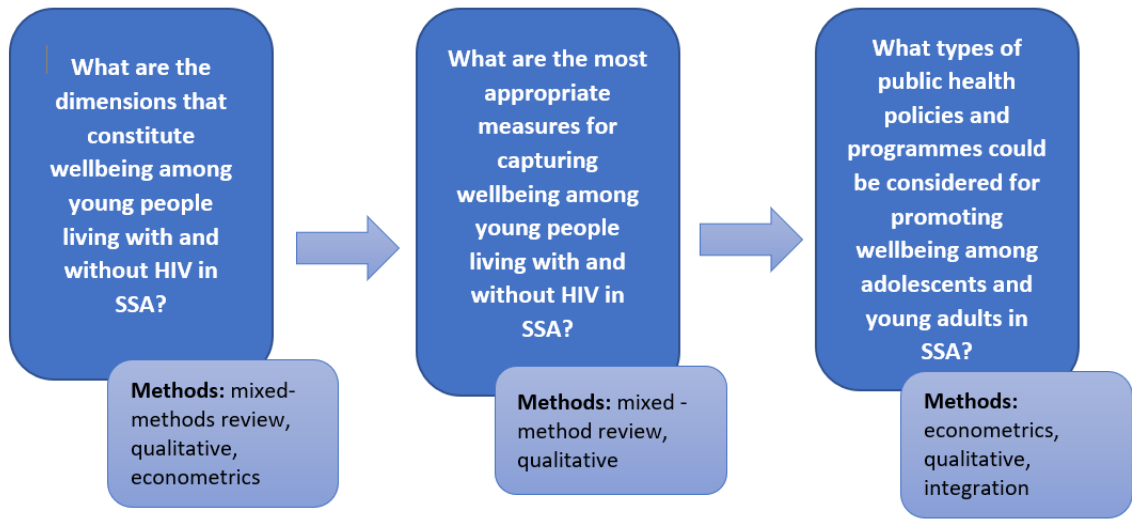
I drew on elements from a sequential exploratory and explanatory mixed method design (Creswell et al., 2003). Mixed method designs can help understand a topic in greater depth and increase confidence in findings. By using multiple data collection methods, it helps generate more evidence and counteracts the limitations of a single data collection method (Tariq and Woodman, 2013). Adoption of a mixed methods approach for the evaluation of wellbeing is aligned to current recommendations (White and Jha, 2014). Similarly, the report by the Commission on the Measurement of Economic Performance emphasises the need for understanding average levels of wellbeing along with peoples diverse experiences (Stiglitz et al., 2009).

Mixed method designs provide a systematic and planned approach to research. According to Creswell et al. (2003), in an exploratory mixed method design, qualitative

data collection and analysis precedes quantitative data collection and analysis. Whereas in an explanatory mixed method design, quantitative data collection and analysis is followed by qualitative data collection. In both designs, the final phase entails integration of both data. Each data collection phase is distinct and given equal weight yet builds upon the other.

I chose a flexible hybrid approach (Figure 1). I first explored the literature on wellbeing among YPLHIV using a mixed method review approach to help narrow my focus. Concurrently, I explored local conceptualisations of wellbeing among young people living with and without HIV via qualitative data collection. This then helped further narrow down my variables in my quantitative secondary data analysis. My quantitative analysis was used to understand general patterns between health and wellbeing. I then used my qualitative data to explain quantitative patterns with more depth. I specifically used the qualitative data to validate and further explain and interpret patterns in my quantitative data, including unexpected findings. Furthermore, I used my qualitative data to contextualise and enrich my understanding of my quantitative data, as well as to generate new knowledge.

My final phase was a joint interpretation of my findings from my review, quantitative and qualitative study. For this phase, I specifically examined results from both phases to identify convergence and lack of convergence in findings.



**Figure 1: Thesis design-Diagrammatic representation of the hybrid mixed method design adopted in this thesis**



## 2.5 PhD study setting

I focused on SSA as this region accounts for more than two-thirds of the total number of adolescents living with HIV. More importantly, adolescents and young adults in SSA, as noted above in Chapter 1, are exposed to multiple disease burdens that likely negatively affect wellbeing.

I specifically focused on South Africa, an upper-middle income country with an estimated GDP per capita of 6331 USD (2018)<sup>1</sup> and high Human Development Index score (0.705) (UNDP, 2019). South Africa has considerably high levels of income inequality (Gini co-efficient -0.63) (World Bank, 2015) and is ranked as one the least happy countries worldwide (World Happiness Report, 2018).

South Africa is divided into 9 provinces which are further divided into 52 districts. Currently it has an estimated population size of 58.8 million, of which 35.1% (20.6 million) are youth (Stats SA, 2019). It is a multi-racial country, with the following population groups <sup>2</sup>: Black African (80.7%), Coloured (8.8%), White (7.9%), Indian or Asian (2.6%) (Stats SA, 2019a). At present, South Africa has an annual population growth rate of 1.4% and average life expectancy at birth of 64.7 years (Stats SA, 2019). According to estimates from the latest community survey, the vast majority of individuals reside in formal dwellings (79.2%), with at least 44% and 60.6% of households that have access to piped water inside the dwelling and flush toilets, respectively (Stats SA, 2016a). Unemployment is concentrated among youth, with this population accounting for 63.4% of the total number of unemployed individuals (Stats SA, 2019b). Moreover, non-completion of secondary school completion among youth

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<sup>1</sup> <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD?locations=ZA>

<sup>2</sup> Population groups in South Africa are defined by race, a social construct that is reflective of the social and political factors that create inequalities. Source: Ellison, G., De Wet, T., Ijsselmuiden, C. & Richter, L. M. 1996. Desegregating health statistics and health research in South Africa. *South African Medical Journal*, 86, 1257-1262. Racial categorisation is considered important in this context as race plays an important role in explaining deprivation. More importantly, government policies seek to redress racial inequalities that are linked with its apartheid history and hence national surveys stratify data by race. Source: Posel, D. 2001. Race as common sense: Racial classification in twentieth-century South Africa. *African Studies Review*, 44, 87-114..

remains considerable (41%) (Branson et al., 2019). In 2016, tuberculosis and HIV/AIDS were the leading causes of mortality among 15-24 year-olds, accounting for 7% and 5.7% deaths, respectively (Stats SA, 2016b).

Globally, South Africa has one the largest generalised HIV epidemics in the world, with an estimated 7.9 million people of all ages living with HIV (PLHIV) (HSRC, 2018) and an HIV prevalence of 20.6% among the general population (15-49 years) (HSRC, 2018). The HIV prevalence among adolescents and young adults is as follows: 15-19 yrs. (10.5%); 20-24 yrs. (20.4%) (HSRC, 2018). To date, South Africa has the largest ART programme in the world, with an estimated 3.9 million HIV-positive children and adults on ART, and approximately 90% of these individuals who are accessing treatment from public-sector clinics and hospitals (UNAIDS, 2016).

## **2.6 Target population**

My empirical studies are focused on young people aged 15-24 years. This age range is aligned with the UN (2008) definition of youth. It partially encompasses WHO's (2014) definition of young people (10-24 years), as it includes older adolescents (15-19 years) and individuals aged 20-24 years. I chose to specifically concentrate on young people aged 15-24 year-olds in this thesis given the high levels of HIV-related mortality and morbidity among this age-group and its likely negative impacts on wellbeing (UNAIDS and UNICEF, 2016). In addition, this age-range for young people is aligned with international HIV epidemiological monitoring indicators (UNAIDS and UNICEF, 2016).

## **2.7 Generalisability**

Findings from this thesis are mainly generalisable to young people living with and without HIV, aged 15-24 years, from South Africa, as the bulk of my empirical studies are based on this setting. However, I draw on the literature from other countries in

SSA and the broader adolescent and young adult literature to contextualise findings and to interpret my data.

## **2.8 Thesis structure**

This thesis is composed of a general literature review and methods section, followed by three paper-style chapters that include chapter-specific literature reviews, method and discussion. The thesis concludes with a final discussion section that aims to draw together and reflect on the findings from the three empirical chapters.

The content of the remaining chapters is outlined below:

Chapter 3 provides an overview of the conceptualisation of wellbeing and then focuses on accounts of wellbeing in social psychology, namely subjective and psychological wellbeing. I discuss the philosophical and theoretical underpinning of these two constructs as well as scales developed from these models. I also briefly highlight the application of these scales in public policy as well as key findings from econometric wellbeing studies. Lastly, I justify the use of the psychological wellbeing (PWB) approach for this thesis.

Chapter 4 provides an overview of the strengths and limitations of each method employed.

Chapter 5 is a mixed method review paper in which I sought to identify the correlates and experiences of YPLHIV in SSA. It concludes with suggestions on appropriate measures.

Chapter 6 provides an econometric analysis that investigated the relationship between health on wellbeing and whether or not expansion of the national HIV policy was positively associated with young people's wellbeing in South Africa.

Chapter 7 consists of a qualitative paper that explored how young people's wellbeing in South Africa is conceptualised and whether or not its dimensions were adequately captured by Ryff model of PWB.

The final chapter presents a summary of the main findings and a reflection of the methodology used. It identifies the limitations of this thesis, including contribution of the research in the light of existing knowledge. It concludes with an exploration of avenues for future research and policy implications.

My appendices section includes my ethics approval letters, consent and assent forms, topics guides and supplementary material linked to each paper chapter. I include supplementary files which detail the search strategy used in my mixed-methods review. For chapter 6, I include a supplementary file that primarily contains additional exploratory analyses and data from robustness checks of my econometric models. For my qualitative study, I include supplementary material outlining dimensions of the Ryff PWB model.

## 2.9 Role of the candidate

The candidate, an overseas PhD student and senior scientist at the Health Systems Research Unit (South African Medical Research Council), conceived the research questions in collaboration with her supervisors (Prof Janet Seeley and Dr Giulia Ferrari). The candidate sought field work funding, obtained ethics clearance and all other necessary local approvals. The candidate oversaw the day-to-day management of field teams and research assistants, with support from her advisor and line manager (Dr Catherine Mathews). The candidate led the implementation, data management, and analysis all three empirical studies. Moreover, the candidate drafted all manuscripts included in this thesis.

## 2.10 Associated publications and conference presentations

Chapter- aim	Outputs
Chapter 5- An investigation on the correlates and lived experiences of wellbeing among YPLHIV (Mixed-methods review)	<ul style="list-style-type: none"> <li>• Presented as an oral at the International Health Economics Association World Congress, Basel, Switzerland (13-17 July 2019)</li> <li>• Submitted to an international peer-review journal (Health and quality of life outcomes). Status: Accepted</li> </ul>
Chapter 6- An investigation on the relationship between health and wellbeing among young people (Econometric analysis)	<ul style="list-style-type: none"> <li>• Plan to submit abstracts to an adolescent health and HIV conference</li> <li>• Plan to submit manuscript to Journal of adolescent health (Q1), and Health Policy and Planning (Q2)</li> </ul>
Chapter 7- An exploration of how wellbeing is locally understood and experienced among young people living with and without HIV (Qualitative study)	<ul style="list-style-type: none"> <li>• Presented as an oral at the 14<sup>th</sup> AIDS Impact Conference, London, United Kingdom, July 2019</li> <li>• Submitted to an international peer-reviewed journal (Social Science and Medicine). Status: Accepted</li> </ul>

## **2.11 Funding and ethical clearance**

I was funded by the South African Medical Research Council through its Division of Research Capacity Development under the Bongani Mayosi National Health Scholarship Programme from funding received from the Public Health Enhancement Fund/South African National Department of Health. The content hereof is the sole responsibility of the authors and does not necessarily represent the official views of the SAMRC.

Funds for fieldwork were obtained from an SAMRC Intramural award (PI: D Govindasamy, RFA-IRF-02-2016), Health Systems Research Unit seed award (PI: D Govindasamy) and National Research Foundation Thuthuka grant (PI: D Govindasamy, TTK160504163987).

Ethical approval to conduct this study was obtained from the London School of Hygiene and Tropical Medicine (Chapter 5-6: approval- 13782 - 1 ; Chapter 7: approval-16217) and South African Medical Research Council (Chapter 5-6: protocol-EC037-11/2016 Chapter 7: protocol- EC017-10/2018).

## **Chapter 3: Literature review**

### **3.1 Chapter introduction**

In this chapter I describe the two main constructs of wellbeing in social psychology, subjective and psychological wellbeing, which lays the foundation for this thesis. In addition, I provide an overview of wellbeing measures and correlates of wellbeing related to each construct. I also briefly highlight definitions of wellbeing outside social psychology. Lastly, I highlight my rationale for selecting a PWB framework for this thesis.

### **3.2 Accounts of wellbeing in social psychology**

#### ***3.2.1 Subjective wellbeing***

The subjective wellbeing (SWB) construct is grounded in Epicurean hedonistic philosophy and examines people's appraisal and evaluation of their own lives (Kahneman et al., 1999). It comprises a person's reflective cognitive judgement of their life, such as life satisfaction, and a balance of positive and negative affect (mood states, emotions) (Diener et al., 1999). The SWB construct has been studied extensively by psychologists and sociologists (Diener et al., 2017, Cummins, 2018, Veenhoven, 2008).

Many psychometric evaluations of SWB scales such as the Satisfaction With Life Scale, Personal Wellbeing Index and Affectometer have shown good reliability and validity (Diener et al., 2018). In South Africa, all three scales have demonstrated good psychometric properties (Wissing et al., 2008, Savahl et al., 2015), particularly among adolescents (Savahl et al., 2015). Epidemiological studies have reported strong associations between SWB measures and mortality and morbidity (Steptoe, 2019). Psychologists have found strong associations between life satisfaction and social

disorders as well as psychological disorders among youth (Park, 2004). Life satisfaction patterns have also been studied to assess the impact of political changes in South Africa (Møller and Roberts, 2017).

In mainstream economics, SWB measures have been widely used as empirical approximations of individual welfare (utility) (Frey, 2019). Hedonic theory underpinning these SWB measures are aligned to Jeremy Bentham's concept of Utilitarianism which suggests that human beings will make a decision based on what produces the greatest happiness (utility) (Frey and Stutzer, 2002). Since utility is the guiding principle in modern welfare economics there has been strong uptake of SWB measures in economics. Several econometric analyses have examined correlates of wellbeing at national and household level. Studies have found that SWB is correlated with covariates at the community and national level (unemployment, social capital, suicide) and individual level (income) (Dolan et al., 2008). A life-course study found that children's emotional health is a strong predictor of their life satisfaction in adulthood (Layard et al., 2014). Work on the intergenerational transmission of wellbeing in the United Kingdom has shown that parental distress (Powdthavee and Vignoles, 2008) and unemployment (Powdthavee and Vernoit, 2013) are important determinants of young people's life satisfaction. Resilience during adolescence has also been shown to reduce the negative effects of life events (e.g. unemployment) on life satisfaction in adulthood (Powdthavee, 2014). Moreover, family functioning has been reported as an important correlate of life satisfaction South African society (Botha and Booysen, 2014). Given its theoretical rigor, empirical robustness, and policy relevance, SWB measures are now collected in large international and national surveys (e.g. Gallup World Poll) (Helliwell et al., 2018). Seminal proponents of the SWB approach have recommended that SWB become a "yardstick" for public policy (Oishi and Diener, 2014, Layard, 2006).



### ***3.2.2 Psychological wellbeing***

In contrast to SWB, broader notions of wellbeing exist in social psychology which embrace a eudaimonic (Aristotelian) perspective that emphasises psychological functioning and human potential (Ryff and Singer, 2013). A key eudaimonic wellbeing is Ryff's PWB model (Ryff, 1989, Ryff and Keyes, 1995) which encompasses six dimensions of positive functioning: 1) self-acceptance, 2) positive relations with others, 3) environmental mastery, 4) autonomy, 5) purpose in life, and 6) personal growth. This model was developed drawing on research in the field of developmental, humanistic, and clinical psychology, and assumes that an individual strives to function fully and realise his or her talents (Ryff, 2014). Keyes (1998) drew on social psychology theory and enriched the eudaimonic tradition of wellbeing, which focused predominantly at the intra-personal level, with an inter-personal focus via development of the social wellbeing model which examines the degree to which individuals are functioning well in their social worlds. His model encompasses the following dimensions: 1) social integration; 2) social acceptance; 3) social contribution; 4) social actualisation; and 5) social coherence. More recently, Seligman and Csikszentmihalyi (2014) extended the scope of PWB to include flourishing which encompasses: 1) positive emotion; 2) engagement; 3) relationships; 4) meaning; and 5) accomplishment.

Scales linked to Ryff's PWB model have exhibited good reliability and stability among adolescent populations (Rose et al., 2017). Moreover, scales linked to the social wellbeing model have shown good psychometric properties in sub-Saharan African settings (Keyes et al., 2008, Wissing et al., 2008). Moreover, However, the application of PWB measures in economic studies are scarce (Frey, 2019).

Several correlates of PWB have been identified in international and regional studies, these include personality traits (e.g. extraversion) and its features (optimism, self-esteem), socio-economic status, and marriage (Ryff, 2014, Khumalo et al., 2012). Family cohesion and family rituals were also found to be correlated with PWB among adolescents (Crespo et al., 2011). Furthermore, in a cross-national study, family and social relationships were found to be key components of happiness among adults from developing and developed countries (Delle Fave et al., 2016).

Quantitative studies have examined differences in PWB by socio-demographic characteristics among adolescents. An earlier South African youth study found lower levels of PWB among black South Africans (mean age 22 years) compared to black Americans (Edwards et al., 2004). Youth studies in Japan (Sun et al., 2016) and Philippines (Perez, 2012) have reported significantly higher PWB scores among females compared to males. In contrast, a study conducted among Italian adolescents, found that PWB was higher among males compared to females (Sagone and Caroli, 2014)}. Gender differences by PWB dimensions also exist, with males exhibiting higher scores for autonomy (Perez, 2012), environmental mastery and self-acceptance (Sun et al., 2016, Sagone and Caroli, 2014), and females showing higher scores for positive relations (Sun et al., 2016, Perez, 2012). In addition, among Italian adolescents, PWB scores were higher among 17-18 year-olds compared to 14-15 year-olds, specifically in personal growth and purpose in life (Sagone and Caroli, 2014). Positive correlates of PWB among young people identified in the literature include resilience (Sagone and Caroli, 2014), self-efficacy (Adeyemo and Adeleye, 2008), self-compassion (Sun et al., 2016), personal growth initiative (Ayub and Iqbal, 2012), emotional intelligence (Adeyemo and Adeleye, 2008), and ego-identity (Abu-Rayya, 2006).

### **3.3 Accounts of wellbeing outside social psychology**

Development scholars have criticised the dominant use of SWB in policy evaluation, and have argued for a broader multi-dimensional perspective that considers the

material and relational dimensions of people's lives (Mcgregor and Pouw, 2016, Sen, 1999, White et al., 2012). Their main critique against this approach is that it considers achievement of the SWB domains as an "individual and internalised task of self-management", with very little account of the social and spatial context that can influence attainment of SWB (White et al., 2012). In the field of development studies, two wellbeing paradigms exist, the capabilities approach and relational wellbeing. The capabilities approach, rooted in Aristotelian philosophy, is a departure from mainstream welfare economics and its approaches to evaluating wellbeing. It focuses on an individual's ability to achieve functioning's that he or she values in life, such as being well nourished or being in control over personal decisions, and his or her ability to choose these functioning's (capabilities) (Sen, 1999, Nussbaum, 2001). The capability framework has been widely applied in development studies to investigate areas such as poverty and empowerment (Clark, 2005). However, the application of the capability framework in the area of multi-dimensional wellbeing over the past decade has highlighted several operational challenges to the use of this broad framework, particularly the empirical measurement of capabilities and selection of functionings (Mitchell et al., 2017, Clark, 2005).

Drawing on the capabilities approach, the Wellbeing in Developing Countries (WeD), an international development research programme, examined the social and cultural constructs of wellbeing in developing countries (Mcgregor et al., 2007). This project found that wellbeing in developing economies encompasses both objective and subjective dimensions, and is considered "the state of being with others, which arises when human needs are met, when one can act meaningfully to pursue one's goals, and when one enjoys a satisfactory quality of life" (Gough et al., 2007). This hybrid notion of wellbeing is grounded in Doyal and Gough's Theory of Human Need, the Resource Profiles Framework and Quality of Life research (Mcgregor et al., 2009). This concept of wellbeing has been applied in studies examining the impact of development programmes on wellbeing (Dawson et al., 2016) and wellbeing among children (Camfield, 2012) in SSA. Emerging anthropological accounts of wellbeing, grounded in

relational ontology, frames wellbeing as an effect, “dependent on the mobilisation of resources from everyday encounters with complex assemblages of people, things and places”(Atkinson, 2013). In recent qualitative research, relational accounts of wellbeing were shown to characterise a good life for people in developing countries (White and Jha, 2018). This overlaps with work conducted in the area of social and cross-culturally psychology more than a decade ago, which originally theorised wellbeing as relational (Ryan and Deci, 2001), and previously demonstrated the importance of relational dimensions of wellbeing in developing countries (Delle Fave et al., 2016).

Overall, it is unknown whether or not young people’s perceptions and experiences of wellbeing in SSA align with these international accounts of wellbeing. Using a theoretically grounded international wellbeing model could help inform measurement selection and explain pathways to wellbeing for this population.

### **3.4 Justification for use of a psychological wellbeing framework**

In this thesis I draw on the PWB construct and underpinning theory to guide my data analysis and interpretation. I chose this approach for the following reasons: 1) the PWB construct has a strong relational focus. Cross-cultural psychology originally theorised wellbeing as relational (Ryan and Deci, 2001, Triandis, 1999, Kitayama and Markus, 2003, Oishi, 2010). More recently, studies have highlighted the importance of relational dimensions of wellbeing in developing countries (Delle Fave et al., 2016, Wissing, 2014, White and Jha, 2018); 2) the PWB approach considers facets that are key in adolescent psychological development (e.g. autonomy, relationships); 3) dimensions of the PWB models align with young people's experiences of wellbeing globally (Proctor et al., 2009) and locally (Govender et al., 2018); 4) under a PWB framework, it is considered that meaning is derived from their socio-cultural environments, and individuals look to these environments to develop values and goals (Adler and Seligman, 2016). This aligns with international perspectives of quality of life "an individual's perception of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" (The WHOQOL Group, 1995)

In Chapter 5 (mixed methods review), I use a relational PWB framework to guide my synthesis and overall interpretation of my data. In Chapter 6 (econometric study), I use a dataset that only includes a SWB measure. Nevertheless, I use a relational framework to guide my variable selection and model structure. In Chapter 7 (qualitative study), I specifically use a PWB model to structure my analysis and assess whether or not accounts of wellbeing aligned with an international PWB model of wellbeing.

## **Chapter 4: General Methods**

### **4.1 Chapter introduction**

In this chapter I describe the main rationale for my choice of research design, perspective, data collection methods and analytical techniques for each of my empirical chapters.

### **4.2 An investigation on the correlates and lived experiences of wellbeing among YPLHIV (Mixed-methods review)**

My mixed method review (Paper 1) aimed to understand the correlates and experiences of wellbeing among YPLHIV. For this review I used a segregated (convergent) design. In this design, quantitative and qualitative evidence are retrieved, analysed and synthesised separately, prior to the final mixed methods synthesis (Sandelowski et al., 2006). This design was selected because quantitative and qualitative research in the area of wellbeing are regarded as complementing each other, and the final mixed synthesis is conducted for the purposes of configuration of complementary research findings in order to generate a set of conclusions (Sandelowski et al., 2006). Moreover, the qualitative data enriched understandings of pathways to and experiences of wellbeing.

For the qualitative review, I used a meta-ethnography design (Noblit and Hare, 1988). A key strength of this design lies in its attempt to maintain the interpretations from the primary data whilst re-interpreting meanings from multiple qualitative studies (Atkins et al., 2008). I specifically used the reciprocal translation meta-ethnography method as translating studies into one another facilitates new and deeper interpretations of a phenomenon (Barnett-Page and Thomas, 2009). This method entailed analysing and synthesising participant views and authors' interpretation to develop higher order constructs.

I adopted a relational wellbeing perspective as increasing research from the fields of social psychology, anthropology and international development have highlighted that relationships are central to the experiences of wellbeing in low- and middle-income countries, particularly studies from SSA (Delle Fave et al., 2016, White and Jha, 2018, Gough et al., 2007).

For the final mixed methods synthesis I drew on the relationality meaning model as proposed by Wissing (2014), which explains how relationships facilitate meaning and wellbeing. I drew on this model as relationships and connections have been shown to be central to formation of wellbeing among young people (Krok, 2018, Crivello et al., 2008, Camfield and Tafere, 2009, Geldenhuys, 2016, Van Schalkwyk and Wissing, 2010). This model has been applied to understand

### **4.3 An investigation on the relationship between health and wellbeing among young people (Econometric analysis)**

In this secondary quantitative analysis (Paper 2), I investigated the magnitude of the association between poor mental and physical health, and wellbeing among young people in South African. In addition, I examined whether ART scale-up policies, assessed via ART access, were associated with wellbeing gains among youth.

I constructed a panel of young people with five waves (2008-2017), using data from South Africa's National Income Dynamics Study (NIDS) which is representative of the country's population in each district. I overlaid this dataset with ART count per capita data (i.e. number of HIV-positive individuals on ART per district per wave divided by the district population in that wave), a measure of ART access, with ART data extracted from South Africa's National Health Laboratory Services data. I used a panel design as the repeated measures allow me to examine changes in wellbeing as young people (15-24 year-olds) transition into adulthood (25-34) (Baltagi, 2008).

For my dependent variable, wellbeing, I used the life-satisfaction measure in the NIDS data as a proxy measure of PWB. Whilst life satisfaction is a SWB and not PWB measure,

it was the only wellbeing measure in the NIDS dataset. Nevertheless, this measure has good psychometric properties (Cheung and Lucas, 2014), is widely used in econometric studies (Dolan et al., 2008) and surveys (Helliwell et al., 2018) and recommended for policy evaluations (OECD, 2013). Furthermore, life satisfaction is correlated with PWB dimensions (Keyes et al., 2002, Ryff and Keyes, 1995). For my independent mental health variable, I used depression score data derived from administration of the 10-item Centre for Epidemiological Studies Depression Scale (CES-D-10) scale in the NIDS. This scale has shown favourable reliability and validity in South Africa (Baron et al., 2017). I used underweight BMI (less than 18.50 kg/m<sup>2</sup>)<sup>1</sup> as an indicator of poor physical health, which I calculated using height and weight data from the NIDS dataset. I used ART count per capita as my main exposure variable to assess the relationship between ART access and wellbeing.

For my analysis, I used multi-level random intercepts models. Multi-level models relax the assumption of conditional independence of individuals living in the same district, and of repeated measurements from the same individual (Rabe-Hesketh and Skrondal, 2012). Using a multi-level random intercepts model, specifically with random effect terms for district and individual, correctly recognises the hierarchical structure of the NIDS data and panel design (Leckie, 2013). Moreover, it accounts for the unobserved heterogeneity at the district and individual level. I conducted my analysis at the level of the district as the NIDS sample was designed to be representative of the population at the district level.

I applied a relational framework as studies have shown that young people's wellbeing is manifested within their social networks (Wissing et al., 2014, Van Schalkwyk and Wissing, 2010). Thus, I used a nested design and I included relational covariates in my

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<sup>1</sup> World Health Organization (WHO). 2018. *Cut-off for BMI according to WHO standards* [Online]. Available: [https://gateway.euro.who.int/en/indicators/mn\\_survey\\_19-cut-off-for-bmi-according-to-who-standards/](https://gateway.euro.who.int/en/indicators/mn_survey_19-cut-off-for-bmi-according-to-who-standards/) [Accessed 02 February 2019].



model such as trust and other key covariates informed by my review and qualitative study

#### **4.4 An exploration of how wellbeing is locally understood and experienced among young people living with and without HIV (Qualitative study)**

Qualitative methodologies are used to understand how or why a phenomenon occurs and to understand individual experiences. In this qualitative study (“the Njabulo study”, Paper 3), I drew on elements of the interpretive phenomenological framework to understand the perceptions and experiences of the wellbeing phenomenon among young people in a peri-urban South African context. This framework is grounded in phenomenology and hermeneutics, and is the preferred framework for psychological qualitative research seeking to understand how people describe and experience a phenomenon, including the meaning they ascribe to this experience (Benner, 1994, Smith et al., 1997, Patton, 2002). This epistemological approach is characterised as being “idiographic, inductive, and interrogative” page 41 (Smith, 2004).

My overall case-study design included three data collection strategies, semi-structured focus-group discussions (FGDs), in-depth interviews (IDIs) and key informant interviews (KIIs). We used multiple-methods to allow for complementary insights and understanding into young people’s wellbeing which may have been challenging to obtain with one single data collection method (Darbyshire et al., 2005).

I used FGDs to understand a wide range of perspectives (Green and Thorogood, 2013) on what constitutes a good or bad life for young South Africans. This method is used to explore knowledge production (i.e. how it is acquired, shared and contested). Thus, through this method I examined how participants communicated and interacted with one another, to understand societal norms and beliefs (Green and Thorogood, 2013). I stratified FGDs by age, sex and HIV status to help capture variation between groups and diverse perspectives

In-depth interviews are used for detailed investigations of personal perspectives and experiences. They are considered appropriate for exploring sensitive topics and complex processes (Green and Thorogood, 2013). Thus, I used this method to obtain authentic accounts of specific lived experiences (e.g. HIV-positive status disclosure, HIV acquisition, death of a family member, pregnancy, poverty), and explored in depth how these experiences affected wellbeing.

I complemented my FGDs and IDIs with participatory approaches. I used Draw-and-Tell techniques in the FGDs (Crivello et al., 2008) and Life-course Timelines in the IDIs. Both these participatory approaches have been found to be effective in understanding wellbeing among children from LMICs setting (Crivello et al., 2008). Draw- and-Tell techniques provide a collective method for obtaining generalised knowledge on wellbeing (Ansell et al., 2012). In addition, it provides a visual display of their social world. This activity was implemented by asking FGD participants draw images of a young person have a good or bad life in the study community. The Life-course Timeline approach allowed us to explore life events in the IDIs within the broader context of their life span (Adriansen, 2012). This activity entailed getting the participant to draw a timeline from birth to current age, and then asking them to highlight to key life events, particularly happy and sad life events. Both participatory methods were used as it has been shown to affirm young people's agency, allowing them to choose images, with discussions centered around these images (Crivello et al., 2008, Adriansen, 2012).

Key informant interviews are conducted with knowledgeable individuals on a specific topic area to obtain data and insights that may be sensitive to obtain via other methods, such as incidents or lived realities within the study community that affect young people's wellbeing (Green and Thorogood, 2013). Thus, I interviewed a range of HCWs that allowed me to gain in-depth and multiple perspectives of the issues affecting young people's wellbeing in the study community and possible programmes and policies that could promote their wellbeing. This method could also be used to gain new ideas on a phenomenon. In addition, I interviewed both local and international academics in this area which helped me gain new insights into wellbeing research

among young people, including key research gaps and ethical challenges (Green and Thorogood, 2013). I subsequently explored some of these ideas in FGDs and IDIs with young people. Key informants can also aid in interpretation of the data (Patton, 2002). Thus, I asked HCWs and experts for their views regarding the interpretation of my data derived with young people, specifically areas that proved to be challenging.

I conducted a framework analysis. This method provides a structured and systematic approach to manage, analyse and identify themes from large volumes of data collected using multiple methods (Ritchie et al., 2013). I applied this method by creating a thematic framework informed by my preliminary data and themes in the literature. Thereafter, I coded, classified and organised data in relation to these main themes and sub-themes.

I used the Ryff model of PWB to structure my analysis. I used this model as several studies have explored wellbeing among adolescents using Ryff's PWB framework, which also has shown alignment with local conceptualisations of wellbeing. Moreover, this model is informed by development stage theories (Erikson, 1994) and theories of positive mental health (Jahoda, 1958b) which have been applied to understand psychological development among adolescents (Hightower, 1990, Miller, 1989, Lerner and Steinberg, 2004). It specifically considers dimensions that characterise positive adolescent development such establishment of positive relationships and sense of autonomy, control and purpose.

## **4.5 Ethical procedures**

### **Secondary analysis- review and econometric study**

In my mixed method review I conducted a quality appraisal of all included studies. Any study with questionable research ethics with YPLHIV was excluded.

For my econometric study, I used survey data (NIDS) and routine HIV laboratory data (NHLS data). Whilst these datasets did not contain personal identifiers (e.g. name and physical address) they contained other identifying information (e.g. enumeration area codes, date of birth, laboratory IDs, HIV status, clinic name). Thus, to prevent any breach of confidentiality, the NHLS dataset was stored on SAMRC's password protected Structured Query Language (SQL) server. This server is maintained centrally with strict security and ensured no datasets were stored on laptops. Only aggregated (district-level) data were exported from this dataset. The secure NIDS datasets were analysed in a secure data office (DataFirst, University of Cape Town), with only district-level analytical outputs taken out from this secure centre, in accordance with NIDS data access agreement.

### **Primary data collection- qualitative study**

Written voluntary informed consent or assent was obtained from eligible individuals prior to participation. Informed consent was obtained from participants older than 18 years. Whereas, for minors (defined as a child less than 18 years of age in South Africa)<sup>2</sup>, written parental consent was obtained prior to obtaining assent from the minor, in line with South Africa's guidelines on ethics in health research (NDoH, 2015). Only if the parent agreed to the minor participating in the study, did the recruiter then proceed with informing the minor about the study. If the minor's biological parents were deceased or not residing with the child, we followed this hierarchy for gaining consent in line South Africa's Children's Act 38 of 2005 (i.e. guardian/foster parent/caregiver) (DoJ & CD, 2006).

Consent and assent procedures were conducted in a private room in the healthcare facility or home of the eligible participant. Assent procedures with minors were conducted in a developmentally appropriate manner, depending on the minor's age and maturity, and not in the presence of their parent. The recruiter read the

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<sup>2</sup> Department of Justice and Constitutional Development (DoJ & CD). 2006. *Children's Act 38 of 2005* [Online]. Available: <https://www.justice.gov.za/legislation/acts/2005-038%20childrensact.pdf> [Accessed 24 March 2017].

information sheet word for word to the respondent, in English or isiZulu, depending on the respondent's preferred choice of language. Furthermore, the recruiter provided sufficient time for the respondent to ask questions for clarification. The recruiter then applied a checklist to assess the parent's and/or adolescent's understanding of the study. Only if the recruiter was satisfied with the parent's and/or adolescent's understanding of the study and assent and/or consent was provided, was the potential participant then enrolled into the study. The recruiter was trained to look for any signs of dissenting behaviours. Parental consent did not override the minor's decision. If a respondent was unable to write a HCW served as a witness and signed on their behalf.

Qualitative interviews were audio-recorded only if permission to record was obtained from participants. Photographs of the participant's artwork were taken, provided the participant provided permission for these to be photographed. All participants received a lunch pack. All adverse events were reported to SAMRC's ethics committee, in line with reporting procedures.

The following standard operating procedures were implemented to reduce and manage the following potential risks associated with the study.

- a. ***Loss of confidentiality and privacy***- Consent and assent forms and other forms containing personal information were stored separately from study forms in a locked cupboard with restricted staff access. Study forms were uniquely identified and did not contain personal or sensitive information (i.e. minor's HIV status). Electronic equipment (i.e. mobile phones, audio-recorders) were stored in a locked safe. The importance of not disclosing any sensitive information during or after FGDs was emphasized during consent and assent procedures as well as at the FGDs.
- b. ***Discomfort or distress***- I together with my study staff underwent research ethics training. Furthermore, we were trained by a qualified adolescent social worker on how to manage distress and pick-up on early signs of discomfort and

distress. In the event respondents presented with signs of discomfort or distress, study activities were terminated. Respondents were briefly counselled by our fieldworker who was a trained counsellor, and actively linked to the appropriate services. In addition, all participants received a referral brochure with contact details of local authorised services they could access to support them in specific area (i.e. anxiety and depression, substance use, HIV-related issues)

- c. ***Reports of abuse and neglect***- I adhered to the reporting requirements of the South African Children's Act 38 of 2005- Section 110 (DoJ&CD, 2006) and the Sexual Offences and Related Matters Amendment Act 5 of 2015 (SAG, 2015), whereby any reports or suspicion of physical abuse resulting in injury; sexual abuse (including sexual offences); and deliberate neglect of a minor, were reported to designated health or social services authority. Furthermore, these minors received referrals to appropriate authorities who were equipped to manage cases of this nature.

## **Chapter 5: An investigation on the correlates and lived experiences of wellbeing among YPLHIV (Mixed-methods review)**

### **Chapter Introduction**

As identified in Chapter 2, there is a need to go beyond narrow treatment outcomes and examine wellbeing for YPLHIV in policy evaluations. However, there is limited guidance on appropriate wellbeing measures for this population in SSA.

This study (Paper 1) describes results from my mixed method review which sought to fulfil objective 2 of this thesis (i.e. to identify the correlates and lived experiences of wellbeing among YPLHIV). This paper has been submitted to BMC- Health and Quality of Life Outcomes and is currently under review.

I include supplementary files that detail the search strategies applied on multiple databases to retrieve quantitative and qualitative studies. The ethics approval letters for this study are included under the Appendices section of this thesis.

## RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

### SECTION A – Student Details

Student ID Number	1402394	Title	Ms
First Name(s)	Darshini		
Surname/Family Name	Govindasamy		
Thesis Title	Wellbeing among adolescents and young adults in sub-Saharan Africa: a mixed methods study of their wellbeing construct, its health correlates and association with access to HIV treatment		
Primary Supervisor	Prof Janet Seeley		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

### SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

\*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

### SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	BMC- Health and Quality of Life Outcomes
Please list the paper's authors in the intended authorship order:	Darshini Govindasamy, Janet Seeley, Ioana D Oлару, Alison Wiyeh, Catherine Mathews, Giulia Ferrari



Stage of publication	Submitted
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**SECTION D – Multi-authored work**

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I conceptualised the study with support from my supervisory team. Thereafter, I developed the full proposal with detailed search strategies. In terms of data management. I managed this process by implementing the search strategy for the respective databases. In addition, I led the screening and data extraction process, with dual screening and checks conducted by co-authors. Finally, I conducted the analysis and write-up. I revised all drafts based on co-author feedback, and submitted the final version to the journal</p>
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**SECTION E**

<b>Student Signature</b>	[Redacted]
<b>Date</b>	19/12/2019

<b>Supervisor Signature</b>	[Redacted]
<b>Date</b>	19/12/2019

# **Research Paper 1: Informing the measurement of wellbeing among young people living with HIV in sub-Saharan Africa for policy evaluations in health economics: a mixed-methods systematic review**

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## **Abstract**

Young people living with HIV (YPLHIV) in sub-Saharan Africa (SSA) are at high risk of having a poor quality of life. Addressing wellbeing explicitly within HIV/AIDS policies could assist mitigation efforts. However, guidance on wellbeing measures to evaluate policies for YPLHIV is scarce. The aim of this mixed-methods review was to identify dimensions of wellbeing among YPLHIV (15-24 years) in SSA to contribute to identifying appropriate measures. We searched six social sciences and medical databases, including grey literature. We included studies that examined correlates and lived experiences of wellbeing, among YPLHIV in SSA, from January 2000 to May 2019. Two reviewers independently screened abstracts and full texts and assessed methodological quality of included articles. We analysed quantitative and qualitative data using descriptive and meta-ethnographic approaches, respectively. Thereafter, we integrated findings using a framework approach. We identified 6527 citations. Of these, 10 quantitative and 30 qualitative studies were included. Being male, higher educational status, less stigma and more social support were likely correlates of wellbeing. Themes that shaped experiences suggestive of wellbeing were: 1) acceptance and belonging— stigma, social support; 2) coping; 3) standard of living. Our final synthesis found that the following dimensions potentially characterise wellbeing: self-acceptance, belonging, autonomy; positive relations, environmental mastery, purpose in life. Wellbeing for YPLHIV is multi-dimensional and relational. Relevant measures include the Personal Wellbeing Index, Ryff's Psychological Wellbeing Scale and Mental Health Continuum Short Form. However, psychometric evaluations of these scales among YPLHIV in SSA are needed.

**Keywords:** wellbeing; mental health; dimensions; measurement; young people living with HIV; mixed-methods review; sub-Saharan Africa

## 1. Introduction

Adolescence and young adulthood are critical periods for wellbeing, an indicator of the quality of life. In addition, this life stage is important for building resources, such as human and social capital, that can sustain wellbeing in adulthood (World Bank, 2007, Layard et al., 2014, Bundy et al., 2018). For young people living with HIV (YPLHIV), who because of greater access to anti-retroviral therapy (ART), can expect to reach adulthood, building and sustaining wellbeing as they grow older is crucial. In sub-Saharan Africa (SSA), there are an estimated 3 million YPLHIV aged 15-24 years (UNAIDS, 2014). However, to date, many YPLHIV in SSA are at high risk for HIV-related mortality (UNAIDS, 2017a) and potentially poor quality of life (Lowenthal et al., 2014, Bernays et al., 2014, Chandra-Mouli et al., 2015, Kagee et al., 2018). According to the United Nations (Un) (2015), the number of YPLHIV in Africa is projected to increase by 44% between 2015 and 2030. Models predict that investment in the quality of life among the rapidly growing youth population in SSA, particularly via addressing health needs, could increase labour productivity and resultantly accelerate economic growth (Bloom et al., 2017). If long-run economic growth is to be achieved, then public health policies need to also promote the wellbeing among YPLHIV, a vulnerable and growing population in this region.

The wellbeing of YPLHIV in SSA is likely to be compromised by the effects of multiple hardships they encounter at all socio-ecological levels (Skovdal and Belton, 2014): 1) individual (e.g. treatment side effects, internalised stigma) (Bernays et al., 2017, Maskew et al., 2016, Enane et al., 2019); 2) household (e.g. death of parent/s, food insecurity) (Ferrand et al., 2010, Cluver et al., 2018); 3) community (e.g. stigma and discrimination within schools) (Enane et al., 2019); and 4) public policy (e.g. lack of psycho-social and sexual reproductive services) (Mark et al., 2017, Ferrand et al., 2010). Importantly, emerging empirical evidence has shown that YPLHIV in this setting are at high risk for depression and anxiety (West et al., 2019, Sherr et al., 2018, Kemigisha et al., 2019) and suicidal ideation (Casale et al., 2019). Mental illness is one of the strongest predictors of wellbeing (Layard et al., 2013). Poor mental health functioning experienced during adolescence may lead to reduced wellbeing in adulthood (Layard et al., 2014, Frijters et al., 2011), which is in turn linked to unfavourable labour-market outcomes such as low earnings (Lundborg et al., 2014, Fletcher, 2013, Healey et al., 2004). This is of major concern as econometric evidence has shown that due to the HIV epidemic, the stocks and

intergenerational transfer of human capital to young people in this region has been eroded (Fortson, 2011, Akbulut-Yuksel and Turan, 2013).

In line with Sustainable Development Goal 3 (“Ensure healthy lives and promote well-being for all at all ages”), wellbeing has emerged as a major policy outcome (Lindert et al., 2015, Kobau et al., 2010). However, to date, HIV policy evaluations focus on narrow clinical and economic indicators (UNAIDS, 2017b, UNAIDS, 2018a, Seckinelgin, 2019). Whilst there is a shift towards including quality of life as an HIV/AIDS programme target (Lazarus et al., 2016), much of the focus has been on health-related quality of life (i.e. physical functioning). These measures do not capture the broader dimensions of quality of life and economic progress as in the case of wellbeing (Cummins et al., 2004), a multi-dimensional construct that considers how one is feeling and functioning across multiple domains of life (Stiglitz et al., 2009, Adler and Seligman, 2016). As the HIV policy landscape moves towards more intersectoral policies, these narrow measures may be inappropriate for the measurement of impact that goes beyond health (UNAIDS and UNICEF, 2016). From a public health policy perspective, understanding the impact of HIV policies on wellbeing could provide a range of ways to direct and strengthen investments for YPLHIV (Fan et al., 2018).

Several wellbeing measures exist in the literature. However, there is a lack of guidance on which wellbeing measures are appropriate for HIV policy evaluations, particularly for YPLHIV in developing economies. The social psychology literature on wellbeing suggests that wellbeing may be conceptualised, experienced, and valued differently across cultures. A better understanding of the correlates and local experiences of wellbeing among YPLHIV in SSA and how these relate to international conceptualisations of wellbeing is required in the selection of culturally sensitive, yet generalisable, measures of wellbeing for SSA. While several studies have explored wellbeing among young people in Africa (Govender et al., 2018, Ushie and Udoh, 2016), to the best of our knowledge, no study has systematically reviewed the evidence on what constitutes wellbeing among YPLHIV on the continent. The objectives of this mixed-methods review are to identify and critically assess: 1) quantitative evidence on the correlates of wellbeing among YPLHIV; 2) qualitative evidence on the lived experiences of wellbeing among YPLHIV; 3) integrate

these two strands of evidence and identify appropriate measures of wellbeing based on dimensions of wellbeing relevant to YPLHIV.

The main reason for using quantitative and qualitative evidence in this review is to provide a broad perspective in order to gain a detailed and thorough understanding of the indicators of wellbeing and potential mechanisms by which factors influence wellbeing (Pearson et al., 2015, Oliver et al., 2005, Ben-Arieh and Frønes, 2011). The findings from this review could guide the selection of wellbeing measures for policy evaluations focused on YPLHIV.

### ***Accounts and measures of wellbeing***

Social psychologists posit a variety of wellbeing constructs. One is subjective wellbeing (SWB), which measures people's emotional and cognitive evaluations of their lives (Kahneman et al., 1999). The three components of SWB include positive and negative affect (mood states, emotions) and life satisfaction (Diener et al., 1999). Frequently applied SWB measures among young people include the Student Life Satisfaction Scale (Huebner, 1991) and the Personal Wellbeing Index (PWI) that measures satisfaction with multiple life domains (family, health, living standards) (Cummins and Lau, 2005). In mainstream economics, unidimensional SWB measures such as the Cantril's Ladder of Life Scale (Helliwell et al., 2018) have been widely used as empirical approximations of individual welfare (i.e. the satisfaction (utility) gained from consuming a good or service) (Frey, 2019). Since utility is the guiding principle in modern welfare economics, there has been a strong uptake of these specific SWB measures.

However, broader constructs of wellbeing exist which emphasise optimal functioning, relationships and human potential (Ryan and Deci, 2001, Ryff, 1989), and may serve as more holistic approximations of utility (Frey, 2019). This has been operationalised via Ryff's multi-dimensional psychological wellbeing (PWB) measure which encompasses six dimensions of positive functioning, defined as follows: 1) self-acceptance — possesses a positive attitude towards self; 2) positive relations with others — has warm, satisfying and trusting relationships with others; 3) environmental mastery — has a sense a competency in managing the environment; 4) autonomy — is self-determining and independent, able to resist social pressures; 5) purpose in life — has goals in life and a

sense of directedness; and 6) personal growth — has a feeling of continued development (Ryff, 2014, Ryff and Keyes, 1995). Keyes (1998) expanded this definition to include social wellbeing, which measures the degree to which individuals are functioning optimally in society. His multi-dimensional measure of social wellbeing, Mental Health Continuum Short-Form, consists of five dimensions, defined as follows: 1) social coherence — being able to make meaning of what is happening; 2) social acceptance — has a positive attitude towards others; 3) social actualisation — believes that the community has potential and can evolve positively; 4) social contribution — a feeling that one's activities contribute to and are valued by society; 5) social integration — a sense of belonging to a community (Keyes, 2009).

## 2. Methods

### 2.1 Epistemological perspective and study design

We adopted a relational wellbeing perspective as increasing research from the fields of social psychology, anthropology and international development have highlighted that relationships are central to the experiences of wellbeing in low- and middle-income countries, particularly studies from SSA (Delle Fave et al., 2016, White and Jha, 2018, Gough et al., 2007). We drew on the relationality meaning model as proposed by Wissing (2014) as relationships and connections have been shown to be central to formation of wellbeing among young people (Krok, 2018, Crivello et al., 2008, Camfield and Tafere, 2009, Geldenhuys, 2016, Van Schalkwyk and Wissing, 2010). According to the relationality meaning model, relationships, with self (intrapersonal) and others (interpersonal) are at the centre of a meaningful life, and play an important role in the connections between people and context (i.e. social, cultural, ecological, physical, spiritual) (Wissing, 2014). This model has a strong PWB orientation and emphasises three key elements: 1 *meaning of life* (experienced in the connectedness to something larger than life and the realisation of values); 2. *meaning in life* (experienced in the belongingness and relatedness to other people); and 3. *meaning to life* (expressed via actions such as expressions of affection and love, longing for belongingness, building relationships). This model hypothesises that meaning of life facilitates the construction of meaning in life which in turn directs activities to provide meaning to life (Wissing, 2014). We specifically applied elements of this model to understand the pathways to wellbeing in order to elucidate dimensions that are relevant in capturing the wellbeing among YPLHIV.

The mixed-methods approach used was a segregated (convergent) design (Sandelowski et al., 2006). We selected this design because we regarded quantitative and qualitative research as complementary. However, we conducted the quantitative and qualitative review separately as different approaches were used and the review criteria differed. For the quantitative review, we followed systematic review methods used in evidenced-based medicine (Higgins and Green, 2011). Whereas for the qualitative review, we used a flexible meta-ethnography design (Noblit and Hare, 1988). Quantitative and qualitative studies were retrieved, analysed and synthesised separately, prior to the final synthesis



(Sandelowski et al., 2006). I used the quantitative data to identify dimensions of wellbeing and used the qualitative to contextualise the dimension for this setting.

## 2.2 Eligibility

The criteria for inclusion of studies are summarised in Table 1.

**Table 1: Eligibility criteria for quantitative and qualitative studies**

	Inclusion	Exclusion
<i>Quantitative studies</i>		
<b>Population &amp; setting</b>	<ul style="list-style-type: none"> <li>Young people living with HIV (aged 15-24 years) in sub-Saharan Africa (as per the 2019 World Bank Country Classification).</li> </ul>	<ul style="list-style-type: none"> <li>Studies were &lt;50% of the population is between the ages of 15-24 years</li> <li>Studies that focus on specific population groups (i.e. orphans, LGBTQI, pregnant or post-partum women, sex workers, homeless youth, patients with co-morbidity)</li> <li>Studies based on samples from African or other countries which are outside the sub-Saharan African region (as per the 2019 World Bank Country Classification).</li> </ul>
<b>Study design</b>	<ul style="list-style-type: none"> <li>Observational research study designs or standard of care arm from a trial</li> <li>Studies that statistically examined factors associated with subjective or psychological wellbeing or any of its dimensions using regression techniques</li> <li>Studies that statistically examined factors associated with mental health (i.e. mental illness-depression, anxiety) using regression techniques</li> </ul>	<ul style="list-style-type: none"> <li>Letters, opinion pieces, editorials, reviews, qualitative studies</li> <li>Psychometric evaluations</li> <li>Studies where the sample size is n &lt;50</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>Predictors of any dimension of subjective or psychological wellbeing or mental health</li> </ul>	<ul style="list-style-type: none"> <li>Outcomes related to physical functioning</li> <li>Outcomes related to objective measures of quality of life (i.e. birth rate, school completion, mortality)</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>Peer-reviewed journal articles and non-published studies (conference abstracts, dissertations, working papers)</li> </ul>	

	<ul style="list-style-type: none"> <li>English and non-English studies</li> <li>Studies conducted between January 2000-May 2019</li> </ul>	
<b>Qualitative studies</b>		
<b>Sample setting &amp;</b>	<ul style="list-style-type: none"> <li>Young people living with HIV (aged 15-24 years) in sub-Saharan Africa (as per the 2019 World Bank Country Classification).</li> <li>Caregivers of young people aged 15-24 years, healthcare workers, educators, other family members</li> </ul>	<ul style="list-style-type: none"> <li>Studies that focus on specific population groups (i.e. orphans, LGBTQI, pregnant or post-partum women, sex workers, homeless youth, patients with co-morbidity)</li> <li>Studies based on samples from African or other countries which are outside the sub-Saharan African region (as per the 2019 World Bank Country Classification).</li> </ul>
<b>Phenomenon of interest</b>	<ul style="list-style-type: none"> <li>Subjective and psychological wellbeing, mental health</li> </ul>	<ul style="list-style-type: none"> <li>Studies examining objective measures of quality of life</li> </ul>
<b>Design</b>	<ul style="list-style-type: none"> <li>Studies incorporating any form of qualitative study design, data collection method or analytical technique</li> <li>Cross-sectional or longitudinal</li> </ul>	<ul style="list-style-type: none"> <li>Studies with YPLHIV in the intervention arm of a trial</li> <li>Reviews, editorials, letters, essays, theoretical and opinion papers</li> <li>Studies evaluating a specific policy, programme or intervention</li> </ul>
<b>Evaluation</b>	<ul style="list-style-type: none"> <li>Studies aimed at understanding the lived experiences of wellbeing or experiences related to any dimension of wellbeing or mental health</li> </ul>	<ul style="list-style-type: none"> <li>Narrow focus on physical functioning, ART adherence, disclosure challenges, sexual reproductive health needs</li> </ul>
<b>Research type</b>	<ul style="list-style-type: none"> <li>Qualitative or mixed methods</li> </ul>	<ul style="list-style-type: none"> <li>Quantitative studies</li> </ul>
<b>Other</b>	<ul style="list-style-type: none"> <li>Peer-reviewed journal articles and non-published studies (conference abstracts, dissertations, working papers)</li> <li>English and non-English studies</li> <li>Studies conducted between January 2000-May 2019</li> </ul>	

**Studies:** We included published and non-published quantitative and qualitative studies. We selected observational quantitative studies reporting on primary or secondary data analysis from cohort or cross-sectional datasets. We deemed any qualitative study design, data collection technique (e.g. group interviews, in-depth interviews, participant observations) or analytical approach (e.g. thematic analysis, framework analysis) eligible for the qualitative arm of this review. Furthermore, we included mixed-methods studies

that satisfied corresponding inclusion and exclusion criteria, separately determining eligibility for quantitative and qualitative components. In addition, we scanned the bibliographies of relevant quantitative or qualitative reviews to identify potentially eligible primary studies not yielded by the primary search.

**Participants:** We selected studies focused on young people, defined as older adolescents and young adults between the ages of 15-24 years, who were living with HIV (UNAIDS, 2016). We focused on this condition only as HIV/AIDS remains the leading cause of mortality among young people in this region (Kassebaum et al., 2017, Patton et al., 2009). We included studies if at least the average age of the sample was within our age-range or results could be extractable for the age-range.

**Outcome measures:** Drawing from the field of social psychology, we conceptualised wellbeing as both subjective and psychological, and thus examined all dimensions linked to these constructs (Keyes, 1998, Diener et al., 1999, Ryff, 1989), particularly relational dimensions in line with the relationality meaning model (Wissing, 2014). In addition, we included mental health as an outcome measure, as both cross-sectional and longitudinal studies have found strong negative correlations between poor mental health and measures of SWB (Layard et al., 2013, Lombardo et al., 2018, Fergusson et al., 2015, Lagnado et al., 2017, Cummins, 2010). Furthermore, studies have shown negative correlations between mental illness and PWB measures (Ryff and Keyes, 1995, Ryff, 2014). Moreover, results from our initial desktop review revealed that among the studies that assessed wellbeing among YPLHIV, most conceptualised wellbeing in terms of mental illness. For this review, we applied a biomedical definition of mental health (i.e. the absence or presence of symptoms of mental illness) (Patel et al., 2007; Westerhof and Keyes, 2010). We included: quantitative studies that assessed factors associated with any dimension of wellbeing or mental health using statistical regression techniques; qualitative studies that explored lived experiences of wellbeing or experiences related to dimensions of wellbeing or mental health.

**Study setting:** We included studies conducted in any setting (e.g. household, clinic, school) in a country within the sub-Saharan African region (World Bank, 2019). We chose to focus on SSA only as this region accounts for the highest number of YPLHIV (UNAIDS,

2014). Furthermore, young people living in this region have the highest risk of HIV acquisition (UNAIDS, 2018b).

***Time and language:*** We restricted the search to studies conducted between 01 January 2000 and 11 May 2019. This timeline covers the key post-ART periods in SSA: 1) ART introduction (2000-2007); 2) expanded ART (2008-2010); and 3) scaled-up ART (2011-2019) (Church et al., 2015). We considered the post-ART period more relevant to the current international HIV policy landscape as treatment for all HIV-positive individuals is now the recommended approach (UNAIDS, 2015). No language restrictions were placed on the search.

### ***2.3 Information sources***

Aiming for a broad interdisciplinary approach, we searched published and grey literature on multiple electronic platforms. We searched 6 electronic databases for eligible peer-reviewed journal articles: Medline, Web of Science, PsychINFO, EconLit, Africa-Wide Information, International Bibliography of the Social Sciences. For grey literature, we searched the dissertation databases (Dissertations and Theses- A&I, World Cat), and the International AIDS Society conference archives (2001-2018). In addition, eligible working papers were identified by searching data repositories of the Organisation for Economic Co-operation and Development, IDEAS and the National Bureau of Economic Research.

### ***2.4 Search strategy***

We searched electronic databases using either compound search strategies containing subject headings that were supplemented with text terms (Supplementary File S1-4) and JEL codes (Supplementary File S3), or simple Boolean logic search strategies with keywords (Supplementary File S5-8). Our search terms were aligned to dimensions of the subjective and psychological wellbeing constructs (e.g. negative and positive affect, life satisfaction, self-acceptance, social relationships) (Diener et al., 1999, Ryff and Keyes, 1995), with a specific focus on relational dimensions. In addition, our search included terms related to the attitudes and symptoms of common mental disorders (i.e. depression, anxiety) among YPLHIV (Mellins and Malee, 2013)

### ***2.5 Study records- data management, selection process, data collection process***

We imported search outputs into an EndNote (X 8) library and removed duplicate references. Thereafter, we imported this library into an online systematic review manager (Covidence systematic review software, Veritas Health Innovation, Australia). DG and IDA dual screened titles and abstracts independently, and 10% of these were dual screened by GF. AW assisted DG with the dual screening of grey literature. DG subsequently resolved conflicts via discussion with the dual screener, obtained the full text for all potentially eligible abstracts and applied the inclusion criteria to these studies. GF, JS, CM randomly checked all full texts. Less than 5% of abstracts were non-English language studies. For these specific studies, we obtained a translated electronic English version of the study.

### ***2.6 Data items***

Once consensus was reached on eligible studies, DG entered relevant data from potentially eligible studies onto electronic data extraction forms. The design of these forms were informed by the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist (Von Elm et al., 2014) and Consolidated criteria for Reporting Qualitative Research (COREQ) checklist (Tong et al., 2007), for quantitative and qualitative studies, respectively.

We extracted information on the following variables from each included study: author, year published, study setting, design, outcome definition, analytical techniques, participant demographics, treatment status, disclosure status. For quantitative studies, we specifically extracted data from regression models (e.g. sample size, measures of associations, confidence intervals and p-values). For qualitative studies, we extracted primary themes or first order constructs (i.e. participants' understanding as reported in the study via verbatim quotes or authors description), and secondary themes or second order constructs (i.e. authors' interpretations of participants' understandings). Co-authors randomly checked data extractions.

### ***2.7 Outcomes***

- a) Quantitative: wellbeing and mental health measures, and explanatory variables associated with wellbeing or mental health.

- b) Qualitative: meanings and manifestations of wellbeing, any dimension of wellbeing or mental health

### ***2.8 Quality appraisal***

All potentially eligible studies were critically appraised by assessing their methodological quality. For quantitative studies, we applied a risk of bias tool, adapted from the Cochrane guidance on assessing risk of bias in non-randomised studies (Higgins and Green, 2011). DG and GF selected items for this tool based on their relevance to observational study designs in epidemiology and psychology. Studies were categorised into three groups, depending on the level of bias: low, medium or high risk of bias. This was assessed by evaluating measures applied to reduce the following biases: 1) selection bias — random sampling techniques; 2) information bias — training of interviewers in the administration of the scale, translation of the scale to local language, assessing the validity and reliability of scale for given population; 3) confounding — adjustments for potential confounders. For qualitative studies, we applied a quality assessment tool adapted from the COREQ checklist (Tong et al., 2007) and key studies (Tracy, 2010, Mays and Pope, 2000). DG and JS selected the following indicators for this tool based on its relevance to qualitative research design 1) rigor — use of appropriate theoretical frameworks, sufficient data collected; 2) sincerity — self-reflexivity, transparency about the methods and challenges; 3) credibility — triangulation of data, inductive nature of derived themes.

### ***2.9 Data analysis synthesis***

We conducted a simple descriptive analysis of key quantitative findings. For the qualitative studies, we applied meta-ethnographic analytical methods (Barnett-Page and Thomas, 2009), as implemented by Atkins et al. (2008). We specifically used the reciprocal translation analytical approach to develop themes. This approach entailed analysing and synthesising participant views (first-order construct) and authors' interpretation (second order constructs) to develop third-order constructs. We implemented this approach by comparing first and second order constructs across studies that were homogeneous in terms of design elements (setting, population and period of ART roll-out) and chronologically ordered studies based on publication date (Atkins et al., 2008). Subsequently, we matched themes across papers ensuring the third order captured similar themes from various studies. We then tabulated translations by

highlighting key third order constructs derived and supporting quotes and narratives. Finally, we interpreted the themes across studies to develop a line-of-argument synthesis describing how all themes interacted to shape wellbeing. We evaluated the quality of the qualitative evidence synthesis using the GRADE-CERQual (Confidence in Evidence from Reviews of Qualitative research) approach (Lewin et al., 2018). This approach includes an assessment of the methodological limitations, coherence, relevance, and adequacy. Lastly, we integrated the main quantitative and qualitative findings by mapping key correlates and themes that emerged from the data to subjective and psychological wellbeing dimensions (Diener et al., 1999, Ryff and Keyes, 1995). Thereafter, we interpreted our data drawing on the relationality meaning model (Wissing, 2014).

### **3. Results**

#### **3.1 Screening protocol**

The electronic database search yielded a total of 7563 citations, and our grey literature and manual search yielded 771 citations (Figure 1). After removal of duplicate entries, 6527 studies were evaluated using title and abstracts; 5909 citations were excluded, and 618 potentially eligible studies were retrieved for full-text assessment (356 quantitative review, 262 qualitative review). Of the 356 citations identified for the quantitative review, 10 studies were included, and 346 studies excluded mainly due to the lack of age-stratified analyses or focus on a biomedical outcome measure. Of the 262 citations identified for the qualitative review, 30 studies were included, and 232 studies were excluded mainly because of a narrow focus on barriers to disclosure or adherence.



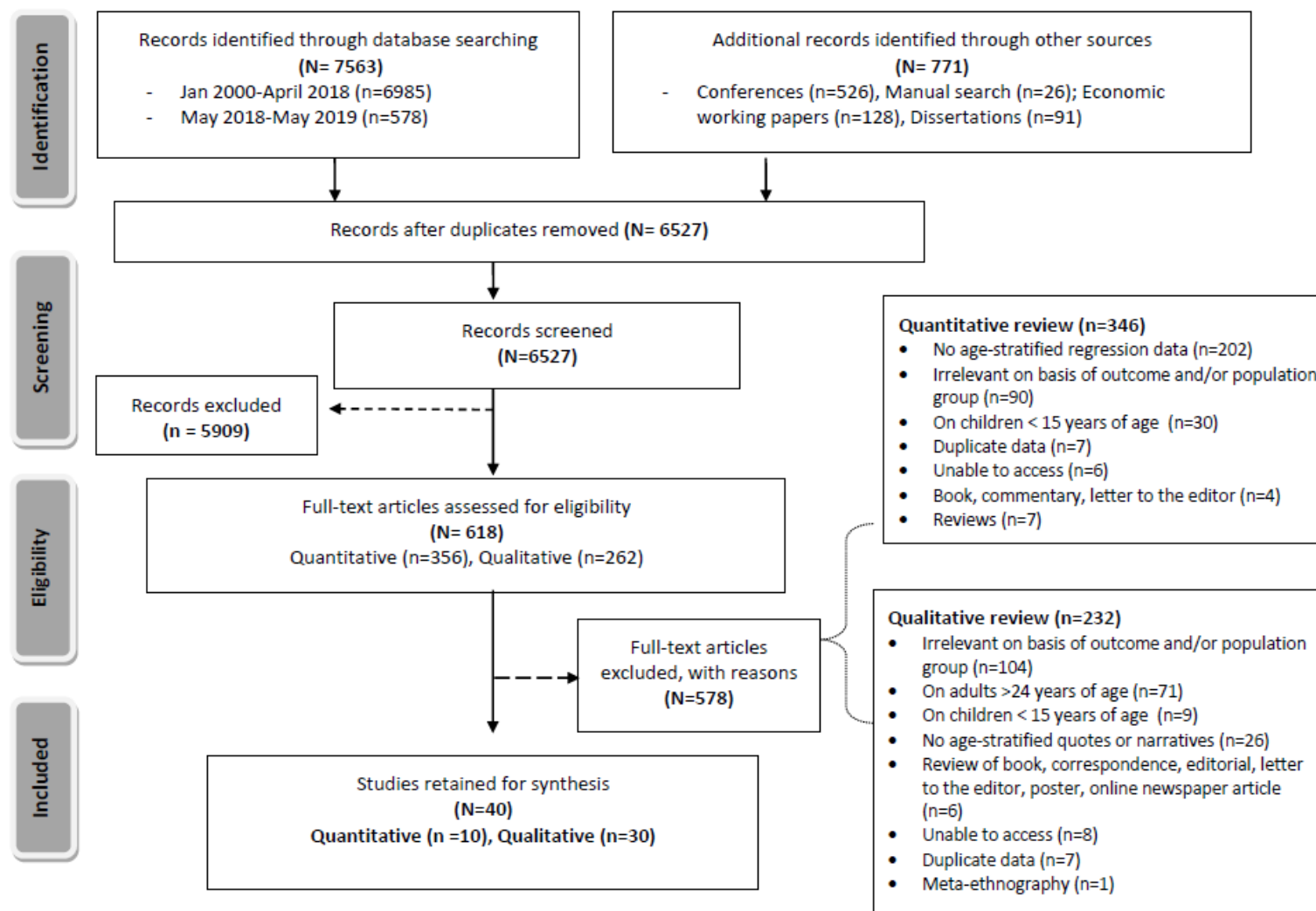


Figure 1: Selection process for the inclusion of studies

### **3.2 Overall study characteristics**

Tables 2 and 3 summarize the main characteristics of the 40 studies (10 quantitative and 30 qualitative). These studies were equally representative of the eastern and southern sub-regions of SSA, with nearly 50% conducted in low-income country settings (n=19). The majority were conducted during the scaled-up ART phase. Participants were mainly between 15 to 19 years of age and sampled from urban public healthcare facilities. None of the included studies directly assessed wellbeing but rather examined mental health or dimensions related to wellbeing.

**Table 2: Description of studies in the quantitative synthesis that examined correlates of wellbeing or mental health among YPLHIV in SSA (N=10)**

Author year	Income Classification (sub-region)	Country	Setting	Study design	Data collection period	Type of participants	Recruited from	Outcome measured (scales used)	Total participated (N)	Mean age (SD)	Female n (%)
<b>(Abebe et al., 2019)</b>	Low income (Eastern)	Ethiopia	Addis Ababa (Urban)	Cross-sectional	May-Jun 2016 (Scaled-up ART)	YPLHIV (15-24 yrs.)	Public hospitals	Depressive symptoms (BDI-II)	507	18.6 (3.02)	272 (69)
<b>(Kim et al., 2015)</b>	Low income (Southern)	Malawi	Zomba, Lilongwe (Urban)	Cross-sectional	2012 (Scaled-up ART)	YPLHIV (12-18 yrs.)	Paediatric HIV clinic, ART clinic in hospital	Depressive symptoms (BDI II, CDRS-R)	562	14.5 (2.0)	315 (56)
<b>(Mbalinda et al., 2015)</b>	Low income (Eastern)	Uganda	Eastern, western and northern regions- (Mixed)	Cross-sectional	Sept 2013-Mar 2014 (Scaled-up ART)	YPLHIV (10-19 yrs.), peri-natally HIV-infected	Public and non-profit private healthcare facilities (n=4)	Health-related quality of life (MOS-HIV)	614	16.2 (2.1)	361 (58.8)
<b>(Mutumba et al., 2017)</b>	Low income (Eastern)	Uganda	Kampala (Urban)	Cross-sectional	May- Sept 2013 (Scaled-up ART)	YPLHIV (12-19 yrs.), aware of HIV status, no clinically documented cognitive limitations	NPO ARV Clinic- Joint Clinical Research Centre	Psychological distress (Psychological distress measure)	464	15.6 (2.21)	249 (53)

<b>(Dow et al., 2016)</b>	Low income (Eastern)	Tanzania	Moshi (Urban)	Cross-sectional	Dec 2013-May 2014 (Scaled-up ART)	YPLHIV (12-24 yrs.), aware of HIV status, living with family and attending a HIV- youth programme	HIV youth clinic	Depressive symptoms (PHQ-9), mental health difficulties (SDQ)	182	17.2 (2.9)	99 (54)
<b>(Gaitho et al., 2018)</b>	Lower middle income (Eastern)	Kenya	Nairobi (Urban)	Cross-sectional	Aug-Dec 2016 (Scaled-up ART)	YPLHIV (10-19 yrs.)	Comprehensive Care Clinic in Hospital	Depressive symptoms (PHQ-9)	270	14.75 (2.6)	125 (47.3)
<b>(Okawa et al., 2018)</b>	Lower middle income (Southern)	Zambia	Lusaka (Urban)	Cross-sectional (Mixed methods)	Apr-Jul 2014 (Scaled-up ART)	YPLHIV (15-19 yrs.), aware of HIV status, registered as clients at the HIV centres	Paediatric and Adult HIV Centres of Excellence -University Teaching Hospital	Depressive symptoms (CES-D)	190	16 (NR)	110 (57.9)
<b>(Gentz et al., 2017)</b>	Upper middle income (Southern)	Namibia	Katutura, Windhoek (Peri-urban)	Cross-sectional	July 2013-Mar 2014 (Scaled-up ART)	YPLHIV (12-18 yrs.), aware of HIV status	Paediatric ARV clinic in hospital	Mental health difficulties (SDQ)	99	14.3 (1.8)	52 (52.5)

<b>(Earnshaw et al., 2018)</b>	Upper middle income (Southern)	South Africa	Johannesburg (Peri-urban)	Cross-sectional	Nov 2015-Jul 2016 (Scaled-up ART)	YPLHIV (13-24 yrs.), aware of HIV status, perinatal HIV-infection	Paediatric Wellness Clinic- in hospital	Depressive symptoms (BDI-II)	250	16.34 (2.67)	103 (41)
<b>(Woollett et al., 2017b)</b>	Upper middle income (Southern)	South Africa	Johannesburg (Urban)	Cross-sectional	Aug 2013-April 2014 (Scaled-up ART)	YPLHIV (13-19 yrs.)	Paediatric clinics- hospital (n=3), community healthcare centre (n=1); primary healthcare clinic (n=1)	Depressive symptoms (CDI-S), anxiety symptoms (RCMAS-2 )	343	16* (IQR 12-19)	181 (52)

**\$= According to the World Bank Country Classification; SD=Standard Deviation; PHQ-9= Patient Health Questionnaire 9; SDQ=Strengths and Difficulties Questionnaire, BDI II= Beck Depression Inventory-II, CDRS-R= Children's Depression Rating Scale-Revised, MOS-HIV= HIV Medical Outcomes Survey, CES-D= Center for Epidemiologic Studies Depression Scale, CDI-S= Children's Depression Inventory-Short Version, RCMAS-2= Revised Children's Manifest Anxiety Scale - Second Edition**

**Table 3: Description of studies included in the qualitative synthesis (N=30). These studies examined lived experiences related to wellbeing or mental health among YPLHIV in SSA**

Reference	Income level <sup>s</sup> (sub-region)	Country	Setting (location)	Data collection period	Aim/s of the study	Participant population	Recruited from (sampling strategy)	Data collection method and analysis type
<b>(Bernays et al., 2017)</b>	Low income (Eastern)	Uganda, UK, Ireland, USA	Urban (Kampala)	Scaled-up ART (2011-2015)	To investigate young people's perspectives on the social and relational challenges encountered in treatment adherence	<ul style="list-style-type: none"> <li>YPLHIV-Ugandan sample (n=26, 11-22 yrs., mean age 16, F=14, M=12)</li> </ul>	Healthcare facility (Convenience and purposive)	<ul style="list-style-type: none"> <li>26 IDIs, 2 follow-up IDIs (3 IDIs per participant), semi-structured</li> <li>Thematic analysis, using a grounded approach and systematic case comparison</li> </ul>
<b>(Campbell et al., 2012)</b>	Low income (Southern)	Zimbabwe	Rural (Manicaland)	Expanded ART (Oct 2009-Mar 2010)	To investigate the social landscape of children's adherence in rural Zimbabwe through	<ul style="list-style-type: none"> <li>Caregivers (n=40)</li> <li>Nurses (n=25)</li> </ul>	Healthcare facility: (snowball, self-selected informants, typical case - caregivers, convenience-nurses)	<ul style="list-style-type: none"> <li>39 IDIs, 3 FGDs</li> <li>Thematic network analysis</li> </ul>

<b>(Dusabe-Richards et al., 2016)</b>	Low income (Eastern)	Uganda	Rural (South-Western, Kalungu district)	Scaled-up ART (2011-2012)	To understand the communication challenges of disclosure and its aftermath within these relationships from the dual perspectives of the older carer and the HIV positive child in their care	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=18, 13-17 yrs., F=8, M=10)</li> <li>▪ Older caregivers (n=18)</li> </ul>	Healthcare facility (Convenience)	<ul style="list-style-type: none"> <li>• 8 IDIs YPLHIV, 18 IDIs caregivers, semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Inzaule et al., 2016)</b>	Low income (Eastern)	Uganda	Urban (Kampala, Fort Portal, Mbale)	Scaled-up ART (May-Aug 2015)	To assess the challenges to long-term adherence in adolescents and adults in three regional HIV treatment centres in Uganda	<ul style="list-style-type: none"> <li>▪ Expert adolescent clients (n=5, age-NR, sex-NR).</li> <li>▪ HCWs (n=28)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 24 IDIs, 2 FGDs, semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Kajubi et al., 2016)</b>	Low income (Eastern)	Uganda	Coastal (Jinja district-Lake Victoria)	Expanded ART (Nov 2011-Dec 2012)	To explore the implications of different family constellations for caregiving and communication with children on ART	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=29; 8-17 yrs., mean age 12 yrs., F=16, M=13)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 29 Participant observations with follow-up for 12 months, and 29 IDIs, semi-structured</li> <li>• Thematic analysis</li> </ul>

<b>(Knizek et al., 2017)</b>	Low income (Eastern)	Uganda	Mixed-urban and semi-urban/rural (Kampala, Masaka)	Scaled-up ART (Jul-Nov 2015)	To investigate both the protective and the risk factors in HIV-infected adolescents' care environment in order to understand what might contribute to negative outcomes and what might provide a protective buffer against harmful life events	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=21, 12-17 yrs., mean age 14.6 yrs., F=12, M=9)</li> </ul>	Healthcare facility (Convenience and purposively sampled )	<ul style="list-style-type: none"> <li>• 21 IDIs with vignettes, semi-structured</li> <li>• Phenomenological approach</li> </ul>
<b>(Kyaddondo et al., 2013)</b>	Low income (Eastern)	Uganda	Mixed-urban, peri-urban, rural (Kampala, Mpigi, and Soroti districts)	Expanded ART (May 2008-Sept 2009)	To examine the moral dilemmas and pragmatic incentives surrounding disclosure of HIV status in contemporary Uganda	<ul style="list-style-type: none"> <li>▪ PLHIV (n=12, 6 aged 18-24 yrs., F=NR, M=NR)</li> </ul>	Healthcare facility (Convenience)	<ul style="list-style-type: none"> <li>• 12 IDIs (6 YPLHIV), 2 FGDs (YPLHIV NR), 6 key informant interviews</li> <li>• Method of analysis NR</li> </ul>
<b>(Loos et al., 2013)</b>	Low income (Eastern)	Uganda	Mixed-urban and rural (Kampala, Kisumu, Kamito and Wagai)	Expanded ART (Jul-Nov 2009)	To assess the impact of HIV and related contextual conditions on identity formation of adolescents living with HIV/AIDS (ALH) in the domains of physical, cognitive, social, and sexual development	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=119, 10-19 yrs., mean age 13.5 yrs., F=64, M=55)</li> <li>▪ Caregivers (n=6)</li> <li>▪ HCWs (n=53)</li> </ul>	Healthcare facility (Convenience)	<ul style="list-style-type: none"> <li>• 16 FGDs (YPLHIV, stratified by age and sex- 10-12, 13-15, 16-19 yrs.); 6 FGDs (caregivers), 6 FGDs (HCWs), semi-structured</li> <li>• Thematic analysis</li> </ul>



<b>(Mathur et al., 2016)</b>	Low income (Eastern)	Uganda	Rural (Rakai)	Expanded ART (Jun 2010-Jul 2011)	To examine relationship and life events to hopefully describe some of the circumstances that influenced young men's HIV vulnerability and acquisition	<ul style="list-style-type: none"> <li>▪ YPLHIV and their HIV-negative partners (n=30, 15-24 yrs., mean age 22 yrs., F=0, M=30)</li> </ul>	Community (Purposive)	<ul style="list-style-type: none"> <li>• 30 IDIs- life history interviews, semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Matovu et al., 2012)</b>	Low income (Eastern)	Uganda	Urban (Kampala)	Expanded ART (Jan-Feb 2009)	To explore how young women with HIV/AIDS in Uganda experience the influence of their everyday life occupations on adherence to HAART after more than 1 year on the medication	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=6, 16-20 yrs., F=6, M=0)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 6 narratives, 2 interviews per participant conducted over 1 month, semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Mutumba et al., 2015)</b>	Low income (Eastern)	Uganda	Urban (Kampala)	Scaled-up ART (Aug-Nov 2011)	To identify the psychosocial challenges and coping strategies among perinatal HIV-infected adolescents in Uganda	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=38, 12-19 yrs., mean age 16.9 yrs., F=20, M=18)</li> </ul>	Healthcare facility- clinical research centre (Purposive)	<ul style="list-style-type: none"> <li>• 38 IDIs, semi-structured</li> <li>• Thematic analysis-grounded in a phenomenological approach</li> </ul>

<b>(Siu et al., 2012)</b>	Low income (Eastern)	Uganda	Urban (Kampala)	Expanded ART (May-Jun 2009)	To describe HIV serostatus and treatment disclosure practices and concerns from the perspective of YPLHA in Uganda, exploring their satisfaction with current norms around HIV serostatus and treatment disclosure- examines disclosure and lived experiences	<ul style="list-style-type: none"> <li>▪ YPLHIV (N=20, 15-23 yrs., median age 20 yrs., F=10. M=10)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 20 IDIs, 2 FGDs (sex-disaggregated), field notes, semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Mattes, 2014)</b>	Low income (Eastern)	Tanzania	Coastal (North-eastern, Tanga city)	Expanded ART (Sept 2008-Sept 2011)	To compare the national guidelines' imaginary versions of HIV disclosure and treatment management with the lived realities of paediatric HIV management in a specific north-eastern Tanzanian Care and Treatment Centre (CTC) and in affected children's social environments	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=13, 9-19 yrs., F=5, M=8)</li> <li>▪ Caregivers (n=11)</li> </ul>	Healthcare facility (Convenience)	<ul style="list-style-type: none"> <li>• 13 IDIs with thematic drawings, participant observations (YPLHIV); Caregivers (NR), semi-structured</li> <li>• Grounded theory approach</li> </ul>

<b>(Abubakar et al., 2016)</b>	Lower middle income (Eastern)	Kenya	Coastal (Kilifi)	Scaled-up ART (2012-2013)	To investigate the experiences and challenges of HIV infected adolescents at the Kenyan coast	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=12, 12-17 yrs., mean age 14.5 yrs., F=3, M=9).</li> <li>▪ HIV uninfected (n=7, 12-17 yrs., mean age=15 yrs., F=5, M=2).</li> <li>▪ Caregivers (n=11)</li> <li>▪ HCWs&amp; CHWs (n=8)</li> <li>▪ Educators (n=6)</li> </ul>	Healthcare facility- YPLHIV, caregivers, HCWs, CHWs; Community-HIV uninfected, Secondary schools-educators (sampling strategy=NR)	<ul style="list-style-type: none"> <li>• 30 KIIs, semi-structured</li> <li>• Framework approach</li> </ul>
<b>(Adegoke and Steyn, 2017)</b>	Lower middle income (Western)	Nigeria	Urban (Ibadan city-Oyo state)	Scaled-up ART (2013)	To explore the experiences of Yoruba adolescent girls living with HIV, particularly factors contributing to their resilience	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=5, 20 yrs., mean ag 20 yrs., F=5, M=0)</li> </ul>	Community NGO (Purposive)	<ul style="list-style-type: none"> <li>• 5 Photo-voice coupled with narratives (participatory action research)</li> <li>• Secondary inductive content analysis</li> </ul>
<b>(Lypen et al., 2015)</b>	Lower middle income (Eastern)	Kenya	Urban (informal settlement) (Kibera-Nairobi)	Expanded ART *(NR)	To better understand the complex social support systems among these youth as well as this support's influence on their HIV management and related coping mechanisms	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=53, 18-27 yrs., mean age 22.8, F=26, M=27)</li> </ul>	Healthcare facility (Modified respondent driven sampling)	<ul style="list-style-type: none"> <li>• 6 FGDs (stratified by sex)</li> <li>• Phenomenological approach</li> </ul>

<b>(Mburu et al., 2014)</b>	Lower middle income (Southern)	Zambia	Mixed- rural and urban (Kalomo, Kitwe, Lusaka)	Expanded ART (Apr-Dec 2010)	To document the experiences of adolescents living with HIV with regard to disclosure, specifically addressing: adolescents who were previously unaware of their HIV-positive status being told about it by their parents, and adolescents who know about their HIV-positive status telling others about it	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=58, 10-19 yrs., mean age 16.8 yrs., F=29, M=29)</li> <li>▪ Caregivers (n=21)</li> <li>▪ HCWs (n=14)</li> </ul>	Healthcare facility, community and youth centres (Convenience)	<ul style="list-style-type: none"> <li>• 8 FGDs, 58 IDIs (YPLHIV); 2 FGDs (caregivers); 3 FGDs, 14 IDIs (HCWs), semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Shabalala et al., 2016)</b>	Lower middle income (Southern)	eSwatini (formerly Swaziland)	Mixed- 1 rural, 1 urban (Manzini region)	Scaled-up ART (Jul 2012-Dec 2013)	To explore the meaning of the family as it applies to Swazi adolescents' everyday life	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=13, 12-19 yrs., mean age 13.6 yrs., F=5, M=8)</li> </ul>	Healthcare facility (Convenience)	<ul style="list-style-type: none"> <li>• 13 IDIs (YPLHIV), FGDs (n=NR), KIIs (n=NR), semi-structured</li> <li>• Thematic analysis using an inductive approach</li> </ul>

<b>(Mackworth-Young et al., 2017)</b>	Lower middle income (Southern)	Zambia	Urban (Lusaka)	Scaled-up ART (Jan-Apr 2015)	To explore the experiences of adolescent girls growing up with HIV in Lusaka, Zambia	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=24, 15-18), F=24, M=0)</li> </ul>	Healthcare facility (Convenience)	<ul style="list-style-type: none"> <li>• 4 participatory workshops (used concept mapping, collages and vignettes); 34 IDIs- 17 interviewed twice, used network tools</li> <li>• Thematic analysis using a grounded theory approach</li> </ul>
<b>(Goudge et al., 2009)</b>	Upper middle income (Southern)	South Africa	Urban (Gauteng province)	ART introduction (2006-2008)	To document the diverse journeys of people living with HIV after the national roll-out of ARV treatment, through ill health, testing, disclosure, and treatment, and their responses to stigma	<ul style="list-style-type: none"> <li>▪ PLHIV (n=5, 20-54 yrs., n=1 20-24 yrs., F=3, M=2)</li> </ul>	Healthcare facility (Random from an existing survey)	<ul style="list-style-type: none"> <li>• IDIs with narratives, interviewed twice over 6 months, semi-structured</li> <li>• Narrative approach</li> </ul>
<b>(Li et al., 2010)</b>	Upper middle income (Southern)	South Africa	Urban (Tygerberg, Western Cape)	Expanded ART (2009)	To explore the experiences and needs of a group of adolescents living with HIV in Cape Town, South Africa	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=26, 7-15 yrs., mean age 12.5 yrs., F=10, M=16)</li> </ul>	Healthcare facility (Convenience)	<ul style="list-style-type: none"> <li>• 4 FGDs, 26 IDIs, used photographs and pictorial messages, semi-structured</li> <li>• Thematic analysis</li> </ul>

<b>(Midtbo et al., 2012)</b>	Upper-middle income, low income (Southern, Eastern)	Botswana, Tanzania	Mixed-Urban and rural	Scaled-up ART (Jun-Sept 2011)	To understand and identify the pathways between HIV-status disclosure, ART, and children's psychosocial wellbeing, including from the perspective of adolescents themselves	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=28, 12-20 yrs., F=17, M=11).</li> <li>▪ HCWs (n=3)</li> </ul>	Community NGO, hospital (Purposive)	<ul style="list-style-type: none"> <li>• 2 FGDS, 28 IDIs (YPLHIV); 3 IDIs (HCWs), participant observations, semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Plattner and Meiring, 2006)</b>	Upper middle income (Southern)	Namibia	Urban (Windhoek)	ART introduction (2003)	To better understand the psychological coping processes from the perspectives of infected people	<ul style="list-style-type: none"> <li>▪ PLHIV (n=10, 20-48 yrs., F=8, M=2)</li> </ul>	Community NGO (Convenience)	<ul style="list-style-type: none"> <li>• 10 IDIs, semi-structured</li> <li>• Circular deconstruction method</li> </ul>
<b>(Jena, 2014)</b>	Upper middle income (Southern)	South Africa	Urban (Eastern Cape-Port Elizabeth)	Scaled-up ART (Nov 2013)	To explore the lived experiences of adolescents living with vertically acquired HIV	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=6, 16-17 yrs., F=4, M=2, all vertically HIV-infected)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 6 IDIs- semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Petersen et al., 2010)</b>	Upper middle income (Southern)	South Africa	Urban (KwaZulu-Natal-Durban)	Expanded ART (2008)	To examine the psychosocial challenges and protective factors for adolescents and their caregivers affected by paediatric HIV within the sociocultural context of South Africa	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=25, 14-16 yrs. F=NR, M=NR)</li> <li>▪ Caregivers n=15)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 25 IDIs</li> <li>• Thematic analysis</li> </ul>

<b>(Pienaar and Visser, 2012)</b>	Upper middle income (Southern)	South Africa	Urban (Gauteng-Pretoria)	Expanded ART (2010)	To describe the experiences of the adolescent who live with HIV and undergo chronic disease management at the Kalafong Paediatric HIV clinic, so as to gain an understanding of the meanings they attribute to their experiences of HIV that informs their identities	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=6, 13-17 yrs., F=3, M=3)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 6 IDIs with follow-up interviews-semi-structured with drawings and storytelling</li> <li>• Narrative analysis</li> </ul>
<b>(Rosenbaum, 2017)</b>	Upper middle income (Southern)	South Africa	Peri-urban (Katlehong Township-Gauteng province)	Scaled-up ART* (NR)	To develop a cultural understanding of how young people living with HIV effectively cope with the adversities that they face and the social ecological resources that contribute to their well-being and resilience	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=7, 17-19 yrs., mean age 18 yrs., F=2, M=5).</li> <li>▪ Mental healthcare provides (n=3)</li> </ul>	Clinic support group (Purposive)	<ul style="list-style-type: none"> <li>• 7 FGDs with photo-voice (YPLHIV), interviews (mental healthcare providers), semi-structured</li> <li>• Thematic analysis</li> </ul>

<b>(Vale et al., 2017)</b>	Upper middle income (Southern)	South Africa	Mixed-rural and peri-urban (Eastern Cape- rural village (Mtembu) and peri-urban informal settlement (Ridgetown))	Scaled-up ART (Aug-Dec 2013, Jan-April 2014)	To understand how tacit inferences about adolescents' mode of infection contribute to their experiences of HIV-related blame, and their ability to achieve care, in their intimate, everyday settings	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=23, 10-19 yrs., F=23, M=0).</li> <li>▪ Caregivers (n=NR)</li> </ul>	Community NGO (Purposive)	<ul style="list-style-type: none"> <li>• 20 IDIs- YPLHIV and mothers, field notes</li> <li>• Narrative approach</li> </ul>
<b>(Woollett et al., 2016)</b>	Upper middle income (Southern)	South Africa	Urban (Johannesburg)	Scaled-up ART (Oct 2014-Nov 2015)	To identify elements of resilience in a group of perinatally infected HIV positive adolescents attending HIV clinics	<ul style="list-style-type: none"> <li>▪ YPLHIV (N=25, 13-19 yrs., F=15, M=10)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 25 IDIs, semi-structured</li> <li>• Thematic analysis</li> </ul>
<b>(Woollett et al., 2017a)</b>	Upper middle income (Southern)	South Africa	Urban (Johannesburg)	Scaled-up ART (Aug 2013- April 2014)	To examine the perceptions of perinatally infected HIV-positive adolescents attending clinics in Johannesburg with respect to their own infection, how they were disclosed to and their mental health state	<ul style="list-style-type: none"> <li>▪ YPLHIV (n=25, 13-19 yrs., mean age 16 yrs., F=15, M=10)</li> </ul>	Healthcare facility (Purposive)	<ul style="list-style-type: none"> <li>• 25 IDIs, semi-structured</li> <li>• Thematic analysis</li> </ul>

§= According to the World Bank Country Classification; NR=not reported



### **3.3 Quantitative studies-characteristics and data synthesis**

Of the ten quantitative studies (Table 2), five were conducted in southern Africa: South Africa (Woollett et al., 2017b, Earnshaw et al., 2018), Namibia (Gentz et al., 2017), Malawi (Kim et al., 2015), Zambia (Okawa et al., 2018). The remainder conducted in eastern Africa: Uganda (n=2) (Mbalinda et al., 2015, Mutumba et al., 2017), Kenya (n=1) (Gaitho et al., 2018), Ethiopia (n=1) (Abebe et al., 2019) and Tanzania (n=1) (Dow et al., 2016). All studies employed a cross-sectional study design. Neither subjective nor psychological wellbeing were measured in any of these studies. All studies measured mental health, specifically symptoms of depression, mainly using the Beck Depression Inventory-II (BDI-II). The key factors associated with mental health outcomes measured are detailed below (Table 4).

#### ***i. Demographics***

Being female was strongly correlated with poor mental health functioning in four studies (note, the outcome definition was different in each of the four studies) (Dow et al., 2016, Gentz et al., 2017, Kim et al., 2015, Mutumba et al., 2017). The largest gender effect was observed in Malawi, with females almost eight times as likely compared to males to exhibit higher depression-related symptoms scores ( $\beta = 2.13$ , 95% CI [0.82-3.43],  $p = 0.002$ ) (Kim et al., 2015). In two urban studies from low income settings, there was between an 8 to 23% increase in depression scores with age (Kim et al., 2015, Dow et al., 2016).

#### ***ii. Standard of living***

Educational attainment was found to have a protective effect on mental health functioning in three low income countries (Dow et al., 2016, Kim et al., 2015, Mbalinda et al., 2015). In the Ugandan study, those with secondary school attainment were five times more likely to have better mental health than those with no education (adjusted odd ratio (aOR)= 5.3, 95 % CI [1.86–15.41],  $p < 0.00$ ) (Mbalinda et al., 2015).

#### ***iii. Psycho-social***

HIV-related stigma was strongly positively associated with poor mental health functioning in six studies (Dow et al., 2016, Gentz et al., 2017, Mutumba et al., 2017, Okawa et al., 2018, Abebe et al., 2019, Earnshaw et al., 2018). Among these studies, the

largest effect of stigma was documented in Zambia, which found that the odds of having higher depressive symptom scores was almost three times higher for YPLHIV who experienced stigma than in those who did not (aOR=2.99; 95% CI [1.07–8.41],  $p=0.01$ ) (Okawa et al., 2018). Having someone to talk to or feeling satisfied with health services or the social support received promoted positive mental health functioning in four studies (Namibia (n=1) (Gentz et al., 2017), Uganda (n=2) (Mbalinda et al., 2015, Mutumba et al., 2017), Zambia (n=1) (Okawa et al., 2018). In an Ethiopian study, Abebe et al. (2019) reported that those with low social support were 2.74 times more likely to develop depressive symptoms than those with strong social support (95% CI [1.42-5.27],  $p<0.01$ ). Moreover, poor adherence was positively correlated with depressive symptoms in three studies (Dow et al., 2016, Abebe et al., 2019, Gaitho et al., 2018).

**Table 4: Results from studies included in the quantitative synthesis (N=10)- correlates associated with wellbeing or mental health among YPLHIV in SSA**

Author year	Regression technique	Outcome 1 (scale)	Univariable/Bivariable analysis (effect size, 95% CI, p value) <sup>s</sup>	Multivariable analysis (effect size, 95% CI, p values) <sup>s</sup>	Outcome 2 (scale)	Univariable analysis (effect size, 95% CI, p values) <sup>s</sup>	Multivariable analysis (effect size, 95% CI, p values) <sup>s</sup>
(Abebe et al., 2019)	Logistic regression	Depressive symptoms (BDI-II)	<ul style="list-style-type: none"> <li>• 15-19 yrs. (OR=2.84, 95% CI 1.92-4.21, p ≤0.2 )</li> <li>• Opportunistic infection (OR=1.89, 95% CI 1.29-2.78, p ≤0.2)</li> <li>• Stigma (OR=2.74, 95% CI 1.88-4.00, p ≤0.2)</li> <li>• Poor adherence (OR=2.11, 95% CI 1.44-3.09, p ≤0.2)</li> <li>• Low adherence (OR=3.22, 95% CI 1.78-5.82, p ≤0.2)</li> <li>• Moderate social support (OR=2.08, 95% CI 1.27-3.39, p ≤0.2)</li> </ul>	<ul style="list-style-type: none"> <li>• 15-19 yrs. (OR=2.20, 95% CI 1.33-3.62, p&lt;0.01)</li> <li>• Opportunistic infection (OR=1.94, 95% CI 1.15-3.27, p&lt;0.01)</li> <li>• Stigma (OR=2.06, 95% CI 1.35-3.14, p&lt;0.001)</li> <li>• Poor Adherence (OR=1.73, 95% CI 1.13-2.64, p&lt;0.01)</li> <li>• Low social support (OR=2.74, 95% CI 1.42-5.27, p&lt;0.01)</li> <li>• Moderate social support (OR=1.75, 95% CI 1.03-2.98, p&lt;0.05)</li> </ul>			

<b>(Dow et al., 2016)</b>	Negative binomial regression	Depressive symptoms (PHQ-9)	<ul style="list-style-type: none"> <li>• Age (per one year) (MR: 1.12, 95% CI 1.05–1.18, p &lt; .001)</li> <li>• Female (MR: 1.62, 95% CI 1.15–2.28; p = .006)</li> <li>• Not in school (MR: 1.65, 95% CI 1.12–2.43; p = .01)</li> <li>• Stigma (per 1 point) (MR: 1.09, 95% CI 1.06–1.13; p &lt; .001)</li> </ul>	<ul style="list-style-type: none"> <li>• Age (per one year) (MR: 1.08, 95% CI 1.03–1.14, p = .004)</li> <li>• Female (MR: 1.52, 95% CI 1.11–2.09; p = .01)</li> <li>• Stigma (per 1 point) (MR: 1.08, 95% CI 1.04–1.11; p &lt; .001)</li> <li>• Incomplete adherence (MR: 1.52, 95% CI 1.07–2.18; p = .02)</li> </ul>	Total difficulties- (SDQ)	<ul style="list-style-type: none"> <li>• Not in school (MR: 1.23, 95% CI 1.02–1.46; p = .03)</li> <li>• Stigma (per 1 point) (MR: 1.03, 95% CI 1.02–1.05; p &lt; .001)</li> <li>• Incomplete adherence (MR: 1.34, 95% CI 1.11–1.62; p = .002)</li> </ul>	<ul style="list-style-type: none"> <li>• Stigma (per 1 point) (MR: 1.03, 95% CI 1.01–1.05; p &lt; .001)</li> <li>• Incomplete adherence (MR: 1.38, 95% CI 1.15–1.65; p = .001)</li> </ul>
<b>(Earnshaw et al., 2018)</b>	Poisson regression	Depressive symptoms (BDI-II)	<ul style="list-style-type: none"> <li>• Internalised stigma (RR=1.27, 95% CI 1.19–1.34, p≤0.05)</li> <li>• Associative stigma (RR=1.55, 95% CI 1.43–1.68, p≤0.05)</li> <li>• Internalised*associative stigma (RR=1.12 (95% CI 1.09–1.14), p≤0.05)</li> </ul>	<ul style="list-style-type: none"> <li>• Internalised stigma (RR=1.23, 95% CI 1.13–1.34, p≤0.05)</li> <li>• Associative stigma (RR=1.59, 95% CI 1.37–1.84, p≤0.05)</li> </ul>			

<b>(Gaitho et al., 2018)</b>	Linear regression	Depressive symptoms	<ul style="list-style-type: none"> <li>• 15–19 years (OR = 2.6, 95% CI 1.6–4.3, p &lt; 0.001)</li> <li>• frequent changing of schools in the preceding 2 years due to repeated adversities (OR = 1.66, 95% CI 0.99–2.81, p = 0.05)</li> <li>• repeating a grade (OR = 1.85, 95% CI 1.11–3.11, p = 0.02)</li> <li>• lack of school fees (OR = 2.01, 95% CI 1.23–6.31, p = 0.005)</li> <li>• unavailability of food (OR = 2.83, 95% CI 1.27–6.31, p = 0.009)</li> <li>• ran away from home (OR = 3.39, 95% CI 1.09–10.58, p = 0.03)</li> <li>• substance use (OR = 3.57, 95% CI 1.29–9.92, p = 0.01)</li> <li>• non-perfect adherence to their medications (OR = 2.62, 95% CI 1.60, -4.28, p ≤ 0.001)</li> </ul>	<ul style="list-style-type: none"> <li>• 15–19 years (OR = 2.34, 95% CI 1.36–4.04, p &lt; 0.02)</li> <li>• having had an experience of repeating a grade (OR = 1.74, 95% CI 1.0–3.05, p = 0.05)</li> <li>• having had an experience of being refused school participation due to lack of school fees (OR = 1.71, 95% CI 1.0–2.91, p = 0.05)</li> <li>• non-adherence to medication (OR = 1.84, 95% CI 1.08–3.14, p = 0.03)</li> </ul>
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<b>(Gentz et al., 2017)</b>	Hierarchical multiple linear regression	Total difficulties- (SDQ)	<i>Total difficulties</i> <ul style="list-style-type: none"> <li>Orphanhood (<math>\beta=0.138</math>, 95% CI NR, <math>p &lt; .05</math>)</li> </ul>	<i>Total difficulties-Final model</i> <ul style="list-style-type: none"> <li>Child assets (<math>\beta=-0.22</math>, 95% CI NR, <math>p&lt;0.05</math>)</li> <li>Stigma (<math>\beta= -0.261</math>, 95% CI NR, <math>p&lt;0.05</math>)</li> </ul>	Sub-domains- (SDQ)	<i>Emotional problems</i> <ul style="list-style-type: none"> <li>Female (<math>\beta= 0.255</math>, 95% CI NR, <math>p&lt;0.05</math>)</li> </ul>	<i>Peer problems-Final model</i> <ul style="list-style-type: none"> <li>Social support (<math>\beta= -0.348</math>, 95% CI NR, <math>p&lt;0.001</math>)</li> </ul> <i>Conduct problems-Final model</i> <ul style="list-style-type: none"> <li>Child assets (<math>\beta= -0.301</math>, 95% CI NR, <math>p&lt;0.01</math>)</li> </ul> <i>Emotional problems-Final model</i> <ul style="list-style-type: none"> <li>HIV-stigma (<math>\beta= 0.308</math>, 95% CI NR, <math>p&lt;0.01</math>)</li> </ul>
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<b>(Kim et al., 2015)</b>	Linear/logistic regression	Depressive symptoms (BDI II)	NR	Final model	Depressive symptoms (CDSR-R)	Final model
				<ul style="list-style-type: none"> <li>• Female (<math>\beta</math>: 2.13, 95% CI 0.82-3.43, <math>p = 0.002</math>)</li> <li>• Not in school/junior primary (<math>\beta</math>: 3.84, 95% CI 1.71-5.98, <math>p = 0.0005</math>)</li> <li>• Nobody in my family has died (<math>\beta</math>: -1.77, 95% CI -3.15- -0.39, <math>p = 0.001</math>)</li> <li>• Did not fail school term/class (<math>\beta</math>: -1.46, 95% CI -2.76- -0.17, <math>p = 0.003</math>)</li> <li>• Bullying for taking medication (<math>\beta</math>: 5.31, 95% CI 3.19-7.43, <math>p &lt; 0.0001</math>)</li> <li>• Never had a boyfriend/girlfriend (<math>\beta</math>: -2.38, 95% CI -4.35- -0.41, <math>p = 0.02</math>)</li> </ul>		<ul style="list-style-type: none"> <li>• Older age (OR: 1.23, 95% CI 1.07-1.42, <math>p = 0.004</math>)</li> <li>• Not in school/junior primary (OR: 3.30, 95% CI 1.54-7.05, <math>p = 0.005</math>)</li> <li>• Bullied for taking medication (OR: 4.20, 95% CI 2.29-7.69, <math>p &lt; 0.0001</math>)</li> </ul>

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- Disclosed and have shared with someone ( $\beta$ : -1.83, 95% CI -3.79-0.13,  $p = 0.02$ )
  - Level of immunosuppression (None or not significant) ( $\beta$ :-2.58, 95% CI -4.29- -0.87,  $p=0.0009$ )
  - Age\* satisfaction with physical appearance interaction ( $\beta$ :-0.93 , 95% CI -1.74- -0.11,  $p =0.03$ )
  - Age\* Height for age z-score interaction - ( $\beta$ : -0.39, 95% CI -0.68- -0.11,  $p = 0.007$ )
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<b>(Mbalinda et al., 2015)</b>	Logistic regression	Physical health functioning- (MOS- HIV)	NR	<ul style="list-style-type: none"> <li>• Secondary (aOR: 0.41, 95% CI 0.20-0.85, p = 0.01)</li> <li>• Northern region (aOR: 0.25, 95% CI 0.16-0.42; p = &lt;0.001)</li> <li>• Currently on ARVs (aOR: 2.07, 95% CI 1.24-3.36; p &lt; 0.05)</li> <li>• Has a friend who is smoking cigarette- (aOR: 0.48, 95% CI 0.29-0.80; p = &lt;0.001)</li> </ul>	Mental health functioning- (MOS-HIV)	NR	<ul style="list-style-type: none"> <li>• Primary (aOR: 3.3, 95% CI 1.18-9.38, p =0.02)</li> <li>• Secondary (aOR: 5.3, 95% CI 1.86-15.41, p = &lt;0.00)</li> <li>• Northern region (aOR:0.50, 95% CI 0.32-0.78; p = &lt;0.001)</li> <li>• Currently on ARVs (aOR: 3.9, 95% CI 2.22-6.92; p &lt; 0.001)</li> <li>• Wants to have a child in the future (aOR: 1.7, 95% CI 1.05-3.00; p=0.03)</li> <li>• Parent and adolescent not communicating on sexuality issues</li> </ul>
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(aOR: 0.6, 95%  
CI 0.40-0.89;  
p=0.01

- Has a friend who is smoking cigarette (aOR: 0.57, 95% CI 0.34-0.98; p=0.04)
- Dissatisfied with the sexual reproductive health service (aOR: 0.34, 95% CI 0.18-0.62; p<0.00)

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<b>(Mutumba et al., 2017)</b>	Hierarchical multiple linear regression	Psychological distress	NR	<p>Final model</p> <ul style="list-style-type: none"> <li>• Female (<math>\beta</math>: 0.061, 95% CI NR, <math>p = 0.08</math>)</li> <li>• Pentecostal (<math>\beta</math>: 0.086, 95% CI NR, <math>p = 0.02</math>)</li> <li>• Paternal orphan (<math>\beta</math>: -0.083, 95% CI NR, <math>p = 0.05</math>)</li> <li>• Double orphan (<math>\beta</math>: -0.094, 95% CI NR, <math>p = 0.07</math>)</li> <li>• Daily hassles (<math>\beta</math>: 0.118, 95% CI NR, <math>p = 0.01</math>)</li> <li>• Negative life events (<math>\beta</math>: 0.209, 95% CI NR, <math>p &lt; 0.01</math>)</li> <li>• HIV-related QoL (<math>\beta</math>: 0.299, 95% CI NR, <math>p &lt; 0.01</math>)</li> <li>• HIV stigma (<math>\beta</math>: 0.089, 95% CI NR, <math>p = 0.02</math>)</li> <li>• Religiosity (<math>\beta</math>: 0.078, 95% CI NR, <math>p = 0.02</math>)</li> <li>• Religious coping</li> </ul>
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( $\beta$ : -0.083, 95% CI  
NR, p=0.02)

- Optimism  
( $\beta$ : -0.063, 95% CI  
NR, p =0.09)
- Satisfied with social  
support  
( $\beta$ : -0.169, 95% CI  
NR, p <0.01)
- General coping style  
and behaviours  
( $\beta$ : -0.160, 95% CI  
NR, p<0.01)

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<b>(Okawa et al., 2018)</b>	Logistic regression (multiple)	Depressive symptoms (CES-D)	<ul style="list-style-type: none"> <li>• Fair/unsatisfied with relationship with family (aOR: 3.01, 95% CI 1.20–7.56, p&lt;0.01)</li> <li>• Fair/unsatisfied with relationship with HCWs (aOR: 2.68, 95% CI 1.04–6.93; p = &lt;0.001)</li> <li>• Experienced HIV stigma (aOR: 2.99, 95% CI 1.07–8.41; p=0.01)</li> </ul>
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<b>(Woollett et al., 2017b)</b>	No formal regression, calculated relative risks using Altman's formula	Depressive symptoms (CDI-S)	<ul style="list-style-type: none"> <li>• Been hit (RR: 1.97, 95% CI NR, p 0.02)</li> <li>• Been inappropriately touched (RR: 2.22, 95% CI NR; p =0.01)</li> <li>• Do not feel like they control their future (RR: 2.55, 95% CI NR; p =0.04)</li> <li>• Do not feel safe at home (RR: 5.17, 95% CI NR; p &lt; .001)</li> <li>• Do not have a dream (RR: 4.62, 95% CI NR; p &lt; .001)</li> <li>• Do not have a safe place in the community for adolescents (RR: 2.31, 95% CI NR; p &lt; .001)</li> <li>• Experienced forced sex (RR:3.55, 95% CI NR; p =0.02)</li> <li>• Experienced peer violence outside of school (RR:2.16, 95% CI NR; p =0.01)</li> </ul>	NR	Anxiety symptoms (RCMAS-2)	<ul style="list-style-type: none"> <li>• Been hit (RR: 2.00, 95% CI NR, p 0.00)</li> <li>• Been inappropriately touched (RR: 1.77, 95% CI NR; p &lt; .001)</li> <li>• Do not feel like they control their future (RR: 2.75, 95% CI NR; p &lt; .001)</li> <li>• Do not feel safe at home (RR: 2.92, 95% CI NR; p &lt; .001)</li> <li>• Do not have a dream (RR: 2.25, 95% CI NR; p &lt; .001)</li> <li>• Do not have a safe place in the</li> </ul>	NR
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- Experienced peer violence at school and outside (RR:1.77, 95% CI NR; p =0.04)
- Reports any form of suicidality (RR: 3.44, 95% CI NR; p < .001)
- Think about a way to kill themselves (RR: 3.54, 95% CI NR; p < .001)
- Think about killing themselves (RR: 3.22, 95% CI NR; p < .001)
- Try to kill themselves- (RR: 3.76, 95% CI NR; p < .001)
- Want to hurt themselves- (RR: 2.74, 95% CI NR; p < .001)
- Wish they were dead- (RR: 3.71, 95% CI NR; p < .001)

- community for adolescents (RR: 2.02, 95% CI NR; p < .001)
- Experienced forced sex (RR:3.01, 95% CI NR; p =0.01)
- Experienced peer violence outside of school (RR:1.62, 95% CI NR; p =0.02)
- Reports any form of suicidality (RR: 2.35, 95% CI NR; p < .001)
- Think about a way to kill themselves (RR: 2.23, 95% CI NR; p < .001)

- 
- Think about killing themselves (RR: 1.95, 95% CI NR; p < .001)
  - Try to kill themselves (RR: 2.52, 95% CI NR; p < .001)
  - Want to hurt themselves (RR: 1.97, 95% CI NR; p < .001)
  - Wish they were dead (RR: 2.54, 95% CI NR; p < .001 =1)

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NR=Not reported, MR=Mean ratio, OR=Odds ratio, aOR= adjusted odds ratio, CI=Confidence interval, QoL=quality of life, RR= risk ratio, \$= factors considered statistically significant (as per the study's definition) are only presented, \*= interaction terms



### ***3.3.1 Quality of studies***

Five of the ten quantitative studies were judged as having low quality as findings were subject to a high risk of bias (Dow et al., 2016, Earnshaw et al., 2018, Gentz et al., 2017, Okawa et al., 2018, Woollett et al., 2017b) (Table 5). The main quality concerns in these studies were the lack of reporting on psychometric properties of the scale and standardisation of scale administration, including the inadequate reporting and interpretation of statistical analyses. Only one study psychometrically evaluated the chosen scale on a similar study population and found it to have good validity and reliability (Kim et al., 2015). None of the studies reported information on the cultural validity of the chosen scale/s. All studies were subject to selection bias as samples were drawn from healthcare facilities, primarily using non-random sampling techniques.

**Table 5: Quality assessment of studies included in the quantitative synthesis (N=10). These studies examined correlates of wellbeing or mental health among YPLHIV in SSA**

Author year	Sampling (max score 4)		Measurement (max score 8)		Reporting (max score 8)			Total score	Quality
	Generalisability	Sample size	Psychometric properties of scale	Scale administration	Description of analysis	Reporting of regression analysis	Adjustment of confounders		
(Abebe et al., 2019)	1	2	1	3	1	3	1	12	Medium
(Dow et al., 2016)	1	2	1	2	1	1	0	8	Low
(Earnshaw et al., 2018)	1	1	0	1	2	3	1	9	Low
(Gaitho et al., 2018)	1	1	0	1	1	4	2	10	High
(Gentz et al., 2017)	1	0	1	2	0	1	2	7	Low
(Kim et al., 2015)	1	2	3	2	2	3	2	15	Medium
(Mbalinda et al., 2015)	1	2	2	1	1	3	2	12	Medium
(Mutumba et al., 2017)	1	2	2	2	1	3	1	12	Medium

(Okawa et al., 2018)	1	2	1	0	1	1	1	7	Low
(Woollett et al., 2017b)	1	2	1	1	0	0	0	5	Low
- The quality assessment tool that was applied was adapted from the Cochrane guidance on assessing risk of bias in non-randomised studies (Higgins and Green, 2011)									

### **3.4 Qualitative studies- characteristics and data synthesis**

Of the 30 qualitative studies (Table 3), most were undertaken in the eastern sub-region (N=14): Uganda (n=11), Kenya (n=2), Tanzania (n=1) and the southern sub-region (N=14) (South Africa (n=9), Namibia (n=1), Swaziland (n=1), Zambia (n=2), Zimbabwe (n=1), with one study conducted in both regions (Tanzania and Botswana). The remaining study was conducted in West Africa (Nigeria n=1). Only six studies focused on a specific gender (females n=5, males n=1). None of the 30 studies specifically examined lived experiences of wellbeing. However, they examined experiences related to dimensions of wellbeing or mental health. The aim of most of the studies was to understand the psycho-social challenges experienced among YPLHIV. Five studies examined broader life experiences associated with wellbeing using ethnographic methods. Data were collected mainly via focus-group discussions and in-depth interviews. Several studies included perspectives from caregivers (n=9) and healthcare workers (HCWs) (n=7), with only one study that included perspectives from educators.

#### **3.4.1 Specific analytical themes**

Three key themes emerged across all studies: 1) acceptance and belonging, 2) coping; 3) standard of living (Table 6, Figure 2). These themes shaped experiences suggestive of wellbeing as detailed below.

##### **i. Acceptance and belonging**

###### **a) HIV-related stigma and discrimination**

All the studies highlighted the role HIV-related stigma and discrimination played in reinforcing social isolation and poor mental health functioning among YPLHIV. Perceived contributors included forms of internalised stigma, characterised as fear of the rejection and isolation if HIV status was accidentally disclosed to peers (Li et al., 2010), partners (Matovu et al., 2012, Mutumba et al., 2015, Mattes, 2014, Petersen et al., 2010) or parents (Mattes, 2014, Kyaddondo et al., 2013, Siu et al., 2012). Hence, keeping one's HIV status undisclosed was often described as an everyday lived experience (Jena, 2014, Pienaar and Visser, 2012, Lypen et al., 2015, Abubakar et al., 2016). Studies described how internalised stigma impeded ability to build "healthy identities" (Rosenbaum, 2017, Petersen et al., 2010, Pienaar and Visser, 2012) and access social support (Matovu et al., 2012). Gendered social expectations appeared to facilitate internalised stigma and

consequently limited disclosure. For example, in Uganda, a young woman living with HIV feared loss of social value if her intimate relationship was curtailed and hence opted for non-disclosure of her HIV status (Matovu et al., 2012). Similarly, young men living with HIV in Uganda felt unable to uphold masculine socio-cultural identities and thus chose not to disclose their HIV status to their parents in fear of the “loss of rights” to endowments (Siu et al., 2012, Kyaddondo et al., 2013). Most studies described the manifestations of HIV-related stigma in terms of experienced stigma, which was encountered in relationships with mothers (Knizek et al., 2017, Vale et al., 2017), family members (Shabalala et al., 2016, Matovu et al., 2012), learners and educators (Inzaule et al., 2016, Mutumba et al., 2015, Jena, 2014), and HCWs (Goudge et al., 2009) (Vale et al., 2017). Authors also described how stigma intersected with gendered attitudes towards sexuality and self-acceptance among young women (Plattner and Meiring, 2006, Matovu et al., 2012, Woollett et al., 2017a, Goudge et al., 2009), including cultural norms such as respect for elders (Dusabe-Richards et al., 2016, Mackworth-Young et al., 2017, Vale et al., 2017).

### ***b) Social support***

The importance of relationships and social connections was expressed in several studies. Shabalala et al. (2016) notes that for YPLHIV in eSwatini (formerly called Swaziland) strong relationships with caregivers were linked with “being accepted, being connected and welcomed”. Mutumba et al. (2015) describes how pill taking between HIV-positive parents and YPLHIV in Uganda fostered bonding “whenever she took hers, I also took mine”. In contrast, in three studies, young women expressed the lack of support from caregivers (Knizek et al., 2017, Matovu et al., 2012, Kajubi et al., 2016). Trusting relationships with family members were frequently described as important (Mutumba et al., 2015, Matovu et al., 2012, Midtbo et al., 2012, Adegoke and Steyn, 2017, Lypen et al., 2015). In a Kenyan study, authors indicate that the acceptance received from siblings served to “validate the participant as a human being” (Lypen et al., 2015). Unsupportive family networks were also described in the literature in the context of poor mental health functioning and reduced wellbeing (i.e. lack of self-acceptance) (Matovu et al., 2012, Shabalala et al., 2016).

Furthermore, studies described how YPLHIV drew on their friendship networks to manage treatment adherence, seek advice and feel accepted (Mburu et al., 2014, Lypen et al., 2015, Petersen et al., 2010). Several participants expressed gratitude for the informational and emotional support received from HCWs (Bernays et al., 2017, Mackworth-Young et al., 2017, Lypen et al., 2015, Jena, 2014). Furthermore, in settings where YPLHIV had access to support groups, feeling “comforted” (Mattes, 2014), “normal” (Mattes, 2014) “welcomed” (Shabalala et al., 2016), “open to share” (Midtbo et al., 2012), and “not alone” (Rosenbaum, 2017) were dominant in the narratives. Caregivers in a South African study highlighted their lack of social support and how it hindered their ability to cope and subsequently support their children (Petersen et al., 2010). In three studies, YPLHIV articulated a deep longing for their deceased parents which authors indicated signified the importance parents played in nurturing belonging and its link with creating meaning in life (Woollett et al., 2017a, Shabalala et al., 2016, Kajubi et al., 2016, Petersen et al., 2010). Moreover, the yearning for one’s father was interpreted as being underpinned by “cultural expectations of being cared for and finding a rightful place in their father’s home” (Shabalala et al., 2016).

## **ii. Coping**

A key positive factor that YPLHIV utilised for coping was religion and faith, especially when support was limited. Religion and faith were primarily expressed as “belief in God” (Lypen et al., 2015, Knizek et al., 2017, Li et al., 2010, Plattner and Meiring, 2006, Mburu et al., 2014, Midtbo et al., 2012, Rosenbaum, 2017, Woollett et al., 2016). Most authors perceived religion as bringing comfort and hope, as well as meaning and purpose in their lives. In addition, in a Namibian study, interpreting HIV acquisition as a “test or punishments from God” helped a young woman to accept her HIV status (Plattner and Meiring, 2006). Another major positive coping strategy that YPLHIV applied was future goal setting such as desire for marriage and children (Woollett et al., 2016, Jena, 2014, Mackworth-Young et al., 2017, Mathur et al., 2016). Educational aspirations were perceived as bringing a sense of purpose or social value to participants’ lives (Adegoke and Steyn, 2017, Jena, 2014). In contrast, YPLHIV also utilised negative coping strategies such as social withdrawal (Rosenbaum, 2017, Pienaar and Visser, 2012, Jena, 2014), self-blame (Mutumba et al., 2015, Mburu et al., 2014) and anticipation of death (Mattes, 2014, Woollett et al., 2017a, Petersen et al., 2010).

### **iii. Standard of living**

Most YPLHIV resided in non-nuclear and skipped-generation households that had encountered multiple losses. These households were often described by authors as lacking economic security and social protection. In Kenya, Zimbabwe and South Africa, caregivers and community HCWs reported how food insecurity challenged ART adherence and positive mental health functioning among YPLHIV (Rosenbaum, 2017, Campbell et al., 2012, Abubakar et al., 2016, Petersen et al., 2010). Young men living with HIV often reported difficulty in establishing economic security as the sole reason for delaying sexual debut, marriage and having children (Mathur et al., 2016, Mattes, 2014, Li et al., 2010). In Uganda, two studies noted how young men had “shattered dreams” (Knizek et al., 2017) as household poverty traps prevented young men from completing their schooling, achieving their career aspirations and entering into the formal labour market. A young man’s inability to contribute to his household made him feel “unwanted” and “hurt” (Shabalala et al., 2016).

**Table 6: Key themes that shaped experiences suggestive of wellbeing among YPLHIV in SSA, as derived from the qualitative meta-synthesis**

Third order labels	Third order constructs	Second order constructs (authors interpretation)	First order (sample of quotes or narratives)
<b>Theme 1: Social acceptance and belonging</b>			
<b>1.1 HIV-related stigma and discrimination</b>	<ul style="list-style-type: none"> <li>○ Stigma compromised wellbeing via several pathways</li> <li>○ Impact of internalised stigma on identity, social interactions and engagement, medical adherence and mental health functioning</li> <li>○ Experienced stigma encountered at various socio-ecological levels exacerbated feelings of isolation and rejection</li> <li>○ Internalised and experienced stigma intersected with gender and cultural norms</li> <li>○ Stigma reduced feelings of social acceptance and social connectedness</li> <li>○ Stigma challenged ability to maintain relationships</li> </ul>	<ul style="list-style-type: none"> <li>- Fear if HIV-positive status was known among the wider community</li> <li>- Caregivers fears on adolescent's risk for rejection, isolation and stigmatisation</li> <li>- Strategies to prevent unintentional disclosure-keeping one's status a secret</li> <li>- Development of negative identities</li> <li>- Fears related to infecting sexual partner</li> </ul>	<ul style="list-style-type: none"> <li>▪ "I've thought about telling them [my friends], but then I stop myself because I'm afraid they'll be mean to me or they'll mistreat me, or they'll avoid me." [15 year-old male, South Africa] (Li et al., 2010)</li> <li>▪ "I think that if I tell other children, they might end up treating him badly or have negative attitudes towards him." [Grandmother-caregiver, Kenya] (Abubakar et al., 2016)</li> <li>▪ "After learning of her daughter's HIV diagnosis, Nandipha's mother reportedly felt ashamed, suggesting that she perceived the diagnosis to also be a reflection on her. To protect themselves from gossip, the family continued to keep Nandipha's status a secret" [15-19 year-old, South Africa] (Vale et al., 2017)</li> <li>▪ "Even at home the children don't know. They see me and ask but mum tells them I have malaria and they don't care. Mum tells me not to tell them.maybe in the future." [18 year-old female, Uganda] (Mutumba et al., 2015)</li> <li>▪ "Up to now, I feel different from other children. Someone who looks miserable without HIV is far better than a person who looks healthy with HIV. [Who told you?] It's how I know it and I believe it's true" [17 year-old female, Uganda] (Mutumba et al., 2015)</li> <li>▪ "Oh, look at that girl who has AIDS". I did rather people see me as Musa than them saying "Oh Musa with AIDS" (16-17 year-old male, South Africa) (Jena, 2014)</li> <li>▪ "So far I am not thinking about having a girlfriend. [...] The problem have is if I infect my partner, does that not even cause more problems? I don't want to infect my partner the way I was infected. So, I think it's better to calm down and wait for the day that a solution will be available." [16 year-old male, Tanzania] (Mattes, 2014)</li> </ul>



			<ul style="list-style-type: none"> <li>▪ “I have a boyfriend, but I cannot tell him am positive, although he says he loves me and this is stressing me a lot because, I want to get married, but I cannot because he will fall sick and I love him, yet I cannot tell him am positive....” [20 year-old female, Uganda] (Matovu et al., 2012)</li> </ul>
		- Non-disclosure to parents-fear of loss of rights and entitlements	<ul style="list-style-type: none"> <li>▪ “For me my father is alive and I am the heir, but if he knows that I am positive he might remove the heirship from me thinking that I will die before him. I must first weigh the possible outcome of disclosing and to whom.” [20-24 year-old male, Uganda] (Kyaddondo et al., 2013)</li> </ul>
		- Stigma experienced by family members and its consequences- feeling unaccepted by family, interference with medical adherence	<ul style="list-style-type: none"> <li>▪ “(...) I grew up when my mother never saw me as a person who can really achieve something in future, because I am the only kid who was born HIV positive. (...) So, she saw me like a failure, I would not succeed in anything. (...) She used to discriminate me among my brothers and sisters. She used to treat them as children, but me as nothing. A bastard at home. “(...) I got to know that mothers are the most creatures that really love their children compared to their dads. (...) But I was really surprised that it’s my dad who loves me more than my mum. So, I would ask myself why my mother was doing such. At times I would tell myself that this world is nothing for me.” [17 year-old female, Uganda] (Knizek et al., 2017)</li> <li>▪ “He did not see eye to eye with his sister-in-law who did not like the fact that Mpendulo was HIV positive...in one incidence the sister-in-law found him eating food from a plate that was not designated for him. She scolded the boy for using the plate; stating that...he will infect her children with HIV. That angered Mpendulo a lot. He said he felt unwelcomed and not wanted.” [Case study of 15 year-old male”, eSwatini (formerly Swaziland)] (Shabalala et al., 2016)</li> <li>▪ “My auntie told me that I do not belong to the family, because of my condition and I was always segregated from other family members. When I go back home my auntie starts throwing insults at me and saying that you have been sleeping around. She doesn't care, if you tell her please aunt buy for me some clothes, she replies with annoyance that I stopped buying for you clothes in Primary five saying that I no longer have value and I don't give you my things, it’s up to you. I remember the doctors called her one time to pick</li> </ul>

			<p>my medication and also to act as the adherence support person and she said, if it means for her to die, let it be so, I will not come. I even contemplated killing myself because of the situation” [16 year-old, female, Uganda] (Matovu et al., 2012)</p>
		<ul style="list-style-type: none"> <li>- Stigma perpetuated by school learners and educators, impact on medical adherence and mental health</li> <li>- Perceived lack of sympathy from HCWs- challenged communication between HCWs and patient</li> </ul>	<ul style="list-style-type: none"> <li>▪ “At first, when I took those medications I was in boarding school. I was coughing all the time and children were laughing at me and I felt bad. I don’t know how the matron got to know but she knew and told them. They back-bitted [gossiped] me whenever I passed” [18 year-old female, Uganda] (Mutumba et al., 2015)</li> <li>▪ “There is a girl we lost, she passed away, she was 18. . . she had [experienced] stigma at school because they came across her drugs in her suitcase, and they pulled them out and they put them there and put her [medical] card on her bed and she was a head-girl and that killed her [spirit]! She had to switch school. Most of them you get these calls, when they are saying they have found out, you see, so she had to switch out schools.” [Counsellor, Uganda] (Inzaule et al., 2016)</li> <li>▪ “Sometimes when I don’t feel like taking my treatment, I don’t. I can’t take my pills with water, and if I don’t have juice, I simply can’t take them. (Matovu et al., 2012)They shout at us when we don’t take our treatment, just like they did today. I wouldn’t be able to say all these things I have said to you to anyone of them. They are strict with us, so we’re scared.” [20 year-old female, South Africa] (Goudge et al., 2009)</li> </ul>
		<ul style="list-style-type: none"> <li>- Sexual norms and gender oppression- impact on women’s mental health</li> <li>- HIV contraction via sexual intercourse- self-blame</li> </ul>	<ul style="list-style-type: none"> <li>▪ “They won’t understand that I got the HIV from my parents. They will think I was sleeping around with older men. ” [(16 year-old female, South Africa] (Jena, 2014)</li> <li>▪ “One of my older brothers once told us that if he heard that one of his sisters was HIV-positive, he’d kill her. I realised that my mother and my elder brother would never accept a person who was HIV-positive. That’s why I have decided to keep it to myself.” [20 year-old female, South Africa] (Goudge et al., 2009)</li> <li>▪ “It’s my irresponsibility. I got infected through unprotected sexual intercourse. So, it’s irresponsibility. . . . No one deserves to get the virus. But when you didn’t care . . . sometimes I say I deserve it. I knew how to protect myself; I knew it. I was a promoter, a person</li> </ul>

			who promoted condom use. But it happened, I don't know how." [22 year old female, South Africa] (Plattner and Meiring, 2006)
<b>1.2 Social support</b>	<ul style="list-style-type: none"> <li>○ Supportive and unsupportive networks and impact on mental health and wellbeing</li> <li>○ Lack of support for caregivers</li> <li>○ Longing for relationships</li> </ul>	<ul style="list-style-type: none"> <li>- Caregiver support-material support, treatment support, emotional support from parents, re-connecting with parents</li> <li>- Supportive siblings- forms of validation and acceptance</li> <li>- Supportive extended family- emotional support</li> </ul>	<ul style="list-style-type: none"> <li>▪ "I didn't find any problem [with the drugs] because my mum used to encourage me to take it a lot. She was also on drugs so whenever she took hers, I also took mine" [15 year-old female, Uganda] (Mutumba et al., 2015)</li> <li>▪ "At home they help me with everything and give me all the support I need. It helps me get through knowing they love me. We take our pills the same times, so we always remind each other. When she takes hers, she calls me to take mine" (16 year-old female, South Africa) (Jena, 2014)</li> <li>▪ "I believed that when one is positive he/she can die any time. I also felt am worthless in this world. Later my brothers came and assured me that there was no need of worrying much because they were there for me. They told me that they will take care of me." [24 year-old female, Kenya] (Lypen et al., 2015)</li> <li>▪ [My uncle] made that promise after my mother was buried; he told me — I'm going to support you in good and difficult times — and right now he still is." [19 year-old, male, Botswana] (Midtbo et al., 2012)</li> </ul>
		<ul style="list-style-type: none"> <li>- Supportive peers-empathetic listening, encouragement</li> <li>- Supportive HCWs- gratitude for care, assisting with non-adherence, providing safe spaces for emotional release</li> <li>- HIV support group- received material support, instilled feelings of connectedness and acceptance</li> </ul>	<ul style="list-style-type: none"> <li>▪ "If I have stress, I can go to my friend's place and explain to her and in turn she will give me advises [sic] that are worthy eventually the stress goes." [19 year-old, male, Kenya] (Lypen et al., 2015)</li> <li>▪ "I also didn't accept myself, I cried and I was asking myself when I get to the house should I commit suicide or what? A nurse took me to a room and asked to cry until all the stress is gone. I really had stress." [24 year-old female, Kenya] (Lypen et al., 2015)</li> <li>▪ "Besides learning more about the disease, the pills and other things, they [who?] also provide me with money that I use to buy food...I feel welcomed. Like I have a family when I am with them. I always look forward to the meetings." [15 year-old, male, eSwatini (formerly Swaziland)] (Shabalala et al., 2016)</li> <li>▪ "I loved that children's group because it comforted me to feel like I'm not the only one and to see that my friends have the same problem. [...] And then we did not discriminate each other, we treated each other just like normal when we met. And we were not in a state of hatred and dislike but in a state of love, we loved each</li> </ul>

			other just like normal.” [17 year-old female, Tanzania] (Mattes, 2014)
		<ul style="list-style-type: none"> <li>- Unsupportive family networks- impact on coping, self-acceptance, social-acceptance</li> <li>- Lack of support for caregivers</li> </ul>	<ul style="list-style-type: none"> <li>▪ “My auntie told me that I do not belong to the family, because of my condition and I was always segregated from other family members. When I go back home my auntie starts throwing insults at me and saying that you have been sleeping around. She doesn't care, if you tell her please aunt buy for me some clothes, she replies with annoyance that I stopped buying for you clothes in Primary five saying that I no longer have value and I don't give you my things, it's up to you. I remember the doctors called her one time to pick my medication and also to act as the adherence support person and she said, if it means for her to die, let it be so, I will not come. I even contemplated killing myself because of the situation. I secretly meet with my sisters, who financially support me, and my auntie does not know, but when am in a hurry to meet with them I forget to take my medicine.” [16 year-old female, Uganda] (Matovu et al., 2012)</li> <li>▪ “He did not see eye to eye with his sister-in-law who did not like the fact that Mpendulo was HIV positive...in one incidence the sister-in-law found him eating food from a plate that was not designated for him. She scolded the boy for using the plate; stating that...he will infect her children with HIV. That angered Mpendulo a lot. He said he felt unwelcomed and not wanted. “ [Case study of 15 year-old male”, eSwatini (formerly Swaziland)] (Shabalala et al., 2016)</li> <li>▪ “we just need a support group and I don't know how it can be done. Some people believe they can just sit at home and cry which does not help, I know I have cried, and I am still crying and have not found help yet.” [Caregiver, South Africa] (Petersen et al., 2010)</li> </ul>

		<ul style="list-style-type: none"> <li>- Multiple losses and complicated grieving-longing for relationships they never got to experience</li> <li>- Longing for fathers-shaped by deep cultural expectations</li> </ul>	<ul style="list-style-type: none"> <li>▪ “It’s that every child wants to have a dad and a mother at the same time...growing up having a dad and a mother because it’s really sad seeing some of my friends having their families and telling me they went out with their dads, then I knew that I didn’t have a dad...so many children do suffer from that thing because you all want parents, both parents.” [17 year-old male, South Africa] (Woollett et al., 2017a)</li> <li>▪ “I sometimes feel like it is empty here [pointing on the left side of his chest], like there is this big hole...like if I had a relationship with my real father, singavaleka lesikhala lengisivako la [this hole I feel in here would be closed]” [15 year-old, male, eSwatini (formerly Swaziland)] (Shabalala et al., 2016)</li> </ul>
<b>Theme 2: Coping</b>			
	<ul style="list-style-type: none"> <li>○ Positive coping strategies facilitates wellbeing</li> <li>○ Negative coping strategies and impact on mental health</li> </ul>	<ul style="list-style-type: none"> <li>- Religion and faith- draw on beliefs and values to cope with stressful situation, relationship with God, source of comfort and hope, brings a sense of meaning and purpose</li> <li>- Aspirations- marriage, children, educational attainment, career goals</li> </ul>	<ul style="list-style-type: none"> <li>▪ “So you know they say God throws challenges at you to make you stronger; God does not throw things that He knows that you cannot handle? He throws things at you that He knows that you can handle...so that’s what keeps me going and to me like that’s what tells me everything happens for a reason. There is a reason it happened [becoming HIV positive] and cannot be changed now and if I want to continue to live, I have to take my tablets and all that...so that’s what keeps me going” [18 year-old male, South Africa] (Woollett et al., 2016)</li> <li>▪ “God is going to give me all of my wishes, my dreams. He's going to . . . God will be there" [15 year-old, male, South Africa] (Li et al., 2010)</li> <li>▪ “I have accepted the Lord. I don't know but if I were not [HIV-] positive, perhaps I would not have accepted the Lord. But it is being positive that makes you turn back from the world so you could also think about God” [24 year-old, female, Namibia] (Plattner and Meiring, 2006)</li> <li>▪ “I definitely want to be married and have my own family and children too when I finish my studies” [16 year-old female, South Africa] (Jena, 2014)</li> <li>▪ “I want to be someone in future, a person that people admire and respects and going to school is my stepping stone” [16 year-old female, South Africa] (Jena, 2014)</li> </ul>

			<ul style="list-style-type: none"> <li>▪ “I want to be a medical doctor and I want to study medicine. Am in Science class. So this picture reminds me of it that I can achieve that goal” [17 year-old, female, Nigeria] (Adegoke and Steyn, 2017)</li> </ul>
		<ul style="list-style-type: none"> <li>- Normalising one’s HIV condition- self-acceptance, not feeling alone, social comparisons</li> </ul>	<ul style="list-style-type: none"> <li>▪ “You are just like a normal person, that means you live, you do your business, you study, you finish, you find work, you can support yourself. So to have [HIV] is like having a common fever.” [19 year-old male, Tanzania] (Mattes, 2014)</li> <li>▪ “When I am dancing, even being with HIV, I am as normal as other children.” [15-19 year-old, male, South Africa] (Rosenbaum, 2017)</li> <li>▪ “I am happy with it because there are some diseases which are bigger than this disease like cancer.” [18 year-old female, Uganda] (Mutumba et al., 2015)</li> </ul>
		<ul style="list-style-type: none"> <li>- Social isolation</li> <li>- Blame</li> <li>- Anticipation of fearful events</li> </ul>	<ul style="list-style-type: none"> <li>▪ “He is always lonely and unhappy until sometimes I cheat him [I tell him] that do not worry you no longer have the virus ...” [Grandmother-caregiver, Kenya] (Abubakar et al., 2016)</li> <li>▪ “They are always asking “why me, why me?” and sometimes they blame and resent their parents.” [Caregiver, Uganda] (Loos et al., 2013)</li> <li>▪ “Yeah and afterwards, after like three years my mom died. I was like “I’m the next, I’m the next, I’m the chosen one”. Then my uncle dies and I was like “shit”...this shit is a really huge measure thing. Over fast, like you’re going down...;. I don’t know, this thing keep on telling me that [I will die], I don’t know why, so yeah...Yeah, it’s like they are beating me up with a five pound hammer, you see, shot after shot, shot after shot, so yeah.” [18 year-old, male, South Africa] (Woollett et al., 2017a)</li> </ul>
<b>Theme 3- Standard of living</b>			
<b><i>Economic insecurity</i></b>	<ul style="list-style-type: none"> <li>○ Food insecurity and impact on adherence and mental health</li> <li>○ Fulfilling socio-cultural roles important for wellbeing</li> </ul>	<ul style="list-style-type: none"> <li>- Hunger and adherence</li> </ul>	<ul style="list-style-type: none"> <li>▪ “The main challenge, they are complaining a lot about hunger. They say because of medication they need a lot of food and you see most of their guardians are not financially able...” [Community healthcare worker, female, Kenya] (Abubakar et al., 2016)</li> <li>▪ “It is because (crying) I sometimes get short of the money . . . it is sometimes so difficult for me to come and collect her medication</li> </ul>

			because of the lack of money . . . I am unable to buy the right food for her because she has a special diet since she is sick” [Caregiver, South Africa] (Petersen et al., 2010)
		<ul style="list-style-type: none"> <li>- Limited schooling- unable to engage in occupations they aspired to</li> <li>- Economic scarcity- delay on sexual debut, marriage, having children, limits ability to feel socially valued</li> </ul>	<ul style="list-style-type: none"> <li>▪ “I really wanted to be a teacher. I was not able to realize this goal. I did not have enough financial ability to help me pursue this goal. ...My parents died long ago. I had to come back from school every evening and look for money, at times I had to miss school because I had no pens.” ....[24-year old male, Uganda] (Mathur et al., 2016)</li> <li>▪ “Until I have built a house for myself, when I have a house like this [referring to his mother’s house] I can slowly start thinking about getting married. But [...] for example if you fail Form IV, you get married, do you have a house to put your girl in? Do you have work to feed your child? You have to fight to get a good job, to build a house, to prepare well. [...] Right now [...] I’m concentrating on books [education], that’s it!” [16 year-old male, Tanzania] (Mattes, 2014)</li> <li>▪ “But he would feel hurt when his uncle complained that Mpendulo did not contribute to the household. He felt his inability to contribute was caused by his brother’s refusal to process his share of their father’s estate, and he himself carried the brunt of this as lack of money often forced him to take his medication on an empty stomach.” [15 year-old, male, eSwatini (formerly Swaziland)] (Shabalala et al., 2016)</li> </ul>



a) Females



b) Males

Figure 2: Word clouds highlighting key themes by gender that were identified in the qualitative evidence. These are words and phrases in themes used by authors of included qualitative studies. These studies examined lived experiences related to dimensions of wellbeing or mental health among YPLHIV in SSA. The text font size indicates frequency



### **3.4.2 Quality of studies**







































Twenty-seven out of 30 qualitative studies were of medium (n=19) to high quality (n=8) (Table 7). The remaining three studies were of low quality largely due to insufficient information on the methods and participant sample, including lack of description in the analysis. For most studies included in this synthesis, findings were presented clearly with concrete detail and discussed in relation to other literature and theories.
















Based on the CERQual assessment, we report moderate confidence in most themes (Table 8).

**Table 7: Quality appraisal of full-text studies included in the qualitative synthesis (N=30). These studies examined lived experiences related to dimensions of wellbeing or mental health among YPLHIV in SSA**

**Quality ranking: Red=low, Yellow=medium, Green=high**

First author and date of pub	Domain 1-Research team and reflexivity	Domain 2-Study design	Domain 3-Analysis and findings	Overall quality
(Abubakar et al., 2016)				Low
(Adegoke and Steyn, 2017)				High
(Bernays et al., 2017)				High
(Campbell et al., 2012)				High
(Dusabe-Richards et al., 2016)				Medium
(Goudge et al., 2009)				High
(Inzaule et al., 2016)				Medium
(Jena, 2014)				Medium
(Kajubi et al., 2016)				High
(Knizek et al., 2017)				Medium
(Kyaddondo et al., 2013)				Low

<b>(Li et al., 2010)</b>				Medium
<b>(Loos et al., 2013)</b>				Medium
<b>(Lypen et al., 2015)</b>				Medium
<b>(Mackworth-Young et al., 2017)</b>				Medium
<b>(Mattes, 2014)</b>				High
<b>(Mathur et al., 2016)</b>				Medium
<b>(Matovu et al., 2012)</b>				Medium
<b>(Mburu et al., 2014)</b>				Medium
<b>(Midtbo et al., 2012)</b>				Medium
<b>(Mutumba et al., 2015)</b>				Medium
<b>(Petersen et al., 2010)</b>				Medium
<b>(Pienaar and Visser, 2012)</b>				Medium
<b>(Plattner and Meiring, 2006)</b>				Low
<b>(Rosenbaum, 2017)</b>				Medium

<b>(Shabalala et al., 2016)</b>				High
<b>(Siu et al., 2012)</b>				Medium
<b>(Vale et al., 2017)</b>				High
<b>(Woollett et al., 2016)</b>				Medium
<b>(Woollett et al., 2017a)</b>				Medium

- The quality appraisal tool was adapted from the COREQ checklist (Tong et al., 2007) and informed by studies in this area (Tracy, 2010, Mays and Pope, 2000)

**Table 8: Assessment of the quality of the qualitative evidence using the CERQual approach. This evidence examined themes that shaped experiences suggestive of wellbeing among YPLHIV in SSA**

Summary of review finding	Studies contributing to review findings	Methodological limitations	Coherence	Adequacy	Relevance	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
<b>Theme 1-Social acceptance and belonging</b>							
<p><b>1.1. HIV-related stigma and discrimination</b></p> <p>Stigma negatively impacted wellbeing by reducing self-acceptance and challenging the ability to maintain positive relationships.</p> <p>Internalised and externalised stigma impeded the ability to derive meaning in and to life and consequently wellbeing. It negatively impacted self-worth, connectedness with others and self-acceptance, particularly among women. Moreover, it challenged the ability to build relationships</p>	30	<p>Minor</p> <p>(16 studies with minor and 11 studies with moderate methodological concerns- i.e. methodological orientation, reflexivity)</p>	<p>Minor</p> <p>(Few concerns on the data from the primary data and review finding)</p>	<p>Minor</p> <p>(Most studies provided thick and rich descriptions on this theme)</p>	<p>Moderate</p> <p>(No study was informed by or discussed in the context of wellbeing theory, geographical spread- 15 studies from eastern sub-region, 15 studies from the southern sub-region , 1 study from West Africa, most studies conducted among 15-19-year-olds living with HIV</p>	<p>Moderate confidence</p>	<p>Minor concerns regarding methodological limitations, coherence and adequacy</p> <p>Moderate concerns regarding relevance</p>

and reciprocate love and affection.							
<p><b>1.2 Social support</b> Positive relations were critical in promoting wellbeing.</p> <p>Supportive relationships with caregivers and trusting relationships with extended family members, peers, HCWs and support groups enhanced social acceptance and belonging. This in turn promoted a sense of meaning in and to life, and ultimately wellbeing</p> <p>Unsupportive relationships reinforced feelings of social isolation.</p> <p>Moreover, sexual norms embedded within these networks compromised wellbeing, particularly among women.</p>	28	Minor  (15 studies with minor and 11 studies with moderate methodological concerns- i.e., methodological orientation, reflexivity)	Minor  (Few concerns on the data from the primary data and review finding)	Minor  (Most studies provided thick and rich descriptions on this theme)	Moderate  (No study was informed by or discussed in the context of wellbeing theory, geographical spread- 14 studies conducted in the eastern sub-region, 14 studies conducted in the southern sub-region , 1 study from West Africa, most studies conducted among 15-19-year-olds living with HIV	Moderate confidence	Minor concerns regarding methodological limitations, coherence and adequacy  Moderate concerns regarding relevance
<b>Theme 2- Coping</b>							
The ability to manage daily lived realities was	23	Minor	Minor	Minor	Moderate	Moderate confidence	Minor concerns regarding

<p>important for wellbeing.</p> <p>YPLHIV drew on religion and faith to help understand the meaning of life. This may have engendered a sense of control, belongingness and relatedness and thereby brought meaning to and in life. Similarly, goals and aspirations brought meaning and purpose to life. Strong social support networks fostered positive coping.</p> <p>Negative coping strategies such as social withdrawal, self-blame and anticipation of death reduced ability to finding meaning in life and thus undermined wellbeing</p>		<p>(5 studies with minor and 18 studies with moderate methodological concerns- i.e. methodological orientation, reflexivity)</p>	<p>(Few concerns on the data from the primary data and review finding)</p>	<p>(Most studies provided thick and rich descriptions on this theme)</p>	<p>(No study was informed by or discussed in the context of wellbeing theory, geographical spread- 12 studies from eastern sub-region, 11 studies from the southern sub-region , 1 study from West Africa, most studies conducted among 15-19-year-olds living with HIV</p>		<p>methodological limitations, coherence and adequacy</p> <p>Moderate concerns regarding relevance</p>
<b>Standard of living</b>							
<p>Fulfilling socio-economic roles were important for wellbeing. It served to enhance meaning in and to life and created purpose in life.</p>	<p>11</p>	<p>Moderate</p> <p>(4 studies with minor and 7 studies with moderate methodological concerns- i.e.</p>	<p>Moderate</p> <p>(Several concerns on the data from the primary data and review finding)</p>	<p>Moderate</p> <p>(Few studies provided thick and rich descriptions on this theme)</p>	<p>Moderate</p> <p>(No study was informed by or discussed in the context of wellbeing theory,</p>	<p>Moderate confidence</p>	<p>Moderate concerns regarding methodological limitations, coherence,</p>

<p>Household food insecurity compromised ART adherence and positive mental health functioning and possibly wellbeing.</p> <p>Broader economic constraints challenged the ability of young men to attain desired educational and career goals. This reduced their sense of social value and threatened wellbeing.</p>		<p>reflexivity, lack of thick descriptions in the analysis or description of diverse cases)</p>			<p>majority of the data are from men and caregivers. Geographical spread- 5 studies conducted in southern sub-region, 5 studies conducted in the eastern sub-region, 1 study conducted in western sub-region</p>		<p>adequacy, relevance</p>
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### **3.5 Overall synthesis**

Both our quantitative and qualitative evidence suggest that social networks were at the core of wellbeing for YPLHIV, which supports a relational construct of wellbeing among YPLHIV. Drawing on the relationality meaning model (Wissing, 2014), our findings suggest that social relationships were critical in fostering belongingness and connectedness. This in turn contributed to a sense of meaning in and to life, and ultimately wellbeing. In addition, socio-cultural norms and values were important to the wellbeing of YPLHIV, as these helped realise the meaning of and in life. In contrast, our synthesis also revealed that in certain instances, social networks and gender norms embedded within these networks compromised wellbeing. Based on our evidence, dimensions that potentially constitute wellbeing for YPLHIV can be mapped onto the following PWB dimensions: 1) self-acceptance — internalised stigma, externalised stigma, social acceptance; 2) belonging — family connectedness; 3) autonomy — disclosure, sexual intercourse; 4) positive relations — social support; 5) environmental mastery — positive and negative coping; 6) purpose in life — religious activities, educational aspirations .

## **4. Discussion**

This review examined the existing quantitative and qualitative evidence to identify dimensions of wellbeing among YPLHIV in SSA. The goal of this review was to inform wellbeing measurement for HIV policy evaluations. We found that no quantitative or qualitative study to date has examined wellbeing using standard wellbeing frameworks or measures, and that the current evidence base on quality of life research among YPLHIV in this region is focused mainly on mental health. Nevertheless, by drawing on the correlates of mental health we can identify possible correlates of wellbeing as factors associated with mental health are likely to be associated with SWB and PWB, as shown in previous studies (Layard et al., 2013, Lombardo et al., 2018, Fergusson et al., 2015, Lagnado et al., 2017, Cummins, 2010, Ryff and Keyes, 1995, Ryff, 2014). Hence, our review provides indirect evidence on pathways to and experiences of wellbeing, and through this, contributes to identifying possible dimensions and measures of wellbeing. Overall, our synthesis found that multi-dimensional measures of wellbeing which include relational dimensions that are specifically sensitive to domains such as family, social

relationships, religion and living standards, are potentially more appropriate for use in this setting as opposed to unidimensional measures of wellbeing. Furthermore, our findings shed light on how wellbeing is shaped by social networks and the socio-cultural norms and values within these networks, which also helps inform measures to be collected alongside wellbeing.

In African culture, empirical evidence from social psychology and anthropology suggests that relationships with others define the self and are central to the conceptualisation and experiences of wellbeing (Delle Fave et al., 2016, White and Jha, 2018), particularly among young people (Wissing et al., 2014). Findings from our review also support a relational construct of wellbeing among YLHIV. Our evidence highlighted the strong positive correlation between social support and positive mental health functioning and the importance of social support in shaping positive lived experiences among YPLHIV. This concurs with international and local reviews on youth wellbeing (Proctor et al., 2009, Govender et al., 2018). Economic studies from high income settings have found robust positive associations between social ties (e.g. family, peers, neighbours) and SWB (life satisfaction, happiness) (Helliwell and Putnam, 2004). However, our findings suggest that social networks have both benefits and liabilities for wellbeing among YPLHIV in this setting, which is consistent with recent evidence that highlights the positive and negative relational mechanisms of social networks on SWB (Huang et al., 2019), particularly among adolescents (Goswami, 2012).

Our quantitative synthesis found a strongly positive correlation between stigma and poor mental functioning. This suggests that stigma is likely negatively associated with SWB due to the negative association between mental illness and SWB (Layard et al., 2013). This is consistent with findings from a multi-national study among adults living with HIV in SSA (Greeff et al., 2010) and high income countries (Hutton et al., 2013a) which both found negative associations between stigma and SWB. Moreover, stigma is likely to be negatively associated with PWB given the strong correlation between SWB and PWB dimensions (Ryff and Keyes, 1995, Keyes et al., 2002, Windle and Woods, 2004, Keyes et al., 2010). Drawing on findings from our qualitative review together with the relational meaning model (Wissing, 2014) and Goffman's accounts of stigma (Goffman, 1963), this may be explained by the fact that internalised stigma, experienced at an intrapersonal

level, may have lowered self-worth (Mutumba et al., 2015). Moreover, externalised stigma encountered at an interpersonal level may have reduced connectedness of self with in-groups such as family members and peers (Knizek et al., 2017, Mutumba et al., 2015, Inzaule et al., 2016). Together, these processes may have challenged self-acceptance. The effects of stigma on wellbeing are likely to be more pronounced for sexually HIV-positive young women, who, due to the intersection of stigma with sexual norms, harbour greater feelings of shame and rejection by their mothers as evidenced in our review (Vale et al., 2017, Plattner and Meiring, 2006). Our synthesis also highlighted the importance of social relationships in bringing meaning to life for YPLHIV. However, caregivers often limited the decision-making of YPLHIV with regards to disclosure (Mutumba et al., 2015) and sexual intercourse (Mackworth-Young et al., 2017), which may have reduced the ability of YPHIV to build relationships and reciprocate affection and love. In addition, the absence of relationships, particularly with fathers, may have reduced belongingness (Shabalala et al., 2016). Family-belonging has been shown to mediate pathways to SWB (King et al., 2018) and PWB (Crespo et al., 2011) among adolescents in developed settings. In rural Kenya, family-belonging was found to promote meaning in life (Goodman et al., 2018). Overall, these findings highlight the relevance of selecting wellbeing measures with dimensions designed to capture self-acceptance, family belongingness and autonomy. In addition, it points to the importance of measuring stigma and examining gender effects when evaluating HIV policies on wellbeing.

Our review revealed a link between strong social support networks and mental health among YPLHIV and thus, plausibly, PWB, consistent with a Brazilian study which found that social support from family and friends was positively correlated with PWB among adolescents (Leme et al., 2015). Accounts from our qualitative synthesis suggest that YPLHIV drew on the emotional support from family, peers and HCWs members during challenging life events (i.e. disclosure, adherence challenges, rejection) which potentially may have helped maintain positive mental health and thus wellbeing (Mutumba et al., 2015, Lypen et al., 2015, Mattes, 2014). This is in concordance with the adaptation phenomenon in development studies (Clark, 2012) and the hedonic capital model in economics (Graham and Oswald, 2010) which indicates that during stressful life events, people draw on psychological resources such as social support to maintain wellbeing levels. Our qualitative synthesis revealed that the emotional and material support

received from caregivers was critical for maintaining medical adherence (Mutumba et al., 2015). However, in instances where supportive social networks were limited, we found that YPLHIV drew on negative coping mechanisms (e.g. social withdrawal, self-blame) (Petersen et al., 2010), which is likely reduced their PWB (Sanjuán et al., 2013). This suggests that social support positively impacts PWB by adding meaning to life, specifically on an intra-personal level such as improving one's sense of environmental mastery (i.e. ability to manage daily activities, a sense of control), a dimension of PWB. Overall, these findings suggest that wellbeing measures should also encompass dimensions related to positive relations and environmental mastery. Moreover, they highlight the importance of measuring social support alongside wellbeing.

Our review also showed that socio-cultural values, norms and beliefs were critical for creating purpose in life among YPLHIV, which is also considered important for positive youth development (Damon et al., 2003). Results from our qualitative synthesis suggest that religious beliefs, values and practices, helped YPLHIV understand the meaning of life, particularly in relation to their HIV status (Plattner and Meiring, 2006). Moreover, their relationship with something larger than self, however defined, may have engendered a sense of belongingness and relatedness, enabling them to find meaning in their new identity (Woollett et al., 2016, Li et al., 2010). This suggest that perhaps religiosity positively impacts PWB by increasing meaning and a sense of purpose in life, as found in previous studies with young people in developing settings (Patel et al., 2009; Aghababaei et al., 2016). Educational and employment aspirations were commonly reported in our qualitative evidence (Mathur et al., 2016, Adegoke and Steyn, 2017, Jena, 2014), and may have helped promote wellbeing by creating a sense of purpose in life (Ryff, 2014). In addition, the desire for economic security among males (Shabalala et al., 2016, Mathur et al., 2016, Mattes, 2014) also suggests that their wellbeing may be rooted in their ability to fulfil socio-cultural roles such as breadwinners, and thereby add purpose to their lives. However, the inability of young men to uphold these socio-cultural values due to broader economic issues in the region may have serious consequences for their wellbeing. The evidence from our review suggests that living standards is an important life domain for YPLHIV. In our quantitative synthesis, educational attainment was negatively correlated with symptoms related to depression and anxiety among YPLHIV (Dow et al., 2016, Kim et al., 2015, Mbalinda et al., 2015). Furthermore, our qualitative synthesis found that the

inability to complete school due to the poverty traps affected the self-esteem and identity of young men (Mathur et al., 2016). Together, these findings suggest that educational status may be positively correlated with PWB, as supported by findings from low-income countries that show a positive association between educational status and SWB (life satisfaction) (Dolan et al., 2008). Furthermore, household food insecurity, a negative correlate of SWB (Frongillo et al., 2017), was also a key theme that emerged in our qualitative synthesis as a lived experience that negatively affected mental health (Abubakar et al., 2016, Petersen et al., 2010). These findings highlight the importance of measuring living standards when examining the wellbeing effects of policies. In summary, wellbeing measures that consider domains such as religion and living standards or dimensions such as purpose in life might be valuable for this population.

Lastly, our findings support the use of multi-dimensional relational wellbeing scales aligned to life domains which are important to YPLHIV. Drawing on the broader literature on quality of life instruments for adolescents and HIV populations (Lindert et al., 2015, Cooper et al., 2017, Losada-Puente et al., 2019), several multi-dimensional wellbeing scales may be applicable. The Personal Wellbeing Index focuses on domains important to YPLHIV in SSA (i.e. personal relationships, religion, standard of living, community connectedness). This SWB scale has shown favourable psychometric properties among children in South Africa (Savahl et al., 2015) and adolescents in developing countries (Casas et al., 2012). Moreover, it has been applied in South Africa's national social attitudes survey of individuals aged 16 years and older (Roberts et al., 2013). Dimension in these scales show strong alignment with themes that emerged in our synthesis (i.e. positive relationships, belonging, self-acceptance, environmental mastery, purpose in life). Both scales have shown good psychometric properties among adolescent populations in the North (Rose et al., 2017, Fernandes et al., 2010). In addition, the Mental Health Continuum Short- Form has shown strong alignment with conceptualisation of a good life among adolescents in South Africa (Van Schalkwyk and Wissing, 2010). However, globally, the application of these three scales among young people living with chronic conditions is scarce. Further studies are needed to validate these measures among YPLHIV in SSA, paying careful attention to translational issues (Oishi, 2010, Møller et al., 2015).

Key strengths of this review include: 1) use of mixed-methods, with qualitative data used to explain patterns in the quantitative synthesis; 2) use of a search strategy with a comprehensive definition of wellbeing that allowed us to examine wellbeing literature from multiple disciplines; 3) inclusion of both peer-reviewed articles and grey literature; 4) quality appraisal of each included study and quality assessment of the synthesised evidence. This review is subject to the following limitations: 1) key population groups such as LGBTQI, sex workers and injecting drug users were excluded, as their lived experiences are likely to be different given the higher levels of stigma they possibly encounter relative to the general population of YPLHIV (Lall et al., 2015, Krug et al., 2015, Napierala et al., 2018); 2) whilst every effort was made to ensure we included all relevant data sources, several applicable regional conferences lack online abstract and thus our review may have missed potentially relevant material; 3) my findings are relevant to urban settings within Eastern and Southern Africa as most of the included studies were conducted in this context. Thus, findings may not be generalisable to other SSA regions. Results from recent studies suggest that there are similarities between YPLHIV in SSA and other developing nations within the South-East Asia Region and Region of the Americas in terms of correlates of mental illness (Mellins and Malee, 2013, Vreeman et al., 2017) and adherence (Kim et al., 2014, Hudelson and Cluver, 2015). Hence, results could be relevant to settings within these regions that have similar disease and socio-economic profiles. Moreover, several gaps in our evidence base were identified. First, no study directly assessed correlates of wellbeing (using a wellbeing scale) or evaluated experiences of wellbeing. Second, there were no data from Central Africa, with only one study from West Africa. Third, our evidence is not generalisable to YPLHIV in the community given that most studies sampled individuals from healthcare facilities. Fourth, variability in outcome definition and scale choice made it difficult to compare between quantitative studies and did not allow for a meta-analysis. Fifth, weaknesses in the study design and analytical techniques used in the quantitative evidence limited our ability to draw out any causal interpretations. Lastly, for the qualitative review, data saturation among 20-24-year-olds and YPLHIV in rural settings was not reached, leaving gaps in our understanding of how these factors may have shaped wellbeing.

## 5. Conclusion

The aim of this mixed-methods review was to identify the dimensions of wellbeing among YPLHIV in order to inform the measurement of this construct in HIV policy evaluations. Understanding the wellbeing effects of HIV/AIDS policies could help steer policies in the direction that meets the broader needs of YPLHIV. This review has shown that social support was a key correlate of poor mental health and that social relationships shaped positive lived experiences. In view of the negative association between poor mental health functioning and measures of wellbeing found in the literature, it is plausible to posit that in this population wellbeing is multi-dimensional and that relational dimensions frame wellbeing among YPLHIV. Multi-dimensional wellbeing scales with a strong relational focus that could be applicable for this group include the Personal Wellbeing Index, Ryff's PWB and Mental Health Continuum Short-Form. Policies and programmes could use these measures in monitoring and evaluation activities or apply these in routine surveys examining SDG progress. Future studies should go beyond the investigation of mental health and examine wellbeing, based on definitions grounded in theory, to provide more accurate data on the wellbeing effects of policies. However, psychometric evaluations of these scales in this population in SSA are warranted, together with validation of these scales against adolescents and young people's subjective experiences in SSA. Future wellbeing studies should consider longitudinal designs and quasi-experimental approaches for causal investigations, particularly examining the relationship between social network characteristics on wellbeing. In addition, our research suggests that the measurement of wellbeing should be measured alongside other variables, such as stigma, social support and living standards, which from the literature we found has shown to be associated with YPLHIV's lived experiences.

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## **Chapter Conclusion**

The results presented in paper 1 offer important insights into domains and dimensions that should be considered when measuring wellbeing for this population. It also highlights potential measures that best capture these dimensions and could be used in policy evaluations. I used this information to inform my topic guides in my qualitative study (Paper 3).

In addition, this study highlighted important factors that should be considered when evaluating health status and policies on wellbeing. I used this information to inform my model building in Paper 2.

The next paper uses econometric techniques to examine the relationship between health and wellbeing as well as the relationship between a health policy (ART scale-up) and wellbeing among young people in South Africa.

# **Chapter 6: An investigation on the relationship between health and wellbeing among young people (Econometric analysis)**

## **Chapter Introduction**

In this paper, I examined the health determinants of young people's wellbeing in South Africa. As suggested in Chapter 1 and my mixed method review (Paper 1), poor mental and physical health may negatively affect social functioning and compromise wellbeing among this age-group. In addition, given the positive benefits of ART scale-up on physical and social functioning, increased access to this treatment may have been associated with wellbeing gains among youth living in households and communities affected by HIV.

Hence, I specifically examined the relationship between two types of health correlates, health status (depressive symptom score , underweight BMI) and ART access, on wellbeing. I applied a relational PWB framework, drawing on findings from my mixed method review (Paper 1), literature review and qualitative study (Paper 3), to inform my model building. I used a panel dataset and applied multi-level random intercept modelling approaches to investigate these associations. I used life satisfaction, a subjective wellbeing measure, as a proxy measure of PWB. .

I am preparing this paper for submission to the journal of Health Policy and Planning. Due to the large content in this paper, I am considering dividing this material over two papers, one focused on the relationship between health status and wellbeing and the other on the relationship between ART access and wellbeing.



## RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

### SECTION A – Student Details

Student ID Number	1402394	Title	Ms
First Name(s)	Darshini		
Surname/Family Name	Govindasamy		
Thesis Title	Wellbeing among adolescents and young adults in sub-Saharan Africa: a mixed methods study of their wellbeing construct, its health correlates and association with access to HIV treatment		
Primary Supervisor	Prof Janet Seeley		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

### SECTION B – Paper already published

Where was the work published?			
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### SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Health Policy and Planning
Please list the paper's authors in the intended authorship order:	Darshini Govindasamy, Till Bärnighausen, Dayanadan Govender, Paidamoyo Bodzo, Catherine Mathews, Janet Seeley, Giulia Ferrari

Stage of publication	Not yet submitted
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**SECTION D – Multi-authored work**

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I conceptualised the study design with support from my supervisors and collaborators. I sought ethics approval and permission to access the datasets from the respective institutions. I completed all necessary coursework to manage and analyse the datasets (i.e. UCT-NIDS data management and analysis course, LSHTM- Analysis of Hierarchical and Dependent Data, LSE-Introduction to Econometrics. I conducted all data management activities, with support received from PD &amp; DG. I conducted all the analyses, with input received from GF &amp;TB. I wrote-up all drafts of this paper, and incorporated feedback from all authors.</p>
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**SECTION E**

<b>Student Signature</b>	[Redacted]
<b>Date</b>	07/01/2020 U

<b>Supervisor Signature</b>	[Redacted]
<b>Date</b>	7/1/2020

## **Research Paper 2: The association between health and wellbeing among young people in South Africa: a multi-level modelling approach**

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## **Abstract**

Investments in young people's wellbeing are linked to favourable long-run health and labour market outcomes in adulthood. Mental and physical health are strong correlates of wellbeing. However, evidence on the relationship between health status and young people's wellbeing in South Africa is scarce. Furthermore, knowing whether or not large public health initiatives such as South Africa's HIV treatment (antiretroviral therapy) scale-up policies are associated with wellbeing gains, could inform investment decisions to promote wellbeing among this age-group. There is limited data on the relationship between antiretroviral therapy (ART) access and young people's wellbeing. In this study we used individual-level South African panel data and employed multi-level regression techniques to estimate the relationship between 1) health status and young people's wellbeing (life satisfaction); 2) temporal variation in district ART access and young people's wellbeing. We found that depressive symptom scores and underweight body mass index are negatively correlated with life satisfaction. In addition, we found a large positive association between HIV treatment access and life satisfaction. These results were robust to alternative estimation techniques. Further studies exploring the causal impact of health and, preferably, multi-sectoral HIV policies on young people's wellbeing using multi-dimensional measures are warranted.

**Keywords:** wellbeing, life satisfaction, depression, underweight, antiretroviral therapy, young people, sub-Saharan Africa, National Income Dynamics Survey, HIV/AIDS

## **1. Introduction**

### **1.1. Background**

There is a growing recognition of the importance in health investments during adolescence to promote positive wellbeing in adulthood (Layard et al., 2014). Enhanced adult wellbeing is associated with several long-run gains such as reduced mortality and morbidity (Steptoe, 2019), educational attainment, and increased future earnings potential (Clark et al., 2018, Graham et al., 2004). Health investments among the rising population of young people on the African continent are even more crucial, given that the demographic transition occurring in this region is linked to future economic benefits that are dependent on a healthy and productive cohort of young adults entering into the labour market (Bloom et al., 2017, Betcherman and Khan, 2018). However, currently young people in this setting, particularly in sub-Saharan Africa (SSA), are exposed to multiple health and economic challenges that likely reduce their wellbeing (Azzopardi et al., 2019). If we can identify what factors and health policies are associated with the greatest wellbeing gains among young people, then this could inform policy decisions in this area .

Wellbeing broadly refers to whether one is thriving across multiple domains of life (Adler and Seligman, 2016) and is measured via an assessment of uni-dimensional subjective wellbeing measures such as affect balance and life satisfaction (Diener et al., 2017); or multi-dimensional psychological wellbeing measures that assess positive (Ryff, 2014) or social (Keyes, 1998) functioning. It is now considered an important outcome of economic relevance, with strong recommendations for it to be used in policy evaluations (Stiglitz et al., 2009). Data from high-income countries indicate that mental and physical health are among the strongest determinants of wellbeing (Dolan et al., 2008). Public health policies are some of the main policies that are currently being invested in to improve population-level wellbeing in high-income countries (Anderson and Mossialos, 2019, Clark et al., 2009). However, there is little evidence on the relationship between health status and wellbeing as well as public health policies and wellbeing in low- and middle-income countries (LMICs), particularly among key population groups. This study addresses this evidence gap by examining the



relationship between health and population-level wellbeing among young people in South Africa. We focus on young people aged 15-24 years in this setting as they account for a substantial proportion (16.2%) of the total population (Stats SA, 2019a) and are exposed to severe health and economic risks such as HIV/AIDS (HSRC, 2018) and unemployment (Stats SA, 2019b) that may negatively affect their wellbeing. We specifically tackle two questions: i) is health status correlated with young people's wellbeing? ii) is South Africa's HIV treatment (antiretroviral therapy) scale-up policies, a large public health initiative targeted at improving population health, associated with any wellbeing gains among young people?

Using a panel, representative of the district population, over the course of 10 years from the National Income Dynamics Study (NIDS) in South Africa, overlaid with district ART count per capita data, we applied multi-level random intercepts models to investigate associations. First, we assessed the health correlates of wellbeing, focusing specifically on the relationship between mental and physical health and life satisfaction scores, a proxy measure of psychological wellbeing. We find that an increase in depressive symptom scores and an underweight body mass index (BMI), markers of poor mental and physical health, respectively, are negatively correlated with life satisfaction. Second, we examined the relationship between district-level antiretroviral therapy (ART) access and life satisfaction. We find a large positive relationship between ART access and young people's wellbeing.

Below, we describe findings from the broader social sciences and health literature that have informed our modelling approach.

## **1.2 Literature review**

### **a. Is health related to young people's wellbeing?**

#### ***i. Mental health-depression***

Mental health is regarded as one of the strongest correlates of wellbeing (Dolan et al., 2008, Layard et al., 2013), across the life course (Layard et al., 2014). A large body of work in economics and psychology, mainly conducted in high-income countries, reports robust negative correlations between depression (a measure of mental health) and life satisfaction (Layard et al., 2013, Lombardo et al., 2018, Fergusson et al., 2015, Lagnado et al., 2017, Cummins, 2010, Rissanen et al., 2013). Findings from cross-national studies that include LMICs, particularly African countries, have also identified a negative association between depressive symptoms and life satisfaction (Simpson et al., 1996, Dorahy et al., 2000), although these were based on exploratory statistical analyses.

Depression affects health and functioning, particularly domains important to wellbeing (i.e. family and other relationships career, education) (Connell et al., 2012). This could potentially explain the observed negative association between depressive symptoms and life satisfaction (Layard et al., 2013, Connell et al., 2012). However, these findings are not surprising given that components of mental health overlap with dimensions of subjective and psychological wellbeing (Westerhof and Keyes, 2010).

A high prevalence of mental illness has been reported among adolescents and young adults in SSA (Gibbs et al., 2018, Owen et al., 2016, Barhafumwa et al., 2016). Depressive symptoms are significantly higher among HIV-positive compared to HIV-negative young people in this region (Lwidiko et al., 2018). Furthermore, poor mental health among young people in this setting is linked to lowered self-esteem (Okwaraji et al., 2016) and weak family functioning (Arat and Wong, 2016, Cortina et al., 2012), which are both negative correlates of wellbeing (Black et al., 2013, Proctor et al., 2009). Overall, there is lack of robust evidence on the relationship between mental illness and wellbeing among young people in this region.

## *ii. Physical health- underweight*

Body mass index is a measure of body fat based on height and weight and is often used as a proxy measure of overall physical health (Vingilis et al., 2002, Gutin, 2018). Several studies, predominantly from high-income countries among adults, report an inverse relationship between BMI and life satisfaction (Habibov et al., 2019, Kuroki, 2016, Böckerman et al., 2014). A BMI outside the healthy weight range (between 18.50 - 24.99 kg/m<sup>2</sup>) is likely to affect psychological health, health-related quality of life (Kolotkin et al., 2001), and other dimensions related to wellbeing (e.g. aspirations, self-acceptance) (Ball et al., 2004), and thus may explain this negative association. An earlier survey among young Australian women aged 18-23 years found that women who had BMI values suggestive of underweight, overweight or obesity were all less likely to be satisfied with family relationships than women with BMI's in the healthy weight range (Ball et al., 2004). In a recent Mexican study, Bargain and Zeidan (2019) found that BMI values suggestive of overweight or obesity were positively correlated with life satisfaction ( $\beta = 0.19-0.25$ ) among those in the poorest socio-economic quintile. The authors indicate that this positive relationship could be explained by the fact that body types associated with overweight and obesity are more socially accepted in this setting. Research suggests that body types associated with overweight and obesity are also more socially accepted in African countries (Ozodiegwu et al., 2019). As social acceptance is a key dimension of wellbeing in SSA, BMIs associated with underweight may have negative effects on social acceptance and thus wellbeing.

In the latest South African nutrition survey, the prevalence of an underweight BMI (26%, 15-17 yrs.; 17.9%, 18-24 yrs.) was found to be higher than BMIs suggestive of overweight (7.3%, 15-17 yrs.; 5.8%, 18-24 yrs.) and obesity (1.5%, 15-17 yrs.; 4.2%, 18-24 yrs.) (HSRC, 2013). An underweight BMI value is likely associated with lowered wellbeing among young people as studies have found that underweight in this group is linked to perceptions of poor health and unhappiness (Pedro et al., 2016) and low self-esteem (Gitau et al., 2014), which are known negative correlates of young people's wellbeing (Proctor et al., 2009). Underweight among adolescents is associated poor mental health functioning and increased risk for depression (Cortese et al., 2009).

Similarly, underweight among YPLHIV in South Africa, has been linked to lowered ability to cope, self-acceptance and stigma, which may negatively affect wellbeing (Nyamaruze and Govender, 2020). However, evidence is sparse about this relationship between an underweight and wellbeing among young people.

### **b. What is the association between health policies and wellbeing?**

The scale-up of ART, a combination of antiretroviral drugs that suppresses HIV and slows the progression of AIDS, has drastically improved life expectancy in several countries within SSA (Wandeler et al., 2016), as well as survival among adolescents living with HIV (Maskew et al., 2019, Ferrand et al., 2009).

Whilst no study has directly assessed the relationship between ART scale-up and wellbeing in SSA, based on findings from previous studies it is likely that ART access is associated with wellbeing benefits. For instance, a review found that expanded ART in SSA was linked to positive health-related quality of life among people living with HIV (PLHIV), specifically mental and physical functioning (Beard et al., 2009), established positive correlates of wellbeing (Dolan et al., 2008). In addition, more recent studies reported positive economic benefits of scaled-up ART among PLHIV for the following outcomes: human capital (Baranov and Kohler, 2018), savings (Baranov and Kohler, 2018), labour supply and productivity (Thirumurthy and Zivin, 2012, Rosen et al., 2014, Larson et al., 2013). Enhanced physical functioning and labour productivity among PLHIV may have increased a sense of perceived control, reinstated their social status and ability to fulfill role-relationships, key dimensions of wellbeing in an African context (Khumalo et al., 2012).

Furthermore, spillover effects of scaled-up ART on the general population have also been identified including increased demand for HIV testing (Baranov et al., 2015) and labour supply (Thirumurthy and Zivin, 2012); improved mental health (Baranov et al., 2015), reduction in HIV-related stigma (Chan et al., 2015), subjective mortality risk (Baranov et al., 2015), and future expectations on health and longevity (Thirumurthy et al., 2016). Moreover, studies have also found positive spillover effects on children living in HIV-affected households such as improved growth and nutrition (Zivin et al., 2009, Lucas and Wilson, 2013) and educational investments among children (Zivin et al., 2009), which are indicators of wellbeing among young people (Proctor et al., 2009).

Globally, South Africa has one of the highest HIV prevalence among 15-49 year-olds (20.6%), with an estimated 7.9 million people of all ages living with HIV (PLHIV) (HSRC, 2018). This country has rolled-out the largest ART programme in the world, with an estimated 3.9 million HIV-positive children and adults on ART, with 90% of these individuals accessing treatment from government clinics and hospitals (UNAIDS, 2016). According to the most recent national HIV survey, an estimated 70.6% of the 15-64 year-olds who are aware of their HIV-positive status are on ART (HSRC, 2018). Since 2008, national HIV care policies have scaled-up access to ART by increasing treatment eligibility (Supplementary File S1). By 2016, South Africa implemented the “test and treat” policy, which meant that all PLHIV were eligible for ART, regardless of CD4 count. Studies have found that ART expansion policies in this setting have been associated with improved life expectancy (Johnson et al., 2013) and other positive spillover effects such as labour productivity (Bor et al., 2012) and reduced risk of HIV acquisition (Tanser et al., 2013). Currently, it is one of the few ART programmes primarily domestically funded, with the state financing nearly 80% of the total programme costs (UNAIDS, 2017). As major investments in universal HIV treatment continue in this region, it would be of value to assess the broader economic benefits of this policy. Estimating the association between ART access and young people’s wellbeing is important for understanding the total societal benefits of this programme. More importantly, it can help gauge whether or not this policy alone can help towards attainment of enhanced wellbeing among young people in SSA.

### **1.3 Hypothesis**

The central hypothesis of this study is that there is an association between health and wellbeing among young people in this setting. Specifically, we posit that there is a negative association between poor mental and physical health, and wellbeing. Based on the adolescent and young adult health literature, depressive symptoms and underweight BMI likely reduce self-esteem (Gitau et al., 2014, Okwaraji et al., 2016, Mchiza et al., 2015, Pedro et al., 2016) and family functioning (Cortina et al., 2012, Arat and Wong, 2016), markers of young people’s wellbeing (Proctor et al., 2009).

We also posit that expanded ART access in this setting is positively correlated with young people's wellbeing given the direct benefits of ART with regards to life expectancy (Wandeler et al., 2016) and mental and physical health (Simms et al., 2019), including the survival benefit of ART for adolescents living with HIV (Maskew et al., 2019). Improved physical and mental health means that PLHIV now have the ability to perform tasks that were expected of them (Beard et al., 2009), which may increase their perceived control and social contribution, important elements of wellbeing in this setting (Khumalo et al., 2012). In addition to the above, there is a relational component to the correlation between ART access and wellbeing. We considered this a possibility given the sizeable literature which suggests that wellbeing is relational, in that it maps over the health and wellbeing among others in social networks (Delle Fave et al., 2016, Wissing et al., 2014, White and Jha, 2018). Studies have also identified inter-generational transfers of wellbeing between parent and child (Powdthavee and Vignoles, 2008, Powdthavee and Verhoef, 2013). Thus, increases in wellbeing due to improved health among parents and other HIV-positive household members, could have also been associated with positive spillovers in their wellbeing to young people living in these households and communities.

#### **1.4 Contribution to the literature**

This study makes four contributions to the literature. First, we fill a gap in the international literature on the health correlates of wellbeing for young people in LMICs (Frey, 2019, Dolan et al., 2008, Proctor et al., 2009). Second, to the best of our knowledge, this is the first study to investigate the relationship between ART access and life satisfaction, a strong proxy measure of psychological wellbeing (Sanjuán, 2011, Chen et al., 2013, Keyes et al., 2010, Diener and Diener, 2009). Third, we use five waves of South African panel data, representative of the district population. Having repeated observations of individuals over time allows us to better understand the factors that influence changes in wellbeing patterns and control for unobserved characteristics of individuals (Baltagi, 2008). Fourth, we apply multi-level random intercept techniques which accounts for the nested structure of our dataset and repeated individual observations, and considers the unobserved heterogeneity at the district and

individual level that may affect our exposure variable of interest (Rabe-Hesketh and Skrondal, 2012).

## **2. Methods**

### **2.1 Data**

The main dataset for this study is drawn from South Africa's NIDS, which was the country's first national household panel survey, conducted by the Southern Africa Labour and Development Research Unit at the University of Cape Town (Leibbrandt et al., 2009). Approximately 29733 individuals and 7200 households were followed-up over five waves, each approximately two years apart, from 2008-2017 (wave 1- 2008, wave 2-2010-2011, wave 3-2012, wave 4-2014-2015, wave 5-2017) (Brophy et al., 2018). The NIDS data is representative of the population at district level. Households were selected using a stratified, two-stage cluster sampling design, with the country's 52 districts being the main strata (Leibbrandt et al., 2009). In the first stage of sampling, 400 primary sampling units<sup>11</sup> were randomly selected from the Master Sample<sup>12</sup>. In the second stage, primary sampling units were then proportionally allocated to each district based on its allocation per district in the Master Sample. Every member of the household aged 15 years and above was interviewed. At each interview, individual-level information was collected on the following domains: demographics, birth and parents' history, labour market participation, income, personal ownership and debt, education, health, subjective wellbeing and social capital. Household-level information such as mortality history, living standards and expenditure was also collected. For this study, we restricted our sample to all individuals aged 15-24 years who were successfully interviewed in wave 1 of the NIDS. This provided us with an unbalanced sample of 5,685 individuals and 27,739 observations. As the five data collection waves in the NIDS overlapped with large expansion of national ART

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<sup>11</sup> This is a geographical area containing census enumeration areas and refers to this first sample selected in a two-stage sampling process. An enumeration area is the smallest geographical unit, usually containing 74 to 250 households.

<sup>12</sup> This Master Samples was derived from Statistics South 2003 Master Sample of 3000 primary sampling units.



coverage, this dataset provided an opportunity to examine the relationship between ART access and wellbeing.

## **2.2 Dependent variable**

Psychological wellbeing was measured using a proxy subjective wellbeing measure, life satisfaction. Life satisfaction was measured using one question, which assesses global life satisfaction: "Using a scale of 1 to 10 where 1 means "very dissatisfied" and 10 means "very satisfied" how do you feel about your life as a whole right now?" (Supplementary File S2). This question was asked consistently in each NIDS wave. Life satisfaction is one of the components of subjective wellbeing and is reflective of an individual's cognitive judgement of their satisfaction with life. Life satisfaction is strongly correlated with PWB dimensions (positive relations, self-acceptance, environmental mastery, purpose in life) (Keyes et al., 2002, Diener and Diener, 2009), particularly among young people (Proctor et al., 2009, Cotton Bronk et al., 2009). Single-item life satisfaction measures for the assessment of subjective wellbeing have shown favourable psychometric properties (Cheung and Lucas, 2014). Furthermore, they are one of the recommended wellbeing measures for policy evaluations (Dolan et al., 2011, OECD, 2013), and have been applied in international surveys (Helliwell et al., 2018). Several econometric analyses examining life satisfaction patterns in South Africa have been conducted using this dataset (Posel and Casale, 2011, Stoop et al., 2019, Ebrahim et al., 2013, Kollamparambil, 2019). In the economics literature this measure is modelled as an ordinal variable (Ferrer-I-Carbonell and Frijters, 2004, Powdthavee and Vernoit, 2013), in line with the ordinal Likert scale response options, and we follow this approach.

## **2.3 Independent variable**

### ***a. Mental health***

We used depressive symptom score as a proxy measure of mental health. We used data from the 10-item Centre for Epidemiological Studies Depression Scale (CES-D-10). This scale measures depression symptomatology during the past week (Radloff, 1977). It specifically asks respondents ten yes or no questions about depressive feelings and

behaviours over the past week, related to mood, sleep patterns, fears, and attitudes towards the future. The four possible response options denote frequency and are scored as follows: rarely or none of the time (score= 0); some or little of the time (score= 1); occasionally or a moderate amount of time (score= 2); and almost or all of the time (score= 3). The depressive symptom score is constructed as the sum over all responses to all ten items (Supplementary File 1). Therefore, the CES-D-10 cumulative score ranges from 0 to 30, with a higher score reflecting a higher depression risk. A cut-off score of  $\geq 12$  was found to be most sensitive to a diagnosis of depression for a South African sample (Baron et al., 2017). The original 20-item scale has well-established psychometric properties and been used as a depression screening tool in the general population (Radloff, 1977). The CES-D-10 has been psychometrically evaluated in a South African sample and has shown good validity and reliability (Baron et al., 2017). It is used in South Africa, in both population health and clinical research (Tomita et al., 2017, Myer et al., 2008). This scale was self-administered consistently in each NIDS wave.

### ***b. Physical health***

We used underweight as a proxy measure of physical health status, given the high prevalence of underweight BMI among this age-group (HSRC, 2013) and its negative impact on social integration (Gitau et al., 2014, Okwaraji et al., 2016, Mchiza et al., 2015, Pedro et al., 2016), a key dimension of young people's wellbeing in this setting. This variable was calculated using the BMI score for each individual based on interviewer-measured data of weight and height at each wave (Supplementary File S1). These BMI scores were then classified as follows, using the international cut-offs (WHO, 2018): underweight (less than 18.50 kg/m<sup>2</sup>); healthy weight (between 18.50 - 24.99 kg/m<sup>2</sup>); overweight (between 25.00 - 29.99 kg/m<sup>2</sup>); obese (greater than or equal to 30 kg/m<sup>2</sup>). We constructed an underweight dummy variable equal to 1 if the BMI score is less than 18.50 kg/m<sup>2</sup> (underweight), and zero otherwise.

### **c. ART access variable**

We used district ART count per capita as our proxy measure of ART access. This measure was constructed by dividing the number of individuals in HIV care per year per district (ART count) by the district population in that period. This measure is more appropriate than number on ART as it considers differences in population size across districts. The ART count data was derived from anonymised HIV laboratory data from the South African National Health Laboratory Services (NHLS) corporate data warehouse (CDW) (Supplementary File 1). Whereas district population estimates per wave was obtained from Statistics South Africa (Stats SA, 2012). We then merged our ART count per capita dataset to our NIDS dataset, using district and NIDS wave year. The NHLS provides all laboratory monitoring services (e.g. CD4 count and viral load monitoring) for South Africa's public sector HIV programme. Thus, the ART count variable captures all those who are accessing HIV clinical care at public sector healthcare facilities, based on the presence of a laboratory record, and not necessarily all those who are on treatment at these facilities. This dataset has been validated (Bassett et al., 2018) and has been used to calculate national ART coverage and treatment progress (Fox et al., 2018, Johnson et al., 2017).

## **2.4 Covariates**

Studies have shown that the construct of wellbeing in South Africa, particularly among young people, is relational in that wellbeing is manifested within relationships (Wissing et al., 2014, Van Schalkwyk and Wissing, 2010, Delle Fave et al., 2016). Given this relational conceptualisation of wellbeing in this setting, we decided to include known relational covariates of wellbeing into the model such as trust (i.e. generalised and personalised) and perceived importance of religion (Helliwell, 2006, Dolan et al., 2008, Helliwell and Putnam, 2004). Self-perceptions of trust and religion in this setting are rooted in relationships (Wissing et al., 2014, Wissing et al., 2019). Generalised trust was assessed by asking respondents: "Imagine you lost a wallet or purse that contained R200 and it was found by a complete stranger. Is it very likely or not likely at all to be returned with the money in it?" Similarly, personalised trust, reflective of interpersonal trust, was asked as follows: "Imagine you lost a wallet or purse that contained, R200

and it was found by someone who lives close by. Is it very likely or not likely at all to be returned with the money in it?” “Not likely” was operationalized as no trust (trust = 0), whereas the latter two as “has trust” (trust = 1) (Supplementary File 1). Religion was assessed by asking respondent to their perception of the importance of religious activities in their life using a 4-point Likert scale: very important/important (religion=1); unimportant/not important at all (religion=0).

Several socio-demographic factors are well-established correlates of wellbeing. Income and race<sup>13</sup> have been found to be associated with life satisfaction in South African surveys (Kingdon and Knight, 2007, Posel and Casale, 2011, Ebrahim et al., 2013, Kollamparambil, 2019). Educational level and employment have also been identified as positive correlates of wellbeing in high-income countries (Cuñado and De Gracia, 2012, Helliwell, 2006) and in South Africa (Khumalo et al., 2012). Studies have found a u-shaped relationship between age and life satisfaction (Blanchflower and Oswald, 2008), and females likely to have higher levels of life satisfaction compared to males (Dolan et al., 2008), including 15-24 year-olds in LMICs. (Mutumba and Schulenberg, 2019). Thus, we controlled for the following socio-demographic factors in our model: gender (=1 if female), age and age squared to account for the u-shaped relationship in the literature, race (=1 if Black), educational status (=1 if completed compulsory education), employment status (0=not economically active; 1=unemployed; 2=employed). Furthermore, we included the log of household expenditure. We used household expenditure (consumption) as opposed to income as this measure is regarded as a more reliable indicator of living standard, particularly for economies with considerable informal markets that are subject to seasonal fluctuations in income (Deaton, 2003), as in South Africa (Charman et al., 2017, Devey et al., 2006). Individuals are more likely to disclose or find it easier to estimate household expenditure compared to income as they likely purchase a narrow range of

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<sup>13</sup> Referring to race as a social construct. We use the term race in this study as it is line with national population group categorisation. Source: Statistics South Africa (Stats SA). 2019. *Mid-year population estimates* [Online]. Available: <http://www.statssa.gov.za/publications/P0302/P03022019.pdf> [Accessed 19 September 2019].

goods or services (Deaton, 2003). This measure was calculated by the NIDS data team (Brophy et al., 2018), using standard approaches (Deaton and Zaidi, 2002).

Income aspirations are negatively correlated with life satisfaction (Stutzer, 2004). Income aspirations are reflective of extrinsic aspirations (e.g. wealth, social status) (Myers, 2000). These extrinsic aspirations are common among South African (Wissing et al., 2014) and other African young people (Hofer and Chasiotis, 2003), and form a key component of their wellbeing (Wissing et al., 2014). Extrinsic aspirations are strongly correlated with the personality trait extraversion (e.g. sociable) and neuroticism (anxious), correlates of wellbeing (Romero et al., 2012). As personality traits were not directly captured in the NIDS datasets, we used income inspirations as a proxy measure for personality trait. In all NIDS waves, adults were asked to assess their economic rank currently and in future years, by identifying their position on a six-rung ladder from poorest (1) to richest (6). Using these data, we derived an income aspiration measure by calculating a score based on the difference between an individual's self-perceived income rank presently compared to 5 years' time. Positive scores suggest positive aspiration.

In addition, we included geographic variables such as districts. The nine provinces of South Africa are divided into 52 districts (44 district municipalities and 8 of the largest urban areas agglomerated to metropolitan municipalities), which are the second level of administration in the country (Stats SA, 2012). NIDS collected Global Positioning System information on each household which allowed us to determine the exact district the household belonged to, using Census 2001 and 2011 boundaries (Brophy et al., 2018). We used 2011 district boundaries as these are currently being used by the NHLS (Fox et al., 2018) and National Department of Health (Massyn et al., 2019), and are more reflective of the post-ART period. We used district as opposed to a more granular geographical layer as the NIDS sample was representative of the district-level and ART scale-up was managed at the district level (Massyn et al., 2019). District boundaries did change between 2008-2017. Thus, to avoid measurement error, we used a recoded variable in the NIDS dataset that defined respondents' district of

residence in terms of 2011 boundaries across all the waves. A small proportion (25%) of survey participants moved districts between waves. Thus, in our main analysis we included the district the individual resided in the most during the 5 waves of data collection.

Furthermore, we included time as a covariate which was reflective of the NIDS wave (Supplementary File 1) .

### 3. Estimation strategy

#### *a. Linear mixed models-Two-level random intercept model*

We applied a multi-level random intercept model, which is a mixed model as it includes both fixed and random effect parameters. The fixed part specifies the relationship between the mean of the outcome and explanatory variables. The random part of the model contains group and individual specific residuals and indicates how the relationship at these levels differ from the overall mean relationship (Rabe-Hesketh and Skrondal, 2012). Thus, these mixed models allow one to capture how fixed effects parameters influence the mean of outcome variable and how random effects influence the variance of the outcome variable. In a random intercept (RI) model, one can make predictions of the random intercept after the fixed parameters have been estimated. Thus, it allows one to explicitly examine the relationship between group level characteristics and individual outcomes as well as the between group variability (Steele, 2014). This is a class of linear models as the outcome variable is modelled as linear function of explanatory variables and error terms. One of the main assumptions of single-level models is that the measured units are independent (i.e. residuals are uncorrelated with one another) (Rabe-Hesketh and Skrondal, 2012). However, multi-level models relax the assumption of conditional independence of individuals living in the same district and of repeated measurements from the same individual. The main assumption of a RI model is that unobserved factors are uncorrelated with the explanatory variable at each time period (Rabe-Hesketh and Skrondal, 2012). Using multilevel models also allows us to include error terms at each level, which accommodates for residual variability at each level across of the models, after accounting for observables. These approaches model the variation between districts and individuals explicitly, yielding more accurate standard errors of the regression estimates in the presence of correlated errors and data hierarchy.

We specifically used a two-level RI model, with two intercepts, one at the district and one at the individual-level, and as many known time invariant and variant controls. This model structure is appropriate for the NIDS dataset as it is a panel design with a hierarchical structure (i.e. individuals are followed overtime and thus we have

repeated measures for each individual, and individuals are clustered within districts. (Leckie, 2013). More importantly, this nested structure is reflective of relational perception of self and wellbeing among young people in this setting (Wissing et al., 2014, Van Schalkwyk and Wissing, 2010). This multi-level random effects approach allows for the exploration of variation at various levels of hierarchy and helps explicitly model the covariance structure due to repeated measures, thereby improving the efficiency of our parameter estimates (Rice and Jones, 1997, Grieve et al., 2005).

Pooled ordinary least squares regression (POLS) models are unable to specifically address datasets with a multi-level context, thus multi-levels are ignored (Rabe-Hesketh and Skrondal, 2012). If we included these higher levels variables as individual level predictors as in a POLS it could lead to an understatement of standard errors, as one value will be replicated across all groups. Alternatively, applying a fixed effects regression would not be appropriate as we are interested in understanding the effects of level 2 variables (e.g. ART per capita) on life satisfaction, and these do not vary within clusters. Using a RI model is considered more appropriate for large samples that are representative of the cluster population as in the case of the NIDS dataset (Baltagi, 2008). Random effects are used to improve the generalisability of results as they estimate the distribution of unit effects, including the mean association in the broader population (Grieve et al., 2005). Whereas in a fixed effects (FE) model, inferences are restricted to the sample. More importantly, in a RI model estimation and testing are based on the restricted maximum likelihood, which can handle unbalanced panel samples (Rabe-Hesketh and Skrondal, 2012). Whilst a FE model may control for individual and district variables that do not change rapidly overtime (i.e. time invariant), co-efficients for these variables cannot be estimated, and issues arise when the number of groups (districts) are large with many extra parameters to estimate (Steele, 2014).

Analyses were conducted using STATA Version 14, College Station, TX: StataCorp LP.



**b. Model specification: The relationship between health and young people's wellbeing**

The specific form for our two-level model RI model is given by the following equation as described by (Leckie, 2013):

$$\begin{aligned}
 LS_{ij} = & \beta_0 + \beta_1 DepSymScore_{ij} + \beta_2 Underweight_{ij} + \beta_3 Female + \beta_4 Age_{ij} \\
 & + \beta_5 Age^2_{ij} + \beta_6 Race\_Black_{ij} \\
 & + \beta_7 CompulsoryEducation\_completed_{ij} + \beta_8 Employed_{ij} \\
 & + \beta_9 LogHouseholdExpenditure_{ij} + \beta_{10} Religous_{ij} \\
 & + \beta_{11} Generalised\_Trust_{ij} + \beta_{12} Personalised\_Trust_{ij} \\
 & + \beta_{13} Income\_Aspiration_{ij} + \beta_{14} DepSymScoreXPersonalised\_Trust_{ij} \\
 & + BWave_{ij} + u_{0j} + e_{0ij} \quad [1]
 \end{aligned}$$

$$u_{0j} \sim N(0, \sigma_u^2)$$

$$e_{0ij} \sim N(0, \sigma_e^2)$$

Where  $LS_{ij}$  is the life satisfaction score for individual  $i$  in district  $j$ . Fixed parameters include  $\beta_0$ - $\beta_{14}$ , and a vector of time dummies (BWave). The intercept,  $\beta_0$ , measures the overall mean of life satisfaction scores ( $LS_{ij}$ ) across all levels and is a fixed quantity applied to all individuals.

*DepScore* is the CES-D-10 depressive symptom score for individual  $i$ . Underweight is a dummy variable (1= underweight BMI). We controlled for known correlates of wellbeing, i.e. socio-demographic characteristics (gender (1=Female), age, race (1=Black race), compulsory education completed (1=Yes), employment status (1=Employed), household expenditure), social capital (perceives religion as important (1=Yes), has a sense of generalised or personalised trust (1=Yes)) and personality traits (income aspiration score). Given the strong degree of relationality in this setting (i.e. individuals self-worth is derived from role-relationships) and the impact depression has on social relationships, we interact depressive symptom score with

personalised trust. *DepSymScoreXTrust* is an interaction term that captures the relationship of depressive symptom score on individual personalised trust. All models controlled for time dummies (i.e. NIDS wave, BWave).  $B$  is a vector of parameters associated with the waves of time 2-5, and represents the mean difference in life satisfaction scores between waves 2/3/4/5 and wave 1 in the median individual in the median district

The random effect parameter,  $u_{0j}$ , is the district intercept (i.e. the difference between district  $j$ 's mean and the overall mean). It represents the random effect of district on the outcome variable in addition to that explained by the explanatory variables. This is a level-2 residual that is a district-specific error component. The second random effect parameter,  $e_{0ij}$ , is the individual intercept (i.e. the difference between individual  $i$ 's mean and district  $j$ 's mean). This is a level-1 residual that is an individual-specific error component which represents the unexplained variation for individuals within a district at a specific wave. These random intercept terms represent the combined effect of all omitted district-level and individual-level characteristics or unobserved heterogeneity that affects health in individuals and districts. The random effects are assumed independent of one another and normally distributed with zero means and constant variances, and covariances ( $\sigma_{u01}$ ) are zero. The variance components (population between-cluster variance ( $\sigma_u^2$ ) and population within-cluster variance ( $\sigma_e^2$ )) measure how variance is allocated across the two levels. We used the identity covariance structure, which assumes that all variances are equal and all covariances are equal to 0.

**c. Model specification: The relationship between ART access and young people's wellbeing**

The form of our two-level model RI model is given by the following equation (Leckie, 2013):

$$\begin{aligned}
 LS_{ij} = & \beta_0 + \beta_1 ARTpc_j + \beta_2 DepSymScore_{ij} + \beta_3 Underweight_{ij} + \beta_4 Female \\
 & + \beta_5 Age_{ij} + \beta_6 Age^2_{ij} + \beta_7 Race\_Black_{ij} \\
 & + \beta_8 CompulsoryEducation\_completed_{ij} + \beta_9 Employed_{ij} \\
 & + \beta_{10} LogHouseholdExpenditure_{ij} + \beta_{11} Religious_{ij} \\
 & + \beta_{12} Generalised\_Trust_{ij} + \beta_{13} Personalised\_Trust_{ij} \\
 & + \beta_{14} Income\_Aspiration_{ij} \\
 & + \beta_{15} ARTpcXPpersonalised\_Trust_{ij} \\
 & + \beta_{16} DepSymScoreXPpersonalised\_Trust_{ij} + BWave_{ij} + u_{0j} \\
 & + e_{0ij} \quad [2]
 \end{aligned}$$

$$u_{0j} \sim N(0, \sigma_u^2)$$

$$e_{0ij} \sim N(0, \sigma_e^2)$$

Where  $LS_{ij}$  is the life satisfaction score for individual  $i$  in district  $j$ . The fixed effect parameter,  $\beta_0$ , is the overall intercept (i.e. mean life satisfaction score across all districts and households).

$ARTpc$  is the district ART count per capita for district  $j$ . We controlled for known correlates of wellbeing, i.e. health (depressive symptom score, BMI); socio-demographic characteristics (age, gender, education status, employment status, household expenditure), social capital (generalised and perceived trust, perceived importance of religion) and personality traits (income aspirations).  $ARTpcXPpersonalised\_Trust$  is an interaction term that measures the association between ART count per capita on individual personalised trust. All models controlled for time dummies (NIDS wave).

The random effect parameters include the district intercept,  $u_{0j}$ , and the individual intercept,  $e_{0ij}$ . These random intercept terms represent the combined effect of all omitted district-level and individual-level unobserved heterogeneity that affects ART access. The random effects are assumed independent of one another and normally distributed with zero means and constant variances, and covariances ( $\sigma_{u_{01}}$ ) zero. We used the identity covariance structure, which assumes that all variances are equal and all covariances are equal to 0.

#### **4. Robustness checks**

Our primary robustness check explored the robustness of our main results to alternate model estimations using POLS, FE and single -level RI models (i.e. one random effect at the individual level). In addition, we examined the robustness of our results to a balanced sample and a lagged model for the assessment of ART access on wellbeing.

In both models, we checked key assumptions of the multi-level random effects models, such as the distribution of the district and individual level residuals (Snijders and Berkhof, 2008).

#### **5. Ethical approval**

This secondary data analysis was approved by the research ethics committee of the South African Medical Research Council (EC017-10/2018) and the London School of Hygiene and Tropical Medicine (16217).

## **6. Results**

### **6.1 Descriptive analysis**

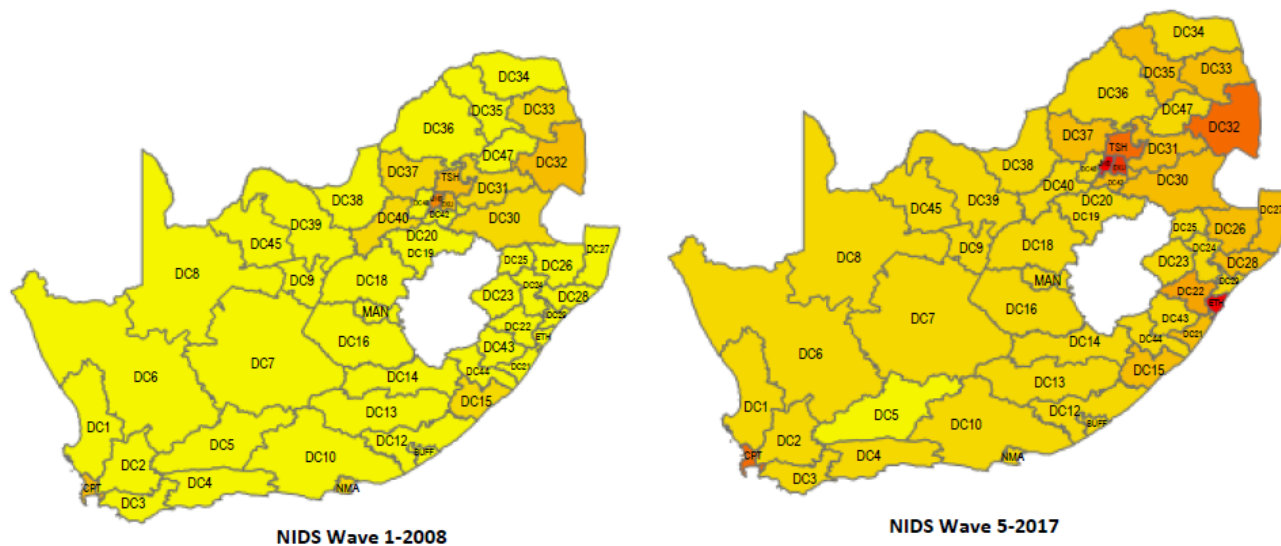
Among the 5685 in our full sample, 51% (2919) were successfully interviewed in all five waves (Supplementary File 2). Summary statistics for the characteristics of the full sample are presented in Table 1. For the full sample over the entire NIDS period, the mean age was slightly over 23 years ( $SD= 4.0$ ), with an equal gender balance, similar to findings from the national census (Stats SA, 2012). Furthermore, the majority of individuals were Black and completed compulsory education, in line with census data (Stats SA, 2012). Only 26% were employed. Nearly two-thirds of young people resided in urban areas, within households where the average household expenditure was approximately ZAR 5500. Only 48% lived in households that had access to basic needs (i.e. formal housing, electricity, piped water and flushed toilet), similar to that found in a previous national adolescent survey (SAMRC, 2008). The mean depressive symptom score in this sample was 6, and 14% were screened positive for depressive symptoms. Most young people had a healthy BMI score (mean = 24.7), with 7.7% who had a BMI score suggestive of underweight and 38% who had a BMI score suggestive of overweight or obesity, similar to findings found in a national health survey (Mchiza et al., 2015). Levels of social trust were fairly low in our sample (18-30%). However, more than two-thirds considered religious activities important in their lives. Young people resided in districts where on average 100 000 PLHIV were in ART care. The average ART per capita was 0.08 ( $SD=0.04$ ).

**Table 1: Summary descriptive statistics of full sample (N=27 739 observations, n=5685). Source: NIDS**

<b>Variable</b>	<b>Mean</b>	<b>SD</b>
<b><i>Individual level</i></b>		
Age (years)	23.74	4.30
Female (%)	50.01	0.50
Race-Black (%)	85.26	0.35
Completed compulsory education-Grade 9 (%)	86.75	0.34
Employed (%)	26.37	0.82
Mothers highest educational attainment (primary school) (%)	57.45	0.49
Depression symptom score ^	6.73	4.18
Depressed ^^	13.63	0.34
BMI score \$	24.75	15.05
Underweight (%) \$\$	7.77	0.27
Overweight/Obese (%) \$\$\$	38.39	0.49
Self-perceived good health status (%)	96.16	0.19
Life satisfaction score	5.12	2.46
Religious (%)	88.54	0.32
Generalised trust (%)	17.92	0.38
Personalised trust (%)	30.56	0.46
Income aspiration level in 5 years' time	1.78	1.15
<b><i>Household level</i></b>		
Household expenditure (ZAR)	5499.97	10327.47
Lives in an urban area (%)	63.59	0.48
Household with basic needs (%)	48.43	0.50
Household members	5.18	3.62
<b><i>District level*</i></b>		
ART count	106182.5	135381.3
ART count per capita	0.076	0.038

SD= standard deviation; \*Data source: ART-NHLS HIV Laboratory data; note-NIDS data are weighted; District population estimates- Stats SA. BMI= Body Mass Index, ^ Based on CES-D-10 scale score, ^^Based on CES-D-10 score of  $\geq 12$ ; \$ BMI=Body Mass Index ( $\text{kg}/\text{m}^2$ ); \$\$ =based on BMI score 15-18.49  $\text{kg}/\text{m}^2$ ; \$\$\$ =based on BMI score  $\geq \text{kg}/\text{m}^2$

Figure 1, highlights variation in ART count by district in the first and last wave. It is evident, that ART count increased per wave, particularly in the high HIV burden districts that encompass the main cities.

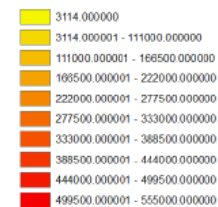


**Figure 1: Diagram depicting number on ART per district in 2008 vs. 2017.** Data source: NHLS Corporate Data Warehouse (March 2019 Data Extract).

Districts:

1. Western Cape: CPT=City of Cape Town; DC1=West Coast; DC2=Cape Winelands; DC3=Overberg; DC4=Eden
2. Eastern Cape: BUF=Buffalo City; DC10=Sarah Baartmen; DC12=Amathole; DC13=Chris Hani; DC14=Joe Gqabi; DC15=O. R. Tambo; NMA=Nelson Mandela Bay Metro; DC44=Alfred Nzo
3. Northern Cape: DC5=Central Karoo; DC6=Namakwa; DC7=Pixley ka Seme; DC8=; ZF Mgcawu District Municipality DC9=Frances Baard; DC45=John Taolo Gaetsewe
4. North West: DC37=Bojanala; DC38=Ngaka Modiri Molema; DC39=Dr Ruth Segomotsi Mompati; DC40=Dr Kenneth Kaunda
5. Gauteng: DC48=West Rand; EKU=Ekurhuleni; ETH=eThekweni; JHB=Johannesburg; TSH=City of Tshwane; DC42=Sedibeng
6. Limpopo: DC33=Mopani; DC34=Vhembe; DC47=Sekhukhune; DC35=Capricorn; DC36=Waterberg
7. Free State: MAN=Mangaung; DC16=Xhariep; DC18=Lejweleputswa; DC19=Thabo Mofutsanyana; DC20=Fezile Dabi
8. Mpumalanga: DC30=Gert Sibande; DC31=Nkangala; DC32=Ehlanzeni
9. KwaZulu-Natal: DC21=Ugu; DC22=UMgungundlovu; DC23=Uthukela; DC24=Umzinyathi; DC25=Amajuba; DC26=Zululand; DC27=Umkhanyakude; DC28=King Cetshwayo District; DC29=iLembe; DC43=Harry Gwala

**LEGEND: ART COUNT**



Most individuals reported a mean life satisfaction of 5.12 (SD= 2.46), and this was consistent across all waves (Supplementary File S3). There were significant differences in terms of socio-demographic characteristics between the balanced and unbalanced sample (Supplementary File S4). In the balanced sample, the average number of people on ART in a district was significantly higher in the balanced versus full sample. The distribution of life satisfaction is presented in (Supplementary File S5). Approximately 40% of individuals had a life satisfaction score below 5. Based on the Shapiro-Wilk test we rejected the null of normality ( $W=0.99$ ,  $p<0.00$ ). Whilst life satisfaction scores were higher among males compared to females in waves 1-2 (i.e. when individuals were aged 15-24 years), by the fifth wave (i.e. when individuals were aged 25-34), this was substantially higher among females (Supplementary File S6). On average, there appeared to be a negative relationship between age and life satisfaction during the period 15-20 years, with a subsequent steady increase in life satisfaction thereafter and decline during the early 30s (Supplementary File S6-7).

We identified a weak monotonic relationship between life satisfaction and key explanatory variables (CES-D-10 score and ART count per capita), as evidenced in scatter plots (Supplementary File S8). Supplementary File S9 reports the pairwise correlation matrix between life satisfaction and key covariates. As can be seen from the table, our variables were not highly intercorrelated. The largest correlations were identified for household expenditure ( $\rho= 0.2370$ ,  $p \leq 0.05$ ), Black race ( $\rho= -0.2012$ ,  $p \leq 0.05$ ), and depressive symptom score ( $\rho= -0.2043$ ,  $p \leq 0.05$ ). Based on our Kruskal-Wallis H test, we rejected the null as there was a statistically significant difference in the different levels life satisfaction and CES-D-10 score ( $\chi^2 = 839$ ,  $p < 0.00$ ) and mean ART count per capita ( $\chi^2 = 212$ ,  $p < 0.00$ ), yet not for underweight ( $\chi^2 = 6.025$ ,  $p=0.734$ ).



## 6.2 Main model: Multi-level random intercept

### *a. The relationship between health and young people's wellbeing*

The regression results using our main two-level RI model are presented in Table 3. Models are organised as follows: Model 1 is the null model with district and individual intercepts; Model 2 includes the main health regressors (depressive symptom score, underweight); Model 3 adds individual- and household-level socio-demographic variables; Model 4, 5 and 6 includes social capital variables, personality trait variables and interaction terms between depressive symptom and personalised trust, respectively. The final model includes time as a fixed effect. There are considerable improvements in model fit as subsequent covariates were added to the model, as confirmed from the lowering of the Akaike Information Criterion (AIC) and log-likelihood moving closer to zero, with Model 7 having the best goodness of fit (AIC=69732.6, log-likelihood= -34843.3).

In the final model, we found that a 1 unit increase in depressive symptom score was associated with a 0.08 decrease in life satisfaction scores ( $p < 0.001$ ), whereas having an underweight BMI was associated with a 0.14 decrease in life satisfaction score, compared to those with a BMI in the healthy or overweight/obese range ( $p < 0.05$ ). The interaction term between depressive symptom scores and personalised trust was statistically significant. Personalised trust was positively correlated with life satisfaction ( $\beta=0.63$ ,  $p < 0.001$ ). But when interacted with depressive symptom score, we found that one unit increase in depressive symptom scores, resulted in a 0.05 decrease in life satisfaction among those who had a sense of personalised trust compared to those that do not. This suggested that depressive symptoms diminished the positive association between personalised trust and life satisfaction. Of note, there was a 0.34 decrease in life satisfaction scores among those who had a sense of generalised trust versus those who did not ( $p < 0.001$ ). Furthermore, race was one of the strongest negative correlates of life satisfaction. ( $\beta= -0.90$ ,  $p < 0.001$ ). Completion of compulsory education, employment, regarding religion as important were found to be positively correlated with life satisfaction. Income aspiration was associated with a minimal decrease in life satisfaction ( $\beta=-0.00$ ,  $p>0.05$ ).

Conditional on fixed-effects covariates, we found that life satisfaction scores between district were weakly correlated (ICC= 2%). Similarly, we found that the correlation between individuals from the same district was small (ICC= 2%). Yet, the variance estimates for each level were significant, highlighting the importance of including these both levels as random effect terms. We then examined the model assumptions by examining level 1-2 residuals (Supplementary File S10a-c). We found that the normality distribution of level 1 (individual-level) and level 2 (district -level) residuals were broadly satisfied as the deviance residuals lied close the line of identity. However, there appeared to be some extremely small level-1 residuals. In addition, level 2 (district-level) residuals showed considerable positive skewness, in keeping with the positive skewness of the raw life satisfaction data.

Lastly, we fitted the data using alternate model specifications. We found that the direction of the association was similar for the POLS and FE compared to the two-level RI model (Supplementary File S11). Co-efficients and estimated significance were also similar across all three model for depressive symptom scores. However, the co-efficient for underweight was not statistically significant in the POLS and FE. Also, the magnitude of these co-efficients were lower compared to the two-level RI model. On average, the POLS had slightly larger standard errors compared to the two-level RI compared. However, standard errors associated with individual district controls were smaller in the POLS compared to the one-level RI model with district controls, suggesting that the POLS would have resulted in biased estimates. In addition, the magnitude for key regressors were smaller, with larger standard errors in the FE compared to the two-level RI model, likely due to the fact that it does not control for time-variant unobservables. Based on the log-likelihood ratio test, we found that the two-level RI model was the preferred model when compared to the one-level RI model ( $X^2= 159.62$ ,  $p<0.000$ ), yet not to the POLS ( $X^2= -159.62$ ,  $p=1.000$ ) and FE ( $X^2= -6589$ ,  $p=1.000$ ). We also find similar results when using a balanced sample only (Supplementary File S12).

**Table 2: Two-level random intercept models examining the relationship between health and life satisfaction among young people for the full NIDS sample. Co-efficient (SE)**

	(1) Null	(2) Health	(3) Socio- demographic	(4) Social Capital	(5) Personality trait	(6) Interaction Terms	(7) Time
	$\beta$ /se	$\beta$ /se	$\beta$ /se	$\beta$ /se	$\beta$ /se	$\beta$ /se	$\beta$ /se
Depressive symptom score		-0.11*** (0.00)	-0.09*** (0.00)	-0.09*** (0.00)	-0.09*** (0.00)	-0.08*** (0.01)	-0.08*** (0.01)
Underweight		-0.04 (0.06)	-0.05 (0.06)	-0.08 (0.07)	-0.10 (0.07)	-0.10 (0.07)	-0.14* (0.07)
Female			0.08* (0.03)	0.03 (0.04)	0.04 (0.04)	0.04 (0.04)	0.02 (0.04)
Age^2			0.01*** (0.00)	0.01*** (0.00)	0.01*** (0.00)	0.01*** (0.00)	0.00 (0.00)
Age			-0.33*** (0.04)	-0.28*** (0.04)	-0.28*** (0.04)	-0.27*** (0.04)	-0.07 (0.05)
Black			-0.83*** (0.07)	-0.86*** (0.07)	-0.90*** (0.07)	-0.90*** (0.07)	-0.90*** (0.07)
Completed compulsory education			0.19*** (0.05)	0.14** (0.05)	0.14** (0.05)	0.14* (0.05)	0.16** (0.05)
Employed			0.37*** (0.05)	0.33*** (0.05)	0.35*** (0.05)	0.35*** (0.05)	0.24*** (0.05)
Log Household expenditure			0.45*** (0.02)	0.44*** (0.02)	0.44*** (0.02)	0.44*** (0.02)	0.42*** (0.02)
Religious				0.40*** (0.06)	0.32*** (0.06)	0.32*** (0.06)	0.35*** (0.06)
Generalised trust				-0.42*** (0.05)	-0.41*** (0.05)	-0.38*** (0.05)	-0.34*** (0.05)
Personalised trust				0.24*** (0.04)	0.24*** (0.04)	0.58*** (0.08)	0.63*** (0.08)

Income aspiration					0.05** (0.02)	0.05** (0.02)	-0.00 (0.02)
Depressive Symptom Score						-0.05*** (0.01)	-0.05*** (0.01)
XPersonalised_Trust							
2.wave							-0.93*** (0.07)
3.wave							-0.68*** (0.07)
4.wave							-0.20** (0.08)
5.wave							-0.21* (0.08)
_cons	5.30*** (0.09)	5.99*** (0.09)	6.82*** (0.49)	6.09*** (0.51)	6.11*** (0.54)	6.01*** (0.54)	4.29*** (0.58)
var(district)	0.38*** (0.08)	0.32*** (0.07)	0.14*** (0.03)	0.12*** (0.03)	0.12*** (0.03)	0.12*** (0.03)	0.12*** (0.03)
var(individual)	0.19*** (0.04)	0.12*** (0.04)	0.00*** (0.00)	0.00*** (0.00)	0.00*** (0.00)	0.00*** (0.00)	0.00*** (0.00)
var(Residual)	5.48*** (0.06)	5.32*** (0.06)	5.18*** (0.05)	5.10*** (0.06)	5.13*** (0.06)	5.12*** (0.06)	5.02*** (0.06)
<i>AIC</i>	89935.5	84713.5	83379.4	77120.4	70040.9	70016.5	69732.6
<i>BIC</i>	89967.0	84760.6	83489.0	77252.3	70178.7	70162.0	69908.7
ICC-district	0.0634	0.0555	0.0254	0.0232	0.0233	0.0229	0.0242
ICC-individual   district	0.0949	0.0767	0.0254	0.0232	0.0233	0.0229	0.0242
Log likelihood	-	-	-41675.7	-	-35002.4	-34989.2	-
<i>N</i>	44963.7	42350.8		38543.2			34843.3
	19633	18658	18569	17230	15628	15628	15628

Standard errors in parentheses; \*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ ; ICC=Intraclass Correlation Co-efficient

### **b. The relationship between ART access on young people's wellbeing**

The main regression results are presented in Table 3. Models are organised as follows. Model 1 is the null model with only time and district fixed terms and district and household intercepts. Model 2 includes the main effect (ART count per capita). Model 3 adds health variables. Model 4-8 controls for the following (socio-demographic, social capital variables, personality trait variables, interaction terms, time) respectively.

After controlling for key covariates, we found a strong positive association between ART count per capita and life satisfaction ( $\beta = 7.25, p < 0.001$ ). Based on the interaction term between ART count per capita and personalised trust, a 1 unit increase in ART count per capita was associated with a decrease in life satisfaction scores by 6 units among those with personalised trust compared to those without. There were considerable improvements in model fit as subsequent covariates were added to the model, as confirmed from the lowering of the AIC and log-likelihood moving closer to zero. Overall, Model 8 had the best goodness of fit (AIC=66347.2 , log-likelihood= -33148.6).

We found that clustering at the district-level was minimal given the low proportion of the variance in this model that occurred within districts (ICC=3%). Moreover, this model suggested that a small variability in life satisfaction scores was due to clustering at the individual- level (ICC=3%). Based on (Supplementary File S13a-c), we find that deviance residuals for each level broadly follow a normal distribution.

Thereafter, we fitted this data using alternate model specifications. We found that co-efficients for ART count per capita were similar in terms of magnitude and statistical significance across all four models. However, standard errors were slightly higher in the POLS and FE compared to the two-level RI model (Supplementary File S14). Yet, standard errors for individual district co-efficients were smaller in the POLS compared to the one-level RI with district controls, suggesting that the POLS model produced biased estimates. Nevertheless, based on the log-likelihood ratio test, we found that the

two-level RI model was the more favoured model compared to the one-level RI model ( $X^2= 160.47$ ,  $p<0.000$ ). The POLS ( $X^2=-160.47$ ,  $p=1.000$ ) and FE ( $X^2= -6323.52$  ,  $p=1.000$ ) appeared to be the preferred models based on the log-likelihood test.. We also found similar results when applied these models to a balanced sample only (Supplementary File S15) and when life satisfaction was lagged (Supplementary File S16).

**Table 3: Two-level random intercept models examining the relationship between ART count per capita and life satisfaction among young people for the full NIDS sample. Co-efficient (SE)**

	(1) Null	(2) ART count per capita	(3) Health	(4) Socio- demographic	(5) Social Capital	(6) Personality trait	(7) Interaction Terms	(8) Time
	b/se	b/se	b/se	b/se	b/se	b/se	b/se	b/se
ART count per capita		2.01*** (0.55)	1.97*** (0.55)	1.52* (0.68)	1.74* (0.69)	1.71* (0.72)	3.08*** (0.77)	7.25*** (0.95)
Depressive Symptom Score			-0.10*** (0.00)	-0.09*** (0.00)	-0.09*** (0.00)	-0.09*** (0.00)	-0.07*** (0.01)	-0.08*** (0.01)
Underweight			-0.03 (0.07)	-0.06 (0.06)	-0.08 (0.07)	-0.10 (0.07)	-0.10 (0.07)	-0.14* (0.07)
Female				0.07 (0.04)	0.02 (0.04)	0.02 (0.04)	0.02 (0.04)	0.01 (0.04)
Age^2				0.01*** (0.00)	0.01*** (0.00)	0.01*** (0.00)	0.01*** (0.00)	0.00 (0.00)
Age				-0.35*** (0.04)	-0.30*** (0.04)	-0.30*** (0.04)	-0.31*** (0.04)	-0.08 (0.05)
Black				-0.84*** (0.07)	-0.88*** (0.07)	-0.92*** (0.08)	-0.94*** (0.08)	-0.94*** (0.08)
Completed compulsory education				0.20*** (0.05)	0.14** (0.05)	0.14* (0.06)	0.14* (0.06)	0.15** (0.06)
Employed				0.36*** (0.05)	0.31*** (0.05)	0.34*** (0.05)	0.35*** (0.05)	0.27*** (0.06)
Log Household expenditure				0.44*** (0.02)	0.43*** (0.02)	0.43*** (0.02)	0.43*** (0.02)	0.42*** (0.02)
Religious					0.40** (0.06)	0.32*** (0.06)	0.32*** (0.06)	0.35*** (0.06)
Generalised trust					-0.43***	-0.42***	-0.38***	-0.33***

Personalised trust					(0.05)	(0.05)	(0.05)	(0.05)
					0.27***	0.26***	0.98***	1.14***
Income aspiration					(0.04)	(0.05)	(0.12)	(0.12)
						0.05** (0.02)	0.05**	0.01
ART count per capita X							(0.02)	(0.02)
Personalised Trust							-4.69***	-6.07***
Depressive Symptom Score X							(1.09)	(1.08)
Personalised_Trust							-0.05***	-0.05***
2.wave							(0.01)	(0.01)
								-1.14***
3.wave								(0.07)
								-0.97***
4.wave								(0.08)
								-0.58***
5.wave								(0.10)
								-0.68***
_cons	5.30***	5.18***	5.84***	7.09*** (0.52)	6.41***	6.50***	6.38***	4.21***
	(0.09)	(0.10)	(0.10)		(0.54)	(0.57)	(0.57)	(0.60)
var(district)	0.38***	0.42***	0.35***	0.14*** (0.03)	0.13***	0.13***	0.13***	0.15***
	(0.08)	(0.09)	(0.08)		(0.03)	(0.03)	(0.03)	(0.04)
var(individual)	0.19***	0.22***	0.15***	0.00*** (0.00)	0.00***	0.00***	0.00***	0.00
	(0.04)	(0.04)	(0.04)		(0.00)	(0.00)	(0.00)	(0.03)
var(Residual)	5.48***	5.49***	5.34***	5.22*** (0.06)	5.14***	5.17***	5.15***	5.04***
	(0.06)	(0.07)	(0.07)		(0.06)	(0.06)	(0.06)	(0.07)
<i>AIC</i>	89935.5	85704.6	80630.3	79370.5	73424.9	66702.5	66659.8	66347.2
<i>BIC</i>	89967.0	85743.8	80684.8	79487.2	73563.6	66847.0	66819.6	66537.3
ICC-district	0.0634	0.0685	0.0606	0.0268	0.0246	0.0246	0.0242	0.0289
ICC-individual   district	0.0949	0.104	0.0855	0.0268	0.0246	0.0246	0.0242	0.0295
Log likelihood	-	-	-	-39670.3	-	-33332.3	-33308.9	-



<i>N</i>	44963.7 19633	42847.3 18685	40308.1 17728	17641	36694.4 16374	14857	14857	33148.6 14857
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Standard errors in parentheses; \*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ ; ICC=Intraclass Correlation Co-efficient

## 7. Discussion

In this study we sought to estimate the relationship between health and wellbeing, including the relationship between ART access and wellbeing among young people in South Africa. The goal of this study was to contribute towards the evidence-base on programmes and policies for improving young people's wellbeing in this setting. We created a panel of young people from the NIDS dataset, which is representative of the district population. We analysed this panel dataset using multi-level RI modelling approaches. We found that depressive symptom scores and underweight, markers of poor mental and physical health, respectively, were negatively correlated with life satisfaction. In addition, we found a strong positive association between ART count per capita and life satisfaction.

Overall, 14% of our sample had a depressive score suggestive of depression which was consistent across all waves and highlights the burden of mental health problems among young people as they transition into adulthood in this setting. This prevalence is lower than that reported in other South African cross-sectional studies that have applied a CES-D measure among 15-34 year-olds (Gibbs et al., 2018, Nduna et al., 2010). Yet, our prevalence estimate is similar to that found in longitudinal studies which have applied various versions of the CES-D measure (Al Mamun et al., 2007, Alaie et al., 2019, Rushton et al., 2002), however these were mainly conducted in high-income settings. Our findings are likely to be robust as this measure has been shown to be valid for young adults in developing settings (James et al., 2020), and score cut-offs for depression have been validated for the South African setting (Baron et al., 2017). We showed that an increase in depressive symptom scores was associated with a 0.08 decrease in life satisfaction scores. Previous studies, predominantly from high-income countries, reported larger effect sizes between self-reported mental health problems and life satisfaction among adults ( $\beta = -0.18$  to  $-0.37$ ) (Flèche and Layard, 2017) and young people ( $-0.50$ ) (Fergusson et al., 2015). Higher levels of depressive symptoms may reduce wellbeing by impairing physical health and self-esteem and negatively

affecting one's cognitive functioning and ability to maintain interpersonal relationship as well as employment (Layard et al., 2013, Layard, 2014, Frijters et al., 2014). Personalised trust in this setting could be largely gained from perceptions of positive social ties, a key positive correlate and source of life satisfaction among young people (Proctor et al., 2009). The negative interaction effects between depressive symptom scores and interpersonal trust suggests that depressive symptomatology may impede life satisfaction by negatively impacting one's perceptions of their social ties. Personality traits linked to hope and optimism are likely to affect the relationship between depression and life satisfaction, as shown in a previous study among Singaporean adolescents (Wong and Lim, 2009). Our findings hold even when we controlled for a measured confounder reflective of personality trait in our model and applied a FE model, that if modelled correctly controls for time-invariant unobservables.

A notable finding was the strong negative association between underweight and life satisfaction, as reported in a previous study (Ball et al., 2004). This negative association was larger than the association we found between depressive symptom and life satisfaction, opposite to findings from previous studies that examine self-reported poor mental and physical health on wellbeing (Flèche and Layard, 2017, Lombardo et al., 2018). Being underweight may reduce wellbeing by affecting key dimensions of psychological wellbeing such as self-esteem (Pedro et al., 2016) and social functioning (Gitau et al., 2014), which in turn may increase one's risk of depression (Cortese et al., 2009).

Social capital variables such as interpersonal trust were strongly correlated with life satisfaction, underscoring the importance of strong social support networks for young people's wellbeing in this setting (Wissing et al., 2014, Van Schalkwyk and Wissing, 2010, Geldenhuys, 2016, Govender et al., 2018, Proctor et al., 2009). However, our results suggest that depressive symptoms substantially reduce the positive benefits of inter-personal trust on life satisfaction. However, generalised trust was found to be negatively correlated with life satisfaction. The generalised trust question used in the

NIDS survey did probe the likelihood someone from the community would return one's lost wallet. Hence, this measure could have been picking up the anxiety or worry linked to the high levels of crime and violence in this setting (Statistics South Africa (Stats Sa), 2018), which are known negative correlates of life satisfaction (Alfaro-Beracoechea et al., 2018), particularly in South Africa (Powdthavee, 2005). Furthermore, race was one of the strongest correlates of wellbeing, with Black young people more likely to report lower levels of life satisfaction compared to young people from other population groups. This pattern concurs with findings from other South African studies (Møller and Roberts, 2017, Ebrahim et al., 2013), and could relate to the lower levels of relative household standing (Posel and Casale, 2011, Kingdon and Knight, 2007) or absolute income (Kollamparambil, 2019) among Black South Africans. More importantly, it could relate to the centuries of oppression and inequality experienced by Black South African under its apartheid regime (Møller, 2013, Møller, 1998). Income aspirations were negatively correlated with wellbeing. Whilst this association was not significant it could highlight the negative affect of extrinsic aspirations on mental health and life satisfaction (Nishimura and Suzuki, 2016, Myers, 2000). Together, these findings underscore the need for greater investments in health programmes that identify and link those at high risk of depression or undernutrition into care and psycho-social support programmes, particularly Black young people. Given the positive correlation between educational status and employment, and wellbeing, policies that promote school completion and promote young people employment could be effective for this setting.

The strong positive and significant correlation identified between ART count per capita and life satisfaction suggests that further investments into ART scale-up may be an appropriate strategy to enhance wellbeing among young people. This finding supports the latest evidence on the economic gains of ART scale-up and further investment in this policy globally (Forsythe et al., 2019). Moreover, it supports earlier research which has reported strong positive effects between ART expansion on health-related quality of life (Beard et al., 2009) and economic outcomes (Baranov and Kohler, 2018, Thirumurthy and Zivin, 2012, Rosen et al., 2014, Larson et al., 2013). Scaled-up ART

access in South Africa may have promoted the physical and mental health of children, young people and adults living with HIV and in turn enhanced their wellbeing at a district level. This may have had led to spillover wellbeing effects among young people, similar to the health and economic spillovers linked to the early phases of ART expansion (Zivin et al., 2009, Lucas and Wilson, 2013, Baranov et al., 2015, Thirumurthy et al., 2016). However, the negative interaction effects between ART per capita and personalised trust could be linked to the high levels of internalised and externalised HIV-related stigma (Simbayi et al., 2007, Williams et al., 2019) at the household and community level, a known negative predictor of life satisfaction (Sanjuán et al., 2013). Stigma may have weakened inter-personal ties and one's trust in others (Greeff et al., 2010, Hutton et al., 2013b) and thereby reduced life satisfaction among young people (Proctor et al., 2009).

This study has several strengths. We used a large panel of young people which aided in understanding the changes in wellbeing over time as young people transitioned into young adulthood. Having repeated measures provided more variability and less collinearity between variables thereby improving the efficiency of our estimates. As a panel contains information on intertemporal dynamics via repeated measures of individuals overtime and on individual entities. Thus, it facilitates the capturing of unobservables at these levels. We applied a multi-level random effects modelling approach that is appropriate for the hierarchical nature of the dataset, and it accounted for individual-level and district level heterogeneity (Rice and Jones, 1997, Grieve et al., 2005). Whilst an individual fixed effect model may reduce endogeneity by removing the unobserved heterogeneity at the group level in the data, and control for time-constant effects, it cannot provide indication on whether variance at a higher level is significant or measure the effects of time-invariant variables (Bell et al., 2019, Mcneish and Kelley, 2019). We controlled for known covariates of wellbeing and included variables that capture relationality, in line with the socio-cultural context and conceptualisation of wellbeing. We used robust and widely applied measures of mental health (depressive symptom scores- CES-D-10) (James et al., 2020), physical health (underweight- BMI) (Bell et al., 2018), and wellbeing (life satisfaction) (Diener et al., 2018). Our results

were largely robust to alternate model specifications, including the use of a balanced sample. In addition, findings from our ART access model was robust to use of a lagged outcome variable.

However, caution should be taken when interpreting our data given the following limitations to our design, sample, and analytical approach. 1) We used life satisfaction as a proxy measure of psychological wellbeing. Whilst this uni-dimensional subjective wellbeing measure is strongly correlated with psychological wellbeing dimensions (Proctor et al., 2009, Keyes et al., 2002), our previous work (Govindasamy et al., 2019) and other studies suggest that multi-dimensional psychological wellbeing measures are more reflective of young people's wellbeing in this setting (Van Schalkwyk and Wissing, 2010, Wissing et al., 2014, Geldenhuys, 2016), and thus could be more responsive to picking up changes in wellbeing. ; 2) A more appropriate measure of ART access would have been district ART coverage (i.e. proportion of people living with HIV who are on ART among those who are living with HIV) (Adam and Johnson, 2009). However, robust estimates of district-level HIV prevalence and count of patients on ART, were not publicly available at the time of data analysis. Our ART count variable is likely to be biased, particularly for districts in the KwaZulu-Natal province, a high HIV burden province that only joined the NHLS in 2010 (Fox et al., 2018). Thus, ART count data for wave 1 in this area is underestimated.; 3) Other covariates used in my model may also be prone to bias. For example, BMI was used as a proxy for physical health. However, it is prone to measurement issues (Burkhauser and Cawley, 2008) and does encompass other elements of physical health status (e.g. smoking status). Moreover, measures of trust used in the NIDS survey may likely be tapping into self-perceptions of risk related to crime and violence in one's community rather than the concept of trust in social psychology, which is considered a generalised expectation that the actions and statements of others can be relied upon and denotes social functioning within inter-personal relationships and relates to personality traits (Evans and Krueger, 2009, Cook, 2005). Future economic surveys could consider applying widely used trust scales from the field of social psychology which examine perceived beliefs on honesty and trustworthiness of others (e.g. Generalised Trust Scale (Yamagishi and

Yamagishi, 1994) and Interpersonal Trust Scale (Rotter, 1967)); 4) There might be selection bias in our sample as we identified differences in socio-demographic characteristics in the balanced versus full sample. In the balanced sample, there were a slightly higher number of females, individuals who completed compulsory education and who were employed, suggestive of higher wellbeing levels. However, we found no statistical difference in life satisfaction scores between these two samples. There was considerable attrition in our sample, largely due to household non-response. These attritors may have been more likely to move households and districts and thus have weaker and unstable social ties and thus lower levels of wellbeing. In addition, they could likely be migrant labourers with a unique wellbeing profile. Furthermore, ART count per capita was significantly higher in the balanced versus full (unbalanced) sample, suggesting that results using the full sample could be prone to negative selection bias. However, the magnitude of the estimates from the two-level RI model using the full versus balanced sample were similar; 5) Due to lack of psychological measures in the NIDS dataset and limitations in the HIV dataset, we were unable to explore how key variables such as social support, resilience or virological suppression mediated pathways using structural equation modelling. 6) whilst our two-level RI model did have smaller standard errors compared to the FE models, it is likely that our co-efficients may be biased as the strict exogeneity assumption of our main model (i.e. the random effects not correlated with covariates) may not hold due endogeneity issues (e.g. omitted variable bias, measurement error, statistical misspecification). In this case, the individual-FE approach may be more appropriate as it allows for individual effects to be correlated with the explanatory variables ; 7) We were not able to infer causation based on our statistical methods used. Future studies could explore quasi-experimental methods (e.g. interrupted time series, regression discontinuity design (Lee and Lemieux, 2010)).

## **8. Conclusion**

The objectives of this study were to examine the health correlates of wellbeing and the relationship between district ART access on wellbeing among young people in South Africa. We used a panel dataset that was representative of the country's district population between 2008 to 2017 and overlaid this with district ART count per capita data. Using a multi-level modelling approach, we found a negative correlation between health (mental and physical) and wellbeing and a strong positive association between ART access and wellbeing. Taken together, these results suggest that combining ART programmes with mental health, economic and social capital programmes that seek to build interpersonal support, financial security and trust could have greater gains on young people's wellbeing. Future econometric studies should explore the use of more robust measures of ART access and multi-dimensional psychological wellbeing as well as the application of causal methods.



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## **Chapter Conclusions**

Overall, I found a strong negative correlation between health status and wellbeing, and a strong positive association between ART access and wellbeing. My findings suggest that policies targeted at promoting mental health, young people educational attainment and employment as well as social integration may be effective in promoting wellbeing among young people in this region. In addition, it highlights that investing in ART access policies may be an effective policy for increasing young people's wellbeing. I use my qualitative data (Paper 3) in the next chapter to help explain and validate these correlations.

## **Chapter 7: An exploration of how wellbeing is locally understood and experienced among young people living with and without HIV (Qualitative study)**

### **Chapter Introduction**

In Chapter 2 I highlighted that there is a gap in knowledge on appropriate wellbeing measures in LMICs. In Chapter 3 I found that there is a lack of research on which international wellbeing models are relevant for understanding young people's wellbeing in SSA. In this paper I present results from my qualitative study that sought to address these gaps in knowledge. I specifically explored how wellbeing is locally understood and experienced among young people living with and without HIV. Furthermore, I explored whether or not the Ryff's PWB model aligns with young people's wellbeing in this setting. This study meets Objective 4 of my thesis.

Themes that emerged in my mixed method review (Paper 1) informed my data collection tools for this study. Moreover, quantitative findings on the health determinants of youth wellbeing in Paper 2, assisted in the interpretation of my data.

This paper was submitted to Social Sciences & Medicine and is currently under review. I include a supplementary file that details dimensions within the Ryff PWB model.

Consent and assent forms and topics guides for this qualitative study are included under the Appendices section of this thesis.

## RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

### SECTION A – Student Details

Student ID Number	1402394	Title	Ms
First Name(s)	Darshini		
Surname/Family Name	Govindasamy		
Thesis Title	Wellbeing among adolescents and young adults in sub-Saharan Africa: a mixed methods study of their wellbeing construct, its health correlates and association with access to HIV treatment		
Primary Supervisor	Prof Janet Seeley		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

### SECTION B – Paper already published

Where was the work published?			
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Where is the work intended to be published?	Social Science and Medicine
Please list the paper's authors in the intended authorship order:	Darshini Govindasamy, Giulia Ferrari, Kealeboga Maruping, Panashe Bodzo, Catherine Mathews, Janet Seeley



Stage of publication	<b>Submitted</b>
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**SECTION D – Multi-authored work**

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I designed the study concept note with support from from my supervisory panel. I subsequently developed the proposal and sought ethical approval. I implemented the protocol, managed the field team and oversaw data management. I conducted interviews with key informants. I coded all transcripts and analysed the data. I led the write-up, revised subsequent drafts based on feedback from co-authors and submitted to the journal.</p>
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**SECTION E**

<b>Student Signature</b>	[Redacted]
<b>Date</b>	26/12/2019

<b>Supervisor Signature</b>	[Redacted]
<b>Date</b>	26/12/2019

# **Research Paper 3: A qualitative enquiry into the meaning and experiences of wellbeing among young people living with and without HIV in KwaZulu-Natal, South Africa**

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## **Abstract**

Young people in sub-Saharan Africa encounter health and livelihood challenges which may compromise their wellbeing. Understanding how young people's wellbeing is defined could strengthen policies to promote their wellbeing. We investigated how young people's wellbeing was conceptualised and whether or not these aligned to Ryff's psychological wellbeing (PWB) model.

Data were collected through focus-group discussions (n=12) and in-depth interviews (n=16) with young people living with and without HIV, selected purposively from South African healthcare facilities. Key informant interviews (n=14) were conducted with healthcare workers and subject-matter experts. Using a framework approach, we situated our analysis around dimensions of Ryff's PWB model: autonomy, self-acceptance, purpose in life, environmental mastery, positive relationships, personal growth.

Young people's wellbeing was rooted in family and peer relationships. Acceptance and belongingness received from these networks fostered social integration. HIV-related stigma, crime and violence reduced their perceived control and social trust. For males, fulfilling gendered roles made them feel socially valued. Self-perceived failure to uphold sexual norms undermined women's social contribution and autonomy.

Social integration and contribution framed young people's wellbeing. However, these dimensions were not fully captured by Ryff's PWB model. Models that consider relationality across socio-ecological levels may be relevant for understanding young people's wellbeing.

**Keywords:** psychological wellbeing, quality of life, adolescence, young adults, young people, HIV/AIDS, sub-Saharan Africa, South Africa

## 1. Introduction

In 2019, Africa accounted for almost one-fifth (221 million) of the 1.2 billion young people aged 15-24 years worldwide (UN, 2019). It is estimated that by 2065, the number of young people in sub-Saharan Africa (SSA) will increase by 89% (UN, 2019). However, this demographic transition signals a major challenge to sustainable development in this region, where currently young people are exposed to numerous health and economic challenges, specifically HIV/AIDS (UNAIDS, 2018) and youth unemployment (ILO, 2016). These challenges pose a major threat to their wellbeing (OECD, 2018).

Wellbeing among young people has emerged as a priority indicator in global health (Azzopardi et al., 2019), in line with Goal 3 of the 2030 Sustainable Development Goals agenda (UN, 2018). Broadly, this construct refers to how well one is thriving across multiple domains in life (Adler and Seligman, 2016). Econometric evidence has shown that wellbeing during adolescence strongly predicts positive human capital and labour market outcomes, including health outcomes in adulthood (Layard et al., 2014). Maximisation of societal utility (wellbeing) is an important economic policy goal (Mcgregor and Pouw, 2016). Direct measurement of people's wellbeing is now recommended for policy evaluations (Stiglitz et al., 2009, Clark et al., 2019). Economic studies have highlighted the value in using wellbeing measures to evaluate the broader impacts of multi-sectoral interventions and policies (Greco et al., 2016, Dolan and Peasgood, 2008). If we can improve our understanding of young people's wellbeing then we can select appropriate measures to evaluate and guide policy investment decisions to effectively promote wellbeing among this vulnerable population (OECD, 2017).

The choice of wellbeing models and measures to guide resource allocation decisions for young people in SSA requires careful consideration to ensure it is aligned to local conceptualisations and experiences of wellbeing (Mcgregor et al., 2009). The lack of data on how to frame and measure young people's wellbeing is considered a barrier to health investments among this group (Azzopardi et al., 2019). Psychological wellbeing (PWB) models may be suitable for the study of wellbeing among young people in SSA given their

alignment to the conceptualisation of wellbeing in African settings (Delle Fave et al., 2016), particularly among young people (Van Schalkwyk and Wissing, 2010, Wissing et al., 2014). A better understanding of how young people's wellbeing is locally constructed could help identify appropriate wellbeing models and subsequently scales which could be used in policy evaluations of public health programmes that aim to promote wellbeing. We used Ryff's model of PWB to structure the analysis of our data, which we derived from focus-group discussions (FGDs) and in-depth interviews (IDIs) with young people in KwaZulu-Natal, South Africa, as well key informant interviews (KIIs) with healthcare workers (HCWs) and experts.

## **2. Theoretical framework and literature**

Ryff's PWB model is rooted in an eudaimonic approach to wellbeing which emphasises meaning-making, self-realisation and growth, relatedness and quality of relationships (Ryff, 2014). Ryff's PWB model encompasses six theory-guided dimensions of positive functioning, defined as follows: 1) self-acceptance: a positive attitude towards self, 2) positive relations with others: quality relations with others, 3) environmental mastery: the capacity to effectively manage one's life and surrounding world, 4) autonomy: a sense of self-determination, 5) purpose in life: a belief that one's life is purposeful and meaningful, and 6) personal growth: a sense of continued growth and development (Ryff, 2014, Ryff and Keyes, 1995) (Supplementary File 1). This model is built on the assumption that an individual strives to function fully and realise his or her talents.

We chose the Ryff PWB model for the following reasons. First, the conceptualisation of wellbeing in this model, as noted above, has a strong eudaimonic orientation, which also underpins conceptualisations of wellbeing in African settings (Delle Fave et al., 2016), particularly among young people in South Africa (Wissing et al., 2014, Van Schalkwyk and Wissing, 2010). Second, our previous work suggests that experiences of wellbeing among YPLHIV encompass supportive relationships, aspirations and coping, which align with dimensions of this model, particularly positive relations, purpose and mastery

(Govindasamy et al., 2019). Third, its dimensions are informed by development stage theories (Erikson, 1994, Jahoda, 1958a) that have been applied to understand adolescent development, specifically identity and relationships (Hightower, 1990, Miller, 1989, Lerner and Steinberg, 2004).

Qualitative studies which have applied a PWB framework, have identified positive relations with family members as a key dimension of adolescents wellbeing in the United States of America (Rose et al., 2016), and South Africa (Geldenhuys, 2016, Van Schalkwyk and Wissing, 2010). Our previous study has shown that social networks may also have negative effects on their wellbeing (Govindasamy et al., 2019), however, the aforementioned studies have not examined this in relation to Ryff's PWB model. Whilst quantitative studies have reported differences in PWB scores between ages-groups and gender among young people in developing settings (Sun et al., 2016, Perez, 2012), it is unknown how and why these differ. Furthermore, the voices of YPLHIV with regards to their wellbeing is missing in the literature. The unique and multiple issues that YPLHIV experience (e.g. stigma, lack of access to social support services, side effects of medication, disclosure) are likely to influence their wellbeing. Thus, their experiences of wellbeing may differ to young people not living with HIV (Skovdal and Belton, 2014, Bernays et al., 2017, Mattes, 2014). Understanding how dimensions of Ryff's PWB model appear and are shaped by socio-demographic factors and HIV status can ensure policy evaluations utilise wellbeing models and measures that align with how wellbeing is understood and experienced in this setting.

In this paper we examine how wellbeing was locally perceived and experienced by young people living with and without HIV in KwaZulu-Natal South Africa, and whether or not these perceptions and experiences aligned to Ryff's PWB model.

## **Methods**

### ***3.1 Study setting***

South Africa is currently in the medium human development category, with a Human Development Index score of 0.699 and average life expectancy of 63 years (UNDP, 2018). However, it has one of the highest levels of income inequality with a reported Gini coefficient of 0.63 (World Bank, 2015). According to the Helliwell et al. (2018), South Africa ranks at 106 in the latest World Happiness Report, making it one of the least happy countries. Furthermore, it has one of the largest HIV epidemics in the world, with an estimated 7.9 million people living with HIV (HSRC, 2018). The current HIV prevalence is 10.5% among 15-19 year-olds and 20.4% among 20-24 year-olds (HSRC, 2018). The country is divided into 9 provinces, with KwaZulu-Natal ranked as one of the poorest provinces, with a GDP per capita of 4507 USD (Stats SA, 2017). This province is further divided into 11 districts, with the eThekweni district, regarded as the epi-centre of South Africa's HIV epidemic (HIV prevalence 0->60 years: 14.5%, 95% CI: 11.2-18.6) (HSRC, 2014). This study was conducted in Umlazi, a peri-urban area within the eThekweni district that has an estimated population size of 404 811 (Stats SA, 2011).

### **3.2 Data collection**

To gain an in-depth understanding of young people's wellbeing from a range of stakeholders, we conducted qualitative interviews with young people living with or without HIV, HCWs, and subject-matter experts. Data were collected between January and August 2018. We purposively sampled young people and HCWs from two clinics within a public-sector hospital. Experts were purposively sampled from academic institutions in South Africa and abroad. Young people were sampled in line with the WHO definition of older adolescent (15-19 years) and young adult (20-24 years) (WHO, 2014).

The eligibility criteria for the following participant groups were as follows:

- a. Young person living with HIV-** aware of HIV status and clinically stable on antiretroviral therapy for more than six months with no other conditions (e.g. tuberculosis, pregnancy)

- b. Young person living without HIV-** no major self-reported health condition (e.g. HIV positive, tuberculosis, pregnancy etc.)
- c. HCW-** any HCW providing care to young people in the study clinic or catchment community
- d. Expert-** a researcher in the area of adolescent HIV or wellbeing

Topic guides were loosely mapped to the dimensions of Ryff's PWB model (Ryff, 2014). This allowed us to ask questions that were relevant to the dimensions of the model, yet it was flexible enough for us to explore other emergent issues outside this model.

Focus-group discussions (n=12) were conducted with young people to obtain a wide range of perspectives on how well- and ill-being were understood. We aimed for creating homogenous groups in order to assess common experiences by age-group and HIV status (Green and Thorogood, 2013). We stratified and grouped individuals by HIV-status, sex and age-range (15-19-year-olds, 20-24-year olds), with approximately 5-10 people per group. FGDs were conducted until theoretical saturation was reached. We incorporated Draw-and-Tell Techniques (Veale, 2005) in our FGDs, as these have been previously used to study child wellbeing in developing settings (Crivello et al., 2008). We randomly divided groups into two, and asked groups to develop images of a young person living a good life and a bad life. Using the participant's artwork, we explored what constituted a good and bad life for a young person in this community. We specifically asked participants the following questions and probed elements in the drawings that were linked to dimensions of PWB: "how does this create a good life?", "what needs to be in place for you to have this good life?", "what can take this good life away?" , "how does this create a bad life?". Trust and confidentiality exercises were conducted to ensure participants felt safe enough to share information and protect participant information. Group members were encouraged not to share personal information during and after the FGD. Basic socio-demographic data were collected from each participant at the start of the FGD.

Approximately 1-2 participants were purposively sampled based on age, gender and HIV-status from each FGD for participation in an IDI (n=16) to explore personal experiences and

to understand how lived experiences differed by groups. In addition, we used the IDIs to revisit themes that emerged in the FGDs. We purposively selected participants who appeared comfortable engaging with study staff in the FGDs, particularly those who appeared at ease with articulating their thoughts and opinions. The duration of each IDI was 1.5-2 hours. Participants' experiences of wellbeing and illbeing were probed using a Life-course Timeline approach (Adriansen, 2012, Crivello et al., 2008, Ferrari, 2019). Each participant was asked to draw a timeline from birth to present age, highlighting important happy and sad life events. The design was flexible, and participants were allowed to write or talk about their life history. We specifically probed the following questions "describe yourself?", "who is your role model and why?", "why would you consider this a happy or sad event (probed psychological elements)?", "what would you say to your younger self?", "how do you cope with stress?", "what would you consider important to you and why?".

Semi-structured KIIs (1-1.5 hours) were conducted with HCWs (n=9) and experts (n=5). Interviews with HCWs sought to understand the psycho-social needs and health system barriers with regards to care and support for young people living with and without HIV. Interviews with experts explored wellbeing measures applied in previous studies with adolescents, findings of wellbeing studies conducted in developing countries, and ethical challenges in this research area. Key findings from the FGDs and IDIs with young people were discussed further with HCWs.

All interviews were audio-recorded and conducted in the participant's preferred language. However, FGDs and IDIs were conducted in isiZulu as this was the predominant language spoken among young people in this setting. An experienced facilitator conducted the FGDs, IDIs and KIIs, with the study fieldworker taking detailed notes regarding the dynamics, interactions and non-verbal communication of the discussants. The first author conducted KIIs with the majority of English-speaking HCWs and all experts. Staff received regular debriefing from a registered social worker in order to manage any difficult feelings or thoughts that may have arisen during the data collection process.

### **3.3 Data analysis**

All audio recordings were transcribed and translated and checked for accuracy. A framework analysis approach was used (Ritchie et al., 2013). Two authors (DG, KM) first read all transcripts and field notes together with the respective artwork to gain a general understanding of each session, and together discussed the key issues and themes that emerged from the data. The first author then developed a list of thematic codes, arising both deductively and inductively. Examples of deductive codes related to the dimensions within Ryff's PWB model (Ryff, 2014) and themes identified in our mixed-methods review on wellbeing (Govindasamy et al., 2019). The first author then applied the framework systematically to all data by coding the data using NVivo version 11. All data were independently coded by a second person to assess inter-rater reliability. While there was good agreement between coders, a few differences emerged which were subsequently resolved through discussion to reach a consensus. A matrix was then developed by re-organising the data into relevant thematic headings and categories. Using this matrix, data from the FGDs were compared and contrasted with IDIs and KIIs to explore convergence, complementarity, and discordance to enhance the validity of the results. We specifically sifted through the data to examine differences and similarities in wellbeing dimensions by age, sex and HIV status. DG conducted thematic interpretations of the data, jointly with KM, GF and JS.

### **3.4 Ethics approval**

Ethical approval was obtained from the South African Medical Research (EC037-11/2016) and the London School of Hygiene and Tropical Medicine (13782 - 1). Approval to conduct this study within healthcare facilities was obtained from the KwaZulu-Natal Department of Health (Health Research and Knowledge Management Division) and hospital management. Written informed consent was obtained for all participants aged 18 years and above. For minors, defined as individuals younger than 18 years in South Africa (Strode and Slack, 2015), written parental permission together with minor assent was obtained. All participants were assigned unique identification numbers. We used pseudonyms in this

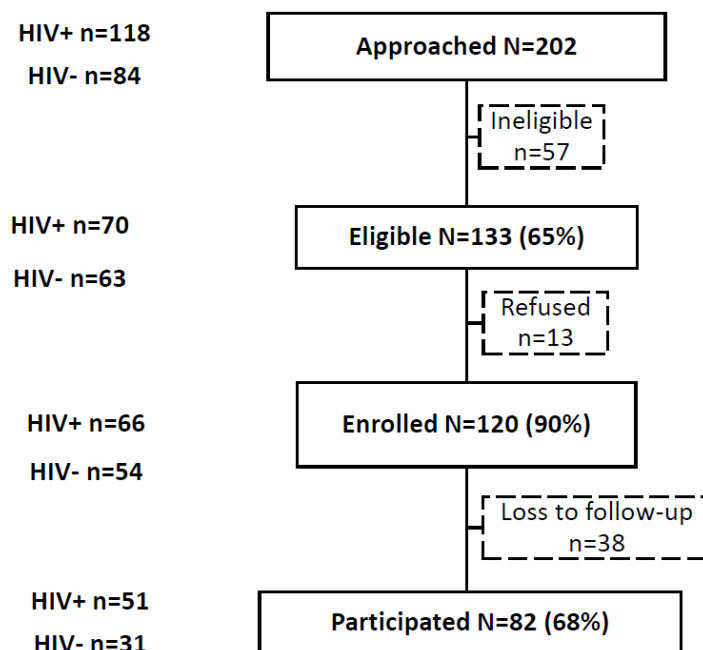


paper to maintain confidentiality. Participants who attended study interviews received a small lunch pack and transport fare.

## 4. Results

### 4.1 Sample description

Overall, 202 young people were approached at the study clinics (Figure 1). Of these, 133 (65%) met the eligibility criteria, and 120 were enrolled. Most refusals were among minors. YPLHIV who were unstable on ART made up the majority of those who were not eligible to participate in the study.



HIV+ = HIV-positive; HIV- =HIV-negative

Figure 1: Recruitment flow of young people living with and without HIV

Of those enrolled, 82 (68%) participants attended one of the 12 FGDs conducted (Table 1). Of these, 8 FGDs were with YPLHIV (n=51, on average 6 participants per group) and 4 FGDs with young people not-living with HIV (n=31, on average 7 participants per group). The

median age of participants in our FGD sample was 19.5 years, with 51% who were female. The majority of young people in this sample were black South Africans, who completed compulsory education (i.e. Grade 9), with 41% who were enrolled in secondary school at the time of data collection. Nearly 80% of participants resided in formal households, without their biological mother or father.

**Table 1: Socio-demographic characteristics- FGD participants**

	Total (N=82) n(%)	HIV-negative (n=31)	HIV-positive (n=51)
Total FGDs conducted	12	4	8
15-19-year-old	6	2	4
<i>Female</i>	3	1	2
<i>Male</i>	3	1	2
20-24-year-olds	6	2	4
<i>Female</i>	3	1	2
<i>Male</i>	3	1	2
Age (median, IQR <sup>^</sup> )	19 (18-22)	20 (18-22)	18.5 (17-22)
Age category			
15-19 yrs.	44 (54)	13 (42)	31 (60)
20-24 yrs.	38 (46)	18 (58)	20 (40)
Gender			
Female	42 (51)	17 (55)	25 (49)
Male	40 (49)	14 (45)	26 (51)
Race- Black	82 (100)	31 (100)	52 (100)
South African nationality	82 (100)	31 (100)	52 (100)
Current economic status			
Enrolled in secondary education	35 (42)	7 (23)	28 (55)
Enrolled in tertiary education	19 (23)	10 (32)	9 (17)
Employed	6 (7)	4 (13)	2 (4)
Unemployed-searching for a job	22 (27)	10 (32)	12 (24)
Completed compulsory education (Grade 9)			
Yes	76 (93)	31 (100)	45 (88)
No	6 (7)		6 (12)
Type of household			
Formal	65 (79)	26 (84)	39 (76)
Informal	17 (21)	5 (16)	12 (24)
Number of household members (median IQR <sup>^</sup> )	5 (4-7)	4 (2-7)	5 (4-8)
Biological mother lives in household			
Yes	32 (40)	15 (48)	17 (33)
No	50 (60)	16 (52)	34 (67)
Biological father lives in household			

Yes	8 (10)	5 (16)	3 (6)
No	74 (90)	26 (84)	48 (94)
Caregiver			
Biological mother	22 (27)	10 (32)	12 (24)
Grandmother	16 (20)	1 (3)	15 (29)
Aunt	12 (15)	4 (13)	8 (16)
Other	32 (40)	16 (52)	16 (31)

^ IQR= Interquartile range

From the FGDs, 16 participants were purposively sampled for IDIs (Table 2). Ten IDIs were conducted with YPLHIV and the remaining six IDIs were conducted with young people not living with HIV. Most IDI participants were aged 15-19 years (n=8), with more than two-thirds who were currently completing secondary school. More than 50% (n=10) reported that their biological father was deceased.

**Table 2: Sample characteristics- IDI participants (N=16)**

IDI participant	HIV status (mode of HIV infection)	Age	Gender	Current economic status	Completed compulsory education (Grade 9)	Highest Grade completed	Type of household	Number of people living in household	Biological mother lives in household	Biological father lives in household	Primary caregiver
Sinothando	HIV-positive (vertically infected)	15	Female	In secondary education	Yes	Grade 10	Formal	4	No	No-deceased (HIV related)	Aunt
Thandi	HIV-positive (vertically infected)	18	Female	In tertiary education	Yes	Grade 12	Formal	5	Yes	No-deceased	Biological mother
Sne	HIV-positive (vertically infected)	19	Female	In secondary education	Yes	Grade 11	Informal	17	No-lives and works in the city	No-deceased	Grandmother
Busi	HIV-positive (vertically infected)	20	Female	In tertiary education	Yes	Grade 12	Formal	3	No-deceased	No-deceased	Aunt
Thembeke	HIV-positive (sexually infected)	24	Female, mother of 1	Unemployed searching for a job	Yes	Grade 12	Formal	10	Yes	No-deceased	Biological mother
Khewsi	HIV-positive (vertically infected)	15	Male	In secondary education	No	Grade 7	Formal	10	Yes	No- does not who father is	Biological mother
Bongani	HIV-positive (vertically infected)	18	Male	In tertiary education	Yes	Year 1- university	Formal	6	No-deceased (HIV-related)	No-disowned by father	Grandmother
Owethu	HIV-positive	18	Male	In tertiary education	Yes	Grade 12	Formal	4	Yes	No-disowned	Biological mother

	(vertically infected)									by father, father has another family	
Andile	HIV-positive (vertically infected)	22	Male, receives disability grant	Unemployed searching for a job	Yes	Grade 11	Formal	Unknown	No-deceased	No-deceased	Sister
Sanele	HIV-positive (vertically infected)	22	Male	Unemployed searching for a job	Yes	Grade 10	Formal	5	No-deceased (HIV-related)	No-deceased (gun-related)	Aunt
Mandisa	HIV-negative	18	Female	In secondary education	Yes	Grade 12	Formal	3	Yes	Yes	Biological mother
Zanele	HIV-negative	23	Female, mother of 1	In tertiary education	Yes	Grade 12	Formal	2	No-deceased	No-deceased	Grandmother
Hlengiwe	HIV-negative	24	Female, mother of 1, originally from rural KZN	In tertiary education	Yes	Grade 12	Informal	1 (Lives on her own)	No-lives in rural KZN	No-deceased	Nil- herself
Sipho	HIV-negative	16	Male	In secondary education	Yes	Grade 10	Formal	4	Yes	Yes	Biological mother
Ayanda	HIV-negative	20	Male, migrated from the Eastern Cape	In secondary education	Yes	Grade 11	Formal hostel	2	No-lives and works in Gauteng	No-father has another family	Himself
Nka	HIV-negative	21	Male	Unemployed searching for a job	Yes	Grade 11	Formal	2	Yes	No-deceased	Biological mother

Among key informants, most were HCWs (n=10), mainly nurses (n=4). Experts included social scientists with expertise in wellbeing or adolescent health research (n=5), based mainly at South African institutions.

## **4.2 Description of wellbeing**

Using the dimensions of Ryff's PWB model, we now present how wellbeing was perceived and experienced in this context.

### **4.2.1 Positive relations**

When we asked young people and key informants what makes a good life for a young person in this setting, most accounts embodied a strong sense of relatedness, with a good life described as *“living together as a family”*, having a *“loving family”* and having *“trusting family members”* that one can communicate with (Figure 2). In a good life, family units were described by young people as groups with *“shared happiness and love”* where you receive physical and emotional support, specifically from caregivers. Supportive relationships with caregivers appeared essential for wellbeing as these ties appeared to facilitate integration within family networks. The importance of caregivers was more strongly expressed in accounts of a good life from YPLHIV compared to those not living with HIV. Several vertically HIV-infected young people expressed deep gratitude for their grandmothers' support who, based on their accounts, played an integral role during their HIV childhood journey, from disclosing their HIV-positive status to supporting them with medical adherence. Young people exhibited strong awareness of the reciprocal nature of relationships, and this was often expressed through their strong desire to one day be able to *“provide”* for their households.



**Figure 2: FGD , 15-19-year-old females, HIV-positive. This drawing highlights the importance of a supportive family networks for young people’s wellbeing**

Positive relations that extended beyond the family were also critical for cultivating social integration and wellbeing. For Sne, seeing “*other children taking pills*” and other “*young people at her HIV clinic*”, helped her feel like she had something in common with others. Being a part of an HIV support group previously conducted at her clinic gave her a sense of belonging:

*“there used to be a group we used to meet as young people...who have HIV would learn from each other, and talk... it was nice... talking... everyone felt comfortable...because we spoke about anything regarding HIV... we would talk and it was nice,.... you even develop friendships there”* [Sne, 19-year-old female, HIV-positive]

In contrast, for 18-year-old Bongani attending church provided him with a space to develop friendships with others who did not engage in “bad stuff”.



Descriptions of sad life events were often linked to experiences of negative relationality and lack of integration within key networks. From FGDs and IDIs with male participants living with and without HIV, it was evident that in a good life, biological fathers played a key role in fostering a sense of belonging. For Sanele and Nka, the lack of acceptance from the paternal family or not having a father in the household, made them feel “out of place”, and likely lowered their wellbeing by reducing a sense of belongingness.

Experiences of HIV-related stigma characterised sad life events for YPLHIV. In particular, HIV-related stigma, encountered within family networks appeared to lower wellbeing primarily through social marginalisation which in turn reduced self-esteem and challenged their ability to build positive relationships. For example, the HIV-related stigma that Owethu encountered from his father destroyed their relationship and created feelings of rejection:

*“Yes and then my father said “okay you have HIV”, he started to reject me but then he said if you come to visit me you are not going to take your pills... not understanding that I am... not understanding that I am at this level that where I might even get AIDS... I’m not going.”*  
[Owethu, 18-year-old male, HIV-positive]

The internalised stigma that Sne harboured affected her self-worth and made it difficult for her to be in an intimate relationship

*“Who will accept the condition I am in now.... Because everyone is scared of HIV.....that means I should not date .... I must stay like this..... be myself..... and not have a boyfriend. Because if he can ever be sick obviously it will be me.... then I realised that no I should not commit myself.”* [Sne, 19-year-old female, HIV-positive]

Similarly, perceptions of a bad life, echoed a sense of lowered social trust and social exclusion, as highlighted by one of the male participants:

*“The sports grounds should be close to where black young people live, young people should not travel long distances, they should not travel long distances going to these grounds because those who are poor might end up not being part of this because of long distance they would travel to go to these grounds to play.” [FGD, 15-19-year-old males, HIV-positive]*

*“You have a degree then you’re sitting at home doing nothing, the government is supposed to fight for that because there are no job opportunities, not at all, I don’t want to lie.” [FGD, 20-24-year-old males, HIV-positive]*

#### **4.2.2 Purpose in life**

When we asked young people what mattered most in their lives, salient in responses among those living with and without HIV was the importance of education and career goals. Pursuit of these goals were perceived as essential for attainment of a good life and this was unanimous among all FGDs. Specific goals that were often expressed included passing high school, obtaining a tertiary qualification and attaining employment. These goals appeared to promote wellbeing by engendering a strong sense of purpose and played an important part in making them feel socially valued as illustrated below:

*“...you see when you’re educated, they even respect you at home... back home if you’re uneducated they’ll say things like “what does she know, she’s uneducated”. So, if you are educated, even the community respects you” [FGD, 15-19-year-old females, HIV-positive]*

Finding meaning in negative life experiences also brought a sense of purpose in life. When we asked a doctor what mattered most to young people’s wellbeing in this setting, she indicated that finding meaning and knowing they could have a future was important to them:

*“...believing that they can have a family, they can get a job, and that they will be well..that HIV is not going to lead to AIDS and it’s not going to lead to an early death” [HIV clinical specialist]*

For Zanele, defining herself as a mother and granddaughter exemplified that fulfilling social roles instilled a sense of purpose.

*“I always say I live for him (referring to her child) and my grandmother. I come last, they are my priority, I study for them.”* [Zanele, 23-year-old female, HIV-negative]

Improving one’s living standards, often depicted as displays of wealth and material possession in drawings (Figure 3) and being able to provide for one’s family and “give back to community” dominated accounts of a good life among males living with and without HIV. When probed further it revealed that attaining a high social status and fulfilling the role of a “provider” was how young males felt they could contribute to society, and thus could live a good life.



**Figure 3: FGD (20-24-year-old males, HIV-negative).** This drawing depicts the importance of social status for young people’s wellbeing, particularly for males.

Religious and spiritual beliefs often helped bring meaning to tragic life events. For instance, Busi, a 20-year-old HIV-positive female, explained that her faith taught her that *“everything that happens on earth has a reason”*.

#### **4.2.3 Self-acceptance**

Many of the HCWs highlighted the lack of psycho-social support services to facilitate HIV disclosure among YPLHIV. In addition, HCWs emphasised the lack of services to support young people in general with managing difficult life events such as death of a family member, an unplanned pregnancy or experiences of gender-based violence. Hence, this challenged young people’s ability to accept their situation and build positive identities, and likely challenged their ability to maintain wellbeing, as explained by one of the HCWs’:

*“A lot have siblings that are negative...they feel like obviously they’re discriminated against.. why am I positive?”*

Expressions of self-acceptance in this setting embodied a sense of relatedness as it was dependent on acceptance from others within close relationships. Asked about whether he has accepted his HIV-positive status, Bongani responded:

*“...her (referring to his girlfriend) accepting me really changed the way I looked at myself...also the family members that knew about my status, telling me that it is okay... they are supporting me in every way.”* [Bongani, 18-year-old male, HIV-positive]

However, in Bongani’s life timeline, he depicted himself as the tree that is dying *“cos of the virus”* and referred to himself and his deceased mum as the *“black sheep of the family”*. This suggested that even in the context of acceptance by some family members and a partner, internally he experienced challenges with coming to terms with his HIV-positive identity and felt socially excluded.

Expressions of self-acceptance were often inter-twined with elements of internalised stigma.

*"I have accepted that I am a human being who has a disease like this, I am HIV positive. Yeah, and I must live with it (referring to HIV) for the rest of my life. Until there is a cure for it."* [Sinothando, 15-year-old female, HIV-positive]

#### **4.2.4 Environmental mastery**

When we asked young people living with and without HIV how they managed some of their complex lived experiences (e.g. disclosure, death of a parent, bullying) most responses suggested that they employed negative coping strategies such as suppressing thoughts via sleep, which corroborated HCWs accounts. This may have negatively affected their wellbeing. However, a few young people, specifically YPLHIV, practiced more positive forms of coping such as "writing down" one's thoughts.

It appeared that positive relations facilitated positive coping. For instance, when Sne felt overwhelmed with anxiety she and her grandmother would draw on their religious beliefs and practices.

*"then Gogo (referring to her grandmother) says "never, never, never"... you let's say, I have a problem, I'm writing exams and I'm lost... Gogo just says "no, no, no, the devil is playing games", she pulls out her bible.. and really we would read it... After that I feel like something has been lifted from me... even when I start with my exams.... I know I am that person who is always sick you know... so if I keep praying every day it's like even sickness goes away, it's that thing.... It's like there's a breeze, I feel fresh."* [Sne, 19-year-old female, HIV-positive].

Several YPLHIV exhibited a strong sense of perceived control in their efforts to prevent inadvertent HIV disclosure to peers mainly via avoiding social interaction, as illustrated below:

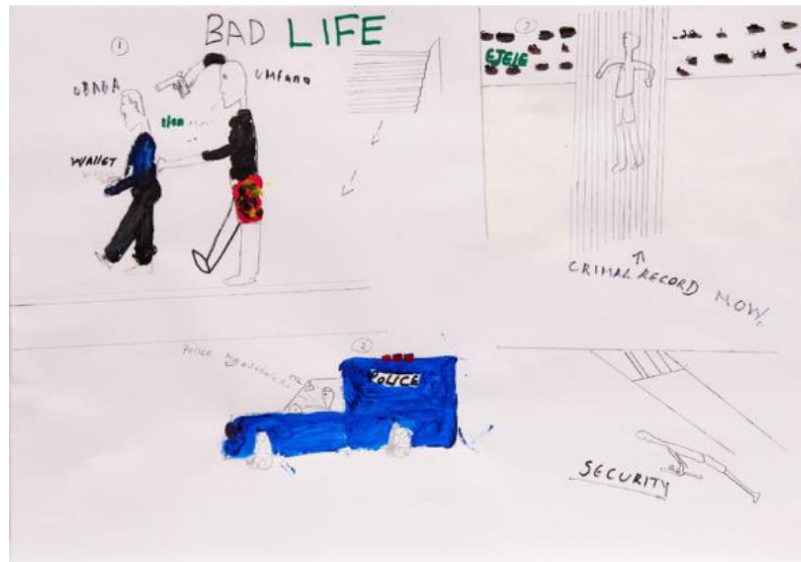
“..so I have to go to the... to the appointment (referring to his HIV clinic appointment)... ..so when I come back they like “where were you?” and I’m like okay ...each and every month I have to think of a lie... so instead I stick to being by myself.” [Bongani, 18-year-old male, HIV-positive]

There was a great awareness of surrounding opportunities (e.g. government bursaries, grants and tenders). Several young people exercised agency in pursuit of these opportunities.

*“In 2016, second semester I didn’t go to school because I didn’t get NSFAS (government bursary scheme), there was not enough money at home. I didn’t want to put pressure on them, I stayed. 2017, I went back until this year, I finally got NSFAS this year.”* [Zanele, 23-year-old female, HIV-]

Common in all drawings of a bad life were scenes that depicted crime and violence in their communities (Figure 4). Discussions linked to these drawings revealed young people’s fears around their lack of perceived control. For example, the violent house robberies that Siphso experienced as a child was a key sad life event for him. This negative experience may have reduced his wellbeing by decreasing his sense of control over his environment and social trust as suggested below:

*“Eh you don’t cope well if you see a person pointing a gun at you that happened in (area X). You get there and you end up suffering abuse under hands of strangers because they rob you and you cannot identify them and then they come back to you and ask for your help because you don’t know who robbed you honestly..... it is hard to cope under criminal conditions....”* [Siphso, 16-year-old male, HIV-negative]



**Figure 4: FGD 20-24-year-old males, HIV-positive. This drawing highlights the high levels of crime and violence that young people in this community are exposed to. Crime and violence framed young people’s understanding of a bad life**

These drawings also illustrate young people’s self-perceived risk of being a victim of crime and violence in their neighbourhoods. This may have limited their ability to form trusting relationships with others in their community, and thereby reduced wellbeing.

#### **4.2.5 Autonomy**

Attainment of financial independence was salient in accounts of a good life, particularly FGDs with young women living with and without HIV. Financial independence appeared to enhance wellbeing via building one’s sense of autonomy and ability to contribute to their homes and communities. Several young women exhibited a strong sense of self-determination and self-efficacy in pursuit of financial independence.

*“so, study agriculture... Then I can start having farms..you see, have my own business. I really want to be independent” [Sne, 19-year-old female, HIV-positive]*

Resistance to community norms and practices (e.g. dress code for women in religious institutions) also embodied a sense of autonomy for young women:

*“yes, I come from a strict family... yes, my grandparents attend a church... at home a girl doesn't wear pants they don't like it... yes, I do wear jeans but then they... they don't like.”*  
[Thandi, 18-year-old female, HIV-positive]

For Zanele and Hlengiwe, their accounts of falling pregnant echoed a sense of loss of independence and rejection for failing to live up to their caregivers' expectations. Thus, their pursuit of academic success may have been linked to the need to regain a sense of autonomy and feel socially valued, and ultimately enhance their wellbeing.

Peer pressure was often described in the context of a bad life, particular for young men living with or without HIV. Whilst conforming to peer norms may have increased their sense of integration within peer networks, it may have negatively affected wellbeing by reducing their autonomy.

*“one of the major problems with the youth is peer pressure others end up smoking especially at school not because you want to but because your friends are smoking.”* [FGD, 15-19-year-old males, HIV-negative]

#### **4.2.6 Personal growth**

When we asked young people what advice they would give to their younger selves', accounts encompassed a sense of enhanced self-knowledge and continued development which may have promoted wellbeing. Bongani's life journey reflected a continuous process of change and self-awareness. His deep reflection of his self and behaviour in relation to his peer networks over time was pronounced in his interview:

*“now I have life goals and relationship goals... and then this is me facing life, and then.... is that all you got to pull me down, like it isn't over yet .... don't compare yourselves to other*



*people.... You don't want to be a jack of all trades .... Because there was a time where I wanted to experiment every single thing... know your strength and weaknesses... because there is stuff that you think you might handle.... But cannot handle” [Bongani, 18-year-old male, HIV-positive]*

Personal growth was particularly pronounced among young mothers' accounts as they reflected on their life journey pre- and post-pregnancy. For example, Zanele's acceptance of her pregnancy and new role as a mother gave her the motivation to improve her situation and move forward with life:

*“I grew under poverty. I lost my two parents when I was young. Ah... and I fell pregnant at a young age, I wasn't, I wasn't mature enough to be a mother.....when I first held my baby with my own hands welcoming him on earth. Yeah, I realised that it was painful, but he is here I must love him, protect him, accept him. And I am also moving on with my life, I am studying, and I can see a bright future ahead of me. I am not like others; others don't get the opportunity to continue with school. I have to be grateful and see it as a golden ticket that I am moving on with my life.” [Zanele, 23-year-old female, HIV-negative]*

## **5. Discussion**

In health economics, there is a growing movement towards the application of wellbeing measures for policy evaluations (Dolan and Peasgood, 2008, Clark et al., 2019). However, it is recommended that measures should be grounded in wellbeing models that are aligned to how wellbeing is locally understood to help improve the effectiveness of wellbeing policies and programmes. Our study aimed to explore how young people's wellbeing was perceived and experienced in South Africa and whether or not these aligned to dimensions of Ryff's PWB model. Whilst accounts embodied elements within Ryff's PWB model, it appeared that these were more rooted in social integration and social contribution, dimensions that extend beyond the Ryff's PWB model. Thus, we recommend the use of an alternate model that better captures these key constructs.

When we asked young people to describe a good life or happy life events, most accounts encompassed eudaimonic components (e.g. social support, belonging, acceptance, contributing to society). Whilst Ryff's PWB model was useful for capturing elements that shape wellbeing at an intra-personal level (e.g. self-worth, self-acceptance, autonomy, personal growth), it did not fully capture inter-personal factors at various socio-ecological levels which affected young people's wellbeing in this setting (e.g. family belonging, community-level HIV-related stigma, acceptance from family and peers, neighbourhood crime and violence). Our findings revealed that it was the broader socio-cultural context that appeared to be critical for shaping young people's wellbeing, in line with other studies on child and youth wellbeing in developing and developed settings (Dunlop-Bennett et al., 2019, Liamputtong and Kurban, 2018, Moosad, 2019, Hong and Goh, 2019), specifically African studies on adolescent wellbeing (Van Schalkwyk and Wissing, 2010, Wissing et al., 2014, Camfield and Tafere, 2009, Meyer et al., 2019)

We found that young people's wellbeing in this setting was described in terms of connections and role-relationships with others, in line with a relational construal of self as identified in previous African psychology studies (Brewer and Gardner, 1996, Adams and Dzokoto, 2003). Hence, dimensions within Ryff's PWB model such as purpose, mastery and self-acceptance were mainly described in the context of social networks. However, as shown in our data, these networks fulfilled more than just attainment of dimensions described in Ryff's PWB model. Their key role was to facilitate belonging (Goodman et al., 2018), a dimension that is overlooked in Ryff's PWB model. For example, shared beliefs and values within family or church networks promoted a sense of shared identity and belonging for young people and thus promoted socially connectedness and engagement (Lim and Putnam, 2010, Saeri et al., 2018). In Keyes's model of social wellbeing, a key dimension is social integration, which denotes the degree to which an individual feels a sense of belongingness in their social networks (Keyes, 1998). This seems to suggest that perhaps this model of social wellbeing may be more appropriate than Ryff's PWB model for understanding young people's wellbeing in this context.

In mainstream economics, social networks are mainly considered beneficial for wellbeing (Helliwell and Putnam, 2004). However, in our study, experiences of negative relationality featured prominently in the lives of young people. Similar to a previous study in eSwatini (formerly Swaziland) (Shabalala et al., 2016), we found that the negative relationships between fathers and sons often led to a lack of belongingness among young men. Unique to the lived reality for YPLHIV, was the negative impact that HIV-related stigma had on close relationships, which often resulted in social exclusion and reduced self-acceptance, in agreement with findings from other studies (Goudge et al., 2009, Hutton et al., 2013b). Furthermore, fear and experiences of crime and abuse featured prominently in the lives of young people living with and without HIV given the high prevalence of crime and violence in this study setting (Stats SA, 2018). These experiences likely reduced wellbeing, as shown in an earlier South African study (Powdthavee, 2005), possibly via reducing perceived environmental control and social trust (Martínez et al., 2019) or by impeding group membership and social engagement, as suggested in a recent South African youth study (De Wet et al., 2018). Whilst Ryff's PWB model does focus on environmental mastery it fails to capture the link between negative relationality on social integration. However, in Keyes's social wellbeing model, rejection experienced within social networks and lack of social trust in relation to social integration is considered (Keyes, 1998). This further highlights the potential relevance of using the social wellbeing model as a key lens for understanding wellbeing in this context.

In our study we found that conceptualisations of wellbeing were aligned to dimensions of Ryff's model such as positive relations, purposeful living and personal growth. However, these were intertwined with the need to uphold socio-cultural norms and values such as respect and caring for others as well as giving back to the family and community. This converges with the concept of Ubuntu, a social philosophy that encapsulates certain values that are embedded within African culture such as "building and maintaining positive relationships, showing empathy" that extends beyond the family to the community and spiritual (Nussbaum, 2003, Van Der Walt, 2010). Furthermore, the ability to uphold these norms were underpinned by a strong desire to feel valued by society. For instance, young men often provided detailed plans for entry into the labour market as they perceived this would

provide the necessary finances to improve household living standards, often depicted as conspicuous displays of wealth. Conspicuous consumption is linked to social status which is a positive predictor of wellbeing (Winkelmann, 2012). Thus, it is likely that unemployed males in our sample may have experienced lowered wellbeing due to their reduced sense of self-esteem which rested on being seen as the financial provider and contributing to their communities (Theodossiou, 1998, Latif, 2010). Ryff's PWB model does not explicitly consider the fulfilment of socio-cultural norms and its importance for integration and feeling socially valued. Conforming to social norms for social integration is explored in the social wellbeing model. Moreover, another key dimension within this model is social contribution, defined by Keyes (1998) as the "evaluation of one's sense of social value" and a "belief that one is a vital member of society". This again suggests that the social wellbeing model may be more appropriate for capturing the socio-cultural reality in relation to young people's wellbeing.

Our findings suggest the following lessons for policy and practice in this setting. First, findings indicate that Keyes's social wellbeing model as opposed to Ryff's PWB model may be more relevant for understanding the pathways to wellbeing among young people. Second, our findings suggest that application of a battery of wellbeing scales grounded in Ryff's PWB and Keyes's social wellbeing model such as Ryff's PWB scale (Ryff, 2014), the Mental Health Continuum-Short Form (Keyes, 2009) and the Warwick-Edinburgh Mental Wellbeing Scale (Tennant et al., 2007) may be appropriate for policy evaluations. Together, these scales encompass a range of dimensions that frame young people's wellbeing in this setting (i.e. social integration, social contribution, purpose in life, perceived control, belonging, acceptance, social status) In addition, these scales have exhibited favourable psychometric properties among young people in developed (Clarke et al., 2011b, Van Dierendonck, 2004, Luijten et al., 2019) and developing (Guo et al., 2015, Gao and Mclellan, 2018) countries. Hence, they could be used in routine surveys to examine progress towards SDG Goal 3. Third, it highlights that programmes focused on building social integration at various socio-ecological levels (e.g. family functioning programmes, HIV support groups, anti-stigma programmes, crime and violence prevention programmes) could be effective in promoting wellbeing among young people. Lastly, it suggests that policies focused on building human capital among young people such as increasing educational attainment and employment,

could in turn promote wellbeing via enhancing young people's sense of social contribution. Future wellbeing programmes could draw on Keyes's social wellbeing model to inform monitoring and evaluation measures and frameworks.

The main strengths of our study include the use of a theoretically informed wellbeing model together with the use of multiple data collections. This may have helped improve the credibility of our data. The FGDs complemented with the Draw-and-Tell approach provided detailed data related to the socio-economic context of young people. It allowed the research team to better understand the social worlds of young people in this setting, and it affirmed young people's agency as they decided what images to draw. The artwork in the FGD helped stimulate and centre the discussions. The Life-course Timeline approach in the IDIs provided in-depth temporal data on key childhood and adolescent lived experiences. Moreover, it stimulated dialogue, helped framed the discussion. It also facilitated rapport as young people were appreciative that we wanted to understand their life story from their lens. When personal experiences regarding child abuse, rape, substance abuse or mental health issues were expressed, the interviewer ensured participants were referred. Moreover, accounts of neglect, abuse or rape among minors were reported to the appropriate local authorities, in line with legal and ethical guidelines.

Our findings are subject to the following limitations. We used the Ryff's PWB model to structure our analysis. This model was originally developed using data from American adults and thus may not be valid for use among younger populations in developing settings. Our study did not include perspectives from caregivers and close family members, a group that played a critical a role in shaping dimensions of young people's wellbeing. The artwork activity in the FGDs made some young people feel anxious as they likened it to a school activity that would be assessed. There was a strong focus on morality and behaviour in the drawings and discussions, which could be attributed to the main question posed on what makes a good or bad life. Drawing of one's life timeline and indicating key periods and events did pose a challenge to most participants, as they may have not been used to this mode of story-telling or it may have triggered memories that may have been suppressed. The 20-24-

year-olds preferred to talk as opposed to using drawing-based participatory approaches. Social desirability bias may have likely influenced our results. For example, reflecting on the responses from YPLHIV, we found that most YPLHIV described how they personally excluded themselves from certain networks. Self-exclusion may have been the narrative they shared with the interviewer to make it less painful for themselves and to exhibit a sense of agency. In addition, most young people portrayed themselves as goal driven and hopeful for the future, and groups acknowledged the importance of religious practices and respect for elders. Again, it may have been their way of showing that they conform to the socio-cultural identity of a “good” young person. Furthermore, KIIs highlighted the treatment and acceptance issues that YPLHIV experienced. Yet none of the YPLHIV mentioned any major difficulty with medication adherence and self-acceptance, perhaps to fit in with current socio-cultural messaging around living positively. Voices from young fathers, immigrants, LGBTQI populations, sex workers and young people not engaged with health services were missing in our data.

## **6. Conclusion**

Our findings indicate that wellbeing for young people living with and without HIV is primarily cultivated within social networks. Whilst perceptions and experiences of young people’s wellbeing encompassed intra-personal elements included in Ryff’s PWB model (i.e. self-acceptance, self-worth, autonomy), these were more strongly rooted in social integration and social contribution, dimensions that went beyond Ryff’s PWB model. Overall, it indicates that investments in programmes and policies that facilitate social integration and contribution (e.g. education bursaries, employment programmes and social support groups) could have considerable wellbeing gains among young people. Further evaluations of alternate wellbeing models that adequately capture relationality across socio-ecological levels among young people are needed.

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## **Chapter Conclusion**

Findings from this paper highlighted the central role that close relationships play in shaping young people's wellbeing. Social integration and social contribution emerged as key dimensions of young people's wellbeing in this study context. These dimensions were not adequately captured by Ryff's PWB model. My findings support the use of a social wellbeing model for understanding young people's wellbeing in this setting.

Key themes that emerged from this study (i.e. belongingness, support, HIV-related stigma, acceptance, need to uphold gender norms) converged with themes identified in my mixed method review (Paper 1). The pursuit of educational goals in order to contribute to society may explain the positive correlation identified between educational attainment and youth wellbeing in Paper 2. Furthermore, the accounts of HIV-related stigma, crime and violence in South and its negative affect on social integration and contribution may explain the negative association identified between depressive symptoms, trust and life satisfaction. In terms of policy implications, this Chapter suggests that policies targeting social integration and contribution by improving educational attainment, employment outcomes and social support could be critical in promoting wellbeing among young people.

## **Chapter 8: Discussion**

I set out to investigate appropriate wellbeing measures and the health determinants of wellbeing among young people in SSA.

In this Chapter, I provide a critical assessment of the main findings of the thesis, note the limitations and strengths, and discuss the implications for research and policy, particularly for policy evaluations.

### **8.1 Key findings**

This section summarises key results arising from the thesis, presented according to the research questions outlined in Chapter 2.

#### **Question 1: What are the dimensions that constitute wellbeing among young people living with and without HIV in SSA?**

In Chapter 5 to 7 I examined the correlates, lived experiences and conceptualisations of wellbeing among this population using mixed method review and qualitative and quantitative methodology. Here, I triangulated these data to elucidate the key dimensions of wellbeing that emanated.

I found that the construct of wellbeing is multi-dimensional. Moreover, it is relational in that inter-relationships are at the core of young people's perceptions and experiences of wellbeing, in line with previous studies that have highlighted the importance of relatedness for wellbeing in LMICs (Delle Fave et al., 2016, White and Jha, 2018, Wissing et al., 2019, Ferrari, 2016). Across all three studies, dimensions identified showed stronger alignment to the PWB construct as opposed to the SWB construct, which corroborates findings in this area (Delle Fave et al., 2011, Ferrari, 2019). My findings suggest that wellbeing was cultivated within various socio-

ecological spaces. More importantly, attainment of wellbeing at an inter-personal level (i.e. family, community, public policies) was a pre-requisite for deriving wellbeing at an intra-personal level (individual).

Below, I describe the two key dimensions of PWB, social integration and social contribution, and its sub-dimensions (i.e. positive relations, self-acceptance, perceived control, belonging, trust, purpose in life) drawing on elements within Wissing's relationality meaning model (Wissing, 2014), Keyes's model of social wellbeing (Keyes, 1998), Ryff's PWB model (Ryff and Keyes, 1995), and the broader literature on adolescent development.

I found that it was through integrating the other with oneself that young people derived meaning in and to life, which in turn promoted acceptance and belonging and ultimately wellbeing (Wissing, 2014, Goodman et al., 2018). Through my qualitative data I found that acceptance was mainly obtained via social support from caregivers and close family members. For 15-19-year-olds, the financial and emotional support received from caregivers was indispensable to their wellbeing. In my mixed method review, I identified social support as a key positive correlate of wellbeing among YPLHIV. My qualitative data showed YPLHIV valued support specifically with regards to medical adherence, disclosure, self-acceptance and coping. However, I found that acceptance for young people was not only about receiving support but also being in position to reciprocate affection and love within inter-personal relationships with caregivers, peers or intimate partners, in line with Ryff's PWB model (Ryff and Keyes, 1995). This also corroborates the broader adolescent psychology literature, which suggests that these close relationships are important for refining their identity and developing inter-personal skills (Steinberg and Morris, 2001, Christie and Viner, 2005). Furthermore, previous studies have shown that acceptance particularly by peer groups is essential for positive social functioning during adolescence through to adulthood (Mcelhaney et al., 2008).

However, my thesis showed how social integration was challenged in multiple ways. My review and qualitative data showed that for young men, it was the acceptance from one's biological father that was a necessary step for integration into the wider paternal family. And thus, the breakdown of the relationship between a father and son reduced their sense of acceptance and belonging and consequently wellbeing. The quantitative synthesis in my review showed that HIV-related stigma was one of the strongest negative correlates of wellbeing. I explored this further in my qualitative IDIs with YPLHIV in South Africa. I found that HIV-related stigma prevented young people from fully integrating into their social networks. It induced severe forms of social rejection and ultimately lowered self-worth (Goffman, 1963). These findings are consistent with previous literature on the negative association between HIV-related stigma and wellbeing (Hutton et al., 2013a, Greeff et al., 2010). More importantly, these results informed the hypothesised association between poor health and wellbeing in my econometrics study. As expected, I found poor health was a negative correlate of wellbeing. Whilst my datasets did not include variables related to social exclusion, based on my review and qualitative findings, it is likely that experiences of social exclusion, as a result of being different to others in terms mental and physical health, contributed to lowered wellbeing among youth in South Africa.

Neighbourhood crime and violence was ubiquitous in young people's lived reality in South Africa, and this often reduced their integration into their wider community and affected their social functioning and sense of perceived control (Keyes, 1998, Alfaro-Beracoechea et al., 2018, De Wet et al., 2018). This could likely explain the low levels of community trust and its negative correlation with life satisfaction among young people in our econometric study.

Social contribution was another key wellbeing dimension that emerged from my data, in accordance with Keyes's social wellbeing model (Keyes, 1998). Through my review and FGDs I found that educational and job success was highly desired among urban and peri-urban young people, predominantly from eastern and southern Africa. Wellbeing studies from high-income countries suggest that this finding is not unique to my



research setting (Proctor et al., 2009). In these more individualistic societies, these goals are important for intrinsic goal attainment (i.e. realisation of one's own potential) (Deci and Ryan, 2000, Proctor et al., 2009). However, some cultures in my study setting and region are known to have a strong collectivist orientation (Eaton and Louw, 2000, Adams and Dzokoto, 2003). Thus, being able to fulfil social roles that are likely rooted in socio-cultural norms. In addition, role-relationships were inextricably could be linked to extrinsic goal attainment (i.e. social status and being seen as a valuable member of society). For young men, attaining educational and career goals increased their likelihood of becoming a financial provider, a socially valued role for males in this setting. For young women who were felt socially marginalised for failure to uphold gender norms for women, participating in roles that were socially valued (e.g. tertiary studies) helped them regain their sense of social contribution. Hence, in this setting achieving a sense of social contribution could help bolster self-esteem and overall wellbeing. Further evidence in support of social contribution as a dimension of wellbeing was given by the strong positive correlation between educational attainment and wellbeing in my review and econometric study. Extrinsic goal attainment in the context of challenging socio-economic conditions has been shown to enhance wellbeing to a lesser extent as evidenced in a study among Zambian adolescent males (Hofer and Chasiotis, 2003). This may explain why accounts among unemployed males and their struggles with finding employment were suggestive of lowered wellbeing in my review and qualitative study.

Overall, these findings highlight the importance of using a multi-dimensional relational model to adequately understand and capture wellbeing among young people in this setting.

## **Question 2: What are the most appropriate measures for capturing wellbeing among young people at a population level?**

I have shown that wellbeing is a multi-dimensional relational concept with strong alignment to the PWB construct of wellbeing. I argue for the application of a battery of PWB scales in policy evaluations given the diversity in experiences of wellbeing, particularly scales that focus on multiple life domains that are of importance to young people in this setting.

Below I highlight three possible scales that could be used in public health policy evaluations for capturing wellbeing among young people in this setting. I discuss the strengths and limitations of each scale based on the following criteria for wellbeing scale selection for policy evaluations in economics (Stiglitz et al., 2009, Clark et al., 2019, Peasgood, 2008): 1) aligned with local conceptualisation of wellbeing- reflective of people's experiences and what people value; 2) theoretically robust- informed by wellbeing theory; 3) psychometrically robust- good reliability and validity; 4) feasible to implement- time, cost, translations

### **a) Mental Health Continuum Short Form**

The Mental Health Continuum Short Form (MHC-SF) (Keyes, 2009) may be a relevant measure for this setting as this scale has been predominantly informed by Keyes's model of social wellbeing (Keyes, 1998), which appears relevant for understanding wellbeing in my study context as revealed in my qualitative study, and consistency with previous studies (Van Schalkwyk and Wissing, 2010). It is a short 14-item scale, with 3-items examining emotional wellbeing, 6-items examining PWB as per Ryff's PWB model, and 5-items that measure the dimensions of Keyes's social wellbeing model, particularly social integration and social contribution, dimensions that are central young people's wellbeing in this setting. It uses a six-point Likert scale, ranging from never to every day. The scale includes questions that align to specific facets of

wellbeing in this setting, namely belonging, purposeful living, and perceived control. Moreover, the development of the MHC-SF was informed by Keyes's work on adult and adolescent wellbeing in the United States of America (Keyes, 2006).

Overall, this scale is known for its strong psychometric properties (Lamers et al., 2011). Whilst this scale was originally developed for adults, it has shown good internal reliability (Cronbach's  $\alpha = 0.91-0.92$ ), convergent and divergent validity among adolescents in developed (Luijten et al., 2019, Bower, 2017) and developing countries (Guo et al., 2015, Lim, 2014). Of note, this scale has exhibited strong internal reliability (Cronbach's  $\alpha = 0.74$ ) and criterion-related validity among South African adults (Keyes et al., 2008). This scale has been translated to one African language, Setswana, predominantly spoken in South Africa, and authors report no major problems with the translation (Keyes et al., 2008). In terms of cost, it is freely available to use with the developer's acknowledgment. Key limitations of this scale include: 1) it has exhibited considerable floor and ceiling effects among Chinese adolescents (Guo et al., 2015), which may pose some issues when investigating the impact of a policy on population-level wellbeing overtime; 2) it has not been psychometrically evaluated among young people in SSA.

### **b) Ryff's scale of PWB**

This scale is grounded in eudaimonic theory (Ryff, 1989) and examines all six dimensions of Ryff's PWB model (i.e. personal growth, autonomy, positive relations, purpose in life, self-acceptance, environmental mastery) (Ryff and Keyes, 1995), most of which are relevant for young people in this setting as evidenced in our review and qualitative study. Various versions of this scale exist (42-items, 18-items, 3-items) (Ryff, 2014). It uses a six-point Likert scale, ranging from strongly agree to strongly disagree. It can be freely accessed with acknowledgement from the developer.

This scale was originally developed for use among adults (Ryff, 2014). However, this scale has exhibited favourable levels of reliability yet sub-optimal construct validity in

a large study among Dutch students (Van Dierendonck, 2004). A key advantage of this scale is that it has been applied in several major national surveys in high income countries (i.e. Midlife in the United States, National Survey of Families and Households II, the Wisconsin Longitudinal Study, Canadian Study of Health and Ageing) (Springer and Hauser, 2006, Clarke et al., 2001), using various modes (self-administered, telephone, in person). Key limitations of this scale have been noted in the literature. Firstly, studies have reported weak construct validity for this scale and have shown that a high correlation exists between scale dimensions (i.e. personal growth, purpose in life, self-acceptance, environmental mastery), with differences noted between modes of administration (Springer et al., 2006, Kafka and Kozma, 2002). Similar findings were found in a study among Portuguese adolescents (Fernandes et al., 2010). This is of concern as it may challenge the ability to examine the responsiveness of dimensions to multi-sectoral policies targeting specific dimensions. Secondly, psychometric evaluations of Ryff's scales have found sub-optimal reliability and construct validity among youth in LMICs (Kitamura et al., 2004, Gao and Mclellan, 2018), specifically African settings (Henn et al., 2016).

### **c) Warwick-Edinburgh Mental Well-Being Scale**

This 14-item examines the positive aspects of mental wellbeing (Tennant et al., 2007). It includes both hedonic (positive affect) and eudaimonic components of wellbeing such as positive functioning (e.g. self-acceptance, autonomy, competence) and satisfaction with inter-relationships (Tennant et al., 2007). Moreover, there are items within this scale that align with the dimensions that I found to be relevant for capturing wellbeing in this setting (i.e. social contribution, perceived control, autonomy, purpose, positive relations). Responses are based on a five-point Likert scale ranging from none of the time to all of the time. A specific version has been created for young people. This scale is free to use with permission from the developers.

A key advantage of this scale is that it has been specifically evaluated for use in national surveys. This scale has also shown good construct validity and internal reliability (Cronbach's  $\alpha=0.87-0.89$ ) among large community adolescent and young adult samples in the United Kingdom (Clarke et al., 2011a, Tennant et al., 2007, McKay and Andretta, 2017), Australia (Hunter et al., 2015) and Norway (Ringdal et al., 2018). Similarly, this scale has exhibited strong psychometric properties among youth and adults in Pakistan and China (Taggart et al., 2013). It has shown to be strongly correlated with socio-economic status and physical health among adolescents in the United Kingdom (Clarke et al., 2011a). This scale has not demonstrated any major floor or ceiling effects, which suggest it is appropriate for use in population surveys (Tennant et al., 2007, Ringdal et al., 2018). It has been previously applied in a national health survey in England. Maheswaran et al. (2012) have shown that this scale is responsive to a wide range of public mental health interventions. Together, these findings suggest that this scale may be appropriate for measurement of population level wellbeing in policy evaluations. However, psychometric evaluations of this scale among young people in SSA are needed.

Overall, dimensions within all three scales align with the definition of wellbeing in my setting. However, the phrasing of questions in these scales should be expanded such

that they are specific to the lived experiences of young people in this setting, and more importantly, capture the diversity in their experiences by age, gender and HIV status. Furthermore, scale items should specifically focus on individual functioning within key social networks that are pivotal for young people's wellbeing (i.e. family, peers), as suggested by previous exploratory analyses of wellbeing in this context (Ferrari, 2019, Wissing et al., 2014, Van Schalkwyk and Wissing, 2010).

Given the complexity and diversity of young people's reality, my evidence supports the conduct of qualitative studies alongside quantitative surveys seeking to evaluate the wellbeing effects of policies and programmes for this age-group. The qualitative data could be used to validate quantitative findings and gain more nuanced understanding of how wellbeing is facilitated and promoted by programmes and policies targeting wellbeing. My findings also highlight the need to measure individual-level wellbeing alongside other individual-level or community-level factors that facilitate or impede young people's wellbeing in this setting such as socio-demographics (i.e. employment status, educational status, race), living standards (community crime and violence) social capital measures (i.e. inter-personal trust, religion); and psycho-social factors (i.e. stigma, community stigma, family functioning).

### **Question 3: What public health policies and programmes could be considered for promoting wellbeing among young people?**

Based on my empirical findings, I outline key policies and programmes that could potentially enhance wellbeing among young people.

In my econometrics study, I found that poor mental health and physical health were negatively correlated with wellbeing. Drawing on young people's experiences of ill health in my qualitative study and mixed method review, this negative relationship could be explained by the fact that poor health status may have challenged integration into one's network and subsequently lowered perceived control and self-acceptance.

These results suggest that policies and programmes targeted at promoting social integration and positive mental health functioning among youth, including youth at risk for lowered wellbeing (i.e. youth at risk for depression or underweight youth) may be effective in improving population-level youth wellbeing. A socially integrated young person in this setting was characterised as someone with supportive parental and family networks, who is accepted by his or her extended paternal family and peers. Positive parenting and family functioning programmes and school-based programmes that promote supportive peer-relationships could be effective in enhancing youth mental health and wellbeing, as suggested in an earlier review on young people from LMICs (Barry et al., 2013). Similarly, community-based support groups for YPLHIV may be effective in promoting related dimensions of wellbeing in this setting (i.e. self-esteem, self-worth), as shown in a recent study conducted in Zimbabwe (Willis et al., 2019).

The strong positive correlation between ART access and life satisfaction found in econometric study suggests that investing in ART scale-up policies and programmes may be effective in promoting wellbeing among young people in SSA. It is likely that ART scale-up has had direct health and economic benefits for YPLHIV and their families, and consequently on their wellbeing. Moreover, ART scale-up may have had positive health and wellbeing spillover effects on communities and household affected by HIV, resulting in the promotion of wellbeing among the general population of young people.

HIV-related stigma was pronounced in this setting and appeared to negatively shape wellbeing as evidenced in my review and qualitative study. I attributed the negative interaction effects between ART access and personalised trust in my econometrics to the high levels of community HIV stigma coupled with sub-optimal HIV treatment outcomes at a population-level, as evidenced in the broader literature and supported by accounts from HCWs and experts in my qualitative study. HIV-related stigma may have infringed on the ability of PLHIV to adequately integrate into society and fulfil social roles, and resultantly comprised wellbeing. This may have had negative spillover

effects on the wellbeing among youth living in households and communities affected by HIV. However, my model cannot explain this, as the datasets did not contain any information on stigma. Nevertheless, together with results from my review and qualitative, my findings suggest that HIV policies and programmes that focus on enhancing community-level awareness of HIV/AIDS to reduce associated stigma could also be effective in promoting wellbeing, as suggested by a pilot study in urban South Africa among PLHIV (Prinsloo et al., 2016). Reducing HIV-related stigma may help promote a sense of social integration and self-acceptance among YPLHIV and thereby improve their wellbeing. In addition, multi-sectoral health policies and programmes could focus on promoting education attainment via student financial aid schemes and study support programmes as attainment of compulsory education was positively associated with youth wellbeing in my econometrics study. Furthermore, promoting youth employment via entrepreneurship programmes may also be effective in promoting population-level youth wellbeing as employment was also positively correlated with wellbeing in my econometrics study. These could allow them to fulfil social roles such as financially providing for their households and in turn enhance their sense of social contribution and wellbeing.

Overall, given that health, socio-demographic and social-capital factors play a key role in shaping wellbeing among this populations, my findings support the implementation of multi-sectoral health policies and programmes that promote social integration and social contribution at all social-ecological levels.



## **8.2 Limitations**

The strengths and limitations of specific methodological and analytical approaches have been discussed in the preceding Chapters. Therefore, in this section I delineate the overarching limitations of my thesis.

### **i. Generalisability and selection bias**

My thesis aimed to contribute to the understanding of wellbeing among adolescents and young adults in SSA. However, my empirical chapters focus only on young people (older adolescents- 15-19 yrs., and young adults-20-24 yrs.), given the high levels of HIV-related mortality and morbidity in this group. Thus, my findings are not generalisable to young adolescents. Moreover, two of my empirical studies are based on South Africa. Furthermore, the majority of the wellbeing literature in social psychology for LMICs that I refer to in this thesis has been conducted in South Africa. South Africa is among the few upper-middle income countries in this region. Even after 25 years into democracy, deep racial disparities continue to persist, such as income equality and lack of access to services. This may have unique consequences for wellbeing in this setting. Thus, the findings may not be generalisable to other low-income African with a specific geo-political history. However, given that some issues such as HIV-related stigma, gender roles, and coping and aspirations may be common to young people in SSA or other LMICs outside SSA, findings could be relevant to these settings with regards to this. Moreover, some issues pertaining to wellbeing could be specific to HIV/AIDS. However, issues on self-acceptance and lack of social support could be common to young people living with other chronic conditions such as mental illness.

Studies within my mixed method review and qualitative study relied on samples drawn from healthcare facilities. This reduced generalisability of findings to young people who are not engaged with healthcare services, particularly marginalised young people.

In my review and qualitative study, I excluded pregnant women. However, through my qualitative fieldwork I realised that pregnancy was a major and common lived experience for young adult women. Given the high prevalence of pregnancy of women in this setting, excluding this group in itself may have limited generalisability to young women. I was unable to account for pregnancy and parity in my econometric as these data were not consistently captured in the NIDS dataset. However, I did explore experiences of motherhood and fatherhood in my IDIs.

In both my qualitative and econometrics study there was a fair amount of attrition in my samples. Those who dropped out or were lost to follow-up may have been vulnerable youth with unstable living arrangements, poor health and risk-taking behaviour. In addition, these individuals could have been migrant youth labourers with weak social ties. These unobservable characteristics may be associated with reduced wellbeing.

In my econometrics review, I created a panel dataset that included only participants that were aged 15-24 years in wave 1. At the end of the last wave, participants were aged 24-34 years. Whilst my empirical studies were focused on the age group 15-24 years (young people), I drew on these data to inform my model building and interpretation of results. However, this may have introduced bias as wellbeing experiences and understandings may differ as young people transition into adulthood. Marital status and childbearing may play a central role for wellbeing in adulthood which was not accounted for in the current model.

## **ii. Measurement**

I used a PWB framework to guide the analysis and interpretation of the data in this thesis.

None of the studies in my mixed methods review measured or assessed PWB. However, most studies did explore mental health function which is related to PWB dimensions which allowed me to make inferences.

The primary outcome measure in my econometric study was based on a uni-dimensional SWB measure (life satisfaction), as this was the only wellbeing measure collected in the NIDS dataset. As this measure is positively correlated with PWB dimensions, it enabled me to make inferences. However, due to the uni-dimensional nature of this measure, I was unable to examine which dimensions or life domains of wellbeing were affected by poor health status or ART access, and how these changed over time. This made it difficult to provide guidance on specific health policies and programmes that could be targeted to promote wellbeing. As my dataset did not include measures of stigma or resilience,, I was not able to account for these potential mediators of wellbeing when examining the pathway between health or ART access and life satisfaction.

I used BMI as a proxy for physical health in my analysis, which may not account for other aspects of physical health status (e.g. smoking status, alcohol consumption, sleep patterns). Moreover, trust measures used in the NIDS survey related more to self-perceived risk of being a victim of crime or violence, as opposed to measures of trust in social psychology which denote relationality, personality and expectations (Evans and Krueger, 2009, Cook, 2005).

### **iii. Linguistic and cultural issues**

The majority of my FGDs and IDIs in my qualitative study were conducted by a black female South African research assistant. Whilst she is fluent in isiZulu, she was not from the study province. She herself identified several differences in the dialect and regularly sought input on wording from our fieldworker who lived near the study community.

But as both staff members were not from the exact study location, they may have had a different outlook and experience in life. Certain attitudes and experiences shared by the participants may have challenged their own beliefs and values. Hence, staff were encouraged to regularly debrief with a trained counsellor and journal thoughts. Furthermore, both staff members were female interviewing young male participants and thus may have restrained their responses around certain topics in line with gender norms. Moreover, the large age difference between my fieldworker and participants may have also contributed to the potential social desirability bias present in my data such as the emphasis on upholding cultural norms such as respect for elders.

I initially sat in on the first few FGDs and IDIs with my staff. However, I together with my staff noticed that my presence in the room often prevented young people from freely expressing themselves. I am a female Indian South African who was raised in this study province and have some exposure to isiZulu culture. However, my privilege as a result of my race, age and role on the study may have created a power imbalance in the interview room and thus may have stifled responses.

As most participants felt more comfortable speaking in isiZulu, I was unable to converse with many as I do not speak isiZulu. Thus, I relied on my interview notes with staff and English transcripts. Transcribers who were not from the study province, experienced challenges in translating what was conveyed isiZulu to English. I ensured that I continuously discussed the data and interpretation of the data with study staff, to try and ensure I countered the linguistic disadvantage that I had.

#### **iv. Time and resource constraints**

I experienced delays in obtaining access to national-level HIV datasets. These delays prevented me from exploring more advanced econometric causal methods and study designs.

The qualitative study in itself was resource heavy. Recruiting HIV-negative young people within healthcare facilities for my qualitative study proved to be time-

consuming and thus fewer HIV-negative FGDs and IDIs were conducted, although our data seem to suggest that saturation was reached. I experienced a few incidents on the study that required reporting to ethics and legal bodies, together with participant referrals and debriefing of staff. However, these incidents in itself enhanced my understanding of socio-cultural context and lived realities of young people. The fieldworker needed to dedicate after-hours and weekends to complete consent and assent procedures with minors and caregivers and contact participants to confirm interview attendance. The high prevalence of crime in this setting meant we had to put in place extra precautions to protect the safety of staff and participants. Strikes at the study clinics reduced the data collection window for 20-24-year-olds. In addition, I experienced a high turnover of staff who conducted the transcription and translations which placed delays in the coding process.

#### **v. Qualitative methodology**

A major limitation in my qualitative study is that the voices from caregivers and family members are missing in my data. These individuals played a key role in shaping young people's wellbeing and thus understanding their perspectives may have brought in additional insights.

I learnt a lot from my use of participatory approaches. For example, the Draw and Tell technique placed young people in a very unfamiliar territory as most were not use to this mode of expression and communication. This induced slight stress and anxiety among participants as they strived for perfection in drawings and saw this activity as a competition in which they had to excel in. This suggested that young people may have actively sort to portray themselves based on what was socially desired in order not to feel excluded. The Life Timelines were also difficult to operationalise. Whilst clear instructions were provided on the artwork, most young people struggled with depicting their life timelines on paper as this method may have triggered painful childhood memories. Hence, most participants, particularly 20-24-year-olds, preferred

just talking. Similar experiences with the use of these methods have been documented in other studies (Adriansen, 2012, Ansell et al., 2012, Crivello et al., 2008).

## **8.3 Strengths**

### **a. Theoretical rigour**

For this thesis I adopted a wellbeing perspective developed in the field of social psychology. This perspective is underpinned by rich philosophy and theory, including robust empirical studies. The wellbeing models (i.e. the relationality meaning model, Ryff's PWB model, Keyes's model of social wellbeing), used to structure and guide interpretation of my data, are also theoretically robust. Furthermore, these models informed my data collection and analytical approach.

### **b. Methodological rigour**

My overarching thesis design was a mixed methods design. I used a flexible design approach, drawing elements from the exploratory and explanatory mixed methods design, that mirrored the sequence of my data collection and analysis approach. I used the qualitative data to explain and validate my quantitative findings. In addition, the quantitative data helped confirm my qualitative findings. In addition, I drew on wellbeing research from an array of fields (i.e. social psychology, economics and international development) to explain and support my findings.

I used a mixed method review approach, and specifically used the qualitative data to understand the socio-cultural context, explain patterns in the quantitative data as well as identify aspects overlooked in the quantitative data.

For my econometric study, I used a large panel of young people, that spanned over 10 years. My modelling approach accounted for the relational context as identified in my review and qualitative study, and I included known covariates of wellbeing in the models. I use two robust and widely applied measures of depressive symptomatology (CES-D-10) and physical health (BMI).

For my qualitative study, I triangulated data collected via multiple methods. In addition, I was able to explore patterns in-depth by age, sex and HIV status as I purposively sampled young people based on these criteria and stratified my analysis accordingly.

## **8.4 Contributions**

My thesis makes key contributions to the field of health economics and wellbeing literature.

### **a. Health economics**

Following the release of the Stiglitz report, leading economists have highlighted the need for more academic research and public debate on wellbeing measures for policy evaluations. Whilst most of the economic literature has proposed unidimensional SWB measures, I explore the use of multi-dimensional PWB measures. Importantly, most of the literature in this area has mainly evaluated health policies on adult wellbeing in the global north. Leading scholars in this field have called for participatory approaches and an assessment of peoples lived reality to inform measures. I used mixed methods to inform measures for youth in SSA, and I considered a key health population, YPLHIV. Furthermore, I specifically conducted an evaluation of one of the most heavily financed public health policies and applied a multi-level modelling approach to examine its relationship with youth wellbeing.

### **b. Wellbeing literature**

I contribute to the emerging literature on the conceptualisation of wellbeing among adolescents and young adults in LMICs. I specifically add to the wellbeing literature on marginalised young people, focusing on YPLHIV. More importantly, I make contributions to the critique of Ryff's PWB model for understanding wellbeing among young people in SSA.



## 8.5 Future research agenda

Below I highlight how findings from thesis could be taken forward in field of public health, particularly in health economics.

Psychometric evaluations of the proposed PWB scales across various countries in SSA are needed prior to application in population surveys. Evaluations should consider cross-cultural validity and incorporate qualitative studies to further inform phrasing of scale items.

Further qualitative research, incorporating audio diaries (Mupambireyi and Bernays, 2019) could provide a more sensitive and detailed approach to learning about young people's lived reality. This information could improve the responsiveness of wellbeing scales.

Population surveys and evaluations could use a battery of PWB scales that have shown good reliability and validity as shown in this thesis. Key socio-demographic, social capital and psycho-social correlates should be measured alongside wellbeing. Panel designs, natural or quasi-experiments and instrumental variables should be used in these evaluations to adequately account for reverse causality and endogeneity. Furthermore, qualitative studies should be conducted alongside these evaluations to validate and explain patterns.

Future evaluations seeking to identify potential policies to promote wellbeing should consider the evaluation of multi-sectoral health policies that specifically promote mental health, social integration and social contribution.

Development of utility weights for multi-dimensional PWB scales among youth in SSA could also aid in the application of the scales for economic evaluations. This multi-dimensional outcome measure may be appropriate for the assessment of multi-sectoral and complex interventions.

## **8.6 Conclusion**

Improving the wellbeing of adolescents and young adults is important for sustainable development in SSA. However, there is lack of evidence on appropriate measures of wellbeing and policies to promote wellbeing among this population. In my thesis, I used a mixed methods design to understand the correlates and conceptualisation of wellbeing, and the relationship of HIV treatment access policies on wellbeing among young people living with and without HIV. I found that wellbeing among young people in this setting is a multi-dimensional relational concept with social integration and social contribution at the core of its meaning. In addition, I found that health is strongly correlated with wellbeing and that HIV treatment access may be effective in promoting young people's wellbeing. Further studies exploring the causal impact of health and, preferably, multi-sectoral HIV policies on adolescents and young adults' wellbeing using multi-dimensional measures are warranted.

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# **APPENDICES**

## **Appendix 1- Ethics approval letter (SAMRC Ethics Committee)**

- i. Paper 1 (Mixed method review) & Paper 3 (Qualitative study)**

11 November 2017

Ms Darshini Govindasamy  
Health Systems Research Unit  
SAMRC Cape Town

Dear Ms Govindasamy

**Protocol ID:** EC037-11/2016  
**Protocol title:** The health-related quality of life and wellbeing among HIV-positive versus HIV-negative adolescents (15-19 years) in KwaZulu-Natal, South Africa: a health economic perspective, version 6, November 2017  
**Meeting date:** 31 October 2017

Thank you for your application to the Ethics Committee, which was discussed at the 28 November 2016 meeting, and your responses dated 7 March, 13 April, 30 September and 3 November 2017. I am pleased to inform you that ethics approval is now granted for the study.

***Please note that the approval is valid for 1 year, i.e. from 31 October 2017 to 30 October 2018. Any changes to the research protocol must be submitted as an amendment. Any adverse events must be reported within 48 hours. Any protocol deviations have to be reported.***

Wishing you well with your research.

Yours sincerely



**MS A LABUSCHAGNE**  
**SECRETARIAT: SAMRC ETHICS COMMITTEE**

**Members present at the meeting:** Prof K Moodley (Chairperson), Ms S Behardien, Prof D du Toit, Ms D Gallant, Ms N Morar, Prof N Morojele, Dr L Nair, Dr SAS Olorunju, Prof J Singh, Dr Y Sikweyiya, Dr S Suffla



ii. Paper 2 (Econometric study)



**HUMAN RESEARCH ETHICS  
COMMITTEE**

12 November 2018

Ms Darshini Govindasamy  
Health Systems Research Unit  
SAMRC Cape Town

Dear Ms Govindasamy

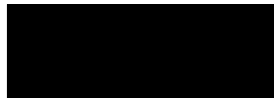
**Protocol ID:** EC017-10/2018  
**Protocol title:** The effects of national ART scale-up on the wellbeing among youth (15-24 years) in South Africa: an econometric analysis  
**Meeting date:** 30 October 2018

Thank you for your application to the Committee, which was discussed at the October 2018 meeting, and your response dated 9 November 2018. I am pleased to inform you that ethics approval is now granted for the study. Please note that you should provide the LSHTM ethics approval before you commence the study.

***Please note that the approval is valid for 1 year, i.e. from 30 October 2018 to 29 October 2019. Any changes to the research protocol must be submitted as an amendment. Any adverse events must be reported within 48 hours. Any protocol deviations have to be reported.***

Wishing you well with your research.

Yours sincerely



**Prof Danie du Toit**  
**Chairperson: SAMRC Human Research Ethics Committee**

**Members present at the meeting:** Prof D du Toit (Chairperson), Adv J Early, Dr H Etheredge, Prof AP Kengne, Ms M Ledwaba, Prof C Lombard, Dr AG Loxton, Mr G Makanda, Prof N Morojele, Prof C Wiysonge



# Appendix 2- Ethics approval letter (LSHTM Ethics Committee)

## i. Paper 1 (Mixed method review) & Paper 3 (Qualitative study)

**London School of Hygiene & Tropical Medicine**  
 Keppel Street, London WC1E 7HT  
 United Kingdom  
 Switchboard: +44 (0)20 7636 8636  
**www.lshtm.ac.uk**



Observational / Interventions Research Ethics Committee

Miss Darshini Govindasamy  
 LSHTM

5 January 2018

Dear Darshini,

**Study Title:** Health-related quality of life and subjective wellbeing among HIV-positive children and adolescents in KwaZulu-Natal, South Africa: a health economic perspective

**LSHTM Ethics Ref:** 13782

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Protocol / Proposal	Appendix 6_Topic guide_Phase 1b_Key Informant Interviews_Experts&HCWs_27102016	27/10/2016	1
Protocol / Proposal	Appendix 9_Demographic Information sheet_Phase 1b_FGDs_Parents_12112016	12/11/2016	1
Investigator CV	PI_CV_Darshini Govindasay_14112016	14/11/2016	1
Investigator CV	Supervisor_CV_Giulia Ferrari_14112016	14/11/2016	1
Investigator CV	Advisor_CV_Cathy Mathews_14112016	14/12/2016	1
Protocol / Proposal	Appendix 7_Topic guide_Phase 1b_FGDs_Parents of 5-11yr olds_06032017_TC approved	06/03/2017	2
Protocol / Proposal	Appendix 8_Topic guide_Phase 1b_IDIs_Adolescents_7-19 yrs_06032017_TC approved	06/03/2017	2
Protocol / Proposal	Appendix 10_Demographic Information sheet_Phase 1b_IDIs_Adolescents 7-19 yrs_06032017_TC approved	06/03/2017	2
Investigator CV	Supervisor_Janet Seeley-2 page CV-for SUTTN	28/03/2017	1
Protocol / Proposal	Scientific proposal_Version 4_UHCASA project_07032017_Submitted to SAMRC REC_29032017	29/03/2017	4
Protocol / Proposal	Appendix 9_Topic guide_FGDs_15-19 yr olds_V1_30092017	30/09/2017	1
Protocol / Proposal	Appendix 12_Screening Form_HIV+ group_V1_30092017	30/09/2017	1

Proposal		
Protocol/ Proposal	Appendix 13_Screening form_HIV negative group_V1_30092017	30/09/2017 1
Information Sheet	Appendix 14_Checklist_Parent and or adolescent comprehension of study_V1_30092017	30/09/2017 1
Information Sheet	Appendix 15_Locator form_V1_30092017	30/09/2017 1
Advertisements	Appendix 16_Letter to parent_V1_30092017	30/09/2017 1
Information Sheet	Appendix 3_Info sheet&consent form_FGDs_Parental permission 15-17 yrs_V2_02112017	02/11/2017 2
Information Sheet	Appendix 4_Information sheet&assent form_FGDs_Adolescents 15- 17yrs_V2_02112017	02/11/2017 2
Information Sheet	Appendix 2_Information sheet&consent form_FGD_Adolescents_18- 19yrs_V2_02112017	02/11/2017 2
Local Approval	Govindasamy-EC037-11-2016 approval 112017	11/11/2017 1
Protocol/ Proposal	Appendix 17_Standard Operating Procedures_Referrals_V1_28112017	28/11/2017 1
Covering Letter	Reply to LSHTM REC_11122017_V3	11/12/2017 3

**After ethical review**

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

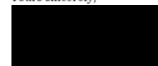
An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: <http://leo.lshtm.ac.uk>

Additional information is available at: [www.lshtm.ac.uk/ethics](http://www.lshtm.ac.uk/ethics)

Yours sincerely,



**Professor John DH Porter**  
Chair

[ethics@lshtm.ac.uk](mailto:ethics@lshtm.ac.uk)  
<http://www.lshtm.ac.uk/ethics/>

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**Improving health worldwide**



## ii. Paper 2 (Econometric study)

### London School of Hygiene & Tropical Medicine

Keppel Street, London WC1E 7HT  
United Kingdom  
Switchboard: +44 (0)20 7636 8636

[www.lshtm.ac.uk](http://www.lshtm.ac.uk)



#### Observational / Interventions Research Ethics Committee

Miss Darshini Govindasamy  
LSHTM

13 December 2018

Dear Darshini

**Study Title:** The effects of national ART scale-up on the wellbeing among youth (15-24 years) in South Africa: an econometric analysis

**LSHTM Ethics Ref:** 16217

Thank you for your application for the above research project which has now been considered by the Observational Committee via Chair's Action.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

#### Approved documents

The final list of documents reviewed and approved is as follows:

Document Type	File Name	Date	Version
Investigator CV	Supervisor_GFERRARI_ResearchCV_Oct2018	31/10/2018	1
Local Approval	Govindasamy-EC017-10-2018 approval 102018_SAMRC	12/11/2018	1
Protocol / Proposal	Scientific proposal_Econometric analysis_14112018_sharing request added	14/11/2018	8
Investigator CV	CV_Darshini Govindasamy_2018	29/11/2018	1

#### After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using the End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: <http://leo.lshtm.ac.uk>.

Further information is available at: [www.lshtm.ac.uk/ethics](http://www.lshtm.ac.uk/ethics).

Yours sincerely,



Professor John DH Porter  
Chair

[ethics@lshtm.ac.uk](mailto:ethics@lshtm.ac.uk)  
<http://www.lshtm.ac.uk/ethics/>

**Appendix 3: Supplementary file for mixed-method review  
(Paper 1)**

**Informing the measurement of wellbeing among young people living  
with HIV in sub-Saharan Africa for policy evaluations in health  
economics: a mixed-methods systematic review**

## S1: Search strategy (Ovid Medline)

1. Quality of Life.mp. or exp "Quality of Life"/
2. health-related quality of life.mp.
3. wellbeing.mp.
4. well-being.mp.
5. (subjective adj1 wellbeing).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
6. (psychological adj1 wellbeing).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
7. (life adj1 satisfaction).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
8. (health adj1 satisfaction).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
9. (well adj1 being).mp.
10. exp Personal Satisfaction/
11. exp Emotions/
12. exp Depression/ec, ep, px [Economics, Epidemiology, Psychology]
13. exp Mental Health/
14. exp Personal Autonomy/
15. exp Mental Competency/
16. exp Resilience, Psychological/
17. exp Social Support/ or exp Social Capital/
18. attitude/ or optimism/ or pessimism/
19. (subjective adj1 well-being).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
20. (psychological adj1 well-being).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
21. mood.mp.
22. Attitude/
23. Sociological factors/
24. Self-concept/
25. (relational adj1 well-being).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
26. (relational adj1 wellbeing).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
27. (lived adj1 experience\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
28. happiness.mp. or HAPPINESS/
29. (psychological adj1 functioning).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
30. or/1-29
31-126: List of sub-Saharan African countries
127. "africa south of the sahara"/ or africa, central/ or africa, eastern/ or africa, southern/ or africa, western/
128. ("africa south of the sahara" or sub-saharan africa or central africa or eastern africa or southern africa or western africa).mp.
129. or/31-128
130. exp HIV/ or HIV.mp. or exp HIV Infections/ or exp HIV-1/
131. AIDS.mp. or Acquired Immunodeficiency Syndrome/
132. 130 or 131
133. 30 and 129 and 132
134. limit 133 to yr="2000 - 2019"

## S2: Search strategy (Ovid PsychINFO)

1. Quality of Life.mp. or exp "Quality of Life"/
2. health-related quality of life.mp.
3. well being.mp. or exp Well Being/
4. wellbeing.mp.
5. exp RELATIONSHIP SATISFACTION/ or exp SATISFACTION/ or exp MARITAL SATISFACTION/ or exp LIFE SATISFACTION/ or exp ROLE SATISFACTION/ or exp JOB SATISFACTION/ or exp NEED SATISFACTION/
6. exp NEGATIVE EMOTIONS/ or exp EMOTIONS/ or exp POSITIVE EMOTIONS/
7. exp PAIN/
8. exp ANXIETY/
9. exp ANGER/
10. exp LONELINESS/
11. mental health.mp.
12. exp STRESS/
13. exp AUTONOMY/
14. exp "Resilience (Psychological)"/
15. exp COMPETENCE/
16. exp Emotional Control/
17. exp Self-Control/
18. exp Coping Behavior/
19. exp Interpersonal Relationships/
20. exp Self-Perception/
21. (subjective adj1 wellbeing).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
22. (subjective adj1 well-being).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
23. (psychological adj1 wellbeing).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
24. (psychological adj1 well-being).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
25. well-being.mp.
26. exp FATIGUE/
27. exp Psychological Engagement/
28. exp Achievement/
29. exp Emotional Content/
30. exp Self-Esteem/
31. exp Positive Psychology/
32. (relational adj1 wellbeing).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
33. (relational adj1 well-being).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
34. happiness.mp. or exp HAPPINESS/
35. exp Emotional States/
36. exp GOALS/
37. exp NEEDS/
38. resources.mp.
39. (lived adj1 experience\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
40. or/1-39
41-88. List of sub-Saharan African countries

89. ("africa south of the sahara" or sub-saharan africa or central africa or eastern africa or southern africa or western africa).mp.
90. exp HIV/ or HIV.mp.
91. exp AIDS/ or AIDS.mp.
92. or/41-89
93. or/90-91
94. 40 and 92 and 93
95. limit 94 to yr="2000 - 2019"

### S3: Search strategy (OVID EconLit)

1. Quality of Life.mp.
2. health-related quality of life.mp.
3. well being.mp.
4. wellbeing.mp.
5. well-being.mp.
6. (subjective adj1 wellbeing).mp.
7. (subjective adj1 well-being).mp.
8. (psychological adj1 wellbeing).mp.
9. (psychological adj1 well-being).mp.
10. (life adj1 satisfaction).mp.
11. (health adj1 satisfaction).mp.
12. (personal adj1 satisfaction).mp.
13. satisfaction.mp.
14. mood.mp. [mp=heading words, abstract, title, country as subject]
15. emotions.mp. [mp=heading words, abstract, title, country as subject]
16. affect.mp. [mp=heading words, abstract, title, country as subject]
17. (positive adj1 affect).mp. [mp=heading words, abstract, title, country as subject]
18. happiness.mp. [mp=heading words, abstract, title, country as subject]
19. pleasure.mp. [mp=heading words, abstract, title, country as subject]
20. (negative adj1 affect).mp. [mp=heading words, abstract, title, country as subject]
21. pain.mp. [mp=heading words, abstract, title, country as subject]
22. depression.mp. [mp=heading words, abstract, title, country as subject]
23. anxiety.mp. [mp=heading words, abstract, title, country as subject]
24. (mental adj1 health).mp. [mp=heading words, abstract, title, country as subject]
25. (mental adj1 stress).mp. [mp=heading words, abstract, title, country as subject]
26. resilience.mp. [mp=heading words, abstract, title, country as subject]
27. (interpersonal adj1 relationships).mp. [mp=heading words, abstract, title, country as subject]
28. (purpose adj2 life).mp. [mp=heading words, abstract, title, country as subject]
29. (self adj1 acceptance).mp. [mp=heading words, abstract, title, country as subject]
30. (self adj1 control).mp. [mp=heading words, abstract, title, country as subject]
31. (personal adj1 growth).mp. [mp=heading words, abstract, title, country as subject]
32. (self adj1 determined).mp. [mp=heading words, abstract, title, country as subject]
33. (hedonic or hedonism).mp.
34. tired.mp.
35. (eudaimonic or eudaemonic or eudaimonism).mp.
36. (positive adj1 psychology).mp. [mp=heading words, abstract, title, country as subject]
37. (psychological adj1 functioning).mp. [mp=heading words, abstract, title, country as subject]

38. "I3\$".cc.
39. "I1\$".cc.
40. "J1\$".cc.
41. "A14".cc.
42. "Z1\$".cc.
43. (relational adj1 well-being).ti,ab,hw,ct.
44. (relational adj1 wellbeing).ti,ab,hw,ct.
45. (lived adj1 experience\$).ti,ab,hw,ct.
46. or/1-45
47-94 List of sub-Saharan African countries
95. ("africa south of the sahara" or sub-saharan africa or central africa or eastern africa or southern africa or western africa).mp.
96. exp HIV/ or HIV.mp.
97. exp AIDS/ or AIDS.mp.
98. or/47-95
99. or/96-97
100. 46 and 98 and 99
101. limit 100 to yr="2000-2019"

#### **S4: Search strategy (EBSCO Africa-Wide Information)**

S85	S78 AND S83 AND S84	Limiters - Scholarly (Peer Reviewed) Journals; Publication Type: Journal Article; Document Type: Article; Year Published: 2000-2019
S84	S81 OR S82	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases
S83	S79 OR S80	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases
S82	AIDS or Acquired Immunodeficiency Syndrome	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases
S81	HIV or HIV-positive or HIV-Positive or HIV-infected or HIV/AIDS or PLHIV	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases
S80	sub-saharan africa or sub saharan africa or subsaharan africa	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases
S79	List of sub-Saharan African countries	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases
S78	S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases
S77	lived AND experience\$	Limiters - Scholarly (Peer Reviewed) Journals; Publication Type: Journal Article; Document Type: Article
S76	relational AND wellbeing	Limiters - Scholarly (Peer Reviewed) Journals; Publication Type: Journal Article; Document Type: Article
S75	relational AND wellbeing	Limiters - Scholarly (Peer Reviewed) Journals; Publication Type: Journal Article; Document Type: Article
S74	AB accomplishments	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases
S73	AB psychological AND functioning	Search modes - Boolean/Phrase Interface - EBSCOhost Research Databases

S72	AB psychological AND engagement	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases
S71	AB depressed or depression	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases
S70	AB tired or fatigue	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases
S69	AB adaptation, psychological	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases
S68	AB resilience, psychological	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases
S67	AB mental AND competency	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases
S66	AB autonomy	Limiters - Scholarly (Peer Reviewed) Journals	
S65	AB personal AND growth	Limiters - Scholarly (Peer Reviewed) Journals	
S64	AB self AND control	Limiters - Scholarly (Peer Reviewed) Journals	
S63	AB self AND acceptance	Limiters - Scholarly (Peer Reviewed) Journals	
S62	AB purpose in life	Limiters - Scholarly (Peer Reviewed) Journals	
S61	AB positive AND relationships	Limiters - Scholarly (Peer Reviewed) Journals	
S60	AB interpersonal AND relationships	Limiters - Scholarly (Peer Reviewed) Journals	
S59	AB environmental mastery	Limiters - Scholarly (Peer Reviewed) Journals	
S58	mental AND health	Limiters - Scholarly (Peer Reviewed) Journals	
S57	AB anxiety or worry	Limiters - Scholarly (Peer Reviewed) Journals	
S56	AB pain	Limiters - Scholarly (Peer Reviewed) Journals	
S55	AB happiness	Limiters - Scholarly (Peer Reviewed) Journals	
S54	AB negative AND emotion	Limiters - Scholarly (Peer Reviewed) Journals	
S53	AB negative AND affect	Limiters - Scholarly (Peer Reviewed) Journals	
S52	AB positive AND emotion	Limiters - Scholarly (Peer Reviewed) Journals	
S51	AB positive AND affect	Limiters - Scholarly (Peer Reviewed) Journals	
S50	life AND satisfaction	Limiters - Scholarly (Peer Reviewed) Journals	
S49	psychological AND well-being	Limiters - Scholarly (Peer Reviewed) Journals	
S48	psychological AND well-being	Limiters - Scholarly (Peer Reviewed) Journals	
S47	psychological AND wellbeing	Limiters - Scholarly (Peer Reviewed) Journals	
S46	subjective AND well-being	Limiters - Scholarly (Peer Reviewed) Journals	
S45	subjective AND wellbeing	Limiters - Scholarly (Peer Reviewed) Journals	
S44	wellbeing or well-being or well being	Limiters - Scholarly (Peer Reviewed) Journals	
S43	hrqol or HRQOL or HRQoL or HRQol or HRqol	Limiters - Scholarly (Peer Reviewed) Journals	
S42	health-related quality of life or health related quality of life	Limiters - Scholarly (Peer Reviewed) Journals	
S41	QOL or Qol or QoL or qol	Limiters - Scholarly (Peer Reviewed) Journals	
S40	quality of life	Limiters - Scholarly (Peer Reviewed) Journals	

### S5: Search strategy (Web of Science)

#36	#35 AND #32
DocType=All document types; Language=All languages;	
#35	#34 AND #33 AND #27
#34	#31 OR #30
#33	#29 OR #28
#32	(((SU=(Arts Humanities) OR SU=(Life Sciences Biomedicine) OR SU=(Social Sciences)))) AND DOCUMENT TYPES: (Article)

#31	((TS=(AIDS) OR TS=(Acquired Immunodeficiency Syndrome))) AND DOCUMENT TYPES: (Article)
#30	((TS=(HIV) OR TS=(HIV-positive) OR TS=(HIV-infect*) OR TS=(HIV/AIDS) OR TS=(PLHIV))) AND DOCUMENT TYPES: (Article)
#29	((TS=(sub-Saharan AND Africa))) AND DOCUMENT TYPES: (Article)
#28	CU=List of sub-Saharan African countries
#27	#26 OR #25 OR #24 OR #23 OR #22 OR #21 OR #20 OR #19 OR #18 OR #17 OR #16 OR #15 OR #14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1
#26	(TI=(lived and experience\$)) AND DOCUMENT TYPES: (Article)
#25	(TS=(relational and wellbeing) OR TS=(relational and well-being)) AND DOCUMENT TYPES: (Article)
#24	(TS=(psychological AND functioning)) AND DOCUMENT TYPES: (Article)
#23	(TS=(Psychological AND engagement)) AND DOCUMENT TYPES: (Article)
#22	(TS=(tired or fatigue)) AND DOCUMENT TYPES: (Article)
#21	(TS=(personal AND growth)) AND DOCUMENT TYPES: (Article)
#20	(TS=(self AND control)) AND DOCUMENT TYPES: (Article)
#19	(TS=(self AND acceptance)) AND DOCUMENT TYPES: (Article)
#18	(TS=(purpose in life)) AND DOCUMENT TYPES: (Article)
#17	(TS=(interpersonal AND relationships)) AND DOCUMENT TYPES: (Article)
#16	(TS=(resilience)) AND DOCUMENT TYPES: (Article)
#15	(TS=(mental AND health)) AND DOCUMENT TYPES: (Article)
#14	(TS=(anxiety)) AND DOCUMENT TYPES: (Article)
#13	(TS=(depression)) AND DOCUMENT TYPES: (Article)
#12	(TS=(pain)) AND DOCUMENT TYPES: (Article)
#11	(TS=(negative AND affect) OR TS=(negative AND emotion*) OR TS=(unpleasant AND affect)) AND DOCUMENT TYPES: (Article)
#10	(TS=(happiness) OR TS=(happy) OR TS=(pleasure)) AND DOCUMENT TYPES: (Article)
#9	(TS=(positive AND affect) OR TS=(positive AND emotion*) OR TS=(pleasant AND affect)) AND DOCUMENT TYPES: (Article)
#8	(TS=(mood) OR TS=(emotion*) OR TS=(emotion AND state*)) AND DOCUMENT TYPES: (Article)
#7	(TS=(life AND satisfaction) OR TS=(health AND satisfaction) OR TS=(personal AND satisfaction) OR TS=(satisfaction)) AND DOCUMENT TYPES: (Article)
#6	(TS=(psychological AND wellbeing) OR TS=(psychological AND well-being)) AND DOCUMENT TYPES: (Article)
#5	(TS=(subjective AND wellbeing) OR TS=(subjective AND well-being)) AND DOCUMENT TYPES: (Article)
#4	((TS=(wellbeing) OR TS=(well-being) OR TS=(well being))) AND DOCUMENT TYPES: (Article)
#3	((TS=(health-related quality of life))) AND DOCUMENT TYPES: (Article)
#2	((TS=QOL)) AND DOCUMENT TYPES: (Article)
#1	(TS=(quality of life)) AND DOCUMENT TYPES: (Article)



**S6: Search strategy (PROQUEST- International Bibliography of the Social Sciences)**

(((((ab(wellbeing) OR ab(well-being) OR ab(happiness) OR ab("life satisfaction") OR ab("quality of life") OR ab ("psychological functioning") OR ab("lived experience") AND ti(HIV OR HIV/AIDS OR HIV-POSITIVE OR HIV-INFECTED)) AND stype.exact("Scholarly Journals")) AND peer(yes)) AND stype.exact("Scholarly Journals")) AND ab("List of sub-Saharan African countries" OR "sub-Saharan Africa")) AND peer(yes)) AND (rtype.exact("Journal Article") AND PEER(yes))

**S7: Search strategy (International AIDS Society Conference abstracts)**

<http://www.abstract-archive.org/>

Search number	
1.	wellbeing or well being
	<i>Filter-Title, contains wellbeing or well being</i>
2.	quality of life or qol
	Filter-Title, contains quality of life or qol
3.	Lived experiences

### S8- Search strategy (Other Databases)

Database	Type	Link	Search strategy
<b>Dissertations and Theses A&amp;I</b>	dissertations	<a href="https://www.proquest.com/libraries/academic/dissertations-theses/">https://www.proquest.com/libraries/academic/dissertations-theses/</a>	Wellbeing AND QOL AND Mental Health AND HIV Filter- SSA countries
<b>World Cat</b>	dissertations	<a href="https://www.worldcat.org/search">https://www.worldcat.org/search</a>	Happiness and HIV Life satisfaction and HIV ("Quality of life") and HIV and Africa Filter- year (2000-2019)
<b>OECD</b>	working papers	<a href="http://www.oecd.org">http://www.oecd.org</a>	Wellbeing AND HIV Filter- Health, 2000-2019, journals and working papers
<b>NBER</b>	working papers	<a href="https://admin.nber.org">https://admin.nber.org</a>	"wellbeing" AND "HIV" Filter- working papers, any date
<b>IDEAS</b>	working papers	<a href="https://ideas.repec.org">https://ideas.repec.org</a>	Wellbeing and HIV Filter- year (2000-2019)
<b>Google scholar</b>	publications	<a href="https://scholar.google.co.za/">https://scholar.google.co.za/</a>	"Wellbeing" AND "Adolescents living with HIV" Filter- year (2000-2019)
			"Mental Health" AND "Adolescents living with HIV" Filter- year (2000-2019)

**Appendix 4: Supplementary File Econometrics Study (Paper  
2**

**The association between health and wellbeing among youth in  
South Africa: a multi-level modelling approach**

## S1: Key ART-scale-up policies

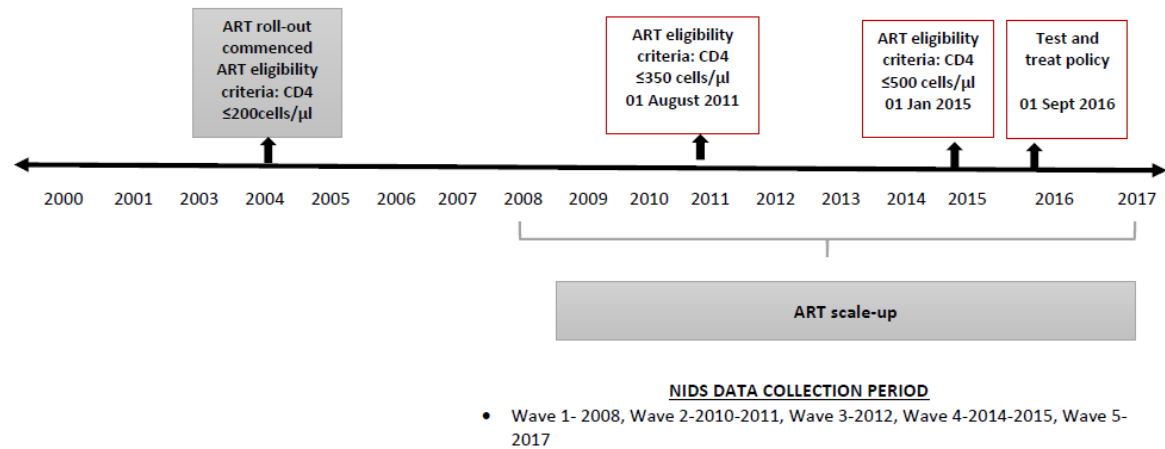


Figure S1: Key HIV treatment eligibility guideline changes in South Africa

## S2: Variable description

**Table S2: Variable description**

Variable	Dataset (Questionnaire type)	Question as stated on the questionnaire	Definition
<b>Dependent variable</b>			
Life satisfaction score	NIDS Individual (adult)	Using a scale of 1 to 10 where 1 means "Very dissatisfied" and 10 means "Very satisfied", how do you feel about your life as a whole right now?	A continuous (ordinal) variable reflective of one's current life satisfaction score
<b>Key regressors</b>			
Depressive Symptom Score	NIDS (Individual adult)	<p>CESD10 Scale (Depressive symptoms)</p> <p>During the past week</p> <ol style="list-style-type: none"> <li>1. I was bothered by things that usually don't bother me</li> <li>2. I had trouble keeping my mind on what I was doing</li> <li>3. I felt depressed</li> <li>4. I felt that everything I did was an effort</li> <li>5. I felt hopeful about the future</li> <li>6. I felt fearful</li> <li>7. I was happy</li> <li>8. I felt lonely</li> <li>9. I could not get going"</li> </ol> <p>Response-</p> <ul style="list-style-type: none"> <li>▪ Rarely or none of the time (less than 1 day),</li> <li>▪ Some or little of the time (1-2 days),</li> <li>▪ Occasionally or a moderate amount of time (3-4 days)</li> <li>▪ All of the time (5-7 days)</li> </ul>	<p>A continuous (ordinal) variable reflecting the sum score to all nine items.</p> <p>Responses are scored as follows:            Response 1 (0);            Response 2 (1);            Response 3 (2);            Response 4 (3). E4 (3). Except responses for Q5 and Q7 are scored as follows: Response 1 (3); Response 2 (2); Response 3 (1); Response 4 (0)</p>

Underweight	NIDS (Individual adult)	Respondent's Height (meters) – Measure 1  Respondent's Weight (kilograms) – Measure 1	A categorical (dummy) variable calculated by dividing weight (kgs) over the square of height (m) BMI = kg/m <sup>2</sup>  1= Underweight (BMI= 15-18.49) 0= Healthy (BMI= 18.5-24.9)/Overweight (BMI= 25-29.9)/Obese (BMI= 30-50)
ART count	NHLS	We summarized the number of infants, children and adults on ART per year per district. We assumed someone was accessing ART if there was a laboratory tests date. We avoided duplicate patient counts by sorting on unique patient identifiers and selecting the most recent laboratory test date per calendar year.	A continuous variable reflecting the count of people in HIV care per district per NIDS wave year
ART count per capita	NHLS and Stats SA (derived from CENSUS 2011 and mid-year population estimates)	ART count divided by the district population	A continuous variable reflecting the number of people on ART relative to district population size
<b>Explanatory variables</b>			
Age	NIDS (Individual adult)	What is your date of birth?	A continuous variable calculated by subtracting date of birth from interview date

Female	NIDS (Individual adult)	What is your gender?	A categorical (dummy) variable taking value 1 for female and 0 for male
Black	NIDS (Individual adult)	What population group would you describe yourself as belonging to?	A categorical (dummy) variable taking value 1 for population group (African) and zero for other population groups (Coloured, Asian/Indian, White, Other)
Completed compulsory education	NIDS (Individual adult)	What is the highest grade in school that you have successfully completed?	A categorical (dummy) variable taking value 1 for those who completed Grade 9 (secondary school level) and 0 for those who did not
Employed	NIDS (Individual adult)	<p>Are you currently being paid a wage or salary to work on a regular basis for an employer (that is not yourself) whether full time or part time? If you work for yourself, we will ask about this later.</p> <p>Have you engaged in any self-employment activities during the last 30 days? For example, you might buy and sell goods, be a commercial farmer, work for yourself as a doctor or hairdresser or be a freelance consultant.</p>	A categorical (ordinal) variable taking value 1 for those employed (full/part-time/self-employed), 0 for those unemployed searching for work, and 2 for those not economically active/not searching for work
Mothers highest educational attainment	NIDS (Individual adult)	What is the highest grade in school that your [...] successfully completed?	A categorical (dummy) variable taking value 1 for those mothers' that completed at least primary school

			(Grade 7), and 0 for those who did not
Self-perceived good health status	NIDS (Individual adult)	How would you describe your health at present? Would you say it is excellent, very good, good, fair, or poor?	A categorical (dummy) variable taking value 1 for very good/good and 0 for fair/poor
Generalised trust	NIDS (Individual adult)	If you lost a wallet with money (R200), how likely is it that it will be returned by a stranger?	A categorical (dummy) variable taking 1 if very/fairly likely and 0 if not likely
Personalised trust	NIDS (Individual adult)	If you lost a wallet with money (R200), how likely is it that it will be returned by neighbor?	A categorical (dummy) variable taking 1 if very/fairly likely and 0 if not likely
Importance of religious activities in your life	NIDS (Individual adult)	How important are religious activities in your life?	A categorical (dummy) variable taking value 1 if very important/important and 0 if unimportant/not important at all
Income aspiration level in 5 years' time	NIDS (Individual adult)	Please imagine a six-step ladder where the poorest people in South Africa stand on the bottom (the first step) and the richest people in South Africa stand on the highest step (the sixth step).  1. On which step are you today? 2. On which step do you expect to be 5 years from now?  Poorest 1 2 3 4 5 Richest 6	A continuous (ordinal) variable created by subtracting income rank today from rank in 5 years' time.
Household expenditure	NIDS (household)	NIDS created variable refer to guidelines (Brophy et al., 2018)  Total household expenditure=Total food expenditure + Total non-food expenditure+ Rental expenditure +	A continuous variable of the NIDS created total household expenditure variable



		Imputed rent for owner-occupied housing	
Lives in an urban area	NIDS (household)	NIDS created variable. Based on geographic area type (urban/rural/traditional) as per Census 2011 demarcations	A categorical (dummy) variable taking value 1 if urban and 0 if rural/traditional
Household with basic needs	NIDS (household)	<p>1. Indicate the type of main dwelling that the household Occupies (Interviewer)  {Dwelling/house or brick structure on a separate stand or yard or on farm; Traditional dwelling/hut/structure made of traditional materials; Flat or apartment in a block of flats; Town/cluster/semi-detached house (simplex, duplex or triplex); Unit in retirement village; Dwelling/house/flat/room in backyard; Informal dwelling/shack in backyard; Informal dwelling/shack not in backyard, e.g. in an informal/squatter settlement or on farm; Room/flatlet; Caravan/tent; Other (specify)}</p> <p>2. Does this household have electricity even if currently disconnected? {Yes, No}</p> <p>3. What is this household's main source of water? (Piped water, {Piped (tap) water in dwelling. Piped (tap) water on site or in yard, Public tap. Water-Carrier/tanker. Borehole on site. Borehole off site/communal. Rain-water tank on site. Flowing water/stream. Dam/pool/stagnant water. Well; Spring; Other (specify); Neighbour}</p>	A categorical (dummy) variable taking value 1 if dwelling type is formal and has electricity and has piped water source and has a flush toilet; and 0 if not

		4. What type of toilet facility is available for this household? [Flush toilet with onsite disposal (septic tank / soak-away); Flush toilet with offsite disposal; Chemical toilet; Pit latrine with ventilation pipe; Pit latrine without ventilation pipe; Bucket toilet; Other (specify)]	
Household members	NIDS (household)	NIDS created based on the following :  Interviewer: List names of all individuals who meet household membership criteria  You are a household member if: 1. You have lived under this "roof" or within the same compound/homestead/stand <b>at least 15 days</b> during the last 12 months OR you arrived here in the last 15 days and this is now your usual residence <b>and</b> 2. when you are together you share food from a common source with other household members 3. you contribute to or share in a common resource pool.	A continuous variable of the NIDS created total household expenditure variable members
District	NIDS-Household	2011 district geographic boundaries (NIDS created)	A categorical variable based on the district the individual spent the most amount of time in over the course of all 5 NIDS waves (2008-2017).  We calculated the proportion time an

			individual spent in each district over the course of the study period. We then assigned the individual to the individual resided in the most. In the event of a tie, we assigned the individual to the district he/she belonged to in their latest wave.
NIDS wave	NIDS-Individual (adult)	Interview date (dd/mm/yyyy) (Interviewer recoded)	A categorical variable based on the wave that data collection occurred  Wave 1 (2008), wave 2 (2010-2011-77% conducted in 2010), wave 3 (2012) , wave 4 (2014-2015-68% conducted in 2015), wave 5 (2017)

Brophy, T., Branson, N., Daniels, R. C., Leibbrandt, M., Mlatsheni, C. & Woolard, I. 2018. National Income Dynamics Study panel user manual. Release.

### S3: Interview Outcomes

**Table S3: Interview outcome description of sample**

	<b>Unbalanced (%)</b>	<b>Balanced (%)</b>	<b>Total (%)</b>
<b>Total observations (N)</b>	<b>13830</b>	<b>14595</b>	<b>28425</b>
<b>Total individuals (n)</b>	<b>2766</b>	<b>2919 (51)</b>	<b>5685</b>
<b><i>Successfully interviewed in all 5 waves</i></b>			<b>2919 (51)</b>
<b><i>Successfully Interviewed in subsequent waves</i></b>	<b>1632 (59)</b>		<b>1632 (29)</b>
<b><i>Loss to follow-up in subsequent waves</i></b>	<b>1134 (41)</b>		<b>1134 (20)</b>
<i>Refused/ Not Available</i>	198 (17)		
<i>Household Level no-response</i>	669 (59)		
<i>Not Tracked in Wave</i>	123.2 (11)		
<i>Moved outside of South Africa</i>	6.2 (0.05)		
<i>Deceased in this wave</i>	55 (0.05)		
<i>Deceased in a prior wave</i>	82 (0.07)		

## S4: Descriptive statistics balanced sample

**Table S4: Descriptive statistics of balanced sample (N=14 595 observations, n=2919)**

<b>Variable</b>	<b>Mean</b>	<b>SD</b>
<b><i>Individual level</i></b>		
Age (years)	23.83*	4.32
Female (%)	51.44*	0.50
Race-Black (%)	90.36*	0.30
Completed compulsory education (%)	87.56*	0.33
Employed (%)	26.59*	0.83
Mothers highest educational attainment (primary school) (%)	54.08*	0.50
Depressive Symptom Score symptom score ^	6.74	4.14
Depressed ^	13.21	0.34
BMI score \$	24.65	5.66
Underweight \$\$	7.74	0.27
Overweight/Obese (%) \$\$\$	37.81	0.48
Self-perceived good health status (%)	96.48	0.18
Life satisfaction score	5.12	2.42
Religious (%)	88.67*	0.32
Generalised trust (%)	18.25	0.39
Personalised trust (%)	29.97	0.46
Income aspiration level in 5 years' time	1.78	1.15
<b><i>Household level</i></b>		
Household expenditure (ZAR)	4483.546*	7298.53
Lives in an urban area (%)	58.05*	0.49
Household with basic needs (%)	43.24*	0.50
Household members	5.41*	3.59
<b><i>District level*</i></b>		
ART access	148886*	135546
ART count per capita	0.078*	0.038

SD= standard deviation; \*Data source: NHLS HIV Laboratory data; note-NIDS data are weighted; \*there were significant differences in these variables compared to the unbalanced sample ( $p \leq 0.05$ ); ^= based on CES-D-10 scale, ^^= Based on CES-D-10 score of  $\geq 12$ ; \$ BMI=Body Mass Index ( $\text{kg}/\text{m}^2$ ); \$\$ =based on BMI score 15-18.49  $\text{kg}/\text{m}^2$ ; ; \$\$\$ =based on BMI score  $\geq \text{kg}/\text{m}^2$

## S5: Distribution of life satisfaction scores

**Table S5a: Life satisfaction summary scores for full sample from NIDS dataset.**

	Observation	Mean	Standard deviation
Overall	19633	5.19	2.46
Wave 1	4162	5.74	2.66
Wave 2	3872	4.80	2.50
Wave 3	3704	4.73	2.32
Wave 4	4097	5.33	2.26
Wave 5	3798	5.34	2.40

Note: Data are weighted

**Table S5b: Distribution of life satisfaction scores for full sample**

	N	%	Cumulative %
1. Satisfaction level 1 (Very dissatisfied)	1,374	7	7
2. Satisfaction level 2	1,386	7.06	14.06
3. Satisfaction level 3	2,310	11.77	25.82
4. Satisfaction level 4	2,844	14.49	40.31
5. Satisfaction level 5	3,561	18.14	58.45
6. Satisfaction level 6	2,340	11.92	70.37
7. Satisfaction level 7	2,146	10.93	81.3
8. Satisfaction level 8	1,589	8.09	89.39
9. Satisfaction level 9	647	3.3	92.69
10. Satisfaction level 10 (Very satisfied)	1,436	7.31	100
<b>Total</b>	<b>19,633</b>	<b>100</b>	

## S6: Data exploration- age and sex vs. life satisfaction

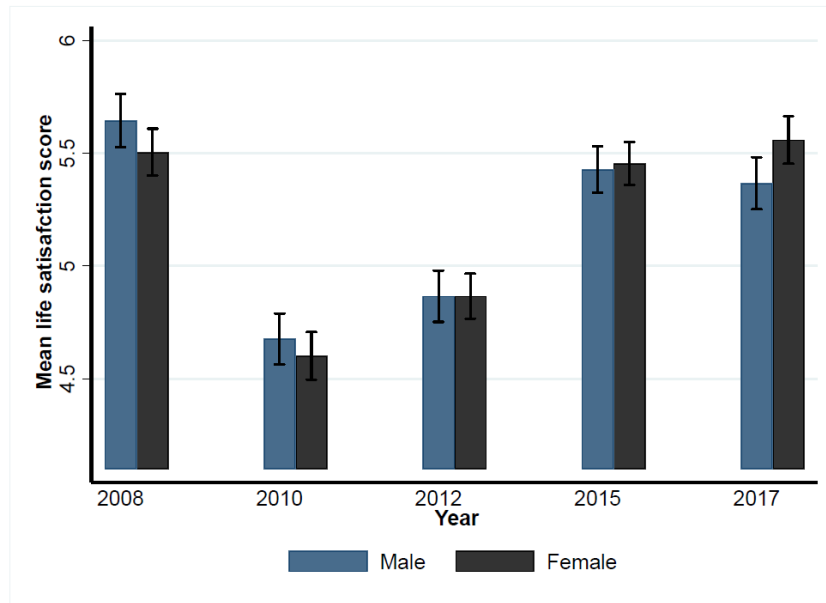


Figure S6a- Figure showing average life satisfaction score per NIDS wave, stratified by gender for the full sample

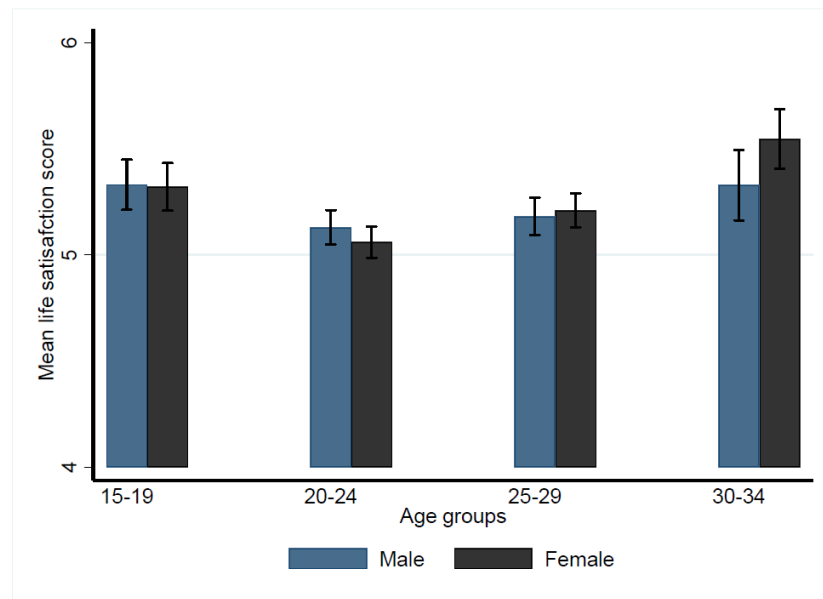


Figure S6b- Figure showing average life satisfaction score per wave, stratified by age for the full sample

### S7: Data exploration: age vs. life satisfaction

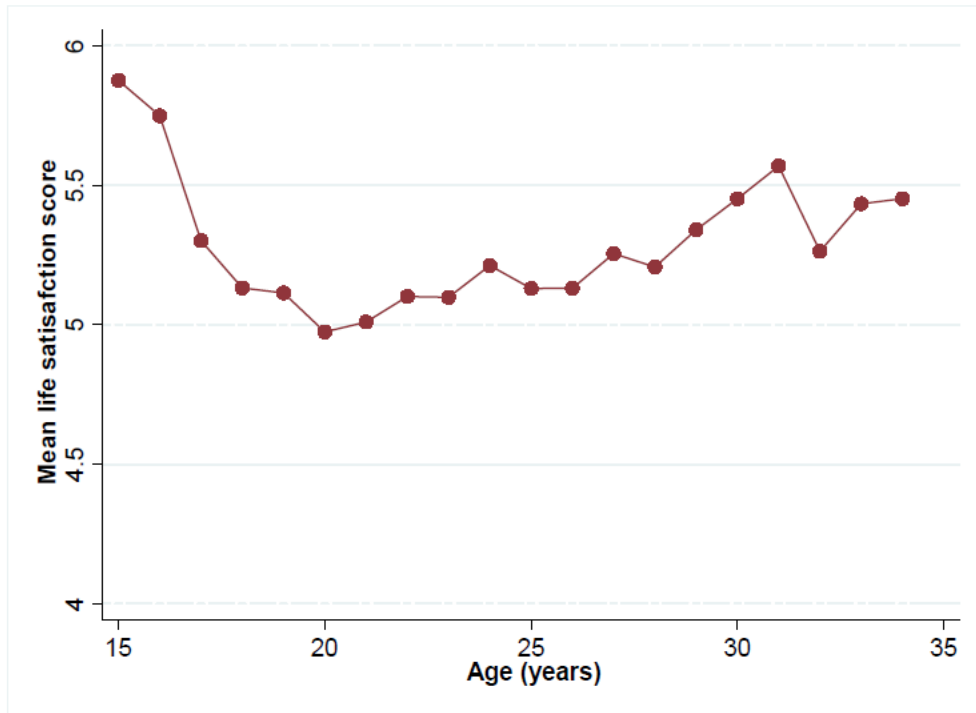


Figure S7: Graph of mean life satisfaction score by age



## S8: Data exploration- key covariates

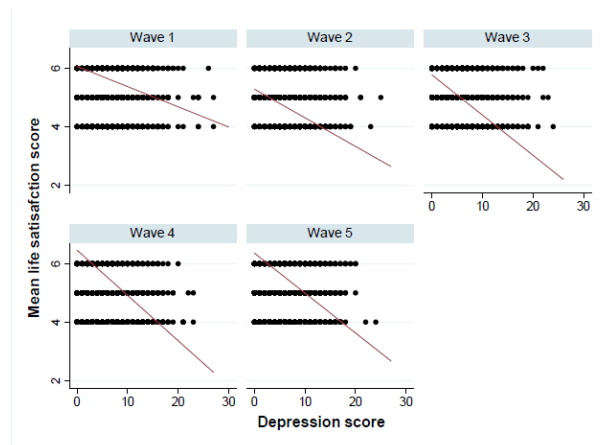


Figure S8a: Scatter plot of mean life satisfaction scores versus CES-D-10 scores and by NIDS wave for the full sample

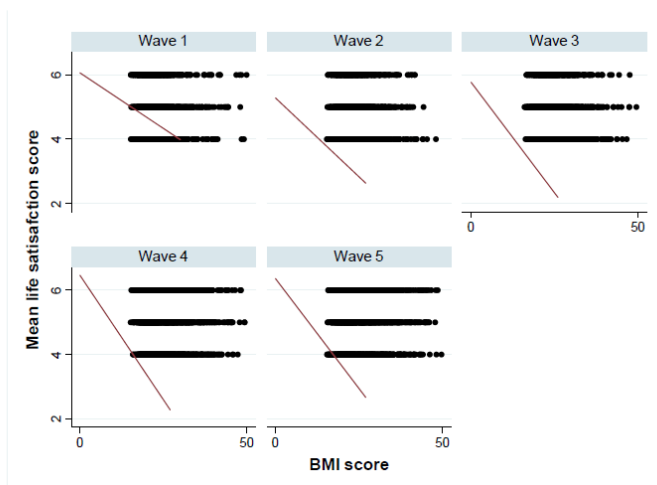


Figure S8b: Scatter plot of mean life satisfaction scores versus BMI scores and by NIDS wave for the full sample

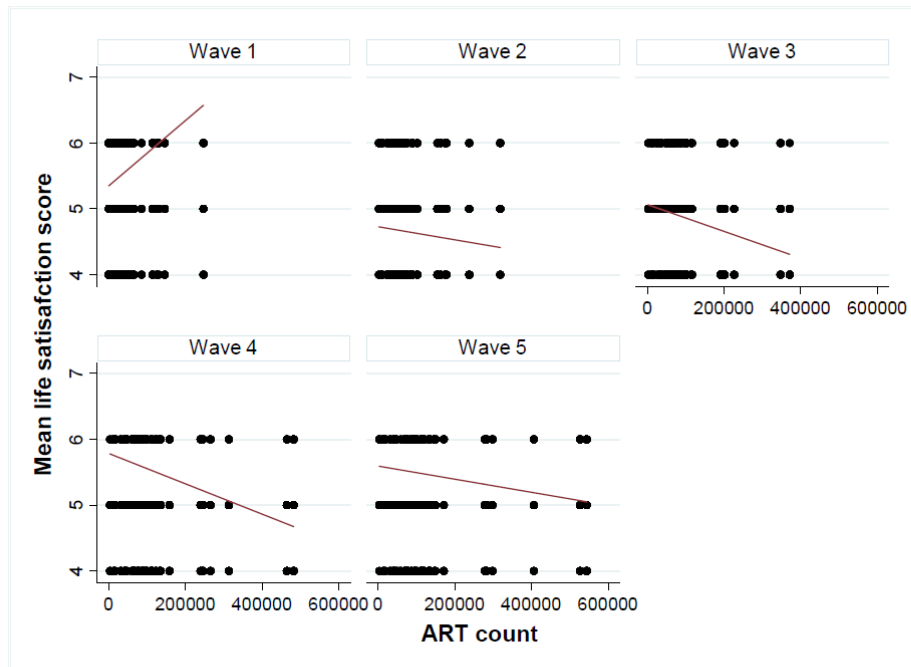


Figure S8c: Scatter plot of mean life satisfaction scores and ART count by NIDS wave for the full sample

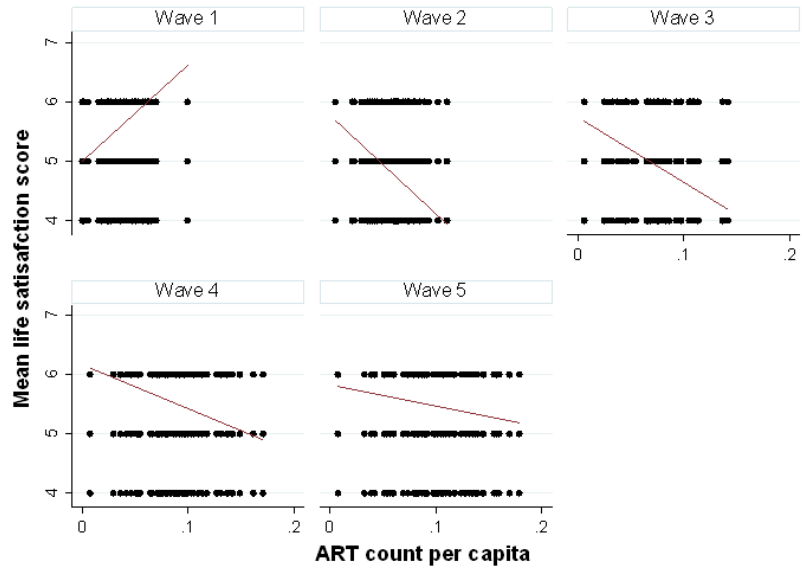


Figure S8d: Scatter plot of mean life satisfaction score and ART count per capita by NIDS wave for the full sample

## S9: Data exploration- correlations

Table S9a: Spearman correlation matrix between parameters. \*p≤0.05

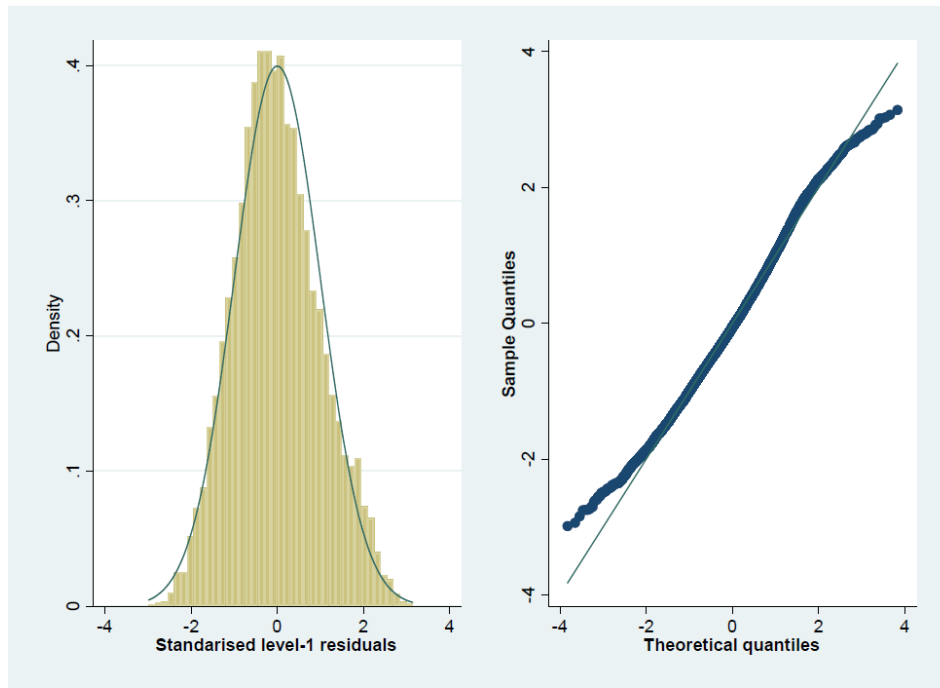
	Life satisfaction	ART count per capita	Age	Female	Black	Completed compulsory education	Employed	CES-D-10 score	BMI Score	Underweight	Religious	Generalised trust	Personalised trust	Income aspiration level in 5 years' time	Household expenditure
Life satisfaction	1.00														
ART count per capita	-0.05*	1.00													
Age	0.02*	0.45*	1.00												
Female	-0.00	-0.01	0.03*	1.00											
Black	-0.21*	0.28*	0.00*	-0.01	1.00										
Completed compulsory education	0.05*	0.11*	0.16*	0.05*	0.03*	1.00									
Employed	0.04*	0.23*	0.24*	-0.04*	-	0.08*	1.00								
Depressive Symptom Score	-0.22*	0.04*	-	0.04*	0.16*	-0.04*	-0.04*	1.00							
BMI score	0.02**	-	0.24*	0.37*	0.02*	0.10*	0.05*	-0.00	1.00						
Underweight	0.01	-	-	-0.13*	-	-0.05*	-0.03*	0.00	-0.48*	1.00					
Religious	0.07	0.01	0.02*	0.16*	-	0.07*	-0.01	-	0.08*	-0.02*	1.00				
Generalised trust	-0.09	0.08*	0.03*	-0.01	0.07*	0.05*	-0.04*	0.05*	0.14*	0.03*	-0.02	-	1.00		
Personalised trust	-0.01	0.08*	0.04*	-0.01	0.07*	0.04*	-0.04*	0.08*	0.03*	-0.02*	0.03*	0.44*	1.00		
Income aspiration level in 5 years' time	0.04*	-	-	-0.01	0.03*	0.03*	0.03*	-	-0.03*	0.02*	0.02*	-0.09*	-0.05*	1.00	
Household expenditure	0.24*	0.12*	0.24*	0.00	-	0.21*	0.08*	-	0.13*	0.06*	0.06*	-0.03*	0.01*	0.01	1.00

**Table 2b: Spearman correlation matrix between life satisfaction score and covariates**

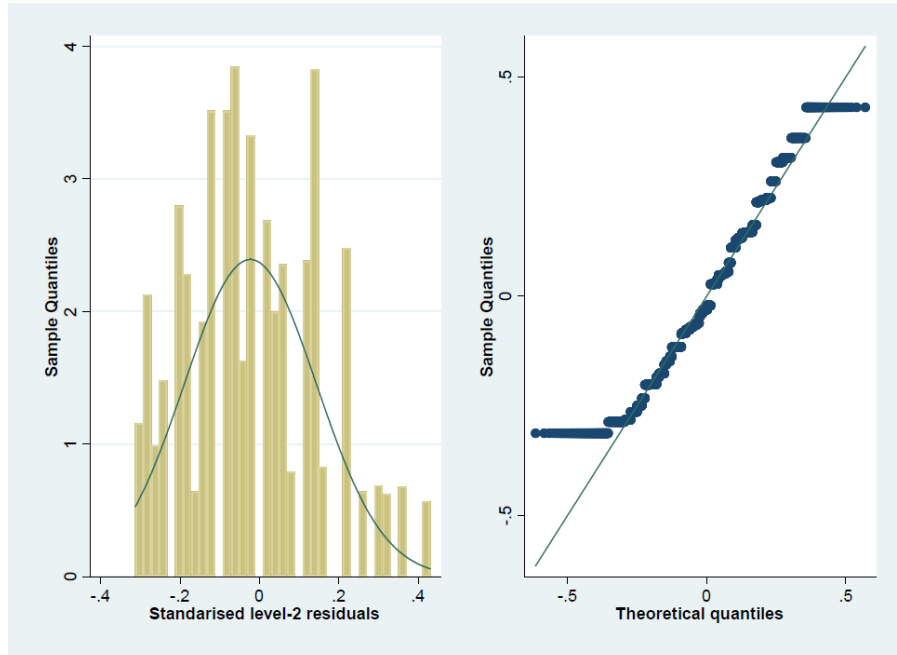
		Full sample	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5
Life satisfaction	rho	1.00	1.00	1.00	1.00	1.00	1
	Obs	19633.00	4162.00	3872.00	3704.00	4097.00	3798
ART count per capita		-0.0534*	0.1517*	-0.1368*	-0.1182*	-0.1149*	-0.0418*
Age		0.0144*	-0.0626*	0.00	-0.0471*	0.01	-0.0209
Female		0.00	-0.0316*	0.01	0.01	0.00	0.0390*
Black		-0.2012*	-0.2249*	-0.2677*	-0.2036*	-0.1614*	-0.1378*
Completed compulsory education		0.0584*	0.0908*	0.0590*	0.0573*	0.0376*	0.0539*
Employed		0.0329*	0.02	0.0739*	0.01	0.0334*	0.0571*
Depressive Symptom Score		-0.2043*	-0.1061*	-0.1681*	-0.2474*	-0.2961*	-0.2422*
BMI score		0.0221*	0.02	-0.0461*	0.02	0.0434*	0.0708*
Underweight		0.0070	0.0065	0.0299	-0.009	0.0020	-0.0204
Overweight/Obese		0.0301*	0.0135	-0.0291	0.0301	0.0545*	0.0651*
Religious		0.0867*	0.0893*	0.1225*	0.1075*	0.0387*	0.0883*
Generalised trust		-0.0812*	0.00	-0.1089*	-0.0630*	-0.0733*	-0.1217*
Personalised trust		0.00	0.0868*	0.00	0.0342*	-0.0555*	-0.0419*
Income aspiration level in 5 years'		0.0416*	-0.0808*	0.1233*	0.0668*	0.00	0.025
time							
Household expenditure		0.2370*	0.2771*	0.2248*	0.2313*	0.2288*	0.1839*

\*p≤0.05

## S10: Model Diagnostics- Health vs. Life Satisfaction



**Figure S10a: Histogram and Q-Q plot of level 1 standardised residuals for the two-level RI model fitted to the full dataset. In the Q-Q plot the quantiles of the standardised deviance residuals from the life satisfaction scores are plotted against the quantiles from a standard normal distribution**



**Figure 10b: Histogram and Q-Q plot of random effects (district-level) standardised residuals for the two-level RI model fitted to the full dataset. In the Q-Q plot the quantiles of the standardised deviance residuals from the life satisfaction scores are plotted against the quantiles from a standard normal distribution**

**S11: Robustness check- Alternate model specification (Health vs. Life Satisfaction)**

**Supplementary File S11: Regression models examining the relationship between health and life satisfaction using alternate model specifications on full sample. Co-efficient (SE)**

	(1) POLS <sup>^</sup> b/se	(2) FE <sup>^</sup> b/se	(3) 2-LEVEL RI b/se	(4) 1-LEVEL RI b/se
Depressive Symptom Score	-0.08*** (0.01)	-0.07*** (0.01)	-0.08*** (0.01)	-0.08*** (0.01)
Underweight	-0.15 (0.08)	-0.02 (0.12)	-0.14* (0.07)	-0.15* (0.07)
Female	0.02 (0.04)	0.00 (.)	0.02 (0.04)	0.02 (0.04)
Age <sup>^2</sup>	0.00 (0.00)	-0.00 (0.00)	0.00 (0.00)	0.00 (0.00)
Age	-0.07 (0.05)	0.09 (0.07)	-0.07 (0.05)	-0.07 (0.05)
Black	-0.85*** (0.15)	-0.94*** (0.13)	-0.90*** (0.07)	-0.85*** (0.08)
Completed compulsory education	0.16* (0.07)	-0.08 (0.13)	0.16** (0.05)	0.16** (0.05)
Employed	0.24*** (0.06)	0.07 (0.08)	0.24*** (0.05)	0.24*** (0.05)
Log Household expenditure	0.42*** (0.03)	0.35*** (0.05)	0.42*** (0.02)	0.42*** (0.02)
Religious Generalised trust	0.34*** (0.08)	0.34*** (0.10)	0.35*** (0.06)	0.34*** (0.06)
Personalised trust	-0.33** (0.10)	-0.30** (0.11)	-0.34*** (0.05)	-0.33*** (0.05)
Income aspiration	0.62*** (0.13)	0.68*** (0.15)	0.63*** (0.08)	0.62*** (0.08)
Depressive Symptom Score X Personalised Trust	-0.00 (0.03)	0.02 (0.03)	-0.00 (0.02)	-0.00 (0.02)
2.wave	-0.05*** (0.01)	-0.06*** (0.02)	-0.05*** (0.01)	-0.05*** (0.01)
3.wave	-0.93*** (0.17)	-1.11*** (0.22)	-0.93*** (0.07)	-0.93*** (0.06)
4.wave	-0.68*** (0.12)	-0.97*** (0.25)	-0.68*** (0.07)	-0.68*** (0.07)
5.wave	-0.19 (0.15)	-0.63 (0.42)	-0.20** (0.08)	-0.19* (0.08)
102.w_dcnew	-0.21 (0.14)	-0.75 (0.54)	-0.21* (0.08)	-0.21* (0.08)
103.w_dcnew	0.43*** (0.03)			0.43 (0.23)
104.w_dcnew	0.27*** (0.03)			0.27 (0.25)
105.w_dcnew	0.23*** (0.05)			0.23 (0.25)
199.w_dcnew	0.82*** (0.02)			0.82*** (0.24)
210.w_dcnew	-0.22* (0.09)			-0.22 (0.22)
212.w_dcnew	0.03 (0.07)			0.03 (0.26)
213.w_dcnew	-0.36* (0.14)			-0.36 (0.36)
	-0.41** (0.14)			-0.41 (0.24)



214.w_dcnew	-0.18 (0.14)			-0.18 (0.25)
215.w_dcnew	-0.02 (0.14)			-0.02 (0.23)
244.w_dcnew	-0.49** (0.14)			-0.49* (0.25)
260.w_dcnew	-0.19 (0.14)			-0.19 (0.39)
299.w_dcnew	-0.42*** (0.12)			-0.42 (0.23)
306.w_dcnew	0.51*** (0.03)			0.51* (0.24)
307.w_dcnew	0.52*** (0.03)			0.52 (0.29)
308.w_dcnew	0.09* (0.04)			0.09 (0.24)
309.w_dcnew	0.29* (0.12)			0.29 (0.25)
345.w_dcnew	0.82*** (0.13)			0.82** (0.26)
416.w_dcnew	1.07*** (0.13)			1.07*** (0.26)
418.w_dcnew	0.38* (0.15)			0.38 (0.25)
419.w_dcnew	0.69*** (0.15)			0.69** (0.26)
420.w_dcnew	0.22 (0.15)			0.22 (0.27)
499.w_dcnew	0.60*** (0.14)			0.60* (0.27)
521.w_dcnew	-0.04 (0.14)			-0.04 (0.22)
522.w_dcnew	-0.46** (0.13)			-0.46* (0.23)
523.w_dcnew	-0.06 (0.15)			-0.06 (0.23)
524.w_dcnew	-0.03 (0.14)			-0.03 (0.24)
527.w_dcnew	-0.23 (0.15)			-0.23 (0.25)
528.w_dcnew	-0.19 (0.15)			-0.19 (0.24)
543.w_dcnew	0.03 (0.15)			0.03 (0.23)
555.w_dcnew	0.41** (0.15)			0.41 (0.23)
556.w_dcnew	-0.52** (0.15)			-0.52* (0.24)
559.w_dcnew	0.17 (0.14)			0.17 (0.24)
599.w_dcnew	-0.11 (0.13)			-0.11 (0.22)
637.w_dcnew	0.87*** (0.14)			0.87*** (0.25)
638.w_dcnew	0.41** (0.15)			0.41 (0.24)
639.w_dcnew	0.56*** (0.14)			0.56* (0.24)
640.w_dcnew	0.68*** (0.13)			0.68* (0.30)
742.w_dcnew	-0.01 (0.14)			-0.01 (0.23)
748.w_dcnew	0.60*** (0.15)			0.60* (0.25)
797.w_dcnew	0.08 (0.13)			0.08 (0.23)
798.w_dcnew	-0.27* (0.13)			-0.27 (0.22)
799.w_dcnew	0.34* (0.14)			0.34 (0.23)
830.w_dcnew	0.21 (0.15)			0.21 (0.23)
831.w_dcnew	-0.30* (0.14)			-0.30 (0.24)
832.w_dcnew	0.16 (0.15)			0.16 (0.22)
933.w_dcnew	-0.28 (0.15)			-0.28 (0.25)
934.w_dcnew	-0.40** (0.15)			-0.40 (0.26)
935.w_dcnew	-0.13 (0.15)			-0.13 (0.24)
936.w_dcnew	0.23 (0.14)			0.23 (0.23)
947.w_dcnew	0.05 (0.14)			0.05 (0.23)
_cons	4.19*** (0.65)	2.54 (1.32)	4.29*** (0.58)	4.19*** (0.60)
var(district)			0.12*** (0.03)	0.00*** (0.00)
var(individual)			0.00*** (0.00)	

var(Residual)			5.02*** (0.06)	5.01*** (0.06)
$R^2$	0.158	0.077		
AIC	69565.0	63132.7	69732.6	69673.0
BIC	69710.5	63270.5	69908.7	70231.9
ICC-district			0.0242	.
ICC-individual   district			0.0242	1.12e-11
Log likelihood	-34763.5	-31548.4	-34843.3	-34763.5
N	15628	15628	15628	15628

^= Models were clustered at district. Standard errors in parentheses

\* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001

## S12: Robustness check- Balanced sample (Health vs. Life Satisfaction)

Supplementary File S12: Two-level random intercept models examining the relationship between health and life satisfaction among young people for the balanced NIDS sample. Co-efficient (SE)

	(1) Null	(2) Health	(3) Socio- demographic	(4) Social Capital	(5) Personality trait	(6) Interaction Terms	(7) Time
	b/se	b/se	b/se	b/se	b/se	b/se	b/se
Depressive Symptom Score		-0.10*** (0.01)	-0.09*** (0.01)	-0.09*** (0.01)	-0.09*** (0.01)	-0.07*** (0.01)	-0.08*** (0.01)
Underweight		-0.02 (0.08)	-0.02 (0.08)	-0.03 (0.08)	-0.09 (0.09)	-0.09 (0.09)	-0.15 (0.09)
Female			0.12** (0.04)	0.06 (0.04)	0.05 (0.05)	0.05 (0.05)	0.04 (0.05)
Age^2			0.01*** (0.00)	0.01*** (0.00)	0.01*** (0.00)	0.00*** (0.00)	0.00 (0.00)
Age			-0.31*** (0.05)	-0.27*** (0.05)	-0.26*** (0.05)	-0.26*** (0.05)	-0.05 (0.06)
Black			-0.82*** (0.09)	-0.83*** (0.09)	-0.90*** (0.10)	-0.91*** (0.10)	-0.92*** (0.10)
Completed compulsory education			0.15* (0.06)	0.11 (0.07)	0.10 (0.07)	0.09 (0.07)	0.10 (0.07)
Employed			0.37*** (0.06)	0.31*** (0.06)	0.33*** (0.06)	0.32*** (0.06)	0.21** (0.07)
Log Household expenditure			0.43*** (0.03)	0.42*** (0.03)	0.42*** (0.03)	0.42*** (0.03)	0.39*** (0.03)
Religious				0.43*** (0.07)	0.35*** (0.08)	0.34*** (0.08)	0.38*** (0.08)
Generalised trust				-0.47*** (0.06)	-0.47*** (0.07)	-0.45*** (0.07)	-0.38*** (0.07)
Personalised trust				0.27*** (0.05)	0.28*** (0.06)	0.62*** (0.10)	0.66*** (0.10)

Income aspiration					0.08**	0.07**	0.02
					(0.02)	(0.02)	(0.02)
Depressive Symptom Score X Personalised_Trust						-0.05**	-0.06**
2.wave						(0.01)	(0.01)
							-0.95**
							(0.08)
3.wave							-0.71**
							(0.09)
4.wave							-0.21*
							(0.10)
5.wave							-0.16
							(0.11)
_cons	5.30**	5.95**	6.74** (0.62)	6.02**	6.07**	5.96**	4.38**
	(0.09)	(0.09)		(0.64)	(0.67)	(0.67)	(0.73)
var(district)	0.38**	0.32**	0.14** (0.03)	0.12**	0.12**	0.12**	0.13**
	(0.08)	(0.07)		(0.03)	(0.03)	(0.03)	(0.03)
var(individual)	0.13**	0.09**	0.00** (0.00)	0.00**	0.00**	0.00**	0.00**
	(0.04)	(0.04)		(0.00)	(0.00)	(0.00)	(0.00)
var(Residual)	5.47**	5.31**	5.19** (0.07)	5.13**	5.15**	5.14**	5.04**
	(0.08)	(0.08)		(0.07)	(0.07)	(0.07)	(0.07)
<i>AIC</i>	58768.8	55736.0	55016.6	50966.1	46092.1	46076.7	45883.0
<i>BIC</i>	58798.6	55780.5	55120.4	51090.9	46222.4	46214.2	46049.5
ICC-district	0.0639	0.0554	0.0255	0.0235	0.0235	0.0230	0.0243
ICC-individual   district	0.0863	0.0714	0.0255	0.0235	0.0235	0.0230	0.0243
Log likelihood	-	-	-27494.3	-	-23028.1	-23019.4	-
	29380.4	27862.0		25466.1			22918.5
<i>N</i>	12853	12288	12240	11365	10267	10267	10267

Standard errors in parentheses; \*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ ; ICC=Intraclass Correlation Co-efficient

### S13: Model Diagnostics- ART count per capita vs. Life Satisfaction

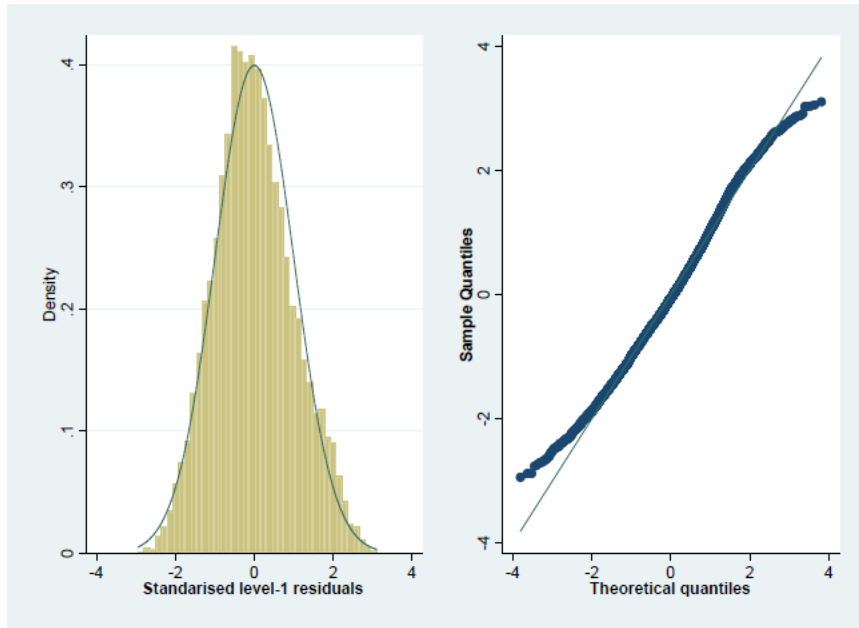
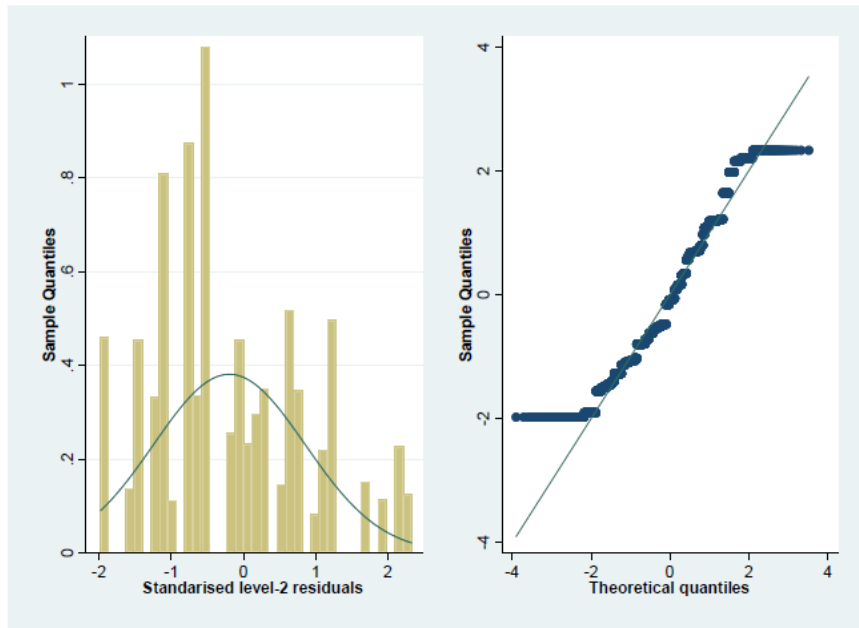


Figure S13a: Histogram and Q-Q plot of level 1 (individual-level) standardised residuals for the two-level RI model fitted to the full dataset. In the Q-Q plot the quantiles of the standardised deviance residuals from the life satisfaction scores are plotted against the quantiles from a standard normal distribution



**Figure 13b: Histogram and Q-Q plot of level 2 (district-level) standardised residuals for the two-level RI model fitted to the full dataset. In the Q-Q plot the quantiles of the standardised deviance residuals from the life satisfaction scores are plotted against the quantiles from a standard normal distribution**

**S14: Robustness check- Alternate model specification (ART count per capita vs. life satisfaction)**

**Table S14: Regression models examining the relationship between ART count per capita and life satisfaction using alternate model specifications. Co-efficient (SE)**

	(1) POLS <sup>^</sup> b/se	(2) FE <sup>^</sup> b/se	(3) 2-LEVEL RI b/se	(4) 1-LEVEL RI b/se
ART count per capita	8.23*** (1.46)	8.42*** (1.55)	7.25*** (0.95)	8.23*** (1.01)
Depressive Symptom Score	-0.08*** (0.01)	-0.07*** (0.01)	-0.08*** (0.01)	-0.08*** (0.01)
Underweight Female	-0.15 (0.08)	-0.04 (0.12)	-0.14* (0.07)	-0.15* (0.07)
Age <sup>^2</sup>	0.01 (0.04)	0.00 (.)	0.01 (0.04)	0.01 (0.04)
Age	0.00 (0.00)	-0.00 (0.00)	0.00 (0.00)	0.00 (0.00)
Age	-0.09 (0.05)	0.06 (0.07)	-0.08 (0.05)	-0.09 (0.05)
Black	-0.85*** (0.15)	-1.17*** (0.17)	-0.94*** (0.08)	-0.85*** (0.08)
Completed compulsory education	0.15* (0.07)	-0.14 (0.13)	0.15** (0.06)	0.15** (0.06)
Employed	0.27*** (0.06)	0.10 (0.08)	0.27*** (0.06)	0.27*** (0.06)
Log Household expenditure	0.42*** (0.03)	0.34*** (0.05)	0.42*** (0.02)	0.42*** (0.02)
Religious Generalised trust	0.34*** (0.08)	0.33** (0.10)	0.35*** (0.06)	0.34*** (0.06)
Personalised trust	-0.33** (0.10)	-0.30** (0.11)	-0.33*** (0.05)	-0.33*** (0.05)
Income aspiration	1.13*** (0.26)	1.20*** (0.27)	1.14*** (0.12)	1.13*** (0.12)
ART count per capita X Personalised Trust	0.01 (0.03)	0.03 (0.04)	0.01 (0.02)	0.01 (0.02)
Depressive Symptom Score X Personalised Trust	-6.05* (2.26)	-5.80** (2.13)	-6.07*** (1.08)	-6.05*** (1.08)
2.wave	-0.05*** (0.01)	-0.07*** (0.02)	-0.05*** (0.01)	-0.05*** (0.01)
3.wave	-1.18*** (0.18)	-1.32*** (0.24)	-1.14*** (0.07)	-1.18*** (0.07)
4.wave	-1.01*** (0.14)	-1.24*** (0.27)	-0.97*** (0.08)	-1.01*** (0.08)
5.wave	-0.65*** (0.18)	-0.98* (0.45)	-0.58*** (0.10)	-0.65*** (0.10)
	-0.75*** (0.17)	-1.15* (0.57)	-0.68*** (0.11)	-0.75*** (0.11)

101.w_dcnew	0.00 (.)	0.00 (.)	0.00 (.)
102.w_dcnew	0.36*** (0.04)	0.00 (.)	0.36 (0.23)
103.w_dcnew	0.19*** (0.04)	0.00 (.)	0.19 (0.25)
104.w_dcnew	0.16* (0.06)	0.00 (.)	0.16 (0.26)
105.w_dcnew	0.83*** (0.03)	0.00 (.)	0.83*** (0.24)
199.w_dcnew	-0.38** (0.11)	0.00 (.)	-0.38 (0.23)
210.w_dcnew	0.25** (0.07)	0.00 (.)	0.25 (0.27)
213.w_dcnew	-0.73*** (0.18)	0.00 (.)	-0.73** (0.25)
214.w_dcnew	-0.47** (0.17)	0.00 (.)	-0.47 (0.26)
215.w_dcnew	-0.35 (0.18)	0.00 (.)	-0.35 (0.24)
244.w_dcnew	-0.76*** (0.18)	0.00 (.)	-0.76** (0.26)
260.w_dcnew	-0.57** (0.19)	0.00 (.)	-0.57 (0.40)
299.w_dcnew	-0.68*** (0.15)	0.00 (.)	-0.68** (0.24)
306.w_dcnew	0.58*** (0.04)	0.00 (.)	0.58* (0.24)
307.w_dcnew	0.34*** (0.04)	0.00 (.)	0.34 (0.29)
308.w_dcnew	0.04 (0.04)	0.00 (.)	0.04 (0.24)
309.w_dcnew	-0.15 (0.17)	0.00 (.)	-0.15 (0.25)
345.w_dcnew	0.61*** (0.15)	0.00 (.)	0.61* (0.26)
416.w_dcnew	0.64*** (0.18)	0.00 (.)	0.64* (0.27)
418.w_dcnew	0.02 (0.19)	0.00 (.)	0.02 (0.25)
419.w_dcnew	0.27 (0.20)	0.00 (.)	0.27 (0.27)
420.w_dcnew	-0.12 (0.19)	0.00 (.)	-0.12 (0.27)
499.w_dcnew	0.25 (0.18)	0.00 (.)	0.25 (0.27)
521.w_dcnew	-0.59** (0.22)	0.00 (.)	-0.59* (0.24)
522.w_dcnew	-0.90*** (0.19)	0.00 (.)	-0.90*** (0.24)
523.w_dcnew	-0.41* (0.19)	0.00 (.)	-0.41 (0.23)
527.w_dcnew	-0.75** (0.23)	0.00 (.)	-0.75** (0.27)
528.w_dcnew	-0.59** (0.20)	0.00 (.)	-0.59* (0.25)
543.w_dcnew	-0.40 (0.20)	0.00 (.)	-0.40 (0.24)
556.w_dcnew	-0.87*** (0.19)	0.00 (.)	-0.87*** (0.24)
559.w_dcnew	-0.21 (0.18)	0.00 (.)	-0.21 (0.24)
599.w_dcnew	-0.45* (0.18)	0.00 (.)	-0.45* (0.22)
637.w_dcnew	0.65*** (0.17)	0.00 (.)	0.65** (0.25)
638.w_dcnew	0.07 (0.19)	0.00 (.)	0.07 (0.24)
639.w_dcnew	0.25 (0.18)	0.00 (.)	0.25 (0.24)
640.w_dcnew	0.14 (0.20)	0.00 (.)	0.14 (0.31)
742.w_dcnew	-0.38* (0.18)	0.00 (.)	-0.38 (0.24)
748.w_dcnew	0.22 (0.20)	0.00 (.)	0.22 (0.26)
797.w_dcnew	-0.22 (0.17)	0.00 (.)	-0.22 (0.23)
798.w_dcnew	-0.61*** (0.17)	0.00 (.)	-0.61** (0.23)
799.w_dcnew	0.08 (0.17)	0.00 (.)	0.08 (0.23)
830.w_dcnew	-0.23 (0.20)	0.00 (.)	-0.23 (0.24)
831.w_dcnew	-0.58** (0.17)	0.00 (.)	-0.58* (0.24)
832.w_dcnew	-0.40 (0.22)	0.00 (.)	-0.40 (0.24)
933.w_dcnew	-0.58** (0.18)	0.00 (.)	-0.58* (0.25)
934.w_dcnew	-0.54** (0.16)	0.00 (.)	-0.54* (0.26)



935.w_dcnew	-0.34 (0.17)	0.00 (.)		-0.34 (0.24)
936.w_dcnew	-0.05 (0.18)	0.00 (.)		-0.05 (0.24)
947.w_dcnew	-0.10 (0.16)	0.00 (.)		-0.10 (0.23)
_cons	4.33*** (0.64)	2.93* (1.38)	4.21*** (0.60)	4.33*** (0.62)
var(district)			0.15*** (0.04)	0.00*** (0.00)
var(individual)			0.00 (0.03)	
var(Residual)			5.04*** (0.07)	5.02*** (0.06)
<i>R</i> <sup>2</sup>	0.163	0.079		
<i>AIC</i>	66178.7	60013.6	66347.2	66280.7
<i>BIC</i>	66338.4	60165.8	66537.3	66828.3
ICC-district			0.0289	.
ICC-individual   district			0.0295	6.81e-10
Log likelihood	-33068.3	-29986.8	-33148.6	-33068.3
<i>N</i>	14857	14857	14857	14857

^= Models were clustered at district. Standard errors in parentheses; \* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001

### S15: Robustness check- Balanced Sample (ART count per capita vs. life satisfaction)

Table S15: Two-level random intercept models examining the relationship between ART count per capita and life satisfaction among young people for the balanced NIDS sample. Co-efficient (SE)

	(1) Null	(2) ART count per capita	(3) Health	(4) Socio- demographic	(5) Social Capital	(6) Personality trait	(7) Interaction Terms	(8) Time
	b/se	b/se	b/se	b/se	b/se	b/se	b/se	b/se
ART count per capita		2.10** (0.68)	2.23** (0.68)	1.54 (0.84)	1.50 (0.86)	1.66 (0.89)	3.20*** (0.96)	6.56*** (1.18)
Depressive Symptom Score			-0.10*** (0.01)	-0.08*** (0.01)	-0.08*** (0.01)	-0.08*** (0.01)	-0.07*** (0.01)	-0.07*** (0.01)
Underweight			0.00 (0.08)	-0.02 (0.08)	-0.04 (0.08)	-0.10 (0.09)	-0.09 (0.09)	-0.15 (0.09)
Female				0.10* (0.04)	0.04 (0.05)	0.03 (0.05)	0.03 (0.05)	0.02 (0.05)
Age^2				0.01*** (0.00)	0.01*** (0.00)	0.01*** (0.00)	0.01*** (0.00)	0.00 (0.00)
Age				-0.33*** (0.05)	-0.28*** (0.05)	-0.28*** (0.06)	-0.29*** (0.06)	-0.06 (0.06)
Black				-0.85*** (0.10)	-0.87*** (0.10)	-0.95*** (0.10)	-0.97*** (0.10)	-1.01*** (0.10)
Completed compulsory education				0.16* (0.07)	0.11 (0.07)	0.09 (0.07)	0.08 (0.07)	0.09 (0.07)
Employed				0.35*** (0.06)	0.30*** (0.06)	0.32*** (0.07)	0.32*** (0.07)	0.23*** (0.07)
Log Household expenditure				0.42*** (0.03)	0.41*** (0.03)	0.41*** (0.03)	0.41*** (0.03)	0.38*** (0.03)

Religious					0.44***	0.35***	0.34***	0.38***
					(0.08)	(0.08)	(0.08)	(0.08)
Generalised trust					-0.49***	-0.48***	-0.45***	-0.38***
					(0.07)	(0.07)	(0.07)	(0.07)
Personalised trust					0.29***	0.30***	1.10***	1.24***
					(0.05)	(0.06)	(0.15)	(0.15)
Income aspiration						0.08***	0.08***	0.03
						(0.02)	(0.02)	(0.02)
ART count per capita X Personalised Trust							-5.39***	-6.76***
							(1.36)	(1.35)
Depressive Symptom Score X Personalised_Trust							-0.05***	-0.06***
							(0.01)	(0.01)
2.wave								-1.14***
								(0.09)
3.wave								-0.97***
								(0.10)
4.wave								-0.56***
								(0.12)
5.wave								-0.57***
								(0.14)
_cons	5.30***	5.16***	5.77***	6.95*** (0.65)	6.21***	6.37***	6.24***	4.21***
	(0.09)	(0.11)	(0.11)		(0.68)	(0.71)	(0.71)	(0.75)
var(district)	0.38***	0.43***	0.36***	0.15*** (0.04)	0.13***	0.13***	0.13***	0.14***
	(0.08)	(0.10)	(0.08)		(0.03)	(0.03)	(0.03)	(0.04)
var(individual)	0.13***	0.16***	0.12***	0.00*** (0.00)	0.00***	0.00***	0.00***	0.00***
	(0.04)	(0.04)	(0.04)		(0.00)	(0.00)	(0.00)	(0.00)
var(Residual)	5.47***	5.49***	5.33***	5.24*** (0.07)	5.18***	5.20***	5.18***	5.07***
	(0.08)	(0.08)	(0.08)		(0.07)	(0.07)	(0.07)	(0.07)

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$R^2$								
AIC	58768.8	55763.8	52838.4	52169.4	48339.3	43729.0	43697.5	43494.5

<i>BIC</i>	58798.6	55800.9	52889.9	52279.7	48470.4	43865.5	43848.3	43674.0
ICC-district	0.0639	0.0712	0.0625	0.0271	0.0248	0.0244	0.0239	0.0274
ICC-individual   district	0.0863	0.0974	0.0823	0.0271	0.0248	0.0244	0.0239	0.0274
Log likelihood	-	-	-	-26069.7	-	-21845.5	-21827.7	-
	29380.4	27876.9	26412.2		24151.7			21722.2
<i>N</i>	12853	12177	11626	11579	10755	9719	9719	9719

Standard errors in parentheses; \*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ ; ICC=Intraclass Correlation Co-efficient

**S16: Robustness check- Lagged model (ART count per capita vs. life satisfaction)**

**Table S16: Regression models examining the relationship between ART count and life satisfaction using alternate model specifications and lagged life satisfaction variable. Co-efficient (SE)**

	(1) POLS <sup>^</sup> b/se	(2) FE <sup>^</sup> b/se	(3) 2-LEVEL RI b/se
lagged life satisfaction	0.03** (0.01)	0.02* (0.01)	0.03*** (0.01)
ART count per capita	8.40*** (1.58)	0.00 (.)	7.03*** (1.09)
Depressive Symptom Score	-0.08*** (0.01)	-0.08*** (0.01)	-0.08*** (0.01)
Underweight	-0.18 (0.10)	-0.11 (0.16)	-0.17* (0.08)
Female	-0.02 (0.05)	0.00 (.)	-0.02 (0.05)
Age <sup>^2</sup>	0.00 (0.00)	-0.00 (0.00)	0.00 (0.00)
Age	-0.11* (0.05)	0.10 (0.10)	-0.10 (0.06)
Black	-0.83*** (0.15)	0.97*** (0.25)	-0.98*** (0.09)
Completed compulsory education	0.20** (0.07)	-0.06 (0.16)	0.20** (0.07)
Employed	0.21** (0.08)	0.01 (0.11)	0.22** (0.07)
Log Household expenditure	0.44*** (0.03)	0.42*** (0.06)	0.44*** (0.03)
Religious Generalised trust	0.37*** (0.10)	0.30* (0.12)	0.38*** (0.07)
Personalised trust	-0.33** (0.11)	-0.28* (0.12)	-0.33*** (0.06)
Income aspiration	1.27*** (0.28)	1.21*** (0.30)	1.26*** (0.14)
ART count per capita X Personalised Trust	0.00 (0.04)	0.04 (0.04)	0.00 (0.02)
Depressive Symptom Score X Personalised Trust	-8.34** (2.53)	-7.84** (2.40)	-8.31*** (1.28)
2.wave	-0.04** (0.01)	-0.04* (0.02)	-0.04*** (0.01)
	-1.18*** (0.21)	-1.47*** (0.27)	-1.12*** (0.09)

3.wave	-0.94*** (0.15)	-1.41*** (0.32)	-0.87*** (0.10)
4.wave	-0.61** (0.21)	-1.38** (0.50)	-0.53*** (0.11)
5.wave	-0.69** (0.20)	-1.68** (0.62)	-0.59*** (0.13)
101.w_dcnew	0.00 (.)	0.00 (.)	
102.w_dcnew	0.56*** (0.05)	0.00 (.)	
103.w_dcnew	0.03 (0.04)	0.00 (.)	
104.w_dcnew	0.04 (0.06)	0.00 (.)	
105.w_dcnew	0.90*** (0.03)	0.00 (.)	
199.w_dcnew	-0.20 (0.11)	0.00 (.)	
210.w_dcnew	0.45*** (0.08)	0.00 (.)	
213.w_dcnew	-0.54** (0.18)	0.00 (.)	
214.w_dcnew	-0.48** (0.18)	0.00 (.)	
215.w_dcnew	-0.36 (0.19)	0.00 (.)	
244.w_dcnew	-0.61** (0.18)	0.00 (.)	
260.w_dcnew	-0.73*** (0.18)	0.00 (.)	
299.w_dcnew	-0.69*** (0.15)	0.00 (.)	
306.w_dcnew	0.82*** (0.05)	0.00 (.)	
307.w_dcnew	0.33*** (0.05)	0.00 (.)	
308.w_dcnew	-0.04 (0.05)	0.00 (.)	
309.w_dcnew	-0.14 (0.18)	0.00 (.)	
345.w_dcnew	0.54*** (0.15)	0.00 (.)	
416.w_dcnew	0.62** (0.19)	0.00 (.)	
418.w_dcnew	0.09 (0.19)	0.00 (.)	
419.w_dcnew	0.35 (0.20)	0.00 (.)	
420.w_dcnew	-0.21 (0.19)	0.00 (.)	
499.w_dcnew	0.32 (0.18)	0.00 (.)	
521.w_dcnew	-0.48* (0.22)	0.00 (.)	
522.w_dcnew	-0.85*** (0.20)	0.00 (.)	
523.w_dcnew	-0.43* (0.19)	0.00 (.)	
527.w_dcnew	-0.61* (0.23)	0.00 (.)	
528.w_dcnew	-0.48* (0.20)	0.00 (.)	
543.w_dcnew	-0.37 (0.21)	0.00 (.)	
556.w_dcnew	-0.85*** (0.19)	0.00 (.)	
559.w_dcnew	-0.30 (0.19)	0.00 (.)	
599.w_dcnew	-0.29 (0.18)	0.00 (.)	
637.w_dcnew	0.61*** (0.17)	0.00 (.)	
638.w_dcnew	0.08 (0.20)	0.00 (.)	
639.w_dcnew	0.31 (0.18)	0.00 (.)	
640.w_dcnew	-0.27 (0.22)	0.00 (.)	
742.w_dcnew	-0.32 (0.19)	0.00 (.)	
748.w_dcnew	0.13 (0.19)	0.00 (.)	
797.w_dcnew	-0.26 (0.17)	0.00 (.)	
798.w_dcnew	-0.59** (0.18)	0.00 (.)	
799.w_dcnew	0.13 (0.17)	0.00 (.)	
830.w_dcnew	-0.14 (0.20)	0.00 (.)	
831.w_dcnew	-0.58** (0.18)	0.00 (.)	

832.w_dcnew	-0.32 (0.23)	0.00 (.)	
933.w_dcnew	-0.62** (0.19)	0.00 (.)	
934.w_dcnew	-0.64*** (0.17)	0.00 (.)	
935.w_dcnew	-0.19 (0.17)	0.00 (.)	
936.w_dcnew	-0.07 (0.18)	0.00 (.)	
947.w_dcnew	-0.21 (0.16)	0.00 (.)	
_cons	4.17*** (0.64)	-0.70 (1.53)	4.05*** (0.71)
var(district)			0.13*** (0.03)
var(individual)			0.00*** (0.00)
var(Residual)			5.01*** (0.07)
<i>R</i> <sup>2</sup>	0.166	0.085	
<i>AIC</i>	46718.1	40581.9	46866.9
<i>BIC</i>	46877.8	40727.1	47055.7
ICC-district			0.0252
ICC-individual   district			0.0252
Log likelihood	-23337.0	-20271.0	-23407.5
<i>N</i>	10504	10504	10504

^= Models were clustered at district. Standard errors in parentheses; \*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$

## S17: Regression- BMI category versus life satisfaction among young people

### Supplementary File S17: Regression models examining the relationship between BMI category and life satisfaction on full sample. Co-efficient (SE)

	(3) 2-LEVEL RI b/se
Depressive Symptom Score	-0.08*** (0.01)
1.Underweight BMI^	-0.12 (0.07)
2. Overweight/Obese BMI^	0.06 (0.04)
Female	0.00 (0.04)
Age^2	0.00 (0.00)
Age	-0.07 (0.05)
Black	-0.90*** (0.07)
Completed compulsory education	0.16** (0.05)
Employed	0.24*** (0.05)
Log Household expenditure	0.42*** (0.02)
Religious	0.35*** (0.06)
Generalised trust	-0.34*** (0.05)
Personalised trust	0.63*** (0.08)
Income aspiration	-0.00 (0.02)
Depressive Symptom Score X Personalised_Trust	-0.05*** (0.01)
2.wave	-0.93*** (0.07)
3.wave	-0.68*** (0.07)
4.wave	-0.20** (0.08)
5.wave	-0.21* (0.08)
_cons	4.33*** (0.58)
var(district)	0.13*** (0.03)
var(individual)	0.00*** (0.00)
var(Residual)	5.02*** (0.06)
<i>AIC</i>	69732.3
<i>BIC</i>	69916.0
ICC-district	0.0244
ICC-individual   district	0.0244
Log likelihood	-34842.1
<i>N</i>	15628

^ Compared to healthy BMI. Standard errors in parentheses; \* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001



**Appendix 5: Supplementary File for Qualitative Study  
(Paper 3)**

**A qualitative enquiry into the meaning and experiences of wellbeing  
among young people living with and without HIV in KwaZulu-Natal,  
South Africa**

## S1 Description of dimensions in Ryff's Psychological Wellbeing model

Extracted from: (Ryff, 2014)

<b>Dimension</b>	<b>Aligned to theory</b>	<b>High scorer</b>	<b>Low scorer</b>
Autonomy	Self-actualisation (Maslow, 1968)  Individuation (Jung, 1933)	Is self-determining and independent; able to resist social pressures to think and act in certain ways; regulates behavior from within; evaluates self by personal standards	Is concerned about the expectations and evaluations of others; relies on judgments of others to make important decisions; conforms to social pressures to think and act in certain ways
Environmental mastery	Personal development (Erikson, 1994)  Basic life tendencies (Buhler, 1959)	Has a sense of mastery and competence in managing the environment; controls complex array of external activities; makes effective use of surrounding opportunities; able to choose or create contexts suitable to personal needs and values	Has difficulty managing everyday affairs; feels unable to change or improve surrounding context; is unaware of surrounding opportunities; lacks sense of control over external world
Personal growth	Individuation (Jung, 1933)  Mental health (Jahoda, 1958a)	Has a feeling of continued development; sees self as growing and expanding; is open to new experiences; has sense of realizing his or her potential; sees improvement in self and behavior over time; is changing in ways that reflect more self-knowledge and effectiveness	Has a sense of personal stagnation; lacks sense of improvement or expansion over time; feels bored and uninterested with life, feels unable to develop new attitudes or behaviors
Positive relations with others	Will to meaning (Frankl, 2014)  Mental health (Jahoda, 1958a)	Has warm, satisfying, trusting relationships with others; is concerned about the welfare of others; capable of strong empathy, affection and intimacy; understands give and take of human relationships	Has few close, trusting relationships with others; finds it difficult to be warm, open, concerned about others; is isolated and frustrated in interpersonal relationships; not willing to make compromises to sustain important ties with others
Purpose in life	Basic life tendencies (Buhler, 1959)	Has goals in life and a sense of directedness; feels there is meaning to present and	Lacks a sense of meaning in life; has few goals or aims, lacks

	Executive processes of personality (Neugarten, 1973)	past life; holds beliefs that give life purpose; has aims and objectives for living	sense of direction; does not see purpose in past life; has no outlooks or beliefs that give life meaning
Self-acceptance	Maturity (Allport, 1961)  Fully functioning person (Rogers, 1963)	Possesses a positive attitude toward the self; acknowledges and accepts multiple aspects of self, including good and bad qualities; feels positive about past life	Feels dissatisfied with self; is disappointed with what has occurred in past life; is troubled about certain personal qualities: wishes to be different than what he or she is

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## S2: Topic guide (FGDs)

<p><b><u>TOPIC:</u></b> FGD on young people’s experiences and perceptions of wellbeing</p> <p><b><u>AIM:</u></b> The aim of the pilot FGD is to get a broad sense of how YP in this community perceive a good and bad life</p>	
<p><b><u>ROLES &amp; RESPONSIBILITIES</u></b></p> <ol style="list-style-type: none"> <li>1. Moderators- Kealeboga Maruping: facilitate the FGD, manage referrals. Siphon to moderate FGD with males with assistance from Kea</li> <li>2. Note taker- Mbalenhle Msweli: contact and invite participants for FGD, await participants at the clinic, take notes, keep time, assist with referrals, icebreakers, lunch, breaks, reimbursements, recorders</li> <li>3. Observer- Darshini Govindasamy</li> </ol>	
<p><b><u>MATERIAL &amp; NEEDED</u></b></p> <ul style="list-style-type: none"> <li>• Appointment roster and participant locator form</li> <li>• Demographic Information Sheet</li> <li>• Art &amp; Crafts Supplies (paint, markers, crayons, glitter glue, colour paper, boards)</li> </ul>	<ul style="list-style-type: none"> <li>• Voice recorders, journal, invoice book</li> <li>• Participant packs (information brochure, grocery voucher, lunch pack, transport fare, certificate of participation)</li> <li>• Name badges (use labels)</li> <li>• Electronic tablets</li> <li>• Soccer ball &amp; string</li> </ul>
<p><b><u>KEY AREAS TO PROBE</u></b></p>	<ul style="list-style-type: none"> <li>• Education, food security, health, employment, household and family, children, marriage/partnerships, sexual relationships, HIV complications, alcohol and substance abuse</li> </ul>

PART A: INTRODUCTION		
	TIME (10:00-10:30 AM)	INSTRUCTIONS/[SCRIPT]/COMMENTS
1. Play video		<ul style="list-style-type: none"> <li>✓ <b>Icebreaker 1-</b> When the majority of the group members have arrived, <b>play the Njabulo study video</b> <ul style="list-style-type: none"> <li>• When the late comers arrive, replay the video for them</li> </ul> </li> </ul>
2. Welcome	2 minutes	<ul style="list-style-type: none"> <li>✓ <b>Introduce yourself and the Njabulo study team.</b> <ul style="list-style-type: none"> <li>• <i>[Hello everyone and thank you for being here today. I know you are all very busy and I want you to know how much I appreciate you taking this time to participate in this <b>team discussion</b>.</i></li> <li>• <i>Before we begin, let me introduce our team members on the Njabulo study:</i></li> <li>• <i>My name is Kea I will facilitate the discussion. My colleague, Mbale, will take down key points from our discussion. In addition, my colleague Darsh will observe the discussion for us. ]</i></li> </ul> </li> </ul>
3. Objectives of the FGDs	1 minute	<ul style="list-style-type: none"> <li>✓ <b>Recap why we are doing this FGD/study and how it could benefit YP in SA.</b> <ul style="list-style-type: none"> <li>• <i>[Just to recap, the reason why we are conducting this study is that we want to know what are the factors affecting quality of life among young people. This can help us better understand how we can improve the lives of young people in this community. ]</i></li> </ul> </li> </ul>
4. Introduce the participants to each other	5 minutes	<ul style="list-style-type: none"> <li>✓ <b>Icebreaker 2-</b> Go around the room and ask each participant and staff member to give us a <b>name</b> they would like us to call them by for today's team discussion. Write this on a label and give it to them to wear. <ul style="list-style-type: none"> <li>• Then, ask the participants to come up with a <b>team name</b></li> </ul> </li> </ul>
5. Breakdown of the planned schedule and Ground rules	5 minutes	<ul style="list-style-type: none"> <li>✓ <b>Provide a brief description of what the group will do today</b> (working in groups, discussion, lunch, teamwork, team spirit). <i>[So, in terms of what we got going today]:</i></li> </ul>

		<ul style="list-style-type: none"> <li>• <i>I will divide you guys into two groups. Each group will have to use this board and draw/paint/write what comes to mind based on my question. I will go to each group to check if there any questions. Note, this <u>not a test/exam/assignment/you not getting any marks for this. There are no right/wrong answers</u></i></li> <li>• <i>We will then come together and discuss each group's artwork</i></li> <li>• <i>At the end, we will have a little snack and close the discussion.</i></li> <li>• <i>We will record our discussion on this device. Note, this device will be stored in locked cupboards, and no one other than our study staff will have access to this. All the information you share will be kept confidential.</i></li> <li>• <i>Remember, when you talk, <u>talk about people you know as opposed to sharing your own personal experience.</u></i></li> <li>• <i>You can speak <u>in isiZulu/English/both</u>, whatever you prefer.</i></li> <li>• <i>You can stop me at any time to explain/repeat something I said.</i></li> </ul> <p>✓ <b>Go through the list of ground rules, and after each point ask if there are any questions</b></p> <ol style="list-style-type: none"> <li>a. <b>Audio recording requirements-</b> <i>phones on silent (call/message can be taken when there is an emergency), volume, stay close to a recorder when talking, try not to speak over another participant, <b>ask the team for 1-2 volunteers who will move the recorder around when each person speaks.</b></i></li> <li>b. <b>Artwork-</b><i>no right or wrong drawing. Indicate that this is not a test/exam/assignment/you are not getting marks for this. Participants can draw/paint/cut/ stick symbols/write based on whatever comes to mind when I give you your group topic, emphasise that you are not looking for best drawer/painter.</i></li> <li>c. <b>Questions-</b> <i>raise your hand if you need me to re-explain or need to take a break/need a glass of water/just need to chat to one of us alone.</i></li> <li>d. <b>Stress that this is a once off group discussion-</b><i>indicate that we have many groups, and all groups will only meet once.</i></li> <li>e. <b>This is not a competition-</b> <i>we are not giving anyone a prize for the best drawing</i></li> </ol>
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		<p><b>f. No pics/selfies-</b> because this a safe space, no pics during and after the FGD are allowed. Whatever we do here stays here, we do not take it back to the outside world.</p>
<b>6. Confidentiality</b>	<b>10-15 minutes</b>	<p>✓ <b>Icebreaker 3: Crossing over the confidentiality line/Zone of trust</b></p> <ul style="list-style-type: none"> <li>• Get participants to line up at the door. Place a string at the entrance. Highlight the meaning of the process. Indicate to them that when they cross over they agree to respect what their team members say and not share it with others outside. You can get them to throw the ball/hold each member's hand as they walk over. <u>Ensure that you and the Njabulo team also cross-over</u></li> <li>• <u>Emphasise the need to talk about people they know as opposed to sharing personal experiences</u>, secure agreement from participants that they will respect team members, whatever is said they will keep private and will not share with others outside this room</li> </ul>
❖ <b>Tips for KM</b>		<ul style="list-style-type: none"> <li>❖ Ensure you get into the group circle before group members arrive. Avoid doing any of the co-ordination activities/being seeing making any calls/ decisions when participants walk in</li> <li>❖ As participants arrive, casually chat to them/integrate yourself into their conversations. Laugh/chat with them. Speak at their level.</li> <li>❖ Complete consensus form</li> </ul>
❖ <b>Tips for MM</b>		<ul style="list-style-type: none"> <li>❖ Wait for participants at the entrance of the clinic, assist them with signing of the clinic register and navigate them to the study room. As you walk with them, reassure them that they do not have to be nervous and this will be a fun team activity.</li> <li>❖ Call any late comers</li> <li>❖ Before the FGD starts, make sure you check the positioning of the recorders, and ensure that the curtain is drawn (entrance is blocked)and there is sufficient airflow</li> <li>❖ Note taking- write down the first keywords spoken by each participant</li> <li>❖ Write down key description of each participants voice to aid in voice recognition during the transcription</li> </ul>

PART B: ARTWORK		
	TIME (10:30-11:00am)	INSTRUCTIONS/[SCRIPT]/COMMENTS
1. Main activity-arts & crafts	30 minutes	<p>✓ Randomly divide the group into two, and allocate each group a room to work in</p> <ul style="list-style-type: none"> <li>• <b>Group 1</b> must be instructed to depict a scenario of a <b>young person</b> doing well in this community</li> <li>• <b>Group 2</b> must be instructed to depict draw a picture of a <b>young person</b> not doing well in this community.</li> <li>• Inform them that they can use any of the arts and craft material supplied.</li> <li>• Emphasise that we are not looking for the best drawers/painters, and there is no right/wrong representation. <i>[We just want to know what comes to mind when you think about the question. Therefore, you can either draw images, cut and paste symbols, paint, write etc. There is no right or wrong answer. You can be as creative as you want!]</i></li> </ul> <p>❖ <b>Note to KM &amp; MM:</b></p> <ul style="list-style-type: none"> <li>❖ Stand outside the room whilst groups are working, check-in with each group at the beginning, middle and end.</li> <li>❖ Do not tell them how much time they have left, rather state in friendly manner the exact time.</li> <li>• Do not give them any hints on what to draw/write. When in the room, check that the recorder is placed in a good angle (away from water/paint). Ask the group if they need any extra material/supplies.</li> <li>• Highlight <u>that this is not a test/exam/assignment/you are not getting marks for this. There is no right/wrong answer.</u></li> </ul>
2. Wash-up & snack	5-10 minutes	<p>✓ Provide participants with soap and paper towels to wash and dry their hands</p> <p>✓ <b>Icebreaker 4: Get them together as a group and provide them with a snack</b></p>



		<ul style="list-style-type: none"> <li>• Leave them to talk amongst themselves. The moderator should sit in the group, eat snacks with them, and listen to their conversation.</li> </ul>
<b>3. Trust reinforcement</b>	<b>1-2 minutes</b>	<ul style="list-style-type: none"> <li>✓ <b>Reinforce the importance of trust/teamwork/ team spirit</b></li> </ul>
❖ <b>Tips for KM</b>		<ul style="list-style-type: none"> <li>❖ Observe and document the engagement within the groups (who is: directing the group, leading the drawing/painting/writing, not participating, working separately from the rest, assisting group members, arguing with other group members)</li> </ul>
❖ <b>Tips for MM</b>		<ul style="list-style-type: none"> <li>❖ Observe and document the engagement within the groups (who is: directing the group, leading the drawing/painting/writing, not participating, working separately from the rest, assisting group members, arguing with other group members)</li> </ul>

PART C: DISCUSSION		
	TIME (11:15-12:45 am)	INSTRUCTIONS/[SCRIPT]/COMMENTS
1. Good life discussion	30 minutes (11:15-11:45am)	<ul style="list-style-type: none"> <li>• Bring participants together in the room and <b>discuss each group's artwork.</b></li> <li>• Indicate that this is not a test/exam/assignment/you are not getting marks for this. There is no right/wrong answer.</li> <li>• Hold the artwork up so everyone can see.</li> <li>• <b>Probe the following</b> <ul style="list-style-type: none"> <li>▪ What do the images/words/drawings symbolise/mean/represent?</li> <li>▪ You mentioned one needs (x, y,z) to have a good life. How does x, y,z benefit young people (the individual), the household and community?</li> <li>▪ What could cause a person to lose this good life and move into a bad life?</li> <li>▪ If that happened, what would the young person need to get back on track towards a good life</li> <li>▪ Was there anything you did not put on this drawing because you did not have time?</li> <li>▪ How do young people define happiness?</li> <li>▪ What do young people consider most meaningful in their lives?</li> </ul> </li> <li>• <b>Ask if there is agreement/disagreement with each key theme</b></li> <li>• <b>Summarize what was said-ask if your summary is correct</b></li> <li>• <b>Repeat the exercise above with the "good life group"</b></li> <li>• <b>Summarize what was said and ask if your summary is correct</b></li> </ul>
2. Lunch & icebreaker	20 minutes (11:45am-12:10pm)	<ul style="list-style-type: none"> <li>✓ <b>Icebreaker 5:</b> Provide the participant with their lunch pack and juice. Inform them that they can use the clinic toilets if they wish (direct them to this).</li> <li>• Play some instrumental music and if time permits get them to dance/play musical chairs</li> </ul>
3. Bad life discussion	30 minutes (12:15-12:45pm)	<ul style="list-style-type: none"> <li>✓ Hold the artwork up so everyone can see.</li> <li>• Indicate that this is not a test/exam/assignment/you are not getting marks for this. There is no right/wrong answer.</li> </ul>

		<ul style="list-style-type: none"> <li>● <b>Probe the following:</b> <ul style="list-style-type: none"> <li>▪ What do the images/words/drawings symbolise/mean/represent?</li> <li>▪ What makes a bad life for a young person on this community?</li> <li>▪ How do these things you mention impact young people (individual), the household, and community?</li> <li>▪ If a young person was experiencing this bad life, what will he/she need to turn it around and move into a good life?</li> </ul> </li> <li>● <b>Ask if there is agreement/disagreement with each key theme</b></li> <li>● <b>Summarize what was said-ask if your summary is correct</b></li> <li>● <b>Repeat the exercise above with the “bad life group”</b></li> <li>● <b>Summarize what was said and ask if your summary is correct</b></li> </ul>
❖ <b>Tips for KM</b>		<ul style="list-style-type: none"> <li>❖ Actively listen. Inserts the probes naturally into their discussion as opposed to making it a Q&amp;A.</li> <li>❖ Assess levels of agreement and disagreement with each key theme mentioned</li> <li>❖ Observe who is not speaking and ask them for input. Observe who is dominating the conversation</li> <li>❖ Try to write down the key words/themes spoken about</li> <li>❖ Ask for clarification if there are phrases/slang words being used</li> <li>❖ If someone brings up a personal experience do not close them off as they may feel what they are saying is shameful and be reluctant to engage. Give them a chance to share their experience.</li> <li>❖ If <u>someone shares a personal experience and becomes distressed/causes distress among others</u>. Continue with the theme in a very sensitive manner/without marginalising/. MM will go the distressed participants and ask them if they want some privacy to talk in the next room.</li> </ul>
❖ <b>Tips for MM</b>		<ul style="list-style-type: none"> <li>❖ Write down which parts of the discussion did major events take place (change in tone, silence, strong expression, several head nodding or shaking from side to side to a response)</li> <li>❖ Observe and document which topics most engaged participants</li> <li>❖ Complete the FGD consensus framework</li> </ul>

PART D: WRAP-UP		
	TIME (12:45-1:15pm)	INSTRUCTIONS/[SCRIPT]/COMMENTS
1. Closure questions	10 minutes	<ul style="list-style-type: none"> <li>✓ Thank the participants and <i>summarise the activity and key themes that emerged.</i></li> <li>✓ <u>Ask them the following:</u> <ul style="list-style-type: none"> <li>• <i>Is there anything else someone would like to say?</i></li> <li>• <i>What would you like to see coming out of our study?</i></li> <li>• <i>If you would like to ask me something alone before you leave feel free to come up to me and we can talk in a private area.</i></li> </ul> </li> </ul>
2. Mourning phase & evaluation	5 minutes	<ul style="list-style-type: none"> <li>✓ <b>Get the group to stand up and officially close the group.</b> <ul style="list-style-type: none"> <li>• Get everyone in the room to hug on another and say their goodbyes</li> <li>• Make participants stand in a line and go over the string at the entrance and bounce the ball back in the room. Highlight the purpose of this</li> <li>• Get them to complete the <b>Participant evaluation form.</b></li> </ul> </li> </ul>
3. Reimbursements	10 minutes	<ul style="list-style-type: none"> <li>✓ <b>Provide the participant with their reimbursements</b> (voucher, certificate of completion and information brochure) <ul style="list-style-type: none"> <li>• Explain to them how to use the voucher, what purchases are not allowed (alcohol and cigarettes), and they should call/SMS should they have any problems with the voucher</li> <li>• Get them to sign the reimbursement forms.</li> <li>• Go through the information sheet with them</li> </ul> </li> </ul>
4. Referrals	5 minutes	<ul style="list-style-type: none"> <li>✓ <b>Assess if any participant requires a referral</b> to any health or social services for support. <ul style="list-style-type: none"> <li>• Ensure you ask the individual to stay behind, and complete the referral form</li> <li>• Say your final goodbye to the group</li> </ul> </li> </ul>

### **S3: Topic guide (IDIs)**

#### **A. INTRODUCTION**

*[Introduce yourself to the participant. Highlight briefly, what you will do in this interview, ask the participant to complete the background information sheet]*

- *Hello, and thank you for being here today. I know you are very busy and I want you to know how much I appreciate you taking this time out to talk with me and help us better understand how we can improve the health of young people in this community.*
- *Let me introduce myself; my name is \_\_\_\_\_. I am a \_\_\_\_\_ and I will be facilitating our interview today.*
- *(If participant has given permission)-To keep a record of your comments, I will be recording our interview on this digital recorder and will be taking some notes.*
- *(If participant has given permission)-I will take a picture of the artwork you develop at the end.*
- *Again, no one outside of this building or at the clinic will see or hear the raw records. Only other researchers and I working on this study will have access to this information.*

*[Emphasise the importance of the topic and what the information will be used for]*

*[Reassure the participant about the confidential nature of this process and for open and honest responses]*

#### **B. INTERVIEW QUESTIONS**

*Prior to beginning the activity with the participant, usher them into the conversation by first talking about their life. Ask them about their background, home life, social life, school life etc. Try to get the participant to talk about their life in such a way that will “paint a picture” of what will go into the timeline.*

##### **1. Ushering participant into the conversation**

- Tell me more about yourself
- Where are you from?
- What kind of family are you from?
- What is your school life like?
- How is your social life?

##### **1.1. Tell me about someone you admire.**

- Why do you admire this person?
- Is there anything significant that you have learnt from this person?
- What lessons do you take into your life from this person?

*If they were part of the focus group probe on some of the key points they brought up that may have been an influence in their life.*

## **2. Clarifying statements from FGD**

### **2.1. Ask the participant to clarify any interesting statements they may have made during the focus group discussion.**

- Try to concentrate on statements that had a lot to do with the self.
- Probe on these statements

### **2.2. Is there any point in the discussion where you felt like bringing up your experiences of living with HIV?**

- What stopped you?

## **3. Activity 1 Life-course timeline approach**

*[From this point onwards alert the participant that the points they make may be important for the activity that will follow and you will be actively taking down notes in order to remind both yourself and them when doing the activity that will follow the conversation]*

### **3.1. Drawing the timeline**

*[Provide participant with paper and arts and craft material].* I would like you to draw a line and highlight key events in your life that took place at particular stages in your life (i.e. when you were a toddler, in primary school and in secondary school). You can highlight happy or sad events. Using the pens and material highlight anything you remember about this day (e.g. new clothes, a birthday cake, a gift you received, how family member felt) and where the event took place (school, home, church)

- Please draw a timeline of your life, highlighting all your happiest and saddest moments (death, birth, passing, hearing shocking news, revealing secrets etc.)

### **3.2. Life course conversation**

*[Explore the following questions for each event, homing in on specific happy and sad events]*

- Describe this day? [Why did it happen, where did it occur, who was with you]
- How did you feel on this day?
- What is it about this day that made you feel this way?
- How did you cope with this day that made you sad? [Probe – individual, household, community, school-related factors, who, what why did they rely on for support]
- Looking back, how do you now feel about this day?
- Now, when you become sad, what do you do to pick yourself up again?

#### **3.2.1. Describe the top memorable moments in your life (from when you were younger up to now)**

- Moments that stand out as the happiest and saddest

- Moments when life altering things happened (e.g. Death of a loved one, moving from one place to another, finding out about status)

*[Probe moments such as HIV disclosure (the day they found out, the day they told a close friend, the day they told their family etc. if the participant is HIV positive)]*

#### **4. Present day**

- Who do speak to when you are feeling down and sad these days?
- Who do you speak to when you want to talk about issues surrounding your HIV status?
- Since you have reflected on past events, what would you tell the younger you?
  - About dealing with problems in general.
  - Your feelings towards HIV and how she/he could better cope with finding out for the first time and daily life after that?
- Would you say you have accepted your status?
  - How/ why would you say you have accepted your status?

#### **C. CLOSURE**

*[Use this opportunity to follow up on anything new and interesting that you heard. Ask the participant if there is anything, they wish to share. Close the interview and thank the interviewee for their participation. Give the participant their reimbursement voucher, and provide refreshments]*

1. Is there anything else you would like to say?
2. From what we have discussed today, what message would you give to someone else in your position?
3. What would you like to see coming out of our study?

#### S4: Topic guide (KIIs-HCWs)

TYPE OF TOPIC GUIDE	<ul style="list-style-type: none"> <li>• Key informant interviews with HCWs working in study clinics</li> </ul>
PURPOSE OF THIS INTERVIEW	<ul style="list-style-type: none"> <li>• To understand what HCWs perceive are the key factors impacting quality of life among young people living with and without HIV</li> </ul>
STUDY TEAM- ROLES	<ul style="list-style-type: none"> <li>• Interviewer- Kealeboga Maruping/Darshini Govindasamy</li> <li>• Note taker- Kealeboga Maruping/Mbalenhle Msweli</li> <li>• Observer- Darshini Govindasamy/Mbalenhle Msweli</li> </ul>
VENUE	<ul style="list-style-type: none"> <li>• Clinic room</li> </ul>
IETMS NEEDED	<ul style="list-style-type: none"> <li>• Topic guide, 2 recorders, lunch packs (sandwich, fruit, juice, water bottle), pens, tissue, wet wipes, Tablet with pics from FGDs and IDIs</li> </ul>

1.	INTRODUCTION (5 minutes)	COMMENTS/QUESTIONS/PROBES	YOUR NOTES
	<i>Welcome</i>	<ul style="list-style-type: none"> <li>• Introduce yourself and team (name, role, institution).</li> <li>• Thank the HCWs for taking time out of their busy schedule to participate in this study</li> </ul>	
	<i>Purpose of study</i>	<ul style="list-style-type: none"> <li>• Highlight the key purpose of this study.</li> <li>• <i>“We are doing this study to better understand what are the factors that impact on a young person’s physical, emotional and mental health”</i></li> <li>• <i>We are trying to understand how wellbeing/QOL is understood by local people to ensure we can measure this construct in the future accurately</i></li> </ul>	
	<i>Breakdown of schedule (Structure, time, break)</i>	<ul style="list-style-type: none"> <li>• <i>“In terms of what we will be doing today. I will ask you a few questions and record it on this device. “</i></li> <li>• <i>“This interview should take us 1 hour. You may break at 30 minutes should you need a break. “</i></li> </ul>	
	<i>Ground rules (confidentiality, recording, cellphones, emergencies,</i>	<ul style="list-style-type: none"> <li>• Everything you say today will be kept confidential and private. All your documents will only contain your study ID and no personal identifiers.</li> </ul>	



	<i>volume, personal info)</i>	<p>We will store these recorders and your information in a locked cupboard.</p> <ul style="list-style-type: none"> <li>Your management/organisation will not have access to the information you supply us with.</li> <li>Only staff working on this study will have access to this data</li> <li>We are recording this interview, so please kindly increase the volume when you speak.</li> <li>Please kindly keep your cellphone on silent. If there is an emergency/if there are any emergencies at the clinic please let me know and we can pause the interview and reschedule if need be</li> <li>During the interview if you wish to highlight a particular patient case feel free but remember not to mention the person's name (call the patient case 1 or 2 etc.)</li> </ul>	
2	BACKGROUND (20 minutes)	QUESTIONS/COMMENTS/PROBES	YOUR NOTES
		<ul style="list-style-type: none"> <li><i>I will begin by asking you a few questions on your role</i></li> </ul>	
		<ol style="list-style-type: none"> <li>1. What is your official job title?</li> <li>2. What is the name of the organisation/s you work for?</li> <li>3. How long have you been in this position?</li> <li>4. Which areas/wards are you responsible for?</li> <li>5. Talk us through your typical workday (what do you do, what are your key responsibilities)</li> </ol> <p>Ice-breaker- refreshments</p>	
		<ul style="list-style-type: none"> <li><i>We will now talk more about young people living with HIV (15-24 years) who attend this clinic</i></li> </ul>	

		<ol style="list-style-type: none"> <li>1. Could you talk us through a patient’s journey in this clinic?       <ol style="list-style-type: none"> <li>a. 15-24 yrs.- what happens when they test HIV+ and get referred to this clinic to start treatment</li> <li>b. What are some the common clinical complications you observe among 15-24-year olds in this clinic?</li> </ol> </li> <li>2. How is it like for you engaging with YPLHIV?</li> <li>3. What are some the key challenges facing this group?       <ul style="list-style-type: none"> <li>- Psycho-social</li> <li>- Socio-economic</li> <li>- Their caregivers</li> </ul> </li> <li>4. Which group of patients are eligible for the disability grant? (Probe- in the past year, did you administer this to any 15-24-year-old?)</li> <li>5. What interventions do you think are needed to reduce the impact of these issues?</li> <li>6. What do you think is important to YPLHIV?</li> <li>7. What do you when you identify any of the following <i>(feel free to talk about specific cases you encountered, without providing us with the individual’s name)</i>?       <ol style="list-style-type: none"> <li>a. A YPLHIV who is defaulting ART and has an unsuppressed VL</li> <li>b. A YPLHIV who is pregnant and defaulting ART</li> <li>c. A caregiver who is struggling to disclose to their child/grandchild their HIV status</li> <li>d. A YPLHIV who is depressed</li> <li>e. A YPLHIV who has a “sugar daddy” or “blesser”</li> <li>f. A YPLHIV who is being abused</li> </ol> </li> </ol>	
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		<p>g. A YPLHIV who discloses being raped</p> <p>h. A YPLHIV who has not disclosed to their status to their caregiver</p> <p>i. A YPLHIV who has not disclosed their HIV status to their partner</p> <p>8. What would be your message to YPLHIV and their caregivers?</p> <p>9. What would be your message to other HCWs working with YPLHIV?</p> <p>Ice-breaker- refreshments/loo break</p>	
3	MAIN INTERVIEW (30 minutes)	QUESTIONS/COMMENTS/PROBES	YOUR NOTES
	Perceptions of key factors associated with quality of life	<ul style="list-style-type: none"> <li>I am now going to ask you a few brief and in-depth questions regarding what you think about quality of life.</li> </ul>	
		<p>1. What <u>do you</u> think makes a good life for a young person in this community?  [Probe factors at each level- individual, community, school, family, household level, and <u>by HIV-status, sex</u>]  <i>[Probe further for any patient cases the interviewee mentions, use visuals to stimulate discussion]</i>  <i>[Discuss Njabulo key findings- family, mother, education, house, gender differences]</i>  <i>[Show pics]</i></p>	
		<p>2. What do you think are the factors that makes a bad life for a young person in this community?  <i>[Probe factors at individual, community, school, family, household level, and by <u>HIV-status, sex</u>]</i>  <i>[Probe further for any patient cases the interviewee mentions, use drawing to stimulate discussion]</i>  <i>[Discuss Njabulo key findings- acceptance, belonging, drug use,</i></p>	

		<i>rejection by father, friendships, gender differences]</i> <i>[Show pics]</i>	
4	CLOSURE (5 minutes)	QUESTIONS/COMMENTS/PROBES	YOUR NOTES
	<i>Summary</i>	<ul style="list-style-type: none"> <li>• Thank you for your time. We have reached the end of this interview.</li> <li>• I would like to summarize what we discussed <ol style="list-style-type: none"> <li>1. <i>Firstly, we discussed what are the key issues YPLHIV face in this community and the support you provide-you indicated it was...</i> <ul style="list-style-type: none"> <li>- <i>Is this summary correct?</i></li> </ul> </li> <li>2. <i>Secondly, we discussed what promotes good quality of life among YPLHIV- and you indicated it was....</i> <ul style="list-style-type: none"> <li>- <i>Is this summary correct?</i></li> </ul> </li> <li>3. <i>Lastly, we discussed what are the factors that can lead to poor quality of life among YPLHIV- and you indicated it was.....</i> <ul style="list-style-type: none"> <li>- <i>Is this summary correct?</i></li> </ul> </li> </ol> </li> </ul>	
	<i>Additional comments</i>	<ol style="list-style-type: none"> <li>4. Is there anything else you would like to say?</li> <li>5. Do you have any questions for me?</li> </ol>	
	<i>Message</i>	<ol style="list-style-type: none"> <li>6. What is the key message you would really like me to take away from today?</li> </ol>	
	<i>Results</i>	<ol style="list-style-type: none"> <li>7. What would you like to see coming out of our study?</li> </ol>	
	<i>Next steps</i>	<ol style="list-style-type: none"> <li>8. I'll be analysing the information you and other HCWs and YP provide us with</li> <li>9. I will meet with you in August to share new findings that have emerged</li> <li>10. We will organize a workshop in August where will share findings and gain input. We will invite you to attend this.</li> </ol>	

	<i>Reimbursement</i>	<p><b>11.</b> I will now officially close the interview.</p> <p><b>12.</b> On behalf of the Njabulo study we wish to say thank you <i>provide HCWS with a water bottle, juice lunch pack, and fruit)</i></p> <p><b>13.</b> NB: Please get the HCWS to sign the reimbursement form</p>	
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## S5: Topic guide (KIIs-Experts)

- **Focus of interview:** wellbeing among young people living
- **Time:** 1 hour
- **Format:** via Skype
- **Interviewer:** Darshini Govindasamy

### A. INTRODUCTION

- Introduce yourself
- Highlight key objectives of the qualitative study
- In terms of the structure of the interview. I will first complete the consent procedures and then move onto the interview
- In terms of the consent, is there anything specific you would like me to touch on that was not clear? But just to re-emphasise
  - a. Confidentiality- our interview will be audio-recorded. The file will be labelled with your unique study ID and stored on our SAMRC drive with restricted access.
  - b. Only staff working on this study will have access to this file (i.e. PC and transcriber)
  - c. Consent forms – are stored in a locked cupboard at SAMRC
  - d. I am conducting this interview in a private room to ensure no one can hear us
  - e. Information shared in this interview may be used in reports and publications. We will ensure these do contain any personal identifiers (i.e. name, academic affiliations).
  - f. Are there any questions
- OK, so now for the main part of the interview. I will begin by asking you a few broad questions on your background and then move onto specific questions regarding your research in this area. At XX, I will move into my study presentation and discuss key emerging findings.
  1. Could you kindly describe your training, your current role and research affiliation, and the type of research you conduct?
  2. In terms of the XX [Key wellbeing/adolescent health project/study they worked on]:

### B. MAIN INTERVIEW

1. Kindly provide an **overview of the research** you conducted in the field of xx research (quality of life/wellbeing/adolescent health).

#### **Probe:**

- i. How did you move into this field? (What drew you to this field)
- ii. Describe some of the key studies you have led in this area? [Probe key studies]

2. Drawing on your previous research on wellbeing in South Africa/SSA/LMICs/HICs
  - i. How has your **understanding of wellbeing** in XX changed over the years?  
**Probe**-Which **theories/frameworks** do you draw on to facilitate your understanding of this concept?
  - ii. What would you say currently are the **key correlates of wellbeing among youth? Probe-** *(by age/sex/race)*
  
3. What are some of the **current gaps** in the area of wellbeing, particularly on youth in South Africa/SSA/LMICs?  
**Probe:**
  - i. Gaps in theory
  - ii. Gaps in measurement
  
4. How do you see this research area (wellbeing among youth in South Africa/SSA/LMICs) **evolving in the future?**  
**Probe:**
  - i. Wellbeing in general
  - ii. Wellbeing and youth
  
5. How has your **research been received** by the following groups? Moreover, what were the key **challenges** in engaging with these groups?  
**Probe:**
  - i. Governments- policymakers, politicians
  - ii. Civil society
  - iii. Research participants
  
6. Discussion on emerging themes from my qualitative study on wellbeing among young people living with and without HIV in KZN, South Africa (**Njabulo study**)  
**Probe:**
  - i. Highlight key themes emerging from the data and challenges
  - Advice on further areas to probe
  - ii. Are my interpretations consistent with previous findings? Do they differ, and how?
  - iii. Advice on further areas to probe

### **C. CLOSE INTERVIEW**

- Ask the participant if they have any questions or comments
- Provide a key summary of the interview
- Reimbursement- indicate this will be sent via post
- Thank you

## **S6: Information sheet, consent and assent forms (FGDs)**

### **i. Young people ( $\geq 18$ years of age)**

#### **PART 1: INFORMATION SHEET**

##### **Introduction**

- Hello. My name is \_\_\_\_\_. I work for the Health Systems Research Unit of the South African Medical Research Council (SAMRC).
- We do studies to help improve the health of young people in South Africa. You are being invited today to take part in a study we are doing on young people (15-24 years) in KwaZulu-Natal (KZN), South Africa.
- Ms Darshini Govindasamy, a researcher at the SAMRC, leads this study. This study is sponsored by the SAMRC.

##### **Why are we doing this study?**

- We want to know what helps young people in this community have a good life, and how they cope with their problems.
- This information can help us come up with ways to better support young people in reaching their full potential.

##### **Why have I been invited to take part in this study?**

- We have chosen young people from this clinic to attend our group chat.
- You have been chosen as we think your feedback as a young person could help us.

##### **What will happen if I decide to take part in this study?**

- After you tell me whether you want to take part or not, I will:
- Give you the date and time for this group chat. This group chat will take about 2 hours and will be done in a clinic or nearby venue, at a time that suits most people in this group.
- On the day of the group chat, I will ask everyone to fill out a short form to get to know them better (e.g. what grade they are in/what work do they do). We will then come into a group and chat in isiZulu or English about what helps and does not help a young person deal with their problems, have a good life, and be happy.
- Groups will be asked to draw pictures to explain their thoughts.
- Should you give me permission, I will take a picture of the groups drawing and provide you with a copy of the photo.
- Your name will not appear on any forms or next to anything you mention. Instead, you will be given your own study number.
- The group chat will be voice-recorded on a device. The voice-recorded file will be copied onto a computer, and then deleted from the device. The voice-recorded file



will be labelled with your group chat number and will not include your name. Researchers working on the study will listen to the recording and write down all the information from the chat.

### **What are my rights?**

- You can decide if you want to take part in the study or not, we will not force you. You can choose NOT to take part in the study.
- The choice that you make will not affect the care you receive from the clinic. If you agree to take part now, you can stop taking part later.
- You can ask questions about this study.

### **What are the risks or inconveniences I may experience?**

- Some questions we may ask might be hard for you to answer. We will not force you to answer anything you cannot or do not want to answer.
- Having to attend this group chat might mean that you will need to take time off work, come in after-school, and travel to the clinic for this chat. However, the chat will take place at a time and date that is most convenient to everyone in the group.
- Someone may overhear us during our chat. However, I will ensure that our chat is conducted in a private room where no can hear us.
- When I contact you via home visit or telephonically to confirm the meeting date someone else could overhear us or pick-up the phone. However, I will ensure I do not reveal any of your personal information to anyone. I will confirm the identity of the person picking up the phone to ensure it is only you with whom I am speaking to. I will only continue to talk to you on the phone if you indicate that you are in a private space, and it is safe for you to speak to me.
- Study items (e.g. my notes, recording device) could be misplaced or stolen. However, the research team will ensure all study items are stored in a locked cupboard.

### **What are the possible benefits of taking part in this study for me?**

- You may not get anything out of this group chat. The information that we get from this group chat will be used to create new ways for helping young people in KZN and elsewhere in South Africa better cope with their problems, and ensure they lead healthy and happy lives.

### **Will I get anything for taking part in this study?**

- You will receive a lunch pack and a grocery voucher to the value of R100 at the end of the group chat to thank you for your time and for taking part.
- At the end of the group discussion, you will be given transport money to reimburse you for any travel costs you had to bear as a result of attending our study FGD.

### Will the information I give be kept private?

- Your information will be kept on a computer file that will be protected with a password, which only staff working on this study will know. Others will not see information that you provide me with in the group chat.
- All my notes, forms, photos and files from this chat will only have your own study number on it and not your name. We will not link your name to the information you give us. All the information you provide us with will be kept confidential, and this information will be stored safely in a locked cupboard.
- We will use the information and photos from this study in presentations and in reports. These presentations and reports will not contain your name.
- If you tell us that you plan to harm a person or yourself, we will need to take steps to protect that person or you. Also, if you tell us that you believe a person is going to harm you, steps will be taken to protect you. If we suspect, or if you tell us that you or someone else has been neglected, or abused, we will have to report it to the relevant authorities such as child welfare or the police.

### Who do I contact if I have any questions about this study?

- If you have any questions about the group chat you may contact →	Contact person: Ms Mbalenhle Msweli Tel: 076 445 7922 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: mbalenhle.msweli@mrc.ac.za
- If you have any questions about the group chat you may contact →	Contact person: Ms Kealeboga Maruping Tel: 079 337 4486 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: kealeboga.maruping@mrc.ac.za
- If you have any questions about the study you may contact the principal investigator: →	Contact person: Ms Darshini Govindasamy Tel: 021 938 0365 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: darshini.govindasamy@mrc.ac.za
- If you have any problems with the way the study was done/concerns about your rights in the study you may contact the local research ethics committee which approved this study: →	Contact person: Prof D du Toit Tel: 021 938 0687 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: adri.labuschagne@mrc.ac.za

## **PART 2: INFORMED VOLUNTARY CONSENT FORM**

Please indicate whether you agree to take part or not in the table below. If you agree, please kindly add your name, signature and date below

Please read and mark each statement below	Please mark with an X	
1. I confirm that I have read and understood the information sheet, for the above study and have had the opportunity to ask questions.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
2. I have received a copy of the information sheet in my preferred language	<input type="checkbox"/> Yes	<input type="checkbox"/> No
3. I understand that my consent is voluntary and that I am free to withdraw this consent at any time, without giving any reason and without my legal rights being affected	<input type="checkbox"/> Yes	<input type="checkbox"/> No
4. Overall, I agree to take part in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to this group chat being voice-recorded	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to have my group's drawing photographed for use in presentations and reports from this study, as long as I cannot be identified	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to quotes or other results arising from what I say in this study being included in any reports about this study, as long as I cannot be identified	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to have an individual interview if I am approached by the researcher	<input type="checkbox"/> Yes	<input type="checkbox"/> No

For patient to complete:

\_\_\_\_\_  
Name and surname of participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For study staff taking consent complete:

*I declare that I have explained the information given in this document to the participant and the participant was given ample time to ask questions*

\_\_\_\_\_  
Name and surname of staff taking

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For witness to complete if participant is unable to write:

*As a witness I confirm that all information about this study was given and the participant verbally consented to taking part*

\_\_\_\_\_  
Name and surname of witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

ii. **Parental consent for minors ( $\leq 18$  years of age)**

**PART 1: INFORMATION SHEET**

**Introduction**

- Hello. My name is \_\_\_\_\_. I work for the Health Systems Research Unit of the South African Medical Research Council (SAMRC).
- We do studies to help improve the health of young people in South Africa. Your child is being invited today to take part in a study we are doing on young people (15-24 years) in KwaZulu-Natal (KZN), South Africa.
- Ms Darshini Govindasamy, a researcher at the SAMRC, leads this study. This study is sponsored by the SAMRC.

**Why are we doing this study?**

- We want to know what helps young people in this community have a good life. We also want to know how they cope with their problems.
- This information can help us come up with ways to better support young people in reaching their full potential.

**Why have we invited your child to take part in this study?**

- We have chosen young people from this clinic to attend our group discussion. Your child has been chosen as we think his/her feedback as a young person could help us.

**What will happen if I decide to allow my child to take part in this study?**

- First, because your child is between the ages of 15 to 17 years old, we need your permission to allow him or her to take part in the study. Then, we will ask your child whether he/she agrees to take part in the study.
- Your child can only take part in this study if you give permission for them to take part and your child agrees to take part. After that, I will:
- Give you the date and time for this group discussion. This group discussion will take about 2 hours and will be done at this clinic or a nearby venue, at a time that suits most people in this group.
- On the day of the group discussion, I will ask all children in the group to fill a short form to get to know them better (e.g. what grade they are in). We will then come into a group and talk in isiZulu or English about what helps and does not help a young person in this community deal with their problems and have a healthy and happy life.
- Groups will be asked to draw pictures to explain.
- Should you give me permission, I will take a picture of the groups drawing and give your child a copy of the photo.

- Your child's name will not appear on any forms or next to anything he/she mentions. Instead, your child will be given his/her own study number.
- The group discussion will be voice-recorded on a device. The voice-recorded file will be copied onto a computer in our study office, and then deleted from the device. The voice-recorded file will be labelled with your child's group discussion number and will not include his/her name. I will listen to the recording and write down all the information from the discussion.

### **What are my rights and my child's rights?**

- You can decide if you want your child to take part in the study or not, we will not force you to give permission or force your child to take part. You can choose NOT to allow your child to take part in the study.
- The choice that you make will not affect the care you or your child receives from the clinic. You can stop your child from taking part at any time.
- You can ask questions about this study.

### **What are the risks or inconveniences I or my child may experience?**

- Some questions we may ask your child might be hard for him/her to answer. We will not force your child to answer anything he/she cannot or does not want to answer.
- Allowing your child to take part might mean that your child will be taking time away from his activities after-school, and your child will have to travel to the clinic for this discussion. However, we will conduct this discussion at a time and date that best suits everyone in the group.
- Someone may overhear us during our group discussion. However, I will ensure that our discussion is conducted in a private room where no can hear us.
- When I contact you or your child via home visit or telephonically to confirm the meeting date, someone else could overhear us or pick-up the phone. When I contact you or your child, I will ensure I do not reveal any of your or your child's personal information to anyone. I will confirm the identity of the person picking up the phone to ensure it is only you or your child with whom I am speaking to. I will only continue our conversation on the phone if you or your child confirm that it is safe to talk.
- Study items (e.g. my notes, recording device) could be misplaced or stolen. However, the research team will ensure all study items are stored in a locked cupboard.

### **What are the possible benefits of my child taking part in this study?**

- Your child may not get anything out of our group discussion.
- The information that we get from this group discussion will be used to create new ways for helping young people in KZN and elsewhere in South Africa better cope with their problems, and ensure they lead healthy and happy lives.

### **Will my child get anything for taking part in this study?**

- Your child will receive a lunch pack and a grocery voucher to the value of R100 at the end of the group discussion to thank him/her for their time or anything else you had to pay for because they had to take part.
- At the end of the group discussion, your child will be given transport money to reimburse him/her for any travel costs he/she had to bear as a result of attending this study group discussion.

### **Will the information my child gives be kept private?**

- Your child's information will be kept on a computer file that will be protected with a password, which only staff working on this study will know. Others will not see information that your child provides me with in the group discussion.
- All my notes, forms, photos and files from this discussion will only have your child's study number on it and not his/her name. We will not link your child's name to the information he/she gives us. All the information your child provides us with will be kept confidential, and this information will be stored safely in a locked cupboard.
- We will use the information and photos from this study in presentations and in reports. These presentations and reports will not contain your child's name.
- If you tell us about plans to harm a person or yourself, I will need to take steps to protect that person or you. If your child tells us about plans to harm a person or themselves, I will need to take steps to protect that person or your child. Also, if you or your child tell us that they believe a person is going to harm you or him/her, steps will be taken to protect you or your child. If we suspect, or if you or your child tells us about any neglect or abuse in the household, we will have to report it to the authorities such as child welfare or the police.

### **Who do I contact if I have any questions about this study?**

- If you have any questions about the group discussion you may contact →	Contact person: Ms Mbalenhle Msweli Tel: 076 445 7922 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: mbalenhle.msweli@mrc.ac.za
- If you have any questions about the group discussion you may contact →	Contact person: Ms Kealeboga Maruping Tel: 079 337 4486 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: kealeboga.maruping@mrc.ac.za
- If you have any questions about the study you may contact the principal investigator: →	Contact person: Ms Darshini Govindasamy Tel: 021 938 0365 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: darshini.govindasamy@mrc.ac.za

<p>- If you have any problems with the way the study was done/concerns about yours/child's rights in the study you may contact the local research ethics committee which approved this study: →</p>	<p>Contact person: Prof D du Toit Tel: 021 938 0687 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: <a href="mailto:adri.labuschagne@mrc.ac.za">adri.labuschagne@mrc.ac.za</a></p>
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## **PART 2: INFORMED VOLUNTARY CONSENT FORM**

Please indicate whether you agree to your child taking part or not in the table below. If you agree, please kindly add your name, signature and date below

Please read and mark each statement below	Please mark with an X	
1. I confirm that I have read and understood the information sheet, for the above study and have had the opportunity to ask questions.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
2. I have received a copy of the information sheet in my preferred language	<input type="checkbox"/> Yes	<input type="checkbox"/> No
3. I understand that my consent is voluntary and that I am free to withdraw this consent at any time, without giving any reason and without my legal rights being affected	<input type="checkbox"/> Yes	<input type="checkbox"/> No
4. Overall, I agree to my child taking part in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• I agree to the group discussion being voice-recorded</li> </ul>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• I agree to have my child's drawing photographed for use in presentations and reports from this study, as long as he/she cannot be identified</li> </ul>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• I agree to quotes or other results arising from what my child's says in this study being included in any reports, as long as my child cannot be identified</li> </ul>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• I agree to having my child undergo an individual interview if I am approached by the researcher</li> </ul>	<input type="checkbox"/> Yes	<input type="checkbox"/> No

For participant to complete:

\_\_\_\_\_  
Name and surname of participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For study staff to complete:

*I declare that I have explained the information given in this document to the participant and the participant was given ample time to ask questions*

\_\_\_\_\_  
Name and surname of study staff taking consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For witness to complete if participant is unable to write:

*As a witness I confirm that all information about this study was given and the participant verbally consented to taking part*

\_\_\_\_\_  
Name and surname of witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)



**iii. Assent form for minors (≤ 18 years of age)**

**PART 1: INFORMATION SHEET**

**Introduction**

- Hello. My name is \_\_\_\_\_. I work for the South African Medical Research Council (SAMRC). We do work to improve the health among young people in South Africa.
- You are being invited today to take part in a study we are doing on young people in KwaZulu-Natal (KZN), South Africa.

**Why are we doing this study?**

- We want to know what helps young people in this community have a good life, and how they cope with their problems.
- This information can help us come up with ways to better support young people in South Africa.

**Why have I been invited to take part in this study?**

- We have chosen young people from this clinic to attend our group chat. You have been chosen as we think your feedback as a young person could help us.

**What will happen if I decide to take part in this study?**

After you tell me whether you want to take part or not, I will:

- Tell you the date, time and place we will meet to have this group chat.
- On the day of the group chat, I will ask all young people in the group to fill a short form to get to know them better (e.g., what grade you are in). We will then come into a group and chat about what helps and does not help a young person cope with their problems, have a good life, and be happy.
- I will ask groups to draw pictures to explain this to me better.
- If you allow me to, I will take a picture of the groups drawing and give you a copy.
- I will not put your name next to anything you say.
- I will tape the group chat on this gadget (voice-recorder) to listen to it again later and take notes. I will make sure I keep this voice-recorder safe and store its information on a safe computer.

**What are my rights?**

- You can decide if you want to take part in the study or not, we will not force you. You can choose NOT to take part in the study.
- You can ask questions about this study.

### **What are the risks or inconveniences I may experience?**

- Some questions we may ask might be hard for you to answer. We will not force you to answer anything you cannot or do not want to answer.
- Having to attend this group chat might mean you will need to take time out from your activities after-school, and travel to the clinic for this chat. However, we will ensure that we have this chat on a day that suits most people in the group.
- Someone may overhear us during our chat. However, I will ensure that our chat is conducted in a private room where no one can hear us.
- When I contact you, via home visit or telephonically, to confirm the date of the group chat, someone else could overhear us or pick-up the phone. However, I will ensure I do not reveal any of your personal information to anyone. I will confirm the identity of the person picking up the phone to ensure it is only you with whom I am speaking to. I will only continue to talk to you on the phone if you indicate that you in private space and it is safe for you to speak to me.
- Study items (e.g. my notes, recording device) could be misplaced or stolen. However, the research team will ensure all study items are stored in a locked cupboard.

### **What are the possible benefits of taking part in this study for me?**

- You may not get anything out of our group chat.
- However, information that we get from you will be used to create new ways for helping young people in South Africa better cope with their problems, and ensure they have happy and good lives.

### **Will I get anything for taking part in this study?**

- You will receive a lunch pack and a grocery voucher to the value of R100 at the end of the group chat to thank you for your time and for taking part.
- At the end of the group chat, you will be given transport money to reimburse you for any travel costs you had to bear as a result of attending our group chat.

### **Will the information I give be kept private?**

- Your information will be kept on a computer file with a password, which only staff working on this study will know. Others will not see information that you provide me with in the group chat.
- All my notes, forms, photos and files from this chat will only have your own study number on it and not your name. We will not link your name to the information you give us. All the information you provide us with will be kept safe, and this information will be stored safely in a locked cupboard.
- We will use the information and photos from this study in presentations and in reports. These presentations and reports will not contain your name.
- If you tell us that you plan to do something bad to a person or yourself, we will need to help that person or you. Also, if you tell us that a person is going to do something bad to you, we will have to ensure you are safe. If we think, or if you tell us that

you or someone in your home is upset, being hit, shouted at or abused, we will have to report it to the right people.

### Who do I contact if I have any questions about this study?

<p>- If you have any questions about taking part you may call →</p>	<p>Contact person: Ms Kealeboga Maruping Tel: 079 337 4486 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: kealeboga.maruping@mrc.ac.za</p>
<p>- If you have any questions about taking part you may contact →</p>	<p>Contact person: Ms Mbalenhle Msweli Tel: 076 445 7922 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: mbalenhle.msweli@mrc.ac.za</p>
<p>- If you have any questions about the study you may call: →</p>	<p>Contact person: Ms Darshini Govindasamy Tel: 021 938 0365 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: darshini.govindasamy@mrc.ac.za</p>
<p>- If you have any problems with the way the study was done you can call: →</p>	<p>Contact person: Prof D du Toit Tel: 021 938 0687 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: adri.labuschagne@mrc.ac.za</p>

## **PART 2: INFORMED VOLUNTARY ASSENT FORM**

Please indicate whether you would like to take part or not in the table below. If you agree, please kindly add your name, signature and date below

Please read and mark each statement below	Please mark with an X	
1. I have read and understood the information sheet for the study and was given time to ask questions	<input type="checkbox"/> Yes	<input type="checkbox"/> No
2. I have received a copy of the information sheet in my language	<input type="checkbox"/> Yes	<input type="checkbox"/> No
3. I understand that I can stop taking part at any time in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
4. Overall, I agree to take part in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to this chat being voice-recorded	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to having a picture taken of my group drawing with a camera	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to have an individual interview with the researcher if needed	<input type="checkbox"/> Yes	<input type="checkbox"/> No

For participant to complete:

\_\_\_\_\_  
Name and surname of participant

\_\_\_\_\_  
Signature or initials

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For study staff to complete:

*I declare that I have explained the information given in this document to the participant and the participant was given ample time to ask questions*

\_\_\_\_\_  
Name and surname of study staff taking  
assent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For witness to complete if participant is unable to write:

*As a witness I confirm that all information about this study was given and the participant verbally assented to taking part*

\_\_\_\_\_  
Name and surname of witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

## **S7: Information sheet, consent and assent forms (DIs)**

### **i. Young people ( $\geq 18$ years of age)**

#### **PART 1: INFORMATION SHEET**

##### **Introduction**

- Hello. My name is \_\_\_\_\_. I work for the Health Systems Research Unit of the South African Medical Research Council (SAMRC).
- We do studies to help improve the health of young people in South Africa. You are being invited today to take part in a study we are doing on young people (15-24 years) in KwaZulu-Natal (KZN), South Africa.
- Ms Darshini Govindasamy, a researcher at the SAMRC, leads this study. This study is sponsored by the SAMRC.

##### **Why are we doing this study?**

- We want to know what helps young people in this community have a good life, and how they cope with problems.
- This information can help us come up with ways to better support young people in reaching their full potential.

##### **Why have I been invited to take part in this study?**

- We have chosen young people from this clinic to attend our interview.
- You have been chosen as we think your feedback as a young person could help us.

##### **What will happen if I decide to take part in this study?**

- After you tell me whether you want to take part or not, I will:
- Give you the date and time for this interview. This interview will take about 2 hours and will be done at this clinic or a nearby venue that is convenient for you.
- On the day of the interview, I will ask you to fill a short form to get to know you better (e.g. what grade are you in/what work do you do). We will then chat in isiZulu or English about your key life events and how you felt on that day. I will ask you to draw pictures to explain your thoughts.
- Should you give me permission; I will take a picture of your drawing and give you a copy of the photo.
- Your name will not appear on any forms or next to anything you mention. Instead, you will be given your own study number.
- The interview will be voice-recorded on a device. The voice-recorded file will be copied onto a computer, and then deleted from the device. The voice-recorded file will be labelled with your study number and will not include your name.

Researchers working on the study will listen to the recording and write down all the information from the interview.

### **What are my rights?**

- You can decide if you want to take part in the study or not, we will not force you. You can choose NOT to take part in the study.
- The choice that you make will not affect the care you receive from the clinic. If you agree to take part now, you can stop taking part later.
- You can ask questions about this study.

### **What are the risks or inconveniences I may experience?**

- Some questions we may ask might be hard for you to answer. We will not force you to answer anything you cannot or do not want to answer.
- Having to attend this interview might mean that you will need to take time off work, come in after school, and travel to the clinic for this interview. However, I will ensure our interview takes place at a time and date that is most convenient to you.
- Someone may overhear us during our interview. However, I will ensure that our interview is conducted in a private room where no one can hear us.
- When I contact you, via home visit or telephonically, to confirm the date of our interview, someone else could overhear us or pick-up the phone. However, I will ensure I do not reveal any of your personal information to anyone. I will confirm the identity of the person picking up the phone to ensure it is only you with whom I am speaking to. I will only continue to talk to you on the phone if you indicate that you are in a private space, and it is safe for you to speak to me.
- Study items (e.g. my notes, recording device) could be misplaced or stolen. However, the research team will ensure all study items are stored in a locked cupboard.

### **What are the possible benefits of taking part in this study for me?**

- You may not get anything out of this interview. The information that we get from this interview will be used to create new ways for helping young people in KZN and elsewhere in South Africa better cope with their problems, and ensure they lead healthy and happy lives.

### **Will I get anything for taking part in this study?**

- You will receive a lunch pack and a grocery voucher to the value of R100 at the end of the interview to thank you for your time and for taking part.
- At the end of the interview, you will be given transport money to reimburse you for any travel costs you had to bear as a result of attending our study interview.

### Will the information I give be kept private?

- Your information will be kept on a computer file that will be protected with a password, which only staff working on this study will know. Others will not see information that you provide me with in the interview.
- All my notes, forms, photos and files from this interview will only have your own study number on it and not your name. We will not link your name to the information you give us. All the information you provide us with will be kept confidential, and this information will be stored safely in a locked cupboard.
- We will use the information and photos from this study in presentations and in reports. These presentations and reports will not contain your name.
- If you tell us that you plan to harm a person or yourself, we will need to take steps to protect that person or you. Also, if you tell us that you believe a person is going to harm you, steps will be taken to protect you. If we suspect, or if you tell us that you or someone else has been neglected, or abused, we will have to report it to the relevant authorities such as child welfare or the police.

### Who do I contact if I have any questions about this study?

- If you have any questions about the interview you may contact →	Contact person: Ms Kealeboga Maruping Tel: 079 337 4486 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: kealeboga.maruping@mrc.ac.za
- If you have any questions about the group chat you may contact →	Contact person: Ms Mbalenhle Msweli Tel: 076 445 7922 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: mbalenhle.msweli@mrc.ac.za
- If you have any questions about the study you may contact the principal investigator: →	Contact person: Ms Darshini Govindasamy Tel: 021 938 0365 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: darshini.govindasamy@mrc.ac.za
- If you have any problems with the way the study was done/concerns about your rights in the study you may contact the local research ethics committee which approved this study: →	Contact person: Prof D du Toit Tel: 021 938 0687 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: adri.labuschagne@mrc.ac.za

**PART 2: INFORMED VOLUNTARY CONSENT FORM**

Please indicate whether you agree to take part or not in the table below. If you agree, please kindly add your name, signature and date below

Please read and mark each statement below	Please mark with an X	
1. I confirm that I have read and understood the information sheet (version number and date), for the above study and have had the opportunity to ask questions.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
2. I have received a copy of the information sheet in my preferred language	<input type="checkbox"/> Yes	<input type="checkbox"/> No
3. I understand that my consent is voluntary and that I am free to withdraw this consent at any time, without giving any reason and without my legal rights being affected	<input type="checkbox"/> Yes	<input type="checkbox"/> No
4. Overall, I agree to take part in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
a) I agree to this interview being voice-recorded	<input type="checkbox"/> Yes	<input type="checkbox"/> No
b) I agree to have my drawing photographed for use in presentations and reports from this study, as long as I cannot be identified	<input type="checkbox"/> Yes	<input type="checkbox"/> No
c) I agree to quotes or other results arising from what I say in this study being included in any reports about this study, as long as I cannot be identified	<input type="checkbox"/> Yes	<input type="checkbox"/> No

For participant to complete:

\_\_\_\_\_  
Name and surname of participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For study staff to complete:

*I declare that I have explained the information given in this document to the participant and the participant was given ample time to ask questions*

\_\_\_\_\_  
Name and surname of study staff taking consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For witness to complete if participant is unable to write:

*As a witness I confirm that all information about this study was given and the participant verbally consented to taking part*

\_\_\_\_\_  
Name and surname of witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)



ii. **Parental consent for minors ( $\leq 18$  years of age)**

**PART 1: INFORMATION SHEET**

**Introduction**

Good day. My name is \_\_\_\_\_. I work for the Health Systems Research Unit of the South African Medical Research Council (SAMRC). We do studies to help improve the health of young people in South Africa. Your child is being invited today to take part in a study we are doing on young people (15-19 years) in KwaZulu-Natal (KZN), South Africa. Ms Darshini Govindasamy, a researcher at the SAMRC, leads this study. This study is sponsored by the SAMRC.

**Why are we doing this study?**

We want to know what helps young people in this community have a healthy and happy life. We also want to know how they cope with problems. This information can help develop solutions to ensure young people reach their full potential.

**Why have we invited your child to take part in this study?**

We have chosen young people from this clinic to attend our one-on-one interviews. Your child has been chosen as we think his/her feedback as a young person could help us.

**What will happen if I decide to allow my child to take part in this study?**

- First, because your child is between the ages of 15 to 17 years old, we need your permission to allow him/her to take part in the study.
- Then, we will get your child's agreement to take part in the study. Your child can only take part in this study if you 1) give us permission for him/her to take part and 2) your child agrees to take part. After you and your child have both agreed, I will:
- Give you with the date and time for this interview. This interview will take about 2 hours to complete and will be done in this clinic or a nearby venue.
- On the day of the interview I will ask your child to fill a short form to get to know him/her better (e.g. what grade they are in, the type of household they live in). We will then sit together and talk in isiZulu about key life events and how it made him/her feel. I will ask your child to draw a picture so he/she can explain their thoughts.
- Should you give me permission, I will take a picture of your child's drawing and provide your child with a copy of the photo.
- Your child's name will not appear on any forms or next to anything he/she mentions. Instead, your child will be given his/her own study number.
- The interview will be voice-recorded on a device. The voice-recorded file will be copied onto a computer in our study office, and then deleted from the device. The voice-recorded file will be labelled with your child's study number and will not

include his/her name. I will listen to the recording and write down all the information from our discussion.

### **What are my rights and my child's rights?**

You can decide if you want your child to take part in the study or not, we will not force you to give permission or force your child to take part. You can choose NOT to allow your child to take part in the study. The choice that you make will not affect the care you or your child receives from the clinic. You can stop your child from taking part at any time. You can ask questions about this study.

### **What are the risks or inconveniences I or my child may experience?**

- Some questions we ask your child might be hard for him/her to answer. We will not force your child to answer anything he/she cannot or does not want to answer.
- Allowing your child to take part might mean that your child will be taking time away from his activities and will need to travel to the clinic for this interview.
- Someone may overhear us during our interview. However, I will ensure that our interview is conducted in a private room where no can hear us.
- When I contact you or your child via home visit or telephonically to confirm the meeting date, someone else could overhear us or pick-up the phone. When I contact you or your child, I will ensure I do not reveal any of your or your child's personal information to anyone. I will confirm the identity of the person picking up the phone to ensure it is only you or your child with whom I am speaking to. I will only continue our conversation on the phone if you or your child indicate that it is safe to talk.
- Study items (my notes, recording device) could be misplaced or stolen. However, the research team will ensure all study items are stored in a locked cupboard.

### **What are the possible benefits of my child taking part in this study?**

Your child may not get anything out of our interview. The information that we get from this interview will be used to create new ways for helping young people in KZN and elsewhere in South Africa better cope with their problems, and ensure they lead healthy and happy lives.

### **Will my child get anything for taking part in this study?**

- Your child will receive a lunch pack and a grocery voucher to the value of R100 at the end of the interview to thank him/her for their time or anything else you had to pay for because they had to take part.
- At the end of the interview, your child will be given transport money to reimburse him/her for any travel costs he/she had to bear as a result of attending our study IDI.

### **Will the information my child gives be kept private?**

- Your child’s information will be kept on a computer file that will be protected with a password, which only staff working on this study will know. Others will not see information that your child provides me with in the interview.
- All my notes, forms, photos and files from this interview will only have your child’s study number on it and not his/her name. We will not link your child’s name to the information he/she gives us. All the information your child provides us with will be kept private, and this information will be stored safely in a locked cupboard.
- We will use the information and photos from this study in presentations and in reports. These presentations and reports will not contain your child’s name.
- If you tell us about plans to harm a person or yourself, I will need to take steps to protect that person or you. If your child tells us about plans to harm a person or themselves, I will need to take steps to protect that person or your child. Also, if you or your child tell us that they believe a person is going to harm you or him/her, steps will be taken to protect you or your child. If we suspect, or if you or your child tells us about any neglect or abuse in the household, we will have to report it to the authorities such as child welfare or the police.

### Who do I contact if I have any questions about this study?

<p>- If you have any questions about the interview you may contact →</p>	<p>Contact person: Ms Kealeboga Maruping Tel: 031 2034712 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: Kealeboga.Maruping@mrc.ac.za</p>
<p>- If you have any questions about the study you may contact the principal investigator: →</p>	<p>Contact person: Ms Darshini Govindasamy Tel: 021 938 0365 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: darshini.govindasamy@mrc.ac.za</p>
<p>- If you have any problems with the way the study was done/concerns about your rights in the study you may contact the local research ethics committee which approved this study: →</p>	<p>Contact person: Prof D du Toit Tel: 021 938 0687 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: adri.labuschagne@mrc.ac.za</p>

**PART 2: INFORMED VOLUNTARY CONSENT FORM**

Please indicate whether you agree to your child taking part or not in the table below. If you agree, please kindly add your name, signature and date below

Please read and mark each statement below	Please mark with an X	
I confirm that I have read and understood the information sheet (version number and date), for the above study and have had the opportunity to ask questions.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have received a copy of the information sheet in my preferred language	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that my consent is voluntary and that I am free to withdraw this consent at any time, without giving any reason and without my legal rights being affected	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Overall, I agree to my child taking part in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• I agree to the interview being voice-recorded</li> </ul>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• I agree to have my child’s drawing photographed for use in presentations and reports from this study, as long as he/she cannot be identified</li> </ul>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• I agree to quotes or other results arising from what my child’s says in this study being included in any reports, as long as my child cannot be identified</li> </ul>	<input type="checkbox"/> Yes	<input type="checkbox"/> No

For participant to complete:

\_\_\_\_\_  
Name and surname of participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today’s date (dd/mm/yyyy)

For study staff to complete:

*I declare that I have explained the information given in this document to the participant and the participant was given ample time to ask questions*

\_\_\_\_\_  
Name and surname of study staff taking consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today’s date (dd/mm/yyyy)

For witness to complete if participant is unable to write:

*As a witness I confirm that all information about this study was given and the participant verbally consented to taking part*

\_\_\_\_\_  
Name and surname of witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today’s date (dd/mm/yyyy)

### iii. Assent form for minors ( $\leq 18$ years of age)

## **PART 1: INFORMATION SHEET**

### **Introduction**

- Hello. My name is \_\_\_\_\_. I work for the South African Medical Research Council (SAMRC). We do work to help improve the health of young people in South Africa.
- You are being invited today to take part in a study we are doing on young people in KwaZulu-Natal (KZN), South Africa.

### **Why are we doing this study?**

- We want to know what helps young people in this community have a good life, and how they cope with their problems.
- This information can help us come up with ways to better support young people in South Africa.

### **Why have I been invited to take part in this study?**

- We have chosen young people from this clinic to attend our interview (chat). You have been chosen as we think your feedback as a young person could help us.

### **What will happen if I decide to take part in this study?**

- After you tell me whether you want to take part or not, I will:
- Tell you the date, time and place we will meet and where we will meet to have this chat.
- On the day of the chat, I will ask you to fill a short form to get to know you better (e.g. what grade you are in, what type of household you live in). We will then chat about key events you remember from the time you were younger and how you felt. I will ask you to draw pictures to explain this to me better.
- If you allow me to, I will take a picture of your drawing and give you a copy of this photo.
- I will not put your name next to anything you say.
- I will tape our chat on this gadget (voice-recorder) to listen to it again later and take notes. I will make sure I keep this voice-recorder safe and store its information on a safe computer.

### **What are my rights?**

- You can decide if you want to take part in the study or not, we will not force you. You can choose NOT to take part in the study.
- You can ask questions about this study.

### **What are the risks or inconveniences I may experience?**

- Some questions we may ask you might be hard for you to answer. We will not force you to answer anything you cannot or do not want to answer.
- Having to attend this chat might mean you will need to take time out from your activities after school, and travel to the clinic for this chat. However, we will ensure that we have this chat on a day that suits you.
- Someone may overhear us during our chat. However, I will ensure that our chat is conducted in a private room where no one can hear us.
- When I contact you, via home visit or telephonically, to confirm the date of the chat, someone else could overhear us or pick-up the phone. However, I will ensure I do not reveal any of your personal information to anyone. I will confirm the identity of the person picking up the phone to ensure it is only you with whom I am speaking to. I will only continue to talk to you on the phone if you indicate that you are in a private space and it is safe for you to speak to me.
- Study items (e.g. my notes, recording device) could be misplaced or stolen. However, the research team will ensure all study items are stored in a locked cupboard.

### **What are the possible benefits of taking part in this study for me?**

- You may not get anything out of our chat.
- However, information that we get from you will be used to create new ways for helping young people in South Africa better cope with their problems, and ensure they have happy and happy lives.

### **Will I get anything for taking part in this study?**

- You will receive a lunch pack and a grocery voucher to the value of R100 at the end of the chat to thank you for your time and for taking part.

### **Will the information I give be kept private?**

- Your information will be kept on a computer file with a password, which only staff working on this study will know. Others will not see information that you provide me with.
- All my notes, forms, photos and files from this chat will only have your own study number on it and not your name. We will not link your name to the information you give us. All the information you provide us with will be kept safe, and this information will be stored safely in a locked cupboard.
- We will use the information and photos from this study in presentations and in reports. These presentations and reports will not contain your name.
- If you tell us that you plan to do something bad to a person or yourself, we will need to help that person or you. Also, if you tell us that a person is going to do something bad to you, we will have to ensure you are safe. If we think, or if you tell us that you or someone in your home is upset, being hit, shouted or abused we will have to report it to the right people.

## Who do I contact if I have any questions about this study?

<p>- If you have any questions about taking part you may call →</p>	<p>Contact person: Ms Kealeboga Maruping Tel: 079 337 4486 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: kealeboga.maruping@mrc.ac.za</p>
<p>- If you have any questions about the study you may call: →</p>	<p>Contact person: Ms Darshini Govindasamy Tel: 021 938 0365 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: darshini.govindasamy@mrc.ac.za</p>
<p>- If you have any problems with the way the study was done you can call: →</p>	<p>Contact person: Prof D. Du Toit Tel: 021 938 0687 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: adri.labuschagne@mrc.ac.za</p>

## **PART 2: INFORMED VOLUNTARY ASSENT FORM**

Please indicate whether you would like to take part or not in the table below. If you agree, please kindly add your name, signature and date below

Please read and mark each statement below	Please mark with an X	
I have read and understood the information sheet (version number and date), for the study and was given time to ask questions	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have received a copy of the information sheet in my language	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that I can stop taking part at any time in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Overall, I agree to take part in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to this chat being voice-recorded	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to having a picture taken of my drawing with a camera	<input type="checkbox"/> Yes	<input type="checkbox"/> No

For participant to complete:

\_\_\_\_\_  
Name and surname of participant

\_\_\_\_\_  
Signature or initials

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For study staff to complete:

*I declare that I have explained the information given in this document to the participant and the participant was given ample time to ask questions*

\_\_\_\_\_  
Name and surname of study staff taking assent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For witness to complete if participant is unable to write:

*As a witness I confirm that all information about this study was given and the participant verbally assented to taking part*

\_\_\_\_\_  
Name and surname of witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)



## **S8: Information sheet, consent and assent forms (KIIs)**

### **i. HCWs**

## **PART 1: INFORMATION SHEET**

### **Introduction**

- Hello. My name is \_\_\_\_\_. I work for the South African Medical Research Council (SAMRC). We do work to help improve the health of young people in South Africa.
- You are being invited today to take part in a study we are doing on young people in KwaZulu-Natal (KZN), South Africa.

### **Why are we doing this study?**

- We want to know what helps young people in this community have a good life, and how they cope with their problems.
- This information can help us come up with ways to better support young people in South Africa.

### **Why have I been invited to take part in this study?**

- We have chosen young people from this clinic to attend our interview (chat). You have been chosen as we think your feedback as a young person could help us.

### **What will happen if I decide to take part in this study?**

- After you tell me whether you want to take part or not, I will:
- Tell you the date, time and place we will meet and where we will meet to have this chat.
- On the day of the chat, I will ask you to fill a short form to get to know you better (e.g. what grade you are in, what type of household you live in). We will then chat about key events you remember from the time you were younger and how you felt. I will ask you to draw pictures to explain this to me better.
- If you allow me to, I will take a picture of your drawing and give you a copy of this photo.
- I will not put your name next to anything you say.
- I will tape our chat on this gadget (voice-recorder) to listen to it again later and take notes. I will make sure I keep this voice-recorder safe and store its information on a safe computer.

### **What are my rights?**

- You can decide if you want to take part in the study or not, we will not force you. You can choose NOT to take part in the study.
- You can ask questions about this study.

### **What are the risks or inconveniences I may experience?**

- Some questions we may ask you might be hard for you to answer. We will not force you to answer anything you cannot or do not want to answer.
- Having to attend this chat might mean you will need to take time out from your activities after school, and travel to the clinic for this chat. However, we will ensure that we have this chat on a day that suits you.
- Someone may overhear us during our chat. However, I will ensure that our chat is conducted in a private room where no one can hear us.
- When I contact you, via home visit or telephonically, to confirm the date of the chat, someone else could overhear us or pick-up the phone. However, I will ensure I do not reveal any of your personal information to anyone. I will confirm the identity of the person picking up the phone to ensure it is only you with whom I am speaking to. I will only continue to talk to you on the phone if you indicate that you are in a private space and it is safe for you to speak to me.
- Study items (e.g. my notes, recording device) could be misplaced or stolen. However, the research team will ensure all study items are stored in a locked cupboard.

### **What are the possible benefits of taking part in this study for me?**

- You may not get anything out of our chat.
- However, information that we get from you will be used to create new ways for helping young people in South Africa better cope with their problems, and ensure they have happy and happy lives.

### **Will I get anything for taking part in this study?**

- You will receive a lunch pack and a grocery voucher to the value of R100 at the end of the chat to thank you for your time and for taking part.

### **Will the information I give be kept private?**

- Your information will be kept on a computer file with a password, which only staff working on this study will know. Others will not see information that you provide me with.
- All my notes, forms, photos and files from this chat will only have your own study number on it and not your name. We will not link your name to the information you give us. All the information you provide us with will be kept safe, and this information will be stored safely in a locked cupboard.
- We will use the information and photos from this study in presentations and in reports. These presentations and reports will not contain your name.
- If you tell us that you plan to do something bad to a person or yourself, we will need to help that person or you. Also, if you tell us that a person is going to do something bad to you, we will have to ensure you are safe. If we think, or if you tell us that you or someone in your home is upset, being hit, shouted or abused we will have to report it to the right people.

## Who do I contact if I have any questions about this study?

<p>- If you have any questions about taking part you may call →</p>	<p>Contact person: Ms Kealeboga Maruping Tel: 079 337 4486 Address: 491 Peter Mokaba Rd, Durban, 4091 Email: kealeboga.maruping@mrc.ac.za</p>
<p>- If you have any questions about the study you may call: →</p>	<p>Contact person: Ms Darshini Govindasamy Tel: 021 938 0365 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: darshini.govindasamy@mrc.ac.za</p>
<p>- If you have any problems with the way the study was done you can call: →</p>	<p>Contact person: Prof D. Du Toit Tel: 021 938 0687 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: adri.labuschagne@mrc.ac.za</p>

## **PART 2: INFORMED VOLUNTARY ASSENT FORM**

Please indicate whether you would like to take part or not in the table below. If you agree, please kindly add your name, signature and date below

Please read and mark each statement below	Please mark with an X	
I have read and understood the information sheet (version number and date), for the study and was given time to ask questions	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have received a copy of the information sheet in my language	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that I can stop taking part at any time in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Overall, I agree to take part in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to this chat being voice-recorded	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to having a picture taken of my drawing with a camera	<input type="checkbox"/> Yes	<input type="checkbox"/> No

For participant to complete:

\_\_\_\_\_  
Name and surname of participant

\_\_\_\_\_  
Signature or initials

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For study staff to complete:

*I declare that I have explained the information given in this document to the participant and the participant was given ample time to ask questions*

\_\_\_\_\_  
Name and surname of study staff taking assent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

For witness to complete if participant is unable to write:

*As a witness I confirm that all information about this study was given and the participant verbally assented to taking part*

\_\_\_\_\_  
Name and surname of witness

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Today's date (dd/mm/yyyy)

## ii. Experts

### **PART 1: INFORMATION SHEET**

#### **Introduction**

- Good day. My name is Darshini Govindasamy. I am a researcher at the Health Systems Research Unit of the South African Medical Research Council (SAMRC).
- You are being invited to participate in my PhD study aimed at understanding the drivers of wellbeing among young people (aged 15-24 years) living with HIV (YPLHIV) in KwaZulu-Natal, South Africa
- I am a PhD student in Public Health and Policy (Health Economics) at the London School of Hygiene and Tropical Medicine. My supervisors are Dr Giulia Ferrari and Prof Janet Seeley (LSHTM), and my local advisor is Prof Catherine Mathews (SAMRC).
- I am the principal investigator of this study. This study is sponsored by the SAMRC.

#### **Why are we doing this study?**

- Internationally, there is strong recommendations for public policy evaluations to measure broader indicators of human development such as wellbeing.
- Improving health and wellbeing is key goal in the Sustainable Development agenda. However, to date HIV/AIDS policy evaluations focus on narrow clinical and economic indicators.
- Burgeoning evidence indicates that YPLHIV in sub-Saharan Africa are at high risk for mental health conditions. Mental health problems occurring in the adolescent phase could result in unfavourable health, social and economic outcomes in adulthood.
- Studies have shown that wellbeing during adolescence is positively correlated with positive mental health, educational attainment and favourable employment outcomes in the long run.
- Hence, as YPLHIV survive into adulthood in this region, monitoring their wellbeing will be of importance to policy makers and programme planners aiming to improve future health and economic outcomes for this population.
- Currently, there is very little guidance on how best to measure wellbeing among YPLHIV in SSA. If we can accurately measure this concept at a population-level based on how wellbeing is locally understood and experienced by YPLHIV, then we can accurately model and predict the determinants of wellbeing. This would provide accurate insights into population-level interventions to enhance wellbeing among YPLHIV.

### **Why have I been invited to take part in this study?**

- You are being invited to participate specifically in our qualitative study that seeks to understand the experiences and perceptions of wellbeing among young people living with and without HIV.
- As part of this study, we are currently conducting focus-group discussions and in-depth interviews with young people living with and without HIV in Umlazi, KwaZulu Natal, South Africa. Moreover, we are conducting key-informant interviews with healthcare workers, including local and international experts in the field of wellbeing or adolescent HIV.
- You are being invited to participate in this study as an expert given your research experience in the field of wellbeing or adolescent HIV. Your feedback could add to our understanding of wellbeing and help us better understand the preliminary qualitative data emerging from our study.

### **What will happen if I decide to take part in this study?**

After you have agreed (consented) to join the study, I will:

- Schedule a date to conduct a one-on-one interview with you. This interview will take approximately 1 hour to complete and will be conducted via skype or at a convenient location (if you are based in KwaZulu-Natal).
- This interview will be structured as follows. Firstly, I will begin the interview by asking you details on previous studies you have conducted in the area of wellbeing or adolescent HIV in developing settings. Secondly, I will seek your feedback on what you believe shapes wellbeing among YPLHIV or young people in general. Lastly, I will seek your expert opinion on what further research is needed in this area, and the ethical implications of doing wellbeing research with this population.
- Your name will not be written on the interview documents or next to any of your responses. Instead, you will be given a unique study number that will identify your responses.
- The interview will be voice-recorded on an electronic device. The voice-recorded file will be copied onto a password protected storage device (USB) and our password protected SAMRC online server, and then deleted from the recording device. The USB will be stored in a locked cupboard at the research study's office. The voice-recorded file will be labelled with your unique study number and will not include your name. I will listen to this recording and transcribe all information. This transcript will be stored on a password protected SAMRC server.

### **What are my rights?**

- You can decide if you want to take part in the study or not. Your participation is voluntary.
- You can choose NOT to participate in the study.
- If you agree to participate now, you can stop taking part later.
- You can ask questions about this study.

### **What are the risks or inconveniences I may experience?**

- Some questions may be difficult for you to answer. I will not force you to answer anything you cannot or do not want to answer.
- Having to attend this study interview may impose on your work time and might mean that you will need to arrange for someone to take over your duties. Hence, we will arrange to conduct this interview at a time and date that is most convenient to you.
- Someone on my end may overhear us during our interview. However, I will ensure that I conduct the interview from a private room.
- Study items (e.g. my notes, recording device) could be misplaced or stolen. However, the research team will ensure all study items are stored in a locked cupboard with restricted access.

### **What are the possible benefits of taking part in this study for me?**

- There will be no direct benefit to you, but your participation is likely to provide us with a more accurate picture of the factors influencing wellbeing among YPLHIV in this region.
- Findings could help policy makers and programme planners improve policies and interventions aimed at enhancing wellbeing among YPLHIV.
- Results will be shared with scientific audiences through publications and conference presentations. In addition, we will engage with participants, study clinics, and the broader community via a community workshop to obtain their interpretation of the data and suggestions on possible interventions to promote wellbeing. Research findings together with feedback from our community consultation will be shared with the local and National Department of Health via a policy brief.

### **Will I get anything for taking part in this study?**

- You will receive a stationery item at the end of the interview to thank you for your time or any inconvenience costs incurred due to participation.

### **Will the information I give be kept private?**

- Your information will be kept on a computer file that will be protected by a password, which only staff working on this study will know. Information that you provide me with will not be seen by other participants or staff.
- All my notes, forms and electronic files from this interview will only have your unique study number on it and not your name. I will not link your name to the information you give us.
- All personal identifying information you provide me with will be kept confidential, and this information will be stored safely in a locked cupboard.
- Information presented at meetings and published will not contain your name.

## Who do I contact if I have any questions about this study?

<p>- If you have any questions about the study you may contact the principal investigator: →</p>	<p>Contact person: Ms Darshini Govindasamy Tel: 021 938 0365 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: darshini.govindasamy@mrc.ac.za</p>
<p>- If you have any problems with the way the study was done/concerns about your rights in the study you may contact the local research ethics committee which approved this study: →</p>	<p>Contact person: Prof D du Toit Tel: 021 938 0687 Address: South African Medical Research Council, PO Box 19070, Tygerberg 7505, Western Cape South Africa Email: adri.labuschagne@mrc.ac.za</p>



## **PART 2: INFORMED VOLUNTARY CONSENT FORM**

Please indicate whether you agree or not to participate in the table below and then add your name, signature and date below

Please read and mark each statement below	Please select an option	
I confirm that I have read and understood the information sheet, for the above study and have had the opportunity to ask questions.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have received a copy of the information sheet	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I understand that my consent is voluntary and that I am free to withdraw this consent at any time, without giving any reason and without my legal rights being affected	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Overall, I agree to take part in this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I consent to this interview being voice-recorded	<input type="checkbox"/> Yes	<input type="checkbox"/> No
• I agree to quotes or other results arising from my participation in this study being included, even anonymously, in any reports about this study	<input type="checkbox"/> Yes	<input type="checkbox"/> No

For participant to complete:

\_\_\_\_\_  
Name and surname of participant      Signature      Today's date (dd/mm/yyyy)

For study staff to complete:

*I declare that I have explained the information given in this document to the participant and the participant was given ample time to ask questions*

\_\_\_\_\_  
Name and surname of study staff taking consent      Signature      Today's date (dd/mm/yyyy)

For witness to complete if participant is unable to write:

*As a witness I confirm that all information about this study was given and the participant verbally consented to taking part*

\_\_\_\_\_  
Name and surname of witness      Signature      Today's date (dd/mm/yyyy)

