

**PROCESSES AND PARTICIPATION IN HIV AND AIDS
COMMUNICATION: USING BODYMAPPING TO EXPLORE THE
EXPERIENCES OF YOUNG PEOPLE**

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**Submitted in fulfillment of the requirements for the Doctor of Philosophy
degree in the School of Human Sciences, Centre for Communication,
Media and Society, at the University of KwaZulu-Natal, Durban**

MARCH 2013

COLLEGE OF HUMANITIES

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ACRONYMS

ABC – Abstinence, Be Faithful, Condomise

ACT – Abstinence, Condomise, Test

AIDS – Acquired Immunodeficiency Syndrome

AR – Action Research

ART – Antiretroviral Therapy

ARV – Antiretroviral Drugs

ASRU – AIDS and Society Research Unit

BAC – Beyond Awareness Campaign

BCC – Behaviour Change Communication

CADRE – Centre for AIDS, Development and Evaluation

CCGs – Community Care-Givers

CCMS – Centre for Communication, Media and Society

CFPD – Communication for Participatory Development

CRBS – Children’s Resource Book Series

D4L – Dance for Life

DRAMAIDE – Drama in AIDS Education

DUT – Durban University of Technology

FBO – Faith-Based Organisation

FOTF – *Focus on the Family*

HEAIDS – The Higher Education HIV and AIDS Programme

HEI – Higher Education Institutions

HIV – Human Immunodeficiency Virus

HIVAN – Centre for HIV AND AIDS Networking

HSRC – Human Sciences Research Council

JHHESA – Johns Hopkins Health and Education in South Africa

KAP – Knowledge, Attitude and Practice

KZN – KwaZulu-Natal

MCP – Multiple and Concurrent Partnerships

NGO – Non-Governmental Organisation

OBE – Outcomes Based Education

OVSA – *One Voice* South Africa

PAR – Participatory Action Research

PEPFAR – President’s Emergency Plan for AIDS Relief

SAB – South African Breweries

SACOMM – South African Communication Association

SPSS - Statistical Package for Social Sciences

STI – Sexually Transmitted Infection

TAC – Treatment Action Campaign

UKZN – University of KwaZulu-Natal

UNAIDS – Joint United Nations Programme on HIV and AIDS

UNICEF – United Nations Children’s Fund

UNIZUL - University of Zululand

USAID – United States Agency for International Development

VCT – Voluntary Counselling and Testing

WHO – World Health Organisation

YFC – *Youth for Christ*

ACKNOWLEDGEMENTS

This research was made possible with a bursary provided by the United States Agency for International Development (USAID) through Johns Hopkins Health and Education in South Africa (JHHESA). I would also like to acknowledge the South African Netherlands Partnership in Alternate Development (SANPAD) for the scholarship that I received to be part of the Research Capacity Initiative Programme for doctoral students.

My thanks go to my supervisors Prof Keyan Tomaselli, Dr Emma Durden and the late Prof Lynn Dalrymple who have been instrumental during this PhD journey, with ongoing support and supervision.

My special thanks extend to Prof Donal McCracken and Prof Keyan Tomaselli for facilitating my two months of research leave to draft the final chapters of my thesis. For this I am most grateful. I would also like to acknowledge the CCMS staff, especially Lauren Dyll-Myklebust, for their support and patience during the final stages of this thesis writing.

Many thanks go to several organisations, and participants in the communities, who so willingly gave their time, and shared their knowledge to contribute to a better understanding of HIV communication.

A special thanks to my mum, who has always been an inspiration to my education and always reminded me, that I can do all things through Christ who strengthens me.

To little Eden-Zoë, my 18 months old princess, thank you for filling my life with endless joy and laughter during the most challenging times of working on this thesis.

To my wonderful husband who has done everything possible to free up my time during the final stages of this PhD. I am sincerely thankful for your inspiration, motivation and endless discussions of applying your engineering mind to exploring social science constructs. These discussions were most engaging and provided great insight in my writing. I am particularly appreciative for your formatting and graphic illustrations throughout this thesis.

Finally, this thesis would not have been possible without my hope and strength that comes from Jesus Christ.

Disclaimer: The opinions expressed herein are those of the author and do not necessarily reflect the views of the United States Agency for International Development.

ABSTRACT

HIV and AIDS is one of the biggest challenges facing South African young people today (Govender, 2010). Young people are at risk, partly through their own behaviour and partly through the attitudes, expectations and limitations of the societies in which they grow up (Panos AIDS Briefing, 1996). There are many HIV prevention programmes developed globally and nationally, specifically for young people but the pandemic still escalates rapidly. The fourth decade now calls for multidimensional approaches when communicating HIV prevention for young people. This thesis explores how young people can contribute to this multidimensional approach through their active participation in the various phases of developing HIV projects. The study does this through a sample of eight youth-focused HIV organisations in KwaZulu-Natal and a sample of students from the University of KwaZulu-Natal, to gain more insight into participation of young people in the development of HIV programmes. Bodymapping, a visual and art-based method, was used to explore young people's understanding of HIV, their perceptions of HIV programmes and the possibilities of their participation in the developing of further HIV projects.

The study used a grounded approach and applied principles of participatory action research to collect data in four phases. The first phase used interviews and focus group discussions with eight sample organisations to give insight into the programmes offered to young people and how they engage and make sense of their participation within these programmes. The second phase draws on previous bodymapping workshops that have been conducted with students from UKZN and young people in various communities to explore the application and relevance of bodymapping. In the third phase, data is presented on two bodymapping workshops conducted, to engage with young people about their contribution to the development of HIV programmes. The final phase draws on two focus group discussions, conducted with bodymapping participants, to examine their experiences and interpretation of the bodymapping process.

Some of the key findings indicate that a blanket approach to HIV programmes will not always work, as young people's sexual behaviour needs to be explored within a wider socio-ecological framework that recognises the inter-relational and interconnected system in which they make their sexual choices. The data indicates that youth and organisations strongly support the importance of participation and the inclusion of participants when developing HIV projects. However, discussions about participation indicated that while young people could identify the importance of participation, they still lacked an understanding of how to participate and how they could learn more about their lived experiences through participation. This was evident in the data where there was a distinction in how participation was defined from those in the UKZN group and those from rural KZN. In understanding what constitutes participation, young people are better positioned to aid the process of developing effective HIV related projects that are participant specific. I argue that bodymapping can be used as a process to initiate and aid the participation of young people in the various phases of developing HIV projects.

A three level model for applying bodymapping and planning processes has been developed to encourage participation with young people where the first step ensures that young people define what participation means to them. This becomes the foundation for how communication practitioners and academics make sense and theorise participation from a participant informed perspective. Bodymapping was pivotal in this process of engaging young people in self-reflection and introspection which encouraged a process of dialogue towards better understanding and defining participation from a participant perspective. Bodymapping in this way can be identified as a catalyst that encourages dialogue as part of communication for participatory development.

CHAPTER ONE: INTRODUCTION TO STUDY

Introduction

This thesis was written between the period of 2009 and 2013 which marks the end of the third decade but also the start of the fourth decade of HIV and AIDS interventions. The fourth decade also reflects South Africa's integrated response, which is a combination of communication and biomedical programmes to address HIV prevention. This period therefore demonstrates significant transitions, coupled by comprehensive and unified approaches to address the effects of this soaring pandemic. This thesis begins with a brief review of some of the developments and trends in HIV and AIDS communication over the last three decades, to provide a landscape of the current state of HIV communication in South Africa.

This chapter offers a comprehensive review of the HIV pandemic's rapid spread in South Africa over the last three decades. The fourth decade of HIV and AIDS is marked with significant interventions, particularly from a communication perspective. The role of communication in HIV prevention is briefly explored using three key national AIDS communication surveys which confirm the importance of communication in effecting direct and indirect social and behaviour change. The chapter discusses the context of my research, the problem statement and briefly outlines the research procedure this thesis follows. The chapter concludes with key research questions which inform this thesis, followed by an outline of each of the chapters.

The Face of HIV – Thirty Years Later

From a global perspective, the first decade of HIV and AIDS was met with considerable AIDS denialism in Africa, accompanied by racial and gender 'labelling', with predominantly biomedical Western solutions to prevent HIV transmission. During this first decade (1980-1989) in South Africa, there was a reported cumulative total of 353 cases of AIDS (Zwi & Bachmayer, 1990), with a prevalence rate of less than 1%. The infections among these 353 reported cases showed similar patterns to the HIV occurrences in America and Europe. A total of 216 infections were a result of relationships where men had sex with men and 72 infections occurred in heterosexual relationships. Out of the 353 cases, 231 were whites, 79 Africans, 13 coloured and three were Indian (Zwi & Bachmayer, 1990: 317). Research in the 1980s revealed that most infections occurred in homosexual relationships; this was supported by a study where 32 out of the 250 blood samples (over 10%) of homosexual men were found to be HIV positive (Sher, 1989). While HIV transmission in South Africa commenced with low infection rates, HIV

prevention strategies either did not feature or were very low on the agenda of the government, health professionals, civil society and community groups.

In many cases, the initial response to the epidemic in the first decade resulted in the development of messages which instilled fear about HIV and AIDS. These efforts always failed to “engage the public in positive behaviour change” (McKee, Bertrand & Becker-Benton, 2004: 26). The silence and lack of national and local responses within South Africa to the HIV infections meant that a culture of fear and silence, instead of knowledge and correct information, was evident among people. Communication was not effectively utilised to transfer consistent and correct information about HIV transmission.

After the first decade of AIDS, Zwi and Bachmayer (1990) suggested that in order to avoid an increase in infection rates in South Africa, the country would need to develop a public health response to address issues of the systematic fragmentation of apartheid, which limited access to health care services. They advocated for health education programmes which recognise culture, language and the importance of context, the involvement of women and youth groups in facilitating understanding of HIV, and an increase in funding for the development of new services and programmes. Their suggestions in the early 1990s emphasised some of the key developments that took place in the second decade of HIV, as infections continued to escalate at astounding rates.

The start of the second decade (1990-1999), saw a balance of HIV infections with homosexual and heterosexual transmission (Whiteside & Sunter, 2000). The HIV prevalence rose from 0.7% to 2.2% in the early 1990s, with over 3816 HIV infection cases reported in South Africa (UNAIDS/WHO, 2000). This is a huge jump from the initial 353 cases that were reported in the first decade of HIV. Van de Vliet (2004) suggested that South Africa, with a prevalence of less than 5%, was ready to take on the epidemic. However, in the transition from apartheid to democracy, South Africa did not identify HIV as a multi-dimensional development issue, but addressed it as a health issue. The number of recorded HIV infections had grown by 60 percent in the country during 1991 and 1992 and was expected to double in 1993. This later escalated to almost 850 000 in the mid 1990s (avert.org).

This second decade was populated with several HIV and AIDS programmes, global funding, a mushroom of non-profit organisations, the roll out of treatment globally, yet very limited access and acceptability of treatment in South Africa, and little emphasis on community involvement and active participation of those who were most infected by HIV. While Auerbach and Coates (2000) observed that this second decade has “taught us that HIV prevention can work” (2000: 1029), this conclusion was not

reached by many practitioners in the field who still found a lack of focus on the role and importance of communication in HIV prevention (Scalway, 2003). The second decade of HIV and AIDS was succinctly described by Thomas Scalway as “Missing the Message,” after 20 years of HIV and AIDS communication and suggested that: “whilst HIV and AIDS information and key health messages remain crucial, it is important to look beyond these messages – no matter how empowering and context-sensitive they might be – and help to develop an environment where vibrant and internally derived dialogue can flourish” (2003: 2). Based on major success stories in AIDS, Scalway proposed that future responses need a common thread of ownership, participation and a politicized civil society (2003: 5).

The South African landscape during the second decade of HIV and AIDS (1990 -1999), however, still did not demonstrate sufficient national prevention initiatives, with poor strategies for prevention of mother to child transmission and a lack of roll-out of antiretroviral treatment (Benatar, 2004: 86). The controversial HIV and AIDS play, *Sarafina II*, launched in 1995 cost over R14.2 million and was criticised for inappropriate messaging which was believed to promote teenage promiscuity, and offered a very “linear process of changing people’s behavior within a stages of change or reasoning process” (Govender, 2011: 69; Tomaselli, 1996¹). Later, the Beyond Awareness Campaign (BAC) was the South African government’s attempt to move beyond awareness and individual behaviour change, to facilitate a multimedia approach for social action (Tomaselli et al, 2002; Parker, 2000). The BAC campaign was an initiative implemented to transition the individual, didactic process of HIV prevention to community involvement in addressing the pandemic. The BAC was therefore able to raise awareness of HIV and AIDS, but also to act as a catalyst for greater collective action against the virus” (Govender, 2011: 70-71).

At the start of the third decade of HIV and AIDS (2000-2009), the South African government released figures estimating that 4.7 million people were infected (Sidley, 2001), with an HIV prevalence at 10.6 % in 2009 (UNAIDS, 2009). This decade also witnessed a clear shift to community-led initiatives and a strong focus on treatment, care and support to accompany the many faces of HIV prevention. As a

¹ The members of the HIV/AIDS and STD Advisory Committee to the National HIV/AIDS and STDs PROGRAMME of the Department of Health, wish to make known their position and views on the criticism of *Sarafina II*.

The primary concern of Committee members is that the unfortunate events surrounding the *Sarafina II* musical play by Mbongeni Ngema will damage the recently established, but carefully constructed, National Programme against HIV/AIDS and STD's. The success of this Programme is critically dependent on public acceptance; the *Sarafina II* controversy can destroy the credibility of the Programme. Accessed on 18 march 2013

For more details see: http://ccms.ukzn.ac.za/index.php?option=com_content&task=view&id=566&Itemid=70

result, Auerbach and Coates (2000) argue that in the third decade of HIV prevention there was a focus on comprehensive and multidisciplinary approaches, integrating biological, behavioural and social science approaches that address primary and secondary prevention with a domestic and international orientation. This third decade saw an increase in biomedical responses in addition to the roll-out of treatment, with the development of microbicides such as Tenofvir, a vaginal gel to prevent HIV transmission, and interventions to support medical male circumcision. Moving away from predecessors of AIDS denialism, the third decade of HIV was marked by a significant shift in attitudes, beliefs and practices from the early 1980s and with these shifts new challenges were posed for the fourth decade of HIV prevention. “HIV and AIDS is a complex biological, behavioural, and social phenomenon, and the science of its prevention requires a complex strategy, governed by a number of specific principles” (Auerbach & Coates, 2000: 1029).

Several HIV programmes emerged in South Africa during this time, some of which used television and radio channels, while others started to integrate a mass media and participatory approach. Soul City has been one of the pioneers in terms of creating synergies by simultaneously employing the media and more participatory grassroots approaches (Tufté, 2001). “Its success in educating people about HIV and AIDS and encouraging both behaviour and social change is indicative of the enormous development potential that lies in combining media diffusion campaigns with participatory interventions” (Govender, 2011: 72). Other programmes offered at the national level with community engagement initiatives include *Scrutinize*, *4 Play: Sex Tips for Girls* and *Intersexions* which all use entertainment education strategies to relate messages which entertain and educate in order to facilitate social and behavioural change.

The HIV landscape highlights specific transitions, shifts and interventions over the last three decades. In the first decade of the epidemic, primary prevention was the central focus of governments, international bodies and donor agencies, while the non-governmental sector scaled up on care and support efforts. The second decade saw a shift to a greater focus on voluntary counselling and testing (VCT), which was an attempt to bridge the gap between prevention and care, support and treatment (McKee et al, 2004: 24-25). This was further supported by the global roll-out of ART’s in the mid-1990s.

The third decade of the epidemic had a greater focus on treatment, particularly in South Africa, after a long period of AIDS denialism; and prevention through more biomedical interventions such as medical male circumcision and microbicides. Salim Abdool Karim (2011) suggests that the fourth decade of the epidemic is going to need an integration of all areas where people are encouraged to test for HIV in

order to access the preventive measures and treatments available. This will further require reduction in stigma, which according to Abdool Karim will need to extend beyond the stigma associated with AIDS denialism to addressing it on the individual and community level. These transitions in how HIV prevention developed and evolved over the last 30 years indicates that communication strategies have also undergone several stages of development and evolution to keep up with the trends in HIV prevention.

Communicating HIV Prevention in the Fourth Decade

The start of the fourth decade of HIV and AIDS commenced with an estimated HIV prevalence rate of approximately 10, 6% in South Africa (Stats SA, Shisana et.al, 2009). The total number of people living with HIV is estimated at approximately 5,38 million in 2011. An estimated 16,6% of the adult population aged 15–49 years is HIV positive. The number of new HIV infections for 2011 among the population aged 15 years and older is estimated at 316 900. An estimated 63 600 new HIV infections will be among children aged 0–14 years (Stats SA)². According to Statistics South Africa (2011: 7), in July 2010, an estimated 263 368 South Africans had died of AIDS related causes within a seven month period.

These escalating figures have seen the core focus of global initiatives in HIV prevention shift in the fourth decade from “material interventions’, such as condom distribution and treatment for sexually transmitted infections” to more “cognitive tools’ or ‘literacy’ for promoting specific behaviours.” These cognitive tools extend beyond information and knowledge about the disease, to enabling people with “assertiveness and communication skills” (Lambert & Wood, 2005: 537). Information and communication offer solutions to many obstacles such as: “limited resources, stigmatization and discrimination, a lack of information to enable appropriate behavioural changes and to counter the dangerous social consequences of misinformation and myths about the disease, and continuing social and political silence and denial about the disease” (Forman, 2005: 173). However, at the same time, “a persistent social and often political silence about the denial of HIV and AIDS” can limit the effectiveness of communication about the disease (Forman, 2005: 181; see also Tomaselli, 2011).

The fourth decade of HIV prevention (2010-2019) is characterised by numerous HIV and AIDS initiatives flooding our national television and radio stations, with a mushroom of community-public-private partnerships and programmes that utilise a range of strategic communication and participatory

² <http://www.statssa.gov.za/publications/P0302/P03022010.pdf>. Accessed 17 Sept 2012

approaches to address HIV-related issues. The internet, journals, academic books and newspapers are inundated with the latest statistics of HIV infection and death rates accompanied by detailed breakdowns of HIV prevalence among children, youth, and adult men and women. The need for consistent HIV prevention still remains the focal point of all programmes, with advocacy for biomedical and social responses to HIV prevention. While academics, health professionals, government and civil society debates about whether large scale media is better than community-driven, participatory initiatives, or whether the social science approaches are more effective than biomedical prevention, or if the needs of the beneficiary are addressed in light of stakeholder and donor objectives, millions of people are still becoming infected and thousands dying annually.

In the midst of all of these debates, young people are still the life blood and human capacity for our next generation of leaders. More efforts are needed to explore how they can contribute to understanding what their lived experiences are in terms of HIV and AIDS, and how they can be actively engaged in promoting HIV prevention. The uncertainty of the HIV and AIDS landscape leaves the communication field in a continuous state of transition, as communication strategies and processes need to be transforming rapidly to keep up with the complexities of HIV and AIDS given the diverse social, cultural and behavioural factors which influence young people. The third and fourth decades have been marked by the development of several communication initiatives to address issues of HIV and AIDS, and extensive evaluations have been conducted to explore the impact on social and behavioural outcomes as a result of exposure to these programmes (see, e.g., Tomaselli & Chasi, 2011; Ige & Quinlan, 2012; Durden & Govender, 2012).

A South African AIDS communication programme survey conducted in 2006 on HIV prevention behavioural outcomes of 19 AIDS communication programmes indicates the influence of condom use, discussions about HIV testing, knowledge of AIDS telephone help lines, and helping someone infected with AIDS (Kincaid et al, 2008: 16). The findings of the survey, for KZN in particular, indicated that while 83% of the sample population, had access to the AIDS programmes through television and radio, 11% of the population did not have exposure to these AIDS initiatives, therefore alternate communication programmes need to be explored to address HIV prevention in KZN (Schierhout et al, 2008).

The national AIDS communication survey conducted in 2009 indicated that 81% of the KZN population who had exposure to AIDS communication programmes on radio and television were predominantly young people. Overall the 2009 survey (with a sample of 10 000) indicated that communication programmes have been successful in improving knowledge, reinforcing beliefs and attitudes about HIV

prevention, promoting care and support and access to treatment (Johnson et al, 2010b). The survey found that communication can positively promote personal behaviour to reduce the risk of HIV infection, such as limiting sexual partners and promoting condom use, while also tackling beliefs, attitudes and social norms that fuel risky behaviour (Johnson et al, 2010: 1a). The 2012 HIV Communication Programme Survey, with a sample of 10 034 respondents, indicated that communication programmes had a direct influence on counselling and testing, medical male circumcision and condom use³.

The three national HIV communication surveys (2006, 2009, 2012) offer significant indicators of the success of communication programmes to advance HIV knowledge, positive behaviour change and discussions around issues of condom usage, testing, and care and support of those infected. These surveys draw attention to a sample of communication programmes offered through television, radio, billboards, newspapers and community forums and demonstrate the importance of incorporating mass media and participatory initiatives. They further highlight the influence that communication has on effecting direct and indirect behaviour and social change. However, these influences do not come without further communication challenges.

Table 1 below summarises the four decades of communicating about HIV and AIDS in South Africa

³ <http://jhhesa.org/research.html>. Accessed on 21 January 2013

Table 1: Four decades of communicating about HIV and AIDS in South Africa

	First Decade (1980-1989)	Second Decade (1990-1999)	Third Decade (2000-2009)	Fourth Decade (2010-2019)
HIV Prevalence (15-49 year olds)	1%	2.2%	10.6%	10.6%
People living with HIV	353	850 000 (mid 1990)	4.7 million	5.83 million
Primary audience infected	homosexuals	Heterosexuals and homosexuals	Women ages 20-24 and men ages 35-39	Women ages 20-24 and men ages 35-39
Focus of intervention	Seen as a biomedical problem – focus on primary prevention	Seen as a health problem – focus on bridging the gap between prevention, care and support	Strong focus on voluntary counselling and testing, supported by roll out of treatment	Integration of biomedical and communication initiatives to offer holistic focus
Communication programmes	None	<i>Sarafina II</i> Beyond Awareness Campaign	<i>Soul City</i> <i>Tsha Tsha</i> <i>Yizo Yizo</i> <i>Sex tips for girls</i> <i>Scrutinize</i> <i>LoveLife</i>	<i>Soul City</i> <i>Scrutinize</i> <i>loveLife</i> <i>Intersexions</i> <i>etc</i>
Focus of message	Fear associated with HIV	Perceived as a health problem Recognizes importance of community initiatives	Entertainment Education Role Modeling Use of national media and small scale participation Biomedical ways to promote prevention	Strong focus on biomedical interventions Discussion for integrated response: social, biomedical, behaviour etc
Stakeholders	Non public or private engagement	Community recognised but low importance of community involvement	Integration of all stakeholders Participation of communities in HIV initiatives	Support of community-public- private partnerships
Way forward	Develop national response Recognize the limited resources, need for cultural context and involvement of women and girls	Create an environment for dialogue Common thread of ownership, participation and politicizes civil society	Integration of biomedical and communication responses Addressing more specific sexual practices of young people More context specific communication practices	Incorporation of all forms of media More focus on young people and participation Reduction of risky sexual behaviour

Problem Statement

Many HIV communication projects have been conducted globally over the last 15 years, but the evidence of their effectiveness is scarce, “partly because rigorous evaluation is difficult to do, not enough has been done, and the results are often not published” (Kincaid et al, 2008: 3). My thesis takes a step further than attributing the lack of effective HIV projects to issues of evaluation and documentation, but extends to explore issues of participation of young people in the development of HIV projects. My assumption is that in the absence of young people’s participation and their inclusion in the various strategic communication processes, the effectiveness of HIV projects is challenged. This thesis therefore explores what strategic communication processes are used through a sample of young people towards identifying the specific phases that inform the development of HIV projects. This is explored using a participatory framework to understand young people’s perceptions of participation and how this is integrated into the strategic phases for developing HIV projects. The bodymapping process which is an arts based method, is used to explore young people’s participation.

Addressing HIV and AIDS for the last three decades indicates the effectiveness of communication as a medium to explore prevention, treatment, care and support options to people. Communication serves as a means to discuss health problems and specific determinants of health with a final goal of ‘translation of science into practice’ (Parvanta et.al, 2011: 84). Communication has been at the forefront of health promotion and awareness for many years, making communication frameworks foundational to all health programmes. It plays a pivotal role during the time of exploration, discovery and unravelling of possible preventive measures to control and contain the virus. However, communication as a medium to transfer information and create a process of dialogue does not occur in isolation and often poses several challenges. Communication constantly enables people to make decisions, explore strategies, discuss community norms and standards and apply new information, but this continual “communication buzz” can either support or constrain people’s choices (Ford et al, 2003: 600).

In order for communication to facilitate or support people’s choices, and address the needs of society, a participatory approach needs to be utilised to incorporate the influence and input of young people before the design and development of communication initiatives. This participatory perspective suggests that a participatory process that works with young people must precede the development of a communication intervention to incorporate the needs and be of relevance to them. There is extensive literature on the importance of participation (see Cohen and Uphoff 1980; Lubombo, 2011; Nair and White, 1993; Bessette, 2004), with a range of participatory models and discussions on levels of

participation, but there is a gap in literature and research that advocates for the inclusion of young people in all phases on developing programmes. Whilst some studies do exist which indicate that young people are participating either in phases of research or facilitation (see Cameron and Theron, 2011; Klindera and Menderweld, 2001; Nygreen, 2006), there are limited studies that argue for participation in all phases of HIV programmes (see Oakley 1991). For communication to be effective from this perspective requires a revisiting of the strategic communication processes that inform the design and development of HIV and AIDS programmes, with a more specific exploration into how young people are participating in these various phases. Revisiting strategic communication processes from a participant informed perspective ensures the active participation of young people in the phases of developing strategic HIV projects.

Within the broader field of communication for development, the modernisation or top-down perspective of communication relies on experts who have access to resources and are knowledgeable in the field to address HIV and AIDS related issues. This perspective can be termed as 'upstream initiatives' as it suggests the complexity of working on HIV programmes that eliminates the active participation of people in identifying their problems and relevant solutions. HIV programmes are then faced with the dilemma of what Parvanta terms as "upstream determinants" which he defines as limited resources, poverty, poor living conditions, health and education problems (Parvanta et al, 2011). These upstream determinants are usually addressed with what he terms as upstream solutions, offered from a policy or national level without taking into account the voices of those who are affected by HIV related issues.

Instead, Parvanta et al, (2011) proposes that downstream solutions, which are often termed in academia as grassroots or community approaches, need to emerge in order to address downstream problems of illiteracy, access to information and treatment, and social and cultural influences. Parvanta et al (2011), in essence, suggests that development problems need to be identified as such by the people who are affected by them, where they collectively identify solutions. There is often a mismatch of addressing development issues when people who are not affected by the development challenges develop solutions to community problems. The downstream solutions advocate for a participatory, dialogic process that includes the beneficiaries to develop flexible communication processes to address issues of HIV and AIDS. This thesis is situated within this downstream framework of communication for development, to address HIV communication processes with the active involvement of young people (this is explored in Chapter Four).

This research is therefore explored from a communication for development framework, particularly examining the downstream solutions to addressing HIV communication processes with young people, in a participatory manner. The field is referred to as communication for participatory development (CFPD). CFPD uses a simple framework to explore who people are, what they want and how can they go about achieving this (Figueroa et al, 2002; Kincaid, 2009). The research therefore recognises the complexities of communication processes designed in a very didactic approach and the challenges it brings to addressing HIV and AIDS, towards exploring the influence of a participatory perspective for interventions and programme design.

A participatory perspective in communication for development requires participant-informed decisions where young people engage in discussions and collective dialogue about issues which affect their social reality (Freire 1976; Figueroa et al, 2002). Brazilian educationalist Paulo Freire argues that people can only become critically conscious of this social reality through a problem-posing perspective, instead of a solution-based response to addressing the needs of a community/target audience. Critical consciousness or conscientization is defined as “a process of developing consciousness that is understood to have the power to transform reality” (Taylor, 1993: 52). In order for this process of consciousness to take place, there is a need to ensure that the target audience can move from a process of *intransitive thought*, where people are dominated, disempowered, and cannot change their condition, to *semi-transitive thought*, where some thought and action is given to a situation, people feel partly empowered, but still fail to relate problems collectively to whole system. The final transition occurs from *semi-transitive* thought to the final process of consciousness which is *critical transitivity* where people are completely empowered and in a position to advocate changing social conditions (Shor, 1993: 32). Transitions through these three processes require a revisit of the levels of participation of participants.

A ladder of participation is proposed by Roger Hart (1997) and Sherry Arnstein (1969) where young people can advance from a position of being completely disempowered (used as a token by those developing or implementing an intervention) to levels of citizen power where the rights and voice of the target audience is heard and influences the decisions which affect them. The active engagement of young people through these various levels of participation requires a range of participatory approaches, discussions and dialogue. The use of various participatory techniques such as role-play, drama, music and art-based approaches offer evidence-based perspectives to the effectiveness of engaging young people in the discourses around complex issues. In this thesis, bodymapping, an arts-based technique,

is used to facilitate discussion about communication processes and young people's active involvement in development of HIV programmes and interventions (this will be detailed in Chapter Five).

Bodymapping is a technique or process which is used in this thesis to explore what young people can contribute to communication processes for HIV and AIDS programme development. To this effect, a participatory approach is utilised to explore discussions about the participatory development of communication processes. Young people aged 18-24 are the target population for this study as the data from three HIV prevalence surveys in South Africa (2002, 2005, 2008) indicate that they are the most at risk of HIV infection. The specific HIV context for young people is explored in Chapter Two. This thesis therefore focuses overall on HIV problems (Chapter Two), specific communication processes (Chapter Four), and the practices and participation (Chapter Five) of young people.

Use of Terminologies

This thesis makes use of a range of terminologies interchangeably. It makes reference to communication processes from a strategic communication perspective which explores the specific phases that inform the development of HIV projects. This is premised on the understanding that every HIV project must be supported by a communication process that is either a one way flow of communication or a dialogical two way flow of communication. Reference to communication process in this thesis is positioned within a dialogical participatory framework and therefore refers to the participation of young people within the process.

Communication processes are also strategically informed and usually follow a step by step process or offers various phases of development for HIV projects. Communication processes for the purpose of this thesis therefore makes reference to the strategic phases of developing HIV related projects, with an understanding that participation of young people is essential to inform the communication process. I also make reference to HIV projects, programmes and communication initiatives interchangeably. This is premised on an understanding that all these initiatives require a strategic communication process within a participatory framework when developing HIV projects.

The terms youth and young people are also used interchangeably and makes reference to young people within the age group of 18-24 years old, who inform this study. While UNESCO defines young people as those between the ages of 15-24, this study only included young people between the ages of 18-24 who were participants of programmes at the various HIV organisations⁴. Chapter Seven also

⁴ <http://www.unesco.org/new/en/social-and-human-sciences/themes/youth/>. Accessed on 18 March 2013

makes reference to young people as students, who participated in focus group discussions but at the same time were registered students. These terminologies are used interchangeably to ensure distinction of sample groups. Extensive review of literature on HIV and AIDS communication indicates an inconsistency in literature where these terms are used interchangeably. It is for this reason that interchangeable terminologies are used through this thesis.

Research Process

This thesis takes a case study approach, exploring young people's involvement in strategic communication processes through a two-step process. This entails, firstly, interviews and focus group discussions with young people who are in some cases facilitators from a sample of eight organisations. Based on these initial findings, derived through a deductive approach, I then advance the more specific observations and common trends/patterns in the data collected towards exploring what is happening in practice with young people and HIV and AIDS communication processes. The second process takes the form of action research, and is an exploration of how young people can actively participate in communication processes, which will be explored through the use of the bodymapping process. The steps of the bodymapping process have been revised to take young people through a process of inquiry, where they share what HIV challenges affect young people. They are also taken through a process of knowledge sharing and reflection, where they discuss ways in which they can participate in the processes of designing HIV programmes.

Theoretical and empirical data is drawn from four specific data collection phases. The first source is the empirical data which emerged from the initial interviews and focus group discussions conducted with eight sample organisations in 2011, in order to give context to organisational communication processes for programme design, with further insight into what programmes are offered to young people and how they engage and make sense of their participation within these programmes. The second component of this thesis draws on previous bodymapping workshops that have been conducted with students from UKZN and young people in various settings to explore the application and relevance of bodymapping. The third data collection phase occurs through two bodymapping workshops, used to explore the use of this process as a means of engaging with young people to learn how they can contribute to the development of HIV programmes. The final phase draws on two focus group discussions, conducted with each group of bodymapping participants after the workshop, to examine their experiences and interpretation of the bodymapping process.

This thesis draws on my extensive participatory work conducted with young people at HIVAN, the Centre for HIV and AIDS Networking from 2004-2008, and my MA thesis which explored the need for student participation in HIV messaging at the University of KwaZulu-Natal (UKZN). My previous work entailed the design and implementation of HIV and AIDS programmes for young people using participatory methodologies such as role plays, drama and art. Of specific relevance was the work conducted with communities and young people, using bodymapping to discuss issues of HIV prevention. My MA research explored the perceptions of young people with HIV messaging and suggested that 90% of students at UKZN wanted to actively participate in HIV and AIDS communication (Moodley, 2007)⁵. I therefore applied my knowledge of participatory methodologies, particularly the use of art-based methods such as bodymapping with postgraduate students (2009-2013 ongoing) at UKZN. This bodymapping process was undertaken to assist postgraduate students to understand more about themselves and their research interests. This thesis therefore builds on my previous work and research with young people aged 18-24 from a sample of eight HIV organisations and postgraduate students at UKZN to constitute a diverse representation of youth from both urban and rural KZN. The University of KwaZulu-Natal therefore become a research site to further explore issues of participation in HIV programmes with students that were highlighted in my MA thesis, and issues of participation from a wider sample of young people from various HIV organisations.

Main Research Question

How can young people's participation contribute to the strategic communication processes for developing HIV and AIDS programmes?

Sub Research Questions

1. What are the HIV prevention messages and communication approaches/strategies offered by selected youth-focused organisations?
2. What are young people's perceptions of communication processes for developing HIV projects?
 - What are participants seeing, hearing, saying and doing regarding their participation in HIV related projects?
3. How can participants be involved in the development of HIV related projects?
 - Can the technique of bodymapping be used to involve participants in developing HIV related projects?

⁵ My MA study was conducted and referenced under my maiden surname Moodley (2007) and later republished as Moodley (2012).

Structure of Dissertation

Chapter One: Introduction

Chapter One offers a brief introduction to the landscape of HIV and AIDS over the last three decades. It introduces the start of the fourth decade of HIV, and later outlines the problem statement for this study, with general and specific research questions.

Chapter Two: The HIV and AIDS Landscape with Young People in South Africa

The context for HIV and AIDS with South African young people is discussed in this chapter with reference to youth who are categorised into those attending tertiary institutions and those attending schools in KZN. The chapter demonstrates some of the main factors which contribute to HIV and AIDS transmission and some of the key studies/programmes conducted to address this. It specifically focuses on the studies conducted by Mulwo (2009), Kunda (2009), Mutinta (2011) and Moodley (2007) on students' perceptions, practices and contexts for HIV and AIDS awareness at UKZN.

Chapter Three: Methodology

The methodology chapter discusses the research design of this study which includes a grounded approach, informed by principles of participatory action research and an auto-ethnographic perspective. The chapter outlines the four specific phases that inform the data collection phases within a PAR process. More specific details of interviews, focus groups and the bodymapping workshop process are also discussed in this chapter. The chapter also offers a discussion on the use of visual methods such as bodymapping. The chapter concludes with a discussion on the application of thematic analysis for this study.

Chapter Four: Communication for (Participatory) Development: HIV and AIDS Programmes in South Africa

This chapter discusses the role of communication in HIV and AIDS programmes with specific reference to the role of strategic communication. It then positions the thesis within a development framework, particularly emphasising the importance of communication for participatory development. The chapter ends with specific references to HIV programmes in South Africa which is discussed with a development framework. The chapter ends with an argument for a more context specific approach to HIV programmes.

Chapter Five: Young People's Participation in Communication Processes: Participatory Practices and Problems

The chapter offers a critical discussion of participation and why it is important. The chapter discusses reasons for young people's participation, and a review of models for participation. It extends to discuss young people's participation in the various phases of developing HIV communication programmes or interventions, and the limitations of participation. It also discusses some of the contrasts of visual methods as a research tool with conventional research practices, and takes a step further to discuss drawing and mapping as visual methods. This provides the background to discuss bodymapping and its application across a range of issues and its specific use in HIV and AIDS.

Chapter Six: Exploring HIV Communication Programmes in KZN (Phase One)

All data generated through desktop review, interviews and focus group discussions from the eight sample organisations is analysed in this chapter. The data is presented to offer an introduction to the various sample organisations and their related programmes. The chapter discusses some of the data on the specific messages offered to address the risky sexual practices which were identified by young people, with a further exploration into some of the factors which influence risky behaviour. The chapter continues to offer an analysis of young people's participation in various phases of developing HIV programmes and ends with some of the limitations of participation.

Chapter Seven: Bodymapping, Exploring its Application (Phase Two)

Chapter Seven discusses the next phase of data collection where focus groups were conducted with UKZN students in 2009 - 2012 to explore the validity of bodymapping to encourage participation of young people. The chapter offers feedback from students, facilitators and lecturers about how the bodymapping process was adapted. Reference is also made to the various bodymapping workshops that were facilitated with young people in various communities between 2004-2008 through my work with HIVAN, The Centre for HIV Networking. The data presented in this chapter therefore explores 10 years of bodymapping experiences, perceptions and reflections of young people and the researcher.

Chapter Eight: Mapping Young Peoples' Participation in HIV Programmes (Phase Three)

This chapter discusses the findings of two bodymapping workshops implemented to discuss young peoples' participation in strategic communication processes, with a particular focus on programme and message design. The bodymaps and the data generated from the workshop process are analysed in this chapter, exploring young people's perceptions about involvement in HIV and AIDS communication

design. The visual data is presented and analysed in order of the steps of the bodymapping process, and is supported by more data collected through one-on-one discussions conducted with each participant.

Chapter Nine: Exploring Young Peoples' Bodymapping Experience (Phase Four)

The last phase of data analysed presents a discussion about the bodymapping process and some of the advantages and disadvantages for using this process with young people. The chapter also discusses the possibilities for young people to participate in the development of HIV programmes based on the data collected from the bodymapping experience.

Chapter Ten: Making Participatory Sense of Bodymapping and HIV Programmes

The final analysis of this thesis draws on all four data sets, to answer the specific research questions set out in this study. A model for bodymapping and encouraging participation in all phases of developing HIV related projects is discussed to provide a youth-informed theoretical perspective of participatory communication processes with young people.

CHAPTER TWO: THE HIV AND AIDS LANDSCAPE WITH YOUNG PEOPLE IN SOUTH AFRICA

Introduction

Chapter One offered a comprehensive overview of the four decades of HIV and AIDS programmes in South Africa, with some insight into the transitions of HIV prevalence from 0.2 % in the early 1980s to 10.6 % at the start of the fourth decade. This chapter takes a step further to explore the trends of HIV prevalence and the sexual behaviour of young people in South Africa, particularly for ages 15-24. Given the chronological review of HIV and AIDS across the four decades in the first chapter, this chapter will continue with a review of HIV and AIDS and its influence on young people, particularly during the third decade of HIV, which will provide a framework of considerations for HIV communication for the fourth decade. The chapter offers an overview from a national perspective, and then moves to specific findings regarding young people in the province of KwaZulu-Natal (KZN), which has the highest HIV prevalence (Shisana, 2009). This will be done through a review of the HIV prevalence and sexual practices with young people at seven universities in KZN and examining studies conducted with young people in schools. A review of studies conducted across universities and schools will provide data on HIV prevalence and sexual practices of 15-19 year olds (usually the school going population), and 20-24 year olds (early employment or the higher education/tertiary population). The chapter will conclude with a brief discussion on some of the key determinants that influence these sexual practices.

The HIV Prevalence and Sexual Behaviour Trends of Young People in South Africa

While HIV and AIDS has asserted itself as a *global* epidemic, Sub-Saharan Africa has struggled the most with the virus, with 1.9 million people becoming newly-infected in 2008 alone (UNAIDS, 2009). However the recent UNAID report (2013) indicates that Sub-Saharan infections have declined by 34% since 2001. South Africa, in particular, has been especially hard-hit and is home to the largest number of people infected with the virus (UNAIDS, 2008; Abdool Karim et al, 2005). In 2005, approximately 5.54 million South Africans were estimated to be living with HIV; 18.8% of the adult population (15-49 years) and an estimated 12% of the general population are affected by the severity of AIDS in their families and communities (HIV and AIDS Strategic Plan for 2007-2011: 7). In 2009, an estimated 5.6 million people were living with HIV and AIDS in South Africa (Avert, 2011), with 390 000 new infections

occurring in South Africa during 2009 (UNAIDS, 2010: 180; 183-184, see also UNAIDS 2013). In 2012, an estimated 6.1 million people were living with HIV in the country (UNAIDS 2012).

Whilst only one-fifth of the global population is between the ages of 10-19, in developing countries young people constitute at least 50% of the population. HIV and AIDS is one of the biggest challenges facing South African young people today (Govender, 2010). Young people are at risk, partly through their own behaviour and partly through the attitudes, expectations and limitations of the societies in which they grow up (Panos AIDS Briefing, 1996). KZN has the highest HIV prevalence in the country (HSRC, 2008) and is also home to the largest school-going population (over 2.7 million) in South Africa (Reddy et al, 2005). The KZN youth population is also predominantly affected and infected by HIV and AIDS (Reddy et al, 2005). It is therefore crucial to explore the HIV prevalence and practices that make South African young people more susceptible and vulnerable to HIV. Three national HIV prevalence surveys were conducted in 2002, 2005 and 2008 and highlight some of the key trends in sexual practices among young South Africans.

In 2002, the Nelson Mandela Foundation and the Nelson Mandela's Children Fund commissioned the Human Sciences Research Council (HSRC) to conduct the first systematically sampled national survey on HIV prevalence for 15-49 year olds across races, gender, age groups, and urban and rural settings. The 2002 survey found that the HIV prevalence was 11.4% among the South African population. The survey highlighted that the highest HIV prevalence was with age group 25-29 (28.4%), with 13.2% for ages 20-24 and 5.9% for ages 15-19. The study found that 57.9% of females and 55.6% of males between the ages of 15-24 were sexually active. This indicated that most young people had their sexual debut at the age of 17, placing them more at risk of unprotected sex and contracting HIV. Multiple and concurrent partners were not found to be high with this age group, "with 84.7% of youth and 93.5% of adults reporting only one partner in the past year" (Shisana et al, 2002: 13). The importance of communication was highlighted in the study, to address the various recommendations to reduce the high prevalence rates, gender imbalances, and to promote safe sexual practices. The study highlighted the importance of supporting communication systems that allow for interactive communication approaches (Shisana et al, 2002: 20).

The 2005 South African HIV prevalence survey indicated that overall HIV prevalence rates was 10.8%, with 15.2% for youth ages 20-24, 5.9% for ages 15-19, and an overall prevalence rate of 10.3% for ages 15-24. This was a 1% increase from 9.3% in the 2002 survey (Shisana et al, 2002). Prevalence rates were significantly higher for females (23.9 %) than males (6%) aged between 15-24 year olds.

(Shisana et al, 2005:38). The overall median age of first sex for ages 15-24 was 17 years of age (Shisana et al, 2005). The survey also indicated that nearly half of males aged 15–19 years (45.2%) had more than one partner in the past year, with a HIV prevalence rate of 29% for females aged 15–19 years, and 34.9% of females aged 20-24 who had partners five or more years older (Shisana et al, 2005: xxix). Whilst the survey highlighted the increase of multiple partners and intergenerational sex, the study also highlighted the importance of communication in addressing these various behavioural determinants. The survey found that the mass media exposure to HIV campaigns was significant, but a wide population still depended on exposure to interpersonal communication through educational events, health services, schools, workplaces, and faith-based organisations (FBOs), friends and families - highlighting the need to support local-level communication and dialogue (Shisana et al, 2005: xxxiv).

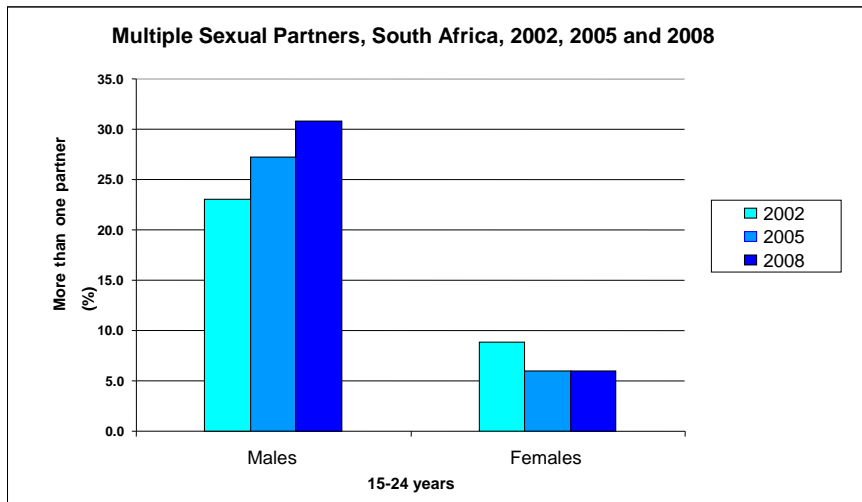
The 2008 national survey indicated that the HIV prevalence rate was 10.9%, with 14.1% for young people between ages 20-24 and 4.6% for ages 15-19. KZN has the highest HIV prevalence of 25.8% for 15-49 year olds. While sexual debut started to occur as early as 15 years old, the number of young people engaging in early sexual debut had not increased but averaged around 8.6% in 2005 and 2008 surveys. HIV prevalence rates were twice as high for females then males between the ages of 20-24 and 25-29, while HIV prevalence for men was high between ages 30-34. The findings of the 2008 survey indicate that there was an increase in the number of young people who have partners older than five years, with a significant increase from 9.6% in 2005 to 14.5% in 2008. This indicated that while messaging around abstinence, delaying sexual debut, and condom usage was working, sexual partners in the form of multiple and concurrent partners, and intergenerational sex was on the rise with young people.

These three national HIV prevalence surveys highlight the trends in HIV transmission, but also provide data to explore the key determinants that make young people more vulnerable and susceptible to HIV. Overall, the surveys indicate that HIV prevalence in the country is now constant around 11% (11.4% in 2002, 10.8% in 2005 and 10.9% in 2008). The three surveys also suggest that whilst KZN had the fourth highest prevalence in 2002 (almost 12%) the province now has the highest HIV prevalence of 16% in 2008. It also shows that whilst the prevalence rate is lower for young people ages 15-20 in comparison to other age groups, the prevalence rate has been increasing with each survey.

One of the biggest concerns of the 2005 and 2008 surveys was the increase in number of females (18.5% in 2005 to 27.6% in 2008) with sexual partners who were more than five years older than

themselves. There was also an increase from 27.2 % (in 2005) to 30.8% (in 2008) of males between the ages of 20-24 engaging in multiple relationships (refer to graph below).

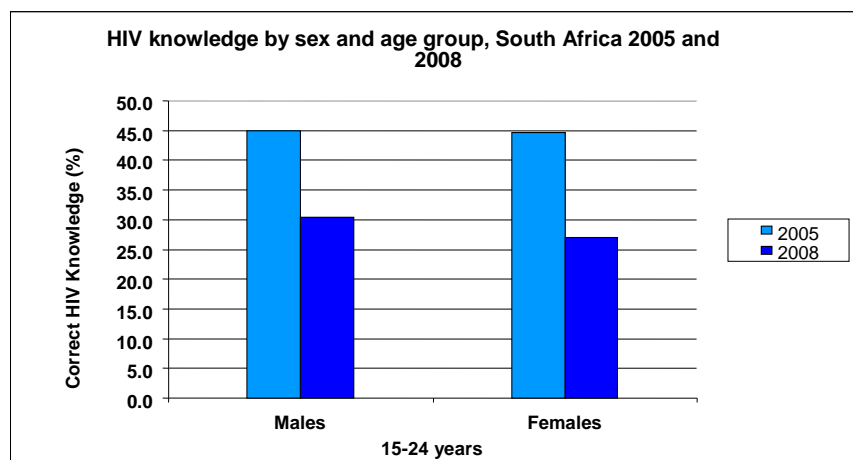
Figure 1: Multiple Sexual Partners, South Africa, 2002, 2005 and 2008



Source: data consolidated from three HIV prevalence surveys

The 2005 and 2008 surveys also indicate that there was a considerable decrease in correct HIV knowledge across all age groups (refer to diagram below). Further studies need to be conducted to explore why there has been a decrease in correct knowledge. The three surveys highlight that although the overall HIV prevalence is stabilising, the HIV prevalence rates differ significantly between age groups and genders. Males in age group 20-24 are engaging in more multiple partnerships, while females are engaging in more intergenerational relationships.

Figure 2: HIV knowledge by sex and age group, South Africa 2005 and 2008



Source: Data consolidated from two national prevalence surveys

The findings of these surveys highlight the importance of addressing HIV prevention and specifically issues of multiple partners and intergenerational sex. All three surveys highlight the importance of communication in advocating correct and consistent HIV messaging which involves a combination of national interventions and interpersonal communication. While young people may be knowledgeable about HIV and AIDS, this does not make them less vulnerable to HIV infection than other populations (Govender, 2010: 3). Given the high prevalence rate in KZN for young people between the ages of 15-24, and the data indicating the increase in multiple partners and intergenerational sex, the next section discusses some of the studies conducted within the province of KZN, specifically with young people who are attending university (usually between ages 20-24) to understand more specific trends in their sexual practices.

Young people attending tertiary institutions are a minor representation of the KZN youth who are exposed to different contextual factors which influence their sexual practices. The next section on exploring sexual practices and influences of students attending university, notes that this is a niche group of young people, so the sexual practices cannot be generalised to the entire population of 20-24 year olds. Exploring the sexual practices of this specific population does provide insight into the contextual factors which influence these practices and how young people can actively participate in the phases of developing HIV projects.

HIV Prevalence and Sexual Behaviour of Young People in Universities in KwaZulu-Natal

A cross-campus university survey was conducted in 2006 and 2007 to explore the sexual practices of young people across seven campuses. The study was commissioned by Johns Hopkins Health and Education in South Africa (JHHESA), funded through USAID/PEPFAR, and conducted by a group of three PhD students and one MA student (myself) who was registered through The Centre of Communication, Media and Society (CCMS), at the University of KwaZulu-Natal (UKZN). The overall study aimed to understand student's sexual practices and perceptions regarding various HIV and AIDS issues. A survey consisted of an initial pilot phase with 100 researcher-administered questionnaires, followed by a survey with 1400 students across seven campuses. These campuses included UKZN (Howard College (Durban), Westville, Pietermaritzburg and Medical School), University of Zululand (UNIZUL) and Durban University of Technology (DUT). Using a multi-stage sampling technique, a selection of 200 students was chosen on each campus across faculties and levels of study, including both male and female students. The data from the omnibus questionnaire was captured on using the

Statistical Package for Social Sciences (SPSS) to derive frequencies and percentages. However, each of the four students who conducted this study designed their own research focus, which fitted in with the broader scope of the project.

The PhD study conducted by Abraham Mulwo (2009), which formed part of the wider project, argued that despite various communication programmes, young people still engage in risky sexual practices. The study explored how young people make sense of behaviour change communication programmes to establish why these programmes do not appear to have any impact on their sexual behaviours. Mulwo maintained that a crucial component, which has often been missed in the literature, is an understanding of the mediation processes involved in HIV prevention communication, within cultural contexts. The uniqueness of Mulwo's study is thus its focus on the structures and processes of meaning production within social groups, with regard to sex and HIV and AIDS, and how the produced meanings affect the interpretation and impact of HIV prevention texts (Mulwo, 2009). Using hermeneutics, reception theory and the social constructionism theory, his study examines how students at UKZN, UNIZUL and DUT make sense of the cultural meanings offered by HIV prevention messages, such as 'Abstinence', 'Be faithful', 'Condomise' (ABC) and Voluntary Counselling and Testing (VCT) (Mulwo, 2009; 2012).

In-depth interviews established that students' sexual behaviours were often shaped by the socially constructed meanings of sex. Mulwo argued that even though students perceived HIV prevention options positively, the social constructions of sex and HIV and AIDS, rather than HIV prevention communication, often informed their sexual practices. The research findings illustrate that the students' interpretations of the ABC and VCT messages were often contrary to the connotative meanings that are intended in the campaigns. Students often interpreted these meanings from alternative frameworks that resulted in negotiated meanings and, in some cases, oppositional ones (Mulwo, 2009).

In terms of behaviour trends, Mulwo's study, similar to the findings of the national prevalence survey (2005 and 2008), indicated that males were more likely to engage with multiple and concurrent partners while females were more likely to engage in intergenerational sex. In the study, sex was often seen as a "commodity of exchange for symbolic signifiers of status, such as visits to expensive restaurants, rides in high-class cars and possession of items of higher social status" (Mulwo, 2012: 95). The survey showed that 39% of the respondents who had engaged in sex in 2006 had more than one sexual partner in the same period - "48.5% of the currently sexually active students in 2007, reported having more than one sexual partner" (ibid). Reasons for the partnerships differed among males and females but ranged from "the majority of males perceiving the number of sexual partners as a symbolic

signifier of social status...convenience when one is at home and university,...protection against untrusting partners,...and among the females often as revenge on cheating partners” (Mulwo, 2012: 95). The Mulwo study offers a critical perspective on some of the key determinants which make young people vulnerable to HIV and confirms the findings of the national surveys, and also highlights specific reasons for the behavioural trends among young people attending university.

The findings of the Mulwo study support the conclusion that students’ responses to HIV prevention messages were often predicated upon their relationships and participation in various social groups. Their decisions to adopt/not adopt these prevention options were often based on how meanings attached to these options articulated with the social significance of sex and sexual practices (Mulwo, 2009). “In the context of intersubjective meaning-formation, therefore, the relational categories of abstinence, being faithful, condomise and VCT should not be conceptualised as discreet, frozen categories, but should rather be understood as open-ended possibilities existing concurrently, coextensively and dialectically” (Mulwo, 2012: 101).

The study conducted by John Kunda (2009) also part of the omnibus survey, drew on the same data sets as Mulwo and was premised on the notion that language is the most powerful representation of what we do and how we do it, when discussing issues of sex (Kunda, 2012). In other words, we can only understand sexuality through language as a signifier of practice (Kunda, 2009). Listening and talking about sex will then address assumptions about sex and also address behaviour which is often culturally loaded with meaning. Kunda’s study therefore proposed that in order to understand cultural myths and sexual practices, language becomes a “legitimate area of inquiry” to understand why young people engage in particular sexual practices (Kunda, 2012: 106). Students have a particular way of talking about their sexual experiences and fantasies. In this time of HIV and AIDS, listening to students’ stories becomes an important entry point into their sexual lives. Kunda (2009) argues that language is the locus of interaction and the site where meaning is negotiated.

Kunda emphasises that a deeper understanding of the cultural and sexual scripts obtained from students is critical for appropriate design and implementation programmes to address HIV prevention. Programmes that only emphasise the rational dimensions of human behaviour are more likely to miss their target audience. Some of the findings of the study indicate that young people have varying perceptions of love and sex. The study found that the concept of love is admired but does not translate into sexual relationships. Some young people prefer to cohabit to get to know their partner better, while for others “it is an expression of love, without the legal or religious prescription” (Kunda, 2012:

115). The study highlighted the distinction between married females who are usually seen as obedient, docile and mother-like, and unmarried women who are perceived as 'hot' and 'good' for casual sex. Males, on the other hand, were identified with the biological myth of not being able to control themselves (ibid).

What is interesting about these findings is that they offer a perspective into what young people are listening to and saying about sex, as well as issues of gender and stereotyping. Kunda's study correlates with the HIV prevalence rates from the three national surveys, which indicate that females are more prone to intergenerational sex and males to multiple and concurrent partners. In addition, students highlighted that the link between sex and HIV is not readily associated, possibly due to the huge gap between infection and death. This means that young people are not thinking about HIV when they are listening, talking or exploring issues of sex.

These findings emphasise the need for more effective communication programmes to address these myths, misconceptions and ideological discourses which are often positioned within cultural, biological or social perspectives. "Despite sexuality being a normal biological feeling that is experienced on the level of body-chemistry and mental influence, its constructed nature shapes attitudes, knowledge and expectations within social interaction" (Kunda, 2012: 115). The Kunda study adopts a critical perspective to explore the disconnections between how messages and information are communicated, and, similar to the findings of Mulwo (2009), how young people are listening and talking about these issues, which are often de-constructed very differently to the initial intention. Young people are therefore negotiating the meaning of sex, not in terms of prevention messages, but in the context of social influence (Mulwo, 2009).

A further study was conducted by Given Mutinta in 2009 and 2010 as a continuation of the initial omnibus survey. This study collected additional data from DUT, and three UKZN campuses to explore perceptions of risky behaviour among university students and how students respond to the content of the national *Scrutinize* campaign. The overall objective of the study was "an attempt to grasp the apparent failure or success of the *Scrutinize* Campus Campaign prevention communication programme to influence behavioural change amongst university students" (Mutinta, 2012: 125). Taking a case study approach, Mutinta explored the campaign's potential efficacy and the students' risky sexual practices, and explored the influences for the risks students take, as well as their risk and protective factors (Mutinta, 2011).

A sample of 96 students were interviewed across the four campuses and findings indicate that “94% of the respondents said that they know students who are engaging in transactional sex”, with “72% of the respondents in the sample viewed transactional sex as a viable and efficient way of meeting their needs and wants” (Mutinta, 2012: 132). Findings on three campuses demonstrated that students were engaging in ‘towing’ or one-night stands. Whilst the female respondents suggested that this experience made them feel abused and used, the male students reported greater sexual satisfaction and a sense of contentment (Mutinta, 2011:134; Mutinta, 2012: 133). The study revealed that 81% of the respondents explained that students have intergenerational or age-disparate sex (sex with a partner who is older by five years or more), with 67% suggesting that these relationships are low risk since the person should be married and in a stable relationship. However, 81% argued that with the age gap and power dynamics, the negotiation of condom usage will be more complex (ibid).

The study found that multiple and concurrent partnerships were considered ordinary behaviour, with 60% suggesting that it was approved behaviour and seen as competition for superiority. One of the striking findings was the high percentage of young people who were not using condoms (76%), with 70% of the respondents more concerned with issues of pregnancy rather than HIV. This also confirms findings that students do not identify the link between sex and HIV (Kunda, 2009; Mutinta 2012). Mutinta’s findings indicate that students at KZN universities engage in several risky sexual practices including unprotected sex, transactional sex, age-disparate sex, multiple and concurrent sexual partnerships, towing, open sexual relationships and cohabitation. His study further reveals that while there are several risk factors for sexual practices, young people were also able to identify protective factors to prevent HIV transmission. Mutinta concludes that when designing HIV programmes the protective factors should not be ignored; placing an importance on addressing both risk and protective factors in HIV messages (Mutinta, 2011; 2012).

The MA study conducted by Moodley (2007) also formed part of the omnibus survey and focused on the assessment of the ABC strategy with students, and explored ways in which students at UKZN could participate in the development of prevention messages and strategies for HIV and AIDS. The study was restricted to two campuses, Howard College and Westville, and 200 students completed the questionnaires on each campus as part of the ABC omnibus project survey (400 in total). This quantitative data was supported by qualitative data collected through two focus group discussions, which were held on each campus.

The study showed that students identified abstinence as the message that was the most frequently heard, yet most students from the sample suggested condom usage as a more realistic approach. “Be faithful” ranked as the lowest realistic option, with students taking preference to either abstinence or condom usage (Moodley, 2007; 2012). The focus group discussions confirmed the quantitative data, where students were in favour of casual sex or having multiple partners, and highlighted that there was no need to ‘be faithful’ as long as condoms were used. The ABC message was therefore identified as problematic since the ‘Be Faithful’ component was not widely encouraged by students (Moodley, 2012). This study, which used a mixed method approach, was later confirmed with the findings of Mulwo (2009), Kunda (2009) and Mutinta (2011), and further correlated with the national prevalence surveys which indicated that there was a ‘turn in tide’ (Shisana et al, 2005; 2009) with the increased rates of intergenerational sex and multiple partners with young people. The Moodley study confirmed that students prefer to rather abstain or use condoms than considering faithfulness as an option.

The Moodley study further showed that even though students recognised the ABC strategy as an appropriate message and in most cases evidenced a positive understanding of the message, there was still a need for their reflection and engagement in the process of design and implementation of prevention messages. A high frequency of 91% of students felt that they understand their sexual practices and are best placed to design messages that will reflect these practices. This implied that students, who engaged in casual sex and/or multiple partners, should be well positioned to construct a realistic message to reflect their safer sexual practices (Moodley, 2007).

Students in the study offered suggestions on how to assess whether the ABC strategy is effective and also ways to address the impact of HIV and AIDS amongst young people. Students equated the number of pregnancies on campus to the failure to use condoms. Unplanned pregnancies showed the lack of adherence to abstaining or condom usage. Students argued that the two major ways of promoting behaviour change were through making HIV and AIDS a reality to students through visits to communities where people are living with HIV and AIDS each day, and also encouraging students to get themselves tested. A study conducted at the University of Durban Westville (now a campus of UKZN) suggested that while campaigns were offered to encourage students to be tested, young people were not involved in the processes of developing university campaigns. University programme officials suggested that greater student involvement in some of the projects and programmes such as the drama campaigns would make for more popular and more successful campaigns (Tesfu, 2012: 68). The Moodley study later found that giving young people a voice in HIV and AIDS prevention, assisted in them understanding how they can contribute to HIV message and programme design. Students

mentioned that the churches taught responsibility and moral uprightness and can be used as vehicles in the promotion of positive prevention messages and sexual practices. Central to all discussions were the need for an “open heart for face-to-face communication” (Moodley, 2007: 105) which was the importance young people placed on dialogue and discussions among their peers and various stakeholders.

The four studies discussed above confirm many of the findings of the national prevalence surveys in 2002, 2005 and 2008. The Higher Education AIDS Programme (HEAIDS) also conducted a national HIV prevalence survey in 2008 and 2009 with 21 of the 22 Higher Education Institutions (HEIs) in South Africa to determine the HIV prevalence among staff and students. Whilst the national HIV prevalence for ages 15-49 was around 10.9% in 2008 (Shisana et al, 2009), the overall national HIV prevalence among university staff and students was 3.4%, with a lower 2.8% for UKZN (HEAIDS, 2010). The report does not suggest reasons for these lower prevalence rates, students at university are a small representation of the total number of young people in South Africa, hence the low prevalence is only reflective of a minority group of young people. The four studies at the universities particularly highlight the increase in multiple and concurrent partners with males, and age disparity sexual relationships with females, with almost 50% of the respondents engaging in multiple partnerships in the Mulwo study (2009). The HEAIDS study also showed that men reported more sexual partners (19%) in the past month when the study was conducted with women (6%) (HEAIDS, 2010: xii), which also confirms the findings of the national and KZN university surveys.

In the case of the Mulwo study (2009), findings revealed that the social constructions of sex and perceptions of HIV informed young people's choices, rather than specific prevention programmes. The meaning of the ABC prevention campaigns and VCT initiatives were often negotiated, with the constructed meanings either misinterpreting or opposing the intentions of the campaign. The Kunda study confirms that ideas about sex are constructed in language, and discourses of meaning regarding sex, love, co-habitation and sexual partnerships are oppositional to many of the accepted AIDS communication campaigns. This study confirmed the rise of casual sex and multiple partners among students, specifically residence students at the university. The Mutinta study highlighted the risky behaviour of young people, with over 76% of students supporting the idea of sex in exchange for fulfilling their material needs. This study also found that while 91% of the students recall the messaging regarding multiple and concurrent partners in the *Scrutinize* campaign, the way in which students interpret these messages are often negotiated or misconstrued (Mutinta, 2012).

The three national surveys and the four studies in KZN highlight the importance of including young people in the design of HIV programmes to ensure the correct representation of their lived experiences, and the development of messages which can be correctly interpreted and engaged with. The study conducted by Moodley indicated that 90% of students identify the need to have more active student participation, and 98% of students found it necessary to be part of all the stages of developing HIV and AIDS prevention messages, including the three aspects of research, design and implementation (Moodley, 2012; See also Parker; 1994, Parker, 1997). The four studies conducted at KZN universities highlight the risky sexual behaviour of young people. The studies also reiterate the need for more youth-informed HIV programming that takes cognizance of the influences and negotiated meaning that contributes to how young people receive HIV prevention messaging. Cohen (2003) suggests that young people are going through various phases in their lives, which require different messages, meaning that they are in the best position to identify and understand the challenges and complexities they face.

Perhaps the study by Mulwo succinctly best summarises the discussion and evidence for more context- and youth-specific approaches for HIV prevention. Mulwo found that “the University of Zululand favoured the ACT (Abstinence, Condomise, Test) approach in which abstinence is highly emphasised in accordance with the values of the local community, while the UZKN approach emphasised “knowing your status” as a starting point in behaviour change; on the other hand, DUT preferred a more balanced approach, with a slight emphasis on abstinence, especially with those programmes operating under funds from PEPFAR” (Mulwo, 2012: 94). This distinction on the focus of specific messages for different universities re-iterates the importance of more audience-informed HIV prevention programmes, which will require young people’s involvement in all communication processes.

HIV Prevalence and Sexual Behaviour of Young People in Schools in KwaZulu-Natal

The previous section provided insight into HIV prevalence and sexual practices of young people in KZN, specifically those attending university. This section will explore some of the sexual practices of the school-going population, nationally and in KZN, as there are limited studies specific to KZN. The subsection thereafter will highlight some of the key determinants which contribute to these risky sexual practices.

A study conducted in KZN identified the challenges of abstinence, suggesting it is not a realistic option for young people (Varga, 2000). She further highlighted the negative connotations of consistent condom use with questions of trust and faithfulness, issues of poor communication and negotiation skills, and argued that gender imbalances pose challenges on the sexual considerations of young people. Varga argues in favour of programmes which promote life skills, where young people can identify their values and make informed choices, supported by the de-stigmatisation of condom usage and the promotion of consistent usage (Varga, 2000). This means that instead of relating pre-designed HIV messages which are not always context specific, young people are empowered with the life skills to make informed choices. Varga's position emphasises the need for downstream solutions that try to bring young people to a position where they are aware of their social reality and empowered to make choices to change this, without the imposition of strategies which tell them what to do. Upstream solutions, evident in programmes designed from a modernisation perspective, follow this top-down approach where young people are told what to do, rather than empowered with skills to deal with sexual decision-making. The study conducted by Varga confirm the high HIV prevalence rates, multiple partners, intergenerational sex, inconsistent condom use and drug and alcohol abuse which were evident in 2002, 2005 and 2008 HIV prevalence national surveys (Shisana et al, 2002; Shisana et al, 2005 and Shisana et al, 2008).

A national study conducted in 2001 with over 1900 school-going, unmarried young people between the ages of 14-25 explored the hypothesis that there is some association with school attendance, low HIV prevalence rates and lower risky behaviour. This study acknowledged the various other studies which indicate that well-educated people can engage in more risky sexual practices due to their higher socio-economic status, but there is a tendency for the educated to consider protective measures such as condom usage (Hargreaves, et.al, 2005). This national study with school-going youth offers similar findings to the study conducted by Mutinta (2011) at UKZN campuses where young people identified the risk factors but also associated protective factors to prevent infection. The study distinguished between school-going young people and those who drop out early from school or do not attend school, and found that those who attended school were less likely to have more than one sexual partner than those who did not attend school (Hargreaves, et.al, 2005). Females were also less likely to have older sexual partners, to engage in sex less often, and their condom usage was higher. The study found that young people who did not attend school were more vulnerable to HIV infection and risky sexual behaviour. As a result, this study suggests that educated young people are more likely to engage in less risky sexual behaviour, therefore having a lower HIV prevalence rate and lower risky behaviour.

What this study highlights is that young people's risk of HIV infection is influenced by their sexual choices, locations and levels of education.

In 2003, following the 2002 National HIV prevalence survey, a survey was conducted specifically with 150 secondary schools across South Africa to assess HIV and AIDS knowledge and sexual behaviour among junior secondary school students between the ages of 13-24. The sample consisted of 3150 students, with 44.1% males and 55.9% female students. The survey found that 46% of the 16 year-old males and 20% of the 15 year-old females were already sexually active. The survey shows a significant shift with condom usage at first sex, with 63.8% of the male and 78.7% of the female students indicating condom use, but "almost half (44%) of those who had had sex before had not used a condom at last sex" (Peltzer & Promtussananon, 2005: 2-3). In an earlier study conducted by Peltzer with rural senior secondary school pupils, over 52% of males and 40.5% females who were sexually active reported never having used condoms (Peltzer, 2000). This correlates with the finding of the HIV prevalence survey in 2005 which suggests that 57% of young people are sexually active between 15-24, with 17 as the median age of sexual debut (Shisana et al, 2006). The age of sexual debut later shifted to 15 years of age in the national prevalence survey conducted in 2008 (Shisana et al, 2009).

The national survey with secondary schools also indicated that one quarter of the students (25.6%), which constituted 31.2% of the females and 22.9% of the male students, indicated having sex with an older person (above 30 years). Over a quarter (27%) reported sex for the exchange of gifts (Peltzer & Promtussananon, 2005). This survey confirms the findings of the national prevalence surveys (2005 and 2008), and the work of Moodley (2007), Kunda (2009), Mulwo (2009) and Mutinta (2011) which demonstrate inconsistent condom use, intergenerational sex, and the exchange of sex for material goods.

A study conducted in 1999 with rural youth aged 12-24 in KZN highlighted several factors which hinder safer sexual practices and negotiation with partners about ways to prevent HIV. These factors included sexual violence, negative connotations of condom usage, gender imbalances and peer pressure (Varga, 1999). HIV projects and programmes therefore need to address these various concerns from a youth-informed perspective.

The first national HIV prevalence survey for young people aged 15-24 only, was later conducted in 2003 with over 11500 respondents across the nine provinces. The HIV prevalence had a significant increase from "4% among 15-16-year-old females to 31% among women age 21 years," and while

prevalence was 3% between ages 15-19 years for males, it increased to 12% for ages 23–24 years. In addition, the survey showed that 48% of 15–19 year olds reported having had sex (vaginal or anal) in comparison with 89% of 20–24 year olds” (Pettifor et al, 2005: 1527). This indicates that young people attending school are less sexually active than those who attend university. One of the reasons for the increase of sexual activity with young people attending universities is the escalating number of young people who stay away from home during their years of study. Peer pressure while away from home is also recognised as one of the contributing factors (Mulwo, 2009; Moodley, 2007; HEAIDS 2010). The national survey (2003) also indicated that females between the ages of 15–19 “with a partner five or more years older...were more likely to be infected with HIV in comparison with women with a partner the same age or younger” (Pettifor et al, 2005: 1531). The findings of this study confirmed the link between the higher prevalence rates for females and intergenerational sex, as was evident in the national HIV prevalence surveys in 2002, 2005 and 2008.

The first national HIV prevalence survey for young people also suggested that “high-risk sexual behaviour, such as multiple sexual partners or older partners, were both associated with HIV infection”. Females in the survey reported limited sexual power which results in “inconsistent condom use and can be associated with HIV infection” (Pettifor et al, 2004: 2000). The study found that less than one third of the females indicated consistent condom use which increases the risk of infection (Pettifor et al, 2004: 2001). Gender inequality and gender-based violence were also highlighted as having strong associations with multiple partners and inconsistent condom use specifically among young people aged 15-24, as this national survey indicated. Programmes for youth, such as *loveLife*, must therefore ensure the continuous promotion of “partner reduction and consistent condom use while also addressing contextual factors” (Pettifor et al, 2005: 1532).

The studies conducted with school-attending young people show findings similar to the national HIV prevalence surveys in terms of risky sexual practices. In all of the above studies, the importance of communication and addressing young people’s needs using a more context-specific approach were encouraged. The next section provides an overview of some of the key determinants of these risky behaviours. The section does not offer a comprehensive discussion of all determinants as this is not the focus of this study, but it does highlight some challenges facing young people’s sexual choices.

Other Key Determinants of Sexual Behavioural Choices for Young People

Young people can play a pivotal role in accessing, discussing and participating in the sharing and transferral of information related to HIV prevention, awareness and education (Govender, 2010).

However, while this chapter has referred to studies that argue for young people's involvement in HIV programme design and messaging, complexities related to behaviour change, the key determinants of infection, the channels through which the information is sent, and the ways in which the message is designed and the information received, can all still pose further challenges. This section will therefore highlight some of the challenges young people face regarding HIV prevention.

While there is evidence that several HIV projects and programmes have not been effective in promoting positive behaviour change, several studies conducted with school-attending populations identified that beyond HIV prevention methods of ABC, there was also a need to address issues such as misconceptions and myths around HIV, gender-based violence and its contribution to AIDS, how sex is really defined, lack of life skills development to support HIV knowledge and also social and cultural determinants of HIV infection and prevention. The social, cultural and economic influences that are shaping young people's sexual desires and experiences are rapidly changing communities and there is need now is to engage with the dis-enabling context that gives sustenance to the dis-enabling attitudinal and behavioural codes that continue to drive the HIV and AIDS epidemic (Leclerc-Madlala, 2002: 35).

A study conducted with 1904 school-going young people demonstrated the complexities of adolescents' misconceptions regarding HIV transmission, despite their rational and critical thinking (Alta Van Dyk, 2008). Her study revealed some of the 'conspiracy themes' among young people to explain the origin of AIDS. These included, *'It's a new age movement'*, *'who wants to destroy a certain part of the population'*, *'AIDS comes from monkeys and it was given to people on Robben Island from where it spread'*, *'it is a disease used to destroy and control black African populations'*, *'AIDS is America's idea to destroy the blacks'* and *'if you fill the condom with water, you will see the viruses inside the water'* (Van Dyk, 2008: 67). The existence of these 'conspiracy themes' demonstrates the urgency for more efforts to relate correct and consistent information through programmes that are mindful of the challenges of AIDS fatigue and knowledge saturation. In addressing these conspiracies, the missing link between sex and HIV infection, as outlined in the Kunda study (2009), can also be introduced to young people. Van Dyk (2008) concludes that young people must be empowered with knowledge, attitude, values and life skills to protect themselves from exposure to HIV. In addition, other associations of sex and HIV indicate that young people identify HIV and AIDS as a disease of the poor, and some considered pregnancy as a more serious threat than HIV, while others identify HIV as a myth and not a reality (Mulwo, 2012).

A study conducted by Claudia Mitchell and Ann Smith on the reception of the award-winning documentary, *Unwanted Images* (director Monica Mak, 2000) in schools in South Africa, highlighted the importance of new context-specific prevention approaches. The drawings by young children highlight the prominence of gender-based violence in the lives of ordinary school children in South Africa, placing a moral imperative to address the connection between such violence and the high incidence of HIV and AIDS amongst girls and women (Mitchell & Smith, 2001). Later, a workshop to understand HIV and AIDS prevention in the context of gender with young people at schools resulted in the following suggestions: “A” is for Aggressive Masculinity, “B” is for Biological Vulnerability, and “C” is for Coercive Sex. Mitchell and Smith comment that to see aggression, coercion and female vulnerability as part of HIV and AIDS prevention strategies is to make use of ABC in a way that furthers the ongoing discourse that more needs to be done for HIV prevention. Through a process of critical consciousness, where young people can become aware of the influences on their sexual practice, young people are then mobilised to understand HIV prevention in the context of their own lives. These issues of gender-based violence need to be explored in the context of multiple and concurrent partners, and transactional and intergenerational sex relationships, which are found to be common risky sexual practices for young people.

Young South Africans are also still perplexed by what sexual intercourse actually means on a practical level, and its relationship to HIV transmission and prevention. A study conducted by Melina Bersamin and colleagues on interpretations of sexual behaviour showed a greater consensus among young people’s reports regarding sexual activities, such as genital touching and vaginal intercourse, but more variability around oral and anal sex (Bersamin et al, 2007). More and more young people tend to associate sexual intercourse with vaginal intercourse, thus assuming that they maintain their virginity while engaging in anal and oral sex. These complexities in how young people define sexual activities amplify the risk of HIV transmission, making prevention initiatives more complex. The findings of this school study also highlight the casual sexual relationships which young people engage in at university (Kunda, 2009; Mutinta, 2011), where there is a reconstruction of how sex is defined and how these relationships are pursued.

Beyond these misconceptions, young people are still not adequately trained to apply the knowledge that they have about HIV prevention. This is often criticised as a grey area in prevention approaches with young people, where emphasis is placed on the knowledge but not on how to implement it in practice. An evaluation study conducted with 22 schools in KZN showed no significant change in the adoption of protective behaviours such as abstinence and condom use (Reddy et al, 2005). This study

further suggested that this may be because the teachers did not focus as strongly on the life skills components as on the factual HIV and AIDS information. *DramAidE*, an NGO which uses drama to educate young people about HIV and AIDS, utilises life skills programmes to empower young people to better understand their sexuality and to make informed choices. The work of *DramAidE* operates outside the knowledge transferral paradigm, instead working from a Freirean perspective to empower young people with the life skills necessary to be able to make informed choices (see Durden & Tomaselli, 2012).

The issue of sexuality, silence and HIV and AIDS is highlighted by Robert Morell who suggests that the silence around HIV between school learners/young people and teachers can be attributed to a broader context of gender inequality. He highlights that silence is an attribute of “gender relations that prevents the negotiation of safe sex, the exploration of the self and the expression of vulnerability, and hence the building of trust and respect” (Morell, 2003: 41). Projects and programmes which fail to address issues of silence, limit the effectiveness of HIV prevention. The risk of HIV, sexually transmitted infections (STIs), pregnancies and sexual reproductive problems also need to be addressed with young people. According to a study conducted by Mba (2003) with young people, it was found that HIV, STIs, and pregnancies were often associated with young people who delayed marriage, based on the notion that marriage encourages safer sexual practices. Whilst marriage cannot solve all problems, or be assumed to encourage safer practices, the delay in marriage increases risky sexual practices. However, Mba suggests that “in order to address young people in sub-Saharan Africa, there is the urgent need for the development of more relevant information, education and communication (IEC) programmes to build knowledge, motivation and skills” (2003: 21).

Conclusion

This chapter has outlined the findings of several surveys which indicate that young people are vulnerable and susceptible to HIV through a range of behavioural practices. Given the direct impact of the pandemic on all areas of their lives, there is a need for more relevant information and knowledge on HIV, particularly on issues of abstinence, delaying sexual debut, faithfulness in relationships and condom usage, as well as safer sexual choices for multiple and intergenerational relationships. Frances Butterfoss and Larry Cohen (2009) suggest that investing in prevention saves lives, improves the health of the population, and saves money for government, business, health care, families and individuals. Beyond issues of prevention is the need for messages and programmes that address key determinants of infection and risky sexual practices of young people. These messages should reflect the lived

experiences of young people and should address widely-held myths, as well as issues of interpretation, negotiated meaning and how this translates into practice. This requires a review of communication processes for the development of HIV programmes, which are youth-specific and youth-informed, and will be discussed in more detail later in this thesis.

CHAPTER THREE: METHODOLOGY

Introduction

This study challenges the use of conventional research methods and applies several principles from various research designs, offering a blended or hybrid approach to address the challenges of young people's participation in a South African context. HIV and AIDS is a complex issue, which requires consideration of various cultural, social and economic factors, therefore rigid or very systematic data collection processes can amplify the severity of the epidemic, especially when the voices of young people are not incorporated into the design of HIV and AIDS programmes. Some of these systematic data collection processes can include the use of interviews, focus group discussions and questionnaires which are often conducted in very structured and formal settings, and can create barriers to how young people participate and engage in discussions about HIV and AIDS.

This thesis argues that a more participatory approach should be taken when working with young people, and highlights some of the participatory methodologies particularly art-based methods, that can be employed to address complex issues of participation, and HIV and AIDS. Working within a participatory paradigm means that practitioners, academics and communication specialists also need to revisit the way we collect data and engage with young people especially in HIV related issues. Beyond the programmes, offered to communicate about HIV and AIDS, the 'processes' of research, design and implementation also need to be revisited and revised. This chapter will focus on how several elements of various research designs are integrated for data collection and analysis in this study.

This study draws on principles from three research perspectives to formulate a fluid methodological process for collecting, analysing and interpreting the data. The central research design for this study is the participatory action research process (PAR) which draws on principles of grounded theory. I refer to this as the 'grounded' approach, which allows for a cyclical process where practice (evident through the data) informs theory, but also ensures that theory can inform practice, and practice later re-inform theory. This is in accordance with the transformative process of PAR which will be explored in detail later. The study will also be supported by my own observations and self-reflections which draw on principles from auto-ethnography. Dyll-Myklebust refers to this multi-faceted data collection and ongoing analysis process, which draws on some principles of grounded theory, participatory action research and auto-ethnography within an applied cultural studies context, as a "hybrid approach" (2011:35). Holloway and Tombres suggest that in order to overcome this tension of methods or to

ensure the flexible application of methods, a researcher must start discussions about the methodology of the study by highlighting the “coherence, consistency and flexibility” of the methods (2003: 356).

This chapter will address these three concepts of coherence, consistency and flexibility by outlining the specific data collection tools used and providing a detailed account of the methodological process followed for this study, which to a certain degree both supports and challenges traditional research and data collection practice. This process of working bottom-up (where practice informs theory) and later top-down (theory informs practice) and bottom-up again, offers an interesting perspective on the transformative processes of PAR which is ‘grounded’ in data and theory, and generated in a cyclical process.

Given the need to address topics like HIV with a cyclical process, that takes into context the social, cultural and economic influences, this study explores the use of an art-based inquiry using the bodymapping process. The bodymapping processes extend beyond data collection as a research tool but also ensure the active participation of young people. The cyclical process of participatory action research ensures that using the bodymapping steps to document how young people can participate, also ensures that they are involved in the processes of how we understand young people. An action research process then becomes an ever evolving and changing process through bodymapping as it is flexible and adaptable to address local problems and challenges within contexts that are always changing.

It is impossible to talk about young people’s involvement or young people’s participation without making reference to its implications when working within a PAR framework. Even though grounded theory and PAR are used in a fluid, flexible and adaptable way, the terms ‘participation’ and ‘involvement’ in research suggest two different experiences. This study will be cautious to observe and make reference to this disparity so that for the purpose of this study *involvement* of young people can imply that they participate but do not take true ownership of and manage the programme research, design and implementation of a specific HIV and AIDS programme. For the purpose of this study, *participation*, on the other hand, will draw on the work of Paulo Freire (1976) which speaks about a liberating participation, which transforms and brings about change on all levels where young people actively and collectively engage “in the way research is conceptualized, practiced, and brought to bear on the life-world” (McTaggart, 1997:28).

Interpretations, Subjectivities and Reflections

This thesis fits within critical forms of research or what is called 'critical enquiry', where the researcher interrogates values and assumptions, and challenges conventional social structures to engage in social action (Crotty, 1998). However, this is supported by the understanding and application of various research methods, where the interpretations and subjectivity of the researcher and the young people cannot be denied or ignored. While critical theory highlights power relations and the notion that false consciousness leads to oppression and manipulation, the interpretivist perspective suggests that the lived experiences of people need to be acknowledged as they influence how we understand our social reality. In this light, critical inquiry requires that I "open myself to new ideas and ways of understanding, and take effective action for change...therefore with every action taken, the context changes and we must critique our assumptions again" (Crotty, 1998). Critical inquiry therefore draws on the work of Paulo Freire and action research as a methodology which suggests a cyclical process of reflection and action.

Brydon-Miller (2003) argues that Freire's notion of conscientisation, developing a critical understanding of social, political and economic issues, and establishing equal partnerships for co-learning during the research process, underlies the work of participatory action researchers. "Freire's theory of conscientisation, his belief in critical reflection as an essential for individual and social change, and his commitment to the democratic dialectical unification of theory and practice have contributed significantly to the field of participatory action research" (McIntyre, 2008: 3). Through reflection and action, people can identify themselves as catalysts for change through a PAR process.

Reflection and action cannot act separately but must take place simultaneously, and this is what Freire (1976) terms praxis, suggesting that only through this process (action and reflection) that conscientisation can take place. The action that Freire (1972) talks about in his writing however, suggests that there has to be some form of intervention that transforms how people see the world, and this is the development of critical consciousness. He also argues that this process of action and reflection cannot take place without dialogue since, "without dialogue there can be no conscientisation...and true dialogue cannot exist without critical thinking" (Crotty, 1998: 153). The data collection methods and tools of enquiry for this study are therefore in support of PAR theoretical and application principles, where interviews and focus groups are supported by workshops (interventions) to facilitate the process of action and reflection towards collective dialogue.

The work of Habermas (1971) also contributes to the application of participatory action research where knowledge is recognised within contexts of social, political and economic contexts, where we learn to understand about the world “through our interactions and relationships with others” (Brydon-Miller, 2003: 190). PAR is also linked to applied cultural studies where a “researcher problematises their position within researcher/researched relations” and allows the researcher to write about the people interviewed as individuals and not as statistics (Dyll-Myklebust, 2010: 59).

My position of critical inquiry, with reference to the work of Freire, and its application through participatory action research also highlights the cyclical process of practice informing theory, and theory informing practice, which aligns to the principles of grounded theory. This study therefore integrates critical inquiry from an interpretivist perspective to explore how young people perceive, make sense, interpret and engage with HIV related projects and its participatory communication processes. This position recognises that interpretations are relative to the beliefs, attitudes and values that govern the realities that are constructed. My subjectivity in relation to the social phenomena being investigated positions this research in a frame where I, ‘the self’, cannot be separated from the young people, ‘the other’ (Tomaselli, 2005). My own perceived ideas, interpretations and prior experience become the lens through which I make sense of young people’s participation. As a researcher, I am therefore unable to be an outsider to the research, but am rather in a position to explore my own interpretations and subjectivities in relation to how young people make sense of communication processes for developing HIV projects (Tomaselli, 2005).

The interpretation of the data extends beyond addressing the insider-outsider relations but also on how this reality is constructed. A constructivist lens is therefore necessary, as “meaning is not discovered but constructed” (Crotty, 1998: 42). Constructivism was applied to this study with the understanding that “all meaningful reality is contingent upon human practices, being constructed in and out of interaction between human beings and their world” and being developed within a social context (ibid). In this way, this study recognises that meaning will continuously be constructed as young people engage with the world in which they are interpreting. The study therefore recognises the importance of interpretation and subjectivity, but suggests that it is pivotal to extend further to understand how these interpretations lead to the construction of meaning and their own social realities in the light of HIV and AIDS. The next section discusses how grounded theory will be applied in this study.

‘Grounded’ in Data and Theory: Which Came First, the Chicken or the Egg?

Grounded theory was developed in the School of Nursing, University of California, San Francisco by sociologists Barney Glaser and Anselin Strauss. It is defined as the discovery of theory from a systematic data collection process, since it constructs theories about various issues such as social welfare, health care services or the lack of health education (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Grounded theory is premised on the idea that the researcher “is informed and ready to make decisions” about the various data collected (Huehls, 2005: 330), towards recognising the “plausible relationships proposed among concepts and sets of concepts” (Strauss & Corbin, 1994: 278). The researcher in this regard is informed because I can make plausible observations, taking field notes and using the data collection tools to engage with young people through questioning, probing and ongoing dialogue. This places me in a better position to make decisions through formulating my observations in a way which contributes to the building of theory and contributing to the body of knowledge in the field of young people’s perceptions of HIV behaviour, and how they participate in the development of HIV projects or programmes.

According to Crookes (2001), grounded theory can be used to explore behaviour of people and social relationships where there is limited knowledge of the contextual factors which affect people. Grounded theory is used to explore underlying processes of what is happening, and can be applied in my study to explore what young people’s concerns are about HIV prevention and how their participation can facilitate youth-informed interventions (Glaser, 1978). The process of constructing theory from a grounded perspective involves the collection of data using various tools such as interviews, focus group discussions and bodymapping workshops. The data is then analysed by constant comparison, initially of data only, progressing to comparisons between various interpretations which are translated into codes and categories. “This constant comparison of analysis to the field, grounds the researcher’s theorizing in the participant’s experiences” (Mills et al, 2006: 3). Chapters Six to Nine of my thesis reflect this process of constant comparison of analysis, where the data, once transcribed, was coded, categorised and then developed into themes and presented as four separate data sets which corresponds with the four phases of data collection. Across the four data analysis chapters, the grounded theory principles of constant comparison are applied to identify the correlations, similarities and differences across the four data sets.

Over the years, grounded theory has been revised to accommodate interpretation and the role of the researcher. This is evident in the departure from the initial work of Barney Glaser and Anselin Strauss (1967) to the work proposed by Anselin Strauss and Juliet Corbin (1990). The work of Glaser and Strauss (1967) proposed a shift from the mere 'testing' of theory to a process of 'creating' theory (Gibson & Brown, 2009: 20). In this process, the researcher was to have no preconceived ideas about the study, and to remain objective during the collection of data (Miller et al, 2006). The early positivist grounded theory approach offers strict linear processes for coding data to ensure accuracy and reliability for codes to 'emerge' from the data.

Whilst grounded theory was highly influential in the social sciences, the debates that emerged over time challenge the objective and positivist position taken by the original theory. The work of Strauss and Corbin (1990) argues that the researcher must take on a role as co-author and cannot be excluded from the interpretation process, but rather the researcher contributes to how the data is collected, analysed and how the theory is developed (Corbin & Strauss, 1990; 1994). It is for this reason, where my interpretations cannot be removed from how I make sense of the data that an auto-ethnographic approach is taken to support this study. The auto-ethnographic approach allows me to draw on my own experiences in the field, subjectivities and my previous work with young people.

Jane Mills and colleagues (2006) term the transitions of grounded theory as "traditional" grounded theory (Glaser, 1969) and "evolved" grounded theory (Strauss & Corbin, 1990), and suggest that this is linked to varying ontological and epistemological positions. The traditional grounded theory proposed by Glaser (1978) suggests that researchers must take minimal pre-conceived ideas to the field and "remain sensitive to the data by being able to record events and detect happenings without first having them filtered through and squared with pre-existing hypotheses and biases" (Glaser, 1978: 3).. The evolved grounded theory perspective according to Miller and colleagues (2006) is what Strauss and Corbin suggest as a construction of theory based on the interpretations of the researcher: "theories themselves are interpretations made from given perspectives as adopted or researched by researchers" (Strauss & Corbin, 1994: 279), and is therefore a more interpretative or social constructivist approach. Mills and colleagues (2006) also found similar distinctions with how literature was used in traditional and evolved grounded theory, with the former (Glaser, 1969; 1978) eliminating the use of literature completely with the idea that it will contaminate or influence the researcher's coding and analysis process, while the latter suggests that it "stimulates our thinking about properties or dimensions that we can then use to examine the data" (Strauss & Corbin, 1998: 45). Mills and colleagues therefore argue that addressing grounded theory from a constructivist perspective was

already suggested on several levels by Strauss and Corbin (1994; 1998) in their writing, even if they did not take an explicit social constructivist perspective to grounded theory.

This study therefore extensively consults the previous literature in the field of HIV communication and participation of young people as a way to position my thesis as contributing to the body of knowledge in this field. Extensive research has been presented in two recent books on health and development communication. One, edited by Keyan Tomaselli and Colin Chasi (2011), offers a critical review of research conducted by scholars from a South African cultural studies and social science perspective. This was followed by a case study publication by Emma Durden and Eliza Govender (2012), which documents ten years of health, development and communication research conducted by graduate students through the Centre for Communication, Media and Society. My own study will contribute to the body of knowledge in this field by exploring the extensive research conducted that explores a range of participatory approaches for addressing HIV. This can also provide the foundation for my study on research about young people's participation in various phases of developing HIV projects. The use of literature from this social constructivist grounded theory perspective recognises that my own interpretations, experiences and subjectivities cannot be separated from the writing of this thesis, and therefore to review previous literature can only assist in how I later construct the social realities and lived experiences of young people.

Kathy Charmaz (2003) accredits the work of Glaser and Strauss to a positivist framework "in which the social world is regarded as being readily available for 'discovery' by researchers" (Gibson & Brown, 2009: 27). Instead, she proposed an interpretivist perspective of the "constructed and contested nature of the social world" (ibid). The work of Charmaz is perhaps more suited to this study as she offers a constructivist grounded theory perspective which recognises the importance of interpretation, the position of the researcher to construct social reality based on their interpretation of the data collected and the importance of reviewing literature to gain insight into the field.

The positivistic perspective of grounded theory erroneously assumes that codes' will 'emerge' from the data collected towards identifying concepts and themes for the development of theory. This can eliminate the researcher's position, subjectivity and interpretations of the data. A researcher can only make sense of the 'other' through a positioning of the 'self.' Charmaz's work highlights the importance of generating meaning in a co-construction between the researcher and the participants. Whilst the original development of grounded theory would suggest that researchers need to take on the role of a

distant expert, Charmaz introduces the researcher as the author and co-producer of knowledge (Mills et al, 2006).

Jane Mills and colleagues offer a succinct perspective on the methodological spiral nature of grounded theory and argue that “all variations of grounded theory exist on a methodological spiral and reflect their epistemological underpinnings” (2006:1). They suggest that the varying forms or critiques of grounded theory are based on the proposed nature of the relationship between researcher and participant. From this perspective, “constructivist grounded theory is positioned at the latter end of this methodological spiral, actively repositioning the researcher as the author of a reconstruction of experience and meaning” (Mills et al, 2006: 1). This position allows for a cyclical process of interpretation, which also promotes various levels of interpretation based on the various phases of data collection which occur with the young people, facilitators and organisational managers. In this instance, whilst young people will construct their experiences of participation in HIV programmes, as a researcher, I will also reconstruct their experiences with my own interpretations and experiences in the field. This subjectivity and reflexivity is unavoidable from a social constructive perspective which recognises that the researcher cannot be separated from the subjects, in this case the young people.

While the work of Glaser and Strauss played a pivotal role in shaping the inductive research approach in social science, their work has been critiqued by several scholars as having numerous flaws. Wasserman and colleagues (2009) highlight two key concerns with grounded theory: the first is the process of identifying codes which ‘emerge’ from the data, but “it provides no systematic or transparent way for gaining insight into the conceptual relationships between emergent concepts” (2009: 356). Thomas and James (2006) argue that grounded theory tends to over-simplify complex meanings and interrelationships, constrains analysis and depends on inappropriate models of induction resulting in “appropriate claims to explanation and prediction” (2006: 768). One of the biggest critiques of grounded theory comes from Wasserman and colleagues who argue that researchers cannot actually be free of any concepts when commencing data analysis. “Rather than clinging hopelessly to such a rigid and overly-simplistic rule of ‘no concept,’ we must take a more sophisticated view and examine which concepts are appropriate and which are not”. (Wasserman et al, 2009: 377).

In a study conducted by Dyll-Myklebust, the process of grounded theory was not followed but it was applied for its ability to adopt strategies of follow-up interviews and inter-relating data collection and analysis, since grounded theory recognises that data collection and analysis is “dynamic and multi-layered” (Dyll-Myklebust, 2011: 48). Grounded theory then becomes a “process of collecting data,

analyzing the data and repeating the process” often referred to as constant comparative method (Williams, 2007: 69). The work of Glaser and Strauss, however, was an ‘invaluable task’ in bringing to general notice the powerful deliberations of qualitative inquiry” through a ‘procedure’ for grounded theory for scholars who want to apply this (Thomas & James, 2006: 790).

Application of a Grounded Approach in this Study

Using grounded theory as part of the research design allows for the exploration of processes, activities and events. Grounded theory in this sense allows the “researcher to derive a general, abstract theory of a process, action, or interaction grounded in the views of participants in a study” (Creswell, 2003: 14). The important term for my study here is ‘grounded’ – whilst my study does not follow the strict processes of grounded theory, the use of this ‘grounded’ framework is to highlight and amplify the views of the participants in this study, making my study ‘grounded’ in the views, perceptions, interpretations and, most importantly, the active participation of young people. Grounded theory will therefore be applied in this thesis where the principles of working in an inductive way, by building theory through a process of making sense of the data, is followed within the wider participatory action research framework of practice, theory and transformation (Winter, 1989).

The criticism around grounded theory demonstrates that no framework or theory is without flaws. Grounded theory is criticised as rejecting simple understandings and imposing method, production and theory, thereby dismissing the validity and import of people’s accounts (Thomas & James, 2006: 790). Despite the limitations of grounded theory, the principles of inductive research, the multi-layered data collection and data analysis processes, and the focus on the development of codes from the data, will be considered during this thesis. As a researcher who is working in the field of health communication and then translating these experiences into an academic setting, it is impossible not to have any preconceived ideas about theoretical implications when collecting data. These theoretical implications are ‘embedded’ in us as researchers, if not on a conscious then on an unconscious level, which is usually triggered when we start to analyse the data collected. Our theoretical background and academic discourses automatically start to make sense of the data within these theoretical frameworks.

Because it is impossible to eliminate any preconceived ideas about the data that would emerge, participatory action research (PAR) and basic principles of auto-ethnography is used to complement this study. The integration of grounded theory principles and PAR processes can be regarded as what McIntyre (2008) calls a ‘cross-fertilization’ of research traditions. The fluid use of grounded theory in this study, with the application of its principles without the implication of its processes, allows for an

integration of a wider research design to inform this study. Given the continuous infiltration of Western culture, concepts and ideas in our education system which follows a very top-down approach, research methods and the way we go about doing research has to adapt to the local culture, settings and contextualised problems (discussed further in Chapter Five).

Participatory Action Research – The Cyclical Process of Data and Theory

It is against this background of the limitation of the ‘grounded’ approach that PAR is positioned in this study. PAR, although different to grounded theory, offers a degree of similarity when it is viewed as “a theory of possibility rather than a theory of predictability” (Wadsworth, 1998:9). The use of participatory action research (PAR) contributes to the *fluid, adaptable, context specific* approach that this study takes, which results in a *blend* of methods and processes to fit the area of inquiry. “What makes participatory action research is not the machinery of research technique” but instead its ability to build a relationship between theory and practice (Kemmis & McTaggart, 2005: 564).

Action research has been described using different terms by various scholars as a result of the methodology advancing and evolving over the years. Some of the common terms used include participatory research, collaborative inquiry, emancipatory research, action learning and contextual action research (O’Brien, 2001). Action research offers a holistic approach to problem-solving and utilises several research tools within a qualitative paradigm that include research journals, document review and analysis, participant observation, surveys with questionnaires and interviews (O’Brien, 2001).

Participatory action research in particular has roots in rural appraisal (Mikkelsen, 2001), critical action research (Kemmis & McTaggart, 2005), community-based participatory research (Minkler & Wallerstein, 2003), and participatory community research (Jason et al, 2004) which are all variants of PAR and lead to a reconfiguration of power structures (McIntyre, 2008). “Participatory action research provides a way for individuals to take part in the process of generating knowledge and advocating positive social change in order to promote more effective health care practices” (Brydon-Miller, 2003: 187). Outcomes of a PAR process are then attainable through “critical examination of action” in order to understand the participant’s social problems and possible social interventions to address these (Dyll-Myklebust, 2011: 58).

PAR focuses on knowledge generation which will precipitate action for specific development issues. PAR is a “recursive process of questioning, reflecting, dialoguing, and decision making and therefore

resists linearity” which offers “adaptable steps of questioning a particular issue, reflecting and investigating the issue, developing an action plan and implementing and refining the plan” (McIntyre, 2008: 7). McTaggart highlights the contradictions of the work of academics and practitioners where there are assumptions that “theory reside[s] in one place and its implementation in another. Such a view is an antithesis of the commitment of participatory action research that seeks the development of theoretically informed practice for all parties involved” (2001: 266):

PAR is context specific means that practitioners draw on a variety of quantitative, qualitative, and creative-based methods to engage participants in the construction of knowledge – for example, surveys, interviews, focus groups, mapping, dramatization, movement, theatre, symbolic art, and photovoice. Owing to the diversity of the researchers and participants to analyze research data (McIntyre 2008:49).

PAR calls for an iterative process that initiates dialogue with stakeholders involved, moves to a phase of data collection leading to action, and then moves back to the process of dialogue. “This action/reflection cycle allows participants to learn from their action and to then translate that learning into even more sophisticated and effective forms of social action” (Brydon-Miller, 2003: 189). This cyclical and iterative process is also what Habermas (1971) refers to as critical knowledge, as it supports the emancipatory interests of people, and can be referred to as the “purest form of participatory action research” since it generates “knowledge through direct social action” (Brydon-Miller 2003: 190, 193).

These cyclical processes confirm the notion of praxis posed by Paulo Freire (1976), and also the circular process of communication for participatory development which suggests that dialogue will inform collective action, and this action will then inform further dialogue (Figuroa et al, 2002; Kincaid et al, 2009). PAR is used for its ‘transformative’ and ‘cyclical’ process of working with theory and data. PAR identifies and allows theory to inform practice but practice is then allowed to inform theory, which is an ongoing process. Winter (1989) offers six principles which can be applied to PAR: a) reflexive critique, b) dialectical critique, c) collaborative resource, d) risk, e) plural structure and f) theory, practice, transformation. Of significant importance for this study are the notions of ‘*reflexive critique*’ and ‘*theory, practice and transformation*’.

Reflexive critique calls for participants in a PAR process to reflect on issues and processes and offer their interpretations. These reflections and accounts will lead to theoretical considerations for the researcher (O’Brien, 2001). The process of reflexive critique suggests several similarities with the principles of grounded theory, or what I refer to as a ‘grounded’ approach, as the data is generated

towards theoretical considerations, instead of analysing the data in the context of applicable theories. This grounded approach and PAR then work inductively to understand real problems in their context, with real people sharing their lived experiences. The reflexive process ensures that data is continuously analysed at various stages and is then informed by theory, and later more data re-informs theory.

This highlights the other principle of the PAR process according to Winter (1989) which is '*Theory, practice and transformation*', where:

Theory informs practice, practice refines theory, in a continuous transformation. In any setting, people's actions are based on implicitly held assumptions, theories and hypotheses, and with every observed result, theoretical knowledge is enhanced.....It is up to the researchers to make explicit the theoretical justifications for the actions, and to question the bases of those justifications. The ensuing practical applications that follow are subjected to further analysis, in a transformative cycle that continuously alternates emphasis between theory and practice (O'Brien 2001:6).

This process of theory, practice and transformation is consistent with the grounded theory perspective that explores the experiences of young people through various forms of data collection, it builds this data into codes and categories, towards the construction of theory, and then allows for an exploration of how this theory can contribute to transforming the current processes of developing HIV projects which are inclusive of young people. The researcher will then take on the role of working as a co-researcher to jointly explore the experiences of young people in the development of HIV programmes. This will be done through a process of investigating what is taking place with communication programmes and young peoples' contributions to the findings will then be presented to the young people, towards theorising a more youth-informed process for HIV programme design.

Applications of the PAR Process for this Study

PAR was used in this study, based on its cyclical process of using practice to inform theory towards transformation and back to revisiting practice again. It was applied to this study by exploring what communication programmes are offered to young people, assessing its effectiveness and young people's participation in the development of HIV related projects. These practices are theorised and inform the bodymapping workshops that allow young people to take part in the processes of transforming how communication processes are used to develop HIV programmes. These theorised practices advocates for revisiting communication processes which often excludes the beneficiaries in the development phases.

A key attribute of the PAR process is the ability to 'listen' before taking action, and engage in a critical discussion about what people are hearing and what people are doing. Dialogue between the participants then becomes essential to building theory (Melrose, 2001). Through the process of listening, discussing and collectively engaging, young people have the opportunity to work on all aspects of a project. This is particularly significant for work conducted on HIV prevention where multiple cultural, social and behavioural factors influence the sexual choices that young people make.

Young people's involvement and contribution to various phases of communication processes can offer a new dimension for social change. "It is by actively engaging in critical dialogue and collective reflection that the participants of PAR recognize that they have a stake in the overall project" (McIntyre, 2008: 1). PAR success can only "be measured by the extent to which the process of research itself develops the skills, knowledge and capacities of participants to use the results themselves" (Kesby, 2000: 424). In addition, the PAR process promotes the working together of the researcher (myself) and the participants (young people), where collectively they can decide what is the most practical way to participate. In this way, "participation is viewed as a choice, not as an imposition" (McIntyre, 2008: 15).

Auto-Ethnography Revisited

An auto-ethnographic approach is adopted for this study, based on the flexibility of the integration of several research methods, my previous experience of working with young people as a facilitator and researcher, and my own interests and writings in the field of participatory and HIV communications. Auto-ethnography is about the research, writing and method that connect "the autobiographical and personal to the cultural and social, and features concrete action, emotion, embodiment, self-consciousness, and introspection" (Ellis, 2004: xix). David Hayano defines auto-ethnography as a qualitative research methodology that emphasises a personal, almost intimate level of study. It provides the researcher and participants with opportunities to explore past and present experiences while gaining self-awareness of these interactions and their socio-cultural effects (Hayano, 1979: 295).

Auto-ethnography for the purpose of this study will not be used in its wider application. Similar to the application of grounded theory, it will be used in a very fluid and flexible way, where key principles are used for this study, without the full spectrum of auto-ethnographic attributes. One of the characteristics of auto-ethnography is the principle of familiarity with the group being explored (Hayano, 1979), which in this case are a specific group of young people, with whom I have maintained ongoing engagement regarding their participation in HIV programme design. Secondly, the application of auto-ethnography

in this study is supported by the understanding that one cannot write about the 'other' without talking about the 'self' (Ricci, 2003) which draws from my experience as a facilitator conducting bodymapping workshops in various communities over a ten year period. An auto-ethnographic approach in this instance will further draw on my previous studies conducted around participatory communication and participatory learning methodologies and my own self-reflective experience of designing, facilitating and researching these workshops.

Hayano (1979) argues that in contrast to the detached-outsider characteristic of researchers, contemporary researchers would be frequently full members of the cultures they studied. "Congruent with its postmodern origins, it creates a tension in the research community between the critical, interpretive, and postmodern sensibilities and those of the positivist, post-positivist, and naturalistic conceptualizations of analyses" (Ricci, 2003: 595). Melkote, however, suggests that, regardless of one's position, information cannot be collected by entirely "objective" means (2003:154). The choice of a problem, method and theory is always affected by one's position and personal/situational factors such as sex, age, degree of rapport, the location of fieldwork, and the restraints of the sponsoring institution (in Hayano, 1979: 102). Therefore, Ricci argues that people always live their lives within a context. For ethnographers, this makes us subjects and participants, and worthy of studying. For auto-ethnographers, it makes us "researchers, scientists, and worthy of reporting" (Ricci, 2003: 593). This concept is premised on the idea that there will be dominant views but also other perspectives and the researcher has an important role in how these other views are observed and represented. Thus an "insider's position is not necessarily an unchallengeable "true" picture; but it represents one possible perspective" (Hayano, 1979: 102).

The term auto-ethnography over the years has become almost exclusively identified with those advocating the descriptive literary approach of auto-ethnography (Anderson, 2006). This is evident in the discussions which Leon Anderson (2006) offers, where he sets up analytic auto-ethnography in opposition to what he terms as 'evocative auto-ethnography'. Analytic auto-ethnography, according to Anderson, ensures that the researcher is a full member in a research group or setting; uses analytic reflexivity; has a visible narrative presence in the written text; engages in dialogue with informants beyond the self, and is committed to an analytic research agenda focused on improving theoretical understandings of broader social phenomena (Anderson, 2006: 375).

Whilst auto-ethnography should be motivated by a focus on the integration of the researcher with "the scholarly purpose, theoretical bases, and disciplinary contributions of the research inquiry, it is instead

guided by the personal experience, experiential value, and evocative qualities for the researcher's personal fulfilment". In this light, Atkinson (2006) supports Anderson's argument for auto-ethnography which is analytic and not evocative (2006:402-403). Leon Anderson's (2006) distinction between evocative and analytic auto-ethnography according to Kevin Vryan (2006) does not cater for evocative auto-ethnography which can cater for some level of analysis, and suggests that "the key difference between analytical and non-analytical (or exclusively evocative) forms of auto-ethnography, is the goal of explicit analysis" (Vryan, 2006: 408).

In response to Anderson, Carolyn Ellis and Arthur Bochner (2006) suggest that a focus on *explicit* analysis, that is, analysis which works towards building theory, can follow a realist ethnography approach, where the only purpose of the researcher is to document the experiences of people, with very limited/if any interaction with the subjects. Auto-ethnography was developed by a desire to "move ethnography away from the gaze of the distanced and detached observer and toward the embrace of intimate involvement, engagement, and embodied participation" (Ellis & Bochner, 2006: 433-434). They go on to argue that their application of auto-ethnography is where they "want to dwell in the flux of lived experience" while Anderson's framework for analytical auto-ethnography wants "to appropriate lived experience for the purpose of abstracting something they call knowledge or theory" (Ellis & Bochner, 2006: 431). They do, however, conclude that Anderson offers stimulating discussion and new insights which in a way also cautions us to not forget the methodological and theoretical considerations of auto-ethnography.

This thesis recognises the significance of evocative auto-ethnography and its research practices which "are performative, pedagogical, and political where writing is from the heart" (Denzin 2006: 421-423). However, in this study I use aspects of the analytic auto-ethnographic approach posed by Leon Anderson (2006), not in opposition to the evocative auto-ethnographic approach, but in an attempt to draw on certain principles of auto-ethnography which are specific to this study. While the latter caters for emotion, personal narrative and self-reflective research, this thesis makes extensive use of data collection tools such as interviews, focus group discussions, workshops, project reports and observation to support my personal experience with initiating student participation and applying the processes of bodymapping.

Recognising that there will always be varying discourses about auto-ethnography and its application implies that it must be used in an adaptable way, which documents people's experiences, taking into account the experience of the researcher, towards the better understanding of a social phenomenon.

This means that there will be opposing discussions, as evident in the case of contention with evocative and analytical auto-ethnography. However, it is important for a researcher to identify their own position when exploring their research topic. Sue Butler (2009) explores the work of Chang (2008) and highlights that, whilst her writing appears to support Leon Anderson in his objective and realist ethnographic perspective, it also extends to focus on the self in its relations to culture, and she often writes from a subjective, constructivist perspective.

The criteria for auto-ethnography, then, must include some prior knowledge of the people, their culture and language, as well as the ability to be accepted as a member of the group or community. Auto-ethnography should be written by researchers who have acquired an intimate familiarity with certain sub-cultural, recreational, or occupational groups. For auto-ethnographers, intensive participant observation is often the most important field method, perhaps to the neglect of other research tools such as questionnaires, structured interviews, psychological tests, field experiments, or formal ethno-scientific procedures (Hayano, 1979). The use of specific research tools will be explored later.

Taking an Auto-Ethnographic Approach to my Study

Auto-ethnography is defined as “where *auto* means directly from within; *ethno* refers to race, people, culture, and *graphy* is the written representation of the research” (Ricci, 2003: 593). An auto-ethnographic approach is taken to allow for my own reflections, experience in the field and observations over a ten year period, to contribute to the data being discussed in the various analysis chapters of this thesis. This is premised on the notion that I cannot separate my role as a facilitator from my own perceptions, observations and reflections of the various bodymapping workshops which I have conducted over the years. It also means that I cannot separate my position as researcher from that of an academic teaching in the field of health and development communication, with a specific focus on participatory communication. My role as a facilitator, academic and researcher in this study all contribute to *auto* which Ricci suggest comes “directly from within” (2003: 593). Hence the various lenses through which this data is analysed cannot be ignored. My position and self-reflectivity is therefore foundational to how I work with young people, make sense of their experiences and, finally, how I write up these experiences, through scholarly writing which according to Anderson (2006) must contribute to knowledge or theory.

While the importance of documenting and understanding the experiences of people, also referred to as *evocative auto-ethnography* is emphasised in the work of Ellis and Bochner (2006), this study draws on these principles but focuses more on Anderson’s (2006) analytical analysis which caters for the use of

data collection tools beyond observation and narrative. This allows for empirical data collected from other sources to offer a richness to the data analysed. In this way, my insider's position contributes to one of the perspective to the study, as suggested by Hayano (1979).

The researcher's interpretation of phenomena implies a degree of personal engagement with the field and with the data. "Auto-ethnography is grounded in an explicit recognition of those biographical and personal foundations" (Atkinson, 2006: 402). "It makes available the bridge linking the personal with the cultural where we cannot write about "other" without revealing something about "self"" (Ricci, 2003: 595). An auto-reflexive form of writing then becomes a process for people to analyse self/other relations, when writing in the others perspective where they have agency to address their concerns, by identifying needs and finding solutions" (Dyll-Myklebust, 2011: 38, 40).

A '*Blended*' Research Design

This methodology chapter reflects the various research perspectives which were 'blended' into what I refer to as participatory grounded research. The methodology proposed in this study is a result of working very 'scattered' in the field, where there is a mixture of rigid and flexible research processes when working with the eight HIV and AIDS programme-implementing organisations. Holloway and Tombres suggest that this mixture or overlap of "epistemological, aesthetic, ethical and procedural concerns" in qualitative research suggests a 'family' approach "where the notion of flexibility becomes an important value and quest", however this flexibility can also "dilute the value of consistently pursuing the integrity of a particular approach from beginning to end" (2006: 346).

This thesis makes use of both the top-down and bottom-up perspectives in addressing the research questions, which suggests a cyclical and transformative process of theory informing practice (top-down) and practice informing theory (bottom-up), which is integral to the PAR process. Top-down perspectives are usually theories that have been developed or formulated prior to the process of collecting empirical data (Gibson & Brown, 2009), therefore making the research a process of 'testing' the theory or addressing the area of enquiry through analysing the empirical data. The bottom-up perspective allows for the data that is collected to influence the identification of concepts, themes and later the development of theory. Working within the HIV and AIDS communication field for the last ten years has helped me recognise that working purely from a top-down or a bottom-up framework restricts a researcher from being able to truly contextualise, reflect and account for what is happening in the field.

The crucial aspect of this methodology is that through a process of rigid data collection processes, a fluid data collection process was adapted. Similarly, traditional action research focuses on the researcher exploring the social condition, “to recognize the political or environmental constraints operating on it, and to work collectively to improve it” (Melrose, 2001: 161). However, more contemporary AR focuses on a “continuous and participative learning process to create sustainable learning capacities and give participants the option of increasing control over their own situation” (Greenwood & Levin 1998: 18). Central to this process is the development of theory from young people’s experiences and reflections on communication processes. Action research, according to Mary Melrose, is about “the building of theory about, in, or from practice that the understanding of the situation by the group is enhanced” (2001:161).

The next section discusses the possibilities of applying an art-based inquiry, drawing on principles of grounded theory, and later discusses how bodymapping can be used within a cyclical process of data collection to understand young people’s experiences of HIV programmes, and possibilities of their participation in developing HIV programmes. The application of visual methods, particularly the use of drawing and mapping are explored in the context of an art-based inquiry, facilitated through a bodymapping process.

Art-Based Inquiry and Challenges of Conventional Research

“Postmodern foundational shifts have brought about a new conceptualisation of how research works, how meaning is made and what social purposes research might serve” (Finley, 2008: 96). Art-based inquiry has emerged in postcolonial, postmodern contexts, as a methodological and theoretical genre which offers a new form of qualitative inquiry to address challenges of traditional techniques of research which are not positioned to adequately handle many questions that need to be asked (Finley, 2008). A reformist movement is inevitable and will bring “art” to inquiry (Guba, 1967:64) for researchers to sort new ways of merging theory and practice (Finley 2008:97). Lincoln (1995) describes art-based inquiry as an emerging tradition of participatory critical action research. Researchers working within this mode of inquiry propose reinterpretation of the methods and seek to construct action-oriented processes for inquiry (Finley 2008:96).

There was two primary issues among academics, researchers and practitioners that facilitated the strong focus on art-based inquiry with young people. First is the academic discourse around the

relationship between researchers and communities, with more support for the roles of researchers and participants to take the form of collaborators or even co-researchers (Finley, 2008). This in turn has blurred the lines between the researcher and the researched, but has also opened up new avenues for how data can be collected, analysed and distributed. Secondly, the question of how do researchers write up research without 'othering' their research partners or leaving out their voice was also instrumental in creating a space for art-based inquiry. This is premised on the notion that it is impossible to separate the processes of researching, designing, implementing or evaluating work, without facilitating the collaboration between young people and researchers, and the co-generation of knowledge.

Research which makes use of visual methods, in particular, allows the researcher to mobilise young people towards their own empowerment, therefore promoting "participation and self development" (Shillingford, 2006: 9). This is made possible by the flexibility offered by visual methods which allows young people the freedom to communicate and engage in research through a medium which they feel comfortable with. Therefore while the researcher is facilitating a visual methods process, the option of choosing which medium of communication is preferred, places the power in the hands of young people to decide their level of participation, and how they will document their perceptions on HIV programmes. Visual methods in this instance allow for researchers to negotiate self/other power relations, by providing young people with a method to explore themselves in relation to others (Kesby 2000). This implies that while researchers are exploring how they fit into the research process, young people are also able to choose their level of participation and engagement in relation to others. This reinstates the power balance between the researcher and young people as the researcher is assessing his/her position, observing and documenting reflections using visual methods to collect data, while young people are given the opportunity to engage in this self-reflexive process using various mediums to communicate and reflect.

Coad (2008) argues that there is an increased need for the active involvement and participation of young people in all processes of development projects, but in order for this to happen more participatory methods have to be introduced to facilitate this participation. Even though the participation of young people can vary according to level of involvement, age, time and ability (Mitchell 2008), young people have embarked on the first level of exploring their opinions, views and interpretations using visual methods. The discussion, interviews, focus groups or reflections to follow are usually what offer a second level of data that unpacks the visual representations offered by young people. Mitchell (2008) makes reference to this process as what Fiske (1989) refers to as the "production text" (how

participants engaged in the process and what they make of the texts) that often involves follow-up interviews.

As a result, art-based research, specifically the application of visual methods, crosses the boundaries of art and research (Finley, 2008: 101), and conventional forms of data collection to extend to methods which accommodate the inclusion of young people as knowledge producers. This “hybrid boundary-crossing approach to inquiry” creates spaces for dialogue which “blur the boundaries among researchers, participants and audiences” and moves people to action through an art-based inquiry which is a radical and revolutionary qualitative inquiry (Finley, 2008: 101). In this light, art-based inquiry is reflective of the work of Freire where it transforms praxis, and mobilises young people to become critically aware of their social realities through a process of working as knowledge producers.

Art-based inquiry recognises that there is a range of “tried and tested methods such as interviews and surveys” but there is also a greater need and willingness to draw on a more diverse repertoire of data collection methods and approaches to analysis (Heath et al, 2009: 3). Heath and colleagues argue that this is specifically applicable in the case of young people where youth-specific context affects the application of conventional or tried and tested methods. The use of conventional research methods and models for addressing local community needs, in particular those of young people, can add more complexity to addressing development or public health issues. For example, the use of interviews, questionnaires and focus groups alone can create barriers to the type of information provided by young people and also poses challenges for their willingness to participate, especially in issues regarding HIV and AIDS. These traditional techniques of inquiry do not always accommodate the role of the researcher and young people working together towards understanding social phenomena and this poses challenges on how the data is collected, what is collected and what can be done with it.

The use of visual methods in research has therefore increased within the social sciences (De Lange et al, 2006). Visual methods are often used to collect data which extends beyond the use of interviews, focus groups and questionnaires to explore a range of development or public health issues (Pink, 2001), as they have the flexibility and fluidness to continuously adapt to address the needs of specific participants (Coad, 2007). Visual methods, given their flexibility and fluidness, were therefore used in this study to inform research phases (such as data collection), intervention phases (development of HIV projects) and to actively engage young people to identify who they are, what they want and how to go about achieving this through a bodymapping process. The diverse use of visual methods in participatory research, however, means that the boundaries of research become increasingly blurred

with “the use of visual texts as modes of inquiry, modes of representation, modes of dissemination and what counts as data” (De Lange et al, 2006: 46). Mitchell argues that the term “visual methodologies” should not be reduced to a specific practice or tool but that it needs to be appreciated as a set of methodologies and practices within its full complexity (Mitchell, 2008: 367). Using bodymapping as a visual method allows young people the freedom to express themselves through writing and drawing, supported by discussions about what they documented.

Application of an Arts-Based Inquiry

The use of art-based methods in this thesis, specifically drawing and mapping processes, were identified for their ability to give young people a sense of control over the research process, and a way to understand young people’s experiences and perspectives which is not always possible through verbal discussions. Verbal discussions about sensitive topics like HIV can bring a level of silence when working with young people due to the stigma and discrimination that are often associated with it. Art based inquiries therefore need to offer a level of adaptability, which allows for flexibility when working with young people who are faced with multiple contextual factors and influences regarding HIV and AIDS. The importance of using drawings and art-based approaches is that they are rarely used in isolation, but are often accompanied by other data collection tools such as interviews and focus groups (Coad, 2007). This thesis therefore tries to integrate art-based inquiry with conventional research within a cyclical process where interviews and focus group discussions inform the use of mapping and drawing activities, followed by more discussions and one-on-one interviews with young people.

Using Drawing as Part of the Art-Based Inquiry

“The word *drawing* is both a noun and a verb; it is both a product and a process” (Guillemin, 2004: 274). Art-based methods like drawing have the ability to bridge traditional barriers to communication, and create opportunities for discussions (Malindi & Theron 2011). The use of drawing as a tool for an arts-based inquiry suggests that drawing needs to work together with conventional research methods to offer richness to the data and also serve as a process of verification. Drawing also offers a level of adaptability to the research context where it can present data as a mode of inquiry, representation or simply as a creative process for young people to participate. Young people are able to take ownership of the research process, where drawing overcomes barriers of communication which are usually evident with conventional research methods. The challenge of the use of drawing, however, is the limitation in how drawing has been used. There is an extensive body of literature on how drawing encourages young people to participate, particularly regarding sensitive issues, but very little literature which indicates that young people can use art and drawing in the various phases of developing an HIV

intervention. This will be explored in the analysis chapter. The application and use of drawing therefore indicates that drawing as a visual method can often be used as a research method for data collection and dissemination, to assist participants with alternate modes of expression and offers multiple layers of interpretation.

Whilst the use of art-based approaches offers participatory ways of working with young people, Coad (2007) suggest that asking young people to create a drawing, collage and/or a poster can also be problematic as not all feel they are able to draw. However, offering young people a choice and level of flexibility with drawing and writing ensures that they do not feel intimidated by the creative process. This means that workshops are facilitated with young people where they are continuously encouraged to work in a medium that they felt most comfortable. This means that while the activities are designed to encourage art and drawing, this is not prescriptive, rather young people can adapt and work in ways in which they are most comfortable. Coad further suggests that researchers can work with the participant after drawing exercises to discuss the “drawing and adding written labels or cards to highlight meanings” (Coad, 2007: 491). Similarly, the bodymapping process was supported by visual and text responses on the bodymaps followed by discussions where young people were allowed to explain their drawings, images, symbols and context of their textual responses. The next section discusses mapping processes and its contribution to the bodymapping process.

Mapping as a Visual Methodology

Mapping refers to maps made or drawn by members of a community on paper or on the ground. It is a process by which information is represented in a spatial form (Narayanasamy, 2009:41). The process of mapping can be traced back to various sources or disciplines such as social anthropology, participatory action research and popular education (Chambers, 2008). Mapping processes are able to capture emotional and personal experiences in an abstract way that can become a tool for young people to share their stories (Amsden & Van Wynsberghe, 2005). It also becomes a tool for participants' interpretations and explanations and can take the form of a small-scale model or full size simulation (Save the Children, 2000). Over the years, mapping processes have been adapted and applied for various participatory methods that include participatory mapping, social mapping, intervention mapping, concept mapping (used to build understanding) and bodymapping. For the purpose of this thesis, only participatory mapping is discussed, as it informs the application of bodymapping. Participatory mapping fits within a broader framework of participatory research methods that engage communities in the collection and generation of information, where they have control over the data generation with the participants themselves (Maman et.al, 2009:370). The rapid spread of participatory mapping is what

Chambers (2006) terms a "pandemic spread", and attributes this to the "versatility and power of participatory mapping, which can be facilitated with the fun, fulfilment and pride which people derive from it, and its multiple uses by so many stakeholders" (Chambers, 2006: 2). There is a long history of participatory mapping where researchers explore local knowledge within specific contexts and places (Emmel, 2008).

For the purpose of this study, participatory mapping used in the data collection, enabled young people to create visual and non-visual data to explore how they understand the challenges of HIV and how they can actively participate in developing participant specific HIV programmes. The processes of participatory mapping therefore extend beyond extracting information and knowledge from young people, to facilitate a process of knowledge sharing and collective action. Mapping processes are central to the processes of bodymapping, where participants map a range of issues, reflections, perceptions, ideas and experiences on a traced outline of their body. The mapping technique can be applied to document spatial mapping (layout of community) and social mapping (people in communities) among others. Below is a discussion on the history and application of bodymapping (life-size images).

Background to Bodymapping and Possibilities for Further Application

The bodymapping process was first introduced to a group of women in Khayelisha, Cape Town who later became known as the A-Team or the Bambanani working group. Bodymapping uses an art-based technique to create life size images of people's bodies, through a process of tracing the outline of their body, while lying on a large sheet of paper. It is also a mapping process used as a "health data gathering tool" (Narayanasamy, 2009: 283) and through representation of the human body through visual forms, people can explore perceptions they have about bodily functions and how medical programmes work in the body. Bodymapping was introduced through the Memory Box project to the A-Team women when the HIV landscape was plagued with denialism, misconceptions around HIV and AIDS and, most importantly, the failure or lack of roll-out of ARVs for HIV positive people in SA. The bodymapping process requires a facilitator to take people through a series of steps towards documenting a range of social, emotional, psychological and thought provoking issues. The use of drawing, visuals and creative materials such as paints, pastels, food colouring and bold markers allow participants to document their lived experiences through visual representations. The bodymapping process was used as a process of "knowledge dissemination by sharing knowledge on physical dynamics of the virus, but also 'promoting understanding of the social context of the illness' which is

integral to the education process” (ASRU, 2004: 12-13). Overall, the process was also intended to empower women, so they could share their own experiences with other people living with AIDS (PLWA) (MacGregor, 2009).

The initial application of bodymapping in South Africa illustrates the power of a visual and mapping technique to mobilise HIV positive women to share their stories and lived experiences. “From an advocacy perspective, the stories told by these women illustrate the life changing benefits of ARV treatment. These narratives have the ability to shift the ARV debate out of the economic, structural and clinical spheres, and into the personal sphere of lived experience” (Almeleh, 2004: 6). The use of narrative in this instance draws attention to new ways of addressing HIV and AIDS.

Based on its wide application in South Africa to address issues of fear, stigma and biological understanding of what is happening to the body through treatment adherence or the lack of, practitioners around the world have adapted this technique to explore the health and psycho-socio issues of their own communities and patients (McGregor, 2009; Cornwall, 1992; Crawford, 2010). Bodymapping has been used in the context of treatment literacy (ASRU, 2004), medical anthropology (Cornwall, 1992, 2000), psychotherapy (which focuses on healing and the integrative power of exploring people’s experiences through words and narrative forms of expression (Crawford, 2010) also known as art and narrative therapy), and recently in body theology and pastoral anthropology (Meiring & Müller, 2010), where bodymapping was used to narrate people’s stories regarding their bodies in relation to their spiritual journeys. These studies indicate that bodymapping, beyond its application in South Africa, has also been applied to diverse issues in various countries. This study uses bodymapping not to address the social or biomedical aspects of HIV and AIDS but rather to highlight the bodymapping process as a ‘tool of enquiry’ that has the potential to engage young people in active participation and to explore the processes of strategic communication. The next section discusses the phases of data collection and how bodymapping processes informed one of the data collection phases.

Data Collection Phases

Given the participatory action research process applied in this study, the data collection and analysis process were done over different phases. In accordance with the cyclical process of PAR, and its ability for transformation between the processes of theory and practice, this thesis builds on the findings of my MA study and ensures that the principles of action and reflection are incorporated in how the data was collected and later analysed (Winter, 1989).

Phase One: Interviews and Focus Groups with Organisations

This phase was designed to address the question of what HIV prevention messages and communication programmes are offered by the sample organisations selected. This question was explored through interviews conducted with either the director or programme managers of each of the eight selected organisations (see Appendix 2). Only one interview was conducted per organisation as the idea was to interview the person who coordinated or managed in the HIV programme with young people. In most organisations, there was only one person who fulfilled this role, hence the data was further supported by focus group discussion with other staff members. Focus group discussions were conducted with facilitators from some of the organisations, based on their availability and willingness to participate (see Appendix 4). All focus groups had more female participants than male participants which also revealed that there were more female facilitators in the community than males. Most of the facilitators were between the ages of 20-35 years old and approximately 8-10 staff participated in each focus group discussion. The data collected in this phase was coded, categorised and developed into themes to explore what programmes are on offer to young people, the key determinants that influence risky sexual behaviour through sexual decisions and practices, and finally how young people are participating or can participate in the development of HIV-projects (more in Chapter Six).

Phase Two: Focus Group Discussions with Young People (Bodymapping Experience)

This phase presents and discusses the data collected through focus group discussions conducted with young people at the end of three separate bodymapping workshops over a three year period (see Appendix 5). Similar to the staff focus groups above, the University focus groups with students had more female than male participants who were between the ages of 20-25 years. The data offered in this chapter addresses the research question which explores how participatory techniques like bodymapping can involve young people in the various stages of developing HIV programmes. Data is also discussed from various other workshops which I conducted during 2004-2013 to explore HIV-related issues and community participation. While phase one addresses specifically what is happening with organisations regarding HIV programmes, phase two assesses the relevance of bodymapping as a participatory technique and a tool for discussing HIV. This phase explores whether bodymapping has a participatory perspective and actively engages young people. The data in this phase makes a case for bodymapping as a participatory process (refer to Chapter Seven).

Phase Three: Participatory Workshops and Review of Bodymaps

After the process of exploring the validity of the bodymapping technique with data collected from focus group discussions, specifically designed bodymapping workshops were conducted with two groups of convenient samples of young people from the University of KwaZulu-Natal (UKZN) and from a sample organisation (*DramAidE*), to explore how they problematise HIV and AIDS and their experiences, particularly addressing issues of participation (see Appendix 6). These two groups were strategically selected, with the one group being young people who are attending University while the others were young people in a deep rural community. These two sample populations were selected to get a broader perspective to issues of participation from various social and economic backgrounds. This phase was designed within the PAR process to address the question of what are young people's perceptions of communication processes for HIV and AIDS programmes, with specific reference to what they are seeing, hearing, saying and doing regarding communication programmes (refer to Chapter Eight). Using the layout of the visual bodymaps, students map and discuss:

- a) what are they 'seeing' regarding HIV and AIDS communication programmes and design (eyes)
- b) what are they 'hearing' regarding HIV and AIDS communication programmes and design (ears)
- c) What are they/and others 'speaking' about regarding HIV and AIDS communication programmes and design (mouth)
- d) How do they feel about HIV and AIDS communication programmes and design (heart)
- e) How do they make sense (intellectualising) about communication programmes and design (head)
- f) What are they 'doing' regarding HIV and AIDS communication programmes and design (hands)
- g) What is the way forward regarding their personal involvement in HIV and AIDS programme design within their institution (UKZN) or organisation (*DramAidE*) (feet)

This bodymapping process commenced with the general and moved to the specific, starting with a review of basic personal information about young people and moving into the more detailed issues. A detailed bodymapping programme and series of steps were developed for this purpose. The bodymaps also serve as the data collection tool and each participant was given an opportunity to share in detail what they depicted on their bodymaps. These discussions were recorded and the data transcribed. This extensive process ensures that a rigorous data set is provided which is analysed continuously in accordance with the processes of participatory action research to inform the next data collection process. The data collected through the bodymapping workshops will address specific questions on

HIV programmes and issues of young people's participation, but will further indicate the possibility for application of bodymapping in various phases of the HIV project development.

Phase Four: Focus Group Discussions

The fourth phase of data collection takes place with two focus group discussions which were conducted after each workshop (see Appendix 7). This phase explores how young people make sense of this process and discusses their suggestions for further bodymapping applications (refer to Chapter Nine). Whilst phase two explored young people's bodymapping experiences specifically to understand whether bodymapping can encourage participation, the fourth level of data collection explores the specific data on the bodymaps around specific issues of young people participating in developing HIV projects.

The overall data collected and analysed offers frameworks and concepts which explore bodymapping as a participatory process but with a specific emphasis on its use as a medium to collect data for young people's involvement in a participatory way. The actual data collected through the bodymaps and the focus group discussions and interviews allowed for the development of themes which reflect how practice informs theory through ongoing observation and interaction with young people in the field. Whilst the steps of the bodymapping process offered a pre-designed and structured format, the technique is utilised to engage young people's participation using various mediums such as writing, drawing and the use of symbols. The bodymapping process was therefore one of the many data collection processes that ensured the data was reviewed in a cyclical process, taking the concepts that emerged through the initial data set and explored this further through fluid and systematic research processes. Below is a discussion of some of the specific data collection tools used for these various phases of the study.

Data Collection Tools

Many modes of data collection are used with specific methods to design and capture data (Henning 2004). For the purpose of this thesis, interviews, focus groups, participatory workshops and observation were used to generate data on how communication programmes are designed and presented to young people. The data gathered through these research tools were interpreted and analysed using thematic analysis. The themes which emerged assisted with understanding how young people can be more actively involved and can participate in the design of HIV projects. The aim of inquiry is understanding

and reconstruction of constructions that people initially hold, but still being open to new interpretations as information and sophistication improve (Guba & Lincoln, 1994).

Qualitative research interviews obtain “qualitative descriptions of the life-world of the subject with respect to interpretation of their meaning” (Kvale, 1996: 124). The research interview is an interpersonal situation, a conversation between two partners about a theme of mutual interest. It is a specific form of human interaction in which knowledge evolves through dialogue (Kvale, 1996). Nine interviews were conducted in total, one interview with the relevant staff working with each of the organisations (and two in the case of *Youth for Christ*), to gain insight into the specific communication programmes offered to young people, with an exploration of what communication processes inform the design of the HIV programmes. Informed consent was received from all respondents before collecting data and the anonymity and confidentiality of respondents has been maintained.

Focus group discussions were used to elicit the responses of young people who also work as facilitators in the school programmes offered by the organisations. Focus groups have the advantage of making use of group dynamics to stimulate discussion, gain insights and generate ideas in order to pursue a topic in greater depth (Bowling, 1997). Some of the topics covered in the discussions included how young people receive the communication programmes offered by the organisations and discussions around their participation in HIV programme design. Focus groups were used as they generate rich data through discussion and also allow for deconstructing young people’s responses through ongoing dialogue. Four focus groups, consisting of six to eight participants, were conducted with facilitators from a sample of four organisations/programmes. Only four focus groups were conducted from the initial eight sample organisations/programmes since three programmes were national and did not have ongoing community programmes which could be evaluated for the purpose of this study. Four organisations were therefore used as a 50% sample representative to explore communication processes with young people. Convenient sampling was used to select young people who are available and willing to contribute to this study.

This thesis then used the bodymapping process to assess how young people make sense of HIV and how they can actively participate in HIV and AIDS programme design and communication processes. Bodymapping is used as a technique that serves as a participatory process of exploration to investigate young people’s involvement. Broadly, this study will also investigate the relevance of bodymapping as a participatory technique for initiating dialogue and discussion on young people’s involvement.

Social scientists are observers of both human activities and the physical settings in which such activities take place (Angrosino & Mays de Perez, 2003). Observation used in non- ethnographic study is not involved in a description of culture but with the objective of collecting specific information that will address a focused issue (Henning, 2004). Observation was used as a tool during the workshop process to collect data on how young people interacted and how they occasionally discussed the range of steps before documenting it on their bodymaps. The principle relating to data acquired by means of interviewing also applies to observation. What is observed (seen or heard) is the researcher's version of what is 'there' (Henning, 2004). Henning argues that observation as a method is under-used in the 'interview society' where there is a reliance on multiple interviews to strengthen emerging themes. However, information from observation can fill in gaps left by interviews. Observations were recorded through reflective journaling, where the notes from my observations were compiled and later referred to during the analysis phases. The next section discusses some of the sample considerations when choosing the organisations for this study.

Sample Criteria

This study comprised of a sample of eight organisations/programmes that combined both mass media and participatory projects designed for young people. Directors, managers, facilitators and young people of these organisations were interviewed and participated in various stages of the data collection phases to offer diverse perceptions of HIV and AIDS communication and specific HIV programmes. Since this study focused on young people in particular, students from UKZN were included in the sample in Phases Two, Three and Four of the data collection phase to offer contrasting perceptions of young people on HIV and AIDS communication. The sample of young people from the HIV organisations were therefore representative of rural youth, while the sample of young people (students) from UKZN were representative of urban youth. This was an important contrast to include in the sample as the experiences of young people differ in various locations and contexts (Govender, 2010). Several studies also indicate the risky sexual practices that students at University engage in and it is therefore imperative to include this group of young people as part of the sample (Kunda, 2009; Mulwo, 2009; Mutinta; 2011; Moodley; 2007).

The eight organisations/programmes included the three largest national HIV communication interventions. All three national initiatives have been previously researched with critiques and suggestions for further review. These three initiatives therefore offer a strong background to the national landscape of HIV and AIDS communication in the country. Conducting a study on young

people's participation in communication processes regarding HIV and AIDS would be flawed without the inclusion of these key programmes in the study.

The selection of the five participatory organisations offering programmes that focus on HIV and AIDS were based on the following criteria:

- a) the accessibility of the organisations, as this study is conducted in KwaZulu-Natal,
- b) organisations which work with young people in locations which include schools, communities and tertiary institutions,
- c) the diversity of the young people in each of these organisations in terms of age, sex and urban and rural locations
- d) HIV and AIDS programme offered specifically for young people.

These five organisations were also selected for the diversity of methodologies employed when working with young people. These included methods of drama and forum theatre (*DramAidE*), music (*Field Band Foundation*), participatory games, role-play and visual mediums (*Youth for Christ* and *Focus on the Family*) and dance with participatory techniques (*One Voice*, SA). These organisations were purposively selected to create a sample with diverse programmes for young people, with an exploration into the communication processes which inform HIV programme design and development.

This table below highlights the eight organisations or programmes selected for this study. I use the words organisations, programmes, projects and interventions interchangeably as the literature has many inconsistencies when referring to work done for HIV and AIDS communication. For the purpose of this study, these terms are used to reflect that a programme is offered either on a national or a small-scale level. In many cases, an organisation which is registered as a non-governmental organisation (NGO) offers several programmes addressing a range of issues and participants. A programme could then be offered as one of the many projects implemented by an NGO. In the sample organisations selected, those working with small-scale participatory programmes with young people offer a specific programme for addressing HIV and AIDS with young people. This is evident in the work of *DramAidE*, *Youth for Christ*, *One Voice*, *Focus on the Family* and *Field Band Foundation*. These five organisations offer a range of programmes addressing various issues of life skills development, and HIV and AIDS for several participants. This particular study only focused on the work conducted with young people on issues of HIV prevention.

The terms interventions and programmes have also been applied broadly to the national interventions offered by *loveLife*, *Soul City* and *Scrutinize*. These programmes almost take the form of a national campaign supported by participatory interventions. In the case of these three programmes, the name of the campaign/programme constitutes the name of the organisation. This implies that it is one key programme/intervention offered on a national and participatory level which is then divided into more specific focuses. The national interventions almost become one main communication product in terms of its focus and application but is applied on a national or mass media level through television, radio, print or social media and supported by participatory initiatives which carry the main campaign/intervention focus in a more engaging way.

Table 2 shows the organisations which participated in the study, and how the interviews and focus groups were conducted.

Table 2: Participating Organisations and Approaches

Organisation/Intervention/ Programme	National intervention	Participatory Intervention	Work with young people	Interviews with Directors	Focus group with facilitators
DramAidE	-	X	X	1	1
Youth for Christ (YFC)	-	X	X	2	1
Focus on the Family (FOTF)	-	X	X	1	
One Voice, South Africa	-	X	X	1	1
Fieldband Foundation	-	X	X	1	1
Soul City	X	X	X	1	
Scrutinize	X	X	X	1	
loveLife	X	X	X	1	

A more detailed description of each of these organisations is offered in Chapter Six of this thesis.

Thematic Analysis

Thematic analysis focuses on identifiable themes and patterns of living or behaviour (Aronson, 1994). The interviews, observation, documents and focus groups provide rich data for analysis. The themes that emerge from the data collected were classified into patterns and sub-themes to form collective experiences, comments and stories of young people. This process is a form of pattern recognition within the data, where emerging themes become the categories for analysis (Fereday & Muir-Cochrane, 2006).

Braun and Clarke (2006) propose six steps to thematic analysis that will be followed to analyse the data. This includes transcribing the data, initial coding of data, searching for potential themes, reviewing the codes in relation to the themes, defining and naming the themes and finally writing up the analysis (Braun & Clarke, 2006). The Nvivo software package was used to assist with coding the themes and concepts that emerge from the interviews and focus groups, and will be constantly compared and contrasted. Kvale (1996) suggests that interview questions can be evaluated thematically with regard to relevance to the research theme and dynamically for the interpersonal relationship in the interview. For this thesis, both these dimensions were explored using thematic analysis to explore the themes which emerge.

Table 3: Phases of Thematic Analysis

Phase	Description of process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set; collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2); generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Source: Adapted from Braun and Clarke (2006: 87)

Rigour and Validity of Research

Rigour is often associated with validity and quality and in the case of action research the rigour is demonstrated through the cyclical process of revisiting the social problem through various phases (Melrose, 2001). The validity in this thesis was achieved through the various levels of data collection. Once there is a level of repetition in the data, this thesis will reach a point of saturation, which can also be argued to demonstrate the validity of the research. The continuous process of exploring practice and theory and theory and practice also validates the research. Melrose also makes reference to Cardno and Piggot-Irvine who echo that action research cycle methodology allows for quality and validity of the study through its cyclical processes.

The first cycle is an exploration of the situation, this was done through the nine interviews and focus group discussions supported by extensive literature searches to gain better insight into issues of HIV and participation with young people. According to Cardno and Piggot-Irvine (1996), this first level of data collection brings rigour to the study. The second cycle to assess rigour means that the data collection process must attempt to improve or change the situation through an intervention. This is evident in the data collection and analysis of the application of bodymapping with various groups and to explore whether it can contribute to the participation. This offers a second level of rigour to the research process. The final level that confirms rigour in research processes is the evaluation of the intervention (Cardno & Piggot-Irvine 1996). This was evident in phases three and four of the data collection and analysis phases where young people were given an opportunity to explore their perceptions of HIV related programmes and possibilities for their participation, this was followed by focus group discussions that explored the effectiveness of the bodymapping intervention. The use of critical reflection in each cycle allows the action (or change or improvement or intervention) to be integrated with research (or building understanding about the process and the practice or evaluating progress or generating theory).

The use of participatory action research therefore offers a level of validity to the research through its cyclical process where each level of data collection and analysis contributes to the overall validity of the research. Butler poses the question: "Is it possible to follow rigorous methodological procedures of data collection and interpretation while embracing opposing philosophical, theoretical and epistemological stances?" (2009: 297).

While this study draws on grounded theory, participatory action research and auto-ethnographic principles, but not their systematic processes, the epistemological position gains its rigour from a constructivist perspective. In response to the question posed by Melrose above, Chang observes that: “the question that will concern the research field will not be whether the author subscribes to an objective or subjective approach to social science research, but why she does not take a clear and substantial position” (Butler, 2009: 298). Chang therefore highlights that rigour can be achieved in a study with multiple methodological procedures but the researcher must make their subjective or objective position very clear.

Limitations of the Research

This study can be limited on several levels when working within this methodological framework. The first is the research design that integrates a grounded perspective, participatory action research, and an auto-ethnographic approach. Each research design has specific theoretical principles that inform its application in specific research areas. Drawing on some of these principles but not specifically applying the theoretical procedures can make the process of research incredibly messy and difficult to theorise.

Secondly the selection of the sample offers a contrast of experiences and perspectives from the organisational level, facilitator level and the participant level, with further contrasts between participants who are attending university in urban areas with those in rural areas. Hence the study offers data that is specific to one population and makes the process of generalisation more complex. It also highlights the complexity in terms of time and resources to conduct participatory communication research, suggesting that there is not quick fit to addressing issues of participation. Thirdly, participation in this research is also voluntary and young people’s participation is not always guaranteed. This study is based on the premise that young people do want to be participate in communication processes (for literature and studies to support this, refer to Chapter Five).

Fourthly, the use of both conventional and art-based method of inquiry can still run the risk of young people not feeling comfortable to express themselves using drawing and writing. This study therefore assumes that youth are willing to engage using drawings and textual documentation, with the idea that it will lead to dialogue and further discussion. Finally, while limited research is conducted about using bodymapping as a tool, bodymapping can be limited as its argued to be very prescriptive about the steps for young people to follow and can therefore limit participation. However, according to McIntyre (2008), if both parties do not contribute to how people participate and in what ways, then practitioners

of PAR run the risk of “telling” people how to do things, thus becoming too pedagogic and/or manipulative (2008: 29). Whilst the use of prescriptive steps in bodymapping does run the risk of telling young people what to do, this programme was be designed to offer open questions for exploration, where young people can express themselves through the use of art and text. This provided some freedom for how young people engage, what they say and how they document this.

CHAPTER FOUR: COMMUNICATION FOR (PARTICIPATORY) DEVELOPMENT: HIV AND AIDS PROGRAMMES IN SOUTH AFRICA

Introduction

This chapter commences with a discussion on exploring HIV and AIDS as a health and development problem. It analyses the responses to challenges posed by HIV and AIDS and the thinking about communication for development from a diffusion perspective and a participatory perspective. The chapter does this by offering a range of examples of HIV and AIDS interventions in South Africa. The discussion is concluded by highlighting the importance of context, particularly the context of participation. The chapter, in particular, tries to make a case for highlighting the importance of participation in HIV and AIDS projects and programmes and suggests that central to all contextual factors of the pandemic is ensuring effective participation. A more in-depth discussion of the concept of participation will be addressed in Chapter 5 of this thesis. As a result, this chapter contextualises HIV and AIDS as a health problem within a developmental problem, but in the context of participation⁶.

HIV interventions directed at large-scale participants, with a one-way transmission of messages, are referred to as top-down approaches. HIV projects and programmes that allow for participation, dialogue and feedback are referred to as bottom-up approaches. However, these approaches cannot be boxed into exclusive categories and do integrate when applied using various channels. The use of predominantly mass media channels epitomises the complexities of an orthodox communication science approach, where HIV and AIDS communication is 'boxed' with the application of linear models and theories that can become a hindrance to effective HIV and AIDS communication. Therefore, this section is written from a cultural and media studies framework, that understands the importance of the researcher or communication planner's perspective in relation to the beneficiary/participants social, cultural and psychological position when researching and designing effective HIV and AIDS programmes.

HIV and AIDS: A Health and Development Problem

The United Nations Millennium Development Goals identify dealing with HIV/AIDS as the sixth goal, aiming to halt and reverse the spread of HIV by 2015, thus positioning the pandemic more as a broad

⁶ Sections of this chapter has already been published in Govender E.M (2011) Tracing development and health communication for HIV and AIDS prevention within a South African context. In Tomaselli, K. & Chasi, C. Development and Public Health Communication. South Africa: Pearson.

development issue, rather than as only a *health* problem (Govender, 2010). UNAIDS, the World Bank, the Gates Foundation, the Global Fund to fight AIDS, Tuberculosis and Malaria, and the President's Emergency Fund for AIDS Relief have become leading authorities in the current global governance of HIV and AIDS in Africa and are instrumental in the shift to perceiving the pandemic as a development problem instead of a health problem since the late 1990s (O'Shaughnessy, 2007). O'Shaughnessy (2007) suggests that the much-needed financial resources at the disposal of the donor agencies have ensured an adoption of the discourse of HIV and AIDS as a development problem.

Seeing HIV and AIDS as a *development* problem results in communities, civil society and government addressing the issue of HIV prevention as part of a larger problem of poverty, inequality and gender relations. On the other hand, HIV and AIDS as a *health* problem focuses on the sexual decisions of individuals as an approach to address behaviour change. Some of the earliest successes, for example, within gay communities in the United States (US) included a range of vertically and horizontally organised communication activities and resources, including combinations of interaction with health and counselling services, epidemiological tracking and disease management, political activism, and peer counselling and support (Parker, 2004). While the success in the US can be attributed to this multi-level communication approach, HIV was still addressed from a health perspective and not a development perspective. The emergence of HIV and AIDS in the early 1980s in other parts of the world was therefore addressed predominantly as a health problem, because the first public awareness of HIV occurred largely within the gay community in the US. However any attempt to address HIV from a health/behaviour change perspective in developing countries immediately reflects a lack of recognition of other important contextual factors.

In an attempt to combat risky sexual behaviours, Western countries adopted strict stages of change or linear models for changing behaviour. These models were based on the understanding that people are given knowledge that changes their attitude and it was assumed that a change in attitude would change their practice/behaviour. Commonly known as knowledge, attitude and practice, or KAP studies, these health theories came under extensive criticism. Their application in developing countries, where the spread of HIV was rapid, was increasingly seen as problematic. A number of critics of the predominantly Western theories of behaviour change have noted that behaviour change does not occur in isolation, but within a framework of various factors such as the individual, the community and society. Studies around HIV and AIDS over the years have shown that the pandemic is a social condition more than an individual problem, hence a more social approach is needed to combat it (Ford et al, 2003; Airhihenbuwa & Obregon, 2000; UNAIDS, 1999; Singhal, 2001).

This chapter explores the diffusion or top-down strategies and participatory approaches as a background which brings perspective when understanding the complexities of HIV and AIDS as a health problem within a development problem. However, addressing HIV and AIDS is often not always about seeing it as a health issue or a development issue, but rather as a context-specific issue.

Addressing HIV and Development Problems through Interventions

The words 'public health' and 'intervention' are often knitted together. Every public health problem requires an intervention through an appropriate channel, offering a specific message. HIV and AIDS, in particular, is a public health and development problem (O'Manique, 2004), and requires various types of educational or biomedical interventions that encourage prevention, treatment, care and support for those infected. Every HIV and AIDS situation therefore calls for an intervention through a communication channel such as the use of the media, marketing, participatory mediums, advocacy or social mobilisation to communicate a specific message to address HIV-related problems. Interventions are therefore a way of intervening where the goal would always be to change or influence a person, a situation or a social institution (Guttman, 2000), using communication as a means to facilitate change either through reducing bad health practices or encouraging good ones.

Communication is not an isolated activity but instead a process of converting the national health strategy, in this case for HIV and AIDS, "into tangible interventions that affect people's lives" (McKee et al, 2004: 54). Communication is also a key component of programmes developed to address a range of social and infrastructural issues in developing countries (Morris, 2003). Interventions also have a strategic communication process that informs the research, development and implementation of a programme, campaign or intervention.

Chapter One of this thesis commences with Forman's statement that information and communication are the only two abundant resources available, describing them as requirements and enablers to address HIV and AIDS in the region (Forman, 2005: 172). This suggests that beyond the use of communication as channels of sending and receiving information, it is a resource to facilitate effective responses to address issues of HIV and AIDS. Communication, in this sense, allows for ongoing dialogue and becomes a medium beyond the transferral of messages, to discussions about responses and messages. Parvanta (et.al, 2011) contributes to this discourse and confirms that communication can be used as a medium to discuss specific issues related to health problems, and takes a step further to highlight that it has a final goal of "translation of science into practice" (2011: 84). This suggests that

communication extends beyond transferral of knowledge and discussions about HIV and AIDS, but also facilitates changes in behavioural practices. Therefore, communication has the ability to link “epidemiological research and social science research in planning effective communication interventions while ensuring quality service delivery” (UNICEF, 2005:1).

The chapter highlights the difference with communicating for development within a diffusion perspective, and communicating for participatory development where participation is central in HIV and AIDS interventions. Through a discussion on the use of mass media or participatory interventions, the chapter makes an argument for the active participation of young people in the development of HIV related projects (refer to Chapter Five).

What is Development?

“The conventional definition of development means bridging the gaps, by means of imitation processes, between traditional and modern, retarded and advanced, or barbarian and civilized sectors and groups, to the advantage of the latter” (Servaes, 1999: 19). Servaes (1999) refers to development as one of the oldest ideas of the West, where it has been traditionally equated with growth. The genesis of the field of communication and development lies in the organised development assistance programmes following World War II (Melkote & Steeves, 2001). Nora Quebral says that if she was pressed for a definition of development communication that she would argue that it is “the art and science of human communication applied to speedy transformation that makes possible greater social equality and the larger fulfilment of the human potential” (Quebral, 1971/2006: 101). Silvio Waisbord (2001) links the origin of development communication to the post-war theories of development and social change. These theories perceived global problems in terms of the absence of progress in the developing world, similar to that in the Western societies.

From the outset, ‘communication for development’ (sometimes referred to as ‘development communication’) has been a strategic process tool to persuade people to change and to improve development processes (Tufte & Mefalopulos, 2009). Development should aim to enrich the lives of individuals by widening their horizons and reducing their sense of isolation. It reduces the afflictions brought on by disease and poverty by not only increasing life spans, but also improving the quality of life (Stiglitz, 1998). Hence, development is seen as a form of transition and growth, and a medium for change to achieve better social, economic and cultural conditions.

Central to the context of development is the transition in defining participation. Modernisation defines participation based on American historical experience and political theory predicated on this experience. Post-modernisation definitions go beyond representation of the masses to focus on social change and an emphasis on self-reliance as an outcome of the development process (Jacobson, 2008: 61). The early 1960s associated development with 'modernising the traditional' and transferring Western ideas and technological advances to Third World countries. In stark contrast, development defined in the health context today is a move away from a focus on individual behaviour change to social change, where emphasis is placed on the role of the community, society and social networks. This emphasis on social structures and cultural influences in addressing development results in effective responses to HIV and AIDS prevention. However, the application of real forms of participation by communities still remains a challenge. Nancy Morris suggests that the field of development communication is dominated by two conceptual models, diffusion and participation. The rest of this chapter discusses diffusion under the section of communication for development and issues of participation under the section of communicating for participatory development. Diffusion or modernisation and participation have "distinct theoretical roots and differing emphases in terms of program designs and goals" (Morris, 2003: 225).

This history of development confirms that the field of development communication is commonly perceived from a Western perspective, as beginning with modernisation and later evolving towards participatory communication. However, Linje Manyozo (2006) suggests that development communication is not a 'homogenous' field that is developed in the same way across the world: "due to geographical, cultural, colonial and historical differences, different development communication evolved differently in various parts of the world" (Manyozo, 2006: 94). Therefore, while this chapter discusses the development communication field from a diffusion or modernisation perspective and then proceeding to the participatory perspective, it is important to remember that development communication is a dynamic, versatile field with a diverse past that develops and emerges differently in various contexts.

Communication for Development

The ongoing transferral of Western ideas manifested through modernising the communication responses to health issues such as HIV and AIDS. Western societies attempted to modernise African countries through mass media interventions, challenging behavioural practices to address HIV at the individual level. The diffusion model, derived from the work of Everett Rogers (1962), places emphasis

on behaviour change of people by providing new information and knowledge, which is the goal of a communication campaign. This process is often facilitated by mass media through the transferral of specific messages for behaviour change. This diffusion model is usually facilitated through strategies of social marketing or entertainment education (Morris, 2003).

The modernisation approach discarded the complexities that arise when addressing the pandemic in Third World countries, with further negligence of the real social and cultural contexts within specific countries. The paradigm drew on a “stereotypical view of traditional individuals” and suggested that their so-called backwardness, laziness and ignorance were the fundamental cause of underdevelopment (Melkote & Steeves, 2001: 90). Individuals and their traditional cultural values are blamed, rather than taking into account infrastructural and political factors.

In the context of HIV and AIDS, individuals are perceived to be in a position to make rational decisions, where communicating safe sexual choices would transform the individual into a modern citizen, aiding the process of communicating and responding to HIV prevention. The mass media was perceived to be instrumental in achieving this goal, aimed at individual change in attitudes and behaviour with the assumption that media messages had a powerful impact in underdeveloped societies (Servaes, 2008; Coulson, 2002). Communication was seen as a pivotal component of development, and crucial to modernise the behaviour of those affected and infected and to address the challenges of HIV and AIDS.

Behaviour change communication (BCC) was the initial strategic response to promote positive health outcomes, based on proven theories and models of behaviour change. The use of preferred models and theories for addressing the behaviour of young people, rather than using theories that were context specific for the sexual practices of young people, was reflective of the modernisation paradigm, which was very top-down and prescriptive in its application. BCC therefore employs a systematic process beginning with formative research and behaviour analysis, followed by communication planning, implementation, and monitoring and evaluation (Piotrow et al, 1997; HCP, 2003). The problem, however, is that BCC often poses certain linear, rational, logical flow models to encourage sexual behaviour change for HIV prevention that is often a non-rational, multi-factor process (Parker, 2004; Airhihenbuwa & Obregon, 2000; Mulwo, 2009; Govender, 2011; Moodley, 2007). Behaviour change theories are limited by a range of conceptual and contextual factors. These factors do not negate the value of ‘choice-based’ behaviour change approaches, but there has been an over-reliance and over-investment in ‘behaviour change communication’ (Parker, 2004).

Airhihenbuwa and Obregon (2000) argue that the flaws in the application of commonly used “classical” models in health communication are a result of contextual differences in locations where these models are applied. They propose that HIV and AIDS communication strategies should be grounded in sound theory where the resulting framework is flexible enough for application in different regional and cultural contexts (see also Kunda & Tomaselli, 2009). This important criterion places emphasis on messages that are sensitive to the local culture and contextual factors, the size of the group that is being worked with and how these respondents can engage and contribute to the development of health programmes. The challenges of modernisation and the focus on very prescriptive models and theories for addressing issues of behaviour, without taking into account the social, cultural and contextual factors that influence sexual practices, is evident in the examples provided below of poor or unsuccessful interventions in South Africa.

HIV Interventions within a Communication for Development Framework

The controversial HIV and AIDS play *Sarafina II* was a landmark in terms of top-down behavioural change communication programmes. *Sarafina II*, launched in 1995 at an enormous cost of R14.2 million, was a musical play intended to tour the entire country. It generated a huge outcry around the appropriateness of its message, since many believed that the play promoted teenage promiscuity, leading to immediate withdrawal of the contract (Phila Legislative Update, 1996). While responding to criticisms about the content of the play, the then minister of health, Dr Nkosazana Dlamini-Zuma, reiterated that it was not aimed at promoting sex and promiscuity among teenagers, but at communicating the message that ‘if you can’t abstain, use a condom’. This argument appears to draw from the ‘Abstain, Be Faithful, Condomise’ strategy founded on individual-centred psycho-social cognitive theories. It draws on psycho-social and cognitive approaches with the aim of educating individuals about practical skills to reduce the risk of infection (Kalichman & Hospers 1997; McKee, 2004).

Early HIV and AIDS initiatives failed in the African context as they were created for a Western context, where individualism instead of community orientation was favoured (Airhihenbuwa & Obregon, 2006; Rawjee, 2002). The emphasis on interventions and prevention programmes towards “knowledge and behavioural change ignore the influences of social and cultural discursive fields” (Baxen & Breidlid, 2009: 12) in which young people receive and make sense of HIV and AIDS messages and then internalise these messages through their own social constructions.

The *loveLife* billboard campaign is another illustration of ineffective BCC campaigns in South Africa. *loveLife* was launched in 1999 with a target of reducing HIV infection among 15–20 year olds by 50% in five years. To achieve this, *loveLife* purports to use “youth-focused television and radio programming, magazines and billboards to promote sexual responsibility and to link young people to counselling and clinical services” (*loveLife* n.d.). The *loveLife* 2003 billboard campaign was found to be ineffective, as it used branding as an instrument to change behaviour without taking account of significant variances in culture, religion, belief systems and socio-economic contexts in South Africa (Jordaan, 2006). Richard Delate (2007) argues that the branding strategy employed by *loveLife* not only proved ineffective, but actually produced negative consequences: “the representation of the *loveLife* lifestyle brand has given rise to a brand identity that positions adolescent sexuality as something that is cool and that everyone is engaged in” (Delate, 2007: 4). These unintentional consequences stemmed from the fact that *loveLife* did not take into consideration the process of active interpretation and decoding by readers.

By failing to engage in consultations and dialogues with its target group, *loveLife* was ignorant of young South Africans’ perceptions and opinions. The semiotic failure of this particular HIV and AIDS campaign suggests the importance of involving the beneficiary community in health and development efforts. While *loveLife* was criticised for its public relations self branding exercise and its use of sex, consumerism and product advertising (Tomaselli, 2011; Delate 2007; Kunda 2009; Govender 2011; Jordaan, 2006; Parker, 2003), other studies conducted failed to engage and acknowledge this previous research by its uncritical adoption of consumerism in *loveLife* (Irwin, 2003, see also Tomaselli, 2011) Given the initial criticism of *loveLife*, the intervention is included as a sample organisation in this study to revisit its communication programmes.

In the cases of *Sarafina II* and the *loveLife* campaigns, the conditions under which these behavioural change theories have been used from a modernisation perspective, through the awareness and BCC campaigns, had minimal impact on the South African HIV epidemic (McKee et al, 2004). With the South African government’s negative experiences with ‘Western’ public health campaigns, leaders instead emphasised the need to find African solutions to African problems (Youde, 2005).

Critics of the modernisation paradigm suggest that the top-down flow of communication did not aid the development of HIV and AIDS interventions as it lacked an in-depth knowledge of the true challenges facing the people in these developing countries (Rogers, 1969; Melkote, 1991; Servaes, 1999). Without knowledge of the audience, community consultation or participatory processes of relating HIV and AIDS information, campaigns are inevitably unsuccessful, as exhibited by *loveLife*. Effective HIV projects and

programmes therefore need to focus on local dialogue and local change where participatory approaches and interactive solutions are based on interpersonal communication (Lie, 2008).

Communication for Participatory Development

The concept of participation in development contexts, also known as *participatory communication*, developed the notion of *participatory development*. According to Nair and White (1987), participatory development communication is a two-way interaction between receivers and the source, and is often mediated by development communicators who facilitate participation of the target group. Participatory communication is viewed not only as an answer to economic development, but also as being crucial in facilitating better learning and the development of critical thinking and critical consciousness. It emphasises a move away from the top-down, one-way flow of communication from the sender to the receiver, to a more interactive dialogue – a communication process that facilitates discussion. Feedback is a fundamental aspect of this model, as the people involved have the ability to discuss, negotiate and make collective decisions.

Participatory communication is commonly associated with the Brazilian educator Paulo Freire and his writings on critical pedagogy. While Freire's focus was directly on education, his ideas have been related to human development in a more holistic sense and have been adapted to suit a much broader development context. Freire (2002) suggests that critical thinking can be developed by democratic participation, and therefore active participation is at the heart of many areas of development. Participation in development communication means that there is a horizontal process of information exchange instead of vertical processes of information transmission. Through the horizontal process, the "purpose of development is to empower people to have greater control over decision making" (Morris, 2003: 226).

The communication for development and communication for participatory development perspectives brought about challenges when developing HIV interventions, as seen by some of the examples in South Africa. However, the theoretical and empirical convergence between the dominant and participatory paradigms is evident in the *communication for social change model*, later called the *communication for participatory development model*, where the media can act as a catalyst for social change in communities (Waisbord, 2001; Figueroa et al, 2002; Kincaid et.al, 2009). Summarising the contrasts and contributions of these theories, Figueroa and colleagues comment:

The call for a model of development communication based on dialogue versus monologue, horizontal versus vertical information sharing, equitable participation, local ownership, empowerment, and social versus individual change continues to be heard and if anything, has grown stronger with the rapid decentralization of authority and increased access to new communication technology that occurred during the 1990s (2002: 3).

HIV Interventions within a Communication for Participatory Development Framework

Communication has over the decades developed to also cater for participation despite the existence and application of the dominant modernisation paradigm today. Participatory approaches strongly promote “the opening of dialogue, continuous source and receiver interaction, thinking constructively about the situation, identifying developmental needs and problems, deciding what is needed to improve the situation, and acting upon it” (Nair & White, 1993: 51). These elements, often described as ‘ideal’ or ‘genuine’ participation, are not only associated as an answer to economic development, but also crucial in facilitating better learning and the development of critical thinking and critical consciousness.

The progression from the top-down, linear flow of communication to more interactive dialogue, is supported by many scholars as key to facilitate discussion amongst the communities involved in the development process (Kincaid, 2009; Freire, 1976; Crotty, 1999). Central to this discussion is the feedback where people involved have the ability to discuss, negotiate and make collective decisions. Communication programmes or interventions to address issues of HIV that are created by ‘experts’ and then transmitted to the audience in a one-way, linear manner are doomed to fail (Forman, 2003; Ford et.al, 2003; Govender, 2011).

When students at the University of KwaZulu-Natal in South Africa were questioned about their perceptions of South Africa’s *Abstinence, Be Faithful, and Condomise (ABC)* campaign, 91% suggested the importance of young people being active participants in HIV and AIDS communication (Govender, 2010). The importance of participation of young people was also identified in the Mulwo (2008) and Kunda (2009) studies as being pivotal to developing HIV programmes that address young people’s sexual practices. The Govender (2010) study indicated that students did not support or relate to the ABC campaign because they believed that its contradictory and confusing messages stemmed from a failure to have engaged or consulted with them as the target audience (Moodley, 2007; Govender, 2010; Moodley, 2012). Communication programmes must be developed with participant involvement and dialogue around HIV related issues, and this is evident in some projects and

programmes that either use only participatory approaches or an integrated approach of media and participatory engagement with people. This is evident in the work of *Soul City*.

Over the years, *Soul City* developed its programme to encourage community engagement, advocacy and empowerment. *Soul City's* work with South Africa's Domestic Violence Act illustrates the importance of partnerships, including direct lobbying of government, community mobilisation and media advocacy, which all contributed to bringing the Act to a speedy reality (UNAIDS, 2007). While the field of development communication tends to be dichotomised along the lines of a top-down mass media approach versus a participatory interpersonal communication approach, the two do not necessarily exist on opposite ends of a spectrum (Morris, 2005). *Soul City* has been one of the pioneers in terms of creating development synergy by simultaneously employing the mass media and more participatory grassroots approaches (Tufte, 2001). For example, the television series has proven to be a conversation stimulant, encouraging families and peer groups to engage in dialogue regarding issues depicted on the series (Gumucio Dagron, 2001).

The selection of the appropriate communication channel to reach the correct target audience has significant value when developing effective communication strategies for HIV and AIDS communication. While radio and television can play a pivotal role in relating correct and consistent prevention messages, this must be identified by the target audience, in this case young people, as the most effective communication channel to achieve the desired outcome (Govender, 2011). Whilst the selection of the correct channel is crucial, the type of approach or rather the focus of the HIV message also plays a pivotal part in developing effective HIV programmes or programmes.

The late 1990s unveiled new attempts by the South African government to introduce a communication approach to HIV and AIDS. The Beyond Awareness Campaign (BAC) (1998–2000) was an attempt to move beyond the focus on awareness and individual behaviour change favoured by most HIV and AIDS communication programmes in South Africa (Soul Beat Africa, 2003; Tomaselli et al, 2002). BAC employed a multimedia approach that encouraged social action, rather than simply relying on the mass media to stimulate individual change (Parker, 2000). One of the campaign's projects, the AIDS Memorial Quilt, encouraged community participation by the creation of quilts in order to address and reduce the stigma surrounding AIDS, promote more dialogue regarding the pandemic and pay tribute to those who had succumbed to the virus. Rather than persuading people to simply change their behaviour, BAC encouraged community involvement. Conceptual and contextual factors were taken into consideration and reflected in the campaign's design and its facilitation at the community level. The

traditional individual, didactic process of HIV prevention was realigned to community involvement and including audible voices in addressing the pandemic (Tomaselli et al, 2002).

The growing realisation of an emphasis on context and audience involvement in HIV and AIDS campaigns was demonstrated through the work of the Treatment Action Campaign (TAC), established in 1998, that advocated that individual behaviour change is not sufficient unless accompanied by collective social change (Kincaid et.al, 2009). The TAC has been responsible for addressing issues of access to treatment, by advocating for increased treatment roll-out, offering care and support services for people living with HIV and developing campaigns to reduce new HIV infections (TAC, 2009). The importance of the TAC's work is its focus not only on individual behaviour change, but also on greater social change to combat the HIV and AIDS pandemic. The TAC's work was also indicative of a profound shift in addressing HIV and AIDS and the relevance of culture, society and community in bringing about change. This shift highlighted the need for context-specific approaches and in some instances nullified the efforts of BCC approaches (Cullinan & Tom, 2010).

The *Scrutinize* campaign, launched in 2008, is one of the latest HIV and AIDS communication programmes and “examines transactions among people within their social and physical settings, over time and across several levels of analysis: personal, familial, cultural and institutional” (Panter-Brick et al, 2006: 2811–12). The television campaign consists of seven ‘animerts’ (animated adverts) aimed at promoting awareness and behaviour change while also encouraging grassroots participation. Through its facilitators’ guide, communities are provided with a toolbox to help them engage in participatory HIV and AIDS interventions using arts, culture, drama and/or discussions in small groups (*Scrutinize*, 2009). The campaign is a result of numerous national surveys conducted to understand South African sexual practices. Each message of the campaign reflects the multiple contextual factors that need to be considered for HIV prevention and is rooted in multiple levels of advocacy, community intervention and interpersonal communication. As a result, *Scrutinize* encourages participation on a social level, by exploring how some of the social influences contribute to the decisions young people make at an individual level.

The complex nature of HIV and AIDS calls for multidimensional strategies for prevention, moving away from conventional awareness campaigns, that are deeply embedded in individual behaviour but moving towards recognising the importance of collective cultural norms through socially accepted behaviour, traditional practices and culturally mandated taboos (Somma et.al, 2003:4-5). The importance of exploring the wider socio-ecological framework in which people make choices is evident in the

television series, *Intersexions*. *Intersexions* is a unique episodic drama series produced by Curious Pictures and Johns Hopkins Health and Education in South Africa (JHHESA) which follows an HIV and AIDS infection chain through 25 inter-connected but independent stories with the final episode bringing all the storyline together. A reception analysis study conducted on the television series, by UKZN postgraduate students indicated that the series was successful in initiating dialogue and discussion beyond the screening of the television series, and was therefore able to diffuse ideas, contribute to social learning, increase positive behaviour outcomes and serve as vehicle of communication and knowledge exchange (Govender et al, 2013). The series was also able to continue discussions about the HIV storyline beyond the medium of television, to social media, such as Facebook where further discussions continued about pertinent HIV issues and young people's perceptions on these various issues (ibid).

The various discourses surrounding HIV and AIDS communication, with questions around the type of channel, mass media or participatory, and the message, behaviour change or social change messaging, indicate that HIV projects and programmes should be participant specific and must reflect the common challenges and lived experiences in a particular community. Similarly, Kunda and Tomaselli reiterate that "effective health communication depends on understanding the knowledge, attitudes and practices of people from given cultural vistas" (2009: 96). They highlight a case in South Africa, where words such as "BMW Z3" and "Channel O" are used to describe HIV, as this luxury car and music channel depict a modern, consumerist lifestyle, thus establishing an association with the virus (Kunda & Tomaselli, 2009). Whilst behaviour change programmes on their own pose crucial challenges in light of the modernisation era, a holistic approach that considers all conceptual and contextual factors will promote the success of any response to HIV and AIDS.

The various discourses surrounding HIV and AIDS communication, suggests that HIV programmes and programmes need to introduce context specific communication for HIV prevention which reflects the common challenges and lived experiences in a particular community. The case of South Africa demonstrates the need to recognise the importance of context specific approaches for HIV prevention strategies. Amidst many conceptual factors that influence the silencing of young people's voices, the programme and message design needs to be renegotiated.

Importance of Context

In tracing the transitions of the communication for development paradigms and the parallel impacts on HIV and AIDS communication, the importance of context is central to all critics of these transitions. The transition from modernisation to the empowerment era of development highlights the importance of the participation of communities involved in addressing development. It also influenced the change from behaviour change communication to social change communication, with the need for actively engaging all participants in the research, development and implementation of HIV and AIDS initiatives.

This level of participation still poses a challenge for addressing HIV and AIDS today. While cultural, social and political contexts are crucial, the overall context of participation must be taken into consideration. UNAIDS (1999) makes a plea for a new context-based direction for communication and proposes five domains of contexts: government policy, socio-economic status, culture, gender relations and spirituality. It is vital that the HIV pandemic should be approached from an understanding of all these contexts, but especially within the ever-growing need for participatory communicative responses.

HIV and AIDS communication in Africa therefore requires a move away from debates about whether HIV is a health-related problem or a development problem. Consideration of all the contextual and conceptual factors affecting the HIV pandemic has not combated the spread of HIV, resulting in a call for health practitioners and researchers to review the real context. This real context is participation, and it is necessary for us to review, recognise and apply genuine participation (Govender, 2010). The ongoing agenda setting by donor agencies, challenges the freedom of programme implementing organisations to address the needs of their respective communities, and this therefore epitomises the recurrence of the modernisation era in what appears to be an empowering development era supposedly characterised by dialogue and diversity. Amid many conceptual factors that influence the silencing of the African voice, the issue of how to achieve participation needs to be re-negotiated.

While there have been tremendous shifts in development communication over the last few decades, approaches to health communication were also undergoing extensive shifts, especially in the approach to HIV and AIDS. A fundamental entry point to understanding these shifts over time is provided by a brief examination of how HIV and AIDS messages have been communicated in South Africa over the last 20 years, with a special focus on successes and failures in communication strategies and messaging. As South Africa is a regional economic power, trends occurring in this country symbolically

impact Southern Africa as a whole, much like the way in which US trends influence the world (Tomaselli, 2009: 571).

Conclusion: The Continuing Challenge of Achieving Participation

The concept of participation still remains a challenge across the transitions from modernisation, to empowerment and behaviour change, to social change communication. The influence of government, donor agendas and the communicative process further contributes to the multiple conceptual and contextual factors that need to be considered for the success of HIV and AIDS prevention strategies. Participation has to re-emerge as the focal point in development and health communication. One of the central issues is to encourage the participation of people in the planning, design, implementation and/or evaluation of the intervention. The 'context' of participation lies at the heart of all the other contextual factors, as cultural, political and social forces all influence how and to what extent participation can be achieved.

The real context is thus the success that real participation can bring to various specific HIV and AIDS contexts. Depending on the particular case at hand, HIV prevention initiatives may be able to achieve true participation and success by combining participatory methods of community dialogue and empowerment with mass media approaches and other forms of informational and motivational communication and advocacy. The goal of such initiatives is to act as a catalyst for action and social change at the individual, community and policy levels (UNAIDS, 2007).

Programmes addressing social, health and development issues need to adapt their approaches to include participants by allowing young people to actively engage in all processes. This would mean that instead of facilitating workshops with young people, we learn to communicate with them, instead of talking at young people, we learn to talk with them, and instead of pushing solutions through our interventions, we learn to listen to their views. The next chapter discusses why participation is important, some models of participation, how participation is used with young people and how participatory communication processes can lead to better HIV programmes. This will be done through discussions of some projects where youth participate in the research, design, development or facilitation of HIV or public health related programmes.

CHAPTER FIVE: YOUNG PEOPLE'S PARTICIPATION IN COMMUNICATION PROCESSES: PARTICIPATORY PRACTICES AND PROBLEMS

Introduction

The previous chapter discussed communication for development, specifically exploring participation in HIV and AIDS programmes. This chapter argues in favour of young people's participation in the various phases of developing HIV projects or programmes. These phases include participation in the research, design or development and implementation or facilitation of a HIV related programme. Through a review of participation in these phases, this chapter provides an argument for participant-informed programme development.

The chapter begins with an exploration of the meaning of participation and moves on to discuss the importance of participation for young people. A review of some models of participation is conducted later in the chapter to explore the processes that need to be followed for youth to participate. The section that follows will firstly outline what the literature says regarding participation, followed by various studies that examine young people's participation in the research, design and implementation of programmes. This literature review highlights either the active participation of youth or the lack thereof within these three categories. On a broader level, this study tries to explore participation on all levels since it links participation in various phases of developing HIV programmes with the use of non-conventional research methods such as bodymapping to encourage participation with young people.

Exploring the Meaning of Participation

In order to explore young people's participation in the various phases of developing HIV related programmes, it is imperative to firstly define participation. Participation has become a widely used concept in mainstream development since the end of the 1970s, with Cohen and Uphoff (1980) suggesting the need for "clarity through specificity" when talking about participation. The term has been loosely applied to indicate inclusion of people in development projects. Participation has also become a politically correct terminology used in many development projects to secure donor funding, as it indicates beneficiary involvement in the deliverables of that project (Lubombo, 2011). This questions the nature of beneficiary involvement or participation in programmes. The literature demonstrates

numerous inconsistencies in how participation is defined and what participation really means (Cornwall, 2003; Cohen & Uphoff, 1980).

Some academics argue that participation is “the opening of dialogue, where the source and receiver interact continuously, thinking constructively about the situation, identifying developmental needs and problems, deciding what is needed to improve the situation, and acting upon it” (Nair & White, 1993: 51). Participation can also refer “to the process of sharing decisions that affect one's life and the life of the community in which one lives” (Hart, 1992: 5). Thomas Tufte and Paulo Mefalopulos define participation as “the involvement of ordinary people in a development process leading to change” (2009: 4). What these three definitions outline is the process involved in attaining participation, the importance of shared decision-making and the need for people to participate in processes of participation. This suggests that young people will need to be agents of change in the process of development programmes, rather than being led by outside agents (Servaes, 1995; Servaes & Malikhao, 2005). The active participation of people in development processes requires the integration of communication mediums either through media or community efforts to stimulate a process of engagement. Guy Bessette describes participatory communication, in particular, as a “planned activity, using local media and dialogue amongst various stakeholders about a common problem or shared goal to develop and implement activities that contribute to its solution” (2004: 4).

The focus on dialogue in the participatory paradigm is influenced by the pedagogy of Paulo Freire (2002). Freire calls for individual participation of learners in the learning process in order to empower them through the development of critical thinking. His pedagogy centres on the notion of critical consciousness, which he asserts can be developed by democratic participation. Conscientization is a process of developing consciousness, but consciousness that is understood to have the power to transform reality (Taylor, 1993: 52). Participation in this sense requires the involvement of people who are directly affected by an issue to define the problem, and to identify steps to resolve that problem (Thompson & Kinne, 1990).

Central to the idea of participation are the principles of ownership and empowerment. The principle of ownership is closely related to participation, as ownership is about youth taking responsibility for and control over the process of change. Thompson and Kinne suggest “change is more likely to be successful and permanent when the people it affects are involved in initiating and promoting it”, suggesting the importance of a people-centred approach (1990: 46). Empowerment provides young people with the opportunities and resources to actively address their own needs and to advocate for

their own social change (Waisbord, 2001). The empowerment of youth is often one of the reasons for their inclusion in designing programmes.

Participation: Why Involve Young People?

There is a difference between participatory research 'with', and participatory research 'on', young people. Specific characteristics of participatory youth projects indicate that young people must participate in all aspects of the research. This promotes a co-learning process between youth and researchers, that involves an enabling and reflective process towards critical consciousness, where there is a balance among the goals of research, action, and evaluation (Wang, 2006). Young people have "powerful statements to make about their own situations, their narratives are powerful: they are insightful; they are veridical; they are deeply engaging; and most importantly, youth have stories that can inform theory and practice" (Cameron & Theron, 2011: 205). This suggests that young people's participation in HIV programmes contributes to what we understand about their experiences in practice, and how this is formulated into theory.

The essence of youth involvement is a partnership between adults and young people. Organisations generally have three attitudes towards youth, they see 'youth as objects', where organisations and professionals know what is best and they attempt to control situations in which youth participate. 'Youth as recipients' is when organisations/professionals dictate terms of involvement and do not allow for meaningful participation; and finally 'youth' as partners are those who respect young people and believe that they have a significant contribution to make. Youth need to be seen as people who have an equal voice, because everyone has a right to engage in critical discussion about their social reality (Freire, 1976). This thesis works with young people as partners to explore how they can contribute to the development of HIV programmes by actively participating in the various phases of developing HIV related projects.

The Importance of Partnerships in Participatory Processes

Programmes developed in partnership with young people and adults are effective in building their skills towards the reduction of sexually risky behaviour (Klindera & Menderweld, 2001). The study conducted by Powers and Tiffany (2004) across four youth programmes indicated that young people can be engaged on multiple levels of participation that include consultation, partnership and leadership. A review of four projects suggest that having adults listen to young people gave them an "increased sense of agency and personal efficacy", the youth were also mobilised beyond "leading the

implementation of different aspects of projects but also in using the results for action planning, and organizational or policy change (Powers & Tiffany, 2004: 85). Powers and Tiffany argue that the processes of research are enhanced through youth participation, especially when traditional methods cannot solicit the information required for developing an effective programme.

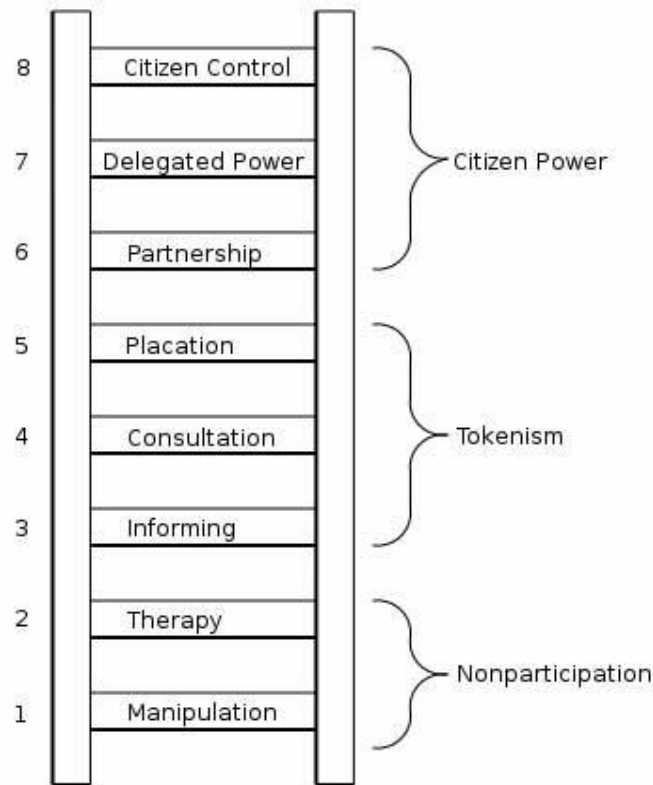
Extensive research conducted in several projects by Nygreen and colleagues, however, indicate that youth and adult alliances are often termed as “youth-led” and “youth-initiated”, when in practice these are developed through adult participation (Nygreen et al, 2006). Hence there is a risk that their involvement can be limited when adults develop projects based on the data they collect from young people without incorporating their views into the design and implementation of programmes (Nygreen et al, 2006; see also Parker 1997). Whilst their study demonstrates the importance of participatory research with youth, it also indicates that adult allies affect the level of participation. The section below explores some of the models used when working with youth to determine what level of engagement constitutes participation.

Models of Participation

The discussion below presents some of the most frequently identified models or typologies used or quoted in literature regarding levels of participation. For the purpose of this study, only three typologies will be discussed as they have direct relevance in their application to this study.

Typologies of participation make reference to the various “degrees and kinds of participation” (Cornwall, 2008: 270). These typologies usually carry normative assumptions that place participation along “an axis of good to bad” with many typologies and ladders of participation focusing on the i) intentionality, ii) associated approach and who iii) initiates participation (ibid). Andrea Cornwall (2008) and Emma Durden (2011) highlight the work of Arnstein (1969) as developing one of the most well-known and first typologies of participation that places the various levels of participation on a progressive ladder. The ladder starts with the lower rungs demonstrating non-participation and progresses up the ladder to tokenism and finally citizen power. Consultation usually sits on the levels of tokenism (consulting, informing, and placation) on the ladder of participation (Arnstein, 1969), is seen as a means of “legitimizing already taken decisions”, where outcomes are “selectively read and used by those with the power to decide” (Cornwall, 2008: 270). Figure 3 **Error! Reference source not found.** below is the ladder of participation developed by Arnstein (1969) that offers an eight rung progression to participation.

Figure 3: Ladder of Participation developed by Arnstein(1969)

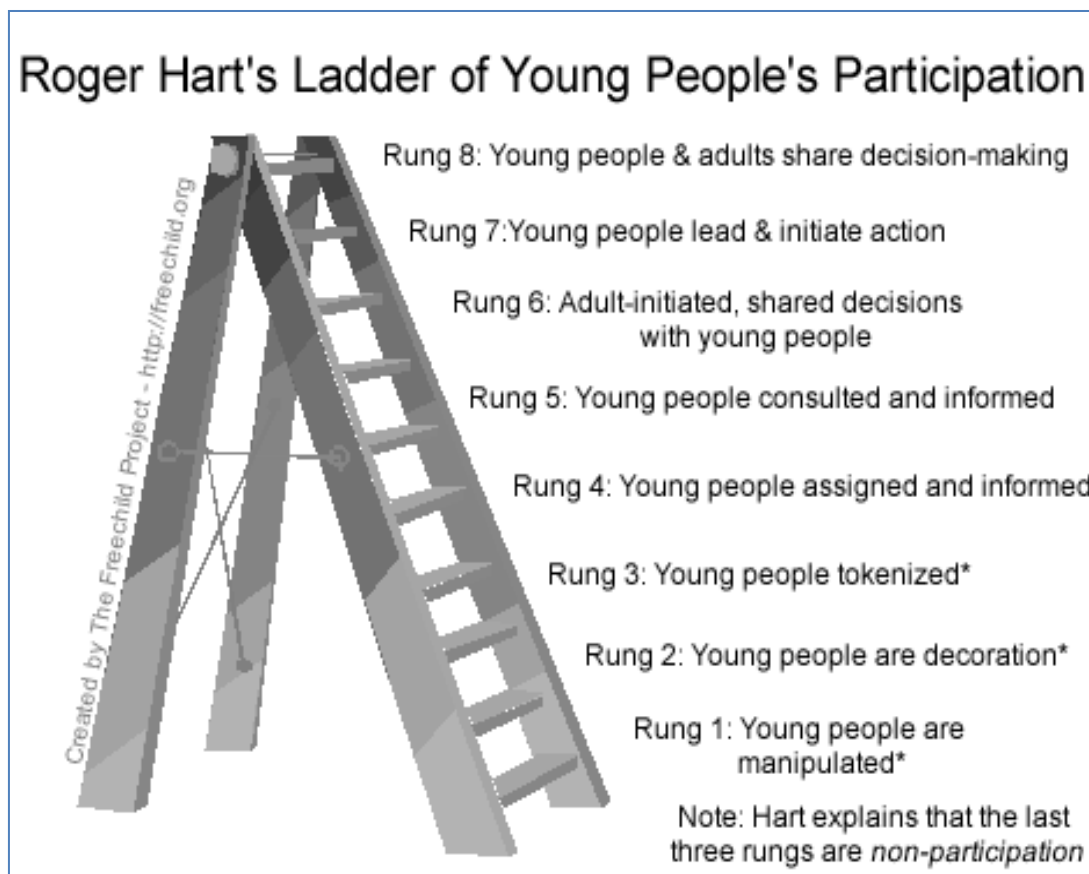


Whilst the ladder offers a step-by-step progression up the ladder, indicating that as you move lower down the ladder young people have less control over their inclusion and decision-making, and as you move up the ladder, the level of control and inclusion increases. Arnstein advocates for citizen power through participation that must ultimately result in citizen control (Choguill, 1996). Thus, Arnstein defines the concept as “the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future” (Arnstein, 1969, in Sulemana & Ngah, 2012: 29). Participation according to Arnstein was therefore designed to focus on the redistribution of power which according to Sulemana and Ngah is an important element for meaningful participation (ibid).

Another well-applied model of participation and empowerment for young people is that of Roger Hart (1992). While the work of Arnstein (1969) was specially developed to understand the levels of participation in general, the work of Hart was developed to specifically apply to youth participation. Hart built on the work of Arnstein’s ladder of participation with a revised eight levels that reflect the first three

levels as non-participatory. Hart argued they serve adult purposes of being seen to consult or involve young people, but in reality they afford no real opportunity to participate (see also Tomaselli, 2007). The top five rungs of the ladder represent increasing degrees of participation (Howard et al, 2002). Figure 4 below is the ladder of participation developed by Roger Hart (1992).

Figure 4: Ladder of Participation developed by Hart (1992)



Hart's ladder of participation is often criticised for its very linear or hierarchical nature with the assumption that lower degrees of participation which are equated to tokenism and manipulation are less valuable than higher levels of participation (with young people's decision-making) (Heath et al, 2009; Barber, 2007; Kirby et.al, 2003) The rungs lower on the ladder suggest this lack of participation. While the typologies offered by Arnstein and Hart differ, both position the levels of participation from the target audience or beneficiary perspective. This does not cater for the power relations or the participants that have to release or hand over control. The typology proposed by Jule Pretty (1995) explores participation from the perspective of those who are the users or apply participatory approaches. Sulemana and Ngah (2012) argue that even though Pretty offers a different perspective, it

is still a normative form of participation that places participation as a progression from bad forms of participation to good participation.

Below is the typology of Jules Pretty which focuses on various types of participation. The first four describe the participant perspective, where they are either manipulated and have no power (manipulative participation), are passive and are told what to do (passive participation), they are consulted but do not engage in any decision-making (participation by consultation) or people participate for material benefits or resources (participation for material incentives). The next three types of participation suggested by Pretty are positioned from the external agents or the implementers, suggesting considerations for participation not from the audience perspective, but from the user perspective.

Table 4: Types of participation by Jules Pretty (1995)

Typology	Characteristics of Each Type
<i>1. Manipulative Participation</i>	Participation is simply pretence, with people's representatives on official boards but who are unelected and have no power.
<i>2. Passive Participation</i>	People participate by being told what has been decided or has already happened. The information being shared belongs only to external professionals.
<i>3. Participation by Consultation</i>	People participate by being consulted or by answering questions. External agents define problems and information gathering processes, and so control analysis.
<i>4. Participation for Material Incentives</i>	People participate by contributing resources in return for food, cash or other material incentives.
<i>5. Functional Participation</i>	Participation seen by external agencies as a means to achieve project goals. Such involvement may be interactive and involve shared decision making, but tends to arise only after major decisions have already been made by external agents.
<i>6. Interactive Participation</i>	People participate in joint analysis, development of action plans and formation or strengthening of local institutions. Participation is seen as a right, not just the means to achieve project goals.
<i>7. Self-Mobilization</i>	People participate by taking initiatives independently of external institutions to change systems. They develop contacts with external institutions for resources and technical advice they need, but retain control over how resources are used.

Functional participation refers to people participating to achieve the objectives of the project or the funding or implementing agency. In this instance, people are not actually participating and participation therefore becomes a form of development support rather than empowering people (Sonderling 2008; Sulemana & Hgah, 2012). Interactive participation is where people become active participants and not spectators of participation. They are collectively participating in the planning, development and analysis of the project and take control over decision-making. Self-mobilisation, which is the last type of participation offered by Pretty, is when people control self-initiatives which are independent of external agencies or government efforts. It is a process where they are self-mobilised to acquire technical assistance and support for development or specific projects.

Arnstein's (1969) ladder of participation and Jules Pretty's (1995) typology of participation offer a shift from control by authorities to control by the people. However, Cornwall highlights an important distinction between these typologies:

What Pretty's typology helps make clear is that the motivation of those who adopt and practice participatory approaches is an important factor – if by no means the only one – in shaping interventions. And what Arnstein's remind us is that participation is ultimately about power and control (Cornwall, 2003: 271).

The early ladder of participation offered by Arnstein (1969) and the typology of participation offered by Pretty (1995) presents a progressive participation that suggests that genuine participation is not achieved unless people progress from non-participation to participation (rung 8) where they exercise all control and share in decision-making. A limitation of Arnstein's (1969) ladder of participation is that measuring participation against this ladder can bring the risk of suggesting that if young people are not engaging in all aspects of development of an HIV intervention, that they are not participating. Pretty's (1995) distinction between the types of participation also runs the risk of suggesting that the lack of participation can be attributed to the role external agents play in facilitating participation and negates the possibility that people may also choose not to participate. Secondly, Pretty (1995) describes manipulative and passive forms as types of participation, and therefore does not set them aside as non-participation.

The above typologies offered by Arnstein (1969) and Pretty (1995) pose a range of questions that aid the process of identifying the level and type of participation for young people in decision-making and power sharing. These two models also offer a balance by taking the focus away from exclusive discussions about which level young people are participating in and offers new insight, and in some cases redirects the focus to those implementing AIDS communication initiatives who need to discuss

who should hold the power, responsibility and decision-making when working with young people. It then motivates the organisation to think about the procedure that needs to be put in place to facilitate this power sharing. Pretty's (1995) typology of types of participation is central to this study for encouraging participation as it sets the focus on how to mobilise the organisation or implementing body to reconsider issues of power and conflict and set procedures to enact participation.

These various models, whilst promoting a progressive process of participation, do not explore the various stages in which participation can occur. The models therefore highlight the need for processes to facilitate participation. They also assume that people want to participate at the highest level of participation. Cornwall argues that questions of participation are more complex than simply distinguishing between "instrumental" participation (participation as a means), and "transformative" participation (participation as an ends), but extends further to questions of the intentionality of those who initiate participation or use participatory methodologies (2003: 274). It is only in establishing the desire or need for young people to participate that this ladder becomes relevant, where young people, in consultation with a researcher, can assess on which rung of the ladder they are located, before devising processes to facilitate movement to the next level of participation.

The roles of young people and researchers are dependent on a range of issues, including the timelines of the project, resources available, purpose of the research and support and motivation for participation (Heath and colleagues 2009). Using the two models to support the cyclical participatory action research process ensures that even though participation in the development of HIV projects and programmes calls for a systematic and linear process, participation can still be adapted by posing questions in a cyclical process instead of a linear step-by-step process of participation. The essence of participation for development "lies in working with citizens to determine their needs and to design and implement programmes to address their needs, rather than imposing an intervention on a community" (Morris, 2003: 226). This study recognises and favours the importance of strategic processes when working in the field of development communication.

Participation in Research, Design and Implementation of Programmes

Participation is a process where youth are mobilised to examine their lived experiences, suggest recommendations and work towards an implementation plan (Cornwall, 1992). There is an exhaustive body of literature on participation of youth in a range of development issues, but there is limited literature on how young people participate in strategic communication processes of research, design,

implementation and evaluation, particularly in the context of HIV and AIDS communication. An extensive review of the literature indicates that young people participate in one of these four phases, but their participation is not integrated into the complete strategic communication processes (Powers & Tiffany, 2006; O'Donoghue et al, 2004; Sulemana & Ngah, 2012; Olnier, 2010; Heath et al, 2009; Suleiman et.al, 2006; Campbell, 2003; Rubin, 2006).

For the purpose of this thesis, discussions about participation in communication processes that include research, design and facilitation can be considered as participatory research, participatory design and participatory facilitation. This is premised on the definition of participation that is used in this study which suggests that participation is an engaging and cyclical process where young people participate in all phases of developing HIV projects and, engage in collective dialogue about who they are, what they want and how they will get it, using participation as a tool to facilitate change.

Young people's lives have been researched by social scientists over the last 100 years. (Heath et al, 2009). Others have studied youth and offered strategies to address the various problems they face. This thesis argues that young people need to study their own lives and, collectively in partnership with adults or researchers, identify possible solutions. Youth are identified as assets rather than problems in society, based on the understanding that they have an inherent ability to share their concerns but also to identify solutions to these concerns (Olnier, 2010). Youth in this sense are empowered to participate in all phases of research, design and implementation through a process of knowledge sharing, transferral and discussion about issues that affect them, in this case HIV and AIDS.

Cohen and Uphoff further identify the importance of participation in various phases of the project cycle that include participation in decision making, participation in implementation, participation in benefits and participation in evaluation (1980). The need for participation in these various phases has a major impact on participatory planning as it increases transparency in the decision making when young people are involved in all phases of planning, and it increases accountability for their decisions. However Cohen and Uphoff (1977, 1980) fail to cover the importance of participation in research. Research or a situation analysis is a pivotal stage of the developing HIV interventions. Anne Ryan (2006) describes this as a problem setting phase where youth are encouraged to pose their own problems that can be explored collectively with others to identify possible solutions. Most young people actively engage in understanding the problem (problem setting), which can be considered as the research phase to build up further research later. This indicated that the only way for a project to be

successful is to persuade the audience to participate in the research and development processes (Sulemana & Ngah, 2012).

This thesis supports participation in all phases of communication processes; however, Cornwall observes:

Involving everyone in planning would be a logistical nightmare. Monitoring takes time and might only involve a dedicated few; implementation might involve only particular kinds of 'beneficiary'; consultation exercises can only ever reach a small proportion of the population and might aim for representation rather than coverage (2003: 280).

Hence, while this thesis explores participation in all phases of the communication process, the study is also mindful of the limitations of facilitating participation on all levels and also the realisation that participation can take place effectively in one phase, while not in others. However young people's contribution to developing HIV interventions, through learning about how to do research, design and plan a project, develop research instruments and work with data, makes them partners and co-generators of knowledge. The focus on youth informed projects and programmes does not deny the expertise that researchers have in the field, but recognises that researchers themselves cannot understand the full experiences of young people, and it is only youth themselves who can make sense of the world around them (Heath et al, 2009). This thesis therefore explores what young people understand participation to be and whether they are participating in these various phases.

Participation sometimes cannot translate to all stages of communication processes (research, design, facilitation and evaluation) and the discussions below indicate that if young people are participating at any phase of developing a project, they are in fact participating (Cornwall, 2003). This challenges the models presented by Arnstein (1969), Rogers (1992) and Pretty (1995) which position non-participation or tokenism at the lower level of the ladder, suggesting that if young people participate in only collecting data and conducting a situation analysis in a community, they are still not participating in other communication processes. Heath and colleagues (2009) argue that youth need to be identified as social actors who have a potential role to play as active partners in the process of research. This study takes a step further to explore young people's active role beyond research, and highlights the significance of their participation in other phases of developing HIV projects that include the design, implementation and evaluation phase. Below is a discussion of studies that reflect young people's participation in these various phases of research, design and implementation. Participation of youth in the evaluation phase has been left out of this chapter due the scarcity of literature available on young people's participation in this phase of projects.

Research Phases - Situation Analysis

Research is the first phase of the communication process and can also be referred to as the situation analysis that investigates what the problem is, towards understanding what is occurring regarding an issue, and what needs to happen to resolve or address it. Participatory research with young people encourages “marginalized groups to collectively study the issues and conditions that affect their health” and to employ a diverse range of methods to address these concerns (Powers & Tiffany, 2006: 79). This moves youth from a position of respondents, informants and subjects, to partners in the research process (O’Donoghue et al, 2004), where they can actively engage in providing local knowledge of their experiences towards the development of solutions to address various problems.

Participation in the research processes improves the quality of research when young people contribute through ongoing dialogue about issues that affect them; this ensures that the data is more reliable. It also improves the data interpretation as the youth who formulate the research questions are empowered to make sense of the data and identify strategies to answer them (Powers & Tiffany, 2004). A review of the literature, however, reveals inconsistencies in studies that support participation as there is an extensive body of literature that argues in favour of participation, but there is a lack of studies that demonstrate the application of participation in communication processes in particular.

In a review of literature around the participation of youth in the research phase of programme development, there appears to be several studies that support and identify the relevance of young people’s participation, but most of this participation occurs in the research phase through the use of conventional research methods such as interviews, questionnaires and focus group discussions (Heath et al, 2009). These often very didactic methods create a rigid process and do not allow for flexibility in how data is collected from young people. This does not suggest that youth need to be given complete freedom in how they address problems relating to HIV and AIDS, but rather advocates for a participatory way in which youth can be allowed to inform all processes of how programmes and interventions develop.

The focus on young people’s input in only the research phase also indicates that young people often contribute to identifying ‘what the problem is’, but not on processes of ‘how to solve the problem’. The communication for participatory development model offers a staged process which allows youth to explore who they are, what they want and how they go about to get this (Figueora et al, 2002; Kincaid, 2009). Through a process of participatory research, young people “can define their own questions, lead

the process of investigation, and create their own solutions for change, this in turn builds skills and capacity, allows for participation in decisions affecting their lives, and they are able to engage in interactions and relationship building” (Amsden & Van Wynsberghe, 2005: 359).

Heath et al (2009) explores young people’s participation, specifically in research processes which they break down into further categories of research design, data generation, interpretation of findings, and peer-led research which involves young people in the whole research process and dissemination of findings. Kirby (2004) and Alderson (2001), however, suggest that youth must participate in the initial design of research, even if they are not involved in data generation. This initial involvement is pivotal for the development of interventions as it will raise questions that researchers may not think about, where youth can refine research questions and make recommendations about specific methods (Heath et al, 2009).

Young people’s involvement was explored in the data generation stage of conducting research by Heath and colleagues (2009), who argue that while youth can play a lead role in fieldwork even if they do not participate in the design of the research, that a real interest in the research can only be established if youth take ownership of the project through all stages of the research process. The position of Heath and colleagues (2009) confirms that participation of young people needs to be adaptable and young people should not be forced to participate in phases on developing projects which they are not keen or supportive of. However, for youth to truly take ownership of a project or intervention, they would have to participate in all processes of developing an intervention. Heath and colleagues suggest that one way of achieving active participation of young people is to ensure that:

Instead of using traditional methods such as surveys; one-on-one or group interviews, young people can be given, or are able to choose, different tasks or activities to carry out on the topic of the research. Such tasks include visual activities such as taking photographs, doing drawings, making posters..... (2009: 65-66).

The importance of participatory methodologies to accompany participatory processes was explored in Chapter Three of this thesis.

Reliability and validity of research

The reliability and validity of research according to Thomas and O’Kane (1998) can be improved by the use of methodologies that allow young people an active role in defining how to approach an intervention, what the design will entail, and how to facilitate or implement the programme. Heath and

colleagues pose questions around the rigour and quality of research, questioning what should be the objective of the research. Is maintaining rigour and quality more important than facilitating young people's participation (or vice versa)? Dyson and Meagher (2001) argue that participatory research is not the same as traditional research and has a catalytic validity that allows marginalised voices to be heard and challenges dominant discourses. Therefore, since it does not have the same purpose as traditional research, it cannot be judged by the same values. Hence, if participatory research does not fulfil the requirements on robustness and reliability, it can bring change through creating avenues for young people to share their views (Heath et al, 2009; Dyson & Meagher, 2001; Thomas & O'Kane, 1998).

Participatory communication has a strategic place in research (Cornish & Dunn, 2009). Participatory communication in research suggest that researchers are not exclusively responsible for "generating the research or communicating about it" but instead those who are researched can have the opportunity to participate by expressing and exchanging the knowledge they have towards empowerment for social, cultural or political change (Cornish & Dunn 2009: 666). Research on the other hand is categorised into two cases, the first is where the researcher tries to facilitate change directly with those who are participating and the second is when it is a process of enquiry "to effect a wider change in policy and practice" (ibid). This thesis is positioned more within the first case of research that applies action research to explore young people's involvement in the various phases of developing HIV programmes.

While there are sufficient studies to indicate that youth participate in the research phases of developing projects, the definitions and categories of phases of design and implementation of HIV projects becomes very blurred. Studies reviewed tend to integrate the phases of designing/planning an intervention, with the facilitation/implementation of an intervention. It is for this reason that the data below recognises this gap in literature and presents the two phases of design and facilitation as a merged category, given the lack of distinction in the case study literature. The next section therefore discusses the participation of young people in the design and implementation of programmes.

Strategic Design and Implementation Phases

There is a consistency again in participatory literature that recognises the importance of young people's participation in developing projects and programmes, however there is a gap in examples or case studies documented that reflect the active inclusion of young people in developing HIV projects in South Africa in particular. The literature further recognises that the integration of young people's participation in the research, evaluation, planning, implementation and youth-led policy development

promotes comprehensive strategies that move youth-led research from a simple academic initiative into processes of social action (Suleiman et.al, 2006: 128). Social action according to the research conducted by Suleiman (et.al, 2006) can be facilitated when there is transparency in the decision-making power, a forming of youth and adult alliances and a realistic timeline to execute the strategies for action. The Suleiman (et.al, 2006) study demonstrates the importance of youth-led research towards social action. “Youth-led social action efforts provide a method for youth to become empowered and to create change around these issues... where the young people and their adult partners begin to strategize about how to move their information into action” (Suleiman et al, 2006: 129).

A study conducted in the UK to explore young people’s lived experiences with health issues, demonstrated the importance of an enquiry-based process that extends beyond simply identifying issues but also creating opportunities to support learning for change (Percy-Smith, 2007). This was facilitated through visual materials such as film and posters to reflect views and experiences about health issues and later presented as ‘qualitative data’ to adult professionals who influence policy and health systems development. Percy-Smith (2007) calls this an ‘alternate’ participative action research approach where the enquiry results in a social action project with the young people and adults/professionals. Suleiman and colleagues (2006) suggest that in order to eliminate health disparities for youth, young people need to become partners with adults and meaningfully participate in social action. The success of this meaningful participation toward social action rests in efforts that integrate young people in all phases of communication and programme processes.

Table 5: Benefits of Engaging Youth in a Youth-Led Health Research, Social Action Framework

Skill Building	Understanding Community Context	Action	Potential Health Outcomes
<ul style="list-style-type: none"> • Research • Planning • Implementation • Evaluation • Understanding of public health 	<ul style="list-style-type: none"> • Housing • Employment • Poverty • Transportation • Education • Service delivery • Crime • Air and water quality • Institutional racism • Political/social equality 	<ul style="list-style-type: none"> • Build partnerships with other youth and adult allies • Analyzing, contesting and building power • Community participation • Political action • Problem solving 	<p>Individual level:</p> <ul style="list-style-type: none"> • Improved quality of life • Increased locus of control • Self-efficacy • Self-empowerment • More informed and effective health promoters <p>Community level:</p> <ul style="list-style-type: none"> • Improved quality of and access to

			services • Reduced health inequities
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Source: Suleiman et al, (2006:30)

This table offered by Suleiman and colleagues indicate that youth involved or youth-led research need to always have a social action outcome. Youth-led research serves as a skills building effort which strengthens and empowers young people to mobilise toward a form of community action or social outcome.

A South African case study (Campbell et al, 2005) found that exclusion of youth in education and work, political representation, respect and recognition, and participation in community networks, meant that effective HIV prevention with youth was undermined. This was based on the assumption that sexual behaviour change is not only facilitated by knowledge about HIV and AIDS, but also by youth solidarity, empowerment, critical thinking and the presence of bonding and bridging social capital (Campbell et al, 2005). Unlike behaviour change which glorifies rational thinking and the ability to make concrete decisions, social change recognises that people need the necessary skills and power to deal effectively with social change in a world that distributes needs, resources, and power unequally.

An evaluation of a programme that involved students in the planning and promotion of alcohol-free social activities indicated a lower rate of alcohol usage with students who were involved in the planning and facilitation of the alcohol-free events compared to students who were not involved in this planning process (Klindera & Menderweld, 2001).

A study conducted by Warren Parker (1997) highlights two key attributes for engaging young people in the various phases of developing HIV projects. The first is his focus on the need for “media products to function within context” (1997: 62). This highlights the importance of communication processes that need to function within context through a process of assessing young people’s involvement in these planning processes. The importance of context is crucial and this can only be used effectively in the development of HIV and AIDS interventions or programmes if youth inform all communication processes. Secondly, Parker highlights that “meaning and interpretation need to be seen as a dynamic process” (1997: 62). In order for this to happen, young people would have to be given an opportunity to influence the communication interventions developed for HIV prevention; this can only be achieved through their involvement in all phases of the planning processes.

The process of research, and developing media products by health professions that is distributed to a wider audience, shows that developers are often 'skewed' by their perceptions of how messages should be framed and what media products should be utilised (Parker, 1997: 58). Parker's concerns about the development of media products are also shared in this study with the lack of young people's involvement in communication processes for HIV and AIDS programmes. Young people's perceptions of what programmes should be used, is not acknowledged or applied, and their participation in all phases of the design of projects is also missing. The action media methodology is therefore one way in which youth are given a voice to address their own lived experiences through a process of collaboration and empowerment (Parker, 1997).

In a study conducted around young people's participation in media prevention campaigns such as *loveLife*, the study explored power dynamics that shape the processes of participation (Trabin, 2006). Trabin (2006) argues that campaigns must include youth in all the aspects of programming to create opportunities for critical engagement for young people. This suggests that in addition to choosing the appropriate communication strategy that is context specific, the participation of youth in addressing issues around HIV and AIDS is equally relevant. Heath and colleagues (2009) suggest that the most extensive participation of young people takes place in peer-led research where youth are part of all processes of research or development of programmes. In these cases, projects utilise peer-led methodologies to explore participation in all phases, and gives a voice to youth about a particular issue. The literature indicates that young people are participating in planning and implementation of HIV projects through peer education and in some cases facilitation of workshops, but this participation does not extend to all phases of developing HIV projects.

Limitations of Participation

Participatory work with youth runs the risk of addressing the need of a very niche group while ignoring other groups with different needs. There is a danger of actively involving small groups in interventions, as there may be an assumption that these are the views and experiences of all people (Heath et al, 2009). This could result in projects and programmes only taking into account the determinants of health of a group of young people who are not homogeneous (Harden et al, 2003), and could result in views of a minority of young people being heard for the development of an intervention, whilst the voices of the majority remain silent (Stafford et al, 2003).

It still remains important that youth do participate, especially when it involves sensitive issues such as sexual practices, and discussions about HIV and AIDS are often associated with stigma and discrimination. Despite the setbacks of participation, young people can still facilitate the participation of themselves and others, “who would otherwise be unwilling to take part in adult-led projects, or who might be difficult for adult researchers to access” (Heath et al, 2009: 71). In order to address the specific concerns with specific groups of young people, small scale programmes will need to be explored in greater detail. However, small scale projects and programmes pose challenges of funding and sustainability of the programmes.

“Given the increasing popularity of participatory research with young people in both academic and social policy arenas, there is a growing probability of such tokenistic gestures, as more researchers and funders of research jump on the participatory bandwagon as a means of securing funding, or of raising interest in their work with little understanding of the wider issues at stake” (Heath et al, 2009: 72). In order to reduce the levels of tokenism, it is important for researchers to ensure that they make youth aware that their participation is entirely voluntary, and that they can choose how they want to participate, and at which level of involvement they feel comfortable. Whilst this thesis presents literature that advocates for young people to participate in all phases of the development of programmes, they must be allowed to choose the stages where they can participate, and negotiate how this involvement will take place, to avoid issues of tokenism or manipulation.

Participatory research also carries an assumption that this will reduce the power imbalance between researchers and young people, but it cannot be taken for granted that participation in the development of HIV interventions will lead to more equal relations between researchers and research participants (Heath et al, 2009). There is also the reality that participation in participatory processes cannot involve everyone, and even when participation is voluntary, selections are made by either the researcher or the community leaders about who should be participating which places certain restrictions on who gets selected to participate.

Projects with participation also need to caution against the assumption that involving youth in a process equates to having a voice in a project. Participation efforts therefore need to ensure that involvement translates to influence (Cornwall, 2003; Gaventa & Robinson, 1998), where the ongoing involvement of youth in various phases of development of interventions results in an influence on effective ways to address social problems and issues.

There is also an assumption that young people want to participate. Discussions that advocate for participation rarely discuss the implications of self – exclusion. There is usually an assumption that the right mechanisms and methodologies will encourage ‘full participation’ (Cornwall, 2003: 279). This thesis is written from the perspective of active participation that is volunteered participation where young people are offered a detailed brief of what the project is, why they need to participate and what form this participation will take. This will ensure that young people can make informed decisions about their participation and not be coerced to participate.

Finally, participation is often described as a flop proof recipe for development and social change. This means that it can often take the form of a linear step by step process of achieving community engagement and development without recognising that this systematic process may in fact discourage the active participation of young people. Hence this thesis applies the principles of participation in a flexible and adaptable way that promotes a more nuanced understanding of participation. Freire’s (1979) work in particular addresses the need to engage people in a process of critical consciousness and was based on a radical literacy method to bring about transformative change. Whilst his work was successful in structural change, it is important to draw on some of his successes to catalyse the process of young people’s participation. Hence using Freirean principles to inform the bodymapping process, does not in any way achieve the radical literacy or transformative change that Freire achieved, but rather it should be seen as a step toward creating a space for young people to share their ideas and experiences in how to better participate in HIV programmes.

Conclusion

Using participatory methodologies must be a reflexive and negotiated process for both the researcher and the participants in a data collection process. One can argue that this integral phase of discussion, negotiations, consultation and joint planning for a research process, is what is often missed by some participatory methodologies. While participatory methodologies are used to elicit information and data in a participatory manner, the initial selection, discussion and design of data collection tools is often an un-negotiated process between researchers and participants. This negotiation, of participatory processes, based on what people are experiencing in various social settings, is crucial to the successful rolling-out a participatory methodology. While conventional research focuses on knowledge generation and knowledge sharing, participatory research is embedded in the mobilisation of participants where their knowledge is used for social action and empowerment. What sets traditional or

conventional research apart from participatory research is the location of power which ultimately must rest with the participants in the various research processes (Cornwall & Jewkes, 1995). The next chapter introduces the data from the first phase of data collection for this thesis.

CHAPTER SIX: EXPLORING HIV COMMUNICATION PROGRAMMES IN KZN (PHASE ONE)

Introduction

The next four chapters' present data from four specific data collection phases that were conducted as part of the participatory action research process. Phase One reviews the HIV programmes offered by organisations, using interviews and focus groups discussions (in Chapter Six). Phase Two explores the experiences of the bodymapping process based on focus group discussions and my work with participants from various communities (in Chapter Seven). Phase Three presents data from two purposively designed bodymapping workshops conducted to explore young people's experience of the process and its contribution to developing HIV projects and programmes (in Chapter Eight). Phase Four is the final phase that offers an analysis of the bodymapping experience (in Chapter Nine). Each phase of data collection was analysed individually to ensure that the findings provided insight for the next phase of data collection, which is a principle of the participatory action research process.

This chapter addresses the first phase of data collected through nine interviews and four focus group discussions with the eight organisations that work predominantly with young people in KwaZulu-Natal.

This chapter presents the data collected in Phase One to specifically address the first two research questions:

- 1) What are the HIV prevention messages and communication approaches/strategies offered by selected youth-focused organisations?
- 2) What are young people's perceptions of communication processes for HIV and AIDS programme and message design?

This chapter commences with an introduction to the eight sample organisations that offer specific programmes or campaigns. Thematic analysis is used to analyse the data generated from the interviews and focus group discussions with the sample organisations. The data was coded, categorised and developed into four main themes.

The first theme discusses some of the organisational programmes or campaigns offered within a mass media or a participatory framework and some of the successes of these programmes (building on

Chapter Four). The second theme explores the data from the organisations on the risky sexual practices of young people (building on Chapter Two). The third theme investigates the importance of young people's participation through the various phases of research, design, facilitation and evaluation (building on Chapter Five). The fourth and last theme highlights some of the benefits of participation, exploring sub-themes within this broader theme (further building on Chapter Five). Overall, this chapter provides an overview of the HIV programmes offered by the sample organisations, the application of specific media or participatory approaches in these programmes, an exploration of some of the risky sexual practices identified through empirical data, the importance of participation in developing these HIV projects and programmes and the benefits of participation as identified by the interviews and focus group discussions.

Introduction to Sample Organisations

Eight organisations/programmes were selected as the sample for my initial study, which ensured the inclusion of the three largest national HIV communication interventions in South Africa, and five smaller participatory organisations. All three initiatives have been previously researched with critiques and suggestions for further review, and therefore offer a strong background to the national landscape of HIV and AIDS communication in the country.

The selection of the five participatory organisations offering programmes which focus on HIV and AIDS were based on several factors which included:

- a) the accessibility of the organisations, as this study is conducted in KwaZulu-Natal,
- b) organisations that work with young people in locations which include schools, communities and tertiary institutions,
- c) the diversity of the young people in each of these organisations, in terms of age, sex and urban and rural placement and
- d) the HIV and AIDS programmes aimed specifically at young people.

These organisations were purposively selected to create a sample with diverse programmes for young people, with an exploration into the communication processes that inform the development of HIV related projects. These five organisations were also selected for the diversity of methodologies they employ. These include methods of drama and forum theatre (*DramAidE*), music (*Field Band Foundation*), participatory games, role-play and visual mediums (*Youth for Christ* and *Focus on the Family*) and participatory workshops (*One Voice, SA*).

One Voice, South Africa

OneVoice South Africa (OVSA) is non-governmental organisation working with young people on HIV and AIDS, and TB prevention. The programme, currently offered to 15 schools in KwaZulu-Natal, targets 14-19 year olds, and promotes meaningful participation of young people to make informed decisions about health and lifestyle, including sexual and reproductive health and rights and knowledge on TB and TB/HIV co-infection. *OVSA* uses a life skills approach to implement a school-based programme in the form of 12 workshops offered throughout the school year. The schools programme was selected for this study because of its use of participatory techniques, its focus on giving young people a voice and empowering them to address sexual reproductive health, gender and human rights issues⁷.

Youth for Christ

Youth for Christ (YFC) KwaZulu-Natal is a mission and development agency which addresses issues such as poverty, HIV and AIDS, gender inequality and offers important life skills to children and youth in KwaZulu Natal. *Youth for Christ* works with young people from grade six to grade 11 across eight schools in KZN (*YFC*, interview, 2011). The organisation offers a range of youth development programmes such as international volunteer placements, internships to work with underprivileged communities, programmes for homeless girls and the Change Agent to promote behavioural change through informed personal choices, and informed decisions about sexual and reproductive health⁸. The organisation was selected as a sample organisation based on its focus on HIV communication programmes, using a life skills approach which is offered to young people in schools and communities.

DramAidE

DramAidE is a non-governmental organisation that takes a participatory perspective, informed by action-research, and uses participatory drama and interactive educational methodologies to address issues of HIV and AIDS, life skills and sexuality education. *DramAidE* works with all people but specialises in work with schools, tertiary institutions and communities of young people. *DramAidE* has a range of programmes that include travelling theatre, programmes for orphans and vulnerable children, working with faith based organisations, and offering peer support and mentoring at universities for people living with HIV and AIDS through the Health Promoters Campaign⁹. *DramAidE* was selected for

⁷ <http://www.onevoice.org.za/our-schools-programme-2011/> accessed 12 October 2012

⁸ http://www.youthkzn.co.za/html/change_agents_project.html access on 4 Dec 2013

⁹ http://www.dramaide.co.za/index.php?option=com_content&view=article&id=58&Itemid=74 accessed on 4 Dec 2013

this study based on the HIV programmes offered, that stimulate discussion and provide information to young people, using drama, role plays and a life skills approach.

Focus on the Family

Focus on the Family (FOTF) Africa is a non profit organisation that provides care, advice, support and encouragement to families at every stage of life based on Christian principles. *Focus on the Family* works with younger people, specifically grades seven to nine who are primarily between the ages of 13-15, through several programmes that provide education and awareness of HIV related issues. The No Apologies programme helps young people make wise choices regarding high-risk behaviour, including sexual involvement before marriage¹⁰. The programme is integrated into the school curriculum with regular workshops conducted with young people to further explore ways of preventing HIV transmission, supported by life skills and discussions around sexuality. The organisation was selected based on its HIV programmes, that adopt a participatory and life skills approach when working with young people.

Field Band Foundation

The *Field Band Foundation* uses the global youth activity known as 'show bands' which is brass music that has a historical presence in South African communities for decades.¹¹ The *Foundation* works with over 175 young people across the country using dance and music as a medium. Through the use of music and dance, the *Foundation* creates opportunities for developing life skills for young people, with a strong HIV and AIDS educational focus. The life skills component addresses health issues, social challenges, puberty, gender parity, and the rights of children. This programme was selected for its work with youth, its focus on HIV and AIDS education and its use of music to address a range of issues.

loveLife

loveLife is a youth-focused programme which aims to help young people develop life skills to protect themselves from HIV while working towards a better future. The organisation initially started with billboard campaigns in the late 1990s and has since evolved to include a multi-layered approach. *loveLife* offers a range of programmes that include community hubs that empower young people with life skills, capacity building initiatives and advocacy, youth leadership programmes, school programmes, a training unit that is responsible for design, development and implementation of national

¹⁰ [http://www.safamily.co.za/index.php?maincontent&global\[category|Sbb_content_categoriesID\]=53](http://www.safamily.co.za/index.php?maincontent&global[category|Sbb_content_categoriesID]=53) accessed on 4 Dec 2013

¹¹ <http://www.fieldband.org.za/Programmes.html>. Accessed on 22 January 2012

trainings and associated material and community dialogues. Community dialogues conducted in *loveLife* are gatherings of various people in a community to participate in a discussion about key issues on the agenda. These discussions are facilitated by a community health care worker. The organisation was selected based on its ongoing work with young people to address HIV related issues, using a range of mass media and participatory projects.

Scrutinize

Scrutinize is a national multi-media campaign targeting young people aged 18-35 on a range of HIV issues¹². The campaign was commissioned by JHHESA through funding from USAID/PEPFAR and aims to encourage and equip youth to take responsibility to reduce their risk of HIV infection. The campaign uses 'animerts' (animated advertisements) through a mass media campaign complemented by a grassroots approach that encourages participation of the audience through dialogue and campus tours at various tertiary institutions. Some of the issues covered by the campaign include risky behaviour through alcohol abuse, intergenerational and transactional sex, inconsistent condom use and multiple and concurrent partners. *Scrutinize* was selected to be part of this study given its focus on addressing young people with an entertainment education campaign which demonstrate the consequences of risky sexual behaviour.

Soul City – One Love Campaign

Employing an entertainment education approach, *Soul City* has been successful in offering a prime-time television series to address a range of health and development issues. Among the several interventions is the *One Love* campaign which aims to get young people thinking and talking about their sexual behaviour¹³. The *Soul City One Love* campaign is targeted at young people aged 16-35 and addresses the importance of being faithful to one partner at a time, indicating the risks of multiple and concurrent partners, intergenerational and transactional sex and the lack of condom use. This campaign was selected for its work with young people, specifically through a community dialogue approach, which encourages young people to discuss the challenges of risky sexual practices, and, through a process of collective dialogue, identify ways to overcome or protect themselves.

¹² <http://www.scrutinize.org.za/about-scrutinize.html> accessed 4 Dec 2013

¹³ <http://www.soulcity.org.za/projects/onelove> accessed 12 October 2012

Theme One: Organisations' Use of Mass Media and Participatory Strategies for Young People

This first theme offers a discussion to address the question of what are the HIV communication strategies used by the eight sample organisations when working with young people. Chapter Four outlines some of the predominant communication approaches that are usually categorised into mass media (television and radio, for the purpose of this study) and participatory approaches (that include community engagement, participation of young people, and participatory communication mediums). This theme therefore presents the data collected within these two categories (specifically through the interviews and focus group discussions with staff, see Appendix 2 & 4) to understand the type of programmes offered by the sample organisations.

From a sample of eight organisations, three have national mass media campaigns that either use television, radio or print media like billboards. These included the *Scrutinize* campaign, the *One Love* campaign and *loveLife*. These campaigns, however, also offered accompanying participatory programmes in the form of workshops or community dialogues. The other five organisations that are part of this sample only conduct participatory programmes with young people in school and communities. These organisations, *One Voice*, *Youth for Christ*, *Field Band Foundation*, *Focus on the Family* and *DramAidE*, however, offer workshops and school programmes which are often in support of and in turn supported by the materials developed for the national media campaigns. For example, *DramAidE* makes use of the *Scrutinize* material when working with young people in communities and tertiary institutions (*DramAidE*, Interview, 2011). *Focus on the Family* adopts some of the principles of the *One Love* campaign, which they position to encourage abstinence or being faithful in cases where young people are already sexually active. *Youth for Christ* draws on some of *loveLife's* work, encouraging young people to love and value their life, in order to make informed choices. The data below therefore indicates that it was impossible to always cluster HIV programmes into exclusive mass media and participatory initiatives, as there is evidence of a co-dependence of these two strategic approaches.

In the case of *Scrutinize*, *One Love* and *loveLife*, national media campaigns were developed using radio and television to address risky sexual practices of young people. In an interview with the Managing Director of JHHESA, (the commissioning body for the development of *Scrutinize*) it was reported that television was the primary medium for *Scrutinize* because it is developed to be a very visual advertising campaign, using entertainment education and inter-personal communication

(*Scrutinize*, interview, 2011). The *One Love* campaign was also aired on television and radio, but adopted the campaign strategy for addressing sexual practices with young people (*One Love Campaign*, interview, 2011). *loveLife*, similar to *One Love* and *Scrutinize*, uses television and radio to relate messages on safer sexual practices. The use of billboards in communities aims to engage young people in discussion about HIV related issues. *Field Band Foundation* also has a national strategy of empowering young people, through the use of music, with various bands sometimes performing on national television for various events like the 2010 FIFA World Cup opening ceremony in South Africa¹⁴. The *Foundation* advocates for HIV awareness and prevention. However, their HIV work, despite a national focus, is more evident in their participatory workshops conducted during the year. These three campaigns, despite their national focus, still presented evidence of participatory engagement with young people in schools and communities. This is a significant shift compared to the work of many organisations in the late 1990s that adopted an exclusive mass media focus (see Delate, 2001, 2007 for the case of *loveLife*).

The data collected indicates that there were supportive participatory elements of all three campaigns. In the case of the *Scrutinize* campaign, university campus initiatives, school programmes and community projects were developed where music, art, culture and celebrities engaged with young people through interactive games using *Scrutinize* as a tool for engagement. The Director of JHHESA further commented that peer educators were trained in different organisations and campuses to use *Scrutinize* methodologies to engage with young people (*Scrutinize*, interview, 2011). *Scrutinize* therefore has a strong television and radio focus that is supported by extensive community dialogues and campus activities to motivate young people to think about, discuss and revisit their risky sexual practices.

The *One Love* campaign also worked with youth in communities to ensure that their experiences are integrated into what is screened on television (*One Love campaign*, interview, 2011). The *One Love* campaign, which promotes the importance of being faithful to one partner through television and radio interventions, is also supported by community dialogues which unpack the communities' understanding of sexual practices and being faithful. The Research Director for the *One Love* campaign reported that they train a group of people and then that group, "with the assistance of a facilitator, runs dialogues in their community about the importance of *One Love* and the risk of having multiple and concurrent partners" (*One Love Campaign*, interview, 2011). The *One Love* campaign, like *Scrutinize* and *loveLife*, supported their television initiatives with community dialogues in various provinces.

¹⁴ http://www.dcu.org.uk/news/news_10046.html Accessed on 12 October 2012.

After extensive controversy regarding their billboard campaigns, *loveLife* (*loveLife*, interview, 2011) now pointed out during the interviews about the existence of their ongoing community engagement initiatives. Programmes like Make My Move, Groundbreakers and *loveLife* Youth Centres work consistently with young people to develop various life skills with an understanding that it will empower them to make informed choices (*loveLife*, interview, 2011). The Groundbreakers programme, for example, helps young people develop their lives after school by providing relevant life skills and leadership skills that they will need for employment (*loveLife*, interview, 2011). Community dialogues with parents and young people also address HIV related issues in communities. *loveLife* has over 300 hubs across the country which help youth to act responsibly and take control of their own lives (*loveLife*, interview, 2011). The data therefore indicates that *loveLife* started to incorporate a more participatory and youth-engaging approach to HIV, that extended beyond their billboard campaigns.

The above-mentioned three national programmes indicate that while HIV information is provided to young people through television and radio, these are coupled with participatory engagement with youth in the community. This is a significant shift from previous HIV interventions that predominantly had a mass media focus, as evident in the production of *Sarafina* (Govender, 2011), the work of *loveLife* in the late 1990s and early 2000s (Delate, 2007; Parker, 2004; Parker, 2008), and *Takalani Sesame*, which was an edutainment programme on television and radio that has been criticised for not including a component of integration into the life orientation sessions for learners in South African schools (Coertze, 2012).

The other five organisations selected for this study, *DramAidE*, *YFC*, *OVSA*, *Field Band Foundation* and *Focus on the Family*, favour this participatory approach, while retaining elements of entertainment in their programmes. *Youth for Christ* suggest that their work is premised on participatory approaches, while remaining fun and entertaining:

The fun aspect of the learning...it is participatory and it's fun, we like participation, we encourage it, with the peer education model...young people taking the responsibility This in turn creates an environment where young people are enthusiastic about learning as opposed to a more formal teacher type model (*YFC*, interview 1, 2011).

The *YFC* programme promotes HIV prevention through offering life skills to youth, while also using discussion guides from various national campaigns. This indicates that young people are receiving HIV information through both participatory engagement and national campaign initiatives. *DramAidE* also uses a range of participatory methods to engage youth. These include the use of games and

icebreakers as an introduction when they meet young people. *DramAidE* also uses puppet performances, theatre and education programmes to engage with primary school learners (*DramAidE*, facilitator focus group, respondent 4, 2011). The Director of *DramAidE* commented that drama was initially used for HIV information, indicating the importance of using diverse tools for engaging youth.

The *One Voice* programme offers ongoing workshops for youth at schools, where they participate in various activities which promote the development of life skills, and empower young people to engage in dialogue about issues which affect them. The data collected from facilitators of *One Voice* suggests that their participatory workshops built the capacity of learners to talk about the issues discussed in the *One Voice* workshops. *Focus on the Family* has a similar presence at schools, offering participatory workshops to young people, and also training of educators to provide HIV information to young people. The organisation has a very strong community mobilisation focus, and builds on other national campaigns before working with youth.

Field Band Foundation also supports its national interventions with participatory mediums to develop life skills through brass musical instruments. HIV Life Skills Workshops are offered every term for young people attending the *Field Band Foundation* to learn about music. Through a range of partnerships and different teaching methods such as drama and role plays, young people are better informed about HIV and AIDS. *Field Band Foundation*, similar to *Scrutinize*, utilises the influence of entertainment education to promote HIV related messages using music and dance in national events and in local communities. Entertainment education is a strategic communication process to entertain and educate through a communication medium to facilitate behaviour or social change (Bouman, 1998; Coleman, 2000; Singhal & Rogers; Tufte, 2001; Dutta, 2012).

An exploration into the strategies employed by each of the eight sample organisations reflects that *DramAidE*, *Youth for Christ*, *Field Band Foundation*, *Focus on the Family* and *One Voice* specialise in school-based or community programmes with young people and adapt a range of activities that include interactive games, role plays, drama, music, storytelling and art to encourage participation and discussion on challenges which affect young people. *Scrutinize*, *loveLife*, and the *One Love* campaign have a stronger focus on national media initiatives through radio and television, but still integrate community engagement, dialogues and the facilitation of workshops when working with young people. The data collected and presented in this theme indicates that there are more integrated and holistic approaches to communication. Whereas some of the literature (also see Chapter Four of this thesis) indicates that exclusive mass media approaches have been used more predominantly in the last three

decades, communication strategies are now integrating the effectiveness of working with media and with the participation of young people (Scalway, 2003; Scalway, 2010).

Theme Two: Risky Sexual Practices of Young People

This second theme explores some of the risky sexual practices that young people often engage in. This section specifically presents data that indicates the prevalence of multiple and concurrent partnerships and intergenerational and transactional sex among young people. These risky sexual practices were not common with all organisations, with many youth still abstaining from sexual interaction and staying faithful in relationships in other instances. This section then moves on to explore some of the factors that contribute to these risky sexual practices. This theme therefore offers a context to some of the challenges that youth have with HIV related issues, factors that influence their sexual choices or lack of choices, and some of the HIV messages offered to address HIV prevention. The data presented will help to understand the context of HIV when working with young people (refer to Chapter Two for a detailed literature review).

Risky Sexual Practices: MCP's and Intergenerational Transactional Sex

Many of the sample organisations and programmes identified issues of multiple and concurrent partners and intergenerational transactional sex as risky sexual behaviour that make young people more vulnerable and at risk of HIV infection. These common risky practices identified in six of the eight sample organisations meant that programmes had to be designed with specific messages to address these sexual practices.

Transactional sex and intergenerational sex were identified as the risk factors often linked to multiple sexual partners (MCP) (*Scrutinize*, interview, 2011; One Love Campaign, interview 2011; *loveLife*, interview, 2011). Interviews conducted with programme managers and directors of *loveLife*, the *One Love* campaign and the *Scrutinize* campaign indicated that there was a strong multiple and concurrent partner trend amongst young South Africans. They supported their claims by discussing some of the research findings conducted nationally and commissioned by each of these organisations that indicated that MCP was a risky sexual practice that contributed to the spread of HIV.

The 2008 HRSC report, *Turning the Tide*, also suggested that in order to address the risky sexual practices of young people, more efforts need to be made to address drug and alcohol abuse, multiple and concurrent partners, and the lack of consistent and correct condom use (Shisana et al, 2009).

These messages are specifically evident in the development of *Scrutinize* and the *One Love* campaign, launched in 2008, and 2009 respectively. These messages also filtered through to the participatory projects. Of considerable interest was the importance placed on partner reduction by *One Voice*, *DramAidE* and *Field Band Foundation*. Yet *loveLife*, *Youth for Christ* and *Focus on the Family* developed programmes to communicate the importance of being faithful to one partner.

The organisations also reported on the varying HIV prevalence rates among males and females, which suggested that younger women (ages 15-24) were most infected, with HIV prevalence also high amongst males over 30. This data indicates that young men are more likely to use condoms compared to young women between the ages of 15 -24, and that condom use amongst men aged 30 plus tends to decline (*Scrutinize*, interview, 2011). The HSRC national survey confirmed that HIV prevalence rates were twice as high for females as for males between the ages of 20-24 and 25-29, while HIV prevalence for men was high between ages 30-34 (Shisana et al, 2009, more details on HIV rates with young people in Chapter Two).

Similar findings were confirmed with *loveLife*, which reported that HIV infections were higher with young women, since males would often date younger girls at school, but settle down with older girls when they wanted to commit to a relationship, therefore placing two young women at risk of infection (*loveLife*, interview, 2011). A facilitator from the *Scrutinize* campaign explained that these types of relationships mean that younger women are becoming sexually active with an already sexually active adult population group, and “this seems to give rise to the very high infection rate amongst young women.” The facilitator suggests that this is partly due to intergenerational sex (*Scrutinize*, interview, 2011).

The issue of transactional sex “has come up a lot in the qualitative data, particularly looking at transactional sex where young women or young men engage in relationships with persons in exchange for gifts or favours” (*Scrutinize*, interview, 2011). Many intergenerational sexual relationships extend to transactional sex where there is an exchange of goods, money or services for sexual favours (Mulwo, 2009; Kunda, 2009; Mutinta, 2011). *One Voice* facilitators indicated that their observations in the field suggest that young people have multiple partners for a range of material goods such as cars, nice clothes, and supporting their families.

Respondent 5: And some girls, they are having four or five boyfriends, they're expecting maybe...one boyfriend is giving a car, the second one is maybe buying clothes, so you're wearing nice clothes.

Respondent 1: Maybe sometimes one of your boyfriends is supporting your family because you're not working. And you need all of those things, so you can't dump them.

Respondent 3: If my mother wants some money to buy the mielie meal at the house, then I will call another one who is the Minister of Groceries (*One Voice*, South Africa, focus group, 2011).

However, not all young people are engaging in intergenerational or transactional sex in exchange for luxury items. In the case of the young people attending the *Youth for Christ* programme, many are in real poverty situations. Issues of forced sexual interaction and “young girls not knowing that they have the right to say ‘No’” are still some of the challenges which the programme faces” (YFC, interview 1, 2011). A study conducted by Suzanne Leclerc-Madlala (2003) in a township in Durban, KZN, found that women were not only engaging in sex for subsistence needs but also for consumption, suggesting that the pursuit of these new needs can be termed commodities of modernity. Her study found that often these material needs were associated with lifestyles and ideals constructed by the media and globalisation and not basic issues of poverty, child-headed households etc.

The above observations of young people's sexual practices emphasise the need for more programmes that engage with the importance of partner reduction, condom use and being faithful in relationships. Issues of transactional sex have to be addressed that explores the factors which also contribute to these risky sexual behaviours. “The facilitators in this instance discuss the difficulties they have in promoting or encouraging the reduction of partners or be faithful messages, as in many cases young people are either engaging in these relationships for basic needs or luxury items¹⁵. In this case, facilitators emphasise the importance of using a condom. One facilitator reported that whilst she cannot stop young people from having multiple partners in her capacity as a facilitator, she does highlight the importance of having one partner and of using a condom correctly and consistently (*One Voice*, facilitator focus group, 2011). The *loveLife* programme also indicated that condom use needs to be promoted in these risky sexual relationships since most young people know the dangers of unprotected sex or have excessive information, yet they are still sexually active (*loveLife*, interview, 2011).

Several programmes like *Scrutinize* and the *One Love* campaign have been developed to offer young people more information about the risk of their sexual practices and the need to encourage safer sexual relationships through messages of partner reduction, delayed sexual debut, consistent and correct condom use and one partner at a time. Many facilitators shared their own opinions on the issue of

¹⁵ A similar finding was found with students at the University of KwaZulu-Natal. The Mulwo (2009) study found that young people were not only engaging in sex for basic needs, but rather for luxury items such as fancy cars, clothes, cellphones and fine dining . *Youth for Christ*, which works in deep rural communities, argues that this is not always the case, and in rural areas intergenerational and transactional sex are for basic needs and sustainability (interview, 2011).

MCPs and transactional sex, and one facilitator commented that material gain did not make a difference to her if her boyfriend was dating several women. She commented that “he can buy me a Kompressor today, but if tomorrow I realise he’s dating five women, I’m sorry, he can go away. Because I cannot manage to love more than one man” (*One Voice*, facilitator focus group, respondent 3, 2011).

The data presented above indicates that most organisations are faced with challenges of multiple and concurrent partners, intergenerational and transactional sex and the lack of consistent and correct condom use amongst young people. This indicated that organisations need to offer HIV prevention messages that centred around partner reduction, consistent and correct condom use, delaying sexual debut, secondary abstinence and faithfulness in relationships. Below is a discussion on the factors that influence these risky sexual practices, which must be considered when developing HIV programmes for young people.

Factors that Contribute to Risky Sexual Practices

Some of the factors identified among the sample organisations as influences that contribute to risky sexual practices include the influence of peer pressure, the lack of follow up procedures when HIV programmes are introduced to young people, role modelling incorrect behaviour, the negative influence of television, misinterpretation of HIV messages, conflicting messages offered to young people and the influence of culture. The discussion below is limited in that it only reflects factors based on the empirical data collected. Other, more varied and specific factors are discussed in Chapter Two of this thesis.

Peer Pressure Contributes to Risky Sexual Practices

Discussions with *loveLife* staff identified common factors as peer pressure, lack of communication and societal norms and influences that contribute to risky sexual practices. *Youth for Christ* similarly found that once young people were willing to discuss issues of HIV, they would identify peer pressure as one of the contributing factors to HIV or “choosing a boyfriend for what you can get out of it” (*YFC*, interview 2, 2011). This could be linked to when young people are engaging in sexual relationships as a transaction for material gain. The programme manager of *loveLife* noted that the root causes of HIV were “underpinned by poverty, accompanied by other issues of peer pressure, lack of parental communication, lack of self-esteem, and also lack of societal norms” (*loveLife*, interview, 2011). *loveLife* found that young people know about the dangers of unprotected sex. They do have information, yet

they are sexually active due to the pressures from friends and people around them (*loveLife*, interview, 2011). Similar issues of peer pressure, lack of parental communication and issues of self-esteem arose in discussions with *Field Band Foundation*, *One Voice* and *Youth for Christ*.

Overall, peer pressure was identified as a strong contributing factor to risky sexual choices and this finding was supported by several studies conducted in South Africa, that commonly indicate the negative influences of peer pressure on risky sexual behaviour (Varga, 1999, 2003; MacPhail & Campbell 2001; Turner & Sherperd, 1999; Milburn, 1995). Peer pressure was often associated with the lack of self-esteem among young people that often resulted in their inability to negotiate safe sexual practices (Hollar & Snizek, 1996). Communication programmes offered by the organisations therefore need to focus on the importance of developing life skills and addressing issues of self-esteem with young people.

The *Field Band Foundation*, in their HIV Life Skills Workshops, assists young people to make future decisions about their sexual activities. The programme also aims to make young people “realise that they are responsible for taking own decisions regarding their future” (*Field Band Foundation*, interview, 2011). This can be attributed to the work of Freire (1976) when he advocates that people need to become critically aware of their lived experiences and become empowered to take responsibility for their own lives. Peer education programmes have been identified as one way of addressing issues of peer pressure as seen in the work of *DramAidE*. A study conducted with schools in KZN however, found that peer education was not always a successful HIV intervention strategy as communities needed to create an environment to support these peer education efforts outside of schools where young people were faced with challenges of poverty, social exclusion and risk of HIV. Campbell and MacPhail (2002) attributed the lack of partnerships and enabling social environments as factors that hindered the success of peer education programmes in schools.

The *DramAidE* peer education programme was found to empower young people to overcome peer pressure and reduce risk and make healthy choices. The *DramAidE* programme at the Durban University of Technology (DUT) demonstrates the ability of health promoters, who were often identified as peer educators, to provide correct and consistent information and empower students with life skills to make informed choices (Botha, 2009). In another study, 90% of the focus group participants at DUT identified peer education as the most effective strategy for HIV prevention (Khumalo, 2012). The Director of *DramAidE* reported that an evaluation of peer educators indicated that they were making an impact and helping young people to make appropriate lifestyle choices (*DramAidE*, interview, 2011).

Issues of peer pressure and lack of self esteem were therefore addressed by all organisations offering a participatory approach to HIV prevention among young people through life skills workshops that encouraged taking responsibility for sexual choices and making informed decisions. Peer education was also a strategy used to work with young people counteracting the effects of peer pressure by reinforcing safe sexual options.

Lack of Follow Up Procedures and Challenges for Peer Educators

A *DramAidE* facilitator outlined the importance of having counsellor and follow-up processes in place at schools when working with young people as it can be very dangerous to introduce young people to new information and not offer support while *DramAidE* is out of the schools (*DramAidE*, facilitator focus group, respondent 2, 2011). Whilst this follow up with young people is important, many organisations recognised the role of teachers as a possible barrier to promoting safer sexual practices. Teachers were seen by learners as “judgemental adults” (*One Voice*, facilitator focus group, respondent 3, 2011), who also take the role of parents to young people, therefore closing a possible avenue for communication (see Ankrah, 1993; Rwenge, 2000; Jewkes et al, 2008). The strategy of using young facilitators who function similarly to peer educators places them in a better position to discuss issues of sex, sexuality and lifestyles with youth. However, not all facilitators reported positively on their peer educator experiences.

Facilitators at *Youth for Christ*, who also appear as peer educators to young people, reported that they were not always taken seriously by learners at schools (*YFC*, facilitator focus group, 2011). In turn, the learners pose a series of questions to the facilitators about their own sexual practices. When the young facilitators were questioned about their position on abstinence and promoting it amongst youth, one suggested that “we sell what we produce” (*YFC*, facilitator focus group, respondent 5, 2011). This indicates that the group of young facilitators, who were working more as peer educators with young people in the communities and schools, were promoting a message that they applied in their own lives. The project coordinator of *Youth for Christ* supported this position, and said:

we can't go to schools and tell young people to abstain, when we're not abstaining. So in a way it holds one accountable, you cannot talk about something that you do not do...Because we do ask these questions, and they do ask about abstinence: “Are you abstaining?” Well I cannot say...one cannot lie. But it sort of gives you an accountability, because young people can actually sense when you're not telling the truth, so it gives us that accountability in that way (*YFC*, interview 2, 2011).

Despite the challenges that peer educators face, facilitators at *Youth for Christ* see themselves as role models suggesting that “we cannot go out there and tell people to abstain while I’m not abstaining...obviously it’s going to be a problem” (*YFC*, facilitator focus group, 2011). Albert Bandura’s (1997) Social Learning Theory, for example, places significant emphasis on the use of role models in affecting behaviour change that in the case of peer educators can serve as positive role models who provide information and support. Peer educators who have a similar set of experiences and culture are therefore likely to be more effective in promoting learning (Turner & Shepherd 1999: 241). Another factor that was identified during the data collection processes with the various organisational staff was the promotion of incorrect behaviour. This is discussed in the next sub section.

Role Modelling Incorrect Behaviour Leads to Risky Sexual Practices

One of the facilitators at *One Voice* reported that incorrect behaviour is praised and supported by their peers rather than positive behaviour. He highlighted how multiple partners and intergenerational sex were not properly deterred in communities and schools, but instead there was evidence of these types of relationships being supported or developed, for example, through teacher and learner relationships. Hence, while facilitators were promoting specific safer sex options, young people were engaging in contradictory behaviour that was not always condemned by communities and schools. He further stated that:

everything in this world that is wrong seems to be praised, because even the teachers that are getting married, putting big rings on their fingers, they are dating learners...and then we come and say: have one partner, but what is being said is not as easily adapted as what is being said (*One Voice*, facilitator focus group, respondent 1, 2011).

The facilitator further indicated that young people follow behaviour that they see rather than what is taught. This implies that youth will mirror behaviour instead of taking cognisance of what is taught about safer sexual practices. Discussions with the sample organisations indicated that if teacher and learner relationships are a common occurrence in a community, the learner is easily attracted to those types of relationships despite organisational work that advocates for safer sex. The idea that youth will follow what they see rather than what they are told, is also suggested by another facilitator at *One Voice* who says, “what I see in the classrooms when I facilitate is that they adapt their parents’ behaviours” (*One Voice*, facilitator focus group, respondent 5, 2011). This also suggests that young people have a tendency to practice what they see through the lives of their parents, community members and teachers. Role modelling of positive and sometimes negative behaviour also extends to television

series. The next sub-section presents data on discussions about the negative effects of television that contribute to risky sexual practices.

Negative Influences of Television

The negative influences of television, music and social networking were identified as catalysts of promiscuity, where some sexual behaviour seen on television can promote risky sexual practices among young people. *Focus on the Family* reported that by working with youth across the country, their research showed that the media largely shapes young people's decision-making. The programme manager of *Focus on the Family* further commented that "the type of programmes we watch, the nudity, promiscuity, sexuality, even in locally-written programmes, let's use *Generations* or *Yizo Yizo*, have an influence on young people" (FOTF, interview, 2011). A study conducted on children's television viewing in South Africa found some correlations between child viewership of soft porn on TV and issues of lack of discipline in schools. The study concluded that schools need to continue to work at instilling discipline in children, and must be supported by families encouraging values of love, discipline and care that need to be a priority in society (Van Vuuren & Gouws, 2005). Music, cell phone technologies like Mxit and Facebook, social networking systems, "allow young people to make sexual propositions without face-to-face contact, and more young people are becoming sexually active through the access of social networking systems" (FOTF, interview, 2011).

However, television can also have a positive influence on young people by providing information that they did not possess before, and portraying the effects of HIV and the consequences of risky sexual practices. Television therefore has the potential to have either a positive or a negative influence on how young people interpret and make sense of their sexuality. "Some of the series we have on TV if they can portray like things, it can open up people's eyes" (*YFC*, facilitator focus group, respondent 4, 2011). The SABC has offered a range of HIV intervention using edutainment as a primary communication strategy to promote a range of safer sexual practices. Some of these programmes include *Gaz'lam*, *Tsha Tsha*, *Soul City* (independently commissioned on SABC), *Yizo Yizo*, *Siyayinqoba Beat It* (magazine show) and *Isidingo* (Milton, 2011). However, many of these edutainment dramas had conflicting viewer responses¹⁶. In addition, television and the use of role models can also pose the challenge of how messages are received and understood by young people. These messages may be

¹⁶ The study conducted by Viola Milton (2011) found that many of the viewers found the graphic sex scenes in an episode of *Gaz'lam* very disturbing. Young people commented that they often had to switch the channel if their parents entered the room while these scenes were screening.

created to have a specific meaning for HIV prevention, but may be understood in a different way by young people. This creates a complexity for HIV messaging as young people may decode messages in a way that was not intended by the message producers. Reception studies to gain an in-depth understanding of how these HIV messages are decoded are crucial for the effective development of HIV programmes. This informs the next sub-section on understanding the factors that influence risky sexual behaviour.

Misinterpretation of HIV Messages by Young People

Other factors that influence risky sexual practices that could be identified are the changes in perceptions of what constitutes a relationship and what constitutes faithfulness. Young people are aware that their partners are unfaithful, and still continue to have 'fun' in the relationship. As a result, there is an acceptance among young people that their partners are just sex partners instead of a boyfriend or girlfriend, which redefines what a relationship means.

The *One Voice* facilitators provide examples of these misinterpretations, when young people start to redefine the terms of *love*, *trust* and *respect*. For example, *trust* is defined as "trust that I love you, although I have someone else"; boundaries in a relationship are to "make sure that you don't touch my phone"; and *love* means "so I love you, please believe that" (*One Voice*, facilitator focus group, respondent 3, 2011). Another facilitator added that *honesty* means "you know that I have someone else, so be honest about that" and *respect* is defined as "if I'm not with you then I'm with so and so, so respect that and don't call me" (*One Voice*, facilitator focus group, respondent 1, 2011).

Focus on the Family attributes the shifts in perceptions about relationships to the moral degeneration in society. The programme manager reported that:

Because people have come to expect moral degeneration as a lifestyle that means: 'I am a single parent, or I have been sexually active, I've had more than five partners, so what?' So you get that approach, the "I don't care" approach, where people are not consciously thinking about the future, but living for today. So the other challenge that we face is that we have a society that is more now-conscious than future-conscious (FOTF, interview, 2011).

The above examples of how young people are re-defining terms of love, trust, faithfulness and honesty indicate that when messages are designed, the encoded message may be different to the decoded message (Delate, 2007). This has been the case for several HIV programmes that were not received by young people in the way in which it was intended.

Conflicting Messages

Conflicting messages offered by teachers and organisations can promote risky sexual practices. *DramAidE* and *Youth for Christ* also identified the contradictions that arise in what youth are taught. *Youth for Christ* reported on these contradictions, by suggesting that youth often report that their parents allow them to have a boyfriend, when the organisation is trying to promote abstinence (YFC, facilitator, focus group, respondent 5, 2011). Another facilitator therefore commented that it makes it difficult because messages offered at school and messages offered at home often differ (YFC, interview 2, 2011). *DramAidE* facilitators similarly found that there were contradictory messages as young people were often taught about issues by their parents but “the same parents are contradicting themselves, they’re preaching this but they’re doing differently (*DramAidE*, facilitator focus group, respondent 4, 2011). *Youth for Christ* indicates that it addresses these different perspectives by also offering programmes with parents, so that when learners ask their parents about certain issues, they are able to support the learners (YFC, interview 2, 2011).

The abstinence message promoted by *Youth for Christ* often conflicts with other messages that young people are given, and this becomes a challenge for facilitators especially when young people are already sexually active (YFC, facilitator focus group, respondent 1, 2011). However, other facilitators at YFC were of the mindset that young people need to know their options and develop self-esteem to make informed choices.

Culture as an Influence

Cultural influence also plays a significant role in influencing the sexual choices and practices of youth, and often contributes to risky behaviour. A *One Voice* facilitator discussed that one boy from his class said that, as a Zulu man, he could have five women because it is ‘his’ culture (*One Voice*, facilitator focus group, respondent 3, 2011). Another facilitator reported that people are using the notion of ‘culture’ as a way to excuse negative behaviour (*One Voice*, facilitator focus group, respondent 7, 2011). The facilitators highlighted the challenges of young people now associating their preferred sexual practices and choices with cultural norms and values. In this way, culture becomes an excuse for young people to pursue their own desires and sexual practices, attributing their sexual behavioural choices to their specific cultural norms and influences (Volpp, 2000).

In addition to young people using culture as an excuse for their sexual choices, cultural influences can also conflict or contradict the messages that are sometimes promoted through organisations or HIV programmes. This case is often seen with young women who are sometimes given the skills to make informed sexual choices, but are forbidden or restricted in their communities based on cultural influences or practices. The *Field Band Foundation* therefore positions itself to address these contradictions and controversies with organisational programmes and cultural practices by conducting home visits to some of the young people's homes to assess if the mothers also need to be educated about issues of abuse and safer sexual practices:

we do home visits, we could even go to the mother and see what type of a mother the child has, whether this mother is actually a mother that can actually help a child get out of this ideology of being suppressed. If the mother is a suppressed mother too, we now encourage them to go for support groups where mothers are taught how to get out of abuse or how to get out of oppression.

(*Field Band Foundation*, focus group, respondent 2, 2011).

The *Field Band Foundation* are therefore aware of the influence of cultural and parental influence on young people's sexual practices, thus addressing root cause issues, rather than addressing the problem of HIV at the surface level. The above example indicates the work of an organisation that is challenging the social norms and cultural barriers which can prevent young people from making informed choices and safer sexual decisions. It also shows the conflict of what young people are educated about in school, and how this differs at home. The *Field Band Foundation*, similar to the work of *loveLife* addresses these concerns from youth and parent perspectives, in order to promote safer sexual practices.

The cultural promotion of virginity testing was also identified by *loveLife* as challenging the youth programme that they offer, and this cultural practice required organisations to address HIV within a broader community. The Programme Director reported that "the problem is we have this pool of virgins, but there are older men that are targeting these virgins because they know they're pure, so those are the kinds of issues we need to get through at community dialogues where we discuss the issue of rights, the issue of choices" (*loveLife*, interview, 2011). Similarly, *One Voice* facilitators suggested that various cultural norms and beliefs have to be addressed by government, who use local infrastructure and government employees to address issues of cultural practices and norms, which need to be challenged and addressed with young people (*One Voice*, facilitator focus group, respondent 2, 2011).

The need to address these diverse cultural views was also echoed by *Youth for Christ*, as there are many myths and misconceptions about HIV that need to be addressed with factual information. The

programme coordinator of YFC commented that “in rural areas, when one gets sick and they become thin, it’s either that they’re bewitched or there’s some ancestral whatever that needs to be done. Therefore communities need to be given the facts all the time, as AIDS is not a problem, it’s people that we need to deal with” (YFC, interview 2, 2011).

The *3 letter Plague*, written by Jonny Steinberg, describes the complexities of HIV in communities where people who exit the testing room soon after the test are deemed negative, whilst those who take time to exit the HIV testing room are perceived to be positive (Steinberg, 2008). His narrative indicates the complexities of stigma and discrimination and the social construction of AIDS by people through their own cultural lens. The *One Love* campaign similarly pointed out the effects of cultural norms and influences which are often victim-blaming, without recognising that people can be in “situations not necessarily through choices they’ve made, but often there are contextual issues”. The campaign therefore offers solutions for young people to escape these situations (One Love campaign, interview, 2011).

The influence of culture therefore needs to be addressed within context. In cases where culture is used as an excuse for young people to pursue risky sexual practices, cultural misconceptions will need to be addressed. In other cases where cultural influences result in power imbalances and gender inequality, women in particular would need to be empowered to address these complexities. The role of dialogue is often advocated to facilitate discussions about complex issues of culture (Kincaid, 2009; Figueroa et al, 2002; Kunda, 2009). The work of *DramAidE* is also centred on balancing culturally appropriate content with HIV messaging (Gumede, 2012; Dalrymple, 1986, Durden & Tomaselli, 2012).

Redefining Faithfulness

The issue of faithfulness in sexual relationships was often discussed by organisations in a context where young people associated faithfulness with being true to themselves. *Youth for Christ* found that young people discussed being faithful in the context of being faithful to oneself, “Be faithful to your partner, not only to your partner but you can be faithful to yourself too” (YFC, facilitator, focus group, respondent 2, 2011). This indicated that young people placed a greater emphasis on being committed to making their own decisions and choices and placed their needs as a priority (YFC, facilitator focus group, 2011). *loveLife*, in a similar light, also promoted the idea that youth should “love themselves first” through a programme introduced in 2011 called “I dig me”, that encourages “young people to understand that they need to love themselves, they don’t need to wait for another person to say ‘I love

you', you need to love yourself first" (*loveLife*, interview, 2011). Being faithful is defined by *Focus on the Family* in the context of marriage; where young people are taught about abstaining until marriage and once married they can practice faithfulness in marriage. While *Focus on the Family* and *Youth for Christ* identified being faithful as being faithful to oneself, and in the context of marriage and developing young people, the *Scrutinize* campaign identified different ways to define faithfulness. Faithfulness was often defined by young people as a process where they are faithful to their partner as long as he/she does not find out that they are cheating.

A lot of people felt that I am faithful to my partner if my partner doesn't find out about the other one, so this was a completely different construction of the meaning of faithfulness meaning that we even had to interrogate using the term 'faithfulness' within the creative execution (*Scrutinize*, interview, 2011).

Similarly, facilitators from *One Voice* commented that young people define faithfulness as commitment to a partner as long as their primary partner does not find out about their secondary relationships. In other words, youth believe that they are only guilty of unfaithfulness when they are caught out by their primary partner as being unfaithful. One facilitator reported that "be faithful to them means to make sure that your straight partner that you call your 'vrou' (Afrikaans, 'wife'), or the partner you are living with at home, you have to make sure that your partner doesn't know about other affairs so that is being faithful" (*One Voice*, facilitator focus group discussion, respondent 2, 2011). The data indicated that often the secondary partner would know about the primary relationship, but the primary partner would never know about the secondary partner (a secret lover). As long as this secrecy was not uncovered by the primary partner young people believed that they were still faithful.

The term 'faithfulness' was often defined to accommodate young people's risky sexual practices and choices, rather than 'one relationship and one love' as intended by the *One Love* campaign. Moodley (2007) found that young people identified abstaining from sex and condom use to be easier messages to adhere to than faithfulness. De Fossard (2004) found that young people in Uganda associated 'be faithful' as going to church regularly, indicating that young people were creating their own meaning and associations of the various HIV messages in the context of their own lifestyles. Young people were engaging in multiple partnerships for a range of issues, and therefore HIV messaging around issues of faithfulness has to be revisited from an organisational perspective.

Workshops that I conducted with community workers and counsellors in 2007 and 2008 indicated that young people chose oral and anal sex as alternatives to vaginal sex, suggesting that it would 'preserve

their virginity' for marriage (Govender, 2010; Moodley, 2007).¹⁷ Discussions at these workshops suggest that youth have an internal way of making meaning of what can sometimes be mixed and confusing messages based on their own social reality and contexts in which they live. HIV messaging therefore runs the risk of offering multiple and contradictory meanings that can suggest that HIV programmes are not working (Moodley, 2007; Govender, 2010; Moodley, 2012).

Theme Three: Getting Young People Involved – Organisation's Reflections

The section below discusses the data categorised into the third theme on young people's participation, and how various organisations include young people in the different phases of developing HIV related projects.

Many organisations mentioned that they created opportunities for young people to feel free and comfortable to discuss issues that affect them. The *Field Band Foundation*, *One Voice*, *YFC* and *DramAidE* all discussed how they mobilise young people to freely express their opinions without a sense of intimidation (*Field Band Foundation*, interview, 2011), and to ensure that they can ask questions in a free and safe environment (*One Voice*, facilitator focus group, 2011). Young people are often not given the opportunity to freely express or openly discuss their experiences and the realities of living with HIV and AIDS (Govender & Reddy, 2011). In her forward for the Phila Impilo! Project, Diane Melvin (in Kruger, 2008) explains that children and youth are severely infected and affected by HIV but their voices are often unheard. Organisations therefore need to provide a space for young people to share their needs and interests; Bessette and Servaes identify this as the first pivotal components of participatory development (Bessette, 2004; Servaes, 1999). The inclusion of young people in developing HIV programmes and programmes was supported by all organisations, which led to discussions about the specific phases that young people could participate in.

Organisation's Phases for Developing HIV Programmes

Discussions with the various organisations about the phases of developing HIV projects was further categorised into four common stages. These included the process of research, design or development of an intervention, facilitation and evaluation. These are usually the four main categories of strategically

¹⁷ A provincial workshop for counsellors and child care workers was held at the Southern Sun Hotel from 12-14 November 2007. During a discussion about HIV prevention and approaches, child care workers shared some of the challenges they face with young people in communities and the misconceptions and confusion caused by the current HIV AND AIDS prevention approach.

developing programmes (McKee et.al, 2004) and were discussed in these phases to understand how young people are participating in these various phases for developing HIV programmes.

Research: The First Step to Developing a HIV Programme

Most of the sample organisations indicated that research informed all the programmes offered to young people. There were various sources of research used to contribute to the design of their HIV programmes. Three common research sources identified included: national studies and research conducted on young people's sexual practices, discussions with various stakeholders about HIV programmes, and discussions with young people and observations from the field.

General Research Determines Key Issues for Young People

Experience from the field and national research findings were central to informing the research phase for developing HIV programmes in *Youth for Christ*, *Focus on the Family*, the *One Love* campaign, *One Voice*, *loveLife* and *DramAidE*. However, many organisations also incorporate discussions with young people into their research phase. *One Voice* relies on the current research obtained through national surveys, attending HIV conferences and various studies conducted on young people to understand the "current epidemic drivers at the time of developing the programme" (*One Voice*, interview, 2011). In the same light, national research such as the HIV prevalence studies conducted by the Human Science Research Council (HSRC) informed the development of the *Scrutinize* campaign. The 2008 survey, for example, indicated that "multiple and concurrent partners was prevalent in particular amongst younger population groups" (*Scrutinize*, interview, 2011).

JHHESA, the commissioning body for *Scrutinize*, indicated that the "quantitative research, which is these big surveys, was then complemented by qualitative research which was done by CADRE, to understand young people's views on multiple sexual partners" (*Scrutinize*, interview, 2011). The development of *Scrutinize* was therefore based on extensive research conducted nationally, as well as more specific qualitative research with young people from various locations. The *One Love* campaign developed by *Soul City* is similar to *Scrutinize* and *DramAidE* as it is informed by extensive research in the field about factors that influence risky sexual behaviour. The Research Director of *Soul City's One Love* campaign suggests that research began in 2006 and confirmed that multiple and concurrent partners were a key issue.

Extensive research also informed the development of *DramAidE* and the specific projects offered within the organisation (*DramAidE*, interview, 2011). The Director of *DramAidE* says that “the *DramAidE* concept emanated from initial work that was done by Lynn [Dalrymple] through CCMS” that was conducted as research for her PhD (*DramAidE*, interview, 2011; Dalrymple, 1986). This was later implemented as the theoretical and methodological foundation for a drama in education programme, *DramAidE*. The project has therefore influenced the drama and HIV field since the late 1990s. Several research projects have been conducted on the work of *DramAidE*, exploring the effectiveness of drama and its contribution to educating young people about HIV and AIDS (see Durden & Tomaselli, 2012; Botha, 2009; Ndhura, 2004; Baxter, 2008; Gumede 2012; Bourgault, 2003; Tomaselli, 2011). What these projects indicate is the importance of research in informing the development of organisations like *DramAidE*.

The organisations therefore considered research to be a central component for developing research-informed HIV programmes, with most of the organisations conforming to a broader data source of research to understand young people’s sexual practices. Campaigns offered through *Scrutinize*, *One Love* and *loveLife* all indicated that national surveys and findings were the key attribute to informing the development of their HIV programmes. The participatory organisations like *Focus on the Family*, *Youth for Christ*, *DramAidE*, *Field Band Foundation* and *One Voice* also drew on national research but also on suggestions from young people in the field.

Discussions with Various Stakeholders about Key Issues of Young People

Organisations such as *DramAidE* and the *One Love* campaign indicated that their use of research in developing HIV programmes also stemmed from the need to include various stakeholders in this process. The research process with facilitators at *DramAidE* is described as firstly going to schools to talk to the principals, teachers, peer educators, and possibly the executive committee, to discuss what is happening in that particular school with young people’s sexual practices and wellbeing. The *DramAidE* team then prepares a workshop that is reflective of the needs of the young people at that specific school. The *One Love* campaign and *Scrutinize* also work with various stakeholders across the country when developing their communication strategy that is also informed by national findings of young people’s sexual practices (*One Love* campaign, interview, 2011; *Scrutinize*, interview, 2011). This indicates that national surveys and discussions with stakeholders play a crucial role in developing HIV projects and programmes and, in some instances, young people do inform part of the stakeholder discussions, as suggested by the work of *loveLife*’s community dialogues.

Young People Determine their Key Issues

The *Field Band Foundation* uses a slightly different approach that is more participant oriented. At the start of a three day workshop, youth are asked to complete an exercise that provides insight into their backgrounds. The facilitator commented that “we collect the books at the end of the day, we go and read all of those exercises and we know how to target individuals that have been identified without exposing the child” (*Field Band Foundation*, focus group discussion, 2011). This approach ensures that each workshop is designed after a review of the needs of the young people attending the workshop. This forms the research phase of the workshop, but facilitators follow through on this initial data with developing the workshop programme. Similarly, *Focus on the Family* reviews the programme and content and discusses ways to tailor the programme for young people (*Focus on the Family*, interview, 2011). The programme manager discusses the various contextual factors such as MCPs, moral dilemmas and lack of sufficient and correct information, and suggests that more research will allow people to learn from each other and draw on knowledge and information from each other towards understanding safer sexual practices. Working with young people allows the organisations to assess if their programmes are successful and for the programmes to be adapted accordingly. *YFC* suggests that they modify the programme each year if young people report that it has been a failure.

Discussions with the sample organisations about the research that informed their development of HIV programmes and interventions mostly indicated that research was either driven by the facilitators working with youth, or based on the findings of national surveys. In the case where facilitators worked with young people, *DramAidE*, *Youth for Christ* and *Field Band Foundation* have discussions with various stakeholders, including learners, to understand the challenges which affect them. Young people in this sense are contributing to the research that informs the development of the workshops, plays and other interventions. The data presented above questions how much youth participation and involvement is taking place within organisations, particularly at the research phase. Many organisations are still more dependent on national surveys and research to reflect young people’s sexual practices, and this can sometimes mean that they lack a thorough understanding of the context or the specific issues that young people face within their own communities. The data therefore highlights the importance of adopting a more inclusive approach to the research phase of developing programmes, where youth can actively participate in HIV prevention.

The Development of HIV Programmes

Development of programmes is usually the second phase when developing HIV projects, and the sample organisations described different processes as well as involving different people in this phase. *One Voice*, for example, does not have the “capacity to develop the content” themselves and therefore approached consultants who are experts in curriculum development, participatory methodology and social change communication to develop the content of training material and toolkits for young people (*One Voice*, interview, 2011). The organisation suggested that even though the content was developed by consultants, the topics addressed were always youth-informed.

In the case of *Youth for Christ*, the programmes and interventions were selected and designed by facilitators based on experiences in the field with young people, as well as using material developed for YFC nationally. *loveLife* built multiple programmes that were mostly developed by experts, but informed by young people. Discussions with the programme manager of *loveLife* indicated that young people were consulted when developing community projects and workshops (*loveLife*, interview 2011). However, previous studies on *loveLife* indicate that their billboards in particular were developed by a team of advertising experts and very rarely reflected the experiences of young people, and were often decoded differently to the way they were intended by the designers (see Prinsloo, 2007; Tomaselli, 2009; Delate, 2007).

The overall message of the *One Love* campaign was developed by experts after consultation with various stakeholders in each of the countries where the campaign was conducted (*One Love* campaign, interview, 2011). However, the design and development of resource material was specific to each country and language requirements. The campaign was supported by the messages integrated into the *Soul City* TV and radio series (*One Love* campaign, interview, 2011). Young people did not inform this design process, but instead participated in the testing of *One Love* as a campaign brand. This indicates that various campaigns and programmes require a different level of participation. Media products cannot always be developed by young people, but youth can provide ideas about what will work for them. Their participation therefore takes a very different form that has to be adapted to suit specific contexts. This is also evident in the case of *Scrutinize*.

The design and initial creative development of *Scrutinize*'s media products was done through Levi's, who sponsored the campaign and developed by Matchboxology, a creative design agency. JHHESA then pre-tested what was developed in three different locations to explore whether the format would be

appropriate to the audience. Whilst the design of *Scrutinize* was done by Levi's and Matchboxology, the process of testing and pre-testing the animerts allowed for young people to comment on how they understood the animerts and to offer possible suggestions. Young people particularly contributed to what types of issues were represented and developed through the animerts, instead of the actual design that had to be the work of professional designers.

Facilitation or Implementation – Peer Education

Facilitation or implementation is the third stage of developing a HIV programme or intervention. Most organisations used either a peer education approach or worked with young facilitators in schools and communities. The schools programme offered by *Youth for Christ* follow a peer educator approach where high school students choose peer educators to work in their schools, but also modify the programme to offer to an affiliated primary school. The programme coordinator of *YFC* reported that “these peer educator programmes also give young people an opportunity to decide what they want to do and how to take action” (*YFC*, interview, 2011).

Peer educators become role models to the young people (*YFC*, facilitator focus group 2011) and also help youth to overcome peer pressure through life skills that emphasise self-esteem for youth. Young people at *One Voice* are encouraged to share the knowledge they receive about HIV with their communities and families, therefore taking on the role of peer educators (*One Voice*, facilitator focus group, respondent 3, 2011). The facilitation of workshops by youth promotes discussion and dialogue among learners and demonstrates the benefits of taking a peer educator approach to facilitation or workshop implementation. Even in cases where the programme was already researched and designed by experts or consultants, the actual implementation of the programme is conducted by young people.

In the case of *DramAidE*, peer education is evident in their Act Alive programme, where youth can practice their life skills in a safe environment. The programme encourages young people to take action, by introducing a range of life skills that provide an opportunity for young people to later participate in projects to practice some of the skills such as communication, organising themselves, goal setting, organising a campaign and learning how to work together as a team (*DramAidE*, interview, 2011). *Scrutinize* has also made use of the peer education approach through its facilitation strategy in tertiary institutions, communities and schools (*Scrutinize*, interview, 2011). In 2008, HIVAN (the Centre for HIV AND AIDS Networking) worked with *DramAidE* to develop some of the participatory games for the university campaigns. Peer educators were recruited on various campuses to assist with the promotion

of the *Scrutinize* message and addressing questions or concerns that arose with students during and after the campaign¹⁸.

Amongst the eight sample organisations, peer education was also a common way of motivating young people to participate in HIV programmes. In most of the organisations, young people between the ages of 18-25 were the facilitators of the programmes. Whilst the facilitators can act as peer educators to the learners, the programme tries to mobilise peer educators among the learners themselves. Peer education makes use of the participants and the facilitators who share similar interests or the same cultural position in order to discuss positive behaviour change and lifestyle choices. Peer education involves the dissemination of health-related information and in some cases condoms by peers to other peers and has recently become one of the most popular and widely used HIV prevention strategies (Campbell & MacPhail, 2002).

In the cases of school and community projects that promote HIV prevention and educate about the risks of HIV, it was often found that specific peer education programmes ensured the inclusion of youth in implementing or facilitating programmes. In cases like *Focus on the Family*, and *Field Band Foundation* that did not have peer educators, young facilitators were used, who could usually relate to the issues that youth face. Peer education was the most common inclusion of young people in the phases of HIV programmes and interventions. In the case of national campaigns like *Scrutinize* and *One Love*, young people often facilitated community dialogues or workshops using the material as a guide to initiate discussion on a range of issues. Overall, the sample organisations and programmes appeared to have the most strength in incorporating young people in communication processes particularly in the phase of facilitation.

Evaluation

Several organisations indicated that it is difficult to measure the impact of their programmes due to funding restrictions, but also because the programmes offered were targeted to small communities and schools with specific needs. In addition, since the success of programmes in an HIV context is often associated with behaviour change, there is a challenge in how this change can be measured. A facilitator from *DramAidE* indicated that “there’s a problem when we talk about services that we offer, because we can’t measure, it’s very hard to measure the impact that *DramAidE* has, as it takes time for

¹⁸ In 2008 I worked with HIVAN in my capacity as a programme developer and researcher during the time of the University campaigns.

people to change” (*DramAidE*, facilitator’s focus group, 2011). However, *DramAidE* does conduct evaluations to ensure that the workshops offered remain adaptable. *DramAidE*’s process is informed by research, for the development of workshops, and “it was piloted and then implemented, but since then we always evaluate our work so that it adapts” (*DramAidE*, interview, 2011).

Overall, most organisations did not include youth in participatory evaluations. *One Voice*, however, indicated that they taught participants how to conduct evaluations through a workshop that was offered to young people on “Project Monitoring and Implementation and Evaluation”. Young learners developed creative project plans and were scored by facilitators for their innovation in developing an HIV intervention that could be evaluated (*One Voice*, Interview, 2011). *One Voice* therefore offered youth an opportunity to learn about evaluations but they did not conduct evaluations on their own programmes of *One Voice* themselves. Young people were therefore excluded from the evaluation phases because many organisations did not have the time or resources to conduct evaluations. In the case of *Scrutinize*, *loveLife* and *One Love* campaigns which are more national campaigns, evaluations were conducted as part of the national communication survey. These evaluations took the form of audience analysis, and therefore they did not include young people.

Participation in Developing HIV Programmes

The discussion above suggests that young people are not actively participating in developing programmes and interventions offered by the various organisations. Instead, participatory approaches are used for engaging youth, but this does not translate to their participation in developing specific programmes that address the needs of young people. The development of programmes therefore lacks a youth-informed perspective in terms of participating in the various phases of development. Participation is therefore taking place, but not in the genuine sense of participation that Cornwall (2002) describes as the involvement of youth in all activities which are often initiated by agencies and donors. Cornwall goes on to discuss Foucault’s (1991) description of participation as “political technology” that is often used to manage projects and processes, through exploring the possibilities of popular engagement (2002:5).

This indicates that the sample organisations are still key contributors to the development and design phase of HIV programmes in consultation with various stakeholders, incorporating the findings of national research and with some participation from young people, Whilst the organisations themselves control the processes of research which inform the programme design, some organisations such as *DramAidE*, *Youth for Christ*, *Field Band Foundation*, *One Voice* and *Scrutinize* work with young people

to jointly explore some of the challenges that affect young people's sexual practices. For example, three workshops conducted with young people in three different provinces resulted in young people suggesting that they could actively participate in HIV interventions by being part of youth advisory boards in the various organisations that they were part of (Dance 4 Life workshop report, 2008). *One Voice* now incorporates youth in their work by establishing a youth advisory board to provide insight into the specific programmes which they attend. The board is one way of ensuring meaningful participation of young people with the objective of providing insight into the real issues which effect young people (*One Voice*, interview, 2011).

Facilitation appeared to be the most shared phase between organisations and young people, through peer education programmes. Many organisations did not have the time, expertise or resources to conduct evaluations that could now be seen as having the potential to draw on young people's involvement in the evaluation phase of developing HIV programmes.

Theme Four: Benefits of Youth Participation

The final section of this chapter presents the fourth theme developed based on data collected from Phase One of this study. Central to all data collected through the interviews with directors and/or programme managers, and focus group discussions with facilitators, was the emphasis on the need to recognise and adopt the benefits of youth participation. Discussions with the eight organisations predominantly pointed to three areas of participation that include: that participation allows for ongoing dialogue and discussion with young people; participation empowers young people to make informed choices; and participation needs to recognise the importance of context.

Participation Allows for Ongoing Dialogue and Discussion with Young People

The terms 'discussion' and 'dialogue' came up very frequently in all interviews and focus groups, indicating that facilitators were engaging in ongoing dialogue with young people on a range of HIV related issues. The sample organisations all offered accounts of how dialogue is used to advance their own programmes with specific reference to the sustainability of community dialogues. Community dialogues have been an integral part of the *One Love* campaign that empowers groups of people to run dialogues in their communities about sexual norms and multiple and concurrent partners in order to understand how communities could support people in *One Love* partnerships (*One Love Campaign*, interview, 2011). *DramAidE* also facilitated a range of community dialogues in KZN in 2011 and 2012, unpacking issues of sex, gender, reproductive health and HIV, among other topics. Feedback on

community dialogues from organisations indicated that young people were keen to use dialogues to explore their ideas, perceptions and solutions to problems. The process of dialogue therefore encourages participation.

One Voice, in particular, found that when young people are engaged in discussion all the time they start to open up and talk about topics with which they are concerned. The *Field Band Foundation* also allows participants to freely express themselves among their peers without a sense of intimidation (*Field Band Foundation*, interview, 2011). *Youth for Christ* reported that young people often debate about topics in class, and the facilitators are trained to handle conflict and to offer solutions by providing correct information. Similarly, *One Voice* identified that youth discuss their problems in class and also go to the facilitator for a one-on-one discussion (*One Voice*, interview, 2011).

Ongoing discussion in the workshops with young people was common in all organisations, with many facilitators indicating that this dialogue encouraged more active participation. My previous experience in workshops that I facilitated for an organisation on meaningful participation indicated that young people were not willing to participate in focus group discussions or engage in dialogue about their ideas and experiences, but rather expressed themselves extensively through the use of collage, fabric painting and role plays. This emphasises the importance of understanding the needs of the target audience and their preferred method of communication, before developing a workshop since adopting the appropriate workshop methodology and method of communication are also important when encouraging participation.

The Director of *Youth for Christ* reported that communication is central for young people to understand who they are and what they need. When young people are able to communicate and accept themselves, peer pressure reduces which then allows them to make informed decisions (*YFC*, interview 1, 2011). The importance of dialogue was also evident when *loveLife* suggested that dialogues and discussion have extended beyond young people simply talking with other young people, but also to create forums for parents and youth to have discussions about cultural practices and conflicts that affect all of them (*loveLife*, interview, 2011). Communication through dialogue therefore encourages a process of participation, where young people are given the space and opportunity through the programmes offered by the organisations to talk about who they are, what they want and how they will go about achieving this. This process is in accordance with what Kincaid (*et.al*, 2007) termed communication for participatory development, where the process of community dialogue can ultimately lead to community action.

Dialogue Promotes the Development of Problem Solving Skills

Through the process of dialogue and discussions that were often encouraged through participatory activities of role play and interactive games, more young people are starting to think critically about the influences of HIV and how to prevent infection. A range of problems were often posed to youth that serve as catalysts for discussion and ongoing dialogue about how to address common problems. Problem-posing methodologies were discussed in the work of *DramAidE* and *loveLife*. *DramAidE* conducts forum theatre which poses problems and encourages young people to solve the problems, “so when they solve the problem, they use what they’re familiar with” (*DramAidE*, facilitator focus group, 2011). Another facilitator indicated that this method is premised on the notion that “we want people to question, and to come to alternatives that work for them and make sense of the world around them, because in that way the responses are going to be more authentic and more applicable to their personal lives” (*DramAidE*, interview, 2011). *DramAidE* reported that teaching young people negotiation skills can equip young girls in particular with life skills for communication, problem solving, decision-making and negotiation, which are skills needed to solve problems (*DramAidE*, facilitator focus group, respondent 2, 2011). Problem-posing involves posing questions that in turn initiates a dialogue between young people and the facilitators about differing views.

The interview with *loveLife* poses a range of questions to youth to assess where they are in life and what they want out of life. Some of the questions posed to young people include “where do you want to be in life, where do I see myself in years to come. Then now that you know where you want to be, what are the things that you are going to do to ensure that you get where you wanted to? Then they tend to own the process, because you’re giving them that sense of ownership” (*loveLife*, interview, 2011). The process of dialogue empowers young people to take ownership for their own situations through a process of problem-posing questions. The work of *loveLife* is informed by a communication for participatory development process that poses three questions of 1) where are young people, 2) where do they want to be, and 3) what do they need to do to get there, and indicates that *loveLife* facilitates the processes of dialogue with young people, that develops their problem solving skills. In this way, the data indicates that in addition to the various catalysts¹⁹ that the CFPD model proposes to initiate community dialogue, a process of problem-posing and problem solving serves as a catalyst towards encouraging dialogue with young people.

¹⁹ The CFSC model highlights six catalysts that can initiate a process of dialogue. These include an internal stimulus, a change agent, an innovation, policies, technology and mass media (Figueroa et.al 2002, 6).

Participation Empowers Young People to Make Informed Choices

The *Field Band Foundation* offers HIV life skills workshops to empower young people to make informed choices. A facilitator from the organisation reported that through life skills workshops young people are empowered to make “better lifestyle choices”, as the use of behaviour change programmes tries to delay the start of sexual activity among young adults. One facilitator reported that “what I like about our workshop is that we make sure we inform them so that they take their decisions. That’s what we say: just *Scrutinize!* Take a closer look, if you feel this is wrong, if you feel that it’s right, it’s up to you” (*DramAidE*, facilitator focus group, respondent 2, 2011). Young people are therefore presented with options for their sexual practices, but are also empowered with life skills to make those informed choices.

Empowering young people was strongly linked to making informed choices and decisions in the work of *Youth for Christ*, with one facilitator reporting that “when we go to schools, we put the emphasis on choices. So as much as people see AIDS as a problem, it’s not, it’s just people need to make good choices” (*YFC*, interview 2, 2011). *One Voice* also commented on the importance of making informed choices, several facilitators commented:

R7: It’s like giving them a choice because we can say ok you can take it or leave it, it’s up to you,

R3: it’s not always the same because their behavioural change...some of them, you can tell them something this year and then maybe it will take them 5 years to change. So the reason why you always need to go back to those communities because whatever we are planting there, though you won’t see the fruit at the same time, but we know that we are planting something there in them, then it’s up to them which decision they take.

R2: give them advice, then it’s up to them what choices they going to be making with their lives.
(*One Voice*, focus group, 2011)

These comments offered by facilitators of *One Voice* indicate that the ultimate decision-making process is left to young people, where facilitators only relate information to young people and provide a free and safe environment for engaging in discussions. Young people then need to make their own decisions about their sexual practices. *Focus on the Family’s* programme gets young people to think about their vision for their life five or ten years from now and the informed choices that need to be made to achieve that objective. The programme encourages youth to map their plans and aspirations for the future, encouraging many of them to give thought to careers and life goals for the first time. Young people are empowered to act on the steps that they decide to achieve these goals, reinforcing the objectives of the

work of *Focus on the Family* which is to ensure that the learner is equipped with enough information to make an informed choice (FOTF, interview, 2011).

In other organisations, life skills are taught to ensure that young people know how to handle conflict, communicate honestly, and make informed decisions. *Youth for Christ* indicates that the key to making decisions is communication with “the ability to communicate honestly about who they are and what they need” (YFC, interview 1, 2011). This indicates that once youth are able to make informed choices, this becomes the first step to empower them to communicate further about their needs and how to fulfil them. Communication for participatory development is therefore particularly evident in the work of *Youth for Christ*, *DramAidE* and *One Voice* where the process of ongoing dialogue would ultimately lead young people to a process of collective action.

The Director of *One Voice* reported that young people at schools developed a sign which said “Protect yourself, Condomise”, which is placed at the entrance of the school. “Young people reported placing the sign at the front of the school “because they wanted people who come in and out of the school to constantly be reminded of that” (*One Voice*, interview, 2011). Young people attending the *One Voice* programme also helped an orphanage where the children did not have food and clothes and collected a donation to contribute to the orphanage. She further highlighted how youth were “suddenly awakened to other issues in their community, they’re becoming active agents almost, to make a change in their community, because they may not have a problem, but other people may have a problem, so these projects also encourage meaningful participation” (*One Voice*, interview, 2011). Another facilitator commented that “once we have given them the information, we also encourage them to go out and give it to their communities. It’s not only within their schools but they’re also able to give it to their families, and their peers also” (YFC, facilitator focus group, respondent 3, 2011). The data therefore indicates that imparting life skills to youth further mobilises them to take collective action in their communities. This advocacy role that is evident in some of the organisations’ work highlights the importance of working beyond just the empowerment of individuals. This information also needs to be shared with their peers, families, and communities that is important in the context of development where the active participation and empowerment of young people is considered within a wider social ecological framework.

Participation Recognises the Importance of Context

The work of several organisations indicates the importance of context. Through a process of ongoing dialogue, and problem-posing and problem solving discussions, the experiences of young people all

indicate that HIV messaging has to be developed with an understanding of the context. The importance of recognising cultural values and social influences were strongly advocated in the *DramAidE* focus group discussions and also highlighted in the interview with the Director. Several facilitators commented on the importance of recognising cultural beliefs and working within the community to address the diverse views. One facilitator discussed this diversity based on her experience in the field, saying that “sometimes you work in a community where it’s a common belief that they must do arranged marriages, or arranged relationships”; the facilitator indicated that the schools programme then has to be adapted to cater for arranged relationships or marriages where young people may already be sexually active or in multiple relationships (*DramAidE*, facilitator focus group, respondent 4, 2011). Another *DramAidE* facilitator echoed the experience of Respondent Four when she commented that “you go to the school and take a play to this school, it’s specifically to the needs of that particular community. And then you go to another school and you change the play, so that you know when they watch the play, they can actually relate to the issues” (*DramAidE*, facilitator focus group, respondent 2, 2011).

loveLife also reported that HIV challenges differed in each community, commenting that “if you get into this community and you tell them the challenges that you think they have, you’ll find that it’s not that” (*loveLife*, interview, 2011). The *Field Band Foundation* adapts their programmes for young people based on the cultural influences and context that affect what HIV messages are given during the workshops. Several facilitators commented that whilst they make use of manuals that are developed for the workshops, the material is always adapted based on their understanding of a particular issue which takes into account cultural and social influences (*Field Band Foundation*, facilitator focus group, 2011). Similarly, discussions at *Youth for Christ* also indicated that root causes of HIV needed to be addressed, where the influence of social and cultural influences could not be ignored.

The *Youth for Christ* Programme Coordinator highlighted that gender imbalances also posed complex constraints on how HIV messages are received. “Looking into the communities that these young people are coming from, looking at our culture, where women are not given much rights, but men are, so dealing with gender issues enables these young women to be able to stand up for themselves when they grow up” (*YFC*, interview 2, 2011). Decision-making was therefore influenced by culture from the experience of *Youth for Christ*: “The culture in black communities, the culture has a lot to do with it. In decision-making our culture has a lot to do with it” (*YFC*, interview 2, 2011). This suggests that even through a process of dialogue, that equips youth with life skills and encourages them to make their own informed choices, the influence of culture still plays a significant role in what decisions can be made. The cultural context therefore has to be acknowledged in the decision-making process.

One Voice also reported that addressing cultural contexts was crucial when working with young people, “during one of these workshops she started talking about sex, and two or three of the Muslim girls said no, we don’t want to talk about this, we’re not allowed” (*One Voice*, interview, 2011). This experience points to the need for HIV projects and programmes to be designed for specific target participants in specific settings. *One Voice* facilitators indicated that young people from rural areas and those from urban areas are very different and sometimes have different issues affecting them. This needs to be considered when designing school programmes for them (*One Voice*, interview, 2011).

Youth for Christ also indicated that the age and context of young people are important, highlighting that the Pietermaritzburg and Durban areas are very different (*YFC*, interview 2, 2011). *DramAidE* reported that the context is very important, “it happens in a context and this context is sometimes just too vast, too vast for us to comprehend. So why do you speak about messaging and not speak about the whole context that society’s change” (*DramAidE*, interview, 2011). The issues of age, gender imbalances, and cultural and social influences all contribute to the context in that young people make decisions about sex, and cannot be ignored when developing HIV programmes. Young people’s participation in the various phases of developing projects and programmes will accommodate and provide new insight into these various contexts that are very specific to different participants.

Most of the organisations attributed processes of youth dialogue and discussions with facilitators, the need to empower youth to make informed choices, and the importance of recognising the context as central for when working with young people. Addressing the importance of dialogue, empowering youth and recognising the importance of context, can be argued to contribute to more effective participation with young people. The challenge of this participation still remains in how to integrate active participation of young people into all phases of developing HIV programmes.

Conclusion

This chapter introduced the first phase of data collection and analysis where interviews and focus group discussions were conducted with eight organisations, focusing on their specific HIV programmes offered to young people. The data indicates that the various organisations that offer national mass media campaigns often support their approaches with community dialogues and participation. The

organisations also address a range of issues that influence risky sexual practices which were also identified by the various national HIV prevalence surveys (Shisana et al, 2002, 2005, 2009).

The research found that the messages offered to youth over the last decade have not changed and still fit within the “ABC” framework, but how organisations relate this information and adapt these messages to the challenges young people face have changed. More specific data on participation indicates that organisations still manage the development of HIV interventions and programmes, with young people participating most in the facilitation phase, with some participation in the research phase. Overall, organisations advocated for continuous dialogue with young people, developing their life skills and empowering them to make informed choices and always recognising the importance of context when developing HIV messages. While participation of young people was not evident in all phases of developing programmes, the organisations were still engaging young people in processes of dialogue for collective action within a wider framework of communicating for participatory development.

The next chapter offers a review of bodymapping as a technique to encourage participation with young people and is based on the data in this phase that indicates that whilst young people do participate in some phases of developing HIV programmes, organisations need to explore other participatory techniques to engage youth in actively participating in developing HIV projects.

CHAPTER SEVEN: BODYMAPPING, EXPLORING ITS APPLICATION (PHASE TWO)²⁰

Introduction

This chapter analyses the data generated from Phase Two of the data collection process that involves an exploration into how young people, specifically students at UKZN and young people in some communities in KZN, experience the bodymapping process. My aim is to identify what their experiences suggest about the use of bodymapping applications towards developing youth-informed HIV programmes. Bodymapping can be applied to a range of socio-economic, cultural, socio-psycho, educational and development issues, this chapter explores the relevance of the bodymapping process for encouraging participation with young people, rather than the specific issues it has been adapted for.

The chapter commences with a discussion on the use of bodymapping with young people at UKZN. Young people's experiences are explored towards understanding how bodymapping can be adapted and applied to encourage their participation in the development of HIV projects. The data collected from phase one and presented in the previous chapter indicates that HIV organisations are giving some consideration to the participation of young people but this is more evident in the methods used to engage young people, rather than their contribution to the various phases of developing youth-informed projects. An exploration of the bodymapping process in this chapter will indicate whether bodymapping can serve as a tool to get young people to engage and participate in the various phases of research, design and facilitation that are the common phases for developing HIV projects. The chapter also addresses the strengths and weaknesses of the bodymapping methodology as identified by the experiences of young people. My ten years of previous bodymapping experiences with young people is interwoven into each of these sections to reflect the different perspectives of bodymapping. This chapter addresses one of the sub-questions outlined in chapter one of this thesis that questions how the techniques of bodymapping might be used to involve young people in the design of HIV programmes.

²⁰ Exploring the perceptions of students' bodymapping experiences in 2009 and 2010 was conducted with assistance from research assistant Sertanya Reddy. The findings of this bodymapping workshop were presented at the SACOMM 2009 conference in Johannesburg, and later drafted into a paper for publication by Emma Durden, Eliza Govender and Sertanya Reddy. The paper is still in its draft stage at the time of submitting this thesis and will be submitted to an appropriate journal.

This chapter therefore highlights the participatory action research perspective as it draws on bodymapping workshops conducted over a long period of time, in some cases with the same participants, and in other cases with new participants each time. The auto-ethnographic perspective is used to describe my experiences and observations as a facilitator and researcher and sometimes as a participant in the various stages of bodymapping. The grounded perspective is applied in a way that allows the data to be coded and categorised, later forming themes that create a broader perspective of bodymapping as a tool for participation.

Exploring the Need for a Bodymapping Process

Bodymapping workshops were an initiative offered by the Centre for Communication, Media and Society (CCMS), annually from 2009 with new post-graduate students. The initial intention of these workshops was to assist students in making informed choices about their choice of research topics and how to research and develop their Honours research projects. The workshops were developed in response to the challenges students faced with class participation that is essential at post-graduate level. Students would often attend class to receive information rather than engage in discussions about a specific topic. Ownership of their learning process was therefore not evident. Lauren Dyll-Myklebust, a lecturer of the post-graduate course, added that “the majority of the students appeared ill-prepared to take such ‘control’ of their own learning” (email correspondence, 2009). This caused tremendous pressure on lecturing staff who often spent several hours in consultation with students to assist them with research projects and to promote participation in class. Whilst this chapter makes reference to examples of bodymapping workshops conducted on postgraduate students, the bodymapping process was important for establishing an understanding of participation.

The importance of participation was also emphasised in workshops I conducted across three provinces for the Dance 4 Life programmes in 2008. Many facilitators identified that youth attending schools would only receive the education provided by teachers at schools without taking ownership for their own education. However, participatory approaches such as dance, drawing and role plays engaged young people in dialogue, discussion and often debates which sparked more meaningful participation among the learners (D4L report, 2008). My own observations during the workshops confirmed that young people would simply answer questions that they were asked, but when placed into a creative and safe environment, the use of collage and poster development encouraged participation and allowed young people to freely express themselves (ibid).

In addressing problems of participation and engagement with post-graduate students, an entire day was allocated to offer an intensive workshop to encourage active participation and dialogue among students. The workshop was an attempt to translate the theory taught in class into practice, making use of the principle devised by Paulo Freire (1976), who suggests that people need to be critically aware of their social reality, in order to be empowered to change it. The workshop applied some of these Freirean principles, and aimed to generate dialogue among the postgraduate students, and to engender self-confidence in addressing the above factors.

My observations from conducting bodymapping workshops for the last ten years has always indicated in both urban and rural areas that bodymapping serves as a crucial introspective tool to help young people to start thinking about challenges in their life and what they can do about these issues. Workshops conducted with groups of women in the Mtunzini, Mtubatuba, Umlazi and Veralum areas in 2006 and 2007 highlighted the process of self-reflection which often takes place through the bodymapping experience (SAB report, 2007). The section below discusses the bodymapping process and how it was adapted specifically for the post-graduate students, and includes some of the findings about the use of bodymapping to engage young people.

Adapting the Bodymapping Process for Postgraduate Students

Bodymapping was developed in 2002 to assist women who are HIV positive to share their life stories. The technique was developed by Jonathan Morgan and Jane Soloman and was first explored with a group of women in Cape Town. Created as an advocacy tool for HIV and AIDS awareness, disclosure and diagnosis, this technique is now used around the world as a process to facilitate HIV and AIDS workshops. Bren Brophy and I adapted the steps of bodymapping to be used at the post-graduate workshop to assist students to identify their research interests and how these can be explored in their research projects. The bodymapping technique of mapping and drawing using a range of creative materials, but the steps or the questions posed to participants were always adapted to cater for the needs of the specific workshop group. This indicates the adaptability of the bodymapping technique, as we were able to apply the bodymapping process to an academic context, addressing the specific needs of students.

The bodymapping process involved each student tracing a life sized outline of their body onto a piece of paper and then 'mapping' their thoughts, ideas, emotions and dreams and plans on the bodymap. The mapping process involved both text and the drafting of small pictorial images in a variety of

mediums. The process of mapping was linked to various body parts with specific steps that tried to gain insight into what the participants were seeing, hearing, speaking and doing. This was done by exploring the power of the eyes, power of the ears, the power of the mouth, the power of the mind, the power of the heart and the power of the hands and feet (for more specific workshop questions, refer to Chapter Three).

Exploring Bodymapping Processes with Young People

The findings below indicate some of the common themes that were evident across all focus group discussion transcripts and students' overall comments at the end of each workshop (2009, 2010, 2012). These comments have been categorised into seven common themes and sub-themes which are discussed below.

Theme One: Bodymapping Increases Confidence to Engage and Participate

The first theme that featured strongly in all focus group discussions centred on the issue of confidence. Overall, youth felt that the bodymapping process helped to develop their confidence which encouraged more self-initiative and active participation for their own studies. When young people are mobilised and feel confident to participate, they are able to define their own problems, lead the process of investigation, and identify their own solutions. Through this process, they are then able to develop the capacity to participate in decisions that affect their own lives (Amsden & Van Wynsberghe, 2005). This suggested that young peoples' confidence levels increased when they participated in the bodymapping process, as the free space, self-reflection and creative mediums of communication made them more pro-active to explore what they needed to do for their own careers and academic year of study.

Lecturers also observed that students were more engaged and confident to participate in CCMS activities.

The change has been remarkable. Timid students who had barely worked together now were confident, actively participated in CCMS activities, volunteered for field excursions and most importantly, felt included, rather than apprehensive (Keyan Tomaselli, email correspondence, 2009)

Students were therefore no longer apprehensive about participating because they were more confident in engaging with staff and students in the Centre. This indicated that when young people interact and have discussions with adults or other people about issues that affect them, it can lead to a greater level of confidence for participation. The bodymapping workshop was directly attributed as the motivation for

a change in attitude with how young people responded to their lecturers, peers and coursework. One student commented:

Gone are those days where I would stand sheepishly in the Media corridor, unsure whether I would be allowed there or not. I began the year with the same apprehensive feeling about the postgrad office. But, soon I changed my attitude (Bhavya Jeena's short observation in *SUBtext*, 2009, p. 4)

Lecturers in classrooms also identified the increased level of confidence, especially in class presentations where students were required to present on a specific topic. This confidence to participate is often associated with trust which is built over a period of time between the beneficiaries of a project and the facilitators, and is often termed social trust. Facilitators from the Dance 4 Life programme commented during workshops I facilitated with school learners that young people felt they could trust their Dance 4 Life facilitators instead of their teachers, as they developed a relationship and built trust with their facilitators (D4L report 2008). This indicates that trust is a crucial aspect of giving young people the confidence to engage in meaningful participation.

Catherine Campbell and Catherine MacQuail conduct extensive studies with young people in South Africa that demonstrate the importance of trust, social capital and secure environments in building the confidence among young people to participate and engage in sensitive topics like HIV. Development is easily attainable when social trust precedes task trust (Servaes, 1999: 77). This was evident during the workshop where the postgraduate students felt comfortable enough to share their personal concerns with facilitators, and facilitators were willing to address student concerns, that often extended beyond academic concerns. This was evident with several discussions with facilitators which occurred beyond the bodymapping workshop. Students developed trust with their facilitators (also their lecturers) and peers, which according to Servaes (1999) and Freire (1976) is an important attribute to achieving genuine participation.

The bodymapping workshop stimulated confidence in young people to pursue their own research, as they were able to take ownership and develop confidence to complete the tasks. One respondent reported that with the bodymapping workshop developed confidence in the students that they could achieve what they needed with their studies but they had to take ownership (Respondent 1, 2009). Another respondent commented on the importance of taking ownership of her own education:

It was during that day of talking and drawing and writing that I began to understand that my education is exactly that: my education. It was during that day of speed-dating, drama skits and bodymapping that I gained a true appreciation for a participatory pedagogy (Reddy, workshop report, 2009)

Through the process of bodymapping, young people were able to identify their education was their own responsibility and therefore took ownership for their education. This was reminiscent of the comments made by women from a series of bodymapping workshops that I facilitated in Mtubatuba, Mtunzini and Umlazi, which are rural areas in KZN, where the women identified the importance of taking control and ownership of their own health while being HIV positive. Many women commented that their health was not the responsibility of their children or government, but it was their own responsibility. Young people, registered as postgraduate students also indicated that the development of their confidence to engage with their peers and the staff encouraged a greater level of participation in their own studies, which as a result gave them a sense of ownership. Arnstein (1969) and Hart (1997) in their typologies of participation indicate that when young people are consulted, empowered and are given a sense of control, they are better situated to participate in decisions which affect their own lives.

Theme Two: Bodymapping Encourages Dialogue

The bodymapping workshop allowed for revisiting two common relationships at university. The first is the relationship between staff and students, and the second is the relationship between students and their peers or class mates. Through a process of building confidence and students recognising the need to take ownership of their own lives, students were also able to see their lecturers through new lenses. The boundaries of staff and students were also challenged in this instance and lecturers were identified as co-generators of knowledge. "I began to see CCMS as a mini Freirean village where knowledge is shared and hierarchical boundaries between so-called 'teachers' and 'learners' are challenged and transcended" (Reddy, workshop report, 2009).

The student's' comments indicated that they had previously felt intimidated by the Centre's staff. However, the workshop had given them an opportunity to engage with their lecturers on a more personal level, as opposed to a 'teacher to student level'. "This breaking down of the barriers between the 'experts' and the target community is a vital part of Freirean philosophy, as this is necessary for engaging in genuine dialogue" (Durden, Govender & Reddy, 2009). The blurring of roles of teachers and learners, to identifying everyone as researchers and co-generators of knowledge, aided the process of participation with the students.

Students also realised that they were no longer just numbers in a class anymore, as staff were able to engage with them on a personal level, because hierarchical boundaries and barriers were overcome through the bodymapping workshop. One student commented that previously, "we were spoken to", whereas during the workshop they felt there was a "person-to-person level", and that they were "not just

student numbers anymore” (Reddy, workshop report, 2009). This indicates that students were not treated as ‘recipients’ where the lecturers dictate what students need to do without meaningful participation, but were rather seen as partners, young people seen as people who have an equal voice (Klindera & Menderweld, 2001).

Students also found that the bodymapping workshop allowed them to establish bonds with their class mates, with whom they had never previously interacted. One respondent indicated that the workshop gave her “bonding time” that aided her future interactions with her peers in class (Respondent 1, 2009). In other cases, students developed new insights into how they could still work together with their class mates, on their research and projects (Respondents, 2012). Observations during the workshop and feedback from the students suggest that the bodymapping workshop was very successful in bringing students together and generating a sense of collegiality. This was a common trend in the workshops that I facilitated in both deep rural and urban areas with young people who had never met before. Even though they work individually on their bodymaps, sharing similar experiences and reflections allows for collectiveness, with a sense of group problem identification, instead of it being an individual problem.

Students also felt that the workshop helped them to come together by developing new relationships and reinforcing their existing network with peers. A number of students felt that the process had broken the ice, helped them get to know each other, and encouraged them to be more open with each other (Durden, Govender & Reddy, 2009). Campbell and MacPhail (2002) recognise the importance of peer networks and suggest peer education as a way of motivating young people to view themselves and make decisions in relation to others. Through their longitudinal study conducted in a township with young people in South Africa, Campbell and MacPhail (2002) propose a conceptual framework for peer education based on Paulo Freire’s notions of critical consciousness, social identity, empowerment and social capital. Students were able to identify their social networks through the bodymapping process and develop peer relationships with other students, who share similar research and social interests. Social identity is premised on the notion that individuals do not make exclusive and independent decisions; but that choices, in this case sexual choices, are made with social influence. The bodymapping process therefore encouraged young people to engage in discussions and build social relationships that were not possible without the facilitation of the bodymapping workshop.

Theme Three: Bodymapping Identifies Similar Challenges

The process of bodymapping allowed many students to find commonalities in their experiences. Many felt relieved and in some cases very shocked that their post-graduate experiences were not exclusive to

them, but collectively shared by many of their classmates. One respondent suggested that: “our relief was the dominant expression on most students’ faces during the workshop as we realised that the problems each of us were facing were actually being experienced by our fellow students” (Reddy, workshop report, 2009). Another respondent reported that there was value in “knowing that you're not the only one with the problem, that there are other students going through the same thing” (Respondent 4, 2009). In 2006, a bodymapping workshop was facilitated with a group of Southern African MA and PhD students during a two week ethnography programme. I attended as a participant and had my second bodymapping experience as a participant, rather than as a facilitator or researcher. Experiencing the commonalities of the challenges we face collectively as young scholars was revealed through the bodymapping process when it came to questions of career goals and mobilisation to attain those goals. Issues of what made us feel stressed, anxious or fearful were also found to be common among the group that made me realise that several challenges are common experiences for many people, including myself.

Students in the CCMS bodymapping workshop in 2012 also commented on the ability of the bodymapping workshop to draw students together and to get to “know each other on different levels”. One respondent indicated that the workshop process gave them a chance to get to know other people and their interpretations and communication about certain issues (Respondent 2, 2012). The group valued the activities that encouraged the process of sharing and finding common ground (Durden, Govender & Reddy, 2009). The sharing of similar challenges, exploring each other’s interpretations and communicating jointly about their post-graduate experiences, gave the students a sense of social inclusion. It also introduced them to peers who were experiencing similar problems therefore encouraging circles of supports for the academic year ahead. The bodymapping process can therefore be argued to have been instrumental in highlighting common experiences, but also developing the social capital for students to address any challenges identified. Social capital is evident through community cohesion where there are high levels of community engagement to address common experiences and issues (Putnam, 2002).

Theme Four: Bodymapping is a Relaxing Way to Connect

The bodymapping process ensured that young people could be relaxed and enjoy the process of the workshop. This relaxation and enjoyment would most likely not have occurred if, instead of a bodymapping workshop, the students had to attend a seminar where information was simply forced onto them. A respondent indicated that “it wasn't the standard type of workshop where you're just kind of sitting in a boring lecture. We were doing things ... it was just like loosening us up” (Respondent 5,

2009). Another respondent reported that “it was an exercise that would allow us to get out of our space of academia” (Respondent 1, 2012).

Other students found it to be a strange contrast of childhood and adulthood, where the art-based approach allowed students to reflect on their childhood and the type of things they did then, but the steps of bodymapping required them to think and write like adults:

It was fun, in the sense that it took you back to childhood, but now that you are an adult the things that you have to think about when you were writing, you know, when you were painting were different (Respondent 1, 2012).

The workshop also allowed students to establish connections with where they are now and where they want to be, giving insight into future plans and development. A respondent felt that it actually gave better understanding of what they are here for and what they want to achieve, “in a sense of what we want to specifically research and where our projects and stuff will actually lead us to” (Respondent 2, 2012). The students enjoyed the process of doing things on their own and exploring how they could play a more pro-active role in developing their own lives. Bodymapping ensured that this happened in a fun, free and stimulating way that encouraged young people to want to participate further.

Theme Five: Bodymapping Encourages Introspection and Self-Reflection

Engaging with Others

Bodymapping was a process that allowed students to think critically and to also engage with other students. In many cases, students had not interacted with their classmates prior to the workshop and the bodymapping experience became a catalyst for dialogue on several issues. One respondent commented:

I realised that bodymapping is actually an exercise, which allows us to engage as students, it also allows us to think critically and it also allows us to communicate amongst ourselves, where we could share our thoughts and feelings as well as to give an introspection about ourselves. (Respondent 3, 2012).

This response indicates that beyond encouraging students to engage with other students, the bodymapping process also allowed for the sharing of thoughts, emotions and taking an introspective approach to their own lives. Bodymapping “creates a platform for young people to express themselves, the way they think and the way they feel” (Respondent 5, 2012). Another respondent suggested that “the bodymapping workshop taught us to be open to ourselves and to the other members of the group” (Respondent 3, 2012). The Bamnanani women’s group, also referred to as the A Team, documented

similar experiences and observations of the bodymapping technique that allowed the women to develop relationships with other HIV positive women, that they previously would not have done. It also allowed for an alternative form of expression through art and drawing, when women did not feel comfortable talking about sensitive issues (ASRU, 2004).

In 2007 and 2008, I conducted workshops in various provinces for the *You, Me and HIV* programme which was a participatory education programme to introduce the biology of the human body and its relationship to HIV. During this time, I had the privilege of co-facilitating with one of the initial bodymapping participants from the Bambanani Women's group in Cape Town. The participant (who was now co-facilitating with me), reflected on her bodymapping experiences and reported that it was a life-changing experience as it helped her take cognizance of her own life and be open not to others but to herself about her experiences. This indicated that the process encouraged her to understand herself better, and the challenges she faced with HIV before engaging with others. This demonstrated that the bodymapping process had the ability to bring her from a place of intransitive thoughts (a place of domination and no participation) to semi-transitive thoughts (partly empowered and start the process of participation), and finally to a place of critical consciousness, where she was critically aware of her own social reality, before discussing this with others (Freire 1976).

The bodymapping technique in this instance meant that participation was only taking place with the individual herself through a self-reflective process that liberated her from her own preconceived challenges, before enabling her to have discussions with others. When people are able to come to a realisation of their own social reality, they can then be empowered to enact change. Bodymapping can become a means of helping people through a process of self-reflection. Whilst Freire's (1976) work offers the theory to support this level of genuine participation, bodymapping in this instance can become that process for catalysing participation.

Overall, the comments from students suggest that the interaction and engagement with their peers was a direct result of the bodymapping experience. The process highlights the importance of communication which allowed for students to discuss and explain their bodymaps and in cases where no explanation was offered, the other students would come up with their own interpretation of the images and symbols on the bodymap. Bodymapping recognises the importance of communication, but allows students the freedom to engage in non-verbal communication that empowers the participants to engage in self-reflection first, before communicating their perceptions, experiences and observations to others. Communication in this context can be argued to contribute to purposive discussions where it is easier

for young people to understand themselves in relation to others. Dialogical communication is conceived as the integration of dialogue and participation to promote cultural identity, trust, commitment, ownership and empowerment (Freire, 1972; Figueroa et al, 2002). The bodymapping process therefore identifies the use of non-verbal communication that is best supported by verbal communication to unpack the content of the bodymaps.

Bodymapping, when used to address issues of disclosure and diagnosis, is often appreciated for its ability to document life stories without always discussing the content. Several participants in workshops that I facilitated for the *You, Me and HIV* programme in 2007 and 2008, and workshops which I conducted with women in Mtunzini and Mtubatuba in particular, reported that they enjoyed the bodymapping process as they did not have to discuss the images that they did not want to with the rest of the group. One respondent commented that she enjoyed being able to document her real life and not feel discriminated by her status, yet she still did not have to share this with the rest of the group.

Introspection and Self-Reflection

Many young people commented that the bodymapping process required an introspective approach where they had to ask themselves several questions in order to explore and understand more about themselves. In some cases, the students commented that they had never thought about these questions before. "I have never asked about myself or I have never asked those questions to myself and I ...actually had to think critically" (Respondent 3, 2012). This critical thinking was supported by introspection where students had to look at their own academic journey and what they wanted to change in order to advance with their post-graduate studies.

One of the respondents, in taking an introspective approach, reflected on what she had to give up in order to pursue her Masters degree at UKZN. Through the process of bodymapping, the student was able to document her decisions and later reflect on them to remind and motivate her to complete her degree:

I think for me the most interesting part about the exercise was the part that we got to write about: "What are you prepared to give up? What did you give up before you came?" And, you know, for me it was really different. I left a good job. I... I am not bragging or anything. I left a good job to come to school, and sometimes I take out my bodymap item and I look at it even now. I still have it and I look at it and think, really, I gave up something good to come, so I really have to give it my all (Respondent 6, 2012).

A bodymapping workshop conducted with young people in the Bergville and Winterton areas near Drakensburg, KZN also demonstrated the decision-making process that was stimulated as a result of a bodymapping workshop. Several participants of the workshop identified the importance of locating or re-applying for their birth certificates to assist their guardians or grandmothers in applying for child grants for them. Many of the participants who attended the workshop commented on the deep poverty which surrounded the community. Through reflections on their own lives, the young people were empowered to explore their experiences and make decisions about how to change these experiences (workshop report, 2006).

Bodymapping also enables students to discuss issues that are usually hidden and not confronted. This is often seen when applied in the HIV context, when issues of stigma, discrimination and treatment adherence often cause people to hide or not speak openly about their status. In this instance where bodymapping was used to help students think about their Honours degree and how they can better cope with their transition from undergraduate to post-graduate study, it meant that students have to identify and address issues with themselves that would not normally surface. One of the respondents indicated that bodymapping engaged her even when she did not want to address things:

There are things that we don't like to discuss, even with ourselves. If that issue comes in you chase it away, because you still don't want to deal with it. But if you throw it down unconsciously it ends up starting to engage with you. The same thing that you don't want to talk about it engage... engages... Engages you back. And you start now... asking yourself why I can't allow myself to engage with it. Because it is written down now it is there; you have to explain it to yourself first before you share it with other people (Respondent 3, UKZN, 2012).

Bodymapping enabled the students to document their experiences and address what they need to start doing and what they need to stop doing in order to successfully complete their research projects and academic year²¹. This left many students overwhelmed when they looked at their bodymaps on the floor, as in many cases it meant that students had to reduce some aspects of their social lives, commit more time to working in the library, read more, watch less television and in some cases spend less time on social networking sites like Facebook and Twitter. This process of bodymapping meant students had to engage in some introspection, which encouraged them to engage and unpack issues on a one-on-one basis. By having it documented and written on their bodymaps, they had to address the problems identified.

²¹ A common thread across all the bodymapping workshops which I facilitated, researched and participated in for the last ten years, reflects one key commonality where participants were able to reflect on their own experiences and problems, and explore ways in which they could change these.

The work of Freire indicates that action and reflection are organically integrated (Servaes, 1999; Freire, 1972, 2002) where the process of action and reflection promote conscientisation. However, findings from the bodymapping process indicated that introspection was commonly associated with reflection. This meant that the students would take introspection into their own lives, and reflect on their experiences, resulting in problem identification and then posing problems for solutions in their own lives. Only after the process of ongoing introspection and reflection, were young people empowered to take action on their decisions. This resulted in more discussions with their lecturers, peer networks being developed and ongoing discussions about their progress.

Some students described this experience as an outside eye or a mirror that helps them to reflect on issues and themselves. "My understanding is that bodymapping gives you a chance to reflect on yourself. It's like a mirror, you know, everything that you write down there about yourself you have a chance to analyse it now looking at it, using a second eye of course" (Respondent 5, 2012). The student later added that reflection is key to the process of bodymapping: "I think the critical point in there is reflection as well. The reflection... people have to be given a chance to reflect on what they are reading" (Respondent 5, 2012). The respondent further added that bodymapping challenged the students, "because it's very hard to draw lies about yourself" (Respondent 5, 2012).

Through this process of reflection, the students themselves become the central focus; one student commented that "you realise it is not about what the other person writes about you" (Respondent 5, 2012). They realised that change can only be enacted when they, as individual students, can identify the problem and find a solution because "now we are able to engage on the things that you are saying about yourself" (Respondent 5, 2012). The process of personal reflection that the workshops encouraged led to these realisations, and in this way allowed for the vital component of reflection in Freirean action-reflection praxis. This made for a transformative process for some of the students (Durden, Govender & Reddy, 2009). Bodymapping therefore cannot be attributed to bring about any form of social transformation or change directly, but can stimulate a process of introspection and reflection towards later enacting action. Three participants of bodymapping workshops conducted in Bergville and Winterton reported a year after the workshop (2007), to have obtained their birth certificates, and their guardians had applied for child grants for the three participants. This demonstrates that the bodymapping process did empower young people, not only by active participation, but also by making them aware of their social reality and their ability to make decisions for themselves and to take action.

Creating an Environment for Discussion

The bodymapping process, as identified by students, creates an environment for students to reflect and engage in introspection. It allows for the creation of an environment for students to engage even further, to the point where they ask themselves about the things that they initially thought they understood very well (Respondent 3, 2012). This implies that students were re-thinking aspects of their studies that they have already visited, and through the process of bodymapping were gaining new insights. The respondent further reported that “young people like open space and they don’t like environment that will channel them into a certain kind of thinking. They want to express themselves the way they think, at that particular moment” (Respondent 5, 2012). Students were therefore encouraged by an environment that stimulated open and free discussion.

Students commented that young people do not want to be confined when engaging in discussions; and the mapping process allowed them to go beyond academic insight to issues of social lives, families and goals. “So, I think it will give young people a space to relate themselves to their environment” (Respondent 6, 2012). The group expressed enthusiasm for the opportunity to be creative and self-expressive, a process that they felt served to enrich and strengthen their personal understanding of the proactive mindset that their post-graduate study demands. The technique also created an environment for students to engage, communicate and share some of their challenges at post-graduate level that was not possible in a classroom set up (Durden, Govender & Reddy, 2009). The participatory bodymapping technique was able to assist and empower students with new knowledge and skills, particularly in assisting students to cope with the requirements of self-initiated post-graduate research.

Theme Six: Art as an Alternate Form of Expression

Power of Symbols

Students indicated that symbols allowed for their own interpretations and offered a safe place to explore their ideas. The documentation of young people’s experiences and perceptions using art has proven specifically effective in addressing sensitive issues, such as HIV and AIDS with young people (Gerteisen, 2008; Pifalo, 2007; Hrenko, 2005). One student indicated that they were overwhelmed with all the questions but the use of symbols allowed for various levels of interpretation:

So many people ask me like “what are you gonna do in five years? What are you gonna do in ten years? What are you gonna do in fifty? Where are you going? What are you gonna do? And do you have a plan?” And that’s really scary and intimidating. So, instead of having to, like, give a straight answer verbally, I was able to, you know, put it into my own symbol so that I could interpret it and it was kind of, like, safe, like, in a safe place for myself and anyone that walked by wouldn’t

be, like, that's a bad plan, because they would even really understand what my symbol was and how it meant... you know, how I interpreted it (Respondent 4, 2012).

Most students were in support of the use of writing, images and symbols to reflect on their experiences, with one student suggesting that “not everyone can express themselves through speaking, but they can express themselves through symbols” (respondent 3, 2012). A case study conducted with HIV positive youth in KZN emphasised the importance of using drawing and textual documentation to give young people the freedom to express themselves in a medium they felt most comfortable working with (Govender & Reddy, 2011). Another student indicated that the application of symbols can evoke different emotional responses and interpretations for different people. The student commented that symbols which were positive for one person could be negative for another (Respondent 1, 2012). The use of symbols therefore offered an alternate form of expression, which could be misinterpreted at times.

A student described how she was paired and working with another student who drew a tortoise when asked to document what represents her place of personal power. The student interpreted the tortoise as a representation of the other student being slow. But the other student highlighted the strength of the shell of a tortoise and indicated that it directly applied to her as she is the kind of person who is strong but not outspoken (Respondent 3, 2012). This example indicates the complexity of interpretation where the one student attributed the characteristics of the tortoise based on its slow movement, while the student who drew the tortoise found the strength of the tortoise in its hard shell, and related it to her personality as being strong and kind.

The use of symbols can provide an alternative means of expression and non-verbal communication through the bodymapping process, but it is pivotal for discussions to follow the use of symbols to avoid misinterpretation. Working in a cultural and historical context in which young people's voices have also been marginalised, has highlighted the need to address the power imbalances that exist between adults and young people, to develop techniques to maximise their participation, and to provide ways in which they could express their understanding and experiences without relying solely on verbal communication (Van der Riet et al, 2005).

Colour Connotations in Bodymapping

Students had discussions about emotions and how they could be represented by the choice of colour. One student indicated that bodymapping helped her to understand that emotions are connected to colour. The student offers an example, “if you want to talk about love... If someone will use a black colour you’ll see that person and how he feels about love ... If he uses a red colour then you see that person is excited about love, but a dark one is probably a person that has been hurt before” (Respondent 5, 2012). She further reported that bodymapping does not dictate how to express yourself (in word or images) or what colours to use, but allows for free expression which does not limit how you express yourself.

In many bodymapping workshops that I facilitated, I often observed how participants re-defined the meaning of colour. For example, in one workshop that I facilitated in Sandton, a participant used blue to indicate danger. This contrasts with how most people associate red with danger. The participant later explained that she would see the blue police lights in her community and she would know that there was danger in the community, either because of domestic violence or crime. These meanings could only be unpacked when participants discussed their bodymaps, failing which the bodymap runs the risk of being left open for misinterpretation.

While a few students commented that the steps for the bodymapping process were very prescriptive, young people were given the freedom on how they wanted to express themselves on the bodymap, either through the use of symbols or writing on their bodymaps. Whilst several models and theories suggest that young people need a voice and have to be active participants in the projects that affect them (Shier, 2001; Arnstein, 1969; Hart, 1992), visual art has been widely researched as a means of encouraging expression with young people (Mitchell et al, 2005; Wallace-Digarbo & Hill, 2006; Mitchell, 2008; Rao et al, 2008).

Theme Seven: Bodymapping Encourages Problem Identification and Problem Solving

The bodymapping process assisted many students through a process of understanding more about their postgraduate studies, and motivated them to change their actions. Many students commented that once they understood and identified their problems, they were better placed to understand why they were pursuing an Honours degree:

Like now that we all knew the problems we were having during Honours so far and then we were like 'ok why are we doing this?' We're doing this Honours for a reason, you know we're actually here because we're like passionate about what we hope to become. So the bodymap thing was really cool (Respondent 5, 2009).

This process of becoming aware of their situation is reminiscent of the philosophy of Freire (1976) which indicates that people are often oppressed because they are not aware of their social reality or the issues which affect them. When people move from this place of not knowing to a position of understanding their problem, they become empowered to take action (Freire, 1972, 1976)²². The bodymapping process was identified by students as assisting them in identifying their problems, making sense of their experiences and re-focusing on what they need to do in order to change their post-graduate experiences for a more positive outcome.

The need for young people to become aware of their social reality was also evident in one student's comment that youth usually see themselves as the problem, not the solution. She reflected on her meetings in communities where elders and adults were of the mind-set that young people have nothing to say because they are seen as troublemakers. "So, they have got that notion that they have got nothing to add. It also makes them, ah, not aware of some of the solutions that they can actually bring, or some of the change that they can actually bring that society" (Respondent 3, 2012). The social exclusion of young people in communities based on cultural beliefs, and the idea that children should be seen and not heard, causes a breakdown in communication, where young people are unable to discuss the challenges they face or offer suggestions for how these can be addressed.

The concept of providing a space for reflection and to engage in problem identification and solution finding was a common observation by facilitators in the four consecutive years during which CCMS offered the bodymapping workshop (2009-2012). This problem-posing approach ensures that young people are capacitated to take ownership of their own learning processes (Freire, 1976; Freire, 2008). A bodymapping workshop that I facilitated with a group of young boys in 2007 indicated that they were able to identify their challenges of being street children and better appreciate the social services, shelter and food offered to them, instead of wanting to go back to the street. Bodymapping in this instance promoted a process of problem identification.

Bodymapping provides a platform and repositions young people to identify the factors that influence or cause problems, rather than identifying themselves as the problem. Bodymapping therefore has an

²² This was also evident with the young people who applied for birth certificates in order to apply for child grants as a way of reducing the impact of poverty in their home in Bergville.

ability to assist young people in identifying the problems they face, from a problem-posing perspective which aligns itself with the work of Freire, who argued that problem posing allows young people to learn through active participation and dialogical exchange with others (Shor, 1987; Wallerstein, 1987; Freire, 1976).

In addition to the problem-posing nature of bodymapping, where students take an introspective approach to resolve their own issues and challenges, most students also found the process cathartic. A student reported that while painting, the session become therapeutic because “it kind of released everything we had been going through the whole time” (Respondent 6, 2009). The participant of the Bambanani working group in Cape Town with whom I later facilitated a bodymapping workshop, commented that she found the whole process most therapeutic, she explained that it helped her to unlock deep issues she was experiencing with being HIV positive, on paper first, before discussing this with people. Dealing first with her own issues, before discussing it with others, made the trauma of stigma and the discrimination associated with HIV easier to cope with. Similarly, the post-graduate students found the bodymapping process as a point of release for the anxiety and stress that they were facing during their studies, which was previously not openly discussed by other students.

Another respondent concluded that the workshop transformed into a group therapy session, where many students started to confess that they were all reeling from the shock of the pressures of post-graduate study (Reddy, workshop report, 2009). Many participants of the Bambanani group also reported that discussing issues of stigma and discrimination with a group of women who share the same experiences, becomes very de-stressing and therapeutic (ASRU, 2004). The bodymapping process gave students a sense of ownership of their problems through problem identification and problem solving. The problem identification phase usually took place through the images and text on the bodymaps, and the problem solving through a process of discussion and dialogue among their peers.

Challenges of Bodymapping

Whilst the above sections describe the many positive attributes of the bodymapping process, a few students found the process frustrating and tense, because they were unsure how to express their emotions and draw these on the bodymap (Respondent 3, 2012). This demonstrates that not all people are comfortable with the process of drawing, and even though the process allows for writing, drawing and the creation of symbols, not all students feel comfortable with the art methodology. One student

reflected on her discussions with another student at the bodymapping workshop where he said “it looks like we are actually, like, kids. Cause I don’t like playing with pens... ja, pens and it’s actually taking up most of my time” (Respondent 3, 2012).

When questioned about which aspect of the bodymapping process the respondent disliked, one student commented that she did not like being unaware of the outcome of the whole bodymapping process. “I think it would have helped me personally if I was actually told what is the end-point of this, because for some people they sort of found this whole link between their passion and their research project. But I didn't see that until right at the end.” The respondent further reported that had she known what she was trying to find through the process, she would have done things quite differently (Respondent 5, 2012). This indicates that the mapping process can create anxiety amongst participants, who may like to have an idea about where the activities are leading. This suggests that participants need to be given an opportunity to discuss in more detail what the bodymapping process will entail, and what the expected outcomes are, before engaging in the process of bodymapping.

Other respondents found that “in order to know where you're going, you have to know where you come from”. The student indicated that the journey of reflection and taking a journey back meant “looking at what you were once passionate about and how you've deviated from that” (Respondent 4, 2012). These findings indicate that young people like to have the full plan of what they are doing, they want to see and plan ahead, which is a principle of outcomes-based education. The bodymapping process must therefore ensure that the participants have an idea of the end result or the outcome of the workshop, before participating in the processes.

Another student raised a concern that “there was no real conclusion as to what were supposed to do now that we have this big body map. Where do we go from there? I guess it just left us just hanging a little bit in that sense (Respondent 3, 2012). Due to time constraints the debriefing session did not take place straight after the workshop, but instead two weeks later during post-graduate orientation, where a presentation was made to put the bodymapping experience into perspective for students. This was a huge disadvantage to the bodymapping process and can negate all the positive outcomes discussed above. All workshops must have a debriefing session straight after the workshop, to address misconceptions, offer a space for interpretation and put the process into context and perspective. The process and style of explanation and facilitation by the facilitator of the process plays an important part in ensuring the comfort of the participants.

A bodymapping workshop conducted with street children to develop their resilience to cope with adverse situations also had similar comments during an evaluation. One participant indicated that he felt he didn't know what to do next after the bodymapping experience, since he discussed several issues but did not know how to address them. Another participant at that point interjected and suggested that the student writes down all the issues which arose which he was not willing to address before and they can discuss with their housemother, how things can be changed at their residence. This indicated a challenge of the bodymapping process where discussion does not precede the workshop, it is important that bodymapping workshops are not just facilitated which leave students expose to issues without collectively discussing with students. In the case of this one participant, he felt that level of exposure as he missed the discussion sessions which followed the bodymapping process due to illness. Facilitators therefore need to accommodate these challenges to ensure that all participants have an opportunity to discuss their challenges which prevents it being an exposure of problems without facilitating solutions with the participants

The comments above indicate that few students did not enjoy the bodymapping activity and indicates that a variety of methodologies must be used to encourage maximum participation. However, overall the analysis of students' responses to the bodymapping workshops suggests that it was a fun and enlightening experience that was useful for the majority of students, and should be continued with other new post-graduate students in the future (Durdin, Govender & Reddy, 2009).

Benefits of Bodymapping

Despite the disadvantages identified by few students about the bodymapping process, most enjoyed the experience. One respondent reported that she never thought of doing a project on art before, until the bodymapping workshop, where she realised that she could express herself through a medium which was her passion. She also got new insight into how she could connect art and her Honours project through bodymapping (Respondent 1, 2012). The students also thought it was a "calming exercise", that helped them find their "happy place", and that allowed them to be "centred on who I am as a person" (Focus Group, 2010). In terms of the educational aspect, they found bodymapping to be a useful tool in discovering what their passions are and then linking this to their research. One student described bodymapping as the "cherry on the top....I think everyone kind of loved the bodymapping, it just made the day better" (Respondent 5, 2012).

In one particular instance, the bodymapping process became such a powerful moment of reflection for the student that it prompted a change of degree direction:

After the bodymapping I actually changed my degree as a whole. I mean I realised that my passion was drama and so to not do drama meant that there was a part of me missing. And for me my academics is actually very personal so the bodymapping and the workshop itself actually reminded me that my personality and my persona, well there's a part of it missing and it made me realise that I'm not going to be very happy if that part is missing, so I found bodymapping very useful (Respondent 6, 2012).

Bodymapping also helped the student to identify and bring out her passions, and to understand the purpose of her postgraduate study (Respondent 6, 2012). The students believed that drawing the link between personal passions and academic research enabled them to leave the workshop feeling excited, because they were now thinking about “all the possibilities” they could pursue during their Honours year (Focus Group, 2010). One respondent indicated that her favourite part of the workshop was the bodymapping exercise “that combined the personal with the academic as we were encouraged to find the connections between what we were studying and what we actually wanted to do with our lives” (Reddy, workshop report, 2009).

Conclusion

This chapter explored the use of bodymapping with students at UKZN, linking this to a range of other experiences in various communities, to understand the relevance of bodymapping. Some of the findings indicate that bodymapping increased the participants' confidence to engage visually and textually on paper, which was later translated into discussions with their colleagues and friends. The participants felt a sense of ownership for their education and the process also repositioned them as co-learners and co-researchers with their lecturers instead of creating a student-teacher relationship. This was important as it indicated that bodymapping has the ability to break down adult-youth or parent-child relationships when working on HIV-related issues, and created a sense of collegiality.

The process also highlighted for many participants that their experiences are not always unique but common to others, therefore giving them a deeper level of confidence to share their experiences, perceptions and ideas. Introspection and reflection were identified as key attributes of the bodymapping process, with art being experienced by most as an effective tool for self-reflection. Overall, the participants enjoyed the process and indicated that it could be adapted to address other sensitive issues like HIV, or also encourage young people to participate through the process.

The experiences of students and young people from other communities indicate that bodymapping is a very introspective approach, and does not directly create dialogue among participants, but rather encourages them to explore their own lives and how it is influenced by various contexts. The introspective nature of the process puts the responsibility into the hands of the participants, where they unpack their own experiences in relation to others. Bodymapping, therefore, can be argued to encourage the participant to engage with themselves first, before participating and engaging in dialogue with others. The data presented in this chapter therefore indicates that bodymapping does have the potential to involve young people in developing HIV projects and programmes through building their confidence in participating, voicing their concerns, and engaging them in reflection and problem-posing processes which are the first step for planning an effective programme.

CHAPTER EIGHT: MAPPING YOUNG PEOPLES' PARTICIPATION IN HIV PROGRAMMES (PHASE THREE)

This chapter presents the data and analysis of Phase Three of this study that includes the two bodymapping workshops conducted with two very different settings. The first workshop was conducted with a group of young people who were studying at the University of KwaZulu-Natal. This group were included to cater for young people who are attending tertiary institutions and who are often categorised as engaging in risky sexual practices (Mulwo, 2009; Kunda, 2009; Mutinta, 2011; Tesfu, 2003; HEAIDS, 2010). The second workshop was conducted with a group of young people who form part of a rural community in Shakaskraal, where *DramAidE* facilitates community dialogues. This group was included to cater for youth who are either attending or have left school, and is identified as a group being at greater exposure to contracting HIV through risky sexual practices (www.avert.org; UNICEF, 2005; UNAIDS, 2008; WHO 2002). A brief of the workshop was provided, so participants had an idea what the workshop was about. The majority of the participants did not have a bodymapping experience before, nor were they familiar with what the process entailed.

The two separate half-day workshops were designed to explore young people's views about what is happening in their community regarding HIV and AIDS, what youth are speaking, hearing and seeing in terms of HIV programmes and interventions, and how they feel they can participate or contribute to the development of HIV programmes. These areas of inquiry were addressed by adapting the bodymapping process to more specific HIV related questions, allowing young people to map their thoughts, ideas and perceptions in the form of writing and drawing on various parts of the body. Young people were asked to map on their bodymaps what they were hearing (ears), seeing (eyes), speaking (mouth), thinking (head), feeling (heart), doing (hands) and planning (feet – way forward for the future) in terms of HIV projects and their participation in these programmes.

This process was developed to address the second research question outlined in Chapter One of this thesis which explores young people's perceptions of communication processes for HIV and AIDS programmes. The discussion below is ordered in these categories of the body (ears, eyes, mouth, head, heart, hands and feet) to offer a presentation of the data collected as a result of the bodymapping process, and my own analysis of the process and the generated data. In discussion about the data collected, I often make reference to young people either *working* or *addressing* each step of the bodymapping process, this implies that they offered their perceptions and experiences to the questions

posed, through the use of visual and/or textual responses that were documented on their bodymaps. Given that this was a participatory workshop employing a participatory action research process, the visual data collected through the bodymaps and the discussion with each participant about their bodymap is integrated into each of these categories to offer a combination of a textual and visual depiction of the findings. For the purpose of this analysis, only close-up shots of the relevant sections of the bodymap are included in this chapter.

Introduction to Workshop and Participants

The workshop commenced with a brief introduction to the purpose of the research and what would happen over the next few hours. Participants were continuously reminded that their participation was voluntary and they did not have to follow the steps, or work on all steps of the bodymapping process. This was evident during the analysis, as many bodymaps did not have names written on them, even though this was a step of the workshop which required that they give their bodymap an identity by writing their name, and their date and place of birth on their bodymaps. Other responses to certain steps were also missing. For example, some participants did not comment on the feet aspect of their bodymaps, which symbolise going forward and what they see happening with HIV projects and programmes (refer to map of Participant 3, UKZN). In another case, one participant skipped quite a few steps of the bodymapping process, such as the hands and feet (refer to map of Participant 4, *DramAidE*). These blank spaces or missing of steps could indicate that participants understood that their participation was voluntary and that they chose not to complete what they were uninterested in. There is also the possibility that they could have struggled with the steps of bodymapping and the type of questions posed, or even having difficulty with either writing or drawing. Lastly, it could indicate that participants were not comfortable to discuss their views, perceptions and experiences on a large piece of paper which everyone could freely view and read. These points will be discussed later in the chapter.

Participants were informed that even though they wrote their names on their bodymaps, these would be excluded from the report and their identities would not be disclosed. I introduced each step of the bodymapping process, one at a time, providing a brief explanation, and in cases where participants were unclear, I gave an example to indicate what the step required. The first part of the bodymapping workshop required participants to team up with a partner and to choose a comfortable position and lie on the large sheet of paper (approximately two metres), to be traced with a marker by their partner. This step was repeated so that their partner also had their own bodymap. Participants were then asked to choose their favourite colour, or a colour which they felt represented them. Their bodymaps were then

outlined in that colour, and participants moved on to provide an identity for their bodymaps by including any details about themselves such as members of their family, school attendance details, degrees they are studying towards, or jobs that they are looking for. These details were documented by participants to provide a context for thinking about their lives. This step was integrated into the bodymapping process to encourage participants to start thinking from a perspective that explores who they are before moving into thinking about what HIV projects and programmes they have in their communities, and what they think about these. After the completion of outlining their bodies and giving themselves an identity, the participants had a framework to start discussing more specific issues related to the development of HIV programmes and young people's participation.

Through posing a series of questions to the participants about HIV programmes and what was happening in their communities, the bodymapping process was completed. Below are the bodymaps developed by participants in both workshops. Through participant observation, some notes were made about the willingness of each participant to engage in the workshop process, and how participants worked on their bodymaps during the workshop. Some of the specific observation notes included, a) whether the participant was eager to respond to each of the questions, b) was there considerable time taken to think about each question before responding, c) did the participant address all the steps of the bodymapping process and d) was there a preference for writing instead of drawing (and *vice versa*), or both?

Group One: UKZN Participants

Participant One, UKZN (P1U)

Participant One in the UKZN bodymapping workshop demonstrated an overall willingness to participate in the processes of the workshop. The participant worked through each of the steps thoroughly and was often found to be spending some time pondering on ideas before starting each step of the bodymap. The participant did address all steps of the bodymapping process, but spent very little time on addressing the step regarding the feet, which required participants to think about going forward, and what they wanted to happen in the future regarding HIV projects. The participant used a mixture of drawing images and symbols, but tended to address each of the steps with more writing than drawing.



Participant Two, UKZN (P2U)

Participant Two at the UKZN workshop was also found to be enjoying the workshop process, and spent time working on specific details on her bodymap. This participant was perhaps the one who spent the most amount of time sitting on the floor next to her bodymap and just thinking, looking at the map and not actually drawing or writing. When the participant did start to work, she often wrote very short answers and drew a range of symbols. The participant used a mixture of both symbols and drawing and writing responses to certain steps, and from my observations, the participant used these two mediums to address the questions. The participant, during the focus group, described the process as empowering and very relaxing. She also indicated that it can encourage extensive introspection and self-reflection (discussed in Chapter Ten). The participant later mentioned in the focus group discussion that she appreciated the moments of silence and reflection, as it provided a rare opportunity where she felt she could take the time to think about her perceptions on various issues. This indicated



that the bodymapping process encouraged self-reflection and created a space where young people could critically think about their participation and perceptions of HIV programmes. The silence in this instance could not be interpreted as a lack of participation, but instead as a process of introspection, where young people engaged with themselves about their own social reality (as posed by the work of Freire, 1976).

Participant Three, UKZN (P3U)

Participant Three also enjoyed the process and showed an eagerness to participate in the steps of the bodymapping workshop. This could be attributed to the type of sampling which this study undertook, where the convenience sampling technique was used, to attract participants that were keen to participate and attend the workshop. This participant did not appear to spend much time reflecting like the other participants, but was continuously working on her bodymap. The participant was often found to still be working on various steps predominantly using drawing and symbols, even when the rest of the group had finished their work on their bodymaps. This could indicate that the participant had a preference for working using visual means rather than writing. It could also indicate that the participant was not comfortable with writing.



Participant Four, UKZN (P4U)

Participant Four had experienced the bodymapping process before, when she attended the post-graduate orientation with CCMS in February 2012. This student enjoyed the process extensively, to the extent that she developed her research projects around the contrasts of Outcome Based Education (OBE) which is implemented at schools, and the very didactic, one-way flow of teaching which occurs at undergraduate level. She explored these contrasts using bodymapping with learners at school to understand how they respond to creative processes as opposed to didactic teaching. The participant did not seem to spend considerable amounts of time reflecting as in the case of Participant Two, but did spend some time reflecting on her responses before addressing the bodymapping steps on paper. All steps were addressed by the participant, and writing was her preferred choice in documenting responses on the bodymap instead of drawing, although she did use detailed symbols and images to accompany some of her writings.



Participant Five, UKZN (P5U)

Participant Five had also been through a bodymapping process before as a CCMS post-graduate student. The participant was completing her Masters degree and working with *DramAidE* in various communities to collect her data. This student had therefore experienced bodymapping in a community and tertiary setting. Considerable time was spent by the participant at the start of each step to think about what she would document. The participant addressed all the steps of the bodymapping process and used both drawings and writing to document her responses.



Participant Six, UKZN (P6U)

Participant Six continuously commented on how she enjoyed the workshop experience while engaging in the bodymapping process and therefore she addressed the various steps with enthusiasm. This participant spent time illustrating some of her responses through drawings and writing, engaging in both mediums to communicate about a range of issues. From my observations, this participant did not spend time thinking through responses for each step but instead worked continuously from one step to the next, visualising and documenting each of her responses. Bodymapping is often used for its simplicity in getting young people to communicate both visually and using written text. This particular participant worked in both mediums and later commented that she enjoyed the richness of both techniques to document her perceptions.



Group Two: Participants from *DramAidE* (Shakasraal)

The overall responses to the bodymapping workshop with the group of young people from a rural community in Shakaskraal differed considerably from the group of tertiary participants. These differences will be discussed later in the chapter. Below is an introduction to the eight participants who participated in the Shakaskraal workshop, hereon referred to as the *DramAidE* or rural KZN workshop.

Participant One, *DramAidE* (P1D)

Participant One worked through all of the steps using writing as her primary medium. This participant struggled to understand the steps and asked for clarification and further examples in all steps. Initially, it appeared as though a language barrier was preventing the participant from understanding the steps, as the young people's home-language was Zulu, and the workshop was conducted in English. Another participant who assisted in arranging the workshop, did extensive translations of each of the steps for Participant One, but she still



struggled to work both visually and textually on her bodymap. This could indicate that the participant was not familiar with HIV-related matters or was not comfortable in using art and writing as a combined method. The bodymapping experience could have also been a very new experience for many participants in this community. This participant later commented during the focus group that discussions on HIV did not occur all the time in her community, she therefore found it difficult to think about the HIV programmes.

Participant Two, DramAidE (P2D)

Participant Two continuously commented on the fun aspect of the workshop, and clearly enjoyed the workshop process. The participant worked continuously on each of the steps without stopping to think about each step. Writing was preferred to drawing, and extensive detail was written to address each of the body mapping steps. The participant did draw a few images on her bodymap, but overall preferred to write.



P2D

Participant Three, DramAidE (P3D)

This participant was very helpful in bringing the group together and helping to clarify certain steps that were unclear to the other participants. This participant spoke very fluent English and understood all the steps of bodymapping without the need for repetition. She commented that she enjoyed the bodymapping process and was keen to work in a creative way to document her perceptions. She later indicated that the steps were progressing too fast, and she needed more time to unpack each step, with her bodymapping reflecting detailed responses to each step. However this position was not shared by all participants of the workshop. She addressed all steps of the bodymapping process and tended to prefer writing to drawing. The participant offered very descriptive explanations for each of the steps on her bodymap, supported by later discussions during the focus group.



P3D

Participant Four, DramAidE (P4D)

Participant Four appeared to have some speech and sight challenges, and therefore struggled throughout the workshop process. He did not address all the steps of the bodymapping workshop, and spent considerable amounts of time on each step, which still did not offer detailed information. From my observations, I assumed the participant had a learning disability and therefore encouraged him to work at his own pace. The participant did not spend time thinking about the steps and preferred to write instead of draw. He also had difficulty speaking about his bodymap during the discussions and also appeared to not have understood all the steps. Working with this participant highlighted the limitations of bodymapping when working with people who have reading and writing disabilities, as the student struggled to document his perceptions and to talk about them.



P4D

Participant Five, DramAidE (P5D)

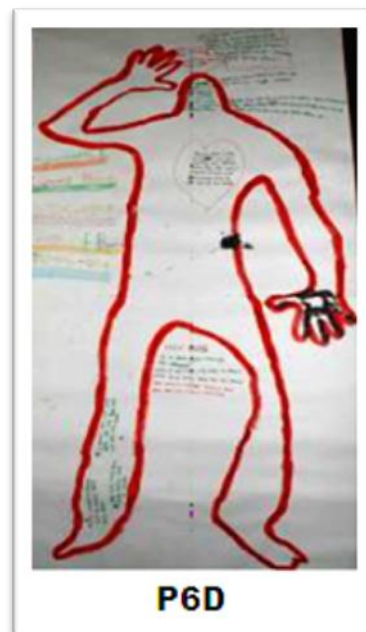
This participant paid great attention to detail. He was focused on his bodymap for the full duration of the workshop, and worked slowly on each of the steps. He wrote extensively to respond to some questions of the bodymapping process but did not document his responses to all steps. This could be a result of the participant over-spending time on some steps, and running out of time on other steps. He did not take time out to think about what should be documented, but simultaneously started working on each step as it was discussed. This participant also responded in writing instead of drawing to each of the questions.



P5D

Participant Six, DramAidE (P6D)

Participant Six continuously commented on how much he was enjoying the process, because he felt like a child again. The participant documented his responses to most of the steps (with the exception of the step of the hands) and spent time thinking about his responses and was occasionally found to be discussing the questions with Participant Three who was working next to him. Writing was used as the primary medium of documenting his responses. This participant was found to be laughing and working in consultation with the other participants which indicates that he was genuinely enjoying the process and working together with his peers. This could also indicate that peer support and discussion were important, where the participant explored his own ideas in the context of others.



Participant Seven, DramAidE (P7D)

Participant Seven also seemed to enjoy the workshop process but worked very independently, unlike Participant Six. He rarely stopped to think about each step before documenting it on his bodymap. This participant addressed all steps and, like most of the other participants, preferred to write instead of draw.



Participant Eight, DramAidE (P8D)

Participant Eight also commented several times about how much he enjoyed the workshop process. This participant worked on all steps of the bodymapping process, and took extensive time to think about his responses. He was often found just staring away from his bodymap and thinking about his responses before working on the next step. Participant Eight also preferred to write his responses, and commented later during the discussion that he enjoyed writing instead of drawing.



The above section introduced the participants and discussed some of my general observations about the participants and how they found the bodymapping process. A more detailed discussion is offered in Chapter Ten of this thesis, where the participants' perspectives on how they experienced the bodymapping process are discussed. The next section presents specific data documented on the bodymaps when participants were asked questions around HIV projects in their community, and their participation. The data is presented in order of how participants responded to the various questions and documented their responses on their ears, eyes, mouth, head, heart, hands and feet on their respective bodymaps. The data within each of these categories has been further arranged into sub-categories to reflect the common experiences or comments of participants during the bodymapping process.

Exploring the Contents of the Bodymaps

What are Young People Hearing about HIV Programmes in their Community (Ears)?

After participants had created an outline of their body and given their body an identity with their name and date and place of birth, the process moved to steps that required the participants to think about HIV projects and programmes in their community or nationally, and evidence of young people's participation. Participants were asked the first question of: "What have you heard about the HIV challenges in your community, with young people and even yourself?" Participants were encouraged to either write or draw some of the HIV and AIDS challenges in their community, with the option of documenting this next to their ears on their bodymaps (either inside or outside), or anywhere else on their bodymap. Even though it was preferable to have participants document this next to their ears on the bodymap, participants had to be given the freedom to participate using writing and drawing anywhere on their maps. This voluntary participation and freedom to work in any medium, with a variety of material anywhere on their pieces of paper, is in accordance with good participatory practice (Chambers, 1994).

Most participants answered this question in two ways. In the first instance they addressed the question by documenting the key HIV issues that affect their communities on their bodymaps. The second way of addressing this question involved many participants writing down the HIV programmes which they heard of in their community or nationally. Most participants identified challenges as: a lack of information, poverty, drug and alcohol abuse, availability of treatment, and teenage pregnancies.

Participant 2D (*DramAidE*) and Participant 4U (UKZN) indicated that some of the challenges of HIV in her community were linked to issues of poverty and lack of information, with P2D (*below*) further

indicating that lack of job opportunities and crime played a key role in HIV challenges in her community. Another participant documented that lack of treatment, issues of poverty and lack of information contribute to the challenges of HIV with young people (P3U, P5D), with P5D also adding that drug and alcohol abuse were key determinants. Several HIV prevalence studies and situation analyses on risky sexual practices of young people in South Africa, indicate that drugs and alcohol abuse, poverty, lack of information, lack of treatment and crime all contribute to HIV infection (Shisana et al, 2002; Shisana et al, 2005; Muula, 2008; Jewkes & Abraham, 2002; Ramlagan et al, 2010; Pithey & Morojele, 2002).



Many of the UKZN participants documented similar challenges to HIV using a mixture of images and writing to document their responses. Whilst most participants indicated that lack of knowledge was a key reason for HIV transmission, P3U (*below*) documented that 'ignorance' was a factor that contributed to HIV. Shermain Mannah (2002) explores some of the complexities of addressing HIV with young people, particularly those still at school, and indicated that poverty and the lack of information promotes the spread of HIV (also see Woods & Jewkes, 1997; Gilbert & Walker, 2010).

P6U offered a mixture of writing and images to indicate the challenges of HIV with young people. During discussions about her bodymap, this participant explained that:

I think the first perception of it is that it is a death sentence, so I drew a face with crosses, which normally symbolises death. The next one I did, I said infection and I used the mathematical sign is greater than prevention, 'cause there seems to be a lot more infection than prevention and then, are ARVs equal to cure, I mean how many people think that by just taking that they are automatically cured from HIV. It's more like a treatment for symptoms, rather than a cure and then the next thing I said was no knowledge equals no power, because obviously people don't know about AIDS or HIV, then they can't really do anything about it, they can't really take precautions or anything.

The next one I did was, well, I did a picture of a family and then I did two huge red crosses on the parents, 'cause there's so many child headed households that have come about of HIV.

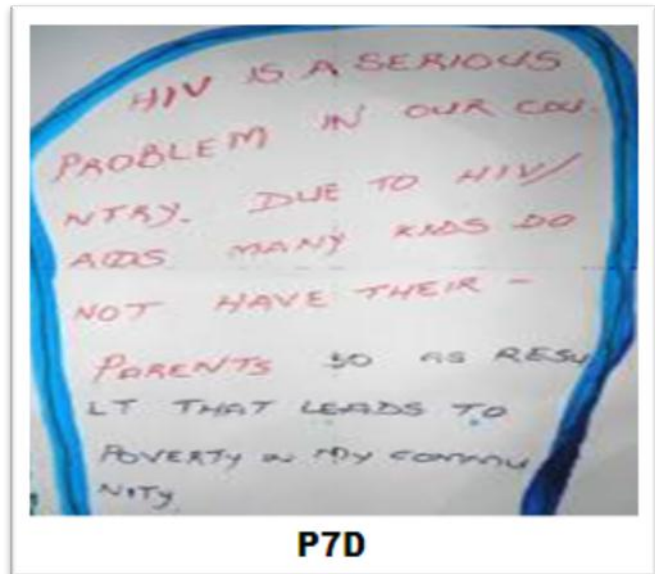
The next one I said precaution equals love, uhm, because many, many guys think, I think, uhm, that if the girl asks him to use a condom then it means that she doesn't trust him, but actually using a condom would be a sign of caring. It would be, wanting to protect your partner (Participant 6, UKZN)



The explanation offered by P6U indicates the challenges of HIV for young people, which extends to issues of the death of family members and friends, accelerating HIV infections, the lack of knowledge on HIV, issues of child-headed households with the death of parents, and the need to take precautions when young people are looking for love. Participants in both workshops offered rich data on what they hear in their communities, providing a realistic account of HIV's impact on deep rural communities in particular.

Whilst many of the participants indicated that poverty, lack of information, teenage pregnancies, shortage of treatment, and drug and alcohol abuse were HIV challenges with young people, many participants at the *DramAidE* workshop confirmed these challenges but also documented poor services, lack of accessibility to clinics, rape and lack of job opportunities as issues affecting HIV in their community (P3D, P5D, P1D).

The issue of not having parents was documented by two participants, one in each of the workshops (P5U, P7D, see below). They also highlighted the discrimination that young people faced when their parents die of HIV. This was not a common challenge discussed by participants, but in the two cases where it was documented, the participants suggested that youth are afraid of the stigma associated with their parents' deaths, as they are also deemed to be HIV positive. The social exclusion that young people face on account of the possibilities of a HIV positive status can be damaging to self-esteem and how they participate in HIV prevention initiatives (Campbell, 2004).



Participants also documented specific issues that they were hearing in their communities, or in discussions with young people. Of considerable interest were the reflections of *DramAidE* participants around three key issues that included issues of HIV testing, taking HIV more seriously, and treating HIV like any other disease. Two participants commented that they hear discussions about young people being positive and that they are only considered negative once they have been tested. "I heard that people are saying that we are all HIV positive until you go out and check out" (P1D).

Discussions in the community were also identified by one participant to be centred on HIV being discussed like the flu and therefore there is no need to take the virus seriously (P2D). Participant Seven suggested that he often hears in his community that "people are saying that, you can't run away from it, so let us treat it like any other disease" (P7D). This indicates that HIV was identified like a common cold in the community, and since people could not prevent it from spreading, they preferred to treat it like any other disease and therefore did not see the need for it to be taken seriously.

Other workshop participants documented the more specific HIV programmes which young people were exposed to through television and radio. "I hear a lot, because I hear that, *LoveLife*, *Intersexions*, *Khomanani*, *Scrutinize* and *Soul City*, ah, programmes, which are being done, elsewhere and not being done in our own community (P8D). The UKZN participants also identified the key national programmes as the most popular programmes which they hear about. The participants, particularly in the rural areas, had heard of several national programmes, but these programmes did not have a presence through community engagement and participation in their community. The HIV programmes that were most commonly heard of by all participants in the *DramAidE* focus group include *Soul City*, *Intersexions*, *Khomanani*, *loveLife* and *Scrutinize*. The national communication survey conducted in 2012 indicated that over 80% of the sample population regularly watched HIV communication programmes (National Communication Survey, 2012).



Many of the UKZN participants identified most of the national programmes, as in the case of *DramAidE* participants, but also indicated that they hear HIV information through other sources including the radio, and campus initiatives. Various participants commented on the services of the campus clinic (P3U, see *below*) and other initiatives:

Around varsity we are always hearing about HIV programmes and there's the Live 8 concert that happens in Europe sometimes, where they raised funds for AIDS (P6U).

And here this is the radio... "Living Positively with Criselda" she is a MetroFM DJ who's living with HIV and she is open about it, and offering support and she has a show on that (P5U)

from where I hear about HIV and Aids – The TV the Radio and on campus - UKZN. (P2U)



The discussions about what young people hear in their communities about HIV resulted in many participants reflecting on the challenges of HIV and some of the common HIV programmes which they are knowledgeable about or have watched before. The identification of the factors that contribute to HIV with participants from UKZN and those from a rural community in KZN were very similar in many cases. However, the rural KZN participants tended to place more emphasis on the lack of jobs, poor clinic and social services and lack of information on HIV in their community. This suggests that whilst the UKZN participants identified these as epidemic drivers of HIV, many young people from rural communities were experiencing the effects of poverty, unemployment and poor social services in their own lives. Most of the HIV programmes that had a presence in their communities centred on caring for people, which suggests there is a shortage of HIV-related programmes and information. This indicates that young people from rural communities have some level of exposure to national programmes, but there is an absence of HIV programmes in their community. This challenges their ability to engage with the notion of participation in developing programmes. Unlike the UKZN participants, who extensively commented on national and community initiatives on HIV especially with specific programmes offered to students at their institutions, the rural KZN participants could not identify any programmes in their community. The next section explores the documentation on the eyes of the bodymap.

What Programmes do Young People see in their Communities (Eyes)?

The power of the eyes was the second step in documenting the participants' responses regarding HIV programmes. The specific task posed was for participants to "think about what programmes they 'see' in their community regarding HIV and AIDS." Participants were asked to write and/or draw the symbols/signs or logos of programmes in the area of their eyes. Once again, participants were given the freedom to document this next to their eyes to show what they see, (or anywhere else on the body). Other probing questions that were given to participants included "what other HIV and AIDS programmes have you seen outside your community on HIV and AIDS?" and also "what are some of

the bigger HIV and AIDS programmes you know of, or have seen". They were encouraged to document these on their bodymaps.

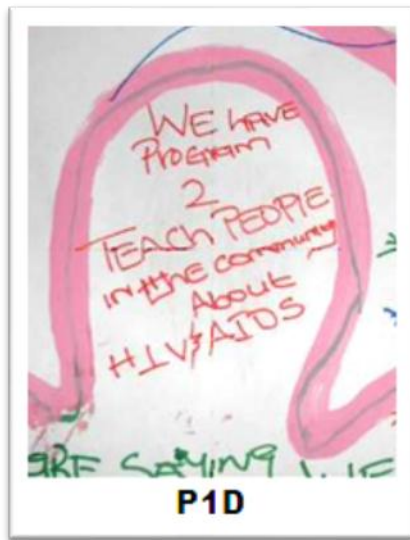
In response to these questions, many participants in both workshops documented programmes that they saw in their communities and those which they identified as national programmes. Below are some of the comments and images from the bodymapping, organised into three sub-categories that were evident from the data documented on the bodymaps. These include programmes in their communities, national programmes or young people not being aware of any programmes.

Programmes in the Community

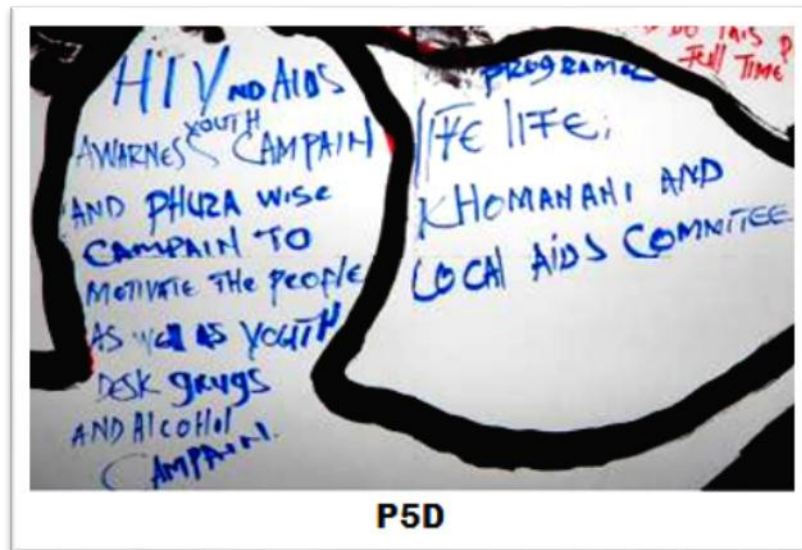
Many participants in rural KZN struggled with the question of what do they see happening in their community with HIV programmes. Participants continuously asked for clarification and often commented that there were no evident programmes which they could think of. This was the general consensus of the group, with some participants indicating that there were programmes which offered care and support for those infected with HIV. These programmes, however, were restricted to care and support and did not extend to cater for prevention, or education surrounding HIV and transmission.

Caring for the infected was commonly identified as an HIV intervention, "we organise some people that must take care for those who are affected by the disease" (P6D). One participant commented that they have programmes which can teach people about HIV and AIDS (P1D), but when asked about more specific details about these programmes, the participant started to talk about programmes which offered care for HIV positive people. This could suggest that participants were not clear about the difference between prevention and care and support; or that they understood that care was a form of prevention for those who were not infected. The emphasis on caring initiatives for those who are already HIV positive, rather than on programmes that advocate for prevention, highlights a gap in HIV prevention efforts in this particular community. Studies conducted by the Centre for Disease Control indicated that there is a need for more programmes which are "packaged HIV-prevention programmes", but these must not only address prevention needs of those who are negative but also those who are positive. It further places emphasis on prevention and care and support (Collins et al, 2010).

Two participants at the *DramAidE* workshop provided more specific details about the type of care offered to HIV positive people in their community. People who offered care to HIV positive people were often referred to as CCGs which was later explained to mean community care-givers. The CCGs often worked with various NGOs which could not be identified by any participant, to care for people living with HIV. “The CCGs, are the ones who help the people who are affected” (P2D). They would often be seen in the community, visiting the patients, teaching them about treatment, and ensuring that they are eating well, and taking their medication (P2D).



The above images indicate that in the place of the participants' eyes on their bodymaps, these two participants identified the HIV programmes available to their community. One image on the left suggests that there is a programme (or programmes) that teach the community about HIV (even though this could not be named). The image on the right suggests that the work of the CCGs is to assist those who are HIV positive. P3D raised an important point when discussing her bodymap and stated that: “CCGs who are only helping the people who are already affected, but my question is what about those who are not HIV positive?” This was confirmed by P1D (image on the left) who suggested that she documented that they do have a programme which teaches about HIV, but this is mostly for people who are positive, not HIV negative. This indicates that while there was a lack of HIV programmes in their community, participants were able to identify the difference between care initiatives and the need for prevention. Young people were concerned about the lack of HIV programmes for those who are negative and want to remain HIV negative. Insufficient programmes that address areas of prevention, exposes young people to more risky sexual practices. Prevention through communication programmes is effective in helping people become more aware of the dangers of risky sexual practices (Forman, 2005; Scalway, 2003).



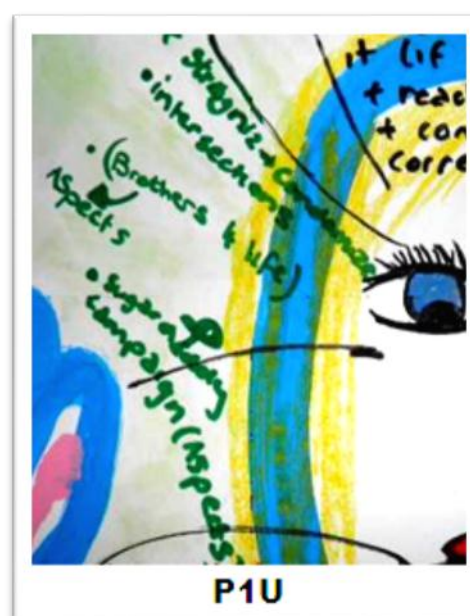
Another participant commented on the *Phuza Wise* campaign which he knew about in his community, which promotes safe alcohol use and motivated young people to be cautious about the abuse of drugs and alcohol (P5D). The participant identified this as a youth campaign linked to HIV and AIDS awareness, as it promotes safe usage of alcohol. When other participants were questioned on the *Phuza Wise* campaign, only half of the participants gave an indication of seeing the campaign in their community, and not many established a link to HIV prevention through this campaign. Similarly the work of *loveLife* was identified to offer HIV messages on billboards which young people were unable to decode and establish the link to HIV prevention (Govender 2011).

This questions the visibility of the campaign in the community, as half of the workshop participants did not comment on the campaign. It could also indicate that young people are selectively noticing campaigns in their community, based on what they identify as being informative or relevant to their own lives. Participants also failing to establish a link between HIV and alcohol indicated that they did not collectively identify alcohol as a key driver of the epidemic. This could also be on account of the lack of HIV prevention programmes in the community to establish this link. The *Scrutinize* campaign, in particular, offers an animert that directly links excessive alcohol consumption with risky sexual practices and exposure to HIV but none of the participants in rural KZN had seen these animerts.

National Programmes

Most of the participants of the UKZN workshop identified national HIV programmes as the common programmes which they were seeing. The UKZN students documented exposure to national HIV communication programmes like *Scrutinize*, *Intersexions*, *loveLife*, *Brothers 4 Life*, and *4Play*, *Sex Tips for Girls* (P1U, P2U, see below). Another participant also indicated that she has seen “the *loveLife* campaign, the Department of Health does a lot of campaigns, uhm, I see free testing happening here on campus. I see *Scrutinize* campaign” (P6U). The participants, when probed to explain more about the Department of Health campaigns, were unable to name specific campaigns or programmes. This could indicate that they had seen advertising by the Department of Health through billboards and posters (as P6U identified), but this was not always linked to specific programmes.

Many of the UKZN participants identified the *Scrutinize* campaign on campus and the availability of HIV testing facilities during the campaigns. Many participants commented that the best prevention was to know your status first, and then make choices to stay negative. The association with HIV testing on campus during the campaign indicates that participants associate prevention and safer sexual practices with testing options. This finding indicates that participants were aware of the importance of testing, and knowing their status when exploring prevention.



While many participants identified the national programmes that everyone in the UKZN group were familiar with, one participant commented on a television programme, also aired on radio, which is popular in the community she lives in. P5U (see below) commented on the *Siyabonga, Beat it*

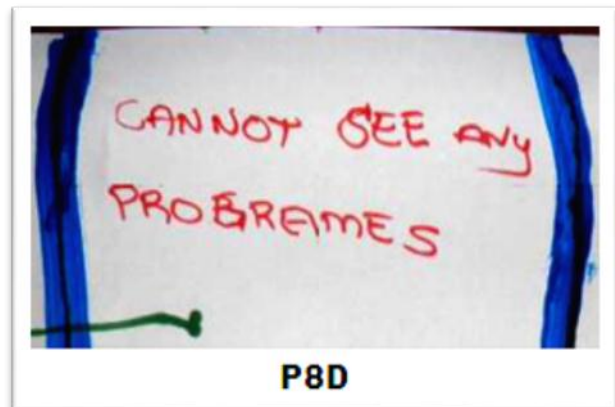
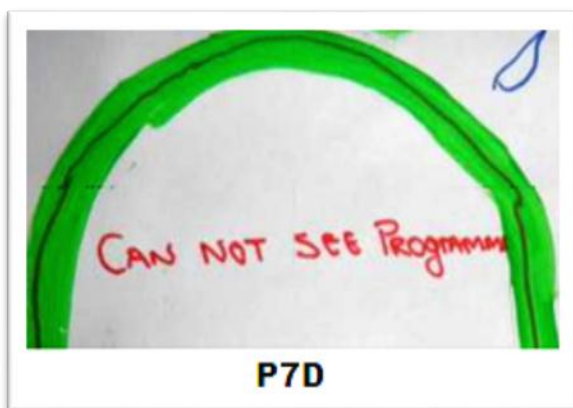
programme which is “an HIV programme that is in my community and I think it’s, it’s across South Africa ‘cause it’s even airing on SABC One”. This indicates that radio is still a prevalent medium of communication in communities. However, many participants from the Shakasraal workshop did not mention radio as an option for learning more about HIV. More initiatives to highlight radio programming as a source of HIV information could be encouraged in rural communities.



While the UKZN group seemed to be well exposed to HIV communication programmes, this was not found with the rural KZN group. In one instance, however, a participant at the *DramAidE* workshop noted *loveLife* as a programme which he had seen before. During the discussion session about each of the bodymaps, the participant confirmed that he did not see any programmes of *loveLife* in his community, but only that which was seen on television (P4D). In discussion with other participants from the *DramAidE* workshop, many identified *Intersexions* as a HIV intervention that they were familiar with, even though this did not reflect on their bodymaps (P3D, P6D, P7D, P8D). This indicates some level of inconsistency with what the participants remembered at the time of bodymapping and at the time of discussion. Many participants were reminded of programmes that they did not document on their bodymaps when other participants commented on national HIV programmes they had seen. This indicates the importance of dialogue as an additional activity after the bodymapping, to stimulate peer discussions and collective thought or action.

No Programmes

Two participants in the *DramAidE* group (P7D, P8D see below) indicated that there were no programmes evident in their community. They also engaged in discussion with other participants during the bodymapping workshop about the lack of programmes in the area. Many of the other participants were in agreement, as most could not identify anything other than the CCGs in the area, who were working with HIV positive people. The participants were also unable to identify the work of *DramAidE* in their community, despite the organisation's extensive facilitation of community dialogues in the Shakasraal area. While *loveLife* demonstrates a high brand recognition, and is criticised as a self branding exercise (see Tomaselli 2011, Govender 2011, Delate 2007, Kunda 2009), the work of *DramAidE* does not have high brand recognition or a visible presence in the community, yet studies have indicated the success of the *DramAidE* programme in initiating dialogue and encouraging social and behaviour change (Gumede, 2012, Durden & Tomaselli, 2012, Dalrymple, 1986, Ndhura, 2004). Below are images of what young people also wrote on their bodymaps to indicate that they did not see any programmes in their communities.



The documentation of what participants are hearing about HIV programmes indicates a distinction between the UKZN participants and those in rural KZN. Whilst many of the *DramAidE* participants could identify a number of national HIV programmes, these were only watched on television and did not roll-out as campaigns in their communities. The absence of HIV programmes confirmed the lack of specific prevention programmes in this rural community. The UKZN participants, on the other hand, commented on various HIV prevention programmes that they were aware of. Whilst the participants in both workshops had seen some of the HIV national programmes, it was predominantly the UKZN participants who saw and experienced the national HIV programmes and their roll-out on campus.

A HIV prevalence survey conducted by the Higher Education HIV and AIDS Programme (HEAIDS) in 2010 with over 24 000 students across 21 South African universities found that the HIV prevalence rate for students was approximately 3%. While the survey demonstrated that the HIV prevalence rate for students is lower than the general population of the country, the survey indicated that over 59% of young people were sexually active by the age of 20, and over 75% were sexually active over 20 (HEAIDS 2010: 25). This survey is supported by findings of other studies conducted at UKZN (Moodley, 2007; Mulwo, 2009; Kunda, 2009; Mutinta, 2011), which indicate that young people are more likely to have their first sexual experience during their time spent at the university. Young people residing in university residence away from home also engage in sexual relationships. Campaigns such as *Scrutinize* and *One Love* are therefore well positioned to address risky sexual behaviour with young people. *loveLife* has also offered billboards and community engagement efforts in a range of communities, but these were not evident in this particular community in Shakasraal. This lack of campaign visibility in communities like Shakasraal suggests that the intended participants for these campaigns are not always reached through national programmes like *loveLife*, *Scrutinize* and the *One Love* campaign, therefore creating a greater dependency and need for community engagement projects to mobilise on issues of HIV.

What are People Saying about HIV Programmes in their Communities (Mouth)?

The third step of the bodymapping process asked participants in both workshops to document, using images and/or writing, what is being discussed about HIV programmes by themselves or by others. The purpose of this step was to document key issues or topics arising out of discussions that participants were engaging in themselves, or discussions that others in their community were having.

The specific question asked for this step was “what are you/your friends or others ‘speaking’/ discussing about these HIV and AIDS communication programmes?” Participants were encouraged to either draw signs/symbols or write next to the mouth on their bodymap - or as a speech bubble directed from their mouths. Participants were also encouraged to think about young people’s involvement or participation in these programmes with a specific question of “What are young people saying about participation and these HIV programmes?”

The data generated on the bodymaps about what people were discussing was categorised into four sub-categories, which included discussions on multiple and concurrent partners, the importance of consulting with their communities, the need for more education and the importance of testing.

Multiple Partners

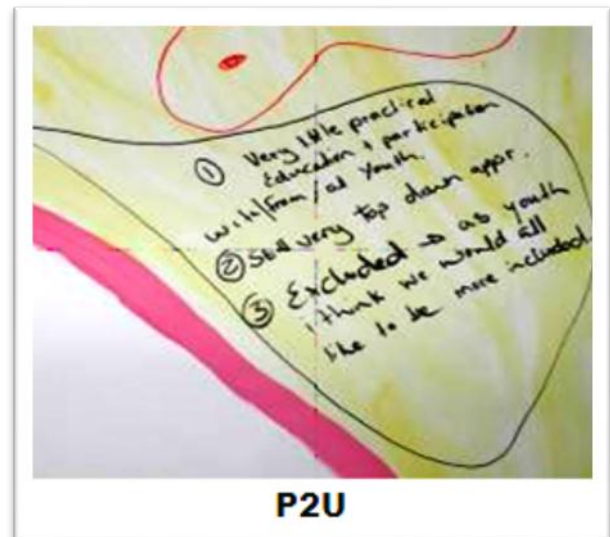
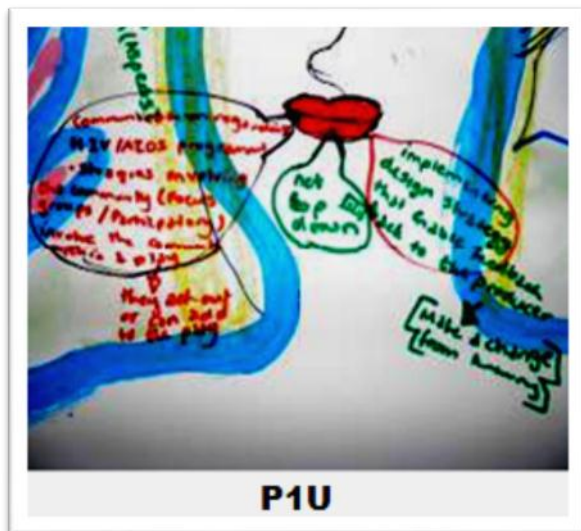
One of the participants indicated that in discussions with her friends they often talked about watching *Soul City* and *Intersexions*, and shared their thoughts on some of the episodes and the content that they watched. Through these conversations, the participant reported that “HIV and AIDS kills”, was a key topic for discussion after watching these episodes. In addition, the participant reported that common discussions centred on the dangers of having more than one partner, suggesting that it was not wise and can lead people who engage in multiple relationships into trouble (P2D). From an individual discussion with P2D after the workshop, it was evident through the engaging storyline in both series, that young people were able to engage in conversations around issues of multiple partners. The participant in this instance highlighted that she would have extensive conversations with her friends about how having many sexual partners leads to more problems. It was clear from the bodymapping material and the discussion with the participant that HIV programmes such as *Intersexions* become a catalyst for discussion about HIV and sexual relationships.

These discussions, that HIV kills and the danger of multiple partners, indicate the effectiveness of television in stimulating discussions amongst the audience after a screening. Scalway (2010) suggests that an integrated approach is needed for HIV and AIDS communication, where media, participation, advocacy and social mobilisation all work together to address the HIV challenges with young people. However the national television series, in the absence of community engagement, was still able to catalyse a discussion on risky sexual practices, where young people could share about their experiences and the need to protect themselves from HIV. This was also evident in the reception analysis study on the television series *Intersexions* where many young people were reported to engage in more discussions about HIV issues after watching an episode (Govender et al, 2013).

Consultation and Involvement of Young People in Communities

Many of the participants, particularly at UKZN, indicated that the most common discussion that they engaged in with their peers, friends and family was around the exclusion of young people in HIV programmes. This was a huge shift from some of the responses received with participants at *DramAidE* that predominantly involved discussions around the specific needs of young people in terms of job creation, poor social services, poverty and lack of initiatives on HIV prevention in their communities. All participants in the rural KZN group were school-leaving young people, who were unemployed. This indicates that the primary conversation among their peers revolved around job possibilities, as poverty

was very evident in the community. Participants at UKZN, on the other hand, offered extensive comments on the importance of empowering young people (P4U), the need for more youth engagement in HIV programmes (P1U, P2U see *below*), and the importance of recognising that young people can make a change in their communities. The UKZN participants therefore extended their conversations beyond attendance at HIV programmes, but more on the need to participate in their development (P1U, P4U, P6U).



In individual discussions about their bodymaps with two of the participants at the UKZN workshop, they indicated that the active participation of young people would increase knowledge and awareness of HIV-related issues (P4U see *below*).



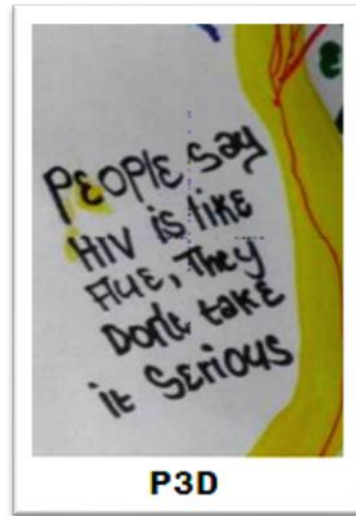
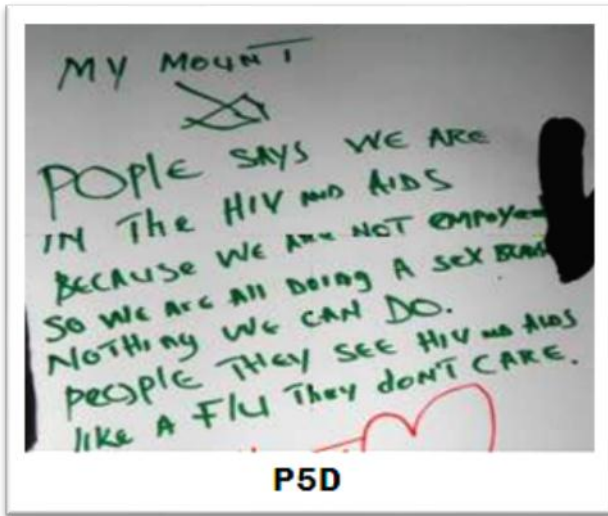
While the UKZN participants strongly advocated for the participation of young people in HIV programmes, the participants from rural KZN did not identify this as a key focus when speaking about HIV programmes. In fact, few participants commented on any community involvement or engagement with HIV-related issues. One of the participants, however, in the individual discussion about his

bodymap, noted that he would “consult a counsellor and call a meeting to hear from the people and then work towards helping the people getting information about what they can do to deal with it” (P7D). This participant took the focus away from what young people can do, and instead emphasised the role of the ward counsellor, a local government representative in his community. The participant further explained that the ward counsellor engages in discussions with the community to understand their key concerns, indicating that some level of community consultation was taking place between the community and the local authorities.

There is a marked contrast in how participants in the UKZN group identified the need for empowerment of young people and participation, and how the rural KZN group relied on the intervention of ward counsellors to initiate discussions in their community. This highlights the varying levels of participation and the power dynamics that exist in communities. Many African cultures identify the elders, and in some cases the men, as being the people who are in charge of making decisions. This is filtered through to young people in the community who then do not address issues on their own, but in consultation with adults. This exacerbated the fact that the epidemic is usually driven by power inequalities between young people and adults, and men and women (Campbell et al, 2007). In order to overcome these power imbalances, young people need to be given the freedom to express their views and ideas for enacting positive change in their communities, especially with issues of HIV and AIDS.

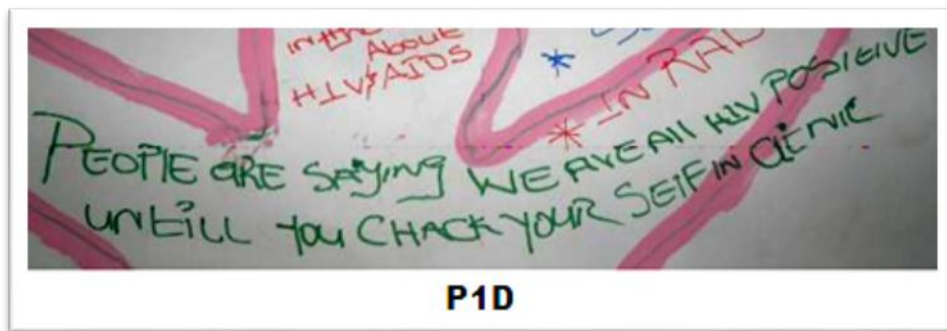
General Discussions on HIV

Common conversations identified by participants in the rural KZN workshop included discussions on the association of HIV with the common flu, boredom of young people, the lack of a cure and the need for more education. P5D (*see below*) reported that young people in his community usually engage in sex as there was not enough job creation and work for young people. They would therefore engage in sex due to boredom. Another participant indicated that there was a lot of discussion about how HIV is killing people and cannot be cured, but only prevented; therefore more information is needed on HIV prevention (P3D *see below*). The misconceptions around HIV, coupled with unprotected sex due to boredom among young people, suggests the need for more information on the transmission of HIV, dangers of unprotected sex, and the need for young people to keep themselves occupied with community projects and programmes, while they are seeking employment.



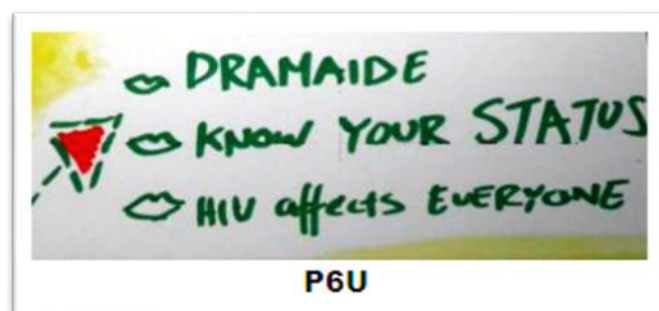
Testing

Discussions around HIV testing were very common in communities, with participants from *DramAidE* reporting that “you are HIV negative until you test positive” (P1D see below). This suggests that the discussion in communities promotes HIV testing among youth that is premised on the assumption that people are HIV positive, unless tested negative. The discussions about young people knowing their HIV status was identified as an important topic when speaking about HIV programmes.



Another participant stated that “there’s people always saying ‘Know your status’” and people saying “HIV affects everyone” (P6U). This indicates that if there were no community initiatives to advocate for the HIV prevention messages of the national campaigns, and there was a lack of organisations working in the community beyond care for those who were HIV positive, then the participants could only be receiving this information from the national television programmes which they watched. Programmes such as *Soul City* and *Intersexions* were familiar among all participants and suggests that these slogans of “Know your Status” and “HIV affects everyone” had to be offered through these national programmes and the discussions among young people.

As a result, the common discussion amongst most of the rural KZN participants revolved around issues of HIV testing and many reported that programmes which supported testing and using protection for safer sex were most needed in their community (P5U, P6U see *below*).



What are Young People Thinking about Developing HIV Programmes (Head)?

The fifth step of the bodymapping process posed a question about what the participants understood about HIV programmes and the specific phases for developing HIV projects. The objective of this question was to collect information and to later engage participants in discussion about their thoughts on their participation in the development of HIV programmes. The instruction to participants was as follows: “On the top of your bodymap, where the head is, mark, draw symbols or write about current HIV programmes.” More specifically, participants were asked to think about “what do you understand about the phases of developing a HIV programme or intervention”, and they were asked to list or draw these phases. Many of the UKZN participants focused on the phases of developing HIV programmes and their perceptions or ideas about these phases. The rural KZN participants addressed this step more from the perspective of mobilisation of young people in their community to get information from

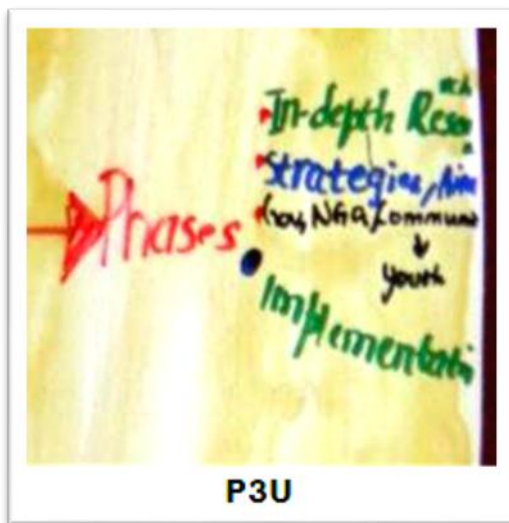
clinics and develop HIV programmes. Given the stark contrast of responses across both workshops, the data for this category is divided into two sub-categories that address the phases of developing HIV programmes, specifically the responses of UKZN students, and the data on what participants thought about HIV programmes in their community, specifically with reference to the responses from the rural KZN participants.

Participant's Thoughts on Phases of Developing HIV Programmes

Most of the participants in the UKZN workshop identified similar phases which need to be followed for the development of HIV programmes. The participants generally noted that the first phase of intervention development included a strong research component. P3U (*see below*) offered a simple three step process which included in-depth research, development of strategies and implementation of those strategies. The participant identified common stakeholders for this design that included the government, NGOs, communities and youth, who had to work in collaboration with each other. P5U (*see below*) expanded on these three phases in her bodymap, to include phases of community outreach, or what she also termed situation analysis, involving the community in the design of HIV programmes, dialogue, planning, implementation and monitoring. This participant introduced two key steps that are often missing in HIV programmes, which includes the active participation of the community (in this instance, young people) and the use of dialogue amongst all key stakeholders to promote or address a specific HIV-related issue.

The phases of development offered by these UKZN participants confirms one of the common strategic communication processes used to develop HIV programmes, which is known as the P-Process. This P-Process, developed by the Centre for Communications Programs at Johns Hopkins University suggests that the main steps for developing a public health intervention would usually require a process of analysis, strategic design, development and testing, implementation and monitoring, and evaluation and re-planning (McKee et.al, 2004). This P-Process has been adapted for the development of many HIV national programmes in the country such as *Intersexions*, *Foreplay*, *Sex Tips for Girls*, *Scrutinize* and *Brothers for Life*. The comments offered by the UKZN participants, however, draw specific attention to the importance of dialogue and target participation in all phases of what is commonly used and applied as the P-Process. The P-Process indicates that capacity strengthening and participation is central to all stages of developing programmes. The UKZN participants succinctly document this as the need for dialogue and participation of people in all phases of development.

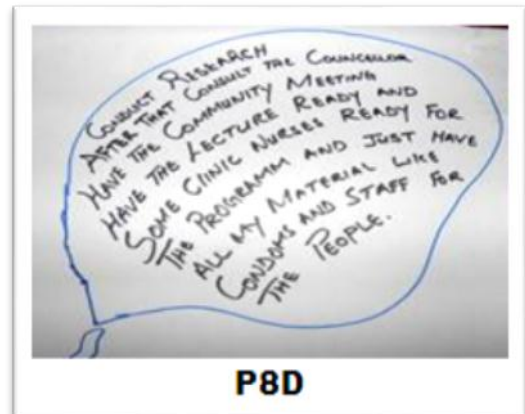
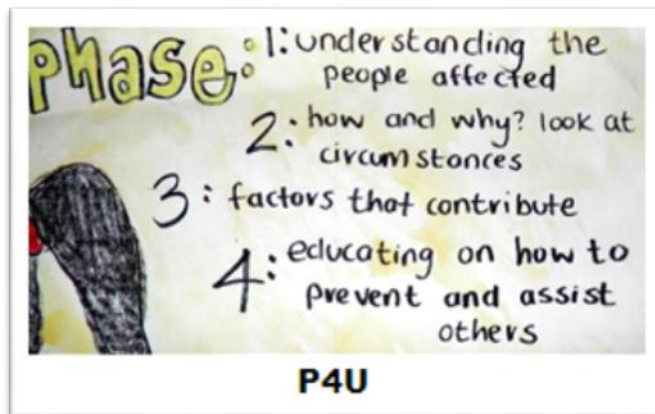
Several communication strategies and models for developing HIV programmes indicate that the problem or issue has to be explored before an intervention is developed or implemented. The 'communication for social change' and 'participatory development' models offer similar step by step processes, that place problem identification through community dialogue as the first phase of initiating development within a community (Figueroa et al, 2002; Kincaid et al, 2009, see also Habermas 1971). The P-Process also places the situation analysis as the first phase of design in the process of developing a communication intervention (McKee et al, 2004)



Other participants at UKZN documented more detailed phases for developing HIV projects. P4U (see below) suggested four phases to developing programmes, adding a phase that included the importance of understanding the target audience, or the people affected. The second phase that the participant suggested was to explore how and why the issue of HIV was a problem in the specific community. She reported that this could be done through a situation analysis or a review of the circumstances. A third phase was proposed as understanding the specific factors that contribute to HIV, and a fourth phase identified the process that entails educating people on how to prevent HIV and assist others. Of significant importance in this process was the focus on three phases of understanding the people, the circumstances and the factors that contribute to HIV, before developing a programme to educate young people on prevention.

The need to explore these multi-layered influences, demonstrates the importance of understanding the individual, community and societal influences that contribute to how young people make sexual choices. These multiple influences will indicate the driving epidemic factors that are specific to the target audience, with more insight into the circumstances which influence risky behaviour. These

multiple influences are often documented through the social ecological model, which highlights the importance of understanding the lived experiences and decisions of young people within their relevant context.



P8D (see above) at the rural KZN workshop was one of the very few participants who were able to identify important phases when developing HIV programmes. This participant indicated that research was the first phase and the most important step when developing HIV programmes. This step was followed by the importance of consultation with the local counsellor of that community, and later through holding community meetings on the issues of HIV in the community. P7D offered a similar comment on his bodymap to P8D, where he reported that he would first consult with the counsellor and have a meeting with the community to hear more about their issues with HIV. However, P7D, unlike participant P8D, resorted to going back to the ward counsellor to explore how the municipality could assist the community. This takes the power out of the hands of the community, and places it in the hands of the government to decide what HIV programmes are needed in that community.

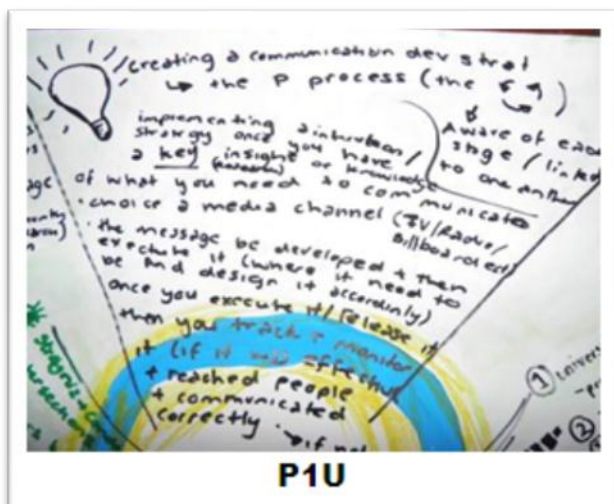
The participant (P8D) identified the importance of understanding the target audience through research, engaging in dialogue with the political authorities in the community, followed by community meetings to ensure that everyone contributes to the discussion on HIV. The suggestions offered by this participant on his bodymap confirms what UKZN participants were documenting on their bodymaps, highlighting the importance of community dialogue and involvement of all stakeholders when developing HIV programmes.

According to Bessette (2004), the involvement of the community in various phases of a community project is integral to its success as it makes the project more context specific and of relevance to the community. The role of community dialogue was therefore identified as an important phase among

various participants in both workshops (see also Habermas, 1971). However, it can be argued that, amongst the *DramAidE* participants, the evidence on the bodymaps indicates a stronger case for involvement of community, stakeholders and processes of discussion and dialogue.

Other suggestions from participants at UKZN centred on the need to understand key issues that need to be communicated to young people, before developing HIV communication strategies. One participant reported that the choice of media channel for the intervention was very important. The participant also reported on the importance of monitoring and evaluating the success of executing a message, to ensure that it reached young people and was correctly communicated (P1U see below). This participant suggested an additional element that other participants did not document, which was specifically on phases of monitoring and evaluating the HIV intervention. Monitoring and evaluation is an integral phase in developing HIV programmes, but for the purpose of this study it has not been explored in detail due to its broad focus.

Another participant reported on the importance of ensuring that HIV programmes created more opportunities for awareness, and stating the facts of HIV (P6U see below). This particular participant, like many others, reported that the lack of knowledge was the cause of high infection rates and risky sexual practices. Studies conducted on South African young people over the last decade indicate that social, contextual and cultural factors contribute to sexual decisions (Parker, 1994; Campbell, 2003), therefore a lack of knowledge is not the only contributing factor but has to be understood within a broader context. The participant further documented on her bodymap about specific strategies that could be used such as fear-based education. The participant in this instance suggested that within the phases of developing HIV programmes, the use of fear was better positioned to get young people to start thinking critically about their sexual practices (P6U).

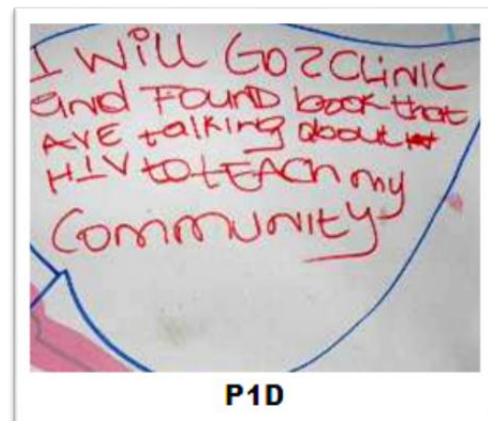
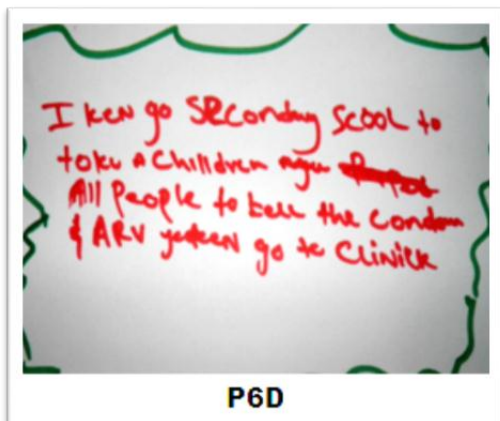


Fear theory operates on the premise that people will undertake an appraisal process if they perceive a threat in their environment. According to Murray-Johnson (2001), an appraisal process increases people's awareness that they are susceptible to a threat and that the threat is severe. Only when people identify the severity of the threat, will they proceed to appraise protective and safe behaviour. Therefore, "the high level of fear, paired with strong efficacy perceptions and the knowledge that they could do something to avert infection, creates optimal conditions for behavioural change, in line with what current fear appeal theory suggests" (Green and Witte 2006: 253).

Mobilisation of Young People in Communities

Many of the *DramAidE* participants did not focus on the phases in which they could develop HIV projects, but instead documented some of the immediate steps that could be taken in their communities to start discussions about HIV programmes or to assist people living with HIV. For many participants, HIV was a reality in their community, but not much has been done to address the HIV challenges beyond caring for those who were HIV positive.

One participant, when responding to what he understood about the development phases of HIV programmes, documented that he could go to schools to talk to young people and tell them about services offered at the clinic (P6D see *below*). This comment indicates that the participant was taking an introspective perspective during the bodymapping process, and his understanding of the phases of developing HIV programmes included his participation in relating information to young people at schools. In a discussion after the bodymapping process, the participant continued to discuss this. This indicates that this participant identified himself as a source of information to other young people, providing a means of communicating about services offered at the clinic, which some young people may be unaware of.

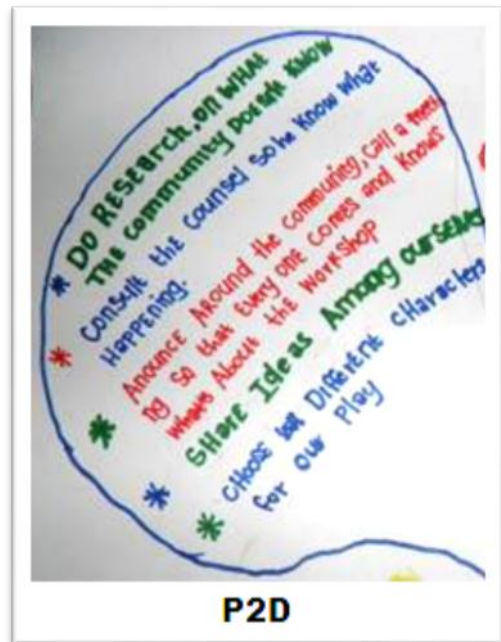
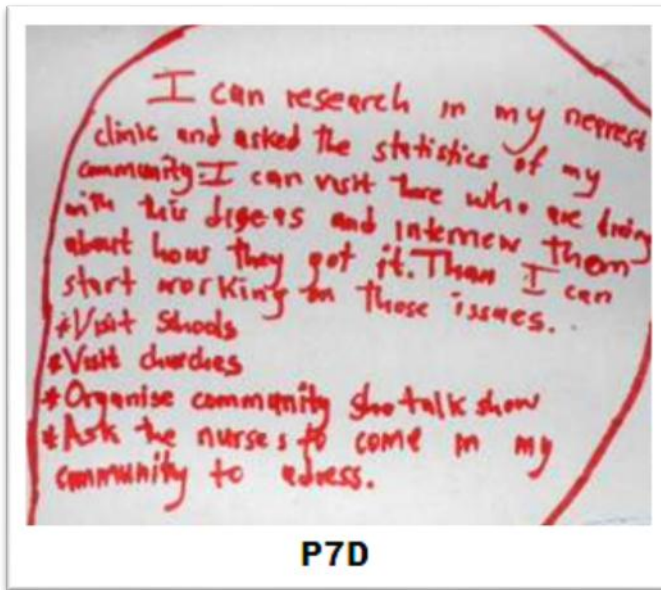


A study conducted with 21 randomly selected schools in the Limpopo province indicated that 66% of the respondents relied on information received through teachers, classrooms, communities and especially peers and other young people, in comparison to 31% of the respondents who relied on mass media for information (Shilumni, 2007). This indicates that young people in the community relied on their social network and educators for information. It also highlights the active role young people can play in developing HIV programmes since they are often considered to be a reliable source of information among their peers. Peer education is therefore an important approach that should accompany HIV programmes (Dickinsons, 2006).

Another participant documented that she would go to the clinic and find a book that talks about HIV and in turn will use this to teach her community, "I will go to clinic and found books and talk about HIV and AIDS, and tell them to go to the community" (P1D *see above*). This also indicates that the participants were exploring ways of being sources of information in their community despite the lack of information. In this instance, the clinic was identified as a place where information about HIV could be obtained to relate to the rest of the community.

Another participant also commented that young people in their community could start a database of all young people who reside in that community, and they can explore the challenges of HIV, and then address these issues. The comments received from the participants indicate the importance of social inclusion and working with various stakeholders to address issues that arise in a community. Young people, when asked about their participation, reflected on how they could incorporate various stakeholders in their communities, indicating that partnerships and working together was part of the participatory process (see Rein et al, 2005).

P7D and P2D (*see below*) at the rural KZN workshop identified the importance of research in their communities, but supported this by suggestions for mobilisation of young people in areas of visiting schools and churches, organising community talk shows, and inviting nurses from the clinic to address specific areas of the community (P7D). P2D suggested that getting the community together to discuss HIV issues was important, but this has to be followed by some form of community initiatives in the form of plays to relate information to young people.



The discussions above indicate that the lack of information is a continuous issue that arose with the rural KZN group, with young people offering suggestions about how they can spread more information about HIV in the community, and how they can mobilise community members to participate in HIV programmes. Partnerships and working together with the community, counsellors and other young people were common mobilisation strategies identified by the participants in the rural KZN group. The UKZN group, on the other hand, discussed the involvement of young people from a different perspective, where they could empower and mobilise themselves to participate in developing HIV programmes. The importance of partnerships and working together in community projects is crucial and its relevance must not be forgotten. However, young people can be disempowered when they are not actively mobilised to engage with their communities in developing HIV programmes.

What do Young People Feel about Participation (Heart)?

The next step of the bodymapping process was to get participants to document what they feel about participation and about being included in the development of HIV projects. This step was developed to build on the previous three steps that asked participants to think about and document what they saw happening in their communities regarding HIV-related issues, what was being said, what they were hearing about HIV programmes and what they themselves were saying about these programmes. This next step was a shift from questions that tried to understand the situation or context, to explore the perceptions and feelings of participants around issues of participation. The specific task given was: "Moving to the middle of your bodymap, close to your heart, either write or draw images on how you feel about being included in communication programmes".

This step was included to get a sense of whether participants believed it was important to participate in the development of HIV programmes. The two follow-up questions were: i) How do you feel about always receiving information about HIV and AIDS and not being part of making those messages?, and ii) How would you feel if you were asked to be part of programme design?

Many participants commented on how participation in HIV programmes lead to feelings of happiness, inclusion and empowerment. Others found that through participation in the development of HIV projects, they could learn more about HIV and then have the knowledge to share with others. Below is a discussion of these findings, arranged into various sub-categories.

Learn More by Participating

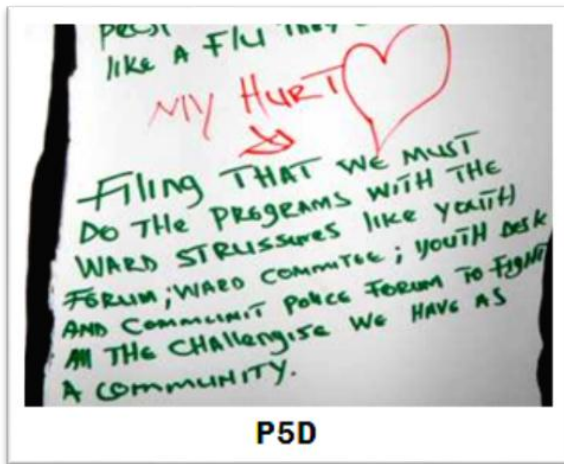
Over half of the rural KZN participants associated participation with learning more about HIV and AIDS. One participant, responding to the question of how he would feel about participating in HIV programmes, reported: “In my heart I feel like I can learn more about HIV and AIDS” (P1D). The participant later commented that participation was important for young people and they can learn more about HIV. Another participant commented that “being part of the HIV and AIDS programme I feel that it’s important, so I can be aware of the disease” (P2D). This indicates that participants associated their inclusion in designing or participating in HIV programmes with becoming more aware of HIV and learning more about HIV and AIDS. Participation can therefore mean different things to different participants, and is often best defined by the target audience of a programme and within the context in which it is applied (Govender, 2010). The rural KZN participants therefore associated having knowledge about HIV with their participation and ability to relate this information to others in their community.

P6D (*see below*) also commented that “it is important for young people to participate in the community programmes so that there will learn more things as they grow up and take responsibilities for themselves” (P6D). This participant, through discussing how he feels about participation, suggested that it is important for young people to participate as it encourages more learning and requires young people to take responsibility for themselves. It can be suggested that responsibility was therefore linked to learning and participation. Young people associated their active participation in developing HIV projects with increasing their own responsibility for their own lives.



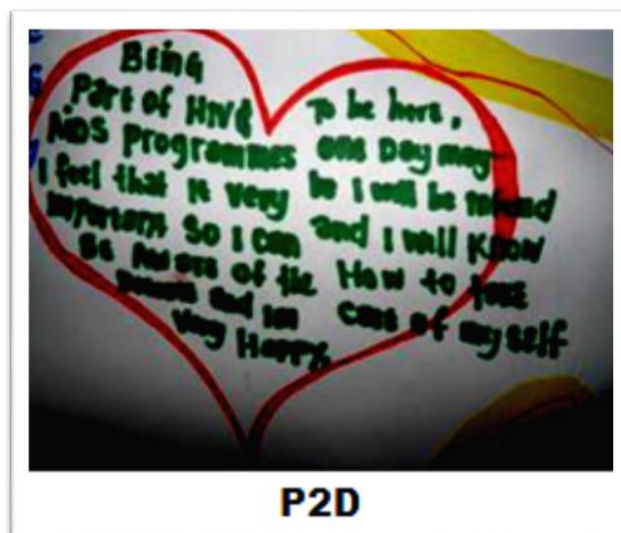
Other participants commented on specific programmes that they felt were necessary, suggesting that initiatives like the youth forum and youth desk could assist organisations to address issues of HIV. P5D did not directly suggest that participation of youth was important, but instead suggested that by offering various youth-centred programmes, young people can fight HIV.

Another participant documented on his bodymap that he felt empowered when he could be involved in his community and could acquire more information on HIV. The participant reported that he would ensure he educates himself on HIV-related issues before getting involved in his community (P7D). This indicates that the participant felt he had to have sufficient knowledge and information before he participates in HIV programmes in his community. This could pose a problem when participation is linked to information, as many participants in the *DramAidE* rural KZN group identified lack of HIV information as one of the biggest concerns in their community. This suggests that young people in rural KZN associate participation with having information. Given the lack of information identified in the community, participants would never feel empowered to participate. The notion that only people with knowledge about HIV are in a place to develop HIV projects or make informed decisions is contradictory to the work of Freire (1979) who advocates for a problem-posing method to encourage participation to build knowledge and empower young people to become more aware of their social reality.



Passing on Knowledge to Help Others

Most participants in the *DramAidE* workshop reported on their willingness to help others in their community with HIV-related issues. One participant reported, “I’m very happy to be here, cause one day maybe I might be affected or infected with the disease or maybe a partner, maybe a family member, and so I can help them” (P2D see below). Another participant suggested that young people’s participation is desirable because “you warning some people that have HIV” (P6D). The participants therefore identified their participation in bodymapping as a process of acquiring knowledge, which will position them to help others or themselves on HIV-related issues. The participants were happy to be part of the bodymapping process and they felt that it assisted them in thinking about how they can help others in the community. P4D also indicated that she felt she could “help people and children” through participation in developing HIV programmes. The participants’ willingness to assist others and share the knowledge they acquire reflects a different level of participation that is inclusive of support, caring and transferral of knowledge.



The comments made by many participants in both workshops indicate that young people identify participation differently. For many participants in the rural KZN group, participation was identified as a means to an end, suggesting that it aids the process of meeting an ultimate goal or deliverable. For example, participation now can lead to helping the community later. For many of the UKZN participants the process of empowerment and the emphasis on young people's voices suggested that participation was an end in itself, where the human rights of the participants were more important than an outcome that results from participation (see Melkote, 2003).

One participant indicated that he believed that HIV programmes can make a change in his community. The participant reflected on the bodymapping process and highlighted that the community can benefit from programmes like this. "I strongly believe that HIV programmes can make a change in my community. I can be very happy if I can be part of these programmes. Most of my community members can gain a lot from these programmes" (P3D). Many participants were able to identify the importance of these HIV programmes taking place in their communities and wanted to be part of the change it could bring to the community in terms of HIV. Participants were therefore internalising their own experiences at the workshop, and commenting on how it could influence the broader community. Acquiring the knowledge to assist or inform the community about HIV-related issues was identified as a form of participation. Knowledge transferral was therefore central to mobilising participants in rural KZN to participate in the development of HIV programmes.

Participants Feel Empowered and Disempowered

Many of the UKZN participants used the term 'empowered' to describe how they would feel if they were to participate in the design of HIV communication programmes. This was not a common term used in the rural KZN group. This suggests the knowledge gap between the rural KZN group and the participants at UKZN, who were exposed to an environment where student participation and engagement was strongly advocated for as part of their learning process. The rural KZN group were not exposed to a similar environment, hence they articulated this differently, but were still able to describe what they could do in the community. The terms 'empowered' and 'disempowered' were not identified by the participants from rural KZN, but many suggested that they were mobilised to acquire knowledge and take a proactive role, suggesting empowerment.

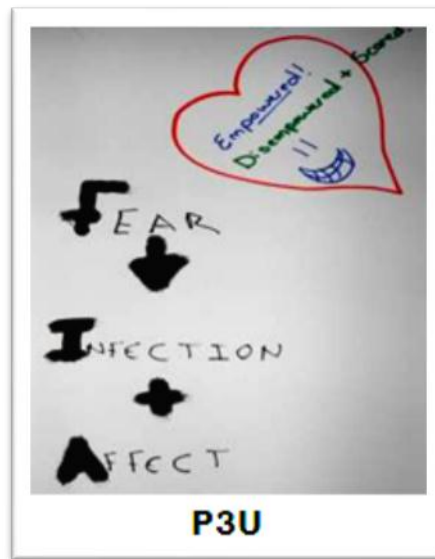
One UKZN participant reported:

If I was asked to be part, to participate in it, I would feel empowered and when I don't often or that I am not included in it, it's a sense of a disempowerment and a sense of fear, because from the studies that we have done, we've seen that if it doesn't include the participants or recipients or whatever... the beneficiaries, it's not always relating to them. So, the right kind of information and knowledge doesn't come out. Uhm, and then just if I am asked, like with this, where I am participating it makes me feel happy– It makes me feel empowered (P2U).

This participant made reference to her studies at the university where she learnt that if people are not included in programme design, the programmes will not always relate to them. This implies that the correct or relevant information and knowledge is not being conveyed to the appropriate participants. This participant perceived lack of participation in developing HIV programmes as a disempowering experience.

Another participant at the UKZN workshop indicated that she often felt empowered when participating in HIV programmes, but disempowered when she thought about HIV in her personal life, as she had a fear of being infected or affected by loved ones who may become infected over time. The fear of infection and affection resulted in a sense of disempowerment (P3U see *below*).

This suggests that some young people feel that they do not have control over their lives, since the actions and decisions made by their partners or families about sexual practices can directly affect them. This finding indicates that even when young people make informed choices about their sexual practices and remain HIV negative, the possibility of infection of their partners or families instills a level of fear and disempowers them. HIV programmes therefore need to explore how to empower young people within their social ecological system where the decisions of their peers, partners, spouses and families directly have an influence on their own lives (see Stokols, 1996; Sallis & Owen, 2003).



Another participant described the discrimination and hate that often arises when discussions are held about HIV. This makes her feel disempowered and she therefore documented on her bodymap, “the heart with the cross, that is like, discrimination and hate” which depicts for her the disapproval of discrimination that is often associated with HIV (P1U). The participant did report that she would feel empowered by participating in HIV-related programmes.

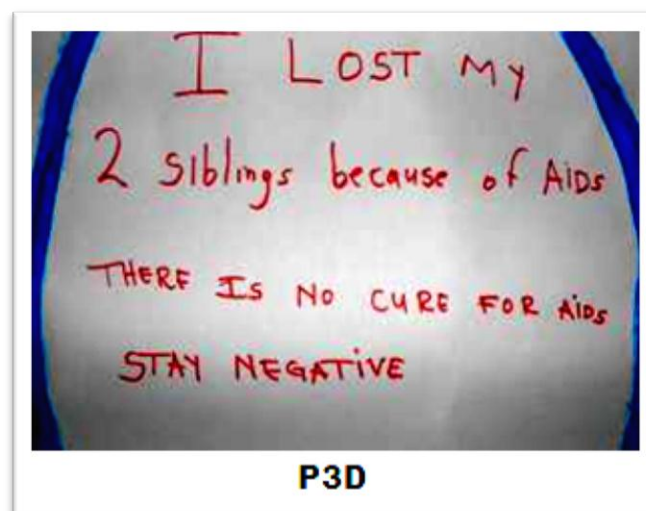
P4U also commented that at times she does not feel like the programmes have an impact on her or directly affect her, and she sometimes feels excluded from how HIV programmes are developed. The participant indicated that more inclusion of young people was necessary in HIV programmes and communication programmes and a better understanding of the issues of HIV and how it really affects communities, must be related to young people.



The participant, however, further commented:

I think it's a good idea to engage in these campaigns and it's a thumbs up, by the way. I tried to draw a thumbs up and, so, I am still kind of confused, in a way, if HIV is overrated or I am not sure if it's obviously a, a good subject, but people still ignore it and they are not comfortable talking about it (Participant 4, UKZN, 2012).

Whilst P4U was grappling with feelings of confusion about why young people still ignore HIV messages and fail to adhere to messages, another participant at the *DramAidE* workshop shared that her feelings about HIV were that young people must stay negative as there is no cure for HIV. She reveals that she lost two siblings to HIV, and therefore young people must remain negative.



The above documentation on the bodymaps indicate that young people have the freedom to express what they feel, with opportunities to provide several or few details about their personal lives when responding to the questions. P3D, in this instance, was using her personal experience as a means of

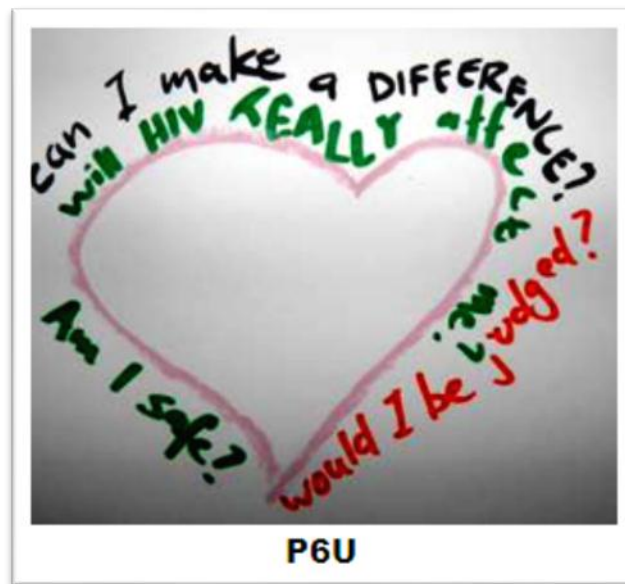
communicating the severity and reality of HIV, highlighting how it made her feel, but also advocating for other young people to stay negative through a message that there is no cure for AIDS.

Another participant also identified the importance of involving young people in HIV programmes as they have the ability to listen to other young people. “I feel that we as young people should participate more in effective programmes, because young people can only listen when cautioned by other young ones” (P8D). This indicates that peer educators could play a significant role in a community to mobilise young people to actively participate in the development of HIV programmes.

Whilst participation and empowerment of young people are important; organisations, parents and communities are often gatekeepers that try to regulate the level of participation of young people. Arnstein’s (1969) and Rogers’ (1992) ladders of participation can be seen as a way in which participation is regulated with various levels of participation that young people need to navigate through. The type of participation promoted also affects the type of empowerment that takes place. Participation and empowerment applied in this study in relation to bodymapping suggests that bodymapping acts as a catalyst for encouraging participation with young people; it engages young people in a creative process where previously they may not have considered taking an active role in developing HIV programmes. ‘Empowerment’ is used as a term with the understanding that the outcome of the bodymapping workshop is an empowering collective experience of identifying the importance of engaging in HIV programme development, and being in a position to identify what those steps may entail. Empowerment in this sense is used in a way that creates critical consciousness around the liberating influence of active participation.

Problem-Posing Questions

A participant at UKZN used the process of bodymapping to document some of the questions that she still needed answers to P6U (*see below*). These questions of “can I make a difference, will HIV really affect me, am I safe and would I be judged?”, demonstrate the introspection that was taking place with the participant as she reflected on issues of participation in the development of HIV programmes. The problem-posing methodology suggested by Freire allows for the engagement of communities in posing questions even if there are no answers available (Wallerstein & Bernstein, 1988). The simple process of posing questions can lead to finding solutions, as the ongoing engagement, discussion and exchange of ideas among young people will direct the group towards exploring common experiences as well as possible solutions (Rikard et al, 2011).



Discussions about the participants' feelings about their participation and involvement in developing HIV programmes sparked diverse responses from both workshops. Many participants were willing to participate and, in some cases, equated the sharing of information and knowledge to participation. The participants also shared examples when they feel disempowered, and what prevented them from participating in HIV programmes. The bodymapping process was effective in getting young people to document their experiences, perceptions and thoughts about their involvement. Many participants wrote down questions on their bodymaps which they could not address, and these were addressed during the discussion session, highlighting that bodymapping can be a tool or catalyst to get young people to pose questions and explore issues with other young people.

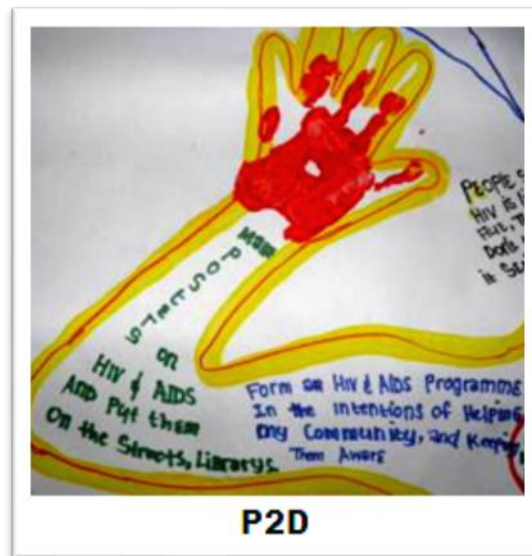
What can Young People Start Doing to Develop HIV Programmes (Hands)?

The next step of the bodymapping process required participants to work on the hands of their bodymaps and, by writing and/or drawing, participants were asked to think about and document on their maps how they could participate in a hands-on way with HIV programmes or projects. The participants were further asked to think about and document what they could start doing practically regarding HIV programmes and design.

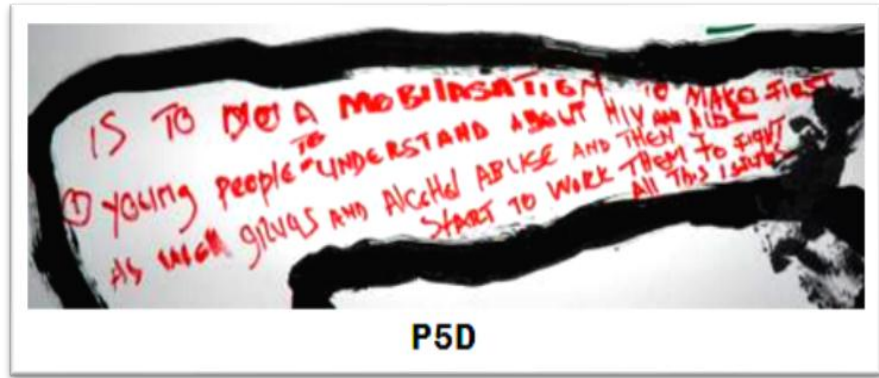
Many participants found this to be an easy step to document, as the prior steps of the bodymapping process had already started the process of introspection and exploration about what they could do in their communities. Many participants commented on the development of materials and the training of participants and young people in their respective communities. Other comments focused on the need for more discussions and collaborations with young people in the community. The data documented on their hands, and later discussed in individual discussions, are categorised into two sub-categories: training and materials development, and HIV awareness.

Training and Development of Materials

Only one participant indicated that he wanted to develop materials and posters on HIV and AIDS-related information for this community. He indicated that he wanted to create more awareness in his community about the disease. "I want to make posters on HIV and AIDS and put them on streets or libraries or tuck shops, so that people can see and then form an HIV and AIDS programme in the community and keeping the aware of the disease" (P2D see *below*).



Another participant indicated that he would want to get practically involved in his community by forming a group and receiving training about HIV and AIDS. Once the group was trained, they could go out into the community to teach others about HIV and AIDS (P3D see *below*). The participant also suggested that they could have HIV positive people come to their communities and share their stories, to create more awareness on HIV and living with the virus, and how to prevent HIV transmission. Albert Bandura's (1997) Social Learning Theory places significant emphasis on the use of role models in affecting behaviour change which, in the case of peer educators, can serve as positive role models who provide information and support. The rural KZN participants identified a process of engaging their communities and creating HIV awareness through a process of social learning, using young people as role models on how to prevent HIV transmission.



HIV Awareness – More Discussions in Communities

Both workshops had several participants documenting on their bodymaps about the ways in which to get young people engaged in more discussions in their communities about HIV-related issues. Participants explored ways in which they could practically start doing something in their communities or university residences. One participant reported that:

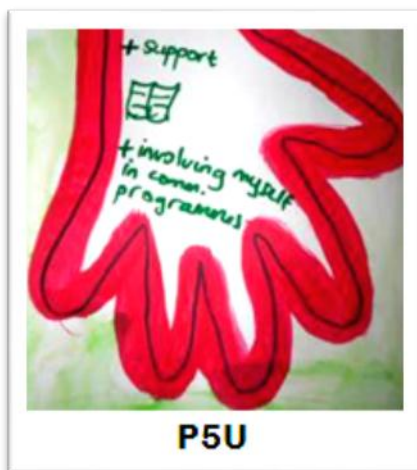
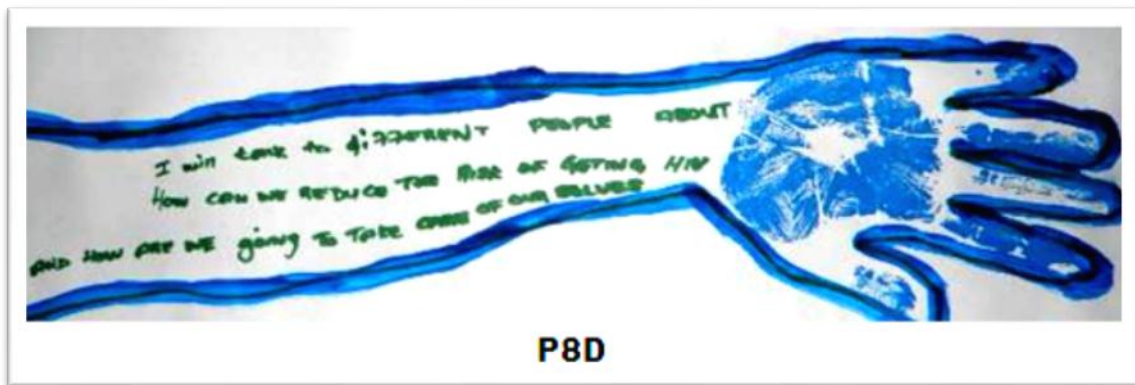
The hands show that we have to create an HIV AND AIDS awareness structure, and talk more about the virus, 'cause that also the reason why people they are just ignorant and not listening, 'cause they think it is just a common disease. Like, we can have those community structures, based on the community (P8D)



The participant indicated that people are not listening to AIDS messages or taking HIV seriously because they see it as a common disease. He proposed that by creating HIV and AIDS structures of awareness in the community, people would be better informed. When the participant was questioned about what he meant by 'structures', he made reference to having more people at various levels participate in communicating about HIV, and offering a range of programmes for everyone (P8D). The

participants from rural KZN continuously reiterated the importance of various stakeholders taking part in developing the necessary programmes for HIV programmes within the community.

Participants at UKZN indicated that young people themselves need to recognise the importance of their participation and the need to be engaged in HIV campaigns. One UKZN participant, similar to P8D (see *below*), also suggested that young people are ignoring the effects of HIV, and therefore commented that “further discussion needs to take place where young people need to be engaged in these campaigns” (P3U see *below*)



Images of the hands on the various bodymaps presented above indicate that participants in *DramAidE* and the UKZN workshops were also documenting the importance of personally becoming involved in communication programmes (P5U see *below*). They also illustrate the need for young people to engage in discussions with their communities about the challenges they experience regarding HIV, and to think about projects which can be implemented in response to these challenges (P3U). Participants at

DramAidE also suggested that they could approach other young people to discuss the problems of risky sexual practices, and the need to reduce such practices (P8D).

One participant at UKZN also reported that talking to peers about issues of HIV was something that she could do. “Just talking about it with you peers, speaking openly about it; not being afraid; not taking away that, stigma (P6U). The participant, during the individual discussions, further commented that the role of peers was important in reducing the stigma or discrimination that could result from HIV. Peer education can therefore play a key role in initiating discussions about topics that would normally be difficult to discuss. The importance of helping communities and participating in HIV awareness was also documented as something that participants could practically do to contribute to HIV awareness and discussions (P3U *see below*). P1U (*see below*) also documented on her bodymap that young people can participate in the design and execution of HIV campaigns which could be an outcome of extensive research conducted through interviews.



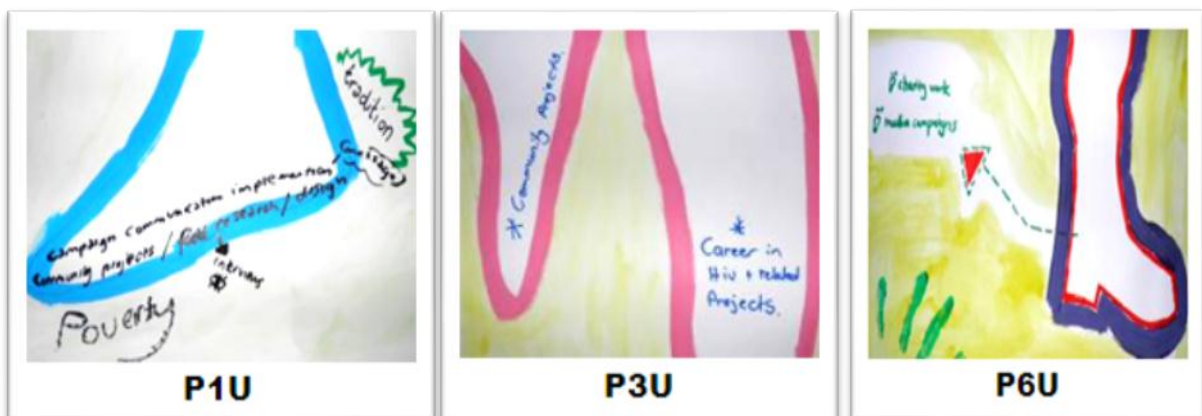
The bodymapping process in this instance was able to assist young people in identifying the need for more HIV awareness programmes in their communities, supported by more discussions about HIV-related issues that could promote more programmes to address the challenges of risky sexual practices. The lack of information or material available to them was documented on the bodymaps of the rural KZN participants, accompanied by suggestions for more material development and training within the community. Bodymapping in this instance serves as a need assessment tool that got the

participants to think about how they can participate, supported by reflections on what they will need to participate.

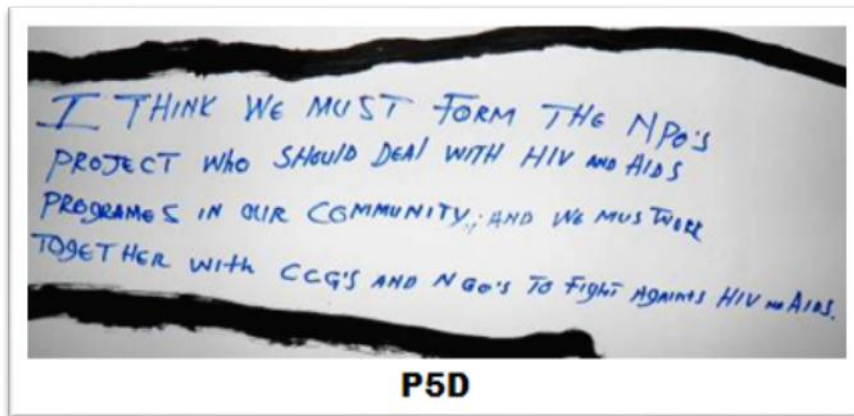
What can Young People do, going Forward to Participate in Developing HIV Projects (Feet)?

The last step of the bodymapping process required participants to think about and document what they would like to see happening going forward with HIV programmes. The specific question posed was: “Working on the feet, walking forward – how would you like to see yourself involved in future HIV projects or programmes?” The question was designed to get participants’ perspectives on what can be done on HIV projects that are youth-informed.

Some of the UKZN participants indicated that there was a need for more communication campaigns and implementation of projects that were specific to HIV. P1U (see below) reported that young people should participate in the field research and design. By field research she made reference to conducting interviews with the relevant communities. P3U (see below) wanted to see more HIV projects and wanted to have a career in HIV-related projects. P6U (see below) also wanted to see more media campaigns around HIV and more charity work done for HIV positive people.



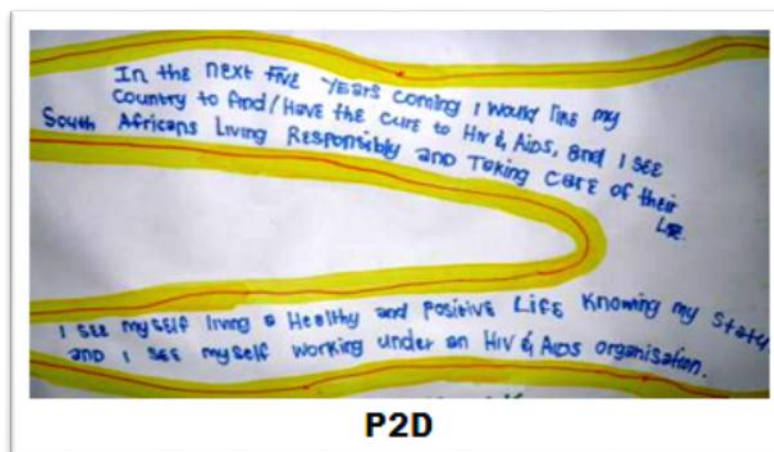
Two of the *DramAidE* participants (P5D see below) commented on the lack of NGOs working in the area, and one participant commented that the community should explore the possibility of establishing a project that works together with CCGs to address HIV in their community. This was premised on the previous discussions that there was nothing happening in their community, beyond the caring of HIV positive people through the CCGs.



Many participants at *DramAidE* shared their own dreams for job creation, family life and the development of HIV programmes in their community. This step of the bodymapping process resulted in many of the participants chuckling about the possibilities and their dreams for the future. One participant indicated that “I see myself talking on the radio, presenting on television about HIV and AIDS, and giving people more information on how can they prevent HIV and AIDS” (P1D).

Another participant indicated that:

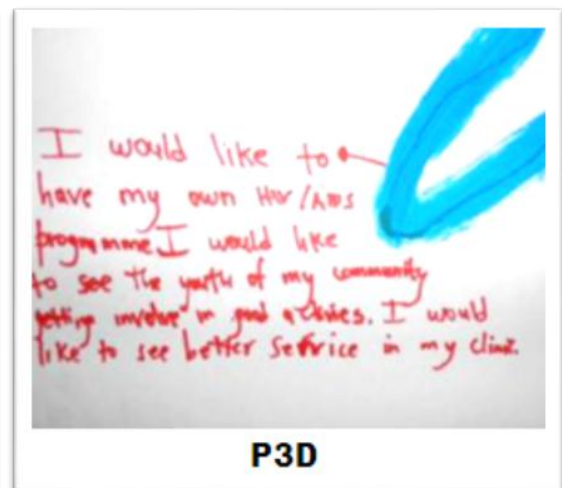
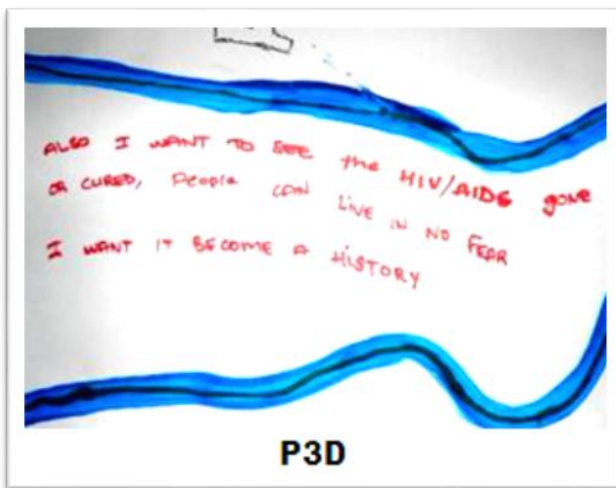
in the next five years coming I would like to see that maybe you could get a cure on HIV and AIDS in our country and I would like to see South Africans living responsibly and taking care of their lives. Ja, I see myself leading a healthy and positive life, knowing my status and I see myself working under an HIV and AIDS organisation (P2D)



The participants, like many others, were reflecting on their own employment and what they would like to see happen for the wider community and the country. “In five years to come I want to see myself living a nice life, having my own house, travelling in my own car, working at my favourite career” (P7D). Many

participants saw themselves working for HIV programmes and were hopeful that a cure could be found for HIV. "I want to see HIV cured and become history in our society" (P7D).

Other participants also reported that better service delivery from clinics was what they wanted to see going forward in their community. "I would like to see myself having my own HIV and AIDS programme. I would like to see the youth of my community getting involved in good activities. I would also like to see a better service in my clinic" (P3D see below). The comments of various participants indicates that young people do not see their lives or careers in isolation or separate to the work that needs to be done with addressing HIV and AIDS. Many participants indicated that they wanted to pursue careers where they could assist people who were HIV positive and in some cases, they wanted to offer their own HIV programmes. These comments were common with the *DramAidE* group from rural KZN, where all participants were out of school and looking for jobs.



Caring for those who are positive was also identified as an important aspect for the community going forward. One participant reported "we can organise some people that must take care for those who are affected by the disease" (P6D) and another participant wanted to see HIV addressed more long-term in his community, "we should deal with HIV and AIDS to the long term" (P5D). Through the workshop, many participants documented that young people were not taking the virus seriously and therefore documented the need for more programmes to create awareness in their communities. This was also evident in the responses of participants when working on the feet. One participant in particular reported that he wanted to see a HIV-free generation where people started to take HIV more seriously.

Well, I would like to see myself with a beautiful wife. Living without fear of being infected with the virus, ah, as we look forward to an HIV free generation, which begins with us and it would make me very happy to say that people have started taking the virus seriously and not as a joke, because it's very disappointing to see that people in this time, ah, getting caught up and infected by the virus when it is being talked about everywhere... Radio stations, TV and the papers (P8D).



One participant at UKZN posed a range of questions about moving forward with HIV programmes and asked questions about what she could participate in, would HIV affect her and would she be safe. These were the same questions that this participant posed when documenting what she could do practically, when she was working on the hands step of the bodymap.

“Will HIV really affect me? Am I safe? Can I make a difference and will I be judged if I do take part in HIV? Will people automatically think “Oh, its because she has AIDS” (P6U)



Conclusion

Participants in both workshops were able to document the common challenges in their communities relating to HIV. This provided more insight into the key drivers of HIV that were specific to their communities.

Discussions in communities centred on issues of multiple and concurrent partnerships, that were identified as a contributing factor to the wide spread of AIDS. Several national programmes dealing with issues of HIV were identified, but strongly documented on the bodymaps was also the absence of community-based programmes focused on HIV prevention. Participants in rural KZN identified care and support as the most visible HIV programmes in their communities, indicating that there is a dire need for HIV prevention efforts. Participants also identified the need for more community consultation, information and prevention to support the strong initiatives on testing.

Participants at UKZN identified the importance of research, planning and implementation as the key phases of developing HIV projects, with continuous involvement of young people and ongoing dialogue that had to be central through all phases of development. Rural KZN participants addressed the need to mobilise young people in their communities with specific activities in order to encourage participation.

The different perspectives documented on their bodymaps indicate the need to develop HIV programmes that are context specific and participant informed. Participants also valued the importance of their participation in developing HIV programmes, suggesting that their participation ensured that they took responsibility for their own lives. The issue of participation was strongly documented and discussed by participants and highlights the varying definitions and meanings associated with participation. These contrasting understandings of participation resulted in further discussion on how young people can mobilise in their communities, and develop their own career goals and aspirations. The data provided in this chapter therefore contextualises participation that is dependent on how different participants make sense of and apply participation to their own contexts.

The bodymapping process can therefore help young people to pose a range of questions as they start to think about what they need to do going forward for themselves, and also for addressing HIV in their communities through participating in developing programmes. Young people are able to identify their own career interests and areas of employment through the bodymapping process. Whilst bodymapping can stimulate discussion and dialogue with participants about a range of issues, and also get them to

think about their own lives, not everyone is willing and enjoys the process of drawing. Bodymapping does offer an opportunity for participants to document their experiences in writing, drawing and the use of symbols, but this can also lead to misinterpretation by other participants and can raise further complexities. The process of bodymapping therefore has to be voluntary, unpacking issues that young people are willing to discuss, through a medium of preference to ensure meaningful participation. The next chapter explores some of the comments about the participants' experiences of the bodymapping process.

CHAPTER NINE: EXPLORING YOUNG PEOPLES' BODYMAPPING EXPERIENCE (PHASE FOUR)

This chapter presents the data from the final phase of data collection that was conducted after the two bodymapping workshops with participants from UKZN and rural KZN. The four phases of the data collection ensure that each phase contributes to the development of the next phase of research, which is in accordance with the cyclical PAR process. Two focus group discussions were held immediately after the workshops to gain better insight into the participants' bodymapping experiences, and also to explore how/if the bodymapping process can be used to encourage young people's in developing HIV programmes.

This chapter takes the data collected in Chapter Eight a step further as it builds on the richness of the data discussed in the previous chapter, to explore the possibilities of using bodymapping as a process to engage young people. Several participants discussed the effectiveness of the bodymapping process during their individual discussions about their bodymaps and the focus group. These comments are discussed below. The chapter firstly explores comments about the workshop and the use of bodymapping. Secondly, there is a discussion on some of the challenges which participants identified with the bodymapping process. The chapter concludes with discussions around young people's ideas about their involvement in HIV programmes, exploring bodymapping as a process to facilitate their inclusion.

Participants' Comments on the Bodymapping Workshop

It was "fun", "interesting" and "relaxing"

Many of the participants described the workshop as "fun" and "interesting" (P1D & P2D). The participants continuously commented on the fun nature of the bodymapping process, with one participant reporting that "it is a fun way to think about ways in how you can be involved and how you feel about it, it also adds a fun dimension of incorporating yourself into the whole HIV thing" (P2U). Participants further commented that they enjoyed lying down and working, as it was something they were not used to doing. In addition, they also enjoyed the messiness of working with paint (P3D). The development of an educational curriculum based on the *Takalani Sesame* TV series revealed the benefits of using fun, interesting and relaxing activities when engaging with young people on HIV-related issues (Segal et al, 2002; see also Mitchell & Smith, 2001; Govender & Reddy, 2011).

One particular participant commented extensively on her bodymapping experience and reported that it was a fun way of expressing her own feelings and views of people and society in the context of HIV (P3U). While participants were having fun and engaging in a relaxed way, they also had an opportunity to explore their own ideas in relation to specific HIV issues being discussed. The relaxing and fun perspective which the bodymapping process brought to the participants created an enabling environment for them to explore their perceptions and experiences in an alternative way (see also Durden et al, 2009). Most participants found that it required them to work “*out of the box*” (P3U) and even though it felt awkward at first, “it was a fun way to just view things in a different way” (P3U). Similarly, other studies have indicated that when young people are engaging in a fun, friendly and relaxing environment, particularly using art and visual methods, their understanding of the issues and their participation increases (Young & Barrett, 2001; see also Cornwall, 2002; Mitchell & Smith, 2001).

One participant commented that the bodymapping workshop was very relaxing because they live such fast paced lives, and are busy all the time, hence the bodymapping process was a good way to just have silence for a while and to relax without saying much (P4U). This was echoed by other participants who also commented that people are always talking, so it was good to have silence where “people were actually thinking to themselves and expressing themselves” (P5U). Discussions about sensitive topics like HIV can bring a level of silence when working with young people, due to the stigma and discrimination that is often associated with it (see Morell, 2003; Mba, 2003). Art-based inquiries in this case offered young people with a process where they could use the silence constructively to reflect on their ideas in a creative way. Bodymapping therefore offers a level of adaptability that allow for flexibility when working with young people who are faced with multiple contextual factors and influences regarding HIV and AIDS, as it creates opportunities for young people to think creatively but at the same time have the freedom to express themselves (Govender & Reddy, 2011).

One participant had been through the bodymapping process before, which had focused on exploring students’ research interests for Honours study. The participant commented that she enjoyed this bodymapping process, which was adapted to explore how young people can participate in developing HIV projects, more than the previous bodymapping workshop. She commented, “I think I enjoyed it more than the other one because, that was still at the beginning of the year, we were all very nervous and that was like a getting to know you class. But this was just relaxed. There was no pressure” (P6U).

This indicates that young people participate in activities better when there is no pressure and possibly when they are familiar with the processes of the workshop, in other words, when they have a sense of

what the activities entail. It is important for facilitators to create a safe and pressure-free environment for young people to work in (see also Bessette, 2004; Nygreen et al, 2006). These comments also indicate that young people may feel free to discuss issues when they do not directly affect them or which require less self-reflection and introspection. In the case of the first bodymap, young people were required to take introspection of their own lives and what they needed to change. In the second set of workshops, they had to explore ways in which they could participate in the development of HIV projects. This could have been less personal and less pressurising for young people, in comparison to when their studies were directly involved or affected by what they mapped on their bodymaps. Visual, and specifically art-based enquires, can therefore be used when working with young people as they have the flexibility and fluidity to continuously adapt to address the needs of specific participants (Coad, 2007).

Another participant indicated that the self-reflective aspect of bodymapping, when it involves looking at your own life five or ten years from now, means people have to reflect a lot on their own lives and young people do not usually do this daily. It therefore makes the process more difficult. The participant commented that the workshop which addressed issues of HIV and youth involvement was easier to relate to, because everyone was affected (P4U). Overall, most participants in the UKZN workshop commented on the value of silence, quiet time to relax, reflect and engage without the busy-ness of the day. Participants appreciated the opportunity to “think to themselves” which was often reiterated as being a rare experience while at university (UKZN participants, 2012).

The participants from the rural KZN group were the most excited about working with paint, the messiness of the activity and the opportunity to participate in a fun and engaging way. The benefits of active, hands-on work is also commented on by Mitchell (2008), who suggests that visual methods have a level of adaptability and play a significant role in education in South Africa, where the focus is on ‘the doing’ as a tool for inquiry. The fact that the UKZN participants valued the silence and time out to think and reflect, as opposed to the rural KZN group who valued the creative, exciting and fun nature of the workshop, indicates that the same workshop facilitated for young people from different social settings can achieve different outcomes and objectives. HIV programmes and programmes therefore need to be context specific (Govender, 2010), but also participant specific to ensure that the intervention meets the needs of the beneficiaries (Cornwall, 2005).

“We were expressing what we feel and then what we see in our community”

The participants of the rural KZN workshops reported that the bodymapping process allowed them to freely express their own ideas, perceptions and experiences which provided an opportunity to explore what they would like to do in their communities in terms of HIV programmes. One participant reported that he enjoyed expressing what he feels, identifying what is happening in his community and what he would like to see in the future (P7D). Many participants reported that the bodymapping process taught them to think about what young people could do for their community (P4D).

The process further resulted in young people thinking about the specific steps to take in their community, based on the bodymapping process that revealed the lack of sufficient HIV programmes available for young people at the local level. Many participants associated the bodymapping experience with teaching young people more about how they can be encouraged to assist their communities. One participant reported that it taught him how to help his community and address issues of HIV and AIDS (P7D). This was similar to a suggestion that arose in the bodymapping workshop in UKZN, where one participant suggested that the bodymapping process be used as a creative way to provide information on HIV. Instead of only using this as a self-reflective tool or for the several other applications discussed in Chapter Seven, bodymapping can be used as a method to relate HIV information visually on the picture of an outlined body.

The participants of the rural KZN workshop were able to explore their own ideas, experiences and perceptions about HIV-related issues before giving thought to how they could mobilise others to develop HIV programmes for their communities. However, the bodymapping process only allowed for self-reflection and problem identification but did not extend to the action that is needed to implement the programmes. Some may argue that bodymapping in this instance does not capacitate the participants to act on their critical consciousness to change their social reality. However, bodymapping needs to be identified for its ability to serve as a self-reflective tool that ignites the process of becoming critically aware about a social issue, and therefore cannot be labeled as a process that empowers and changes young people’s social reality (Freire, 1976). Bodymapping can therefore be seen as a catalyst that starts the process of self-reflection, which can then later stimulate positive action in communities (Kincaid et al, 2009). For now, the bodymapping process ensures a process of self-reflection and introspection which Freire’s (1976) advocates for in order to attain critical consciousness. The process of self-reflection is often what is missing in most action orientated programmes, and the discussions

with young people emphasise the strong component of self reflection and introspection that is evident in the bodymapping process.

The fact that participants were able to identify the relevance of their work in communities, through the bodymapping process, suggests that participatory mapping and drawing equips young people with resources to develop ideas, document experiences, and make suggestions for future developments through a process of mapping, followed by discussions (see Chambers, 2006; Emmel, 2008). The importance of this technique is that young people can immediately see what they have documented and can contribute to discussions about what they can do in their communities (Kesby, 2000). These “innovative methods are readily available to community members to generate knowledge and to guide planning for both individual and collective action” (Brydon-Miller, 2003: 197). One of the challenges of the bodymapping process is the need for data to be interpreted within the cultural context, yet more analysis takes place through face-to-face interactions with participants in the field (Kesby, 2000).

“It wasn’t just about yourself, but placing yourself in a context”

A central attribute that most participants identified about the bodymapping process was its ability to get the participants to think and engage through silence. With the exception of one participant from the rural KZN group, who constantly engaged in discussion with his peers during the bodymapping process, most participants were rarely found conversing and discussing steps with each other. Instead, young people engaged in an internal dialogue with themselves through the bodymapping process. Many respondents enjoyed the focus of plotting their thoughts and ideas on various parts of their body, indicating that self-reflection was a stronger attribute of the bodymapping process than dialogue.

Dialogue was encouraged after the bodymapping process, to explore the ideas of young people in relation to HIV prevention and their participation in developing HIV programmes. The bodymapping process therefore did not exclude the processes of dialogue, but participants explored their own perspectives and experiences before sharing this with the rest of the participants. The benefit of bodymapping in this instance is that it ensures participants can offer their own subjective views and experiences, without comparing their experiences with the opinions of others. It also encourages the participation of all participants, as everyone will have something documented on their bodymaps that can be voluntarily discussed with others.

This process of thinking about their own life and experiences provided a new perspective for many participants where they were able to still think about others and wider social issues while thinking about

themselves. One respondent commented that he had enjoyed “the fact that it wasn’t just about yourself, but placing yourself in a context” (P4U). This indicates that while bodymapping encourages a self-reflective process, it is almost impossible for participants not to think about their wider social setting. The social ecological perspective suggests that the influences of the environment, social settings, human behavior and the cultural, social, physical and economic factors, all contribute to how we make sense of our life in relation to others (Stokols, 1996). Therefore, the bodymapping process encourages individual experiences and perceptions, but this has to be adapted to accommodate the social ecological influences on how young people address issues like HIV and AIDS. The bodymapping process, while encouraging self-reflection, must therefore use this process of self-reflection to catalyse dialogue among participants (see Freire, 1976; Kincaid et al, 2009). This process of dialogue will extend bodymapping from the individual context to a wider context of understanding the complexities of HIV and young people’s participation in prevention programmes.

The bodymapping process of incorporating what young people are seeing, hearing, doing, saying and feeling, was described by one participant at the UKZN workshop, as an interesting way to connect their senses to express themselves. Another participant commented that bodymapping was not only about talking, but about using all aspects of the body (P4D). This indicated that young people usually have an expectation of discussion groups when participating in workshops, but the bodymapping experience challenged this norm by engaging the participants in a different form of participation. Through this process, young people were engaging in fewer discussions, but more visual and textual representations, which stimulated different parts of their brain to think about HIV issues in a different way. Cognitive stimulation of ideas and experiences can often vary depending on the medium used; and art has the ability to explore new learning when working creatively (Zull, 2002).

Methodologies must be participant specific

One UKZN participant who was completing post-graduate research on the work of *DramAidE* at the time of writing this thesis (2012-2013), indicated that bodymapping does not work with all groups. She commented that bodymapping workshops that were held with women in deep rural areas in Pietermaritzburg and Harrismith indicated that the older generation were not happy to engage in bodymapping activities. When the paper was rolled out, “everybody just stood there and watched them, like, okay, “Haibo! We are not drawing. We prefer talking. We are not going to draw and write images. Let’s sit down and talk” (P5U). The participant drew this in contrast to workshops with young people such as those attending high schools who actually had fun doing the activities. She commented that

they were involved and were really expressing themselves through the use of arts-based methods. The participant concluded that “different methodologies don’t really work for all people” (P5U).

“They actually have their own, you know, thoughts and perceptions”

The bodymapping process sparked conversation among participants and indicated that youth do have their own ideas and perceptions about HIV, further identifying that these ideas and perceptions may differ from others. The interesting attribute of bodymapping was its ability to demonstrate the commonalities of young people’s experiences and challenges, yet it also demonstrated the uniqueness of young people’s thoughts, ideas and perceptions. Bodymapping promotes individual thought and therefore raises diverse and multiple perceptions which are not always evident in focus group discussions or community dialogues, as young people may easily conform to the views of others. Bodymapping can therefore reveal diverse information about participants and their experiences. The complexities, however, arise when there is a focus only on the common perceptions documented on the bodymaps, which marginalises the minority responses or issues identified by young people.

The discussions about addressing the diverse views documented on the bodymaps directly relate to the importance of those developing HIV programmes to know their participants. The various perceptions and ideas identified on the bodymaps need to be considered when developing HIV programmes and can only happen if young people actively participate in designing HIV programmes.

Many participants reported that there is a distance between the people who are affected by HIV and those who are creating the programmes for communities. One participant reported that when she works with young people and asks them what they think about something, they have their own perceptions and ideas about HIV and their sexual practices (P4U). Many participants questioned if the developers of HIV programmes actually know their target participants. One participant asked, “do you actually know them? Can you get inside their heads, because if you get in their heads then you really know what going on and what do they actually need” (P4U). Young people themselves raised this issue of knowing the audience, and this provides further motivation for the need for full participation of young people in programme development.

“Images rather than writing?”

The lack of visual representations in the rural KZN workshop was a stark contrast to the workshops conducted with UKZN students, who responded to most of the questions using images and drawings. The participants of the rural area workshop indicated that they were not used to such activities. While

they found the process fun and interesting, the workshop was a new experience and they preferred to write instead of draw (P5D). This indicates that not all participants communicate well in the same medium; while some prefer drawing, others prefer to write. In a similar manner, while some participants preferred the quiet time to work on their bodymaps, others prefer to talk.

Many participants suggested that it was good that they could choose between writing and drawing, as many felt that writing was easier and something that they could confidently do. One participant reported that he enjoyed the combination of writing and painting, but tended to use writing more, as he enjoys writing (P2D). Another participant indicated that he was glad he could choose between writing and drawing, as he was not good at drawing, and therefore felt more at ease with writing (P3D).

The participants recognised that each person has a preferred way of expressing themselves, and this expression could take place through drawing or writing, depending on what they felt more comfortable with: "some people, generally speaking, are better at expressing themselves through pictures and some people are better at expressing themselves through colour and writing" (P4U). One participant reported that her bodymap was more writing-based but also included symbols to represent different things. Another respondent suggested that she preferred "to do the images rather than writing, because as you can see my one is more images" (P4U).

Another participant, when asked about whether they prefer writing or drawing, reported that even though her degree was in art, she still preferred to write. This participant attributes the preference for writing over art to having a lot to say which is easier to express in writing. "It's so weird. Like I don't know if it's because I have so much to say, I just like put everything down. So, I think that I use like, few images" (P1U). The participant also concluded that she is afraid that if she used symbols she may later forget or not remember what the symbol represents or means. This indicates that while symbols allows young people to retain the meaning and only discuss this when they are comfortable, the use of symbols also runs the risk of youth not remembering at a later stage what those symbols represented for them during the workshop process. The use of writing and drawings, despite the challenges of misinterpretation, can still provide young people with a comfortable medium to communicate freely about their experiences.

The richness of the images became evident when one participant shared about the details of her bodymap. The participant explained the images that she documented on the hand of her bodymap. She explained that the truck on a road indicates her proposed field research taking place within a

community, and the image of the eye indicates the observation that could take place as part of research (P1U). In the case of these drawings, the images indicate the abstract nature of bodymapping, as interpretation is only provided when the participant gives meaning to the images. This allows a participant to have some freedom in what they document, which can also remain very private in many instances. This notion of privacy is an important one when dealing with sensitive issues such as HIV that may bring up thoughts or feelings that the participants want to document, but do not want to make public.

The data collected through the bodymapping process highlights the use of symbols, images and text to document responses to issues such as HIV. The bodymapping process offers young people a means to communicate about issues which affect them, where they can still be in control of what they document, how they document this, and what they later share with the facilitator and other participants. Should a participant choose to document their responses in an abstract or cryptic way using drawings, writing, colour and images, only the participant can give meaning to this, and is free to share the details of their bodymap at a time when they are comfortable, or they can still choose not to share any details of their bodymaps. Alternatively, youth can use the process simply as a way of introspection for themselves, offering opportunities for self-reflection with discussion about the contents of their bodymap with others. This, however, would only work in cases where young people choose to work in an abstract way, as some images can be very obvious and can also run the risk of misinterpretation, which leads to further challenges for the participant. These need to be addressed or catered for when following a bodymapping process.

“Okay, it’s your turn. Now you (young people) can ask us questions”.

Several participants at the UKZN workshop indicated that different mediums were needed to get young people’s attention. Since young people do not believe that HIV affects them, they need new approaches to engage them. One participant reported that bodymapping would be a good tool to use beyond self-reflection, as a communication tool to get young people to engage with important information on HIV (P3U). When the group was asked how this could be done, another participant indicated during the discussion session that young people need to be told that they have a space to ask their own questions. The participant commented:

I think the ideal would be, like, during the discussion where you can, you know, tell the participants “Okay, it’s your turn. Now you can ask us questions. What are kind of the things that you wanna know? What are the things that bother you?” Then you can also kind of get an idea of what people don’t know and what they do know. So, at the same time it’s also helping you to shape you project or gain research on any kind of HIV project or campaign that you want to create, because then you

are not only gaining information of what they want, but what they do know and what they don't know (P2U).

The participant posed a series of questions which the rest of the group acknowledged as important when trying to understand the experiences, perceptions and needs of young people. Many participants reported that bodymapping could be used to get young people to ask questions and address issues that they need help with. Another participant suggested that bodymapping could be used to get young people to document their ideas and thoughts on the map, where specific questions are asked such as:

What do they know about HIV? And they write it down or the draw it. You will be able to tell from there how much information they actually have access to (P4U).

The participant further added an example of her nephew who saw something on television and started drawing HIV on a page to depict what he saw. The participant reported:

He started drawing it on the page, he drew, like, ugly images, and he said "This is HIV. It's not pretty." So, I was quite shocked at what he did because he was five years old. He said "I don't like it", but that's interesting, because an image can tell you a lot about what they know and what they don't know (P4U).

The participants were therefore suggesting that bodymapping could be used not only as a self-reflection tool that takes young people through a journey of introspection, but could also be used to understand what they know and do not know about HIV, through a process where the participants are posing the problems. This indicates that bodymapping can take participants a step further from self-reflection to engaging in discussion and dialogue that leads to problem-posing and problem identification. Nyirenda (1997) suggests that Freire (1976) advocated for a process where the facilitator could work with the participants, not in a top-down manner, but one where there is a shared investigation or problem-posing processes between the participants and the facilitator.

"How can I, you know, become involved? How can I help?"

Overall, the bodymapping process resulted in participants exploring how they could participate in developing HIV programmes in their communities. Many participants recognised the importance of their involvement in the design of HIV projects, identifying areas of contribution that they did not explore before. Participants commented that bodymapping was a great way to engage with young people, where it not only provided information but also got them to ask questions about their own lives and how they could participate more actively in addressing issues of HIV. Bodymapping serves as a medium for people to explore their participation through visual representation, in a "less directive interviewing style" (Cornwall, 1992: 1).

I think this is a great medium to kind of get people involved and to get people thinking and get people more educated on it. it will be a great way for young people to also get information (P2U)

The bodymapping experience was also a means of putting HIV into context and perspective for many participants, as it stimulated discussion and self-reflection on how young people can participate in HIV projects. Cornwall highlights one of the fundamental attributes of bodymapping, where it is used not only to address biomedical and HIV-related issues, but penetrates beyond its knowledge generation ability, to its 'participatory data collection ability' when working with young people (1992:1). One participant commented that:

It encouraged me to think about how I fit into the context of HIV and how it affects me. Because I think for the most part I really don't think about how it affects me. I don't see myself as someone who is directly influenced by it. So, for me thinking about it: "How can I, you know, become involved? It kind of opens up that whole discussion where you have to think about how you fit in it (P2U).

Participants continued to describe how close they felt with issues of HIV because it affected their lives in some way. One participant described how she felt affected by HIV because her mother works at a hospital where people are affected and infected. Hence she either saw people who were HIV positive quite regularly, or would hear of cases that her mother spoke about (P4U). The participant later commented that the reality of HIV in her life through these experiences motivated her to become involved in assisting others with information on HIV.

Participants described the bodymapping step of the heart as being the most engaging and thought provoking, as it allowed participants to reflect on what they thought and how to participate in HIV projects for young people. The hand activity of the bodymapping process was also described by many participants as making them feel like there is so much which needs to be done to address HIV, and how they (young people) are currently not doing anything. Participants in the UKZN group also commented that there are many programmes out there but they do not feel as though they are contributing or getting involved enough (P1U, P3U, P5U, P6U). In this light, bodymapping serves as more than a tool to gain information or explore people's perceptions around medical issues, but can also serve as a research tool, to generate participatory data on how young people can participate in HIV and AIDS programme design and also promote the active participation of young people in the phases of developing HIV projects

One participant commented that the bodymapping process helped him identify that:

We must have, like, an HIV awareness campaign structure which will have us involved in making sure that we have those programmes. These programmes should be, like, day in and day out, especially for the youth, 'cause, ah, they are not taking this very seriously. They just enjoy the booze and then they get themselves hooked up. The youth is more affected by the virus so if we can, like, have those programmes running we know that it can maybe change somebody's life – if not many (P4D).

The comments by several participants in rural KZN indicated that they were able to associate some of the risky sexual practices of young people in their community with the lack of HIV programmes. The process of bodymapping then highlighted the importance of these participants developing HIV programmes to educate the community about risky sexual practices towards advocating for safer sexual practices.

Bodymapping extends beyond being a data collection or a research tool, but also ensures the active participation of young people. The cyclical process of participatory action research ensures that through the steps of documenting how young people can participate using bodymapping, they are taking action and participating in the processes of how we understand young people. An action research process then becomes an ever evolving and changing process through bodymapping as it is flexible and adaptable to address local problems and challenges within contexts that are always changing. As a result, this process turns young people into researchers where they can reflect on issues that face them and bodymapping provides a medium to discuss how to address these challenges (O'Brien, 2001).

Many of the suggestions that participants made regarding HIV communication programmes in the community focused on talking to people and telling them to go to the clinic (P2D). Another participant suggested that perhaps the young people who participated in the bodymapping workshop could form a group and go to the nearest clinic to get more information about testing, and then start speaking to their peers and other community members about the need to test and know more about HIV (P3D).

The process of bodymapping encouraged participants to think of how they could mobilise their peers and communities to address HIV. The discussion that resulted from the documentation on the bodymaps served as catalyst for dialogue. The extensive dialogue about how young people can participate culminated in suggestions for collective action. Community dialogue is essential for collective action to take place (Figueora et al, 2009). The process of dialogue also encourages self-efficacy where young people in the community were encouraged to address HIV, and also collective efficacy, where they wanted to mobilise others to bring about change in their communities.

Following the need to be involved in the community, young people were asked about how they would go about doing this. Some participants indicated that a form of educational programme, that they termed a '*rehabilitation programme*,' could be offered, where they educate the people in their communities and provide information about safe sexual practices (P3D). The desire for collective efficacy was also evident when participants expressed their desire to get involved in this type of action.

In addition, the participants also highlighted the importance of young people being trained by staff or health professionals who were knowledgeable about HIV. Nurses were identified as people who could assist young people with information on HIV-related issues (P4D). Young people were also keen to do sketches or plays in communities to educate their community about HIV (P4D). Many participants also discussed how they could get other young people to participate through meetings, talks with youth and churches and having discussions with friends (P6D).

These comments from the participants in rural KZN reflect the value placed on collective action in the community. Only in a few instances did discussions centre on the possibilities of young people promoting HIV information by themselves, but in most cases they voiced that it should be a community initiative. Kincaid et.al (2009) suggests that after a process of extended community dialogue, discussions about collective action are usually evident in a community. This process of dialogue is usually initiated by a catalyst, which in this case was the process of bodymapping. The bodymapping process can lead to introspection and self-reflection, resulting in collective action that fits the model of communication for participatory development. This model does not look at implementing change on a linear level, but instead takes a multi-level approach where individuals act in their own capacity, yet function and contribute in accordance with a larger social system and structure (Govender, 2010). This process of exploring what the participant can do on their own before involvement with the wider community, was strongly evident in the data gathered for this research, indicating that when a process of community dialogue for collective action takes place, participatory development is inevitable.

The bodymapping process stimulated discussion around how to get young people to participate in the development of HIV programmes. Some of the suggestions included helping young people to identify their problems, and also facilitating community dialogues to address these concerns. One respondent reported that it was important to get young people to participate in identifying the problems surrounding HIV and AIDS through community dialogues, where young people can get an opportunity to hear more about the experiences of other people, and what they may not know about HIV (P5U).

These suggestions for problem-posing and problem identification within the community echo the work of Freire (1976) who suggests that this process of problem-posing can only occur when conscientization takes place. In this instance, conscientization can lead a community to take collective action to change their social realities (Nyirenda, 1997). The model of communication for participatory development is therefore premised on the work of Freire who conceived of communication as dialogue and participation for the purpose of creating cultural identity, trust, commitment, ownership and empowerment (Figueroa et al, 2002).

Many participants commented that the bodymapping process makes young people reflect on their own lives and how they can participate. This can also raise the question of whether young people do see the need to participate in HIV programmes, or if it is simply a response to being asked to participate. If participation is seen merely as a process of consultation or informing young people about the issues, where they are asked to participate and document their experiences, the bodymapping process can run the risk of what Arnstein (1969) terms as non-participation or tokenism. This implies that young people are only consulted about HIV issues but do not participate in how HIV projects are designed and implemented.

Many scholars argue that sometimes people advocate for active participation of the beneficiaries when the beneficiaries themselves do not see the need or reason to participate (Besette, 2004; Cornwall, 2003; Sonderling, 1997). This is a common challenge in development communication where there is an assumption that people need to have their human right to participate acknowledged, and a space has to be created to facilitate their participation. However, several studies have indicated that people do not always want to participate and sometimes they do not have the solutions to their own problems (Lewis report, 2008; CRBS report, 2007; SAB report, 2007).

The need for participation and the involvement of young people in developing HIV programmes must be explored first before initiating a process of participation. The study conducted by Moodley (2007) indicates that young people do want to participate in developing HIV messaging and they feel that they do have valuable contributions to make in understanding how to address problems within their own communities.

What didn't we like?

Of considerable interest was that when participants were asked about what they did not like about the bodymapping workshop, most of them did not comment on any particular steps or processes of

bodymapping that they did not like, but rather about how they were represented through the drawings. This was more common with the participants from the rural KZN group than those from the UKZN group.

One participant said that her partner drew her head so small and her body so big, and therefore commented “that’s the only part I didn’t like” (P1D). When the *DramAidE* group was asked about anyone not enjoying the bodymapping process or not enjoying any particular step of bodymapping, there was complete silence in the room for a few seconds. Participants were asked again if they disliked anything about the bodymapping process and all shook their heads to indicate that there were no steps which they did not enjoy. The same process was followed with the UKZN group, and the same response was received. The silence and nodding of heads could indicate that all participants in both groups did enjoy the bodymapping process.

One participant indicated that even though she enjoyed bodymapping, she felt that it would not be something everyone enjoys, “I don’t think this is everybody’s type of thing” (P6U). Another UKZN participant commented that the application of bodymapping had to be selective for specific participants as not all young people in schools may enjoy the technique. The participant further reflected on her own work with young people at high schools and how many girls whom she worked with preferred to talk, which would make the processes of bodymapping complex. She concluded that bodymapping “is not everybody’s cup of tea, so have to be really selective as to who you are targeting and, and how you are doing it” (P4U).

Conclusion

The fourth phase of data collection presented in this chapter was discussed in the context of exploring the possibilities of the bodymapping process to advance the development of HIV projects and programmes through youth participation. For many participants, the bodymapping process reflected a fun, relaxing and interesting way of engaging young people to understand more about themselves but within a wider social context. Participants were able to identify the self-reflective approach which bodymapping promotes, and it encouraged them to adopt an introspective perspective into their own lives towards helping others.

The process of expressing themselves therefore had direct links to how they observed and wanted to help others in their community with HIV-related issues. The participants were also mindful that the bodymapping process has to be adapted and implemented for the appropriate participants, as some

age groups prefer to talk instead of write or draw. The participants, however, appreciated the flexibility of the technique which allowed for the use of both writing and drawing, depending on the medium which young people felt comfortable working with.

Bodymapping also had the ability to reveal challenges in their community in terms of the lack of information and the need for more programmes. The participants were therefore in support of using the bodymapping process as a tool or first step towards developing HIV projects as it aided the process of understanding young people's perceptions, ideas and experiences, which could lead to suggestions for youth-informed HIV programmes. Community initiative was strongly promoted during the bodymapping process where young people identified the importance of engaging in dialogue for collective action. This process of dialogue is usually initiated by a catalyst according to Kincaid et.al (2009), which in this case was the process of bodymapping. The bodymapping process was found to lead young people through a process of introspection and self-reflection. The use of introspection and self-reflection is essential for dialogue and this informs the model of communication for participatory development. The bodymapping process was therefore able to stimulate dialogue for young people to identify their problems, and also facilitate community dialogues to address these concerns. Bodymapping in this instance demonstrated that the process of problem-posing and problem identification can lead to critical conscientization for many young people.

CHAPTER TEN: MAKING PARTICIPATORY SENSE OF BODYMAPPING AND HIV PROGRAMMES

Introduction

The previous four chapters presented data collected in the field over a three year period, supported by my own observations of working with participatory communication practices over the last ten years. This chapter firstly explores each of these research questions in light of the data analysed. Secondly, it will offer a theoretical understanding of participation, towards making an argument for the application of the bodymapping process as a participatory tool of engagement when working with young people. Thirdly, the chapter offers a model for the participation of young people by applying bodymapping to the various phases of developing HIV projects. It highlights that the importance of this process is based on how young people *define* participation. The chapter ends with some of the limitations of this study and offers a way of concluding, given the theoretical contributions this study makes to the field of communication for participatory development.

The main research question that this study set out to address is how young people's participation can contribute to the various phases of developing HIV projects. The study explored this question through a cyclical data collection process using participatory action research principles to specifically address the following questions:

1. What are the HIV prevention messages and communication approaches/strategies offered by selected youth-focused organisations?
2. What are young people's perceptions of communication processes for developing HIV projects?
 - What are participants seeing, hearing, saying and doing regarding their participation in HIV projects?
3. How can participants contribute in the development of HIV related projects?
 - Can the technique of bodymapping be used to encourage youth participation in developing HIV projects?

Post-Positive Lens to Explore the Empirical Data

This thesis has been explored from a position that I am conducting research *with* participants, rather than conducting research *on* them. Through the process of conducting research with participants, I was also able to understand what participants think about various HIV projects and their participation in the

development of these projects. Participatory action research was adapted as a process to conduct research with participants through the use of bodymapping techniques to explore youth perceptions of participation and developing HIV related projects.

This study involved asking questions, conducting workshops, and observing processes which meant that my role interchanged continuously from that of a researcher, to a facilitator, to one who is trying to learn as well. Bodymapping was used as a tool to allow me to interchange between these various roles, ensuring that I was conducting research with the participants, but also learning more about their participation in developing HIV projects. Ryan (2006) describes the use of these non-conventional methods coupled with a post-positivist position as a way to disrupt the predictability of data, which can occur when using traditional interviews.

Given my constructivist position, I did not aim to solve the problems of participation or engagement of participants, nor did this thesis attempt to solve the communication problems of designing HIV projects. Instead, this thesis set out to pose the problems that are involved in understanding the complexities of participation and HIV project development. This process is described by Anne Ryan (2006) as problem-setting instead of problem solving, where problem-setting implies developing the right questions or posing a range of problems that need to be understood based on the empirical data collected. This indicates that whilst I worked from a grounded perspective, exploring what the data can tell me about practice, I was open-minded to what I could discover with participants, but this could never be free from my own ideas, experiences and observations in the field. Ryan (2006) makes reference to Wolcott (1990: 31) who suggests that 'empty-headedness' is not the same as 'open-mindedness'. This suggests that researchers working from a grounded perspective cannot eliminate their previous knowledge in the field they are working in, but instead need to be open-minded to the new issues that can arise and this needs to be discussed in context.

Through the research processes, participants were allowed to share their experiences of participating in developing HIV projects, and as a researcher I had to be open-minded to explore the issues raised by the participants despite my own pre-conceived ideas, ensuring that my own critical perspective and views did not set the problem for them, but that participants were able to explore issues of participation and developing HIV programmes with minimal interference from outsiders.

Ryan (2009) suggests that good research opens up the nature of the problems and when research reaches valuable conclusions, these conclusions can change over time. The discussion of the findings

below, collated over a four phase data collection process, therefore does not propose to be conclusive on issues of participation with participants in developing HIV projects. Instead, the data collectively analyses the issues of participation with participants in a wider context, using bodymapping as a process to encourage participants to talk about HIV and their experiences in developing HIV related projects.

The key comparisons with students at UKZN and young people in rural KZN is tabulated below and discussed in further detail in sections to follow.

Table 6: Comparing UKZN and KZN participant's responses

HIV Programmes and Youth Participation	University of KwaZulu-Natal (KZN) Participants	Rural KwaZulu-Natal (KZN) Participants
Determinants that influence risky sexual behaviour	the lack of jobs, poor clinic and social services and lack of information	poverty, drug and alcohol abuse, availability of treatment, and teenage pregnancies
HIV programme exposure	Exposure to all national programmes	No exposure to national programmes
Community initiatives	Exposure to community programmes and campaigns like Scrutinize	Only community initiatives was through community care-givers (CCG)
Focus of HIV programmes nationally or in community	Prevention, treatment, care, support and testing	Only care for HIV positive people
Access to HIV information	Excessive exposure to HIV information	Shortage of HIV information
Defining participation	associate their participation with empowerment and giving participants an opportunity to engage and share their views	associate participation with doing something, or working on an activity
Outcome of participation	Having a voice	Participating in activities and distributing information on HIV
Determinant to encourage participation	Opportunities for discussion and sharing their views	Access to information
Development of HIV projects	Young people can actively participate to develop projects	Young people can mobilise with the various stakeholders in the community (elders, government representative, community workers)
Bodymapping (use of writing and drawing)	Participants preferred to predominantly draw, but also used a mixed documentation process of writing and drawing	Participants preferred to write only, minimal graphical depictions or drawing on their bodymaps
Enabling Environment	Participants enjoyed the silence and quiet time to work, away from their busy lifestyles	Participants enjoyed the messiness of bodymapping, the fun, and creative space to work

Section One: The HIV Landscape with Participants

The first research question set out to explore the HIV landscape with regard to programmes and HIV messages offered by the sample organisations. The purpose of this question was to ascertain what is currently being done by the organisations to address HIV with young people. The data collected in four phases with various stakeholders, which included organisational programme managers/directors, facilitators and young people, provided an overview of the HIV programmes. In addressing this research question, the data explored in the last four chapters are discussed by focusing firstly on the risky sexual practices that participants are engaging in and secondly some of the determinants that influence their sexual choices. Understanding these specific risky sexual practices provides a context of HIV when working with participants.

The data identified a range of risky sexual practices, with many of the sample organisations and programmes suggesting that multiple and concurrent partners, intergenerational transactional sex and the lack of consistent and correct condom use contribute to risky sexual behaviour that make participants more vulnerable and at risk of HIV infection. This common risky sexual behaviour identified in six of the eight sample organisations were directly linked to specific determinants that influence these risky sexual practices.

The data collected from interviews with organisations suggest that issues of poverty, alcohol, and the influence of peers and culture were strong determinants to these risky sexual behaviours. Issues of peer pressure, exacerbated by alcohol consumption, were identified as a key attribute to risky sexual behaviour with six of the eight organisations. In order for issues of peer pressure to be addressed, HIV programmes need to focus on life skills development for participants. The *DramAidE* peer education programme is an example of an initiative that empowers participants to overcome peer pressure, reduce risky behaviour, and make healthy choices. Given the influence of peers in making decisions that affect sexual practices of participants, it is imperative that HIV programmes consider the influence of social networks and peer influences since sexual practices often do not occur in a vacuum but within wider social systems. I argue that an understanding of these wider social systems can only materialise through the active participation of participants in discussions and dialogue that result in the development of youth-informed HIV projects.

Cultural determinants also play a significant role in influencing the sexual choices and practices of participants. However, many organisations commented that HIV programmes do not always take into

consideration the influences of culture. In other cases, culture was often identified as an excuse for risky sexual behaviour (evident in the feedback from *One Voice*), where participants pursued their own sexual desires and pleasures and aligned this with their cultural practices. Given the complexity of how culture is adapted and used when considering risky sexual practices, it is imperative to unpack these discourses with participants before designing an HIV project (Govender 2010; Cornwall 2002; Parker, 1997).

Several HIV programmes therefore run the risk of failure as they do not explore the factors that contribute to risky behaviour, and how participants make sense of these determinants when interpreting HIV programmes. The only way in which these complexities can be addressed and integrated into HIV programmes is through the active participation of participants. More specifically, participation would encourage a process of dialogue to facilitate discussions about complex issues such as peer pressure and cultural influences (Kincaid, 2009; Figueroa et al, 2002; Kunda, 2009). The active engagement with participants on these various discourses then provides a framework for developing more effective youth-informed HIV projects.

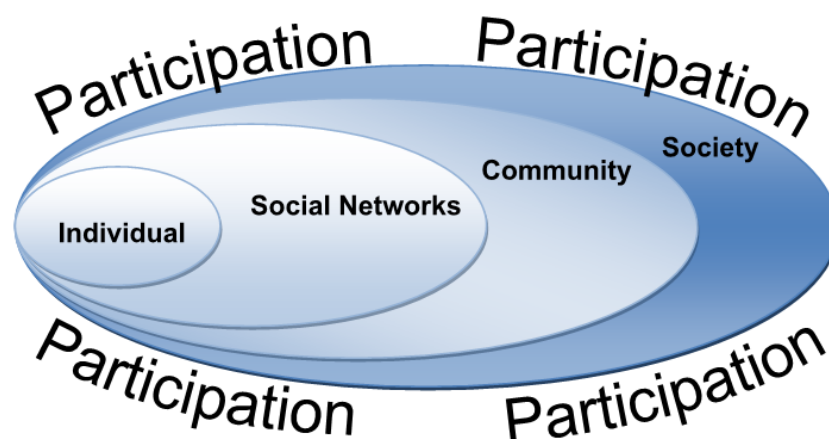
The findings from the bodymapping workshops further emphasised the contrasting determinants identified by participants from UKZN and those from rural KZN when discussing the influences on sexual practices. The rural KZN group placed more emphasis on the lack of jobs, poor clinic and social services and lack of information on HIV in their community. The UKZN group, on the other hand, identified poverty, drug and alcohol abuse, availability of treatment, and teenage pregnancies as key issues that affect their community. While the UKZN group had more exposure to national HIV programmes, most of the rural KZN group pointed out that the only HIV programmes in their communities centred on caring for people, which indicates that there was a shortage of HIV-related programmes and information (refer to Table 6). These contrasting determinants and exposure to HIV programmes further indicates that a 'one size fits all' approach cannot be adopted when addressing HIV related issues. Instead, there is a need to explore the social ecological environment in which these decisions are made to ensure effective HIV programme. Exploring this social ecological environment can only result when participants are actively engaging in the various phases of developing projects that includes their participation in the research, design and implementation of HIV related programmes.

Discussions with organisations and the bodymapping process with participants further suggested a contradiction in how information on HIV is perceived. The organisation's programme managers and facilitators indicated that there was a level of AIDS fatigue, and that participants were not short of

information. However, the data collected through the bodymapping process with participants indicates that there is a lack of sufficient information on HIV prevention. Of more interest, was the contrast with participants from UKZN and those from rural KZN. The participants in rural KZN commented extensively on the shortage of information in their community which was a stark contrast to the UKZN participants who reported having excessive exposure to HIV programmes (refer to Table 6). This indicates that programmes need to be very participant-specific to address the specific needs and experiences of participants. Participants from rural KZN, however, were able to identify, document and later discuss the influences of the lack of information in their personal lives and in their communities through the bodymapping process. The process of bodymapping suggests that participation is central to exploring these experiences within context and hence can engage participants in thinking about issues which can be discussed in a wider forum.

The data indicates the diversity of sexual choices and practices among participants and suggests that these multiple behaviour traits and the factors that influence these sexual behavioural decisions need to be acknowledged for contextually relevant HIV programmes. The data highlights that a blanket approach to programmes will not always work, as participants' sexual behaviour needs to be explored within a wider socio-ecological framework that recognises the inter-relational and interconnected system in which participants make their sexual choices. This inter-relational nature refers to the relationship between young people and their social, economic and cultural environments that cannot be separated from how they make decisions. The interconnected system makes references to how family, peers, community and society influence the sexual practices that participants engage in (Sallis & Owen, 2002). The diversity of sexual practices and the factors that influence these practices makes a social ecological perspective increasingly relevant to understand how to design context specific HIV related projects. Exploring HIV projects from a socio-ecological framework ensures that a systems approach is taken that acknowledges the complexities of the social system in which sexual decisions are made. The socio-ecological framework therefore advocates for a review of the individual, social networks community and societal influence in order to align strategic HIV programmes that are needs-specific and culturally relevant (Stokols, 1996).

Figure 5: Interconnected System adapted from Sallis and Owen (2002)



Exploring the data through these lenses therefore emphasises the importance young people's participation in how these programmes are developed. Excluding participants in the processes of developing HIV projects means that this interconnected and inter-relational system, in which sexual practices usually occur, is ignored, making the programmes culturally irrelevant and negating the needs of participants. The diagramme above illustrates that whilst considering participants' sexual practices in light of the individual, social, community and societal influences, the participation of young people becomes a central way to understand their experiences. Participation ensures that participants are actively engaging through discussions and dialogue to understand the influence of the socio-ecological system on their sexual practices since an understanding of this system is not possible without their ongoing participation. The next section explores the importance of participation within the social ecological framework discussed in the above section.

Section Two: Exploring Young People's Ideas on Participation

This section attends to the second research question outlined in this study that explores participants' perceptions of participating in the development of HIV projects. More specifically, this study asked the question of the nature of young people's participation in communication programmes? This was explored through the bodymapping process but also drew on data collected through interviews and focus group discussions. The data presented in this section therefore integrates findings on issues of participation from the four chapters with all stakeholder input which includes the perceptions of management, facilitators and participants.

The data indicates the importance of participation and the inclusion of participants when developing HIV projects. In order for participants to express their ideas for developing HIV related projects, understanding how they participate and what they define as participation provides a better foundation to understand their risky sexual practices. Many studies tend to focus simply on whether young people are participating but many research projects fail to ask the question of *how* do participants define participation?

Discussions about participation indicated that while participants could identify the importance of participation, they still lacked an understanding of how to participate and how they could learn more about their lived experiences through participation. This was evident in the data where there was a distinction in how participation was defined from those in the UKZN group and those from rural KZN. Most participants at UKZN tended to associate their participation with empowerment and giving participants an opportunity to engage and share their views, while the rural KZN group associate participation with doing something, or working on an activity (refer to Table 6). This stark contrast highlights the knowledge gap and its influence on how young people make sense of participation. In the case of the UKZN group, who are exposed to extensive knowledge systems through their studies and their exposure to television and HIV national campaigns, their understanding of participation and engagement differs considerably to the rural KZN group. The rural KZN group believes they are participating if they start HIV activities or discussions in their communities. This raises the question of whether we can conclude that young people are not participating in HIV programmes, when the data shows that they identify this differently to the normative idea of participation.

For many participants in the rural KZN group, participation was identified through activities that needed to be done in the community to increase the level of knowledge and information on HIV. Hence, suggestions on participation by participants in rural KZN culminated in discussions that were goal-based or outcome driven. This indicates that participation in rural KZN was identified as a means to an end, where it is a process of meeting an ultimate goal or deliverable. For many of the UKZN participants the process of empowerment and the emphasis on participants' voices suggest that they perceive participation as an end in itself, where the human rights of the participants are more important than an outcome that results from participation (see Melkote, 2003). These varying views of participation have to be considered when advocating for participation in HIV related projects, since the data indicates that what one group deems as participation may not be regarded as participation by another group.

These contrasting perceptions of participation became further evident when the rural KZN group indicated that having access to information was a key determinant to encourage participation. The rural KZN group emphasised that participants have to be educated about HIV related issues and have to possess extensive information before participating in community projects (refer to Table 6). This contradicts the work of Freire (1976) who advocated for a problem-posing perspective to collective action, where people actively participate through dialogue in order to become critically aware of their social reality. It also indicates that participants in the rural KZN group do not identify participation as a human right or process which they had to engage in, but instead associated participation with an end goal.

The data gathered with the various organisations indicates that participants are also making an association between participating in community programmes and taking responsibility for their own lives. Participants at the rural KZN workshop suggested that the process of learning is stimulated through their inclusion in developing HIV programmes and therefore encourages more responsibility in terms of safer sexual practices. Understanding sexual responsibility in the context of their active participation introduces a new perspective to how risky behaviour can be addressed. This suggests that participants are more likely to act responsibly and to make responsible sexual choices when they actively participate in HIV programmes.

The data further challenges our notion of participation when young people commented on the importance of participating through listening. Participants from the rural KZN workshop suggested that young people must be involved in HIV programmes as they have the ability to listen to each other. The data draws an association with the importance of listening as a catalyst for participation. Quarry and Ramírez (2009) suggest that one of the biggest hurdles of participatory communication and development is that those developing programmes do not listen before planning and do not engage people in discussion before telling them what to do. This finding confirms one of the conclusions raised in the Kunda study (2009) which suggests that participants have ears but they do not hear. The commonalities of the argument with Quarry and Ramírez (2009) and the findings of the Kunda (2009) study indicate that communication specialists are not listening to participants and participants in turn are not listening to communication specialists or HIV messaging.

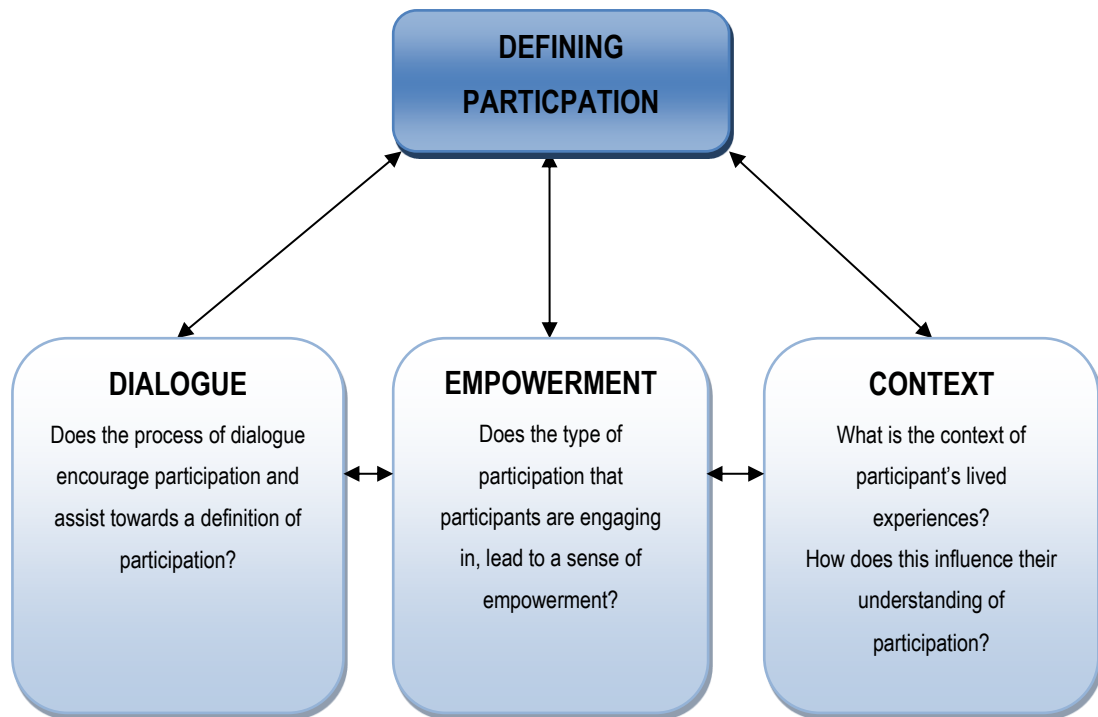
I argue that the breakdown in communication arises in how we define participation. Communication specialists are not listening to young people because they do not understand how youth make sense of their world, nor do they allow for opportunities to reflect on how they perceive their world and the

challenges they face. In turn, young people are not listening to communication specialists because they are not engaged in the process of developing HIV programmes. The central aspect missed in this equation is: understanding how young people define participation. In understanding what constitutes participation, young people are better positioned to aid the process of developing effective HIV related projects that are participant specific. The data provided in this study, with particular emphasis on the contrast of how participants in UKZN and rural KZN identify participation, indicates that the lack of contextually defining participation can contribute to situations where communication specialists are not listening to young people, and in turn youth are not listening to communication specialists. Central to all data collected through the interviews with directors and/or programme managers, and focus group discussions with facilitators, was the emphasis on the need to recognise and adopt the benefits of youth participation. The bodymapping process further provided extensive data on participants' perceptions of participation and the need for their ongoing involvement in HIV projects. The data in this study therefore provides a case for how to define contextually relevant participation to further encourage participation in developing HIV projects.

Participation: Dialogue, Empowerment and Context

In the context of these varying definitions of participation, and the need for identifying a contextually relevant framework, three key attributes were identified in the data by participants when thinking about participation. These attributes are in no way conclusive of what constitutes participation, but instead offer a grounded perspective to understand how youth make sense of participation rather than us imposing a rigid definition of participation. The three attributes therefore illustrate the messiness of participation where in theory it follows a rigid process yet in practice it can take any form to achieve participation. The diagramme below is therefore not inclusive of all necessary attributes of participation, but rather offers a youth-informed perspective to understanding how they make sense of participation. These attributes include the importance of dialogue, the need for a process that empowers participants and the need to recognise context. The UKZN group strongly suggested that the two key steps that are often missing in HIV programmes, includes the active participation of the community (in this instance, participants) and the use of dialogue amongst all key stakeholders to promote or address a specific HIV-related issue.

Figure 6: Defining Participation



Research and extensive literature searches have indicated that dialogue is essential to effect social change and empowerment within communities (Dutta, 2011, see also Habermas 1971). Dialogue is also regarded as an essential process to encourage active participation. Community dialogues were identified by participants as an integral part of many of the national and community based programmes. Participants during the data collection phase also stressed the importance of these community dialogues facilitated by the various organisations to explore their ideas, perceptions and solutions to problems. Through ongoing dialogue, youth are encouraged to explore what their needs are in their community regarding HIV and AIDS, how they define their participation and how this participation can influence the development of HIV related projects.

Many participants in both groups found that through participation in the development of HIV projects, they could learn more about HIV themselves, have the knowledge to share with others and the ability to pose problems they faced regarding HIV. They posed a range of questions on their bodymaps which suggests that through their participation they have the ability to identify problems (problem identification), and also pose problems (problem-posing). Problem-posing involves posing questions, which in turn initiates a dialogue between participants and the facilitators about differing views.

The *loveLife* approach, like *DramAidE*, poses a range of questions to participants to assess where they are in life and what they want out of life. Some of the questions posed to participants included, where do you want to be in life, and where do you see yourself in years to come? Participants are then encouraged once they identified where they want to be, to think about the steps they have to take to ensure that they get where they want to be. *loveLife* and *DramAidE* suggested that this gives participants ownership of the process and their own lives through a process of problem-posing and problem identification. What is clear from the work of *loveLife* in communities is that there is now a shift in how they work with participants. Their programmes, like the work of *DramAidE*, *Youth for Christ* and in some cases *One Voice*, are informed by a communication for participatory development (CFPD) process which poses three questions of 1) where are participants, 2) where do they want to be, and 3) what do they need to do to get there? In adopting this CFPD process, many of the organisations encourage participants to engage in collective dialogue which is a process to encourage participation.

It is through this process of dialogue that participants can develop problem solving skills, negotiation skills and communication skills. The data indicates that participants, through a process of dialogue, commonly associate their participation with developing problem solving skills. A common finding among all organisational programmes was the emphasis on developing life skills for participants to make informed decisions and negotiate their sexual practices. The process of dialogue therefore encourages participants to become more actively involved in making decisions for their own lives, and can be an empowering process for participants.

Through a process of ongoing dialogue, and problem-posing discussions, many of the participants who informed this study argued in favour of recognising cultural values and the social influences that often inform the context for participation. This was also strongly advocated in the *DramAidE* focus group discussions with several facilitators commenting on the importance of recognising cultural beliefs and working within the community to address diverse views. This suggests that even through a process of dialogue, which equips participants with life skills and encourages them to make their own informed choices, the influence of culture still plays a significant role in how decisions are made. The various influencing contexts therefore need to be acknowledged when understanding how participants participate and how they make informed choices. Organisations like *One Voice* and *Youth for Christ* further emphasised that participants from rural areas and those from urban areas are very different and sometimes have different issues affecting them, with influences of age, gender imbalances, and cultural and social influences contributing to the context in which participants make decisions about sex.

Discussions with the eight organisations therefore predominantly pointed to three areas: that participation allows for ongoing dialogue and *discussion* with participants; participation *empowers participants* to make informed choices; and participation needs to recognise the *importance of context*. Exploring participation through this youth-informed lens brings some clarity in understanding participation, despite the messiness of its application and its varying definitions. According to Suleman and Ngah there is a lack of clarity on what participation really means and how to achieve it, since participation tends to “mean different things to different people” (2012: 24). Definitions of participation offered by various academics in some cases suggest that it is a step by step process of shared decision making, community engagement, collective dialogue and active participation of various stakeholders in all planning processes (Hart, 1992; Tufte & Mefalopoulos, 2009; Bessette, 2004; Cornwall, 2008; Servaes & Malikhao, 2005; Nair & White, 1993). The definition by the World Bank (1998) differentiates participation in the context of various participants, suggesting that for some it is a principle, for others it is a practice, and yet for others, it is an end in itself, and therefore there is no comprehensive definition for participation. Given the complexity of making sense of participation, this study does not attempt to offer a linear understanding of participation, but rather offers a youth-informed perspective to understand how to apply the process of participation when developing HIV related projects. The three attributes of participation are therefore not inclusive of all of the considerations when working within a participatory framework, but rather attempts to offer a practice-informed perspective which is youth-informed instead of a normative understanding of participation.

Getting Participants Involved in Developing HIV Projects

Participation, despite its varying definitions evident in the data collected from participants, still needs to be integrated into the development of HIV projects. Part of the data collection process for this study explored what are the phases of developing HIV projects and how participants can participate in these various phases. The data collected with the organisations’ management and facilitators, supported by the bodymapping process, offered a youth-informed perspective to these various phases.

Participants categorised the phases of developing HIV related projects, and indicated that the first phase was the situation analysis. The UKZN group provided more insight for this phase that included:

- a) the importance of understanding the participants,
- b) exploring how and why the issue of HIV was a problem in the specific community,
- c) understanding the specific factors that contribute to HIV and
- d) identifying the process that entails educating people on how to prevent HIV and assist others.

These criteria identified by participants when considering the situation analysis phase places an importance on the need to understand the people, the circumstances and the factors that contribute to their behaviour in the context of HIV, before developing HIV programmes to educate participants on prevention.

Most of the sample organisations indicated that research informed all the programmes offered to young people. Three common research sources were identified, that included national studies and research conducted on youth's sexual practices, discussions with various stakeholders about HIV programmes, and discussions with young people. Organisations such as *DramAidE*, *One Voice*, the *One Love* campaign and the *Scrutinize* campaign identified research as a central component for developing research-informed HIV programmes, with most of the organisations conforming to a broader data source such as national research and surveys to understand participants' sexual practices. Participants, in contrast, termed this process as *situation analysis*, offering a detailed range of questions that constituted their idea of a situation analysis. The questions posed by participants to inform the situation analysis suggest the important role participation can play when developing HIV related projects through a youth-informed perspective.

The *Field Band Foundation* uses a more participant-oriented approach, where youth document their key challenges before the workshop which allows the facilitators to compile a participant specific programme to address these challenges. Working with youth allows the organisations to assess if their programmes are successful and then to adapt the programmes accordingly. Many organisations are still more dependent on national surveys and research to reflect young people's sexual practices, which can sometimes lead to a lack of understanding of the context or the specific issues particular communities. The data therefore highlights the importance of adopting a more inclusive approach to the research phase of developing programmes, where young people can actively participate in HIV prevention.

The *design of projects* was identified as the second phase for developing HIV projects, and organisations like *One Voice*, the *Scrutinize* campaign, and the *One Love* campaign indicated that whilst the HIV issues addressed were youth informed, the development of the content was conducted by experts. In the case of *Youth for Christ*, the programmes were selected and designed by facilitators based on experiences in the field with participants, as well as using material developed for *YFC* nationally. This indicates that whilst national campaigns cannot be developed by participants, they can still participate by providing ideas about how the project is received and possibilities for adapting

projects to suit the needs of participants. Their participation therefore takes a very different form, where they are not involved in the design of a project, but they can contribute to how the interventions are adapted to suit specific contexts. This was evident in the case of *Scrutinize*.

The development of HIV projects were not discussed extensively on the bodymaps of the participants from rural KZN, with only two participants suggesting that research was the most important phase when developing HIV projects. This was followed by the phase of extensive consultation in their community with council wardens and community meetings. The interesting contrast between how participants in UKZN and rural KZN identify their participation in developing HIV projects indicates that whilst the UKZN group explored ways to mobilise themselves, the rural KZN group placed importance on consultation with various stakeholders in the community (refer to Table 6). Overall, this contrast suggests that while participants can identify the phases of developing an HIV intervention, how they define participation and engage in the processes of participation differs considerably.

Facilitation or implementation is the third stage of developing a HIV programme. Most organisations used either a peer education approach or worked with young facilitators in schools and communities. The school programmes offered by *Youth for Christ*, *DramAidE* and *One Voice* follow a peer educator approach where high school students choose peer educators to work in their schools, but also modify the programme to offer to an affiliated primary school. Even in cases where the programme was already researched and designed by experts or consultants, the actual implementation of the programme was in most cases found to be conducted by participants. The facilitation of programmes therefore encourages youth participation and suggests that they do have a pivotal role to play in how HIV related issues are communicated. Several organisations, however, indicated that it is difficult to measure the impact of their programmes due to funding restrictions, because the programmes offered were targeted to small communities and schools with specific needs. Evaluations were therefore identified as the final phase of developing HIV related projects, but were not often conducted due to financial and time constraints.

Section Three: Exploring the Benefits of Bodymapping

Section One addressed the varying sexual practices and HIV programmes offered, where I argued that the key determinants of risky sexual practices needs to be explored within a social ecology framework. In order for this to happen, the ongoing participation of participants must be promoted to provide a contextual framework in which to explore and understand their sexual practices. The participation of

young people in discussions and dialogue to understand their lived experiences, perceptions and challenges of HIV, better enables the development of effective HIV projects. Section Two explored the concept and the need for participation further, by exploring specific participatory experiences and reflections of participants and organisations when developing HIV programmes. Discussions on participation indicated that whilst participation directly promotes responsibility in sexual practices, there is a distinct contrast with how participants in different social settings understand the concept of participation. Put more simply, participation has to be defined for various contexts and participants. When the participants in this research engaged in discussions, the importance of dialogue, empowerment of participants and the need for understanding the context, were attributed as key determinants when thinking about participation. It is against this backdrop, that this section addresses question three of this study that explores these possibilities for participation through the use of a bodymapping process. This section focuses more specifically on how the bodymapping process can encourage the participation of young people when developing HIV projects. The section to follow addresses the specific research question that explores whether bodymapping encourages participation and is a viable participatory technique.

The findings of this study revealed that bodymapping does encourage participation. This is represented schematically in Table 7.

Table 7: Table Summarised with findings from Chapter Seven

BODYMAPPING ENCOURAGES PARTICPATION

Bodymapping increases confidence to engage and participate

Bodymapping encourages dialogue

Bodymapping identifies similar challenges

Bodymapping is a relaxing way to connect

Bodymapping encourages introspection and self-reflection

Bodymapping encourages art as an alternate form of expression

Bodymapping encourages problem identification and problem solving

The participant's specific constructs of participation in terms of its ability to encourage dialogue, recognise the importance of context, and to encourage empowerment is discussed below with empirical data to suggest that bodymapping is participatory.

Bodymapping Encourages Dialogue through Introspection and Self-Reflection

The bodymapping process was succinctly described by many participants as a process that allowed for an understanding in their own lives in relation to others. Participants, particularly from the UKZN group, commented that the process allowed for visual expression about the way they think and feel, making them explore their own thoughts, emotions and perceptions in an introspective way. They also commented that the bodymapping process required an introspective approach where they had to ask themselves several questions in order to explore and understand more about themselves.

The bodymapping process indicates that introspection is commonly associated with reflection. This means that participants would take introspection into their own lives, and reflect on their experiences, resulting in problem identification and posing problems for solutions in their own lives. Only after the process of ongoing introspection and reflection, were participants empowered to discuss this with a wider audience and explore more specific problems they were facing. Many participants commented that reflection was a distinct attribute of the bodymapping process. Reflection is pivotal to encouraging participation, as Freire's (1979) pedagogy suggests the need for the action-reflection praxis when empowering people to participate. The bodymapping process only allows for self-reflection and problem identification but did not extend to the action which is needed to implement the programmes. Bodymapping can be seen as a catalyst that starts the process of self-reflection, which can then later stimulate dialogue for positive action in communities. Many participants enjoyed the focus of plotting their thoughts and ideas on various parts of their body, indicating that self-reflection often precedes a process of dialogue.

Dialogue – Problem Posing and Problem Solving

The bodymapping process was identified by participants as assisting them in identifying their problems, making sense of their experiences and re-focusing on action steps within their respective communities. Their discussions suggest that dialogue was the first step to engage participants about their active participation in developing HIV programmes. Through the process of dialogue, participants started to further discuss the problems posed on their bodymaps within a collective forum. This indicates the

importance of self-efficacy which later contributes to collective efficacy within the broader group. In addition to the problem-posing nature of bodymapping, it was a cathartic process for most participants who took an introspective approach to resolve their own issues and challenges with HIV. The problem identification phase usually took place through the images and text on the bodymaps, and the problem solving through a process of discussion and dialogue among their peers. This indicates that bodymapping can take participants a step further from self-reflection and problem posing to engaging in discussion and dialogue which leads to problem-solving (Freire, 1976; Durden et al, 2009). The participants were therefore suggesting that bodymapping could be used not only as a self-reflection tool which takes participants through a journey of introspection, but could also be used to understand what they know and do not know about HIV.

An important attribute to engaging in a problem posing discussion is the participants' ability to develop confidence to participate. When participants are mobilised and feel confident to participate, they are able to define their own problems, lead the process of investigation, and identify their own solutions. The data suggests that when participants interact and have discussions with adults or other people about issues which affect them, it can lead to a greater level of confidence for participation. The bodymapping process enabled participants to identify their participation as their own responsibility, and this in turn developed their confidence and willingness to participate. Similar findings were found in the bodymapping workshops conducted with students during postgraduate orientation where through a process of building confidence, they recognised the need to take ownership of their own lives, and saw themselves as co-generators of knowledge (Reddy, workshop report, 2009).

This level of confidence resulted in many young people' thinking about how they could be relevant to their communities with offering HIV projects. Many, from rural KZN group commented that the bodymapping process positioned them to develop ideas, think critically and explore what needs to be done from a youth perspective in their communities. The bodymapping process therefore serves as a tool to allow participants to document their experiences, reflect on their ideas and use their documentations and reflections as a means to facilitate discussions.

Bodymapping Supports Various Contexts

Dialogue was encouraged after the bodymapping process, to explore the ideas of participants in relation to HIV prevention and their participation in developing HIV projects. The bodymapping process supported the process of dialogue and critical thinking where the participants explored their own lives within a wider social and cultural context. This process of dialogue, which followed the bodymapping

process, extended from the individual context to a wider context of understanding the complexities of HIV and young people's participation in developing prevention programmes.

Many participants commented that the bodymapping process allowed them to connect their own experiences to the wider community experiences through an exploration of what participants are seeing, hearing, doing, saying and feeling about HIV in their community. The steps of the bodymapping process were also described by one participant as clearly requiring them to explore their own lives and then how they could contribute to HIV programmes for the broader community. The participant particularly highlighted that the steps of what they were seeing, hearing and speaking about HIV, required them to explore their individual perspectives, whilst questions of what do they want to do in their communities, drew attention to a wider context in which HIV decisions were made.

The bodymapping process sparked conversation among the participants and demonstrates that even though they have similar experiences and challenges with HIV, these challenges often have to be understood within the various contexts. The interesting aspect of bodymapping is its ability to demonstrate the commonalities of participants' experiences and challenges, but at the same time also to demonstrate the uniqueness of participants' thoughts, ideas and perceptions. The bodymapping exercises were found to promote individual thought and therefore raises diverse and multiple perceptions which are not always evident in focus group discussions or community dialogues, as participants may easily conform to the views of others. The bodymapping experience was also a means of putting HIV into context and perspective for many participants, as it stimulated discussion and self-reflection on how participants can be involved in HIV programmes. Comments from the participants in rural KZN reflect the value placed on collective action in the community. Only in a few instances did discussions centre on the possibilities of participants promoting HIV information by themselves, in most cases they voiced that it should be a community initiative.

Bodymapping Promotes Self-Efficacy and Collective Efficacy

A common trend in both bodymapping workshops was the ability of participants to individually identify the challenges they were experiencing regarding HIV through self-efficacy. This was later enhanced to a collective identity when the participants engaged in group discussions about their common experiences. These discussions indicated that there was a sense of collectiveness and of group problem identification, instead of HIV being an individual problem.

The process of bodymapping allowed many students to find commonalities in their experiences. The sharing of similar challenges, exploring each other's interpretations and communicating jointly gave these participants a sense of social inclusion. The bodymapping process was instrumental in highlighting common experiences, but also developing the social capital for these participants to address any challenges identified. They were able to identify their social networks through the bodymapping process and develop peer relationships with other students, who share similar research and social interests.

Bodymapping Promotes Empowerment

The bodymapping process was found to offer participants a means to communicate about issues which affect them, where they can still be in control of what they document, how they document this, and what they later share with the facilitator and other participants. The use of symbols, images and text to document responses offered a flexible and adaptable process for the participants in this research to later discuss their issues with HIV. The bodymapping process allowed for freedom of expression with a diverse range of mediums to communicate, affording participants an opportunity to depict their ideas, perceptions and experiences in an abstract way, with the freedom to discuss what they are comfortable with and withhold what they did not want to discuss. In this way, bodymapping can also be regarded as a therapeutic tool as many of the participants felt empowered to document their experiences without the pressure of talking about them if they were not comfortable. These participants therefore used the bodymapping process as a way of introspection for themselves, with the process offering opportunities for self-reflection with discussion about the contents of their bodymap with others.

Bodymapping recognises the importance of communication, but as indicated in the application allows participants the freedom to engage in non-verbal communication that empowers them to engage in self-reflection first, before communicating their perceptions, experiences and observations to others. The bodymapping process, as learned from my applications, therefore draws on non-verbal communication which is best supported by verbal communication to unpack the content of the bodymaps.

Participants Empowered to Share Opinions and Offer Ideas for Action

Many participants recognised the importance of their participation in the design of projects, identifying areas of contribution which they did not explore before. The bodymapping process took them through a journey of discovery where they were in the first instance able to associate some of the risky sexual

practices of participants in their community with the lack of HIV programmes, and secondly explore what they could do to develop HIV projects which advocate for safer sexual practices.

Specific examples around mobilisation of participants in communities extended to the participants identifying the need for more HIV awareness programmes in their communities, supported by more discussions about HIV and participants taking on a proactive role to promote programmes that address the challenges of risky sexual practices. Some of the UKZN participants indicated that there is a need for more communication campaigns and implementation of projects which are specific to HIV. Many participants indicated that they want to pursue careers where they can assist people who were HIV positive and in some cases, they wanted to offer their own HIV programmes. Through the workshop, many participants documented that youth are not taking the virus seriously, indicating the need for more programmes to create awareness in their communities. This was also evident in the responses of participants when working on the feet on their bodymaps. One participant in particular reported that he wanted to see a HIV-free generation where people started to take HIV more seriously.

Bodymapping Promotes an Alternate Form of Expression

Bodymapping was often described as an alternate form of expression where participants used symbols, images and drawings which were subject to various interpretations. The documentation of participants' experiences and perceptions using art has proven particularly effective in addressing sensitive issues, such as HIV and AIDS. Through the bodymapping process art becomes an alternative means of expression and non-verbal communication, but it is pivotal for discussions to follow the use of symbols to avoid misinterpretation. Bodymapping also allows for expression through colour that is not possible when engaging in conversations. The art-based approach of bodymapping allows for adaptability and flexibility when working with young people who are faced with multiple contextual factors and influences regarding HIV and AIDS

Bodymapping Provides an Enabling Environment for Participation

Overall, the participants in this research commented on how they enjoyed the messy and fun nature of the bodymapping process which they felt was not a conventional way of engaging with youth. The relaxing and fun nature of bodymapping created an enabling environment for the participants to explore their perceptions and experiences in an alternative way. The participants from the rural KZN group were the most excited about working with paint, the messiness of the activity and the opportunity to participate in a fun and engaging way. The fact that the UKZN participants valued the silence and time

out to think and reflect, as opposed to the rural KZN group who valued the creative, exciting and fun nature of the workshop, indicates that the same workshop facilitated for participants from different social settings can achieve different outcomes (refer to Table 6). The participants enjoyed the process of doing things on their own and exploring how they could play a more proactive role in developing their own lives. Bodymapping ensured that this happened in a fun, free and stimulating way, which encouraged the participants to want to participate further. The bodymapping process allowed for an environment where youth could engage in a creative and self-expressive way. Scalway (2003), in his critique of the first 20 years of HIV programmes and messaging, suggests that communication projects need to explore the wider influence of creating an enabling environment where dialogue can flourish and lead to empowerment and contextually relevant projects.

The participants were able to point out the key attributes to understand participation that included the need for dialogue, empowerment and understanding of context. In order to explore whether bodymapping can be used as a participatory tool, this study explored this data collected through bodymapping in the framework of these three attributes of participation and concludes that bodymapping can serve as a tool to facilitate young people's participation in developing HIV programmes.

Participatory research factors in communication as an integral part of the methodological process (Cornish & Dunn, 2009). Participatory research within a communications framework, values the richness of visually documented content that is not always evident in textual ways of documenting and expressing experiences (Mowlana, 2001). This was evident throughout the process of bodymapping, where thoughts, ideas and perceptions were expressed in creative and meaningful ways. Participatory approaches to communication can be visual, expressive and co-constructed rather than the traditional approaches used to communicate research findings (Cornish & Dunn, 2009: 670). Bodymapping in this instance offered participants an opportunity to be expressive through the creative mediums of drawing uses colours, textures, symbols and images to communicate in a visual way that was later supported by discussion and dialogue. The process of bodymapping also allowed for the co-construction of meaning where, after the bodymapping process, the participants collectively constructed their lived experiences amidst varying contextual influences.

Below is a discussion on the importance of understanding bodymapping and participation of youth, which is supported by the development of a model for using bodymapping processes within a wider participatory framework. The more specific data discussed in the previous four analysis chapters and

the sections above, offers a way of generalising these findings into an adaptable framework for further participatory communication programmes, particularly in a HIV context.

A Model for Applying Bodymapping and Participatory Phases for Developing HIV Projects

The data collected and discussed in this study suggests that participatory communication can only take place when the participants are actively engaged in a process of collective dialogue to set specific problems on the agenda for discussion towards a solution. This usually requires the application of participatory methodologies to mobilise youth to participate. The application of participatory methodologies in turn ensures that participants are engaging at all stages of the project, which usually entails the research, design, and development or implementation stage.

Servaes (2008:21) succinctly summaries this cyclical process of participation by suggesting that a participatory model of communication must be based on:

- a) concepts of context, culture and multiplicity that highlights the importance of cultural identity of the target audience,
- b) demonstration of participation on all levels, and;
- c) a strategy which is promoted by those who receive the message or intervention (Servaes 2008: 21).

The process of participation outlined by Servaes (2008) confirms the similarities identified in the data collected with the organisations and participants through the four phases of data collection. The data indicates a dire need to create contextual and participant specific definitions of participation. Servaes (2008) refers to the importance of context within a framework of cultural identity, which was evident in this study about how young people understand HIV issues within a wider socio-cultural framework, indicating the importance of youth specific projects. Servaes (2008) points out the importance of participation on all levels, drawing further similarities with this study as the data collected indicates that participants do need to be actively involved in participation on all levels, with specific emphasis on how their participation can be integrated into the various phases of development of HIV programmes.

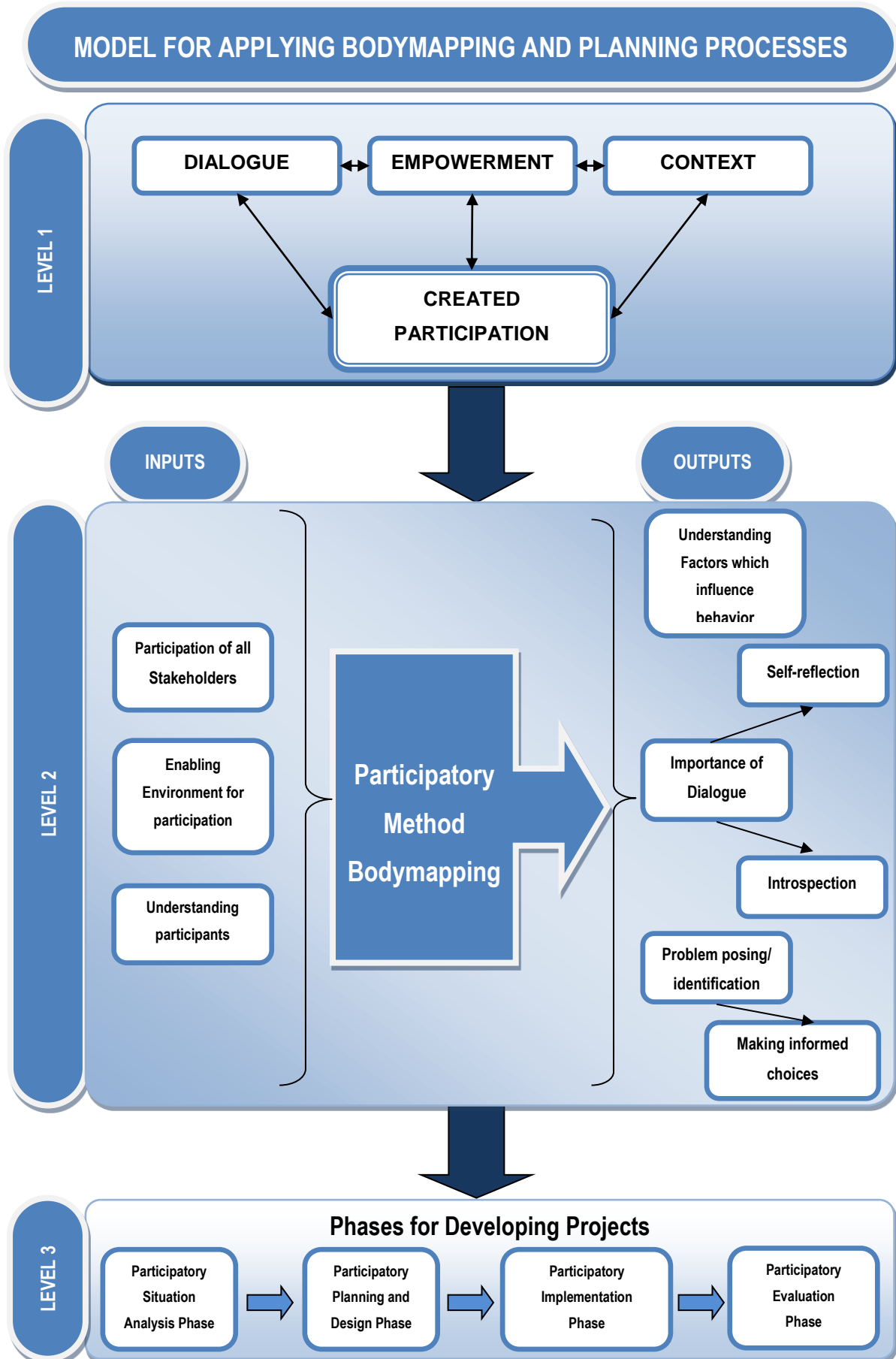
The final process of participation suggested by Servaes (2008) indicates that a strategy needs to be promoted by those who receive the intervention. This step emphasises the importance of mobilising the participants who has engaged in participation to promote their own programme on a specific issue. This

study was therefore positioned to explore how youth can go about the development and promotion of their own programmes, through an exploration of their participation in the various phases of development. This is premised on the notion that they need to be involved in all phases of developing HIV programmes. The data collected through the bodymapping process indicates that young people are keen to participate and further offered ways to engage them in HIV programmes and information sharing.

To illustrate this process of participation based on the data analysed in this study, the diagramme below reflects some of the key attributes of defining participation which I term 'created participation'. I term the process of defining participation as *created participation* as it requires participants to specifically think about the key attributes of how they understand participation and create their own idea of what they expect from projects that are deemed participatory. The model below reflects the three key attributes that participants, through the bodymapping process, identified as crucial when thinking about created participation.

The first level discussed below explores how participants can create their collective definition of participation (created participation). The second level offers bodymapping as a participatory methodology, outlining specific inputs and outputs which can aid the process of participation and engagement. The third level deals with the youth-informed phases of developing projects with a further suggestion on how bodymapping can be adapted to ensure the active participation of youth in all the phases of developing projects. Whilst this model depicts these three levels in a linear process, where one process feeds into the next, it is important to recognise that participation does not take place in a rigid setting, and the model is designed to ensure that young people can be actively participating at any level of the model. Unlike levels-of-participation typologies that are criticised for staging participation in a linear process and for suggesting that people on the bottom of the level are not participating, while people on the top are participating, this study instead argues that participants can participate at any level of the model. The model is set up to enhance the active participation of youth based on a framework that positions how they define participation, which is the pivotal indicator of whether participation happens in the rest of the project. For example, if participants define participation as the need to only share ideas with the organisations on any particular issue, and the organisation then develops the project, then this process cannot be labelled as non-participatory, since the participants perceive their input as active participation.

Figure 7: Model for Applying Bodymapping and Planning Processes



Level One: What Constitutes Participation?

A youth-informed perspective suggested three specific attributes of participation, which include the need for dialogue, the importance of recognising context and the need for participation to promote empowerment.

The first attribute identified by all organisations centred on the importance of engaging participants in *discussion and ongoing dialogue* about their needs and how to address them within an HIV context. Participation challenges the linear process of sending information to participants without allowing for their feedback, interpretation, subjectivities and perceptions on HIV related information. In order to create effective strategic HIV related projects, young peoples' participation is pivotal and this can only happen through a dialogical process. Through a process of ongoing dialogue, reflection and action leads to praxis. The study found that many participants advocated for dialogue as it capacitates them to engage in participatory processes by having more insight into who they are, what they want, and discussions about how to get it. This process of dialogue is integral to the communication for participatory development process, and can therefore be supported by data to indicate that dialogue is a key determinant for active participation.

The need for a *context specific approach* is the second attribute to effectively define what constitutes participation. The young people and organisations in this research commented that youth participation ensures that context specific approaches address the direct needs of participants. Participation therefore cannot have a universal definition but needs to be defined in accordance with how participants understand it and how it is implemented in practice. The importance of context extends to understanding the social-economic, cultural, psycho-social influences on young people's decision making, therefore making the context in which decisions are made pivotal to how programmes are developed.

The third attribute of participation is the need for the process to encourage the empowerment of participants. Many participants associated the importance of their participation with attaining the outcome or the objectives of HIV related projects. In this way, the developing of life skills such as negotiation skills, problem posing and problem solving skills and the ability to communicate through a process of dialogue suggest that participants were empowered. This empowerment is only possible when participants are actively participating.

Created Participation

Given the various definitions of participation, it becomes evident that the development of a definition revolves around the needs and objectives of a project which have to be fulfilled for participants through a process of inclusion of all stakeholders. In this regard, the term participation needs to be defined within context and has to have a self-created meaning for the specific needs of a community and the intended outcome of a specific project. I term this context specific participation as “created participation” which ensures that the collectively defined idea and terms of participation determine whether people are participating, instead of a generic definition of participation. This definition can only be established by engaging participants to offer a definition of what participation means to them at the inception of a project. If participation is always defined by a community in the initial development processes of a project, the project avoids the risk of not being inclusive or failing to meet the needs of the community. These requirements for participation have to be addressed when developing HIV projects, as participation does not exist in a vacuum but is influenced by various factors of agency, agenda, policy, audience needs, and social and cultural influences.

Giving the participants an opportunity to define their own understanding of participation, or to create their own meaning of participation, can be equated with the importance of empowering the participants to define who they are, what they want and how they will go about to achieve this. This in turn reinstates the decision making process to that particular group, where, based on how they define participation, they can choose what level of participation they want to engage in. Cohen and Uphoff (1977) suggest that participation is about decision making processes, particularly in implementing or developing programmes and evaluating the outcome of a project

Level Two: Validating the Bodymapping Process in the Context of Participation

The use of the bodymapping process as a participatory method and art-based inquiry reflected key determinants for encouraging participation. The discussion in the previous section indicates that bodymapping provides an opportunity for participants to engage in dialogue, and recognises the importance of context and how this leads to processes of empowerment. Created participation can also encourage the process of dialogue. In addition, the data from this study indicates that there are three key attributes for a bodymapping process to initiate participation with youth and these are labelled as inputs. These inputs include the active participation of *all* key stakeholders, an understanding of the

participants by those who are developing the project, and having an enabling environment to encourage participation. Three outputs were identified from the bodymapping process that includes enabling an understanding of the factors or circumstances that influence participants' sexual choices, the importance of dialogue and its relation to self-reflection and introspection, and finally the problem posing/problem solving nature of bodymapping that encourages informed choices.

Inputs

Input One: Active Participation of All Key Stakeholders

Discussions with youth about their participation in developing HIV programmes offered strong suggestions for the active participation and engagement of all relevant stakeholders. In the case of *DramAidE*, *loveLife* and *Scrutinize* in particular, extensive consultation and discussions are conducted with stakeholders from various settings before developing HIV programmes. Participants during the bodymapping process emphasised that they would consult with various stakeholders such as nurses, doctors, ward counsellors and senior elders or dignitaries in their communities before participating or developing HIV programmes. This implies that participants, through the process of bodymapping, are able to identify the importance of active participation of all stakeholders in all phases of developing HIV projects. It also emphasises that decisions in some communities are made collectively, and these wider social, political and cultural contexts need to be identified and acknowledged when working on development and health issues such as HIV and AIDS.

The importance of working as co-researchers or co-learners was also identified through the bodymapping process where the participants commented that the process allowed them to work together with adults and professionals to address common HIV related problems. Bodymapping resulted in several participants commenting on the importance of participants being actively involved in HIV projects.

Input Two: Enabling Environment

The participants also valued the opportunity to have a *free space to express their feelings*. Through the bodymapping process, participants found that it promoted their *confidence to engage* in discussions and to actively participate. The bodymapping experience was a *relaxing way to connect* with others and many suggested that it *created a space for discussion*, where they had a space to share their experiences. The bodymapping process, which was adapted to explore how participants can participate

in developing HIV projects, also gave insight into issues of participation. Most of the participants found the bodymapping process very relaxing, fun and engaging, often commenting on how they appreciated the silence and opportunity to engage with themselves. The feedback collected from participants reflects that an enabling environment was created through the bodymapping process.

Input Three: Understanding the Participants

A common finding with the data collected with organisations, facilitators and participants in this study is the importance of understanding the participants and offering age-appropriate HIV messaging and programmes. The organisations, particularly *Youth for Christ*, *Focus on the Family*, *One Voice* and *DramAidE* were able to offer age appropriate messaging to participants through a range of programmes. The need for understanding participants and offering age specific messaging was evident in the ABC strategy still being a predominant message for participants at schools. Understanding the participants and their specific needs through a process of bodymapping facilitates more context and participant specific messaging and HIV programmes. The bodymapping process also aids the process of understanding the various views, perceptions and experiences of participants within a context, where the participants have to be understood from an individual and collective perspective.

Outputs

Output One: Understanding the Factors which Influence Behaviour

Understanding the factors and circumstances that influence participants' behaviour is an evident output when implementing a participatory method, in this case the bodymapping process. The organisational discussions and the bodymapping process with participants suggest that factors which contribute risky sexual behaviour must be understood within context and with varying participants. Bodymapping in this sense serves as a means of situation analysis or a process of research that allowed the participants to creatively explore their experiences and perceptions within a context. The data generated on the bodymap served as a tool to better understand the complexities of HIV, towards promoting further dialogue about how to address this issue.

Output Two: Dialogue

The bodymapping process requires participants to work individually on their bodymaps but also serves as a tool to initiate dialogue about the content documented on the bodymaps. In this study, the discussions that followed the documentation on the bodymaps indicate that bodymapping is able to serve as a catalyst for discussion and dialogue about the range of HIV related issues. The CFPD model suggests that dialogue is always preceded by a catalyst that sparks a discussion. Since the bodymapping process catalysed dialogue among participants, it can be suggested that a participatory method like bodymapping can act as a catalyst to initiate a process of dialogue with participants. However, in order for dialogue to be initiated, dialogue was catalysed by the extensive self-reflection and introspection that was facilitated through the bodymapping process. Bodymapping, with its key attributes of self-reflection and introspection, become catalysts for dialogue and therefore offers another perspective to initiating a process of dialogue within a communication for participatory development framework (as discussed in chapter 4 of this thesis).

Self-Reflection

The bodymapping enabled the participants in this study to think critically about issues that they would not normally think about, but further work is required that unpacks these self-reflections into plans of action. Bodymapping in this regard is a self-reflection tool that helps participants become critically aware of their perceptions and experiences in an HIV context, which can later contribute to changing their social reality. Art through the bodymapping process was also identified by participants as *a tool for self reflection*, where participants can work independently, but reflect on their experiences.

Introspection

Introspection was extensively discussed as a process that helps participants to review their own lives and take cognisance of their participation in HIV programmes. Introspection is often an attribute that is missed out when developing HIV projects. The projects often fail to create an environment where individuals can explore their own perceptions, experiences and how they make sense of their world in relation to others. The introspection that takes place through a bodymapping process provides a framework for discussion and dialogue.

Output Three: Problem-Posing/Problem Identification

Bodymapping aids the process of participants identifying that they could learn more through their active participation in developing HIV projects, this in turn will give them the knowledge and power to help others in their community about HIV. Many participants posed a range of questions that they wanted addressed on their bodymap, indicating the problem posing attributes of bodymapping. Problem posing was also strongly identified by participants when they posed problems individually, that was later confirmed collectively in the wider group. A process of community dialogues then followed to address the identified issues. The young people also commented that bodymapping revealed that there were collective problems amongst the participants, and they therefore did not have to deal with their problems in isolation. Bodymapping is therefore able to allow people to reflect on individual problems when working on their bodymaps, and later through collective discussion, demonstrating the ability of bodymapping to serve as a tool for self –efficacy and collective-efficacy when solving problems.

Several organisations *indicated the lack of problem solving skills* among participants, and suggested that participation with other participants to address their challenges can develop problem solving skills. Participants also commented on the ability to pose questions and to explore their own problems with HIV and specifically their participation in relation to other participants' experiences. Problem posing methodologies aided the process of problem identification that was explored through a process of dialogue. The organisations in this study also suggested that life-skills development in general was required to empower participants with skills of negotiation, communication and problem solving.

Informed Choices

The need for participants to *make informed choices* was strongly advocated for by the organisations, which argued that participants should not only be provided with information, but part of engaging them means empowering them to make informed choices. *Youth for Christ*, in particular, suggested that when participants are empowered to make informed choices, they will have the ability to communicate about who they are and what they need. Participation in this instance requires participants to acquire the life-skills that empower them to participate and make their own informed choices, towards understanding more about themselves and what they need. Bodymapping therefore can enable participants to identify the relevant skills that they need in order to make informed choices. These discussions arose as a result of the issues documented on their bodymaps.

The overall framework of inputs and outputs is positioned within a participatory framework that tries to encourage youth participation. Bodymapping explores the key inputs that need to be considered when working in a participatory context, and the expected outputs promotes bodymapping as a catalyst to stimulate a process of introspection and self-reflection. Bodymapping can therefore be regarded as a transformative process that creates a platform for action-reflection for praxis where dialogue is central to the process of achieving social change.

Level Three: Planning Processes for Developing HIV Programmes

The third level of the model suggest phases for the development of HIV projects and are reflective of the youth-informed phases identified through the bodymapping workshops. Whilst participants provided a detailed breakdown of considerations for developing a situation analysis, details for the other phases of developing HIV related projects were still lacking. However, the phases presented below are discussed within a framework that promotes participation of youth and therefore suggests that bodymapping can be applied as a tool to facilitate their participation in the various phases of developing HIV projects.

Participatory Situation Analysis

Participants identified the situation analysis as the first phase of developing HIV projects, as it allows for assessing the needs of participants. The exclusion of participants in identifying their own challenges before exploring solutions, can offer incorrect programmes on HIV prevention. The situation analysis phase according to the youth-informed data suggests that the participants needs have to be explored and understood before developing a programme. The situation analysis also requires an understanding of the specific issue, where there is an exploration of how and why the specific issue affects that specific group of people. The third step of the situation analysis requires an understanding of the specific issues that contribute to the issue being explored.

These three steps identified by participants when considering the situation analysis phase places an importance on the need to understand the people, the circumstances and the factors which contribute to their behaviour in the context of HIV, before developing a programme to educate participants on prevention. Bodymapping in this instance offered a process to explore these issues through a creative and self-engaging process that contributed to a wider discussion with other participants. The bodymapping process serves as a research tool to address this situation analysis phase which participants described as central to developing HIV related programmes. It therefore offers youth a

creative and meaningful way to document how they make sense of their experiences and the factors that influence their experiences.

Participatory Planning and Design Phase

The data analysed in this study indicates that participants are participating in HIV projects designed by external organisations, but they are not directly involved in developing these projects. Instead, participants mostly participate through peer education, forming and participating in youth advisory boards, engaging in interactive games and facilitating HIV programmes in some instance. Data collected from interviews with youth-focused HIV programmes reveals that the design and development of HIV programmes was in most cases a strong consultative process among the participants and its various stakeholders. The bodymapping process can also be identified as a planning and development process when working on HIV projects. While participants identified a consultative process as their form of inclusion and participation in developing HIV project, the bodymapping process indicated that the participants in this study were able to document and later discuss specific ideas on programmes to implement in their communities, and more specific steps to take in their community regarding HIV and AIDS.

The application of the steps such as power of the hands, power of the feet and power of the heart offered participants a way to extend beyond their lack of participation in developing HIV projects, to thinking about practical steps that they can follow to start actively participating. In this way, the bodymapping process can extend beyond identifying possible participation that participants can engage in, to ways in which their ideas can materialise into more specific planning and development of HIV projects. The bodymapping process also serves as a tool to address cases of disagreements or conflicts that arise by allowing the documentation to lead to dialogue that advocates for negotiation and social cohesion towards mutual agreement. Sometimes this mutual agreement may require an acknowledgement that there will be differing views and opinions, but in the best interest of the project and the participants, the group collectively agrees to move ahead with a project. This is often also called a convergent process where despite the diverse opinions and interests, the group converges towards a joint project outcome (Kincaid et al, 2009).

Participatory Implementation Phase

The research found that the facilitation or programme implementation phase had more participation of youth than the planning and development phase, as many participants worked as peer educators with HIV organisations. This phase of developing projects therefore has immense possibilities for the inclusion of participants through their active participation in facilitating the programmes. Some participants identified that they were not involved in identifying the HIV related issues that participants face, but through the process of facilitation and peer education, they could actively engage other participants in discussions about HIV. This suggests that while each of these phases contribute to the development of HIV projects, the active involvement of participants in this implementation or facilitation phase indicates that some participants identify this process as their complete participation. This challenges the notion that participants need to be actively involved in all phases of developing programmes to deem it participatory. Instead, the data shows that participation in any of these phases can still be defined as participation for participants.

The bodymapping process in this phase can be used as a tool to relate information to various groups of participants. In the UKZN workshop, one participant suggested the possibility of bodymapping not only being used as a tool to explore perceptions, but also as a tool for communication and information. This implies that bodymapping can be adapted to offer information to participants, creating avenues for further discussion. It could also be applied as a facilitation tool, where peer educators can take other participants through a process of bodymapping to explore their own experiences and perceptions of HIV.

Participatory Evaluation Phase

In the phase of evaluation, participants rarely participated in evaluations of programmes as the organisations lacked the funds or time to conduct their own evaluations. The data was very thin when discussing youth participation in evaluations of programmes. This indicates a lack of assessment by the organisations due to time and resources, but also the exclusion of participants in participatory evaluations. In this instance, bodymapping can serve as a cost effective and participatory tool for evaluations in order to explore the participants' perceptions and experiences of HIV projects. The steps of the bodymapping process can be revised to be a participatory evaluation process where the participants can engage in a creative process to explore the effectiveness of an intervention.

The application of bodymapping in this final phase of developing HIV related projects suggests that bodymapping can be adapted to work through all phases of developing projects, where it can be used as a research tool, a planning tool, an implementation framework for programmes or a process for participatory evaluations of projects.

Young People's Participation in the Phases of Developing HIV Projects

All organisations and participants identified research which they specifically defined as situation analysis as the first phase of developing programmes. Young people's participation was mostly concentrated at this situation analysis phase of developing HIV projects. However, participants commented that they were often participating, even if this only occurred at the situation analysis phase level, through contributing to an understanding of what the problem is, how to address the problem and a better understanding of the target audience. This indicates that while there is an assumption that participants need to engage in all phases of developing HIV projects, they were of the mindset that they were participating, even if this was only on one level. This implied that participants still accredited their participation in only the situation analysis phase as their active participation, therefore suggesting that participation is defined differently by various participants. Whilst this study assessed if participants were participating in all phases of developing HIV projects through the sample organisations, the data indicates that participants were mostly involved in the situation analysis phase, which they deemed as their full participation. This finding therefore challenges my own preconceived ideas about participation but also highlights the importance of defining participation in a particular context and adopting a participant specific approach, since participation means and is applied differently with different people. The data also indicates that participants were able to share their experiences, specifically the challenges of HIV in the bodymapping process, and to articulate what they could do to change this. There was no action involved in this process, but participants instead were able to provide a picture of their lived experiences.

Limitations

Several limitations have been outlined in the methodology chapter (Chapter Three) and the participation chapter (Chapter Five). The limitation suggested below is therefore not a comprehensive list, but highlights some of the key limitations of the data analysis and the proposed model.

Bodymapping was often described by most participants as a new medium of communicating with young people. Some participants choose to talk or write about HIV related issues and their participation while

other documented their perceptions through images, drawings and symbols. However, not everyone valued the drawing phases, and in a few cases, bodymapping decreased the level of participation through drawing suggesting that bodymapping is a process that does not work for all participants. In some cases, older participants tend to have a preference for discussion instead of writing and drawing on bodymapping. It is therefore important for facilitators to understand their participants and how to communicate with them, before developing a programme to work with them. The blank spaces or missing of steps in some bodymaps also indicated that participants chose not to complete what they were uninterested in. There is also the possibility that they could have struggled with the steps of bodymapping and the type of questions posed, or even having difficulty with either writing or drawing. The bodymapping process therefore needs to accommodate for these complexities as it may not work well with literate communities, where writing and visual documentation may not be familiar to them.

The selection of students attending University and young people in rural communities was done to offer a diverse sample and include young people from different locations. The contrast of urban and rural, educated and the uneducated, and the varying HIV programmes and information offered to these two very different groups were succinctly reflected in the data in previous chapter. The model proposed must therefore be explored within the context of this restricted sample, and must keep in mind that the sample is a minimal representation of the wider population of young people in South Africa. Many of the UKZN students for example were well educated and exposed to HIV campaigns on campus, with some students already having insight into communication and planning processes for development projects. This was in stark contrast to many rural young people. However, this thesis working from a grounded perspective and emphasising the importance of an action research approach, recognises that despite the limited sample, UKZN students are part of the *now* generation and their experiences need to be explored within these varying contexts to ensure a better understanding of how they can participate in HIV projects and programmes.

The bodymapping process is also limited in that it cannot initiate collective action, but it can catalyse a process of dialogue towards social change. Discussions shared by participants therefore did not equate to any action. While it will require visiting the community again and chatting with participants about what they have done since the workshop, the process was only set in place to explore how bodymapping can encourage participation, hence it only serves as a catalyst in this regard.

Conclusion

This study concludes that a blanket approach to HIV programmes will not always work, as young people's sexual behaviour needs to be explored within a wider socio-ecological framework, which recognises the inter-relational and interconnected system in which they make their sexual choices. The data collected and analysed over several phases within a participatory action research process indicates that youth strongly support the importance of participation and their inclusion when developing HIV projects. However, discussions about participation indicated that while young people could identify its importance, they still lacked an understanding of how to participate and how they could learn more about their lived experiences through participation. This was further evident in the data where there was a distinction in how participation was defined from those in the UKZN group and those from rural KZN. The study found that there was a breakdown in communication in how young people define participation. In understanding what constitutes participation, young people are better positioned to aid the process of developing effective HIV related projects that are participant specific.

Participation in research and design processes should also not be something participants talk about, but rather experience, engage in and are empowered by. The use of structured research collection tools like focus groups and interviews, limits young people's participation in understanding the specific situation and their participation in all phases of the project development. The diverse use of visual methods however, means that visual texts can act as "modes of inquiry, modes of representation and modes of dissemination" (De Lange et al, 2006: 46). This was evident in the application of bodymapping in this thesis which was used as a process to initiate and aid the participation of young people in the various phases of developing HIV projects

The data presented in this chapter suggests that bodymapping has the potential to involve young people in developing HIV projects, through building their confidence to participate, engaging in self-reflection, and problem-posing processes for planning effective HIV programmes. The model developed is reflective of the co-generation of knowledge, with young people which contributed to broaden the theoretical understandings of participation, and the diverse application of bodymapping.

The bodymapping process therefore allowed me to reconstruct participant's experiences into a meaningful model that represents their understanding and implications of participation. This reconstruction of participant's experience from practice into a way that theorises confirms the grounded nature of this study (Mills et al 2003). Holloway and Tombres (2003) suggest that the application of

methods must ensure coherence, consistency and flexibility. The findings from the bodymapping process indicate that it was able to coherently relate the experiences of the participants using writing and drawings. It offered a consistent data collection process with different participants and it was flexible and adaptable to suit the needs of the participants.

The model for bodymapping and planning processes indicate that participation needs to be defined within an age appropriate framework, and has to be context-specific. It unpacks three key attributes of participation identified by young people particularly: the importance of dialogue, the need to promote empowerment and recognizing context. These three attributes suggest that bodymapping encourages participation. This thesis therefore concludes that bodymapping as a participatory process can be used to initiate participation of young people in the various phases of developing HIV projects.

In addition the model also provides a framework of inputs and outputs that researchers and participants need to explore when working with participatory projects, specifically with art based methods like bodymapping. The planning processes indicates the four common phases of developing projects, but takes a step further to indicate that participants must explore how they define participation, that must be applied within an enabling environment. A participant perspective and further inclusion of all stakeholders will result in self-reflection and introspection. When participants are critically thinking about their lives in a problem posing manner, they are empowered to explore the necessary life skills which will allow for social change or action.

This model tries to succinctly emphasise the need for young people to participate in all phases of developing projects and accredits participation in any phase as genuine participation. This is based on youth specific definitions of participation which I termed created participation. The findings of this study indicate the social construction of participation within varying contexts and experiences. The construction of participation, strategically created to suite the needs, perceptions and experiences of participants bears similarity with the findings of the Kunda (2009) and Mutinta study (2011) that suggests that sex is socially constructed with participants making sense of their sexual relationships within a framework of exploring their risk factors, but also the accompanying protective factors to support their behaviour. In a similar way, participation is also socially constructed to reflect their willingness or lack of willingness to participate in HIV projects. This social construction of participation is also intensively influenced by the cultural, social and political frameworks that contribute to how participants engage and participate in HIV projects.

Bodymapping, with its key attributes of self-reflection and introspection, promotes dialogue within a communication for participatory development framework. Since the bodymapping process encouraged dialogue among participants, it can be suggested that a participatory method like bodymapping can act as a catalyst to initiate a process of dialogue with participants. The application for bodymapping within this context suggests that it can adapt to all phases of developing projects, where it can be used as a research tool, a planning tool, an implementation framework or and evaluation process. Bodymapping can therefore be regarded as a transformative process that creates a platform for action-reflection for praxis where dialogue is central to the process of achieving participation.

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APPENDIX 1: INFORMED CONSENT FORM

I am doing research on a project entitled: PROCESSES AND PARTICIPATION IN HIV AND AIDS COMMUNICATION: USING BODY MAPPING TO EXPLORE THE EXPERIENCES OF YOUNG PEOPLE

The aim of this project is to explore young peoples participation in the development of HIV communication interventions, through a further exploration of the body mapping technique. This research is conducted by Eliza Govender (Student No: 200268424) towards my degree. This project is supervised by Professor Keyan Tomaselli and Dr Emma Durden at the Centre for Communication, Media and Society, University of KwaZulu-Natal. Should you have any questions our contact details are:

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Email: govendere1@ukzn.ac.za or elizamoodley@gmail.com

Thank you for agreeing to take part in the project. Before I start I would like to emphasize that:

- your participation is entirely voluntary;
- you are free to refuse to answer any question;
- you are free to withdraw at any time.

The information you provide in the body map/Focus Group Discussion (researcher to tick where necessary) will be kept strictly confidential and will be available only to members of the research team. Excerpts from the Interview/Focus group discussions may be made part of the final research report but your identity will not be reflected in the report.

Please also indicate if you are happy for me to take photos of your bodymap { YES / NO}

Please also indicate if you are happy for these photos to appear in my thesis chapter, your name will be removed from the body map, to ensure that you remain anonymous. {YES/ NO}

If you give consent to participate in the study, please sign this form to show that you have read the contents

I..... (Full names) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time should I so desire.

Signature of the Participant.....Date.....

APPENDIX 2: PHASE ONE INTERVIEW SCHEDULE GUIDE

Need to start off interview by clarifying the difference between:

- interventions/programmes
- HIV messages

1) What are the interventions/programmes used by your organisation to address HIV and AIDS prevention?

How are these interventions/programmes selected and implemented?

Why are these interventions/programmes selected /preferred to others?

Do you think these interventions/programmes are successful?

What in your experience, makes these un/successful?

2) What are some of the HIV prevention messages offered in these interventions/programmes?

What are some of the prevention messages taught to young people?

Why are these messages selected?

Do you think these messages are effective?

Who decides what should be taught (the messages) to young people about HIV prevention in your programme?

Defining the problem

What do staff define as the problem causing HIV?

What do young people define as the problem causing HIV?

What do funders define as the problem causing HIV?

Offer a definition of values here

3) What are some of values which underpin these HIV prevention messages and programmes? (ie: is it based on responsible sexual choices, HIV/AIDS prevention, *loveLife*, family values, liberal values, accountability, negotiation or a particular belief system)

What is the organisations understanding of values?

What are some of the values which underpin your organisations programmes and messages?

Why are these values selected for the HIV messages and programmes?

Who makes these selections?

Are these values made explicit in your programmes/interventions?

Do you identify any implicit values in your programmes which young people may not be easily exposed too?

How do your HIV prevention messages and programmes differ from other programmes/organisations that you are aware of?

4) What are the values of your funder regarding HIV and AIDS Communication?

What are the values of your organisations regarding HIV and AIDS Communication?

What are the values of the young people you work with regarding HIV and AIDS Communication?

What could be considered as challenges to using a value based approach to effective HIV and AIDS communication?

Are there any values which conflict with each other?

If so, how does this conflict effect intervention selection and implementation?

5) Can a value centered approach promote more effective communication?

What are some of the necessary questions to ask/consider for a value centred approach?

What must be considered to incorporate diverse values for effective HIV and AIDS communication?

Can a value centred approach serve as a strategy to develop more context relevant HIV and AIDS interventions?

APPENDIX 3: PHASE ONE: FOLLOW UP INTERVIEW QUESTIONS

Thank you for the information you provided through the interviews which was conducted last year. In conducting the analysis, I found that two questions still need to be revisited further.

Please can you take 10 minutes to respond to the two questions below. I would really appreciate your assistance in the final stages of this PhD research. Many, many thanks. Eliza

1. Does the One Love campaign incorporate young people's participation in the development of the intervention?
 - If yes, how?
 - If no, why?

2. Which phases of the development process are young people involved in?
 - **Research** about the problem/situation or possible intervention
 - **Design** of campaign or intervention
 - **Development** of the campaign or intervention
 - **Facilitation** of the intervention (either through community dialogues, workshops etc)
 - **Evaluation** (collecting data or evidence of success or failure of programme or intervention)

APPENDIX 4: PHASE ONE: FOCUS GROUP DISCUSSION GUIDE

Warm-up and explanation

A. Introduction (by the moderator)

“You are all welcome to this focus group discussion. I am happy that you are able to spare some time to share your thoughts and views on some of the topics I will be discussing. Let’s begin by introducing ourselves.”

- The moderator should introduce himself/herself first and then each member of the research team should do the same.
- The moderator should ask each focus group discussion (FGD) participant to introduce themselves, using a nickname, and emphasize that this is the only name that should be used for the purpose of the discussion, and that participants should not use anyone’s actual or real name in the discussion group.
- Participants should not refer to individuals outside of the discussion group—the point of the discussion is to talk about young peoples understanding and experience of the HIV prevention messages and programmes offered by the two organizations.
- The moderator should ask participants to mention their favorite hobbies as an icebreaker (5minutes).

B. Purpose of the discussion (by the moderator)

All the issues that we will be discussing are of importance for understanding HIV prevention approaches which work with young learners. We are interested in the ideas, comments and suggestions from each one of you. Please remember that there is no preferred answer. Your views are very important. This research is mainly to have more information that will enable improvement in the quality of health of young people. All information will be treated as confidential.

(3 minutes).

C. Explain the ground rules for discussion (by the moderator)

We would like you to have a friendly discussion about these issues. There is no right or wrong answer. Everyone should feel free to air his/her views and opinions. We would like to have one speaker at a time and there should be no side discussions during the session. Anyone can contribute to the discussion at any time. You should all feel free to agree or disagree in a friendly manner. We also need your permission to tape this

discussion, if anyone is uncomfortable with this recording please let us know now. We will spend between one – one and half hours in total and some refreshments will be served midway through the discussion. I will let you know at least 10 minutes before we end the discussion (3 minutes).

Focus Group Discussion Guide – with a group of 5-8 facilitators from each organisation

1. What are some of the HIV prevention messages used by (name of organisation)?

- Do you think these messages are effective?
- Why does your organisation promote these messages?

Anddoes it reflect some of the young people experiences?

- What does :

a) Abstinence

b) Be faithful

c) Condomise mean for young people today

- What other prevention approaches work with young people today?
- Given the messages promoted by the organisation and your exposure to the realities of young people, what message do you think works best for young people?
- Why do you think so?
- How are programmes/interventions selected (by your organisation) and do you as facilitators play a role in the design of interventions?

2. What do you understand by values?

What are some of the values of your organisation?

What are some of the values of the HIV programmes (ie: is it based on responsible sexual choices, HIV/AIDS prevention, accountability, negotiation or a particular belief system?)?

Why do you think this organisation promotes/ Is guided by this value?

How do you think the values of (name of organisation) and the programmes contribute to HIV prevention for young people?

- Which values do you think makes HIV prevention effective?
- Why is this most important?
- Is this value the same for all programmes you implement?

Does the values of your organisation conflict with your own values? If so, does it change the way you facilitate the programme?

- As a facilitator, your understanding of the organisational values being promoted is important. Do the organisational values make a difference to how you understand HIV prevention?
- Do these values make a difference to young people's sexual choices?

APPENDIX 5: PHASE TWO: FOCUS GROUP DISCUSSION - FREIREAN WORKSHOP EXPERIENCES

QUESTIONS FOR STUDENTS

1. What (in your mind), was the purpose of the body mapping workshop?
2. What were your initial impressions or expectations of the body mapping workshop?
3. How did you find the body mapping process?
4. Were there any particular steps which you liked/disliked?
5. Did this process (of body mapping) challenge the class room settings or structured discussions which are often used at University?
6. Do you think body mapping encourages young people's involvement and participation? Why?
7. Did the workshop make you more conscious of being an active participant in your studies?

QUESTIONS FOR STAFF

- 1: What was the motivation behind the intervention?
- 2: Have you seen any change in students' attitudes / confidence/ ability in the wake of the workshop?
- 3: How would you see similar interventions becoming part of the department's programme in future?

APPENDIX 6: PHASE THREE: PARTICIPATORY WORKSHOPS – EXPLORING BODYMAPPING AS A TECHNIQUE

This thesis will investigate the relevance of body mapping as a participatory technique for initiating dialogue and discussion on young people's involvement.

After the process of exploring the validity of the body mapping technique with students at UKZN, a full day body mapping workshop will be conducted with two groups of convenient samples of young people from the University of KwaZulu-Natal (UKZN) and from a sample organisation (*DramAidE*) to explore how they problematise HIV/AIDS and their experiences. Using the layout of the visual body maps, students will map and discuss:

what are they 'seeing' regarding HIV/AIDS communication programmes and design (eyes)

what are they 'hearing' regarding HIV/AIDS communication programmes and design (ears)

What are they/and others 'speaking' regarding HIV/AIDS communication programmes and design (mouth)

How do they feel about HIV/AIDS about communication programmes and design (heart)

How do they make sense (intellectualizing) about communication programmes and design (head)

What are they 'doing' regarding HIV/AIDS communication programmes and design (hands)

What is the way forward regarding their personal involvement in HIV and AIDS programme design within their institution (UKZN) or organisation (*DramAidE*) (feet)

Body Mapping steps

Facilitated by Eliza Govender adapted from J. Solomon and J. Morgan.

Part One: Introduction (30 minutes)

Choose a partner: draw with any colour markers around each other's bodies. NB: Lie in any position you choose.

Write your name, where and when you were born on the cardboard – nice and big - outside of your body outlines. Add any family details, details of your school, community etc

Choose a colour to represent you and paint around the outline of your bodies.

Choose another colour that represents you, and do hand prints on your body map

Give your map a face with ears, eyes, mouth etc.

write down some of the HIV and AIDS challenges in your community/or that you are aware of (outside the body)

write any HIV challenges that directly affect you through your immediate family and friends (write this inside your body)

Part Two: What do I see? (10 minutes)

What programmes do you 'see' (in your community) regarding HIV and AIDS?

Draw the symbols/signs or logos of the programmes in your area. This could appear next your eyes to show what you see, or anywhere else on the body.

Part Three: What do I hear? (10 minutes)

What other HIV and AIDS programme have you heard of in your community? (what are some of the bigger HIV and AIDS programmes you know of, have seen or heard of – write down on your body map how you came to hearing about these campaigns. This could appear next to your ears on the bodymaps (either inside or outside)

Part Four: What do I speak? (10 minutes)

What are you 'speaking'/ discussing about these HIV/AIDS communication programmes. Draw signs/symbols or write next to the mouth or as a blurb coming out of the mouth.

Think about young peoples involvement or participation in these programmes. What are young people saying about participation and these HIV programmes.

Part Five: What do I feel? (15 minutes)

Moving to the middle of your body map, close to your heart, either write or draw images about:

How do you feel about being included in communication programmes?

How do you feel about always receiving information about HIV and AIDS and not being part of making those messages?

How would you feel if you were asked to be part of programme design?

(heart)

Part Six: What do I Understand? (15 minutes)

On the top of your bodymap, where the head is, mark, draw symbols or write about current HIV programmes? What do you understand about the phases of developing a HIV programme or intervention? Can you list or draw these phases? Who is usually involved in these phases? (head)

Part Seven: What am I doing? (10 minutes)

Working into the hands of your body map, draw or write about how you could be involved HAND ON with HIV programmes or projects? (what you can start 'doing' practically regarding HIV programmes and design) (hands)

Part Eight: What can I do next? (5 minutes)

Working on the feet, walking forward – how would you like to see yourself involved in future HIV projects or interventions?“.

(feet)

Part Nine: Colour in your body map with food colouring (10 minutes)

APPENDIX 7: PHASE FOUR: FOCUS GROUP DISCUSSION - FREIRIEAN WORKSHOP EXPERIENCES

1. How did you find the body mapping process?
 - What did you like
 - What did you dislike

2. Did you enjoy the use of art, drawing and writing?
 - Were there any methods which you preferred more than others (ie: drawing instead of writing etc?)

3. What were the benefits of bodymapping to you? Did the process teach you anything? What did it teach you?

4. Which step did you enjoy the most? Eyes, ears, mouth, head, heart, hands or feet. Why?

5. Did this exercise get you thinking more about HIV and AIDS communications programmes? Why?

6. Did the exercise make you feel like you could be more involved in communication programmes? How?

7. Do you think this might be a good way to get other young people involved in communication programmes? How?