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**Making Sexual and Reproductive Health & Rights  
Real in South Africa:  
A baseline study of selected sites in four provinces  
(Year 1)**

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## ACRONYMS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>AFSA</b>	AIDS Foundation of South Africa
<b>ANC</b>	African National Congress
<b>ANC</b>	Antenatal Care
<b>ARV</b>	Antiretroviral
<b>CBO</b>	Community-Based Organisations
<b>CTOP</b>	Choice on Termination of Pregnancy
<b>CYPR</b>	Couple Year Protection Rate
<b>DCST</b>	District Clinical Specialist Teams
<b>DoH</b>	Department of Health
<b>EC</b>	Eastern Cape
<b>ECAC</b>	Eastern Cape Aids Council
<b>ECHCAC</b>	Eastern Cape Health Crisis Action Coalition
<b>GALA</b>	Gay and Lesbian Memory in Action
<b>GDP</b>	Gross Domestic product
<b>GLN</b>	Gay and Lesbian Network
<b>HCW</b>	Health Care Workers
<b>HIV</b>	Human Immunodeficiency Virus
<b>HSRC</b>	Human Sciences Research Council
<b>ICPD</b>	International Conference on Population and Development
<b>KAP</b>	Knowledge, attitudes, and perceptions
<b>LAC</b>	Local Aids Council
<b>LGBT</b>	Lesbian, Gay, Bisexual, Transgender and Intersex people
<b>MARPS</b>	Most at Risk Populations
<b>MMR</b>	Maternal Mortality Ratio
<b>MPMS</b>	Mpumalanga Men's Study
<b>MSM</b>	Men who have Sex with Men
<b>NHI</b>	National Health Insurance
<b>NGO</b>	Non-Governmental Organisations
<b>NPHSA</b>	National Plan for Health in South Africa
<b>PEP</b>	Post Exposure Prophylaxis
<b>PERSAL</b>	Personal and Salary System
<b>PMTCP</b>	Prevention of Mother to Child Transmission Programs
<b>SANAC</b>	South African National AIDS Council
<b>REC</b>	Research Ethics Committee
<b>RHAP</b>	Rural Health Advocacy Project
<b>SADC</b>	Southern African Development Community
<b>SG</b>	Superintendent-General
<b>SRHR</b>	Sexual and Reproductive Health Rights
<b>SRH</b>	Sexual and Reproductive Health
<b>StatsSA</b>	Statistics South Africa
<b>STI</b>	Sexually Transmitted Infections
<b>TAC</b>	Treatment Action Campaign
<b>ToP</b>	Termination of Pregnancy
<b>ToR</b>	Terms of Reference
<b>UNPF</b>	United Nations Population Fund
<b>WHO</b>	World Health Organisation

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## EXECUTIVE SUMMARY

This report presents insights from a baseline study commissioned by the *AIDS Foundation of South Africa (AFSA)* as a research package in AFSA's three-year programme (2014-2017) to advance the realisation of Sexual and Reproductive Health Rights (SRHR) in South Africa. AFSA's programme is intended to strengthen SRHR and community-based HIV/AIDS interventions, and to build the evidence base for effective regional responses. The programme is designed to deliver: (1) Strategic support for community-based organisations (CBOs) and national advocacy/policy actors engaged in effective HIV/AIDS and SRHR interventions; (2) Demonstrable improvements in the realisation of SRHR in South Africa; and (3) A measureable contribution to the knowledge and evidence base on HIV/AIDS in the Southern African region (Southern African Development Community (SADC)). The report provides some emerging evidence to inform the work of implementing partners and potentially to assess the outcomes and the mechanisms by which positive changes resulting from the implementation of AFSA's programme have been achieved.

**Objectives of the study:** The study focuses on (1) system failures in the public health sector and on (2) the effects of systemic failures on sexual and gender minorities (including LGBTI<sup>1</sup> persons). The information and lessons from this baseline should be used to improve government and civil society interventions and form the basis for policy and research development. The primary objective of this study is to provide a preliminary evidence-base in relation to these two focal areas. A separate study was conducted to address each of the focal areas. A mixed method approach was taken.

### Effects of systemic failures on sexual and gender minorities/LGBTI

Qualitative methodologies were utilised to collect empirical data about these person's experiences of the public health system. Participants were drawn from two gay and lesbian organisations, GALA (which has a national footprint with its primary base in Johannesburg, Gauteng) and GLN (which is based in Pietermaritzburg, KwaZulu-Natal). In-depth interviews (10) examined the effects of systemic failures on LGBTI persons and key informant interviews (4) the experiences of practitioners and activists who have vast working knowledge of the public health care system. (See chapter 4).

#### *Key findings*

1. Participants reported similar problems related to systemic failures to the general population (e.g. waiting times, stock outs, cost, language barriers), but these were compounded by discrimination within the system.

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<sup>1</sup>This acronym is used to refer to Lesbian, Gay, Transgender and Intersex persons. It is used in this report, but it is noted that this does not cover all sexual identities and practices. Therefore, the term sexual and gender minorities is used more frequently in order to be more inclusive. This term would include men who have sex with men, but do not identify as gay; women who have sex with women, but identify as heterosexual; and other local understandings of sexual identity and practice.

2. Participants reported various negative experiences related to their sexual identity in public health facilities, including negative staff attitudes, refusal to provide care (gatekeeping), breaches in confidentiality and even abuse.
  3. The staff's behaviour, especially their compromising of participants' confidentiality, was described as a major deterrent to help-seeking in public facilities.
  4. Participants sought alternative routes to meet their SRH needs, rather than attend public facilities.
  5. Participants described the system as alienating and not geared to their needs, e.g. staff lacked knowledge about sexuality and acceptable contraception and prophylaxes were generally said to be unavailable
  6. The discriminatory treatment experienced within facilities is an extension heterosexist attitudes and norms within the broader socio-cultural setting
  7. Personal agency for LGBTI individuals is affirmed through close, supportive friendship circles and these relationships offer a means of stigma management
- ❖ We can therefore conclude that negative and discriminatory experiences in the public health system, which are reinforced by and reinforce wider social attitudes and norms, potentially compromise the SRHR of sexual and gender minorities, such as those who participated in our study. This already marginal group is made further marginalised. Their SRH needs remain unmet and/or they accrue unnecessary financial costs in seeking alternative care.

### **Systemic failures**

A Desk review was conducted drawing on academic research, grey literature, and civil society documents focused on the Eastern Cape and Mpumalanga. This review of secondary data focused on issues related to facilities, services, health outcomes, access to justice and the realisation of rights, and co-ordination among civil society organisations and between civil society and government.

### *Key findings*

1. Available data from Mpumalanga and the Eastern Cape suggest that rurality and relative deprivation play a key role in shaping SRHR outcomes, particularly in accessing quality services without having to travel significant distances
2. The spatial legacy of apartheid compounds service delivery issues in these provinces
3. In the Eastern Cape and Mpumalanga key SRH concerns are related to a combination of systemic failures and socio-cultural factors, such as stigma.
4. High rates of maternal and pregnancy-related mortality is a significant challenge in both provinces and are related to barriers to accessing antenatal care and safe, legal ToP services
5. The steady decline in both the number and type of public ToP services is felt keenly in rural provinces such as Eastern Cape and Mpumalanga

6. Social stigma is a barrier to accessing safe ToP services. It also affects access to other SRH services for younger/unmarried women; young mothers; pregnant teenagers; migrants; and HIV positive persons who are all subject to judgement and moralistic attitudes.
7. Teenage pregnancy has increased in these areas; this is largely due to high poverty levels and associated issues such as vulnerability to unwanted sex, violent/coercive sexual relations, timing of sexual debut, age of male partner. Other factors include: cultural beliefs (e.g. proving fecundity before marriage), lack of knowledge and use of contraception, and problems in health service provision.
8. There is little information on the functioning of Local Accountability Structures (especially AIDS Councils) or their relationship with civil society. Implementing partners do not document these activities consistently or uniformly. What is documented suggests that LAS are not fulfilling their intended function.
9. In terms of marginalised groups and SRHR, implementing partners tend to focus on those who are HIV positive, with some attention to migrants and rural communities. The interventions thus far do not contain a special focus on gender identity or sexual identity.

## **Recommendations**

### **Systemic issues**

1. Programming around SRH needs to take an explicit gender focus and involve men as partners in SRH issues; attention should also be given to sexuality
2. Further advocacy is needed which takes cognisance of the privileging of hetero-patriarchal practices and thinking that facilitates discriminatory institutional cultures in order to improve the range, quality, access, functionality and affordability of SRHR services for all marginalised and vulnerable groups (LGBTI, women, and people with disabilities).
3. Stigma reduction training for all workers in the healthcare sector is needed. Stigma reduction work should move beyond AIDS stigma and include information, education, and communication around early pregnancy and abortion, as well as misconceptions related to non-normative sexual identities and practices
4. Government support is needed in addressing the gaps identified above; community dialogues may be useful for raising awareness of persistent gaps and evaluating new approaches
5. In order to address access barriers (especially transport and confidentiality breaches) to facilities, partners should:
  - a. advocate for the extending SRH services (preventative, basic screening, surveillance) into households and communities through community health care workers and similar mechanisms
  - b. contribute to policy development in order to clarify the scope and practice of community health workers

- c. support school health programme and other school-based interventions, particularly with respect to teenage pregnancy and knowledge about abortion, advocating for comprehensive sex education
  - d. advocate for greater inclusivity in terms of languages used in public health settings, including the use of official languages on forms and information provided
6. The accessibility and functionality of ToP services is a key part of SRHR and should receive adequate attention in lobbying for the improved service delivery. Part of this work involves addressing attitudes of health workers and the broader community.
  7. CSO and CBO need to consistently and clearly document activities, particularly work with LACs, and findings of investigations related to SRHR in order to build an evidence base

### **Sexual and gender minorities/LGBTI**

1. Advocacy is needed for national guidelines for health workers on the treatment of sexual minorities
2. Training of health workers should include a broad range of the spectrum of sexualities and sexual activities.
3. There is a need for the development of effective systems of accountability, regarding service delivery and patient care, either through complaints mechanisms, performance management or/and disciplinary processes. This may be facilitated by having a 'supporter' or 'advocate' in health settings, as proposed by research on sex work.
4. Interventions need to recognise the complexity of needs that gender and sexual non-conforming people have, including the need for economic empowerment initiatives to be woven into alternative health care programs, advocacy and training initiatives.
5. Programmes targeting most at-risk or key populations should be aware that narrowing the focus of interventions (e.g. to be MSM-specific) may leave out certain people. Lesbian and bisexual women and transgender persons are frequently left out of interventions.
6. Civil Society interventions aimed at empowering LGBTI persons, should focus on encouraging safe, supportive friendship circles
7. Interventions to deal with the marginalisation of sexual and gender minorities in primary healthcare setting should involve community outreach and engagement with various stakeholders and groups, such as community members, schools, FBOs, CBOs
  - a. Alternative public discourses and representations of LGBTI individuals, couples and families are needed to counter pervasive heterosexism
  - b. violence prevention programmes must be geared to the needs of LGBTI
8. Interventions should consider the distrust and fear that many sexual and gender non-conforming people have of public health facilities and involve outreach programmes that take cognisance of the needs of LGBTI persons (e.g., around contraception). Mobile clinics such as those used by the *Anova* Institute and SWEAT are an example of such an intervention.

9. Appropriately trained Community Health Workers could work with civil society groups that support LGBTI rights in order to reach LGBTI persons who are unwilling or unable to attend facilities with information about where and how to access appropriate services.
10. Effective 'gay friendly' clinics and health services should be emulated where possible. Best practices and lessons need to be collected from these organisations.
11. Possible partnerships between state facilities and gay friendly clinics could be established so that staff members who are unsure how to deal with specific issues (or unwilling to do so) can make referrals.

### **Suggestions for future Research**

1. Address gaps between policy intent and the application of policy in the sector by conducting an audit for efficiency, gaps and improvements
2. Further research and an improved evidence base is required to have a full picture of systemic failures in the health sector and knowledge, attitudes, perceptions and experiences of LGBTI people in accessing quality health care in the country,
3. Further research is required into the attitudes, perceptions and experiences of healthcare workers towards LGBTI persons
4. Further research is needed on LGBTI-specific SRH services. Research should document best practices and lessons from these organisations, and the ways that these can be connected with public health services.

## CHAPTER 1: INTRODUCTION

### 1.1. PURPOSE AND BACKGROUND

Sexual and reproductive health (SRH) is “manifest in the extent to which people feel comfortable about their sexuality and gender identity and are able to make decisions about their sexual and reproductive lives, including if, when, and how to engage in sexual relationships and if, when, and how to have children in a social, cultural, and interpersonal context free of coercion, discrimination, and violence” (Department of Health, 2011, p. x). Sexual and reproductive health rights have been noted as playing a fundamental role in the transformation of society, particularly for women. However, those who work in the field of sexual and reproductive health have noted that persistent inequities in health act as barriers to people’s ability to exercise their sexual and reproductive health rights. These inequalities are rooted in social conditions of vulnerability (e.g. poverty, migration, and social exclusion); institutions (e.g. schools); and behaviours (e.g. sexual violence or coercion) (World Health Organisation (WHO), 2010a, p. 8).

The *AIDS Foundation of South Africa (AFSA)* has initiated a three-year programme (2014-2017) to advance the realisation of Sexual and Reproductive Health Rights (SRHR) in South Africa. In particular it is intended to strengthen SRHR and community-based HIV/AIDS interventions, and to build the evidence base for effective regional responses. The programme is designed to deliver: (1) Strategic support for community-based organisations (CBOs) and national advocacy/policy actors engaged in effective HIV/AIDS and SRHR interventions; (2) Demonstrable improvements in the realisation of SRHR in South Africa; and (3) A measureable contribution to the knowledge and evidence base on HIV/AIDS in the Southern African region (Southern African Development Community).

The report provides some emerging evidence to inform the work of implementing partners and potentially to assess the outcomes and the mechanisms by which positive changes resulting from the implementation of AFSA’s programme have been achieved. The study focuses on (1) the public health sector and on (2) the effects of systemic failures on the attitudes and practices of LGBTI people. The information and lessons from this baseline should be used to improve government and civil society interventions and form the basis for policy and research development.

This introductory chapter provides a contextual backdrop, locating the study within the socio-political context in which sexual and reproductive health unfolds, first, briefly, from a global and continental perspective and then honing in on South Africa. The discussion of the South African context considers the history and reform of the public health system, driven largely by the agenda of socio-political transformation, and how this has shaped sexual and reproductive health services. Throughout this discussion it is stressed how the inequitable distribution of resources has played a key role in health system reform. Also provided in this chapter is the objective and research questions that drove the study and, finally, an overview of the rest of the report.

## **1.2. CONTEXTUAL BACKGROUND**

### **1.2.1. Health systems and SRH**

A health system comprises organisations, people, and actions primarily focussed on promoting, restoring or maintaining health (World Health Organisation, 2010a). This includes both direct health-improving activities as well as work to influence the determinants of health, including its social determinants (e.g. poverty, violence, social exclusion, stigma etc.). The core functions of health systems are usefully outlined by the World Health Organisation (WHO, 2010a), and these include:

1. Efficient, effective, and accessible health services
2. Availability of sufficient well-trained staff
3. Health information systems that generate useful data on health determinants and health system performance
4. Equitable access to medicines, vaccines, and medical technologies
5. Adequate funds for health raised by health financing systems
6. Effective oversight, regulation, and accountability by leadership

Globally, health systems have undergone significant changes to in order to promote health rights, including sexual and reproductive health rights<sup>1</sup>. The pandemic of Human Immunodeficiency Virus (HIV) has played a pivotal role in the transformation process by drawing attention to the social and cultural dimensions of sexual and reproductive health (Corona, Coleman, & Mazin, 2002). In recent years, there have been global advances in the development of policies, guidelines, legislation, contraceptive technologies, medication for sexual dysfunction and other reproductive health services (Corona et al., 2002; Ramkisson et al., 2010).

In contrast to the global trend, Africa has made slower progress toward addressing sexual and reproductive health issues (WHO, 2013). The SADC Social Protection protocol has made a number of advances in providing an overview and some comparison between health services in member countries (Nyenti & Mpedi, 2012). These authors argue that the public health systems in SADC member states play a crucial role in the testing and treatment of HIV/AIDS, particularly when it comes to the dispensing of free antiretroviral (ARV) therapy to medically eligible individuals. Access to the life-saving ARVs, which should be treated as essential healthcare in the light of the HIV/AIDS scourge in most SADC countries, is improving. Considerable progress has been noted with regard to HIV, AIDS and other STIs in the SADC region when evaluated against the targets of MDGs 6A and 6B (SADC, 2012). Nyenti and Mpedi (2012, p. 264) identify some of the successes of the health systems as evidenced by UNAIDS. In Botswana, Namibia, South Africa and Swaziland, coverage of antiretrovirals for preventing transmission of HIV in utero reached more than 80%.

This progress is however is not at the same level in all the countries from this region (SADC, 2012). Despite several initiatives, African countries' scaling up has not been far reaching enough to change the status quo (WHO, 2013). Increased levels of HIV infection, particularly among women for instance is a major problem. According to Van Rensburg (2009), "National HIV prevalence rates exceed 15% in eight SADC countries (Botswana, Lesotho, Mozambique, Namibia, South Africa,

Swaziland, Zambia and Zimbabwe)” (p.1132). Furthermore Van Rensburg (2009) identifies that, “More than 30% of the households had a member who was ill for more than three months and more than 10% of the households lost a member after an illness of three months in the past 12 months” (p.1135).

Access to healthcare remains a challenge for many people on the continent. There are still challenges that remain in people getting access to health services and this is most apparent in Malawi and Zimbabwe, but also problematic in Mozambique, Namibia, and Zambia (SADC, 2012). Recent statistics published by the World Health Organisation (2013) show that in most African countries less than half of the population has access to health services. In general, those living in urban areas have more reliable and consistent access to healthcare. For example, rural residents’ access to health services varied from 3% to 75% as opposed to 45% to 97% for urban residents. Access to healthcare also varied in terms of wealth, ranging from 1% for the lowest (poor) quintile to 98% for the highest (rich) quintiles. There is a persistent concern that the lack of National Health Insurance systems is a huge barrier for quality and accessible health care in a majority of SADC countries (Nyenti & Mpedi, 2012). This is a concern in South Africa too; although attention is being given to addressing this (see chapter 5).

Improved access to primary health care for pregnant women and their children marks one of the significant successes of SADC member states. Nevertheless, maternal mortality in most countries remains a problem and in countries like Namibia there has actually increased. Antenatal care has been available for decades in most countries, but has not been fully made use of. (See chapter 5 for a discussion on antenatal care in South Africa). Another related concern is access to contraception and family planning. The popularity or acceptance of contraceptive from the SADC countries increased during the 1990s and 2000s, but there is still an unmet need for family planning in all of them (SADC, 2012).

Other issues impacting on African health systems are poverty and its implications for access to and provision of health, teenage fertility rates, early and forced marriage, female genital cutting, insufficient skilled health workers, as well as inadequate infrastructure, equipment, medicines and technologies, all of which have made activism for sexual and reproductive rights a complex endeavour in many African countries (Essack & Strode, 2012; WHO, 2013).

In comparison to the rest of the region, South Africa is the most developed economy and also has progressive legislation, for example legalised abortion and civil rights for lesbians, gay men, and other sexual and gender minorities. The country fares well in comparison in some areas (like maternal mortality and contraceptive uptake) and poorer in others (like access to antenatal care) (Sheimekka et al., 2009). The following sections take a closer look at the South African context in terms of the overall health system and how sexual and reproductive health services form a part of the system.

### **1.2.2. Reformation of health systems in South Africa**

The Health System in South Africa has also undergone significant change, particularly in the last two decades, since the beginning of the new democratic regime. Prior to this the health system “was

highly fragmented” (DoH, 2011, p. 13). In the apartheid state, access to services was determined mainly by geographical location, socioeconomic status, and, one’s designated racial categorisation (DoH, 2011; London, 2004). Rejecting proposals made in the 1940s for a needs-based National Health Service, the Nationalist Party implemented several changes on assuming power that have contributed to the current shape of health services. During the 1980s, health services were not only separated along racial lines, but the health sector was deregulated and privatised. This translated into massive barriers to access, especially for those classified as Black, and ultimately to poor health outcomes, despite high government spending on health (Buissman & García-Gómez, 2015).

The task for the new democratically elected government in 1994 was to provide redress for the inequities created during apartheid. The government proceeded to initiate pro-equity policies to enhance all citizens’ health status, removing obstacles to accessing public healthcare services for poor citizens (Buissman & García-Gómez, 2015). Health services were consolidated into one South African healthcare system with a unified National Department of Health. A key piece of legislation in the reconstruction of the health system is the 1994 National Plan for Health in South Africa (NPHSA). This plan was underpinned by the principle of achieving “social and economic justice” in health (Heywood, 2014). In line with this vision, the aim was to create a healthcare system based on the primary healthcare approach, with health seen as a fundamental human right for all (DoH, 2011).

The new structure of the health system was outlined in the *White Paper on the Transformation of the Public Health System* in 1997, which specified the following health sector strategies.

- The health sector must play its part in promoting equity by developing a single, unified health system.
- The health system will focus on districts as the major locus of implementation, and emphasise the primary health care (PHC) approach.
- The three spheres of government, NGOs and the private sector will unite in the promotion of common goals.
- The national, provincial and district levels will play distinct and complementary roles.
- An integrated package of essential PHC services will be available to the entire population at the first point of contact.

The intention was to transform the health system into an integrated, comprehensive, national service accessible to all citizens (Cooper et al., 2004; Coovadia et al., 2009; London, 2004). Today our “public healthcare system consists of basic primary healthcare provided in district hospitals and community health centres, which are mainly nurse-driven services in clinics. On the other hand, the private healthcare system includes private hospitals and general practitioners mostly funded by medical schemes. The private sector provides highly specialised hi-tech healthcare services” (Buissman & García-Gómez, 2015). Following the District Health Services model of the overall health system, sexual and reproductive health rights services are now implemented at the district level, with provincial oversight.

The progressive realisation of the right to health, including sexual and reproductive health, is enshrined in the South African constitution. Moreover, several new pieces of legislation served to

transform the healthcare system into an integrated, comprehensive national service intended to ensure access to all citizens, which had been restricted by apartheid laws (Coovadia et al., 2009; London, 2004).

### **1.2.3. Transformation and re-orientation of sexual and reproductive health services**

During apartheid, racialised population politics also governed services that dealt with sex and reproduction. These services were approached from a family planning perspective, which preceded the now-dominant reproductive health framework. This perspective was informed by demography and focused largely on population control (Morison & Macleod, 2015). Programmes were chiefly aimed at married, heterosexual women and were deeply entwined with the apartheid agenda, with the aim of increasing White population numbers and decreasing Black population numbers (London, 2004; Stevens, 2008).

During the early years of democracy, there were broad reforms in addressing equity issues and women's health (Stevens, 2008). A key part of the transition was the move to a rights-based approach, with the acknowledgement of women's rights as human rights, that ushered in the paradigm within which services are now framed, viz., the sexual and reproductive health and rights approach (Stevens, 2008). This approach was officially brought into the mainstream by the 1994 International Conference on Population and Development (ICPD) (Mundigo, 2000) and was clearly evident in the initial policy statement around sexual and reproductive health in South Africa: the Health Care section of the African National Congress's Reconstruction and Development Programme (cited in Macleod & Tracey, 2009). This stated that:

One important aspect of people being able to take control of their lives is their capacity to control their own fertility. The government must ensure that appropriate information and services are available to enable all people to do this. Reproductive rights must be guaranteed and reproductive health services must promote people's right to privacy and dignity. Every woman must have the right to choose whether or not to have an early termination of pregnancy according to her own individual beliefs. Reproductive rights must include education, counselling and confidentiality.

Thus, the initial policy statement around sexual and reproductive health in South Africa is underwritten by a human rights perspective, upon which subsequent policy has been based (Macleod & Tracey, 2009). Since the advent of democracy, a raft of laws, policies, and guidelines have been developed around sexual and reproductive health. This new approach can be seen in subsequent policies and legislation, notably in section 27(1a) of the South African Constitution which promises all "the right to have access to health care services, including reproductive health care".

### **1.2.4. South African SRH laws, policies, and guidelines**

In line with the rights-based approach outlined above South Africa's laws, policies, and guidelines for sexual and reproductive health transformed in accord with the general legal framework. Before 1994, South Africa had no comprehensive sexual and reproductive health policies and the emergence of HIV/AIDS was essentially ignored by the government of the time (Stevens, 2008).

Now, in contrast, the country is not only one of the few that offers formal legal protection of sexual and reproductive rights (Ramkissoon, Searle, Burns, & Beksinska, 2010), but its sexual and reproductive health policies and laws are said to be “among the most progressive and comprehensive in the world in terms of the recognition that they give to human rights, including sexual and reproductive rights” (Cooper et al, 2004, p. 70). Crucially, this legislation acknowledges the absolute centrality of SRHR to women’s equality and, accordingly, takes a comprehensive view of sexual and reproductive health as encompassing more than contraceptive and maternal services, including abortion on demand under certain legislated conditions (Klugman, 2007; Macleod & Tracey, 2010). In addition to women, the rights of various other marginalised groups are recognised, including LGBTI persons.

In the rest of the African region, most policies contain the rhetoric of equity and inclusion, but do not specify mechanisms for ensuring this in practice. In South Africa the participation of civil society, including gender and health activists, has been key to the development of laws grounded in a rights-based perspective, and the monitoring of their implementation (London, 2004; Stevens, 2008). (A list (taken from DoH (2011) and updated) of these SRH laws, policies, and guidelines appears in Table 1.)

Current policies and legislation acknowledge the absolute centrality of sexual and reproductive health rights to women’s equality and, accordingly, takes a comprehensive view of sexual and reproductive health as encompassing more than contraceptive and maternal services, including abortion on demand under certain legislated conditions (Klugman, 2007; Macleod & Tracey, 2010). In addition to women, the rights of various other marginalised groups are recognised, including those of gender and sexual minorities.

However, as Ramkissoon and colleagues (2010) note, “While South Africa has many good policies and guidelines, the main challenge lies in the effective implementation of these” (p. 34). The authors maintain that policy implementation is impeded by “political actors, financial and human resources and health system factors” (p. 35). Poor policy implementation is not unique to the health department but is a problem across government clusters that include sectors such as social development, justice and corrections, and so forth. These factors are reviewed in the following section, in which challenges to health system functioning and their impact on SRH services are discussed. Before proceeding to this discussion, it is worth noting some further critiques of South African SRH policies. (See Appendix 10 for regional laws and policies.) Klugman et al. (2007) identify two shortcomings in their extensive review. The first is the lack of attention to diversity of sexual and reproductive health needs across three different areas: failure to attend to sexual function across the life cycle (e.g., during menopause); inadequate recognition of the role that interpersonal violence plays in sexual and reproductive health; and superficial attention to sexual and gender identity in relation to sexual and reproductive health. The second shortcoming identified is the failure to keep policies and laws aligned with emerging evidence and good practice, particularly in relation to HIV (DoH, 2011), where, for example, there has been increasing medical and public evidence and interest in medical circumcision as a preventative HIV strategy.

Further criticisms of policy include the lack of integration, which leads to duplication, contradiction, and poor implementation, as well as the failure to uniformly apply a rights-based lens across policies (DoH, 2011; Stevens, 2008). (This issue is discussed further in Chapter 5 in relation to the structure of SRH services in the overall district health system.) Finally, existing policy is critiqued for insufficient attention to gender as an equity issue. Although policy tends to centre on heterosexual women (and children), this tends to be an instrumentalist approach, and women's rights are not treated with the same fervour as other equity issues, particularly in relation to HIV (Stevens, 2008). Thus, despite the progressive legislation and promising shifts discussed above, the provision and accessibility of *quality* SRH services remains problematic.

**Table 1: South African sexual and reproductive health laws, policies, and guidelines**

<b>Laws/ Legal Acts</b>	<ul style="list-style-type: none"> <li>– Sterilisation Act 44 (1988); Sterilisation Amendment Act 3 (2005)</li> <li>– Choice on Termination of Pregnancy Act 92 (1996); Amendment Acts (2004, 2008)</li> <li>– Domestic Violence Act 116 (1998)</li> <li>– Promotion of Equality and Prevention of Unfair Discrimination Act 4 (2000), Amended: Judicial Matters Amendment Act 22 Section 16(2005)</li> <li>– National Health Act 61 (2003) – Amended to National health amendment Act 12 (2013).</li> <li>– Alteration of Sex Description and Sex Status Act 49 (2003)</li> <li>– Criminal Law (Sexual Offences and Related Matters) Amendment Act 23 (2007); National Directives and Instructions on Conducting a Forensic Examination on Survivors of Sexual Offence cases in terms of Act 23 (2007); Government Notice 223, 6 March 2009</li> </ul>
<b>Policies</b>	<ul style="list-style-type: none"> <li>– African Charter on Human and People's Rights</li> <li>– Protocol to the African Charter on the Rights of Women</li> <li>– White Paper of Population Policy 1998</li> <li>– A Comprehensive Primary Health Care Package for South Africa (2001); Core Package for Four Levels of Care: A Discussion Document (2007)</li> <li>– National Contraception Policy: Guidelines within a Reproductive Health Framework (2001) à revision</li> <li>– A Policy on Quality in Health Care for South Africa (2007)</li> <li>– National Youth Policy 2008 – 2013 – amended to National Youth Policy 2009-2014</li> <li>– National Service Delivery Agreement for Outcome 2: A Long and Healthy Life for All South Africans (October 2010)</li> <li>– HIV/AIDS and STI Strategic Plan for South Africa 2007 – 2011 (2007) – Amended to National Strategic Plan for HIV, STIs and TB, 2012-2016.</li> <li>– National Policy on Rape, Sexual Assault and Other Related Sexual Crimes 2010 draft, drawing on National Sexual Assault Policy 2005)</li> </ul>
<b>Guidelines</b>	<ul style="list-style-type: none"> <li>– National Guidelines for Cervical Screening Programme (2000) -the update to the SA HPV Advisory Board 2010 guidelines</li> <li>– Policy Guidelines for Youth and Adolescent Health (2001) – amended to National Adolescent and youth health policy (2012)</li> <li>– Gender Guidelines for Public Health (2002)</li> <li>– The School Health Policy and Implementation Guidelines (2003)</li> <li>– National Contraceptive Service Delivery Guidelines within a Reproductive Health Framework (2003)- amended to the National Contraception and Fertility Planning Policy and Service Delivery Guidelines (DOH 2012) and its companion, the National Contraception Clinical</li> </ul>

Guidelines (DOH 2012)

- National Strategic Plan for the implementation of the Choice on Termination of Pregnancy Act (2004)
- Draft National Policy for Conscientious Objection in the Implementation of the Choice on Termination of Pregnancy Act of 1996 (2007)
- Guidelines for Maternity Care in South Africa: A Manual for Community Health Centres and District Hospitals (2007)
- Saving Mothers: Essential Steps in the Management of common Conditions Associated with Maternal Mortality (2007)
- First Line Comprehensive Management and Control of Sexually Transmitted Infection According to the Essential Drug List (2008)
- Policy Guidelines: Child and Adolescent Mental Health (2008)
- Primary Health Care Supervision Manual: A Guide to Primary Health Care Facility Supervision (2009)
- Clinical Guidelines: Prevention of Mother-to-Child Transmission (2010)
- Clinical Guidelines for the Management of HIV/AIDS in Adults and Adolescents (2010)
- Guidelines for the Management of HIV in Children (2010)
- National HIV Counselling and Testing Policy Guidelines (2010)
- Guidelines for Tuberculosis Preventative Therapy among HIV infected individuals in South Africa (2010)

Despite this legislative framework that promises access to SRH rights and services, there are several significant factors that prevent many South Africans from accessing these. These barriers include: poverty, gender inequity and other sources of prejudice, notably homophobia, violence, lack of stewardship and poor management of district health systems, and lack of information for planning, monitoring, and decision-making (Department of Health, 2011).

In line with this approach, the South African Department of Health's stated aim is empowering people to make informed choices about pregnancy, sex, and childbearing. We have thus witnessed the roll out of free condoms in public facilities and the passing of progressive legislation like the Choice on Termination of Pregnancy (CTOP) Act of 1996, which legalises abortion on request up to 12 weeks and thereafter under specified conditions. The current focus is congruent with international policy and is on making available reliable information for decision-making (Morison & Macleod, 2015).

More recently, however, there have been some questions around the rights-based approach, suggesting that perhaps it needs to be extended. The first question concerns the language of rights in the health sector and whether this coheres with the articulation in the constitution. The notion of rights needs to be interpreted more broadly than simply anti-discrimination, but also to include socio-economic entitlements (London, 2004). The second question is related to the individualistic focus of rights language, and often the emphasis on choice in relation to SRH rights. The Rights paradigm often does not take sufficient cognisance of the real life contextual barriers (such as poverty, stigma, or gender norms) that prevent people from *exercising* their rights and *acting* on choices (Morison, 2013b). In dealing with SRHR, it is imperative to acknowledge "the dimensions of sexuality and reproduction that are inscribed into the broader

organisation of social and economic life” (Klugman, 2007, p. 88). Thus, it has been suggested that the notion of Rights be paired with that of Sexual and Reproductive Justice. Such a conceptual approach, which is taken in this research, allows researchers to consider how peoples’ SRH experiences and needs are shaped by their social/ socioeconomic/ historical circumstances, in order to better understand and make sense of the obstacles and challenges that they face in exercising their sexual and reproductive health rights (Gillam, Neustadt, & Gordon, 2009; Smith 2005; Cook & Dickens, 2009).

#### **1.2.5. The present day situation: Service delivery and access to healthcare**

The preceding discussion shows that the process of health reform has occurred within the context of socio-political transformation and what remains a profoundly unequal society. It is largely owing to our socio-historical context, the South African situation is marked by large health inequalities. These inequalities cohere around socio-economic status, which often correspond with racial categorisation, and are also related to gender and geographical location.

A major source of inequity, which remains, is evident in the bifurcation of the health system into the private and public healthcare sectors. The latter is the most under-resourced, yet intended to serve the majority (around two thirds of the population) who cannot afford private care (including private health insurance) (Benatar, 2013; Coovadia et al., 2009; Morison, 2013). The proposed National Health Insurance scheme, which is currently being piloted, is seen as a necessary solution to accessing adequate care (Benatar, 2013).

Healthcare in the public health sector is generally sub-optimal. “There are substantial inequities across the country in both the availability and the quality of services” (Department of Health, 2011, p. 11). The public health system suffers from a range of issues related to the lack of adequate resources and human resource capacity (Coovadia, et al., 2009; Stevens 2008), that have been well-documented both by academics and those in civil society (Harrison, 2009). (These issues are taken up in chapter 2 in the review of literature, as well as in chapter 5 which focuses on 2 specific geographic areas, viz., Eastern Cape and Mpumalanga.) Thus, despite the promise of progressive legislation and policies, “an extensive and depressing academic literature records the missed opportunities for health transformation. Instead of charting the rise of a Primary Care system, the renewal and equitable distribution of a health workforce, the literature records its demise” (Heywood, 2014, p. 5). The Health Minister himself is cited (in Department of Health, 2011, p. 11) as saying that: “We need to urgently re-engineer our health system” because it is “unsustainable”, “destructive”, “costly”, and does not emphasise preventative care (Health Minister Aaron Motsoaledi, 24 May 2011).

Although the policy framework discussed above is progressive, its implementation has been thwarted by “failures in leadership and stewardship and weak management” (Coovadia et al., 2009, p. 817). According to Coovadia and colleagues (2009), the general failure of the public healthcare system, is fundamentally linked to poor governance and management. This is confirmed in Harrison’s (2009) review of the literature, in which among the greatest challenges identified are:

- (1) the allocation of resources, including the distribution of financing and spending and availability of personnel; and

- (2) systems management, including quality of care, operational efficiency, devolution of authority, health worker morale, and effective leadership.

In terms of the provision of quality SRH services in particular, access to healthcare in general has improved to some extent, but remains compromised by factors similar to those that prevented access during apartheid, viz., geographical location and socio-economic status (which still maps onto apartheid-generated racial designations). For instance, most of those covered by medical aids are classified as 'White', followed by those categorised as 'Indian/Asian', then 'Coloured' and lastly, those classified as 'Black African' (Statistics South Africa (StatsSA), 2011). (See info-graphic above)

Access to SRH is diminished not only by physical issues, such as service delivery failure or lack of transport and facilities for people living in rural areas (Eagar, 2014), but also due to inter-related socio-cultural factors (see info-graphic above). This includes societal attitudes and power inequalities. Despite our progressive legislative framework that promises access to SRH rights and services, there are several significant barriers that prevent many South Africans from realising their sexual and reproductive health rights.

### **1.3. OBJECTIVES AND RESEARCH QUESTIONS**

The study provides a preliminary evidence-base in relation to two focal areas. The first is SRHR service delivery and systems failure in the public sector. In order to address this focal area a desk review was conducted. The second focal area was the effects of systemic failures, and attitudes and practices of healthcare workers on the SRHR of sexual minorities (LGBTI). This aspect of the research was explored through analysing people from sexual minority groups' personal narratives in accessing health care systems. Each component was guided by the following research questions.

#### ***Service delivery and systems failure in the public health sector***

1. What are the local system failures in the promotion and protection of SRHR (in the context of national provision)?
2. What is the state of SRHR in the target communities in which the programme will be implemented?
3. What are the barriers (including socio-cultural) to the realisation of SRHR by the target communities?
4. To what extent does civil society participate in health governance structures at local level?

#### ***Sexual identity (LGBTI)***

1. What are the layers of social discrimination that affect your everyday living?
2. How is this discrimination experienced? How does it affect you? And how do you deal with it?
3. In which social situations do you feel the most discrimination? Among family, community, and/or when accessing state services (health, police, and justice)? Explain.
4. How can discrimination and social stigma be dealt with by government, the community, researchers and social justice advocates?

5. Are there ways of integrating sexuality rights and protection into mainstream health systems or are separate facilities a safer option? Explain.

#### **1.4. STRUCTURE OF THE REPORT**

The remainder of the report comprises 6 chapters. **Chapter 2** offers a review of the critical literature (namely scientific, policy and “grey”) which provides the conceptual framework for the study, and considers in broad terms the main themes, issues, trends and gaps relevant to understanding and strengthening sexual and reproductive health rights in South Africa. **Chapter 3** outlines the approach and methods used in developing the research, including the development of the research instruments and the collection of data. It also identifies some limitations. **Chapter 4** summarises findings of the qualitative data (notably focused on key informant interviews and in-depth discussions) and presents these in terms of the broader themes that emerged. **Chapter 5** provides a discussion of insights from a desk review of secondary data focusing on system failures and SRHR barriers, reporting on the results and analysing their meaning. **Chapter 6** extrapolates and discusses a set of recommendations drawn from the literature review, in conjunction with the qualitative and quantitative findings.

## CHAPTER 2: LITERATURE REVIEW

Sexual and reproductive health and rights depend on good service delivery in the larger health system. However, as discussed in the preceding chapter, health systems themselves are embedded in larger socioeconomic and historical contexts, which in the South African case means that they function, or are expected to function within the context of structural divides including a rural-urban divide, a public-private health sector divide and enduring racial and economic divides. There remain substantial disparities across the country in terms of availability, accessibility, and quality of health services which are embedded in this highly unequal context. Poor functioning of the overall system compromises people's ability to exercise their rights in relation to sexuality and reproduction (DoH, 2011), which means we need to grasp a picture of the overall system within which SRH rights are being struggled for. This chapter begins with a review of the literature concerned with the functioning of the overall system is examined and the implications that this has for sexual and reproductive health services are discussed. The focus here is on systemic and structural issues that impact on people's ability to exercise their sexual and reproductive rights. Thereafter, the literature dealing with the socio-cultural factors that shape SRHR is reviewed.

### 2.1. HEALTH SYSTEM CHALLENGES

There is a relatively large body of literature documenting the reform of the healthcare system and associated challenges, as well as a large number of reviews and evaluations that track system functioning. The general consensus is that although several gains may have been made in the early days of democracy (e.g. free universal access; policy development; establishment of district health system) many of these gains have unfortunately been lost in recent years (Harrison, 2009; Rispel, Moorman, & Munyewende, 2014). According to Heywood (2014) "an extensive and depressing academic literature records the missed opportunities for health transformation. Instead of charting the rise of a Primary Care system, the renewal and equitable distribution of a health workforce, the literature records its demise" (p. 5). Indeed Health Minister, Motsoaledi (cited in Department of Health, 2011, p. 11) contends that our health system is "unsustainable", "destructive", "costly" and in need of re-engineering.

One significant reason for the poor functioning of the health system is the disease burden, particularly related to HIV/AIDS. Nevertheless, a number of recent reviews conclude that even with the disease burden "healthcare outcomes should be better" (DoH, 2011, p. 16). Likewise, for the relatively high spending on health in South Africa one would expect to see better outcomes. Several evaluations and investigations point to the fundamental role of poor governance and management in the poor functioning of the health system (e.g., Coovadia et al., 2009; Harrison, 2009; Mayosi et al., 2009), and more generally to issues related to human resources for health (e.g. Coovadia, et al., 2009; Stevens 2008; van Rensberg, 2014). Poor governance and management have led to problems with the allocation of resources, including the distribution of financing and spending, and,

ultimately, to generally poor quality of care (Harrison, 2009). Thus, the goal of providing equitable health care has not yet been achieved.

### **2.1.1. The role of historical antecedents and the public-private divide in system functioning**

The poor functioning of the health sector needs to be understood in relation to the broader historical and socio-political contexts and power relations (Ataguba & Alaba, 2012), which were discussed in the preceding chapter. These have led to structural challenges—evidenced most clearly in the structuring of the health sector into parallel private and public systems—that health reformists have tried to overcome (Rispel et al., 2014). This divide plays a large role in the poor functioning of the health system, even with the reforms that have been put in place. In short, the public sector is under-resourced and over-used, while the private sector absorbs the majority of trained staff and resources (Buissman & García-Gómez, 2015). Access to the private sector is facilitated mainly through medical schemes, which allows a small proportion of South Africans access to good quality healthcare (StatsSA, 2011). The infographic below provides a good summary of the disparities in this regard.

The divided health system affects people's access to quality care (as discussed further below) and means that despite the pro-equity enacted since 1994, the system remains profoundly inequitable and retains many of the characteristics seen during apartheid, especially those that cohere around racial categorisation (Buissman & García-Gómez, 2015; Kon & Lackan, 2008; Myburgh, Solanki, Smith & Lalloo, 2005). An extensive literature documents these inequities and the causes (e.g. Ataguba & Alaba, 2012; Ataguba & McIntyre, 2013; Coovadia et al., 2009; Harries et al., 2009; Harrison, 2009; Mayosi et al., 2009; McClaren, Arlington, & Leibbrandt, 2014; van Rensburg, 2014). The implementation of a district health system was meant to rectify this and to improve access, but it has not functioned as it was intended to. Reasons for this include: the failure to devolve authority from provincial to district level, a lack of leadership, and low staff morale (Harrison, 2009).

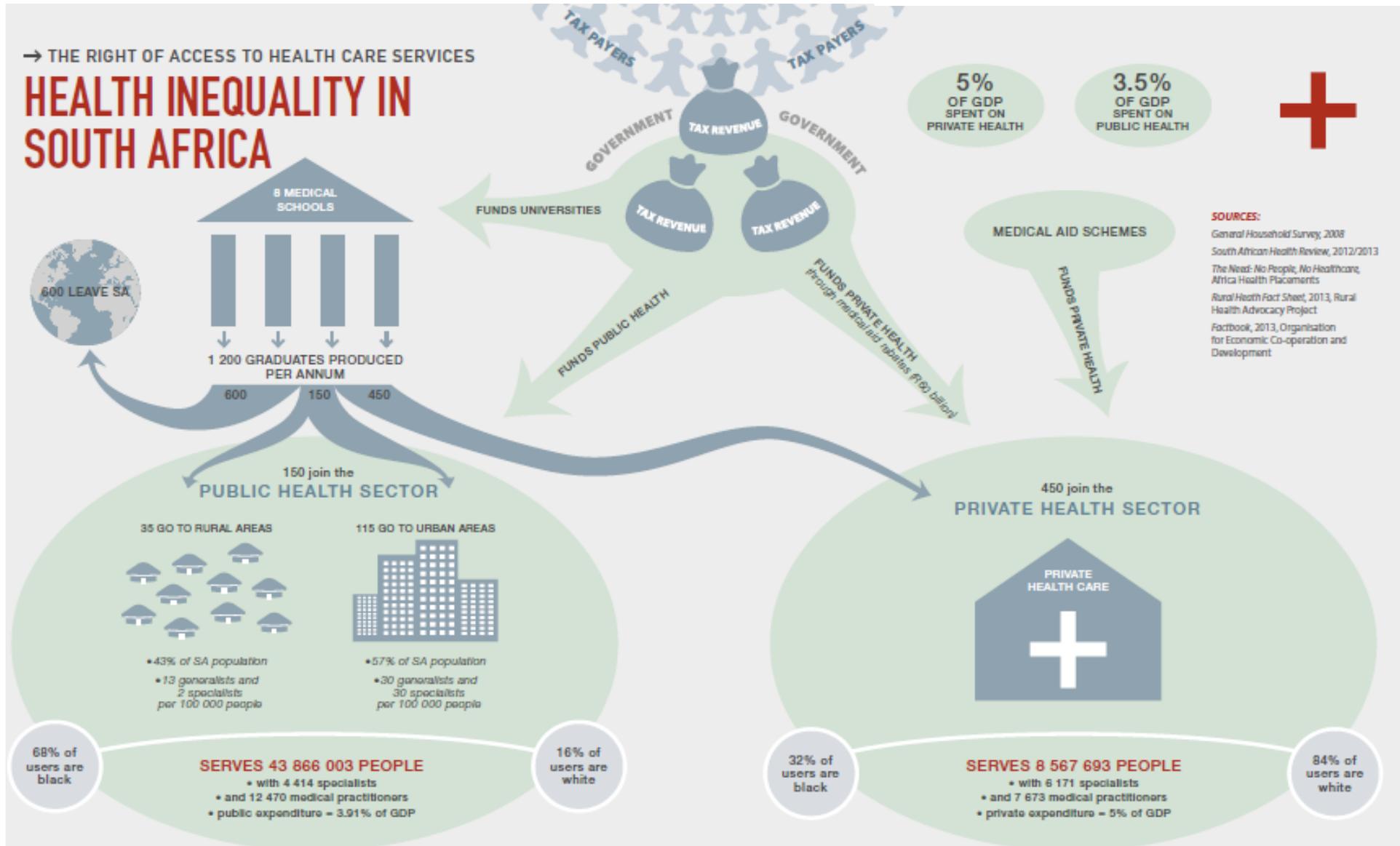
Poor governance and management have been fundamentally linked to the general failure of the public healthcare system (Coovadia et al., 2009). Several commentators (e.g. Harrison, 2009; van Rensburg, 2014; Buissman & García-Gómez, 2015) highlight poor leadership, stewardship and managerial capacity as a key problem in the public health sector. Extending from this issue are broader issues related to so-called 'human resources for health' (van Rensburg, 2014), including: the number and distribution of health workers across the system; skills deficits; preparation and fitness of the cadre of health workers (van Rensburg, 2014); poor morale (Harrison, 2009); and, relatedly, increased medical migration from public sector to private sector (Buissman & García-Gómez, 2015). These problems point to further issues of medical training and retention of staff in the public sector, often under adverse working conditions and for lesser remuneration (van Rensburg, 2014). The latter remains an ongoing challenge, particularly in rural and remote areas (Eagar, personal communication).

### **2.1.2. Inequalities and Access to healthcare**

The pervasive inequity in relation to health care service provision and the systemic issues discussed above create barriers to both utilisation and access (Buissman & García-Gómez, 2015). For care to be accessible, the state must provide “affordable, available and acceptable services [that are] responsive to patients’ needs and expectations” (Harris et al., 2014). Reviews of national surveys indicate a number of common barriers that act as access barriers, these include rural- urban location and distance to facilities; socio-economic status, insurance status, and racial categorisation (Harris et al., 2011; Kon & Lackan, 2008; Gilson & McIntyre, 2007a&b; McLaren et al., 2014). Patients commonly report long waiting times, unavailability of medications, and poor treatment from staff as problems with public health services, which may deter patients from going to these facilities and thus delay help-seeking or result in defaulting on medication (Hasumi & Jacobsen, 2014).

Several investigations show that the greatest barriers are encountered by “black Africans, poor, uninsured, and rural” citizens (Harris et al., 2011, p. S102). Researchers concluded, therefore, that “access barriers continue to inequitably affect many who experienced the dispossession and structural violence of apartheid - poor, black, rural and informal-urban communities - as well as newer marginalized groups, including refugees and migrants” (Harris et al., 2014, p. 2). Takahiro Hasumi and Kathryn Jacobsen’s recent work suggests “that differences in satisfaction with healthcare services in South Africa by racial/ethnic group and income level are due in large part to different rates of use of private providers” (Jacobsen & Hasumi, 2014, p. 172; see also: Hasumi & Jacobsen, 2014). They found that those who use private healthcare are more likely to be from higher income households, while those using public healthcare, which tends to suffer more problems, are more likely to be Black Africans and from lower income households (Jacobsen & Hasumi, 2014). This finding is also borne up by earlier research (e.g. CASE 1995 & 1999). Further evidence in relation to access barriers is provided by studies that explore health system users’ self-reports and lived experiences (e.g. Bogart et al., 2013; Harries et al., 2014; Myburgh et al., 2005) of the care they receive in terms of availability, acceptability and affordability of services.

The accessibility, affordability, and acceptability of services play a role in the degree to which people actually use services. This also has implications for adherence to medications and delayed health-seeking, which might mean, for example, that conditions become worse or antenatal care is not received. Most recently Harries and colleagues (2014) concluded that health worker’s treatment of patients also plays an important role and can help counteract access barriers. The researchers analysed patient and provider accounts of seeking and delivering care, they conclude that “Although many providers were sympathetic to patient barriers of poverty and difficult life circumstances, for patients, suffering was more than adverse socio-economic conditions. It was exacerbated by uncaring, hostile or dismissive providers and certain health system arrangements, which were often intended to curb defaulting, yet added to the risk of patients dropping out of the system (p. 47). Conversely, Harris et al., (2014) propose that “caring, respectful communication, individual acts of kindness, and institutional flexibility and leadership may mitigate key access barriers” (p. 35).



Further, the inequities discussed above may mean that those who actually need services most are unable to access them. For instance, Buissman and García-Gómez (2015) explored utilisation of in-patient services in relation to need for services and report that “The rich are more likely to use in-patient healthcare than the poor, given the same need” (p. 194). This confirms earlier findings (e.g., Ataguba & McIntyre, 2013; Gilson & McIntyre, 2007 a& b). Such findings suggest that financial barriers remain a major obstacle in accessing care, despite the removal of user fees for the most disadvantaged. Poverty is a significant social issue in South Africa, and acts as a pervasive barrier to social and individual access to general healthcare as well as SRH (Department of Health, 2011; Ramkisson et al., 2010). Poverty is experienced through social exclusion, and access to resources and capital.

Another key issue, which often goes hand-in-hand with poverty and deprivation, is that of rurality. More than 85% of the country’s landmass is made up of rural areas, with approximately 40% of the population residing there. While rural areas are economically important (to tourism, mining, and agriculture especially), Eagar (2014, p. 3) notes that they

...continue to suffer from the effects of historical neglect in terms of development and social investment. Rural communities remain the most impoverished in the country and have the least access to basic social and economic necessities. In terms of health, this means that rural communities in South Africa carry a disproportionate burden of disease and can expect to have significantly less access to care than their urban counterparts.

In the last twenty years, significant progress has been made toward improving the quality of healthcare services in rural areas. As a means to counter historically poor infrastructure, the government has electrified a number of rural facilities, given individuals access to potable water, and hired many extraordinary health personnel. The reality is, however, that many individuals in rural areas still struggle to receive access to good quality healthcare (Eagar, 2014).

A recent study on equity in health care access in South Africa indicated that the cost of transport was the most determinant factor in ascertaining if or when rural people accessed care (Harris et al., 2011). When rural clinics are unable to provide essential resources and services patients are forced to travel extra distances to an urban facility. Additional transportation costs (often hundreds of Rand) impacts on household income and often means that people refrain from accessing services they need; this in turn results in negative health outcomes like, unmet contraceptive needs, and sometimes even death (Eagar, 2014). The task of health care reform, therefore, is in “achieving equitable universal health coverage requires the provision of accessible, necessary services for the entire population without imposing an unaffordable burden on individuals or households” (Harris et al., 2011, p. S102).

## **2.2. BARRIERS TO THE REALISATION OF SEXUAL AND REPRODUCTIVE HEALTH & RIGHTS**

Similar problems plague the delivery of quality SRH services to those outlined above. As underlined throughout this review, “South Africa’s apartheid past still shapes health, service, and resource inequities. Racial, socio-economic, and rural-urban differentials in health outcomes, and between the public and private health sectors remain challenging” (Harries et al., 2009, p. S103). Klugman

and colleagues highlight several challenges in their recent extensive review conducted for the Department of Health. These challenges include:

...the impact of poor implementation of existing norms and standards on SRHR; the failure to use information for planning, monitoring, and improving service delivery; the lack of service integration and effective referral systems between levels of care; and the inadequate infrastructure and technology. In addition, both healthcare providers and clients complain of disrespect and abuse (Department of Health, 2011, p. 11)

A major impediment for delivering quality sexual and reproductive healthcare in particular is the fragmented and verticalised approach to services. This is a result of the lack of a centralised directorate responsible for developing sexual and reproductive health rights policies, norms, and standards. This has led to differing approaches and quality of services across provinces. In some provinces services are determined according to disease clusters (e.g. HIV, AIDS & TB; maternal, women's and child health etc.), and in others, according to broad functions. Another issue that is somewhat unique to SRH is the moral evaluations that cohere around matters related to sex and reproduction which then also act as barriers as they shape the attitudes and perceptions of service providers, community members and other role players in sexual and reproductive health (WHO, 2010a). This may include stigma associated with HIV/AIDS (Bogart et al., 2013); termination of pregnancy (Mbali & Mthembu, 2012; Trueman & Magwentshu, 2013); or negative attitudes to young peoples' sexuality or early pregnancy (Macleod & Tracey, 2009 & 2010; Wood & Jewkes, 2006). People with disabilities may also experience both physical and social barriers to care (Department of Health, 2011), while many LGBTI persons may also fail to access SRH care, due to homophobia (Muller, 2013 & 2014).

An extensive literature provides evidence that shows how social factors, which are beyond individual control, influence and contribute to inequalities in service use and ultimately to poor SRH outcomes. It is important to consider these in order to improve SRHR, especially among socially marginalised groups who are often most subject to stigma and discrimination (WHO, 2010a). Thus, at present SRH care is not oriented to meet the different needs of the diverse range of people who require these services, including "men, transgender people, people with disabilities, people living with HIV, adolescents and young people, women not of reproductive age, sex workers, or people with diverse sexual orientations, among others" (Department of Health, 2011). A number of socio-cultural barriers affect access to SRH, but given the primacy of gender and sexual identity in relation to sex and reproduction, inequities in these areas are key obstacles to realising SRHR (Department of Health, 2011). In the remainder of this chapter we consider, first, how gender inequities affect women's and men's access to services and, second, marginalisation within SRH in relation to sexual identities. Of course (as the findings in chapter 4 show), gender and sexuality do at times overlap, and also intersect with other social characteristics like age, relationships status, race and so forth.

In the following, we discuss the particular challenges that gender power differentials create for women, as well as the issue of involving men in sexual and reproductive health rights work in order to promote not only the realisation of health rights, but also contribute to a gender equitable context in which choices can be made and rights can be exercised.

### **2.2.1. Gender inequity and the realisation of SRHR**

Not only are women physiologically, anatomically and socially more susceptible to ill-health and disease, but it is difficult to separate women's health needs from their gendered identities and different positions of powerlessness. Women are more vulnerable to violence, which may compound sexual and reproductive health outcomes (due to forced or coerced sex or intimate partner violence, for example). Structural barriers may disadvantage women to a greater extent than men, for instance, women in rural areas are less likely to obtain care and women perform care roles within families. Moreover, discrimination in health systems remain embedded within institutional cultures at clinics and hospitals that reflect the broader gender norms of society. As a result, many women have trouble accessing SRH care, particularly those from stigmatised groups such as HIV-positive women, rape survivors, adolescent girls, young/unmarried mothers, and sex workers (de Bruyn, 2005; Department of Health, 2011).

There is much research to show that gendered norms and power disparities hamper women's right to determine their own choices regarding their sexual and reproductive health. De Bruyn (2005) reports that HIV-positive women are frequently denied access to treatment and care (specifically obstetrical and gynaecological care), experience breach of confidentiality, and face stigma and discrimination in health settings; for instance, being forced to participate in clinic-based Antiretroviral Therapy (ART) support groups as a precondition for treatment. These women also face stigma, and even violence, within their homes and the community, which may prevent them from disclosing their status and seeking treatment.

Similarly, health provider and community attitudes have been found to be a barrier to younger and/or unmarried women accessing SRH services. Research on young women's use of clinics suggest discrimination based on age; for example, young women in O'Reilly and Washington's (2012) study were told by health workers that they were too young to have sex and were denied access to contraceptives and sexual health education. They also experienced confidentiality breaches and longer waiting times. A lack of access to information on contraception, especially in rural areas, and late presentation at health facilities (during the second or third trimester) are also problems related to young women's SRH (Kanku & Mash, 2010). Very little is known about the experiences of young men, from a range of cultural and socio-economic backgrounds, in relation to teenage pregnancy (Swartz & Bhana, 2009).

Another group, which is heavily stigmatised and thus especially vulnerable in relation to SRH, is women who engage in commercial sex. Despite the high HIV prevalence among sex workers, limited research has been conducted among this population (Scorgi et al., 2013). Sex workers, Richter (2008) notes, constitute an 'invisible population' within the health system owing to the historical stigma attached to the 'sale of sexual services, the on-going criminalisation of sex work and the squalid conditions under which many work' (p. 327). What research has been done, has shown that sex workers are significantly marginalised by the health system (South African National AIDS Council, 2013) and encounter significant discrimination (Richter, 2009) and ill treatment from health workers (Nairne, 1999; Stadler & Delany, 2006).<sup>ii</sup>

Some sector responses to address the SRH of marginalised women include integrated services for HIV Positive women that include the options of counselling on gender and sexual violence (Muller and McGregor, 2013). In the Western Cape, an NGO, MOSAIC<sup>iii</sup> currently provides an integrated package of services to women that include SRH services as well as options for counselling and support on issues of gender and sexual violence. Mobile clinics that offer HIV testing, pregnancy tests, PAP smears, family planning advice and so forth to women engaged in sex work (Richter, 2008). Further research with sex workers identifies training of health providers and the provision of a 'supporter' or 'advocate' in health settings as ways of addressing the needs of sex workers in health care settings. These interventions could provide models for addressing the diverse health needs of other marginal populations, including sexual and gender minorities.

The examples from literature discussed above deal with women from stigmatised groups, but it is important to note that *all* women may face access barriers in the public health system at one time or another. Despite the turn to the reproductive rights paradigm (discussed in chapter 1), the system at present retains a very narrow focus and does not take the complexity of women's SRH needs into consideration, let alone those of other groups. In their recent extensive review conducted for the Department of Health Klugman and colleagues concluded that SRH care is at present not oriented to meet the different needs of the diverse range of people who require these services, including "men, transgender people, people with disabilities, people living with HIV, adolescents and young people, women not of reproductive age, sex workers, or people with diverse sexual orientations, among others" (Department of Health, 2011).

Current policy has focused on the importance of including men in SRH issues, in order to combat gender inequities, as well as extending services to men. This policy shift was catalysed by the 1994 International Conference on Population Development which emphasised the need for increased attention to men and "male responsibilities and participation" in sexual and reproductive health (Helzner, 1996). The ICPD's 20-year Programme of Action (cited in Alan Guttmacher Institute, 2003a) enjoined countries to

promote the full involvement of men in family life and the full integration of women in community life, to ensure equal female-male partnerships, and, in particular, to call attention to men's shared responsibility and to promote their active involvement in responsible parenthood, sexual and reproductive behaviour, including family planning; prenatal, maternal and child health; prevention of sexually transmitted diseases, including HIV; [and] prevention of unwanted and high-risk pregnancies (, p. 7).

It is clear that this mandate is underpinned by goals of social justice, notably female empowerment. The task then for those involved in SRH has been to find meaningful ways of including men that do not detract from the empowerment of women.

Originally, men were only included in research and programmes because of the effects that they had on *women's* sexual and reproductive health and were often simply seen as 'impregnators' and barriers to women's contraceptive use (Greene & Biddlecom, 2000). Currently, the inclusion of men in sexual and reproductive health programmes and research is not only generally considered to be integral to the social justice goal of gender equity, but it is also considered to be necessary to meeting other reproductive health goals, such as decreasing population growth rates and lowering

rates of sexually transmitted infection (STI) (especially HIV) (Helzner, 1996). The Men-as-Partners framework—widely used in South Africa—attempts to uphold the ICPD ideal of female empowerment. The Men-as-Partners framework aims to address and engage men as partners, both in the sense of being women’s partners as well as in partnering with women to meet sexual and reproductive health goals and the overarching objective of gender equity. (See Chitiga-Mabangu et al., (2014) for a review of some successful interventions using this framework.) In the section that follows we turn to a consideration of sexuality and the possible barriers that impede full realisation of SRHR.

### **2.2.2. Sexualities (LGBTI) and the realisation of SRHR**

The barriers that people from gender and sexual minority groups face in accessing SRH services are due both to indirect and direct prejudice. Indirect prejudice is manifest in the lack of attention given to the SRH needs of sexual minorities. The healthcare system, and particularly with regard to SRH, is structured in heteronormative ways that renders the needs of sexual minorities invisible within the health care systems (Muller, 2013). This is evident, for example, in the heteronormative focus of health policies (Coovadia et al., 2009; Muller, 2013). As a result, health services in general have largely been oriented toward heterosexual people and their needs (Rispel et al., 2011). Representatives from civil society argue that the near absence of national guidance in public health facilities severely cripples the care sexual and gender non-conforming persons receive in relation to specific health concern (Muller, 2014). For instance, Rispel and colleagues maintain that “current policies and public health programmes are largely unresponsive to the needs of MSM [Men who have Sex with Men]” (Rispel et al., 2011, p. S138). Another example is that of infectious disease education, including around HIV and other sexually transmitted infections. Researchers have noted that the heteronormative focus of guidelines means that health workers do not pay adequate attention to the necessary messages of prevention and treatment when dealing with sexual minorities (Muller, 2013; Muller, 2014; Rispel et al., 2011). As a result, inadequate information about HIV prevention is provided and an already marginalised group of people are potentially placed at greater risk (Muller, 2013). The invisibility of sexual minorities means that their health care needs are misrecognised and their constitutionally guaranteed rights go unprotected.

Another crucial issue that arises due to the heteronormative bias of the health system is the lack of training regarding the basic issues that are critical for providing adequate care to sexual and gender minorities. Researchers have therefore pointed to the need for medical training curricula to include the needs, and the rights of sexual minorities, as well as health prevention and promotion messages to include the needs of sexual and gender minorities. A lack of adequate training means that health workers lack relevant information, understanding, and knowledge to provide suitable care to people from sexual minority groups. In addition, they are not required to reflect on their own beliefs and attitudes toward sexual and gender minorities, or how to manage these (Muller, 2014). This is important, because discriminatory social attitudes and practices have been identified as a significant obstacle to obtaining SRH services for this group of people (Rispel et al., 2011).

Direct discrimination occurs in the healthcare system in the form of negative attitudes and intolerance of sexual or gender non-conformity. Several South African studies report discrimination on the basis of sexual identity in the public health sector (e.g. Graziano, 2004; Lane, Mogale, Struthers, McIntyre & Kegeles, 2008; McIntyre, 2010; Reddy, Sandfort, & Rispel 2009; Muller, 2013 & 2014; Rispel et al., 2011). Health workers have been reported to engage in discriminatory practices toward LGBTI individuals such as lack of care towards sexual minorities (Muller, 2014). For example, in a study in Johannesburg, patients who identify as lesbian reported being ridiculed and subjected to religious judgment. They were refused pyjamas, prohibited from sleeping in wards with other female patients, and their HIV status was disclosed without their consent (NAPWA, 2012).

Such experiences of stigma, discrimination, and negative health worker attitudes affects health service utilisation by people from this marginalised group (Rispel et al., 2011). The participants in Rispel and colleagues (2011) study, for instance, “were reluctant to use public sector healthcare services and to disclose their sexual orientation to health workers because of past negative experiences” (p. S147). Muller (2013) also argues that discriminatory behaviour by healthcare workers further exacerbates feelings of social isolation and exclusion that many sexual and gender non-conforming persons already experience. Many people from sexual minority groups turn instead to Non-Governmental Organisations to gain access to services, including *OUT LGBT well-being; Durban Lesbian & Gay Community and Health Centre; Gay and Lesbian Network (GLN); Triangle Project; Health4Men; Sex Workers Education & Advocacy Taskforce (SWEAT)*. Such NGOs have attempted to counter the gap in the public sector by providing support, guidance, advocacy and lobbying services, and establishing support groups for those living with HIV (NAPWA, 2012).

### **2.3. CONCLUSION**

South Africa has made some strides in overcoming structural divisions in health services and additionally developed policies particularly on sexual and reproductive health. However, the problems lie in the implementation, lack of integration and lack of uniformity in policies and policy application. Policy implementation is hampered by the continuing socio-economic divides between communities which impacts access to affordable and quality health care. This means that quality and access is distributed differently between two health care systems, the public and private. As indicated, the district health system is expected to provide better access to people but it has not been able to achieve this due to poor management and governance.

Socio-cultural barriers that still rest on ‘identity markers’ (such as race, ethnicity, gender, sexuality, and age) shape access to health care for sexual minorities (including LGBTI). These social –cultural barriers are restrictive and reinforce heteronormative paradigms within public health facilities. Furthermore, the social context of poverty is inescapable, and still shapes the quality of care, people, particularly Black African rural women will receive in public health facilities.

We explore the impact of systemic failures of the public health care system on LGBTI person further in Chapter 4. Before doing so, the methodological approach to this baseline study is outlined in the following chapter.

## **CHAPTER 3: METHODOLOGY**

This baseline study is an evaluative assessment that provides a picture of the public healthcare environment prior to the inception of the AFSA programme. It is intended to produce data from which implementing partners can draw when conducting their work as well as offering an evidence base for ascertaining the contribution that implementing partners have made to changes in relation to SRHR in target communities. This study adds to the research on the public healthcare system. It also builds on existing work by established civil society organisations. In particular, this study foregrounds the effects of systemic failures on LGBTI individuals and communities. Aggleton (2009) confers that “small-scale studies and operations research can be valuable in evaluating pilot programmes to reduce inequity across class and other inequalities, and to introduce real comprehensiveness of healthcare services for sexual minorities” (p11). A mixed-methods approach was envisaged for data collection. Initially this was planned as a qualitative study comprising of individual, in-depth interviews and survey. However, due to delays in gaining provincial DoH permission the survey was replaced by a desktop review. The specific data collection procedures for each of the focal areas are outlined below.

### **3.1. IN-DEPTH INTERVIEWS AND KEY INFORMANT INTERVIEWS**

We examined the effects of systemic failures on LGBTI persons by conducting qualitative interviews with LGBTI persons, recruited mainly through two implementing partners, GALA (Gay and Lesbian Memory in Action, Gauteng) and GLN (Gay and Lesbian Network, Kwa-Zulu Natal).

#### **3.1.1. Data collection**

The in-depth interview schedule explored participants experiences of discrimination both outside of and within the public health system, examining how they dealt with and responded to experiences of discrimination in the public health system. We conducted four key informant interviews that examined the experiences of practitioners and activists who have vast working knowledge of the public health care system. These key informants were referred to us by the implementing partners (GALA and the GLN) as they are identified as knowledgeable on the effects of systemic failures on LGBTI persons. The interview schedule focused on asking participants about the successes, challenges and gaps within the current health care system and explored options for redress.

The research questions were formulated, an in-depth individual interview schedule was developed (Appendix 6) to explore the participants’ broader experiences of social discrimination, and then particularise it in relation to the experiences of the public health care system. The key informant Interview schedule (Appendix 7) was developed based on the research questions, as well as defined specifically in relation to the (assumed) vast experience and knowledge of the public health care system of potential participants.

### 3.1.2. Participants

As indicated, the qualitative interviews for the section on effects of systemic failures on LGBTI persons were conducted with two organisations: GALA (five interviews), GLN (five interviews) and four interviews with key informants referred by implementing partners. (The institutional profiles of these organisations are presented as appendix X and appendix Y.) Interviews were held at the respective organisations’ offices. This ensured that there was further emotional and psycho-social support if needed. Ten participants who volunteered to take part self-identified primarily as lesbian and gay and came from Pietermaritzburg and Johannesburg, and most lived in informal settlements. Two of the participants identified as refugees, who came to South Africa from Zimbabwe. Participants were willing to share personal and, in some instances, extremely painful information. There were also four key informants interviewed for the study. The demographic particulars of the participants are summarised in the table below.

ROLE	PSEUDONYM	GENDER	AGE	‘RACE’/ ETHNICITY	PLACE OF RESIDENCE
Participants	Abigail	Female	21	Black	Braamfontein, Johannesburg
	Zukile	Male	22	Black	Braamfontein, Johannesburg
	Tafuma	Male	31	Black	Johannesburg (Originally from Zimbabwe)
	Evelynne	Female	24	Black	Johannesburg (Originally from Zimbabwe)
	Siya	Male	23	Black	Edendale, Johannesburg
	Eric	Male	28	Black	Pietermaritzburg
	Dlamini	Male	25	Black	Pietermaritzburg
	Ntombomzi	Female	21	Black	Lay Centre, Pietermaritzburg
	Lerato	Female	28	Black	Mbali, Section 14, Pietermaritzburg
	Nozuko	Female	26	Black	Pietermaritzburg
Key informants	Mandisa	Female	34	Black	Pietermaritzburg
	Jabu	Male	26	Black	Ashdown
	Palesa	Female	35	Black	Sweetwaters
	John	Male	38	Black	Soweto

### 3.1.3. Data analysis

Working within the broad conceptual framework of Sexual and Reproductive Justice, a narrative approach was taken to data generation that emphasised allowing participants to tell their ‘full story’, rather than focusing exclusively on the experience of accessing health rights in a narrow and limited way. The data were generated through in-depth qualitative interviews with LGBTI persons. The participants’ accounts were then analysed using a thematic approach to narrative analysis, which involves searching for commonalities across stories in relation to the research questions. This approach views narratives as a way of accessing the participants’ experiences (Riesman, 2008). The emerging themes addressed a number of issues related to public health care settings, including: access, the quality of care, the roles of healthcare professionals in and experiences of homophobia and discrimination (to be discussed in more detail in chapter 4 that follows).

### **3.2. DESK REVIEW**

An analysis of secondary data that had already been generated was conducted. This component of the baseline comprises a desktop review of available secondary data and is explored in more depth in chapter 5. In other words, the review does not include new empirical data, but focuses on data that have already been generated by other researchers. The review is concentrated on the period prior to the commencement of the programme in May 2014. The data that were used comprise: academic literature; civil society reports ('grey' literature) and documents; and government reports and policy documents. The review also makes use of national population level data and health systems data, including (but not limited to) the District Health Barometer, the South African Health Review, General Household Surveys, the National Demographic and Health Survey Reviews. Data were also drawn from reviews and audits, in particular the National Healthcare Facilities Baseline Audit.

The desk review provides a snapshot of the general situation of SRHR in the country in relation to the target groups. The primary focus of this baseline study is on two main geographical areas, where the implementing partners have planned focused interventions. The first is the **Oliver Tambo District, Eastern Cape**, which is an important site given the issues identified by the Eastern Cape Health Crisis Action Coalition, outlined in the literature review in chapter 2. The second site is **Gert Sibande Municipality, Mpumalanga**. Given that this is currently an NHI Pilot site, valuable information can be collected regarding the impact that NHI activities have in the area, as well as potential problems with future roll out identified in the pilot. Both of these areas, as described earlier are experiencing severe problems in relation to service delivery and systems failures.

### **3.3. ETHICS**

The research process was conducted according to the guidelines of International Ethical Practice for Research with Human Subjects and was approved by Research Ethics Committee (REC) of the HSRC. The research instruments were also shared with AFSA for comment and suggestions. Principles of informed consent and confidentiality were explained in the form of a verbal briefing to participants. Fieldworkers were trained to explain the purpose of the study to potential respondents, obtain informed consent, and inform respondents about their rights and benefits in a factual and neutral way without coercing people to participate. Fieldworkers were also trained to conduct this research sensitively.

Participants were thus fully informed of potential risks and rewards of participation, any limits to confidentiality and how the information they provided would be used by the researchers. They were informed about how they may access support services such as psychological counselling which could be easily facilitated due to the partnership with organisations such as GALA and GLN.

### **3.4. COORDINATION WITH STAKEHOLDERS**

The primary stakeholders for the qualitative data collection are the implementing partners GALA and GLN. Section 27 and TAC assisted with the necessary information for the secondary data collection. All organisations are registered Non Profit Organisations (NPOs) and engage with sexual

and reproductive health and rights in low-income communities. We have communicated with these organisations throughout the duration of the project and they are familiar with local, community and provincial public health care structures. They also assisted the research team in negotiating entry and access to the necessary structures. We will be employing Section 27 and TAC as fieldworkers for Year 2 of the study. We also liaised with the provincial Departments of Health in the Eastern Cape and Mpumalanga to gain access and permission to conduct the research (requests for permission to conduct research at public health facilities were submitted in November 2014; permission to access these sites by the provincial Health Departments was only received in February 2015).

### **3.5. STUDY STRENGTHS & LIMITATIONS**

As stated, no survey data could be collected because Departmental permission (from the provincial departments of health) to assess healthcare sites was not granted in time. Since the programmes and interventions were already well underway by the time permission was granted, this would confound any observations for a baseline intended to provide an assessment of the state of affairs prior to the intervention. Nevertheless, doing a secondary data review at this point will prevent duplication when primary data are collected. In addition it is valuable for 'generating hypotheses and identifying critical areas of interest that can be investigated during primary data gathering activities'. This will ultimately strengthen future collection of primary data (McCaston, 2005).

A limitation with regard to use of secondary data is the quality of statistical data. The limited nature of the information systems, especially the District Health Information System, means that some of the data is not disaggregated at district level. In such cases, provincial statistics are provided. Further to this, data collected for particular sexual and reproductive health issues, notably pregnancy termination and teenage pregnancy are unreliable. This chapter provides a detailed description of the situation in the focal provinces and an analysis of some sexual and reproductive health issues, which is useful for establishing a reference point when considering the contribution made by various implementing partners working in these geographical areas. This is discussed in more detail in chapter 5.

Of course, the findings from the qualitative study, which we discuss in the next chapter, are not generalizable. This is not the aim of qualitative research, but rather to provide deep and nuanced data that can build on what it already known and/or provide avenues for further research. We turn to these findings next.

## **CHAPTER 4: SEAMLESS CONNECTIONS: THE PUBLIC HEALTHCARE SYSTEM, DISCRIMINATION AND COMMUNITY EXCLUSIONS**

The purpose of the qualitative component of the research was to develop an understanding of the effects of systemic failures of the public health care system on LGBTI individuals. As stated in the method chapter (chapter 2), individual in-depth interviews were conducted with LGBTI participants (10) and key informants (4) referred via GALA and GLN. A narrative approach was taken in conducting the qualitative interviews, which takes cognisance of the larger, lived experiences of participants in order to gain insight into their social context. The experiences of identifying as LGBTI intersects with other social identities that places this group of participants ‘on the margins’, and at the juncture of multiple levels of discrimination and social inequality. The resultant poor quality of treatment, care, and support from within the public health care system that participants reported confirms findings of other similar studies. Our argument in this chapter is that what happens behind the clinic walls—experiences of exclusion and marginalisation—echoes what happens beyond the clinic walls. As we shall show, the participants’ accounts indicate that stigma, heterosexism, and intolerance are widespread within the spaces that they live and that these same attitudes are repeated and reinforced within clinics and other medical spaces. This has implications for future interventions which should address the connections between experiences within facilities and the broader context in which they are located.

### **4.1. EXPERIENCES IN HEALTHCARE FACILITIES**

#### **Public Health System**

Systemic failures affect LGBTI participants within public health facilities, primarily through institutional culture and institutional practices. An institutional culture that privileges hetero-norms and heteropatriarchy as the standard organising frame for ‘how things are done and why things are done’ justifies, fuels and enables the discriminatory practices of health care professionals. The quality of care patients receive within public health systems is determined by the ‘correctness’ of their sexual orientation and not by citizenship status. This is an indication that there is problematic relationship between health care workers’ personal beliefs and how they interpret their professional responsibilities. As we shall show, the participants’ discussion of the public health system focused primarily on the attitude and behaviour of healthcare workers, and secondly, access to medication (such as Post Exposure Prophylaxis (PEP)) and different kinds of condoms.

#### **4.1.1 Institutional Culture & Healthcare Workers’ Practice**

In the narrative interviews there was a general consensus that public health facilities are problematic especially with providing services to the LGBTI community, but that poor treatment also affects the general public and people with disabilities. For instance, Mandisa maintained that English as the primary language of discourse (especially on forms) is problematic as not everyone understands English and also mentions that for some, even a R20 cost is excessive and the fee should be waived. John explained his frustration with the system:

Personally I had many struggles with the health care facilities; the biggest obstacle that deaf people face there are no South African sign interpreting service[s] in these facilities. The medical facilities, like clinics, are pathetic! (John, Interview, 2015).

A number of factors were identified as facilitators of unfair and discriminatory treatment at public health facilities toward LGBTI persons in particular. Many participants identified unprofessional attitudes and behaviours of healthcare workers, for example health care workers were perceived as judgmental, lacking adherence to confidentiality, and actively preventing treatment of LGBTI individuals. The overwhelming concern was with the attitudes and behaviours of public health workers.

All of the participants spoke of their clinic visits being directly impacted by the healthcare worker they encounter on a particular day. Overall they found healthcare workers to be insensitive, lacking tact and having little regard for privacy of patients. When some LGBTI individuals visited clinics to be tested, the nurse would call her other colleagues before diagnosing the patient. Patients often found this embarrassing and described it to be a gross infringement of their basic human rights as suggested by Bongani and Palesa (key informant). Siya<sup>iv</sup> recounted an incident where he overheard a nurse gossiping about another homosexual man who had just walked into the clinic. Overhearing this conversation prevented him from disclosing the real reason he was visiting the clinic on that particular occasion: an anal sex injury. Similarly, Ntombomzi recalled a visit to a clinic where she heard healthcare workers gossiping about her supposedly promiscuous behaviour. She maintained that she had not been treated well by healthcare workers in clinics. She has taken to getting her own medication through a friend who works at a medical centre in order to avoid this lack of privacy and judgmental attitudes. On a separate occasion when she went for an HIV test, she was not counselled but simply given the results. Because of this lack of care, she then advised her cousins who had accompanied her and were waiting to be tested after her, not to go in. These reports of compromised confidentiality were corroborated by key informants. Palesa (a key informant) said that “Nurses would shout out patients’ essential medication and summon them to the corner to collect it in front of other patients. As a result patients stop going to the clinics to pick up their ARVs”. Healthcare worker attitudes and behaviours exposes LGBTI individuals to the possibility of further illness or/and harm because the medication and health services are not accessed as regularly or as immediately as they could be. This finding is not new but rather serves to reinforce previous research (Rispel. et. al, 2011 and Muller, 2013). Rispel et al (2011) state, “At times they avoid certain health care facilities if the service is of a poor quality and rather travel further for better service” (p.147). Other implications of this finding are that constitutional rights are not guaranteed when accessing health services.

Other participants spoke about overt negative treatment and abuse by healthcare workers. Palesa highlighted an incident where a lesbian who had been raped was told by nurses to shower, knowing very well that evidence would be washed away. Mandisa, who was visibly shaken in recounting her experiences with healthcare workers, said: “I have a headache now just thinking about this”. She recalled repeatedly being shouted at, disrespected, and undermined during her clinic visits. In general, nurses were described as rude to the patients, giving out expired medication

and refusing to admit patients during the night. Zukile noted, “They do not speak polite[ly] to you when they speak to you. They don’t even want to understand you are sick. They are so impatient”. For some participants it seemed like for nurses, their jobs have become a means to an end, earning money, rather than an ethical and professional obligation as a public servant. Ntombomzi questioned whether the staff members were even properly educated. Mandisa highlighted the lack of accountability for this behaviour. Dissatisfied with the slow pace at which the nurses work, she left a written complaint in the feedback box. She said that she also left her number in the feedback box but was never contacted.

In some cases people were refused treatment because of their sexual orientation, in others, nurses would pray for them. Palesa (a key informant) reflected on her own experience trying to access healthcare, saying she was denied access to counselling and HIV/AIDS testing because the nurse was convinced that lesbians cannot contract HIV/AIDS. Healthcare workers therefore act as gatekeepers to services, preventing access for LGBTI persons. As a result of their treatment, many LGBTI persons seek alternative means of accessing care. Ntombomzi stated that because of her negative experience, she depends on a home HIV test that she is able to administer herself rather than going for testing. Echoing Ntombomzi, Mandisa maintained, “Even if I die, I’d rather die at home than die in a hospital where there is help that I don’t get”.

The participants offered several solutions to these problems. Both Siya and Ntombomzi suggested that workshops should be held for healthcare workers to address negative attitudes that created breaches in confidentiality. Siya suggested that nurses should participate in a workshop to understand different sexual orientations so they are able to identify problems without discriminating, rejecting or making a spectacle of the patient. Ntombomzi suggested that workshops that will help with “reaching out to the healthcare workers, letting them know about LGBTIs, maybe [getting] to know them more so that they will not judge them when they come for help”. She also suggested that a few healthcare workers and nurses in conjunction with the LGBTI community should attend the AFSA workshops together.

One participant suggested that an effective public health care system should be modelled after the MSM clinic created by the ANOVA Health Institute, as this facility takes into consideration the needs of the LGBTI community, more specifically for men who have sex with men (MSM). There was a concern that not all of the NGOs are as helpful as they could be and that NGOs are not effective in addressing the current status quo of the public health facilities. Key informants indicated a level of ignorance among doctors and nurses. It was highlighted that the focus of the training health professionals receive at nursing colleges and medical school is primarily heteronormative, has a gender bias (assumptions of the masculine norm) and lacks a comprehensive holistic view (which would include the broader dimensions of sexuality). Siya felt that training and the hiring of more gay personnel is the only solution to address the problem of homophobia amongst healthcare professionals.

However, some participants noted that there has been some change in health worker attitudes. This is attributed to good management, NGO training, and education and sensitisation to issues around sexuality and gender. Dlamini had only had one negative experience a healthcare

facility (a misdiagnosis). Instead, he talked about a particular time a healthcare worker followed up with him after his visit by calling and checking on his progress. Nevertheless, he remained slightly suspicious of the motives of healthcare workers, expressing concern that health care workers might be displaying sensitivity simply because they are legally required to do so or afraid of losing their jobs.

#### **4.1.2 Access to Medication, and Safer Sex Resources**

Systematic failures in the public health system were flagged in all the key informant interviews. Key informants argued that the government, both at a provincial and national level, was under resourced and failing LGBTI individuals. One key informant even expressed the belief that the government only showed an interest in LGBTI persons during the election period. After this period, “they were never available”. A key failure highlighted throughout all four interviews was the inability of government to provide condoms suitable for diverse sexual orientations. Presently, clinics predominantly provide patients with access only to male condoms. There is a lack in the distribution of female condoms. Palesa (a key informant) estimated that only approximately four to five female condoms were available at every clinic. Furthermore, ---Mandisa (also a key informant) stated that commodities are a huge challenge in the public health system. He pointed out that LGBTI individuals cannot gain access to lubricants or dental dams in clinics.

Lesbians find it difficult to protect themselves because they need those dental dams. Government does not provide dental dams. Government also does not provide PEP. It’s a programme that needs to be implemented 24 hours after a rape incident occurs. If you [are] going for PEP and you[’re] a male, it’s difficult because they assume it’s only for women. Also there is a lack in finger cots. We only have condoms, specifically male condoms. Yet male[s] do not use condoms. They don’t use it because they say it gives off an unpleasant smell.

This highlights that health care facilities and health care workers are unprepared to respond to the variety of sexual health needs of LGBTI individuals, and to some extent it is an indication of the narrow understanding of the SRH needs of LGBTI on the part of healthcare personnel.

## **4.2. EXPERIENCES IN COMMUNITIES**

### **4.2.1. Homophobia and social discrimination against LGBTI individuals within communities**

Living as an LGBTI individual exposes one to danger and harm in communities. The levels and layers of homophobia are shaped through experiences at home, in families, at schools and on the street corners, and in communities. While LGBTI rights are constitutionally guaranteed in South Africa, in reality for many it is not an easily accepted reality which is evident in the widespread discrimination and in several instances, hate crimes experienced particularly by lesbians. Constitutionally, sexual autonomy is protected in the Bill of Rights Bill of Rights; however, constitutional rights are often contested, denied or even dismissed, which is reflected in the continued stigmatisation of lesbian and gay people, rejection by families and communities upon disclosure of sexual orientation, and in particularly horrific instances, the rape and even murder of LGBTI individuals”. The fact that the right to sexual orientation exists on paper and is legally sanctioned is not necessarily the social

discourse that circulates in communities and the public health care system; *formal* rights do not, in other words, automatically translate into *substantive* rights.

Discrimination toward sexual minorities was described in the participants' accounts of their everyday realities. The participants' stories corroborate existing research that suggests that although progress has been made around advocating LGBTI rights, widespread discrepancies exist between what is on paper and what is happening in reality (Mkhize, Bennet, Reddy, & Moletsane, 2010; Muller, 2013). Participants recounted many instances of discrimination, for instance Eric talked about his high school teacher who raised concerns about his sexuality as well as his local pastor who condemned all homosexuals, demanding they leave the church. Participants also told many stories of violence directed at them and other LGBTI persons they knew. One participant revealed that he was beaten by a family member for being gay, and in another instance following a confrontation with some community member about the treatment of his gay friend his life was subsequently threatened for being gay; "*they said 'we have to kill this thing'*". He also told of a lesbian friend who was gang-raped by her heterosexual male friends. Zukile related several violent attempts on his life as a result of his sexuality. Such experiences are not unusual in South Africa, given the fact that hate crimes against LGBTI have increasingly become more violent, leading to murder and death (Mkhize, Bennett, Reddy & Moletsane, 2010).

According to Swarr (2009), "Many lesbians and gay men are the targets of homophobic violence and murders, and this violence is exacerbated by (mis)understandings of *stabane*" (p.537). The epithet '*stabane*'<sup>v</sup> was described in participants' accounts. Participants had to navigate this name-calling, and the underlying attitudes that they represent, in their everyday lives. For instance, Siya recalled from his early teenage years that other men would ridicule him for appearing feminine—mocking his soft voice, how he "talked like a girl", and his physical build—and referring to him and other gay men as 'ladies'. He also recalled being harassed by a group of men in the community who would repeatedly call out "*istabane*"<sup>vi</sup>. Likewise, Patience mentioned being judged for being in a relationship with a woman by members of her community. For instance when she would walk to the shops, they might call out "hey you *stabane*" or "don't you have a child" and things of that nature. These stories illustrate how much of the stigma experienced by queer people was related to gender non-conformity. Participants pointed out that the discrimination would be based on the fact that they displayed behaviour and/or "gestures" that were deemed to be incorrect for their gender.

The use of the term '*stabane*' suggests feelings of confusion, ambivalence, and fear of same sex desire and practices. A key theme was community members' confusion and misapprehensions around gender and sexual identities. Dumisani, who identified as gay, recounted challenges related to his family and community not understanding what 'homosexuality' is and how it could be possible. He recalled that when he disclosed his sexuality to his mother, she simply could not understand and took him for psychological evaluation though he mentioned that she came around after attending counselling sessions with him. Three of the participants who identified as bisexual spoke about their community's inability to understand the term bisexual. Nozuko asserted that most people in her community do not understand bisexuality and think "you just want everything".

She shared that she tries to explain her sexuality to those who are curious. Lerato acknowledged that the notion of bisexuality is not a term that people in her life or community adequately understand, and this is further complicated by the fact that she has a child. Some bisexual participants maintained that they even experienced discrimination from other queer people. Jabu, for example, felt that the most intolerant people of his bisexual identification were other homosexuals. Not only was the term contested by some of his family and friends (even some AFSA workshop participants) but he was also called “greedy” and “confused” because he cannot “choose” between men and women.

Participants also recounted the misconceptions and stereotypes that their communities held about queer people. For example, Eric said, “if there are community meetings, if I’d go there, no one would want to come sit next to me and there were these mean statements [like] ‘gay men are all HIV positive, if you touch a gay man you’ll be HIV positive, gay is a disease that is spreadable’”. Likewise, Patience stated that some community members had accused her of “introducing gayism” in her community, that is, causing other people in the community to accept homosexuality or become queer themselves. In some instances her friends were even physically threatened when they visited her. Ntombomzi recounts a story about being discriminated against in high school when she was accused of harassing another female student and was suspended because of this incident. Ntombomzi also described the sorts of sentiments that fuel the notion that a queer person, especially lesbian women, can be ‘corrected’. She expressed frustration with heterosexual men harassing her about her choice to be with women. The men claim that she is “too beautiful” and therefore “needs a man”.

A common theme in the narratives was that of tolerant versus intolerant spaces. For his part, Dumisani frequently drew maintained that rural areas are less accepting of homosexuality compared to urban settings. For him, challenging the conservative worldview in the rural areas has shown to be very difficult as he has to continuously redirect and re-negotiate his sexual identity and behaviours into ‘correct’ and ‘safe’ ways of behaving to prevent further prejudices. This juxtaposition of rural and urban illustrates a sense of belonging and exclusion across different geographical areas. In this vein, participants who are foreign nationals identified South Africa as a country where sexuality could be explored more freely yet when they arrived in South Africa, they experienced discrimination. Nevertheless, these participants also acknowledged that sexuality is still controversial in South Africa as illustrated in Evelyn’s comment: “At home, people said in South Africa, gay people have freedom like everyone else. But I heard lesbians are bashed, raped. That’s what’s happening in South Africa. Even though the constitution declares that everyone has equal rights, many have never read the constitution”.

Similarly, participants also described particular groups as being less tolerant. Some spoke of religious people being discriminatory. Tafuma defined homosexuality as being “unAfrican”, hence, fewer Black African people are accepting of homosexuality compared to other ethnic groups. He also related this to the difference between peoples’ perceptions in the rural and urban areas. These findings resonate with those from other research (e.g. Graziano, 2004; Reid, 2013).

This extended to the individualised ways that participants managed stigma. Many described limiting their social circles to other queer people only. Zama described a strategy of ‘passing’ as straight: “I can pretend but inside me I do know what I want, or how I feel. Yes, I can cover-up amongst straight people but I know that I am gay – a man who likes other men”. They also managed their responses to stigma, rather than challenging it.

These findings show how communities regard and treat LGBTI individuals as ‘other’, as the exception to the norm and in some ways want to retain a sense of ownership about what is allowed and what is not allowed within townships and communities. The idea of different forms of sexual desire is a huge challenge to existing social norms. Tucker (2010) explains, “Yet in township locations, a key reason suggested here to explain why homophobia today is so prevalent stems from the sudden visibility of groups positioning themselves as distinct from wider society post-apartheid” (page, 115). The norms of hetero-patriarchy often mean that men (within a system of patriarchal hegemony) want to retain dominance and control of communities, through the social control of bodies (both male and female). In this way the public health system is an extension of community cultures and the two systems become constituted through each other. LGBTI people are often compelled to navigate between these spaces that are often harmful and dangerous but it is difficult to change the one without the other.

Families also entrench gender and sexuality norms. Some participants identified the discrimination and antagonism they received from their own families because of their sexuality. The family presents a huge challenge because it is privately organised and hence, privately, owned. Participants’ performances of gender and sexuality through the stylisation of their bodies, which sometimes or often result in derogatory comments, highlights the significance of engaging families and communities more broadly on the rigid enforcement of gender binaries of masculinities and femininities. Yet families are in a state of change and flux. Some participants had to be responsible both for themselves and for younger siblings from a very young age, which could arguably allow them to create spaces for different social norms. Additionally, some participants created and developed their own circles of safety by socialising and forming friendships only with LGBTI individuals. This demonstrates the agency of participants to create alternative pathways for living safely and happily. Institutional cultures in public health care facilities, community cultures as well as family cultures need re-vision and redefinition.

#### **4.3. “RISING ABOVE”: RESPONSES TO SOCIAL STIGMA AND DISCRIMINATION**

Interestingly, for the most part participants did not easily recognise structural issues as contributing to discrimination that they encountered (unlike participants in Graziano’s (2004) study). Participants do not really mention institutional structures of race or class in their accounts or how these may affect them. Interestingly, some of the younger participants see themselves as “born free”; free to do whatever they want to do and be who they want to be. In contrast, an older participant, Eric, recounted how his immediate surroundings, his family, class and the effects of apartheid had resulted in him not revealing his sexual orientation to his parents. He explains that if

his parents had been exposed to homosexuality before this would have allowed him to come out about his sexual orientation.

Nevertheless, what was commonly expressed by the participants was an individualised response to their challenges, including poverty and discrimination, described above, in order to 'rise above' their current condition i.e. believing that they hold the key to pulling themselves out of whatever circumstance (despite financial disadvantage and lack of resources). This involved personally managing one's responses or outlook expressed in the view: "*If I hold steadfast in my belief, my life will change*". Siya said: "I'm not going to give up" (despite the fact that he is unemployed, financially dependent on his boyfriend and has no money to return to school). Lerato expressed: "I want to see us living a better life than we are living right now" (she is unemployed and is financially unable to go to school). Mandisa expressed: "Stay motivated, positive thinking in whatever I do and I have to believe in myself" (despite being unemployed, financially dependent on her girlfriend and having no money to return to school). Tafuma said that he is "hopeful for the future" (he has a degree but is unable to find a job).

The participants described themselves as strong, resilient people. They referred to themselves as survivors. They all had similar dreams and aspirations for the future: to have a job, a car and a house. Siya also mentioned that he would like to make financial contributions to LGBTI organisations. Mandisa emphasised the importance of an education for herself, her siblings and her son. Patience mentioned that she wanted to work actively to mend her relationship with her mother. Nevertheless, structural factors impact on participants' ability to disclose their identities, to integrate into communities, and ultimately to ensure that their SRHR needs are met. This resonates with work done by Graziano (2004, p. 312) in Johannesburg, who reports that,

Socioeconomic status affected participants' quality of health care. Despite a strong desire for more health and sexuality education, the lack of training and acceptance of gay men and lesbians at township clinics kept participants from visiting them. These negative and prejudice attitudes may hinder Black gay men and lesbians from seeking general health care, leaving them with feelings of distrust, discomfort, and a lack of medical professionals to whom they can divulge personal health-related information.

A strong recommendation from this research, which is discussed further in the final chapter, regards tackling institutional cultures within public health facilities. The issues highlighted in this chapter echo the findings of other researchers and practitioners working in sexual and reproductive health (e.g., Graziano, 2004; Lane, Mogale, Struthers, McIntyre & Kegeles, 2008; McIntyre, 2010; Reddy, Sandfort, & Rispel 2009; Muller, 2013 & 2014; Rispel et al., 2011). Much of this work has provided recommendations to address the marginalisation of sexual and gender minorities, as well as other marginalised groups, and stresses the need for working with health care workers. Recommendations have included partnering with local LGBTI organisations to educate LGBTI-affirming health workers; including issues about sexuality, norms, and prejudice in nursing college and medical school curricula; continuous medical education courses and in-facility training on LGBTI health; sensitisation training for all staff; and providing better resources for LGBTI people. While this is a good start, it is clear from the discussion above, that in order to address marginalisation in the public health sector, one has to look beyond the clinic walls. Healthcare spaces are not distinct

from the communities and the broader context in which they are located. Based on findings from the research thus far, some practical suggestions are made for holistic ways of working to improve the experiences of sexual and gender minorities within the health sector so that they may be better able to make choices and realise their sexual and reproductive rights. These are listed in the final chapter.

#### **4.4. CONCLUSION**

The preceding discussion provided a description and brief analysis in broad terms outlining major insights in the qualitative data. Without generalisation the data confirms that the participant interviews provide a deep sense of the everyday struggles of living as an LGBTI individual. On-going discrimination and prejudice haunts 'ways of living' and 'ways of being' and beckons the need to navigate ways to remain safe (from the violence) that is constituted by close relations and communities of proximity. The seamless heteronormative prejudice that connects public health facilities, communities and families is also testament to the pervasiveness of harm and danger for LGBTI persons. The issue of structural and ideological change is slow and difficult. Yet, in listening to the voices of participants, it seems that anything short of this will always 'miss the mark' and not create the necessary and meaningful changes that are urgently required. Central in our estimation is the urgency to change institutional cultures and practices to bring about the substantive equality that is necessary. While 'everywhere' (e.g. public health, communities, and families) might not be able to be addressed simultaneously, the connections however, need to be named. Within the public health care system, the professionalisation of healthcare workers has to be addressed through a naming and unlearning of an institutional culture (training cannot only focus on the notion of sexual and reproductive 'rights'). Alternative public discourses and representations of LGBTI individuals, couples and families are needed to counter the pervasive homophobia and specific violence prevention programmes must be geared to the needs of LGBTI. Yet, interventions cannot also remain purely at the level of social discourse; these have to include economic empowerment initiatives as well.

The perspectives of health workers would further enhance the findings from this study. In Year 2, healthcare workers will inform the sample so that the intersections that health care workers find themselves in (between the state and communities) might add another layer of complexity to better understand and respond to SRHR services for LGBTI individuals (chapter 6 extrapolates some key recommendations aligned to the dataset discussed here). In the next chapter we examine in more detail the 'state' of healthcare in two selected provinces, Eastern Cape and Mpumalanga.

## CHAPTER 5: DESK REVIEW: SYSTEM FAILURES & SRHR BARRIERS

In this chapter, a comprehensive overview is provided of the general situation of SRHR in the geographical areas where the implementing partners have planned to focus interventions, namely, the Eastern Cape Province and Mpumalanga. We focus in on two associated districts, namely, O.R. Tambo District (Eastern Cape) and Gert Sibande District (Mpumalanga). The rationale for this selection is discussed below. The chapter provides an assessment of SRHR services and barriers for each of these provinces. The chapter begins with a contextual overview of the focal areas. This *first section* describes the areas and the major problems they face and then singles out two pertinent issues, viz., (i) their spatial location, particularly in relation to rurality and (ii) poverty and multiple deprivations. These are foregrounded at the outset because they form a significant part of the broad contextual background within which the issues presented in the chapter are located. Following this, in *section two*, evidence is presented related to public health system failures. Thereafter, the focus is narrowed to consider SRHR issues in these geographical areas in *section three*, moving into a discussion of specific barriers for target communities from these areas in *section four*, including HIV status; gender; gender identity and sexual orientation (LGBTI); and rural health. The chapter closes (*section five*) with a discussion of the work done by the implementing partners, TAC and *Section27*, and local accountability structures (particularly Local AIDS Councils (LACs)).

### 5.1. CONTEXTUAL OVERVIEW OF THE FOCAL AREAS

The review, as mentioned above, focuses on 2 provinces—Eastern Cape and Mpumalanga—and two associated districts—O.R. Tambo and Gert Sibande. Both O.R. Tambo and Gert Sibande districts were selected for the National Health Insurance Pilot; the latter is being monitored closely by both *Section27* and TAC. The districts selected for the Pilot are situated in every province, specifically in areas with high levels of underserved communities. This is certainly the case with the districts that we focus on, which are both situated in rural, and relatively impoverished provinces.

The **Eastern Cape** is the second largest and third most populous province in the country, containing 13.5% of the total population (Eastern Cape Aids Council (ECAC), 2012). OR Tambo is one of six districts in the Eastern Cape Province with a population of approximately 1,358,917 and 298 229 households. It includes former homeland Transkei and is formed by five local municipalities. TAC and *Section27* are members of the Eastern Cape Health Crisis Action Coalition and active in this district. The TAC provincial offices are based in this district.

In the Eastern Cape, the economic burden of the province is exacerbated by high rates of HIV/AIDS, which necessitates expenditure for treatment and grants, as well as further inhibits economic participation. The poor health status of the Eastern Cape population is also indicated by the high rates of infant and maternal mortality (ECAC, 2012). (See below for an in-depth discussion of the SRH challenges of the province.) High levels of teenage pregnancy have also been associated

with the intersection of poverty and power differentials between women and men, as discussed further below.

**Mpumalanga** has a total population of around 4,039,939 (GHS 2013; StatsSA, 2014) distributed across three districts (Ehlanzeni, Gert Sibande and Nkangala) and 18 sub-districts. Gert Sibande is the largest of the three districts in Mpumalanga with a population count of 1,056,178. The area is 61% rural and 39% urban, thus the community experiences challenges in accessing health services, as discussed below (Gert Sibande District Profile, 2010).

In Mpumalanga, overall, the health problems and challenges experienced are influenced by high levels of unemployment, alcohol abuse, and unsafe sexual practices such as intergenerational and transactional sexual partnerships. Because of the demographic spatial arrangement of the province, there is a high number of trucking communities passing through the province, which in turns contributes to an active sex work industry. A recent mapping study of sex workers across the country supports this since the majority of the province's sex workers are found in small towns along trucking routes. Mining activity in the province further contributes to the sex work industry (SANAC, 2013). The province has an HIV prevalence rate of 14.1%, second only to KwaZulu-Natal that has the highest HIV prevalence of all provinces at 16.9%. It is estimated that 90% of the population in Mpumalanga is dependent on the state for the provision of all their health services (DoH, 2011b; KYR Report, 2010). A more detailed discussion of the status of SRHR in these focal areas follows.

#### **5.1.1. The spatial legacy of apartheid and the role of rurality**

The situation in both of these provinces must be contextualised according to the spatial legacy of apartheid, as well as the role that rurality plays. “The spatial legacy of apartheid means that poor South Africans are concentrated spatially and tend to reside either in formerly racially segregated “townships” around cities ... or in former homelands” (Noble, Zembe, Wright, & Avenell (2013) cited in Day & Gray, 2014, p. 211). Research has shown that areas located in the rural former ‘homelands’ or ‘bantustans’ are the most deprived in the country (Noble & Wright, 2012). This is relevant to the Eastern Cape, which suffers from high levels of poverty, unemployment and lack of infrastructure. The situation is most severe in the O.R. Tambo district of which 80 *percent* is former homeland territory and thus highly under-developed, with poor road infrastructure and access to public transport, and poor access to basic services (Massyn et al., 2014, Office of the Premier, 2007). Indeed, most of the districts classified as ‘most deprived’ correspond with the former homeland areas (South African Health Review (SAHR), 2014). We discuss below the role that multiple deprivation plays in the two focal provinces in relation to SRH.

Another factor to consider when assessing the situation of SRHR in these two provinces is the role that rurality plays in maintaining inequities related to health. ‘Rural provinces’ are those where more than half the population resides in rural areas; these include: Limpopo (88%), Mpumalanga (59%), Eastern Cape (58%), North West (55%), and KwaZulu Natal (53%) (Eagar, 2015). Areas such as these

...continue to suffer from the effects of historical neglect in terms of development and social investment. Rural communities remain the most impoverished in the country and have the least access to basic social and economic necessities. In terms of health, this means that rural communities in South Africa carry a disproportionate burden of disease and can expect to have significantly less access to care than their urban counterparts (Eagar, 2015, p. 3).

The Rural Health Advocacy Project highlights the following health-related concerns for rural populations (Eagar, 2015):

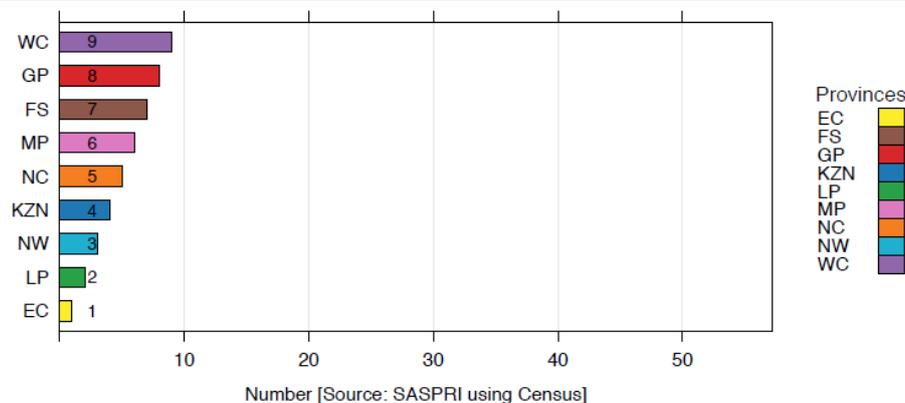
- high levels of relative deprivation (see discussion on deprivation below)
- reliance on the public system
- greater consequences of out of pocket expenditure for healthcare
- access to facilities takes longer and is more costly
- neglected in terms of health expenditure
- disadvantaged by the distribution of human resources for health
- worse health outcomes than urban counterparts

These factors certainly play a role in shaping the SRHR situation in the Eastern Cape and Mpumalanga and the role of rurality is thus highlighted throughout this chapter.

### 5.1.2. Poverty, deprivation, and health

One of the major obstacles to the attainment of SRHR in both the Eastern Cape and Mpumalanga is high levels of poverty (which equates to the lack of resources required to meet needs) and deprivation, that is, people’s unmet needs. Thus, poverty leads to deprivation (Day & Gray, 2014). Deprivation is assessed according to the South African Index of Multiple Deprivation (SAIMD) along four domains: income and material deprivation, employment deprivation, education deprivation and living environment deprivation. All of these domains to some extent have a bearing on SRH outcomes. Rankings according to the SAIMD are shown in figure 1 below. It is possible to see that the Eastern Cape is ranked lowest at one and Mpumalanga somewhat higher at six out of the nine provinces. Figure 2 extrapolates these rankings across the four domains discussed above.

**Fig. 1: SA Index of Multiple Deprivation rank (1=most deprived) by province, 2011**



[Source: District Health Barometer 2013/14]

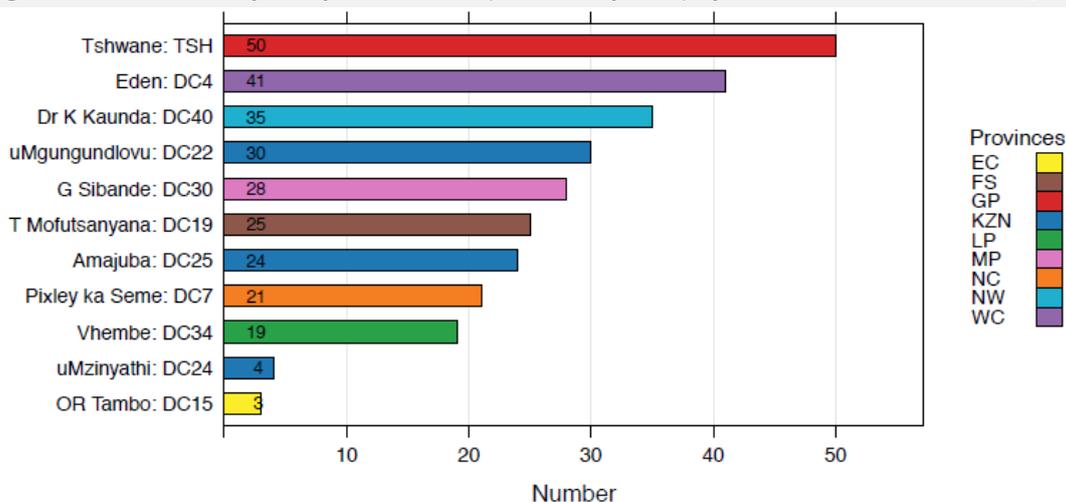
Table 1: Provincial rates of deprivation for the 4 domains of the South African Index of Multiple Deprivation, 2011

Province	Overall rank order of population (1 = most deprived)	Material deprivation	Employment deprivation	Education deprivation	Living environment deprivation
EC	1	50.2	47.3	28.5	59.6
LP	2	40.2	46.4	24.3	71.9
NW	3	41.7	37.9	28.7	55.4
KZN	4	43.0	42.3	23.4	55.3
NC	5	39.5	34.1	30.0	32.1
MP	6	34.9	38.2	24.4	54.5
FS	7	33.3	38.9	23.4	32.9
GP	8	30.8	29.8	12.6	21.5
WC	9	24.8	26.1	16.8	19.1
SA	-	37.1	36.0	20.9	43.8

Source: South African Health Review 2013 – 14

The following figure shows relative deprivation at district level. It is possible to see that both O.R. Tambo and Gert Sibande districts fall into the lowest ranks, with O.R. Tambo ranked lowest.

Fig. 4: SA Index of Multiple Deprivation rank (1=most deprived) by NHI district – bottom ranks, 2011



[Source: District Health Barometer 2013/14]

High levels of deprivation mean that people do not have access to the means to promote and sustain good SRH, such as access to care, nutrition, preventative measures (e.g. birth control, screening) and so forth. Further, not only does a lack of resources mean dependence on the public health system, which does not always provide the adequate SRH services or those needed (see discussion below), but, as discussed in the literature review, this often presents a significant barrier to accessing services. As further discussed below, this poses problems, for example, with antenatal care and treatment adherence.

### ***Deprivation in the Eastern Cape and OR Tambo***

The Eastern Cape Province has been ranked the 'most deprived' (SEQ = 1) province on the South African index of multiple deprivation rank, as shown in figure 1 below. The province is largely under-developed, with economic activity well below its potential. It suffers from immense poverty-related challenges such as high income inequality and food insecurity. The following are key socio-economic indicators:

- second lowest average household income nationally (after Limpopo) (StatsSA, 2011)
- 27% unemployment (one of the highest rates in the country) (ECAC), 2012)
- 78% of households classified as food insecure (Socio-Economic Review Outlook, 2013)
- more than 50% of population depends on social grants (StatsSA, 2011)
- 10.9% medical aid coverage (compared to 16.9% nationally) (Massyn et al., 2014; Rural Health Advocacy Project (RHAP), 2013).

Ten of the 'most deprived' districts fall within Eastern Cape provincial borders, *all of which are situated in rural areas* (Massyn et al., 2014). These appear in red on figure 1. O.R. Tambo district is classified as one of the worst-off districts, with a deprivation index of 4.5. It is ranked as the third most deprived district on the South African index of multiple deprivation rank and the most deprived district out of all the NHI pilot sites (Massyn et al., 2014). The latter ranking can be seen in figure 4 below. The district experiences great deprivation even though it is the fourth largest economy within the province, with a contribution value of 9% of the province's Gross Domestic product (GDP) (Socio-Economic review Outlook 2013). The following statistics illustrate deprivation across domains:

- 81% household food insecurity
- 67.9% of households access piped water – district with most people without such access
- 70% of households have electricity
- 54.2% unemployment for individuals between the ages of 15-34 years
- 80.5 per 100 dependency ratio<sup>vii</sup>
- 4.6% medical aid coverage – third lowest district in terms of coverage (Massyn et al., 2014).

### ***Deprivation in Mpumalanga and Gert Sibande***

While Mpumalanga province's performance on the South African Index of Multiple Deprivation is not as severe as the Eastern Cape, it has a deprivation index of 6 (SEQ = 6), indicating a continued pattern of higher deprivation in rural areas than in urban areas of the country (Massyn et al., 2014). (See further discussion on rurality below.) Mpumalanga's population base exhibits low economic activity, beyond coal mining (GHS 2013; KYR report, 2010; Gert Sibande district profile, 2010).

Of the NHI pilot districts, Gert Sibande rates more positively than OR Tambo - noted earlier as the most deprived district of all the pilot sites, but still records a deprivation rank of 28 (of 52), indicating that resource allocation in the district still does not meet the population need (Massyn et

al., 2014). In general, Gert Sibande is a district riddled with numerous structural challenges that require attention.

- 44.3% of households have access to piped water inside the dwelling
- 83.4% of households electricity for lighting
- 29.7% unemployment rate
- the dependency ratio is at 56.50 people per 100 people
- 28.0% of citizens <20 years have Grade 12
- 9.1% of citizens <20 years have higher education (DHB, 2013; Gert Sibande District profile, 2010; NSP Review 10).

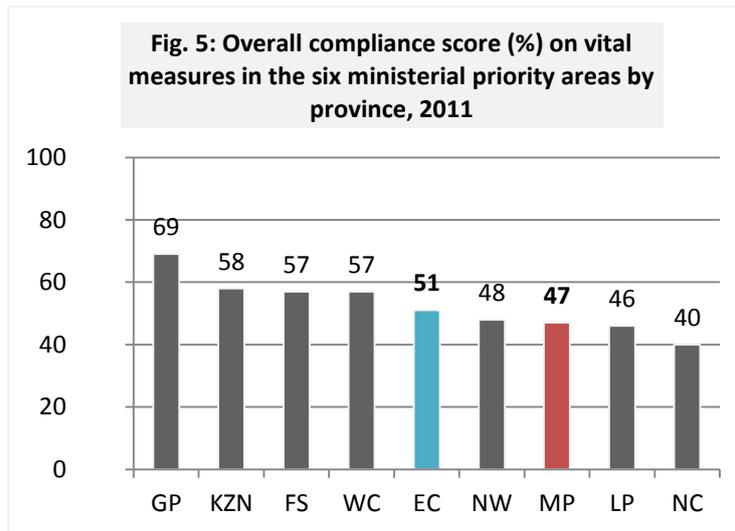
In addition, a high youth unemployment rate places young people at a disadvantage; as such most of the households in the district depend on one or more support grants. Since the people in the district have a limited amount of financial freedom, this influences their livelihood in terms of access to information and services.

The multiple deprivations described above are linked to the social determinants of health, as discussed in the literature review (see chapter 2). As we discuss below, deprivation affects access to services and delays in seeking treatment. It also makes people more vulnerable to exploitation, violence, and risky sexual behaviours, contributing to sexually transmitted infections and unintended pregnancy.

## **5.2. THE STATE OF HEALTH SERVICES**

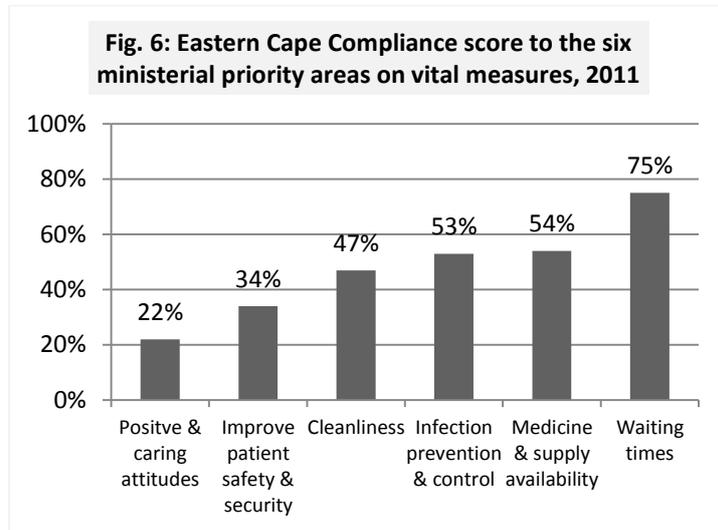
Public health facilities in the country are supposed to offer a comprehensive range of integrated services, which include sexual and reproductive health services. However, as noted by the DoH (2011), services are often compromised by factors ranging from financial to staff's lack of specialised knowledge or unwillingness to provide services, resulting in a lack of particular treatments or services in public facilities. The recent National Healthcare Facilities Baseline Audit (DoH, 2012) reported on the condition of facilities and health service provision in respect to the six priority areas for quality patient centred care, namely: (1) improving patient safety and security; (2) staff's positive and caring attitudes; (3) cleanliness; (4) availability of medicines and supplies; (5) infection prevention and control; and (6) waiting times.

As figure 5 shows the Eastern Cape received a score of 51%, slightly lower than the national average of 53%, and was ranked fifth out of the nine provinces. Mpumalanga province was rated lower than the Eastern Cape receiving an overall compliance score of 47%, also lower than the national average of 51%.

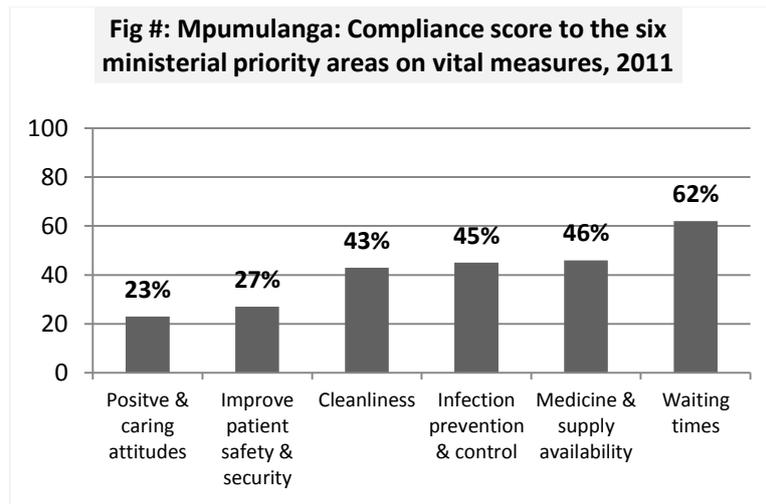


Source: National Healthcare Facilities Baseline Audit (2012)

In terms of the individual performance of the Eastern Cape, according to the audit, the particular weaknesses across the province then relate to the ways that the staff interacts with patients, patient safety and security, and the cleanliness of facilities. This is shown in the figure below. When evaluating Mpumalanga's performance in the recent National Healthcare Facilities Baseline Audit (DoH, 2012), the main challenges for the province relate to staff attitudes, patient security and safety. This is illustrated in figure 8.



Source: National Healthcare Facilities Baseline Audit (2012)

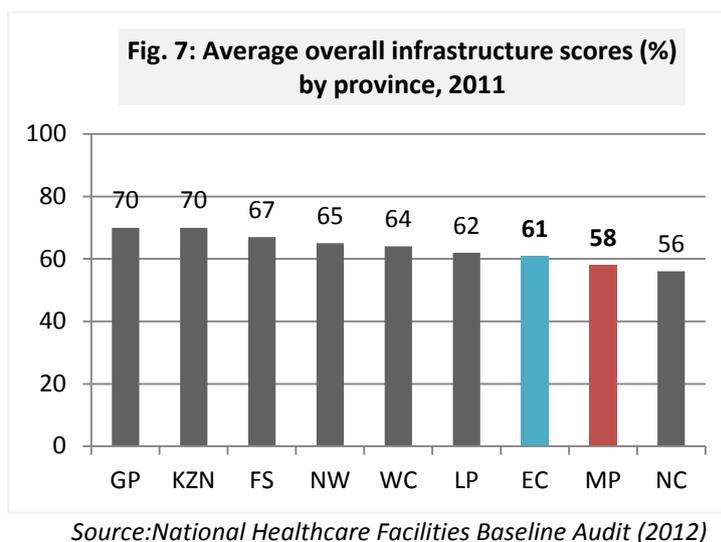


Source: National Healthcare Facilities Baseline Audit (2012)

At district level, OR Tambo district received a score of 54% compliance in the National Facilities Baseline Audit, which is 1% above the national average, and a ranking of 29 out of 52 districts. While it was ranked mid-way overall, the district was ranked third last (50 out of 52) in terms of infrastructure at facilities (DoH, 2012). Gert Sibande also performed poorly, with a score of 36% on overall compliance measures (compared to the national average of 53%) (DoH, 2012). Infrastructure has also been identified as an issue for Gert Sibande (NSP Review 10).

### 5.2.1. Infrastructure

The major challenge for the Eastern Cape was shown to be infrastructure, including: buildings, facilities infrastructure management (e.g. security, maintenance, sanitation, laundry and food services etc.) and space standards. The province's ranking on this criterion falls from midway overall (fifth) to seventh out of the nine provinces, as shown in the figure below. It is also possible to see that Mpumalanga fares worse than the Eastern Cape. The infrastructure compliance score for Mpumalanga was even lower than Eastern Cape - at 58% compliance it is ranked second lowest of all the provinces.



According to the Public Services Accountability Monitor, “the health infrastructure in the Eastern Cape is greatly in need of upgrading and refurbishment. The NHI system will certainly not be sustainable if most of the health care facilities in the province are not improved upon” (Mtslongo, 2013, p. 7). The Eastern Cape Health Crisis Action Coalition (ECHCAC) has also documented the poor infrastructure in the province and their list describing the conditions of various facilities appears as APPENDIX 9. The conditions are summarised by former Health MEC Dr Thomas in her analysis for report entitled ‘Death and Dying in the Eastern Cape’ published by Section27 and TAC in 2013. This is her assessment:

Conditions in the Eastern Cape healthcare system are now at an all-time low. The decrease in budgets continues in a context where the Superintendent General for the health department reports a staff vacancy level of 46 percent, six hospitals condemned but still operating, 17 hospitals without water, more than 42 health facilities without electricity, 68 percent of hospitals without essential equipment, 16 percent of hospitals without telephones, and many clinics that are only physically accessible in good weather (TAC & Section27, 2013, p. 28).

The Coalition has also drawn attention to the persistent problem of insufficient Emergency Medical Services (EMS) and Planned Patient Transport (PPT) in the province, as discussed in detail below (Human Rights Commission (HRC), 2014). This presents a major obstacle for accessing services, especially for those in remote areas (Massyn et al., 2014), and compounds the problem of late presentation at facilities for antenatal care by women from rural villages (Eagar, personal communication). According to budget analyses “the province is caught in an infrastructure capacity trap: its budget is based on the system’s capacity to absorb funds, while its ability to increase this capacity will require an increase in funding” (Section27 & TAC, 2013).

Availability of medicines and supplies is also of concern. Mpumalanga is the third most affected province after the Free State and Limpopo in terms of access and shortage to ART/TB treatment. Out of the 224 facilities that responded to queries in Mpumalanga, 58 (25.9 %) reported ART and/or TB medicine outs or shortages in the 3 months prior to the SSP Stock Outs National survey (HST, 2013). This poses significant problems for health outcomes as the province is the

second most affected province in the country by HIV/AIDS (DoH, 2012). The situation in the Eastern Cape has been described as ‘catastrophic’ and the stock-out of the Mthatha Depot has been well documented by the EHCAC (S27 & TAC, 2013) (See further discussion below, section 5.5.) The implications of drug shortages is particularly dangerous for those on ARVS and TB medication who are put at risk for developing fatal drug resistance.

### **5.2.3. Lack of financial management capacity**

Analysts have linked financial problems in the health system with a lack of capacity, both in terms of sufficient personnel and the ability of current employees to allocate resources efficiently. This is linked to the issue of attracting and retaining critical skills. Further problems include poor management of contracts for infrastructure development and weak supply chain management, largely due to bloated administrative bureaucracy that creates overly-complex and highly inefficient systems for expenditure.

In the Eastern Cape the financial situation Has been said to be in crisis. This has been spotlighted by the work of the EHCAC. The provincial DoH has been described as being in financial crisis. Analyses of the provincial budget point to “longstanding problems with the management of the health budget, which have persisted for more than a decade. Underfunding, poor financial management and corruption are endemic and persistent features of the Eastern Cape health system” (Eagar in Section27 & TAC, 2013). Eagar (2012) has identified several common problems in provincial budgeting that appear to explain the state of finances in the Eastern Cape:

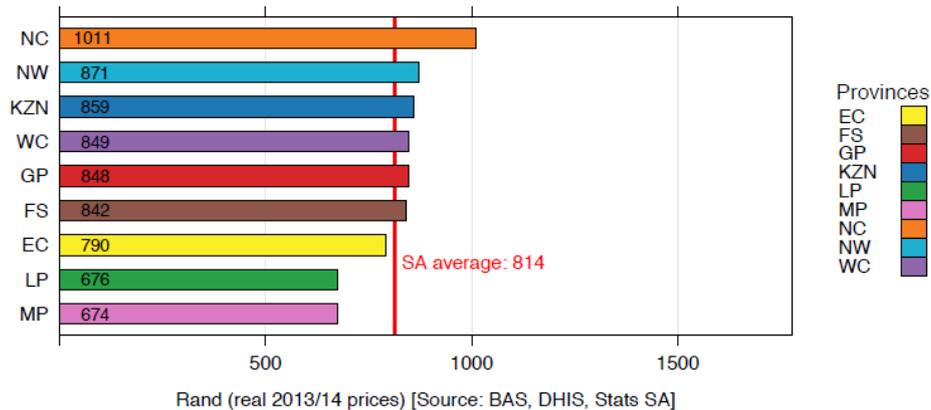
- 1) an annual over-spend on employee compensation, including drawing off funds allocated to infrastructure, equipment, and medicines. Part of this is also related to the compensation of staff members no longer employed by the department, due to the faulty remuneration system (PERSAL).
- 2) interventions that are already underway, but not budgeted for, place pressure on the budget.
- 3) failing to devolve authority to districts and centralising administration at the provincial level (e.g. purchasing goods and services) is highly inefficient.
- 4) ongoing corruption and fraud robs millions from provincial budgets on a yearly basis.
- 5) Monitoring and Evaluation systems are dysfunctional or non-existent.

In 2012 *Section27*, *TAC*, *RHAP* and other partners reported a massive shortfall of between R2.5 and R3 billion. The budget at the time was considered insufficient to meet the department’s needs and thus likely to negatively affect provincial service delivery. At that time problem areas included a growing demand on services due to increased disease burden, poor budgeting resulting in underfunded or unfunded initiatives, and poor management systems and corruption (Eagar & Heywood, 2012). Civil society at that time requested greater clarity on the extent of the crisis (Eagar & Heywood, 2012).

#### 5.2.4. Underspending on budgets and unmet needs

Underspending on health budgets is a symptom of poor financial management. This is related to a lack of capacity, both in terms of capable personnel, but also in terms of the capacity to utilise available resources. This is a problem in both the Eastern Cape and Mpumalanga and, when considered in relation to the regions' deprivation measures, spending is clearly not aligned with the levels of need. Based on the expenditure in these areas, one can assume that high levels of unmet need remain. Provincial expenditure per capita is shown in the figure below.

**Fig. 9: PHC expenditure per capita (uninsured) by province, 2013/14**



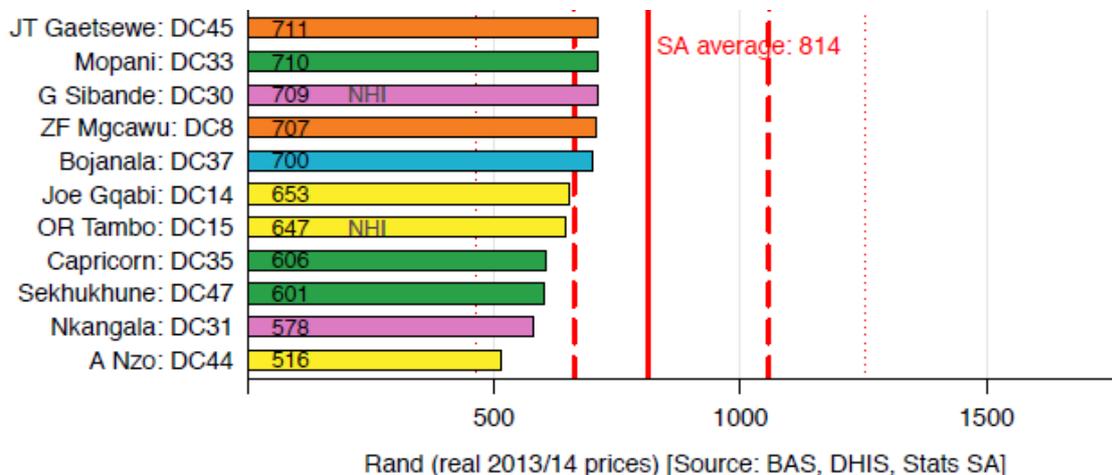
Source: DHB 2013/14

It is possible to see that in Mpumalanga spending per capita on primary health care is the lowest of all provinces (at R674 per person not covered by a medical scheme) as indicated in the figure 9 (DHB, 2013/2014). This obviously compares poorly to the national average (which is R814) (Massyn et al., 2014). The Eastern Cape also has among the lowest spending per capita on primary health care, despite being the most deprived province (Massyn et al., 2014). In particular, underspending on hospital revitalisation grants in this province is a concern, particularly given the need for improving infrastructure, discussed above. In 2012 the province was reported to have underspent by 52 percent (R191 million) (Bateman, 2012). The following year this figure dropped to 32% (R218 million), according to the Public Service Accountability Monitor (Mtslango, 2013).

A major problem has been that funds are distributed on the basis of historical budgeting (i.e. what was allocated in the past) and tend to be allotted to areas with greater absorptive capacity (i.e. working infrastructure and staff to make use of the funds). This distribution of funding results in the capacity trap discussed earlier. Yet, "there has been increased equity in resource allocation over the past 10 years and more spending has been allocated to those districts that are most deprived. However, these averages conceal some districts in the most deprived socio-economic quintile (e.g. Alfred Nzo and OR Tambo, both in the Eastern Cape) which have per capita expenditure below the average for South Africa" (Massyn et al., 2014, p. 6). Gert Sibande District, of all the NHI pilot sites, has the second lowest primary healthcare expenditure per capita at R709, followed by OR Tambo at R647. Figure 10 shows O.R. Tambo district is one of the bottom five districts in terms of primary healthcare expenditure per capita, despite it being one of the most

deprived areas in the country. The implication is that SRH needs are not being met on the supply side in these districts.

**Fig. 10: PHC expenditure per capita (uninsured) by district; lowest ranks out of 52 - 2013/14**



Source: DHB 2013/14

### 5.2.5. Corruption

The Eastern Cape provincial department’s inability to implement and oversee proper systems of financial management and accountability has led to endemic fraud and corruption. Various audits and inquiries in recent years have shown that tens of millions of rand are stolen on an annual basis due to a combination of fraud, improper oversight and poorly managed supply chain systems (S27 & TAC, 2013). For instance, Madras-Nelson (2012) reports that the Superintendent-General’s (SG) audit showed that the department was suffering from corruption within the supply chain, the tender processes, and human resource management. 3,000 people were registered more than once on the supplier database, duplicate payments were being made to single companies (totalling a theft of R34, 109,375.56), tender fraud was commonplace and ‘the most expensive’ form of corruption, and a quarter of the staff were illegally receiving government grants. The exposure of these problems resulted in death threats against the SG. Similarly, a Special Investigations Unit (SIU) investigation revealed that between January 2009 and June 2010 DoH officials and their associates defrauded the department of more than R800-million (S27/TAC, 2013).

### 5.2.6. Staff shortages and distribution of expertise

The national average is 55 doctors and 383 nurses per 100,000 people. This falls short of the World Bank’s recommendation (which includes economic criteria) of a general ratio of 180 doctors per 100 000 people. As a middle-income country this rate is much lower than equivalent middle-income developing countries like Mexico (198 per 100 000) and Brazil (185 per 100 000) (George et al., 2012). At present there is a staff shortage in the Eastern Cape public health system and Mpumalanga too is confronted with significant staff shortage (George et al., 2012). An investigation by the South African Human Rights Commission (SAHRC) in 2013 found that healthcare facilities in the province were suffering from critical shortages of doctors, nurses and

other healthcare professionals (SAHRC, 2013). The Eastern Cape also suffers from a high post vacancy rate (RHAP, 2013). The current vacancy rate is reported as 46 percent (Section27 & TAC, 2013; Bateman, 2012).

Vacancy rates in general are related to the failure to produce, as well as to harness and retain, skilled professionals. It is also a result of attrition from the system (George et al., 2012). The problems with financial management and infrastructure outlined above have been linked to problems with staffing in the province, as noted above (Mtsolongo, 2013; Section27 & TAC, 2013). PSAM linked this under-spending on infrastructure to the high vacancy rate experienced in the Eastern Cape province:

So far, the slow pace of upgrading of these facilities has posed an enormous challenge for many critical clinical health care staff in efficiently attending to health care clients. In many cases this has led to the discouragement and loss of many health care workers, particularly those based in less developed parts of the province. That in itself has created a double blow for the province where the Department has been left with many vacancies to fill as a result of critical staff shortages (Mtsolongo, 2013, p. 7).

In the Eastern Cape healthcare workers have also been reported as leaving the system due to difficult working conditions or becoming ill, and often leave for other provinces (RHAP, 2013; Section27 & TAC, 2013).

#### 5.2.7. Skewed staff distribution across the system

The issue is not just one of sheer numbers, but also the distribution of skills and expertise within the system (RHAP, 2013). Several evaluations of South African human resources for health have drawn attention to the skewed distribution of staff between the public and private health sectors and between rural and urban areas (George et al., 2012). This is certainly true for the Eastern Cape, Mpumalanga and other ‘rural provinces’. The Eastern Cape province has one of the highest vacancy rates for all health care professionals, as well as for specialists (RHAP, 2013). The ratio of doctors and nurses to the population has remained relatively low when compared with the national average and in comparison to other provinces, as illustrated in table 4. Rural provinces are shaded in green.

**Table 4: Ratio of health care workers across provinces by year**

Province	<i>Medical practitioners per 100 000 population</i>			<i>Professional nurses per 100 000 population</i>	
	Year			Year	
	2001	2004	2010	2006	2008
GP	173	126	102	565	529
WC	182	147	135	543	512
KZN	70	52	53	456	492
FS	69	54	55	387	410
NC	54	42	37	370	339
MP	42	30	50	286	290
EC	34	27	31	289	328
NW	30	23	20	336	403
LP	21	18	17	303	365

Source: George et al., (2012)

Table 5 summarises the distribution of healthcare personnel across provinces, according to geographical location (rural/urban) and sector (public/private).

**Table 5: Number of medical practitioners per 10 000 pop**

	EC	FS	GP	KZN	LP	MP	NC	NW	WC	SA
Public	2.97	3.00	4.02	4.69	2.68	3.16	5.39	2.30	4.52	3.66
Private	1.77	3.10	7.32	2.93	0.97	2.11	1.97	2.37	7.64	3.76
Total	2.53	3.04	5.23	4.05	2.06	2.77	4.13	2.32	5.67	3.70

Source: RHAP (2013)

As this table shows, the urban provinces tend to have more medical practitioners and a higher concentration of practitioners in the private sector. The Eastern Cape has one of the lowest numbers of practitioners, but more public than private doctors (RHAP, 2013). The lesser number of doctors in private sector may have to do with poor medical aid coverage in the province (Eagar, personal communication).

The preceding discussion highlights particular problematic areas in the regions reviewed, indicating that there is still much to be done in terms of improving services and access to services. As mentioned in chapter 2, in order for people’s SRH needs to be met the overall system needs to be functional and accessible. In the following section we focus in on SRH services in particular and how particular issues, such as unintended and/or early pregnancy and maternal mortality, are exacerbated by poor service delivery and access barriers.

### 5.3. THE STATE OF SRH IN THE FOCAL AREAS

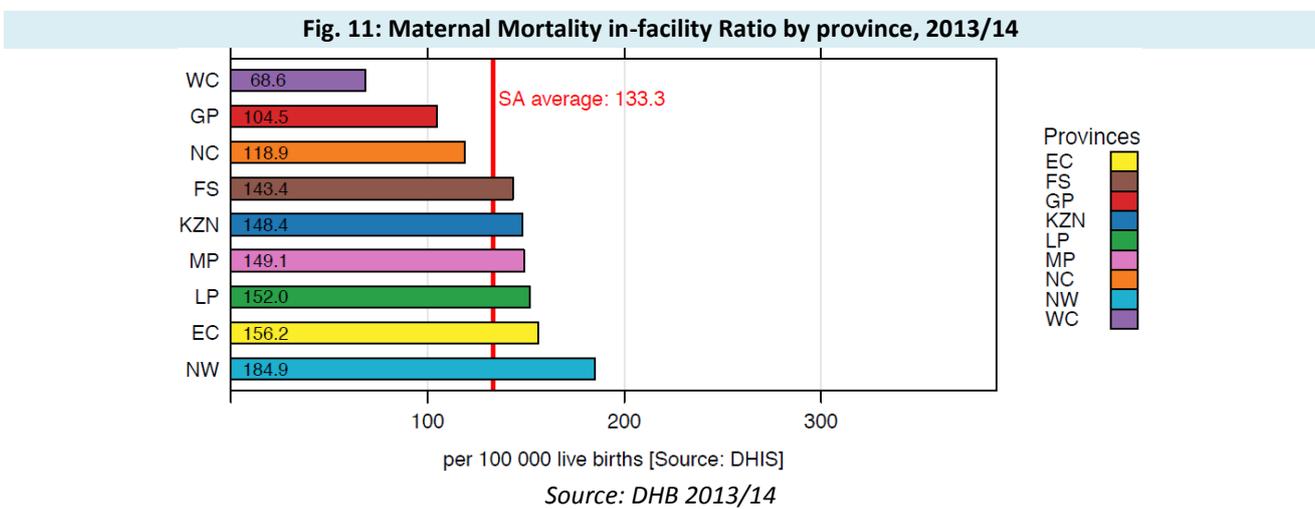
Specific problems identified in reports and academic literature, which are discussed in detail below, include a high HIV infection rate; high rates of maternal and pregnancy-related mortality, low rates of presentation for antenatal care (ANC) before 20 weeks of pregnancy; and high teenage pregnancy rates. The discussion below provides a description of the state in both the Eastern Cape and Mpumalanga provinces, for the purposes of establishing a baseline, as well as offering some analysis regarding the contributing factors and consequences of these issues.

#### 5.3.1. Maternal mortality

South Africa’s performance in relation to women’s/maternal health services is poor, given its situation as a middle-income country with a sizable health infrastructure, available staff, legal abortion, free health care for pregnant women and high levels of utilisation of delivery services (DoH, 2011a). The situation, much like other facets of women’s health, is paradoxical, according to Osman (2011). “The last Demographic and Health Survey (DHS) of 2003 states that 90 percent of pregnant women received antenatal care and 91 percent of births were attended by a skilled health practitioner, yet the latest estimates of maternal mortality in the country approximate the maternal mortality ratio (MMR) at up to 625 per 100 000 live births” (Osma, 2011). Although there have been improvements since 2011, (See Kassebaum et al (2013)) the rate remains far higher it ought to be, making it unlikely that the fifth Millennium Development Goal<sup>viii</sup> will be met (DoH, 2011a;

Ramkissoon et al., 2010). It has been estimated that 60% of deaths related to pregnancy, childbirth, and termination of pregnancy are avoidable (NCCEMD, 2012). It must be noted of course that data on maternal mortality are difficult to gather and evaluate, since increased numbers can be a result of both increased reporting and actual deaths. Nevertheless, the consensus is that maternal mortality is increasing and thousands of women still die needlessly each year (Stevens, 2012).

The **Eastern Cape**, according to the district health barometer, is among the four provinces that have showed increases in their maternal deaths (along with Free State, North West and the Western Cape) (Massyn et al., 2014). “Of all South Africa’s nine provinces, the Eastern Cape had the highest increase in maternal mortality between 2001 and 2007, and has the highest levels of infant mortality (children dying under the age of one), the second highest number of child deaths under the age of five, and the lowest rate of facility deliveries” (Human Rights Watch, 2011, p. 4). The figure below shows the MMR by province, with the Eastern Cape showing the second highest ratio. The four provinces with the highest ratios, notably, are all rural provinces.



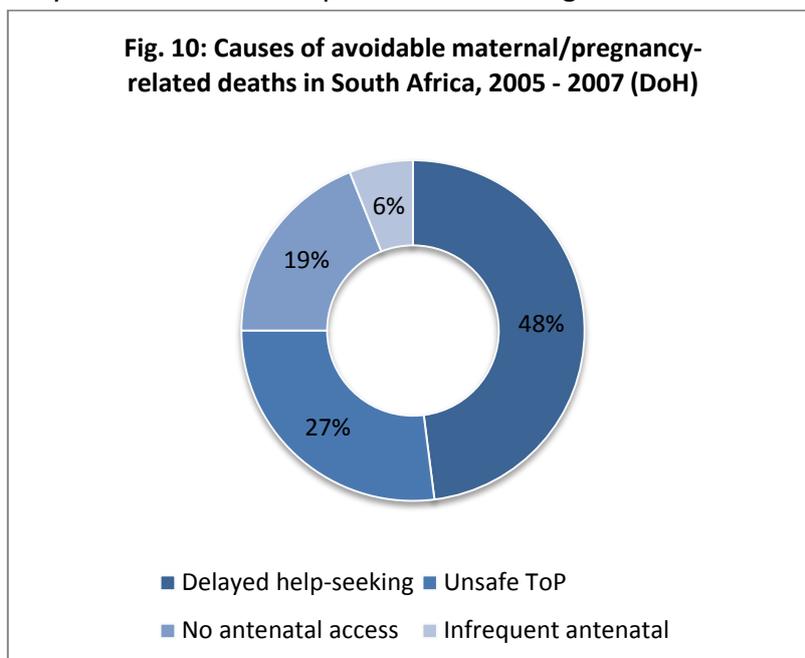
At the district level, O.R. Tambo also shows poor performance in relation to maternal and pregnancy-related deaths. The key indicators for this district are summarised in the table below (Massyn et al., 2014). In comparison to other districts, OR Tambo was ranked the third worst in relation to maternal mortality.

**Table 6: Key maternal mortality statistics, O.R. Tambo District**

O.R. TAMBO DISTRICT	Maternal deaths	Live births	MMR
	74	32,220	229.7

It is also possible to see from figure 11 above that **Mpumalanga** too experiences a high rate of pregnancy-related mortality. It has been reported that this rate has also increased in Mpumalanga and is currently at 197.1 per 100 000 live births - a considerable increase from 76.4 per 100 000 live births in 2011/12 and a rate much higher than provincial and national averages. This spike is also reflected in the Gert Sibande District where maternal mortality has doubled from 76.4 deaths per 100 000 live births in 2011/12 to 187.6 per 100,000 in 2012/13 (Antenatal Health Statistics, 2012; NSP Review 10).

The main reasons behind South Africa’s high rate of pregnancy-related deaths are related to high levels of inequality, the impact of HIV, and systemic issues, including poor administrative and financial management, poor quality care, and lack of accountability (DoH, 2011a; HRW, 2011). A recent report by Amnesty International (2014) also highlights presentation for antenatal care as an important factor. A number of studies also show the role of abortion stigma and illegal abortions in contributing to mortality among pregnant women (DoHa, 2011; Stevens, 2012). The leading causes of avoidable pregnancy-related deaths are presented in the figure below.



Source: Morison, 2013

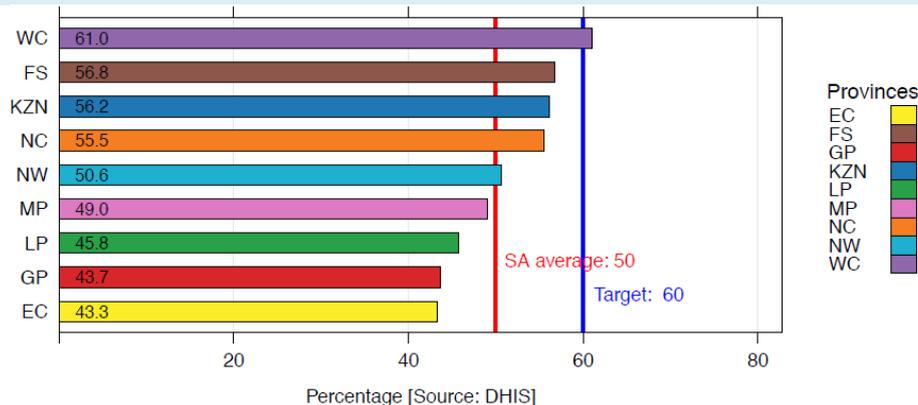
According to Amnesty International (2014), “Appropriate and timely antenatal care plays an important role in improving maternal and child health, and preventing maternal deaths ... Early attendance at antenatal clinics is particularly important for pregnant women and girls living with HIV [who] ... are over five times more likely to die during pregnancy or shortly after birth than those without the virus” (p, 9). Delays in accessing ANC have been linked to a quarter of avoidable maternal deaths (Amnesty International, 2014).

### 5.3.2. Access to Antenatal Care (ANC)

Many pregnant women’s first attendance at antenatal care is later than is desirable. Less than 30 percent book before 20 weeks gestation, with a large number accessing services later in pregnancy. The lowest rate of antenatal first visits before 20 weeks is in the Eastern Cape, as shown in figure 12 below. At the district level, approximately one third (18 out of 52) of all districts are reported as having rates below the national average of 50%, with six out of eight districts in the **Eastern Cape** (EC) in this group, including OR Tambo, which had a rate of 34.4% (Massyn et al. 2014).

In **Mpumalanga** 49% of women have their first antenatal care visit before 20 weeks, just shy of the national average of 50% and falling far short of the target of 60% (DHB, 2013/2014). At a district level, antenatal care is at a much lower 42.1%, leaving Gert Sibande District ranked as the third lowest NHI district (after OR Tambo and Tshwane) (DHB, 2013/2014).

**Fig. 12: Antenatal 1st visit before 20 weeks rate by province, 2013/14**



*[Source: District Health Barometer 2013/14]*

A number of contributing factors for low early ANC attendance rates have been identified. The District Health Barometer lists the following:

- Unavailable or poor quality pregnancy test kits, or when these are available, they are of poor quality;
- clinic inaccessibility;
- negative staff attitudes;
- clinic overcrowding resulting in pregnant women being given alternative booking dates;
- lack of social responsibility and cultural issues cited as confounding factors; and
- the perception in many communities that a pregnancy should be 'visible' before women go to clinics (Massyn et al., 2014).

Amnesty International (2014, p. 10) found that factors for delay or avoidance of ANC include:

- Lack of privacy, patient confidentiality and informed consent at health facilities, especially around the implementation of HIV testing during antenatal care.
- Lack of information and knowledge about sexual and reproductive health and rights, including lack of training on the part of health care workers.
- Persistent problems relating to the availability and costs of transport.
- Hostile and moralistic treatment by health care workers, with young women who are pregnant.

They report that these factors are compounded by social factors linked to poverty and gender discrimination, which often increase during pregnancy.

Rurality also plays a role in that many women from remote areas cannot afford transport or experience poor emergency medical services, especially ambulance services that cannot, or will not, travel to rural areas (Eagar, personnel communication). The issue has also been raised as a persistent one, reported on in the rapid appraisal of service delivery in 2006 and also more recently highlighted by the ECHCAC. It was noted in the public hearing to the SAHRC that the vast majority of the former Transkei has no ambulance service (SAHRC, 2013). In the **Eastern Cape** Province an

investigation by Human Rights Watch, published in 2011, focused on 16 health facilities in O.R. Tambo, Amatole, and Nelson Mandela Metropolitan Municipality districts. The investigation reports the following issues: substandard care and negligence; poor communication with patients; problems with informed consent; physical and verbal abuse; services in exchange for “gifts” or bribes; poor patient awareness of rights and complaints procedures; and a severely compromised complaint procedure. The result was that many women, especially migrants and refugees, delayed or avoided seeking care; the few who could afford to do so, paid for help in the private sector.

Similar problems of inadequate and safe transport have been reported in **Mpumalanga**. For example, Amnesty International (2014, p. 48) reports that in "remote rural communities and women and girls who live and work on commercial farms .... have to find their way from the farm to the main road, and then pay for transport or walk to the nearest clinic. A health care worker in Mpumalanga confirmed that many women from farms start antenatal care late for this reason". These findings are corroborated by findings from the DoH Confidential Enquiry into Maternal Deaths, which cite poor transport facilities, insufficient resources and tools, lack of emergency health care facilities, and shortage of appropriately trained staff as factors (DoH, 2012).

### **5.3.3. Access to & utilisation of safe Termination of Pregnancy (ToP) services**

Improving the quality and coverage of reproductive health services, namely contraceptive and safe abortion services, has been recommended for reducing the number of maternal/pregnancy-related deaths (Orsmon, 2011; Stevens, 2012). Access to safe pregnancy termination services has significantly reduced abortion-related mortality (by 90%) since the CTOP act's introduction in 1996. Nationally the number of Terminations of Pregnancy performed continues to rise; this likely indicates improved access to this service but at the same time cautions that access to contraception might not be adequate for all women (DHB, 2013/2014). While numbers are increasing, access to TOP facilities remain constrained (Macleod & Tracey, 2009).

Over the years there has been a steady decline in both the number and type of public ToP services, leading to a gap between policy and accessibility (Ramkissoon, 2010). There is inconsistency in accessibility across provinces. The reliability of collected data has also been questioned, further complicating the problem (DoH, 2011a; Makiwane & Dan, 2010). This trend is suggested by the low number of functioning state facilities, the concomitant rise of abortions in the private sector with decline in the public sector (DoH, 2011a), the persistence of mortalities related to unsafe, illegal abortions (Orsman, 2011). The available data on abortion for the country in general is poor (Makiwane & Dan, 2010), and the data on the functioning ToP facilities does not appear to be disaggregated by province or district. The District Health Barometer reports that in 2011 only 57% of designated facilities across the country were functioning. The Eastern Cape had 58.1% of its facilities functioning in 2003 (10% below the national rate at that time) (Massyn et al., 2014). Mpumalanga has the second lowest percentage of functioning designated TOP sites at 41.7% (Macleod & Tracey, 2009).

The consensus is that services are unevenly distributed and insufficient, particularly in rural areas (DoH, 2011a; Meel & Kaswa, 2009; Ramkissoon et al., 2010). In addition to lack of facilities,

other barriers to exercising the right to choose ToP include: provider attitudes and opposition (Harries, Orner, & Stinson, 2009; Harries, Orner, Gabriel, & Mitchell, 2007); stigma toward both the women seeking abortions (Meel & Kaswa, 2009; Harries et al., 2007) and the health care providers providing abortions (Harries et al., 2012); and poor knowledge of SRH rights (Jewkes et al., 2005; Macleod, Seutlwadi, & Steele, 2014; Meel & Kaswa, 2009). Meel and Kaswa's (2009) research in Umtata in the **Eastern Cape** suggests that these barriers may be exacerbated for women living in rural areas in the former Transkei. The researchers state that "The lack of TOP clinics in rural areas has made many rural folk seek assistance from traditional healers, particularly as they are easily accessible ... speak the patients' language and give the patients a sense of comfort and wellbeing" (p. 80).

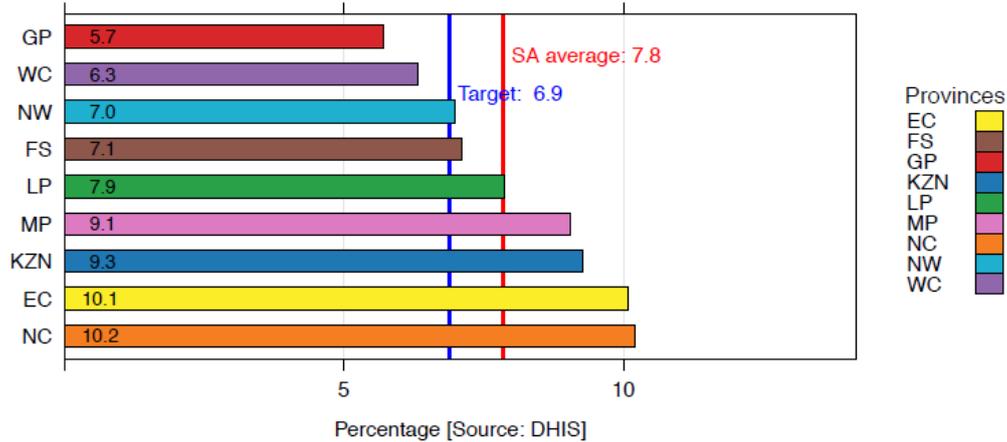
There is evidence that women who are younger and/or HIV positive experience a great deal of opposition from health care workers (DoH, 2011a; Orner et al., 2011). As a result of the inaccessibility of services and the barriers mentioned above, many women who cannot afford private care delay seeking care or resort to illegal abortions (Jewkes et al, 2005). For example, the South African National Youth Risk Behaviour Survey (cited in DoH 2011) reports that of those learners who reported terminating a pregnancy, only half (51.5%) took place in a hospital or clinic. Unsafe abortion therefore persists as one of the leading causes of *avoidable* (and patient-related) causes of death among pregnant women (Osman, 2011; Stevens, 2012), with the latest available data showing that there was a 44% increase in deaths due to unsafe abortions during the period 2004 – 2007 (Stevens, 2012).

#### **5.3.4. Teenage pregnancy**

There has been a downward trend in teenage fertility in recent years (Macleod & Tracey, 2010). Some reasons for this trend could be the uptake of the sub-dermal contraceptive implant by teenagers and possible the impact of the Integrated School Health Programme (ISHP), which promotes contraceptive use and supports in-school peer education and health promotion; although investigation to verify the effect is needed. Most recently, this downward trend has been interrupted, with a slight increase in the delivery rate in facility under 18 years in South Africa<sup>ix</sup> from 7.7% in 2012/13 to 7.8% in 2013/14 (Van Schaik & Day, 2014).

Provincially, the **Eastern Cape** had the second highest delivery rate in facility under 18 years for the past year (10.1%), only slightly lower than the Northern Cape (10.2%) (Massyn et al., 2014). This is evident below in figure 13. In **Mpumalanga**, the delivery rate in facilities for women under the age of 18 years is recorded as 9.1%, a marginal increase from the previous District Health Barometer. This is compared to the national average of 7.8% and the target is 6.9% (DHB, 2013-2014). Mpumalanga reported the highest provincial prevalence of learners indicating that they have been involved in a pregnancy, as per the SA National Youth Risk Behaviour Survey (Reddy et al., 2003). Both Mpumalanga and the Eastern Cape rank as the provinces with the lowest age of sexual debut (i.e. younger age of first sex) (Pettifor et al., 2005).

**Fig. 13: Delivery in facility under 18 years rate by province, 2013/14**



Source: DHB, 2013-14

At district level, the **Eastern Cape** also had four of the five districts with the highest delivery rate in facility under 18 years; although it must be noted that these districts have a higher percentage of the population aged 10 to 17 years, partially explaining the higher rates. In addition, eight of the 11 NHI pilot districts had delivery rates in facility under 18 years higher than the national average (of 7.8%), including O.R. Tambo where the rate was 12.2 percent. This makes it the third highest rate by district (along with JT Gaetsewe, in the Northern Cape, which also had a rate of 12.2%) (Massyn et al., 2014). In **Mpumalanga**, Gert Sibande recorded a delivery rate for teenage women of 9.9%. It is noted in the District Health Barometer (2013/2014) that increased uptake of sub-dermal contraceptive implants coupled with improved roll-out of the Integrated School Health Programme (ISHP) with its focus on contraception use, may reduce teenage pregnancy over time.

There is a wealth of literature in South Africa that explores the causes and consequences of teenage pregnancy (see Macleod & Tracey (2010) for a review). Some reasons offered as contributing to teenage pregnancy include: knowledge and use of contraception, timing of sexual debut, age of male partner, violent/coercive sexual relations, cultural factors, and health service provision (Macleod & Tracey, 2010). Massyn and colleagues (2014) provide some reasons for the high delivery rate mentioned above in the District Health Barometer. These include: a failure or lack of education through school health programmes; cultural issues including that one should have a child before marriage; and poverty. They also stress the importance of access to contraception and education. Indeed, Macleod and Tracey's (2010) review of the literature highlighted these issues in the Eastern Cape. The research indicates that young women in the Eastern Cape, along with those in Mpumalanga, from rural areas and with lower levels of education, reported the lowest condom use. The age of sexual debut has also been found to be particularly low in the Eastern Cape (and Mpumalanga). This is frequently related to an inability to negotiate sex, due to the age of the male partner, transactional, and coercive sex.

As noted, the Eastern Cape Province and OR Tambo district in particular are incredibly impoverished areas and the link between poor reproductive health, and unwanted or unsupportable pregnancies in particular, is well established (WHO, 2010). The intersection of

poverty with unequal gender power relations puts young women in a vulnerable position, often trapping them in a cycle of poverty (Amnesty International, 2014). Young mothers may not be able to finish schooling and may experience insecure employment or be consigned to lower-paid or unpaid labour. This may result in economic dependence on men, including through transactional sex, and mean that they remain stuck in abusive relationships, have less control over resources and decision-making power, including in relation to sex and reproduction (Amnesty International, 2014; DoH, 2011b). Indeed, poorer women are vulnerable to unintended (and unsupportable) pregnancy and their chance of contracting HIV is increased by 13% compared to other women (Amnesty International, 2014).

#### 5.4.2. Access to contraceptive methods

As mentioned above, access to contraceptive methods is an important factor for preventing unintended teenage pregnancies, and for better health outcomes in general. As stated in the National Contraception and Fertility Planning Policy and Service Delivery Guidelines (DoH, 2012),

Contraception is one of the most powerful public health tools for any country. Providing women with access to safe and effective contraception is a critical element of women's health. Enabling women to make choices about their fertility is empowering and offers women better economic and social opportunities. Birth spacing also improves the opportunities for children to thrive physically and emotionally. Engaging men in sexual and reproductive health encourages shared responsibility in their roles as partners and parents (p. 2).

The Couple Year Protection Rate (CYPR), a crude indicator to evaluate dispensation of various contraceptive methods, measures the percentage of women 15 to 49 years who are protected against unplanned pregnancies for a year using different contraceptive methods. The CYPR in South Africa remains low. After remaining static the CYPR has steadily increased in all provinces (except Free State) since 2011, and increased by 6.1 percentage points in **Mpumalanga** in the year 2013/2014 to reach the national target of 36.0%. The **Eastern Cape** lags behind however, with a rate of 30.9% (Van Schaik & Day, 2014). It is one of the provinces with a higher percentage of unmet need for contraception than the national average. These statistics are however not disaggregated to indicate access to and uptake of contraceptive methods by vulnerable or marginalised groups. This is part of a general lack of evidence regarding unmet needs for contraception (DoH, 2012).

It is noted in the District Health Barometer (2014) that the performance of the NHI districts varied greatly and included both the best and worst performing districts. **Gert Sibande District** however reported a CYPR percentage close to the national target, at 35.6% (Van Schaik & Day, 2014). **O.R. Tambo District** falls short of this target with a rate of 29.2 *percent*. As noted, there is a lack of research on contraceptive use and need, but some studies have been conducted in **Mpumalanga**. Research by Mbokane and Ehlers (2006) conducted in the Gert Sibande District, cites "non-availability of certain contraceptive methods, counselling received about the method of choice, the attitudes of the providers, lack of equipment and resources, [and] side-effects occurring as a result of using contraceptives" as some of the challenges that hinder access to and effective use of contraceptives in the district (p. 45). Research in Philadelphia District in Mpumalanga

supports the finding that inadequate pre-contraceptive counselling, particularly about side-effects, contribute to non-compliance and discontinuation of contraceptives, as reported by women who access ToP services (Van Bogaeret, 2003). Other reported reasons include being denied access to contraception by clinic nurses, partners or family members as well as distance to healthcare facilities and the costs of transport (Van Bogaeret, 2003).

#### **5.4.1. HIV prevalence**

The incidence of HIV infection plays a crucial role in SRH in the country, and often receives the most focus in terms of SRH programming, intervention, and research. There is therefore an extensive body of research on HIV its causes, consequences, and socio-cultural dimensions. Nevertheless, the country remains encumbered by the largest burden of HIV/AIDS and has the largest antiretroviral treatment (ART) programme in the world. **Mpumalanga** is one of the top four provinces in terms of prevalence rates. Antenatal HIV prevalence among women is currently at 35.1% and sexually transmitted infection prevalence at 14.1%. Furthermore, similar to national statistics, women in general are disproportionately affected by HIV compared to men, with overall prevalence rates of 14% and 9.9% respectively (Shisana et al., 2014). The Gert Sibande district has the highest HIV rate among pregnant women in South Africa (46% in 2013) and the antenatal client initiated on ART rate is at 75.1% - while in line with the provincial rate of 74.2%, it remains below the national target of 90% (NDH, 2011). The **Eastern Cape** fares somewhat better in terms of prevalence. The HIV prevalence among antenatal women is reported at 29,9% (ECAC, 2012). The provincial prevalence rate stands at 11.6% (Shisana et al., 2014), somewhat lower than other provinces, but it has the third highest number of new infections, at an estimated annual incidence rate of 1,5%, which is slightly higher than the current national incidence rate of 1,2% (ECAC, 2012).

Government healthcare facilities do not collect systematic data on HIV prevalence among Most-at-Risk Populations (MARPS). Shisana et al. (2014) identify some of these as younger Black women (20–34 years), Black males aged 25–49 years, disabled persons, high-risk alcohol drinkers (15 years and older), and recreational drugs users. Sexual and gender minorities have also been flagged as being most-at-risk (Lane et al., 2014). SRH-related data for these groups are not available. There is, however, one study that reports on MSM and HIV prevalence and risk in the province: The Mpumalanga Men's Study (MPMS) provides baseline data on HIV prevalence and associated risk behaviour, as well as HIV testing, treatment and care among men who have sex with men in two districts in Mpumalanga- Gert Sibande and Ehlanzeni (Lane et al., 2014). The baseline findings indicate that HIV prevalence is highest among MSM in Gert Sibande (28.3%) compared to Ehlanzeni with an HIV prevalence of 13.7%. Gert Sibande is also characterised by low HIV testing and treatment seeking behaviour among MSM (Lane et al., 2014). Emerging research points to previously unacknowledged HIV prevalence among lesbian women, ranging between 5% and 9.6% in research conducted in Sub-Saharan Africa (Wells & Polders, 2004; Sandfort et al., 2013; see also Matebeni, Reddy, Sandfort, and Southey Swartz, 2013). Sandfort et al. (2013) note sexual violence as the main risk factor for HIV among lesbian women; while there is no province or district specific data regarding lesbian women's vulnerability to violence, high general levels of SGBV point to the

need to ensure adequate HIV and SGBV services to this group. Monitoring and preventing infection among MARPs is crucial to reducing overall prevalence rates. “For this reason, it is necessary to identify the most-at-risk groups in order to encourage those implementing interventions to increase the resources directed to this population” (Shisana et al., 2014, p. 53).

#### **5.4. SOCIAL BARRIERS TO SRHR SPECIFIC TO TARGETED MARGINALISED GROUPS IN FOCAL AREAS**

The above review has pointed to particular barriers both within the healthcare system and beyond. As discussed, there are several **systemic obstacles** that threaten the realisation of SRH rights, especially for under-represented, vulnerable, and marginalised groups, these present in the form of access barriers that prevent certain people from accessing services and/or constrain their choices within the system (Ramkissoon et al., 2010). “The evidence is consistent that certain population groups – such as the poor, women with less education, those living in rural or remote areas, and adolescents; are underserved by current services. Evidence is mounting that the needs of other population groups – such as migrants, ethnic minorities, and individuals with disabilities; are also not being met” (WHO, 2010, p. 9).

Systemic problems affect accessibility and uptake of SRH services, viz., lack of availability, access to, or poor provider knowledge of medication, contraception, or services (e.g. PEP); lack of particular treatments or services in the public sector (e.g., medical abortion); cost of certain procedures, services, or treatments (e.g. the HPV vaccine); lack of services for diverse populations; and lack of specialised knowledge among HCWs. Women’s options are limited by a lack of options to prevent pregnancy, including ToP and particular kinds of contraception; a lack of information on contraception and fertility options, the inability to use contraception consistently and effectively (due to lack of supply or power dynamics in heterosexual partnerships); ignorance of HIV status when pregnant; and drug interactions, for which little research is being done. The SRH needs of diverse women (who deviate from the norm in some way) are even more marginalised, since “SRH services, except for HIV and AIDS services, predominantly target adult [heterosexual] women of reproductive age” (DoH, 2011a). Most information and programming for men is virtually non-existent. Ultimately, these gaps limit the sexual and reproductive choices that are available to people and reduce their ability to exercise their SRH rights (DoH, 2011a; Ramkissoon, 2010).

In South Africa, another major systemic problem for SRHR in terms of the health system itself, cited by several researchers, is the fragmented nature of services (Cooper, Mantell, Moodley, & Mall, 2015; DoH, 2011a; Ramkissoon et al., 2010; Stevens, 2008). Bateman (2013) illustrates the problem:

Imagine a pregnant woman going to a provincial clinic for prenatal care. The moment her baby is born, she has to visit a municipal clinic for the child’s immunisation. If that child falls sick she has to go back to the provincial clinic. She’s counted as two patients. Instead of one nurse seeing the mother and baby and doing it all, there was this enormous, artificial workload!

In addition to the inefficiency, this system also has cost implications both tangible (e.g. transport) and intangible (e.g. time off work, emotional strain) and most disadvantages those living in remote,

rural areas (DoH, 2011a). There is also evidence that this approach may exacerbate stigma by reducing privacy.

The SRH issues discussed above cannot be treated separately from their social antecedents and effects and thus, the social drivers of these issues—notably poverty, gender power imbalances, and violence—need to be made central to their prevention and treatment (WHO, 2010). The analysis of secondary data indicates that barriers to exercising SRHR and constitutional rights, are compounded for groups marginalised on the basis of HIV status, gender, gender identity, sexual identity, and geographical location (rural communities). It is important to attend to **social barriers** that prevent people from exercising their SRH rights; we discuss some of the main social barriers for targeted communities in the Eastern Cape and Mpumalanga in the sections below.

#### **5.4.1. Stigma and discrimination**

As mentioned (in chapter 2), “sexual and reproductive health services often evoke judgemental and moralistic attitudes among providers – as well as among members of communities in which services are situated” (WHO, 2010, p. 8). Negative judgements and attitudes are therefore encountered both within the system, from healthcare workers, and beyond, within the community, and both act as significant barriers to care-seeking, access to and use of preventative services, care, and treatment (WHO, 2010). They can also make people susceptible to further poor SRH outcomes.

Within the system, much literature documents rights violations by health workers; much of this is as a result of stigma and discrimination. As discussed in the review of the literature, and also intimated in the preceding discussion, those who often experience punitive and judgemental responses from health workers are young people (; O’Reilly & Washington, 2012; Jewkes, Morrell, & Christofides, 2009); pregnant young women and young mothers (Amnesty International, 2014; HRW, 2011); women with HIV who are or want to become pregnant (de Bruyn, 2005; Essack & Strode, 2012; HRW, 2011); women seeking ToP (Stevens, 2012; Trueman & Magwentshu, 2013); migrants (HRW, 2011); sex workers (Richter & Chakvinga, 2012); and members of sexual and gender minority groups (Lane et al., 2014; Müller, 2014; Rispel et al., 2011). In OR Tambo, AIDS stigma has been found to be a particular barrier. In 2012, The National Association of People living with HIV and AIDS in South Africa, reported that “HIV-related stigma and discrimination is ongoing and acts as a barrier for people living with HIV to access HIV prevention, treatment and care services in OR Tambo District” (p. 11). The researchers maintain that “over 10% of respondents (11.2%, n=89) reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions”. The majority of these respondents (79.8%) did not seek redress for rights violations, many felt intimidated or scared to take action. This points to the client-provider power dynamic (WHO, 2010), which complicates the issue of holding service providers accountable for violations, as raised by Human Rights Watch in their investigation in the Eastern Cape discussed earlier (HRW, 2011).

#### **5.4.2. Breaches of confidentiality**

There is also evidence that fear of community gossip or negative responses prevent people from accessing services (Amnesty International, 2014). (This finding was corroborated in the qualitative component of this baseline study. See chapter four for a discussion of this in relation to the interviews conducted.) This is particularly problematic in smaller towns and villages, where health workers and patients often know one another. In such cases, especially in rural settings, people sometimes travel to neighbouring villages or larger cities in order to access services, particularly for pregnancy termination. This is a strategy that people working in the Eastern Cape report being used in the OR Tambo district (Eagar, personal communication). The need to travel to another facility to avoid stigma and breaches of confidentiality places an unfair burden on already marginalised persons and disadvantages those who cannot afford to do this. For those living with HIV/AIDS, for example, “being HIV-positive confers a disadvantage and reinforces existing inequalities” (NAPWA, 2012, p. 11) such as exacerbating poverty, creating social exclusion, and preventing access to employment and education. The investigation of the National Association of People living with HIV and AIDS in South Africa (2012) showed that people with HIV in O.R. Tambo district are excluded from social gatherings, family activities, religious activities and places of worship. They also reported fears of being gossiped about.

The literature points to the relationship between multiple conditions of vulnerability—which interact in complex ways—and sexual and reproductive health outcomes. Social determinants together with systemic issues, are a challenge, particularly in an area of health “which is highly sensitive and susceptible to fluctuations in political pressure and public opinion” (WHO, 2010, p. 9) and thus also to fluctuations in political will and funding. Many of the gaps and barriers in the health system, particularly with respect to marginalised populations, are addressed by civil society organisations. In the following section the work of two such organisations, who are implementing partners in the *AFSA* programme, is reviewed, viz., *Section27* and the *TAC*. In addition to looking at the scope and the focus of their work, the planned work for the *AFSA* project is also described. This overview will form a basis for the follow-up research in which the work of these organisations in relation to their mandate from *AFSA* will be assessed.

#### **5.4.3. Lack of targeted programmes for vulnerable groups**

Access barriers for LGBTI persons are not limited to discrimination in the form of homophobia and transphobia, but also result from inappropriate or non-existent services. The NSP notes that men who have sex with men (MSM) and LGBTI persons are groups that have particular “access needs” (MPAC, n.d., p. 58). The extent to which this translates to more than superficial inclusion into the formulation and implementation of targeted intervention programmes is unclear.

There are no established LGBTI-focused NGOs in the province that provide direct health- and psycho-social services to LGBTI persons or advocate for the provision of such services in mainstream healthcare facilities (this is in contrast to Gauteng, KZN and the Western Cape having some, albeit limited, civil society capacity for providing specialised services to LGBTI persons). The consequence of this is that government health facilities cannot benefit from partnerships with

LGBTI-focused organisations and LGBTI persons have no alternative to often inaccessible government provided services. An exception is the recent rollout of the Health4Men programme by *Anova Health Institute* in Mpumalanga, aimed at training clinic staff at selected Mpumalanga Provincial Department of Health referral clinics in providing competent HIV and STI care for MSM (Lane et al., 2014). Further to this, even programmes targeting most at-risk or key populations (MARPS), narrow the focus of such interventions to be MSM-specific, which means that the lesbian and bisexual women and transgender persons are not included in programmatic work.

Sex workers, another vulnerable group identified in the NSP as requiring targeted interventions, face discrimination and health rights violations exacerbated by the continued criminalisation of all aspects around sex work in South Africa. In addition to high levels of stigma and discrimination from health care workers, multiple concurrent partners, barriers to negotiating condom use, unsafe work conditions and lack of services all contribute to high vulnerability to HIV/AIDS and other STI's (Richter & Chakuvunga, 2012). "HIV prevalence among sex workers and sex worker clients is about 10 to 20 times higher than among the general population in sub-Saharan Africa" (SANAC, 2013b, p. 4). Limited targeted programming directed at this group and their clients is cause for concern; both the Eastern Cape and Mpumalanga are provinces with high numbers of migrant workers and are on trucking routes and Mpumalanga is a mining area - all factors associated with a more thriving sex work industry (SANAC, 2013a). In 2013 the 'National Strategic Plan for HIV prevention, care and treatment for sex workers' was launched, providing a framework for service providers to reduce HIV prevalence in this sector and while the current NHI pilot activities do not include a focus on this vulnerable group, civil society advocacy could be directed at encouraging the integration of such a focus (SANAC, 2013b). The national organisation Sex Workers Education and Advocacy Taskforce (SWEAT) has partnered with other organisations to conduct mapping research in all nine provinces that can support the development of a scaled-up coordinated HIV response for this population; SWEAT has an office in the Eastern Cape, providing a potential resource for implementation partners in that province (SANAC, 2013b).

#### **5.4.4. Impact of NHI pilot on improving SRHR of vulnerable and marginalised groups**

The NHI pilots are focused on improving health outcomes for the most vulnerable in South Africa, and amongst others to reduce maternal mortality and the burden of disease borne by women. The different pilot sites were selected based on performance on a number of indicators, including Health Service Performance Indicators of HIV prevalence; antenatal coverage; delivery in facility; and couple year protection rate. Maternal and reproductive health services are prioritised as part of a number of "non-negotiable" components of a successful health system and accordingly to be protected from under-funding (Motsoaledi, 2012). However, the NHI pilot plan makes no specific mention of marginalised or vulnerable groups in key objectives or in activities in support of the objectives. It has no activities aimed at removing barriers to access for targeted communities, such as training healthcare workers (HCW) to provide professional and competent services to LGBTI persons or addressing discrimination by HCWs toward young pregnant women that prevent them from accessing services.

Since the launch of the pilot sites in 2012, several reviews have been conducted to monitor implementation of the NHI. A review of the NHI pilot districts conducted in 2013 focused predominantly on human resource capacity, infrastructure, management and mechanisms for quality assurance; there was therefore no specific assessment of SRH indicators in relation to the NHI pilot (SARRAH, 2014). While the NHI pilot has as one of its key objectives the improvement of access to quality health services, with a particular focus on rural and previously disadvantaged areas, the activities in support of this objective are however limited to harnessing private sector resources, such as GPs and specialists, improving referral systems and strengthening specialist capacity such as District Clinical Specialist Teams (DCST) with the required dedicated senior obstetrician, gynaecologist and midwife, as per the NHI. Performance of the pilot districts has however been variable; for example, Gert Sibande indicated only partial achievement in staffing District Clinical Specialist Teams and the district has a generally poor ability to attract and retain specialists and skilled professionals; only the nursing specialists have been recruited to the DCST ('NHI pilot districts 12 months progress report', 2013; NHI Gert Sibande Business Plan, 2013). This highlights the importance of initiatives aimed at evaluating the impact of the NHI pilot programmes on SRHR of marginalised groups to monitor the establishment, functioning and impact of the DCSTs in the pilot areas. Considering that no monitoring and evaluation data are being collected for groups such as LGBTI persons and sex workers within the mechanisms of the NHI pilot, the need for primary data collection as part of civil society monitoring and evaluation is emphasised.

## **5.5. CIVIL SOCIETY INTERVENTIONS**

This section examines what is being done by civil society organisations in the Eastern Cape and Mpumalanga to combat the collapse of the public health sector in South Africa. The focus is on the work of *Section27* and *TAC* and will also consider the ways that these organisations attempt to address SRHR barriers. As indicated in previous sections of the report, there is a lack of established and sustained civil society activity in more rural provinces such as Mpumalanga and the EC, compared to other provinces such as the Western Cape, Gauteng and KZN. This is especially true for organisations that work with vulnerable and marginalised groups such as LGBTI persons and sex workers, requiring organisations such as *TAC* and *Section27* to be responsive to the need for health rights advocacy for such groups.

### **5.5.1. SECTION27**

*Section27* is a public interest law centre that seeks to influence, develop and use the law to protect, promote and advance human rights. The name is drawn from the section in the South African constitution which enshrines each citizen's socio-economic rights (health care, food, water and social security). The NGO collaborates closely with organisations such as the *Treatment Action Campaign*, *Médecines Sans Frontières*, the *Rural Health Advocacy Project*, the *National Association of School Governing Bodies* and *COSATU* (S27, 2013a). It works across the country and does remedial work—offering legal advice and services, litigating and mediating—in relation to rights violations. In this way it aims to hold government accountable for services not delivered. It also

aims to promote systemic change by informing people of their rights and mobilising them to demand that these be upheld. A key part of the NGOs strategy is that citizens become socially aware and realise their own power in holding government accountable and that they mobilise to do so. Another part of their strategy is building relationships between various civil society bodies (trade unions, CBOs, FBOs etc.). The work done by the organisation for the two years preceding the start of the *AFSA* programme is clearly geared toward this, as summarised below.

It is evident that *Section27* prioritises discrimination and access to legal services in its work. The organisation has provided legal assistance in cases of discrimination. The cases have been in relation to individual's HIV status (e.g. SA National Defence Force; Al Jazeera); and obtaining medication and/or health insurance. The organisation has systems in place for admission and referral of those seeking legal assistance. It also undertook to set up a special legal clinic dealing especially with HIV and TB and health rights. Further to this, S27 has received concessions from insurers to ensure that persons with HIV are able to be covered by medical schemes and have also been involved in establishing local AIDS councils who can assist with holding government accountable and using local knowledge to operationalise the NSPs programmes aimed at marginalised groups (e.g. women, people with disabilities etc.). In addition to discrimination on the basis of HIV status, the organisation has also been involved in ensuring that migrants get access to primary health care. It has worked with other organisations, in the Migrant Health Forum, and attempted to empower migrants by increasing their awareness of their rights. Pamphlets, for example, have been printed for this purpose.

The work of *Section27* is clearly motivated by the general lack of knowledge of human rights and legal awareness. A large part of the NGO's work involves publicising rights violations and systems failures in the mainstream media, as well as through the NSP Review. In terms of campaigns, there are two notable campaigns that are relevant to this review, viz., the Stop Stock-outs project (SSP) and the ECHCAC, the latter utilising a combination of legal strategising along with media advocacy and community mobilisation.

The SSP was catalysed by the massive stock-out of the Mthatha medical depot in 2012, which affected around 300 Eastern Cape facilities and led to the taking over of the depot by the TAC and *Médecins Sans Frontiers* (MSF). It was initiated in partnership with *TAC*, *Rural Health Advocacy Project*, *Southern African Clinicians Society*, *Rural Doctors Association of South Africa*, and MSF. The focus is on anti-retroviral and TB medication. The project has expanded beyond the Eastern Cape and involves the collection of evidence for reports, a national mechanism for reporting stock-outs, and rights awareness workshops. Thus the campaign sought also to empower and transfer knowledge about rights to communities.

The Eastern Cape Health Crisis, as it has been termed, is well documented. In 2013 *Section27* undertook "to focus intensively and systematically on health care services in the Eastern Cape" with the aim of advocating for "meaningful turn-around plans in both Provinces, an end to drug and equipment shortages, as well as active monitoring of these plans" (S27, 2013a). The formation of a coalition in 2013 of 25 organisations was a notable part of the strategy for change.

The efficacy of this campaign appears to have been in the establishment of relationships across civil society. As the founder member *Section27* was able to offer legal expertise—collecting affidavits from people in the Eastern Cape and engaging with the DoH. Partner organisations, notably the TAC, were able to assist with media awareness of the issue and mobilising communities by marching and raising awareness about their rights. This dual strategy put considerable pressure on government to act, producing some changes and commitments to act. In 2013 litigation succeeded in compelling the National DoH to build a temporary clinic in Lusikisiki and commit to the construction of a new day hospital in 2014. Yet, no comprehensive strategy has been produced to date and S27 continues to conduct research, community mobilisation, government engagement and preparing for possible legal action in 2014.

The review of S27’s work show that it revolves around access to health care in general, with an emphasis on HIV, AIDS, and TB. Insofar as barriers to SRHR are addressed specifically, this is primarily in relation to systemic barriers and AIDS stigma. Accordingly, marginalised groups that have received specific attention include those who are HIV positive, and some attention has also been given to migrants and rural communities, who are especially vulnerable to stigma and rights violations. The interventions thus far do not contain a special focus on gender identity or sexual identity.

**Contribution to AFSA programme**

S27 has endeavoured to place emphasis on helping communities to know their rights and to utilise the rights-based legal framework. The two planned contributions are tabulated below, along with the planned activities for each.

**Table 7: Section27 Work Areas for AFSA programme**

<b>Work area 1: Strengthening Health Systems functioning</b>
a) Advocating for increased access and improved health services, with emphasis on HIV, AIDS, & TB - Monitoring NSP & NHI
b) Strengthening communities to ensure service delivery - Strengthening national and local accountability structures (SANAC and LACs)
c) Monitoring and advocating for changes in the private health sector to increase accessibility
<b>Work area 2: Removing barriers to rights uptake, especially for marginalised groups</b>
a) Advocacy and campaigns
b) Provision of legal services
c) Empowerment and knowledge transfer initiatives

It was envisaged that this work would create an empowering environment to support other focus areas such as initiatives on sexual health rights, particularly for gender and sexual minorities (according to their work plan).

**Table 8: Section27’s Activities and Objectives for AFSA programme**

<b>Planned activity</b>	<b>Stated objectives</b>
<i>Advocacy for increased</i>	a) Build Alliances and Strengthen the capacity of community organisations working on access to health care, particularly for key populations

<i>access &amp; improved health services, especially HIV, AIDS, &amp; TB</i>	<ul style="list-style-type: none"> <li>b) Mobilise and empower communities with knowledge of health care rights and policy</li> <li>c) Ensure the South African National AIDS Council (SANAC) to ensure it is effective as a body of leading and implementing the national response to HIV and AIDS and improving access to health care services</li> <li>d) Strengthen the capacity of Local, District and Provincial AIDS councils in selected districts to ensure (1); HIV treatment, care and prevention programmes are provided for in provincial and district work plan budgets; programmes are implemented and (3); increased public participation un councils means the voice of the people and communities more affected by HIV and AIDS are heard.</li> </ul>
<i>Strengthening communities &amp; accountability structures</i>	<p>Conduct monitoring, advocacy and where necessary litigation to ensure that the provision of healthcare services upholds the rights set out in the National Health Act and the Constitution</p> <p>Monitor implementation of the NSP in HIV TB and STIs (2012 – 2016) – Including ensuring appropriate budgeting for and expenditure in relation to HIV/AIDS programmes and the promotion of human rights and access to justice, particularly for the NSP’s key populations</p> <p>Continue to monitor and advocate for the implementation of a National Health Insurance that strengthens health systems and increases access to health care services</p> <p>Ensure that officials responsible for realising the right to health deliver and are held accountable</p> <p>Ensure a comprehensive new National Strategic Plan, fir-for-purpose and supported by all key stakeholders, is agreed to provide a framework for the national response to HIV and AIDS from 2017</p>
<i>Monitoring &amp; advocating for changes in the private health sector</i>	<ul style="list-style-type: none"> <li>a) Improve the legal and policy framework regulating private health services and ensure that role-players within the private health care sector respect their Constitutional obligations not to operate in a manner that restricts access to health care services.</li> <li>b) Reform of South African patent laws to improve affordability and access to life-saving drugs in South Africa</li> <li>c) Strengthen the capacity of Civil Society to engage with the private sector and build public awareness of the health care obligations of the private sector</li> </ul>
<i>Advocacy &amp; campaigns</i>	<ol style="list-style-type: none"> <li>1. Ensure that discrimination of key populations in access to health care services is at the core of our advocacy work</li> </ol>
<i>Provision of legal services</i>	<ol style="list-style-type: none"> <li>2. Ensure the legal system is accessible to, and provides effective relief to, those who suffer violations of their rights as they relate to health care and HIV in particular</li> </ol>
<i>Empowerment &amp; knowledge Transfer initiatives</i>	<ol style="list-style-type: none"> <li>3. Transfer rights based knowledge to empower those communities with which we work and who are most affected by rights violations</li> </ol>

In addition to the planned activities and objectives above, S27 has identified two provincial interventions related to healthcare access as focus areas, viz., Eastern Cape and Mpumalanga provinces. As stated, this is the rationale for our focus on these areas in this baseline report. It is envisaged that follow up research will occur on these areas where the organisation is focusing its efforts. The stated objectives for *Section27’s* work in these areas are to build alliances and increase collaboration with regional civil society organisations in order to:

1. Create greater awareness of the link between local, national and regional challenges and responses
2. Promote the right to access health care; and
3. Strengthen the regional knowledge and evidence base to improve the response to HIV and AIDS in Southern Africa.

### **5.5.2. Treatment Action Campaign**

The Treatment Action Campaign (TAC) is a non-profit organisation founded in 1998 with the initial mandate of helping to provide access to HIV and AIDS treatment. The TAC is a very influential civil society organisation, now more broadly advocating for access to treatment as well as general access to a just public health care system. A noteworthy achievement of the organisation is winning its case against the NDOH on the Constitutional Court ruled in 2002. The government was compelled to provide anti-retroviral drugs to pregnant mothers to prevent vertical transmission of HIV to infants.

TAC continues to advocate for prevention, treatment and care for all people living with HIV/AIDS and other illnesses (Treatment and Action Campaign Constitution, 2008). As a predominantly community-based HIV treatment advocacy group, TAC is often engaged in mass protest, litigation, and media interaction to improve the public health system and to leverage action from the National Department of Health SAHR (2013). In addition, TAC officers co-ordinate training, mobilisation, and also target advocacy at provincial governments (Heywood, 2009).

The organisation operates on three levels: in branch, provincial and nation levels. The branch level operates mainly in urban or rural areas, areas with a low socio-economic status. Branches are composed of volunteer activists and are mainly led by individuals who are living with HIV and AIDS. TAC is found in 7 provinces, including the Eastern Cape and Mpumalanga. At a provincial level, the structure coordinates the work of the branch level through the Provincial Executive Committee (PEC) in which TAC operates. And at national level TAC monitors the provincial structures through the National Executive Committee (NEC) which is elected every two to three years (Heywood 2009). TAC's members are an indispensable part of the organisation. The members have a firm footing on the ground and can attest to the daily realities of the masses and with that the organisation can speak to the needs of the communities and demand accountability and quality healthcare service in the respective areas.

When reviewing the work of the TAC it is clear that the strength lies in social mobilisation and outreach. As with S27, the primary focus of the work is on HIV, AIDS, and TB, with much work around prevention and treatment literacy and combatting AIDS stigma. The organisation has also addressed some other SRHR over-and-above systemic barriers, such as, gender-based violence, LGBTI advocacy, HPV vaccination, and screening campaigns. The work is community-based and also occurs in schools. The TAC has also been involved in health systems strengthening work, as noted above, it is an ECHAC member and was central to the Stop Stock-outs project. In these cases the organisation was involved in lobbying government, mobilising citizens in health care workers, and collecting evidence. It must be noted, in conducting the review, that the documentation of TAC activities is not always consistent and somewhat piecemeal. This is most likely due to it being a grassroots organisation with a fluctuating membership, as noted in available provincial reports.

**Table 9: TAC Planned outcomes for AFSA programme**

<p><b>Outcome:</b> Duty Bearers ensure progressive realisation of rights promised in Section 27 of the constitution and other SRHR legislation, and institute redress to correct system failures.</p> <p>Activities</p> <ul style="list-style-type: none"> <li>• Organise meetings with key government departments &amp; actors to discuss implementation of NHI, NSP and health services</li> <li>• track SRH related service delivery and systems functionality in the public sector</li> <li>• Lobby, advocate and litigate to ensure duty institute corrective measures and redress</li> <li>• Develop proposals to address violations, failures and barriers to SRHR realisation.</li> <li>• Undertake ongoing monitoring and advocacy to ensure government plans implemented</li> </ul>
<p><b>Outcome: Targeted marginalised groups and community members</b> demand their SRHR rights and services, and redress for rights violations.</p> <p>Activities</p> <ul style="list-style-type: none"> <li>• Conduct workshops with target populations on rights literacy, access to services &amp; strategies to effect change</li> <li>• Conduct SRHR advocacy campaigns &amp; engage with persons of influence/duty bearers to leverage improved services</li> <li>• Conduct ongoing monitoring, advocacy, &amp; community capacity building</li> </ul>
<p><b>Outcome:</b> Targeted community leaders (religious, cultural, persons of influence) create climate of tolerance and acceptance of (including LGBTI people), an enabling environment for all to claim their SRHR rights, and condemn harmful and distorted practices.</p> <p>Activity</p> <ul style="list-style-type: none"> <li>• Train &amp; sensitise community leaders on issues of gender, culture &amp; health, SRHR &amp; LGBTI</li> <li>• Conduct interventions to promote and strengthen healthy and protective aspects of cultural practices</li> <li>• Include community leaders in community dialogues and interventions to transform discriminatory attitudes &amp; behaviour and discourage harmful practices toward target populations.</li> </ul>
<p><b>Outcome:</b> Targeted Service Providers ensure equal access to quality basic service.</p> <p>Activity</p> <ul style="list-style-type: none"> <li>• Make resources available to service providers to enable them to better understand &amp; deal with the particular service needs of targeted populations</li> <li>• Develop proposals to address system failures, integrate services &amp; respond to complaints</li> <li>• Conduct ongoing monitoring and advocacy for improved service provision at public health facilities</li> </ul>
<p><b>Outcome:</b> Local accountability structures are inclusive and effective in executing their mandate.</p> <p>Activity</p> <ul style="list-style-type: none"> <li>• Conduct situational analyses/research into the composition &amp; functionality of Local Accountability Structures (LAS)</li> <li>• Develop proposals &amp; recommendations for LAS to become more inclusive &amp; effective</li> <li>• Continued monitoring and advocacy to ensure LAS hold service providers to account</li> </ul>
<p><b>Outcome:</b> Targeted LGBTI people advocate for transformed attitudes, practices and systems.</p> <p>Activities</p> <ol style="list-style-type: none"> <li>1. Conduct training on LGBTI rights and advocacy skills</li> <li>2. Support LGBTI groups to develop plans and strategies for advocacy</li> <li>3. Mentor &amp; support LGBTI people to participate &amp; be more visible in public platforms</li> <li>4. Build civil society solidarity alliances to challenge discrimination, violence &amp; heteronormative beliefs</li> </ol>

### 5.5.3. Civil Society involvement in Local Accountability Structures

A key part of the strategy of *Section27* and the *TAC* is revitalising and participating in local accountability structures, notably provincial and district AIDS councils. *Section27* and the *TAC* have been important in rebuilding AIDS councils. The South African National Aids Councils were set up as an association of institutions to build consensus between civil society and government to try and

fight the HIV/AIDS and TB epidemic. (<http://sanac.org.za/about-us>). According to the SANAC website the responsibility of the Aids Councils are to:

- Foster dialogue between government, civil society and all other stakeholders and to oversee the country's response to HIV, TB and STIs;
- Advise government on HIV and AIDS, TB and STI policy and strategy and related matters;
- Strengthen the governance, leadership and management of the response to HIV, TB and STIs at national, provincial, district and local levels;
- Strengthen the multi-sectoral response to HIV, TB and STIs as a contribution to the overall social and economic development of South Africa, including but not limited to policy review, programme management and co-ordination, technical assistance and capacity building and sectoral support;
- Mobilise resources domestically and internationally to finance the response to HIV, TB and STIs, including but not limited to estimating expenditure and resource needs, fund-raising from domestic and international institutions, including Treasury, donor co-ordination and investigating new sources of funding for the multi-sectoral response and the NSP;
- Ensure the monitoring of progress against the targets set in the NSP and ensure mid and end of term evaluations for the prevailing NSP;
- Create and strengthen partnerships for an expanded national response in South Africa to HIV, TB and STI among government agencies, non-governmental organisations (NGOs), donors of funds, agencies of the United Nations, the South African private sector and people living with HIV, TB and STIs.

The councils work in a three tiered system, with local aids councils (LAC) at ward level, a district AIDS council at provincial level and finally to SANAC itself at a national level. These councils are meant to facilitate dialogue between community members, civil society and government about issues relating to problems in the public health sector (NSP Review; pg 32). In Mpumalanga, *Section27* and the *TAC* have been instrumental in monitoring the effectiveness of these councils. They also are continuing to make sure that Premier of Mpumalanga remains involved in the AIDS councils.

However, even though *Section27* and the *TAC* have continued to play an active role in trying to maintain the effectiveness of the councils. There have been severe setbacks. In April 2013 the organisations petitioned a meeting with the deputy president Motlanthe, as there was growing concern that the Premier of Mpumalanga had shown no interest in the creation of LAC. They also demanded that the local AIDS councils be fully functional by June 2013. After *Section27* and the *TAC* met with the deputy president, Premier Mabuza committed to leading the AIDS councils (*Section27*, Director's report, September 2013).

The petition was relatively successful and Premier Mabuza chaired a meeting where the creation of LAC's was put on high priority, and by September 2013 five out of the seven LACs were set up in Gert Sibande. Although this was a step in the right direction, they are still struggling to make the local LAC's functional. (Implementation of the National Strategic Plan 2012-2013 p. 20)

In October 2014, the *TAC* stated that the Local AIDS councils were dysfunctional and that since the meeting in 2013 nothing had been done to improve the situation. During a protest in Secunda the *TAC* voiced its concerns about SANAC and the AIDS councils.

"SANAC has for example remained silent on the collapse of the Free State, Mpumalanga and Eastern Cape healthcare systems and on the ongoing severe problem of medicines stock-outs. The

national TB conference's call that MDR-TB be treated as a public health emergency has not even been discussed".<sup>2</sup>

They also voice their concern that SANAC was being "side-lined by the department of health" and that Cyril Rhamaphosa had shown no real commitment to his role as the Chairperson of the committees. (<http://www.tac.org.za/news/tac-says-south-african-national-aids-council-must-rise-face-real-challenges-hiv-and-tb>). In 2014, SARRAH—a five-year DFID funded programme of over 20 million pounds, to aid South Africa's fight against HIV/AIDS—evaluated SANAC, its conclusion was not positive. The report stated that,

Nearly all interviews, and several documents, suggested that SANAC does not bring any "bark to its bite." It is viewed by some as a body that does not have buy-in from all sectors. Nearly all respondents stated that SANAC does not, and presently is unable, to hold sectors or groups accountable for achieving results (Mid-term evaluation of the SARRAH programme 2014, 30).

The inefficacy of the national AIDS council has led *Section27* and other NGOs to focus their efforts on district and provincial AIDS councils.

#### 5.5.4. Challenges

Funding has always been a challenge for civil society organisations. This has been more keenly felt since the 2008 economic crisis. Government funding for health has also been cut due to the financial crisis<sup>3</sup>. The economic crisis has also had a negative impact on big international donors (with the exception of DIFID) both the Global fund and PEPFAR, have to radically reduce its expenditure. This means that civil society organisations are often unable to grow their organisation and often have to scale back their operations due to constant funding crises. In Ndinda, Chilwane and Mokomane's (2013, p. 68) report on civil society and health care they state that, "Unlike before when they would get involved in programmes for a full period, now they have had to cut down on the time spent on critical programmes hence the lack of their visibility on critical issues relating to the epidemic. The HIV and AIDS organisations also note that lack of funding affects their ability to meet operational costs."

The financial crisis has had a huge impact on the TAC. In 2014 constant funding cuts has meant that the TAC needs to find 10 million rand in order to continue its work. One of its co-founders, Mark Heywood, spoke at a debate at the Belgium Development Conference in December 2014. During his address he stated that the organisation's annual budget had been halved because big international donors had pulled out. He argued that the "TAC's budget was 2.5 million dollars per year. This year the British Department for International Development (DFID) decided to stop our funding, following the example of the Swedish, the Dutch and other governments."<sup>4</sup>

Another key challenge is working with Government. Both the *TAC* and *Section27* mainly focus on litigation, community mobilisation, training and public demonstrations. Although these are often very effective ways to force change they can sometimes put these organisations on a collision

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<sup>2</sup> <http://www.tac.org.za/news/tac-says-south-african-national-aids-council-must-rise-face-real-challenges-hiv-and-tb>

<sup>3</sup> <http://www.ngopulse.org/article/effects-global-economic-crisis-examining-impact-hiv-and-aids-funding>

<sup>4</sup> <http://www.equaltimes.org/funding-cuts-create-a-ticking-time?lang=en#.VQF4mmSUc8Y>

course with government and multi-national companies who are also potential funders. For instance, a deadlock between government and the EHCAC arose in 2013. The Coalition had handed over a memorandum to the Superintendent-General of the Eastern Cape Department of Health. In his response the memorandum the minister stated that the department was taking steps to solve the problem (Minster of health Speech, p. 9). Yet by August 2014, the Coalition noted that very little had been done to solve the health crisis in the province. In their press statement they argued that, “EHCAC wants to work with the MEC and Premier to fix the Eastern Cape health system, we are willing to be their eyes and ears on the ground, to mobilise communities around priority programmes, to provide ideas on where and how the system can be fixed. But if they refuse a meaningful partnership, fail to be honest about the challenges and to make all plans public, then we have no option but to mobilise communities to fight for their rights. Members of EHCAC feel enough is enough”.<sup>5</sup>

Ndinda, Chilwane, and Mokomane (2013, p. 69) comment on the dangers of constant clashes with government: “In seeking access treatment, care and health rights, it becomes easy to make enemies with groups or institutions that should be partners. There is always a need to strike a balance and ensure that the purpose of the strategy (litigation or demonstration) is to secure the treatment and health rights of PLWAs.” Similarly, in the recent *Civicus* report on the state of civil society, it was argued that in order for civil society to flourish and be successful there needs to be an ‘Enabling Environment’. Government compliance and support is crucial in order facilitate the change that these organisations wish to make. Civil Society members need to be able to strike a balance between confronting government for their failures in the public health sector and working with government in a collaborative manner in order to ensure a good relationship is maintained in order to speed up implementation.

There are instances of such collaboration in the work of the NGOs under review, however. For instance, the take-over and turn-around of the Mthatha medical depot by NGOs is an example. In this instance, the NGOs handed control of the depot back to the Department when it was once again operational and prevented many patients from having to default on antiretrovirals and TB medication. Another example is the work at Lusikisiki village clinic as an example of civil society and government successfully managing to make inroads to solving the health crisis in the Eastern Cape. Working together, the government and NGOs (MSF, TAC) and the Eastern Cape Department of Health managed to turn around the situation and meet the needs of the community in Lusikisiki (Everson & Stokke 2010; Section27, 2013b, Death and dying). However, the situation changed in 2012 when the Department shut down the clinic and relocated the clinic to tents on the outskirts of the village, forcing staff and patients to endure terrible conditions. This eventually led to the EHCAC intervention with litigation against government the seen as the only possibility to change the situation. An analysis of what caused the successful partnership between civil society and government to breakdown might further the conversation about how civil society and government can successfully work together.

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<sup>5</sup> <http://www.psam.org.za/news/1407418390.pdf>

## 5.6. CONCLUSION

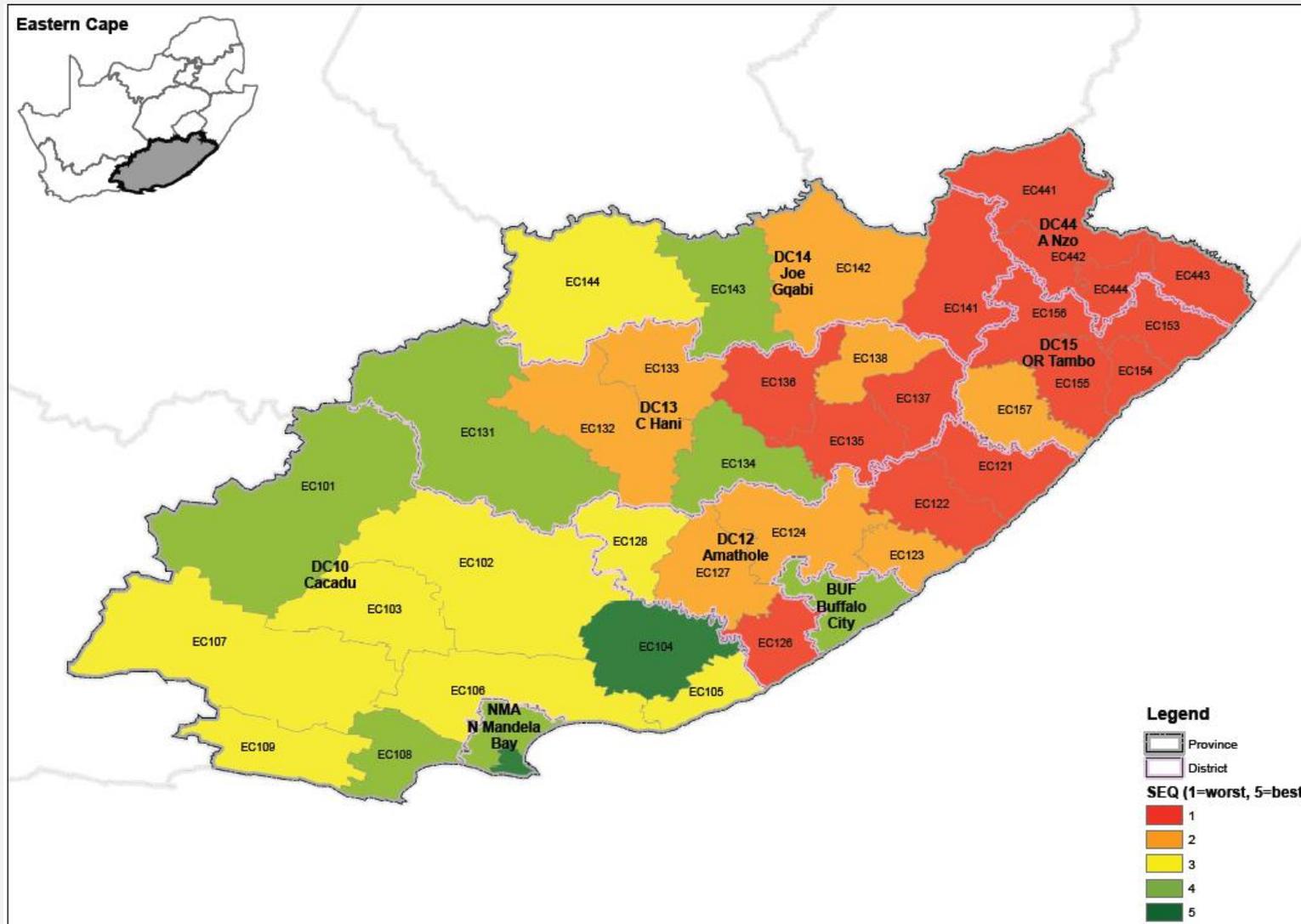
This chapter has presented data on the Eastern Cape and Mpumalanga provinces, as well as the O.R. Tambo and Gert Sibande districts in order to provide a picture of the state of their sexual and reproductive health services, with respect to local system failures. In addition, evidence was presented in respect to the degree to which target populations are able to exercise their SRH rights. Several barriers were identified and these, along with the systemic issues described, are fundamentally linked to the relative socio-economic deprivation of these areas. It is no coincidence that these areas are rural provinces, and throughout this chapter the challenge of rurality has been underscored. A further issue, has been conservative and traditional values and norms, which produce judgmental and moralistic attitudes and responses to SRH issues.

Reviewing the work of *TAC* and *Section27* organisations showed that the majority of their work has been focussed on systemic issues and, as far as SRH is concerned, on HIV and although marginalised groups are mentioned, the major issue dealt with is AIDS stigma. There is not a strong gender focus in this work and LGBTI issues are not dealt with in a systematic way. These trends will all have implications for the work planned for the *AFSA* programme.

The challenge for gathering an evidence base was two-fold. First, both provinces tend to be under-researched, with scattered SRH literature. Second, the activities of civil society are not always well-documented and/or documentation is not readily available. This is particularly the case with *TAC*, which though a powerful grassroots organisation, often experiences inconsistency in staffing and capacitation issues (Eagar, personal communication; *TAC*, Eastern Cape Provincial Report, 2014). A further challenge in compiling an evidence base is the quality of health-related statistics available, as discussed above. Data disaggregated at district level (which is both consistent and comprehensive) are needed.

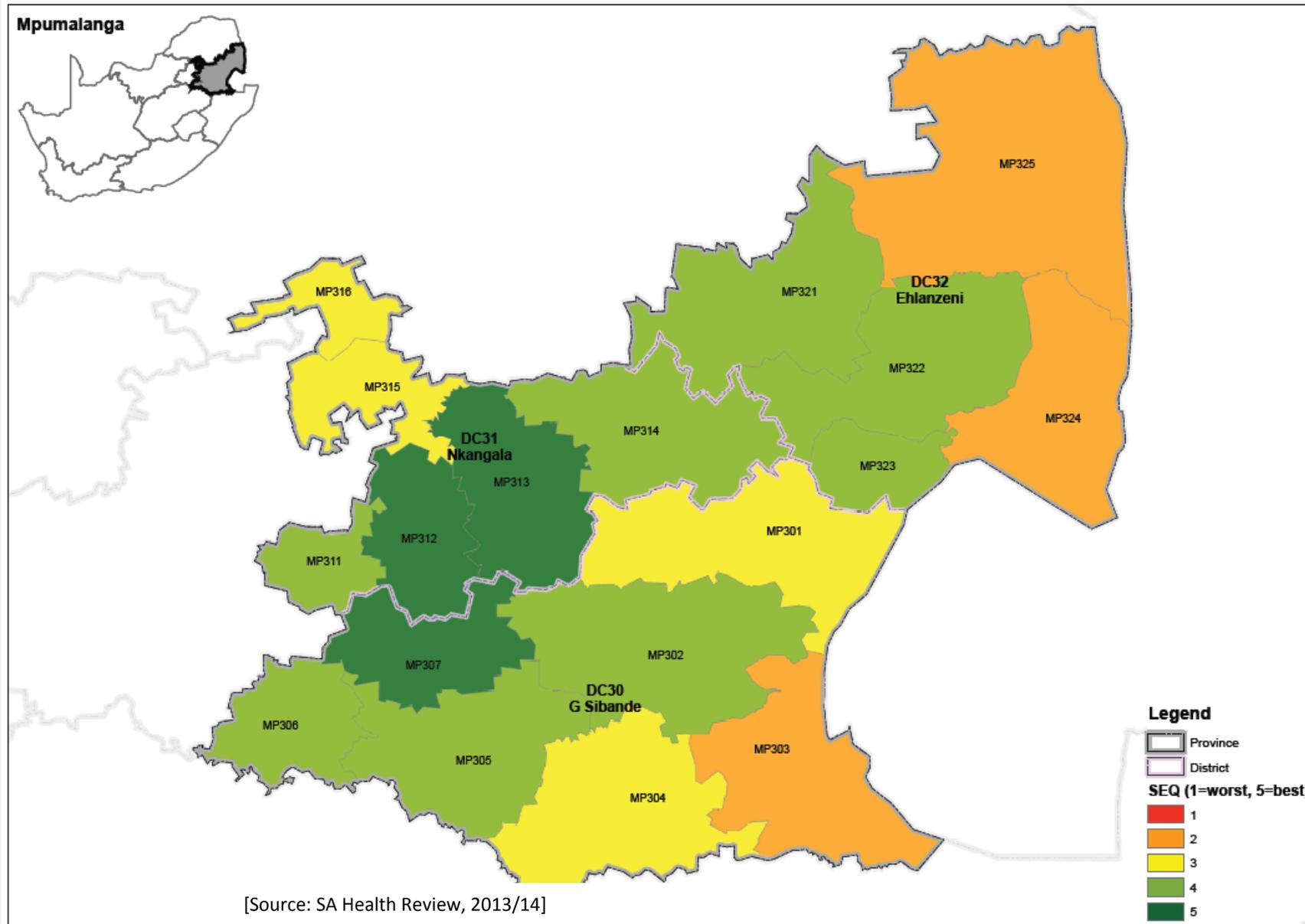
Nevertheless, despite challenges, a picture does emerge of severely compromised provincial and district health systems that make rendering of any health services, let alone SRH services, extremely problematic. Particular SRH issues were identified for the regions, including: high maternal mortality rates, driven by poor ToP and antenatal access and uptake; high teenage pregnancy rates, linked to contraception and information access, gender power disparities, and poverty.

Fig. 2: Districts and municipalities of the Eastern Cape showing socio-economic quintiles (SEQ)



[Source: SA Health Review, 2013/14]

Fig. 3: Districts and municipalities of Mpumalanga showing socio-economic quintiles (SEQ)



**Table 10: SUMMARY OF KEY HEALTH INDICATORS FOR FOCAL REGIONS**

Key health indicators	Eastern Cape Province	OR Tambo district	Mpumalanga Province	Gert Sibande District
<i>Population:</i>	6 562 053 <sup>x</sup>	1 358 917 <sup>xi</sup>	4 128 000, 7.8% <sup>xii</sup>	1 056 178 <sup>xiii</sup>
<i>Water access:</i>	28.4 Inside yard% & 49.4% outside yard <sup>xiv</sup>	8.90 <sup>xv</sup>	86.8% <sup>xvi</sup>	91.1% <sup>xvii</sup>
<i>Energy supply: (access to electricity):</i>	Access to electricity 74.8% <sup>xviii</sup>	70.2% use electricity for lighting <sup>xix</sup>	89.3% <sup>2</sup>	83.4% <sup>2</sup>
<i>HIV/AIDS &amp; other STIs</i>	29.9% <sup>xx</sup>	31.5 recorded in 2010 <sup>xxi</sup>	35.1% <sup>xxii</sup>	4.1% <sup>xxiii</sup>
<i>Estimated people living with HIV</i>	715,736 <sup>xxiv</sup>	31.5% <sup>xxv</sup>	4.1% <sup>xxvi</sup>	46.1% <sup>2</sup>
<i>Antenatal HIV prevalence</i>	28.1% <sup>xxvii</sup>	30.1 <sup>xxviii</sup>	35.1% <sup>xxix</sup>	35.1 <sup>xxx</sup>
<i>Average STI prevalence</i>	1.8% <sup>xxxi</sup>	-	4.1% <sup>4</sup>	4% <sup>xxxii</sup>
<i>HIV prevalence for gender &amp; age</i>	Age 2-14 years 1.2 % Age 15- 24 years 6.2% Age 25-> years 22.0%	-	Male = 9.9% Female = 14.4% 2-14yrs = 1.7% 15-24yrs = 10% 15-49yrs = 21.8% 50+yrs = 10.1% <sup>xxxiii</sup>	-
<i>HAART treatment:</i>	70.4% <sup>xxxiv</sup>	-	66.5% 2011/2012 <sup>4</sup>	54079 adults & 3762 children as of 2012-2013 <sup>xxxv</sup>
<i>HIV treatment by gender:</i>	Women -107,448 Men- 63,105 <sup>xxxvi</sup>	-	Women 61 035 (2011/2012) Men 34 440 (2011/2012) <sup>4</sup>	-
<i>Total fertility rate:</i>	3.13% <sup>xxxvii</sup>	3.0	2.86% <sup>1</sup>	
<i>Contraception rate:</i>	31.2 <sup>xxxviii</sup>	30.9 <sup>xxxix</sup>	30.9% <sup>xi</sup>	36% <sup>3</sup>
<i>Male condom distribution rate:</i>	17.6% per male with the target of 50 per male of 15 years or older <sup>xii</sup>	23.0 per male in the target of 50	44 322 000 Male (2011/2012) <sup>4</sup>	29.2% <sup>1</sup>
<i>Female condom distribution rate:</i>	7.2 per 100 females (recorded in 2002) <sup>xiii</sup>	No data	460 000 (2011/2012) <sup>4</sup>	-
<i>Maternal death:</i>	156.2% per 100 000 live births <sup>xiiii</sup>	224 per 100 000 live births <sup>xlv</sup>	135/ 100000 live births <sup>3</sup>	187.6/ 100000 <sup>4</sup>
<i>Delivery rate in facility:</i>	83.3% Annualised <sup>xlv</sup>	98.8% for individuals under the age of 18 <sup>xlvi</sup>	90.5% (2011/2012) <sup>3</sup>	11.3% Delivery in facility U18yrs rate <sup>xlvii</sup>
<i>Antenatal care attendance:</i>	8.5%	43.3 before 20 weeks <sup>xlviii</sup>	Before 20 weeks = 37.5% (2011/2012) <sup>4</sup>	42.1% <sup>1</sup>
<i>Abortion facilities:</i>	Not available	No data	85% <sup>xlix</sup>	-
<i>Deaths due to incomplete abortion:</i>	----	No data	No data	-
<i>Number of legal abortions:</i>	12 397 <sup>l</sup>	14 357 <sup>li</sup>	3.158 in 2012 at 3.1% <sup>lii</sup>	-
<i>Rapes reported:</i>	Sexual assault 9,897 <sup>liii</sup>	No data	Decrease by -7.4% <sup>liv</sup>	-

## CHAPTER 6: CONCLUDING DISCUSSION

This baseline study forms critical formative work in developing an overview and an emerging evidence-base in relation to (1) SRHR service delivery and systems failure in the public sector and (2) the effects of systemic failures, attitudes, and practices on the SRHR of LGBTI people. There is a need for further replication in other sites and in partnership with other organisations to gain a fuller picture of the extent and scale of challenges related to service delivery and systems failures in the public health sector, but also in relation to attitudes and practices on the SRHR of LGBTI people within the overall strategy of AFSA's three-year programme.

This baseline focused on four selected sites, producing information that provides some evidence for the questions we listed at the outset of this study:

- What systemic issues have been identified as currently problematic in the public healthcare system (focused on access and quality; knowledge, attitudes and perception; government responses)?
- In which social situations do you experience discrimination? Among family, community and/or when accessing state services (health, police and justice)? Explain
- How can discrimination and social stigma be dealt with by government, community, researchers, and social justice advocates?
- Are there ways of integrating LGBTI rights and protection into mainstream health systems or are separate facilities a safer option?

As indicated in our introduction, to address the questions we (1) produced a detailed literature review (focused on the scholarly, policy and 'grey' literature); (2) conducted in-depth interviews and key informant discussions with members of the LGBTI community in two organisations (*GALA* and *GLN*); and (3) produced a desk review foregrounding system failures and barriers for target communities specifically in relation to HIV status; gender; gender identity and sexual orientation (LGBTI); and rural health to provide a snapshot of the general situation of SRHR in the geographical areas where the implementing partners (*Section27* and *TAC*) have planned to focus interventions.

Although the findings are not generalisable, they do support the evidence that there are a number of challenges, namely systemic barriers that compromise the realisation of SRH rights, especially for under-represented, vulnerable, and marginalised groups, these present in the form of access barriers that prevent certain people from accessing services and/or constrain their choices. These challenges have a direct bearing on improving (1) support for community-based organisations (CBOs) and national advocacy/policy actors engaged in effective HIV & AIDS and SRHR interventions; (2) the realisation of SRHR in South Africa; and (3) the knowledge and evidence base on HIV & AIDS in the Southern African region.

Having explored issues, insights and arguments in a little more depth in the literature review, and the qualitative and desk review chapters respectively, we now turn to consider several key conclusions and recommendations that are framed in relation to information gleaned from the data. In this chapter we synthesise the evidence presented in each of the data driven chapters

(namely, chapters 2, 4 & 5) and provide some recommendations based on common threads running throughout.

## **6.1. Key findings**

### ***Sexual and gender minorities/LGBTI***

1. Participants reported similar problems related to systemic failures to the general population (e.g. waiting times, stock outs, cost, language barriers), but these were compounded by discrimination within the system.
  2. Participants reported various negative experiences related to their sexual identity in public health facilities, including negative staff attitudes, refusal to provide care (gatekeeping), breaches in confidentiality and even abuse.
  3. The staff's behaviour, especially their compromising of participants' confidentiality, was described as a major deterrent to help-seeking in public facilities.
  4. Participants sought alternative routes to meet their SRH needs, rather than attend public facilities.
  5. Participants described the system as alienating and not geared to their needs, e.g. staff lacked knowledge about sexuality and acceptable contraception and prophylaxes were generally said to be unavailable
  6. The discriminatory treatment experienced within facilities is an extension heterosexist attitudes and norms within the broader socio-cultural setting
  7. Personal agency for LGBTI individuals is affirmed through close, supportive friendship circles and these relationships offer a means of stigma management
- ❖ We can therefore conclude that negative and discriminatory experiences in the public health system, which are reinforced by and reinforce wider social attitudes and norms, potentially compromise the SRHR of sexual and gender minorities, such as those who participated in our study. This already marginal group is made further marginalised. Their SRH needs remain unmet and/or they accrue unnecessary financial costs in seeking alternative care.

### ***Systemic failures***

1. Available data from Mpumalanga and the Eastern Cape suggest that rurality and relative deprivation play a key role in shaping SRHR outcomes, particularly in accessing quality services without having to travel significant distances
2. The spatial legacy of apartheid compounds service delivery issues in these provinces
3. In the Eastern Cape and Mpumalanga key SRH concerns are related to a combination of systemic failures and socio-cultural factors, such as stigma.
4. High rates of maternal and pregnancy-related mortality is a significant challenge in both provinces and are related to barriers to accessing antenatal care and safe, legal ToP services
5. The steady decline in both the number and type of public ToP services is felt keenly in rural provinces such as Eastern Cape and Mpumalanga

6. Social stigma is a barrier to accessing safe ToP services. It also affects access to other SRH services for younger/unmarried women; young mothers; pregnant teenagers; migrants; and HIV positive persons who are all subject to judgement and moralistic attitudes.
7. Teenage pregnancy has increased in these areas, this is largely due to high poverty levels and associated issues such as vulnerability to unwanted sex, violent/coercive sexual relations, timing of sexual debut, age of male partner. Other factors include: cultural beliefs (e.g. proving fecundity before marriage), lack of knowledge and use of contraception, and problems in health service provision.
8. There is little information on the functioning of Local Accountability Structures (especially AIDS Councils) or their relationship with civil society. Implementing partners do not document these activities consistently or uniformly. What is documented suggests that LAS are not fulfilling their intended function.
9. In terms of marginalised groups and SRHR, implementing partners tend to focus on those who are HIV positive, with some attention to migrants and rural communities. The interventions thus far do not contain a special focus on gender identity or sexual identity.

## **6.2. Recommendations**

### **Systemic issues**

1. Programming around SRH needs to take an explicit gender focus and involve men as partners in SRH issues; attention should also be given to sexuality
2. Further advocacy is needed which takes cognisance of the privileging of hetero-patriarchal practices and thinking that facilitates discriminatory institutional cultures in order to improve the range, quality, access and affordability of SRHR services for all marginalised and vulnerable groups (LGBTI, women, disabled).
3. Stigma reduction training for all workers in the healthcare sector is needed. Stigma reduction work should move beyond AIDS stigma and include information, education, and communication around early pregnancy and abortion, as well as misconceptions related to non-normative sexual identities and practices
4. Government support is needed in addressing the gaps identified above; community dialogues may be useful for raising awareness of persistent gaps and evaluating new approaches
5. In order to address access barriers (especially transport and confidentiality breaches) to facilities, partners should:
  - a. advocate for the extending SRH services (preventative, basic screening, surveillance) into households and communities through community health care workers and similar mechanisms
  - b. contribute to policy development in order to clarify the scope and practice of community health workers
  - c. support school health programme and other school-based interventions, particularly with respect to teenage pregnancy and knowledge about abortion, advocating for comprehensive sex education

- d. advocate for greater inclusivity in terms of languages used in public health settings, including the use of official languages on forms and information provided
- 6. The accessibility and functionality of ToP services is a key part of SRHR and should receive adequate attention in lobbying for the improved service delivery. Part of this work involves addressing attitudes of health workers and the broader community.
- 7. CSO and CBO need to consistently and clearly document activities, particularly work with LACs, and findings of investigations related to SRHR in order to build an evidence base

### **Sexual and gender minorities/LGBTI**

1. Advocacy is needed for national guidelines for health workers on the treatment of sexual minorities
2. Training of health workers should be provided to health workers that includes a broad range of the spectrum of sexualities and sexual activities.
3. There is a need for the development of effective systems of accountability, regarding service delivery and patient care, either through complaints mechanisms, performance management or/and disciplinary processes. This may be facilitated by having a 'supporter' or 'advocate' in health settings, as proposed by research on sex work.
4. Interventions need to recognise the complexity of needs that gender and sexual non-conforming people have, including the need for economic empowerment initiatives to be woven into alternative health care programs, advocacy and training initiatives.
5. Programmes targeting most at-risk or key populations should be aware that narrowing the focus of interventions (e.g. to be MSM-specific) may leave out certain people. Lesbian and bisexual women and transgender persons are frequently left out of interventions.
6. Civil Society interventions aimed at empowering LGBTI persons, should focus on encouraging safe, supportive friendship circles
7. Interventions to deal with the marginalisation of sexual and gender minorities in primary healthcare setting should involve community outreach and engagement with various stakeholders and groups, such as community members, schools, FBOs, CBOs
  - a. Alternative public discourses and representations of LGBTI individuals, couples and families are needed to counter pervasive heterosexism
  - b. violence prevention programmes must be geared to the needs of LGBTI
8. Interventions should consider the distrust and fear that many sexual and gender non-conforming people have of public health facilities and involve outreach programmes that take cognisance of the needs of LGBTI persons (e.g., around contraception). Mobile clinics such as those used by the *Anova* Institute and SWEAT are an example of such an intervention.
9. Appropriately trained Community Health Workers could work with civil society groups that support LGBTI rights in order to reach LGBTI persons who are unwilling or unable to attend facilities with information about where and how to access appropriate services.
10. Effective 'gay friendly' clinics and health services should be emulated where possible. Best practices and lessons need to be collected from these organisations.

11. Possible partnerships between state facilities and gay friendly clinics could be established so that staff members who are unsure how to deal with specific issues (or unwilling to do so) can make referrals.

#### **Suggestions for future Research**

5. Address gaps between policy intent and the application of policy in the sector by conducting an audit for efficiency, gaps and improvements
6. Further research and an improved evidence base is required to have a full picture of systemic failures in the health sector and knowledge, attitudes, perceptions and experiences of LGBTI people in accessing quality health care in the country,
7. Further research is required into the attitudes, perceptions and experiences of healthcare workers towards LGBTI persons
8. Further research is needed on LGBTI-specific SRH services. Research should document best practices and lessons from these organisations, and the ways that these can be connected with public health services.

#### **6.4. Conclusion**

Our findings and recommendations, which provide an in-depth analysis of two LGBTI organisations (GALA and GLN) and a desk review focused on Mpumalanga and the Eastern Cape South Africa, provide important and valuable insights into a number of areas that should be addressed. These findings suggest that we have opportunities to learn lessons and consider options for future work and interventions in the broad context of SRHR and the realisation of healthcare rights more broadly. The study confirms the need to integrate SRHR issues into research, policy, and programmatic planning in the broader context of improving sexual and reproductive health, well-being, the realisation of justice and rights. Addressing the challenges should ultimately stimulate uptake of SRH services, increase the sexual and reproductive choices that are available to people and maximise their ability to exercise their SRH rights.

## REFERENCES

- African National Congress. (1994). *The Reconstruction and Development Programme*. Johannesburg, South Africa: Umanyano Publication.
- Aggleton, P. (2009). Researching same-sex sexuality and HIV prevention in V. Reddy, T. Sandfort, and L. Rispel (Ed), *From social silence to social science. Same Sex Sexuality, HIV and AIDS, and Gender in South Africa. Conference Proceedings*, (pp. 2-13), Cape Town: Human Sciences Research Council.
- Alan Guttmacher Institute. (2003). *In their own right: Addressing the sexual and reproductive health needs of men worldwide*. New York & Washington: Alan Guttmacher Institute. Retrieved April 2007 from [http://www.guttmacher.org/pubs/itor\\_intl.pdf](http://www.guttmacher.org/pubs/itor_intl.pdf)
- Amnesty International. (2014). *Struggle for maternal health: Barriers to antenatal care in South Africa*. London, United Kingdom: Amnesty International.
- Ataguba, J.E., & Alaba, O. (2012). Explaining health inequalities in South Africa: A political economy perspective. *Development Southern Africa*, 29(5), 756 - 764.
- Ataguba, J.E., & McIntyre, D. (2013). "Who benefits from health services in South Africa? *Health Economics. Policy and Law*, 8(1), 21 - 46.
- Bateman, C. (2012). Academics appeal to State: 'Help us train where the needs are'. *South African Medical Journal*, 101(8), 496 – 500.
- Bateman, C. (2013). Partnering up to get Eastern Cape healthcare delivery working. *South African Medical Journal*, 103(12), 889 – 890.
- Beall, J., Crankshaw, O., & Parnell, S. (2000). The Causes of Unemployment in Post-apartheid Johannesburg and the Livelihood Strategies of the Poor. *Tijdschriftvooreconomischeensociale geografie*, 91(4), 379-396.
- Benatar, S.R. (2013). The challenges of health disparities in South Africa. *South African Medical Journal*, [Online], 3(103), 154-155. Retrieved September 2014 from: <http://www.samj.org.za/index.php/samj/article/view/6622/4918>
- Bezuidenhout, S., Ogunsanwo, D.A., & Helberg, E.A. (2014). Patient satisfaction at accredited antiretroviral treatment sites in the Gert Sibande District. *African Journal of Primary Health Care and Family Medicine*, 6(1), 1-6.
- Bhana, D. (2014). Ruled by hetero-norms? Raising some moral questions for teachers in South Africa. *Journal of Moral Education*, 43:3, 362-376.
- Bogart, L.M., Chetty, S., Giddy, J., Sypek, A., Sticklor, L.R.P., Losina, E., & Katz, J.N. (2013). Barriers to care Among People Living with HIV In South Africa: Contrasts between patient and healthcare provider perspectives. *AIDS Care*, 25(7), 843-853.
- Buisman, L.R., & García-Gómez, P. (2015). Inequity in inpatient healthcare utilisation 10 years after Apartheid *Development Southern Africa*, 2(32), 193-208.
- Chitiga-Mabangu M., Karuaihe, S., Reddy, V., Motala, S., Morison, T., Botsis, H., Ntuli, M., & Tsoanamatsie, N. (2014). *South African Women as champions of change*. Cape Town: HSRC Press.
- Chu, K., Moyo, S., Ogunmefun, C., Mbatha, T. & Bock, P., & English, R. (2011). *District hospital performance assessment: Mpumalanga state province 2008 -2010*. Durban: Health Systems Trust.
- Corona, E., Coleman, E., & Manzin, R. (2002). *Defining sexual health: Report of a technical consultation on sexual health*, 28–31 January 2002, Geneva.
- Community Agency for Social Enquiry (1995). *A National Household Survey of Health Inequalities in South Africa*. Retrieved from <http://www.healthlink.org.za/uploads/files/case.pdf>
- Community Agency for Social Enquiry.(1999). *The Second Kasier Family Foundation survey of healthcare in South Africa*. Retrieved from <http://www.hst.org.za/uploads/files/sahousesurvey.pdf>.
- Cook, R.J.& Dickens, M. (2009). *Surviving pregnancy and childbirth an international human right*. Centre for Reproductive Rights Briefing Paper. Available at [www.reproductivejustice.org](http://www.reproductivejustice.org)
- Cooper, D., Morroni, C., Orner, P., Moodley, J., Harries, J., Cullingworth, L.M., & Hoffman, M. (2004). Ten years of democracy in South Africa: Documenting transformation in reproductive health policy and status. *Reproductive Health Matters*, 12(24), 70-85.
- Cooper, D., Mantell, J.E., Moodley, J., & Mall, S. (2015). The HIV epidemic and sexual and reproductive health policy integration: Views of South African policymakers. *BMC Public Health*, 15(1), 217 – 233.
- Coovadia, H., Jewekes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: Historical roots of current public health challenges, *Lancet*, 374, 817- 834.
- Day, C., & Gray, A. (2014). Health and related indicators. In A. Padarath & R. English (Ed.), *South African health review 2013/2014*(pp. 201-346). Durban, South Africa: Health Systems Trust.
- De Bruyn, M. (2005). *Reproductive rights for women affected by HIV/AIDS? A project to monitor Millennium Development Goals 5 and 6*. Chapel Hill, NC: Ipas.

- Department of Health (2011a). *Sexual and reproductive health and rights: Reviewing the evidence*. Pretoria, South Africa: Department of Health.
- Department of Health (2011b). *Sexual And Reproductive Health And Rights: Fulfilling Our Commitments 2011-2012 And Beyond*. Pretoria, South Africa: Department of Health.
- Department of Health (2011c). *The National Antenatal Sentinel HIV and Syphilis Prevalence Survey, South Africa*. Pretoria, South Africa: Department of Health.
- Department of Health (2011d). 'Saving Mothers 2005- 2007: Fourth Report on Confidential Enquiries into Maternal Deaths in South Africa', available at: [http://www.doh.gov.za/docs/reports/2011/saving\\_b.pdf](http://www.doh.gov.za/docs/reports/2011/saving_b.pdf).
- Department of Health (2012). *National Healthcare Facilities Baseline Audit*: Pretoria: South Africa.
- Dombo, M. (2014). Mpumalanga province. In N. Massyn , C. Day , N. Peer , A. Padarath, P. Barron, & R. English (Ed.), *District Health Barometer 2013/14* (pp. 541-545). Durban: Health Systems Trust.
- Eagar, D., & Heywood, M. (2012). Financial crisis in the Eastern Cape Department of Health. Section27 Press Release, 30 May 2012. Retrieved from [www.section27.org.za](http://www.section27.org.za)
- Eagar, D. (2012). *Provincial budget blues*. NSP Review, 5(November), 6 – 11.
- Eagar, D. (2014). *Re-Imagining Rural Health – The State of Rural Health 20 years into Democracy*. Retrieved September 2014 from <http://www.rhap.org.za/re-imagining-rural-health-20-years-democracy/>
- Eagar, D. (2015). *Rural-proofing for health guidelines: A guide to accounting for rural contexts in health Policy, strategic planning and resourcing*. Johannesburg: Rural Health Advocacy Project.
- Eastern Cape AIDS Council (2012). *Annual Performance Plan*. Eastern Cape, South Africa: Eastern Cape AIDS Council.
- Essack, Z., & Strode, A. (2012). "I feel like half a woman all the time": The impacts of coerced and forced sterilisations on HIV-positive women in South Africa. *Agenda*, 26(2), 24-34.
- Geary, R.S., Gómez-Olivé, F.X., Kahn, K., Tollman, S., & Norris, S.A. (2014). Barriers to and facilitators of the provision of a youth-friendly health services programme in rural South Africa. *BMC Health Services Research*, 14(259), 1-8.
- George, G., Quinlan T., Reardon, C., & Aguilera J-F. (2012). Where are we short and who are we short of? A review of the Human Resources for Health in South Africa. *Health SA Gesondheid*, 17(1), Art.#622, 7 pages.[Online.] <http://dx.doi.org/10.4102/hsag.v17i1.622>
- Gilliam ML, Neustadt A & Gordon R (2009). A call to incorporate a reproductive justice agenda into reproductive health clinical practice and policy. *Contraception* 79(4): 243–246
- Gilson, L., & McIntyre, D. (2007a) Post-apartheid challenges: Household access and use of health care in South Africa. *International Journal of Health Services*, 37(4), 673-691.
- Gilson, L., & McIntyre, D. (2007b). Are South Africa's new health policies making a difference? *Equity Briefing*, September, 1 -3.
- Graziano, K., (2004). Oppression and resiliency in a post-Apartheid South Africa: Unheard voices of Black gay men and lesbians. *Cultural Diversity and Ethnic Minority Psychology*, 10(3), 302–316
- GNP+, NAPWA SA (2012). HIV Leadership through Accountability Programme: *PLHIV Stigma Index OR Tambo Region Assessment, Germiston, NAPWA SA*.
- Govender, I., & Eche, M. (2012). Health-seeking behaviour of people with sexually transmitted infections in the community of Nkomazi East, Mpumalanga. , *Southern African Journal of Epidemiology and Infection*, 27(4), 195-198.
- Greene, M.E., & Biddlecom, A.E. (2000). Absent and problematic men: Demographic accounts of male reproductive roles. *Population and Development Review*, 1(26), 81-115. 26(1),
- Greene, M.E., Mehta, M.E., Pulerwitz, J., Wulf, D., Bankole, A., & Singh, S. (2006). Involving men in reproductive health: Contributions to development. Background paper to the report Public choices, private decisions: Sexual and reproductive health and the Millennium Development Goals. *Millennium Project*, [Online], Available from: [http://www.unmillenniumproject.org/documents/Greene\\_et\\_al-final.pdf](http://www.unmillenniumproject.org/documents/Greene_et_al-final.pdf). [March 2007].
- Greene, M., Mehta, M., Pulerwitz, J., Wulf, D., Bankole, A., & Singh, S. (2006). Involving men in reproductive health: Contributions to development. Background paper prepared for the United Nations Millennium Project. Accessed June 24, 2006.
- Griffiths, S., Ahmar, S., Seager, J., Simbayi, L., & Mbelle, N. (2014). *Mid-Term Evaluation of the SARRAH programme*. Pretoria, South Africa: Coffey International Development.
- Harris, B., Eyles, J., Penn-Kekanna, L., Thomas, L., & Gouge, J. (2014). Adverse or acceptable: Negotiating access to a post-apartheid health care contract. *Globalization and Health*, 10, 35-49.
- Harris, B., Goudge, J., Ataguba, J.E., McIntyre, D., Nxumalo, N., Jikwana, S.M., & Chersich, M. (2011). Inequities in access to health care in South Africa. *Journal of Public Health Policy*, 32(1), S102 - S123.
- Harries, J., Lince, N., Constant, D., Hargey, A., & Grossman, D. (2012). The challenges of offering public second trimester abortion services in South Africa: Health care providers' perspectives. *Journal of Biosocial Science*, 44, 197-208.
- Harries, J., Orner, K., & Stinson, P. (2009). Health care providers' attitudes towards termination of pregnancy: A qualitative study in South Africa. *BMC Public Health*, 9(1), 296 – 308.

- Harries, J., Orner, K., Gabriel, M., & Mitchell, E. (2007). Delays in seeking an abortion until the second trimester: A qualitative study in South Africa. *Reproductive Health*, 4, 7 – 154(7), 13-26.
- Harrison, D. (2009). *An overview of health and health care in South Africa 1994 – 2010: Priorities, progress and prospects for new gains*. A Discussion Document for the National Health Leaders' Retreat Muldersdrift, January 24-26 2010.
- Hasumi, T., & Jacobssen, K.H. (2014). Healthcare service problems reported in a national survey of South Africans. *International Journal for Quality in Health Care*, 26(4), 482-489.
- HIV Leadership through Accountability Programme: GNP+, NAPWA SA (2012). *PLHIV Stigma Index OR Tambo Region Assessment*, Germiston, NAPWA SA.
- Human Rights Commission (2013). *South African Human Rights Commission hearing on emergency medical services in the Eastern Cape, Issues paper*. Eastern Cape, South Africa: Human Rights Commission.
- Human Rights Watch (2011). *'Stop making excuses': Accountability for maternal health care in South Africa*. New York: Human Rights Watch.
- Helzner, J.F. (1996). Men's involvement in family planning. *Reproductive Health Matters*, 4(7)146-153.
- Heywood, M. (2014). *The broken thread: Primary health care, social justice and the dignity of the health worker*. Briefing paper presented at WISER Public Positions seminar, Wits University, South Africa
- Heywood, M. (2009). South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health. *Journal of Human Rights Practice*, 1, 14–36.
- Human Sciences Research Council & Nelson Mandela Foundation (2005). *Emerging voices: A report on education in South African rural communities*. Retrieved from [https://www.nelsonmandela.org/images/uploads/Emerging\\_Voices.pdf](https://www.nelsonmandela.org/images/uploads/Emerging_Voices.pdf)
- Jacobs, P., & Hart, T. (2014). Pro-poor rural development in South Africa?: A 20 year review of freedom and democracy. In T. Meyiwa, M. Nkondo, M. Chitigamabugu, & M.F. Sithole (Eds.), *State of the Nation (1994-2014)* (pp. 158-170). Cape Town: HSRC Press.
- Jacobsen, K.H., & Hasumi, T. (2014). Satisfaction with healthcare services in South Africa: Results of the national 2010 General Household Survey. *Pan African Medical Journal*, 18, 172-183.
- Jewkes, R.K., Gumedde, T., Westaway, M.S., Dickson, K., Brown, H., & Rees, H. (2005). Why are women still aborting outside designated facilities in metropolitan South Africa? *BJOG*, 112(9), 1236–1242.
- Jewkes, R., Morell, R., & Christofides, N. (2009). Empowering teenagers to prevent pregnancy: Lessons from South Africa. *Culture, Health & Sexuality*, 11(7), 675-688.
- Kanku, T., & Mash, R. (2010). Attitudes, perceptions and understanding amongst teenagers regarding teenage pregnancy, sexuality and contraception in Taung. *South African Family Practice*, 52(6), 563-572.
- Kassebaum, N.J. et al., (2013). Global, regional, and national levels and causes of maternal mortality during 1990–2013: A systematic analysis for the Global Burden of Disease Study 2013. *The Lancet*, 384(9947), 980–1004.
- Lane, T., Osmand, T., Marr, A., Shade, S.B., Dunkle, K., Sandfort, T., Struthers, H., Kegeles, S., & McIntyre, J.A. (2014). The Mpumalanga Men's Study (MPMS): Results of a baseline biological and behavioural HIV surveillance survey in two MSM communities in South Africa. *PLoS ONE*, 9(11), e111063.
- Klugman, B. (2007). Parallel or integrated 'other worlds': Possibilities for alliance-building for sexual and reproductive rights. *Journal of International Women's Studies*, 3(8), 88 - 112.
- Kon, Z.R., & Lackan, N. (2008). Ethnic disparities in access to care in post-Apartheid South Africa. *American Journal of Public Health*, 98(12), 2272-2277.
- Levers, L.L., Magweva, F.I., & Mpofo, E. (n.d.). A literature review of district health systems in east and southern Africa: Facilitators and barriers to participation in health. Retrieved June 2014 from <http://www.equinafrica.org/bibl/docs/DIS40ehsLOPEZ.pdf>
- London, L. (2008). "What is a human rights-based approach to health and does it matter? *Health and Human Rights*, 1(10), 65 - 80.
- London, L. (2004). Health and Human Rights: What Can Ten Years of Democracy in South Africa Tell Us? *Health and Human Rights*, 1(8), 1-25.
- Macleod, C., Seutlwadi, L., & Steele, G. (2014). 'Cracks in reproductive health rights: Buffalo City learners' knowledge of abortion legislation', *Health SA* 19(1), Art. #743, 10 pages. <http://dx.doi.org/10.4102/hsag.v19i1.743>
- Macleod, C., & Tracey, T. (2009). *Review of South African research and interventions in the Development of a Policy Strategy on Teen-aged Pregnancy*. Pretoria, South Africa: World Health Organization & Department of Health.
- Macleod, C.I., & Tracey, T. (2010). A decade later: follow-up review of South African research on the consequences of and contributory factors in teen-aged pregnancy, *South African Journal of Psychology*, 40(1), 18-31.
- Madras-Nelson, M. (2012). Corruption in the Eastern Cape. *NSP Review*, 5, 14-17.
- Makiwane, M., & Dan, C. (2010). *The people matter: The state of the population in the Eastern Cape*. East London: Research and Population Unit, Eastern Cape Department of Social Development.

- Marlise, R., & Pamela C. (2012). Being pimped out - How South Africa's AIDS response fails sex workers, *Agenda*, 26(2), 65-79.
- Massyn, N., Day, C., Peer, N., Padarath, A., Barron, P., & English, R. (2014). *District Health Barometer 2013/14*. Durban, South Africa: Health Systems Trust.
- Matsoso, M. P., & Fryatt, R. (2013). National health insurance: The first 18 months. In A. Padarath & R. English (Eds.), *South African Health Review 2012/2013* (p. 21-33). Durban, South Africa: Health Systems Trust.
- Matebeni, Z., Reddy, V., Sandfort, T., & Southey-Swartz, (2013). "I thought we are safe": Southern African lesbians' experience of living with HIV. *Culture, Health & Sexuality*, 15(S1), S34 – S47.
- Mbokane, A.N., & Ehlers, V.J. (2006). Contraceptive challenges experienced by women who requested termination of pregnancy services in the Mpumalanga province. *Health SA*, 11(1), 43-57.
- Mayosi, B.M., Lawn, J.E., van Niekerk, A., Bradshaw, D. & Karim, S.S.A.&.C.,H.M. *Health in South Africa: Changes and challenges since 2009*. The Lancet, 6736(12), 61814-61815.
- Mbali, M., & Mthembu, S. (2012). The politics of women's health in South Africa, *Agenda*, 2(26), 4-14.
- Mbokane, A.N., & Ehlers, V.J. (2006). Contraceptive challenges experienced by women who requested termination of pregnancy services in the Mpumalanga province. *Health SA Gesondheid*, 11(1), 43-57.
- McClaren, Z.M., & Arlington, C., & Leibbrandt, M. (2014) Distance decay and persistent health care disparities in South Africa. *BMC Health Services Research*, 14, 541-550.
- Meel, B.L., & Kaswa, R.P. (2009). The impact of the Choice on Termination of Pregnancy Act of 1996 (Act 92 of 1996) on criminal abortions in the Mthatha area of South Africa. *African Journal of Primary Health Care & Family Medicine*, 1(1), Art. #36, 3 pages. DOI: 10.4102/phcfm.v1i1.36
- Mkhize, N., Bennett, J., Reddy, V., & Moletsane, R. (2010). *The country we want to live in: Hate crimes and homophobia in the lives of black lesbian South Africans*. Cape Town: HSRC Press
- Morison, T. (2013). *Moving from reproductive choice to reproductive justice*. *HSRC Review*, [Online]. Retrieved from <http://www.hsrc.ac.za/en/review/hsrc-review-may-2013/moving-from-reproductive-choice-to-reproductive-justice>.
- Morison, T., & Macleod, C. (2015). *Men's pathways to parenthood: Silence and heterosexual gendered norms*. HSRC Press: Cape Town.
- Motsaoleli, A. (2012). *National Health Insurance: Presentation on NHI pilot districts selection*. Pretoria: Department of Health.
- Mtsolongo, T. (2013). *Eastern Cape Department of Health budget analysis*. Grahamstown: Public Service Accountability Monitor. Available from: <http://www.psam.org.za/outputs/Budget%20Analysis%201%201%202013-14.pdf>
- Mpumalanga Provincial Aids Council. (2012). *Mpumalanga PSP 2012-2016*. Mpumalanga, South Africa: Mpumalanga Department of Health.
- Müller, A. (2014). Professionalism is key in providing services to lesbian, gay, bisexual, transgender and intersex South Africans. *SAMJ*, 104(8), 558-559.
- Müller, A. (2014). Professionalism is key in providing services to lesbian, gay, bisexual, transgender and intersex South Africans. *South African Medical Journal*, 8(104), 558-559.
- Müller, A. (2013). "A call to action: Healthcare for lesbian, gay, bisexual and transgender people. *AIQ*, March/April, 23-29.
- Müller, A., & McGregor, H. (2013). *Evidence Report 3: Sexuality, Poverty and Law. Sexual and Reproductive Health Rights of Women Living with HIV in South Africa.*, Institute of Development Studies, United Kingdom.
- Mundigo, A.I. (2000). The role of men post-Cairo era. *Culture, Health & Sexuality*, vol. 3, no. 2, pp. 323-337.
- Myburgh, N.G., Solanki, G.C., & Smith, M.J., & Lalloo, R. (2005). Patient satisfaction with health care providers in South Africa: The influences of race and socioeconomic status. *International Journal for Quality in Health Care*, 6(17), 473-477.
- Nairne, D. (2000). "We Want the Power" Findings from Focus Group Discussions in Hillbrow, Johannesburg." *BMC Health Services Research* 3(June): 3–5.
- National Committee on Confidential Enquiries into Maternal Deaths (NCCEMD). *10th Interim Report 2011 and 2012*. Pretoria: Department of Health.
- National Department of Health (2011). *The National Antenatal Sentinel HIV and Syphilis Prevalence Survey*, South Africa. Pretoria: Department of Health.
- Ndinda, C., Chilwane, D., & Mokomane, Z. (2013). *Civil society activism in accessing healthcare in South Africa: A technical research report*. Pretoria: Council for Social Science Development in Africa (CODESRIA).
- NHI Gert Sibande Business Plan. (2013). Available from: <http://www.health-e.org.za/wp-content/uploads/2013/11/NHI-Business-Plan-Gert-Sibande-2013-14.pdf>
- Noble, M., & Wright, G. (2012). Using indicators of multiple deprivation to demonstrate the spatial legacy of apartheid in South Africa. *Social Indicators Research*, Online DOI 10.1007/s11205-012-0047-3

- NSP Review Special Edition (2013, September) *Death and Dying in the Eastern Cape – An investigation into the collapse of a health system*.
- Nyenti, M., & Mpedi, L.G. (2012). The Impact of SADC Social Protection Instruments on the Setting Up of a Minimum Social Protection Floor in Southern African Countries. *Potchefstroom Electronic Law Journal*, PER 8. Available from <http://www.saflii.org/za/journals/PER/2012/8.html>
- Ochse, A. (2011). Real women and real lesbians': Discourse of heteronormativity amongst a group of lesbians. *South African Review of Sociology*, 42(1), 4-20.
- Office of the Premier. (2007). *Rapid assessment of service delivery and socio-economic survey in the Eastern Cape: Chapter 7 - Primary health care and emergency services*. Available from [www.ecprov.gov.za](http://www.ecprov.gov.za)
- O'Reilly, M. & Washington, L. (2012). Young women from informal settlements report on their experiences of accessing sexual and reproductive and other health services from clinics. *Agenda*, 26(2), 126-138.
- Orner et al. (2011). Access to safe abortion: building choices for women living with HIV and AIDS. *Journal of the International AIDS Society*, 14, 54 – 63.
- Osman, S. (2011). Women's Reproductive Health in South Africa - A Paradox, *NGO Pulse*, <http://www.ngopulse.org/blogs/women-s-reproductive-health-south-africa-paradox>
- Pettifor, A.E., Rees, H.V., Kleinschmidt, I., Steffenson, A.E., MacPhail, C., Hlongwa-Madikizela, L., Vermaak, K., & Padian, N.S. (2005). Young people's sexual health in South Africa: HIV prevalence and sexual behaviours from a nationally representative household survey. *AIDS*, 19, 1525-1534.
- Phaweni, K., Peltzer, K., Mlambo, G., & Phaswana-Mafuya, N. (2010). Factors influencing pregnancy desires among HIV positive women in Gert Sibande districts in Mpumalanga. *Gender & Behaviour*, 8(2), 2960-2975.
- Panday, S., Makiwane, M., Ranchod, C., & Letsoalo, T., (2009). *Teenage Pregnancy in South Africa - With a Specific Focus on School-going Learners*. Pretoria: HSRC.
- Ramkissoo, A., Searle, C. & Burns, C., & Beksinska, M. (2010). *Sexual and reproductive health and rights*. *South African Health Review*, 3, 33-48.
- Reddy, S.P., Panday, S., Swart, D., Jinabhai, C.C., Amosun, S.L., James, S., Monyeke, K.D., Stevens, G., Morejele, N., Kambaran, N.S., Omadien, R.G., & Van den Borne, H.W. (2003). *Umthenteuhlabausamila: First South African National Youth Risk Behaviour Survey*. Cape Town: MRC.
- Reddy, V. & Sandfort, T., & Rispel, L. (2009). *From social silence to social science: Same-sex sexuality, HIV & AIDS, and Gender in South Africa*. Cape Town: HSRC Press.
- RHAP (2013). *Rural health fact sheet*. Available at [www.rhap.org.za](http://www.rhap.org.za)
- Richter, M. (2008). Sex work, reform initiatives and HIV/AIDS in inner-city. Johannesburg, *African Journal of AIDS Research*, 3(7), 323-333.
- Richter, M., & Chakvinga, P. (2012). Being pimped out - How South Africa's AIDS response fails sex workers, *Agenda*, 26(2), 65-79.
- Rispel, L.C., Metcalf, C.A., Cloete, A., Moorman, J., & Reddy, V. (2011). You become afraid to tell them that you are gay: Health service utilisation by men who have sex with men in South African cities. *Journal of Public Health Policy*, 32(S1), 137-151.
- Rispel, L., Moorman, J., & Munyewende, P. (2014). Primary health care as the foundation of the South African health system: Myth or reality? In T. Meyiwa (Ed.) *State of the Nation 1994 – 2014: A twenty year review of freedom and democracy*. Cape Town: HSRC Press
- Rural Health Advocacy Project (2013). Factsheet. Available from [www.rhap.org](http://www.rhap.org)
- Panday, S., Makiwane, M., Ranchod, C., & Letsoalo, T. (2009). *Teenage pregnancy in South Africa - with a specific focus on school-going learners*. *Child, Youth, Family and Social Development*, Human Sciences Research Council. Pretoria.
- SADC (2012). *Sexual and Reproductive Health Business Plan for the SADC Region*. (Version 3). Available from: [http://www.sadc.int/files/3613/5293/3504/SADC Sexual and Reproductive Health Business Plan 2011-2015.pdf](http://www.sadc.int/files/3613/5293/3504/SADC_Sexual_and_Reproductive_Health_Business_Plan_2011-2015.pdf)
- SAHR (2013). *South African Health Review 2013/14*. Durban, South Africa: Health Systems Trust.
- SAHRC. (2013). *SAHRC expresses grave concern at the state of public health facilities in Mpumalanga*. Available from: [www.sahrc.org.za/home/index.php?ipkArticleID=254](http://www.sahrc.org.za/home/index.php?ipkArticleID=254)
- SANAC. (2013a). *Estimating the size of the sex worker population in South Africa, 2013*. Research report available from: [http://www.sanac.org.za/resources/cat\\_view/7-publications/9-reports](http://www.sanac.org.za/resources/cat_view/7-publications/9-reports)
- SANAC (2013b). *National Strategic Plan for HIV Prevention, Care and Treatment for Sex Workers*. Pretoria, South Africa.
- Sandfort, T.G.M., Baumann, L.R.M., Matebeni, Z., Reddy, V., & Southey-Swartz, I. (2013). Forced sexual experiences as risk factor for self-reported HIV infection among Southern African lesbian and bisexual women. *PLoS ONE*, 8(1), e53552.
- SARRAH (2014). *Mid-Term Evaluation of the SARRAH programme*. Coffey International Development.

- Scorgie, F., Nakatob, D., Harperc, E., Richter, M., A. Msekoe, S., Naref, P. & Smita, J. & Chersich, M. (2013). We are despised in the hospitals: Sex workers' experiences of accessing health care in four African countries. *Culture, Health & Sexuality*, 15(4), 450 - 465.
- Section27 & Treatment Action Campaign (TAC) (2012). *NSP Review 3: Engaging with South Africa National Strategic Plan for HIV, STI*.
- Section27&Treatment Action Campaign (TAC)(2013) NSP Review 9: Engaging with South Africa National Strategic Plan for HIV, STI and TB, HIV POSITIVE Is South Africa winning? Taking stock of the response to children, PMTCT, adolescents, prevention, treatment, retention in care, TB, palliative care, pain control.
- Section27, Director's Report, May 2013
- Section27, Director's Report, September 2013
- Section27 & TAC (2013). *Death and Dying in the Eastern Cape*.
- Section27 (2013a). Open letter on Section27's priorities in 2013. Retrieved from [www.section27.org.za](http://www.section27.org.za)
- Sember, R. (2009). Sexuality research in South Africa: The policy context. In V. Reddy, T. Sandfort and L. Rispel (Eds.), *From social silence to social science: Same sex sexuality, HIV and AIDS, and gender in South Africa*. (pp14-31.) Cape Town: HSRC Press.
- Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste, S., Zungu, N., Labadarios, D., & Onoya, D. (2014). *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012*. Cape Town: HSRC Press.
- Sheimekka, R. et al., (2009). *Reproductive health in southern Africa: Government policies and changes in sexual and reproductive health and rights*. Retrieved March 2015 from [www.mv.helsinki.fi/home/rraitis/SRHR\\_FR.pdf](http://www.mv.helsinki.fi/home/rraitis/SRHR_FR.pdf)
- Smith, A. (2005). Beyond pro-life versus pro-choice: Women of color and reproductive justice. *NWSA Journal*, 17(1), 119 - 140
- Smuts, L. (2011). Coming out as a lesbian in Johannesburg, South Africa: Considering Intersecting Identities and social spaces. *South African Review of Sociology*, 42(3), 23 - 40.
- Sonke Gender Justice (2012). *Building Male Involvement in SRHR: A Basic Model for male involvement in Sexual and Reproductive Health and Rights*. Cape Town: Sonke Gender Justice.
- Stadler & Delany (2006). The healthy brothel. The context of clinical services for sex workers in Hillbrow, South Africa. *Culture, Health and Sexuality. An International Journal of Research, intervention and Care*. 8:5, 451-463, DOI:10.1080/13691050600872107
- StatsSA 2011. Census 2011. Pretoria: StatsSA. Available at [http://www.statssa.gov.za/?page\\_id=3839](http://www.statssa.gov.za/?page_id=3839)
- StatsSA. (2012). *General Household Survey: Statistical Release. Pretoria, South Africa: Statistics South Africa*. Available from: <http://www.statssa.gov.za/publications/p0318/p0318april2012.pdf>
- Statistics South Africa (2013). *General Household Survey: Statistical Release*. Pretoria, South Africa: Statistics South Africa.
- Stevens, M. (2008). *Sexual and Reproductive Health and Rights indicators: A case study from South Africa*. UNGASS report on sexual and reproductive health indicators.
- Stevens, M. (2012). Maternal mortality, HIV, and unsafe abortion: A silent epidemic. *Agenda*, 26(2), 44-50.
- Swarr, A.L. (2012). Paradoxes of butchness: Lesbian masculinities and sexual violence in contemporary South Africa. *Journal of Women in Culture and Society*, 37(4), 961-986.
- Swarr, A.L. (2009). Stabane, intersexuality, and same-Sex relationships in South Africa. *Feminist Studies*, 35(3), 524 - 548.
- Swartz, S., & Bhana, A. (2009). *Teenage Tata: Experiences of young fathers in impoverished communities in South Africa*. Cape Town: HSRC Press.
- Trueman, K.A., & Magwentshu, M. (2013). Abortion in a progressive legal environment: The need for vigilance in protecting and promoting access to safe abortion services in South Africa. *American Journal of Public Health*, 103(3), 397 - 399.
- Tucker, A. (2010). Shifting boundaries of sexual identities in Cape Town: The appropriation and malleability of 'gay' in township spaces, *Urban Forum*, 21, 107 - 122.
- Turok, I., & Borel-Saladien, J. (2014). Continuity, change and conflict in South African cities. In T. Meyiwa, M. Nkondo, M. Chitiga-Mabugu & M., & N. Sithole (2014). *State of the Nation (1994-2014): A 20 year review of freedom and democracy*. (pp. 183-197.) Cape Town: HSRC Press.
- UNAIDS (2010). *Report On The Global Aids Epidemic*. Available from: [http://www.unaids.org/globalreport/documents/20101123\\_GlobalReport\\_full\\_en.pdf](http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf)
- Van Bogaeret, L. (2003). 'Failed' contraception in a rural South African population. *SAMJ*, 93(11), 858-861.
- Van Rensberg, H.C.J. (2014). South Africa's protracted struggle for equal distribution and equitable access: Still not there. *Human Resources for Health*, 12, 26-42.
- Van Rensberg, M.S. (2009). Measuring the quality of life of residents in SADC communities affected by HIV. *AIDS Care*, 21(9), 1132 - 1140.

- Van Schaik N., & Day, C. (2014). Reproductive health. In N. Massyn, C. Day, N. Peer, A. Padarath, P. Barron, R. English (eds.) *District Health Barometer 2013/14*. (pp. 180-194). Durban: Health Systems Trust.
- Wells, H., & Polders, L. (2004). *Levels of empowerment among LGBT people in Gauteng, South Africa*. Pretoria: OUT LGBT Wellbeing.
- Wood, K., & Jewkes, K. (2006). Blood blockages and scolding nurses: Barriers to adolescent contraceptive use in South Africa. *Reproductive Health Matters*, 14(27), 109-118.
- World Health Organization (2010a). *Social determinants of sexual and reproductive health: Informing future research and programme implementation*. Geneva, Switzerland: World Health Organisation Press.
- World Health Organisation. (2010b). *Monitoring the building blocks of health systems: A handbook of indicators and their measurement strategies*. Available from:  
[http://www.who.int/healthinfo/systems/WHO\\_MBHSS\\_2010\\_full\\_web.pdf?ua=1](http://www.who.int/healthinfo/systems/WHO_MBHSS_2010_full_web.pdf?ua=1)
- World Health Organisation (2010). *Social determinants of sexual and reproductive health: Informing future research and programme implementation*. Available from:  
[http://www.who.int/social\\_determinants/tools/WHO\\_SocialDeterminantsSexualHealth\\_2010.pdf](http://www.who.int/social_determinants/tools/WHO_SocialDeterminantsSexualHealth_2010.pdf)
- World Health Organisation (2013). *The World Health Report. Research for Universal Coverage*

## APPENDICES

### APPENDIX 1: INFORMATION AND CONSENT FORMS (PUBLIC HEALTH WORKER SURVEY)

#### INFORMATION SHEET AND CONSENT FORM: Public Health Worker Survey Questionnaire

#### **Making Sexual and Reproductive Health Rights Real in South Africa: A Baseline Study in selected sites in four provinces**

##### **Who we are**

I work at the Human Sciences Research Council. I am part of the research team in a project commissioned by the *Aids Foundation of South Africa (AFSA)*.

##### **What we are doing**

We are conducting research on the **Making Sexual and Reproductive Health Rights Real in South Africa in selected sites in four provinces**. We are inviting you to take part by completing this survey. It has a number of questions about your work as a healthcare provider, and any difficulties you have. We are especially interested in services for reproductive health (family planning, pregnancy, contraceptives etc.).

##### **Your participation**

We are asking you whether you will complete survey about your knowledge and opinions of the issues associated with sexual and reproductive health care, such as reproductive health (family planning, pregnancy, contraceptives etc.). If you agree, we will ask you to participate by completing one survey which will take approximately 20 minutes.

Please understand that **your participation is voluntary** and you are not being forced to take part in this study. The choice of whether to participate or not, is yours alone. If you choose not to take part, you will not be affected in any way whatsoever. If you agree to participate, you are free to withdraw from and to stop participating in the research at any time and tell me that you don't want to go continue. If you do this, there will be no penalties and you will not be prejudiced in any way.

##### **Confidentiality**

All identifying information and electronic files will be kept in a locked password protected computer and paper-based materials will be filed and stored in a locked filing cabinet and will not be available to others and will be kept confidential to the extent possible by law. The records from your participation may be reviewed by people responsible for making sure that research is done properly, including members of the ethics committee at the Human Sciences Research Council (All of these people are required to keep your identity confidential). Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

We will not record your name anywhere and no one will be able to connect you to the answers you give. Your answers will be linked to a fictitious code number or a pseudonym (another name) and we will refer to you in this way in the data, any publication, report or other research output.

##### **Data Curation**

All future use of the stored data will be subject to further Research Ethics Committee review and approval.

##### **Risks/discomforts**

At the present time, we foresee minimal risk of harm from your participation. The risks associated with participation in this study could be emotional or environmental risk, meaning that the questions might elicit

uncomfortable feelings (if you require additional support we will refer you to a local counselling agency). Even though we will conduct the interview in a private area, the health care environment might make you feel uncomfortable and awkward at times. Please feel free to share these discomforts with us.

**Benefits**

There are no immediate benefits to you from participating in this study. However, this study will be helpful to us to promote understanding of the sexual and reproductive health care, rights, access and protection in health care systems in South Africa, and in particular for sexually diverse/different (and/or vulnerable) persons

If you would like to receive feedback on our study, we will record your phone number on a separate sheet of paper and can send you the results of the study when it is completed sometime after the 31 March 2015. We will also conduct feedback sessions with stakeholders on completion of data collection (at dates to be determined) where we will share information with you based on our interviews.

**Who to contact if you have been harmed or have any concerns**

This research has been approved by the HSRC Research Ethics Committee (REC). If you have any complaints about ethical aspects of the research or feel that you have been harmed in any way by participating in this study, please call the HSRC’s toll-free ethics hotline 0800 212 123 (when phoned from a landline from within South Africa) or contact the Human Sciences Research Council REC Administrator, on Tel 012 302 2012 or E-mail [research.ethics@hsrc.ac.za](mailto:research.ethics@hsrc.ac.za)

If you have concerns or questions about the research you may contact the project leader, Prof Vasu Reddy at 012 302 2200 or [vasureddy@hsrc.ac.za](mailto:vasureddy@hsrc.ac.za)

**CONSENT FOR PARTICIPATION**

I hereby agree to participate in research on the *Making Sexual and Reproductive Health Rights Real in South Africa: A Baseline study in selected sites in four provinces*. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop participating at any point should I not want to continue and that this decision will not in any way affect me negatively. I understand that this is a research project whose purpose is not necessarily to benefit me personally in the immediate or short term. I understand that my participation will remain confidential.

.....  
**Signature of participant**

**Date:**.....

**CONSENT FOR DATA CURATION**

I understand that the information that I provide will be stored electronically and will be used for research purposes now or at a later stage.

.....  
**Signature of participant**

**Date:**.....

## APPENDIX 2: INFORMATION AND CONSENT FORMS (USER SURVEY)

### INFORMATION SHEET AND CONSENT FORM:

#### Sexual and Reproductive Health Rights User Survey Questionnaire

#### **Making Sexual and Reproductive Health Rights Real in South Africa. A Baseline Study in selected sites in four provinces**

##### **Who we are**

I work at the Human Sciences Research Council. I am part of the research team in a project commissioned by the *Aids Foundation of South Africa (AFSA)*.

##### **What we are doing**

We are conducting research on the **Making Sexual and Reproductive Health Rights Real in South Africa. A Baseline Study in selected sites in four provinces**. We are inviting you to take part by completing this survey. We want to know how easy or difficult it is for you to get healthcare services so that we can work with healthcare providers to improve services. We are especially interested in services for reproductive health (family planning, pregnancy, contraceptives etc.). The survey has a number of questions about your healthcare providers and institutions, and any difficulties you have as a patient.

##### **Your participation**

We are asking you whether you will complete survey about your knowledge and opinions of the issues associated with sexual and reproductive health care, such as reproductive health (family planning, pregnancy, contraceptives etc.). If you agree, we will ask you to participate by completing one survey which will take approximately 20 minutes. (The clinic/hospital will not know what you have said, because we will not write your name on your answer sheet.)

Please understand that **your participation is voluntary** and you are not being forced to take part in this study. The choice of whether to participate or not, is yours alone. If you choose not to take part, you will not be affected in any way whatsoever. If you agree to participate, you will be free to /withdraw from and stop participating in the research at any time and tell me that you don't want to go continue. If you do this, there will be no penalties and you will not be prejudiced in any way.

##### **Confidentiality**

All identifying information and electronic files will be kept in a locked password protected computer and paper-based materials will be filed and stored in a filing cabinet and will not be available to others and will be kept confidential to the extent possible by law. The records from your participation may be reviewed by people responsible for making sure that research is done properly, including members of the ethics committee at the Human Sciences Research Council (All of these people are required to keep your identity confidential). Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

We will not record your name anywhere and no one will be able to connect you to the answers you give. Your answers will be linked to a fictitious code number or a pseudonym (another name) and we will refer to you in this way in the data, any publication, report or other research output.

##### **Data Curation**

All future use of the stored data will be subject to further Research Ethics Committee review and approval.

**Risks/discomforts**

At the present time, we foresee minimal risk of harm from your participation. The risks associated with participation in this study could be emotional or environmental risk, meaning that the questions might elicit uncomfortable feelings and that even though we will conduct the interview in a private area, the health care environment might make you feel uncomfortable and awkward at times. Please feel free to share these discomforts with us.

**Benefits**

There are no immediate benefits to you from participating in this study. However, this study will be helpful to us to promote understanding of the sexual and reproductive health care, rights, access and protection in health care systems in South Africa, and in particular for sexually diverse/different (and/or vulnerable) persons

If you would like to receive feedback on our study, we will record your phone number on a separate sheet of paper and can send you the results of the study when it is completed sometime after the 31 March 2015. We will also conduct feedback sessions with stakeholders on completion of data collection (at dates to be determined) where we will share information with you based on our interviews.

**Who to contact if you have been harmed or have any concerns**

This research has been approved by the HSRC Research Ethics Committee (REC). If you have any complaints about ethical aspects of the research or feel that you have been harmed in any way by participating in this study, please call the HSRC's toll-free ethics hotline 0800 212 123 (when phoned from a landline from within South Africa) or contact the Human Sciences Research Council REC Administrator, on Tel 012 302 2012 or E-mail [research.ethics@hsrc.ac.za](mailto:research.ethics@hsrc.ac.za) .

If you have concerns or questions about the research you may contact the project leader, Prof Vasu Reddy at 012 302 2200 or [vasureddy@hsrc.ac.za](mailto:vasureddy@hsrc.ac.za)

## APPENDIX 3: INFORMATION AND CONSENT FORMS (INDIVIDUAL INTERVIEWS)

### INFORMATION SHEET AND CONSENT FORM: INDIVIDUAL INTERVIEWS

#### **Making Sexual and Reproductive Health Rights Real in South Africa. A Baseline Study in selected sites in four provinces**

##### **Who we are**

I work at the *Human Sciences Research Council*. I am part of the research team in a project commissioned by the *Aids Foundation of South Africa (AFSA)*.

##### **What we are doing**

We are conducting research on the **Making Sexual and Reproductive Health Rights Real in South Africa. A Baseline Study in selected sites in four provinces**. We are gathering data and information on the attitudes and behaviour of healthcare personnel towards sexual diverse/different (and/or vulnerable) populations in healthcare systems.

##### **Your participation**

We are asking you whether you will allow us to conduct one interview with you about your knowledge and opinions of the issues associated with sexual and reproductive health care, rights, access and protection in health care systems in South Africa. If you agree, we will ask you to participate in one interview for approximately 60 minutes.

Please understand that **your participation is voluntary** and you are not being forced to take part in this study. The choice of whether to participate or not, is yours alone. If you choose not to take part, you will not be affected in any way whatsoever. If you agree to participate, you are free to withdraw from and stop participating in the research at any time and tell me that you don't want to go continue. If you do this, there will be no penalties and you will not be prejudiced in any way.

##### **Confidentiality**

All identifying information and electronic files will be kept in a locked password protected computer and paper-based materials will be kept in a locked filing cabinet and will not be available to others and will be kept confidential to the extent possible by law. The records from your participation may be reviewed by people responsible for making sure that research is done properly, including members of the ethics committee at the Human Sciences Research Council (All of these people are required to keep your identity confidential). Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

We are asking you to give us permission to tape-record the interview so that we can accurately record what is said. We will not record your name anywhere and no one will be able to connect you to the answers you give. Your answers will be linked to a fictitious code number or a pseudonym (another name) and we will refer to you in this way in the data, any publication, report or other research output.

##### **Data Curation**

All future use of the stored data will be subject to further Research Ethics Committee review and approval.

**Risks/discomforts**

At the present time we foresee minimal risk of harm from your participation. The risks associated with participation in this study could be emotional risk, meaning that the questions might elicit uncomfortable feelings and memories. Please feel free to share these discomforts with us.

**Benefits**

There are no immediate benefits to you from participating in this study. However, this study will be helpful to us to promote understanding of the sexual and reproductive health care, rights, access and protection in health care systems in South Africa for sexually diverse/different (and/or vulnerable) individuals.

If you would like to receive feedback on our study, we will record your phone number on a separate sheet of paper and can send you the results of the study when it is completed sometime after the 31 March 2015. We will also conduct feedback sessions with stakeholders on completion of data collection (at dates to be determined) where we will share information with you based on our interviews.

**Who to contact if you have been harmed or have any concerns**

This research has been approved by the HSRC Research Ethics Committee (REC). If you have any complaints about ethical aspects of the research or feel that you have been harmed in any way by participating in this study, please call the HSRC’s toll-free ethics hotline 0800 212 123 (when phoned from a landline from within South Africa) or contact the Human Sciences Research Council REC Administrator, on Tel 012 302 2012 or E-mail [research.ethics@hsrc.ac.za](mailto:research.ethics@hsrc.ac.za).

If you have concerns or questions about the research you may I contact the project leader, Prof Vasu Reddy at 012 302 2200 or [vasureddy@hsrc.ac.za](mailto:vasureddy@hsrc.ac.za)

**CONSENT FOR PARTICIPATION**

I hereby agree to participate in research on the Making Sexual and Reproductive Health Rights Real in South Africa. A baseline study in selected sites in four provinces I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop participating at any point should I not want to continue and that this decision will not in any way affect me negatively. I understand that this is a research project whose purpose is not necessarily to benefit me personally in the immediate or short term. I understand that my participation will remain confidential.

.....  
**Signature of participant** **Date:**.....

**CONSENT FOR TAPE RECORDING**

I hereby agree to the tape-recording of my participation in the study.

.....  
**Signature of participant** **Date:**.....

**CONSENT FOR DATA CURATION**

I understand that the information that I provide will be stored electronically and will be used for research purposes now or at a later stage.

.....  
**Signature of participant** **Date:**.....

## APPENDIX 4: PUBLIC HEALTH WORKER QUESTIONNAIRE



**Human Sciences Research Council**

### Baseline study: SRH Public Health Worker Questionnaire

<b>FIELD RESEARCHER TO COMPLETE</b>	
Researcher name: _____	Province: _____
Facility name: _____	Type of facility: _____
Language of interview: _____	
<b>SCREENING QUESTION: How old are you? _____</b>	
<b>Only proceed if person is 18 or older</b>	

<b>SECTION A: DEMOGRAPHIC</b>
<b>Q1. How old are you (years)?</b>
<b>Q2. What is your gender?</b> (1) Female      (2) Male      (3) Other
<b>Q3. How would you describe your sexuality?</b> 1) Attracted to men (2) Attracted to women (3) Attracted to both women & men (4) Other: _____
<b>Q4. What is your relationship status?</b> (1) Dating (2) Married (customary/civil partnership/conventional) (3) Domestic partnership (4) Co-habiting (5) Other: _____
<b>Q5. What is the main language spoken in your home?</b> (1) Afrikaans (2) English (3) Ndebele (4) Sotho (5) Pedi (6) Swati (7) Tshivenda (8) Tswana (9) Xhosa (10) Xitsonga (11) Zulu (12) Other
<b>Q6. How would you describe yourself in terms of your race?</b> (1) Black/African (2) Coloured (3) White (3) Indian/Asian (4) Other: _____ (5) Prefer not to say
<b>Q7. What is your religion?</b> (1) None (2) Christian (3) Hindu (4) Muslim (5) Jewish (6) Other: _____
<b>Q8. What is your highest qualification?</b> (1) None (2) Primary (3) Secondary (4) Higher (university / FET)

<b>SECTION B: WORK CONTEXT</b>		
No.	Question	Response
Q1	What is your job title?	
	How long have you worked in your organisation?	(1) Less than 1 year (2) 1 year + (3) 2 years + (4) 3 years + (5) 4 years + (6) 5 years +
Q2	What is your current pay scale/salary level	(1) (2) (3)

		(4)
Q3	How many hours a week are you contracted to work?	.....Hours
Q4	How many hours a week do you actually work?	.....Hours
Q5	Do you receive any of the following allowances? (Circle all that apply)	(1) Rural allowance (2) Housing allowance (3) Accommodation allowance (4) Transport allowance (5) Medical allowance (6) Pension allowance (7) Overtime/extra duty allowance (8) Uniform allowance (9) Risk allowance (10) Non-practice allowance (11) Other (specify) ....
Q6	If you travel or attend workshops, do you receive any <i>per diems</i> ?	(1) Yes (2) Yes, but it's not enough (3) Sometimes (4) No (5) Not sure
Q7	Do you ever receive additional income / gifts from patients?	(1) Yes (2) No (4) Prefer not to say
Q8a	How satisfied are you with the income from your current job?	(1) Very Satisfied (2) Quite Satisfied (3) Not Satisfied (4) Very dissatisfied
Q8b	Can you provide a reason for your answer above?	
Q9a	How often do you supplement your main income with other work?	(1) Never →SKIP TO Q 13 (2) Occasionally (3) On a regular basis
Q9b	What is the nature of this work?	(1) Private healthcare work (2) Other (specify)...
Q9c	How many hours a week do you engage in this additional work?	5 – 10 h 11 – 15 h 15 – 20 h More than 20 h
Q10a	Have you had any in-service training since being employed?	(1) Yes (2) No → SKIP TO 11 (3) Not sure
Q10b	Have you had any in-service training in the last year?	(1) Yes (2) No → SKIP TO 11 (3) Not sure
Q10c	How satisfied are you with the amount of in-service training you have received?	(1) Very Satisfied (2) Quite Satisfied (3) Not Satisfied (4) Very dissatisfied
Q11	Are there any factors that stop you from doing your job efficiently?	(1) No (2) Yes (specify) ...

SECTION C: SEXUAL & REPRODUCTIVE HEALTH SERVICES		
Q12	What kinds of sexual and reproductive health services are provided at this facility?  <ul style="list-style-type: none"> <li>• CIRCLE ALL MENTIONED</li> <li>• IF RESPONDENT DOES NOT MENTION ANY OF THE OPTIONS LISTED: PROBE BY READING THE LIST.</li> <li>• IF NONE OF THE OPTIONS APPLY: WRITE IN "OTHER".</li> </ul>	(1) Voluntary Counselling and Testing for HIV
		(2) Family planning services
		(3) Pregnancy care and delivery
		(4) Contraceptive
		(5) Termination of Pregnancy (abortion)
		(6) Education and counselling regarding SRH
		(7) Miscarriage/Post-abortion care services
		(8) STI treatment and counselling
		(9) Mental health and psychosocial support
		(10) Pregnancy testing
		(11) Don't know
		(12) Other (specify)...
Q13	In general, how accessible do you consider these services to be to patients?	(1) Very accessible
		(2) Somewhat accessible
		(3) Not accessible
Q14	Are there certain patients/groups that cannot access these services?  <ul style="list-style-type: none"> <li>• CIRCLE ALL MENTIONED</li> <li>• IF RESPONDENT DOES NOT MENTION ANY OF THE OPTIONS LISTED: PROBE BY READING THE LIST.</li> <li>• IF NONE OF THE OPTIONS APPLY: WRITE IN "OTHER".</li> </ul>	(1) People living in rural / remote areas
		(2) Younger women / girls
		(3) Younger men / boys
		(4) Teenagers
		(5) People with disabilities
		(5) Men who have sex with men
		(6) Women who have sex with women
		(7) Lesbian, Gay, Transgender, Intersex persons
		(8) Women seeking ToP (abortion) / post-abortion care
		(9) Other: _____
(10) Everyone is able to access SRH services		
Q15a	In your opinion, are there certain people (maybe some mentioned in the previous question) who SHOULD NOT access any SRH services?	(1) No, everyone should be able to access SRH services → SKIP TO 16
		(2) Yes
Q15b	Which people SHOULD NOT access services and why?	
Q16a	In your opinion, are there any SERVICES that should not be offered?	(1) No, all these services should be offered →SKIP TO Q17
		(2) Yes
Q16b	Can you give a reason for your answer above? (Specify who and which services)	
Q17a	How welcome do you think people feel at this facility?	(1) Very welcome
		(2) Quite welcome
		(3) Not very welcome
Q17b	Can you give a reason for your answer above?	
Q18a	Do you think that there are people from any groups that do not feel comfortable accessing the facility?  <ul style="list-style-type: none"> <li>• CIRCLE ALL MENTIONED</li> <li>• IF RESPONDENT DOES NOT MENTION ANY OF THE OPTIONS LISTED: PROBE BY READING THE LIST.</li> <li>• IF NONE OF THE OPTIONS APPLY: WRITE IN</li> </ul>	(1) Everyone feels comfortable →SKIP TO 22
		(2) Don't know →SKIP TP 22
		(3) Young women/girls
		(4) Young men/boys
		(5) Teenagers
		(6) People with STIs / HIV
		(7) People with disabilities
		(8) Men who sleep with men
		(9) Women who sleep with women

	"OTHER".	(10) Lesbian/Gay/Transgender/Intersex (11) Women seeking ToP (abortion) or post-abortion care (11) Other (specify)
Q18b	Can you give a reason for your answer above?	
Q19a	Have you ever turned patients away?	Yes No →SKIP TO 20
Q19b	Can you say why patients were turned away?	
Q20	Overall, how satisfied are you with the SRH services that the facility provides?	(1) <i>Very dissatisfied</i> ; (2) <i>Quite dissatisfied</i> ; (3) <i>Satisfied</i> ; (4) <i>Very satisfied</i>
Q21	Overall, how satisfied are you with the communication you have with patients?	(1) <i>Very dissatisfied</i> ; (2) <i>Quite dissatisfied</i> ; (3) <i>Satisfied</i> ; (4) <i>Very satisfied</i>
<b>Q22</b>	<b>How would you rate the following IN RELATION TO SRHR SERVICES?</b>	
	• Level of human resources available for you to do your job	(1) Awful; (2) Bad; (3) OK; (4) Good; (5) Excellent; (6) Unsure; (7) Prefer not to say
	• Your work premises compared to other public health premises	(1) Awful; (2) Bad; (3) OK; (4) Good; (5) Excellent; (6) Unsure; (7) Prefer not to say
	• Availability of equipment needed for SRH services	(1) Awful; (2) Bad; (3) OK; (4) Good; (5) Excellent; (6) Unsure; (7) Prefer not to say
	• Availability of medicines needed	(1) Awful; (2) Bad; (3) OK; (4) Good; (5) Excellent; (6) Unsure; (7) Prefer not to say
	• Convenience of location to you	(1) Awful; (2) Bad; (3) OK; (4) Good; (5) Excellent; (6) Unsure; (7) Prefer not to say
	• Convenience of location to patients	(1) Awful; (2) Bad; (3) OK; (4) Good; (5) Excellent; (6) Unsure; (7) Prefer not to say
	• Financial costs to patients	(1) Awful; (2) Bad; (3) OK; (4) Good; (5) Excellent; (6) Unsure; (7) Prefer not to say
	• Patient waiting times	(1) Awful; (2) Bad; (3) OK; (4) Good; (5) Excellent; (6) Unsure; (7) Prefer not to say
<b>Q23. Would you like to provide more detail for any of your answers above?</b>		
<b>Q24. How do you think any of the problem areas could be addressed?</b>		

THANK YOU FOR YOUR TIME!

## APPENDIX 5: SRH USERS QUESTIONNAIRE

### Human Sciences Research Council

### Baseline Study: SRH Healthcare User Questionnaire

FIELD RESEARCHER TO COMPLETE			
Researcher	name:	_____	Province:
Facility	name:	_____	Type of facility:
Language of interview: _____			
SCREENING QUESTION: How old are you? _____		<b>Only proceed if person is 18 or older</b>	

<b>SECTION A: DEMOGRAPHIC</b>
<b>Q1. How old are you (years)?</b>
<b>What is your gender?</b> <input type="checkbox"/> (1) Female <input type="checkbox"/> (2) Male <input type="checkbox"/> (3) Other: _____
<b>Q2. How do you describe your sexuality?</b> (1) <input type="checkbox"/> Attracted to men                      (2) <input type="checkbox"/> Attracted to women (3) <input type="checkbox"/> Attracted to both women and men    (4) <input type="checkbox"/> Other: _____
<b>Q3. What is your relationship status?</b> (1) Dating (2) Married (customary/civil partnership/conventional) (3) Domestic partnership (4) Co-habiting (5) Other: _____
<b>Q4. What is the main language spoken in your home?</b> (1) Afrikaans (2) English (3) Ndebele (4) Sotho (5) Pedi (6) Swati (7) Tshivenda (8) Tswana (9) Xhosa (10) Xitsonga (11) Zulu (12) Other
<b>Q5. What is the highest level of school you attended?</b> (1) <input type="checkbox"/> None    (2) <input type="checkbox"/> Primary    (3) <input type="checkbox"/> Secondary    (4) <input type="checkbox"/> Higher (university / FET)
<b>Q6. How would you describe yourself in terms of your race?</b> <input type="checkbox"/> (1) Black/African <input type="checkbox"/> (2) Coloured <input type="checkbox"/> (3) White <input type="checkbox"/> (4) Indian/Asian <input type="checkbox"/> (5) Prefer not to say <input type="checkbox"/> (6) Other: _____
<b>Q7. Are you working &amp; for whom?</b> <input type="checkbox"/> (1) Yes, employed by other <input type="checkbox"/> (2) Yes, self-employed <input type="checkbox"/> (3) Yes, as a volunteer <input type="checkbox"/> (4) No, unemployed <input type="checkbox"/> (5) No, on disability /boarded <input type="checkbox"/> No, retired/pensioner
<b>Q8. What ways do you support yourself? SELECT ALL THAT APPLY</b> <input type="checkbox"/> Salary/wages /trade <input type="checkbox"/> My partner supports me <input type="checkbox"/> My family supports me <input type="checkbox"/> Grants <input type="checkbox"/> My friends support me <input type="checkbox"/> Other; please specify:
<b>Q9. Are you covered by any medical aid?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No

<b>SECTION B: ACCESS TO GENERAL CARE</b>		
No.	Question	Response
<b>Q1</b>	What was the <u>main service</u> that you came for today?	
<b>Q2</b>	How did you get here today?	(1) Drove myself
		(2) Public transportation (e.g. taxi, bus, train)
		(3) Someone else drove me
		(4) Walk
		(5) Other:
<b>Q3</b>	How long did it take you to get here?	(1) Under 1 hour
		(2) 1 – 2 hours
		(3) 3 – 5 hours

		(4) More than five hours
<b>Q4</b>	Did you receive the service that you needed?	(1) Yes (2) No → SKIP TO Q7
<b>Q5</b>	How long did you wait to be seen	(1) Under 1 hour (2) 1 – 2 hours (3) 3 – 5 hours (4) More than five hours
<b>Q6</b>	Overall, how satisfied are you with the care you received today?	(1) Very satisfied (2) Quite satisfied (3) Neutral (4) Dissatisfied (5) Very dissatisfied
<b>Q7</b>	[IF NO TO Q4] what was the reason that you did not receive care?	<i>[Open-ended in pilot, list for main survey]</i>
<b>Q8</b>	Is your experience today what it is usually like here?	(1) Yes, this is what it is usually like (2) No, the service is usually better (3) No, the service is usually worse (4) Don't know, first time at the facility
<b>Q9</b>	In the past, were you ever unable to get any treatments or medicines prescribed for you?	(1) Yes, I was able to get the medicine (2) Yes, but with some delay (3) No, I was unable to get medicine (4) I have not been prescribed medicine
<b>Q10</b>	Has there ever been a time when you do not receive care when you come to the clinic/hospital?	(1) No, I have always received care (2) Yes, one time (3) Yes, a few times (2 or 3) (4) Yes, many times (more than 3)
<b>Q12</b>	<i>In general</i> , what challenges do you have in receiving the healthcare you need? <ul style="list-style-type: none"> <li>• CIRCLE ALL MENTIONED</li> <li>• IF RESPONDENT DOES NOT MENTION ANY OF THE OPTIONS LISTED: PROBE BY READING THE LIST.</li> <li>• IF NONE OF THE OPTIONS APPLY: WRITE IN "OTHER".</li> </ul>	(1) None (2) Transport to the facility – transport (3) Time taken to get the facility (4) Getting time off work (5) Waiting times (6) Cost of medicines (7) Availability of medicines (8) Other:
<b>Q11</b>	In the past, have you had any problems communicating with doctors or other healthcare professionals? <i>[Clarify: trouble understanding or being understood]</i>	(1) No → SKIP TO SECTION C (2) Yes
<b>Q12</b>	Can you give a reason why you answered yes to the previous question?	

### SECTION C: KNOWLEDGE, ATTITUDES AND UTILISATION OF SEXUAL & REPRODUCTIVE HEALTH SERVICES

<b>Q13a</b>	Is there a place in your community where people can go to talk and find out about relationships, sex, contraception, sexually transmitted infections, HIV/AIDS, etc.?	(1) Yes (2) No → SKIP TO Q15 (3) Don't know → SKIP TO Q15
<b>Q13b</b>	Can you name the facility and/or tell me where it is?	
<b>Q14</b>	What kinds of services are provided? <ul style="list-style-type: none"> <li>• CIRCLE ALL MENTIONED</li> <li>• IF RESPONDENT DOES NOT SPONTANEOUSLY MENTION ANY OF THE OPTIONS LISTED: PROBE</li> </ul>	(1) VCT for HIV (2) Family planning services (3) Pregnancy care and delivery (4) Contraceptive (5) Termination of Pregnancy (abortion)

	<p>BY READING THE LIST.</p> <ul style="list-style-type: none"> <li>IF NONE OF THE OPTIONS APPLY, WRITE IN THE SERVICE IN "OTHER".</li> </ul>	<p>(6) Education and counselling regarding SRH</p> <p>(7) Miscarriage/Post-abortion care services</p> <p>(8) STI treatment and counselling</p> <p>(9) Mental health and psychosocial support</p> <p>(10) Pregnancy testing</p> <p>(11) Other:</p> <p>(12) Don't know</p>
<b>Q15a</b>	Have you ever visited a health facility or other place to get these sexual and reproductive health (SRH) services in the last year?	<p>(1) Yes</p> <p>(2) Wanted to, but services/ facility not available/ accessible →SKIP TO Q28</p> <p>(3) Not needed / desired →SKIP TO Q28</p>
<b>Q15b</b>	Have you ever visited a health facility or other place to get SRH services in the last three months?	<p>(1) Yes</p> <p>(2) Wanted to, but services/ facility not available/ accessible →SKIP TO Q28</p> <p>(3) Not needed / desired →SKIP TO Q28</p>
<b>Q16a</b>	Where did you go for your most recent visit to obtain SRH? (name facility and location)	
<b>Q16b</b>	<p>What was the reason for your most recent visit to a health facility for SRH services?</p> <ul style="list-style-type: none"> <li>CIRCLE ALL MENTIONED</li> <li>IF RESPONDENT DOES NOT SPONTANEOUSLY MENTION ANY OF THE OPTIONS LISTED: PROBE BY READING THE LIST.</li> <li>IF NONE OF THE OPTIONS APPLY, WRITE IN "OTHER".</li> </ul>	<p>(1) Education and counselling regarding SRH</p> <p>(2) VCT for HIV</p> <p>(3) Miscarriage/Post-abortion care services</p> <p>(4) Family planning services</p> <p>(5) STI treatment and counselling</p> <p>(6) Pregnancy care and delivery</p> <p>(7) Vaccination</p> <p>(8) To get condoms</p> <p>(9) To get contraceptives (the pill, injection, etc.)</p> <p>(10) To get mental health and psychosocial support</p> <p>(11) Termination of pregnancy (abortion)</p> <p>(12) Other (specify) _____</p>
<b>Q17</b>	<p>Who did you talk to or see at the health facility the last time you went?</p> <ul style="list-style-type: none"> <li>CIRCLE ALL MENTIONED</li> <li>PROBE BY READING LIST.</li> <li>IF NONE OF OPTIONS APPLY, WRITE IN "OTHER".</li> </ul>	<p>(1) Doctor</p> <p>(2) Nurse</p> <p>(3) Health Aid</p> <p>(4) Peer educator/counsellor</p> <p>(5) Other (specify) _____</p>
<b>Q18</b>	<p>What was the service provider like in general?</p> <ul style="list-style-type: none"> <li>CIRCLE ALL MENTIONED</li> <li>PROBE BY READING LIST.</li> <li>IF NONE OF OPTIONS APPLY, WRITE IN "OTHER".</li> </ul>	<p>(1) Knowledgeable and well-qualified</p> <p>(2) Friendly and polite</p> <p>(3) Interested in you and your problems</p> <p>(4) A good communicator</p> <p>(5) Respectful</p> <p>(6) Concerned about your privacy</p> <p>(7) Honest and direct</p> <p>(8) A good listener</p> <p>(9) Able to help you</p> <p>(10) None of the above</p>
<b>Q19</b>	Did the service providers explain things to you in a way that you understand?	<p>(1) Yes</p> <p>(2) Not really</p> <p>(3) No</p>
<b>Q20</b>	How well do you feel that you are/were listened to at the facility?	<p>(1) Very Well</p> <p>(2) Quite Well</p> <p>(3) Neutral</p> <p>(4) Quite poorly</p> <p>(5) Very Poorly</p>
<b>Q21</b>	<b>How would you rate the following aspects of that facility: (CIRCLE THE RESPONSE)</b>	

	<ul style="list-style-type: none"> <li>• Skill and ability of the staff?</li> </ul>	(1) awful; (2) bad; (3) OK; (4) good; (5) great
	<ul style="list-style-type: none"> <li>• Overall how clean the facility is?</li> </ul>	(1) awful; (2) bad; (3) OK; (4) good; (5) great
	<ul style="list-style-type: none"> <li>• Overall how efficient nursing care is?</li> </ul>	(1) awful; (2) bad; (3) OK; (4) good; (5) great
	<ul style="list-style-type: none"> <li>• Friendliness and politeness of the staff?</li> </ul>	(1) awful; (2) bad; (3) OK; (4) good; (5) great
	<ul style="list-style-type: none"> <li>• Nearness of location to you?</li> </ul>	(1) awful; (2) bad; (3) OK; (4) good; (5) great
<b>Q22</b>	Would you return to that health facility again?	(1) Yes → SKIP TO Q24 (2) No (3) Not sure
<b>Q23</b>	What is the reason that you won't return to the health facility?	(1) Takes too much time (2) Too difficult to get there (3) Costs too much (4) Not enough privacy (5) Mistreated by staff (6) No staff of the same sex available (7) Too embarrassing (8) People in the community gossip about me (9) Other (specify)
<b>Q24</b>	<u>In general</u> , do you think that your experiences have been affected by who you are (i.e., your gender, sexuality, age, etc.)	(1) Yes (2) No → SKIP TO Q26 (3) Not sure
<b>Q25</b>	If you said yes, can you please explain your answer?	
<b>Q26</b>	Overall, how would you rate the general SRH services that you have received in the past?(CIRCLE THE RESPONSE) (1) = awful; (2) = bad; (3) = OK; (4) = good; (5) = great	
<b>Q27</b>	Is there something that you think could be done to SRH improve services in general?	
<b>Q28a</b>	Would you feel comfortable going to a health facility found in your area for sexual and reproductive health services?	(1) Yes → END (2) No (3) Depends
<b>Q28b</b>	Why wouldn't you feel comfortable going to a health facility in your area for sexual and reproductive health services? ( <i>Circle All Mentioned</i> )	(1) Not confidential (2) Too embarrassed (3) Staff unfriendly (4) Costs too much (5) Other (specify) _____

**Thank you for your time!**

## APPENDIX 6: INDIVIDUAL IN-DEPTH INTERVIEW SCHEDULE

### MAKING SEXUAL AND REPRODUCTIVE HEALTH RIGHTS REAL IN SOUTH AFRICA. A BASELINE STUDY IN SELECTED SITES IN FOUR PROVINCES

#### *In-depth Interview Schedule: LGBTI Persons*

- Tell me a little bit about your life.
- Where did you grow up? (Probe - School, family, community)?
- Describe your adolescence and early teen years? What are some of your experiences (Probe 'highlights' and/or 'low moments' during these years)?
- What were your friendships like? (Probe: Did you make friends easily? Did you find it difficult to meet like-minded people? Did you meet people who were different that you liked? Did you feel respected and supported)?
- What do you understand discrimination to mean? What words, images, ideas come to your mind?
- How have you experienced and addressed discrimination in your life? Has your personal approach to addressing discrimination worked for you? Why/not?
- Have you ever experienced any discrimination in the public health care system because of who you are (your identity)? Give examples, and mention how you responded?
- How would you describe your identity? For example, what are some of the significant moments, insights and decisions that have guided your life to describe who you might be now? Explain
- What would you change and how?
- Describe how you would like to see your life in 5 years' time?

## APPENDIX 7: KEY INFORMANT INDIVIDUAL INTERVIEWS

### MAKING SEXUAL AND REPRODUCTIVE HEALTH RIGHTS REAL IN SOUTH AFRICA. A BASELINE STUDY IN SELECTED SITES IN FOUR PROVINCES

#### *Individual Interview Schedule: Key Informant Interviews*

- Describe your experience working in the sexual and reproductive rights arena, and specifically within the LGBTI sector? (Probe: Have you worked for specific organisations across the years?)
  - What prompted you to become involved in this kind of work? Please explain
  - Do you work specifically on issues of public health and LGBTI rights? Explain what you do in this area of work?

#### **In relation to: Sexual and reproductive rights, specifically within the LGBTI community and the public health care system:**

- What have been the successes (over the years)?
- What have been the challenges?
- What are the current gaps?
- What are the opportunities?
- What can be improved upon?
- What is government (provincial and national) doing well? And what should they improve upon?
- What are NGOs doing well? And what should they improve upon?
- How can more resources (finance, capacity, policies) be brought into the sector? And whose responsibility should this be?
- What would a fully functioning and effective public health care system that is responsive to the needs of LGBTI individuals and communities look like? Describe

Thank you for participating in this research  
HSRC Team

## **APPENDIX 8: Eastern Cape Health Crisis Action Coalition Report of Challenges at Healthcare Facilities in the Eastern Cape**

[Extracted from open letter to the superintendent-general, 9 December 2013]

### **Amathole District**

**Cwili Clinic** experiences serious human resource problems. Our reports indicate that there is only one nurse on staff at the clinic and that this nurse also acts as the operational manager at the clinic. The nurse has little practical experience and yet receives no supervision. The nurse is unable to leave the clinic to provide health awareness services in the community. There is no one to follow up on TB patients and no one qualified to provide mental health services. Visits from a doctor to the clinic are infrequent and it is difficult to arrange a consultation with a doctor even in emergencies. The staff shortage means that patients have to wait in long queues. The staff shortage also generally negatively affects patient care and, ultimately, health outcomes. There is no accommodation for staff at the clinic. There is no security at the clinic. There is insufficient space for the number of patients visiting the clinic, which means that there is not enough space for private consultations with patients to take place and also results in problems with medication storage. Some of the equipment at the clinic, including the scales, does not work. Patients are forced to wait a very long time for ambulances. In the case of a power failure, there is no backup power. Medication is not delivered to the clinic. Instead, the clinic waits for a person to go to town to collect the medication for the clinic. While there is a grievance box in the clinic, grievances are never attended to.

**Komga Primary Health Care Clinic** is short staffed and has no operational manager. The mobile clinic has stopped operating due to staff shortages. Although new dental equipment was recently delivered to the clinic, there has been no dentist visiting the clinic since 2010. The equipment is, therefore, not used. The only nurse trained to provide mental health services is also in charge of the ARV clinic and as a result her time is very limited. The staff shortages also mean that consultations with patients are shorter and patients have to wait a long time to see a nurse, sometimes waiting outside due to the number of people attending the clinic. Proper preventative care cannot be offered; for example, pap smears are inconsistently offered and nutritional assessments are not offered. Due to time constraints, bin cards cannot always be properly filled out.

**Mathomela Clinic** is too small and therefore the staff find it difficult to assist the number of patients that come through.

**Mtyolo Clinic** is located far from the community. This has led to a problem wherein patients do not go for their regular check-ups. The roads in the area are terrible and make it even more difficult for patients to travel to and from the clinic on a regular basis. The staff at the clinic has recommended that a mobile clinic is needed to attend to the medical needs of the patients. All these issues have been reported to the councillor, but there have been no improvements.

### **Chris Hani District**

**Clinic Gardens** in Queenstown experiences frequent and ongoing shortages and stockouts of medication. There is also a nurse shortage, which leads to long wait times for patients.

**Machibini Clinic** experiences frequent and ongoing shortages and stockouts of medication. We have been told that staff members often arrive late to open the clinic and certain staff members are consistently unavailable. To add to this, there appears to be a shortage of staff at the clinic. There is insufficient space at the clinic, leading inevitably to a lack of privacy for patients receiving treatment. The referral system at the clinic is unreliable. Patient transport services are poor and the ambulance service is slow and unreliable.

**Nomzamo Health Centre** suffers from a poor referral system and we have received allegations of poor staff attitude including ignoring or shouting at users or being otherwise rude to them.

**Zola Clinic** experiences frequent and ongoing shortages and stockouts of medication. This places patient care at risk. There is also a shortage of staff, leading to long waiting times and staff members being required to perform roles that they are neither trained nor paid to perform. Infection control at the clinic is poor. There is insufficient space in the clinic for the numbers of patients visiting it and this leads to a lack of privacy in the treatment of patients. Patients describe staff members as frequently arriving to the clinic late and having poor attitudes, including ignoring and shouting at patients. The ambulance services are slow and unreliable and sometimes do not respond at all to calls.

### **OR Tambo District**

**Banstana Gateway Clinic** staff members have not received an increase of wages from R1 600. The staff members have also not received any form of new training or certificates on new developments and medication.

**Canzibe Gateway Clinic** - staff members have experienced difficulties in getting paid the correct amount. There are staff shortages, which have resulted in a decrease in the services offered. There is no form of communication available to the staff at the clinic, meaning that they have to use their own cell phones in an emergency. There is only a small fridge for the storage of medicines and the clinic runs out of vaccines because it has to limit the amount ordered based on the size of the storage space. Patients wait a long time to see nurses. There is no doctor that visits the clinic. Community Healthcare Workers perform functions for which they are not trained or paid because of the shortage of staff. These issues have been reported to management, but there has been no response.

**Jalamba Clinic** is short staffed and lacks basic equipment such as sufficient blood pressure machines. The clinic frequently runs out of medicines and vaccines.

**Kotyana Clinic** has no electricity and uses rainwater tanks for all of its water needs. Therefore, water runs short during periods without rain. The water is not piped into the clinic, which renders cleaning and hand washing difficult. There are insufficient nurses to serve the number of people using the clinic and insufficient staff accommodation. Due to the absence of electricity, there is no telephone, computer or fax machine at the clinic and when the head office wants documents from the clinic, one of the nurses has to use her own money to take a taxi to Mthatha. The same happens twice a month when medication is ordered: a nurse has to deliver the order form to the supervisor. The nurses are not reimbursed for this. Nurses have to use their own cell phones to call an ambulance. There is no cleaner or caretaker at the clinic.

**Lusikisiki Village Clinic** experiences frequent shortages of medication, including contraceptive injections (Depo Provera and Pectogen), saccharin (for diabetes) and simple fever, pain and cough medication and mixtures. Patients report receiving less than a full month's worth of arthritis ointment due to shortages. Patients report that clinic staff advises patients that they should buy medications that are out of stock at the clinic at private pharmacies. Patients report having been forced to do so at great expense. Patients also report only being given as little as five days worth of antiretrovirals instead of a full month's supply because of shortages. This has resulted in patients running out of antiretrovirals. Patients are told by nurses to borrow ARVs from friends when there are shortages and stockouts. Patients report being prescribed inadequate or inappropriate alternative medication for illnesses because the appropriate medication is out of stock. Patients complain that paying for transport to the clinic is expensive and that they waste money each time they are turned away from the clinic without medication or the correct amount of medication. If they receive insufficient medication, this increases the frequency of their visits and therefore their transport costs. Patients report defaulting on ARV treatment because they were unable to pay for transport to return to the clinic after having being provided with as little as five days' worth of ARVs due to stockouts. Patients report children being vaccinated without being weighed due to there being no available scales. Patients report that devices for checking blood pressure are not working, resulting in patients with high blood pressure and diabetes not being able to have their blood pressure checked. Pursuant to a settlement agreement between the Treatment Action Campaign and the Eastern Cape Department of Health and National Department of Health, the clinic was recently moved into a temporary structure pending the completion of a permanent structure. The TAC has advised us that they are monitoring progress on the permanent structure. Shortages and stockouts of medication continue.

**Makotyana Clinic** has problems with shortages and stockouts of medication.

**Mthatha Gateway Clinic** suffers from shortages and stockouts of medication, including ARVs, as well as ambulance shortages. Patients have had to be brought to the clinic in private vehicles. Patients referred to the Mthatha General Hospital have waited for ambulances coming from it that never arrived. In at least one instance, nurses had to pay for a patient to be transported to the Hospital. There is a shortage of qualified nurses at the clinic. There are also complaints about staff attitudes and suggestions that nurses have negative attitudes towards patients. Newly erected toilets are not stocked with toilet paper or soap and people are forced to bring their own. People with disabilities are forced to stand in long queues when waiting for medical attention, which causes them great suffering.

**Mthatha Medical Depot** suffers from serious problems that continue even after the intervention of TAC and Médecines Sans Frontières (MSF) in late 2012/early 2013 to avert a stockout crisis. A follow up survey spanning 70 facilities serviced by the Depot, which was conducted by the TAC between March and May 2013, indicates that 24% of facilities reported ARV stockouts between March and May, whilst 19% of facilities reported stockouts of TB treatment in the same period. Another follow up by the Stop Stockouts Project (SSP) conducted in September and October of 2013 revealed that one in five facilities in the Eastern Cape had a stockout or shortage of medication for TB or HIV in the prior three months. In facilities that rely on the Mthatha Depot, the figure was closer to two out of every five. The SSP is collating the data specific to facilities reliant on the Mthatha Medical Depot and will release it in 2014. The improvements implemented during TAC and MSF's intervention seem to have been dismantled and systems that were put in place abandoned. The ECDoh continues to fail to implement its own internal recommendations, which were provided for in a memorandum authored by the former Superintendent-General. There appears to be no viable, implemented plan to prevent the stockouts and shortages that continue to place thousands of patients at serious risk. The Depot is critically understaffed and has a shortage of crucial packing staff and manual labourers. Disciplinary hearings of 29 suspended employees are reportedly not completed and so the Depot relies on temporary support staff for the Depot's basic services.

**Ngangelizwe Clinic** experiences frequent shortages of medicines, in particular diabetes medication. Patients are therefore often referred to Mthatha General Hospital for diabetes medication. There are complaints about the general deterioration of services and there is also a shortage of doctors at the clinic. Patients complain that they are turned away if they do not register their names at the clinic between 8am and 12pm. This makes it difficult to access healthcare services if a patient is not available to attend the clinic during these times.

**Nkanga Clinic** has problems with shortages and stockouts of medication and we have received reports about nursing staff being hostile toward patients and eliciting bribes.

**Philisa AIDS Project** is an NPO that provides home based care services. The home based caregivers' efforts to serve the community are undermined by shortages of equipment and medication, which the Eastern Cape Department of Health is supposed to provide. These problems have been reported to the management of Canzibe Hospital, but there has been no response.

**Pilane Clinic** has no electricity, meaning that medication requiring cold storage is kept in a gas refrigerator. The refrigerator periodically runs out of gas, which then is difficult to procure. When there is no gas, the medication is kept in a refrigerator at a local shop. The clinic is short staffed and applications for employment at the clinic have been lost at the head office. There are long queues of patients and it is not always possible for the nurses to see all the patients who wait each day. The pit latrines at the clinic are full and filthy. There is no soap for hand washing. There are no ambulance services in the area. There is no staff accommodation and crumbling infrastructure. Severe medicines shortages and stockouts are experienced at the clinic including items such as pectogen injections, TB medication, panado, vitamin A supplements, and FDC. Community Healthcare Workers, who are unqualified to do so, provide chronic care and perform other duties outside of their training and pay grade. There is no doctor that visits the clinic. One of the nurses has to collect medication for the clinic and to pay for a taxi in which to transport the medicine back to the clinic. This is always the case for ARVs and frequently the case for other medicines.

**PilaneProject** is an NPO that provides home based care services. The home based caregivers' efforts to serve the community are undermined by shortages of equipment, which the Eastern Cape Department of Health is supposed to provide. Their efforts are also undermined by the lack of ambulance services in the area.

**Qaukeni Clinic** – We have received a report of inappropriate treatment of a patient by a nurse at Qaukeni Clinic, which resulted in a medical problem not being identified in sufficient time for preventative measures to be taken. This patient died at home after the ambulance failed to arrive after over six hours of being called. The ambulance driver had requested that the person—an elderly, weak man who was dying—be transported to a bus stop to wait for the ambulance. The ambulance shortage has also resulted in non-governmental organisations (TAC) having to hire vehicles to take patients to hospital.

#### **Cacadu District**

**Baviaans Clinic** suffers from staff shortages and insufficient support from doctors.

**BrugStraat Clinic** has closed down due to staff shortages (in March 2013), despite being used by the community and being in the centre of town.

**Kwazamukucinga Clinic** has unreliable access to running water and the water tanks have not been installed.

**Port Alfred Town Clinic** is housed in a building that has been condemned and poses a risk to patients and health care workers. The clinic suffers from a shortage of staff and there have been no cleaners since 2011, which means that Community Healthcare Workers, who are not paid to do so, have to clean the clinic. Much of the equipment at the clinic is missing or broken, including the lack of a Blood Pressure Machine. One of the mobile clinics is broken, which leaves people in very vulnerable conditions without services or with inadequate services. Staff members at the clinic are frequently paid incorrectly.

**Wongelethu Clinic** suffers from staff shortages and insufficient support from doctors.

### **Buffalo City District**

**Mooiplaas Clinic** has a problem with poor administration as well as a more general human resources problem. The clinic is run without any operations managers or data capturers. The clinic does not have sufficient staff, especially nurses. The staff are not provided with good transport to and from the clinic, therefore there are no appointed outreach programs.

**Kwelera Clinic** has a human resources problem. The clinic is being running without an operations manager. The staff and patients often feel unsafe at the clinic as there is no security in and around the clinic.

### **Hospitals**

**Canzibe Hospital** has serious problems with the management of supplies and equipment. The X-ray machine is not calibrated and cannot be used. The grounds are in a state of disrepair including toilets, storage, and long grass that grows around the facility. The staff accommodation is grossly inadequate, with filthy showers and toilets and no water or electricity. There is a severe shortage of doctors. This means that doctors are on call more often than they should be and cannot provide outreach services. Elective surgery cannot be performed due to the staff shortages. Preventative health care services cannot be provided by doctors. There are long queues to see doctors and each patient can only be attended to for a short period of time by a doctor, increasing the risk that symptoms are missed. Emergency services are unreliable and ambulances cannot access the hospital when it rains because of the muddy hill leading to the hospital. Ambulances do not go to clinics or patients' homes at all. The hospital suffers from poor management and a lack of dedication to the filling of posts. The management of the hospital is frequently absent. There are problems with oxygen supply and the transport of blood products and patients alike. Medicines stockouts are common including in respect of ARVs, FDC, TB medication and pain killers. Much of the equipment required by the hospital is either broken or missing. The oxygen metre and ventouse are broken. There is no qualified radiographer to run the x-ray machine meaning that an unqualified operator operates it.

**East London Hospital Complex** hospitals suffer from poor administration both at the hospital level and at head office level. Equipment that breaks is not repaired, resulting in further deterioration and eventually requiring the replacement of equipment that, if dealt with early, could have been fixed. An example of this is the laser machine used to treat Diabetic Retinopathy. Theatre equipment is currently out of commission due to the need for maintenance. Foreign doctors have to sign one-year contracts and when they expire the doctors are forced to work without pay until the next contract is signed. This has led to numerous doctors leaving the hospital. There is an eight to twelve month wait for a pair of spectacles, which are only appropriate for use for a total period of two years. This means that patients only use their spectacles for a year before needing new ones. The delay also results in many patients not collecting their spectacles, causing huge wastage. Staff members are paid late or incorrectly and PMDS is not implemented. There is a 24-hour delay for the receipt of medicines from the Cecilia Makiwane pharmacy due to staff shortages. The unavailability of some basic medicines and supplies, largely due to supply chain problems, results in the use of more expensive equipment and treatment.

**Frere and CMH hospital** has a human resources problem. There is a shortage of emergency resuscitation equipment as well as general equipment, particularly with ECG machines. The staff has been reporting these issues for the past three years, but there has been no noticeable change under new management.

**Frontier Hospital** in Queenstown experiences frequent and ongoing shortages and stockouts of medication. We have also received reports of incompetence and poor attitudes on the part of nursing staff.

**Holy Cross Hospital** is understaffed and has suffered dearly from poor leadership. The services offered are limited due to the staff shortages, meaning that no outreach or prevention services are offered, no caesarean sections are available on weekends, and staff members have insufficient time to fill out disability grant forms. Staff morale is low and this exacerbates staff shortages. Hospital management and administration also contribute to poor patient care and staff shortages. There are frequent stockouts and shortages of essential medicines, including ARVs. The accommodation available for nurses is extremely poor, including fungus growth on the buildings and unreliable access to running water. Payments to staff are frequently late or incorrect. Ambulance services and patient transport services are unreliable.

**Livingston Hospital** - suffers from staffing shortages, delays in appointments and non-payment of staff. Our information indicates that there may be several "ghost workers" on the payroll who do not actually work in the facility.

**Madwaleni Hospital** has had human resources problems for some time. Staff members experience difficulties in getting their appointments approved, they are frequently paid incorrect amounts in respect of both salaries and rural allowances. The hospital has had difficulty appointing foreign doctors and community service doctors. The hospital has a high turnover and health care professionals have to take on managerial roles without being trained for those roles or paid for performing them. Clinical Associates frequently work without supervision because there are insufficient doctors to supervise them. Outreach services have also suffered due to the shortage of doctors. There is no Hospital CEO, Clinical Manager or Admin Manager and the Nursing Manager has, for some time, been acting in the position of Hospital Manager. The Rehabilitation Team is understaffed and has difficulty in procuring crutches, wheelchairs and frames, all of which are vital to provide rehabilitative services. There is a shortage of vehicles available for home based care. There has been a deterioration in the services offered by the hospital because of the staff shortages. Staff accommodation is in a poor condition. There are frequent medication shortages and a lack of equipment such as pulse oximeters, ET tubes and blood pressure machines. The anaesthetic machine needs a service and has been out of service for some time, meaning that procedures requiring general anaesthetic cannot be performed. Record keeping at the hospital is poor, in particular because folders have not been procured; record keeping therefore takes place on patient cards, which do not have sufficient space for this purpose. Ambulance services are problematic and there is a minimum of approximately a 90 minutes wait for an ambulance called to the hospital to transport a patient, although the wait is usually much longer. These issues have been reported to the human resources manager in Bisho, but nothing has been done.

**Matjie Venter Hospital** has poor ambulance services, meaning that patients cannot be transported quickly and efficiently to receive needed care. Patients also wait for a long time for treatment.

**Molteno Hospital** experiences severe human resources problems. Staff are frequently not paid or not paid the correct amount, benefits owed to staff and retired staff are denied and staff are not promoted or paid according to their experience. There are numerous vacant posts at the hospital and it is critically short staffed.

**Nelson Mandela Academic Hospital** has insufficient beds for the patients using the facility, resulting in patients having to share beds. The wards are unsanitary and we have received reports of nurse neglect and poor treatment of patients, including a report of a nurse telling the wife of a man receiving treatment for cancer that "if he were a goat rather than a human being, he would be killed". We have received reports of bad food, a shortage of blankets, and unreliable electricity in the maternity ward meaning that babies need to be delivered by the light of cell phones.

**Port Alfred Hospital** has significant human resources problems including staff shortages, inefficient and long process for appointments preventing the filling of posts, the freezing of posts before it is possible to fill them, late or incorrect staff payments and problems with staff not being elevated to the correct scales. Staff accommodation is not provided in all cases that it should be. Patient transport services are poor, often leaving patients who have been waiting since 4am for a lift to the hospital waiting on the side of the road. The ambulance services are similarly slow and unreliable. Understaffing in the rehabilitation team results in inadequate rehabilitative services. There is only one physiotherapist in the Cacadu District. The rehabilitation team is based in the old Port Alfred Hospital, which is unsafe and leaks when

there is rain. The leak renders staff unable to store files in the building. Heavy rains cause floods, which have led to the destruction of equipment. There is insufficient rehabilitation equipment. There are long delays in the delivery of rehabilitative equipment. Complaints to the District Office and hospital management about these and other issues have been ignored.

**Port Elizabeth Health Complex** suffers from staffing shortages, delays in appointments and non-payment of staff. Our information indicates that there may be several “ghost workers” on the payroll who do not actually work in the facility.

**S.A.W.A.S Memorial Hospital** experiences a shortage of doctors, nurses and administrative staff. There is no pharmacist. Vacant posts are frozen before they can be filled. Staff members are paid incorrectly or late. There are persistent shortages and stockouts of medication and equipment. Much of the equipment is faulty or missing, including the lack of a functioning x-ray machine, broken resuscitation equipment in the paediatric ward and a broken defibrillator.

**Settlers Hospital** suffers from human resources problems including a shortage of staff, mainly doctors. This issue is known to management in Bisho but there has been no effective change.

**St Elizabeth Hospital** has experienced severe and persistent water shortages in recent months, seriously affecting the ability of clinical staff to ensure infection control. No reasonable alternative is provided when running water is unavailable. There is a shortage of staff and the administration throughout the hospital is poor. This has been reported but nothing has been done to date. We received a report of a patient at St Elizabeth Hospital who was prescribed an incorrect combination of ARVs (including Aluvia) and TB treatment. This led to the patient having severe side effects including a minor stroke and ongoing disability.

**Zithulele Hospital** has problems primarily with the payment of staff and the unavailability of medicines, equipment and transport at the hospital, all of which significantly affect patient care.

## APPENDIX

## **APPENDIX 9: CONTEXTUAL AND DESCRIPTION OF THE PROGRAMMATIC WORK OF GALA AND GLN**

### **GALA**

Established in 1997, GALA (see also <http://www.gala.co.za>) was originally the acronym for 'The Gay and Lesbian Archives' and is based in Johannesburg while have a pan-African focus. The organisation focuses on the production and representation of the stories and experiences of LGBTI people from official archives, histories and other spaces in Africa. However, over the years the scope of GALA work has expanded considerably to include a range of activities that focused on the creation of dialogue on same-sex sexuality and gender identity, education of the public, and building community among LGBTI people, by inspiring action. In 2007 GALA changed their name to Gay and Lesbian Memory in Action (while retaining the acronym GALA) to better reflect this development. As an important entry point for people who are interested in the study, promotion and preservation of the history, culture and contemporary experiences of LGBTI people in Africa, GALA provides a rich databank with their archives and research facility which represents an extensive, well-utilised resource for researchers, students, development professionals, journalists, filmmakers, policy and public-opinion makers, and other interested persons from around the world. GALA collections encompass organisational and individual records and narratives, community histories and cultural artefacts. The organisation also undertakes original research projects that provide a strong evidence-base for advocacy and programmatic activities. Central to their work is its programme in Archives and research; culture and education; and pioneering work that prioritises disability (especially their deaf programme) which encompasses work in HIV & AIDS and support groups.

GALA uses a human rights framework to strengthen the building of a society which is democratic, just and peaceful and strives to be progressive, transformative, democratic, inclusive, respectful of diversity, non-racist, non-sexist, non-xenophobic, empowering, and to provide equal opportunities. Core to GALA's mission is a commitment to transforming oppressive gender relations in order to achieve true gender equality.

The following activities inform the work of GALA:

- Mainstreaming of appropriate exhibitions into museums
- Promotion, development and dissemination of information through seminars, workshops, conferences, publications and public dialogues
- Development of relevant platforms to promote the work of queer African writers and artists and documentary films
- Facilitating and initiating appropriate campaigns, advocacy and other outreach initiatives.

In all of the above, GALA acts as a catalyst for the preservation, production and dissemination of knowledge on the history, culture and experiences of LGBTI people in South Africa and the rest of the continent.

### 3.1.2. Gay and Lesbian Network, Pietermaritzburg

Founded in 2003, the Gay and Lesbian Network (hereafter GLN; see also <http://www.gaylesbiankzn.org>), Pietermaritzburg, works with primarily young, unemployed and marginalised lesbian, gay, bi-sexual, transgender and intersex (LGBTI) people living in and around Pietermaritzburg. The GLN was established in response to the need for LGBTI's to have a safe and enabling place to meet and socialize, because no such spaces or facilities were available in Pietermaritzburg. Today the GLN has developed into a fully functional NGO that offers a range of programmes and services to the LGBTI community in which the LGBTI community can access services and be treated with respect and without discrimination or fear of violence. Although GLNs mission is to support LGBTI persons across all age, race and class groupings, black, unemployed, low-income youth (under 30) have organically emerged as the population most interested and in need of the direct services offered. These young people experience discrimination on multiple levels: not just as a result of poverty, lack of access to education and opportunities but further discrimination on the basis of their sexual orientation. GLN has developed a range of support services to assist them to (1) develop their own potential, (2) become more aware of their human and legal rights as well as (3) awareness of health issues particularly HIV/AIDS.

Based on the fact that prejudice against gender non-conforming people is deeply embedded and LGBTI's experience discrimination not just in communities but when trying to access a wide range of services, GLN's programmes focus on working with the following groups in a variety of ways including training, awareness raising and active advocacy and lobbying. GLN works with these groups both at a provincial and local government level and also at a community level:

- Health practitioners
- Educational institutions
- Religious and traditional leaders
- Police and the criminal justice system

Although GLN works with LGBTI persons and stakeholders throughout the Pietermaritzburg Midlands, the Greater Edendale area is where GLN focuses its outreach work. It is a peri-urban settlement 15kms from central Pietermaritzburg with a population of 250, 000 (estimate). It is made up of 19 townships. From GLN baseline research it emerges that Unit BB of Imbali is the most centrally located and easily accessible and office space has been identified in one of the municipal buildings there. 2012 saw the planned roll-out of an initial range of services for the local community. GLN works directly with service providers and groups indicated above with the aim of

sharing information and changing attitudes towards the LGBTI population that they serve in Greater Edendale.

Three key strategic objectives underpin the work of the GLN:

- To create an enabling environment and advocate for Change
- To facilitate LGBTI Organisation and Community Development
- To develop the organisation Capacity

The GLN operates and undertakes essential activities in the context of and with full recognition that discrimination and abuse of human rights continues against the LGBTI community in South Africa that combines with a lack of understanding and cultural and conservative perceptions; the latter results in many LGBTI people that live in a climate of fear, where they are unable to be themselves.

## APPENDIX 10: POLICY FRAMEWORK FOR SRHR IN SADC REGION

<b>International Convention on Elimination of All forms of Discrimination against Women (CEDAW).</b>	First international human rights promoting the rights of women and prohibiting discrimination in all its various forms.
<b>The African Charter on Human and People’s Rights.</b>	Article 3 provides for equality before the law. Article 19 of the charter outlines the principle of non- discrimination on the basis of sex, age, ethnicity, race among others, in any sphere of life in enjoyment of all rights. It further provides in Article 18(3) for the elimination of discrimination against women and ensuring the protection of women’s rights as articulated in international and regional instruments and policies including the right to health.
<b>United Nations World Conference on Human Rights. (Vienna 1993)</b>	Adopted the slogan that “women rights are human rights” This includes sexual and reproductive rights of women.
<b>UN International Conference on Population and Development. (ICPD, Cairo)</b>	Provided new impetus for demands for respect and protection of women’s rights and promotion of gender equality. Sexual and reproductive rights for the first time defined. It moved away from the focus on family planning.
<b>Beijing Declaration and Platform for Action adopted at the Fourth World Conference on Women.</b>	It reaffirmed the new thinking in ICPD Cairo.
<b>Charter on the Rights and Welfare of the Child[1].</b>	In its article 3, every child is guaranteed rights without discrimination. It further guarantees the right to health[2].
<b>The Protocol to the African Charter on Human and People’s Rights on the Rights of Women in Africa or the “Maputo Women Protocol”.</b>	It entered into force on the 25th November 2000. It provides a continental legal framework for addressing issues of gender inequality and the underlying aspects of society’s arrangement that perpetuate women’s subordination, disempowerment and contribute to their marginalization. The Protocol provides in Articles 8 that legal reforms should take places in order to bring the national laws in line with the provisions of the Protocol.
<b>The Solemn Declaration on Gender equality in Africa (SDGEA).</b>	It promotes Gender Equality in Africa. Notably, the SDGEA is an important African instrument for promoting gender equality and women’s empowerment as it strengthens African ownership of the gender equality agenda and keeps the issues alive at the highest political level in Africa[3].  Another mechanism for intervention on gender and women’s empowerment includes the AU Conference of Ministers responsible for Women Affairs and Gender. During the first Conference held in Dakar, Senegal, in October 2005 the ministers developed two documents to facilitate implementation of the SDGEA. These are the Guidelines for reporting and the implementation framework[4].
<b>Abuja Declaration (2001) on HIV/AIDS, Tuberculosis (TB) and other related Infectious Diseases.</b>	To commit up to 15 % of government Budget to Health.
<b>Maputo Plan of Action on Sexual and Reproductive Health and Rights of</b>	In order to ensure universal access to comprehensive sexual and reproductive health services in Africa by 2010, the special session of the AU Conference of

<p><b>operationalization of the Continental Policy Framework on Sexual and Reproductive Health and Rights.</b></p>	<p>Ministers of health meeting in Maputo in September 2006 adopted the Maputo Plan of Action (MPoA) for the operationalization of the Continental Policy Framework on Sexual and Reproductive Rights[5]. The framework ran for the initial period of 2006-2010 and during the HOSG Summit held in Kampala in July 2010, it was extended to 2015 to align it with the timeframe for the review of the MDGs and the ICPD Cairo.</p>
<p><b>The African Health Strategy (2007-2015).</b></p>	<p>This is an inspirational framework within which to fulfill the health roles. The Strategy proposes strengthening of health systems with the goal of reducing the disease burden through improved use of resources, systems, policies and management. This will contribute to equity throughout the system to be able to reach the poor and those most in need of health care[6]. The Health Strategy reiterated the urgent need for implementation of the Maputo Plan of Action on Sexual and Reproductive Health and Rights, the Abuja Declaration on HIV/AIDS, TB and other Infectious Diseases, the Continental Policy Framework on Sexual and Reproductive Health and Rights, among many other commitments.</p>
<p><b>Campaign on Accelerated reduction of Maternal Mortality in Africa (CARMMA).</b></p>	<p>Approved at the 4th Session of the Conference of African Ministers of Health in 2008. The theme of the Campaign is “Africa Cares: No Women should die whilst Giving Life”. The main objective of CARMMA is to accelerate the availability and use of universally accessible quality health services including those related to sexual and reproductive health that are critical for the reduction of maternal mortality[7]. In April 2010, the AUC organized a continental Conference on Maternal and Child Health in Africa. The theme was on “Achieving the MDGs through Accelerated Reduction of Maternal and Child Mortality in Africa.</p>

## NOTES

- <sup>i</sup> The World Health Organisation (WHO) defines sexual and reproductive health rights according to five core aspects: (1) improving antenatal, perinatal, postpartum, and new-born care; (2) providing high-quality services for family planning, including infertility; (3) eliminating unsafe abortion; (4) combating sexually transmitted infections, including HIV, reproductive tract infections, cervical cancer, and other gynaecological morbidities; (5) and promoting sexual health (WHO, 2004, p. 21).
- <sup>ii</sup> It is important to note that sex workers are also male and transgender are often 'treated as objects of curiosity by health providers' (Scorgi et.al, 2013, p.460).
- <sup>iii</sup> MOSAIC – www.mosaic.org.za
- <sup>iv</sup> All names in this chapter are pseudonyms
- <sup>v</sup> Swarr (2009) indicates that *isi-stabane – used in Zulu vernacular to describe an inter-sexual person* (p.525)
- <sup>vi</sup> Stabane- used in Zulu vernacular to describe an intersexual person-that is, to be called stabane is to be seen as having both a penis and a vagina.
- <sup>vii</sup> The dependency ratio (ratio of the child and aged population (0-14 and 65+)) to the working age population (15-64) gives an indication of areas likely to have greater need of social and financial support.
- <sup>viii</sup> Undertakes to improve maternal health, contains two targets: to reduce the maternal mortality ratio by three-quarters between 1990 and 2015, and to achieve universal access to reproductive health by 2015.
- <sup>ix</sup> An indicator used as a proxy to track success in the prevention of teenage pregnancies.
- <sup>x</sup> <http://www.localgovernment.co.za/provinces/view/1/eastern-cape>
- <sup>xi</sup> Census 2011 Municipal Fact Sheet, published by Statistics South Africa.
- <sup>xii</sup> STATSA 2014, mid-year population estimates 2013
- <sup>xiii</sup> District Health Barometer 2013/2014
- <sup>xiv</sup> StatsSA Census 2011
- <sup>xv</sup> Census 2011 Municipal Fact Sheet, published by Statistics South Africa.
- <sup>xvi</sup> General household survey 2013, StatsSA
- <sup>xvii</sup> Gert Sibande District Municipality, IDP 2014/2015
- <sup>xviii</sup> StatsSA Census 2011
- <sup>xix</sup> District Health Barometer 2013-2014
- <sup>xx</sup> SA\_UNFPA
- <sup>xxi</sup> SA\_UNPA 2012-2013
- <sup>xxii</sup> Shisana et al., 2014
- <sup>xxiii</sup> Shisana et al., 2014
- <sup>xxiv</sup> SANAC 2011)
- <sup>xxv</sup> Eastern Cape Aids Council Provincial Strategic Plan 2012 -16
- <sup>xxvi</sup> DoH, 2011b
- <sup>xxvii</sup> Antenatal Survey 2012
- <sup>xxviii</sup> DHB 2013-15
- <sup>xxix</sup> Annual Health Statistics 2012
- <sup>xxx</sup> Shisana et al, 2014
- <sup>xxxi</sup> HST 2013/14
- <sup>xxxii</sup> DoH, 2011b
- <sup>xxxiii</sup> Shisana et al, 2014; SA National HIV prevalence, incidence and behaviour survey, 2012.
- <sup>xxxiv</sup> Annual health statistic 2012
- <sup>xxxv</sup> NSP Review 10
- <sup>xxxvi</sup> Annual Health Statistics11/12
- <sup>xxxvii</sup> StatsSA Mid- Year Population estimates
- <sup>xxxviii</sup> Gray et al 2013 Health Review 12-13
- <sup>xxxix</sup> DHB 2013-14
- <sup>xl</sup> District Health Barometer 2012/2013, 2014
- <sup>xli</sup> Annual Health Statistics 2012
- <sup>xlii</sup> South African Health Review 2008
- <sup>xliiii</sup> District Health barometer 2013/14
- <sup>xliiv</sup> DHB 2013-15
- <sup>xli v</sup> Annual Health Statistics 2012/13
- <sup>xli vi</sup> recorded in 2011 HST district profile OR Tambo
- <sup>xli vii</sup> IDP Gert Sibande District Municipality 2013-2014
- <sup>xli viii</sup> DoH, 2011c
- <sup>xli ix</sup> National Primary Health care facilities survey 2003, Mpumalanga 2004.
- <sup>i</sup> SAHR, 2013,
- <sup>ii</sup> South African Health Review 2013
- <sup>iii</sup> South African Health Review 2013
- <sup>iiii</sup> Crime Research and Statistics - South African Police Service (2013/14)

