

# **Privacy, Secrecy and Confidentiality**

**Changing Paradigms in the face of the HIV pandemic**

**August 2003**

University of Cape Town

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## **Declaration**

I, Steven Murray Andrews (Student Number ANDSTE007)

Herby declare that this dissertation is being submitted the University of Cape Town in partial fulfillment of the requirements for the degree of MPhil (Bioethics).

I declare that the work of this dissertation is my original work and that neither the whole work nor any part of it is submitted for another degree.

Signed



Date: 25 August 2004

***“...on admittance to hospital, a nurse read her clinical notes and, discovering the woman was HIV positive, shouted, “Shoo! You HIV positive AIDS ! in the presence of other people.”***

***Mail and Guardian, April 2002***<sup>1</sup>

***“Medical Confidentiality, as it traditionally been understood by patients and doctors, no longer exists....”***

***Mark Stiegler***<sup>2</sup>

## Acknowledgments

The author would like to thank the many people who have contributed to this dissertation.

While it is impossible to thank each individually, certain people should be mentioned due to the special input they provided to what proved to be a far more ambitious project than at first appeared.

First and foremost, my wife and life partner Lyndall, who put up with the many hours of time spent on this project and stolen from time rightfully belonging to her, who shared the learning curve with me, believed in me, corrected my spelling and grammar, listened to numerous drafts of the project without complaint, and who bore us a beautiful daughter while this dissertation was being completed.

To my daughter Sarah Kathryn, who brought me more understanding about philosophy and insight into life's mysteries in the very first hours of her life than in all the years of learning and reading preceding her birth, and who continues to delight and push the boundaries of my own learning, challenging me to move from the safety of the theoretical to the reality of the practical on a daily basis.

To my brother Matthew, who assisted with many discussions about this topic, and whose expertise with statistics allowed practical interpretation of my experimental data.

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To my classmates: Paul, Leslie, Denise and Jonathan. I learned a lot from you. Jonathan, I will miss you.

To all those who are afflicted with and affected by this illness, May this work contribute to bringing a solution to this pandemic.

## **Dissertation Structure**

This dissertation will deal with the ethical dilemmas created by the interplay of the needs of society and the rights of the individual with regards the protection of doctor – patient confidentiality in the context of the HIV pandemic.

This paper stems from discussion of real life problems experienced at a local state hospital, and that have been presented to the University of Cape Town Bioethics Centre. These problems will be outlined from their social, medical and ethical perspectives. The dilemmas relating to confidentiality and disclosure of HIV status will be illustrated by empirical research data conducted in an HIV treatment unit, and with reference to the broad literature on this subject. It will be argued that confidentiality issues are poorly understood by healthcare professionals and their patients. In addition, and related to this lack of understanding, is a failure to construct and implement policies to protect specific confidentiality needs in the healthcare environment.

The practical problem of patient disclosure of HIV status will be explored using data generated from the author's own practice.

A review of the debate regarding confidentiality in the healthcare context will be provided, with reference to the literature on the subject.

Guidelines for drafting a facility specific confidentiality policy will be provided, along with a draft policy for use as a template in this situation.

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## **1: Introduction :**

### **1.1. Introduction and Contextual data:**

In healthcare facilities across South Africa, the rapidly maturing HIV pandemic, with its increasing burden of young dying people, is contributing to a progressive lowering of staff and patient morale. In this environment, the medical and paramedical staff, often very young and inexperienced people themselves, are faced with agonising medical, social, legal and moral dilemmas. In many circumstances, these problems are significantly aggravated by resource constraints, increasing the complexity of often already very difficult decisions, required to be made by practitioners not formally trained in ethical decision making. Problems are compounded by challenges posed by the very nature of South African society itself. This nation's turbulent history, multitude of cultures, and 11 national languages, compounded by the tensions inherent in providing excellent medical care in resource limited settings pose further issues when constructing practical and ethical policy and procedures for implementation.

Among the most pressing problems facing healthcare workers are issues pertaining to confidentiality in the modern team – based approach to provision of healthcare, now challenged by the multifactorial dilemmas generated by the patient with HIV. These dilemmas are commonplace in medical care, but assume special significance when viewed in the context of an illness viewed across the spectrum of humanity as a modern day plague, with the attendant stigma such views engender. Issues regarding truth telling are challenged by the complexities of patient disclosure of HIV status to others, and the healthcare worker's place in these transactions. Disclosure issues include diagnostic situations, questions of sexual partner and family notification, healthcare team notification and death certification. Areas where legal provisions and ethical principles may seem to be at odds include legal age of consent for HIV testing, sexually transmitted disease testing and treatment, and age of consent for consent to contraception as opposed to legal age of consent to sexual intercourse. Clinical dilemmas include the problems of HIV testing in the unconscious or demented patient, and the problems associated with substituted consent (breaching confidentiality in the perception of the patient's best interest). Finally, occupational health issues present significant confidentiality dilemmas with the care of the HIV infected individual in the workplace.

With all the challenges posed above, the requirements to respond medically, ethically, efficiently, and with speed to meet the medical, social, legal and other demands presented by each situation often generates extremely difficult and highly emotionally charged discussions. In order to assist in these settings, clear and justifiable ethical guidelines are necessary, facility specific and translated into practical policy framework with clear paths of implementation. The development of comprehensive HIV policy, inclusive of medical, moral and legal arguments, and covering all aspects pertaining to HIV management, is vital to the continuing function of the South African medical system.

In essence, it is essential to maintain confidentiality with attention to right to privacy that provides the framework within which confidentiality is to operate. The concept of human rights and their protection under constitutional law must not be forgotten in the heat of this very real crisis. These issues stem from the common moral principle of respect for people and their autonomy, a central principle that also requires further scrutiny in the complex multi-cultural society in which we live, but which is beyond the scope of this dissertation.

In considering HIV policies, it is recognised that the Groote Schuur group of hospitals has a set of existing HIV / AIDS policy guidelines, more than 10 years in the formulation under the able guidance of Professor Gary Maartens.<sup>3</sup> It is of importance to state that this latter document *already* contains an unequivocal statement on patient confidentiality:

*“ As for any other patient, strict confidentiality of the HIV – positive / AIDS patient's diagnosis and condition MUST be maintained unless other people are endangered by maintaining confidentiality....under no circumstances should an HIV – positive / AIDS patient's identity or diagnosis be revealed to the media or employers.... Patients should be told by their Medical Practitioners that their diagnosis will be revealed to the health care workers who will take care of them. ”<sup>4</sup>*

This dissertation is not intended as a replacement for the existing guidelines. It is however, an attempt to probe more deeply the issues of healthcare worker team – based confidentiality dilemmas in the HIV era. In doing so, to provide a challenge to preconceptions regarding privacy, secrecy and confidentiality, how these impact on HIV management, and to provide policy suggestions regarding this specific area of care.

## **1.2. A Global Assessment of HIV:**

The accuracy of data regarding the global burden of HIV disease is adversely affected by a multiplicity of social, political, economic, and ideological factors that confound the collection and reporting of such data. However, the efforts of organisations such as the World Health Organisation (WHO) and the United Nations AIDS Organisation (UNAIDS) have provided an overall picture that reflects that magnitude of this devastating pandemic.

Recent figures, released on World AIDS day (1 December 2002) based on worldwide HIV prevalence figures collated at the end of 2002, reveal a total of approximately 42 million people worldwide living with HIV / AIDS (Appendix 12.1 UNAIDS global estimates of people living with HIV – end 2002<sup>5</sup>). In excess of 3 million people are estimated to have died of AIDS in 2001, with new HIV infections during 2001 exceeding 5.3 million. The pandemic continues to grow, with the third world, and in particular Sub-Saharan Africa, currently hardest hit by the illness. Of the total number of people living with HIV / AIDS at the end of 2001, approximately 70% live in Sub Saharan Africa (28.1 million people).<sup>6</sup> This region, home to only 10 percent of the world's population, and consuming approximately 1 percent of the world's economy,<sup>7</sup> bears the brunt of this pandemic. The predominant form of transmission in this region is heterosexual, with infected women outnumbering infected men approximately 55% to 45%. The 2001 adult prevalence rate was estimated at greater than 8.4% in the Sub Saharan region.

## **1.3. The Scope of the Problem – HIV in South Africa:**

***“Survived Apartheid....Dying for lack of Medicine”<sup>8</sup>*** (Banner Headline on Doctors without Borders Homepage)

Estimates of HIV prevalence indicate that 4.7 million South Africans were infected by the end of 2000 (up from 4.2 million in 1999).<sup>9</sup> This latest figure has been widely criticised as being too low<sup>10</sup> with other estimates putting the true figure at 5.4 million infected. In either scenario, South Africa has more of its citizens infected with the virus than any other country in the world. Unless an effective response to the epidemic is developed, projections are that, by 2010, average life expectancy will fall by more than 20 years, with over a million children orphaned in South Africa alone, and an estimated 14 million AIDS orphans in sub-Saharan Africa. The current problems of widespread poverty, homelessness and illiteracy are likely to

expand exponentially with the relentless spread of the disease.<sup>11</sup> In this setting, the economy is predicted to contract by at least 20 percent by 2010.<sup>12</sup> A lack of political will to tackle this problem, alongside widespread poverty and the exorbitant cost of antiretroviral agents and the complexity of systems required to administer them and contain the pandemic, has resulted in a rapid rise in the numbers of afflicted persons.

The accuracy of the South African HIV prevalence figures has repeatedly been brought into question. There is a large dependence in statistical models on state based antenatal clinic (ANC) figures (Appendix 12.2 Antenatal Clinic data – South African State Antenatal Clinic Figures<sup>13</sup>). Arguments have been raised as possible counters to the use of ANC figures as a basis for statistical modelling among the people of this country.<sup>14</sup>

These include, but are not restricted to: debates regarding the lack of assessment of risk factors in men; apparently conflicting statistics in the private healthcare sector, and the absence of variables that take account of the risk factors of less sexually active persons in the population.

On the other hand, the antenatal figures almost certainly represent an underestimation of true numbers of potential HIV positive antenatal clinic attendees. The approximately 25% diminished fertility of the HIV infected woman (when adjusted for the individual decreased life expectancy associated with HIV) further complicates this picture. Accurate modelling programmes, such as the Metropolitan Doyle Model,<sup>15</sup> allow incorporation of additional data from various sources. This model, along with the antenatal clinic data, (collected from the same Antenatal Clinic settings every year since 1990), allows assessment of data from a similar longitudinal cohort. The strength of this data is in its longitudinal demonstration of the growth of the heterosexual epidemic in a sexually active population which is generally not “AIDS sick.” (Appendix 12.2 Antenatal Clinic data – South African State Antenatal Clinic Figures)

The potential impact of these figures on the growing population has been demonstrated by the Actuarial Association of South Africa's (ASSA) projections. The most recent modelling (ASSA 2000) shows a statistically significant congruence between projected and observed antenatal HIV prevalence figures from 1990 to 2000 (Appendix 12.3 Actuarial Society of South Africa 2000 model projections with overlaid observed data – antenatal clinic HIV prevalence South Africa 1990 to 2000<sup>16</sup>), with the same degree of statistical fit seen in the projected and observed male death figures over the period 1999/2000 (Appendix 12.4 Actuarial Society of South Africa – projected male deaths 1999/2000 with overlaid observed data as taken from death certificate records<sup>17</sup> )

Data from all recent mortality surveys, as well as the data and models presented above, have been compiled by Statistics South Africa and the South African Department of Home Affairs. This has been formally reported by the Medical Research Council. (Annual Report 2000 – 2001).<sup>18</sup> The MRC report has shown that death registration has increased from approximately 50% in 1990 to over 90% of adult deaths registered in 1999. This allows much better assessment of mortality trends. Of note are the following:

1. Child mortality, declining in the early 1990's, has been increasing since 1992. This is in keeping with the antenatal survey of HIV trends in pregnant women.
2. Adult mortality, fairly stable during the 1980's, has shown an increase in the 1990's, with fairly consistent increases in mortality for young men and women. This is most noticeable for young women 25 – 29 years, where mortality rates are now 3 fold what they were 10 years ago. Mortality increases among men are spread across a wider age grouping. This is in keeping with the different age patterns of HIV infection in men and women – a consequence of older men having sex with younger women.
3. The MRC estimates that at least half of the deaths in the 15 to 49 year old age group are now AIDS related. If the alteration in child death profiles is incorporated, AIDS is estimated to account for 25% of deaths, and is the biggest single cause of death in South Africa today. Assuming no further interventions (particularly antiretroviral therapies which are currently unavailable to the majority of patients in South Africa), the MRC forecasts 5 – 7 million deaths from AIDS in the next decade.

South Africa has, since its first free and fair democratic elections of 1994, been divided into 9 provinces. Given the differing population dynamics, levels of migrant labour, basic

infrastructure of each province and financial ability to deal with problems such as HIV, disease prevalence from province to province varies markedly (Appendix 12.5 HIV percentage prevalence by province 1997-1999 estimates<sup>19</sup>). Traditionally wealthy, well financed provinces currently show lower levels of HIV prevalence than historically less privileged provinces. However, this does not imply that the lower sero-prevalence provinces will remain low, but rather that, in the absence of effective intervention to prevent, treat and control this illness, all provinces are likely to reach equally serious HIV prevalence levels in the first decade of the new century. This informed prediction is being borne out by the reported 2002 Antenatal HIV prevalence figures (released September 2003). Previously low prevalence provinces show indications of catching up to levels of higher prevalence provinces.<sup>20</sup> The Western Cape Province has lower than average estimated sero – prevalence figures. This is expected to increase in line with the remainder of the country, if no urgent steps are taken to remedy the situation. Antenatal sero-prevalence figures for 2000 suggest a climbing provincial prevalence rate, with the most recent estimate (2000) at 8.7% (Appendix 12.6 HIV sero-prevalence 1997-2000 Western Cape<sup>21</sup>).

## **1.4. Healthcare systems in South Africa:**

South Africa has a two-tiered healthcare system, with public services, in general under funded and understaffed, servicing the majority of the population; while an increasingly small segment of the population has access to private funding mechanisms, offering the potential for healthcare provisions not generally available in the state service (for example Highly Active Antiretroviral Therapy regimes - HAART)

### **1.4.1. Approximate access to healthcare funding sources in South Africa:**

- **+/- 15%** Access to private healthcare funding to various degrees. (Slightly increased access to private hospital funding in an additional +/- 3% of patients, but no outpatient or chronic care funding). Little to no funding for antiretroviral therapy.
- **+/- 40%** Patients in the formal or informal employment sectors. Little to no access to private medical care.

- +/- 45% Patients mainly unemployed. No access to private healthcare. Entirely state dependant. As of 2004, the state sector has commenced an antiretroviral access plan which projects access to 1.4 million people by 2009.

This dissertation deals with problems which arise within both the private and public sectors. These problems, identified in the public sector, have been confirmed by observational data in the private sector. (See section 1.4 – disclosure of HIV sero-status by patients presenting to a general practice in Rugby, Cape Town)

The approach taken to investigate the problems identified in the public sector with data derived from work in the private sector has been determined by lack of access to specialised HIV care mechanisms in the public sector, most notably the provision of antiretroviral agents. While HAART is a relatively scarce treatment even in the private sector, mainly due to its prohibitive cost, the experience with these agents outside of clinical trial protocols has, up to this point, almost exclusively been gained in the private sector. Providing solutions to ethical dilemmas in relation to HIV medicine thus requires analysis of questions and answers from both sectors of the healthcare community.

This dissertation was initiated from a discussion document generated by medical staff working at one of the Western Cape's regional hospitals, G.F. Jooste Hospital (Appendix 12.7 Draft Response: Medical staff issues regarding HIV/AIDS at the Jooste Hospital<sup>22</sup>).

## **2. An introduction to dilemmas identified at a regional hospital in the metropole region of the Western Cape, as presented to the Bioethics Centre at the University of Cape Town.**

### **2.1. G.F. Jooste Hospital – An Overview:**

The G.F. Jooste Hospital in Mannenberg, Cape Town, is a regional state hospital<sup>23</sup> (regional hospitals – level 2 – require the services of full-time general specialists in medicine, surgery, O&G, paediatrics, orthopaedic surgery and anaesthetics; working as part of a specialist led team) which services the adjacent areas of Mannenberg and Gugulethu, while also draining patients from the Khayelitsha and Strand regions.<sup>i</sup>

Large numbers of formally unquantified HIV positive patients are seen in the hospital's outpatient, casualty, and inpatient units daily. The hospital has 45 male and 45 female medical beds, with a small number of patients kept overnight on a daily basis in the trauma unit for purposes of observation and intravenous rehydration. Dr A Aboo, Chief Physician at Jooste Hospital estimates that upwards of 70% of the patients occupying beds in his medical wards have stages 3 and 4 HIV disease (personal communication). It is anticipated that the challenges of HIV at this hospital may even get worse, The high rate of AIDS related illnesses presenting to Jooste hospital in the absence of effective antiretroviral medication and the limited availability of drugs required to effectively treat and prevent opportunistic infections,<sup>24</sup> results in an ever increasing death rate from AIDS in this hospital. In some sectors of the community the impact of these realities has extended to the generation of the myth that admission to the hospital environment actually causes AIDS.

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<sup>i</sup> The author would like to express his thanks to all the people in medical and professions allied to medicine who assisted in the collation of data about hospitals in the Western Cape, the hospital system in general, and G.F Jooste in particular. I would especially like to thank Dr Liz Blumenthal, whose assistance with maps of drainage areas and admission profiles has proved invaluable.

The author has personally observed the response of both patients and family to referrals to this hospital. Referral is seen as a “death sentence”, and the notion of “sending a patient to Jooste” has far more than biomedical implications, extending to social effects associated with the spectre of death. The heavy case load at this hospital provides a significant opportunity for several interventions. These could include: increased education of medical and associated staff regarding treatability of many of the opportunistic infections associated with the illness, and efforts to acquire access to Highly Active Antiretroviral Interventions. The discipline of bioethics has great potential for a positive contribution in this scenario, particularly in relation to policy formation and implementation, research and education.

### **3. Disclosure of HIV sero-status by patients presenting to a general practice (Brooklyn Medical Center – BMCR) in Rugby, Cape Town**

#### **3.1. Introduction**

Information regarding HIV status of an individual patient is often lacking at the time of initial presentation to the healthcare team. Significant resistance is also often experienced from patients and attending health care staff (for the purpose of research) in obtaining such information. This information, however, may be considered vital to a conceptual model regarding decision making in the context of effective HIV management. Knowledge of the patient's HIV status facilitates appropriate investigations, as well as open discussion of the topic and potential for increased disclosure to medical staff and others that may decrease staff anxieties, alleviate patient fears, and enable staff to deal effectively with the stigma associated with this illness.

In order to examine the problems faced by clinicians, family's patients, and medical personnel, it is helpful to remove the variable represented by the individual's knowledge of his / her HIV status. For this reason, a study was undertaken in a private HIV referral facility, to determine general levels of disclosure of HIV status among patients who fit the profile of patients presenting to such a unit. In such a specialist referral unit, the problem of this unknown variable (the HIV status of the patient) is absent, as the patient presents with the diagnosis already disclosed, specifically for the purpose of assistance with management of the disease, and the issues of disclosure and stigma in a specialist HIV team environment is arguably less. The ability to investigate problems surrounding disclosure in the absence of other variables could shed light on the problems raised by the staff at G.F Jooste Hospital in appendix 12.7.

#### **3.2. Study Abstract:**

**Background:** HIV interventional programmes in South Africa are perceived to be hampered by a lack of disclosure of HIV status by patients aware of their HIV diagnosis.

**Methods:** A record analysis of patients presenting to BMCR between 4/98 and 4/01 was undertaken. In order to approximate the patient population presenting to the public health sector, patients on clinical trial protocols, or those receiving antiretroviral agents (unavailable in the state sector) were excluded. Demographic data as well as levels of disclosure are routinely collected as part of initial patient workup. Disclosure was assessed as “none” (not to any other person than the examining clinician); “minimal” (to one other person only); “full” (to more than one other person).

**Results:** 106 clinical records were reviewed. 47 patients (44%) were female, 59 (56%) male, 69 (65%) were black, 7 (6.6%) coloured, 30 (28.3%) white. 86 (81%) were between the ages of 20 – 44 years. Mean time of known HIV infection at time of presentation was 2.6 years. The majority of the cohort (78 patients - 74%) was assessed as having no / minimal HIV disclosure. This was statistically unrelated to age, sex, race or WHO clinical stage of illness.

**Conclusions:** Non disclosure of HIV status was found to be a real and troubling factor in this group of patients. Fear of stigmatisation and perceived guilt were common reasons for this phenomenon. This is a potential impediment to the ongoing clinical care of the patient, in addition to constituting a psychosocial burden for the patient.

## **Disclosure of HIV Status by patients presenting to an HIV / AIDS unit in Rugby, Cape Town**

### **3.3. Ethical Approval:**

Ethics approval for this study was obtained from the University Of Cape Town Faculty Of Health Sciences Research Ethics Committee

### **3.4. Aim:**

*To assess the degree of disclosure regarding their diagnosis of HIV positive patients seen in a private HIV clinic in Rugby, Western Cape, South Africa.*

### **3.5. Methods:**

A retrospective record analysis was undertaken of patients presenting to the Brooklyn Medical Center (BMC) between 4/98 and 4/01. The patient group selected to as closely as possible resemble patients presenting to a public health casualty unit, was a subset of patients selected who are seen at the BMC unit. Patients seen at the BMC unit are grouped into various categories according to the reason for presentation, and the intervention intended.

Categories are defined as follows:

*Group A: New Patients under assessment for antiretroviral intervention*

*Group B: Patients requiring alterations or changes in their ART management*

*Group C: Patients on HAART trials, and expanded access programmes*

*Group D: Patients presenting for assessment – not suitable for ART*

*Group E: Patients presenting in terminal phase*

*Group F: Patients deceased*

Because antiretroviral drugs are not available in the state sector, groups A and B were excluded from the study. In addition, because the BMC unit runs numerous clinical trial protocols, (which generally are not undertaken in public health casualty units), group C was also excluded from this review. 106 Patients remained in groups D – F. These patients' records were assessed by the same reviewer, and all the initial clinical assessments were performed by the same clinician (SA). Demographic data regarding sex, age and race was

collected. Patients were assessed in terms of average time since HIV diagnosis (as reported by the patient) and WHO (World Health Organisation) clinical stage of HIV disease (Appendix 12.8 World Health Organisation Clinical staging for adults and adolescents<sup>25</sup>):

***Stage 1: clinically asymptomatic***

***Stage 2: increased “minor morbidities”***

***Stage 3: major morbidities – non -AIDS defining illnesses***

***Stage 4: AIDS defining illnesses***

Patients were further assessed (as below) in terms of level of disclosure of HIV diagnosis to others. Three categories of disclosure were defined:

***No Disclosure: any disclosure to any person other than the clinician***

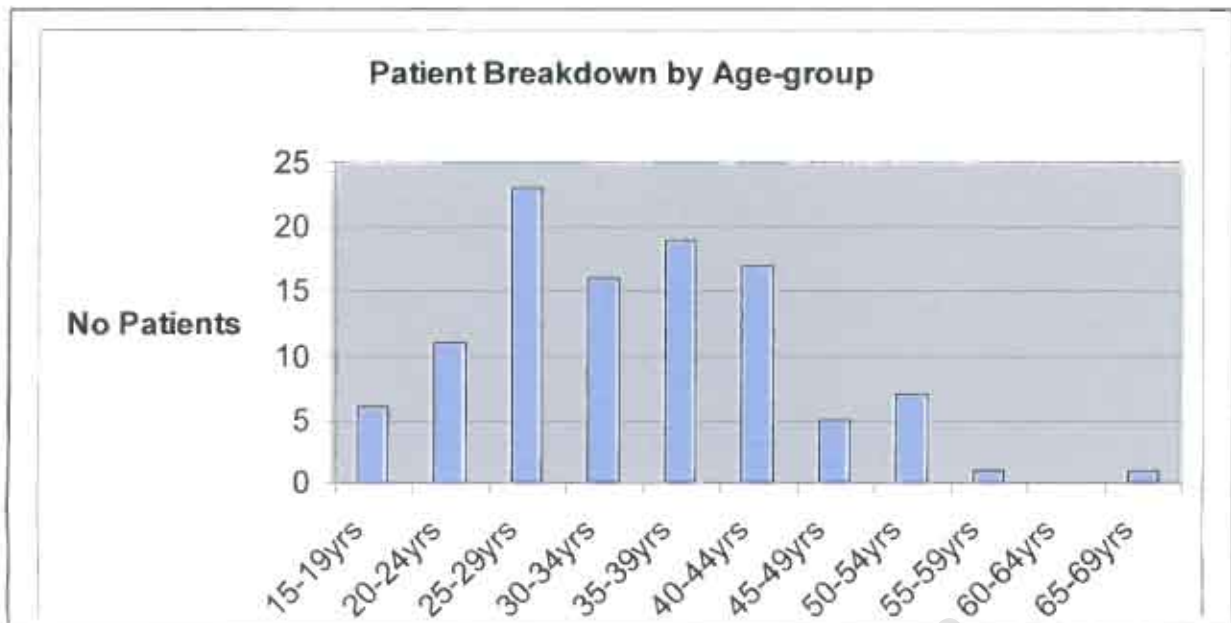
***Minimal Disclosure: Disclosed to one other person – Generally a spouse, friend, and, in 3 cases, an employer***

***“Full” Disclosure: to more than one person; generally family and friends.***

No formal assessment was made of why people did and did not disclose their HIV status, as this was found to be a highly individual and personal matter, not accurately declared to the clinician at the initial assessment.

### **3.6. Results:**

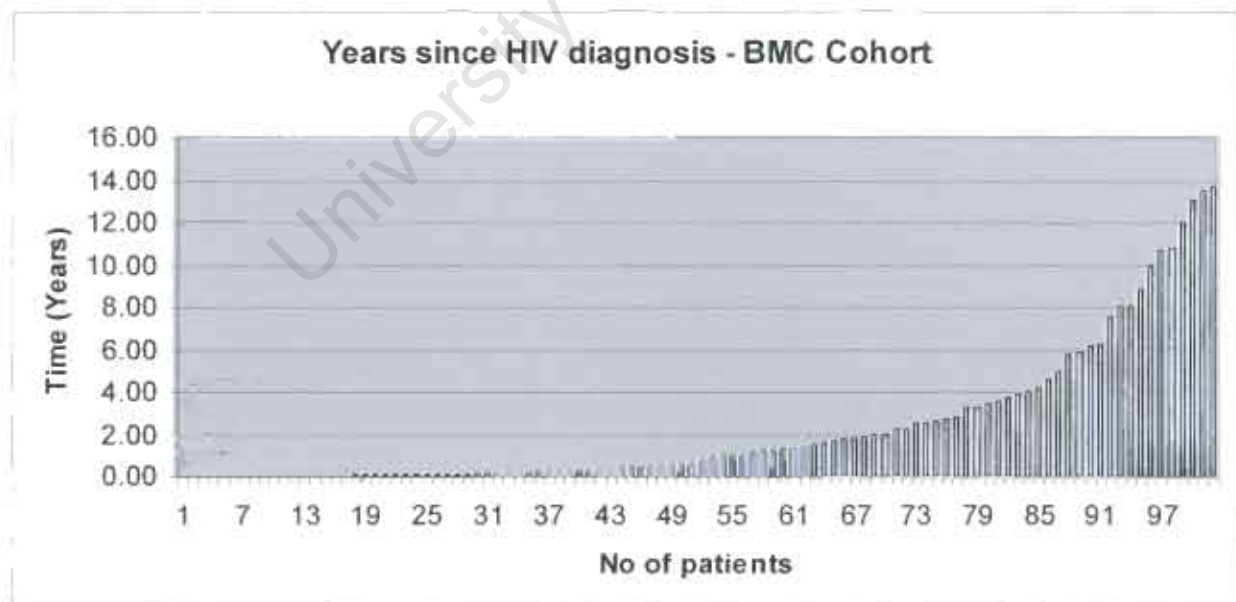
- 106 clinical records were reviewed, representing patients presenting to the clinic between April 1998 and April 2001.
- Sexual distribution: 47 women (44%); 59 men (59%)
- Racial distribution: black 69 (65%); coloured 7 (6.6%); white 30 (28.3%)
- 86 (81%) of the patients were between the ages of 20 to 44 years <FIGURE ONE>.



**FIGURE ONE: Age Breakdown BMC Cohort**

- Patients presented to the clinic in the following WHO clinical stages :  
15 (14%) stage 1; 31 (29%) stage 2; 23 (22%) stage 3; 37 (34%) stage 4
- Average time since diagnosis of HIV in this cohort was 2.19 years

< FIGURE TWO >

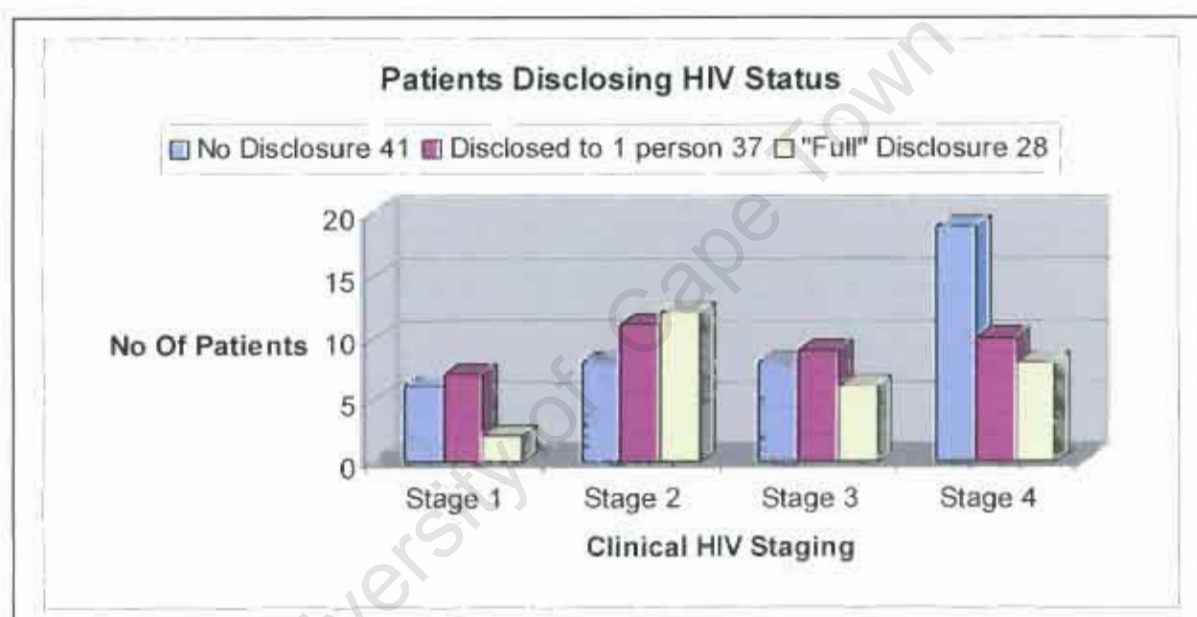


**FIGURE TWO: Months since HIV diagnosis: BMC cohort**

### 3.6.1. Disclosure of HIV status to others:

In this cohort, no or minimal disclosure of their HIV status characterized 78 (74%) of the patients, with 28 (26%) of patients falling into the “full disclosure” category. in this cohort, no or minimal disclosure of HIV status was unrelated to age, sex, race or clinical stage of illness. Further assessment of disclosure related to clinical stage of presentation showed no statistical relation between stage of HIV illness and:

1. No disclosure
2. Minimal disclosure
3. “Full” disclosure. <FIGURE THREE>



**FIGURE THREE: Patients disclosing HIV status as a function of WHO clinical staging**

### **3.7. Statistical Analysis:**

No statistically significant relationships were found in the data. A standard least squares regression (the simplest approach to conducting this kind of analysis) showed that disclosure variation (measured either by the binary yes/no variable or the 1,2,3 labelled disclosed variable – no, minimal or “full” disclosure) is not explained at all by either the kind of information a medical practitioner can access (i.e. patients’ age, race, gender, etc) or information that might encourage patients to reveal their condition (length of presentation, the 'goodness of fit' measure, or r-squared, is extremely low, less than 1% of variation in responses is shown) Furthermore, the regression shows that no kind of information accessible to practitioners, or information held by patients, is significant when trying to explain variation in disclosure (all the t and p scores are low)<sup>ii</sup>

This data was not further separated into disclosure specifically related to disclosure to sexual partners versus disclosure to other persons. While it is recognised that this is a crucial health issue, the complexity of sexual partner disclosure (addressed in the discussion portion of this dissertation) is beyond the scope of this observational study. The disclosure noted is seen to be important for medical, psychological, emotional, and financial and multiple other reasons.

This study thus showed that comprehensive social data assessment, with particular attention to the variables immediately available to the doctor (age, gender, WHO Clinical staging, and declared disclosure of HIV status) is not useful in predicting disclosure.

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<sup>ii</sup> The author would like to thank Dr .M.R Andrews for his assistance with statistical calculations.

### **3.8. Discussion:**

The majority of patients in this cohort were found to have provided minimal or no disclosure of their HIV status to others despite an average time since diagnosis in excess of two years. The absence of any clear racial, sexual or clinical stage grouping related to this finding regarding HIV status implies that the reasons for maintaining such extreme levels of secrecy are spread across the South African communities regardless of the barriers which have traditionally separated them. While no formal assessment of why people did or did not disclose their HIV status to others was performed, the experienced medical examiner's view was that reasons fell into three broad yet interrelated categories:

#### **1. Fear**

Fear of spouse, family, and employer and community responses both to the diagnosis and to what the patient felt it might imply or reveal about them. (The quotations utilised below are direct statements as recorded in the clinical notes of individual patients.)

- a. "My boyfriend will kill me"
- b. "I will be thrown out of my home"
- c. "I will lose my job"

#### **2. Denial**

Associated with fear was a large degree of denial regarding the illness and its prognosis.

- d. "I do not want to die"
- e. "I will be cured by using traditional herbal remedies"

#### **3. Shame and Guilt**

- f. "My family do not know that I am gay."
- g. "People will think that I am a woman who sleeps around".
- h. "This will "kill" my parents / family / non – sexually intimate loved one"

These claims are representative of the sum-total of the commentary supplied by the patients assessed.

These findings and subsequent claims are borne out by several case reports in the medical and lay literature. On 16 December 1998, Gugu Dhlamini, a voluntary worker for the South African AIDS advocacy group NAPWA (National Association of People Living with AIDS) was stoned and beaten with sticks after publicly revealing her HIV + status to the community she lived and worked in. Ms Dhlamini died of her injuries the following day, even as her community accused her of degrading the neighbourhood by revealing her sero-status.<sup>26</sup> The victimisation of the HIV seropositive person had taken a very dark and brutal countenance, contributing to the fears of the HIV sero-positive and sero-negative populations alike, and feeding the flames of shame and guilt, while providing positive reinforcement for denialist stances and behaviours.

The proposal by the South African government in 1999 to make HIV a notifiable illness,<sup>27</sup> but with no plans in place or even under consideration to treat those identified as positive, was seen by the activist community, and certainly by the vast majority of those patients in the author's practice, as a breach of the constitutional right to privacy. Given the level of stigma and discrimination surrounding this illness in South African communities, with severe outcomes, such as the death of Gugu Dhlamini, it is perceived that such a move would decrease disclosure rather than enhance it. Similar moves to make disclosure to sex partners mandatory by law in Botswana have been criticised as having precisely the same effect when applied practically.<sup>28</sup>

Many examples of such events are described, but it is their homogeneity which reveals that the phenomenon is not related exclusively to South African society, but is a feature of most societies worldwide.

Landor<sup>29</sup> reports on a case of fever of unknown origin in a patient who failed to disclose a known diagnosis of HIV to his doctors and/or medical care team, a status of which he had been aware for 8 years. This refusal to disclose his HIV status continued through repeated requests to perform HIV serological testing and through multiple invasive diagnostic procedures over a prolonged period of time. This resulted in a prolonged hospital stay as an inpatient with a plethora of unnecessary tests. The author postulated that the reasons for failing to disclose were related to the very real social stigma associated with perceived "immorality and homosexuality", as well as the association that this illness has with terrible suffering and death. (This being true even in the presence of Highly Active Antiretroviral Therapies (HAART) which significantly alters morbidity and mortality<sup>30</sup>) In resource poor settings, the lack of options to access HAART<sup>31</sup> increase the potential for failing to disclose HIV status, as the risk for death and suffering is markedly increased. In these settings, the fear

associated with an essentially untreatable illness reinforces the denial manifested by the majority of these patients.

Controversial correspondence followed this report, and covered issues such as patient– doctor confidentiality, the utility of weighting confidentiality and medical need,<sup>32</sup> patient rights to privacy in the face of identifiable risk to others,<sup>33</sup> and clinician responsibility to patients refusing HIV testing in non emergency settings.<sup>34</sup> One response from Spain claimed that:

*“...requiring informed consent only for HIV testing not only provokes absurd diagnostic difficulties, but also contributes to the psychological burden and stigma associated with HIV infection.”*<sup>35</sup>

Despite these arguments, Landor argues for the defence of individual patient autonomy, partially because of the “overwhelming stigma that continues to accompany HIV infection and because of the enormous personal, social, and medical consequences of a diagnosis of HIV.”<sup>36</sup> He points out that, due to the aforementioned factors, and without the requirement for informed consent, patients will fail to present for testing due to fear of being tested without their consent, (with all the real and perceived consequences thereof.) In addition, this fear could seriously impair the relationship between physician and patient and exacerbate all the problems of non-disclosure of HIV, particularly in unfamiliar medical situations such as casualty units and emergency rooms.

In Canada, the case of British Columbia Resident Henry Cuerrier, who was retried for assault following his repeated unsafe sexual exposure to his sex partner without disclosing his HIV status, raised many issues regarding the criminalisation of non disclosure associated with perceived transmission risk situations. AIDS activists criticised the action, arguing that the increased stigmatisation of people with the illness would decrease disclosure and exacerbate the problem.<sup>37</sup> A similar problem arose in India, where an organised marriage was suspended on the ruling of the supreme court that the groom to be was HIV +. The patient was severely ostracised by his society as a result.<sup>38</sup> In Israel, revelation that the death of singer Ofra Haza from AIDS sparked public debate regarding her “requirement” as a public figure to disclose her illness. While argument was led that public disclosure of her illness would have helped to de-stigmatise the condition, her express wish (violated after her death) was that her diagnosis was to remain undisclosed.<sup>39</sup> Whether the final exposure of this person after her death was an act of great epidemiological responsibility, or a deplorable violation of her rights as a person is a subject perhaps without answer. Certainly, as an encouragement to disclose one’s HIV status, it sends a strong message of disregard for final requests for preserving autonomy (and

perhaps dignity), and could conceivably decrease HIV sero-status seeking behaviour, disclosure of positive status, and even early healthcare seeking behaviour.

While attempting to reconcile the broader utilitarian ethic of balancing conflicting good and bad outcomes at the individual and broader community levels; with the deontological principle of respect for people as ends in themselves, it is important to remember the centrality of the individual patient in the context of the AIDS pandemic.

In contemplating the enormity of 42 million + infected people worldwide, the concept of human rights and ethical principles are easily forgotten. Yet, the management of transmitting infection, be it preventive or therapeutic, takes place at the individual level. No control of the pandemic is possible without the partnership between doctor and patient. As this dissertation reveals, a large proportion of the population studied at the BMC had provided minimal or no disclosure of their status to any person other than the clinician. The study is complicated by its selection of patients who do not exactly conform to the patient population presenting to government clinics. It does, however, represent the state of disclosure of patients across the spectrum of South African society and HIV disease as represented in this clinic. Further, the low levels of disclosure in this private clinic, despite the absence of the time constraints for adequate communication that typify care in the public health sector, re-emphasises the need for returning to a central role for the patient both in decision making and in ongoing management of the illness. This study, as well as the evidence documented in the medical literature, suggests a failure of coercive methods (such as the threat of notification of this illness - about which a discussion was taking place nationally at the time this study was performed), either at the individual, societal or legislative level, to secure adequate disclosure of HIV status to sexual partners, family and medical personnel. Voluntary counselling and testing for HIV, disclosure of HIV status, and treatment seeking behaviour can and will only be achieved in an environment of patient rights, with strong attention paid to ethical principles. Society must adapt to this pandemic, and the medical profession must lead the way, both as our ethical responsibility to our patients and to society, and because, without adherence to patient rights and ethical principles, our ability to manage this pandemic will be severely hampered.

In moving from the observed data regarding HIV to a discussion of the rule of confidentiality and the policies which do and which perhaps should govern it, this dissertation will address the following :

- A broad separation of the terms Privacy, Secrecy and Confidentiality

- An overview of ethical theories governing decision making about morally troubling problems
- A review of the medical and bioethical literature relating to confidentiality
- A re-definition of the concept of confidentiality in the context of the modern team – based approach to health care.
- A systematic approach to HIV related policy formation for institutions

The conflict between the physician's duties to his or her individual patient and to society as a whole pervades daily practice and is revealed in professional oaths. A closer examination of certain of these oaths reveals the conflation of the terms of secrecy and confidentiality, setting the scene for a discussion of privacy, secrecy and confidentiality in the professional milieu.

- ◆ “All that may come to my knowledge in the exercise of my profession or outside of my profession or in my daily commerce with men, which ought not to be spread abroad, I will keep secret and never reveal”

#### Hippocratic Oath

- ◆ “A physician may not reveal the confidences entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of patients, unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community”

#### AMA 1957

- ◆ “ A physician shall safeguard patient confidences within the constraints of the law”

#### AMA 1980

- ◆ “I will respect the secrets which are confided in me, even after the patient has died.... A doctor shall preserve absolute secrecy on all he knows about his patient because of the confidence entrusted to him”

#### Declaration of Geneva WHO<sup>40</sup>

(All emphasizes the author's own and intended to highlight both the conflation of terms such as secrecy and confidentiality, and the inaccuracy of use of such language in these settings. The

arguments relating to this conflation of terms, as well as their relation to the concept of privacy will be further explored later in this dissertation.)

The inaccurate and conflated use of the terms “secrecy” and “confidentiality”, as well as how these relate to the concept of privacy, complicate the arguments which pertain to our understanding of the issues surrounding confidentiality in medicine. Questions regarding the nature and extent of confidentiality, its relationship to privacy rights and secrecy, and even the most basic of questions regarding whether healthcare professionals, as part of their confidentiality obligations are obliged to keep their patients’ secrets, remain difficult to define, and even more complex to answer. In this situation, the arguments regarding how exactly we ought to respect the (purported) right to confidentiality are applicable. From this examination must come some guidance on how to proceed in the definition of confidentiality, the protocols arising from such definitions, and the implementation of confidentiality policies following from such protocols. This examination will form the basis of the remainder of this dissertation.

## **4. A discussion of the ethical rules regarding confidentiality and disclosure**

Ethics involves the study of concepts involved in moral reasoning. Applied ethics situates moral reasoning within particular areas of concern, such as healthcare, law or business. The field of applied ethics generally known as bioethics considers ethical problems specifically generated by medical and / or biological practice. Some of these problems relate to resource allocation, patient and physician autonomy, experimental study, application or denial of life-saving interventions, and, in this dissertation, to the arguments pertaining to privacy, secrecy and confidentiality. The debate on confidentiality embraces more than how confidentiality is defined in lay and professional realms, and includes how it may be distinguished from such concepts as privacy and secrecy, as well as how it is perceived to be applied. The possibilities and practicalities of practical application within the modern team approach to medical care without violating the concept are also explored. In order to achieve these goals, and to chart a way forward to practically assist with protocol formation regarding confidentiality in healthcare settings, a starting point is the study of ethics in its abstract form, and to begin to explore the conflicts generated by opposing ethical theories.

While the idea of confidentiality can be derived from many sources, the commonly discussed ethical theories from which the rule of confidentiality is derived are utilitarianism and deontology. From a deontological perspective confidentiality is essential as an end in itself. This is the sense in which confidentiality is viewed in traditional medical ethics, such as outlined in the Hippocratic Oath, or when it is seen as a human right. From a utilitarian perspective confidentiality is valued because it is perceived to have high social utility. However, from this perspective confidentiality can be broken if the utility value is greater than when it is preserved. For example, confidentiality is not maintained about such infectious diseases as tuberculosis where breaking confidentiality has a high social utility value. Here, concern for public health requires notification of individual cases of tuberculosis to the public health department in order to implement tracing of contacts which could be diagnosed early, cured and prevented from spreading the disease to others. The challenge for healthcare professionals is to balance the rights of individual patients with the protection of society as a whole. Arguments from deontological and utilitarian theory need not be mutually exclusive, but a basic understanding of these philosophical theories illuminates the arguments to follow.

## 4.1. Consequentialist Theories:

Following the French Revolution, the fall of the Napoleonic Empires, and the upheavals created by the fall of slavery and the civil wars raging in the Americas, the hold of legalistic rules over moral behaviour and thought driven by the church and monarchy were increasingly challenged. At that time, a theory loosely put forward by David Hume (1711 – 1776), and definitively formulated by Jeremy Bentham (1748 – 1832) and later John Stuart Mill (1806 – 1873)<sup>41</sup> argued that knowledge must come from the senses, and not be invented by the mind<sup>42</sup>; further that the definition of morality did not reside in the pleasing of a deity or a religious order, nor in the slavish following of rules or laws put forward in what could be considered an abstract fashion. Instead, Bentham wrote that morality is as simple as the generation of as much happiness as possible in the world. The broadest expression of this theory came to be known as consequentialism, a term used to broadly define the concept that all actions are morally right or wrong by virtue of their consequences alone.<sup>43</sup> Bentham's formulation of the theory was known as utilitarianism, and his definition of right or wrong resided in the degree of happiness or unhappiness generated by a particular action or omission (a stance known as hedonistic utilitarianism, the initial definition of utility).

Defining his ultimate moral principle (“The Principle of Utility”) in societal terms, he stated that, given the choice between alternate actions, the moral choice will be that which generates the best possible outcomes (in terms of happiness) for the majority of the population. This he published as his “principle of utility”:

*“.....By the Principle of Utility is meant the principle which approves or disapproves of every action whatsoever, according to the tendency which it appears to have to augment or diminish the happiness of the party whose interest is in question; or what is the same thing in other words, to promote or oppose that happiness.”<sup>44</sup>*

The term “consequentialism“ became more useful philosophically as newer generations of thinkers, seeking to retain the principle of utility, and the concepts of utilitarianism, but broaden the scope of what is meant by “utility”, began to explore the concept. Further exploration and examination led to the separation of utilitarianism into “act” utilitarianism (always acting so as to maximise utility) and “rule” utilitarianism (selecting and following rules which produce maximum utility when followed)

In addition, pluralism began to become acceptable in defining utility.

*“...what makes an individual life good: to pleasure or happiness we might add understanding, accomplishment, deep personal relationships, and so on. This form of pluralism stays within the confines of individual well-being.”<sup>45</sup>*

As the concept began to be further explored, it became generalised from those things making an individual life good, to other features of consequences, such as the concepts of the equal distribution of human rights, and the equal distribution of individual goods. In this way, we add to moral weighting of individual goods, those goods traditionally considered moral goods (such as equality and respect for human rights).

Certain philosophers such as Parfit<sup>46</sup> and Slote<sup>47</sup> further generalize the utilitarian standard of maximization of resources. From an absolutist viewpoint, they move to a more general notion of “optimum”, preserving the concept of consequentialism (Consequentialist theorists might then hold that it is morally wrong not to produce that which is defined as the optimum). This may be even further generalized from “maximization”, to “optimum”, and from there to define the standard(s) of moral right and wrong to the concept of “satisfactory” (as defined in the individual or even in the general sense). From here the strict concepts of utilitarianism as outlined by Bentham and Mill move to a more general use of the theory which we may define as consequentialism. It retains the central concepts of the principle of utility, but expands the concept to more general use, particularly in terms of the general population, and the definition of what is or can be meant by utility.

#### **4.1.1. Problems with Consequentialism :**

While consequentialism is an attractive theory, it is open to criticism at the level of the theory itself. Several of these criticisms are outlined below:

1. A common criticism levelled at the theory is the general unimportance of motive in assigning moral value. In that consequences and their assigned utility are deemed to determine moral value, it may be argued that this constitutes a poor basis for a moral theory. If a theory ignores motive and only recognises outcome, it would seem odd that what is ethical is seen as being no more than “good” outcomes, while a true assessment of whether an act is “good” must surely extend to involve “good” motives, and “good” thoughts.

2. In that consequentialism assigns moral value to consequences, assumptions are made that consequences are predictable with a high degree of certainty. Without entering a debate regarding the relative merits of possibilities and probabilities in predicting outcomes, it is a truism that consequences cannot ever be accurately predicted with certainty. In this setting, if morality is assigned to the consequence of an act, rather than the motives of the agent performing the act, and all outcomes cannot be predicted, this presents significant problems for the theory. If outcomes cannot be accurately predicted, it is thus impossible to assess utility and disutility ratios. In overall assessment, utilitarianism is vulnerable to criticism as a theory because the outcomes the theory deems relevant relate to rightness of actions to occur in the future, and thus presumes to know what will happen before it does.

3. While utilitarianism has moved beyond the hedonistic utilitarian theories of Bentham et al, the theory of classic hedonistic utilitarianism (which has lent a framework to the multiple advancements on the theory) is vulnerable to the criticism that morality consists of much more than “happiness”, and involves issues such as personal preference and action.

4. A further criticism of the theory relates to the broader question of whether consequences are the only factors which are important in moral outcomes. This is a separate criticism to that raised in (1) above. If considering outcomes, and some other factor is important in determining outcome (whether good or bad), utilitarianism is in danger of being undermined. It must be considered that other moral factors are important in determining whether actions are right or wrong. Examples of such variables are :

**a. Justice :**

Consequentialism may be seen as incompatible with the idea of individual justice. Justice requires that we treat individuals fairly, within the context of the society as a whole; however, ignoring the individual arguably violates the concept of justice, as justice requires that we treat the individual fairly, according to their individual needs and requirements, not according to the purist demands of utility.

**b. Human Rights :**

Because utilitarianism focuses on the overall good of society, it has less focus on the rights of individuals. As such, the theory may potentially lead to the abrogation of the rights of the individual.

5. Utilitarianism is arguably too demanding. Utilitarian theory eliminates the distinction between obligatory actions (morally required) from supererogatory actions (praiseworthy but not morally required) A focus on pure utilitarianism is unlikely to lead to supererogatory actions, to stimulate any one individual to act “beyond the call of duty”.

6. Personal Relationships : Because none of us is impartial, it is arguably difficult to fulfil moral outcomes based on population outcomes when we are so tied to individual outcomes and our own perceptions of individual morality.

However, regardless of how critical one may be of consequentialism, the major problem for moral injunctions remains – in any and all situations :

*How does one persuade people to choose the moral good?*

Immanuel Kant (1724 – 1804), believed essentially that morality derived from understanding and observing duties. <sup>48</sup> His theories (and those of philosophical thinkers who follow this mode of thought) are termed “deontological”.

## **4.2. Deontological Theories:**

Deontological theories of ethics refer to those theories according to which certain acts must be committed or omitted regardless of consequence.

Certain acts are thus seen as wrong in themselves (Kant, Ross<sup>49</sup>). An example often cited is that of promise breaking (of particular reference to this dissertation, as promises are intricately linked with the confidentiality assurances in the healthcare worker – patient relationship), an act seen as wrong regardless of the outcome it might generate. Note that not all deontologists would hold to an absolutist point of view about this. Ross for example, argues that in exceptional circumstances, lying or breaking a promise might not be morally wrong. Kant, on the other hand, formulates his ethics in absolutist terms. He held that our lives are governed by various moral “oughts”. These inform our actions in various situations. Kant argues that the enacting of these oughts is possible through reason. These oughts he further defined as obligatory.) From these arguments, Kant reasoned that morality could be summed up in one principle, defined in his “categorical imperative”:

*“...act only according to that maxim by which you can at the same time will that it should become a universal law.”<sup>50</sup>*

A further formulation of the same imperative is often stated thus :

*“...act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means alone.”*

In Kant's theory, people have an intrinsic right to be treated as ends in themselves, and not merely as means to an end. They may be treated as means, but not exclusively as means. Human rights and consequent duties are elevated beyond the utilitarian viewpoint of moral utility and accorded moral value in their own right.

Modern thinkers in diverse fields such as philosophy, economics, politics and medicine have adopted this approach to thinking, often in association with mixtures of other philosophical ideas, and Kant has been influential in driving areas of thought on topics such as justice, with the most influential thinker in this area formulating his theory of justice along deontological lines :

*“...each person possesses an inviolability founded on justice that even the welfare of society as a whole cannot override.”<sup>51</sup>*

#### **4.2.1. Problems with deontological theory:**

The primary problem with this theory, in whichever form it is presented, is the inflexibility it presents in situations where following an imperative such as that presented above (e.g. “it is wrong to lie”) could place the clinician in the untenable position of having to disclose a patient's HIV status to all who specifically requested it (e.g. employer, insurance company) with or without his or her consent, leading to consequences which could adversely affect him or her (loss of work, stigmatisation, etc). Kant would argue that the categorical imperative had been adequately followed, but the consequences for the patient would be devastating. This is not an argument for consequentialism, but a viewpoint on what the author perceives as failings of the deontological viewpoint.

A second problem arises out of the situations presented by so – called real and theoretical “conflict cases”. In a situation where deontological theory would make it absolutely wrong to perform action “x”, while at the same time absolutely wrong to perform action “y”, and no other alternative presents itself, what does the deontological theorist do? In such cases, deontologist theorists argue, only one of these rules or “maxims” would be found to be absolute. However, when there is more than one absolute maxim they could conflict.

Other problems with the classic deontological theories relate to the non-status of animals, as the dignity accorded humans and underpinning their right to be treated as ends in themselves does not extend beyond the ambit of the genus homo-sapiens.

In essence, then, the discussion regarding medical confidentiality, particularly as it relates to the complexities of the HIV pandemic, returns with regularity to this dilemma. How does a health care professional practise ethically by maintaining the privacy and confidentiality of their individual patient, while also fulfilling his or her duty to protect society from what is perceived to be a highly contagious and yet highly preventable illness.

The concept of confidentiality, then, must move from being viewed as an absolute obligation of one to one health care worker to individual patient, to a broader understanding taking into account the realities of the modern team based approach to medical management, as well as the realities of this contagious illness. A move from absolutism to a more realistic approach encompassing the needs of patients within the modern healthcare environment, while still preserving the doctor-patient relationship is vital.

Complicating this consideration is a plethora of other philosophical theories (e.g. virtue theory) that could impinge on the argument, and the potential severity of the social and medical consequences of making a “wrong decision.” The dearth of trained and educated people at all levels with regard to HIV makes this even more difficult, but lends urgency to the discussion regarding the pros and cons of maintaining confidentiality in the medical (and particularly in the HIV) setting, and to allow for increasingly rational and moral decisions to be implemented in the guidelines provided for citizens, patients, and healthcare workers.

## **5. A Separation of the concepts of Privacy, Secrecy and Confidentiality:**

The interweaving of the related fields of medicine, law and ethics has resulted in a laxity in the common use of terminology relating to the problems under discussion. In particular, the terms "privacy", "secrecy" and "confidentiality" are used in interchangeable fashion throughout the literature. Separation of these terms is integral to an understanding, not only conceptually, but also in practical terms, of the problems presented by the issue of medical confidentiality. While dictionary definitions will be used to initiate this argument, they will not be utilized as more than starting points for discussion. It is recognized that they reflect common usage, not philosophical and / or ethical argument. These will be covered in later sections of this dissertation.

### **5.1. Privacy:**

*"....the quality of being apart from the company or state of others....isolation. Or freedom from unauthorised oversight or observation (protected by law in the enjoyment thereof)"<sup>52</sup>*

Privacy may be viewed as a protection of our activities as citizens beyond the scrutiny of others. Privacy is protected by law under the South African and other constitutions. Privacy is a complex topic, encompassing multiple areas of ethical thought, including but not limited to, the concept of intimacy. For the purposes of this dissertation, however, privacy is limited to its role in doctor patient confidentiality. In this setting, privacy may be considered as essentially a legal concept, restricting the involvement of government in the life of the individual citizen, as well as the individual in relation to all other people. In the South African Constitution, the right to privacy is entrenched in the bill of rights. (Section 9.6).

*"The right also protects particular aspects of bodily and psychological integrity. Various aspects of individual privacy are protected, for example, private communication, lifestyle, residence and family life. The Constitution describes various ways in which the right may not be infringed. The right includes:*

- *Not to have your person, home or property searched;*
- *Not to have your possessions seized; and*
- *Not to have the privacy of your communications seized."*<sup>53</sup>

Despite its place as a principle which applies to the protection of the individual from the state, it requires a mention in the consideration of patients who are treated at state organizations, in this case a state hospital, and who have constitutional privacy rights that should be upheld.

When considering, for example, the confidentiality of state facility generated medical records. It does not follow that state officials should therefore have unrestricted access to that person's private social and medical information without his or her consent, and in violation of his or her constitutional right to privacy.

This consideration of privacy, in legal circles the grounding for the concept of confidentiality<sup>54</sup> provides for a broader defense of said confidentiality in the medical framework.

## **5.2. Secrecy:**

*“The habit or practice of keeping secrets or maintaining privacy or concealment .... The condition of being hidden or concealed.”<sup>55</sup>*

*A secret is defined as follows:*

*“Kept from knowledge or view; concealed; hidden..... synonyms covert, clandestine, stealthy, surreptitious, furtive, underhand, underhanded, : secret is a general term applicable to anything hidden, concealed, known, or known about by a limited few.”*

While secrets are part of the fabric of society, and not necessarily a bad thing (see discussion below) this definition suggests that secrets, and the practice of secrecy may under certain circumstances be considered undesirable, and even potentially destructive. While this definition is perhaps best understood in the context of a military or government secret, it has implications for the shroud of mysticism which has occluded the real nature of HIV in South Africa. With nearly a decade of political and bureaucratic failure to publicly acknowledge the link between HIV and AIDS, this illness has assumed the nature of a societal secret. This secrecy extends to the benefits of HIV therapies, and has fostered a culture of public and private HIV denialism. This culture of denial manifests in the ongoing practice of unsafe transmission behaviors, of poor uptake of antiretroviral strategies where available, and of late diagnosis and failure to accept diagnoses of AIDS defining illnesses. In the professional environment, secrecy generated denial leads to a culture of learned helplessness in diagnosing and treating patients, failure to lobby for effective therapies for sufferers, and, in amazingly

large numbers, healthcare workers refusing by both active and passive means, to treat patients at all.

By comparison authors Tom Beauchamp and James Childress, define “confidentiality” as follows:

### **5.3. Confidentiality:**

*“Confidentiality is present when one person discloses information to another, whether through words or examination, and the person to whom the information is disclosed pledges not to divulge that information to a third party without the confider’s permission.”<sup>56</sup>*

The different roles of secrets and confidentiality in society need to be understood in order to understand the ethical distinction being argued in this paper. Separating secrecy and confidentiality is vital to prevent the complicity with secrecy alluded to above from adversely affecting the doctor - patient relationship. Unless the healthcare worker is able to understand, explain and offer care for HIV in a manner congruent with a societal understanding of the illness in a manner respectful of the patient’s right to confidentiality but not complicit with societal denial, the doctor – patient relationship will lose therapeutic power.

Without arguing for the following, I would state as a premise that people are self interested beings. (This dissertation does not allow for a more detailed analysis of this statement.) This self interest of humans has bearing on societal formation and functioning and on the role of secrets in society. Communities are formed, perhaps by the mechanisms of formal or implied social contracts described by Hobbes and other social contractarians, to protect the self interest of individuals. Regardless of the theoretical arguments pertaining to development and sustaining of communities however, certain facts are evident. People come together to form relationships, build families, and develop communities. Different communities have different cultures, believe different things, and yet are bound by common morality, even though this may be expressed in very different ways. Certain moral principles are essential to community well being, and the well being of the individual is complexly interwoven with that of the community. Privacy and the retaining of those things private to one enhances growth as an individual, and allows for the strengthening of intimate and other bonds as private things are shared in confidence that they will remain private. This is an important role for the doctor patient relationship, where complicity with secrecy which could be damaging to society is not

encouraged, but where the maintenance of confidentiality fosters trust and increases access to healthcare education, prevention and treatment of disease.

Arguing broadly for when secrets are appropriate and inappropriate is not the place of this dissertation. It is however, appropriate to investigate the issue of HIV / AIDS specifically, and the place of secrecy and confidentiality within the ambit of the medical consult.

Understanding the sometimes subtle differences between secrecy and confidentiality is essential to the reasoning behind abolition of secrecy in treatment of HIV / AIDS while retaining confidentiality as a cornerstone of the doctor patient relationship. Not all authors, however, believe that confidentiality is a desirable aspect of medical care, while still others feel that, as stated above, it does not exist in any meaningful sense at all in the manner in which it is defined or theoretically understood. As such, it is argued that it cannot be practiced in the manner currently understood.

## **6. A review of the literature regarding professional confidentiality:**

As suggested in the previous section, the concept of confidentiality, on surface a simple one, may be difficult to understand, to rank in importance, and to implement meaningfully. In this chapter, an examination is made of whether it is also difficult to define and further to defend as a core principle of clinical practice. As has already been pointed out, exponents of opinions regarding this subject tend to adopt fairly absolutist views regarding confidentiality in healthcare. Practical approaches to confidentiality are of necessity neither absolute nor relative, but somewhere in between. The focus on the extreme ends of the spectrum is useful to address the literature in its entirety, but the importance of process in analysing problems of confidentiality must not be underestimated, despite cautions such as offered by Kottow<sup>57</sup> that:

*“ The contemporary expansion of ethics in general and medical ethics in particular harbours the danger of increasing scholasticism to the point where not even pressing practical problems are being offered workable solutions .... even traditionally straightforward practices, such as confidentiality, have been subject to extensive review and analysis, which have proved incapable of offering committed stances or unequivocal guidelines for action. ”*

This literature review will lay the groundwork for practical responses to the problems presented by the application of medical confidentiality in the practice setting, and specifically as regards the HIV infected patient, and, indeed the HIV infected community. With attention to the literature and the laws of logic, it is important not to deviate from the prime purpose of such a review – to promote clarity in defending the well being of the patient and the community, through the crafting of sound and immediately practicable ethical and legal policy for application in the care of HIV infected persons.

This subject has a vast literature, with diametrically opposite views among authors. Michael Kottow, for example, in his provocative paper, “ Medical confidentiality: an intransigent and absolute obligation”, argues that, due to the extremely sensitive nature of confidentiality – an interpersonal communications strategy and agreement which can only, again by its nature, be voided after the confidential information is disclosed – the introduction of grounds for breaching such a strategy would make it inherently unreliable. He argues that allowing for breaking confidentiality would introduce unfairness and arbitrariness into the medical consultation. He thus opines that not applying confidentiality in an absolutist fashion would be inherently unethical, and certainly counterproductive to the personal and broader medical profession, as well as to the health of the community. Michael Siegler, in an equally provocative work, dismisses modern views on confidentiality as out of date and essentially useless to the modern practice of medicine. He hammers this point home, in his 1982 article in the New England Journal of Medicine, in which he refers to our current understanding of confidentiality as a “decrepit concept.”<sup>58</sup> His argument is based on an empirical case study (discussed below). Notably, both these authors cling to the vital nature of confidentiality in the doctor – patient contact, despite differing views on theoretical background and practical implementation. This is true of the writings of other many other authors, such as Kornrad:

*“.....it (confidentiality) acknowledges respect for the patient’s sense of individuality and privacy.....is important in improving the patient’s health care - a basic goal of medicine.....this bond of trust between doctor and patient is vitally important both in the diagnostic process and subsequently in the treatment phase....”<sup>59</sup>*

But while Kottow calls for a return to absolutism, Siegler suggests a rebuilding of a new understanding on the shreds that remain of the old. It is important to begin this argument with an analysis of just what has been proposed as the meaning of “confidentiality”

From ancient to contemporary times, rules of confidentiality have been common in works on ethics. Emphases have changed in Western Culture, from a state of total openness in the middle Ages regarding what was disclosed beyond the realms of the consultation, to the absolute secrecy required of nineteenth century physicians.<sup>60</sup> No ethical guideline, however, is complete without a (generally) highly interpretable reference to medical confidentiality.

*“All that may come to my knowledge in the exercise of my profession or outside of my profession or in my daily commerce with men, whom ought not to be spread abroad, I will keep secret and never reveal”<sup>61</sup>*

#### The Hippocratic Oath

Here the venerable father of medicine is quoted as extending professional confidentiality beyond the bounds of the consulting room to the world and life in general. Confidentiality, it would seem, can easily become conflated with generalized secrecy, this definition in addition being highly subject to the opinions of the professional “...which ought not to be spread abroad...” The weight of the beneficence model of medical care is clearly felt in this statement. Further, this “confidentiality” is all encompassing, and seemingly meant to be extended beyond the grave. All these points can be seen as contentious, and instead of providing a fairly rigid guideline for what and how to maintain confidentiality in the professional context, introduces further problems for the clinician.

*“A physician may not reveal the confidences entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of patients, unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community”*

American Medical Association Position Statement 1957

Once again, this statement is open to interpretation regarding the conflict between “...the individual and the community.” Are the autonomy, privacy and welfare of the index patient the driving influence here, or is the utilitarian model more in effect? Beneficence as opposed to autonomy models of care were still very much in their ascendancy at this time, but introduced in this statement is the requirement to, when necessary (again potentially creating dilemmas for the professional), subordinate the professional judgment to the law “...unless he is required to do so by law...”. While this removes the previous objection of this author to the paternalistic practice of leaving all the decisions to the professional, it does beg the question of whether the law should guide and / or decide the ethical question or the other way around. This is not to decry the role of the law and the judiciary in acting in situations of

societal or individual peril, but regards a fundamental question, becoming increasingly problematic in modern ethics. Do we, as physicians, make ethical decisions guided by the law, and, indeed, guide the process of law-making as it relates to our profession, or do we allow lawyers to make these decisions for us?

*“A physician shall safeguard patient confidences within the constraints of the law”*  
American Medical Association Position Statement 1980<sup>62</sup>

While comment on this review of the earlier AMA ethical statement is very much in accordance with the previous paragraph, a sterner injunction regarding the law has found its way into these guidelines for ethical practice in medicine. The language regarding the patient has also softened, “safeguard patient confidences” being a long way from “I will keep secret and never reveal” The influences of paternalism, with utilitarianism as its motivation are evident. This Position Statement was influenced by the rulings in the Tarasoff cases of 1974<sup>63</sup> and 1976.<sup>64</sup>

This landmark legal process began in 1969, at the University of California, Berkeley. Prosenjit Poddar, a voluntary outpatient, sought psychiatric attention following a friend’s concern that he was becoming unnaturally obsessed with a student, Tatiana Tarasoff. Poddar was assessed by a psychiatrist, started on a neuroleptic agent, and entered into a therapeutic psychotherapeutic relationship with a staff psychotherapist. During psychotherapy sessions, Poddar revealed fantasies of harming and perhaps even killing Tarasoff. Information was also brought to the therapist’s attention that Poddar had acquired a handgun. Shortly thereafter, Poddar absconded therapy, and the medical staff requested the intervention of the campus security in order to facilitate evaluation for possible hospitalization. Following this assessment, it was felt that he did not pose any danger to Tarasoff, particularly as he denied any intention of harming her. Two months later, following University vacation, Poddar fatally stabbed Tatiana Tarasoff. A conviction of 2<sup>nd</sup> degree murder was overturned on the grounds of improper jury instruction, and Poddar returned to India, to play no further role on the legal and ethical battleground he had helped create.<sup>65</sup> In 1974, the Tarasoff family, in a civil case, sued the University, the campus police, and the medical professionals involved for negligence in the death of their daughter. Their prime argument regarded their perception that the authorities had failed to warn their daughter of a known threat to her life. In a split judicial decision, the legal obligation to warn an identifiable person of an identifiable risk was created. The court did not, however, find the medical professionals or the campus security negligent in their actions. In a rarely employed option, and because of the implications this ruling had for the practice of therapeutics of many kinds, the California Supreme Court reheard the case in

1976. The court reinforced the majority opinion of the initial justices, and held that the duty was not merely to warn, but to protect in the situation of identifiable risk to intended victim. How this was to be carried out practically was not clarified, but has resulted in the ability of therapists in many states in America to discharge this duty by a telephonic “Tarasoff” warning.

Given the tragedy of this case, as well as the tensions it creates between moral deontological thought and a calculation of potential and probable outcomes in a utilitarian model, the 1980 reworking of the ethical guidelines can be seen to come down firmly on the side of a policy which weighs consequences of confidentiality violations, and acts in a utilitarian fashion, backed by the repeated injunctions of the law. In many states in North America, it is not only compulsory to notify the state authorities of a HIV positive patient’s status, but also to notify known sexual and other at risk partners in this regard.

A backlash followed the two Tarasoff findings, with increasing concern from members of the psychotherapeutic field that the responsibility to protect patient confidentiality was now so compromised, that patient care would be compromised, treatment efficacy decreased, and, ultimately public safety reduced. The data suggested otherwise. Studies performed separately by del Rio<sup>66</sup>, Schmid et al<sup>67</sup>, and Stone<sup>68</sup> suggested that the public and specifically certain groups (of psychiatric patients’) responses supported the empirical feeling that medical ethics rests firmly on the mutual responsibilities to protect the confidentiality of the patient while at the same time safe-guarding the greater society. However, neither duty can be seen as absolute, and, while medical confidentiality should be protected whenever possible, there is an increasing body of opinion that, when the welfare of third parties and the welfare of society are threatened, confidentiality should be breached. In balancing the arguments of absolutism and relativism with respect to confidentiality, the middle ground of compromise should be pursued.

A wave of post Tarasoff rulings regarding breaching Professional Confidence have called into question, however, the limitations of the duty to protect, while not questioning the legitimacy of that duty. Coinciding with (and perhaps contributing to the impetus) of a wave of modern bioethical writings which have seen an increased focus on the autonomy of the patient and less on the primacy of beneficence in medical decision making, have been a series of rulings in the United States.

<b>Decision</b>	<b>Court</b>	<b>Duty</b>	<b>Liability</b>	<b>Victim</b>	<b>Violence Foreseeable</b>
Tarasoff 1974	California Supreme	Warn	No	Specified	Yes
Tarasoff 1976	California Supreme	Protect	No	Specified	Yes
Macintosh 1979	New Jersey Superior	Protect	No	Specified	Yes
Thompson 1980	California Supreme	None	No	Not Specified	No
Lipari 1980	Federal District	Protect	No	Not Specified	Yes
Leedy 1981	Federal District	None	No	Not Specified	No
Doyle 1982	Federal District	None	No	Not Specified	No
Hasenei 1982	Maryland Appeals	None	No	Not Specified	No
Furr 1983	Federal District	None	No	Not Specified	No
Jablonski 1983	Federal District	Protect	Monetary Damages	Specified	Yes
Brady 1983	Federal District	None	No	Not Specified	No
Hedlund 1983	California Supreme	Protect	No	Not Specified	Yes
Petersen 1983	Washington Supreme	Protect	Monetary Damages	Not Specified	No
Clark 1984	New York Appeals	Protect	Monetary Damages	Not Specified	Yes
Schrempf 1985	New York Appeals	None	No	Not Specified	Yes
Peck 1985	Vermont Supreme	Protect	No	Specified	Yes

The rulings in these cases, utilizing Tarasoff as their basis, move from specified harm to identifiable person/s to broader legal applications, in some cases effectively ruling in favor of a confidentiality breach when neither the proposed harms nor the purported victim can be identified prior to their occurring. This legal wrangling, along with a move away from paternalistic models of medical care, is evidenced in later formulations of professional ethical codes. An emphasis on the centrality of the patient, as well as the legal and moral rights of the patient in the doctor – patient relationship, enters the definition of the concept. The conflict between deontological positions and consequentialist views remains uneasy, however, despite the increasing recognition of societal gain from recognition of individual rights.

*“I will respect the secrets which are confided in me, even after the patient has died.... A doctor shall preserve absolute secrecy on all he knows about his patient because of the confidence entrusted to him”*

Declaration of Geneva –Position Statement World Health Organisation

*“...the duty of keeping secret all information that is given by a patient is seen as one of the most important characteristics of the profession. As such it is a deeply rooted value within the health professions. The indispensable professional good faith is based on the right to confidentiality....”<sup>70</sup>*

*“Clinicians’ work depends on sincere and complete disclosures from their patients”<sup>71</sup>*

*“...Confidentiality, or the promise not to share personal information inappropriately, is fundamental to the clinician – patient relationship....”<sup>72</sup>*

*“...Few moral rules in the health professions are as widely accepted as those of confidentiality and privacy.... In addition to these utilitarian justifications for rules of confidentiality and privacy, the injunction to respect the autonomy of patients demands respect of their confidences and thus provides an additional, if not primary, moral warrant for such rules.”<sup>73</sup>*

While it is clear that most, if not all, authors hold a notion of professional confidentiality in high regard, it is clear that confidentiality is a complex issue, requiring clear thinking and direction... It is arguable that professional ethical statements should be brief guidelines as opposed to didactic rules covering every eventuality.<sup>74</sup> This does not change the fact that these guidelines should offer some consensus definition of the concepts they seek to define. This having been stated, the issues at stake should be considered. These will be discussed as broad issues, but with specific reference to the subject of HIV.

## **7. Specific Issues of Confidentiality:**

### **7.1. Individual vs. Social Consequences:**

In addressing the issues surrounding confidentiality, the first and arguably most important issue relates to the problem of degree of harms done to individuals versus harms and potential harms perpetuated on society as a whole. More bluntly put, is the risk to the confider outweighed by the risk to broader society? In the day to day business of medicine, the question arises continually, and in many variations: – Is more harm done by occasionally breaching patient confidentiality or by always respecting it regardless of the local and broader consequences? It would seem from this continual tension that breaching confidentiality always requires a form of justification. The physician is entrusted with private and secret information in confidence, and the breaching of that information, post disclosure, requires a justification on the part of the confidant. While the breaching may be considered justified when weighing risk: benefit ratios, it remains a breach of confidentiality, and should be perceived as such, with all the attendant problems and potential loss of substance and trust in the doctor patient relationship this could generate. The violation of professional confidentiality creates the violation of autonomy and privacy rights of the confider. This may be considered justified, and the confider may indeed reduce his or her rights by the nature of the confidence, or the nature of his or her mental state. The importance of maintaining confidentiality is highlighted by examining the potential harms generated to the confider by this violation. The impact of loss of autonomy and privacy may take many forms, including loss of friends and lovers, loss of earning ability and potential exposure to legal jeopardy, physical harm, and even loss of life. All of these issues need consideration in the decision to break confidentiality. In the context of HIV illness, the risk: benefit assessment of harms to individual vs. harms to society should be considered.

#### **7.1.1. Risks of HIV Transmission:**

The first and possibly most obvious potential harm involves the risk of HIV transmission to “innocent” parties. Transmission risks should be independently evaluated in order to assign ethical argument to risk benefit scenarios.

HIV transmission is recognised to occur through infected blood / blood stained or containing fluids, or sexual fluids from HIV infected individuals. (Other sources of contagion are the laboratory created HIV/SIV and other viral mutants, and viral cultures created from infected

fluids from HIV infected people. This mode of transmission is of vital importance to the healthcare worker community, as well as to all those who may be exposed to such risks (kindergartens refuse removal people etc) there is variation between geographical zones regarding predominant modes of transmission, but these may be summarized as follows:

<b><u>Transmission Mode</u></b>	<b><u>Approximate Percentage Prevalence (world)</u></b>
Heterosexual	70 – 85%
Mother to Child Transmission (As % of total MTCT)	15-30%
- In Utero	(5-10%)
- At Delivery	(70%)
- Post Partum (Breastfeeding)	(20 –30%)
Men who have sex with men (MSM) - incorporating homosexual and bisexual men	5-10 %
Intravenous Drug Users (IVDU)	5-10%
Occupational and blood/organ transplants	< 0.1%

*Summarised from UNAIDS<sup>75</sup>*

It is evident from the above that the highest risk to other individuals occurs outside the hospital setting, and is sexual in nature. Risk of HIV infection from exposure to an HIV infected source has been estimated, and is represented below, giving an idea of potential incidence figures.

<b><u>Exposure</u></b>	<b><u>Probability of Infection/ 10 000 exposures</u></b>
Needle Sharing (IVDU)	67
Percutaneous (occupational exposure)	30
Receptive Anal Intercourse	10 – 30
Receptive Vaginal Intercourse	8- 20
Insertive Vaginal Intercourse	3-9
Insertive Anal Intercourse	3

*From Bartlett and Gallant 2001/2<sup>76</sup>*

From these figures it becomes evident that the objectified risk while not non – existent, is actually not very large in terms of each individual contact with known high risk fluid in a high risk transmission situation. In the African situation, a study in Uganda assigned an overall

unadjusted probability of HIV – 1 transmission per unprotected coital act (penile: vaginal) of 0.0011 (95% CI 0.0008 – 0.0015).<sup>77</sup> This risk of transmission was increased by incrementally elevated viral loads in the source patient, as well as by the presence of genital ulceration (0.0041 vs. 0.0011 without). Transmission probabilities per act did not increase according to HIV –1 clade type, other forms of diagnosed STI (sexually transmitted infection) or symptoms of discharge or dysuria in the positive partner.

In regard to the healthcare worker (HCW), quantification of occupational risk has been achieved. From an HIV positive source (with high viral load, hollow bore needle, deep inoculum of blood once needle having been in source patients; vein or artery) Risk is estimated at 0.3% without Antiretroviral Prophylaxis (reducing risk by +/- 70% by use of 28 day prophylaxis regimen of Zidovudine). While this risk profile may seem high, it is sobering to compare it to that of seroconversion from needle-stick injury from Hep BeAg + patient (37 – 62%) or HCV + (1.8%).<sup>78</sup>

Thus it becomes clear that there are significant confounding factors when assessing the risk that the single HIV infected person represents to society (in the form of sexual partners (willing and unwilling – as in the case of rape, and in the less quantifiable but equally real disempowerment of women, leading to an inability to refuse intercourse due to individual and social disempowerment; children infected by vertical transmission, and the potential risk to healthcare workers and others exposed to potentially infectious material). What is clear, however, is that the individual risk profile (one HIV + individual transmitting to another HIV - individual) is actually very low. What is also clear is that people in general have a lot of sex, and are subsequently exposed to many sexually transmitted illnesses, including HIV. When analysing the risk versus benefit of breaching professional confidentiality, these facts need to be borne in mind. The dangers of HIV and the reality of death from AIDS can generate a level of hysteria which can make lay and professional people alike incapable of rational and logical thought regarding actual risk profiles.

### **7.1.2. Risks to HIV positive patients on disclosing HIV status:**

This topic has been alluded to at least twice in the preceding pages, but bears repeating in this context. Too often, the risk: benefit analysis ignores the variable presented by the potential damage done to the patient who discloses his or her HIV status. This risk may extend beyond the index HIV + patient to the family and friends of such, fulfilling the criteria of risk to others. The lessons learned by the violent death of Gugu Dhlamini (as an index case

representing a multitude of equally horrific stigma related events in this and other countries) in South Africa as well as the damage done to families and children who are HIV infected and denied access to formal schooling by psychologically and physically violent tactics by other parents and “concerned citizens” cannot be ignored. The recent spate of South African lawsuits bears further testament to this phenomenon.<sup>79</sup> When assessing risk: benefit in terms of danger to others and notifiable risk, particularly in the aftermath of the Tarasoff rulings, ethical judgement would require evaluation of risk to parties on both sides of the equation.

### **7.1.3. Does the disclosure of HIV status alter seroseeking behaviour and/ or risk taking behaviour?:**

A slightly different angle on the individual vs social harms argument concerns the actions of the individual(s) to whom sensitive information is disclosed. It is a sobering thought that, while many sources, including the South African Medical Association, believe that knowledge of a person’s HIV status may be extremely relevant to the provision of the best possible health care, the Health Professions Council of South Africa notes that there is no persuasive evidence that knowledge of a patient’s HIV status diminishes incidence of risky exposure incidents.<sup>80</sup> This point of view is echoed by Lewis and Ross.<sup>81</sup> In a 1995 study of the Australian gay dance party “pandemic”, they charted various variables relating to who, why, how, and using what forms of recreational substances, gay men attended such parties. One marked observation was the response to being informed of either a positive or a negative HIV test result. The physical action was identical – to attend a party, do many drugs and have unsafe sex. Regardless of the psychological mechanism operative, suggested and arguably different forms of denial, the incidence of highly risky sexual exposures remained unaltered. A 1996 New England Journal “Sounding Board” took up this issue, with the argument that it was of more value to stress individual self protection than self (or doctor / legislative) disclosure of HIV status. Various arguments were lead in this regard, primarily those relating to the false sense of security engendered by the disclosure of a few HIV positive people, with those unknowingly infected not disclosing their status due to ignorance of it, and those not wishing disclosure not seeking help for their illness, and thus remaining a risk to others. Finally, it was argued that those at high risk for infection would avoid testing due to societal stigmatisation. This would engender a false sense of security among the general public, ironically increasing general risk of HIV infection. Each sexually active adult, it was argued, should be responsible for his or her own sexual protection.<sup>82</sup> (“To one who consents, no harm is done - Caveat Emptor” (let the buyer beware). This argument for individual personal

responsibility, however, is complex, and assumes certain infallibilities and abilities which are not practically operative. Contraception is very often not desired for reasons of procreation. In addition, using condoms at all times would only represent an appropriate intervention of self protection if condoms were 100% safe. Further, barrier devices would be more effectively utilised if sexuality were not so interwoven with trust in interpersonal relationships. “Unsafe sex within a so-called faithful union helps a woman to maintain a state of denial and her belief that her partnership is one of love, trust and fidelity....AIDS risk denial is tied to monogamy ideals....”<sup>83</sup> In those relationships where interpersonal power dynamics are seriously skewed (generally in the favour of the male versus the female in heterosexual relationships, as well as in favour of one partner at the expense of another in homosexual relationships) protective measures with regard to sex acts may be impossible, and even dangerous to implement. Finally, in this era of common sexually related violence (including, but not limited to, rape); exercising self-protection is not always possible.

#### **7.1.4. Disclosure of HIV sero-status by celebrities:**

A final area of contention regarding societal versus individual needs relates to those people whose fame or infamy in one field or another has accorded them the status of “celebrities”. Already discussed is the post mortem disclosure of Israeli singer Ofra Haza’s HIV status against her expressed wishes to the contrary. No evidence exists as to whether this disclosure increased HIV awareness in her country and worldwide, nor whether it increased HIV sero-status seeking behaviour in the general public informed of her HIV status. This question is more objectively addressed in a 1989 article in the *New England Journal of Medicine*.<sup>84</sup> In this paper, the authors write of the “impressive benefits” of celebrity disclosure of their own HIV status on public health. They demonstrate that, following disclosure of HIV status of such celebrities as Rock Hudson, “Magic” Johnson and Arthur Ashe, there was a dramatic increase in anonymous HIV testing in Orange County, California, USA. The associated percentage of negative tests resulting from this testing, however, would seem to indicate that such disclosures increase test seeking among low HIV risk populations, while having little impact on the high risk populations.<sup>85</sup> Other authors (Barat et al) suggest that such campaigns fail in their educational role regarding HIV transmission risk, and that this leaves the general population prone to hysteria; “Public awareness in the form of hysteria cannot be construed as a positive effect of disclosure”<sup>83</sup> The authors of the original article decry this criticism, defending the criticisms levelled at them by acknowledging the facts presented, but pointing out that Orange County is an area of isolated risk profile, that is, men who have sex with men, and that seroprevalence is generally low. This, in their opinion, does not invalidate their

arguments. They also deny any contribution to public hysteria, and defend their treatment of disclosure of individual celebrity HIV status by acknowledging the difficulties of societal stigma, but arguing that this stigma will not be defeated without the input of social, cultural and political leaders.

Barat<sup>86</sup>, in reply, does not deny the effect of disclosure of HIV status by celebrities, and offers the evidence of requests for voluntary counselling and testing at Boston General Hospital following the disclosure of his HIV status by “Magic” Johnson. He also states that these testing levels remain at an elevated level one year post celebrity disclosure. What Barat points out, however, is that the disclosure of HIV status by “Magic Johnson” was the only disclosure in this group and to this point in time made willingly by a celebrity. The disclosure of Arthur Ashe, Liberace and Anthony Perkins came only after their last terminal illness, or indeed, after their death. This could hardly be considered voluntary disclosure of HIV status.

Barat’s point (and that as an HIV infected physician in his own right) is that many people will refuse to undergo voluntary counselling and testing for fear of a lack of confidentiality both while alive, and after death. The suggestion that the patient’s celebrity status should alter the consideration of his or her wishes is distasteful. Despite considerable public opinion, however, that celebrities have a “duty” to disclose health problems, in particular illnesses such as HIV and AIDS, the right of any individual to privacy is not superseded by the real or perceived utility to society of undermining that right.

*“Physicians caring for a person with HIV, regardless of that person’s celebrity status, must do what they think is in the patient’s best interest. Anything less would be to compromise the care of that person”.*<sup>83</sup>

## **8. Trust and Fidelity Requirements of the Doctor – Patient**

### **Relationship:**

Confidentiality reinforces the trustworthiness of the doctor – patient relationship, and, some would say, is inherent to it<sup>87</sup>. Breaching such confidentiality can create potentially harmful situations, not only to the confidant, but also to the larger society, as medical and other problems could remain undisclosed for fear of exposure, and people may seek other, more damaging avenues of release. This is particularly problematic in the HIV scenario, where non – disclosure of HIV status (as illustrated by the study earlier in the dissertation) creates ongoing interpersonal infection, rapidly reaching pandemic levels. While not a proponent of the politicised “innocent” versus “guilty” moralising which characterises HIV infected societies, the promotion of any policy or doctrine designed to damage the confidentiality

between those disclosed to (medical staff) and those disclosing, can lead to increased transmission to those unaware of risk, such as children. Analysing studies of perceptions and expectations of confidentiality reinforces the importance of the trust issue to both doctors and patients, as well as enhancing the divide which exists between perceptions of what is expected, what is provided, and what the concept means to professionals and to those entrusted to their care.

### **8.1. Patients' Perceptions of Trust, Fidelity and Confidentiality:**

A Harris poll performed in the United States in 1979 found that only 17% of patients found fault with the manner in which privileged information was dealt with by their physicians, but that few could identify what they meant when questioned regarding what was actually done with that information.<sup>88</sup> A study published in 1982 addressed this issue. Questions were addressed to patients visiting the family practice centre at a central hospital in Tucson, Arizona, as well as to the attending medical staff and medical students at the same facility.<sup>89</sup> It was designed to question whether the expectations patients had of the confidences revealed within the trust boundaries of the physician-patient relationship were in congruence with the actual management of such confidences by the confidants themselves. Questionnaires to the groups of subjects regarding perceptions of confidentiality revealed the following results:

<b><u>Confidentiality Questionnaire</u></b>	<b><u>Percentage</u></b>		
	<b><u>"YES"</u></b>		
	<b><u>Answers</u></b>		
<b><u>Perceived Handling of Confidential Information</u></b>	<b>Patients n=177</b>	<b>House Staff n=109</b>	<b>Med Students n=53</b>
<i>Does an Informal Consultation with one or a few physicians for a second opinion constitute a violation of confidentiality?</i>	96	100	100
<i>Does a Case Discussion at large physician meetings and medical staff for other opinions constitute a violation of confidentiality?</i>	69	94	81
<i>Is a patient specific presentation at large academic meetings (because it is interesting) a violation of confidentiality?</i>	51	90	77
<i>Is a discussion of a patient with office Nursing Staff violation of confidentiality?</i>	50	69	83

<i>If a case may be submitted to medical journal, does this constitute a violation of confidentiality?</i>	25	58	28
<i>If a patient might be identified by name in discussions with other physicians, does this constitute a violation of confidentiality?</i>	23	60	55
<i>If the case is told as an interesting story at a party to other physicians is this a breach of confidentiality?</i>	18	60	57
<i>If discussed with spouse / partners is this a violation of confidentiality?</i>	17	51	70
<i>If told as interesting story at party with non-medical friends does this constitute a violation of confidentiality?</i>	9	36	45
<i>If the patient might be identified by name to non- medical personnel does this constitute a violation of confidentiality?</i>	2	6	8

*Adapted From: "Confidentiality Expectations of Patients, Physicians and Medical Students" Weiss B.W<sup>90</sup>*

A further observation of this study was the low percentage of questionnaire returns from house staff as opposed to medical students and patients (39% vs 59% vs 88% return rate). While Weiss allows for the possibility of mechanical difficulty in house staff return rates, he also raises the argument, picked up by Beauchamp and Childress, that:

*"Confidentiality is not of adequate interest to busy house staff...."<sup>91</sup>*

What is very evident is that physicians, and, in this study, physicians in training, perceive confidentiality—both at the practical, and by implication, at the ethical level—differently. Patients are also unaware of physician behaviour in this arena, and may not even consider certain of the areas of confidentiality violations seen as normal and commonplace by their medical confidants. This lack of congruence between confider and confidant, in the crucial area of information confidentiality, is vital to understanding both the problems experienced by HCW and by patients regarding what is meant by “medical confidentiality.”

## **8.2 The Unconscious/ Demented patient:**

The problems posed by the unconscious/ demented patient have long been a source of concern for ethicists, as the clinical scenarios presenting require rapid and accurate clinical decision

making in the setting of a patient who cannot expressly direct the interventions undertaken and choices made on his/her behalf.<sup>92</sup> The dilemmas posed by the diagnosis and management of the HIV infected patient are intensified in this setting. Ethical problems associated with this category of patient and HIV may present as problems of informed consent, where the outcome of an HIV test will direct further investigation and therapy. Other problems manifest as issues relating to resource allocation decision making, where HIV test results may direct facility policy regarding allocation of scarce resources such as CT scanning. Ethical decision making requires a balancing of the clinician's duty to beneficence in acting in the patient's best interests, the requirements of justice as manifested in the reality of having to make decisions regarding resource allocation, and the potential violation of patient autonomy by testing for HIV without express consent.

Ethical problems regarding confidentiality and consent in the unconscious patient may present in a variety of ways. Where the physician who has an existing therapeutic relationship with the currently unconscious patient, and is aware of the patient's HIV positive status is called upon to perform interventions requiring patient consent, this may require consent from a third party (a "substituted judgement") who may be unaware of the patient's HIV status. This third party would commonly be a family member or life partner. Breaching confidentiality may impact on the one-to-one confidentiality requirements previously agreed upon between the doctor and patient. The breaching of patient confidence to a family member in order to gain a substituted judgment regarding proposed interventions may in addition adversely affect the patient's societal relationships and functioning once his/her HIV status becomes known. Where the patient is previously unknown, and it is considered necessary to perform an HIV test in order to proceed with appropriate interventions, usual practice would require consent for HIV testing from a relative or guardian. As regards the diagnosis of HIV, this may have serious socio – economic consequences for both the index patient and the family involved, and the need for investigation (i.e. HIV testing) should be very carefully weighed against the broader societal harms potentially caused. Obtaining a substituted judgment in this setting must thus be approached with caution. Discussing this possibility with the patient prior to the acute presentation (if the patient is previously known to the clinician) may be helpful, and, if uncertain, a substituted judgment from a non-involved but legally representative third party (for example the hospital superintendent) may be sought.

Further ethical dilemmas associated with the unconscious patient and HIV testing concern the use of the HIV test as a means of triage. In settings where HIV is commonly associated with a clinically predictable cause of symptoms and signs, and where this cause may be treated without further expensive investigations, the use of the HIV test has been advocated as a

means of rationing such expensive and scarce investigations. One common presentation associated with the unconscious/ demented patient is the presence of intracranial mass lesions on CT scanning. While good medical practice would make the use of CT scanning mandatory in well-resourced settings which supported the use this investigation in all such patients, poorly resourced environments are faced with difficult rationing decisions regarding which patients will be treated further without the benefit of this investigation. In these settings, a case has been made for compulsory HIV testing of all patients with suspected intracranial lesions, in order to guide appropriate therapy, as well as to ration interventions such as CT scanning. In HIV positive patients, a case has been made for treating presumptively, without expensive interventions such as CT scanning. This argument is based on the principle that the presenting pathology is fairly predictable in the HIV positive patient, and differs markedly between HIV positive and negative patients. The clinical evidence would suggest that, while there is a fair degree of predictability regarding aetiology of intracranial mass lesions in the HIV positive patient, the degree of difference in clinical presentation is not that marked between the HIV positive and HIV negative groups. A study of common intracranial mass lesions occurring in HIV positive patients was performed by Bhigjee in Durban, South Africa, in 1999.<sup>93</sup> Of note is that all 45 patients presented with one or more of the following:

- Headache (75%)
- Seizures (45%)
- Focal signs (93.5%)

38 of these 45 patients underwent stereotactic brain biopsy. Histological results were as follows:

<b><u>Final Diagnosis</u></b>	<b><u>No of pts (n = 38)</u></b>
Toxoplasmosis	15
Brain Abscess	6
Tuberculoma / Mycobacterial Infection	4
Encephalitis	7
Cryptococcoma / Cryptococcal Meningitis	2
Brain Infarct	1
No Definite Diagnosis	3

The clinical presentation and presenting pathology is very similar in the HIV positive and the HIV negative groups as a whole. (When stratifying by CD4 count within the HIV positive group, the diagnostic probability increases, but this investigation is poorly available in

resource limited settings) What is not clear from this study, however, is the frequency of presentation by group (HIV infected versus HIV non-infected), nor the demography of the presenting patient group. While large scale cohort evidence is still lacking, clinical observation would suggest that the probability of an HIV positive result in this setting is more common than an HIV negative result, particularly in the young adult patient. This observation, alone, however, is insufficient to use as the basis for a justification for utilizing the HIV test as a means of triage in order to limit CT scanning in the HIV positive group. A large cohort study needs to be done looking at all patients presenting with this symptom complex, and correlating HIV test result and CT scan outcome. Should this show that the prevalence of intracranial lesions associated with HIV positive tests is significantly higher than that of HIV negative patients, an argument for macroscopic rationing policy and selectively withholding CT scanning on the basis of an HIV positive test result could be made. Due to the heterogeneity of presenting aetiologies, this rationing argument, however, would need to be sustained by a beneficence argument of equally good outcomes data for HIV positive patients treated presumptively without CT scanning, and those treated following CT scan investigation. Issues of confidentiality regarding HIV test outcomes would need to be addressed, with individual test results remaining confidential within the healthcare team if possible. Should the numbers in the HIV positive and HIV negative groups approximate, no rationing argument for withholding CT scanning on the basis of HIV test result alone could be justified.

## **9. Third Party Interests:**

### **9.1. Funders of care costs:**

Access to funding for the ever increasing costs of medical care is a perennial problem. Whether practising in a well resourced setting, or in the poorest mission hospital, *the flow of money for the provision of care eventually dictates the availability of that care*. This has the potential to generate significant conflict regarding who “owns” medical and other data generated by the provision of the care. In South Africa, the split between public and private healthcare becomes even more complex at this stage. If a patient presents to a public hospital, receives treatment, and leaves, a question hangs over who is entitled to use the data generated by history taking (by admission clerks, nurses and medical staff), medical examinations, special investigations and other observations recorded while the patient is receiving care in the facility owned and operated at the state expense? Should hospital staff wishing to collate this data for research purposes have to obtain the patient’s permission (prior to use of

information) to use this data, given that confidentiality as well as ownership issues are at stake?

Further complications arise when the patient in his or her own right pays or co-pays (through self funding, a medical fund, medical aid scheme or managed care scheme) for treatment. This expands the pool of people with access to, and people who might have access to sensitive individual patient data. How can these issues be resolved, particularly as data collection increases to include ever increasing areas of intimate data?

*“...as medicine expands from a narrow, disease-based model to a model that encompasses psychological, social and economic problems....more sensitive information (such as one’s personal habits and financial information) will now be included in the medical record and will no longer be confidential.”<sup>94</sup>*

The conflict potentially generated here is between those who receive the care, and who provide the data (either directly or through observation and investigation, as in the case of HIV testing – even if consent is provided for all of these activities) and those who actually pay for it. Patients have a justified interest in preserving confidentiality regarding their diagnosis and care. On the other hand, funders of care have a vested interest in ensuring that only necessary investigations and care modalities are provided. Health care workers must balance their obligations to protect patients’ confidentiality with their ethical duties to society.

The disclosure of confidential information to third parties is also an issue in the setting of occupational health. This occurs particularly when a health care practitioner is performing medical examinations on behalf a corporate or company. While it would not seem inherently unethical to provide such services (for example yearly executive medical examinations on key personnel), the degree and means of provision of data to the employer (including HIV results)<sup>95</sup> should be made clear prior to any examination or intervention. Before performing an annual medical examination on behalf of an employer, the nature and extent of the confidentiality of any data disclosed or discovered should be absolutely clear to both employee and employer. In terms of HIV testing, the South African law is clear;

*“No employee, or applicant for employment, may be required by their employer to undergo an HIV test in order to ascertain their HIV status. HIV testing by or on behalf of an employer may only take place where the labour court has declared such testing to be justifiable in accordance with section 7(2) of the Employment Equity Act.”<sup>96</sup>*

All Health Care Workers should be aware that requirements for ethical handling of confidential information, in particular HIV results, is not nullified by employment medical examinations or other third party provider requests and/ or demands on the access to, or the collection of such data. This principle has also been tried in a South African setting, with the case of Hoffman versus South African Airways. Settled out of court in the favour of the plaintiff, this case, primarily dealing with non discriminatory workplace practice and HIV, also offers insight into informed consent and protection of privileged data by health care workers.<sup>97</sup>

## **9.2. Insurance Companies:**

The wealth of sensitive data held by insurance companies represents another area to be considered as regards confidential medical records. The Life Officers Association (LOA)<sup>98</sup> of South Africa permits the collection of intimate medical, financial and social data, as well as investigations such as HIV tests, and the retaining of such data as intellectual property by the insurance company involved.. In the presence of a signed and properly informed consent to contractually break confidentiality, neither the LOA nor the doctor commits a breach of confidentiality in providing data as contracted. Where the patient was not informed, and /or coerced into signing, the contract may be considered void, and this would need to be established prior to disclosing confidential information such as HIV sero-status. The South African Medical Association's Human Rights and Ethical Guidelines on HIV<sup>99</sup> suggest that a standard reply for requests re confidential data in this regard should be as follows:

*"Patient confidentiality is protected by legislation and ethical rules binding medical practitioners. Unless the patient (or in the case of a deceased person his / her next of kin) provides informed consent (amongst others by knowing what will happen if the status is disclosed), no medical information may be provided to third parties. If you are relying on any existing legislation, contract or agreement binding on yourself and the patient, please provide us with a copy thereof so as to facilitate a proper evaluation as to the possibility of disclosure."*

## **9.3. Doctors' managed care groupings:**

The increasing pressure on private medical practise to form corporate structures, standardise medical and surgical techniques and formularies, and to generally survive financially in the harsh modern economic climate, has created a move towards the commoditisation of medical

care... The extract below from a large South African Independent Practitioners' Association (IPA) newsletter reveals this approach, but also begins to hint at the infringements that will be made on patient data previously considered "confidential".

*"In order to face the challenges presented in running a practice we need to realise that a mind shift has to occur. General Practitioners need to speedily and voluntarily move into the new age of electronic, alpha – numeric reporting and recording of your records. The ability to continue to run the erstwhile General Practice off hand written records, from which no data can be retrieved without massive manual input, is giving way to the realisation that the only way we can increase our perceived worth in the eyes of Funders, is to generate information on outcomes, savings, and diagnoses."*<sup>100</sup>

Statements such as this, associated with very broad ranging requests for carte blanche access to confidential practice data, without requesting consent in an informed fashion from the individual patient, are beginning to form a part of the daily family practice (and shortly the broader private practice) milieu.<sup>iii</sup> (Appendix 12.9 Authorisation to release confidential practice data)

#### **9.4. Other members of family and friends:**

Perhaps the most controversial area relating to breaching of confidential information, particularly in the area of HIV medicine, is the role of family and friends, and their desire (or some would claim their "right") to know confidential details regarding their loved one. Individual agendas are often impossible to assess, as is realistic individual risk in the presence of an infectious illness such as HIV.

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<sup>iii</sup> Neither is the state system immune to this form of confidentiality violation. Access to "confidential" records and patient data has long been a source of hospital audits. Prospective and retrospective access to such files has generated many an academic paper, and launched many an academic career.

In areas of medical care, the societal privilege accorded to privacy within the confines of the family may be considered both narrower and more restricted. Various reasons are put forward for this, but in the healthcare setting two interrelated areas of concern come to the fore. In the first instance, the doctor is often the first to recognise or be able to intervene in familial disputes and abuse (for example marital violence and child abuse), while in the second the conventional means of dealing with such issues, such as police action, are often powerless in such circumstance.

The question of providing contraception to underage minors, and of performing abortions on the same group of patients, is another grey area where, ideally, the family should have access to the confidential information regarding such procedures, but where the law and risk-benefit analysis to the patient would preclude this violation of confidentiality.<sup>101</sup>

In the area of HIV medicine, the intimate relations of the index patient can complicate the medical and social issues substantially. Two areas of concern present themselves. The first relates to the real (or perceived contagion risk) the patient may present. As this has previously been dealt with at some length, it will not be dealt with in any detail here, other than to point out the serious fears relating to real and perceived contagion may be a source of significant pressure on both the patient and the Health Care Worker.

The second area of concern relates to the HCW's desire to inform the family for reasons of public health interests and social interventions. What is evident, both from law and from ethical guidelines in this field<sup>102</sup> is that the family has no right to know the HIV status of the index patient. Only in the presence of an identifiable risk of contagion to an identifiable person can this breach of confidentiality be permitted, and then only to the identified person at risk following extensive counselling of the index patient to encourage self-disclosure.

It is important to inform the patient, on an ongoing basis during therapy, of the advantages to telling one's family. These may include social, emotional and financial support, as well as preparation for terminal care. On the other hand, it is vital to remember that the patient knows his or her family better than the HCW, and the realities of ostracism, rejection, violence (both emotional and physical,) and even death may be the result of untimely and uncontrolled disclosures.

Finally, it is important to inform the index patient that next of kin (in the ordinary hierarchy of spouse/partner, major child/children, parents, brother/sister etc) may obtain access to

confidential documents and / or third party information after the index patient' death. This can lead to severe post mortem repercussions regarding family dynamics. The ongoing good health of the patient should always be at the forefront when considering what information is provided and decisions made. The index patient requires a full picture of the consequences of confidentiality related decisions both on him or herself, as well as on the intimate relationships he or she is involved in and surrounded by.

### **9.5. Access to data after death – death certificates:**

The declaration of Geneva (as amended at Sydney 1968)<sup>103</sup> states:

*"I will respect the secrets which are confided in me, even after the patient has died."*

This viewpoint is not held by all authorities, and the subsequent codes of medical ethics generated by local and international bodies do not hold to this absolute secrecy code post-mortem. This is, in part, due to the increasing intermeshing of healthcare, insurance and commercial interests relating to the deceased party, as well as due to the interests of living descendants both in emotional and financial terms in the confidential data disclosed after death. In addition, the wishes of the deceased are often not clear. While the living may be considered as a 'person,' in philosophical terms, with all the attendant rights accruing to this status, the nature of duties to the dead are not as clear. The tension between utilitarianism and deontological thought, particularly as relates to outcomes regarding the dependants' well-being becomes almost unbearable in this setting. It is perhaps most useful to rank confidentiality duties to the living (relatives and family, however defined) as higher than ongoing duty to the dead. Thus, while not dismissing the ethical duties potentially due to the deceased, ethical duties to the living are seen as paramount, and not necessarily in conflict with duties to the dead. This approach allows one to deal with duties to both the living and the dead.

The issues relating to contractual obligations, insurance documentation and other financial contracts drawn up ante mortem and without substantial coercion have already been discussed. Other documentation relating to confidential medical documentation, particularly that which relates to HIV diagnosis and treatment protocols, may become available to living family members after the death of the patient. This is, however, not in any way absolute, as the proposed access through the Information Act does not guarantee carte blanche access to all information, and in particular, not to medical information.

In the matter of death certificates, another issue that has received much press and attention from medical staff in the public and private sectors, the new regulations on death certification, implemented in 1998, are of importance. Whereas previously the death certificate was a one page document stating cause and mode of death, the new certificate has two pages. The first page, (Appendix 12.10 Notification/Register of death/still birth page one), contains only demographic particulars, as well as an assessment from the attending physician regarding whether the death was caused exclusively by natural causes, or whether a post mortem is required as the assessment is one of non – natural causes requiring a post-mortem. Page two of the death certificate deals with detailed personal information regarding the deceased (often only obtainable by questioning relatives and friends and a potential source of breaching confidentiality in its own right), and lists a medical certification as to an immediate cause of death, as well as an underlying cause of death. (Appendix 12.11 Notification/Register of death/still birth page two). Much concern has been raised regarding these questions particularly regarding the ‘ethics’ of undertakers and others who would deal with the body, and thus with the information regarding the means of death. These issues should technically not enter the picture, regardless of pleas from undertakers, South African Police Services and other bodies who claim ownership of the body and the documentation. The second page of the document clearly states:

*“Information for medical and Health Use Only. (After completion seal to ensure confidentiality) “(Appendix 12.11 Notification/Register of death/still birth page two )*

Further, SAMA guidelines regarding this issue state that:

*“The second page is sent to the department of home affairs and is not to be given to any other person, not even a family member.”<sup>104</sup>*

Resolving the issue of protection of confidentiality in this respect, then, would seem to be a mechanical rather than an ethical one. Medical and paramedical staff need to be advised of the correct channels of communication, particularly regarding the second page of the death certificate, and materials need to be available to correctly seal the document, as well as ensure its unimpeded travel to the department of home affairs. (Access to courier services etc). Demands from the police services, undertaking services, and other interested parties (with diverse but mainly financial interests, for example the existence of a clause in a burial contract voiding the contract on confirmation of HIV + status) that the second page *must*

accompany the body need to be firmly dealt with by healthcare professionals, armed with the salient facts laid out above.

## **9.6. Electronic and other sources of medical data:**

Medical data is considered different to many other forms of data due to its intimacy, sensitivity and potential for use to stigmatise and discriminate against those to whom it refers. Current forms of data storage, generally paper based, and prone to their own forms of misuse and abuse, but less easily accessible in mass form, are giving way to various forms of increasingly accessible electronic databases. (As has been previously discussed, patients generally feel that the protection of paper data by physicians is well secured.) This has prompted responses to protect such media, such as the United States Health Insurance Portability and Accountability Act of 1996 (HIPPA).<sup>105</sup> While this legislation does not take effect until 2003, the Food and Drug Administration is currently implementing legislation (21 CFR (11))<sup>106</sup> in order to tie research use of such media to such exacting standards that, given current technology, the use of such electronic means of research data gathering<sup>107</sup> may prove impractical in the short to medium future.

While these proposed legal measures may temporarily delay the impact of privacy violations on research applications, the broader research community has already challenged the validity of the legislation.<sup>108</sup> Of more concern is the potential for violation of confidentiality resulting from the increasing use of electronic media in less secure environments, such as hospitals, private practices and other places where data (from basic demographic details to complete medical records) are accumulated. The ethical obligations of medical institutions are to ensure secure intranet facilities, with even tighter password controlled firewalls if systems to provide external access to data from off-site facilities are to be utilised. Integrity of data (issues of data ownership having already been discussed) is the central issue here. Should this security not be achieved, it could be argued that electronic data storage and access techniques should not be utilised until such time as this is attained. Further, the patient should be informed of all information to be kept in electronic and other formats, and be apprised of methods utilised to protect it.

## **9.7. Translators:**

The problems generated by multiple languages and dialects are not unique to the South African situation, but do pose a significant ethical dilemma as regards medical confidentiality

when requiring a medical history from a patient who does not speak the same language as the doctor. With ongoing constraints imposed by finance, few medical settings afford the luxury of paid and trained medical translators. This implies that translators (if available) are likely to be drawn from support staff, family and friends of the patient, other patients waiting to see the medical staff, and the “good Samaritan” passing by. This generates difficulty in assessing the quality of the information received, as well as the comprehension of the information given. It further generates ethical problems in that the information given and received is, by its nature, confidential, and the understanding of confidentiality by such ad-hoc translators cannot be assumed to be the same as those required of and understood by medical staff. Requesting permission to test for HIV and delivering HIV diagnoses in this scenario will seriously compromise confidentiality. What needs to be answered at an ethical level is whether the immediate need (or medium to long-term need if the language requiring translation is such that a translator is unlikely to be found in this time period) for HIV testing and/or diagnostic test disclosure is such that this test should be performed prior to the finding of a translator acceptable to the patient in terms of confidentiality.

### **9.8. The team approach to modern medicine:**

The modern approach to healthcare is increasingly moving from the one-on-one consult, with a single practitioner providing any and all healthcare needs, to an ever widening team becoming involved in caring for people, both in the in and outpatient settings. While this has undoubtedly led to an improvement in overall healthcare, with increased expertise being brought to bear on each individual case, and can also increase the holistic manner in which any one individual’s care is administered, it has ramifications for our understanding of medical confidentiality.

In a now classic case study, Siegler, on challenge by a patient regarding the limits of confidentiality he had been promised on admission to hospital, did an audit of those HCW’s who had access to, and who had to have access to the patients’ files in order to perform their tasks. The results were revealing:

<b>Type of Staff</b>	<b>Number</b>	<b>Staff Specifics</b>
HCW	18	6 attending physicians; 12 house Officers
Professions allied to	11	6 respiratory therapists; 3

Medicine		nutritionists; 2 clinical pharmacists;
Nursing Staff	20	3 shifts
Students	15	Medicine; nursing; respiratory therapy; clinical pharmacy
Secretaries	4	General
Financial Auditors	4	Hospital financial officers; chart
Reviewers	4	reviewers; Quality and Audit
	4	Controllers
<b><u>TOTALS</u></b>	80	Diffuse staff Complement

Siegler points out that this patient was relatively uncomplicated as regards requirement for intensive intervention by multiple medical and other disciplines, and did not require multiple technical interventions, which would have made this number of health professionals having access to his confidential information even larger. The question posed here is whether the patient's interests in maintaining confidentiality at a one-on-one level, is sufficient reason to compromise his or her access to the best possible healthcare as offered by the team approach of modern times. As the team expands, the potential for improved care may increase, but the reality of the loss of confidentiality also expands. The patient and the health care provider need to be aware of situations requiring informed decisions regarding the optimising of healthcare and the protection of medical confidentiality.

### **9.9. Health Care Worker Indiscretionary Behaviour:**

The revealing of confidential information by HCW and support staff in non – medical settings has already been alluded to. Why it deserves mention in its own right is the ongoing and avoidable breaching of sensitive information which occurs between staff members in and out of healthcare facilities. This includes the discussion of patient confidential data in hospital meeting rooms, waiting rooms, and the infamous “corridor consult”. This may be inadvertent, and may also relate in part to the already identified discrepancy between what HCW's and patients consider to be confidential.

A recent Mail and Guardian article<sup>109</sup>, simultaneously identifying “broken confidentiality” as the most common problem cited by patients at state institutions, focussed on this problem of indiscretion. While certain of the problems identified were seen as mechanical – with inadequate space and conditions existing to facilitate privacy, many other issues related primarily to insensitive and “rude” behaviour at the hands of the HCW's.

This concept is also addressed by Siegler, who reiterates the points above, citing Percival's Code of Medical Ethics of 1803, including the following admonition:

*“.Patients should be interrogated concerning their complaint in a tone of voice which cannot be overheard.”<sup>110</sup>*

The dignity of the patient and the recognition of that dignity by the HCW are at the core of this issue. While the concept of discussion and intra-colleague consultation regarding difficult medical and / or social cases may be considered vital to the practice of modern medicine, what an ethical approach to this requirement needs is a simple consideration of such dignity.

## **10. Research Interests:**

The myriad of issues surrounding research involving human subjects (prospective and/ or retrospective) has spawned a multitude of guidelines to attempt to control this enormous industry. Of these, the International Harmonised Guidelines on Good Clinical Practice,<sup>111</sup> based on various declarations, most recently the declaration of Helsinki (whether the 1996<sup>112</sup> amendment or the 2000<sup>113</sup> amendment is followed), are the most commonly adhered to in the developed world, in the design and implementation of clinical research protocols involving human subjects. What is concerning is that, although the number of guidelines continues to multiply, measures to protect patient confidentiality seem to fade further from the picture as the protection of sponsoring companies become tighter.

Two issues are of primary concern. The first relates to the unblinding of clinical protocols in the so-called “roll-over protocols” providing life saving medication on contract to the patient, but at the expense of the same patient's anonymity. This would seem a “catch 22” situation, as South Africa's laws do not permit access to unregistered medication on a non-named patient basis (section 21 registration). It does, however, fly in the face of anonymity contracts signed on entry to the trial. Said contracts also guarantee access to drug, generally until the test drug is available / licensed in the country of testing. The access to HIV information specifically by name can have serious ramifications, as has already been discussed. It is also a violation of trust to change confidentiality agreements half way through a trial process, damaging the trust between clinician and patient. The informed consent process in clinical trials requires focus on the specifics of who exactly (named) will have access to clinical data in the form of source documentation and clinical research documentation.

The second issue is of perhaps more concern. While the first relates to a “post-protocol” situation (always a grey area in trial work), the second relates to the maintenance (by regulatory requirement) of a named patient register in the investigator file of each trial. This is not a blinded document, and has value in the event of later down the line having to track the whereabouts of trial subjects. However, as the data available to trial monitors, trial sponsors and/ or both internal and external auditors, it represents a breach of confidentiality to which the patient cannot possibly consent. This is arguable in that the patient cannot specifically know who will have access to his or her records, and therefore cannot give specific consent to record access by named individuals, and yet all consent forms for trial protocols guarantee anonymity. In that the patient cannot know who will have access to these records; the informational aspect of informed consent cannot be fulfilled. It may then be argued that such documents may cause the informed consent procedure to be flawed, if not null and void. In essence then, the trial procedure, while seemingly securing a high level of confidentiality fails to do so. This makes a mockery of the entire process of ICH/ GCP. A discussion with an auditor from PHARMOVS, South Africa’s foremost clinical trial auditing firm, failed to resolve this issue, but it was agreed that the conflict existed and needed resolution.

## **11. Defending Confidentiality:**

The preceding discussion illustrates the importance of confidentiality and hence the need to protect it. The concept is a complicated one, and while all may not agree on its definition, such definition would need to take cognisance of the following in the field of HIV

1. Individual versus Social Harms
  - a. Risks of HIV transmission
  - b. Risks to HIV positive patients on disclosing their HIV status
  - c. Disclosure of HIV status altering serostatus and / or risk taking behaviour
2. Trust and Fidelity Requirements of Doctor- Patient Relationships
  - a. Patient perceptions of trust, fidelity and confidentiality
  - b. The unconscious/ semi – conscious or demented patient
3. Third Party Interests
  - a. Funders of health care costs
  - b. Insurance Costs
  - c. Access to databases (electronic access etc)
  - d. Doctors' Managed Care Companies
  - e. Access to information by other members of family and friends
  - f. Access to data after death – particularly death certificates
4. The Modern Team Approach to Modern Medicine
  - a. Translators
  - b. Health Care Workers indiscretionary behaviour
  - c. Research interests

It has been argued that all attempts to define and redefine confidentiality are little more than attempts to provide patches over the inevitable conclusion that, although we highly value this concept, we fail to identify it in terms which are practically applicable in the modern approach to medical care. The history of medical ethics moving from paternalistic models to patient autonomy models also plays a role in this conflict. What seems necessary is not a discarding (whether total or partial) of the concept of paternalism, nor a return (if this was, in fact, ever a reality) to an absolutist viewpoint on paternalism, but a frank look at the realities of medical practice both past and present, as well as more explicit inclusion of the patient in a definition which, after all, belongs to, and is designed for his or her protection. This new approach to medical care, based more on autonomy than on paternalistic principles, may offer a realistic

viewpoint on confidentiality, inclusive of the interests and needs of both health care professionals and patients.

*Confidentiality, then, is here defined in terms of a contractual agreement between doctor and patient. This includes the informational provision of all the issues complicating confidentiality, as outlined above. It involves an interactive relationship with the patient, which initially brings both patient and clinician to a mutual understanding of “confidentiality”, and what each expects of the other in this regard. At this point it should also be explained how, for example a medical healthcare team, though aware of a diagnosis, would protect the confidentiality of that diagnosis. Grounds for approaching others with the diagnosis (i.e. violating confidentiality) should be agreed to, if possible, in writing. The process should be ongoing, and interactive.*

*In the case of the unconscious or demented patient, this is not possible. However, the call for a “substituted judgement” can also be, as discussed previously, an impossible dilemma to resolve. If the patient requires emergent intervention, the risk: benefit assessment may require violation of confidentiality even if this renders potential harm to the family and society. If the intervention can wait, or the HIV aspect (testing, counselling, etc) can be delayed, the patient can possibly engage in the process as described,*

*What is important is that the physician realises the importance of patient involvement in the process as an equal decision maker regarding how the management of the confidential aspects of the patient’s healthcare is to be achieved, and how this management can be either positively contributory or detrimental to his or her healthcare, as patient and clinician manage the confidentiality issues.*

## **12. Guidelines for drafting a facility confidentiality policy:**

In the South African National Department of Health Antiretroviral Operational Plan, accreditation of Antiretroviral sites providing antiretroviral agents requires, as a minimum entry criterion, the presence of a confidentiality policy<sup>114</sup>.

In drafting facility-specific policy regarding confidentiality, the complex nature of the topic must be taken account. No policy can read as a simple check-list of requirements, taking no account of individual situation requirements. Instead, such a policy should serve as a guideline for clarifying decision-making, and as a guide to ethical behaviour.

This guideline has two components:

12.1: Procedural elements for drafting a confidentiality policy.

12.2: A policy template for use in creating and implementing facility specific documents

### **12.1. Procedural elements in drafting a facility-specific confidentiality policy:**

12.1.1: The facility must have a written confidentiality policy relating protection of confidentiality within the healthcare-worker: patient relationship.

12.1.2: Policy should be drafted by a facility staff and patient committee, including appropriate community representation. This committee should preferably be under direct supervision of a bioethicist or bioethical committee. If a bioethicist is not directly available, review of draft policy by a bioethicist should be sought.

12.1.3: Policy input should include representation from as wide a spectrum of involved community and staff as is feasible (either as members or via wide dissemination of a draft policy for written comment.)

12.1.4: The policy should be a “living document”, reviewed formally at least annually.

12.1.5: Policy should specify nature, extent and practical implementation of training for healthcare workers as regards policy understanding and implementation.

12.1.6: Policy should specify communication of policy contents to staff and community.

12.1.7: The policy should be distributed to each staff member, and be available for distribution to any individual patient or patient caregiver requesting it.

12.1.8: The policy should be made available to the general public in the most accessible forum available to the facility (bulletin boards, posters, open meetings etc)

12.1.9: The policy should be implemented in all areas of the facility.

## 12.2. Policy template for use in creating and implementing facility specific confidentiality policies:

**Name of Facility**

### **Draft policy regarding healthcare-worker: patient confidentiality in the facility**

**Policy no:** \_\_\_\_\_

**Date issue:** \_\_\_\_\_

**Revision date:** \_\_\_\_\_

**Drafted by:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Authorised by:** \_\_\_\_\_ **Date:** \_\_\_\_\_

*This policy amends/ replaces policy no. of:* \_\_\_\_\_

A policy on the ethical management of confidentiality issues between healthcare-workers and patients should include the following:

#### **12.2.1 Purpose of the policy:**

Confidentiality between healthcare-workers and patients is uniformly seen as a cornerstone of biomedical care. In the modern team-based healthcare environment, a new understanding of the nature and implementation of confidentiality is required in order to preserve this essential facet of excellence in care.

Confidentiality should be defined in terms of the interactions between the healthcare team and patient, and, where necessary, the family and patient support team.

Staff should be informed regarding facility confidentiality policy. These staff should be trained with regard to making ethical decisions as pertains to confidentiality. Patients and caregivers should be informed regarding facility confidentiality policy.

### **12.2.2 Ethical Standards:**

The tensions between human rights and public health considerations in making ethical decisions regarding confidentiality need to be taken into account, accepting that neither stance presents all the answers in any given situation, and that the principles of patient autonomy and justice should inform both definition and implementation decisions

Current and updated legislation should form part of the living policy.

Referral pathways to bioethical support, as well as ethics review boards ruling on ethical principles should form part of the policy.

### **12.2.3: Ethics Committee / Bioethical Support:**

The access to bioethical support and/or an ethics committee should be stipulated. The composition of such a committee, including qualifications and experience should be recorded.

### **12.2.4: The team approach to modern medical care:**

The policy should outline the practicalities of the multidisciplinary team involvement in individual patient care. Policy should specify that both staff and patients (and, as necessary, patient support teams) should be made aware of the multidisciplinary team approach, and of the vital nature of team-based confidentiality to the practice of quality healthcare. Further, and as far as is possible, patients should be made aware of the make-up of such team(s), and the individual healthcare professionals comprising the team who will have access to the confidential information, and the extent of such information. The ideal is for patients to be introduced to individual members of the team.

### **12.2.5: Breaches of Confidentiality:**

The policy should define the nature of a breach of confidence, of the severity of every such action, and how every attempt will be made to preserve confidentiality. Breaching confidentiality should be viewed in a serious light, in terms of costs as well as potential benefits to patients, society and healthcare-worker: patient dynamics.

12.2.5.1: Attempts to preserve confidentiality should be undertaken at all times by all members of the healthcare team.

12.2.5.2: Situations in which there are high risks of unavoidable breaches of confidentiality should be identified in order to obviate the need for unnecessary breach, and to place prospective plans in motion to consistently deal with breaches when these are unavoidable. These areas should be defined and highlighted in ongoing education for all members of the healthcare team.

Such situations will include at least the following:

- Healthcare Worker occupational injury and HIV exposure
- When patients' perceptions of trust, fidelity and confidentiality are undermined
- The unconscious/ demented patient
- When third party interests are prominent; for example the interests of
  - funders of healthcare costs
  - insurance companies
  - managed care groupings
  - members of family and friends
  - those who require access to data after death (death certificates etc)
  - those using electronic and other sources of data
  - translators
  - other members of the health care team in modern medicine
- when there is indiscretionary behaviour by health care workers
- In the presence of research interests

12.2.5.3: Proposed breaching of confidentiality should be discussed (anonymously if necessary) with other members of the healthcare team, and, wherever possible, with senior staff. Facility management should, as a matter of policy, ensure that mechanisms exist for emergency and elective consultation with appropriate senior staff in these settings. If possible and viable, formal bioethical input on an emergency basis should be provided.

12.2.5.4: Breaching confidentiality should only be undertaken in “unavoidable” situations, be clearly reported in writing, and must be justifiable in terms of the specific situation and problem arising. Breaching confidentiality should be viewed as an “adverse event”, and should be subject to specific facility adverse reporting policy and implementation procedures.

12.2.5.5: Access to a review committee (and preferably a trained bioethicist) should be provided to allow for the discussion of issues of confidentiality and breaches of confidentiality to be openly discussed without prejudice. Policy should ensure that mechanisms for such discussion forums are available and implemented.

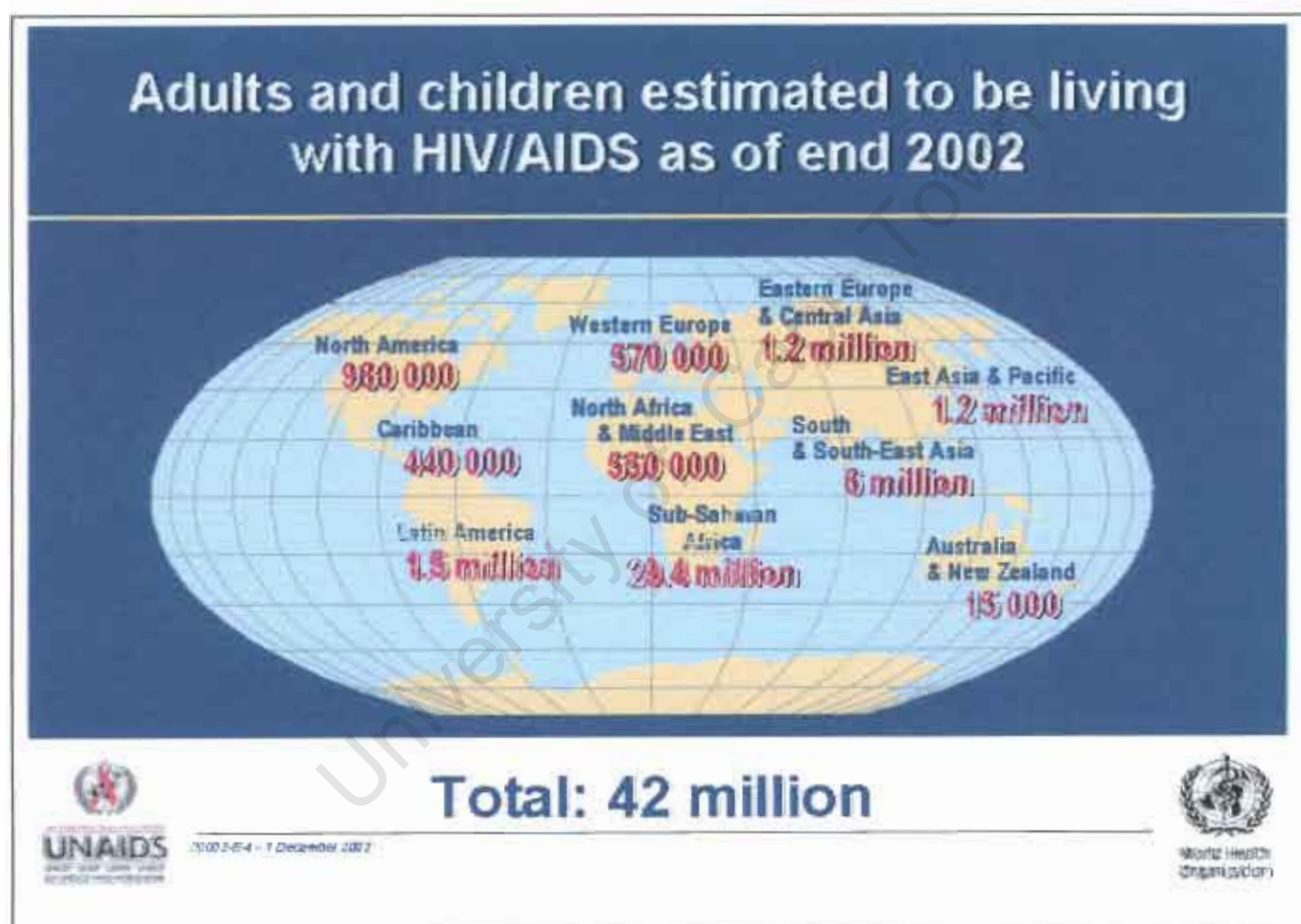
12.2.5.6: Where confidentiality is breached gratuitously, and/or in violation of facility policy, provincial and national norms and standards, as well as national legislation, a mechanism should be in place to allow for full investigation of the event, and the provision of disciplinary action as necessary.

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Designation:** \_\_\_\_\_

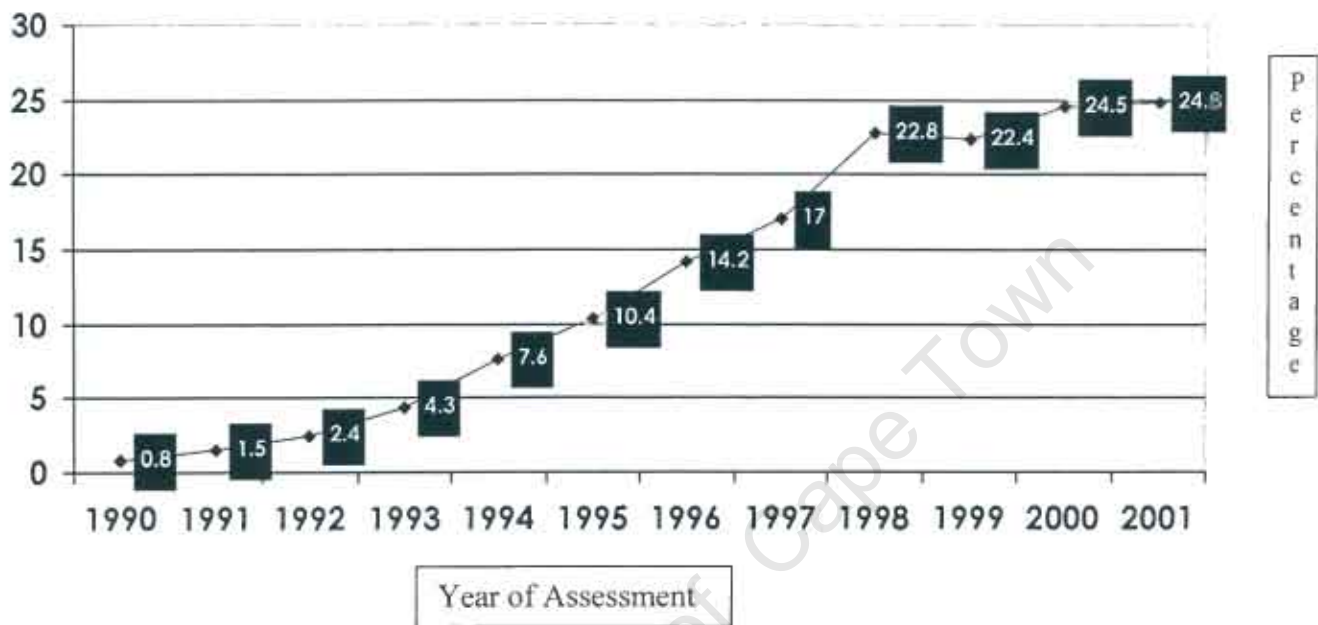
## 13. APPENDICES

### 13.1. UNAIDS Global estimates of People Living with HIV – end 2002

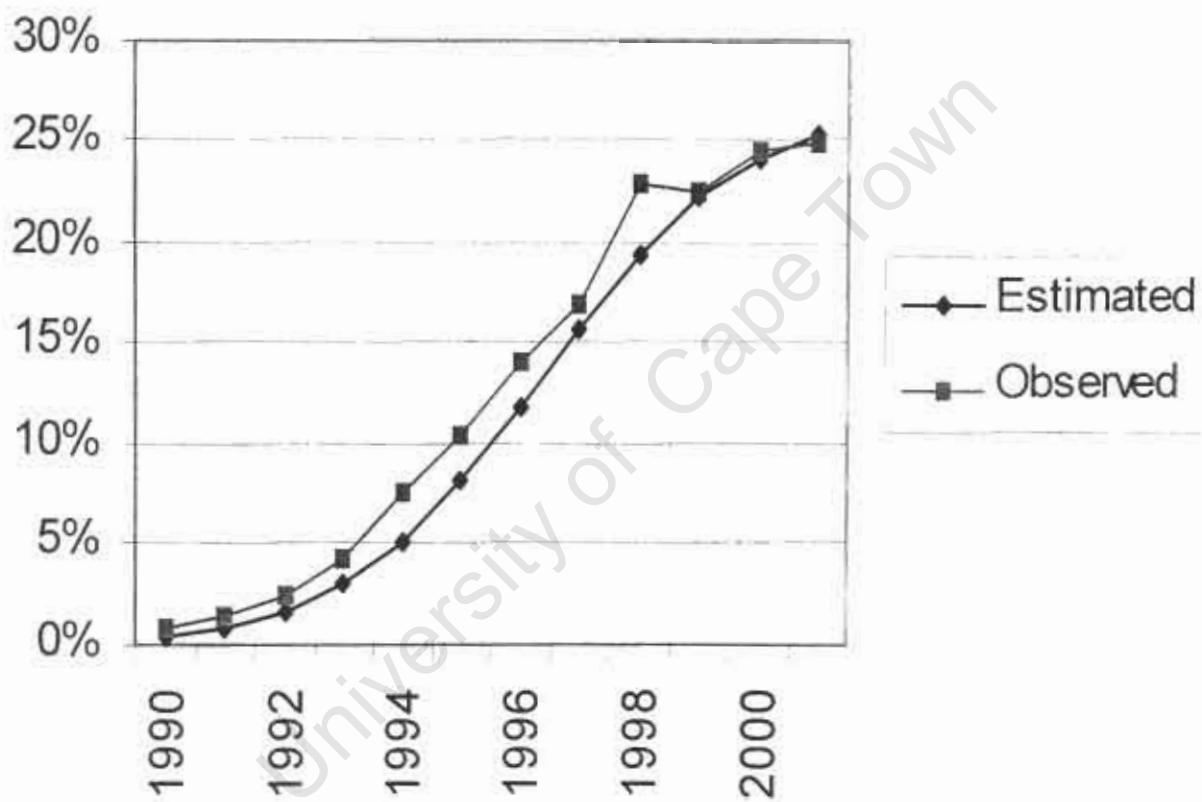


### 13.2. Antenatal Clinic Data – South African State Antenatal Clinic

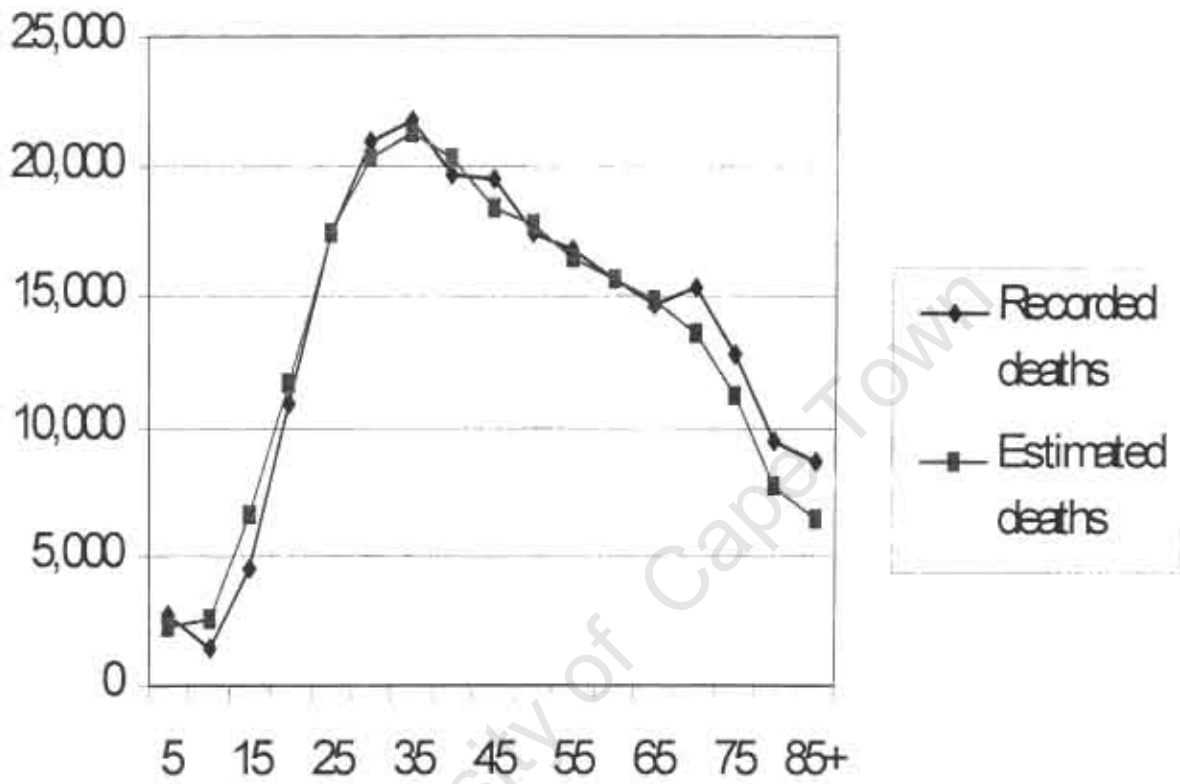
#### Figures



**13.3. ASSA 2000 Model projections with overlaid observed data**  
**– Antenatal Clinic HIV prevalence South Africa 1990 to 2000**



**13.4. ASSA 2000 Model – Projected male deaths 1999/2000 with overlaid observed data as taken from death certificate sources**

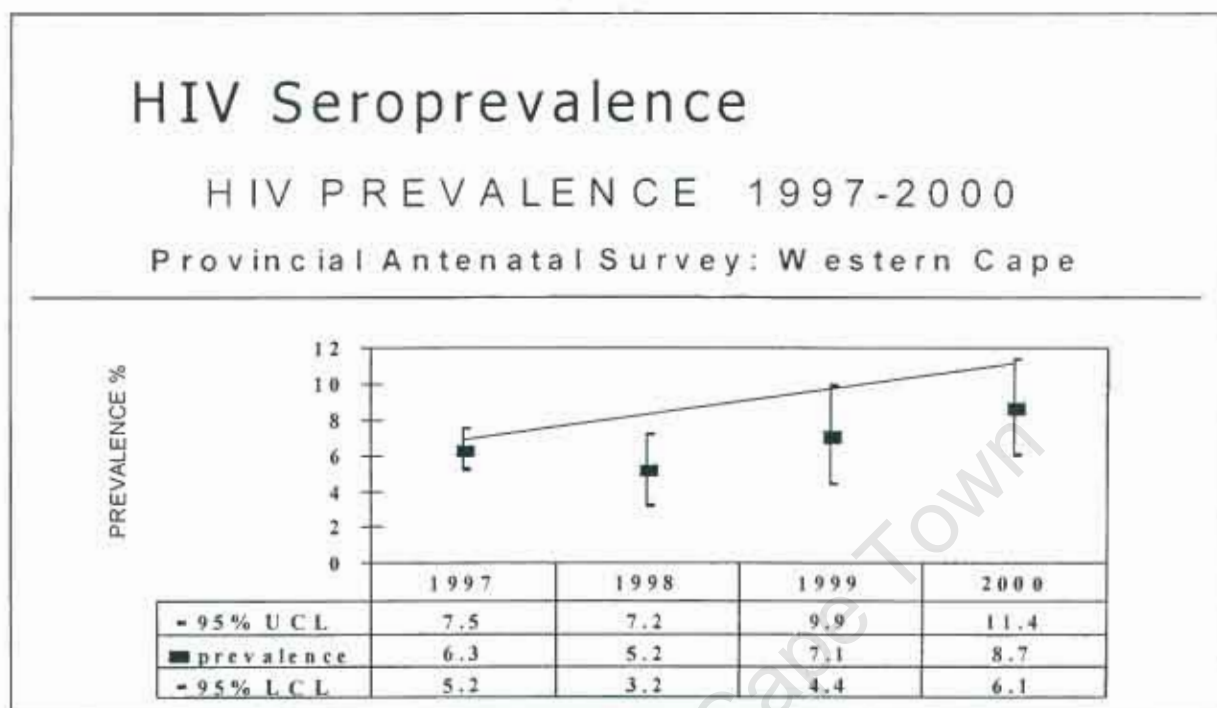


### 13.5. HIV % Prevalence by Province – 1997 – 1999 (estimates)

Province	Est % 1997	Est % 1998	Est % 1999
KwaZulu Natal	26.9	32.5	32.5
Mpumalanga	22.6	30.0	27.3
Free State	20.0	22.8	27.9
Gauteng	17.1	22.5	23.9
North West	18.1	21.3	23.0
Northern Province	8.2	11.5	11.4
Eastern Cape	12.6	15.9	18.0
Northern Cape	8.6	9.9	10.1
Western Cape	6.3	5.2	7.1
National	17.04	22.8.	22.4

### 13.6. HIV Seroprevalence 1997 – 2000 Western Cape

Source : Dr F. Abdullah, Provincial Administration of the Western Cape



(personal communication – data Provincial Administration of the Western Cape)

#### **Key :**

This bar and whisker graph represents actual prevalence assessments performed in various municipal districts. The solid bars represent the prevalence assessed, and the whiskers the upper and lower confidence limits of the data.

95 % UCL – 95% Upper Confidence Limit

95% LCL – 95% Lower Confidence Limit

## **13.7. Draft Response : Medical Staff Issues regarding HIV / AIDS at the Jooste Hospital**

Professor S.R Benatar (Head Dept Medicine University of Cape Town and Groote Schuur Hospital / Head Bioethics Unit University of Cape Town)

During several visits to discuss ethical issues in medicine at the Jooste Community Hospital the staff have presented many of the dilemmas they face in relationship to the escalating HIV / AIDS pandemic. It is clear that currently the individual approach of doctors to these problems in the absence of defined policy is creating considerable distress both for individual practitioners themselves – most of whom are young and carrying great responsibility, but also for their patients and families whom they see struggling to deal with HIV / AIDS in the context of denial at many levels.

It is clear to me that it is necessary to draft a policy covering many of the issues that have been raised in order to facilitate the development of a coherent, accountable and consistent approach to such problems.

A brief listing of the problems which have been raised with me follows :

1. Approximately 30% of patients in the medical beds are HIV positive. Between 5 and 10% of patients in the surgical beds are also HIV positive. The difference in incidence reflects the different demographics of the patients in these areas of the hospital.
2. Within the cohort of patients who are HIV positive, almost 90% are black, with approximately 10% being from the coloured population group. This is anecdotal information and not an accurate statistic so it needs to be reviewed cautiously. However, it reflects the view that HIV positive patients are overwhelmingly Black Africans.
3. Although many patients die of AIDS-related diseases, this is never indicated on death certificates. Death Certificates are therefore inaccurate and those who handle the body are potentially exposed to infection without being aware of this. I presume that universal precautions are taken by undertakers to protect themselves. In the absence of a Code of Professional Conduct requiring undertakers to preserve confidentiality it would seem inappropriate to inform them of the deceased's HIV status. However, there is the dilemma of not placing accurate information on death certificates and this concerns many medical practitioners who believe that honesty in filling out a death certificate is required of them as a responsibility to society and to those who use mortality data for public health reasons.

4. Communicating with families about HIV / AIDS is a major problem. A large number of children are admitted who are either HIV positive or who have AIDS related diseases. There is often reluctance to communicate this information to the mother. Where such information is communicated mothers generally do not wish the information to go beyond them to other members of the family despite the implications this might have for other family members. Similarly there is difficulty in informing spouses about partners' positivity. This presents itself in two forms

- a. When one partner in Cape Town brings in a partner from another part of the country to Cape Town for medical attention and the partner is found to be HIV positive but does not wish their local spouse to know this.
  - b. When the local person is ill, brings the spouse to Cape Town from elsewhere to look after him / her, but does not wish the spouse to know the HIV status.
- Under all these circumstances medical and nursing staff in the hospital are gravely concerned about their responsibility to be frank and open with patients and to discuss with them and their families the implications of the disease.

5. Young girls over the age of 14 years are able to give legal consent for termination of pregnancy. However, it is not until they are 18 that they are able to give consent for HIV screening. This poses a problem in doing HIV screening on pregnant girls between the ages of 14 and 18 years.

6. A further problem relates to dealing with confused patients. Here it would be ideal to know the HIV status as the management of the confused patient who is HIV positive is significantly different due to the different differential diagnosis under these circumstances. For example, most HIV negative patients who are admitted in a state of confusion are either postictal, suffering from alcohol abuse or occasionally suffering from organ failure eg uraemia. No CT scan of the head or lumbar puncture is required in these patients.

In patients who are HIV positive the cause of confusion is usually an intracranial problem such as tuberculosis, meningitis, cryptococcal meningitis or toxoplasmosis. Here CT scan and lumbar puncture are essential for appropriate therapy. If the HIV status is unknown, then many more patients are subjected to CT scanning and lumbar puncture than necessary.

7. The final problem relates to insurance companies requesting information regarding the person's illness after he or she has died and a claim has been placed with the insurance company.

This brief outline serves to illustrate the need for systematically thinking through how these problems should be dealt with. Formulating a policy that can be made public and debated with those involved seems essential.

We suggest that such a policy be developed pursuant to the model employed by Groote Schuur Hospital to formulate a policy for rationing scarce ICU resources. The goal of the policy would be first to ensure the best possible treatment for the patients, given resources available; and second, within legal and ethical parameters, to provide information that families and the broader community need to allow them to deal with both the patient's medical and emotional needs and with the possible impact on family and community's health.

The first step would be to appoint a Joint Committee consisting of participants from the Jooste Hospital staff and the UCT bioethics centre (the latter would include several ethicists plus a member of the UCT law faculty). The Joint Committee would carry out the following tasks with the assistance of hospital personnel :

1. Collect facts and data relating to the above matters and canvass the practices and attitudes of hospital staff about how these issues are presently being handled and how they might be resolved;
2. Research the literature relevant to the legal, ethical and public health issues and develop principles and criteria for use at the Jooste Hospital, and develop an outline of a proposed policy for resolving the issues;
3. Present the proposed policy to peer groups within and outside the hospital, as well as to a group involving representatives of the effected public and seek comments, critiques and recommendations (an article should be submitted for publication in a medical journal); and
4. Finalise the detailed version of the policy and submit it for approval to hospital and government authorities.

Following this process will help to ensure that the resulting policy is medically, ethically and legally justifiable and that it has been developed in a far and transparent fashion.

## **13.8 WHO Staging System for HIV infection and disease in adults and adolescents**

### **Clinical Stage 1:**

1. Asymptomatic
  2. Persistent Generalised Lymphadenopathy
- Performance Scale 1: asymptomatic, normal activity

### **Clinical Stage 2:**

3. Weight loss, 10% of body weight
  4. Minor mucocutaneous manifestations (seborrheic dermatitis, prurigo, fungal nail infections, recurrent oral ulcerations, angular cheilitis)
  5. Herpes zoster within the last five years
  6. Recurrent upper respiratory tract infections (i.e. bacterial sinusitis)
- And/or performance scale 2: symptomatic normal activity

### Clinical Stage 3:

7. Weight loss, >10% of body weight
  8. Unexplained chronic diarrhoea, >1 month
  9. Unexplained prolonged fever (intermittent or constant) >1 month
  10. Oral candidiasis (thrush)
  11. Oral hairy leukoplakia
  12. Pulmonary tuberculosis within the past year
  13. Severe bacterial infections (i.e. pneumonia, pyomyositis)
- And/or performance scale 3: bedridden <50% of the day during the last month.

### Clinical Stage 4:

14. HIV wasting syndrome: weight loss >10% of body weight, plus either unexplained chronic diarrhoea (>1 month) or chronic weakness and unexplained prolonged fever (>1 month)
15. Pneumocystis carinii pneumonia
16. Toxoplasmosis of the brain
17. Cryptosporidiosis with diarrhoea >1month
18. Cryptococcosis, extrapulmonary
19. Cytomegalovirus disease of an organ other than liver, spleen or lymph nodes
20. Herpes simplex virus infection, mucocutaneous >1month or visceral any duration
21. Progressive multifocal leukoencephalopathy
22. Any disseminated endemic mycosis (i.e. histoplasmosis, coccidioidomycosis)
23. Candidiasis of the oesophagus, trachea, bronchi or lungs
24. A typical mycobacteriosis, disseminated
25. Non-typhoid Salmonella Septicaemia
26. Extrapulmonary tuberculosis
27. Lymphoma
28. Kaposi's Sarcoma
29. HIV Encephalopathy clinical findings of disabling cognitive and/or motor dysfunction interfering with activities of daily living, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection which would explain the findings.

**13.9. Received February / March 2002 - Identifying names removed**

**AUTHORISATION TO RELEASE CONFIDENTIAL PRACTICE DATA**

**Dear Sir**

*I, \_\_\_\_\_, ID Number \_\_\_\_\_, am a registered or prospective shareholder of LTD IPA.*

**I HEREBY AUTHORISE TO UNDERTAKE ON MY BEHALF, THE FOLLOWING:**

1. To obtain extracts of the data generated by my practice, from any or all of the following sources;
  - Copies of scripts (or any other written form of such script data)
  - data transport companies, including
  - databases which store data generated by my practice, including those operated by
  - various software houses, medical aid schemes, or medical consulting firms managing such data on behalf of such schemes
  - any other source through which my data may be housed.
2. To utilize that data and/or statistical extracts at the discretion of for the purposes of:
  - Peer Review
  - Research
  - Sale to interested parties
  - Any other purpose, which the Board of Directors may decide upon.

To store that data on a central database approved by the Board of Directors, which undertakes to implement such reasonable measures as necessary to prevent unauthorised access to my data.

I understand:

that in actioning the above, will honour my commitment to patient confidentiality, always utilize the authority I have vested in them in a manner which is ethical and above reproach.

- that I will at all times have access to information from , relating to all companies and other legal persona receiving or utilizing my data.
- that income streams generated from the side of my practice data shall accrue to me after deduction of expenses, and in accordance with the directive from the BOD.

***This authority revokes any previous authority issued to any Doctors Group (other than ) prior to the date reflected hereon, and in respect of any data source mentioned above, Should I at any stage wish to withdraw the above authority vested in , I will do so in writing directly to , who will be obliged to honour this with immediate effect.***

**SIGNED:** \_\_\_\_\_ **DATE:** \_\_\_\_\_  
**PRINT NAME:** \_\_\_\_\_ **HPCSA No** \_\_\_\_\_

**LOCAL IPA:** \_\_\_\_\_ **(SAMDC)**

**WITNESS:** \_\_\_\_\_ **PR No. (ALL)**  
 \_\_\_\_\_

**TO BE COMPLETED BY EVERY INDIVIDUAL DOCTOR IN EVERY PRACTICE,  
 INCLUDING ASSISTANTS.**

University of Cape Town



## Appendix 13.11 Notification/register of death/still birth page two

## NOTIFICATION / REGISTER OF DEATH / STILL BIRTH

BI - 1663

INFORMATION FOR MEDICAL AND HEALTH USE ONLY

Page 2

(After completion seal to ensure confidentiality)

Space for Bar Code

SERIAL No:

A 01 546994

FILE No: DATE:

## F DEMOGRAPHIC DETAILS

Initials and Surname of deceased Identity Number Place of death 1. Hospital: (Inpatient  ER/Outpatient  DOA  ) 2. Nursing Home  3. Home  4. Other (Specify) 

FACILITY NAME (If not institution, give street and number)

Usual residential address of deceased #  Suburb Town / Village Name of Plot, Farm, etc.  Census Enumerator Area Street name and number  Magist. Dist. Deceased's Education (Specify  only highest class completed/achieved)

None	Gr1	Gr2	Gr3	Gr4	Gr5	Gr6	Gr7	Gr8 Form 1	Gr9 Form 2	Gr10 Form 3 NTC1	Gr11 Form 4 NTC2	Gr12 Form 5 NTC3	Univ Tech	CODE	Postal Code <input type="text"/>	Province <input type="text"/>	Country <input type="text"/>
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USUAL OCCUPATION OF DECEASED (give type of work done during most of working life. Do not use retired)

TYPE OF BUSINESS / INDUSTRY (e.g. Mining, Farming) refer to instructions

Was the deceased a smoker\* five years ago? (  ) : Yes  No  Do not know  Not applicable (minor) 

## G MEDICAL CERTIFICATE OF CAUSE OF DEATH

PART 1. Enter the disease, injuries or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock, or heart failure. List only one cause on each line.

IMMEDIATE CAUSE (Final disease or condition resulting in death) a.  Due to (or as a consequence of) Sequentially list conditions, if any, leading to immediate cause. Enter UNDERLYING CAUSE last (Disease or injury that initiated events resulting in death) b.  Due to (or as a consequence of) c.  Due to (or as a consequence of) d.  Due to (or as a consequence of) PART 2. Other significant conditions contributing to death but not resulting in the underlying cause given in Part 1. If a female, was she pregnant 42 days prior to death? (  ) : Yes  No If stillborn, please write mass in grams Do you consider the deceased to be: African  White  Indian  Coloured  Other  (Specify) 

Method of ascertainment of cause of death:

1. Autopsy  2. Opinion of attending medical practitioner  3. Opinion of attending medical practitioner on duty 4. Opinion of registered professional nurse  5. Interview of family member 6. Other  (Specify) 

FOR OFFICE USE ONLY

ICD-10

# Where someone lived on most days

\* Someone who smokes tobacco on most days

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