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Muskat-Gorska, Zuzanna

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PRIVACY, SURVEILLANCE AND HIV/AIDS IN THE WORKPLACE: A SOUTH AFRICAN CASE STUDY

Zuzanna Muskat-Gorska

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Supervisor: dr Andries Bezuidenhout

Research report

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DRAFT OF CONTENTS

1. Chapter 1: Introduction 6

1.1 Concerns 6

1.2 Research Problem 8

1.3 Research Objectives 8

1.4 Scope of the Study 9

1.5 Significance of the Study 10

1.6 Methodology 10

1.1.2.DataCollection 11

1.1.3.Data Management 15

1.1.4.Confidentiality 15

1.7 Outline of Chapters 15

2. Chapter 2: (Medical) data protection in the workplace -Theoretical considerations 17

2.1 Introduction 17

2.2 New surveillance 17

2.3 Medical surveillance 19

2.4 Workplace - Surveillance as power 20

2.5 Privacy and HIV/AIDS in South Africa 20

2.6 Summary 25

3. Chapter 3: The Right to Privacy, Medical Privacy and Confidentiality of HIV/AIDS status in South Africa – Legal aspects *26*

3.1 Introduction 26

3.2 Data privacy international regulation 26

3.3 Data privacy national regulation 30

3.4 Data privacy in South Africa *31*

3.5 South Africa – privacy rights record 37

3.6 Summary 38

4. Chapter 4: South Africa - HIV/AIDS Information in the Workplace 39
4.1 Introduction 39
4.2 Corporate and trade unions‘ response to HIV/AIDS in South Africa 40
4.3 HIV/AIDS policies of 3 South African companies 43
4.4 Summary 46
5. Chapter 5: HIV/AIDS Workplace Management and Confidentiality Issues in South Africa – interviews 48
5.1 Introduction 48
5.2 Interviews with trade union representatives 48
5.2.1 Discrimination *48*
5.2.2 Perceptions of confidentiality *51*
5.2.3 Getting tested - Outsourcing/internally *52*
5.2.4 Data treatment as a trade union issue *54*
5.3 Interviews with business representatives 54
5.3.1 The interest of the employer in the workers‘ HIV/AIDS data *55*
5.3.2 Insourcing/outsourcing of HIV/AIDS management *56*
5.3.3 Interest of providers in confidentiality safeguards *58*
5.4 Summary 59
6. Chapter 6: Discussion of the Findings 61
6.1 Introduction 61
6.2 Space for cooperation 62
6.3 Form of HIV/AIDS workplace management and confidentiality 63
6.4 Data treatment as a workplace issue 64
5.5 Recommendations 66
Bibliography: 68

Annexes

- interview with COSATU HIV/AIDS Coordinator 12.11.07.
- interview with NUM HIV/AIDS Officer 13.11.07.
- interview with NUM HIV/AIDS Coordinator 19.11.07.
- interview with NUM Eskom Coordinator 19.11.07.
- interview with NUM Anglo American Coordinator 19.11.07.
- interview with the SABCOHA representative, 19.11.07.
- interview with Qualsa representative, 30.11.07.
- interview with Lifeworks representative, 03.12.07.
- interview with AIDS Law Project Attorney 04.12.07.
- interview with Aurum representative 05.12.07.

Abstract

The study focus on socio-legal dimension of medical data surveillance in the workplace on the example of the South African workplace response to HIV/AIDS. The strating point is the problem of growing data gathering and monitoring as an institutional feature of the information/surveillance society. Studying the problem in the context of workplace aims at indicating possibilities for social partners to respond to the new developments in the area of workplace surveillance and HIV/AIDS management in particular. The empirical data has been drawn from document analysis and interviews with trade union and business representatives from South Africa, involved in developing workplace response to HIV/AIDS. Particularly, the study is interested in identifying ways in which trade unions can make personal data treatment a trade union issue.

1. Chapter 1: Introduction

1.1 Concerns

The starting point of this study was my interest in data privacy and surveillance in the workplace. It is fascinating (and also alarming) to observe new developments in this area, which only yesterday would have seemed more like ideas for science fiction movies. Nevertheless, it is not fiction anymore. Just to bring two recent examples:

- In February 2008, an Ohio video surveillance company, CityWatcher.com, has embedded silicon chips into two of its employees. The chips are planted in the person's upper right arm and "read" by a device similar to a card reader. The company says it is testing the technology as a way to limit access to a security area.[1]
- In January 2008 Microsoft filed a patent application for a new computer software that can monitor the employees' performance and state, by means of wireless sensors linking workers to their computers. The system is capable of measuring employees' movements, heart rate, blood pressure, brain signals, body temperature or face expression and can even "automatically detect frustration or stress in the user".[2]

These are the new workplace surveillance issues trade unions (among other organizations concerned with on-job privacy) have to deal with.

New technologies obviously play a crucial role in these developments. However, it does not mean that they do not take place in the developing world. Transfer of digital technology is nowadays cheap and instant. For instance, in South Africa, where

[1] EPIC (2008) "U.S. Company Implants Chips Into Two Employees" (13.02.08). In 2004, the Food and Drug Administration approved the use of an implantable computer chip for health care information applications. Called the VeriChip, it is a radio frequency identification (RFID) device about the size of a grain of rice. For more information, see EPIC's radio frequency identification (RFID) pages and VeriChip pages. http://epic.org/privacy/medical/ [13.02.08]

[2] EDRI-gram (2008) "New spying tools patented by Microsoft" Number 6.2, 30 January 2008 http://www.edri.org/edrigram/number6.2/spying-tools-microsoft [04.02.2008].

reportedly an estimated 50% of the country's 44 mln population lives below poverty line,[3] there were 31 million cell phone users in in 2007 according to statistics supplied by the International Telecommunication Union. [4]

At the same time, the developing world, while often lacking progressive legal safeguards for data privacy (at least in case of Africa) is challenged by the growing attempts of data commodification while citizens are not even aware of the number of times their health information is disclosed to third parties without their consent. In June 2004, several major South African newspapers published information that the South African Post Office would sell the personal information of all registered citizens contained in its National Address Database (NAD)[5]: The personal information intended for sale constituted „income segmentation derived from enumerator area, date of birth, gender, ethnic group, addresses and phone numbers" (Pretoria News, 15.06.2004, The Star 16.06.2004) [6]. The personal information contained within the NAD was collected via census records, TV licence payments, telephone accounts held and national identity document records held by the Ministry of Home Affairs (Kalideen 2004; Kalideen & Zeilhofer 2004). [7] The issue was reported in the 2005 PI Privacy and Human Rights Report (PI 2005)

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[3] CIA World Factbook – South Africa Country Report https://www.cia.gov/library/publications/the-world-factbook/print/sf.html [28.02.2008].

[4] ITU (2008) „ICT Statistics Newslog – Africa" http://www.itu.int/ITU-D/ict/newslog/CategoryView,category,Africa.aspx [28.02.08].

[5] The website of the product is available at http://www.nad.postoffice.co.za/. .

[6] "State to Sell Your Privacy," The Star, June 15 2005, available at http://www.thestar.co.za/index.php?fSectionId=129&fArticleId=2113150 . National Common Voters' Roll, Electoral Commission Release, June 15, 2004, available at http://www.info.gov.za/speeches/2004/04072309451003.htm.

[7] National Common Voters' Roll, Electoral Commission Release, June 15, 2004, available at http://www.info.gov.za/speeches/2004/04072309451003.htm. The Post Office later clarified their intention as not aimed at selling personal data, but only to provide address-verification services to client companies. "Post Office Dives for Cover, June 16, 2004, available at http://www.thestar.co.za/index.php?fSectionId=129&fArticleId=2114859 The government continued to express support for NAD. Presentation by Minister of Minerals and Energy, Phumzile Mlambo-Ngcuka, on behalf of the Economic Cluster I1 Sector," February 18, 2005, where Minister Mlambo-Ngcuka stated that "[i]n the next few months, together with the South African Post Office and Statistics South Africa, the Department of Communications will be launching the National Address Database and Registry, whose aim is to ensurethat all South Africans have addresses."

The data surveillance / data protection picture in South Africa is complicated by the scope of HIV/AIDS epidemic, which provides some reasonable justifications for medical data monitoring, also in the workplace, which is heavily affected by the epidemic. At the same time, HIV/AIDS confidentitality debate (security – privacy) illustrates that the human rights argument can be manitpulated to both suport and oppose privacy safeguards – the outcome depending lagrely in whether more emphasis is given to the right to the right of an individual to privacy or the right of the other individual to security. Another trend is a tendency to artificially juxtapose these rights againds each other.[8] Therefore, I was interested how it is possible to conceptualize recent changes in HIV/AIDS workplace monitoring in South Africa (from identification and dismissal to HIV/AIDS management through data collection) as the chance not to develop more universal, perhaps procedurally oriented attempt to address workplace (HIV/AIDS) privacy issues.

1.2 Research Problem

The research attempts to answer the following question:

Given the current general erosion of rights deriving from the widely argued need for security as well as new technological possibilities, the extent of the social crisis brought about by the HIV/AIDS pandemic in South Africa, and the need to balance the control of the HIV/AIDS epidemic and requirements of protection of peoples' privacy: What is the interplay between the practice of dealing with HIV/AIDS data and goals of the company's HIV/AIDS monitoring policy?

1.3 Research Objectives

The research aims at answering the following objectives:

1. To describe the social and political context of HIV/AIDS and protection of HIV test information;

[8] A similar observation was made by Mark Heywood in reference to the HIV/AIDS testing policy debate and its two poles – RCT, routine counceling and testing vs. VCT, voluntary councelling and testing (Heywood 2005, 15).

2. To draw a general picture of HIV/AIDS monitoring and privacy issues in the South African workplace.

3. To analyse the current and changing regulations and practices towards gathering, storing, profiling and disseminating data about employees‘ HIV/AIDS status in South Africa;

4. To begin to explore how the existing daily routines, decision making processes and policy changes on the level of the South African workplace address the tension between privacy rights and the need to monitor the disease.

While much of the report has a sociolegal orientation, its approach is essentially cross disciplinary. For the most part, the analysis is broad-brush; the focus of the project is the **“big picture**”.

1.4 Scope of the Study

The study covers the following areas: South African legal regulation of data protection, legal regulation concerning confidentiality of HIV/AIDS status in the workplace, both in terms of legislation and case-law, evaluation of corporate HIV/AIDS policies in South Africa on the example of companies chosen in 2005 as examples of good practice by UNAIDS (Anglo American, Eskom, BHP Billiton). To cover this scope, the study examines South African law in the context of international data privacy protection developments and gathers comments of trade unionists from COSATU (Confederation of South African Trade Unions) and NUM (National Union of Mineworkers), both advanced in adressing HIV/AIDS in the workplace. Further, the study gathers comments of representatives of workplace HIV/AIDS management providers, as well as representative of the SABCOHA (South Avrican Business Coalition on HIV/AIDS) and attorney of the AIDS Law Project.

1.5 Significance of the Study

Personal health information is considered to be one of the most sensitive categories of information and deserving of special protection. As a matter of public policy, the right to privacy is a fundamental human right that implies clear responsibilities on the part of states. Except in narrow circumstances that must be legally and ethically justified, all people, including those living with HIV/AIDS, should have the power to decide how, when, to whom, and to what extent their personal health information is shared. People living with HIV/AIDS often suffer discrimination related to the unauthorized disclosure of their HIV status. As a result, many lose their jobs, housing and insurance, and see their personal relationships with family and friends compromised. Protecting and promoting the human right to privacy is essential to meeting the public health goals of lessening the impact of HIV/AIDS on individuals and communities and minimizing its transmission and to recognizing the inherent dignity of people affected by HIV/AIDS.

Several studies link issues of HIV/AIDS to privacy rights, but none of these systematically consider the implications of "new surveillance" for how we balance privacy rights and the need for data on this pandemic in the workplace. This study will attempt to begin to fill this gap in our knowledge.

1.6 Methodology

1.1.1. General design

The research part of the project comprised of a combination of qualitative and quantitative methods and multiple-data-collection techniques.

A content analysis and semi-structured interviews with key informants was used to document and analyze the current regulation and practice in relation to HIV/AIDS information treatment. These activities included interviewing and data collection. A document analysis was conducted in order to describe global social and political context of HIV/AIDS and protection of HIV test information. This part of the research focused on international regulation dealing with HIV/AIDS surveillance in general and

HIV/AIDS surveillance in the workplace as well as current legislative developments and official policy changes in relation to protection of personal data in South Africa.

While representing developments in legislation and government policy-making, the research attempted to address the issue of the existing daily routines, decision making processes, and policy changes on the level of the South African workplace in relation to HIV/AIDS data treatment and confidentiality of HIV/AIDS status. The research focused on three big South African companies, Anglo American, Eskom and BHP Billiton, chosen by the UNAIDS as examples of best practice in providing HIV/AIDS treatment in the private sector workplace in 2005. Their HIV/AIDS policies were reviewed basing on the UNAIDS document, and then compared with the other relevant corporate documents concerning HIV/AIDS management in the workplace.

Subsequently, interviews were conducted, which gathered opinions of key informants, HIV/AIDS officers of South African trade unions present in the above mentioned companies, as well as managers from professional HIV/AIDS workplace management enterprises that had some experience with Anglo American, Eskom and BHP Billiton. In order to get some expert opinion outside the workplace an interview with the attorney from AIDS Law Project, an organisation that specialises in helping people with HIV/AIDS to deal with discrimination was conducted.

1.1.2. Data Collection

Documentary Analysis

The document analysis targeted the existing legal regulation on data privacy and HIV/AIDS confidentiality, reporting and protecting of HIV/AIDS test information as well as documentation tracking the various stages of policy development and implementation – like official South African Government's documents on HIV/AIDS on data protection and workplace.

The following international documents were used in order to describe global social and political context of HIV/AIDS and protection of HIV test information:

- ILO Code of Practice on HIV/AIDS and the World of Work, Geneva, 2001
- ILO Protection of Workers' Personal Data, Geneva, 1997
- Organization for Economic Cooperation and Development (OECD) 1980 Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data
- Council of Europe Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data European Treaty Series No. 108; adopted 28th Jan. 1981; in force 1st Oct. 1985
- HIPAA Health Insurance Portability and Accountability Act, 45 CFR Parts 160 and 164, U.S. Congress Act, with amendments, 2003
- Directive 95/46/EC on the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of such Data, 1995.

The South African regulatory context was described with the use of the following documents:

- Constitution
- Employment Equity Act (EEA)
- Investigation reports of the South African Law Reform Commission (SALRC) project entitled "Privacy and Data Protection" (2004) (Project 124):
    - SALRC Discussion Paper No 109 „Privacy and Data Protection" (2005)
    - SALRC draft Protection of Personal Information Bill (2005)
    - SALRC Issue Paper

The document analysis part of the case study (enterprise) focused on workplace policy concerning HIV/AIDS monitoring and data reporting, HIV/AIDS test information confidentiality as well as workplace occupational HIV/AIDS exposure, and organization of work of the infected and non-infected workers. The research focused three South African enterprises, chosen by UNAIDS as best practice examples in providing HIV/AIDS treatment in the workplace in 2005 (see above). The background information

was gathered from the original UNAIDS report.[9] Then, this information was confronted with other corporate documents on HIV/AIDS, specifically:

- Anglo American (2005) „Anglo American plc Group HIV/AIDS policy“www.angloamerican.co.uk/static/ uploads/Aids%20Policy%202005.pdf [27.10.07]
- Anglo American (2003) „Anglo American AIDS update“ December 2003, http://www.angloamerican.co.za/static/uploads/AIDS%20Update%200313.pdf [01.11.2007]
- Eskom (2006) „Eskom's response to HIV and AIDS“ Commitment through Partners in Action
- Eskom (2007) Eskom Annual Report 2007 - Information sheets – HIV and AIDS
- Eskom & HPADRA (2002) "Addressing HIV/AIDS Stigma and Discrimination in a Workplace Program: Emerging Findings," Eskom in partnership with the Horizons Program and Development Research Africa, interim report June 2002
- BHP Billiton (2007) "HIV Treatment And Management Programs In Southern Africa" http://www.bhpbilliton.com/bb/sustainableDevelopment/caseStudies/2007/hivTreatmentAndManagementProgramsInSouthernAfrica.jsp

Semi-structured interviews

A total of ten in-depth interviews with key informants were conducted. Five of them were conducted with trade unionists – HIV/AIDS representatives and company coordinators from National Union of Mineworkers (NUM) which covers all three companies concerned (Anglo American, Eskom and BHP Billiton) and a National HIV/AIDS Coordinator from COSATU, a trade union confederation to which NUM is affiliated. The following persons were interviewed:

- COSATU National HIV/AIDS Coordinator;
- NUM National HIV/AIDS Coordinator;
- NUM National HIV/AIDS Officer;
- NUM Anglo Gold Coordinator;

[9] UNAIDS (2005) „Access to treatment in the private-sector workplace. The provision of antiretroviral therepy by three companies in South Africa“ UNAIDS Best Practice Collection, Geneva

- NUM Eskom Coordinator.

Interviews with company coordinators covered Anglo Gold (a part of Anglo American) and Eskom. BHP Billiton was covered generally in interviews with NUM and COSATU HIV/AIDS representatives.

Futhermore, interviews covered a representative of the South African Business Coalition on HIV/AIDS (SABCOHA), an organization that aims to co-ordinate a private sector response to the HIV/AIDS, as well as managers or medical practitioners from HIV/AIDS workplace management providers – professional enterprises that deliver comprehensive research and/or medical services for business in the area of HIV/AIDS. The following persons were interviewed:

- Chief Executive Officer of SABCOHA;
- Executive Manager of Qualsa (who was previously working for Anglo American on HIV/AIDS management issues. Qualsa is HIV/AIDS workplace management provider);
- Senior Medical Practitioner of Lifeworks (Lifeworks provided HIV/AIDS workplace management for Eskom and BHP Billiton);
- HIV/AIDS Programme Director of Aurum Institute (Aurum is a research institute established by Anglo American, currently not-for-profit Public Benefit Organisation. Aurum provided HIV/AIDS workplace manageent for Anglo American).

Also, in order to get comments from the perspective outside an interview with the attorney from AIDS Law Procject was conducted.

The interviews were more scheduled sessions, the questions prepared in a semi-structured protocol, i.e., a series of open ended questions that were designed to allow the respondent to describe, in his/her words, the rationale, goals, problems and policy solutions.

The purpose of these interviews was to develop a firsthand understanding of the interplay between the practice of dealing with HIV/AIDS data and goals of the company's HIV/AIDS monitoring policy.

1.1.3. Data Management

The interviews were noted down during the session, typed up using Microsoft Word after the session and kept in files organizationally and by topic. Since HIV/AIDS is still a sensitive and politicized topic I decided not to record the interviews in order to benefit from more informal character of the session and, hopefully, get more open and less politically correct answers. Interviews are attached as annexes to the research report.

1.1.4. Confidentiality

The research does not require gathering of personalized information about HIV/AIDS status.

1.7 Outline of Chapters

Chapter 2 presents theoretical considerations on medical and workplace surveillance in the context of new technologies, having the Michel Foucault' concepts of panopticon and discipline as a starting point. Then it presents some historical (Apartheid) and cultural (communitarianism) influences on conceptualizations of the right to privacy in the context of HIV/AIDS in South Africa.

Chapter 3 focus on legal aspects of the right to (medical) privacy and confidentiality of HIV/AIDS status in South Africa. It starts with an overview of international legal instruments and regulation of the right to data privacy. Then it describes the position of privacy rights in the South African legal system, summarizing constitutional, judiacial and statutory safeguards for data privacy as well as HIV/AIDS confidentiality. The Chapter aims at analyzing to what extend law can serve as an efficient tool for protecting confidentiality of HIV/AIDS information in South Africa.

Chapter 4 presents an overview of workplace response to HIV/AIDS in South Africa. It presents some aspects of HIV/AIDS workplace policies of 3 South African companies, Eskom, Anglo American plc and BHP Billiton, whose HIV/AIDS ARV programmes

were chosen as best practice examples by UNAIDS in 2005. For each of the companies, the company HIV/AIDS policy is described, as well as its practices of HIV/AIDS confidentiality and data management. This Chapter aims at contextualizing interviews conduceted in the frames of the project.

Chapter 5 is based on interviews with trade union as well as business representatives. The first part analyzes interviews with trade unionists from COSATU and NUM. This part focuses on the following issues: discrimination, perceptions of confidentiality, implications of outsourcing of HIV/AIDS management, data treatment as a trade union issue. The second analyzes interviews with representatives of 3 HIV/AIDS workplace management providers (Lifeworks, Qualsa, Aurum Institute) and the SABCOHA reperesentative. This part focuses on the following issues: perceptions of the employer's interest in HIV/AIDS data of its employees, outsourcing of HIV/AIDS management, interest of providers in confidentiality safeguards.

Chapter 6 presents discussion of the findings. It summarises conclusions of the theoretical and legal analysis presented in Chapters 2 and 3. Then it analyzes the findings of the empirical part of the research presented in Chapters 3 and 4. It ends with some recommendations on HIV/AIDS data treatment.

2. Chapter 2: (Medical) data protection in the workplace - Theoretical considerations

2.1 Introduction

Studying socio-legal dimension of (medical) data surveillance in the workplace necessitates better understanding of surveillance and commodification of information processes as well as the changing conditions of labor over time. This chapter aims at presenting theoretical considerations on the „new surveillance", medical surveillance and workplace surveillance. Then, the chapter covers the issues of privacy and HIV/AIDS in South Africa as influenced by socio-historical (Apartheid) as well as cultural (communitarianism) factors.

2.2 New surveillance

Mass media and visual and communication technologies and surveillance in the everyday, routine sense are omnipresent elements of post-industrial society, the so-called information society (Wallen&Silbey 2002, 439, Giddens 1985, Giddens 1998, Castells 2000, Lyotard 1984).[10] Surveillance is one of the four equally important "dimensions of postmodernity", "institutional clusters", through which societies are constantly changing (Giddens 1985).[11] Consequently, to omit surveillance in the analysis is to fundamentally misread the nature of modern society (Giddens 1985, Taylor 1986, Foucault 1979). As

[10] The term "postmodernity" refers to "a structure characterized by separations of time and space, and flexible, instrumental, distanced, and disembedded social relations as well as high degrees of reflexivity and trust in expert systems. Giddens refers to theses as the consequences of modernity; Harvey describes it as postmodernity" (Willis& Silbey 2002). knowledge has become the principle force of production over the last few decades

[11] The four dimensions of a modern society are: "capitalism", "industrialism", "heightened surveillance" and "consolidation of centralized control of means of violence" (Giddens 1985, 5). Peter Taylor writes; "And this, of course, is the error Giddens finds in modern social discourse whether it to be the Marxist's concentration on capitalism or the sociologist's concentration on industrialism. Both neglect the surveillance and violence that have been the hallmark of the modern state" (Taylor, 1986).

Foucault illustrates, each process of modernization entails disturbing effects with regard to the power (1979). Together with the development of new technologies[12] toward the end of the 20th century (Marx, forthcoming) comes the new form of intrusive social surveillance and control. New technologies play a crucial role in the process of organizing and transforming the new surveillance, being a material dimension of power (Zuboff 1988, Wilcocks 2006) in the information/surveillance "carceral" society, while providing with practically unlimited possibilities of collecting, storing, profiling and transmitting data. As greater quantities of information are collected and transmitted to a greater number of people, the ability of people to control the disclosure of their information has been eroded. The new surveillance technologies are primarily focused on data and are often applied categorically[13] in the way in which surveillance that used to be authorized in exceptional circumstances becomes the rule[14] while information gathered through surveillance (e.g. individual data) become commodified - in the same way in which, according to Lyotard, knowledge is transformed into a commodity in a postindustrial society (1984, 5). The other feature of new surveillance is accumulation into an integrated, inter-related, global system. With almost unlimited possibilities of storing and transmitting data steming from a number of parallel developments in the worlds of technology, law, and politics increasing quantities of information are collected and shared among an ever-increasing number of users. At the same time, individuals' ability to control the dissemination of personal information is sharply reduced. The process of accumulation and commodification of data gathering and surveillance is most problematic where surveillance meets health information, arguably the most personal and private sources of data about us. The unauthorized release of medical records is perhaps one of the greatest threats we face in the information age.

[12] Examples include: video cameras; computer matching, profiling and data mining, computer and electronic location monitoring; DNA analysis; drug tests; brain scans for lie detection etc.

[13] E.g. all employees are drug tested or travellers are searched, rather than those whom there is some reason to suspect (Marx, forthcoming).

[14] Surveillance becomes a **"**fishing expedition**"** where criminal activities are hopefully sought to be discovered, as opposed to being investigated.

2.3 Medical surveillance

With regards to medical surveillance, Foucault associated the control of the body of the „subject" and the regulation of biological processes by the state with forms of „discipline" which includes the discipline of „public health" (Foucault 1997, Lemke 2001).[15] Bio-surveillance, which relies upon continuous monitoring of bodily or biological processes through, among others, gathering of medical data, "have emerged as defining characteristics of post-disciplinary social control" (Campbell, 2004, 79). Our bodies are most often considered to be biological, material and individual. It is only recently that the body has become an important focus of sociological analysis rather than being seen solely as the object of study for the natural sciences. In this context, organization of medical data in centralized databases can be conceptualized as as a panopticon model (Foucault 1972, 1979) of the reinforced power of the authorities that are implementing control, notwithstanding commonly argued benefits of centralized management of medical data: health research, the organization of health systems, the prevention of health fraud, and treatment outcomes.[16] Patterns of the disease are fundamentally shaped by relationships of power. „*A disesase is absolute physical entity but a complex intellectual construct, an amalgam of biological state and social definition*" (Roseberg 1962, Packard & Epstein 1992). Therefore, reproduction of power structures through medical surveillance is possible to study on the example of workplace relationships, when health data gathering (through drug testing, DNA checking or HIV/AIDS management) enters the space of labour relationships, as power is a central feature of all workplace interactions.

[15] The idea of „public health" as opposed to that of the individual, was introduced after dr John Snow successfully terniated a London cholera epidemic by removing the handle of a public water pump in the 1850s to prevent the „population" from acessing contaminated water In particular, The eventual mathematicisation of public health practice and data resulted in the scientific discipline of epidemiology (Thornton 2007, 4).

[16] On the one hand, record-keeping and surveillance systems may be feared for their power to record and map personal lives, on the other – their rationale is to protect these lives. This is what Anthony Giddens calls a "dialectic of control" (Giddens 1985, Wallen & Silbey 2002).

2.4 Workplace - Surveillance as power

Foucault did not write much about the labour process, ("*perhaps because he did not see as crucial to understand power as Marxists do*", Sakolosky 1992, 237), seeing surveillance at work as part of a wider interaction of social forces (Sewell 1999, 5). Nevertheless, the relevance of his work to understand labour process is obvious. Especially, if we take into account that capitalism can be defined as a "power/knowledge regime", a particular form of domination, which is "the site of power" (Sakolosky 1992, 236) and Foucault sees power inherently linked to knowledge in the sense that power implies knowledge and knowledge implies power relations (Sakolosky 1992, 236). In this sense, discipline is a form of domination linked to information as knowledge. In the capitalist workplace, the desire to place employees under surveillance can be attributed to the need to maintain control of a workforce (Sewell 1999,3).

Consequently, in the workplace surveillance functions as a resource for the execution of power built into the machinery and processes of production. However, the ethical status of workplace HIV/AIDS surveillance (among other forms of workplace medical monitoring) can be expressed as a question of competing interests, between the employer's right to use testing to reduce HIV/AIDS related harms and maximize profits, over against the employee's right to privacy (Cranford 1998, 1806). That is why AIDS requires that we re-examine fundamental workplace assumptions, just as it forces us to re-examine policy in so many other areas (Schulman, 1990).

2.5 Privacy and HIV/AIDS in South Africa

"HIV/AIDS is a workplace issue and should be treated like any other serious illness/condition in the workplace. This is necessary not only because it affects the workforce but also because the workplace, being part of the local community, has a role to play in the wider struggle to limit the spread and effects of the epidemic" The ILO Code of Practice: Key principles (4.1)

HIV/AIDS has a significant impact on the workplace. Of the approximately 40 million people living with HIV worldwide, at least 26 million are workers in their productive

prime (between the ages of 15 and 49).[17] The full impact of the epidemic is not easy to assess.[18] The overwhelming majority of people with HIV (some 95% of the global total) live in the developing world (Gilbert&Walker 2002, 1099; UNAIDS). South Africa is one of the countries most affected by HIV/AIDS. It is also the country where labor relations are deeply affected by the experience of colonialism and Apartheid (the system of domination, power and control of one racial group over the other). These factors, together with cultural influences to some extend shape South African responses to privacy and confidentiality. The legal aspects are presented in the Chapter 3. Several particularities of the cultural influences on privacy in South Africa are listed below.

Apartheid

Although the Apartheid government implemented some practical interventions (like blood screening, annual antenatal HIV surveillance), it was only in the beginning of 90ties, after unbanning of the African National Congress, where the National AIDS Convention of South Africa (NACOSA) has been formed (1992).[19] Public health issues in South Africa have never been politically neutral. They were deeply racially influenced (Brandt 1998, Horwitz 2002, Marks 2002, Walker 2004, Webb 1997, Zwi&Cabral 1991) and, consequently, nowadays South Africa continues to be the country with a deeply politicised HIV/AIDS debate. On the one hand, Apartheid South Africa had statements like „*if AIDS stop black population growth, it would be like father Christmas*" in its offcial parliamentary records.[20] Still, the post-Apartheid government actions on

[17] According to estimates, this means that the size of the labour force in high-prevalence countries (like South Africa) will be 10%–35% smaller by 2020 than it would have been without the AIDS epidemic (ILO 2004). The remaining workforce will contain a higher proportion of younger workers who are less experienced and less well-educated than the current group. Furthermore, dramatic reductions in life expectancy are predicted in some of the worst-affected countries.

[18] Even in South Africa, the well developed country of the region, there is very little reliable information about the true costs of HIV and AIDS to enterprises (Rosen et al. 2000) The media has reported productivity losses of between 2% and 50% (Michael 2000).

[19] During the 80ties, when the HIV/AIDS epidemic developed in Africa, South Africa was to some extend protected by its strong isolation policy pursued by the Apartheid government. However, despite the first two (white, homosexual) South African cases were diagnosed in 1982, the first black case in 1987, there were practically no political responses to the disease in the 80ties.

[20] Conservative Party member Clive Derby-Lewis, Debates of Parliament, 18.05.1990, col.9797. Cited after Van der Vliet (2006, 51).

HIV/AIDS have little credibility among white right wing groups, for racist reasons.[21] On the other hand, sadly, the post-Apartheid Government remained inactive about HIV/AIDS, despite that in the 90ties HIV/AIDS was skyrocketing in the country. Many had hoped that Nelson Mandela, like president Yoweri Museveni in Uganda, would personally lead South African's HIV/AIDS fight.[22] This has not been the case and Mandela himself recognized this failure as one of the few major weaknesses of his presidency (Van der Vliet 2006,55). During the presidency of Thabo Mbeki South African Government became involved in „AIDS denialism" and, unfortunately, often played the role of the enemy of the civil society organizations trying to countract the epidemic in the country[23] and several times became subject of the international scrutiny.[24] The factor of inequality cannot be omitted in the analysis of weak South African response to HIV/AIDS. In the same way as during the Apartheid government – currently South Africa, alhough the wealthiest in the region, is still one of the most (racially) unequal in the distribution of the per capita income in the world[25] - and HIV/AIDS is the disease spread by inequality (Marks 2002).[26]

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[21] When the government educated about limited ways of contracting HIV (not through casual contact) it was accused by white right wing groups of pursuing the „politically correct" process of desegregation in public amenities (hospitals, schools, blood banks) on the cost of increasing the danger of infection to „low risk groups" (an euphemism for whites) (Van der Vliet 2006, 50).

[22] However, Mandela, perhaps because of his age and the conservatism surrounding open public discussion of sexual matters among South Africans, black and white, did not deal with AIDS policy (Van der Vliet 2006, 55).

[23]Since 1998 the Ministry of Health fought not to provide AZT treatment, the drug that cuts mother-to-child transmission by 50%. It has to be underlined that anti-retroviral therapy has not been available through public health clinics before 2004. This policy caused the formation of Treatment Action Campaign movement in 1998, one of the most successful civil society organziations in pressuring both the government and transnational pharmaceutical companies to privide HIV/AIDS treatment, see: http://www.tac.org.za .

[24] E.g. after anti-AZT statements of the Thabo Mbeki Health Minister Dlamini-Zuma the international academic world considered boycott of the AIDS 2000 conference that was to be taking place in Durban, South Africa.

[25] See, for instance, Economic Policy Institute 2006
http://www.epi.org/content.cfm/webfeatures_snapshots_20060419 [24.11.2007)

[26] There is also element of growing inequalities North and South and public health crisis. Links between poverty, lack of basic health care, ecological disturbances and the appearance of dangerous microbes were keys to the emergence of new infectious diseases in the twentieth century (Marks 2002).

The political and racial divisions, created and inflamed by apartheid, which are still in place, made everything to do with AIDS „political" and sensitive. HIV/AIDS policies had to operate in such complicated social context, that no matter what measure has been adopted, it always ended highly politicised, in the sense of heated public argument, mobilization and conflict[27] or, on the contrary, ended addressed by silence (Van der Vliet 2006, 81). Silence and sensitivity around HIV/AIDS in South Africa have impact on the position of the privacy rights and HIV/AIDS confidentiality in this country, together with other notions, said to be culturally influenced – communalism, „shared confidentiality", communal fellowship.

Privacy as communitarian concern

The legal concept of (data) privacy rights is rooted in European and North American philosophy of individual rights.[28] Privacy in the African context is believed to be affected by the philosophical concepts of communalism, collectivity and cooperation[29] as well as communal fellowship[30] emphasized by African philosophers (Diavara 1998; Oyserman et al. 2002, 3-72; Wiredu 1980, 21; Kigongo 1980). These philosophical concepts are said to affect the evolution of societal norms that play a major role in appreciation and

[27] For instance, promoting condom usage in South Africa can be accused of trying to stop black polulation growth through fertility control. Failing to promote condom usage can be accused of counting that AIDS would stop population growth by killing black South Africans (Van der Vliet 2006, 50)

[28] Legal regimes for data privacy are least developed in the African countries taken as a whole. As often mentionned, the African Charter on Human and People's Rights of 1981 omits mentioning a right to privacy in its catalogue of basic human rights. Moreover, none of the African countries have enacted comprehensive data privacy laws (see Chapter 3).

[29] However, it should be underlined that they did so not because they are unfamiliar with individualism but because they have seen the value of the collective idea (Bakibinga 2004). Review of Manthia Diawara, In Search of Africa, Cambridge: Harvard University Press, 1998, posted at http://www.asante.net/articles/manthia-n.html viewed on 3/11/2004. See D. Oyserman, H. Coon and M. Kemmelmeier; 'Rethinking Individualism and Collectivism: Evaluation of Theoretical Assumptions and Meta-Analyses', Psychological Bulletin 2002, Vol. 128. No 1. 3-72, cited in Bakibinga 2004.

[30] Kwasi Wiredu; Philosophy and an African Culture, Cambridge, Cambridge University Press, 1980, p.21, cited in J.K. Kigongo; 'The Concepts of Individuality and Social Cohesion: A Perversion of two African cultural realities', posted at http://www.crvp.org/book/Series02/II-2/chapter_iv.htm viewed on 3/11/2004. Cited by Bakibinga 2004.

respect for human rights. They also spill into private realm in the way that individuals may not be aware of their rights („privacy myopia“) or may not be keen on complaining about invasions (Bakibinga 2004). Communal considerations over-riding individual are believed to result in underdevelopment of data privacy regimes, starting from the African Charter of Human Rigths which, unlike all the other major international human rights documents, does not have provisions on the right to privacy (Bygarve 2004, 319-348, 328, see Chapter 3).

It is indeed possible to find arguments that confidentiality is a „Western“ concept, forced on the developing world, that adds to the spread of HIV/AIDS in (South) Africa. Policy of confidentiality is blamed for causing dangers for non infected people.[31] To some extend, HIV/AIDS in the developing world develops through different patterns that in the developed world (starting with the scope of the epidemic) and, perhaps, if Western countries be in a comparable state of public health emergency caused by HIV/AIDS, they would not care much for individual rigths. Also, the way to address HIV/AIDS policy has been imposed on the developing world in somewhat neo-colonial way (Illife 2006) through money and power of the developed coutries. However, it seems that facing the new challenges of technological data surveillance it is time to reexamine the privacy debate in the African context. Therefore, there is a need to argument advanced data privacy provisions while respecting cultural values "*One can have privacy and still be part of the community*“ - this was the conclusion of Ms. Elizabeth Martha Bakibinga,

[31] The emphasis on individual and the practice of mainataining confidentialityy is reported as being seen highly problematic by health professionals, especially those with experience of rural areas. For instance, on the local level, counsellors, even if they see that a HIV positive person is practicing unprotected sex and causing the risk of infecting the partners, are bound by confidentiality and therefore feel helpless (Seidel 1996, 423). Examples of reactions expresed by nurses at the Meeting of the regional NACOSA home-based care commission held at Amatikulu Primary Health Care Training Centre in northern Kwazulu-Natal, in September 1995, were cited by Gill Seidel from Africa Research Unit, Social and Economic Studies, University of Bradford, UK (1996),„*This confidentiality thing does not help us. It holds us back. We cannot care for patients";„They taught us this thing when we went for training in counselling. Then we didn't know any better and we listened to them. Now we know that this secrecy is not good for our patients“.„It is Eurocentric – perhaps it is goos for white people. But we Africans are different – we care about others, we care about our neighbours (…) This secrecy is killing us. It is not our way. These white doctors have too much power“*. Nurses and nurse-councellors whose work is primarly hospital-based in towns and cities, are aware of the potential law suits for transgression of confidentiality guidelines. That might have been the cause of their concern.

Senior Legislative Counsel of the Parliament of Uganda, at the Africa Electronic Privacy Symposium in Cape Town, South Africa 06.12.2004 (EPIC Alert 2004).

2.6 Summary

To omit surveillance in the analysis is to fundamentally misread the nature of modern society. the new form of intrusive social surveillance and control that comes along with the development of new technologies (being a material dimension of power), is characterised by routine monitoring, commodification of information, accumulation accumulation into an integrated, inter-related, global system. This process is most problematic where surveillance meets health information, arguably the most personal and private sources of data, in the form of the discipline of public health. This is because patterns of the disease are fundamentally shaped by relationships of power. When advanced health data gathering (through drug testing, DNA checking or HIV/AIDS management) enters the space of labour relationships we have to deal with the problem of re-examining fundamental workplace assumptions, like in case of HIV/AIDS in South Africa. In this country, the political and racial divisions, created and inflamed by apartheid, which are still in place, made everything to do with AIDS „political" and sensitive. Silence and sensitivity around HIV/AIDS in South Africa have impact on the position of the privacy rights and HIV/AIDS confidentiality in this country, together with other notions, said to be culturally influenced – communalism, „shared confidentiality", communal fellowship. However, facing new challenges of technological data surveillance it is time to reexamine the privacy debate in the African context.

3. Chapter 3: The Right to Privacy, Medical Privacy and Confidentiality of HIV/AIDS status in South Africa – Legal aspects

3.1 Introduction

In 2004 the Electronic Privacy Information Centre, a public interest research center based in Washington, established to focus public attention on emerging civil liberties issues and to protect privacy,[32] held the African Electronic Privacy Symposium in Cape Town, South Africa. The symposium featured panel discussions on, among others, data protection in Africa and African perspectives on confidentiality. Participants discussed the role of privacy as a „foreign" concept to most Africans, both in terms of their culture of community openness and as a concern of only the elite. Panelists believed privacy is an important issue for Africa, and they felt this needs to change quickly, and there is broad-based support for considering privacy issues in the contexts of information technology and in the World Summit on the Information Society (EPIC Alert 2004). This event showed that there is a growing concern about the privacy issues in Africa, which are rightfully being placed in the context of technological change and digitalization of data.

This chapter aims at examining data privacy international regulation, medical privacy international regulation, as well as an important contemporaneous law-reform developments in the area of data privacy and medical privacy protections in South Africa.

3.2 Data privacy international regulation

Of all the human rights in the international catalogue, privacy is often said to be the most difficult to define (PI 2006, Liberty 2007). However, the lack of a single definition

[32] Electronic Information Privacy Centre, http://www.epic.org

should not imply the lack of importance. As one writer observed, "in one sense, all human rights are aspects of the right to privacy“ (Volio 1989).[33]

The modern privacy benchmark at an international level can be found in the 1948 Universal Declaration of Human Rights (UDHR), which specifically protects territorial and communications privacy.[34] The main fundamental rights instruments,[35] along with the main regional human rights treaties[36] expressly recognize privacy as a human right (PI 2005, Rotenberg 2003).[37] The only exception is the African Charter for Human Rigths. However, still there does not exist a truly global convention or treaty dealing specifically with data privacy although interest in the right of privacy increased in the 1960s and 1970s with the advent of information technology (Flaherty 1989). The closest to such an instrument is the 1981 Council of Europe Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (Bygarve 2005, 328).[38]

On the regional level, the strongest data protection instrument is the Directive 95/46/EC on the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of such Data (hereinafter “E.U. Directive”). It also does have a

[33] Cited after PI (2006). Note that recognition of the right to privacy can be found in, among others, the *Qur'an* and in the sayings of Mohammed, the Bible, the Jewish law, in classical Greece and ancient China, See PI (2005).

[34] Universal Declaration of Human Rights, Article 12 states: “*No one should be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks on his honour or reputation. Everyone has the right to the protection of the law against such interferences or attacks*”.

[35] Such as (apart form the UDHR – Article 12), the International Covenant on Civil and Political Rights (ICCPR - Article 17). The same language is also adopted by the United Nations (UN) Convention on Migrant Workers (Article 14), and the UN Convention on Protection of the Child (Article 16).

[36] Such as the European Convention on Human Rights and Fundamental Freedoms (ECHR – Article 8), the American Convention on Human Rights (ACHR – Article 11), the Cairo Declaration on Human Rights in Islam (Article 18(b) – (c)). See also Article V of the American Declaration of the Rights and Duties of Man (O.A.S. Resolution XXX; adopted 1948).

[37] The establishment of fundamental rights (also the right to privacy) strengthens their protection and gives them a higher status in the sense that they are applicable to all law, and are binding on the executive, the judiciary and state organs as well as on natural and juristic persons.

[38] European Treaty Series No. 108; adopted 28th Jan. 1981; in force 1st Oct. 1985. While this is a European instrument, it is envisaged to be potentially more than an agreement between European states, as it is open to ratification by states not belonging to the Council of Europe (see Article 23). However, it has yet to be ratified by a non-member state.

significant impact on the evolution of data protection measures worldwide. The Directive imposes an obligation on member states to ensure that the personal information relating to European citizens has the same level of protection when it is exported to, and processed in, countries outside the European Union. This requirement has resulted in growing pressure outside Europe for the passage of privacy laws. (PI 2005, Overview). All of these provisions give an impression that the E.U., in effect, is legislating for the world. Equally, they nourish accusations of "regulatory overreaching" (Bygrave 2000, 252-257).[39]

Apart from international and regional treaty law there are numerous soft law instruments (guidelines, recommendations, codes of practice related to data protection.[40] Some of them are of sectoral application only. Among them, a noteworthy instance with regards to workplace data privacy is the Council of Europe's recommendation on the protection fo personal data used for employement purposes[41] as well as the code of practice issued by the International Labour Organization (I.L.O.) on data privacy in the workplace.[42] To sum it up, the international regime for (data) protection privacy is still complex and fragmented.

[39] This issue will not be discussed in this report. See particularly the criticism of Article 4(1)(c) in Bygrave (2000, 252-257) . See also the more general criticism (from U.S. and Australian quarters) in Lukas, A., Safe Harbor or Stormy Waters? Living with the EU Data Protection Directive, Trade Policy Analysis Paper no. 16, 30th Oct. 2001, Cato Institute, Washington, D.C. 2001; Ford, P., Implementing the EC Directive on Data Protection – an outside perspective, Privacy Law & Policy Reporter 2003, vol. 9, p. 141–149 – cited after Bygrave (2005).

[40] Apart from the above legal instruments, there exist numerous international and regional instruments on data privacy which take the form of guidelines, recommendations, or codes of practice. For advanced industrial states generally, the most significant of these instruments are the 1980 Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data, adopted by the Organization for Economic Cooperation and Development (OECD). Of potentially broader reach are the United Nations (U.N.) Guidelines Concerning Computerized Personal Data Files adopted 1990 (Bygarve 2005). The Guidelines have been very influential on the drafting of data privacy laws ans standards in non-European jurisdictions, such as Australia, New Zealand and Canada (Bygrave 2005, 335). Also, they influenced legislatory process of data protection in South Africa (Currie 2006). It is interesting to notice that the OECD Guidelines contain similar but weaker principles in comparison to those stipulated in the CoE Convention. Maybe that is the reason why the OECD instrument have been much more influential than the CoE Convention or the UN Guidelines (Bygrave 2005, 335).

[41] Recommendation No R (89) 2 on the protection fo personal data used for employement purposes (adopted 18.01.1989).

[42] . Protection of Workers' Personal Data, I.L.O., Geneva 1997.

Medical Privacy international regulation

When it comes to medical data privacy it has to be underlined that, although since the creation of the Hippocratic oath about 400 B.C.[43] protecting the privacy of patients has been an important part of physicians' code of conduct, over time, health information has come into use by many organizations and individuals who are not subject to medical ethics codes, including employers, insurers, government program administrators, attorneys and others. At the same time, uses of medical information multiplied tremendously. So have regulatory protections for this highly sensitive and deeply personal information. The international medical privacy requirements are partly derived from the standards such as the US Health Insurance Portability and Accountability Act (HIPAA) privacy rules,[44] EU privacy directives, European Standards on Confidentiality and Privacy in Healthcare,[45] as well as Principles of the OECD Privacy Guidelines. The international regulation is influenced mostly by the EU and the US medical privacy regime (the US, while having no general data privacy regulation, introduces privacy safeguards sectorally, see Bygrave 2004, PI 2006).

Some medical privacy protections apply only to information held by government agencies. Some protections apply to specific groups, such as federal employees or school children. Some protections apply to specific medical conditions or types of information, such as information related to HIV/AIDS or substance abuse treatment. The regulatory regime for protecting privacy of health information is therefore even more complicated than general data privacy regulation.

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[43] *Whatsoever things I see or hear concerning the life of men, in my attendance on the sick or even apart therefrom, which ought not be noised abroad, I will keep silence thereon, counting such things to be as sacred secrets"*. Oath of Hippocrates, 4th Century, B.C.E.

[44] Health Insurance Portability and Accountability Act Privacy/Security/Enforcement Regulation Text, 45 CFR Parts 160 and 164, U.S. Congress Act, with amendments, 2003.

[45] The European Standards on Confidentiality and Privacy in Healthcare, EuroSOCAP Project, 2005, apply to all healthcare professionals and to healthcare provider institutions and address the areas of healthcare confidentiality and informational privacy, http://www.eurosocap.org/eurosocap-workshop.aspx [28.02.08].

3.3 Data privacy national regulation

Well over thirty countries have enacted data privacy laws, and their number is growing steadily (Bygrave 2005, 338; PI 2006). The bulk of these countries are European. Indeed, Europe is home to the oldest, most comprehensive and most bureaucratically cumbersome data privacy laws at both national and provincial levels.

When it comes to Africa it has to be underlined that here legal regimes for data privacy are the least developed in the world (Bygrave 2005, 338; PI 2005, 2006). As noted above, the African Charter on Human and People's Rights of 1981 omits mentioning a right to privacy in its catalogue of basic human rights. Moreover, none of the African countries have enacted comprehensive data privacy laws.

Nevertheless, some countries display increasing interest in legislating on data privacy. This is partly due to the obligations imposed by the ICCPR.[46] It is also probably due partly to a desire to meet the adequacy requirements of the EU Directive.[47] In some cases, stimulus is also provided by recent first-hand experience of mass oppression. The Republic of South Africa has come furthest along the path to establishing a comprehensive legal regime on data privacy. Express provision for a right to privacy is made in section 14 of its Bill of Rights set out in Chapter 2 of its Constitution of 1996[48] and work is proceeding on a bill for separate data privacy legislation.[49] Kenya is also drafting a new Constitution containing similar rights as found in the South African

[46] the International Covenant on Civil and Political Rights (Article 17).

[47] Articles 25–26.

[48] Also included (in section 32 of the Constitution) is a broad right of access to information held in both the public and private sectors. The latter (access to information held in the private sector) is unique on the global scale and forms one of the most progressive regulations of the right of access to information (Bygrave 2005, 343). Freedom of information (F.O.I.) legislation based on the latter right was enacted in 2002. *See* The Promotion of Access to Information Act 2 of 2000. Further on the Act, *see* Currie, I. and Klaaren, J., *The Promotion of Access to Information Act Commentary*, Siber Ink, South Africa 2002 – cited after Bygrave (2005, 343).

[49] See Investigation reports of the South African Law Reform Commission (SALRC) project entitled "Privacy and Data Protection" (2004) (Project 124): SALRC Discussion Paper No 109 „Privacy and Data Protection" (2005); SALRC draft Protection of Personal Information Bill (2005); SALRC Issue Paper.

Constitution (Bygrave 2005, 343).[50]

3.4 Data privacy in South Africa

As it was mentioned above, in South Africa privacy is protected by the 1996 Constitution (Section 14).[51] This general privacy protection right[52] is protected by a private law action.[53] The common law right of privacy is protected under the law of delict (Currie 2006b).[54]

When it comes to data privacy the situation is less clear. Even the Constitution does not expressly deal with data privacy and it is debatable whether data privacy is covered by the constitutional right to privacy. However, the most dominant argument is that information privacy is encompassed in the constitutional protection of privacy (Currie 2006). The right to information privacy is not yet recognized in SA law by either statute or any case law and there is no general data protection law yet (like the Data Privacy Act

[50] See sections 14 (right to privacy) and 47 (right of information access and rectification) of the draft Bill for the Constitution of the Republic of Kenya.

[51]The right to privacy is dealt with in section 14 of the Constitution which proves that „everyone has the right to privacy, which includes the right not to have – (a) their person or home searched; (b) their property searched; (c) their possessions seized; or (d) the privacy of their communications infringed".Tthe Constitution of the Republic of SA Act 108 of 1996. It is important to underline that even the right to privacy (although recognized by the Constitution) is **not absolute.** As a fundamental right it can be limited in terms of law of general application and has to be balanced with other rights entrenched in the Constitution (in accordance with the limitation clause of the Constitution contained in section 36).

[52] The definition adopted by the South African Constitutional Court is that the concept of 'privacy' in the Bill of Rights extends to those aspects of existence in regard to which a 'legitimate expectation of privacy can be harboured'. A 'legitimate expectation of privacy' has two components 'a subjective expectation of privacy . . . that the society has recognized . . . as objectively reasonable'. [Bernstein v Bester NO 1996 (2) SA 751 (CC) para 75.] Privacy is, in other words, what feels private, though that feeling has to be a reasonable one, ie a feeling of privacy that is objectively shared rather than entirely personal or eccentric (Currie 2006).

[53] Private law action to interdict current or anticipated privacy infringements or to recover damages for infringements that have already occurred.

[54] There is no South African legislation dealing specifically with the protection of the right to privacy. It is therefore important to evaluate the right to privacy in the light of both the common law and the Constitution.

the Law Commission is working on, see further) (Currie 2006a, 2006b).[55] In the interim, a number of important sector-specific laws containing information privacy provisions have been introduced.[56] These provisions are however regarded as interim measures and will only stay in force until more specific data privacy laws are formulated and implemented (SALC IP24). That is why the SA Law Commission of the Parliament is currently working on the comprehensive data privacy law.

3.4.1 New Data Privacy Law in South Africa

South African Law Reform Commission (parlamentary body) is currently in the process of drafting general personal data protection legislation, a new act on Privacy and Data Protection which is required by the Constitution.[57]

Works started in 2000 and already have taken eight years. The earliest possible date for the legislation to be finalised was the end of 2007. In all likelihood however, Parliament will enact a Protection of Personal Information Act in 2008 and will make provision for a lengthy phasing-in period for the legislation (Currie, 2006b).

[55] When it comest to an alleged infringement of the right to information privacy, it is not correct to talk about these infringements as unlawful or illegal as this form of infringement of the right to privacy is not yet recognized in SA law by either statute or any case law. This does not mean that an individual cannot institute legal proceedings alleging an infringement of the right to privacy.

[56] Examples of such legistalation are the Promotion of Access to Information Act 2 of 2000, the Electoral Act 73 of 1998 and the Electronic Communications and Transactions Act 25 of 2002. The Promotion of Access to Information Act protects personal information from disclosure in response to a request made in terms of the Act, but has no application outside the context of such a request (Currie 2006b). The envisaged general application of POPIA means that, once enacted, it is intended take the place of the data protection provisions of these laws (Currie 2006a). Electronic Communications and Transactions contains the basic universal accepted principles for dealing with personal data collected in electronic transactions. It is important to underline that the future Protection of Personal Information Bill will amend the above mentionned acts.

[57] In 2000 the Parliament begun considering a new act on Privacy and Data Protection which is required by the Constitution. First, the Parliament's Law Commission published an **Issue Paper** in September 2003. Afterwards, the Commission Commission published its **Discussion Paper No 109 on 'Privacy and Data Protection' (the so-called draft Protection of Personal Information Bill** is in the Annexure B of the Discussion Paper)) in October 2005. The Bill was published for comment and during 2006 the Commission has been considering a large volume of received comments. Afterwards it published its **recommendations** (the end of 2006?) which were made to to the Minister of Justice in order for him to make the decision whether to introduce the legislation in Parliament (Currie, 2006b).

The future South African data privacy law, in the currently recommended form (the SALC Draft Protection of Personal Information Bill) follows the most rights' oriented international and national legal instruments in the world (Currie 2006b).[58]

The Act principally protects information privacy by prohibiting the processing[59] of personal information other than in accordance with the conditions set out in the Act. These principles are derived from the OECD Guidelines as elaborated on in the EU Directive and also form the basis of a number of national privacy laws (Currie 2006b).

In addition, certain specific forms of sensitive personal information (including health information) are subject to heightened protection In essence, such information cannot be processed without the "explicit consent" of the person concerned (Part B of Chapter 3 of the draft Bill; Currie 2006b).

The parliamentary works on data protection law in South Africa are promising but they are still in progress. That is why this work focuses on the current regulation. Several weaknesses of these provisions are listed below:

- The SA Constitutional Court has delivered a number of judgements on the right to privacy.[60] None of them relate to data privacy (PI SA Country Report 2003; Michelson 2004).
- There have been no reported cases around privacy at common law which deals specifically with information privacy.[61] Therefore, it is not clear whether data

[58] Mainly: the OECD's 1981 Guidelines; the EU's 1995 Data Protection Directive; the Netherlands' Wet Bescherming Persoonsgegevens (2000) (conforming closely to the EU Directive); the New Zealand Privacy Act (1993) (conforming closely to the OECD Guidelines) (Currie 2006b).

[59] These 'operations' need not be automated or computerised -- according to s 3(a) the Act applies to 'the fully or partly automated processing . . . and the non-automated processing of personal information entered in a record'. So, the Act will apply, on the one end of the spectrum, to a massive computer database intended for data mining and, on the other end, to a business's handwritten card catalogue containing the names and addresses of customers .

[60] The judgements of the SA Constitutional Court on privacy relate to the possession of indecent or obsecene photograps, the scope of privacy in society and searches. On details and cases references see PI South Africa Country Report (2003). http://www.privacyinternational.org/survey/phr2003/countries/southafrica.htm

privacy is covered by the common law right to privacy. There is also the absence of a definition of „personal data/personal information“ (Michelson 2004, PI SA Country Report 2003).

- Under the common law, violation of privacy because of negligence is not liable. To award damages on the grounds of negligence, the court would have had to develop the common law.[62]

All of the above mentionned weaknesses of the current regulation may negatively influence implementation of the future data privacy regulation. „The inherent conservatism of the courts“, and the fact that the protection of privacy is still very underdeveloped in South African law will mean that the courts may not adequately protect privacy in future (Ncube 2004) even if the new data privacy law is established.[63] It is thus clear that the right to privacy in the context of information privacy needs to be fully developed.

3.4.2 Confidentiality and HIV/AIDS in South Africa – legal issues

For over a decade, the duty to obtain informed consent for HIV testing was one of the most inviolable elements of the human rights approach to the HIV epidemic. In 2004, however, a change toward a „new approach“ to HIV testing gathered significant number of supporters (Heywood 2005). The two poles of the testing policy debate (RCT, routine counceling and testing vs. VCT, voluntary counceling and testing) illlustrate that the human rights argument can be manipulated to both support and oppose the routine offer of HIV tesing – the outcome depending largely, in rights terms, in whether more

[61] There is established case law in South Africa on all the concepts of privacy (bodily privacy, privacy of communications, territorial privacy), except for data privacy.

[62] Compare commentaries on the famous South African de Lille case concerning HIV/AIDs privacy, e.g. Business Day (2004) „*Generous judgment instils stigma*“ by Jonny Steinberg 24.07.2007 http://www.businessday.co.za/articles/topstories.aspx?ID=BD4A445289 [14.03.08].

[63] See also: Neetling et al. (2002, 589), Neethling J, Potgieter JM & Visser PJ (2002) Law of Delict (Butterworths: Durban) – cited in Ncube (2004).

emphasis is given to the right to life of and individual as well as the right of others not to be infected, or the right to personal autonomy (Heywood 2005, 15). The purpose of this work is not to go deep in the RCT – VCT debate. However, it is important to underline that HIV/AIDS status confidentiality plays a major role in the approach to the epidemic and testing/treatement. Therefore, these issues (testing policy and confidentiality) are interconnected. Choosing RCT as a policy option will have impact on data privacy.

In South Africa voluntarity of HIV testing and confidentiality of HIV/AIDS status in its general form has been already introduced in the ethical as well as legal regulation. There are several important proffessional sets of ethical guidelines for treatment of medical data.[64] All of them contain general references to privacy saying that disclosure of the patient's HIV/AIDS status as well ad testing for HIV should only take place with the informed consent of the patient (ALP 2007). The Code of Good Practice on Key Aspects of HIV/AIDS and Employment refers to the right to HIV/AIDS privacy in the workplace.[65] However, in any of these documents there is no guidelines on HIV/AIDS data treatment (gathering, storing, processing of this data).

When it comes to legal rules, the only employement law which specifically refers to HIV/AIDS is the Employment Equity Act[66] which only states that the employer cannot unfairly discriminate due to HIV status and cannot test an employee for HIV without lobour court authorisation. Therefore, the right to privacy about your HIV status at work is a common law right (ALP 2003). The first South African case concerning confidentiality of HIV/AIDS status is from 1993 (the so-called McGeary case).[67] It concerned unauthorised disclosure of the patient's HIV status by the doctor. The court

[64] These are: The Health Professions Council of South Africa (HPCSA) Guidelines of 2001, the South African Medical Associacion (SAMA) Guidelines, the South African Nursing Council (SANC) Guidelines (ALP 2007). The HPCSA replaced the South African Medical and Dental Council (SAMDC) and revised its guidelines of 1994.

[65] The Code states that all employees have a right to privacy which means that an employee does not need to disclose their HIV status to their employers.

[66] Employment Equity Act, No 55 of 1998

[67] See the judgement of the Supreme Court of Appeal of South Africa Jansen van Vuuren and Another NNO v Kruger (675/91) [1993] ZASCA 145; 1993 (4) SA 842 (AD) (28 September 1993) http://www.saflii.org/za/cases/ZASCA/1993/145.html [13.09.08].

firmy defended individual right to confidentiality, recognizing that a doctor cannot disclose HIV status even to other doctors without the consent of the patient unless there is a clear legal duty to do this. The court recognized as well that patients have a legal right to expect that health care workers will obey the ethical guidelines (like HPCSA etc.) (ALP 2003). However, it is important to stress that HIV/AIDS issues are often racially determined, especially in South Africa, due to the Aparteid experience. From this perspective, it has to be underlined that McGeary, the first confidentiality case took place in 1993. It concerned a white, middle class man. 15 years passed untill the South African court defended the right to HIV/AIDS status confidentiality of black, disempovered women, despite the fact that HIV/AIDS is a heterosexual, black women's disease in (South) Africa.[68] The so-called de Lille case[69] concerned disclosure of positive HIV status of three women that participated in a clinical drug trial that ended after concerns were raised regarding illness and fatalities among trial participants. Their names have been mentionned in a book, a biography of a politician, without their consent. Consequently, they faced severe stigmatization in their community (CALN 2007). Mark Heywood, of the NGO AIDS Law Project, commented that this was the first case heard by the Constitutional Court which was brought by very poor people who had tried, in vain, to protect their privacy rights against invasion by very powerful people (CALN 2007, Heywood, 2007).

Apart from the right to HIV/AIDS status confidentiality there is also case law regulating circumstances in which the Labour court allows the employer to organize HIV/AIDS testing in the workplace. In the Joy Mining v NUMSA 2002 case the Labour Court gave

[68] Women are disporportionately affected by the HIV epidemic in multiple ways, not only biologically (when the women are more at a disadvantage since HIV is more easily transmitted sexually from men to women than vice versa) but also due to the influence of gender. HIV-related risks are often greatest in situations where women are socialized to please men and defer to male authority. Certain harmful tradional practices such as female genital mutilation, the lack of social support for single women, sexual virginity testing, wife inheritance, rape and violence against women also have important consequences for HIV prevention. Sumultaneuously, women's inability to negotiate sex, let alone safer sex, their economic and societal reliance on men, their lower positioning within family and social structures and their traditional roles as caregivers make it next to impossible for most women to ensure protection from HIV (UNAIDS 1999, Mane&Aggleton 2001, 25).

[69] NM and Others v Smith and Others (CCT 69/05) [2007] ZACC 6 (4 April 2007). The full text of the judgment is available via http://www.saflii.org.

perimssion to a HIV test in the workplace provided (amongs others) that testing would be voluntary, anonymous, performed by an independent consulting company and Joy Mining would not be involved in the process in any way[70]. In I&J Ltd v Trawler&Line Fishing Unions et al. 2003 the Court confirmed that if HIV testing in the workplace is voluntary, anonymous and performed by an independent company the employer does not need authorisation from the Labour Court.[71] In PFC Building Glass Ltd. V CEPPAWU et al. 2003 the court granted an order allowing anonymous and voluntary HIV testing in the workplace. It held further that if the employee consented to the testing, then there was no need for the employer to approach the Labour Court for authorization.[72] In all three reported cases the trade unions supported the applications to run these programs (ALN 2005, 94-95). Nevertheless, although the HIV/AIDS voluntarity and confidentiality case law constitutes an important legal development in the area of data privacy it is still of a general character and does not directly address the problem of for instance, unlimited gathering of data.

3.5 South Africa – privacy rights record

The latest Privacy International' Privacy Ranking for 2007 highlated the following issues in relation to South Africa (PI 2007):

- No comprehensive private law or data privacy authority
- Interception law followed minimal consultation, requires intercept capability by design
- All service providers must gather detailed personal data on individuals before signing contracts or selling sim cards, with no specified length of retention period, but communication-related information is stored for 12 months
- New banking law came into effect in 2007, requiring court orders for access to financial information, and regulate credit bureau information

[70] Joy Mining Machinery v NUMSA & Others (2002) 4 BLLR 372 (LC).

[71] I&J Ltd v Trawler & Line Fishing Union & Others (2003) 24 ILJ 565 (LC).

[72] PFG Building Glass (Pty) Ltd v Chemical Engineering Pulp Paper Wood and Allied Workers Union & Others (2003) 24 ILJ 974 (LC).

- New smart ID cards began deployment in 2007, and in particular for refugees and asylum seekers

South Africa has been classified as the country with „systemic failures to uphold safeguards".

3.6 Summary

With the multiplying technological possibilites of gathering and profiling unlimited amounts of data medical information has come into use by organizations that are not bound by medical ethics codes. Therefore there is an urgent need for the law to regulate this situation. Although privacy is internationally recognized as a human right the right, still there is no global data protection act. The exisitng international instruments (the Council of Europe Convention, the OECD Guidelines and, most important, the EU Data Protection Directive) and (in the area of medical privacy) also the US HIPPAA do have harmonising objectives but they rather leave countries a significant degree of freedom in development of their respective data privacy regimes.

The African countries have the least developed data privacy protection regimes in the world. Together with their regional international instrument, the African Charter on Human and People's Rights not including the right to privacy. However, there is a growing interest in developins protections, since technology transfer is quick, easy and relatively cheap an there is a growing gap between technical possibilities of gathering, storing and profiling unimaginable amounts of data and the underdeveloped legal regulation.

South Africa has come the furthest, with its draft Protection of Personal Information Act (while having some privacy safeguards in the Constitution as well as in the common law). Nevertheless, the new law is still in the process of pending works which have already taken 8 years. That is why there is a need for awareness raising on the importance of developing information privacy safeguards, using the law for such protection as well as forming a broad social consensus.

4. Chapter 4: South Africa - HIV/AIDS Information in the Workplace

4.1 Introduction

According to the literature (Rosen 2000, Mundy&Dickinson 2004, 177), the size of workforce and reliance on skilled labour play an important role in the corporate response to HIV/AIDS (UNAIDS 2005, 12).[73] Accordingly, the development of HIVAIDS best practice in the workplace, including the provision of VCT and ARV – has been limited to a few large corporations (big workforce and demand for the skilled labour), with small and medium enterprises dailing to follow this lead, either worldwide (UNAIDS 2005, 12) and in South Africa (SABOHA 2004, Mundy&Dickinson 2004, 177).[74] The following section presents an overview of workplace response to HIV/AIDS in South Africa. In the second part, this section presents some aspects of HIV/AIDS workplace policies of 3 South African companies, Eskom, Anglo American plc and BHP Billiton. These are the companies chosen as best practice examples by UNAIDS in 2005. For each of the companies, the company HIV/AIDS policy is described, as well as its practices of HIV/AIDS confidentiality and data management.

[73] In 2004 the ILO carried out a pilot survey of HIV and AIDS activities undertaken by companies in 11 countries; 5 in Africa, 5 in Latin America and the Caribbean, and in China. Preliminary returns from the 42 surveyed companies revealed that the size of their workforces—which ranged between 12 and 310,000 employees—was a major factor. Most of them provided on- site occupational health services, applied The ILO Code of Practice on HIV/AIDS and the world of work, and had workplace programmes to prevent HIV. However, all three services were more likely to be found in larger companies. On the other hand, few companies provided antiretroviral treatment, care and support services to family members or to the community (ILO 2004, UNAIDS 2005, 12).

[74] For companies with relatively unskilled staff the burden of AIDS is modest. Companies can easily replace employees – putting the burden of treatment onto the government. By contrast, in sectors where there is the need for access to a more skilled and limited workforce (like, among others, tourism and mining) the impact is greater – and the response from employers has tended to be greater (UNAIDS 2005, 8). For smaller companies, the impact of HIV is small and most lack the resources to develop their own programmes.

4.2 Background – corporate and trade unions' response to HIV/AIDS in South Africa

Corporate HIV/AIDS programs are gathering a lot of attention as it seems that they can create a space for succesful partnerships with government agencies, NGOs etc. (UNAIDS 2005, 8). The specifics of corporate HIV/AIDS response in South Africa is that business has gone ahead with such programmes before the roll-out of a public-sector universal treatment plan in 2004 (UNAIDS 2005, 6).[75]That is why these programs form a significant part of the response to the epidemic as well as an important sphere for research in the social dimension of HIV/AIDS. This makes corporations a very important actor in the South African attempt to manage one of the most severe cases on HIV/AIDS epidemic in the world.

In South Africa, in the late 1980s, HIV/AIDS was skyrocketing in the neigbouring African countries (many of them being home countries for migrant workers employed in South Africa) and was about to start in South Africa. That was the time when many companies begun to carry out pre-employment testing. For instance, Eskom was among them, and this fact is today openly acknowledged by the company, together with its current devotion to countract HIV/AIDS stigma and discrimination (Eskom 2006).There were also other cases of serious workplace HIV/AIDS discrimination, like the case A v x (Pty) Ltd, where a worker was dismissed for wearing a „HIV positive" T-shirt under his work clothes)[76] or pre-employement HIV/AIDS discrimination case "A" v South African

[75] ARV treatment is available through public clinics in South Africa only since 2004 (the so-called „Comprehensive Plan", pursued in 2003 to make ART universally accesible over 5 years, NDoH 2003NdoH (2003) „Operational plan for comprehensive HIV/AIDS management and treatment for South Africa" Pretoria, Deartment of Health www.doh.gov.za/aids/index.tml

[76] The case A v X (Pty) Ltd concerns an employee who was allegedly dismissed from work in November 2001. Before the dismissal, the employee had fainted at work and was taken by his employer, Mr X, acting on behalf of X (Pty) Ltd, to a local clinic. At the clinic, the employer saw that Mr A was wearing a t-shirt with the words "HIV-positive" printed on it. When he returned to work, the employer questioned Mr A about this. An argument ensued about whether Mr A should go for an HIV test, after which, Mr A alleged that he was dismissed. Judge Landman dismissed the case on the basis that Mr A had not discharged the onus of proving that he had been dismissed. http://www.alp.org.za/modules.php?op=modload&name=News&file=article&sid=212 [20.07.07]. Full judgement can be downloaded from: http://dedi20a.yourserver.co.za/alp/images/upload/A%20v%20X.doc [08.02.08].

Airways (SAA).[77]

Nevertheless, the attitude of big corporations in South Africa has recently changed, from the attempts to keep HIV/AIDS out of the workplace (pre-employment testing, dismissals of positive employers) to HIV/AIDS „management" in the workplace. The change was brought when business finally realized that pre-employment testing was ineffective tool to "keep HIV/AIDS out" since people were quite likely to become HIV-positive after joining the company.[78]Workplace HIV/AIDS management usually means gathering statistical data on prevelence, adopting a HIV/AIDS policy, making antiretroviral therapy available through the company's medical schemes. Companies make effort to combact discrimination, focusing, however, on HIV/AIDS related stigma coming from peer, not management. The argument that workers fear stigma from their colleagues more than discrimination by their employers (Eskom & HPADRA 2002)[79] form a mainstream business argument of HIV stigma in the workplace, being repeated both by UNAIDS (2005) as well as Global Business Coalition on HIV/AIDS (GBCOHA 2003).

Trade unions (COSATU) which would become part of the ruling government alliance in 1994, got interested in AIDS in 1989, passing its first resolution targeting the epidemic (Van der Vliet 2006, 52). Subsequently, few unions attempted to put AIDS programs in

[77] The case was brought by the ALP on behalf of a man who had been refused employment by South African Airlines, one of South Africa's largest employers. ALP was able to show that SAA had created a policy based on misinformation and generalisations about HIV. The court settlement in the Labour Court in 2004 (after 6 years of proceedings) marks an important step towards bringing South Africa's business practices in line with its laws.

[78] Subsequently, it became increasingly clear that for a number of reasons, the majority of Anglo American's employees in South Africa (its mining workers) were at risk of contracting HIV infection, so did about 30% of the overall South African workforce. (migration, dispersion of the families, the biggest socio-economic inequality gap in the world - Marks 2002; Packard & Epstein 1992; Setel 1999; Schneider 2002; Walker et al. 2004).

[79] To address stigma, Eskom is working with the Horizons Programme (a global HIV and AIDS operations research programme) and Development Research Africa on an intervention programme in KwaZulu-Natal. Qualitative research has been carried out to explore how stigma and discrimination become apparent in the workplace, family and community (Eskom & HPADRA 2002, UNAIDS 2005).

place, but in the politically difficult years in the 90ties AIDS was often not prioritised.[80] However, later, when the government focused on questioning whether HIV causes AIDS instead of dealing with epidemic, trade unions stood up against the government they supported, stating publicly that the link between HIV and AIDS was irrefutable (Van der Vliet 2006, 61). Currently, South African trade unions work hard on making HIV/AIDS a social dialogue priority. Also, at the company level, the research shows that lack of trade union support for the workplace VCT practice (even temporary e.g. associated with the implementation of a non-cooperation policy in escalation of a coincident industrial dispute) appears to have been a major barrier to participation or those who perceived non-support to equate to VCT confidentiality concerns (Mundy & Dickinson 2004, 186).[81] This shows that participation of union representatives is key to the success of workplace HIV/AIDS interventions. It also shows that trade unions may play a very important role in responding to the new privacy challenges in the area of data management.

The problem of trade unions response to HIV/AIDS is that, according to the research, the disease is still seen as a personal and therefore confidential issue, but confidential in the sense of an „unspeakable subject" in the workplace due to, among others, lack of openness of public talking about sex, lack of sexual education,[82] patriarchal attitudes towards sexual relationships(Mapolisa et al. 2004, 166). All these elements create considerable barriers to introducing the subject. At the same time HIV/AIDS is subject to „othering" responses, while it is often presented as problem of blue-collar workers (class), black South Africans (race), the youth (generation), other nations – migrant

[80] For instance, in 1996 the Department of Health sent out a questionnaire on the issue to 150 trade unions – only 12 responded (Van der Vliet 2006, 53). Given that HIV/AIDS was undoubtedly something which would be critical to workers, it was suprising that there had been „hardly a squeal from the official guardians of working class people, who seemed to have little time, capacity and - dare we say it – will to deal with these issues" (Heywood 1997, 28-29).

[81] However, this particular research showed that lack of support of trade unions for workplace VCT programs was not the most important factor influencing the uptake.

[82] South Africa remains a conservative country, with decades of public and even academic debate about „promiscuity" of Africans. Nelson Mandela publicly admitted that he did not address the growing problem of HIV/AIDS during his presidency because of feeling uncomfortable about discussing sexual matters (while admitting that not adressing HIV/AIDS was one of the greatest mistakes of his presidency (Illife 2006).

workers and those who use services of sex workers (behaviour). HIV/AIDS remains a personal issue and it is only beginning to be constructed as a typical workplace concern.

4.3 HIV/AIDS policies of 3 South African companies

In 2005 the UNAIDS chose three South Adrican companies as examples of good practice in providing ARV therepy in the workplace: Eskom[83], Anglo American[84] and BHP Billiton[85] (UNAIDS 2005). The three companies have been working on HIV and AIDS for some time: Anglo American and Eskom since the late 1980s, BHP Billiton since the early 1990s. In 1986, Anglo American was involved in one of the first important prevalence studies of HIV in southern Africa. At that time, no black South Africans were known to be HIV-positive, only white gay men. Of the 18 450 mineworkers in South Africa tested for the study, 4 tested HIV-positive (0,02%) (UNAIDS 2005, 20).[86] Their HIV and AIDS policies and programmes are viewed as pioneering efforts and examples of best practice.

In all these companies decision about introducing a workplace HIV/AIDS program has been taken before the official involvment of the Government. It is worth to mention that until 2004, antiretroviral therapy was not provided by any South African public health system. Furthermore, the national government denied the link between HIV and AIDS

[83] Eskom is a public company that generates and distributes electricity. It was incorporated in July 2002 and is wholly owned by the South African Government. It has about 30 000 employees spread over 37 sites. It is among the world's top seven electricity utilities in terms of generation capacity, and the top nine in terms of sales http://hivatwork.org/program/case-study.htm [17.10.07]

[84] Anglo American plc is one of the world's largest mining and natural resources companies. The company has 193 000 employees in 61 countries, with by far the largest number (139 000 employees) in eastern and southern Africa. The national branch of Anglo American is the largest company in South Africa.

[85] BHP Billiton was formed in June 2001 as a merger between two companies. It employs around 35 000 permanent employees; another 32 000 contractors are employed at various operation sites. About 30% of the company's operations are based in southern Africa 40% of the permanent employees work there. BHP Billiton relies heavily on the migrant labour. The company is a global leader in providing aluminium, energy, coal and metallurgical coal, copper, ferro-alloys, ironore and titanium minerals, and has substantial interests in oil, gas, liquefi ed natural gas, nickel, diamonds and silver.

[86] Prevalence of 0.02% compared with 0.34% of mineworkers in Botswana and 3.76% of mineworkers in Malawi at that time (UNAIDS 2005, 20).

and refused to make antiretroviral therapy available nationwide through the public health-care system (Illife 2006). Eskom' own health insurance provided some antiretroviral therapy to people living with HIV from the 1990s (Eskom 2006), as one of the first companies in South Africa to do this.[87] Anglo American and BHP Billiton decided about providing ARV in 2002. It is worth to mention that Anglo American' HIV/AIDS programme is unique in its scope [88] The company is the largest single business customer for AIDS drugs in the world (UNAIDS 2005, 42).

The companies use different mechanisms to fund and provide antiretroviral therapy. Anglo American has its own comprehensive health-care services linked to all its operations. It also used to have, perhaps unusually, its own health research subsidiary—Aurum Health Research—which is fulfilling the disease-management role. In 2005 Aurum was promulgated as an independent, not-for-profit Public Benefit Organisation.[89] Still it does research into the surveillance, treatment and management of epidemic for Anglo American but also for other companies. BHP Billiton and Eskom have divested themselves of their inhouse facilities and use medical aid societies to fund private health care for employees (UNAIDS 2005). Eskom as well as BHP Billiton managements declare that they do not know the number of their employees on antiretrovirals, since the treatment is provided by an outsourced medical establishment and this data is confidential (UNAIDS 2005, 37, 45).

All the three companies reported that many of their workers refuse testing because of the stigma surrounding HIV and AIDS. However, a slow change is observed. For instance, for VCT the assumed company standard is 50% of Eskom staff to have undergone voluntary counselling and testing for the review period. This was achieved with a VCT

[87] The Eskom HIV/AIDS policy was completed in 1988 as probably the first formal workplace policy to be produced by a South African company; it covered education, training and counselling. It stressed the importance of education and information, confidentiality, voluntary counselling and testing, and non-discrimination (Eskom 2006).

[88] there are an estimated 33 000 Anglo American employees living with HIV in South Africa (out of a total of almost 140 000 Anglo American workers in eastern and southern Africa) (UNAIDS 2005, 20).

[89] http://www.auruminstitute.org/about.php [02.03.08]

level of 50,5% (50,3% in 2006) (Eskom 2007). The same is with Anglo American and BHP Billiton.

Although, according to standards, all policies and programmes should ensure confidentiality for all employees, and confidentiality procedures need to be seen as completely reliable by staff (UNAIDS 2005, 13), privacy issues are often subject to negotiation. For instance, in 2006 the chief medical officer for South Africa of de Beers company (part of Anglo American), Tracey –Peterson, complained that because of trade union pressure, the company had to outsource its treatment program to an an external healthcare organization, which has resulted in lack of data on workers on treatment. The idea was to ensure there was no identification of HIV positive staff, which could lead to discrimination. Consequently, the result has been to make it impossible to trace the impact of treatment of individual employees on productivity“ (Financial Times 2006). This story shows that sometimes cost – benefit analysis may enhance interest in identifiable HIV/AIDS data even if the company is ready to to declare commitment to protecting workers privacy.

The other possibility is that the companies, providing for workplace testing and treatment schemes, may start to treat the HIV/AIDS related data as their property, open to profiling and, perhaps, sale (even if delinked from individualized data). It has to be underlined that it is there are already first signs of implementing new technologies to deal with HIV/AIDS workplace information in South Africa. In 2006 Financial Times reported on testing of an electronic pen that electronically “reads” medical forms for HIV patients as doctors and nurses fill them in by hand. The pen was tested by Aurum Institute, a research body of Anglo American in Johannesburg. The initiative was „the latest in wide-ranging efforts to both better implement and assess the effects of antiretroviral treatment programmes for employees – replacing cumbersome and inaccurate paper records, without the disruptiveness and cost of computers“ (Financial Times 2006). This entails new challenges to confidentiality and management of HIV/AIDS data.

4.4 Summary

The importance of corporate response to HIV/AIDS is widely recognized. The common hope is the possibility of successful private-public partnerships in targeting HIV/AIDS, in the lines of corporate social responsibilities. It has to be underlined that in South Africa corporate responses to HIV/AIDS were developed before the roll out of a public sector universal treatment plan. This adds a lot to the general trust for and reliance on business' initiatives to address the epidemic, especially in Africa. Although publicity by large employers about their treatment programs should be interpreted cautiously,[90] corporations remain very important actors in managing HIV/AIDS in South Africa.

However, corporate response is to some extent driven by cost-benefit analysis which has not been fully quantified yet (Rosen & Simon 2002, Larson & Rosen 2002, Rosen et al. 2003, Rosen 2005, Connelly & Rosen 2005). [91] Hopefully, business would not loose interest in financing ART (it seems that although costs are important, there are much more profitable undertakings to invest money in than organizing the company ART programme. Therefore, it might be argued that such initiative is always to some extend influenced by ethical considerations). Nevertheless, more alarming is the possibility that, driven by cost benefit analysis, business might begin to treat HIV/AIDS related data gathered in the course of running the company HIV/AIDS programme (testing and/or treatment) as their property they paid for. Taking into account their strong position as an active partner in addressing HIV/AIDS epidemic it might happen that there will be a friendly political climate for business to win on that. That is why it is so important to come up with the rights oriented, privacy rights aware proposals and tools to educate and assist both companies and their social partners (like trade unions).

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[90] While there is a high level of access to treatment in biggest South African corporations, uptake of services is low and only a small fraction of employees medically eligible for antiretroviral therapy are receiving it. The research involved South African companies with more than 6000 employers (52 out of the concerned 64 companies agreed to respond) Approximately 27% of suspected HIV-positive employees were enrolled in HIV/AIDS disease management programs, or 4.4% of the workforce overall. Fewer than 4,000 employees in the entire sample were receiving antiretroviral therapy. In-house (employer)disease management programs and independent disease management programs achieved higher uptake of services than did medical aid schemes (Rosen 2005).

[91] It is estimated that currently it takes 3 years for workplace treatment programs pay for themselves due to reduced absenteesm and decline in healthcare charges (Rosen 2005).

Conducting a prevalence survey of HIV across a company is the first step for a company considering introducing workplace HIV/AIDS progamme (UNAIDS 2005, 13). Consequently, the problems how to tackle confidentiality of HIV/AIDS data arise in the very moment of making a decision about implementing a HIV/AIDS policy. Sometimes it might seem that the type of HIV/AIDS management in the workplace (e.g. in house managment or outsourcing to a professional health care provider) might influence HIV/AIDS data confidentiality practices, but also responsibility of the employer. While sometimes companies justify outsourcing of HIV/AIDS management by the need to improve confidentiality perceptions among workers (Eskom, BHP, Biliton), the same companies then declare that they do not know the number of their employees on antiretrovirals, since the treatment is provided by an outsourced medical establishment and this data is confidential. Therefore, outsourcing, while good for HIV/AIDS data confidentiality, may create gap for escaping responsibility for HIV/AIDS assistance in the workplace.

5. Chapter 5: HIV/AIDS Workplace Management and Confidentiality Issues in South Africa – interviews

5.1 Introduction

This chapter is based on interviews with trade union as well as business representatives. The first part analyzes interviews with trade unionists from COSATU (National HIV/AIDS Coordinator) and NUM (National HIV/AIDS Coordinator, National HIV/AIDS Officer, National Coordinator for Anglo Gold, National Coordinator for Eskom). This part focuses on the following issues: discrimination, perceptions of confidentiality, implications of outsourcing of HIV/AIDS management, data treatment as a trade union issue. The second analyzes interviews with representatives of HIV/AIDS workplace management providers and the SABCOHA reperesentative. This part focuses on the following issues: perceptions of the employer's interest in HIV/AIDS data of its employees, outsourcing of HIV/AIDS management, Interest of providers in confidentiality safeguards.

5.2 Interviews with trade union representatives

5.2.1 Discrimination

Argument that workers are more fearful of discrimination from their peers than from the company itself is sometimes used to show that it is because of stigma and discrimination from the part of co-workers that people do not come forward to receive ARV therapy, even if provided by the company and „prefer" to „go home and die". This argument is presented (understandably) mostly by employers, it was also cited in UNAIDS Report (2005 43,45).[92]

[92] „*Confidential voluntary counselling and testing was widely available within the companies, but people were reluctant to come forward because of the stigma attached to HIV and AIDS. Company policies and programmes aimed to coun- teract stigma and discrimination, but it takes time to eradicate such culture-bound attitudes. Interestingly, a survey carried out among some Eskom employees showed that they were more fearful of discrimination from their peers than from the company itself*" (UNAIDS Report 2005,43). *„In a few cases, stigma and discrimination are preventing people living with HIV from coming forward to receive antiretroviral therapy. At Eskom, Roos said there have been several people who have "preferred to*

It has to be underlined that both trade unionists (and HIV/AIDS management providers interviewed – see part 2) were of the opinion that workers are indeed afraid of discrimination from their peers, but they are very much afraid of discrimination from the company. At the same time, ALP activists and trade unions mentionned that the everyday practice in South Africa shows cases of attempts to eliminate HIV-positive workers from worplace as well as cases of indirect discrimination on grounds of HIV/AIDS (like incapacity dismissals,[93] misconduct dismissals,[94] limiting assistance for occupationally acquired diseases,[95] misleading workers by occupational doctors as to treatment possibilities provided by the company in order to make them leave the workplace,[96] cases in which occupational doctors were disclosing their patients' HIV/AIDS status to the employer.[97]

Therefore, trade unionists interviewed said that discrimination is present in both the relationship between the HIV positive worker and the employer as well as in the relationship between the HIV positive worker and the co-workers.[98] Discrimination from the part of the co-workers is seen as rooted in lack of trust in information received.[99]

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go home and die." In some cases, low take-up has been a problem for the company partly because people have ill-founded fears about the toxicity of antiretroviral drugs" (UNAIDS Report 2005, 45).

[93] See the interview with ALP Attorney 04.12.07.

[94] See the interview with ALP Attorney 04.12.07. and the interview with COSATU HIV/AIDS Coordinator 12.11.07.

[95] The problem of using HIV/AIDS status of a worker for not qualifying his disease as silicosis, giving him the right to compensation for occupationally acquired disease, but as TB, an opportunisic disease to HIV/AIDS. See the interview with NUM HIV/AIDS Officer 13.11.07.

[96] See the interview with COSATU HIV/AIDS Coordinator 12.11.07.

[97] See the interview with NUM HIV/AIDS Coordinator 19.11.07.

[98] See the interview with NUM HIV/AIDS Coordinator 19.11.07., NUM HIV/AIDS Officer 13.11.07., COSATU HIV/AIDS Coordinator 12.11.07.

[99] E.g. workers do not trust that they will not get infected by the everyday contact with HIV positive co-workers and refuse to eat with them, sit next to them etc. The existence of alternative medicine concepts is typical for South Africa. Lack of trust in information received (eg. on the ways of infection) may explain the severity of workplace HIV/AIDS discrimination from the part of coworkers (eg. common example of banning HIV positive worker from using common kitchen and bathroom, refusing to eat in the same room with a HIV positive person etc.) or from the part of the community. If people do not believe arguments of

However, in the view of the interviewed trade unionists one is not justified to make these two discriminations „equal", as in practice these are co-workers who carry the burden of HIV/AIDS in the workplace, being responsible for taking the sick collegue's shifts or assisst him/her at work when he/she is not feeling well. That is why, while there are many cases where co-workers refused to work or live and eat with the HIV positive person, this relationship is more complex.[100]

What is important, noone of the interviewed trade unionists mentionned the need to prioritize the interest of the not-positive workers over the rights of the HIV/AIDS positive individual. Occupational risk of HIV infection was seen as easily manageable through simple health and safety measures.[101] The need to identify HIV-positive workers in order to make their collegues able to better protect themselves was not recognized as justification for limiting confidentiality of HIV/AIDS status. The interviewed trade unionists saw relation of the individual rights of a HIV positive person and the rights of his/her HIV-negative collegues in terms of the COSATU principle „ an injury to one is an injury to all".[102] The way to protect HIV-negative workers against the infection was seen in education and awareness-raising activities directed both at HIV-positive and HIV-negative workers.[103] Solidarity among workers, eliminating discrimination and developing an inclusive labour response to HIV/AIDS was seen as a cornerstone of action on HIV/AIDS in the workplace.[104]

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conventional doctors that it is not possible to get HIV otherwise than through sex or blood the diesease and infected persons might seem much more dangerous for the „public health". This issue will not be explored in this research. On alternative perceptions of medicine and HIV/AIDS.

[100] See the interview with NUM HIV/AIDS Officer 13.11.07.

[101] See the interview with NUM HIV/AIDS Officer 13.11.07. and the interview with COSATU HIV/AIDS Coordinator 12.11.07.

[102] See the interview with COSATU HIV/AIDS Coordinator 12.11.07. and the interview with NUM HIV/AIDS Coordinator 19.11.07.

[103] See the interview with COSATU HIV/AIDS Coordinator 12.11.07.

[104] See the interview with NUM HIV/AIDS Coordinator 19.11.07., NUM HIV/AIDS Officer 13.11.07., COSATU HIV/AIDS Coordinator 12.11.07.

To sum it up, it has to be underlined that workplace discrimination on grounds of HIV/AIDS status comes both from the employer and co-workers while the first one is much more dangerous for the HIV positive person, as it comes in the form of dismissal. As to discrimination coming from peers, it seems that there is already a sufficient space to introduce confidentiality safeguards as a workplace and a trade union issue.

5.2.2 Perceptions of confidentiality among trade unions

Among the interviewed trade union representatives from COSATU and NUM, perceptions of confidentiality of HIV/AIDS data in the workplace are **low** (LM, PM, JB).[105] Trade unionists are of the opinion that still many employers are interested in identifying and dismissing HIV positive workers. They also point to various examples of breaches of confidentiaslity in the workplace, starting from cases of dismissals in the moment of learning (or suspecting) about a worker's positive HIV status.

In the view of trade unions the fear of weak confidentiality definitely plays a crucial role in a weak uptake of VCT in the workplace. Trade unions are of the opinion that employers do not accept their responsibilities to create a non-discriminatory, inclusive workplace. On the earlier stage they were more interested in investigating the disease and identifying the HIV-positive workers while at the same time they wanted to escape the responsibility of implementing a company HIV/AIDS policy. That is why they argued that before knowing the exact number of HIV-positive workers they could not implement such policy. Nowadays, in the view of trade unionists interviewed, the situation has changed. Many big employers did adopt HIV/AIDS policies and created possibilities of ARV treatment. Now they argue – the treatment is available, but workers do not use it and the uptake is very low. In the view of the interviewed trade unionists the problem is that these programs lack structural safeguards that would allow workers to take advantage of them, as provisions for confidentiality are not created. Accordingly, saying that it is the workers' fault not to use opportunities of treatment in the workplace is viewed as a

[105] See the interview with COSATU HIV/AIDS Coordinator 12.11.07, NUM HIV/AIDS Officer 13.11.07, NUM HIV/AIDS Coordinator 19.11.07.

run away from the responsibility for providing treatment options workers would be able to actually use.[106]

To conclude, confidentiality safeguards are seen as one of the most urgent issues in negotiating HIV/AIDS management in the workplace, since weak perceptions of confidentiality might be counterproductive in addressing HIV/AIDS in the workplace, as many workers will not decide to get tested or treated, being too scared and embarassed that the co-workers, their spouses and community will learn about their condition.

5.2.3 Getting tested - Outsourcing/internally

Trade unions (NUM, COSATU) encourage workers to get tested.[107] If the proper confidentiality safeguards be implemented, trade unions would not be against an internally run HIV/AIDS management in the workplace (that is, organized by the company – eg. through occupational clinics). From the perspective of coherence and transparency of responsibility such arrangement could be evaluated as better than outsourcing of the management of HIV/AIDS.[108] However, although the situation improved significantly during the last 5 years, still there are cases of identifying and dismissing HIV positive employees. For instance, in de Beers company (part of Anglo American), when the employer decided to introduce HIV/AIDS VCT, trade unions did not allow on-site testing. Having serious concerns about confidentiality they made the employer to outsource an external medical unit to run the VCT programme.[109]

However, in trade unions‘ view, also outsourcing of HIV testing and/or treatment currently does not guarantee confidential management of the workers HIV/AIDS data.

[106] See the interview with COSATU HIV/AIDS Coordinator 12.11.07

[107] See the interview with NUM HIV/AIDS Coordinator 19.11.07., NUM HIV/AIDS Officer 13.11.07., COSATU HIV/AIDS Coordinator 12.11.07, NUM Eskom Coordinator 19.11.07, NUM Anglo American Coordinator 19.11.07.

[108] See the interview with NUM HIV/AIDS Coordinator 19.11.07.

[109] See the interview with COSATU HIV/AIDS Coordinator 12.11.07.

The concern is that commercial character of the relationship between the employer and the company providing HIV/AIDS management in the workplace will make this data vulnerable to informal unauthorised disclosure to the employer.[110] Consequently, the wish of the provider to satisfy its customer (the employer) will be stronger than the general rule of liability for unauthorised disclosure.

In the view of the perceived dangers of the commercial relationship between the employer and the provider of HIV/AIDS management in the workplace for the confidentiality of the HIV/AIDS data COSATU and NUM rather advice workers to test and get treatment outside the company scheme, in order to prevent the employer from finding out about HIV status of his workers.[111] Consequently, we have to deal with a problematic situation: trade unions encourage workers to take adventage of testing and treatment available through public clinics („since the Government has finally decided to make ARV accessible there is no reason why workers should not use it“)[112] while, at the same time, confidentiality concerns make them reluctant to do the same in case of testing and treatment possiblities available through company schemes. Accordingly, eventhough these possibilities exist, there might be underused.

In other words, it seems that neither of management options (insourcing/outsourcing) guarantees better perceptions of confidentiality among workers, at least in the view of the interviewed trade unionists. While outsourced HIV/AIDS management is perhaps more trusted by workers, still, trade unions avoid to make any general recommendations also in case of outsourced HIV/AIDS management in the workplace and rather advice workers to get assistance (testing or treatment) outside the schemes provided by the company.

[110] See the interview with NUM HIV/AIDS Officer 13.11.07.

[111] See the interview with COSATU HIV/AIDS Coordinator, 12.11.07 NUM HIV/AIDS Coordinator 19.11.07., NUM HIV/AIDS Officer 13.11.07

[112] See the interview with COSATU National HIV/AIDS Coordinator 12.11.07.

5.2.4 Data treatment as a trade union issue

Trade unionists interviewed recognized confidentiality as a cornerstone od workplace action in the area of HIV/AIDS. They explicitly declared that they will never support the employer's HIV/AIDS activities (providing testing and/or treatment) if confidentiality is not guaranteed.[113] Trade unions recognized HIV/AIDS in the workplace as a trade union issue and a part of a struggle for a non-discriminatory workplace.[114] However, while talking about HIV/AIDS confidentiality, noone of the trade unionists interviewed made more detailed demands about data treatment. The references to HIV/AIDS data confidentiality were general. In other words, HIV/AIDS data treatment (as oppose to data confidentiality) has not become a trade union issue yet in South Africa. Nevertheless, other trade union policy priorities, especially peer education in partnerships with the employer,[115] make room for **new initiatives** aiming at making data confidentiality a tool to win workers' involvement in HIV/AIDS workplace inintiatives, like, for example, introducing confidentiality as a training module in the planned peer education programs.

5.3 Interviews with business representatives

The management of HIV and AIDS workplace programmes is a growing business in itself in South Africa. There is some evidence that employees welcome contracted-out service arrangements because they provide a greater sense of confidentiality and discretion since they are located and operated separately from the employer (GBCOHA 2003b).

[113] See the interview with COSATU HIV/AIDS Coordinator, 12.11.07., NUM HIV/AIDS Coordinator 19.11.07., NUM HIV/AIDS Officer 13.11.07.

[114] See the interview with COSATU HIV/AIDS Coordinator, 12.11.07.

[115] See the interview with COSATU HIV/AIDS Coordinator, 12.11.07.

5.3.1 The interest of the employer in the workers' HIV/AIDS data

The interviewed managers recognized that the traditional doctor - patient relationship is curently sunbject to change. In the area of workplace HIV/AIDS management there is no more a dual doctor – patient relationship but a triangle relationship with the employer as a third part. This situation has significant implications for confidentiality of workers' medical data and sometimes may put HIV/AIDS data confidentiality at stake.[116] The interviewed managers also admitted that the company, even if intrested in HIV/AIDS data, is not entitled to any information it asks and that a standard of good business for external providers of HIV/AIDS workplace management is not to provide identifiable HIV/AIDS data of workers.[117] They were of the opinion that in case of ethical employers there will be no illegitimate demands for too much data. The respect for personal data confidentiality was seen as a part of ethical employment. The practical reason for that was seen in awareness that with low perceptions of confidentiality of HIV/AIDS status it will be impossible to succeed with any workplace HIV/AIDS initiative.[118]

Therefore, all the managers interviewed were in accordance saying that their companies have never been asked to provide identifiable HIV/AIDS data and that in the majority of cases basic data on HIV/AIDS in the workplace – numbers, statistics – are sufficient.[119] The source of this attitude was seen in the changing character of corporate HIV/AIDS policy in South Africa. In the view of the interviewed managers, in general, the South African big, progressive employers are currently moving away from their (previous) often discriminatory practices towards HIV positive workers. However, the interviewed

[116] See the interview with the SABCOHA representative, 19.11.07, Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

[117] See the interview with the SABCOHA representative, 19.11.2007, Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

[118] See the interview with the SABCOHA representative, 19.11.07.

[119] See the interview with the SABCOHA representative, 19.11.2007, Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

managers confirmed that workplace HIV/AIDS discrimination from the part of the companies still exist.[120]

When it comes to the monitoring of HIV/AIDS in the workplace all the interviewed managers were of the opinion that the argument about the need for more personalized data to evaluate costs and efficiency of corporate HIV/AIDS programs cannot defend itself.[121] The employer can adequately manage HIV/AIDS related risk without infringement of its employees privacy rights and the company does not need identifiable HIV/AIDS information in order to assess costs and efficiency of workplace HIV/AIDS policies. [122]

5.3.2 Insourcing/outsourcing of HIV/AIDS management

In relation to the role of confidentiality perceptions in VCT and ARV uptake, all of the interviewed managers were of the opinion that HIV/AIDS data confidentiality does play a very important role in low uptake of testing and treatment in the workplace.[123] They called for recognition of how inherently confidentiality of workers‘ HIV/AIDS data is interconnected with other workplace matters. Accordingly, they called for a broad perspective on HIV/AIDS data confidentiality. In the view of interviewed managers the way to improve confidentiality safeguards (which in turn will positively affect HIV/AIDS testing and treatment uptake) is to strenghten the position of the HIV/AIDS management providers. The aim would be to ensure that these companies can operate freely from any

[120] See the interview with SABCOHA representative 19.11.07, who specifically pointed at the agriculture sector in South Africa.

[121] See the interview with the SABCOHA representative, 19.11.2007, Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

[122] See the interview with the Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

[123] See the interview with the SABCOHA representative, 19.11.2007, Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

pressure to disclose workers‘ data on their HIV/AIDS status and that they implement appropriate safeguards in order to secure safety of this data.[124]

Some of the interviewed managers underlined that outsourcing of the workplace HIV/AIDS management might be beneficial for personal data confidentiality. It is because of external position of providers which are independent from the workplace. Specifically thanks to their independent position they are solely interested in providing treatment. For them individualized HIV/AIDS data are only the means to monitor state of health of a given person and, if necessary, to administer councelling and drugs. Therefore, there will never be situation in which identified positive HIV/AIDS status will lead to workplace discrimination.[125] Also, in case of the external management HIV/AIDS will not cumulate with discrimination on other grounds – for instance, identified positive status will not lead to dismissal of a worker unwanted for other reasons – from personal to those related to gender, race, sexual preference etc.[126] As one of the managers put it „*confidentiality alone is a good reason for outsourcing HIV/AIDS management in the workplace*.[127] However, other managers were more cautious in linking higher uptake with outsourcing of HIV/AIDS management. According to their arguments, changes in uptake are always influenced by more than one condition and is brought about by a combination of factors.[128]

In the view of the interviewed managers another problem which makes outsourcing interesting for HIV/AIDS data confidentiality safeguards is the traditional and historical conflict between workers and employers which is evident in South Africa that dates back to the anti-Apartheid struggle. According to this argument, perceptions of confidentiality

[124] See the interview with the SABCOHA representative, 19.11.2007, Qualsa representative, 30.11.07.

[125] See the interview with the SABCOHA representative, 19.11.2007, Qualsa representative, 30.11.07.

[126] See the interview with the SABCOHA representative, 19.11.2007, Qualsa representative, 30.11.07.

[127] See the interview with the Qualsa representative, 30.11.07.

[128] See the interview with the Lifeworks representative, 03.12.07

are subjective and it is evident that a current South African workplace is to large extent characterized by workers‘ mistrust in employers. That is why one has to be aware that sometimes even if security of workers‘ HIV/AIDS data is in place, perceptions of confidentiality of HIV/AIDS status may remain low because of general lack of trust in labour relationships in South Africa.[129]

5.3.3 Interest of providers in confidentiality safeguards

The interviewed managers reported several technical confidentiality safeguards implemented in order to protect workers‘ confidentiality in HIV/AIDS programs. One of the most popular confidentiality safeguards is flexible reporting securing practical anonymity. All of the interviewed providers confirmed that they adjust data made available to the employer in order not to allow identification of particular HIV-positive workers.[130] Commonly, the office units that deal with HIV/AIDS related information are separated, with the strictly controlled assess for the staff only.[131] HIV/AIDS information is also placed in separate databases to which access is restricted.[132] When it comes to anonymization of information details usually the companies use identification numbers which are added to the file of every employee that is in the database. The system may be organized in a data warehouse, central for the whole company. When the data is pulled out from the database identifiable information is delinked. It is possible to access linked information (e.g. the profile and medical data on treatment of an individual worker) only working on the database). [133]

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[129] See the interview with the SABCOHA representative, 19.11.2007

[130] E.g. if in there one out of 10 workers will be a woman and she will be found HIV-positive, the provider will not make available statistical data on HIV/AIDS and gender in the enterprise . See the interview with the Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

[131] See the interview with the Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

[132] See the interview with the Qualsa representative, 30.11.07, Lifeworks representative, 03.12.07, Aurum representative 05.12.07.

[133] See the interview with the Qualsa representative, 30.11.07.

None of the interviewed managers, although working for enterprises which main activity is data gathering and processing was aware of a case of data leak. They did not see it as a threat, underlining that their companies are insured and therefore they could pay the costs of liability for unauthorised data disclosure. [134]

The interviewed managers to some extend agreed that the culture of data privacy is not very well developed, at least in the sense that people give away their data quite easily and are not aware of rights they have.[135] However, which was not mentioned be the interviewees, there is also space to educate business on privacy standards. For instance, one of the interviewed managers argued that workplace surveillance is the right of the employer, even if monitoring is secret.

The interviewed managers recognized an important role **trade unions** play in protecting workers‘ HIV/AIDS rights, especially the right to non-discrimination.[136] However, they were also of the opinion that trade unions should be more active and should work on overcoming political constraints of their action on HIV/AIDS, such as (in case of COSATU) being a part of the ruling political coalition in South Africa, where the Government’s position on HIV/AIDS was not always clear.[137] Certainly, there is a need for more cooperation between employers, HIV/AIDS management providers and trade unions.

5.4 Summary

The interviewed trade union representatives said that in the workplace discrimination is present in both with the employer as well as in the relationship with the co-workers. However, in the view of the interviewed trade unionists one is not justified to make these two discriminations „equal“, as in practice these are co-workers who carry the burden of

[134] See the interview with the Qualsa representative, 30.11.07.

[135] See the interview with the SABCOHA representative, 19.11.07.

[136] See the interview with the Qualsa representative, 30.11.07.

[137] See the interview with the Qualsa representative, 30.11.07.

HIV/AIDS in the workplace. Noone of the interviewed trade unionists mentionned the need to prioritize the interest of the not-positive workers over the rights of the HIV/AIDS positive individual. Workplace HIV/AIDS action was seen as depending on solidarity among workers. HIV/AIDS confidentiality was recognized as crucial to achieve better testing and treatment uptake and its perception in the workplace was low. According to the interviewed trade unionists many companies implement HIV/AIDS programs without structural safeguards for confidentiality, blame workers for not getting involved and in this way run away from the responsibility for providing treatment options workers would be able to actually use.In relation to the form of HIV/AIDS workplace management (insourcing/outsourcing) the interviewed trade unionists were more interested in practical confidentiality safeguards, not the form itself. Insourcing was evaluated better from the perspective of coherence and transparency of responsibility (keeping the employer accountable for the efficient HIV/AIDS action in the workplace), while both options were raising important confidentiality concerns. That is why trade unionists underlined that they rather advice workers to go tested and treated outside the company scheme. This rises concerns that these schemes may be underused. Trade unions, while aware of the importance of confidentiality, have not yet made any more detailed data treatment demands.

The interviewed reperesentatives of HIV/AIDS workplace management providers recognized confidentiality of HIV/AIDS data as part of ethical employement. The employer should not ask for identifiable HIV/AIDS data of workers and, if asked, should not be given by the HIV/AIDS management company. Outsourcing of HIV/AIDS testing and treatment actions was seen as more appropriate for securing HIV/AIDS data confidentiality. The provider was seen as impartial and solely interested in organizing healthcare. The interviewed managers reported several technical confidentiality safeguards implemented in order to protect workers‘ confidentiality in HIV/AIDS programs. None of the interviewed managers, although working for enterprises which main activity is data gathering and processing was aware of a case of data leak whixh might indicate that data treatment issues have not been analyzed in detail yet.

6. Chapter 6: Discussion of the Findings

6.1 Introduction

HIV/AIDS is a complex social disease as well as a pathogen. HIV prevention and treatment require long-term social changes (eradication of inequalities), not short term fixes. Workplace is still a problematic space for managing HIV/AIDS data. Discrimination on grounds of HIV/AIDS status may get combined with workplace discrimination on grounds of race, sex, trade union membership etc.

On the example of the transition of HIV/AIDS workplace management in South Africa – introduction of legal prohibition of discrimination on HIV/AIDS grounds (through e.g. anouthorised, involuntary testing) and emergence of professional HIV/AIDS managment providers – we can observe how medical surveillance gets routine and accumulates into integrated, inter-related systems through the application of new technologies (as it was argued in Chapter 2). At the same time, we can see consequences of this change for the the labour process – the ways in which reproduction of power structures structures among the same dominate (employer) and subordinate (workers) subjects take place; employers, once aiming at identifying and eliminating HIV positive workers or work-candidates (pre-employement testing) now turn into outsourcing of HIV/AIDS workplace management, which means extensive data gathering. The newly created digitalized databases with health information of workers can be seen as a panopticon model of the reinforced power of the authorities that are implementing control.While paying for "management" as well as healthcare (antiretrovirals, treatment of opportunistic diseases) employers are still able to cumulate information (knowledge) and execute dominant power.

As it was argued in the Chapter 3, legal regulation of data privacy (affecting regulation of HIV/AIDS data confidentiality) in South Africa suffers from fragmentation and vagueness. This legal underdevelopment, together with conservatism of the court, may

negatively influence implementation of the future data privacy regulation (which in itself stands for the very promising and progressive regional development in the area of data privacy law). It has to be underlined that, as it was argued in Chapter 2, HIV/AIDS in South Africa, as well as the position of data privacy rights, are not only deeply politicised but also influenced by cultural concepts. The lack of advanced legislation on workplace (HIV/AIDS) privacy, together with these factors, has a negative effect on the privacy expectations, results in "privacy myopia" and reinforces imbalance of power in the workplace.

It is thus not clear if the law would be an effective tool in protecting privacy in South Africa. That is why, when it comes to HIV/AIDS confidentiality in the workplace, social dialogue is so important in South Africa.

The empirical data gathered in the frames of the project (interviews) allowed to identify the following:

6.2 Space for cooperation

Eventhough possibilities of testing and treatment through South African company schemes exist, there might be currently underused because of lack of trust in confidentiality of getting HIV/AIDS assistance in the workplace. It seems that strenghtening confidentiallity safeguards is in the interest of companies which more and more frequently outsource HIV/AIDS management ot professional providers. The cost paid for organizing testing and treatment in the workplace will be useless if these benefits remain untaken. In the view of the interviewed trade unionists, even is still not trusted, employers may play a crucial role in addressing HIV/AIDS, as they have capabilities and resources to enforce advanced HIV/AIDS policies, not only in the area of treatement but also in awareness raising and education (which are crucial for prevention). At the same time, the interviewed representatives of HIV/AIDS workplace management business sector recognize the crucial role trade unions play in *successful workplace HIV/AIDS*

interventions involved in the workplace HIV/AIDS actions.[138] Therefore, it seems that there is a significant space for cooperation between social partners in negotiating confidentiality safeguards and limits on information gathering, eventhough currently it trust is limited (partially for historical, partially for practical reasons – like numerous examples of HIV/AIDS workplace discrimination in South Africa. One could also make an argument about higher ethical responsibility of South African business for adressing HIV/AIDS, taking into account to what extend business benefited from colonial and Aparteid arrangemets to provide with cheap, rightless labour (esp. migrant work), social and cultural erosion/disruption etc. All of these are found liable for the extent of HIV/AIDS epidemic in South Africa.

6.3 Form of HIV/AIDS workplace management and confidentiality

It seems that form of HIV/AIDS workplace management (insourcing, outsourcing) does not in itself guarantee better perceptions of confidentiality among workers, at least in the view of the interviewed trade unionists. While internally run HIV/AIDS management, in the absence of confidentiality safeguards, was seen as making the employer virtually in possession of workers' HIV/AIDS data, in case of outsourcing, the commercial character of the relationship between the employer and provider was not reported to make workers trustful either. It seems, however, that outsourcing is seen as a slightly better option in terms of confidentiality of HIV/AIDS data but, at the same time, it is also seen as a means for the company to transfer risk and responsibility for HIV/AIDS management in the workplace. That is why I would say that the choice of HIV/AIDS management model does not in itself guarantee more trust and involvement from the part of workers. What is decisive is what obligations towards confidentiality have been accepted, in other words,

[138] Undoubtedly, trade unions have an important role to play in developing and monitoring workplace HIV/AIDS programs. At the company level, the research shows that lack of trade union support for the workplace VCT practice (even temporary e.g. associated with the implementation of a non-cooperation policy in escalation of a coincident industrial dispute) appears to have been a major barrier to participation or those who perceived non-support to equate to VCT confidentiality concerns (Mundy & Dickinson 2004, 186) However, this particular research showed that lack of support of trade unions for workplace VCT programs was not the most important factor influencing the uptake.

what practical privacy safeguards (in terms of mechanisms as well as regulations) were provided, regardless the form of the management.

6.4 Data treatment as a workplace issue

It seems that in South Africa trade unions make very general and vague demands concerning confidentiality (during interviews there were no more detailed comments on treatment of HIV/AIDS data durign the management process). This indicates that confidentiality of data treatment has not become yet a trade union/social dialogue issue. Also, data monitoring concerns/demands has not been linked with workplace surveillance issues. The cause might be low awareness of the problem, low privacy expectations, impression that South African workplace, often sharing as a Third world characteristic, is not yet threatened by technological challenges such as accumulation of data gathering, storage, profiling and commodification. This is not true, as technology transfer (in surveillance techniques) to the developing world is being more and more affordable and accessible. Enough to say that the interview with the NUM Eskom coordinator (19.11.2007) was taking place just in the middle of workplace negotiations on new technology surveillance developments planned by the company – on the day of the interview Eskom informed the unions about plans to introduce routine camera monitoring of all truck drivers working for Eskom.[139]

There is a growing need for trade unions to address the problem of data privacy in the workplace, which is affecting also the way in which business (and the Government) respond to HIV/AIDS in South Africa. The demands should be inspired by rights oriented monst favorable for privacy international standards.

Corporations, on their part (both employer and HIV/AIDS management providers) need to understand that data protection is the key to successful workplace HIV/AIDS response.

[139] Information about works on introducing cameras in trucks in order to record driver actions is found in the Eskom Annual Report 2007: „Vehicle safety. Eskom constantly seeks new ways to improve driver safety; for example: The Distribution division is piloting the drive-camera programme to monitor driver actions in the vehicle.“ www.eskom.co.za/annreport07/annreport07/info_sheets/safety.htm [09.02.2008]

Notwithstanding the poor South African policy and practice in that matter, the problem is that some confidentiality safeguards are often in place. Especially in cases where mechanisms for confidentiality protection already exist, it is crucial to inform workers about them. It is also important to make official policy statements that the company is not interested in identifiable HIV/AIDS information as treatment options are in place and ready to be used. Both information on confidentiality safeguards as well as appropriate policy statements should become a part of HIV/AIDS education programs and create a promising and creative platform for partnerships between trade unions and the company. Trade unions, on their part, could higlight good practice examples in the area of confidentiality safeguards and pro-privacy policy statements made by companies in order to encourage positive change in this area.

Privacy in the African context is believed to be affected by the philosophical concepts of communalism that spill into private realm in the way that individuals may not be aware of their rights or may not be keen on complaining about invasions. My belief is, however, that without engaging too deeply into the debate on communalism vs individualism it is possible to argument privacy provisions not only while respecting communal values („"One can have privacy and still be part of the community,") but even using them as rationale. In other words, if privacy protections are guarding the „natural habitat" of anonymity in which people used to live up to now (thanks to lack of technological possibilities of gathering and storing data) then the more individual data is protected the better for the community. In this way, protecting individual data privacy adds to „data safety" of the community and can be supported by the famous notion of „ubuntu".[140] Adressing HIV/AIDS in the workplace through social dialogue may offer promissing possibilities of developing response not only to the epidemic but also to the more general problem of regulating adequate workplace monitoring practices.

[140] *Ujamaa*-collectiveness, *Ubuntu* - a philosophy that promotes the common good of society and includes humaneness as an essential element of human growth - „ *It takes a village to raise a child*. „*In African culture the community always comes first. The individual is born out of and into the community, therefore will always be part of the community"*. See: Venter, E. (2004) „*The Notion of Ubuntu and Communalism in African Educational Discourse* "Studies in Philosophy and Education 23 (2-3), March - May, 2004 Kluwer Academic Publishers, cited in Bakibinga (2004).

5.5 Recommendations

Making HIV/AIDS data confidentiality a workplace issue, a trade union issue, should lead to developing trade unions policy on workplace privacy in general, in order to address increased employee monitoring, being a part of the battle of security vs. privacy in the workplace. The following recommendations are made in order to describe advanced data privacy standards. These recommendations are partly derived from the OECD Guidelines as elaborated on in the EU Directive as well as conlusions discussed at the African Electronic Privacy Symposium in Cape Town, South Africa in 2004 (EPIC Alert 2004, Bakibinga 2004).

- Limitation of processing – only minimum of data should be collected.[141]
- Purpose specification – the purpose of data collection has to be specified.[142]
- Further processing – not allowed.[143]
- Information quality - complete, not misleading, up to date and accurate.
- Openness – transparency about collection and processing of information.[144]
- Security of information. – protection against risks such as loss, unauthorised access, destruction, use, modification or disclosure.
- Individual participation.[145]

[141] This is also known as the collection limitation principle. Processing of personal information must be in accordance with the law (including most directly the Protection of Personal Information Act itself). No more data should be collected than the minimum necessary to serve the purpose of collection, and it should be collected directly from the subject of the information rather than from third parties.

[142] Personal information must be collected only for a specific, explicitly defined purpose and the subject of the information must be aware of what that purpose is. Information should only be held as long as necessary to achieve the purpose for which it was collected.

[143] This principle works in tandem with the previous one. Information collected for one purpose must not be used for another.

[144] There should be transparency about the processing of information. Information should not be collected clandestinely so that the subject of the information is unaware that it is being collected.

[145] As we saw above, a important aspect of the right of informational self-determination is the ability of an individual to find out whether their personal information is being processed, to know the content of that information and to be able to insist on correction of inaccurate information.

- Accountability – of the responsible party, requirement to appoint information protection officers. [146]
- Data gathering should never become centralized – the procedural way to protect privacy is though disperced gathering of data.
- Law enforcement officers need laws and guidelines to keep them in line with the requirements of privacy laws so as to prevent abuse.
- Companies should develop privacy policies.
- More education and awareness raising of privacy as a right.
- Capacity building for role occupants remains crucial in the area of legal issues pertaining to privacy concerns.
- Government agencies should enforce standards of networks and monitor systems so to ensure that all systems are secure from leaks, illegal surveillance.
- Parliament should make a special requirement for the Uganda Human Rights Commission to report on the state of privacy in Uganda to be able to develop benchmarks on the basis of which regulators can operate.
- Only with collaborative efforts from all stakeholders can data privacy be achieved.

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[146] This principle places the responsibility for complying with the above principles on the responsible party. This term is defined as the person or body which 'determines the purpose of and means for processing personal information'. The determinative aspect of this definition is control over the information - in other jurisdictions the equivalent concept is termed the **data controller**. Section 46 of the Bill additionally proposes requiring the appointment of **information protection officers** by all responsible parties. This officer will be the person reponsible for ensuring compliance with the Act within an organisation.

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