

ICD DIAGNOSTIC CODES AND THE CONSTITUTIONAL RIGHTS OF PATIENTS

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SUMMARY

The South African Department of Health has identified the need to improve the healthcare delivery systems within the country through the National Health Information System of South Africa. One of the mechanisms implemented is the ICD-10 coding system. This enables them to collect health information and to monitor the health status of the South African people. However, the implementation of the ICD-10 codes through the Medical Schemes Act is problematic, specifically as name-based data is collected, mostly without patients' consent or consent obtained under duress. This information is used by medical aids to adopt policies to design medical aid benefits. Apart from this potential disadvantage to patients, the coding system also impacts on doctor-patient confidentiality and the patients' fundamental rights to privacy and dignity.

"That whatsoever I shall see or hear of the lives of men or women which are not fitting to be spoken, I will keep inviolably secret."¹

1 INTRODUCTION

The national strategy for the implementation of the National Health Information System of South Africa (hereinafter "NHISSA") was facilitated by a Committee established by the Minister of Health in 1994 arising from the Department of Health White Paper for the Transformation of the Health

¹ The Hippocratic Oath.

System in South Africa (White Paper).² The then existing health information systems were neither comprehensive nor co-ordinated – causing a lack of reliable health information.³ Most systems in the public sector were manually driven with minimum computerisation. If computers were used, software was often incompatible and not user-friendly.⁴ Although the private sector was computerised, poor data collection and billing practices as well as a lack of standards for health information existed according to the Council for Medical Schemes (hereinafter “CMS”).⁵ As the ability to consolidate information from both the public and private sector is dependent on the standardisation of health information,⁶ the ICD-10 coding system was adopted by the NHISSA as part of the Health Informatics Standards to be established at national level.⁷

ICD-10 codes are acronyms for the International Statistical Classification of Diseases and Related Health Problems, 10th revision, and it consists of detailed coded descriptions of diseases and injuries. ICD codes are maintained by the World Health Organization (WHO) as one of the international standards for diagnostic classification of diseases, injuries and related health problems used for epidemiological and other health management purposes.⁸ The coding system describes every medical state with a unique code of up to five characters. The core classification codes are generally (but not always) four characters in length: one letter followed by a three-digit decimal number.⁹ For example, J152 would indicate “Pneumonia due to staphylococcus”; F200 “Paranoid schizophrenia” and B21.0 HIV disease resulting in Kaposi’s sarcoma.¹⁰ For the system to be functional and effective, accurate coding is clearly of the utmost importance.¹¹ It should be noted that the ICD coding system is not the only coding system used internationally, but merely the one chosen by the South African Department of Health.¹²

² White Paper (Chapter 6) as read with the Editorial *NHISSA Bulletin* 1(1) accessed in January 1998 <http://legacy.hst.org.za/doh/nhissa/jan98.htm>.

³ White Paper (Chapter 6).

⁴ White Paper (Chapter 6).

⁵ *CMS Recommendations of the Committee on Standardization of Data and Billing Practices* (Feb 2003) 4.

⁶ *CMS Recommendations of the Committee on Standardization of Data and Billing Practices* (Feb 2003) 4.

⁷ White Paper (Chapter 6).

⁸ Jones “CPT and ICD: What Why and When? Izindaba” 1999 89(3) *South African Medical Journal* 234.

⁹ *Ibid.*

¹⁰ Sourced electronically from <http://www3.who.int/icd/currentversion/fr-icd.htm>.

¹¹ Dada and McQuoid-Mason “Medico-legal Aspects of Pathology – Current Dilemmas Regarding Confidentiality and Disclosure” November 2005 95(11) *SAMJ* 877, with reference to the coding on death certificates.

¹² There is no universally acceptable coding with a single interpretation of medical illnesses (Coiera “Medical Informatics” May 1995 *British Medical Journal* <http://www.ndu.edu/inss/books/3>). Other surveys are also conducted to obtain information about various diseases and other medical data such as the South African Demographic and Health Survey (accessed <http://www.doh.gov.za/facts/stats-notes.html>). Other coding systems include the NAPPI and the CPT4 codes (ICD-10 National Task Team Patient Confidentiality Subcommittee Report (2006) 7 (“National Task Team Report”).

From 1 July 2005 all South African healthcare service providers, able to render an account to a medical aid, became legally obliged, by the Medical Schemes Act 131 of 1998, to include the ICD-10 diagnostic codes on all claims and accounts for medical services rendered.¹³ The healthcare providers¹⁴ include the private medical practitioner, pharmacists and other auxiliary medical service providers as well as in-patient hospital physicians.¹⁵ The code requirements, however, do not extend to the traditional healers.¹⁶

The provisions of the Medical Schemes Act under discussion forms part of the bigger plan as set out in section 74 of the National Health Act:¹⁷

“Co-ordination of national health information system

- (1) The national department must facilitate and co-ordinate the establishment, implementation and maintenance by provincial departments, district health councils, municipalities and the private health sector of health information systems at national, provincial and local levels in order to create a *comprehensive national health information system*. (own emphasis).
- (2) The Minister may, for the purpose of creating, maintaining or adapting databases within the national health information system contemplated in subsection (1), prescribe categories or kinds of data for submission and collection and the manner and format in which and by whom the data must be compiled or collated and *must be submitted to the national department*.” (own emphasis).

¹³ S 59(1) of the Medical Schemes Act 131 of 1998 as read with Regulation 5(f) (GN R1262 in GG 20556 of 1999-10-20). See in general the Council for Medical Schemes “Recommendations of the Committee on Standardisation of Data and Billing Practices” (2003).

¹⁴ The Medical Schemes Act 131 of 1998 defines “health service” broadly to mean any healthcare treatment of any person by a person registered in terms of any law, which treatment has as its object (a) the physical or mental examination of that person; (b) the diagnosis, treatment or prevention of any physical or mental defect, illness or deficiency; (c) the giving of advice in relation to any such defect, illness or deficiency; (d) the giving of advice in relation to, or treatment of, any condition arising out of a pregnancy, including the termination thereof; (e) the prescribing or supplying of any medicine, appliance or apparatus in relation to any such defect, illness or deficiency or a pregnancy, including the termination thereof; or (f) nursing or midwifery; and includes an ambulance service, and the supply of accommodation in an institution established or registered in terms of any law as a hospital, maternity home, nursing home or similar institution where nursing is practised, or any other institution where surgical or other medical activities are performed, and such accommodation is necessitated by any physical or mental defect, illness or deficiency or by a pregnancy (s 1).

Healthcare providers have been defined to including a person providing health services in terms of the following statutes: Allied Health Professions Act 63 of 1982, the Health Professions Act 56 of 1974, the Nursing Act 50 of 1978, the Pharmacy Act 53 of 1974 and the Dental Technicians Act 19 of 1979 (National Task Team Report 12). See for example the status of physiotherapists in the Compensation for Occupational Injuries and Diseases Act 130 of 1993 and the regulations published in this regard (GN 823 in GG 28965 of 2006-06-30). See also the Health Professions Act 56 of 1974 and the regulations published in terms thereof for Physiotherapy, Podiatry and Biokinetics (GN R1065 in GG 25235 of 2003-07-28); and, McQuoid-Mason and Dada “The National Health Act: Some Practical Implications for Family Practice” January 2005 24(1) *CME* 12).

¹⁵ This is similar to the situation in Germany (Bleumer and Schunter “Privacy Orientated Clearing for the German Health System” accessed <http://www.citeseer.ist.psu.edu/bleumer97privacy.html>).

¹⁶ The date of commencement of the Traditional Health Practitioners Act 35 of 2004 is still awaited. See also Etkind “Bridging the Gap between Biomedicine and Traditional Healing” March 2006 *Business in Africa Magazine (Southern Africa)* accessed <http://www.businessinafrica.net/health/176209.htm>.

¹⁷ 61 of 2003.

The intention is to collect health information through the implementation of the ICD-coding system *inter alia* in both the private and public sector for the monitoring of the health status of the South African population by the Department of Health.¹⁸ On the one hand the implementation of these codes in the public health sector has been described as “a challenge”¹⁹ and there are concerns in terms of readiness and resources.²⁰ On the other hand the Medical Schemes Act’s implementation focuses on the private sector, linking the duty to include the information to the payment for services.²¹ By the beginning of 2006 this sector was more than 90% compliant.²²

2 THE PARAMETERS OF THE ARTICLE

“ICD-10 codes are clinical diagnostic codes detailing the diagnosis of the health encounter between the patient and the healthcare provider and/or the health establishment. Health care providers and health establishments are concerned about the notion of releasing these clinically specific details of the patient’s encounter, regardless of the reasons, to others.”²³

The article commences with a brief overview of the history of the ICD diagnostic coding system as a vehicle to collect health information for public purposes, its advantages and disadvantages. However, the aim of this article is to ascertain whether the legislative requirements enforcing the ICD-10 coding system on medical professionals with regard to medical aid patients is constitutional. The constitutionality of the legislative provisions is assessed in light of the constitutional principles of equality, privacy and dignity as interpreted in the South African legal system and measured against the broader societal good.

The document focuses specifically on the doctor-patient scenario, although the implications of the conclusion could be applicable also to other healthcare service providers as well. It should further be noted that the information under discussion is so-called personal health information (hereinafter “PHI”) that has been defined²⁴ as “information about an identifiable, natural person that relates to the physical and mental health,

¹⁸ Department of Health “Strategy Priorities for the National Health System 2004-2009” accessed <http://www.doh.gov.za/facts/stats-notes.html> 6.

¹⁹ *Ibid.* One of the key activities identified for the next five years by the Department is to establish an integrated disease surveillance system (14).

²⁰ CMS *Recommendations of the Committee on Standardization of Data and Billing Practices* (Feb 2003) 7.

²¹ S 59 of the Medical Schemes Act as read with reg 5(f).

²² Council of Medical Schemes 2005-2006 *Annual Report* 11-12 sourced electronically from http://www.medicalschemes.com/publications/ZipPublications/Annual%20Reports/CMS_annual_report_2005-6.pdf. (hereinafter “CMS Annual Report”).

²³ National Task Team Report 7.

²⁴ National Task Team Report 13. See also the corresponding definitions in the Promotion of Access to Information Act 2 of 2000 and the Electronic Communications and Transactions Act 25 of 2002, where both the Acts define “personal information” to include information relating to the medical history of the individual or information relating to financial transactions in which the individual has been involved (s 1(b)).

well-being or disability of the individual or to the provision of health services to the individual; thus including ICD-10 codes reflecting such information".²⁵

3 HISTORY

The reporting of infectious diseases on a case-by-case basis can be dated back to the 14th century in Italy and the 16th century in England, with the first statistical study of disease done by John Graunt in 1662 in the macabre *London Bills of Mortality*.²⁶ These bills were devised as an early warning system against the onset of bubonic plague between 1660 and 1700 in England. Initially the bills reflected only burials, but later cause of death information was included. In 1854, when cholera struck England, John Snow began plotting the locations of the deaths related to this disease and proved his argument that cholera was spread through contaminated food and water.²⁷

By 1853 the Frenchman Jacques Bertillon prepared a uniform classification of causes of death which was reported and adopted by the International Statistical Institute in Chicago. This classification was called the *Bertillon Classification of Causes of Death*.²⁸ The system was revised in 1900 during the first international conference for the revision of the *Bertillon* or *International List of Causes of Death*. The necessity for periodical revisions was recognized; this recognition was important to adapt to advances in the medical sciences and the classification was called ICD-1.²⁹ From 1900 the list was revised every 10 years until 1979 (ICD-9).³⁰ The 1979 code was only revised 20 years later in 1999 to give rise to the current ICD-10 codes.

²⁵ This information may include (1) information about the registration of the individual for the provision of health services; (2) information about payment or eligibility for healthcare in respect to the individual; (3) a number or symbol assigned to an individual to uniquely identify the individual for health purposes; (4) any information about the individual that is collected in the course of the provision of health services to the individual, including ICD-10 codes; (5) information derived from the testing or examination of a body part or bodily substance; and (6) identification of a person (eg, a healthcare provider which renders health services to the individual) (National Task Team Report 13).

²⁶ Graunt "National and Political Observations Made upon the Bills of Mortality, 1662" in Moro and McCormick (eds) *Surveillance in Health and Disease* (1998) 172.

²⁷ See in general Brody, Rip, Vinten-Johansen, Paneth and Rachman "Map-making and Myth-making in Broad Street: The London Cholera Epidemic, 1854" 2000 356(9223) *The Lancet* 64-68.

²⁸ See in general Israel "The History of the International Classification of Diseases" 1991 49(1) *Health Bulletin* 62-66.

²⁹ Knibbs "The International Classification of Disease and Causes of Death and its Revision" 1 1929 1 *Medical Journal of Australia* 2-12.

³⁰ The sixth revision's title was changed to "Manual of International Statistical Class of Diseases, Injuries and Causes of Death to Reflect Addition of Morbidity and Mortality Conditions".

4 BENEFITS OF DIAGNOSTIC CODING

"Sharing and disseminating electronic medical records while maintaining a commitment to patient confidentiality is one of the biggest challenges facing medical informatics and society at large."³¹

The broader aim of any health information coding system is to facilitate storage, statistical analysis and interpretation of medical data, in comparable format, for the benefit of mankind, the so-called common welfare.³² Comprehensive retrievable medical data should improve the quality of care and promote the welfare of the population.³³ NHISSA collects information for two main reasons: firstly, it supports surveillance,³⁴ for example: cause-specific mortality data is used by epidemiologists to generate hypotheses about disease etiology, to track changing disease patterns and to depict the prevalence of diseases amongst different population groups and in different geographical areas;³⁵ and, secondly, health information also enables better management of health systems including the administrative and financial areas.³⁶ Health statistics also allows for comparison of data on a national and international level. South Africa, as a member of the WHO, would be able to submit health data as required by WHO.³⁷

Generally the benefits for the healthcare industry as a whole are the improvement of efficiency of healthcare through easy storage, retrieval and analysis of information for patient care, research, performance improvement, healthcare planning and facility management.³⁸ It documents all episodes of healthcare, wherever it takes place and provides immediate access to the data, saving time and costs.³⁹ Another advantage of electronic records is that the retention and durability is in a legible format, resulting in fewer errors.⁴⁰

From the perspective of combination treatments for patients, the benefits are that communication takes place in a predictable, consistent and reproducible manner, enabling reliable interaction about healthcare data among many participants in the healthcare industry in a standardized manner.⁴¹ It could also be argued that it is in the interest of the medical

³¹ Sweeney "Maintaining Patient Confidentiality when Sharing Medical Data Requiring a Symbiotic Relationship between Technology and Policy" May 1997 A.I. Working Paper No AIWP-WP344b accessed <http://www.privacy.cs.cmu.edu> 1.

³² The term is borrowed from Pommerening "Medical Requirements for Data Protection" 1994 paper delivered at the International Federation for Information Processing (hereinafter "IFIP") Congress accessed [http://www.staff.uni-mainz.de/pommeren/ Artikel/ifip.pdf](http://www.staff.uni-mainz.de/pommeren/Artikel/ifip.pdf) 5.

³³ Amatayakul *Electronic Health Records. A Practical Guide for Professionals and Organizations* 2ed (2004) 5.

³⁴ Editorial *NHISSA Bulletin* 1(1) (January 1998) as read with Chapter 6 of the White Paper.

³⁵ Israel, Rosenberg and Curtin "Analytical Potential for Multiple Cause-of-death Data" 1986 124 *American Journal of Epidemiology* 161-166.

³⁶ Editorial *NHISSA Bulletin* 1(1) (January 1998) as read with Chapter 6 of the White Paper.

³⁷ Circular 46 of 2004 as quoted by the National Task Team Report 6.

³⁸ *Ibid.* No public record could be found indicating that information had been submitted to the WHO.

³⁹ Amatayakul 5.

⁴⁰ Amatayakul 26.

⁴¹ Circular 46 of 2004 as quoted by the National Task Team Report 6.

fraternity to be informed as soon as possible of the diagnosis of the disease of the patient, especially where they might be personally at risk such as in the case of a person infected with HIV/AIDS.⁴²

One of the main beneficiaries of the current implementation of the coding system in the private health sphere is the medical aids themselves. The coding system, as it facilitates efficient payment of claims from providers, should improve clinical and financial risk management practices at medical schemes.⁴³ It should increase the efficiency of the healthcare organisations in general that should result in a reduction of costs of services,⁴⁴ and enable fair reimbursement for health services provided.⁴⁵ The coding system should specifically enable successful implementation of the Risk Equalization Fund in South Africa in order to minimize the clinical and financial risk of each of the individual medical schemes.⁴⁶ Medical Aid Schemes are fully informed of all diagnosis of their members. Although the coding system might assist with the reduction in fraudulent misuse of funds, the schemes could also theoretically use the data to adopt policies, in terms of benefit design. This may well disadvantage certain groups, leaving them without funds for their specific healthcare needs.

What are the benefits for the patient, the medical aid beneficiary? The Council for Medical Schemes argues that ICD-10 coding is important for medical scheme beneficiaries in that it assists them in the following ways: firstly, enabling patient access to healthcare and secondly, as a beneficiary's medical scheme entitlements are based on conditions covered in the particular option that the main member would have chosen, reimbursements for the relevant health services are then linked to the diagnosis and procedures that the provider renders to the beneficiary.⁴⁷ The flipside hereto is that failure to disclose such information would make it impossible for the scheme to assign benefits appropriately; and, to determine to what extent the benefits should be covered.⁴⁸ As a result, a beneficiary might forfeit his or her entitlements as per the Prescribed Minimum Benefit (PMB) regulations.⁴⁹

⁴² The debate as to whether HIV/AIDS should be a reportable disease is not included in this article. See in general Simon *South Africa in Southern Africa: Reconfiguring the Region* (1998).

⁴³ Circular 46 of 2004 as quoted by the National Task Team Report 6.

⁴⁴ Amatayakul 5. *Eg*, the information could be used to predict the number of myocardial infarctions (hereinafter "MIs") expected each year as they would know from the ICD-10 codes that most MIs occur between x and y and at what rate. By looking at the medical aid membership a prediction (educated guess) is possible.

⁴⁵ Circular 46 of 2004 as quoted by the National Task Team Report 6.

⁴⁶ *Ibid.*

⁴⁷ *Ibid.*

⁴⁸ Ss 29, 59 and reg 5 of the Medical Schemes Act, 131 as quoted in Circular 46 of 2004 as quoted by the National Task Team Report 6.

⁴⁹ Circular 46 of 2004 as quoted by the National Task Team Report 6. PMB's are a set of statutory benefits consisting of a diagnosis and treatment combination. Every medical scheme can interpret these benefits as chosen resulting in poor monitoring and evaluation (CMS *Recommendations of the Committee on Standardization of Data and Billing Practices* (Feb 2003) 14).

5 DISADVANTAGES OF ICD CODING

“This issue surrounding medical information is not unique to South Africa. It has been noted in the US that ‘confidentiality is increasingly difficult to maintain in this era of computerised record keeping and electronic data processing, faxing of patient information, third-party payment for medical services, and the sharing of patient case amongst numerous medical professionals and institutions’.⁵⁰ The introduction of modern open information and communication systems into healthcare more and more exposes the most sensitive data of a person. The enthusiasm for computers wipes away all scruples.”⁵¹

To understand the disadvantages of the current system, some detail is expedient. The implementation of the coding system via the Medical Schemes Act creates an obligation based on the name and details of the patient. The system is implemented by the entering of a valid and hopefully accurate ICD-10 code on the invoice to be submitted to the medical aid.⁵² The codes are added to the document containing the medical aid member’s personal details.⁵³ Although the patient and the doctor have the right of refusal to disclose medical information, by including the U98.0 and U98.1 codes respectively, these codes are seldom reflected on documentation.⁵⁴

The consequence of the inclusion of the codes on the account and the prescription is that the diagnosis of the medical practitioner (and thus the medical condition of the patient – assuming that the doctor is correct) is not only the privilege of the doctor, but is also available to any person dealing with the payment of the account; at the very least the personnel of the doctor, pharmacy and medical aid as well as their administrators, and also to any further person or institution the information is disseminated such as drug companies and medical researchers.⁵⁵ To illustrate: X is HIV positive and as a result thereof he developed Kaposi’s sarcoma. The relevant code is also included on the account that is sent to X’s medical aid, together with all his details. The doctor, when prescribing medication includes the B21.0 code on the prescription. The (confidential) information between doctor and patient is now available to the pharmacist, as well as the medical aid and the administrator’s personnel. All without X necessarily ever having consented thereto, or even being aware of the fact, making a mockery of the patient’s

⁵⁰ American College of Physicians “Ethics Manual: Fourth Edition” 1998 128(7) *Annals of Internal Medicine* 576.

⁵¹ Pommerening 1994 paper delivered at the IFIP Congress accessed [http://www.staff.uni-mainz.de/pommeren/ Artikel/ifip.pdf](http://www.staff.uni-mainz.de/pommeren/Artikel/ifip.pdf) 2.

⁵² Reg 5(f) as read with s 59 of the Act. Before 2005 a pharmacist would only have access to the prescribed medication without insight into the diagnosis of the doctor.

⁵³ Reg 5 provides for a list of information to be submitted.

⁵⁴ Pharmaceutical Society of South Africa “ICD10 coding for Pharmacies in South Africa” *Communication No 171*.

⁵⁵ For a discussion of the problem faced in the USA, see Morgan and McDermott “Implementing the HIPAA Transaction Standards in Managed Care Pharmacy Settings” November 2003 16(1) *Health Law* 14 17, with HIPAA being the Health Insurance Portability and Accountability Act of 1996. See also Coiera May 1995 *British Medical Journal* <http://www.ndu.edu/inss/books> 3. It should be noted that the US and UK systems differ and that in the US, unlike the UK, it is not regarded as necessary or desirable to have all codes come from a single master system (Coiera May 1995 *British Medical Journal* <http://www.ndu.edu/inss/books> 3).

privacy rights and veneer of confidentiality as is discussed infra. This is specifically true in HIV cases where the need for confidentiality is especially compelling as a result of the serious personal and social consequences for the patient.⁵⁶

Thus, the main disadvantage of the current implementation of the system is that the information is name-based.

Another disadvantage is the uncertainty about the terms of the divulging of the information by the medical aids to third parties. According to Dada and McQuoid-Mason "prospective members of medical aid funds and managed care organizations (MCO's) are required to sign a general release form on enrolment in the plan. These forms authorize the release of medical information to the funders. However, patients may not be aware that funders request data on disease and tests such as laboratory request forms and ICD-10 codes."⁵⁷

The selective nature of the implementation only on a small percentage of the population is a disadvantage of the system.⁵⁸ If the main aim of the coding system is to create a database for the national department, the selective implementation would lead to a warped picture of health in the country. Private healthcare is mainly funded by medical schemes and only about 16% of the South African population belongs to medical aids.⁵⁹

It should also be noted that there is some resistance by medical practitioners about the implementation of the codes that has been forced upon them, making their daily tasks more onerous and time-consuming without any financial reward.⁶⁰

Another concern with the system is the lack of education, knowledge and information given to patients.⁶¹

However, the major issue is the problems that could manifest when medical information is not kept confidential, but disseminated broadly. These problems are tersely illustrated by the following two US examples mentioned by Sweeney: firstly, in 1995 a Maryland banker cross-referenced a list of patients with cancer against a list of people who had outstanding loans at his bank so that he could call in the loans, which he did; and secondly, research has shown that 35% of the Fortune 500 companies use medical records to make decisions about their employees.⁶²

⁵⁶ Cameron "Confidentiality" January 1999 Presentation to Judges' Workshop on HIV/Aids in Mumbai 8. As mentioned above, from the perspective of the medical fraternity, such prior disclosure via the ICD-10 coding system could also be viewed in a positive light as it could potentially reduce their risk for infection.

⁵⁷ Dada and McQuoid-Mason 2005 95(11) *SAMJ* 877.

⁵⁸ See discussion above.

⁵⁹ Cullinan "The High Costs of Private Health" *Health-e* 1, accessed <http://www.health-e.org.za/news/article.php?uid=20030402>.

⁶⁰ CMS Annual Report 11.

⁶¹ *Ibid.* As in the USA, "few organizations are committed to educating patients about their health information and few providers are able or willing to take the time to provide this education" (Amatayakul 30).

⁶² Sweeney May 1997 A.I. Working Paper No AIWP-WP344b accessed <http://www.privacy.cs.cmu.edu> 2.

These examples re-affirm the wide concern of the Organization for Economic Cooperation and Development, regarding the legal problems of automatic data processing: “the ubiquitous use of computers for the processing of personal data, vastly expanded possibilities for storing, comparing, linking, selecting and accessing personal data, and the combination of computers and telecommunications technology which may place personal data simultaneously at the disposal of thousands of users at geographically dispersed locations and enables the pooling of data and the creation of complex national and international data networks”.⁶³

These incidences would not have been problematic had there not been a legal and ethical expectation of confidentiality by patients when disclosing information to their medical practitioner. The patients are further unaware of the consequences of the disclosure, and in which ways it might disadvantage them even in an indirect manner.

6 CONFIDENTIALITY

“[T]he automation of health information raises privacy and confidentiality issues. Many patients appreciate the value of sharing information among their care providers; however, for various reasons others do not want their information to be shared or at least want control of how and when it is shared.”⁶⁴

6.1 The rule

Medical data are amongst the most sensitive data of a person.⁶⁵ One of the main features of the doctor-patient relationship and contract is the confidential nature of the contents of the discussions.⁶⁶ The reason for this rule is that patients need to know that their full disclosures⁶⁷ of an intimate and personal nature would be held in confidence by the medical personal treating them.⁶⁸ Without assurances of confidentiality, patients will be reluctant to disclose information about themselves that might be necessary for their medical care.⁶⁹

This principle of confidentiality has been accepted in the common law,⁷⁰ legislation⁷¹ and applied in judicial precedent.⁷² This rule is prominent in

⁶³ See discussion in par 8 below.

⁶⁴ Amatayakul 30.

⁶⁵ Pommerening 1994 paper delivered at the IFIP Congress accessed [http://www.staff.uni-mainz.de/pommeren/ Artikel/ifip.pdf](http://www.staff.uni-mainz.de/pommeren/Artikel/ifip.pdf) 1.

⁶⁶ See discussion below in par 8, about right to privacy.

⁶⁷ Where patients do not make such full disclosures for whatever reason it would greatly inhibit their treatment (McQuoid-Mason “Legal Aspects of Medical Practice” in Dada and McQuoid-Mason (ed) *Introduction to Medico-Legal Practice* (2001) 17).

⁶⁸ McQuoid-Mason 17.

⁶⁹ Howard and Bogle *Medical Law and Ethics* (2005) 39.

⁷⁰ *Tohill v Forster* 1925 TPD 857.

⁷¹ National Health Act 61 of 2003.

⁷² *Jansen van Vuuren NNO v Kruger* 1993 4 SA 842 (A) 856G-H where the court held that the common law right to privacy of a patient was invaded by the doctor who revealed information about this patient’s HIV status to a third party where there was not a duty to disclose. This principle is also found in other Western countries such as the USA (HIPAA

many documents relating to ethical healthcare policy regulation.⁷³ The point of departure of the legal (and ethical) rule is that medical practitioners may not divulge information about their patients without their consent.⁷⁴ Section 14(1) of the National Health Act specifically states that “all information concerning a user, including information relating to his or her health status, treatment or stay in a health establishment is confidential”.⁷⁵

It follows that the expectations of the patients regarding confidentiality will not be met if large numbers of people have access to the contents of the documents which include, *inter alia*, their diagnosis.⁷⁶ Certain statutes,

Regulations on Privacy 45 CFR §§ 16 & 164 (2002)) and the UK (*R v Department of Health, ex parte Source Informatics Ltd* [1999] 4 All ER 185).

⁷³ See *inter alia* (1) Ethical Rules of Conduct for Practitioners registered under the Health Professions Act 56 of 1974 (GN 29079 GG R717 dated 2006-08-04) (rule 13); (2) Medical and Dental Professions Board Guidelines for Good Practice in Medicine, Dentistry and the Medical Sciences. National Patients' Rights Charter (July 2002) (s 2.7); (3) the General Ethical Guidelines of the Core Ethical Values And Standards For Good Practice, the Professional Guidelines of registered Healthcare Practitioners with the Health Professions Council of South Africa (hereinafter “HPCSA”) (note 1.2 and 2.4); (4) HPCSA Guidelines for the Management of Patients with HIV Infection or AIDS (ss 2.5 and 10); (5) National Patients' Rights Charter (s 2.7); (6) the Health Professions' Act 56 of 1974 Guidelines for Good Practice in Medicine, Dentistry and the Medical Sciences – Confidentiality: Protecting and Providing Information (Booklet 14) (guideline 3.1) and Guidelines for Good Practice in Medicine, Dentistry and the Medical Sciences – Guideline on Keeping Patient Records (Booklet 11) (guideline 8.3) dealing with termination of pregnancy (Number (6) sources from the National Task Team Report 26-27). (7) With regard to nurses, see the South African Nursing Council (hereinafter “SANC”) rules setting out the acts and omissions in respect of which the Council may take disciplinary steps (GN R387, R 866 and R 2490 dated respectively 1985-02-15, 1987-04-24 and 1990-20-26) published in terms of the Nursing Act 50 of 1978 and the Nursing Act 33 of 2005 (as quoted in National Task Team Report 36). See also Pera and Van Tonder *Ethics in Healthcare* 2ed (2005) 50; and (8) Regulations and Ethical Rules issued by the South African Pharmacy Council (hereinafter “SAPC”) (rule 9) published in terms of the Pharmacy Act 53 of 1974 as read with s 22(4).

⁷⁴ McQuoid-Mason and Strauss “Medicine, Dentistry, Pharmacy and other Health Professions” in Joubert (ed) *The Law of South Africa Vol 17* (1999) par 205; and McQuoid-Mason 17. The consent should be obtained by the patient himself if he is over 14 years of age; or from the parents or guardian if the patient is a minor under the age of 14; or if the patient is deceased, from his next-of-kin or the executor of his estate (Ethical Rules of Conduct for Practitioners registered under the Health Professions Act 56 of 1974 (GN 29079 GG R717 dated 2006-08-04) (rule 13(2)).

⁷⁵ No person may disclose any information unless the user consents to that disclosure in writing; a court order or any law requires that disclosure; or non-disclosure of the information represents a serious threat to public health (s 14(2)). The only other exception is where “a health worker or any healthcare provider that has access to the health records of a user may disclose such personal information to any other person, healthcare provider or health establishment as is necessary for any legitimate purpose within the ordinary course and scope of his or her duties where such access or disclosure is in the interests of the user” (s 15(1)). See also the Mental Health Care Act 17 of 2002 (s 13).

The National Task Team Report states that there is no duty of confidentiality placed on practitioners or therapists in terms of the Allied Health Professions Act 63 of 1982, including Ayurveda, doctors of Chinese medicine and acupuncturists, chiropractors, homeopaths, naturopaths and osteopaths. In terms of rule 11 of the Schedule the disclosure by a practitioner of PHI of a patient is an act that is subject to possible disciplinary steps unless there was consent by the patient, a court order or where the practitioner was legally compelled to disclose the information (National Task Team Report 18-19).

⁷⁶ Sweeney May 1997 A.I. Working Paper No AIWP-WP344b accessed <http://www.privacy.cs.cmu.edu> 2. Ignorance and confusion exist amongst many patients regarding the meaning and aims of the coding system. Consent forms are not signed by most patients and they are unaware of their right to refuse consent. Patients are not necessarily aware that the coded scripts and claims change hands a number of times before medical benefits are paid and that their confidentiality could be compromised.

dealing with the transfer of information in general, confirm a general right to privacy of personal information, subject to certain exceptions.⁷⁷

The obligation is on doctors to ensure that they have the required confidentiality agreements in place with their employees, practice management software vendors, accounting bureaus and other contracted third parties who may have access to identifiable patient information in their records and systems. Section 17(1) of the National Health Act provides that the person in charge of a health establishment in possession of a user's health records must set up control measures to prevent unauthorised access to those records and to the storage facility in which, or system by which, records are kept. Failure to do so or unauthorised distribution is an offence.⁷⁸

A doctor or other healthcare provider may examine a patient's health records *inter alia* for the purposes of study, teaching or research. However, authorisation of the patient, the head of the health establishment concerned and the relevant health research ethics committee is required unless the information used is unidentifiable.⁷⁹ The Medical Schemes Act also requires medical schemes to keep information confidential.⁸⁰ The National Task Team Report emphasizes the need for medical schemes to contract with all their third party service providers, including administrators, managed care companies, switching companies and data management / data transfer companies, to ensure protection of the confidentiality of individual member information and not to use identifiable patient information for purposes other than stipulated in the Medical Schemes Act.⁸¹ The National Task Team Report notes that it is critical that patients are guaranteed that their codes would only be used for the reasons for which they gave consent, and no other.⁸² This, currently, does not legally include a release of the information to any third parties.⁸³

One sector that would benefit from the coding system-information is drug companies, as this would assist with research and development planning.⁸⁴

⁷⁷ Electronic Communications and Transactions Act 25 of 2002 (s 50-56); and the Promotion of Access to Information Act 2 of 2000 (ss 34 and 63 dealing respectively with public and private bodies).

⁷⁸ S 17(2) of the National Health Act. Non-adherence to this section is an offence with a sentencing option of a fine or imprisonment for a period not exceeding one year or to both a fine and such imprisonment. See also the National Task Team Report 28; Dada and McQuoid-Mason November 2005 95(11) *SAMJ* 857.

⁷⁹ S 16 of the National Health Act.

⁸⁰ Reg 15D-J promulgated in terms of the Medical Scheme Act. See National Task Team Report 29.

⁸¹ National Task Team Report 29.

⁸² National Task Team Report 29. The Report recommends that the CMS should consider changes to the Medical Schemes Act.

⁸³ "From a strictly legal perspective, medical schemes are not in a position to use the ICD-10 information for any other reason than that stipulated in s 59 of the MSA and elaborated on in regulation 5" (National Task Team Report 29).

⁸⁴ *R v Department of Health, ex parte Source Informatics Ltd* [1999] 4 All ER 185 192h; 196a-b; 197f and 198d-e. This is illustrated by the 1999 UK case where S, a drug-company, brought an application for the disclosure of confidential information, via software installed by pharmacists relating to the prescription habits of general practitioners in the UK, which is believed to be of value to the drug companies. The court held that in the absence of the consent of the patient the abstracting by pharmacists would involve the unauthorised use of

However, the fear is that “the mere existence of documents containing identifying information about patients tempts people to use the information for secondary purposes”.⁸⁵ The argument is not that all the information should be kept secret, but that the rights of the patient should be protected in the dissemination process.

6 2 The exceptions to the rule

The confidentiality rule is not absolute.⁸⁶ The patient may firstly consent⁸⁷ to the divulging of the information and secondly, certain legal exceptions to the rule exist.⁸⁸ Most of the documents mentioned above that include the rule,⁸⁹ make specific provision that the confidentiality rule, subject to an order of court,⁹⁰ any law or legislation,⁹¹ is adhered to unless there is an overriding reason for such disclosure.⁹² In selective instances no exception to the rule of confidentiality exists, except for written informed consent.⁹³

confidential information. The decision was made on the grounds of public interest to ensure confidentiality, even if anonymity could be guaranteed.

⁸⁵ Bleumer and Schunter <http://www.citeseer.ist.psu.edu/bleumer97privacy.html> 4. They argue that it is in infringement of the confidentiality principle for a medical aid to even know to which physician the patient goes (Bleumer and Schunter <http://www.citeseer.ist.psu.edu/bleumer97privacy.html> 5).

⁸⁶ See the documentation referred to in fn 73 above.

⁸⁷ The consent required is informed consent and must be to the particular disclosure to be made, the manner in which it will be disclosed and the person to whom the disclosure is made (McQuoid-Mason 22). In terms of the Choice on Termination of Pregnancy Act 92 of 1996 (and its regulations (specifically reg 7(c)), it is specifically provided for that the identity of the woman must remain confidential at all times, unless she chooses to disclose the information (s 7(5)). See also Neethling, Potgieter and Visser *Neethling's Law of Personality* 2ed (2005) 250.

⁸⁸ See in general Dada and McQuoid-Mason 2005 95(11) *SAMJ* 876.

⁸⁹ With the exception of the HPCSA Guidelines for the Management of Patients with HIV Infection or AIDS. It is significant to note that within the HPCSA HIV policy it is acknowledged that there was no legal clarity regarding whether this situation is an acceptable limitation of the right to confidentiality (s 10.3 of the document).

⁹⁰ Howard and Bogle 40; The Ethical Rules of the HPCSA require that the doctor first protests so that the court can weigh the possible damage to public interest against the possible damage to the patient (see discussion by Dhai, Dada, Kirk and McQuoid-Mason “Confidentiality – A Dying Wish?” 2001 91(2) *SAMJ* 123 125). In the case of *Parks v Parks* 1916 CPD 702 the doctor was ordered to answer a question relating to his patient's examination even though he claimed privilege. The court regarded the information as necessary for the administration of justice, as the issue before the court related to a claim for adultery by a wife against her husband as he contracted a venereal disease from a person other than herself. It should, however, be noted that in light of the 1979 Divorce Act, the outcome of this case might be different today. See also *Botha v Botha* 1972 2 SA 559 (N).

⁹¹ Child Care Act 74 of 1983 (s 42); Compensation for Occupational Injuries and Diseases Act 130 of 1993 (s 42(1)).

⁹² One possible reason would be where third parties are endangered as “protected privilege ends where the public peril begins” (McQuoid-Mason 22 and his reference to the American case of *Tarasoff v Regents of the University of California* (1976) Cal SCT, 17 Cal Rep 3rd series 425); and Howard and Bogle 41.

⁹³ Ethical Rules of Conduct for Practitioners registered under the Health Professions Act 56 of 1974 (GN 29079 GG R717 dated 2006-08-04) (schedule 12, rule 24) where it is provided that a psychologist may only disclose confidential information with written informed consent. This exception is, however, not applicable to court proceedings. See also the Guidelines for Good Practice in Medicine, Dentistry and the Medical Sciences – Guideline on Keeping Patient Records (Booklet 11) (guideline 8.3), dealing with termination of pregnancy.

The issue of consent, for the submission of personal information,⁹⁴ is discussed in more detail. The duty of the health provider (doctor) concerning confidentiality of medical information is clear: full and informed consent of the patient is required prior to disclosing the codes to a third party including a medical aid.⁹⁵ Where the patient is unlikely to be affected by a disclosure, the patients should nonetheless be told that their records may be revealed to third parties, and be informed of the right to object to the release of the information.⁹⁶ This is in line with the Promotion of Access to Information Act⁹⁷ where provision is made for a mandatory exception to the right to access information in instances where the individual's privacy rights might be affected.⁹⁸ The right of a patient to access information about him/herself is excluded from this discussion.⁹⁹

The National Task Team Report argues that to enable a patient to grant informed consent for the submission of PHI, certain information must be given to the patient: firstly, the reasons and purpose for the disclosure; secondly, the likely consequences of disclosure; thirdly, the intended recipient of information; and, lastly, the likely consequences of non-disclosure by the patient who is entitled to medical scheme benefits, namely that the medical scheme may elect not to reimburse the claim of the patient.¹⁰⁰

Another question to be asked is whether the consent required by the Medical Schemes Act is not given under duress or coercion of non-payment, or could it amount to legal consent? Where consent is refused, it could lead to non-payment by the medical aid for the services. Benatar argues that very few people would willingly disclose private medical information to insurance companies if they did not fear the alternative of being medically uninsured and that the disclosures, in effect, are coerced by circumstance.¹⁰¹ The same argument is valid for disclosure to medical aids. According to CMS, codes for non-disclosure of clinical information are valid and cannot be rejected by medical schemes on this ground alone, although this may impact on reimbursement.¹⁰² The National Task Team Report notes that patients should be informed that the use of the above codes may result in either the medical scheme electing to pay the claim from day-to-day / acute benefits, or electing to pay the claims from the member's savings account or electing to reject the claim. It is in the discretion of the medical scheme to decide how

⁹⁴ See National Task Team Report 47.

⁹⁵ Howard and Bogle 40; Dada October 2005 *Bulletin of the HPSCSA* as quoted by Knobel "Consent, with particular reference to HIV and Aids" February 2006 24(2) *CME* 79 81.

⁹⁶ Howard and Bogle 40.

⁹⁷ Act 2 of 2000.

⁹⁸ See ss 34 and 63 of the Act.

⁹⁹ See Dada and McQuoid-Mason 2005 95(11) *SAMJ* 875; and London and Baldwin-Ragaven "Human Rights Obligations in Health Care" January 2006 24(1) *CME* 20 23.

¹⁰⁰ National Task Team Report 47. For a discussion on how the HPCSA views informed consent, see National Task Team Report 47-48.

¹⁰¹ Benatar "Confidentiality" January 2003 21(1) *CMS* 11 14.

¹⁰² Circular 33 of 2006 dated 25 July 2006.

to proceed when these codes are omitted.¹⁰³ In the light hereof, could a patient's consent be regarded as truly voluntary?

The uneasiness of the medical profession with the lack of consent regarding the inclusion of the ICD10 codes is also intimated to in the *pro forma* "Agreement between Doctor and Person Responsible for Account" prepared by the South African Medical Association's Human Rights, Law and Ethics Unit for doctors which include the following clause:

"In accordance with legal requirements the doctor is granted permission to disclose any information about me, including medical information and/or diagnosis or diagnostic codes, to relevant third parties (such as funders, administrators, switching companies, prescriptions to pharmacies, and the like) for purposes of processing payment of accounts in respect of medical services which have been rendered to the patient and/or dispensing medicines; as required by a specific Act or statute, professional ethics or formal policy or directive applicable to the situation. I have been informed that, in certain circumstances, such as the disclosure of ICD-10 codes, the exact consequences of disclosure of such information is unknown to my doctor and that this information may be obtained by me from the third party to whom the information is disclosed."

It is submitted that the signature hereof might constitute consent by the person signing the document, but as the signatory is not necessarily the patient, it does not necessarily follow that all patients of the doctor consented to the disclosure of the information if this document is signed. It should be noted that consent *vis-à-vis* a minor is more problematic, especially where a minor requests the doctor for care without divulging the information to the account-paying parent.¹⁰⁴

6 3 Consequences of improper disclosure

The consequences of an unjustified breach of the confidentiality rule by a doctor, according to Dhai *et al* is firstly, a civil action for damages based on *inter alia* the breach of the doctor-patient contract and/or an invasion of the patient's privacy;¹⁰⁵ and, secondly, HPCSA disciplinary hearing on charges of improper or disgraceful conduct resulting in sanctions that include a caution and/or a reprimand, suspension from practice or removal from the role of practitioners.¹⁰⁶

¹⁰³ National Task Team Report 62.

¹⁰⁴ This aspect falls outside the scope of the article. See in general Slabbert "Parental Access to Minor's Health Records in the South African Health Care Context: Concerns and Recommendations" December 2005 24 Med & L 743; and Dada and McQuoid-Mason November 2005 95(11) SAMJ 876.

¹⁰⁵ Dhai *et al* 2001 91(2) SAMJ 126 with reference to *Tohill v Foster* 1925 TPD 857 (not AD as quoted) and *Jansen van Vuuren NNO v Kruger* 1993 4 SA 842 (A). See also Dada and McQuoid-Mason November 2005 95(11) SAMJ 876. The delictual issue is briefly discussed below in par 8.

¹⁰⁶ Dhai *et al* 2001 91(2) SAMJ 126.

7 THE RIGHT TO PRIVACY

The principle of confidentiality between a doctor and his patient is closely connected to the right to privacy of a patient. This right to privacy has been recognized in South African law as an independent personality interest.¹⁰⁷ Moreover, section 14 of the Bill of Rights guarantees a general right to privacy.

Neethling notes that privacy, from a private law perspective, can only be infringed by an “acquaintance with personal facts by outsiders contrary to the determination and will of the person whose right is infringed” – either through intrusion or disclosure.¹⁰⁸ He argues that the acquaintance with private facts should firstly, not be contrary to will of the prejudiced party; and, secondly, and viewed objectively, not be unreasonable or contrary to the legal views of the community.¹⁰⁹ Where there is a specific confidentiality relationship, such as between a doctor and his patient, the disclosure of the information may be wrongful depending on the context of the disclosure, taking into account all the surrounding circumstances.¹¹⁰ The wrongfulness of the invasion of the privacy should be excluded where there is a ground for justification.¹¹¹

The private law approach forms a useful starting point for the constitutional discussion.¹¹² The concept of privacy is underpinned by two ideas: firstly, personal autonomy, namely the right to make decisions about oneself; and secondly, the belief that respecting an individual’s autonomy and thus his or her privacy is a “necessary condition for human flourishing”.¹¹³ In this article the focus is on the aspect of informational privacy: the right to keep personal information private.¹¹⁴

The right to privacy has been interpreted by the Constitutional Court, per Ackerman J, in *Bernstein v Bester NNO*, to mean a subjective expectation of privacy that is reasonable and in the “truly personal realm”.¹¹⁵ The court

¹⁰⁷ Neethling 217. See also *National Media Ltd v Jooste* 1996 3 SA 262 (A) 271; *O’Keeffe v Argus Printing and Publishing Co Ltd* 1954 3 SA 244 (C); and *Jansen van Vuuren NNO v Kruger supra* 849.

¹⁰⁸ Neethling 221. See also Rautenbach “The Conduct and Interests Protected by the Right to Privacy in Section 14 of the Constitution” 2001 1 *TSAR* 116.

¹⁰⁹ Neethling 221 with reference to *inter alia* *Financial Mail (Pty) Ltd v Sage Holdings Ltd* 1993 2 SA 451 (A) 462; and *Bernstein v Bester NNO* 1996 2 SA 751 (CC) 789A-B. See also Rautenbach 2001 1 *TSAR* 118.

¹¹⁰ Neethling 236. See discussion in par 7 1 and 7 2 above.

¹¹¹ See in general the discussion of Neethling 240 and further. An example of such justification would be a necessity, *eg* where the medical practitioner reveals a patient’s HIV/AIDS status to the latter’s sexual partner as the patient’s right to privacy must outweigh the sexual partner’s right to life (Neethling 241 fn 190).

¹¹² Rautenbach 2001 1 *TSAR* 116.

¹¹³ Cameron January 1999 Presentation to Judges’ Workshop on HIV/AIDS in Mumbai 2 with reference to Fledman *Civil Liberties and Human Rights in England and Wales* (1993) Chapter 8. See also Rautenbach 2001 1 *TSAR* 119.

¹¹⁴ Cameron January 1999 Presentation to Judges’ Workshop on HIV/AIDS in Mumbai 2.

¹¹⁵ *Bernstein v Bester NNO* 1996 2 SA 751 (CC) 789A-B. See Currie and De Waal *The Bill of Rights Handbook* 5ed (2005) 319. See, however, the criticism of Woolman and Botha “Limitations” in Woolman, Roux, Klaaren, Stein and Chaskalson (eds) *Constitutional Law of South Africa Volume 2* 2ed Original service 07-06 34-24 ff in light of *Beinash v Ernst &*

noted that the constitutionally protected right to privacy can be arranged in concentric circles, ranging from the inner circle with inviolable expectations of privacy, to peripheral privacy where the expectation of privacy would not be reasonable.¹¹⁶ The same court in *Magajane v Chairperson, North West Gambling Board*,¹¹⁷ however, amended the expectation of privacy and found that privacy is not limited to the inner sanction of the home, but can extend also to other areas.¹¹⁸ Rautenbach argues that the bearer of the right to privacy must have a subjective expectation of privacy which society must consider reasonable.¹¹⁹ In the light of the *Jansen van Vuuren* judgment,¹²⁰ it is submitted that medical confidentiality creates a subjective expectation of privacy that is reasonable and falls within the “truly personal realm” – especially seeing that the right to privacy includes control over private information.¹²¹

It should also be noted that the right to privacy and the principle of medical confidentiality also impacts on human dignity, protected in terms of s 10 of the Bill of Rights. This inherent right to dignity is the most important human right that underlines all other human rights and the right to privacy is no exception.¹²²

Everyone is bound by the Bill of Rights in the Constitution of the Republic of South Africa, 1996, including the legislature, executive, judiciary, all organs of state¹²³ as well as private persons.¹²⁴ All legislation should be tested against the Constitution – including the legislation and regulations prescribing the compulsory inclusion of the coding system.¹²⁵

In deciding whether a breach of privacy would be unconstitutional, a two-stage analysis must be employed: first, the scope of the right to privacy must be assessed to determine whether law or conduct has infringed the right to privacy, and secondly, if there has been an infringement of the right, it must

Young 1999 2 SA 116 (CC). A full discussion hereof, as well as the authors' suggested approach, falls outside the scope of this article.

¹¹⁶ *Bernstein v Bester NNO supra* par 79. See discussion of Rautenbach “Overview of the Constitutional Court Decisions on the Bill of Rights – 2006” 2007 2 TSAR 391 399.

¹¹⁷ 2006 10 BCLR 1133 (CC).

¹¹⁸ *Magajane v Chairperson, North West Gambling Board supra* par 42. See discussion by Rautenbach 2007 2 TSAR 398.

¹¹⁹ Rautenbach 2007 2 TSAR 399.

¹²⁰ *Jansen van Vuuren NNO v Kruger supra* 842.

¹²¹ Neethling 229; and Currie and De Waal 323. See in general the case of *Mistry v Interim National Medical and Dental Council of South Africa* 1998 4 SA 1127 (CC), although this matter dealt with search and seizures.

¹²² Human dignity has been described as the pre-eminent value – a central value of the “objective, normative value system” (*Carmichele v Minister of Safety and Security* 2001 4 SA 938 (CC) par 56; *S v Makwanyane* 1995 3 SA 391 (CC) par 144; and Currie and De Waal 272-274). See the discussion and criticism by Woolman and Botha 116.

¹²³ S 8(1). See discussion of Rautenbach “The Bill of Rights Applies to Private Law and Binds Private Persons” 2000 2 TSAR 296 308.

¹²⁴ Rautenbach 2001 1 TSAR 119.

¹²⁵ Medical Schemes Act (s 59(1)), including regulations, as read with the National Health Act (s 74).

be determined whether the infringement is justifiable under the limitation clause, section 36.¹²⁶

As discussed above, it is submitted that the legislation, as it now reads, infringes on the privacy rights of patients. Section 59(1) of the Medical Schemes Act requires that a supplier of a health service (doctor) must furnish the member (patient) with an account reflecting certain particulars, including, in terms of regulation 5(f) the relevant diagnostic code. This compulsory name-based disclosure of personal information via ICD-10 coding to medical schemes, it is submitted, is an infringement of the privacy rights of the patient. Where the coding is done without the consent of the patient, it is a direct infringement of the patient's right to privacy and dignity. It is further submitted that even if there was consent, the consent was obtained under duress. Seen in a broader light, the vehicle used by the Department of Health to collect private health information is unnecessary. The health information can be obtained in another, non-name-based format, directly from private health professionals, without the inclusion of the medical schemes. The aim of the National Health Act will still be met, without the infringement of the privacy rights of the patients – by separating the PHI from the codes at the offices of the supplier of the health service.

If it is thus accepted that the constitutional rights to privacy of the patients are infringed by the implementation of the statute, the next stage is to determine whether the infringement is reasonable and justifiable. The limitation clause, section 36(1), reads as follows:¹²⁷

“The rights in the Bill of Rights may be limited only in terms of laws of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including (a) the nature of the right; (b) the importance of the purpose of the limitation; (c) the nature and extent of the limitation; (d) the relation between the limitation and its purpose; and (e) less restrictive means to achieve the purpose.”

Unfortunately, the limitation clause does not provide ready-made answers to all the practical problems. It merely provides a framework within which the limit must be considered and all relevant arguments raised.¹²⁸ The first requirement is that the limitation must be authorized by a law of general application that must apply impersonally and equally to all.¹²⁹ Legislation qualifies as such a law.¹³⁰ The National Health Act's provision for a comprehensive national health information system is an act of general application and not at issue here. However, it is the partial implementation of the aim of that Act, in private healthcare, as provided for in the Medical Schemes Act, that raises some questions. Some practical information is expedient. Private healthcare is mainly funded by medical schemes, but only

¹²⁶ See in general Currie and De Waal 317; *Bernstein v Bester NNO supra* par 71; and *Harksen v Lane NO* 1998 1 SA 300 (CC) par 53. See also Devenish *The South African Constitution* (2005) 183.

¹²⁷ For an in-depth discussion of the limitation clause see Woolman and Botha Chapter 34.

¹²⁸ Rautenbach 2000 2 TSAR 296 312.

¹²⁹ Currie and De Waal 169.

¹³⁰ *Ibid.*

about 16% of the South African population belongs to medical aids.¹³¹ The public sector, not touched by the Medical Schemes Act, on the other hand consumes 50% of the total volume of pharmaceuticals in SA.¹³² There is currently no effective system for the collection of state data from the public healthcare. It is submitted that, as the legislation only applies to patients belonging to medical aids, about 16% of South Africans, the limitation is not one of general application. The practical result is thus not in line with the purpose of the National Health Act, which is to collect information to inform the general health policies. The promotion of health and prevention of diseases are very important in a country like South Africa where many people do not have access to proper medical care. Only the more affluent people belong to medical aids. The majority of South Africans cannot afford to belong to medical aids, especially in the rural areas. Different disease patterns could theoretically exist between private and public patient populations. Thus it cannot be said that the coding system, as it is currently implemented, would necessarily benefit the country as a whole, especially the disadvantaged communities. This makes the mission of the Department as well as the aim of the coding system a charade. With one of the government missions being that healthcare should consistently improve healthcare delivery systems with a focus on access, equity, efficiency, quality and sustainability, the question may well be asked whether the *de facto* information collection system is in line with the noble objects of the Department. The bottom line is that the implementation of the coding system, the infringement on the privacy rights of patients, may be *prima facie* contained in a law of general application, although the practical effect is not generally applied. One could argue that the law culminates in parity of treatment of "similarly situated persons alike",¹³³ but the difference in the effect of the treatment of the two groupings (those with a medical aid and those without) is not in line with the purpose of the legislation.

With regard to the issue whether the limitation on the rights of the patient could be regarded as reasonable and justifiable, the courts generally consider the issue of proportionality.¹³⁴ To decide whether the infringement of a patient's rights is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, the potential benefits must be weighed against the infringement.¹³⁵ This is not a mechanical check-list but a balancing exercise resulting in a judgment of proportionality.¹³⁶ The section refers to various factors that should be considered in the making of the decision. When considering the nature of the human right – *in casu* the rights to privacy – it should be borne in mind that these rights are fundamental human rights closely connected to the identity

¹³¹ Cullinan *Health-e* 1, accessed <http://www.health-e.org.za/news/article.php?uid=20030402> 1.

¹³² *Ibid.*

¹³³ Woolman and Botha 34-48.

¹³⁴ See the general discussion of Woolman and Botha 34-69ff with reference to *S v Makwanyane supra*.

¹³⁵ The Constitutional Court has noted that when balancing the rights under the limitation clause, one must ask how the central constitutional value of dignity is affected as it has a residual value (Currie and De Waal 10.2).

¹³⁶ Woolman and Botha 34-70 with reference to *S v Manamela* 2000 3 SA 1 (CC).

of the person. Woolman and Botha argue that the more important the right is to an open and democratic society, the more compelling the justification for the limitation of the right should be.¹³⁷ *In casu*, it is submitted, the right is of vital importance, yet the justification for the limitation weak.

In evaluating the importance of the purpose of the limitation, two assessments are necessary: an identification of the purpose of the limitation, and, an appraisal of its importance.¹³⁸ The purpose of the limitation is to gather medical information. It is an important purpose. However, the nature and extent of the limitation that forms the basis of the proportionality evaluation,¹³⁹ is where the problem *in casu* lies. The limitation is not narrowly tailored to achieve its objective.¹⁴⁰ The information could be collected, without the infringement of the rights of the individual, by not using a name-based system. The information could be encoded and anonymized at the offices of the healthcare provider, although such processes are not necessarily infallible¹⁴¹ or without problems.¹⁴² The extent of the current limitation is unnecessarily wide and there is no close relation between the limitation itself and its purpose. Anonymized information would be a far less restrictive means to achieve the same purpose. With technological developments it is possible to protect the privacy of the individual whilst it is still possible to collect medical data for medical research and disease identification and control.¹⁴³ It seems as if the relationship between the limitation and its purpose is out of synchronization and disproportionate. Moreover, the last factor referred to in section 36 is whether less restricted means to achieve the purpose exists. As discussed *supra* this is indeed the case. Rights should be limited no more than is necessary. It is submitted that the limitation under discussion should be regarded as unjustifiable as it can be achieved by less restrictive means – with a similar administrative burden and similar funding.

¹³⁷ Woolman and Botha 34-71.

¹³⁸ Woolman and Botha 34-73.

¹³⁹ *Ibid.*

¹⁴⁰ Woolman and Botha 34-74.

¹⁴¹ See Sweeney (May 1997 A.I. Working Paper No AIWP-WP344b accessed <http://www.privacy.cs.cmu.edu>) for a discussion of the problem of possible re-identification of persons from anonymous-looking data in the US.

¹⁴² Pommerening (1994 paper delivered at the IFIP Congress accessed <http://www.staff.uni-mainz.de/pommeren/Artikel/ifip.pdf>), with reference to the situation in Germany, argues that the conflict between the common welfare and the individual rights must be solved by politicians on the basis of public discussion. A similar argument could be made for South Africa. He makes some recommendations that might be useful here: one, doctors can be given the right or obligation to report cases without consent of the patient, but only if the registry stores the information anonymously; two, legal rules should be drafted for the professional discretion of researchers; three, epidemiologic research projects and data access should only be available to projects approved by a review board; four, there should be legal protection against confiscation of epidemiologic data by authorities; and five, anonymization of data should be enforced: aggregation for statistics and encryption for storage (Pommerening 1994 paper delivered at the IFIP Congress accessed <http://www.staff.uni-mainz.de/pommeren/Artikel/ifip.pdf> 5).

¹⁴³ See in general the articles of Pommerening (1994 paper delivered at the IFIP Congress accessed <http://www.staff.uni-mainz.de/pommeren/Artikel/ifip.pdf>) and Bleumer and Schunter (<http://www.citeseer.ist.psu.edu/bleumer97privacy.html>) on the position in Germany. See also the USA HIPAA which regulates the safeguarding of health records against information loss, tampering and unauthorized access.

This article would be incomplete without reference to the South African Law Reform Commission Discussion Paper 109 *Privacy and Data Protection*.¹⁴⁴ Although the discussion paper deals with the broader issues of privacy and data protection, some of the recommendations that have been included in the Draft Bill on the Protection of Personal Information deserve noting, although further comments have been invited on the issues. There is no indication if and when the SALRC or the legislature would proceed with the process or what information and comment it has received on its document. The information available is, however, included for purposes of completeness. Firstly, the SALRC Discussion Paper acknowledges that the duty rests on the legislature to address the issue of data protection that should include the protection of all files, including paper and electronic files, as well as CAT Scans, ECG's and EEG's.¹⁴⁵ Secondly, the principles of information protection included in the Bill include the lawfulness of procession of information; that the collection of information should (explicitly) be purpose-specific; other suggestions include limitations to privacy; the quality of the information; openness; security; individual participation including the right to correct information; as well as accountability.¹⁴⁶ Thirdly, there should be a general prohibition on the processing of special personal information (including health information), although exceptions would be possible.¹⁴⁷ Fourthly, the recommendations included that there are no objections to the compiling of statistics, although anonymized and de-identifiable information might be problematic due to the risks involved.¹⁴⁸ Fifthly, it was suggested that an independent oversight authority be created to investigate and institute legal proceedings in addition to the remedies currently available to an individual.¹⁴⁹ Although these recommendations would clearly assist with the general privacy rights of patients, it is early in the legislative process. Moreover, it does not address all the specific issues identified above specifically with regard to the medical aid schemes.

The protection of privacy when dealing with medical data is not unique to South Africa. Many other countries are grappling with similar issues and have been finding solutions.¹⁵⁰ Although such foreign law may only be of persuasive value, it might be useful for the purpose of comparison. In 1997, the Chief Medical Officer in the UK commissioned a review under chairmanship of Dame Caldicott to examine the ways in which patient information was being used and the best ways to ensure that confidentiality is not undermined, particularly in relation to developments in information technology. The Report highlighted six principles: (1) justify the purposes of

¹⁴⁴ Project 124 dated October 2005 (hereinafter "SALRC Discussion Paper"). The aim is not to discuss the Paper fully, but merely to highlight certain issues that are relevant to this article.

¹⁴⁵ SALRC Discussion Paper 53-59.

¹⁴⁶ SALRC Discussion Paper 112-202.

¹⁴⁷ SALRC Discussion Paper 208. These exceptions could include medical practitioners as well as insurance companies (211).

¹⁴⁸ SALRC Discussion Paper 327. The SALRC specifically invited comments on this point (SALRC Discussion Paper 90).

¹⁴⁹ SALRC Discussion Paper 284.

¹⁵⁰ A discussion of foreign systems is the focus of another article and not included herein. See *inter alia* the SALRC Discussion Paper 372 ff.

the use of identifiable patient information; (2) do not use patient-identifiable information, unless it is absolutely necessary; (3) use the minimum necessary patient-identifiable information; (4) access to patient-identifiable information should be strictly on a need-to-know basis; (5) everyone with access to patient-identifiable information should be aware of their responsibilities; and (6) understand and comply with the law.¹⁵¹ Whether the South African scenario meets these requirements is debatable.

In terms of the Constitution, in interpreting the Bill of Rights, international law must be considered.¹⁵² Various treaties protect the general right to privacy, such as the International Covenant on Civil and Political Rights (art 17)¹⁵³ and the European Convention of Human Rights (art 8). Two other international legal instruments, dealing specifically with information, must be noted even though South Africa is not a party thereto: the Council of Europe *Convention for the Protection of Individuals with regard to the Automatic Processing of Personal Data* (1981);¹⁵⁴ and the Organization for Economic Co-operation and Development (OECD) *Guidelines Governing the Protection of Privacy and Transborder Flow of Data* (1980).¹⁵⁵ See also the 1995 Directive 95/46/EC of the European Parliament and of the Council¹⁵⁶ on the protection of individuals with regard to the processing of personal data and on the free movement of such data.¹⁵⁷ All these international instruments confirm the notion of confidentiality and that countries should protect the privacy rights of its people in an era of electronic information flow. Article 6 of the 1981 Convention specifically notes that personal data revealing *inter alia* the personal data concerning health or sexual life may not be processed automatically unless domestic law provides adequate safeguards. The OECD recognized that countries have a common interest in protecting privacy and individual liberties, and in reconciling fundamental but competing values such as privacy and the free flow of information (preamble).¹⁵⁸

8 REPORT OF THE PATIENT CONFIDENTIALITY SUBCOMMITTEE OF THE ICD-10 NATIONAL TASK TEAM, 2006

The objectives of this Report is set out to ensure the integrity, privacy, confidentiality and security of personal health information across the data chain; to identify the manner in which informed consent to disclosure of

¹⁵¹ Howard and Bogle 43.

¹⁵² S 39(1)(b) of the Constitution.

¹⁵³ SA ratified convention in 1999.

¹⁵⁴ Sourced electronically from <http://conventions.coe.int/Treaty/en/Treaties/Html/108.htm>.

¹⁵⁵ Sourced electronically from http://www.oecd.org/documentprint/0,2744,en_2649_34255.

¹⁵⁶ 24 October 1995.

¹⁵⁷ Sourced electronically from <http://www.cdt.org/privacy/eudirective>. See in general the discussion in the National Task Team Report (40) of the directive as read with the draft Protection of Personal Information Bill where the processing of personal information about a person's health is dependant on explicit consent.

¹⁵⁸ The OECD is a group of 30 countries sharing a commitment to democratic governance and the market economy (sourced electronically from <http://www.oecd.org/about>).

patient health information (PHI) should be obtained from the patient; to define the purpose and consequences of the disclosure; and, to enable the disclosure of PHI to other healthcare providers to ensure quality and continuity of health services in respect of the patient.¹⁵⁹

Although the Report notes that laws and their implementation can be subjected to constitutional scrutiny, and therefore the objectives of disclosure of the PHI must be clear¹⁶⁰ (presumably to be covered in terms of the limitation clause), the Report does not deal with the constitutionality of the legislation at all. The recommendations of the Report are however important as it reiterates the problems relating to confidentiality.¹⁶¹

The recommendations include: firstly, that patient data including ICD-10 diagnostic codes that are to be used for research, training, education or benchmarking purposes should be de-identified or anonymized as soon as identifiable information is no longer required along the data chain / information pathway.¹⁶² We submit that it should be done before the information is disseminated by the doctor and not as the Medical Scheme Act provides. The second recommendation is that the healthcare industry must develop or review codes of conduct, policies, and standard operating procedures that cater for privacy and confidentiality and in particular, the use of personal health information.¹⁶³ Other recommendations include education and training, confidentiality agreements, setting of access rights with password protection divulged on a “need to know” basis; and continued risk assessment.¹⁶⁴

It is specifically proposed that the Department of Health as part of its strategy for the National Health Information System of South Africa adopt confidentiality and security standards for the healthcare industry.¹⁶⁵

The Report included specific recommendations for healthcare providers around the protection of the privacy of all patients, including minors; control measures; written informed consent; confidentiality and non-disclosure agreements; and patient awareness.¹⁶⁶ Other specific recommendations for Medical Scheme, Medical Scheme Administrator and Managed Care Organisation, include that medical scheme contracts with members should state the reasons for disclosure of personal health information such as ICD-10 codes, the likely consequences of disclosure as well as non-disclosure and the intended recipients of PHI such as ICD-10 codes; and, the need for medical schemes to contract with all their third-party service providers to ensure the protection of the confidentiality of PHI. This view is also supported by the CMS in its document titled “Putting Members First: Towards Better Governance of Medical Schemes – Findings and

¹⁵⁹ National Task Team Report 10.

¹⁶⁰ National Task Team Report 17.

¹⁶¹ National Task Team Report 61-64.

¹⁶² National Task Team Report 61.

¹⁶³ *Ibid.*

¹⁶⁴ National Task Team Report 61-62.

¹⁶⁵ National Task Team Report 63.

¹⁶⁶ *Ibid.*

Recommendations of the Governance Theme Project”;¹⁶⁷ which relates to ongoing education; review of access to PHI and other procedures.¹⁶⁸ The final set of specific recommendations was for the Council for Medical Schemes. In this regard, that the CMS may have to consider changes to the Medical Schemes Act depending on the intended use of personal health information such as ICD-10 codes. This is critical as patients should be guaranteed that their personal health information will only be used for those reasons for which they gave informed consent. The CMS should ensure that all medical schemes, as part of the accreditation process, have evidence of such contractual agreements with third party service providers and formulate uniform guidelines for the industry.¹⁶⁹

The impact of this Report on the practices in the healthcare sector and the legislation remains to be seen.

9 CONCLUSION

“The problems with (medical) data protection are of a political, legal, administrative, or technical nature. The basic ... problem is to control the balance between conflicting goals, e.g. privacy of medical data versus efficiency of healthcare.”¹⁷⁰

A vast majority of the South African population has experienced infringements of their fundamental rights, including rights to healthcare services, for many decades.¹⁷¹ However, the Department of Health is *prima facie* committed to the promotion and protection of people’s rights.¹⁷² The mission of the Department of Health is to improve the health status of the population through prevention and promotion of healthy lifestyles and to consistently improve the healthcare delivery systems by focusing on access, equity, efficiency, quality and sustainability.¹⁷³ Co-operation between the private and public health sectors is important to improve the health system and to address the inequities and divisions of the past.¹⁷⁴

The ICD-10 codes form part of the NHISSA and play an important role in the fulfilment of the health mission. It will enable the Department of Health to collect health information and monitor the health status of the South African people. However, the implementation of the ICD-10 codes through the Medical Schemes Act is problematic. Name-based data is collected, mostly without patients’ consent or consent obtained under duress, and used by

¹⁶⁷ May 2006.

¹⁶⁸ National Task Team Report 63-64.

¹⁶⁹ *Ibid.*

¹⁷⁰ Pommerening 1994 paper delivered at the IFIP Congress accessed [http://www.staff.uni-mainz.de/pommeren/ Artikel/ifip.pdf](http://www.staff.uni-mainz.de/pommeren/Artikel/ifip.pdf) 1.

¹⁷¹ SAMA *National Patient’s Rights Charter* sourced electronically from <http://www.samedical.org/page.asp?pageid=14>.

¹⁷² *Ibid.*

¹⁷³ Department of Health “Strategy Priorities for the National Health System 2004 – 2009” sourced electronically from <http://www.doh.gov.za/facts/stats-notes.html> 6.

¹⁷⁴ Tsabalala-Msimang, Minister of Health during the presentation of the new National Health Act, sourced electronically from <http://www.info.gov.za/speeches/2004/04081914451005.htm>.

medical aids to adopt policies in terms of the design of these patients' medical aid benefits. Apart from this potential disadvantage to patients, the coding system also impacts on doctor-patient confidentiality and the patients' fundamental rights to privacy and dignity. A relatively small percentage of the population of South Africa, belonging to a medical aid, is targeted by this strategy of the government that infringes their basic human rights. This infringement is, however, not justifiable in an open, democratic society based on human dignity, equality and freedom.

The National Task Team Report is a positive step in that the urgency and necessity to deal with the issue of privacy and confidentiality is acknowledged, and it is in the process of being addressed. The confidentiality issues relating to the ICD-10 coding is not insurmountable. With education of patients and healthcare professionals and amendments to the application of the system, it will be ensured that the privacy rights of patients are not infringed, and thus the relevant information could be made available to the Department of Health as intended. It is submitted that reg 5(f) promulgated as read with section 59 of Medical Schemes Act is unconstitutional. Other non-intrusive and more comprehensive avenues are available to obtain information for the national department. Dada and McQuoid-Mason recommend that "before forwarding medical records to a medical aid funder, managed care organizations, utilization review programmes or other health programme, doctors, pathologists, hospitals, and others should obtain a signed copy of the patients' consent to release their medical records".¹⁷⁵ Because of the coerced nature of consent our suggested solution is simpler: separate the details of the patient and the codes before it leaves the healthcare practitioner's offices. The information required by the national department could then be made available without the infringement of the rights of patients. One can only hope that the issue will be addressed by the legislature in due course as has been suggested, already in 2005, by the SALRC.

¹⁷⁵ Dada and McQuoid-Mason November 2005 95(11) *SAMJ* 877.