

Privacy and Confidentiality Standards

Since these principles were written and proposed, various events have coloured both law and politics concerning the right to privacy and data, including the passing of the National Health Bill, the SA Law Commission Issue Paper on Privacy and Data-protection and the controversy relating to the sale of data for commercial purposes, sparked by the alleged Post Office sale of addresses. It is suggested that the Electronic communications and transactions Act of 2002 also be considered in more detail, including the provisions on voluntary adherence to data-protection principles.

Moreover, in the health care funding industry health data no longer only relates to "whether to pay or not", but also to "whether to intervene/manage or not". Furthermore, risk calculations may still be bound to health data relating to current and past medical scheme members (within a particular scheme or within a particular group of schemes), requiring access to as comprehensive a health care picture as possible. Proposals in terms of a social health insurance system may affect the basis on which data is collected, from whom it is collected and the purposes for which it is used.

Until data-legislation is passed, interim measures have to be instituted in line with applicable legislation and general constitutional principles.

The initial document is kept and some issues are raised for consideration and discussion. It is important that the practical implementation of the various principles are considered, that may prompt further research and investigation. Some principles may be consolidated and this may serve as the document that could impact on the health sector part of envisaged Data Protection legislation.

Definitions

"health care role player" refers to medical schemes, administrators, service providers, intermediaries and their employees, governing bodies, trustees and Boards of Directors.

"personal- or health information" refers to all information that is personal or could be re-linked to a particular person or group and that pertains to the health and/or health care, treatment, diagnosis, tests, procedures, stay in health care facilities, and any other related health care information of any person or group. It includes any record that contains these types of information, irrespective of its format or type.

Principle 1: All parties dealing with patient health care and personal information have to take into account relevant legislation, such as the Constitution of the RSA of 1996, the Medical Schemes Act of 1998, the Promotion of Access to Information Act of 2000, the National Health Bill of 2003 and specific provisions contained in health- and health care legislation.

Principle 1.1: Information may be disclosed by a service provider to a medical scheme in execution of a managed care agreement as provided for

in the regulations to the Medical Schemes Act of 1998. Where such disclosure is made to an administrator or any third party on the basis of a contract between the scheme and such administrator or third party in terms of this specific regulation, the administrator or third party is bound by the same provisions as the scheme. Access to patient information is limited in scope by the exact provisions of the contract between the managed care organisation and the scheme and the *purpose* for which the information is provided, e.g. evaluation of benefits, motivation for pre-authorisation, etc. This information should not be passed on to any other department within that organisation, scheme or administrator which does not deal with managed care.

Principle 1.2: Administrators and intermediaries are obliged to keep all information and material in their possession and relating to its duties *vis á vis* a medical scheme and/or service provider, confidential, and is bound by the same principles governing the conduct of the scheme and/or service provider in relation to patient information confidentiality and disclosure.

Principle 1.3: Any third party request for information is to be dealt with in terms of the Promotion of Access to Information Act of 2000.

ISSUES UP FOR CONSIDERATION AND DISCUSSION:

The National Health Bill provision on confidentiality, reads as follows:

14. (1) *All information concerning a user, including information relating to his or her health status, treatment or stay in a health establishment, is confidential.*

(2) *Subject to section 15, no person may disclose any information contemplated in subsection (1) unless -*

(a) *the user consents to that disclosure in writing;*

(b) *a court order or any law requires that disclosure; or*

(c) *non-disclosure of the information represents a serious threat to public health.*

Specific consideration has to be given as to whether the Medical Schemes Act and regulations provide for sufficient authority (in terms of section 14(2)) for the various disclosures that take place during (a) medical scheme membership administration (including dependent administration) (b) health service provisions (c) accounts, payments and billing (d) evaluation of member health status, risk analyses and/or managed care. It is also important to note that the Promotion of Access to Information Act of 2000 does not allow for health care information to be withheld if a patient requests such information. It may be difficult to withhold a person's health status from him or her if ICD10 coding is used that appears on an account.

Third party access, if such a third party is a health care provider, is regulated by section 15(1) that states that "a health worker or any health care provider that has access to the health records of a user may disclose such personal information to any other person, health care 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" and section 16 states that "A health care provider may examine a user's health records for the purposes of- (a) treatment with the authorisation of the user...". The issue is whether medical advisors, case managers, clinical reviewers, etc., in the employ of a funder or managed care organization, are also covered by this provision.

Principle 2: For all uses and disclosures of health information all "health care role players" should remove personal identifiers consistent with maintaining the usefulness of the information, unless legislation authorises specific personalised disclosures. Nothing prevents the compilation and/or manipulation of anonymous information for the purposes of financial- or other planning, for risk calculation or for statistical purposes, related to the core business of the entity in possession of the information. The role player compiling and/or manipulating such information lawfully owns such information.

ISSUES UP FOR CONSIDERATION AND DISCUSSION:

The right to privacy entails "having control over his or her personal information" (SALC par 1.2.1). The sale of data, and the use of such data for purposes other than for what the person has expressly (or implicitly?) consented to (in writing? - see NHB) have to be considered in this context.

Principle 3: Privacy protections should follow the data, irrespective of the number of intermediaries between the patient, as initial provider of the information, and any final destination. This also applies to electronic messaging.

ISSUES UP FOR CONSIDERATION AND DISCUSSION:

Section 17 of the National Health Bill places a duty on health establishments to ensure that there is no unauthorised access to records, which implies the setting up of mechanisms to verify record and data requests, even where these are from funding institutions or data warehouses. Failure to do so constitutes an offence under the Bill.

Principle 4: An individual should have the right to access his or her own health information, as regulated by the Promotion of Access to Information Act of 2000 and other relevant legislation, and the right to supplement such information.

ISSUES UP FOR CONSIDERATION AND DISCUSSION:

In terms of the National Health Bill a person's right to know his or her health status may be withheld "in circumstances where there is substantial evidence that the disclosure of the user's health status would be contrary to the best interests of the user" (section 6 – possible repercussions discussed above under principle 1).

Principle 5: Health care role players should, in effecting their duties in terms of section 57(4)(i) of the Medical Schemes Act, establish policies, procedures and

review mechanisms regarding the protection of confidentiality, as well as the collection, use, and disclosure of health information.

ISSUES UP FOR CONSIDERATION AND DISCUSSION:

Section 57(4) relates to the duties of trustees to medical schemes, who may need guidance from staff and/or administrators. Subsections (4)(g) and (h) could also be applied so as to ensure compliance.

Principle 6: Individuals should be given notice about the (possible) uses-, purposes- and disclosures of their health information in the chain of health care and health care financing. Individuals have to be informed about their rights with regard to that information. This should be done at the point of potential delivery of health care, as well as the point of application for medical scheme membership or health insurance.

ISSUES UP FOR CONSIDERATION AND DISCUSSION:

In order for members/patients to have control over their information, they should at some point consent to the variety of uses to which their information may be put. In terms of section 52ff to the Electronic Communications and Transactions Act of 2002, some databases may be declared "critical databases" and certain measures have to be instituted to secure the database and access to it.

Principle 7: Health care role players should implement security safeguards for the storage, use, and disclosure of health information, irrespective of the format of such information.

Principle 8: Personally identifiable health information should not be disclosed without patient authorisation, except in circumstances authorised by law or with the patient's specific, full and informed consent.

National Health Bill requires written consent.

Principle 8.1: Informed consent means that the patient or member should know the reasons why the disclosure is necessary (e.g. for the execution of duties in terms of a specific section of the Medical Schemes Act on, for example, waiting periods, and/or a specific regulation). The patient should also know and understand the implications such disclosure for him or her in terms of health care delivery and -financing. Health care role players are encouraged to formulate the various purposes for which private information is required or should be disclosed, and whether such are authorised by legislation or whether specific patient consent/member is required.

Principle 8.2: Existing legal rules in terms of consent by minors under the age of 14 and persons incapable of consenting to a disclosure have to be abided by.

Principle 8.3: The same rules of confidentiality and consent to disclosure apply to dependants and steps have to be taken to ensure sufficient protection of dependant/ beneficiary confidentiality.

Principle 9: Where financial, ownership or shareholding links exist between a third party and a health care role player (such as a medical scheme, administrator, intermediary or any health care role player), confidential- or personal information obtained by such role player in the course of its business as service provider, managed care organisation, medical scheme, administrator, broker may not be passed on to-, or be used by- or utilise in any manner by such third party institution or organisation for the purpose of conducting their business. The same prohibition applies where medical scheme benefits are linked to the conditions of work and/or employment contract. A contribution made by an employer towards an employee's medical scheme does not entitle that employer to access any personal- or health care information held by the scheme or any health care role player.

Principle 10: Health care organisations should use an objective and balanced process to review the use and disclosure of personally identifiable health information for research purposes. The provisions of internationally accepted research documents, such as the Helsinki Declaration have to be adhered to.

It is important to note that this applies to all research, even where researcher only uses existing file of patient and has no patient-contact at all.

Principle 11: Health care role players should not disclose personally identifiable health information to law enforcement officials or any other person acting in a capacity of investigating any alleged or suspected offence, absent a compulsory legal process, such as a warrant or court order.

Relates to various constitutional protections found in the SA Constitution and the general principle that rights may only be limited if authorised by a law of general application that would pass the section 36-muster.

Principle 12: Health privacy protections should be implemented in such a way as to enhance and not undermine, existing laws prohibiting discrimination such as the Promotion of Equality and Prevention of Unfair Discrimination Act of 2000 and the Employment Equity Act of 1998. This principle also applies to issues such as profiling of practices and patient groups.

Principle 13: Strong and effective remedies for violations of privacy protections should be established, including employee training and -disciplinary measures, appropriate contractual provisions and penalties with any party contracting with a health care role player, etc.

Principle 14: All role players that handle healthcare information should be held accountable for breaches of privacy and confidentiality for information in their hold. Aggrieved persons should have access to internal procedures and/or outside institutions at which to lodge complaints.

The National Health Bill create penalties for health establishments and their staff in terms of violations of privacy/data protection, but similar penalties should exist for other role players in this sector.