Journal of US-China Medical Science 19 (2022) 1-19
doi:10.17265/1548-6648/2022.01.001

Disclosure of Genetic Information as Matter of Medical Ethics and Patient Rights: The Relevant Legal Context

Alfred P. Minei[1] and Sam O. Kaipu[2]

1. School of Law, University of Papua New Guinea, Waigani. National Capital District, Papua New Guinea

2. Supreme & National Courts of Papua New Guinea, Waigani. National Capital District, Papua New Guinea

Abstract: The ethical debate surrounding disclosure of genetic information to family members has received ample ethical attention in recent years. Genetic information is often perceived as requiring unique ethical and legal attention because it is predictive, has the potential to be used in harmful ways (to stigmatize and discriminate), and not only has implications for the patient but also for biological kin. Genetic information allows inferences to be drawn about individuals other than the individual to whom the information most directly relates, most importantly about the individual's blood genetic relatives. The information about one person may be relevant to the clinical treatment of that person's genetic relatives. This brings up the questions about how the individual patients and health care workers, including medical staff and genetic councilors, should collect and deal with genetic information about genetic relatives derived in the course of diagnosis, treatment or counseling. The collection and disclosure of family genetic information, and rights of access to such information, are also central to the operation of genetics registers and to the conduct of genetic counseling. The quality of medical records created in a health setting depends largely on the individuals making entries. Health professionals—medical, nursing, and other personnel, as well as students and others who write in patient records, must understand the importance of creating legible, complete, and accurate records and the legal and medical implications of failing to do so. This article offers a review of these recent contributions, preceded by a description of the relevant legal context.

Key words: Constitutional right to privacy, genetic information, diagnosis, treatment, counseling, legal implication.

1. Introduction

In this paper, we advance the more cautious argument that far from reducing subjectivity to genetics, genetic knowledge is incorporated and resisted in complex ways. We draw our assessment from a sample (n = 80) of individuals we interviewed who have attended a medical service in Port Moresby General Hospital in Papua New Guinea (PNG). The individuals were aged over 21 years, and represented organizations in PNG, professionals, patients, students and the general public. We met the individuals during the medical clinic, at the place of work, and their homes. We say the study is based on the existing situation in PNG, it said the law will fall behind and not be able to adequately protect the privacy of the individuals. This paper describes the right not to know about genetic risk and the literatures relating to general knowledge of genetic, genetic testing and information.

The collection of family medical history information is an established part of medical practice. When providing health care service, health workers may need to collect information about an individual's family medical history in order to accurately diagnose a patient's condition. Information may relate to the health, or cause and age of death, of individuals closely genetically related to the patient. It may also include social medical history, for example information regarding marital status, health of spouse, children and other household members and what social support is available.

Family medical history information takes on particular significance in the practice of genetic medicine [1, 2]. Disclosure of genetic information within the family raises particular ethical issues. On

Corresponding author: Alfred P Minei, Ph.D., Candidate, research fields: Law in medicine.

one hand like any other type of health information, it is private and confidential and its unwarranted disclosure can harm the individual. On the other hand, disclosure can have significant benefits for family members, as it can inform them about health risks and predispositions to conditions that may be preventable or treatable. These benefits can be so significant that some ethicists suggested relatives have a "right to know" [3] and that patients have an ethical responsibility to disclose this information to relevant family members [4]. Cases where patients refuse to share clinically relevant genetic information with family members therefore raise ethical difficulties. Indeed, much of the bioethics literature surrounding disclosure has been framed as a conflict between the ethical principle of respect for autonomy (i.e. the duty of the clinician to respect patient confidentiality) and the principles of beneficence and "do no harm" (i.e. the clinician's duty to warn others). This framing is based on the assumption that patients' refusal to disclose stems from reasons that are self-centered meant to promote their own interests at the cost of the well-being of others. Studies have repeatedly demonstrated that it is in fact a common human desire to protect family members and ethical tension surrounding disclosure is more often raised by a hesitation regarding how to best protect them.

From the patients' perspective, the ethical dilemma is rarely framed as a tension between their own right to privacy and their relatives' right to know, or even their possible "right not to know" [5]. Rather, they are preoccupied by the ethical dimensions of their so-called "genetic responsibility" to warn family members in order to "foster" their health [6] and by "conflicting senses of responsibilities: to provide potentially valuable information and prevent harm that may arise from this knowledge". Thus, the need to disclose is rarely contested but patients are conflicted about questions such as what why, to whom, when and how genetic information should be disclosed in order to minimize adverse reactions and out-comes [7] such as being blamed by others [8]. In a previous publication, Hallowell and co-workers brought attention to the great value of empirical research in ethics and aimed to demonstrate "how empirical evidence can be used to frame ethical debates and inform clinical practices" [9]. Building on empirical findings, she concludes that evidence-based ethics is necessary to properly frame the debate surrounding disclosure of genetic information to family members. Since the publication of Hallowell's work, numerous empirical studies have been conducted to assess the perceptions of patients' relatives and clinicians in order to support best practice standards and develop evidence-based strategies for disclosure [9]. These are discussed in this article.

Genetic diagnosis is not always possible from a sample or information provided by one person and it may be desirable to test genetic relatives as well as immediate patient. Such testing may be necessary to establish inheritance patterns correctly, to confirm the mutation in at least one other affected member of the family (as part of developing a "family-specific" genetic test) or in conducting susceptibility testing for at-risk families [1, 2]. Even if genetic relatives are not actually tested, the verification of a genetic diagnosis usually involves the provision of information from or about relatives (or family pedigree).[1]

Information about the medical history of genetic relative assists health professionals to provide effective health services to their patients [1]. Such information may assist in diagnosis, the provision of medical advice about genetic risk to the patient or to present or future children, and the treatment or prevention options and in genetic counseling generally. Conversely, if this information is not collected the medical care or advice provided to the patient may be compromised.

[1] The information to construct family pedigree may come from living relatives, death registers; autopsy results; cancer or other registers; medical records of relatives who have died; deposits of stored tissue; or other research studies.

2. Failing to Comply to Rules and Procedures

A health setting that fails to comply with the hospital practices, policies and federal and state records laws risks loss of licensure, accreditation, and eligibility to participate in other government incentives and or federal reimbursement programs [1]. The court decisions have shown that a hospital's exposure to negligence liability increases if it condones improper entries by its staff. If a hospital can demonstrate by testimony that, in accordance with its policy and procedures, it regularly keeps complete and accurate records, the absence of certain notations may be used in the hospital's defense. For example,

In Smith v Rogers Memorial Hospital, "The hospital's records did not show that the patient had complained of certain symptoms, and testimony that the hospital's records were generally reliable, was important evidence in rebutting the patient's claim that she had complained of the symptoms and had not received proper care" [10].

Similarly, in Hurlock v Park Lane Medical Ctr, "The treating physician had ordered the patient turned in bed every two hours, but a notation of each turning did not appear in the patient's medical chart. The patient argued that the absence of notes was evidence that the hospital nurses negligently had failed to follow the physician's order, causing the patient to develop serious bedsores and necessitating amputation of her leg" [11].

Expert testimony established that, while proper nursing practice required notations to be placed in the patient's record, nurses sometimes get very busy and fail to document each action taken for patients such as the plaintiff who require special attention [12]. In such cases, accepted nursing practice places patient care in priority over proper documentation. Without any direct evidence that the hospital nurses have failed to turn the patient as directed, equally plausible inferences about the hospital's action arose from the medical record, so the court ruled, and dismissed the suit.

The medical information often is the single most important document available to a health setting in the defense of a negligence action and ordinarily is admissible as evidence of what occurred in the care of the patient.

3. Right to Privacy

In PNG does the Constitution adequately recognize the "familial or collective nature" of genetic information?

Constitution Section 49, Right to Privacy, "Every person has the right to reasonable privacy in respect of his private and family life, his communications with other persons and his personal papers and effects, except to the extent that the exercise of that right is regulated or restricted by a law that complies with Section 38 (general qualifications on qualified rights)." [13].

One issue involves the constraints and limits that the national privacy principle imposes on the collection of relevant genetic information by medical doctors and other health professionals about the genetic relatives of their parents. In a situation, a guardian of the patient asks the doctor, "If the family knew what healthcare worker collected from patient and the guardian would like to be present at the clinical examination room …"

That is the case; this study draws this attention to section 49. In terms of the Constitution so far as concerns the right to privacy, the statement of section 49 or the national principle of privacy contains a matter pertinent to the right of privacy. Look at the commencement, "Every person has the right to reasonable privacy in respect to his private and family life …" [13].

The principle says every person be dynamically involved in the protection of a person's right to be left alone or that restricts public access to personal information. Every person has an obligation to promote this principle. On the contrary, this principle does not provide protection for those rights in respect of which section 38 of the Constitution applies [14].

Generally, an organization must not collect personal information unless the information is necessary for its functions and must collect personal information only by lawful and fair means and not in an unreasonably intrusive way. Individuals must be informed about various matters such as their access rights, the purposes of collection and to whom the organization usually discloses information of that kind. An organization must collect personal information about an individual only from that individual, rather than from any third party, unless it is not "reasonable and practicable" to do so. The National Health Administration Act (1997) implied that a health provider may collect health information without an individual's consent when the collection is necessary to provide a health service to that individual and collection is carried out according to certain professional rules of confidentiality [15]. We are not aware of any existing professional rules [16] apart from the National Medical Officers Code of Ethics and Nurse Code of Ethics which comply with the requirements of the National Health Administration law and thus the national principle [13]. Therefore, in some circumstances, the collection of family medical history information without the consent of family members by health professionals would breach the provisions of the national principle. There is no other enabling legislation that provides for Section 49 of the Constitution; it is self-executing.

In Australia, however, an organization generally must not collect sensitive information including genetic and other health information unless the individual has consented [1, 2]. The Australian Commonwealth principle then sets out an extensive codification of circumstances in which an organization may collect sensitive information without consent. Most relevantly, these include specified circumstances relating to the provision of health services.

4. Disclosure of Genetic Information to Genetic Relative

The disclosure of genetic information to genetic relatives is important. For example, in what circumstances should the patient or their medical doctor inform other members of the family about genetic information relevant to their health or well-being? It is important that those tested should be advised to consider carefully with whom the test result should be discussed, before testing takes place. However, following testing, if the patient is unwilling to inform his or her relative(s), should the doctor take steps to inform them? These issues have been referred to as "a looming area of medical and legal controversy" [1] and have generated a great deal of comments around the world. Genetic information may also reveal a pre-disposition to illness in the future which may have implications for insurance and employment. The confidentiality of such information is both crucial and problematic.

In law the protection given to patient information is not absolute. In some situations, the health professional may be required to break confidentiality by statute or at common law. In addition, there is a grey area relating to information which, while generally protected by the obligation of confidentiality, may be disclosed in certain situations if, for example, it is in the public interest to do so. The overriding responsibility of the health care worker or clinical geneticist remains with the patient and not to any other family members and certainly not to society because of the public health effects of the mutant gene.[2]

5. Disclosure and Prevention of Harm

The disclosure of genetic testing information could allow the prevention of serious health consequences in genetic relatives in some circumstances. The obvious practical benefits in disclosing this information to

[2] The question of whether a mutant gene present in one member of a family constitutes clear-cut danger to others in the family, thereby justifying warning family members regardless of a patient's preference, has not yet been answered satisfactorily.

family members include the early detection and treatment of inherited genetic disorders. Issues surrounding the disclosure of information to genetic relatives may become increasingly important as further preventative measures become available to mitigate genetic risk [1]. Professor John MacMillan observed in Australia that, at present, maintaining individual privacy to genetic information is not likely to physically harm others in the family to a greater extent that they would be harmed without access to the information. However, MacMillan noted that this will change in the future as knowledge gained from genetic testing may enable effective prevention of some adverse outcomes. In such circumstances, he said restricting the information to the single individual tested may fail to offer the opportunity for preventative action in respect of other at risk family members [1].

Developments in genetic medicine have implications for the extent to which the confidentiality of the doctor and patient relationship should be given primacy over other ethical considerations. That is, where genetic information only reveals an inherited susceptibility to a disease or cancer that is unpreventable, it is easier to argue that the information should remain confidential as compared to situation where denying access may place family members at increased risk [1].

Clinical geneticists and others provided many examples of such situations. Dr. Graeme Suthers of the Familial Cancer Service in South Australia referred to a situation below, based on an actual case (names have been changed) [1].

"Deidre has had breast cancer and has been shown to have an inherited mutation in the BRCA1 gene. Her mother, Marjorie, also had breast cancer and presumably carries the same mutation. Marjorie has a large extended family with many young women at risk of having the mutant gene and of developing early-onset breast cancer. Deidre had given me the address of her mother and had agreed that she (and other relatives) could be informed of the outcome of genetic testing. This would pave way for genetic testing of Marjorie's unaffected relatives. However, on receiving the test result Deidre changes her mind and revokes permission for this information to be released to her relatives."

At this stage none of her relatives are aware that she has had a genetic test. Whose rights should prevail, Deidre's right to the confidentiality of her test result, or Marjorie's right to be informed of a result she doesn't know about but which may be life-saving?

At the Royal Melbourne Hospital in Australia concerns were expressed about existing constraints on disclosure to genetic relatives. For example, where genetic testing confirms FAP (Familial Adenomatous Polyposis) standard advice is that the affected and genotyped individual passes the information of the availability of predictive testing to relatives at risk; however, some do not pass the information onto all relevant family members, for a variety of reasons, and avoidable deaths do occur because of this [1].

The literature dealing with genetic information and confidentiality issues also contains examples where disclosure is clearly capable of averting significant health dangers. One author concluded that, at least presently, disclosure to genetic relatives is arguably most justified in the case of FAP [1, 17]. The risk is serious; it is a potentially lethal condition. The diagnosis is certain. There is an effective intervention, for monitoring, and surgery is needed. Yet the risk could not be described as imminent. For these reasons, it is believed that the common law exception is sufficient. Other situations may be identified where the benefits for genetic relatives of knowing they are at increased risk are merely speculative and may not, therefore, be capable of justifying any breach of confidentiality [1, 17].

In many situations where there are benefits in informing relatives, consent to do so may be obtained following discussion with the person tested. Existing ethical guidelines emphasize that when genetic

information is to be shared with family members, the most appropriate person to make the initial contact is the individual who has undergone the genetic test. It is clinical practice to request the individual's permission to pass on relevant genetic information to relatives [3]. What is the legal position where the patient is unwilling to communicate with their relatives? In what circumstances does the law permit the medical professional to take steps to inform genetic relatives about information relevant to their health?

5.1 Examples of Motivations of Disclosure Decisions

Research workers have shown that disclosure decisions are complex and influenced by numerous factors [18]. The conflict between the patient's "right to privacy" and her relatives' "right to know" does not address the full reality of patients' experiences. In reality patients who prefer not to disclose genetic information to their relatives are most often motivated by a desire to "shield from distress" rather than by a desire to keep the information confidential in order to protect their own interests or by difficulties related to "poor family relation-ships" [19]. Informants' main ethical concern is how to best protect their relatives from genetic risk however, and from negative feelings on the other. Although some studies have shown that only a minority of informants and informed relatives report negative reactions such as grief, existential conflict, guilt and communication problems following disclosure [20, 21] concerns regarding such reactions still influence the disclosure dilemma. The motivations of the disclosure decision thus become the perceived degree of medical necessity [22]. We describe the motivations are related to the clinical repercussions of the disclosed information in terms of perceived treatability and preventability of reproductive implications and risk perception [7]. Still, when information is deemed medically essential, timing is often an important issue. Words from a nurse worker indicated why: "Family members who came to visit and spent time with their sick relative left soon after they were told about their member's medical condition."

Informants often feel that information should be disclosed "at the right moment" and evaluate the "readiness" of their relatives to receive the information. A healthcare professional said, "The family relatives or the guardian of the patient, many of whom are illiterate and so any information passed to them about the patient's medical condition should be explained well and understood."

An important factor is the relative's ability to understand the meaning of the disclosed information. Another healthcare worker said, "Family members usually the immediate members including parents, young people are ones who take care of the sick person. They live together usually in the same family home and share food and many things together as family. In times of sickness, death, security, etc. they help each other."

Informants tend to acknowledge that the impact and relevance of the information may differ greatly with personality, maturity and life stage, as in the case of planning a pregnancy [23]. Finally, the informant's perception of who is considered family and of the closeness of the familial relationship was found to influence disclosure as well. In PNG, the immediate family members are first to know about the health conditions of the sick member. Closeness is measured from four different perspectives: biological, emotional, geographical and financial, all of which were suggested to have an influence on disclosure [24].

Some workers suggested that pattern for disclosure may vary between men and women [25]. However, no consensus was yet reached on this topic and the gendering of disclosure still remains largely unresolved. For mothers, a central motivation for disclosure was suggested to be their desire to allow their children informed reproductive choice [26] and their need for support from family members [27]. In PNG both husband and wife make this choice but the choice may be affected in rural areas because other

members of the extended family that are involved.

Cultural and social values can also influence disclosure. For example, a study of British-Pakistani adults shows the importance of cultural influence on family dynamics in the context of disclosure. Within the studied community, spouses tended to withhold information to protect their partners from "blame, stigma or feelings of marital insecurity", and parents tended to withhold relevant information from their child in order to prevent gossip in the community and to protect the child's marriage prospects [28]. The ethical tension between the confidential nature of genetic information and potential benefit of its disclosure to family members has been addressed by the legal system as well. From a legal perspective, genetic information—like any other type of medical information—is confidential. It is widely accepted that the choice to disclose genetic information to family members should remain in the hands of the patient, rather than in those of health care providers. The confidential nature of genetic information was reaffirmed, for example, by the American Health Insurance Portability and Accountability Act of 1996 [29]. At the same time, due to its unique nature and possible implications for the health of genetic relatives, a strict application of confidentiality has been challenged by litigation in certain cases.

Thus, nuances have emerged through statutory amendments and court decisions, gradually modifying the legal context. For example, the legal tension between medical confidentiality and the duty to warn was enhanced in the US in the mid-nineties following two opposing court decisions: one stating that the clinician's duty to warn is limited and accomplished once the patient has been warned regarding the familial and heritable nature of the condition and the other stating that the duty to warn is not limited to one's patient and can extend to "immediate family members" [30].

The issues are further discussed with reference to common law duties of confidentiality, national privacy principle of PNG and similar provisions of overseas privacy legislation particularly Australia.

6. Duties of Confidentiality

The requirement to protect patient confidentiality has been long included in the ethical codes of health care professionals. It has been argued that confidentiality is necessary to ensure that patients are willing to come forward to receive treatment. It is also claimed that confidentiality is part of the patient's right to control access to his own personal information, his right to informational privacy.

Authors including Larry Gostin define the health information privacy as being, "An individual's claim to control the circumstances in which personal health information is collected, used, stored and transmitted" [31].

Gostin goes on to define confidentiality as being, "A form of health information privacy that focuses upon maintaining trust between two individuals engaged in an intimate relationship, characteristically a physician-patient relationship" [31].

Article 8 of the European Convention of Human Rights (ECHR) provides that: (1) Everyone has the right to respect for his private and family life his home and correspondence; (2) There shall be no interference by a public authority with the exercise of his right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

It would be noted that Article 8 has been interpreted by the European Court of Human Rights as affording protection to individual privacy [32] and this has also been extended to cover personal health information [33]. In English law there is no overarching protection given to privacy [34], but nonetheless there are considerations in Article 8 of the ECHR in relation to information that privacy underpins domestic law

protection of the confidentiality of health information. English law provides protection for confidential information through equitable remedy of breach of confidence. The basis in law for restraint of disclosure of confidential information is usually that of the equitable remedy of breach of confidence.

The grounds on which an action for breach of confidence may be brought are stated in A.-G. v Guardian Newspapers (No. 2) [35]. A duty of confidence arises where confidential information comes to the knowledge of a person (the confidant) in circumstances where he has notice, or is held to have agreed, that the information is confidential with the effect that it would be just in all the circumstances that he should be precluded from disclosing the information to others. The use of the word "notice" is advisedly done in order to avoid the question of the extent to which actual notice is necessary, though it is understood that knowledge to include circumstances in which the confidant has deliberately closed his eyes to the obvious [35]. The existence of this broad general principle reflects the fact that there is such a public interest in the maintenance of confidentiality that the law will provide remedies for this protection.

Usually an action for breach of confidence may be brought by the person to whom the confidence is owed [36]. This may be a patient where he or she is competent to do so, but it may equally be another person or body, for example, a health authority. A breach of confidence may constitute unsatisfactory professional conduct and form grounds for proceedings before medical registration authorities [36].

In general terms, the common law duty of confidentiality may be breached where there is an unauthorized use of the information covered by it, that is, where the information is used for a purpose inconsistent with the purpose for which consent was expressly or impliedly given [36].

The doctor-patient relationship is one of the categories of relationships protected by the equitable remedy of breach of confidence. It appears certain that the courts would extend this protection to other health care relationships such as, for example nurse-patient. Alternative grounds for legal proceedings do exist. Actions may be brought in contract and in negligence. In many circumstances, patients may be taken to have consented to certain disclosure of information, especially disclosure for purposes related to their own treatment, such as to other health service providers who assist their doctor to facilitate diagnosis or treatment of family members which cannot ordinarily be implied and will likely breach the duty of confidentiality, unless the disclosure is covered by some exception recognized by the law. Negligence was held in a New Zealand case to be the basis on which an obligation of confidentiality arose [37]. There is no clear authority on this point in England and Wales in the medical context, although the potential for such an action can be seen by analogy to an action for negligent breach of disclosure of a police informer's identity in Swinnery v Chief Constable of the Northumbria Police [38]. Here the principle of such an action was recognized although on its facts the case failed.

The exceptions to the common law duty of confidentiality permit disclosure of the information in ways that would otherwise infringe the duty. One exception is where a patient consents to the disclosure.[3] A second exception is where there is a statutory obligation to disclose information.[4] The third exception permits the release of confidential information where to do so is in the public interest. The possible application of the public interest exception to disclosure of genetic information is of particular relevance.

---

[3] It is the patient to whom the duty and so he or she can choose to permit information to be released, including to facilitate and diagnose or treatment of a genetic relative.

[4] This is regularly exercised in the compulsory disclosure of certain notifiable diseases or other conditions for which there is a statutory register. It also includes compulsion to disclose information in court proceedings as the duty of confidentiality does not generally give a medical practitioner a justification for refusing to disclose such information.

This study notes that the obligation of a healthcare professional is to maintain patient confidentiality and frequently it extends beyond his or her ethical codes. The terms and conditions of healthcare worker require her to keep patient information confidential, for example, patients have a right to expect that information about them will be held in confidence by their doctors.

Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to give doctors the information they need in order to provide good care. The courts have referred to this principle when considering the scope of breach of confidence. Breach of confidence may lead to disciplinary proceedings. A corresponding duty to maintain patient confidentiality is imposed upon members of the nursing profession. Further, the unauthorized disclosure of confidential information may lead to an action under the equitable remedy for breach of confidence.

7. Public Interest Exception

It has been stated that the public interest exception to the duty of medical confidentiality "is notable for its extraordinary flexibility" [1, 39]. It can potentially be invoked to justify the disclosure of confidential patient information in a wide range of circumstances. Whether the circumstances might encompass some disclosure of confidential information to genetic relatives, is very much open to debate. At least some legal commentators [1, 39] believe that the public interest exception might be used in this way and consider that the public interest exception could cover cases such as:

(1) Where the patient's medical condition presents an infection risk to others;

(2) Where a patient's ill health renders him or her unfit to continue certain activities because others would be placed at risk, or;

(3) Where inherited genetic disorders should properly be disclosed to other family members [1, 39] (emphasis added).

There has been no reported case in PNG in which disclosure of genetic information has been found to be justified. In other jurisdictions, commentators have cast doubt on whether the public interest exception would extend to the disclosure of genetic information, given the limitations the relevant case law places on the circumstances in which disclosure may legally occur.

For example, Dean Bell and Bellinda Bennett of Australia state that disclosure must be confined to "exceptional circumstances", where "another's life is immediately endangered and urgent danger to the public" [1]. Secondly, Bell and Bennett cited cases in which the courts have emphasized that disclosure should be to a responsible authority [40]. Bell and Bennett concluded that these limitations suggest that the public interest basis for disclosure to family members of a genetic condition has not, to date, been contemplated for a situation such as disclosure to a family member of genetic condition. This is because such a condition will rarely, if ever, present an immediate life threat and also because such disclosure would ultimately have to be disclosed to the family member rather than a responsible authority (although if the relative is not a patient of the doctors, it may be disclosed to that patient's treating doctor) [40]. This is not to say that the point might not be argued sometime in the future in relation to a disclosure of genetic information.

A researcher suggested that the factors that a court might take into account in weighing up such a public interest claim might include the possible effects of allowing disclosure of genetic information on the willingness of individuals to take advantage of genetic tests in the future, and the likely public health outcomes of such a policy [1, 17]. Professor Skene concluded that the common law public interest exception may not always be sufficient to protect health professionals making disclosures of genetic risk to relatives [1, 17].

In Thomas Mappes and David DeGrazia, in June 1987, "A young woman who was pregnant was shot with an arrow fired from a hunting bow by a young man who was engaged in an argument with another person. Emergency workers from the Fire Fighting services were called to the scene, administered resuscitation to the profusely bleeding woman and took her to a local hospital where she died shortly afterwards. Her child, delivered by emergency Caesarean section, died the next day. This tragedy would have been quickly forgotten as yet another incident of random urban violence if it had not been later learned that the woman was infected with the AIDS virus. A nurse at the hospital decided on her own initiative that the rescue workers who had brought the woman to the emergency room should be informed that they had been exposed to HIV-infected blood and contacted them directly" [41].

This case and others like it raise difficulty and weighty ethical and public issues: What are the limits of medical confidentiality? Who, if anyone, has a right to know that they may have been exposed to AIDS or other dangerous infectious diseases? Whose responsibility is it to inform the sexual contacts of AIDS patients or others who may have been exposed to the infection? Dr. Roger Magnusson states that the scope of the discretion to disclosure under the public interest defense to a breach of confidentiality action is uncertain in Australia and probably requires High Court resolution [1].

This study says protecting patient confidentiality may give rise to some very difficult moral and legal dilemmas. The provision of health care is more complex than it has ever been. The patient who enters the hospital is cared for by many different health care practitioners, all with access to his records. The rise in personal genetic information has led to new challenges. Furthermore, we observed that personal information obtained from DNA sequencing can reveal information not only about an individual but also information relevant to family members [42].

8. A Duty to Warn

In some situation, it might be argued that a health professional has a positive "duty to warn" third parties even if doing so would infringe the duty of confidentiality. Such a duty might be derived from common law principles relating to the tort of negligence based on the concept of a duty of care. Legal cases in the USA, and in particular Tarasoff v Regents of University of California have established that, where there is a foreseeable risk of significant harm to an identified individual, doctors and other health professionals may have a duty to warn those individuals [43].[5] In that case, "Tatiana Tarasoff was murdered by Prosenjit Poddar, who was a patient of psychotherapist employed by the University of California Hospital. Her parents brought an action against the university regents, doctors, and campus police. The Tarasoffs complain that the doctors and police had failed to warn them that their daughter was in danger from Poddar. In finding for the Tarrasoffs, Justice Tobriner argues that a doctor or psychotherapist treating a mentally ill patient has a duty to warn third parties of threatened dangers arising out of the patient's violent intentions. Responding to the defendants' appeal to the important role played by the principle of confidentiality in the psychotherapeutic situation, Tobriner argues that the public interest in safety from violent assault must be weighed against the patient's right to privacy" [43].

In this regard, the legal position in the United States appears to differ from existing law in other countries. Some of these United States cases involved genetic risks. For example, in Pate v Threlkel, "A woman (daughter) whose mother was diagnosed as having a genetic disease, Medullary Thyroid Carcinoma, sued her mother's doctor for not warning her that she too might be at risk. The Supreme Court of Florida held

[5] This case is edited. The language is that of the court. The facts and majority opinion are written by Justice Tobriner. The dissenting opinion is written by Justice Clark.

that while a doctor may owe a duty of care to family members of a patient in circumstances in which this includes a duty to warn of a genetic condition, the duty will be satisfied by warning the patient that family members should seek medical care" [44].

In the USA yet, a different approach was taken in Safer v Pack [45]. In that case, "The doctor had treated a patient for Retroperitoneal Cancer, ulcerative adenocarcinoma of the colon and adenomatous polyps. Twenty-six years after the patient died, his daughter developed cancer of the colon and multiple polyposis. She sued, claiming that her father's doctor had breached duty to warn of the hereditary risk to her health and had deprived her of the chance of monitoring, early detection and early treatment. Applying an infectious disease precedent, the Superior Court of New Jersey held that there can be a duty to warn genetic relatives directly" [45].

We agree with the view that the court failed for not giving sufficient recognition to the differences between infectious disease and genetic conditions for example, warning genetic relatives about genetic risks will not prevent them from having the gene and potential psychological harm resulting from disclosure should also be considered, especially where the genetic condition is not preventable. We say that the cases dealing with warning people about genetic risks are different from those dealing with violence or infectious disease since there are already social policies embodied in laws that are aimed at preventing violence or contagion. Thus, breach of confidentiality furthers an established social policy that has been subject to legislative debate in many countries. In contrast, society's position on genetic disease is not so clear cut. There is some limited recognition in the Australian law that a doctor may owe duty of care to someone who is not a patient. In BT v Oei, "The Supreme Court of New South Wales held that a duty of care was owed by a doctor to a patient to exercise reasonable care in advising the patient to in relation to the need for an HIV test" [1].

It has been suggested that, therefore, a doctor or genetic counselor may owe a duty of care to third parties to explain to the patient the implications of a genetic test for the future health of third parties, where disclosure by the patient could ameliorate future genetically-caused harm [1]. However, there is no direct legal authority for the imposition of a Tarasoff-style duty to warn in Australia. Professor Skene in 1998 said arguments that doctors have a duty to warn genetic relatives are unlikely to be successful in Australia [1, 17].

In this study, we observed that like in PNG, New Zealand and Australia laws on duty to warn are less developed than that in the USA and there has been no case in which a doctor has been held with a duty to warn in such a case. In any event, as in the USA, this is unlikely to be an issue in the genetic context because single gene disorders that cause immediate effects are rare.[6] Another aspect of the familial nature of genetic information involves the constraints that the laws on Privacy impose on the disclosure of relevant genetic information by doctors and other health professionals to genetic relatives of their patients. In particular, the privacy laws appear to prohibit the disclosure of clinically relevant information to genetic relatives, in circumstances where it is possible to argue there is no breach of ethical or common law duties of confidentiality in particular, because the public interest exception to the duty of confidentiality may apply.[7] Question which arises is: does PNG have law which imposes such a duty on health professional?

9. Liability for Improper Disclosure of Medical Information

A release of medical records information that has not been authorized by the patient or that has not been made pursuant to statutory, regulatory, or other legal

[6] See Professor Loane Skene, Consultative Report/Submission, (2001), supra notes.
[7] Ibid.

authority may subject the health institution and its staff to civil and criminal liability. States may impose criminal or professional disciplinary sanctions for violation of statutory confidentiality requirements. In addition, three possible civil liability actions are available to patients who show injury as a result of a disclosure of information in their medical records by hospitals or physician: defamation, invasion of privacy, and breach of contract.

10. Penalties for Improper Disclosure

States statutes may impose both criminal sanctions and civil liability on health care providers that improperly disclose medical records information in an unauthorized manner. For example, in Tennessee in the USA [39], its law addresses both forms of liability, "A willful violation of the provisions of [the Medical Records Act] is a Class C misdemeanor … No hospital, its officers, employees, or medical and nursing personnel practicing therein, shall be civilly liable for violation of [the Medical Records Act] except to the extent of liability for actual damages in a civil action for willful or reckless or wanton acts or commissions constituting such violation. Such liability shall be subject, however, to any immunities or limitations of liability or damages provided by law. Unlike a criminal proceeding, which is initiated by state officials, a civil lawsuit must be instituted by a private individual. In some states in USA, they have Mental Health &Developmental Disabilities Confidentiality Act that is more specific as to civil remedies available to the patient: "Any person aggrieved by a violation of this Act may sue for damages, an injunction, or other appropriate relief. Reasonable attorney's fees and costs may be awarded to the successful plaintiff in any action under this Act."[8]

In some states, statutes impose specific penalties for revealing particular medical records information, such as whether a patient is HIV-positive [46]. For example, in Wisconsin, "An individual who negligently discloses a patient's HIV status may be liable for actual damages and costs, as well as $1000 in exemplary, or punitive damages. An individual who intentionally discloses such information may be liable for up to $5000 in exemplary damages. If the disclosure causes bodily or psychological harm to the patient, the individual who disclosed the information may be fined up to $10000 and sentenced to nine months in jail. In Virginia, the penalties for disclosing an individual's HIV-status are more lenient. A person who willfully or through gross negligence discloses such information may recover actual damages or $ 100 (whichever is greater) and attorney's fees and court costs".[9]

10.1 Defamation

Defamation is one legal theory on which patients may base lawsuits for improper disclosure of medical records information. Defamation may be defined as a written or oral communication to someone other than the person whose reputation is called into question [47]. If the individual bringing the defamation suit is a public official or public figure, the individual will recover only if the speaker knew the statement was false or acted with reckless disregard of its truth or falsity.[10]

Medical records may contain information that is inaccurate and that, if published, would affect a person's reputation in the community adversely, attracting special damages. Thus, oral disclosure by a hospital to an unauthorized person could result in an action for defamation. However, the possibility of a patient's obtaining a recovery against a hospital for defamation for release of medical records information

[8] See Tennessee Code Ann. S 68-11-311 (1993), supra notes.

[9] See Barry R. Furrow, Thomas L. Greaney, Sandra H. Johnson, Timothy S. Jost, Robert L. Schwartz, (2001), supra notes.

[10] There are two types of defamation; libel is written form of defamation, while slander is oral. Libel is actionable without proof of actual damages, although slander suits ordinarily require special or actual damages.

is slight.[11] Medical records entries ordinarily are true and, as a general rule, truth of the published statement is an absolute defense to a civil cause of action for libel or slander, irrespective of the publisher's motive. Although the rule has been modified in some states to allow application of the defense only where the publisher's motive was good, the traditional rule, even as modified, provides substantial protection for hospitals.

Patients who sue healthcare providers for defamation first must show that the statement that is the basis of suit was published, that is, that it was revealed to someone other than the patient or health care provider. For example, a state appeals court affirmed a judgment in favor of two physicians when the allegedly libelous statement was contained in a letter that the physicians mailed to the patient.

"The physicians prepared a letter containing the results of a patient's physical examination, including a statement that the patient had had gonorrhea in 1985, during the patient's marriage. In fact, the patient had had gonorrhea years before he was married. When the letter arrived at the patient's home, the patient's wife opened it and read it to him over the telephone. The patient and his wife sued the physicians for libel, claiming that the defamatory contents of the letter caused marital discord. The court rejected the patient's suit because the letter was sealed and addressed only to the patient. The letter was not published to the patient's wife, except by the patient, who had asked her to read it to him over the phone." [48]

Moreover, the law recognizes two privileges that may preclude liability upon publication of even false statements that are injurious to the subject's reputation.[12] In Gilson v Knickerbocker Hospital, for example, "A patient sued a hospital which maliciously had allowed the publication of false and defamatory matter in the individual's medical record [49]. The record contained an observation that the plaintiff was under the influence of alcohol. The court denied the patient's claim, stating that the defendant's act was absolutely privileged because it was acting pursuant to lawful judicial process (letter from physician to probate judge absolutely privileged) [50]; Bond v Becaut, (letter from psychologist relevant to custody proceedings and within judicial privilege)." [51]

10.2 Invasion of Privacy

A second legal theory upon which a patient could base a suit for improper release of medical records information is invasion of privacy.

Releasing patient information to unauthorized individuals, agencies, or news media may make a hospital liable to the patient for an invasion of privacy. A cause of action for invasion of privacy can be sounded in state common law (as developed by the courts), state or federal constitutional law, or state statutory law. In the case of PNG, section 49 of the PNG's Constitution would be applicable.

In the common law, an invasion of an individual's right of privacy has been defined as an unwarranted appropriation or exploitation of that individual's personality, the publication of the person's private concerns in which the public has no legitimate interest, or a wrongful intrusion into the person's private activities. However, the right of privacy is not an absolute right.[13] To give rise to an action for damages, this exploitation, publication, or intrusion must be done in a way that would cause outrage or mental suffering, shame, or humiliation to a person of ordinary sensibilities [47]. There is some overlap between the theories of defamation and common law invasion of privacy. However, several factors

[11] See Prosser William, L., & Keeton Page, supra notes.

[12] These are absolute privilege and qualified privilege. Publications made in legislative, judicial, and administrative proceedings are absolutely privileged, and thus do not give rise to a cause of action in defamation. Disclosure of defamatory medical records information in a court therefore would not be actionable.

[13] The purpose of the right is to protect the individual from mass dissemination of information concerning private, personal matters.

distinguish the two causes of action.[14] As for the Common law invasion, because medical records are highly personal, improper disclosure of patient information can expose hospitals and physicians to liability for invasion of privacy.[15]

Unconstitutional invasion of privacy claims occurs less frequently. A patient who brings a claim for improper disclosure of medical records which are highly personal, the improper disclosure of patient information should be based on the federal or state constitution and typically must show that the individual had a "reasonable expectation of privacy" in the information that was disclosed [52]. Courts will consider factors such as the content of the disclosure and the circumstances under which the patient provided the information to the health care worker. Finally, a patient may sue a health care provider under a state statute creating a right to sue for certain invasions of privacy. For example, the Massachusetts statute states that, "A person shall have a right against unreasonable, substantial, or serious interference with his privacy" [52]. The patient who expressly consents orally or in writing to disclosure of private information cannot complain later that the disclosure was an invasion of privacy.

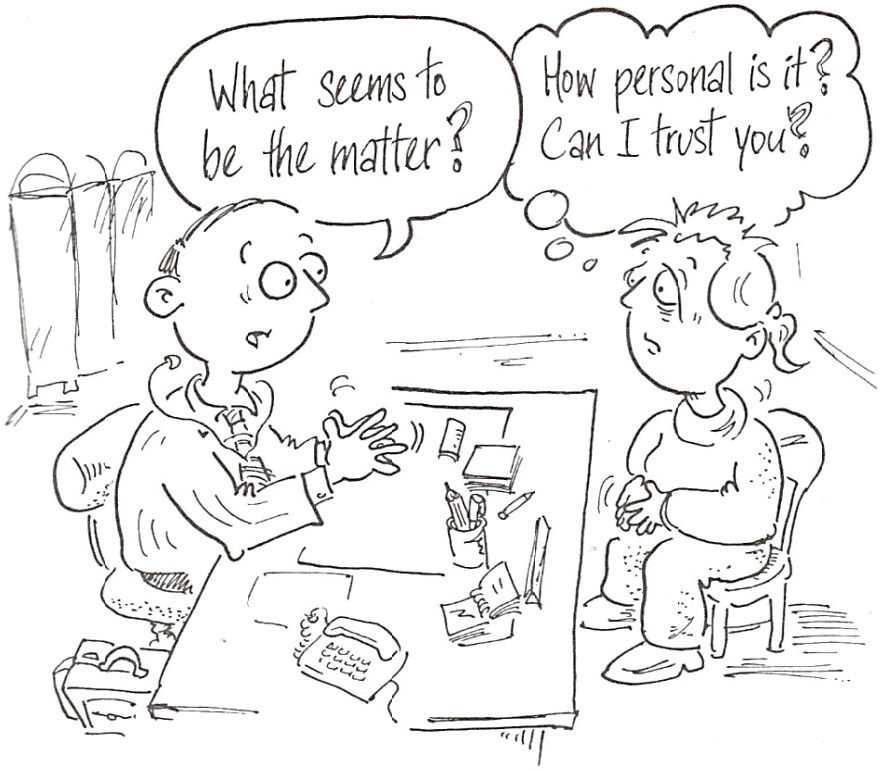
The patient's consent protects the hospital if the individual wanted the information disclosed for personal benefit and the hospital disclosed the information in the manner the patient authorized [53]. Patient had authorized physician to disclose incomplete information about his illness; plaintiff therefore was stopped from claiming that he had not consented to the disclosure of the underlying cause of the illness—alcoholism. Therefore, the hospital should endeavor to obtain the patient's written consent to the disclosure of information. If a patient authorized a disclosure but refused to sign an authorization form, hospital personnel should note that consent on the form, properly sign and date the note, and insert the form in the patient's medical record.

The healthcare worker obtains personal information from the patient, s/he should use that information constructively and to respect it as private and confidential. [54].

Courts have held care providers liable for the first type of invasion of privacy, an improper appropriation of the plaintiff's likeness for the defendant's benefit, primarily where the provider exploited the patient for commercial benefit. However, courts also have imposed liability in situations where a health care provider used a patient's name or likeness for a noncommercial benefit by applying the theory of intrusion upon solitude as invasion of privacy [35]. This theory can lead to liability even if the photographs were not published. In Clayman v Bernstein, for example, the court prohibited a physician from using photographs of a patient's facial development in connection with medical instruction [55]. The court found that even taking the picture without the patient's express consent was an invasion of privacy; it was not necessary to show that the physician had used the photographs improperly or shown them to others to establish liability.

[14] First, truth of the information published is not a defense to an invasion of privacy suit, although it often is a defense to an allegation of defamation. Thus, an unauthorized disclosure even of accurate medical information could subject a hospital to liability for invasion of a patient's privacy. Second, to recover for an invasion of privacy, the plaintiff need not prove special damages, unlike the plaintiff in a defamation action, who often must prove that the disclosure actually harmed the individual. Third, the two theories provide redress for different types of injury arising from unauthorized disclosure of favorable information. Defamation, on the other hand, focuses on the injury to the plaintiff's reputation. Fourth, although an action for invasion of privacy often involves publication, it is not a necessary element for recovery. Thus a single human agency can invade an individual's privacy. The law of defamation normally requires publication to a second person.

[15] Common law invasion of privacy can be divided into four categories: (1) appropriation of plaintiff's name or likeness for the defendant's benefit, (2) intrusion upon the plaintiff's solitude or private concerns, (3) public disclosure of embarrassing private facts, and (4) publicity that places the plaintiff in a false light in the public eye.



The illustration above shows the healthcare worker relationship, patient make decisions all the time about what secrets to tell, what to let you see, and how much to trust you.

10.3 Patient's Autonomy and the Right to Self-determination

One of the fundamental principles of modern medicine is constituted by the ethical and legal doctrine of a patient's autonomy and the right to self-determination. It is founded on the premise about the empowering character of medical information which, it is assumed, enables conscious decisions and choices free of external pressure. Such a right imposes on health professionals a duty to inform patients about one's health status, and withholding information from a patient is seen as a form of the old paternalistic practice that destroys the relationship between both parties and may, additionally, become a source of allegation of negligence and malpractice.

Claims about patient right to information are grounded on the WMA's (World Medical Association) Declaration on the Rights of the Patient published in Lisbon in 1981 (art. 7a).[16] In PNG law, the Constitution contains 16 rights and freedoms including the 11 that were under the Human Rights Ordinance 1971. In SCR No. 5 of 1985, Re Raz v Matane (1985) PNGLR 329, the Supreme Court held that the words "right or freedoms" mean the "rights" or "freedom" guaranteed by the Constitution. Some of these rights and freedoms are available, while others can be altered in special circumstances [56]. Because of the complexity of the constitutional structure on rights and freedoms, we deal only with Section 49, "right to privacy", to assist the better understanding of this paper.

The right to privacy (section 49) must be read

[16] WMA Declaration of Lisbon on the Rights of the Patient. Adopted by the *34th World Medical Assembly*, Lisbon, Portugal, September/October 1981 and amended by the *47th WMA General Assembly*, Bali, Indonesia, September 1995 and editorially revised by the *171st WMA Council Session*, Santiago, Chile, October 2005 and reaffirmed by the *200th WMA Council Session*, Oslo, Norway, April 2015.

together with the right to the freedom from arbitrary search and entry (section 44) [13, 14]. The Supreme Court has maintained that the right to privacy is a special right of person and it will not hesitate to come to the aid of any person whose right to privacy has been violated through unlawful means. It has ruled that the records of patients are private and should not be disclosed to other people; SCR No. 2 of 1984; Re Medical Privilege (1985) PNGLR 247.[17] The court has also ruled that taking the photo of a voter for election purposes is a violation of his or her right to privacy: SCR No. 5 of 1992 (1992) PNGLR 114 (at 115). The right to privacy cannot be restricted by an Emergency Regulation during a state of emergency; Re Internal Security Act (1994) PNGLR 341 (at 354). An Emergency Act can, however, restrict this right. In Koimo v PNG (1995) PNGLR 535 (at 539), the court ruled that even during a police raid, the right to privacy must be respected by the police [56]. The raid does not give police a license to violate the rights of citizens and non-citizens.

Similar legislation can be found in most European countries. At the same time, as it is widely acknowledged, the results of genetic testing have implications not only for the individual but also for their relatives, including children, and it is emphasized that one's right not to know is strictly related to the duty to inform others about any genetic risk. The emergence of the informative model provoked the shift from the principle of beneficence to the principle of personal autonomy, which promotes a complementary although opposite right—"the right not to know" or simply to "ignorance". One of the first documents which recognized this right was the WMA Declaration (art. 7d).[18] Nowadays, it is grounded in the European Convention on Human Rights and Biomedicine (art. 10 and Explanatory Report), and is also mentioned in UNESCO's Universal Declaration on the Human Genome and Human Rights (art. 5c) and the World Health Organization's Review of Ethical Issues in Medical Genetics from 2003 (art. 10.2) [57].

We suggest that developments in new genetics result in the emergence of new molecular ethics which stresses that individuals have a moral and political duty to undergo the test, know the risk, and disclose that information to others. Some have argued that advances in molecular genetics will lead to the geneticisation of identity and the subsequent reduction of the human subject to their genetic complement [58]. We also argue that genetic literacy becomes a source of biological citizenship.

11. Conclusion

One of the fundamental principles of modern medicine is constituted by the ethical and legal doctrine of a patient's autonomy and the right to self-determination. It is founded on the premise about the empowering character of medical information which, it is assumed, enables conscious decisions and choices free of external pressure [59, 60]. Such a right imposes on health professionals a duty to inform patients about one's health status [61], and withholding information from a patient is seen as a form of the old paternalistic practice that destroys the relationship between both parties and may, additionally, become a source of allegation of negligence and malpractice.

We concur that the role of professionals in relation to disclosure decisions remains to date a controversial issue in the literature. It is suggested that most feel a personal responsibility to warn relatives about genetic risks but they also believe that such direct disclosure should not be made without the permission of the patient [62], in order to maintain a good doctor-patient relationship, foster trust, protect medical secrecy and

[17] See Kwa Eric, L., (2011), supra notes.

[18] WMA Declaration of Lisbon on the Rights of the Patient. Adopted by the *34th World Medical Assembly*, Lisbon, Portugal, September/October 1981 and amended by the *47th WMA General Assembly*, Bali, Indonesia, September 1995 and editorially revised by the *171st WMA Council Session*, Santiago, Chile, October 2005 and reaffirmed by the *200th WMA Council Session*, Oslo, Norway, April 2015.

respect the patient's right to intimacy [22]. As genetics tests ordered by physicians have implications not only for patients but also their relatives, they create a bioethical dilemma for both clinicians and patients. Especially when a patient is reluctant to undergo the test, know the genetic risk, and share such information with others. While international biomedical law recognizes the right not to know one's genetic status, it has been criticized for many reasons. This paper describes the right not to know about genetic risk.

There is a consensus that patients who receive genetic information which has implications for the health of their relatives are morally responsible to pass on the information to them, especially if disclosure can help the relatives avoid physical harm or reduce its risk. This is shared by proponents of a patient-centered approach who highlight the importance of patients' right to confidentiality. The assumption that patients have a moral responsibility to warn their relatives raises the question of whether this responsibility should be translated into an imposition of legal liability in tort when the patient's (passive) non-disclosure compromises the relatives' interests in avoiding physical harm and making informed choices about their life and health. We agree that familial genetic information is not of private genetic information. The distinction is quite clear: personal genetic information identifies a particular family member as a carrier of a particular hereditary condition [63]. For example, "Private genetic information means that Mrs. X is a BRCA1 carrier, which means that she is at an increased risk of developing breast and ovarian cancer. Familial genetic information implies that there is a risk running in the family to develop an inherited form of breast cancer. While Mrs X may refuse to inform her relatives that she is a BRCA1/2carrier (or at an increased risk to develop breast cancer), she may agree that her relatives be informed that there is an increased risk in their family to develop hereditary breast cancer. Thus, the position proposed here is that the patient should owe a legal duty either to alert the relatives that there is familial genetic information which they can obtain via the National Health Service, or allow the clinician to do so. The duty does not require the patient to approach the relatives directly and tell them that she carries a mutation of a specific genetic disease, but merely to make the relatives aware—directly or via the clinician—of the availability of genetic information. However, imposing liability raises theoretical and practical difficulties." [58].

The main goal of genetic services is to provide genetic diagnoses and accurate risk information to clients so that they can make informed decisions to manage their risk, to make reproductive decisions and to plan for the future. But, there is also a moral imperative attributed to clients or patients—a responsibility to disclose information to other family members who may be genetically at risk [63]. Public health professionals and clinical practitioners strongly advocate family risk communication as a preventive measure to reach potentially at risk individuals. It is generally considered that disclosure of risk information to relatives provides the means by which an autonomous decision can be made [63]. Family members have a "right to know" and ought to be informed of their risk at the earliest opportunity, especially if genetic disorders are preventable, treatable or have reproductive implications. Therefore, the goal of genetic diagnosis and risk assessment is to produce an autonomous subject who will act responsibly in relation to their genetic risk [57]. But as demonstrated in the literatures, the research findings problematise the assumption that genetic risk information produces new forms of autonomous and responsible individuality.

Acknowledgements

We thank for the contribution in this research the following persons from University of PNG: Late Professor Rudy James, School of Law; Associate

Professor Andrew Masta, Geneticist, School of Medicine & Health Science.

References

[1] Australian Law Reform Commission (ALRC). 2001. Protection of Human Genetics Information. Issue Paper 26, ALRC, Sydney.

[2] Commonwealth of Australia. 1999. *Health & Medical Research Strategic Services: The Virtuous Cycle, Working Together for Health & Medical Research.* Wills Report, Canberra.

[3] Etchegary, H., and Fowler, K. 2008. "They Had the Right to Know." *Psychology Health* 23 (6): 7070-7. doi: 10.1080/1476832070127549.

[4] Roy, G. 2007. "Communicating Genetics Information in the Family: The Familial Relationship as the Forgotten Factor." *Journal of Medical Ethics* 33: 390.

[5] Stol Yrrah, H., Menko, F. H., Westerman, M. J., and Janssens, R. M. J. P. A. 2010. "Informing Family Members about a Hereditary Predisposition to Cancer: Attitudes and Practices among Clinical Geneticists." *Journal of Medical Ethics* 31 (7).

[6] Klitzman, R., Thorne, D., Williamson, J., and Marder, K. 2007. "The Roles of Family Members, Health Care Workers, and Others in Decision-Making Processes about Genetic Testing among Individuals at Risk for Huntington." *Genetics in Medicine* 9: 358-71. https://www.nature.com/articles/gim200759.

[7] Gaff Clara, L., Clarke, A. J., Atkinson, P., Sivell, S., Elwyn, G., Iredale, R., Thornton, H., Dundon, J., Shaw, C., and Edwards, A. 2007. "Process and Outcome in Communication of Genetic Information within Families: A Systematic Review." *European Journal of Human Genetics* 15: 999-1011.

[8] Arribas-Ayllon, M., Sarangi, S., and Clarke, A. 2008. "Managing Self-responsibility through Other-Oriented Blame: Family Accounts of Genetics Testing." *Social Science & Medicine* 6 (7): 1521-32.

[9] Hallowell, N., Ardern-Jones, A., Eeles, R., Foster, C., Lucassen, A., Moynihan, C., and Watson, M. 2005. "Communication about Genetic Testing in Families of Male BRCA1/2 Carriers and Non-carriers: Patterns, Priorities and Problems." *Clin Genet* 67: 492-502.

[10] Smith v Rogers Memorial Hospital. 1978. [382 A2. d 1025 (D.C.Ct. App. 1978, cert. denied, 439 U.S. 847.

[11] Hurlock v Park Lane Medical Ctr. 1985. [709 S.W. 2d 872 (Mo. Ct. App.).

[12] Topel v Long Island Jewish Medical Ctr. 1981. [431 N.E. 2d 293 (Ct. App.)

[13] Gov. PNG. 1975. Constitution, Section 49, Right to Privacy.

[14] Gov. PNG. 1975. Constitution Section 38.

[15] Gov. PNG. 1977. National Health Act.

[16] Gov. PNG. Medical Registration Act, Chapter 398. National Medical Council, Department of Health.

[17] Skene, L. 1997. "Access to and Ownership of Blood Samples for Genetic Tests: Guthrie Spots." *Journal of Law and Medicine* 137: 40.

[18] Seymour, C. K., Addington-Hall, J., Lucassen, A. M., and Foster, C. L. 2010. "What Facilitates or Impedes Family Communication Following Genetic Testing for Cancer Risk? A Systematic Review and Meta-Synthesis of Primary Qualitative Research." *Journal of Genetic Counseling* 19: 330-42.

[19] Angus, C., Richards, M., Kerzin-Storrar, L., Halliday, J., Young, M. A., Simpson, S. A., Featherstone, K., Forrest, K., Lucassen, A., Morrison, P. J., Quarrell, O. W. J., and Stewart, H. 2005. "Genetic Professionals' Reports of Nondisclosure of Genetic Risk Information within Families." *European Journal of Human Genetics* 13: 556-62.

[20] Afsaneh, H. R., Lampic, C., Rosenquist, R., and Nordin, K. 2010. "Disclosing Cancer Genetic Information within Families: Perspectives of Counselees and Their At-Risk Relatives." *Familial Cancer* 9 (4): 669-79.

[21] Iris van, O., Meijers-Heijboer, H., Duivenvoorden, H. J., Bröcker-Vriends, A. H. J. T., van Asperen, C. J., Sijmons, R. H., and Seynaeve, C. 2007. "The Common Sense Model of Self-regulation and Psychological Adjustment to Predictive Genetic Testing: A Prospective Study." *Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 16 (12): 1121-9.

[22] Roygnan, C. 2008. "Le cancer colorectal enoncogénétique: le cas-index face à la communication à la famille." *Psycho-Oncologie* 2 (3): 146-52. doi: 10.1007/s11839-008-0086-9. (in French)

[23] Gregory Simon, G., Schmidt, S., Seth, P., Oksenberg, J. R., Hart, J., Prokop, A., Caillier, S. J., Ban, M., Goris, A., Barcellos, L. F., Lincoln, R., McCauley, J. L., Sawcer, S. J., Compston, D. A. S., Dubois, B., Hauser, S. L., Garcia-Blanco, M. A., and Pericak-Vance, M. A. 2007. "Interleukin 7 Receptor α Chain (*IL7*) Shows Allelic and Functional Association with Multiple Sclerosis." *Nature Genetics* 39: 1083-91.

[24] Keenan, F. K., Teijlingen, E., McKee, L., Miedzybrodzka, Z., and Simpson, S. A. 2009. "How Young People Find Out about Their Family History of Huntington's Disease." *Social Science & Medicine* 68 (10): 1892-900. https://doi.org/10.1016/j.socscimed.2009.02.049.

[25] MacDonald, T. J., Pollack, I. F., Okada, H., Bhattacharya, S., and Lyons-Weiler, J. "Progression-Associated Genes in Astrocytoma Identified by Novel Microarray Gene Expression Data Reanalysis." In *Microarray Data*

Analysis, Part of the Methods in Molecular Biology™ book series (MIMB, volume 377) Spring Link, pp 203-21.

[26] Rose, C., Cupples, G., Scamell, A., and McCourt, C. 2019. "Women's Experiences of Induction of Labor: Qualitative Systematic Review and Thematic Synthesis." *Midwifery* 69: 17-28. https://doi.org/10.1016/j.midw.2018.10.013.

[27] Stoffel Elena M., Kim Turgeon, D., Stockwell, D. H., Zhao, L. L., Normolle, D. P., Tuck, M. K., Bresalier, R. S., Marcon, N. E., Baron, J. A., Ruffin, M. T., Brenner, D. E., and Syngal, S. 2008. "Missed Adenomas during Colonoscopic Surveillance in Individuals with Lynch Syndrome (HNPCC)." *Cancer Prev Res (Phila)*. 1 (6): 470-5. doi: 10.1158/1940-6207.CAPR-08-0098.

[28] Shaw, A., and Hurst, J. A. 2008. "What Is This Genetics, Anyway? Understandings of Genetics, Illness Causality and Inheritance among British Pakistani Users of Genetic Services." *J Genet Couns*. 17 (4): 373-83. doi: 10.1007/s10897-008-9156-1.

[29] Gallo Linda, C., Penedo, F. J., de los Monteros, K. E., and Arguelles, W. 2009. "Resiliency in the Face of Disadvantage: Do Hispanic Cultural Characteristics Protect Health Outcomes?" 17 November 2009. https://doi.org/10.1111/j.1467-6494.2009.00598.x.

[30] Kohut Garry, F., Burnap, C., and Yon, M. G. 2010. "Peer Observation of Teaching: Perceptions of the Observer and the Observed." *College Teaching* 55 (1): 19-25. https://doi.org/10.3200/CTCH.55.1.19-25.

[31] Gostin, L. 2000. *Public Health Law: Power, Duty and Restraint.* Los Angeles: University of California Press, p. 128.

[32] Malone v UK Applications No. 8691/79, 1984.

[33] MS v Sweden. 1997. 45 B.M.L.R. 133.

[34] Wainwright v Home Office. 2003. 4 All E.R. 969.

[35] A.-G. v Guardian Newspapers (No. 2). 1988. 3 All E.R. 545 at 658, (1990) 1 A.C. 109.

[36] Frazer v Evans. 1969. 1 All E.R. 8.

[37] Furniss v Fitchett. 1958. N.Z.L.R. 396.

[38] The Times (New Zealand), May 25, 1999.

[39] William Roach, Jr., and the Aspen Health Law Center. 1993. *Medical Records and the Law* (2nd ed.). An Aspen Publication, USA.

[40] Bell, D., and Bennett, B. 2001. "Genetic Secrets and the Family." *Medical Law Review* 9 (2): 130-61.

[41] Mappes, T., and DeGrazia, D. 1996. *Biomedical Ethics* (4th ed.). USA: McGraw-Hill.

[42] Australian Academy of Science, Submission G 097, 21 January 2002: in ALRC Issue Paper Sydney.

[43] Tarasoff v. Regents of the University of California. 1976. 17 Cal.3d 425.

[44] Pate v Threkel. 1995. 661 So.2d 278.

[45] Safer v Pack, Superior Court of New Jersey, Appellate Division, 1996. 291 N.J. Super. 619, 677 A.2d 1188.

[46] Furrow, B. R., Greaney, T. L., Johnson, S. H., Jost, T. S., and Schwartz, R. L. 2001. *Bioethics: Health Care Law and Ethics* (5th Ed.). American Casebook Series. USA: Thomson West Publishing Co.

[47] Prosser Wiliam, L., and Page, k. 1985. "Law of Torts, 849-868." *California Law Review* 73 (6): 1735-828. https://doi.org/10.2307/3480373.

[48] Dowell v Cleveland Clinic Found., No. 59963 (Ohio Ct. App.1992).

[49] Gilson v Knickerbocker Hospital, 116 N.Y.S.2d 745 (App. Div. 1952).

[50] O'Barr v Feist, 296 So. 2d 152 (Ala. 1974).

[51] Gilson v Knickerbocker Hospital [561 F.Supp. 1037 (N.D. III. 1983), aff'd 734 F.2d 18 (7th Cir. 1984).

[52] Urbaniak v Newton, 226 Cal.App.3d 1128 (Ct. App. 1991).

[53] Clark v Geraci, 208 N.Y.S.2d 564 (Sup. Ct. 1960).

[54] Catherine Berglund. Ethics for Health Care, Third Edition, Oxford University Press (2007), p. 63.

[55] Clayman v Bernstein. 38 Pa.D. & C. 543 (1940).

[56] Kwa Eric, L. 2011. *Constitutional Law of Papua New Guinea*. Law Book Co.

[57] Jan, D. 2015. "Patient Rights, Risk, and Responsibilities in the Genetic Era—A Right to Know, a Right Not to Know, or a Duty to Know?" *Ann Agric Environ Med*. 222 (1): 156-62. doi: https://doi.org/10.5604/12321966.1141387.

[58] Roy, G. 2016. "The Passive Patient and Disclosure of Genetic Information: Can English Tort Law Protect the Relatives' Right to Know?" *International Journal of Law, Policy and the Family* 2016: 1-26. doi: 10.1093/lawfam/ebv015.

[59] Jennings, B. 2004. "Genetic Literacy and Citizenship: Possibilities for Deliberative Democratic Policymaking in Science and Medicine." *Good Society* 13 (1): 38-44.

[60] Harris, J., and Keywood, K. 2001. "Ignorance, Information and Autonomy." *Theor Med*. 22 (5): 415-36.

[61] Takala, T. 1999. "The Right to Genetic Ignorance Confirmed." *Bioethics* 13 (3-4): 288-93.

[62] Kelly, K., Manno, M., Gallinger, S., and Esplen, M. J. 2007. "Should Healthcare Providers Have a Duty to Warn Family Members of Individuals with an HNPCC-Causing Mutation? A Survey of Patients from the Ontario Familial Colon Cancer Registry." *J Med Genet*. 44 (6): 404-7. doi: 10.1136/jmg.2006.047357.

Hallowell, N., Ardern-Jones, A., Eeles, R., Foster, C., Lucassen, A., Moynihan, C., and Watson, M. 2005. "Men's Decision-Making about Predictive BRCA1/2 Testing: The Role of Family." *Journal of Genetic Counseling* 14 (3). doi: 10.1007/s10897-005-0384-3.