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A Study on the Applicability of Laws and Regulation in Genetics and Its Influence in Papua New Guinea*

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Information about whether genetic information requires special treatment in law varies around the world and many aspects are not clear. In this study, we draw upon knowledge gained from various disciplines, such as genetics, medicine, law, philosophy, psychology, sociology, anthropology, insurance, and economics, which have all contributed to the study of genetic information, and discrimination based on genetic traits. With this in mind, we are able to set this research study into perspective. We make no claim on behalf of any field of study. Nevertheless, we say the development in the field of genetics is in its infancy and that knowledge of an individual genome would be essential not only for counseling but could also be used for stigmatization and discrimination. The purpose of the study is to help provide useful links concerning legal and ethical issues in human genetics and particularly where it deals with the laws, regulations, and policies concerning genetic information. We deal with the legal and ethical aspects in human genetics that influence genetic information. We examine government policies and the existing legislation in Papua New Guinea (PNG) that deal with genetic information and analyze discrimination cases due to genetic traits and describe its magnitude in PNG. This study places importance on the examination of qualitative data collected by a questionnaire survey from individual subjects representing various organizations in PNG including Department of Health, Insurance companies, General Federation of Employers' Associations, Trade Unions, and professional workers such as lawyers, District Court magistrates, medical doctors, healthcare workers, students, and private individuals. The study was conducted in towns in PNG although the majority of the participants live in the National Capital District. A sample of individuals (patients) were enrolled in a cross-sectional questionnaire survey. Individual information was obtained to describe the situation of the area. However, this study did not use administrative records based on health information from the Department of Health which describes the prevalence of genetically disordered individuals. All selected individuals or subjects were interviewed or completed a questionnaire. The data were assessed to characterize the study subsets. The findings of this study are made available to clinical practice in law, medical and public health, and private and public institutions including insurance companies, employers' federation, mining companies, and workers' unions in PNG, and academics and researchers. Educational programs on the basic principles of genetics, ethics, and law in relation to insurance will have to be developed to improve the knowledge of insurance, medical, and the cost of long-term care.

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Introduction

The question that inspired this study is: can genetic information which informs about individuals' personal health status contribute to the understanding of privacy and confidentiality of information of an individual and in turn lead to the subsequent prevention of discrimination based on individuals' genetic traits? This question was reduced to form the following issues:

1. Whether the study into the relationships between legal and ethical issues would lead to better and improved privacy and confidentiality of genetic information of an individual.

2. Whether the existing Constitutional guarantee under section 49 is adequate to appropriate protection of individual personal health information in accordance with existing government policies.

3. Whether the findings in this study would lead to an establishment of an appropriate legislative recognition of genetic information of individual and an improved and better understanding in the prevention of discrimination using genetic traits.

This study draws from the experiences of other previous workers studying the links between legal and ethical issues in human genetics (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999; Godard et al., 2003). Other potential areas of study including medicine, anthropology, social science, psychology, and economics would be considered but are not the emphasis in the study (Commonwealth of Australia, 1999; European Commission, 2001; Office of the Press Secretary of the White House, 2002).[1] Past and present attempts to understand the roles of genetic information leading to subsequent enactment by a legislative recognition in countries including USA, Australia, Great Britain, Canada, India, and New Zealand have contributed immensely to the prevention of discrimination based on genetic traits of individual persons in those countries.

Discrimination is an anti-social act, which all members of the society have agreed is wrong. It is also a social phenomenon that appears to be common in all societies. Discrimination commonly occurs with changes in the socio-economic status of a society (Australian Law Reform Commission, 2001). If discrimination should be reduced or eliminated, this depends much on the efficiency of the criminal justice system. Discrimination was viewed in the past from purely religious and philosophical perspectives. Contemporary research and study of discrimination have shifted from studying discrimination to studying the person's mind and laws made to prevent discrimination (Australian Law Reform Commission, 2001). Modern theories have moved well away from studying discrimination to studying an individual's mind that affects his or her conduct and that in turn makes discrimination criminal (Minei, 2011). A genetically disordered individual or patient is more likely to be at risk than with non-genetically disordered one and appear to become a prey or victim in his or her work place and in the community because of his or her health condition.[2]

Papua New Guinea

PNG has among the Pacific Island countries a very high prevalence of crimes from year to year. Recent crime statistics show an increase in the percentage of crimes committed, the most common being sexual offences,

[1] See Executive Order 12975, 3 October 1995, United States. Many workers contributed through submissions forming part of the reports as country based report.

[2] *Personal Communication* with Dr. Andrew Masta, Clinical Geneticist, Biochemistry Department of Basic Medical Science, School of Medicine, University of PNG.

stealing, and murder. It is uncertain regarding the discrimination of individuals due to genetic traits but could be prevalent in the work force and communities.[3] Among the provinces there are great variations however, there is not much data available to verify this situation. If discrimination has significant impacts on the lives of genetically disadvantaged people, it is likely to contribute to lawlessness within the communities and subsequent law and order problem. As well, there is an increased risk of dislike in the workforce and community, especially if the authorities of both public and private institutions are failing to perform their functions to protect the individual's right of privacy and information confidentiality.[4]

One important area where questions still arise with regards to health care is the peoples' customs, cultures, and languages. There are factors between peoples of differing circumstances which can greatly alter how they view consent in a medical setting which could mean a waiver of right to privacy and information confidentiality. Some groups would involve people in the decision-making process that may not traditionally be involved in the decision making of a medical decision such as in the case of Japanese traditional culture (Saldov, Kakai, McLaughlin, & Thomas, 1998). Other groups may dislike certain medical procedures as in PNG. And certain people have different views on what should be disclosed of the patient's condition. Customs are common phenomena which continue to affect the daily lives of many thousands of people. It is unclear in PNG about the characteristics of customs on health care because there is no published information on informed consent and issues that affect the making of informed consent. A patient should be informed of anything which would affect his or her personal decisions, such as anything which would upset any belief the patient has, particularly among female patients where rules of custom are adhered to in the community (Culver & Gert, 1982). Where customs, beliefs, and opinions of individuals are taken into account in informed consent, patients make better considered decisions which affect their health care. Beliefs associated with illness experiences are embedded in customs and cultural values that may have implications for the implementation of medical procedures (Marshall et al., 2006).

The differences in these values could influence judgements about the amount and kind of information that should be disclosed by healthcare professionals to the patients. The health care professionals may know ways of treating the patient-doctor relationship. In situations such as dealing with women patients, usually the physician and patient participate in the process of deciding what the best mode of treatment is for the patient. Unless the patient willingly forgoes her decision-making power and leaves her fate in another's hands, then the doctor must work at creating an atmosphere conducive to the patient's understanding and response to the various treatment options.

There are also inequities within the population groups because of high unemployment and low literacy in the community. The basic health care is unaffordable or out of reach for most of the local population, therefore the majority still patronize traditional healers for their health care needs. Under these circumstances any offer of medical assistance is often seen as better than nothing, thus encouraging undue influence, coercion, and medical paternalism. Perhaps there is a further dichotomy in the organization of the healthcare services in PNG, which is dual in nature, consisting of public health care and private medical service. The private service is patronized by a small portion of the population who can afford private health care insurance or possess the financial means to pay for the private care. We say that within certain social and economic positions in a society, the issues of

[3] *Personal Communication* with Dr. Erick Kwa, School of Law, University of PNG.

[4] Reducing discrimination will bring peace and harmony among workers and their employees, citizens in the community and thus improve family well-being. If the behavior of the individual is related to the prevalence of discriminatory criminal-behavior, then discrimination could be further reduced through effective prevention programs in the community.

patients being misinformed can be more or far less prevalent. Some ideas may not translate well across language barriers or other ideas may seem more offensive within certain cultural boundaries. In other traditional settings where inhibiting customs are widespread, patients may refuse to make a medical decision for their health care needs. Further, we say that a patient may have cultural beliefs or opinions which would affect his or her own personal decisions, and though they may not be supported by scientific evidence, they are still completely relevant to the patient's final decision, and so the information given should be relevant to that.

These observations have led the authors to question whether genetic information that informs about a genetic trait of an individual and, or patient can contribute to improvement of government policies and a legislative recognition of individual privacy and information confidentiality, and in turn influence discrimination (Minei & Kaipu, 2022). We examined the situation prevailing in PNG at the present time. Factors of interest are policies, laws, and regulations of PNG which also are of major concern.

Purpose of the Study

The purpose of the study, and why in particular the subjects were asked to participate, what would be expected of them and the personal benefits and risks of participation (a report on the survey findings), were explained to the subjects by the lead author (or author). It was made clear to the participants that they were able to withdraw from the study without explanation at any stage. The lead author also informed that all questionnaires or interview forms given would be treated in the strictest confidence and that no individually-identifying information would be disclosed or published. The University Postgraduate Research Committee gave its approval of the research study.

Methodology

In designing this study, it was recognized that a representative sample of individuals representing organizations and the industries were enrolled into a cross-sectional questionnaire survey. Individual information was obtained to describe the situation in PNG. In the analysis of the data, the aspects of legal and ethical issues in human genetics and their applicability were assessed in light of the role in the prevention of discrimination using genetic traits. This link was studied to describe the situation in PNG context (Minei, 2011). However, this study did not use administrative records based on health information which describes the prevalence of genetically disordered individuals. Instead a cross-sectional survey was conducted of individuals from various institutions and the public at large living mainly in the National Capital District (NCD) of PNG. Other centers including Lae (Morobe Province), Mt. Hagen (Western Highlands Province), and Lorengau (Manus Province) also participated in the study. During the course of the survey, data were collected on genetic, medical care, public health, insurance, employment, and law at that time and evidence of past and present work. Data on past and present work (Minei, 2011) sought through interview or questionnaire warrant the situation in PNG. All selected individual subjects were interviewed or completed a questionnaire. The data were assessed to characterize the study subsets.

Collection of the Data

Each participant was assigned a code number and asked to use it and not their names on all the questionnaires. The code number was recorded with basic identifying information on a separate document held by the authors to allow follow-up to be made after the survey. All interview forms and completed questionnaires have been stored in a locked filing cabinet. They will be securely stored for six years and then destroyed. Individual identities were

obliterated with code numbers and tabulated results rather names, and therefore no violation of confidentiality resulted. All individuals aged 21 years or more participated in this study. Extensive research (Minei, 2011; Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999), into this type of study or similar has shown that this group or older would be able to respond to the type of questions such as the ones in this study or similar.

NCD was the center where most of the participants were surveyed. The sample consisted of young adults, older adults, and senior citizens living in the city. The participation of medical doctors, health care workers, and lawyers were encouraged by a variety of methods, such as visiting them at their place of work and telephone calls during the time of survey. The participants were informed through a visit and were given letters informing about the research study. The actual survey work commenced in the NCD. Individuals and institutions were visited and persons were systematically surveyed. The types of data collected were relevant to this study. Data from health, genetic information, laws, policies, etc. were asked and responses were recorded into the survey questionnaires. No other ways were used to collect the data. To ensure acceptability and clarity of the questions, the questionnaires were first tested on a number of staff and students from the School of Law and School of Medical and Health Sciences, followed by 20 individuals living in NCD.

The study did not include people aged less than 21 years. Adults aged 21 years or more were enrolled and cross-sectional data were obtained using self-survey questionnaire forms and interview conducted. Informed consent was facilitated through a completed form presented to all participants who participated in the survey. Those who wished to proceed were then provided with a written summary of the aims, purposes, and requirements of the study and asked to register their intention to the author. This was achieved by signing the participant list which was returned to the author. There were no refusals although few participants did not complete the questionnaire or found no time to be interviewed.

Data Entry and Computation

We ensured all survey questionnaires were numbered, checked, and locked away in a safe place. To avoid a decline in the quality of data collected over time, checks of the completeness of the data collection forms at the beginning, during and end of surveys were performed. We checked on the survey questionnaire already completed and collected. Any omissions or discrepancies found in the data collection were resolved before the results were registered on a data base generated using Microsoft Excel.

The data collected were summarized in terms of genetics, medical, legal, and others. English language was the main medium of communication and the questionnaires were explained clearly to the respondents. No checks were made to confirm the response from the respondents. A review of reports and administrative information was undertaken for the following reasons: to critically study the general situation; to establish whether a similar study had been conducted; and to establish an understanding of the various aspects of genetics, ethics, and the law in PNG. A search was conducted in various ways using interviews with relevant authorities including lawyers, medical doctors, courts, other institutions, and many other individuals.

Analysis

The data were analyzed using range and scores. Frequency distribution and percentages were used to describe the results. Data from the questionnaires were entered and down-loaded onto a personal computer. Data manipulation and cleaning were performed manually. All questionnaires and interview responses were coded or scored onto the computer. To process the data, tables were developed and acted as guide in processing. Data

cleaning involved checking for missing information and ensuring only true information is filled in. Missing data were dealt with by record deletion in the analysis. Systematic checks of raw data and repeated entry of single sets of data also confirmed the accuracy of data.

Results and Findings of the Study

We described the aim of the study, looked at the type of study employed to collect the data, the population studied, data collection, and its management. We studied the aspects of ethics and law to throw light on genetic information. We went on to study the laws and regulations concerning genetic information in other jurisdictions. We also examined policies and the existing legislation in PNG. Then, we further examined the applicability of the relevant laws and regulations, and policies in respect to privacy and confidentiality of genetic information by advancing the understanding of genetic information in discrimination prevention.

Pilot Study

We described, first, the results of the pilot study to check if the questionnaires followed the procedures to collect data and standardize the questionnaires, the response of the participants, the characteristics of the population, and the collection of data during the surveys.

The pilot study was conducted on 10 academic staff members and 20 students residing at Waigani and Taurama campuses of the University of PNG, and 10 professional people, that is, five lawyers and five medical doctors living in NCD, Lae, Mt. Hagen, and Lorengau. The study did not include people aged less than 21 years. Adult participants were enrolled and cross-sectional data were obtained using self-survey questionnaire forms and interview conducted. Hence 40 subjects were surveyed in the pilot study. The purpose was to determine the repeatability of the collection procedures.[5]

Response

This study targeted institutions that were concerned with genetic information and its uses. The study surveyed professionals including medical doctors, healthcare workers, lawyers, magistrates, and individuals and the selected members of the general public. Of the total of 80 questionnaires distributed to the participants, as many as 70/80 (87.5%) only, completed the questionnaires which were collected, checked, and then examined. Ninety percent (90%) of the sample that participated in the survey lived in NCD and only 7/70 (10%) were residents in Lae, Mt. Hagen, and Lorengau, making up the total number of persons who participated in this study. Subjects less than 21 years of age were excluded out of this study.

The coverage in the study is comparatively higher in PNG given the kind of unwillingness by many people who refuse to complete or participate in such studies. In fact, the present study had recorded a greater number of professionals representing both public and private institutions, and individuals and members of the general public. Overall, the high response rate provided an adequately large sample (87.5%) to provide useful information for this study. The subjects were predominantly heads of institutions, professional workers as well as individuals and members of the general public from PNG. An estimated 30/70 (43%) were medical doctors, medical students, and other health workers, 20/70 (29%) lawyers and legal practitioners, 4/70 (6%) magistrates of the District Courts in PNG, and the individuals and the members of the general public make up 16/70 (23%) of the total sample in this study.

[5] The procedure involved filling the questionnaire forms, interview by a single time, and the subjects served as informants of the study. The purpose was to standardize the questionnaires.

Questionnaires

The informants were given questionnaire forms and completed the forms (n = 70). Questions ranged from general knowledge in genetics and medical to genetic testing, genetic information, and protection of genetic information, ethics, health services, and insurance and employment in the context of privacy and confidentiality of genetic information (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999). The informants completed the questionnaires, which were then collected and examined by the lead author. There was no special criterion validity of the questionnaire that was used although the author checks the forms for completeness of the response and consistency in most knowledge in genetic and medical, ethics, and the law. The data derived from the questionnaire have been accurately derived from the informants. Using this approach of data collection, questions were at times repeated to the informants to check the consistency of response and understanding of the questions (Minei, 2011). In this pilot study, many informants refused to be interviewed. The informants agree to complete the exercise by filling the questionnaire. The questionnaire forms were standardized and agreed by the author. The results from the questionnaire and interview showed understanding of the questionnaires and the result corroborated this expectation.

The findings from the questionnaire forms in the following areas as are presented:

1. General knowledge,
2. Genetic testing,
3. Genetic information,
4. Protection of human genetic information and ethical consideration,
5. Human genetic research, data base and health service,
6. Insurance, and
7. Employment.

The results (only) alluded to questions which were answered by the participants. Where questions were not answered, the following were given as reasons: the question is not applicable to the situation in PNG; the question is difficult to answer; the question requires an expert in the area to answer; and or no answer is provided. However, all participants in this study attempted most of the questions on the questionnaire forms. The descriptions of the response are presented separately. The method in this presentation is such that for each question under each area as listed above, the responses are described.

General Knowledge in Genetics

General knowledge about genetics, ethics, law, and their linkages, and whether the participants knew what these words meant were asked of the participants. One hundred percent (100%) of the participants answered “Yes” to knowing the word genetics, ethics, law, and attempted to explain the linkages but only on a general basis, the participants understood what the words are, and their meaning and relationship.

On the question of the situation in PNG in relation to law or regulation that controls dissemination and the use of genetic information, 50% of the participants agreed that there should be law(s) or regulation that should regulate dissemination and the use of genetic information, 40% said also there must be law(s) and regulations made to regulate this type of information. Final 10% said if PNG relied on the Constitution section 49 to provide for right of privacy, their views were that enabling Act of Parliament is required whose purpose is to protect individual privacy and discrimination over the dissemination and use of their personal information.

All participants expressed a need for an enactment of a law in this area but said the field in genetic science and technology is progressing fast, meaning the number of developments in genetics, medicine, science, and technology, and this would place pressures on the world all over, including PNG, to make laws or make law reform relevant to these developments taking place around the world.

Other issues were pointed out by 5% of the participants, including issues such as pressures on government, employers, insurers, and others to uncover genetic information about individuals with whom they interact. The participants said screening of individuals or groups or a population would facilitate the collection of much other sensitive health information about individuals even the communities they live in. They said also that even with the use of computer technology and development of new software, this would permit the linkages of health data from other sources including pathology, research studies, and clinical records. This they said would create new and powerful information but also heighten concern about the privacy of such information.

Forty-three percent (43%) of the participants said the Department of Health collects all types of health information arising from all medical conditions, including genetic in PNG. They said also that other private health institutions particularly private medical clinics, also have their genetic information records. They are uncertain as to whether the records also hold the names of individuals with genetic conditions, although medical practitioners would know their patients.

Some (60%) of the participants were informed of the experience of other countries including Australia, USA, and Great Britain as having their own (federal) laws on “Privacy” and “Discrimination” and at the same time paving ways for their states to create their local legislation for the purposes of protection of privacy.

As many as 70% of the participants said that there was a need to enact a law to affect the national principle as in section 49 of the Constitution as their perception on the potential benefits flowing from advances in human genetics in PNG is very strong. They said that PNG will fall behind and not be able to adequately protect the privacy of the individuals against inappropriate discriminatory use of the genetic information. The participants thought the government and other public and private institutions should be more sensitive to the dynamic environment in which medical, scientific, and technological developments are taking place.

The participants (100%) agreed that if a law is to be enacted and is successful, a multidisciplinary approach to the issue would work. The participants noted the users of the genetic information: medical practitioners, medical researchers, individuals, police, lawyers and litigants, employers, insurers, and government agencies.

Genetic Testing

About 20% of the participants provided responses to the question that only very little genetic testing is available in PNG. However, they say that most patients and others request tests to be carried out from overseas institutions. PNG Medical Research Institute also conducts genetic testing but only for the purposes of medical research. They say the patients and the general public are becoming increasingly aware of the situation in PNG and issues of accreditation of PNG laboratories are frequently asked by patients and others. The cost to conduct genetic testing in PNG is unclear although indications are: it is quite expensive and most patients and others prefer tests being conducted overseas with accredited laboratories. Those participants noted that the Department of Health in PNG has no scheme for accreditation of laboratories in the country.

Most participants (65%) said they have no knowledge as to the number of Insurance companies in PNG but say they are not aware of any public health insurance or private health insurance in the country.

Some participants (45%) said they are not aware if there are steps to take in order to obtain a genetic test including referrals for testing and genetic counseling. However, they say the medical practitioners decided.

Numerous participants (68%) also said that there are no laws and practice manuals to guide laboratory protocols, or they say if there are laws they are not aware of the laws. Participants say there is a Central Public Health Laboratory at the Port Moresby General Hospital but they are not aware of the types of genetic tests the laboratory could perform. They said the laboratory supports the work by the public hospitals for patients in the country on requests only by public medical practitioners.

Minority of the participants (20%) expressed that the Department of Health should regulate the competence of genetic testing where it should create an association of testing authorities so that the body operates as an association for accreditation, and standards must be adjusted by pathology laboratories for accreditation.

Thirty percent (30%) of the participants said that in PNG, because there is no scheme of accreditation of laboratories, the non-accredited testing may not comply with accredited standards as observed in Australia. This raise concerns in relation to quality control and, at least in relation to parentage testing, consent to testing, and a chain of custody issues. The participants said legislation should be enacted to require laboratories that conduct genetic testing to be accredited in PNG. They said also that, if the testing is conducted overseas, the legislation could require that the testing be conducted to equivalent accreditation standards recognized by the Department of Health or a similar authority.

Twenty percent (20%) of the participants said that the supply and advertising of home use genetic testing in PNG through advertising services on the internet should be prohibited by legislation. They also said genetic information may be derived from easily accessible bodily sample such as hair follicles, saliva left on a glass or cigarette, cheek cells left on a tooth brush, etc. They said, because of the improvement in bio-medical science and technology, human genetic samples are open to the potential for collection and testing without the knowledge or consent of the individual to whom they relate.

Genetic Information

When asked what is genetic information, 80% of the participants explained what these words meant and how they understood it to be in terms of health. For example, genetics is a study of genes; genetics is about DNA; genetics is about life, what we are, etc. As many as 50% of the participants said the issues of genetics privacy and discrimination have become much more prominent and of greater public concern in recent years around the world, including PNG, and this is because of the advent of advanced DNA testing technology.

About 40% of the participants said genetic information may be different from other forms of personal health information, and so it may require special regimes, for example, with respect to consent, privacy, and discrimination to regulate its collection, use, and disclosure. They said that protective mechanisms need to be put in place in each of the various relevant contexts, for example, to control the use and avoid the misuse of genetic information. They said for sensitive health information it must have a high level of protection especially genetic information that has a familiar dimension, for example, in insurance and employment where exceptional features of genetic information may justify special treatment.

Over 80% of the participants said that it would not be fair to allow genetic information to be used in such a way as to stereotype people about their future ability to function and the probability that disease would occur, rather than relying on evidence of actual disease and ability, and thus creating the real risk of establishing a new “genetic underclass” of people who are fit and able, but are locked out of securing insurance, employment or

access to other goods, services, and entitlements. Majority (90%) of the participants knew of instances of discrimination based on an individual's genetic information which has occurred in their settings however those affected have failed to report the cases.

On the question as to whether genetic-specific privacy law will contribute to a better appreciation of an individual's privacy and prevent discrimination, many participants (30%) did not believe the law would improve the situation however, strongly said the law would only contribute yet another layer of legal complexity while constituting a major irritant to health providers themselves. Others (56%) thought that integrating genetic safeguards in the mainstream privacy legislation may ensure a more consistent and open process of adaptation to new social values and needs. And majority (90%) of the participants said there is a need for much more public and professional education about genetics, and the sensible application of genetic information within a range of important contexts.

Protection of Human Genetic Information and Ethical Consideration

Majority of the participants said PNG need to establish a nationally consistent regime for the protection of health information which was applied both to public and private sectors. Under half of the participants (40%) said to set a rule to handle health information meant that an enactment of a national health privacy law should be necessary for the purpose of regulating the handling of health information.

Applying the privacy laws to genetic information, some participants (30%) said that special issues may be raised by the familial nature of genetic information and by its predictive power, especially in relation to an individual's "right to know", individuals should know about their long-term health progress.

Majority (90%) of the participants agreed that PNG needs a formal regulation of dealing with genetic information to supplement or replace reliance on professional or personal ethical standards. Further, nearly all the participants (95%) said individuals and families require specialized education in ethics.

Human Genetic Research, Human Genetic Data Bases, and Health Service

The importance of human genetic research, and the need to balance the interests of research and the individual participating in the research are important issues which should be settled. In this study, over 80% of the participants agreed that for research there is a need to access human genetic samples and information from many sources. And as for the individuals and their relatives their rights to autonomy and privacy must be respected. All participants agreed that the concept of consent is fundamental to the legal and ethical regulation of medical and other human research and to the protection of privacy.

On the question, "do you think the privacy of genetic samples and information could be more adequately protected by allowing some property rights other than possession to be exercised over genetic samples?", over half the number of participants (55%) agreed that maybe reform of relevant property laws could provide individuals with means to protect the privacy of their genetic information in PNG. Only 30% of the participants thought that a property approach to protect genetic samples would be appropriate. They further thought that the disclosure of genetic testing information could allow the prevention of serious health consequences in genetically-related relatives. The confidentiality of the doctor and patient relationship is an important issue, and 68% of the participants believed that the issue should be given priority over the other ethical considerations.

Insurance

Only 20% of the participants responded to questions on insurance. They said that there are four main types of insurance policies in PNG, which is in life, health, and general insurance. However, they further noted that

there is no specialized insurance company; most companies operate on a general basis. The participants are not sure whether the collection and use of genetic information is likely to have the greatest impact on insurance policies at this stage. Although they said insurance policies collect and use health information, that is, they require an assessment of an applicant's risk of mortality or morbidity and use this information in underwriting. The process of underwriting enables the insurer to determine whether it will accept the applicant's risk, and if so, on what terms.

No one participant reported an instance in terms of antidiscrimination and privacy of an individual's personal health information. Nevertheless 15% of the participants said PNG requires a regulatory framework to protect the privacy of human genetic samples and information in a number of contexts, including insurance. No participant knew or was aware of the type of genetic information collected by insurance companies the way in which it is used to underwrite insurance policies, and problems that can arise from that use, including possible unlawful discrimination.

One other issue which concerned 5% of the participants is: do insurance companies share genetic information? No clear response was given by the participants, however they said if the insurers are sharing genetic information then they think this practice raises concerns about the protection of the privacy of genetic information.

Employment

As regards the question, "do PNG employers request information about a job applicant's or an employee's genetic information?", many participants (70%) were not able to respond to it although some (30%) said employees employed by mining companies undergo a thorough medical examination procedure, including blood tests, a requirement each employee must complete to be considered for employment.

As to what types of genetic information are used in employment, these are unknown but information regarding health of an individual, such as whether the individual has TB, leprosy, etc., is the kinds of information individuals are obliged to provide. In some situations, according to a few participants (10%), an employer would ask an employee or job applicant to disclose information about his or her family medical history. For example, an applicant was asked to complete a pre-employment questionnaire outlining any family illnesses, and in this study the family medical history is a form of genetic information.

Most participants (77%) said there are unreported cases of discrimination by employers in PNG on the basis of genetic information and that there is potential for discriminatory use of family health information in the workplace.

Background and Summary of Findings

It may be unrealistic to choose a situation to study if there are few or no past data about the situation (population and variation) in the chosen study area. This study claims that background data on genetics, ethics, and law and their relationships have not been studied in PNG. Hence, we relied heavily on our past knowledge and experiences of working in the health sector. These were used to guide the plan and conduct of the study. This study enrolled professional people (including medical doctors, healthcare workers, and lawyers) and students and the general public, who all participated in the self-study survey. It is expected that the findings reflect the true situation in PNG in the population studied. In any study, inaccuracies in the collection of data are inevitable, and it is quite possible that only a fraction of the relevant information in this population may be reported (Minei, 2011). A pretest of the questionnaire forms, and comparison of academic staff members of the University of PNG, medical and law students, and lawyers and medical practitioners, were carried out prior to the actual survey. The

subjects were selected randomly so the only differences to be expected were those occurring by chance. The aim of the pretest was to standardize the questionnaires. It was important to know whether the standard procedure was adhered to, and to see if the responses obtained same results. To minimize the degree to which chance agreements affect the interpretation of such data, we conducted the interviews and individuals who liked to fill the questionnaires were given time to complete it. All questionnaires were checked at the end of each day. However, no measure of agreement was used in this survey. The genetics, ethics, and law, in particular the application of law regulating the discrimination and use of genetic information, are of interest in this study. The survey data collected were regarded as particularly reliable and informative. This study described the situation from the data obtained through the survey.[6]

This work used cross-sectional data from the self-study survey. A number of distinct characteristics exist in this type of data collected. Firstly, the cross-sectional data could in fact be due totally or in part to the authors' interests about the sample studied. The principal author supervised this study and conducted all the interviews, checked and examined all the questionnaires at the end of each meeting. It would be useful to know whether the relationship would be significant in this circumstance. If this occurred, this raises a question whether the data collected reflect the true situation in this population. Making judgments about whether this particular study result represents a true situation is an important one. We (authors) examined the legal and ethical issues in human genetics and its applicability in PNG. Furthermore, the present work has no plan to examine chance, bias, or confounding as likely alternative explanations for the findings. Indeed, we did not attempt to answer a research question or test a hypothesis. The authors have sufficiently described the errors that may have influenced the results. Care was taken to judge the relevance of the methodology used. For example, we met regularly during the survey to ensure that the procedures, terminologies, and aims of the study are followed. In essence, this work has attempted to describe the general situation in PNG through the sample studied in a realistic context. Thus, it is prudent to regard the results of this study using the data described as providing only an approximate picture of the truth. A mathematical model rarely fits the facts perfectly (Everitt, 1989, pp. 31-33). It is probably wise not to take the findings in this study too literally.

Discussion

Methodological Issues

The study examined the suitability of the cross-sectional design as a method of collecting data in this study, problems of this design, background data, issues of analyses, and contributions to knowledge of the relationship in genetics, ethics, and law, in particular the application of law in regulating the dissemination and use of genetic information, and makes its recommendations. There are various options in study designs that can also be used in this study, such as prospective study and case control study. Each kind of study has its own special features, which affect the use of its results. Many of the methodological issues (see later) are, nonetheless, not properly appreciated until the methods are actually put into practice.

[6] There is no other information except documents obtained from various organizations from policy papers to legislation which were collected through administrative source, which we considered in the present study. However, there has not been a study using cross-sectional data in this area of study among this population. Perhaps, it is not possible to directly compare the results of this study with other related studies in PNG. There are other types of studies that can be used for comparative purposes: for example, studies that examined the relationship of genetic, ethics, and law elsewhere.

A number of reasons exist to support the survey design as a suitable tool for studying the general situation in PNG. On a scientific view, cross-sectional studies are highly attractive to this type of survey. They can be executed quickly and at low cost (Hennekens & Burning, 1987). This type of data collection has been frequently used in the public sector and for policy planning, with secondary analyses carried out on the original data set on an ad hoc basis. As evidence of its growing popularity, cross-sectional design has been used as a method in this self-survey for data collection. In fact, the proportion of papers reporting cross-sectional studies appears to be on the increase (Parmar, Gunvanti, Sangita, & Ashish, 2016; Minei, Arafia, & Roldan, 2018). Incidentally, a general trend toward larger study subjects, and more study authors was also noted (Everitt, 1989, pp. 31-33). In the present study, the criteria for choice of design depended largely on efficiency, that is the cost and time it would take to collect the required data. Factors such as the nature of the problems under investigation and type of factors (e.g., the individual people and institutions) to study, though important, did not influence the authors' choice of study design. This work employed a self-study survey to assess the situation in this study. The authors with limited resources and time, conducted this study. The speed, cost, and time advantages of this design (Hennekens & Burning, 1987) made it the ideal candidate for the present work in the context of the adequacy of the data available.

There were shortcomings inherent in the research, which have to be taken into account when interpreting the results. Due to time constraints, only selected variables of individual characteristics were included in the questionnaire to obtain an overall view of the individual's circumstance. Few individuals decided not to participate in the survey and were not included. Understanding of the survey objectives by the interviewee was felt a barrier when interviewing especially when probing is required. This research deals with the kind of study used to collect data and attempts to explain why the appraisal of the data cannot be used to describe causal processes. There are many study designs to collect data and this study used cross-sectional study approach in collecting the data.[7] However, it is observed that each kind of study approach has its own special features, which affect the use of its results. As for this study, cross-sectional data were collected. The aspects in genetics, ethics, and law were investigated by studying the situation in PNG, that is, it deals with data collected from individuals, examination of policies and legislation and their applicability in PNG. The individuals were aged over 21 years, and represented organizations in PNG, professional groups, students, and the general public. The principal author visited various places, including place of employment, and met with individuals. Questionnaire forms were distributed following their acceptance by signing the consent form to participate. Responses were either yes or no answers and some description was required by the respondent. Questions as in general knowledge of genetic, genetic testing, genetic information, etc. were asked. The forms were either sent by mail or collected but most forms were distributed by the author. The questionnaires were checked and examined, however, questions which were answered were analyzed and described, forming the results in the study.

How Does This Work Contribute to Knowledge of Genetics, Ethics, and Law in PNG?

We examined and described the effects of the relationship in light of the prevailing situation in PNG in genetics, ethics, and the law, in particular the application of law regulating the dissemination and use of genetic information. The issues are explained in the following pages.

There has been work in other jurisdictions including Australia, USA, and Great Britain. This work also studied the relationships in genetics, ethics, and law and described the situation in PNG. Whilst data by other

[7] It is a study of population group (or a representative sample of them), in which information is collected about the present and the past characteristics or experience of individuals.

workers were collected over a period of time, the data in this study were collected by a cross-sectional study design. A number of distinct differences between this work and other work also exist. Firstly, the relationship in genetics, ethics, and law could be due to other unmeasured baseline differences in the population studied. The other workers collected data from a huge population size assessed nationwide but not in this study. Secondly, unlike the other work which collected huge data set, this work only studied a small population who has knowledge about the area of studying, living, and working in PNG.

Past studies suggested that patterns of disclosure may vary in different settings between men and women (Forrest, Curnow, Delatycki, Skene, & Aitken, 2008; Hallowell et al., 2005; Finlay et al., 2008). However, no consensus was yet reached on the issue of gendering of disclosure between males and females. For mothers, a central motivation for disclosure was suggested to be their desire to allow their children to be informed of reproductive choice (Coates et al., 2007) and their need for support from family members (Stoffel, 2008; Stol, Menko, Westerman, & Janssens, 2010). Cultural and social values can also influence disclosure. For example, a case of group of traditional indigenous inhabitants of the atolls of Western Manus in PNG shows the importance of customary rules[8] on family affairs (Minei, Kaipu, & Minei, 2020). Another 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 (Shaw & Hurst, 2009).

In this study, we say that the issue of whether the words genetics, ethics, and law were understood by the subset of population studied is beyond doubt. This study found that overwhelming majority of the subjects understood the terms. The types of responses and information provided reflected their knowledge. The level of knowledge may also depend on the educational attainment and whether the individual understood the areas also in the context of their professions. For example, lawyers and magistrates and law students would provide more information in the area of ethics and law and be comfortable in providing their responses whilst the medical and health workers would respond well in genetics and ethics. The differences in the responses were not compared but were used in explaining the situation in PNG. The responses, further indicated that there is increased concern in this study to improve laws or regulations to regulate the dissemination and use of genetic information however, others said if a specific privacy law was established it will only contribute yet another layer of legal complexity while constituting a major irritant to health providers themselves (Minei, 2011).

A specific privacy law is required for the purposes also to protect individual privacy and confidentiality of information and discrimination over the use of personal information. The effect on the individual's right to privacy would continue depending on the frequency of the violation of individual personal information. There are many unreported incidences of denial of privacy rights.[9] Individuals who are exposed to conditions such as that, experience more attacks of their privacy right and those individuals suffer greatly in personal injuries and their constitutional right deprived. The information obtained in this study showed similarities in the responses among the individual subjects. That is, the subjects were stunned and complained that there is a real need to enact a privacy law or similar enactment. Author is fortunate enough to practice as healthcare professional in public health and hospital setting and legal counsel had taken the time to educate the participants in this study about

[8] Customs that prevail in the community only and constitutes a sources of law for that place only.

[9] *Personal Communication* with Dr. Andrew Masta, Clinical Geneticist, Biochemistry Department of Basic Medical Science, School of Medicine, University of PNG.

ethics as well as about law, about communication and interpersonal relations, about health policy in general, and about the role of the various faiths playing in health care decision making. The level of knowledge may be explained by the responses provided in the study but there are similarities in the types of responses by individuals studied which may be related to the persistent breaches of individual's right to privacy by the perpetrators rather than the absence of a law or a regulation.

It is apparent in this study that the national principle under the Constitution, section 49 ("right to privacy"), would be increasingly forced to confront the question of when rights and privileges of individual persons are less uncertain. The fundamental constitutional right[10] and common law extend to cover both competent and incompetent individual persons. However, the Courts may have greater difficulty determining which rights, if any, attach to a breach in privacy right of personal information. The trend since 1975 in PNG has been that a specific enactment is necessary to recognize that individual privacy right affected can be an independent victim for purposes of tort and criminal law. For example, in many states in Australia, they permit a tortious action to be filed by a victim whose privacy right has been violated (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999). Just a few years ago, states in Australia required that the victim is denied his right before any right to sue would attach (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999). Similarly, many states in the U.S. now extend the protection of their right to privacy to all their citizens; several years ago that extension was very unusual in the U.S. and Australia (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999). However, the extent of any constitutional protection of citizens in PNG under the national principle is far less certain whilst without an enactment of privacy law or similar (Minei, 2011).

The fear of dislike, un-employment, or un-insurability has driven much of the concern over genetic discrimination as this study attempted to elucidate from amongst the study population in PNG. This study found that there are pressures on government institutions, employers, and insurers to uncover genetic information about individuals with whom they interact. The screening of individuals (personal) or groups (e.g., employment) or a population (e.g., research) would facilitate the collection of much other sensitive health information about individuals, even the communities in which they live. The present study used some underlying issues (in the Introduction) to describe the situation in relation to law or regulation that regulates dissemination and the use of genetic information.[11] In essence this work has attempted to describe the relationship of genetic, ethics, and law in PNG and has assessed the situation, prevailing during this time in a realistic context using cross-sectional data. There is belief suggesting that the findings in this work would lead to a better and improved knowledge about genetics, genetic information, and education in ethics and the law (Ross, 2001).

The underlying issues are:

(1) Legal and ethical issues would lead to better and improved privacy and confidentiality of genetic information of an individual.

(2) Existing constitutional guarantee under section 49 is adequate for appropriate protection of individual personal health information in accordance with the existing government policies.

(3) Findings would lead to an establishment of an appropriate legislative recognition of genetic information of individuals and improve a better understanding in the prevention of discrimination using genetic traits.

[10] Constitution section 49, GovPNG (1975).

[11] Truth Telling (honesty, integrity). The principle that one's ought to disclose all pertinent information about a person to that person.

(4) Findings of this study would lead to an establishment of health, insurance, or health insurance code.

We discuss these issues, point-by-point, in the following paragraphs.

Legal and ethical issues. Most countries in the world today have yet to establish and develop laws to protect individual genetic information, and PNG is no exception. U.S. has made more progress in developing both federal and state laws, policies, and guidelines on genetics and genetic information. The laws in the U.S. especially recognize what is genetic and/or genetic testing (Kobrin, 1983; Suter, 1993). In the U.S., information derived from genetic testing shall be confidential and privileged and may be released only to the individual tested and to persons specifically authorized by such individual to receive the information. A genetic diagnosis:

> It generally, provides great benefit to patients. It helps patients understand their disorder, especially when the condition is rare and the patient has struggled to find a diagnosis. Oftentimes, patients spend years living with a condition without knowing its name or cause. Diagnoses usually lead to improved treatment options and access to support services. It also helps other family members make decisions about their own lives.
>
> May lead to negative reactions, too. The science of genetics can be confusing, and patients are often frustrated until they understand the nature of their condition. Patients identified with a mutation may consider themselves at fault or "broken" or interpret their diagnoses as leading to something they cannot fight. A genetic diagnosis can lead to fears about insurance and employment discrimination (direct quote).

The reaction to a diagnosis varies from individual to individual and is affected by many factors including gender, education, and religious and cultural beliefs. By being aware of these differences and understanding the patients' backgrounds, communication with patients is effective.

We agree that the choice of an appropriate communication strategy should therefore take into account the type of genetic information that will be disclosed in an attempt to foresee the impact on familial relationships and mitigate potential adverse conclusions. The duty of the professionals in relation to disclosure decisions remains to date a controversial issue in the present level of knowledge. It is suggested that most feel a personal responsibility to make relatives aware of the genetic risks, but they also believe that such direct disclosure should not be made without the permission of the patient (Kohut, Manno, Gallinger, & Esplen, 2007), in order to maintain a good doctor-patient relationship, foster trust, protect medical secrecy, and respect the patient's right to intimacy (Roygnanm, 2008).

Any other person or authority that possesses information derived from genetic testing may not release the information to any third party without the explicit written consent of the individual tested. Similarly, information derived from genetic testing may not be sought by any person, e.g., an insurer or an employer. The disclosure of genetic tests results would lead to civil fines and payment of damages for the disclosure of results of a test for a genetic characteristic to any third party (Minei & Kaipu, 2022). We observe that physicians have duty to warn at-risk family members of possible harm from genetic variations. In the USA, the courts provide limited and conflicting guidance, as in these case examples:

In the 1995 case of Pate v. Threlkel, the plaintiff, Mrs. Pate, inherited medullary thyroid carcinoma from her mother and sued her mother's physician for negligent failure to warn the mother that her children might inherit the cancer risk.[12] Mrs. Pate alleged that the physician "knew or should have known" of the risk to his patient's children and had an affirmative duty to recommend immediate testing for the patient's children. Had she been warned, Mrs. Pate argued, she would have sought preventive treatment for the disease at an early stage in its development. In that case, the court ruled in favour of the physician that "in any circumstances in which the

[12] Pate v Threlkel, 661 So2d 278 (Fla 1995).

physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient". However, the court did not impose a duty upon the doctor to warn a third party, but merely to encourage the patient to warn her at-risk relatives.

One year later (1996), a New Jersey appellate court came to a different decision. In Safer v. Estate of Pack, the plaintiff's father had died of multiple polyposis, an inherited condition that can develop into cancer if it is left untreated.[13] Because the plaintiff, Mrs. Safer, was a child when her father died, she only learned of her predisposition to developing the disease when she was diagnosed with multiple polyposis herself in adulthood. The plaintiff sued her father's physician, alleging a duty on the part of the doctor to warn at-risk relatives of the possibility that they might develop this treatable condition. That court ruled that "the duty to warn might not be satisfied in all cases by informing the patient". Sometimes, the decision went on to say, the physician might have to resolve the "broader duty to warn and…fidelity to the expressed preference of the patient that nothing be said to family members" about the disease. These holdings and case law in general are inadequate to apply to the gamut of scenarios which physicians face in medical practice routinely.

We say that while some research workers have called for the adoption of a system in which genetic information is shared among family members by default, others prefer to quantify the levels of genetic risk and probability of harm on a case-by-case basis (Liao, 2009). Until legal agreement is achieved on when and how to make sensitive disclosures to at-risk family members, clinicians can at least fulfil their duty to fully educate their patients about the meaning and scope of their diagnosis (American Medical Association, 2012). The American Medical Association (AMA) Code of Medical Ethics, however, does not construe finding and notifying family members as a physician's duty, though it does recommend that physicians inform patients in advance of what they expect them to disclose to their families and be available to assist in this communication (American Medical Association, 2012).

Damages for economic, bodily, or emotional harm which is proximately caused by the act follow. Codes have been established for genetic testing, confidentiality of medical information, health and safety, insurance, etc (Wolf, 1995, p. 345). In the U.S. the state and federal governments have enacted privacy laws and laws on discrimination, aimed at protecting the use of genetic information of individuals from being misused (Furrow, Greaney, Johnson, Jost, & Schwartz, 2004, p. 181). We concur that genetic information is commonly perceived as requiring unique ethical and legal attention because it is predictive. Research reveals that the impact of disclosure on familial relationships may vary depending on the predictive power of the genetic result (Weiner, 2011). For instance, breast cancer gene(s) testing (susceptibility to breast cancer with relatively high predictive power) was found to have significant impact on familial relationships, some positive (such as feeling closer, improved communication and support or more appreciation of the relative) and negative (such as the emergence of conflicts, feelings of guilt towards children and carrier siblings, imposed secrecy or communication problems) (Oostrom et al., 2007). Anyhow susceptibility to Alzheimer's disease with relatively low predictive power did not alter family dynamics completely, but rather seemed to reinforce for good or for bad "pre-existing family dynamics and ideas about family susceptibilities for disease" (Chilibeck, Lock, & Sehdev, 2011). Genetic information 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 (Etchegary & Fowler, 2008). Because of these characteristics, disclosure of genetic information within the family loudens particular ethical issues. On one hand,

[13] Safer v Estate of Pack, 677 A2d 1188 (NJ Super Ct App Div 1996).

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" them (Etchegary & Fowler, 2008, pp. 707-727) and that patients have an ethical responsibility to disclose this information to relevant family members (Gilbar, 2007; Davey, Newson, & O'Leary, 2006).

We agree that genetic disorders impact not only the physical health, but also the psychological and social well-being of patients and their families. Understanding the unique aspects of genetic information and anticipating reactions to genetic tests and diagnoses can help guide a course of action to minimize distress and maximize benefit for both the patient and family. Further, we say that an increased genetic risk or a genetic diagnosis can substantially impact medical management as well as the psychological and social well-being of the patient and family. The personal and permanent nature of genetic information raises a range of emotions including guilt, fear, and helplessness. Specialists such as genetic counselors, social workers, and psychologists, as well as support groups, can be extremely helpful to patients and families as they deal with these difficult issues.

Cases where patients refuse to share clinically relevant genetic information with family members therefore raise ethical difficulties (Dupras & Ravitsky, 2013). We concur 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' point of view, Stoffel and co-workers expressed that 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" (Stoffel et al., 2008, pp. 333-338). Rather, they are preoccupied by the ethical dimensions of their so-called "genetic responsibility" to warn family members in order to "foster" their health (Klitzman, Thorne, Williamson, Chung., & Marder, 2007) and by "conflicting senses of responsibilities: to provide potentially valuable information and prevent harm that may arise from this knowledge" (Gaff et al., 2007, pp. 999-1011).

Whilst there is more being progressed in the U.S., many other developed countries, including Australia and UK, have commenced work also in the development of laws especially specific for privacy rights of individuals and their protection (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999). We observe that work in human genetics has been a continuing source of intriguing, and at times formidable, ethical issue.[14,15] From the standpoint of bioethics, research in HGP presents no completely novel ethical questions, at least for now (Furrow, Greaney, Johnson, Jost, & Schwartz, 2004). That is partly because other authors (or scholars) and others have wrestled with the questions before and further means that we do not have to invent every response totally anew, but rather can draw on the history of scholarly analysis that has gone before. The acceleration of knowledge about human genetics promised by HGP (or genome research) assures that the ethical questions presented will be plentiful and significant. Debate about the ethics of workplace genetic testing has focused on the purposes for which such tests might be used (Wolf, 1995). Four purposes have been identified, namely, diagnosis, research, information, and exclusion. Genetic tests, like many other procedures, can be helpful in diagnosis and research. Their use in those contexts is governed by the ethics of medical diagnosis and treatment and the ethics of research with human subjects.

[14] Campbell (Appellant) v MGN Limited (Respondents).
[15] Morland J [2002] EWHC 499 (QB).

Genetic tests may also be used before hiring or placing a particular worker to uncover a genetic susceptibility believed to put the individual at greater risk of occupational disease associated with hazards in that workplace. We say that many of the ethical questions are relative to the attitudes and customs of the particular society in which they arise; that is, they believe that the rightness or wrongness of an action or practice cannot be determined apart from the cultural or societal context (Arras & Rhoden, 1989; Furrow et al., 2004, p. 8) in which the action occurs. The crucial distinction is between giving the tests voluntarily, with the information given to the worker who then decides whether to accept any additional risk, or compelling workers to take the tests and using the results to exclude workers who may have genetic susceptibilities. A program of voluntary testing to inform workers of their risks is ethically defensible. In general, maybe the individuals affected are the ones with the greatest ethical right to decide whether or not to accept risks. There are some risks that are so nearly certain to occur and cause grievous harm that would limit choices for individuals. Except for such circumstances, competent adults usually decide for themselves that risks are acceptable to them (Suter, 2001). With pre-symptomatic genetic testing, a program of workplace genetic testing should include effective education and counseling to prevent misunderstanding of the results and to deal with emotional responses to learning that one has genetic risks. A carefully designed program of workplace genetic testing to inform workers, leaving the choice up to individual workers about whether to accept risks, does not confront any insure mountable ethical barriers. The same cannot be said for compelled genetic testing. Compulsory genetic testing, leading to possible exclusion from jobs, has been controversial. Critics argue that it violates deeply held notion of individual autonomy and could be used in socially undesirable ways. For example, testing for sickle cell anemia followed by exclusion of those with the trait would effectively exclude one of every eight black job candidates in the U.S. Where workers are plentiful, employers might prefer to screen out susceptible workers rather than invest in equipment to reduce exposure to hazards. The prospect of such undesirable effects, along with respect for individual liberty and choice, makes compulsory workplace genetic testing ethically problematic.

The most important movement in the ethics of workplace genetic testing has been away from the original vision of a public health measure of screening as a way of reducing illness-related diseases. There is increasing reason to believe that genetic screening for common diseases such as arterial disease (including coronary disease), stroke, and cancer may soon be possible. Other disabling diseases, including mental diseases such as depression and schizophrenia, might also become the targets of genetic screening. Employers might find such tests as attractive ways to save money by screening prospective employees and hiring those without evidence of genetic susceptibilities to disease. Employee illness, at least in the U.S., costs employers' money (Furrow, Greaney, Johnson, Jost, & Schwartz, 2004, p. 181). With health insurance costs becoming an increasingly larger proportion of employers' expenses, employers are looking for ways to diminish health-related costs, including health insurance, disability insurance, the cost of lost productivity from ill workers, and the cost of training replacement workers for skilled positions. The combination of increased employer concerns about the costs of illness and the prospect of genetic tests for predisposition to common, costly diseases are fertile ground for the use of such tests to screen workers.

We have examined the relevant laws in PNG including the Employment Act (Chapter 373) and the Public Service (Management) Act 1995 and concluded that they lacked rigor. However, in other jurisdictions, for example, in the USA, most states have addressed the use of genetic information in employment decisions in the 1970s and 1980s with protections from discrimination for job applicants with the sickle cell trait. Wisconsin was

the first state to ban genetic testing and discrimination in the workplace in 1991.[16] Genetic nondiscrimination in employment laws are now in place in 34 states and Washington, DC. The scope and functions of these laws vary widely. All laws prohibit discrimination based on the results of genetic tests; many extend the protections to inherited characteristics, and some include test results of family members, family history, and information about genetic testing, such as the receipt of genetic services. Most states also restrict employer access to genetic information, with some prohibiting employers from requesting, requiring, and obtaining genetic information or genetic test results, or directly or indirectly performing or administering genetic tests.[17] Some states may also make exceptions to statutory requirements if, for example, genetic information may identify individuals who may be a safety risk in the workplace.

The ethics of genetic screening for non-workplace-related diseases differ in part from genetic screening for workplace-related diseases. Working in a particular workplace does not put the worker at an increased risk; the disease to which the person may be susceptible is not related to the workplace. The information to be gained from such tests is not relevant to the individual's choice of whether or not to work in that environment, although it might be relevant to other life choices, such as diet, exercise, and other health-related behavior. Being denied a job because of predisposition to a non-workplace-related disease, is as great an affront to an individual's liberty as a denial for predisposition to a workplace-related disease. But here there is no compensating reduction in risk to the individual's denied employment nor is there any public health benefit; those who will die from heart disease or cancer will still die from it, unemployed and possibly unemployable. Employers are not the only ones likely to be interested in people's predisposition to common disabling and killing diseases. Companies selling life, disability, or health insurance are also interested in genetic tests (Prince, 2019).

Insurance works on the principle of sharing risk. When the risk is equally uncertain to all, then all can be asked to contribute equally to the insurance pool. Not all individuals have the same risk of dying, for example. The older one is (beyond early childhood), the greater the risk of death. Older people are charged more for the same amount of life insurance than younger people. Some occupations are riskier than others. Test pilots pay more for life insurance than accountants. None of this seems unfair. The ethics of discriminating according to genetic predisposition, on the other hand, seems much more ethically complex.

Insurance companies have begun to think about what to do with tests for genetic predisposition to disease. Two factors may force insurers to use genetic tests. First, once such tests become available in medical practice, individuals can be tested privately to learn whether they have enhanced risks of disease. People who learn they have higher risks are more likely to buy insurance and are more likely to buy larger amounts. Second, competition among insurance companies will tend to drive companies toward screening for predisposition. If one company begins using such tests, it would be able to offer lower rates to individuals who do not have genetic predisposition to disease and higher rates to those with such predispositions. Individuals offered the lower rates are more likely to purchase insurance from that company, whereas the ones with genetic predisposition to disease will seek insurance from another company that does not do genetic testing. The latter company will either have to raise its rates (to avoid bankruptcy) or it will also have to use genetic tests.

One of the most common ethical and legal questions is whether and to what extent a person is responsible for something (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999), that is, we ask:

[16] NCSL National Conference of State Legislatures. Updated January 2008. Ncsl.org/research/health/genetic-employment.laws.aspx.

[17] See NCSL National Conference of State Legislatures. Updated January 2008.

(1) If the individual who committed a violent act was responsible for his behavior, morally blameworthy, legally culpable;

(2) If the inventor was responsible for the new device (credit rather than blame being at stake here), the scientist for the discovery, and the author for the idea, style, and specific words;

(3) About responsibility for larger issues than discrete acts or inventions;

(4) Whether the overweight person is responsible for his or her obesity, and by extension, for the illnesses to which obesity is a contributing factor, and perhaps for the expense of caring for those illnesses; and

(5) Whether alcoholics are responsible for their addiction and for the consequences of acts committed while they were inebriated.

On an even broader level, we ask whether groups who do especially well (or especially poorly) in various social and economic realms experience the outcomes they do because of some intrinsic traits and abilities or because of lack of opportunity.

Genetics frequently provides an explanation or excuse for individual behaviors or traits, as well as for group differences. The genome research project will enhance the tendency to give genetic explanations for individual and group differences in two ways. First, research will suggest genetics correlates with a wide range of human traits and behavior. Some may prove to be spurious, but others will withstand scrutiny. Whenever such a genetic correlation is suggested for some ethically, legally, or economically consequential outcome, there will be a temptation to it as fundamentally that is exclusively or exhaustively genetic, and hence outside the individual's responsibility or capacity to control. Second, in the initial rush of findings of genetic connections to important human traits and behavior, both scientists and the public may become too eager to embrace genetic explanations for a vast range of ethically significant phenomena. The phenomena in question may range from illness, including mental illness, to the educational and occupational attainments of different racial and ethnic groups.

History is rich with examples of scientific perspectives used inappropriately for political purposes (Murray, 1996, pp. 547-551). Frequently, genetic or earlier hereditarianism theories have been the subject of such misuse. The first large-scale intelligence testing program in the U.S. was the Army alpha program, which was designed to screen incoming recruits according to their intellectual capacities (Murray, 1996). Certain groups did not fare well on the test, including immigrants from southern Europe. Because the results conveniently fit the beliefs of those overseeing the testing, they accepted the tests as valid measures of intrinsic ability rather than as the profoundly culture-bound instruments they were. They also overlooked the fact that many of these immigrants spoke English poorly or not at all, and the test was in English. The question raised here also has, as George Annas (1989, pp. 19-21) said, importance, in some instances profoundly important, legal ramifications that must be thoroughly explored. "Although we are utterly unprepared to deal with issues of mandatory screening, confidentiality, privacy, and discrimination, we will likely tell ourselves that we have already dealt with them well …" (Annas, 1989, pp. 19-21).

The point here is not that we should ignore the influence of genetics on human affairs. Scientists should be the last people to abandon evidence in favor of a sentimental, comforting illusion. Lucidity demands that we confront the truth as it is, however, we must learn not to over interpret what we find. We must learn how not to communicate effectively among ourselves and with the public about the limits of our knowledge.

Lastly, we must recognize the limited ethical and political importance of our genetic knowledge. When the founders of the U.S. wrote that all men (all people) are created equal, they did not mean this as a statement of biological fact, but as an ethical, legal, and political proclamation: before the collectivity of the state, all persons

must be regarded as equal, each due equal respect, equal liberty, and equal protection, among other fundamental rights (Furrow, Greaney, Johnson, Jost, & Schwartz, 2004, pp. 181). The sciences of inequality, with genetics at the forefront, will force us to interpret what equal treatment and equal regard mean in an immense range of contexts. But they need not threaten the ethical core of that commitment (Furrow et al., 2004).

This study now contributes to a better appreciation of an individual's privacy and confidentiality[18] of information. And this in turn will lead to an understanding of the right of privacy of the individual and hence prevent discrimination. This study believes that, with education of individuals in understanding the right to privacy, maybe individuals and institutions could consider integrating genetic safeguards in the mainstream health or an appropriate legislation may ensure a more consistent and open process of adaptation to new social values and needs. This study increases a need for much more public and professional education about genetics, and the sensible application of genetic information within a range of important contexts.

We say that the market for private health insurance in PNG is small[19] or nonexistent, the possible use of genetic information in insurance and employment has gradually generated debate and increasingly causes concern (Beatrice et al., 2003). Medical geneticists' concerns extend beyond the traditional ethical guidelines in medicine.[20] For instance, genetic testing for insurance and employment purposes could disturb family relations. Family cooperation is often necessary to detect genetic problems, but genetic information may affect an entire family rather than only one individual, and the choices of the present may affect future generations. Genetic information links the members not only of families but also of whole communities. Genetic disorders are often over-represented in ethnic groups and intensive genetic research on some populations could exaggerate the presence of problems. A patient at the interview articulated that, "Genetic information through family history was already used by some insurance companies before anyone considered genetic testing, and individuals were covered or denied coverage or charged higher premiums according to family history."

Nevertheless, the progress made in predicting diseases alters the information available with regard to the risk of disease. Genetic information contains more certainty than information traditionally gathered by insurers to investigate the existence of diseases running in the family (Lemmens & Bahamin, 1998; Association of British Insurers, 2000). This may have important consequences for insurance industry.

Concerns of employers and of insurers are similar (Prince, 2019). The main difference between life insurers and employers is that for employers, sickness represents a greater financial risk than death, while for health insurers, the opposite is usually the case. It is in employers' interests to have a healthy workforce.[21] Some employers provide facilities to encourage the staff to achieve a good health, like regular medical check-ups and sport. It has been argued that if it could be demonstrated that genetic screening would encourage healthier lifestyles, it would be possible to envisage that employers would fund such screening for their staff (Goedvolk, 1999). "A patient expressed that insurance companies are interested with employees' job which earned more money through their salaries."

Employers are particularly interested in the health of the employees for jobs where there is a substantial investment in genetic information and testing, in insurance and employment, in training or for very senior

[18] The principle that when information is divulged by one person to another with the implicit promise that will not be revealed to any other person that implicit promise should be respected.
[19] Workers' Compensation Act Chapter No. 179 (Part IV and V), GovPNG.
[20] *Personal Communication* with Dr. Andrew Masta, Clinical Geneticist, Biochemistry Department of Basic Medical Science, School of Medicine, University of PNG.
[21] Wrongs (Miscellaneous Provisions) Act Chapter No. 297, GovPNG.

positions. Different sources of information can be used to assess whether an individual has a risk of either sickness or death: medical examination, medical history, family history, age, lifestyle. Genetic testing might confirm the risk of developing a genetic disease, for which some jobs could make the person unacceptable (Bonn, 2000). What would also change is that some employees would move from 50% to 0% chance and they would have opportunities which have currently denied them. For most jobs, employers do not insist on intensive health testing of prospective employees, because the extent of the employers' investment in new employees is not great enough to warrant such expense (Goedvolk, 1999). The prospective employees are simply asked to make a declaration about their state of health.

The challenge in PNG is to maintain our moral and ethical compass, supporting these aspects of genetic science, which reduce pain and suffering and increase quality of life, whilst firmly resisting the lazy or pervers use of this knowledge in such a way that tends to diminish personal freedom and periodic responsibility, and creates new opportunities for unfair discrimination.

Constitutional guarantee under section 49. Over the years, concerns about genetic privacy have arisen. Of particular interest is the scope of rights of ownership to genetic information and the way this information can be used to create threats to individual and familial privacy. One issue is that whether section 49 of the PNG Constitution would adequately supply appropriate protection of individual health information.

In 1975 Parliament passed the Constitution of PNG which continues to be relevant to the legal regulation of right to privacy. This provision was introduced for one apparent reason: the legislators at that time had adopted that particular provision from the U.S. Constitution which actually promotes rights of people to privacy. But, we do not believe this particular law was made and meant for the purpose of right to privacy of information and confidentiality as such. That law was written for the purposes of freedom for all people and that no person was to interfere with another person's privacy or choice, it has political significance. The authors believe section 49 was adopted for the similar excuse as in U.S., but not for health, medical, or genetic significance in the context of individual privacy and confidentiality of information. We further believe that as such no legal protection may be afforded to individuals under section 49 for privacy and confidentiality of information. Unfortunately, there is no case law based on this circumstance. If there would be a situation arising out of the above circumstance, we believe that a need for an enactment to be introduced to close this loophole may be recommended. Moreover, we believe that health workers may not be protected under any other legislation but under their professional code of conduct which defines their duties and responsibilities relating to privacy and confidentiality of medical information (Minei & Kaipu, 2022). There is still a need to enact a law or possibly integrate privacy and confidentiality matters in the mainstream health or a similar legislation to affect the national principle. This is necessary as the social value on the potential benefits flowing from advances in human genetics, is taking place.[22] The government, both national and provincial, and public and private institutions should be more sensitive to the dynamic environment in which medical, scientific, and technological developments are taking place (Minei, 2011). The users of the genetic theory including medical practitioners, medical researchers, individuals, police, lawyers and litigants, employers, insurers, and government agencies, as individuals and or organizations, should work together.

Some features of genetic information do provide plausible grounds for giving it special attention under PNG laws. For example, individuals and families often worry about genetic conditions that are stigmatizing, more than

[22] PNG will fall behind and not be able to adequately protect the privacy of individuals against inappropriate discriminatory use of genetic information. However, if a law is to be enacted and is successful a multidisciplinary approach to the issue would work.

worry about health problems (Minei & Kaipu, 2022). As in screening for HIV information, the risks of genetic screening and testing required are primarily psychosocial. Because of the risks, genetic screening and testing require justification in terms of their probable benefits, which vary from genetic condition to condition, depending on whether the screening and testing are for disease, disposing condition, or carrier status, whether preventive or treatment measures are available, whether the information is important for reproductive decisions, and the like. For any genetic screening or testing, fundamental questions concern who will use the resulting information, how they will use it, and for what purposes. Discriminatory uses of information are a major concern. We explain further.

Genetic testing has the potential to facilitate the exclusion of the genetically vulnerable from life and health insurance coverage, and potentially from employment (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999). Many recognized from the start of the genome research project that genetic screening (that is, sorting out an asymptomatic population to locate persons at elevated risk of genetic problems) would present issues of privacy and confidentiality involving employers, insurers, bankers, credit raters, and many others. Predictive uses of genetic information are not sufficiently developed to affect a large number of underwriting decisions, and they are not cost-effective but Human Genome Project (HGP)[23] initiative will increasingly create a larger volume of predictive information to be added to the genetic information already available. If this information is obtainable, it will encourage insurance companies to make genetic tests cost effective (Annas, 1982). Companies can then deny coverage, increase charges, initiate exclusions, and the like. Such information also would be obtainable by persons at risk of disease, and they are more likely than others to purchase the relevant type of insurance in maximal amounts because they are more likely to experience claims in excess of premiums.

The cost of health care gives employers a reason to avoid hiring persons who may get sick and file claims. Many companies already carry limited coverage in the case of diseases such as AIDS. At the present time, corporate policy often restricts group insurance to ever-smaller subgroups, eliminating from the larger group persons who potentially will be costliest. The private health insurance industry views these strategies and adjustments as justified, because insurance policies are designed to limit risk as well as to protect the healthy, but a morally unsatisfactory feature marks the current insurance scheme. A few patients said: “Insurers want to avoid those most in need of insurance; the more insurance you need, the less you can obtain, or the more you pay”.

A basic question about a system of access to healthcare is whether it is ethical even to allow second parties to obtain information about genetic risks in the context of contracting for insurance policies, or whether health insurance should instead be distributed in accordance with the luck of the natural lottery, totally blinded from genetic information. It seems to be a clear morally unjustified act of discrimination to exclude persons from a health insurance pool merely because they were unlucky in the genetic or any other natural lottery. Employment discrimination is closely linked to these problems. A PNG company executive said that, “Some employers find it advantageous to exclude potentially costly employees”.

Although relatively few employers currently use genetic testing, this situation will change as the benefits of testing shift and as the market fosters incentives to engage in testing. Studies in U.S. over worries about genetic discrimination considered issues (Furrow et al., 2004) including:

[23] The more recent explosion of knowledge in genetics is the result of the Human Genome Project (HGP). The HGP is a multi-national Project involving 16 countries (including the USA, Great Britain, France, Japan, etc.).

(1) Whether incidents involving genetic discrimination are already common in the workplace,

(2) Access to social services,

(3) Insurance underwriting, and

(4) The delivery of health care.

The studies described many difficulties that respondents had encountered in obtaining insurance coverage, finding or retaining employment, and the like. This and many other cases reported in U.S illustrate discrimination against persons who are completely asymptomatic; their only "abnormality" lies in their genotypes. Though healthy, these persons are treated as if disabled or chronically ill. If this information were protected as private (allowing an exception in the case of individuals who apply to increase or purchase extra coverage), such discrimination could not occur.

If we could protect privacy and confidentiality so that we could reduce the level of discrimination, or prevent information from being used for discriminatory purposes altogether, then individuals and families might find it more reasonable, on a risk-benefit calculation, to undergo genetic testing. As matters now stand, women with a family history of breast cancer sometimes refrain from undergoing genetic testing out of fear that the information, even if presented as private and confidential, will be used to discriminate against them in employment or health insurance.

The differences between genetic and other medical information are matters of degree rather than kind. Public policies therefore should address the privacy (and confidentiality) of medical information, in general, and then add special, additional protections for genetic information, if needed, we state the views of a few senior officials of the superfunds companies, "We necessarily surrender some of our privacy when we grant others access to our personal histories or bodies, but we also retain some control over information generated about us, at least in diagnostic and therapeutic contexts and in research".

For example, physicians are obliged not to grant an insurance company or a prospective employer access to information about patients unless the patients authorize its release. When others gain access to protected information without our consent, we sometimes say that their access infringes our right to confidentiality and at other times say that it infringes our right to privacy.

From one standpoint, confidentiality is a branch of informational privacy, it prevents re-disclosure of information that was originally disclosed within a confidential relationship. The basic difference between the concepts is this: An infringement of a person's right to confidentiality occurs if the person (or institution) to which the information was disclosed in confidence fails to protect the information or deliberately discloses it to someone without first-party consent. By contrast, a person who without authorization enters a hospital record room or computer data-bank violates rights of privacy rather than rights of confidentiality. Only the person (or institution) who receives information in a confidential relationship can be charged with violating rights of confidentiality (World Medical Association Declaration of Helsinki, 2013). Rules of confidentiality have long been common in codes of medical ethics. Requirements of confidentiality appear as early as the Hippocratic Oath (Edelstein, 1967) and continue in, for example, the World Medical Association's Declaration of Geneva (Dawson, 1954, pp. 1474-1478), which asserts an obligation of "absolute secrecy" and includes the following pledge:

> I will respect the secrets which are confided in me, even after the patient has died. The World Medical Association's International Code of Medical Ethics states the most stringent requirement of all: A doctor shall preserve absolute secrecy on all he knows about his patient because of the confidence entrusted to him. (Dawson, 1954, pp. 1474-1478)

Some commentators ridicule such official rules as little more than a ritualistic formula or convenient fiction, publicly acknowledged by professionals but widely ignored and violated in practice.[24] To make this point graphic, let's look at the case of a patient who became concerned about the number of people in the hospital with apparent access to his record and threatened to leave prematurely unless the hospital would guarantee confidentiality. Upon inquiry, it was discovered that many more people than suspected had needs and responsibilities to examine the patient's chart. When the patient was informed of the number, approximately 75, he was assured that "these people were all involved in providing or supporting his healthcare services." The patient retorted, "I always believed that medical confidentiality was part of doctors' code of ethics."

This reaction is reasonable in contemporary health care. When X tested positive for HIV at the medical center in New Jersey where he worked as an otolaryngologist and plastic surgeon, he received calls of sympathy within a few hours from members of the medical staff.[25] Within a few days, he received similar calls from his patients, and shortly thereafter his surgical privileges at the medical center were suspended and his practice ruined. Despite his expectation of and request for confidentiality, the medical center took no serious precautions to protect his medical records. If physicians as patients cannot protect themselves in the system, it is unlikely that the system will adequately protect other patients.

Threats to confidentiality also emerge in many institutions with a capacity to store and disseminate confidential medical information, such as medical records on file, drugs prescribed, medical tests administered, and reimbursement records. In occupational medicine, for example, computerized records in corporations are growing rapidly, and data in these records can be searched quickly and thoroughly (Siegler, 1986). If the company routinely offers medical examinations by a corporate physician, records can be computerized and merged with all claims filed by an employee's private physician for reimbursement under corporate insurance policies. Many employees (especially in industries with hazardous work environments) are concerned that this extensive, two-track medical history will be used against them if a question of continued employment arises. Companies can reduce this risk by severely limiting access to computerized information, but generally at least one physician and at least one employee in data-processing will have access to the full set of records, and access may also be granted to company epidemiologists, union officials, and the like. "It may be possible to alter current practices in the delivery of care to approximate more closely the traditional ideal of confidentiality, but a gulf will always remain because of the need for access to information in medicine."

At least at the present time, section 49 under the PNG Constitution may provide limited protection. We think that the public interest in privacy and confidentiality of genetic information outweighs to a substantial degree the public interest in full adherence to the national principle because taking of medical history, including in counseling and therapeutic settings, is central to good health care. Public health would be jeopardized by strict compliance with the national principle accompanied by the professional code of conduct which would be an unrealistic curtailment on the core and essential practices of health providers.[26] In some states, the parameters of the privilege and the manner in which it can be waived are governed by statute. In other states, the privilege was developed through common law. Most courts that have considered the question have held that a physician who

[24] "Confidentiality in medicine" is a "decrepit concept", because what both physicians and patients have traditionally understood as medical confidentiality no longer exists. Rather, it is compromised systematically in the course of routine medical care.
[25] Behringer v Medical Center at Princeton 592 A.2d 125 (N.J. Super.Ct. 1991).
[26] We say that a breach of confidentiality is also known as breach of physician-patient privilege.

violates the physician-patient privilege is liable for damages.[27]

Establishment of an appropriate legislation. In the past in PNG, the recognition of genetic information of individuals had generally not been a concern. However, controversy has arisen regarding the ownership of the resultant genetic information; in the context of privacy and confidentiality of information leading to advice and treatment, and of those incapable of consenting by reason of disability. Many educated young people have criticized the lack of a legal framework to protect the privacy and confidentiality of genetic information of individuals and families. Whilst there has been a general "national principle" of Constitution section 49, there is no enactment directly or indirectly to regulate from the purview of obscenity and or through the scrutiny of the courts in PNG. The subject continues to be a concern among educated persons, professionals, academics, students, and the public. Elsewhere, the major problem has concerned the privacy and confidentiality of the individual genetic information, especially since a crucial factor is the manner in which the information is used or may be used.[28]

Genetic testing has been an ongoing activity forming part of the purpose provided for the National Health Administration Act, and the service has been available throughout the major hospitals in PNG. Even as of now, testing is available at few of the major private medical clinics in the country. At present, National Department of Health (NDOH) is charged to manage all medical information collected through or by health service, meeting the requirements set in the Health Administration Act. NDOH by law assumes the responsibility of all medical information derived through the health services; and by virtue of the Medical Act the PNG Medical Board checks registration of health workers and monitors the conduct of each professional health worker. The health service facilities, public or private, or a laboratory must adhere to the policies as stipulated under the National Health Plans.[29] A health facility that does not comply with the policies, fails in respect of the prescribed policies and or rules and procedures, risks loss of licensure, accreditation, and eligibility to participate in programs operated for the provision of health services in PNG. By the same token, a health facility, through negligence of its employees, it increases liability if it condones improper acts. Information derived through the provision of health services assists health professionals provide effective health services to their patients.[30] Such information may assist in diagnosis, provision of medical advice about genetic risk, to the patient or to present or to 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. The provision of genetic testing by private medical clinics has grown rapidly over the last 10 years, reflecting both increased need for such service and reduced availability of the service in PNG. Unfortunately, detailed information about genetic testing and resultant information cannot be obtained from NDOH.

There is no distinction between genetic information on the one hand and other health information on the other. However, notwithstanding some continuity between the values put on the genetic information than on other health information, genetic information has provoked much greater controversy. In the last decades, the debate on importance of genetic information has become increasingly polarized around the world including the U.S., Australia, and UK (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999). The debate has nevertheless continued to be construed as a debate between two polarized camps, for and against. However,

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[27] See e.g., Anker v Brodnitz, 413 N.Y.S.2d 582 (Sup. Ct. 1979).
[28] Pangallo v Murphy, 243 S.W.2d 496 (Ky.Ct.App. 1951).
[29] Health Plans (2011-2020), GovPNG.
[30] National Health Administration Act (NHAA), GovPNG (1977).

although these competing moral, political, and legal positions seem logically irreconcilable, they encompass many different shades of opinions which lead us to the conclusion that genetic information is best viewed as a spectrum encompassing a range of opinions. The authors' view is that it is likely that most people who reflect on the genetic information issue are not necessarily or inevitably committed to the extreme positions.

In practice, our view is that section 49 right to privacy would opt for the pragmatic course of permitting medical information in a limited range of circumstances. It is envisaged that an enactment of legislation indeed would address the rights of individual privacy. In part this is a result of the qualified rights which dictated section 49. In addition, section 49 is also concerned about the certainty of the common law regarding the circumstances in which privacy and confidentiality of medical information premise. Further, whether genetic information would be given a special attention was a contentious issue in many developed countries, based on pragmatic arguments, and thus it was argued that unless law tolerates protection of genetic information, we would face further discrimination in workplaces, communities, insurance, and employment. One consequence of the pragmatic stance is that if the law is to be established, legal status of genetic information may be inconsistent. What is clear is that PNG laws have not recognized genetic information or medical information of individuals to whom rights may be attributed (Minei & Kaipu, 2022). Any rights which the individual has are contingent on is being consented to. However, it has been argued that attempts to vindicate individual rights in law rest on waiving that right through consent by the individual (Minei & Kaipu, 2020).

As a general rule, hospitals should not release medical records or other patient information to law enforcement personnel without the patient's authorization.[31] In the absence of statutory authority or legal process, a police agency has no authority to examine a medical record. If, however, a law enforcement official provides the facility with a valid court order or subpoena, the hospital, upon the advice of its attorney, should provide the information requested. On the advice of its counsel, the hospital may determine that it would be in the community's best interest to release specific medical record information to law enforcement personnel. To do so, the hospital may rely on the doctrine of qualified privilege.[32]

The common law doctrine permits a party (i.e., the hospital) with a duty or a legitimate interest in conveying the information to engage in communication to a second party (i.e., the law enforcement agency) with a corresponding interest in receiving the particular information. The data transferred must be made in good faith, given without malice, and based on reasonable grounds[33], as the court held in a certain case that the physician or the hospital had an affirmative duty to report a patient to law enforcement agencies because the patient's medical record or psychological condition represented a foreseeable risk to third persons. The physician or hospital in this situation should have disclosed information that the patient had threatened to kill the eventual victim since the physician and hospital are protected by the doctrine of qualified privilege.[34] Thus the doctrine protects the hospital only if the law enforcement officer who receives the medical record information acts under the authority of law. Before releasing such information, hospital personnel should determine that there is a basis for the request and that the officer making it is performing official duties. The information released should be only what is appropriate to the purpose for which the particular request is made; a hospital should not release a patient's record in whole unless there are reasonable grounds for doing so. For example, if the law enforcement officer is

[31] Tenn. Code of Laws Annotated. Title 68-311 (1993).
[32] Moses v McWilliams, 549 A.2d 950 (Pa. Super. Ct. 1988).
[33] Tarasoff v Regents of the University of Cla., 551 P.2d 334 (Cal. 1976).
[34] Hicks v U.S., 357F.Supp. 344 (D.D.C. 1973).

requesting the results of a blood alcohol test, the hospital should not release information concerning the patient's unrelated prior hospitalization for a fractured leg.

In addition to the doctrine of qualified privilege and cases involving court subpoenas, there are statutory exceptions to the general rule requiring hospitals to refrain from releasing patient information to law enforcement agencies in the absence of patient consent. State law varies widely as to the release to the government agencies of medical record information without patient authorization. In South Carolina, U.S., for example, the medical records confidentiality statute allows disclosure of medical record information without a patient's consent only in certain instances, including when disclosure is necessary in cooperating with law enforcement, health, welfare, and other agencies, or when furthering the welfare of the patient or family.[35] Thus some patient records, such as those involving victims of crime or carriers of contagious disease not specifically designated by statute, may be revealed to government officials without the patient's consent in the course of routine police investigation or public health inquiries. However, such disclosure should be made only pursuant to the state's statutory confidentiality restrictions.[36,37] In such situations, the hospital should demonstrate respect for the patient's privacy rights by seeking disclosure consent from the patient, preferably during the hospital admissions process. State law also varies as to a hospital's duty to report certain kinds of information, such as cases involving gunshot or knife wounds. With respect to child abuse and disorders affecting a motorist's ability to drive safely in States having these types of reporting statutes, a patient's consent is not required in order to release the record. In fact, under some statutes hospitals may be guilty of criminal misdemeanor if they fail to report certain cases.

To date, in the absence of any legislation in PNG, there has been some evidence of genetic tourism, with PNG citizens travelling overseas, especially to Australia, Singapore, Philippines, and Thailand, to receive medical attention including genetic testing. The issue on privacy and confidentiality of information is important in PNG and may be settled by a law or some other mode of determination by the national parliament. We believe that the effect of an enabling law is to ensure that organizations can continue to collect family medical history information without breaching the national principle of privacy where the collection of health information from an individual about another individual, a third party, is necessary for the organization to provide a health service directly to the individual and to diagnose, treat, or care for the individual; and the third party is a member of the individual's family or household, or the third party's information is otherwise relevant to the individual's family medical history or social medical history. Issues concerning the collection of health information about genetic relatives will also arise under section 49 of the Constitution which contains privacy principle similar to those in Australia's legislation. To explain this point further, we give an example in Victoria's legislation. The Victorian legislation, the Health Records Act 2000 (Australian Law Reform Commission, 2001; Commonwealth of Australia, 1999), contains provisions requiring an individual's consent to the collection of health information about that individual, organizations to collect health information about an individual only from that individual (if it is reasonable and practicable to do so) and requiring individuals to be informed about the circumstances of collection where health information about them is collected from someone else.

In case of a "serious genetic disease", clinicians do have a legal obligation to "communicate to the patient or their legal representative the consequences that his or her silence may have on the health of family members"

[35] South Carolina Code of Laws Annotated. Title 44: Health, Chapter 22, section 44-22-00 (1991).
[36] Constitution section 49, GovPNG (1975).
[37] See South Carolina Code of Laws Annotated, supra notes.

(Black & McClellan, 2011, pp. 605-613), but this obligation to inform the patient does not violate her right to choose whether or not to actually disclose.

Collection of family medical history information without the consent of family members by health care workers may breach some or all of these provisions of the Victorian legislation. We express that PNG needed a formal regulation of dealing with genetic information to replace reliance on professional or personal ethical standards.

Establishment of health, insurance, or health insurance code. In PNG, there are no specialized insurance companies although those in practice operate on a general base, dealing in life, health, property, and general insurance. It is uncertain whether the insurance companies in PNG also use genetic information but it is being noted that large scale mining and petroleum companies in PNG have developed policies making medical examination of an individual an employment requirement. Any potential employee must undergo a full and thorough medical checkup including blood tests, x-rays, family history, and personal information about tuberculosis and leprosy status. The personal information is used by the companies for the purpose of employment, and whether the individual's personal information is shared with a third person is unknown.

Insurance policies require personal health information which insurers use for assessment of the applicant's risk of mortality or morbidity. Insurers eventually use this information in underwriting insurance policies. This process enables the insurer to decide whether it will accept the applicant's risk, and if so, on what terms? And problems can arise from that use of the personal information, including possible unlawful discrimination, however there are no reported cases in PNG about instances of discrimination. Further, it is unknown in PNG whether the insurance companies share individual personal information but if they did, this practice raises concerns about the protection of the privacy of genetic information.

Insurance practices generally base the price and availability of coverage on the health status of the insured individual or group although insurance companies generally prohibit group health plans, basing eligibility on an individual's health status including genetic information, and do not treat genetic conditions differently from other medical conditions. And U.S. has Disabilities Act (1990) which also prohibits discrimination in insurance. At present time, there are many projects which look at the issue of genetics and insurance. There are individuals or groups in the U.S. who are calling the structure of the health insurance system be changed rather than providing for special treatment for genetically related conditions (Roach & The Aspen Health Law Center, 1994). Although fears of un-insurability have driven much of the concern over genetic discrimination, there is some evidence that insurers do not yet, and perhaps will not, use genetic information in health insurance decisions (Hall, 1999). But insurers' statements do show that they would refuse to issue long-term care and disability coverage in the state because of the new statute (Hall, 1999). Thus, the consensus of some work already undertaken on whether there be established a Health or Insurance or Health Insurance Code is that nowadays insurance companies will not use genetic information in underwriting insurance policies decisions. Indeed, in U.S. state governments have passed laws barring health insurers from using genetic information (Roach & The Aspen Health Law Center, 1994).

Limitations of the Study

The study has several limitations. First, it is based on a small number of interviewees. Secondly, the majority of participants in the study suffer from genetic disabilities, and, although patients with other long-term illnesses were also included, further evidence is required to examine whether the type of illness influences the attitude to

family involvement in their health care. Thirdly, for ethical reasons, the clinicians treating the patients who were interviewed were not asked to provide their own account of the discussions they had had with the patients and their relatives. The clinicians provided only their general views about family involvement in clinical care and decision making. Further research should include the clinicians' perspective on the particular patient's case. Fourthly, only small groups of participants (n = 7/70) were from Lae, Mt Hagen, and Lorengau who participated through questionnaire. The majority of the participants were males (65%), precluding an assessment of whether gender had an influence on the involvement of their close relatives at the interview process and decision-making. Further research did not examine the impact of this factor. Finally, the impact of ethnic and cultural background was not examined, as all the participants were from PNG. As the literature shows, cultural factors affect the attitude to family involvement in a medical and genetic procedure, and decision-making process.

Conclusion

Of the findings, responses were quite good in most areas of general knowledge in genetic, genetic testing, genetic information, protection of human genetic information and ethical consideration, human genetic research, data base and health service, however, not many participants completed the Insurance and Employment questionnaire forms. Based on the responses following examination of all the completed questionnaire forms, it seemed that the population surveyed understood most of the questions and responded satisfactorily, in many instances, providing some good responses and competently explaining the situation in PNG as it relates to this study. The findings show there is ample knowledge in terms of genetics, ethics, and law amongst the population. The majority of the sample believed that, whilst PNG has a national privacy principle as provided for under section 49 of the Constitution, they still think an enactment of a legislation is necessary to further protect the rights of individuals particularly in terms of personal health information and the disclosure of their information which may lead to serious misuse and subsequent discrimination of the individual. Many individuals expressed a need to develop a legal framework as developments in human genetics are occurring rapidly in developed countries, and developing countries including PNG are now confronted with the dilemma of sustaining the developments in genetic science and technology. Genetic information (or genetic test results) can be used to prevent the onset of diseases, or to assure early detection and treatment, or to make reproductive decisions. This information can also be used for nonmedical purposes, such as insurance and employment purposes. Insurers might wish to use a genetic test result for underwriting, just as other medical or family history data (Godard et al., 2003). Employers too might wish to ensure that an individual does not have a genetic risk which might affect his ability to work or which might lead to problems of safety to the individual or to others. The fear of genetic discrimination remains intense, perhaps because there are very few data to support or refute that discrimination is actually taking place (Godard et al., 2003). How do they reassure people and protect them? Can a law provide a solution to the problems of insurance, employment, and genetics? There are diverging approaches among the various states which have sought to establish binding norms. The legislative activities in several countries show a growing consensus on the need to define the use of genetic information for insurance purposes. As to genetic testing by employers, it should stay limited to screening individuals at risk for developing diseases that may result from certain exposures that exist in the workplace.

In this study, the participants were conscious of the need of law reform to be sensitive to the dynamic environment in which developments are taking place in the field of genetics in developed countries. The participants said PNG would fall behind and not be able to adequately protect the privacy of the individuals

against inappropriate discriminatory use of the individual's genetic information in a number of contexts including insurance and employment. The participants are informed that there are instances of discrimination by insurers and in the workplace but the cases are unreported.

The fear of genetic discrimination by insurers and employers has spread throughout society (Reilly, 1998; Rothstein & Knoppers, 1996; Mossialos & Dixon, 2001). It is likely that many people who might benefit from such testing will be reluctant to be tested unless laws are in place to protect them (Wauters & Van Hoyweghen, 2016). However, a law is not enough to provide a comprehensive solution to genetic discrimination in insurance. One cannot be certain in the present economic context, that pressure might not be put upon applicants for genetic information and testing in relation to insurance and employment contracts in order to obtain genetic information about them (Prince, 2019). Nor can one exclude the possibility that the candidates themselves might wish to produce the information spontaneously if it were in their favor. Countries have adopted various regulatory mechanisms to address insurer use of genetic information in private, individually underwritten insurances, like life, critical illness, long-term care, and income protection (Joly, Feze, Song, & Knoppers, 2017; Lemmens, 2003; Knoppers, Godard, & Joly, 2004). These regulatory solutions range from legislative bans on use, to moratoria, to restrictions on when insurers can use the information, to industry self-guidance (Joly, Braker, & Huynh, 2010). Education is needed. Insurance decisions are sometimes made by inexperienced people, or because of a lack of knowledge about particular genetic conditions. Educational programs on the basic principles of genetics and insurance will have to be developed to improve the insurance coverage. This is important, especially since the funding problems of most welfare programs lead many governments to shift a portion of the State's financial burden onto private insurers, particularly in relation to medical costs and the costs of long term care.

We say that over the years, the majority of the people in PNG have used the health care delivery system as a means of helping only the sick. Why, then, construct a policy that treats all the people as if they were sick? The National Health Plans[38], National Health Administration Act[39], and other health care laws should adopt this view and change the approach conveyed by healthcare professionals and in the professional guidelines accordingly. On the whole, the situation existing in PNG could simulate depressed regions in developing countries where no privacy laws or regulations exist. The susceptibility to violation of individual privacy, inappropriate discriminatory use of genetic information, and instances of discrimination, are of interest in this study. However, it is clear in this study that the purpose of thinking ahead in this fashion is not to provide an accurate picture of the situation in PNG but to improve decision-making in the present. We state the following based on this study[40]:

> We acknowledge the contribution of empirical ethics in this area is extremely valuable, the limitations of studies are recognized,
>
> We articulate that continuous research is required to clarify and update our understanding of the influence of various factors on the perception of genetic responsibility and the right to know, as well as on effective strategies to facilitate disclosure, and
>
> We say that continuous research is also required to integrate these insights into a conceptual normative analysis that can engage relevant ethical frameworks such as ethics of care or narrative ethics to inform the development of appropriate approaches to disclosure.

[38] Health Plans (2011-2020), GovPNG.
[39] National Health Administration Act (NHAA), GovPNG (1977).
[40] Truth Telling (honesty, integrity). The principle that one's ought to disclose all pertinent information about a person to that person.

The situation in PNG is such that it is faced with a dilemma of sustaining the rapid developments in genetic science and technology. This research is conscious of the need of law reform to be sensitive to the dynamic environment in which this development is taking place in the developed countries including Australia and New Zealand. The study further forecasts that based on the existing situation in PNG, the law will fall behind and not be able to adequately protect the privacy of the individuals. This study is not testing for relationship of the study factors so the usual statistical procedures are employed as in a scientific research. Based on this remark, the study says that there is no compelling reason(s) to check for the strength of an association of the study factors. In conclusion, as long as the underlying assumptions above are valid, data such as this will improve the present understanding of the prevailing situation in PNG in relation to laws or regulations that control dissemination and the use of genetic information. This work also improves on the knowledge of the relationship of genetic, ethics, and the law and assesses the circumstances in PNG in a more realistic context.

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