

# Challenges of Obtaining Informed Consent in Poorly Coordinated and Funded Healthcare Services: Papua New Guinea Situation

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**Abstract:** During a semi-structured interview we ask the participants several questions based on the perceived role of the interviewee within the informed consent process. We asked questions pertaining to how informed consent unravels itself across barriers. Few question topics included how the issue of socio-economic, geography and custom of the people are addressed, and how the medical professionals deal with different groups of people and how the interviewees understood informed consent. Interviews for each group were asked with different sets of questions and were open enough to allow for probing questions in order to gain additional information when the opportunity presented itself. The data were analyzed using interpretative approaches and the various themes and concepts from each question and response qualitatively counted and uncovered patterns in the various group perspectives. We examined the participants' perspectives and opinions using a visual table for comparing themes and concepts, and we presented the interviewees' views.

**Key words:** Healthcare laws, healthcare system, human rights, Papua New Guinea (PNG).

## 1. Introduction

This paper will discuss the sites where the research was undertaken by the authors. The discussion will encompass an examination of the situation in Papua New Guinea (PNG) in terms of its social, demographic, economic, health and the legal aspects as relevant to PNG. We met with several key staff members of the National Department of Health (NDoH), practicing senior specialist medical doctors and nurse practitioners in Port Moresby and conducted anecdotal interviews with patients and academics during the planning stages of the study which showed up the different perspectives of the medical situation in PNG.

In PNG the majority of the people live on their own land in rural areas and only when they are sick they visit the hospital or a healthcare centre. Because they live in rural areas or are far distant from the nearest

health care institution or cannot afford to pay for the medical service, most patients would either turn to the traditional healers or simply remain home and use herbs to treat their illnesses. A minority of the people receive their healthcare from private medical centres however this minority is growing in size as more people become better off. Many healthcare facilities are owned by churches, the majority by the Catholic Church in rural areas and a few have a medical professional (a doctor). In the public healthcare sector, doctors serve as far as the district hospitals and occasionally they visit sub-district health centres. Private healthcare services are mainly found in urban areas but only in major towns. Many people visit the modern public healthcare facilities, many still consult traditional healers, and many patients are not bothered at all. The reasons for abstaining from going to a healthcare facility to receive assistance are only known to the patients and their families. However, with people increasingly visiting the modern care facilities in

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public or private medical centres, and with such frequency, the issue of informed consent will come up as patients have to consent to any number of procedures. With numerous issues generated by social and economic situations of PNG, the possibilities of patients being misinformed can be far more prevalent, not clear. Cultural traditions are a driving force in the lives of many people, and the issue of informed consent is no exception. Traditions and practices of different cultural groups can involve more than just their cultural upbringing. In addition one's religion can affect medical practice in much the same way as cultural considerations. There are times when certain cultural and religious practices are in opposition to the western ideals such as informed consent. In many cases they complicate the medical situations.

For example, those who come from Islamic cultures tend to dislike being examined by members of the opposite sex [1]. There are plenty of times when the ideal of a certain faith contradicts the ideals of the medical community. For instance transfusing blood is against the belief of Jehovah's Witnesses, and therefore most will speak against blood transfusions

Some ideas may not translate well across language barriers, or perhaps other ideas simply seem more offensive within certain cultural boundaries. For example, a nurse practitioner in a walk-in-clinic said that if they had a patient who does not speak English well, they must find a member of their staff who can speak the language the patient understood and so they will use their bilingual staff. Patients and the healthcare providers treating them are often concerned not only with various cultural or religious or language barriers during the informed consent process but are also concerned with economic barriers and other difficulties. Economic barriers are present throughout different cultures. The majorities of such people are from the rural areas or unemployed or have cultural difficulties or language barriers. Because of these, patients of different cultures experience economic difficulties and barriers, and make medical considerations based on these barriers.

There are many people with many different cultures, all of which require medical advice at a point in their lives. In addition there were only a few major hospitals, private medical centres, urban clinics, health centres and sub-health centres, rural community health posts and walk-in-clinics in the provinces that were selected to participate in this study. Further, there are many traditional healers who operate out of their own homes and, or operate outside of the medical settings to help patients who refuse to receive healthcare from the modern care facilities. These responses together, allowed us to draw information from as many of these sources as time allowed for.

We met the research goal by utilizing mixed quantitative and qualitative research approaches such as interviews directed at professionals in the medical and nursing fields and harnessing their experiences and those of the traditional healers. In order to obtain the patients' sufficiently informed consent and understand the process, we examined the situations of the patients when seeking medical advice and determined the information presented at the interviews from the participants. Anecdotal information was collected from other healthcare personnel but no consent form to participate was given to them though the information gave a balanced view of the situation of the health services in PNG.

In this study we focus on the PNG's healthcare situation in terms of its socio-demographics, geography, economy and the impacts these have on the healthcare delivery system in the country and thus how these could influence the doctor-patient relationship in terms of informed consent to a medical or surgical procedure.

### *1.1 Demography and Government Operations*

PNG became an independent state after gaining its full independence from Australia on the 16 September 1975. It is located 160 km north of Australia in the South Pacific and shares a land border with Indonesia to the west, and an ocean border with the Solomon

Islands to the east and Australia to the south. It is a geographically diverse country, comprising over 600 islands and 5,152 km of coastline, and has a total land area of 462,840 square kilometers [2]. Only 27% of the total landmass is inhabited. In 2011 the national census had an estimated population [3] of 7,275,324 which may now have reached 8 million. The majorities (80%) of the people live in rural areas, and most rely on subsistence agriculture as their primary means of living.

PNG consists of 22 provinces, which includes the Autonomous Region of Bougainville and the National Capital District. There are 89 districts, and 318 local-level governments. The primary responsibility for service delivery in PNG is entrusted to the sub-national government (provincial- and local-level governments) as prescribed in the Organic Law on Provincial Government and Local Level Government [4]. The quality of decentralized service delivery has, however, remained below ideal standards and levels of performance for a variety of reasons including sector-specific policy and operational challenges such as human resource distribution, health financing levels and flow, and logistic systems challenges and inter-sectoral issues related to weaknesses in public administration and governance, such as tight and volatile fiscal environment, public financial management, policy coordination and coherence, and human resources management [5].

### *1.2 Economy in Context*

PNG is a lower-middle-income country [6], it has a dual economy: a “modern”, formal, cash-based economy that includes natural resources and extractive industries, manufacturing, cash crops, construction and service sectors; and a “traditional”, informal economy based on subsistence activities and unregulated commerce. The country’s economy is heavily reliant on the natural resources sector, with mining and petroleum projects accounting for about a third of gross domestic product in 2015 [7]. Translating resource

income into better social and economic development outcomes has been an ongoing challenge for PNG since independence in 1975. This critically depends on government development programmes, and the effectiveness of public expenditure and its responsiveness to shocks. There is no evidence of any decline in poverty over this period, and some evidence that poverty in Port Moresby increased and became more severe [8]. The World Bank estimated that 38.0% of the population lived in extreme poverty (at \$1.90/day) in 2009, the highest in the Pacific region [6].

### *1.3 People, Ethnicity and Language*

PNG consists of many tribes that live scattered all over the country. It is one of the most linguistically and culturally diverse nations in the world. There are over 800 languages spoken in the country, which represents 12% of the world’s living languages. Each language group has a distinct culture, and there are large socio-cultural differences within and between provinces [9]. PNG has mixed Melanesian ethnicity, with small communities of Polynesians and Micronesians on outlying atolls. The non-indigenous population is small, several thousand Australians and small but very visible Chinese and Indo-Asian populations especially in the capital Port Moresby. English is the most common and official language used in communication and dissemination of information. Adult literacy rates remain low at 63.4%. However, this has increased over the past 35 years from 32% [2].

### *1.4 Education and Religion*

The Government introduced the tuition fee-free policy in 2012, which effectively eliminates tuition fees from elementary school to Grade 10 as part of the Basic Universal Education Plan 2010-2019. The policy, combined with the reintroduction of a national scholarship programme, aims to address poor school attendance. The proportion of Nursing, Medicine, and Dentistry and Health Sciences graduates of the total

higher education graduates across 2010-2013 was 8% [10].

Christianity is enshrined in PNG's Constitution, which declares that PNG is a Christian country. Christianity, an entrenched cultural legacy of missionaries in the 19th century, is practised by 96% of all Papua New Guineans [2], with 73.6% following a Protestant denomination (Evangelical Lutheran 18.4%, United Church 10.3%, Seventh-Day Adventist 12.9%, Pentecostal 10.4%, Evangelical Alliance 5.9%, Anglican 3.2%, Baptist 2.8%, other Protestant 9.7%). The remaining 26% are Roman Catholics [2]. The churches play an integral and important role in the delivery of education and healthcare services across the country.

### *1.5 Family Structure*

In PNG, the family and extended family play a central role in everyday life, underpinning the basic social support system. This support system is known as the wantok system and can be loosely defined as the system of relationships or obligations between individuals of some or all of the following: common language, common kinship group, common geographical area of origin, or common social associations or religious groups. It is a prominent feature of social organization, particularly in urban areas, and plays an important role in caring for the sick, disabled and older family members. The family structure is typically patriarchal, although there are some matriarchal societies—mainly in the New Guinea Islands Region and Milne Bay Province. Overall 88.3% of households are headed by men, and 11.7% by women [2].

Land is the most important family asset and is passed down either patrilineally or matrilineally, depending upon the culture of the relevant language group. The highest level of respect is conferred upon the oldest members of the family and society, and the male patriarch makes the decisions on behalf of the family members in some areas. Polygamy is practised in PNG and is the most prevalent in the Highlands region

where 29% of women are in polygynous unions, followed by the Momase region with 12%, islands region with 11% and southern region with 10% [2].

### *1.6 Gender*

In most parts of PNG where customary traditions and beliefs are widespread, women have a lower status than men, with the exception of some matriarchal societies. Work is typically divided across traditional gender roles. Women are responsible for child care, cooking as well as gardening, while the men hunt, build and prepare ground for gardening. In male-dominated communities in PNG, women are struggling to make their mark. Generally in PNG men are the key decision-makers in the society, across the public, political and private spheres, as reflected in the lack of representation of women in Parliament, where no woman was elected to the Parliament in the last few national elections.

PNG also endorsed or ratified the major international and multilateral conventions, and agreements on gender equality, including the Convention on the Elimination of all Forms of Discrimination against Women however they have not been effectively implemented [2]. There has been some progress in improving legislation and policy around gender issues, such as the Lukautim Pikinini Act [11] and the National Health Sector Gender Policy [12]; however, inadequate capacity to uphold law and order makes the laws largely ineffectual. Apart from the various traditional forms of gender relations that contribute to the high gender disparity, unequal access to education, healthcare and business opportunities, as well as inadequate institutional responses to preventive measures and a wide social acceptance of violence against women, also exacerbate the issue.

### *1.7 Land and Governance*

Most of the people (about 80% of the population) live in rural areas, and most rely on agriculture as their primary means of subsistence. Income is also

unequally distributed, with 38.0% of the population living in extreme poverty (2009) and a third (31.0%) of the income held by 10% of the population [13].

In PNG, 97% of all land is held under customary tenure, which reflects the strong culture and social systems. Land tenure is not absolute, and land rights are held in common with other members of the clan, family or group. There is no land title system because there is no traditional hierarchical system of ownership. Many publicly run health facilities are on customary land, and therefore it is not unusual for health facilities to close due to land ownership disputes [12].

### *1.8 Conclusion*

While various reports from 2010 up to the present time show falls in the government's efforts to keep the economy moving, it should be borne in mind that it would take more than a decade until proper economy recovery plans to restore the economy, and ultimately the engagement of review committees to monitor the implementation are put in place. One might wish to believe that what has happened is a thing of the past and those past leaders still hide its collective head in shame for their ethical stumbles, unfortunately this is not the case. While stricter enforcement of rules and introduction of new plans (or lessons to learn) may have dramatic effect on the past unethical conduct of the country's economy plan, this cannot be said of other neighbouring countries in the region where PNG provided financial aid: the Solomon Islands, Vanuatu and Fiji and a few other Pacific Island countries. While these issues are beyond the scope of this thesis, it is important to understand that they do continue and have serious implications on the health sector in PNG.

In the next segment, we discuss specifically the health status of PNG.

## **2. Health Status**

Like other nations in the Western Pacific Region who are at a similar stage of development (such as the Solomon Islands, Vanuatu and Lao People's

Democratic Republic), PNG is in the early phases of epidemiological transition, facing a double disease burden with a rapid growth in Non-communicable Diseases (NCDs) and a continuing high prevalence of communicable diseases. Nevertheless mortality rates for both women and men have been dropping over the past 25 years [12].

Since 1990 the overall life expectancy has increased by 5 years. The PNG females have a longer life expectancy than men and this is in line with the global trends, but living on average 5 years more. Despite this progress, overall life expectancy for Papua New Guineans is shorter than the majority of their Pacific neighbours [12].

Infant and under-5 mortality has been steadily decreasing since 1990; however, estimates in 2011 indicated that the country made insufficient progress to meet its Medium Development Goals targets. The infant mortality rate in 2011 was 45 per 1,000 (the 2015 target was 24 per 1,000) and in 2014 under-5 mortality was 46.2 per 1,000 (the 2015 target was 32 per 1,000) [12]. As for malnutrition, the prevalence of stunting is high, 48.2% in 2010, and is much higher in rural areas (50%) compared to urban areas (35%). Wasting on the other hand is frequent especially among the young children (0-60 months) in areas where the prevalence of infectious diseases (e.g., malaria) is high [14].

Improvement in health has not kept pace with the country's economic growth over the past 10 years, and in part reflects the difficulty in access to primary healthcare (PHC) services. There has been a gradual decline in the percentage of functioning health facilities in some parts of the country over the past 20 years [12]. In 2014, only around 70% of aid posts were operational nationally [15]. Some of the bottlenecks reflect the lack of constant availability of basic commodities, including essential drugs, as well as a lack of health staff in adequate numbers and with the proper qualifications. The unsuitability of the health infrastructure contributes to the erosion of public confidence in the health system [15].

No honest discussion of PNG health care can deny that the health care system is in crisis. The various research workers conveyed some leading reasons for concern: public programs are permanently destabilized. The urban poor, living where no doctor ever goes, crowd hospital emergency rooms and outpatient clinics. Hospitals respond with costly, often long-delayed care. Medical-aide and other payers are hit with a new round of hospital increases. The increased doom legislative plans to fund more primary care for poor neighbours, in part to ease hospital crowding. Unfortunately, the problems plaguing the PNG Health care system appear to be worsening. There is widespread pharmaceutical and drug shortages throughout PNG coupled with misuse of funds by the Department of Health, the health cost will continue to rise, the PNG government will have to find more funds and will devote a staggering amount of money to meet the health care cost for some more years. Only a few people and a certain group of workers have health care coverage but the majority depended on the public care funding through public institutions. So far the present trends do not seem to look improving and eventually many privately sponsored citizens will lack coverage as well. Because many Papua New Guineans are disadvantaged by the present trends, it is not surprising that, as reflected in the public outcry by doctors and nurses associations, women's groups, students and the general public have favoured health care reform.

Given the background of the situation about health services in PNG, I have a grasp of the major health issues affecting the health care services; I explore briefly some of their implications for health care.

From ancient times physicians have recognized that the health and well-being of patients depends on a collaborative effort by the government, health services and health care workers. Patients share with the health care professional the responsibility for their own health care.

I encourage a vision of medical ethics in which virtue of ethics and duty-based ethics are each essential

components. Citing several important codes of medical ethics including the Hippocratic Oath, I argue for the process of informed consent as a system of obligations incumbent upon the physicians. Hippocratic Oath imposes certain duties like the protection of confidentiality, avoiding dangerous procedures, not harming the patient. The Hippocratic physician also pledges: "...in purity and holiness I will guard my life and my art." [16]. This is an exhortation to be a good person and a virtuous physician, in order to serve patients in an ethically responsible way. We expect the virtuous person to do the right and the good even at the expense of personal sacrifice and legitimate self-interest. At the very least, this statement attests to the recognition of the patient cannot be fully protected by rights and duties alone [16]. Some degree of supererogation is built into the nature of the relationship of those who are ill and those who profess to help them.

Informed consent is a process of information exchange and autonomous decision-making. The patient needs to understand the key issues in a proposed or sought treatment, and then, before that treatment is given, the patient must have made an informed, voluntary, competent decision to go ahead with it. During the questionnaire interview I had short sessions with each patient participant, asked questions and provided answers at the same time. Fewer patients have been through the informed consent process. I explained ... patients often sign a consent form, but this signing is not, in itself, informed consent. It is merely one way of documenting a whole process. In addition I informed that the responsibility for information disclosure falls largely to the healthcare worker. In PNG nurse practitioners work with medical professionals and understand the process of obtaining informed consent. The care worker or doctor knows how to describe the process, and knows its risks and benefits (and their likelihood), as they are known to the professions. These should be communicated to the patient so that a decision can be made whether to go

ahead with the treatment or management plan. However not all responsibility for information disclosure falls to the health worker. Some information about the patient's values, preferences, or wishes needs to be voiced also, as this may make a difference to the type or range of treatment offered [17]. Ideally this information should be voiced by the patient.

Informed consent to medical treatment lies at the heart of concerns in ethics for patient autonomy. Informed consent is about patients giving permission for examinations or procedures with the optimal amount of information available to them. It is the quality of health care that is being given increasing attention in health care contexts and in the training of health practitioners. A planned study was conducted to understand how informed consent was obtained from patients in two provinces in PNG.

### *2.1 The People and Population of the Study Areas*

The two areas were selected to represent the urban and rural areas of PNG. National Capital District (NCD) comprises a mixed population of Papua New Guineans who live within the city of Port Moresby and utilizes the health care facilities more frequently. There are many people from different parts of the world including the general population of PNG moving into NCD from the other 22 provinces. Kwikila District in the Central Province (CP) represents the rural people who live mainly in villages within the medical settings and frequently utilize the health care facility. The provinces have a wide variety of different groups of people, mainly Melanesians and Polynesians and the geographical settings exemplify many of the socio-economic challenges of PNG and the tropical South Pacific and Indonesia. The total population is close to 800,000 people and the geography is similar to that of the West Papua Province of Indonesia and other South Pacific Islands. The provinces have similar socio-cultural institutions such as the extended family system and patrilineal and matrilineal inheritance [18]. Traditions of marriage, kinship and family building

underscore the security and economic values of the people.

In terms of economy, NCD is largely a service and manufacturing industry. CP has a small band of well-off businesses but is largely subsistence agriculture and fisheries. Most people in the urban areas are mainly paid workers in government and non-governmental organizations.

Literacy rate in PNG has improved although it is still very low in many rural areas, particularly among the old age and young children. Religious affiliations in both NCD and CP, while largely Christian, also include many different faith groups. Catholics claim the biggest group, then Seventh Day Adventist and protestant churches, and others. There are also several Buddhist, Baha'i and Muslim congregations in NCD, however, the majority of the people are Christians. This research was carried out in those provinces.

The focus in this study is how informed consent can be improved and best be implemented. The research suggests that the only criterion for consent to be acquired is through administering of relevant and optimal information to the patient. Further this research suggested that there is need for real consent or true consent and said that simple consent was not sufficient for medical procedures, instead, sufficient disclosure of possible risks and complications, allowing "informed consent", was necessary for patients to make autonomous decisions, whether regarding a medical or surgical or dental procedure, or a medical experiment.

In the next section of this paper, we discuss the laws and legal aspects regarding health services. We state the existing laws that provide the legal framework for health care services in PNG.

## **3. Statutory Duties of Health Services in PNG**

The NDoH has a general duty to oversee the establishment, maintenance, and development of the healthcare system in PNG. The following legislations were established to ensure this duty is performed with

protection of the interests of patients and healthcare professionals in mind.

### *3.1 National Health Administration Act (1977)*

The Act was developed to provide the legal framework for linking and consolidating the functions of all levels of government and other agencies involved in the delivery of healthcare [19]. It supported the introduction of national standards, defined administrative functions, and established relevant boards and management committees at the national, provincial and district levels. The Act also ensures that the provincial governments coordinate the operation of health facilities and the provision of health services and programmes in the provinces [12].

### *3.2 Public Hospitals Act (1994)*

This Act defines the role of provincial hospitals, funded by and reporting to the NDoH for the operation and provision of services by public hospitals, and the hospitals' role in supervising and supporting rural clinical services in Public Health care facilities within the provinces [20]. Provincial and local governments are responsible for all other services (health centres and sub-centres, rural hospitals and aid posts) with the NDoH centrally purchasing medical supplies that are distributed throughout the provinces for their onward distribution within the provinces. However, many problems were identified with this provincial two-system approach, including cost inefficiencies, limited human resource capacity and management issues [12].

### *3.3 Provincial Health Authority Act (2007)*

The Provincial Health Authorities Act (PHAA) enabled the creation of a statutory body, Provincial Health Authority at the provincial level that is responsible for both hospital and rural health services [20]. The unified provincial health service supports the health services ensuring a unified provincial health service and a set of standards for health service

delivery has clarified the functions of the various (seven) levels of the health-care system [21]. So far, starting in 2017, 10 provinces (out of 22) have enacted this system, and all provinces are expected to introduce the reform eventually.

Based on a Primary Health Care (PHC) approach, it consists of a network of 2,500 aid posts (1,800 functional), approximately 800 sub-/health centres, 21 provincial hospitals and one national referral hospital (which also operates as a provincial hospital). The government and church-based service providers predominantly provide health services [9]. The Department of Health is responsible for the national referral hospital and 21 provincial hospitals (three which also operate as regional referral hospitals). The provinces and LLGs are mandated by law to provide PHC services through the rural health service network of district hospitals, sub-/health centres, aid/community health posts and outreach services [9].

### *3.4 Overall Legal Framework*

The Minister for Health and HIV/AIDS has the portfolio responsibility for health as determined by the Prime Minister. The Minister executes government health policy and is assisted by the NDoH to discharge that responsibility [12]. The NDoH has an overarching governance role in the health-care system:

- (1) It has statutory responsibility to oversee the establishment, maintenance and development of a health-care system in PNG [22].
- (2) It also sets policy and standards for improvement of the health of the population [23].
- (3) It provides technical advice and support for the operation of health facilities and the delivery of health services and maintains a national health information system [22].

The NDoH also oversees the management of public hospitals in accordance with the Public Hospitals Act of 1994 and the roll-out of the recent legislative changes in the PHAA, 2007 (see next paragraph). The health sector responded to the passage of the new

Organic Law which re-defined decentralization in the PNG Government system by introducing legislation to enable this to be implemented in the health sector (so-called enabling legislation).

The NHAA of 1997 was intended to provide the legal framework for linking and consolidating the functions of all levels of government and other agencies involved in the delivery of healthcare. Instruments to support this included the introduction of national standards, definition of administrative functions, and establishment of relevant boards and management committees at national (National Health Board), provincial (Provincial Health Board) and district levels (district health committees). The responsibility of the provincial government was to coordinate the operation of health facilities and provide health services and programmes in the province, other than the operation of public hospitals [22].

The Organic Law also meant that health budgets were now in the control of the Provincial Administration, and not the remit of the health sector [24]. However, concerns were raised about the lack of attention by the provincial governments, including the lack of funding being made available for provincial health services. This has made it difficult for most of the provincial health offices to access and control the required level of resources to implement their annual plans. Maintenance of health facilities has been severely neglected, rendering many inoperable [26]. The results of this neglect were critical weaknesses in the medical supply chain within the province resulting in health facilities being out of stock of medicines for months and forced closure of facilities. There was also widespread anxiety that the decentralized functions and roles for provinces and lower levels of government were poorly understood, and that many of the District Health Management Committees were not functional [26]. The PHAA was also introduced in 2007 enabling the creation of a statutory body at provincial level responsible for both hospital and rural health services.

The NDoH is headed by the Secretary for Health and supported by executive management branches.

### *3.5 Provincial and Local-Level Governments*

The health functions of the Provincial Governments (PG) and Local Level Governments (LLGs) are primarily determined in accordance with the Organic Law on PG&LLGs and the NHAA.

The Organic Law details the law-making powers of provincial governments on a range of specified health matters, including sale and distribution of alcohol; community, urban and rural development; rural health; and town and urban planning [28].

The National Health Administration Act (NHAA) 1997 extends these powers to include aid posts, health centres and sub-centres, and rural hospitals; health-care and dental-care services other than those provided in a public hospital; preventive health services; and disease control [29]. It provides that “the responsibilities of a Provincial Government are to coordinate the operation of health facilities and the provision of health services and programmes in the province, other than the operation of public hospitals and the provision of services in public hospitals [29]. The NHAA also establishes provincial health boards that are chaired by the Provincial Administrator and their functions include advising the Provincial Governments on health policy, coordinating implementation of the NHP, advising the Joint Provincial Planning and Budget Priorities Committees, and monitoring the implementation of plans and standards [12].

The Provincial Governments Administration Act (PGAA), 1997 [30] further extends the health function responsibility for provincial governments, outlining principal administrative functions for provinces. The additional functions created under the PGAA are: establishing the basic minimum needs for the development of rural and urban areas; and maintaining minimum standards as required by law in relation to health facilities, the health programme and hygiene;

safe and accessible water; and safe environment and proper rubbish disposal [12, 21].

The Organic Law grants the following law-making powers of LLGs in relation to health: cemeteries; town, city, village and community planning; control on consumption and use of alcohol, betel nut and betel nut related products or any other marketable items; hygiene and sanitation; village communities; and local aid posts and clinics [12, 21].

Under the NHAA, LLGs have the responsibility to ensure that adequate funds are budgeted for to meet the expenses of health-care facilities, services and programmes that service the population of the LLG.

The present Government of PNG (GovPNG) is committed to promoting improved accountability of district-level politicians for health sector performance. Several measures are proposed to support this approach. Simplifying the presentation of the National Health Services into checklists and managerial tools that can be more easily used by district managers and political leaders is one approach. Accountability and transparency will also be promoted through development of local-level planning and budgeting tools that can be linked to the national health information system and to health workforce data.

### *3.6 Public Hospitals and Provincial Health Authorities*

Public hospitals are established as statutory authorities and are administered under the Public Hospitals Administration Act (PHAA) (1994). Public hospital boards and provincial health boards report directly to the Minister for Health and HIV/AIDS. Under the PHAA, 2007, provincial governments can enter into a partnership agreement with the Minister to establish a Provincial Health Authority (PHA), which is responsible for both hospital and rural health services in a province. Under the arrangements for the provincial health authorities, the Provincial Administrator delegate's responsibility is as the departmental head in relation to provincial health staff to the Chief Executive Officer of the PHA. All

provinces are expected to have introduced the reform after 2018.

### *3.7 Other Key Stakeholders*

At the national level stakeholders include the Departments of Finance, Treasury, Personnel Management, National Planning and Monitoring, Provincial Affairs and Local Government, Community Development, the National Economic and Fiscal Commission, the Churches Medical Council (CMC), the Central Agencies Coordinating Committee, the PNG Institute of Medical Research, University of Papua New Guinea (UPNG) and various tertiary education institutes.

At the provincial and district levels, stakeholders include the provincial assemblies, provincial/district administrators, joint provincial/district planning and budget priorities committees, provincial health boards, provincial hospitals, district health offices, aid posts, health centres, the church health service, community-based health-care providers and users of the health-care system.

### *3.8 The Churches and Health Service Delivery*

The role played by the churches in service delivery in PNG today can be directly attributed to their ongoing involvement since colonial times, filling the gaps in remote areas and taking up the role of the Government where services have failed because of governance reforms and capacity constraints [31, 32]. Church health services currently provide almost 50% of the rural health services, subsidized by the State [9]. The integral role of churches can be traced back to the Christian missionaries who first arrived in 1848 [33] and were further followed in the 19th and 20th centuries by the missionary nurses [34].

These communities have grown and spread across much of the country [31]. Further, churches are responsible for running six of PNG's nine nurse training facilities and 14 training facilities for community health workers [33]. Churches are also

active in the provision of HIV/AIDS-related services [34]. Because of this history, in some rural and remote areas, church-based health facilities have a stronger presence than government facilities.

The churches report technical and clinical data through the NHIS in line with the overall health system reporting requirements. However, each Church health service is responsible for the management of its own facilities, which it supervises, both clinically and administratively. For church health services, each facility receives funding from the National Government Church health service grants, through its respective Church Health Secretary. Each facility has a board or Management Committee, which provides day-to-day management [2].

The Churches Medical Council (CMC) is an umbrella organization established in 1972 to represent church health service providers. It represents 27 (of 82) registered church agencies from 14 different Christian denominations. The CMC has the role of negotiating funding and human resource issues with the Government. It also functions as a voice for a diverse group of Church-based organizations to exchange views on health reforms and to disseminate health information.

This mechanism has the potential to contribute to policy dialogue and coordination, given the strong role of churches in the health sector [32].

### *3.9 Private Providers*

There is a relatively small but growing for-profit private health sector in PNG. This consists of local private providers, some blurred public/private provision, and a significant contribution from large mining and plantation companies to direct provision [35, 36]. Private medical clinics are mainly staffed by general practitioners, a few clinical specialists and allied health practitioners, mainly urban-based, and their number is increasing. Standards of practice and levels of fees vary greatly due to a lack of regulation. These services are largely utilized by individuals who

have the means to pay and those who are covered by health insurance. There is little collaboration between the private sector and public hospitals and urban clinics [36].

## **4. Informed Consent: PNG's Perspectives**

The already underrated national budget and the widespread instability in the healthcare system it has produced are providing the impetus for national healthcare reform. In this segment, we have attempted to look at the issue of informed consent with a view to improving how to deal with it so as to improve the quality of clinical care. The goal is to identify the process of granting informed consent within the doctor-patient relationship and to analyse the effectiveness of models of delivery for at-risk communities with widespread differences based on the healthcare professional and the patients' wishes.

We describe the situation as we assess it based on the past studies on informed consent in PNG [35-39]. There are many patients from many different parts of PNG and all of whom have received or are receiving medical treatment at the healthcare facilities which participated in our assessments. There are different hospitals and healthcare facilities in the areas that were studied. We have considered as well the patients with varying socio-economic standing, from different cultural contexts and other issues that may affect the patients' decision to receive medical treatment. In this paper we study the current socio-economic, demographic and geographic situation in PNG we face in reforming the healthcare system. We focus on the option of improving the quality of clinical care through understanding the concept of informed consent and improve the existing informed consent process while maintaining the existing national health plans.

### *4.1 The Practical Situation*

Many years of rising costs have destabilized the PNG healthcare system. The educated Papua New

Guineans and the middle class will join the nation's poor in doubting its protection against medical bills. Employees would fear changing jobs and losing their insurance while employers edgily seek to shift coverage costs to workers' shoulders. In other countries workers strike to defend their health benefits more than any other cause. In fact defending against rising costs often adds more costs for example recruitment of new administrative staff. With poor economic performance of the country's status and this combined with the COVID-19 pandemic rising costs, any hope of survival of the poor people and the rural communities in PNG is being shredded away. As waves of new costs increase daily, patients seek ingenious ways to avoid paying huge medical bills. Business with small people is drying up as well.

Public programs are destabilized. As the urban poor people from rural communities where no doctor ever goes, crowd hospital emergency rooms and out-patient clinics, hospitals respond with costly, often long-delayed care. Even those who are working for salaries or have private care insurance are hit with new rounds of hospital fee increase.

In the rural areas where many patients refuse to go to the healthcare facilities to receive treatment instead see the traditional healers and pay some fees for the service. The patient describes his or her symptoms, and allows the healer to make assessment of the symptoms and proposes a treatment plan after deciding what treatment to offer, could be herbal leaves or juice. The healer combines this with massage if the patient has body aches, and provides counseling based on customs. One healer disclosed at a meeting in this study that he collects about \$1.50 cents from each patient during a visit. The situation arising in rural areas among the urban poor dooms legislative plans to fund more primary healthcare for poor neighbourhoods, in part to ease hospital overcrowding. This pressure will continue to grow if it goes unchecked, and will create even more pressures to ration healthcare for the poor and the elderly.

In truth, the majority of the patients use public healthcare facilities more often than private medical services. From the rural areas patients are brought to the healthcare facilities when they are too sick and require urgent medical help. Most sick persons demand that they are accompanied by a family member usually a parent, spouse or a family relative. This person acts as the representative and gives the patient confidence to remain calm, speaks on behalf of the patient and communicates with the healthcare professional. It is not customary for female patients to disclose information that is private and personal, personal even if only because it has her name on it. They do so with an understanding of why it is asked for, and what it will be used for. Personal and private information includes verbal information, information about one's body, and uncovering one's body to view. While the term "informed consent" is not known to a great majority of the people, one thing is for certain, they understood what it means to agree to the healthcare worker to do his or her best so that s/he gets well soon [35, 39].

In PNG, the healthcare worker would be allowed to perform his or her job. The patient expects the care worker to be truthful in doing his or her job. Generally among the women they care more about their personal details and personal things. Women would speak about their personal health and give personal details and things that they would not routinely disclose or see. It is only when that personal information potentially becomes available to a wider audience that the person becomes worried about privacy and confidentiality [37]. The patient is worried because they have lost control over how and what the information is used for. The healthcare provider is in that privileged position so that s/he can help. Some health information is private, but that does not mean that patients need to tell everybody everything, or that healthcare workers should expect to know everything about the patient. The care worker needs to know as much as is necessary to provide proper care, and no more [36]. However, for female patients, the mothers or guardians ensure

respect for the patient's integrity is demonstrated by allowing the patient to make a decision about what is too private (or unnecessary or unacceptable) to disclose. Generally, the majority of the patients feel uncomfortable to meet or even speak about their medical conditions to the healthcare professional or let alone be examined by a male healthcare worker.

In a modern healthcare facility, this is one difficult issue that affects both patient and healthcare professional and affects the formalities the healthcare worker would wish s/he could perform prior to giving medical treatment. The healthcare professional plays the role in delivering those benefits to others. To be successful s/he will need to communicate clearly to the patients what is reasonable for them to expect, and what responsibility can be shouldered by the care professional. The patient makes his or her decision regarding care following consultation with the family members or a representative.

For most patients it does not matter which facility or who they see, whether a healthcare worker or traditional healer, the patient merely expects to receive help when sick and to get well soon. The traditional healer who lacks knowledge in the field of medicine does not know how to deal with the patient's concerns. Lack of healthcare awareness by NDoH for patients to check their medical records and treatment has gone unchecked by patients. A healthcare professional said "... patients are not concerned about their health safety messages or show interest to take heed of the essential 'health watch' information. There are healthcare posters meant for patients and the general public however not many people see or read health posters on display. Many people play ignorant or behave illiterate." Of course, even in contemporary times not all situations such as this work out so smoothly to address a wrong behaviour and attitude of the people. One area that needs to be looked into by the healthcare workers is that NDoH should aim to train traditional healers or educated persons who live in the communities with the people, to become competent

healthcare educators to promote good health and correct wrong or bad behaviours. However this is not the focus in this paper.

Patients and healthcare professionals should work together so that the expectations of patients and carers are similar and they can understand each other's responsibilities. There are factors that may impede the effective operation of informed consent, thus considerations such as customs, costs of treatment, and poor understanding of the medical condition of the patient are issues that affect both the patient and healthcare worker.

Prestigious institutions like the World Medical Association spoke broadly that informed consent was important to clinical care and if properly conducted, experience of many developed countries, it could reduce the amount of time on litigation. The action if taken questions the doctors' credibility, and the expenses incurred on individuals and hospitals throughout the litigation including the legal costs. Informed consent is relevant to medical torts, distributive and propriety medical claims, and doctor-patient relationship. Majority of patients do not feel comfortable to speak to healthcare professionals and the communication between the parties often fails. Communication hindrance is attributed mainly to differences in education, status, culture and other features which distinguish healthcare workers from their patients. In PNG female patients often stick to their traditional customs and beliefs and practice them more often than men. Young women or single women allow their parents or married women allow their husbands to make their healthcare decisions. Nowadays there is increasing emphasis on the active obligation of patients to be part of the management plan, to take responsibility for attention to their treatment, and to take responsibility for their recovery and future health. These clearly lead to more educational awareness to empower women to make their own decisions although it is not the focus in this paper.

In the next segment we discuss informed consent from the clinical perspective and how it is being dealt with by the health care professionals and the patients.

#### *4.2 Clinical Examination Room*

The different healthcare professionals including the doctor, nurse and other health care workers should collaborate. They have different skills and these differently skilled workers should tackle healthcare together. For example in a real clinical environment, a doctor and nurse spend hours working on a patient but they need the support from the laboratory technician, x-ray technician, pharmacist, physiotherapist and clinical nutritionist. The basic aim of all health professions is to take care of patients, to be beneficent towards them and the community that is served. Yet sometimes there seems to be differences in attitude among health professionals. For example few workers may seem to be at loggerheads over health-system priorities or decisions over individual client or patient care.

A health system is, after all, made up of many professional people who have chosen to become healthcare workers. These care professionals must work together because they need each other's skills to provide proper healthcare to the patient. A common example of professionals working together is that of doctors and nurses. Nurses acknowledge both the difficulty and the importance of working with doctors who have different skills and objectives. Working in a team does not mean working under another profession, it means being aware of and working towards a goal, and on occasions being guided by others who possess greater knowledge and expertise.

Patients must talk to draw on the doctor's interest to help. In healthcare relationships patients make decisions all the time; about what secrets to tell, what to let the professional see, and how much to trust the healthcare professional to use that information constructively and to respect it as private and confidential [37-39]. A good doctor-patient

relationship involves establishing trust and ground rules, before tackling the difficult issues that have prompted the patient to seek help from the doctor. The initial stages of counselling relationship are as follows: meeting the patient, during which time both the doctor and the patient are on their "best behaviour"; discussion of surface issues, in which the patient feels able to discuss everyday issues; and then revelation of deeper issues, which occurs in the context of a developed relationship in which the patient feels confident and trusts the doctor. The doctrine of informed consent rose to dominance not so long ago. It replaced a medical ethos founded on trust in physicians' decisions, often on the assumption that "doctor knows best", with an ethos that sought to put patients in charge of their own healthcare.

Experienced clinical doctors have skills in setting their patient at ease through the initial stage, and gradually encourage self-revelation. Doctors must master this skill, as it is required for an ethical relationship with patients to develop. So much depends on understanding both the patient and the problem at hand. This meant that the doctor may have to spend a few meetings with the patient to achieve this. If that is not possible, the bed-side manner is all the more important. A similar appreciation of privacy is expected in relation to exposure of the physical body. A practitioner becomes used to draping patients so as to expose only as much of their bodies as necessary, and to letting patients dress and undress in as much privacy as possible. The patient usually discloses information and gives access to their personal thoughts and feelings, the doctor begins to know the patient, tries to understand what has happened to them and how serious it is [39]. The doctor takes notes and starts thinking about what to do to help the patient. A medical record of the patient starts or is added to one that has already been started. The initial record is a crucial piece in any treatment relationship. They should be accurate and complete, they can be initiated or added to by any healthcare worker; and they become the basis of noting

and assessing progress as the patient is engaged in treatment. This area is examined to understand the care service that is intended to be given to the patients, the diagnosis of the illness and the procedure to undergo are important steps to achieving proper patient care [39]. However when the patient feels unsatisfied s/he does not cooperate anymore with the care professional [35].

In PNG the situation as seen in many healthcare facilities is that many patients are withdrawing and/or refusing medical procedure or treatment for essential care for reasons that are only known to them. In most situations patients return to their homes, live with their families but without realising that they have not taken up or completed their treatment regime. They are still sick though living among the families and their community. The prevalence rate of infections is increasing and new cases of the same illness are reported [40]. Many would consult with traditional healers who live within the local setting, have familiarity with the area and the people, speak similar language and knew the local customs. Many times people hung on to their ways of lives and ignore the things that would bring benefits to improve their health conditions.

The Health Department generally recognises the importance of health records, and issues guidelines like the following: a health record is a documented account of a patient's illness and treatment during each visit or stay at the hospital, nursing home, community health centre or other healthcare facility. Medical records are not just the responsibility of the medical practitioners but of all other care providers in different clinical settings [29]. Yet the basic requirements apply to all: entries must be legible and non-erasable, identified as relating to a particular person, organised chronologically, and made available to authorised persons. The accuracy and completeness of the records must be relied upon by others, and is an essential supplement, but not replacement, for a full verbal handover-takeover between the staff [39].

This work examines an important aspect in medical practice. It explores the notion of consent and determines its underlying theory and important attributes. Consent is a permissive state of mind that waives the right to bodily integrity. Once it is communicated to the actor the permission takes effect by justifying the intervention and legitimizing the virtuous exercise of the doctor's power.

## **5. Conclusion**

National health is a decentralized system. It is based on the PHC approach. The network consists of 1,800 community-level facilities called aid posts and approximately 800 sub-health/health centres. The secondary (or curative) healthcare level consists of 22 provincial hospitals, one of which is also the national referral hospital. The Government and the Churches are the main providers of health services, both services being funded by the Government. The churches play an important role in providing healthcare service, operating over 50% of the rural health service network [12].

The NDoH has statutory responsibility to oversee the establishment, maintenance and development of the health-care system in PNG. The NHAA of 1997 was established to provide the legal framework for linking and consolidating the functions of all levels of government and other agencies involved in the delivery of healthcare [29]. The NHAA supports the introduction of national standards, defines administrative functions, and establishes relevant boards and management committees at national, provincial and district levels.

The responsibility of the PGs is to coordinate the operation of health facilities and the provision of health services and programmes in the provinces. The Public Hospitals Act 1994 defines the role of provincial hospitals, funded by and reporting to the NDoH for the operation and provision of services by public hospitals, and the hospitals' role in supervising and supporting rural clinical services in PHC facilities within the province [12].

Provincial and local governments are responsible for all other services (health centres and sub-health centres, rural hospitals and aid posts). The NDoH centrally purchases medical supplies then distributes to the provinces for their onward distribution within the provinces. However, many problems were identified with this provincial two-system approach, including cost inefficiencies, limited human resource capacity and management issues [12]. The PHA had introduced a unified provincial health system under which a single provincial health authority becomes responsible for both the hospital and rural health services. This is presently being rolled out throughout the country after a slow start. To support this unified provincial health service, a set of standards for health service delivery has clarified the functions of the various (seven) levels of the health-care system [29]. The National Department of Health Corporate Plan in 2017 identified seven priority areas for action, which included effective leadership, workforce planning, medical supply reforms, health infrastructure and equipment, PHA reform, health financing, and monitoring and evaluation. These include sector-wide planning approaches, better integration of the health planning with LLG planning, facility-based planning and budgeting, and more direct models of resource allocation at provincial and district levels.

Many people would dispute that the healthcare system is deeply troubled. Majority of people are uninsured, healthcare costs continue their exuberant growth, and bureaucracy increasingly intrudes in the examining room and opinions on solutions are more divided. Maybe the NDoH must look to other similar situations of other countries and ensure an improved reform system to approach healthcare in PNG. The runaway healthcare spending, and the widespread instability in the healthcare system it has produced are providing the major impetus for national healthcare reform. The focus of attention is on directly controlling spending; all roads lead to financial reform.

We have explored the situation regarding PNG and

the perspectives relating to health services and its role in providing healthcare to the people. In addition we acknowledge the healthcare institutions, healthcare professionals and many other stake-holders who are playing significant roles in ensuring, as far as possible, that basic care services reach the majority of the peoples, and this is despite the larger socio-economic and geographic challenges that affect the delivery of healthcare.

The socio-economic and geographic challenges are difficult to manage for PNG. Perhaps it is timely to make reform to the existing healthcare system. To do that would mean to promote more transparent and integrated programs and rolled over a period of time by the major health service providers and stakeholders, including the government Departments of Treasury and Finance, and the donor agencies who will assist with the finance to the Department of Health, and everyone involved must work together. The NDoH would provide the team leadership in this whole exercise. There are many areas of concerns to the country's health services and many aimed to promote better clinical care for the patients. One aspect important in influencing the provision of clinical care is to value the work of doctor-patient relationship in the context of informed consent.

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None.

## Authors Contributions

AM: Conception and design, acquisition of data, analysis and interpretation of data, drafting of the manuscript, critical revision of the manuscript for important intellectual content, administrative, or material support, and supervision.

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