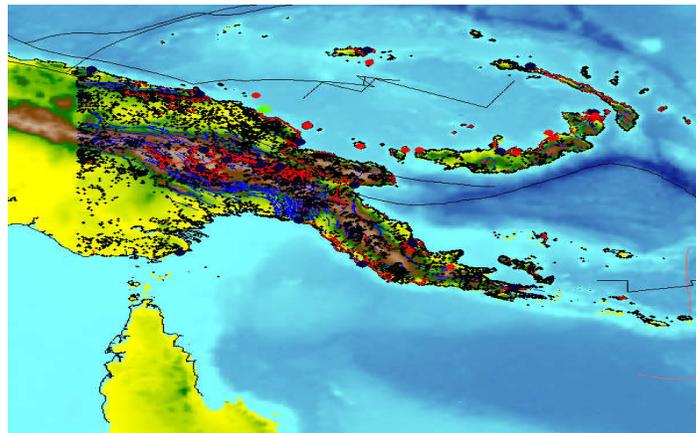


Transformation Papua New Guinea

An International Cancer Charity for the
Development of Cancer Services in the
Independent State of Papua New Guinea



“Breaking through to achieve the impossible”

Contents

Introduction	p3
Summary Statement, Vision and Mission	p3
Empowering framework	p3-4
Areas of concern	p4
The Global Cancer Challenge	p7-9
Introduction: Papua New Guinea	p10-13
Cancer in Papua New Guinea	p14-17
Case Study: Cervical Cancer in Papua New Guinea	p18-30
Other Concerns	p30
Process of Operation Transformation PNG	p31-34
References	p35-38
Appendix 1 World Cancer Declaration 2006	p39-41
Appendix 2 Telepathology Proposal 2007	p42-52
Document author and contact details	p53

Introduction

Transformation PNG is a not-for-profit charity dedicated to making a difference to Papua New Guinean nationals affected by cancer. This document serves as a foundation paper outlining the purpose of Transformation Papua New Guinea (TPNG). The document explains in detail the rationale for its operation and clarifies key areas of concern and action through its proposed grant making functions.

Summary Statement

This charity is launched to make the possibility of freedom to accessible and effective health care, real for all people affected by cancer, in Papua New Guinea. There are many challenges to this freedom; infections (for example; Hepatitis B and Human Papilloma Virus), poor diet, poverty, illiteracy, tobacco and hopelessness.

These factors are compounded in Papua New Guinea which has limited resources to tackle these inequalities. It is an imperative now to make profound and lasting endeavours to enable people to empower themselves to be free; equipping them, their families and communities to produce sustainable development and transform their experience of life. Being fully alive and filled with joy and hope to make a difference to those suffering with cancer is this charity's passion and goal.

Vision

"Transformation PNG" stands for a Papua New Guinea, where every individual, family and community affected by cancer, is free to access quality preventive, curative and

palliative cancer care services. Each and every constraint to that freedom being broken through to unleash unique potential, which will empower effective actions that make a difference.

Mission

The transformation of life to create an unprecedented future of freedom and beauty irrespective of any and every circumstance or outcome for every individual, family and community affected by cancer.

Empowering Framework

Every program will be performed with:

1. Unstoppable belief

The focus on an empowering vision calls for actions that will continue in the face of any and all circumstances that would limit or threaten its impact.

2. Teamwork

The heart of this goal is the self evident equality of all people regardless of any other consideration. Every member of the team has an equal and valid part to play.

Participatory methods will be employed as essential mechanisms to facilitate this process of inclusion, capacity and team building.

3. Strategy

Strategic plans will be made based on the needs of that individual or group contextualised to the total environment, with participatory and innovative community health models forming the structural implementation.

4. Sustainability

Inherent to the process will be facilitation of training and apprenticeship to enable Papua New Guinea to be self sustaining in the comprehensive provision of cancer care. The programs will aim to counter any dependency and generate liberation and growth.

5. Monitoring

Evaluation will be an integral part of the framework of analysis to maximise the impact of any action performed. A clear framework of monitoring will be in place.

6. Focus

A timetable of goals that is reflexive and adaptable will be encouraged. All members of the team will be responsible for the surveillance of progress and invaluable in responses to challenges that will inevitably occur during the life of a project.

An explicit, SMART goal will be set and objective indicators used to demonstrate its fulfilment.

Areas of Action

Cancer in Papua New Guinea

- **Development of a National Comprehensive Cancer Control Program (NCCP)**
- **Development of a National Papua New Guinea Oncology Service (NPNGOS) provided by Papua New Guinean doctors, nurses and allied health professionals with the development of international networks and collaborative efforts**
- **Eradication of Cervical Cancer, through a national cervical screening and Human Papilloma Virus (HPV) vaccination program**
- **Comprehensive preventive and treatment program for Oral Cavity Cancer**

- **Development of a program for the treatment of adult and paediatric Leukaemia and Lymphoma**
- **Development of a medium term telepathology reporting system to accelerate diagnostic services**

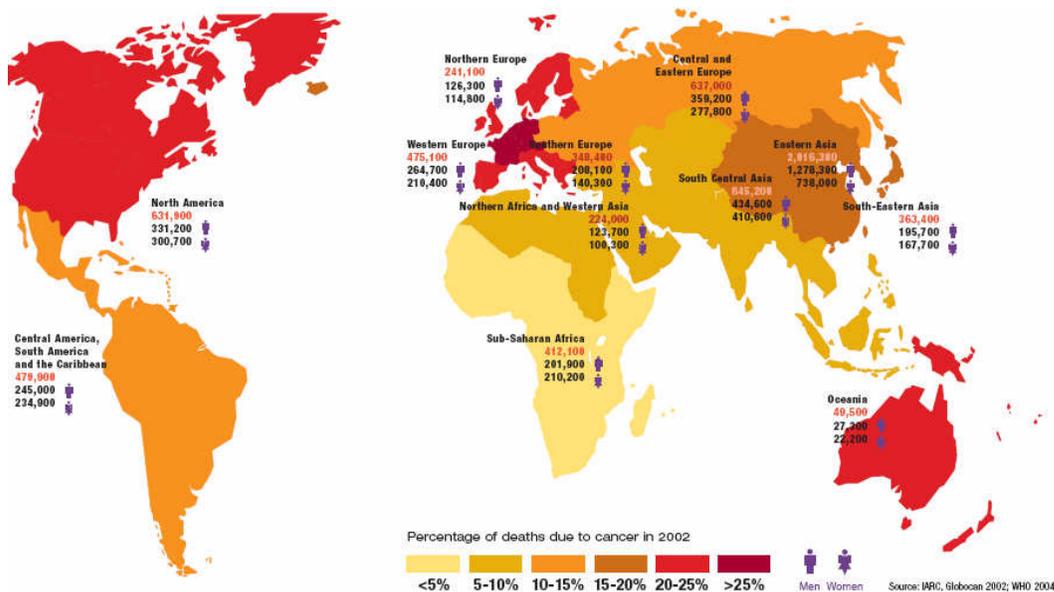
The Global Cancer Challenge

There is major global effort in the world oncology community for urgent prioritisation and action in the sphere of global cancer therapy and control. This is illustrated most vividly by the UICC World Cancer Congress launching, in Washington DC 2006, a World Cancer Declaration (**appendix 1**), a segment of which is quoted below. This declaration provides for a powerful framework for action, building upon the Charter of Paris in 2000 (1) and the World Health Assembly declaration 58.22 in May 2005 (2).

“It is now possible to make dramatic worldwide strides against cancer- even in the poorest countries- through public health efforts targeting prevention and early detection, as well as advances in cancer treatment. The opportunity for collective action has never been greater and the need has never been more urgent” [appendix 1]

Estimates by the International Agency for Research in Cancer (IARC), predict 10.3 million cancer deaths by 2020, an increase of 3.6 million upon 2002, together with a staggering, potential 50% increase in newly diagnosed cancer cases to 16 million cases in 2020, if no remedial action is taken [3]. This mortality alone is already greater than all annual deaths from Tuberculosis, HIV/AIDS and malaria combined.

Figure 1: %Contribution of Cancer to Global Mortality



IARC global trends data, shown in figures 1 and 2, demonstrate graphically the current global situation and the dramatic increase predicted [4]. This rising burden of cancer in the developing world, due to a diverse range of epidemiological factors, is alarming and estimated at 73% by 2020 [5, 6].

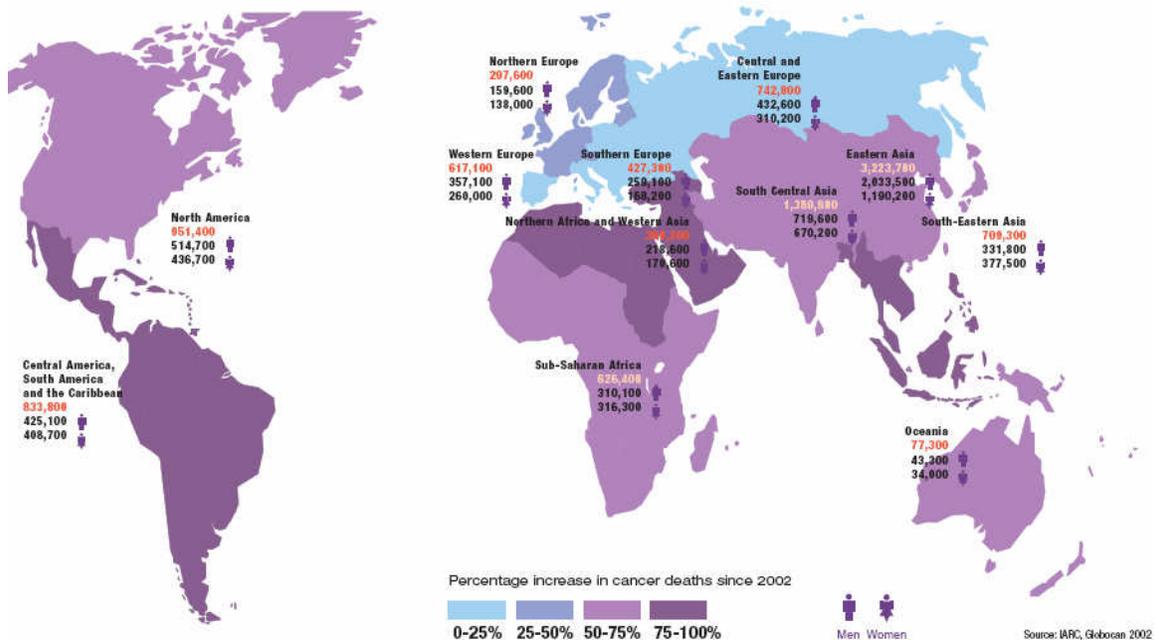
Furthermore this burden will disproportionately impact developing countries, in which 70% of all cancer incidence occurs within, the very countries least prepared to

tackle such an increase in cancer diagnoses and subsequent need for treatment and palliative care [7, 8].

For example the developing world represents 85% of the world’s population and yet has only 40% of the total radiotherapy equipment [9]. Hence initiatives such as Programme of Action on Cancer Therapy (PACT), a collaboration of the International Atomic Energy Agency (IAEA) and the World Health Organisation (WHO), is focussed, amongst many other objectives, in catalysing the provision of such radiotherapy services.

In response to this call for action to such a profound global need, this charity is driven to make a difference in the area of cancer care. This contribution is specifically directed at Papua New Guinea, which will be Transformation PNG’s unique distinction.

Figure 2: % increase in cancer deaths since 2002



Introduction: Papua New Guinea

As an organisation Transformation PNG is focussed on the people of Papua New Guinea. Why the focus on this state? During 2003-2005 the author of this foundation paper worked in the Highlands of Papua New Guinea as a District Medical Officer. During this seminal experience both the great needs of those living and dying with cancer and the lack of current provision became powerfully evident. The opportunity to design participatory programs that would transform this situation is embodied in the creation of this organisation and its mission.

Papua New Guinea is in the southern hemisphere at between 0 and 10 degrees latitude. It occupies the eastern half of the second largest island in the world, New Guinea, the western half being part of Indonesia. It covers an area of 462,840 square Km.

Figure 3: Map of Papua New Guinea



Whilst Forest covers 294, 400 square Km (64%), which are mostly unexplored due to the remote and inaccessible geography. Papua New Guinea is one of the most linguistically diverse countries in the world with over 800 indigenous languages. Papua New Guinea became an independent state on 16, September 1975 from Australian territorial administration, and hence it still has close ties with Australia.

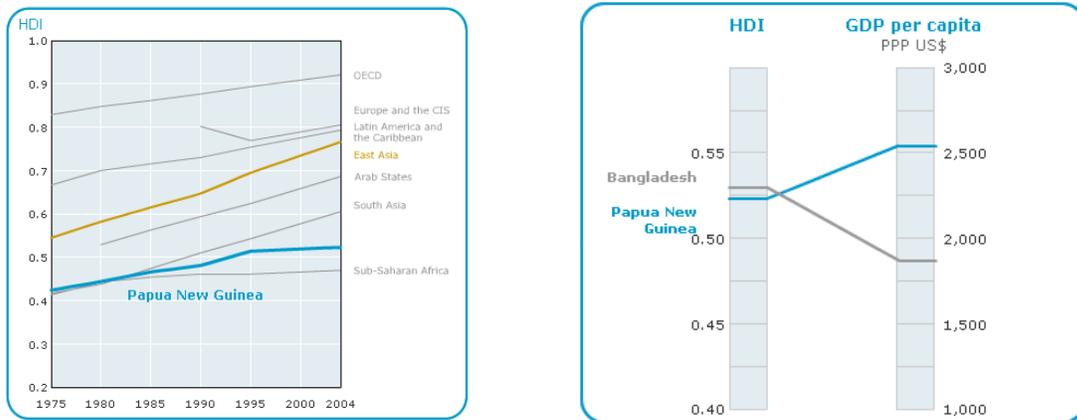
Papua New Guinea is within the Western Pacific WHO region and is a constitutional monarchy administered by a national parliament with 109 members. Total Population, in 2005, was estimated to be 5.9 million with a population growth rate of 2%, Gross domestic product being US \$3.9 billion [10]. Papua New Guinea is rich in natural resources and the mining and petroleum sector accounts for an estimated 28.8% of Gross Domestic Product (GDP) and 77.3% of total exports [11]

Papua New Guinea is ranked 139th in the Human Development Index, 2006 (which is a composite measure of 3 dimensions of human development: living a long and healthy life (measured by life expectancy), being educated (measured by adult literacy and enrolment at primary, secondary and tertiary institutions) and having a decent standard of living (measured by purchasing power parity in US dollars). In the Human Development Report 2006, through 2004, Papua New Guinea has fallen in ranked overall human development and since 1995 there has been stagnation in the trend [12]. This is illustrated well in Figure 4.

Selected measures for Papua New Guinea include; Life expectancy at birth (2000-2005) 55.1 years, Adult literacy is 57.3%, with combined primary, secondary and tertiary enrolment in education 41% and health expenditure as a proportion of GDP is 3.8%.

Gross National Income per capita is US\$660 and is therefore characterised as a low income country, with a Gross domestic Product per capita of US\$2,543 (in Purchasing Power Parity with the US\$) [10,13].

Figure 4: Human Development Index 1975-2004 and GDP per capita 2004 for Papua New Guinea from reference [12]



It is clear that any cancer control program must be contextualised within the prevalent health climate. These indicators give a frank illustration of the great challenges and key constraints present within the Papua New Guinea health service presently. WHO has already in place a modular process for the building of National Cancer Control Programmes [14], and it is at this stage, pre-planning and planning phases, that the key progress will be focussed, drawing together all stakeholders in Papua New Guinea and the pacific region.

The outlook may appear bleak but there is good reason for optimism; cancer is potentially preventable and there are many examples of successful programs that have overcome great constraints in low income/resource countries.

Table 1: Health indicators Papua New Guinea 2004 from references [10, 13]

Indicator	Data 2004
HIV prevalence	1.8%
Infant mortality rate	68.4/1,000 live births
Under 5 mortality	92.6/1,000 live births
Probability of not surviving to age 40 (2000-2005 cohort)	22.5%
No Access to an improved water source	61%
Proportion living on less than 1\$/day	40%
Human development index	0.523
Tuberculosis cases detected under DOTS	19%
Access to sustainable improved sanitation	44%
Immunisation measles (12-23 months)	44%
Children underweight for age (under 5)	35%

For example:

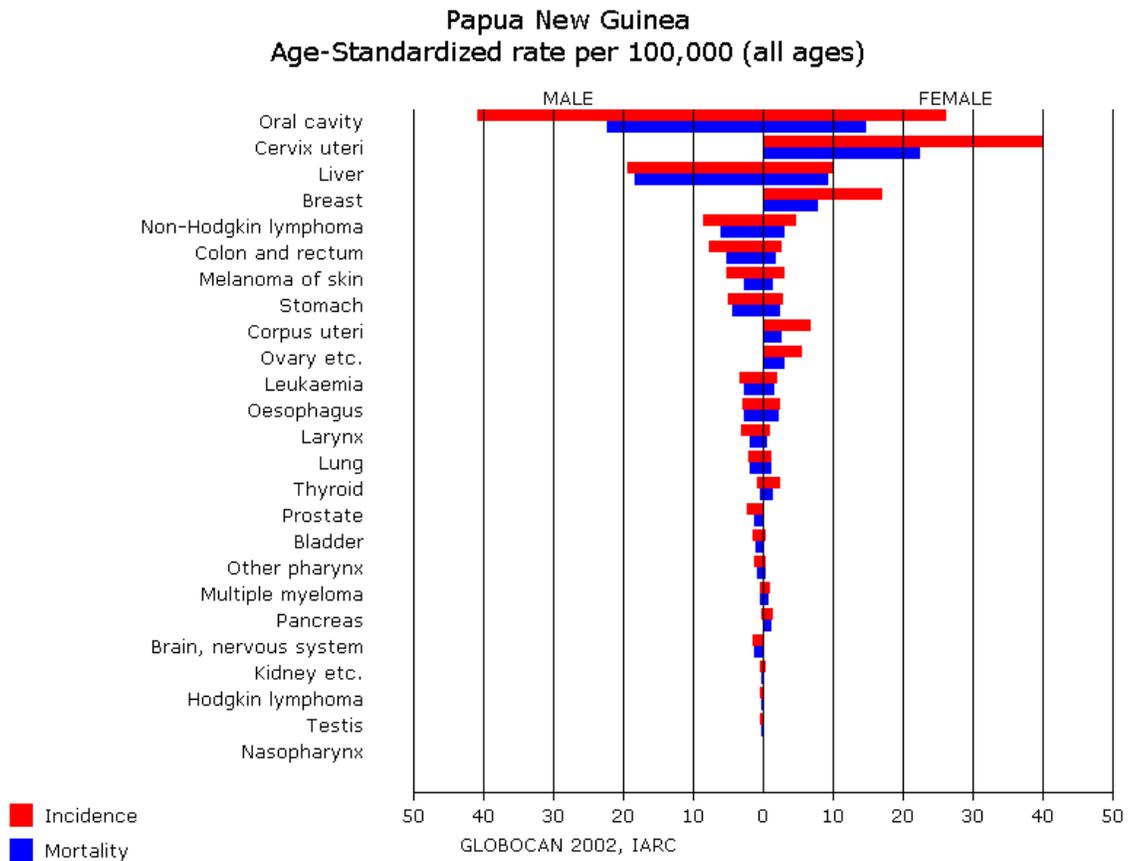
- Visual Inspection with Iodine (VIA) Cervical Cancer program in Kenya [15]
- Single visit prevention schemes for cervical cancer in Thailand [16]

- Breast Cancer Pilot Project in Ethiopia [17]
- Glivec International Patient Assistance Program (GIPAP) [18]

Cancer in Papua New Guinea

Cancer is common in Papua New Guinea (Figure 5) contributing, at minimum, 20% to all disease presentations, and is rising at a rate of 50% over the last 5 years (IARC data). Thus it with great prescience that cancer in Papua New Guinea is recognised both

Figure 5: National PNG Incidence of Malignancy



in the Papua New Guinea National Health Plan 2001-2010 [19] and “The Hidden Burden; Cancer in Papua New Guinea” [20] as a major affliction carried by many citizens and those who care for them.

Cancer Services have declined in terms of their coordination, provision of awareness and preventative strategies, training and the provision of expert human resources, diagnosis, treatment and nursing care [21], whilst in parallel cancer has remained a key potentially preventable disease that claims 12,750 lives and produces an estimated 15,000 new cases annually [22].

Illustrative of this dilemma are the absence of a national radiation or medical oncologist and the subsequent decommissioning of the Cobalt-60 radiotherapy apparatus at Angau Memorial Hospital in Lae, leading to an absence of curative and palliative radiotherapy services for the country. Similarly the clinical experience in Western Highlands Province is that for example the 5 year survival rate for paediatric acute leukaemia is currently negligible [23], in Port Moresby a study in 2001 of 58 cases of paediatric leukaemia comments; “Treatment and survival rates are low.” [24] and nationally the patient faces a disease course without access to effective analgesia for severe pain [25] and little health care professional knowledge of palliative care [26].

The National Health Plan in addressing the challenge of malignant disease has as its goal; “To reduce illness, suffering and deaths by preventing cancers and improving treatment and palliative care.” [27]. This vision was reemphasised and further clarified in 2001 by both; “The Hidden Burden, Cancer in Papua New Guinea” and the Annual Medical Society Symposium having its theme of Cancer.

“The Hidden Burden, Cancer in Papua New Guinea” advocated the creation of a National Cancer Control Program and recommended a timetable in which transformation of services was to take place within. This was not wholly adopted by the Department of Health which followed the National Health Plan priorities of:

- Improve community awareness and education
- Strengthen screening, diagnostic, treatment and palliative services
- Review the Tobacco Products (Health Control) Act (1987) and regulations
- Increase the Hepatitis B vaccination coverage, particularly in the Highlands
- Update the knowledge and skills of health care workers
- Improve surveillance and reporting [19]

Elements of the report recommendations were implemented, however the progress and direction identified has remained piecemeal. A great opportunity exists in achieving these goals in a step by step manner that is resource cogniscent, by being creative and thinking “outside of the box”.

It is in this spirit that developments between international stakeholders within the Pacific region will have the potential for major impacts in cancer service provision. This is essential to the prioritisation of cancer, generating effective and sustained political will to make a difference. Australia is the largest donor to Papua New Guinea, with an estimated A\$332.2 million of Overseas Aid for 2006/2007 through AusAID [28]. The

Cancer Council of Australia has advocated for recognition of cancer within overall AusAID policy, its key recommendations reproduced below:

Key recommendations

The Cancer Council Australia makes the following key recommendations in the context of the Federal Government's regional aid White Paper development process.

- That cancer control be recognised as a regional aid priority.
- That AusAID engage with Australian and international cancer control agencies to set measurable goals and scope specific priorities for the Asia-Pacific.
- That AusAID consider forming a partnership with The Cancer Council Australia, WHO Western Pacific Regional Office and other cancer control agencies in both government and non-government sectors, aimed at extending regional networks and maximising aid resources to support cancer control in the Asia-Pacific.
- That cancer control in the Asia-Pacific be identified as an opportunity to achieve broader medium- and long-term regional aid goals.
- That cancer control be recognised as a common challenge in the Asia-Pacific and that consideration be given to collective regional responses, particularly in tobacco control (see below), measures to reduce the incidence of precancerous disease, and building environmentally safer working and living areas.
- That tobacco control in the Asia-Pacific be identified as a key regional health priority in the context of Australia's aid program and the implementation of our treaty obligations under the WHO Framework Convention for Tobacco Control.
- That AusAID take an active role in facilitating and supporting tobacco control networks involving Australian and international health promotion agencies.
- That AusAID, The Cancer Council Australia and health promotion allies collaborate to scope measures to build early diagnosis and treatment capacity for cancer in the Asia-Pacific.
- That AusAID, The Cancer Council Australia and health promotion allies collaborate to scope ways in which Australian capacity in cancer registration and data management can be shared with developing nations in the Asia-Pacific.
- That AusAID explore options to substantially subsidise the provision and distribution of palliative medicines to developing Asia-Pacific nations, to alleviate pain and improve symptom control in people with incurable cancer.

Taken from Reference [29]

Transformation PNG's aim is to facilitate and catalyse cancer services in an integrated strategy to fulfil on possibility of breakthrough in the area of cancer control and its therapy.

Case Study: Cervical Cancer in Papua New Guinea

Key themes occur in the challenge of meeting global cancer needs. Cervical cancer is a case in point and illustrates well these issues both in the provision and development of cancer healthcare services. Important points related to cervical cancer are summarised below:

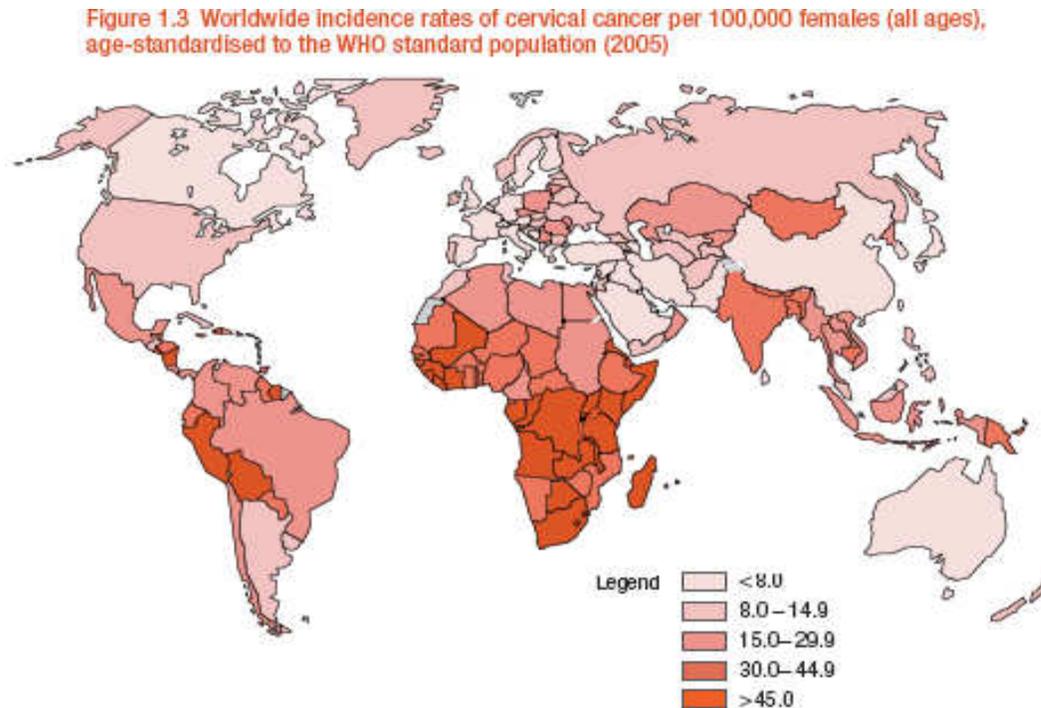
Key points

- Cervical cancer is one of the leading causes of cancer death in women in the developing world.
- The primary underlying cause of cervical cancer is infection with human papillomavirus (HPV), a very common virus that is sexually transmitted.
- Most HPV infections resolve spontaneously; those that persist may lead to the development of precancer and cancer.
- It usually takes 10 to 20 years for precursor lesions caused by HPV to develop into invasive cancer.
- Effective interventions against cervical cancer exist, including screening for, and treatment of, precancer and invasive cancer.
- An estimated 95% of women in developing countries have never been screened for cervical cancer.
- Over 80% of women newly diagnosed with cervical cancer live in developing countries; most are diagnosed when they have advanced disease.
- The cure rate for invasive cervical cancer is closely related to the stage of disease at diagnosis and the availability of treatment. If left untreated, cervical cancer is almost always fatal.
- Because of its complexity, cervical cancer control requires a team effort and communication between health care providers at all levels of the health care system.

Taken from Reference [30]

Cervical cancer generates a significant global burden of disease, with 493,000 annual cases, Figure 6 demonstrating the global geographic incidence and distribution.

Figure 6; Worldwide Incidence rates of cervical cancer 2005



Taken from Reference [30]

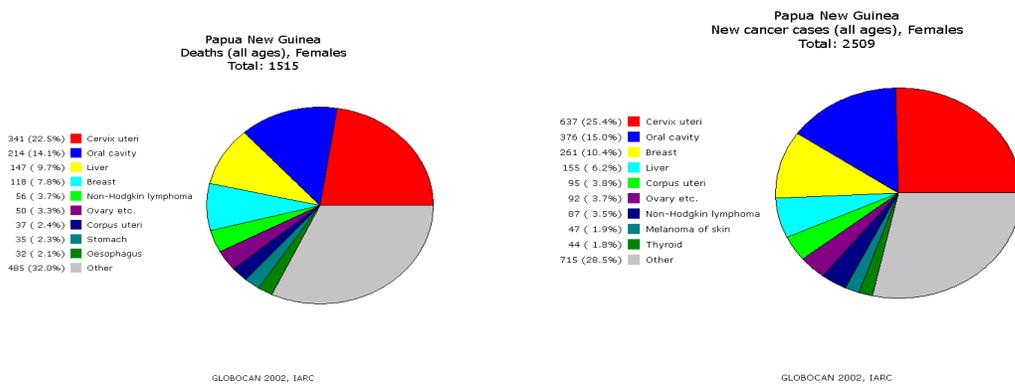
Approximately 1.4 million women are living with cervical cancer, and it is estimated that 7 million (based on the known epidemiology) may have early pre-invasive changes that require treatment [31]. A video excerpt; “Kill or Cure? Cervical Cancer”, produced by the British Broadcasting Corporation (BBC), through the Alliance for Cervical Cancer Prevention (ACCP) is accessible through this web link:

<http://www.alliance-cxca.org/english/kill-or-cure-video.php> [32]. This summarises the global implications of cervical cancer and its disproportionate impact on developing countries for the very reasons of poor infra-structure and resources to provide adequate preventative, early detection, treatment and palliative care services across the spectrum of care.

In Papua New Guinea, with a population of 5.9 million [10], cervical cancer is the most prevalent of all cancers affecting women. GLOBOCAN 2002 data from the International Agency on Research on Cancer (IARC), suggests an incidence of 40 cases/100,000, with a mortality rate of over 50% of those diagnosed with cervical cancer.

Furthermore IARC data from 2002 show that of cancers in women, in Papua New Guinea, cervical cancer contributes to 22.5% of all cases, as illustrated below in Figure 7.

Figure 7: All Cancer Mortality and Incidence rate in Women in PNG 2002



There were 637 reported cases of cervical cancer in Papua New Guinea in 2002, representing 25% of all incident cases. This is likely to be an underestimate, as an incident rate of 40/100,000 predicts an annual incidence of 2,400 cases. A multitude of

reasons exist for this discrepancy; there being only basic cancer registry information held in Port Moresby and from the areas easily accessible to the National Capital District only, limited histopathological services, remoteness of the vast majority of the population in rural areas (85%), poor transportation and fixation of samples and poor health education of both the population and healthcare professionals to recognise the signs of cancer to allow referral.

Data from the Cancer Registry 1979-1988, first established in 1958, based on the work of Martin et al [33], reports 654 cases of cervical cancer over this 10 year period, which at that time represented a threefold increase in cervical cancer registration, again demonstrating the problems inherent in cancer registration in Papua New Guinea.

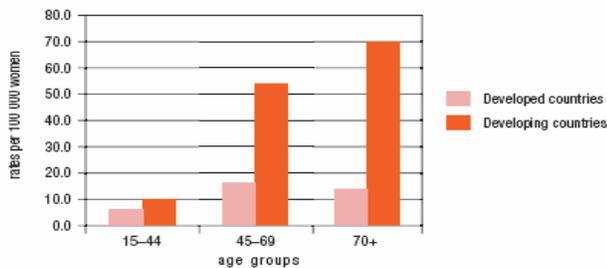
Given that cervical cancer with a cervical cancer screening program is preventable, and now with the advent of quadrivalent vaccines against Human Papilloma Virus, the overwhelming cause of cervical cancer, there is hope on the horizon of eliminating this disease and empowering all women to lead fulfilled lives not overshadowed by this cancer. **There exists a great window of opportunity to seize in order to transform the health of women in Papua New Guinea.**

These health parameters inherent in cervical cancer display and express the disempowerment and poor status of women, not only in Papua New Guinea, but globally. The Millennium Development Goals [34] set by the United Nations recognise this and a key goal is the improvement of the status of women. Cervical cancer programs when performed in a participatory manner, with a woman centred model, has the potential to make a great difference in this regard.

Many women will also be mothers or become future mothers and therefore this is a key opportunity to impact the health of children, through educative strategies and other opportunistic programs. Integrative to any health education structure will be sexual health education because of the transmission of HPV as a sexually acquired infection; such policy may directly contribute to improving health [35]. Similarly with Papua New Guinea facing a major HIV epidemic there is a vital opening for HIV education to become a fundamental cross cutting theme throughout all parts of any cervical cancer prevention program [35].

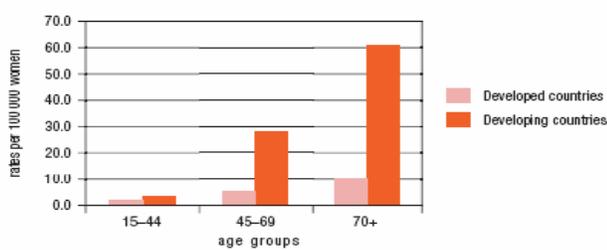
Figure 8: Disproportionate Impact of Cervical Cancer in Developing Countries

Figure 1.1 Age-standardized incidence rates of cervical cancer in developed and developing countries (2005)



Source: WHO, *Preventing chronic diseases: a vital investment*, Geneva, 2005.

Figure 1.2 Age-standardized mortality rates of cervical cancer in developed and developing countries (2005)



Source: WHO, *Preventing chronic diseases: a vital investment*, Geneva, 2005.

Taken from reference [30]

Great challenges lie ahead, principally because of the way cancer mortality and morbidity is compounded in developing countries. This is illustrated in Figure 8, above, data from the WHO. A multitude of factors give rise to this disparity in healthcare outcome. In Papua New Guinea these include the low status of women, illiteracy and poor universal primary education, high rates of STI, lack of condom use, inaccessibility to screening programs, poor access to surgical oncology services, no national cancer registry, and no provision of radiotherapy or chemotherapy services.

Therefore the significant issues can thus be summarised:

- Cervical cancer is globally prevalent with a high disease burden
- Cervical cancer is eminently preventable with current technology, the challenge is its adoption and adaptation into low resource settings where most of the cancers occur
- Cervical cancer principally affects poor and marginalised women
- Cervical cancer exemplifies the disempowerment of women in discursive power relations around sexuality [36]
- Developed countries have designed preventative strategies through principally PAP smear programs
- Women in developed countries have access to treatment programs through colposcopy, gynaecology and oncology services
- These programs have been effective in reducing mortality from cervical cancer for women in developed countries
- Most cervical cancer occurs in the developing world

- Most developing countries do not have national cervical cancer prevention programs leading to great health disparity between northern and southern countries
- The mortality for cervical cancer in developing countries is 6 times that in developed countries
- The incidence of cervical cancer is 5 times that for poor countries than developed countries
- The first vaccine against Human Papilloma Virus (HPV), a quadrivalent form against genotypes 16, 18, 6 and 11 was licensed summer 2006, with another vaccine product being launched late 2007
- Early clinical trials suggest both a robust vaccine immune response and high efficacy in prevention of high grade cervical lesions in screening programs allied to the vaccination program.

Currently there is no nationally coordinated cervical cancer screening program however there are growing efforts and vision to provide such a service. MERIPATH, a not for profit NGO, linked with CARITAS (Catholic Aid agency) now works in over 26 centres in PNG, providing over 5,000 annual pap smear reports [37].

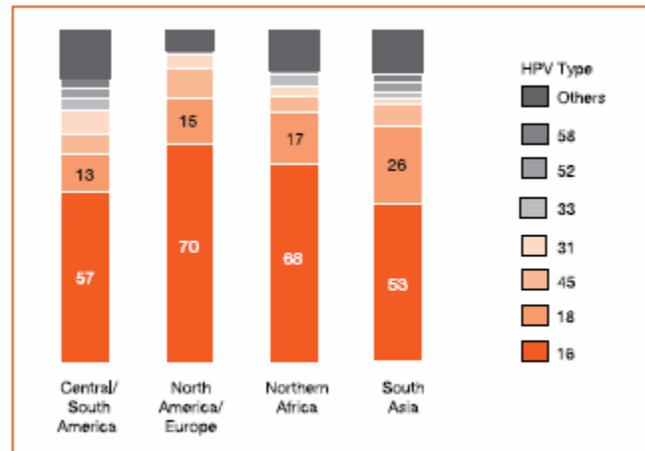
With this opportunity in mind, a principal area of concern for Transformation PNG is the design, expansion and implementation of a national cervical screening program with an integrated HPV vaccination program.

Additionally more research, into the genotypes of Human Papilloma Virus prevalent in Papua New Guinea, would greatly impact the choice of vaccine product and

the efficacy of any vaccine program. Indeed, Mgone et al [38] has shown a prevalence of 33% of HPV genotypes 16 and 18 in a small study of 114 women in Eastern Highlands Province.

Figure 9: Prevalence of HPV serotypes by geographic region

Figure 2. Prevalence (%) of different HPV types among women with cancer, by region



Source of data: Muñoz N et al Against which human papillomavirus type shall we vaccinate and screen? The international perspective. *International Journal of Cancer*, 2004, 111:278–285.

Taken from Reference [35]

The known global data on HPV genotype geographical distribution is shown in figure 8. Clinical trials of HPV Vaccine, [39-43], have heralded the possibility of prevention of HPV infection and thus the opportunity to prevent Human Papilloma Virus persistence and the attendant oncogenic effects leading onto pre-cancerous and then invasive cancer.

This strong clinical trial evidence forms the foundation for advocating national vaccination programs giving at least 80% of those women in the target community access

to cervical cancer prevention, complemented for the long term with a cervical screening program until the vaccination cohort both reaches all population segments and maturity.

Both WHA 57.12 and the Global Health Reproductive Strategy, adopted by member states of WHO, have a distinct focus on cervical cancer prevention strategies, which in alliance with the Global Immunisation Vision and Strategy (GIVS), provides the foundation for a global cervical cancer vaccine strategy. It is only in such comprehensive networks that cervical cancer can be impacted in a systematic and committed way. The GIVS vision is outlined below.

Indeed the World Health Resolution 58.22 [2] requests of the Director-General “to promote research on development of an effective vaccine against cervical cancer”, which has become reality with these well reported clinical trials and provides for the possibility of action against cervical cancer.

Table 2: Summary of efficacy of HPV Vaccines

TABLE 3. Summary of quadrivalent human papillomavirus (HPV) vaccine efficacy studies in the per protocol populations*

Outcome and protocol	Quadrivalent vaccine		Placebo		% Efficacy	(95% CI) [§]
	No. [†]	Cases	No.	Cases		
HPV 16- or 18- related CIN 2/3 or AIS						
Protocol 005**	755	0	750	12	100.0	(65.1–100.0)
Protocol 007	231	0	230	1	100.0	(-3734.9–100.0)
Protocol 013	2,200	0	2,222	19	100.0	(78.5–100.0)
Protocol 015	5,301	0	5,258	21	100.0 ^{††}	(80.9–100.0)
Combined protocols ^{§§}	8,487	0	8,460	53	100.0 ^{††}	(92.9–100.0)
HPV 6-, 11-, 16-, 18- related CIN (CIN 1, CIN 2/3) or AIS						
Protocol 007	235	0	233	3	100.0	(-137.8–100.0)
Protocol 013	2,240	0	2,258	37	100.0 ^{††}	(89.5–100.0)
Protocol 015	5,383	4	5,370	43	90.7	(74.4–97.6)
Combined protocols ^{§§}	7,858	4	7,861	83	95.2	(87.2–98.7)
HPV 6-, 11-, 16-, 18- related genital warts						
Protocol 007	235	0	233	3	100.0	(-139.5–100.0)
Protocol 013	2,261	0	2,279	29	100.0	(86.4–100.0)
Protocol 015	5,401	1	5,387	59	98.3	(90.2–100.0)
Combined protocols ^{§§}	7,897	1	7,899	91	98.9	(93.7–100.0)

Taken from reference [44]

UNICEF/WHO Global Immunization Vision and Strategy (GIVS)

A new vision for immunization, the Global Immunization Vision and Strategy (GIVS) developed by WHO and UNICEF, has been endorsed by the 58th World Health Assembly. GIVS is striving for a world in 2015 in which:

- immunization is highly valued
- every child, adolescent and adult has equal access to immunization as provided for in their national schedule
- more people are protected against more diseases
- immunization and related interventions are sustained in conditions of diverse social values, changing demographics and economies, and evolving diseases
- immunization is seen as crucial for the wider strengthening of health systems and a major element of efforts to attain the Millennium Development Goals
- vaccines are put to best use in improving health and security globally
- solidarity among the global community guarantees equitable access for all people to the vaccines they need.

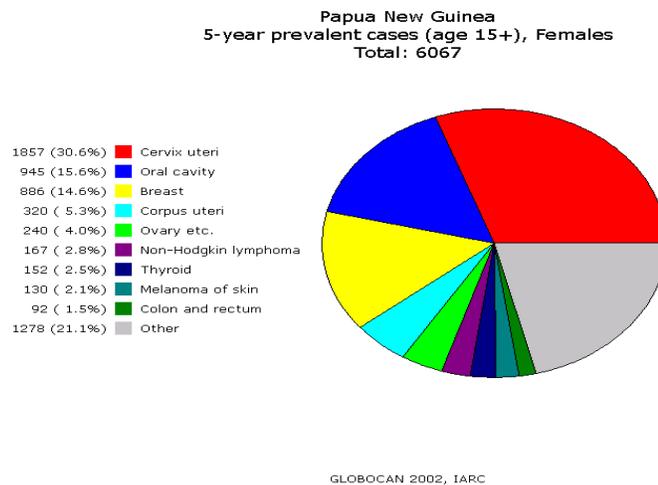


Taken from Reference [35]

It is recognised that 1857 women, as illustrated graphically in figure 10, are already living with cervical cancer and it is clear that integral to the program will be delivering support and care for the whole spectrum of women's experience of cervical cancer. It is therefore the aim of transformation PNG to advocate for the provision of quality clinical care of women in all phases of their cancer journey. Figure 11 demonstrates the different phases through time of a diverse range of health care foci. All facets of this must be integrated to give a truly multidisciplinary approach and comprehensive care.

Currently provision of surgical oncology is through tertiary level hospitals in the major cities that have general/gynaecological surgeons. Few centres if any offer adjuvant or palliative chemotherapy, and there is no provision of radiotherapy. Some citizens may go to receive care in Australia/New Zealand, who have sufficient resources.

Figure 10: All cancer 5 year prevalence in PNG

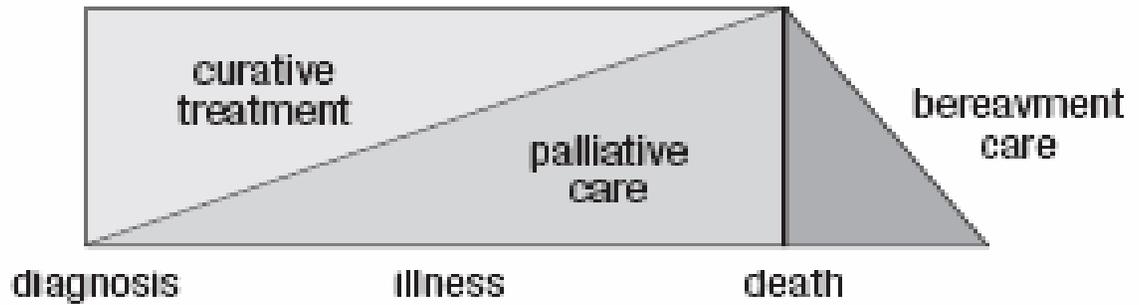


Similarly the use of imaging is very limited with there being only one Computed Tomography (CT) scanner in the capital Port Moresby, where scans are prohibitively expensive for the vast majority of the rural poor; exactly the demographic that is most likely to need treatment. Ultrasound scanning is more usually accessible, and it may be possibly used in staging strategies.

The strategy of prevention is key to the success of reducing the mortality and morbidity from cervical cancer. The need for a cervical screening program will remain because of:

- vaccine non-response
- failure of access

Figure 11: The spectrum of cervical cancer care



Taken from reference [30]

- suboptimal vaccination (timing, communication and supply)
- impaired vaccine efficacy (storage)
- adherence issues

Any program will also need to address, define and have in place clear referral networks for the dealing with women with high grade or invasive cancers with strategies of:

- Cryotherapy
- Loop excision of the cervix
- Hysterectomy
- Adjuvant chemotherapy
- Adjuvant Radiotherapy
- Follow up program

- Palliative care
- Bereavement care

Much of this service can be facilitated to be undertaken in the community in which the women affected will live and die. The challenge will be to design and implement sustainable strategies that both tackle this disparity in provision and simultaneously their disempowerment as both women and mothers. As illustrated broader cross cutting health and sexual health education to must link all programs to provide a truly comprehensive care system.

Other Concerns

A clear case of need has been established for a cervical cancer control program against the wider background of a National Cancer Control Program.

Transformation PNG will advocate for such a program to provide the momentum and political will to drive forward a comprehensive approach to cancer control, taking in other malignancies, such as leukaemia and lymphoma in both adults and children, and oral cavity cancer.

The touchstone for all such interventions will be participatory development of programs that involve collaboration and networking from local participants to international supporters and empowerment of those minorities subject to discursive power relations.

The goal is the transformation of the experience of the Papua New Guinean with cancer and the creation of, as yet, an unimagined future.

Process of Operation of Transformation PNG

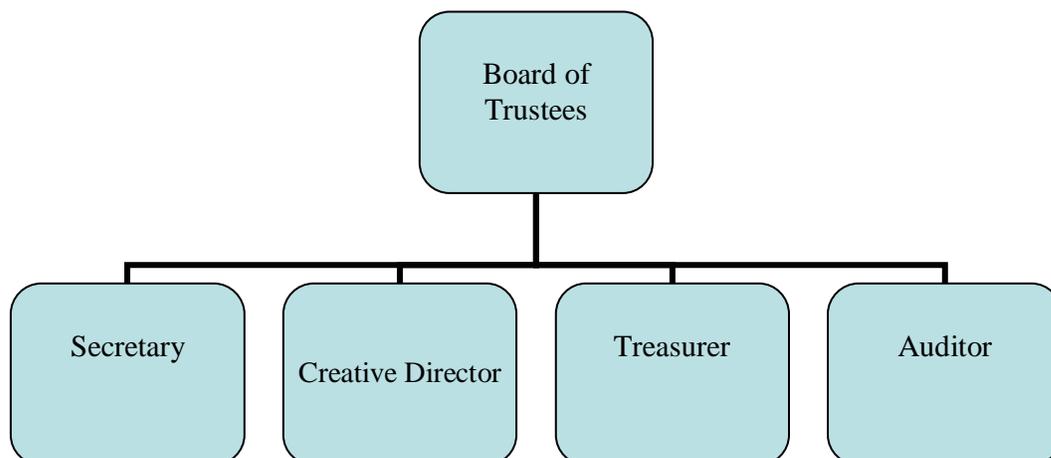
Projects will be received by the organisation that address and fulfil its vision, mission and aims in the relevant areas of concern from interested stakeholders.

These will be reviewed by the Board of Trustees twice a year and awards/grants made to support the project from its grant making fund.

Each project will go through a cycle of planning, implementation, monitoring and evaluation until its goals are identified as complete. A report is made to each Board of Trustees meeting on the project progress.

Once the project goals are fulfilled a completing report is made to the Board of Trustees

Organisational Framework



A board of trustees will form the key decision making body. Its purpose will be:

- To meet twice a year
- Strategise and prioritise goals to move the charity forward
- To assess projects recommended to it according to the underlying core principles
- Assign funding to each project, if accepted, according to the annual budget presented by the treasurer
- Receive an annual audit of the financial accounts and approve if acceptable
- Receive an annual report by the secretary and treasurer and approve if acceptable
- Review reports on projects that are in operation
- Promote the work of the organisation

Funding

This will be from a variety of means to support the vision, aims and objectives of the organisation:

- Fundraising events
- Regular donations
- One time donations
- Bequests
- Sale of merchandise
- Website

- Donation of human resources
- Donation of equipment

All funds raised will be directed into a grant making interest bearing account ready for disbursement upon the recommendation of the Board of Trustees. Specific funds will also be allocated for particular focussed campaigns.

Training of Trustees

The trustees will have opportunity to have train and reflect on their personal contribution and to be more effective in realising the vision and mission. This will be encouraged by the use of validated training courses.

Website for Transformation PNG

This will act as the key communication medium between Trustees, supporters and participants around the globe and facilitate:

- Linking trustees
- Trustee secure subsite for discussion on projects
- Display of funding and accounts
- Achievements
- Friendship registration

- Human interest stories and videos
- Advertisement
- Links to other charities, NGO's and governments
- Facilitating meetings
- Fundraising
- Communication about vision and mission
- Project updates
- Photo-essays
- Project application documents
- Application process online
- Awareness raising
- Ordering and purchasing gifts

Trustees Appointed

Dr Chi-Chi Obauya

Rev Chris Dowd

Dr Ian K Garbett

Accountant

Mr Stephen Bentley

Website Designer

Mr Andrew Wong

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Appendix 1



Preamble

We, the participants from 139 countries, from governments, foundations, national and international non-governmental organizations, professional bodies, academia and civil society from all continents, assembled in Washington DC, USA to participate in the 2006 World Cancer Congress on July 8-12, 2006 recognize that:

- Currently, approximately 11 million people worldwide are diagnosed with cancer, and almost 7 million people die of the disease each year. Additionally, more than 25 million people are surviving for years after a cancer diagnosis;
- By 2020, more than 16 million new cancer cases and 10 million cancer deaths are expected annually. Seventy percent of these deaths will likely occur in developing countries that are unprepared to address their growing cancer burden;
- It is now possible to make dramatic worldwide strides against cancer—even in the poorest countries—through public health efforts targeting prevention and early detection, as well as advances in cancer treatment. The opportunity for collective action has never been greater and the need has never been more urgent;
- The new vision of the world cancer control community is a world where cancer is eliminated as a major threat for future generations. It is a world where cancer control knowledge and competencies are equitable, shared and accessible, where new scientific findings are transferred to clinical settings, where disparities in prevention, early detection, treatment, and cure of cancers are systematically reduced and eventually eliminated, and where all cancer patients receive the best possible care.
- Such an outcome calls for a global movement that makes cancer control an important worldwide priority of this decade. It will require a massive, focused, and determined effort to stimulate the global cancer community across the public, private, and nonprofit sectors to join forces in carrying the initiative forward to every region of the world.

PURPOSE

The purpose of this Declaration is to build on the Charter of Paris 2000 and call for urgent action to address the worldwide cancer burden. Progress reports on the actions in this Declaration will be provided to assist in the development of future World Cancer Declarations which will come out of every World Cancer Congress.

	<p>VACCINES</p> <ul style="list-style-type: none"> • Develop a collaborative international plan for implementing HPV vaccination programs in low and middle income countries where the burden of cervical cancer is high which outlines specific actions to reduce costs and provide public and professional education, public policy and research. • Integrate Hepatitis B vaccine with other routine infant vaccination programs in countries, particularly those with high rates of liver cancer. <p>EARLY DETECTION/TREATMENT</p> <ul style="list-style-type: none"> • All countries should adopt appropriate evidence-based guidelines for early detection and treatment programs and deliver relevant priority actions tailored to different socioeconomic, cultural and resource settings. Concurrent with these services should be national public and health professional education programs which stress the benefits of early detection. Additional investments in health services infrastructure may be required for the extra disease burden resulting from early detection. <p>PALLIATIVE CARE</p> <ul style="list-style-type: none"> • Increase the number of countries with national cancer control programs that make pain relief and palliative care an essential service in all cancer treatment institutions and home-based care, including access to opioids such as oral morphine, symptom control, psychological support and family support. <p>MOBILIZING INDIVIDUALS FOR ACTION</p> <ul style="list-style-type: none"> • Increase the number of opportunities that empower people living with cancer and those touched by cancer to fully participate in community, regional, and country cancer control efforts. Examples include training (e.g., media and advocacy) and partnership development (e.g., coalition building and collaboration) that create compelling voices for action. <p>SUPPORT OF ACTION STEPS</p> <ul style="list-style-type: none"> • Develop and implement a process for the monitoring of these actions and development of future actions which includes evaluation of progress, reports on progress and identification of roles of organizations working in international cancer control.
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An Innovative Strategy for
Accelerating Cancer
Diagnostic Services in the
Highlands of Papua New
Guinea

CONCEPTUAL DRAFT
POLICY

April 2007

Introduction

Cancer in Papua New Guinea is recognised in both the National Health Plan 2001-2010 [1] and “The Hidden Burden; Cancer in Papua New Guinea” [2] as a major affliction carried by many citizens and those who care for them.

Cancer Services have declined in terms of their coordination, provision of awareness and preventative strategies, training and the provision of expert human resources, diagnosis, treatment and nursing care [3, 4], whilst in parallel cancer has remained a key potentially preventable disease that claims 12,750 lives and produces an estimated 15,000 new cases annually [5].

Illustrative of this dilemma are the absence of a national radiation/medical oncologist and the subsequent decommissioning of the Cobalt-60 radiotherapy apparatus at Angau Memorial Hospital in Lae, leading to an absence of curative and palliative radiotherapy services for the country. Similarly the clinical experience in Western Highlands Province is that for example the 5 year survival rate for paediatric acute leukaemia is currently negligible [6], in Port Moresby a study in 2001 of 58 cases of paediatric leukaemia comments “Treatment and survival rates are low.” [7] and nationally the patient faces a disease course without access to effective analgesia for severe pain [8].

The National Health Plan in addressing the challenge of malignant disease has as its goal; “To reduce illness, suffering and deaths by preventing cancers and improving treatment and palliative care.” [9]. This vision was reemphasised and further clarified in 2001 by both; “The Hidden Burden, Cancer in Papua New Guinea” and the Annual Medical Society Symposium having its theme of Cancer.

“The Hidden Burden Cancer in Papua New Guinea” advocated the creation of a National Cancer Control Program and recommended a timetable in which transformation of services was to take place within. This was not wholly adopted by the Department of Health which followed the National Health Plan priorities of:

- Improve community awareness and education
- Strengthen screening, diagnostic, treatment and palliative services
- Review the Tobacco Products (Health Control) Act (1987) and regulations
- Increase the Hepatitis B vaccination coverage, particularly in the Highlands
- Update the knowledge and skills of health care workers
- Improve surveillance and reporting [10]

Elements of the report recommendations were implemented, however the progress and direction identified has remained piecemeal. A great opportunity exists in achieving these goals in a step by step manner that is resource cogniscent, by being creative and thinking “outside of the box”. This proposal suggests one such integrated strategy to fulfil on possibility of transformation and breakthrough in the area of cancer control and its therapy.

An Innovative Breakthrough

Currently upon obtaining a specimen of potentially malignant tissue, it is transported to histological services in Port Moresby General Hospital and the University of Papua New Guinea for analysis. The time from acquiring the sample to provision of a result is often between 3-6 months, as Papua New Guinea currently is severely resource constrained in provision of histopathologists. Furthermore difficulties in transportation may occur during this process that impairs preparation of the material or loss of the entire specimen. The flow of steps required to effect a patient intervention is illustrated in diagram 1.

Clearly the implication of this delay is to diminish the efficacy of appropriate treatment best afforded by access to histological grading and staging. Empirical therapy is often substituted where rapid answers are clinically essential. This approach necessitates exposure of the patient to excess side effects concurrent with the modality of treatment chosen. A case example is given below to illustrate the *many* factors involved in providing for an optimal patient outcome. Outcome is determined by the entire range of factors that influence health that operate especially within a resource limited country such as Papua New Guinea, helpfully summarised in appendix 1.

Innovative strategies are already operating to enhance the current system. For example the formulation of the “Meripath” service, whereby cervical smear interpretation is performed in Australia, has been a successful initiative by the Catholic Health Service in East New Britain Province that can be accessed nationally.

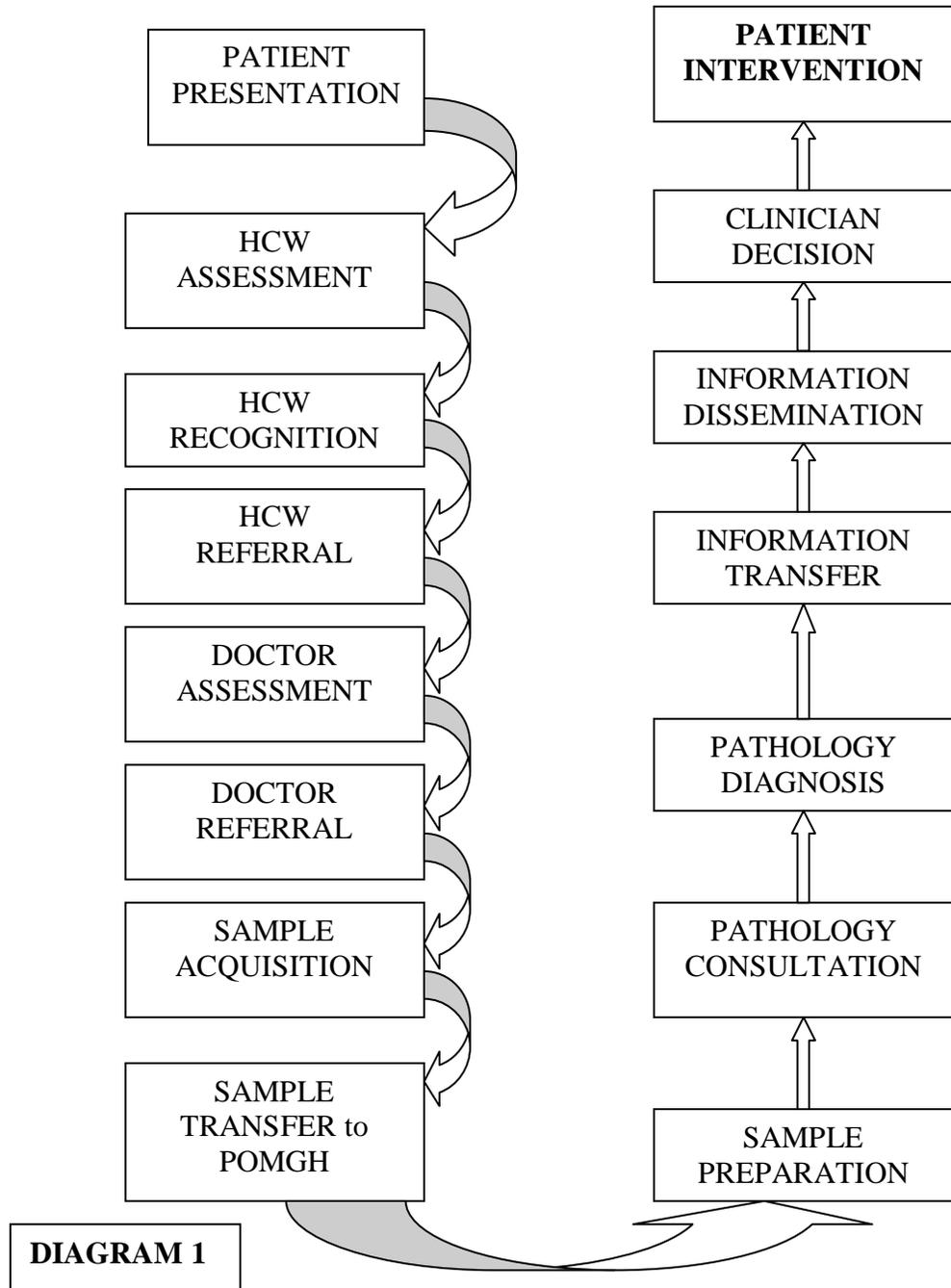
Case Example

A 30 year lady presented in October 2003 to Tinsley District Hospital in Western Highlands Province with a keloid like lump on her back. The lump was excised and sent to Port Moresby General Hospital. A malignant diagnosis of Non-Hodgkin’s Lymphoma was received 4 months later. Through tribal fighting she was lost to follow up until June 2004 where she had major local disease and distant lymph node involvement. Chemotherapy was given initially with good response; however the tumour relapsed with spinal cord metastases. The lady died peacefully in hospital requiring intramuscular morphine for pain control.

The theme of expanding and strengthening diagnostic services runs throughout the National Health Plan and this proposal strategically addresses this development of cancer services.

In a pilot collaborative project between 4 hospitals in Western Highlands and Enga Provinces; Mount Hagen General Hospital, Kujip Nazarene Hospital, Kompam District Hospital and Tinsley District Hospital together with the pathology service at Port Moresby General Hospital; the creation of a telepathology service is advocated to fulfil the medium term priorities and future direction of the National Health Plan with regard to malignant disease.

CURRENT FLOW PATHWAY INDICATING NECESSARY STEPS FOR A PATIENT INTERVENTION



Proposal Aim

This proposal presents an innovative strategy to provide a rapid and expert pathological diagnostic service by using the vehicle of telepathology through digital imaging and internet technology. It is a framework document and the intention is to generate discussion from all the key stakeholders involved in the project within a set timeframe.

This possibility was described in 2001 in regard to recruitment solutions; “The problem of recruiting of a Specialist Oncology Doctor (and they do not come cheap) could be overcome by linking up again with an Oncology Department in Australia and then introducing new technology that is now quite common to remote areas and countries such as PNG. This technology is linking up with medical establishments and specialist in Australia or other overseas countries via the internet.” [11]

It is anticipated this proposal will be a medium term solution to the current resource crisis in Papua New Guinea. It is envisioned that within a 15 year period more nationally trained histopathologists will commence work within the Government Health Service, as is occurring in the National Department of Health vision for training in other specialties such as Surgery and Internal Medicine at the post-graduate level.

The aim of this proposal is: **“To provide, in the setting of a pilot project, a rapid, accurate and quality assured pathological diagnostic service to transform the care of the patient with cancer in remote, rural Papua New Guinea.”**

The overarching objectives to achieve this aim are:

- Enhance current referral pathways to gain specimens that require a pathological diagnosis to optimise patient intervention and outcome
- Create a sustainable telepathology service to provide a pathological diagnostic service whose decisions are disseminated rapidly
- Use digital image and internet technology to ensure information flow is uninterrupted
- Expand and strengthen the knowledge and awareness of the community, health care workers and doctors to cancer and its treatment

The detailed activities will be described in four areas of:

- **Technology**
- **Sustainable Human Resource Training**
- **Sustainable Awareness and Education**
- **Research and Data Collection**

Technology

1. Collaborate with Pathologists in Port Moresby to detail a needs analysis of equipment in order to produce quality pathological specimens
2. Source appropriate technology to produce and analyse pathological specimens (microscope, microtome, paraffin, fixatives, special stains, slides)
3. Collaborate with centres with established telepathology programs to detail a needs analysis (for example University of Basel, Switzerland and University of Pittsburgh, USA and the Nuffield Institute, UK)
4. Source appropriate technology to produce digital images from a microscope set up (digital camera, cables)
5. Source suitable portable computers that can effectively handle, store and transmit images and with the capacity to run the software required
6. Utilise appropriate software packages that can handle such images and facilitate their transfer
7. Create an internet linkage between sites using Very Small Aperture Technology (VSAT) able to access broadband internet technology by collaborating with service providers, such as PNG Telikom and CRMF (Christian Radio Missionary Fellowship).

Sustainable Human Resource Training

1. Pathology technician (already trained and working at Tinsley District Hospital) to attend refresher course in modern techniques at Port Moresby General Hospital Pathology Department and other Pathological institutes who will collaborate with the project.
2. Pathology Technician then facilitates the training of one other pathology personnel member in each centre
3. Technology consultant to implement digital image capture, software and internet links for the centres and for this professional to train one member in each centre to conversancy with the technology
4. Identify a group of national and international histopathologists familiar with telepathology reporting to provide a service
5. Identify project co-ordinator
6. Run trainer of trainer course in cancer medicine and palliative care for health care workers
7. Run participatory workshops to train community members to become community health advocates for cancer awareness
8. Set up virtual clinico-pathological conferences for specialist clinicians and resident doctors and medical students to enhance knowledge of cancer diagnosis and therapy
9. Run training courses in palliative care for specialist clinicians and resident doctors and medical students

Sustainable Awareness and Education

1. Allied to the project implement a cancer awareness a program to encourage risk avoidance and risk reduction behaviour change (for example in smoking, betel nut chewing, Hepatitis B and sexual acquired infections as risk factors for Human Papilloma Virus (HPV)infection)
2. Develop a health care education program in developing awareness on the causes of cancer, early recognition, appropriate referral, patient education and ways of treating cancer curatively and care at the end of life
3. Education for medical students, residents and postgraduate specialists through the use of virtual education sessions and clinico-pathological conferences. This will enable the sharing of current advances and introduce younger doctors to the nature of cancer and palliative care strategies

Research and Data Collection

1. Develop a clear ethical basis for the project to operate within and to describe and implement culturally appropriate notions of consent and confidentiality to those patients participating in the program
2. The collection of baseline data especially to demonstrate current levels of key indicators will be important to then be in a position to judge the efficacy of the program by those same indicators
3. Commence a comparative prospective double blind trial to determine pathological correlation for the telepathology versus the standard approach for pathological diagnosis. One will take the null hypothesis as there being no difference between the two methodologies and built into the program an analysis of this hypothesis to ensure patient safety, closing the study if probability constraints are breached.
4. Data will be compatible with the National Tumour Registry facilitating data entry
5. Utilisation of standard data collection forms and appropriate software to analyse patient outcomes of morbidity and mortality

Summary

This proposal is a framework document that defines the key objectives and illustrates the activities to be undertaken for the acceleration of diagnostic services for malignancy in the rural highlands of Papua New Guinea.

This document's intention is to generate discussion between key stakeholders involved in the project. This will enable and empower all those involved in its creation to have ownership of the design process, its implementation and its impact and results on the community the project will serve.

Once the document is disseminated the period of consultation will complete at the Church Medical Council meeting in May 2006 in Port Moresby. Contact details are given at the end of the proposal.

Draft List of Key stakeholders

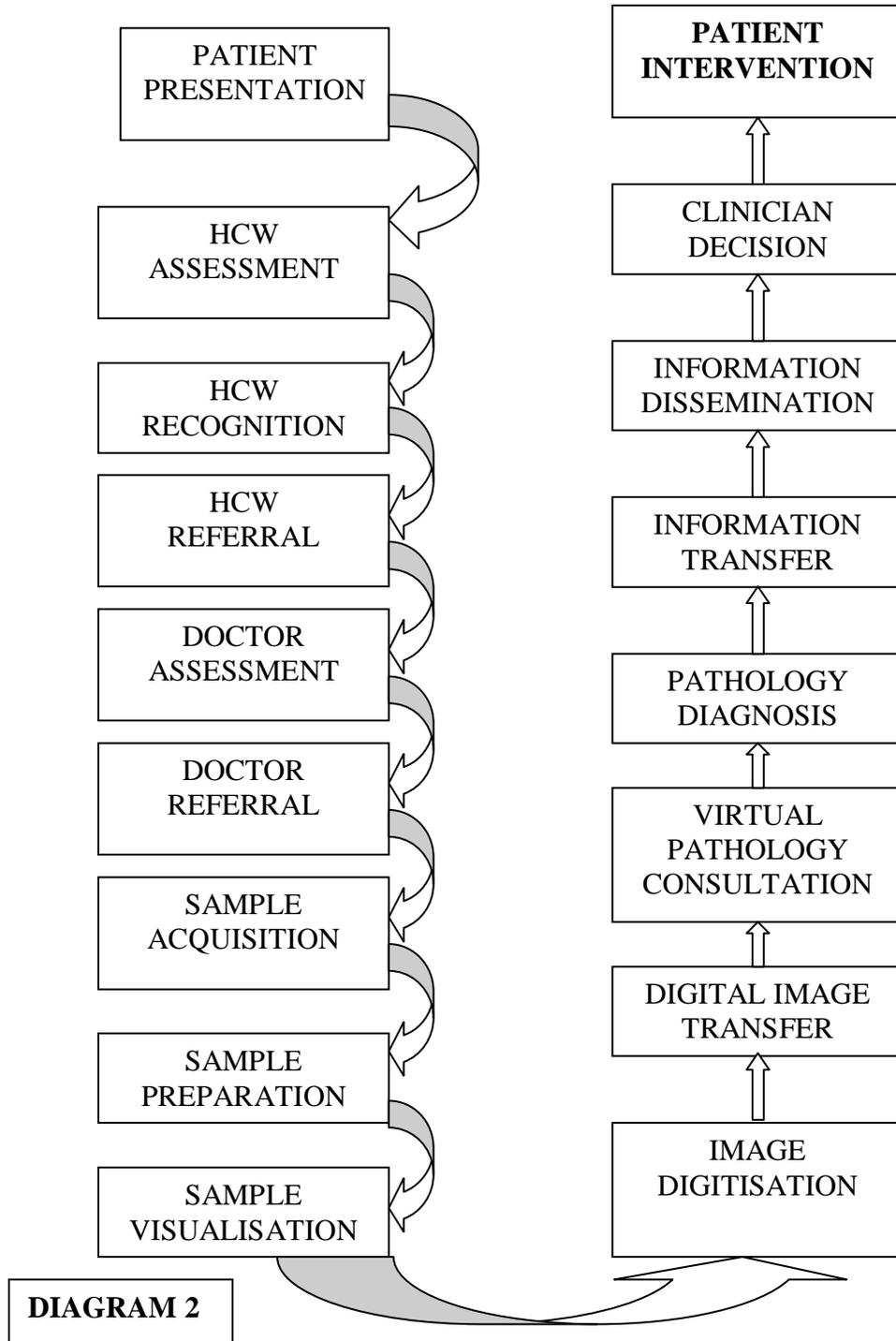
Kudjip Nazarene Hospital
Mount Hagen General Hospital
Kompam District Hospital
Tinsley District Hospital
Pathology Department Port Moresby General Hospital
Telepathology Unit, University of Basel, Switzerland
Nuffield Institute, UK
Division of Curative Health, National Department of Health, Port Moresby
Telepathology Unit, University of Pittsburgh, USA
PNG Telikom, Port Moresby, Papua New Guinea
Dr Evelyn Lavu, Consultant Haematologist, University of Papua New Guinea
Dr Goa Tau, Chief Physician, Port Moresby General Hospital
Professor J Vince, Port Moresby General Hospital
CRMF, Goroko
Asian Development Bank
British Telecom, UK
National Cancer Treatment Department, Angau Memorial Hospital, Lae
PNG Cancer Relief Society
Cancer Research UK

Suggested Indicators for the Program

The following describe a list of possible indicators of the impact, and evaluation of the project:

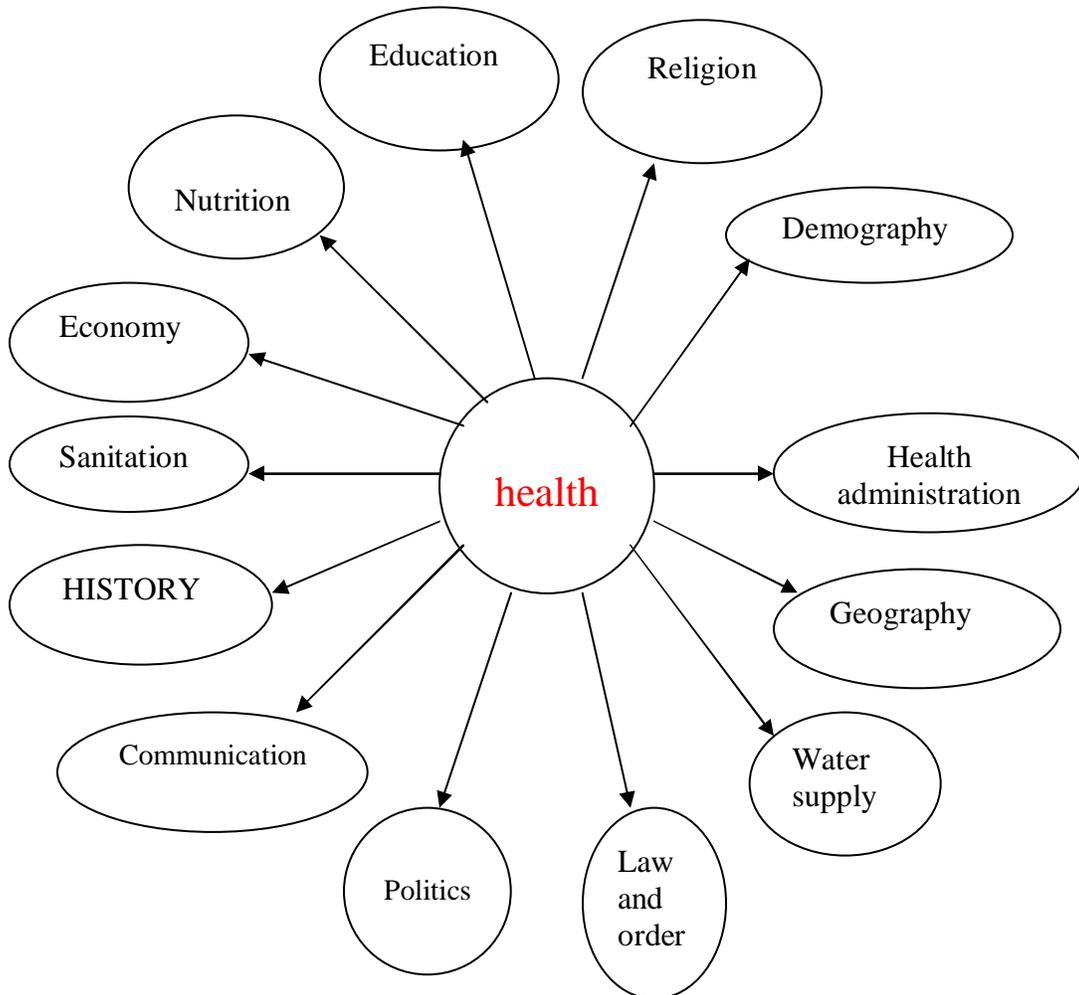
1. Pathological diagnostic correlation comparing digital and real time interpretation
2. Turnaround time (from sample acquisition to clinical decision for patient intervention)
3. Patient Outcome- Mortality and Morbidity
4. Level of community cancer awareness
5. Level of HCW knowledge and skill
6. Level of doctor knowledge and skill
7. Implementation of Palliative care approaches determining for example patient's experience of pain
8. Clinician satisfaction with the program
9. Clinical research paper publication in peer reviewed journal

ADAPTED FLOW PATHWAY INDICATING THE NECESSARY STEPS FOR A PATIENT INTERVENTION



Appendix 1

The range of components determining health



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