

RETENTION OF PATIENTS ON ANTIRETROVIRAL THERAPY
IN THE HIGHLANDS OF PAPUA NEW GUINEA

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ABSTRACT

SARTHAK DAS: Retention of Patients On Antiretroviral Therapy
In the Highlands of Papua New Guinea
(Under the direction of Sandra Greene)

Over 4 million HIV positive people are on antiretroviral therapy (ART) worldwide; the gap in access remains steep with over 20 million in need of life saving treatment. With proper access to HIV care and treatment services, HIV is no longer a life ending condition and can be managed as a chronic illness. This, however, requires a high level of adherence to an ART regimen for the rest of a patient's life making retention in ART programs of critical importance. While a myriad of programs exist to improve patient retention in the developing world, very little research has been undertaken to examine the effectiveness of case management to address patient lost to follow-up. In Papua New Guinea (PNG), the epicenter of HIV in the Asia Pacific Region, there is a dearth of research related to HIV services, despite over 10,000 people currently on ART. Through a comprehensive chart review of patient data from two Government operated ART clinics, this study examined the efficacy of a Case Management system in the Highlands of PNG. The Eastern Highlands have been implementing Case Management for ART patients since 2006 while Case Management is not being implemented the Western Highlands.

Results indicate patients in the Eastern Highlands have a higher likelihood of survival at 12, 24, 36, and 48 months. It is important to note that the Case Management intervention occurred simultaneously amidst the challenge of decentralizing services to nine District sites. Case Management appears to be a promising intervention though it is inextricably linked to the limitations posed by a resource constrained health system.

The complexity of HIV care, the need to reach patients closer to where they live, and the commitment by the Government of PNG to providing free anti retroviral treatment have merged to create a unique window of opportunity. A novel time has emerged for HIV-related resources to be used to strengthen primary health systems for the rural poor in PNG. This study provides an evidence-based foundation for launching an effort to reduce inequity while bringing voice to some of the world's most poor and most remote communities.

This dissertation is dedicated to my wife Andy Carmone,
whose courageous commitment to the rural poor of PNG and
tireless support to our family made this study possible.

It is also dedicated to the late Mary Drua,
the nation's first Case Manager/HIV Provincial Services Coordinator
and a pioneer in health for the people of Papua New Guinea.

May our efforts be worthy of your blessing.

ACKNOWLEDGEMENTS

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I am indebted to the erudite guidance of Dr.Sandra Greene, my Dissertation Chair who did not give up on me despite the many second, third, and fourth tries to meet deadlines and change research approaches. Dr.Sue Hobbs and Dr.Ned Brooks: I will always remember my interview to enter the DrPH program as I sat in the Highlands huddled around a phone in the early morning hoping to be fortunate enough to gain admission. I cannot express what an inspiration in leadership and humility you both have been and am eternally grateful to both of you for bringing me into the UNC circle. This, I hope, is only the beginning of our journey together. I am also thankful for the input offered by Dr.Bruce Fried and Dr.Dale Frank in this effort. A special thanks to Dr.Molly Franke who helped with the data analysis and much more. I am indebted to many others here on the CHAI team and in the health system of PNG. Moreover, I want to acknowledge my dear friend, mentor, and inspiration, Dr.Paul Farmer, whom played a major role in a thesis project nearly twenty years ago and who continues to be a source of motivation. And last but not least I want to thank my Cohort 5 colleague for their friendship, humor, and support throughout.

PREFACE

Deep in the Highlands of New Guinea, on a damp dirt floor, amidst half eaten corn and avocado pits, Mary Biga struggled to stay warm. Her skin was burning hot and though the diarrhea had subsided, her body was too weak to sip from a gourd half full with murky water. Weak after lapsing on her anti-retroviral treatment and struggling with active TB, Mary lay still, occasionally eyeing the narrow slivers of sky visible through the leaking thatch roof of the pigsty where she had been left. Occasionally, someone would drop a cooked sweet potato through an opening. The blood relations of Mary's deceased husband are not dreadful: after witnessing her husband's death from AIDS, the haus lain or clan had abandoned hope. Sorcery beliefs, common among Highlanders, compounded with lack of basic HIV knowledge, led them to keep her far from the clan. On a break from school, Francis, Mary's son, discovered his mother lying near death in isolation. Without help to carry her to the road, he was lost. Ever determined, he set off for help. The nearest large health facility, Goroka General Hospital was at least a day's walk through the mountains of Eastern Highlands.

It was 2006 and, in the Eastern Highlands of Papua New Guinea, the National Department of Health and Provincial Health Authority had begun a partnership with the Clinton Health Access Initiative and launched a pilot program called the Rural Initiative. Case Management, a central intervention component intended to both improve patient retention and treatment outcomes, had just begun.

A sleepless Francis serendipitously met with the new Case Managers who piled into a Toyota Land Cruiser and accompanied Francis back two hours by road to the pigsty where his journey had begun barely twenty four hours ago; the Case Management

team carried Mary to the waiting ambulance. Over the next weeks, she commenced TB treatment, and resumed ART. She also received protein to supplement her mono-starch diet and ongoing counseling from the Case Management team.

Today Mary farms kaukau (sweet potato) in her Highlands garden and is reunited with her clan. They've accepted her, incredulous at her recovery. Mary is adherent to her treatment now that she is supported with bus fare to reach her review appointments; as a result of the Rural Initiative, she can be treated at a Health Center closer to her village.

The Rural Initiative, Hospital, and Case Management teams form a battle-worthy tribe. Armed with ARVs instead of arrows, bed nets instead of bows, they are a coalition is fighting to deliver HIV treatment to rural communities while at the same time revitalizing primary health. Though total victory is distant, this tribe is advancing their cause. In the daunting world of building a continuum of quality care for rural and remote communities, there are slow but steady signs of progress.

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LIST OF ABBREVIATIONS

ADB	Asian Development Bank
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ART	Antiretroviral Treatment
ARV	Antiretroviral
AusAID	Australian Agency for International Development
CHAI	Clinton Health Access Initiative
CST	Care Support and Treatment (for HIV)
EHP	Eastern Highlands Province
FBO	Faith Based Organization
GFATM	Global Fund to Fight AIDS, Tuberculosis, and Malaria
GoPNG	Government of Papua New Guinea
HIV	Human Immune-deficiency Virus
IMAI	Integrated Management of Adult Illness
MCH	Maternal and Child Health
MoU	Memorandum of Understanding
NACS	National AIDS Council Secretariat
NDoH	National Department of Health
NGO	Non Governmental Organization
OIC	Officer-in-Charge
PEPFAR	President's Emergency Program Fund for AIDS Relief
PHA	Provincial Health Authority
PIH	Partners in Health
PICT	Provider Initiated Counseling and Testing
PLHA	People Living with HIV/AIDS

PMTCT	Prevention of Mother to Child Transmission
PNG	Papua New Guinea
POC	Point-of-Care
SCM	Supply Chain Management
SHP	Southern Highlands Province
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	United Nations AIDS
UNDP	United Nations Development Fund
UNICEF	United Nations Children's Fund
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
WHP	Western Highlands Province

CHAPTER 1

INTRODUCTION

Statement of the Issue

As the world approaches the fourth decade of the AIDS pandemic, an HIV vaccine remains elusive; meanwhile thousands, mostly in the world's poorest countries, continue to perish from one of most pernicious pathogens modern history has experienced. Since the epidemic began, 60 million people have been infected with 25 million deaths from HIV related illness. In 2009, UNAIDS estimates there were 1.9 million deaths from AIDS; globally, over 90 percent of these occurred in resource-limited settings (UNAIDS: 2011).

Over the past ten years, hope has emerged in the developing world through initiatives such as the WHO's *3 x 5 Campaign* (three million people on ART by 2005) and the advent of funding mechanisms such as the Global Fund to Fight Tuberculosis, AIDS, and Malaria (GFATM), as well as the United States' Presidential Emergency Program for AIDS Relief (PEPFAR). Such efforts have facilitated large-scale access to previously unaffordable anti-retroviral therapy. It is also critical to acknowledge the catalytic role of Partners in Health (PIH), an international NGO, who began the successful provision of ART to poor communities in Haiti while the international health community still debated the feasibility of ART in resource constrained settings (Mukherjee, Farmer, et al.: 2003). Today, over 4 million people are on ART worldwide; the gap in access, however, remains steep with an over 20 million who remain in need (UNAIDS: 2009).

With the expansion of ART and, given its nature as a life-long treatment, a major area of concern has been patient retention. Recent meta-analyses reveal that, despite the

expansion of ART programs, there have been significant rates of patient attrition or patient “lost to follow-up” (e.g. patients who miss multiple review appointments and who can no longer be tracked). In sub-Saharan Africa, in 2007, a major review estimated two-year retention in ART programs at 62% or nearly 40% ART patients were unaccounted for within two years (Rosen & Fox: 2007). Other studies reveal a combined mortality rate of 46% among patients traced in African ART programs (e.g. follow-up on patients who had been lost) (Weigel: 2011). Inadequate access to transportation, clean water, basic nutrition, and stigma are among obstacles to successful retention.

What, then, is the value in rapid “scale-up” of therapy if, after 24 months, significant percentages of enrolled patients are missing or have died? Interventions that reduce the rate of lost-to-follow up and improve patient retention have emerged as a critical area of research in HIV care and treatment. The rigorous study of ART programs that have produced significant improvements in patient retention may provide tangible solutions to an ever-growing problem not only in PNG, but also in other resource limited settings.

Background

While millennia have passed in isolation for the Highlanders of Papua New Guinea, HIV has penetrated mercilessly: PNG (population 6.6 million) has the fastest growing epidemic in the Asia-Pacific region accounting for 98 percent of all new infections in the region in 2008 (UNAIDS: 2009). Though initially urban, HIV has quickly followed trade routes of commercial and corporate exploitation leading HIV to become a disease of PNG’s rural majority. An ever-growing population of migrant laborers demanded by timber, oil, gas, and mining exploration (locals say PNG is “a piece of gold floating in a sea of oil”) combined with extreme poverty may fuel the rising epidemic. Cultural dissolution, contributing to a high tolerance of informal and formal transactional sex, social practices of polygamy or multiple partners during courtship, male attitudes towards extramarital sexuality, and widespread ignorance of modes of HIV transmission

particularly among rural communities, (where access to education is severely limited by unattainable school fees) also underpin the spread of HIV (Eves: 2003, Wardlow: 2007).

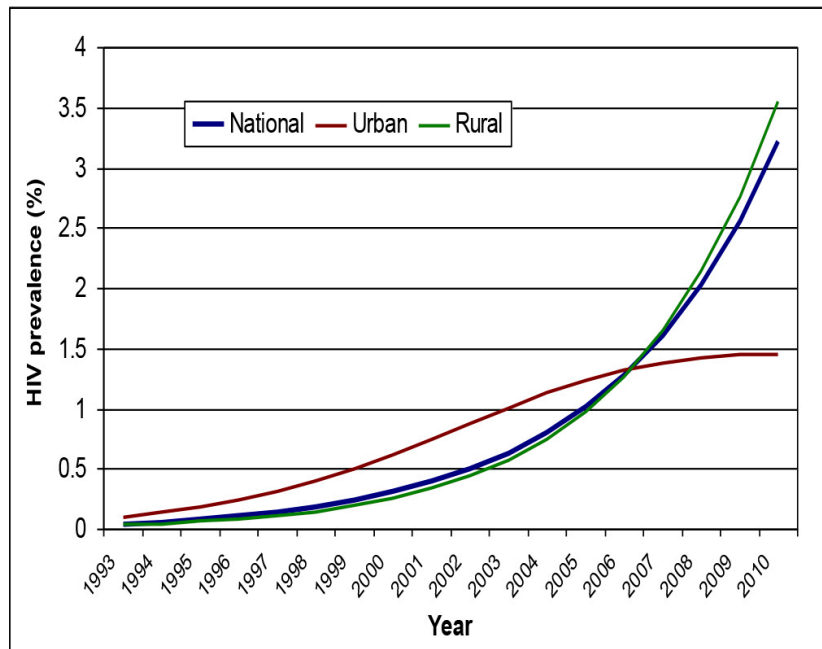
In the Highlands, “rural” assumes new meaning; it is a seeming endless sea of green, rugged mountains, ridge top hamlets, and deep forest dwellings. Compounding the challenge of the provision of HIV testing, care and treatment is a hobbled rural public health infrastructure: it is estimated that over 60 percent of all rural primary health facilities are closed (NDOH: 2009). Where they remain open, poor road access, human resources, and weak logistics for delivery of diagnostics and drugs challenge delivery of basic health services. Subsequently, the capacity to deliver HIV services, let alone decentralize and diffuse HIV testing care and treatment to rural communities, has remained minimal. Along with lives, entire languages, clans and cultures stand at risk.

Epidemiology of HIV

PNG, the most bio-diverse country on earth had its first case of HIV in 1987; since 1997 there has been an average annual increase in incidence of over 30% (Papua New Guinea National Department of Health: 2008). National prevalence is estimated near 1% but PNG has essentially two epidemics: low prevalence (less than <1%) in the coastal and surrounding areas and higher prevalence (2-4%) in the Highlands Region. There are approximately 6,000 adults on treatment with an estimated 36,000 to 54,000 in need (Papua New Guinea National Department of Health: 2009). Recent years have revealed a significant shift from an urban to predominantly rural epidemic. Of the rural majority, 2.5 million reside in the Highlands, and 90% of all reported infections come from locations along the Highlands Highway, the lone artery cutting a swath across the Highlands region (NDOH: 2009). The country’s main social indicators, such as life expectancy (57 years), infant mortality (57 per 1,000 live births), and maternal mortality (733 per 100,000 deliveries) remain low; PNG ranked 148 out of 182 countries in the 2009 Human Development Index compiled by the United Nations Development Program. (UNDP: 2009)

A number of PNG health indicators are the lowest performing in the Pacific Region: life expectancy is 15 years less and maternal mortality 3.5 times higher in PNG than in Fiji (Papua New Guinea National Department of Health: 2010).

Figure 1: Urban vs. Rural Epidemiology of HIV-1 in PNG



Heterosexual sex is the predominant mode of HIV transmission in PNG, although the mode of transmission is not recorded for over 51% of reported HIV infections (PNG National AIDS Council Secretariat: 2010). In addition to concurrent and multiple sexual partnerships, unprotected intercourse, and high prevalence of untreated sexually transmitted infections in the general population also drive the epidemic. More than fifty percent of the population lives in poverty with unemployment fueling rural migration to urban areas.

Decentralization of HIV Services

The rugged terrain of PNG is divided into 21 Provinces; the Highlands Region accounts for five of these Provinces. Until late 2006, the primary efforts

in the National response have been focused on major urban centers. This response has been funded largely through donors (e.g. UN, the Australian Agency for International Development and the Global Fund to Fight AIDS, Tuberculosis, and Malaria) with a focus on prevention; testing, care, and treatment have minimally expanded to the rural majority.

In 2006, the National Department of Health requested the Clinton Foundation to undertake a pilot program to develop a Rural Model for HIV testing, care, and treatment, which could be replicated in other high prevalence Provinces. The program was undertaken in Eastern Highlands Province (pop. 432, 972), an area divided into 8 Districts: Lufa, Kainantu, Goroka, Daulo, Okapa, Obura-Wonenara, Henganofi, and Ungaii-Bena. Goroka General Hospital is the main Provincial referral hospital; there is at least one Health Center in each of the eight Districts. When the pilot program began in 2006, ART was available only in Goroka General Hospital. The goal of the pilot has been to decentralize high quality HIV testing, care, and treatment to the Districts while revitalizing basic primary health services. The project has sought to create a functional unit where there is centralized coordination of data collection, clinical supervision, and supply chain management at the Provincial hub with decentralized or diffused provision of HIV testing, care, and treatment across District level Health Centers.

From the very beginning, a key emphasis has been on the implementation of strategies designed to improve patient retention and treatment outcomes. At present, the pilot program has been in implementation for 48 months. This research seeks to investigate the importance of integrated approaches to HIV patient care through Case Management in resource poor settings as a means to both improve clinical outcomes and strengthen health systems.

CHAPTER 2

LITERATURE REVIEW

Goal

While this study seeks to examine lost-to-follow up among two cohorts of ART patients in the Highlands of PNG, this literature review requires broadened parameters that: 1) Assemble existing literature on patient retention and ART programs in other resource poor settings and 2) Gather existing literature related to HIV/AIDS and ART in Papua New Guinea.

Search Parameters

This review utilized a number of sources to locate not only peer-reviewed articles, but also unpublished reports. Pub Med, AIDS Info and EMBASE were the primary databases. The search was conducted using the following search terms: “Human Immunodeficiency Virus”, “Acquired Immunodeficiency Syndrome”, “HIV”, “AIDS”, “STD”, “STI” “Papua New Guinea”, “PNG”, “rural”, “care and treatment”, “anti retroviral treatment”, “lost to follow-up”, “retention”, “adherence” and “case management.” The search was limited to citations from 2000 onward and those that have been published in English or *Tok Pisin* (the *lingua franca* of PNG). In addition, in-country sources such as the National Department of Health, the National AIDS Council Secretariat, Church’s Medical Council, Institute for Medical Research in PNG, Australian Agency for International Development, Asian Development Bank, Divine Word University, major Hospitals in the Highlands Region, and the University of Papua New Guinea were also consulted for unpub-

lished documentation of ongoing projects, reports, or studies related to this field.

Categorization of Studies

Studies were divided into two broad categories: PNG vs. non-PNG. Within each of these categories, they were further separated into: 1. Information on ART scale up in resource poor settings 2. Studies related to issues pertaining to lost to follow-up and retention in ART programs.

Key Criteria

Inclusion

As the literature on HIV in PNG was surmised to be relatively thin, the search included most articles relevant to any aspect of HIV in PNG. In some cases, broader health systems research in PNG also provided important evidence. Other studies that document the personal experiences of HIV in the country or the influence of faith based or other non-governmental agencies in the National response were also included. Examples of successful retention efforts in the decentralization of HIV services in other rural resource-poor settings, and literature on Case Management of HIV were also incorporated.

Exclusion

Literature which pertains to HIV testing and treatment outside of PNG in non-rural, non-resource limited settings were excluded as were studies that separated HIV -services from retention related efforts. Also, HIV and ART related research from middle and high-income countries was also excluded.

Results

As expected, the literature on HIV/AIDS in Papua New Guinea was minimal; the research on HIV in rural PNG was even more limited. The search methodology employed used the following terms:

Table 1: Search Terms

Disease Specific Terms		Intervention/Strategy/Area		Target Geography
Human Immunodeficiency Virus	AND	ART	AND	Papua New Guinea
OR HIV		Retention		OR
OR		Rural OR Remote		PNG
Acquired Immune Deficiency Syndrome OR AIDS		Scale-Up		OR
		Case Management		None Specified
		Treatment		
		Lost to follow-up		

Though it was originally proposed to include the search terms “resource poor” and “high quality” these terms were omitted, as they did not yield results that would be useful in this review. In addition, the methodology had previously sought to discount all research prior to 2004, which coincides with the introduction of ART to PNG. This was, however, unrealistic given the dearth of literature available specific to PNG therefore the search was broadened to include literature from 2000 onward.

The “grey” literature, particularly relevant reports from the Australian Agency for International Development and the National Department of Health, Papua New Guinea also proved useful. With respect to the databases consulted, the AIDS Info database did not yield any searches that were specific to PNG and did not offer information other than clinical guidelines in the management of opportunistic infections and AIDS related illness. The relevance of the studies was based on whether or not they reflected a quality of information related to the following main categories of interest:

In Papua New Guinea

- Have a direct relevance to HIV in PNG either through descriptive, qualitative or quantitative study
- Assist in providing an understanding of the epidemiological context of HIV in PNG
- Reflect knowledge of the Health Systems in PNG
- Provide insight into the role of Faith Based Organizations (FBOs) in the scale-up of HIV services (FBOs provide 40% of all HIV services in PNG)

In Non-PNG Context

- Address broader issues of scale-up within weak public health infrastructure
- Present decentralized models of HIV services which operate through Government systems
- Place an emphasis on retention and lost to follow-up
- Maximize use of non-physician interventions with an emphasis on Nurses and Community Health Workers
- Reflect methodologies which offer a patient centered approach in the development of models of HIV care and treatment

With respect to articles that deal directly with the HIV in the Papua New Guinean context there was a paucity of information. Using the search terms Papua New Guinea and HIV/AIDS yielded only 79 results total while variations on this (e.g. HIV and PNG, AIDS and PNG) produced similarly small totals. Most of these articles were not quantitative, there were no randomized control studies, the number of observational cohort studies was limited, and few were published in international peer reviewed journals. Of those have been published internationally a majority are anthropological, descriptive, or pertain to faith based publications. While there are some cohort and observational studies the literature search yielded only three articles pertaining directly to ART in PNG in rural areas. The first was an observational study based on speculations about the barriers to ART scale-up rather than any analysis of actual attempts to scale-up HIV treatment services in rural PNG; the second did address barriers to ART adherence based on a sampling of over 300 patients across six provinces but not all of these were in the rural context nor did it pertain to efforts to remove barriers to care. A third study, published by the Institute of Medical Research in Papua New Guinea, is a qualitative account of barriers to ART Adherence.

Based on the available literature, PNG-specific documents can be broadly categorized into five categories:

1. Christianity and Responses to the HIV/AIDS Epidemic
2. Cultural Norms /Practices and Impact on HIV Transmission
3. Roles of Women and Men in PNG and Influence on Epidemiology
4. Stigma, Discrimination, and Living with HIV
5. Surveillance and National Department of Health Reports of Current State of the Epidemic

Rather than exclude all articles from the above categories for their failure to include the provision of ART in the document, selections were made after a full

review of the article for those that were deemed to provide useful information in establishing the context of the epidemic in PNG. Were this not done, the review would be left with virtually no information on HIV within the PNG context within which to situate research questions related to HIV care and treatment.

Reviewing the Non-PNG Specific Literature

Given the dearth of information on ART PNG, the literature review sought to broaden the scope of the search to include efforts to scale-up HIV Services in other resource limited settings. A considerable additional amount of research has been conducted over the past five years, particularly in sub-Saharan Africa, to examine the efficacy of ART program retention. Several permutations were attempted using the search terms that were inclusive of the rural and case management terminology. A large number of these were clinical in nature and focused on discrete treatment outcomes rather than broader questions related to public health or systematic reviews of programs aimed at creating sustainable continuums of care that address retention issues.

Lost to Follow Up

The literature reveals that as access to treatment has increased, available data, and published studies on attrition or lost-to-follow up continues as a major area of concern (Rosen & Fox: 2007). In other words, expanding the breadth and scope of HIV services to rural communities has carried with it the significant issues in making sure those that access treatment are able to stay on treatment.

Case Management

The conceptual origins of Case Management emerged in the 1800's as social movement to address the needs of the poor. Since that time, it has existed in a number

of forms, always defying a rigid description. Case Management services have run the spectrum from a lone social worker trying to link individuals to social services to multi-disciplinary teams who coordinate comprehensive packages of psychosocial and clinical support. By the 1970's in the US, case management was widely regarded as a means to help the vulnerable to navigate the social service system.

The HIV epidemic in the US and subsequent domestic policy response through the Ryan White Care Act of 1990 “mandated HIV case management to ensure service coordination and continuity” (Fleisher and Hendrickson as cited in Murphy et al. 2003). Those affected by HIV often face a number of unique social, economic, clinical, and cultural challenges that require support from a range of services. Case Management seeks to address multiple layers of the health system, which work together to coordinate the clinical, and psychosocial services necessary for persons affected by HIV/AIDS (Craw et al: 2008). Case management can include:

1. Assistance through the referral process within the health system
2. Access to other support services such as the provision of transport subsidies, protein supplements, or other psychosocial services
3. Education about drug adherence

With respect to HIV, all three of the aforementioned areas addressed by Case Management are critical, irrespective of the treatment setting. Case Managers themselves, in the Western medical context, are often trained Social Workers (often specialized in Medical Social Work).

HIV Case Management & Resource Limited Settings

Though Case Management is common practice in the US and other developed countries, it is infrequently a model employed in more resource-limited settings. While a number of ART programs in resource poor settings emphasize patient support measures such as nutrition, adherence counseling, or case workers,

very few implement an approach modeled after the type of case management that is practiced in the US, Europe, and other non-resource limited settings. Of those programs that do employ some form of Case Management, there have been qualitative studies of efficacy but no systematic reviews of clinical outcomes through chart reviews (Thurman et. al: 2010).

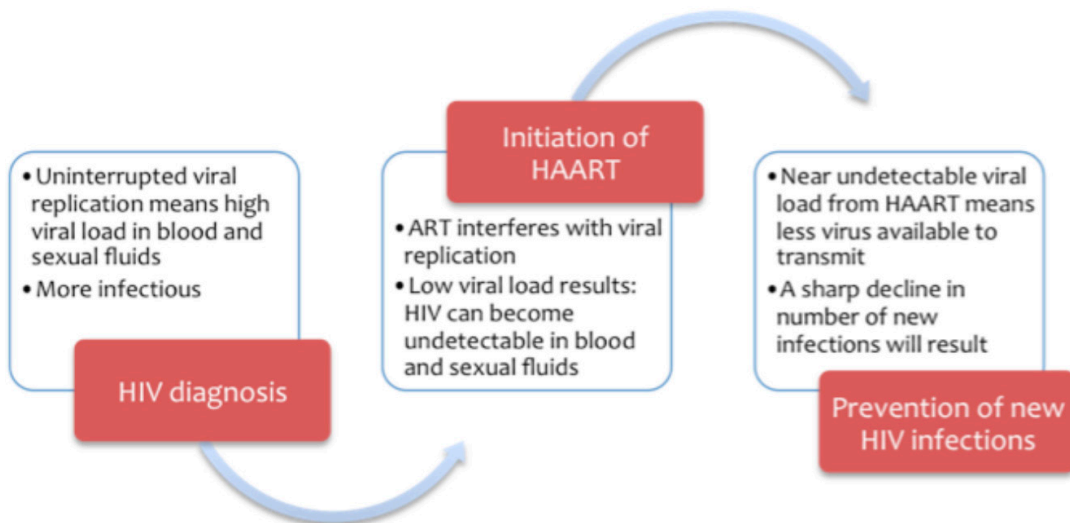
HIV patients are identified across a range of settings in any given health system: apart from freestanding voluntary counseling and testing (VCT) facilities, they may be identified in TB, STI, Ante Natal Clinics, as well as in patient wards. In resource limited settings it is critical that identified patients (many of whom may have limited education and resources and lack familiarity with navigating the health system) have both clear referral pathways and provider support to ensure they receive the necessary care and treatment services once identified as HIV positive. Approaching a fragmented health system can be daunting for literate, middle class people in the developed world. The challenges of a “silo-ed” health system are magnified for a rural based HIV positive patient who may travel a great distance from their village to a referral hospital and who may lack the education or confidence to move amidst the many areas of hospital, its pharmacy, and various clinics.

Once enrolled in and ART program, an intricate web of clinical, social, economic, and cultural factors all influence HIV care and treatment. For example, prior stigmatization as HIV positive may lead to a client being ostracized from his/her community. This can in turn influence ability to generate income, secure transportation, and make necessary review appointments. It is widely accepted that patients with HIV often have a multiple, complex social needs many of which can impact patient care. Moreover, HIV is most often a disease of the poor and marginalized which means a host of socio-economic, cultural, and historical factors can impinge on successful treatment (Farmer: 2004, Cunningham: 2008).

With its emphasis on both the coordination of referral pathways and retention of patients through a focus on reducing the material obstacles to care, case management is a critical aspect of strong HIV treatment programs. Equally important is the impact on drug adherence. Non-adherence to HIV regimens risks not only treatment failure but also the development of drug resistance (El-Khatib et. al: 2011). In turn, better HIV treatment programs with case management can have the secondary effect of serving as an important prevention strategy. As some have noted “improving linkage to HIV medical care and treatment directly benefits patients; it is also an important prevention strategy for reducing transmission of HIV infection, because patients on antiretroviral therapy who have low viral loads are less likely to infect others through heterosexual risk behaviors” (Craw et. al: 2008).

A growing body of evidence also demonstrates that ART can play significant role in preventing transmission of HIV. In 2011, the HPTN 052 study demonstrated the efficacy of treatment as prevention was 96% – that is HIV-positive people taking ARVs were more than twenty times less likely to infect their partners than untreated people.¹

Figure 2: ART and Treatment as Prevention



Therefore, a key contribution to HIV prevention is the reduction of viral load in those taking up ART. Strong patient retention programs then, become even more important; not only to retain HIV positive patients who are on treatment but also to serve as means to prevent additional infections among at risk HIV negative individuals.

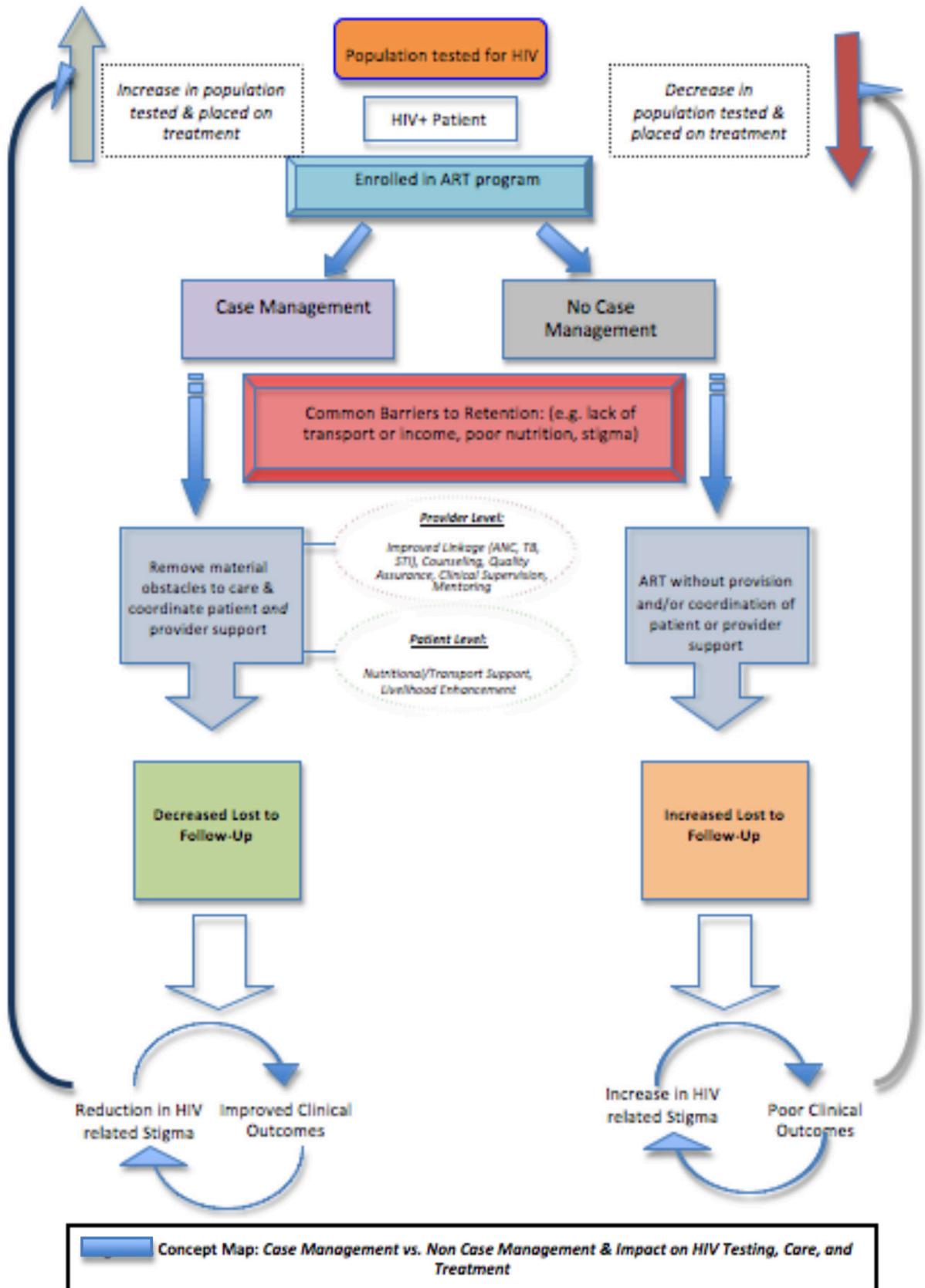
Case Management in the PNG Context

As part of PNG's first effort to decentralize HIV services to rural populations at the District level, a Case Management model was proposed and implemented in 2006, which employ additional health workers as part of a Case Management team that seeks to:

1. Coordinate a package of patient support services to reduce material obstacles to care including transportation and nutritional support.
2. Augment existing health care providers in the provision of ART and the monitoring of current ART patients.
3. Support clinic staff in the collection and maintenance of patient data.
4. Conduct clinical mentoring and supervision for new ART providers both at the main referral hospital and, on a rotational basis, at the District ART clinic level.

At the Provincial Hospital level, Case Management teams consist of 2 Health Extension Officers (these are mid-level providers, the equivalent of Nurse-Practitioners in many Western countries), 2 Nurses, 2 Community Health Workers, and a Driver. District level facilities receive support from Case Management teams at the Provincial level but do not currently have extra human resources for Case Management activity. Clinical mentoring, supervisory visits, assistance with ensuring adequate supplies of essential drugs and test kits, and support in the

Figure 3: Conceptual Framework for Case Management & HIV Service Delivery



maintenance of patient data are all functions of the Case Management team at the Provincial Hospital and District Health Center levels.²

Figure 3 is a depiction of a conceptual model to describe the potential impact of case management systems on HIV patient outcomes. This model employs theoretical frameworks used to describe system behavior developed by Meadows, Meadows, Randers, and Behrens through their conceptual modeling techniques described in *Limits to Growth* (Braun: 2002). The use of feedback loops is placed in the context of a broader conceptual map of the hypothesized impact of case management on HIV testing, care, and treatment outcomes.

The column on the left describes a cascade where Case Management services coordinate a package of patient and provider support. That is to say, in addition to the removal of material obstacles to care for patients, Case Management in the PNG context also supports providers by: 1. Improving the quality of counseling, 2. Ensuring linkages between key clinical referral pathways where HIV patients are detected (i.e. antenatal, STI, and TB clinics), and 3. Placing emphasis on both quality assurance and clinical outcomes in an effort to strengthen the health system overall. The phrase “Case Management,” therefore, may need to be revisited as the term can connote a patient-centered approach whereas the model employed here emphasizes not only individualized patient care and the coordination of support services, but also serves as a system to meet the needs of health care providers.

In an environment where HIV related stigma remains high, good treatment outcomes can help reduce stigma. It is hypothesized that improved retention culminates in a balancing “positive” feedback loop where Case Management results in a reduction of stigma. This can occur when patients are visibly functioning better thus challenging the notion that HIV/AIDS is a terminal condition. . Improved drug adherence and reduced stigma in turn will positively influence the number of people who seek HIV testing and therefore the number who enroll in Case Man-

agement services.

Conversely, the cascade in the second column describes an absence of support mechanisms that in turn lead to poor adherence and higher rates of lost to follow-up. This can produce a negative, reinforcing feedback loop where HIV positive patients are stigmatized thereby discouraging others from seeking HIV services and, ultimately, increasing the level of stigma associated with HIV. Though this study is focused on rates of retention, and does not measure stigma it is important to acknowledge the impact of stigma on the uptake of HIV services.

Chapter 2 Endnotes

1. Grinsztejn et al. *Effects of Early versus Delayed Initiation of Antiretroviral Therapy (ART) on HIV Clinical Outcomes: Results from the HPTN 052 Randomized Clinical Trial* IAS Rome 2011

2. It is essential to note that Case Management still operates within the environmental constraints of the public health system in rural PNG. As such, it should be understood that fundamental building blocks of the health system such as supply chain management, laboratory support, human resources for health, and underfunded health programs are among factors that affect the ability of Case Management services to operate.

CHAPTER 3

METHODOLOGY

Operational Definitions

Patient retention and its converse, patient “lost to follow up” has a variety of meanings across various patient monitoring and data systems. In the context of the HIV care and treatment, retention and lost to follow-up have taken special significance given the importance of adherence to ART which is a life long commitment. For the purposes of this study, lost to follow-up will be defined as a patient who has missed either two review appointments or for whom 90 days have elapsed since the last scheduled appointment.³ A patient is considered “retained” when the date at which they have last been seen at a clinic is equal to or greater than the specified number of months (e.g. 12, 24, 36, or 48) from the date at which they initiated ART.⁴

Study Design

To this researcher’s knowledge, no analysis has been performed on patient retention using clinic level data at ART centers in the Highlands of Papua New Guinea. The study design involved a quantitative analysis of secondary data comparing two patient groups enrolled in ART programs in the Eastern and Western Highlands of PNG. The following section outlines the methods used in this research study.

Research Question

Does the use of a Case Management system reduce patient attrition (e.g. patients lost to follow-up) among adults enrolled in ART programs in the High-

lands of Papua New Guinea?

With respect to this question, the researcher hypothesized that Case Management is an important intervention in improving the quality of HIV care and treatment services.

Hypothesis:

The coordination of patient care through a Case Management approach will result in significant reductions in the number of ART enrolled patients who are lost-to follow-up.

Sub Hypotheses:

1. There will be greater uptake of HIV testing in the catchment where Case Management is present.
2. There will be a higher percentage of patients referred from other clinical areas (e.g., STI, and ANC) in the Case Management cohort.

In seeking to answer the research question and test the sub-hypothesis above, there were three primary goals in undertaking this study:

Study Aims

1. To assess the impact of the Case Management system on patient lost to follow-up among adult ART patients in the Highlands
2. To evaluate correlations between key demographic factors (e.g. age, gender), the uptake of HIV testing, and the effect of the Case Management
3. If the data yield substantive evidence of the efficacy of Case Management in improving retention, advocate for the adoption of an improved model of HIV service delivery through national level policy in Papua New Guinea that includes Case Management.

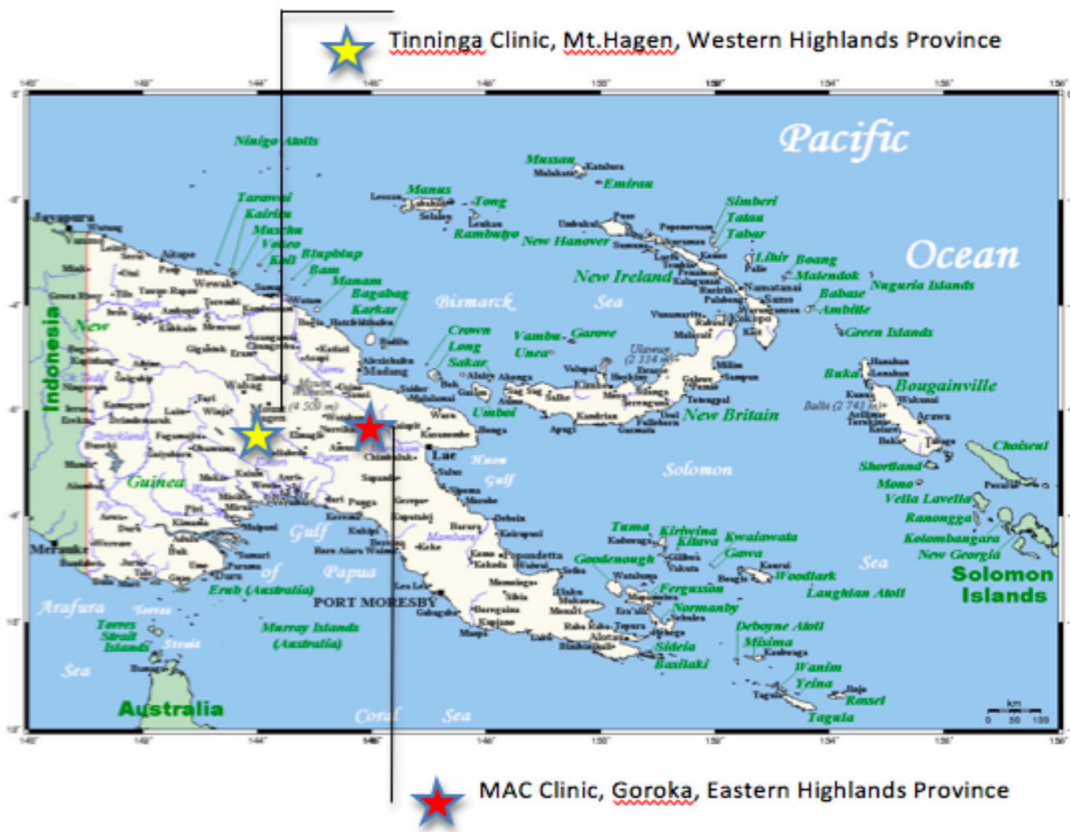
It is intended that this research will serve as the basis for a policy document presented to the Papua New Guinea Ministry of Health will lead to adoption of Case Management as part of a rural model for HIV care and treatment and will guide Government policy in the National HIV care and treatment response.

Study Locations

The patient data was collected from two provinces: one in the Eastern Highlands Province (pop.432, 972) which covers an area of 11,200 square kilometers and is divided into eight districts and a second catchment to the west in Western Highlands Province (pop.440, 025) which covers an area of 8,500 square kilometers and is divided into seven districts. Both Provinces have one main Provincial Referral Hospital, each with its own ART clinic: in Eastern Highlands this is Michael Alpers Clinic, Goroka General Hospital and in Western Highlands this is Tinninga Clinic, Mt.Hagen Hospital. These facilities are roughly 200 kms apart or 4-5 hours by road.

Resources from the Global Fund to Fight AIDS, Tuberculosis, and Malaria were used to open five ART centers in major Provincial referral hospitals in 2005; Mt.Hagen Hospital and Goroka General Hospital were among these five.⁵ Both of these Hospitals are situated in locales of high cultural diversity. For example, there are 28 different language groups in the Eastern Highlands alone. There are five provinces in the Highlands Region: Simbu, Eastern Highlands, Western Highlands, Enga, and Southern Highlands Province. Of the five, Eastern Highlands and Western Highlands have more well developed health systems though they still remain quite weak in comparison to other resource limited settings. While there are a number of smaller, faith based health facilities these are the only major referral Hospitals serving a total Highlands population of nearly three million.

Figure 4: Site Map of ART Clinics in the Highlands Region



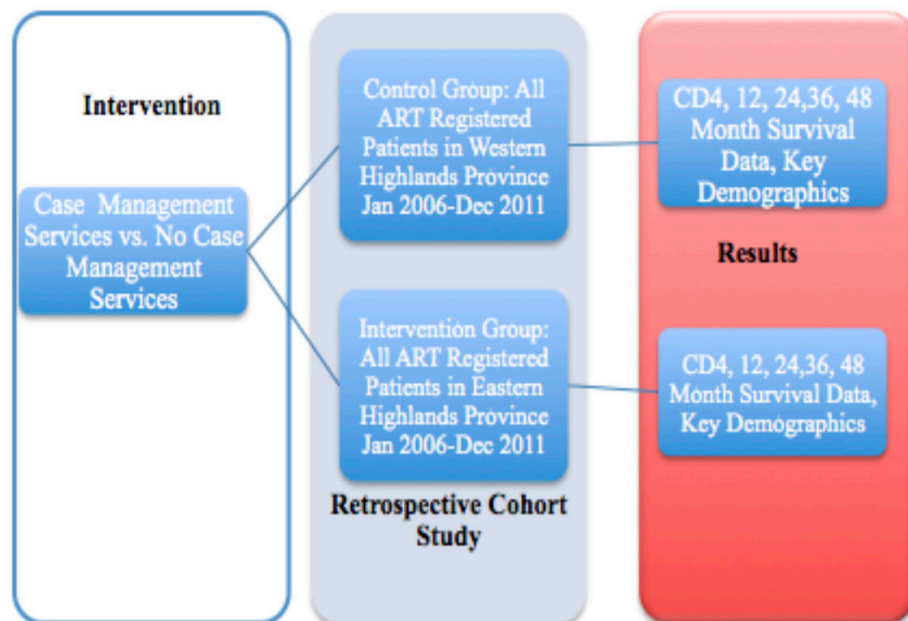
Case Management services have been available in Goroka General Hospital since 2006. These services have evolved over time as the number of registered patients has risen steadily: from 184 registered patients in December 2007 to 2171 as of September 2012. While Case Management has matured as a system, its primary aim (the reduction of material obstacles to patient care) has remained a constant. As of September 2012, Case Management services are in the initial stages of roll out in Mt.Hagen Hospital; there were no Case Management services available during the study period.

Data Collection Methods

Through a retrospective case/control study design, patient data was compared from the two ART Clinics:

1. *Intervention Group*: ART Enrolled Patients from Michael Alpers Clinic, Goroka General Hospital, Eastern Highlands Province who received Case Management services.\
2. *Control Group*: ART Enrolled Patients from Tinninga Clinic, Mt.Hagen Hospital, Western Highlands Province who received the Government standard of ART care.

Figure 5: Overview of the Study Design



The initial iteration of the research design intended to generate a sample of 500 patient charts from each clinic but the researcher elected to review all patient charts in the study time period (this is discussed further below in this section). A patient chart was eligible for inclusion in the study if that patient was registered in their respective ART program anytime between January 1, 2006 and December 31st, 2011; adult patients, in the PNG context, are defined as anyone over the age of 15. This comprehensive chart review was conducted using all available and eligible patient charts of patients registered at either Tinninga ART Clinic in Western Highlands or Michael Alpers ART Clinic in Goroka,

Eastern Highlands Province. These data were collected between April -September 2012.

There are a very limited number of reliable data sources within each clinic. Though patient databases do exist at both sites, there are frequently gaps in data entry leaving the databases unreliable sources of patient information. Similarly, ART logbooks exist at both sites that capture initial information on patient registration in the ART clinic. The logbooks, however, do not provide information on the patient's current status (e.g. alive and on treatment, lost to follow-up, transferred out, or died). For these reasons, only the paper based patient charts themselves are reliable in terms of verifying patient data.

Initially, a data extraction form was developed for the manual chart review (see Appendix 1) including key demographic data (e.g. age, marital status, gender, level of education), select clinical data (e.g. CD4 count, WHO Stage at initiation of ART), and whether or not the patient was still actively enrolled in the ART program at 12 months, 24 months, and, where applicable, 36 (or even 48) months (e.g. if a patient was registered January 1, 2008 that patient can tracked to see if there were still enrolled at 48 months given the January 1, 2012 end date for data collection). Patients were defined as lost to follow-up if they had missed two or more consecutive review appointments or had not attended the clinic in 90 days.

A pilot of the data extraction was performed by the researcher and the existing Case Management /ART clinic staff at Michael Alpers Clinic, Goroka Hospital, and Case Management / ART clinic staff at Tinninga Clinic, Mt.Hagen Hospital. The researcher conducted training with clinic staff at each site. The data abstraction form was reviewed, along with parameters related to patient eligibility (e.g. dates for inclusion/exclusion). All clinic staff was made aware of the purpose of the research and the relevant approvals from both the National AIDS Council Secretariat, Medical Research Advisory Council, and CEO's of each Hospital were shared with the teams. Issues related to patient confidentiality, security of the data, and other relevant research protocols were also discussed.

The data collection occurred under the direction and supervision of the respective

Hospital CEOs as well as the Officer's In Charge of each Clinic. Patient names, addresses and medical record numbers were not abstracted. The data abstraction forms were numbered sequentially. A key linking numbered abstraction form with patient identifiers was kept by the researcher and stored in a secure office.

A pilot evaluation study to determine the quality of the data abstraction forms was conducted. 20 data abstraction forms and their respective patient charts at each site were selected at random and reviewed by the researcher along with clinic staff. The review revealed glaring omissions, gaps in data entry, and inconsistencies in the information provided at both sites. After extensive discussions with Officer In Charge and clinic staff at both sites, it was determined that many of clinic staff did not have the time to conduct the data collection without additional outside assistance. Staff also admitted that, in some cases, they might not have reviewed charts as thoroughly as they should have due to time pressure. They also experienced frustration that many of the data points being sought were either unavailable in the patient charts (e.g. CD4, WHO Stage at Initiation) or too difficult to extract (e.g. BMI, Distance to Clinic).

Given these challenges in data abstraction, the clinic and Case Management staff requested that the study be used an opportunity to create their own reliable patient databases as these were lacking at both sites. This required reviewing the charts of all registered patients in both Eastern and Western Highlands and entering their information into a new database. This also included patients from 2005 and 2012, though these were excluded in the data analysis for this analysis. Additional support from the Clinton Health Access Initiative was also requested and granted for this exercise to work alongside clinic staff to ensure proper review of patient charts could be completed during the study period. A very important, additional reason for the adjustment in methodology was not only to generate more robust data but also to use this research opportunity as a means to strengthen clinic level medical records. While this increased the amount of time needed for data collection (since all records were reviewed and not only those in the eligible time

period for the study) it fostered a sense of ownership among the clinic staff for the data itself.⁶

A simple excel spreadsheet was created at each site which recorded patient age, gender, home province, date of registration, data of initiation, date of last appointment as well as a limited selection of other key patient clinical data (e.g. CD4, TB status, last known ART regimen). After an additional training at both sites, all patient charts at each clinic were reviewed and entered into excel sheets, and the files were then merged. A total of 2173 patient charts were reviewed in Eastern Highlands and 2569 patient charts were reviewed in Western Highlands; 993 patients were eligible for inclusion in this study from the Eastern Highlands and 1464 patients were eligible for inclusion from the Western Highlands.

To ensure data integrity patient charts were routinely (approximately 10 for each 100 entries) selected at random and compared against the excel spreadsheet form to ensure that the data has been entered correctly. The entire process of reentering all patient level data took five months and was concluded in September of 2012. Staff from the Clinton Health Access Initiative's monitoring and evaluation team worked along side clinic staff at both sites to facilitate the process of data collection.

Data Analysis Methods

Demographic data was examined for correlations between lost to follow-up status and gender, age, and province. Is there an association between age at time of initiation or gender and retention? Can conclusions be drawn on the efficacy of Case Management based the 12, 24, 36, or 48 month retention rates? These are among many questions explored from the data in subsequent chapters.

The retention rates described in the next chapter calculated patient retention as:

$$\frac{\text{Number of patients alive and on treatment at 12 months (or 24, 36, 48 months)}}{\text{Number of patients eligible to complete that amount of follow-up.}}$$

For example, all patients in each cohort had at least 12 months of follow-up. These patients fell into three categories at 12 months:

1. Transferred out
2. Retained (e.g. alive and on treatment at 12 months)
3. Not retained (died or lost to follow-up)

Not all patients were eligible to complete two years of follow-up (i.e. patients who that started at the end of 2010) therefore these patients did not contribute to the two year follow-up calculation.

For each ART patients, an actual follow-up time (Date of last review - Date Initiated ART) was calculated; subsequently, a potential follow-up time (Date of Data Collection - Date of ART Initiation) was calculated. To contribute to the 1-year calculation the patient had to have a potential follow-up time of 365 days (720 for two years, etc). Among patients with a potential follow-up time of 365 days, if the actual follow-up time was at least 365 days they were considered retained. Similarly, among patients with a potential follow-up time of 720 days, people who had an actual follow-up time of at least 720 days were considered retained at 24 months, etc.

In terms of patients who were present for less than a year, this did not influence calculations in the data analysis because anyone who presented for less than a year should have been either transferred out or not retained. The graphs and the multivariable analysis tables presented are person-time analyses. Given the outcome of interest was retention, the person-time of people who transferred out while they are in the program were removed from the analysis on their transfer date.⁷

Data were collected on both the date that a patient was registered at the ART clinic and the actual date the patient initiated ART. In most cases, these dates are not the same as a patient may receive an HIV positive test and register for the ART program. The same patient, however, will be scheduled for a follow-up appointment to actually receive ART counseling and commence treatment. As there was anecdotal evidence that there may be significant loss of patients in the first 90 days after initiation, the data analysis also includes cohort construction that examines differences in retention rates based on including all patients and then excluding those who were not retained in the first 90 days.

The primary predictor variables were whether or not patients are receiving the Case Management intervention while the primary outcome variable was patient adherence as measured by the rate of patients lost to follow-up. From the data collected, univariate and multi-variate data analysis using Cox Proportional Hazards Regression was performed to as well as survival analysis using Kaplan Meier survival curves.

Related to the sub hypotheses, the chart review was to include data on referrals to examine the strength of Case Management in linking services within the Hospitals from major points HIV case detection (e.g. TB, Ante Natal, and STI Clinics). These data could not however, be collected, as they did not exist in most of the patient charts. Related to the second sub hypothesis, overall HIV testing data from each province in each year of data collected was available. If there is a significant difference in the uptake of HIV testing among the broader population, some associations were drawn between the impact on testing of higher retention and more positive treatment outcomes.

Potential Sources of Bias and Confounding Factors

The most central confounding factor was the inherent difference in comparing

the impact of Case Management in a setting where decentralization of ART was occurring (e.g. the Eastern Highlands) to a setting where services were completely centralized. The confounding influences of the centralized vs. decentralized HIV service delivery and its potential impact on Case Management cannot be underestimated. There are inherent challenges in bringing the complexity of HIV care and treatment to poorly resourced rural Districts while at the same time implementing a new health service delivery model. Comparative patient retention rates should be taken with the caveat that in the Eastern Highlands the data comes from a care delivery system spanning nine ART sites whereas in Western Highlands ART is provided at one site. The data analysis takes this into consideration when analysing site level data both individually and comparatively.

In terrain as rugged and remote as PNG, distance to the clinic and availability of treatment in proximity to patient homes will be a major confounding factor. The data analysis could not control for this, as data related to distance from the clinic was not consistently present in the patient charts. In a similar vein, and given the breadth and depth of the tribal diversity of PNG, it could be difficult to ascertain if the impact of Case Management is due to the system itself, or some cultural confounding bias. Again, patient charts did not always indicate native language or reliable information on province of origin to enable controlling for this in the data analysis.

An additional area of concern is the quality of Case Management that will, inevitably, vary widely based on the provider and fidelity of the model itself. Was impact (or lack thereof) of Case Management attributable to particular provider(s) and not to the actual system itself? Did consistency exist in the manner in which Case Management, as a service model, delivers care? What were the potential influences on the efficacy of case management as result of human resource or ancillary service constraints (e.g. laboratory diagnostics, logistics, quality assurance)? While it was not possible to control possible variations or other influences on service delivery, the sample size and time period of the study this research suggest that there may be argument for an average consistency of

service over time that accounts for the spectrum of sub-standard to superior Case Management services.

Permissions, Data Privacy, & Confidentiality

IRB approval was obtained from UNC. In addition, approval was sought and granted from the from the Research Advisory Council of the National AIDS Council Secretariat and the Medical Research Advisory Council, Papua New Guinea's equivalent of the IRB for all HIV/AIDS related research. In addition, permission to access the medical records was given by the CEOs of Goroka and Mt.Hagen Hospital.

Privacy of data was maintained by de-identifying all patient information, storing paper records in locked cabinets, and maintaining all electronic files on secure servers which were password protected; access was limited to the lead researcher and PNG collaborators. Though the research effort sought to assist clinics in rebuilding their patient databases, as mentioned earlier, the data extraction form was de-identified. Routine checks where conducted by the researcher and data collection team leads to ensure that the security of patient data had not been compromised.

Chapter 3 Endnotes

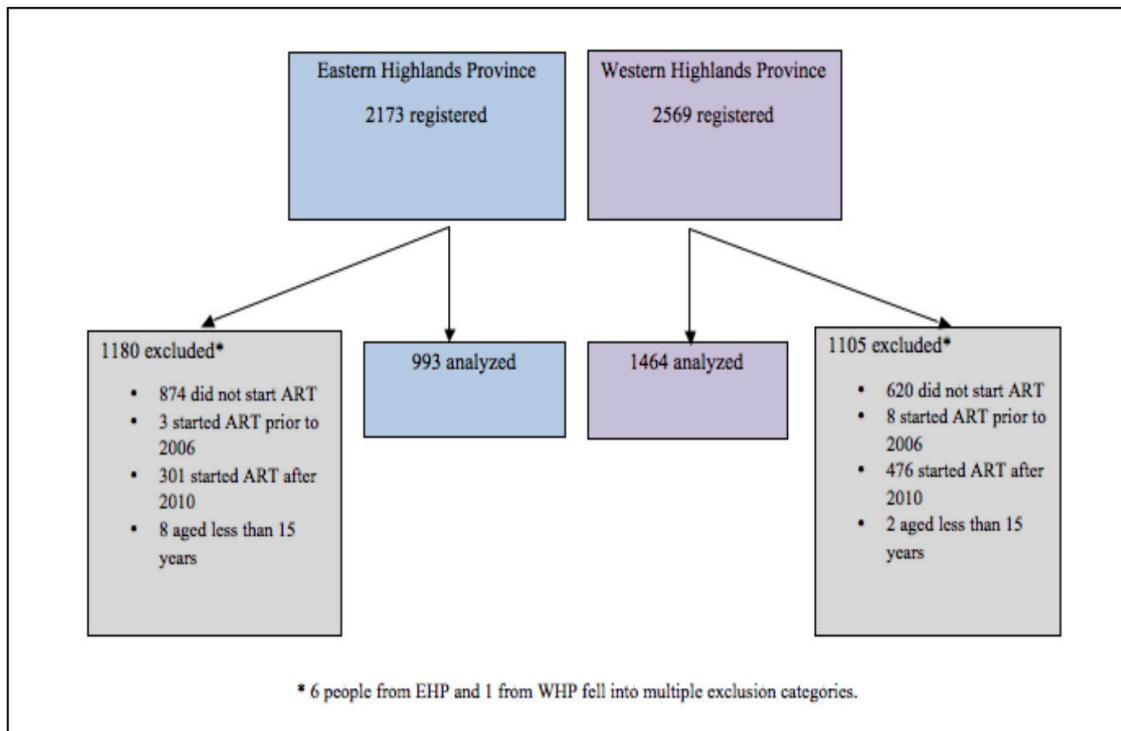
3. This is consistent with the accepted WHO standard definition of lost to follow-up used in Papua New Guinea by the National Department of Health.
4. For example, a patient who initiated ART on January 1, 2006 would be considered retained at 12 months if they were last seen at the ART clinic on January 1, 2007
5. Through funding made available from the Global Fund Round 9 Grant the other locations with the initial ART sites were Madang, Madang Province, Port Moresby, National Capital District and Lae, Morobe Province.
6. Based on anecdotal evidence from speaking staff at both clinics, it was widely cited that many external clinic based research projects in PNG do not take the time to leave something that actually builds the capacity of the clinic to manage its own data needs so this approach towards the data collection exercise was welcomed.
7. Some retention calculations exclude patients who are transferred out from the denominator; this analysis chose not to do this to potentially examine differential patterns of transfer out.

CHAPTER 4

RESULTS

Chapter Three outlined the main methods used to collect and analyze data from the chart review. Of 2173 patient charts reviewed in the Eastern Highlands, 993 patients were included for analysis; in the Western Highlands out of 2569 patient charts reviewed, 1464 were included in this study.

Figure 6: Overview of Cohort Construction



As described earlier, though all patients who had ever registered for ART at either of the two clinics had their charts reviewed and data entered into the excel spreadsheet,

only those who met the inclusion criteria of ART initiation between January 1, 2006 and December 31, 2011 were included in the study. Patients were excluded if they were under 15 years (these patients are part of pediatric HIV care and treatment program).

Review of Study Aims

Aim 1: To assess the impact of the Case Management system on patient lost to follow-up among adult ART patients in the Highlands

Aim 2: To evaluate correlations between key demographic factors (e.g. age, gender), the uptake of HIV testing, and the effect of the Case Management

The lack of key data in the patient charts prevented as detailed a picture as was initially sought with respect to demographics: information on patient income levels, distance to clinic, or marital status was often incomplete or missing. Patient charts varied widely in terms of the forms used: though the National Department of Health has issued standard intake forms for ART Registration as well as standardized charts for patient review, there was wide variability in the content of the patient charts themselves. In some cases, detailed demographic information was present using the Government standard forms; quite frequently, however, patient charts may have been clinical notes that left most fields blank in both the review and intake forms. In other instances, patient charts had none of the standard forms and consisted of clinician notes written on blank paper. This clearly affected the researcher's ability to collect more robust data; at the same time it points to an area in need for further attention to improve the overall quality of patient care.

Patient Characteristics

Since the National Department of Health began comprehensive reporting on HIV testing, the majority of reported HIV cases in PNG Nationally have been women. (Na-

tional Department of Health: 2010). As described in Table 2, women in the Eastern Highlands were considerably more likely to have been initiated on ART than men, almost at a ratio of 2:1 whereas in Western Highlands they formed a slight majority of patients. In both cases, this is consistent with the assumption in PNG that women are more likely to seek health services than men including HIV related services. Based on these data, there are broader implications for partner testing and co-location of family oriented health services.

In both Provinces, the majority of patients fell between 15-40 years of age; in the Western Highlands, nearly one fourth of all patients were over 40. Patients in the Eastern Highlands were more likely to be younger and to enroll later. Again, unfortunately, the marital status of these patients is unknown though further research is warranted to further understand the demographic profile of these cohorts; previous HIV research by the Papua New Guinea Institute for Medical Research has suggested that being a married women is a risk factor for HIV though these data cannot corroborate this.⁸

Table 2: Patient Characteristics of ART Cohorts in Eastern Highlands and Western Highlands Provinces

Characteristic	Eastern Highlands Province (N=993) N(%)	Western Highlands Province (N=1464) N(%)
Sex		
Male	368 (37.1)	646 (44.1)
Female	625 (62.9)	818 (55.9)
Age (years), (N=2455)		
15-40	811 (81.8)	1089 (74.4)
>40	181 (18.3)	374 (25.6)
Ever diagnosed with TB	103 (10.4)	205 (14.0)
Year of ART initiation		
2006	59 (5.9)	149 (10.2)
2007	163 (16.4)	345 (23.6)
2008	203 (20.4)	332 (22.7)
2009	232 (23.4)	354 (24.1)
2010	284 (33.8)	336 (19.4)

While the current residence was listed and recorded in the patient database, information related to province of origin was limited across patient records: this is a vital characteristic as cultural variation may influence retention patterns (and health-seeking behaviour in general) due to belief systems that may bear impact on HIV related stigma. Language groups, local customs, and community practices can also affect a patient's ability to remain on ART.⁹

Data Analysis

Using the inclusion/exclusion criteria and methods described earlier, 12, 24, 36, and 48-month retention rates were calculated for patients in both Eastern and Western Highlands Provinces.

Table 3: Unadjusted Retention Outcomes at 12, 24, 36, and 48 Months, by Province

		12-month		24-month		36-month		48-month	
		WHP (N=1464)	EHP (N=993)	WHP (N=1380)	EHP (N=693)	WHP (N=1071)	EHP (N=447)	WHP (N=745)	EHP (N=238)
Retained	n	1075	741	874	477	591	281	389	142
	%	73.4	74.6	63.3	68.8	55.2	62.9	52.3	59.7
	95% CI	(71.1 – 75.7)	(71.8 – 77.3)	(60.7 – 65.9)	(65.2 – 72.3)	(52.2 – 58.2)	(58.2 – 67.4)	(48.6 – 56.0)	(53.1 – 66.0)
Transferred out	n	73	35	111	33	122	26	100	9
	%	5.0	3.5	8.0	4.8	11.4	5.8	13.4	3.8
	95% CI	(3.9 – 6.2)	(2.5 – 4.8)	(6.7 – 9.6)	(3.3 – 6.6)	(9.6 – 13.5)	(3.8 – 8.4)	(11.0 – 16.1)	(1.7 – 7.1)
Not retained	n	316	217	395	183	358	140	256	87
	%	21.6	21.9	28.6	26.4	33.4	31.3	34.4	36.6
	95% CI	(19.5 – 23.8)	(19.3 – 24.6)	(26.3 – 31.1)	(23.2 – 29.9)	(30.6 – 36.3)	(27.0 – 35.9)	(31.0 – 37.9)	(30.4 – 43.0)

While slightly higher in terms as a percentage, patient retention at 12, 24, 36, and 48 months was not significantly different between Eastern and Western Highlands if examined unadjusted for other factors. In the case of these data, though, the broader cohort

of patients in Western Highlands are seen in only one ART clinic facility, Tinninga Clinic at Mt.Hagen Hospital while in Eastern Highlands, the data are aggregated from 10 distinct ART sites spread over the eight rural Districts.

Table 4: Retention of Patients by District in Eastern Highlands Province

		12-month		24-month		36-month		48-month	
		Retained	Transferred out	Retained	Transferred out	Retained	Transferred out	Retained	Transferred out
Goroka	n	420/577	28/577	278/412	24/412	169/274	22/274	85/145	8/145
	%	72.8	4.9	67.5	5.8	61.7	8.0	58.6	5.5
	95% CI	(69.0, 76.4)	(3.3, 6.9)	(62.7, 72.0)	(3.7, 8.5)	(55.6, 67.5)	(5.1, 11.9)	(50.2, 66.7)	(0.02, 10.6)
Nupuru	n	24/29	1/29	16/21	1/21	5/6	0/6	2/2	0/2
	%	82.8	3.5	76.2	4.8	83.3	0	100	0
	95% CI	(64.2, 94.2)	(0.1, 17.8)	(52.8, 91.8)	(0.1, 23.8)	(35.9, 99.6)	(0, 45.9)	(15.8, 100)	(0.0, 84.2)
Kainantu	N	121/152	1/152	78/103	2/103	56/74	0/74	29/38	0/38
	%	79.6	0.6	75.7	1.9	75.7	0	76.3	0
	95% CI	(72.3, 85.7)	(0.2, 3.6)	(66.3, 83.6)	(0.2, 6.8)	(64.3, 84.9)	(0.0, 4.9)	(59.8, 88.6)	(0, 9.3)
Okapa	N	14/21	3/21	4/13	2/13	0/7	2/7	--	--
	%	66.7	14.3	30.8	15.4	0	28.6	--	--
	95% CI	(43.0, 85.4)	(3.1, 36.3)	(9.1, 61.4)	(1.9, 45.5)	(0, 41.0)	(3.7, 71.0)	--	--
Asaro	N	96/135	2/135	59/94	3/94	33/59	1/59	17/36	1/36
	%	71.1	1.5	62.8	(3.2)	55.9	1.7	47.2	2.8
	95% CI	(62.7, 78.6)	(0.2, 5.3)	(52.2, 72.5)	(0.7, 9.0)	(42.4, 68.9)	(0.0, 9.1)	(30.4, 64.5)	(0.1, 14.5)
Henganofi	N	44/54	0/54	28/35	1/35	12/20	1/20	5/9	0/9
	%	81.5	0	80.0	2.9	60.0	5.0	55.6	0
	95% CI	(68.6, 90.6)	(0, 6.6)	(63.1, 91.6)	(0.1, 14.9)	(36.1, 80.9)	(0.1, 24.9)	(21.2, 86.3)	(0, 33.6)
Lufa	n	5/5	0/5	4/9	0/9	0/3	0/3	0/2	0/2
	%	100	0	44.4	0	0	0	0	0
	95% CI	(47.8, 100)	(0, 52.1)	(13.7, 78.8)	(0, 33.6)	(0, 70.8)	(0, 70.8)	(0.0, 84.2)	(0.0, 84.2)
Sighere	n	12/15	0/15	9/11	0/11	5/6	0/6	4/5	0/5
	%	80	0	81.8	0	83.3	0	80.0	0
	95% CI	(51.9, 95.7)	(0, 21.8)	(48.2, 97.7)	(0, 28.5)	(35.9, 99.6)	(0, 45.9)	(28.4, 99.5)	(0, 52.1)
Marawaka	n	5/5	0/5	1/1	0/1	1/1	0/1	--	--
	%	100	0	100	0	100	100	--	--
	95% CI	(47.8, 100)	(0, 52.1)	(2.5, 100)	(0, 97.5)	(2.5, 100)	(0, 97.5)	--	--

Of note in these data are the relatively higher rates of patient retention among patients from District sites in Nupuru (76%), Kainantu (76%) and Henganofi (80%). These are all sites at least 1-2 hours by road (and at least one day by foot) from Michael Alpers Clinic at Goroka General Hospital. Though the sample sizes are modest, the 24-month retention rates are relatively strong for this level of facility considering the resource constraints at the site level.

Late Entry into Care

Based on discussions with health workers, it was asserted that a number

of cases who initiated ART were in advanced stages of illness. The patient charts, however, were frequently lacking in data as to the WHO Clinical Staging I, II, III, or IV; these data would indicate the progression of HIV illness at the time of ART initiation.¹⁰ Based on the premise that many of those patients who had been detected may have already been too ill for ART to be effective, a secondary analysis was conducted that included only patients who were retained after 90 days (e.g. survived the first 90 days after being initiated on ART). Patient retention was markedly better in this analysis as seen in Table 5 below. The Eastern Highlands cohort showed progressively better outcomes with longer time periods in the 24-month (79.6% in EHP vs. 76.6. % in WHP), 36-month (73.2% in EHP vs. 67.2 % in WHP), and 48-month (71.4% in EHP vs. 62.3% in WHP) groups.

Table 5: Unadjusted Outcomes at 12, 24, 36, 48 Months Among Those Retained After 90 Days by Province

		3 to 12-month		3 to 24-month		3 to 36-month		3 to 48-month	
		WHP (N=1213)	EHP (N=856)	WHP (N=1141)	EHP (N=599)	WHP (N=880)	EHP (N=384)	WHP (N=624)	EHP (N=199)
Retained	n	1075	741	874	477	591	281	389	142
	%	88.6	86.6	76.6	79.6	67.2	73.2	62.3	71.4
	95% CI	(86.7 – 90.4)	(84.1 – 88.9)	(74.0, 79.0)	(76.2 – 82.8)	(64.0 – 70.3)	(68.5 – 77.5)	(58.4 – 66.2)	(64.5 – 77.5)
Transferred out	n	40	22	78	25	95	18	81	6
	%	3.3	2.6	6.8	4.2	10.8	4.7	13.0	3.0
	95% CI	(2.4 – 4.5)	(1.6 – 3.9)	(5.4 – 8.5)	(2.7 – 6.1)	(8.8 – 13.0)	(2.8 – 7.3)	(10.4 – 15.9)	(1.1 – 6.5)
Not retained	n	98	93	189	97	194	85	154	51
	%	8.1	10.9	16.6	16.2	22.1	22.1	24.7	25.6
	95% CI	(6.6 – 9.8)	(8.9 – 13.1)	(14.5 – 18.9)	(13.3 – 19.4)	(19.4 – 24.9)	(18.1 – 26.6)	(21.3 – 28.3)	(19.7 – 32.3)

Overall improved retention in this group indicates that those patients who are detected earlier in the progression of HIV and initiated on ART are more likely to survive. It is especially encouraging to note here that close to 90 percent of patients in both Provinces were alive after 12 months and nearly 80 percent of all

patients who survived the first 90 days were still alive after 24 months.

Multivariate Analysis and Kaplan Meier Estimates

Additional multivariate analysis was conducted using Cox Proportional Hazards Regression to adjust for the range of factors and characteristics that were recorded during data collection. This data analysis is based on the patient retention data presented in Table 3; that is to say, the regression analysis does not exclude those who may have died or been lost to follow-up in the first 90 days (discussed in the previous section) and includes all patients. Following common practice, a standard of a p-value less than .05 was deemed as statistically significant.

Table 6: Multivariable Analysis of the Relationship between Province and Attrition from Treatment* (N=2457)**

Characteristic	Univariable		Multivariable	
	RR [95% CI]	p-value	RR [95% CI]	p-value
Eastern Highlands	0.90 [0.78, 1.04]	0.14	0.84 [0.72, .96]	0.01
Female	1.00 [0.88, 1.15]	0.95	0.92 [0.79, 1.1]	0.25
Age, continuous (years)	0.99 [0.98, 0.99]	0.0002	0.99 [0.98, 0.99]	0.0002
Year of ART initiation				
2006			--	
2007	1.0 [0.77, 1.34]		1.0 [0.75, 1.3]	
2008	1.2 [0.90, 1.56]	0.003***	1.2 [0.88, 1.5]	0.002***
2009	1.4 [1.05, 1.82]		1.4 [1.0, 1.8]	
2010	1.5 [1.09, 1.92]		1.4 [1.1, 1.9]	

*Attrition defined as death, LTFU, or default

** Two people who were missing data on age were excluded from multivariable analyses

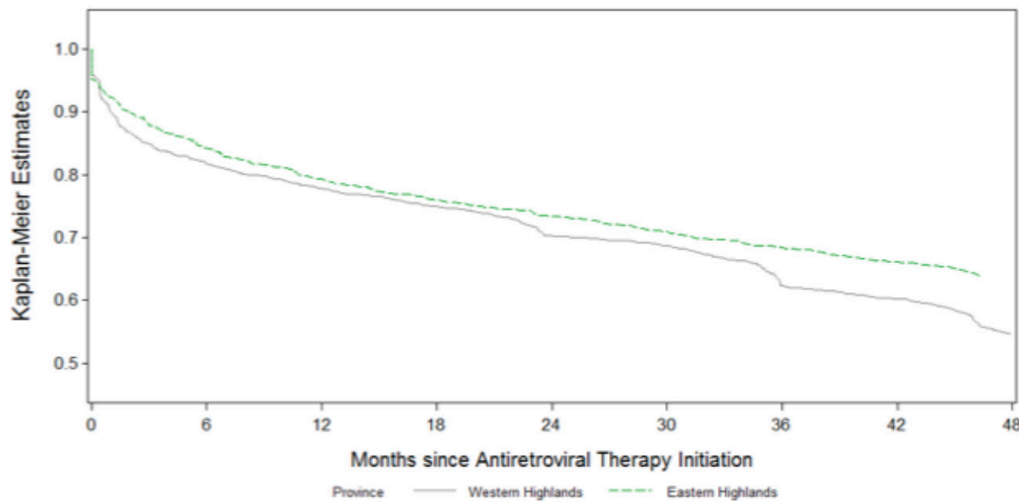
***Likelihood ratio p-value

Based on the multi-variable regression analysis, being older had the strongest protective factor on patient retention with a p-value of .0002. Being from the Eastern Highlands was statistically significant in terms of the likelihood of being

retained when adjusted for all factors.

Understanding the longer-term impact of Case Management and its associated impact on population survival is also of interest. Because this study involved significant numbers of patients who have been lost to follow-up, Kaplan-Meier analysis was a useful method as it allows estimation of survival over time, even when patients drop out or are studied for different lengths of time.¹¹ Data from both the Eastern and Western Highlands were plotted on a survival curve adjusting for gender, age, and year of treatment initiation. This method allowed for taking into account patients who were lost to follow-up at some point during the study period.

Figure 7: Retention Probabilities in Eastern and Western Highlands Provinces Adjusted for Gender, Age, and Year of Treatment Initiation



Patients in the Eastern Highlands appear to have a higher likelihood of survival, particularly post 24 months and continuing towards 36 and 48 months.

Analysis of HIV Testing Data & Patient Retention

Aim 2 of this study sought to evaluate correlations between key demographic factors (e.g. age, gender), the uptake of HIV testing, and the effect of

the Case Management. HIV testing data by Province was reviewed to determine if any association could be drawn between testing and patient retention. As the highlighted column in the table below illustrates, there were over 20,000 HIV tests performed in 2008 in Eastern Highlands.¹² As per the multivariable analysis discussed previously, the relationship between likelihood of patient retention and 1) being from the Eastern Highlands (p-value .01) along with 2) initiating ART in 2008 (p-value .002) was statistically significant. One possible explanation for 2008 being positively associated with higher patient retention is that HIV positive patients were detected earlier.

Table 7: HIV Testing in Eastern & Western Highlands Provinces 2006-2010

PROVINCE	2006	2007	2008	2009	2010
	# Tests	# Tests	# Tests	# Tests	# Tests
Western Highlands Province	1,824	3,746	12,946	21,252	12,100
Eastern Highlands Province	336	4,656	20,421	13,822	13,237

The testing data for 2008 would support this as extensive rural outreach and HIV testing was conducted in Eastern Highlands in 2008 with links to Case Management for HIV positive clients. In fact, Eastern Highlands performed more HIV tests in 2008 than, not only Western Highlands, but also all other provinces in PNG. Though 2009 data shows Western Highlands Province to have conducted a similarly high number of tests (with a concomitant decrease in Eastern Highlands), multivariable analysis did not reveal a statistically significant association between patient retention and either ART initiation in 2009 or being from the Western Highlands.

Chapter 4 Endnotes

8. Presentation to Eastern Highlands Province HIV/AIDS Stakeholders, May 2011 at Institute for Medical Research, Goroka, Eastern Highlands Province
9. Schwartz, N. *Blessed are the Virtuous?* Published by the Melanesian Institute in 2011 covers the topic of indigenous belief systems, HIV, and ART extensively through patient, provider, and community focus group interviews.
10. WHO assigns a classification scheme I-IV to stage patients infected with HIV. Particularly in cases where CD4 counts are unavailable, WHO staging is used as a tool for clinicians in determining initiation of ART. In the continuum, Stage I patients are asymptomatic while Stage IV patients are in the advanced stage of illness with acute complications resulting from HIV. Adapted from *Revised WHO Clinical Staging of HIV/AIDS for Adults and Adolescents (2005) WHO Publications, Africa Region*
11. For each interval, survival probability is calculated as # patients surviving /by # patients at risk. Patients who have died, are lost to follow-up, or who have not reached the time period end are not counted as “at risk.” Patients who are lost are considered “censored” & are not counted in the denominator. The probability of surviving to any point is estimated from cumulative probability of surviving each of the preceding time intervals (calculated as the product of preceding probabilities) as cited from <http://biostat.mc.vanderbilt.edu/wiki/pub/Main/ClinStat/km.lam.pdf> accessed on Oct 3, 2012
12. Data provided by PNG National Department of Health Cumulative HIV Surveillance Reports 2006-2010

CHAPTER 5

DISCUSSION

The primary aim of this research was to ascertain if use of a Case Management system reduces patient attrition (e.g. patients lost to follow-up) among adults enrolled in ART programs in the Highlands. Despite the limitations of this study there is a plethora of data to suggest that a meaningful positive association can be drawn between Case Management and reduced lost to follow-up. Sample sizes are robust enough for the data analysis that has been presented. And while there are inherent difficulties in drawing comparisons between the Eastern and Western Highlands, there are enough similarities between the settings to form a reasonable basis for comparison.

Contextual Similarities: Eastern & Western Highlands Provinces

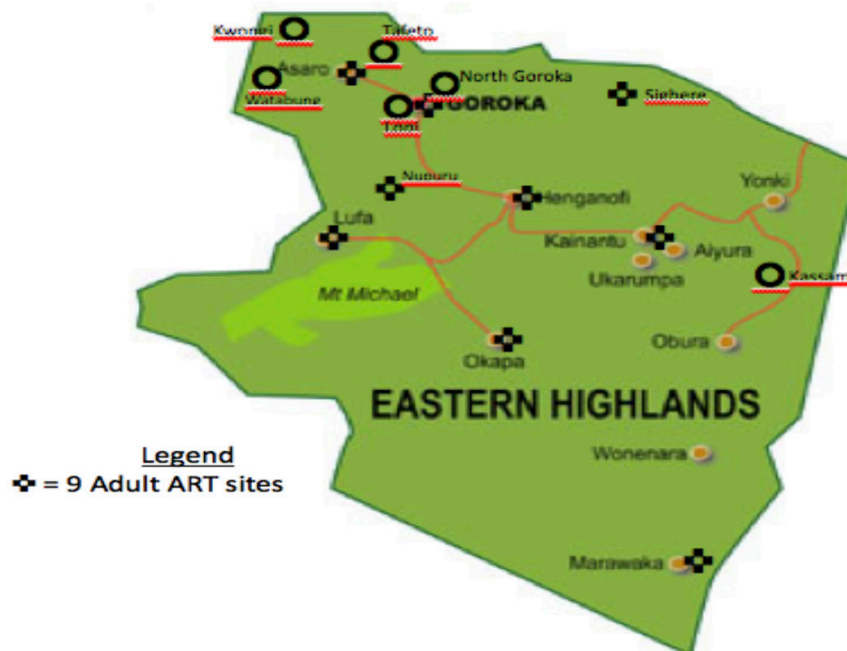
Geographically, both provinces are similar in terms of the population distributions, road network, and infrastructure challenges; accesses to transportation issues are similar between the Eastern and Western Highlands. The main ART Centers and Provincial Hospitals in Mt.Hagen and Goroka are Government operated (and not faith based services) and therefore have comparable human resource, infrastructure, and health system constraints. While there are differences in cultural practices within Eastern and Western Highlands provinces they remain more akin to one another than comparisons that would involve Highlands and non-Highlands based communities, such as those in coastal areas and/or islands where cultural practices are vastly different. There are common perceptions around HIV related stigma and discrimination among rural Highlands communities (Schwarz: 2011). In

addition, there are shared issues related to food insecurity and protein deficiencies between these provinces. These contextual factors are critical when addressing the utility of comparison across sites.

Decentralization of ART Services

The decentralization of HIV care and treatment has occurred during the study period in a phased manner across Eastern Highlands as part of the Rural Initiative pilot program. The first District level ART site was at Asaro Health Center which was opened in 2007 and lies to the west of Goroka, the Provincial capital. Marawaka and Sighere were among the last District facilities, added in 2010; Marawaka is accessible by foot or air only. At present 45% of all registered ART patients in Eastern Highlands are seen at District level facilities.

Figure 8: Decentralized District ART Sites in Eastern Highlands Province



Data related to decentralization is significant as these sites are delivering HIV care and treatment services in a setting different from the Provincial Hospital, often a setting

that is more resource constrained. While there is the benefit of bringing access to treatment closer to where patients live, there are the additional challenges associated with ensuring an HIV care delivery system can function in such rural and remote areas while remaining able to provide the needed logistical, laboratory, and clinical support services.

Previous to this study, there has been no examination of the ability to deliver ART at the District level in PNG through Government operated health facilities. For this reason, it is important to examine patterns of retention among District sites. While these sites cannot be examined comparatively against Western Highlands, which provides centralized services through the main Provincial referral hospital, presentation of District level retention data is important as many in PNG have questioned the ability of the Government health system to deliver HIV treatment at this level.

The Impact of Decentralization on Analysis of Results

As previous sections have mentioned, a truer comparison to evaluate the efficacy of Case Management would have involved either:

- Two sites with centralized services, one with Case Management/one without
- Two sites with decentralized HIV services, one with Case Management/one without

A central confounding factor in this research has been the difference in environments given that Eastern Highlands was in the process of rolling ART out to 8 additional sites while establishing the Case Management system. In addressing this issue, it is important to explore whether the process of expansion would present greater challenges in delivering quality patient care or if the converse would be true: that expanding the number of sites would necessarily make it easier to provide better services. It is difficult to imagine that the latter would be the case when taking into consideration the logistical hurdles in managing multiple ART sites.

The delivery of routine primary care in rural Highlands Health Centers is highly challenging. Transport of samples to the Provincial laboratories from the field can be difficult given poor road conditions; this also affects the reciprocal flow of essential drugs, diagnostics, test kits, and reagents to health centers from the Provincial center. HIV testing, care, and treatment, with its need for consistent supplies and referral pathways to manage complications and/or co-infections (e.g. TB) presents an additional layer of complexity for the health system to manage. Moreover, there is a critical human resource issue of clinical training, mentoring, and supervision for providers across a number of sites vs. providers who are based at one location. While it is true that bringing services closer to where patients live could improve the probability of being retained, the fact that these HIV care and treatment services are part of a severely resource constrained health infrastructure should not be underestimated. Therefore, when considering the influence on patient retention, it is most likely the case that the challenges of decentralized HIV services coupled with the addition of multiple ART sites make the delivery of quality patient care more rather than less difficult.¹³

Aim 1: To assess the impact of the Case Management system on patient lost to follow-up among adult ART patients in the Highlands. Based on the multi-variable analysis that adjusted for all factors, there was indeed a statistically significant association between likelihood of retention and being from the Eastern Highlands. A key issue, however, is that the actual retention rate itself, when inclusive of all patients (and not just those retained after 90 days) remains below eighty-five percent.

Aim 2: To evaluate correlations between key demographic factors (e.g. age, gender), the uptake of HIV testing, and the effect of the Case Management.

With respect to Aim 2, the most powerful association may be the link between HIV testing data from 2008 and the multivariate analysis that reveals connections between being from the Eastern Highlands, initiation of ART in 2008, and likelihood of retention. In other words, the significantly higher number of HIV tests conducted in 2008 in Eastern Highlands may indeed mean that those patients were identified earlier as HIV positive, linked to the ART program through Case Management, and initiated on ART at a more optimal time than counterparts in study period.

Aim 3: If the data yield substantive evidence of the efficacy of Case Management in improving retention, advocate for evidence to support the adoption of an improved model of HIV service delivery national level policy in Papua New Guinea that includes Case Management.

The influence of a myriad of clinical, demographic, socio-economic, and cultural factors coupled with issues of where services are physically located pose a challenge in determining whether Case Management services truly influence retention or if there are other covariates at work. But while there is room for improvement in the Case Management system's ability to improve further on retention rates (e.g. 90% or greater at 24 months), it nonetheless appears to be a promising intervention in a setting in need of strategies for HIV care and treatment. Further time and study are needed to allow the full potential of the model to be realized.

Limitations of this Study

While the analyses of these data provide a range of possible associations between Case Management, patient retention, age, and the uptake of HIV testing, there are a number of study limitations. Primary among these is the appropriate basis for comparison

between the Eastern and Western Highlands given the lack of decentralization in Western Highlands. Would retention outcomes have been different if the care delivery system in the Eastern Highlands was not, simultaneously, being pushed to extend care and treatment to rural health facilities? Was the quality of care affected by expansion of these services? A more accurate comparison to determine the impact of Case Management may involve two main referral sites where one received the intervention and one did not but both are in the process of decentralization of HIV services.

There are also a range factors that cannot be controlled for which influence the quality of patient care (with or without the implementation of a Case Management model). Human resource limitations at clinics in both provinces could contribute to poor clinical outcomes as a result of lack of adequate clinical training, mentoring, or supervision. Poor laboratory and diagnostic support (as evidenced by the lack of adequate data on CD4 counts in patient charts at both sites) also contributes to later initiation of treatment. Finally, interruptions in the drug supply due to poor forecasting, supply chain management, and logistics issues all impinge on patient outcomes.

Inability to accurately assess patients who may have transferred out of care and sought services in another facility but who were recorded as lost to follow-up is another key limitation of this study, as these patients should have been recorded as transferred out instead of lost to follow-up. Given that the vast majority of patient charts did not contain information that recorded if a patient had transferred care, these patients were always reported as lost.

While attempts were made to ensure minimal errors in data collection, the number of charts reviewed combined with a purely paper based record system with non standardized forms and variable staff ability to work with patient charts in data extraction may have contributed to human error in recording patient level data. Though these data were both verified through routine sampling and then cleaned after data collection, it remains possible that some data from patient charts were incorrectly recorded due to an inability

to read the charts themselves.

As alluded to previously, an additional limitation of this study is the inability to ascertain true fidelity to the Case Management model. Training curricula, standard operating procedures, job descriptions, referral pathways, intake forms, and integration with clinic staff all evolved over time as the model matured. There were also no quality assurance or accreditation mechanisms in place to gauge adherence to Case Management guidelines.

Finally, the lack of patient and provider voices to corroborate either the effectiveness or deficiency of Case Management is an important limitation of this research. From the patient perspective, it is both important to understand what factors contribute to successful retention in ART programs or what might contribute to patient lost to follow-up. Purely quantitative analysis can only reveal so much about what are the major drivers of loss. In addition to patients, it is equally important to understand, from the provider perspective, how patient retention efforts are compromised at the clinic level and what the benefits and drawbacks there may be to the implementation of Case Management.

Chapter 5 Endnotes

13. It is also important to note that, as described in the Conceptual Model presented in Chapter Two, Case Management in the PNG context is a system which not only involves the removal of material obstacles to care for patients, it also entails providing support to health care providers via improved referral pathways and strengthened systems for clinical mentoring, supervision, and quality assurance.

CHAPTER 6

PLAN FOR CHANGE

Making strategic alliances across national borders in order to treat HIV among the world's poor is one of the last great hopes of solidarity across a widening divide.

Paul Farmer, Co-Founder Partners in Health¹⁴

As in much of the developing world, significant resources to address the HIV epidemic in Papua New Guinea present an unprecedented opportunity to both save lives while revitalizing a health system in desperate need. There is a unique window of opportunity to support health systems strengthening through addressing the needs to expand HIV treatment in PNG. Indeed, while this study provides a sample of the potential of case management to improve health outcomes for those on ART, more importantly, it demonstrates the extent to which it is difficult to remove Case Management from its broader operating environment. A multitude of fundamental health system building blocks form the base from which Case Management can support patients. Without adequate laboratory or clinic infrastructure, simple diagnostics and access to water issues trump ART management. Human resource or supply chain limitations in the health facility make the delivery of ART a challenge let alone the provision of support systems like case management to reduce material obstacles to care. Therefore, to advocate for further advancement or dissemination of the case management model without systematically addressing broader health system constraints would be misguided. Used properly, these research results have the potential to both encourage the adoption of a promising strategy for retention and to support improvements to the health system to ensure those gains are sustained.

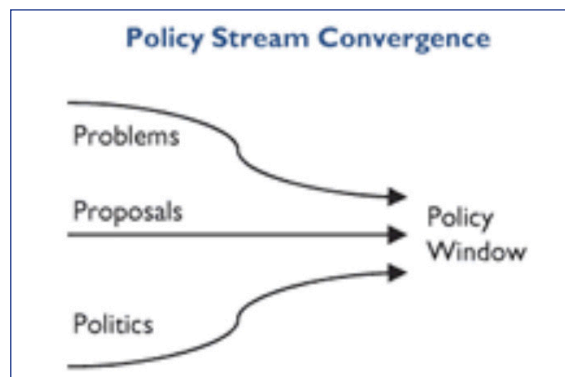
But how can this research be transformed into meaningful policy change? What

models can be employed to encourage transformation of the health delivery system in PNG based on these results? And what type of leadership approach is required to drive this change? This chapter has three overarching goals: 1) To outline a conceptual framework linking this research and policy change using concepts from John Kingdon's "Policy Streams" model; 2) To provide specific, actionable recommendations that form the substance of the change itself; and 3) To provide a leadership model for catalyzing change using John Kotter's framework of "Eight Steps for Leading Change."

Linking Research & Policy: Applying the "Policy Streams" Model

How does research inform the policies that ultimately guide service delivery? What contributes to setting the agenda? The making of policy itself defies linearity. Though some scholars have attempted to provide rational logical frameworks that map a linear process of research to policy, in practice it is difficult to find examples where policy formulation has proceeded as such (Nutley: 2007). Kingdon's model provides a more fluid macro view which relies on the concept that the process of policy change is one that is based on the organic interplay between three policy streams broadly defined as the "problems," "proposals," and "politics" streams. Kingdon posits that when these three streams converge, the opportunity presents for a shift in setting the agenda.

Figure 9: Policy Streams¹⁵



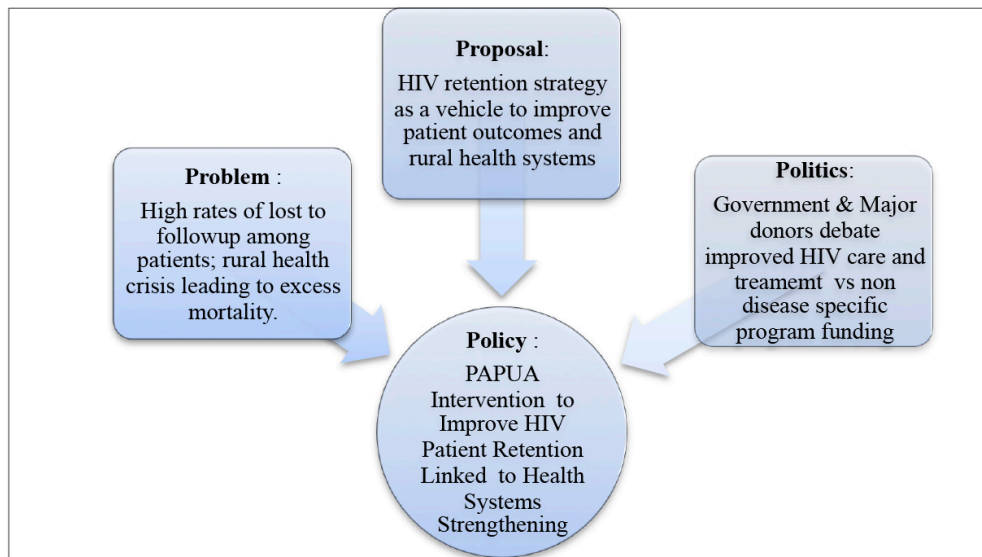
The “problem stream” refers to the issue(s) that policy makers need to take notice of and, more specifically, the process of ensuring one problem is noticed over others. How dire a situation i.e. the seriousness of the problem and how it is conveyed will often determine to what extent is elevated in stature. The “proposals (or “policies”) stream” refers to what Kingdon calls the “primeval soup” where a multitude of policy proposals are crafted, drafted, and debated. Many proposals may exist that attempt to address the same problem; to make it to the “short list” technical feasibility, cost, and scalability are all key factors in determining what will influence agenda setting.¹⁶ Broadly speaking, the “political stream” refers to the broader milieu of community, governmental, and non governmental leaders, advocates, and stakeholders who have a key voice in determining how the agenda is set for a given problem and the approach to addressing it.

At times, a problem may exist prominently in the community of national consciousness; proposals may already exist to address the given problem; both the problem and the solution may have begun to take hold of those in the political stream. Kingdon’s model holds that the convergence of these streams results in a meaningful opportunity for the agenda setting and policy breakthrough.

With respect to this study, applying this model illuminates a number of factors in each stream, which indicate that this may, in fact, be the collective moment ripe for the window of convergence.

In the “problem stream” there is a rural health crisis in PNG. Apart from poor patient retention among ART patients, high infant mortality, maternal mortality, and a lack of basic rural health services persist. Meanwhile, in the “politics stream” a cacophony of voices, often at odds, clamor for solutions to both the acute HIV crisis and the spectrum of rural health problems. “Silo-ed” solutions abound in the proposals or policies stream in response the preponderance of vertical programs that, in many in cases, seem to shun ideas of an integrated approach to health as either too costly or too complex.

Figure 10: Applying the Policy Streams Model



Recommendations for Change

This study shows Case Management is ripe with promise to reduce patient attrition and improve clinical outcomes; yet the intervention requires a number of accompanying pieces to be fully realized. The researcher thus proposes a broad strategy towards improving HIV patient care called P.A.P.U.A, the Patient And Provider Unified Approach, which seeks to encompass both patient and health provider systemic needs. Case management, among other components, will be part of this effort, which is articulated in the recommendations that follow. This strategy assigns an acronym that acknowledges providers, patients, and the significance of the place. In other words, the title seeks to address: consensus and diffusion of leadership (in naming both providers and patients as being unified) and being a locally grown solution (the PAPUA acronym).

As the National response in HIV Care and Treatment nears ten years (and over twenty five years since the first diagnosed case of HIV in PNG), locally generated HIV related research that can be used to inform National policy in PNG remains limited. While programs targeting HIV service delivery maintain robust funding streams from external donors and partners such as Australian Agency for International Development and

the Global Fund to Fight HIV/AIDS, Tuberculosis, and Malaria, many interventions that benefit from this funding lack an evidence-based approach that is specific to the complexities of the PNG context. When programs do maintain strong systems for monitoring and evaluation or operational research, all too often this data is not appropriately shared *in country*. PNG has a long legacy of being a fertile ground for external researchers. Unfortunately, and all too often, local entities are left with piles of published articles, reports, and recommendations minus the benefit or support from the original researchers to find avenues to translate findings into action.

This is not from a lack of interest: PNG's Ministry of Health, the National AIDS Council Secretariat, National Department of Health, Provincial, and District level partners are all keen to acquire data and lessons learned to guide policy formulation. Government entities, however, lack the human resource capacity to examine the efficacy of programs amidst the overwhelming demands of managing a National response despite severe resource challenges. And even when non-governmental implementing partners direct available funding towards examining the effectiveness of program interventions and sharing those results, there are no formal channels within Government through which policy suggestions in HIV care and treatment can be directed.

The results presented show a promising start for HIV care and treatment in the Highlands while illuminating areas for further improvement that would likely benefit not only the Highlands but service delivery efforts for the rural majority of PNG. Twelve and twenty four month survival and retention rates show a strong foundation has been established though Case Management but that longer term care requires further support and strengthening of ART programs. This study has provided insight not only into retention of patients, but also into tangible suggestions for how HIV care delivery systems could be further strengthened. Based on the findings of this study Eight Key Recommendations have emerged that provide an enabling environment to both improve patient retention and, more broadly, HIV service delivery.

Table 8: PAPUA – Key Recommendations for Improved HIV Patient Retention

1. Build Human Resource Capacity
2. Improve Rural Clinic Infrastructure
3. Develop Regional Centers of Excellence
4. Standardize Case Management
5. Strengthen Patient Information Systems
6. Conduct Operations Research in HIV Care and Treatment
7. Create a National HIV Technical Working Group on Policy for Care and Treatment
8. Market PAPUA

This section will explore each of these recommendations within the context of four central considerations: 1) Why is the recommendation being made? 2) What specific actions may be taken and what resources are required? 3) Who will be needed both to support and actualize the recommendations? 4) What is the environment in terms of the socio-political, ethical, and legal parameters? A more detailed implementation plan and evaluation framework to enact these eight recommendations will be formulated (see Annex 3) to ensure a unified approach. Specific outcomes to measure progress of the implementation plan against key indicators and milestones will be part of this framework.

Recommendation 1: Increase Human Resource Capacity

Why Is This Important?

Health providers in Papua New Guinea are operating in the face of severe resource constraints which include a lack of adequate staff, disruptions in the flow of essential drugs and test kits, poorly functioning laboratory diagnostic services,

and an absence of support for training, mentoring, and supervision. These constraints to service delivery are a result of human resource issues at both the Provincial and District level of service delivery.

Quantity and quality both matter in terms of human resources support. That is to say, it is not only an issue of hiring additional staff, but also ensuring that staff are properly supported for their roles and responsibilities. Development in the health sector in PNG is rife with examples of funding support for more human capital, but the concurrent investment in their development often lags.

In terms of clinical training in HIV and prescription of ART, the current system requires an in-service training curriculum, which consists of two weeks of didactic training followed by one month of practicum at the Provincial level, either at the ART clinic in Goroka General Hospital or Port Moresby General Hospital's Heduru Clinic. This system consumes tremendous human resources. Critical clinic teams, often already working in a setting with acute staff shortages, are lost for over one month. In addition, there are substantial costs associated with providing housing, food, and per diems during the near two-month training period.

Provincial Hospital ART Clinics

Both Tinninga Clinic in Western Highlands and Michael Alpers Clinic in Eastern Highlands are high volume STI clinics in addition to being the main point of referral for HIV care and treatment services throughout their respective provinces. The personnel and staffing plans, as per National Department of Health guidelines, of both clinics have remained the same despite the introduction of ART programs in 2005. Additional support was made available via the Global Fund Round 9; however, those positions have since lost their funding. These positions were not absorbed by the Hospital systems nor were they well integrated into existing clinic teams.

Though Case Management staff are also funded separate from the Hospital recurrent budgets they are better integrated into the hospital ART programs, perhaps too well integrated: During the course of the data collection period, which spanned nearly six months, it was routinely observed that the existing clinical staff at both Michael Alpers Clinic in Goroka Eastern Highlands and Tinninga Clinic in Mt.Hagen relied heavily on Case Management teams (who were also trained in the prescription of ARV's) to provide direct patient care. As mentioned, among the primary functions of Case Management teams are coordinating a package of patient material and psychosocial support services, improving clinical care quality, and developing patient information systems. While, as described in Chapter Two, Case Managers themselves are clinicians trained in the management of HIV care, the system was not designed with Case Managers as the lead providers of patient care; the requirement of training in the prescription of antiretroviral medication is to ensure that they can be a "gap filler" on occasion and so that they liaise more effectively with clinical care teams. The frequent reliance on Case Managers often left them little time to attend to the primary case management function, if at all.

An additional issue which directly affects quality of care at the Provincial ART clinic level is the availability of a Medical Officer (e.g. Doctor), to provide referral support in the management of HIV care such as addressing complications and switching patients to second line therapy. In the case of Tinninga Clinic in Mt.Hagen, this position is not filled, and the Regional Medical Officer serves as the primary referral point for clinic staff. At Michael Alpers Clinic in Goroka General Hospital, the post has been vacant for nearly three years with clinicians relying on the attending physician in the Hospital's Adult In-patient Medical Ward, often on an ad hoc basis.

With ever increasing registrations in the main ART clinics but no concomitant increase in the number of health workers assigned to provide HIV care, the

reliance on Case Managers, coupled with a lack of proper support for complicated cases, has likely impinged on the quality of patient care.

District Level Hospital ART Clinics

At the decentralized District level sites (which are even more physically remote) ART clinic staff have even less support. A District Health Center serves a catchment of 30,000-50,000 people. A small inpatient ward (approximately 10 beds) exists along with outpatient antenatal services, maternity and newborn care, immunization programs, STI and TB services. As per the current health service delivery standards, District Health Centers should be staffed by: 1-2 Health Extension Officers, 2-3 Nurses, and 3-4 Community Health Workers. Similar to the case of Provincial Hospitals, ART programs were rolled out to District level health facilities though the Government has not provided additional human resources to provide HIV services. Rather, HEOs are expected to operate ART clinics in addition to providing oversight to the main health services mentioned including the provision of direct patient care. With a single ART provider at the District level, clinics are also vulnerable to patient care being suspended should the provider be unable to attend to the ART program.

Under current National guidelines, the initiation of ART and patient monitoring can only be conducted by Medical Officers (e.g. Doctors), Health Extension Officers, and Nurses. The majority of available providers in rural areas are actually Community Health Workers who are trained health professionals. Community Health Workers are, at present, officially not allowed to monitor for side effects among HIV patients or refill prescriptions in the case of routine patient reviews. The significant time spent on non-HIV related patient care has left health workers overburdened and HIV patients without the adequate time with providers for the level of in depth counselling often required for ART specific needs.

What Needs to Be Done?

At the Provincial Hospital level, additional clinical staff should be hired including the addition of at least one Medical Officer and one Health Extension Officer whose primary responsibilities will be for HIV patient care. The post of Officer In Charge (i.e. Clinic Director) should be filled at all clinics, preferably by a Medical Officer, to provide support in the referral of complications (i.e. switching of patients to second line therapy) and other areas of consultation requiring a higher level of expertise.

Provincial staffing plans at the District level ART Clinics need to provide adequate human resource allocation such that a minimum of 2-3 providers are trained in prescription of ART at each District level facility. To support District level ART providers, Community Health Workers should be authorized by the National Department of Health to manage basic HIV care, monitor for side effects, and in the refilling of prescriptions in the case of routine HIV care.

Training Needs

In addition to providing the additional staffing mentioned above, there are important training improvements that will dramatically improve quality of care and clinic efficiency. As mentioned, training in ART prescription currently occurs through the Integrated Management of Adult Illness (IMAI) curriculum that is delivered at considerable time and expense. HIV medicine should be made part of the pre-service curriculum for health providers. There is ample support among leadership in both academic institutions that train health providers at the National Department of Health. The main issue has been lack of coordination and support to coalesce the needed partners (e.g. curriculum review boards, academic professionals, and senior management from the National Department of Health) to facilitate this transition. Mainstreaming HIV training for health professionals will also serve

to lower current negative perceptions and stigma even among health providers.

Basic management training for clinical and laboratory staff who manage clinical and/or lab personnel would be of great benefit. At present most clinic or lab staff lack in any formal administrative or program management training. A result is often poorly developed systems, particularly, for staff management as well as monitoring and quality assurance functions. With improvement in the ability to provide in service training in management, turnover may be reduced. Common blocks to service inefficiencies such as poor turnaround time of samples or frequent stock outs of reagents may also be more adequately addressed.

Data Management

Additional human resources for the management of data at each Provincial level clinic are essential. At least one additional data clerk for ART and patient recordkeeping is required in addition to the existing data clerk staff currently at all STI/HIV sites. The routine updating for patient charts into a patient base, particularly as the number of patients and sites grow, is an area that is currently under-resourced. Also, part time IT assistance to ensure anti virus updates are completed and patient data is properly backed up should either be provided by local contractors or Hospital IT staff (both Goroka and Mt.Hagen Hospitals have newly formed IT Departments and they are being phased into most major Provincial referral hospitals in PNG).

Recommendation 2: Improve Clinic Infrastructure

Why Is This Important?

Key infrastructure required to enable provision of effective health services includes water, electricity, sanitation, safe medical waste disposal, information

technology systems, communication and adequate housing for staff at remote sites. In particular, HIV related services require space for counselling on both testing and adherence. Without attention to these areas, patient care suffers, clinic outcomes decline, and, there is poor uptake of services. In the health facilities of the Highlands, many of these areas are either in need of considerable attention or are altogether unaddressed.

Infection control is essential; for HIV patients, given the synergy between HIV & TB, proper ventilation, circulation, and airflow in waiting areas is of paramount importance.¹⁷ Both Tinninga Clinic and Michael Alpers Clinic have very poor infection control and leave patients, many who are already immune-suppressed, more vulnerable to TB. Water, electricity and staff housing are available in urban health facilities but are commonly not available in many of the rural and remote health centers. There is a need to upgrade sanitation and medical waste disposal at most District health centers. In rural and remote areas, staff housing is required to attract and retain staff to work in rural health centers. All aspects of infrastructure development will strengthen the capacity of health facilities to provide both HIV-related and non-HIV services.

What Needs to Be Done?

It will be necessary to undertake an assessment of ART clinics based at Health Centers to quantify the type and extent of infrastructure needs. Specialists in infrastructure should be engaged to conduct the assessment. Health Centers that are surveyed will need to be visited for structural assessments and identification of local suppliers and laborers/contractors that can implement facilities improvements.

- Through site visits, identify and prioritize the infrastructure needs for health facilities that will be part of PAPUA.
- Identify the most appropriate types of infrastructure development,

taking account of the rural and remote locations of many health centers. For example, the type of electrical support (e.g. mini-hydro, solar cell, generator set), water supply (e.g. rain water catchment) and medical waste management technology to be used.

- Assessment of non-incineration technology for medical waste disposal.
- Identify strategies to minimize the risk of infrastructure theft, (i.e. solar cells).
- Include plans for ensuring quality standards are applied in infrastructure development.
- In collaboration with Government and NGO partners, formulate an infrastructure development plan which sets out a phased approach, aligned with the roll-out of PAPUA
- Develop a plan for how infrastructure will be maintained by health services and Provincial Health Authorities, including budget estimates.
- Develop a plan for government to meet operational costs such as electricity and water, fuel for generators, including budget estimates.
- Quantify the level of funding required for the different components of infrastructure work and development of budget sharing plans with districts.
- Include plans for development of local capacity in infrastructure development and maintenance, including employment of PLHA.
- Make recommendations on the appropriate aid modality for the infrastructure development (for example, project contract), including technical oversight of the work.

The infrastructure sub-design should incorporate flexibility with the option

of additional infrastructure development should funding be made available by other donors or the National Department of Health. Cost-sharing the infrastructure component with Provincial governments would be optimal. The infrastructure sub-design should incorporate clear plans for Provincial Health offices to be responsible for operational and maintenance costs and seek the agreement of districts for this to be their responsibility. To ensure expert technical oversight of the infrastructure component of PAPUA, it is proposed that the Facilities Branch at the National Department of Health be involved in two ways:

- Developing the terms of reference for the infrastructure sub-design with CHAI and in consultation with NDOH Health Unit.
- Technical oversight of the sub-design and subsequent infrastructure development work by a contractor.

These functions most appropriately rest with the NDOH Facilities Branch, given their technical expertise. Sustainability will be enhanced by choosing infrastructure solutions with feasible maintenance requirements in rural and remote areas, development of anti-theft strategies and realistic maintenance plans with a requirement for budget allocation by Provincial Health Departments for facilities monitoring and maintenance. Problems with maintenance would be addressed through technical advice and advocacy to the Provincial Health Department.¹⁸

Recommendation 3: Develop Regional Centers of Excellence

Why Is This Important?

A major issue in the provision of quality HIV testing care and treatment, both at the Provincial level and at the district level is the lack of a strong Provincial hub for clinical training, mentorship, and supervision. At present, roll out of training occurs in a fragmented manner with most training issued from the capital

of Port Moresby, which is accessible only by air from Goroka and Mt.Hagen. This results in a vast amount of time and resources spent in delivering trainings in a variety of clinical areas with little to no coordination from the National level. This also makes it difficult for clinics to function properly as staff may frequently be absent to attend training.

Similarly, Provincial Hospitals are not properly supported to provide mentorship and supervision outside the Hospital in District ART sites. The lack of clinical support from more experienced providers often means that District level providers may not feel confident in either initiating patients on ART and/or in managing any potential complications. In addition, while a number of interventions or approaches have been taken by individual hospitals to improve referral pathways or clinical standards, there has not been a coordinated effort to pull these best practices under one umbrella so that dissemination can be facilitated. Finally, sites such as Mt.Hagen and Goroka Hospital have been, despite numerous challenges, delivering ART for nearly 8 years. An effort to designate them as Regional Centers of Excellence, even if some deficiencies persist, serves to boost morale among health workers who already work under difficult and challenging conditions.

What Needs to Be Done?

Centers of Excellence (CoE) could serve as both regional referral centers for complicated cases and as a base for expert teams that will facilitate the decentralization process through training, mentoring and monitoring in health center. This model is in the process of being employed in Indonesia through a massive ART scale-up effort. In PNG, PAPUA will similarly consolidate current training materials for CST, VCT, PITC, TB and HIV management, PMTCT, and integrated management of adult illness (IMAI) and create efficiencies to optimize training.

Provincial and district staff selected from hospitals and health centers will be trained as trainers so that the province and districts can train locally and are not dependent on Port Moresby. The National Department of Health and Provincial Health Authority in each Province should work together review the supply chain needs of the expanded ART program as well as the need for TB commodities and ensure that there are appropriate projections, budgets and logistic arrangements in place.

Special areas of focus for hospital-based care will be:

- Comprehensive, one-stop services for HIV, TB, and STIs. (PMTCT will be provided through MCH services)
- Improved HIV testing strategies:
 - o HIV testing offered to all hospital and health center patients using a PITC approach
 - o HIV testing offered to all pregnant women
 - o HIV screening all new TB patients
 - o HIV screening of all STI patients
 - o Promotion of HIV testing for the partners of HIV positive people
- Removal of barriers to initiation of treatment:
 - o Establishing reasonable adherence targets
 - o Monitoring of treatment delays
 - o ART for all HIV positive mothers
 - o Early ART treatment of TB positive people
- Roll out POC CD4 testing to facilitate early treatment of asymptomatic cases
- Strengthen laboratory systems
- Task shifting to nurses or CHWs wherever appropriate
- Improvement of data management and use by hospital and districts
- Establishment of SOPs for linkages between hospitals and health centers for:
 - o Referral of patients
 - o Laboratory examinations
 - CD4
 - Viral load for treatment monitoring
 - GeneXpert testing for TB diagnosis
- Establish linkages with churches to provide adherence and social support for infected and affected individuals and to promote testing and reduce disease associated stigma

As decentralization continues, the CoE teams will make regular mentoring and monitoring visits.¹⁹

Recommendation 4: Standardize Case Management

Why Is This Important?

While many important steps have been taken to embed and apply the concept of Case Management in local ART programs, there is also a significant need for a more uniform set of operating requirements, job descriptions, standard operating procedures, training materials, data collection forms, and other technical guidelines which ensure the model is properly delivered. Case Management has grown organically within the context of a broader pilot program to expand access to HIV care and treatment. It is very promising as a retention strategy and clearly has a distinct role to play in improving the quality of patient care. But it remains without the proper documented support to articulate clearly: 1) How Case Management should function 2) What the standardized training tools, protocols are in Case Management, and 3) A Guide for providers and health care administrators to learn more about the purpose and importance of Case Management. These tools need to underscore the importance of ideas such as patient adherence and retention, and how and why these concepts are important and impact a broader health system, which now cares for thousands of patients on life long therapy.

What Needs to Be Done?

Existing materials such as Case Management specific training materials and curricula, intake forms, referral pathways, and terms of reference for positions should be gathered, reviewed, and assembled into one comprehensive set of documents that becomes a manual for delivery of Case Management services. A quality assurance mechanism of some type must also be developed to ensure that the service can be consistently delivered. Staff from the current Case Management teams will need to work with Hospital, District, and Clinton Health Access Ini-

tiative partners to develop these materials, field test them, and then seek approval from the National Department of Health to roll these curricula out to additional ART sites.

These systems and materials need to be assembled within the context of the overall PAPUA approach concept. That is to say, Case Management should be understood as an intervention that requires the support of other components of the health system. For example, it should be made clear in all materials and communications that inadequate staffing of health facilities will result in Case Management not being able to fulfil its intended purpose.

Recommendation 5: Develop Patient Information Systems

Why Is This Important?

As described in Chapter Three, proper medical records and maintenance of patient level data is an area of pressing concern at ART clinics. In the Eastern Highlands, ART patient registries have grown from less than 50 patients less than six years ago to over 2000 as of 2012; these patients are no longer being seen at one facility but now ten. In the Western Highlands, the number is rapidly approaching 3000 registered ART patients; this clinic had no functional patient database until this study provided a comprehensive patient database in excel as a result of the patient chart review.

Managing HIV care and treatment requires a system that can provide life long medicine for patients; high levels of adherence are critical for ARVs. Good record keeping systems are, among other things, essential for proper stock management, ordering, and drug forecasting. Sound patient information systems also help ensure that patients who miss review appointments are quickly followed up with to prevent being lost to follow-up. Moreover, strong medical records help refer

patients to other clinical areas as needed (e.g. STI, TB, Antenatal Services) which is very important in HIV care where multiple points of the health system often intersect.

Apart from the importance at the patient level, poor information systems are resulting in missed opportunities for both providers and for policy-making bodies such as the National Department of Health to understand progress in scaling up HIV treatment at District, Provincial, and National levels. What was, ostensibly, a simple process of trying to understand how many patients were alive at 12, 24, or 36 months at two ART clinics, revealed patient recordkeeping systems unable to keep pace with the steady increase in ART enrolment. Lastly, purely paper-based systems have their own limitations as there is no adequate system for backing up patient charts and copies of individual records do not exist.

What Needs to Be Done?

The primary contributing factor to weak medical records is that current staffing of ART

Clinics do not cater for clinic data needs. Appropriate staffing plans would include not only a minimum of two additional data positions at each ART site, but also training in data management and working with basic medical records. Current data collection systems should be reviewed with the NDOH to create a leaner system that only collects data that will be used.

This research also provided the opportunity to support each major Provincial ART clinic with an excel workbook that contains basic available data on all registered patients irrespective of their ART initiation status. A next critical step is overseeing the importation of these data into a new HIV Patient Database and making sure that this database can be properly resourced at each clinic. IT support for each Data Manager and Data clerk is also critical at ART sites.

Once the database has been developed, low tech and low cost systems should be explored that address patient retention and issues related to lost to follow-up. In PNG, many patients do have access to mobile phones. Innovations such as an automated SMS based system for appointment reminders and alerts for missing patients may also be worth exploring once the patient databases are functional.

Recommendation 6: Conduct Operations Research in HIV Care and Treatment Services

Why Is This Important?

Operational research is needed to generate reliable evidence on how to improve services; such research is also often referred to as implementation science as it focuses on how interventions work when they are implemented. While the quantitative analysis of patient retention has provided some understanding of where each clinic stands with respect to rates of lost to follow-up, additional research into the major drivers of lost to follow-up will be of great value to further improve patient retention efforts. And, of course, a stronger study design that more appropriately accounts for the contextual differences may yield a better understanding of the efficacy of case management.

Given that the data within the patient charts themselves often lacked potentially useful demographic information (e.g. patient distance to clinic, marital status, and income) it is difficult to gain a rich understanding of what population based similarities or differences may exist among patients who have been lost to follow-up or died. Similarly, understanding more about the common features and characteristics of those with long-term survival would also help refine retention activity. Qualitative research using focus groups may provide important insights into patient adherence and drivers of loss that are missed through quantitative methods.

On a clinical level, patient data at intake on stage of HIV progression at the time of initiation was not consistent. Further research on the leading causes of death among ART patients could also be helpful in improving care and treatment.

What Needs to Be Done?

Firstly, the Case Management intervention should be reevaluated in a more controlled study where the operating environments are appropriately matched; a mixed method approach should also be considered so that the quantitative analysis can be complemented by a qualitative component. Taking a prospective rather than retrospective approach to data collection may also be useful so that program data can be analyzed and utilized along the way in a monitoring function respond to program weaknesses and strengths. The early inclusion of the NDOH, Provincial Hospitals, and Districts will ensure that these research questions are program-relevant and that those most likely to use the results know about the research from the start. Where appropriate, members of communities among whom research will be conducted will be included in the agenda setting and research design discussions.²⁰

In order to ensure that data are actively used in program management, regular feedback meetings will be structured with leadership at the Provincial and District levels which present data to key health staff and management. At a National level, key operational research projects and findings should be shared at least twice a year to review their progress and present areas of promising best practice. Early support from the National AIDS Council, the Medical Research Advisory Council, National Department of Health, and leadership at the Provincial Health Authority level so that they are engaged from the beginning in operational research efforts, will be of paramount importance.

Recommendation 7: Create a National HIV Technical Working Group on Policy for Care and Treatment

Why Is This Important?

Though the previous recommendation provides an important guidance on generating a better understanding of the impact of Case Management, drivers of patient loss, and HIV service delivery in general, there is currently no vehicle for driving policy change at the national level. While a committee exists to contend with the revision of clinical guidelines and issues related to the medical aspects of care and treatment, there is no entity to which evidence based practice in HIV service delivery could be presented. The absence of such a National level vehicle for driving policy leaves change in HIV public health programs occurring on an ad hoc basis.

What Needs to Be Done?

A National Technical Working Group for Policy on HIV/AIDS should be formed whose purpose is to provide coordination, oversight, technical advice and technical approval primarily to the National Department of Health but also for any other development partner funding, additional grants or pilots directly related to the health service delivery components of the National STI, HIV and AIDS programs. Such a technical working group could draw together the broad technical input related to overall HIV and AIDS programming. A number of other working groups already exist for specific technical areas such as HIV Surveillance, Prevention of Parent to Child Transmission (PPTCT), HIV Counseling and Testing (HCT), and Care and Treatment, TB/HIV, and Sexually Transmitted Infections. These working groups could provide feedback and input to the Technical Working Group. The function of the group would also be to take operational research, implementation

lessons and other research evidence and ensure that it is used to inform policy making, revision of policies and inform programming, planning and implementation where appropriate. By providing high quality technical advice and technical sign off on any proposal or pilot for health related HIV and AIDS service delivery, there would be a mechanism to ensure that there is an evidence based process for policy review and development, linked to training and dissemination that emanates from the National Department of Health.

The Clinton Health Access Initiative could support the establishment of the Working Group Secretariat within the National Department of Health assist policy review and development by expert panels. This group would be accountable to the National Department of Health and would be chaired by the Principal Advisor for STI & HIV/AIDS. Priorities for policy review and development will be set by the Technical Working Group in consultation with stakeholders who would include Governmental and Non Governmental Partners as well as multilateral and bilateral donors who maintain a technical focus in HIV service delivery. Final approval for policy will remain with the Director for Disease Control and the Secretary for the National Department of Health.

Recommendation 8: Marketing PAPUA

Why Is This Important?

Recommendations 1-7 propose addressing major systemic gaps in health service delivery. While implementation of the strategy will be rational and systematic, there will need to be significant buy in from a variety of stakeholders to ensure the approach receives the proper support at National and Provincial level. Significant resources will be required from both Governmental and non-governmental donors and partners. Proper attention to appropriately marketing this pro-

posed strategy would attract technical, material, and other essential human resources necessary to roll it out.

What Will Need to Be Done?

Following basic marketing principles and applying them to a public health intervention, the marketing of PAPUA will require attention to the four “P”s: Product, Price, Place, and Promotion. The “Product” in this case is the PAPUA model itself. A communication strategy will need to be put in place, which carries the message that while the gift of life saving therapy of HIV exists in PNG a distressing number of patients are not surviving after 12 to 24 months. A massive intervention is needed which will simultaneously address the need to improve patient outcomes while strengthening health systems of the rural poor. For marketing purposes, the price in this case will not be price related to the project costing, but rather the price on the health system (as estimated through a costing analysis) of expensive long term in patient care for patients who are experiencing treatment failure. In other words, by investing in better patient retention and earlier detection and treatment, PNG will save on the “price” of treating those affected by HIV. Place in this case will be in the Highlands region where the majority of HIV cases are. And the “promotion” will occur in the many forums, which occur at the Development Partner, National Department of Health Donor summits, and key stakeholder meetings, which are held at the Provincial levels.

Whose Support will be Needed?

Officers in Charge at both Provincial and District level ART clinics will be required to support the human resource needs; in their respective Province, they will need to collectively voice their concerns and human resource needs to Director’s of Medical Service of their respective Hospitals and, to the CEO at the

Provincial Health Authority level. The support of these CEOs is indispensable as they can make decisions in terms of staff ceilings for their public hospitals and rural health clinics. Authority to allocate budgets lies with the National Department of Health who establishes minimum standards and approves budgets for Provincial Health and Hospitals (which now fall under one overarching Provincial Health Authority). Support for such change, however, must be established at the Provincial and District levels, as this is where facility level staff plans and budgets are formulated. Other key players will include the Deputy Secretary for Health Standards, Secretary for Health, Minister for Health and HIV/AIDS, UNICEF, WHO, and leadership of the AusAID Health Program.

What Will it Cost?

The proposed PAPUA model for HIV service delivery improvement would be a multi-year effort which would seek joint funding from both Government and larger bilateral or multilateral donors such as the Global Fund to Fight AIDS, Tuberculosis, and Malaria, the Asian Development Bank, US Agency for International Development or the Australian Agency for International Development, all of whom are active in the development space in PNG. While a detailed costing of this effort is beyond the scope of this research, it is estimated that covering at least one Health Center in all Districts of the Highlands along with strengthening the Provincial Hospital services would roughly be a \$20-\$25 million USD program over 4 to 5 years.²¹

Model for Leading Change

The key to the effective implementation of any strategy requires the ability to articulate the need for change, formulate a blueprint for strategic objectives, build a committed team, and communicate the mission to a broader audience to

generate support for long term change; the relevant strategy must take into account changes in the external environment and be situated within the setting's strengths and weaknesses. Leadership, be it direct (e.g. focused on users to drive behaviors), or indirect (e.g. a result of influence processes) is fundamental in the effort to drive change (Yukl: 2006). In the complex operating environment of Papua New Guinea, an appreciation of three key factors is needed to lead strategic change:

- 1) **Consensus**: with its vast cultural diversity, there is a need for consensus building on multiple levels (National, Provincial, and local)
- 2) **Diffusion of Leadership**: In the Melanesian, tribal context, one leader is never enough; only a strong council or coalition of chiefs and leaders can drive change. A process of shared influence which is diffuse and where members may exhibit leadership at any time (Yukl: 2006)
- 3) **Local solutions**: there is an extraordinary value placed on “proof of concept” on PNG soil before adoption and implementation can be considered.²²

Taking into the account the above, this study suggests a leadership model that incorporates the Eight Step Process for Leading Change by John Kotter that takes advantage of the “policy window of opportunity” outlined earlier in this chapter. Kotter's 8 steps for leading change encourage first and foremost establishing a sense of urgency. In the case of patient retention and the PAPUA effort, the urgent case needs to be widely made that an already weakened health system will not be able to cope with massive numbers of patients experiencing treatment failure, needing the transition to expensive second line therapy, and the possibility of drug resistant ART due to poor adherence.

The second step of a guiding coalition should, again, be one that reflects the consensus-based decision-making that permeates PNG. Support will be needed from top leadership at the National, Provincial, and District levels in addition to those that manage major donor-partners. UN bodies will also be important such as

UNICEF and WHO to provide the technical seal of approval.

The change vision, Step 3, should be one that communicates the essence of PAPUA—that is a simple motto such as “saving lives, strengthening systems” which, as Kotter says, can be easily shared at all levels and that encompasses all aspects of the broader effort. The table below highlights Kotter’s suggested steps along with the specific application of each to the PAPUA effort. Step 4, “Communication of the Vision” will assume the form of widely distributed materials that are brief, simple, and allow leadership across the spectrum of key stakeholders. This communication will also embody the strategy outlined in the Recommendation 8 of Marketing the PAPUA approach.

Step 5, “Empowering Broad Based Action” will seek to address the familiar bottleneck facing so many development efforts: the inability to disburse funds and resources from National to Provincial levels. By encouraging the establishment of direct partnerships and funding mechanisms with Provincial Health Authorities and public hospitals these delays will enable greater ownership and decision making at the ground level.

“Short Term Wins”, Step 6, will take the form of results, which can be seen at six-twelve months such as rapid improvements in patient retention rates or sample turnaround time for lab results as a result of PAPUA interventions. Step 7, “Never Letting Up” will ensure that the guiding coalition continues to push PAPUA; specifically, this will mean moving ever closer to where communities and the rural poor access services and improving the service delivery systems. This may include, for example, newer initiatives that are consistent with PAPUA such as a drive to eliminate maternal to child transmission of HIV using village based health workers linked to local facilities or traditional birth attendants who are brought into the efforts to decentralize prevention of mother to child transmission programs.

Table 9: Applying the 8 Steps for Change Model

<p>1. Establish Sense of Urgency</p>	<p>The need for improved patient retention is critical given the high rates of lost to follow-up and potential development of ART drug resistance associated with poor adherence. Low indicators in maternal and infant mortality must be addressed through a comprehensive approach; left unchecked, the health system will be overburdened more than it already is with patients failing on treatment and the development of drug resistant HIV</p>
<p>2. Create Guiding Coalition</p>	<p>Leadership at the National Department of Health; Director of Disease Control & Secretary for Health; Key Provincial Health Authority and Hospital CEOs; Director of major donor programs i.e. AusAID, USAID, and Global Fund</p>
<p>3. Developing a Change Vision</p>	<p>PAPUA: “Saving lives, strengthening systems”; creating a vision of better treatment outcomes for patients and improved health systems for providers.</p>
<p>4. Communicating Vision for Buy In</p>	<p>The PAPUA approach is simple and shared widely among Government Departments and non-governmental partners through one page fact sheets, brochures, and briefing materials for health leadership</p>
<p>5. Empowering Broad Based Action</p>	<p>Encourage Local Authority: Address structural management and funding barriers by facilitating flow of funds, staff, and other resources directly to Provincial level after National endorsement of Papua;</p>
<p>6. Generating Short Term Wins</p>	<p>Improvement in 6 month retention rates, reduced lab turnaround time, and improved patient support measures through Case Management resulting in improved quality of life (as measured in QoL surveys)</p>
<p>7. Never Letting Up</p>	<p>Leadership pushes new initiatives such as the employment of expert clients and village level health workers to improve HIV case detection and follow-up</p>
<p>8. Incorporating Change Into the Culture</p>	<p>Ensure integrated, systems approaches to future funding applications and interventions and not vertical disease programming.</p>

Finally, Step 8, incorporating a culture of change will encourage a paradigm shift away from disease specific funding modalities that ignore broader health systems constraints. By demonstrating that PAPUA can have a positive impact on patient retention overall while strengthening the health system overall future PNG

public health efforts in the rural sector should be required think, plan, and program in an integrated fashion that builds primary health service delivery for the poor and underserved rural majority.

In keeping with the principles outlined above, the leadership itself will necessarily come from a “council of chiefs or leaders” in local and national public health. While an entity such as the Clinton Health Access Initiative or a similar, neutral organization can serve as a convener, the roots of leadership in this area of development need to emanate locally.

Evaluation

At the outset, an evaluation would be recommended for the overarching PAPUA effort. An evaluation team, rather than one evaluator, would likely be necessary as their wide range of topical expertise is required to make an adequate assessment of the project efforts, which would include:

- Knowledge of HIV/AIDS
- Health systems strengthening experience
- PNG specific experience at both National and Provincial levels

With this in mind, it would be proposed that the evaluation team have a team leader who has HIV/AIDS and health systems strengthening experience from both PNG and internationally. In addition, the team should have the benefit of a Papua New Guinean health expert who has an intimate knowledge of the operating environment and also understands issues pertaining to working within government health systems. This approach suggests incorporating both the decision-oriented and participant oriented perspectives. As the Team leader, the former could provide the “decision-oriented” focus. The latter would provide the “participant-oriented evaluator” perspective and could also facilitate the involvement of a broader group of stakeholders (Fitzpatrick et al.: 2011) who may be unknown to the Team

Leader. It will be critical that the evaluation itself consults with a broad spectrum of stakeholders and audiences for this review. In applying Fitzpatrick’s “Checklist of Potential Stakeholders and Audiences” the following table provides abbreviated version of stakeholders and partners that must be involved.

Stakeholders & Audience Checklist

Individuals, Groups, or Agencies	To Be Consulted	To React
AusAID In-Country Program Representatives	X	X
National AIDS Council Secretariat		X
Minister and Secretary for the National Department of Health		X
Principal Advisor on STI/HIV AIDS	X	
Director of the Central Public Health Laboratory	X	X
Provincial Level Health Departments	X	X
Other Development Partners (WHO, UNICEF, UNAIDS)	X	

In addition, field level assessments will need to be conducted where interviews could be undertaken with both facility level health workers and people living with HIV who are direct beneficiaries of the program.

Evaluation Design Issues

The questions that the evaluation team will be attempting to address are complex and multi-layered. Ultimately, the donor (s) will seek to assess if there is “value for money” in the PAPUA effort. This will not only be, for example, a purely quantitative assessment of the numbers of people retained on treatment or numbers of health facilities improved but also a qualitative assessment of what kind of capacity has been built and what is the overall quality of the services

being provided.

Given the breadth and scope of the program and the broader questions that any donor would seek to answer, it would be proposed that the Evaluation Design utilize a mixed method, triangulated approach. More specifically, it would be best served to be divided as a Mixed method component designs where methods (are) implemented as discrete aspects of the overall inquiry and remain distinct throughout the inquiry: The combining of different method components occurs at the level of interpretation and conclusion rather than at prior stages of data collection or analysis.” (Caracelli and Greene: 1997). The evaluators can thus “choose different methods at the key methodological stages of design, data gathering, and analysis.” (Green cited in Fitzpatrick et al.: 2011).

The components of such a design will include using the quantitative measures cited in the programs logical framework (e.g. number of patients on treatment, percentage of patients lost to follow-up, etc.) along with a descriptive design which is a qualitative, case study approach to understanding how both PAPUA did or did not work in terms increasing both the access and quality of HIV services.

Data Collection Approaches

The primary source of data would be internal monitoring and evaluation data maintained by the program and health facility level data at target sites. The PAPUA team would assemble a range of program briefs that summarize the accomplishments across all programs as well as challenges faced. Training lists and financial reports would also be provided.

In addition to overall observation, interviews should be conducted across the range of stakeholders. Focus groups with health care providers and/or direct beneficiaries would also be useful for this evaluation. Because of the large numbers involved, such groups would provide the opportunity to gain a better a sense

of how the program has interacted with target groups; this would otherwise not be possible in the individual interview setting. Electronic interviews, telephone interviews, or other surveying using these modalities would not be appropriate for the rural PNG setting.

In drafting the Terms of Reference, it will be critical that the evaluation team work not only to assess whether or not the objectives have been met but also structure how key stakeholders will be involved in the data interpretation. This will not only add validity to the findings but also enable the key partners to better use the information moving forward post-evaluation (Fitzpatrick et. al: 2011).

Use of the Evaluation Findings

With the dearth of information on HIV services in rural Papua New Guinea, the results of this evaluation will provide key direction in terms of potential best practice in the rapid scale-up of anti-retroviral treatment, patient retention, and health systems strengthening. The findings should also be presented in manner which aligns with the reading ability of a variety of stakeholders: this should include not only senior officials within the Government of Papua New Guinea and the Ministry of Health but also those working at the Provincial level since the majority of service delivery occurs in these areas. The avoidance of jargon, use of anecdotes, pictures, and illustrations will also be very important in the final report (Fitzpatrick et. al: 2011).

Because there will inevitably be negative findings from the report, it will be very important for the evaluation team to share such findings with the PAPUA team through an oral debrief and preliminary written report. This will allow the organization to better assimilate this news and may also permit the project team to present other barriers or challenges in implementation that the evaluation team may not have been aware of.

Chapter 6 Endnotes

14. Farmer, Paul. "Introducing ARVs in Resource-poor Settings." Plenary Address World AIDS Conference. Barcelona. 11 July 2002
15. See <http://www.hfrp.org/evaluation/the-evaluation-exchange/issue-archive/advocacy-and-policy-change/evaluation-based-on-theories-of-the-policy-process> accessed October 12, 2012
16. See <http://www.hfrp.org/evaluation/the-evaluation-exchange/issue-archive/advocacy-and-policy-change/evaluation-based-on-theories-of-the-policy-process> accessed October 12, 2012
17. Globally, TB is the most common opportunistic infection among those infected with HIV and the most common cause of death among HIV patients.
18. Lowe, D., Chow, P. (2012) through CHAI Indonesia's REACH Proposal provided key guidance in the framing of infrastructure considerations in the scale-up of ART services.
19. Wignall, S. Lowe, D., Chow, P. through CHAI Indonesia's REACH Proposal provided guidance in the Centers of Excellence concept in the scale-up of ART services.
20. The Clinton Health Access Initiative in both PNG and Indonesia are undertaking significant efforts to incorporate robust approaches towards M&E and Operational Research and this section has consulted CHAI's program design's in each country in the establishing this recommendation
21. Estimate based on recent multi year health development projects funded through Aus-AID, Global Fund, and US AID in PNG
22. A prime example is the use of the global standard in most resource poor settings of the two HIV rapid test algorithm for point of care HIV confirmation. Despite the fact that this has been widely implemented throughout sub Saharan Africa for over a decade, PNG undertook a validation of the method which took over four years in multiple settings across PNG. (*Clinton Health Access Initiative QAI Reports 2010-2011*)

CHAPTER 7

CONCLUSIONS

A certain confusion regarding the quite different goals of research and service has hobbled effective responses to HIV disease in the poorest communities. The point of bringing new funding to allay the suffering caused AIDS, tuberculosis, and malaria was not merely to mimic existing transnational research projects, already struggling with serious ethical dilemmas, but rather to remediate inequalities of access to proven therapies. This goal should be embraced without apologies. Embracing this goal helps us to answer the question, 'What is the purpose of such operational research?' ...The very purpose of this research is to do a better job bringing the fruits of science and public health to the poorest communities.

Paul Farmer, Co Founder Partners in Health

This research has afforded a unique opportunity to not only understand the potential efficacy of an intervention to save lives, it has provided a window into understanding how resources for a specific disease (in this case HIV) can practically be leveraged to improve a health system. It may be facile to apply the results of a multivariate analysis that show considerably a statistically significant relationship between being from the Eastern Highlands and being retained and declare Case Management a success overall. Yet to do this, without acknowledging the extensive limitations of the analysis and the fact that retention rates still require considerable improvement, would be naïve. The intervention is a promising start. But there is considerable work to be done.

Each recommendation presented as part of the PAPUA model has had the explicit goal of improving the health system with the implicit goal of patient retention. For such an implementation plan to be successful convening leadership of the National Department of Health leadership and Provincial Health Authorities is of utmost importance. A presentation of findings will be convened for the Ministry of Health and other relevant stakeholders in the National HIV care and treatment response. From these proceedings, it is

hoped that the *Minimum Standards on HIV/AIDS Care and Treatment* can be revisited and that the PAPUA approach can serve as a vehicle for implementing these standards. This document serves as the guiding framework for all health facilities in PNG. There are, also, potentially significant implications outside of PNG. Though there are an ever-growing number of people on ART in resource-limited settings, patient adherence remains a major challenge. Interventions, which are both efficacious and cost effective, are needed not only in PNG, but other high burden HIV countries in sub-Saharan Africa.

To summarize, the key features of PAPUA are:

- PAPUA is fully aligned with the National Department of Health National HIV Strategy 2010-2015.
- The interventions are evidence based and tailored to the PNG setting.
- PAPUA seeks to revitalize primary health systems while improving the breadth and quality of HIV service delivery
- PAPUA will promote Papua New Guinean leadership
- PAPUA will be flexible and seek to adapt as needed
- PAPUA will place a special emphasis on strengthening primary health care for the most poor and most remote
- PAPUA will work to improve data collection in both Health and HIV services programming in other parts of Papua New Guinea and other areas of health care.
- PAPUA will work to appropriately transition key staff to Government positions during the course of the program.

Ultimately, evaluating the efficacy of patient retention in the Highlands has not been solely about one disease specific intervention or two clinics in rural and remote communities. It has brought to the fore broader issues of what is needed in building realistic, sustainable, locally driven solutions for building health systems.

It is important to always understand health interventions in PNG, which strives to

achieve basic health standards, within the context of severe resource constraints. While it may be convenient to seek the “magic public health bullet”, the reality of building health capacity for the rural poor is that an integrated, systemic approach is the only way to ensure enduring systems. Most centrally, these must be solutions that serve in solidarity with the people of PNG and rely on a commitment to fostering trust, community, consensus, and local leadership.

APPENDIX 1:

SURVEY DATA COLLECTION TOOL

Participant ID:

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DEMOGRAPHIC AND CLINICAL DATA. Mark with an X.

1	Gender	<input type="checkbox"/> Female <input type="checkbox"/> Male																				
2	Age	<table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table> years of age																				
3	Weight	<table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table> . <table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="width: 20px; height: 20px;"></td> </tr> </table> kg																				
4	Height	<table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table> . <table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="width: 20px; height: 20px;"></td> </tr> </table> cm																				
4	Province of Origin	<input type="checkbox"/> Enga <input type="checkbox"/> Chimbu <input type="checkbox"/> Western Highlands <input type="checkbox"/> Eastern Highlands <input type="checkbox"/> Southern Highlands <input type="checkbox"/> Morobe <input type="checkbox"/> Central																				
6	Date of ART initiation	<table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> <tr> <td align="center">d</td> <td align="center">d</td> <td align="center">-</td> <td align="center">-</td> <td align="center">m</td> <td align="center">m</td> <td align="center">-</td> <td align="center">-</td> <td align="center">y</td> <td align="center">y</td> </tr> </table>											d	d	-	-	m	m	-	-	y	y
d	d	-	-	m	m	-	-	y	y													
5	CD4 at initiation	<table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table> cells <input type="checkbox"/> none																				
6	WHO Clinical Stage at initiation	<input type="checkbox"/> Stage I <input type="checkbox"/> Stage II <input type="checkbox"/> Stage III <input type="checkbox"/> Stage IV																				

7	12 Month Follow-Up Status* <i>(review chart data from closest appointment to 12 months from date of ART initiation)</i>	<input type="checkbox"/> Alive and on Treatment <input type="checkbox"/> Lost to Follow Up (<i>skip to #</i>) <input type="checkbox"/> Dead (<i>skip to #</i>) <input type="checkbox"/> Unknown/Data Missing
8	CD4 at 12 Months	<input type="text"/> <input type="text"/> <input type="text"/> cells <input type="checkbox"/> none
9	24 Month Follow-Up Status* <i>(review chart data from closest appointment to 24 months from date of ART initiation)</i>	<input type="checkbox"/> Alive and on Treatment <input type="checkbox"/> Lost to Follow Up (<i>skip to #</i>) <input type="checkbox"/> Dead (<i>skip to #</i>) <input type="checkbox"/> Unknown/Data Missing
10	CD4 at 24 Months	<input type="text"/> <input type="text"/> <input type="text"/> cells <input type="checkbox"/> none
11	36 Month Follow-Up Status* <i>(review chart data from closest appointment to 36 months from date of ART initiation)</i>	<input type="checkbox"/> Alive and on Treatment <input type="checkbox"/> Lost to Follow Up (<i>skip to #</i>) <input type="checkbox"/> Dead (<i>skip to #</i>) <input type="checkbox"/> Unknown/Data Missing
12	CD4 at 36 Months	<input type="text"/> <input type="text"/> <input type="text"/> cells <input type="checkbox"/> none

Comments: _____

APPENDIX 2:

ETHICAL APPROVAL FROM NATIONAL AIDS COUNCIL SECRETARIAT



NATIONAL AIDS COUNCIL SECRETARIAT

P.O. Box 1345, BORO KO NCD Papua New Guinea
Telephone: (+675) 3236161 Facsimile: (+675) 325 9148 Website: www.nacs.org.pg



RESEARCH COORDINATION UNIT

Clinton Health Access

Dear Sarthak Das,

Subject: Executive Approval for RES 10 023

Das: *“Reducing lost to follow up and the Efficacy of case management: Comparative Analysis of Secondary Data from ART in Goroka and Mt Hagen Hospitals”.*

This is to notify you that the Chairman of the RAC has given Executive Approval for this Study. Please proceed with the study.

This is as per Email from the Chairman dated May 20 2012

Thank you

Julie Airi

Behavior, Information and Research Manager

National AIDS Council Secretariat.

APPENDIX 3:

APPROVAL FROM GOROKA GENERAL HOSPITAL

GOROKA GENERAL HOSPITAL
P.O.Box 392
GOROKA
EASTERN HIGHLANDS PROVINCE 441
PAPUA NEW GUINEA
TELEPHONE: (675) 531 2100, 531 2148
FACSIMILE: (675) 532 1081, email address: info@ggh.org.pg

OFFICE OF THE CHIEF EXECUTIVE OFFICER

Our ref: CEO 12-1-7

November 2, 2010

Medical Research Advisory Council

To the Council,

As you may be aware, the Clinton Health Access Initiative has been working in partnership with Goroka General Hospital since 2006 to develop our country's first District level system of decentralized HIV care and treatment. In Eastern Highlands we have ART available in all eight Districts; the system is supervised and coordinated by the Hospital through an innovative Case Management system.

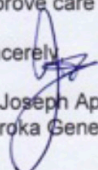
Given the initial success of our collaboration, called the Rural Initiative, the NDOH has requested that more rigorous, scientific evaluation of the effort be conducted so that it can, potentially be scaled up nation-wide. It is my understanding that NDOH and Clinton Health Access Initiative seek to undertake two distinct but linked studies in an effort to better measure the impact of the Rural Initiative and, in particular, the Case Management intervention.

These two studies are:

1. Measuring ART Adherence through a Comparison of Lost to Follow-Up Rates
2. Measuring the Quality of Life Among ART Patients Using the SF12 survey instrument and Viral Load to evaluate the efficacy of Case Management

With our Hospitals facing increasing burden from in-patient care of individuals experiencing complications from HIV related illness, there an increasing need for to document evidence-based practice HIV care and treatment. Goroka Hospital wholeheartedly supports this effort to examine the Rural Initiative and Case Management—we hope that it yields important lessons in the Nation's effort to improve care and treatment for HIV positive individuals.

Sincerely,


Dr. Joseph Apa, C.E.O.
Goroka General Hospital

APPENDIX 4:

APPROVAL FROM MT. HAGEN GENERAL HOSPITAL



MOUNT HAGEN GENERAL HOSPITAL

PO Box 36, Mount Hagen, WHP, Papua New Guinea. Phone (675) 542 1166 Fax (675) 542 2127
Ph: (675) 542 1174 / 542 2084
Mobile: 6871385
E-mail: jkintwa@dalton.com.pg

TO: Office of the CHIEF EXECUTIVE OFFICER

19th November 2010

The Chairman
Medical Research Advisory Council

Dear Sir

Re: ENDORSEMENT OF RESEARCH BY CLINTON FOUNDATION

As you may be aware, the Clinton Health Access Initiative has been working since 2006 to develop our country's first District level system of decentralized HIV care and treatment. This program, the Rural Initiative, will be replicated in Western Highlands Province, beginning in January of 2011. With Mt. Hagen Hospital as the hub of the program, we look forward to the program as supervised and coordinated by the Hospital through an innovative Case Management system.

Given the initial success of the Rural Initiative, the NDOH has requested that more rigorous, scientific evaluation of the effort be conducted so that it can be scaled up nation-wide. It is my understanding that NDOH and Clinton Health Access Initiative seek to undertake two district but linked studies in an effort to better measure the impact of the Rural Initiative and, in particular, the Case Management intervention.

These two studies are:

1. Measuring ART Adherence through a Comparison of Lost to Follow-Up Rates
2. Measuring the Quality of Life Among ART Patients Using the SF12 survey instrument and Viral Load to evaluate the efficacy of Case Management.

With our Hospitals facing increasing burden from in-patient care of individuals experience complications from HIV related illness, there an increasing need to document evidence-based practice for HIV care and treatment. Mt. Hagen Hospital wholeheartedly supports this effort to examine the Rural Initiative and Case Management - we hope that it yields important lessons in the Nation's effort to improve care and treatment for HIV positive individuals.

Yours sincerely

Mt Hagen General Hospital

Dr. James Kintwa
Chief Executive Officer

CAUTION

This e-mail and any files transmitted with it are confidential. If the recipient of this message is not the intended recipient, please notify the sender immediately by e-mail. If you have received this message in error, please notify the sender immediately and return the original message to us by mail.

APPENDIX 5:

APPROVAL FROM PROVINCIAL AIDS COUNCIL



**NATIONAL AIDS COUNCIL SECRETARIAT
(Western Highlands PACS)**



"Together Striving to Control and Prevent HIV / AIDS in Papua New Guinea"

P.O. Box 91
Mt Hagen 281, WHP
Papua New Guinea

Telephone: (675) 542 3835
Facsimile: (675) 542 1418

Director
National AIDS Council
P O BOX 1345
Boroko, NCD

20th May, 2011

Attention: National AIDS Council Secretariat Research Advisory Committee

Dear Chairman,

**RE: LETTER OF SUPPORT FOR LOST TO FOLLOW – UP STUDY IN
GOROKA & MT. HAGEN HOSPITAL**

In western Highlands Province, a high percentage of patients on HIV treatment have either died or defaulted on treatment. The need for programs which improve patient retention are critical to improve good HIV treatment programs.

With Mt. Hagen Hospital and the Provincial Health Authority, the Clinton Health Access is working to improve HIV care and treatment. As part of this effort, they would like to undertake an analysis of secondary clinic data to assess rates of lost to follow-up.

This letter is in support of the research proposal "*Reducing Lost to Follow-up and Access is working Efficacy of Case Management: A Comparative Analysis of Secondary Data from Art program in Goroka and Mt. Hagen Hospital.*"

In WHP, we understand that this is a key area of operational research; we hope that by supporting this study we can improve HIV treatment outcome for the people of western highlands and for the people of PNG.

Yours Sincerely,

Rev. James Koi-Chairman
Western Highlands Provincial AIDS Committee
Cc: Medical Research Advisory Council

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