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Improving Women's Uptake and Retention in Option B+
Prevention of Mother-to-Child Transmission of HIV
in Papua, Indonesia

Submitted by

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ABSTRACT

Background

Mother-to-child transmission (MTCT) accounts for 90% of HIV in children. Globally, HIV has resulted in the deaths of 120,000 children. African countries have reduced MTCT risk from 25-30% to less than 5% through prevention of MTCT (PMTCT) using antiretroviral therapy (ART), elective caesarean section, and replacement feeding. Indonesia implemented PMTCT in 2004, yet the MTCT risk (26.6%) remains the highest in the world.

MTCT is the second cause of new HIV infections in Papua, Indonesia. Nearly half of (29,083) HIV-infected people in Papua are women within childbearing age of 15-49 years. Despite the implementation of Option B+ PMTCT in Papua since 2012, new HIV infections in children continue to rise, suggesting low PMTCT coverage or ineffective PMTCT programs. There was limited literature on PMTCT implementation and outcomes in Papua. This research aims to investigate the performance of Option B+ PMTCT in Papua and to identify factors that influenced women's uptake, adherence, and retention in the program.

Methods

This research used a mixed-methods research design comprising of three studies: 1) Papua Study, 2) Indonesia Study, and 3) Global Study. Study 1 included field observations and in-depth interviews of 20 HIV-positive women and 20 PMTCT health workers in Papua. Study 2 involved analyses of PMTCT data in Indonesia in 2017, and

Study 3 comprised a realist review of Option B+ for PMTCT in resource-limited settings.

Results

Using a quantitative approach, Study 2_Indonesia found high ART uptake (98%) but low ART retention (33%) in Papua. Health facility characteristics that predicted women's retention in PMTCT program were hospitals, hospitals class A/B, generalized HIV epidemic, and high HIV program priority.

Using a realist synthesis approach, Study 3_Global identified three program theories, consisting of Context-Mechanism-Outcome Configurations of Option B+ PMTCT in resource-limited settings. The program contexts identified are similar to the factors identified in Studies 1 and 2. Mechanisms identified in Study 3_Global included: women's willingness, readiness, and motivation to participate in Option B+ PMTCT; and health workers and women's confidence in the PMTCT program. These mechanisms are triggered by enabling program contexts to achieve the desired outcomes.

Conclusions

This research contributes to a greater understanding of Option B+ PMTCT in Papua by describing program performance using local data and identifying factors that influenced women's uptake, adherence, and retention. Findings suggested an improvement of women's participation through the creation of enabling program contexts. Recommendations include: provision of high-quality HIV counselling to increase

women's belief in ART efficacy or to gain partner support, reduction of community stigma and discrimination through campaigns, training to improve health workers' skills to deliver the program, availability of clear guidelines to ensure high quality PMTCT services are delivered, and continuation of free HIV services to reduce financial burden. Future studies are warranted to investigate cultural factors related to pregnancy care in Papua, and to identify mechanisms that are likely to be more influential to increase women's uptake, adherence, and retention in Option B+ PMTCT in Papua.

DECLARATION

The following declaration page, signed by Christina Lumbantoruan, is to certify that:

- I. The thesis comprises only my original work towards the Doctor of Philosophy in Public Health except where indicated in the Preface,
- II. Due acknowledgement has been made in the text to all other material used,
- III. The thesis is fewer than 100,000 words in length, exclusive of tables, maps, bibliographies, and appendices.

Christina Lumbantoruan

October 2019

PREFACE

This thesis includes original work designed, managed, and carried out by Christina Lumbantoruan as a part of the PhD degree at the University of Melbourne. This thesis resulted in three papers developed in partnership with other parties as listed below.

Contributions of authors in Study 1_Papua titled: “Understanding women’s uptake and adherence in Option B+ for prevention of mother-to-child HIV transmission in Papua, Indonesia: A qualitative study” published by PloS One on 18 June 2018, are listed below:

Name of Author	Nature of Contribution
Christina Lumbantoruan	Background research, instrument development, data collection, interview transcribing and translation, data analysis, write up, editing, and submission.
Professor Margaret Kelaher	Oversight and direction for the formation of conceptual framework. Provided theoretical guidance for instrument development and results analysis.
A/Prof Michelle Kermode	Oversight, guidance, and assistance with editing.
Dr. Aloisius Giyai	Assistance with data collection, instrument adjustment to local context, and editing.
Dr. Agnes Ang	Assistance with data collection, instrument adjustment to local context, and editing.

Contributions of authors in Study 2_Indonesia titled: “Health facility characteristics and ART retention in PMTCT programs in Indonesia: A quantitative analysis” submitted for publication to BMJ Open on 20 September 2019, are listed below:

Name of Author	Nature of Contribution
Christina Lumbantoruan	Background research, instrument development, data collection, data analysis, write up, editing, and submission.
Professor Margaret Kelaher	Oversight and direction for the formation of conceptual framework. Provided theoretical guidance for instrument development and result analysis.
A/Prof Michelle Kermode	Oversight, guidance, and assistance on editing.
Dr. Endang Budi Hastuti	Assistance with data collection, instrument adjustment to local context, and editing.

Contributions of authors in Study 3_Global titled: “Women’s Uptake and Retention in Option B+ for Prevention of Mother to Child Transmission of HIV: A Realist Synthesis” in revision following peer review by BMC Health Services Research, are listed below:

Name of Author	Nature of Contribution
Christina Lumbantoruan	Background research, data collection, data analysis, write up, editing, and submission.
Professor Margaret Kelaher	Oversight and direction for the theoretical concept.
A/Prof Michelle Kermode	Oversight and direction for the theoretical concept, assistance with editing.

All co-authors have provided their written consent for inclusion of the publications in this thesis and acknowledgment of the PhD researcher’s main contribution in each paper. The PhD Advisory Committee has also approved the inclusion of the published material.

Academic proofreading and editing was provided by Dr. Kate van Dooren, who has a background in public health.

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I embarked on this journey out of a passion for HIV-free indigenous Papuan future generations. As expected of a PhD journey, I learned to explore hidden opportunities when facing challenges and difficulties. Never in my life, have I experienced such a growing process, which greatly changed my perspectives about life and human beings. I owe this amazing growth and enjoyable journey to many people who were there for me throughout my PhD.

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ABBREVIATIONS

AFASS	Acceptable, feasible, affordable, sustainable, and safe
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal care
ART	Antiretroviral treatment
ARV	Antiretroviral
ASES	Adherence self-efficacy scale
cHCT	Couple HIV counselling and testing
CMO	Context-Mechanism-Outcome
CMOC	Context-Mechanism-Outcome Pattern Configuration
CST	Care, support and treatment
CTL	Cytotoxic T-lymphocytes
DNA	Deoxyribonucleic Acid
ECS	Elective caesarean section
ELISA	Enzyme Linked Immunosorbent Assay
EMTCT	Elimination of mother-to-child transmission
HESC	Humans Ethics Sub-Committees
HIV	Human Immunodeficiency Virus
IBM	International Business Machines
IEC	Information, Education and Communication
KPS	Kartu Papua Sehat
LPDP	Lembaga Pengelola Dana Pendidikan
LTFU	Lost to follow up

MCH	Maternal and child health
MTCT	Mother-to-child transmission
NGO	Non-government organisation
PHC	Primary health centre
PCR	Polymerase Chain Reaction
PITC	Provider-initiated HIV testing and counselling
PLHIV	People living with HIV
PLS	Plain language statement
PMTCT	Prevention of mother-to-child transmission
PNG	Papua New Guinea
PWID	People who inject drugs
RAMESES	Realist And MEta-narrative Evidence Syntheses: Evolving Standards
RDT	Rapid Diagnostic Test
RNA	Ribonucleic Acid
RSUD	Rumah Sakit Umum Daerah / Public hospital
SAIA	Systems analysis and improvement approach
SIHA	System Information for HIV/AIDS and sexually transmitted infection
SOP	Standard operational procedure
SPSS	Statistical Package for Social Sciences
STI	Sexually Transmitted Infection
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
YHI	Yayasan Harapan Ibu

CHAPTER 1

INTRODUCTION

1.1. Scope of the thesis

1.1.1. Mother-to-child transmission of HIV

Globally, mother-to-child transmission (MTCT) is the major cause of Human Immunodeficiency Virus (HIV) in children below 15 years of age, accounting for 90% of HIV in children [1, 2]. Currently, 1.8 million children worldwide live with HIV [3]. Despite the global effort to reduce HIV in children, there were 160,000 new HIV infections in children in 2018 [3]. This number had declined from 240,000 new HIV infections in 2010 [3]. Despite this progress, the Global Plan target set by The Joint United Nations Programme on HIV/AIDS (UNAIDS) to eliminate HIV in children was not achieved. HIV elimination in children was defined as achieved if fewer than 40,000 new HIV infections occurred in children by 2018 and 20,000 by 2020 [3].

HIV remains the underlying cause of death among children under the age of five years worldwide [4]. The survival rates of children infected with HIV are much lower than children without HIV: children living with HIV are eight times more likely to die than children without HIV [4]. In resource-limited settings where there is a lack of access to HIV treatment, one in three children will die before their first birthday and one in two before their second birthday [5]. Globally, HIV disease progressions have resulted in the deaths of 120,000 children [3], with the majority of deaths occurring in less developed countries.

MTCT is more common in less developed countries. Without intervention, MTCT risk in less developed countries is 25–30% compared to 14–25% in industrialised countries [6]. Industrialised countries have successfully reduced the risk of MTCT to less than 1% through Prevention of MTCT of HIV (PMTCT) programs that involve antiretroviral (ARV) treatment (ART), elective caesarean sections (ECS), and avoidance of breastfeeding. Through PMTCT programs, several less developed countries have significantly reduced MTCT risk. Uganda, Namibia, South Africa, and Botswana have reduced the MTCT risk to less than 5% (4.1–4.8%) [7]. Despite the implementation of a PMTCT program in Indonesia, the risk of MTCT remains high (26.6%) [7]. Overall, less developed countries accounted for the majority of new global HIV infections in children in 2017 [3].

HIV morbidity and mortality in children are greater in less developed countries than industrialised countries, due to challenges in the implementation of PMTCT and limited access to ARV. The percentage of pregnant women receiving ART to prevent MTCT significantly increased from 51% in 2010 to 80% in 2017. However, the success of ART to prevent new HIV infections in children was halted by challenges in maintaining women in effective ART during pregnancy and throughout the breastfeeding period. Despite the efficacy of ART to prevent HIV progression to AIDS, only 52% of 2.1 million HIV-infected children received treatment in 2017 globally. The remaining 48% of HIV-infected children who did not receive ART were at risk of HIV progression to Acquired Immune Deficiency Syndrome (AIDS) and death. The ineffective implementation and uptake of PMTCT programs remains a burden in resource-limited settings, including Indonesia, and particularly in Papua Province, where these conditions are more prevalent.

1.1.2. HIV in Papua, Indonesia

Indonesia is a country in Southeast Asia, with a population of over 261 million individuals scattered across more than 17,000 islands and 34 provinces. Currently, UNAIDS estimates 630,000 Indonesians live with HIV: 390,000 (320,000–470,000) men; 220,000 (190,000–260,000) women; and 14,000 (13,000–16,000) children. The main mode of HIV transmission in Indonesia is through heterosexual behaviours [3].

Papua province is one of the provinces with the lowest populations in Indonesia (3.2 million people). It is a geographically challenging province and the majority (91%) of its population, indigenous Papuan people, reside outside of the urban city Jayapura [8]. Based on the latest national HIV/AIDS statistics, Papua is currently the province with the highest HIV prevalence in Indonesia. It has a generalised HIV epidemic of 2.3% of its general population [9], five times higher than the national HIV prevalence of 0.43% [3].

HIV most commonly infects Papuans of reproductive age through heterosexual contact. The highest HIV prevalence (3.1%) occurs among young people aged 15–24 years, followed by people aged 25–49 years (1.8%) [10]. Currently, 29,083 Papuans live with HIV; almost 86% are aged 15–49 years, and half are women [11].

Papua greatly contributed to new HIV infections in children in Indonesia, accounting for 27% of HIV cases in children nationwide [10]. HIV in children is likely to be attributed to low ART coverage and/or ineffective ART among HIV-positive pregnant women in Papua [12]. Nationally, only 13% HIV-positive pregnant women in Indonesia received ART in 2017 [3]. Presumably, ART coverage among HIV-positive pregnant

women in Papua is lower than the national coverage, given this high prevalence of HIV infections in children.

As a result of the generalised HIV epidemic, the high number of AIDS cases, and new HIV infections in children, Papua is one of the most prioritised areas for HIV program intervention in Indonesia. Accordingly, the Ministry of Health, Republic of Indonesia has introduced Option B+, the most proactive PMTCT approach, to Papua.

1.1.3. Option B+ PMTCT

Option B+ is the latest World Health Organization (WHO) recommendation for PMTCT. In previous PMTCT options, such as Option A and Option B, ARTs were recommended only for HIV-positive pregnant women in the AIDS stage. However, in Option B+, all HIV-positive pregnant women, regardless of HIV clinical stage, are eligible for ART [13]. Since all HIV-positive women are eligible for ART, Option B+ eliminates the risk of HIV-positive women not having access to ART in resource-limited settings where the CD4 test that determines HIV clinical stage is rarely available. Option B+ also minimises the risk of MTCT, which is likely to occur when pregnant women in early HIV stages have a high maternal viral load.

Papua adopted Option B+ for PMTCT following the WHO recommendation in 2012. PMTCT is implemented as an integral part of antenatal care (ANC). Health workers offer HIV testing to all pregnant women who visit antenatal clinics and subsequently enrol women in ART if they test positive for HIV [14]. As part of the PMTCT program, HIV-positive women should continue ART throughout breastfeeding (to prevent MTCT during breastfeeding) and for life (to prevent MTCT in future pregnancies).

Provision of ART during pregnancy and breastfeeding aims to suppress maternal viral load to undetectable and non-transmittable levels, thus reducing the risk of MTCT. To achieve these aims, HIV-positive women in Papua need to access health facilities that provide PMTCT programs, start ART, and continue the treatment for life.

Prior to Option B+, Papua had reported low ART uptake, adherence, and retention in Options A and B. In other resource-limited settings, the reasons for low ART uptake, adherence, and retention in Option B+ included HIV-related stigma in the community and health facilities [15], scarcity of health workers [16], and side effects of ARVs [17]. In contrast, women's uptake, adherence, and retention in PMTCT programs were due to HIV testing counselling [18] and advanced HIV clinical stage [19].

Six years after Papua implemented Option B+, MTCT remains a strong contributor to new HIV infections in children nationwide. This implies a low ART coverage or ineffective ART among HIV-positive pregnant women. To date, there is insufficient data to describe the progress of Option B+ PMTCT in Papua. At the onset of this thesis, the challenges experienced by HIV-positive pregnant women in Option B+ PMTCT in Papua were unknown. These limitations warrant the need to investigate performance of Option B+ PMTCT in Papua and factors that influence Papuan women's participation in the program.

1.2. Significance of the research

At the commencement of this thesis, limited literature had investigated Option B+ PMTCT in Papua. Only one study in Papua had examined the role and effects of the health system on PMTCT in the Jayawijaya district [20]. This study found several

health system challenges in the implementation of PMTCT program: the scarcity of PMTCT services, lack of human resources to deliver PMTCT services, geographical constraints and health facility unpreparedness, poor reporting systems, lack of funding, lack of PMTCT campaigns in the community, and lack of PMTCT adaptation to the local context [20]. However, this study did not explore women's experiences of the PMTCT program in Papua. Given that women are the recipients of the PMTCT program, it is important to gain their perspectives of factors beyond the health system that can contribute to PMTCT performance in Papua.

In the international literature, one study reported associations between health facility characteristics and women's uptake and retention in the Option B+ PMTCT program. This study found a large variation in models of care implemented by health facilities delivering Option B+ PMTCT in Malawi, Africa. Two models of care that resulted in a higher retention of women were: 1) health facilities that referred HIV-positive pregnant women from ANC to HIV clinics for ART initiation and monitoring; and 2) health facilities where HIV-positive women received ART at a HIV clinic that did not involve ANC [21]. In principle, both models suggested higher retention among women who received ART in HIV clinics instead of in ANC clinics. Health facilities in Indonesia implement a variety of models of care, which vary according to characteristics such as the type of health facility (hospital vs primary health centre). In primary health centres, HIV-positive women are referred to hospitals for ART initiation. In hospitals, HIV-positive women are referred to HIV clinics within the hospitals for ART initiation [22]. To our knowledge, no studies have assessed associations between health facility characteristics including models of care with women's retention in Option B+ PMTCT in Papua.

Finally, several studies in resource-limited settings have investigated reasons for low ART uptake and retention in Option B+ PMTCT [16, 17, 23-27]. These factors include lack of motivation or readiness for lifetime ART; lack of belief in ART efficacy; fear of HIV status disclosure; ART side effects; and health facility-related factors including low ratio of health workers to women, and long wait times. However, to our knowledge, no studies have explained how these factors influence women's uptake and retention in Option B+ PMTCT in resource-limited settings such as Papua. This limits the ability to replicate the success of Option B+ PMTCT in other resource-limited settings to Papua. The realist synthesis offers a new approach to understanding a complex program and creating similar mechanisms in different contexts to produce similar expected outcomes. These mechanisms were not explored in previous Option B+ PMTCT studies. This thesis aims to address these gaps in the literature.

1.3. Aims and objectives

The primary aim of this thesis is to investigate performance of Option B+ PMTCT in Papua and identify factors that influence Papuan women's uptake, adherence, and retention in the PMTCT program. The secondary aim of this thesis is to provide recommendations to improve outcomes of the Option B+ PMTCT program in Papua. To accomplish these aims, this thesis encompasses the following objectives:

Objective 1: To describe pregnant women's uptake, adherence, and retention in Option B+ PMTCT in Papua.

Objective 2: To identify factors that influence women's uptake, adherence and retention in Option B+ PMTCT in Papua.

Objective 3: To investigate the relationship between health facility characteristics and women's uptake and retention in Option B+ PMTCT in Papua.

Objective 4: To provide recommendations to improve women's uptake, adherence, and retention in Option B+ PMTCT in Papua.

1.4. Thesis outline

This thesis consists of seven chapters. Chapter 2 provides an overview of HIV and AIDS including HIV clinical stages, HIV diagnosis and monitoring. It follows with a review of HIV and AIDS epidemiology across the world, Indonesia, and Papua. Factors that influence PMTCT implementation and outcomes in Papua such as political aspects, geographical constraints, and antenatal coverage are discussed in the next section. This chapter also discusses combination interventions to prevent PMTCT including ART, ECS, and breast milk substitutes. This is followed by a description of PMTCT implementation and outcomes in Indonesia and Papua, and the limitations of the extant literature related to Option B+ PMTCT in Indonesia and Papua. Last, this chapter discusses PMTCT facilitators and barriers in Option B+ implementation in resource-limited settings, as well as strategies to improve program outcomes. The results of the literature review presented in this chapter highlight the research context and contribute to the development of the overall research design.

Chapter 3 explains the research procedures followed in this thesis to address the research aims and objectives. It starts with an overview of the mixed-methods research design consisting of three studies: Study 1_Papua, Study 2_Indonesia, and Study 3_Global. It explains the gaps in the literature on Option B+ PMTCT in Papua, which

provide the context for the mixed-methods research designs, and how the three studies will address these gaps. This chapter describes the three studies' aims and objectives, the study setting, sampling method, data collection instruments, and data analysis. It also discusses ethical approval, research permits, and risk managements related to ethical considerations. In addition, this chapter describes changes made to the data collection resulting from the pilot testing of the interview guides in the Papua Study and delays in attaining the research permits in the Indonesia Study.

Chapter 4 contains the published paper on the qualitative study of women's uptake and adherence in Option B+ PMTCT in Papua (Study 1_Papua). This chapter describes the results of the seven-month fieldwork visit in Papua, highlighting factors across various socioeconomic levels that were enablers for or barriers to women's uptake and adherence in Option B+ PMTCT in Papua from the perspectives of HIV-positive women and health workers in two selected hospitals in Jayapura, the capital city of Papua province.

Chapter 5 reports the results of the PMTCT quantitative study in Indonesia (Study 2_Indonesia). It describes women's uptake and retention in PMTCT in Indonesia in 2017. This chapter also demonstrates the performance of Option B+ PMTCT in Papua five years after its adoption in 2012. This is followed by descriptions of health facility characteristics that influenced women's retention in the PMTCT program using Poisson Regression analysis. This chapter is a research paper that has been submitted to BMJ Open and is currently under peer review.

Chapter 6 presents mechanisms that influenced women's uptake and retention in Option B+ PMTCT in resource-limited settings (Study 3_Global). This chapter describes how

the realist synthesis approach was utilised to identify, test, and refine the configurations of context-mechanisms-outcomes, also known as program theories. This chapter is a research paper that has been submitted to BMC Health Services and is currently under peer review.

Chapter 7 presents the principal findings of the three studies, and how they contributed to the achievement of the research aims and objectives. It presents a comparison of the key research findings with previous studies, and a discussion on the interpretations and implications of the study results. This chapter also discusses the strengths and limitations of the study and their implications for the future research directions.

CHAPTER 2

LITERATURE REVIEW

This chapter first provides an overview of HIV and AIDS, including definitions, clinical stages, diagnosis, and monitoring. It follows with a discussion on HIV and AIDS epidemiology across the world, Indonesia, and Papua. The next section describes challenges in implementation of Option B+ PMTCT in Papua due to unstable political context, geographical challenges, and low antenatal coverage. This chapter describes combination interventions to prevent PMTCT including ART, ECS, and breast milk substitutes and how they were implemented in Indonesia and Papua. This is followed by a section highlighting the limitations of the literature relating to Option B+ PMTCT in Papua, providing the rationale for this research. Finally, this chapter concludes with a discussion of facilitators and barriers in Option B+ PMTCT in resource-limited settings that were considered in the development of the research methodology, including research instruments.

2.1. HIV and AIDS overview

HIV is a virus that attacks and destroys the CD4 cells or T cells, which are white blood cells that play an important role in the fight against infections and disease [28]. HIV is present in certain body fluids such as blood, semen, pre-seminal fluids, rectal fluids, vaginal fluids, and breastmilk. It enters the body through the mucous membrane inside the rectum, the vagina, the opening of the penis, and the mouth. HIV transmits through damaged tissue or direct injection into the bloodstream via unprotected sexual activities, unsterile needle or syringe use, and perinatal transmission [28].

CD4 count is a test that counts the number of CD4 cells in the body. CD4 counts help determine whether the immune system is functioning in HIV-infected people. A lower CD4 count indicates a weaker immune system, while a higher CD4 count indicates a stronger immune system. In people without HIV, CD4 counts range from 500 to 1,600 cells per cubic millimetre of blood (cells/mm³). In HIV-infected people, the CD4 count is fewer than 500 cells/mm³. When a CD4 count is reduced to fewer than 200 cells/mm³, the HIV disease is considered to have progressed to AIDS [29].

2.1.1. HIV clinical stages

There are three stages of HIV progression: acute HIV infection, chronic HIV infection, and AIDS. The WHO classifies these three stages based on the clinical symptoms and the virus growth in the body, as shown in Figure 1 [29].

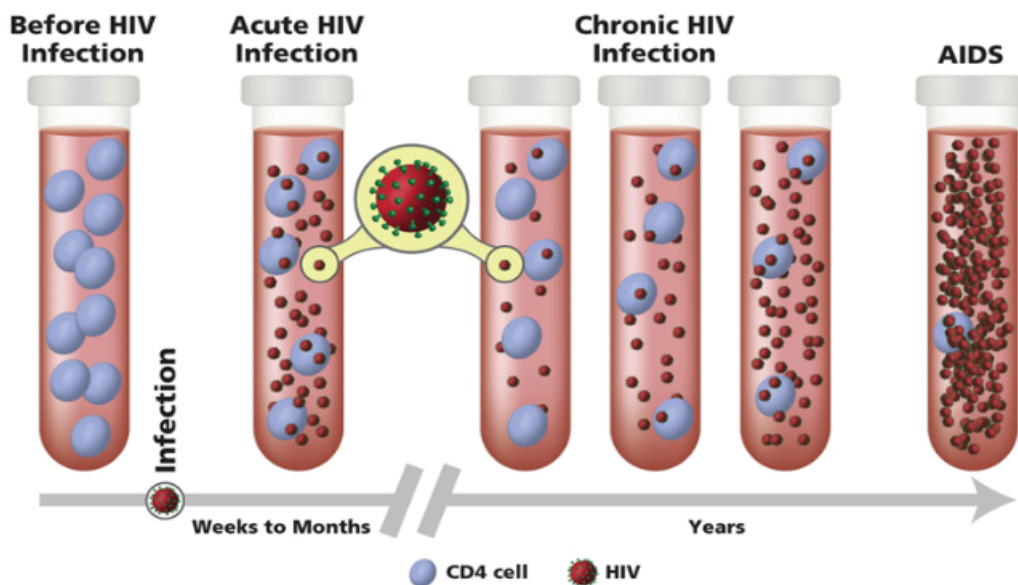


Figure 1. HIV disease progression.

Source: U.S. Department of Health and Human Services, 2019 [30].

The three stages are described in detailed below.

Stage 1. Acute HIV infection (2–4 weeks after HIV infection)

Acute infection, or the ‘seroconversion’ stage, is an early stage in which the immune system responds to HIV and develops antibodies to fight the virus. Differences in the immune system between individuals influence the length of time until seroconversion occurs, ranging from one to three weeks after the HIV infection. During this stage, 80% of people experience temporary flu-like symptoms including headache, fever, sore throat, rash, and swollen lymph glands, while 20% remain asymptomatic. Due to the subtleness and impermanence of the symptoms, people in acute HIV infection are usually unaware of HIV infection [29].

If an HIV-infected person undergoes a HIV test before the seroconversion begins, also referred to as the ‘window period’, the test results will be negative. Despite the negative HIV test results, the risk of HIV transmission during the window period is high. As shown in Figure 1, HIV replicates rapidly in the acute HIV infection stage and therefore the body contains a high viral load [29].

Stage 2. Chronic HIV infection (up to 10 years after HIV infection)

Chronic HIV infection is also known as ‘asymptomatic’ HIV infection or clinical latency. In the second stage, the virus replication slows down and HIV becomes dormant or inactive. HIV-infected people generally feel healthy and do not experience HIV-related symptoms [29].

Regardless of the asymptomatic stage, HIV tests will give positive results because the seroconversion has taken place, and, therefore, HIV antibodies have developed. As

shown in Figure 1, the number of viral loads is relatively low, particularly within the first two-thirds lifetime of the chronic HIV infection period. Without HIV treatment, the asymptomatic stage can last up to a decade, but it can be shorter for some people due to variation in the disease progression between individuals. The risk of HIV transmission during this stage can be assessed using a viral load test, which measures the number of HIV particles or copies in the blood. There is a risk that HIV-positive people could transmit HIV to others if a viral load test detects the virus, but the risk is minimal if the test does not detect the virus [29].

Stage 3. AIDS (3 years)

AIDS is the final stage, whereby HIV has severely destroyed the CD4 cells of the immune system, preventing the body from fighting infections and diseases. Due to a weakened immune system, HIV-infected people in this stage experience more frequent and severe infections such as tuberculosis, hepatitis, lymphoma, pneumonia, weight loss, mouth/anus/genital sores, repeated fever, long-term diarrhea, and constant tiredness. People with AIDS can survive for up to three years [29].

Figure 1 shows that in this AIDS stage, a very high viral load and a very low CD4 count (fewer than 200 cells/mm³) are present. Due to a very high viral load in the body, people in this stage are at high risk of transmitting the disease to other people [29].

2.1.2. HIV diagnosis and monitoring

Diagnosis and monitoring of HIV infection requires laboratory tests on body fluids such as blood or plasma. Different laboratory markers can be used in HIV diagnosis and monitoring, including [31]:

- HIV antibodies including IgG, IgM, and CD4 cells
- P24 antigens
- HIV nucleic acid (RNA/DNA).

Figure 2 illustrates the changes in the laboratory markers during HIV disease progression in months and years. The relative value represents the changes in the levels of laboratory markers in the body. The CD4 count decreases over time in HIV-infected people. The lowest CD4 count indicates HIV disease progression to AIDS. Conversely, the amount of viral load in the body increases with HIV disease progression, with the highest viral load indicating AIDS stage. HIV antibodies are undetected during the seroconversion stage but are detectable after the seroconversion is completed. HIV Cytotoxic T-lymphocytes (HIV CTL), which are important for controlling virus replication, increase rapidly in response to HIV infection but then decrease rapidly during the AIDS stage [31].

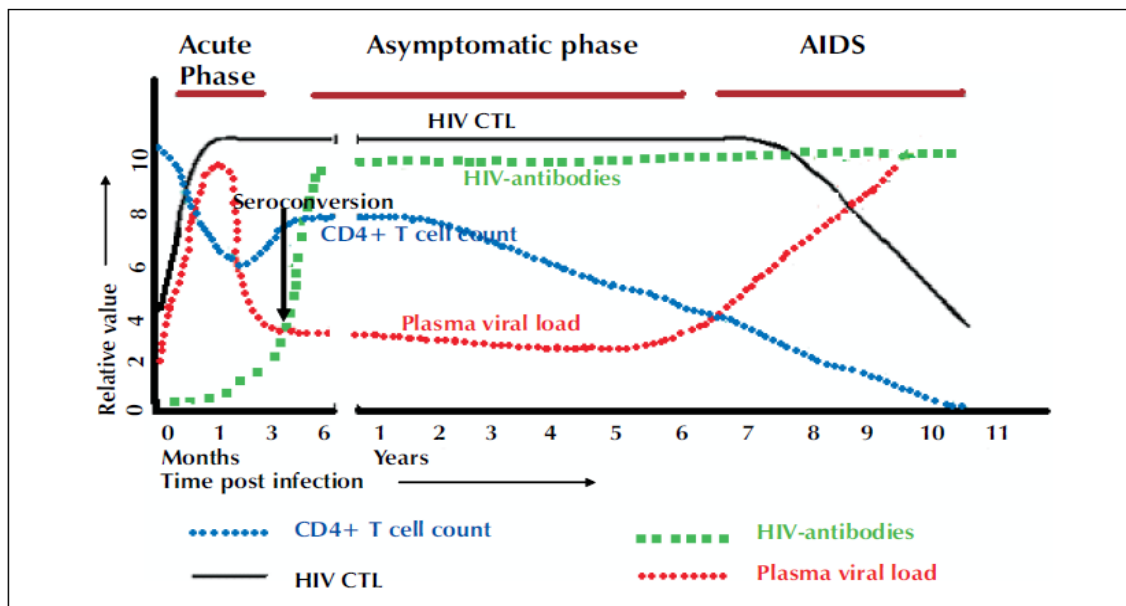


Figure 2. Laboratory markers and HIV progression.

Source: WHO, 2009 [31].

Understanding these laboratory markers is useful in assessing the impact of HIV tests available in resource-limited settings on HIV treatment and monitoring. The following section discusses the various HIV tests available for HIV diagnosis, early infant diagnosis, and ART initiation and monitoring.

HIV diagnosis (antibody/antigen test)

The most common method to diagnose HIV infection is the use of serum and plasma in an antibody/antigen test. This test offers an economical HIV diagnostic and rapid result, which can be administered in most laboratories. There are three types of antibody/antigen tests: Rapid Diagnostic Test (RDT), Enzyme Linked Immunosorbent Assay (ELISA), and Western Blot [31, 32]. These tests are described in detail below.

1. Rapid Diagnostic Test (RDT)

RDT is a simple and visual test, which means it does not involve a machine reader. Therefore, it can be used in most laboratories, and health workers can be trained to do the test and interpret its results. The reliability of RDT results is comparable to ELISA if it has been validated for use in its testing environment. RDT comes in smaller packs with its own procedural control system, which makes it suitable for laboratory use with a small number of blood samples. Most RDT kits can be stored at ambient temperature between 20° C and 25° C [31, 32].

2. Enzyme Linked Immunosorbent Assay (ELISA)

ELISA is an antibody test that requires a device reader to interpret its results. It requires a skilled laboratory technician to operate, and the device needs proper maintenance to provide reliable results. It is more suitable for a higher number of blood samples than RDT. There are four generations of ELISA, which are different in the types of antibodies/antigens used and test characteristics (Table 1) [31].

Table 1. ELISA generations.

Generation	Antigens/antibodies	Comment/characteristics
First	Antigens from HIV lysates	Lack of sensitivity and specificity
Second	Recombinant proteins and/or synthetic peptides	Improved sensitivity and production of combined HIV-1/HIV-2 assays
Third	Use labelled antigen as conjugate	Very high sensitivity and able to detect IgM antibody; reduce the window period considerably
Fourth	Detection of both HIV antigen (p24) and antibody	Further reducing the window period

Source: WHO, 2009 [31].

Three of four ELISA generations use antigens of different types, while the second generation use recombinant proteins and/or synthetic peptides. The latter ELISA generations improve test sensitivity and reduce the window period of HIV detection [31].

3. Western Blot (Immunoblot)

Western Blot was a test previously used to confirm the result of ELISA. This test uses an electrical current, blotting paper, and an enzyme to determine the presence of HIV antibodies. It is a costly and complex test to perform. Several issues, including lack of standardisation and a high range of indeterminate results, have limited its usage [31, 32].

Early infant diagnosis

HIV infection diagnosis in infants born to HIV-positive women requires unconventional types of antibody tests, because the presence of HIV antibodies in newborn infants does not indicate HIV infections. Hence, positive results could be due to maternal HIV antibodies transmitted to infants, which disappear between 12 and 18 months after birth. Instead, HIV testing using antibodies by the age of 12 months provides an indication of a child's HIV infection status. A confirmatory test after 18 months of age is required to confirm the child's HIV infection.

HIV testing that uses viral components, instead of serum/plasma, can detect HIV infections more accurately in children aged less than 18 months. These tests include p24

and DNA/RNA Polymerase Chain Reaction (DNA/RNA PCR) [31]. These tests are described in detail below.

1. p24

HIV p24 is the core protein of HIV, which can be detected two to three weeks after HIV infection. This test is complex to administer, and requires proper maintenance of the testing equipment [31, 32].

2. DNA/RNA PCR

DNA/RNA PCR is the gold standard for early infant diagnosis or diagnosis of HIV in children younger than 18 months (Figure 3).

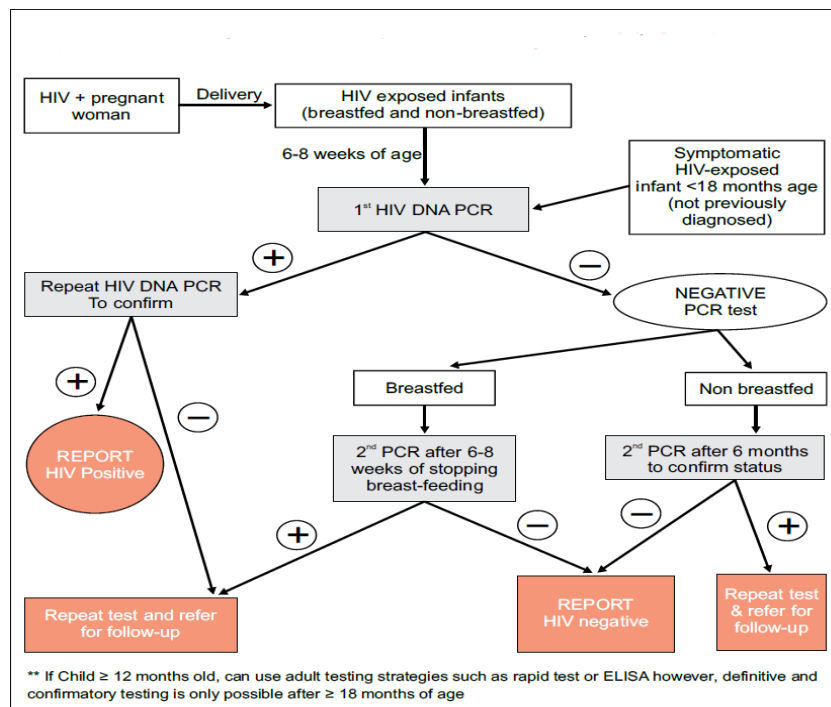


Figure 3. Early infant diagnosis for children aged less than 18 months.

Source: WHO, 2016 [33].

The WHO recommends the administration of the PCR test around the time infants initiate prophylaxis treatment to prevent the development of resistance among HIV-infected infants who require ART instead of prophylaxis treatment. The recommended test times are at the first 14 days of life, at 1–2 months age, and repeated at 3–6 months of age. For HIV exposed infants, HIV diagnosis can be established at six weeks if two PCR tests give positive results. For breastfeeding infants, PCR test results are reliable if conducted six weeks after the cessation of breastfeeding [33].

ART initiation and monitoring

ART initiation and monitoring requires tests that measure the amount of CD4 and viral load in the body. The CD4 count in the body determines the HIV disease progression and the types of treatment to prescribe. Meanwhile, the amount of viral load informs the effectiveness of the ART. Descriptions of CD4 and viral load are provided below.

1. CD4

CD4 count is useful to determine HIV clinical stage, immediate risk of death, ART eligibility, and ART monitoring. People in AIDS stage require rapid ART initiation and additional tests for cryptococcal infection and tuberculosis [32]. The CD4 test is complex, with a limited timeframe between the specimen collection and testing. For instance, FACSCount assay allows a maximum of 48 hours. The specimen requires an ambient temperature between 20°C and 25°C during transportation to prevent specimen destruction [31].

2. Viral load

DNA/RNA PCR is a nucleic acid-based test to measure the amount of viral load in the body. The baseline viral load test is conducted before ART initiation. For ART monitoring, the viral load monitoring test is repeated at 6 months, 12 months, and then every 12 months. The viral load test determines the effectiveness of the ART to suppress the virus. The ART is not effective if the amount of viral load increases. This increase could be due to viral resistance to the ART; in this case, the treatment would need to be modified to increase its effectiveness. Viral load replaces CD4 count in monitoring of HIV-positive people whose viral load has been suppressed by ART [31, 33].

2.1.3. Summary and interpretation

There is a risk of HIV transmission during the three stages of HIV regardless of its asymptomatic period and negative HIV diagnostic results during the ‘seroconversion’ process or ‘window period’. Women who are pregnant or breastfeeding in each stage are therefore at risk of transmitting HIV to their child. Several HIV diagnostics are available to assess maternal HIV disease progression: effectiveness of maternal ART, and whether an infant has contracted an HIV infection. However, most of the advanced HIV diagnostics, such as p24, CD4, and viral load tests, require more complex procedures and maintenance, which limit their use in resource-limited settings in Indonesia, particularly Papua.

2.2. Epidemiology of HIV and AIDS

2.2.1. HIV epidemic global situation

HIV is one of the major public health and development challenges in the world. Currently, 36.9 million people live with HIV. Of these, 35.1 million are adults and 1.8 million are children aged less than 15 years [1]. In 2017, there were 1.8 million new HIV infections globally. The number of new HIV infections has declined by 47% from 3.4 million in 1996 but remains below the target of fewer than 500,000 new HIV infections by 2020 (Figure 4).

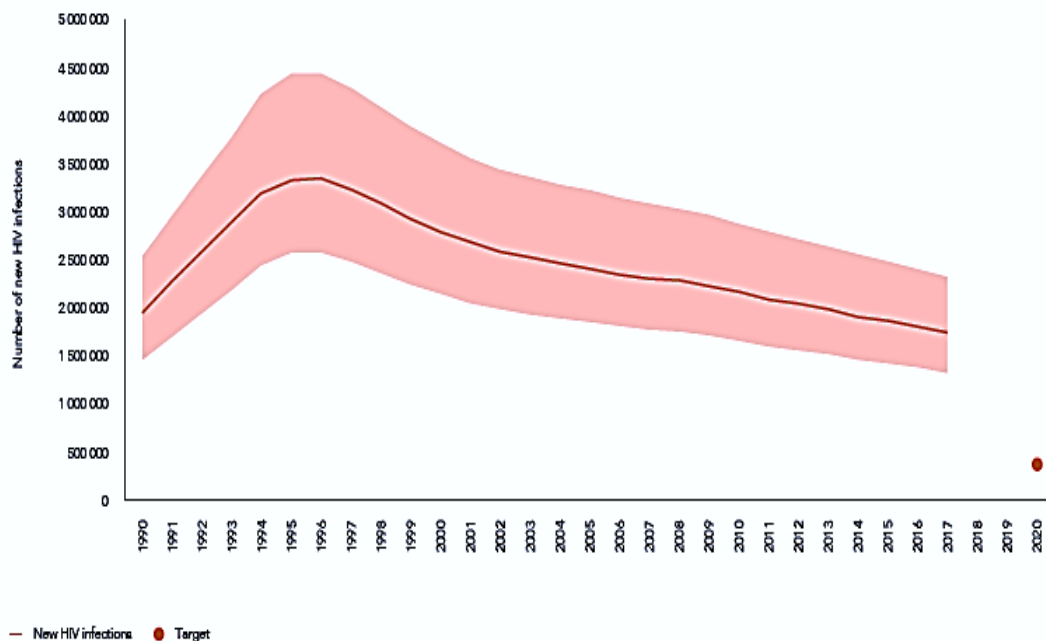


Figure 4. Global new HIV infections from 1990 to 2017 and 2020 target.

Source: UNAIDS, 2018 [3].

Incidence of HIV worldwide has been linked to poor access to HIV prevention, care, and treatment. HIV has no cure to date, and an effective method to prevent new HIV transmissions is using ARV drugs to control the number of the virus in the body. In resource-limited settings where the HIV disease burden is high, people living with HIV have poor access to HIV testing and ARVs. Despite advancements in HIV testing and treatment, in 2017, 9.4 million people were unaware that they were infected with HIV, and 15.1 million HIV-infected people did not access ART. This results in the greatest burden of disease occurring in resource-limited countries.

Eastern and southern Africa have the highest HIV burden in the world, accounting for 19.6 million HIV cases, followed by western and central Africa with 6.1 million HIV cases. Asia Pacific ranks third, with 5.2 million people living with HIV [3]. The lowest HIV burden is seen in the Middle East and North Africa with around 220,000 HIV cases (Table 2). Regions with high HIV disease burden account for the highest mortality due to AIDS-related deaths worldwide.

Table 2. Global HIV and AIDS statistics in 2017.

Regions	People living with HIV	New HIV infections	Deaths due to AIDS
Eastern and southern Africa	19.6 million	800,000	380,000
Western and central Africa	6.1 million	370,000	280,000
Middle East and North Africa	220,000	18,000	9,800
Asia Pacific	5.2 million	280,000	170,000
Latin America	1.8 million	100,000	37,000
Caribbean	310,000	15,000	10,000
Eastern Europe and central Asia	1.4 million	130,000	34,000
Western and central Europe and North America	2.2 million	70,000	13,000
TOTAL	36.9 million	1.8 million	940,000

Source: UNAIDS, 2018 [3].

Globally, mortality from AIDS-related diseases has declined by more than 51% since its peak in 2004 [3]. In 2017, there were 940,000 deaths from AIDS-related diseases, a significant decrease from 2004, when there were 1.9 million AIDS-related deaths [3]. This decrease was mainly due to the progress in regions that had higher AIDS-related deaths such as eastern and southern Africa, where mortality has decreased by 42%, western and central Africa (24%); Asia Pacific (39%); western and central Europe and North America (36%); and the Caribbean (23%) [3]. However, some countries experienced much slower progress, such as Indonesia, where current AIDS-related deaths are three times greater than the number of deaths that occurred in 2004 [34].

2.2.2. HIV epidemic in Indonesia

In the Asia Pacific, Indonesia ranks third in the number of people infected with HIV, following India and China. However, HIV prevalence in Indonesia (0.43%) is slightly higher than in India (0.2%) and China (<0.1%) [3]. UNAIDS estimates that there are 630,000 HIV-positive people in Indonesia, accounting for 12% of HIV cases in Asia Pacific [3]. New HIV infections in Indonesia have declined by 79% from 62,000 in 2005 to 49,000 in 2017 [34]. However, this number is higher than the projection estimated by the Ministry of Health, Republic of Indonesia, of 46,357 new HIV infections in 2017 [35].

In Indonesia, HIV infection is more prominent among people within reproductive ages. The highest burden occurred among people aged 20 to 49 years (83.1%–91.0%); 65% are men and 35% are women [34].

Similar to other countries in the Asia Pacific, the HIV epidemic in Indonesia is concentrated among key population groups or people who have higher risks for contracting HIV, such as people who inject drugs (PWID), sex workers, men who have sex with men, and transgendered people [22]. The HIV epidemic in key population groups between provinces in Indonesia ranges from 21% to 52% in PWID, 1% to 22% in female sex workers, and 3% to 17% in transgendered people [14]. The main mode of HIV transmission in Indonesia is through heterosexual contact. This accounts for 70.3% HIV transmissions nationally, followed by injecting drug use (8.4%), homosexual behaviours (6.6%), and perinatal transmissions (2.9%) [34].

HIV affects all 34 provinces of Indonesia. HIV infects 0.43% of the total population in the provinces of Indonesia [3] except Papua, which is 2.3% of the total population [9]. Table 3 shows the six provinces most affected by HIV in Indonesia in 2018: The Special Capital Region of Jakarta (66,918), East Java (63,828), Papua (53,495), West Java (39,989), and Central Java (35,690). Progression of HIV to AIDS was higher in some provinces such as Papua (39%), East Java (24%), Central Java (22%) and slightly lower in Jakarta (12%) and West Java (15%) [34].

Table 3. HIV and AIDS statistics of six provinces in Indonesia in 2018.

Province	People Living with HIV	People living with AIDS	Deaths due to AIDS	Proportion of AIDS
Jakarta	58,877	8,041	1,891	12%
East Java	48,241	15,587	4,242	24%
Papua	32,629	20,866	1,672	39%
West Java	34,149	5,840	909	15%
Central Java	27,692	7,998	2,113	22%
Bali	19,235	7,515	475	28%

Source: Ministry of Health, the Republic of Indonesia, 2019 [34].

HIV progression to AIDS occur for several reasons, including late ARV treatment due to late HIV diagnosis or delayed treatment uptake, and ineffective ARV treatment due to poor adherence to the medication. High levels of HIV progression to AIDS in Indonesia are associated with low levels (20%) of ARV treatment coverage among HIV-infected people [10] due to some reasons such as low HIV testing and high stigma and discrimination. This means 80% of people living with HIV (PLHIV) have not started ARV treatment and have the risk of advancing from HIV to AIDS stage. And, among the 20% of PLHIV who started ARV treatment, less than 50% retained the treatment [34]. This means over 50% of PLHIV, who stopped their treatment, were at risk of AIDS-related deaths. Consequently, Indonesia reported an increased number of AIDS-related deaths in 2018 due to low ARV treatment coverage and retention [34].

2.2.3. HIV epidemic in Papua

Papua is one of provinces most burdened by HIV in Indonesia. Compared with other provinces in Indonesia, it ranks fourth in the total number of HIV-infected people and ranks first in HIV prevalence and the percentage of people who have progressed from HIV to AIDS (Table 3) [34]. Although Papua ranks fourth in the total number of people living with HIV, the epidemic in Papua is more severe than in other provinces in Indonesia considering its high HIV prevalence.

Papua has an HIV prevalence of 2.3% among the general population [9], which is much higher than the 0.43% national HIV prevalence [3]. The HIV epidemic in Papua affects men and women almost equally, with an HIV prevalence of 2.3% and 2.2%, respectively [10]. The risk for infection with HIV is much higher among indigenous Papuan (2.9%) than non-indigenous Papuan (0.4%) due to high-risk sexual behaviours [10].

The Papua Provincial Health Office reported that there are 41,616 PLHIV in Papua; of these, 52% are female and 3% are children under the age of 15 years [36]. New HIV infections in Papua have gradually increased from 2,499 in 2010 to 3,546 in 2018 [9]. Together with the 33 provinces in Indonesia, the increase in new HIV infections in Papua has contributed to a higher than projected increase in new HIV infections in Indonesia in 2018 [34].

HIV infects Papuan people of reproductive age, with the majority reported having sex for the first time at 20 years of age in the IBBS survey in 2013 [10]. The highest burden occurs among people aged 25 to 49 years (58%), followed by people aged 15 to 24

years (35%). In Papua, there were more women (52%) living with HIV than men (47%), which is the opposite of the national HIV/AIDS statistics [36].

Based on Papua HIV/AIDS statistics in 2019, the main mode of HIV transmission in Papua is heterosexual contact (97%), followed by perinatal transmissions (2%) [36]. Other risk factors that are more prevalent at the national level such as homosexual behaviour and injecting drug use [34] are uncommon in Papua.

HIV spreads in all the 29 cities and districts of Papua. Table 4 shows the five cities and districts most affected by HIV and AIDs in Papua in 2019: Nabire District (7,510), Jayapura City (6,892), Jayawijaya District (6,242), Mimika District (5,914), and Jayapura District (3,046). Progression of HIV to AIDS in these five districts was very high, ranging from 48% in Mimika District to 71% in Jayawijaya District [34].

These data suggest that the high proportion of PLHIV and AIDS may be attributed to the delay in HIV diagnosis, ART uptake, and ineffective ART due to poor adherence or low retention. As seen in HIV/AIDS data released by the Provincial Health Office Papua, ART retention in Papua was 30%. Given the low retention rate, there were higher risks of HIV progression to AIDS, and subsequent deaths due to AIDS-related diseases. Papua is currently the highest contributor to AIDS-related deaths in Indonesia. The death rate due to AIDS-related diseases in Papua is 620.56 per 100,000 people. This is almost 20 times higher than the national average [9]. Possible reasons for HIV disease progression to AIDS and AIDS-related deaths were scarcity of health facilities [37], poor transportation access, and high HIV stigma in the community [10].

Table 4. HIV AIDS statistics of five cities and districts in Papua in 2019.

City/District	People Living with HIV	People living with AIDS	Deaths due to AIDS	Proportion of AIDS
Nabire	2,829	4,681	445	62%
Jayapura City	2,450	4,442	350	64%
Jayawijaya	1,784	4,458	508	71%
Mimika	3,050	2,864	203	48%
Jayapura	1,355	1,691	356	56%

Source: Ministry of Health, the Republic of Indonesia, 2019 [34].

2.2.4. Summary and interpretation

Although HIV is a global disease, countries in resource-limited settings, including Indonesia, bear the greatest burden of the HIV epidemic globally. In contrast to the progress of most countries in reducing new HIV infections and AIDS-related deaths, Indonesia showed an increase in HIV morbidity and mortality predominantly among people of reproductive age (15 to 49 years). The main causes for these increases were low ARV treatment coverage and retention. These problems were common in the 34 provinces of Indonesia; however, Papua province was impacted more severely due to its generalised HIV epidemic. There were more women infected with HIV in Papua, and 93% of them were of childbearing age. Consequently, due to low ART coverage and retention, these women transmitted HIV to their children. Currently, MTCT HIV transmission is the second greatest risk factor for new HIV infections in Papua.

2.3. Papua province: An overview

Papua is the easternmost province of Indonesia, located in the western part of New Guinea (Figure 5). It is the only Indonesian territory that is situated in Oceania. It borders with Papua New Guinea to the east, West Papua province to the west, the Pacific Ocean to the north, and the Arafura Sea to the south [40]. Papua is the largest province of Indonesia with an area of 316,553 km², which accounts for nearly 20% of the total area of Indonesia. In 2017, there were 3,265,200 people living in Papua; 53% were male and 47% were female. The higher proportion of male than female may be related to high maternal mortality in Papua [38]. The main religion is Christianity [40]. There were 255 ethnics in Papua, each with its own dialect. However, Indonesian is the official language at schools and in daily conversations. According to the national statistics in 2018, 3 out of 4 indigenous Papuan speak fluent Indonesian [37].



Figure 5. Papua province with its national and international borders.

Source: Map Resources, 2008 [39].

Papua province is divided into 28 districts and one capital city, Jayapura [38]. Due to the small number of populations living in Papua, some districts, such as Mamberamo Raya District, have only one person living per km² [38]. Health infrastructure is usually built in more populated areas where there are more people in need of health services [40]. In 2018, Papua had 451 health facilities: 43 hospitals and 408 primary health centres. Out of 451 health facilities, only 37 health facilities reporting PMTCT indicators in 2018 [34]. The ratio between primary health centres and sub-districts was 0.73, which means there were areas without any health facilities in the community [41]. Hence, PMTCT services might not be accessible to HIV-positive pregnant women living in these areas without a health facility or at health facilities not reporting PMTCT indicators.

2.3.1. Political environment

Papua has been integrated with Indonesia since 1963. Papua is the current and official name since 2002. Prior to this, it was known as West Papua (1961–1963), Dutch New Guinea or Netherlands New Guinea (1963–1969), Irian Barat or West Irian (1969–1973), and Irian Jaya (1973–2002) [42]. Papua experiences unstable politics due to prolonged conflict related to resistance from a group of people following its integration with Indonesia. Unstable political conditions and lack of security slow the development of health infrastructure and the availability of PMTCT services in Papua [43].

Other influential political aspects including the adoption of donor-led HIV programs without sufficient adjustment to the local context such as indigenous Papuan practices

related to pregnancy and childbirth, exclusion related to lack of indigenous Papuan working at the health facilities, and marginalization of indigenous Papuan as a result of competition with Indonesian migrants [44]. Altogether these aspects influence indigenous Papuan women's access to PMTCT services.

2.3.2. Geography

The location of primary health centres in Indonesia is dependent on the geographical landscape. Based on the regulation of the Ministry of Health, the Republic of Indonesia, primary health centres need to be easily accessed by most community members [40]. Papua terrains are predominantly highlands covered by ancient forests and are therefore difficult to access using transportation. A smaller proportion of the terrains are lowlands or coastal areas that are less difficult to access [10]. Primary health centres are built in each district of Papua. However, due to geographical challenges, delivery of PMTCT services are often characterised by lack of transportation access (usually running once a week and subject to weather or only accessible by helicopter or on foot); long distance to the district (more than 3 hours' drive one way), and limited or no access to electricity (that limits the types of HIV diagnosis test available) [40] and mass media (as the source of HIV-related information).

Below is the classification of Papua districts and cities according to its terrain [37], in which public transportation and HIV care were less accessible in the highlands than in the lowlands:

- a. Lowlands or coastal areas: Jayapura City, Jayapura District, Keerom, Sarmi, Biak, Supiori, Yapen Island, Waropen, Mamberamo Raya, Central Mamberamo, Nabire, Timika, Merauke, Asmat, Mappi, and Boven Digoel.
- b. Highlands: Jayawijaya, Tolikara, Yalimo, Lanny Jaya, Yahukimo, Bintang Mountains, Puncak Jaya, Puncak, Nduga, Paniai, Intan Jaya, Dogiyai, and Deiyai.

2.3.3. Climate

Papua has a tropical climate consisting of two seasons: dry season (May to September) and rainy season (October to April). The temperature ranges from 16° C to 33° C [37]. Lack of electricity access has limited HIV testing diagnostics in Papua using RDT. However, maintenance of these testing kits is somewhat challenging in areas that have temperatures less than 20° C and more than 25° C. Therefore, primary health centres in these areas may have to transport pregnant women to district health facilities for HIV testing, ART initiation, and ART monitoring.

2.3.5. Fertility and life expectancy

Papua has an expansive population pyramid, which means it has a high birth rate and a low life expectancy. As shown in Figure 6, Papua has a predominantly young population, with a smaller proportion of aging people [38]. In 2017, 59% of Papuans were within the reproductive ages of 15 to 49 years, and children aged below 15 years account for 30% of the total population.

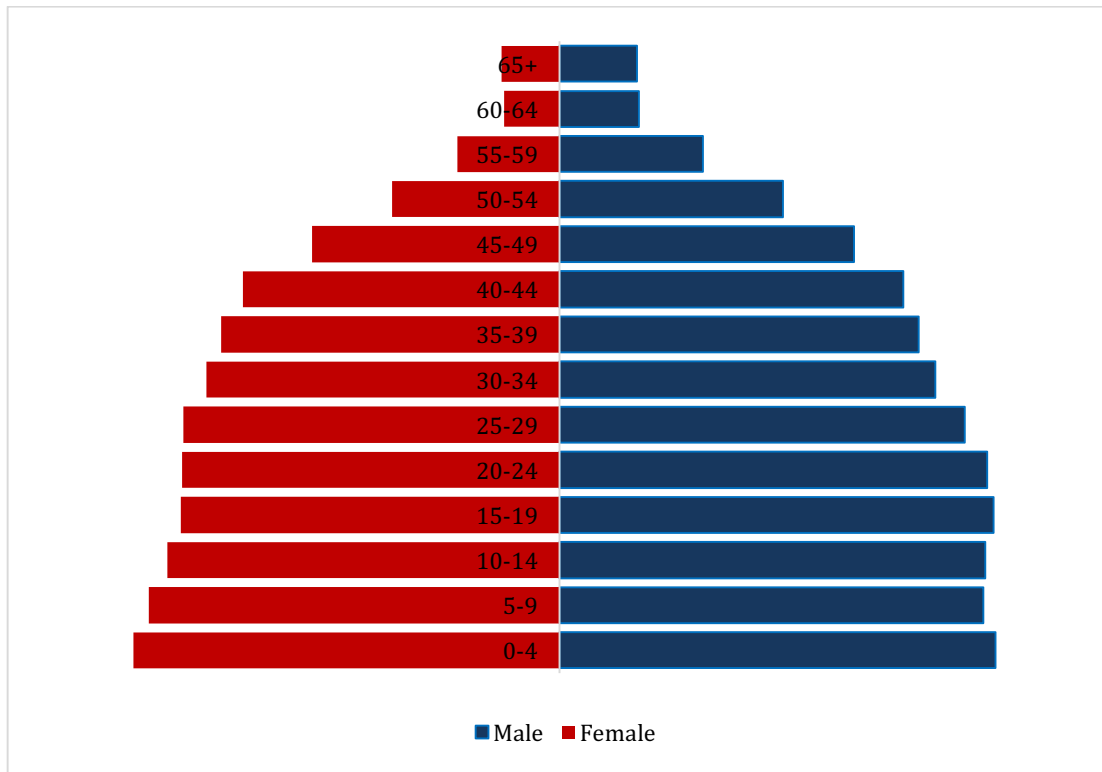


Figure 6. Papua population pyramid in 2017.

Source: Papua Provincial Health Office, 2017 [38].

Life expectancy in Papua is nearly five years lower than the national life expectancy of 71.06 years in 2017. Papua has the second lowest life expectancy in Indonesia at 65.14 years following West Sulawesi at 64.34 years. At the regional level, Mimika has the highest life expectancy of 71.93 years, followed by Jayapura Capital City at 70.00 years. The lowest life expectancy is seen in Nduga at 54.60 years, which is nearly 10 years shorter than Papua province average. One possible reason was the scarcity of health facilities (0 hospital, 6 PHCs) [37] resulted in poor access to health care and therefore low life expectancy.

Further analysis by gender shows that Papuan females have a slightly longer life expectancy (66.97 years) than males (63.3 years). This is consistent with the global

pattern that females live longer than males. However, in comparison to the national life expectancy, Papuan women live seven years less than Indonesian women on average, while Papuan men live six years less than Indonesian men on average [37].

2.3.6. Literacy and education

Education level influences the availability of human resources to deliver health services, including PMTCT services. A previous study in Papua reported a high proportion of migrant health workers delivering PMTCT services in Papua due to the lack of local human resources [43]. This resulted in cultural gaps and communication barriers between health workers and HIV-positive women [20, 43], which were also due to lower literacy level in Papua.

Papua is the province of Indonesia with the lowest literacy level of 76.79%, far below the national literacy level of 95.66%. This means around 24% Papuan population aged above 15 years were illiterate, or unable to read and write [41]. Lower literacy levels could be linked to lower education levels. Currently, the net enrolment rate for students within official school age in primary education (Grades 1 to 6) in Papua was 79.14%; in higher education levels, including junior secondary education (Grades 7 to 9) was 57.09%; and in high school education (Grades 10 to 12) was 44.31% [41].

Meanwhile, one of the main sources of HIV knowledge in Papua was health facilities and schools. Hence, lower school enrolment and communication barriers due to low literacy level resulted in poor HIV knowledge, which leads to HIV stigma in the community [10].

2.3.7. Economy and poverty

Poverty influences access to healthcare, including to PMTCT services in Papua. The majority of Papuans living in poverty (877,440 people) reside in rural areas, while a minority (37,780 people) reside in urban areas [37]. Papuans living in rural areas have less access to PMTCT services and spend more on transportation costs to access health facilities located in the district.

In 2018, 27.43% of Papuan lived in poverty, which accounts for 4% of the 10% of people living in poverty in Indonesia. Hence, Papua is the province with the highest poverty rate in Indonesia. Figure 7 shows an increased in number of people living in poverty in Papua since 2007 [41].

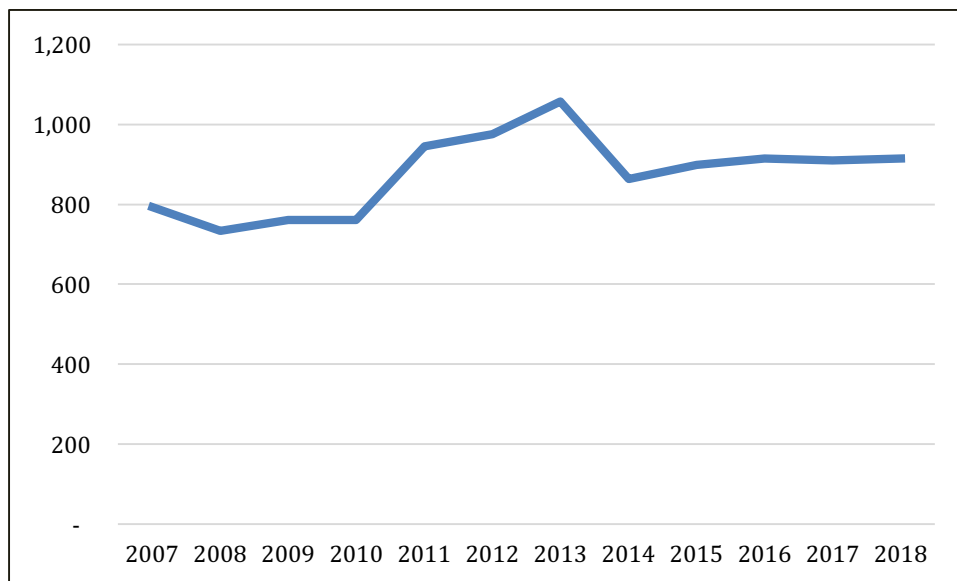


Figure 7. Number of people living in poverty in Papua in thousands.

Source: Kementerian Kesehatan Republik Indonesia, 2019 [41].

Poverty in Papua is likely linked to the types of employment available there. The majority of Papuans (68%) worked in agriculture, forestry, hunting, and fisheries. Of these, 47% were unpaid workers and 21% were paid workers [41].

2.3.8. Antenatal care

Health facilities that provide health services according to the national standard are necessary for the success of Option B+ PMTCT in Papua. However, nearly half of hospitals (47%) and the majority of primary health centres (83%) in Papua had not met the national standard [41]. This indicates that the majority of health facilities in Papua did not provide PMTCT services or deliver high-quality PMTCT services.

Papua has a unique feature due to high involvement of traditional birth attendants in pregnancy and childbirth practices. There were 614 traditional health workers in Papua, which accounts for 62% of the total in Indonesia. Antenatal care coverage at health facilities in Papua was less than 50%, the lowest in Indonesia. Of 78,420 pregnant women, only 31,949 (40.74%) visited health facilities for pregnancy care at each trimester. Among 74,856 births in 2018, 54% were assisted by traditional birth attendants, while 46% were assisted by the health workers at the health facilities [41]. Low ANC coverage resulted in a high women mortality rate during childbirth, which was 573 deaths of 100,000 live births [38].

In Papua, the percentage of women who exclusively breastfeed their children is lower than in other provinces in Indonesia. In 2018, less than 50% of women exclusively breastfed their children, while more than 50% either did not breastfeed or practiced mixed-feeding [41].

2.3.9. Cultural beliefs and practices

Cultural beliefs and practices influence health-seeking behaviours in society. Majority of indigenous Papuan ethnics define themselves as healthy as long as they can carry out daily activities such as going to work or performing domestic tasks [45]. This cultural belief might interfere with health-seeking behaviours among people with asymptomatic HIV because the disease does not interfere with routine activities. People could seek HIV care when they reach the AIDS stage when the symptoms are more severe and hinder physical activities. The causes of sickness including black magic, evil spirit, environment destruction, and violations of local traditions were more prominent among indigenous Papuan people living in the highlands and rural areas than in the lowlands and urban areas in Papua [45].

These cultural beliefs also influenced health practices related to pregnancy, childbirth, and postpartum care. In a study in Mimika [46], pregnancy was the full responsibility of women; it did not require men's involvement and traditional birth attendants came first before skilled health workers in baby deliveries. This study also found the cultural beliefs that blood in deliveries brought diseases to men and children, so women usually gave births in an isolated place. It was also taboo for women to expose their private body parts to outsiders such as migrant health workers; therefore, women needed approval from their spouse and parents to use health facilities for childbirth. Lastly, maternal deaths are normal outcomes because pregnancy is a critical life event full of risks including death [46] [45]. Cultural beliefs and practices created challenges in the Option B+ for PMTCT programs such as low rates of childbirth assisted by health

workers, particularly among indigenous Papuan women living in the highlands and rural areas.

2.3.9. Summary and interpretation

Papua is the youngest, but largest province of Indonesia. Several issues hinder PMTCT program delivery in Papua, including: an unstable political context due to the Papua freedom movement, geographical challenges, climate, low education and literacy levels, and poverty. Unstable political conditions have hindered the development of health infrastructures. Geographical and climate-related factors have limited the type of HIV diagnostics available for HIV testing, ART initiation, and ART monitoring. In addition, geographical challenges limit availability and access to health facilities providing PMTTC services. Lower education levels have resulted in the recruitment of migrant health workers, which further creates cultural gaps and communication barriers with women. A low percentage of Papuan women giving births assisted by health workers at the health facilities creates challenges in HIV diagnosis and ART treatment of HIV-positive women.

2.4. Mother-to-child HIV transmission

MCTC is the transmission of HIV from mother to child during pregnancy (*in utero*), labour and childbirth (intrapartum), and breastfeeding (post-partum) [2, 47-49]. It accounts for 90% of new HIV infections in children aged below 15 years [1]. MTCT risk in less developed countries (25–30%) is higher than MTCT risk in developed countries (14–25%) [6].

2.4.1. Timing and probability of MTCT

MTCT rates vary during pregnancy and breastfeeding periods. Figure 8 shows that the highest MTCT risks (50%) occurred after 36 weeks of pregnancy [50, 51] and among children who breastfed between the ages of 18 and 24 months (30–45%) [52]. In addition, several studies found that MTCT risk is higher among children receiving mixed feeding, which might relate to the damage of gastrointestinal barrier due to non-sterile supplementary feeding [53-55]. Meanwhile, MTCT risk is lower among children receiving exclusive breastfeeding, which is believed to strengthen the ability of tissues to resist the virus [56].

a. From pregnancy through labour [50]



b. From pregnancy through breastfeeding [51]



Figure 8. Timing and probability of MTCT.

2.4.2. Risk factors for MTCT

HIV is likely to be transmitted through the placenta during pregnancy, maternal cervical secretions or blood during childbirth, and breast milk during breastfeeding [1]. Maternal, infant, and obstetric factors related to these periods influence MTCT risks. These factors are described in detail below.

Maternal factors that increase MTCT risks include low maternal CD4 counts [57], high maternal plasma HIV RNA level [58, 59], low maternal Vitamin A level in pregnancy [60, 61], infections, and breastfeeding problems such as nipple lesions and mastitis [62-64]. Previous studies reported that lower CD4 counts increased the risks of HIV vertical transmissions [54, 55, 57, 62, 65, 66] in pregnancy and post-partum. The risk of transmitting HIV is doubled or tripled when maternal viral load is detectable [67] during pregnancy, labour and childbirth, and breastfeeding [57, 68-73].

Child factors that elevate MTCT risks consist of premature birth [54, 70, 74-76], underweight [54, 65, 74], and mouth sores for breastfeeding infants [63]. The roles of premature birth and underweight are likely related to child's inadequate or incomplete development of immune levels to resist the virus.

Obstetric factors that enhance MTCT risks include vaginal delivery [53], early and prolonged membrane rupture [54, 65, 77], instrumentation (episiotomy, vacuum extraction, and forceps), and birth trauma [78]. MTCT risk increases with the length of children's exposure to the maternal body fluid that contains HIV [2].

2.4.3. Prevention of mother-to-child HIV transmission (PMTCT)

Prevention efforts to minimise MTCT risks focus on the management of risk factors during pregnancy, labour and childbirth, and breastfeeding. PMTCT prevention consists of three main interventions: ART, ECS, and breast milk substitute. The PMTCT interventions are described below.

Antiretroviral therapy (ART)

Previous studies have demonstrated the efficacy of ART to reduce HIV transmissions from mother to child during pregnancy, labour/childbirth, and breastfeeding [79-83]. ART prevents HIV transmissions by increasing the number of CD4 cells and suppressing the virus to undetected and uncontaminated levels [84]. Women who start ART early in their pregnancy reduce MTCT risks to less than 1% [65, 85-87], even in vaginal delivery [88-94].

The WHO released three ART guidelines for PMTCT: Option A, Option B, and Option B+ (Table 5). These guidelines mainly differ in the CD4 count requirement to initiate ART and the duration of the treatment for HIV-positive women. In Option A and Option B, HIV-positive women start lifetime ART when they have a CD4 count of 350 cells/mm³ or fewer. Women receive short-term prophylaxis (Option A) or ART (Option B) when they have a CD4 count of over 350. In Option B+, all HIV-positive women receive ARV treatment for life regardless of their CD4 count. In Option A and Option B, the CD4 test is essential to determine whether an HIV-positive woman qualifies for ART or Prophylaxis. In Option B+, the CD4 test is not

used to determine women's treatment because all HIV-positive women start lifetime ARV treatment regardless of their CD4 count [13].

Table 5. PMTCT Options.

Woman receives:			
	Treatment (for CD4 count ≤350 cells/mm ³)	Prophylaxis (for CD4 count >350 cells/mm ³)	Infant receives:
Option A^a	Triple ARVs starting as soon as diagnosed, <i>continued for life</i>	<i>Antepartum:</i> AZT starting as early as 14 weeks gestation <i>Intrapartum:</i> at onset of labour, sdNVP and first dose of AZT/3TC <i>Postpartum:</i> daily AZT/3TC through 7 days postpartum	Daily NVP from birth through 1 week beyond complete cessation of breastfeeding; or, if not breastfeeding or if mother is on treatment, through age 4–6 weeks
Option B^a	Same initial ARVs for both ^b :		Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method
	Triple ARVs starting as soon as diagnosed, <i>continued for life</i>	Triple ARVs starting as early as 14 weeks gestation and <i>continued intrapartum and through childbirth if not breastfeeding or until 1 week after cessation of all breastfeeding</i>	
Option B⁺	Same for treatment and prophylaxis ^b :		Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method
	Regardless of CD4 count, triple ARVs starting as soon as diagnosed, ^c <i>continued for life</i>		

Note: "Triple ARVs" refers to the use of one of the recommended 3-drug fully suppressive treatment options.

^a Recommended in WHO 2010 PMTCT guidelines

^b True only for EFV-based first-line ART; NVP-based ART not recommended for prophylaxis (CD4 >350)

^c Formal recommendations for Option B+ have not been made, but presumably ART would start at diagnosis.

Source: WHO, 2012 [13].

For infants born to HIV-positive women, the treatment does not vary between PMTCT Options. Prophylaxis duration across the three Options is provided to infants up to age six weeks, except in Option A in which the Prophylaxis is extended until one-week post breastfeeding [1].

Elective Caesarean Section (ECS)

The longer a child is exposed to the maternal body fluid that contains HIV, the higher the risk of MTCT [2]. ECS reduces an infant's exposure to HIV-infected maternal body fluid in the genital tract if conducted before the membrane rupture [57, 95-98]. A meta-analysis of North America and European studies showed that ECS alone reduced MTCT by more than 50% [97]. However, ECS requires adequate medical equipment and trained health workers to prevent maternal complications in HIV-infected women [99].

Breast milk substitutes

Previous studies have shown a higher MTCT risk in breastfeeding population [1, 52], which can be reduced through breast milk substitutes or replacement feeding. WHO recommended replacement feeding only if it is acceptable, feasible, affordable, sustainable, and safe (AFASS) [94]. Fulfilment of the AFASS criteria is important because non-sterile supplementary feeding [53-55] increases MTCT risk and children mortality due to other diseases such as diarrhea and malnutrition [100, 101]. In the absence of replacement feeding that meets AFASS criteria, previous studies showed that breastfeeding improved children's survival [89-91, 102], even among children born to HIV-positive mothers [92, 93, 103].

2.4.4. Summary and interpretation

MTCT risk is higher in less developed countries including Indonesia. The risk is higher during the last trimester of pregnancy and increases with the length of breastfeeding. Various risk factors including maternal, infant, and obstetric factors

need to be managed properly to reduce MTCT risks. A combined prevention of ART, ECS, and replacement feeding are effective to reduce MTCT risk to 1%. This reduced risk is also achievable if women start ART early in the pregnancy and retain in the treatment for at least six months. In addition, ECS needs to be safe for women and replacement feeding must meet AFASS criteria. In resource limited settings, such as Papua, these conditions are rarely met, which makes PMTCT less effective.

2.5. PMTCT implementation in Indonesia

The PMTCT program has been implemented in Indonesia since 2004, particularly in Papua where the HIV epidemic was generalised [104]. In the national PMTCT guideline, PMTCT is a part of the national effort to manage HIV through integration with ANC. Hence, PMTCT services are delivered at hospitals and primary health centres. HIV testing is part of routine laboratory tests for pregnant women in areas experiencing high HIV epidemics. In low HIV epidemic areas, HIV testing targets pregnant women with infectious diseases [22].

Figure 9 illustrates the PMTCT cascade in Indonesia. This cascade begins with HIV testing that is offered to all pregnant women visiting the health facilities. If tested HIV positive, pregnant women then initiate ART regardless of their pregnancy age, CD4 count, or HIV clinical stage. For childbirth, women can have an ECS or vaginal birth, depending on their ART progress and pregnancy condition. Women also receive counselling on safe breastfeeding practices including avoidance of mixed breastfeeding. Infants born to HIV-positive women receive Prophylaxis at childbirth and continue until the establishment of HIV diagnosis at 18 months (Figure 9) [22].

The steps from HIV testing to ART retention in PMTCT programs in Indonesia are described below:

HIV testing

Indonesia implements provider-initiated HIV testing and counselling (PITC), in which HIV testing becomes a part of routine tests for pregnancy care, and health workers proactively offer HIV testing to pregnant women. Consent for HIV testing is incorporated in the consent form for routine pregnancy tests. In generalised HIV epidemics such as Papua, HIV testing is offered to all pregnant women visiting the health facilities for antenatal care. In provinces with concentrated and low HIV epidemics, HIV testing is offered to all pregnant women who have risk factors for HIV including partners of PWID, pregnant women who show clinical symptoms for HIV, and infants born to HIV-positive women [22].

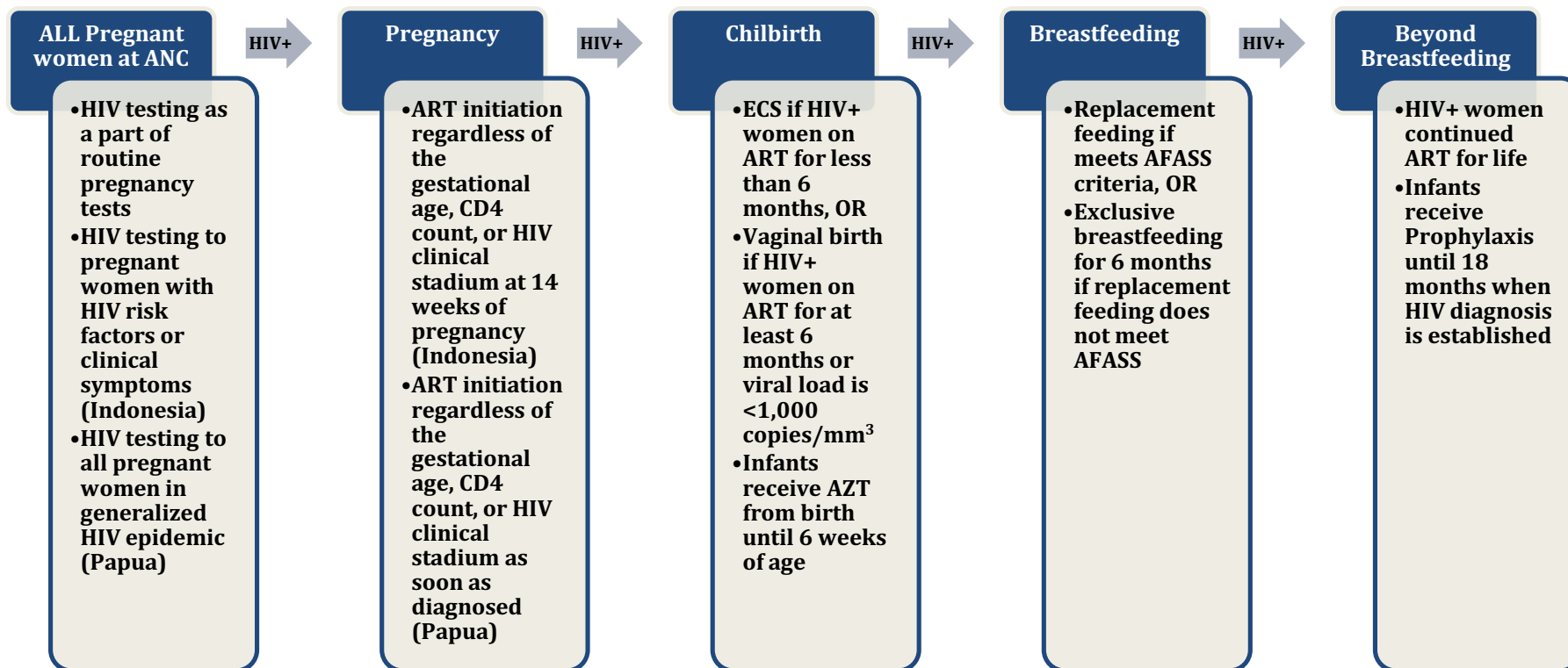


Figure 9. PMTCT cascade in Indonesia.

HIV diagnosis

For HIV diagnosis, most health facilities in Indonesia including Papua use RDT. There are three RDT serial tests using three different reagents. Health facilities with more advanced HIV equipment may also use ELISA for HIV diagnosis. Pregnant women with HIV risk factors should be repeatedly tested for HIV in the next trimesters, or three months after receiving negative HIV results. Hence, women can be tested three times during pregnancy to account for the HIV window period [22].

ART initiation and monitoring

Since 2011, all HIV-positive pregnant women started ART initiation regardless of CD4 count. HIV disease progression is assessed using the WHO clinical staging criteria. The CD4 test is used for ART monitoring. Asymptomatic women start ART at 14 weeks of pregnancy, and symptomatic women start ART as soon as they are diagnosed with HIV. Infants receive prophylaxis ART at birth until the age of six weeks [22].

Childbirth

Through counselling, health workers recommend the safest childbirth option (ECS vs. vaginal birth) based on ART treatment. Women who have taken ART for at least six months or have viral loads of fewer than 1000 copies/mm³ may opt for vaginal birth. For pregnant women who have taken ART for less than six months or whose viral load is more than 1000 copies/mm³, health workers should recommend ECS. However, in providing the recommendation, health workers need to consider several aspects

including the safety of ECS based on the woman's health condition, availability of ECS at the health facilities, and cost and affordability of ECS [22].

Replacement feeding

Counselling on the risk of HIV transmission during breastfeeding is conducted before childbirth. Health workers recommend the safest infant feeding practices and subsequently support women to implement their choice effectively. Health workers should recommend replacement of breastfeeding with infant formula if the AFASS criteria can be met. If the AFASS criteria is not met, women who have taken ART for at least four to six weeks should be recommended to breastfeed exclusively for six months. In any case, women should be advised to avoid mixed feeding [22].

HIV diagnosis in children

HIV diagnosis in children born to HIV-positive mothers is conducted using RDT and/or ELISA, depending on availability at the health facilities. HIV diagnosis in children using RDT is conducted after 18 months of age. If conducted earlier, between 9–12 months, the test should be repeated at 18 months. This is the most common method for HIV diagnosis for children in Indonesia. Early infant diagnosis using DNA/RNA PCR is currently only available at Darmais Hospital in Jakarta [22].

PMTCT referral and satellite system

PMTCT implementation in Indonesia uses a referral and satellite system, in which PMTCT satellites (hospitals or primary health centres) conduct HIV testing and refer

HIV-positive pregnant women to PMTCT referrals (hospitals) for ART initiation. If it is not possible to refer women to PMTCT referral hospitals, a trained health worker at the PMTCT satellite, who is appointed by the head of the District Health Office, conducts ART initiation. After ART initiation and when women show a positive response to the treatment, PMTCT referral hospitals refer women back to the PMTCT satellite closer to their home to continue their ART treatment [105].

Non-governmental organisations (NGOs)

PMTCT implementation in Indonesia is supported by non-governmental organisations (NGOs) and peer groups. NGOs work with health workers to provide HIV education for the community, while peer groups support HIV-positive women to maintain ART [22]. There are local NGOs that provide temporary shelters to people who relocated to the urban areas for HIV care such as Jayapura Support Group and Surya Kasih Kota Jayapura, and Yasanto Merauke. Some NGOs provides peer support and conduct outreach to deliver HIV education for the community in rural areas such as Yayasan Pengembangan Kesehatan Masyarakat (YPKM) in Wamena. And some NGOs focus on women including Yayasan Harapan Ibu Papua, which offers peer support for women who are HIV-positive or experience gender-based violence. All of these NGOs are located in urban areas, and funding availability greatly influenced these services.

2.5.1. Summary and interpretation

Papua experiences several challenges in PMTCT implementation. Due to limited resources, health facilities in Papua rely on RDT for HIV diagnosis of pregnant women

and children. As described in laboratory markers (section 2.1.2), the use of RDT alone potentially delays HIV diagnosis in pregnant women and children due to its lack of ability to detect women's HIV antibodies during the window period and to conduct early infant diagnosis. Hence, women are at risk of transmitting HIV to their children during this infectious stage, and HIV-positive children can potentially develop drug resistance due to delays in ART of 18 months. Other implementation issues include limited number of health facilities providing ECS and lack of replacement feeding that meets AFASS criteria.

2.6. PMTCT performance in Indonesia

Indonesia has implemented PMTCT programs since 2004. Despite this, the UNAIDS estimated in 2017 that the MTCT rate in Indonesia is 26.6%, currently the highest in the world (Figure 10). This indicates that the PMTCT program in Indonesia is less effective than in other resource-limited settings such as Malawi, Africa. One of the reasons for this is lower ART coverage.

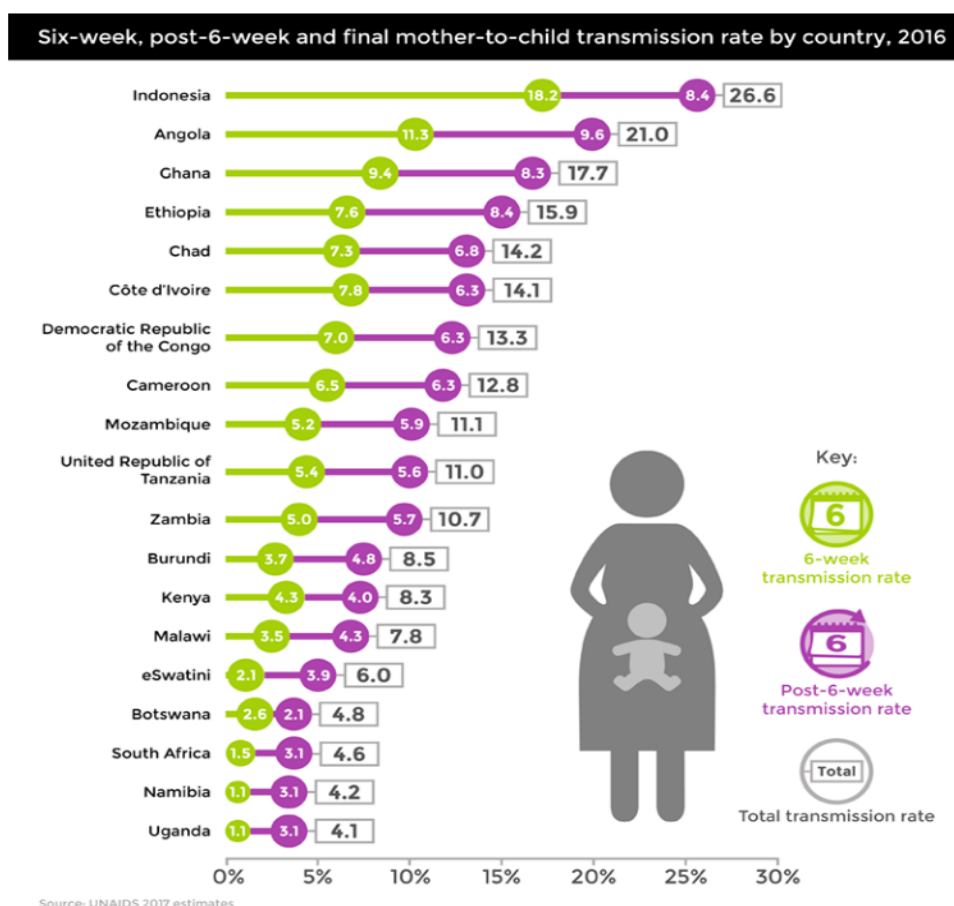


Figure 10. MTCT rate by country in 2016.

Source: UNAIDS, 2017 [3].

The PMTCT program in Indonesia covered only 8% of the total number of HIV-positive pregnant women in need of the program [14]. Hence, 92% of HIV-positive pregnant women in Indonesia did not participate in a PMTCT program and potentially transmitted HIV to their children. As shown in Figure 11, despite the national PMTCT efforts, new HIV infections in children aged below 15 years has increased from fewer than 500 in 2009 to over 11,000 in 2018 [34].

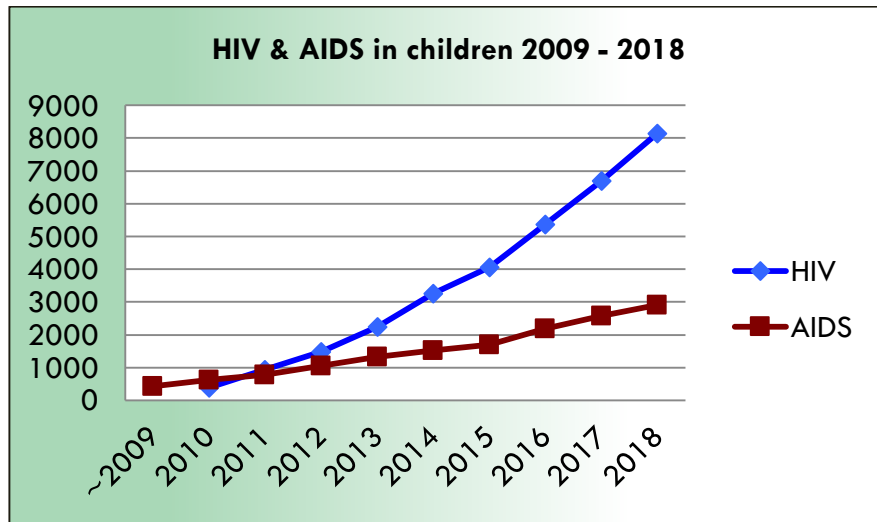


Figure 11. Total of HIV infections in children below 15 years in Indonesia

Source: Kementerian Kesehatan Republik Indonesia, 2019 [34].

2.6.1. PMTCT performance in Papua

PMTCT coverage in Papua is presumably lower than the national performance given that only one third of estimated HIV-positive pregnant women accessed antenatal care at health facilities in Indonesia [106]. A larger proportion of HIV-positive pregnant women were not tested for HIV, and these women were at risk of transmitting HIV to their children. Moreover, when this thesis started, among women who were tested positive at the health facilities, only 30% had started ARV treatment [14].

PMTCT is effective in reducing MTCT when HIV-positive women adhere to and are retained in ART [107-109]. The target for PMTCT set by the Ministry of Health of the Republic of Indonesia in 2017 was 1,800 HIV-positive pregnant women to begin ARV treatment in Papua [14]. Statistics for ART uptake, adherence, and retention of HIV-positive pregnant women in Papua are unknown and require further investigation.

2.6.2. Summary and interpretation

PMTCT coverage in Indonesia and Papua are low, with a high proportion of HIV-positive pregnant women not tested for HIV and at risk of transmitting the disease to their children. There is a lack of data on ART uptake and retention among pregnant women who started ART, which requires further investigation. Nonetheless, high MTCT rates and increased new HIV infections in children after the implementation of PMTCT since 2004 indicates ineffectiveness of the PMTCT program. Further investigation is warranted to describe ART uptake and retention among HIV-positive pregnant women in PMTCT program in Indonesia and Papua.

2.7. PMTCT facilitators and barriers

A literature review was conducted to identify PMTCT facilitators and barriers in Indonesia. There were limited literature with only three studies investigating: the role of health system to support PMTCT program implementation in Jayawijaya in Papua [20], women's experiences in PMTCT in West Java [110], and the local dynamic of PMTCT in Jakarta [111]. The study designs and key findings from these studies are presented in Table 6.

Socioecological factors that facilitated PMTCT uptake among pregnant women across the three studies in Indonesia were:

- *Individual level*: the possibility of having a healthy 'HIV-negative' baby
- *Institutional level*: confidentiality of HIV status and high-quality HIV counselling
- *Policy level*: free-of-cost HIV medication.

These three studies did not identify facilitators at interpersonal and community levels. Moreover, there were more barriers than facilitators identified in the PMTCT program. The barriers to PMTCT uptake were:

- *Individual level*: lack of information on PMTCT, unintended pregnancies
- *Interpersonal level*: fear of isolation/separation from friends and family
- *Community level*: stigma and discrimination
- *Institutional level*: low ratio of health workers to women, long wait times, stigma and discrimination, sub-optimal treatment from health workers, lack of health worker skill to deliver the program
- *Policy level*: scarcity of PMTCT services, long distance to health facilities, costly administration fees, low budgeting prioritisation of PMTCT, and poor integration of the PMTCT into the local context.

Stigma and discrimination

Stigma and discrimination at the community and institutional levels were identified as barriers to the implementation of PMTCT program [43, 44, 112, 113]. Stigma refers to the negative beliefs, feelings and attitudes toward people living with HIV, which can result in discrimination. Discrimination refers to the negative behaviours toward people living with HIV [114]. Several factors that influence stigma and discrimination including poor HIV knowledge [10], social norms that associates HIV with certain populations (men who have sex with men, sex workers, injection drug users, etc.), and laws and policies that criminalize people living with HIV [115] such as imprisonment

for transmitting HIV to others. These factors contribute to high level of HIV stigma and discrimination in Indonesia, including Papua.

There are several limitations pertaining to the three studies. The Papuan study was conducted in 2014, two years after the adoption of Option B+ PMTCT in Papua. However, this study did not clarify if Jayawijaya had implemented Option B+ or if it was in a transition process from Option A/B to Option B+. This study explored perspectives of the program providers but not the perspectives of HIV-positive women. The study conducted in West Java focused on HIV testing and uptake of prophylaxis, instead of lifetime ART uptake. The study conducted in Jakarta investigated health workers and women's engagement in the PMTCT program in Indonesia in 2009 prior to the adoption of Option B+. As such, the sample included only HIV-positive pregnant women in the AIDS stage who received ART. Overall, the Indonesian studies focused on factors that influenced PMTCT uptake among women eligible and ineligible for ART. They did not explore how those factors influenced ART retention among HIV-positive pregnant women in Option B+ PMTCT.

Table 6. PMTCT studies in Indonesia as of June 2016.

Study Reference	Research Design & Location	Samples and Size	Key Findings
Preventing mother-to-child transmission of HIV in Vietnam and Indonesia: Diverging care dynamics[111] Type: Research article, 2009	Qualitative study: 1.Observations of health facilities 2.Focus group discussions 3.Semi-structured interviews Location: NGO Yayasan Pelita Ilmu, Jakarta and Karawang, Indonesia	Participants • 20 HIV-positive women in PMTCT program in Jakarta • 37 HIV-positive women in Jakarta and Karawang • 13 PMTCT health workers Type: key population (IDUs, partners of IDUs, and sex workers)	Facilitators to PMTCT uptake: • The possibility to have a healthy baby • Free-of-cost medication Barriers to PMTCT uptake: • Scarcity of PMTCT services • Long wait times • Costly administration fee • Long distance to the health facilities • Stigma and discrimination
A qualitative study on HIV positive women experience in PMTCT program in Indonesia[110] Type: Poster Presentation (master thesis), 2012	Qualitative study: 1.In-depth interview Location: Hasan Sadikin Hospital, Bandung, West Java, Indonesia	HIV-positive women • 9 HIV-positive women in PMTCT Type: key population (partners of IDUs)	Facilitators to PMTCT uptake (HIV Testing): • Confidentiality of HIV status • High quality HIV counselling Barriers to PMTCT uptake (Prophylaxis Treatment): • Lack of information on PMTCT • Unintended pregnancies • Stigma and discrimination • Fear of isolation/separation from friends and family • Sub-optimal treatment from healthcare workers
The role of health system to support PMTCT program implementation in Jayawijaya regency[20] Type: Local publication (master thesis), 2015	Qualitative study: 1.Observations of health facilities 2.Interviews 3.Documentations Location: Jayawijaya district, Papua, Indonesia	Stakeholders/Health providers • PMTCT health facilities • District health office • AIDS prevention commission • NGOs	Barriers to PMTCT uptake: • Scarcity and irregularity of PMTCT services • Long distance to the health facilities • Stigma and discrimination • Low ratio of health workers to patients • Lack of health workers' skills to deliver the program • Low budgeting priority to support PMTCT program • Poor integration of PMTCT into the local context

Facilitators and barriers in Option B+ PMTCT in resource-limited settings

To mitigate the limited literature on Option B+ PMTCT in Indonesia, the review was extended to include other resource-limited settings such as African countries that implemented Option B+ PMTCT. This was conducted to ensure a better understanding of challenges experienced by women and health workers in Option B+ PMTCT in Papua. Globally, there were limited studies on Option B+ PMTCT considering the WHO released the guideline in 2012 and its implementation occurred four years ago. Despite this, the literature in resource-limited settings identified several factors that influenced women's uptake and retention in the program.

Socioecological factors that facilitated women's uptake and retention in Option B+ PMTCT included:

- *Individual level:* CD4 count less than 350 or in AIDS stage were more likely to uptake and retain in ART, as reported in a Swaziland study [19]
- *Interpersonal level:* partner support such as socioeconomic and psychological support in Malawi and South Africa [116, 117]
- *Institutional level:* high-quality HIV counselling and accessibility of PMTCT services in Ethiopia [18]
- *Policy level:* PMTCT model of care in which HIV clinics initiated and monitored women's ART in Malawi [21]

Meanwhile, socioecological barriers to women's uptake and retention in Option B+ PMTCT included:

- *Individual level:* food insecurity in Malawi and Zimbabwe [24, 118, 119] and ART side effects among asymptomatic women in Malawi [17]
- *Interpersonal level:* lack of male partner's support in rural Tanzania [16]
- *Community level:* stigma and discrimination in Malawi, Tanzania, Sub-Saharan Africa, and South-East Asia [15, 16, 24, 120]
- *Institutional level:* stigma at the health facilities in Malawi [24] and low ratio of health workers to pregnant women which resulted in long wait times in rural Tanzania, Ethiopia, and Zimbabwe [16, 25, 119].
- *Policy level:* scarcity of health facilities providing PMTCT services, resulting in lack of access and high transportation costs in rural Tanzania, Malawi, and Ethiopia [16, 24, 25].

2.7.1. Summary and interpretation

More Option B+ PMTCT barriers than facilitators were reported in resource-limited settings including Indonesia and Papua. Lack of research on Option B+ PMTCT in Papua indicated the need to further investigate women's uptake and retention to fill the gaps in the literature, and to understand what caused low PMTCT performance in Papua. Findings from the PMTCT studies in Indonesia and resource-limited settings contributed to the research design.

2.8. Strategies to improve ART uptake and retention in Option B+ PMTCT

UNAIDS reported in 2018 that countries in eastern and southern Africa have made significant progress in HIV program coverage by testing 81% of people living with

HIV, enrolling 66% HIV-positive people in ART, and achieving 52% viral suppression among people on ART. UNAIDS also reported that HIV program performance in Indonesia was one of the lowest, with 42% HIV testing coverage among people living with HIV and 14% ART coverage among HIV-positive people [3]. This may explain why Indonesia had the highest MTCT rate (26.6% of 30%) in the world.

This section provides a few examples of strategies implemented in other resource-limited settings including African countries, which improved women's uptake and retention in Option B+ PMTCT.

2.8.1. Strategies to improve ART uptake

Three key strategies have been trialled to improve the uptake of PMTCT: the integration of ANC-ART clinics, improvement of service quality, and PMTCT system analysis.

A Kenyan study compared ART uptake among women in clinics providing both ANC and ART services compared to non-integrated PMTCT services in which women received ANC at ANC clinics and ART at ART clinics. ANC-ART integration improved ART uptake to 69%, much higher than 36% in the non-integrated PMTCT services [121].

A Zambian study sought to improve ART uptake by improving the quality of the service. Several strategies were implemented at the same time, including training for health workers, supportive supervision, availability of clear performance standards/standards operating procedures, regular assessments of service quality, and delegation of PMTCT education tasks to lay workers to reduce health workers' workload. This strategy improved ART uptake from 1% to 34% [122].

In Kenya and Mozambique, the systems analysis and improvement approach (SAIA) to optimise PMTCT was developed to improve ART uptake in PMTCT. The SAIA intervention consists of three components: 1) cascade analysis to identify gaps in PMTCT cascades, 2) mapping of possible modifications and their economic values, and 3) iterative testing and adjustment of selected modifications. The SAIA increased ART uptake by three-fold from 4% to 13% [123, 124].

All three studies [121-123] suggest that health services delivery has an important impact on ART uptake.

2.8.2. Strategies to improve ART retention

Two studies have tested interventions to improve ART retention. These include customised text messaging to improve ART follow-up and couple HIV counselling and testing (cHCT).

A Kenyan study to improve ART retention in PMTCT developed text messages through focus group discussions using the Health Belief Model. Health workers sent 14 text messages to women: 8 for intrapartum and 6 for postpartum. This increased ART retention from 11.8% to 19.6% [123].

cHTC in Malawi increased women's ART adherence through increasing adherence self-efficacy as measured by the culturally adapted adherence self-efficacy scale (ASES) [125]. This strategy was recommended by the WHO to facilitate mutual HIV status disclosure. In this strategy, couples were tested together for HIV infection, and then health workers facilitated HIV status disclosure among them. Couples then decided together on ART treatment and prevention for themselves and their unborn children

[126]. Malawi reported a significant median difference in ASES scores among women before and after cHTC, which was significantly associated with ART adherence [125].

The studies [123, 125] suggested that interventions aimed at both women and at couples have an important role in improving retention in ART.

2.8.3. Summary and interpretation

The coverage of HIV testing and ART in Indonesia was much lower than in other countries such as Malawi. These resulted in high HIV transmission risks in the population including from mother to child (26.6% of a maximum 30% MTCT risks). Indonesia could benefit from other strategies implemented in other resource-limited settings to improve ART uptake and retention in Papua. However, to identify relevant recommendations to improve women's uptake and retention in Option B+ PMTCT in Papua, there is a need to address the current gaps in the literature through investigations of PMTCT performance in Papua, and factors that influence women's participation in the program at various levels using the socioecological framework.

CHAPTER 3

METHODOLOGY

This chapter provides an overview of the mixed methods research design used in this thesis to address the gaps identified in Chapters 1 and 2. The rationale and the development of the design for the three studies: Study 1_Papua, Study 2_Indonesia, and Study 3_Global are described, with a focus on the study aims and objectives, study settings, sampling methods, data collection instruments, and data analyses. This chapter also describes ethical approval, research permits, and risk managements related to ethical considerations. This chapter discusses amendments made to the data collection of Study 1_Papua and Study 2_Indonesia following pilot testing of the interview guides and delays in attaining the research permits in Indonesia.

3.1. Overview of research methodology

This research adopted a convergent parallel mixed methods research design that achieved the research aims: 1) to investigate the implementation and outcomes of Option B+ PMTCT in Papua; and 2) to identify strategies to improve women's uptake, adherence, and retention in Option B+ PMTCT. These aims were accomplished through the four study objectives: 1) to describe pregnant women's uptake, adherence, and retention in Option B+ PMTCT in Papua; 2) to identify factors that influence women's uptake, adherence and retention in Option B+ PMTCT in Papua; 3) to investigate the relationship between health facility characteristics and women's uptake and retention in Option B+ PMTCT in Papua; and 4) to provide recommendations to improve women's uptake, adherence, and retention in Option B+ PMTCT in Papua.

Convergent parallel mixed-methods is a research design in which the quantitative and qualitative studies are conducted and analysed separately, but the results are combined for an overall interpretation [127]. This method enables a better understanding of Option B+ PMTCT by interpreting the quantitative and qualitative data together.

The research project comprises three studies:

1. A study of women's uptake, adherence, and retention in Option B+ PMTCT in Papua (Qualitative study)
2. A study of health facility characteristics and PMTCT performance in Indonesia (Quantitative study)
3. A realist synthesis of Option B+ PMTCT in resource-limited settings (Literature review).

3.2. The context for the mixed methods research design

In Chapter 2, the literature review highlighted a lack of studies describing outcomes and experiences of women and health workers in Option B+ PMTCT in Papua. This lack of studies is likely due to limited available data to determine women's uptake, adherence, and retention in the program.

These limitations provided the rationale for the three studies as depicted in Figure 12 and discussed below.

First limitation: unavailability of data to determine ART uptake, adherence, and retention among HIV-positive pregnant women in Option B+ PMTCT in Papua.

The Ministry of Health Republic of Indonesia reported that 30% of HIV-positive women who accessed health facilities for Options A and B treatments did not uptake PMTCT program in Papua. Despite Option B+ treatment introduced in 2012, the high HIV morbidity among Papuan children suggested challenges in the implementation of Option B+ PMTCT in Papua.

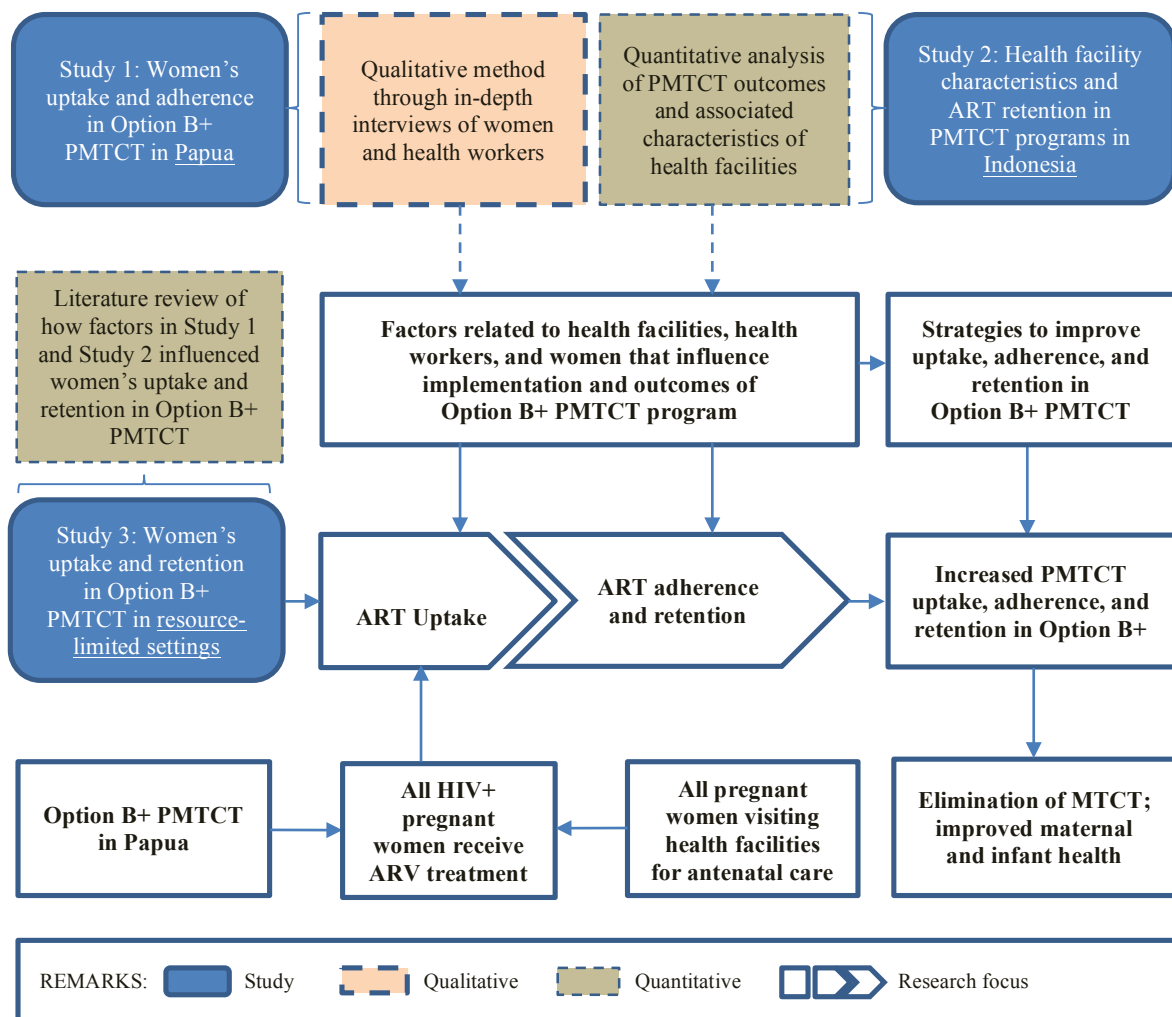


Figure 12. The contribution of the three studies to address the gaps in the literature related to Option B+ PMTCT in Papua.

However, there is a lack of literature that describes the outcomes of Option B+ PMTCT on women's uptake, adherence, and retention in Papua. Study 2_Indonesia aims to

address this limitation. Study 2_Indonesia described women's uptake and retention in the program by analysing PMTCT data collected by the Ministry of Health.

Second limitation: limited literature describing experiences of women and health workers in Option B+ PMTCT in Papua.

There is a lack of information in the literature on what facilitated or prevented uptake and retention of Option B+ PMTCT in Papua among women. To improve the program outcomes, there is a need to identify the evidence and practice gaps in Option B+ implementation [128, 129]. Study 1_Papua aims to identify the types of factors related to health facilities, health workers, and women that influenced outcomes of Option B+ PMTCT in Papua. Further, Study 3_Global explains the mechanisms for how those factors influenced women's uptake and retention in Option B+ PMTCT using evidence reported in other resource-limited settings.

Methods to ensure that the three studies address these limitations are described in the following sections.

3.3. A qualitative study on women's uptake and adherence in Option B+ PMTCT in Papua (Study 1_Papua)

3.3.1. Aims and study design

This qualitative study contributes to achievement of the first research aim by describing the outcomes of Option B+ PMTCT in Papua and factors that influenced those program outcomes. Study 1_Papua meets two research objectives by describing women's uptake and retention in Option B+ PMTCT in Papua (Objective 1) and factors that influence women's uptake, adherence, and retention in Option B+ PMTCT in Papua (Objective 2).

The qualitative methods included field observations and in-depth interviews of women and PMTCT health workers at antenatal clinics, maternity wards, laboratories, and Care Support, and Treatment (CST) clinics. In-depth interviews are effective when collecting primary data [130] regarding a complex program, such as Option B+ PMTCT programs [131-134]. Study 1_Papua also utilised field observations, which increased the validity of the interview analyses and provided a better understanding [135] of Option B+ PMTCT in Papua.

This study investigated women's ART uptake and adherence in Option B+ PMTCT in Papua. ART uptake was defined as HIV-positive women who started ART on the same day they received post-test HIV counselling [136, 137]. ART adherence referred to women who had 100% ART compliance or never missed any ARV dose as measured by the number of pills provided by the health workers. ART non-adherence referred to

women who missed at least one appointment and were not treated with ARVs during pregnancy, childbirth, or breastfeeding.

3.3.2. Study design amendments

At first, Study 1_Papua aimed to investigate ART retention and not ART adherence to Option B+ PMTCT. Retention refers to the continuation of women in ARV treatment until the MTCT risk from pregnancy to childbirth and breastfeeding is eliminated. However, preliminary discussion with health workers suggested that all HIV-positive women continued their ARV treatment since the implementation of Option B+ PMTCT in Papua. Although some women missed their appointments, the health workers invited them to resume their treatment. Hence, the focus of the study changed from ART retention to ART adherence to reflect the treatment history of Papuan women in Option B+ PMTCT.

3.3.3. Study setting

The qualitative study involved two PMTCT referral hospitals; Jayapura Hospital (urban) and Abepura Hospital (suburban). These hospitals have provided PMTCT services since 2004 [104] and receive PMTCT referrals from PMTCT satellites in Papua.

3.3.4. Sampling and inclusion criteria

Study participants consisted of 20 HIV-positive women and 20 health workers. Table 7 summarises the sample size and inclusion criteria for study participants.

Table 7. Summary of sample size and inclusion criteria.

Sampling criteria	Sample Size
1) Women	1) Women (N=20)
<i>Inclusion criteria:</i>	a) HIV-positive women who met the inclusion criteria and 100% adhered to ARV treatment or never missed any ARV dose (n=10)
- ALL HIV-positive pregnant and postpartum women with the youngest child aged younger than 18 months.	b) HIV-positive women who met the inclusion criteria but missed at least one ARV dose (n=10)
<i>Exclusion criteria:</i>	
- ALL HIV-positive women with the youngest child aged 18 months or older.	
2) Health Workers	2) Health Workers (N=20)
<i>Inclusion criteria:</i>	a) Medical doctors (n=2)
- ALL health workers providing PMTCT-related health services in the past 12 months at ANC clinic, maternity ward, and CST clinic at selected hospitals.	b) Counsellors (n=2)
	c) Midwives/nurses (n=6)
	c) Laboratory specialists (n=2)
	d) Pharmacists (n=4)
	e) Admin and data staff (n=4)
<i>Exclusion criteria:</i>	
- ALL health workers at ANC clinic, maternity ward, and CST clinic who did not provide PMTCT services at selected hospitals.	

Women

HIV-positive women included pregnant women and postpartum women with their youngest child aged less than 18 months. The inclusion criteria of the youngest child's

age ensured that only HIV-positive women who enrolled after implementation of Option B+ PMTCT were included in the study.

Health workers

Health worker participants consisted of medical doctors, HIV counsellors, pharmacists, laboratory specialists, and data staff. Health workers were eligible if they had provided PMTCT services at an ANC clinic, maternity ward, and CST clinic in the past 12 months.

The study used a purposive sampling method to identify 20 women who adhered (n=10) or did not adhere (n=10) to ART in Option B+ PMTCT. Each category consisted of 10 women [138] to achieve data saturation [139]. The initial sampling design proposal included a third category of women who did not start ART after testing HIV positive (n=10). However, pilot testing with the health workers and peer groups revealed that since the implementation of Option B+ PMTCT, *all* HIV-positive pregnant women started ART. Analysis of the interview results also confirmed that all women started ART after receiving HIV post-test counselling.

3.3.5. Research induction at the hospitals

A research induction session was conducted with health workers at Rumah Sakit Umum Daerah (RSUD) (public hospital) Jayapura and Abepura to recruit study participants. The session covered various topics including an overview of the study aims and objectives, recruitment of participants, and ethical conduct. The session provided an

opportunity to discuss study-related concerns and strategies to minimise unexpected outcomes, such as non-voluntary participation in the study.

The following amendments were made to the study design following the induction session between the PhD researcher and the health workers:

- *Health worker participation in the recruitment process.* Health workers assisted with the identification of women using the inclusion criteria but were not involved in obtaining consent from women to participate in the interviews.
- *Recruitment procedure.* Identification and recruitment of women participants occurred on the same day women visited the health facilities. Invitation of women to participate in the study through other means of communication, including phone calls or text messages, was not used. Women participants, however, could inform their peer/s about the study and they could contact the researcher directly if they were interested in participating in the interviews.
- *Papuan language interpreter.* The PhD researcher is an Indonesian national who is a native speaker of the Indonesian language. A Papuan language interpreter was included in the first proposal to address language barriers between the PhD researcher and Papuan women. However, health workers confirmed that all Papuan women registered at the health facilities spoke fluent Indonesian. Therefore, a Papuan language interpreter was not required.
- *Transportation reimbursement.* Information about the transport and meal reimbursements was removed from the plain language statement (PLS) to ensure voluntary participation in the program. Information about \$10 transportation and meal reimbursements was provided at the conclusion of the interviews.

- *Private interview room.* Health facilities allocated a private room in the CST clinic for the conduct of the interviews.

All participants received a verbal and written PLS in the Indonesian language. The PLS was firstly provided to women (Appendix A) and health workers (Appendix B) and written informed consent (Appendices C and D) was subsequently obtained from those who agreed to participate in the study and conduct the interview on the same day. Those who did not agree to participate in the study on the same day the PLS was given were asked for written informed consent on the day of the interview.

3.3.6. Interview guides

The interview guides consisted of open-ended questions that explored themes identified in the literature using the adjusted socioecological framework. Themes included: sociodemographic characteristics, PMTCT facilitators and barriers, PMTCT implementation, and recommendations to improve the implementation and outcomes of PMTCT. The last question in the interview guides allowed an exploration of other potential themes that were not identified in the literature that the participants may have experienced. The development of the interview guides was firstly conducted in English (Appendices E and F): guides were then translated into the Indonesian language by the PhD researcher (Appendices G and H).

3.3.7. Pilot testing of interview guides

A pilot testing of the translated interview guides occurred in Abepura Hospital and *Yayasan Harapan Ibu*, a local peer support group for HIV-positive women in Jayapura.

The pilot testing involved three participants: one medical doctor and two HIV-positive women. Through the pilot interviews, participants confirmed the appropriateness of the interview language for the local context and there were no ambiguous questions or missing topics in the interview guides. The amount of time the participants needed to complete the interviews was also identified: 15 minutes for women and 45 minutes for health workers, similar to the time estimate in the PLS. Participants also suggested locally appropriate sentences to inquire sensitive questions or to manage strong reactions using “maaf, ya mama...” or “if you don’t mind, ma’am...”. Last, the pilot testing also helped refine the recruitment criteria for women. Refinements included: a) removing the criteria of women who did not uptake the PMTCT program since both peer groups and hospital claimed that since the implementation of Option B+ PMTCT in Papua all women commence ART; and b) inclusion of women with the youngest child aged younger than 18 months since the PMTCT program includes monitoring of women’s treatment until establishment of the child’s HIV diagnosis.

3.3.8. Data collection

Data collection was conducted through face-to-face, in-depth interviews using the interview guides. The interviews of the women and health workers occurred in a private room at both hospitals between August and December 2016. With the consent of participants, interviews were recorded with an audio recorder. All women were proficient in the Indonesian language and did not require a Papuan language translator.

3.3.9. Data analysis

Audio-recorded interviews were transcribed into Microsoft Word documents. Initial coding and thematic analysis using template analysis was conducted using NVivo 11. Transcribing refers to verbatim transcription of each participant interview into one single word document for each woman and health worker. Initial coding involved classification of interview results into *a priori* themes (Appendix I) identified in the development of the interview guides. The coding process also included identification of *new themes*, which were themes that did not fit *a priori* themes, and modification/replacement of themes that did not appear in the interviews. The coding template with added *new themes* and modified/replaced *a priori* themes then became the final coding 'template'. The final coding 'template' (Appendix J) guided identification of major themes for the Option B+ PMTCT program in Papua, as discussed in Chapter 4.

Figure 13 shows the three steps for conducting the data analysis of the interview results from the development of *a priori* themes until the data interpretation using the final coding 'template'.

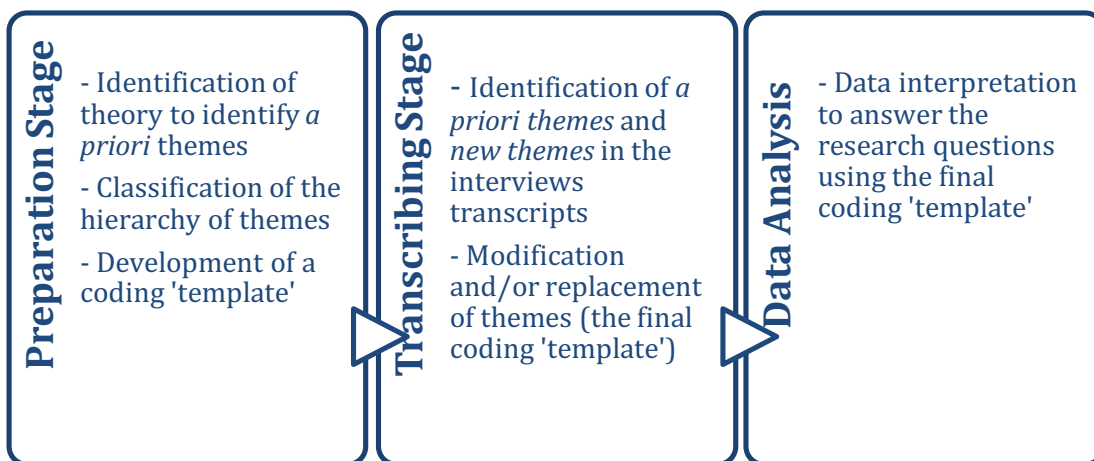


Figure 13. Data analysis process for the interview results.

Template analysis comprises a hierarchical classification of themes, which consists of broad themes such as ‘barriers to retention in ART’ and more specific themes including ‘lack of partner support’. These themes were modified or replaced to incorporate new themes identified during the data analysis process. The PhD researcher initiated the classification of themes, which were then reviewed by the supervisors. The final coding ‘template’ (Appendix J) consists of the final themes used in the final data interpretation [140].

3.3.10. Ethics approval

The three studies received ethics approval from the Health Sciences Humans Ethics Sub-Committees (HESC), the University of Melbourne in Australia. The study was granted five research permits in 2014 as per the regulation of the Ministry of Home Affairs No 7 (Table 8). This regulation applies to all research conduct in the Republic of Indonesia conducted by Indonesian researchers involving foreign institutions, including post-graduate research [141].

The relevance of each research permit for the thesis is described below:

1. Research recommendation from the Ministry of Home Affairs, Republic of Indonesia.

A research permit from the Ministry of Home Affairs is required for research conducted in more than one province in Indonesia [141]. Study 2_Indonesia covered all 34 provinces in Indonesia and therefore a national research permit was required.

Table 8. Research permits in Indonesia and Papua.

No	Research Permit Issuer	Location
1	Ministry of Home Affairs, Republic of Indonesia	Jakarta
2	Directorate General of Disease Prevention and Control, Ministry of Health, Republic of Indonesia	Jakarta
3	Papua Provincial Health Office	Papua
4	Jayapura Hospital	Papua
5	Abepura Hospital	Papua

2. Research recommendation from the Directorate General of Disease Prevention and Control, Ministry of Health, Republic of Indonesia.

The research recommendation from the Ministry of Health is required to meet two research aspects: thesis relevance and procedural requirement. Thesis relevance ensured research alignment with the national health program priority and research needs. Procedural requirement ensured research alignment with the Indonesian bureaucracy that places the PMTCT program under the supervision of the Directorate General of Disease Prevention and Control.

3. Research recommendation from the Provincial Health Office, Papua.

The research recommendation from the Papua Provincial Health Office was attained to meet two research aspects: thesis relevance and procedural requirement. Thesis relevance ensured research alignment with the regional health program priority and research need. Procedural requirement ensured research alignment with the

Indonesian bureaucracy that places hospitals under the supervision of the Provincial Health Office.

4. *Research recommendations from the director of Jayapura Hospital and the director of Abepura Hospital.*

The research recommendations from the hospital directors were required to gain access to the PMTCT-related clinics, health workers, and HIV-positive women for Study 1_Papua.

The five research permits were required to ensure that the thesis was of relevance to the PMTCT program needs in Papua and Indonesia and aligned with the research requirements and procedures at various levels. Documents required for the research permit included the complete research proposal, interview guides, PLSs and consent forms, ethical clearance, and research support letters from Papua Provincial Health Office.

The duration for the research permits approval ranged from two weeks to several months. The PhD researcher began the ethics application process and sought research supports from the Ministry of Health of the Republic of Indonesia and Papua Provincial Health Office early in the first year of the PhD. Research permit from the Ministry of Home Affairs was granted in the second year of the PhD before travel to Papua for the field work. To receive access to PMTCT clinics, research permits were also sought from Jayapura Hospital and Abepura Hospital before the interviews occurred.

3.3.11. Ethical considerations

The research addressed several ethical considerations concerning pregnant women participants, consistent with the *Australian National Statement on Ethical Conduct in Human Research* [142] such as management of potential pressure to participate and risk-management strategies.

Management of potential pressure to participate

As previously described in Section 3.3.5, health workers were not involved in the recruitment process, to minimise the potential pressure placed on women to participate [143]. While health workers were responsible for assessment of women's criteria against the inclusion criteria, the recruitment process was the full responsibility of the researcher.

Similarly, the recruitment of health workers did not involve their supervisors. Therefore, the PhD researcher was able to maintain the confidentiality of health workers who participated in the interviews.

Health workers and women received verbal and written PLSs (Appendix A and B), which assisted them to decide about their participation in the study. The PLS consists of information on the researchers' names and institutions the research aim; voluntary participation; and expected participation including types of information collected, time commitment, and the freedom to withdraw from the study at any time. It also highlights the protection of confidentiality through de-identification and the use of pseudonyms in the publication of research results as journal articles, as well as access to the research results. Local and international contact details to deliver concerns and complaints about the study conduct were also included in the PLS.

To ensure adequate understanding of the PLS, the researcher asked women and health workers to summarise the information they received in their own words. All participants had opportunities to ask questions related to the study. At the same time, the researcher also observed nonverbal gestures and asked if they felt any pressure to participate in the study. A few women asked for clarification about the protection of their HIV status in the publication of the study. These women then received repeated information related to the protection of confidentiality through deidentification and pseudonym. They also received repeated information about voluntary participation in the study and the option to withdraw or not participate without consequences. After receiving this repeated information, women were more confident in the study.

Risk-management strategy

The research included several measures to mitigate a few anticipated risks related to women's participation in the study. These risks included unwanted HIV status exposure due to engagement in the study, withholding honest opinions about health workers and the PMTCT program, and distressed when discussing negative experiences (Table 9).

Table 9. Ethical risks and management strategy.

No	<i>Ethical Risks</i>	<i>Risk-management Strategy</i>
<i>1.Unwanted HIV status exposure due to participation in the study.</i>	The study did not include HIV-negative women as controls; therefore, there was a risk that people might identify women as HIV-positive when they participated in the study.	The risk mitigation included protection of HIV status confidentiality through the conduct of the recruitment process at the HIV clinic that women regularly visited. This measure ensured their participation in the study did not increase their current risk of HIV status exposure. Women also had an option to propose an interview location where they felt more comfortable and more protected from unwanted exposures.
<i>2.Holding back information related to topics investigated in the interviews.</i>	The power imbalance between health workers and women [144] was a risk in which the interviews with women might not result in useful information about the actual PMTCT program implementation, relationships with health workers, and their expectations about a better PMTCT program implementation.	The key measure to mitigate this risk was through building a good rapport with the women during the recruitment process. Another measure was through protection of the confidentiality of information given by women through deidentification and pseudonym.
<i>3.Psychological risks.</i>	Interviews related to women's past experiences when diagnosed as HIV positive might create psychological distress. Women who had not disclosed their HIV status to their partner might feel pressure to disclose. Women who stopped participating in the PMTCT program might feel guilty of transmitting HIV to their child.	Various measures to mitigate the psychological risks included provision of psychological support and counselling referral option to an external counsellor of their choice, a repeated reminder of women's option to withdraw their participation in the research at any time and to only answer questions they felt comfortable with, and a debrief at the end of the interviews to assess women's psychological state.

3.4. Health facility characteristics and PMTCT outcomes in Indonesia (Study 2_Indonesia)

3.4.1. Aims and study design

The quantitative study contributed to the achievement of the first research aim to investigate performance of the Option B+ PMTCT program and to identify factors that influence Papuan women's uptake and retention in PMTCT programs. This study met research objectives 1 and 3 to describe women's uptake and retention in Option B+ PMTCT in Papua and to investigate health facility characteristics that influence uptake and retention.

There were two data collection process conducted in this study. The first was extraction of secondary data on PMTCT uptake and retention from the Indonesian System Information for HIV/AIDS and sexually transmitted infection (SIHA). The second was extraction of health facility characteristics such as class of health facility, type of health facility, PMTCT Option, HIV epidemic, and HIV program priority from various government documents including Indonesian health profiles, Indonesian HIV/AIDS statistics quarterly reports, provincial health profiles, and hospital profiles. These data were linked by the health facility names and were combined in an excel spreadsheet.

Considering the study objective to describe PMTCT outcomes and to investigate associations between health facility characteristics and women's uptake and retention in Option B+ PMTCT, quantitative research design was the most appropriate method. A cross-sectional study design was used, in which ART uptake and retention of HIV-positive women in Option B+ PMTCT in 2017 was investigated. This study design enabled objective predictions [145] of the relationships between the health facility characteristics and PMTCT outcomes.

3.4.2. Study design amendments

The initial proposed study design involved health facility surveys conducted by PMTCT program managers to collect primary data on health facility characteristics that influenced women's uptake and retention in PMTCT program. Health facility characteristics in the first study design consisted of the maturity of PMTCT program implementation at the health facility, number of pregnant women visiting ANC clinics per month, PMTCT target, infrastructure to support PMTCT implementation, PMTCT-related logistics, human resources to deliver PMTCT services, PMTCT Option, ARV treatment initiation and follow up (models of care based on referral system and procedures), and strategies to improve women's retention and adherence in the PMTCT program.

Secondary data extraction of health facility characteristics replaced the health facility surveys due to delays in receiving PMTCT data and a renewed research support letter from the Ministry of Health of the Republic of Indonesia. Delays in receiving PMTCT data was due to extended time needed to complete data collection at all health facilities and data verification between the Ministry of Health and the health facilities. The delays in the renewal of the research support letter was associated with a change of leadership at the Sub-Directorate of HIV, AIDS and STIs of the Ministry of Health of the Republic of Indonesia. Data were requested at the end of year 1 of the PhD in 2016 and received by the end of year 3 of the PhD in 2018. By the time the PhD researcher received both the PMTCT data and renewed research support letter, it was no longer feasible to proceed with the health facility surveys given the restricted duration of the PhD program.

3.4.3. Study setting

The quantitative study involved all health facilities that implemented PMTCT programs in Indonesia. Given the small sample size (27/664) of health facilities who implemented PMTCT in Papua, the inclusion of health facilities in other provinces in Indonesia increased the statistical power of the quantitative analysis.

3.4.4. Sampling and inclusion criteria

The Ministry of Health, Republic of Indonesia provided the latest PMTCT data in 2017. The quantitative analysis included only health facilities that provided a PMTCT program to at least one woman in 2017. Around 60% (373/664) of health facilities met this inclusion criteria (Figure 14).

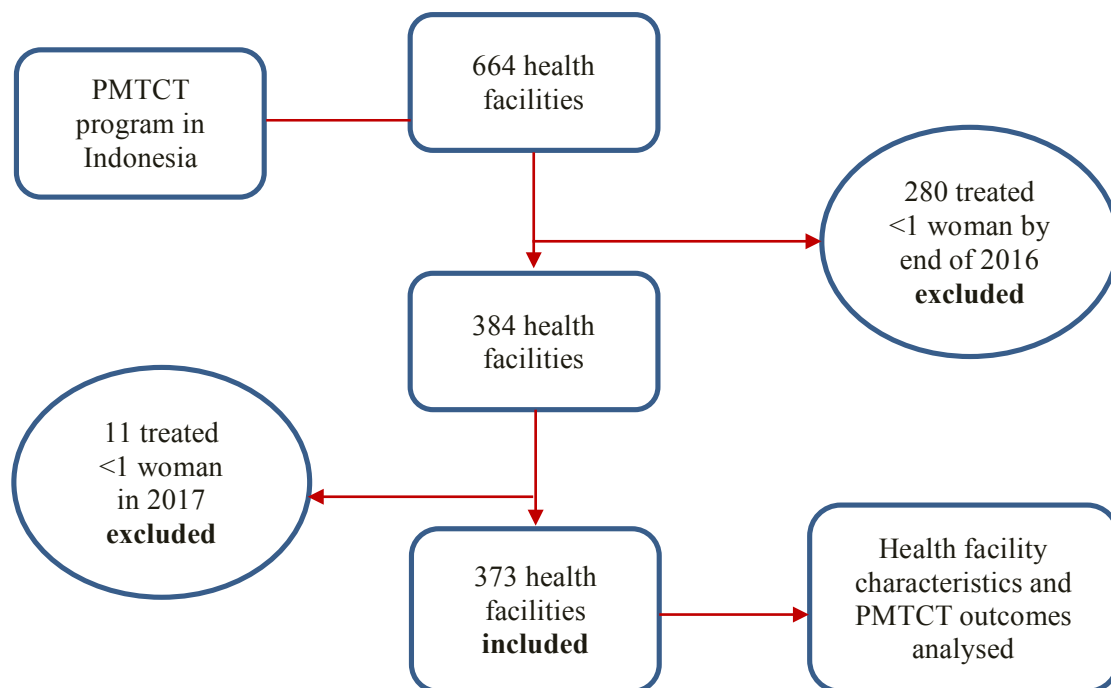


Figure 14. The process for selection of health facilities.

3.4.5. Data variables, definitions, and classifications

PMTCT Data

This quantitative study involved extraction of PMTCT variables considered to be important in the data cleaning process. For PMTCT uptake and retention, these variables included the number of women who were enrolled in a PMTCT program, started ARV treatment, were referred out, died, stopped, were lost to follow up (LTFU), or were still on ARV treatment. Table 10 provides the details of PMTCT data variables, definitions, and classifications in the statistical analysis.

Table 10. PMTCT data variables, definitions, and classifications.

No	Variable	Definition	Categories
1	Started ARV treatment	Number of HIV positive women started ARV treatment in 2017	1 = No uptake 2 = Uptake
2	On ARV treatment	Number of HIV-positive women who were still on ARV treatment by the end of December 2017	1 = LTFU 2 = Retention
3	Enrolled in PMTCT	Number of HIV-positive women enrolled in PMTCT program in 2017	N/A
4	Eligible for ARV treatment	Number of HIV-positive women eligible for ARV treatment in 2017	N/A
5	Referred Out	Number of HIV-positive women referred out to other health facilities or giving childbirth in 2017	N/A
6	Died	Number of HIV-positive women died in 2017	N/A
7	Stopped	Number of HIV-positive women stopped ARV treatment in 2017	N/A
8	LTFU	Number of HIV-positive women missed their appointment for the last 3 months in 2017	N/A

Remark: N/A means variables were not part of statistical analysis but were included in the data cleaning process.

Health facility characteristics

Health facility characteristics included type of health facility, class of health facility, type of HIV epidemic, HIV program priority, and PMTCT Option. Table 11 provides the details of health facility data variables, definitions, and classifications in the statistical analysis.

Table 11. Health facility characteristics, definitions, and classifications.

No	Variable	Definition	Classification
1	Type of health facility	1. Primary health centres (PHCs) are health facilities located at sub-district level and provide primary health services which focus on health promotion and disease prevention in the community [22]. 2. Hospitals are health facilities that provide secondary health services including inpatient, outpatient, and emergency health services [146].	1 = PHC 2 = Hospital
2	Class of health facility [146]	1. Primary health centres (PHCs) are health facilities that could be upgraded to become a hospital, and - Provides basic general medical and dental services. - Employs at least nine health workers; a medical doctor, a dentist, a nurse, a midwife, a public health worker, an environmental health worker, a medical laboratory technology expert, a nutritionist, and a pharmacist. 2. Hospital Class D is a hospital that is in a transition process to become a hospital class C, and - Provides general medical and dental services. - Employs at least six medical doctors, three pharmacists, and 2:3 nurse to bed ratio. 3. Hospital Class C is a non-teaching hospital that: - Provides limited specialist and subspecialist services. - Employs at least 15 medical doctors, 8 pharmacists, and 2:3 nurse to bed ratio. 4. Hospital Class B is a teaching and non-teaching hospital that: - Provides broad specialist but limited subspecialist services. - Employs at least 23 medical doctors, 13 pharmacists, and 1:1 nurse to bed ratio. 5. Hospital Class A is a teaching hospital that: - Provides comprehensive specialist and subspecialist services. - Employs at least 37 medical doctors, 15 pharmacists, and 1:1 nurse to bed ratio.	1 = PHC and Hospital Class D 2 = Hospital Class C 3 = Hospital Class B and A
3	Type of HIV epidemic [9, 147]	1. Concentrated HIV epidemic is HIV prevalence over 5% in one or more defined subpopulations but among pregnant women is less than 1%. 2. Generalised HIV epidemic defined is establishment of HIV in the general population, and HIV prevalence among pregnant women exceeds 1%.	1 = Concentrated 2 = Generalised

No	Variable	Definition	Classification
4	HIV program priority [148]	1. Low priority area, which is defined as an area with a concentrated HIV epidemic, and there are no more than 4,000 people living with HIV. 2. Medium priority area defined as an area with a concentrated HIV epidemic, and there are between 4,000 and 11,000 people living with HIV. 3. High priority area defined as an area with a generalised or concentrated HIV epidemic, and there are more than 11,000 people living with HIV.	1 = Low 2 = Medium 3 = High
5	PMTCT Option	1. Non-Option B+ if not all HIV-positive women were eligible for ARV treatment 2. Option B+ if all HIV-positive women were eligible for ARV treatment	1 = Non-Option B+ 2 = Option B+

3.4.6. Data collection

The Monitoring and Evaluation Team of the Sub-directorate of HIV, AIDS and STIs extracted PMTCT data from SIHA. PMTCT data extraction of PMTCT variables (Table 10) was conducted in Excel. Extracted data covered PMTCT outcomes that occurred between December 2016 and December 2017 in 664 health facilities. The PMTCT data extraction was completed in June 2018. Health facility characteristics from various government reports and health facility profiles were extracted by the PhD researcher between July and September 2018. Data were combined in an Excel spreadsheet and linked by the health facility names.

3.4.7. Data cleaning

Data cleaning was conducted to ensure accuracy of data analysis results. The PhD researcher conducted data cleaning by ensuring that the number of women enrolled in the treatment was equal to the number of women reported in PMTCT outcomes. The common errors found in the data cleaning process were missing PMTCT outcomes for some women. This missing data were then added to the number of women not retained in ART. Hence, cleaned data

described women's ART uptake and retention more accurately. Data cleaning was conducted data between January and March 2019 on all hospitals included in the statistical analysis.

3.4.8. Data analysis

To test the associations between the health facility characteristics and PMTCT outcomes, statistical analyses, including Chi square tests and Poisson regressions, were conducted using IBM SPSS 24. Chi square tests assessed the differences between health facility characteristics and PMTCT retention. Poisson regressions assessed the associations between health facility characteristics (predictor variables) and PMTCT retention (dependent variable). The associations were considered statistically significant if the p-values were < 0.05 .

3.4.9. Secondary data analysis: limitation and mitigation

A notable limitation of secondary data analysis is the potentially low awareness of the researcher about the program setting and the data collection process which limits the interpretation of the data [149]. In this study, field experiences of the PhD researcher in HIV programs in Indonesia and Papua helped mitigate this limitation. The PhD researcher held a certificate in recording and reporting of HIV data in Indonesia, which was attained through a training provided by the Ministry of Health of the Republic of Indonesia. Moreover, during the field visits to Abepura Hospital and Jayapura Hospital in Papua, the PhD researcher also clarified that there were no changes in PMTCT data interpretation since her training.

3.5. A realist synthesis of Option B+ PMTCT in resource limited settings (Study 3_Global)

3.5.1. Aims and study design

The third study contributed to the achievement of the second research aim to explain how factors identified in Study 1_Papua and Study 2_Indonesia influenced women's uptake, adherence, and retention in Option B+ PMTCT in Papua. This understanding is necessary to develop recommendations that are relevant for the Papuan context to achieve the national target to eliminate MTCT. This study met research objective 4 by identifying mechanisms that increased women's uptake, adherence, and retention in Option B+ PMTCT.

The method used was a literature review of Option B+ PMTCT using the Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) publication standard [150]. Realist synthesis is a new systematic and theory-driven approach to understanding complex programs such as Option B+ PMTCT. It views mechanisms as essential program components that influence program outcomes. Mechanisms were the products of complex interactions between program interventions, contexts, and users.

Realist synthesis enabled the development of three program theories that emphasised the essential mechanisms that need to be present in PMTCT settings to ensure women's ART uptake, adherence, and retention. It also enabled the development of hypotheses on variations in PMTCT outcomes if essential mechanisms were not present or present in a lesser degree in a program setting. Realist synthesis is able to explain the reasons for women's ART uptake and retention in Option B+ PMTCT in Papua.

3.5.2. Realist synthesis

Realist synthesis or realistic evaluation is a theory-driven approach developed by Pawson and Tilley [151] with a main view about program active changes. Hence, it works differently in different circumstances and for different people.

The realist evaluation further explains this view through the four facets of programs:

1. Programs are theories

This facet means programs are developed by policy makers based on multiple *theories* that certain interventions will result in desired outcomes, which are then delivered to program implementers, and sometimes program users. The effectiveness of the programs is therefore influenced by the efficacy of theories used by the policy makers in the program development.

As highlighted in Chapter 2, there were no previous studies that investigated program theories surrounding WHO's recommendation for Option B+ PMTCT in resource-limited settings. The first purpose of this study was therefore to identify *program theories* surrounding the development of Option B+ policy to improve women's uptake, adherence, and retention in PMTCT program in resource-limited settings.

2. Programs are embedded

This facet refers to the effect of *social systems* on behaviours of program implementers and program users, which influence the program outcomes. The social systems encompass personal factors such as motivation in PMTCT programs, interpersonal relationships between HIV-positive and women health workers, institutional factors such as internal referral

systems at health facilities, and infrastructural factors such as availability of a private room for HIV post-test counselling.

The second purpose of this global study was then to document the *social systems* of women and health workers in Option B+ PMTCT, and the influence of these social systems on the PMTCT outcomes.

3. Programs are active

This facet explains that program outcomes are subject to the *reasoning* of program implementers and program users. Different engagement levels of health workers and women in the programs resulted in different PMTCT outcomes. To achieve desired outcomes, there is a need to understand the reasoning and engagement levels of women and health workers in the PMTCT program.

As previously described in Study 1_Papua, the qualitative study collected information about the reasoning of women and health workers in Option B+ PMTCT in Papua. This study collected the *reasoning* of women and health workers in Option B+ PMTCT in resource-limited settings including Papua.

4. Programs are open systems

This facet specifies the *self-transformational* characteristic of a program, which refers to the mutual ability of the program and its external factors to influence and change each other. Therefore, the programs are always implemented differently and are not constant. Different program implementations then result in different program outcomes.

The last purpose of this global study was, therefore, to identify Option B+ PMTCT factors that were *modified* by health workers, HIV-positive women, decision makers, and the influence of those *modifications* on the PMTCT program outcomes.

The realist evaluation further explains the complex interactions between the four program facets and their influence on the program outcomes using the concepts of *Mechanism (M)*, *Context (C)*, *Outcome pattern (O)*, and *Context-Mechanism-Outcome pattern Configurations (CMOCs)*. The relationship between these components is shown in Figure 15.

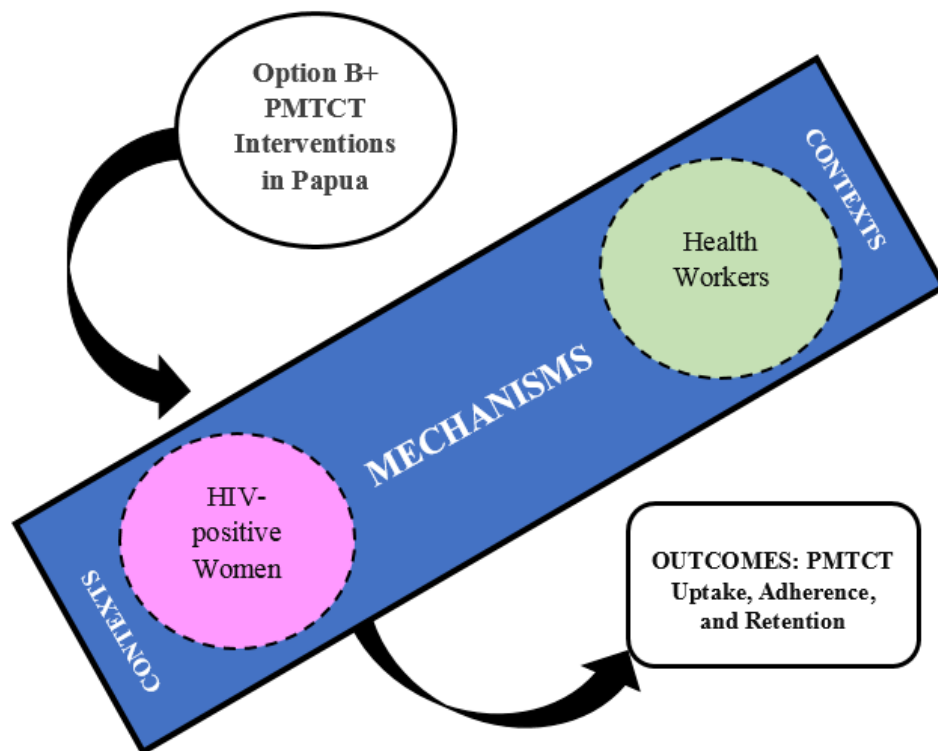


Figure 15. The CMOCs framework for Option B+ PMTCT in Papua.

1. Mechanism (M)

Mechanisms are the core aspects of realist evaluation that explain the fundamental and *invisible* processes of interpretations and responses of the program implementers and program users towards a program, which influence the program outcomes.

In Option B+ PMTCT in Papua, one of the interventions was inclusion of HIV testing as a part of routine laboratory testing for pregnancy care. This intervention might trigger different mechanisms such as *perceptions of HIV testing as a mandatory testing* (M1), which women might refuse if a separate consent form was required for HIV testing or *wasting reagents* (M2) because some pregnant women tested might be HIV negative. It might as well trigger *healthcare seeking avoidance* (M3) if women were not ready to find out her HIV status. To improve women's uptake, adherence, and retention in Option B+ PMTCT in Papua, this study helped identified three mechanisms triggered by various program contexts.

2. Context (C)

Context refers to the conditions in which programs are implemented including individual characteristics and other wider norms that the program implementers and the program users have. A successful program implementation requires enabling contexts that produce mechanisms to achieve desired outcomes.

HIV testing as a part of regular pregnancy care might result in *healthcare seeking avoidance* (M3) due to *stigma and discrimination in the community* (C1) [152] or *lack of partner support* (C2) [153, 154]. Literature reviews showed that community stigma and discrimination were one of the main reasons for women's ART non-adherence and discontinuation. To improve women's uptake, adherence, and retention in Option B+

PMTCT in Papua, this study identified various program contexts that influenced the three mechanisms.

3. Outcome pattern

Outcome patterns refer to the patterns of both desired and undesired outcomes as results of program implementation, which consider differences in the program context and the mechanisms it activates. Therefore, realist evaluation does not use a single performance measurement that determines the success or failure of a program, but it produces outcomes patterns that explain how, why, and for whom a program results in desired or undesired outcomes.

In Option B+ PMTCT in resource-limited settings such as Malawi, women who received financial and social supports from their partners were both retained and LTFU in the PMTCT program [154]. This study identified several mechanisms that resulted in ART non-retention such as *loss of hope* (M4) or *doubts about ART efficacy* (M5) to improve health among HIV-positive pregnant women in Papua. While for some other women, lack of partner support did not result in women's loss to follow up since the *motivation to have a healthy baby* (M6) overcame lack of partner support. This study showed differences in women's uptake and retention due to differences in mechanisms created by various contexts.

4. Context-mechanism-outcome pattern configuration (CMOCs)

CMOCs are models that predict and explain the variations of program outcomes as the combined results of different contexts and mechanisms. Hence, the realist evaluation does not support the view that a program has the same effectiveness for everyone and in every context.

Previous studies have reported various outcomes in Option B+ PMTCT, which were associated with the program contexts such as demographic aspects of women and health workers or the characteristics of the health facility, such as model of care [21, 155]. In other qualitative studies including the Papuan study in this thesis, variations in Option B+ PMTCT outcomes were due to mechanisms including partner support [153], whereby influence on women's ART depends on the presence of other more influential mechanisms, or not. To improve women's ART uptake, adherence, and retention in Option B+ PMTCT in Papua, this study resulted in three CMOCs.

3.5.3. Study setting

The realist synthesis was conducted on Option B+ PMTCT in resource limited settings, defined as settings that have only basic resources to manage life-threatening illness [156]. This selection ensured the similarities of study settings with the resource-limited setting in Papua, to allow the generalisation of the review results to Option B+ PMTCT in Papua.

3.5.4. Sampling and inclusion criteria

The WHO released the official guideline for Option B+ PMTCT in 2012. The literature search on Option B+ PMTCT was conducted from 01 January 2010 to 14 November 2018. Literature prior to the release of Option B+ PMTCT in 2012 contributed to *program theories development*, while literature after the release of Option B+ PMTCT to 14 November 2018 contributed to the *program theories testing and refinement*.

Program theories development

Consistent with the RAMESES publication standard, program theories development consisted of scoping review of scientific and grey literature on Option B+ PMTCT from inception until the WHO released the official guideline in 2012. Articles in the scoping review included comments, responses, discussions, and WHO guidelines. During the scoping review, three program theories (CMOs) that supported the release of Option B+ PMTCT in resource-limited settings were identified. This review enabled a better understanding of Option B+ PMTCT components that were expected to surpass Options A and B in resource-limited settings.

Program theories testing and refinement

Testing and refinement of program theories included reviews of scientific literature on implementation of Option B+ PMTCT in resource-limited settings. The literature review in this stage tested and refined the three program theories based on the actual implementation and outcomes of the Option B+ PMTCT in resource limited settings. In this stage, the study refined the three program theories (CMOCs) by highlighting what worked in Option B+ PMTCT, for what type of user (women, health workers, and health facilities), to what extent, and in which contexts.

3.5.5. Data collection

Consistent with the realist synthesis approach, data collection focused on program theory development, testing, and refinement. Guided by the framework, as described in the literature review in Section 3.5.2, data collected in the program theories development, testing, and refinement consisted of:

- Contexts: social systems of women and health workers
- Mechanisms: the *reasonings* of women and health workers
- Outcomes: variations in PMTCT outcomes
- CMOs: program theories or hypotheses surrounding Option B+ PMTCT.

The PhD researcher extracted CMOs from each article explaining PMTCT uptake, adherence, and retention in Option B+ PMTCT. Extracted CMOs were recorded in an Excel spreadsheet. Since most studies did not utilise the realist synthesis approach, most studies provided only contexts and outcomes related to Option B+ PMTCT. A few studies discussed mechanisms as factors that influenced the PMTCT outcomes. These factors were then extracted to form the basis for defining the program mechanisms. Data extraction was conducted until conceptual saturation was achieved to ensure there was enough data to develop, test, and refine the CMOs configurations.

3.5.6. Data analysis

Data synthesis was conducted on data extracted from reviewed articles. The PhD researcher classified extracted data into CMOs, and discussion ensued with supervisors about the accuracy of the classification of CMOs. The main challenges were to identify the ‘Mechanisms’ based on factors that were extracted from the reviewed articles. In the synthesis process, most of the factors reported in the studies were the products of Mechanisms’ not explicitly mentioned in the studies. The PhD researcher and supervisors defined hypothetical Mechanisms and identified repeated patterns in both confirmatory and contradictory findings. In this process, the PhD researcher and supervisors challenged each hypothetical Mechanism using various scenarios in reviewed articles. Mechanisms were finalised when repeated CMOs patterns were confirmed, and no new hypothetical

Mechanisms emerged during the discussions. The CMOs configurations were used to form the hypotheses regarding women's uptake, adherence, and retention in Option B+ PMTCT in resource limited settings including Papua.

These results of the three studies contributed to overall understanding of women's uptake and retention in Option B+ PMTCT in Papua. Study 1_Papua and Study 2_Indonesia identified factors that influenced women's participation in the program, while Study 3_Global explained whether those factors belong to Contexts or Mechanisms. Factors identified in the three studies shaped the development of recommendations to improve women's uptake and retention in Option B+ PMTCT in Papua.

CHAPTER 4

STUDY 1_

PAPUA

Chapter 4 describes the results of the qualitative study investigating factors that influenced women's uptake and adherence in Option B+ PMTCT in Papua (Study 1_Papua). This qualitative study achieved the first research aim to investigate performance of Option B+ PMTCT in Papua and identify factors that influence Papuan women's uptake, adherence, and retention in the PMTCT program. This study identified factors that influenced women's participation in the program based on experiences of HIV-positive women and health workers in Papua. This Papua Study addressed the research objectives to describe women's uptake and retention in Option B+ PMTCT in Papua (Objective 1) and factors that influence women's uptake, adherence, and retention in Option B+ PMTCT in Papua (Objective 2). This study utilised qualitative methods consisting of field observations and in-depth interviews of women and PMTCT health workers at two selected hospitals in Papua.

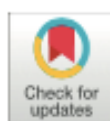
RESEARCH ARTICLE

Understanding women's uptake and adherence in Option B+ for prevention of mother-to-child HIV transmission in Papua, Indonesia: A qualitative study

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Abstract

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Data Availability Statement: Data available on request. Voice recordings may not be shared due to confidentiality issues. As regulated by Health Sciences HESC of the University of Melbourne, research data should be managed by the research centre. Further data requests can be sent by email to centre manager Tracey Mayhew at t.mayhew@unimelb.edu.au.

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Background

Despite a more proactive approach to reducing new HIV infections in infants through lifelong treatment (Option B+ policy) for infected pregnant women, prevention of mother-to-child transmission of HIV (PMTCT) has not been fully effective in Papua, Indonesia. Mother-to-child transmission (MTCT) is the second greatest risk factor for HIV infection in the community, and an elimination target of <1% MTCT has not yet been achieved. The purpose of this study was to improve understanding of the implementation of Option B+ for PMTCT in Papua through investigation of facilitators and barriers to women's uptake and adherence to antiretroviral therapy (ART) in the program. This information is vital for improving program outcomes and success of program scale up in similar settings in Papua.

Methods

In-depth interviews were conducted with 20 women and 20 PMTCT health workers at two main referral hospitals for PMTCT in Papua. Development of interview guides was informed by the socio-ecological framework. Qualitative data were managed with NVivo11 software and themes were analysed using template analysis. Factors influencing women's uptake and adherence in Option B+ for PMTCT were identified through final analysis of key themes.

Results

Factors that motivated PMTCT uptake and adherence were good quality post-test HIV counselling, belief in the efficacy of antiretroviral (ARV) attained through personal or peer experiences, and a partner who did not prevent women from seeking PMTCT care. Key barriers for PMTCT participation included doubts about ARV efficacy, particularly for

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asymptomatic women, unsupportive partners who actively prevented women from seeking treatment, and women's concerns about community stigma and discrimination.

Conclusions

Results suggest that PMTCT program success is determined by facilitators and barriers from across the spectrum of the socio-ecological model. While roll out of Option B+ as current national policy for pregnant women in Papua has improved detection and enrolment of HIV-positive women, health facilities need to address various existing and potential issues to ensure long-term adherence of women beyond the current PMTCT program, including during pregnancy, childbirth and breastfeeding.

Introduction

In 2012, the World Health Organization (WHO) recommended Option B+ as a novel approach to eliminate mother-to-child transmission (MTCT) of HIV [1]. This approach requires routine HIV testing for all pregnant women and lifelong antiretroviral therapy (ART) for positive cases irrespective of HIV clinical status or CD4 count [2]. Based on WHO criteria, elimination of mother-to-child transmission (EMTCT) of HIV is achieved when there is less than 2% MTCT in non-breastfeeding populations or less than 5% in breastfeeding populations, and if per 100,000 live births there are no more than 50 new pediatric infections [3].

Papua is the largest province of Indonesia that comprises most of Western New Guinea, and is the homeland to over three million indigenous Papuans. To the east, it is bordered by the nation of Papua New Guinea (PNG) and by West Papua province to the west. Papua is internationally known or referred to as 'West Papua', especially among the free movement coalitions [4].

Papua is one of the least populated, but most geographically challenging regions, in Indonesia with limited health infrastructure development, resulting in poor health status of the Papuan people [5]. Antenatal coverage is the lowest in Indonesia with less than 25% of pregnant women completing four mandatory antenatal clinic (ANC) visits (K4) during pregnancy, [6] and the child mortality rate is the highest in the country with 115 deaths per 1,000 live births [7]. Moreover, it is the only region in Indonesia that has documented a generalised HIV epidemic at 2.3%, which is mainly transmitted through heterosexual contact, [8] with perinatal transmission the second main risk factor for HIV. With an estimated 3.6% of 87,230 pregnant women in Papua being HIV positive [9], the Indonesian government has committed to elimination of MTCT in Papua through adoption of Option B+ since 2012.

Prior to Option B+, PMTCT performance in Indonesia was suboptimal with 86 new HIV infections in 1,145 (7.5%) live births among HIV-positive women who received the intervention [9]. During this period, PMTCT implementation was limited because of stigma and discrimination, long distances to health facilities, and long waiting times [10–12]. After adoption of Option B+, little is known about the experiences of HIV-positive women attending the PMTCT program, and the policy impact of PMTCT uptake/adherence and MTCT prevalence in Papua and at the national level.

To address this lack of evidence, our study aimed to document the impact of Option B+ and women's experiences in PMTCT through qualitative (Papua) and quantitative (national) study. This paper reports on results from the qualitative study about women's experiences of Option B+ in Papua, Indonesia. The quantitative study that examined PMTCT uptake and

adherence, and the MTCT rate with Option B+, is being conducted at a national level and will be completed by the end of 2018.

Methods

Study setting

The study was conducted at government health facilities providing PMTCT services in Jayapura city, Jayapura Hospital (urban) and Abepura Hospital (suburban). Both hospitals have implemented the PMTCT program since 2004 [13] and are PMTCT referral sites for satellite primary health centers (PHC) and public hospitals within and outside of Jayapura city. Jayapura Hospital has nine satellite facilities (six PHCs in Jayapura city, one PHC in Waropen District, and two PHCs in Keerom District) and Abepura Hospital has eight satellite facilities (five PHCs in Jayapura city, three hospitals in Puncak Jaya District, Yapen Island, and Keerom District) [14].

Similar to HIV programs for other populations, PMTCT is implemented at referral hospitals and satellite centres. For PMTCT purposes, all pregnant women newly diagnosed with HIV at satellite centres are referred to referral hospitals for post-test HIV counselling and PMTCT initiation. Women from satellite centres have the option to continue the PMTCT program at the original satellite centre or at a referral site. Exceptions apply to pregnant women from other districts, such as Waropen, Keerom, Puncak Jaya and Yapen, requiring air transportation to reach Jayapura city. In this case, satellite centres initiate and monitor women in PMTCT programs through coordination with referral hospitals and report data to their referral hospital on a monthly basis [15].

PMTCT program implementation at both referral hospitals involves antenatal clinic (ANC), maternal ward, laboratory, and Care Support and Treatment (CST) clinic. According to the national PMTCT guideline [15], every pregnant woman visiting an ANC and every woman in a maternal ward with an unknown or negative HIV status should be tested for HIV. Upon testing positive, women are referred to the CST clinic for HIV post-test counselling and PMTCT initiation and monitoring, while the ANC focuses on pregnancy care. However, while national guidelines outline ideal procedures, field implementation may vary based on resource availability at implementing health facilities.

Study population and sampling

This study investigated factors influencing women's uptake and adherence in Option B+ based on experiences of women and health workers in the PMTCT program. Hence, participants in this qualitative study were pregnant and postpartum HIV-positive women with live birth who attended the ANC at Jayapura Hospital and Abepura Hospital, as well as health workers who provided PMTCT services at both health facilities.

We defined PMTCT uptake and adherence by combining the WHO definition of MTCT, the WHO guideline for Option B+ PMTCT, and the national guideline for PMTCT. WHO defined MTCT as transmission of HIV from mother-to-child during pregnancy, childbirth and breastfeeding [16]. Option B+ PMTCT requires HIV-positive women to start lifetime ART as soon as diagnosed, while the infant receives prophylaxis for six weeks regardless of infant feeding method [17]. In this study, we defined PMTCT uptake as HIV-positive women starting ART on the day HIV diagnosis is informed through post-test HIV counselling [18, 19]. Meanwhile, adherence was defined as 100% ART compliance based on pill count and confirmed by clinical observation during pregnancy, childbirth and breastfeeding. Women who missed appointments and were therefore without ART for some time during the MTCT period were classified as non-adherent.

Women participants were purposively selected to meet a target of 20 women representing two categories of participants in Option B+. These two categories were: 1). Women who accepted PMTCT, but were non-adherent to the program ($n = 10$), and 2). Women who accepted PMTCT and were retained in the program ($n = 10$). A minimum sample of 10 women per category was established to achieve data saturation [20], which was detected by CL during the last few interviews, and confirmed during data analysis.

In the original design, we included a third category of women who declined the offer of PMTCT, but returned for pregnancy or infant care, including immunisation or infant HIV diagnosis, at 18 months. However, we removed this category because health workers claimed that all pregnant women had accepted the PMTCT offer at both hospitals since Option B+ was implemented.

The first category was also revised from 'women who accepted PMTCT, but discontinued the program' to 'women who accepted the PMTCT, but were non-adherent to the program' due to the strategy implemented by both health facilities to bring women who missed their appointments back into the program through follow up phone calls or coordination with ANCs and maternal wards.

All health workers providing PMTCT services for at least 12 months ($n = 20$) at ANC, CST, and maternal wards of both hospitals were included in the study. Health workers interviewed consisted of HIV counsellor/head of ANC ($n = 2$), HIV counsellor/head of maternal ward ($n = 2$), CST GP/specialist ($n = 2$), CST HIV counsellor nurse/midwife ($n = 2$), CST nurse ($n = 3$), CST pharmacist ($n = 4$), CST laboratory/logistics ($n = 2$), and CST data and administration ($n = 3$).

Selection and recruitment of participants

As part of the recruitment process, CL conducted preliminary visits to both hospitals to discuss the women they encountered and women required for the study. CL also visited peer support groups for women, Yayasan Harapan Ibu (YHI), and met with a peers in Jayapura city to identify HIV-positive pregnant and lactating women who were not in PMTCT, but without success.

We therefore continued with recruitment of respondents at both hospitals in collaboration with health workers. Prior to data collection, CL conducted an information session with health workers at each hospital to explain the purpose and approach of the study. Health worker involvement in the study was limited to assessing each visiting woman against study criteria, with study introduction and recruitment of women conducted by CL.

Each woman referred to CL received written and verbal study information in Indonesian, the national language spoken in Papua, by CL. A written consent form was signed by women who agreed to participate. Acceptance rate was 100% (20/20). All participants, including health workers, were informed of the right not to participate and to withdraw from the study at any time.

Women who agreed to participate were asked about their time and location preference for interviews. All women preferred to be interviewed on the same day at the hospital while waiting for their appointment, other than one woman who requested to return for an interview the following day. Length of interviews ranged from 15 to 45 minutes with an average of 29 minutes, excluding icebreaking conversation that took around 5 minutes per interview.

Health worker participants were individually approached by CL and were informed about the voluntary nature of the study. All health workers (20/20) participated voluntarily in interviews. As preferred by health workers, interviews were conducted at the hospitals after

working hours or during less busy hours. Duration of interviews with health workers was between 16 and 60 minutes with an average of 38 minutes.

Data collection

CL, who was experienced in qualitative interviewing techniques, conducted all one on one in-depth interviews from August to December 2016 in a private room at the care support and treatment (CST) clinic. In-depth interviews with HIV-positive women and health workers were guided by a conceptual framework, explained in the following section. The framework was developed based on study objectives and key findings from literature on HIV and PMTCT in Indonesia and other low and middle income countries.

Interview guides were developed in English and translated into Indonesian before being piloted at YHI, the local peer support NGO group and at Abepura Hospital in Jayapura city. All interviews were audio-recorded with consent from participants. Sociodemographic data was gathered from both participant groups. Women participants were asked what motivated them to participate in the PMTCT program, what helped them to remain in the program, and what prevented them from remaining in the program. Health workers were asked about work responsibilities, management of pregnant women newly diagnosed with HIV including pre and post HIV test counselling, privacy and confidentiality, and factors facilitating and inhibiting women's acceptance and continuation in the program. Interviews also explored participant recommendations for improvements to PMTCT uptake and adherence. The interviewer used the conceptual framework as a guideline to explore key themes not mentioned by participants but found in literature reviews or identified by the interviewer during her previous work with the HIV program in Papua.

Ethics approval and consent to participate

Ethical clearance for the study was obtained from the Health Sciences Humans Ethics Sub-Committees (HESC) of the University of Melbourne, Australia, as well as written research approvals from the Indonesian Ministry of Home Affairs, Papua Provincial Health Office, Jayapura Hospital, and Abepura Hospital. Participation in the study was voluntary and participants were free to withdraw at any stage. Study information was provided in writing and verbal form, and written consent was obtained. Confidentiality and anonymity of participants was maintained by de-identification of personal data and non-inclusion of information that might identify individual participants.

Conceptual framework

An adjusted socio-ecological framework [21] informed development of *a priori* themes for qualitative analysis of interview transcripts. This model consists of five levels of influence: individual, interpersonal, institutional, community and policy factors, as presented in Fig 1. Individual-level factors were defined as a woman's knowledge of HIV and the PMTCT program, reasons for HIV testing, belief in ARV efficacy, personal motivation to initiate engagement with the PMTCT program, and personal motivation to continue or discontinue with the PMTCT program. Interpersonal-level factors included willingness to disclose HIV status to partner and family members (or not), and quality of interactions with PMTCT health workers. Institutional-level factors focused on the health care system supporting PMTCT at health facilities, including waiting times, quality of HIV post-test counselling, confidentiality and privacy, stigma and discrimination from health workers, distance to health facilities, and cost of transportation to health facilities. Community-level factors included HIV status disclosure to non-family members, and stigma and discrimination in the community. At the policy level,

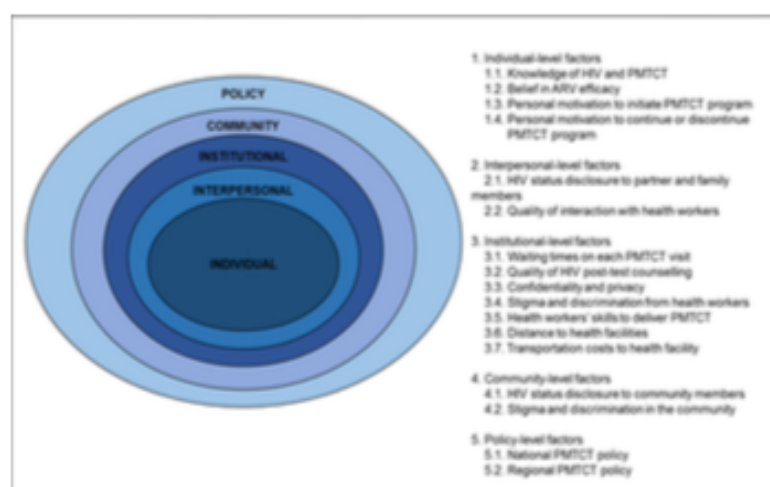


Fig 1. The modified socio-ecological framework consists of five levels of *a priori* themes. PMTCT = Prevention of Mother-to-Child Transmission of HIV.

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identified factors were national policy and the hospital policy for PMTCT that influence the nature and quality of program delivery at health facilities.

Data analysis

CL initially transcribed interviews in Indonesian language and then translated into English. Data was managed using NVivo11 software followed by application of template analysis, a form of thematic analysis that utilises hierarchical coding with adjustable structures for analysing qualitative data [22]. CL conducted the first coding using *a priori* themes established by the research team prior to data collection, and added new emerging themes. Themes were then discussed with MR and ME for validation and finalisation. The research team followed eight steps for conducting template analysis:

- Step 1. Development of *a priori* themes based on literature related to the PMTCT program in Indonesia and other low and middle income countries, as shown in Fig 1.
- Step 2. Data familiarisation by reading interview transcripts.
- Step 3. Preliminary data coding by highlighting parts of transcripts relevant to *a priori* themes and new information relevant to research questions.
- Step 4. Refinement of *a priori* themes to integrate new emerging themes.
- Step 5. Organisation of themes into groups and establishment of hierarchical and lateral relationships between groups.
- Step 6. Development of an initial coding template after coding five interviews that contained the greatest variation in responses.
- Step 7. Application of the initial coding template, and revision after coding of another five interviews.

Step 8. Finalisation of the coding template and its application on the full data set.

Results

Participant characteristics

Data from 40 interviews, 20 HIV-positive women (10 women who were non-adherent, 10 women who were 100% adherent) and 20 health workers (health workers providing PMTCT service at both hospitals for at least one year), were analysed. Women in the non-adherent category stopped taking ART between seven days and over three months with an average of 49.7 missing days. All HIV positive women participants were indigenous Papuans, but ethnicity varied with the majority belonging to ethnic groups residing outside of Jayapura (Table 1). Health workers were predominantly from other parts of Indonesia and had migrated to Papua during childhood or for work placement, but nevertheless identified themselves as Papuans. The majority of HIV-positive women were Christian, while health workers were predominantly Muslim. Ninety per cent of women described themselves as either married or living with their partners. A majority of health workers were married. Most women were high-school graduates, with only four having attended college or university.

Findings are presented based on final themes for each level of the socio-ecological framework that influenced PMTCT treatment uptake and adherence by HIV-positive women in Papua (S1 File).

Facilitators and barriers to Option B+ uptake and adherence

1. Individual-level factors. HIV counselling and PMTCT treatment uptake: In both adherent and non-adherent groups, contrary to health worker information, some women claimed they had no idea their blood was tested for HIV. As explained by a health worker:

"HIV testing in Option B+ was offered as a part of regular antenatal examination package that does not require a separate consent form. Hence, provision of pre-test HIV counselling which was combined with other health information might not be obvious to some women" (HealthWorker#18, 35 years)

However, women who reported not receiving pre-test HIV counselling did not object to this oversight and said that post-test HIV counselling improved their understanding of the disease and its treatment. Most women said they accepted PMTCT treatment as a result of post-test HIV counselling. As explained by a woman who was tested for HIV around the time of childbirth:

"I did not know I was tested for HIV. Later after the result came out, I [first] heard about it at the maternity ward and then I was brought here [CST clinic], I was really shocked. . . I cried. . . cried. . . but they encouraged me and advised that if I take the medicine regularly, it means I can be healthy like other normal people. So, I started the treatment" (Woman#3, 30 years)

Belief in ARV efficacy and PMTCT adherence: While good knowledge of HIV and PMTCT helped women in our study accept the program, it did not necessarily guarantee adherence to medication or the program. In this cohort, belief in the efficacy of ARV was an important factor promoting adherence to the program. Some women's beliefs about treatment efficacy were reinforced by personal experience or witnessing positive health outcomes of

Table 1. Sociodemographic characteristics of participants (n = 40).

Characteristics	Frequency	
	HIV-positive women	Health workers
Participants		
Age		
Younger than 25 years	8	0
26–30 years	6	3
31–40 years	6	13
Over 40 years	0	4
Gender		
Male	0	4
Female	20	16
Marital status		
Married	5	16
Living with partner	13	1
Divorced/Separated	0	1
Single	2	2
Number of Children		
No children	0	4
1–3 children	18	16
More than 3 children	2	0
Education level		
Elementary	3	0
Secondary	2	0
High school	11	0
College/University	4	20
Religion		
Christian	18	9
Muslim	2	11
Ethnicity		
Papuan from Jayapura city/district	3	2
Papuan from outside of Jayapura	17	2
Non-Papuan	0	16
HIV status		
Partner tested and both HIV positive	9	N/A
Partner tested but HIV negative	4	N/A
Partner not tested for HIV	7	N/A

N/A = Not Available

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peers after taking ARVs. For others, trusted knowledge was provided by health workers who stated that without ARV their health would deteriorate, advancing from asymptomatic to symptomatic HIV. In this study, non-adherent women either had doubts about the efficacy of ARVs (4/10) or experienced prolonged side effects (1/10). One woman who stopped her medication explained:

"I have not experienced any benefit of the medication. Each morning I wake up feeling dizzy...very dizzy...I had been taking the medicines for two months and the dizziness did not disappear. So, I don't feel like returning for the medicines" (Woman#4, 18 years)

Another woman stopped her treatment for three months:

"I find it hard to believe that ARVs would help prevent its transmission to my infant. It is incurable; there really is no hope for us." (Woman#13, 34 years)

2. Interpersonal-level factors. HIV status disclosure and partner support: The majority of women in this study (16/20) had disclosed their HIV status to their partners and requested they get tested for HIV. Sero-discordant and HIV positive partners were reported to be more supportive than partners who refused to get tested. The latter could be mentally or physically abusive, and prevented women from adhering to treatment. The presence of domestic violence (3/10) before and/or after HIV status disclosure became a main reason for PMTCT non-adherence reported by women. As stated by one woman:

"My partner was still upset because of my illness. I did not drink my medicines for two weeks because he threw away all of my medicines when I was not home. When I asked him, he said 'I was collecting rubbish in the house', so he threw them away. I could not return to the health facility to get more medicines because he wouldn't give me any money for transport" (Woman#16, 23 years)

However, having a supportive partner did not guarantee women's adherence to the program. As a non-adherent woman explained:

"My partner is very supportive. He is the one to remind me to take my medicines and bring me to the hospital to top up my drugs. He would persuade me to drink my medicine when I didn't feel like it" (Woman#4, 18 years)

3. Institutional-level factors. Health workers explained the increasing number of patients they managed at CST clinics because HIV+ pregnant women no longer stopped ART after childbirth/breastfeeding as occurred pre- Option B+. They explained major infrastructure and human resources changes were less likely to occur in the short-term, so the PMTCT program was adjusted to meet available resources. Consequently, there was a reduction in quality of care, such as long wait times and lack of privacy, but women and health workers rarely identified these as barriers to PMTCT uptake and adherence. Frequently mentioned facilitators of program adherence were respect for confidentiality and stigma-free care from health workers.

Wait times: All women (20/20) stated wait times were long, between two to five hours, depending on the number of child patients on the day. Nearly all women (19/20) understood and accepted this situation, but a few women (2/20) hoped wait time could be reduced in the future. Only one woman identified long wait time as a reason for non-adherence:

"Too long. Wasting time. Also, I waited for so long (from morning until past lunch time) until I felt very hungry. All these make me reluctant to comeback" (Woman#13, 34 years)

Privacy and confidentiality: Both health workers and women commented on respect for confidentiality during post-test HIV counselling. The majority of women (19/20) received the test result in person, in a private counselling room, uninterrupted, and unheard by other patients or health workers at the clinic. There was an exceptional case involving a woman who received her HIV test result at a satellite health facility in the presence of a second health worker who stayed in the room during the counselling process. While this made the woman feel uneasy, it did not deter her from attending the PMTCT program.

Health workers explained strategies they use to maintain confidentiality of women's HIV status outside of the health facility:

"Only health workers in the CST clinic know their HIV status. We explained to them that all of us in the clinic need to know because each of us deals with them for different reasons, such as blood testing, drug distribution, adherence monitoring, etc. But we promised them that we would do everything we can to make sure all information about them remain in this [CST clinic] room" (HealthWorker#1, 30 years)

"In the community setting, it is up to them to talk [to us] or not. There are patients who do not talk to us outside of this CST clinic. But it is okay. It is their right. We would not initiate a conversation with them unless they started. This to prevent people from assuming their HIV status because people know we are working in HIV clinic" (HealthWorker#2, 40 years)

Stigma and discrimination at health facility: Discrimination was not observed during field observations at both health facilities. There was no excessive use of precautions, including masks and gloves, in executing routine tasks or when meeting HIV+ women. Women participants also claimed they were not treated differently (20/20) after HIV diagnosis. No participant reported discontinuing treatment due to discrimination at the health facilities.

Women-health worker relationships: The relationship between health workers and women seemed to be satisfactory as all women (20/20) described health workers as either friendly or kind, while health workers felt 'kasihan', or sympathy, for women and their children. A minority of women (2/20) mentioned health workers becoming angry with them when they missed their doses, but they believed it was 'a sign of caring', rather than dislike. One woman, however, preferred health workers explaining things without being angry.

4. Community-level factors. Stigma and discrimination in the community: Perceived stigma and consequent discrimination in the community was seen by women as an important barrier to continued participation in the PMTCT program. Hence, a large proportion of women (16/20) sought treatment at a health facility outside of their neighborhood to avoid detection of HIV diagnosis by family members or friends. For this group, this meant travelling between 45 and 60 minutes using public transportation ($n = 7$) or continuing PMTCT treatment at referral hospitals instead of returning to nearby satellite PHCs ($n = 9$). Of 10 women who were adherent to PMTCT treatment, only one woman lived less than 30 minutes from the health facility.

Some women preferred to increase the distance from home to health facility, as explained by one woman:

"I decided to move out of our previous neighborhood since diagnosed with HIV. Now we live far away from people we know. There is another hospital near our current house but I have family members working there. I am afraid they will find out. It is safer if I come here" (Woman#10, 30 years)

A woman who lived near the health facility attributed fear of discrimination as a reason for discontinuing ART:

"I am afraid of being found out by my relatives and friends if returning to this clinic. I've got friends and family living around here. Every time I come, there are many people seeing me coming. Only HIV positive people come to this clinic for medication. So, I feel ashamed.

All this makes me reluctant to come back. I stopped my treatment for this reason"
(Woman#13, 34 years)

All adherent and non-adherent women in this study experienced increased transportation costs as increased travel distance was a less significant issue compared to anticipated stigma and discrimination. However, two women had missed appointments due to lack of money for transportation.

5. Policy-level factors. Regional health insurance: A main facilitator for women's uptake and adherence in the PMTCT program was 'free of charge' HIV services funded by the government through the Papua Health Scheme 'Kartu Papua Sehat/KPS' implemented by the Papua government in 2014. This scheme provides free health services, including medicines and laboratory testing, for underprivileged indigenous Papuans. As stated by health workers:

"Majority of Papuan women sought HIV treatment using KPS. They do not have any health insurance so we registered them for KPS" (HealthWorker#2, 40 years)

"Everything is free. HIV-positive people receive special treatment. Free medicine. Free laboratory testing" (HealthWorker#5, 25 years)

While benefiting the women, health workers mentioned a disadvantage of KPS in terms of difficulty recruiting additional health workers at CST clinics due to absence of incentives:

"Many health workers are unwilling to take their post at the Voluntary Counseling and Testing/VCT clinic because there is no incentive [KPS does not contain any incentives for health workers. Other health insurance schemes including The Indonesian National Health Insurance System 'Badan Penyelenggara Jaminan Sosial/BPJS' provides monthly incentives for health workers based on the number of patients treated] to claim. I say, only people with a serving heart work here. We tried to request for additional workers because we need more forces, but without result because the appointed health workers never showed up"
(HealthWorker#4, 28 years)

Discussion

This qualitative study conducted at two PMTCT referral hospitals identified several motivators and barriers to women's uptake and adherence in Option B+ that are comparable with findings from previous studies in resource-limited settings [23–26]. Factors motivating uptake and continuation in the program were a constellation of individual, interpersonal, institutional, and policy factors. Factors associated with increased uptake and adherence included good quality post-test HIV counselling, belief in the efficacy of ARVs to prevent transmission and improve health, confidentiality of HIV status, absence of stigma and discrimination at health facilities, positive women-health worker relationships, and free HIV services [25–32].

Our findings are consistent with previous research regarding the importance of post-test HIV counselling in helping women understand the disease and consequently promote participation in PMTCT programs [24, 27, 31–32]. Similar to a study in rural Tanzania, we found that PMTCT knowledge alone did not ensure women's adherence to the program [33], which is in contrast to findings from Malawi and Uganda [34]. In our study women who were adherent to the program not only had good knowledge of ARV and PMTCT, but they also believed in the efficacy of ARVs to improve health status and prevent HIV transmission. Though the term 'belief in ARV efficacy' was not specifically mentioned, our findings are similar to other

studies that reported desire for personal and infant health as a facilitator of PMTCT adherence [18].

Women participants in our study enrolled and remained in the program as a result of HIV post-test counselling that was understandable and provided them time to think. Effective communication at post-HIV test counselling and positive health worker-women relationships were also found to be important for adherence in the PMTCT program in other studies [25, 35]. This is different to findings of a study conducted in the highland of Papua, Indonesia, where migrant health workers were a barrier to PMTCT uptake and adherence [36]. The more positive outcomes in this study may relate to health workers' self-identifying as Papuans, rather than as migrant workers, thus having better understanding of Papuan culture. Also, as explained by a health worker, the national government's health policy for implementation of Option B+ for all pregnant women in Papua was accompanied by a range of training that significantly improved health worker knowledge and skills to effectively deliver the PMTCT program, including reduction of stigma and discrimination. Women seeking treatment in Jayapura city did not experience noticeable discriminatory behaviours on the part of health workers.

The women in our study did not necessarily require a partner who actively supported their treatment in order to remain in the program, unlike findings in other studies [23, 25, 37, 38]. A majority of women continued their treatment due to personal belief in ARV efficacy even without active encouragement from their partner. However, consistent with findings of other studies, partner support is important to retain women who are financially dependent on the partner [25, 26, 37, 39, 40].

The main barriers to adherence were disbelief in ARV efficacy to prevent HIV transmission from mother to child, unsupportive partners, and fear of stigma and discrimination from community members [23, 38, 41–43]. Women's doubts regarding ARV efficacy were commonly reported as a main challenge to adherence in PMTCT for asymptomatic participants, as documented in several studies in East Africa [19, 33, 44], as they do not experience a tangible benefit from treatment. Similar to experiences of women in our study, some women who were not adherent felt healthy without treatment and others did not believe that ARVs would make a difference for them and their infants [19, 33, 44].

A review of the PMTCT program pointed out the role of stigma and discrimination at the community level as a barrier to PMTCT participation [45]. In this study, a majority of women sought treatment far outside their neighborhoods due to fear of HIV status exposure in the local community. This unnecessarily added to the burden of the PMTCT program for women by increasing travel time and cost of transportation. Though both consequences were not reported as a major barrier to PMTCT adherence by women participants, it did become a reason why financially-dependent women missed appointments.

The Indonesian government aims to eliminate PMTCT by reducing HIV vertical transmission to less than 1% and by implementing the PMTCT program nationwide by 2019 [46]. Findings of this study highlight changes that can be made to improve women's uptake and adherence in the PMTCT program. Various studies have suggested a need to improve HIV post-test and follow up counselling quality [47, 48] to increase women's awareness and knowledge of HIV and PMTCT. Other studies suggested a need to engage male partners in PMTCT [23, 49] to increase mutual communication and create support systems needed by women. In this study, this was particularly relevant for women who missed their appointments due to unsupportive partners. To address anticipated stigma and discrimination in the community, various interventions could be considered including reduction of stigma in the community through continuous campaign, prevention of internalisation of perceived community stigma, and targeting the development process of perceived stigma [50]. Lastly, even though women in

our study did not identify the following factors as barriers to PMTCT uptake and adherence, quality of care could be much improved through recruitment of adequate numbers of health workers, improvement of privacy and reduction of wait times [25, 51].

Study limitations. In this study, interviews explored themes beyond the *a priori* themes and were enriched through use of field observations that we consider a strength of the study. Both health facilities selected for this study are located in urban and sub-urban Jayapura, but the majority of women participants were from outside of Jayapura. This contributed to richness of information we collected. However, we also realise that the information collected is limited to reported experiences of participants in the PMTCT program at referral hospitals, with a glimpse of PMTCT implementation at satellite health facilities provided by referred women as we did not conduct physical visits to satellite centres. Moreover, participants in this study were women attending referral hospitals and may not necessarily reflect the situation of women at satellite facilities or more remote areas of Papua. Therefore, caution needs to be applied when interpreting and generalising study findings to other districts in Papua and Indonesia by taking into account possible variations influencing factors at all levels.

Conclusions

Our study argues the clear importance of motivating factors that outweigh barriers to PMTCT uptake and adherence at five levels of the socio-ecological framework. The roll out of Option B+ as policy for pregnant women in Papua, which means inclusion of HIV testing as a routine part of pregnancy screening, has improved identification of HIV-positive women and their enrolment in the program. Further strengthening of the PMTCT program is necessary to ensure continuous enrolment of new cases while maintaining adherence of women in HIV care by addressing barriers or potential inhibitors to long-term treatment. These include availability of strategies to identify and counsel women with doubts regarding ARV efficacy early in the program, establishment of support for women in need, a continuous campaign to reduce stigma and discrimination at the community level, availability of adequate human resources, reduction of long waiting times, and increased privacy during return visits.

Supporting information

S1 File. Final themes of motivators, barriers and recommendations related to PMTCT uptake and adherence in Papua, Indonesia.

(DOCX)

S2 File. Interview guide for women in English.

(DOCX)

S3 File. Interview guide for women in Indonesian.

(DOCX)

S4 File. Interview guide for health worker in English.

(DOCX)

S5 File. Interview guide for health worker in Indonesian.

(DOCX)

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CHAPTER 5

STUDY 2_

INDONESIA

Chapter 5 provides the results of the quantitative study investigating PMTCT performance and health facility characteristics that influenced women's retention in Option B+ PMTCT in Papua (Study 2_Indonesia). The previous qualitative study achieved the primary research aim to investigate performance of Option B+ PMTCT in Papua and identify factors that influence Papuan women's uptake, adherence, and retention in the PMTCT program. This Indonesia Study addressed the research objectives to describe women's uptake and retention in Option B+ PMTCT in Papua (Objective 1) and to investigate the relationship between health facility characteristics and women's uptake and retention in Option B+ PMTCT in Papua (Objective 3). This study utilised quantitative methods consisting of descriptive analysis and Poisson Regression analysis to determine associations between health facility characteristics and women's retention in the program.

Pregnant women's retention and associated health facility characteristics in the prevention of mother-to-child HIV transmission in Indonesia: a cross-sectional study

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Abstract

Objectives: Despite the national effort to integrate PMTCT program into antenatal care clinics in Indonesia, the rate of mother-to-child HIV transmission remains high. This national study was conducted to describe PMTCT program performance, and to identify health facility characteristics associated with this performance in order to inform program planning and policy development.

Design: A retrospective cross-sectional study in December 2017.

Setting: All health facilities providing PMTCT programs in Indonesia.

Participants: All health facilities registering at least one woman in antenatal care in 2017.

Intervention: PMTCT data extraction from the national reporting system on HIV/AIDS and government reports.

Outcomes: Women retention in the PMTCT program for at least three months and associated health facility characteristics.

Results: A total of 373 health facilities registering 6502 HIV-positive women in antenatal care were included in the analysis. One-third of women (2099) never started ARV treatment. Of the 4403 women who started, 2610 (57%) were retained, 462 (10%) were not retained, and the retention status of 1252 (28%) women referred out of the health facilities was unknown. Compared with primary health centres, hospitals were more likely to retain women (OR=2.88, 95%CI 2.19-3.79). The odds of retention was higher in hospitals type A and B (OR=3.89, 95%CI 3.19-4.76), located within concentrated HIV epidemic areas (OR=2.09, 95%CI 1.83-2.38), and a high priority area for the HIV program (OR=1.83, 95%CI 1.60-2.09). We observed no differential retention between women who initiated PMTCT under different Options (B+/non-B+).

Conclusions: We observed low retention of HIV-positive pregnant women in the PMTCT program in Indonesia in 2017. Additional efforts are needed to improve women's retention in the PMTCT program. Retention could be increased through the delivery of PMTCT programs by replicating strategies implemented at hospitals type A and B located in concentrated HIV epidemic area where HIV program is a high priority.

Article Summary

Strengths and limitations of this study

- This is the first study to report on PMTCT program performance in Indonesia since its official implementation in 2004
- This study is among the few studies investigating health facility characteristics associated with HIV-positive women's retention in the PMTCT program, with a sufficiently powered sample size
- The use of secondary data in this analysis limited types of health facility characteristics entered in the Poisson regression analysis
- SIHA data recorded women's retention in the PMTCT program until childbirth, therefore, it does not reflect women's retention postpartum

Introduction

Mother-to-child transmission (MTCT) is the most common cause of HIV in children below 15 years of age. Globally, MTCT accounts for 90% of HIV in children,[1, 2] infecting 1.8 million children.[3] Despite the global effort to reduce HIV in children, there were 160,000 new HIV infections children in 2018, which is far from achieving the elimination of MTCT.[3]

Without interventions, the rate of MTCT is higher in less developed countries (25-35%) than in industrialized countries (14-25%). However, industrialized countries have successfully reduced the risk to less than 1%[4] through combined prevention consists of antiretroviral treatment, elective caesarean sections, and avoidance of breastfeeding. In 2017, the UNAIDS estimated that countries with higher HIV burdens, including Uganda and Botswana, have reduced the MTCT risk to less than 5% (4.1% - 4.8%). Meanwhile, MTCT risk in Indonesia was estimated at 26.6%, which is currently the highest in the world.[5]

From 2004, Indonesia has integrated PMTCT program into antenatal care clinics as a part of the national HIV programs. In 2017, there were 664 health facilities providing PMTCT programs all over Indonesia. However, despite the national effort, the number of new HIV infections due to perinatal transmission remains unchanged.[2] Since its implementation, there was no publication describing women's retention in the PMTCT program in Indonesia. Also, no literature investigated the associations between health facility characteristics and women's retention in the PMTCT program. The study aimed to describe women's retention in the PMTCT program in Indonesia and health facility characteristics associated with their retention.

Methods

Study design and population

A retrospective cross-sectional study was conducted on health facilities providing PMTCT program in 2017. We calculated women's retention in the PMCTC program for at least three months at one single point in time during December 2017. All health facilities registering at least one HIV-positive pregnant woman and reporting through the National System

Information for HIV AIDS (SIHA) between January and December 2017 were eligible. SIHA is the Indonesian monitoring system for HIV programs. It enables data verification and validation between the Ministry of Health, Provincial/District Health Offices, and the health facilities.[6]

Sampling

In 2017, 373 health facilities in Indonesia registered at least one HIV-positive pregnant woman in antenatal care and regularly reported PMTCT program indicators through SIHA.

Data collection

PMTCT data of 6,502 HIV-positive women registered for antenatal care at 373 health facilities were extracted from SIHA. Types of PMTCT data extracted included the number of HIV-positive pregnant women: registered for antenatal care, eligible for antiretroviral treatment, started ARV treatment, still on ARV treatment, stopped ARV treatment, died on ARV treatment, and lost to follow-up for three months consecutively. Health facility characteristics were extracted from the Ministry of Health (MoH) report on data and information of Indonesian health profile 2017[7] as presented in Table 1.

Table 1. Characteristics of health facilities reporting PMTCT outcomes in 2017

Health Facility Characteristics	Category	n (%)
Type	PHC	71 (19%)
	Hospital	302 (81%)
Class	PHC and hospital class D	96 (26%)
	Hospital class C	119 (32%)
	Hospital class A and B	158 (42%)
Epidemic	Concentrated	339 (91%)
	Generalised	34 (9%)
Priority	Low	55 (15%)
	Medium	90 (24%)
	High	228 (61%)
Option	Other than B+	60 (16%)
	Option B+	313 (84%)

Outcomes and Variables

SIHA recorded women's retention for at least three months in the PMTCT program until childbirth.[6] In the Poisson regression analysis, the dependent variable women's retention was categorised into a dichotomic variable 'retained' (yes/no). Independent variables health facility characteristics (Table 1) were categorised as below:[8-11]

- Type of health facilities: primary health care centres (PHCs) or hospitals,
- Class of health services: hospitals providing broad specialist and subspecialist services (A) or limited subspecialist services (B), hospitals providing limited specialist and subspecialist services (C); hospitals providing general medical and dental services (D) or health centres providing basic general medical and dental services, health coaching and public health functions at sub-district level (PHC),[8]
- HIV epidemic based on WHO classification: concentrated (HIV prevalence over 5% in one or more defined subpopulations but among pregnant women is less than 1%) or generalised (establishment of HIV in the general population with HIV prevalence among pregnant women exceeds 1%),[9]
- HIV program priority: high (generalised epidemic or concentrated epidemic areas with more than 11,000 population living with HIV), medium (concentrated epidemic areas with between 4,000 and 11,000 population living with HIV, or low (concentrated epidemic areas with less than 4,000 population living with HIV,[10] and
- PMTCT policy: Option B+ (all HIV-positive pregnant women are eligible for ARV treatment) or other PMTCT Options (only pregnant women with advance clinical status are eligible for ARV treatment).[11]

In data analysis, we grouped several health facilities based on similarities in characteristics to meet the minimum sample requirement for conducting regression analysis. These combined categories were: hospitals type D and PHCs (both only provide general services), hospitals type C (provides subspecialized services), and hospitals type A and B (both offer specialized services).

Statistical analysis

Data analysis was conducted using IBM SPSS Statistics 24. Chi-square test was done for assessing differences between health facility characteristics and PMTCT retention. Poisson

regression was used to evaluate the associations of health facility characteristics: type of health facility, class of health facility, PMTCT Option, HIV epidemic, HIV program priority, and PMTCT retention. Results were statistically significant if the *p-value* is <0.05.

Patient and public involvement

We designed this study using participants' experience in the PMTCT programs in Indonesia. In interviews we conducted in 2016, HIV-positive women and health workers reported variations in PMTCT program deliveries between health facilities. We plan to disseminate the results to the policy makers, health workers, and HIV-positive women in a discussion forum.

Results

Women's enrolment in the PMTCT program

Among 6502 HIV-positive pregnant women, 2099 (32%) were ineligible for ARV treatment while 4403 (68%) were eligible for ARV treatment. Of eligible women, more than a quarter (1252) was referred out of the health facilities or the PMTCT program at childbirth. Therefore, their postpartum retention was not recorded in the PMTCT indicators. A small percentage of women (2%) died while on ARV treatment while 2610 (59%) retained in the PMTCT program for at least three months (Table 2).

As presented in Table 2, the majority of women (2517) retained in ARV treatment were in hospitals rather than in primary health centres (93). Of those women, 1874 (72%) were in class A and class B hospitals. Women living in a generalised HIV epidemic accounted for nearly 76% of women retained in the PMTCT program in 2017, while less than 10% (286) were from concentrated HIV epidemic areas. A larger proportion of women retained in the PMTCT program were located at health facilities within high priority areas for HIV program, 2152 (70%) and implementing Option B+ policy, 2637 (86%).

Women's retention was significantly different ($p<0.001$) with respect to type of health facility, class of health facility, HIV epidemic, and program priority.

Table 2. Comparison of health facility characteristics and PMTCT outcomes

Health Facility Characteristics	Category	Total Women (N)	Women Retained (n)	Women Retained (%)	P value
Type	PHC	157	93	59.2%	.000
	Hospital	2915	2517	86.3%	
Class	PHC and Hospital class D	283	193	68.2%	.000
	Hospital class C	693	543	78.4%	
	Hospital class A and B	2096	1874	89.4%	
Epidemic	Generalised	2691	2324	86.4%	.000
	Concentrated	381	286	75.1%	
Priority	Low	291	246	84.5%	.000
	Medium	628	529	84.2%	
	High	2153	1835	85.2%	
Option	Other than B+	435	388	89.2%	.504
	Option B+	2637	2222	84.3%	

Remark: *p* value <0.05 for statistical significance

Health facility characteristics and PMTCT retention

Health facility type, class, HIV epidemic, and HIV program priority were significantly associated with women's retention in PMTCT program (*p* value <0.05). In our model, secondary health care facilities (OR=2.88, 95%CI 2.19-3.79), facilities providing health services class A and B (OR=3.89, 95%CI 3.19-4.76), within generalised HIV epidemic areas (OR=2.09, 95%CI 1.83-2.38) and with high HIV program priority (OR=1.83, 95%CI 1.60-2.09) were more likely to have higher PMTCT retention scores (Table 3).

Table 3. Poisson regression analysis between health facility characteristics and ART retention

Health facility characteristics	Category	OR	95% CI	P value
Type	Hospital	2.88	2.19 – 3.79	.000
	PHC*	1	.	.
Class	Hospital class A and B	3.89	3.19 – 4.76	.000
	Hospital class C	1.46	1.18 – 1.79	.000
	PHC and hospital class D*	1	.	.
Epidemic	Generalised	2.09	1.83 – 2.38	.000

	Concentrated*	1	.	.
Priority	High	1.83	1.60 – 2.09	.000
	Medium	1.42	1.22 – 1.65	.000
	Low*	1	.	.
Option	Option B+	1.04	0.93 – 1.16	.504
	Non-option B+*	1	.	.

Remark: *p* value <0.05 for statistical significance. * references for the regression model

Based on these results, we concluded that 74% $((2.88)/(1+2.88))$ of women enrolled in the hospitals were more likely to continue in the PMTCT program until childbirth compared to women enrolled in primary health centres.

A higher probability of retention level was also shown by the health facilities providing health services class A and B than class D, with women who started PMTCT in class A and B facilities were 80% $((3.89)/(1+3.89))$ more likely to retain in the program.

Furthermore, women seeking treatment at health facilities where the HIV epidemic was generalised were 68% $((2.09)/(1+2.09))$ more likely to remain in the program than women in a concentrated HIV epidemic.

Medium to high HIV program priority was also associated women's retention in PMTCT programs, increasing the likelihood by 65% $((1.83)/(1+1.83))$ and 59% $((1.42)/(1+1.42))$ in comparison to women enrolled in health facilities with low program priority.

Discussion

Prevention of mother to child transmission of HIV remains a major public health challenge in less developed countries where multi-factorial issues influence retention and LTFU in PMTCT programs.

In this study, the level of retention in the PMTCT program for at least three months among 3,072 HIV-positive pregnant women until childbirth was 59%, lower than 70% retention of 1062 women reported in Uganda and much lower than 88% 6-month retention in a smaller study of 268 women in Cameroon.[12, 13] Women's retention postpartum in Indonesia might

be lower than 59% when the motivation to prevent vertical HIV transmission had decreased after childbirth, as reported elsewhere.[14]

A high percentage of women, 2099 (32%), were ineligible and therefore never started ARV treatment until childbirth, which imposes further perinatal HIV transmissions if the maternal viral load is high.[15] There were also 1252 (28%) HIV-positive women whose retention in ARV treatment were unknown due to transfer to other health facilities or childbirth. Previous studies reported a lower retention among women during transfer process and postpartum.[12, 16] These women were therefore at risks of transmitting HIV to their children if they did not continue their ARV treatment.

Our study found significant associations between health facility characteristics and women's retention in ARV treatment. Women were more likely to retain in the ARV treatment if they enrolled in the PMTCT program in hospitals rather than in primary health centres, particularly hospitals class A and B that were located in a generalised HIV epidemic area and had a high priority for HIV program.

Type of health facility. Our finding is that women were more likely to be retained in PMTCT programs based in specialized hospitals is consistent with a Haitian study that found women were less likely to be retained in primary health centres due to the poor quality of the services[17]. This is different from other studies in Swaziland and northeast Ethiopia,[16, 18] which found that women's retention in the PMTCT program was lower at secondary care facilities or hospitals. The difference might be explained by the reasons for women's low retention when these studies are compared with our study. In Southern Swaziland, women's attrition at the hospital was due to poor understandings of PMTCT long-term benefits for mothers and breastfeeding infants. Meanwhile, in Indonesia, this might be related to community stigma and discrimination toward HIV.[19] Primary health centres are usually located within the local community area while hospitals are mainly located in the district or city area, outside of the local community area. Consistent with a review of evidence related to PMTCT,[20] fear of stigma and discrimination in the community is one of the main reasons for LTFU in the PMTCT program in Indonesia and other countries including Mozambique.[19, 21]. Women reported that the risk of being identified as HIV positive by the community members was much higher if seeking care at the primary health centres, and therefore they were less likely to retain in the PMTCT.[19, 21] On the other hand, attending

the PMTCT program at hospitals minimised the risk of community stigma and discrimination, and therefore promoted a higher PMTCT retention.

Class of health facility. Overall the comprehensiveness of health services and capacity of health facilities is indicated by the class of health facility assigned by the Ministry of Health, the Republic of Indonesia. Type B and A are awarded to hospitals with more comprehensive health specialist and sub-specialist services, adequate human resources, medical equipment and infrastructure requirements including beds and building.[8] Both types are also education hospitals, and they receive PMTCT referrals from lower-class hospitals (C and D) and primary health centres.[22] This finding that the higher classes health facilities were more likely to retain women in the PMTCT program is consistent with other studies highlighting the positive impact of the bigger patient capacity of health facilities and adequate staffing on PMTCT retention.[12, 23]

HIV epidemic. Higher PMTCT retention was found in health facilities where the HIV epidemic was generalised. This result is consistent with a study of PMTCT in 23 countries where the PMTCT program was more successful in countries with generalised HIV epidemics.[24] Greater awareness and knowledge among the health workers and women about HIV and prevention of transmission from mother to child could explain higher retention in these regions.[19, 25] Also, HIV care for women in a generalized HIV epidemic area might be more intensive than for women in a concentrated epidemic area, which could result in better retention.[24]

HIV program priority. The classification of HIV program priority was based on the total number of HIV-positive people identified in a region, regardless of its epidemic. In this study, 13 regions were categorised as high priority HIV program areas, including Papua as the only region documenting a generalised HIV epidemic in Indonesia.[10] Our study found higher retention among women enrolled in health facilities where the HIV program was a high priority. This could be due to the Indonesian government's intensified effort to improve PMTCT services in targeted areas through training of health workers alongside the provision of free-of-cost HIV drugs.[11]

This study is the first to describe PMTCT program performance in Indonesia since its official implementation in 2010. This study is one of the very few quantitative studies investigating

associations between healthcare characteristics and women's retention in ART treatment in PMTCT programs. Our sample size of over 4,000 women who started ARV treatment is much larger than the samples of two previous quantitative studies on PMTCT retention.[12, 13] Moreover, this study has national coverage, which allows the generalisation of the results across the Indonesian context. And lastly, the use of regression analysis made it possible to identify the health facility characteristics associated with ART retention in Indonesian PMTCT programs.

However, we also acknowledge several limitations of our study that require further research. First, despite the large sample size of women in this study, our modelling did not include all possible confounding factors such as demographic characteristics of women and health workers, which is likely to be different in different parts of the country and contribute to the results in unknowable ways. As reported by a study in Uganda,[26] demographic factors such as younger age and lower education of the women contributed to higher LTFU in PMTCT programs.[27]

Furthermore, the use of routine PMTCT data collected by the Ministry of Health which is not designed for research purposes somewhat limited our options for analysis as several relevant, contextual healthcare-related variables such as the ratio between women and health workers, strategies implemented by the health facilities to ensure women's retention, external supports received by the health facilities to implement the program, or technical aspects of PMTCT monitoring, were absent.

Conclusions

Indonesia has increased its efforts to reduce transmission of HIV by making PMTCT programs available at many health facilities throughout the nation. Nevertheless, to eliminate new HIV infections in children, more efforts are needed to ensure the success of the PMTCT program. Future efforts need to more effectively promote HIV-positive pregnant women's retention in the PMTCT program until childbirth and postpartum, and a reporting system that incorporates women's retention after referrals and postpartum needs to be initiated. Routine data could also differentiate between referrals made by health workers and those made by women, along with the reasons for referrals. This information is essential considering a high proportion of women in our study (28%) were in this category. The national PMTCT

program might benefit from documenting strategies adopted by hospitals type A and B that were located in generalized HIV epidemic areas where HIV program was a high priority.

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Footnotes

Author contributions: Christina Lumbantoruan (CL) developed the study design and coordinated with the health government of the Republic of Indonesia for data collection. CL performed data cleaning, carried out data analysis and then drafted this manuscript. Margaret Kelahe, Michelle Kermode, Endang Budi Hastuti provided input for data analysis methodology and verified statistical analysis results, which were then revised by CL. All authors consented to the final version of the manuscript before submission to the publisher.

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Data availability statement: We have included all data relevant to the study in the manuscript.

CHAPTER 6

STUDY 3_

GLOBAL

Chapter 6 presents the results of the literature review on Option B+ PMTCT in resource-limited settings (Study 3_Global). This review achieved the second research aim to provide recommendations to improve women's uptake, adherence, and retention in Option B+ PMTCT in Papua. This Global Study addressed the fourth research objective by explaining the mechanisms that influenced the PMTCT outcomes and program contexts that triggered these mechanisms. This study used a realist synthesis approach that views Option B+ PMTCT as program theories consisting of Context-Mechanism-Outcomes Configurations.

Women's Uptake and Retention in Option B+ for Prevention of Mother to Child Transmission of HIV: A Realist Synthesis

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Abstract

Background: Option B+ was recommended by WHO in 2012 to escalate prevention of mother-to-child HIV transmission in resource-limited settings. This paper describes the initial assumptions/theories that justified recommendation of Option B+ and refined these using evidence reported in various studies following its implementation, by utilizing the realist evaluation approach. As relevant to the basic principles of realist evaluation, we aimed to identify mechanisms that trigger both positive and negative outcomes in different contexts. Hence, to provide feedback for program implementers in improving its field implementations and outcomes.

Methods: We searched five electronic databases and identified literature for initial theory development (before Option B+ implementation) and for testing and refining the initial theories (after Option B+ implementation). Regardless of study designs and outcomes, we included all Option B+ studies relevant to our study purposes: (a) description of Option B+ program in resource-limited settings, (b) motivators and barriers to PMTCT participation, (c) mechanisms triggered by different interventions in various contexts, (d) strategies to improve women's participation in PMTCT program, and (e) outcomes of different PMTCT interventions on uptake, adherence and retention. We conducted realist synthesis guided by RAMESES standards for theory development, data collection, data extraction, synthesis of the findings, and theory testing and refinement. We used a qualitative systematic review method to identify and explain the interaction between context, intervention, mechanism and outcome.

Results: 39 papers met our inclusion criteria. We identified three main theories that explain variations of outcomes in Option B+ implementation in different contexts. Positive outcomes are more likely to be achieved when health facilities implement interventions or strategies that support the delivery of a high quality Option B+ PMTCT services. High quality services

led to confidence of health workers and service users in the PMCT program, which increased uptake, adherence and retention.

Conclusions: Different interventions and strategies suit different health workers/women in different health facility settings. When designing or choosing interventions/strategies, program implementers need to take account of context and ensure that the program design will trigger necessary mechanisms to produce positive outcomes. We offer three refined program theories to aid program implementers to improve PMTCT performance.

Background

Rationale for review

Prevention of mother to child transmission of HIV (PMTCT) is a major public health challenge accounting globally for 160,000 children newly infected with HIV in 2016 [1]. HIV in children is associated with reduced life expectancy; fifty per cent of HIV-infected children will die by their second birthday if not treated [2]. To successfully eradicate MTCT, HIV-positive women are required to achieve at least 90% adherence to antiretroviral treatment (ART) during pregnancy and breastfeeding periods [2].

However, implementation of PMTCT programs in resource-limited settings is complex and challenging even after introduction of Option B+ policy in 2012 that recommends:

1. ART prescription which is “one size fits all” [3-5]
2. Elimination of the need for HIV staging through CD4 testing that was mandatory requirement in the previous PMCTC program Options [3-8].
3. Universal HIV testing and counselling (HTC) of all pregnant women as the main feature of Option B+ [9]. This means provision of HCT to all women visiting health

51 facilities for ANC or delivery care for the first time, and on subsequent visits for
52 women who previously tested negative. Health workers need to respond to all HIV-
53 positive test results by providing post-test HIV counselling that covers PMTCT
54 knowledge including Option B+ benefits and risks [10] and enrolling women in
55 lifetime ART on the same day.

56
57 Despite this recommendation, developing countries report low uptake and retention of
58 women in PMTCT services [11-17]. Adherence and retention in these services are keys to
59 successful PMTCT outcomes [18], without which viral load suppression will not be achieved
60 and drug resistance is likely to occur. Various studies have investigated factors influencing
61 women's uptake and retention in PMTCT programs , and identified lack of motivation or
62 readiness for lifetime medication [19], lack of belief in ART efficacy [19], fear of HIV status
63 disclosure [15, 20, 21], ART side effects [22], and health facility-related factors including
64 low ratio of health workers to women and long wait times [15, 21, 23, 24]. Strategies to
65 improve PMTCT uptake and retention have included use of mobile texting technology [25,
66 26], community-based interventions such as mobile clinics [27], and male partner
67 involvement [28, 29]. Despite this, there is limited explanation to inform both policy makers
68 and program implementers as to how and why Option B+ in particular results in variable
69 PMTCT outcomes such as uptake and retention.

70 71 *Objectives and focus of review*

72 To reduce vertical transmission of HIV, there is a need to understand why and how Option
73 B+ for PMTCT works or does not work for different women in different settings. The aim
74 of this review is to produce programme theories that identify various mechanisms influencing
75 women's uptake and retention in Option B+ for PMTCT.

76

77 A realist approach views outcome variations as products of different *mechanisms* activated by
78 an intervention in different contexts and for different people [30]. As defined by Pawson and
79 Tilley [31], context is the circumstances in which the program is introduced; some contexts
80 are supportive to the program and some are not. Mechanisms are the processes undergone by
81 those involved with a program when interpreting and responding to it, resulting in measurable
82 or observable outcomes. For example, mandatory HIV testing as a part of Option B+ package
83 (intervention) for all pregnant women visiting antenatal care in health facilities with
84 inadequate numbers of health workers to manage the consequent increase in workload when
85 more women enrolled in the PMTCT programs (context) triggered anxiety among health
86 workers (mechanism) that resulted in selective testing, which contributed to sub-optimal HIV
87 testing coverage among pregnant women (outcome). This example highlights how
88 understanding mechanisms is central to improvement of programme outcomes [32] including
89 Option B+ for PMTCT.

90

91

92 **Methods**

93 Realist synthesis was conducted following RAMESES standards for realists synthesis [33]
94 which consists of the steps outlined below:

95

96 *Rationale for using realist synthesis*

97 Realist synthesis is a systematic and theory-driven approach to understand the mechanisms
98 triggered by an intervention, taking into account differences in contexts and users. Instead of
99 classifying an intervention as ‘successful’ or ‘not successful’, it seeks to explain ‘what works
100 for whom, in what circumstances, in what respects, and how?’ [30]. The realist approach

utilises programme theories or hypotheses that articulate interactions between interventions, contexts, mechanisms and outcomes (CMOs) [34, 35]. This approach is appropriate as the review aims to uncover the mechanisms contributing to variations in women's uptake and retention (outcomes) in Option B+ for PMTCT (intervention) in various settings (contexts).

Scoping the literature

An initial exploratory scoping was conducted through reviews of all documents published in English pertaining to Option B+ for PMTCT prior to release of the official document from WHO in 2014. We decided to include comments, responses, discussions, and guidelines regarding Option B+ and exclude all studies on Option B+ implementation because the scoping review was intended to identify program theories underpinning and informing its design. Therefore, initial program theories consist of information on how the Option B+ for PMTCT intervention was expected to work or not to work before it was tested in the field [30]. Initial program theories were drawn from the literature through a deductive process [36].

Initial scoping of the relevant literature [3-7, 9, 10, 18, 21] resulted in three initial key theories of how the program was expected to work. A summary is provided in Table 1 and described in detail as follows:

- *Theory one maintains that in resource-limited settings (context) if Option B+ is optimally implemented (intervention) women are willing to attend PMTCT services (mechanism) that will result in improved PMTCT uptake and retention (outcomes). Optimal implementation consists of supportive and effective policies and guidelines for PMTCT-HIV care integration in maternal and child health (MCH) services,*

adequate numbers of trained health workers, functioning monitoring and supervision systems, continuous availability of PMTCT-related supplies, and a robust quality assurance system for HIV rapid testing [5, 9].

On the contrary, in a resource-limited setting in which the health facilities face implementation challenges such as inadequate supplies and human resource constraints (context), delivery of a sub-optimal Option B+ program (intervention) can result in women not being willing or able to remain in the system (mechanism), which may increase PMTCT uptake but not adherence and retention in the program (outcomes).

- Theory two is about women who can overcome factors that negatively influence them such as fear of HIV status disclosure and financial constraints (context) through a high-quality HIV post-test counselling provided by the health workers (intervention) which then improves women's readiness and motivation (mechanism) to initiate ART in accordance with PMTCT guidelines (outcome).
- Theory three relates to minimisation of existing and predicted barriers to uptake of the Option B+ program such as fear of side effects (context) using an effective multi-strategy approach adopted by the health facility (intervention) that increases women's and health workers' confidence (mechanism) which in turn improves uptake, adherence, and retention (outcomes) of HIV-positive women in the program.
- The multi-strategy approach consists of every strategy adopted by the health facility to ensure uptake, adherence and retention of women in Option B+. For instance, availability of support [5] particularly from peers [9], as peers share information on

how to achieve a lifestyle that helps reduce ART side effects and improves adherence by discussing the advantages peers have gained through participation in the PMTCT program. On the contrary, barriers such as transportation costs to clinic, stigma in the community leading to avoidance of HIV disclosure, food insecurity, and providers' attitudes towards HIV-infected pregnant women [37] (context) that are unmanaged in Option B+ implementation (intervention) created health workers' and women's uncertainties regarding women's capacity to adhere to the program (mechanism) and reduces women's uptake, adherence, and retention in PMTCT program (outcomes).

Table 1. Theories predicting program outcomes of Option B+ for PMTCT

Description		Theories related to Option B+ implementation
Theory 1	C	Limited resource setting
	I	Optimal Option B+ implementation
	M	Women's willingness to attend PMTCT services
	O	Increased uptake and retention
Theory 2	C	Factors that negatively influence women such as fear of disclosure and financial constraints
	I	High-quality HIV counselling to overcome these negative factors
	M	Women's readiness and motivation to participate are improved
	O	PMTCT uptake is improved
Theory 3	C	Barriers to Option B+ implementation such as medication side effects
	I	Multi-strategy program implemented such as peer support to manage medication side effects
	M	Increase women's and health workers' confidence
	O	Increased uptake, adherence and retention

PMTCT = Prevention of mother-to-child HIV transmission.

C = Context. I = Intervention. M = Mechanism. O = Outcome.

The realist synthesis: literature search, appraisal and extraction

Searching process

Consistent with realist review, iterative purposive literature searching was conducted until conceptual saturation was reached or until identification of all CIMO configurations. Electronic databases searched were ProQuest, PubMed, Web of Science, CINAHL and Google Scholar. Search results were managed using EndNote X8. The search was conducted using broad criteria “Option B+ AND PMTCT” (see Additional File 1) to capture literature relevant to the three theory areas.

Selection and appraisal of documents

This stage involved use of realist synthesis to systematically review evidence in the literature pertaining to the effectiveness of Option B+ programs that had been implemented and evaluated in a range of settings so that the theories implicit in the findings from the identified studies can be compared to the theories implicit in the Option B+ design and advocacy documents. Selection of literature used the following inclusion criteria:

- Women’s uptake and retention in Option B+ for PMTCT
- Strategies to improve women’s uptake and retention in Option B+ for PMTCT
- Barriers and facilitators to women’s uptake and retention in Option B+ for PMTCT
- Full text electronic documents, regardless of its publication status, on Option B+ for PMTCT in English and Indonesian language

First screening of title, abstract and keywords against inclusion criteria was conducted by one reviewer (CL). Results were recorded in an Excel document and then discussed with the other two reviewers (MK1, MK2) for consensus about inclusion. Final judgments made, and date of consensus were then also recorded. Using a similar process , re-screening for the purpose of data appraisal was conducted for full text articles meeting the two criteria below [30]:

- a. Relevant to at least one of the three theories being tested

- b. Rigour of studies was sufficient as assessed using critical appraisal checklists relevant to the quantitative study design in the research [38] and Guba's criteria for qualitative research [39]

Data extraction

Data extraction was conducted on documents that passed the full text screening using a data analysis matrix. As relevant to the three theory areas of Option B+ for PMTCT, data extracted consists of:

- a. Descriptions or details of Option B+ for PMTCT in different contexts
- b. Findings related to motivators and inhibitors for uptake and retention in Option B+ for PMTCT
- c. Explanations on how and why Option B+ for PMTCT work in particular contexts
- d. Information on strategies to improve women's uptake and retention and how they work
- e. Outcomes of different interventions on PMTCT uptake and retention

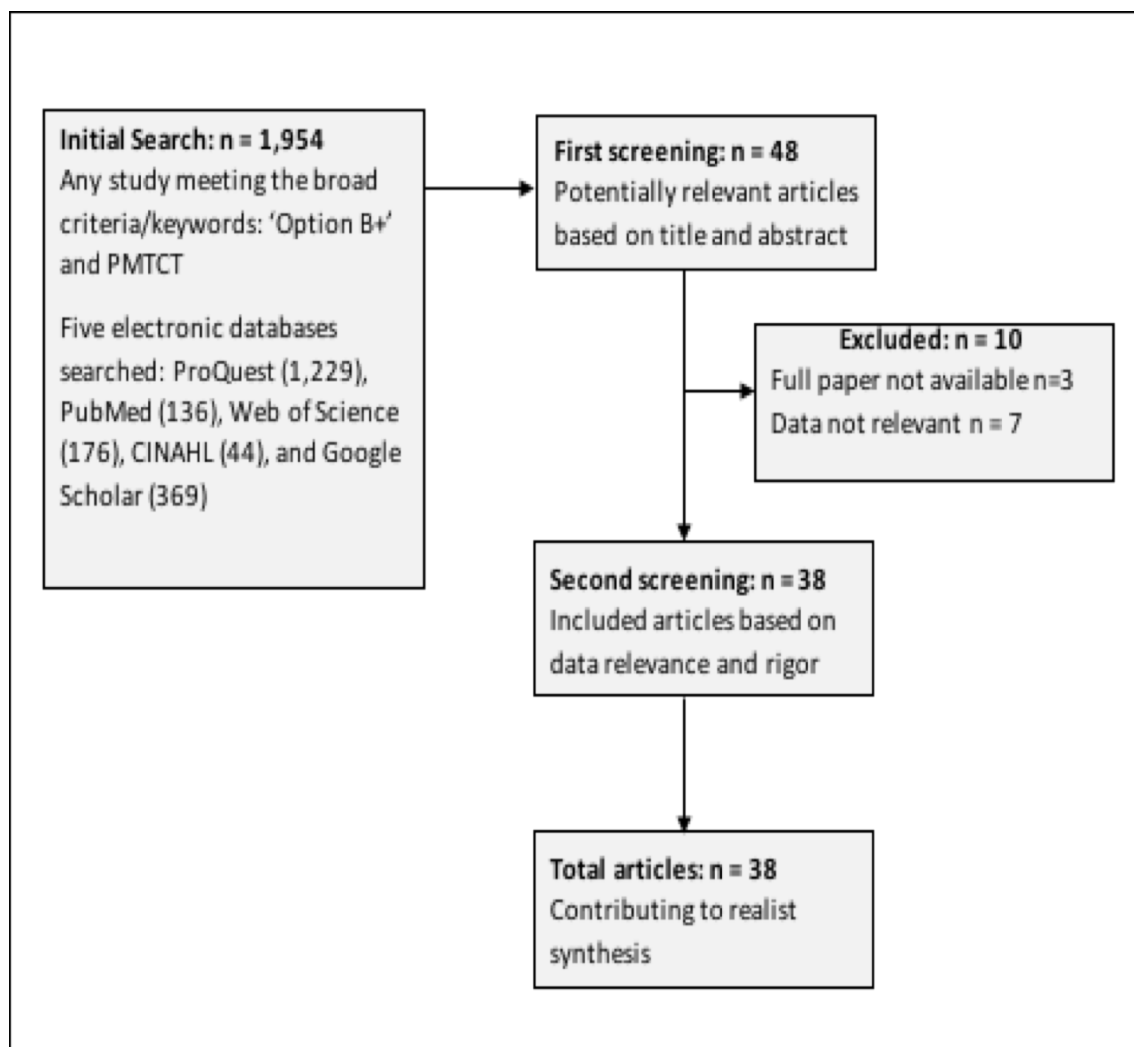
Analysis and synthesis processes CMO configurations were determined through identification of recurrent patterns in the data extracted from the literature, both confirmatory and contradictory findings. Data analysis and synthesis processes focused on identification of mechanisms that influenced the recurrent CMO patterns. The final program theories presented in the results section were the tested and refined forms of the three program theories identified in the initial scoping literature..

Results

Document flow diagram

A flow diagram presented as Figure 1 illustrates the search and process of selecting documents. The figure lists search result volume, number of data excluded or included, and judgement criteria for the decision made.

Figure 1. Flow diagram of document search and selection process



Document characteristics

We included 38 peer reviewed articles [28, 40-76] consisting of five randomized control trials, three mixed method studies, 9 qualitative studies, and 21 quantitative studies. Fifteen studies reported on health system preparedness, 22 studies explored women's factors associated with adherence and retention, and one study focused on male involvement in PMTCT. Additional File 2 summarises characteristics of included articles as well as two-stages of screening process and justification for each judgement. This file also demonstrates various mechanisms discussed by the authors of the paper to explain variable intervention outcomes.

Main findings

CMO configurations

Based on analysis of the 38 articles, we tested and refined the three initial program theories as below.

CMO1. In resource-limited settings (Context), an optimal Option B+ implementation (Intervention) result in health workers deliver high quality PMTCT services that women are willing to attend (Mechanism) increases women's uptake and retention in PMTCT program (Outcomes).

An optimal Option B+ implementation means fulfilment of WHO requirements for Option B+ implementation which involves health system preparedness including availability of high quality program supplies, effective PMTCT strategies in place such as an integrated ANC-ART service, supportive PMTCT policies and management, and adequate numbers of qualified health workers [5, 9].

Of the 38 articles included, fourteen studies [40, 45, 46, 49-51, 53, 61-64, 72, 76, 77] discussed three intervention characteristics related to health system preparedness and its impact on PMTCT outcomes in Option B+. These are: sense of ownership that resulted in improved linkage and better coordination between ANC/MCH and ART clinics [45, 53], a clear system of monitoring [46, 50], and supportive supervision [46] of health workers in implementing Option B+.

Sense of ownership that resulted in improved linkage and better coordination is realised by integration of ANC-ART or MCH-ART service delivery, which results in improved PMTCT uptake [53] and 18 months postpartum retention [45]. These studies found integration of ART and ANC/MCH was simpler and more effective for both health workers and women than if mother-infant pairs visited different clinics for HIV services.

Clarity of monitoring system is linked to the availability of clear standard operational procedures (SOPs) enables health workers to follow necessary steps to ensure women's adherence [50] and reduce early attrition [46] in PMTCT program. Both studies utilised SOPs to regulate various steps that need to be followed by health workers including referral process, topics of HIV counselling, appointment tracking, and dealing with missing appointments.

A supportive supervision system [61, 63, 64, 72] following provision of adequate trainings will contribute to the delivery of high quality services (intermediate outcome), which in turn promotes uptake, retention and adherence in PMTCT program (final outcome). Supervision is important in Option B+ as health workers' level of knowledge, training and experiences

influences their capacity to follow the guidelines. As described in a randomized control study [50], supportive supervision assisted health workers to manage their workload, which enabled them to monitor and follow-up patients, which in turn increased women's retention in the program.

On the contrary, in resource-limited settings (Context), delivery of poor quality PMTCT services due to a sub-optimal Option B+ implementation (Intervention) deters women from continuing to participate in the program (mechanism), which reduces uptake and retention in PMTCT program (Outcomes).

We found nine studies that documented improved linkage to PMTCT [28, 50, 53, 55, 58, 59, 68, 69, 74] but also high loss to follow-up (LTFU) rates [28, 50, 58, 59, 68, 69, 74] and low adherence postpartum [55]. These studies showed significant increases in women's access to PMTCT from 26% to 90%. However, LTFU ranged between 20% and 36%, with adherence at 12 and 18 months postpartum was only around 20%.

The implementation of Option B+ has considerably improved HIV testing and PMTCT enrolment as documented in included studies. HIV testing is the first step in the PMTCT cascade. The Option B+ guidelines require all women visiting the health facility to be tested for HIV. Though better than in previous options, studies still report gaps in HIV testing [53, 59] and PMTCT enrolment with Option B+ [53, 59]. Implementation of Option B+ at health facilities with human resource constraints and/or lack of program supplies (Context) caused health workers' anxiety about offering HIV testing to all women (mechanism) which resulted in HIV testing gap (Outcome) [53].

Option B+ implementation was therefore not supported by adequate interventions to create a facilitating context such as ineffective PMTCT strategies, health workers' lack of skills to implement the program, lack of infrastructure (such as no private space for counselling), absence of clear SOPs, and weak monitoring systems [40, 44, 49]. For instance, a study in Zambia reported on a PMTCT strategy of allocating a separate day for HIV+ mothers and infants (Intervention) [76] in order to deal with infrastructure and human resources constraints (Contexts). However, this strategy actually reduced accessibility of the service (Mechanism) and resulted in attrition of women who could not attend on the allocated day (Outcome) [70].

In addition, five studies [50, 59, 63, 65, 76] that implemented Option B+ (Intervention) where there were health worker shortages and lack of skills (Context) resulted in missed opportunities to provide services for women throughout the PMTCT cascade (mechanism). Hence, lower uptake and retention in the program (Outcome).

CMO2. In resource-limited settings (Context), high quality HIV counselling provided by health workers to all women following an HIV positive diagnosis (Intervention) increases women's readiness and motivation (Mechanism) to participate in the program which then improves women's uptake and retention in PMTCT program (Outcome).

The second hypothesis emphasized the importance of a high quality HIV post-test counselling provision to all women testing positive for HIV (Intervention) to improve women's motivation to prevent HIV transmission to their unborn babies [52] and for their own health [69] (Mechanism), which increased their participation in the PMTCT program (Outcome) [52]. However, a study in Malawi found that asymptomatic and healthy women's

motivation to uptake PMTCT was lower compared to symptomatic women [69]. Nonetheless, belief in ART efficacy that could result from witnessing others' improved health outcomes with Option B+ became an important mechanism for PMTCT enrolment [65] and retention [42] for both asymptomatic and symptomatic women [41].

While PMTCT enrolment on the same day of diagnosis is a main feature of Option B+, there were concerns from both health workers and women regarding the short period of time given between accepting HIV status and starting PMTCT [52, 69]. Hence, in some cases, women who were provided with PMTCT initiation on the same day of HIV diagnosis (Intervention) were more motivated by the desire to protect the baby instead of the long-term benefit after childbirth and during breastfeeding (Mechanism) [47, 52]. Lack of privacy in HIV counselling (Intervention) due to infrastructure limitations (Context) reduced HIV counselling effectiveness (Mechanism) [76] resulted in delays of PMTCT uptake for some women (Outcomes).

CMO3. To minimize existing and anticipated barriers to Option B+ (Context) requires an implementation of an effective multi-strategy at the health facility (Intervention) which will increase health workers' and women's confidence (Mechanism) that increases women's uptake and retention in the program (Outcomes).

Multi strategy refers to every approach implemented at the health facility to ensure uptake, adherence and retention of women in Option B+ such as support, mobile texting technology, community-based interventions such as mobile clinics, and male partner involvement. We found that support from partners, family members, peers, friends, or other community members is an important factor contributing to women's willingness to enrol and remain in

the Option B+ program, which requires personal and financial commitment. The absence of this support can contribute to ART discontinuation or non-adherence [54, 70, 74, 75]. Support is a complex matter that connects to other factors influencing uptake and retention in Option B+ programs such as HIV status disclosure, HIV stigma, and relationship quality [48, 57].

HIV status disclosure is the first step to attaining support from partners, family members, peers, friends, or other community members. Following disclosure of HIV status, the support provided is dependent on the receivers' responses and actions. In some cases, disclosure results in positive support, while in others it results in domestic violence and stigma. Hence, women who anticipate negative consequences in the existing relationship following disclosure usually delayed disclosure or do not disclose at all. Furthermore, they are more likely to be LTFU in their effort to conceal their HIV status, or due to lack of necessary support [54, 56, 57].

Several studies demonstrated an unsupportive environment as a barrier to retention for some women [52, 57, 65, 70, 74]. For instance, stigmatizing behaviours of other family members (Context) in Option B+ for PMTCT (intervention) discouraged women to seek care (Mechanism) and resulted in a few women discontinued PMTCT or dropped out of ART (Outcome) [59, 70]. A popular programmatic strategy to address this barrier is provision of couple HIV counselling and testing to increase chances of attaining partner support [28] by promoting women-partner mutual awareness of the importance of the program and supportive behaviours (Mechanism).

375 Considering those negative impact of barriers on women's uptake and retention in the
376 program, lack of confidence in effectivity of multi-strategy implemented at the health facility
377 to address those barriers therefore resulted in women's lower uptake and retention in the
378 program.

379
380 On the contrary, the presence of unmanageable barriers (Context) that are not resolved
381 through Option B+ strategies adopted by the health facilities (Intervention) create
382 uncertainties among women and health workers regarding the effectiveness of PMTCT
383 program (Mechanism), which contributes to reduced uptake, adherence, and retention
384 (Outcomes).

385
386 The counter hypothesis refers to other barriers such as treatment side effects that are not
387 addressed by the multi-strategy approach adopted by the health facility. In previous PMTCT
388 options (prior to Option B+), side effects were more bearable because of their short-term
389 duration, however, they are more challenging when contemplating a lifetime on ART [70, 74,
390 75]. Moreover, feeling unwell due to side effects (Context) also reduced women's belief in
391 ART efficacy (Mechanism) [70] which reduced women's adherence and retention in the
392 program (Outcomes).

393
394 In addition, demographic characteristics of the women were found to contribute to retention
395 and adherence. Younger women were more vulnerable to ART attrition [50, 58, 74], while
396 women with a higher education level were more likely to be retained in the program [68].
397 However, none of the studies explained the mechanisms underlying the influence of age and
398 education.

Discussion

Summary of findings

There was some evidence to support the three programme theories of Option B+ for PMTCT that explained the underlying mechanisms contributing to different outcomes for different women. The realist synthesis approach helped to provide a clearer description of interconnections between mechanisms and outcomes. For instance, lack of privacy due to limitation of rooms (theory one) reduced the quality of counselling (theory two), which was important for better uptake of PMTCT. Furthermore, women's adherence to ART and retention in the PMTCT program were somewhat influenced by the health system preparedness (theory one), quality of HIV counselling (theory two), availability of personal supports (theory three) to overcome uncertainties (theory three) related to barriers in Option B+. Hence, there is a need for a multifaceted approach to address various issues in PMTCT implementation in order to improve its outcomes.

We also found that the evidence was somewhat variable. For instance, while the presence of certain mechanisms such as partner support helped to promote women's retention, some other women still discontinued their treatment regardless of a supportive partner. This suggests that, some women may require more extensive support or other barriers remain influential despite the fact that they have partner support. Also, further studies are needed to better understand women's decision making regarding PMTCT, given the variability within the same setting.

Implications of the findings

This review highlights the importance of *high quality services* (theory one) for successful implementation of Option B+, and its influence on outcomes linked to the other two theories.

A high-quality service requires health system preparedness from infrastructure such as availability of rooms for counselling, logistics, policies/guidelines, multi-strategy to address barriers, to human resources' availability and quality. While it may not always be possible to build new infrastructure or to recruit additional health workers, a few studies highlighted the benefit of some PMTCT strategies [50, 76]. For instance, clear SOPs, supportive supervision, and capacity building increased health workers' skills to implement a better quality program.

In addition, program implementers need to be aware of the fact that different women will be affected differently by the strategies implemented [70]. As explained by the realist view, a program will never work the same for all people in every circumstance. Hence, each health facility needs to identify types of women negatively-affected by certain strategies, and tailor specific intervention for them. For instance, for women who were LTFU because they were not able to return on PMTCT days, discussion on the return visit schedule and possible barriers might result in better outcomes.

As expected, Option B+ implementation has successfully scaled up women's access to and uptake of PMTCT [52, 61, 63-65, 72]. This was mainly due to universal and "same day" HIV testing and treatment. However, studies have highlighted several issues related to "same day initiation" that need further discussions and research. The purpose of "same day initiation" in Option B+ was to prevent missed opportunities for PMTCT enrolment, and it resulted in immediate enrolment of women in PMTCT. Some of these women embarked on a lifetime ART when they were not ready for it or had not had time to fully accept their HIV status [52,

69]. To ensure retention, there is a need to address issues surrounding readiness for lifelong treatment and acceptance of HIV status. A few asymptomatic women mentioned that positive results from repeated testing finally helped them to accept their status. Hence, this could be a promising strategy to speed up HIV status acceptance for healthy women.

Women's readiness for lifetime ART was influenced by various factors from perceived or actual availability of partner and family supports needed for retention in ART, their capacity to manage anticipated challenges, as well as other individual factors including women's level of motivation to enrol in PMTCT. High-quality counselling was found to be an important aspect across the PMTCT cascade as counselling plays a role not only in influencing women's participation in PMTCT [52, 69, 76] but also in the mobilisation of various supports by preparing the women for HIV status disclosure to others, or through direct interventions such as couple counselling [28]. Some women also recognised the benefit of counselling in the management of side effects, which further resulted in retention instead of LTFU. This indicates the need to strengthen the quality and continuity of HIV counselling in PMTCT program to help women manage challenges that arise over time.

Lastly, due to variability of evidence, we recommend the need for further studies to understand phenomena surrounding women who are retained even though they are experiencing barriers to the PMTCT program, and those who discontinued when they had the support of partners and/or family.

Strengths, limitations and future research

We conducted a realist review to identify and describe mechanisms that influence women's uptake and retention in Option B+ for PMTCT. However, we found that most studies were not using a realist approach and therefore rarely explained the mechanisms that influenced the study outcomes in different contexts. Through the use of the RAMESES publication standard was useful in guiding the whole review process, and we successfully identified CMO configurations to test and refine the three theories from the existing literature. The limitation of the study includes lack of literature to explain a few aspects of theory two which require more information regarding earlier PMTCT options which were beyond of our current scope. Nonetheless, to our knowledge, this document has reached conceptual saturation based on available literature on Option B+ for PMTCT.

Comparisons with existing literature

Realist synthesis is a relatively new approach that is recommended for evaluation of a complex intervention such as Option B+ for PMTCT. This document is the first to utilise realist approach to develop, test, and refine Option B+ theories. Also, this is the first document that systematically review Option B+ for PMTCT. Hence, we were unable to compare this review results with other reviews of similar topics.

Conclusions and recommendations

This realist review covers existing evidence on Option B+ for PMTCT in resource-limited settings. The main challenges in PMTCT implementation in resource-limited settings include poor quality of PMTCT services in Option B+, and lack of effective strategies to manage health system limitations and their negative influences for certain women. This realist document presents various CMOs that signpost strategies for improvement of Option B+

implementation, until future studies present new evidence on other more effective approaches. This review also highlights the need for further research to better understand mechanisms that contribute to retention in the Option B+ program in the presence of barriers, or women's treatment drop out in conducive environments. Understanding these mechanisms will be useful when developing new evidence-based PMTCT strategies.

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and material

The datasets supporting the conclusions of this article are included in this article and its supplementary information file.

Competing interests

We declare that we have no competing interests.

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Authors' contributions

CL initiated the review and conducted the two-stages of selection process. MK1 and MK2 reviewed the selection process and finalised the review results with CL. CL drafted and finalised the manuscript. MK1 and MK2 reviewed and commented on the draft manuscripts. All authors have read and approved the final manuscript.

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Additional material

Additional File 1.docx: **Search links**. Additional File 1 contains the search keywords and results for the five databases used.

Additional File 2.xlsx: **Summaries of characteristics of included articles including the two-stages of screening process**. Additional File 2 summarises the study designs, the interventions, and various mechanisms to explain variable PMTCT outcomes.

Additional File 3.docx: **The RAMESES publication standards for realist synthesis**.

Additional File 3 contains the RAMESES publication standard for realist synthesis and the location of each publication criteria in the paper.

CHAPTER 7

DISCUSSION

Option B+ PMTCT was introduced in Papua in 2012. To date, there have been limited studies about the performance of Option B+ PMTCT in Papua and factors that influence Papuan women's uptake, adherence and retention in the program. This thesis aims to address these gaps in the literature. Chapter 7 describes the principal research findings of each of the studies: enablers and barriers of ART uptake and adherence, performance of Option B+ PMTCT in Papua, health facility characteristics associated with ART retention, and configurations of CMOs that influenced outcomes of Option B+ PMTCT. This is followed by a critical evaluation and interpretation of these findings. Recommendations to improve Option B+ PMTCT in Papua are then discussed. Finally, this chapter highlights the research strengths and weaknesses, and future research implications.

7.1. Principal findings

To our knowledge, this was the first study that explained factors that influence women's uptake and retention in Option B+ PMTCT across three levels of study: regional level (Study 1_Papua), national level (Study 2_Indonesia), and resource-limited settings level (Study 3_Global). Study 1_Papua identified the enablers and barriers for women's participation in Option B+ PMTCT in Papua using a socioecological framework. Study 2_Indonesia described PMTCT outcomes and health facility characteristics associated with women's retention in Indonesia and Papua. Study 3_Global explained how those factors influenced women's retention in Option B+ PMTCT using a realist synthesis approach of program

theories, consisting of CMO configurations. These program theories explained mechanisms that increased women's retention in Option B+ PMTCT through manipulation of program contexts. Study 3_Global further classified factors identified in Studies 1 and 2 as either contexts or mechanisms to explain how Option B+ PMTCT worked and could be improved in Papua.

7.1.1. Enablers of and barriers to ART uptake and adherence

In Study 1_Papua, the socioecological framework demonstrated the roles of individual, interpersonal, institutional, community, and policy-level factors in women's uptake and adherence in Option B+ PMTCT in Papua. Several enablers and barriers were identified across the five-levels of the socioecological framework.

The key enabler was high -quality HIV counselling (institutional level), which improved women's understanding of HIV disease (individual level) and belief in the efficacy of ARV to prevent perinatal HIV transmission (individual level). Partner support (interpersonal level) was an important enabler for women, but the types of support needed varied between women. For financially dependent women, partner support was related to economic enablers of treatment such as transportation costs. For women who were financially independent, partner support was related to socio-psychological aspects, for example, allowing women to return to health facilities to receive ART. At the health facilities (institutional level), women were more likely to uptake and adhere to ART if there was no stigma and discrimination from the health workers, and there was a positive women-health worker relationship. Implementation of free HIV services (policy level) was also reported as an enabler of women's participation in the Option B+ PMTCT program in Papua.

The key barriers resulting in non-adherence to the PMTCT program were stigma and discrimination (community level) and women's lack of belief in the ability of ARV to prevent MTCT (individual level). Stigma and discrimination (community level) were the most common barriers to Option B+ PMTCT reported by women who did and did not adhere to the ART. Even among women who were strongly motivated to seek ART (individual level), community stigma and discrimination resulted in women seeking treatments at health facilities that were far from their homes. Some of these women missed their ART appointments due to increased transportation costs and travel distances. Less motivated women discontinued ART because of community stigma and discrimination. Meanwhile, doubts about ARV efficacy to prevent MTCT were more common among asymptomatic women due to the lack of immediate and visible treatment benefits on their physical health. The presence of ARV medication side effects in the first weeks of ART was often confused as signs of 'decreasing' instead of 'increasing' health conditions.

Comparison with previous studies

Factors that influenced women's uptake and retention in Option B+ PMTCT in Papua (Chapter 4, Papua Study) corresponded with the findings of previous studies in resource-limited settings [136, 154, 157-161]. In Papua, women's uptake and retention in Option B+ PMTCT were influenced by interactions of several factors at the individual, interpersonal, institutional, and community levels.

Individual factors that promoted uptake and retention in Option B+ PMTCT in Papua were women's understanding and belief in the benefit of ART as the result of high-quality, post-test HIV counselling [152]. The vital role of post-test HIV counselling in Option B+ PMTCT

was reported in previous studies [157-160]. High-quality HIV counselling improves women's knowledge and understanding of HIV disease and its treatment.

Interpersonal factors, such as partner support, were also influential to the success of Option B+ PMTCT in Papua. This is consistent with previous study findings [157-160]. In the Papua study, this factor was more prominent among women who were dependent on financial support from their partners than among women who had another source of income [152].

Institutional factors, including health workers' effective communication skills, confidentiality, and care free from stigma and discrimination at the health facilities, increased women's uptake and retention in Option B+ PMTCT in Papua [152]. These results are similar to previous study findings in sub-Saharan Africa and Malawi studies [136, 154].

Community factors that greatly influenced women's uptake and retention in Option B+ in Papua included community stigma and discrimination [152]. This finding was consistent with the result of a global review of evidence related to PMTCT programs that reported stigma and discrimination as barriers to women's participation in the PMTCT program [161]. In Papua, community stigma and discrimination resulted in women seeking care at health facilities outside of their neighbourhood, which resulted in unnecessary burden, including increased travel distance and costs of transportation [152].

Policy factors related to free-of-cost HIV care were rarely mentioned in the interviews most likely because it has been a part of Papua's Health Scheme for all diseases, not only to HIV [152]. Some women reported lack of socioeconomic support as the reason for not adhering to ART, since this policy covers HIV care such as medicines and diagnostics but not transportation costs to return to health facilities for ART.

7.1.2. Health facility characteristics and ART retention

The findings of Study 2_Indonesia showed high ART uptake (98% vs. 95%) but low ART retention (33% vs. 59%) in Papua and Indonesia, respectively. Retention in this study refers to three months' retention in ART. ART retention status was unknown for a high proportion of women in 2017: 49% in Papua and 28% in Indonesia. Several health facility characteristics were associated with women's retention in the PMTCT program in Indonesia and Papua: type of health facility (secondary health facilities), class of health services (hospital class A/B), HIV epidemic (generalised), and HIV program priority (high or medium). The study did not find any significant differences in retention of women in ART between health facilities implementing Option B+ and other Options.

Comparison with previous studies

Health facility characteristics (Chapter 5, Indonesia study) that increased women's uptake and retention in Option B+ PMTCT included type of health facility (secondary care facility), class of health services (Class A or B), HIV epidemic type (generalised), and HIV program priority (high). The following paragraphs discuss comparisons between these health facility characteristics and previous studies.

Study 2_Indonesia found that hospitals (secondary health facilities) retained more women in ART than primary health centres (primary health facilities). This finding contrasts with the results of previous studies conducted in Swaziland and Ethiopia, where women were more likely to be retained by primary health facilities [26, 162]. The difference is likely to be attributed to community stigma and discrimination in Papua, which leads women to seek ART in primary health facilities located away from their neighbourhood. As reported in a

Mozambique study [163], community stigma and discrimination were the main reasons for low ART retention among women in Option B+ PMTCT.

PMTCT services provided by hospital class A/B (as opposed to hospital class C/D or PHCs) were a significant predictor of women's uptake and retention in Option B+ PMTCT in Papua. This concurred with a previous study in Malawi that highlighted the positive impact of bigger health facilities with more adequate staffing on retention [21]. As described in Chapter 3, hospital class A/B in Indonesia is characterised by the availability of more comprehensive health services, a higher volume of health workers, advanced medical supplies and equipment, and a higher patient capacity [146].

Generalised HIV epidemic areas were also significantly associated with women's retention in Option B+ PMTCT in Papua. This finding is similar to that reported in a study involving 23 countries, whereby women in generalised HIV epidemic areas were more likely to adhere to ART due to more intensive treatment and care [164]. Generalised HIV epidemic areas have a higher percentage of people infected with HIV than concentrated areas, thus health workers are more likely to have a higher awareness and knowledge of the importance of retaining women in the program to reduce HIV transmissions [152, 165].

HIV program priority, determined by the number of people infected by HIV in a province, also predicted women's uptake and retention in Option B+ PMTCT in Papua. Papua is a high priority area for intervention given its high HIV prevalence. In high priority areas, health government bodies (i.e., Ministry of Health, Provincial Health Offices, and District Health Offices) provide more intensive training to health workers and closely monitor PMTCT outcomes at health facilities as part of the national response to the generalised epidemic.

7.1.3. Context-mechanism-outcome configurations and desired PMTCT outcomes

Using a realist synthesis approach, Study 3_Global developed, tested, and refined three key CMOCs to produce desired PMTCT outcomes in resource-limited settings. Enabling program contexts creates certain mechanisms to ensure women's ART uptake, adherence, and retention in Option B+ PMTCT. The mechanisms identified included: women's willingness, readiness and motivation to participate in Option B+ PMTCT; and health workers' and women's confidence in the PMTCT program. The relationships between enabling CMOs in Option B+ PMTCT were described using the three CMOCs, as detailed below.

CMOC-1. Implementation of high-quality services (context) increases women's willingness (mechanism) to uptake and retain in Option B+ PMTCT (outcomes).

High-quality services are enabling environments that stimulate women's willingness to uptake and adhere to Option B+ PMTCT. The quality of services are influenced by availability of resources and health system preparedness to deliver Option B+ PMTCT through three key mechanisms:

- a. Improved linkage and better coordination between health workers and various clinics involved in women and children's health including ANC, MCH, and HIV clinics.
- b. Clarity of monitoring systems related to PMTCT programs in clinics involved in women and children's health. Monitoring systems include internal and external referral processes, adherence counselling, and appointment management (such as dealing with missing appointments).
- c. A supportive supervision system that ensures health worker capacity to implement the program according to the WHO guideline, and skills to manage their workloads while providing client-oriented PMTCT services.

Consequently, poor quality PMTCT services will discourage women's uptake and retention in Option B+ PMTCT.

CMOC-2. Provision of high-quality HIV counselling (context) increases women's readiness and motivation (mechanism) to uptake and retain in Option B+ PMTCT (outcomes).

High-quality HIV counselling is an enabling environment, which influences women's readiness and motivation to uptake and retain in Option B+ PMTCT. Women who were motivated to improve their personal health (long-term goal) were more likely to uptake and adhere to lifetime ART than women who focused on their infant's health (short-term goal). Furthermore, women with doubts about the efficacy of ART were less likely to adhere to Option B+ PMTCT. As such, HIV counselling plays a vital role in improving women's readiness and motivation to uptake and adhere to Option B+, while managing doubts related to ART efficacy. When the quality of HIV counselling was compromised due to a lack of privacy and health worker skills, women were less likely to uptake, adhere, and adhere to Option B+ PMTCT.

CMOC-3. Availability of effective strategies to address current and future barriers (context) increases health workers confidence (mechanism) to deliver the services (outcome) and women's confidence (mechanism) to uptake and adhere to Option B+ PMTCT (outcomes).

Effective strategies are enabling environments that increase health workers' confidence to deliver Option B+ PMTCT and women's confidence to uptake and adhere to the program. As

explained below, each strategy relates to multiple PMTCT barriers; therefore, all related barriers should be considered to ensure effectiveness of the strategies.

For instance, one of the effective strategies to increase ART uptake and retention among financially dependent women is the availability of socioeconomic support from a partner, family members, peers, friends, or other community members. This strategy is dependent on HIV status disclosure, which is most likely to occur in an environment free of stigma and discrimination. This means attainment of socioeconomic support is an effective strategy only if HIV status disclosure is likely to result in attainment of support instead of stigma and discrimination. Health workers are more confident initiating financially dependent women into ART if socioeconomic support is attainable.

Peer support is another effective strategy for increasing ART retention among asymptomatic women experiencing ART side effects. This strategy is related to sharing experiences from peers who have experienced ART side effects but have successfully passed that stage. Peer support is also dependent on HIV status disclosure from women to peers. It is an effective strategy if women are willing to disclose HIV status to receive peer supports for the management of ART side effects, which leads to an increase in the confidence of the women experiencing side effects to adhere to ART.

Comparison with previous studies

Enabling mechanisms (Chapter 6, Global study) to increase women's uptake and retention in Option B+ PMTCT in resource-limited settings such as Papua included: women's willingness to participate in the Option B+ PMTCT program; readiness for a lifetime of ART; motivation to participate in the PMTCT program; and confidence among health workers and women in the PMTCT strategies. This study was the first to investigate women's uptake and retention

in Option B+ PMTCT using a realist synthesis approach with CMOCs. Given that the contexts and outcomes are consistent across the program theories, the study comparisons focused on the mechanisms component of the program that determined women's uptake and retention in Option B+ PMTCT, instead of on the configurations of CMOCs. The mechanisms are described below.

Willingness. Study 3_Global found that women's willingness to uptake Option B+ PMTCT was influenced by the quality of PMTCT services at the health facilities. The quality of PMTCT services measured through health system preparedness was documented in previous studies as a motivator for women's uptake and retention in Option B+ PMTCT [13, 166]. Health system preparedness aspects found in this study included integration of ANC/MCH and ART clinics to improve linkage and coordination [155, 167], a clear monitoring system [168, 169], and supportive supervision [169].

Readiness. Option B+ PMTCT resulted in immediate enrolment of women in ART as soon as they were diagnosed with HIV. Despite this, some women may not be ready to adhere to a lifetime of ART. This finding is consistent with previous studies [136, 137], in which a lack of readiness for lifetime ART compromised women's retention in Option B+ PMTCT.

Motivation. Findings related to the influence of motivation on women's uptake and retention in Option B+ PMTCT were documented in previous studies [136, 137]. These include lack of motivation for asymptomatic women, or short-term motivation to prevent MTCT but no long-term motivation to improve personal health. Consistent with previous study findings [136], this study found that women were more likely to retain in Option B+ when motivated by their own personal health. Infant health motivated women to uptake ART up until childbirth; however, it did not result in women being retained in ART after the child was born.

Confidence. In this study, confidence refers to certainty among women and health workers in women's retention in Option B+ PMTCT based on their assessment of available strategies. These strategies include ensuring availability of HIV-related logistics (health facilities), skills to deliver the PMTCT program (health workers), socioeconomic support (women), management of stigma and discrimination (health facilities, community, family), and confidentiality of HIV status [13, 166].

7.2. Interpretations and implications

The findings contributed to the overall study aims to describe the performance of Option B+ PMTCT in Papua; to identify factors that influenced Papuan women's uptake, adherence, and retention in the PMTCT program; and to provide recommendations to improve the PMTCT program implementation.

The use of a mixed-method research design enabled data triangulation across the three studies. All three studies identified a wide range of factors that facilitated or hindered women's uptake, adherence, and retention in Option B+ PMTCT in Papua. Study 1_Papua highlighted that facilitating factors (HIV counselling, women's belief in ART efficacy, partner support, absence of stigma at the health facilities, positive health worker-women relationships, and free-of-costs HIV services) increased women's uptake and retention in Option B+ PMTCT. Study 2_Indonesia showed low ART retention (33%) in Option B+ PMTCT in Papua and quantified its relationships with health facility characteristics (hospitals, hospital class A/B, generalised HIV epidemic area, and high HIV program priority). Study 3_Global identified three main mechanisms that influence women's uptake, adherence, and retention in Option B+ PMTCT, which were related to the quality of PMTCT services such as HIV counselling and effectiveness of PMTCT strategies at the health

facilities. The contexts and mechanisms in Study 3_Global are reflective of factors identified in Studies 1 and 2.

The section below discusses the interpretations of the key findings related to “stigma and discrimination” and “high-quality services” in the PMTCT program in Papua. This section also consists of comparisons between the local evidence in Papua against the national and international evidence on PMTCT program.

7.2.1. Interpretations of key findings on Option B+ PMTCT in Papua

The key findings were classified into two parts: stigma and discrimination, and high-quality HIV services. The first part focuses on the lack of accurate knowledge about HIV as the main factor for high stigma and discrimination in the community and health facility. The second part discusses aspects that influence high-quality PMTCT services.

Stigma and discrimination

Indigenous Papuan women reported HIV-related stigma as the major barrier to women’s engagement in the PMTCT program in both the lowlands [152] and highlands [20, 43] of Papua. In further investigation, stigma in the community was more prominent in Jayapura [152] and Wamena [20], while stigma at the health facilities was an unresolved issue in Yahukimo [43]. In the classification of Papua districts and cities according to its landscape (page 31-32), Wamena and Yahukimo are highlands while Jayapura is lowland. HIV-related stigma from community and health worker differs across highlands and lowlands because of the data collections period. Data were collected in 2011 in Yahukimo, 2014 in Wamena and 2016 in Jayapura. The study in Yahukimo was conducted before the implementation of

Option B+ for PMTCT when HIV services were only provided to people with AIDS symptoms and were available at selected health facilities.

This finding is consistent with the national literature where PMTCT services focused on key populations (Option A and B) and not all MCH clinics implemented PMTCT program [170]. Since Papua implemented Option B+ for PMTCT in 2012, HIV testing has been offered to all pregnant women, and there was also a large scale up of HIV services to other health facilities in Papua including in the highlands. Moreover, Ministry of Health of the Republic of Indonesia also trained health workers to minimize HIV-related stigma at the health facility as a part of the implementation strategy for Option B+ for PMTCT [152]. Similarly in the international literature, HIV stigma at the health facilities was also less evident in Option B+ [171] than in Option A/B [161, 172]. Therefore, implementation of different PMTCT policy (Option A, B, and B+) influences HIV-related stigma and discrimination at the health facilities.

IBBS survey conducted in 2013 [10] documented high HIV-related stigma and discrimination in the community in Papua. Overall, more than 50% of participants reported discriminative behaviours by avoiding social interactions with people living with HIV in a social setting, school, or workplace. Compared to the lowlands, HIV-related discrimination was higher in the highlands in which indigenous Papuan people were more reluctant to take care of family members infected with HIV (65% vs. 44%) and to disclose HIV status (78% vs. 49%) [10]. At the national level, HIV stigma and discrimination in the urban areas (85%) were as high as in the rural areas (87%). This rate was much higher than HIV stigma and discrimination in the community in Papua.

High stigma and discrimination were related to lack of knowledge about HIV. The proportion of indigenous Papuan people who had correct knowledge about HIV transmission,

prevention, and treatment has increased from 2.2% in 2006 to 9.2% in 2013 [10]. Nevertheless, this percentage is still very low to reduce HIV-related stigma and discrimination in Papua. The main sources of HIV knowledge in Papua were health workers at the health facilities (63%) and teachers at schools (60%). Scarcity of health facilities and schools coupled with a preference for traditional healers and low enrolment in formal education [41] contributed to poor HIV-related knowledge in Papua, particularly in the highlands. For people who attended health facilities and schools, transfer of HIV knowledge might be hindered by cultural gaps between migrant health workers/teachers and indigenous Papuan people due to ineffective communication. In addition, cultural beliefs that sickness was due to violations of traditions [45] might also reduce the community acceptance on the modern explanations of HIV disease. These were contributing reasons to the poor HIV-related knowledge and therefore high stigma and discrimination in Papua.

Nationally, only 15% of Indonesian people had accurate knowledge about HIV [173]. In demographic and health survey in 2017 [173], more than 80% accessed HIV information through mass media such as television. This reflects a lack of HIV information in the mass media that might link to the concentrated HIV epidemic at the national level. Hence, HIV-related information was available for the key populations but not the general population.

Unaddressed stigma in the community created other issues that reduce the effectiveness of the PMCT program strategies. To avoid community stigma and discrimination, HIV-positive indigenous women sought care at health facilities that were far away from home [152]. The PMTCT program uses a referral system strategy in which women should be advised to continue their treatment at the closest health facility to their home. The referral system did not work if Papuan women prefer to access HIV care at health facilities where the health workers do not recognize them. This lessens the community health workers' opportunity to

monitor women's treatment progress in the community setting but also increases burdens for women due to increased travel distance and transportation costs. Another issue was a more limited health facility option for women in the highlands [106]. They might relocate to another district/city and separate with their partner or family members because of the scarcity of health facilities. Stigma and discrimination therefore change economic and socio-psychological aspects that are essential for women's participation in the PMTCT program.

The national literature rarely mentioned about HIV-positive people seeking care outside of the community area to avoid stigma in the community. There was no study reporting increased travel distance and travel cost due to scarcity of health facilities. The possible explanations were a high population density, which resulted in a high number of health facilities [106] in Indonesia, except Papua. Therefore, health facilities were more accessible using public transportations that are usually inexpensive. The finding is comparable to international literature on HIV-positive women in rural Tanzania [113] and Malawi [24] that also reported high HIV stigma in the community which resulted in increased transportation cost due to scarcity of health facilities.

Lastly, stigma and discrimination delay HIV status disclosure, which is the requirement for attaining socioeconomic and psychological support. At the same time, HIV status disclosure may also result in a loss of socioeconomic and psychological support. Majority of indigenous Papuan women who disclosed HIV status to the partner or the closest family members such as parents or siblings attained socioeconomic and psychological support regardless of the partner HIV status [152]. However, there was a minority of women who had interrupted ARV treatment due to abuse and violence from the partner as the outcomes of HIV status disclosure [152] due to the partner's stigma and discrimination toward people living with HIV. In national [111] and international literature [174], HIV-positive women also reported delays in status disclosure due to HIV stigma, which then contributed to a lack of socioeconomic and psychological support in the PMTCT program.

High-quality services

The quality of PMTCT services played a vital role in increasing women's participation in PMTCT program in Papua. The WHO [175] defined high-quality services as “care that is:

- *Safe*: avoiding harm to people for whom the care is intended
- *Effective*: providing evidence-based health care services to those who need them
- *People-centred*: providing care that responds to individual preferences, needs and values
- *Timely*: reducing waiting times and sometimes harmful delays for both those who receive and those who give care
- *Efficient*: maximizing the benefit of available resources and avoiding waste
- *Equitable*: not treating patients differently because of personal characteristics such as ethnicity and religion, providing care that does not vary in quality on account of age,

sex, gender, race, ethnicity, geographical location, religion, socioeconomic status, linguistic or political affiliation

- *Integrated*: providing care that is coordinated across levels and providers and makes available the full range of health services throughout the life course.”

The study findings indicate the implementation of patient *safety* in Option B+ for PMTCT in Papua including lifetime ARV treatment for all HIV-positive pregnant women regardless of the disease stage, high priority HIV program, free-of-costs HIV services, and implementation of strategies to increase women’s adherence to ARV treatment. Enrolment of HIV-positive women in ARV treatment reduces HIV disease progression to AIDS and HIV transmission from mother to child in future pregnancies, including in vaginal deliveries. Option B+ policy protects the health of women and unborn infants, while reduces the risks of deaths due to AIDS. Establishment of Papua as a high priority area for HIV interventions due to its generalized HIV epidemic increased availability of HIV care and access to PMTCT services. At the same time, the provision of ARVs at no cost eliminates the risk of ARV treatment interruption due to financial constraints. The PMTCT program also employed strategies to ensure women’s adherence, including couple HIV testing and counselling or engagement of peer support groups and NGOs to create a support system for the women. However, the patient safety aspect of the Option B+ policy is only achievable if women access the PMTCT services and retain in HIV care. Meanwhile, Papua reported low retention rate among women in the PMTCT program as also reported in national and global levels.

Limited evidence suggested the *effectiveness* of PMTCT services in Papua. The WHO PMTCT guidelines recommend ECS and infant formula if women have ARVs for at least 6 months. However, all women interviewed in Jayapura had ECS and gave formula milk to their infants regardless of their ARV treatment duration. Health workers recommended ECS

to all pregnant women was more likely due to the absence of viral load machine to confirm the success of the ARV treatment. A minority of indigenous Papuan women interviewed gave births assisted by traditional birth attendants due to cultural beliefs and practices. Moreover, there is not enough data to conclude that infant formula is safer than breastfeeding in Papua context. Infant formula is costly, and there is a lack of clean water resources in Papua. Lack of integration of the local evidence compromises the effectiveness of the PMTCT program in Papua.

Research findings also suggested the inclusion of the *people-centred* aspect and the gaps in the PMTCT implementation in Papua. Women reported that HIV post-test counselling helped improved their correct and comprehensive understanding of HIV (needs). Through HIV counselling sessions, health workers challenged women's beliefs about the efficacy of ARVs. Health workers also engaged women in HIV status disclosure plan such as when and how to bring their partner to the health facility. The majority of women followed the ECS advice from the health workers because they were reliable sources of health information. However, a few HIV-positive Papuan women interviewed gave births with assistance from a traditional birth attendant without a prior discussion with the health workers. There was a lack of discussion about women's preference and values related to pregnancy and childbirth in the counselling sessions.

Indigenous Papuan women reported poor *timeliness* due to long waiting times and delays in the PMTCT services. Mothers waited a long time (i.e. over four hours) for paediatric care for their infants because there was no paediatrician at the PMTCT clinic. A low ratio between health workers and women also resulted in a long queue for ARVs and follow-up counselling. At times, women should return on another day because there was no one to replace absent health workers. Nonetheless, only indigenous Papuan women with lack of

motivation reported non-adherence to ARV treatment as the result of poor timeliness. The possible reason for the majority of women not demotivated by the long wait times and delays could be because they encountered the same issues at other health services in Papua. Poor timeliness may not be an issue specific to PMTCT services, but it reduces the quality of PMTCT services. It is also harmful to women who did not return for care to avoid long wait times.

There is an effort to ensure *the efficiency* of PMTCT services in Papua. Health facilities involve available resources such as midwives at midwifery and maternity clinics, paediatricians at paediatric clinics, and HIV counsellors at VCT clinics to deliver PMTCT services in Papua. Therefore, the health facilities did not create a new PMTCT clinic but integrated the PMTCT services to different clinics responsible for the pregnancy, childbirth, child health, and HIV care. PMTCT referrals between PHCs and hospitals also indicated the efficiency of resources, in which hospitals cover PMTCT services that are not available at the PHCs. The system does not encourage women to seek full PMTCT services at the hospitals to prevent patient overload at the hospitals. However, stigma and discrimination in the community reduce the efficiency of PMTCT services because the majority of Papuan women decided to remain at the hospitals throughout the PMTCT program.

Absence of stigma at the health facilities and positive health workers-women are examples of *equitable* PMTCT services in Papua. Indigenous Papuan women reported receiving the same treatment regardless of their characteristics such as sex, gender, ethnicity, religion, and socioeconomic status. Improved equitable treatment in PMTCT services was the outcomes of training to reduce stigma at the health facilities after the launching of Option B+ in Papua. HIV training reduced stigma at the health facilities in Papua due to differences in ethnicity

and religion between migrant health workers and indigenous Papuan people. Free-of-cost HIV care is accessible to all people in Papua regardless of the socioeconomic status.

The main barrier to high-quality PMCTCT services in Papua might be the *integration* aspect. Indonesia uses a referral system from PHCs to hospitals to ensure comprehensive PMTCT services for HIV-positive women. However, geographical constraints that limited access to electricity, mobile phone, and internet services in the majority of highland areas obstructed the coordination between PHCs and hospitals. Limited transportation access also reduced the effectiveness of integrated care, particularly for women living in areas only accessible by helicopter or on foot. In health facilities that are accessible by public transportation and communication services are available, common issues are lack of human resources and equipment to implement the PMTCT services. Therefore, successful integration is more achievable at health facilities that have enough health workers and equipment to deliver a full range of PMTCT services, usually at hospitals, particularly type A and B.

The national HIV policy guided the implementation of PMTCT services in Papua. Therefore, aspects such as *safety, people-centred, timeliness, efficiency, and equitable* aspects in Papua reflect the national health system. However, there are differences in the quality of PMTCT services between Papua and national due to geographical differences such as effectiveness and integration aspects. The recommendations for ECS and replacement feeding are more *effective* at the national level because ECS and clean water resources are more available on the national level. *Integrated* care was also more achievable on the national level because of the availability of email, landline, and mobile phone communications to improve coordination across levels and providers. The impact of geographical constraints on reduced quality of PMTCT services in Papua was comparable to experiences of countries in resource-

limited settings such as Malawi (constrained water resources) and sub-Saharan Africa (poor electricity access).

The implications of the study findings on ART uptake, adherence and retention, and target audiences for Option B+ PMTCT in Papua are discussed below.

7.2.2. Implications for Option B+ PMTCT in Papua

The study findings have several implications for ART uptake, adherence, and retention in Option B+ PMTCT. Implications are discussed in three parts: ART uptake, ART uptake and adherence, and ART retention. The first part focuses on HIV-positive pregnant women's ART uptake in Papua and Indonesia using the findings from Study 2_Indonesia. The second part discusses overlapping factors that influenced women's ART uptake and adherence, as identified across all the studies. The last part focuses on factors that influenced women's ART retention, as identified in all the studies.

ART uptake

Findings from Study 2_Indonesia showed similar ART uptake among women in Papua (98%) and Indonesia (95%). Despite the similarity in ART uptake, there was a difference between Papua and Indonesia in the proportion of HIV-positive women who were eligible for ART. In Papua, where Option B+ was implemented, all HIV-positive women were eligible for ART. At the national level, one third of HIV-positive women were ineligible for ART, which could have potentially led to the transmission of the disease to their children. This may be one of the reasons for the increase in new HIV infections in children in Indonesia. Overall, the study findings showed a higher coverage of PMTCT among HIV-positive pregnant women in

Papua than in Indonesia. These findings suggest that Option B+ policy is more effective than Option A and B in increasing ART uptake in the PMTCT program.

ART uptake and adherence

Study 1_Papua identified eight factors that influenced women's uptake and adherence at different levels of the socioecological framework. Using the realist synthesis concept of program theories (Study 3_Global), these factors can be classified into contexts or mechanisms, as shown in Table 12.

Table 12. Factors that influenced women's ART uptake and adherence in Papua.

Socioecological Level	CMOC-1	CMOC-2	CMOC-3
Individual		<i>Mechanism:</i> - belief in the efficacy of ART to prevent MTCT and to improve personal health	
Interpersonal			<i>Context:</i> - supportive partner
Institutional	<i>Contexts:</i> - absence of stigma and discrimination at health facilities - positive women-health worker relationships, - confidentiality of HIV status	<i>Context:</i> - quality of HIV post-test counseling	
Community			<i>Context:</i> - community stigma and discrimination
Policy			<i>Context:</i> - free-of-cost HIV-

			related health services
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Of the eight factors that influenced women's uptake and adherence in Option B+ PMTCT in Papua, seven factors were context-related, and one factor was mechanism-related. All these factors were the intersections between the quality of PMTCT services, cultural aspects, and HIV stigma in the community. Of seven aspects of quality of PMTCT services, three aspects were more influential on indigenous Papuan women's uptake and adherence in Option B+ for PMTCT. These three aspects were: *safety* (free-of-cost HIV-related services), *people-centred* (confidentiality and quality of HIV counselling that also addresses women and partner's cultural beliefs and practices related to HIV, pregnancy, and childbirth), and *equitable* (absence of stigma at the health facilities and positive health workers-women relationship). These findings signs aspects of quality PMTCT services, women, and community to prioritize in a resource-limited setting in Papua.

ART retention

Study 2_Indonesia found a low (33%) ART retention among HIV-positive pregnant women in Papua. Several barriers to ART retention were identified in Study 1_Papua: community stigma and discrimination, and women's doubts about ART efficacy to prevent MTCT and improve health. In contrast, Study 2_Indonesia and 3 identified several factors that increased women's retention in Option B+ PMTCT in Papua.

The factors are shown in Table 13 according to socioecological levels and CMOC-1.

The findings from Study 3_Global, in particularly CMOC-1, can be used to further explain the possible mechanisms related to the health facility characteristics at the institutional and policy levels along with their implications on women's ART retention in Option B+ PMTCT in Papua.

Table 13. Factors that influenced women's ART retention in Papua.

Socioecological Level	CMOC-1
Institutional	<i>Contexts:</i> - hospitals/secondary health facilities - hospitals type A/B <i>Mechanism:</i> - improved linkage and better coordination between health workers in PMTCT-related clinics and health facilities - a supervision system that supports delivery of high-quality PMTCT services according to the PMTCT SOPs and guidelines as well as development of health workers' skills to manage PMTCT barriers such as increased workload due to limitations of human resources
Policy	<i>Contexts:</i> - generalised HIV epidemic - high priority area for HIV program <i>Mechanism:</i> - clarity of PMTCT monitoring system across the health facilities and clinics including referral process, adherence monitoring, and management of missing appointments

The three mechanisms at institutional and policy levels implied the importance of *integration* aspect of high-quality PMTCT services on women's retention in resource-limited settings such as Papua. Paragraphs below provide the implications of each mechanism.

Mechanism 1. Improved linkage and better coordination between health workers in PMTCT-related clinics and health facilities.

The national PMTCT guideline recommends PMTCT-ANC integration at health facilities and referrals between PMTCT referral and satellite sites.

Study findings implied the need to strengthen linkage and coordination across clinics within a health facility (internal linkage and coordination) and between health facilities (external coordination) involved in the PMTCT program. Long waiting times at paediatric clinics was an indication of lack of internal coordination between the HIV clinic and paediatric clinic in Jayapura (Study 1_Papua) [152].

As identified in Study 2_Indonesia, hospitals particularly type A/B retained more women in the PMTCT program. This finding implied better linkage and coordination in health facilities hospitals type A/B than in hospitals type C/D and PHCs. The possible reason could be that hospitals type A/B required internal referral system because of availability of comprehensive PMTCT services within the hospitals compared to hospitals type C/D and PHCs that also required external referral systems due to less comprehensive health services in the health facilities. Majority of health facilities in Papua were hospitals type C/D and PHCs. These study findings suggested a strengthening of internal and external linkage and coordination across clinics and health facilities to improve women's retention during and post the PMTCT program.

Mechanism 2. Clarity of PMTCT monitoring system across the health facilities and clinics including referral process, adherence monitoring, and management of missing appointments.

As described in Chapter 2, Papua uses a referral-satellite system in which some women continue their ART at a satellite health facility in their neighbourhood after initiating ART at a referral hospital. In Study 1_Papua, women refused to return to PMTCT satellite sites due to stigma and discrimination in the community. However, In Study 2_Indonesia, a high

percentage (28%) of women on ART were referred to other health facilities, whose ART retention was unknown. The current PMTCT reporting system was not able to monitor the women's ART status after referrals, whether retained or LTFU. Hence, there is a need to strengthen current monitoring and reporting systems to ensure women's retention in HIV care.

Mechanism 3. A supervision system that supports deliveries of high-quality PMTCT services according to the PMTCT SOPs and guidelines as well as development of health workers' skills to manage PMTCT barriers such as increased workload due to limitation of human resources.

Findings in Study 2_Indonesia suggested that the supervision systems might function better in health facilities located in generalised HIV epidemic areas and high priority areas for HIV programs. SOPs and guidelines were more likely to be available and implemented at these health facilities. In addition, health workers might receive more training, which could in turn improve their awareness, knowledge, and skills to ensure women's retention in the ART. The government might also allocate more resources such as funding and health workers to these health facilities, which could lead to increased ART retention in the PMTCT.

7.2.3. Recommendations for Option B+ PMTCT target audiences

Based on these study findings and implications, several recommendations to increase women's uptake, adherence, and retention in Option B+ PMTCT in Papua are proposed. The recommendations for HIV-positive women, health workers, program managers, and policy makers are described below.

HIV-positive women

Women's beliefs in ART efficacy to prevent HIV transmission to children and to improve their personal health are essential factors that influenced women's uptake, adherence, and retention in the program. Health workers need to provide PMTCT services that are more *women-centred* by using counselling sessions to explore women's needs (i.e. partner/peer support, doubts about ART efficacy, witnessing negative health outcomes among peers, or prolonged negative side effects that may be perceived as a decrease in overall health); preferences (ECS vs. vaginal birth, traditional childbirth attendants vs. skilled health workers); and values (i.e. cultural or religious beliefs and practices). HIV counsellors could then focus on topics that matter to women in the follow-up sessions. Moreover, health workers and women could discuss a childbirth plan regardless of their preference. Health workers could also involve the traditional childbirth attendance in the PMTCT program as recommended in a sub-Saharan Africa study [176].

Retention of women in Option B+ PMTCT in Papua was more likely when they received support from their partners. Financially dependent women required socioeconomic support, such as meeting transportation costs, while financially independent women required socio-psychological support such as facilitating access to ART. Women who did not receive any support from their partners and relied on their personal resources were unlikely to adhere to ART in the long-term. In Study 1_Papua, some women missed their ART appointments due to a lack of partner support. Hence, attainment of partner support was vital to women's ART retention in Option B+ PMTCT. To improve partner support, Malawi implemented a strategy involving male partners in the PMTCT program [177, 178], resulting in an increase in mutual communication and fostering a support system for the women. Another strategy implemented

in Kenya was cHCT [179], in which couples were tested together for HIV infection, and health workers assisted with the HIV status disclosure discussion between the couples. Couples were also engaged in the decision-making process related to ART treatment for the HIV-infected partner and HIV prevention for the uninfected partner or future children.

Papuan cultural practices might hinder men's involvement in the PMTCT program because pregnancy and childbirth are women concerns [45]. Hence, before deciding the scope of men's participation, there is a need to involve men to define their roles in the PMTCT program, such as providing financial support for women or approving child deliveries at the health facilities. In a previous study of four African countries, the involvement of the community leaders increased men engagement in the PMTCT program [180]. This strategy might work considering the significant roles of community leaders in Papua community.

Community members

Community stigma and discrimination prevented women from participating in Option B+ PMTCT in Papua. This is also the most common barrier encountered by HIV-positive pregnant women in 23 countries [161]. Papua has a generalised HIV epidemic and several HIV campaigns were disseminated across the community. However, women in Study 1_Papua reported poor understandings of HIV transmissions and treatment before they received HIV counselling at the health facilities. IBBS in 2013 recorded low level of correct HIV knowledge among indigenous Papuan men and women as well as high HIV stigma and discrimination toward people living with HIV. As shown in a Thailand study, strategies such as distribution of EIC materials, routine campaigns, and public events were effective in reducing HIV stigma and discrimination in the community level [181].

In Papua, health facilities and schools are the main sources of HIV knowledge. HIV is now a part of the school curriculum in Papua. However, low utilization of health facilities and low

enrolment in schools in Papua required additional strategies to deliver HIV knowledge to the wider community. Possible solutions are collaborations with the community leaders, religious leaders, and traditional healers to deliver HIV education at the community level. EIC materials need to meet the literacy and education level of the community members. There is also a need to include local contexts such as cultural beliefs and practices in HIV education to increase acceptance.

Health workers

Health workers played a significant role in the success of Option B+ PMTCT through delivery of high-quality PMTCT services and counselling sessions [136, 154]. Hence, there is a need to increase the number of health workers delivering the PMTCT program to increase women's participation in the program. As reported in Study 1_Papua, human resources constraints existed in the health facilities in Papua [152]. Moreover, health workers need to continuously update their knowledge and skills to implement new effective strategies to manage barriers experienced by women, such as the delivery of cHCT. This will help increase health workers' and women's confidence in the success of Option B+ PMTCT.

Program managers

Program managers oversee the implementation of Option B+ PMTCT at the health facilities and supervise health worker performance. Program managers need to ensure that Option B+ PMTCT SOPs or guidelines are made available at health facilities. They need to ensure that all health workers are trained to implement the SOPs or guidelines and monitor their implementation on a regular basis. In addition, program managers need to ensure regular and continuous training for health workers to build their capacity to deliver high-quality

counselling, and to develop effective strategies and plans to manage barriers to Option B+ PMTCT including those encountered by health workers, such as lack of privacy. As identified in Study 3_Global, SOPs or guidelines should include aspects such as internal and external linkage and coordination systems, management of ART follow-up and missing appointments, and monitoring of women's ART adherence throughout the Option B+ PMTCT cascade.

Hospitals types A/B retained more women in the PMTCT program. However, upgrading resources at hospitals type C/D and PHCs to become like hospitals type A/B requires a long process and therefore is not visible in immediate term. Instead, program managers at the health facility levels could ensure availability and implementation of a functioning supervision system to ensure delivery of PMTCT services occurs according to the SOPs and guidelines. More training is also required for health workers to improve their knowledge, awareness, and skills to deliver Option B+ PMTCT and to retain women in ART.

Current online reporting system does not include monitoring of referred women's retention in ART program as well as women's ART retention post-PMTCT. This result in inaccurate HIV data reporting and recording and lack of ability to calculate the success of Option B+ for PMTCT in retaining women in lifetime ART. National program manager at Sub-directorate HIV AIDS could consider the integration of these data into SIHA, the current reporting system to improve monitoring of women's retention in HIV care.

Policy makers

The MTCT rate intrapartum in Indonesia is the highest in the world at 26.6% of a maximum of 30%. Depends on the Ministry of Health's prioritisations and availability of funding to provide free-of-cost ARVs, the government may consider the implementation of Option B+

for all HIV-positive pregnant women in Indonesia. At the minimum, short-term ART for ineligible HIV-positive women using regimens that are proven to be effective in other resource-limited settings can be considered. For Papua, the provision of free-of-cost HIV-related services needs to be continued, given that Papua is the province with the highest poverty rate in Indonesia. Provision of transportation money may not be visible due to funding limitation for HIV program. However, maintenance of the current health scheme will prevent additional expenses for women. Stigma and discrimination from health workers at the health facilities implementing the PMTCT program were rarely reported. However, national evidence suggested the presence of HIV stigma from health workers that are not implementing HIV programs but working on blood and body fluids such as in dental clinics. Policymakers may consider provisions of HIV-related education and training for health workers providing other health services regardless of the HIV epidemic in their area. HIV-related universal precaution needs to become mandatory training for health facilities providing health services involving blood and body fluids. These strategies will reduce discrimination toward people living with HIV.

7.3. Methodological considerations

This thesis has considerable strengths including the use of a mixed-method research design across three geographical levels: regional level (Study 1_Papua), the national level (Study 2_Indonesia), and the resource-limited settings (Study 3_Global). This resulted in a comprehensive investigation of women's uptake and retention in Option B+ PMTCT. The three studies provided an opportunity to conduct an iterative process of testing and refinement of mechanisms for the success of Option B+ PMTCT in Papua. The study limitations included the use of secondary data, which limits the types of health facility

characteristics included in the analysis of PMTCT uptake and retention in Indonesia. These methodological issues are discussed in greater detail below.

7.3.1. Strengths and limitations

The strength of the thesis was the use of a mixed-method research design, which allowed an extensive and profound understanding and validation of factors influencing women's uptake and retention in Option B+ PMTCT. In addition to identifying factors that influence women's uptake and retention in Option B+ PMTCT, a common approach used in previous studies, this study provided an explanation for how those factors influenced PMTCT outcomes using a new approach, the realist synthesis. Finally, the mixed-method research design also provided an opportunity for data triangulation during the development, testing, and refinement of CMO configurations vital for the success of Option B+ PMTCT in Papua, Indonesia. Figure 16 depicts the data triangulation process using a mixed-methods study design (qualitative, quantitative, and realist synthesis)

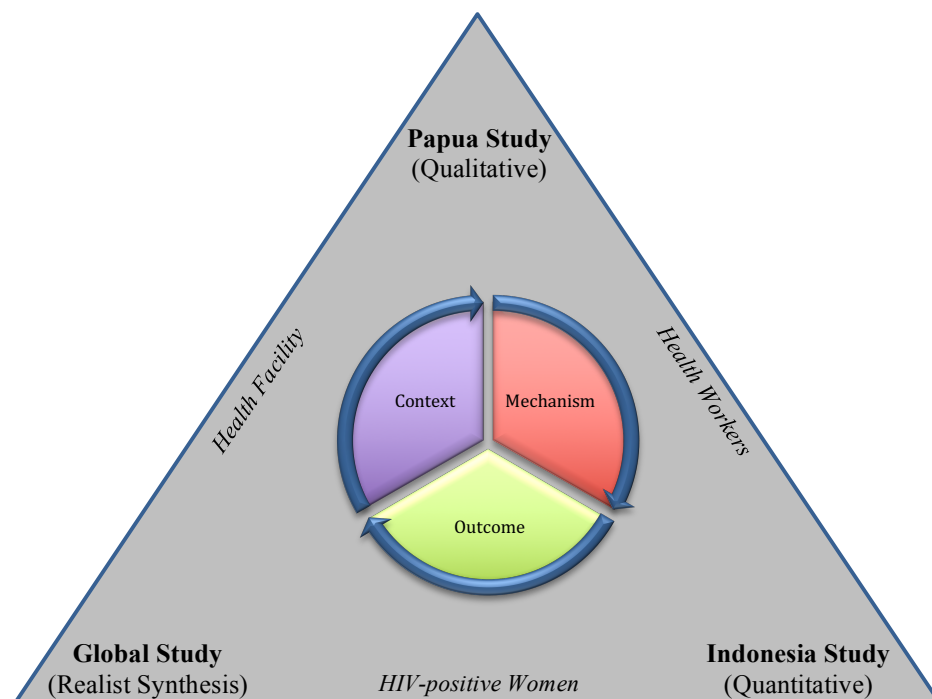


Figure 16. Data triangulation and the mixed-method study designs in the three studies.

Other strengths attributed to the methodology used in each study are summarised below:

Study 1_Papua

A significant strength of the Papua study was the use of *a priori* themes and the socioecological framework, both of which were developed through literature reviews of Option B+ PMTCT in Papua, Indonesia, and other resource-limited settings. During the in-depth interviews, *a priori* themes allowed a systematic exploration and verification of *individual, interpersonal, institutional, community and policy* factors that influenced women's uptake and adherence in Option B+ PMTCT in Papua. It also provided an opportunity to compare experiences of women and health workers in Option B+ PMTCT in Papua with those in other resource-limited settings including Indonesia.

The second strength of the Papua study was data triangulation that occurred during the field visits through verifications of information attained from women and health workers. This included field observations of information attained from the in-depth interviews including health worker-women relationships, wait times, internal referral systems, and external and internal linkage and coordination between clinics providing PMTCT-related services.

The third strength of the Papua study was the study location of the two public hospitals. The hospitals were PMTCT referrals for other PMTCT satellites in Papua province. Even though both hospitals were located within the Jayapura city area, the majority of pregnant women seeking treatment at the health facilities resided in other districts outside of Jayapura city. Hence, an opportunity existed to explore external referral and coordination systems in explaining women's ART uptake and retention in Option B+ PMTCT in Papua.

There were several limitations in this study including limited generalisability of factors that influenced women's uptake and retention in Option B+ PMTCT in Papua, given that the

study was conducted in only two hospitals in Jayapura city. For example, stigma and discrimination at the health facilities were not reported by the women in Jayapura Hospital and Abepura Hospital. Although some of the women who attended these hospitals resided in other districts in Papua, most of them never attended PMTCT services at the health facilities in their original hometown or residence. As such, there was limited information on stigma and discrimination at other health facilities in Papua.

Study 2_Indonesia

The strength of the Indonesia study was the use of secondary data with a large sample size. There were over 3,000 women receiving ART in 373 health facilities providing PMTCT services across Indonesia. This was much larger than previous quantitative studies conducted in Cameroon and Uganda investigating associations between health facility characteristics and women's uptake and retention in Option B+ PMTCT in resource-limited settings [182, 183]. At the Papua and Indonesia level, this was the first study to describe women's uptake and retention in Option B+ PMTCT and to identify and quantify health facility characteristics that influenced those outcomes. Given that all health facilities providing PMTCT services in Indonesia were included in the study, it was possible to generalise the results to other health facilities providing PMTCT services in Indonesia.

The use of regression analysis allowed identification of health facility characteristics that influenced women's retention in PMTCT programs. Unlike simple correlational analysis, which assesses the effect of one health facility characteristic and outcome, regression analysis assessed interaction effects between all health facility characteristics entered in the model. Hence, this study was able to identify health facility characteristics that were statistically significant, adjusting for other health facility characteristics included in the model.

The findings of the Papua and Indonesia studies contributed to the design of the Global study. Specifically, the findings showed that various factors influenced women's ART uptake and retention in Papua. Therefore, the focus of the Global Study was to explain how those factors influenced women's uptake and retention in Option B+ PMTCT by reflecting on study findings in other resource-limited settings.

The use of secondary data extracted from SIHA, which was designed as a monthly monitoring tool and not for research purposes, limited the types of health facility characteristics included in the regression analysis model. The following factors were not available in SIHA: demographic characteristics of HIV-positive women and health workers, health worker to women ratios, and information about referral and coordination systems between clinics and health facilities. To overcome this limitation, these factors were investigated in the Papua Study; however, they only reflected the characteristics of Option B+ PMTCT in the two hospitals.

Study 3_Global

The realist synthesis was a robust approach to synthesise the literature. However, since Option B+ PMTCT was introduced recently (in 2010), limited literature has described the impact of Option B+ PMTCT on women's uptake and retention in the program in resource-limited settings. The findings from Study 3_Global showed that some women who believed in ART efficacy (mechanism, at the individual level) adhered to Option B+ PMTCT despite the presence of barriers such as community stigma and discrimination (context, at the community level). However, the current realist synthesis is unable to explain whether some mechanisms are more influential than others.

7.4. Future research directions

Further studies are required to address the study limitations discussed above. It is vital for future studies to investigate Option B+ PMTCT delivery in the community level by involving primary health facilities. This is particularly important since primary health facilities are the main points of care for ANC in Indonesia and Papua. At the same time, there is a need to investigate cultural aspects related to pregnancy and childbirth practices in the Papuan community. This may help explain the low percentage of births assisted by health workers in Papua and why most women in Papua seek pregnancy care in the last trimester of the pregnancy.

Due to the change in the design of Study 2_Indonesia from surveys to analysis of secondary data, it was not possible to quantify the associations between several factors related to health facility, women, and health workers that might influence PMTCT outcomes. It is recommended that future studies conduct primary data collection focusing on the following factors: demographic characteristics of HIV-positive women and health workers, health worker to women ratios, external and referral linkage, and coordination systems. This will provide a better understanding of the reasons for low ART retention in Papua and in Indonesia, where geographical aspects are unlikely to be as challenging as Papua.

The realist synthesis did not identify whether some mechanisms were more influential than others. Future studies could extend the current realist synthesis to address this gap. This will be beneficial for program implementers and policy makers to focus their resources on the most influential mechanisms, if identified. Finally, future studies are needed to assess differences between mechanisms required in different PMTCT Options including A and B. This will allow policy-makers to consider the most suitable PMTCT Option to be adopted in health facilities based on the feasibility of creating mechanisms for each Option treatment.

7.5. Conclusions

One of the most significant factors that resulted in new HIV infections in children aged under 15 years in Papua is low ART retention in Option B+ PMTCT. The findings from the three studies in this thesis suggested that factors at various levels influence women's uptake and retention in Option B+ PMTCT, including: belief in ART efficacy, partner support, community stigma and discrimination, quality of PMTCT health services including HIV counselling, and free of cost HIV services. These factors influence the mechanisms that determine women's uptake and retention in the program. There are opportunities to improve Option B+ PMTCT outcomes in Papua by manipulating the program contexts to enable the creation of mechanisms to achieve the desired outcomes, as detailed throughout this thesis.

The success of Option B+ as a more proactive approach has been reported to increase women's uptake in PMTCT program in resource-limited settings since implemented in 2012. However, it also requires additional efforts to ensure women's retention in the program. Papua, as the only province with a generalised HIV epidemic in Indonesia, needs to address several issues that impact hindered women's retention including community stigma and discrimination. Moreover, Papua needs to integrate cultural aspects throughout its program delivery to ensure community acceptance and program success.

The use of a mixed-method research designs offered rigorous results that can be used as evidence for improving Option B+ PMTCT in Papua. Results from both the Indonesia and Global studies are generalisable to Option B+ PMTCT in Papua. Future research is required to address several limitations identified in this research including cultural practices related to pregnancy and childbirth practices in Papua.

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APPENDICES

Appendix A. Plain language statement for HIV-positive women

Informasi Penelitian

Pusat Kebijakan Kesehatan



Penelitian: Meningkatkan Penerimaan dan Kesiambungan Perawatan dalam Program Pencegahan Penularan HIV dari Ibu ke Anak di Papua, Indonesia

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Pengantar

Saudara diundang untuk berpartisipasi dalam penelitian S3 yang dilakukan oleh Christina Lumbantoruan. Saudara terpilih sebagai pengguna layanan kesehatan yang sedang diteliti.

Tujuan Penelitian

Penelitian ini bertujuan untuk meningkatkan layanan pencegahan HIV dari ibu ke anak di Papua. Untuk itu, diperlukan pemahaman yang lebih baik terhadap hal-hal yang mendukung maupun menghambat wanita untuk menggunakan layanan yang ada.

Partisipasi apa yang diminta dari saudara?

Apabila saudara setuju untuk berpartisipasi, saudara akan diminta untuk menjawab beberapa pertanyaan terkait:

- 1). Pengalaman saudara sebagai pengguna layanan kesehatan ibu dan anak di RSUD Jayapura,
- 2). Alasan saudara untuk menerima/tidak menerima dan melanjutkan/tidak melanjutkan layanan kesehatan pencegahan penularan HIV dari ibu ke anak
- 3). Saran dan masukan untuk memperbaiki layanan tersebut.

Jawaban saudara akan direkam supaya informasi yang saudara berikan tercatat dengan baik dan tidak ada yang terlupakan. Rekaman ini hanya akan didengarkan oleh peneliti mahasiswa dan bukan untuk didengarkan oleh orang lain. Jika saudara merasa tidak nyaman, rekaman dapat dimatikan atas permintaan saudara. Apabila saudara merasa tidak nyaman membicarakan topik tertentu, saudara boleh memilih untuk tidak menjawab pertanyaan tersebut.

Appendix B. Plain language statement for health workers

Informasi Penelitian

Pusat Kebijakan Kesehatan



Penelitian: Meningkatkan Penerimaan dan Kesiambungan Perawatan dalam Program Pencegahan Penularan HIV dari Ibu ke Anak di Papua, Indonesia

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Pengantar

Kami mengundang saudara untuk berpartisipasi dalam penelitian yang dilaksanakan oleh Christina Lumbantoruan (Mahasiswa doktoral) dibawah bimbingan dari Professor Margaret Kelaher (Pembimbing Utama) dari Pusat Kebijakan Kesehatan di Universitas Melbourne; Drg. Aloysius Giyai, MKes (Pembimbing Lokal) selaku kepala dinas kesehatan Provinsi Papua; dan A/Prof Michelle Kermode. Saudara dipilih karena peran saudara sebagai pemberi layanan PPIA HIV di fasilitas kesehatan ini.

Tujuan Penelitian

Tujuan penelitian ini adalah untuk meningkatkan penerimaan dan keberlangsungan wanita dalam PPIA HIV di Papua melalui pemahaman yang lebih baik terhadap metode pelaksanaan layanan PPIA HIV yang dijalankan maupun faktor-faktor yang mendukung maupun menghambat wanita positif HIV untuk mengikuti program PPIA. Penelitian ini telah disetujui oleh Komisi Etik dari Universitas Melbourne di Australia.

Partisipasi apa yang diminta dari saudara?

Apabila saudara setuju untuk berpartisipasi, maka saudara akan diminta untuk menjawab beberapa pertanyaan terkait 1). Peran dan tanggungjawab saudara sebagai pelaksana program PPIA HIV, dan 2). Apa yang menurut saudara merupakan alasan wanita untuk menerima/tidak menerima dan melanjutkan/tidak melanjutkan program tersebut. Saudara juga akan dimintai 3). Saran dan masukan untuk pengembangan program PPIA ke depannya. Jawaban saudara akan direkam supaya informasi yang saudara berikan dapat dipahami dengan tepat. Rekaman ini hanya akan didengarkan oleh peneliti dan digunakan untuk tujuan penelitian ini saja. Jika saudara merasa tidak nyaman, alat perekam dapat dimatikan atas permintaan saudara. Demikian juga hanya apabila saudara merasa tidak nyaman untuk membicarakan topik tertentu, saudara dapat memilih untuk tidak menjawab pertanyaan tersebut.

Appendix C. Consent form for HIV-positive women

Format Persetujuan

Pusat Kebijakan Kesehatan



Penelitian: Meningkatkan Penerimaan dan Kestinambungan Perawatan dalam Program Pencegahan Penularan HIV dari Ibu ke Anak di Papua, Indonesia

Mahasiswa Peneliti: Christina Lumbantoruan

Peneliti Lainnya: Professor Margaret Kelahe (Pembimbing I), A/ Prof. Michelle Kermode (Pembimbing II), dan Drg. Aloysius Giyai (Pembimbing Lokal)

Nama Peserta: _____

1. Saya bersedia untuk berpartisipasi dalam penelitian ini yang mana rinciannya telah dijelaskan kepada saya melalui lembar informasi penelitian dan secara lisan.
2. Saya memahami bahwa penelitian ini bertujuan untuk meningkatkan layanan pencegahan HIV dari ibu ke anak di Papua, Indonesia.
3. Saya memahami bahwa partisipasi saya adalah untuk tujuan penelitian.
4. Saya menyatakan bahwa saya sudah mendapatkan penjelasan tentang dampak dari partisipasi saya dalam penelitian ini.
5. Dalam penelitian ini saya akan diminta untuk menjelaskan pengalaman saya terkait layanan pencegahan HIV dari ibu ke anak, apa yang menjadi alasan saya untuk menerima/tidak menerima atau melanjutkan/tidak melanjutkan layanan dimaksud. Saya juga akan dimintai saran dan masukan untuk meningkatkan layanan tersebut.
6. Saya memahami bahwa wawancara ini akan direkam.
7. Saya memahami bahwa keikutsertaan saya adalah sukarela dan bahwa saya dapat menarik diri dari penelitian ini kapan saja. Selain itu, saya juga berhak untuk membatalkan data yang sudah saya berikan sebelum diproses.
8. Saya memahami bahwa data penelitian ini akan disimpan di Pusat Kebijakan Kesehatan Universitas Melbourne untuk kemudian dihancurkan setelah masa 5 tahun.
9. Saya telah diberitahu bahwa kerahasiaan informasi yang saya berikan akan dijaga sesuai dengan persyaratan hukum yang berlaku dan bahwa data pribadi saya akan digantikan dengan nama samaran.
10. Saya memahami bahwa ada kemungkinan orang lain dapat menduga keikutsertaan saya dalam penelitian ini mengingat sedikitnya jumlah peserta.
11. Saya memahami bahwa formulir persetujuan yang sudah saya tandatangi

Appendix D. Consent form for health workers

Format Persetujuan

Pusat Kebijakan Kesehatan



Penelitian: Meningkatkan Penerimaan dan Kestinambungan Perawatan dalam Program Pencegahan Penularan HIV dari Ibu ke Anak di Papua, Indonesia

Mahasiswa Peneliti: Christina Lumbantoruan

Peneliti Lainnya: Professor Margaret Kelaher (Pembimbing I), A/ Prof. Michelle Kermode (Pembimbing II), dan Drg. Aloysius Giyai (Pembimbing Lokal)

Nama Peserta: _____

1. Saya bersedia untuk berpartisipasi dalam penelitian ini yang mana rinciannya telah dijelaskan kepada saya melalui lembar informasi penelitian.
2. Saya memahami bahwa penelitian ini bertujuan untuk pengembangan program PPIA HIV di Papua, Indonesia.
3. Saya memahami bahwa partisipasi saya adalah untuk tujuan penelitian.
4. Saya menyatakan bahwa saya sudah mendapatkan penjelasan tentang dampak dari partisipasi saya dalam penelitian ini.
5. Dalam penelitian ini saya akan diminta untuk menjelaskan peran dan tanggungjawab saya sebagai pelaksana layanan PPIA HIV untuk wanita hamil dan juga apa yang menurut saya menjadi alasan wanita untuk menerima/tidak menerima ataupun melanjutkan/tidak melanjutkan program PPIA HIV. Saya juga akan dimintai saran-saran untuk pengembangan program PPIA HIV.
6. Saya memahami bahwa wawancara saya akan direkam.
7. Saya memahami bahwa keikutsertaan saya adalah sukarela dan bahwa saya bebas untuk menarik diri dari penelitian ini kapan saja tanpa harus memberikan penjelasan. Selain itu, saya juga berhak untuk membatalkan data yang sudah saya berikan sebelum diproses.
8. Saya memahami bahwa data penelitian ini akan disimpan di Pusat Kebijakan Kesehatan Universitas Melbourne untuk kemudian dihancurkan setelah 5 tahun.
9. Saya telah diberitahu bahwa kerahasiaan informasi yang saya berikan akan dijaga sesuai dengan persyaratan hukum, data saya akan digantikan dengan nama samaran dan hanya dapat diakses oleh peneliti yang disebutkan dalam dokumen ini.
10. Saya memahami bahwa tidak mungkin untuk menjamin anonimitas saya sepenuhnya mengingat sedikitnya jumlah peserta dalam penelitian ini.
11. Saya memahami bahwa formulir persetujuan yang sudah saya tandatangi akan disimpan oleh peneliti.

Appendix E. Interview guides for HIV-positive women in English

Interview Guide Centre for Health Policy



Project: Understanding women's uptake and adherence in Option B+ for prevention of mother-to-child HIV transmission in Papua, Indonesia: A qualitative study

Interview process: The student researcher will conduct one on one in-depth interviews with women. The student researcher will explore each theme provided by participants and ask additional questions for missing or undetected themes before continuing to the next topic.

I. Demographic information

1. Age: _____ (years)
 - c. Divorced
 - d. Widow
2. Ethnic background: _____
3. Religion: _____
4. Educational background:
 - a. Did not complete primary school
 - b. Primary school
 - c. Junior high school
 - d. Senior high school
 - e. College/University
5. Occupation:
 - a. Housewife
 - b. Casual worker
 - c. Private business
 - d. Private sector
 - e. Civil servant
6. Marital status:
 - a. Single
 - b. Married
7. Number of biological children: _____ (person/s)
8. ANC visits for previous pregnancy(ies) _____
9. Status of last pregnancy: _____ (weeks) or age of the last child _____ (months)
10. Distance from home to the health facility: _____ (hours)
11. Transportation cost to health facility: _____ (Indonesian rupiah)/trip
12. Modes of transportation involved: _____

HREC Number: 1646772.1 Project Start Date: 1 August 2016 Version: 1

III. Interview topics	Themes to explore
Topic 1: HIV testing experience during ANC visits. Question: “<i>Can you tell me about your HIV testing experience during ANC visits?</i>”	• Knowledge of HIV • Knowledge of PMTCT • Health workers-patient interaction • Reasons for HIV testing acceptance • Previous history of HIV testing
Topic 2: Experience in PMTCT enrolment. Question: “<i>How did you learn about the result of your HIV test?</i>”	• Waiting time for the test result • Counselling duration • Confidentiality and privacy • Reasons for enrolment/not enrolment in PMTCT program • Health workers’ attitude toward the woman before and after tested positive for HIV
Topic 3: Experience in PMTCT retention. Question: “<i>What drives you to (not) remain in the program?</i>”	• Facilitators and barriers to retention in PMTCT program: - Transportation cost - Distance to health facility - Stigma and discrimination - Dietary requirements - Belief in PMTCT efficacy
Topic 4: Suggestions to improve PMTCT program. Question: “<i>How do you think the current PMTCT program could be improved?</i>”	• PMTCT strategies for pregnant women under various circumstances: - Social constraints (stigma and discrimination) - Geographical constraints - Financial constraints - Other issues mentioned by the woman
Topic 6: Closing Question: “<i>Is there anything more you would like to add?</i>”	

Interview Guide Centre for Health Policy



Project: Understanding women's uptake and adherence in Option B+ for prevention of mother-to-child HIV transmission in Papua, Indonesia: A qualitative study

Interview process: The student researcher will conduct one on one in-depth interviews with health workers. The student researcher will explore each theme provided by participants and ask additional questions for missing or undetected themes before continuing to the next topic.

II. Demographic information

13. Age: _____ (years)

14. Ethnic background: _____

15. Religion: _____

16. Educational background:

- f. Did not complete primary school
- g. Primary school
- h. Junior high school
- i. Senior high school
- j. College/University

17. Occupation:

- f. Medical doctor
- g. Midwife
- h. Nurse
- i. Counsellor
- Logistic staff

18. Marital status:

- e. Single
- f. Married
- g. Divorced
- h. Widow(er)

19. Length of involvement in PMTCT program:

_____ (months) _____ (weeks)

20. Lists of PMTCT training(s) received and year(s):

III. Main Questions	Themes to explore:
Topic 1: Roles and responsibilities in PMTCT program. Question: “Can you tell me about what you do in PMTCT program?”	• Roles and responsibilities • Other roles and responsibilities at the hospital
Topic 2: Management of pregnant women visiting ANC clinic for the first time. Question: “What happens when a pregnant woman come to the clinic for the first time?”	• PITC (provider-initiated testing and counselling) vs VCT (voluntary counselling and testing) • Patient flow system for PMTCT • PMTCT guideline adopted • Pre-test counselling: - Counselling content - Methods to verify women’s understanding - Estimate duration of counselling - Factors affecting the duration - Confidentiality and privacy
Topic 3: Enrolment of women in PMTCT program. Question: “What are the procedures taken when a pregnant woman requires a PMTCT program?”	• Post-test counselling: - Counselling content - Methods to verify understanding - Estimate duration of counselling - Factors affecting the duration - Confidentiality and privacy • Reasons for enrolment/not enrolment in PMTCT program
Topic 4: Retention of women in PMTCT program. Question: “What kinds of measures are available to ensure women’s retention in the program?”	• Facilitators and barriers to retention in PMTCT program: - Referral system - Community outreach - Commitment to the program - Stigma and discrimination - Logistic issues
Topic 5: Suggestions to improve PMTCT program. Question: “How do you think the current PMTCT program could be improved?”	• PMTCT strategies for pregnant women under various circumstances: - Social constraints - Geographical constraints - Financial constraints
Topic 6: Closing Question: “Is there anything more you would like to add?”	

Panduan Interview Pusat Kebijakan Kesehatan



Proyek: Memahami penerimaan dan kepatuhan wanita dalam Opsi B+ untuk pencegahan transmisi HIV dari ibu ke anak di Papua, Indonesia: Sebuah studi kualitatif

Proses Interview: Mahasiswa peneliti akan melakukan wawancara mendalam satu persatu dengan perempuan. Mahasiswa peneliti akan menggali setiap tema yang disebutkan oleh peserta dan mengajukan pertanyaan tambahan untuk tema yang hilang atau tidak disebutkan sebelum melanjutkan ke topik berikutnya.

III. Informasi demografis

- | | |
|--|---|
| 21. Usia: _____ (tahun) | k. Cerai
l. Janda |
| 22. Latarbelakang etnis: _____ | 27. Jumlah anak biologis:
_____ (orang) |
| 23. Agama: _____ | 28. Kunjungan KIA pada kehamilan terdahulu
_____ |
| 24. Latarbelakang pendidikan:
k. Tidak menyelesaikan sekolah dasar
l. Sekolah dasar
m. Sekolah menengah pertama
n. Sekolah menengah atas
o. Universitas | 29. Status kehamilan: _____ (minggu) atau
usia anak terakhir _____ (bulan) |
| 25. Pekerjaan:
j. Ibu rumah tangga
k. Pekerja sambilan
l. Usaha pribadi
m. Sektor swasta
n. Pegawai negeri sipil | 30. Jarak dari rumah ke fasilitas
kesehatan: _____ (jam) |
| 26. Status pernikahan:
i. Tidak menikah
j. Menikah | 31. Biaya transportasi ke fasilitas kesehatan:
_____ (rupiah)/perjalanan |
| | 32. Jenis transportasi yang dibutuhkan:
_____ |

III. Topik-topik interview	Tema-tema untuk digali
Topik 1: Pengalaman test HIV testing selama kunjungan-kunjungan KIA. Pertanyaan: “<i>Bolehkan anda menceritakan pengalaman test HIV anda pada saat kunjungan-kunjungan KIA?</i>”	• Pengetahuan tentang HIV • Pengetahuan tentang PPIA • Interaksi petugas kesehatan-pasien • Alasan-alasan untuk menerima test HIV • Sejarah test HIV sebelumnya
Topik 2: Pengalaman masuk dalam program PPIA. Pertanyaan: “<i>Bagaimana kisahnya anda mengetahui hasil test HIV anda?</i>”	• Waktu tunggu untuk hasil test • Durasi konseling • Kerahasiaan dan privasi • Alasan-alasan untuk masuk/tidak masuk dalam program PPIA • Sikap petugas kesehatan terhadap wanita sebelum dan sesudah terbukti HIV positif
Topic 3: Pengalaman kelanjutan dalam PPIA. Pertanyaan: “<i>Apa yang mendorong anda untuk (tidak) lanjut dalam program?</i>”	• Fasilitator dan penghambat retensi dalam program PPIA: - Biaya transportasi - Jarak dengan fasilitas kesehatan - Stigma dan diskriminasi - Kebutuhan makanan - Keyakinan akan efikasi PPIA
Topik 4: Saran-saran untuk meningkatkan program PPIA. Pertanyaan: “<i>Bagaimana menurut anda program PPIA dapat ditingkatkan?</i>”	• Strategi PPIA untuk wanita hamil dengan berbagai kondisi: - Kendala sosial (stigma dan diskriminasi) - Kendala geografis - Kendala finansial - Isu-isu lainnya yang disebutkan oleh wanita
Topik 6: Penutup Pertanyaan: “<i>Adakah hal lainnya yang ingin anda tambahkan?</i>”	

Panduan Interview Pusat Kebijakan Kesehatan



Proyek: Memahami penerimaan dan kepatuhan wanita dalam Opsi B+ untuk pencegahan transmisi HIV dari ibu ke anak di Papua, Indonesia: Sebuah studi kualitatif

Proses interview: Mahasiswa peneliti akan melakukan wawancara mendalam satu persatu dengan petugas kesehatan. Mahasiswa peneliti akan menggali setiap tema yang disebutkan oleh peserta dan mengajukan pertanyaan tambahan untuk tema yang hilang atau tidak disebutkan sebelum melanjutkan ke topik berikutnya.

IV. Informasi demografis

33. Usia: _____ (tahun)

34. Latarbelakang etnis: _____

i. Daftar pelatihan-pelatihan PPIA yang diterima dan tahun-tahunnya:

35. Agama: _____

36. Latarbelakang pendidikan:

- a. Tidak menyelesaikan sekolah dasar
- b. Sekolah dasar
- c. Sekolah menengah pertama
- d. Sekolah menengah atas
- e. Universitas

f. Pekerjaan:

- o. Dokter
- p. Bidan
- q. Perawat
- r. Konselor
- s. Petugas logistik

g. Status pernikahan:

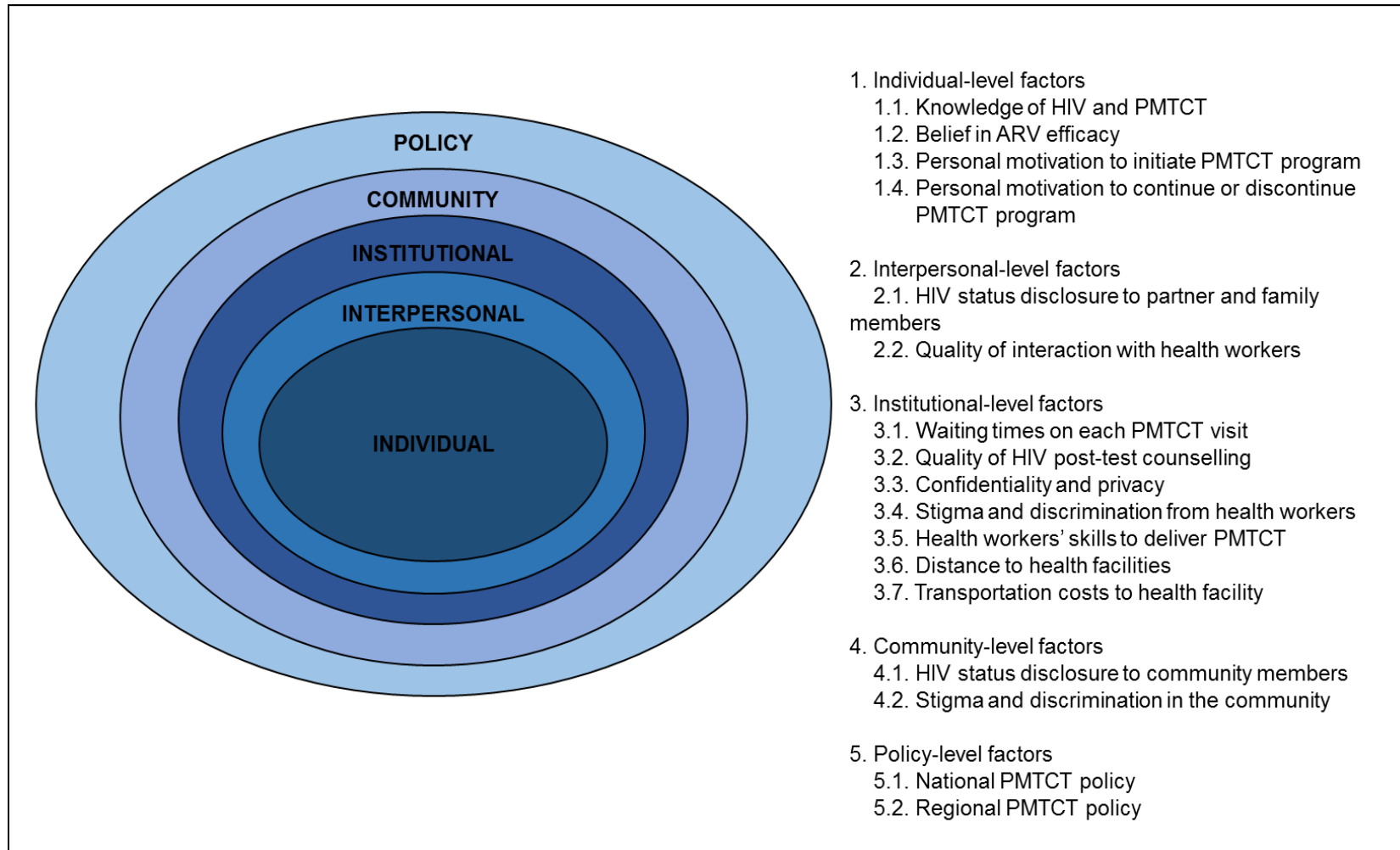
- m. Tidak menikah
- n. Menikah
- o. Cerai
- p. Janda/duda

h. Lama keterlibatan dalam program PPIA:

_____ (bulan) _____ (minggu)

III. Pertanyaan Utama	Tema-tema untuk digali
Topik 1: Peran dan tanggungjawab dalam program PPIA. Pertanyaan: “<i>Dapatkah anda menceritakan tentang apa yang anda lakukan dalam program PPIA?</i>”	• Tugas dan tanggungjawab • Tugas dan tanggungjawab lainnya di rumah sakit
Topik 2: Manajemen ibu hamil yang mengunjungi klinik KIA untuk pertama kalinya. Pertanyaan: “<i>Apa yang terjadi ketika seorang wanita hamil datang ke klinik untuk pertama kalinya?</i>”	• KTIP (konseling testing inisiatif petugas) vs KTS (konseling dan testing sukarela) • Alur pasien untuk PPIA • Panduan PPIA yang digunakan • Konseling pre-test: - Isi konseling - Metode untuk mengecek pemahaman wanita - Perkiraan durasi konseling - Faktor-faktor yang mempengaruhi durasi tersebut - Kerahasiaan dan privasi
Topik 3: Pendaftaran wanita dalam program PPIA. Pertanyaan: “<i>Bagaimana prosedurnya jika seorang wanita hamil membutuhkan program PPIA?</i>”	• Konseling post-test: - Isi konseling - Metode untuk mengecek pemahaman wanita - Perkiraan durasi konseling - Faktor-faktor yang mempengaruhi durasi tersebut - Kerahasiaan dan privasi • Penyebab-penyebab masuk/tidak masuk dalam program PPIA
Topik 4: Retensi wanita dalam program PPIA. Pertanyaan: “<i>Jenis tindakan apa yang tersedia untuk memastikan retensi perempuan dalam program?</i>”	• Fasilitator dan penghambat retensi dalam program PPIA: - Sistem rujukan - Penjangkauan komunitas - Komitmen terhadap program - Stigma dan diskriminasi - Isu-isu logistik
Topik 5: saran-saran untuk meningkatkan program PPIA. Pertanyaan: “<i>Bagaimana menurut anda program PPIA saat ini dapat ditingkatkan?</i>”	• Strategi-strategi PPIA untuk wanita hamil dengan berbagai kondisi: - Kendala sosial - Kendala geografis - Kendala finansial
Topik 6: Penutup Pertanyaan: “<i>Adakah hal lainnya yang ingin anda tambahkan?</i>”	

Appendix I. *A priori* themes using socioecological framework



Appendix J. Final themes

Facilitators	Barriers
1. Individual Level	
1.1. Knowledge of HIV and PMTCT	1.1. Knowledge of HIV and PMTCT
1.1.1. Source of knowledge	1.1.1. Source of knowledge
1.1.1.1. HIV post-test counsellor	
1.1.1.2. Peers who are on HIV treatment	1.1.1.1. Peers who are not on HIV treatment
1.1.1.3. Personal search that supports existing knowledge	1.1.1.2. Personal search that questions existing knowledge
1.1.2. Accuracy of knowledge	1.1.2. Accuracy of knowledge
1.1.2.1. Correct knowledge	1.1.2.1. Correct but incomplete knowledge
1.1.3. Belief in the knowledge	1.1.3. Disbelief in the knowledge
1.2. Belief in ARV efficacy	1.2. Disbelief in ARV efficacy
1.2.1. Personal experience	1.2.1. Personal experience
1.2.1.1. Improved health outcomes	1.2.1.1. ARV side effects or worse health outcomes
1.2.2. Close person's Experience	1.2.2. Close person's Experience
1.2.2.1. Improved health outcomes	1.2.2.1. ARVs' side effects or worse health outcomes
1.2.3 Other people's experience	1.2.3 Other people's experience
1.2.3.1. Improved health outcomes	1.2.3.1. ARVs' side effects or worse health outcomes
1.3. Personal motivation to initiate PMTCT program	1.3. Personal motivation to initiate PMTCT program
1.3.1. Expectation for a better health status	1.3.1. Feeling guilty
1.3.1.1. As a mother	1.3.1.1. As the source of HIV in unborn infant
1.3.1.1.1. To take care of her children	1.3.2. Feeling obligated
1.3.1.2. An HIV-negative infant	1.3.2.1. A good mother will get treatment for the sake of the unborn child

Facilitators	Barriers
1.4. Personal motivation to continue PMTCT program	1.4. Personal motivation to discontinue PMTCT program
1.4.1. Motivation to initiate treatment	1.4.1. Weak motivation to initiate PMTCT to begin with
1.4.1.1. Continuity of motivation	1.4.2. Emerging challenges related to return visits
1.4.1.2. Improvement of motivation	1.4.2.1. Financial issues
	1.4.2.1.1. Transportation cost
	1.4.2.2. Conflicting priorities
	1.4.2.2.1. Working
	1.4.2.2.2. Mobility
2. Interpersonal Level	
2.1. HIV status disclosure to partner	2.1. HIV status disclosure to partner
2.1.1. Partner	2.1.1. Partner
2.1.1.1. Partner was informed and got tested	2.1.1.1. Partner was informed and refused to get tested
2.1.1.1.1. Both are HIV positive and on treatment	
2.1.1.1.2. Only the woman is positive, but partner supports her treatment	2.1.1.1.1. Only the woman's HIV status is known, and partner does not support her treatment including domestic violence related to HIV status
3. Institutional Level	
3.1. Patients' aiting times for each PMTCT visit	3.1. Patients' aiting times for each PMTCT visit
3.1.1. Understanding the reasons for the waiting times	3.1.1. The waiting times could be reduced if wanted
3.1.2. Acceptance of the waiting times as a normal circumstance	3.1.2. The waiting times resulted in negative consequences such as cranky children and hungry mothers
3.2. Confidentiality and privacy	3.2. Confidentiality and privacy
3.2.1. HIV post-test counselling	
3.2.1.1. High confidentiality and privacy	

Facilitators	Barriers
3.2.2. Return visits	3.2.1. Return visits
3.2.2.1. Lack of confidentiality and privacy, but patients are not aware of the other's reasons to visit	3.2.1.1. Lack of confidentiality and privacy that prevents a woman from returning
3.3. Stigma and discrimination from health workers	
3.3.1. Health workers' attitude to women	
3.3.1.1. Friendly and kind	
3.3.1.2. Not friendly but still doing their jobs	
4. Community Level	
4.1. HIV status disclosure to family members	4.1. HIV status disclosure to family members
4.1.1. Parents	4.1.1. Parents
4.1.1.1. Parents are informed and support woman's treatment	4.1.1.1. Parents were not informed on HIV status
4.1.1.2. Parents share responsibilities with woman to take care of her child/children	
4.1.2. Other family members	4.1.2. Other family members
4.1.2.1. HIV status is known to other family members, and they support her HIV treatment	4.1.2.1. HIV status is unknown to other family members
4.2. Stigma and discrimination in the community	4.2. Stigma and discrimination in the community
4.2.1. Overcome by the need to be on HIV treatment	4.2.1. Fear of gossips and social alienation
5. Policy Level	
5.1. National PMTCT policy	5.1. National PMTCT policy

Facilitators	Barriers
5.1.1. Papua as an HIV program priority	5.1.1. Low ratio of health workers to patients
5.1.1.1. All pregnant women should be tested for HIV	5.1.1.1. Priority on HIV-positive women, curative rather than preventative
5.1.1.2. All HIV-positive women should enrol in HIV treatment	5.1.1.2. The importance of adherence to prevent drug resistance
5.1.1.3. Free medication	
5.2. Regional PMTCT policy	5.2. Regional PMTCT policy
5.2.1. Flexibility in the use of health insurance	5.2.1. Patients' negative response to changes in health insurance
5.2.1.1. Absence of ID card accepted	5.2.2. Absence of incentive and difficulty in human resource recruitment