

https://dspace.org/

Pre-ART program service delivery at a PHC facility level: access and retention of patients in care in the city of Johannesburg, South Africa

Nyasulu, Juliet Yauka-Kumwenda

2016-10-19
http://hdl.handle.net/10539/21246

Downloaded from a DSpace repository. https://dspace.org/

Pre-ART program service delivery at a PHC facility level:

Access and retention of patients in care in the City of Johannesburg, South Africa.

University of the Witwatersrand, Johannesburg

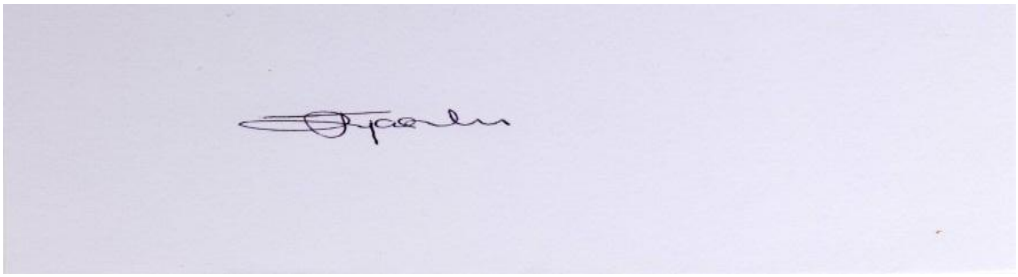
Juliet Yauka-Kumwenda Nyasulu (MPH, BSC Community Health)

Person Number: 534853

Date: 20th April 2016

Declaration

I, Juliet Yauka Kumwenda Nyasulu, declare that this research thesis is my own work. The thesis is being submitted for the degree of Doctor of Philosophy in the field of public health at the University of the Witwatersrand, Johannesburg. The thesis has not been submitted before for any degree of examination at this or any other university.



……

Juliet Yauka Kumwenda Nyasulu

Date:20th April 2016

Dedication

This thesis is dedicated to my children Wanangwa Nyasulu and Angella Nyasulu and my husband Professor Peter Subirakwenda Nyasulu with all my love and gratitude. I also wish to dedicate this to my mum and dad Lyness Nyabongololo Gondwe and Simon Yauka Kumwenda who taught me the beauty of education.

Scientific contribution

Original paper

NYASULU, J., MUCHIRI, E., MAZWI, S. & RATSHEFOLA, M. 2013. NIMART roll out to primary health care facilities increases access to antiretrovirals in Johannesburg: An interrupted time series analysis. *South Africa Medical Journal,* 103**,** 232-236.

Conference presentations

1. **NYASULU, J**., FONN, S. & MANDERSON, L. 2015. Retaining people in pre-ART care in Johannesburg PHC facilities. *South African AIDS Conference.* Durban, South Africa.
2. **NYASULU, J.** & MANDERSON, L. 2015. Linkages to care for ineligible newly diagnosed HIV+ individuals – A register audit in the City of Johannesburg, South Africa. *PHASA Conference.* Durban, South Africa.
3. **NYASULU, J.,** MUCHIRI, E. & FONN, S. 2013a. Factors contributing to retention and timely ART referral for pre-ART patients in the city of Johannesburg - A pre-ART care program baseline assessment. *PHASA Conference.* Cape Town, South Africa.
4. **NYASULU, J.,** MAZWI, S. & KGOPA, M. 2011. NiMART roll-out to PHC facilities. A tool to increasing access to care and reduce workload for referral facilities in Region F – Johannesburg *PHASA Conference. (Poster # 104).* Sandton, Johannesburg, South AFrica. November 2011.
5. SELEPE, M., SETSIBA, K., LEDWABA, M., MATHEKGA, K. & **NYASULU, J.** 2014. Mentoring and coaching: Improving documentation gaps in pre-ART register at Roedtan Clinic, Waterberg District, Limpopo Province. *PHASA Conference.* Polokwane, Limpopo, South Africa. 3-6 September 2014.

Awards

Foundation for Professional Development (FPD) grant for President's Emergency Plan for AIDS Relief (PEPFAR) fellow. The fellow worked on the PhD pre-ART project for 6 months (March – Aug 2012) as a coordinator, under my supervision and mentorship. She was instrumental in data collection and entering. After mentorship, she gained employment as a project manager for a research project under WRHI.

Table of contents

Declaration **2**
Dedication **3**
Scientific contribution **4**
Original paper **4**
Conference presentations **4**
Awards **5**
Table of contents **6**
List of tables **11**
List of figures **12**
Acknowledgements **13**
Definition of terms **15**
Acronyms **17**
Abstract **20**
Chapter One **20**
Background Information **22**
1.1 Problem statement 24
1.2 Conducting the PhD study 26
1.3 Thesis organisation 30
1.3.1 Literature review 30
1.3.2 Methodology 31
1.3.4 Results 31
1.3.5 Discussion 32
1.3.6 Conclusion and recommendations 32
Chapter Two: Literature Review **33**
2.1 Introduction 33
2.2 Pre-ART and ART roll-out in South Africa 35
2.2.1 1982-2003: First HIV diagnosis and wellness care 36
2.2.2 2004-2009: Antiretroviral therapy (ART) roll-out 37
2.2.3 2010 - present: Down-referral and the Nurse Initiated Management of ART (NIMART) roll-out 38
2.3 Why early ART initiation? 40
2.4 Why pre-ART care? 41
2.4.1 Six monthly CD4 cell count monitoring 42
2.4.2 Patient education about HIV/AIDS 44
2.4.3 Tuberculosis (TB) Isoniazid Preventive Therapy (IPT) 46
2.4.4 Psychosocial support of patients receiving pre-ART care 47
2.4.5 PMTCT services and retention into care 51
2.4.6 Cervical cancer screening 55
2.5 Youth Friendly Health Services (YFHS) 56
2.6 Medical pluralism among HIV+ individuals 59
2.7 Reasons for poor retention in pre-ART care 62

2.8 Good practices on pre-ART care service delivery 63
2.10 Conceptual framework 64
2.10.1 Rational models of organisational change 64
2.10.2 Rogers' diffusion of innovation classical theory of change 66
2.10.3 Addressing the quality of health services gaps in the SA health systems 66
2.11 Research question 70
2.12 Aim and objectives 70
2.12.1 Goal 70
2.12.2 Objectives 70
Chapter Three: Methodology 72
3.1 Study setting 72
3.1.1 Study site 72
3.1.2 Health services in Johannesburg and referral system 74
3.1.3 Referral system 75
3.1.4 Study period 77
3.2 Study design 77
3.3 Study sampling 80
3.3.1 Sampling methodology of participants for interviews: 80
3.3.2 Inclusion criteria for patients in NIMART roll-out 84
3.3.3 Sampling methodology of participants for the consultative workshop 85
3.4 Data collection 85
3.4.1 Data collection tools 85
3.4.2 Pretesting of data collection tools 87
3.4.3 Data collectors 88
3.4.4 Data collection process 89
3.5 Data processing and analysis 91
3.5.1 Quantitative data 91
3.5.1.1 Quantitative data from patient and staff interviews 91
3.5.1.2 Quantitative data from patient register and file audits**Error! Bookmark not defined.**
3.5.1.3 Statistical analysis for data from NIMART roll-out implementation 91
3.5.2 Qualitative data 93
3.6 Triangulation of data 93
3.7 Quality control 94
3.8 Ethics considerations 95
3.9 Dissemination of results 96
3.10 Limitations and special factors considered in the study 96
3.10.1 Selection bias 96
3.10.2 Information bias 97
3.10.3 Situational Factors 98
Chapter Four: Results 99
4.1 Interviews with pre-ART care patients 100

4.1.1 Socio-demographic characteristics and 6 monthly CD4 count check ups 100
4.1.2 CD4+ count levels for the interviewed pre-ART care patients 101
4.1.3 Patient pathways in accessing pre-ART care services 102
4.1.4 HIV/AIDS knowledge levels among pre-ART care patients 114
4.1.5 Services accessed by participants 117
4.1.6 Patients' awareness and access to available services 118
4.1.7 Sources of HIV/AIDS information 119
4.1.8 Disclosure of participants' HIV status 120
4.1.9 Identified gaps 121
4.2 Pre-ART service providers' interview results 133
4.2.1 Demographic information 133
4.2 Awareness and recording 133
4.2.3 Patient access to care pathway 134
4.2.4 Referral systems 134
4.2.5 Pre-ART services information systems 135
4.2.6 Comparison of pre-ART and NIMART services roll-out 136
4.2.7 Inability to monitor pre-ART care uptake and progress 137
4.3 NIMART roll-out 139
4.3.1 NIMART roll out process 139
4.3.2 "Where there's a will, there's a way" 141
4.3.3 NIMART training, mentoring and coaching of CoJ nurses by WRHI 143
4.3.4 Acceptability of the NIMART rollout 144
4.3.5 ART initiations and decrease in patients load 145
4.3.6 Total ART initiations in Region F 145
4.4 ART register audit results 148
4.4.1 Demographic characteristics, CD4 cell count and access to pre-ART care 148
4.5 Services accessed by patients in pre-ART care program 149
4.6 HCT register audit results 150
4.6.1 CD4 count levels at first HIV test 152
4.6.2 Gender, age and CD4 count levels at the time of the first HIV test 153
4.6.3 Collection of CD4 cell count results after the first HIV test. 154
4.7 Findings from the consultative workshop 155
4.7.1 Service Delivery 157
4.7.2 Health workforce 157
4.6.3 Health information systems 158
4.6.4 Access to essential medicines 158
4.6.5 Financing 158
4.6.6 Leadership/governance 159
Chapter Five: Discussion 160
5.1 Accessibility of pre-ART services 160
5.2 Awareness of available pre-ART services among pre-ART patients 163
5.3 CD4 cell count monitoring among patients retained in pre-ART care 164
5.4 First CD4 count check and collection of results 166

5.5 Categories of identified gaps through interviews with patients and staff 167
5.6 Time related factors 168
5.7 Pre-ART patients' knowledge levels around HIV/AIDS 171
5.8 Negative staff attitudes 172
5.9 Seeing beyond an HIV- baby 173
5.10 Service delivery costs, monitoring systems and accountability 176
5.11 Incompleteness of data and monitoring of pre-ART services 178
5.12 Referral system of complicated cases 179
5.13 NIMART roll-out 180
Chapter Six: Conclusion and Recommendations 183
6.1 Summary 183
6.2 Government's commitment to improving access to care 187
6.3 Recommendations 188
6.3.1 Service Delivery 188
6.3.2 Health workforce 192
6.3.3 Health Information Systems (HIS) 193
6.3.4 Access to essential medicines, ... 193
6.3.4 Leadership/Governance and Financing, ... 193
6.4 Areas for further research 194
6.5 Conclusion 196
7.0 References 198
8.0: Appendices 224
8.1 Pre-ART services checklist 224
8.2 Research ethics approval certificate 225
8.3 The University of the Witwatersrand research title approval letter 225
8.4 City of Johannesburg research approval letter 225
8.5: Data collection tools 225
8.5.1: Consent forms 225
8.5.1.1 Patient Interview consent forms 225
8.5.1.2: Staff interview consent form 225
8.5.2: Patient interview questionnaire 225
8.5.3 Staff interview questionnaire 225
8.5.4: Pre-ART register audit tool 225
8.5.5: File audit tool 225
8.5.6: NIMART Readiness assessment tool 225
8.6 Training program for data collectors 225
8.7: NIMART training content 225
8.8: CoJ Referral Form 225

8.9: Publications and conference outputs..... 225
8.9.1: NIMART Roll out publication..... 225
8.9.2 Factors contributing to pre-ART care access- 2013 PHASA conference..... 225
8.9.3 Pre-ART care access register audit- 2015 SAAIDS conference..... 225
8.9.4 Mentoring and coaching in pre-ART register documentation – 2014 PHASA Conference..... 225
8.9.5 NIMART roll out – 2011 PHASA Conference..... 225
8.9.6 Pre-ART Linkage to care abstract – 2015 PHASA conference..... 225

List of tables

Table 2.1 Research questions and objectives 71
Table 3.1 Data source and time period 77
Table 3.2 Qualitative and quantitative study questions 79
Table 3.3 STATA sample size calculation output 81
Table 3.4 Sampling methodology for register and file audits 84
Table 3.5 Changes made to data collection tools after pretesting 87
Table 3.6 Description of data collection processes 90
Table 3.7 Triangulation of different sources of data 94
Table 4.1 Study participants 99
Table 4.2 Socio-demographic characteristics and 6 monthly CD4 cell count monitoring ... 100
Table 4.3 Basic HIV/AIDS knowledge and six monthly CD4 cell count check-ups 115
Table 4.4 Disclosure of participants' HIV+ status 121
Table 4.5 Clinic A NIMART readiness results 141
Table 4.6 Clinic A assessment results after addressing the identified gaps 143
Table 4.7 Segmented regression model and most parsimonious model 147
Table 4.8 Pre-ART patients' demographic characteristics and access to care 148
Table 4.9 Services accessed by pre-ART patients 150
Table 4.10 CD4 count levels according to respondents' characteristics 152
Table 4.11 Collection of CD4 cell count results after the first HIV test 152
Table 4.12 Summary table of the identified gaps and causes. 156
Table 8.1 A sample of pre-ART care checklist 224

List of figures

Figure 2.1 HIV care in South Africa 35
Figure 2.2 quality improvement process 65
Figure 2.3 Conceptual framework 69
Figure 3.1 Map of South Africa and City of Johannesburg indicating Region F 72
Figure 3.2a The inner city of Johannesburg commercial area of Marshalltown 73
Figure 3.2b a degraded building in Joubert Park 73
Figure 3.3 Referral system flow diagram 75
Figure 3.5 Pre-ART patient file audit selection process flow diagram 81
Figure 3.6 Pre-ART filing cabinets and shelves 81
Figure 4.1 CD4 cell count levels for interviewed patients 101
Figure 4.2 Lusungu' s pre-ART care pathway 105
Figure 4.3 Nabandas's pre-ART care pathway 109
Figure 4.4 Chisomo' s pre-ART care pathway 113
Figure 4.5 Pre-ART services accessed by interviewed patients 117
Figure 4.6 Access and awareness of the services among pre-ART patients 118
Figure 4.7 Distribution of sources of information 119
Figure 4.8 Facility signane for opening hours 122
Figure 4.9a Patients in a queue outside the facility 126
Figure:4.9b Patients waiting for services inside the facility 126
Figure 4.10 Pre-ART patient care pathway reported by service providers 134
Figure:4.11 Pre-ART and ART cae registers" completeness 138
Figure:4.12 Ten steps in rolling out NIMART 140
Figure 4.13 Trends in ART initiations done at a PHC referral facility 145
Figure 4.14 Trends in ART initiations done at a PHC referral facility 146
Figure:4.15 Number of patients included in the Pre-ART care register 151
Figure 4.16 Kernel density estimate for CD4 cell count distribution 153
Figure 5.1 A synthesis of patient reported interrelated factors to pre-ART access 168

Acknowledgements

I thank my supervisor Professor Lenore Manderson for all her support and guidance, mentoring and caring attitude throughout the supervision period. I have personally grown professionally whilst executing this PhD project, enabling me to understand access to pre-ART care with reference to multiple factors affecting quality and access, and how they interrelate and affect each other. “Chiuta amutumbikeni Prof Manderson (May the Lord bless you Professor Manderson)!”

I would like to acknowledge my employer, the Health Systems Trust (HST), for its support by providing me with a favourable environment to complete my thesis and providing me with financial support towards the PhD study. Pursuing my PHD whilst working for HST has enabled me to learn how changes in the existing body of scientific knowledge directly affect service delivery and approaches to be used in providing HSS technical support.

I am grateful to FPD for funding the PEPFAR fellow Petronella Goliath-Soyizwaphi, who coordinated my PhD project at the time I needed the support most.

I would like to give special appreciation to the School of Public Health for the support structures put in place especially the Interdisciplinary PHD program which enabled me to progress against all odds! In addition, the Head of School of Public Health Professor Laetitia Rispel for her support at the time I needed it most.

I am grateful to the City of Johannesburg, staff and pre-ART patients from the study sites, for allowing me to collect the data and for participating in the study.

My special thanks go to WRHI especially Professor Francois Venter, the Deputy Executive Director for giving me a favourable environment to develop the proposal for my PhD

research and the opportunity to lead the implementation of NIMART in the City of Johannesburg.

I would like to acknowledge Professor Sharon Fonn for all her support when I was transferring the research project from WRHI to Wits School of Public Health (SOPH).

I would like to thank Lucy Chimoyi from WRHI for her support in designing the map to suit my PhD project

My special thanks to the data collection team: Tshepiso Allies, Stephen Ralephosa, Nhlanhla Ndlovu, Gladys Msane, Plexcedes Mapako and Petronella Goliath-Soyizwaphi - for their commitment throughout the data collection process including the debriefing sessions.

Special thanks to my siblings: My late sister, Mrs Violet Jamu (surviving through my dear niece Naomi Jamu) who inspired me to become the best I can. She was my guardian but passed away when I had just finished my first degree. I also thank my siblings Mrs Doreen Chimaliro, Moffat Kumwenda, Khwima Kumwenda, Msopa Kumwenda, Lumbani Kumwenda, Mrs Jean Chilinda, Persy Grace Kumwenda and Judgement Kumwenda, for giving me the courage to pursue my education further. This PhD is a standard set for my siblings, and specifically for their children, my beloved nieces and nephews.

Finally I would like to thank my one and only husband, Professor Peter Subirakwenda Nyasulu for the motivation, inspiration and setting the standards for academic achievements for me and my children. My two children, Angella and Wanangwa, for being always there for me as I multi-tasked as their mother, a PhD student and as a full time worker. My children have been an inspiration as I continued the process of setting the academic achievement standards their father had initiated.

Definition of terms

Stats: The term used by the City of Johannesburg Health Services providers to refer to statistical data that is collated from facilities on a monthly basis to monitor services, using the service point registers and other documents as data sources.

Service providers: Staff or service providers are used interchangeably in this report in reference to health workers providing services in the health facilities

PLWHAs: All people who test HIV+ and are living with the virus.

CD4 cell count cut-off point for ART: The criteria used to decide on the CD4 cell count level at which an HIV+ person gets initiated on ART. This criterion changed three times during this research study from ≤200 cells/µl to ≤350 cells/µl and currently at ≤500 cells/µl.

Pre-ART individual: An individual who has tested HIV+ and has a CD4 cell count of >350 without TB (not eligible to start ART).

Pre-ART program: A package of care that targets those individuals not yet eligible for ART and pre-ART service providers.

Timely initiation on ART: When an HIV+ individual has been initiated on ART at the CD4 count level of ≤350cells/µl or ≤200 cells/µl, depending on the CD4 cell count cut off point for ART initiation at the time of data collection.

Youths: Individuals aged 18 ≤24 years

Retention in Pre-ART care: A minimum of one subsequent CD4 cell count check in the previous 6 months

Youth friendly health services: Services that are based on a comprehensive understanding of what the young people in a particular society or community want, rather than being based on what service providers believe they need. It is about creating a service that young people trust and feel is there for them and that meet their needs.

Men friendly health services: Men friendly services are those that are welcoming and accessible for men, especially addressing both primary prevention and disease management.

Acronyms

3TC	Lamivudine
AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Care
ARIMA	Autoregressive Integrated Moving Average
ART	Antiretroviral therapy
ARV	Antiretroviral
AZT	Zidovudine
CACX	Cancer of the Cervix
CAM	Complementary and Alternative Medicine
CASCADE	Concerted Action on Sero-Conversion to AIDS and Death in Europe
CCMT	Comprehensive, Care Management and Treatment
CD4	Cell Differential Count
CDC	Centre for Disease Control
CHC	Community Health Centre
CMJAH	Charlotte Maxeke Johannesburg Academic Hospital
COJ	City of Johannesburg
CPT	Cotrimoxazole Prophylaxis Therapy
DASH	District Approach to System Strengthening in Health
DHIS	District Health Information System
DOH	Department of Health
FDC	Fixed Dose Combination
FHI	Family Health International
FPD	Fellowship for Professional Development
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HIV-	Human Immunodeficiency Virus Negative
HIV+	Human Immunodeficiency Virus Positive
HIS	Health Information System
HREC	Human Research Committee
HSS	Health Systems Strengthening
IAS-USA	International AIDS Society – United States of America

IEC	Information, Education and Communication
IHI	Institute for Health Improvement
INH	Isonicotinic Acid Hydrazide
IPT	Isoniazid Preventive Therapy
IQR	Inter Quartile Range
LTFU	Loss To Follow-Up
M&E	Monitoring and Evaluation
MDGs	Millennium Development Goals
MPH	Master of Public Health
NAFCI	National Adolescent-Friendly Clinic Initiative
NDOH	National Department Of Health
NGO	Non-Governmental Organisations
NHI	National Health Insurance
NHLS	National Health Laboratory Services
NIMART	Nurse Initiation Management of Antiretroviral Therapy
NLS	National Lab Services
NSP	National Strategic Plan for HIV, STIs and TB
NVP	Nevirapine
OHSC	Office of Health Standards and Compliance
OI	Opportunistic Infections
PDSA	Plan, Do, Study and Adopt/Abandon
PEPFAR	President's Emergency Plan for AIDS Relief
PHC	Primary Health Care
PI	Patient Interview
PLHIV	Persons Living With HIV
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission of HIV
POC	Point of Care
Pre-ART	Pre- Antiretroviral Treatment
QI	Quality Improvement
QIM	Quality Improvement Mentoring
QIP	Quality Improvement Plan
RHRU	Reproductive Health Research Unit
ROR	Rationalisation of Registers

RSA	Republic of South Africa
SA	South Africa
SD	Standard Deviation
SI	Staff Interview
SMS	Short Messaging System
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
TB	Tuberculosis
TM	Traditional Medicine
TST	Tuberculin Skin Test
UN	United Nations
UNAIDS	United Nations for Acquired Immunodeficiency Syndrome
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNGASS	United Nations General Assembly Special Session on HIV and AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization
WRHI	Witwatersrand Reproductive Health Research Institute
YFHS	Youth Friendly Health Services

Abstract

Introduction

South Africa (SA) has more than 6 million people infected with HIV, of whom 2.4 million have been initiated on Antiretroviral Treatment (ART). HIV positive non-pregnant women, and both women and men without tuberculosis and with a CD4 cell count of >500 cells/μl, were not eligible for ART initiation at the time of the study. These were transferred to a wellness (pre-ART) program for regular counselling and follow up. However, in SA, as in many other countries, previous data reported that there has been poor retention of HIV positive individuals prior to initiation on ART. This was particularly the case for youths and men. If people do not participate in a pre-ART program and are not regularly followed up, they often present for ART only when they are sick. Without an appropriate pre-ART program in PHC facilities, patients may end up delaying for ART initiation, leading to poor treatment outcome.

Objective

The objective of the study was to establish the existing gaps in pre-ART care service delivery and draw recommendations that would improve the quality of the delivery of pre-ART care and retain patients in care.

Methodology

This was a mixed method study conducted in the City of Johannesburg (CoJ). Both qualitative and quantitative data were collected through interviews, register and file audits and the District Health Information System (DHIS). A total of 2,018 participants were involved in this study through patient (73) and staff (12) interviews, an HCT register audit (1715), ART register and file audits (203), and consultative workshop with health services managers (15). In addition, we used records from DHIS data base for NIMART uptake before (6957) and after (13578) the NIMART roll-out in the CoJ. STATA version 12.0 was used to analyse quantitative data whilst qualitative data was analysed manually. Ethics approval was obtained from the University of the Witwatersrand Committee for Research on Human Subjects. Prior to each interview session, informed consent was obtained.

Results

The following pre-ART service delivery challenges were identified: long waiting times, multiple clinic visits, drug stock-outs, shortage of staff, unplanned disclosure of ones' HIV+ status, poor staff attitudes to patients, length of time spent on documentation by service providers, and cost implications in accessing pre-ART care. Factors contributing to these challenges with potential solutions to overcome these were identified. The study also established that men (P=0.001) and youths (p=0.05) were less likely than their counterparts to collect their first CD4 cell count results. The majority of patients retained in pre-ART care did not access the available pre-ART care services and there was no difference in timely ART initiation between those who accessed pre-ART before ART initiation and those who did not – meaning that the current pre-ART care program was not working. However, being knowledgeable of the fact that an HIV+ person can lead a normal life through getting married and having an HIV- child was positively associated with retention in pre-ART care (p=0.001), i.e. attendance for 6 monthly monitoring. Rolling out NIMART into primary health care facilities in the CoJ significantly increased ART uptake, and reduced the workload in the referral facilities.

Conclusion and recommendations

Multiple interrelated pre-ART care service delivery challenges were identified in this study, consistent with other studies conducted in SA and elsewhere. This is a cause for concern as the provision of effective HIV services is compromised, leading to poor outcomes. In contrast, poor access and delayed ART initiation for patients retained in pre-ART care, established in this study, have not been reported previously. Therefore there is a need to improve access to quality pre-ART care services by those patients retained in pre-ART care. This can be attained by reducing pre-ART care access time through established innovations like Point of Care (POC) CD4 cell count collection and Central Chronic Medicines Dispensing and Distribution Programme (CCMDD), and addressing shortages of staff. In addition, raising patients' awareness on available services, addressing poor staff attitudes, and strengthening linkages to pre-ART care after patients test HIV positive, would improve the uptake of pre-ART care especially among men and youths.

Chapter One

Background Information

Human Immunodeficiency Virus (HIV) has now been known for about 35 years (CDC, 1981). Since this time, more than 60 million people have been infected (Merson et al., 2008), resulting in about 25 million deaths (UNAIDS, 2015). In addition, about 33 million people were estimated to be living with the virus in 2012 (UNAIDS, 2014b), which had increased to about 37 million in 2014 (UNAIDS, 2015), the majority in resource poor settings (UNAIDS, 2014b). At first, as research was being conducted to establish aetiology, diagnosis and management of the disease and its transmission, the response to the HIV pandemic was prevention. From early 2000, however, care was incorporated into a package. At that time, this included psychosocial support, STI and TB screening, management of opportunistic infections, and care for the terminally ill through home-based and palliative care. It also included care for orphans and vulnerable children due to AIDS morbidity and mortality, programs for Prevention of Mother to Child Transition (PMTCT), and Antiretroviral Therapy (ART) (Harries, 2002).

ART was introduced around 1996 (Palella et al., 1998), but at first it could only be afforded by high income countries. In 2001, the United Nations General Assembly Special Session (UNGASS) convened in New York criticised the inequalities of ART access, leading to a global commitment to universal access to ART with other HIV services by 2010 (UNAIDS, 2001). For example, in 2002 when the first HIV Management Guidelines were published by WHO, about 6 million people from resource limited countries were in need of ART, but only about 230,000 had access of this, of whom half were from Brazil (WHO, 2002). In order to mobilise resources for poor countries, the then UN General Secretary, Kofi Annan, requested that a Global AIDS Alliance be established, through which funds could be mobilised to

improve access to essential HIV services, including ART, in resource limited countries (UNAIDS, 2001). When ART was rolled out in these countries, a CD4 cell count cut off point of ≤200 cells/μl was used (WHO, 2003). Globally, there was a backlog of people eligible for ART waiting to be initiated. In 2006, Uganda was the first African country to initiate more patients than its target of 60,000, as 65,000 patients were initiated on ART (WHO, 2006). In addition, the WHO Guidelines recommended the need to prioritise action on those who were not yet eligible to start ART to ensure that they were continuously monitored and so could be initiated in a timely manner (WHO, 2003). Since then, this priority is advocated, although there is little implementation evidence as major implementation gaps (to be discussed in detail later in this thesis) exist in pre-ART care.

South Africa has over 6 million people living with HIV (Shisana et al., 2014), and has the largest Antiretroviral Therapy (ART) program in the world (UNAIDS, 2014b). There have been challenges around the retention of patients in HIV care programs among those initiated on ART (Brinkhof et al., 2008, Fox and Rosen, 2010, Clouse et al., 2013) and major attrition among those not yet eligible for ART and at different stages of viral infection (Kranzer et al., 2012, Losina et al., 2010), and among those eligible but still in the process of being initiated on ART (Tayler-Smith et al., 2010, Micek et al., 2009). Poor retention in pre-ART care has been shown to delay ART initiation, as patients mostly return for care only when sick (Lessells et al., 2011).

By 2014, over 2.4 million people are on ART in South Africa (UNAIDS, 2014b). This large ART program has been possible due to government commitment to increase access to ART in line with international recommendations. Varying over time, the CD4 cell count cut off point for ART initiation increased from ≤200 cells/μl in 2010 (SA, 2010a) to ≤350 cells/μl (SA, 2013d) in 2013, and in 2014, ≤500 cells/μl (SA, 2014b). In addition, HIV+ patients who are

pregnant and have been diagnosed with TB are initiated on ART regardless of their CD4 cell count level. As a result, more than 300,000 people are initiated on ART each year, resulting in increasing pressure on limited public health resources (Venter and Barker, 2013). It is important that these limited resources are equally disbursed to all HIV service points, including pre-ART.

1.1 Problem statement

In primary health care facilities in South Africa, in line with WHO recommendations, patients who are not yet qualified to start ART are transferred to a pre-ART care program for monitoring, and to enable them to access prescribed pre-ART care services, including HIV counselling and testing (HCT), INH Prophylaxis Therapy (IPT), Cotrimoxazole Prophylaxis Therapy (CPT), PMTCT and psychosocial support (SA, 2013d, WHO, 2013a). However, as already indicated, there is overwhelming evidence of patients not retained in pre-ART care and lost to follow-up (Boulle et al., 2010, Cornell et al., 2010, Lessells et al., 2011, Rosen and Fox, 2011). Research evidence indicates that the continuing loss of patients in antiretroviral treatment programs, among people already on treatment and among those waiting to start treatment, is a sign of failure in the health system, not just the fault of patients (Zachariah et al., 2010).

Various factors related to both patients and health systems contribute to patients not being retained in pre-ART care. Attrition from care programs is more likely to occur among men, youths and those with higher CD4 cell counts (Rosen and Fox, 2011, Ahmed et al., 2013), while women and those who are married are more likely to remain in care programs (Ahmed et al., 2013). The documented health system factors include poor monitoring, medication stock-outs, inadequate pre-ART care, and lack of staff confidentiality leading to unplanned HIV+ status disclosure and stigma (Muhamadi et al., 2010). In addition, lack of

documentation of next date of visit on their medical chart is associated with attrition and loss to follow up (Ahmed et al., 2013). Best practices which increase pre-ART care retention include a range of medical and social services. These are: CD4 cell point of care (Faal et al., 2011, Jani et al., 2010); Cotrimoxazole prophylaxis accompanied by efficient referral (Kohler et al., 2011); integration of all services delivered in a facility, the provision of medical and food incentives; strengthened counselling and peer support (Kundu et al., 2012, Marson et al., 2013); and the provision of accurate information on HIV to patients (Smith et al., 2013).

Boyles and Wilkinson (2011) wrote a position paper highlighting the fact that the WHO and RSA Guidelines did not provide clear guidance on the pre-ART care services package and its implementation, leading them to emphasise an urgent need to develop pre-ART guidelines, based on best practices in pre-ART care services. To date, no collective well-packaged interventions have proven to be effective in the pre-ART period to reduce poor retention, and further operational research is needed to identify local solutions (Govindasamy et al., 2014).

In addition, the lack of well-packaged and appropriate pre-ART programs in PHC facilities appear to lead to patients using multiple health care modalities, including practitioners in private and traditional health sectors; this has also been associated with delays in ART initiation (Moshabela et al., 2009). The assumption is that greater effort and resources are put into ART initiations, while patients not yet qualified to start ART receive little attention. In the real world, resource limited, high demand environment of health services in contemporary SA, there are competing demands on service providers' time and conflicting priorities. Developing a feasible pre-ART package is a challenge. An intended outcome of this study will be to develop recommendations for a feasible and well-structured pre-ART program package that will improve the timely referral of patients for ART in South Africa.

1.2 Conducting the PhD study

In the early 2000s, I developed a special interest in factors affecting access to HIV services, when I was working as a HIV Program Manager for GOAL, an Irish NGO based in Malawi which focused on strengthening the Malawian health system in the roll-out PMTCT. At that time, there were no HIV counselling and testing (HCT) centres in primary health facilities in Malawi. GOAL started by establishing HCT centres in public health facilities, and through these centres, the PMTCT program for HIV+ women was rolled out. Major barriers appeared to prevent women from joining PMTCT services; this led me to conduct a study on barriers to their uptake of PMTCT (Nyasulu and Nyasulu, 2011a) and the decision making of women to join PMTCT (Nyasulu and Nyasulu, 2011b).

When I moved to South Africa in 2009, I started working for Wits Reproductive Health Research Institute (WRHI) as a Regional Quality Improvement Mentor (RQIM), providing health systems strengthening support to the City of Johannesburg. In this context, I focused on access to quality HIV/TB services. At this time, I realized that unlike in Malawi, where women had difficulties in accessing PMTCT, in SA access to PMTCT was not a challenge: the uptake in SA was above the 95% WHO target (WHO, 2013b, Goga et al., 2012), compared to 38.8% in Malawi at the time (Malawi, 2010). However, I observed that there were gaps in proper follow-up systems for patients not yet eligible for ART. Our project reports indicated that high numbers of healthy HIV+ individuals and PMTCT mothers who were not yet eligible to start ART after delivery dropped out of pre-ART care. This led to individuals returning into care late, when they already had a very low CD4 cell count, compromising the effectiveness of treatment. This observation ignited my passion to improve access to HIV services, and I decided to enroll for a PhD with a focus on exploring pre-ART care in Johannesburg. My goal was to develop recommendations that would strengthen pre-ART care service delivery and improve access to quality services.

Initially, according to the approved PhD protocol, I was interested in the impact of a well-structured and appropriate pre-ART program package at a PHC facility level on the timely referral for Antiretroviral Treatment (ART) initiation of HIV+ pre-ART individuals. In line with this, I had intended to:

- Conduct a baseline assessment through interviews with staff and patients and to undertake file audits on the pre-ART program, to identify existing gaps to be addressed in a program which I would design. I anticipated that patients and staff who were to be interviewed would provide possible solutions to the existing gaps;
- Conduct a consultative workshop with the City of Johannesburg to present and validate the baseline assessment findings, discuss the gaps identified, the causes, and the possible solutions; and
- Develop and test the impact of a well-structured and appropriate pre-ART program package in PHC facilities, to ensure the timely ART referral of pre-ART individuals.

During the assessment of the PhD proposal, it was suggested to me that the project was beyond the scope of and not feasible for a PhD, and that it would be expensive to implement and test the impact of a newly designed pre-ART program. At that time, I was able to defend my proposal, as it was possible to implement an intervention in the context of my own role, and that of the team I was managing as an RQIM at WRHI. The team was composed of medical doctors, nurses and data quality improvement mentors (QIM), who were already providing health systems strengthening (HSS) technical support in the City of Johannesburg through quality improvement (QI) approaches. Unfortunately, at the end of 2012, a year after my PhD registration, there was no further funding for the project, and I and others in the team were retrenched. After leaving WRHI, in January 2013, I joined Health Systems Trust (HST), working as a quality improvement technical advisor for five provinces of South Africa. This

excluded the City of Johannesburg. By this time, the PhD project baseline assessment data had been collected, and I then conducted the second phase of my project, the consultative workshop with CoJ health services managers. However, I was not in a position to design and initiate a pre-ART program to be implemented by doctors, nurses and data QIMs.

However, the same training, mentoring and coaching approach proposed to be applied in implementing and testing the designed pre-ART program was applied by the same team in rolling out Nurses Initiation Management of Antiretroviral Therapy (NIMART), in the same study sites of the inner City of Johannesburg. As a result, I decided to use the data from the NIMART roll-out for this research project, and so I describe and analyze it as a potential innovation that could be applied more widely to strengthen the implementation of pre-ART care service delivery. The NIMART roll-out significantly improved ART uptake, as described in the publication provided in Appendix 8.9.1.

By incorporating the NIMART roll-out innovation, I then reworked the PhD topic, so retrospectively changing the study. The revised PHD research involved the following steps:

- Conduct a baseline assessment through interviews with staff, patients and file audits on the pre-ART program to identify gaps to be addressed in a new program. Patients and staff were to be interviewed to provide their perceptions of existing gaps and possible solutions.
- Conduct a consultative workshop with the City of Johannesburg to present and validate the baseline assessment findings, discuss the gaps identified, the causes and the possible solutions.
- Document the NIMART roll-out innovation in the City of Johannesburg.
- Identify lessons learnt from piloting the NIMART roll-out and form possible solutions from pre-ART care patients and service provider interviews and the consultative

workshop, and draw on these to develop recommendations for appropriate pre-ART care to improve access to available services and to retain patients in care.

Currently, working as a mentor and HSS technical advisor on access to quality HIV and TB services at HST, I support HST mentors at provincial, district and facility levels in applying quality improvement approaches to health systems strengthening. I have learnt that the gaps identified in the City of Johannesburg are cross-cutting, occurring in all South African provinces. At HST, we also document the best practices and disseminate them. Given the incompleteness of pre-ART care records, a finding in my baseline assessment in CoJ, I supported a project facility mentor and DoH facility staff to use QI approaches to address the gap in their facilities. This improved the completeness of the records, and a paper for one of the facilities in Limpopo province was presented at Public Health Association of South Africa (PHASA) international conference in September 2014, winning the award of the best oral presentation (see Appendix 8.9.4). It has also been documented as a detailed case study by the HST communications and editing team (King, 2015).

Timeliness was the other challenge I encountered in executing this project. The research project needed to be conducted in a timely manner to make a meaningful contribution to the fast evolving body of knowledge related to ART. For example, as noted above, when I started working on the project proposal in 2012, the CD4 cell count threshold for ART initiation was at 200 cells/µL. In March 2012, it had increased to 350 cells/µL, and then later in January 2015 to 500 cells/µL (Motsoaledi, 23 July 2014, SA, 2014(b)). These changes provided me with a better understanding of the SA government's allocation of efforts and resources on ART compared to pre-ART. This led me to pose the question: "By increasing the cutoff point, are we reaching all eligible people or just a specific category of HIV+ individuals?" It is importance to mention that the findings, arguments and recommendations drawn from this

project are not just applicable to pre-ART care, but embrace issues around linkages to care and access to HIV and other services.

As a Health Systems Strengthening (HSS) Technical Advisor (TA), the experience I have had in conducting this PhD research project has enabled me to better understand the complexity of strengthening access to HIV services by people living with HIV, the interrelationships of the health systems strengthening building blocks, how they complement each other, and the importance of tackling them all in addressing access to available services. Most importantly, it was important to understand the lived experience of people living with HIV, and the attached stigma and discrimination to HIV. In addition, the never-ending process of normalizing HIV as any other chronic disease, easily described by service providers, was clearly an unending struggle for those living with the virus. Going through their interview scripts from my collected data and reviewing literature on their lived experience, I was able to appreciate and think about becoming a better TA in HSS on access to HIV services.

1.3 Thesis organisation

My PhD thesis begins with a description of the background to the study, which is the problem setting section for the thesis. In it, I have provided an overview of the HIV burden globally and in South Africa, and the SA government's priorities for, commitments to and investment in pre-ART and ART service delivery. I have also included a problem statement. The factors that motivated and inspired me to conduct a study in pre-ART care, and my lived experience in executing the study, are also covered in this section.

1.3.1 Literature review

In this chapter, I provide a synthesis of the existing body of scholarly knowledge in the area of HIV/AIDS, ART and pre-ART service delivery, globally and within South Africa. I also provide more details on how HIV care was rolled out in South Africa, from the time the first

person was diagnosed with HIV to date. I describe the theoretical concepts upon which this study was based and present a conceptual framework. I conclude this chapter with research questions and objectives.

1.3.2 Methodology

In this chapter I describe how mixed methods were applied to explore the implementation of the existing pre-ART service delivery in South Africa. Since five different sources of data were used in this study, I also describe the triangulation of the data in answering the research question. The processes involved, as described, sampling of participants, data collection, analysis, quality controls and ethical issues.

1.3.4 Results

In this chapter I describe findings from all five data sources: pre-ART care staff and patient interviews, pre-ART file audits, pre-ART register audit and the District Health Information System (DHIS) database for the City of Johannesburg. I established that there is poor retention of pre-ART patients in the City of Johannesburg. Poor access to the available pre-ART services for those retained in care was also established, leading to delays in ART initiation even for those retained in care. Interrelated factors, which contributed to poor retention and access to pre-ART services, ranged from health systems, staff and patient-related factors. The NIMART roll-out innovation has shown how the training, mentoring and coaching of service providers on a newly rolled out programme improves the uptake of services. In order to provide more meaning to these findings, more detailed information is given through four case studies from patient interviews, and through describing the NIMART roll-out.

1.3.5 Discussion

In this chapter I provide a synthesis and discussion of the study findings in relation to the existing body of knowledge. In addition limitations to the study are highlighted. I also highlight new findings, illustrating how this thesis contributes to the existing literature. Throughout the discussion section, I anticipate recommendations and possible solutions from the study findings. Lastly, I describe the predetermined limitations of the study and some special situational factors that needed to be acknowledged.

1.3.6 Conclusion and recommendations

In this chapter, conclusions are drawn from the findings and I present and discuss the recommendations. I also interpret the key study findings in relation to the implications they have on the South African ART and pre-ART service delivery agenda. It is critical to mention that the findings and recommendations for this study can be applied not only in pre-ART care but services delivery across HIV/TB services as well as other services. As a result, even if the policy changes to treating all HIV+ people regardless of their CD4 cell count, the project findings will still be useful and applicable in different set ups. The recommendations in this section mainly focus on how the study findings can be translated or incorporated into the existing South African public health policies. Throughout the process of conducting this PhD study, more questions were raised, highlighting the need to further supplement the existing body of knowledge of pre-ART and ART service delivery. As a result, this section also outlines proposed areas for further research.

Chapter Two

Literature Review

2.1 Introduction

Globally, about 36.9 million people were estimated to be living with HIV in 2014, a rise from preceding years primarily as more people benefited from antiretroviral therapy (ART) (UNAIDS, 2015). According to the ART calculator by, stipulating that only about one third of all HIV+ individuals are eligible to start ART at a given point in time, about 24 million people are HIV+ but are not yet eligible to start ART (Leydon et al., 2010). The global recommendation by WHO is that HIV+ individuals initiate on ART when their CD4 cell count is below 500 cells/µl (WHO, 2013a), although different countries use different ART initiation CD4 cell count cut-off points depending on available resources and feasibility of implementing the policy (WHO, 2013b). A landmark moment has been reached towards meeting the 2001 declaration goals (UNAIDS, 2001) as 15 million people have already been initiated on ART (UNAIDS, 2015). Even though we have reached ART uptake 2011 target, more ambitious 90-90-90 target has already been set -- meaning that 90% are (1) diagnosed, (2) on ART and (3) virally suppressed – a goal towards elimination of HIV by 2030 (UNAIDS, 2014a).

Reflecting this, UNAIDS has reported a global decline in the incidence of deaths due to AIDS by 42% since 2005, representing fewer deaths than the preceding decade due to the benefits of the roll-out of ART, and ART is estimated to have prevented 7.8 million AIDS-related deaths worldwide (UNAIDS, 2015). However, globally, the HIV epidemic continues to disproportionally affect sub-Saharan Africa (SSA) as 70% of all new HIV infections occur in the region (UNAIDS, 2013), despite a 35% decline in new HIV infections per year from 2001 to 2014 (UNAIDS, 2015). The established reasons for the high HIV burden in SSA

include poverty, which has been shown to lead to high rates of sexual trade (Mbirimtengerenji, 2007). Secondly, cultural practices (Moyo and Müller, 2011) are still prevalent in sub-Saharan countries as in Malawi, such as *fisi*, whereby a man hires another man to have sex with his wife if he cannot impregnate the wife (MHRC, 2005), or rites of passage to puberty when counsellors hire a male adult to have sex with newly initiated girls (MHRC, 2005). Gender inequalities lead to intimate partner violence and unprotected sex (Jewkes, 2002, Durevall and Lindskog, 2014), and these are also implicated in the continued transmission of HIV (Jewkes, 2002, Barker, 2007).

In South Africa, an estimated 6.4 million people live with HIV and there was a slight increase in HIV prevalence among the SA general population from 10.6% in 2008 to 12.2% in 2012 (Shisana et al., 2014). There is an addition of about 100,000 new HIV positive cases yearly (SA, 2013a). According to the mid-term review on progress towards achieving HIV/AIDS targets and elimination commitments in South Africa, about 2.1 million HIV+ individuals were on ART in 2013, making South Africa's program the largest ART program globally (SA, 2013a). Increased access to ART in South Africa has been possible because in April 2010, the SA government decentralised ART services, enabling nurses to prescribe and dispense ARVs in all PHC facilities (Gordhan, 2010). Reflecting the numbers of people on ART, there has been a significant decline in AIDS related mortality in recent years, with about 780,000 deaths averted between 2003 and 2012 (WHO, 2013b).

Despite these key advances in initiating patients on ART, delays in determining the ART eligibility have been well documented (Boulle et al., 2010, Cornell et al., 2010, Rosen and Fox, 2011, Lessells et al., 2011). For instance, while encouraging South Africans to test for HIV to accelerate diagnosis (Alcorn 2010), the average CD4 count level for patients initiating on ART in SA is lower than the CD4 cell count cut-off point now used for ART eligibility

(Boulle et al., 2010, Cornell et al., 2010). The main contributing factor is poor retention among pre-ART patients, resulting in individuals returning to care later than ideal, so negatively affecting the effectiveness of ART (Lessells et al., 2011). Men also appear to be less likely to be retained in care than women (Mugglin et al., 2012). South Africa's experience is consistent with that of other countries in the region; a systematic review of pre-ART care retention in sub-Saharan Africa established that patient management before ART initiation posed huge challenges, with only approximately 18% remaining continually in care until they were eligible to start ART. Again younger individuals and men are most often lost to follow-up (Rosen and Fox, 2011).

2.2 Pre-ART and ART roll-out in South Africa

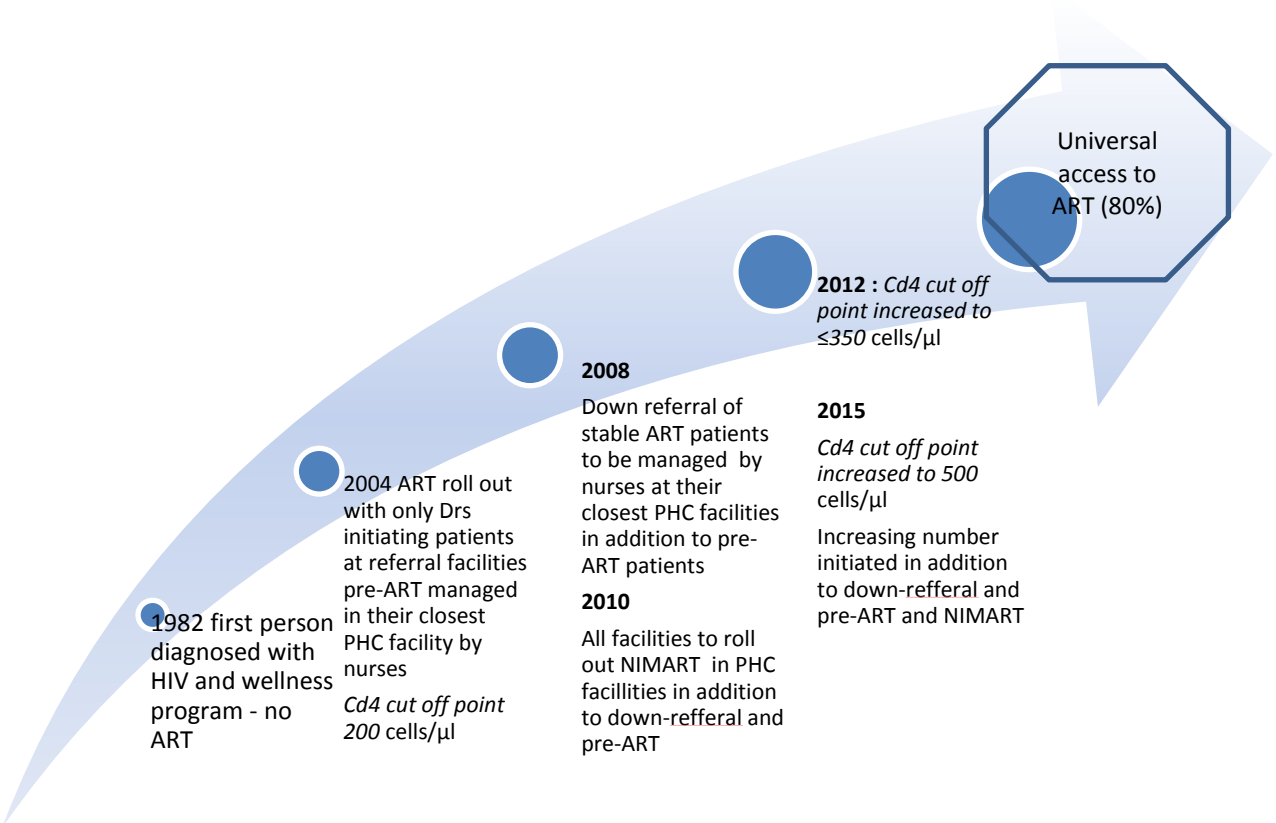


Figure 2.1: HIV care in South Africa

As we talk about pre-ART care, it is important to understand the history of the type of care given to HIV+ individuals prior to accessing ART. This evolved from the time when ART

was not available to HIV+ individuals in the public health sector, to when the CD4 count cut-off point for ART initiation has been increased to 500 cells/µl. A synthesis of how ART has evolved in SA is set out in Figure 1 above and discussed in the text that follows.

2.2.1 1982-2003: First HIV diagnosis and wellness care

The first person was diagnosed with HIV in South Africa in 1982 (Ras et al., 1983). From 1996 to December 2003, ART became available in the private sector though not available in the public health facilities, and so was mainly accessed by the rich (UNAIDS, 2001, AVERT, 2015). During this period, in the public health facilities of South Africa, the main focus in HIV care was diagnosis and wellness, with HIV+ individuals followed up by nurses and doctors to be provided with multivitamins and treated for opportunistic infections; resources were directed to the wellness program (SA, 2000a). In 2003, the South African Cabinet approved an ART roll-out operational plan – a major government long-term commitment to allocate resources to procure ARVs and implement the roll-out (SA, 2003). The actual ART roll-out was implemented from 2004, with the eligibility criteria determined by an individual's CD4 cell count cut-off point of ≤200 cells/µl and WHO clinical staging; this was a useful tool to assist clinicians to decide ART initiation eligibility in the absence of CD4 cell count laboratory results (WHO, 2007). The WHO clinical staging of HIV is the system of grouping HIV+ individuals into 4 stages reflecting the HIV disease progression according to the WHO HIV case definition guidelines (WHO, 2007) as follows:

- Primary stage: Asymptomatic
- Clinical stage 1: Asymptomatic with persistent generalized swelling of the lymph nodes
- Clinical stage 2: Some unexplained weight loss, repeated respiratory tract and other common infections

- Clinical stage 3: Conditions where a possible diagnosis can be made on the basis of clinical signs like chronic diarrhea, severe weight loss, TB and other infections
- Clinical stage 4: AIDS defining illness stage, diagnosis can also be made clinically.

2.2.2 2004-2009: Antiretroviral therapy (ART) roll-out

In 2004, the ART initiation criteria was introduced in the South African HIV Care Policy; according to this, all HIV+ patients with a CD4 cell count of ≤200 cells/µl or WHO Stage 4 of HIV infection were to be initiated on ART (SA, 2004). Emphasis was placed on ART initiation and patient follow-up by doctors through SA referral hospitals (SA, 2004). Those who had a CD4 cell count >200 cells/µl and/or were categorised as WHO Stage 3 or lower were followed up by nurses in their nearest facilities, mainly PHC facilities, while awaiting for ART eligibility and up-referral for ART initiation by doctors (SA, 2004).

As described above, at the beginning of ART roll-out, ART was classified as one of complex care, and only doctors and not nurses were allowed to initiate patients on ART (SA, 2004). Doctors are highly trained health care providers, with training over six years and with SA having the highest cost in Sub-Saharan region (about US $59,000 to train one doctor) (Mills et al., 2011). On the other hand, professional nurses train for 4 years, covering both general nursing and midwifery (SA, 2005a). As a result, the ratio of doctors to population is 77/100,000, which translates into about 1:1300 (Strachan et al., 2011) compared to a nurse-population ratio of 1:451 for nurses (Joubert, 2009). Coupled with the HIV burden, the policy that doctors only could initiate patients on ART led to the overburdening of doctors (Sanne et al., 2010).

Therefore clinical mentoring and coaching of nurses in ART initiation and management (NIMART) was an option, to increase the confidence of nurses and improve professional development, so enabling them to manage so called “complex” ART patients (Green et al.,

2014). In addition, in 2007, research was conducted in Botswana to establish the possibility of nurses initiating patients on ART, with results reflecting that there were no differences in patient outcomes whether ART was initiated by a doctor or a nurse (Miles, Clutterbuck, Seitio, Sebego, & Riley, 2007). As a result, task shifting of ART initiation and management from doctors to nurses proved to be cost-effective with similar patient outcomes (Sanne et al., 2010).

2.2.3 2010 - present: Down-referral and the Nurse Initiated Management of ART (NIMART) roll-out

Using the same CD4 ART initiation cut-off point of 200 cells/µl, in SA, by 2009 about 1.2 million HIV+ individuals were estimated to be eligible for ART, way beyond the capacity of the referral facilities where doctors were initiating (Klaussner et al., 2011). The solution to reducing the referral site workload was the introduction of decentralised ART services through the down-referral of stable patients on ART to their nearest PHC facilities. This improved the retention of ART patients and enabled referral sites to focus on problematic patients (Klaussner et al., 2011, Zachariah et al., 2007). At the same time, the referral of patients to facilities closer to their homes reduced their time and transport costs in accessing ART (Mukora et al., 2011). This meant an added task for nurses at PHC facilities to monitor these ART initiated stable patients, in addition to providing care to people not yet eligible for ART and awaiting up-referral for doctors' ART initiation. Even so, in South Africa and elsewhere, further research reported that NIMART improved access, was cost-effective, and was not inferior to doctor-managed ART (Miles et al., 2007, Sanne et al., 2010).

In response to this, in April 2010 the South African Government committed to rolling out ART initiation in all the 5,500 facilities from primary, secondary and tertiary levels of health service delivery – a mandate that led to Nurse–Initiated Management of Antiretroviral

Treatment (NIMART) (Motsoaledi, 13 April 2010). This meant ART was no longer a doctors' only prescription but could be prescribed by nurses- in all SA government PHC facilities. This led to the need to train, mentor and coach nurses in NIMART (Motsoaledi, 13 April 2010). The roll-out of NIMART in the City of Johannesburg significantly increased the uptake of services, as demonstrated in a paper published from this research project (Nyasulu et al., 2013) (Appendix 8.9.1). Throughout the ART roll-out process, the government was responsible for national initiatives aimed at increasing ART access. For example, the national HIV Counselling and Testing (HCT) campaign launched in July 2010 targeted testing 15 million people by the end of June 2011 (Zuma., 2009).

Whilst NIMART was being rolled-out, the CD4 cut-off point for ART initiation was increased from ≤200 to ≤350 cells/μl in 2012 (SA, 2013d), and then to ≤500 cells/μl by January 2015 (SA, 2014b), so that many people who were not eligible before were now able to be initiated on ART according to the ART calculator (Leydon et al., 2010). However, at that time, it was not clear whether the increase in the CD4 count cut-off points for ART initiation necessarily translated into increased uptake, since from the time ART was rolled-out to date, the average CD4 cell count initiation at each point in time has been way below the WHO recommended cut-off point (Boulle et al., 2010, Cornell et al., 2010). This is a clear indication of gaps in monitoring those not yet eligible to start ART who then end up presenting for ART late (Lessells et al., 2011). Since 2004, greater effort appears to have been placed in ART initiation service delivery, while pre-ART, although considered crucial in promoting timely referral for initiation on ART and retention after initiation, is neglected (Lessells et al., 2011). This question can best be answered by closely scrutinising the investment of resources, including capacity building in human resources in the service delivery areas.

2.3 Why early ART initiation?

Globally ART has been shown to assist in reducing the mortality rate of people living with HIV from AIDS, and in reducing morbidity and the transmission of tuberculosis and HIV (WHO, 2013b). Documented benefits to ART access globally rank from reducing the risk of HIV transmission by 96% (Cohen, 2011), reducing Cryptococci meningitis among HIV+ individuals (Jongwutiwes et al., 2007), and reducing the incidence of other opportunistic infections (Losina et al., 2007). Early ART initiation has also been shown to improve quality of life, for example, in Kwazulu Natal, the province with the highest HIV prevalence in RSA (Shisana et al., 2014), life expectancy was 11.3 years higher in 2011 than in 2003 when ART roll-out commenced (Bor et al., 2013). ART has also been shown to improve quality of life and productivity, reflected through an increase of people on ART employed from 27% to 42% in a cohort initiated on ART over three years (April et al., 2013). Great survival benefits are also attributable to ART (April et al., 2013, Vermund, 2013), and if an adult person is initiated on ART with a CD4 cell count of above 200 cells/µl, he or she can have an almost normal life expectancy (Johnson et al., 2013).

On the other hand, ART initiation with very low CD4 cell count reduces the likelihood of success. For example, data from resource limited countries shows that people who started ART at less than 25 cells/mm^3 faced more than three times the risk of death compared to those who started at CD4 cell counts above 50 cells/mm^3 (Brinkhof et al., 2008). Even those who survive after starting ART at a low CD4 cell count have been shown to have higher morbidity, and utilize more medical resources than would otherwise be necessary (Leisegang et al., 2009). Starting ART at higher CD4 cell counts, or longer pre-ART monitoring and care, has been predicted to be more cost effective in running ART programs, due to lower rates of sickness, resulting in less hospitalisation for those with higher CD4 cell counts (Eaton et al., 2014, Leisegang et al., 2009).

2.4 Why pre-ART care?

Pre-ART care is a service provided to HIV+ individuals from the time they test HIV+ to the point at which they need ART: this may be anything from a few months to years, depending on an individual's CD4 cell count levels at the time of first presentation and enrolment into the program (Burtle et al., 2012). Pre-ART care needs to be set up appropriately within various facilities that provide HIV testing and care, with the design and functionality dependent upon infrastructure and available human resources (WHO, 2013a). This implies that people with HIV but without TB, at WHO Clinical Stages 1 and 2, or who have primary HIV infection and are not eligible for ART, should be offered a package of care and support that includes regular checks of their clinical status and CD4 cell count, the provision of Cotrimoxazole Prophylaxis Therapy (CPT) for opportunistic infection prevention as indicated (WHO, 2008, WHO, 2013a), the prevention of malaria, malnutrition, and unplanned pregnancies (Mermin et al., 2006), and access to regular TB screening services and INH Prophylaxis Therapy (IPT) (Sonnenberg et al., 2005).

According to both the South African and WHO Guidelines, all individuals who are HIV+ and not eligible to start ART should be enrolled into a pre-ART program (SA, 2013d, WHO, 2013a). With proper pre-ART care, patients are expected to undergo adherence counselling to prepare for the time when they will be eligible for ART, as adherence counselling has been shown to improve ART retention (Etienne et al., 2010, Torpey et al., 2008). Adherence to ART is vital in ensuring treatment success, as failure to adhere to treatment regimens allows viral replication and the accumulation of resistance mutations; these in turn may lead to treatment failure, requiring a switch to more complex drug regimens with lower resistance barriers and possibly greater toxicity (Liu et al., 2006). More complex regimens are also more expensive; for example, the second-line ART regimen is 2.4-fold higher in price per year than first-line treatment (Long et al., 2010). Patients and treatment providers are faced with the

prospect of drugs being priced out of reach if a significant proportion of the population requires second-line drugs (MSF, 2010).

As the above discussion indicates, pre-ART care is regarded as critical in ensuring that HIV patients are monitored and referred in a timely manner when they are eligible for ART, and that they understand the value of ART and so adhere to regimens of care. For example, global and national HIV testing and ART guidelines have emphasised the importance of linkage to care from the time of HIV+ diagnosis to the time of ART initiation (SA, 2013d, SA, 2013e, WHO, 2013a, WHO, 2012). Below is a description of the services from which HIV+ individuals can benefit if retained in pre-ART care.

2.4.1 Six monthly CD4 cell count monitoring

HIV infection leads to the destruction of CD4 cells, with billions of CD4 cells destroyed on a daily basis as the body responds by replacing the cells. As a result, the CD4 cell count among HIV+ individuals falls over time, at a variable rate, lowering the immunity of an individual to fight against infections (Burtle et al., 2012). The global and SA national guidelines stipulate that the CD4 cell count for HIV+ ineligible clients must be monitored on a six monthly basis to ensure timely ART referral (SA, 2013d, SA, 2013e, WHO, 2013a, WHO, 2012) – hence the concern that PLWHAs not yet qualified for ART remain in pre-ART care (WHO, 2013a).

Whilst focusing on CD4 cell count levels as cut-off points for ART initiation, there is need to always consider factors that affect CD4 cell count level progression. For instance, gender differences in CD4 cell count levels, at each point in time from the time of sero-conversion, have been established and debated for two decades, as men have been shown to have a lower CD4 cell count than women at any time (Prins et al., 1999, CASCADE-Collaboration, 2003, Loupa et al., 2006, Manolescu and Marinescu, 2013). Women reach CD4 cell count level for ART initiation 12 months later that their male counterparts (Prins et al., 1999). These CD4

cell count level differences continue even after ART initiation (Maskew and McNamara, 2013), although further research is needed to establish whether or not these differences negatively influence the progression of disease among women after initiation on ART. Many other non-HIV factors that effect CD4 cell count levels have been documented, including the use of hormonal pill, implant or injectable contraceptives, menstrual cycles and smoking (Maini et al., 1996), psychological stress (Irwin, 2001) and many others.

Continuity of care from the point of testing HIV+ to pre-ART, ART and other care and support services is critical (WHO, 2012). Large cohort studies conducted in South Africa and elsewhere have established that low CD4 cell counts are associated with higher rates of deaths from all causes, as described above in section 2.3, including hepatitis and non-AIDS defining malignancies (Smit et al., 2006, Baker et al., 2008, Monforte et al., 2008). With early ART initiation, such deaths can be prevented (WHO 2013). Higher CD4 cell counts at ART initiation, which can be achieved through patients accessing pre-ART care (Lessells et al., 2011), provide the greatest benefit for patients with significant reductions in opportunistic infections like pulmonary tuberculosis and severe bacterial infection, risk of HIV transmission, reduced mortality (Emery et al., 2008, Siegfried et al., 2010, Cohen, 2011, Lessells et al., 2014, Severe et al., 2010), and reduced defaulting from care (Ford et al., 2010). Co-occurrence of TB and HIV, to be discussed further below, has been established and other studies have shown that early ART initiation has the utmost absolute risk reduction of TB (Lawn et al., 2011, Severe et al., 2010). In addition, if HIV+ individuals are monitored for a longer period of time before initiation on ART, they are more likely to lessen early costs (Leisegang et al., 2009) because opportunistic infections are treated in a timely manner.

With all the documented benefits of early ART initiation, the International Antiviral Society (IAS)-USA Guidelines highlight the importance of initiating all HIV+ individuals regardless

of their CD4 count, as affordable and implemented in some developed countries (Thompson et al., 2012). At the same time as trying to treat HIV early, the WHO Guidelines for resource-limited settings have been revised, increasing the CD4 cell count threshold for ART initiation in asymptomatic HIV-positive patients from 200 to 350 or 500 cells/mm,^{3} as already noted (WHO, 2013a). Since this means increasing resources for the delivery of ART programs, decision makers, especially in resource limited countries, have to consider whether to allocate more resources to expand ART programs or increase other health programs like pre-ART and HIV counselling and testing (HCT). These latter programs may yield greater benefits in the long-term but do not address the immediate illness, higher mortality and suffering (Eaton et al., 2014). Even so, resource limited countries like South Africa would be unable to afford ART for all HIV+ people regardless of CD4 cell count levels, and so pre-ART needs to be prioritized to ensure close monitoring and timely ART initiation (Lessells et al., 2011).

In July 2014, in his budget speech, the SA Health Minister announced that the country had taken the challenge of increasing ART initiation to 500 cells/mm^3 for adults, and for all pregnant women to be initiated on ART regardless of CD4 cell count, by January 2015 (Gordhan, 2014). Using the ART eligibility calculator, at that time, this implied that about two million individuals would be eligible to start ART between 2015-2017 (Leydon et al., 2010), in addition to the 2.1 million already on ART (SA, 2013a). This indicated the need for greater attention to strengthening health systems to cope with the increased workload, ensuring that the limited resources would be available for both ART and pre-ART services (WRHI, 2014).

2.4.2 Patient education about HIV/AIDS

The relationship between HIV knowledge levels and positive behaviour change has been widely debated for more than a decade, as one school of thought stipulates that higher

knowledge levels do not necessarily lead to positive behaviour change (Williams et al., 2003). Others have shown how awareness of services increase uptake (Nyasulu and Nyasulu, 2011, Tshuma et al., 2014, Chimoyi et al., 2015), while higher HIV/AIDs knowledge levels among those who are HIV+ enable them to participate in prevention practices (Shisana et al., 2014), so stimulating HIV prevention behaviours (Agnew-Blais et al., 2008). Prevention of HIV transmission from those who know their HIV+ status is among the objectives for positive prevention approaches and provision of HIV information, and education about risk reduction methods for PLWHAs is key to preventing HIV (IHA, 2007). In this case, a pre-ART care program can be used as an entry point to prevent transmission.

Knowledge levels among the SA general population about the cause of HIV infection, modes of transmission, and cure of HIV have been well researched from the 1990s. In the early years, knowledge was shown to be low. For example, in 1992, two studies in SA showed that only 52% of study participants could identify sexual intercourse as a mode of HIV transmission (Blecher et al., 1995, Govender et al., 1992). The latest South African National HIV Prevalence, Incidence and Behaviour Survey still shows low knowledge levels, with only 28.6% of individuals aged 15-24 years properly recognizing ways of preventing HIV e.g. by the correct and consistent use of condoms, and rejecting incorrect beliefs about HIV transmission such as contracting HIV through sharing food with an HIV+ person (Shisana et al., 2014). These results suggest almost no change since 2009, when only 28.9% had correct knowledge levels (Shisana et al., 2009). Even though the decrease in knowledge levels is not significant, there has been decreased condom use in all age groups in their previous sexual encounter, dropping from 65% in 2009 (Shisana et al., 2009) to 40% in 2012 (Shisana et al., 2014). This regression is a great cause of concern, hence the critical need for people to be given correct basic information about HIV/AIDS and its prevention.

On the other hand, from the mid-2000s when ART was rolled-out in SA public health facilities, knowledge levels among HIV+ individuals receiving ART were shown to be high (Nachega et al 2005). However, in South Africa and elsewhere, no research has been conducted on the knowledge levels of HIV/AIDS, CD4 cell count, pre-ART and ART care among pre-ART program patients. Yet, as stipulated in the latest National Strategic Plan (NSP) for HIV/AIDS and TB, this is critical in implementing an appropriate pre-ART care (RSA, 2012). Unlike the school of thought that indicates that there is no relationship between knowledge levels and behaviour change described above (Williams et al., 2003), high knowledge levels about available services were shown to increase access to services, as demonstrated in the City of Johannesburg and elsewhere (Nyasulu and Nyasulu, 2011, Tshuma et al., 2014, Chimoyi et al., 2015).

2.4.3 Tuberculosis (TB) Isoniazid Preventive Therapy (IPT)

TB is the most common cause of death amongst PLWHAs in Africa and elsewhere (Munsuff et al 1998, Corbett et al 2003 & WHO 2013). HIV+ individuals on ART have been shown to have a ten times higher risk of getting TB than those who are HIV- in the same community (McIlleron et al., 2007). In addition to increasing TB incidence, HIV also increases the risk of rapid TB progression after an individual is infected or re-infected with TB (Daley et al., 1992). As a result of this relationship, the HIV epidemic has led to increased TB morbidity and mortality. For example, in 2012, PLWHAs accounted for 1.1 million (13%) of 8.7 million individuals who developed TB worldwide (WHO, 2013b). Even though globally, there has been a decline in TB associated deaths since 2003, still about 320,000 deaths from TB were associated with HIV in 2012 worldwide (WHO, 2013b).

Almost three decades ago, IPT was acknowledged as integral in TB and HIV patient management to reduce TB incidence among HIV+ individuals (Selwyn et al., 1989). By

1998, the WHO and UNAIDS had endorsed the use of targeted IPT for PLHIV, and this is still being implemented globally (Wilkinson et al., 1998, WHO/UNAIDS, 1998). Other studies have shown that IPT as a prophylaxis is more effective when an individual's tuberculin skin test (TST) is positive (RR 0.38) than when it is negative (RR 0.89) (Akolo et al., 2010, Samandari et al., 2011). These studies have led to debates around using TST as a screening test before IPT initiation, and to a change in the South African IPT Guidelines whereby IPT is only initiated when the TST is positive (SA, 2014).

South Africa has a high TB burden, with an estimated one per cent of the population; this translates into about half a million people who develop active TB annually, with an increase by about 400% over the past 15 years (SA, 2011a). In 2012, SA reported 370,000 PLWHAs initiated on IPT, accounting for 71% of the total (WHO, 2013b), but there are challenges around the availability of resources, and other constraints in implementing the IPT program at all levels, from policy makers to program implementers in health facilities (Getahun et al., 2010). The use of IPT as a stand-alone intervention has been shown to be challenging, and needs to be integrated into other services which HIV+ individuals seek (Getahun et al., 2010, Granich et al., 2009). As a result, both international and national guidelines recommend IPT services to be provided to ART ineligible PLWHAs during pre-ART care (WHO 2013, RSA 2013). IPT for pre-ART patients plays a dual role of TB prevention (Selwyn et al., 1989) and so delays ART initiation because in SA, since 2012, TB as an opportunistic infection has been a criteria for ART initiation, in line with the WHO ART Guidelines (SA, 2014).

2.4.4 Psychosocial support of patients receiving pre-ART care

Counselling is an integral part of patient care at all stages in HIV care and service delivery, even though limited research has been conducted to establish its effectiveness in retaining HIV+ individuals in care (Kranzer et al., 2012). HIV+ individuals require comprehensive

counselling and support before ART initiation, to enable them to understand and accept their situation and to promote adherence to treatment (Visser et al., 2009). In addition, because these individuals experience stigma and discrimination, they need a safe space, as might be provided by PLHWA support groups, to discuss matters with others facing similar difficulties (Ramlagan et al., 2010). In this case, pre-ART psychosocial support programs can provide a safe space for pre-ART patients.

For many years now there has been consistent advocacy against stigma and discrimination against people who are HIV+, and stigma has been reported to dropped (Simbayi et al., 2007, Strebel et al., 2006), particularly with close relatives (Thorsen et al., 2008). Even so, it is still prevalent (Visser et al., 2009, Ncama et al., 2008). The existence of stigma and discrimination in SA has been demonstrated to lead to PLWHAs remaining reluctant to disclose their positive status for fear of being rejected, and to resist using condoms; stigma therefore leads to lost opportunities for behaviour risk reduction among PLWHAs (Cloete et al., 2010). In Tshwane district, Gauteng Province, a high level of apparent community stigma was established especially among those with low HIV/AIDs knowledge levels. Further, the first ever HIV stigmatisation index study was recently released, which showed that stigma is still in existence; in particular, internal stigma was still at 40% (SA, 2015b). Since low HIV/AIDS knowledge levels has been shown to increase stigma in the community, there is a need for more efforts to focus on increasing community HIV/AIDS knowledge levels in order to change stigmatizing attitudes (Visser et al., 2009).

Since the roll-out of ART, which has resulted in PLWHA regaining their health, there have been talks around normalising HIV as any other chronic condition (Colvin, 2011). Normalisation for those living with HIV is defined differently depending on who is defining it. For service providers, it means that PLWHAs are adhering to prescribed care, including

ART and pre-ART, nutritional requirements and other recommendations to promote health when HIV+ (Whyte et al., 2013); to patients themselves it may mean achieving their day to day family responsibilities, and accomplishing life developments or plans that may have been interrupted due to HIV+ status (Mattes, 2014). For example, an HIV diagnosis has been shown to lead to reduced or no sexual performance with more time needed to develop a sexual response for both men and women (Scanavino and Abdo, 2010). This negatively affects their sexual and reproductive health rights (Igonya and Moyer, 2013). When HIV is destigmatised, PLWHAs are (in theory) able to live a fully functional life not just in the biological context but also in terms of social-economic participation, resumed sexual activity, and reconstructed sense of self (Beckmann, 2013, Mattes, 2014, SA, 2015b). However, with the continued presence of stigmatisation, transitioning to normality for PLWHAs is difficult to attain, leading to a permanent transition process (Mattes, 2014). It is even more difficult for an HIV+ adolescent to transition into a normal adult (Philbin, 2014). Given that HIV as a disease is considered to be exceptional from other chronic diseases, resulting in associated stigma (Moyer and Hardon, 2014), we appear to be far from reaching normalisation of HIV (Mattes, 2014, Philbin, 2014).

The South African Department of Health recommends the establishment of PLWHA support groups for pre-ART, ART and PMTCT in all public health facilities (NDOH 2009 (FHI, 2012)). The main aim of support groups is to assist clients to take control of their lives by providing them with knowledge and skills, so to assist them to cope and accept their situation (Vintges et al., 2007). However, strategies in scaling up PLWHA support groups need detailed, participatory planning involving PLWHA themselves (De Barros et al., 2004). According to Ramlagan and colleagues (2010), through peer support, participants develop advocacy and activist skills to enable them to support themselves and others. HIV education also helps them to correctly know about the transmission of the HIV virus, and this may

assist the community at large to understand HIV. This in turn may help reduce stigma and discrimination against those who are HIV+ (Ramlagan et al., 2010).

There is need to continuously support pre-ART patients to disclose their HIV+ status as recommended in the pre-ART care guidelines (SA, 2013d, WHO, 2008, WHO, 2013a). Rates of disclosure are associated with social support (Kalichman et al., 2003). The fact that someone has joined a support group means that the individual has disclosed his or her HIV+ status, and this is considered to be critical in adherence to services (Unge, Södergård, & Marrone, 2010. Although people may be reluctant to disclose to partners and other community members because disclosure may lead to negative outcomes including gender-based violence, stigma and discrimination (Gari et al., 2010, Nyasulu and Nyasulu, 2011), it is an important component in pre-ART care in preparation for ART initiation (Worley et al., 2009).

Furthermore, access to programs like PLWHA support groups, ART, and nutrition have been shown to lead to new ways of disclosure of one's HIV+ status other than individual intentional or unintentional disclosure (Wilhelm-Solomon, 2013, Mogensen, 2010, Whyte et al., 2010). Many PLWHAs have declined to access services for fear of being known to be HIV+ because of their concern about stigma and discrimination. For example, in Malawi, at the time PMTCT program was being rolled out, HIV+ pregnant mothers declined to join the PMTCT program for fear of being known to be HIV+ (Nyasulu and Nyasulu, 2011b, Nyasulu and Nyasulu, 2011a). In Northern Uganda in camps for internally displaced people, access to a support group and nutritional supplements for those living with HIV led to unplanned disclosure, resulting in stigma and discrimination (Wilhelm-Solomon, 2013). Therefore, since disclosure of HIV status has to be on voluntary basis, there is need for further discussion and

rationalisation around striking a balance between involuntary disclosures versus access to the available HIV therapeutic services.

2.4.5 Prevention of Mother to Child Transmission of HIV (PMTCT) services and retention into care

Prevention of Mother to Child Transmission of HIV (PMTCT) is one of the main strategies towards eliminating HIV (WHO, 2013b). Pre-ART care services for HIV+ women of reproductive age can assist them to access family planning services and plan for their pregnancies, and avoid unplanned pregnancies (Alkema et al., 2013). According to WHO PMTCT guidelines (2010) for countries across the globe to adopt, depending on practicality to implement the guidelines in each country, pregnant women from gestational age of 14 weeks are initiated on ART, using different options as described as follows:

1. Option A – initiation on Zidovudine (AZT) immediately after 14 weeks gestation with lamivudine (3TC) and Nevirapine (NVP) during labour then, 3TC /AZT tail for 1 week. The infant receives NVP throughout the breastfeeding period
2. Option B - initiation on a triple therapy from 14 weeks throughout labour, delivery until the baby stops breastfeeding (WHO, 2010, Mofenson, 2010).
3. Option B+ - life-long ART initiation from 14 weeks (Schouten et al., 2013).

As described above, Options A and B use CD4 cell count level to determine therapy, while under Option B+ all HIV+ pregnant women are initiated on life-long ART regardless of their CD4 cell count. Option B+ was an effort to curb the missed opportunities in reaching pregnant women with PMTCT without CD4 cell count checking, since CD4 count checking was shown to be a barrier to accessing services (Wettstein et al., 2012). Malawi rolled out Option B+ about two years ago (UNAIDS, 2013), and a year later it had registered the largest decline of 67% in the HIV transmission rate from mother to child (UNAIDS, 2014b). The

plausible explanation of this would be women's commitment to accepting therapy, as determined under Option B+.

Global consensus was reached by UNAIDS signatories in 2011 when an announcement was made advocating for the elimination of new HIV infection among the children and ensuring healthy HIV+ mothers and children by 2015 (UNAIDS, 2011). In response to this, globally country-led actions have taken steps towards reaching this goal (WHO, 2013b). According to the latest UNAIDS progress report, there has been an increase in access to antiretroviral prophylaxis by pregnant women, and this is estimated to have prevented more than 1.4 million children from acquiring HIV by 2014 (UNAIDS, 2015). On the other hand, a great improvement was recorded in ART uptake by HIV+ pregnant women, from 58% in 2012 (UNAIDS, 2013) to 73% when receiving ART, even though treatment coverage amongst children living with HIV still remains lower than the coverage for adults (UNAIDS, 2015). WHO has argued that more effort is required to link HIV+ antenatal women and children to HIV treatment and care services (WHO, 2013b).

The prevalence of HIV among ANC clients in SA plateaued at around 30% from 2009 to 2013 (Shisana et al., 2014). In line with the 2011 UNAIDS declaration, SA has gone further and developed the "count down to zero declaration," with an action framework which declared zero new HIV infections among children by 2015 with better health for the mothers, spouses and children (SA, 2012a). Currently RSA has reached the international targets by achieving HIV coverage among pregnant women to 100%, with 90% accessing ART (WHO, 2013b, Goga et al., 2012); however, efforts need to be extended to reach the remaining 10% not accessing ART. Since 2009, the mother to child HIV transmission risk has also declined from 3.5% to 2% (Dohert et al., 2009, Goga et al., 2012).

To ensure an increase in ART uptake among pregnant women, in March 2013, the PMTCT Guidelines were updated, recommending Option B, that is immediate initiation of a triple therapy ART initiation regimen for all pregnant women, regardless of CD4 cell count during pregnancy and breastfeeding (SA, 2013a). In January 2015, a change to Option B+ was made, such that all pregnant women were to be initiated on a lifelong ART regardless of their CD4 cell count (SA, 2014b).

Despite positive strides in enabling pregnant women to access PMTCT services, there are still challenges in the PMTCT cascade. For example, only 54% of HIV+ babies are initiated on ART and HIV testing at 18 months for children born to HIV+ mothers is also low (SA, 2013a). According to unpublished monthly progress reports for CoJ facilities, PMTCT mothers were not keen to continue with ART after delivery; and at the time of Option A and B implementation, those with CD4 count >350 did not remain in the wellness program after receiving the PMTCT ART course after delivery. Among pregnant women who qualified and were initiated on ART (CD4 count <350), many were lost to follow-up after delivery of the baby (CoJ unpublished reports 2010-2012). In order to develop a program that promotes the retention of women, it is necessary to identify why women drop out.

Various factors have been identified that contribute to higher rates of loss to follow-up (LTFU) among mothers in the PMTCT program (Boyles et al., 2011, Maqutu et al., 2010). Firstly, according to WHO Guidelines, an HIV+ pregnant woman has to be fast tracked to ensure timely ART initiation (WHO, 2013a). For example, with the current Option B+ regimen, mothers should be initiated on ART on the same day of HIV diagnosis (SA, 2014b). This speeding up lessens both the time of patients' treatment preparation, and their access to counselling and support structure sessions, so leading to poor adherence (Boyles et al., 2011). Documented practical experience on the implementation of Option B+ in Malawi has

established 17% attrition from care within the first six months of their ART. Those initiated whilst pregnant with high CD4 cell count were five times more likely to be lost to follow-up than those initiated with low (<350) CD4 cell count of WHO clinical stage 3 and 4 (Tenthani et al., 2014). Secondly, individuals attending clinics for reasons not related to HIV, like antenatal care, although diagnosed to be HIV+, are less likely to adhere compared with those who present for HIV testing due to possible exposure to HIV. As a result, it is critical to prioritise identification of appropriate strategies to ensure adherence in the PMTCT program (Maqutu et al., 2010). Thirdly, depression has been shown to be very high during both the prenatal and postnatal period, particularly among women who know they are HIV-infected (Chibanda et al., 2010). If this depression is not treated, it may impair adherence to ART among the women (Uthman et al., 2014, Ammassari et al., 2004). Lastly, after delivery, women may need time to be home to care for the newborn, hence attending the facility post-delivery may no longer be a priority (Boyles et al., 2011). In addition, decision making on feeding options in trying to prevent the risk of transmission to the baby can lead to unplanned disclosure. For example, a woman who chooses not to breast feed, or who opts for exclusive breastfeeding, may result in inadvertent disclosure in a cultural environment that expects all mothers to breastfeed but with some other feeding; this results in women not adhering and retaining in PMTCT care (Nyasulu and Nyasulu, 2011, Shongwe and Mkhonta, 2015), To ensure women are retained in care, PMTCT programs need to address these challenges.

Globally, the national reviews submitted to UNAIDS as progress reports on the implementation of PMTCT programs have identified several challenges, outlined below (UNAIDS, 2013). These include firstly, operational issues around how the services are delivered, for example poor service awareness; loss to follow-up of mothers and HIV exposed babies; poor involvement of spouses; and challenges around implementing infant feeding polices and others. Secondly, there are issues of programmatic reach such as delays

in diagnosing HIV status among pregnant women, as many countries have a high rate of deliveries in homes rather than in health facilities, leading to unsafe delivery and difficulties in following up the mother-baby pairs after delivery. Finally, policy issues exist around the effects of stigma and discrimination against those who are HIV+ (UNAIDS, 2013).

2.4.6 Cervical cancer screening

Notwithstanding the effectiveness of pap smears for early diagnosis and treatment, cancer of the cervix is the seventh most common cancer worldwide, with 528,000 new cases and 266,000 deaths reported in 2012 (WHO-GLOBCAN, 2012, Ferlay et al., 2015). In Sub-Saharan Africa, women have shown to be disproportionately affected with cervical cancer, accounting for one out of every eight of all female cancers (Mbulaiteye et al., 2011). In South Africa, about 2.5% of women develop cervical cancer (SA, 2000b).

HIV+ individuals have a higher occurrence of various kinds of non–AIDS-defining cancers, compared to the overall population (Patel et al., 2008), and HIV+ women have a far greater risk of cervical cancer than do those who are HIV- (Batra et al., 2010, Serraino et al., 1999, Snyman, 2013), and develop cancer ten years earlier than the women who are HIV- (Snyman et al., 2006). In most cases, the diagnosis is made when the cancer is advanced, with treatment effectiveness complications resulting in a higher risk of dying for HIV+ women (Maiman 1998). Given this, it is important to actively prevent cervical cancer among HIV+ women (Franceschi and Jaffe, 2007). The SA Cervical Cancer Screening Guidelines currently under review stipulate that women above 30 years of age without symptoms of cervical cancer should be screened for every five to ten years (SA, 2000b). The latest pre-ART care guidelines which are part of the ART guidelines recommend yearly cervical cancer screening for all HIV+ women; this is a great opportunity to reach all HIV+ women (SA, 2014(b)). However, the implementation of the cancer screening program to reach eligible women in SA

is still a challenge (Snyman, 2013, Batra et al., 2010). According to a recent WHO report, in South Africa, the screening coverage is still only 13%. An estimated eight women die every day and this is projected to increase to twelve deaths per day by 2025 (WHO/ICO, 2014). In an effort to curb the cervical cancer rate, in 2014, the SA government launched an HPV vaccination program targeting girls from the age of nine years in public schools, with the goal of reaching almost half a million of girls (Richter et al., 2014).

2.5 Youth Friendly Health Services (YFHS)

Youth Friendly Health Services (YFHS) are those services that consider all aspects of young people's well-being, with particular attention to sexual and reproductive health (SRH) (Baloyi, 2006). According to the Declaration of the 2001 United Nations General Assembly Special Session (UNGASS), the main purpose of establishing YFHS is to improve access by young people to information, reducing their susceptibility to being infected by HIV (UNAIDS, 2001). In 2004, UNESCO developed characteristics of YFHS to be adopted globally for use in different settings, and these are still being used (UNESCO, 2004). These characteristics were categorised into service provider, health facility and program design. I summarise these as follows:

Service Provider Characteristics: (1) Service providers are to be trained to be knowledgeable of Sexual Reproductive Health (SRH) issues that affect youths, e.g. contraceptives and to have special interpersonal skills to work with the youths, to encourage younger people to feel at ease to talk to service providers. (2) Service providers need to have respect for young people and be able to relate with the youths with respect, without judging adolescents' sexual activity. (3) Privacy and confidentiality observed whereby young people are to be counselled and examined in private, and to be reassured that their information will not be shared with anyone not working in the health service. (4) There is a need for sufficient consultation and

interaction time with service providers, since young people need more time than the older people with the service provider, as they may be frightened and anxious about presenting to the health facility. There is a need for more time to reassure them to open up and to explain things that may be well understood by adults, depending on age and knowledge levels. More time is also needed to address all their questions. (5) Peer counsellors should be available because young people prefer conversing with their peers on sensitive issues; hence it is critical that youth peer counsellors are recruited, trained and involved in provision of youth services

Health Facility Characteristics (1) There is a need for allocated time and space for youths since convenient times and special spaces, or both, are important in delivering YFHS, as youths may not feel free to mix with adults and may not be able to take time off from school to present to a clinic. (2) There needs to be enough space and privacy when providing services to the youths to ensure that services are offered out of sight and sound of other people, as also argued above. (3) Generally young people like a comfortable environment that matches their taste and interests, with posters and décor that encourage them and ensure a welcoming environment.

Program Design Characteristics: (1) There is need to involve youths themselves in identifying what they need and ways of addressing the needs to be incorporated in the design of the facility services. For example before designing YFHS, program designers need to engage with youths for their input on the package and design of services. (2) Long waiting times including fear of exposure discourage clinic attendance and return by youths and introducing ways of reducing waiting times would attract more young people to the service. (3) The services should be affordable as young people may not have their own source of income. (4) Encouraging the male or female partner or friend of the young person attending

the clinic to join in, where appropriate, without judgement if no regular is accompanying the youth would make young people feel comfortable. (5) The facility should have a wide range of services including the above described SRH services and others like minor and major ailments delivered as a one stop shop, as young people will rarely go if referred to access services at another service point (UNESCO, 2004 page 1-7).

Unfortunately, the setup of reproductive health services in many countries limits access by youths. For instance, in the USA, male adolescents described how stressful it was to obtain sexual health services, due to personal psychological barriers like embarrassment, and external service barriers including lack of respect from providers, poor confidentiality, and difficulties negotiating the healthcare system (Lindberg et al., 2006, Langhaug et al., 2003).

In South Africa, although the occurrence of HIV among young individuals aged 15-24 years dropped from 8.7 in 2008 to 7.1 in 2012 ($p<0.001$) (Shisana et al., 2014), there are knowledge gaps in HIV/AIDS among youths, and a need to address these gaps (Shisana et al., 2014). Many South African youths have difficulties in accessing health services due to negative attitudes of service providers, poor timing of services, lack of privacy, feelings of shame by young people if they are seen by others to be waiting for the services, lack of YFHS training for service providers, and lack of information given to young people about their diagnosis, to enable them understand their condition (Seekoe, 2006, Ehlers, 2003, Geary et al., 2014). In Eastern Cape (EC), this poor access has been associated with the high pregnancy rates among primary, secondary and tertiary school learners (Department of Basic Education 2013: 25, unpublished data).

Currently, the government and other implementing partners have acknowledged the poor access to HIV services by young people and are working towards addressing the gap (SA, 2013c). A quality improvement initiative in youth friendly services in public primary health

facilities, supported by the Reproductive Health Research Unit (RHRU), established some lessons learnt which were used to develop the National Adolescent-Friendly Clinic Initiative (NAFCI) in South Africa (WHO, 2009). Some of these documented lessons in implementing YFHS were: need for facility clinic support, capacity building of service providers, resource limitations, and most importantly, the involvement of the youths themselves in planning and implementing the YFHS (WHO, 2009).

In pre-ART care services, there is similar emerging evidence on poor access by youths. For example, less than 50% of patients diagnosed with HIV in SA who are not yet qualified for ART have been reported to remain in clinical care, and youths, along with men and individuals with higher CD4 cell counts, are most likely to be lost to care (Rosen and Fox, 2011, Lessells et al., 2011). Ensuring that the pre-ART services are youth-friendly would assist in improving access and their retention in care to these critical services by the youths.

2.6 Medical pluralism among HIV+ individuals

Pre-ART care patients frequently drop out of regular care and are lost to follow up, as explained above, returning to health services only when they are already ill. One important question is what they do until they are symptomatic and sick. Do they take no action to maintain their health or do they seek care outside of biomedicine, taking advantage of medical pluralism as available in South Africa? Pluralism in accessing health care refers to the use of more than one health or medical modality, which might be alternative or complementary to (conventional) biomedicine (Shih et al., 2009). An individual using biomedicine through private and public facilities, or self-medication concurrently or subsequently, can also be regarded as practicing medical pluralism (Moshabela et al., 2009), to the extent that they are engaging with multiple providers and may be receiving varying advices.

Complementary and alternative medicine (CAM) includes knowledge-based theories and practices used in the prevention or treatment of illness or promotion of health and wellbeing, which are not part of biomedicine (WHO, 2013c). These can include Chinese medical therapy, or aspects of it such as acupuncture and moxibustion (Manheimer et al., 2009). It also includes herbal therapy, naturopathy or homeopathy, and in South Africa, this also includes advice and treatment from *sangoma*s and spiritual healers (Cook, 2009). Sangomas are lawfully known in South Africa as "traditional health practitioners", and may include diviners, herbalists, traditional birth attendants, and traditional surgeons (SA, 2005b). About 80% of South African black patients are reported to use traditional healers before consulting with modern medicine (Cook, 2009). Although traditional and complementary medicine plays a big role in influencing people's health seeking behaviours and access to care, it is however an underestimated part of health service delivery (WHO, 2013c). As a result, it is important to collaborate with these alternative practitioners to better understand how patients under their care can access and adhere to medication such as ART (WHO, 2013c, Wreford and Esser, 2008, Pantelic et al., 2015). In 2005, a Traditional Healer's Act was adopted in South Africa which legally recognised the role of Traditional Medicine (TM) in delivering care and in potentially supporting people to access conventional healthcare. Under this act, traditional healers included diviners, herbalists, prophets, traditional surgeons, and traditional birth attendants (SA, 2005b).

Patients seek complementary and alternative medicine for many reasons. These include: in relation to HIV, confirmation of diagnosis or seeking an alternative diagnosis, especially when the person is still in denial of the diagnosis (Wringe et al., 2009) and when it is known that biomedicine cannot heal the disease (Schatz et al., 2013). The main challenge is when these ideas contradict each other, so requiring action to ensure that there is a consensus between them (Schatz et al., 2013), to avoid a person abandoning and defaulting from

prescribed medication like pre-ART or ART when they opt for alternative healing (Daniel et al., 2008, Wanyama et al., 2007, Akusoba, 2013).

Medical pluralism is common among HIV+ individuals in South Africa (Moshabela et al., 2009, Cleary et al., 2013, Pantelic et al., 2015, Moshabela, 2012) and users of traditional healers such as sangomas have reported that these healers are holistic in their approach to managing sickness, treating both the physical and spiritual well-being of their patient, and that they are also much more affordable (Ritcher, 2003, Tais and Zoberg, 2013). Nonetheless, there is evidence across SA of compromised care of HIV+ people by traditional healers due to failure to conform to WHO minimum standards like: HIV training received, systematic evaluation of their products, quality control measures, record keeping and others (WHO, 2004). This makes it difficult to integrate traditional healer practitioners and biomedical sectors (Walwyn and Maitshotlo, 2010).

Alternative medicine can be cheaper than biomedicine (Ritcher, 2003, Tais and Zoberg, 2013), but these expenses may increase where people combine treatments from different modalities. In one study in SA among ART clinic attendees in a workplace, 84% of the ART patients reported ever using traditional medicine with a monthly expenditure of around £4 – £27 (an equivalence of R80- R540) per month (Babba et al., 2007). Those practicing medical pluralism were shown to be more likely to borrow money and pay for healthcare out of their pocket, with a higher level of expenditure than non-plural users (Moshabela et al., 2009). In addition, medical pluralism has shown to be a barrier to timely ART initiation in South Africa (Pantelic et al., 2015, Moshabela et al., 2009).

HIV+ individuals are reported to practice higher medical pluralism before ART initiation than after initiating on ART, with greater levels of expenditure (Moshabela et al., 2009). Therefore defaulting from care for a pre-ART patient may mean that the patient is seeking

alternative health solutions, with greater expenditure, but without effective treatment and poor, delayed or no cross-referral to the modern medicine system.

2.7 Reasons for poor retention in pre-ART care

Many studies within SA and elsewhere have documented factors contributing to retention in care by pre-ART patients and this section outlines a summary of these factors. As noted above, being male and young, but also, having a higher baseline CD4 cell count, unmarried patients, low socio-economic status, patients whose next visit date was not documented on their medical chart, and those with lower educational level, are all factors associated with attrition in pre-ART care (Ahmed et al., 2013, Lessells et al., 2011, Marson et al., 2013, Mugglin et al., 2012, Rosen and Fox, 2011). The costs, mainly on the patients' side, have also been shown to negatively affect patient retention in pre-ART care (Rosen et al., 2007).

In addition, stock outs of ART and related medication, insufficient or poor pre-antiretroviral care, and lack of privacy lead to poor retention (Diabate et al., 2007, Muhamadi et al., 2010). The other point is the lack of availability of packaged comprehensive pre-ART care services (Boyles et al., 2011, Govindasamy et al., 2014). Furthermore, motivation is important in enabling an individual to access care, and non-existence of motivation or incentives for HIV+ individuals not yet sick to come back for follow-up sessions is implicated in poor retention (Lessells et al., 2011, Boyles et al., 2011). Lack of recognition of the importance of a specific health services by patients or clients can lead to poor uptake and retention. For example, a position paper highlighted the fact that an understanding amongst HIV+ individuals that ART is only necessary as a last option when one gets sick, in spite of other efforts to stay well though living with HIV, reduces their retention in pre-ART care whilst healthy (Boyles et al., 2011).

2.8 Good practices on pre-ART care service delivery

Despite the challenges documented around poor retention and high LTFU in pre-ART service delivery, the introduction and maintenance of best practices in South Africa and elsewhere have shown ways to retain patients, as described in summary in this section. Immediate receipt of CD4 cell count results at the time of HIV testing care (Faal et al., 2011, Jani et al., 2010, Larson et al., 2013, Wynberg et al., 2014) and issuing of Cotrimoxazole for prophylaxis, accompanied with efficient referral and integration of pre-ART care into existing PHC services, have proven effective especially in retaining patients in pre-ART care (Kohler et al., 2011).

In addition, according to Smith and others (2013), retention is higher where there is the integration of services, provision of medical and food incentives, and strengthened counselling and patient education which provide pre-ART care patients with accurate information on immune function, HIV disease progress and treatment. This supports pre-ART patients to appreciate the significance of pre-ART care and so retain them in care (Smith et al., 2013). In addition, peer support (Lambdin et al., 2013, Kranzer et al., 2012) and decreasing operational and resource draining demands of HIV care (Smith et al., 2013) may support retention in pre-ART care.

Furthermore, in urban clinics in Africa, putting in place interventions targeting men and accounting for patients' mobility due to employment may improve uptake and retention (Marson et al., 2013). The other documented best practice is the provision of food incentives to pre-ART care patients (Kundu et al., 2012), although nutritional supplements can lead to unintentional disclosure of one's HIV+ status and so stigma and discrimination (Wilhelm-Solomon, 2013, Mogensen, 2010). This unplanned disclosure when accessing HIV therapeutic programs like nutrition, support groups and provision of ART is even worse in

displacement camps, as shown in Uganda (Wilhelm-Solomon, 2013), because populations are under closer surveillance than would be the case in urban settings.

2.10 Conceptual framework

In general, conceptual frameworks systematically characterise ideas about a phenomenon in a meaningful way (Meleis, 1997, Tiffany and Johnson-Lutjens, 1997). The conceptual framework employed in this thesis draws on some basic principles from the rational models of organisational theories (Shortell and Kaluzny, 1988), Rogers' diffusion of innovation classical theory of change (Rogers, 1995), and quality improvement processes.

2.10.1 Rational models of organisational change

According to Shortell and Kaluzny (1988), rational models focus on four stages in the organisational change process which are: (1) identification of the gap; (2) identification of a possible intervention to address the gap; (3) the actual implementation of the intervention; and lastly (4) institutionalisation, where the change is accepted and intervention adopted. These four stages are similar to a simple quality improvement cycle that can be applied when addressing gaps in health care. A typical example used for more than a decade is the Plan-Do-Study-Adopt cycle (PDSA) cycle, one of the quality improvement approaches used to develop solutions to address an identified gap (SA, 2012b, Hughes, 2008). The four stages of rational models organisational change process, mentioned above, take a similar approach of quality improvement cycle (Shortell and Kaluzny, 1988). This is commonly used by the health care quality improvement NGO, the Institute for Healthcare Improvement (IHI), for rapid cycle improvement (Berwick, 1998, Hughes, 2008). In addition, quality improvement approaches have shown to greatly improve quality of care and compliance with standards in low and middle income countries (Franco and Marquez, 2011). The PDSA as a quality improvement process was first used in Japan in car manufacturing (Walton, 1986) and later in

the health sector (Best and Neuhauser, 2005). The quality improvement process is further discussed below.

In order to improve the quality of services in South Africa, the Department of Health established the National Core Standards (NCS) for all levels of health service delivery (SA, 2011b). The NCS assessment tools (discussed further in section 2.10.3 below) and many other different DoH existing tools are used to identify gaps to be addressed through quality improvement projects. For example, the NIMART readiness tool was used in this study to identify gaps that would hamper NIMART implementation. The diagram below describes a quality improvement process:

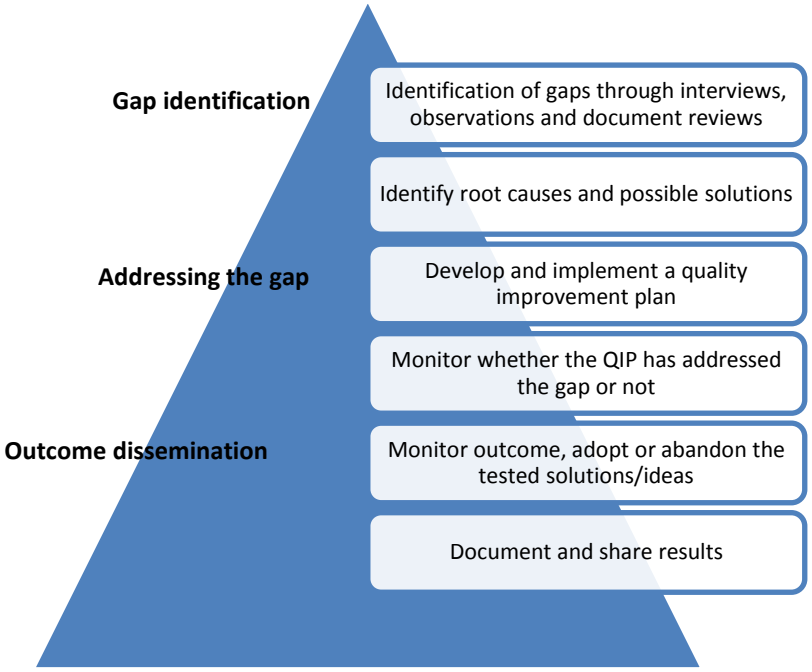


Figure 2.2: Quality Improvement Process

As shown in the above diagram, quality improvement starts with the identification of gaps and causes, using the available tools. If the QIP addresses a specific gap, the tested idea can be adopted; if there is no outcome or a negative outcome, the tested idea or action can even

be abandoned. Both the adoption and abandonment of ideas can be documented and disseminated in different forums.

2.10.2 Rogers' diffusion of innovation classical theory of change

This classical theory of change is concerned with the importance of being aware of innovation, and persuasion towards making a decision to adopt a change, as critical stages towards adoption of any form of change (Rogers, 1995). For instance, I managed the process of rolling out the NIMART in the PHC facilities of the City of Johannesburg, following a systematic 10 step process, which later on significantly increased the uptake of ART, documented as an innovation (Nyasulu et al., 2013). The implementation of the NIMART roll-out was conducted in the same CoJ facilities as the pre-ART care assessment. As a result, in this study, the lessons learnt from implementation of the NIMART roll-out innovation were further examined to establish how they can be applied to address the identified pre-ART care gaps.

2.10.3 Addressing the quality of health services gaps in the SA health systems

The South African Government has shown commitment in ensuring universal access to good quality health services including HIV and pre-ART services. The government has been documented to be taking a lead in Africa in its commitment to financing and driving the response towards the HIV/TB epidemic, with a five-fold increase in its budget for ART service delivery from the time ART was being rolled out in 2003 to 2010 (UNAIDS, 2015).

Currently, to ensure access to services including ART and pre-ART in all facilities across the country, there are plans to implement National Health Insurance (NHI) in South Africa. This is currently being piloted in ten of 52 districts across the provinces (Matsoso and Fryatt, 2012). To date, the government has allocated resources to multiple initiatives which all aim at improving the quality of health, focusing on health systems strengthening through

compliance to standards, with measures which are used to identify the gaps and to address these through QIP. The government's vision is that if all facilities meet the minimum standards in providing health care services, then NHI can be fully implemented (SA, 2011b). In addition, in 2014, an ideal clinic initiative was also launched which enables facilities to meet the National Core Standards (NCS). The ideal clinic focuses on eight workstreams as outlined by the president at the launching ceremony as follows: Service Delivery, Waiting Times, Human Resources, Infrastructure, Financial Management, Supply Chain Management, Scaling up and Sustainability, and Institutional Arrangements (Zuma, 2014). The underpinning principles for ideal clinic, NCS and all other initiatives to improve the quality of care at facility level, are the six ministerial priority areas outlined below:

1. Health service providers respect the service users and have a caring attitude
2. The facilities should be clean
3. Service users must access care fast and there should be shorter waiting times
4. There should be a better expected outcome of patient care with fewer mistakes and errors.
5. There is a reduction in facility-based infection through infection control approaches
6. Medicines to be accessed by service users and are available when needed without stock outs (SA, 2011b pages 21-41).

In this study, I incorporated ideas from Rogers' diffusion of innovation classical theory with a focus on use of an innovation for quality improvement and access to services, the rational models of organisational change theory, and general quality improvement principles. In Figure 2.3, I set out a conceptual framework diagram which shows how the gaps and causes identified in pre-ART services were planned to be incorporated with lessons learnt from implementing the NIMART roll-out, to develop recommendations for improvements in the quality of pre-ART services. These principles enabled me to better understand what is

involved in delivering pre-ART and ART care, with the baseline assessment helping me to identify gaps and causes and solutions. According to an analysis of organisational theories by Shojania and others (2004), it is important also to note that the rational model empowers organisational management, in this instance the pre-ART service providers, while reflecting on the needs of the clients, to implement change according to the interests of the organisation (Shojania et al., 2004). In addition to identifying pre-ART service delivery gaps, it is critical to develop recommendations on the appropriate pre-ART reflecting the documented innovations and best practices. I return to this in the conclusion of the thesis.

The research has three target areas: patients, health workers and health systems. The baseline assessment of pre-ART care identified gaps in and the causes affecting the efficacy of pre-ART service delivery. As shown in Figure 2.3 below

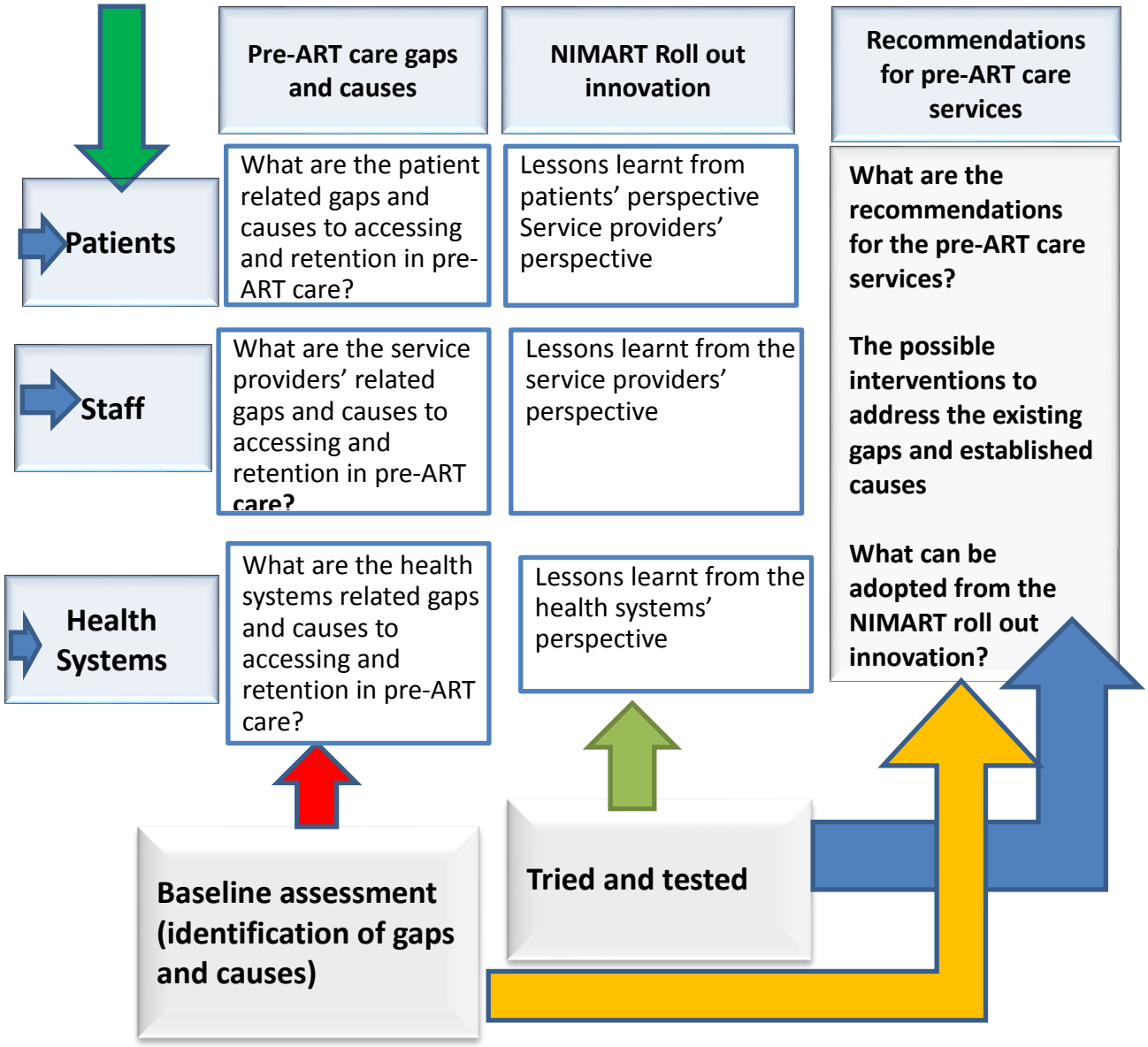


Figure 2.3 Conceptual framework for the study

2.11 Research question

- What should be done to improve access to and retention in pre-ART care?

To answer the research question, five sub-problems were developed:

- *Problem 1*: What are the gaps in the existing pre-ART program?
- *Problem 2*: What are the causes of these existing pre-ART care gaps?
- *Problem 3:* What possible interventions might address the existing gaps in the delivery of pre-ART care?
- *Problem 4:* What lessons can be learnt from the NIMART roll-out implementation
- *Problem 5:* What are the documented best practices that can be adopted to improve the quality of pre-ART care?

2.12 Aim and objectives

2.12.1 Goal

To establish the existing gaps in pre-ART care service delivery and draw recommendations that would improve the quality of the delivery of pre-ART care and retain patients in care.

2.12.2 Objectives

1. To identify gaps in the delivery of pre-ART services
2. To identify, describe and analyse the causes of pre-ART service delivery gaps, drawing on interventions already underway
3. To explore possible interventions to address pre-ART service delivery gaps

4. To establish lessons learnt in implementation of an effective NIMART roll-out to be adopted in pre-ART service delivery, and
5. To develop recommendations that would improve the quality in delivery of pre-ART care services and retain patients in care

Each objective answered each of the five research questions stated above. Different data sources and methods were used to answer the research question, and to meet the objectives, as shown in Table 2.1 below:

Table 2.1 Research questions and objectives

	Research Questions	**Objectives**
1	What gaps exist in the pre-ART program	To identify gaps and causes in the delivery of the pre-ART services
2	What are the causes of existing pre-ART care gaps?	To establish causes to the pre-ART service delivery gaps
3	What possible interventions can address the existing gaps in the delivery of pre-ART care?	To identify possible interventions to address the pre-ART service delivery gaps
4	What lessons can be learnt from the NIMART roll-out implementation	To establish lessons learnt in implementation of an effective NIMART roll-out to be adopted in pre-ART service delivery, and
5	What are the documented best practices that can be adopted to improve the quality of pre-ART care?	To develop recommendations that would improve the quality in delivery of pre-ART care services and retain patients in care

Chapter Three

Methodology

3.1 Study setting

3.1.1 Study site

The study was conducted at two facilities in Region F of the City of Johannesburg (CoJ) (Figure 2.1). The CoJ municipality is situated in Gauteng Province, South Africa, and has 7 regions (A-F), with a total population of approximately 4.4 million. This accounts for 36% of the Gauteng population and four percent of the national population (SA, 2015a).

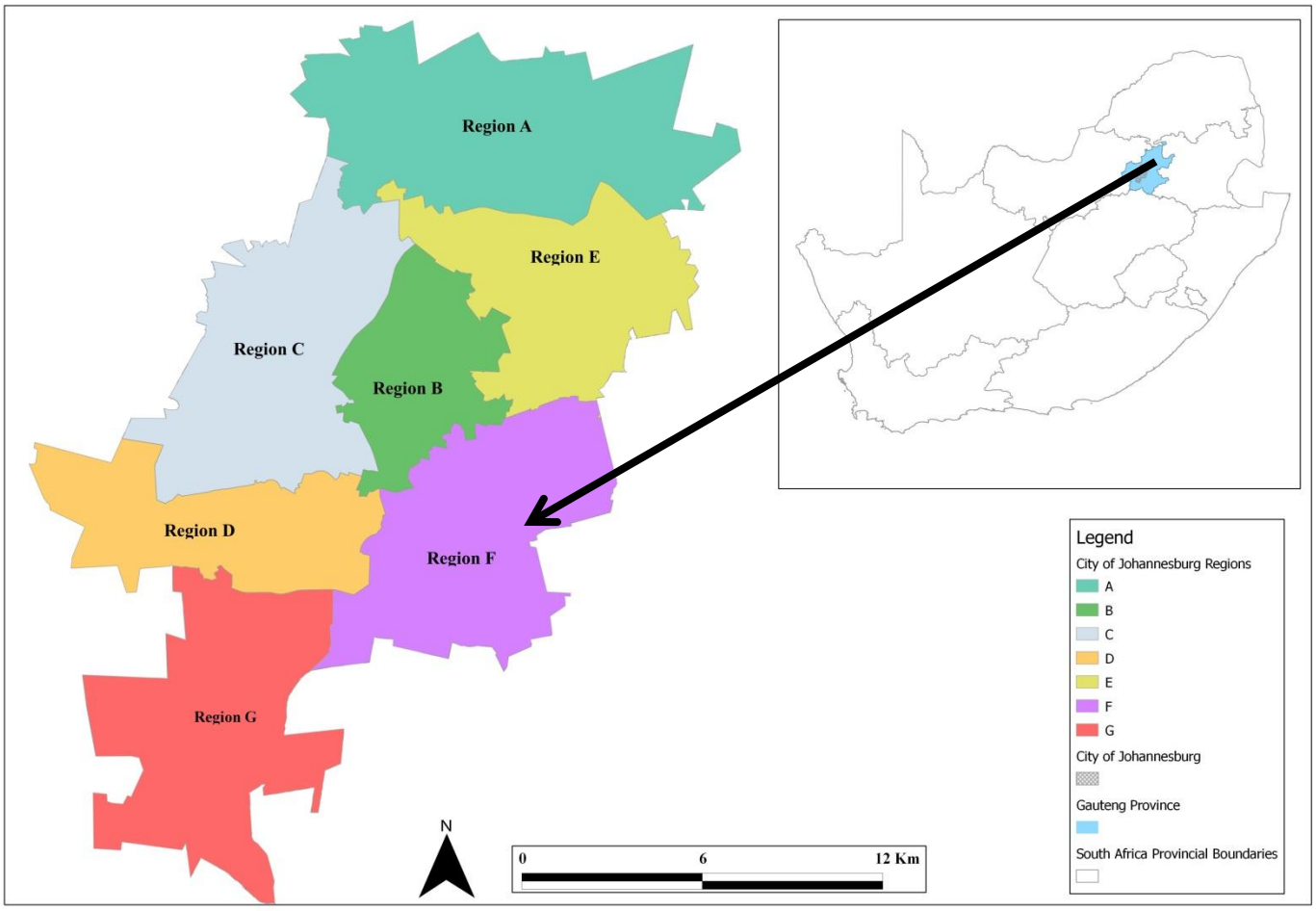


Figure 3.1: Map of South Africa and City of Johannesburg indicating Region F

Region F is the inner city of Johannesburg, with an estimated population of 478,000 (DHIS data base 2012), including migrants from other SA provinces and other African nationalities (SA, 2015a). The latest statistics indicate that in CoJ, only 24.8% of the population is employed, and about 17% live in informal settlements (SSA, 2012). The 2011 census showed that 84.6% of the population in CoJ were born in SA while the rest had migrated to SA from other countries - a drop from 97.1% in 2001 (COJ, 2013a). This migration to CoJ reflects the fact that city continues to draw people from other countries looking for better economic prospects and quality of life (COJ, 2013a, SA, 2015a). In addition to registered immigrants, the inner city is a hub of illegal immigrants not registered officially and hence, the population estimate of total numbers and numbers of immigrants is probably much lower than the true figures (SA, 2015a).



http://commons.wikimedia.org/wiki/File:Johannesburg.jpg

Figure 3.2a Marshalltown, inner COJ



http://victordlamini.com/news/joburgs-inner-city-

Figure 3.2b A degraded building, Joubert

As shown in the above Figures, the inner city has extremely varied regions, which range from severely degraded residential areas, to the rather stable commercial and educational institutional area of Braamfontein. In most cases, the migrants who cannot afford

accommodation use abandoned buildings, and many live without access to water and sanitation facilities.

3.1.2 Health services in Johannesburg and referral system

In Region F of Johannesburg, services are delivered at different levels namely: tertiary, secondary, community and primary levels (CoJ, April, 2015). Reflecting this, the region has one tertiary level hospital, one secondary level hospital, one Community Health Care (CHC) facility and 17 Primary Health Care (PHC) facilities. I describe these below.

Charlotte Maxeke Academic Hospital, formerly known as Johannesburg General Hospital, is an academic hospital and a tertiary level referral hospital for the city. This hospital has an HIV clinic and at this level of care, all diagnosis, treatment and plans of care are prescribed by specialist doctors; nurses provide nursing support care. **South Rand Hospital** is a secondary hospital located in the southern part of CoJ. All diagnosis, treatment and plans of patient care are undertaken by specialists and general practitioner doctors, while nurses provide nursing support, mainly guided by doctors. **Community Health Centres (CHC)** were developed to serve a population of up to 300,000, and act as first level referral sites for Primary Health Clinics (PHCs). Services provided by CHCs include curative care, maternal and child health (including maternity care), immunisation, health promotion activities, community outreach and minor surgical theatre. All CHCs provide 24-hour services. Hillbrow is the only CHC in Region F of CoJ. Lastly, **Primary Health Clinics (PHCs)** are intended to serve a population of about 100 000 people and provide the following services: curative care, maternal and child health, health promotion activities, community outreach and daily medical services of eight to 10 hours. The PHC facilities are mainly headed by a nurse and PHC nurses are trained in clinical diagnosis and prescription. They take the lead in the diagnosis, treatment and planning of patient care at PHC facilities. In complicated cases,

there are clear guidelines on referral of patients to the different levels of care described above (CoJ, April, 2015).3.1.3 Referral system

The referral system is an important component of health service delivery. The CoJ health service has referral systems in place in line with the WHO referral system, as illustrated below:

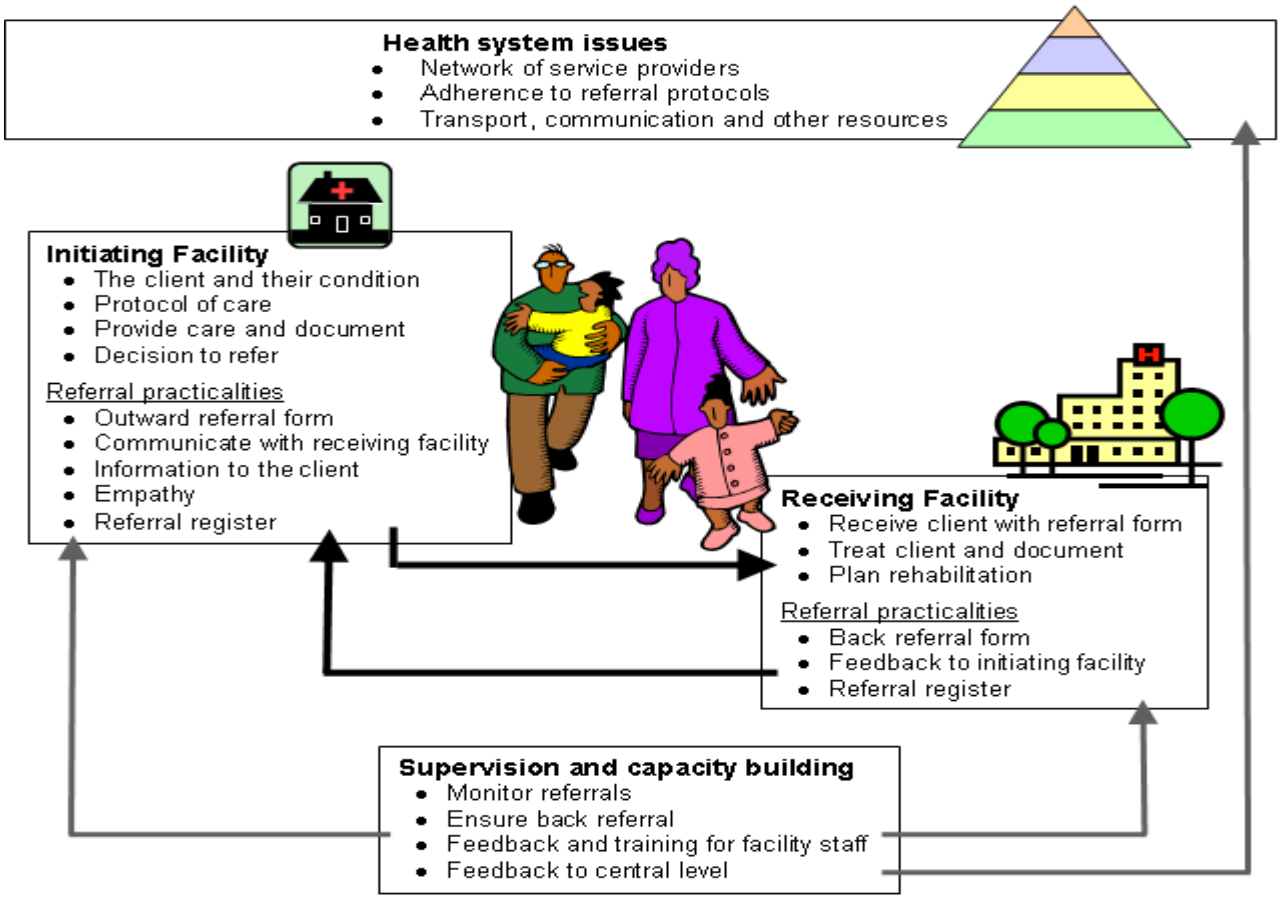


Figure 3.3 Referral system flow diagram (WHO, 2015)

As shown in the above figure adapted from WHO referral notes, in the CoJ referral system, constant communication between the different levels of the referral system is required. In CoJ, using an outward referral form, complicated cases are referred from PHCs to CHC, secondary or tertiary levels depending on the complexity of the case. All stable cases at receiving sites are expected to be back referred to PHC or CHC levels, depending of the case,

by completing the back referral form (Appendix 8.8). In addition, outward and back referrals are used as supervision and capacity building opportunities for both the initiating and receiving facilities. The underpinning principle is that patients access care at the nearest facility whenever possible.

Predominantly, patients who are not yet eligible to start ART are managed at their PHC facilities unless they have complications needing referral to CHC, secondary or tertiary health facilities. As a result, this study focussed on the PHC facilities in Region F, CoJ. At the time of data collection, the Department of Health (DoH) had designed systems to ensure that all foreigners had translators based in the facilities and provided access to services for those without legal identity documents. All PHC facilities provide HIV testing services and CD4 cell counts to determine patients' eligibility to start ART. Patients with CD4 count >500, with no TB, are expected to be enrolled into a pre-ART care program for monitoring and other pre-ART care services.

3.1.4 Study period

Data for this study were collected through interviews with pre-ART care patients and service providers, consultative workshops with health services managers, ART and HCT register audit as well as DHIS data on ART uptake in CoJ. Below is a table showing the time period applied for each data source:

Table 3.1 Data sources and time periods

Data source	Time period
Interviews with pre-ART care patients and service providers	July 2012
Consultative workshops with health services managers	March 2013
ART register audit	February 2012-July 2012
HCT register audit	May 2011-April 2012
DHIS data on ART uptake in CoJ	Oct 2009-Feb 2012

3.2 Study design

This study used a mixed methods design (Tashakkori and Teddlie, 2003), with both quantitative and qualitative data used at various stages to understand the research problem as completely as possible (Creswell, 2009). In this study, I used an embedded model of mixed methods, whereby a quantitative design had a nested qualitative component, enabling me to collect both quantitative and qualitative data within a traditional quantitative design (Creswell and Plano Clark, 2011).

The purpose for using mixed methods was to collect complementary data, as neither qualitative nor quantitative were sufficient by themselves to capture the trends and details of the situation, either in relation to pre-ART care and NIMART roll-out (Green et al., 1989, Tashakkori and Teddlie, 1998). Mixed methods provided an in-depth understanding of the

pre-ART care service delivery and questions around access (Blaxter et al., 2010, Creswell, 2009). This approach helped to validate findings from different data sources (stated in Table 3.2), so achieving triangulation (Barnes 2012), and they ensured that the weaknesses of one method were offset by the strengths of another (Tashakkori and Teddlie, 1998). Lastly, the pre-ART care research study had both qualitative and quantitative questions requiring both numerical and textual data, hence again the applicability of mixed methods (Williams, 2007). Data were collected from qualitative and quantitative methods, as shown in the table below:

Table 3.2 Qualitative and quantitative study questions

Question	Methods	Study population
What are the demographic characteristics of pre-ART care patients?	Quantitative	Pre- ART care patients
What are the pre-ART care patients' knowledge levels in relation to HIV/AIDS, CD4 cell count, pre-ART and ART services rendered in their facilities?	Quantitative	Pre- ART care patients
Are the facilities youth and male friendly?	Quantitative and quantitative	Pre- ART care patients
How was NIMART rolled-out in the CoJ and what was its effect on ART uptake?	Quantitative and qualitative	NIMART project information and DHIS database
What were the differences between rolling out NIMART and pre-ART services?	Quantitative and qualitative	NIMART project information and pre-ART service providers
What was the pre-ART patients' pathway of care from their first encounter at a facility to the date of interviews?	Qualitative	Pre- ART care patients and service providers
What are the common gaps and underlying causes in delivering pre-ART care services at the facility?	Qualitative	Pre- ART care Patients and service providers
What are the possible recommendations to address existing facility gaps?	Qualitative	Pre- ART care Patients and service providers

3.3 Study sampling

3.3.1 Sampling methodology of participants for interviews:

When selecting participants (pre-ART care patients and staff) for interviews for this study, multistage sampling was employed (Kirkwood and Sterne, 2009), with three stages as described below;

1st Stage: Selection of facilities

At the time of the study, pre-ART care patients were managed by nurses at their nearest PHC facilities. As a result, in order to access pre-ART care patients and service providers, all PHC facilities in CoJ were included for sampling. Due to time and financial constraints as a self-funded PhD student, only two facilities were randomly selected out of the 17 PHC facilities. This was done by writing names on small pieces of papers, which were mixed; then a volunteer was asked to pick out two pieces of paper.

2nd Stage: selection of pre-ART patients still in care:

It is important to determine the appropriate sample size in order to make inferences to the study population based on our findings from the sample (Kirkwood 2009). A number of variables were of interest in this study. These included process variables such as cervical screening, IPT, CPT, CD4 cell count checks ups and family planning being offered to pre-ART patients. There was one outcome variable - timely referral for ART initiation. In order to estimate sample size, I focused on the proportion of patients who were referred for ART on time. To estimate this, a pilot study was undertaken. A file audit was undertaken of all patients who were initiated on ART over the preceding six months, between January and August 2012, at the clinics, in order to estimate the proportion of pre-ART patients referred for ART initiation in a timely manner. A total of 203 files were audited, of which 30 were

referred from pre-ART care. Only three of these patients (10%) from the pre-ART program had timely ART initiation. The flow diagram below shows the results:

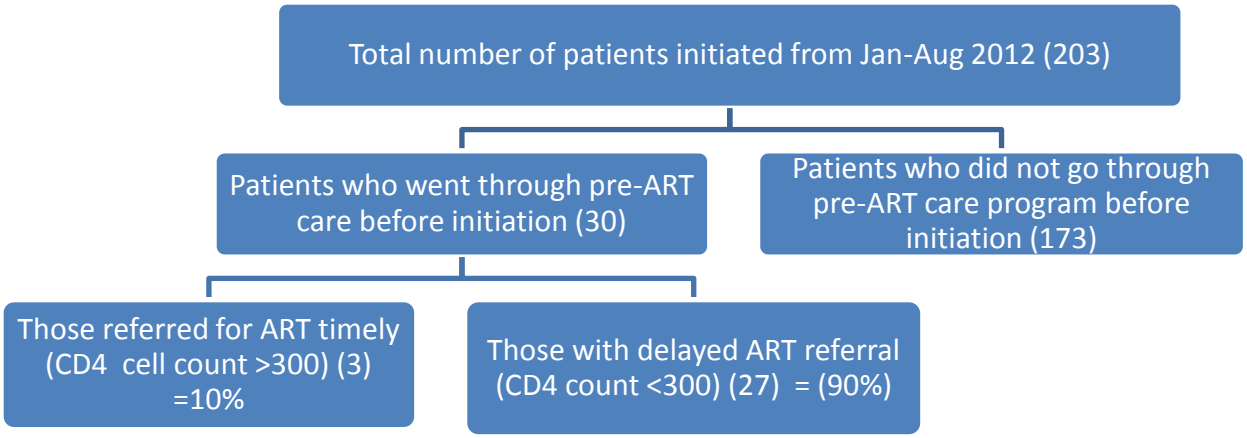


Figure 3.4 Pre-ART patient file audit selection process flow diagram

The initial plan was to conduct a baseline or pre-test assessment, and then later, after piloting a designed intervention, a post-test assessment would be conducted. As a result, comparison of two proportions was applied (at baseline assessment and project evaluation) (Kirkwood and Sterne, 2009). Individuals sampled at baseline assessment were unexposed to the appropriate pre-ART care program intervention, whilst the sample at the project evaluations was considered exposed to the intervention. The timely ART referral at baseline was at 10%, and it was expected to increase to 30% after the pre-ART intervention.

Using the 80% power and 95% two sided significance level, the sample size was calculated using the formula below:

$$\text{n1 or n2} = f(\alpha, \beta) \times \frac{\pi_1(100 - \pi_1) + \pi_2(100 - \pi_2)}{(\pi_1 - \pi_2)^2}$$

Where: n1 = Sample size at baseline, n2 = Sample size at project evaluation, α =5%, β =80%, $\pi_1 = 10\%$ and $-\pi_2$ =30%. Using this formula adapted from Kirkwood and Sterne (2009), sample size was calculated with STATA as shown in the output below:

Table 3.3 STATA sample size calculation output

Two-sided significance level(1-alpha):	95%
Ratio of sample size, Unexposed (baseline)/Exposed (evaluation):	1
Percentage of those referred for ART timely before intervention:	10%
Power	80%
Percentage of those referred for ART timely after intervention.	30%
Risk/Prevalence Ratio:	3%
Risk/Prevalence difference:	20
Sample size exposed	72
Sample size not exposed	72
Total sample size	**144**

As shown above, 72 pre-ART program patients were to be selected for interviews at baseline (non-exposed) and evaluation (exposed) phases; in total 144 patients were to be interviewed.

All patients attending pre-ART care services in the week 6 – 10 July 2012 were selected for interviews, until the sample size of 72 was reached. These patients were not expected to be homogeneous, since patients are scheduled for either monthly or three monthly appointments, depending on the type of services to be given or their clinical condition. In addition, during the same week, all health service providers involved in the pre-ART care program were selected for interviews. The above register and file audits pilot study processes involved in

sample size calculation yielded some key preliminary results which will be elaborated further in the chapters four and five that follow.

3rd Stage: selection of pre-ART care patients who dropped out from care

People who dropped out from the program were systematically selected and telephoned to come for interviews. To identify non-attending but registered patients, I manually reviewed clinic records. Paper files for people who were registered for and/or attended pre-ART services were organized alphabetically on shelves, as shown in the photograph below (Figure 3.6).



Figure 3.5 The pre-ART filing system cabinets and shelves

This filing system allowed me to identify patients who had not presented at the facility for the past 12 months. The first file on each drawer, of a patient who had not attended, and for whom a telephone contact number was available, was invited to participate in the study. A total of 15 files were selected and patients were phoned to schedule an interview. The phone numbers for six patients were not working; five of the nine patients who were called accepted

to participate and were scheduled for interviews. Four did not come after the phone call; of these, two had moved out of the City of Johannesburg whilst the other two just refused, indicating that they no longer wanted to do anything with pre-ART care for unspecified reasons.

All pre-ART care service providers in the two facilities were included in the study. Using the above selection criteria, the baseline assessment included a total of 73 patients (30 male and 42 female) and 12 service providers (4 male and 8 female) for interviews.

Table 3.5 Sampling methodologies for register and file audits

	Category	Inclusion criteria	# included
1	*HCT register audit*	All patients who tested HIV+ over a 12 months (May 2011 – April 2012) period were included for auditing	1715
2	*ART register audit*	All patients who were initiated on ART between February- July 2012	203
3	*Pre-ART care file audit:*	This is a subset of (2) patients who were initiated on ART between February- July 2012 after attending pre-ART before their CD4 count levels dropped to a level when they become eligible for ART	30
Total			1918

3.3.2 Inclusion criteria for patients in NIMART roll-out

All from Region F, initiated on ART from October 2009 to March 2012, were included. All patients who had transferred to Region F facilities from other regions or districts were excluded. A total of 20535 iinitiated on ART were included, of whom 6,957 patients (both adults and children) were initiated before the NIMART intervention (October 2009-September 2010) and 13,578 after NIMART (October 2010-February 2012).

3.3.3 Sampling methodology of participants for the consultative workshop

Choosing the appropriate participants is particularly important in the research process as it directly affects the quality of the study outcomes (Jacobs, 1996). However, adopted from the Delphi technique, the workshop participants were recruited based on their expert knowledge on the pre-ART service delivery gaps, causes and possible solutions, and willingness to participate (Hsu and Sandford, 2007, Lofmark and Thorell-Ekstrand, 2005, Powell, 2003). The participants were health services managers in the City of Johannesburg from a health background. Fifteen participants were involved in a consultative workshop (Delbecq et al., 1975). These managers were decision makers who would utilise the recommendations drawn from the study.

3.4 Data collection

3.4.1 Data collection tools

3.4.1.1 Questionnaires for patient and staff interviews

I used the South African National Clinical Guidelines for ART and WHO Guidelines on Standard pre-ART Care and Information to be offered to pre-ART program patients (SA, 2013d, WHO, 2008) to develop the data collection tools for pre-ART care patients and staff (see Appendix 8.5). Some questions from the Wits Reproductive Health Institute (WRHI) questionnaires, used in studies among HIV+ individuals in the same population (in Johannesburg), were also adopted. In order to establish factors contributing to men and youths being most often lost to follow-up in pre-ART care, a component of measures to assess youth and male friendliness of the facilities was also included. These tools were used to collect data from participants on the following areas:

- Demographic characteristics.

- Pre-ART patients' pathway of care from first encounter at a facility to the date of interviews
- Participants' knowledge levels on HIV/AIDS, CD4 cell count, pre-ART and ART services rendered in their facilities.
- Participants' perceptions of male and youth friendliness of the facility, which included asking the participants the definition of youth and male friendliness, whether they felt that facilities were friendly to youths and men, and the gaps and possible solutions to making the facilities youth or male friendly.
- Participants' perceptions of the common gaps in delivering pre-ART care services at the facility, and
- Participants' perceptions of possible recommendations to address the existing facility gaps.

These interview tools had both closed and open-ended questions, enabling the collection of both quantitative and qualitative data through interviews with pre-ART care service providers and patients.

3.4.1.2 Checklist for pre-ART care register audit: The pre-ART care register checklist covered the following areas: Age, gender, TB screening, the CD4 cell count value, CD4 testing, collected their CD4 cell counts results (see Appendix 8.5.4).

3.4.1.3 Checklist for ART patients' file audit: The file audit checklist covered the following areas: gender, initiation date and the CD4 cell count level at the time of initiation (see Appendix 8.5.5).

3.4.1.4 NIMART readiness assessment tool: This was a Department of Health tool used to assess facility readiness to start implementing NIMART. The tool covered the following

areas: General information around recording and reporting of facility, basic HIV/AIDS Services delivered by the facility, availability of policies and National Treatment Guidelines, availability of laboratory and pharmacy services and capacity and lastly, HIV/AIDS Service Point Access to care, treatment and support.

3.4.2 Pretesting of data collection tools

The tools were pre-tested to ensure feasibility of the study, and to identify questions that were poorly understood, ambiguous or inconsistent (Armstrong et al., 2001). Pretesting of tools was conducted in one of the CoJ facilities which was not part of the study. Comments from the participants during the pilot study enabled me to finalise the questions through the modification of questions, adding and removing other questions, as described in Table 3.5 below:

Table 3.5 Changes made to data collection tools after pretesting

Before pre-testing	After pretesting
What are the possible solutions to address the gaps in pre-ART care in this facility?	This question did not elicit much information from respondents. As a result we included the list of pre-ART care services in a table as follows: What do you think should be done to improve the services below? HIV counselling and testing (HCT), disclosure and prevention, on-going counselling, PLWHA support groups, TB IPT – client education, screening and administration of IPT, social grant acquisition support, nutrition (food parcels and infant feeds), and adherence support
Do you think the facility is youth friendly?	We realised that not all respondents understood what youth and male friendliness of the facilities meant. As a result the questions changed as follows:
Do you think the facility is male friendly?	What is a youth friendly facility? (if the respondent does not know, the interviewer should define it to him/her) Do you think this facility is youth friendly? Why?

Before pre-testing	After pretesting
	What is a male friendly facility? (if the respondent does not know the interviewer to define it to him/her) Do you think this facility is male friendly? Why?
Initially we had a separate additional page for PMTCT patients	Because there was some repetition of questions, later we incorporated the question into the pre-ART patient questionnaire and removed the repetitive questions.
The flow of questions was inconsistent as some questions did not make sense when asked in the initial flow	The flow of questions was revised and numbering was changed.

3.4.3 Data collectors

Data through interviews for this research were collected in July 2012 by seven people including me, the project coordinator, and five others (three males and two females) recruited to conduct patient interviews. The project coordinator, who had a Master's degree in Public Health (MPH), was recruited with support from Foundation Professional Development (FPD) on a full time basis, as a project fellow, for 6 months (March – August 2012). The fellow was responsible for register and file audits under my direct mentorship and supervision. She also co-managed the greater part of the staff and patient interview data collection week through facilitating the logistics, co-facilitating the training for the data collectors, and she conducted some of the staff interviews. Five data collectors were recruited. The criteria for recruitment was matric level (a qualification on completion of high school) and previous experience in collecting qualitative and quantitative data. These data collectors were mainly sourced from

the Wits Reproductive Health Research Institute (WRHI), which as a research organisation had a database of data collectors.

These five data collectors were also trained and experienced HIV/AIDS peer-educators attached to WRHI project on part time basis. As a result, the team was well conversant on the basic principles when talking to people who were living with HIV. In addition, because of their role with WRHI, these data collectors were scheduled for bi-monthly psychological debriefing sessions with a qualified clinical psychologist. Before the actual data collection through interviews with staff and pre-ART patients, the data collectors were trained, covering the following areas: introduction to pre-ART and research study, overview of the patients' and service provider's interview questionnaires, conducting interviews, data quality checks, debriefing sessions, a practical session on conducting interviews, feedback sessions and a plan for the data collection week. Further information on this is provided in Appendix 8.6.

3.4.4 Data collection process

Data collection for pre-ART care patients and service providers' registers and files for auditing and ART naïve patients for NIMART roll-out innovation was carried out as shown in the table below:

Table 3.6 Description of data collection processes

Category	Process
Pre-ART care patients and service providers interviews	***First round:*** Five data collectors with experience in conducting interviews were trained and oriented by me on how to use the questionnaires, for them to familiarise themselves with the tools. At the end of each data collection day, as a principal investigator, I facilitated a debriefing session whereby the data collectors presented on how the data collection process went on the day and the highlights on findings from each interview conducted. Particularly focus was placed on the open ended (qualitative) questions. This enabled me to capture the qualitative data highlights from the interviews conducted on the day, and to identify emergent issues to guide later interviews and establish when saturation was reached. ***Second round:*** This phase focused on validating the findings from the baseline assessments, establishing the possible causes of the identified pre-ART care service delivery gaps and developing possible recommendations. This was done through a consultative workshop with the health service managers, whereby the findings on identified gaps in the pilot facilities, with proposed recommendations from the baseline assessments, were presented to the team of health services managers. The presentation was followed by further discussions on the causes and possible recommendations. In order to avoid the risk of domination by specific individuals, forcing other participants conforming to their view point (Oh, 1974, Adams, 2001), I facilitated this in such a way that the dominant participants were controlled while quieter ones were encouraged to contribute.
HIV+ HCT register audit	The following parameters were used to audit the registers: Age, gender, whether they were screened for TB, whether their CD4 cell count was checked, the CD4 cell count level, whether they collected their CD4 cell count results.
ART and pre-ART file audit.	The ART register for patients initiated between February and July 2012 was audited to establish their gender, initiation date and the CD4 cell count level at the time of initiation. The files for the same list of ART patients were traced and audited to establish whether they attended pre-ART care before becoming eligible for ART. The ART file audit checklist covered the following areas: Gender, the date a decision was made to initiate the patient, date the patient was initiated on ART and whether they accessed the following pre-ART

	care services: TB screening, cervical cancer screening, IPT, CPT and multivitamin tablets.
ART care patients initiated through NIMAMRT	We documented the 10 step process of rolling out NIMART and compared uptake of ART in the CoJ before and after NIMART roll-out, to establish the effect of NIMART on ART uptake.

3.5 Data processing and analysis

3.5.1 Quantitative data

3.5.1.1 Quantitative data from patient and staff interviews

Quantitative data were entered into Epi Info 2003 (US Centres for Disease Control, Atlanta, GA, USA) and analysed using Statistical Package STATA software version 12 (STATA Corporation, College Station, TX, USA). HIV/AIDS knowledge levels of the participants were established through HIV/AIDS knowledge questions, using both unipolar and bipolar Likert scales (Strener and Norman, 2003). During data analysis, the HIV/AIDS knowledge levels and socio-demographic characteristics were compared to whether the respondent had his/her CD4+ cell count checked within the past six months according to WHO/SA pre-ART care guidelines. Chi-square or Fisher's exact test were used for categorical variables. In addition, CD4 cell count levels at the time of the interviews, access to pre-ART care services, disclosure on HIV+ status, and sources of HIV/AIDS information were analysed and presented in tables or graphs.

3.5.1.2 Quantitative data from patient register and file audits

Patient register and file audit data were captured in Excel and imported into STATA for analysis. Age (whether a youth aged 18-24 or not) and gender were the two main variables for the file and register audits. We performed a chi-square test to compare differences in proportions between the two groups. A chi-square P value of ≤ 0.05 was considered significant. The mean CD4 cell count, return visit for collection of CD$ cell count results,

and access to pre-ART services i.e. TB screening, IPT and CPT were compared by gender and age groups.

3.5.1.3 Statistical analysis for data from NIMART roll-out implementation

Continuous data were expressed as means (standard deviation [SD]), medians or interquartile range [IQR]. Categorical data were presented as frequencies and percentages. The Durbin-Watson statistic was used to test for auto-correlation between NIMART roll-out and ART uptake. The time series data were modelled using segmented regression analysis of interrupted time series which, as suggested by Wagner and others (2002), has the advantage of controlling for baseline level and trend. The time series patterns before and after the intervention to assess differences were compared. The trends before and after the intervention were analysed to assess whether passage of time was associated with increased ART initiation. The change in average numbers of those initiating ART immediately after intervention was estimated and tested for significance. The specific model used was:

$$Y_T = \beta_0 + \beta_1 * \text{time} + \beta_2 * \text{intervention}_t + \beta_3 * \text{time after intervention}_t + e_t,$$

where Y_t is the total number of new ART initiations in a month in Region F, which is the response variable in this model; *time* is a continuous variable indicating time in months at time *t* from the start of the observation period; *intervention* is an indicator for time *t* occurring before (intervention = 0) or after (intervention = 1) NIMART rollout, which was implemented at month 13 in the series; and *time after intervention* is a continuous variable counting the number of months after the intervention at time *t*, coded 0 before NIMART and 1 - 18 after NIMART. In this model, β_0 is the estimate of baseline level of outcome, being the mean number of patients initiated on ART at time zero; β_1 estimates the mean change in total number of ART initiations that occurred in each month before NIMART rollout, β_2 estimates the level change in the mean number of initiations after NIMART; and β_3 estimates the

change in the trend in the mean monthly number of ART initiations after NIMART compared with the monthly trend before NIMART intervention. The error term *et* at time *t* represents the random variability not accounted for by the model. Throughout a two-tailed *t*-test at a 5% level of significance was used.

3.5.2 Qualitative data

The last part of the questions from the patient and staff interviews, looking at the existing gaps in pre-ART care, and possible solutions to address them, was open ended, and the verbatim text provided qualitative data. On each day after data collection, a debriefing session was conducted whereby each interviewer narrated data generated from each participant. During the debriefing sessions, relevant individual quotations were identified. Qualitative data were then manually analysed to construct themes and matrices. Later, all qualitative data were transcribed as individual scripts for each participant. Word processing was used to develop themes manually, based on the interpretation of the fundamental importance on a higher analytical level as compared to more descriptive categories.

3.6 Triangulation of data

Triangulation of data has been shown to establish validity and credibility of research findings (Guion et al., 2011). In order to establish trustworthiness and validity of results, different sources of data were chosen, including clinic monthly statistics, pre-ART patients' and service providers' interviews, and patients' file and register audits. Throughout the data collection and analysis processes, consistencies and inconsistences in the findings from the different data sources were observed and analysed, as described in the table below:

Table 3.7 Triangulation of different sources of data

Consistency observation	Data source
The type of services indicated to be offered at the facility by the staff and actual services accessed by the patients and what was documented in the files and HCT registers of patients who accessed pre-ART care in the facilities	PIs, staff interviews, register and file audits
Clinic ART and pre-ART statistics	Staff interviews and clinic statistics
The pathway in which patients access care, i.e from HIV pre-test counselling to initiation on ART?	Staff and PIs
Pre-ART care staff availability	Staff and PIs
HIV/AIDS knowledge levels	Staff and PIs

3.7 Quality control

In this study, quality control measures were taken to ensure that the data generated were of good quality. Firstly, the research data collectors were trained prior to conducting data collection. In addition, at the end of each data collection day, a detailed debriefing session was conducted. In this session, the data collectors made brief presentations on the interviews conducted in the day, highlighting the key findings; this gave us all a sense of new issues emerging from the interviews and those which required more probing. Data were double entered by myself and the pre-ART project research fellow, and cleaned to take care of all inconsistencies. Missing values were checked and data were corrected. Lastly, verification of data with the original questionnaires was done throughout the process, even at the time of writing up the research report, to ensure that the analysis and report were reflections of the study findings.

3.8 Ethics considerations

The study was approved by the University of the Witwatersrand Committee for Research on Human Subjects (see Appendix 8.2), with supporting approval from the City of Johannesburg (see Appendix 8.4). All interviews were conducted in privacy, consent was sought and the signed consent forms did not have the participants' name. No incentives were given to study participants. However, transport money was provided to patients to attend interviews if they had not come for pre-ART services for 12 months and were phoned to come for interviews. The amount of transport money reimbursed ranged from R30-R50 ($3-$5), depending on where the participant lived.

With the realisation of the fact that asking people about their lived experience of HIV can sometimes lead to psychological trauma for the interviewer as well as the respondent, a debriefing support structure was established to deal with such issues. Throughout the data collection process, no psychological trauma case was identified during the debriefing sessions. In addition the data collectors attended scheduled WRHI bimonthly debriefing sessions as a support structure for them as HIV/AIDS peer-educators, as described earlier in this chapter.

Initially, the facilities were named and facility managers had different questionnaires from the other pre-ART service providers. The ethics committee recommended that facilities not be named and that I merge the questionnaires for facility managers and the rest of the staff to ensure privacy and confidentiality of the responses, as there were only two facilities and managers participating in the study. For this purpose, throughout this thesis, where there is a risk of breech of confidentially, I neither refer to a facility name nor link staff respondents to their roles to pre-ART care.

3.9 Dissemination of results

The first phase on dissemination of the results was after baseline assessments. The baseline results, highlighting the identified gaps and possible recommendations, were presented to the facility and regional health managers of CoJ. At this time, ideas were sought from the CoJ partners to be included in developing recommendations for pre-ART services. In addition, findings for the study were published or written up as abstracts for international conferences (see Appendix 8.9).

3.10 Limitations and special factors considered in the study

One of the most important responsibilities of researchers is to report on the limitations and challenges in their study. It is important to be aware of the problems or limitations before commencing the study. Many are unavoidable, hence the need to acknowledge them at the report writing phase (Fisher et al., 2002). Below I elucidate the limitations in this study.

3.10.1 Selection bias

In both quantitative and qualitative research, the selection of study participants and methodology used is crucial in drawing broader inferences from the findings (Kirkwood and Sterne, 2009, Polit and Beck, 2010, Kirkwood and Price, 2013). This study was conducted at primary health care facilities in the City of Johannesburg, which may be different to those in other provinces of SA and elsewhere. However, as discussed in Chapter 1, drawing on my knowledge acquired in my role as a QA technical advisor in five provinces across South Africa (not including CoJ), I believe that the identified gaps in these clinics are similar to those that exist across South Africa. As a result, the recommendations in the study can be generalized at PHC level across South Africa, although with caution, as the study site was urban, and its population mainly migrants, in contrast to other South African provinces which are rural with a large population of local residents. In addition, since most people were

migrants, they travel to their homes over Christmas and on other similar occasions, to be with their families, leading to a low uptake of services at different times of the year. Selecting clinic attenders during these periods may lead to selection bias. However, to be more inclusive in this study, data were collected five months before the festive season.

Some patients lost to follow were not traced for interviews. However, efforts were made by phoning to get hold of the patients and to schedule interviews at an appropriate time and place. This was not always successful as described above (3.3.1). Given the possibility that the characteristics and lived experiences were different from those people who were interviewed, it is difficult to generalise the findings to a wider population (Campbell and Machin, 1999, Kirkwood and Sterne, 2009).

3.10.2 Information bias

All registers were in place for the pre-ART and ART programs; however, as described in this thesis, there was poor data recording especially with pre-ART registers. At the time of the study, most ART registers were well completed, whilst the pre-ART and HCT registers were mostly incomplete. Every possible effort was made to compare the registers with the source documents, such as patients' files or cards, to ensure completeness of data. In addition, the triangulation of data, using the interviews with 73 patients and service providers and workshop with health services managers, was used to validate and verify findings.

Even though all patients still in pre-ART care and selected for interviews voluntarily accepted to be interviewed, it is important to acknowledge that some of the information required them to recall what happened (for example, narration of their care pathway from the time they were diagnosed). People tell particular stories emphasising one area not others, leading to recall bias (Campbell and Machin, 1999, Kirkwood and Sterne, 2009). However, since the patients were interviewed after collecting their files, the interviewers assisted in

validating the information by checking what was documented in the patients' files when necessary.

3.10.3 Situational Factors

It is important to take an account of all other factors and processes taking place in the health systems that may affect the results of the study. Below I set out these factors:

6.2.3.1 Population mobility

Region F of the City of Johannesburg, where the study was conducted, is comprised of a highly mobile population, as discussed above. The recommendations developed from this study have been critically reviewed as to whether they are applicable for both mobile and stable populations.

6.2.3.3.2 CD4 cell count cut-off point

HIV service delivery is one of the areas with a fast evolving body of knowledge due to ongoing research in the area. For example, the CD4 cell count at the time of initiation of the research project in 2011 was at ≤200 cells/µl which increased to ≤350 in 2012 with a further increase to ≤500 cells/µl in January 2015. These changes may have affected the number of patients on pre-ART care, and may affect the applicability of the results in South African context.

Chapter Four

Results

In this section, I present both qualitative and quantitative findings from data collected in the study. In addition, outcomes from a consultative workshop with health services managers in the City of Johannesburg, and documentation of the NIMART roll-out processes, are presented. A total of 2018 participants were included in this study, as shown in the table below:

Table 4.1 Study participants

	Category	**Number**
1	Patient interviews	73
2	Staff interviews	12
3	Consultative workshop with CoJ health services managers	15
4	HCT register audit	1715
5	ART register audit and pre-ART file audit	203
Total participants in the study		2018

In addition, 6957 and 13578 people from the DHIS ART initiation data base were included in the before and after NIMART roll out time series analysis respectively.

4.1 Interviews with pre-ART care patients

4.1.1 Socio-demographic characteristics and 6 monthly CD4 count check ups

In this study, I established the socio-demographic characteristics of the participants in order to better understand their association with access, adherence and retention in pre-ART care. In this case, CD4 cell count testing within the past 6 months, at the time of the interviews, was used to approximate adherence. In Table 4.2, I present the participants' socio-demographic characteristics and their CD4 cell count 6 monthly check-ups.

Table 4.2 Socio-demographic characteristics and 6 monthly CD4 cell count monitoring

Socio-demographic variables	No (%)	CD4 count, 6 monthly	No CD4 count 6 monthly	P value
All respondents (73)	73 (100)	50 (68.5%)	23 (31.5%)	
Gender				
Male	30 (41)	21 (70)	9 (30)	0.82
Female	43 (59)	29 (67)	14 (33)	
Employment				
Employed	13 (18)	9 (69)	4 (31)	0.95
Unemployed	60 (82)	41 (68)	19 (32)	
Age				
<24yrs	23 (32)	19(83)	4 (17)	0.68
>24yrs	50 (68)	41(82)	9 (18)	
Educational level*				
≤ Grade 4	64 (87)	44 (69)	20 (31)	
≥Grade 5	9 (13)	6 (67)	3 (33)	0.9
Marital status				
Married	25 (34)	19 (76)	6 (24)	0.32
Not married	48 (66)	31 (66)	17 (34)	

As illustrated in the table above, most patients interviewed were unemployed (82%), illiterate (87%), aged >24yrs (68%) and not married (66%). Consistent with WHO and SA Guidelines that each pre-ART patient should to be tested for CD4 cell count every six months (SA, 2014(b), WHO, 2013a), the majority (68%) adhered to six monthly CD4 cell count check-up. There were no significant differences in the uptake of the six monthly CD4 cell count check-ups according to different demographic characteristics.

4.1.2 CD4+ count levels for the interviewed pre-ART care patients

At the time of the interviews, I established the current CD4 cell count levels for participants. Almost all (99%) mentioned that they had their CD4+ count checked at least once since they had tested HIV+. Further, two thirds had their CD4+ cell count checked within the six months period prior to the interview. Below is a summary of the exact CD4 count levels for the patients at the time of the interviews:

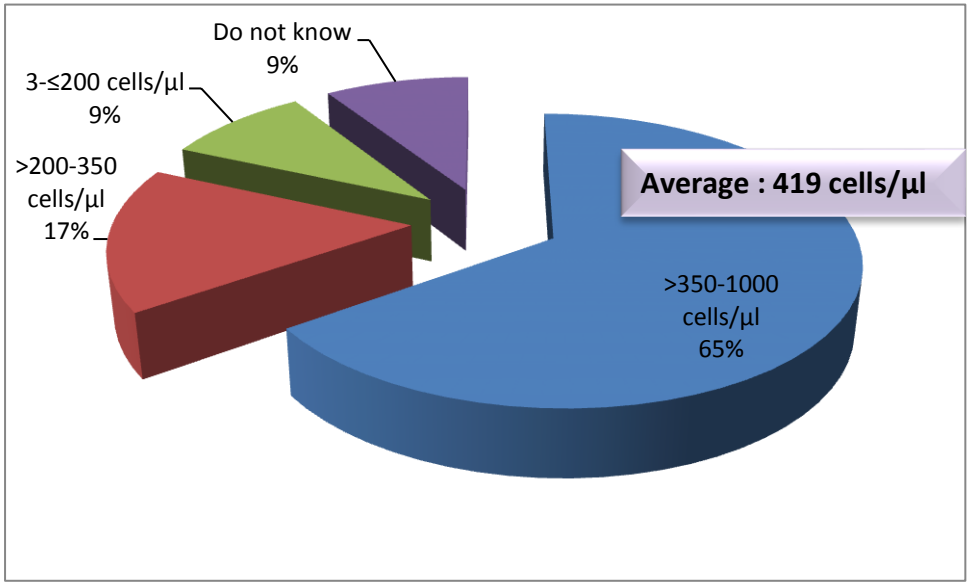


Figure 4.1 CD4 cell count levels for interviewed patients

As illustrated above, the CD4+ cell count levels for participants who knew their CD4 cell count levels, mostly documented also in their files, ranged from 3 to 1000 cells/mm^3 with an

average of 419 cells/µl. Only 64% had a CD4+ cell count of > 350 cells/µl and (27%) had ≤350 cells/µl, such as 3-200 cells/µl (9%), and >200-350 cells/µl (17%), qualifying these patients to be on ART and not in the pre-ART program at the time of the study. The majority of those with CD4 cell count <350 were attending recommended ART preparedness counselling sessions for ART initiation, while nine percent did not know their CD4 cell count levels; when this was checked, I established that their CD4 cell count was not documented in their pre-ART files. The one person with a CD4+ cell count of 3cells/mm^3 had not yet been booked for initiation counselling sessions at the time of the interview, and he was referred to the service provider for urgent attention as described in the section below. I discuss this further below, including in relation to the ethical issues associated with this low cell count.

In summary, even though the majority (two thirds) of interviewed patients had their CD4 cell count checked within the recommended previous 6 months, delays in ART initiation among patients retained in pre-ART program was established.

4.1.3 Patient pathways in accessing pre-ART care services

In order to understand the patient care pathways, patients were asked to narrate their experience of accessing pre-ART care. The majority (56%) of patients interviewed did not test HIV+ at the facility where they were accessing pre-ART care. Due to mobility to and within CoJ (COJ, 2013a, SA, 2015a), some patients tested positive in a facility nearer to where they used to stay, and they received a formal transfer letter to the current facility after they moved. In addition, SA had a large HIV Counselling and Testing (HCT) campaign, launched in December 2009 by the president and encouraging all to be tested and know their HIV status (Zuma, 2009). Since then, some non-governmental organisations have started mobile HIV testing in busy spots in the city, such as at taxi ranks and markets. As a result, some patients interviewed had tested positive at a mobile clinic and were then referred to the

facility for CD4 cell count checking and follow-up. None of the study sites at the time of interview provided patients with immediate CD4 cell results; rather, people were asked to come back to collect their CD4 count results after 2 weeks. In this section, I present three diagrams on patient's experience, reflecting two patients who had defaulted from care and another who had not defaulted, despite considerable challenges.

4.1.3.1 "Committed to accessing pre-ART care regardless of access challenges": The story of Lusungu

Lusungu (pseudonym) was a 33 year old man. He was single. He had continued his education to secondary school, and was working for a construction company at the time of interview. On the day of interview, he came to the clinic for a CD4 cell count check. Lusungu had tested HIV+ at a taxi rank mobile clinic run by WRHI in May 2009, and he had been referred to the study site clinic to check for CD4 cell count levels and for referral to care. Two months after testing positive, in July 2009, Lusungu reported at the clinic, his CD4 cell blood sample was taken and he was asked to come back in two weeks for the results. After two months, in September 2009, Lusungu came back to collect the results. These were missing, and as a result, he had to give another sample of blood for a CD4 cell count, and to come back again in two weeks for results.

Lusungu went back to the clinic after four weeks in October 2009 to get the CD4 cell count results, which was at 900 cells/µl. On that day, he was registered for pre-ART care, screened for TB (which he did not have), was put on IPT to prevent TB infection, and was provided with a supply of multivitamins. In December 2009, he returned for multivitamins and was told that they were out of stock; he would have to come back the following week when the tablets would be available. Lusungu did not return until July 2010, when his CD4 cell count was redone. He was then supplied with multivitamins, and advised to return in two weeks for the CD4 cell count results.

When Lusungu came back for the CD4 cell count results after four weeks in August 2010, he was advised that he had a CD4 cell count of 950 cells/µl. Lusungu reported that he was delighted by this improvement – "When I learnt that my CD4 cell count was higher than before, I was very happy!" Lusungu returned again after about nine months when his CD4 cell count was rechecked and more multivitamin tablets distributed. The CD4 cell count at this time was not known as Lusungu did not mention it and it was not documented in the file. Lusungu then did not come back for CD4 cell count results for 17 months, until the day of interview. His March 2011 results indicated that his CD4 count had dropped to 450 cells/µl from 950 cells/µl; he was due for another CD4 cell count check on the interview day. Lusungu was worried because his CD4 cell results 16 months earlier (in March 2011) had dropped by 500 cells/µl from those of July 2010: "I am very scared, maybe my CD4 cell count has dropped further by now. Maybe I need to start taking the serious HIV medication!" Lusungu regarded multivitamins and IPT as "not serious" medications, but he considered ARVs as serious HIV medication.

Lusungu's pathway captures how patients are asked to come back for blood results, especially CD4 cell counts, and how loss of blood results and drug stock-outs result in patients having to make multiple visits. Even though Lusungu did not return precisely at 6 monthly intervals for CD4 cell count visits, he was still retained in care three years after diagnosis. Lusungu's care to pathway is summarised in the figure below.

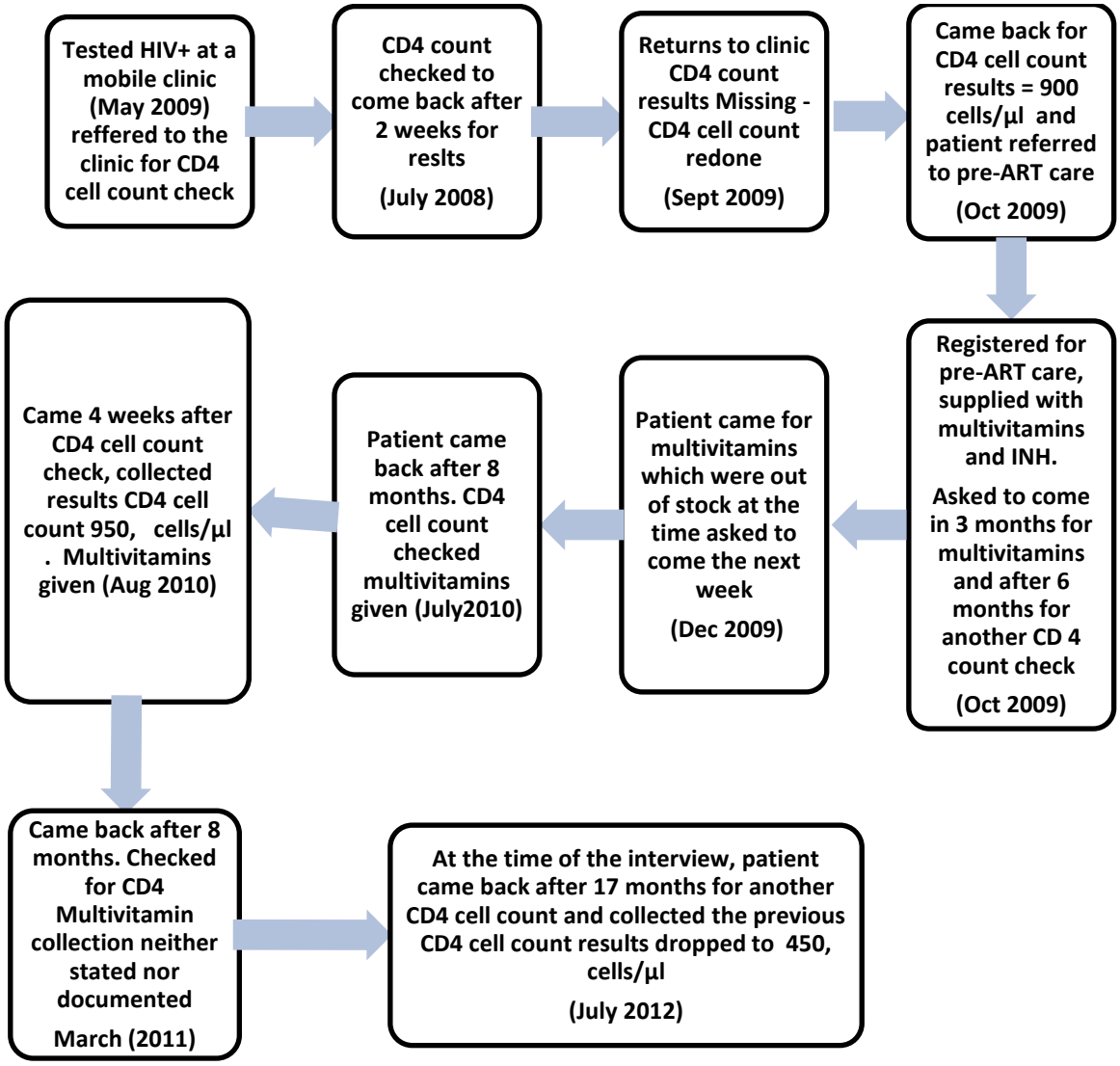


Figure 4.2 Lusungu's pre-ART care pathway

Lusungu explained to the interviewer that he had disclosed his HIV+ status to his partner but not to parents, family and friends. He was very knowledgeable of the difference between HIV and AIDS. Even though he was not able to explain the meaning of the CD4 cell count, later this was explained to him by the interviewer, Lusungu knew that a CD4 cell count of ≤350 cells/µl meant that a person would need to start ART. He reported that his main source of information was the facility counsellors.

Lusungu's knowledge levels around HIV and ART were good. Lusungu knew that he needed to use condoms even if both he and his partner were HIV+. As noted above, he knew that if his CD4 cell count reached < 350 cells/µl, he would have to start ARVs, and that this would help him feel better and live longer. He was not aware of which room to go to for ART Initiation but he did understand the implications of treatment: "My friend told me that if time comes for me to start real treatment, I will go to one of the rooms on that side but am not sure of the exact one." What I know is that after I start taking ARVs, I am not supposed to stop even if I feel better." However, he was not aware of the services available for HIV+ individuals not yet eligible for ART, despite accessing some of these services. He explained that no one had told him about such services.

Lusungu was able to describe what male and youth friendly services were supposed to be, and stated that the facility was not friendly to youths or to men. The main reason for this perception of unfriendliness was that there were no fast queues for youths, which would cater for young people going to school, or for men who were working. Lusungu also referred to drug stock-outs and long waiting times: "Tablets are always out of stock and delays of services lead to waiting for much longer time."

Lusungu had ideas about possible solutions to the above gaps: use of a patient appointment booking system so that a patient only needed to come in at the booked time, the facility to have youths serving youths and men serving male patients, and fast queues for youths and working men especially in the morning. Lusungu believed that men need to be scared to force them come to access care as reflected in this quote: "Give HIV pamphlets to men to scare them so that they come to take their treatment."

4.1.3.2 "I was still in denial": Nabanda

Nabanda was a 37 year old woman, married and living with her partner. She had remained in school until Grade 5 (upper primary school) and was working as a domestic worker. In 2008, Nabanda fell pregnant. In July 2008, when she went to the clinic for Antenatal Care (ANC), she was offered an HIV test as an entry point to PMTCT and she tested HIV+. If she were not pregnant, Nabanda would not have had an HIV test. She disclosed her HIV+ status to her partner and he also tested positive for HIV.

Nabanda had defaulted from pre-ART care, and was traced to be interviewed during the data collection period. When Nabanda's knowledge levels around HIV/AIDS were assessed, she was able to differentiate HIV and AIDS, and she knew that one could get married and have an HIV- baby even when the person was HIV+. She was also able to explain what a CD4 cell count meant, and that one needed to start ART if the CD4 cell count was at <350 cells/µl. She also gave a good definition of ART, although she was not sure where she had to go if she was to start ART. "I was not aware of all the available pre-ART care services even though I accessed the PMTCT program and multivitamins." She had limited knowledge of the youth and male friendliness of the health facility. Even though the source of information for her HIV/AIDS knowledge was the counsellor in the clinic, she proposed that the best way to sensitise people about pre-ART care services was through community sensitisation and clinic health talks.

Even though she went through counselling sessions, Nabanda claimed that she was "still in denial." On the first visit, she was asked to join a PMTCT program. At that time, according to the PMTCT guidelines, Nabanda received AZT and her blood was taken for a CD4 cell count and she was asked to come back after 2 weeks for the results; if the CD4 cell count was ≤350 cells/µl , she was advised that she would start the lifelong ART.

Nabanda reported that even though she was "in denial' about being HIV+, she still joined the PMTCT program for the sake of her unborn child. When she came back for the CD4 cell count results, Nabanda reported that her CD4 cell count was very high, although she could not remember the exact count level and this information was not recorded in her file. At that time, according to the current PMTCT guidelines, she continued on AZT and was advised that if she chose to breastfeed after delivery, she would continue to remain on AZT until the child stopped breastfeeding. Nabanda commenced treatment on the PMTCT program and delivered her baby in November 2008. During the period of pregnancy and delivery, she came to all scheduled visits, including the visit held six weeks after delivery, when the baby was tested for HIV through a PCR test. When she came after two weeks for the PCR test results, she was told that her baby was HIV negative.

That same day, Nabanda registered for pre-ART care and was given six months' supply of multivitamins. Since that day, she had never returned to the clinic and she decided to stop breastfeeding her baby. Nabanda went back to work, and her mother assisted her by taking the baby to the clinic until all immunisations were complete.

Nabanda stopped receiving care because, she said, she was "in denial" that she was HIV+: she explained that "I was not ready to be tested and I did not believe I could be HIV+!" In addition, she felt the quality of counselling given to her did not provide all the information that she needed, and the attitude of the service provider was not that good: "The nurse who assisted me was also not very nice to me." She did not provide examples of why she thought this.

Nabanda said she tested to protect her baby from becoming HIV+ and since the baby was HIV-, she felt that she had no reason to continue with pre-ART care. Below is a graphic presentation of the pathway of access to the care for Nabanda:

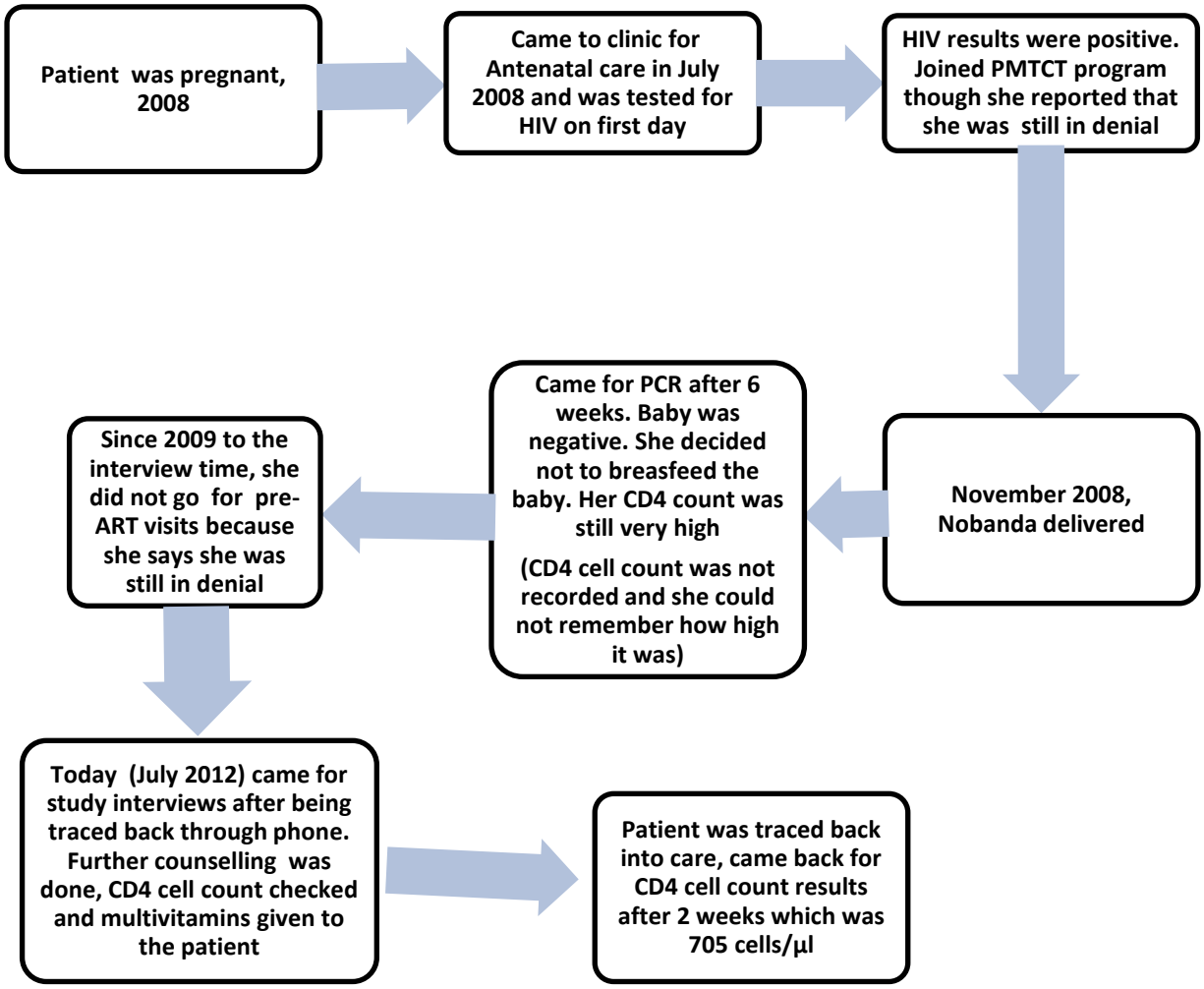


Figure 4.3 Nabandas's pre-ART care pathway

From the time Nabanda defaulted from care, until the time she was traced and asked to come to the clinic for an interview to share her experience, she had not been followed up by a service provider. After data collection, she was followed up and after further counselling, she returned to care for regular monitoring.

4.1.3.3 "But I tested HIV+ on time": Chisomo

Pre-ART care is aimed at people who test HIV+ and have high CD4 cell counts, and care includes monitoring their CD4 cell levels so that ART can be initiated on time. However, many patients are lost to pre-ART care, or return to care when they are already ill (Lessells et al., 2011). In addition, as already noted, patients seek care from different sources, and this has

been shown to delay access to ART (Moshabela et al., 2009, Pantelic et al., 2015). The participant with the lowest CD4 cell count is described in the case study below, to highlight factors leading to his delay in ART initiation.

Chisomo (pseudonym) had been enrolled into pre-ART care, and when he was interviewed, he had an exceptionally low CD4 cell count level of 3 cells/μl. Chisomo was 38 years old, and married. He had attained a secondary level of education and had a full time job as an accounts clerk at the time of interview. He said he had learnt about the HIV services provided at the facility through a friend, in 2008, and he came to the facility to be tested. He tested HIV+. At that time his CD4 cell count was 950 cells/μl. He was told that he was not eligible to start ART, but that he should come regularly for multivitamins and CD4 cell count monitoring.

Because he was employed full time, Chisomo found it difficult to come to the clinic, and so sought care from private general practitioners whose clinics were open at weekends when he was off work. As a result, he was able to find time to access care: "I had a full time job. As a result I was not able to come to this clinic; as you know, they only open during the week from 8-4pm. To save my job, I had to seek care from private clinics."

Chisomo did not go to one specific clinic, but changed clinics from time to time, leading to a lack of continuity of care. Although asked, he could not give any reason for switching doctors. At the private clinics, he mentioned that he was prescribed multivitamins, but could not always afford to purchase these. Because of the costs involved in having his CD4 cell count checked at a private laboratory, he did not monitor his CD4 cell count levels between the initial count in 2008 and when we met in June 2012.

Early June 2012, the private practitioner emphasised to Chisomo the importance of checking his CD4 cell count, as clinically his health was deteriorating and the doctor felt that he might

need to start ART. Chisomo decided to look for money, and tested for the CD4 cell count level which was 03 cells/µl. Chisomo was immediately referred back to the public health clinic to be initiated on ART as he could not afford ART in private facilities.

To be able to attend the public health facility clinic, Chisomo had to take time off from work. According the SA ART guidelines at the time of the interviews, before ART initiation, patients were supposed to receive three ART readiness counselling sessions, and to have routine baseline blood samples done before ART initiation (SA, 2013d). On the day of the interview, Chisomo reported that he had been coming to this facility for the past three days, but the ART baseline bloods had not been drawn. He also reported negative staff attitudes: "I have been here since Monday, but not yet initiated on ART. The staff attitude is bad, I approached one of the nurses and he said he cannot help."

When questions were asked about his knowledge around the meaning of HIV/AIDS, and prevention when a person was HIV+, Chisomo could not identify the difference between HIV and AIDS, nor did he understand the need to use a condom if both partners were HIV+, although he had disclosed his HIV+ status to his partner. In addition, he could not define or explain the meaning of CD4 cell count, although he knew what ART meant and he knew the room where he was supposed to go to be initiated on ART. He thought that ART would cure him of HIV, and that he could stop taking ART if he felt better. At the end of the HIV/AIDS knowledge and pre-ART and ART service awareness section of the interview, after identifying major knowledge gaps, the interviewer, a trained HIV/AIDS adherence counsellor, conducted a counselling session with Chisomo in order to address the identified gaps.

Chisomo also had little awareness of available pre-ART care services. He considered the main gaps in pre-ART service delivery to be long clinic waiting time, negative staff attitude

and poor integration of services, and he recommended that the facility reduce the waiting time and integrate pre-ART services; although there were no longer relevant to him, they could be relevant to his partner and others accessing pre-ART services. For example, he argued for integrating adherence counselling and bloods in the same day: "Reduce waiting time. Do everything to the patient in one day not making patient come back and forth for different services taking for ever; for example, combine adherence counselling with blood checking." Even though he was aware of HIV counselling, testing, CD4 count tests, and ART services delivered at the clinic, he was not aware that the facility also had PLWHA support groups, IPT, adherence and disclosure counselling, and PMTCT services, nor that it provided nutritional and social grant support, even though his main source of information on available pre-ART services was from clinic counsellors. Chisomo proposed counselling, IEC materials, community sensitisation, and health talks as ways to sensitise people to the available pre-ART services.

I had joined the interview in the course of the discussion around challenges in accessing care, and, as indicated above, Chisomo's CD4 cell count was 3 cells/μl – an unimaginably low level. Chisomo looked very sick, and had a severe skin rash; skin was flaking from his body and there was some discolouration on his face. I intervened, asking one of the service providers to attend to him as a matter of urgency. I negotiated with the PHC nurse to assist so that blood was drawn. Whilst we were not yet through the questionnaire, Chisomo was called in to give bloods for ART initiation preparation, and we could not continue with the interview. Below is a figure showing Chisomo's pathway to accessing care

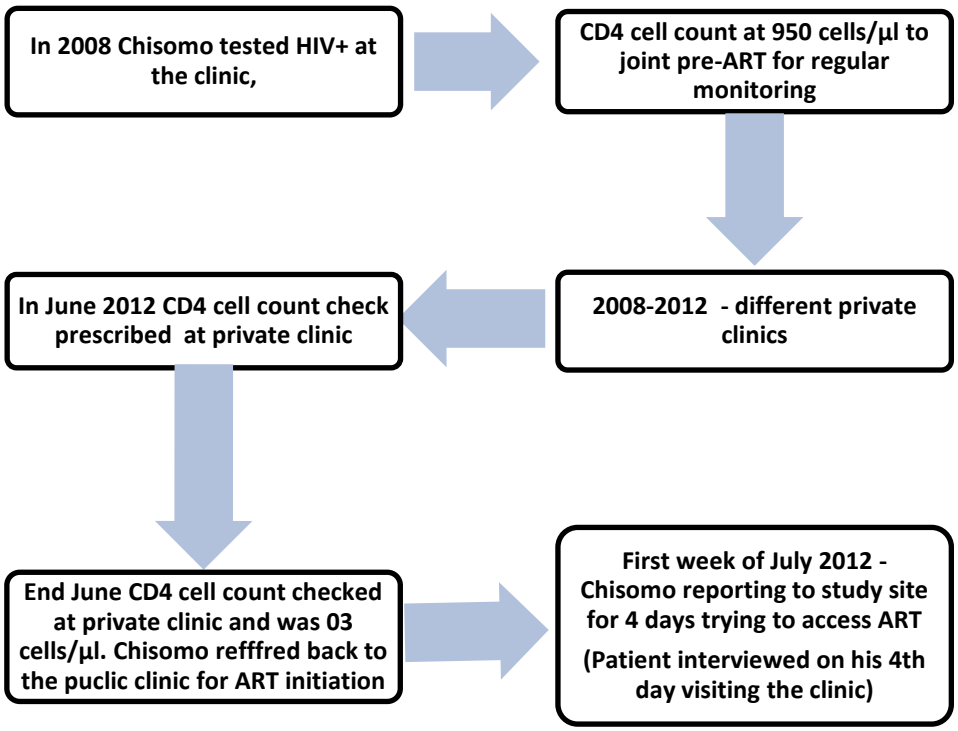


Figure 4.4 Chisomo's pathway to care

The above figure summarises Chisomo's story as described, reflecting the fact that he tested HIV+ on time with a high CD4 cell count, he then defaulted from public health clinic care and instead accessed care through different private clinics, and only returned back into care when he was extremely ill.

4.1.3.4 Analysis of pre-ART patients' pathway to care

None of the 73 interviewed patients gave an account of a pathway to care that fitted directly with the WHO/SA Guidelines of pre-ART care, that is, no one gave an account of care that included all elements: 6 monthly CD4 cell count check, access to IPT if they had no symptoms of TB, and accessing the prescribed pre-ART care services as outlined in chapter 3 above. Major challenges to accessing pre-ART care have been identified in this study. These challenges were related to patients themselves, service providers and health systems consistent with the conceptual framework illustrated in figure 2.3. These challenges will be discussed further in chapter five.

The timelines of the processes involved in accessing care were compromised in this study, as many patients could not remember the exact months each step took place. However, interviewers tried to verify the narratives with what documentation was on file. Not all of what was said by patients during interviews was documented in their files, and this made it difficult, especially when other care was accessed outside the current facility.

4.1.4 HIV/AIDS knowledge among pre-ART care patients

Basic HIV/AIDS knowledge levels were established among pre-ART patients participating in this study. In order to establish the association of knowledge levels and retention 6 monthly CD4 cell check-up was used as a proxy for retention, as shown in the table below:

Table 4.3 Basic HIV/AIDS knowledge and six monthly CD4 cell count check-ups

Variables	No (%)	6 monthly CD4	No 6 monthly CD4	P value
All respondents	73 (100)	50 (68.5%)	23 (31.5%)	
Patients' knowledge about HIV/AIDS (Meaning and prevention when HIV+)				
HIV is the same as AIDS (False)	20 (27)	17 (85%)	3 (15%)	0.062
Do you have to use a condom use when both of you are HIV+? (yes)	28 (36)	8 (35%)	15 (65%)	0.67
Having a normal life after being HIV+				
Can one still get married whilst HIV+? (yes)	23 (38)	15 (87)	15(13)	0.03
Can one have a baby whilst HIV+? (yes)	51 (70)	41 (82)	10 (18)	0.001
Patients knowledge about CD4+ count				
What is the CD4+ count cut-off point for one to start ART (< 350)	41 (56)	13 (26)	28 (58)	0.79
Knowledge/awareness of Pre-ART services				
Which of the following services are provided in this facility?				
PLWHA support groups (yes)	15 (21)	10 (67)	5 (33)	0.86
CD4 cell count monitoring (yes)	69 (95)	50 (72)	19 (28)	0.6
IPT (21/73)	21 (29)	14 (67)	7 (33)	0.83
Nutritional supplements (food items)	12 (16)	10 (83)	2 (17)	0.23
Multivitamin supplements	69 (95)	52 (75)	17(25)	0.71
HIV counselling services	52 (72)	36 (69)	16 (31)	0.73
ART Knowledge				
If you had to start ARVs, do you know which room to go to be initiated on ART? (yes)	48 (66)	12 (25)	36 (75)	0.097
ART will cure me of HIV (False)	19 (26)	13 (68)	6 (32)	0.99
I can stop the ARV drugs once I am feeling better (False)	18 (25)	11 (61)	7 (39)	0.44

As shown in the above table, HIV/AIDS knowledge gaps among pre-ART patients were established and compared to the CD4 cell count checked within the last 6 months. I describe these further below.

4.1.4.1 Patients' knowledge about HIV/AIDS

The knowledge levels of the pre-ART care patients on the meaning of HIV/AIDS, prevention when HIV+, and disease progression from HIV to AIDS were assessed. Less than half (36%) of the patients knew that there was a need to use a condom when both partners were HIV+. There were no differences in 6 monthly CD4 count check between those knowledgeable or not knowledgeable about the meaning of HIV/AIDs and prevention.

4.1.4.2 The fact that one may have normal life after being HIV+:

Patients were asked about their perception that one could lead a normal life after being diagnosed HIV+, through getting married and having an HIV- baby. Patients' perceptions of leading a normal life after being diagnosed HIV+ were analysed to establish its association with pre-ART care adherence, retention and access to 6 monthly CD4 cell count check-ups. Less than half (38%) of the respondents thought one could get married, but over two thirds believed that a person who was HIV+ could have a baby who was HIV-. Those who reported that one could live a normal live through getting married (P=0.03) and having a baby (P=0.001) were more likely to have had their CD4 cell count checked within the last 6 months.

4.1.4.3 Patients' awareness of the available pre-ART services

In my earlier study on access to PMTCT services among pregnant women in Malawi, I established that awareness on the available services affects access to and utilisation of services (Nyasulu and Nyasulu, 2011). In this study, I sought to establish whether pre-ART care patients were aware of the available services. In both study sites, the facilities provided

all pre-ART care services as prescribed by the SA Guidelines (see chapter one) However, lack of awareness of available pre-ART care services was established as only a few knew about the available PLWHA support groups (21%), IPT (29%), or knew about nutritional supplements (16%). The majority (95%) were aware that multivitamin tablet supplements were provided and that CD4 cell count monitoring took place in the facility.

4.1.4.4 ART Knowledge

Knowledge gaps among patients around ARVs were also established. Patients who are initiated on ART are expected not to stop treatment when they feel better, as ARVs do not cure HIV/AIDS. In this study, only 26% of interviewed patients knew that ART would not cure HIV, and 25% thought they could stop taking ARVs if they felt better. In addition, patients need to know which room to go to be initiated on ART when eligible, but only 68% of the pre-ART patients interviewed knew which room they would go to, for this purpose.

4.1.5 Services accessed by participants

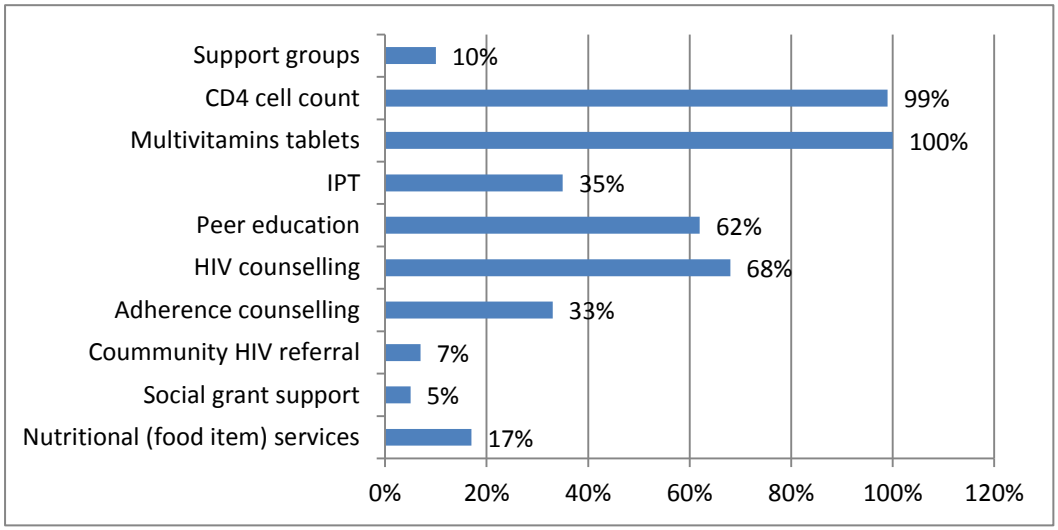


Figure 4.5 Pre-ART services accessed by interviewed patients

Patients were also asked about the services they accessed during the period they were attending pre-ART services, as shown in the figure above. Even though pre-ART care

services are supposed to be provided as a comprehensive package of care, interviewed patients retained in care did not receive all prescribed services. Multivitamin tablets and CD4 cell count monitoring were the minimum package of care given to patients. As a result, almost all interviewed patients received multivitamin tablets and had been checked for CD4 cell count at least once, the majority (68%) had received HIV counselling, and about a third each (35% and 33%) had received IPT and adherence counselling services. The South African Government has a social grant system aimed at improving the living conditions of the disabled and poor, which includes PLWHA (Mitra, 2010). In addition, health facilities distribute nutritional food items to PLWHAs who are in need. At times they also refer the PLWHAs to community based organisations and structures that provide PLWHA support. However, very few had accessed care to receive a social grant (5%), community referral (7%), or nutritional services (17%) and only 10% had attended a support group.

4.1.6 Patients' awareness and access to available services

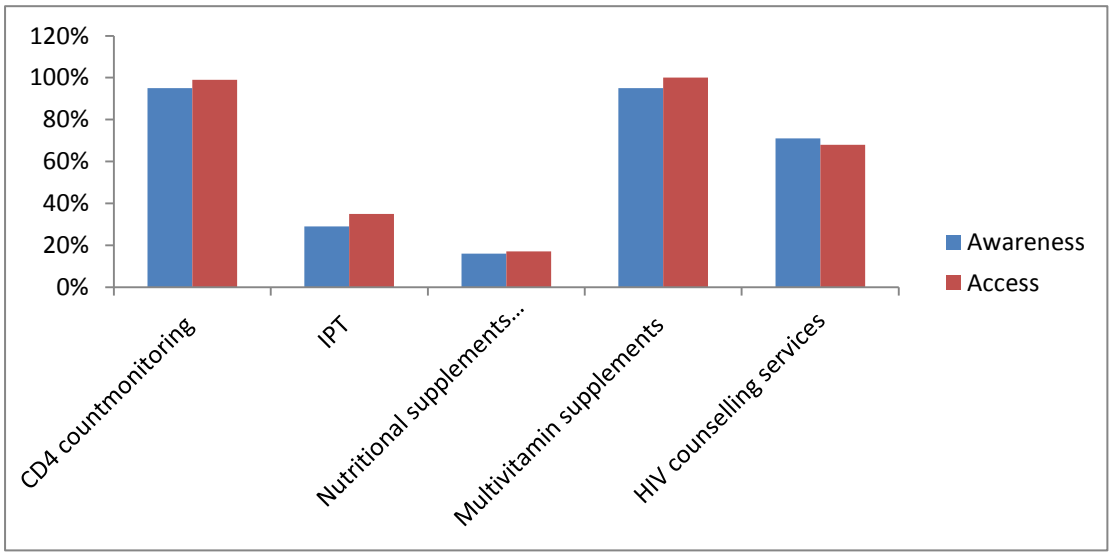


Figure 4.6 Access and awareness of the services among pre-ART patients

In order to establish patients' awareness and access to the available pre-ART care services, I compared the relationship between awareness and uptake of the specific pre-ART care

services graphically, as shown above. As illustrated, access to services is slightly higher than awareness except with HIV counselling services, where access is slightly lower than awareness. Generally, the uptake of services was directly related to awareness of the available services.

4.1.7 Sources of HIV/AIDS information

Participants were asked about the sources of information in relation to HIV/AIDS, CD4+ cell count, pre-ART and ART care. Their main sources of information in the facility are set out below:

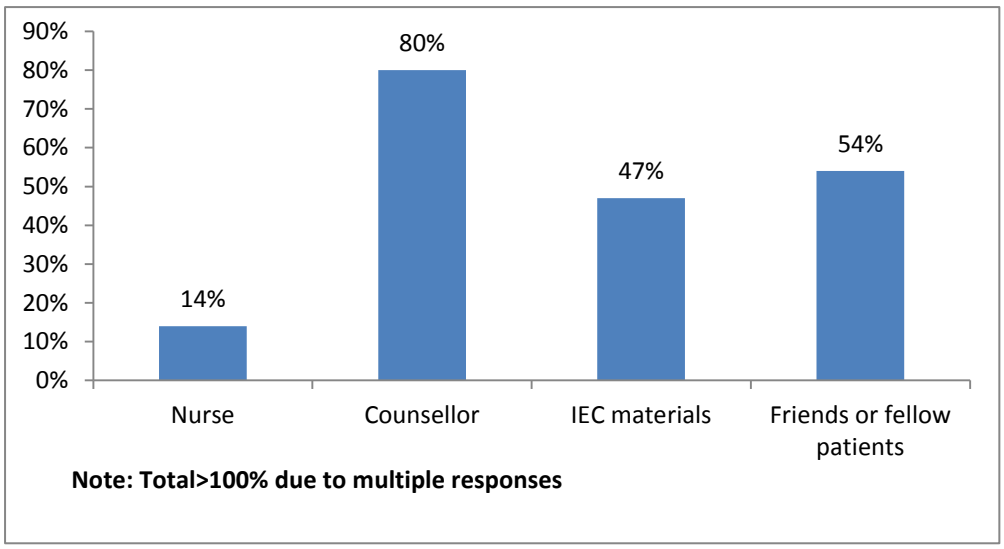


Figure 4.7 Distribution of sources of information

The majority (80%) mentioned counsellors as the main source of information in the facility and nurses were mentioned least often (14%). Information, education and communication (IEC) materials accessed in the facility, and friends and/or fellow patients, were mentioned by 54% and 47% respectively.

4.1.8 Disclosure of participants' HIV status

Understanding factors that affect disclosure among pre-ART patients is critical in planning for interventions that would promote disclosure to ensure adherence. In this study, I established the number of patients who disclosed their HIV+ status and analysed this response to establish the association between disclosure of one's HIV+ status and their socio-demographic characteristics.

Table 4.4 Disclosure of participants' HIV+ status among interviewed pre-ART patients

Disclosure of HIV status to:	N=73 N (%)	Demographic characteristics									
		Gender		Employment		Age		Marital status		Educational level	
		Male (30)	Female (43)	Yes (13)	No (60)	Youths (23)	Adult (50)	Married (25)	Not Married (48)	Illiterate (9)	Literate (64)
Partner	54(75)	23(77)	31(72)	10(78)	39(53)	17(74)	37(74)	18 (72)	36 (75)	6(66)	48(75)
PValue	N/A	0.8		0.05		0.99		0.8		0.6	
Friend	24(33)	13(43)	11(25)	7(53)	17(28)	10(43)	14(28)	7(28)	17(35)	1(11)	23(35)
PValue	N/A	0.1		0.04		0.2		0.5		0.1	
Family	40(55)	17(57)	23(53)	6(46)	34(57)	10(43)	30(60)	18(72)	36(75)	4(44)	36(56)
PValue	N/A	0.8		0.5		0.2		0.8		0.5	

Pre-ART patients were asked whether they had disclosed their HIV+ status to someone, and the following was established: the majority of patients (74%) had disclosed their HIV+ status to their partners, 55% to family and 33% to friends. Those who were employed were more likely to disclose their HIV+ status to their partners (p=0.04) and friends (p=0.05) than were people who were unemployed.

4.1.9 Identified gaps

Participants were asked to identify gaps with possible solutions in the existing pre-ART program, which might be relevant to developing recommendations for an appropriate pre-ART care program to promote timely ART referral and retain patients in the program. The questions to elicit information on these gaps were open-ended, and as a result, qualitative data were generated. These gaps were classified into three categories: patient, staff and health systems related gaps.

4.1.9.1 Patient related gaps

Time spent to attend clinic

At the study sites, PHC facilities operate between 7.30 am to 4.30 pm, as illustrated below.



Figure 4.8: Clinic signage for the clinic opening hours

These hours were reported to be the normal working hours for those participants who were employed, as for those undertaking piece work or casual employment, and this was also the time when those who were not employed sought jobs. The majority of patients reported having difficulty in finding time to visit the clinic, as it was difficult to get time off from work or to interrupt job seeking:

> Taking time off from work on monthly basis is a challenge (PI, M, # 32);
>
> The truth is that I stopped coming here because most of the time I look for jobs (PI, F, # 49).

Time spent on attending pre-ART services also translated into costs, for example time spent travelling to and from the clinic and waiting for services is costly for those who had to pay for public transport and whose salaries were deducted if they took time off work.

> Tablets are always out of stock! As a result we have to come here many times. To find time off to come here is a salary deduction and even the transport money is expensive (P1 #05).

> We do appreciate that these services are free but truly speaking, we still need money for our transport and when we spend time here instead of working we also lose money (PI, M, # 42).

When patients were asked about the possible solutions to address the identified gaps in pre-ART services, many mentioned having flexi-hours with services provided outside of normal working hours. Others thought of innovations whereby pre-ART care patients could receive their multivitamins outside the facility, or just collect them quickly without spending much time at the clinic:

> To tell the truth, if these services were provided outside our working hours, many of us would not be missing our appointments (PI, M, # 19).

> We are not sick people. Why can't they make it fast when we come to collect medication, just come to the clinic, pick-up medication and off we go without waiting? (PI, F, and # 26).

> The staff must schedule medication collection accommodating client's time table for example those who are working or self-employed staff to be seen either first thing in the morning or last thing in the evening (PI, M, # 42).

> I wish we would just collect these medications from somewhere. For example, a certain place without coming to the clinic, that would reduce our clinic visits and maybe we need to only come here once a year for blood check-ups (PI, M, # 61).

Privacy and Confidentiality

Patients felt that pre-ART care clinic visits had the potential to compromise privacy and confidentiality related to their HIV+ status. This breach of confidentiality was mainly a concern among men, as women were able to access clinics easily while healthy for services like family planning, bringing children to under-five clinics, and accessing other children's services. Men's clinic visits are mainly associated with sickness. Most patients in the pre-ART care program were healthy, and patients who were interviewed believed that clinic attendance especially among men created a suspicion among others that the person was HIV+.

> Women have many reasons to come to the facility, like family planning injections and tablets; they can bring children whilst we men mainly come here when we are sick (PI, M, #20).

> If I keep coming to the clinic every month, people will know that there is something wrong like HIV. You know people are always suspicious! (PI, M, #38).

> The other point is the fact that; who wants people to see him/her at the clinic now and again? They will make their conclusion that we have AIDS and yet we are not sick! (PI, M, #53 – youth).

The possible solutions to address breaches of privacy indicated by participants mainly focused on ways to reduce the number of facility visits, as well as reducing the time spent in the facilities. Patients proposed some innovative ideas to address this:

> The best is to look at ways that would reduce the number of visits we come to the clinic or making us not come to the clinic at all- like collect the vitamins from somewhere outside the clinic and only come once a year for blood check-ups (PI, M, #40).

> Just pack our medication so that when we come to the clinic, we can just pick-up then pack and go without waiting at all (PI, M, #10).

Not ready to test for HIV

In all CoJ PHC facilities, people are tested for HIV either after voluntarily coming to the facility to be tested or through provider-initiated counselling and testing (PICT), whereby the service providers initiate the HIV testing conversation and offer services to the patients. For example, all pregnant women accessing ANC services are offered HIV testing on their first and consecutive ANC visits to ensure that they access PMTCT services in the event that they are HIV+. If they test positive for HIV, service providers are expected to provide them with post-test counselling, which includes the meaning of HIV/AIDS, modes of transmission, and how it can be prevented. Referral options are also offered to patients, for example, if a patient is positive, he or she can be referred for a CD4 cell count check, TB screening, clinical staging or pre-ART care, according to the SA Guidelines (SA, 2010b). In this study, some participants who tested positive through Provider Initiated Counselling and Testing (PICT) felt they were not ready to test:

> I tested because I was pregnant and I had to use PMTCT for the sake of my baby. I was not well counselled and given all the needed information from clinic staff. I was not ready to be tested and I did not believe I could be HIV+. I then stopped coming to the clinic because I was still in denial. (PI, F, #60).

Other non-PMTCT patients whose HIV testing conversation was initiated by service providers also reported that they were not prepared to test on the day they tested. Some participants looked at this as being "taken by surprise," as shown in the quotation below:

You know what, my brother (referring to the interviewer), it is very difficult to make a decision to come here and test for HIV especially when you doubt that you may have it. Like me I was just taken by surprise to be asked to test for HIV while I came here for another illness! Unfortunately, I tested positive (PI, M, #6).

4.1.9.2 Staff related gaps

Shortage of staff

Patients mentioned shortages of staff as a major gap in delivery of pre-ART care influencing access to care with long queues of people waiting to be seen by one clinician. We established that in these clinics, each professional nurse (PN) was consulting an average of about 50 patients per day, significantly above the 40/PN/day recommended by the Department of Health (DoH) as the maximum. The average waiting time was three hours at the time of the study, again higher than the DoH recommended two hours.

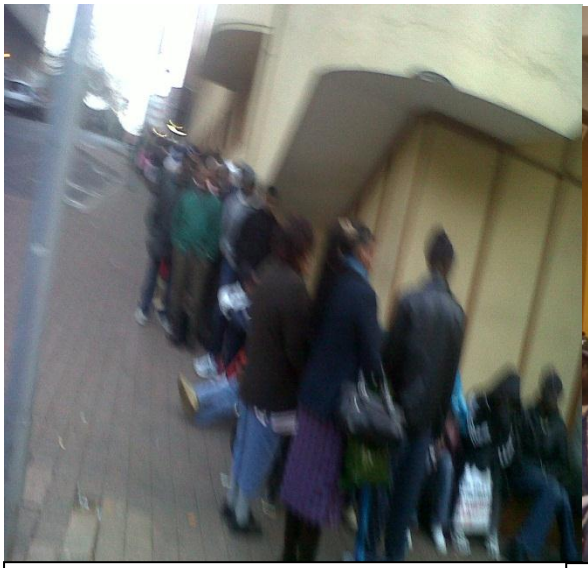


Figure 4.9a Patients in a queue outside the clinic



Figure 4.9b Patients waiting for services inside the clinic

As shown above (Figures 4.9a and 4.9b), there were long queues of patients waiting to be seen by the service providers.

> There is too little staff and too many clients. As a result, we wait for too long in the queues. There is need to hire more staff (PI, M, # 19).

> There is too long waiting time. Imagine, people waiting for three hours without someone in the consultation room. (PI, M, #12).

> The services are too slow and the facility looks short staffed (PI, F, #7).

Increasing the number of staff was the most common proposed solution to address their perceived shortage. In addition, some innovative solutions on enabling patients to collect their medication outside the facility were seen as reducing the workload on the service providers.

Staff attitude

Staff attitude is a ministerial priority area of the South African Government in the delivery of all health services (SA, 2011b). In this study, negative staff attitudes and rudeness towards pre-ART care patients were reported by some of the interviewed patients. A number of patients narrated how negative staff attitude made them feel stigmatised and discouraged them from coming to access pre-ART care services, as shown in the quotes below, including from one woman who dropped out of care and had to be traced back for an interview:

> When I came back for my CD4 count check-up, the nurse became rude to me, and I felt stigmatised, hurt and disappointed. The clinic staffs are not welcoming and as a result, I decided not to come back. After all, I am not sick, my CD4 count is still high (PI, F, # 62).

> Staff attitude to us as patients is not good. There is need for staff to love and have positive attitude towards HIV+ patients. Staff must be friendly to patients (P1, M, #14).

> Customer care is poor and patients are being shouted at (P1, M, and #18).

Quality of counselling

According to the SA HIV Counselling and Testing Guidelines, during each HIV pre- and post-test counselling session, the service provider is expected to provide the patient with all the information on HIV/AIDS, including its definition, modes of transmission and how it can be prevented. Referral options are also offered to patients. For example, if a patient is positive, he or she is post counselled and then referred for a CD4 cell count check, TB screening, clinical staging or pre-ART care (SA, 2010b). Patients are given a chance to ask questions for clarity of the information given and any other HIV/AIDS related knowledge areas. For successful pre- and post-test counselling sessions, service providers are expected to be knowledgeable and well conversant about HIV/AIDS knowledge area. In this study, participants felt service providers, especially counsellors, showed major HIV/AIDS knowledge gaps during counselling sessions, even though they reported the counsellors to be the main source of HIV/AIDS information. Below is a quote from a patient interview, in response to questions on the difference between HIV and AIDS and whether ART could cure HIV or not; after the interview, the interviewer addressed all the questions from the participant:

> The fact is that a lot of information is not given to us as patients during counselling sessions. Some of the counsellors seem not to know what they are telling us. For example I never knew most of the information you have just briefed me … counsellors should have more workshops on updated HIV/AIDS information (PI, M, # 16).

Emphasis was also placed on the need for service providers to prioritise those who have not had formal education with HIV/AIDS information, as shown in the quote below:

> The staffs do not teach us and give us enough information especially for those of us who have not done much school (PI, F, # 15).

In addition, another patient reported that she never received any counselling in the process of being tested for HIV and accessing care after testing HIV+.

> I never received any kind of counselling. They took my blood for CD4 count, but I never received any kind of counselling to explain what it was. The counsellors told me to go home. You have just met me here by chance but I had stopped coming for more than a year. (PI, F, #66).

4.1.9.3 Systems-related gaps

Loss of CD4 cell count results

The patients also reported loss of CD4 cell count results. As described above, after their blood was taken for CD4 cell count, patients were asked to come back and collect results after two weeks. When they returned to the facility for results, some patients would find their results missing and they were asked to either come another time or give another blood sample to be resent to the laboratory. As a result, at the time of the interviews, there were patients who did not know their CD4 cell count results.

> I don't know my CD4 count results. The results are missing and I am here today looking for my results (PI, M, # 03).

> Each time I come here, my blood results go missing now my file is missing (PI, F, #30).

For example, a 20 year old girl indicated that after being in the program for 18 months, she has never had her CD4 cell count results:

> I was checked for CD4 count 18 months ago but up to now I don't know the results because they got lost. I never wanted to check again because the hand from which the blood was drawn is still sore. After all I do not want to start ARVs now (PI, F, # 13).

Youth unfriendliness

In this study, youth friendly services (YFHS) were defined in ways consistent with that provided by Baloyi and colleagues (2006), as those services that incorporate all areas of young (<24yrs) people's well-being, with particular attention to sexual and reproductive health (SRH). The majority (56%) of patients and staff interviewed knew the meaning of YFHS. For those who did not know, the interviewer defined it to them so that they were able to respond to subsequent questions. Seventy percent of interviewed patients reported that the facilities were not youth friendly and when asked to elaborate, they stated that youths were not put on fast queues, there were no youth peer educators, and youths were consulted together with adults. This was embarrassing and delaying.

> There is need for separate youth counselling rooms from adults and recruit youth peer educators. It is not nice when they mix us adults with youths. They can't feel comfortable and may stop coming to the clinic (PI, M, # 20).

> As youths, we wait with everybody in the queue and this is at times embarrassing for us, the young ones (PI, M, Youth, # 59).

> There is need to provide peer educators for youths (PI, F, # 52).

There was also a realisation among respondents that most youths are sexually active, and if HIV+ they can easily spread the disease. As a result, they felt that it was important to priotise providing HIV+ youths with HIV prevention strategies:

> More and special attention must be given to us youths, ourselves as youths we must also find ways of preventing HIV. As you know us youths, we are young and still very active sexually and can easily spread the HIV disease very fast (PI, M, # 53 - youth).

Drug stock outs

At each clinic visit, pre-ART care patients are provided with multivitamins to be taken throughout the pre-ART care period, and those eligible for TB prophylaxis are given Isoniazid Preventive Therapy (IPT) for a period of six months. Patients mentioned stock-outs of pre-ART medications including IPT and multivitamins, so that they received either small quantities or no medication, and were asked to come back at a later time for the medication. This led to multiple visits to the facilities, with an increase in the costs of transport and other opportunity costs. At times, patients were asked to buy the multivitamins themselves.

> Vitamins are sometimes out of stock and we have to go and come back (PI, F, and # 38).

> I stopped coming to the facility because each time I came, I would be told that there is no medications after standing in the queue for a long time. Then I just gave up (PI, F, and # 63).

> When I came again to get vitamins, I was told that there were no vitamins and was told to buy from the chemist. It is very expensive to be buying the vitamin on my own and I felt I would rather sit back and not come to the facility again. (PI, M, # 61).

Patients frequently explained the drug stock outs in terms of government system failure and the most commonly mentioned solution to address the gap was for the government to take action:

> The government must make sure that all required medications are always available (PI, M, # 40).

Multiple clinic visits

Pre-ART care involves patients getting multivitamins, CD4 count 6 monthly check ups, IPT if they have no TB symptoms, psychosocial support, cervical cancer screening and family planning for women, and other services in accordance with the SA pre-ART Care Guidelines (SA, 2013d). In this study, it was established that these services were not well integrated, leading to patients being given different appointments for different services. This led to multiple visits. As a result, pre-ART patients ended up presenting at the facility almost every month. Patients found this frustrating and saw this as a particular challenge:

> Frequency of facility visits must be reduced; they are too many. They give us different dates for similar services we can get in one day! Look at me: I am not sick, so why should I always be at the facility every month? Something has to be done! (PI, F, # 21).

> It would be better if they could give medication every three months as opposed to monthly since taking time off from work on monthly basis is a challenge (PI, F, # 32).

Pre-ART services not prioritized

The study site facilities provide under-five children wellness services, treat minor and chronic diseases, and provide Sexual and Reproductive Health (SRH), TB and HIV/AIDS services (CoJ, 2013b). Pre-ART care is rendered as a part of HIV services for individuals who are still healthy. Some patient participants felt that because pre-ART patients are usually not sick, the service providers pay relatively less attention to them compared with those who are sick.

Below is a quotation from a female patient who thought that the service providers gave them relatively little attention:

> As you know this facility is very busy. Those of us with high CD4 cell counts are not sick and we are healthy. The staffs do not take us seriously so that we remain healthy! It is high time that the staff also prioritise us, even though (we are) healthy! (PI, F, # 21).

4.2 Pre-ART service providers' interview results

4.2.1 Demographic information

A total of 12 pre-ART care service providers (4 males and 8 females) participated in the study, which included facility managers (2), professional nurses (4), administration assistants (2), counsellors (2) and one health promoter. Their age ranged from 23 – 46 years, although only one service provider was aged < 24years. Three out of nine service providers indicated that they were not trained in filling out the pre-ART care register. Almost all service providers were aware of the available pre-ART care services in the facilities.

4.2 Awareness and recording

Even though the majority of pre-ART care patients were unaware of the available pre-ART services at the facility, almost all service providers (11/12) were able to mention all the pre-ART services rendered in the facilities. Providers were able to describe their involvement in the delivery of pre-ART services, and most of them (10/12) reported that the pre-ART care patients were aware of all available pre-ART care services.

In the study sites, the facilities had nurses, counsellors, health promoters and administration clerks working in pre-ART care on a day-to-day basis, whilst the other staff categories like doctors, social workers, psychologists and dieticians could be accessed by patients on request

upon referral. All staff respondents reported that the facilities did not have enough staff to deliver pre-ART services.

4.2.3 Patient access to care pathway

When the pre-ART service providers were asked to describe the pathway by which patients with >350 CD4 cell count could access care in the facility, they were able to describe the process as below:

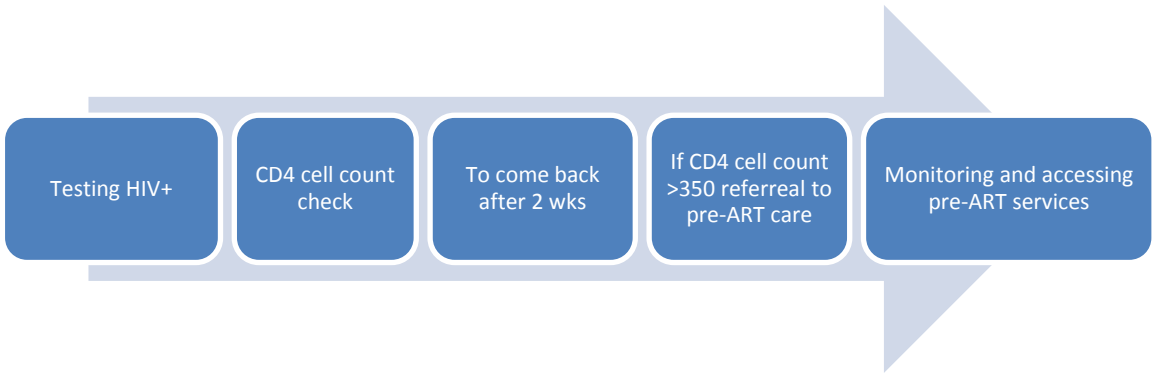


Figure 4.10 Pre-ART patient care pathways as reported by service providers

The challenges in patients accessing these services, mentioned by the services providers, were shortage of staff, with an example of having no nurse to see pre-ART care patients at times (a similar example given by patients in the section above), and stock outs of medication, whereby patients are requested to buy their own multivitamins or were asked to come back when stocks were available. No staff members mentioned loss of blood results to be a major challenge, although this was reported by patients themselves.

4.2.4 Referral systems

The main referral points for complicated pre-ART care patients mentioned by service providers were Hillbrow Community Health Clinic (CHC) and Charlotte Maxeke Academic Hospital. Although the study sites had contact persons for their referral sites, the service

providers reported that they do not get feedback on what happened to patients. One of the respondents reported that this was a lost learning opportunity:

> When we refer patients to these facilities there is poor feedback system. There is need to give us feedback on what happened to the patients, because we can learn on how patients are managed at that level (SI, # 1).

The interviewed staff reported that the Department of Health provides transport for patients to go to referral sites. However, they also reported that at times patients would wait for transport for the whole day to go to the referral sites. By the time they arrived at the referral sites, the outpatient departments would already be closed.

4.2.5 Pre-ART services information systems

All pre-ART service providers mentioned that they were involved in the collection and collation of pre-ART related data at different levels, for example, the data clerk was responsible for the registration of patients, the counsellors and nurses recorded data on their daily service registers as they consult with patients in the consultation rooms. The facility managers indicated that they were responsible for the collation of data on a weekly and monthly basis, for monthly submission to DHIS by the seventh of each month. The main concern raised by the majority was the fact that there was too much documentation, and that this took up a lot of health service providers' time:

> Each one of us knows our roles in pre-ART, for example, I as a professional nurse, I am responsible for clinically assessing the patient and depending on my judgement, make a plan of care like supply patient with multivitamins, IPT or check CD4 cell count. I am supposed to record everything in the registers, bloods file, patients' file tally sheet, there is just too much recording, taking away much time we can use to see more

patients, but I have to do it as at the end the facility manager will need stats from me (SI # 2).

There is too much work mainly due to too much administrative work involved in ART services (staff interview # 10).

4.2.6 Comparison of pre-ART and NIMART services roll-out

Some of the service providers we interviewed were already working in the CoJ facilities at the time ART and pre-ART were rolled out in the facilities and so were able to compare the two. Service providers who had been employed at the time of ART and pre-ART roll-out in 2004 felt that not much focus had been placed on decentralizing pre-ART services to PHC facility nurses, as there were no clear cut guidelines and the nurses themselves were not well trained in pre-ART care:

> We as nurses, from the beginning, we were not well oriented and capacitated for pre-ART services. I felt like they left us to swim from the deep end on our own (SI, # 10).

In contrast, nurses felt that NIMART was better when rolled-out since they were well trained, mentored and coached by doctor and nurse mentors from WRHI, which was supporting the NIMART roll-out process. By this time, there were clear ART guidelines. The NIMART roll-out also had clear indicators to monitor progress. As a result, nurses were able to report the numbers initiated and retained on ART, as I discuss further below. This was not the case for pre-ART services, however, as there were no clear indicators for progress monitoring at the time of the interviews.

What I can say is that pre-ART was just allocated to us nurses as just one of an additional task without much capacitation of nurses and ways of monitoring progress -

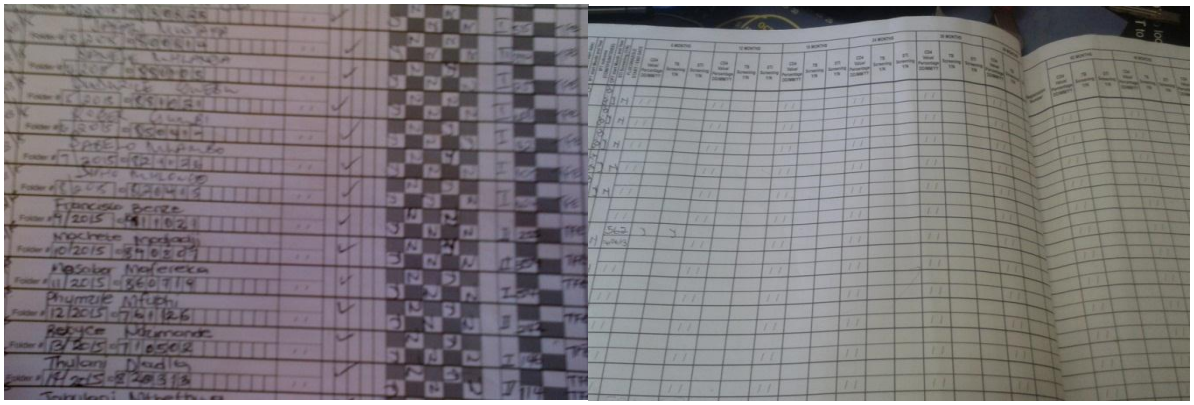
very different with NIMART where nurses are well trained to do the job with guidelines (SI, # 09).

4.2.7 Inability to monitor pre-ART care uptake and progress

Poor record keeping tracking retention

In order to monitor the progress of service delivery, all facilities are supposed to report on uptake and retention in care. South Africa, as a signatory to the global Millennium Development Goals (MDGs), monitors progress towards achieving the goals (SA, 2013b), and had set national targets to reach them (RSA, 2012). These targets were decentralised to provincial, district and then facility levels. In the study sites, it was reported that facility managers on a monthly basis, in their monthly meetings, update the facility staff on ART uptake progress towards their facility target. As a result, the majority of the staff interviewed had an idea of the patients enrolled and retained on ART in their facilities.

At the time of the study, the reporting was done either through the District Health Information System (DHIS) if the indicators for the data element were included in the DHIS, or at facility level only if the indicator was not part of DHIS. For example, the data element to monitor uptake of pre-ART care services was the number of patients registered and retained in pre-ART care. At the time of the study, pre-ART care uptake and retention data elements were not part of DHIS and were monitored at facility level, while ART uptake and retention indicators were monitored through the DHIS monthly reporting system. The facilities kept records on HIV Counselling and Testing, pre-ART care and CD4+ cell count, but most of these were incomplete. The ART registers, in contrast, were mostly complete and way better recorded, as shown in the figure below:



Complete ART register	Incomplete pre-ART register

Figure 4.11 Completeness of pre-ART and ART patient registers

The incompleteness of these pre-ART services registers made it difficult to track the linkage to care from HIV testing to CD4 cell count check, and later on to track whether these people were registered and retained in pre-ART care. In contrast, it was much easier to monitor ART uptake and retention as the registers were complete:

> I am not sure of how many we have for pre-ART, but the facility manager updates us on monthly basis on how many we have on ART because we are supposed to report daily to the facility manager and we have a target to meet (SI, # 06).

> Though not sure of the exact numbers, but I know that patients not yet eligible for ART mostly do not come back. As long as they are still healthy (SI, # 12).

Lack of monitoring of uptake of services and retention in pre-ART care may lead to inability of the service providers to identify the gaps in the delivery of the pre-ART services.

4.3 NIMART roll-out

4.3.1 NIMART roll out process

At the time ART was rolled out, initiation of eligible clients was undertaken only by doctors, as described in Chapter 3. Primary Health Care nurses would prescribe other medications but not ART. Around 2010, several studies in South Africa and other countries established that there were no differences in patient outcomes between nurses' and doctors' ART initiation, and nurses ART initiation proved to be more cost effective (Miles et al., 2007, Sanne et al., 2010). This led to the SA presidential mandate that all facilities start initiating patients on ART, and consequently a call was made to roll out ART to all facilities through NIMART, with support from non-governmental partners (Motsoaledi, 13 April 2010).

At that time WRHI was a PEPFAR funded partner for the City of Johannesburg. From October 2010, it took up the role of providing technical support to the CoJ in the decentralisation of ART, from referral hospitals where the ART initiation had been conducted by doctors to PHC facilities where ART was to be initiated by nurses. During this process, I managed a team of clinical quality mentors (nurses and doctors) and data quality mentors, who trained, mentored and coached nurses at PHC facilities to initiate patients on ART, following a ten staged process described below.

This was accomplished by applying quality improvement approaches through training, mentoring and coaching health service providers. WRHI supported NIMART roll-out in the CoJ by designing a ten step approach. The steps followed in rolling out NIMART were intended to ensure buy-in and sustainability, as shown below:

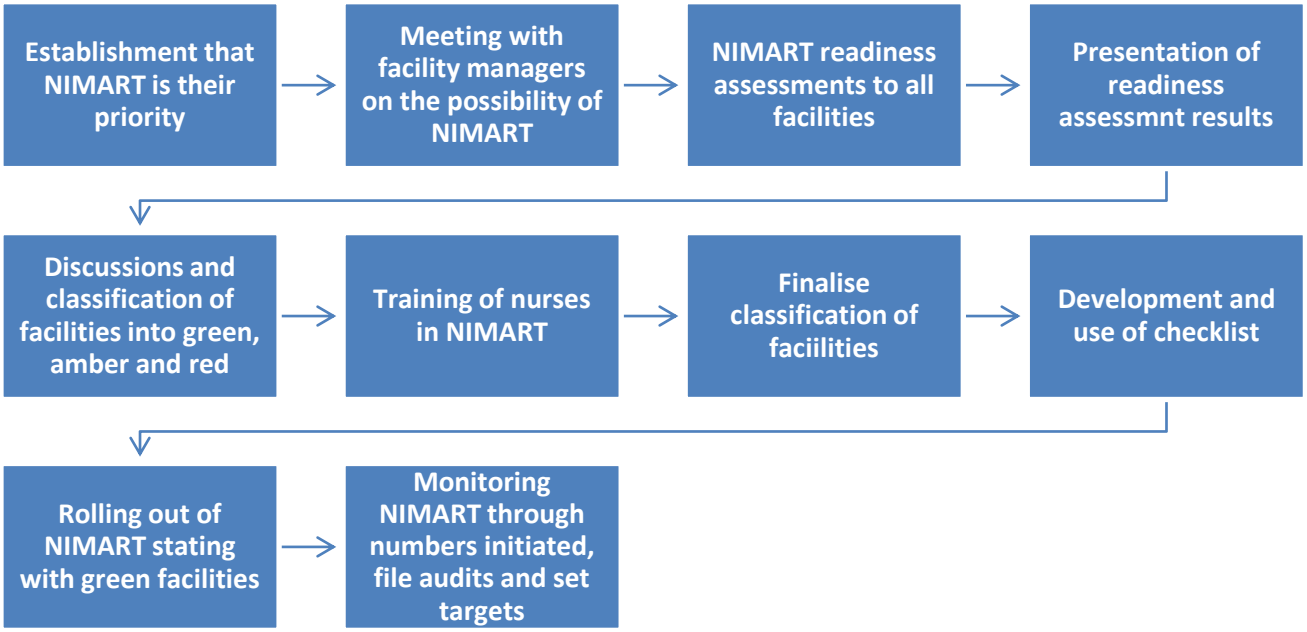


Figure 4.12 Ten steps in rolling out NIMART

Throughout the process the WRHI engaged with the DoH/CoJ partners in order for them to share a common vision and acquire ownership of the program, in the hope that this would lead to sustainability.

Using the above assessment process, the facilities were grouped into green if they had all the minimum standards, amber if they had minor gaps, and red if they had major gaps. The assessment results were then presented to the City of Johannesburg health services management team in a consultative workshop in November 2010. The main purpose of the workshop was to discuss and classify facilities into green, amber and red. CoJ Region F health management team and facility managers also discussed around which gaps could be fixed quickly to ensure the facilities were green. As a result, facilities which met the minimum standards were the first to implement NIMART and were put in batches according

to their readiness to start NIMART as follows: green as first batch, the second batch labelled amber while red was the last batch.

Of interest was the commitment shown by the facility manager for Clinic A, as described in the following case study. The clinic was one of the two clinics that were labelled red, and so one of the last to implement NIMART.

4.3.2 "Where there's a will, there's a way"

Using the above assessment tool, Clinic A attained the following results:

Table 4.5 Clinic (A) NIMART readiness assessment result

Assessment area	Colour Score	Description
General		No counselling rooms
Basic HIV/AIDS Services		All listed services provided
Policies and National Treatment Guidelines		Did not have National Nutritional Guidelines for PLWA and TB
Laboratory Capacity		No lab in the facility was supported by National Health Laboratory Services (NHLS)
Pharmacy Capacity		Very limited storage space which could not accommodate ARVs if NIMART rolls out
HIV/AIDS Service Point		The clinic had no trained nurse to initiate patients on NIMART, and there was no dedicated person to manage the ART section of the clinic services.

Clinic A was one of the facilities in the southern part of the City of Johannesburg, with an annual headcount (an annual average number of all patients accessing the clinic each month)

of 2268 from 2009-2010, of whom about one third (650) were children under 5 years. A monthly average of 75 individuals was tested for HIV; of these an average of 28 was HIV+. Of the 28 positive individuals, seven had a CD4 cell count of <200 and were referred to a nearest secondary facility described in section 3.1.2 for ART initiation.

The above findings for Clinic A were presented during the health services managers' consultative workshop. The Clinic A facility manager also participated in the workshop, and a decision was made that this clinic and another one were to be scored red, so indicating that these would be the last two facilities to roll-out NIMART. This was because CoJ had to procure park homes (demountable buildings) as temporary office structures to create more space to accommodate counsellors and provide storage space for the medicines.

Regardless of the identified major challenges to implement NIMART in this facility, the facility manager was motivated and committed to using the available resources to meet the minimum standards to implement NIMART. Below were some of the efforts she made to reverse the decision about delayed implementation of NIMART;

Within a month after the readiness assessments, WRHI scheduled NIMART training for nurses from CoJ. The Clinic A facility manager made an effort to ensure that she and one of the professional nurses went through this training progam, which provided them with technical capacity to implement NIMART in their clinic. She created space in one of the consultation rooms to store the additional ART medication, so resolving the problem of storage. Instead of waiting for CoJ to procure a park home for extra space, she partitioned a very large consultation room into two rooms, and turned the second room into a counselling room. In addition, when she worked in the clinic, she asked the counsellors to use her office as an HIV counselling room. At the same time, she acquired the National Nutritional

Guidelines for PLWA and TB from WRHI, which was missing at the time of the assessment. After these efforts, the clinic assessment changed, as reflected below:

Table 4.6 Clinic (A) clinic assessment results after addressing the identified gaps

Assessment area	Colour Score	Description
General		1-2 counselling rooms
Basic HIV/AIDS Services		All listed services provided
Policies and National Treatment Guidelines		Acquired the National Nutritional Guidelines for PLWA and TB from WRHI
Laboratory Capacity		No PHC facilities have a laboratory; the facility was supported by National Health Laboratory Services (NHLS)
Pharmacy Capacity		Created space in one of the consultation rooms for storage of medicines hence had enough space for ARVs
HIV Service Point		Two nurses trained in NIMART

Within three months, this facility manager had turned her clinic from red to green, so allowing the facility to be ready to implement NIMART. As a result, the clinic started initiating patients on ART by nurses at the same time as those facilities which had been rated green on the initial assessment.

4.3.3 NIMART training, mentoring and coaching of CoJ nurses by WRHI

From October 2010 to July 2011, the WRHI mentoring team of doctors and nurses trained and mentored professional nurses in NIMART from the 17 CoJ PHC facilities. This involved a five day training session (three days covered adult ART initiation and two days ART

initiation in children) held at WRHI offices. The DoH NIMART training manual was used, covering the following areas, as described in Appendix 8.7: HIV basic science refresher, Staging and opportunistic infections, PMTCT refresher including infant feeding, Case finding/diagnosis cases, HIV Staging and Opportunistic Infection (OI) cases, adult/children ARV initiation and management, ARV regimens, when to start, how to start, monitoring and side effects, adherence, TB/HIV co-infection, TB infection control and quality improvement. All nurses wrote pre- and post-tests during the course. The nurses were then supported and mentored in their PHCs by WRHI mentors to begin initiating patients on ART.

A total of 46 nurses from CoJ were trained in NIMART. The first phase of mentoring was done by those trained in NIMART filling in a self-assessment questionnaire on their skills for mentors to identify the skills gaps on which to focus during the mentoring sessions. This was followed by onsite and telephonic mentoring and coaching them to initiate patients on ART. In addition the WRHI mentors would observe the nurses initiating a patient on ART or conduct file audits to monitor progress of the mentees towards ART initiation skill.

4.3.4 Acceptability of the NIMART rollout

The WRHI NIMART mentoring team engaged with the CoJ and DoH partners to establish the NIMART rollout and associated processes. This led to buy-in on the part of the CoJ to roll-out NIMART, and CoJ health services management and service providers consequently took the lead in rolling out the program by ensuring that the nurses are relieved from day-to-day clinic duties to attend the NIMART training. In addition CoJ supported the facilities to address the identified gaps, including the procurement of lockable cupboards for storage of ARVs, to ensure they meet the minimum standards to implement NIMART. This approach strengthened the sustainability of the program. Before NIMART rollout, only one of the 17 PHCs was able to initiate patients on ART, with all initiations undertaken by doctors. By

October 2011, all 17 CoJ facilities were initiating patients on ART by nurses. In addition, there was a sense of ownership with an understanding that NIMART was not a WRHI program but their own, and was supposed to continue even after WRHI withdrew from supporting CoJ.

4.3.5 ART initiations and decrease in patients load

In the 12 months before the NIMART commenced, the referral Community Health Centre (CHC) facility was initiating a monthly average of 389 patients (SD 82.27). After NIMART a growing number of patients were initiated by nurses in the PHC facilities leading to a monthly average decrease to 238 12 months after NIMART, as shown below:

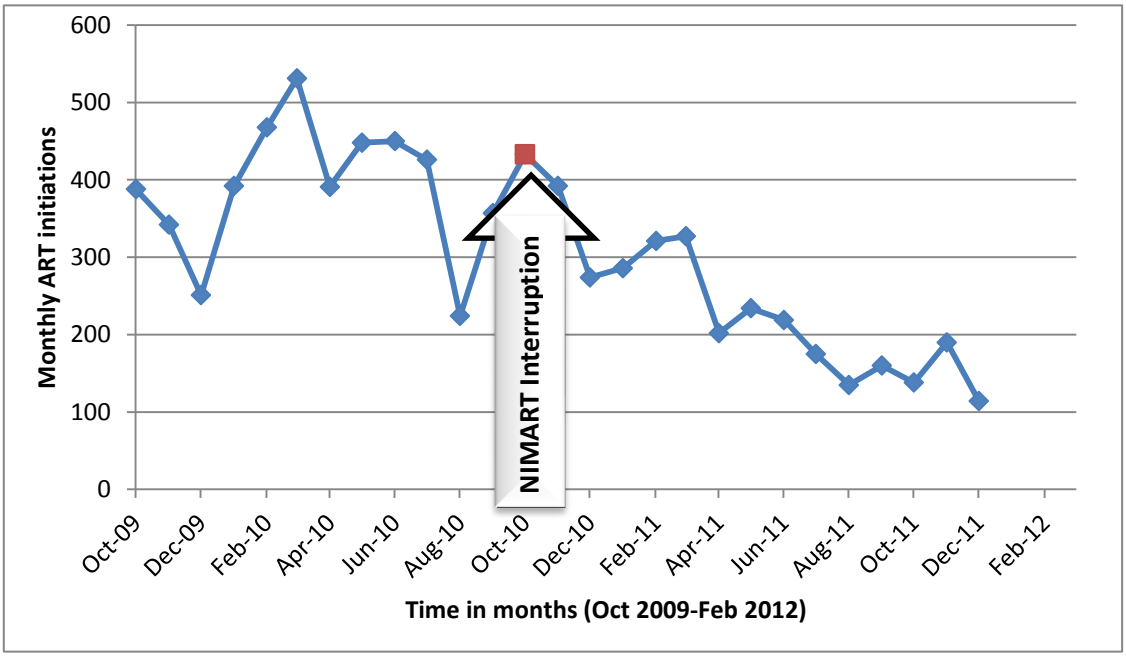


Figure 4.13 Trends in ART initiations at a PHC referral

4.3.6 Total ART initiations in Region F

In the 12 months before the NIMART rollout, the mean number of patients initiated monthly on ART in Region F was 580 (SD 80.48). In the 12 months following NIMART, initiations

increased significantly to a monthly mean of 732 (±SD 71.29) illustrated in the figure below:

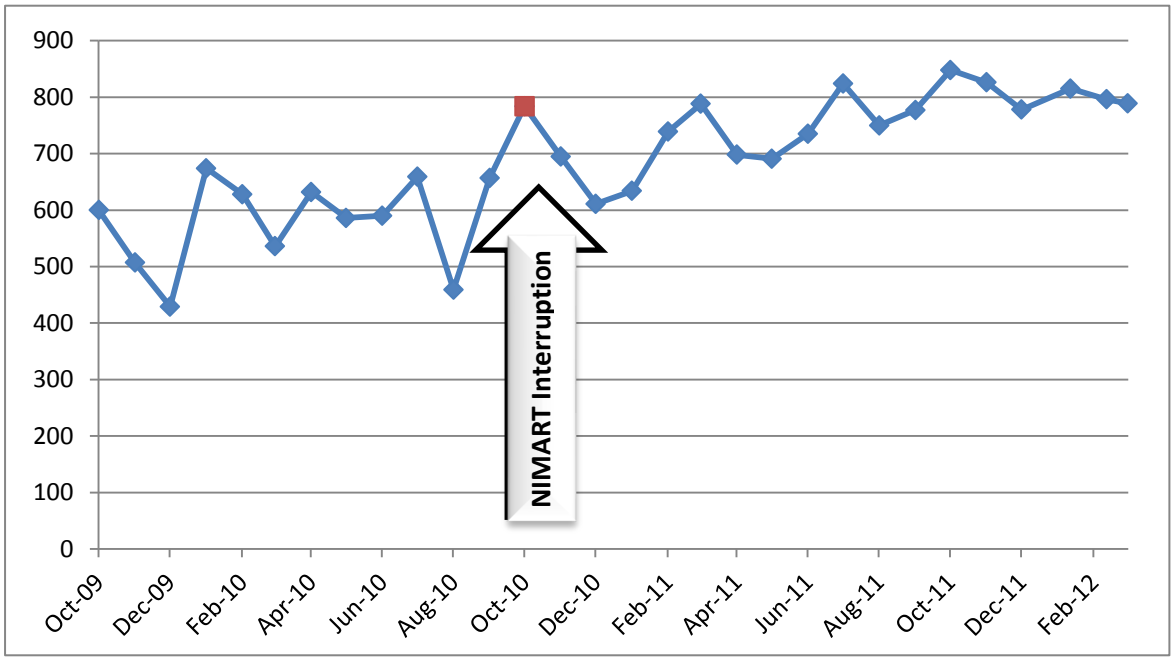


Figure 4.14 Trends in total ART initiations in Region F

The above figure visually displays the number of ART initiations in Region F. The trend was stable before intervention and decreased steadily after NIMART rollout. ART initiations are shown to steadily increase, even though there is a visible interruption after initiation of NIMART. There was a brief decline in August 2010 when the civil servants, including nurses and doctors, were on strike demanding salary increments and better working conditions. To assess chance and control for other effects, a time-segmented regression analysis was fitted. Results are set out in Table 4.7 below:

Table 4.7 Segmented regression model and most parsimonious model

	ART Initiations at referral hospitals			Total ART Initiations in Region F		
	Coefficient*	***Standard error***	***p-value***	***Coefficient***	***Standard error***	***p-value***
a. Full Segmented regression model						
Intercept β_0	391	42.19		548.95	40.44	
Baseline trend β_1	-0.30	5.73	0.958	4.73	5.49	0.396
Level Change after NiMART β_2	-10.65	52.53	0.853	73.03	48.14	0.141
Trend change after NiMART β_3	-17.39	7.02	0.027	3.20	6.25	0.612
b. Most parsimonious segmented regression model						
Intercept β_0	389	19.35		579.75	18.87	
Level change after NiMART β_2	-12.34	46.08	0.791	99.09	37.29	0.013
Trend after NiMART β_3	-17.69	4.44	0.01	7.94	2.97	0.013

**** Month 13 was excluded as this was when NiMART was introduced***

Results from the segmented time series model, presented in Table 4.7, show that initiation at referral facilities gradually decreased after introduction of NIMART, while the total initiations in Region F increased. Model (a) presents a full segmented model, which shows that the month-to-month decrease in number of initiations in the Region F referral hospital before NIMART was non-significant (p=0.958). After NIMART, the number of initiations dropped by 11, with a month-to-month decrease of 17 (p=0.027). For the total initiations in Region F, no model term was significant; the non-significant terms were eliminated by stepwise elimination and the most parsimonious model introduced. Model (b) is the most

parsimonious model, and shows that initiations at the referral hospital had an average month-to-month decrease of 18 (p=0.01). The total initiations decreased by 12 (p=0.791) immediately after NIMART introduction, a result that was not statistically significant. In addition to a decreasing trend in referral hospital initiations, the total number of ART initiations in Region F PHCs increased by 99 (p=0.013) immediately after NIMART, the trend afterwards showing an average increase of 8 (p=0.013) every month.

4.4 ART register audit results

The ART register audit included patients who were initiated on ART within six months at the time of the study from the two facilities, and included a total of 203 patients (77 males and 126 females). The ART register audit provided preliminary results for this research project because they were part of the processes involved in sample size calculation described above in chapter three. Below is a description of the preliminary results yielded at this stage.

4.4.1 Demographic characteristics, CD4 cell count and access to pre-ART care from ART Register audits

Table 4.8 Pre-ART patients' demographic characteristics and access to care

Demographic characteristics		**N (%)**	**CD4 count ≤350**	**P value**	**Pre-ART**	**P value**
All respondents		203 (100)	15 (7)		30 (15)	
Gender	Male	77 (38)	2 (3)	0.04	7(9)	0.07
	Female	126 (62)	13 (10)		23(18)	
Pre-ART	Accessed	30	3(10)	0.6		
	No access	173	12(7%)			

The CD4 count levels at the time of initiation and access to pre-ART care, before becoming eligible for ART, were established in this study as shown in the table above. During the

period selected for file audits, the CD4 cell count cut-off point for ART initiation was ≤350 cells/µl. Out of the 203 (77 males, 126 females) people initiated on ART within six months, only 15 (7%) patients had been initiated on ART when their CD4 cell count was ≤350 cells/µl, of whom 2/77 (3%) were men and 13/126 (10%) were women. This suggests that women were more likely than their male counterparts (p 0.04) to be initiated on ART in a timely manner.

Only 30 (15%) of those initiated on ART were recorded to be in the pre-ART care program before they became eligible to start ART. The odds of being in the pre-ART program before ART initiation was twice as much for women (18%) as for men (9%), though the p value was almost significant (0.07). The audit also established that even those who were in the pre-ART program before ART initiation did not initiate on time. Only three (10%) out of 30 accessed ART on time, whilst 12 (7%) of the 176 who did not access pre-ART care before ART initiation had timely ART initiation. There were no significant differences in timely ART initiation between those who accessed and did not access pre-ART care before ART initiation (p = 0.6).

4.5 Services accessed by patients in pre-ART care program

Files for those patients who accessed the pre-ART care program before being initiated on ART (30/203) were further audited to determine the type of pre-ART services they accessed. As recommended by WHO and SA Guidelines and discussed in section 2.4, this should include: TB screening, IPT, CPT, multivitamins, family planning, cervical cancer screening and CD4 cell count monitoring. Below are the details of the accessed services:

Table 4.9 Services accessed by pre-ART patients

List of services	All (N=30)	Gender		P value
		M (7/30 = 23%)	F (23/30 =77%)	
TB Screening	14(47)	2(29)	12 (52)	0.3
IPT	9(30)	1 (4)	9(30)	0.3
CPT	16(53)	3(43)	13(57)	0.5
2nd CD4 cell count	21(70)	6(86)	15(65)	0.3
Multivitamin	30 (100)	7(100)	23(100)	N/A
Family planning	0(0)	N/A	0(0)	N/A
Cervical cancer screening	0(0)	N/A	0(0)	N/A
Support group	0(0)	N/A	0(0)	N/A

This file audit established that being in the pre-ART care program did not necessarily result in access to all available pre-ART care services in the facility and in fact, the majority of patients accessed limited pre-ART care services (Table 4.8). Being male or female did not result in significant differences in the uptake of pre-ART care services (p=0.3 – p=0.5).

4.6 HCT register audit results

All patients who tested HIV+ at the study sites were recorded in a pre-ART register of all care received in the facility before ART initiation. We conducted a register audit for the period of May 2011 to April 2012 in the facilities to gain an understanding of the pre-ART care given to a pre-ART patient in the first 12 months. The data elements which were supposed to be recorded in this register were: Date file was opened; Patient name; Telephone number; Age; Gender; TB screening done; CD4 testing; CD4 cell count value (1st, 2nd, 3rd and 4th CD4 cell count values); Collected their first CD4 cell counts results; Eligible for IPT/INH;

IPT Commenced; Eligible for CPT; CPT commenced; Referred to Wellness clinic; Patient attended Wellness clinic; Patient still at Wellness clinic, and whether Patient was initiated on ART. These records were documented in the registers either with dates or ticks. The CD4 cell count cut-off point for ART initiation during the period of the register audit (May 2011-April 2012) was at ≤200 cells/µl and as a result the file audit excluded those with CD4 cell count of ≤200 cells/µl. There were major gaps established in the completeness of the register and only the most completed variables were included for analysis for this research project. The valuables dropped off from the study due to incompleteness of the records were: 2nd, 3rd and 4th CD4 cell count levels, Eligible for IPT/INH, IPT Commenced, Eligible for CPT, CPT commenced, Referred to Wellness clinic, Patient attended wellness clinic, Patient still at wellness and if patient was initiated on ART. Below (Figure 4.13) are details of number of patients included in the audit.

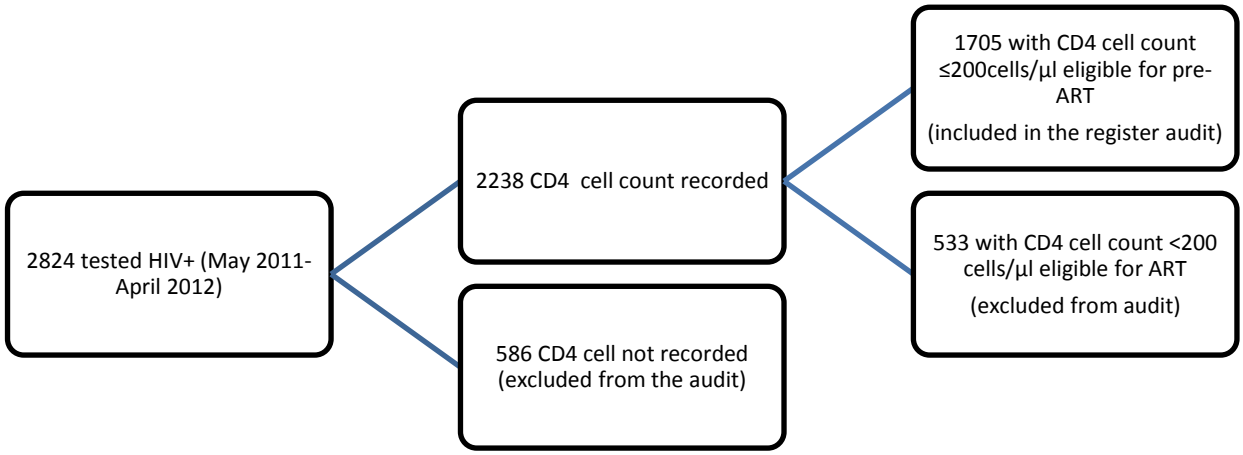


Figure 4.15 Number of patients included in the pre-ART care register.

A total of 2824 patients tested HIV+ in the facilities and the mobile HIV testing sites surrounding the facilities' catchment areas. Of these, 1705 were included in this study, as shown in the above flow chart.

The CD4 cell count cut-off point for ART initiation during the period of the register audit (May 2011-April 2012) was at ≤200 cells/µl and as a result, the file audit excluded those with CD4 cell count of ≤200 cells/µl as they were ineligible to join pre-ART care. There were major gaps established in the completeness of the register and only the most completed variables were included for analysis for this research project. The variables dropped off from the study to incompleteness of the records were: 2nd, 3rd and 4th CD4 cell count levels, Eligible for IPT/INH, IPT Commenced, Eligible for CPT, CPT commenced, Referred to pre-ART clinic, Patient attended pre-ART clinic, Patient still at pre-ART and if patient had been initiated on ART.

4.6.1 CD4 count levels at first HIV test

The protocol during the audited period was that if an individual tested HIV+, blood for a CD4 cell count check was drawn, and he or she was asked to come back in two weeks' time to collect their CD4 count results. Data were analysed to determine the average CD4 count levels for pre-ART patients at the time of testing HIV+. There were 1,713 patients who tested HIV+ and had a recorded CD4 cell count level of >200 cells/µl. These people were eligible for pre-ART care program according to the then SA ART guidelines (SA, 2013d). The mean for their CD4 cell count was 464 cells/µl.

In order to better understand the data, this mean was further tested as to whether there was a normal distribution using a kernel density estimate (KDE). The KDE is a non-parametric way to approximate the likelihood concentration function of a random variable, and it smothes inferences about the population (Janert, 2009). Below is a normal distribution graph for the register audit CD4 cell count:

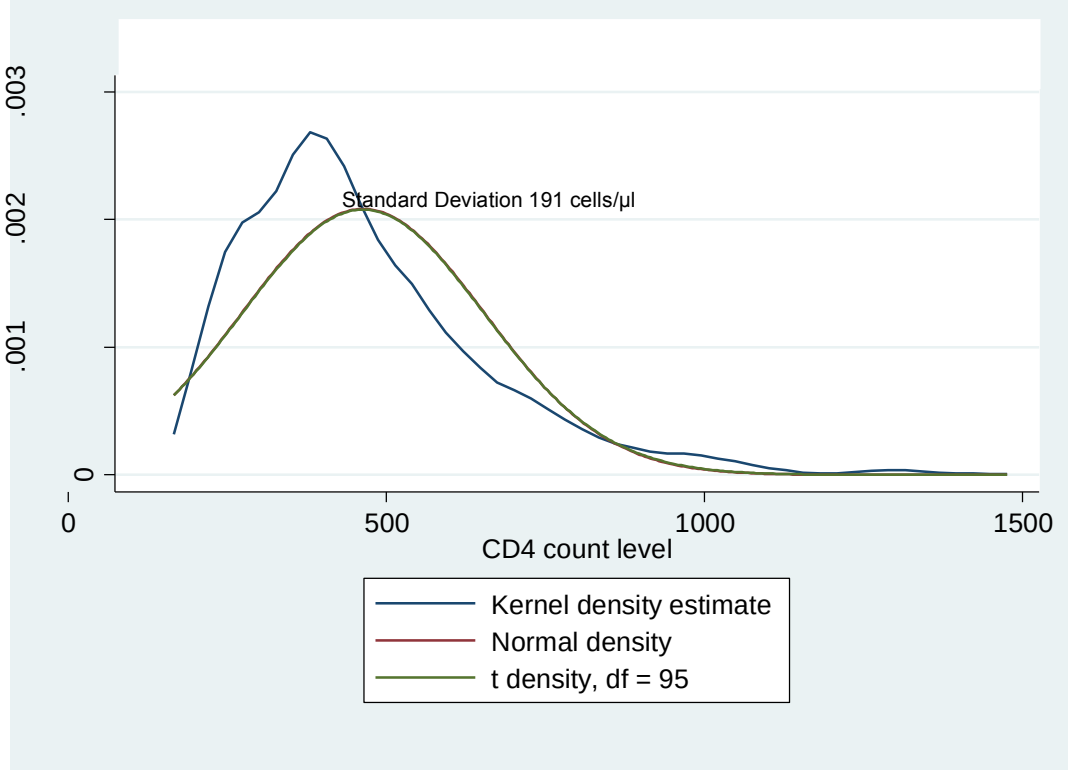


Figure 4.16 **Kernel density estimate for CD4 cell count distribution**

As shown in the above figure, the CD4 cell count distribution appears to be normal with a Standard Deviation (SD) of 191 cells/µl.

4.6.2 Gender, age and CD4 count levels at the time of the first HIV test

A total of 1713 of the 2238 patients were eligible for enrollment into the pre-ART care. Their average CD4 count levels were further compared to the patients' gender and age. As indicated in the table below; the first CD4 cell counts mean for women was significantly (p=0.000) higher than men. Even though the mean CD4 cell count for those >24 year olds were higher than their counterparts, the differences were not significant.

Table 4.10 CD4 count levels according to respondents' characteristics

Characteristics		Observations	Mean(cells/µl,)	SD (cells/µl)	P value
All respondents		1713	464		
Gender	Female	1220	479	200	0.000
	Male	493	426	162	
Age	<24	179	462	202	0.9
	>24	1534	479	190	

4.6.3 Collection of CD4 cell count results after the first HIV test.

All patients recorded in the register, who tested HIV+ during the period of the register audit, gave blood for a CD4 count check and were asked to come back after a minimum of two weeks. The register audit established that not all patients came back to collect their CD4 cell count results as in table below;

Table 4.11 Collection of CD4 cell count results after the first HIV test

Demographic characteristics		N (%)	CD4 results collection	P Value
All respondents		1705 (100)	1230 (72)	N/A
Phone Contact	Yes	1545	1112 (73)	0.021
	No	160	103 (64)	
Gender	Male	485	320 (66)	0.001
	Female	1216	904 (74)	
Age	<24	179	118 (66)	0.05
	>24	1526	1112 (73)	

As shown, 72% of patients testing positive for the first time came back to collect for their CD4 cell count results. Comparing those with and without phone numbers, 73% of those who had phone contacts in the register collected their CD4 cell count results; this was significantly (p=0.02) higher than those who did not have phone numbers. The main plausible reason for this is that the counsellors were able to follow them up telephonically. In addition, women (74%) were more likely (p=0.001) to come back for CD4 cell count results than men (66%). The other finding is that those who were <24yrs (66%) were less likely (p=0.05) to come back for their CD4 cell count results compared with those who were aged >24yrs (73%).

4.7 Findings from the consultative workshop

Once data collection through interviews with patients and staff, and file and register audits, was completed, the findings related to the identified gaps in pre-ART care service delivery were summarised and presented to health service managers for the City of Johannesburg in a consultative workshop held on 30 March 2013, at CoJ Health Services Eureka House, located in the inner city of Johannesburg. In line with the quality improvement processes described in section Chapter two, the workshop had three main objectives:

- To verify if the findings were a true reflection according to the managers' experiences.
- To discuss the causes of the identified gaps, and
- To come up with possible and appropriate solutions to address the identified gaps.

In this section, I outline the identified gaps through interviews with patients and staff, and the possible causes and solutions established through the interviews and the consultative workshop with the health services managers.

Table 4.12 Identified gaps and causes by pre-ART patients and services providers

Identified gap	Causes
1. Service delivery	
Pre-ART services not youth and male friendly	Staff not oriented or trained in youth and male friendly services
Long queues and waiting times	Lack of triage of patients upon arrival
Multiple clinic visits	Drug stocks not enough for longer period
	Lack of proper packaging and integration of pre-ART
Loss of CD4 and other blood results	Poor record keeping for lab results, sometimes blood did not go to lab And no feedback on results from the lab
2. Health workforce	
Shortage of staff	High staff turn over
	Insufficient funds to recruit new or additional staff
Lack of HIV knowledge among facility HIV counsellors	Poor support and mentoring of counsellors
3. Health information systems	
Facility staff not familiar with facility stats on Pre-ART and ART timely referral	Lack of awareness and usage of pre-ART statistics
	Little and poor documentation of pre-ART statistics
4. Access to essential medicines,	
Drug stock outs	Insufficient funds to procure and stock sufficient pre-ART medication
	Delays in reordering stocks
5. Financing	
Shortage of staff	Insufficient funds to recruit staff
Drug stock outs	Insufficient funds to procure and stock sufficient pre-ART medication
6. Leadership/governance	
Shortage of staff	Demotivated staff leading to resignations
	Lack of funds to recruit additional staff

During the consultative workshop, these gaps were further grouped according to the WHO Health System framework/Health Systems Strengthening (HSS) as it relates to pre-ART service delivery, as described above in table 4.12. As reflected below, depending on the causes, some of those gaps are applicable on more than one HSS building block.

4.7.1 Service Delivery

Good health services are those which provide good quality health care which can be easily accessed by those who need them, regardless of their socio-economic status, whilst maximising available resources (WHO 2007). Gaps related to pre-ART service delivery established in this study were: (1) youth and male unfriendliness of the services, (2) long and queues and waiting times, (3) multiple clinic visits, (4) loss of CD4 cell count and other laboratory results, (5) shortage of staff, and (6) lack of HIV knowledge among facility HIV counsellors.

4.7.2 Health workforce

A health workforce that is performing well is one which responds to the needs of the service users in an efficient and effective way to achieve the best possible health outcomes while ensuring the fair distribution of staff (WHO 2007). This study established a shortage of staff to provide pre-ART care services, and knowledge gaps among HIV counsellors who were reported to be the main source of HIV counselling information to pre-ART patients. In addition, when the shortage of staff reported during the assessments was further discussed during the consultative workshop it was established that there were no funds to hire staff. The other factor identified and related to shortage of staff was staff turnover, whereby staff resign from the public health services due to demotivation as a result of lack of incentives, heavy work load and burn-out.

4.7.3 Health information systems

A well-functioning health information system is one that warrants the creation, scrutiny, dissemination and use of high quality of information on the performance of health systems which is critical for decision making (WHO 2007). The study established gaps in the documentation of pre-ART care information for patients. In addition, service providers were not aware of the pre-ART monthly progress data for their facilities which are important for decision making and planning.

4.7.4 Access to essential medicines

A well-functioning health system ensures equitable access to vital medical supplies which are technically sound and of high quality, while maximising the use of the available resources (WHO 2007). Both pre-ART patients and service providers reported drug stock-outs, which led to patients not getting their prescribed medication or receiving less medication than they required. In turn, this led to multiple clinic visits. This also increased the workload of service providers and resulted in long waiting times for patients increasing their frustration.

4.7.5 Financing

A good health financing system sources sufficient funds to run the health system and ensures that services are affordable to those who utilise them (WHO 2007). Even though pre-ART services were reported to be free, people carried direct costs including transport and food and indirect costs associated with time spent travelling to the facilities and waiting for the services. This was made worse when patients had to make multiple visits to the facility, were reported to negatively affecting the uptake of pre-ART services.

4.7.6 Leadership/governance

Good leadership and governance guarantees strategic direction of the health systems, and includes policies and processes that promote maximum benefits on the available resources (WHO 2007). One aspect of strategic direction assessed in this study was allocation and management of resources. For example, even though shortage of staff was reported by both staff and patients, the managers reported that at the time of the consultative workshop, there were no funds to recruit new nurses or counsellors This meant that with the limited resources, staff recruitment was not prioritised for resource allocation at that time despite that this was crucial for service delivery.

Chapter Five

Discussion

5.1 Accessibility of pre-ART services

In line with the conceptual framework illustrated on page 69 of the thesis, many factors related to patients, staff and health systems emerged as preventing patients from accessing care, and although some remained in care. This was only for CD4 cell count checks and multivitamins. Others dropped out of care completely. As described above in Lusungu's pathway to care, some patients were able to endure the challenges and remain in care; others like Nabanda had no choice but to drop out of care.

There was no proper follow-up system to trace pre-ART patients lost to follow-up. Of those people traced back for interviews in this study, none had been followed up by the service providers. A plausible reason for this would be the poor recording system, also established in this study, making it difficult for service providers to identify those defaulting from care. Enhancing patient and provider engagement through follow-up phone calls and in-person visits when a patient misses appointment has shown to improve the retention of HIV+ patients in care (Sendzik, 2004, Thomson et al., 2011). Similarly strengthening counselling of pre-ART patients, in order to provide them with accurate information about HIV and disease progression, has been shown to contribute to motivate patients to remain in care (Smith et al., 2013). In our case the patients who were traced back for the study interviews after defaulting for > 12 months received further intensive counselling and they all later returned into care – implying that if patients were properly followed up in our study sites, they might have been retained in care.

The file audit for patients initiated on ART established that only 30/203 (14.7%) of people initiated on ART and included in the study, had participated in the pre-ART program beforehand. The majority did not have any pre-ART care documented in their files. This indicates that most people test late, i.e. when they are already eligible to start ART. This is a sign of delay in testing for HIV, probably due to the many documented barriers to people testing for HIV in the city of Johannesburg. These include younger age group and negative health worker attitude towards service users (Tshuma et al., 2014). In addition to these barriers, the other plausible reason is poor linkage to care, when patients test positive and are neither motivated to continue in care nor linked to care and return only when sick (Boyles et al., 2011; Lessells et al., 2011). Addressing these barriers to HIV testing and guaranteeing appropriate linkage to care after a positive HIV test is critical to ensure timely ART initiation (Lessells et al., 2011, Tshuma et al., 2014).

I have established that the majority (95%) of patients who were retained in pre-ART care accessed CD4 cell count check and multivitamins at least once. However, most patients did not take advantage of other services included in pre-ART care and likelihood is that they were not offered. For example, the file audits revealed that female patients included in the pre-ART patient file audits had neither cervical cancer (CA CX) screening nor family planning documented in their files. Lack of CA CX screening is a lost opportunity for pre-ART care women who are at higher risk of developing CA CX (Batra et al., 2010, Serraino et al., 1999, Snyman, 2013). Yearly screening is therefore critical (SA, 2000b, SA, 2014(b)) for early diagnosis, management and to avert unnecessary and premature deaths among HIV+ women (Franceschi and Jaffe, 2007, Maiman, 1998).

In addition, family planning is critical to be accessed by HIV+ women to prevent unplanned pregnancies, as part of the PMTCT strategy towards elimination of mother to child

transmission of HIV (WHO/UNICEF, 2007). Unintentional pregnancies among HIV+ women have been well documented in South Africa and elsewhere, calling for focus on ensuring that HIV+ women are accessing the reproductive health services, including family planning (Akelo et al., 2013, Sutton et al., 2014, Schwartz et al., 2012).

The other point is that only about a third of patients in this study had received IPT and adherence counselling. This is another missed opportunity as HIV+ individuals have ten times higher risk of getting TB (McIlleron et al., 2007), and IPT reduces TB incidence (Selwyn et al., 1989). In addition, comprehensive adherence counselling before ART initiation is critical to enable people to understand and accept their situation and promote adherence on ART (Visser et al., 2009). Adherence to ART is important for treatment success, as poor adherence on ART leads to viral replication and resistance mutations which may result in treatment failure, so requiring switching the patient to more complex and expensive regimens (Liu et al., 2006, Long et al., 2010).

CD4 cell count monitoring and multivitamins are the bare minimum pre-ART services. Retention in care for these services does not mean access to the available prescribed comprehensive package of services, defeating the purpose of the establishment of the pre-ART care program. There is considerable focus on retaining pre-ART care patients in care as it is low in South Africa (duToit et al., 2014) as well as elsewhere in sub-Saharan Africa (Rosen and Fox, 2011), but it is also critical that those retained in care are prioritised to access the full comprehensive package of pre-ART services.

In South Africa, there is no single reason to explain poor access to the prescribed comprehensive package of services, even when patients present at the facilities. The challenges affecting the health system service delivery emanate at different levels of the system. These challenges are pervasive. For example, *Mail and Guardian* reported a case of a

65 year old man who died at a hospital in Free State Province; his wife blamed the hospital for "killing her husband" (Malan, 2015). When reporters followed the story, it was established that there was shortages of staff, medicine and supplies to manage patients at the hospital and service providers were working under pressure with little support from the decision makers and politicians. The identified gaps in this story included poor leadership, poor governance, and budget constraints leading to staff shortages, coupled with high staff turnover, stock-outs of medicine and supplies. These multiple factors lead to patients presenting at the hospital where there were no resources to help them, including in this story no porters to carry dead bodies to the mortuary (Malan, 2015 pp 2-5). The Free State story cannot be generalised to CoJ facilities; circumstances vary across facilities, and so it does not explain directly the poor access of pre-ART services by patients who present at the facilities in CoJ. However, it is critical to further explore the origin of such gaps whenever they occur in order to address them at the right levels, to ensure that patients are able to access available services and that the services that are available are appropriate and affordable.

5.2 Awareness of available pre-ART services among pre-ART patients

While the majority (95%) of patients in this study were aware of CD4 cell count monitoring and multivitamin supplementation, very few knew that there were other important pre-ART services. For instance, only 17% and 12% were aware of the availability of nutritional supplements and of support group services. Access to the available services was shown to be associated with levels of awareness, as demonstrated in Figure 4.6. Even though no studies have quantified awareness and access to services, strengthening education to raise awareness of HIV and the disease progression has been reported to improve retention, resulting in access to available services (Smith et al., 2013, Nyasulu and Nyasulu, 2011).

Although the majority of patients reported that they were not aware of the available services, the interviewed staff thought that the patients were aware of all available pre-ART services. This discordance in knowledge meant that no efforts were made to address the gap. Without the identification of a gap, no quality improvements processes can be put in place (SA, 2012b).

5.3 CD4 cell count monitoring among patients retained in pre-ART care

In the study site facilities at the time of the study, CD4 testing was conducted by the National Health Laboratory Services (NHLS) at a centralised place, and all patients, whose blood was collected for CD4 cell check, were asked to come back after two weeks to collect their blood results. Almost all interviewed patients (99%) had had their CD4 cell count checked at least once after they had tested HIV+, and about two thirds (68%) had had their CD4 cell count checked within the past six months, consistent with the WHO and RSA pre-ART guidelines (SA, 2014(b), WHO, 2013a). This was higher than what has been reported in Cape Town (duToit et al., 2014) (46%) or in a review of studies in sub-Saharan Africa where (14/28) studies included in the review were from South Africa, where the six monthly CD4 cell check-up was at 46-68% at different stages of pre-ART care (Rosen and Fox, 2011). Six monthly CD4 cell count is critical for timely ART initiation (SA, 2014b). Delays in ART initiation lead to an increase in the costs as a result of high morbidity and mortality of patients after ART initiation (Brinkhof et al., 2008, Eaton et al., 2014, Ingle et al., 2010, Leisegang et al., 2009, WHO, 2013b).

Demographic characteristics did not show significant differences in 6 monthly CD4 cell count checking among the interviewed patients. However, those who indicated that an individual can get married ($p=0.03$) and have an HIV- baby ($p=0.001$) whilst HIV+ were more likely than others to be checked for CD4 cell count within the past 6 months. Despite

the fact that high knowledge levels may not necessarily lead to positive behaviour change (James et al., 2004, Rubin et al., 1992, Williams et al., 2003), knowledge around normalising HIV+ status, i.e. one can lead a normal life even though HIV+,- has been shown to positively affect CD4 cell count checking behaviour. A plausible reason for this would be the fact that the availability of ART and PMTCT has positively affected child bearing desires (Ndlovu, 2009), hence the motivation of PLWHAs to adhere to care and access timely ART (Cooper et al., 2007). In addition, having a healthy baby was used as a sign for normal life (Igonya and Moyer, 2013, Moyer et al., 2013). This finding may mean that an understanding that one can lead a normal life by getting married and having an HIV- healthy baby, inspite of being HIV+, can positively affect retention in care, in this case as reflected by the 6 monthly CD4 cell count monitoring among pre-ART patients. Therefore, though difficult to achieve (Mattes, 2014), normalisation of HIV as a disease can lead to retention in pre-ART care, as shown in this study.

However, in this study, even those pre-ART care patients who were retained in pre-ART care delayed ART initiation. These delays of timely ART initiation were established through both interviews and pre-ART file audits. The file audits showed no significant difference ($p=0.6$) in timely ART initiation between those who went through pre-ART and those who did not. In addition, 35% of interviewed patients were eligible to start ART and one patient had an extremely low CD4 cell count of 03 cells/μL. Delays in timely ART initiations have been documented in other studies, primarily because of poor retention and loss to follow-up in pre-ART care program, leading to individuals returning to care too late for effective treatment (Lessells et al., 2011, Fox and Rosen, 2010). Poor access to prescribed pre-ART care services by those retained in care has not established in other studies, but was established in this study. This could lead to further delays to timely ART initiation. The commonly cited recommendation of pre-ART care retention leading to timely ART initiation is futile if

retained patients are not offered and do not access the prescribed services and still delay ART initiation.

5.4 First CD4 count check and collection of results

The established average CD4 cell count levels for those with CD4 cell count above 200 cells/µl was 464 cells/µl, with women having significantly higher CD4 cell counts than men (p 0.000). This finding is consistent with other findings, which illustrate that women have higher CD4 cell counts without HIV infection (Maini et al., 1996), and that with HIV infection, women reach the ART initiation point twelve months later than men and the differences exist even after ART initiation (Prins et al., 1999, CASCADE-Collaboration, 2003, Loupa et al., 2006, Manolescu and Marinescu, 2013). This consistent finding raises questions about the need to differentiate the CD4 cell count cut-off point for ART initiation so that women start at a higher CD4 cell count than men (CASCADE-Collaboration, 2003, Kumarasamy et al., 2008).

The pre-ART register audit indicated that women and >24 yr olds were more likely to come back and collect their CD4 cell count (p=0.001 and p=0.05 respectively). This finding was consistent with the findings from interviews with pre-ART patients where both male and female participants reported that women had more opportunities of visiting the clinic, resulting in their increased access to results of tests as well as other aspects of pre-ART care. Similar to other studies, men and youths were most often lost to follow-up in pre-ART (Mugglin et al., 2012, Rosen and Fox, 2011, Ahmed et al., 2013, Lessells et al., 2011) because they had no reason to visit the facility other than for pre-ART care.

Those who had phone contacts documented in the register were more likely to come back to collect their first CD4 cell count results than those without recorded phone numbers. The main purpose for recording the patient phone numbers was to call them back into care in case

they miss their appointments. However, patients were not phoned to advise them to return and collect their results because, although the phone number was collected for patient follow-up purposes, there was no allocated phone to use for pre-ART patient follow up at the time of this study. Could it mean that in addition to being compelled to access services, leaving their phone contacts made them feel obliged to return to the facility? Or is having a phone or contact number associated with some enabling factors to retention in care like being a proxy for a higher economic or educational status? A PMTCT program access study conducted in sub-Saharan Africa within which South Africa was included, showed significantly higher adherence to the program among the mothers who had phone contacts (Nassali et al., 2009), though there is need for more research to answer these questions. Nonetheless, telephone call approaches have been tried and tested to minimise attrition in HIV care stages, and have shown to reduce attrition in HIV care with up to 64.8% of those lost to care traced back in care (Dalal et al., 2008).

5.5 Categories of identified gaps through interviews with patients and staff

A number of barriers to care in the current pre-ART care program have been established, leading to the attrition of patients from the time they test HIV+ to timely ART initiation. These gaps have been categorised into (1) patient-related gaps: including lack of time to attend clinic, breech of privacy and confidentiality of HIV+ status, patients not ready to test for HIV and HIV/AIDS knowledge gaps (2) staff-related gaps: including shortage of staff, staff attitude and lack of HIV knowledge among facility HIV counsellors and (3) health systems-related gaps: youth unfriendliness of the services, drug stock outs, poor record keeping to track retention, multiple clinic visits and pre-ART services not prioritized by service providers. Below I discuss these in detail.

5.6 Time related factors

A consistent problem reported by pre-ART care patients was lack of time to attend clinic appointments, as many were either working or seeking some casual work to earn a living. This is consistent with other study findings (Nakigozi et al., 2013, Moshabela, 2012). This lack of time was aggravated by other related factors, as illustrated in the Figure 5.1 below.

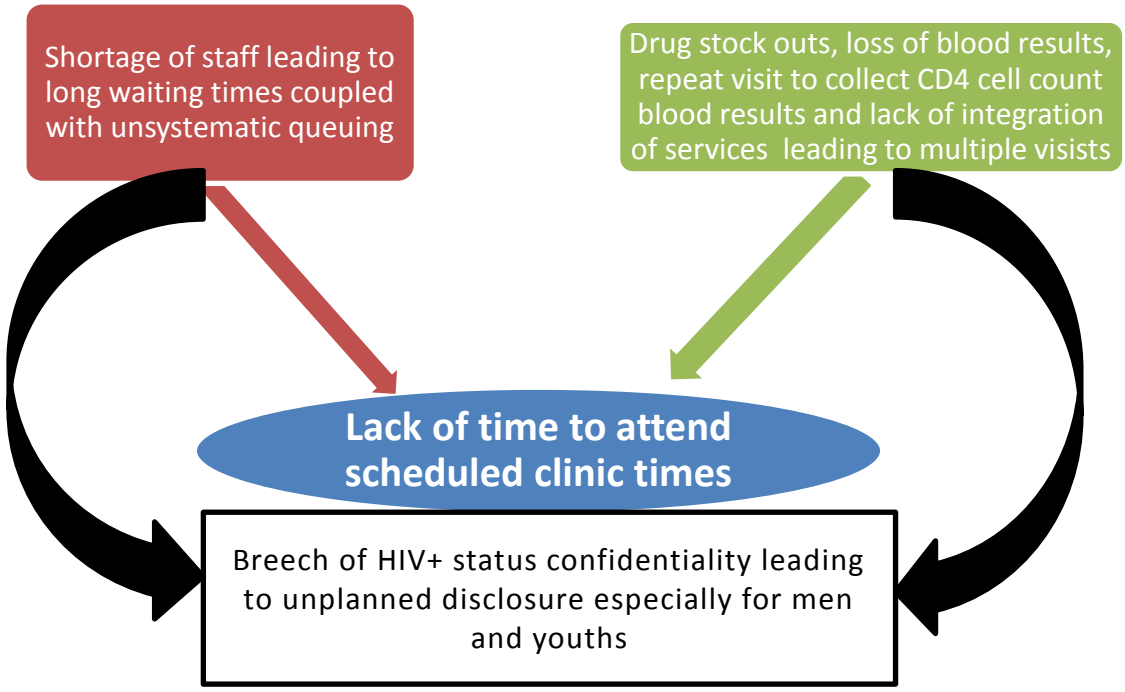


Figure 5.1: A synthesis of patient reported interrelated factors to pre-ART access

Firstly patients described how attending the clinic lead to financial loss, especially in terms of transport costs and time spent on travelling and waiting for the services in the clinic. For some, it meant a deduction in their wages, while for others, this resulted in lost opportunities for them to look for a job. Transport costs, traveling and clinic waiting times have been well documented as costly for patients, negatively affecting access to services among both adolescents and adults (Philbin, 2014, Pinto et al., 2013). Working on ways of reducing time spent on seeking pre-ART services can positively affect uptake of the services.

Secondly, the long time spent in the facility by healthy pre-ART care patients had the potential to breech the confidentiality of their HIV+ status, especially among men and youths. Women have many other reasons for visiting a clinic, as I have already noted. This finding can be a possible reason for men and youths being most likely to be lost to follow-up in pre-ART care, as reported from other studies in SA and elsewhere in sub-Saharan Africa (Rosen and Fox, 2011, Lessells et al., 2011). Therefore addressing factors that cause multiple clinic visits, as discussed above would also reduce unplanned disclosure of the patients' HIV+ status and reduce the stigma and discrimination that may result. Reducing time spent in the clinic by pre-ART patients may reduce loss to follow-up, particularly among youths and men.

Only some of the pre-ART patients interviewed had disclosed their HIV+ status to their partners (74%), family (55%) or friends (33%). In this study, I established that those employed were more likely to disclose to partners and friends than their unemployed counterparts (P=0.05 and p=0.04 respectively). The plausible reason could be the fact that being employed indicates financial independence, hence less financial reliance on the partner or friend (Makin et al., 2008). Although people may be reluctant to disclose to partners and other community members because disclosure may lead to negative outcomes including gender-based violence, stigma and discrimination (Gari et al., 2010, Nyasulu and Nyasulu, 2011, Cloete et al., 2010), it is an important component in pre-ART care programs in preparation for ART initiation (Worley et al., 2009). Rates of disclosure are associated with social support (Kalichman et al., 2003) and improved adherence to treatment (Unge et al., 2010).

Possible solutions through best practices to address the above identified gaps have been documented; these include establishing CD4+ cell count at the point of care (Manabe et al., 2012), reducing drug stock outs (Muhamadi et al., 2010) and reducing waiting times through

the improved triage of patients (Sokhela et al., 2013). However, synthesising these tried and tested ideas into a feasible pre-ART care guideline is still a challenge in South Africa (Boyles and Wilkinson, 2011, Govindasamy et al., 2014). Therefore, there is need to develop recommendations to assist in establishing guidelines in pre-ARTR service delivery to increase quality of care and hence improve retention.

I have established a lack of integration of pre-ART services, and that this increased the number of clinic visits for patients, making it difficult for them to attend to all clinic appointments. Integration models in service delivery have been shown potentially to be more efficient, although there is a need for further research in the area (Siapka et al., 2014). In addition training and mentoring of health workers to provide integrated HIV services has been recommended as a solution to maximise the limited human resources and to provide a comprehensive package of care at PHC level (see also Nyasulu et al., 2013).

Loss of CD4 cell count results, as reported by respondents in this study, requires that patients undergo a further CD4 cell count check and this increase the number of clinic visits, further increasing time spent in the facility by patients. In addition, not all patients come back to collect their CD4 cell counts, leading to poor linkage to care (Faal et al., 2011, Larson et al., 2013, Losina et al., 2010). Loss of CD4 cell counts results for those who come back for results just exacerbated the existing challenges for linkage to care. For example, in an earlier study conducted in Johannesburg, only 50% of HIV+ pregnant women who returned within 60 days after CD4 cell count check had their CD4 results recorded in the register (Schnippel et al., 2013).

Some patients reported that they were not ready for an HIV test at the time they tested for HIV, and spoke of "being taken by surprise." This unreadiness made it difficult for them to accept the HIV+ test results. Denial of results can be a catalyst for further transmission of

HIV coupled with secrecy and non-disclosure, which leads to poor access and retention in HIV services (Rankin et al., 2005). Denial may also be a problem among pre-ART care patients as they are mostly healthy and do not have any signs that they are HIV+ (Greeff et al., 2008). The HCT guidelines recommend the importance of pre-test counselling to ensure readiness of individuals before they are tested for HIV (SA, 2010b).

5.7 Pre-ART patients' knowledge levels around HIV/AIDS

HIV/AIDS knowledge gaps were established in this study, especially in relation to patients' understanding of disease progression from HIV to AIDS. Only 27% stated that HIV is not the same as AIDS. HIV knowledge levels are still low among the general population in South Africa (Shisana et al., 2014). No study has established pre-ART care patient knowledge levels around HIV disease progression. Patients demonstrated major knowledge gaps around the prevention of re-infection when both partners are positive, and only 38% of interviewed pre-ART care patients knew that there was a need to use a condom when both partners are HIV+. This is consistent with findings from a demographic health survey conducted in eight sub-Saharan African countries, which revealed very low use of condoms amongst HIV+ men and women in their last sex encounter; only 8% of HIV+ married men in Uganda reported that they had used condoms in their last sex (Wenjuan et al., 2012). Not knowing prevention of HIV transmission for pre-ART care patients is a lost opportunity for positive prevention (IHA, 2007). Prevention of HIV transmission from those who know their HIV+ status to others is amongst the objectives for positive prevention approaches, and the provision of HIV information, and education about risk reduction methods for PLWHAs is key to positive prevention of HIV (IHA, 2007). Even though HIV prevention knowledge may not necessarily mean positive behaviour change (Williams et al., 2003), it is important for those who are HIV+ engaging in HIV prevention practices (HRSC report 2013).

The other point of concern is the fact that even though counsellors (80%) were the main source of information in the facility and nurses (14%) the least, the patients reported lack of HIV knowledge among facility HIV counsellors and poor quality of counselling. The patients themselves recommended the need for training of counsellors to improve quality of counselling: "Counsellors should have more workshops on updated HIV/AIDS information." Quality of counselling should be considered the most important factor for all counsellors, as this could motivate service seeking and uptake (Gatta and Thupayagale-Tshweneagae, 2012). Even though no study has been documented on quality of counselling given to pre-ART program patients, poor quality and compromised information from counsellors has been documented in PMTCT programs in South Africa and elsewhere, negatively affecting the decision making for feeding choices and utilisation of services by PMTCT patients (Chopra et al., 2005, Rea et al., 2007, Manuela de Paoli et al., 2002). In order to ensure good quality of counselling, it is critical that HIV counsellors are trained, mentored and coached in quality counselling.

5.8 Negative staff attitudes

Negative staff attitudes emerged as a barrier to retaining patients in care, consistent with findings in a study among ART initiated patients (Nakigozi et al., 2013) and another study done among service providers and patients highlighting the health services' affordability and availability barriers in the post-apartheid era (Harris et al., 2014). Some patients felt that pre-ART service providers stigmatised them, and since the patients were in most cases healthy, they were never prioritised and taken seriously when they reported to the facility to access care. Staff attitude is a ministerial priority area in delivering health services, as already described above (SA, 2011b). However, negative attitudes towards HIV+ patients in South Africa and elsewhere are well documented (Famoroti et al., 2013, Mukora et al., 2011, Mulaudzi et al., 2011). For example, a study done in Kwazulu Natal, South Africa also

established that staff were stigmatising people who were HIV+ people by testing patients before surgery to avoid infection and gossiping about patients' HIV+ status, so breaching the privacy and confidentiality policy (Famoroti et al., 2013).

One area we need to look at is how the pre-ART patients respond to negative staff attitude: do they hold the service providers accountable or they just feel powerless to resist? As reported in this study, the stigmatisation by health workers discouraged pre-ART patients from continuing in care, as patients felt powerless to complain and take those involved to task to be accountable for their actions: "The nurse became rude to me and I felt stigmatised, hurt and disappointed, I decided not to come back. After all, I am not sick." However, the South African government has put in place a protocol that provides information and guidance to the public on how to complain and how management can handle and resolve those complaints in a timely manner – this protocol recommends that patients not happy with the services should be able to lodge a complaint with an assurance that the process of resolving the complaint will not negatively affect the services offered to the complainant but rather well address the complaint for the benefit of all who access the facility (SA, 2014 August). In this study, there is evidence that the pre-ART care patients were not aware of this protocol and processes involved, resulting into them defaulting from care when unhappy with the services. It is therefore important to sensitise health facility service users on the complaints management protocol for them to maximise its benefits.

5.9 Seeing beyond an HIV- baby

Currently, globally and in South Africa, there is a clear acknowledgment that in addition to having an HIV- baby, the health of the mother is of paramount importance to the survival of the child (Burton, 2013). The South African Government has emphasized this in the latest radical change in the PMTCT guidelines to Option B+ (SA, 2014(b)). Under the previous

guidelines, ART was provided to women in pregnancy, but discontinued after delivery or breastfeeding (Option B) (SA, 2013e). The PMTCT Option A and B regimens led to mothers being lost to follow up (Wettstein et al., 2012). In South Africa, Option A showed attrition whereby only two out of 72 (2.8%) ART eligible women were initiated on ART within 30 days (Schnippel et al., 2015), and even in countries like Malawi where Option B+ was rolled out two years ago, although there is improved retention, there is still attrition, with women again lost to follow-up (Tenthani et al., 2014). Under the revised guidelines, 'Option B+' requires that all pregnant women are initiated on lifelong ART (SA, 2014(b)). The main goal for Option B+ is to ensure that mothers are initiated early, without delays due to CD4 count checks, and retained in care to ensure there is increased maternal life expectancy, and so reduced mortality and morbidity (SA, 2014(b)).

Some PMTCT mothers in this study reported that all they wanted was an HIV- baby and they were interested in neither pre-ART nor ART after delivery. This finding is of great concern because, regardless of the HIV status of the child, a child is 3.8 times more likely to die if the mother is terminally ill or dead than if the mother is alive and healthy (Nakiyingi et al., 2003). Generally one might expect women to want to see their children grow, so how do we explain Nabanda's attitude, for example? After delivery, Nabanda left her child with her mother as the caregiver, and went back to work without continuing with pre-ART care. This is not uncommon in South Africa as maternal grandparents regularly help out as caregivers to ensure that children get optimum care, at times because of single parenthood and need for mother to work; mothers would not be available if the child stayed with his or her mother. This results in nearly eight percent of all children being cared for by grandparents (Holborn and Eddy, 2011).

The other plausible reason for Nabanda defaulting from pre-ART care is the possibility that she was still in denial that she was HIV+. Denial of one's HIV+ status has been shown to lead to medical pluralism and "doctor shopping" as people try to confirm and find an alternative to diagnosis as well as treat the symptoms (Wringe et al., 2009). The other point is that those who are in denial are not in a position to disclose and are particularly afraid of stigma and discrimination (Nakigozi et al., 2013). Therefore supporting those in denial, like Nabanda, with intensive counselling and education to accept their HIV+ status, to support them to disclose (SA, 2010b), and to emphasize the importance of pre-ART care would retain patients, so ensuring continuation of treatment once they commenced on ART (Smith et al., 2013). After further counselling and education, Nabanda returned to care and resumed pre-ART care.

One aspect that may be relevant in understanding this was that Nabanda was South African; she had grown up under Apartheid and had had only limited primary school education. During Apartheid, black men particularly were separated from their families, as they went to cities or to mines or other industries where family accommodation was not possible. Wives and children were left at home (Holborn and Eddy, 2011). Although Apartheid came to an end 20 years ago, South Africa still experiences the long-term ripple effects of this extended period of structural violence and racist control (Harris 2014). For example, poor access to education under the apartheid era had a negative effect on Nabanda's generation, separated families due to migration can affect the way the generation of people who were children at the time relate with their own children. Lastly, the HIV prevalence is the highest among the blacks (15%) compared to whites (0.3%), Coloured (3.1%) and Indians/Asian (0.8%) (Shisana et al., 2014). The Apartheid era migration for black South African men could be one of the contributing factors to this high prevalence, since migration places individuals in situations where they are at higher risk of contracting HIV (Lurie et al., 2003). Finding

employment still involves family separation. Currently only 30% of black children in South Africa live with both their parents, compared with >80% Indian and white children who live with both parents (Holborn and Eddy, 2011). Indicators of dysfunction or changes in family structure emerge from a comparison of 1996 and 2009 data in South Africa; among black Africans especially, the number of registered marriages has reduced, whilst the number of single headed households and absent fathers has increased. The after effects of the Apartheid era may directly and indirectly effect the decisions made by Nabanda and other pre-ART care patient to access health care and to take responsibility for their own children. In South Africa, when reflecting on strengthening access to health systems, it is important therefore to consider not only proximate issues, but the continued impact of Apartheid and the structures of social exclusion on contemporary families and decision making regarding family responsibilities and care. As a result there is need for more research to better understand the ripple effects of to better address these health accessibility gaps (Harris, 2014)

5.10 Service delivery costs, monitoring systems and accountability

The latest UNAIDS progress report has recognised South Africa as taking lead in their commitment to mobilising resources towards meeting the global targets in HIV service delivery (2015). The cost of ART in public health facilities for SA is higher than other African countries, at an estimated average of $682/person/year (Tagar et al., 2014). This estimate includes personnel, laboratory and other costs (Tagar et al., 2014). Another study showed that the mean monthly cost for managing an ART patient ($2415) was two times more than that of a pre-ART ($1207) at a referral hospital research project in Johannesburg this costing (Martinson et al., 2009). This costing reflects the fact that ART service delivery is higher than pre-ART probably due to the costs of ARVs and multiple blood tests for monitoring. This means that if people can use pre-ART services, the cost of care is reduced. These cost differences are evidence that the government invests more resources in ART

patients than pre-ART patients and as a result, there is the likelihood that more efforts are put in monitoring ART service delivery than are for pre-ART. For example, the results showed that better monitoring systems are in place for ART service delivery, demanding accountability from the facility on monthly performance. On the other hand, even though there are registers to record pre-ART services, there is poor recording leading to incomplete records and less accountability as facilities are not requested to collate and report pre-ART indicators on a monthly basis.

This trend drills down to patients themselves when they referred to pre-ART as "simple treatment," whilst ART was regarded as "serious treatment," as one patient explained: "I am very scared, maybe my CD4 cell count has dropped further by now. Maybe I need to start taking the serious HIV medication (referring to ART)!" There is logic in the patients' interpretation, as ART medication (ARVs) is expensive, requiring prescription and close monitoring, it is a more serious treatment than pre-ART multivitamins, which need no prescriptions nor close monitoring. However, the patients' assumption that since the pre-ART medication is not serious then the program can be ignored is critical, and needs to be urgently addressed as it is important for the patients to see the link of pre-ART to ART. This assumption could be the plausible reason for poor retention in pre-ART compared to ART reflected in this study. Another study conducted in Johannesburg, that followed up a cohort from HIV diagnosis for one year, showed a higher attrition among pre-ART (57%) than after ART initiation (2.1%) (Clouse et al., 2013). Drawing on the above assumptions, evidenced by increasing CD4 cell count cut off point from ≤200-≤500 cells/μl within between 2012-2014 (SA, 2014(b)), we could say that currently ART is a more serious business for government, service providers and patients themselves than pre-ART. The challenge is that increasing the ART CD4 cell count initiation cut off points without prioritising pre-ART care can only reach those accessing pre-ART care and will miss those not accessing the current pre-ART

services. Yet it is critical that pre-ART care be prioritised by the government, service providers and patients themselves, because poor retention leads to delays in ART and PLWHA missing out on all the benefits, described above. In addition, those who are on ART and virally suppressed reduce the risk of HIV transmission (Cohen, 2011) whilst the risk of HIV transmission for pre-ART patients is high, making it critical to target pre-ART care patients as a source of HIV infection to curb the spread of HIV.

5.11 Incompleteness of data and monitoring of pre-ART services

During the file and register audits, major gaps in relation to pre-ART data collection were established. In both study sites, the pre-ART registers were far less complete than the ART registers. The main reason for this was that, at the time of the study, most of the ART register data elements were used in monthly progress reporting of DHIS indicators whilst most data elements for the pre-ART register were used only for monitoring at a facility level, as described in Chapter four. As a result, the facility managers responsible for the compilation of monthly DHIS data would monitor and remind staff to ensure proper recording and timely reporting for the DHIS data elements but not those data elements not included on DHIS. Facility data can be used in monitoring the quality of services provided in the facility and adjustment of care through quality improvement processes which can best be achieved if data is of high quality (Pass, 2010). Nonetheless, the incompleteness of data found in this study is similar to that found in the South African public health sector (Ndabora et al., 2013, Nicol and Bradshaw, 2010). It compromises five components of data: accuracy, completeness, reliability, precision and integrity (Pass, 2010). This finding indicates that the degree of accountability on program areas directly affects the quality of data. This is in line with a quote from the latest UNAIDS report “measure what you treasure: when it comes to data, what gets measured gets done” (UNAIDS, 2015: 408). Unless the pre-ART indicators are

captured and included in the DHIS, the service implementation will neither be done nor documented.

However, the interviewed staff complained that there was too much documentation required and spoke of completing the different registers, reducing time spent on patients and so potentially compromising the quality of patient care. This was triangulated in this same study as nurses rated the lowest as sources of HIV information for pre-ART patients. An assessment conducted in 2011 established that there were a minimum of 54 registers in the health facilities which were found to consume patient care time and took up a lot of space in the patient consultation rooms and other areas (Dombo et al., 2014). As a result, DoH with the support from HST technical advice integrated and reduced the registers from 54 to six. This was piloted in 2012 and currently the Rationalisation of Registers (ROR) project is being rolled out across all South African provinces (Dombo et al., 2014). I envisage that this is a possible solution to problems in time constraint related gaps due to documentation. Therefore supporting the implementation of ROR in the facilities should address this gap in all facility service points including pre-ART.

5.12 Referral system of complicated cases

A referral system was in place for PHC facility staff from the study sites for complicated pre-ART care patients to go to Hillbrow CHC clinic or Charlotte Maxeke Academic Hospital (CMAH). However, there was a poor feedback system from the referral sites which the staff felt was a "missed learning opportunity." Communication between the referral initiation and receiving facilities is critical to ensure continuity of patient care (SA, 2009) and this established disconnection in communication of patient management at different levels of care can lead to discontinuity of care. In addition, documentation on the referral of patients at different levels can be used by supervisors for capacity building (SA, 2009, WHO, 2015);

hence this finding is indeed a missed learning opportunity for service providers at both levels of care. To ensure continuity of patient care and monitoring of the referral system, it is critical to strengthen documentation and feedback at all levels of care.

5.13 NIMART roll-out

WRHI as a PEPFAR partner for CoJ provided technical support in rolling out NIMART. This was a ten step process. The first step was to conduct the third to fifth stages of this process focussed on NIMART roll out readiness assessment to identify gaps to be addressed in order to implement NIMART. Throughout the process, there was the need for a sense of ownership and commitment to address the gaps in order to make NIMART implementation a reality. Of interest was Clinic A's facility manager, described in the case study (4.3.1), who was committed to implement NIMART. Her commitment led the facility to improve from being least likely to participate in NIMART, to be among the first to implement NIMART. The case is a good example of maximising available resources to address quality gaps. The facility manager's commitment and innovative ideas enabled her to quickly address facility health problems in readiness for NIMART implementation. Engaging with the service providers themselves in quality improvement processes can enable them to find ingenious solutions to address gaps using available resources (Rahimza et al., 2014).

Decentralisation of ART initiation through NIMART in Region F in the CoJ significantly increased uptake of ARVs by a monthly average of 99 patients immediately after rollout ($p=0.013$). This is consistent with findings from other studies, as rolling out NIMART to PHC facilities reduces the distance for patients to travel and requires fewer levels of referral for ART initiation, potentially leading to an increase in ART patient retention and access to services (Brinkhof et al., 2008, Zachariah et al., 2007). However, patient dissatisfaction with lack of trained HIV clinical staff, and negative patient-nurse interactions, compromising

confidentiality and stigma at lower levels of ART services has been highlighted (Decroo et al., 2011). Better mentoring and support for nursing staff are indicated to address these problems.

I have shown how the ten-step process involved in rolling out NIMART succeeded, with support from partner organisations, ensuring buy-in and sustainability of the program. Establishing that rolling out NIMART was a priority, and engaging with service providers, enabled both WRHI mentors and CoJ partners to have a shared vision, which inspired and motivated implementers in achieving sustainable change (Hunting and Tilbury, 2006).

The roll out of NIMART led to a steady reduction in the number of patients requiring initiation of treatment in the main referral health facility. This decrease allowed for the treatment of more complicated cases being managed at the referral site (Chan et al., 2010), while straight forward cases continue to be managed at a local PHC facility by nurses. The advantage of primary health care involvement at a local level in ART service delivery, especially in resource-limited settings, has been emphasised previously (Wester et al., 2005, Zachariah et al., 2007). However, there is a need for proper guidelines for upwards referral of complicated cases to prevent unnecessary delays in line with the WHO referral system adopted in SA (WHO, 2015). Providing ART initiation without increasing human and space resources resulted in an increased workload in CoJ primary health clinic levels. Staff shortage and lack of sufficient consulting rooms has been documented as a barrier to rolling out NIMART (Cameron et al., 2012, Jones et al., 2012). It is important to ensure capacity building, training and mentoring of nurses to integrate HIV services in order to reduce workload and provide a comprehensive package of care to patients. Partnership with the DoH/CoJ proved integral to increasing outputs as well as to sustainability of the NIMART program.

Introduction of NIMART resulted in an immediate increase in the number of ART initiations for Region F. The number of initiations was initially high but eventually stabilised, with evidence of an increasing trend in monthly initiations after NIMART. Decentralisation of ART through down-referral and NIMART services has also shown to be cost-effective, increase access and strengthen retention of patients on ART, owing to the closer proximity to their homes and decreased costs (Brinkhof et al., 2008, Miles et al., 2007, Sanne et al., 2010, Zachariah et al., 2007).

Chapter Six

Conclusion and Recommendations

6.1 Summary

This research project was conducted to understand retention in and access to pre-ART services, with the goal that this information would allow me to draw recommendations to improve the quality of pre-ART services delivery. These research aims were achieved through a cross-sectional survey to establish the gaps in pre-ART service delivery, their causes and solutions to address the identified gaps. In addition, I documented the implementation of NIMART, with a focus on the effectiveness of this mode of service delivery and the lessons learnt that are applicable in pre-ART service delivery, as provided by nurses at primary health care service delivery level. In this study, I established that there was poor access to the available comprehensive services (described in sections 2.3-2.4) by patients retained in pre-ART care. The majority of the retained patients only accessed the minimum CD4 cell count monitoring and multivitamin tablets and not the whole prescribed comprehensive package of pre-ART services, although all these services were available at the facilities. Currently, there is evidence of high loss to care of pre-ART care patients with less than half retained in care (Rosen and Fox, 2011, Clouse et al., 2013, Lessells et al., 2011). According to these study findings, even the few patients retained in pre-ART care do not access the available comprehensive pre-ART care package. This is a critical new finding not found in other studies (Fox and Rosen, 2010, Fox et al., 2014, Lessells et al., 2011) and a great lost opportunity with the realisation of the importance of accessing all services (Chapter two).

The results showed lack of awareness of the available comprehensive pre-ART package and this was directly associated with poor uptake of services (Figure 4.6). As a result, one

possible reason to this lack of access to pre-ART care services for patients retained in care would be lack of awareness of the comprehensive pre-ART package, as shown in other studies (Tshuma et al., 2014, Chimoyi et al., 2015, Nyasulu and Nyasulu, 2011b). This means that raising awareness of the available services may improve access consistent with other findings (Smith et al., 2013, Nyasulu and Nyasulu, 2011a).

Stigma against patients who were HIV+ was established to still occur in pre-ART care services. To date, even though there are multiple advocacy efforts to fight against stigma, HIV has not been normalised and discriminatory attitudes continue. As a result, people with HIV are reluctant to present to pre-ART care services, lest others suspect that they are HIV+. Some patients felt stigmatised by pre-ART service providers and even though no specific examples for this claim were given by the patients themselves, the finding is consistent with other findings (Famoroti et al., 2013).

In addition, there is a lack of normalisation of men accessing health facility care compared with women. Participants explained that it was normal in this society to see a healthy woman accessing care in a health facility, whilst it is an anomaly for men to access care with the same frequency. This has led to men's reluctance to access available pre-ART care. Pre-ART care patients who are healthy are able to lead a normal life, and are therefore not expected to visit a clinic. On the other hand, it is also important to emphasise that one's HIV+ status is expected to be treated as private and confidential, disclosed only by the HIV+ person or the service provider with consent from that person.

At the time of this study, patients were not able to collect CD4 cell count blood results on the same day of providing blood samples; they were asked to come back to the clinic after two weeks. At times when they came back to collect their blood results, the results were missing, requiring them to be retested. Other studies have shown attrition in care between testing

HIV+ and linkage to care, including the collection of CD4 cell count results (Faal et al., 2011, Larson et al., 2013, Losina et al., 2010, Schnippel et al., 2013). Loss of blood results established in this study appeared to be associated with attrition. Currently multiple studies in South Africa, of which one was conducted in the inner City of Johannesburg, have shown that point of care (POC) collection of CD4 cell count results increases retention in care (Faal et al., 2011, Jani et al., 2010, Larson et al., 2013, Wynberg et al., 2014) worth considering.

Many times, when gender is discussed in relation to access to care, the scale tips towards men as the ones in control of finances and decision makers, leading to barriers for women to access care (Nyasulu and Nyasulu, 2011b, Nyasulu and Nyasulu, 2011a, HIarlaithe et al., 2014). In contrast, this study has established the fact that men are most often lost to follow up and the contributing factors that explain why men and youths are most often lost to follow-up are consistent with those in other studies (Mugglin et al., 2012, Rosen and Fox, 2011). Men, mainly bread winners, explained that they lacked time to attend pre-ART care clinic which was aggravated by multiple interrelating factors (Figure 5.1), meaning they had competing priorities to using their time to access pre-ART care. Likewise, young people have other priorities in life, including socialisation, as well as education and employment - hanging out with friends rather than sitting in the queue at a health facility (SA, 2013c). Women were better able to attend the clinic as they had many other reasons, including family planning and infant and child health care, to visit the clinic; youths and men were seen by others as presenting only for pre-ART or ART. Unless efforts are made to reduce clinic time for men and youths, and indeed for all people, the health system is likely to continue to lose them from care.

Lack of disclosure of HIV+ status by pre-ART care patients was also established in the study. Those who were employed were more likely to disclose than their unemployed counterparts.

This means that the financial gains and self-reliance that comes with employment puts an individual in a better position to disclose (Makin et al., 2008), as financial reliance on someone like a partner has been reported to be a barrier to access to services, as this risks unplanned disclosure (Nyasulu and Nyasulu, 2011b). Even though disclosed HIV+ status can lead to stigma and discrimination, disclosure is important if pre-ART patients are to access the comprehensive pre-ART care package; supporting adherence to care, especially through building up the support structure around the individual (Worley et al., 2009, Unge et al., 2010).

In addition to patient-related factors highlighted above, health service delivery gaps were identified in this study. One finding was the lack of use of facility data for planning of service delivery. The compilation and completeness of monthly data mainly depended on what was reported through the District Health Information System (DHIS). At the time of the study, ART indicators were included on DHIS and not pre-ART indicators. As a result, I was able to establish that there was poor recording and collation of pre-ART indicators, which led to service providers not knowing the uptake and progress of pre-ART services. This contrasted with ART indicators, which had well completed registers with proper monthly collation for DHIS monthly reporting. However, pre-ART care is equally important as ART because for its relevance in ensuring timely ART initiation and in preventing HIV transmission.

Lastly but not least, the introduction of NIMART in the CoJ, through training, mentoring and coaching of nurses, with clear patient outcome indicators, was shown to have a positive impact on the uptake of ART services. However, in the case of pre-ART care roll-out with nurses, there was no training, mentoring and coaching of service providers, nor were there clear indicators to monitor progress. Therefore, although pre-ART care appeared to be

already in progress, there is need to put systems in place to train, mentor and coach pre-ART service providers and monitor pre-ART service uptake progress.

6.2 Government's commitment to improving access to care

There are several efforts by the South African Government in investing resources to improve the quality of care and access in public health services, for example, ensuring that all facilities meet the minimum standards through the implementation of NCS through the OHSC, the NHI piloting (SA, 2011b), Rationalisation of Registers (ROR) (Dombo et al., 2014), implementation of ideal clinics (Zuma, 2014) and other initiatives. These efforts are key to improving quality of health services and access. However, there is lack of clarity on how these efforts are related to each other as they are mostly implemented as parallel separate structures, confusing the implementers at facility level.

The latest UNAIDS report (2015) has commended the commitment shown by South African Government in taking lead in the African continent in expanding the ART program. For instance, SA increased the CD4 cell count levels for ART initiation from ≤200 cells/µl to ≤350 cells/µl then of late to ≤500cells/µl in line with the changing body of knowledge aiming to attain maximum benefits of ART to South Africa as a whole (SA, 2014(b)). Currently SA is focusing on achieving the 90-90-90 target which is the latest UNAIDS global strategy towards elimination of HIV (UNAIDS, 2014a). Even though these efforts have high immediate national budgetary implications (Nene, 2015, Motsoaledi, 23 July 2014), they have massive benefits in averting new infections, curbing morbidity and mortality, and improving the quality of life of all people (Granich et al., 2012).

From the time of ART roll-out to date, the South African ART guidelines were being produced in four different sets which were: (1) HCT, (2) Pediatric, (3) PMTCT and (4) Adolescent and Adult guidelines (SA, 2013d, SA, 2013e, SA, 2010b). This posed a

challenge as service providers had to consult different sources when managing different categories of patients, and so wasted time. On a positive note, the latest 2015 South African ART guidelines have been consolidated into one source document (SA, 2014b). This change will strengthen the integration of patient management, whereby a pregnant woman can be managed together with her child and spouse using one guideline reference document.

6.3 Recommendations

In view of the findings in this study, in order to strengthening health systems and improving access and retention in pre-ART care, recommendations are made. This study, although conducted among pre-ART and ART patients, identified many health systems gaps and the consequent recommendations are applicable to different service delivery points and can still be relevant even if the policy changes to treating all HIV+ persons regardless of their CD4 cell count level. These recommendations are in line with the study's conceptual framework illustrated in section 2.10 of this thesis. For better understanding and application, the recommendations are classified according to the WHO health systems building blocks, already described in Chapter Four which are: Service Delivery, Health Workforce, Health Information Systems, Access to Essential Medicines, Financing and Leadership/Governance. These are outlined below.

6.3.1 Service Delivery

- At all levels (from strategic to service delivery levels), there is an urgent need to address the existing gaps in the pre-ART care service delivery and improve access by those already in care, even before thinking of following up on those lost from care or registering more in care. In addition to increasing resources to increase the numbers of people initiated on ART, it is critical that the South African government's HIV

policies and guidelines prioritise access to comprehensive pre-ART care by those retained in care, and then to address those lost from care or not linked to care.

- Service providers should maximize the use of time patients spend at the clinic while waiting to be seen by raising awareness of available pre-ART services among patients. This can be accomplished through health talks and posters on the pre-ART services provided at the facility, which were not available at the time of the study. The content in the poster and health talk should answer the following questions:
    - What is pre-ART care?
    - Why is pre-ART care important?
    - What pre-ART care services are available in the facility? and
    - What one can do to access the available pre-ART care services?
- Working on ways of reducing time spent on seeking pre-ART services can positively affect uptake of the services. This can also reduce unplanned disclosure of the patients' HIV+ status mainly among youths and men. This can be achieved through initiatives at different levels such as:
    - Integration of pre-ART care by service providers with other existing services like family planning and cervical cancer screening, just to mention a few; this was recommended mainly by patients themselves in this study. Patients reported that parallel service structures at PHC level led to different service points giving different clinic appointment days, increasing the number of days and times that pre-ART care patients needed to spend in the facilities. Integration of services has always been recommended in South Africa, but was still not in existence at the study sites at the time of the study. The plausible contributing factor to lack of integration is that service providers are not multi-skilled and so are unable to provide a one stop shop service package. Currently

the South African health system is rolling out the implementation of the Ideal Clinic concept which focuses on multi-skilling service providers, enabling them to provide all services in one room (Zuma, 2014). Therefore the SA Government – Ministry of Health (MoH) needs to prioritise incorporating Pre-ART care services in the Ideal Clinic roll-out; after all, the integration of pre-ART care into current primary health care services has already been shown to retain pre-ART patients in care (Kohler et al., 2011, Smith et al., 2013). In addition, it is critical that the Ministry of Health (MoH) clarifies the integrative efforts towards achieving the common goal of improving access and quality of health care inclusive of pre-ART.

- Service providers to pre-pack pre-ART medications (multivitamins and IPT) to ensure that patients do not wait in the queues to collect them.
- Currently with technical support from Health Systems Trust, the South African government is piloting a program that provides alternative chronic medicine access to public sector patients through the Central Chronic Medicine Distribution and Dispensing Programme (CCMDDP) (HST, 2015 April, Du Toit, 2014). The first phase for this project targets HIV+ ART-initiated individuals who are adherent and virally suppressed, with the second phase incorporating many other chronic diseases, such as TB continuation phase, hypertension treatment, Diabetes Mellitus type 2, epilepsy and dyslipidemia (Du Toit, 2014). More chronic conditions will be added as the programme matures. I recommend that the Ministry of Health adds pre-ART medication to this list for those patients who are stable and are not scheduled for blood tests.

- SA Government - MoH needs to consider POC CD4 cell count results in order to reduce the number of patient clinic visits to ensure retention among pre-ART care patients (Larson et al., 2013, Faal et al., 2011, Jani et al., 2010, Wynberg et al., 2014), even though two to four times much more expensive (Cassim et al., 2014).

- It is critical that South Africa explores new ways of addressing the existing stigma and discrimination against those who are HIV+. Focussing on normalising HIV+ status in the community and among service providers, as an approach to reduce stigma against people who are HIV+, may result in greater retention among pre-ART care patients. In addition, unless clinic visits by men is normalised, the public health system will continue to lose men from care, not just in pre-ART care but also at many other service points.
- There is a need for service providers to continuously support pre-ART patients to disclose their HIV+ status, to ensure they have a support structure around them as stipulated in the pre-ART care guidelines (SA, 2013d, WHO, 2008, WHO, 2013a). This type of support structure has shown to improve retention in HIV care (Rankin et al., 2005).
- There is need for service providers to ensure that pre-ART patients access the comprehensive pre-ART care package and not just CD4 cell check and multivitamin tablets supplies when patients present at a health facility. In order to address this, I have designed a checklist (Appendix 8.1) on all pre-ART services to be offered at each visit. If this checklist were put in the patients' files, it would remind service providers and patients themselves to discuss what services can be accessed on the day of their visit.

- Service providers must ensure that health service facility users are sensitised on the available complaints management protocol for them to maximise its benefits.
- Service providers should incorporate interventions targeting men, with a focus on providing services that account for their mobility due to employment. This may result in retention in pre-ART and improved uptake of HIV services (Marson et al., 2013).

6.3.2 Health workforce

- Heath service delivery management should strengthen quality and frequency counselling of pre-ART patients with a focus on building capacity of facility HIV counsellors through training, mentoring and coaching on HIV counselling to pre-ART care patients. This would include providing counsellors with accurate information about HIV prevention and the disease progress.

- It is important that service providers are trained, mentored and coached in using the existing tools to identify service delivery gaps and causes in order for them to apply the quality improvement processes to address the existing gaps.
- There is need for the CoJ health service delivery management to establish YFHS in all facilities through training mentoring and coaching service providers in YFHS as well as availability of youth peer educators.
- Although pre-ART care appeared to be already in progress, there is need for CoJ health service delivery management to put systems in place to enable training, mentoring and coaching of pre-ART service providers in implementation and monitoring of pre-ART service uptake progress.

6.3.3 Health Information Systems (HIS)

- The HIS team needs to prioritise supporting service providers in documentation, completeness of records and use of information for pre-ART services' facility planning. This can also be achieved by including more pre-ART care uptake progress data elements in monthly DHIS monitoring, as it directly calls for facilities to be accountable for their pre-ART services that they deliver in the facilities - "measure what you treasure: when it comes to data, what gets measured gets done" (UNAIDS, 2015: 408).
- Linkage to care from the point of testing HIV+ to joining pre-ART care program is a challenge. Use of e-health facilities, whereby electronic registers are used, would assist to link patients to care from testing to pre-ART program enrolment would strengthen linkage to care.

6.3.4 Access to essential medicines

- Pre-ART medicine stock outs have been established in this study, leading to increased clinic visits or the expectation that patients would buy medication that they mostly could not afford. Therefore there is need for facility managers to ensure timely re-ordering of medications as well as allocation of resources by CoJ health service delivery management to ensure the timely procurement of the medications.

6.3.4 Leadership, governance and financing,

- The national as well as the CoJ health service delivery leadership and management should prioritise the allocation of resources for additional staff recruitment in order to curb the staff shortage problems in the facilities and improve supply chain management.

- A number of gaps identified are in relation to the key health ministerial six priority areas, described above in Chapter Two of this thesis. Long waiting times, negative staff attitude, and drug stock outs are an indication of how far implementation of pre-ART care services are from meeting the six priority areas. Access to services in a facility can easily be achieved if the SA MoH leadership provides support and guidance for health service facilities to work towards meeting these key ministerial priority areas in all service points, including pre-ART.

6.4 Areas for further research

The findings presented in this thesis point to the need for more research to further explore the complex factors contributing to poor access to pre-ART services, especially for patients retained in care. In addition, more research needs to be done on testing some innovative ideas in addressing the identified gaps to improve access to available pre-ART services. Below are proposed areas for further research:

- More research needs to be done on those patients not retained in pre-ART care, to explore ways of retaining them in care. These factors can be complex and much of the time, out of control of the service providers and patients themselves, but it is critical when working on the research questions to think broadly by involving decision makers, politicians and the community as they also influence these factors.
- Normalising HIV+ status may enhance retention results among pre-ART care patients. However, more research needs to be done on defining and establishing the normalisation of HIV+ status, care of people with HIV, and the role of HIV+ status normalisation in retention of HIV+ patients in care.
- There is need for further research on integration models in delivery of pre-ART services (Siapka et al., 2014).

- The pre-ART care checklist (Appendix 8.1) needs to be tested to determine its effectiveness in improving access and retention in pre-ART care.
- Despite the many challenges in the health service delivery system, there are still many service providers who are committed to providing quality patient care. More research needs to be done to explore motivation factors for health service providers.
- One recommendation from both service providers and patients themselves was to provide six monthly pre-ART medication packs to reduce patient clinic visits to twice a year. More research should be done to establish if reducing the number of visits for patients might improve retention in care for pre-ART patients.
- Other patients felt it would be better if they could collect the pre-ART care medications near to their place of residence or work, rather than from the clinic. One example of this model would be to use community distribution agents or expert patient-volunteers to dispense medication at a household or community level, or for patients to collect their medication from a chemist near their place of residence or work. Others preferred to collect their medication at the facility but outside working hours, and proposed that facilities provide the services during the weekend or after working hours. This latter suggestion would allow a wide range of services consistent with pre-ART; the former two assume that pre-ART involves only basic medication. These delivery innovations need to be tested to see if they can improve retention of pre-ART patient in care.
- Another option that requires testing would be fast queues for pre-ART care patients through the pre-packing of medication, so that patients just come and collect their medication without waiting in the queue, unless they are scheduled for a 6 monthly CD4 cell count and comprehensive services.

- There is need for operational research that would test the effect of some innovative ideas targeting men and youths to retain them in pre-ART care; for example, fast queues for working men and school going youths, and consulting pre-ART care youths separately from adults. Mainly innovations need to be developed and tested to reduce waiting times, and clinic visibility of pre-ART youths and men.
- More research should be done on the importance of documentation, complete records and use of information for health facility planning. For example, with the current implementation of ROR project, it is critical to establish whether the reduction of registers has created time for longer consultation to allow delivery of comprehensive pre-ART care.

6.5 Conclusion

In conclusion, the study has established poor access to prescribed pre-ART care services for those retained in care, a gap not yet identified in other studies. Many interrelated factors have been established to negatively affect access to available pre-ART services, such as lack of awareness of the available services, negative staff attitude, and lack of time to attend the clinic, aggravated by poor service integration, loss of blood results and no immediate CD4 cell count results. Stigma and discrimination against those living with the HIV virus has also shown to lead to lack of normalisation of HIV as a disease, making it difficult for people to disclose their HIV+ status. Access to the available pre-ART services has shown to lead to fear of unplanned disclosure, especially among youths and men in this study. However, training, mentoring and coaching of service providers in NIMART has been shown to significantly improve ART uptake in this study, suggesting that if a similar approach were applied to pre-ART it may yield similar results. To improve uptake of pre-ART, care services, it is critical that resources are invested in addressing the above identified gaps. In addition more research around the lived experiences of pre-ART care patients, their

challenges, causes and possible solutions to poor care address these is needed to better understand the Health Systems Strengthening (HSS) approaches to be used.

7.0 References

1. ADAMS, S. J. 2001. Projecting the next decade in safety management: A Delphi technique study. *Professional Safety,* 46, 26-29.
2. AGNEW-BLAIS, J., PERKINS, J., KHAN, K., CARNEVALE, J. & GROPPER. Lack of HIV/AIDS knowledge among school-age children and caregivers in an area of high HIV/AIDS prevalence: A descriptive analysis of a peri-urban population outside Lusaka, Zambia. American Public Health Association Conference, San Diego, California. 25-29 Oct 2008.
3. AHMED, I., GUGSA, S. T., LEMMA, S. & DEMISSIE, M. 2013. Predictors of loss to followup before HIV treatment initiation in Northwest Ethiopia: A case control study *BioMed Central Public Health,* 13, 1186.
4. AKELO, V., GIRDE, S., BORKOWF, C. B., ANGIRA, F., ACHOLA, K., LANDO, R., MILLS, L. A., THOMAS, T. K. & LECHER, S. L. 2013. Attitudes toward family planning among HIV-positive pregnant women enrolled in a Prevention of Mother-To-Child Transmission (PMTCT) study in Kisumu, Kenya. *PLoS ONE,* 8, e66593.
5. AKOLO, C., ADETIFA, I., SHEPPERD, S. & VOLMINK, J. 2010. Treatment of latent tuberculosis infection in HIV infected persons. *Cochrane Database Systmatic Reviews*, CD000171.
6. AKUSOBA, K. 2013. *Barriers to adherence to antiretroviral therapy among adult patients in a rural hospital in the Eastern Cape.* Masters in Public Health Mini-Thesis, University of the Western Cape, Cape Town, South Africa. [Online]. Available: http://etd.uwc.ac.za/xmlui/bitstream/handle/11394/3926/Akusoba_MPH_2013.pdf?sequence=1. (19/06/2015)
7. ALKEMA, L., KANTOROVA, V., MENOZZI, C. & BIDDLECOM, A. 2013. National, regional and global rates and trends in contraceptive prevalence and unmet need for family planning between 1990 and 2015: A systematic and comprehensive analysis. *Lancet Infectious Diseases,* 381, 1642–1652.
8. AMMASSARI, A., ANTINORI, A., ALOISI, M. S., TROTTA, M. P., MURRI, R., BARTOLI, L., MONFORTE, A., WU , A. & STARACE, F. 2004. Depressive Symptoms, Neurocognitive impairment, and adherence to highly active antiretroviral therapy among HIV-infected persons. *Consultation and Liaison Psychiatry,* 45, 394–402
9. APRIL, M., WOOD, R., BERKOWITZ, B., PALTIEL, D., ANGLARET, X., LOSINA, E. & FREEDBERG, K. A. 2013. The Survival benefits of antiretroviral therapy in South Africa. *Journal of Infectious Diseases,* 209, 491–499.
10. ARMSTRONG, B. K., WHITE, E. & SARACCI, R. 2001. *Principles of Exposure Measurement in Epidemiology,* Oxford, UK: Oxford University Press.
11. AVERT. 2015. *HIV and AIDS in South Africa* [Online]. Available: http://www.avert.org/hiv-aids-south-africa.Htm. (19/09/2015)
12. BABBA, D., PEMBA, L., SEATLANYANE, P., CHARALAMBOUS, S., CHURCHYARD, G. & GRANTA, A. 2007. Use of traditional medicine by HIV-infected individuals in South Africa in the era of antiretroviral therapy. *Psychology, Health & Medicine,* 12, 314-320.

13. BAKER, V., PENG, G. & RAPKIN 2008. CD4 cell+count and risk of non-AIDS diseases following initial treatment for HIV infection. *AIDS*, 22, 841–848.

14. BALOYI, G. O. 2006. *The Evaluation of the National Adolescent Friendly Clinic Initiative (NAFCI) Program in the Greater Tzaneen Sub-District, Limpopo Province: South Africa.* Master of Arts in Health Studies, University of South Africa, Pretoria. Availble at http://uir.unisa.ac.za/bitstream/handle/10500/1640/dissertation.pdf?sequence=1. (20/06/2015)

15. BARKER, G. 2007. Engaging men and boys in changing gender-based inequity in health: Evidence from programme interventions. Geneva, Switzerland: WHO Press.

16. BATRA, P., KUHN, L. & DENNY, L. 2010. Utilisation and outcomes of cervical cancer prevention services among HIV-infected women in Cape Town. *South African Medical Journal,* 100, 39-44.

17. BECKMANN, N. 2013. Responding to medical crises: AIDS treatment, responsibilization and the logic of choice. *Medical Anthropology: Cross-Cultural Studies in Health and Illness*, 20, 160-74.

18. BERWICK, D. M. 1998. Developing and testing changes in delivery of care. *Annals of Internal Medicine* 128, 651-656.

19. BEST, M. & NEUHAUSER, W. 2005. Edwards Deming: Father of quality management, patient and composer. *Quality and Safety in Health Care,* 14, 310–312.

20. BLAXTER, L., HUGHES, C. & TIGHT, M. 2010. *How to Research: Open Up Study Skills*, Berkshire, UK: McGraw.

21. BLECHER, M. S., STEINBERG, M., PICK, W., HENNINK, M. & DURCAN, N. 1995. AIDS knowledge, attitudes and practices among STD clinic attenders in the Cape Peninsula. *South African Medical Journal,* 85, 1281-6.

22. BOR, J., HERBST, A. J., NEWELL, M. L. & BARNIGHAUSEN, T. 2013. Increases in adult life expectancy in rural South Africa: Valuing the scale-up of HIV treatment. *Science,* 339, 961-5.

23. BOULLE, A., VAN CUTSEM, G., HILDERBRAND, K., CRAGG, C., ABRAHAMS, M., MATHEE, S., FORD, N., KNIGHT, L., OSLER, M., MYERS, J., GOEMAERE, E., COETZEE, D. & MAARTENS, G. 2010. Seven-year experience of a primary care antiretroviral treatment programme in Khayelitsha, South Africa. *AIDS,* 24, 563-72.

24. BOYLES, T. H. & WILKINSON, L. S. 2011. How should we care for patients who are not yet eligible for ART. *Southern African Juornal of HIV Medicine,* 12, 11-13.

25. BOYLES, T. H., WILKINSON, L. S., LEISEGANG, R. & MAARTENS, G. 2011. Factors influencing retention in care after starting antiretroviral therapy in a rural South African programme. *PLoS ONE,* 6, e19201.

26. BRINKHOF, M., DABIS, F. & MYER, L. E. A. 2008. Early loss of HIV-infected patients on potent antiretroviral therapy programmes in lower-income countries. *Bull World Health Organization*, 86, 559–67.

27. BURTLE, N., WELFARE, W., ELDEN, S., MAMVURA, C., VANDELANOTTE, J., PENTHERIC, E., WALLEY, J. & WRIGHT, J. 2012. Introduction and evaluation of a Pre-ART care service in Swazilland: An operational research study. *British Medical Journal,* 15;2, e000195.

28. BURTON, R. 2013. Maternal health: There is cause for optimism. *South African Medical Journal,* 103, 520-521.

29. CAMERON, D., GERBER, A. & MBATHA, M. 2012. Nurse initiation and maintenance of patients on antiretroviral therapy: Are nurses in primary care clinics initiating ART after attending NIMART training? *South African Medical Journal,* 102, 98-100.

30. CAMPBELL, M. & MACHIN, D. 1999. *Medical Statistics – A Common Sense Approach,* New York: John Wiley and Sons.

31. CASCADE-COLLABORATION 2003. Differences in CD4 Cell Counts at Seroconversion and Decline Among 5739 HIV-1–infected individuals with well-estimated dates of seroconversion. *Journal of Acquired Immune Deficiency Syndromes,* 34, 76-83.

32. CASSIM, N., COETZEE, L. M., SCHNIPPEL, K. & GLENCROSS, D. K. 2014. Estimating implementation and operational costs of an integrated tiered CD4 service including laboratory and point of care testing in a remote health district in South Africa. *PLoS ONE,* 9, e115420.

33. CDC 1981. Kaposi's sarcoma and Pneumocystis pneumonia among homosexual men in New York City and California. *Morbidity and Mortality Weekly Report.* 03/07/1981 ed.

34. CHAN, A., MATEYU, G., JAHN, A., SCHOUTEN, E., ARORA, P., MLOTHA, W., KAMBANJI, M. & VAN LETTOW, M. 2010. Outcome assessment of decentralization of antiretroviral therapy provision in a rural district of Malawi using an integrated primary care model. *Tropical Medicine and International Health,* 15, 90-97.

35. CHIBANDA, D., MANGEZI, W., TSHIMANGA, M., WOELK, G., RUSAKANIKO, S., STRANIX-CHIBANDA, L., MIDZI, S. & SHETTY, A. 2010. Postnatal depression by HIV status among women in Zimbabwe. *Journal of Women's Health,* 19, 2071–2077.

36. CHIMOYI, L., TSHUMA, N., MULOONGO, K., SETSWE, G., SARFO, B. & NYASULU, P. S. 2015. HIV-related knowledge, perceptions, attitudes, and utilisation of HIV counselling and testing: a venue-based intercept commuter population survey in the inner city of Johannesburg, South Africa. *Global Health Action,* 8, 26950.

37. CHOPRA, M., DOHERTY, T., JACKSON, D. & ASHWORTH, A. 2005. Preventing HIV transmission to children: Quality of counselling of mothers in South Africa. *Acta Paediatrica,* 94, 357-63.

38. CLEARY, BIRCH, S., CHIMBINDI, N., SILAL, S. & MCINTYRE, D. 2013. Investigating the affordability of key health services in South Africa. *Social Science and Medicine,* 80, 37-46.

39. CLOETE, A., STREBEL, A., SIMBAYI, L., VAN WYK, B., HENDA, N. & NQEKETO, A. 2010. Challenges faced by people living with HIV/AIDS in Cape Town, South Africa: Issues for group risk reduction. *Interventions AIDS Research and Treatment,* 2010, 1-8.

40. CLOUSE, K., PETTIFOR, A., MASKEW, M., BASSETT, J., VAN RIE, A., BEHETS, F., GAY, C., SANNE, I. & FOX, M. P. 2013. Patient retention from HIV diagnosis through one year onm antiretroviral therapy at a primary healthcare clinic

in, Johannesburg, South Africa. *Journal of Acquired Immune Deficiency Syndrome,* 62, e39–e46.

41. COHEN, M. 2011. Prevention of HIV-1 infection with early antiretroviral therapy. *New England Journal of Medicine,* 365, 493–505.
42. CoJ 2013a. *City of Johannesburg:2012/16 Integrated Development Plan: 2013/14 Review - Corridors of Freedom "Re-stitching our City to create a new future"* [Online]. Available: http://www.joburg.org.za/images/stories/2013/June/2013-16%20idp%2017may2013%20final.pdf. (31/03/2015)
43. CoJ 2013b. *Primary Health Care Facility List (public sector clinics) [as on 16 April 2013]*. [Online]. Available: http://www.joburg.org.za/images/stories/2013/April/copy%20of%20health%20facility%20list%20with%20services%20provided%20as%20in%20april%202013%20_city%20of%20johannesburg.pdf. (16/04/2015)
44. CoJ. April, 2015. *Official Website for the City of Johannesburg : Health* [Online]. Available: http://www.joburg.org.za/index.php?option=com_content&task=view&id=41&Itemid=9. (05/04/2015)
45. COLVIN, C. 2011. HIV/AIDS, chronic diseases and globalization. *Globalization and Health 2011,* 7, 31.
46. COOK, C. 2009. Sangomas: Problem or solution for South Africa's health care system. *Journal of the National Medical Association*, 101, 261-5.
47. COOPER, D., HARRIS, J., MYER, L., ORNER, P. & BRAACKEN, H. 2007. "Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa. *Social Science and Medicine*, 65, 274-283.
48. CORNELL, M., GRIMSRUD, A. & FAIRALL, L. 2010. Temporal changes in programme outcomes among adult patients initiating antiretroviral therapy across South Africa 2002-2007. *AIDS*, 24, 2263-2270.
49. CRESWELL 2009. *Research Design Qualitative, Quantitative, and Mixed Methods Approaches.* Thousand Oaks, CA: SAGE.
50. CRESWELL & PLANO CLARK, V. L. 2011. *Designing and conducting mixed methods research* Thousand Oaks, CA: SAGE.
51. DALAL, R. P., MACPHAIL, C., MQHAYI, M., WING, J., FELDMAN, C., CHERSICH, M. F. & VENTER, W. D. 2008. Characteristics and outcomes of adult patients lost to follow-up at an antiretroviral treatment clinic in Johannesburg South Africa. *Journal of Acquired Immune Deficiency Syndromes,* 47, 101-107.
52. DALEY, C. L., SMALL, P. M. & SCHECTER, G. F. E. A. 1992. An outbreak of tuberculosis with accelerated progression among persons infected with the human immunodeficiency virus. *New England Journal of Medicine,* 326, 231–235.
53. DANIEL, O. J., OLADAPO, O., OGUNDAHUNSI, O. A., FAGBENRO, S., OGUN, S. A. & ODUSOGA, O. A. 2008. Default from anti-retroviral treatment programme in Sagamu, Nigeria. *African Journal of Biomedical Research,* 11, 221-224.
54. DE BARROS, G., CAMAL, C. & CHIGANZE, F. 2004. Supporting the increase of support groups in Mozambique: RENSIDA and SAT's collaboration. *International Conference of AIDS.* Maputo, Mozambique: Rensida.
55. DECROO, T., TELFER, B., BIOT, M., MAı¨KE´RE, J., DEZEMBRO, S., CUMBA, L., DORES, C., CHU, K. & FORD, N. 2011. Distribution of antiretroviral treatment

through selfforming groups of patients in Tete province, Mozambique. *Journal of Acquired Immune Deficiency Syndromes,* 56, e39-e44.

56. DELBECQ, A. L., VAN DE VEN, A. H. & GUSTAFSON, D. H. 1975. *Group Techniques for Program Planning.,* Glenview, IL: Scott, Foresman, and Company.
57. DIABATE, S., ALARY, M. & KOFFI, C. K. 2007. Determinants of adherence to highly active antiretroviral therapy among HIV-1-infected patients in Cote d'Ivoire. *AIDS,* 21, 1799–1803.
58. DOHERT, T., CHOPRA, M., NSIBANDE, D. & MNGOMA, D. 2009. Improving the coverage of the PMTCT programme through a participatory quality improvement intervention in South Africa. *BMC Public Health,* 9, 406.
59. DOMBO, M., SEUTLWADI, L., MDEBUKA, H. & ENGLISH, R. 2014. Rationalisation of vertical health registers project. Durban, South Africa: Health Systems Trust.
60. DUREVALL, D. & LINDSKOG, A. 2014. Intimate partner violence and HIV in ten sub-Saharan African countries: What do the Demographic and Health Surveys tell us? *The Lancet Global Health,* 3, e34–e43.
61. DUTOIT, J. 2014. Improving accessibility to medicine: The "missing link." *South African Pharmaceutical Journal,* 8, 38-40.
62. DUTOIT, E., VANSCHALKWYK, C., DUNBAR, R., JENNINGS, K., YANG, B., COETZEE, D. & BEYERS, N. 2014. Missed opportunities for retention in pre-ART care in Cape Town, South Africa. *PLoS ONE* 9, e96867.
63. EATON, J., MENZIES, N., STOVER, J., CAMBIANO, V., CHINDELEVITCH, L., CORI, A., HONTELEZ, J. & AL, E. 2014. Health benefits, costs, and cost-effectiveness of earlier eligibility for adult antiretroviral therapy and expanded treatment coverage: A combined analysis of 12 mathematical models. *The Lancet Global Health,* 2, e23 - e34.
64. EHLERS, V. 2003. Adolescent mothers' utilization of contraceptive services in South Africa. *International Nursing Review,* 50, 229–41.
65. EMERY, S., NEUHAUS, J. A., PHILLIPS, A., BABIKER, A., COHEN, C., GATELL, J., GIRAUD, P., GRUND, B., LAW, M., LOSSO, M., PALFREEMAN, A. & WOOD, R. 2008. Major clinical outcomes in antiretroviral therapy (ART)- naïve participants and in those not receiving antiretroviral therapy at baseline in the SMART study. *Journal of Infectious Diseases,* 197, 1133–1144.
66. ETIENNE, M., BURROWS, L., OSOTIMEHIN, B., MACHARIA, T., HOSSAIN, B., REDFIELD, R. R. & AMOROSO, A. 2010. Situational analysis of varying models of adherence support and loss to follow up rates: Findings from 27 treatment facilities in eight resource limited countries. *Tropical Medicine & International Health,* 15 Suppl 1, 76-81.
67. FAAL, M., NAIDOO, N., GLENCROSS, D. K., VENTER, W. D. & OSIH, R. 2011. Providing immediate CD4 count results at HIV testing improves ART initiation. *Journal of Acquired Immune Deficiency Syndrome* 58, e54–e59.
68. FAMOROTI, T., FERNANDES, L. & CHIMA, S. 2013. Stigmatization of people living with HIV/AIDS by healthcare workers at a tertiary hospital in KwaZulu-Natal,

South Africa: A cross-sectional descriptive study. *BMC Medical Ethics*, 14(Suppl 1), 1-10.

69. FERLAY, J., SOERJOMATARAM, I., DIKSHIT, R., ESER, S., MATHERS, C., REBELO, M., PARKIN, D. M., FORMAN, D. & BRAY, F. 2015. Cancer incidence and mortality worldwide: Sources, methods and major patterns in GLOBOCAN 2012. *International Journal of Cancer,* 136, E359–E386.
70. FHI 2012. Guidelines for conducting HIV support groups, http://www.fhi360.org/sites/default/files/media/documents/Guidelines%20in%20Arabic%20and%20English%20for%20conducting%20HIV%20support%20groups_0.pdf (14/06/2015)
71. FISHER, A. A., FOREIT, J. R., LAING, J., STOECKEL, J. & TOWNSEND, J. 2002. *Designing HIV/AIDS Intervention Studies: An Operations Research Handbook.* New York: Population Council.
72. FORD, N., KRANZER, K., HILDERBRAND, K., JOUQUET, G., GOEMAERE, E., VLAHAKIS, N., TRIVINO, L., MAKAKOLE, L. & BYGRAVE, H. 2010. Early initiation of antiretroviral therapy and associated reduction in mortality, morbidity and defaulting in a nurse-managed, community cohort in Lesotho. *AIDS,* 24, 2645-2650.
73. FOX, M. & ROSEN, S. 2010. Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007-2009: Systematic review. *Tropical Medicine & International Health,* 15, 1-15.
74. FOX, M., SHEARER, K., MASKEW, M., MEYER-RATH, CLOUSE, G. & SANNE, I. 2014. Attrition through multiple stages of pre-treatment and ART HIV care in South Africa *PLoS ONE,* 9, e110252.
75. FRANCESCHI, S. & JAFFE, H. 2007. Cervical cancer creening of women living with hiv infection: A must in the era of antiretroviral therapy. *Oxford Journals Medicine Clinical Infectious Diseases,* 45, 510-513.
76. FRANCO, M. & MARQUEZ, L. 2011. Effectiveness of collaborative improvement: Evidence from 27 applications in 12 less developed and middle-income countries *British Medical Journal: Quality & Safety,* 20, 658-665.
77. GARI, T., HABTE, D. & MARKOS, E. 2010. HIV positive status disclosure among women attending ART clinic at Hawassa University Referral Hospital, South Ethiopia. *East African Journal of Public Health,* 7, 87-91.
78. GATTA, A. A. & THUPAYAGALE-TSHWENEAGAE, G. 2012. Knowledge of, and attitudes towards, voluntary HIV counselling and testing services amongst adolescent high school students in Addis Ababa, Ethiopia. *Curationis,* 35, e1-e8.
79. GEARY, R. S., GOMEZ-OLIVE, F. X., KAHN, K., TOLLMAN, S. & NORRIS, S. A. 2014. Barriers to and facilitators of the provision of a youth-friendly health services programme in rural South Africa. *BioMed Central (BMC) Health Services Research,* 14, 259.
80. GETAHUN, H., GRANICH, R., SCULIER, D., GUNNEBERG, C., BLANC, L., NUNN, P. & RAVIGLIONE, M. 2010. Implementation of isoniazid preventive therapy for people living with HIV worldwide: Barriers and solutions. *AIDS,* 24 Suppl 5, S57-65.
81. GOGA, A., DINH, T., JACKSON, D., DLAMINI, N., MOSALA, T. & LOMBARD, T. 2012. Impact of the national prevention of mother-to-child transmission of HIV

(PMTCT) program on perinatal mother-to-child transmission of HIV (MTCT) measured at six weeks postpartum, South Africa (SA). *XIX International AIDS Conference.* Washington, DC. 22-27 July 2012. Available: http://pag.aids2012.org/abstracts.aspx?aid=8933. (31/03/2015)

82. GORDHAN, P. 2010. Budget Speech. Minister of Finance. Cape Town, Parliament of RSA. *In:* SA Treasury (ed.) Pretoria, South Africa: National Treasury Communications Unit.
83. GORDHAN, P. 2014. Budget Speech. Minister of Finance. Cape Town, Parliament of RSA. *In:* SA Treasury (ed.) Pretoria, South Africa: National Treasury Communications Unit.
84. GOVENDER, V., BHANA, R., PILLAY, A., PANCHIA, R., PADAYACHEE, G. N. & DE BEER, M. 1992. Perceptions and knowledge about AIDS among family planning clinic attenders in Johannesburg. *South African Medical Journal,* 81, 71-4.
85. GOVINDASAMY, D., KRANZER, K. & FORD, N. 2014. Strengthening the HIV cascade to ensure an effective future ART response in sub-Saharan Africa. *Transactions of the Royal Society of Tropical Medicine and Hygiene,* 108, 1093.
86. GRANICH, G., GETAHUN, H., REID, A., RAVIGLIONE, M. & DE COCK, K. 2009. Erring on the side of action: time for HIV programs to implement isoniazid preventive therapy HIV/AIDS *International Journal of Tuberculosis and Lung Disease,* 13**,** 925-926. Available: http://www.who.int/hiv/topics/tb/granich_time_fo_hiv_programmes_in_int_j_tuberc_lung_dis_2009.pdf. (21/02.2015)
87. GRANICH, R., KAHN, G., BENNETT, R., HOLMES, C., GARG, N., SERENATA, C., SABIN, M., MAKHLOUF-OBERMEYER, C., DE FILIPPO MACK, C. & WILLIAMS, P. 2012. Expanding ART for treatment and prevention of HIV in South Africa: Estimated cost and cost-effectiveness 2011-2050. *PLoS ONE,* 7, e30216.
88. GREEFF, M., PHETLHU, R., MAKOAE, L. N. & AL., E. 2008. Disclosure of HIV status: Experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative Health Research,* 18, (3), 311–324.
89. GREEN, A., DE AZEVEDO, V., PATTEN, G., DAVIES, M., IBETO, M. & COX, V. 2014. Clinical mentorship of nurse initiated antiretroviral therapy in Khayelitsha, South Africa: A quality of care assessment. *PLoS ONE,* 9, e98389.
90. GREEN, J. C., CARACELLI, V. J. & GRAHAM, W. F. 1989. Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis,* 11, 255-274.
91. GUION, L., DIEHL, D. & MCDONALD, D. 2011. Triangulation: Establishing the Validity of Qualitative Studies, Department of Family, Youth and Community Sciences, Florida Cooperative Extension Service, Institute of Food and Agricultural Sciences, University of Florida. Available: http://edis.ifas.ufl.edu/. (31/03/2015)
92. HARRIES, A. D. 2002. Management of HIV in resource-poor countries, with a focus on sub-Saharan Africa. *Leprosy Review,* 73, 268-75.
93. HARRIS B, EYLES J, PENN L. 2014. Adverse or acceptable: negotiating access to a post-apartheid health care contract. *Global Health*. 10, 1744-1748.
94. HIARLAITHE, M. O., GREDE, N., DE PEE, S. & BLOEM, M. 2014. Economic and social factors are some of the most common barriers preventing women from

accessing maternal and newborn child health (MNCH) and prevention of mother-to-child transmission (PMTCT) services: a literature review. *AIDS Behaviour,* 18, S516-30.

95. HOLBORN, L. & EDDY, G. 2011. First Steps to Healing the South African Family. Johannesburg, South Africa: South African Institute of Race Relations.HST 2015 April. Easy Access to Chronic Medication for NHI districts. *HST @ Work: Internal Newsletter*. Durban, South Africa: Health Systems Trust
96. HSU, C. & SANDFORD, B. A. 2007. The Delphi technique: Making sense of consensus. *Practical Assessment Research & Evaluation,* 12. pp. 1-8. [Online]. Available: http://pareonline.net/pdf/v12n10.pdf. (31/03/2015)
97. HUGHES, R. G. 2008. Tools and strategies for quality improvement and patient safety. *Patient Safety and Quality an Evidnce-Based Handbook for Nurses.* Rockville, MD: Agency for Health Care Research and Quality (US).
98. HUNTING, S. & TILBURY, D. 2006. *Shifting towards sustainability: Six insights into successful organisational change for sustainability*. Sydney, Australia: Australian Research Institute in Education for Sustainability (ARIES).
99. IGONYA, E. & MOYER, E. 2013. Putting sex on the table: Sex, sexuality and masculinity among HIV-positive men in Nairobi, Kenya. *Culture, Health & Sexuality,* 15, S567-S580.
100. IHA 2007. *Positive prevention:Prevention strategies for people with HIV/AIDS.* Brighton:UK: International HIV/AIDS Alliance. [Online]. Available: http://www.aidsalliance.org/includes/Publication/Positive_prevention.pdf. (23/06/2016)
101. INGLE, S. M., MAY, M., UEBEL, K., TIMMERMAN, V., KOTZE, E. & ABERG, J. 2010. Differences in access and patient outcomes across antiretroviral treatment clinics in the Free State province: A prospective cohort study. *South African Medical Journal,* 100, 675–681.
102. IRWIN, M. 2001. LOW CD4+ T LYMPHOCYTE COUNTS: A variety of causes and their implications to a multifactorial model of AIDS. [Online]. Available: http://www.virusmyth.com/aids/hiv/milowcd4.htm. (15/06/2015)
103. JACOBS, J. M. 1996. *Essential assessment criteria for physical education teacher education programs: A Delphi study.* Doctoral dissertation, West Virginia University, 1996. Dissertation abstract international, 57, 2928. Morgantown, WV.
104. JAMES, S., REDDY, S. P., TAYLOR, M. & JINABHAI, C. C. 2004. Young people, HIV/AIDS/STIs and sexuality in South Africa: The gap between awareness and behaviour. *Acta Paediatrica,* 93, 264-269.
105. JANERT, P. 2009. *Gunplot in Action: Understanding data with Graphs,* Greenwich, CT: Manning Publications.
106. JANI, I., SITOE, N., ALFAI, E., CHONGO, P. & LEHE, J. 2010. Point-of-care CD4 improves patient rentention and time-to-initiation of ART in Mozambique. *XVIII International AIDS Conference 2010.* Vienna, Austria. [Online]. Available: http://pag.aids2010.org/Abstracts.aspx?SID=641&AID=17805. (25/052014)
107. JEWKES, R. 2002a. Intimate partner violence: causes and prevention. *Lancet,* 359, 1423–1429.

108. JOHNSON, L. F., MOSSONG, J., DORRINGTON, R. E., SCHOMAKER, M., HOFFMANN, C. J., KEISER, O., FOX, M. P., WOOD, R., PROZESKY, H., GIDDY, J., GARONE, D. B., CORNELL, M., EGGER, M. & BOULLE, A. 2013. Life expectancies of South African adults starting antiretroviral treatment: Collaborative analysis of cohort studies. *PLoS Medicine,* 10, e1001418.

109. JONES, M., STANDER, M. & VAN ZYL, M. E. A. 2012. Recall of lost-to-follow-up pre-antiretroviral therapy patients in the Eastern Cape: Effect of mentoring on patient care. *South African Medical Journal,* 102, 768-769.

110. JONGWUTIWES, U., KIERTIBURANAKUL, S. & SUNGKANUPARPH, S. 2007. Impact of antiretroviral therapy on the relapse of cryptococcosis and survival of HIV-infected patients with cryptococcal infection. *Current HIV Research,* 5, 355-60.JOUBERT, P. 2009. Nurse shortage in South Africa: Nurse/Patient ratios. *Solidariry Sarbeidsforum.* Solidarity Research Department. [Online]. Available: www.solidariteitinstituut.co.za/docs/Addendum%205.1_reg.pdf. (06/07/2015)

111. KALICHMAN, S. C., DIMARCO, M., AUSTIN, J., LUKE, W. & DIFONZO, K. 2003. Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behaviour Medicine,* 4, 315-32.

112. KING, J. 2015. *The SA SURE Project's Stories of Change: The picture of health, South Africa's Sustainable Response to HIV, AIDS and TB,* Durban, South Africa: Health Systems Trust.

113. KIRKWOOD, A. & PRICE, L. 2013. Examining some assumptions and limitations of research on the effects of emerging technologies for teaching and learning in higher education: Special Issue- Emerging Technologies and Transformation Effect on Pedagogy. *British Journal of Educational Technology,* 44, 536–543.

114. KIRKWOOD, B. & STERNE, J. 2009. *Essential Medical Statistics,* Oxford, UK: Blackwell.

115. KLAUSSNER, J. D., SEENTA, C., O'BRA, H., MATTSON, C. L., BROWN, J. W., WILSON, M., MBENGASHE, T. & GOLDMAN, T. M. 2011. Scale-up and continuation of antiretroviral therapy in South African treatment programs, 2005-2009. *Journal of Acquired Immune Deficiency Syndromes,* 56, 292-295.

116. KOHLER, P., CHUNG, M., BENKI-NUGENT, S. & MCGRATH, C., ATTWA, M. ET AL. 2011. Free CTX Substantially Improves Retention among ART-ineligible Clients in a Kenyan HIV Treatment Program. *18th Conference on Retroviruses and Opportunistic Infections 2011.* Boston, MA. [Online]. Available:. https://sites.google.com/a/kenyaresearchgroup.org/kenya-research-program/Home/conferences/18th-conference-on-retroviruses-and-opportunistic-infections-croi--boston-ma-february-27--march-2-2011/free-cotrimoxazole-substantially-improves-retention-among-art-ineligible-clients-in-a-kenyan-hiv-treatment-program. (14/06/2015)

117. KRANZER, K., GOVINDASAMY, D., FORD, N., JOHNSTON, V. & LAWN, S. 2012. Quantifying and addressing losses along the continuum of care for people living with HIV infection in sub-Saharan Africa: A systematic review. *Journal of International AIDS Society,* 15, 17383.

118. KUMARASAMY, N., VENKATESH, K., CECELIA, A. J., DEVALEENOL, B., SAGHAYAM, S., YEPTHOMI, T., BALAKRISHNAN, P., FLANIGAN, T., SOLOMON, S. & MAYER, K. 2008. Gender-based differences in treatment and

outcome among HIV patients in south India. *Journal of Women's Health,* 17, 1471-1475.

119. KUNDU, C. K., SAMANTA, M., SARKAR, M., BHATTACHARYYA, S. & CHATTERJEE, S. 2012. Food supplementation as an incentive to improve preantiretroviral therapy clinic adherence in HIV positive children experience from Eastern India,. *Journal of Tropical Pediatrics,* 58, 3137.

120. LAMBDIN, B. H., MICEK, M. A., SHERR, K., GIMBEL, S., KARAGIANIS, M., LARA, J., GLOYD, S. S. & PFEIFFER, J. 2013. Integration of HIV care and treatment in primary health care centers and patient retention in central Mozambique: A retrospective cohort study. *Journal of Acquired Immune Deficiency Syndromes,* 62, e146-52.

121. LANGHAUG, L. F., COWAN, F. M., NYAMURERA, T. & POWER, R. 2003. Improving young people's access to reproductive health care in rural Zimbabwe. *AIDS Care,* 15, 147-57.

122. LARSON, B., SCHNIPPEL, K., BRENNAN, A., LONG, L., XULU, T., MAOTOE, T., ROSEN, S., SANNE, I. & FOX, M. 2013. Same-day CD4 testing to improve uptake of HIV care and treatment in South Africa: Point-of-care is not enough. *AIDS Research and Treatment,* 2013, 941493.

123. LAWN, S. D., HARRIES, A. D. & WILLIAMS, B. G. 2011. Antiretroviral therapy and the control of HIV-associated tuberculosis. Will ART do it? *International Journal Tuberculosis and Lung Disease,* 15, 571-581.

124. LEISEGANG, R., CLEARY, S., HISLOP, M., DAVIDSE, A. & REGENSBERG, L. 2009. Early and late direct costs in a Southern African antiretroviral treatment programme: A retrospective cohort analysis. *PLoS Medicine,* 6, e1000189.

125. LESSELLS, MUTEVEDZI, P., IWUJI, C. & NEWELL, M. 2014. Reduction in early mortality on antiretroviral therapy for adults in rural South Africa since change in CD4+ cell count eligibility criteria. *Journal of Acquired Immune Deficiency Syndromes.,* 65, e17–e24.

126. LESSELLS, MUTEVEDZI, P. C., COOKE, G. S. & NEWELI, M. 2011. Retention in HIV care for individuals not yet eligible for antiretroviral therapy: Rural KwaZulu-Natal. *Journal of Acquired Immune Deficiency Syndrome,* 56, e79-e86.

127. LEYDON, N. G., VENTER, F., WEBSTER, P. D., MOLEKO, W., OSIH, R. & BARKER, P. M. 2010. Achieving the HIV and AIDS national strategic plan: A practical calculator for local target setting in district health facilities. *South African Medical Journal,* 100, 420-424.

128. LINDBERG, C., LEWIS-SPRUILL, C. & CROWNOVER, R. 2006. Barriers to sexual and reproductive health care: Urban male adolescents speak out issues. *Comprehensive Pediatric Nursing,* 29, 73-88.

129. LIU, H., MILLER, L., HAYS, R., GOLIN, C., WU, T. & WENGER, N. 2006. Repeated measures longitudinal analyses of HIV virologic response as a function of percent adherence, dose timing, genotypic sensitivity, and other factors. *Journal of Acquired Immune Deficiency Syndromes,* 41, 315-22.

130. LOFMARK, A. & THORELL-EKSTRAND, I. 2005. An assessment form for clinical nursing education: a Delphi study. *Journal of Advanced Nursing,* 48, 291-298.

131. LONG, L., FOX, M., SANNE, I. & ROSEN, S. 2010. The high cost of second-line antiretroviral therapy for HIV/AIDS in SA. *AIDS*, 24, 915-9.

132. LOSINA, E., BASSETT, I. & GIDDY, J. 2010. The "ART" of linkage: Pre-treatment loss to care after HIV diagnosis at two PEPFAR sites in Durban, South Africa, *PLoS ONE*, 5, e9538.

133. LOSINA, E., YAZDANPANAH, Y., DEUFFIC-BURBAN, S., WANG, B., WOLF, L. L., MESSOU, E., GABILLARD, D., SEYLER, C., FREEDBERG, K. A. & ANGLARET, X. 2007. The independent effect of highly active antiretroviral therapy on severe opportunistic disease incidence and mortality in HIV-infected adults in Cote d'Ivoire. *Antiretroviral Therapy*, 12, 543-51.

134. LOUPA, C. V., RODRIGUEZ, B., MCCOMSEY, G., GRIPSHOVER, B., SALATA, R. A., VALDEZ, H., LISGARIS, M. V., FULTON, S. A. & LEDERMAN, M. M. 2006. Gender differences in human immunodeficiency virus (HIV) RNA and CD4 cell counts among new entrants to HIV care. *Clinical Microbiology and Infection* 12, 389-391.

135. LURIE, M. N., WILLIAMS, G., ZUMA, K., MKAYA-MWAMBURI, D., GARNETT, G., STURM, W., SWEAT, D. & GITTELSOHN, J. 2003. The impact of migration on HIV-1 transmission in South Africa: A study of migrant and nonmigrant men and their partners. *Sexually Transmitted Disease*, 30, 149–156.

136. MAIMAN, M. 1998. Management of cervical neoplasia in human immunodeficiency virus-infected women. *Journal of the National Cancer Institute* 43-9.

137. MAINI, M., GILSON, R., CHAVDA, N., GILL, S., FAKOYA, A., ROSS, E., PHILLIPS, A. & WELLER, I. 1996. Reference ranges and sources of variability of CD4 cell counts in HIV-seronegative women and men. *Genitourinary Medicine*, 72, 27-31.

138. MAKIN, J., FORSYTH, B., VISSER, M., SIKKEMA, K., NEUFELD, S. & JEFFERY, B. 2008. Factors affecting disclosure in South African HIV-positive pregnant women. *AIDS Patient Care and STDs*, 22, 907-916.

139. MALAN, M. 2015. 'It's the Free State hospital that killed my husband, Frik'. *Mail and Guardian*, 20 March, pp 2-5.

140. MALAWI MoH 2010. Malawi HIV and AIDS Monitoring and Evaluation Report: 2008-2009 UNGASS Country Progress Report Reporting Period: January 2008-December 2009. [Online]. Available: http://www.malawi_2010_country_progress_report_en.pdf. (09/02/2014).

141. MANABE, Y. C., WANG, Y., ELBIREER, A., AUERBACH, B. & CASTELNUOVO, B. 2012. Evaluation of portable point-of-care CD4 counter with high sensitivity for detecting patients eligible for antiretroviral therapy. *PLoS ONE*, 7, e34319.

142. MANHEIMER, E., WIELAND, S., KIMBROUGH, E., CHENG, K. & BERMAN, B. 2009. Evidence from the Cochrane Collaboration for Traditional Chinese Medicine Therapies. *Journal of Alternative and Complementary Medicine*, 15, 1001–1014.

143. MANOLESCU, L. & MARINESCU, P. 2013. Sex differences in HIV-1 viral load and absolute CD4 cell count in long term survivors HIV-1 infected patients from

Giurgiu, Romania. The Romanian Journal of Laboratory Medicine 21, 217-224. [Online]. Available: http://biomedfrontiers.org/infection-2014-3-6/. (14/09/2015)

144. MANUELA DE PAOLI, M., MANONGI, R. & KLEPP, K. 2002. Counsellors' perspectives on antenatal HIV testing and infant feeding dilemmas facing women with HIV in northern Tanzania. *Reproductive Health Matters,* 10, 144-156.

145. MAQUTU, D., ZEWOTIR, T., NORTH, D., NAIDOO, K. & GROBLER, A. 2010. Factors affecting firstmonth adherence to antiretroviral therapy among HIV-positive adults in South Africa. *African Journal of AIDS Research* 9, 117-124.

146. MARSON, K. G., TAPIA, K., KOHLER, P., MCGRATH, C. J., JOHNSTEWART, G. C., RICHARDSON, B. A., NJOROGE, J. W., KIARIE, J. N., SAKR, S. R. & CHUNG, M. H. 2013. Male, mobile, and moneyed: loss to followup vs. transfer of care in an urban African antiretroviral treatment clinic. *PLOS ONE,* 8, e78900.

147. MARTINSON, N., MOHAPI, L., BAKOS, D., GRAY, G. E., MCINTYRE, J. A. & HOLMES, C. B. 2009. Costs of providing care for HIV-infected adults in an urban HIV clinic in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndromes,* 50**,** 327-30. [Online]. Available: http://www.ncbi.nlm.nih.gov/pubmed/19194308. (14/06/2015)

148. MASKEW, M. & MCNAMARA, L. 2013. gender differences in mortality and CD4 count response among HIV-positive patients virally suppressed within 6 months of antiretroviral therapy initiation. *Journal of Women's Health,* 22, 113-120.

149. MATSOSO, M. & FRYATT, R. 2012. The policy objective of NHI is to ensure that everyone has access to appropriate, efficient and quality health. *South African Health Review* 2012/13. [Online]. Available: http://www.hst.org.za/publications/south-african-health-review-2012/13. (21/03/2013)

150. MATTES, D. 2014. Caught in transition: the struggle to live a 'normal' life with HIV in Tanzania. *Medical Anthropology: Cross-Cultural Studies in Health and Illness,* 33, 270-87.

151. MBIRIMTENGERENJI, N. D. 2007. Is HIV/AIDS outcome of poverty in Sub Saharan Africa? *Croatian Medical Journal,* 48, 605-617.

152. MBULAITEYE, S. M., BHATIA, K., ADEBAMOWO, C. & SASCO, A. J. 2011 HIV and cancer in Africa: Mutual collaboration between HIV and cancer programs may provide timely research and public health data *Infectious Agents and Cancer 2011,* 6, 16.

153. MCILLERON, H., MEINTJES, G., BURMAN, W. & MAARTENS, G. 2007. Complications of antiretroviral therapy in patients with tuberculosis: Drug interactions, toxicity, and immune reconstitution inflammatory syndrome. .*Journal of Infectious Diseases,* 196, S63–S75.

154. MELEIS, A. 1997. *Theoretical Nursing. Development and Progress.* New York: Lippincott.

155. MERMIN, J., EKWARU, J. P., LIECHTY, C. A., WERE, W., DOWNING, R., RANSOM, R., WEIDLE, P., LULE, J., COUTINHO, A. & SOLBERG, P. 2006. Effect of co-trimoxazole prophylaxis, antiretroviral therapy, and insecticide-treated bed nets on the frequency of malaria in HIV-1-infected adults in Uganda: A prospective cohort study. *Lancet,* 367, 1256–1261.

156. MERSON, M. H., O'MALLEY, J., SERWADDA, D. & APISUK, C. 2008. The history and challenge of HIV prevention. *Lancet Infectious Diseases,* 372, 475–488.

157. MHRC 2005. Cultural practices and their impact on enjoyment of Human rights, particularly the rights of women in Malawi. [Online]. Available: http://www.medcol.mw/commhealth/publications/cultural_practices_report.pdf. (20/02/2013).

158. MICEK, M. A., GIMBEL-SHERR, K., BAPTISTA, A. J., MATEDIANA, E., MONTOYA, P., PFEIFFER, J., MELO, A., GIMBEL-SHERR, S., JOHNSON, W. & GLOYD, S. 2009. Loss to follow-up of adults in public HIV care systems in central Mozambique: Identifying obstacles to treatment. *Journal of Acquired Immune Deficiency Syndrome,* 52, 397-405.

159. MILES, K., CLUTTERBUCK, D., SEITIO, O., SEBEGO, M. & RILEY, A. 2007. Antiretroviral treatment roll-out in a resource constrained setting: Capitalising on nursing resources in Botswana. *Bull World Health Organization,* 85, 555-560.

160. MILLS, E., KANTERS, S., HAGOPIAN, A., BANSBACK, N., NACHEGA, J., ALBERTON, M. A.-Y., C., MTAMBO, A., BOURGEAULT, I., LUBOGA, S., HOGG, R. & FORD, N. 2011. The financial cost of doctors emigrating from sub-Saharan Africa: Human capital analysis. *British Medical Journal,* 343, d7031

161. MITRA, S. 2010. Disability cash transfers in the context of poverty and unemployment: The case of South Afria. *World Development 2010,* 38, 1692-1709.

162. MOFENSON, L. 2010. Prevention in neglected subpopulations: Prevention of mother-to-child transmission of HIV infection. *Journal of Clinical Infectious Diseases,* 50(Suppl 3), 130–148.

163. MOGENSEN, H. 2010. *New Hopes and New Dilemmas: Disclosure and Recognition in the Time of Antiretroviral Treatment.* New York: Berghahn Books.

164. MONFORTE, A. D., ABRAMS, D., PRADIER, C., WEBER, R., REISS, P., BONNET, F., KIRK, O., LAW, M., DE WIT, S., FRIIS-MOLLER, N., PHILLIPS, A. N., SABIN, C. A. & LUNDGREN, J. D. 2008. HIV-induced immunodeficiency and mortality from AIDS-defining and non-AIDS-defining malignancies. *AIDS,* 22, 2143-53.

165. MOSHABELA, M.2012. *Understanding patterns of health system utilisation among people living with HIV/AIDS attending rural HIV Services.* PHD, University of the Witwatersrand, Johannesburg, South Africa.

166. MOSHABELA, PRONYK, P., WILLIAMS, N., SCHNEIDER, H. & LURIE, M. 2009. Pattern and implications of medical pluralism among HIV/AIDS patients in rural SA. *AIDS,* 23, 631-6.

167. MOTSOALEDI, A. 13 April 2010. Minister of Health. Budget speech delivered to the National Assembly, Parliament of the Republic of South Africa. *In:* Health (ed.). [Online]. Available: http://www.info.gov.za/speeches/2010/10041315551001. (19/06/2015)

168. MOTSOALEDI, A. 23 July 2014. 2014 Health Budget Speech by the minister of health. [Online]. Available: http://www.info.gov.za/speeches/2010/10041315551001. (14/09/2015)

169. MOYER, E., BURCHARDT, M. & VAN DIJK, R. A. 2013. Editorial introduction: Sexuality, intimacy and counselling: perspectives from Africa. *Culture, Health and Sexuality,* 15, S431-S439.

170. MOYER, E. & HARDON, A. 2014. A disease unlike any other? Why HIV remains exceptional in the age of treatment. *Medical Anthropology: Cross-Cultural Studies in Health and Illness,* 33, 263-269.

171. MOYO, N. & MÜLLER, J. C. 2011. The influence of cultural practices on the HIV and AIDS pandemic in Zambia. *Theological Studies,* 67, 1-5.

172. MSF 2010. Untangling the Web of Antiretroviral Price Reductions Geniva: Rue de Lausanne. Available at www.msf.or.jp/library/pressreport/pdf/UTW_13th_edition_jul2020.pdf. (14/09/2015).

173. MUGGLIN, C., JANNE ESTILL, J., WANDELER, G., BENDER, N., EGGER, M., GSPONER, T. & KEISER, O. 2012. Loss to programme between HIV diagnosis and initiation of antiretroviral therapy in sub-Saharan Africa: Systematic review and meta-analysis. *Tropical Medicine and International Health.,* 17, 1509–1520.

174. MUHAMADI, L., NSABAGASANI, V., NAZARIUS-TUMWESIGYE, M., WABWIRE-MANGEN, F., EKSTRÖM, A., PETERSON, S. & PARIYO, G. 2010. Inadequate pre-antiretroviral care, stock-out of antiretroviral drugs and stigma: Policy challenges/bottlenecks to the new WHO recommendations for earlier initiation of antiretroviral therapy (CD < 350 cells/μL) in eastern Uganda, *Health Policy* 97, 187-194.

175. MUKORA, R., CHARALAMBOUS, S., DAHAB, M., DAHAB, M., HAMILTON, R. & KARSTAEDT, A. 2011. Study of patient attitudes towards decentralisation of HIV care in an urban clinic in South Africa. *BioMedical Central Health Services Research,* 11, 205.

176. MULAUDZI, M. V., PENGPID, S. & PELTZER, K. 2011. Nurses' knowledge, attitudes, and coping related to HIV and AIDS in a rural hospital in South Africa. *Ethnographic Medicine,* 5, 25-32.

177. NAKIGOZI, G., ATUYAMBE, L., KAMYA, M., MAKUMBI, F., CHANG, L., NAKYANJO, N., KIGOZI, G., NALUGODA, F., KIGGUNDU, V., SERWADDA, D., WAWER, M. & GRAY, R. 2013. A qualitative study of barriers to enrollment into free HIV care: perspectives of never-in-care HIV-positive patients and providers in Rakai, Uganda. *BioMed Research International,* 2013, 470245.

178. NAKIYINGI, J., BRACHER, M., WHITWORTH, J., RUBERANTWARI, A., BUSINGYE, J., MBULAITEYE, M. & ZABA, B. 2003. Child survival in relation to mother's HIV infection and survival: evidence from a Ugandan cohort study. *AIDS,* 17, 1827-34.

179. NASSALI, M., NAKANJAKO, D., KYABAYINZE, D., BEYEZA, J., OKOTH, A. & MUTYABA, T. 2009. Access to HIV/AIDS care for mothers and children in sub-Saharan Africa: Adherence to the postnatal PMTCT program. *AIDS Care,* 21, 1124-1131.

180. NCAMA, P. A., MCINERNEY, B. R. & BHENGU 2008. Social support and medication adherence in HIV disease in KwaZulu-Natal, South Africa. *International Journal of Nursing Studies,* 45, 1757–1763.

181. NDABORA, E., CHIPPS, J. A. & UYS, L. 2013. Systematic review of health data quality management and best practices at community and district levels in LMIC. *Information Development,* 30, 103-120.

182. NDLOVU, V. 2009. Considering childbearing in the age of highly active antiretroviral therapy (HAART): Views of HIV-positive couples. *Journal of Social Aspects of HIV/AIDS,* 6, 58-68.

183. NENE, N. 2015. Highlights of the South African National Budget Speech 2015/16 delivered by Finance Minister Nhlanhla Nene to Parliament on Wednesday, Cape Town. [Online]. Available: http://www.sacommercialpropnews.co.za/south-africa-economy/7134-highlights-of-south-africa-budget-speech-2015.html. (13/04/2015)

184. NICOL, E. & BRADSHAW, D. 2010. Maternal, newborn and child survival: Data challenges. *South African Health Review,* 2010.

185. NYASULU, J., MUCHIRI, E., MAZWI, S. & RATSHEFOLA, M. 2013. NIMART roll out to primary health care facilities increases access to antiretrovirals in Johannesburg: An interrupted time series analysis. *South Africa Medical Journal,* 103, 232-236.

186. NYASULU, J. & NYASULU, P.-. 2011b. Decision making for women to access prevention of Mother to Child Transmission (PMTCT) of HIV services in Blantyre and Balaka districts - Malawi. *Journal of Rural and Tropical Public Health,* 10, 95-100.

187. NYASULU, J. & NYASULU, P. 2011a. Barriers to uptake of prevention of mother to child transmission (PMTCT) services in rural Blantyre and Balaka districts. *Journal of Rural and Tropical Public Health,* 10, 48-52.

188. OH, K. H. 1974. Forecasting through hierarchical Delphi. Columbus, OH: The Ohio State University.

189. OPHDI., 2010. Multidimensional Poverty Index. Oxford Poverty & Human Development Initiative [Online]. Available: http://www.ophi.org.uk/policy/multidimensional-poverty-index/. (29/04/2016)

190. PALELLA, J., DELANEY, K., LOVELESS, M., FUHRER, J., SATTEN, A., ASCHMAN, J. & HOMBERG, D. 1998. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *New England Journal of Medicine,* 338, 853-60.

191. PANTELIC, M., CLUVER, L., BOYES, M., TOSKA, E., KUO, C. & MOSHABELA, M. 2015. Medical pluralism predicts non-ART use among parents in need of ART: A community survey in KwaZulu-Natal, South Africa. *AIDS Behaviour,* 19, 137-44.

192. PASS, H. I. 2010. Medical registries: Continued attempts for robust quality data. *Journal of Thoracic Oncology,* 5, S198-9.

193. PATEL, P., HANSON, D., SULLIVAN, P. & NOVAK, R. E. A. 2008. Incidence of types of cancer among HIV-Infected persons compared with the general population in the United States, 1992–2003. *Annals of Internal Medicine,* 148, I-46.

194. PHILBIN, M. 2014. "What I got to go through": Normalization and HIV-positive adolescents. *Medical Anthropology: Cross-Cultural Studies in Health and Illness,* 33, 288-302.

195. PINTO, D., VANLETTOW, M., RACHLIS, B., CHAN, K. & SODHI, K. 2013. Patient costs associated with accessing HIV/AIDS care in Malawi. *Journal of International AIDS Society,* 19, 18055.

196. POLIT, D. F. & BECK, C. T. 2010. Generalization in quantitative and qualitative research: Myths and strategies. *International Journal of Nursing Studies,* 47, 1451-1458.

197. POWELL, C. 2003. The Delphi technique: myths and realities. *Journal of Advanced Nursing,* 41, 376-382.

198. PRINS, M., ROBERTSON, J. R., BRETTLE, R. P., AGUADO, I. H., BROERS, B., BOUFASSA, F., GOLDBERG, D. J., ZANGERLE, R., COUTINHO, R. A. & VAN DEN HOEK, A. 1999. Do gender differences in CD4 cell counts matter? *AIDS,* 13, 2361-2364.

199. RAHIMZA, M., NAEEM, A., HOLSCHNEIDER, S. & HEKMATI, A. 2014. Engaging frontline health providers in improving the quality of health care using facility-based improvement collaboratives in Afghanistan: case study. *Conflict and Health,* 8, 21.

200. RAMLAGAN, S., PELTZER, K., PHASWANA-MAFUYA, N. & AQUILERA, J. F. 2010. Support group needs for people living with HIV and AIDS (PLWHA) in communities around Durban. *Journal of Psychology in Africa,* 20, 127-131.

201. RANKIN, W., BRENNAN, S., SCHELL, E., LAVIWA, J. & RANKIN, S. H. 2005. The stigma of being HIV-positive in Africa, *PLoS Medicine,* 2, e247.

202. RAS, G. J., SIMSON, I. W., ANDERSON, R., PROZESKY, W. & HARMESMA, T. 1983. Acquired Immunodeficiency Syndrome: A report of two South African cases. *South African Medical Journal* 64, 140-142.

203. REA, M. F., DOS SANTOS, R. G. & SANCHEZ-MORENO, C. C. 2007. Quality of infant feeding counselling for HIV+ mothers in Brazil: challenges and achievements. *Acta Paediatr,* 96, 94-9.

204. RICHTER, K. L., DREYER, G., LINDEQUE, B. G. & BOTHA, M. H. 2014. HPV vaccine: Can we afford to hesitate? *South African Medical Journal,* 104, 522-3.

205. RITCHER, M. 2003. *Traditional medicines and traditional healers in South Africa.* University of the Witwatersrand- AIDS Law Project. Durban, South Africa: Health Systems Trust.

206. ROGERS, E. 1995. *Diffusion of Innovations.,* New York: Free Press.

207. ROSEN, S. & FOX, M. 2011. Retention in HIV care between testing and treatment in sub-Saharan Africa: a systematic review. *PLoS Medicine,* 8, e1001056.

208. ROSEN, S., KETLHAPILE, M., SANNE, I. & DESILVA, M. B. 2007. Cost to patients of obtaining treatment for HIV/AIDS in South Africa. *South African Medical Journal,* 97, 524-9.

209. RSA 2012. RSA National Strategic Plan (NSP) on STI and TB (2012-2016). [Online]. Available: http://www.sahivsoc.org/upload/documents/National_Strategic_Plan_2012.pdf**.** (17.07/2013).

210. RUBIN, S. A., EARLS, F., DORE, P. & CUNNINGHAM, R. 1992. Changes in AIDS related risk behavior after adolescence: Relationships to knowledge and experience concerning HIV infection *Pediatrics,* 89, 950-966.

211. SA 2000a. HIV/AIDS and STD strategic plan for south Africa 2000-2005. *In:* HEALTH (ed.). Cape Town: CPT printers. [Online]. Available: http://www.doh.gov.za/docs/index.html. (24/06/2015).

212. SA 2000b. National Guideline on Cervical Cancer Screening Programme. *In:* Health (ed.). Pretoria, South Africa: SA Department of Health. [Online]. Available: http://data.unaids.org/topics/nsp-library/nsp-africa/nsp_south_africa_2000-2005_en.pdf. (24/06/2015).

213. SA 2003. Operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa. *In:* HEALTH (ed.) 19 December ed. [Online]. Available: http://www.hsph.harvard.edu/population/aids/southafrica.aids.03.pdf. (20/03/2013).

214. SA 2004. National Antiretroviral Treatment (ART) Guidelines. *In:* Health (ed.) first edition, printed by Minuteman Press. Available at http://southafrica.usembassy.gov/media/2004-doh-art-guidelines.pdf. (14/03/2015).

215. SA 2005a. Nursing Act No. 33 of 2005. *In:* Nursing (ed.). Pretoria, South Africa: Government printer.

216. SA 2005b. Traditional health healers practitioners' Act. *Act 34 0f 2004.* Government Gazette [Online]. Available: http://www.saflii.org/za/legis/num_act/thpa2004335.pdf. (07/07/2015).

217. SA 2009. *Primary Health care supervision Manual: A guide to Primary Health Care Supervison,* Pretoria, South Africa: Quality Assurance Directorate, Department of Health.. [Online]. Available: www.inpracticeafrica.com/.../Guidelines/SA_NDOH_Primary_Supervision_manual_pdf. (06/07/2015).

218. SA 2010a. Clinical guidelines for the management of HIV & AIDS in adults and adolescents National Department of Health. [Online]. Available: http://www.fidssa.co.za/Guidelines/2010_Adult_ART_Guidelines.pdf.

219. SA 2010b. National HIV Counselling and Testing Policy Guidelines. [Online]. Available: http://www.uj.ac.za/EN/CorporateServices/ioha/Documentation/Documents/hct_policy_guidelines%202010.pdf. (24/06/2015).

220. SA 2011a. End of term review of the 2007-2011 National Strategic Plan (report). Pretoria, South Africa: Department of Health.

221. SA 2011b. *"Towards Quality Care for Patients" National Core Standards for Health Establishments in South Africa* Tshwane, South Africa: Department of Health. [Online]. Available: www.sanacws.org.za/.../4feac9f1ef9ca-version-dec-15th-action-framework-emtct-5-pdf. (24/06/2015).

222. SA 2012a. National Action Framework for "No Child Born with HIV by 2015 & Improving the Health and Wellbeing of Mothers, Partners and Babies in South Africa." *In:* Health (ed.). Pretoria, South Africa: Department of Health.

223. SA 2012b. Quality Improvement Guide - Quality Improvement, a key to providing improved quality of care. [Online]. Available: http://www.doh.gov.za. (06/02/2014).

224. SA 2013a. Mid-Term review of progress in achieving the 2011 UN General assembly political declaration of HIV/AIDS targets and alimination commitments in South Africa. Pretoria: Health. [Online]. Available: www.sanac.org.za. (27/02/2015).

225. SA 2013b. The Millenium Development Goals Country Progress report: The South Africa I know, The home I understand. Pretoria, South Africa: Statistics South Africa. [Online] Available: http://beta2.statssa.gov.za/MDG/MDGR_2013.pdf. (09/11/2014).

226. SA. 2013c. National Strategic Plan Review: Engaging with South Africa's National Strategic Plan for HIV: Taking stock of the response to children, PMTCT, adolescents, prevention, treatment, retention in care, TB, palliative care, pain control. Is South Africa winning? *NSP review*, Dec 2013. [Online]. Available: http://www.section27.org.za/wp-content/uploads/2013/12/NSP-Review-9.pdf. (09/11/2014).

227. SA 2013d. The South African antiretroviral treatment Guidelines *In:* Health (ed.). Pretoria: NDOH. [Online]. Available: http://www.sahivsoc.org/upload/documents/2013%20ART%20Guidelines_Short%20Combined%20FINAL%20draft%20guidelines%2014%20March%202013.pdf. (28/12/2014).

228. SA 2013e. The South African Guidelines for Prevention of Mother to Child Transmission of HIV (PMTCT) *In:* HEALTH (ed.). Pretoria, South Africa: Department of Health [Online]. Available: www.hst.org.za/publications/pmtct-guidelines-2013. (11/10/2014).

229. SA 2014. South Africa National Adult TB Guidelines 2014. *In:* HEALTH (ed.). Pretoria, South Africa: Department of Health. [Online]. Available: http://www.health-e.org.za/wp-content/uploads/2014/06/NTCP_Adult_TB-Guidelines-27.5.2014.pdf. (09/07/2015).

230. SA 2014 August. A National Complaints Management Protocol for the Public Health Sector of South Africa. *In:* Office of Health Standards and Compliance (OHSC) (ed.). South Africa: Department of Health. [Online]. Available: http://www.health-e.org.za/wp-content/uploads/2014/10/National-Complaints-Management-Protocol-Aug-2014.pdf. (29/06/2015).

231. SA 2014(b). National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults. *In:* HEALTH (ed.). Pretoria, South Africa: Department of Health.

232. SA 2015a. *The Local Government Handbook : A Complete Guide to Municipalities in South Africa*, Pretoria, South Africa: YES Media. [Online]. Available: http://issuu.com/yesmedia/docs/lgh2015 (30/08/2015).

233. SA 2015b. The People Living With HIV Stigma Index: South Africa 2014. SANAC. [Online]. Available: file:///C:/Users/Juliet.Nyasulu/Downloads/Abridged%20Stigma%20Index%20Report%20(1).pdf. (19/07/2015).

234. SAMANDARI, T., AGIZEW, T. B. & NYIRENDA, S. 2011. Six-month versus 36-month isoniazid preventive treatment for tuberculosis in adults with HIV infection in Botswana: A randomised, double-blind, placebo-controlled trial. *Lancet*, 377, 1588-1598.

235. SANNE, I., ORRELL, C., FOX, M. P., CONRADIE, F., IVE, P., ZEINECKER, J., CORNELL, M., HEIBERG, C., INGRAM, C., PANCHIA, R., RASSOOL, M., GONIN, R., STEVENS, W., TRUTER, H., DEHLINGER, M., VAN DER HORST, C., MCINTYRE, J., WOOD, R. & TEAM., C.-S. S. 2010. Nurses versus doctor management of HIV-infected patients receiving antiretroviral therapy (CIPRA-SA) : A randomised non-inferiority trial. *Lancet* 376, 33-40.

236. SCANAVINO, T. & ABDO, H. 2010. Sexual dysfunctions among people living with AIDS in Brazil. *Clinical Science,* 65, 511–519.

237. SCHATZ, E., GILBERT, L. & MCDONALD, C. 2013. 'If the doctors see that they don't know how to cure the disease, they say it's AIDS': How older women in rural South Africa make sense of the HIV/AIDS epidemic. *Journal of AIDS Research,* 12, 95-104.

238. SCHNIPPEL, K., MONGWENYANA, C., LONG, L. & LARSON, B. 2013. Missing visits, missing opportunities: Losses from care during PMTCT at primary health care clinics in Johannesburg, South Africa. *International Conference on AIDS and STIs in Africa. (ICASA)* Cape Town, South Africa, 7-11 Dec 2013.

239. SCHNIPPEL, K., MONGWENYANA, C., LONG, L. & LARSON, B. A. 2015. Delays, interruptions, and losses from prevention of mother-to-child transmission of HIV services during antenatal care in Johannesburg, South Africa: A cohort analysis. *BMC Infectious Diseases,* 15, 1-6.

240. SCHOUTEN, J., JAHN, A., CHIMBWANDIRA, F., HARRIES, D. & VAN DAMME, W. 2013. Is Option B+ the best choice? *Lancet,* 381, 1272-1273.

241. SCHWARTZ, S. R., REES, H., MEHTA, S., DANIEL, W., VENTER, F., TAHA, E. & BLACK, V. 2012. High incidence of unplanned pregnancy after antiretroviral therapy initiation: Findings from a prospective cohort study in South Africa. *PLoS ONE,* 7, e36039.

242. SEEKOE, E. 2006. Reproductive health needs and the reproductive health behaviour of the young in Mangaung in the Free State province: A feasibility study. *Curationis,* 28, 20-30.

243. SELWYN, P. A., HARTEL, D. & LEWIS, V. A. E. A. 1989. A prospective study of the risk of tuberculosis among intravenous drug users with human immunodeficiency virus infection. *New England Journal of Medicine,* 320, 545-550.

244. SENDZIK, D. Retaining HIV-positive patients in care. XV International AIDS Conference, 2004 Bangkok, Thailand.

245. SENDZIK, D. 2004. Retaining HIV-positive patients in care. In: Program and abstracts of the XV International AIDS Conference (Bangkok, Thailand). July 2004. Abstract WePeE6683. [Online]. Available: https://www.aids2014.org/Default.aspx?pageId=12&abstractId=2170101. (31/03/2015)

246. SERRAINO, D., CARRIERI, P., PRADIER, C., BIDOLI, E., DORRUCCI, M. & GHETTI, E. E. A. 1999. Risk of invasive cervical cancer among women with, or at risk for, HIV infection. *International Journal of Cancer,* 82, 334-337.

247. SEVERE, P., JUSTE, M. A., AMBROISE, A., ELIACIN, L., MARCHAND, C., APOLLON, S., EDWARDS, A., BANG, H., NICOTERA, J., GODFREY, C., GULICK, R. M., JOHNSON, W. D., PAPE, J. W. & FITZGERALD, D. W. 2010. Early versus standard antiretroviral therapy for HIV-infected adults in Haiti. *New England Journal of Medicine,* 363, 257-65.

248. SHIH, C., SU, Y., LIAO, C. & LIN, J. 2009 Patterns of medical pluralism among adults: results from the 2001 National Health Interview Survey in Taiwan. *BMC Health Services Research,* 10, 191.

249. SHISANA, O., REHLE, T., SIMBA, L. C., ZUMA, K., JOOSTE, S., PILLAY-VAN WYK, V., MBELLE, N., VAN ZYL, J., PARKER, W., ZUNGU, N. P. & PEZI, S. 2009. *South African National Prevalence, Incidence, Behaviour and Communication Survey 2008: A turning tide among teenagers?* Cape Town, South Africa: HSRC Press.

250. SHISANA, O., REHLE, T., SIMBAYI, L. C., ZUMA, K., JOOSTE, S., ZUNGU, N., LABADARIOS, D. & ONOYA, D. 2014. *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012.* Cape Town, South Africa: HSRC Press.

251. SHOJANIA, K. G., MCDONALD, K. M., WACHTER, R. M. & OWENS, D. K. 2004. Closing The Quality Gap: A Critical Analysis of Quality Improvement Strategies *In:* Agency for Healthcare Research and Quality, Rockville, MD: AHRQ Publications.

252. SHONGWE, M. C. & MKHONTA, N. R. 2015. The experiences of HIV-positive mothers breastfeeding exclusively in Swaziland. *African Journal of Food Agriculture, Nutrition and Development,* 15, 9592-9606.

253. SHORTELL, S. M. & KALUZNY, A. D. 1988. *Health Care Management: A Text in Organization Theory and Behavior.,* New York: John Wiley and Sons.

254. SIAPKA, M., REMME, M., OBURE, C., MAIER, C., DEHNE, K. & VASSALLA, A. 2014. Is there scope for cost savings and efficiency gains in HIV services? A systematic review of the evidence from low- and middle-income countries. *Bull World Health Organization,* 92, 499–511.

255. SIEGFRIED, N., UTHMAN, O. A. & RUTHERFORD, G. W. 2010. Optimal time for initiation of antiretroviral therapy in asymptomatic, HIV-infected, treatment-naive adults. *Cochrane Database of Systematic Reviews* 3, CD008272.

256. SIMBAYI, L. C., KALICHMAN, S., STREBEL, A., CLOETE, A., HENDA, N. & MQEKETO, A. 2007. Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science & Medicine,* 64, 823–1831.

257. SMIT, C., GESKUS, R. & WALKER, S. 2006. Effective therapy has altered the spectrum of cause-specific mortality following HIV seroconversion. *AIDS,* 20, 741–749.

258. SMITH, L. R., AMICO, K. R., SHUPER, P. A., CHRISTIE, S., FISHER, W. A., CORNMAN, D. H., DOSHI, M., MACDONALD, S., PILLAY, S. & FISHER, J. D. 2013. Information, motivation, and behavioral skills for early preART engagement in HIV care among patients entering clinical care in KwaZuluNatal, South Africa. *AIDS Care: Psychological and Sociomedical Aspects of AIDS/HIV,* 25, 1485-1490.

259. SNYMAN, L. C. 2013. Prevention of cervical cancer – how long before we get it right? *South African Journal of Obstetrics and Gynaecology,* 19, 2-3.

260. SNYMAN, L. C., ZONDAGH, B. A., DREYER, G., LINDEQUE, B. G. & LOUW, M. 2006. Urine cytology as a screening test for bladder infiltration in cervical cancer. *International Journal of Gynecological Cancer* 16, 1587-1590.

261. SOKHELA, D. G., MAKHANYA, N. J., SIBIYA, N. M. & NOKES, K. M. 2013. Experiences of Fast Queue health care users in primary health care facilities in eThekwini district, South Africa. *Curationis,* 36, E1-8.

262. SONNENBERG, P., GLYNN, J. R., FIELDING, K., MURRAY, J., GODFREY-FAUSSETT, P. & SHEARER, S. 2005. How soon after infection with HIV does the risk of tuberculosis start to increase? A retrospective cohort study in SA gold miners. *Journal of Infectious Diseases,* 191, 150–158.

263. SSA 2012. Census 2011 Municipal Report, Gauteng, Report 03-01-52 Statistics South Africa. Available at http://www.statssa.gov.za/Census2011/Products/GP_Municipal_Report.pdf. (16/10/2014).

264. STRACHAN, B., ZABOW, T. & VAN DER SPUY, Z. M. 2011. More doctors and dentists are needed in South Africa. *South African Medical Journal,* 101, 523–528.

265. STREBEL, M., CRAWFORD, T. & SHEFER 2006. Social constructions of gender roles, gender-based violence and HIV/AIDS in two communities of the Western Cape, South Africa. *SAHARA,* 3, 516–528.

266. STRENER, D. & NORMAN, G. 2003. *Health Measurement Scales A Practical Guide to Their Development and Use.* Oxford, UK: Oxford Medical Publications.

267. SUTTON, M. Y., PATEL, R. & FRAZIER, E. L. 2014. Unplanned pregnancies among HIV-infected women in care-United States. *Journal of Acquired Immune Deficiency Syndromes,* 65, 350-358.

268. TAGAR, E., SUNDARAM, M., CONDLIFFE, K., MATATIYO, B., CHIMBWANDIRA, F., CHILIMA, B., MWANAMANGA, R., MOYO, C., CHITAH, B., NYEMAZI, J., ASSEFA, Y., PILLAY, Y., MAYER, S., SHEAR, L., DAIN, M., HURLEY, R., KUMAR, R., MCCARTHY, T., BATRA, P., GWINNELL, D., DIAMOND, S. & OVER, M. 2014. Multi-Country Analysis of Treatment Costs for HIV/AIDS (MATCH): Facility-Level ART Unit Cost Analysis in Ethiopia, Malawi, Rwanda, South Africa and Zambia. *PLoS ONE,* 9, e108304.

269. TAIS, S. & ZOBERG, E. 2013. The economic evaluation of complementary and alternative medicine: The growing importance of including naturopathic doctors in healthcare reform *Natural Madicine Journal,* 5, 3.

270. TASHAKKORI, A. & TEDDLIE, C. 1998. *Mixed Methods Combining Qualitative and Quantitative Approaches,* New Delhi, India: SAGE.

271. TASHAKKORI, A. & TEDDLIE, C. E. 2003. *Handbook on Mixed Methods in the Behavioral and Social Sciences.* Thousand Oaks, CA: SAGE.

272. TAYLER-SMITH, K., ZACHARIAHA, R., MASSAQUOIB, M., MANZIA, M., PASULANIB, O., VAN DEN AKKERB, T., BEMELMANSB, T., MWAGOMBA, B. & HARRIES, H. E. A. 2010. Unacceptable attrition among WHO stages1 and 2 patients in a hospital-based setting in rural Malawi: Can we retain such patients within the general health system? *Transactions of the Royal Society of Tropical Medicine and Hygiene* 104, 313–319.

273. TENTHANI, L., HAAS, A., TWEYA, H., JAHN, A., VAN OOSTERHOUT, J., CHIMBWANDIRA, F., CHIRWA, Z., NG'AMBI, W., BAKALI, A., PHIRI, S., MYER, L., VALERI, F., ZWAHLEN, M., WANDELER, G. & KEISER, O. 2014. Retention in care under universal antiretroviral therapy for HIV-infected pregnant and breastfeeding women ('Option B+') in Malawi. *AIDS,* 28, 589-598.

274. THOMPSON, M., ABERG, J., HOY, J., TELENTI, A., BENSON, C., CAHN, C., ERON, J., GÜNTHARD, H., HAMMER, S., REISS, P., RICHMAN, D., RIZZARDINI, G., THOMAS, D., JACOBSEN, D. & VOLBERDING, P. 2012.

Antiretroviral treatment of adult HIV infection: 2012 Recommendations of the International Antiviral Society–USA Panel. *Journal of the American Medical Association,* 2012;308, 387-402.

275. THOMSON, K. A., O., E., CHETIA, E. O. & TONY REID, T. 2011. Implementation and outcomes of an active defaulter tracing system for HIV, prevention of mother to child transmission of HIV (PMTCT), and TB patients in Kibera, Nairobi, Kenya. *Transactions of the Royal Society of Tropical Medicine and Hygiene,* 105, 320–326.

276. THORSEN, V. C., SUNDBY, J. & MARTINSON, F. 2008. Potential initiators of HIV-related stigmatization: Ethical and programmatic challenges for PMTCT programs. *Developing World Bioethics,* 8, 43-50.

277. TIFFANY, R. & JOHNSON-LUTJENS, L. 1997. *Planned Change Theories for Nursing. Review, Analysis and Implications,* Thousand Oaks, CA: SAGE.

278. TORPEY, K. E., KABASO, M. E., MUTALE, L. N., KAMANGA, M. K., MWANGO, A. J., SIMPUNGWE, J., SUZUKI, C. & MUKADI, Y. D. 2008. Adherence support workers: A way to address human resource constraints in antiretroviral treatment programs in the public health setting in Zambia. *PLoS ONE,* 3, e2204.

279. TSHUMA, N., MULOONGO, K., SETSWE, T., CHIMOYI, L., SARFO, B., BURGER, D. & NYASULU, P. S. 2014. Potential barriers to rapid testing for human immunodeficiency virus among a commuter population in Johannesburg, South Africa. *Dove Press,* 2015, 11-19.

280. UNAIDS 2001. United Nations General Assembly Special Session on HIV/AIDS. Declaration of Commitment on HIV/AIDS. Geneva, Switzerland: UNAIDS. [Online]. Available: www.unaids.org/UNGASS/docs/AIDSDeclaration_en.pdf. (10/07/2013).

281. UNAIDS 2011. Countdown to Zero: Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, (2011-2015). Geneva, Switzerland: UNAIDS [Online]. Available: www.unaids.org/.../20110609_jc2137_global-plan-elimination-hiv-children_en.pdf. (09/11/2014).

282. UNAIDS 2013. AIDS Epidemic Update. Geneva, Switzerland: UNAIDS. [Online]. Available: www.unaids.org/sites/default/.../UNAIDS_Global_Report_2013_en_1.pdf. (21/09/2015).

283. UNAIDS 2014a. 90-90-90: An ambitious treatment target to help end the AIDS epidemic. Geneva, Switzerland: UNAIDS. [Online]. Available: http://www.unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf. (29/06/2015).

284. UNAIDS 2014b. The Gap Report. Geneva: Switzerand, UNAIDS. [Online]. Available: http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf. (25/10/2015).

285. UNAIDS 2015. How AIDS changed everything- MDG 6: 15 years, 15 lessons of hope from the aids response to all to all who have worked to achieve the millennium development goals. Geneva, Switzerland: UNAIDS. [Online]. Available: www.unaids.org/sites/default/files/media_asset/MDG6Report_en.pdf. (15/08/2015).

286. UNESCO. 2004. Focusing Resources on *Effective School Health* (FRESH) Tools for Effective School Health First Edition: Characteristics of youth friendly health

services. [Online]. Available: http://toolkit.ineesite.org/toolkit/INEEcms/uploads/1040/Characteristics_Youth_Friendly_Spaces.PDF. (19/10/2014).

287. UNGE, C., SÖDERGÅRD, B. & MARRONE, G. 2010. Long-term adherence to antiretroviral treatment and program drop-out in a high-risk urban setting in sub-Saharan Africa: a prospective cohort study. *PLoS ONE*, 5, 13613.

288. UTHMAN, O. A., MAGIDSON, J. F., SAFREN, S. A. & J.B., N. 2014. Depression and adherence to antiretroviral therapy in low-, middle- and high-income countries: A systematic review and meta-analysis. *Current HIV/AIDS Reports*, 11, 291-307.

289. VENTER, F. & BARKER, M. 2013. Raising the CD4+ initiation threshold with our eyes wide open. *South African Medical Journal*, 103, 834.

290. VERMUND, S. H. 2013. Massive benefits of antiretroviral therapy in Africa. *Journa of Infectious Disease*, 209, 483-485.

291. VINTGES, M., MARINCOWITZ, G. & PERKINS, Q. Tools to start wellness programme in preparation for ART at clinic level SA AIDS Conference, Durban: South Africa, 5-8th June 2007. In Tried and Tested Models for scale up of HIV prevention. [Online]. Available: http://www.ihi.org/resources/Documents/TriedandTested_ModelsforScaleUpHIVPrevention_Book.pdf. (29/09/2014).

292. VISSER, M. J., MAKIN, J. D., VANDORMAEL, A., SIKKEMA, K. J. & FORSYTH, B. W. 2009. HIV/AIDS stigma in a South African community. *AIDS Care*, 21, 197-206.

293. WALTON, M. 1986. *The Deming Management Method.* New York: Penguin Group.

294. WALWYN, D. R. & MAITSHOTLO, B. 2010. The role of South African traditional health practitioners in the treatment of HIV/AIDS: A study of their practices and use of herbal medicines. *Southern African Journal of HIV Medicine*, 11, 2.

295. WANYAMA, J., CASTELNUOVO, B., WANDERA, B., MWEBAZE, P., KAMBUGU, A., BANGSBERG, D. R. & KAMYA, M. R. 2007. Belief in divine healing can be a barrier to antiretroviral therapy adherence in Uganda. *AIDS* 2007, 1486–1487.

296. WENJUAN, W., ALVA, S. & WANG, S. 2012. *HIV-Related Knowledge and Behaviors Among People Living with HIV in Eight High HIV Prevalence Countries in Sub-Saharan Africa. DHS Analytical Studies.* Silver Spring, MD: USAID.

297. WESTER, C., BUSSMANN, H., AVALOS, A., NDWAPI, N. & GAOLATHE, T. E. A. 2005. Establishment of a public antiretroviral treatment clinic for adults in urban Botswana: Lessons learned. *Clinical Infectious Diseases*, 40, 1041–1044.

298. WETTSTEIN, C., MUGGLIN, C., EGGER, M., BLASER, N., VIZCAYA, L. S., ESTILL J, BENDER, N., DAVIES, M., WANDELER, G. & KEISER, O. 2012. Missed opportunities to prevent mother-to-child-transmission: Systematic review and meta-analysis. *AIDS*, 26, 2361-2373.

299. WHO-GLOBCAN 2012. *Cervical Cancer: Estimated Incidence, Mortality and Prevalence Worldwide in 2012 In:* Health (ed.). Geneva, Switzeland: WHO. [Online]. Available:http://globocan.iarc.fr/old/FactSheets/cancers/cervix-new.asp (03/10/2014).

300. WHO 2002. *Scaling Up Antiretroviral Therapy in Resource-limited Settings Guidelines for Public Health Approach. In:* HIV/AIDS (ed.). Geneva, Switzerland.:

WHO. [Online]. Available: http://www.who.int/hiv/pub/prev_care/ScalingUp_E.pdf. (09/06/2013).

301. WHO 2003. *Scaling Up Antiretroviral Therapy in Resource-limited Settings: Treatment Guidelines For a Fublic Health Approach.* Geneva, Switzerland: WHO. [Online]. Available: http://www.who.int/3by5/publications/documents/arv_guidelines/en/. (09/11/2014).

302. WHO 2004. *WHO Guidelines on safety Monitoring of Herbal Medicines in Pharmacovigilance Systems.* Geneva, Switzerland: WHO.

303. WHO 2006. *From Access to Adherence: The Challenges of Antiretroviral Treatment: Studies From Botswana, Tanzania and Uganda.* Geneva, Switzerland: WHO. [Online]. Available: http://www.who.int/medicines/publications/challenges_arvtreatment15Aug2006.pdf. (03/10/2013).

304. WHO 2007. *Case Definitions of HIV for Surveillance and Revised Clinical Staging and Immunological Classification of HIV-related Disease in adults and Children.* Geneva, Switzerland: WHO. [Online]. Available: http://www.who.int/hiv/pub/guidelines/HIVstaging150307.pdf. (20/09/2013).

305. WHO 2008. *Strengthening Health Services to Fight HIV/AIDS: Essential Prevention and Care Interventions for Adults and Adolescents Living with HIV in Resource-limited Settings*. Geneva, Switzerland: WHO. [Online]. Available: http://www.who.int/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf. (27/11/2013).

306. WHO 2009. *Adolescent-Friendly Clinic Initiative in South Africa, (Analytic Case Studies): Initiatives to Increase the use of Health Services by Adolescents).* Geneva, Switzerland: WHO. [Online]. Available: http://whqlibdoc.who.int/publications/2009/9789241598361_eng.pdf. (18/10/2014).

307. WHO 2010. *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants. Recommendations for a public health approach 2010 In:* HIV/AIDS (ed.). Geneva, Switzerland: WHO. [Online]. Available: www.avert.org/pmtct-guidelines.htmwww.avert.org/pmtct-guidelines.htm. (23/02/2014).

308. WHO 2012. *Service Delivery Approaches to HIV Testing and Counselling (HTC): A Strategic HTC Programme Framework.* Geneva, Switzerland: WHO. [Online]. Available: http://apps.who.int/iris/bitstream/10665/75206/1/9789241593877_eng.pdf. (24/05/2015).

309. WHO 2013a. *Consolidated Guidelines on the use of Antiretroviral Drugs for Treating and Preventing HIV Infection Recommendations for a Public Health Approach.* Geneva Switzerland WHO Press. [Online]. Available: www.who.int/iris/bitstream/10665/85321/1/9789241505727_eng.pdf. (18/12/2014).

310. WHO 2013b. *Global update on HIV Treatment 2013: Results, Impact and Opportunities.* Geneva Switzerland WHO Press in partnership with UNICEF and UNAIDS. [Online]. Available: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2013/20130630_treatment_report_en.pdf. (22/01/2015).

311. WHO 2013c. *WHO Traditional Medicine Strategy 2014-2023. Geneva: World Health Organization.* Geneva Switzerland WHO Press. [Online]. Available: http://apps.who.int/iris/bitstream/10665/92455/1/9789241506090_eng.pdf.

312. WHO. 2015. *Referral Systems - A Summary of Key Processes to Guide Health Services Managers.* Geneva Switzerland WHO. [Online]. Available: www.who.int/management/Referralnotes.doc. (19/05/2015).

313. WHO/ICO 2014. *Human Papillomavirus and Related Cancers.* Geneva Switzerland WHO. [Online]. Available: http://apps.who.int/hpvcentre/statistics/dynamic/ico/country_pdf. (15/07/2015).

314. WHO/UNAIDS 1998. *Policy Statement on Preventive Therapy Against Tuberculosis in People Living with HIV.* Geneva, Switzerland: WHO in pattnership with UNAIDS. [Online]. Available: http://apps.who.int/iris/bitstream/10665/64509/1/WHO_TB_98.255.pdf. (02/05/2013)

315. WHO/UNICEF 2007. *Guidance on Global Scale-Up of The Prevention of Mother-To-Child Transmission of HIV: Towards Universal Access for Women, Infants and Young Children and Eliminating HIV and AIDS among Children.* Geneva, Switzerland: WHO. [Online]. Available: http://www.unicef.org/aids/files/PMTCT_enWEBNov26.pdf. (27/11/2013).

316. WHYTE, S., WHYTE, M. & KYADDONDO, D. 2010. *Health Workers Entangled: Confidentiality and Certification,* New York: Berghahn Books.

317. WHYTE, S., WHYTE, M., MEINERT, L. & TWABAZE, J. 2013. Therapeutic clientship. Belonging in Ugandan's Projectified lanscape of AIDS care. *In When People Come First: Critical Studies in Global Health.* Princeton, NJ: Princeton University Press.

318. WILHELM-SOLOMON, M. 2013. The Priest's Soldiers: HIV therapies, health identities, and forced encampment in Northern Uganda. *Medical Anthropology: Cross-Cultural Studies in Health and Illness,* 32, 227-246.

319. WILKINSON, D., SQUIRE, S. B. & GARNER, P. 1998. Effect of preventive treatment for tuberculosis in adults infected with HIV: Systematic review of randomised placebo controlled trials. *British Medical Journal,* 317, 625–629.

320. WILLIAMS, TALJAARD, B., CAMPBELL, D., MC GOUWS, C., NDHLOVU, E., VAN DAM, J., MICHELF, C. & A., B. 2003. Changing patterns of knowledge, reported behaviour and sexually transmitted infections in a South African gold mining community *AIDS,* 17, 2099-2107.

321. WILLIAMS, C. 2007. Research methods. *Journal of Business & Economic Research* 5, 65-72.

322. WORLEY, S., DIDIZA, Z., NOMATSHILA, S., PORTER, S., MAKWEDINI, N., MACHARIA, D. & HOOS, D. 2009. Wellness programmes for persons living with HIV/AIDS: Experiences from Eastern Cape province. *South Africa Global Public Health,* 4, 367 – 385.

323. WREFORD, J. & ESSER, M. 2008. Including traditional african healers in hiv programmes: Preliminary experience from the Western Cape. *South African Journal of HIV Medicine* 9, 18-20, 22.

324. WRHI 2014. Minister of Health announces expansion of HIV treatment plan. Johannesburg, South Africa: WRHI. [Online]. Available: http://www.wrhi.ac.za/Documents/newsletterfnl00104.pdf. (24/05/2015).

325. WRINGE, A., ROURA, M., URASSA, M., BUSZA, J., ATHANAS, V. & ZABA, B. 2009. Doubts, denial and divine intervention: Understanding delayed attendance and poor retention rates at a HIV treatment programme in rural Tanzania. *AIDS Care,* 21, 632-7.

326. WYNBERG, E., COOKE, G., SHROUFI, A., REID, S. & FORD, N. 2014. Impact of point-of-care CD4 testing on linkage to HIV care: a systematic review. *Journal of International AIDS Society,* 17**,** 18809.

327. ZACHARIAH, TAYLOR SMITH, K., MANZI, M., VAN GREINSVEN, J., VANDRBULKE, A. & HARRIES, A. D. 2010. High loss-to-follow-up rate among individuals in urgent need of antiretroviral treatment in Malawi and Kenya – Cohort reporting that does not include this group is biased and misleading. *Eighteenth International AIDS Conference , abstract MOAE0301, 2010.* Vienna. [Online]. Available: http://www.aids2010.org/WebContent/File/AIDS2010_Abstracts_Vol_1_Monday_19July_web.pdf. (11/03/2013).

328. ZACHARIAH, TECK, R., BUHENDWA, L., LABANA, S. & CHINJI, C. 2007. Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 101, 79-84.

329. ZUMA, J. 2014. Address by President Zuma at the launch of Operation Phakisa 2: Ideal Clinic Realisation and Maintenance, Sefako Makgatho Presidential Guest House, Pretoria, South Africa. Available at http://www.thepresidency.gov.za/pebble.asp?relid=18448. (26/06/2015).

330. ZUMA., P. J. 2009. Address on the occasion of World AIDS Day, Pretoria Showgrounds. [Online]. Available: http://www.dfa.gov.za/docs/speeches/2009/jzum1202.html (09/11/2012).

8.0: Appendices

8.1 Pre-ART services checklist

Pre-ART services received	**Patients' Name**																	
	Patients' facility visits																	
		1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**
Counselling																		
TB Screening																		
Family Planning																		
CA screening																		
CD4 cell count																		
Multivitamin																		
Support group																		
Social grant																		

8.2 Research ethics approval certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mrs Juliet Nyasulu

CLEARANCE CERTIFICATE	M110970
PROJECT	Appropriate Pre-ART Wellness Programme Package: The Effect of an Appropriate Wellness Programme in a PHC Facility on the Retention of HIV Positive Pre-ART Individuals in Johannesburg
INVESTIGATORS	Mrs Juliet Nyasulu
DEPARTMENT	Wits Reproductive Health Institute (WRHI)
DATE CONSIDERED	30/09/2011
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 16/01/2012 **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof Sharon Fonn et al

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

8.3 The University of the Witwatersrand research title approval letter

Faculty of Health Sciences

Medical School, 7 York Road, Parktown, 2193 Fax: (011) 717-2119

Tel: (011)717-2745

Reference: Ms Mathoto Senamela

E-mail: mathoto.senamela@wits.ac.za 17 January 2013 Person No: 537853 PAG

Mrs J Nyasulu

133 Mulberry Lane

Leslie Avenue

Bryanston Sandton 2196 South Africa

Dear Mrs Nyasulu

Doctor of Philosophy: Approval of Title

We have pleasure in advising that your proposal entitled "*Pre-ART program service Delivery at a PHC facility level: Access and retention of patients in care in the City of Johannesburg, South Africa."* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely



Mrs Sandra Benn Faculty Registrar Faculty of Health Sciences

8.4 City of Johannesburg research approval letter

Joburg
a world class African city

ENQUIRIES: C Fraser
Tel: +27(0) 11 407 7437
Tel: +27(0) 11 407 6840

4th Floor B Block
Metropolitan Centre
158 Loveday Street
Braamfontein

PO Box 31244
Braamfontein
SouthAfrica
2017

Tel +27(0) 11 407 7513
Fax +27(0) 11 339 2866

15 June 2012

Dear Ms. Nyasulu

APPROVAL TO CONDUCT RESEARCH WITHIN HEALTH IN THE CITY OF JOHANNESBURG

Permission has been granted to you to conduct research in the Health Department within the City of Johannesburg.

Topic: The Effect of an appropriate Wellness Programme In a PHC facility on the Retention of HIV+ Pre-ART Individuals in Johannesburg.

Please contact the following person(s) before you commence with your project and to gain access to the clinics:

Region	Regional Health Manager	Contact No.	Cell phone
F	Mr Oupa Montsioa	011 681 8130	082467 9423

Should you have any queries please do not hesitate to contact our department.

We look forward to your Final Research Report.

Thank you

DR. R. BISMILLA
Executive Director
City of Johannesburg
Health and Social Development

8.5: Data collection tools

8.5.1: Consent forms

8.5.1.1 Patient Interview consent forms

Information Sheet and Informed Consent – Patient

1. Introduction

Hello, my name is _____. I am a researcher at the Wits Reproductive Health Institute (WRHI) of the University of the Witwatersrand. We would like to ask you to participate in a research study, entitled "The effect of an appropriate wellness program in a PHC facility on the retention of HIV+ pre-ART individuals in the city of Johannesburg."

This consent form will give you information to help you decide whether you would like to participate by answering a questionnaire on client satisfaction.

1. Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, and risks, and your right to withdraw from the study at any time.

   This information leaflet is to help you to decide if you would like to give your permission to participate. You should fully understand what is involved before you decide to take part in this study.

2. If you have any questions, do not hesitate to ask me.

3. You should not agree to take part unless you are satisfied about all the procedures involved.

4. If you decide to take part in this study, you will be asked to sign this document to confirm that you understand the study. You will be given a copy to keep.

2. Purpose of the study

We have been commissioned by Wits reproductive Health Institute (WRHI) senior management and DASH program managers to conduct a baseline assessment now and a project evaluation at least a year later on the wellness programs in the PHC facilities. The evaluation has been endorsed by managers from the CoJ and the Gauteng DOH. The baseline assessment will assist in identifying gaps in how the pre-ART program services are delivered at PHC level. The identified gaps from the assessments will be used to inform future program decision and to improve the quality of the program.

3. Why we would like to interview you

Your experience in accessing services at this PHC which is one of the sites offering pre-ART care services is integral to us understanding the strengths and challenges facing this program. The purpose of the interview with you is to obtain a general impression regarding service delivery around the Pre-ART or wellness program and your views around access and quality of care being provided to you as a client.

4. Length of the study and participants

The study is being performed in selected City of Johannesburg Primary Health Facilities. The study is running from July 2012 to July 2014. We will interview patients accessing pre-ART care and their health service providers in selected facilities in the city of Johannesburg.

5. Procedures

One research team member will interview you and take notes using a semi-structured questionnaire. The interview will take approximately 45 minutes. All findings of the study will be anonymous i.e. you will not be identified. Your views along with clients interviewed will be collated and analysed, however as mentioned, we stress confidentiality and anonymity of the information you provide.

6. Will any of the study procedures result in any inconvenience?

During the interview, we will ask you questions about your experience in accessing and using certain services at this clinic. You do not have to answer any of the questions if you do not feel comfortable doing so. We will maintain confidentiality of your responses, only the researchers will have access to any identifying information. We assure you that information you may share with us will remain confidential and anonymous i.e. none of the information will be shared with the health care workers, therefore you will not be victimized in any way. There are no risks to this research as it does not involve using any drugs or taking blood tests. There are also no discomforts. However you may be referred to facility based counsellors for counselling, care, support and further referral when necessary.

7. Benefits

There are no direct benefits to participating in the interview. However, your answer will help program managers to understand the issues around implementing the pre-ART program. The answers you provide may help to improve the quality pre-ART or wellness program in the future.

8. Rights as a participant in the study

Your decision to participate in this study is completely free and you can decline to be part of the study at any time, without stating any reason. Your decision to participate in this study will not affect your relationship to the WRHI or other partner organisations in any way.

9. Financial arrangements

There is no cost to you for being in the study. There is no cost to you for taking part in the interview. WRHI will cover all costs related to implementation of the study.

10. Reimbursement for study participation

You will not be paid if you decide to participate in this study.

11. Ethical approval

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee.

12. Confidentiality

All information obtained during the course of this study, including hospital records, personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.

The information might be inspected by the University of the Witwatersrand, Human Research Ethics Committee (HREC), these records will be utilised by them only in connection with carrying out their obligations relating to this study.

13. For More Information

The 24-hour telephone number through which you can reach Juliet Nyasulu or other authorized persons is: 0739735487

If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact the Chairperson of the University of the Witwatersrand, Human Research Ethics Committee (HREC), which is an independent committee established to help protect the rights of research participants at (011) 717 2301.

Should you have any questions concerning this study, please contact us:

Juliet Nyasulu Tel: 0739735487 Email: jnyasulu@wrhi.ac.za

Dr Vivian Black Tel 0113585500 Email vblack@wrhi.ac.za

Our supervisor is Professor Eugene Sickle and he is contactable on:

Tel: +27 11 358 5500 Email: sickle@wrhi.ac.za

WRITTEN PARTICIPANT INFORMED CONSENT – PI

The effect of an appropriate wellness program in a PHC facility on the retention of HIV+ pre-ART individuals in the city of Johannesburg.

I hereby confirm that I have been informed by _____ about what my involvement in this in-depth interview would entail. I have also received, read and understood the above written information regarding the study. I am aware that the results of the study will be anonymously processed into a study report. In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by _____ or on their behalf.

I may, at any stage, without prejudice, withdraw my consent and participation the interview. I am not required to give a reason for withdrawal, and leaving the study will not affect my future relationships with WRHI or partner organisations. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate.

If you want a copy of this signed consent form we will provide it for you.

1. I confirm that I have read and understood the information sheet for the above study and have had opportunity to ask questions. yes /No
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving reasons. yes /No
3. I agree to take part in the study. yes /No
4. I agree to access to my clinical records by the study team yes/No
5. I agree to the interview being audio recorded. yes /No

PARTICIPANT:

I have read this consent form (or had it read and explained to me), and all of my questions have been answered to my satisfaction. My signature below confirms that I agree to take part in the study.

Printed Name Signature Date and Time

INTERVIEWER:

I, _____, herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Printed Name Signature Date and Time

VERBAL PARTICIPANT INFORMED CONSENT

(Applicable only when participants cannot read or write)

An appropriate pre-ART program at a PHC facility level that would promote retention, access to services and timely referral for Antiretroviral Treatment (ART) initiation of HIV+ pre-ART individuals in the city of Johannesburg, South Africa

- I, the undersigned, interviewer. …….....have read and have explained fully to the participant, named .....……. the participant information leaflet.

- The account I have given has explained both the possible risks and benefits of the study. The participant understands these.

- The participant indicated that he/she understands that the participant will be free to withdraw from the study at any time for any reason and without jeopardising his/her subsequent treatment.

I hereby certify that, the participant:

1. Has confirmed that he/she has understood the information sheet for the above study and has had opportunity to ask questions. yes /No
2. Has understood that his/her participation is voluntary and that he/she is free to withdraw at any time without giving reasons. yes /No
3. He/she agrees to take part in study. yes /No
4. He/she agrees to access to his/her clinical records by the study team yes/No
5. He/she agrees to the interview being audio recorded. yes /No

PARTICIPANT:

Printed Name Mark or Thumbprint (if applicable) Date and Time

Interviewer/Fieldworker:

Printed Name Signature Date and Time

8.5.1.2: Staff interview consent form

Information Sheet and Informed Consent – Service provider

Introduction

Hello, my name is _____, a researcher at the Wits Reproductive Health Institute of the University of the Witwatersrand. We would like to invite you to consider participating in a research study, entitled; "An appropriate pre-ART program at a PHC facility level that would promote retention, access to services and timely referral for Antiretroviral Treatment (ART) initiation of HIV+ pre-ART individuals in the city of Johannesburg, South Africa."

This consent form will give you information to help you decide whether you would like to participate in the interviews as part of the study.

Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, and risks, and your right to withdraw from the study at any time. This information leaflet is to help you to decide if you would like to give your permission to participate. You should fully understand what is involved before you decide to take part in this study.

- If you have any questions, do not hesitate to ask me.
- You should not agree to take part unless you are satisfied about all the procedures involved.
- If you decide to take part in this study, you will be asked to sign this document to confirm that you understand the study. You will be given a copy to keep.

Purpose of the study

We have been commissioned by Wits Institute to conduct a baseline assessment and then a project evaluation of the project in the city of Johannesburg. The baseline assessment and the project evaluation have been endorsed by managers from the CoJ and the Gauteng DOH. The research will establish how an appropriate wellness program should be delivered in a PHC facility whilst ensuring retention of HIV+ pre-ART individuals.

Why we would like to interview you

You are one of the core staff responsible for implementing the pre-ART program. Your experience in managing the delivery of these services, and with the strengths and challenges of the program, will give us an understanding of how the wellness program is working on the ground.

Length of the study and number of participants

The study is being performed in selected City of Johannesburg Primary Health Facilities. The study is running from July 2012 to July 2014.

Procedures

One of the research team members will interview you and take notes using a semi-structured questionnaire. The interview will take approximately 45 minutes. Your responses will be audio-recorded. We may also ask your assistance in gathering information on aspects such as staffing, drug supplies and facility statistics. The interview will take about one hour or so to complete. All the findings of the study will be anonymous. Your views will be combined with those of other health workers your name will not feature in the report.

Will any of the study procedures result in any inconvenience?

During the interview, we will ask you questions about your work and about your opinion on certain services in the clinic. You do not have to answer any of the questions if you do not feel comfortable doing so. We will maintain confidentiality of your responses, only the researchers will have access to any identifying information.

Benefits

There are no direct benefits to participating in the interview. However, your answer will help program to understand the issues around implementing the program. The answers you provide may help to develop an appropriate wellness program which will improve retention of patients in the wellness program quality of ART services in general.

Rights as a participant in the study

Your decision to participate in this study is completely free and you can decline to be part of the study at any time, without stating any reason. Your decision participate in this study will not affect your relationship to the WRHI or other partner organisations in any way.

Financial arrangements

There is no cost to you for being in the study. There is no cost to you for taking part in interviews. WRHI will incur all the costs related to conducting the interviews.

Reimbursement for study participation

You will not be paid if you decide to participate in this study.

Ethical approval

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee.

Confidentiality

All information obtained during the course of this study, including hospital records, personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies neither your facility nor yourself as a participant in this study.

The information might be inspected by the University of the Witwatersrand, Human Research Ethics Committee (HREC), these records will be utilised by them only in connection with carrying out their obligations relating to this clinical study.

For More Information

The 24-hour telephone number through which you can reach Juliet Nyasulu or another authorized person, is 0739735487

If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact the Chairperson of the University of the Witwatersrand, Human Research Ethics Committee (HREC), which is an independent committee established to help protect the rights of research participants at (011) 717 2301.

Should you have any questions concerning this study, please contact us:

Juliet Nyasulu Tel: 0739735487 Email: jnyasulu@wrhi.ac.za

Dr Vivian Black Tel 0113585500 Email vblack@wrhi.ac.za

Professor Eugene Sickle Tel: +27 11 358 5500 Email: sickle@wrhi.ac.za

WRITTEN PARTICIPANT INFORMED CONSENT:

The effect of an appropriate wellness program in a PHC facility on the retention of HIV+ pre-ART individuals in Johannesburg.

I hereby confirm that I have been informed by _____ about what my involvement in this interview would entail. I have also received, read and understood the above written information regarding the study. I understand that what I say will be audio-recorded. I am aware that the results of the study will be anonymously processed into a study report. In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by _____ or on their behalf.

I may, at any stage, without prejudice, withdraw my consent and participation the interview. I am not required to give a reason for withdrawal, and leaving the study will not affect my future relationships with WRHI or partner organisations. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate.

PARTICIPANT:

If you want a copy of this signed consent form we will provide it for you.

6. I confirm that I have read and understood the information sheet for the above study and have had opportunity to ask questions. yes /No
7. I understand that my participant is voluntary and that I am free to withdraw at any time without giving reasons. yes /No
8. I agree to take part in study. yes /No
9. I agree to the interview being audio recorded. yes /No

Printed Name **Signature** **Date and Time**

INTERVIEWER:

I, _____, herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Printed Name **Signature** **Date**

8.5.2: Patient interview questionnaire

Participant No:

Interview Form for Patients

1. Interview details

1.1 Interview schedule No: _____

1.2 Interviewer: _____

1.3 Date of interview: _____

1.4 Facility code: _____

1.5 Data capturing: Date_____ By_____

2. Demographic Information

2.1 Age: _____ 2.2 Gender: Male_____ Female_____

2.3	Please state your level of education?	1. Never went to School 2. STD 1-5 3. Secondary school 4. Tertiary	
2.4	What is your marital status	1. Married or living with a partner 2. Single 3. Divorced 4. Windowed 5. Others specify	
2.5	What is your occupation	1. Teacher 2. Nurse 3. Casual Labourer 4. Not employed 5. Others specify	

3.0 Access to care

3.1 Why did you come for this service? I was referred from another service _____

I decided to come on my own? _____

3.2 Regarding the services, can you describe to me the pathway in which you accessed care i.e from HIV pre-test counselling to initiation date?

[Prompt: guide me to draw the pathway of your care through the system from your first encounter at the facility to date]

4.0 Basic HIV knowledge

4.1. The following statement focus on knowledge of HIV/AIDS. After each statement, please tell me whether it is true or false [Interviewer, only 1 answer is applicable for each question]

[Mark with an X where appropriate]

Statements	True	False
4.2.3 HIV is the same as AIDS		

4.2 The following statements focus on the perceptions and behaviour surrounding HIV/AIDS. After each statement, please tell me whether it is true or false [Interviewer, only 1 answer is applicable for each question]

[Mark with an X where appropriate]

Statements	True	False
4.2.1 If you have HIV you cannot get married		
4.2.2 If you have HIV you cannot have an HIV- baby		
4.2.3 If both partners have HIV then there is no need to use condoms		
4.2.5 I have told my parents that I have HIV		
4.2.6 I have told my family that I have HIV		
4.2.7 I have told friends that I have HIV		
4.2.8 I have told have told my partner that I have HIV		

4.3 In your own words, what does it mean to YOU PERSONALLY if an individual has HIV? _____

4.4 In your own words, what does it mean if an individual has AIDS?

_____

5. CD4 Count Knowledge and Reasons for Return

5.1 Do you know what a CD4 count is? 1=Yes____ 2=No_____

[Interviewer if the answer is no, explain the answer to the patient and Skip to 5.4]

[Interviewer continue to 5.2 below if the answer is Yes]

5.2 In your own words what is a CD4 count and what does it tell you?

_____
_____

5.3 If you do know what a CD4 count is, how did you learn about it?

(Counselling, educational material other)

[Skip if participant doesn't know]

_____
_____

5.4 What do you think happens if your CD4 count is above 350? _____

[Interviewer, mark an X where appropriate and fill in code above as well]:

Don't know	1
Start ARVs or medication for HIV	2
You are sick	3
You are not sick – no need for ARVs	4
Others	5

5.5 What happens if your CD4 count is less than 350? _____

[Interviewer, mark an X where appropriate and fill in code above as well]:

Don't know	1

Start ARVs or medication for HIV	2
You are sick	3
You are not sick	4
Other	5

6. ARV Knowledge

6.1 Do you know what antiretroviral therapy (also known as ART/ARVs) is?

1=Yes _____ 2=No _____ 0 =Don't know_____

[[Interviewer if the answer is no, explain the answer to the patient and Skip to 7)

[Interviewer continue to 6.2 below if answer is Yes]

6.2) If you had to start ARVs do you know where you would start treatment? [Name of clinic]

_____

6.3) If you know where you would start ARVs, how did you find out this information?

_____

6.4). the following questions focus on knowledge and perceptions of ART. Please tell me if you think the following statements are true, false or don't know, so that we can understand your knowledge and perceptions of ART.

Statements	True=1	False=2	Don't know=3
6.4.1 ARVs will cure me of HIV			
6.4.2 I can stop the ARV drugs once I am feeling better			

6.5) For how long do you have to take ARVs once you start taking them?

3-6 months	

6-12 months	
1-3 years	
3-5 years	
5-10 years	
>10 years	
forever	

Pre-ART care or wellness services

7 What services are lendered to individuals who are not yet eligible to start ART (CD4 count >350) in this facility.

	Components	Tick if the respondent mentions the service
1	Voluntary counselling and testing, (HCT)	
2	Disclosure and prevention, ongoing counselling,	
3	health literacy and peer education,-	
4	PLWHA support groups	
5	TB IPT – client education, screening and administration of IPT	
6	TB IPT – client screening of IPT	
7	TB IPT – client administration of IPT	
8	Social grant acquisition support	
9	Nutrition – (food parcels and infant feeds)	
10	Multivitamin supplements	
11	adherence support,	
12	Voluntary counselling and testing, (HCT)	

7 Which of the following wellness programs have you accessed at this facility?

	Wellness program components	YES/NO
1	Voluntary counselling and testing, (HCT)	
2	Disclosure and prevention, ongoing counselling,	
3	health literacy and peer education,-	
4	PLWHA support groups	
5	TB IPT – client education, screening and administration of IPT	
6	TB IPT – client screening of IPT	
7	TB IPT – client administration of IPT	
8	Social grant acquisition support	
9	Nutrition – (food parcels and infant feeds)	
10	Multivitamin supplements	
11	adherence support,	
12	Voluntary counselling and testing, (HCT)	

8 What exact service was offered to you in relation to the services below?

	Components	Description of exact services
1	Voluntary counselling and testing, (HCT)	
2	Disclosure and prevention, ongoing counselling,	
3	health literacy and peer education,-	
4	PLWHA support groups	
5	TB IPT – client education, screening and IPT administration	
6	TB IPT – client screening of IPT	
7	TB IPT – client administration of IPT	
8	Social grant acquisition support	
9	Nutrition – (food parcels and infant feeds)	
10	Multivitamin supplements	

11	adherence support,	
12	Voluntary counselling and testing, (HCT)	

10 What do you think should be done to improve the services below?

	Components	Description on what to be done
1	Voluntary counselling and testing, (HCT)	
2	Disclosure and prevention, ongoing counselling,	
3	health literacy and peer education,-	
4	PLWHA support groups	
5	TB IPT – client education, screening and IPT administration	
6	TB IPT – client screening of IPT	
7	TB IPT – client administration of IPT	
8	Social grant acquisition support	
9	Nutrition – (food parcels and infant feeds)	
10	community- and home-based care,	
11	adherence support,	
12	Voluntary counselling and testing, (HCT)	
13	Disclosure and prevention, ongoing counselling,	

11 Have you been educated on the following areas?

	Area	Content
1	Appropriate methods for family planning for spouse and yourself	
2	What happens in case you become pregnant	
3	Counselling and appropriate referral for TOP	

4	Counselling and information for violence abuse where required	
5	Information on pap smear how often do you need to have it? (if male skip the question)	
6	Whether spouse tested for HIV	

12.0 Men/Youth Friendly Health Services (YFHS)

12.1 Do you think your facility provides YFHS?

12.2 What do you think must be done to ensure that your facility provides YFHS?

12.3 In your own understanding does your facility provides men friendly health services?

12.4 Do you think your facility provides men friendly health services?

2.5 What do you think must be done to ensure that your facility provides men friendly health services?

---

13 Regarding all the services accessed by you at this facility, what are the gaps or problems you have personally observed in delivering HIV related service?

_____
_____

14. From your own opinion how do you think these problems can be solved

_____
_____
_____

Do you have any questions you would like to ask me?

[END OF INTERVIEW]

Thank you very much for your time and participation!

Interview stop time: _____

INTERVIEWER NOTES AND COMMENTS:

8.5.3 Staff interview questionnaire

Serv provider No:

Interview Form for Service Provider

1. Interview details

1.1 Interview schedule No: _____

1.2 Interviewer: _____

1.3 Date of interview: _____

1.4 Staff category: _____

1.5 Facility code: _____

1.6 Data capturing: Date_____ By_____

2. Demographic Information

Age: _____

Gender: Male_____ Female_____

2.0 Description of the clinic profile

2.1 Clinic profile and staffing

Can you tell me what staff you have available in this clinic and their involvement in wellness program? (Applicable if facility manager)

Category	Female	Male	Youths	Involvement in Wellness program	Partner/CoJ staff
Doctors					
Professional nurses					
Doctors					
Professional nurses					
Enrolled nurses					
Enrolled nurse assistant					
Health promoters					

Dietician					
Social worker					
Psychologist/ Counsellor					
Clerical staff					
Others					
Others					

2.2 Please describe to me how the staffs are allocated to activities in this clinic? Highlight those involved in wellness program

Probe overlapping functions; rotations

2.3 Can you tell me if each of these services is available? (Fill in second column)

Which of the following wellness program components are offered at your facility?

Wellness program components	YES/NO
Voluntary counselling and testing, (HCT)	
Disclosure and prevention, ongoing counselling,	
health literacy and peer education,-	
PLWHA support groups	
TB IPT – client education, screening and administration of IPT	
TB IPT – client screening of IPT	
Nutrition – (food parcels and infant feeds)	
TB IPT – client administration of IPT	
Social grant acquisition support	
community- and home-based care,	
adherence support,	
Voluntary counselling and testing, (HCT)	
Disclosure and prevention, ongoing counselling,	

Do you think you have enough staff to deliver HIV related services? If not why

---

3.0 Access to care

Regarding ART services, can you describe to me the pathway in which patients access care i.e from HIV pre-test counselling to initiation on ART?

[Prompt: guide me to draw the pathway of your care through the system from your first encounter at the facility to date]

4.0 Basic HIV knowledge

4.1 The following statements focus on knowledge of HIV/AIDS. For the following statements please tell me if you strongly agree, disagree, strongly disagree, or do not know [Interviewer, only 1 answer is applicable for each question]

[Mark with an X where appropriate]

Statements	Strongly agree=1	Agree=2	Disagree=3	Strongly Disagree= 4	Don't know=5
4.1.1 HIV is the virus that causes AIDS					
4.1.2 If you have HIV you are going to die sooner					

4.1.3 If you have HIV it means you also have AIDS					
4.1.4 Tests for HIV are not always correct					

4.2 The following statements focus on the perceptions and behaviour surrounding HIV/AIDS. After each statement, please tell me whether you strongly agree, agree, disagree, strongly disagree or don't know

[Interviewer, only 1 answer is applicable for each question]

[Mark with an X where appropriate]

Statements	Strongly agree=1	Agree=2	Disagree=3	Strongly Disagree=4	Don't know=5
4.2.1 If you have HIV you cannot get married					
4.2.2 If you have HIV you cannot have an HIV- baby					
4.2.3 If both partners have HIV then there is no need to use condoms					
4.2.4 If one partner is positive and the other negative the couple cannot have a baby?					
4.2.5 HIV+ patients must encourage their partners to test for HIV					

4.5 In your own words, what does it mean to YOU PERSONALLY if an individual has HIV? _____

4.6 In your own words, what does it mean if an individual has AIDS?

_____

5. CD4 Count Knowledge and Reasons for Return

5.1 Do you know what a CD4 count is? 1=Yes____ 2=No_____

[Interviewer Skip to 5.4 if answer is No]

[Interviewer continue to 5.2 below if the answer is Yes]

5.2 In your own words what is a CD4 count and what does it tell you?

_____
_____

5.3 If you do know what a CD4 count is, how did you learn about it?

(Counselling, educational material other)

[Skip if participant doesn't know]

_____
_____

5.4 What do you think happens when an HIV+ individuals' CD4 count is 350? _____

[Interviewer, mark an X where appropriate and fill in code above as well]:

Don't know	1
Start ARVs or medication for HIV	2
You are sick	3
You are not sick	4
Other	5

6 Which of the following wellness program do you have at this facility and which one do you have knowledge and skills to provide? (Fill in the table below)

	Wellness program components	Availability (Y/N)	Skills & knowledge (S&K)

1	Voluntary counselling and testing, (HCT)		
2	Disclosure and prevention, ongoing counselling,		
3	health literacy and peer education,-		
4	PLWHA support groups		
5	TB IPT – client education, screening & administration of IPT		
6	TB IPT – client screening of IPT		
7	TB IPT – client administration of IPT		
8	Social grant acquisition support		
9	Nutrition – (food parcels and infant feeds)		
10	community- and home-based care,		
11	adherence support,		
12	Voluntary counselling and testing, (HCT)		
13	Disclosure and prevention, ongoing counselling,		

7 What are the challenges for this facility in delivering the services below?

	Components	**Challenges**	**Possible solutions**
1	Voluntary counselling and testing, (HCT)		

	Components	**Challenges**	**Possible solutions**
2	Disclosure and prevention, ongoing counselling,		
3	Contraception for HIV+ women		
4	Cervical cancer screening for HIV+ women		
5	health literacy and peer education,-		
6	PLWHA support groups		
7	TB IPT – client education, screening and administration of IPT		
11	Social grant acquisition support		
12	Community- and home-based care,		
13	Adherence support,		
14	Voluntary counselling and testing, (HCT)		
15	Disclosure and prevention, ongoing counselling,		

8 What advice do you give to an HIV+ female patient of the reproductive age group?

	Area	Content
1	Appropriate methods for family planning for spouse and yourself	
2	What happens in case female HIV patient becomes pregnant	
3	Counselling and appropriate referral for TOP	

	Area	Content
4	Counselling and information for violence abuse where required	
5	Information on pap smear how often do you need to have it? (if male skip the question)	
6	Whether spouse tested for HIV	

9 What are the possible solutions to improving the services in the table above? (Fill in the table above)

10 Referral systems

10.1Where do you refer complicated patients who need additional Wellness program care (*if not provided on site*)?

Name of facility

If you refer Pre-ART cases, do you (*read out each question*):

Know the name of the person in charge of the Pre- ART service where you refer patients?	Y	N
Ever discuss the management of individual patients with staff in the Pre-ART service?	Y	N
Receive information back from the ART service on your patients you referred?	Y	N
Provide transport for patients to get to the Pre-ART service?	Y	N

Comments on referral system

10.2 Do you have any challenges with the up-referral system?

11.0 Men/Youth Friendly Health Services (YFHS)

11.1 In your own understanding what does Youth Friendly Health Services (YFHS) mean? (If cannot define then define the YFHS to the participant)

11.2 Do you think your facility provides YFHS?

11.3 What do you think must be done to ensure that your facility provides YFHS

11.4 In your own understanding what does Male friendly health Services mean? (If cannot define then provide the meaning to the participant)

11.5 Do you think your facility provides men friendly health services?

11.6 What do you think must be done to ensure that your facility provides men friendly health services?

12 Regarding all the services accessed by patients at this facility, what are the gaps or problems you have personally observed in delivering HIV related service?

_____
_____
_____

13 From your own opinion how do you think these problems can be solved?

_____
_____
_____

14 Information Systems

14.1 I'd like to know now about the collection of statistics in this clinic. Can you describe to me how the system of collecting statistics in this clinic works?

[Prompt: the RDQA will verify this, but it would be useful to know the human element face behind this activity] Write verbatim response

---

What is your role in collection or generation of monthly, quarterly and annual statistics for this facility? Write verbatim response

---

5.2 Do you know, more-or-less, the following statistics for your clinic?

[Prompt: review if facility manager and other staff members know the approximate # of patients entering the HIV care cascade]

# of HIV tests conducted?	
# HIV +	
# get CD4 count	
# CD4> 200	
# CD4 <200	
# suspected TB cases in the last month?	
# HIV + clients screened for TB?	
# HIV +v clients registered on pre-ART care	
# HIV + clients initiating on ART	
# clients initiated on IPT	

Write verbatim response

According to your observation or experiences what have been the differences in rolling out and or implementation of NIMART and pre-ART? Write verbatim response;

Do you have any questions you would like to ask me? **[END OF INTERVIEW]**

Thank you very much for your time and participation!

Interview stop time: _____ INTERVIEWER NOTES AND COMMENTS:

8.5.4: Pre-ART register audit tool

Pre-ART Register tool

Data variables	**Patient numbers**													
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**
Date of file was open														
Patient name														
Phone No														
Age														
Gender														
Youth or not														
TB screening														
CD41 testing														
Cd4 cell count value														
Collected results														
CD4 2 testing														
Cd4 cell count value														
Collected results														
CD4 2 testing														
Cd4 cell count value														
Collected results														
Eligible for IPT/INH														
IPT Commenced														
Eligible for CPT														
CPT commenced														
Referred to Wellness clinic														
Patient attended Wellness clinic														
Patient still at wellness														

8.5.5: File audit tool

Data variables	**Patient numbers**													
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**
Gender														
Initiation decision month														
First CD4 cell count														
ART initiation month														
1st pre-ART registration date														
TB screening														
First DC4 cell count														
Second CD4 cell count														
Third CD4 cell count														
Cervical cancer screening														
IPT														
CPT														
Family planning														
Multivitamin supply														

8.5.6: NIMART Readiness assessment tool

FACILITY ART SERVICE READINESS FORM

Note: All items marked with an asterisk (*) are regarded as minimum requirements for accreditation.

Province: GAUTENG

District: JOHANNESBURG DISTRICT

Sub-district: REGION F

Facility Name: _

Type of facility: Clinic ☐ CHC ☐ Hospital ☐

Other ☐ Specify: Phase I accreditation

If hospital, indicate the level: N/A ☐ II ☐ III ☐

If hospital, indicate total number of beds: ☐

Does the hospital have a designated gateway clinic? ☐

If yes, name of gateway clinic: ☐

Facility representative: Facility Manager

(Phone): 011 432 3546 Fax): 011 682 1455 E-mail):

Other facility representatives: _____Tel: _____Cell_____,

Fax: _____

1. GENERAL

1.1 Recording and reporting of facility.

1.1.1	A print out or softcopy of the DHIS PHC data elements / hospital data set of the facility available containing monthly data for the past 12 months			
1.1.2	If yes in 1.1.1, what is the last reporting month according to the said data set?			
1.1.3	The DHIS PHC data set complete for every month over the past 12 months			
1.1.4	A data set available for the VCT monitoring form for every month over the past 12 months			
1.1.5	A data set available for the PMTCT monitoring form for every month over the past 12 months			
1.1.6	A data set available for TB for every quarter in the past 12 months			
1.1.7	A data set available for nutritional services over the past 12 months			
1.1.9	A data set available for STI services over the past 12 months			
1.1.10	A data set available for PEP services over the past 12 months (Occupational Exposure)			
	Sexual Assault			

24hr s Comments: PEP: Sexual assault clients are referred to Hillbrow CHC where the service is available for 24 hrs.Starter pack is available on site for occupational exposure.

1.2 Projected HIV & AIDS patient load during the first 6 months (please apply formula).

			Month						
			May	June	July	Aug	Sept	Oct	Tota
1.2.1	Number of patients in ARV assessment period:	Adults							
		Children							
1.2.2	Number of patients ready and waiting for treatment: Comment: All Children are referred to Referral Hospitals	Adults							
		TB							
		PMTCT							
		Children							
1.2.3	Number of patients already on ARV treatment:	Adults							
		Children							

1.3 Physical space, communication and medical waste management.

Intent: Sufficient space is required for consultation and treatment considering confidentiality, and for counselling and for storage in order to accommodate projected patient case-load, communication and waste management.

1.3.1	The facility has the following number of consultation/ treatment rooms*		
1.3.2	The facility has the following number of counselling rooms*		
1.3.3	The facility has sufficient storage space for nutritional supplements		

1.3.4	The facility has the following number of consultation and counselling rooms for children*		
1.3.5	The facility has a Medical Waste Management System in place*?	Yes	
	Name Medical Waste Management System: PICK IT UP		
1.3.5	The facility has a dedicated cell or land line for patient communication*	Yes	
1.3.6	Patients/ Clients' complaints and compliments are recorded and settled	Yes	

Other additional comments noteworthy: Operational Manager is allocated a Council cell-phone. The clinic has one landline and a separate phone-fax line, two extension lines.

2. BASIC HIV & AIDS SERVICES – CURRENTLY AVAILABLE

Services currently available		Available On-site	Referral Off-site	Not Available	Comments
2.1	Family Planning*	Yes			
2.2	Antenatal services*	Yes			
2.3	VCT* (Include Self & Med ref.ANC ,PCR &TB Clients)	Yes			

2.3.1	Number of VCT clients currently seen for 6 months	776	
2.3.2	Would facility be able to manage more VCT clients per month?		

2.4	IMCI / EPI*		Yes				
2.5	PMTCT*		Yes				
	2.5.1	Number of enrolled PMTCT patients over past 6 months				114	
	2.5.2	Number of children followed up over the past 6 months				18	
2.6	TB Management*		Yes				
	2.6.1	What is the current TB cure rate?				Region F = (Site) =	
	2.6.2	What is the current TB Defaulter rate?				Region F = (Site) =	
	2.6.3	What is the current TB Sputum turnaround time? Days				Region F < 48 HRS (Site) < 48 HRS	
	2.6.4.	Dots coverage				Region F = (Site) =	
2.7	STI*	2.7.1	1st line management	Yes	277		
	2.7.2		2nd line management		No		

2.8	PEP [Occupational exp: 24h access]*		No		
2.9	PEP [Sexual assault victims: 24h]*	Yes			
2.10	Nutritional Support*		No		
	2.10.1 Nutritional Supplement		No		
2.11	Social Worker Support*	Yes			

Additional *Basic HIV and AIDS Services* Comments: DOTS Supporters from nearby NGO's are involved in treatment supervision, support and patient tracing. Sexual assault clients are referred to Hillbrow CHC where the service is available for 24 hrs.Starter packs is available on site for stat doses.

3. POLICIES AND NATIONAL TREATMENT GUIDELINES/ PROTOCOLS

3.1	The facility has a written Confidentiality Policy*		
3.2	The facility has written Universal Infection Precaution Policies*		
3.3	National ARV treatment guidelines are adhered to*		
3.4	National guidelines for management of HIV infected children are adhered to*		
3.5	Contraceptive service delivery guidelines are adhered to*		
3.6	National Antenatal Services guidelines are adhered to*		

3.7	National VCT guidelines are adhered to*		
3.8	National PMTCT guidelines are adhered to*		
3.9	National TB Management guidelines are adhered to*		
3.10	National STI Treatment guidelines are adhered to*		
3.11	National Post Exposure Prophylaxis guidelines are adhered to*		
3.12	National Nutritional guidelines for people living with TB, HIV & AIDS are adhered to*		

4. LABORATORY CAPACITY

4.1	Is there a laboratory in the facility?					
	4.1.1					
	4.1.2					
4.2	If there is no laboratory in the facility, is there a laboratory depot?					
	4.2.1	If yes, is there a centrifuge in depot?				
	4.2.2	If yes, is there cool storage for specimens [2 - 8°C]				
	4.2.3	If yes, is specimen details recorded electronically?				
4.3	Facility utilizes the NHLS					
4.4	Utilizes other outside/ private lab services					
4.5	System to transport specimens to lab					

4.6	System in place to receive results from lab				
4.7	Is there a Laboratory Information System currently in use? If yes, which system?				
4.8	Phlebotomist or trained nurse on lab staff*				
4.9	Specimen preparation protocols available*				
4.10	Standard operating procedures are available for all laboratory tests				
4.11	CD4 testing capacity available				
4.12	HIV viral load capacity available				
4.13	Full blood count capacity available				
4.14	Liver function test capacity available				
4.15	HIV DNA PCR capacity available				
4.16	TB testing capacity available				
4.17	Lipid profile testing capacity available				
4.18	Viral hepatitis testing capacity available				
4.19	An equipment maintenance plan in place				
4.20	All equipment is calibrated to a national standard				
4.21	A copy of the NHLS Safety Manual signed by all lab staff is available				
4.22	The laboratory participates in a Quality Assurance accreditation scheme/ program				

	4.22.1	If yes, what scheme/ program?				
4.23	Biohazard & chemical waste are disposed					
	If yes, how is it done? : PHAMBILI Waste Management					

4.24	Current staffing of laboratory	N/A
		Rank	Number in rank
	4.24.1	Supported by NHLS	
	4.24.2		
	4.24.3		
	4.24.4		
	4.24.5		
	4.24.6		

Additional *Laboratory* Comments:

5. PHARMACY CAPACITY

Please indicate how the drug capacity indicators are performing against current volumes and anticipated increases (refer back to 1.2).

	Drug capacity Indicators	Yes	No	N/a	*Response/ Comments*
5.1	The facility has its own pharmacy				
5.2	Standard operating procedures (SOPs) for drug dispensing are followed				
5.3	A computerised medicine inventory				

	system is in place					
	Drug capacity Indicators					
5.4	A computerised drug ordering system is in place (Langlaagte Pharmacy)					
	Storage space sufficient					
	5.5.1	Against current volumes				
	5.5.2	Against anticipated increases				
5.6	Security adequate [according to minimum certification requirements]					
5.7	Dispensing ‘Schedule 5’ drugs					
5.8	Cold storage for drugs					
	5.8.1	Against current volumes				
	5.8.2	Against anticipated increases				
5.9	At least one Full Time Equivalent pharmacist/ pharmacist assistant					
5.10	Professional nurse licensed to dispense, on site*					
5.11	Currently stocking ARV medication					
5.12	Fluconazole/ Diflucan available					
5.13	Pharmacy meets minimum certification requirements					

	5.13.1	Implementation of SOPs for receiving, storing and dispensing Schedule 5 drugs				
	5.13.2	Four weeks of supply of buffer stock				
	5.13.3	Registered pharmacist on site				

Additional *Pharmacy* Comments: Site will be supported by Hillbrow ARV Pharmacist

6. HIV AND AIDS SERVICE POINT

6.1 Access to care, treatment and support.

Intent: Care; treatment and support to HIV patients are available 24 hours per day at, (a) the facility, and/or (b) on referral.

		Days/week		Hours/day	
		At facility	On referral	At facility	On referral
6.1.1	Casualty/ Emergency Room[s]				
6.1.2	High care unit				
6.1.3	Intensive care unit				
6.1.4	Nursing care*				
6.1.5	Clinician care*				
6.1.6	Outpatients Department				

Comments: Referral Hospitals are: Hillbrow CHC, Charlotte Maxeke Johannesburg Hospital, South Rand Hospital and Germiston Hospital

6.2 Access to expert consultation.

Intent: Access to specialist and sub-specialist services does exist or is being planned.

Speciality		Available on site	Available off-site	If off-site, is transport available?		Comments and/or plans
				Yes	No	
6.2.1	HIV Clinical expertise*					
6.2.2	Gastro-enterology*					
6.2.3	Paediatrics*					
6.2.4	Internal medicine*					
6.2.5	Dermatology*					
6.2.6	Gynaecology & Obstetrics					
6.2.7	Surgery*					
6.2.8	Neurology*					
6.2.9	ENT*					
6.2.10	Oncology*					
6.2.11	Ophthalmology*					
6.2.12	Pulmonary medicine*					
6.2.13	Oral health services*					
6.2.14	Infectious diseases*					
6.2.15	Antenatal services*					
6.2.16	Cardiology*					
6.2.17	TB services*					

6.2.18	X-ray/ Ultrasound*					
6.2.19	STI services*					

6.3 Appropriately trained staff managing HIV and AIDS services at service point.

Intent: Current number of trained staff members managing HIV and AIDS Services at facility and additional numbers needed to meet projected patient load for ARV treatment.

		Current status		*Additional requirements*	*How determined?*
		Trained	*Not trained*		
6.3.1	*Medical officer*				
6.3.2	Professional Nurse *				
6.3.3	*Staff Nurse**				
6.3.4	*Enrolled nurse assistant*				
6.3.5	*Dietician/ Assistant **				
6.3.6	*Pharmacist*				
6.3.7	*Pharmacist Assistant **				
6.3.8	*Social Worker **				
6.3.9	*Lay counsellor **				
6.3.10	*Administrative Clerk **				
6.3.11	*Data capturer **				

- *EPW*

6.4 Project Management

Intent: A dedicated person is required to supervise the treatment component of the Comprehensive Plan implementation and expansion. This person may provide a service to more than one service point.

		Yes	No	N/a	Comments
6.4.1	A project manager has been appointed				
6.4.2	The terms of reference for the project manager is available				

6.5 Access to home/ community based services.

Intent: Home/ community based services are utilised by service points to ensure a continuum of care. Facilities refer patients to or receive patients from these services *[Provide numbers for the past 12 months]*

Patients referred to and from home/ community based services				*Yes*	*No*	*Number of patients*	*Name services*
6.5.1	*NGOs*	*6.5.1.1*	*Referred to*		No		
		6.5.1.2	*Received from*				
6.5.2	*CBOs*	*6.5.2.1*	*Referred to*				
		6.5.2.2	*Received from*				
6.5.3	*FBOs*	*6.5.3.1*	*Referred to*				
		6.5.3.2	*Received from*				
6.5.4	*Other patient support groups*	*6.5.4.1*	*Referred to*				
		6.5.4.2	*Received from*				

6.5.5	*Traditional healers*	*6.5.5.1*	*Referred to*				
		6.5.5.2	*Received from*				

Comments: Most of the clients are TB patients. Meeting with DOT supporters are held monthly. DOT Supporters visit the clinic daily. Support group meetings are held every Friday.

6.6 Patient Management Systems at the service point.

Intent: Systems are in place to, (i) identify, contact, schedule and locate patients, (ii) capture patient information and maintain medical records, (iii) transmit core data to a central data collection point, and (iv) refer patients successfully.

		Yes	No	Comments
6.6.1	Standard patient referral and reporting letter used			
6.6.2	Appointment system for patients in place			
6.6.3	Patient identification system in place [*name system*]			
6.6.4	Patient tracking system in place [*name system*]			
6.6.5	Patient ID & tracking systems can identify defaults and reschedule			
6.6.6	The specific content of clinical records in line with the National requirement is available			
6.6.7	Standardised diagnosis & procedural codes are used			
6.6.8	Clinical records contain adequate information to support the diagnosis			
6.6.9	Clinical records contain adequate information to justify the care and treatment			

6.6.10	Clinical records contain adequate information on the course and results of treatment			
6.6.11	The author can be identified for each patient record entry			
6.6.12	Clinical records of patients include information on the organisation that referred			
6.6.13	Data or information is contributed to a central collection point			
6.6.14	The facility compares its performance using the central data collection point's data			
6.6.15	Core data is transmitted without compromising security			
6.6.16	Core data is transmitted without compromising confidentiality and correctness			
6.6.17	The facility uses a patient-kept patient record			
6.6.18	The facility uses a facility-kept patient record			

6.7 Governance and management.

Intent: The facility (service point) assures that the community actively participates in the planning and monitoring processes of the facility. The facility also builds formal relationships with the relevant official structures of government at local and provincial level.

		Yes	*No*	*Comments*
6.7.1	*The service point closely interacts with the District Management Team*			
6.7.2	*The service point closely interacts with the HIV and AIDS Unit in the provincial office*			
6.7.3	*Agendas and minutes of a functioning hospital board are available*			
6.7.4	*Agendas and minutes of a well-functioning clinic / CHC committee are available*			

6.8 Information, Education and Communication (IEC).

Intent: Initial and ongoing HIV education is provided to patients, family members and the community.

		Yes	*No*	*Comments*
6.8.1	*An IEC plan is in place*			
6.8.2	*A Communication Strategy is in place*			
6.8.3	*HIV & AIDS educational material is available*			
6.8.4	*Mind-set Health Channel is available*			

6.9 Equipment and building maintenance.

Intent: The building and equipment is viewed as a major asset and thus managed accordingly.

		Yes	*No*	*Comments*
6.9.1	*A procurement system is in place*			
6.9.2	*The facility has a maintenance plan for the building*			
6.9.3	*The facility has a maintenance plan for equipment*			
6.9.4	*An inventory for equipment is kept & regularly updated*			

Comments: Inventory list in each room and file are available and updated. Invoices file has been created.

7. ACCREDITATION TEAM MEMBERS

NAME	POSITION	E-MAIL	TEL NO

Date of amendment

ANNEXURE A

a) Please list all the facilities that are referring to you and indicate the type of facility, e.g. clinic, CHC, hospital, FBO, CBO (hospices), NGO, and THP:

1. Type:
2. Type:
3. Type:
4. Type:
5. Type:
6. Type:

(b) Over the past 12 months:

1. From public health facilities as listed in (a) above ---
2. From NGOs, CBOs and & FBOs ---
3. From the private sector ---
4. From traditional health practitioners ---

ANNEXURE B

a) Please list all the facilities to which your facility is referring to and indicate the type of facility, e.g. clinic, CHC, hospital, FBO, CBO (hospices), NGO, and TH:

1. Type:
2. Type:

3. Type:

4. Type:

5. Type:

b) Provide accurate numbers of patients/ clients that over the past 12 months have been referred by your facility to the following:

Facilities listed in (a) above [added totals for 1.1 to 1.6]

1. Family planning services (off-site) __
2. Antenatal services (off-site) __
3. VCT services (off-site) __
4. PMTCT services (off-site) __
5. TB Management services (off-site) __
6. STI services (off-site) __
7. NGOs, CBOs and & FBOs __
8. The private sector __
9. Traditional health practitioners __

ANNEXURE C

Terms of Reference of the Project Manager

8.6 Training program for data collectors

Date: 4th-7th -July 2012; Venue: 3rd Floor boardroom – Esselte clinic

Training content	**FACILITATOR**
Pre-ART project and research study summery	Juliet
Overview of the questionnaires Patients' /YFHS/MFHS *Discussion of emerging issues and feedback*	Petronella
Conducting interviews Introduction Characteristics of a good interviewer behavioural techniques for building rapport in interviews Unbiased versus leading questions Examples of effective probes (direct and indirect probes) Other check points after the in-depth interviews What to take to an interview (preparation for an interview *Discussion of emerging and feedback*	Juliet
Data quality checks -*Discussion of emerging and feedback*	Juliet
Debriefing sessions -*Discussion of emerging and feedback*	Juliet
Practical on conducting interviews using the questionnaires-*Discussion of emerging and feedback*	Petronella/Juliet
Role-play on conducting interviews *Discussion of emerging and feedback*	Petronella/Juliet
Feedback sessions *Discussion of emerging and feedback*	Petronella/Juliet
More practice on conducting interviews *Discussion of emerging and feedback*	Petronella/Juliet
Way forward and planning for the data collection week	Petronella/Juliet

8.7: NIMART training content

NIMART Capacity building programme

Date:

Sessions for the 5 day training
Welcome, introduction, learning objectives and pre training assessment
HIV basic science refresher including diagnosis
Staging and opportunistic infections
PMTCT refresher including infant feeding
Case finding/diagnosis cases
Staging and OI cases
Participant reflections and action plans
Adult ARV initiation and management: Regimens, when to start, how to start, monitoring and side effects
Adherence
Adult ARV initiation and management cases
Participant reflections and action plans
TB/HIV co-infection
TB infection control
Quality improvement
TB/HIV cases
Way forward: mentoring visits, assessment process, participant case documentation tools
Participant reflections and action plans
NIMART post-training assessments
NIMART course evaluation
Close

8.8: CoJ Referral Form

City of Johannesburg

Joburg
a world class African city

Region F

80 Albert Street Clinic
MARSHALTOWN
011 334 6009

REFERRAL LETTER

TO: .....

DATE: .....

Dear Sir/Madam: .....

Re:..... D.O.B: .....
Address.....
..... Tel: .....

The above named person was assessed at .....
Reason for referral.....
.....
.....

The completion and return of this form will be of great value to us

Yours truly,
.....
FOR COMMUNITY HEALTH
Please ask for: .....
Telephone: .....

Summary report of findings: .....
.....
.....

TREATMENT RECEIVED OR RECOMMENDED: .....
.....

RETURN VISIT RECOMMENDED: .....
OUR REFERENCE: .....

SIGNATURE: ..... DATE: .....

8.9: Publications and conference outputs

8.9.1: NIMART Roll out publication

NIMART rollout to primary healthcare facilities increases access to antiretrovirals in Johannesburg: An interrupted time series analysis

J C Y Nyasulu, E Muchiri, S Mazwi, M Ratshefola

Wits Reproductive Health and HIV Research Institute, School of Clinical Medicine, and School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg; and Health Systems Trust, South Africa's Sustainable Response to HIV and TB (SA SURE Project) Midrand, Gauteng Province, South African
J C Y Nyasulu, BSc, MPH

Wits Reproductive Health and HIV Research Institute, School of Clinical Medicine, University of the Witwatersrand, Johannesburg, South Africa
E Muchiri, BSc (Statistics), MSc (Medical Statistics), Dip Information Technology
S Mazwi, Dip Information Technology
M Ratshefola, BSc, MB ChB, Dip HIV Management, Dip Occupational Health, Cert Advanced Health Management

Corresponding author: *J C Y Nyasulu (juliet.nyasulu@hst.org.za; julietnyasulu@gmail.com)*

Introduction. South Africa has made remarkable progress in rolling out antiretroviral therapy (ART), with the largest number of people (more than 1.4 million) enrolled on antiretrovirals in the world. Decentralisation of services to primary health centres (PHCs) has strengthened retention of patients on ART and reduced the burden of managing uncomplicated cases at referral hospitals.
Methods. This was a ten-step Nurse Initiatied Management of Antiretroviral Treatment (NIMART) rollout intervention in which nurses from 17 primary healthcare facilities of Region F, City of Johannesburg, South Africa, were trained and mentored in NIMART by the Wits Reproductive Health and HIV Research Institute (WRHI) to commence patients on ART in their PHCs. A total of 20 535 patients initiated ART during the 30-month study period. Monthly initiations at both PHCs and referral clinics were monitored. To test the statistical significance of the impact of NIMART rollout on the referral hospital initiations and Region F monthly initiations, interrupted time series analysis was applied.
Findings. Ten-step NIMART rollout was applied, with the first step being establishment of NIMART as a priority in order to obtain primary buy-in by the Department of Health (DoH) and City of Johannesburg (CoJ). Forty-five professional nurses were trained in NIMART by WRHI quality improvement mentors. By the end of September 2011, all 17 PHCs in Region F were initiating patients on ART. Total initiations significantly increased by 99 patients immediately after NIMART rollout (p=0.013) and continued to increase by an average of 9 every month (p=0.013), while referral facility initiations decreased by 12 (p=0.791) immediately after NIMART and then decreased by an average of 18 every month (p=0.01).
Conclusion. In this study, decentralisation of ART initiation by professional nurses was shown to increase ART uptake and reduce workload at referral facilities, enabling them to concentrate on complicated cases. However, it is important to ensure capacity building, training and mentoring of nurses to integrate HIV services in order to reduce workload and provide a comprehensive package of care to patients. Engaging and having buy-in from DoH/CoJ partners in rolling out NIMART was crucial in increasing outputs as well as for sustainability of the NIMART programme.

S Afr Med J 2013;103(4):232-236. DOI:10.7196/SAMJ.6380

It is estimated that there were 33.3 million people living with the human immunodeficiency virus (HIV) at the end of 2009, compared with 26.2 million in 1999 – a 27% increase.[1] In 2010, the World Health Organization revised treatment guidelines and recommended earlier initiation of antiretroviral therapy (ART), at a CD4 count of <350 cells/μl.[2] According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) report,[1] these new criteria increased the total number of people medically eligible for ART by roughly 50% – from 10 million to 15 million. The report estimates that of the 15 million people living with HIV in low- and middle-income countries who needed ART by 2009, only 5.2 million (35%) had access to it. From 2004 to 2010, ART access increased 13-fold.[1] As a result of the scaling up of treatment access in many countries, there was a 19% decline in deaths of people living with HIV between 2004 and 2009, and those with HIV were living longer.[1]

South Africa (SA) has made remarkable progress in rolling out ART, with the largest number of people in the world enrolled on antiretrovirals (ARVs).[3] The SA ART programme reached 81% of children and 55% of adults in need of ARVs in 2009.[4] By the end of 2011, this had increased to approximately 1 400 000 individuals.[5]

At the end of 2009, however, there remained an estimated 1.2 million people requiring treatment in the next 2 years. This would exceed the capacity of the healthcare system if treatment continued to be initiated by doctors only.[6] Decentralisation of ART services has been proven to strengthen retention of patients on ART and reduce the burden of managing uncomplicated cases at referral hospitals.[7,8] Moreover, down-referral from major hospitals to primary health centres (PHCs) has benefits such as closeness to home, altruism, and savings of transport costs and time.[9] At the same time, Nurse

Initiated Management of Antiretroviral Treatment (NIMART) has been shown to improve access, to be cost-effective, and not to be inferior to doctor-managed ART.[10,11]

In the past 3 years, the SA government has been responsible for national initiatives aimed at increasing ART access. The HIV Counselling and Testing (HCT) campaign was launched in July 2010 with a target of testing 15 million people by June 2011, and in April 2010 there was a presidential mandate that ARVs be made available at all the country's 5 500 health facilities and that nurses be trained to prescribe and manage patients on the life-prolonging drugs.[12,13] By the end of 2009, 497 facilities were initiating patients on ART and by July 2010 the number had increased to 814.[14] Initiation by nurses resulted in 2 552 facilities initiating patients by April 2011.[5]

The Wits Reproductive Health and HIV Research Institute (WRHI) is an internationally renowned African academic institute supporting Region F of the City of Johannesburg (CoJ) in rolling out NIMART through training and mentoring nurses. This is achieved through a multidisciplinary quality improvement mentoring team that has been collectively responsible for providing a comprehensive programme of technical assistance in quality improvement to 17 PHCs since 2010. The importance of mentoring NIMART nurses has been documented previously.[15,16] By October 2010, only one of the 17 PHCs in the region was initiating patients on ART. This meant that patients required referral to hospitals, which became overburdened with uncomplicated cases. The main purpose of rolling out NIMART to all Region F PHCs was therefore to increase access to ART services and reduce the workload at referral hospitals.

Methods

Study design

We employed a quasi-experimental design with interrupted time series analysis to estimate the impact of NIMART on the number of patients initiating ART. The number of patients initiating ART monthly was collected before NIMART (October 2009 - September 2010) and after NIMART (October 2010 - March 2012). The intervention began in October 2010 and is ongoing. The analysis was exempted from ethical approval because it was an evaluation of an ongoing public health service programme.

Participants

We included 20 535 ART-naïve patients from Region F of the CoJ who were initiated on ART from October 2009 to March 2012. All patients transferred to Region F facilities from other regions or districts were excluded. A total of 6 957 patients (both adults and children) were initiated before the NIMART intervention and 13 578 after NIMART.

Setting

Region F represents the inner city of central Johannesburg and has a population of 478 000 (District Health Information System (DHIS) database 2012).

Intervention

Nurses from the 17 PHCs in Region F were trained in NIMART over 5 days (3 days covered adult initiation and 2 days initiation in children). All nurses wrote pre- and post-tests during the course. The nurses were then supported and mentored in their PHCs by WRHI mentors to begin initiating patients on ART. The ten steps that were followed in rolling out NIMART to ensure buy-in and sustainability are shown in Fig. 1.

Throughout the process the WRHI engaged with the Department of Health (DoH)/CoJ partners in order for them to share a common vision and aquire ownership of the programme, leading to sustainability.

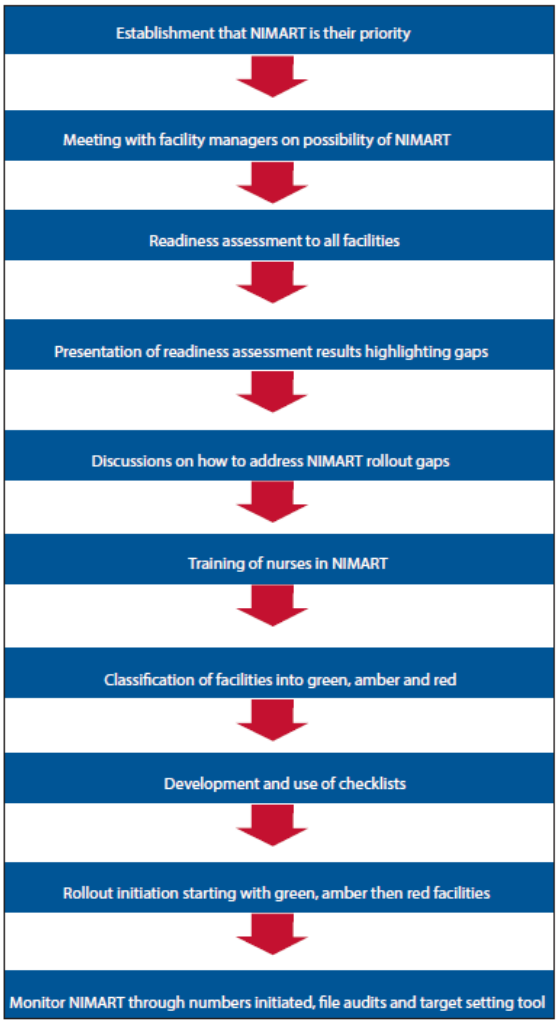


Fig. 1. Ten steps followed in rolling out NIMART.

Data collection

Data were collected from the PHCs' monthly reports. Monitoring of patients was undertaken on a monthly and quarterly basis. From May 2011, the number of patients initiated on ART through NIMART was also captured on the government-owned DHIS. Data over the clinics in the region were aggregated and recorded for each month over the study period.

Outcome measures

The primary outcome of the study was the number of patients in the 17 PHCs initiated on ART following NIMART intervention.

Statistical analysis

Continuous data were expressed as means (standard deviation (SD)) or medians (interquartile range (IQR)). Categorical data were presented as frequencies and percentages. The Durbin-Watson statistic was used to test for autocorrelation. We modelled the time series data using segmented regression analysis of interrupted time series which, as

suggested by Wagner *et al.*,[17] has the advantage of controlling for baseline level and trend. We compared the time series pattern before and after the intervention to assess differences. The trends before and after the intervention were analysed to assess whether passage of time was associated with increased initiations. The change in average numbers of those initiating ART immediately after intervention was estimated and tested for significance.

The specific model is:

$Y_t = \beta_0 + \beta_1 * \text{time} + \beta_2 * \text{intervention}_t + \beta_3 * \text{time after intervention}_t + e_t$,

where Y_t is the total number of new ART initiations in a month in Region F, which is the response variable in this model; *time* is a continuous variable indicating time in months at time *t* from the start of the observation period; *intervention* is an indicator for time *t* occurring before (intervention = 0) or after (intervention = 1) NIMART rollout, which was implemented at month 13 in the series; and *time after intervention* is a continuous variable counting the number of months after the intervention at time *t*, coded 0 before NIMART and 1 - 18 after NIMART. In this model, β_0 is the estimate of baseline level of outcome, being the mean number of patients initiated on ART at time zero; β_1 estimates the mean change in total number of ART initiations that occurred in each month before NIMART rollout, β_2 estimates the level change in the mean number of initiations after NIMART; and β_3 estimates the change in the trend in the mean monthly number of ART initiations after NIMART compared with the monthly trend before NIMART intervention. The error term e_t at time *t* represents the random variability not accounted for by the model. Data preparation was done in MS Excel 2010 and analysis in STATA 12, Stata Corp. Throughout we used a two-tailed *t*-test at a 5% level of significance.

Results

Acceptability of the NIMART rollout by the DoH/CoJ

The WRHI NIMART mentoring team engaged with the CoJ and DoH partners in establishing NIMART rollout and all processes involved. This led to buy-in on the part of the CoJ, while the DoH had ownership and took the lead in rolling out the programme. This approach strengthened sustainability of the programme.

Number of facilities initiating ART

Before NIMART rollout, only 1 of the 17 PHCs was initiating patients on ART, all undertaken by doctors. From October 2010, the WRHI started training and mentoring professional nurses in NIMART. By October 2011, all 17 facilities were initiating patients on ART with a sense of ownership.

ART initiations and decrease in burden of patients on the Region F PHC referral hospitals

In the first 12 months before NIMART rollout, every month the referral hospital facilities were initiating an average of 389 patients (SD 82.27). This decreased to a monthly average of 238 patients in the 12 months after NIMART (Fig. 2).

Total ART initiations in Region F

In the first 12 months before NIMART rollout, the mean number of patients initiated monthly on ART in Region F stood at 580 (SD 80.48). In the 12 months following NIMART, initiations increased significantly (Fig. 3) to a monthly mean of 732 (±SD 71.29).

Statistical analysis

Fig. 2 visually displays the number of ART initiations at Region F PHC referral hospitals. The trend was stable before intervention and decreased steadily after NIMART rollout. In Fig. 3, ART initiations are shown to steadily increase, even though there is a visible interruption after initiation of NIMART. To assess chance and control for other effects, a time-segmented regression analysis was fitted. Results are set out in Table 1.

Results from the segmented time series model presented in Table 1 show that initiations at referral facilities gradually decreased after introduction of NIMART, while the total initiations in Region F were increasing. Model (a) presents a full segmented model, which shows that the month-to-month decrease in number of initiations in the Region F referral hospital before NIMART was non-significant (p=0.958). After NIMART, the number of initiations dropped by 11, with a month-to-month decrease of 17 (p=0.027). For the total initiations in Region F, no model term was significant; the non-significant terms were eliminated by stepwise elimination and the most parsimonious model introduced. Model (b) is the most parsimonious model, and shows that initiations at the referral hospital had an average month-to-month decrease of 18 (p=0.01). The total initiations decreased by 12 (p=0.791) immediately after NIMART introduction, a result that was not statistically significant. In addition to a decreasing trend in referral hospital initiations, the total number of ART initiations in Region F PHCs increased by 99 (p=0.013) immediately after NIMART, the trend afterwards showing an average increase of 8 (p=0.013) every month.

Discussion

The key finding from the study is that decentralisation of ART initiation through

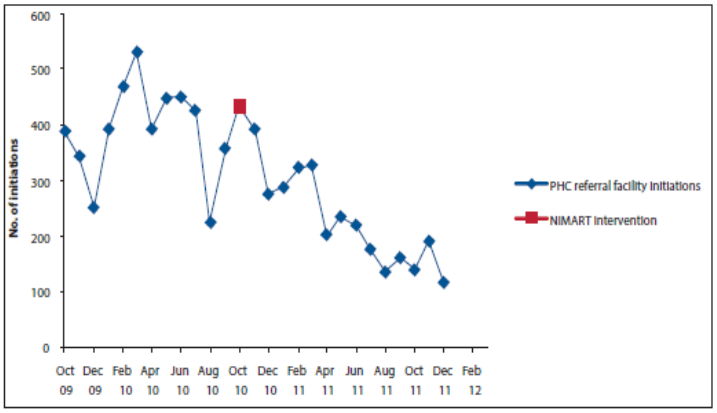


Fig. 2. Trends in ART initiations at the Region F PHC referral facility.

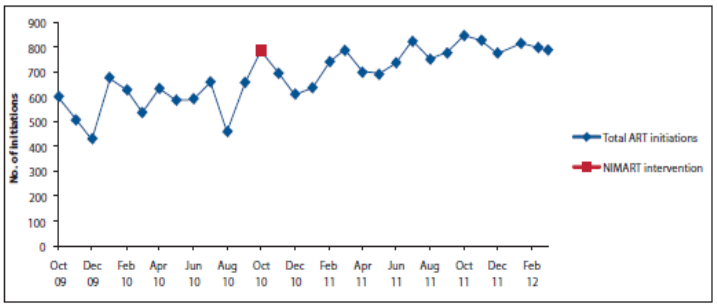


Fig. 3. Trends in total ART initiations in region F PHCs.

Table 1. Results from segmented regression model, parameter estimates, standard errors (SEs) and *p*-values for full model and most parsimonious model

	ART initiations at referral hospitals			Total ART initiations in Region F		
	Coefficient*	SE	*p*-value	Coefficient*	SE	*p*-value
Full segmented regression model						
Intercept β_0	391	42.19		548.95	40.44	
Baseline trend β_1	-0.30	5.73	0.958	4.73	5.49	0.396
Level change after NIMART β_2	-10.65	52.53	0.853	73.03	48.14	0.141
Trend change after NIMART β_3	-17.39	7.02	0.027	3.20	6.25	0.612
Most parsimonious segmented regression model						
Intercept β_0	389	19.35		579.75	18.87	
Level change after NIMART β_2	-12.34	46.08	0.791	99.09	37.29	0.013
Trend after NIMART β_3	-17.69	4.44	0.01	7.94	2.97	0.013

*Month 13 was excluded, as it was when NIMART was introduced.

NIMART in Region F in the CoJ was shown to significantly increase uptake of ARVs by an average of 99 patients immediately after rollout (p=0.013). This is consistent with findings from other studies, as rolling out NIMART to PHC facilities meant less distance for patients to travel and fewer levels of referral for ART initiation, potentially leading to an increase in ART patient retention and access to services.[7,8] However, since patient dissatisfaction with lack of trained HIV clinical staff, negative patient-nurse interactions, compromised confidentiality and stigma at lower levels of ART services had been highlighted,[18] better mentoring and support for nursing staff are called for.

This study has shown how the ten-step process involved in rolling out NIMART succeeded, with support from partner organisations ensuring buy-in and sustainability of the programme. Establishing that rolling out NIMART was a priority, and engaging with service providers, enabled both WRHI mentors and government and CoJ partners to have a shared vision, which inspired and motivated implementers in achieving sustainable change.[19]

Rolling out NIMART led to a steady reduction in the number of patients requiring initiation of treatment in the main referral health facility. This decrease translated into more complicated cases being managed at the referral site.[20] The advantage of primary health care involvement at a local level in ART service delivery, especially in resource-limited settings, has been emphasised previously.[7,18] However, there is a need for proper guidelines for upwards referral of complicated cases to prevent unnecessary delays. Providing ART initiation without increasing the available human and space resources resulted in an increased workload at primary health clinic levels. Staff shortage and lack of sufficient consulting rooms has been documented as a barrier to rolling out NIMART.[15,16] It is therefore important to ensure capacity building and training and mentoring of nurses to integrate HIV services in order to reduce workload and provide a comprehensive package of care to patients. Partnership with the DoH/CoJ proved integral to increasing outputs as well as to sustainability of the NIMART programme.

Introduction of NIMART resulted in an immediate increase in the number of ART initiations for Region F and decreased referral hospital initiations. The number of initiations was initially high but eventually stabilised, with evidence of an increasing trend in monthly initiations after NIMART. Decentralisation of ART through down-referral and NIMART services has also shown to be cost-effective, increase access and strengthen retention of patients on ART owing to the closer proximity to their homes and decreased costs.[7,8,10,11]

The main study limitation was that we used public health facility data, which are sometimes incomplete; however, data quality tracing and verification were applied in order to verify the DHIS data with the PHC data sources.

Conclusion

In order to promote accessibility of ART services, there is need to decentralise services to PHCs through training and mentoring professional nurses in ART initiation. ARV initiation of non-complicated cases at PHCs will reduce the workload of referral hospitals, enabling them to concentrate on complicated cases. It is important to capacitate nurses to integrate HIV services in order to maximise the limited human resources and provide a comprehensive package of care at PHC level. To ensure sustainability of NIMART, partnership with DoH/CoJ partners in mentoring should be prioritised.

Conflicts of interest. None declared.

Authors' contributions. JCYN conceived the research topic, and was involved in designing the study, data collection, analysis and report writing. She was also central to development, revision and finalisation of the article for submission. EM performed data analysis and interpretation, wrote sections of the methods and results, and critically revised the manuscript. SM was involved in managing all the data quality issues, and managed the DHIS data and monitoring and evaluation of the project. MR was district manager for the quality improvement team and participated in all processes. All authors read and approved the final manuscript. JCYN is the guarantor of the manuscript.

Acknowledgements. The authors would like to thank the WRHI District Approach to Systems Health (DASH) programme staff, namely Mamotho Khotseng (provincial head) and the quality improvement mentors, Marietta Booysen, Alinah Denge, Didi Mojapelo, Martin Motimele and Teboho Kekana, for their significant role in training and mentoring of the partners. Special thanks go to Alfred Musekiwa, a WRHI statistician, for his enormous support in data analysis and interpretation, and Region F DoH and CoJ partners for their co-operation and hard work in rolling out NIMART.

References

1. References United Nations Program on HIV/AIDS (UNAIDS). UNAIDS Global Report on the Global AIDS Epidemic 2010. http://www.unaids.org/documents/20101123_globalreport_em.pdf (accessed 14 August 2012).
2. World Health Organization. Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants: Towards Universal Access. Geneva: WHO, 2010. http://www.avert.org/pmtct-guidelines.htm (accessed 10 July 2012).
3. United Nations Program on HIV/AIDS (UNAIDS). UNAIDS Country Progress Indicators, Excel spreadsheet, 2008. http://www.unaids.org/en/media/unaids/contentassets/restore/jc1510_2008_global_report_pp235_324_en.pdf (accessed 20 May 2012).
4. Republic of South Africa. Country progress report on the declaration of commitment on HIV/AIDS 2010. Report – reporting period: January 2008 - December 2009. http://data.unaids.org/pub/report/2010/southafrica_2010_country_progress_report_en.pdf (accessed 15 March 2012).
5. Republic of South Africa. RSA National Strategic Plan on STI and TB (2012-2016). http://www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf (accessed 28 September 2012).
6. Klaussner JD, Seenta C, O'Bra H, et al. Scale-up and continuation of antiretroviral therapy in South African treatment programs, 2005-2009. J Acquir Immune Defic Syndr 2011;56(3):292-295. [http://dx.doi.org/10.1097/QAI.0b013e3182067d99]
7. Zachariah R, Teck R, Buhendwa L, Labana S, Chinji C. Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi. Trans R Soc Trop Med Hyg 2007;101(1):79-84. [http://dx.doi.org/10.1016/j.trstmh.2006.05.010]
8. Brinkhof M, Dabis F, Myer L, et al. Early loss of HIV-infected patients on potent antiretroviral therapy programmes in lower-income countries. Bull World Health Organ 2008;86(7):559-567. [http://dx.doi.org/10.2471/BLT.07.044248]
9. Mukora R, Charalambous S, Dahab M, et al. Study of patient attitudes towards decentralisation of HIV care in an urban clinic in South Africa. BMC Health Serv Res 2011;11(1):205. [http://dx.doi.org/10.1186/1472-6963-11-205]
10. Miles K, Clutterbuck D, Seitio O, Sebego M, Riley A. Antiretroviral treatment roll-out in a resource-constrained setting: Capitalising on nursing resources in Botswana. Bull World Health Organ 2007;85(7):555-560. [http://dx.doi.org/10.2471/BLT.06.033076]
11. Sanne I, Orrell C, Fox MP, et al. Nurse versus doctor management of HIV-infected patients receiving antiretroviral therapy (CIPRA-SA): A randomised non-inferiority trial. Lancet 2010;376(9734):33-40. [http://dx.doi.org/10.1016/S1040-6736(10)60894-X]
12. President Jacob Zuma. Address on the occasion of World AIDS Day, Pretoria Showgrounds, 1 December 2009. http://www.dfa.gov.za/docs/speeches/2009/jzum1202.html (accessed 28 September 2012).
13. Dr A Motsoaledi, Minister of Health. Budget speech delivered to the National Assembly, Parliament of the Republic of South Africa, 13 April 2010. http://www.info.gov.za/speeches/2010/10041315551001.htm (accessed 29 September 2012).
14. Butler N. Clinical guidelines for antiretroviral management of HIV disease: Origins and history of the HIV epidemic. SA Pharmaceutical Journal 2010;77(10):42-49.
15. Cameron D, Gerber A, Mbatha M, et al. Nurse initiation and maintenance of patients on antiretroviral therapy: Are nurses in primary care clinics initiating ART after attending NIMART training? S Afr Med J 2012;102(2):98-100.
16. Jones M, Stander M, Van Zyl M, et al. Recall of lost-to-follow-up pre-antiretroviral therapy patients in the Eastern Cape: Effect of mentoring on patient care. S Afr Med J 2012;102(9):768-769.
17. Wagner AK, Soumerai S, Zhang F, et al. Segmented regression analysis of interrupted time series studies in medication use research. J Clin Pharm Ther 2002;27(4):299-309. [http://dx.doi.org/10.1046/j.1365-2710.2002.00430.x]
18. Wester CW, Bussmann H, Avalos A, et al. Establishment of a public antiretroviral treatment clinic for adults in urban Botswana: Lessons learned. Clin Infect Dis 2005;40(7):1041-1044. [http://dx.doi.org/10.1086/428352]
19. Hunting SA, Tilbury D. Shifting towards Sustainability: Six Insights into Successful Organisational Change for Sustainability. Sydney: Australian Research Institute in Education for Sustainability (ARIES) for the Australian Government Department of the Environment and Heritage, 2006. http://aries.mq.edu.au/projects/insights/files/InsightsBooklet.pdf (accessed 14 December 2012).
20. Chan A, Mateyu G, Jahn A, et al. Outcome assessment of decentralization of antiretroviral therapy provision in a rural district of Malawi using an integrated primary care model. Tropical Medicine and International Health 2010;15(suppl.1):90-97. [http://dx.doi.org/10.1111/j.1365-3156.2010.02503]

Accepted 28 December 2012.

8.9.2 Factors contributing to pre-ART care access- 2013 PHASA conference

Title: Factors contributing to retention and timely ART referral for pre-ART patients in the city of Johannesburg - A pre-ART care program baseline assessment.

Nyasulu J C Y., Muchiri E., Fonn S.

Corresponding author: Nyasulu J C Y:

Telephone: +2779735487; Fax: +27865213132 Email: Juliet.nyasulu@hst.org.za or julietnyasulu@gmail.com

Introduction: Delays in timely treatment of known HIV+ patients leads to patients presenting sick and increased mortality. How pre-ART care is best set up and managed within the general health system is currently unknown and requires operational research. The study aim is to identify gaps in implementing Pre-ART program in order to develop and test the impact of an appropriate per-ART program that increases timely ART referral in PHC facilities in the city of Johannesburg.

Methods: This is a baseline assessment for an intervention study in two primary PHC facilities from the city of Johannesburg. Data was collected through interviews with pre-ART care service providers and patients and document review. STATA version 12.0.1 was used to analyse quantitative data.

Findings: A total of 12 service providers and 73 pre-ART care patients (24 males & 48 females) of whom 9 were youths were interviewed. Seventy one percent of the pre-ART patients had their CD4 count checked within the past 6 months. Gaps established were: long waiting times, staff shortage and negative staff attitudes, lack of monitoring systems, lack of acceptance of one's HIV+ status, drug stock outs, lost CD4 count and other blood results, youth and male unfriendliness. In addition, lack of knowledge about HIV/AIDS, CD4 cell count, pre-ART and ART care was also established.

Conclusion: There are major gaps in the pre-ART care services leading to poor patient retention and delays in ART initiation. Therefore, to ensure timely ART referral and access to pre-ART care, there is urgent need to design an appropriate pre-ART care program that would address the existing gaps targeting patients, staff and health systems in PHC facilities.

Key words: *Pre-ART care, CD4 count, Timely ART referral, ART initiation*

8.9.3 Pre-ART care access register audit- 2015 SAAIDS conference

Title: Retaining people in pre-ART care in Johannesburg PHC facilities

Nyasulu J C Y[1,2,], Fonn S[1] and Manderson, L[1].

Affiliations

[1] University of the Witwatersrand, Faculty of Health Sciences, School of Public Health, 7 York Road, Park Town, Johannesburg, South Africa. [2]Health Systems Trust (HST), 1st Floor, Block J, Central Park. 400 16th Road, Midrand

Background and Objectives: Pre-ART is believed to be critical for timely ART initiation. Many studies have documented poor retention in pre-ART, but there has been little research on access to care by pre-ART patients retained in care. The aim of this study was to establish factors influencing access to pre-ART care services by pre-ART care patients in the City of Johannesburg (COJ).

Methods: Two COJ facilities were randomly selected for file audits on patients initiated on ART between February 2012 – August 2012. Patient files were audited on the pre-ART care services accessed during their pre-ART care period.

Results: A total of 203 patients were initiated on ART during the study period. Of these, 7% had >350 CD4 cell count. Women were more likely to initiate on ART timely than male (P=0.04). Only 30 of the 203 patients initiated on ART had gone through pre-ART care. Being on pre-ART was not associated with timely ART referral (p=0.6). Out of the 30 patients, 16 were screened for TB, 10 were initiated on IPT, and all received multivitamins and checked their CD4 count at least once. Family planning and cervical cancer screening were not documented in their files.

Conclusion: Most patients initiated on ART do not go through the pre-ART care program as documented by other studies. Poor access to prescribed pre-ART care services by those retained in care, not found in other studies, indicates the urgent need to prioritise access to services for patients still in care. Raising awareness of available pre-ART care services and priotising pre-ART care access by those retained in care is critical for pre-ART care service delivery.

Key words: *Access, Pre-ART, Care, Services, retention*

8.9.4 Mentoring and coaching in pre-ART register documentation – 2014 PHASA Conference

(Award winning: Best oral presentation – PHASA 2014)

Title: Mentoring and coaching: Improving documentation gaps in pre-ART register at Roedtan Clinic, Waterberg District, Limpopo Province

M Selepe[1], K Setsiba[2], M Ledwaba[2], K Mathekga[2], J Nyasulu[1]

[1]Health System Trust; [2]Limpopo Department of Health

BACKGROUND

Pre-ART care for HIV-positive individuals with high CD4 cell counts is critical to strengthen monitoring and ensure timely referral for ART. However, poor documentation in pre-ART care is reported in South Africa and elsewhere. Significant gaps in documentation were identified at Roedtan Clinic.

OBJECTIVE: To improve service providers' information recording in the pre-ART care register in Roedtan Clinic, Waterberg District.

METHODS: The Clinic's pre-ART register was audited to identify documentation gaps and their causes. A quality improvement plan was developed in collaboration with the facility and district staff. The clinic's pre-ART care service providers were trained, mentored and coached by the HST facility mentor in completing the pre-ART register and managing pre-ART clients according to national guidelines. A routine process was established for reviewing register completeness.

RESULTS: Pre-intervention baseline figures in April 2013 reflected a total of 17 HIV-positive clients in the HCT register, with only six in the pre-ART register, and with 16 incomplete fields (e.g. no CD4 results). With training, mentoring and monthly register review, by April 2014 the HCT register recorded 12 HIV-positive clients and all were linked to pre-ART, with 100% of data fields completed.

CONCLUSION: The project identified major documentation gaps in the pre-ART register, which could lead to poor monitoring and management of patients in the pre-ART care programme. Training, mentoring and coaching of service providers on the importance of pre-ART care data led to improved documentation and strengthened lines of care from HCT to pre-ART.

Key words: *Pre-ART, Pre-ART register, Documentation, Mentoring and coaching*

8.9.5 NIMART roll out – 2011 PHASA Conference

P 104 - NiMART roll-out to Primary Health Care (PHC) facilities a tool to increasing access to care and reduce workload for referral facilities in Region F – Johannesburg

J Nyasulu, S Mazwi, M Kgopa

Wits Reproductive Health and HI Institute (WRHI); Faculty of Health Sciences, University of the Witwatersrand, Hugh Solomon Building, Hillbrow, Johannesburg

INTRODUCTION

South Africa has made remarkable progress in rolling out antiretroviral treatment, with the largest number of people enrolled on ARVs in the world UNAIDS (2008). Since the roll-out of ART services, decentralisation of ART services has also proved to strengthen retention of patients on ART and reduce burden of managing uncomplicated cases at referral hospitals. By October 2010, only one out of the 17 PHC facilities in the region F of City of Johannesburg (CoJ) was initiating patients on ART. This lead to loss of patients who were being referred to hospitals for initiation and referral hospitals being overburdened with non-complicated cases

AIM: The aim of the intervention was to reduce work overload of non-complicated cases at referral hospitals and increase access to ART services.

METHODS: This was a NIMART roll-out intervention whereby nurses from 17 PHC facilities of Region F city of Johannesburg were trained and mentored In NIMART by WRHI to start initiating patients on ART in their PHCs. Number of patients initiated on ARVs PHCs and referral hospitals were monitored.

FINDINGS: 100 Professional nurses were trained and mentored in NIMART by WRHI. By the end of August 2011, 16 out of 17 PHC facilities were initiating patients on ART and 1,400 Patients were initiated through NIMART. Monthly initiation coverage for Region F increased from 642 to 746 per month and initiations at the referral CHC facility significantly ($p=0.04$) reduced.

CONCLUSION: In order to promote accessibility of ART services, there is need to decentralise services to PHC facilities through training and mentoring professional nurses in ART initiation. ARV initiation of non-complicated cases at PHC facilities will reduce the workload at referral hospitals enabling them to concentrate on complicated cases.

Key words: *NIMART roll-out, PHC facilities, Time series analysis and ART uptake*

8.9.6 Pre-ART Linkage to care abstract – 2015 PHASA conference

Title: Linkages to care for ineligible newly diagnosed HIV+ individuals – A register audit in the City of Johannesburg (CoJ), South Africa

Nyasulu J C Y[1,2] and Manderson, L[1].

Background: Linkages to care for those diagnosed with HIV is critical for monitoring to ensure timely ART initiation. However, delays in ART initiation have been established in South Africa and elsewhere, with poor linkages to care the main contributing factor. The aim of the study was to establish factors contributing to poor linkage of newly diagnosed HIV+s in the City of Johannesburg.

Methodology: A pre-ART register file audit was conducted in two facilities in the inner city of Johannesburg. Patients who tested HIV+ with CD4 cell count of >200 cells/µl from May 2011 to April 2012 in these facilities were included. Data were analysed using STATA 12.0 to establish these factors.

Results: A total of 1705 patients were included and major gaps around incomplete registers were established. The average CD4 cell count for ART ineligible patients was 464 cells/µl. Women were more likely to have higher CD4 cell count levels (p=0.000) and collect CD4 cell results (p=0.001) than males (p=0.000). Those aged >24yrs (p=0.05), and those who had phone contact numbers (p=0.021) were more likely to collect their CD4 cell count results than those < 24 years and those without phone numbers.

Discussion/Conclusion: Consistent with other findings, poor linkages to care was coupled with poor documentation from testing HIV+. Being a man and young (<24yrs) has shown to negatively affect collection of CD4 cell count results which is important for clinical decision making and linkage to care. In addition those who had phone contacts, even though the phone numbers were not used to follow then up, were more likely to come back for CD4 cell count results than those without phone numbers. Therefore, strengthening documentation and prioritising men and young people may strengthen linkage to care for people still not yet eligible for ART.

Key words*: Linkage to care, CD4 cell count, ART ineligible and HIV+*